From Data to Action:
CDC's Public Health Surveillance of Women, Infants and Children

(second edition)

DEPARTMENT OF HEALTH & HUMAN SERVICES·USA

CDC

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CDC's Public Health Surveillance for Women, Infants and Children

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FOREWORD

James S. Marks, MD, MPH
Lynne S. Wilcox, MD, MPH

"The indicators a society chooses to report to itself about itself are surprisingly powerful…. A nation that keeps a watchful eye on its salmon runs or the safety of its streets makes different choices than does a nation that is only paying attention to its GNP."

Donella Meadows

The Global Citizen 5/20/93

The initial edition of *Data to Action: CDC's Public Health Surveillance for Women, Infants and Children*, published in 1994, was the first comprehensive description of the Centers for Disease Control's many surveillance and data system activities related to the health of women and children. It covered critical public health concerns, spanning the life cycle from infancy to reproductive-age women, with each chapter structured similarly so that differences and connections could be more easily discerned. We are excited to introduce the second edition, nearly 25 years later.

The quote above from the ecologist Donella Meadows, a seminal systems thinker, takes the classic public health mantra of "what gets measured, gets done" to a more profound level. It says society must choose what it cares about and measure the relevant indicators. Some may be health measures; some may be more connected to general wellbeing. A key leadership role for the public health professional is to ensure our society measures the true fundamentals for success. The public, policy makers, and public health professionals need information on classic health measures among women and children, but also need understanding of the underlying issues that affect interdependent risks.

There has been great success in women and children's health since the end of the twentieth century. According to the Youth Risk Behavior Survey, the percent of youth who are sexually active has decreased, and births to teenage mothers (ages 15-19*)* declined from 56.0 babies per 1000 teens in 1995 to 17.4 in 2018. Rates of Sudden Infant Death Syndrome (SIDS) have decreased with educational outreach on infant sleeping positions.

We have a better understanding of the lifelong impact of adverse childhood experiences, the implications of early life stress for the brain architecture, and social and executive function in early childhood as predictors of successful adulthood. We have gained insight into how the ways people live, learn, work, and play--the social determinants of health--affect the likelihood of individuals becoming ill or injured.

But challenges remain. Women in the U.S are more likely to die from childbirth than women in other developed countries, and black and American Indian/Alaska Native women are more likely to die than their white peers during delivery. Opioid use disorder per 1,000 delivery hospitalizations rose between 1999 and 2014, from 1.5 to 6.5. Although SIDS deaths have decreased, there remain marked racial and ethnic differences in infant mortality. The percentage of youth reporting suicidal ideation or attempted suicide continues to rise. Some old problems are new again--pediatric measles infections, once eliminated from the United States, have returned with the challenge of vaccine hesitancy among parents. Infant deaths from congenital syphilis are on the increase. New threats, such as Zika virus, continue to appear.

Since the first edition of this book was published, we have seen vast technological improvements in what and how surveillance data can be gathered and used for maternal and child health. CDC, for example, conducted a four-year initiative to modernize its surveillance systems, moving toward cloud-based electronic tracking systems, electronic web-based death reporting, integrating disease reporting into physicians' daily workflows, automating electronic laboratory reporting, and promoting interoperability between surveillance systems. Such systems offer new opportunities in surveillance design and function.

This monograph also emphasizes the critical partnerships throughout the public system to address women and children's health and well-being. CDC professionals, health officials at every level, and representatives from other governmental entities such as education, housing, and agriculture, as well as non-governmental organizations such as the March of Dimes Foundation, American Academy of Pediatrics, and the American College of Obstetricians and Gynecologists, are all crucial to choosing the right indicators for measuring women and children's health and for providing support for the actions that will lead to lasting changes in health and well-being.

We are all committed to improving the health of women and children, and we must continue to be vigilant in health surveillance. We hope this book will be useful to our partners in the field of women and children's health.

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Commentary on CDC's Public Health Surveillance for Women, Infants, and Children

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In July 1991, the British Medical Research Council reported results from a randomized controlled trial that daily consumption of dietary supplements containing 4 mg of folic acid produced a 72 percent reduction in the recurrence of neural tube defects (NTDs). A month later, CDC issued an interim recommendation that women with a history of an infant or fetus with a neural tube defect take 4 mg/day of folic acid, starting when they planned to become pregnant. Then, in 1992, the US Public Health Service, working with CDC, HRSA, NIH and the Office of Assistant Secretary of Health, recommended that all women of childbearing age who are capable of becoming pregnant should consume 0.4 mg of folic acid per day. By 1995, however, only 52% of women surveyed by CDC and March of Dimes were aware of the benefits of folic acid, and only 28% were consuming daily multivitamin containing folic acid. This led to rulemaking by the FDA which required folic acid fortification of cereal grain products in the United States beginning in 1998. Analysis of blood samples from National Health and Nutrition Examination Survey (NHANES) in 1999 demonstrated a substantial increase in serum and red blood cell folate concentrations among women after folic acid fortification. This, along with public health outreach campaigns led by CDC, HRSA, state Title V programs, and other public health partners, contributed to a 36% reduction in NTDs from 1996 to 2006 and prevented an estimated 10,000 NTD-affected pregnancies, resulting in a savings of $4.7 billion in direct costs. This has been hailed as one of the great public health achievements in the first decade of the 21st century.[1,2]

The folic acid story is one of many examples of how CDC's Public Health Surveillance for Women, Infants, and Children is making a difference. Public health surveillance is the continuous, systematic collection, analysis and interpretation of health-related data needed for the planning, implementation, and evaluation of public health practice.[3] It is an essential element of assessment, which is one of the core functions of public health.[4] Many of HRSA's maternal and child health programs rely on CDC's public health surveillance data. For example, the Title V Maternal and Child Health Block Grant relies on data from CDC's Behavioral Risk Factor Surveillance System, National Immunization Survey, National Vital Statistics System (NVSS), Pregnancy Risk Assessment Monitoring System (PRAMS), and Youth Risk Behavior Surveillance for ongoing performance measurement. Many State Title V programs also use these data for program planning and policy development. CDC's Pregnancy Mortality Surveillance System provided data support for the Alliance for Innovations in Maternal Health, a collaborative effort among HRSA, CDC, and many other public and private partners to address rising maternal mortality and severe morbidities in the United States. Most recently, HRSA used CDC's public health surveillance data extensively in developing its programs to support children affected by congenital Zika infection.

With increasing population needs and emerging public health threats, the need for public health surveillance for women, infants, and children is greater than ever. And with advancing data science, the opportunity to improve population health through public health surveillance has also expanded exponentially. Our experience with the Collaborative Improvement and Innovation Network (CoIIN) on infant mortality demonstrates the importance of making public health surveillance data available in real time to drive real-time population health improvements[5]. Improving health systems integration for children and families, across levels of care, domains, and the life course, calls for better vertical, horizontal, and longitudinal data integration[6]. Big data and public health genomics hold big promise (but also challenges) for improving the precision of not only clinical but public health interventions[7]. We look forward to continuing to partner with CDC's Public Health Surveillance to protect the health and wellbeing of our nation's women, children and families.

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Commentary on CDC's Public Health Surveillance for Women, Infants, and Children from the March of Dimes Foundation

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Public health practitioners are fond of saying: "If you treasure it, measure it." Those who treasure maternal and child health need reliable and timely data to improve the health and well-being of women, infants and children.

The March of Dimes' mission is to improve the health of babies by preventing birth defects, premature birth, and infant mortality. To monitor our nation's progress in improving the health of mothers and babies and preventing these outcomes, the March of Dimes relies on data from the CDC. These data must be accurate and expressed clearly. Therefore, we are excited about the publication of this new edition of *From Data to Action*.

Among the many topics covered in this volume, those especially important to prevent premature birth include: *Unintended Pregnancy and Childbearing*; *Preconception Health; Behavioral Risk Factors Before and During Pregnancy; Prenatal Care*; *Preterm Births*; *Low Birth Weight and Intrauterine Growth Retardation;* and *Pregnancy in Adolescents*. Topics related to prevention of birth defects include: *Prevalence of Birth Defects and State Use of Birth Defects Surveillance*. Since preterm birth and preterm related conditions are the leading cause of infant mortality and birth defects are the second,[1] all of these preceding topics are relevant to our mission to prevent infant mortality. Additional topics related to infant mortality include: *Fetal Deaths* (as an extension of infant mortality into the prenatal period); *Breastfeeding*; *Newborn Screening; Infant Deaths (Neonatal and Postneonatal)*; *Sudden Infant Death Syndrome (SIDS), Sudden Unexplained Infant Death (SUID), and Sleep-Related Infant Deaths*; and *Infectious and Vaccine-Preventable Diseases.*

Examples of the data-reliant partnership between the March of Dimes and the CDC include our work to prevent neural tube defects (NTDs), preterm birth (PTB), and Zika-caused birth defects. For NTD, the March of Dimes led a coalition of organizations advocating for folic acid fortification of flours, including those from cereal grains and corn masa; the CDC provided the data documenting the reduction of NTDs by fortification.[2,3]

For PTB, the March of Dimes has led an ongoing prevention campaign that began in 2003[4] and was invited to participate in CDC's Public Health Grand Rounds on this topic to highlight our work.[5] CDC's National Center for Health Statistics provides the data documenting the eight years of PTB rate reductions from the peak in 2008 through 2014, followed by a small but concerning increase in 2015.[6] Related to Zika, the March of Dimes uses the data and guidance from the CDC on Zika in pregnancy to educate the public and professionals on prevention of Zika-caused birth defects.[7,8]

The March of Dimes relies on CDC's surveillance data to advocate at the federal, state and local levels for policies, including laws and regulations, to prevent PTB, birth defects and infant mortality. We convert these critical surveillance data about women, infants and children into action.

Because we treasure the health of women and babies, we must, therefore, measure it. CDC partners with the March of Dimes and many other organizations to improve health through data.

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Commentary on CDC's Evaluation of Public Health Surveillance Systems in From Data to Action: CDC's Public Health Surveillance for Women, Infants, and Children

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CDC and other public health agencies have a major role in public health in "aggregating, analyzing and disseminating surveillance data"[1] and recognize the need for regular evaluation of public health surveillance systems. Without regular and ongoing evaluation of surveillance systems, we cannot be sure that issues of public health importance are being monitored effectively and efficiently.[2,3]

CDC's surveillance strategy goals[4] of establishing new structures, strengthening processes, and improving public health surveillance outcomes speak to the importance of ongoing surveillance and its corresponding evaluation. The strategy is focused on US surveillance systems, but many components help build the framework for non-US partners who seek to improve their surveillance activities. Through surveillance evaluation we can make recommendations to improve data timeliness, availability, and quality; identify outdated or redundant surveillance systems; and advocate for, and advance the use of, electronic health records and technologies to maximize the effectiveness of agency resources for surveillance.[1,4] This latest edition of *From Data to Action: CDC's Public Health Surveillance for Women, Infants, and Children* is well-timed to help fulfill the strategy's goals.

Epidemiologists and other public health officials work to detect, assess, and respond to events of public health importance. Surveillance in the maternal and child health (MCH) population is particularly important because of the large number of people impacted by MCH issues (e.g., women of reproductive age, their sexual partners, and children) and the potential long-term health consequences of MCH issues. For example, maternal mortality, although a rare event, has major long term consequences for the family and is a particular public health concern. Thus in 1986, CDC and many state health departments initiated pregnancy-related death surveillance in the United States to better understand causes of maternal death. Analysis of this surveillance data indicated an increasing pregnancy-related mortality ratio and a potential change in the risk profile of women giving birth, particularly in terms of chronic disease.[5]

Adapting and innovating surveillance to account for revised case definitions, new health-related events, new data sources, and protecting sensitive MCH data is a continuing challenge. Public health partners, particularly at the state, local, tribal and territorial level, frequently look to CDC for support and leadership in using and evaluating surveillance systems and using data to make impactful changes in health outcomes. Surveillance is the key to knowing what kind of response a health event needs and the magnitude of resources necessary. Emerging diseases like Zika virus reflect serious global MCH concerns with long-lasting implications and the need for surveillance across the lifespan for Zika-affected children. Zika surveillance among pregnant women and exposed infants is frequently sought, as well as mosquito surveillance and control, to provide effective public health protection.[6]

CDC's guidelines for evaluating surveillance systems[2] state, "Public health surveillance systems should be evaluated periodically, and the evaluation should include recommendations for improving quality, efficiency, and usefulness." Surveillance should be evaluated at three levels: 1) Public health importance of the event, 2) usefulness and cost, and 3) explicit attributes of the quality of the system (sensitivity, specificity, representativeness, timeliness, simplicity, flexibility, and acceptability).[7] Each year approximately 80 CDC Epidemic Intelligence Service (EIS) officers undertake surveillance evaluations as a first task of their applied epidemiology training. EIS is a two-year applied epidemiology fellowship program built on a foundation of learning and training through service. Other programs following this model of trainees evaluating surveillance include Council of State and Territorial Epidemiologists (CSTE) Applied Epidemiology Fellowship and the international Field Epidemiology Training Program (FETP). The surveillance evaluation training exercise can have real world implications and impact in improving surveillance systems and surveillance systems from states or other countries to track national and international events. These yearly projects contribute to ensuring surveillance systems get reviewed. The suggested improvements from the evaluations should be implemented to improve functioning. A recent systematic review of existing surveillance evaluation approaches highlights the need for regular and relevant surveillance system evaluations to improve performance and cost-effectiveness; it also demonstrated the need for more detail in completed evaluations to help evaluators effectively implement recommendations.[8]

For example, a recent surveillance evaluation in Liberia focusing on maternal mortality undertaken by an EIS officer demonstrates the lessons learned from the EIS training exercise in action. The maternal mortality rates in Liberia reflect the impact of a prolonged civil war followed by an Ebola outbreak that lasted for almost two years. While rates had started to decrease following the end of the war, those gains were lost during the Ebola outbreak. Estimates of the maternal mortality ratio range from 725-1,070/100,000[9,10] – one of the highest rates in the world. Rates are so high that in summer 2016, the Minister of Health declared maternal mortality a public health emergency. An EIS officer conducted an evaluation of the existing maternal mortality surveillance systems focused on identifying specific actions to improve surveillance. Surveillance that produces high quality data is an integral component in reducing deaths by allowing healthcare systems to identify and target the key preventable causes of and contributors to death. While it is too early to determine whether surveillance improved since the evaluation, it served to highlight the problem of discrepancies between two maternal death surveillance systems and identified areas for improved streamlining and integration.

Beginning epidemiologists often do not have experience evaluating MCH surveillance systems. Guidance from partners to identify potential issues surrounding field data collection and the use of CDC evaluation guidelines[2,3,7] provide essential supports for completing evaluation work. This is particularly true in situations where the evaluation involves comparing data collected from one or more systems across multiple data aggregation levels that can easily become both complicated and overwhelming. The use of both qualitative and quantitative data can provide both greater depth of analysis as well as rich context for understanding the environment within which surveillance takes place. Methods may include in-depth review of death registers and case files of facilities to identify if maternal deaths were not captured by existing systems; conducting key informant interviews at each level of the system (e.g., community, facility, district, national); assessing data for consistency, accuracy, congruence, and completeness.

However, the realities of the field both domestically and internationally - incomplete ledgers, missing patient charts, non-standardized forms, and local language barriers - create challenges for full use of the tools. Still valuable information can be gained despite these challenges. Past surveillance evaluation projects have been able to identify specific gaps or challenges in surveillance systems including: 1) infrastructure challenges (power, internet, and phone connectivity) that may lead to underreporting; 2) multiple incompatible systems operating to collect similar data; 3) reliance on inconsistent templates and forms creating opportunities for data entry error; and 4) lack of stakeholder buy-in around reporting.

Policy makers are often aware of some of these issues surrounding surveillance. This creates challenges to improve reporting of MCH outcomes given stakeholders often direct MCH resources towards intervention programs to reduce maternal and perinatal deaths. The best path to balance resources between surveillance and programmatic activities varies for each setting. Streamlining the reporting process from data collection to final reports by standardizing the forms and reporting mechanisms is vital and can help reduce staff burden as well as decrease reporting errors. Staff adequately trained in surveillance activities and data management can better ensure effective implementation of surveillance guidelines. Increasing supervisor oversight, follow-up, mentoring and incorporating leadership, and mentoring training for staff required to supervise these activities will also improve surveillance system functioning. Because evaluating systems is not a one-time event, follow-up evaluations completed on a regular basis are essential to ensure continued implementation of the evaluation recommendations.

Using this surveillance e-book and working collaboratively, MCH epidemiologists, from beginner to expert, can help ensure that data collected by surveillance systems and the evaluations of those systems, will lead to specific actions to improve data use, efficient functioning, and identification of improved evaluation methods. One trend affecting epidemiology identified in a 2015 epidemiology paper is the increased availability of data from previously atypical data sources. These atypical sources range from social media to billing data (big data) and the emerging ability to link social and demographic characteristics with data systems such as electronic health and laboratory records.[11] Epidemiologists will need to evaluate how large the bias is from these sources of surveillance data and whether better data sources exist to identify issues more efficiently and effectively. Evaluation will be imperative to improve surveillance with these new tools and to link research and practice.

In settings with limited resources, evaluating surveillance cannot always help answer the tough questions of resource placement but can provide guidance and evidence for making changes. Engaging those collecting the data to help them understand their importance to the success of surveillance can help with their investment in surveillance and ongoing evaluation. Continued follow-up is essential to inform additional changes needed, track if changes are occurring in morbidity and mortality, and continue an evidence-based plan for using the data to make informed and cost-effective decisions. This e-book will be valuable for both novice and expert epidemiologists to affect positive changes in maternal and child health.

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Overview

Public health professionals have always been concerned with measuring health events across the life span. Maternal and child health surveillance captures data on reproductive health, pregnancy, birth, infancy, childhood, adolescence. Public health planners need to know the data that are available and how to use that information. In turn, public health data systems need to respond to the needs of stakeholders by providing and interpreting data that can be translated into appropriate action. The demand for such information is rapidly increasing in the public health community and will become even more critical in the face of emerging public health crises and emergency preparedness and response.

This monograph is a step toward making the surveillance systems of the Centers for Disease Control and Prevention (CDC) more accessible to persons concerned with the health of women, infants, and children. It aims to note achievements from previous decades as well as identify new and ongoing challenges. Data needs evolve over time, and surveillance systems can adapt and respond to these challenges. This monograph offers health practitioners and planners at national, state, local and tribal levels a better appreciation of the uses and limitations of these surveillance systems, and enables us to think more critically about improvements in measuring the health of these populations.

According to CDC's formal definition, public health surveillance is the ongoing systematic collection, analysis, and interpretation of health data essential to the planning, implementation, and evaluation of public health practice, closely integrated with the timely dissemination of these data to those who need to know. In broad terms, public health surveillance is the monitoring of diseases, injuries and conditions for their frequency, risk factors, consequences, and health service needs. Examining and interpreting the reported data, recommending and implementing public health action, and evaluating that action through continued surveillance are critical steps to move data for action to reduce mortality and morbidity and improve outcomes.

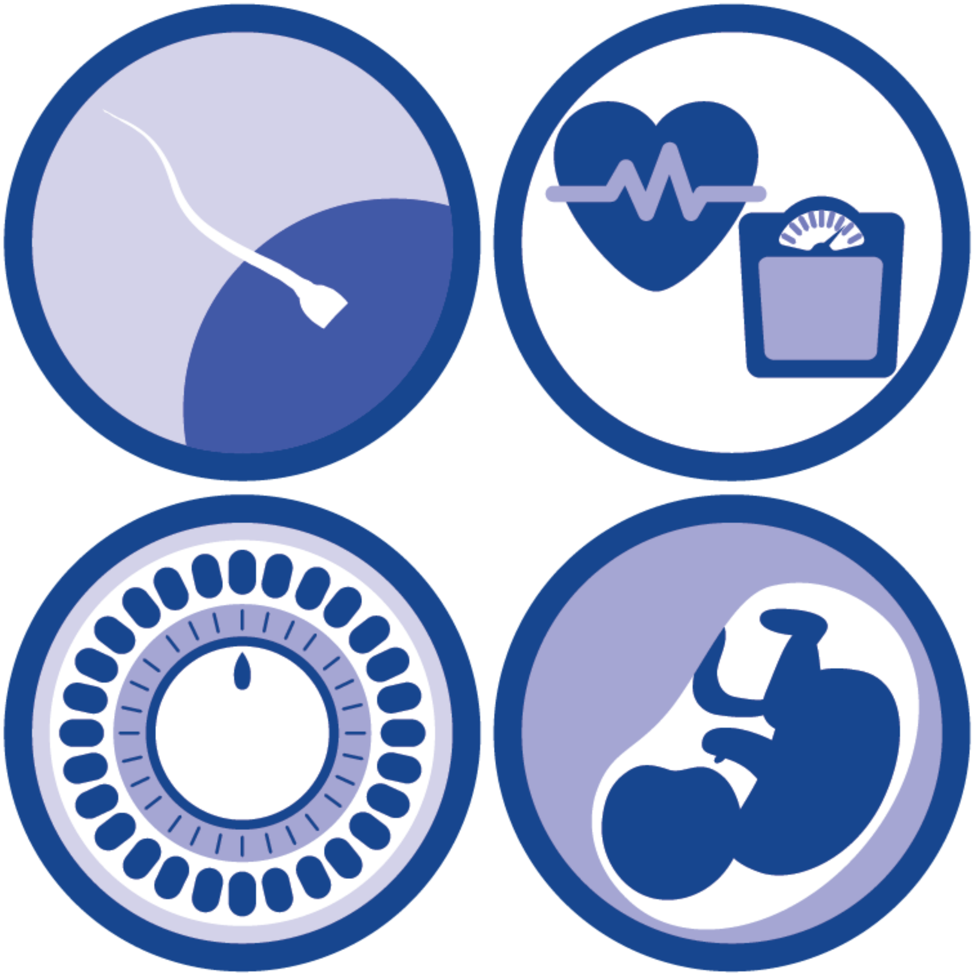
The first section in this monograph describes topics related to reproductive health including contraception, infertility, sexually transmitted diseases, and men's reproductive health. The second section addresses preconception health and healthcare, prenatal care, pregnancy-related morbidity and mortality, vaccine preventable diseases during the perinatal period, fetal death and global maternal and perinatal health. The third section on infant health includes topics related to birth weight, preterm birth, breastfeeding, newborn screening, birth defects, Sudden Unexpected Infant Death and infant mortality. The fourth section discusses the health of the growing child, including vaccine preventable diseases, environmental hazards, injury, childhood nutrition and developmental disabilities. The fifth section focuses on issues to consider as adolescents mature to young adulthood including youth risk behaviors, teen pregnancy and birth and injury and violence.

Each chapter describes surveillance for a public health topic in terms of 1) public health importance, 2) history of data collection, 3) CDC surveillance systems, 4) general findings, 5) data gaps and limitations, 6) examples of using data for action, and 7) future issues regarding the surveillance of each topic.

This monograph is not intended to provide step-by-step instructions on the analysis of surveillance data. It does discuss the utility of data published from these data-collection systems, and it provides examples, references, and additional resources for public health professionals who would like to know more about surveillance for these topics. In addition, this monograph does not exhaust the list of surveillance programs at CDC that include reproductive and child health data, nor does it include all topics that are important to for promoting the health of women, infants and children. As with any monograph, there are topics that could have been included, and topics included that could have received more attention. Strategies related to data modernization, such as machine learning and data linkages are not discussed in depth but are important strategies to consider. Nevertheless, we believe these chapters will be useful in bringing to the forefront these important surveillance issues in the field of women and children’s health.

Special thanks to authors of the commentaries and chapters who devoted their time over a period from 2016 to 2018 developing content. Since then, many surveillance systems, including Vital Statistics and the Pregnancy Risk Assessment and Monitoring System (PRAMS), have sped up the release of data. As such, much of the general findings described are not the most recent data available at the time of publication, yet the surveillance systems, strengths and limitations of data, trends, and disparities have mostly remained the same. Of note, topics areas covered demonstrate persistent racial, ethnic, and geographic disparities in maternal and child health. Applying a health equity lens to the interpretation and utilization of surveillance data is a critical step to identify and deploy strategies for action that can support improvements in health outcomes for populations most impacted.

We hope that these books will continue to be useful to our partners in the field of women and children's health and that this monograph will aid in collecting, examining, and applying data to improve the health of women, infants and children.



Reproductive Health

Commentary on Reproductive Health

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Surveillance is an essential tool to document trends in reproductive health outcomes, expose health inequities, and identify underlying factors that drive these inequities. Surveillance data, in turn, can help inform and evaluate program and policy efforts to improve health and, in particular, close the gaps in reproductive health outcomes among different population groups. While national data are essential for understanding overall trends and developing national policy, conducting surveillance at the state and local levels is equally important, given state-by-state differences in reproductive health outcomes, access to reproductive health services, demographics, and social and economic conditions.

At the New York City Department of Health and Mental Hygiene (DOHMH), we have embraced a sexual and reproductive justice (SRJ) framework that informs our work, including surveillance. This approach was adapted from the Reproductive Justice framework developed in 1994 by Black women to acknowledge and incorporate the historical and ongoing injustices faced by women of color into a social justice and human rights approach to reproductive health.[1] Applying this framework, we have come to realize that while surveillance on reproductive health outcomes such as contraceptive use is important, so is identifying measures to assess whether individuals are receiving comprehensive, woman-centered counseling to inform and support their decision-making on conception. The SRJ framework challenges us to rethink the kinds of data collection questions we should be asking on contraception (and other reproductive health outcomes), in order to promote individual agency and ensure that all women have the ability to make informed decisions about their reproductive health. It also challenges us to incorporate new questions and/or data sources to better contextualize our findings, including structural factors that impact on reproductive outcomes such as poverty, housing, and racism.

The DOHMH administers the *New York City Community Health Survey (CHS)*, an annual telephone survey based upon the CDC's *Behavioral Risk Factor Surveillance System*, to collect data on the health of New Yorkers. In 2013, several questions related to contraception were added to the survey with the intention of acquiring population estimates of contraceptive use and pregnancy planning. This data helps us identify unmet need for family planning services, evaluate existing programmatic work to fulfill that need, and guides future initiatives. We are also able to analyze these findings with other CHS variables that may impact contraceptive use, including health insurance coverage and household poverty.

In some cases, reproductive health surveillance data can reveal missed opportunities for public health action. In adherence to CDC guidance, the DOHMH adapted the *Induced Termination of Pregnancy (ITOP)* form to collect data on induced abortion procedures performed in New York City. This form provides valuable demographic and epidemiological information, which can be used to identify priority areas for programmatic work. Analysis of these data revealed that 53.8% of the induced abortion procedures were to women who had at least one previous abortion.[2] This led to the question of whether contraception was available to women immediately following an abortion. To this end, a question was added to the *ITOP* form in May of 2012 soliciting information on the contraceptive method prescribed or dispensed at the time of the abortion procedure. Data analysis revealed that across all abortion providing facilities citywide, only 38.2% of patients are prescribed or dispensed a contraceptive method immediately following their procedure.[2] As a result, the DOHMH discovered a gap in family planning service delivery and identified increasing access to immediate post-abortion contraception as an important public health strategy. One fundamental piece of this work has been provider engagement, which includes provider training and education, as well as the development and dissemination of a guidance document on best practices for immediate post-abortion contraception, including offering counseling on contraceptive options and making all contraceptive methods available for patients who would like to start a method the same day as their abortion procedure.[2]

A deeper dive into the data can also illuminate disparities in risk factors that underlie disparate health outcomes. The Pregnancy Risk Assessment Monitoring System (PRAMS) is an integral part of the NYC reproductive health surveillance toolkit, as it provides information on attitudes, experiences and behaviors around the time of pregnancy; PRAMS sites can add questions to the core surveillance tools to address local needs. For example, there is considerable evidence that psychosocial stress *(*defined as stressful life events including death, job loss, and relationship conflict), both prior to conception and during pregnancy, plays an important role in birth outcomes and is associated with increased risk of lower birth weight and pre-term birth.[3,4] In addition, 'racism stress,' often measured at the individual level as perceived exposure to racial prejudice, is associated with higher risks of preterm birth and low birth weight.[5-7] In examining stressors among New York City women in the twelve months before giving birth, we found that 40% of Black women reported three or more stressors, compared to 12% of White women, 26% of Latina women, and 18% of Asian or Pacific Island women.[8] We also added a question about racism stress, and found that 20% of Black women reported experiencing racism stress in the twelve months before giving birth. These findings speak to the role of data in helping us understand racial/ethnic disparities in health outcomes and to develop strategies to address them.

Reproductive health data surveillance is also critical for establishing the connection between chronic disease – including obesity, hypertension, diabetes, and heart disease – among women of reproductive age and adverse maternal and infant health outcomes, including severe maternal morbidity, maternal mortality, and infant mortality. While these health outcomes are covered in later chapters of this monograph, health before pregnancy, or preconception health, drives these outcomes. In a recent data report, *Pregnancy-Associated Mortality, New York City, 2006-2010*, more than half of women who experienced a pregnancy-related death had a pre-existing chronic condition, most commonly obesity.[9] Striking racial disparities were also observed, with Black women 12 times more likely than White women to die from pregnancy-related causes.[9] As noted in the report:

> Although the causal relationships for the increased risk of death for Black, non-Hispanic women are not well established, pregnancy-related mortality is associated with obesity, underlying chronic illness and poverty – all conditions that disproportionately affect New York City's Black population. The chronic stress of racism and social inequality also likely contribute to racial disparities in health, such as differences observed in infant mortality, preterm birth and low birth weight, and may play a role in pregnancy-related mortality, as well.[9]

Health equity is an important lens through which to view public health surveillance. Disparities in reproductive health outcomes are visible across racial and ethnic groups, as well as income levels. In addition to monitoring health outcomes and trends, data are needed on social determinants of health and structural factors, such as education, employment, and racism, as these data impact health outcomes and drive disparities. Our surveillance can help tell this story and assure that solutions include efforts to address societal and neighborhood factors and injustices that play a critical role in determining health behaviors and outcomes.

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Contraception

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The National Survey of Family Growth (NSFG), along with other complementary data, provides information used to monitor the use of contraception. These data provides measurable targets related to the Department of Health and Human Service's Healthy People objectives on reducing unintended pregnancies and improving contraceptive access. As with other survey data, timeliness of data releases and declining response rates challenge the use of the NSFG for action.

PUBLIC HEALTH IMPORTANCE

Family planning, defined as "the ability to achieve desired birth spacing and family size," was noted as 1 of 10 "achievements in public health" in the 20th century because of its contributions to the health of infants, children, and women.[1] Reducing the percentage of all pregnancies that are unintended has been one of the national Healthy People health promotion objectives since they were first established in 1980.[2-4] Reducing teen pregnancy rates by 20% between 2007 and 2015 was also set as a target for the Centers for Disease Control and Prevention's (CDC) Winnable Battles and has been met and exceeded.[5,6] Use of contraception and the effectiveness of the method used to prevent pregnancy are major factors affecting pregnancy and birth rates and the ability of women and their partners to plan their pregnancies and avoid unintended pregnancies. Medical professionals, researchers, policy makers and others rely on information about contraception use to inform patients, develop public policy, and plan health and social service programs.

HISTORY OF DATA COLLECTION

National data on contraception for the United States has been produced from the National Survey of Family Growth (NSFG) since 1973. The NSFG, conducted by the National Center for Health Statistics (NCHS), is designed to provide national data that supplement and complement the National Vital Statistics data on registered births in the United States by collecting data on the factors that affect those birth rates — including sexual activity, marriage, divorce, cohabitation, infertility, and contraceptive use. The survey is nationally representative of women and men ages 15 to 44 years in the household population. The data are used to describe and understand subgroup differences and changes over time in contraceptive use, pregnancies, and births.

The NSFG was first conducted in 1973 (Cycle 1) with Cycles 2-6 conducted periodically in 1976, 1982, 1988, 1995, and 2002. In 2006 the NSFG shifted to continuous interviewing allowing for more frequent data releases, greater responsiveness in changes to survey content, and cost control. Except for a break from mid-June 2010 to mid-September 2011 to award a new fieldwork contract, interviewing has been continuous from June 2006 to the present time. The NSFG initially included only women, but an independent sample of men was added starting in 2002. After release of the 2006 to 2010 public use files, NSFG data, under the continuous fieldwork design, have been released about every two years (2011 to 2013 and 2013 to 2015) thus far. The response rate for the most recent file release, 2013 to 2015 data, was 69.3% (71.2% for female respondents and 67.1% for male respondents). The NSFG age range was expanded from 15 to 44 years to 15 to 49 years beginning with interviews conducted in September 2015. For additional historical information on the NSFG, see the 2011 to 2013 methodology reports on the NSFG website; the reports describing the survey design and methodology for 2006 to 2010;[7,8] or the chapter on contraception in the earlier edition of this book.[9]

CDC SURVEILLANCE ACTIVITIES

As the main CDC surveillance activity on contraception, NSFG's data files released in October 2016 include data from 10,205 interviews conducted from September 2013 to September 2015 with 4,506 men and 5,699 women. The NSFG interview includes a variety of questions about contraceptive use. In the female questionnaire, women are asked to report on monthly use of contraception and sexual activity for up to four years before the interview using a life history calendar. In addition to detailed information on current use and pregnancy risk, women are asked to report about contraceptive methods they have ever used in their lifetime, the first method ever used, the method used at first sexual intercourse, the method used with recent partners, consistency of method use, and method discontinuation.

NSFG data are relied upon routinely to provide timely profiles describing methods used in a woman's lifetime as well as current method use defined as "use at the time of the interview." The life history calendar reporting of monthly method use and sexual activity, along with pregnancy histories, collected in the interview are also used to produce population-based estimates of contraceptive method failure,[10] infertility,[11] and postpartum method use[12] among other topics. The NSFG also collects information on the use of family planning services, including checkups, counseling, and receipt of a contraceptive method or prescription for a method.[13]

The male NSFG questionnaire includes a variety of questions about contraceptive use but does not include a life history calendar as used in the female questionnaire. Male NSFG respondents are asked about contraceptive use at their first and last (or most recent) sex with current spouses and cohabiting partners, partners in the last 12 months, and their first partner ever.

While the NSFG is the main CDC surveillance activity on contraception, it is not the only one. The Youth Risk Behavior Surveillance System (YRBSS) is a national survey of health and health risk behaviors that includes questions on contraceptive use among high-school students and also permits analysis at the state and local levels.[14] The Pregnancy Risk Assessment Monitoring System (PRAMS) is a coordinated effort among CDC and state health departments to collect information on the health of mothers and infants based on a sample of recent live births from birth certificate data and produce population-based state estimates.[15] PRAMS respondents are asked about contraceptive use before they became pregnant and after the birth of their child. The Behavioral Risk Factor Surveillance System (BRFSS) is a state-based survey of adults ages 18 years and older about their health, health-risk behaviors, and use of preventive services, which includes questions on contraceptive use by women that have been used to describe risk for unintended pregnancies.[16]

GENERAL FINDINGS

NCHS regularly publishes reports based on NSFG data to update population estimates of contraceptive methods by women's current contraceptive status (a "snapshot" of US women based on the month of interview) as well as ever used by women ("lifetime" up to the time of interview). [17, 18] Current contraceptors are also examined by their specific method used and non-contraceptors by their reason for not using contraception.[17,18] MSFG has been used o develop a series of reports that provide more detail on contraceptive use and describe variation by characteristics such as age, Hispanic origin and race, educational attainment, marital status, parity, religion, and expectations for additional births.[17-19] Other NSFG reports focus on teenagers and describe their contraceptive use and sexual activity.[20] A bibliography of reports and journal articles published using NSFG data is available on the NSFG website (https://www.cdc.gov/nchs/nsfg/index.htm).

Current contraceptive status

Table 1 shows current contraceptive status for all women ages 15 to 44 years in 2011 to 2015 based on information provided for the month of interview. The table shows women currently using contraception and breaks them down by the specific methods they are using as well as women not using contraception by their reasons for non-use.

Table 1. Number of women aged 15-44 years and percent distribution of women aged 15-44 by current contraceptive status: United States, 2011-2015.

	Number in thousands
All women	61,263
	Percent distribution (standard error)
Total	100.0
Using contraception (contraceptors)	61.6 (0.70)
Female sterilization	14.3 (0.66)
Male sterilization	4.5 (0.32)
Pill	15.9 (0.60)
Long-acting reversible contraceptives (LARC)	8.0 (0.41)
Intrauterine device	6.8 (0.38)
Implant	1.2 (0.15)
Injectables (Depo-Provera™)	2.6 (0.17)
Contraceptive ring or patch	1.7 (0.20)
Diaphragm	*
Condom	9.2 (0.41)
Periodic abstinence—calendar rhythm	1.0 (0.14)
Periodic abstinence—natural family planning	0.2 (0.05)
Withdrawal	3.9 (0.28)
Other methods[1]	0.4 (0.08)
Not using contraception[2]	38.4 (0.70)
Surgically sterile—female (noncontraceptive)	0.7 (0.10)
Nonsurgically sterile—female or male	2.1 (0.18)
Pregnant or postpartum	5.0 (0.31)

Seeking pregnancy	4.6 (0.27)
Other nonuse	
Never had intercourse	10.9 (0.50)
No intercourse during 3 months before interview	7.9 (0.38)
Had intercourse during 3 months before interview	7.1 (0.30)
* Figure does not meet NCHS standards of reliability or precision.	
[1]Includes other methods available during that time period, not shown separately above.	
[2]Includes all other reasons for nonuse not included below.	
NOTES: Percentages may not add to 100 due to rounding.	
SOURCE: CDC/NCHS, 2011-2015 National Survey of Family Growth, specially tabulated by NCHS for this chapter.	

Table 1 shows that in 2011 to 2015 among women aged 15 to 44 years, 61.6% were currently using a method of contraception. The pill and female sterilization were the leading methods among all women ages 15 to 44 years; about 15.9% of women were currently using the pill, and 14.3% were relying on female sterilization, together accounting for nearly one-third of all women. Almost 10% of women and their partners relied on the male condom (9.2%). Looking at the use of intrauterine devices and contraceptive implants, 8.0% of women reported the use of one of these long-acting reversible contraceptive (LARC) methods.

About 38.4% of women ages 15 to 44 years in 2011 to 2015 were not currently using contraception. About 10% of women were not using contraception because they were seeking a pregnancy (4.6%) or pregnant or postpartum (5.0%). About 11% of women were not using contraception because they had never had intercourse.

Ever use of contraception

Table 2 shows ever use (use in their lifetime to time of interview in 2011 to 2015) of contraception among women who have ever had sexual intercourse (also called sexually experienced women) based on the NSFG data from 2011 to 2015. While Table 1 describes current contraceptive status for all women ages 15 to 44 years in 2011 to 2015, the population of interest for Table 2 is reduced to sexually experienced women.

Table 2. Number of women aged 15-44 years who have ever had sexual intercourse and percentage who have ever used the specified contraceptive method: United States, 2011-2015.

All women (in thousands)	53,580		

Method	Percentage (standard error)		
Any method	99.3	(0.12)	
Female sterilization	17.1	(0.75)	
Male sterilization	11.4	(0.55)	
Pill	79.3	(0.74)	
Long-acting reversible contraceptives (LARC)	18.0	(0.68)	
Implant	3.5	(0.28)	
Intrauterine device (IUD)	15.0	(0.63)	
1-month injectable (Lunelle™)	0.4	(0.08)	
3-month injectable (Depo-Provera™)	25.4	(0.80)	
Contraceptive patch	10.6	(0.41)	
Contraceptive ring	10.9	(0.53)	
Emergency contraception	20.0	(0.70)	
Today™ sponge	1.7	(0.19)	
Diaphragm	1.6	(0.17)	
Condom	95.0	(0.35)	
Female condom	1.4	(0.15)	
Periodic abstinence, calendar rhythm[1]	16.3	(0.63)	
Periodic abstinence, natural family planning	3.3	(0.28)	
Withdrawal	64.8	(0.93)	
Foam alone	3.9	(0.32)	
Jelly or cream alone	2.4	(0.21)	
Suppository or insert	2.0	(0.23)	
Other methods[2]	0.5	(0.11)	

[1] In 2013-2015 a second question was added about specific types of calendar rhythm methods.

[2] Includes the cervical cap and other methods.

SOURCE: CDC/NCHS, 2011-2015 National Survey of Family Growth, specially tabulated by NCHS for this chapter.

Among women who have ever had sexual intercourse, 99.3% had ever used any contraceptive method and 17.1% reported that they had received a sterilizing operation. Looking at use of the male condom and oral contraceptive pill, 95.0% of women reported that they or their partners had ever used a male condom and 79.3% of women reported that they had ever used the oral contraceptive pill. About 64.8% of sexually experienced women reported having used the withdrawal method sometime in their lives. Fifteen percent of sexually experienced women reported ever having used an intrauterine device (IUD) and 20.0% had ever used emergency contraception.

DATA GAPS AND LIMITATIONS

While the NSFG provides nationally representative data for men and women ages 15 to 44 years in the US household population, this data source has some limitations for population surveillance purposes including those related to contraceptive use. Due to the survey design, the NSFG cannot be used to produce estimates for single calendar years or for specific states. In addition, although interviewing is ongoing, questionnaire changes can only be made at certain times during the survey contract period, which limits how responsive the survey content can be to emerging health issues. Also, given the sample size of the NSFG, estimates on some rare behaviors cannot be produced due to the risk of disclosure of respondents and concerns about the statistical reliability of estimates from small sample sizes. This limits the ability of the NSFG, and other surveys with similar sample sizes, to be used to collect information on rare behaviors or characteristics. Finally, while the NSFG includes a wealth of information about contraceptive methods individuals have used over the course of their lifetime, there is less information in the survey about correct or consistent use of the reported methods. Questions are limited to asking about correct and consistent recent use of condoms, consistency in use of condoms or any method of contraception in the past year, and frequency of missed oral contraceptive pills in the past four weeks.

The other datasets mentioned earlier in this chapter can fill some of the gaps in information from the NSFG, such as the ability to produce state estimates, but they lack the detail available in the NSFG and have their own limitations such as sampling only a subset of women (e.g., women with recent live births as in PRAMS; high school as in YRBSS). BRFSS makes a family planning module available that states can choose to add on their state surveys to produce state estimates of recent contraceptive use for all women of reproductive age, but without the same level of detail available in NSFG. Researchers interested in learning more about the strengths and weaknesses of these other data sources can learn more on their websites listed below in the additional resources section.

USING DATA FOR ACTION

Numerous federal agencies and other researchers rely on NSFG data files or information presented in NCHS' periodic reports as benchmarks or to monitor progress toward a set public health goal. As mentioned above, NSFG data have been used to track progress toward some of the national Healthy People health promotion objectives since they were established in 1980. For example, Healthy People 2020 family planning (FP) goals FP-10 and FP-11 are to increase the proportion of sexually active persons aged 15 to 19 years who use condoms (FP-10) and to increase the proportion of sexually active persons aged 15 to 19 years who use condoms and hormonal or intrauterine contraception (FP-11) to prevent pregnancy and provide protection against sexually transmitted infections.[4] FP-16 is to increase the percentage of women ages 15 to 44 years who adopt or continue using the most effective or moderately effective methods of contraception. NSFG data are used to track progress toward these and other Healthy People goals. The Office of Population Affairs relies on the NSFG for data on the use of family planning services. *Health, United States*, the annual report on health statistics from CDC, includes information on contraceptive use from the NSFG.[21]

The contraceptive use data from NSFG has also been used to evaluate potential responses to changes in the public health system. The shift to continuous interviewing and more frequent file releases allows for more research using the NSFG that focuses on responses to recent changes. For example, numerous studies using the NSFG describe time trends in use of LARC methods. These have been used to explore possible changes after the passing of the contraceptive mandate as part of the Affordable Care Act.[22-24] Because the age range of the NSFG includes teens ages 15 to 19 years and asks all respondents about method use or non-use at first intercourse, the NSFG has become a widely used source for research on teen sexual activity and contraceptive use.[25-27] The information on contraceptive use among teens, along with information about abstinence from sexual activity, has been used to help examine declines in the teen birth rate as shown in National Vital Statistics Reports.[28,29]

Another example of NSFG data being used for action is the calculation of contraceptive method failure rates. Manufacturers of contraceptive methods provide estimates of contraceptive failure when methods are used exactly as directed (called ‘perfect use failure rates’) based on clinical studies. The month-by-month information available about recent sexual activity and contraceptive method use along with information about intended and unintended pregnancies during the same timeframe is used by researchers to calculate an additional set of method failure rates when used in the household population. These estimates are called ‘typical use failure rates’. NSFG data have been relied on for calculations of typical use failure rates for some contraceptive methods for many decades.[30]

FUTURE ISSUES

As large surveys continue to serve as the main source of national data on contraception, issues related to rising costs of survey administration, including decreasing response and eligibility rates, may challenge the ongoing production of high-quality data related to contraception use and behavior. Specific to contraceptive use, the NSFG is also challenged to remain up to date by including newer contraceptive methods in the questionnaire. As mentioned previously, despite the shift to continuous interviewing, substantial changes to the questionnaire can only be made periodically. Failure to keep up to date on new methods, such as newer types of intrauterine devices and to ensure they are added to the questionnaire as soon as possible, will limit the usefulness of the NSFG, and potentially other surveys, in describing and examining recent changes in specific contraception use. The NSFG and other surveys will also need to continue to produce timely, regular data to ensure that long-term trend evaluation may continue.

ADDITIONAL RESOURCES

- The National Survey of Family Growth
  http://www.cdc.gov/nchs/nsfg/index.htm
- CDC Division of Reproductive Health https://www.cdc.gov/reproductivehealth/index.html
- Office of Population Affairs
  https://www.hhs.gov/opa/
- Youth Risk Behavior Surveillance System
  https://www.cdc.gov/healthyyouth/data/yrbs/
- The Pregnancy Risk Assessment Monitoring System
  http://www.cdc.gov/PRAMS/index.htm
- The Behavioral Risk Factor Surveillance System
  https://www.cdc.gov/brfss/
- Healthy People 2020
  https://www.healthypeople.gov/

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Unintended Births in the United States

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This chapter describes and presents key aspects of the topic of unintended pregnancies and births: it summarizes the importance of the topic of unintended pregnancy and birth in the United States; describes sources of national data; and describes data that is used for monitoring the prevalence and trends in the United States. Background and details are provided for the measurement of intendedness, or wantedness, of pregnancies in the National Survey of Family Growth (NSFG). NSFG data are used to present estimates of, and trends in, unintended births through 2015, and data limitations are described. The chapter concludes with examples of how the data are used, and future issues that warrant exploration to further understanding of this topic.

PUBLIC HEALTH IMPORTANCE

Reduction of unintended pregnancy is a public health priority given its associations with risks to health and wellbeing at the individual level and costs at the societal level.[1,2] Just under half of all pregnancies and one-third of births in the United States are unintended by the mother at the time she becomes pregnant.[3,4]

Disparities exist in rates of unintended pregnancy and births in the US. Unintended pregnancies and births are more likely to occur among teenagers, women who are unmarried, those with low income, those with less than a college education, and non-Hispanic black women (as compared to non-Hispanic white and Hispanic women). These disparities have been documented for pregnancies since the early 1980s and for births since the early 1970s and persist to this day.[3,5-12]

Unintended pregnancy is associated with adverse maternal and child health and wellbeing, although the nature of the linkages is difficult to establish and continues to be the subject of research.[2,13] Studies find a link between mistimed and unwanted pregnancies and lower likelihood of early prenatal care and a higher likelihood of cigarette smoking during pregnancy, even after taking into account differences in background characteristics between mothers with unintended births and those with intended births,[14-17] although not all studies find evidence of an independent association regarding smoking. Some studies have found unintended pregnancy to be associated with low birth weight,[15] and further, that this association operates through detrimental maternal behaviors.[18] Research consistently finds a relationship between unintended pregnancy and breastfeeding; mothers with unintended pregnancies are less likely to initiate breastfeeding and breastfeed for shorter durations.[19,17,20,21] There is some evidence that the cumulative effects of these outcomes persist beyond childhood in ways that include poorer quality mother-child relationship and mental health problems.[22,19,20,23,24,25]

Since unintended births occur disproportionately to women with lower incomes, maternity and infant care for these births is more likely to be covered by public insurance programs including Medicaid, compared to births from intended pregnancies. The public-sector cost associated with maternity and infant care for unintended births in 2006 was estimated at $11.1 billion.[1]

The importance of unintended pregnancies to public health is explicitly recognized by its inclusion in the Department of Health and Human Services public health initiative, “Healthy People,” since it began in 1978, continuing through the most recent iteration, “Healthy People 2020.”[26] Reducing the prevalence of, and disparities in, unintended pregnancies is among the group of objectives under the topic Family Planning.[27]

HISTORY OF DATA COLLECTION

This section describes three sources of nationally representative data on unintended pregnancy: the National Survey of Family Growth (NSFG), the Pregnancy Risk Assessment Monitoring System (PRAMS), and the National Longitudinal Survey of Youth (NLSY).

The National Survey of Family Growth (NSFG is a multi-purpose survey conducted by the National Center for Health Statistics (NCHS)). The NSFG provides nationally representative data that supplements data on registered births in the United States from the National Vital Statistics system. Topic areas covered by the survey in addition to wantedness of pregnancies include: marriage and cohabitation, sexual activity, STD risk behaviors, use of contraception, infertility, and use of family planning services. The first NSFG surveys were conducted by the National Center for Health Statistics in 1973, 1976, 1982, 1988, and 1995 with interviews of women aged 15-44 years; men of the same range were added with the 2002 cycle. Beginning in 2006, the NSFG shifted from periodic to continuous interviewing to allow for more frequent data releases and increased efficiency of operations. Continuous interviewing is ongoing, and data files have been released for interviews conducted in 2006-2010, 2011-2013, and 2013-2015. The NSFG age range was expanded from 15-44 years to 15-49 years beginning with 2015 interviews. The response rates for two recent releases of the NSFG are as follows: 77% in the 2006-2010 NSFG and 73% in the 2013-2015 NSFG. A large body of reports and research using the NSFG wantedness data focuses on unintended births, that is, pregnancies ending in live birth that were unintended at conception. NSFG can also be used to estimated wantedness among pregnancy outcomes other than live births (e.g. fetal loss or abortion). Given the underreporting of pregnancies ending in abortion in all self-reported survey data, including the NSFG, estimates of unintended pregnancies regardless of pregnancy outcome (that is, live birth, fetal loss, or abortion) are sometimes supplemented with data from the Guttmacher Institute's Abortion Provider Census. More information can be found in the "CDC Surveillance Activities" section in this chapter.

Results from NSFG are used for a range of purposes, including tracking national health objectives, informing health and social policies and programs, evaluating reproductive health services and receipt of services, and for statistical studies based on the wide range of topics covered in the survey. Reports are available which provide more information on the history of the NSFG and details about operations and design.[28,29]

Another source of data on unintended births that provides state-level estimates (for live births) is the Pregnancy Risk Assessment Monitoring System (PRAMS). PRAMS is a mixed mode survey, which includes mailed questionnaires and telephone follow-up calls, developed in 1987 between CDC, 13 states and the District of Columbia. All PRAMS reporting areas use a standardized data collection method developed by CDC. This standard method includes mailed questionnaires beginning two to three months after the delivery of a live-born infant to allow for collection of information related to postpartum maternal and infant experiences and up to 15 telephone follow-up calls with non-responders during the first nine months of the postpartum period. Findings from each state's PRAMS' samples are generalizable to that state's population of recently post-partum women with a live birth. Over time, participation in PRAMS has increased to include 47 states, the District of Columbia, the Great Plains Tribal Chairmen's Health Board (GPTCHB), New York City and Puerto Rico. As a result, 83% of all live births in the United States are represented in PRAMS.[30] Standardization of

PRAMS data collection methods across all participating states allows for interstate comparisons. Response rates vary by state and by year. PRAMS data for states that meet a predefined response rate threshold is made available for researchers; the majority of states meet this threshold.

The National Longitudinal Survey of Youth (NLSY) is another survey with a history of collecting data on wantedness of pregnancies. It is one of a collection of surveys sponsored by the US Bureau of Labor Statistics (BLS) and conducted by the Center for Human Resource Research at Ohio State University. There are two cohorts of the NLSY: the earlier, begun in 1979, contains questions on wantedness of pregnancies very similar to those on the NSFG; the later cohort, begun in 1997, did not include these questions. The NLYS79 is a national probability sample of 12,686 young adults aged 14 through 21 years in 1979. Respondents were interviewed annually through 1994 and biennially thereafter, and the retention rate has remained very high. The most recent wave, conducted in 2012, had a retention rate of 73.3%. Health and developmental information is also collected on respondents' children born within the study window. Even though the sample's age range with wantedness data is limited, this dataset provides a valuable opportunity to examine the associations and causal effects of pregnancy intendedness on mother and child outcomes over time.[31,32,20] Given the NLSY's cohort design, it cannot be used for surveillance of the prevalence of unintended pregnancies or births in the US population, but it provides valuable data for research on its causes and consequences.

CDC SURVEILLANCE ACTIVITIES

The NSFG is the primary source of nationally representative data on pregnancy intendedness.[33] From each female interviewed, the NSFG collects a complete history of pregnancies, regardless of outcome, asking about dates, characteristics, circumstances and selected maternal behaviors surrounding them, including the intendedness of each pregnancy at time of conception. Many published reports focus on unintended births.[6-10] Births are one of three possible outcomes of pregnancy, the other two being spontaneous fetal loss and induced abortion. These reports focus on live births because pregnancies resulting in abortion tend to be underreported in this and other such surveys.[34] Findings that focus on births unintended at conception are of special interest given documented associations of wantedness with factors affecting maternal and child wellbeing, such as prenatal care, breastfeeding, and longer-term effects throughout childhood. Surveillance of unintended pregnancies provides a picture of prevalence including all possible pregnancy outcomes. It requires special analysis using the NSFG wantedness data in addition to the Abortion Provider Census (APC), described in the previous section, to allow for the correction of this underreporting. The APC has been conducted 17 times since 1973 with the most recent occurring in 2014.[35] Analyses by the Guttmacher Institute, combining the NSFG data, the APC and vital statistics data on live births, provide a series of estimates on unintended pregnancies spanning 1994 through 2011.[3,11,12,36,37]

Statistics on unintended births using data for men have also been published,[4,38,39] although not as regularly. Measures of men's wantedness for their partners' pregnancies, resulting in live births, provide trend data beginning with 2002 and covering more than a decade.

The standard measure of unintended pregnancy is based on a series of questions that ask respondents to think about the time right before they became pregnant. Their responses to this series results in pregnancies categorized into three groups: intended (occurred at the right time or later than wanted); mistimed (occurred too soon); and unwanted (occurred when the woman wanted no (more) future pregnancies). This measure provides an important demographic perspective on pregnancies in the US and is recognized as the indicator for the US of long-term trends and differentials, given the consistency in the questions and wording used since the earliest surveys.[40] It has served as a model for questions in other surveys with this purpose.[41,42] However, by the 1990s, analysts had recognized the need for additional measures to capture nuances, multiple dimensions, and differing meanings of pregnancy wantedness for different subgroups.[43,44] Questions were thus added to the 1995 survey to supplement the existing series:

- A question asking the respondent to choose a number from 1 to 10 representing how happy or unhappy she was when she found out she was pregnant. (This scale has also been included on the male questionnaire since 2002, referring to his partner's pregnancy.) This question addressed the need to distinguish between different dimensions of intendedness: "intentionality or planning plus an affective dimension expressing happiness or dismay over being pregnant."[44]

- A question for those who reported their pregnancies occurred "too soon," asking how many months or years too soon the pregnancy occurred. Analyses have shown that pregnancies that occurred two or more years too soon are closer to those that were unwanted, in terms of their consequences, than those occurring less than two years too soon.[15,43]

Further enhancing the series beyond the standard questions, beginning with the 2002 NSFG, several more questions were added to the series for females:

- Two scales asking respondents to choose a number from 0 to 10, representing: 1) how much she was trying to/trying not to get pregnant (behavioral dimension); and 2) how much she wanted to avoid a pregnancy/get pregnant (affective dimension).[45]

- A question asking if she wanted/did not want a baby *with that partner.*

- For respondents who were not using contraception before the unintended pregnancy, a question capturing the reasons for nonuse of contraception.[46]

These measures added in 1995 and 2002 have been used extensively by researchers to model pregnancy wantedness/intendedness to capture additional complexities of women's experiences.[47]

PRAMS provides data on attitudes, behaviors and experiences before, during and after pregnancy[48,16] among women with a recent live birth. Topics include prenatal care and infant health measures, in addition to wantedness of most recent pregnancy resulting in live birth.[49] These data are used by researchers and state officials to improve maternal and child health (MCH) and allow assessment of the impact of state policies, including health care coverage and family planning and reproductive health services.[48,50] Analyses of PRAMS allows estimates of unintended births and related factors such as contraceptive use preceding pregnancies.[51] Estimates can be presented for the states reporting with a sufficient response rate at the time of the analysis, which has grown with time to include a larger number of states[52] and for individual states.[14,52,53]

Wantedness of births at time of conception is determined in PRAMS by responses to questions with categories comparable to those from the NSFG. Women classify themselves as having wanted to become pregnant later (classified as a mistimed pregnancy) or not having wanted to become pregnant at that time or any time in the future (classified as an unwanted pregnancy) or "I wasn't sure what I wanted" (classified as ambivalence or uncertainty). Women who reported a mistimed pregnancy were also asked how much longer they wanted to wait to become pregnant (analogous to "How much too soon did the pregnancy occur?" in the NSFG, described above). In addition, some states elected to add a question assessing how hard the woman was trying to get pregnant or avoid pregnancy, and two questions on wantedness of the pregnancy from her husband or partner's perspective.

GENERAL FINDINGS

These findings from NSFG data present the standard measure of unintended births along with data on the "degree of mistimed" among mistimed births as above. Trends are presented, followed by descriptive results by basic sociodemographic characteristics, for which patterns with unintended births are well documented. All differences described below are statistically significant ($p<0.05$) unless otherwise noted.

Trend

Table 1 shows the trend in unintended births across three decades. It presents the percent distribution of births by their intendedness at conception, for five time points of NSFG data: 1982, 1988, 2002, 2006-2010 and 2011-2015. In 2011-2015, one-third (33%) of births were unintended at conception. This percent was lower than the percent of births unintended in 2006-2010 (37%). Also, in 2011-2015, 13% of births were unwanted and 20% mistimed at conception.

Unintended Births by Sociodemographic Characteristics

Table 2 shows descriptive statistics based on the 2011-2015 NSFG on the percentage of births within the prior five years that were unintended, by race and Hispanic origin and age of the mother at the time of the birth.

The percentage of births that were unintended was higher among younger age mothers. Table 2 shows that among births to teenagers, 69% were unintended; among those born to women aged 20-24, 45% were unintended, and among those born to women aged 25-44, 24% were unintended. Although teenagers had the highest percent of unintended births, young adults, aged 20-24, had higher *numbers* of unintended births because they had higher numbers of births overall (their birth rate in 2014 was 79 for every 1,000 women aged 20-24 compared to 24 per 1,000 among teenagers.[54]

Table 2 shows differences in unintended births by race and Hispanic origin. In the five years preceding the 2011-2015 interview, non-Hispanic black women and Hispanic women had higher percentages of unintended births than non-Hispanic white women. Among births to non-Hispanic black women, 49% were unintended, and among those to Hispanic women, 43% were unintended, compared to 26% of births to non-Hispanic white women.

In addition, Table 2 shows births in the five years preceding 2011-2015 by whether they were seriously mistimed (occurred two or more years too soon) or moderately mistimed (occurred less than two years too soon). Among all women aged 15-44 years, 12% of births were seriously mistimed and 8% moderately mistimed at conception.

The extent of mistiming also varied by age at birth and race and Hispanic origin. The groups for whom unintended births were more common also had higher percentages of births that were seriously mistimed (greater than two years too soon), as presented on Table 2 in the rightmost columns. A higher percent of births to teenage mothers were seriously mistimed (43%) than those to women who were older at the birth, and a higher percent of births to non-Hispanic black and Hispanic women were seriously mistimed (17% and 16%, respectively) than those to non-Hispanic white women (9%).

DATA GAPS AND LIMITATIONS

Because pregnancy history and intendedness reporting is retrospective, there is the chance the intendedness reporting about the time of pregnancy at conception becomes biased with time toward a positive report, particularly after a baby is born. The 2002 questionnaire addressed this issue by adding a preface to the series emphasizing the importance of thinking about the time right before pregnancy when answering. A strategy for data analysis is to examine only births occurring within five years. This may limit possible bias but it cannot be eliminated. Thus, the prevalence of unwanted and mistimed births can be regarded as conservative and, in reality, it may be larger. Analysis of unintended pregnancies can also be limited to pregnancies occurring within a short time before the year for which estimates are being calculated.

Since abortions are underreported in the NSFG, analyses of intention status of all pregnancies requires supplementation using a more complete source of abortion prevalence as found in the census of abortion providers conducted periodically by the Guttmacher Institute.[35]

USING DATA FOR ACTION

Data on unintended pregnancies and births are used by researchers, practitioners, policymakers, and other organizations, including The National Campaign to Prevent Teen and Unplanned Pregnancy, a nonprofit organization formed in 1996 to help reduce the number of teen pregnancies in the US and expanded in 2007 to add reduction of unwanted pregnancies as a goal. Accurate and timely data on unintended pregnancies and births allow the Campaign to disseminate information about it to different audiences and to commission and conduct research leading to improved understanding of what is needed in services aimed at helping women avoid pregnancies they do not want and to optimally time those they do want. For example, the National Campaign launched a program called, “Bedsider,” an online birth control support network for women aged 18-29 years, which also included a mobile application. The customizable Bedsider app is used to set reminders for when to take birth control. This feature would be used to help maintain consistency in the use of birth control, thus reducing the risk of unintended pregnancy.

The Healthy People 2020 objective for unintended pregnancies is found in the Family Planning section (worded in terms of intended pregnancies rather than unintended pregnancies). With a baseline of 51% of pregnancies intended in 2002, the goal is 10% improvement or an increase to 56% of pregnancies intended by 2020.[27] The overview of the topic notes disparities and that the groups with the highest rates of unintended pregnancies include women ages 18 to 24 years, those who were cohabiting, those whose income is below the poverty line, those with less than a high school diploma, and Black or Hispanic women. High quality trend data on unintended pregnancies and births are essential for tracking progress.

The PRAMS data translate into action at the state level, as its data are used to raise awareness of the issue of unintended pregnancy, to track its prevalence compared to other states and to the nation, and to develop policy and programs specifically to reduce unintended pregnancy. This can take the form, for example, of directing funding toward increasing access to contraception and family planning services.[52] Since more states have begun administering PRAMS, resulting in more robust state-level data, new benchmarks have recently been developed[54] to gauge differences according to varying state policies.

FUTURE ISSUES

Understanding access to and use of the most effective contraception is an ongoing focus in the effort to reduce unintended pregnancies and births. There is evidence that access to and reduction in costs of LARC (long-acting reversible contraception) have been improved under the implementation of the Affordable Care Act (ACA), which includes a provision to improve access to contraception.[56,57] Increases in the use of LARC have been documented with NSFG data,[57] and some have attributed a recent decline in the incidence of unintended pregnancy to this trend.[3] Ongoing trend data from the NSFG will help assess progress, or lack thereof, among subgroups and over time.

A large proportion of unintended births, about 60%, occur when women were not using contraception at all.[11] Research has shown that nonuse of contraception, while at risk of unintended pregnancy, is more common among the same groups for which unintended and seriously mistimed births are more common, including: women with less education; women who are not married (including those who are cohabiting and those who are not); and non-Hispanic black women. According to NSFG data from 2006-2010, the most common reason women gave for not using contraception before a pregnancy leading to an unintended birth was belief that they could not get pregnant.[46] Further study is needed, using the most recent data available, to understand this reason and other circumstances leading to nonuse of contraception while at risk of unintended pregnancy. Continued efforts are needed to explore both the definition and meaning of intendedness[6,15,40,43,44,47] and the consequences of unintended pregnancy.

Table 1. Births in the 5 years before the interview to women aged 15-44: intendedness at conception: United States - 1982, 1988, 2002, 2006-2010 and 2011-2015

			Intendedness							
							Unintended			
Year of interview	Number of births in thousands	Total	Intended		Total Unintended		Unwanted		Mistimed	
			%	s.e	%	s.e	%	s.e	%	s.e
1982	18,442	100.0	63.5	(1.25)	36.5	(1.25)	9.80	(0.80)	26.7	(1.23)
1988	19,020	100.0	60.9	(1.25)	39.1	(1.25)	12.4	(0.65)	26.7	(1.04)
2002	21,018	100.0	65.1	(1.28)	34.9	(1.28)	14.1	(0.90)	20.8	(0.92)
2006-2010	21,161	100.0	62.9	(1.51)	37.1	(1.51)	13.8	(0.78)	23.3	(1.14)
2011-2015	20,579	100.0	67.1	(1.13)	32.9	(1.13)	13.4	(0.86)	19.5	(0.85)

Source: CDC/NCHS, 2011-2015 National Survey of Family Growth and adapted from Mosher WD, Jones J, Abma JC. Intended and unintended births in the United States: 1982–2010. National Health Statistics Reports No. 55. Hyattsville, MD: National Center for Health Statistics. 2012; 1- 28.

Table 2. Births in the 5 years before the interview to women aged 15-44: intendedness at conception by mother's age at birth and Hispanic origin and race, United States - 2011-2015

			Intendedness											
					Unintended									
									Mistimed					
Characteristics	Number of births in thousands	Total	Intended		Total Unintended		Unwanted		Total Mistimed		<2 years too soon (Moderately mistimed)		2+ years too soon (Seriously mistimed)	
			%	s.e.	%	s.e.	%	s.e.	%	s.e.	%	s.e.	%	s.e.
Total	20,579	100.0	67.1	(1.13)	32.9	(1.13)	13.4	(0.86)	19.5	(0.85)	7.8	(0.55)	11.6	(0.69)
Age at birth														
15-19 years	1,689	100.0	30.7	(3.24)	69.3$	(3.24)	19.2$	(2.70)	50.1	(3.16)	6.9	(2.51)	43.1	(2.85)
20-24 years	5,102	100.0	55.1	(2.22)	44.9	(2.22)	15.1	(1.62)	29.8	(1.89)	9.0	(1.00)	20.6	(1.81)
25-44 years	13,788	100.0	76.0	(1.22)	24.0	(1.22)	12.1	(0.92)	12.0	(0.81)	7.4	(0.63)	4.4	(0.44)
Hispanic origin and race														
Hispanic or Latina	4,761	100.0	57.5	(2.35)	42.5	(2.35)	17.6	(1.51)	24.9	(1.70)	9.1	(1.17)	15.6	(1.65)
Non-Hispanic White, single race	11,119	100.0	74.5	(1.49)	25.5	(1.49)	9.0	(0.95)	16.5	(1.13)	7.5	(0.77)	8.9	(0.84)
Non-Hispanic Black, single race	2,614	100.0	51.4	(2.25)	48.6	(2.25)	26.2	(2.63)	22.4	(2.06)	4.9	(0.95)	17.3	(1.84)

Source: CDC/NCHS, 2011-2015 National Survey of Family Growth.

ADDITIONAL RESOURCES

- The National Survey of Family Growth
  http://www.cdc.gov/nchs/nsfg/index.htm
- The Pregnancy Risk Assessment Monitoring System
  http://www.cdc.gov/PRAMS/index.htm
- The National Longitudinal Survey of Youth 1979
  http://www.bls.gov/nls/nlsy79.htm
- The National Campaign to Prevent Teen and Unplanned Pregnancy
  http://thenationalcampaign.org/
- The Guttmacher Institute
  https://www.guttmacher.org

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Legal Induced Abortion

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In 1973 induced abortion was legalized as a medical procedure nationwide in the United States. Following legalization, the total number, rate and ratio of documented abortions performed each year increased rapidly, reaching their highest levels in the 1980s. Since then, the incidence of abortion has declined continuously; however, the incidence of abortion remains considerably higher among certain demographic subpopulations. Recent estimates suggest that each year 1.1 million abortions are performed in the United States.

PUBLIC HEALTH IMPORTANCE

In 1973 induced abortion (hereafter referred to as *abortion)* was legalized nationwide as a medical procedure in the United States. Following legalization, the total number, rate (number of abortions per 1,000 women aged 15through 44 years), and ratio (number of abortions per 1,000 live births) of documented abortions performed each year increased rapidly, reaching their highest levels in the 1980s. Since then, the incidence of abortion has declined continuously,[1-8] with only a brief interruption in this downward trend during 2006–2008.[9-12] However, the incidence of abortion remains considerably higher among certain demographic subpopulations,[13-17] and recent estimates suggest that each year 1.1 million abortions are performed in the United States.[4]

Abortion rates in the United States are linked to rates of unintended pregnancy. Despite the recent decline in unintended pregnancy in the United States, estimates suggest that 45% of all pregnancies in the US are unintended, with large disparities occurring by age, marital status, income, education, and race/ethnicity.[18] Unintended pregnancies account for nearly all abortions, preceding 95% of all such procedures.[19] Efforts to ensure the availability of affordable family planning services, access to the range of contraceptive methods, and counseling on unintended pregnancy prevention may further reduce unintended pregnancy, and thereby the rates of unintended pregnancy in the United States. Abortion data are needed, therefore, to identify populations at risk for unintended pregnancy and to guide and evaluate programs and policies for providing family planning services.

Abortion surveillance is also needed to monitor the safety of abortion procedures and assess trends in clinical practice patterns. Ongoing surveillance has shown that abortion-related deaths are rare with the case fatality rate remaining below 1 in 100,000 or less than 10 deaths per 1 million abortions since the period immediately following nationally legalized abortion.[8, 20] However, the risk of morbidity and mortality increases with gestational age,[20-24] and the safety of emerging medical practices, such as increasing the gestational age limit for early medical abortion, needs to be monitored. Data on the number of abortions performed through different methods (e.g., medical or curettage) and at different gestational ages provides the denominator data necessary for analyses of the relative safety of abortion practices.

Finally, abortion surveillance is needed in combination with data on births and fetal losses to examine total rates of pregnancy and provide a comprehensive picture of current reproductive trends. For example, from 1991 to 2014 the adolescent birth rate declined 61%, from 61.8 to 24.2 births per 1,000 females aged 15 through 19 years, the lowest rate ever recorded for the United States.[25] Pregnancy data through 2010,[26] along with abortion data through 2012,[8] show substantial decreases among adolescents in abortions as well as live births. These data suggest that the substantial decreases in adolescent births over the past two decades can be attributed to decreases in adolescent pregnancies overall, rather than an increase in the proportion of adolescent pregnancies ending in abortion compared with live birth.

HISTORY OF DATA COLLECTION

During the late 1960s and early 1970s, states began to legalize induced abortion as a medical procedure, but, at the time, the incidence of induced abortion was unknown. With the original intent of monitoring the safety of abortion, CDC's Family Planning Evaluation Activity Epidemiology Program began conducting surveillance in 1969 by collecting aggregate reports from hospitals and state health departments in five states where abortion was legal.[27] CDC has since expanded its abortion surveillance and used this surveillance system to publish an annual summary of legal abortions and has provided a continuous record from 19692012.

In 1978 the National Center for Health Statistics (NCHS) initiated abortion data collection through a system resembling its other vital statistics data collection systems.[28, 29] As part of this effort, NCHS developed a standard abortion reporting form, paid states that met quality standards to submit individual level records, and published a detailed annual report using a single standardized data set. However, the last report NCHS published contained 1998 data from only 14 states.[30] Never expanding beyond this size, NCHS discontinued compiling state records a few years later due to funding constraints.[28, 29]

CDC's abortion reporting system is now housed within the National Center for Chronic Disease Prevention and Health Promotion (NCCDPHP) in the Division of Reproductive Health (DRH). While CDC initially obtained data for this system from hospitals and other facilities providing abortions, today all data are obtained by requesting an aggregate report directly from the central vital statistics agencies of each state, New York City, and the District of Columbia. These reporting areas provide the aggregate reports to CDC voluntarily, with the state vital statistics agencies holding the sole responsibility for recording, collecting, and managing abortion data.[28, 29]

At present, 47 states, New York City, and the District of Columbia collect and report abortion data to CDC.[8] In most of these reporting areas, collection of abortion data is facilitated by state laws requiring hospitals, facilities, and healthcare providers to report all performed abortions to their central vital statistics agency.[31] However, medical providers report abortions voluntarily in the District of Columbia and New Jersey, and thus records for these reporting areas are incomplete. California, Maryland and New Hampshire do not currently collect or report abortion data to CDC. Maryland and New Hampshire attempted to run voluntary abortion reporting systems in the past but stopped compiling records because they were so incomplete. California has never run an abortion reporting system.

In addition to the abortion data compiled by the federal government, the Guttmacher Institute has conducted a periodic census of abortion providers since 1974, through which it obtains a total count of the number of abortions performed in the United States.[4] Guttmacher Institute makes extensive efforts to identify and follow up with all abortion providers to obtain a more complete count of abortions performed in the United States. However, this census obtains little information beyond the total count of abortions performed, and while it was conducted annually during the first few years, the Guttmacher Institute has conducted this census just once every three to four years since 1979. To supplement this information with the characteristics of women obtaining abortions, the Guttmacher Institute conducted four nationally representative surveys of women obtaining abortions in 1987; 1994–1995; 2001–2002; and 2008.[13-16]

CDC SURVEILLANCE ACTIVITIES

For the purposes of surveillance, CDC has defined a legal induced abortion as an intervention performed within the legal limits of state law by a licensed clinician (e.g., a physician, nurse-midwife, nurse practitioner, or physician assistant) that is intended to terminate a suspected or known ongoing intrauterine pregnancy and produce a nonviable fetus. Each year, CDC sends example templates to the reporting areas to request aggregate data on abortions organized according to the following variables: maternal age in years; gestational age in weeks at the time of abortion; race; Hispanic ethnicity; procedure type; marital status; number of previous live births; number of previous induced abortions; and maternal residence. In addition to providing example templates for compiling information on race and ethnicity as separate variables, CDC's templates accommodate tabulation of aggregate cross-classified race/ethnicity data. Further, CDC requests that aggregate numbers for certain variables be cross-tabulated by a second variable. These cross-tabulations include gestational age (separately by maternal age, by procedure type, by race, by ethnicity, and by race/ethnicity) and maternal age and marital status (separately by race, by ethnicity, and by race/ethnicity).

To encourage more uniform collection of data according to these variables, CDC has collaborated with the National Association of Public Health Statistics and Information Systems (NAPHSIS) to develop reporting standards and provide technical guidance for vital statistics personnel who collect and summarize abortion data within the United States. However, while reporting areas have this guidance to reference, because reporting areas hold the sole responsibility for collecting and managing abortion data, they may develop their own reporting forms, which do not necessarily contain all the information CDC requests.

CDC checks the tabular data it receives each year for numerical accuracy, logical consistency with current abortion practices and trends, and concurrence with published state reports. Discrepancies are resolved by communicating with the reporting areas. Using these data, CDC publishes a report each year as an *MMWR Surveillance Summary*. The data from each reporting area are compiled into standard categories to produce a comprehensive set of tables that make the full subject content of the information CDC receives available to the public without disclosing potentially identifiable information. Abortion rates (number of abortions per

1,000 population) are calculated by using the U.S. Census Bureau estimates of the resident female population of the United States compiled by NCHS.[32] Abortion ratios (number of abortions per 1,000 live births) are calculated using live birth data from NCHS natality files.[33] Trends in abortion numbers, rates and ratios, overall and for certain key variables (e.g., maternal age and gestational age) are reported for a ten-year period. To control for differences that might occur due to areas coming in and out of the analysis, calculation of trends is restricted to continuously reporting areas that have provided data for every year covered by the period of analysis.

GENERAL FINDINGS

Trends reported in CDC's 2012 *Abortion Surveillance Report* [8] show historic decreases have occurred in the total number, rate and ratio of reported abortions, particularly in the past five years. From 2003 to 2012, among the 47 areas that provided data every year, the total number, rate and ratio of reported abortions declined, 17%, 18% and 14%, respectively, with all three measures reaching historic lows in 2012. Additionally, the most recent data indicated decreases have been accelerating, with all three measures of abortion having a greater annual rate of decrease in 2008–2012 compared with 2003–2007. During 2008–2012, the number of reported abortions decreased by 31,698 abortions per year, the abortion rate decreased by 0.63 abortions per 1,000 women per year, and the abortion ratio decreased by 5.2 abortions per 1,000 live births per year. In contrast, during 2003–2007, the number of reported abortions actually increased by 248 abortions per year, while the abortion rate only decreased by 0.03 abortions per 1,000 women per year and the abortion ratio only decreased by 3.6 abortions per 1,000 live births per year.

During 2003-2012 women in their 20s consistently accounted for the majority of abortions (56%-58%).[8] In 2012, women aged 20-24 and 25-29 years accounted for 33% and 25% of all abortions, respectively, and had abortion rates of 23.3 and 18.9 abortions per 1,000 women aged 20–24 and 25–29 years, respectively (Figure 1). In contrast, in 2012, women aged 30–34, 35–39, and ≥40 years accounted for 16%, 9%, and 4% of all abortions, respectively, and had abortion rates of 12.4, 7.3, and 2.8 abortions per 1,000 women aged 30–34 years, 35–39 years, and ≥40 years, respectively. Adolescents aged <15 and 15–19 years accounted for 0.4% and 12% of all abortions in 2012, respectively, and had abortion rates of 0.8 and 9.2 abortions per 1,000 adolescents aged <15 and 15–19 years, respectively. From 2003 to 2012 the abortion rate decreased 10%-24%

among women aged 20–24, 25–29 and 30-34 years, but increased 8% among women aged ≥40 years. The largest decrease in the abortion rate, 40%, occurred among adolescents 15–19 years (Figure 2).

Despite substantial declines in abortion rates and ratios that have occurred across all race-ethnicity groups, notable disparities remain. In 2012, the abortion rate was 7.7, 27.8, and 15.0 abortions per 1,000 non-Hispanic white, non-Hispanic black and Hispanic women, respectively. The abortion ratio was 127, 435, and 190 abortions per 1,000 live births to non-Hispanic white, non-Hispanic black and Hispanic women, respectively.[8]

CDC surveillance data indicate that nearly all abortions are performed early in gestation. In 2012, 91.4% of all abortions, were performed by ≤13 weeks' gestation, 7.2% were performed between 14–20 weeks' gestation and just 1.3% were performed at ≥21 weeks' gestation. Moreover, the percentage of abortions performed very early in gestation (≤6 weeks) is rising (Figure 3). Among the subset of abortions performed at ≤13 weeks' gestation from 2003 to 2012, the percentage performed at ≤6 weeks' gestation increased 24%. By contrast, the percentage performed at 7–12 weeks' gestation decreased up to 19%, and throughout the period of analysis, the percentage contribution was progressively lower for each additional week of gestation.[8]

The trend of obtaining abortions earlier in pregnancy has been accompanied by an increase in the use of early medical abortion (a nonsurgical abortion at ≤8 weeks' gestation). In 2012, among the 40 reporting areas that included medical abortion on their reporting form, 69.4% of abortions were performed by curettage at ≤13 weeks' gestation, 20.8% were performed by early medical abortion, and 8.7% were performed by curettage at >13 weeks' gestation; all other methods were uncommon. The percentage of all abortions reported as early medical abortions increased 10% from 2011 to 2012 and 140% from 2003 to 2012. In 2012, among abortions performed at ≤8 weeks' gestation that were eligible based on gestational age for early medical abortion, 30.8% were completed by this method.

USING DATA FOR ACTION

Unintended pregnancy precedes 95% of all abortions,[19] and can be attributed to inconsistent or improper contraceptive use, or the lack of any contraceptive use, among women at risk.[34] Increasing access to long-acting reversible contraception (LARC), specifically intrauterine devices and implants, is one key strategy for reducing unintended pregnancy. LARC requires no user effort after insertion, thereby eliminating the potential for inconsistent or improper use, and has a typical-use failure rate comparable to sterilization (<1%) and lower than other commonly used reversible methods (i.e., oral contraceptives: 9%; condoms: 18%).[35]

Given the promise of LARC for reducing unintended pregnancy and therefore abortion, initiatives in St. Louis, Missouri; Colorado; and Iowa aimed to increase women's ability to access LARC by training providers on LARC insertion and removal; increasing women's awareness of LARC through use of a client-centered counseling approach; and providing LARC at reduced or no cost for women. All three initiatives have used abortion surveillance data to demonstrate their impact.[36-38]

The Contraceptive CHOICE Project was a prospective cohort study in St. Louis, Missouri that enrolled over 9,000 women aged 14 through 45 years at risk for unintended pregnancy during 2007-2011.[39] Participants received contraceptive counseling regarding all reversible contraceptive methods in order of effectiveness and were given the method of their choice at no cost. Authors obtained total and repeat abortion numbers from the Missouri Department of Health and Senior Services and total abortion numbers from the largest abortion provider in St. Louis (i.e., accounting for 90% of all abortions reported to the Missouri Department of Health and Senior Services for St. Louis residents). Abortion data for CHOICE participants were then compared with data for residents of the St. Louis area (the CHOICE catchment area, including St. Louis City and County), and with data for residents of the rest of Missouri. Abortion rates among CHOICE participants were standardized to the age and race distribution of women in the St. Louis area. Findings from the CHOICE Project showed the majority of participants (75%) selected LARC, with smaller percentages choosing oral contraceptives, the vaginal ring, depot medroxyprogesterone acetate or the contraceptive patch.[37] During 2006-2010, the number of abortions for residents of the St. Louis area decreased 20.6%, as compared with no change (0%, $p=0.39$) for the rest of Missouri. Similarly, during 2006-2010, repeat abortions as a proportion of all abortions decreased significantly in the St. Louis area as compared with the rest of Missouri ($p<0.001$). In 2008-2010, abortion rates for CHOICE participants were significantly lower (after adjusting for age and race) than rates for residents of the St. Louis area ($p<0.001$).

The Colorado Family Planning Initiative (CFPI), started in 2009 by the Colorado Department of Public Health and Environment, used private funds from an anonymous foundation to provide LARC at no cost in 37 of 64 Colorado counties.[38] Efforts to increase access to LARC for women at the highest risk for unintended pregnancy included staff training on insertion, removal and counseling techniques; technical assistance on coding, billing and stocking; and community outreach to increase awareness of LARC. CFPI obtained abortion data from the state health department for 2008 and 2011 to measure abortion rates per 1,000 women aged 15-24 years within the 37 CFPI counties as compared with the 27 non-CFPI counties. Findings indicated that abortion rates for women aged 15-19 years in CFPI counties declined significantly from 2008 to 2011 from 11 to 7 per 1,000 (34%), as compared to a decline from 14 to 10 per 1,000 (29%) in non-CFPI counties ($p<0.01$ for the difference). Among women aged 20-24 years in CFPI counties, abortion rates also declined significantly from 2008 to 2011 from 22 to 18 per 1,000 (18%, $p<0.01$), while the decline was not significant among women in non-CFPI counties (26 and 28 abortions per 1,000 in 2008 and 2011, 6%). New data now show a significant 48% decrease in the abortion rate among women aged 15-19 years and an 18% decrease in abortions among women aged 20-24 years from 2009 through 2014.[40]

The final example took advantage of the timing of Iowa's Medicaid family planning expansion in 2006, and the implementation of a privately funded LARC initiative in 2007-2011, both of which occurred around the same time that access to abortion services increased within the state.[36] Efforts of the private initiative included staff training in LARC insertion, removal and counseling; expanding operating hours and locations among agencies serving low-income women; providing funding to reduce the cost for women to obtain LARC; and community outreach to increase awareness of LARC. Concurrent with this initiative, starting in 2008, women in Iowa could obtain medical abortion via telemedicine, and the number of abortion facilities in the state increased. Authors calculated change in the percentage of family planning clients who adopted or continued use of LARC since 2005 among all agencies funded by the private initiative, and they obtained annual abortion data from the Iowa Department of Public Health Vital Statistics for 2005-2012. The authors found that greater regional increases in LARC use were associated with reduced odds of abortion (adjusted odds ratio 0.96, 95% confidence interval 0.94-0.97).

DATA GAPS AND LIMITATIONS

On a national level, CDC remains the only annual source of abortion data and continues to compile key variables that are unavailable elsewhere, i.e., maternal state of residence (versus the state of service), gestational age, and the method used for completing abortions. Nonetheless, there are limitations to the information obtained voluntarily through CDC's Abortion Surveillance System.

First, during 2003–2012, five of the 52 reporting areas did not provide CDC data on a consistent annual basis, and for 2012, CDC did not obtain any information from California, Maryland, or New Hampshire.[8] In addition, whereas most reporting areas that send abortion data to CDC have laws requiring medical providers to submit a report for every abortion they perform to a central health agency, medical providers in New Jersey and the District of Columbia submit this information voluntarily.[31] As a result, the abortion numbers these areas report to CDC are incomplete. Moreover, even in states that legally require medical providers to submit a report for all the abortions they perform, enforcement of this requirement varies and as a consequence, several other reporting areas provide CDC with incomplete numbers. Consequently, during the period covered by CDC's most recent surveillance report, the total annual number of abortions reported to CDC was approximately 70% of the number recorded by the Guttmacher Institute.[4, 41]

Second, because reporting requirements are established by the individual reporting areas, many states have developed their own reporting forms and do not collect all the information CDC compiles. Although missing demographic information can reduce the extent to which CDC data represent all women in the United States, nationally representative surveys of women obtaining abortions [13-16] have produced percentage distributions for most characteristics that are similar to the percentage distributions reported by CDC. The one exception is the percentage distribution of abortions by race/ethnicity. In particular, the percentage of abortions reported to CDC for non-Hispanic black women has been higher than the percentage based on a recent nationally representative survey of women obtaining abortions.[16] This difference is likely attributable to the number of states that report to CDC by race/ethnicity is lower than for other demographic variables which reduces the representativeness of CDC data.

Similar to the case for race/ethnicity, the absence of medical abortion as a specific category on the reporting form used by some states[31] might reduce the precision of CDC's estimates of the use of this method relative to other abortion techniques. Furthermore, even in states with medical abortion on their reporting form, it is possible that this method is disproportionately undercounted: a higher percentage of the abortions provided in physician's offices and smaller caseload facilities are medical abortions,[12, 42] and these practices might not be fully captured with passive surveillance efforts.[42] Nonetheless, a recent comparison of CDC data with mifepristone sales data suggests that CDC's Abortion Surveillance System accurately describes the use of medical abortion relative to other abortion methods in the United States.[43]

Finally, abortion data are compiled and reported to CDC by the central health agency of the reporting area in which the abortion was performed rather than the reporting area in which the woman resided. This likely results in an overestimation of abortions for reporting areas in which a high percentage of abortions are obtained by out-of-state residents and an underestimation of abortions for states with limited abortion services, more stringent legal requirements for obtaining an abortion, or geographic proximity to services in another state. To adjust for these reporting biases, CDC attempts to categorize abortions by residence in addition to geographic occurrence. However, in 2012, CDC was unable to identify the reporting area, territory, or country in which the woman obtaining the abortion resided for 12.4% of reported abortions.[8]

FUTURE ISSUES

The representativeness of CDC's abortion surveillance system continues to limit the completeness and demographic details available in the data CDC receives from reporting areas each year. Nonetheless, ongoing abortion surveillance, including information on populations at highest risk of unintended pregnancy, is critical for monitoring the success of family planning programs. Recent estimates for the United States suggest unintended pregnancy rates declined from 2008 to 2011 after having plateaued from 2001-2008; while notable disparities remain, declines occurred in nearly all demographic groups, including those defined by age, income, education, race and ethnicity.[18] The authors of the paper documenting the recent decline in unintended pregnancies discuss many reasons that may account for this trend but in particular, they note national data indicating that LARC use has increased in nearly every demographic subgroup.[44, 45] Ongoing abortion surveillance will be needed to monitor the success of future initiatives at bringing down unintended pregnancy rates overall and reducing disparities across groups.

ADDITIONAL RESOURCES

- **CDC Abortion Surveillance**
  http://www.cdc.gov/reproductivehealth/Data_Stats/Abortion.htm
- **CDC Abortion Surveillance Reports**
  http://www.cdc.gov/reproductivehealth/data_stats/index.htm
- **Pregnancies by Outcome**
  http://www.cdc.gov/nchs/data/hestat/pregnancy/2010_pregnancy_rates.htm

http://www.cdc.gov/nchs/data/databriefs/db136.htm

www.cdc.gov/nchs/data/nvsr/nvsr60/nvsr60_07.pdf

- **State Abortion Reporting Requirements**

  www.guttmacher.org/statecenter/spibs/spib_ARR.pdf

- **Guttmacher Institute Data Center**

  http://www.guttmacher.org/datacenter/

- **National Association of Public Health Statistics and Information Systems**

  http://www.naphsis.org/

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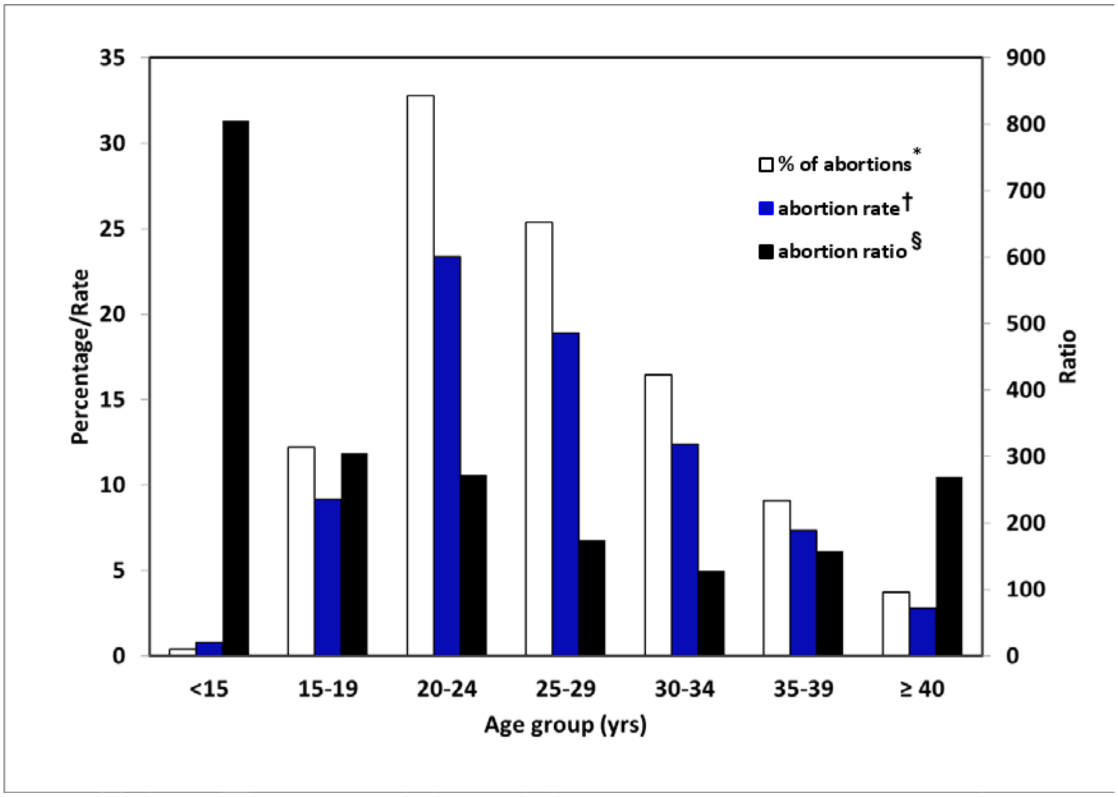
Figure 1:

Percentage of total abortions,* abortion rate, † and abortion ratio, § by age group of women who obtained a legal abortion – selected reporting areas,¶ United States, 2012



*** Percentage of abortions occurring per specified age group.**

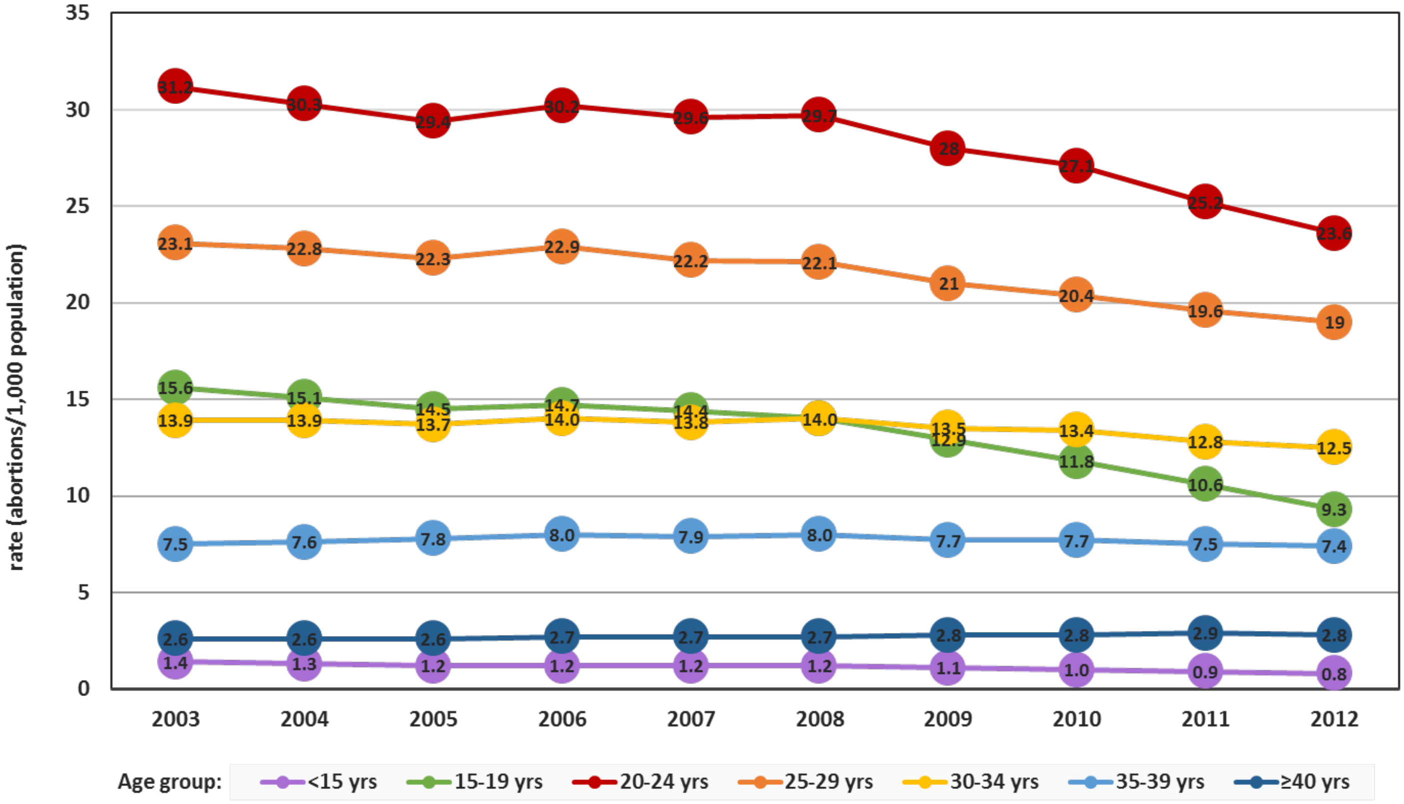
† Abortions per 1,000 women aged 15-44 years.

§ Abortions per 1,000 live births.

¶ Data are for 45 areas; excludes 7 areas (California, District of Columbia, Florida, Maryland, New Hampshire, Vermont and Wyoming) that did not report, did not report by age, or did not meet reporting standards.

Figure 2:

Abortion rate* by age group of women who obtained a legal abortion — selected reporting areas,§ United States, 2003--2012

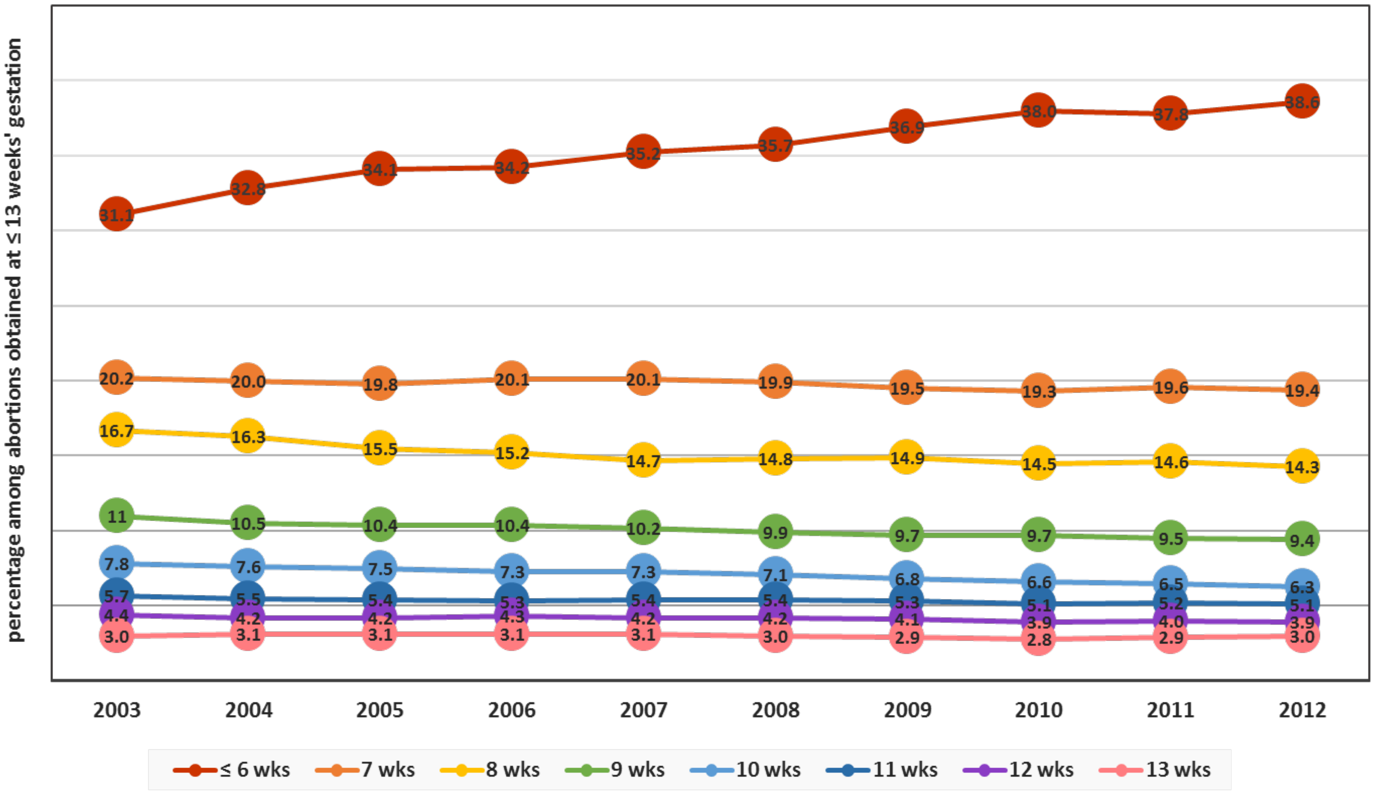


* Number of abortions obtained by women in a given age group per 1,000 women in that same age group. Adolescents aged 13–14 years were used as the denominator for the group of adolescents aged <15 years, and women aged 40–44 years were used as the denominator for the group of women aged ≥40 years.

§ Data from 42 reporting areas; excludes 10 reporting areas (California, District of Columbia, Florida, Louisiana, Maine, Maryland, New Hampshire, West Virginia, Vermont, and Wyoming) that did not report, did not report by age, or did not meet reporting standards for ≥1 year.

Figure 3:

Abortions obtained at ≤13 weeks' gestation, percentage by week of gestation and year — selected reporting areas,* United States, 2003–2012



*Data from 30 reporting areas; by year, these reporting areas represent 83%–89% of the abortions reported to CDC at ≤13 weeks' gestation during 2003–2012. Excludes 22 reporting areas (Alaska, California, Connecticut, Delaware, District of Columbia, Florida, Illinois, Louisiana, Maine, Maryland, Massachusetts, Mississippi, Nebraska, Nevada, New Hampshire, New York State, Pennsylvania, Rhode Island, Vermont, West Virginia, Wisconsin, and Wyoming) that did not report, did not report by gestational age, or did not meet reporting standards for ≥1 year.

Sexually Transmitted Diseases

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The incidence of sexually transmitted diseases is highest among young people in the United States between the ages of 15 through 24. The most commonly reported infections in the United States, chlamydia, gonorrhea, and syphilis, are on the rise. Most chlamydial infections are found among young women due to recommended screening of all sexually active women under the age of 25. While most cases of syphilis are among gay and bisexual men, there have been concerning increases in congenital syphilis in recent years reflecting increases among women. Improved surveillance of the sequelae of STD infections will be necessary to best assess and evaluate prevention programs in the future.

PUBLIC HEALTH IMPORTANCE

Sexually transmitted diseases (STDs) are the most commonly reported infections in the United States, with an estimated 20 million new cases occurring annually when including both reportable and non-reportable STDs.[1,2] The most commonly reported STDs are chlamydia, gonorrhea and syphilis, and the combined number of these infections is at an all-time high in the United States as of 2015. Younger women and men are an important population in terms of STD risk since almost two in three chlamydia infections and one in two gonorrhea infections reported are in young adults (ages 15 through 24) (Figure 1). Race/ethnicity and region of residence in the United States are also associated with STD prevalence rates. Although a majority of STDs in women are asymptomatic, negative health consequences have been well described. These include an increased risk of pelvic inflammatory disease (PID), infertility, pregnancy complications and HIV acquisition. Deleterious neonatal and infant outcomes attributable to STD infection in pregnancy include stillbirth, low birthweight, preterm delivery, neonatal pneumonia and congenital syphilis.[3] STD treatment and prevention is of public health importance due to the financial impact on the U.S. health care system with the annual cost for STD treatment of $16 billion in 2008.[4]

Chlamydia is the most common reportable disease in the United States with more than 1.5 million cases reported in 2015. It is caused by the intracellular bacteria, *Chlamydia trachomatis* and infection in women can present as abnormal vaginal discharge, lower abdominal pain or urethritis. Most infections are asymptomatic. Routine annual screening has been recommended by CDC since 1993 for all sexually active women younger than 25 years of age and high risk women greater than or equal to 25 years of age. Current guidelines recommend screening with nucleic acid amplification tests (NAAT) on urine or swab specimens from the endocervix or vagina; available NAATs have excellent test characteristics.[5] Reported rates of chlamydia have increased over the past 20 years in the setting of improved screening rates and the availability of more sensitive diagnostic tests. Untreated chlamydia infection can lead to PID, ectopic pregnancy and chronic pelvic pain. Infection during pregnancy can cause ophthalmia neonatorum, which may result in blindness and neonatal pneumonia. Chlamydia is treatable and the first line recommended therapy (oral azithromycin or doxycycline) is associated with cure rates greater than 97%.[6-8]

Gonorrhea is also caused by a bacterial pathogen, *Neisseria gonorrhoeae.* Before chlamydia became nationally notifiable, gonorrhea was the most commonly reported notifiable disease in the country. Reported rates of infection in the United States were at an all-time low in 2009 (98 cases per 100,000 population) but then increased to a rate of 124 per 100,000 population with more than 395,000 cases reported in 2015. Gonorrhea in women causes similar clinical syndromes and complications as chlamydia, although there is a stronger association between gonorrhea in pregnancy and spontaneous preterm birth.[9] Antimicrobial resistance remains an important consideration in the treatment of gonorrhea as *Neisseria gonorrhoeae* has developed resistance against every antibiotic recommended to treat it. The potential threat of untreatable gonorrhea is of great concern worldwide.[10,11] CDC's Gonococcal Isolate Surveillance Project (GISP) (Figure 2) monitors resistance patterns in the United States; 40% of isolates collected by CDC in 2015 had documented resistance to penicillin, tetracycline and/or ciprofloxacin.[12] The current treatment recommendation for gonorrhea is combination therapy with ceftriaxone and azithromycin, but newer treatment options are urgently needed.[8]

Syphilis is caused by the spirochete bacteria, *Treponema pallidum*. It is well known for protean clinical manifestations, transmissibility and high complication rates when infection occurs during pregnancy. Although there was potential of elimination of syphilis in the United States when rates reached historic lows at the turn of the century, the reported rate has steadily increased since 2001. In 2015, there were 7.5 reported cases per 100,000 population, the highest rate since 1994.[2] The rapid increase in rates of early syphilis in the United States has been driven mostly by cases among men who have sex with men, and the annual infection rate in women has also increased in every region of the country since 2013. Similarly, the domestic rate of congenital syphilis has been rising at the same time. In a review of more than 6,000 congenital syphilis cases reported in the United States between 1999 and 2013, the highest infection proportions were seen in women with limited or no prenatal care and higher non-treponemal test titers (RPR ≥1:8).[13] Congenital syphilis is preventable in 98% of cases if the infection is recognized early in pregnancy and women receive the recommended penicillin therapy in a timely manner.[14]

There is a well-known synergy between HIV and other STDs. Infection with chlamydia, gonorrhea, syphilis and trichomonas in women is associated with an increased risk of HIV acquisition. In 2014, one in four people living with HIV in the United States were women, and most acquired HIV from sex with an infected male partner. Women diagnosed with STDs are an important group for risk reduction and targeted HIV prevention efforts.[15,16]

Most women in the United States have used contraception at least once in their lifetime, and many choose methods that do not prevent acquisition of STDs from an infected partner. According to a large population-based survey during 2006-2010 of US women ages 15 through 44, 62% of women were actively using at least one method of contraception and 16% reported condom use[17]. Over time, rates of condom use have declined while rates of long-acting reversible contraception (LARC) use have increased.[17] This has been coincident with a 61% reduction in the teen birth rate between 1991 and 2014.[18] While highly effective in terms of pregnancy prevention, LARC use does not protect women from acquiring STDs. Recent studies show that dual use of LARC and condoms in young women is infrequent, but data on STD acquisition rates is limited.[19-21]

HISTORY OF DATA COLLECTION

In the late 1930's, a number of states began to require premarital blood tests, antenatal screening for syphilis, and reporting of syphilis and gonorrhea cases. Since 1941, state health departments have reported cases of syphilis (including congenital syphilis), gonorrhea and chancroid annually to CDC. Chlamydia has been a nationally notifiable condition since 1996, but surveillance data are more complete since 2000 after reporting was required for all 50 states and the District of Columbia.

CDC SURVEILLANCE ACTIVITIES

National surveillance of STDs is the responsibility of the Division of STD Prevention (DSTDP) within CDC's National Center for HIV/AIDS, Viral Hepatitis, STD and TB Prevention (NCHHSTP). Cases of notifiable STDs are reported to CDC's Center for Surveillance, Epidemiology and Laboratory Services by health departments in all 50 US states, five territories, and two local health departments (New York City and District of Columbia) on a weekly basis and then provided to DSTDP.[22] The nationally notifiable sexually transmitted diseases are chlamydia, gonorrhea, syphilis (including congenital syphilis) and chancroid.

The Council of State and Territorial Epidemiologists (CSTE) works in collaboration with CDC to establish case definitions for nationally notifiable diseases. Reporting of infectious diseases is mandated at the state, territory and local levels, but national reporting to CDC is voluntary. CSTE recommends that health departments report STDs to CDC's National Notifiable Diseases Surveillance System (NNDSS) using well-defined and periodically updated case definitions (https://www.cdc.gov/std/stats15/appendixc.htm).

CDC receives data in the form of electronically submitted case reports for chlamydia, gonorrhea, syphilis and chancroid. These reports include individual-level information about race/ethnicity, age, county of residence and gender. Information about the source of the case report is also captured (i.e., STD clinics, hospital emergency rooms, prenatal care clinics, family planning clinics). Additional details are collected for syphilis cases (i.e., sexual behavior, HIV status).

In 1983, CDC began collecting detailed demographic and clinical data on congenital syphilis cases for national public health surveillance. CDC case reports from state and local health departments include the infant's date of birth, vital status, birth weight, gestational age, signs of congenital syphilis, and case classification. These reports also include the mother's age and race/ethnicity, whether she sought prenatal care, the date of her first prenatal care visit, the date she was treated for syphilis, and the medication used for treatment.

STD incidence (per 100,000 population) is calculated annually using Bureau of the Census population estimates, and race is reported using the Office of Management and Budget (OMB) race standards. STD rates are also calculated for the 50 largest metropolitan statistical areas (MSAs) within the United States. This is useful for understanding the relative rates of disease that may vary within a particular state or territory. Rates of congenital syphilis are calculated by using live birth data from information coded by the states and provided to the National Center for Health Statistics.

Data on antimicrobial susceptibility in *Neisseria gonorrhoeae* are collected through the Gonococcal Isolate Surveillance Project (GISP), a sentinel system of 25-30 US STD clinics and 4 regional laboratories that was established in 1986. GISP collects urethral samples and demographic and clinical information from the first 25 men who present to STD clinics each month with gonococcal urethritis. Susceptibility testing by agar dilution is currently performed for azithromycin, cefixime, ceftriaxone, gentamicin, ciprofloxacin, penicillin, and tetracycline. As testing for gonorrhea is increasingly conducted with molecular diagnostics (NAATs) instead of culture techniques, GISP has become one of the few sources of antimicrobial susceptibility surveillance data for *Neisseria gonorrhoeae* in the country (Figure 2).[11]

In 2005, CDC established the STD Surveillance Network (SSuN) as a collaborative network of state, county, and/or city health departments to conduct sentinel and enhanced STD surveillance activities following standardized protocols. SSuN currently conducts two core STD surveillance activities: 1) monitoring patients who attend STD clinics and 2) enhanced surveillance, including interviews, of a sample of individuals diagnosed with gonorrhea.

GENERAL FINDINGS

The year 2015 marked the second consecutive year in which increases were noted in three nationally reported STDs: chlamydia, gonorrhea, and syphilis. There were 1,526,658 cases of chlamydia; 395,216 cases of gonorrhea; and 23,872 cases of primary and secondary syphilis reported in 2015. The rate of infection per 100,000 population was 479 for chlamydia (a 6% increase from 2014); 124 for gonorrhea (a 13% increase from 2014); and 7.5 cases for syphilis (a 19% increase from 2014). Similarly, an increase was noted in the number and rate of congenital syphilis infections in 2015. The majority of reported STDs in 2015 were reported from clinical settings outside of designated STD clinics – 78.4% and 74.2% of chlamydia and gonorrhea cases, respectively.

Chlamydia

Chlamydia infection rates are consistently higher in women compared to men because screening is recommended in women and more cases are, therefore, detected in women. However, the reported rate of chlamydia only increased 0.3% in women compared to a 20% increase in men between 2011 and 2015 (Figure 3). In data collected from women and men, there were differences in chlamydia rates among different racial and ethnic populations. Blacks overall (1,098 cases per 100,000 population) had a rate 5.9 times that of whites (187 cases per 100,000), while the rate among American Indians/Alaska Natives (709 cases per 100,000) was 3.8 times the rate of whites.

Gonorrhea

In 2009, there was a historic low in the nationally reported gonorrhea rate. However, this rate increased during 2012-2015 (Figure 4). From 2014-2015, the rate of reported gonorrhea infection increased 6.8% among women and 18.3% among men. Increases were noted in every region across the United States, notably in the West and the South. The reported rate of gonorrhea infection is highest among blacks (424.9 cases per 100,000 population) and American Indians/Alaska Natives (192.8 per 100,000 population) compared to the rate in whites (44.2 per 100,000 population).

The treatment of gonorrhea infection has been complicated by the emergence of antimicrobial resistance. Antimicrobial susceptibility is measured by the minimum inhibitory concentration (MIC) for various antibiotics. The MIC is the lowest drug concentration that inhibits bacterial growth in the laboratory. The GISP project monitors MIC trends and characterizes emerging antimicrobial resistance. Data are collected from selected STD clinical sites and regional laboratories (Figure 2). From 2007-2015, the percentage of GISP isolates that exhibited elevated ceftriaxone MICs (MICs $\geq$ 0.125 µg/ml) fluctuated between 0.1-0.4%. In 1992, susceptibility testing began for cefixime and azithromycin. The percentage of isolates with elevated cefixime MICs (MICs ≥ 0.25 µg/ml) declined from 1.4% in 2011 to 0.5% in 2015. Reduced azithromycin susceptibility (MICs ≥ 2 µg/ml) ranged from 0.3% to 0.6% from 2011-2013. During 2013-2015, this percentage increased from 0.6% to 2.6%.

Syphilis

Rates of primary and secondary syphilis have been increasing since 2001, mostly among men who have sex with men. From 2014 to 2015, the rate increased 19% overall, and 90% of cases were among men. Since 2013, however, the rate has also increased among women with a 27% increase observed in the past year. There were 487 cases of congenital syphilis in 2015 with a rate of 12 cases per 100,000 live births, a 6% increase since 2014.

Population Trends

Young individuals and homosexual and bisexual men are disproportionately affected by STDs in the United States, according to the findings of the 2015 STD surveillance report. Individuals aged 15 through 24 experience the highest number of cases and rates of chlamydia and gonorrhea infection (Figure 3). In 2015, nearly two-thirds of chlamydia and half of gonorrhea cases were noted in men and women aged 15 through 24. The majority of new primary and secondary syphilis cases were noted in men who have sex with men (MSM) (82% of male primary and secondary syphilis cases) and resistance to antibiotics treating *Neisseria gonorrhoeae* is generally higher in this group.[2]

DATA GAPS AND LIMITATIONS

Although notifiable disease surveillance is critical for understanding disease rates and trends for chlamydia, gonorrhea and syphilis, gaps remain in our understanding of other STDs and their sequelae that impact the health of women and infants in the United States. This includes genital ulcers caused by herpes simplex virus (a reportable disease in some jurisdictions), vaginitis caused by *Trichomonas vaginalis* and lesser known but increasingly recognized pathogens such as *Mycoplasma genitalium*.

Laboratory-based reporting has facilitated timely national reporting of STDs, but estimates based on reported cases continue to underestimate the actual disease rate. For example, some women may receive presumptive therapy for an STD in the absence of diagnostic testing, or STD testing may be performed at the point of care without confirmatory testing or centralized documentation of results. Also, since the most common venue for STD testing is the private outpatient medical office, not all women with compatible clinical syndromes may receive a diagnostic evaluation that includes STD testing. Many asymptomatic infections may also be missed by variable screening practices. Finally, women may be unaware that they are at an increased risk of acquiring an STD or they may not feel comfortable sharing information about risk behaviors with their medical providers, and thus may not be appropriately tested.

The CDC STD surveillance report is able to highlight differences in reported rates of chlamydia, gonorrhea, syphilis and congenital syphilis in terms of sex, age, region of residence and race/ethnicity since these basic demographic data are collected as a part of disease reports. However, there are important gaps in our current surveillance system in terms of our understanding of STD susceptibility, transmission and infection outcomes in women. This includes individual-level data about socioeconomic status, access to health care, risk behaviors, presence or absence of symptoms, coinfection status, treatment information, partner infection status and adverse outcomes of infection. Some of this information is captured within the context of CDC-supported enhanced surveillance programs such as the SSuN clinics and the GISP database, as described above. Other systems and large national datasets (such as the National Health and Nutrition Examination Survey (NHANES) or analyses of health insurance claims data including Medicaid) have been used to contribute to our understanding of national STD disease rates and to supplement national STD surveillance data with the capture of testing data and additional indicators at the level of a facility, region, or state. These additional data sources provide useful information to contextualize reportable disease surveillance data.

USING DATA FOR ACTION

Given the burden of STDs in 15- to 24-year-olds, it is important to emphasize increased screening for STDs. This can be facilitated by dispelling stigma and myths related to STD screening, targeting social networks, and improving access to STD testing and treatment. STD prevention programs targeted at adolescents should consider accessibility, availability, and privacy in the provision of healthcare services. Such services include: school-based clinics, extended STD clinic hours, elimination of explanation of benefits for STD-related visits, urine based STD screening, and opt-out STD screening in areas of high prevalence and among those at highest risk. Together, these provisions may improve access to and treatment of STDs among at-risk individuals. STD prevention education for front-line healthcare providers (specifically in Pediatrics, Family Medicine, Obstetrics and Gynecology and Emergency Medicine) may enhance awareness and improve efforts to increase STD screening rates among adolescents.

Resources for public and private clinical sites that offer STD screening needs to be enhanced since the majority of STDs are diagnosed outside of STD clinics. Resources should be allocated to enhance healthcare provider education at these sites and improved collaboration with local and state public health departments in regions with high reported cases of chlamydia, gonorrhea, and syphilis. Ongoing collaboration with reproductive health care providers is another key strategy in STD reduction efforts since many women seek care and family planning services in women’s health clinics where a discussion of STD risk mitigation and prevention strategies including condom use can readily occur.

Programs targeting treatment of sexual partners with expedited partner therapy should be supported to prevent recurrent and persistent STD infection, and the STD-related morbidity of pelvic inflammatory disease, chronic pelvic pain, ectopic pregnancy and tubal factor infertility. Reproductive-aged women endure the most serious sequelae associated with asymptomatic chlamydia and gonorrhea infection. Programs that emphasize the treatment of partners are important to curbing national rates of chlamydia and gonorrhea.[23]

FUTURE ISSUES

STD surveillance is challenging because of the varied nature of the infections themselves, their epidemiology and clinical presentations. It is also a challenge because the sheer number of cases creates issues for complete data collection and follow-up, processing and transmission. The collection of data associated with notifiable diseases may improve as electronic medical record systems are developed and implemented to assume the task of automated reporting. This is expected to reduce the burden on healthcare providers and health department staff but any reporting is limited by the documentation in the medical record and the screening practices of clinicians. The availability of limited data may be partially addressed through enhanced surveillance in a limited number of sites or jurisdictions as has been done in GISP and SSuN. The subsequent challenge is in determining how to extrapolate the findings from a limited number of sentinel sites or jurisdictions to what can be generalized to the entire United States population to guide national prevention strategies.

While the focus of STD surveillance efforts has been on case reporting of the most common bacterial STDs, syphilis, chlamydia and gonorrhea, for which there are federally funded prevention programs, the broader goal is to prevent morbidity and mortality due to a range of sexually transmitted pathogens. Emerging issues in sexually transmitted pathogens include sexual transmission of Zika[24] and the role of sexual transmission in rising rates of Hepatitis B and C.[25] Improved surveillance of the sequelae of these STD infections at the local and national levels will be necessary to best assess and evaluate prevention programs in the future.

Figure 1. Reported Chlamydia and Gonorrhea Infections by Age, 2015

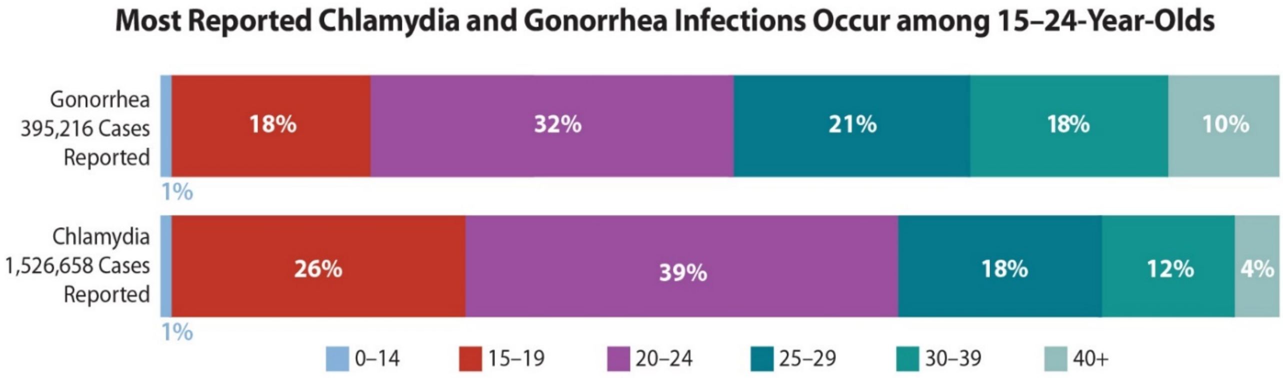
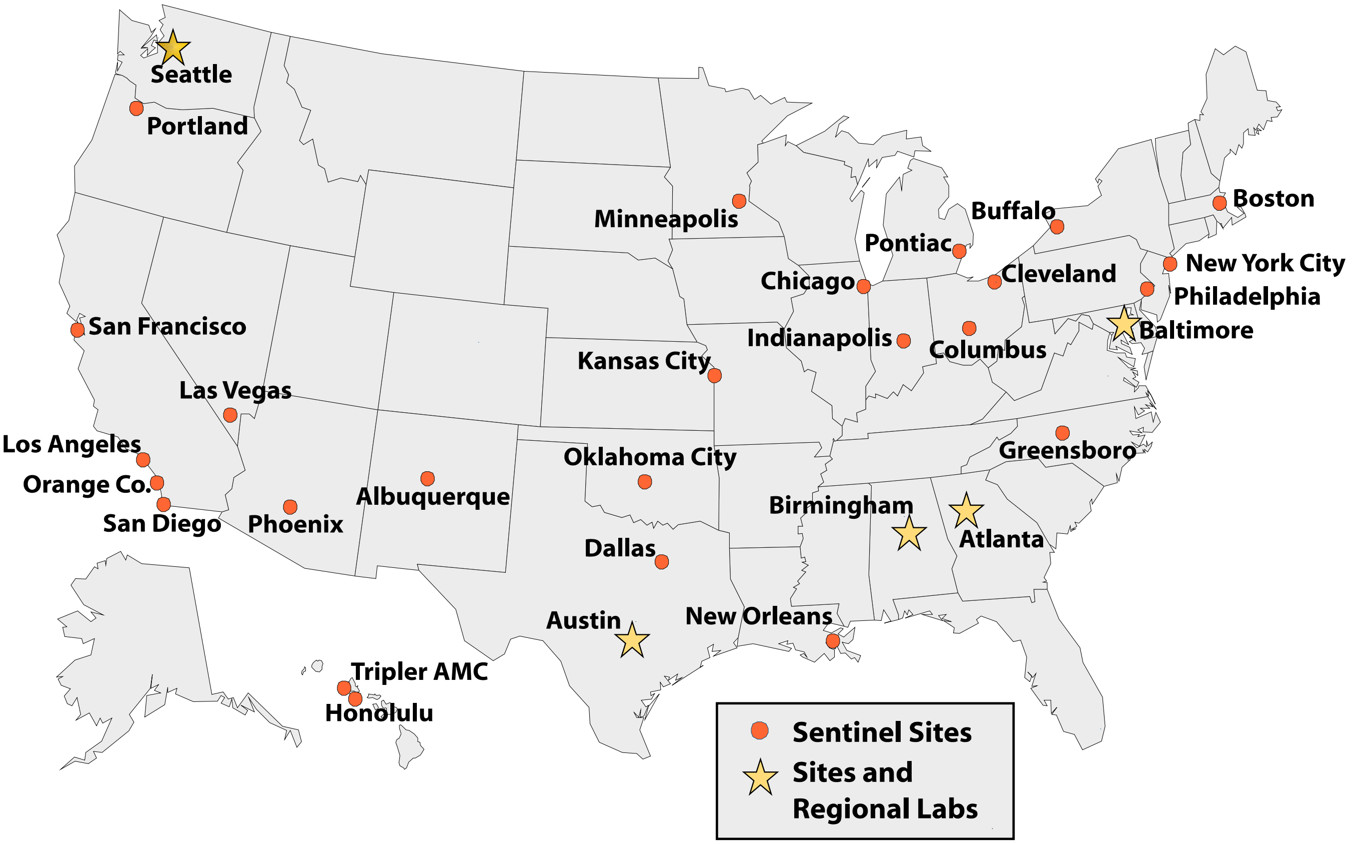
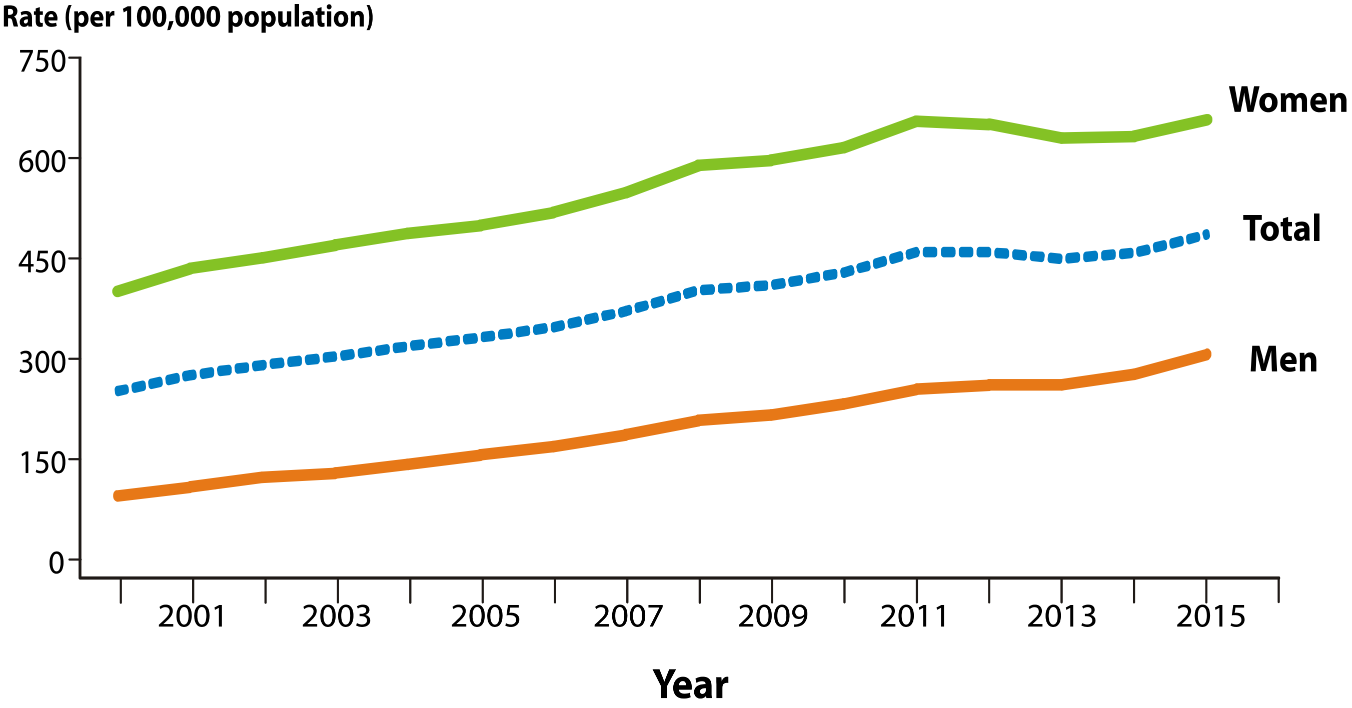


Figure 2. Location of Participating Sentinel Sites and Regional Laboratories, Gonococcal Isolate Surveillance Project (GISP), United States, 2015



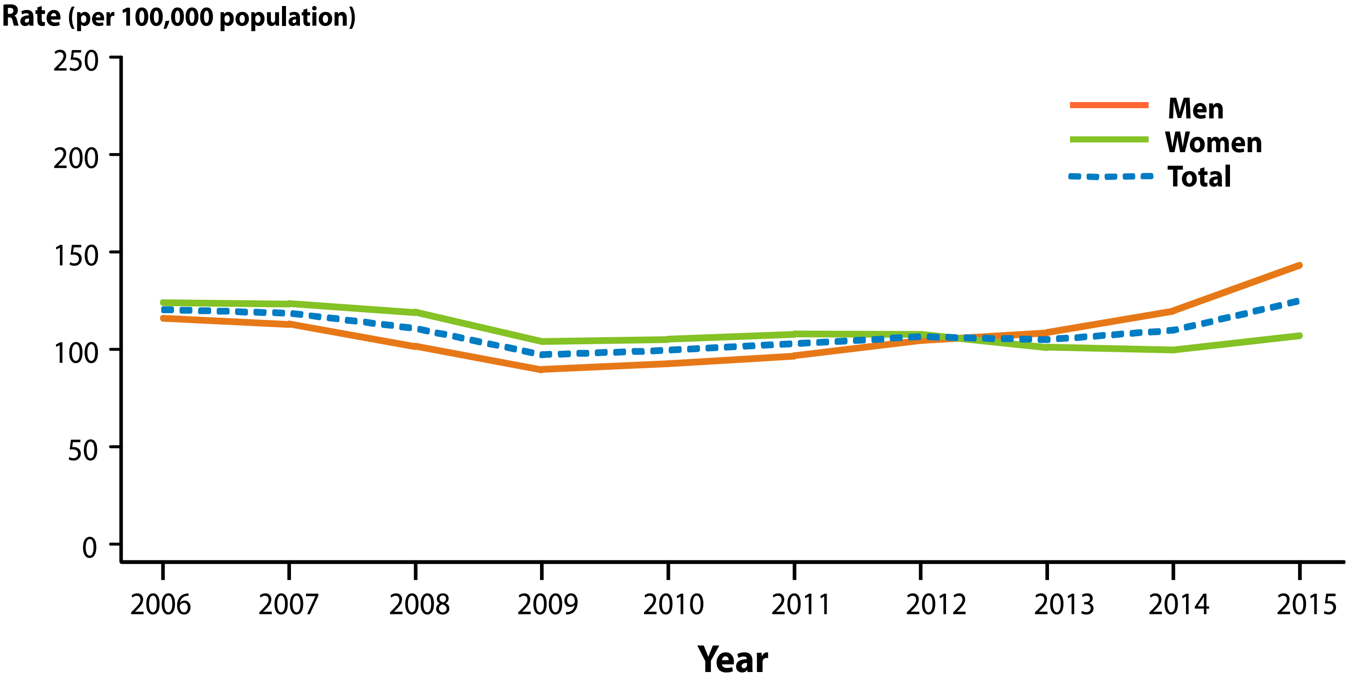
NOTE: Austin is a regional laboratory only.

Figure 3. Chlamydia — Rates of Reported Cases by Sex, United States, 2000–2015



NOTE: Data collection for chlamydia began in 1984 and chlamydia was made nationally notifiable in 1995; however, chlamydia was not reportable in all 50 states and the District of Columbia until 2000. Refer to the National Notifiable Disease Surveillance System (NNDSS) website for more information: https://wwwn.cdc.gov/nndss/conditions/chlamydia-trachomatis-infection/.

Figure 4. Gonorrhea — Rates of Reported Cases by Sex, United States, 2006–2015



NOTE: Data collection for gonorrhea began in 1941; however, gonorrhea became nationally notifiable in 1944. Refer to the National Notifiable Disease Surveillance System (NNDSS) website for more information: https://wwwn.cdc.gov/nndss/conditions/gonorrhea/ .

ADDITIONAL RESOURCES

- **CDC 2015 Sexually Transmitted Diseases Surveillance Report**
  https://www.cdc.gov/std/stats15/toc.htm
- **CDC 2015 STD Surveillance Report: Profile on Women and Infants**
  http://www.cdc.gov/std/stats15/womenandinf.htm
- **CDC Gonococcal Isolate Surveillance Project (GISP)**
  http://www.cdc.gov/std/GISP/default.htm
- **CDC 2016 GISP Protocol**
  http://www.cdc.gov/std/gisp/gisp-protocol-may-2016.pdf
- **CDC STD Surveillance Network (SSuN)**
  http://www.cdc.gov/std/ssun/default.htm
- **CDC 2015 STD Treatment Guidelines**
  http://www.cdc.gov/std/tg2015/default.htm
- **STD Expedited Partner Therapy**
  http://www.cdc.gov/std/ept/default.htm
- **CDC National Network of STD Clinical Prevention Training Centers**
  http://nnptc.org/

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Human Immunodeficiency Virus

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Human immunodeficiency virus (HIV) infection was first recognized in the 1980s in its latter stages as acquired immunodeficiency syndrome (AIDS). Through public education, early diagnosis, and treatment advances, progress has been made in controlling the spread of HIV in the United States. However, HIV still remains a major cause of morbidity and premature mortality among people of all ages, genders, races and ethnicities.

PUBLIC HEALTH IMPORTANCE

Human immunodeficiency virus (HIV) infection was first recognized in the 1980s, via its manifestation as acquired immunodeficiency syndrome (AIDS). Since then, much progress has been made in controlling the spread of HIV in the United States. However, HIV still remains a major cause of morbidity and premature mortality.

The principal target of HIV is the immune system. HIV infects the T helper lymphocytes (CD4 T-cells), whose main role is activating the immune response against invading bacteria, viruses, and other potentially harmful agents. The resultant lowered CD4 count limits the immune response, making the host vulnerable to a variety of secondary opportunistic infections and cancers that an otherwise fully functional immune system could resist. The progression of HIV disease can be divided into three clinical stages: acute HIV infection, clinical latency, and AIDS.

Clinical Progression of HIV infection

Acute HIV Infection

In the first few weeks following HIV infection, many, but not all, people develop flu-like symptoms such as fever, swollen glands, sore throat, and headache. This "primary HIV infection" is the body's natural response to the HIV infection. Large amounts of virus are produced and large numbers of CD4 cells are destroyed during this period, making the CD4 cell count fall rapidly. However, for most people the body's immune system is able to contain the virus to a relatively stable level. An increase in CD4 count follows, but most often does not return to pre-infection levels. People in this stage may not recognize the infection. However, the infection is highly contagious in this stage and may be transmitted to sexual or drug-using partners. HIV can also pass from an HIV-infected mother to her infant during pregnancy, labor and delivery, or while breastfeeding.

Clinical Latency

The stage of "clinical latency" comes next, representing a period where the virus is living in the host without producing symptoms. The virus continues to reproduce but at low levels. If left untreated, this stage lasts an average of 10 years. If placed on medication (antiretroviral therapy or ART), clinical latency may last for several decades. Individuals in this stage are able to transmit HIV to others, even if receiving ART. However, ART greatly reduces the risk of transmission.[1]

AIDS

This is the final stage of HIV infection, the hallmark of a damaged immune system, characterized by a CD4 cell count of less than 200 cells per microliter of blood, or evidence of one or more opportunistic illnesses (see section on surveillance case definition).

Burden of Disease

In the United States, by year-end 2014, there were 955,081 persons living with a diagnosed HIV infection.[2] At the end of 2013, persons living with diagnosed HIV were estimated to represent 87% of all persons living with HIV in the United States, translating into an estimated 161,200 persons living with HIV in the United States who were unaware of the infection.[3] In recent years, the overall rate of HIV diagnoses (per 100,000 population) has remained stable or decreased, but the rates vary by sub-groups (e.g., the rates among women have decreased more sharply than among men). Historically, persons infected with HIV experienced early mortality and thus shortened life expectancy after HIV diagnosis. With a better understanding of the disease and the introduction of ART, the outlook has improved. It is estimated that the average life expectancy after HIV diagnosis improved from a low of 10.5 years in 1996,[4] to 28.9 years in 2011.[5] However, the life expectancy remains below that of the general population, contributing to significant years of life lost to pre-mature mortality.[6]

As HIV affects the immune system, both men and women face mostly similar types of health issues and challenges. However, specific gynecological issues faced by women include: abnormal cell growth or dysplasia of the cervix, cervical cancer, genital warts and increased frequency or severity of infections such as herpes and yeast infection (candidiasis).[7]

While having no known cure, HIV is a preventable infection and effective interventions result in reduced transmission and prolonged life.[8] The important first step in the prevention of transmission is for people to know their HIV status. People who get tested for HIV and learn that they are infected can make modifications to their behavior to reduce the risk of transmission of infection to their sex or drug-using partners. Of an estimated 45,000 HIV transmissions in 2009, persons with undiagnosed infections accounted for 30% of these transmissions, despite representing only 18% of people living with HIV.[9] Another 61% of the transmissions were attributed to persons with diagnosed infection but who were not retained in care or not receiving ART. Together, the two sub-groups were responsible for over 91% of transmissions, highlighting not only the strong transmission potential of undiagnosed and untreated infections, but also the immense impact these simple interventions (testing and adopting ART) can have in containing the spread of the virus. Following HIV testing, a person who receives a negative test result and is at higher risk for HIV can also modify their behavior (e.g., condom use) or adopt biomedical interventions (e.g., pre-exposure prophylaxis (PrEP)) to help ensure they do not acquire HIV.

HISTORY OF DATA COLLECTION

Since the first cases of AIDS were recognized in the United States in the 1980s, data collection activities have evolved as needs and technology changed. The following timeline summarizes some of the key changes in surveillance:

- 1981 – AIDS surveillance was initiated in the United States. Persons with AIDS, indicated by diagnosis of particular opportunistic infections or malignancies associated with otherwise unexplained severe immunosuppression, were initially reported by healthcare providers directly to CDC, but later were reported to CDC through state and local health departments.
- 1983 – HIV was identified as the cause of AIDS.
- 1985 – With the development of the serologic antibody test for HIV, the AIDS case definition was expanded to include additional opportunistic illnesses if accompanied by a positive HIV test result. Also, states began to report HIV infection (including cases that had not yet progressed to AIDS) in addition to AIDS. However, the timeline of implementation of HIV infection reporting varied from state to state.
- 1994 – CDC implemented a uniform system for national, integrated HIV and AIDS surveillance, and 25 states began submitting data to CDC from confidential, name-based reporting systems.
- 2004 – CDC began monitoring the behaviors of people at increased risk for HIV infection by conducting cross-sectional annual surveys (National HIV Behavioral Surveillance (NHBS)). Three populations are sampled: men who have sex with men; people who inject drugs; and heterosexuals at increased risk for HIV. The surveys are conducted in rotating three-year cycles.
- 2005 – CDC began the Medical Monitoring Project (MMP). This surveillance system is a national population-based project that collects information on clinical outcomes and behaviors of people living with HIV in the United States.
- 2008 – By April 2008, all 50 states, the District of Columbia, and six dependent areas had fully implemented name-based reporting of HIV infection. Laboratory evidence of HIV infection became a requirement for newly identified cases; the diagnosis of AIDS with unexplained immunodeficiency was no longer accepted.

Additionally, CDC has implemented various ancillary activities throughout the years to enhance HIV case surveillance: incidence surveillance, molecular surveillance, perinatal HIV exposure reporting, and geocoding and data linkage. Incidence surveillance uses testing history information and results of recency tests to estimate incident cases. Molecular surveillance uses sequence information to better understand trends in transmitted drug resistance, HIV subtypes, and transmission networks. Geocoding allows for the analysis of social determinants of health and their impact on HIV diagnosis rates and care outcomes. Through perinatal exposure reporting, infants known to be HIV-exposed are monitored after birth up to 18 months of age to determine HIV infection status of the child. The primary goals are to monitor and evaluate perinatal HIV transmission and evaluate prevention efforts.

CDC SURVEILLANCE ACTIVITIES

National HIV Surveillance

To monitor HIV trends, assess prevention and care outcomes, and forecast the public health resources that will be needed for prevention activities and the care of people living with HIV, CDC conducts and coordinates HIV surveillance activities through cooperative agreements with state and local health departments. These HIV surveillance activities support standardized methods for data collection and management. State and local health departments collect information, including the patient's and physician's names, the patient's mode of HIV exposure, demographic data (age, race/ethnicity, sex, date of birth, date of death), clinical data (opportunistic illness diagnosis, ART prescription), and laboratory results. Information is obtained by active and passive surveillance methods, including on-site medical record reviews by health department personnel, in-person or telephone contacts with infection control nurses, physicians, or other health-care providers, and mandated reporting by laboratories and health professionals. Health department personnel enter the data into their local databases and each month send CDC encrypted data without personal identifiers. To avoid double-counting cases that are reported by more than one jurisdiction, CDC provides a list of cases that match on key characteristics to health departments, and asks them to determine if the two cases represent the same or different people. Data are collected under a federal assurance of confidentiality and are maintained in accordance with strict security and confidentiality protections. Using these data, the National HIV Surveillance System (NHSS), CDC produces an annual surveillance report as well as supplemental reports and other publications.

Surveillance Case Definition for HIV infection

The surveillance case definition for an HIV infection has and will continue to evolve as more knowledge about the disease is obtained. Currently, a person meets the HIV case definition if they test positive for the virus using a two-test algorithm.[10] This definition applies for anyone 18 months or older or for infants under 18 months whose mothers were not infected. For infants under 18 months whose mothers were known to be infected or whose infection status was unknown, the criteria is complicated by the fact that a mother's antibodies are shared with the fetus while in the womb. An antibody is the body's response to the presence of an infectious agent. Therefore, a positive antibody test does not necessarily indicate an infection in an infant. In order for an infant to be considered an HIV case, there needs to be a positive result from a test that measures the presence of the virus.[10]

Stage 3 (AIDS) is diagnosed by a low CD4 count or the presence of an AIDS-defining opportunistic illness. This applies to all ages, although the threshold for the CD4 count varies with age. To be classified as stage 3 (AIDS), infants under 1 year need a CD4 count less than 750 cells/µl, children 1 to 5 years old need a CD4 count less than 500 cells/µl, and people 6 years or older need a CD4 count less than 200 cells/µl.[10]

Behavioral and Clinical Surveillance

CDC collects behavioral data on people at increased risk for HIV acquisition and behavioral and clinical data on individuals living with diagnosed HIV infection. This is done using two different surveillance systems – NHBS and MMP. NHBS is conducted in routing three-year cycles among groups at increased risk for HIV infection – people who inject drugs (PWID), men who have sex with men (MSM), and heterosexuals at increased risk. It is currently conducted in 22 cities throughout the United States with high numbers of people living with AIDS. MSM are sampled by venue-based time-space sampling, which involves recruiting MSM from a random selection of venues and day-time periods. PWID and heterosexuals are recruited by response-driven sampling (RDS), a type of chain-referral sampling. RDS is conducted by selecting a few study participants through formative research that serve as "seeds" who then recruit their peers. Recruitment continues with each wave of participants recruiting more peers until the sample size is met. NHBS study participants complete a computer-based personal interview that covers demographic information, sexual and drug use behaviors, and HIV testing history. All participants are also offered an anonymous HIV test. The data from NHBS provide information on what specific behaviors contribute to an increased risk of HIV infection and whether preventive interventions are having an impact.

MMP collects data on an annual basis among people living with HIV aged 18 years or older. Prior to 2015, sampling was done through HIV care facilities, but since 2015, MMP has been updated to select a random sample of individuals from NHSS. Data are collected via a computer-based personal interview and medical chart abstraction. The two data sources provide valuable information on key behavior elements such as patients' access to, use of, and barriers to HIV-related secondary prevention services; utilization of HIV-related medical services; and adherence to drug regimens. They also provide information on clinical conditions that occur in HIV-infected persons, the HIV care and support services being received, and the quality of these services.

GENERAL FINDINGS

Among adults and adolescents, women accounted for 19% of HIV diagnoses in 2014 (Table 1) and 24% of people living with HIV at year-end 2013 (Table 2). Among women, the majority of HIV diagnoses were among black/African American women (61%) with a rate of 26.2 per 100,000 population. Hispanic/Latino women accounted for 15% of diagnoses while white women accounted for 19%. However, the rate among Hispanic/Latino women (5.3) was higher than among white women (1.6). The majority (86%) of infections among women were attributed to heterosexual contact, and 13% were attributed to injection drug use. Among children, approximately 3 out of 4 diagnosed infections were attributed to perinatal exposure. The majority of diagnoses among children (63%) occurred among black/African American children (Table 1). More detailed data are available in the annual surveillance report.[2]

The number of women living with HIV has been increasing as people with HIV are living longer, but the number of annual diagnoses has been decreasing (Figure 1A). Decreases in diagnoses could be due to a decrease in incidence or a decrease in testing. However, there is evidence to suggest that there has been a decrease in incidence, which could be due to behavioral changes and an increase in prevention programs.[11] Decreases in diagnoses has also been seen among men, although at a slower rate (Figure 1B). In children, both the number of annual diagnoses and the number of prevalent cases have been decreasing (Figure 1C). The number of children living with HIV has decreased due to children aging out of the category while fewer children are being infected. With improved treatment options, the risk of perinatal infection is very low. However, cases of perinatally acquired HIV infection still occur every year. According to the 2013 MMP surveillance report, 24% of HIV-positive women in care reported being pregnant since testing positive,[12] but, with proper treatment, most of these pregnancies can avoid perinatal HIV transmission. Monitoring exposure is important for guiding interventions to prevent perinatal HIV transmission.

In 2013, 52.3% of women and 55.5% of men living with diagnosed HIV infection had a suppressed viral load; however, viral suppression varied by race/ethnicity, age, and transmission category.[3] In 2011, viral suppression was higher among older women than younger women. By race/ethnicity, viral suppression was lower among black women (41.6%) than white women (46.5%) and lower among women whose infections were attributed to injection drug use (41.5%) compared to those whose infections were attributed to heterosexual contact (45.7%). The latter two disparities persist despite comparable retention in care.[13]

In the 2013 cycle of NHBS that sampled high-risk heterosexuals, 3% of women tested positive for HIV, of whom 59% were aware of their infection.[14] Almost a quarter (24%) of women had condomless anal sex in the prior 12 months, and 91% had condomless vaginal sex. However, there is evidence that women modify their behavior to reduce the risk of transmission once they are aware of their HIV infection (condomless anal sex: 8% of HIV+ aware; 37% of HIV+ unaware; 25% of HIV-). HIV testing is recommended at least annually for persons at increased risk for HIV infection.[15] However, among this sample of women at increased risk for HIV, only 41% reported having an HIV test in the prior 12 months.[14] Nevertheless, this is substantially higher than the testing rate among the general US population of women. According to the National Health Interview Survey, in 2010 only 12% of women received an HIV test in the prior 12 months, and this was unchanged from 2003 rates of testing.[16]

DATA GAPS AND LIMITATIONS

As with any other large surveillance program, the data collected through HIV surveillance can vary in quality from one jurisdiction to another, although the variations are minimal and estimates generated at the national level are robust. The most important issue is incomplete reporting of laboratory test results, particularly CD4 and viral load test results, to the health departments. Such reporting requires laws at the local level that authorize and make reporting mandatory for all HIV-related tests that can be used for evaluating receipt of quality medical care. While tremendous gains have been made, there are still some jurisdictions that do not have complete laboratory reporting. Furthermore, reporting of diagnoses, relevant laboratory data, and deaths to the health departments and subsequently to CDC may be delayed. Therefore, data for the most recent time period must be interpreted with caution. To accurately count cases, it is important to identify cases reported from multiple sources. Through routine review of potential duplicates, deduplication of cases occurs at the jurisdiction and national data level.

USING DATA FOR ACTION

Government agencies use HIV surveillance data to determine how to distribute resources and plan programs for areas and populations most in need. For example, two of the largest federally funded HIV programs use HIV surveillance data as part of their funding formulas. The Ryan White HIV/AIDS Program statute authorizes the Health Resources and Services Administration (HRSA) to distribute funds for primary HIV medical care, treatment, and support services for people living with HIV who are uninsured or underinsured, based on the number of reported HIV and AIDS cases in states and metropolitan areas.[17,18] The Department of Housing and Urban Development (HUD) uses surveillance data in their funding formulas to identify metropolitan areas eligible to receive funding for housing assistance and related services for people living with HIV, under their Housing Opportunities for Persons with AIDS (HOPWA) Program.[19] In June 2015, the Integrated HIV Prevention and Care Plan Guidance, developed jointly by CDC and HRSA, was released.[20] HIV surveillance data plays a pivotal role in the development of statements of need and also serves as the source for data points needed for monitoring the progress of activities designed to address the needs identified.

Recently, CDC has encouraged jurisdictions to use surveillance data to improve individual care outcomes. This program is referred to as Data to Care. For this activity, surveillance data are used to generate a list of people living with HIV who may be out of care or in care but not virally suppressed. The local health departments use this information to try to locate these individuals and reengage them in medical care, or they could share this information with HIV health care providers so they can try to locate and reengage patients. However, for this type of effort to work well and efficiently, the surveillance system needs to receive all laboratory reports in a timely manner and have up-to-date contact information for patients. Maintaining the security and confidentiality of the surveillance data is also a key aspect of these programs.

HIV surveillance data are also used to monitor progress towards the following National HIV/AIDS Strategy (NHAS)[21] and Healthy People 2020 goals[22]:

- National HIV/AIDS Strategy goals:[21]
    - Reduce the number of people who become infected with HIV.
    - Increase access to care and improve health outcomes for people living with HIV.
    - Reduce HIV-related health disparities.

- Healthy People 2020:[22]
    - Prevent HIV infection and its related illness and death.

FUTURE ISSUES

New cases of HIV represent missed opportunities for prevention and treatment efforts. As we move into the future, the use of HIV surveillance data to improve the health outcomes of people living with HIV and the use of data to identify opportunities for prevention of transmission will continue to grow. Strengthening of HIV surveillance, particularly in areas with high diagnosis rates, will enable jurisdictions to better evaluate the impact of their HIV prevention efforts. For ART to continue to be effective, the availability of care for persons in need and monitoring of any emerging drug resistance will be important. Molecular HIV Surveillance will better monitor drug resistance as well as growing clusters of persons with early HIV infection that are indicative of recent transmission. By identifying these clusters, they can be prioritized for investigation and public health action.

For Data to Care, improving the timeliness and completeness of reporting is one of the key factors for health departments' successful implementation of Data to Care programs. Data to Care relies heavily on complete lab reporting to accurately determine who is not in care, but it is also critical to have up-to-date address information and vital statistics data. Currently, not all jurisdictions are considered to have complete reporting of lab results with some jurisdictions still needing to put regulations in place to even allow complete reporting. Achieving complete reporting in every state is a critical first step towards using surveillance data for action. In addition, continued focus on identifying and resolving duplicate cases is needed to assure accurate case counts and aid Data to Care activities. Once people have been identified as out of care through surveillance data, they need to be re-engaged in care and be able to access support services to remain in care and on treatment.

Lastly, to be effective, prevention programs will need to be able to estimate future program needs and costs. Surveillance can adjust to emerging information needs, such as the recent addition of more detailed collection of information on PrEP, to support program planning and evaluation and deliver data needed for resource allocation and modeling.

Table 1: Diagnoses of HIV infection, by sex, age at diagnosis, race/ethnicity, and transmission category, 2015– United States

	Adults and Adolescents (≥13 years)				Children (< 13 years)	
	Males		Females			
	No.	(%)	No.	(%)	No.	(%)
Age (years)						
< 13	–	–	–	–	120	(100)
13-19	1,469	(5)	254	(3)	–	–
20-29	12,783	(40)	1,811	(24)	–	–
30-39	7,711	(24)	1,920	(26)	–	–
40-49	5,129	(16)	1,591	(21)	–	–
50-64	4,269	(13)	1,597	(22)	–	–
≥ 65	630	(2)	229	(3)	–	–
Race/Ethnicity						
American Indian/Alaska Native	152	(<1)	55	(1)	2	(2)
Asian	816	(3)	132	(2)	7	(6)
Black/African American	13,070	(41)	4,524	(61)	76	(63)
Hispanic/Latino[a]	8,147	(25)	1,131	(15)	12	(10)
Native Hawaiian/Other Pacific Islander	71	(<1)	8	(<1)	0	(0)
White	9,060	(28)	1,431	(19)	18	(15)
Multiple races	675	(2)	121	(2)	5	(4)
Transmission category[b]						
Male-to-male sexual contact	26,376	(82)	–	–	–	–
IDU	1,412	(4)	980	(13)	–	–
Male-to-male sexual contact and IDU	1,202	(4)	–	–	–	–
Heterosexual contact[c]	2,948	(9)	6,391	(86)	–	–

Perinatal	–	–	–	–	86	(72)
Other[d]	53	(<1)	31	(<1)	34	(28)
Total	31,991	(100)	7,402	(100)	120	(100)

Source: CDC. HIV Surveillance Report, 2015; vol. 27.

Note. Data include persons with a diagnosis of HIV infection regardless of stage of disease at diagnosis. Data for 2015 are preliminary (subject to change) because they are based on only a 6-month reporting delay.

[a] Hispanics/Latinos can be of any race.

[b] Data have been statistically adjusted to account for missing transmission category.

[c] Heterosexual contact with a person known to have, or to be at high risk for, HIV infection.

[d] Includes hemophilia, blood transfusion, and risk factor not reported or not identified, and, among adults and adolescents, perinatal exposure.

Abbreviation: IDU, injection drug use.

Table 2: Persons living with diagnosed HIV infection, by sex, race/ethnicity, and transmission category, year-end 2014 – United States

	Adults and Adolescents (≥13 years)				Children (< 13 years)	
	Males		Females			
	No.	(%)	No.	(%)	No.	(%)
Race/Ethnicity						
American Indian/Alaska Native	2,136	(<1)	762	(<1)	10	(<1)
Asian[a]	10,036	(1)	2,202	(1)	90	(4)
Black/African American	264,670	(37)	139,058	(60)	1,593	(64)
Hispanic/Latino[b]	157,885	(22)	40,252	(17)	319	(13)
Native Hawaiian/Other Pacific Islander	706	(<1)	150	(<1)	5	(<1)
White	260,481	(36)	39,343	(17)	332	(13)
Multiple races	26,330	(4)	8,593	(4)	128	(5)
Transmission category[c]						
Male-to-male sexual contact	508,676	(70)	–	–	–	–
IDU	78,699	(11)	52,013	(23)	–	–
Male-to-male sexual contact and IDU	52,357	(7)	–	–	–	–
Heterosexual contact[d]	74,879	(10)	171,470	(74)	–	–
Perinatal	4,528	(1)	4,997	(2)	1,995	(81)
Other[e]	3,106	(<1)	1,880	(1)	482	(19)
Total	722,244	(100)	230,360	(100)	2,477	(100)

Source: CDC. HIV Surveillance Report, 2015; vol. 27.

Note. Data include persons with a diagnosis of HIV infection regardless of stage of disease at diagnosis.

[a] Includes Asian/Pacific Islander legacy cases.

[b] Hispanics/Latinos can be of any race.

[c] Data have been statistically adjusted to account for missing transmission category.

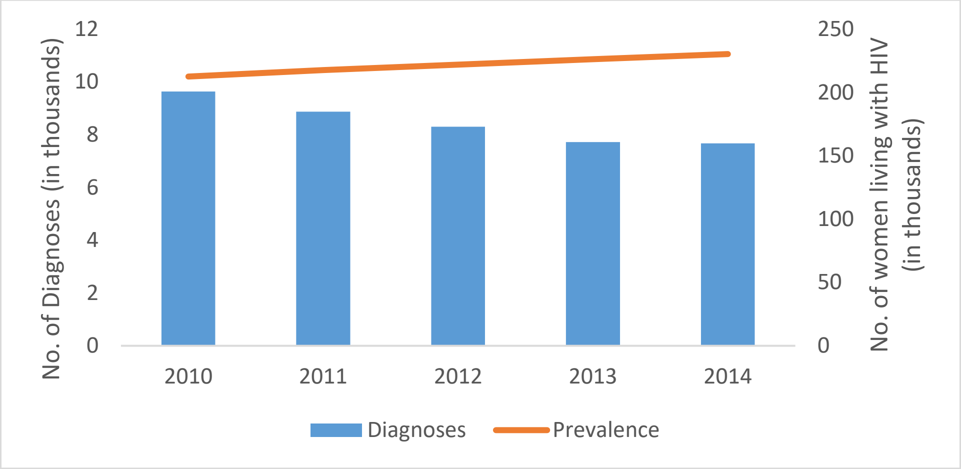
[d] Heterosexual contact with a person known to have, or to be at high risk for, HIV infection.

[e] Includes hemophilia, blood transfusion, and risk factor not reported or not identified.

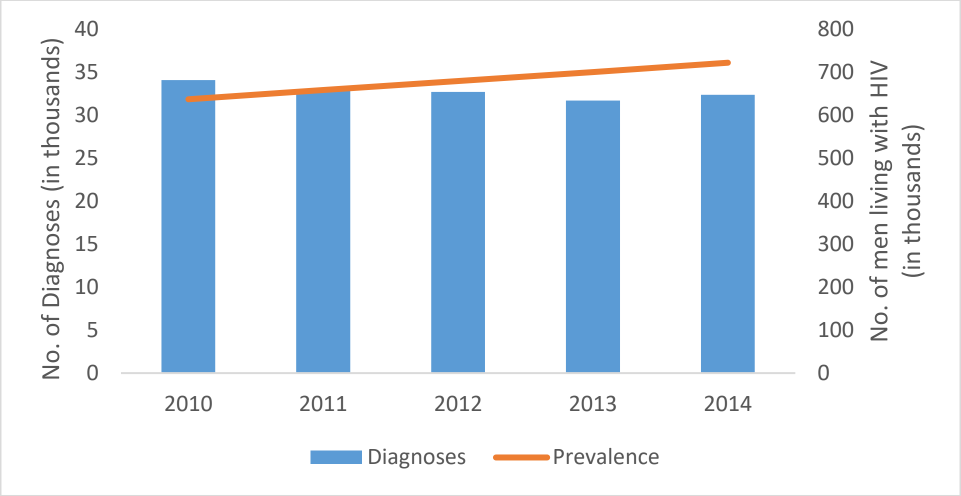
Abbreviation: IDU, injection drug use.

Figure 1. Diagnoses of HIV infection and number of people living with HIV – United States

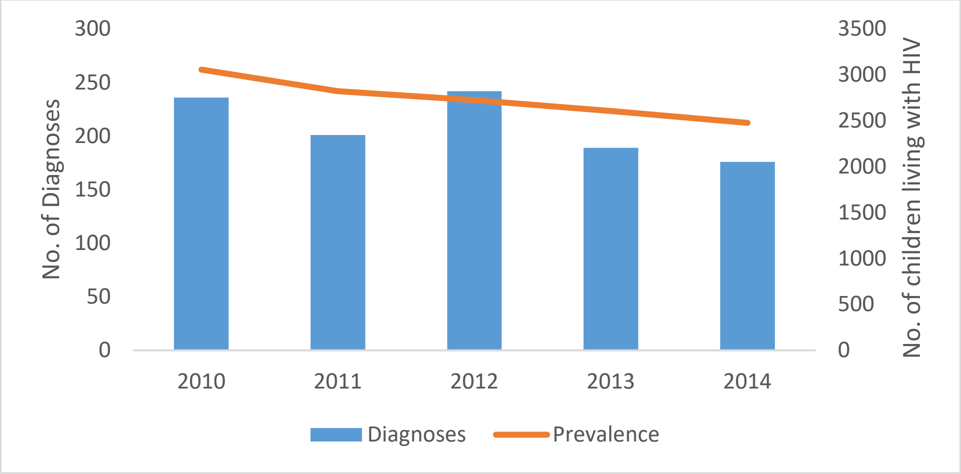
A. Female adults and adolecents



B. Male adults and adolescents



C. Children



Source: CDC. HIV Surveillance Report, 2015; vol. 27.

ADDITIONAL RESOURCES

- CDC HIV web page
  http://www.cdc.gov/hiv/
- CDC. Monitoring Selected National HIV Prevention and Care Objectives by Using HIV Surveillance Data – United States and 6 dependent areas – 2014. HIV Surveillance Supplemental Report 2016; 21(No.4). http://www.cdc.gov/hiv/library/reports/surveillance/. Published July 2016.
- CDC. HIV Surveillance Report, 2015; vol. 27. http://www.cdc.gov/hiv/library/reports/surveillance/. Published November 2016.
- Data to Care Improving Health and Prevention.
  https://effectiveinterventions.cdc.gov/en/HighImpactPrevention/PublicHealthStrategies/DatatoCare.aspx
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13. Nwangwu-Ike N, Hernandez AL, An Q, et al. The epidemiology of human immunodeficiency virus infection and care among adult and adolescent females in the United States, 2008-2012. *Women's Health Issues.* 2015;25(6):711-719.

14. CDC. HIV infection, risk, prevention, and testing behaviors among heterosexuals at increased risk of HIV infection - National HIV Behavioral Surveillance, 20 U.S. cities, 2013. *HIV Surveillance Special Report.* 2015;13. http://www.cdc.gov/hiv/library/reports/surveillance/#panel2. Accessed March 18, 2016.

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Infertility

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More than 10% of women of childbearing age in the United States experience problems with infertility or impaired fecundity, which may be caused by contributing diseases, behavioral factors, or environmental agents. The World Health Organization, the American Medical Association, and the American Society for Reproductive Medicine defines infertility as a disease of the reproductive system, and both infertility and impaired fecundity becomes more prevalent as childbearing is delayed. Population surveillance data help define and monitor these health indicators on a national level.

PUBLIC HEALTH IMPORTANCE

Although some perceive infertility as a quality-of-life or lifestyle issue, the World Health Organization, the American Medical Association, and the American Society for Reproductive Medicine define infertility as a disease of the reproductive system.[1-5] Physicians and researchers in the United States typically classify couples (whether married or cohabiting) as infertile if they have been unable to conceive a pregnancy with this same spouse or partner after 12 months or more of vaginal intercourse without contraception. Based on data from the National Survey of Family Growth (NSFG), this definition of *infertility* applied to 6.7% of married[1] women aged 15-44 years in 2011 through 2015.[6]

Another useful population-based measure of fertility problems that is defined for all women regardless of

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[1] The numbers of cohabiting women in the NSFG sample who meet the definition of 12-month infertility are small, so estimates of infertility are not shown separately for this group in this chapter. In addition, while it is possible that some unmarried, non-cohabiting women may also have tried to conceive a pregnancy with the same partner for 12 months or longer, the NSFG data do not include sufficient dates and other details for these sexual partnerships to permit reliable construction of the 12-month infertility measure for unmarried, non-cohabiting women. Prior research with NSFG and other data have documented greater likelihood of contraceptive use among cohabiters and unmarried non-cohabiters, relative to married women[11,15] and lower percentages who are seeking pregnancy. For these reasons, percentages of infertility are only shown for married women in this chapter.

marital or cohabiting status is *impaired fecundity,* which refers to women who have difficulty conceiving or carrying a pregnancy to term. In 2011 through 2015, again based on NSFG data, 12.1% of women aged 15-44 years in the US had impaired fecundity.[6] Taking both of these measures together, 13.1% of all women aged 15-44 years (regardless of marital or cohabiting status) in the US had fertility problems in 2011 through 2015, either infertility or impaired fecundity.

Infertility and impaired fecundity may be caused by a range of factors of interest to public health, including genetic abnormalities, acute and chronic diseases, treatments for certain conditions (e.g., autoimmune disorders, cancer); behavioral factors (e.g., sexually transmitted infections, smoking, obesity); and fetal or childhood exposures to environmental, occupational, and infectious agents.[3,7] Many of these factors that impair fertility are well-known, preventable risks to overall health.

In recent decades, a number of demographic and social factors, in particular, patterns of delayed marriage and childbearing, have increased the proportion of women trying to have a first child at older ages when fecundability, or the physiological ability to conceive and carry a baby, is lower.[8-13] These trends, along with the aging of the large baby boom generations through the peak reproductive years, generated larger numbers, but not larger age-specific percentages, throughout the past 30 years of women and couples who experienced infertility challenges and who have pursued medical services to help them have a baby.[14-17]

Even as the prevalence of infertility and impaired fecundity has remained fairly stable over time,[15,18] monitoring these conditions, along with the medical services used to prevent or treat them, has importance for public health. Prevention strategies at both the individual and population level may involve assessment and monitoring of behavioral factors, as well as exposure to infectious, environmental, and occupational agents. Treatments for infertility can carry health risks for women, men, and their children. Infertility services can be costly and insurance coverage for these services can vary widely, which raises questions about equitable access to appropriate diagnosis and treatment by individuals of different socioeconomic status, race, ethnicity, age, and other groups. In addition to these concerns, infertility can be associated with significant psychological distress and adverse consequences for the couple and family.[2,3,19,20]

HISTORY OF DATA COLLECTION

In the United States, the only source that has provided long-term, nationally representative data on the population-based prevalence of infertility and impaired fecundity for reproductive-aged women is the NSFG and its predecessor surveys: the Growth of American Families Study in 1955 and 1960 and the National Fertility Survey in 1965 and 1970. From 1973 to 2002, the National Center for Health Statistics (NCHS) has conducted the NSFG at periodic intervals. Starting in 2006, the survey moved to a continuous fieldwork design,[21-24] with public use file releases for 2006-2010, 2011-2013 and 2013-2015, thus far. The NSFG is a multipurpose survey designed to ask women aged 15-44 years about their pregnancies, contraceptive use, reproductive health, marriages and relationships, and basic socioeconomic characteristics. As part of this interview, information is gathered from all women on their possible experience with infertility, impaired fecundity, and use of medical services to help them have a baby. Since 2002, the NSFG has interviewed an independent sample of men aged 15-44 years, including a scaled down but similar set of questions about infertility and the use of infertility services. These data are described briefly in the Data to Action chapter on male reproductive health by Warner and Besera. Beginning in 2015, the NSFG age range was expanded to men and women 15-49 years of age.

Additionally, since 2004, CDC, in collaboration with the Society for Assisted Reproductive Technology (SART), has supported the National ART Surveillance System (NASS)—a web-based system for clinics to report data on assisted reproductive technology (ART). NASS began after the Federal Trade Commission intervened in a case of false advertising by a fertility clinic. As a result, the Fertility Clinic Success Rate and Certification Act of 1992 (FCSRCA, Section 2(a) of P.L. 102–493 (42 U.S.C. 263a-1(a))) was passed, which mandated that CDC collect information yearly about ART cycles performed at clinics in the United States. NASS is estimated to capture about 98% of the estimated ART procedures performed annually in the United States. It also collects data on patient demographics, medical history, and infertility diagnosis; clinical information regarding ART procedure type; and information pertaining to resulting pregnancies and births. Prior to the development of NASS, CDC obtained ART data for 1995-2003 from SART.[25-28]

Other data collection systems that can potentially be used to determine infertility prevalence and evaluate infertility and the use of selected infertility services include the following:

- National Vital Statistics System (NVSS)[29] - The 2003 revision of the US birth certificate included information on the use of infertility treatment in connection with the birth and has been used to study associations between these treatments and various indicators of maternal and infant health (e.g., low birth weight and prematurity) among recently pregnant women.
- Pregnancy Risk Assessment Monitoring System (PRAMS)[30] – PRAMS is a surveillance project of CDC and

state health departments established in 1987; covering about 83% of births, it collects state-specific data on maternal attitudes and experiences before, during, and shortly after pregnancy. PRAMS includes supplemental questions that states can optionally add to their surveys, including questions on the use of assisted reproduction during the most recent pregnancy that ended in a live birth (i.e., if fertility treatments were used, type of treatment, length of time/how many cycles used). These data could be useful in examining any associations between infertility/infertility treatments and adverse health outcomes for mothers and infants.

- Behavioral Risk Factor Surveillance System (BRFSS)[31, 32] – BRFSS is a national telephone-based survey initiated in 1984 that collects data on health-related risk behaviors, chronic health conditions, and use of preventive services (but not reproductive history) from all US states, territories, and Washington, DC but questions can be added to the survey, as was done in 2013, when selected states also asked female respondents about reproductive history, family planning and contraception, and infertility. Previously validated questions were used asking if respondent or her partner experienced infertility, including carrying to term; types of infertility treatments received; and the result of the most recently used infertility treatment.
- National Health and Nutrition Examination Survey (NHANES)[33] – Using a combination of interviews and physical examinations, NHANES is designed to assess the health and nutritional status of the US population. NHANES was based on a series of cross-sectional surveys conducted periodically from the 1960s through 1999 among a nationally representative sample of US adults and children and shifted to a continuous design in 1999. The reproductive health portion of the questionnaire includes questions asking if female respondents had unsuccessfully attempted to become pregnant over a period of at least one year and been to a medical provider because she was unable to become pregnant.

CDC SURVEILLANCE ACTIVITIES

As noted, CDC's primary source of surveillance data on infertility and the ever-use of infertility services, not limited to ART, in the *general household population* is the NSFG. NASS is CDC's primary source of surveillance data from patients who underwent ART.

NSFG

Since 1982, the NSFG has routinely been used to produce estimates based on two measures of fertility problems: infertility and impaired fecundity. Unlike the single-question measurement of infertility in other CDC surveys such as BRFSS and NHANES, both of these NSFG measures are constructed based on detailed questions and event history data on pregnancies, contraceptive use, sexual activity, and marital/cohabiting status.

The **infertility status** measure reflects the standard medical definition of 12-month infertility used in the United States - a case in which a married or cohabiting couple is not surgically sterile, has had sexual intercourse with no use of contraception for at least 12 consecutive months, and has not become pregnant for at least 12 months. This measure is intended to provide a standard metric by which to gauge population prevalence, as well as to help clinicians identify couples who may warrant medical evaluation to see whether fertility treatment services could help them have a baby. This measure has traditionally been limited to married or cohabiting women because infertility is a couple-based phenomenon; unless he or she is completely sterile, either partner may potentially achieve pregnancy with a different partner. This measure does not attempt to distinguish whether the infertility stems from the female or male partner. Also, the measure requires at least 12 months of sexual relationship with the same partner and reliable reporting of contraception and pregnancy, and married or cohabiting women's reporting of these experiences is less prone to misreporting.

Fecundity status describes the physical ability of a woman to have a child and not simply to conceive a pregnancy. This NSFG measure is defined for all women regardless of their marital or cohabiting status. As with the infertility measure, married or cohabiting women are classified as surgically sterile or having impaired fecundity if their husbands or cohabiting partners meet the criteria of these categories.

Fecundity status is generally presented with three main categories: surgically sterile, impaired fecundity, and the residual category of "presumed fecund." Impaired fecundity is comprised of women in the following three subgroups of women who are not surgically sterile (i.e., neither she nor her husband or cohabiting partner is surgically sterile):

- <u>Nonsurgically sterile</u> – Women for whom it is physically impossible to have a baby or for their current husband or cohabiting partner to father a child.

- <u>Subfecund</u> – Women who have physical *difficulties* having a baby, either getting pregnant or delivering the child.

- Long interval without conception (or 36-month infertility) – Women who have been continuously married or cohabiting for at least the 36 months prior to interview, were sexually active with no contraception in each of those 36 months, and had not had a pregnancy in that span of 36 months or longer.

Women are coded into these three categories of impaired fecundity in the sequence shown. For example, if they do not meet the definition of "nonsurgically sterile," they may meet the definition of "subfecund," and only if they do not meet the definitions of the first two categories, they are assessed for the "long interval without conception" category. As with the infertility variable, the fecundity variable is constructed based on responses to NSFG survey questions, and not necessarily based on or confirmed by a medical examination. The directly asked questions about nonsurgical sterility and subfecundity are prefaced with "as far as you know," to further distinguish these as self-reported assessments of their physical or medical barriers to having a child. Further information on the infertility and impaired fecundity measures, including more detail on the questions used and the potential overlap between these measures, has been published elsewhere.[15] In addition, to permit analyses of the full population of women aged 15-44 years, the two NSFG measures have sometimes been combined into a single measure of "current fertility problems;" that is, women who have either 12-month infertility or impaired fecundity at the time of interview.

Infertility service use. In each NSFG survey since 1982, all women, regardless of their marital status or pregnancy experience, have been asked two separate questions about medical services they or their spouses or partners have ever received to help them get pregnant or help them prevent miscarriage. If they reported each type of medical help, they were then asked follow-up questions about specific types of infertility services they may have received. Since men were included in the survey in 2002, they have also been asked about infertility services they or their spouses or partners have ever received. Results from the infertility services data as reported by women and men in the NSFG have been published periodically,[16,34-37] and selected tabulations from 2006-2010 NSFG are shown in this chapter.

NASS

NASS provides surveillance data from patients who underwent ART. ART includes fertility treatments in which eggs or embryos are handled in a laboratory; generally, this involves surgically removing eggs from a woman's ovaries, combining them with sperm in the laboratory, and returning them to a woman's body.[25] Women who undergo ART are at an increased risk of delivering multiple-birth infants compared to women who conceive naturally; and multiple births pose risks to both mothers and infants (e.g., obstetric complications, preterm delivery, low birthweight of infants). Thus, NASS is used to collect data on ART procedures, maternal and infant outcomes, and maternal demographics and medical history including infertility diagnoses.[28] Data are analyzed and used to prepare CDC's annual reports and other pertinent publications.

For NASS, consistent with definitions from ASRM (American Society for Reproductive Medicine) and other professional medical organizations, infertility is defined in general as the inability to conceive after 12 months of unprotected intercourse; for women aged 35 years and older, inability to conceive after 6 months of unprotected intercourse is considered infertility for the purpose of initiating medical treatment.[28] Information on live births is collected by ART clinics either directly from the patients or from the patients' obstetric providers. The data file includes one record per ART procedure performed with the intent of transferring at least one embryo.[28]

GENERAL FINDINGS

NSFG

This section presents basic statistics using NSFG data from 2011-2015. The combined 2011-2015 NSFG file includes data from 11,300 women aged 15-44 years who were interviewed within the 4-year period of September 2011 and September 2015. The response rate was 72% for women aged 15-44 years over the survey period of 2011-2015. Further demographic and behavioral analyses have been published with 2006-2010 and prior survey years.[15,16] As noted under the description of the 12-month infertility above, this measure can be defined for married and cohabiting women. However, because the numbers of cohabiting women in the NSFG sample is considerably smaller than the numbers of married women, the results for 12-month infertility shown in Table 1 focus on married women only. For ease of comparison in Table 1, results for impaired fecundity are shown for married women and for all women. Further tabulations, including cohabiting women, can be found in other reports.[15]

Infertility and Impaired Fecundity

Table 1 presents percentages of women aged 15-44 years in 2011-2015 who met the definitions of 12-month infertility or impaired fecundity, or the combined measure of current fertility problems based on having either infertility or impaired fecundity. The first two columns are based on married women and may also reflect infertility conditions of these women's current husbands. The expected association of age with fertility problems was seen only when looking at women who have had no births (i.e., nulliparous women). For example, infertility among nulliparous married women ranged from 1.6% among those aged 15-24 years to 24.4% among those aged 35-44 years. Using the broader definition of impaired fecundity, 39.6% of married, nulliparous women aged 35-44 years had impaired fecundity, compared with 15.1% of those aged 15-24 years. The percentages of 12-month infertility or impaired fecundity among married women were similar among the Hispanic origin and race groups shown. Among *all* women aged 15-44 years and particularly, among those who have had no births, older age was associated with higher percentages with impaired fecundity and with the combined measure of current fertility problems. For example, 7.1% of nulliparous women aged 15-24 years had current fertility problems, compared with 30.8% of those aged 35-44 years. As seen among married women, the percentages of all women aged 15-44 years with impaired fecundity or current fertility problems were similar among the Hispanic origin and race groups shown.

Use of Medical Services for Infertility

Table 2 summarizes infertility service use among women aged 15-44 years in 2011-2015, among whom 12.0% ever used some form of medical help to get pregnant or prevent miscarriage – 8.2% reporting ever-use of medical help to get pregnant and 5.4% ever-use of medical help to prevent miscarriage. Overall in 2011-2015, the four most commonly used infertility services ever used among women aged 15-44 years were advice (6.3%), medical help to prevent miscarriage (5.4%), infertility testing (female or male) (5.2%), and ovulation drugs (4.2%). Higher percentages ever using any of the service types shown were seen among older women, women having had one or more births, and women with current fertility problems. The exceptions were with ART and parity where similar percentages of service use were seen. Unlike the lack of differences seen in the percentages of women with infertility and impaired fecundity by Hispanic origin and race in Table 1, percentage of ever-use of nearly all types of infertility services shown was significantly higher for non-Hispanic white women than for Hispanic women or non-Hispanic black women. The exceptions showed no significant difference in the percentages who ever had surgery or treatment for blocked tubes or who ever had medical help to prevent miscarriage.

NASS

This section focuses on 2014 ART surveillance data.[28]

ART Use and Resulting Births

In 2014, 169,568 ART procedures (with the intent to transfer at least one embryo) were performed in the United States and reported to CDC. The total number of ART procedures performed per million women of reproductive age (i.e., proxy for ART usage rate) was 2,647. A total 56,028 live-birth deliveries resulted from the ART procedures, which accounted for 1.6% of all infants born in the United States during 2014.

Specifically, ART contributed to 18.3% of all multiple-birth infants, including 18% of all twin births and 26.4% of all other higher-order infant births. Among ART-conceived infants, 38% were twins and 2% were higher-order.

Among all infants born in the United States in 2014, ART-conceived infants contributed to 5.5% of all low birthweight infants (i.e., <2,500 g) and 4.7% of all preterm infants (i.e., <37 weeks). Among ART-conceived infants, 27.8% were low birthweight (compared to 8% of all infants) and 33.2% were preterm (compared to 11.3% of all infants).[28]

More detailed results, including results by state[28] and by ART cycle type,[27] can be found elsewhere.

USING DATA FOR ACTION

Using the infertility survey and surveillance data provided by NSFG, NASS, and other data collection systems, CDC, in partnership with numerous governmental and non-governmental organizations, released the *National Public Health Action Plan for the Detection, Prevention, and Management of Infertility* (*National Action Plan)* in 2014. The plan highlighted the need to better understand and address issues of infertility at the population level in both women and men. It specifically focused on promoting healthy behaviors that can help maintain and preserve fertility; promoting prevention, early detection, treatment, and management of medical conditions that can threaten fertility; and reducing exposures to environmental, occupational, infectious, and iatrogenic agents that can threaten fertility.[2]

The national surveys and surveillance systems described here also have been used to evaluate state-level infertility-related legislation in several areas. These include policies or mandates for insurance coverage of infertility,[38.39] and the effect of targeted prevention programs like CDC's Infertility Prevention Program. Furthermore, surveillance data have been used to better understand trends in the number of embryos transferred to patients, particularly for women who are good candidates for elective single embryo transfer. From a public health standpoint, the transfer of one embryo at a time can reduce the likelihood of multiple births occurring, and correspondingly, the number of infants born in the United States who are preterm or low birth weight. Data from NASS can be used to evaluate differences in access to and use of ART by the presence of state-mandated insurance coverage. For example, three of the four states with comprehensive mandate coverage had rates of ART use at least 50% higher than the national average in 2014.[28]

DATA GAPS AND LIMITATIONS

In general, systems that collect population-based data on infertility are constrained by the fact that the field lacks a uniform consensus on how an infertility case should be defined in terms of time frame to be used and denominators of "at risk" individuals that would be most appropriate for infertility among both women and men. Perhaps more than other medical conditions, infertility may only become known if individuals are actively seeking to have a baby, which is itself sometimes correlated with age and other factors correlated with the likelihood of having fertility problems. This selectivity in potentially recognizing a fertility problem and other measurement challenges make comparisons of infertility prevalence across data systems difficult. Additionally, no single surveillance system currently provides in-depth information on the full set of key indicators for couples experiencing infertility and seeking infertility services (e.g., range of specific types of infertility in both men and women, success rates and use of most infertility treatments (except assisted reproductive technology)), and adverse maternal and infant health outcomes.[2] NSFG data are useful in being able to document selectivity associated with recognition of fertility problems and pursuit of medical care for infertility beyond ART procedures, which have been shown to comprise a small fraction of overall service use.[16,40] However, the data collected in NSFG on specific services or treatments are limited; for example, NSFG collects no dates for specific services or treatments reported, which limit the ability to tie them to specific pregnancies or other outcomes.

The primary limitation of NASS is that it collects data only on ART procedures. As noted above, no parallel surveillance system collects data on non-ART fertility treatments, which are believed to be several-fold more common than ART in any given year.[40] Moreover, non-ART treatments contribute more heavily to multiple births associated with fertility/ovulation drug treatments than ART.[41] Specific limitations inherent to NASS data include the fact that data are reported for each ART procedure performed rather than for each patient who used ART; that adverse infant health outcomes (e.g., prematurity and birthweight) could be associated with factors not entirely related to ART procedures (e.g., factors contributing to the underlying infertility); and the lack of data on long-term health outcomes both for women using fertility treatments and their children.

FUTURE ISSUES

Research to date with population-level data has documented trends and correlates of infertility, including behavioral and sociodemographic factors associated with infertility. Considerable research has illustrated that the choice of measures matters for defining prevalence and identifying populations at potentially higher risk for infertility;[42-45] however, consistent measurement is also vital for population surveillance and evaluation of trends over time. Consistent measures in surveys and population-based studies can help better understand the underlying causes of infertility for women seeking ART and how these may affect the outcomes of infertility services on mothers and infants.

Data have shown that infertility and impaired fecundity may not vary significantly by variables associated with socioeconomic status; however, the use of infertility services does indeed vary widely by socioeconomic factors such as education and household income.[2,3,16,36,46,47] The economic, legal and ethical questions raised by these disparities in access to infertility services have been examined in numerous studies[20,48,49] and may warrant further attention, given the public health importance of infertility[2] and evidence suggesting that socioeconomic factors cannot fully explain differentials in use and success of infertility services.[46,47,50-52]

Table 1: Infertility and impaired fecundity among women aged 15-44 years by selected characteristics: United States, 2011-2015.

Characteristic	Infertility among married women[1]	Impaired fecundity among married women[2]	Impaired fecundity among all women[2]	Current fertility problems among all women[3]
	Percent (standard error)			
Total[4]	6.7 (0..52)	15.5 (0.79)	12.1 (0.41)	13.1 (0.43)
Age				
15-24 years	4.6 (2.01)	15.4 (3.04)	7.8 (0.68)*	8.2 (0.69)*
25-34 years	6.3 (0.78)	14.7 (1.18)	12.6 (0.69)	14.4 (0.73)
35-44 years	7.3 (0.87)	16.1 (1.22)	15.7 (0.90)	16.6 (0.91)
Parity and age				
No births	14.2 (1.63)[$]	23.6 (2.59)[$]	11.2 (0.74)	12.2 (0.74)
15-24 years	1.6 (0.98)*	15.1 (4.65)*	7.0 (0.76)*	7.1 (0.77)*
25-34 years	11.7 (1.83)	16.3 (2.11)	12.3 (1.23)	14.6 (1.28)
35-44 years	24.4 (3.90)	39.6 (5.83)	28.7 (3.11)	30.8 (3.04)
1 or more births	4.9 (0.56)	13.5 (0.84)	12.8 (0.57)	13.8 (0.56)
15-24 years	7.6 (3.74)	15.7 (4.67)	11.9 (1.49)	13.5 (1.54)
25-34 years	4.5 (0.84)	14.1 (1.42)	12.8 (0.86)	14.3 (0.92)
35-44 years	4.9 (0.77)	12.9 (1.13)	13.0 (0.93)	13.6 (0.93)
Hispanic origin and race				
Hispanic or Latina	8.3 (1.18)	14.5 (1.58)	11.0 (0.73)	12.1 (0.77)
Non-Hispanic white, single race	5.9 (0.67)	14.8 (1.12)	12.4 (0.63)	13.4 (0.64)
Non-Hispanic black, single race	10.3 (2.87)	20.0 (3.96)	11.9 (1.04)	12.7 (1.06)

[1] Married women are classified as infertile if they have been exposed to the risk of pregnancy with the same husband for at least 12 consecutive months but have not had a pregnancy. See reference 15 for further details on this measure.

[2] Impaired fecundity indicates physical difficulties in getting pregnant or carrying a pregnancy to live birth. See reference 15 for further details on this measure.

[3] Women with current fertility problems have either impaired fecundity or 12-month infertility at time of interview.

[4] Includes women of other or multiple race and origin groups, not shown separately.

[$] The percentage for women with 1 or more births was significantly higher than that for women with 0 births ($p<0.05$).

*Older age among nulliparous women was significantly associated with a higher percentage with the specified fertility problem ($p<0.05$).

Table 2. Ever-use of infertility services by women 15-44 years of age (or their husbands or partners), by selected characteristics: United States, 2011-2015

				Specific types of medical help to get pregnant						
Characteristic	Number in thousands	Any infertility service	Any medical help to get pregnant	Advice	Tests on woman or man	Ovulation drugs	Surgery or treatment of blocked tubes	Artificial insemination	Assisted reproductive technology (ART)	Any medical help to prevent miscarriage
		Percent (standard error)								
Total for women 15-44[1]	61,263	12.0 (0.51)	8.2 (0.46)	6.3 (0.38)	5.2 (0.36)	4.2 (0.32)	0.7 (0.12)	1.4 (0.19)	0.6 (0.13)	5.4 (0.34)
Total for women 15-44 with current fertility problems[2]	8,022	32.1 (1.88)	25.4 (1.92)	19.8 (1.69)	17.7 (1.58)	15.7 (1.73)	3.0 (0.71)	6.0 (1.03)	3.1 (0.76)	12.1 (1.24)
Age										
15-24 years	19,937	3.3 (0.46)*	1.4 (0.29)*	1.3 (0.29)*	0.4 (0.13)*	0.3 (0.09)*	-*	DSU	-*	2.2 (0.41)*
25-34 years	21,091	12.9 (0.82)	8.6 (0.62)	6.9 (0.55)	5.3 (0.54)	3.7 (0.45)	0.4 (0.20)	0.9 (0.28)*	0.2 (0.11)	5.9 (0.68)
35-44 years	20,236	19.5 (1.15)	14.5 (1.02)	10.5 (0.85)	9.8 (0.77)	8.5 (0.78)	1.6 (0.29)	3.4 (0.49)	1.6 (0.37)	8.1 (0.68)
Parity										
No births	27,619	6.9 (0.59)[$]	5.7 (0.52)[$]	4.7 (0.45)[$]	3.6 (0.43)[$]	2.5 (0.32)[$]	0.3 (0.08)[$]	0.8 (0.15)[$]	0.2 (0.21)	2.0 (0.36)[$]
1 or more births	33,645	16.1 (0.82)	10.3 (0.70)	7.6 (0.55)	6.5 (0.56)	5.6 (0.49)	1.0 (0.20)	2.0 (0.33)	0.2 (0.29)	8.2 (0.55)
Hispanic origin and race										
Hispanic or Latina	12,303	8.9 (0.76)	5.3 (0.56)	4.0 (0.51)	2.7 (0.38)	2.1 (0.33)	0.5 (0.16)	0.7 (0.17)	0.2 (0.12)	4.4 (0.63)
Non-Hispanic white, single race	34,087	14.2 (0.76)[#]	10.4 (0.71)[#]	8.1 (0.57)[#]	6.6 (0.58)[#]	5.6 (0.51)[#]	0.8 (0.19)	2.1 (0.33)[#]	0.7 (0.18)[#]	6.0 (0.48)
Non-Hispanic black, single race	8,407	8.7 (1.15)	4.2 (0.76)	2.6 (0.49)	2.7 (0.66)	1.4 (0.36)	0.3 (0.10)	0.4 (0.13)	0.1 (0.05)	5.3 (0.99)

[1] Includes women of other or multiple race and origin groups, not shown separately.

[2] Current fertility problems include either impaired fecundity or 12-month infertility at time of interview. See table 1 for definnitions of impaired fecundity and infertility, or reference 15 for further details on these measures.

[$] The percentage ever using the indicated service for women with 1 or more births was significantly higher than that for women with 0 births ($p<0.05$).

[#] The percentage ever using the indicated service for non-Hispanic white women was significantly higher than that percentages for non-Hispanic black women or Hispanic women ($p<0.05$).

- Zero quantity

DSU - Figure does not meet standards of reliability or precision. Based on fewer than 5 cases in numerator.

Source: CDC/NCHS, 2011-2015 National Survey of Family Growth

ADDITIONAL RESOURCES

- CDC/NCHS National Survey of Family Growth (NSFG) https://www.cdc.gov/nchs/nsfg/index.htm
- CDC National ART Surveillance System (NASS) www.cdc.gov/art/NASS.htm
- CDC/NCHS National Vital Statistics System (NVSS) - Birth Data www.cdc.gov/nchs/nvss/births.htm
- CDC Pregnancy Risk Assessment Monitoring System (PRAMS) http://www.cdc.gov/PRAMS/index.htm
- CDC Behavioral Risk Factor Surveillance System (BRFSS) https://www.cdc.gov/brfss/
- CDC/NCHS National Health and Nutrition Examination Surveys (NHANES) https://www.cdc.gov/nchs/nhanes/index.htm

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Men’s Reproductive Health

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Historically, few surveillance systems have examined the reproductive health of men; most have focused solely on how improvements in men’s health also contributes to the wellness of women and infants. However, as surveillance systems expand to garner information directly from men, new insights may be found that improve male reproductive health.

PUBLIC HEALTH IMPORTANCE

Although both men and women have reproductive health care needs, the reproductive health of men is often viewed exclusively in relation to how it can improve the health of women and infants.[1-4] According to the World Health Organization (WHO), however, “reproductive health . . . implies that people are able to have a responsible, satisfying and safe sex life and that they have the capability to reproduce and the freedom to decide if, when and how often to do so.”[5] This definition, adopted and internationally accepted at the 1994 International Conference on Population and Development (ICPD) in Cairo, Egypt,[6] applies to men as well as women. Both this conference and the Fourth World Conference on Women held in Beijing a year later represented major milestones for clearly defining reproductive health and for explicitly recognizing the need for male involvement.[7] Specifically, the ICPD *Programme of Action*, which was adopted by 179 countries, noted the need for innovative programs that make information, counseling, and services for reproductive health easily accessible to adolescents and adult men.[6] Such calls for action have provided the foundation for expanding reproductive services to men. National performance measures, guidelines, and programs have increasingly noted the importance of men seeking reproductive care. For example, one Healthy People 2020 Objective calls for increasing the proportion of males who receive reproductive health services.[8] Further in 2014, the Department of Health and Human Services’ Centers for Disease Control and Prevention (CDC) and Office of Population Affairs (OPA) released recommendations for providing quality family planning services to men as well as women, including contraceptive, preconception health, STD, and basic infertility services.[9] Similar federal efforts have addressed how to facilitate men's engagement in reproductive health. For example, beginning in the early 2000s, OPA, which administers the National Title X Family Planning Program, successfully increased the number of men who use Title X services by funding demonstration projects and training to improve outreach and male-centered service delivery.[1,10] In 2010, CDC held its first-ever consultation where researchers, program managers, and clinicians learned about emerging areas of public health activities related to male reproductive health.[11] More recently, the Department of Health and Human Services' Office of Adolescent Health and CDC jointly funded projects that support rigorous evaluation of innovative interventions designed for young men aged 15-24 years old to reduce their risk of fathering a teen pregnancy.[12]

The reproductive health needs of men should be met to improve their own health and well-being, as well as that of their partners and offspring. Helping partners prevent unintended pregnancies, protect themselves and their partners against STDs, including HIV infection, receive information and counseling services related to reproductive health care (including preconception care), and prevent, diagnose, and treat infertility and reproductive cancer, are among the reproductive needs of men.[3,4,13] Nevertheless, there are considerable challenges in providing services to men, including their perceived lack of need for and lower use of preventive services, combined with a general lack of provider awareness regarding men's reproductive health care needs.[2,13-15] For example, an analysis of data from the 2006–2010 National Survey of Family Growth (NSFG) found that the majority (60%) of US men aged 15–44 years were in need of preconception care, based on intentions to have children in the future and self and partner fecundity status.[13] Another NSFG analysis found that more than half (52%) of sexually experienced men aged 20–44 years did not receive any sexual and reproductive health care in the 12 months prior to the survey.[2] Additionally, addressing the reproductive health needs of adolescent males is critical given they experience a number of changes associated with puberty and tend to initiate sexual behavior during this time.[16] Behaviors formed during adolescence may also influence behaviors, morbidity, and mortality during adulthood related to reproductive and overall health.[16,17] Finally, diverse populations of males, including men who have sex with men (MSM) and LGBTQ, have unique needs that should be addressed when providing reproductive health services.[9]

A variety of data sources at CDC include information to assess the status of the reproductive health of men. Selected longstanding surveys and surveillance systems that collect data related to men's reproductive health are described in this chapter. Of note, we highlight those systems and surveys that collect information directly from males. Data systems that rely on partner reports or medical records of males are beyond the scope of this chapter.

HISTORY OF DATA COLLECTION

The primary source of data related to men's reproductive health collected at CDC is the National Survey of Family Growth (NSFG) (http://www.cdc.gov/nchs/nsfg/). Since 1973, the NSFG has been conducted periodically to provide national estimates related to family life and reproductive health. The first five cycles (1973, 1976, 1982, 1988, and 1995) of the NSFG interviewed a national probability sample of women 15-44 years of age in the civilian, non-institutionalized population of the United States. CDC and collaborating federal agencies decided in the 1990s to additionally include a nationally representative, independent sample of men in the NSFG.[18] This decision reflected changes in family structure and sexual activity, such as changes in non-marital childbearing and patterns of marriage, divorce, and cohabitation, which made it potentially problematic to rely on women to report on men's fertility, sexual, and family-related behaviors.[18] Nearly 30 years from its inception, during the sixth cycle of the NSFG conducted in 2002, a sample of males 15-44 years of age was surveyed for the first time. The male survey includes a number of questions about attitudes and experiences around fertility, family formation, sexual behavior, contraceptive use, and father involvement[18] and provided national estimates on these indicators that were lacking in other national survey and surveillance systems.[19] Starting in 2006, the NSFG shifted to continuous interviewing and beginning in fall 2015, expanded the age range for both men and women from 15-44 to 15-49 to recognize that family formation efforts during the reproductive years continue beyond the mid-40s. The NSFG continues to be a rich source of data on family life, marriage and divorce, pregnancy, infertility, use of contraception, and men's behaviors related to reproductive health, including those related to risk for HIV and other STDs.[18] For complete details about the NSFG, see additional resources listed at the end of this chapter.

CDC SURVEILLANCE ACTIVITIES

In addition to the NSFG, there are a number of publicly available national and state-based surveys and surveillance systems from CDC that capture aspects of men's reproductive health. Select data sources and specific measures are detailed below.

Youth Risk Behavior Surveillance System

The Youth Risk Behavior Surveillance System (YRBSS) (http://www.cdc.gov/healthyyouth/data/yrbs/index.htm) monitors a variety of health-risk behaviors every two years, including behaviors that contribute to unintentional injuries and violence, sexual behaviors, alcohol and drug use, tobacco use, unhealthy dietary behaviors, and inadequate physical activity, among male and female high school students in the United States. From 1991 through 2015, YRBSS has collected data from more than 3.8 million high school students from 37 states and 19 large urban school districts.[20] YRBSS contributes to the understanding of the sexual and reproductive behavior of adolescent males by collecting information on behaviors that contribute to unintended pregnancy and sexually transmitted infections, including HIV infection.[21] Specific measures include sexual activity, number of sexual partners, age at first intercourse, alcohol and other drug use related to sexual activity, condom use and other contraceptive use, and receipt of testing for HIV. For complete details about the YRBSS, see additional resources listed at the end of this chapter.

National HIV Behavioral Surveillance

The National HIV Behavioral Survey (NHBS) (http://www.cdc.gov/hiv/statistics/systems/nhbs/) was created in 2003 to conduct behavioral surveillance among persons at high risk for HIV infection, specifically gay, bisexual, and other men who have sex with men, persons who inject drugs, and heterosexuals at increased risk for HIV infection.[22] Surveillance is conducted in rotating annual cycles in these three different populations. During each cycle, a minimum of 500 eligible persons from each participating project area are interviewed and offered HIV testing. As of 2016, 22 project areas with high HIV prevalence were funded to conduct surveillance.[22] The NHBS collects information from these high-risk populations on risk behaviors for HIV, HIV testing behaviors, access and exposure to and use of prevention services, and HIV testing results.[23]

Behavioral Risk Factor Surveillance System

Established in 1984, the Behavioral Risk Factor Surveillance System (BRFSS) (http://www.cdc.gov/brfss/) is a state-based system of health-related telephone surveys that collects information on chronic health conditions, health-related risk behaviors, and use of preventive health services.[24] BRFSS is the world's largest ongoing telephone health survey and currently collects data in all 50 states, the District of Columbia, American Samoa, Palau, Puerto Rico, the US Virgin Islands, and Guam. More than 400,000 male and female adults (18 years of age and over) are interviewed each year.[24] Topics addressed in BRFSS include health status, health care access, chronic health conditions, tobacco use, consumption of fruits and vegetables, and physical activity.[25] Starting with the 2009 questionnaire, male (and female) respondents were asked whether they had ever been told by a health-care professional that they had cancer, and if so, their age when told they had cancer, how many different types of cancer, and which type of cancer they had.[26] Data regarding male reproductive cancers (i.e., of the prostate and testis) were collected from survivors and will be repeated in the BRFSS questionnaire every five years.[27] States may also choose to ask questions regarding follow-up care, treatment plans, and pain management received by men diagnosed with cancer.[27] For prostate screening, the survey also contains questions for men aged 40 years and older to assess whether a health provider ever talked with them about or recommended a Prostate-Specific Antigen (PSA) test, whether they ever had a PSA test and how long it has been since their last test, and the main reason they had a PSA test.[28]

National Health and Nutrition Examination Survey

The National Health and Nutrition Examination Survey (NHANES) (http://www.cdc.gov/nchs/nhanes/) is a program of studies that assess the health and nutritional status of children and adults by combining data from interviews with physical and laboratory examinations.[29] NHANES began in the early 1960s as a series of surveys focusing on different populations or health topics and, in 1999, the surveys became a continuous program.[29] A nationally representative sample of about 5,000 noninstitutionalized persons (male and female) are surveyed each year from counties across the country.[29] The NHANES interview covers a variety of topics, including demographic and socioeconomic information, current health status, medical conditions, health insurance coverage, physical fitness and activity, weight, and dietary intake, and lifestyle behaviors, including illicit drug, alcohol, and tobacco use.[29] The examination component is administered by trained medical personnel and consists of medical, dental, and physiological measurements, and laboratory tests.[29] Specifically related to men's reproductive health, NHANES collects information on sexual behavior, sexually transmitted diseases, prostate conditions, and other risk factors that may have implications for men's reproductive health, such as occupational history and environmental exposure to chemicals.

GENERAL FINDINGS

Sexual Activity, Contraception, and Fertility (NSFG)

Among men aged 15-44 years, the mean age at first vaginal sexual intercourse has remained about the same at approximately 17 years of age since the 2002 survey.[30] In 2002, the median number of opposite-sex partners in lifetime reported among men aged 25-44 years was 6.7, which decreased in 2006-2010 to 6.0, and increased in 2011-2013 to 6.6.[31] Among men who had intercourse within 12 months of their interview, most reported contraceptive use at last intercourse. Specifically, in 2002, 70.5% reported use by themselves or their partner of any method, which increased to 75.1% in 2006-2010, and declined slightly to 74.6% in 2011-2013.[32] In 2011-2013, the most commonly used method reported was the condom (34.4%) followed by the pill (22.1%).[32] In the NSFG, infertility status among men is based on questions that ask about surgical sterility and men's physical ability to father a child.[33] Among men aged 15-44 years in 2002, 11.1% reported some type of infertility, with 5.6% being nonsurgically sterile and 5.5% subfertile.[33] In 2006-2010, nearly one of every 10 men (9.4%) reported some type of infertility with 4.2% being nonsurgically sterile and 5.2% subfertile.[33] NSFG also collects information from men on the use of infertility services. In 2006-2010, 9.4% of men aged 25-44 reported that they had ever used, or their wives or partners had ever used, infertility services.[34] The most common services were advice, tests on man or woman, and ovulation drugs.[34]

Sexual Behavior among High School Students (YRBSS)

Among male high school students, the proportion who ever had sexual intercourse was highest in 1991 (57.4%) and lowest in 2015 (43.2%). Additionally in 2015, 30.3% of students reported having sexual intercourse with at least one person during the three months before they completed the survey and were considered currently sexually active. The proportion of high school males who ever had sex and were currently sexually active increased with grade level, and in 2015, the highest proportion of males who were sexually active was in the 12th grade (45.4%) and the lowest proportion in the 9th grade (17.3%). Among high school males who were sexually active, 61.5% used a condom while 12.2% did not use any method to prevent pregnancy during their last sexual intercourse.

HIV Risk Behaviors and Testing Behaviors among MSM (NHBS)

An HIV Surveillance Special Report summarized key results from cycle 4 of NHBS data collection efforts conducted among MSM in 2014.[35] Of 9,640 men participating in the survey, 64% reported having anal sex without a condom with a male partner (either main or casual) during the past 12 months.[35] Also, 11% of MSM reported having vaginal sex and 4% reported having anal sex with a female partner.[35] Nearly all participants (94%) had been previously tested for HIV during their lifetime. Among MSM, 13% reported a diagnosis of chlamydia, gonorrhea, or syphilis during the 12 months before interview.[35] A separate analysis of NHBS data indicates that HIV prevalence among MSM was around 18% in 2011 and highest among men who were older, black, and had lower education and income.[36]

DATA GAPS AND LIMITATIONS

The surveys and surveillance systems highlighted here collect information on a variety of topics related to men's reproductive health. A major strength of these systems is that they collect information on behaviors directly from men, rather than relying on information reported by their partner or in medical records. There is currently not a single CDC surveillance system that includes the full spectrum of indicators related to men's reproductive health. With the exception of the health examination component of NHANES, the data systems in this chapter rely only on self-reporting information. Additionally, all surveillance systems noted are cross-sectional in nature, so there are also the inherent limitations associated with recall bias and establishing temporality of exposures and reproductive outcomes.

USING DATA FOR ACTION

Data from the survey and surveillance systems highlighted here have been used for monitoring the nation's progress in meeting Healthy People 2020 objectives related to men's reproductive health. Specific examples include data from the NSFG, which are used to track progress on Healthy People 2020 objectives related to family planning and HIV such as, "increase the proportion of sexually experienced males aged 15 to 44 years who received reproductive health services (FP-7.2), increase the proportion of adolescents and adults who have been tested for HIV in the last 12 months (HIV-14.1), and increase the proportion of sexually active unmarried males aged 15 to 44 years who use condoms (HIV-17.2)."[8] NSFG data are also used to monitor a number of objectives related to male contraceptive use, sexual activity, and receipt of education on sex and birth control. Data from the NHBS are also used to track Healthy People 2020 objectives[40] and are commonly used to document the burden of disease and trends in HIV prevalence among populations at high risk for HIV infection.[41] Data from the NHBS have been used to assess changes in HIV prevalence and indicate the success or lack of progress of HIV prevention interventions and have been used to monitor the use of HIV prevention services in different jurisdictions.[41,42]

In 2009, a CDC report identified key reproductive health indicators from multiple surveys and surveillance systems regarding sexual risk behavior and reproductive health outcomes such as pregnancy, births, HIV/AIDS and sexually transmitted diseases, among young males and females aged 10-24 years in the United States.[17] This summary integrated data from a variety of surveillance systems, making information more easily available and accessible to policy makers, researchers, and program providers who are working to improve the reproductive health of adolescents and young adults. Efforts are underway to update this report to monitor progress made on key indicators related to the reproductive health of adolescent and young adult males.

FUTURE ISSUES

The overwhelming majority of surveillance efforts to date on fetal and infant outcomes has focused on understanding women's reproductive health and improving maternal health and behavior. To better understand the influence of paternal factors on pregnancy outcomes and the effect of becoming a father on men's overall health, additional population-based data on men both prior to and during fatherhood are needed. Currently, the NSFG remains the only primary source of information from males regarding their attitudes and experience fathering pregnancies and involvement in daily activities with their children.[43] Other surveys and surveillance systems could be leveraged to include this type of information directly from males. The Pregnancy Risk Assessment Monitoring System (PRAMS), for example, is a longstanding surveillance system of CDC and state health departments that collects state-specific, population-based data on maternal attitudes and experiences before, during, and shortly after pregnancy. PRAMS is a rich data source for maternal and child health that has been used to understand the relationship between maternal behaviors and pregnancy and infant outcomes. However, PRAMS includes very limited information on fathers, and the information that is currently included relies entirely on maternal report. It is not only important for surveys and surveillance systems to collect data that can be used to monitor men's reproductive health, but also data to monitor possible health effects on their child(ren). Existing surveys and surveillance systems, such as PRAMS, could be expanded to support the measuring and monitoring of key indicators of men's reproductive health and their relationship to health outcomes, not only for men, but also for outcomes related to pregnancy, birth, and children's health. A feasibility study examining the inclusion of fathers within the PRAMS sample, PRAMS for DADS is currently underway and has yielded promising results.[43] In addition, other surveys or surveillance systems could be expanded to include more measures on males. For example, the inclusion of measures of fatherhood could be explored with CDC's National Health Interview Survey, which has been the principal source of information on the health of the civilian noninstitutionalized population of the United States since the 1950s.[44] Collection of this information would provide the opportunity to assess the health and well-being of fathers, especially as it relates to affecting different aspects of their health status and potentially their child(ren)'s health. Also, a module of state-added questions related to men's reproductive health could be included in future surveys of the Behavioral Risk Factor Surveillance System (BRFSS) as was recently done for women's reproductive health regarding contraception, infertility, and pregnancy history in the 2013 survey.[45]

ADDITIONAL RESOURCES

- **NSFG:** Information related to NSFG, including, questionnaires, datasets, related documentation key statistics, and publications can be found at: http://www.cdc.gov/nchs/nsfg.htm
- **YRBSS:** Youth Online is an interactive online tool that allows users to analyze national, state, and local YRBSS data from high school and middle school surveys. This tool can be accessed at: https://nccd.cdc.gov/youthonline/App/Default.aspx.
- **NHBS:** Detailed information about the NHBS including contacts, publications, reports, and operations (protocols with questionnaires, formative research manuals, data collection instruments, etc.) can be accessed at: http://www.cdc.gov/hiv/statistics/systems/nhbs/index.html.
- **BRFSS:** There are a number of prevalence data and data analysis tools for BRFSS, which can be found at: http://www.cdc.gov/brfss/data_tools.htm.
- **NHANES:** Information related to NHANES including questionnaires, datasets, and related documentation can be accessed at http://www.cdc.gov/nchs/nhanes.htm.

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Preconception, Pregnancy, and Perinatal Health

Preconception, Pregnancy, and Perinatal Health Commentary

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The landscape for measuring preconception, perinatal, and infant health has shifted dramatically since the first data book was published in 1994. One of the foundational changes is the application of the life course framework which posits that health is impacted by events throughout the life span, especially those occurring during early critical life stages. This frame has focused on the importance of health from early childhood through young adulthood, underscoring the significance of infant mortality as barometer of intergenerational health and socioeconomic status.[1] With the release of recommendations to improve preconception health and health care,[2] new attention has been paid to prevention for non-pregnant women and men of reproductive age. There have been tangible shifts in three primary indicators: infant mortality, preterm birth, and maternal mortality. The US infant mortality rate has experienced a sharp decline and in more recent years, preterm birth has also declined. Maternal mortality, however, has not improved.

Despite the progress for the US population overall, significant racial, ethnic, and socioeconomic health inequities persist. Black women have among the highest rates of maternal mortality, infant mortality, and preterm birth, even when adjusted for known risk factors such as education and smoking. Research suggests that these intractable disparities are the result of structural racism, a concept that is now acknowledged by the maternal and child health profession, but for which few effective remediation strategies have been derived.[3-5]

Current prevention efforts are guided in part by the January 2013 report of the Secretary's Advisory Committee on Infant Mortality (SACIM), which set six strategic directions:

1. Improve the health of women before, during, and beyond pregnancy.

2. Ensure access to a continuum of safe and high-quality, patient-centered care.
3. Redeploy key evidence-based, highly effective preventive interventions to a new generation of families.
4. Increase health equity and reduce disparities by targeting social determinants of health through both investments in high-risk, under-resourced communities and major initiatives to address poverty.
5. Invest in adequate data, monitoring, and surveillance systems to measure access, quality, and outcomes.
6. Maximize the potential of interagency, public-private, and multi-disciplinary collaboration.[6]

SACIM highlighted that the nation's vital statistics system, perinatal surveys, Medicaid perinatal data, quality measurement systems, and other data systems should be dramatically improved. Action steps include investing in the National Vital Statistics Surveillance and Pregnancy Risk Assessment Monitoring System (PRAMS), as well as incentivizing states to report a uniform set of quality and outcome measures. Timely and accurate data are needed to inform the development and implementation of policies and programs as well as to assess progress on achieving health equity.[3]

Measurement is particularly important for the Title V Maternal and Child Health Block Grant Program, which aims to improve the health and well-being of women, mothers, and children. This program has undergone a transformation to better demonstrate how Title V programs improve health outcomes. As part of this transition, the Health Research and Services Agency (HRSA) Maternal and Child Health Bureau (MCHB) required states to submit an Action Plan with specific, measureable, attainable, realistic and time-bound (SMART) objectives in alignment with three categories of measures. The new measures aim to increase accountability and allow for flexibility to respond to the unique challenges in populations among diverse regions in the United States. These measures include key maternal and child health (MCH) domains including: Women/ Maternal Health, Perinatal/Infant Health, Child and/or Adolescent Health, Children with Special Health Care Needs, and Cross Cutting Life Course.[7]

New National Outcome Measures are intended to represent the desired result of Title V program activities and interventions from a long-term perspective. National Performance Measures (NPM) are intended to drive improved outcomes relative to one or more indicators of health status for the MCH population. States must select eight of fifteen measures and propose strategies to support implementation. These include: well-woman visit, low-risk cesarean delivery, perinatal regionalization, breastfeeding, safe sleep, developmental screening, injury, physical activity, bullying, adolescent well-visit, medical home, care transition, oral health, smoking, adequate insurance coverage. Evidence-based Strategy Measures, tied to a national data source, aim to improve accountability of performance, and better demonstrate impact and returns on investment for Title V resources.[7]

Underscoring the urgency of achieving national change, HRSA MCHB launched the Collaborative Improvement and Innovation Network to Reduce Infant Mortality (CoIIN), a multiyear national movement engaging federal, state and local leaders, public and private agencies, professionals and communities to employ quality improvement and collaborative learning to improve birth outcomes. The Infant Mortality CoIIN identified six strategy focus areas including: Improve safe sleep practices; Reduce smoking before, during and/or after pregnancy; Promote optimal women's health before, after and in between pregnancies, during postpartum visits and adolescent well visits; Incorporate evidence-based policies/programs and place-based strategies to improve social determinants of health and equity in birth outcomes; Prevent preterm and early term births; and Increase the delivery of higher risk infants and mothers at appropriate level facility.[8] Diverse stakeholders in teams from all states and territories are participants in CoIIN learning networks. Teams implement evidence-based strategies with a focus on data to benchmark change and shared learning. This collaborative learning model has provided training on the development of primary and secondary drivers for change as well as on the development of new data partnerships to support change management.[8]

Advancing a paradigm shift, the Preconception Health and Health Care Initiative (PCHHC) has been focused on advancing the health of women and men prior to and between pregnancies since 2005. In a reconvening of the National Preconception Health Select Panel, leaders identified challenges around measures as major roadblock for advancing preconception care into practice.[9] Clinicians from across the country came together to create Consensus Guidelines for Preconception Wellness. The Guidelines propose nine surrogate measures for preconception wellness, assessed at a first prenatal assessment, which include indicators for: 1) Pregnancy intention, 2) Access to care, 3) Preconception multivitamin with folic acid use, 4) Tobacco avoidance, 5) Absence of uncontrolled depression, 6) Healthy weight, 7) Absence of sexually transmitted infections, 8) Optimal glycemic control in women with pre-gestational diabetes, and 9) Teratogenic medication avoidance. The focus of the proposed measures is to quantify the effect of health care systems on advancing preconception wellness. The Workgroup recommends that health care systems adopt these measures to monitor performance of preconception care practice.[10] Baseline measures will establish benchmarks and allow for comparison within and across regions, health care systems, and communities to drive improvements. Exciting work is underway to augment the clinical guidelines with a new targeted set of population health measures, based in part on the 2011 efforts of Broussard, et. al.[11]

Looking forward to the next decade, our surveillance systems must be prepared for emerging crises, such as Zika Virus, that can impact the health of mothers and/or their fetuses. Our understanding of men's preconception health and contribution to fetal development will continue to expand and therefore will require new surveillance methods and measures. The 2010 Patient Protection and Affordable Care Act offered an opportunity to expand affordable health care access to Americans. Important provisions for women's health are the equalization of premiums for men and women, the standardization of included benefits such as well-women visits, contraception, and maternity care, the elimination of cost-sharing for preventive services, and the expansion of Medicaid to states that opted to participate. Accompanied by policy changes is growth in healthcare data and analytics. Integration of new data such as claims and electronic health records will allow for a more complete understanding of the content, quality, and access of health services. Enhanced surveillance capabilities can provide needed data to identify disparities, and monitor and evaluate programs and policies that have the potential to increase health equity and address persistent, disparate intergenerational adverse pregnancy and infant outcomes.

While population surveillance requires working with large scale quantitative data, leaders should consider mechanisms for advancing qualitative and communications research to better elevate the voices and concerns of those most impacted by disparities. With new opportunities presented by social media and widespread shifts in communication technology that have given rise to outreach approaches such as Text 4 Baby, exploration of new means of surveillance and research should capitalize on this opportunity. Preconception, pregnancy, and perinatal health messages are centered on young adults who are often the trendsetters and among the first to adapt to new cultural norms and technological shifts. We must continue to take advantage of existing and new data sources to forecast what lies ahead and create opportunities to keep pace with a rapidly changing landscape.

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Preconception Health and Preconception Care

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The reproductive years are a time period offering a critical window in preventing the development of chronic conditions and in promoting optimal health status. The status of women's health in the context of preparing for a healthy pregnancy and infant is often referred to as preconception health. Health systems can provide clinical care focused on reducing the risk factors that adversely impact pregnancy and, ultimately, babies, but there are still many gaps in knowledge about preconception health and preconception care. This chapter examines the progress made on this topic at the national, state, and local levels

PUBLIC HEALTH IMPORTANCE

Preconception health (PCH) is a broad term that encompasses the overall health of non-pregnant women during their reproductive years (defined as 18 through 44 years of age). Preconception care (PCC) includes a broad range of screenings and clinical interventions that reduce the biomedical, behavioral, and social risk factors which can impact the long-term health of women, men, and future pregnancies.[1-3] Although PCH and PCC are important for women and men alike, this chapter focuses only on women of reproductive age.

Improving PCH and PCC is important for all women of reproductive age, even those who may not be actively trying to conceive, since nearly half of all pregnancies are unintended.[2,4] Unintended pregnancy has been linked to delayed prenatal care, depression, and anxiety, preterm birth (PTB) and short inter-pregnancy intervals (i.e., conception within 18 months of the most recent previous birth).[5,6] Short inter-pregnancy intervals are associated with increased risk of PTB, low birth weight, small infant for gestational age, as well as increased risks for recurrent PTB and severe maternal complications.[7-9] Although most women in the United States have at least one live birth in their lifetime, it is estimated that approximately 12% of women never become pregnant or have a child.[10,11] Among non-fecund women, PCH equates to "women's health," and PCC parallels "well-woman care."

Many PCH risk factors are also risk factors for chronic disease and more specifically, cardiovascular disease, the third leading cause of death among US women ages 18 through 44 years.[12] Evidence-informed interventions can mitigate or eliminate PCH risk factors that are identified in the clinical setting and are associated with adverse health and pregnancy outcomes (e.g., tobacco use, obesity, and diabetes).[13] The purpose of this chapter is to highlight selected findings related to PCH and PCC (i.e., obesity, diabetes, contraception, pregnancy intention, folic acid, depression, recommended health care) and provide examples of using related data to stimulate action. The chapter *Behavioral Risk Factors Before and During Pregnancy* addresses additional PCH risk factors, including use of tobacco, alcohol, and drugs. Of note, other behavioral risk factors, such as physical activity impact PCH and PCC outcomes such as obesity and control of diabetes.

HISTORY OF DATA COLLECTION

Ten recommendations for improving PCH and PCC in the United States were published in 2006.[1] Among these recommendations was one to maximize public health surveillance to monitor PCH- and PCC-related changes. The three primary data sources for PCH and PCC surveillance are the Pregnancy Risk Assessment Monitoring System (PRAMS), the Behavioral Risk Factor Surveillance System (BRFSS), and the National Vital Statistics System (NVSS). PRAMS has included questions on PCH and PCC since its inception, beginning with only 6 sites in 1987 and growing to 41 sites currently (hereafter referred to as "reporting areas"). BRFSS was established in 1984 with standardized data collection on behavioral surveillance in 15 states, including several important PCH risk factors (e.g., smoking, alcohol use, and hypertension). BRFSS became a nationwide surveillance system in 1993 and began to include cell phone interviews in its samples in 2011.[14] NVSS data pertaining to PCC have previously been described, but several additions were made to the US standard birth certificate in 2003 that pertain to PCH and PCC, namely new information about the mother's pre-pregnancy risk factors (e.g., smoking, height/weight, diabetes, and hypertension) and about any infertility treatment received.[15]

CDC SURVEILLANCE ACTIVITIES

CDC maintains surveillance systems to monitor changes in PCH and PCC through PRAMS and BRFSS. In 2007, a group of policy/program leaders and epidemiologists working in seven states (California, Delaware, Florida, Michigan, North Carolina, Texas, and Utah) identified 45 core state PCH and PCC indicators (hereafter referred to as "core indicators") that primarily rely on these surveillance systems.[16] The core indicators were intended for monitoring the health of reproductive age women and encompass measures of general health status, social determinants of health, health care, reproductive health, tobacco and substance use, nutrition and physical activity, mental health, emotional and social support, chronic conditions, and infections. Additionally, some states that do not implement PRAMS maintain their own state-based surveillance systems to monitor PCH and PCC. CDC collects state-specific PCH data on births and sexually transmitted infections through NVSS and the National Notifiable Diseases Surveillance System. Finally, CDC produces national estimates of PCH and PCC indicators through several cross-sectional surveys: the National Survey of Family Growth, the National Health Interview Survey, and the National Health and Nutrition Examination Survey. This chapter focuses on state level surveillance activities only.

Details on PRAMS methodology have been described previously, and are available on the PRAMS website at http://www.cdc.gov/PRAMS/.[17] All PRAMS reporting areas use standardized data-collection methods allowing for comparisons among reporting areas. Survey data are linked to selected birth-certificate data and weighted to account for complex sample design, non-response, and non-coverage. The birth certificate is a useful vital record source of clinically reported birth outcome information, and because birth certificates are issued for virtually all births, they serve as an ideal sampling frame for PRAMS. From 2011 through 2015, PRAMS data represented approximately 78% of all live births in the United States. PRAMS data are available for researchers for reporting areas that achieve a predefined overall weighted response rate. PRAMS is an ideal data source for examining PCH characteristics, because it samples women with recent live births.

BRFSS is an ongoing state-based telephone survey of non-institutionalized adults 18 years of age and older that is conducted by state and territorial health departments with assistance from CDC. BRFSS is the main source of data for states on health-risk behaviors, chronic health conditions, and available preventive-health services primarily related to chronic disease and injury in the United States. It is the source for 17 of the core indicators.[16] Details on BRFSS methodology are available from the BRFSS website at http://www.cdc.gov/brfss/.[14] BRFSS uses a multistage sampling design based on random-digit-dialing methods to select a representative sample in each US state and three territories. The median response rate for all states and territories with 2013 BRFSS data obtained through land lines was 50% and 38% for cell phones, and women of reproductive age (18 through 44 years) comprised 16% of the 2011 sample. In addition to BRFSS data that are available in all states, in 2013 seven states (Connecticut, Kentucky, Massachusetts, Mississippi, Ohio, Texas, and Utah) added 12 BRFSS questions pertaining to reproductive history, family planning, and infertility.

GENERAL FINDINGS

CDC has published two *Morbidity and Mortality Weekly Report (MMWR) Surveillance Summaries* of weighted state-specific data on PCH and PCC.[18,19] The 2007 *MMWR Surveillance Summary* described prevalence estimates for 11 core indicators for the 26 reporting areas with 2004 PRAMS data. That publication reported both overall prevalence estimates and subgroup estimates by age group, race/ethnicity, pregnancy intention (i.e., whether the pregnancy was planned and desired), and insurance status.[18] The 2014 *MMWR Surveillance Summary* reported overall prevalence estimates and subgroup estimates by age group and race/ethnicity for 39 core indicators with 2009 PRAMS data (29 reporting areas) and 2009 BRFSS data (51 reporting areas).[19,16] Several publications have examined women's PCH and PCC in a limited number of states using PRAMS data, and others have reported national prevalence estimates of PCH indicators based on BRFSS data.[20-31] Below, we review selected findings from the 2014 *MMWR Surveillance Summary* of core indicators,[19] and report selected findings for PCC using 2011-2012 PRAMS data (Tables 1-4).

Core indicators, 2009 BRFSS and PRAMS data

Of non-pregnant women ages 18 through 44 years (data source=BRFSS):[19]

- One-quarter (25%) were obese (defined as having a body-mass index [BMI] greater than or equal to 30). Younger women (ages 18 through 24 years) had the lowest prevalence of obesity (17%) compared with older women, and non-Hispanic black women had the highest prevalence (40%) compared with women of any other race/ethnicity.
- Two-thirds (66%) reported having a routine check-up in the past year with higher prevalence among non-Hispanic black women (79%) than among women of any other racial/ethnic groups.
- Approximately 3% reported ever being told by a health-care provider that they had diabetes, not

including gestational diabetes (GDM). Having diabetes was more prevalent among non-Hispanic black women (5%) than among non-Hispanic white women (2%).

Of women ages 18 through 44 years with a recent live birth (data source=PRAMS):

- Approximately 30% reported taking a daily multivitamin, prenatal vitamin, or folic acid vitamin during the month before pregnancy. Self-reported daily vitamin use increased with age (range 17% – 42%). In addition, daily vitamin use before pregnancy was lower among non-Hispanic black (20%) and Hispanic (23%) women than among non-Hispanic white women (34%) or women of other racial/ethnic groups (33%).
- Overall and within each age group, over half of women (among those not trying to get pregnant) reported not using contraception at the time of conception. Hispanic women were the only group with less than 50% prevalence of not using contraception at the time of conception (46%).
- The overall prevalence of unintended pregnancy was 43%. Twice as great a percentage of women ages 18 through 24 years (62%) than women ages 35 through 44 years (29%) reported that their pregnancies were unintended. In addition, unintended pregnancy was substantially higher among non-Hispanic black women (65%) than among any other racial/ethnic group.
- Postpartum symptoms of depression (defined as feeling down, depressed, or sad; hopeless; or slowed down by a substantial degree since their infant's birth) were reported by 12% and were more prevalent among younger women 18 through 24 years (15%) compared with older women ages 35 through 44 years (10%). In addition, non-Hispanic black women reported postpartum depressive symptoms more frequently (14%) than non-Hispanic white women (12%).
- Most women (88%) reported receiving a postpartum check-up, although prevalence was somewhat lower among younger (84%) and Hispanic (80%) women than among members of other groups.

Preconception care, 2011-2012 PRAMS data

- One third (33%) of women ages 18 through 44 years had talked with a health-care provider about how to improve PCH before their most recent pregnancy.
- Postpartum women frequently reported that a health-care provider had talked with them before pregnancy about taking vitamins with folic acid (81%).

- Most of the women reported that they had received preconception counseling about being a healthy weight before pregnancy (63%) and about the effects of alcohol (60%) and smoking (58%) during pregnancy.
- Fewer women reported that their health-care provider had talked with them about controlling medical conditions such as diabetes and high blood pressure (33%) or about getting counseling or treatment for depression or anxiety (23%).

USING DATA FOR ACTION

No state reports data on all of the core indicators, but 26 Title V programs have calculated at least some of them (personal communication with the Association of Maternal & Child Health Programs [AMCHP]). Title V is a federal program that provides mothers and children (in particular those with low income or with limited availability of health services) access to quality maternal and child health services. Some states have also reported data on selected core indicators in Title X grant applications and annual reports (unpublished AMCHP assessment, 2016). Title X is a federal program that provides subsidized family planning services. States often disseminate those data in data books, fact sheets, or reports to state legislatures. Some states have also used the data for maternal and child health (MCH) needs assessments, priority setting, or have taken steps to change practice based on the data.

Illinois

The Illinois Department of Healthcare and Family Services (IDHFS), that state's Medicaid agency, submits perinatal data to the Illinois Governor and General Assembly biennially, using claims and data from PRAMS, BRFSS, vital records, and other sources. The data describe the status of perinatal health in the state and are used in state-level program planning and resource allocation decisions. As a result of these biennial reports, policy makers have increased understanding of the high prevalence of medical and social risk factors that contribute to premature births, and costs related to prematurity. In 2012, IDHFS financed almost 54% of the state's births, and of those, almost 60% represented unintended pregnancies. Additionally, 40% of the total deliveries resulted in adverse birth outcomes (e.g., low or very low birth weight, fetal death, and other adverse conditions), which account for 70% of the total birth costs. These statistics heightened state legislators' awareness and led to a state-mandated Task Force on Prematurity in Illinois led by the Illinois Department of Public Health (IDPH). The Task Force made recommendations for evidence-based medical and public health strategies as well as state-wide system and policy changes to reduce PTBs in Illinois. Most recently, IDPH used 2013 BRFSS findings to leverage support for a new Title V PCH priority. Given that only about 6 in 10 Illinois women ages 18 through 44 years reported receiving an annual health-care exam, and 20% reported having no personal health-care provider, a new priority was identified for 2015 to assure accessibility, availability, and quality of preventive and primary care for all women, particularly women of reproductive age. Title V will develop more specific strategies to support this priority over the next year. IDHFS leveraged private foundation funding to support a preconception screening tool project. IDHFS partnered with Illinois' Quality Improvement Organization, to develop and pilot test a preconception risk assessment tool and establish PCC guidance. Next, based on a priority recommendation to add Medicaid coverage for a preconception visit and inter-conception care to address health issues and plan for a healthy pregnancy and birth, the IDHFS established an adult risk-assessment code that allows eligible medical providers to be reimbursed for administering the preconception screening tool.

Ohio

As part of initiatives on preconception and inter-conception health at the Ohio Department of Health (ODH), two different data summaries were produced and published in print and electronic form (2010 and 2011) to assist both internal programs and external entities in improving women's health. The 2010 data publications used 2004 through 2008 PRAMS data to summarize the status of 37 PCH indicators in Ohio. This information was used by many different programs at ODH and was also made available online to the public. Subsequently, a work group at ODH was identified to monitor these indicators over time. It identified the PCH indicator, "Percentage of women having a live birth who had a postpartum check-up," as the highest priority. While PRAMS survey data showed that 90% of women reported receiving a postpartum check-up, prevalence was lower in some subgroups, including non-Hispanic black women (87%), Medicaid-insured (86%), and women with less than a high school education (80%). ODH selected this indicator as a priority based on the severity of the problem and because it was already a focus of their current MCH program and state Strategic Plan. They had high quality data to monitor it, and they believed that they could impact it. In 2010, as part of an action-learning collaborative sponsored by AMCHP, CDC, and the National Association of Chronic Disease Directors, the maternal-child health and chronic disease programs at ODH formed a collaborative unit to work on decreasing the development of type 2 diabetes mellitus (T2DM) among women with a history of GDM. According to BRFSS data, 6% of women ages 18 through 44 years old in Ohio reported that they had ever been

told that they had diabetes or GDM. Prevalence was even higher among women who were ages 35 through 44 years (8%), non-Hispanic black (9%), and those with less than a
12th grade education (11%).

The second ODH data publication (2011) described the epidemiology of GDM and T2DM among Ohio women of reproductive age using 2006 through 2008 data from vital records, PRAMS, BRFSS, Medicaid claims, ODH prenatal care programs, and Ohio Hospital Association's discharge records. Analysis and dissemination of those data leveraged new funding for a quality improvement project. That project engaged sixteen provider sites to improve timely evidence-based care for postpartum women with GDM and supported the development and implementation of provider and patient toolkits. The data and synergy from these activities also stimulated Medicaid policy changes in some states.

Florida

In June 2010, the Florida Department of Health (FDOH) completed its first PCH indicator report. The report used PRAMS, BRFSS, vital records, and other sources of data to provide a comprehensive look at the status of PCH among Florida's women of childbearing age. The three most pressing PCH concerns identified were consistently high and unyielding rates of unintended pregnancy (47%), lack of contraceptive use among women not trying to become pregnant (57%), and high prevalence of overweight/obesity (46%). Dissemination of data from that report, concurrent findings from Florida's Pregnancy-Associated Mortality Review (PAMR), and the identification of unintended pregnancy as a priority for both of the Florida Title V and Title X needs assessments spurred new collaborations and funding in the state to improve PCH and PCC. The FDOH used grant funding and collaborated with the Florida March of Dimes and the PAMR to facilitate six hospital grand rounds presentations across the state. Another strategy that was implemented required all Healthy Start and local health department clients to include a reproductive life plan in their charts and update it annually to ensure that all non-sterile clients received and completed a Preconception and Counseling Check List. To improve access to contraception, FDOH developed and distributed marketing materials for a statewide outreach campaign to improve the use of Medicaid Family Planning Waiver inter-conception care and counseling for up to 18 months among Healthy Start women at risk of poor pregnancy outcomes. Finally, to address the high prevalence of obesity among women of reproductive age, FDOH launched a public awareness campaign to promote healthy weight prior to pregnancy.

National

PCH data have also been translated to action on the national level. First, PRAMS data are used to monitor progress toward six Healthy People 2020 objectives, under the category of PCH (16.1-16.6) and all three developmental objectives related to postpartum health.[18,19,32,33] Second, CDC and the Office of Population Affairs will use PRAMS data in the future to compile annual surveillance summaries that monitor the ongoing need for family planning service, the burden of PCH risk factors, and the impact of the recommendations for *Providing Quality Family Planning* (QFP) *Services.*[2] Those recommendations defined a set of family planning services that included PCC. The PCH indicators included in the QFP surveillance summaries are postpartum contraceptive use, PCH risk behaviors (pre-pregnancy smoking, pre-pregnancy alcohol use, non-daily multivitamin use prior to pregnancy), and PCH counseling.

DATA GAPS AND LIMITATIONS

Preconception surveillance data are subject to the limitations of the principal data sources. PRAMS does not represent women who had miscarriages, stillbirths, or women who cannot or choose not to get pregnant. The targeted sampling impacts generalizability, since adverse pregnancy outcomes are associated with PCH risk factors such as smoking, hypertension, and diabetes.[33-36] Declining survey response rates are problematic, and may be attributed in part because of increased reliance on cell phones and increased mobility of populations that make it difficult to reach respondents with mailed surveys. Because BRFSS does not have a required reporting threshold, low response rates can be a limitation when using those data. Limitations of PRAMS and BRFSS data include self-reported data with social desirability and recall biases. As a result, negative behaviors might be underestimated and positive behaviors might be overestimated. Finally, information bias is possible for birth certificate data (NVSS) because the source and mode of data collection varies by state. More specific variables of interest may not be available (e.g., birth certificates specify previous PTB but not gestational age of previous PTB).

Changes in data collection methods compromise the ability to identify and analyze trends. State surveillance systems such as PRAMS and BRFSS can change with shifts in national priorities, emerging issues, and state needs. However, seven of the eight core indicators with published findings highlighted in this chapter are based on survey questions from PRAMS and BRFSS that have remained relatively stable over time.

Environmental exposures such as smokeless tobacco and emerging infections may be important for surveillance of PCH in the future. Use of smokeless tobacco, marijuana, and hookahs may command attention because of growing levels of use/exposure and the potential for impacting PCH. Environmental exposures and fathers' PCH and PCC are new areas of research and may be candidates for future surveillance. Given that 76% of men father a child by age 40 years, the lack of PCH and PCC surveillance for men constitutes an important gap.[10] The case for filling this gap in knowledge and surveillance is strengthened by the recent outbreak of Zika virus, which has been shown to be sexually transmitted from men to their sex partners and has been causally linked to microcephaly and other severe brain anomalies in children born to mothers who were infected with the virus.[37,38]

The QFP Services guidelines[2] clarify which clinical services should be included in PCC and recommend reproductive life plan (RLP) assessments for all women and men of reproductive age.[2] However, surveillance systems are not in place for ongoing monitoring of RLP assessment.[2] Clinicians assess RLPs by asking patients if they want to have any (more) children at any time in the future. Emphasis of PCC is then based on the patient's response (e.g., if a female patient is ambivalent or does not desire pregnancy within the next year, emphasis is placed on family planning and counseling about optimal inter-pregnancy interval). Unfortunately, RLP assessment is currently not included in the core PRAMS or BRFSS surveys that are administered in all reporting areas.

Enhancing data collection is the initial step in improving PCH and PCC surveillance. Increasing PRAMS and BRFSS response rates and the timeliness of data are fundamental actions that are needed. Additionally, PRAMS expansion to additional states and territories will strengthen generalizability of PCH and PCC surveillance estimates that are based on those data. Oversampling of subpopulations with elevated risks and the poorest outcomes is also needed. For example, American Indian populations generally exhibit substantially higher prevalence of PCH risk factors than do members of the overall population, including high blood pressure, diabetes, obesity, smoking, and frequent mental distress.[39] Several states (Michigan, New Mexico, Oregon, Washington, and Wyoming) have recently undertaken initiatives to improve outreach and response rates among American Indian women to improve the availability of representative data on this population. More comprehensive data is needed, including county-level data and data for social determinants of health such as neighborhood socioeconomic status. Robust PCC surveillance data from medical providers' perspectives are lacking. Finally, another gap in the data is coordination of care, which is particularly relevant for PCC, since women of reproductive age intermittently use specialty care providers (i.e., family planning, prenatal care, and primary care).

FUTURE ISSUES

Given that PCH encompasses both the overall health of women during the reproductive years and maternal health before and between pregnancies, a wide net approach has historically been used for PCH surveillance. As a result, a lengthy set of core indicators has been identified, which straddle “maternal health” and “women’s health.”[16] The utility of such a wide net approach has been debated. According to results from an unpublished 2011 AMCHP survey, most states indicated that they have calculated some of the 45 indicators, but none of the 50 states or 9 territories surveyed reported calculating all of them. Typically, states reported only using a subset of the 45 indicators. It is unclear which indicators are most useful. However, what is clear is that a smaller set of population-based indicators is needed for evaluating the effectiveness of PCH programs, assessing the need for PCC enhancements, and garnering support for new PCH and PCC initiatives. A condensed set of indicators will also facilitate comparisons across states. CDC, in partnership with AMCHP and state health departments, has worked to prioritize a smaller set of indicators that can be used by states for PCH and PCC surveillance.

A challenge for the future is to establish the evidence base that links PCH and PCC indicators to concrete health outcomes. Interventions have been shown to effectively reduce some PCH risk factors, which support the need for continuous access to comprehensive, high quality preventive health care for women of reproductive age, particularly before pregnancy.[40] Future research needs to build the evidence linking PCH and PCC interventions with improved pregnancy outcomes. Innovations through the use of data linkages, electronic health records, administrative data, and market research data may hold the most promise for improving PCH and PCC.

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ADDITIONAL RESOURCES

- Core State Preconception Health Care Indicators: An online inventory describing all 45 core preconception health indicators, including data availability (PRAMS and BRFSS), calculation of numerators and denominators, significance, limitations, and related Healthy People objectives.
- PRAMStat: An online PRAMS data platform that can generate estimates of over 250 variables for a single year or across all available years to examine trends in the data. In addition, 17 variables are available for stratification options, and results may be viewed in map, chart, or table format.
- WEAT: A Web Enabled Analysis Tool that provides cross tab and logistic analyses using BRFSS data.
- Behavioral Risk Factors Data: A portal that provides access to a wide range of chronic disease BRFSS data, risk factor indicators and policy measures and produces estimates of chronic disease burden, common risk factors, and population trends.
- Sortable Stats: An interactive BRFSS data set comprised of behavioral risk factors and health indicators for the 50 states, District of Columbia, and US territories from various published CDC and federal sources. Allows users to view, sort, and analyze data at state, regional, and national levels.
- WONDER: A menu-driven system that queries public-use data sets about mortality, cancer incidence, HIV and AIDS, tuberculosis, vaccinations, natality, census data and many other topics. Results may be viewed in map or chart formats.
- National Center for HIV/AIDS, Viral Hepatitis, STD, and TB Prevention Atlas: An online tool that gives you the power to analyze trends and patterns in HIV, STD, hepatitis, and TB data using more than 10 years of data that are reported to CDC. Results may be viewed as maps for diseases by year, area, and population, or tables that allow for comparisons of diseases, areas, and populations.
- Life Course Indicators: An online inventory from multiple data sources that describes 59 life course indicators in detail, including calculation of numerator and denominator, data source, similar measures in other indicator sets, and national comparison data.
- Health Indicators Warehouse: A data hub that provides access to data on population health, determinants of health, and health care system and access from multiple data sources. Topics include maternal and infant health, chronic disease and conditions, health behaviors, and others –

encompassing numerous preconception health indicators. Data on the indicators can be displayed as tables, charts, or maps and downloaded.

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TABLE 1. Overall prevalence of selected core preconception health indicators, US reporting areas, 2009		
Core Preconception Health Indicator	**Overall** [a]	
	%	**95% CI**
Non-pregnant, women ages 18 through 44 years (BRFSS) [b]		
Obese based on body mass index ≥30	25	24.0–25.3
Had a routine check-up in the past year	66	65.7–67.0
Ever been told by a health-care provider that she had diabetes, not including gestational diabetes	3	2.7– 3.2
Women ages 18 through 44 years with a recent live birth (PRAMS)		
Took a multivitamin, prenatal vitamin, or a folic acid supplement every day of the month before pregnancy [c]	30	29.0–30.5
Contraceptive non-use at time of conception among women not trying to get pregnant [c]	53	51.3–53.9
Most recent pregnancy was unintended (unwanted or wanted later) [c]	43	42.0–43.8
Experienced symptoms of depression after pregnancy [c]	12	11.3–12.5
Had a postpartum check-up [d]	88	87.4–89.0

Abbreviations: BRFSS: Behavioral Risk Factor Surveillance System, United States; PRAMS: Pregnancy Risk Assessment Monitoring System; CI: confidence interval.

[a] Percentages and their associated confidence intervals are weighted to adjust for complex survey design and non-response.

[b] 51 reporting areas.

[c] 29 reporting areas.

[d] 16 reporting areas.

TABLE 2. Prevalence of selected core preconception health indicators, by age group, US reporting areas, United States, 2009

Core Preconception Health Indicator	Age group (years) [a]					
	18 - 24		25 - 34		35 - 44	
	%	CI	%	CI	%	CI
Non-pregnant, women ages 18 through 44 years (BRFSS) [b]						
Obese based on body mass index ≥30	17	15.1–18.2	26	24.8–26.8	28	27.2–28.9
Had a routine check-up in the past year	65	63.0–66.9	64	62.4–64.6	70	68.7–70.5
Ever been told by a health-care provider that she had diabetes, not including gestational diabetes	1	0.7–1.5	2	2.1–2.8	5	4.1–5.0
Women ages 18 through 44 years with a recent live birth (PRAMS)						
Took a multivitamin, prenatal vitamin, or a folic acid supplement every day of the month before pregnancy [c]	16	14.9–17.4	35	33.4–35.6	42	40.1–44.7
Contraceptive non-use at time of conception among women not trying to get pregnant [c]	55	52.5–56.6	51	49.2–53.0	51	47.5–55.1
Most recent pregnancy was unintended (unwanted or wanted later)[c]	62	59.9–63.2	35	34.3–36.6	29	27.1–31.5
Experienced symptoms of depression after pregnancy [c]	15	13.6–16.0	11	10.0–11.4	10	8.8–11.5
Had a postpartum check-up [d]	84	81.9–85.3	91	89.4–91.4	90	87.7–92.0

Abbreviations: BRFSS: Behavioral Risk Factor Surveillance System, United States; PRAMS: Pregnancy Risk Assessment Monitoring System; CI: confidence interval.

[a] Percentages and their associated 95% confidence intervals are weighted to adjust for complex survey design and non-response; Chi-square p-value significant at $p<0.05$ for age group.

[b] Behavioral Risk Factor Surveillance System, United States, 51 reporting areas.

[c] 29 reporting areas.

[d] 16 reporting areas.

TABLE 3. Prevalence of selected core preconception health indicators among women ages 18 through 44 years, by race/ethnicity, US reporting areas, United States, 2009

Core Preconception Health Indicator	Race/Ethnicity[a] [b]							
	White		Black		Other		Hispanic	
	%	CI	%	CI	%	CI	%	CI
Non-pregnant, women ages 18 through 44 years (BRFSS) [c]								
Obese based on body mass index ≥30	22	21.0–22.4	40	37.3–41.8	18	16.2–20.4	28	26.3–30.1
Had a routine check-up in the past year	65	64.3–65.9	79	77.1–80.9	64	61.4–67.1	63	60.9–64.9
Ever been told by a health-care provider that she had diabetes, not including gestational diabetes	2	2.1–2.6	5	4.2–6.2	3	2.4–4.3	4	2.9–4.5
Women ages 18 through 44 years with a recent live birth (PRAMS)								
Took a multivitamin, prenatal vitamin, or a folic acid supplement every day of the month before pregnancy [d]	34	33.2–35.2	20	17.9–21.2	33	30.5–35.7	23	20.3–24.8
Contraceptive non-use at time of conception among women not trying to get pregnant [d]	54	52.5–55.8	55	52.0–57.0	55	51.5–59.3	46	42.2–49.6
Most recent pregnancy was unintended (unwanted or wanted later) [d]	37	36.3–38.4	65	63.3–67.2	38	35.3–40.5	46	43.2–48.7
Experienced depression symptoms after pregnancy [d]	12	11.2–12.5	14	12.7–15.5	10	8.7–12.0	11	9.5–12.9
Had a postpartum check-up[e]	92	90.8–92.4	87	84.9–88.1	88	85.7–90.4	80	77.3–82.9

Abbreviations: BRFSS: Behavioral Risk Factor Surveillance System, United States; PRAMS: Pregnancy Risk Assessment Monitoring System; CI: confidence interval.

[a] White = non-Hispanic white; Black = non-Hispanic black; Other = non-Hispanic other.

[b] Percentages and their associated 95% confidence intervals are weighted to adjust for complex survey design and non-response; Chi-square p-value significant at $p<0.05$ for race/ethnicity.

[c] 51 reporting areas.

[d] 29 reporting areas.

[e] 16 reporting areas.

TABLE 4. Percentage of women ages 18 through 44 years who received preconception counseling with a health-care provider about specific content areas, PRAMS, US reporting areas, United States, 2011-2012

Counseling Content	**Overall** [a]	
	%	**95% CI**
How to improve health before pregnancy [b]	33	32.0–34.4
Taking vitamins with folic acid before pregnancy [c]	81	79.1–83.2
Being a healthy weight before pregnancy [c]	63	60.3–65.5
How drinking alcohol during pregnancy can affect a baby [d]	60	57.7–62.9
How smoking during pregnancy can affect a baby [d]	58	55.6–60.8
Controlling any medical conditions such as diabetes and high blood pressure [c]	33	30.4–35.1
Getting counseling or treatment for depression or anxiety [d]	23	21.3–25.6

Abbreviations: PRAMS: Pregnancy Risk Assessment Monitoring System; CI: confidence interval.

[a] Percentages and their associated confidence intervals are weighted to adjust for complex survey design and non-response.

[b] Includes Hawaii, Maryland, Maine, Michigan, Minnesota, New Jersey, Utah, West Virginia.

[c] Includes Maryland, Michigan, Nebraska, New Jersey, Tennessee, Vermont.

[d] Includes Maryland, Michigan, Nebraska, New Jersey, Tennessee.

Prenatal Care

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Prenatal care became a prominent health service in the United States during the 1900s and since then, has ensured healthier pregnancies and provided vital parental education in maternal and infant care. However, barriers to inadequate prenatal care may include the lack of medical insurance, transportation, and available hours. Measuring the utilization and quality of prenatal care promotes understanding in pregnancy outcomes and its associated risks with an overall goal of providing care for women throughout their reproductive life span.

PUBLIC HEALTH IMPORTANCE

Care during pregnancy, or prenatal care (PNC), is a frequently used health service that was first proposed by Dr. J.W. Ballantyne in the late 19th century in Europe.[1,2] During the 1900s the concept gained traction and spread to the United States.[3] In 1985, PNC received special prominence in the American health care system due to the landmark publication, “Preventing Low Birthweight” by the Institute of Medicine (IOM),[4,5] which led federal and state legislators to expand funding for PNC services for low-income pregnant women, a population more likely to be uninsured and at increased risk for adverse birth outcomes.[5]

PNC encompasses multiple visits to a health care provider during which a woman is screened and monitored for health problems that may affect her pregnancy and her overall health during pregnancy; she learns about the progress related to her pregnancy, and may be referred for other essential services.[6] The receipt of early and adequate PNC can reduce infant and maternal morbidity and mortality through early detection and control of illnesses in the mother (such as diabetes or hypertension) and intrauterine abnormalities in the developing fetus.[7] Therefore, accurate measurement of PNC utilization is a critical component for understanding the relationship between PNC services and pregnancy outcomes and monitoring risks for inadequate care.[8] Several measures or indices have been developed to describe this relationship.

The earliest PNC measure was the IOM Index or the Kessner Index. Developed in the 1970s, the IOM/Kessner index combined two continuous numeric measures (month PNC began and number of visits adjusting for length of gestation) and grouped PNC into one of three levels: "inadequate," "intermediate," or "adequate."[9] Despite wide adoption in public health and policy research assessing the association between PNC and birth outcomes, the IOM/Kessner index has limited utility. Subsequent measures, such as the Graduated Index of Prenatal Care Utilization (GINDEX) developed by Dr. Greg Alexander, expanded the IOM/Kessner index to six categories of PNC utilization: "missing," "no care," "inadequate," "intermediate," "adequate," and "intensive." Others, such as the Adequacy of Prenatal Care Utilization index (APNCU), were developed independently from the IOM/Kessner index.[10] APNCU was developed by Dr. Milton Kotelchuck based on birth certificate data. It used two separate and distinct dimensions for defining adequacy – *adequacy of initiation of PNC and adequacy of received services*. APNCU grouped PNC into four categories: "Inadequate" (less than 50% of expected visits or PNC initiation later than the 4th month of pregnancy); "Intermediate" (50%–79% and initiation by the 4th month); "Adequate" (80%–109% and initiation by the 4th month); and "Adequate Plus" (≥110% and initiation by the 4th month).[10]

As designed, these indices are only able to measure PNC utilization and are unable to address content, quality, or appropriateness of PNC received. They, however, have been extensively used in studies assessing the association between the adequacy of PNC and birth outcomes, but multiple studies have not found consistent improvement in outcomes such as low birth weight (LBW) with increases in PNC utilization.[11–14]

Over the last several decades, efforts have been made to shift the emphasis from simply expanding PNC or its utilization to enhancing its content, structure, and delivery.[15] Care coordination/case management programs,[16,17] home visitation services,[18,1] group PNC[20,21] and telemedicine [22,23] initiatives have emerged as alternative ways to deliver PNC.[15] Additionally, evidence-based clinical guidelines for risk-appropriate obstetric and neonatal care emphasize the importance of PNC. The "Guidelines for Perinatal Care," published by the American College of Obstetricians and Gynecologists and the American Academy of Pediatrics, outlines risk-appropriate care for both pregnant women and newborns, and recommends standard, routine PNC for all women in the US.[24] Finally, the Healthy People initiative has included early initiation and utilization of PNC as one of its achievable health improvement priorities since inception. The most recent version, Health People 2020, has a goal of 77.9% for first trimester PNC initiation among pregnant women.[25]

HISTORY OF DATA COLLECTION

National Vital Statistics System

The first questions on PNC - month of pregnancy in which PNC began and the number of PNC visits – were added to the 1968 revision of the US Standard Certificate of Live Birth.[26] The 2003 birth certificate revision[27,28] modified the timing of the first PNC visit from the month PNC began to the date of the first visit allowing for better measurement of how soon women initiated PNC and utilized services. In addition, the 2003 revision added new recommendations that PNC information be gathered from the PNC or medical record.[29] The different formats and potentially different sources of information for the two questions resulted in data which were not comparable, creating discontinuity in the measure of month prenatal care began starting in 2003.

Further, the change to the PNC timing question, beginning with 2003, was part of a larger revision of the birth certificate, with different reporting areas adopting the 2003 revision in different years. The resulting staggered implementation of the 2003 birth certificate revision was not completed until 2016, leaving a lack of national data on the timing of PNC and inconsistent reporting across areas from 2003 through 2015. Consistent national data inclusive of all reporting areas will once again become available starting with the 2016 data year.

Pregnancy Risk Assessment Monitoring System

Pregnancy Risk Assessment Monitoring System (PRAMS) is an ongoing surveillance project of CDC, states, cities, and tribal health departments that collects population-based data on maternal attitudes and experiences before, during, and shortly after pregnancy. It was established in 1987 in an effort to improve the health of mothers and infants and to decrease infant and maternal morbidity and mortality by reducing adverse outcomes of LBW.[30] PRAMS was intended to supplement vital records and generate state-specific risk factor data so comparisons among states could be performed.[31] From its inception, PRAMS has included core questions on PNC that assessed timing and content. In 1987, only five states (Indiana, Maine, Michigan, Oklahoma and West Virginia) and the District of Columbia were participating in the survey. In 1996, this number had increased to 11 and by 2014, 40 states and New York City were participating. PRAMS now covers about 83% of all US births.[30]

National Survey of Family Growth

The National Survey of Family Growth (NSFG) is a nationally representative, household-based, in-person survey of the noninstitutionalized civilian population aged 15–44 years in the United States. Data collection focuses on factors that help explain trends and group differences in birth rates and related factors, such as contraceptive use, infertility, sexual activity, and marriage. It was first conducted by the National Center for Health Statistics (NCHS) in 1973 and was administered in six previous cycles – 1973, 1976, 1982, 1988, 1995, and 2002– and continuously since 2006. Information on PNC was first collected during the 1982 survey.[32] Data are available at the national and regional levels.

CDC SURVEILLANCE ACTIVITIES

National Vital Statistics System (NVSS) and PRAMS continue to be the primary sources of public health data on PNC.

National Vital Statistics System

NVSS is the oldest example of inter-governmental data sharing in Public Health. PNC data are collected on birth certificates filed through the vital registration systems of each of the 50 states, Washington, DC, New York City, and five territories. These data are maintained and operated by the individual states and territories where the original certificates are filed.[26, 27] Data are sent to NCHS, which then compiles, reviews, and edits the data and develops reports and national data files for dissemination. Data are available typically within 6–12 months of the calendar year through 1) preliminary and final reports of the data (summary tabulations);[33] 2) downloadable public-use data files;[29] and 3) the interactive data access site, CDC WONDER.[34]

NCHS promotes uniformity among state birth certificates by collaborating with state vital statistics offices, medical providers, and data users to develop the standard certificates which serve as a template for the vital statistics jurisdictions. As noted earlier in this chapter, the latest revision took place in 2003.[27, 28, 35]

Pregnancy Risk Assessment Monitoring System

PRAMS collects core data on timing of PNC initiation, type of health insurance, content of PNC (including discussion on smoking cessation and other substance abuse), discussion on chronic conditions, nutrition, breast feeding, domestic violence and other preventive behaviors, such as seat belt use and flu immunization. Questions on PNC location, satisfaction, and barriers were core questions in previous phases of PRAMS but were dropped from the core and are currently standard questions that states may opt to include.[36] Additional details on PRAMS methodology are available on the PRAMS website at http://www.cdc.gov/prams/. The advantage of PRAMS, compared to other survey data sources, is in its state-specific design, which allows it to be used for planning and assessing state-specific perinatal health programs. Additionally, because it is a self-administered tool, it increases the likelihood that surveyed women would report socially undesirable behaviors, such as smoking and drug use.[37]

GENERAL FINDINGS

Timing and adequacy of prenatal care – birth certificate data

Overall, 76.7% of women in the included jurisdictions initiated PNC in the first trimester in 2014, 17.4% began receiving care in the second trimester, while 6.0% began PNC in the third trimester or did not receive PNC at all (Table 1). Using the APNCU index, a total of 75.1% of women giving birth in 2014 received adequate or adequate plus PNC, 9.7% received intermediate care, and 15.2% received inadequate care (Table 2).

First trimester initiation of PNC varied by race and Hispanic origin (Table 1). In 2014, non-Hispanic white (81.6%) and Asian (80.2%) women had the highest rates of first trimester PNC. Lower percentages of Hispanic (71.7%), non-Hispanic black (65.8%), American Indian or Alaska Native (AIAN) (63.0%) and Native Hawaiian or other Pacific Islander (NHOPI) (52.3%) women received PNC care in the first trimester. There were similar disparities in adequacy of care (Table 2), with lower percentages of non-Hispanic white (11.3%) and Asian (12.8%) women receiving inadequate care, and higher percentages of NHOPI (38.1%), AIAN (28.3%), and non-Hispanic black women (23.8%) receiving inadequate care.

Women giving birth before 20 years of age had the lowest percentage of first trimester PNC (61.4%), particularly the youngest mothers, those under age 15 (37.1%) (Table 1). In comparison, at least 78% of women, who were at least 25 years of age received first trimester PNC. Younger women also had the highest percentage of inadequate care (Table 2).

Receipt of first trimester PNC increases with maternal education among women 25 years of age and older. Women with less than a high school education had the lowest percentage of first trimester PNC (62.7%) compared with women with at least a Bachelor’s degree (88.1%) (Table 1). Prenatal care measured using the APNCU showed similar patterns (Table 2).

Source of payment is reported on the birth certificate at the time of delivery, which is not necessarily the same source of payment as for PNC (Table 1). For the jurisdictions included in 2014, just over half (55.2%) of women who self-paid for delivery received first trimester PNC compared with nearly 9 out of 10 (87.2%) women with private insurance. Among women with Medicaid, 67.5% received first-trimester care. Self-paying women were the most likely to have inadequate care (34.6%), whereas women with private insurance were the least likely (7.3%); 21.7% of women with Medicaid had inadequate care (Table 2).

Barriers and facilitators to accessing PNC – PRAMS

According to 2009–2010 PRAMS data, 17.2% of recent mothers reported that they did not receive PNC as early as they had wanted. Adolescent mothers (under 20 years of age), reported the highest frequency of barriers to accessing PNC with the rate of reported barriers to accessing care declining as maternal age increased.[41] The most common barriers reported by PRAMS mothers who did not receive PNC as early as they wanted or at all included lack of money or insurance (38.7%), inability to get an appointment when wanted (37.8%), not knowing about the pregnancy (37.1%), and not having a Medicaid card (36.4%). Transportation, childcare needs, work/school schedules, and not wanting anyone to know about the pregnancy were also noted.[41] A literature review of women's perceptions of access to PNC in the US identified many of these same barriers to care.[42] Additionally, key structural barriers to accessing PNC included: clinic location, hours, and wait times; languages spoken by clinic staff and providers; attitudes and communication skills of staff and providers; and poor quality of care provided.

USING DATA FOR ACTION

Massachusetts

In 2010, the Massachusetts PRAMS team examined timing of PNC initiation and barriers to PNC using 2007–2008 PRAMS data.[43] Overall, 86% of Massachusetts mothers entered PNC during the first trimester, short of the *Healthy People 2010* goal of 90%. One out of every five mothers reported experiencing at least one barrier to receiving PNC. The three most frequently reported barriers were 'not being able to get an appointment,' 'too many other things going on,' and 'lack of transportation to the clinic or doctor's office.' Massachusetts PRAMS suggested these strategies to improve timely initiation of PNC: 1) promoting the development of reproductive life plans; 2) working with providers and payers to facilitate initiation of PNC in the first trimester; 3) promoting group PNC such as Centering Pregnancy; and 4) identifying and implementing culturally appropriate outreach and services to increase timely PNC utilization by minority groups. In response, Massachusetts placed enhanced focus on reproductive life planning or the process of setting life goals in terms of child bearing and in-home visiting programs including the Massachusetts Maternal Infant and Early Childhood Home Visiting (MA MIECHV) Program and the Early Intervention Partnerships Program (EIPP).

Analysis of 2012–2013 Massachusetts PRAMS data demonstrated improvement in the timeliness of PNC initiation; 91% of Massachusetts mothers initiated PNC during their first trimester, a significant increase. The extent to which this improvement can be attributed to the efforts described above is unknown. However, dissemination of the PRAMS prenatal fact sheet findings to a broad and diverse audience, both internal and external to the Massachusetts Department of Public Health, motivated the need to adopt efforts to improve access to quality PNC and focus on reducing barriers to PNC utilization. PRAMS data will continue to be used to monitor the population impact of these efforts.

Ohio

In 2010, the Ohio Department of Health formed a collaborative between Maternal and Child Health (MCH) and chronic disease programs to examine gestational diabetes mellitus (GDM) and make changes to improve women's health during and after pregnancy. The collaborative examined three sources of data: 1) Ohio PRAMS data from 2006 to 2008 to determine the percent of pregnant women with GDM and identify high risk groups; 2) Survey of Ohio healthcare providers to understand gaps in knowledge about risk factors for type 2 diabetes (T2DM) development among women with a GDM history and understand gaps in resources for caring for these women; and 3) focus groups of Ohio women to recognize barriers they faced in reducing risks for GDM and T2DM.

To improve clinical practice, including the content of PNC around GDM, the collaborative launched an 18-month quality improvement project with three components: 1) development of educational and clinical care resources (toolkits) for providers and patients to use during the PNC visit; 2) rapid cycle data feedback to promote clinician engagement and monitor progress during PNC, and 3) monthly learning sessions facilitated by clinical subject-matter experts to provide training on specific topics, answer questions, and facilitate discussion among clinical sites. More than 70 provider and 2,345 patient toolkits were distributed. Analysis of patient charts revealed improved delivery of prenatal patient education around GDM and T2DM risk. For the measure of timeliness of prenatal GDM screening, an almost 100% screening improvement was noted by the end of the project. Participating sites achieved high rates of prenatal education on all topics (e.g., breastfeeding, smoking cessation, and importance of postpartum care) at the end of the quality improvement project period. This data to action demonstrates that PRAMS data can be used to lay the foundation for a quality improvement project in changing PNC quality. [44]

DATA GAPS AND LIMITATIONS

While randomized controlled trials might be an effective way to document and understand the effectiveness of PNC, ethical considerations render this impossible. Therefore, data on PNC's usefulness and effectiveness have been indirectly measured. Understanding the impact of PNC is further complicated by the fact that PNC is not a single intervention but rather a series of assessments, anticipatory guidance, and treatments, and most studies about PNC have relied on quantitative differences in PNC utilization rather than on measuring and incorporating differences in quality. Similarly, PNC surveillance is limited by the scope, purpose, and information collected by a few principal data sources. NVSS is subject to missing data due at least in part to incomplete or missing PNC records available to the individual completing the birth certificate. In a validity study comparing birth certificate data with information from hospital medical records, the two sources were shown to have at least moderate (60.0%–74.9%) agreement on the date of the first PNC visit, whereas the number of PNC visits were less well reported.[45]

With the NSFG, women are asked to provide PNC information for all their pregnancies ending in live birth, fetal death or pregnancy loss in the five years before the interview, therefore the quality of the data may be limited by recall bias. PRAMS is subject to similar issues with recall bias, although participating women are only two to six months postpartum. Finally, the PRAMS sample is based on live births and cannot capture PNC data for women who experienced miscarriage or stillbirth. This selection bias impacts the overall generalizability of its surveillance findings.

FUTURE ISSUES

Despite the 30 years since the landmark IOM report that led to the dramatic expansion of PNC services, the effectiveness of PNC in improving birth outcomes, particularly in preventing LBW and prematurity, has not been conclusively demonstrated.[5, 46, 47] Part of the issue is the heterogeneous and inequitable content and quality of PNC that is influenced by social determinants of health, pre-existing and emerging maternal medical conditions, maternal behaviors, and insurance access. The efforts of policy makers to focus attention on PNC, to the exclusion of women's health as a whole, led to provision of health insurance coverage for most women limited to prenatal and obstetrical care.[48] Additionally, the majority of the surveillance information collected about PNC is either from self-reported (PRAMS) data or birth certificate (NVSS) data. Neither provides insight into the quality of the care and effects of the care on mothers and infants.

A challenge for the future is identifying other data sources to provide information on PNC quality. For instance, non-traditional sources, like the data collected by Fetal and Infant Mortality Reviews (FIMR), provide rich, descriptive PNC data on the experiences of women whose pregnancies result in a fetal demise or later infant death.[49–51] Assessment of FIMR programs throughout the United States indicate that comprehensive analysis of PNC data occurs more often in communities implementing FIMR.[52] Other data collected through social media activities like *text4baby* provide additional information on how often and when during pregnancy women access information on PNC, PNC health literacy materials, and other pregnancy-related materials [53,54] offering additional insight into the access and quality of PNC.

Another non-traditional source of electronic data is the electronic health record (EHR). Starting in 2011, Medicaid began offering incentive payments to Medicaid health care providers who adopted and used EHR technology.[55] Since then, some research has shown EHR to provide more information about PNC[56, 57] and add to the overall improvement in the quality of maternal and child care services.[58, 59] For instance, Meghea et al., 2016 found that women who received PNC from a provider who adopted and used EHR were more likely to have also attended the appropriate number of well-child visits during their infant's first year of life.[59] While not statistically significant, they also noted possible associations between implementation and use of EHR and increased adequacy of PNC as well as increased likelihood of receiving appropriate postnatal visits.[59] NCHS and the National Association for Public Health Statistics and Information Systems have also collaborated to develop national standards for the automatic transfer of medical and health birth certificate data directly from the hospital electronic records to state electronic birth registration systems;[60] pilot studies have been fielded and more are underway.

Administrative claims data contain a wide variety of information important to public health authorities including socio-demographic characteristics, medical diagnoses, prescriptions, and health care delivery. In 2012, the Center for Medicare and Medicaid Innovation (CMMI) began a four-year initiative, "Strong Start for Mothers and Newborns," with the aim of testing distinct approaches to providing enhanced PNC to women enrolled in Medicaid. CMMI hopes to improve on the traditional method of PNC delivery by addressing additional factors, such as behavioral and psychosocial, that may be present during pregnancy and contribute to birth outcomes. Claims-based data will play an essential role in evaluating the outcomes targeted by the "Strong Start for Mothers and Newborns" program.[61] Claims-based data will also play a pivotal role in evaluating the delivery of PNC, through Medicaid programs, for low income women most at risk for adverse pregnancy outcomes. For example, the National Committee for Quality Assurance has several healthcare effectiveness data sets quantifying the frequency and initiation of PNC used by Medicaid programs and health plans to monitor PNC among its population.[62]

Another aspect of administrative claims data affecting PNC surveillance is all payer claims databases. These databases are designed to inform cost containment and quality improvement efforts. Collected information such as private health insurance, Medicaid status, and children's health insurance are available from many administrative data sources: state employee health benefit programs; prescription drug plans; dental insurers; self-insured employer plans; and Medicare.[63] The structure and systems process for Medicaid will likely also change. For instance, Medicaid is evolving from an entirely fee-for-service payment model to one in which two-thirds of beneficiaries are enrolled in Medicaid managed care (MMC) plans through contracts negotiated between states and managed care organizations (MCOs).[64] Evidence from several states indicates conflicting findings on PNC utilization with this change to MMC.[65–68] Regardless, states will continue utilizing MCOs to manage cost and encourage innovation in health care delivery. It will be important to monitor the impact of capitated payments and global billing on the use of claims and encounter data for PNC surveillance.

As the impact of preconception or pre-pregnancy care in improving pregnancy outcomes becomes better understood, quality care over the course of a woman's reproductive life, including during pregnancy, along with surveillance data, may move closer to reaching the goals initially set forth by the IOM of reducing LBW and improving birth outcomes.

ADDITIONAL RESOURCES

- Vital statistics data are available from the following interactive online data platforms
  CDC WONDER http://wonder.cdc.gov/
  Vital statistics unit records files are available for download at
  http://www.cdc.gov/nchs/data_access/vitalstatsonline.htm

- NSFG data are available for download at http://www.cdc.gov/nchs/nsfg/nsfg_questionnaires.htm
- PRAMS data are available for researchers by request https://www.cdc.gov/prams/prams-data/researchers.htm

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Table 1. 1st trimester prenatal care and late or no prenatal care[1] by selected characteristics: United States, 2014

Selected Characteristic	Timing of Prenatal Care			
		Late or no care		
	1st trimester	Total[2]	3rd trimester	No care
	Percent			
Total[3]	76.7	6.0	4.4	1.6

Race and Hispanic origin				
Non-Hispanic				
White	81.6	4.3	3.3	1.0
Black	65.8	9.8	6.8	3.0
AIAN	63.0	11.6	8.7	2.8
Asian	80.2	5.1	4.5	0.7
NHOPI	52.3	18.0	13.8	4.2
Hispanic	71.7	7.5	5.3	2.2
Age of mother				
Under 20	61.4	10.5	7.8	2.7
Under 15	37.1	24.6	18.6	6.0
15-19	61.6	10.4	7.7	2.7
20-24	69.5	7.8	5.8	2.1
25-29	78.0	5.6	4.1	1.5
30-34	82.2	4.5	3.3	1.1
35-39	81.7	4.6	3.4	1.2
40 or older	78.8	5.3	3.9	1.4
Mother's educational attainment[4]				
Less than high school	62.7	10.7	7.2	3.5
High school	73.5	6.8	4.7	2.1
Some college	80.4	4.4	3.4	1.1
Bachelor's degree or higher	88.1	2.9	2.5	0.4
Source of payment				
Medicaid	67.5	8.3	6.2	2.1
Private Insurance	87.2	2.6	2.0	0.5
Self-pay	55.2	18.6	11.9	6.7
Other	74.9	7.8	5.6	2.1

[1] Includes care that began in the 3rd trimester and no prenatal care.

[2] Late and no care may not add to total due to rounding.

[3] Excludes data for Connecticut, New Jersey, and Rhode Island.

[4] Excludes women under 25 years of age in order to give the population a chance to complete their education.

SOURCE: NCHS, National Vital Statistics System

Table 2. Adequacy of prenatal care utilization[1] by selected characteristics, 2014

Selected Characteristic	Inadequate	Intermediate	Adequate	Adequate Plus
	Percent			
Total [2]	15.2	9.7	41.2	33.9
Race and Hispanic origin				
Non-Hispanic				
White	11.3	8.9	43.7	36.1
Black	23.8	10.6	33.8	31.8
AIAN	28.3	12.7	34.1	24.8
Asian	12.8	10.3	44.1	32.8
NHOPI	38.1	12.1	28.7	21.1
Hispanic	18.7	10.7	39.8	30.8
Age of mother				
Under 20	26.9	10.2	35.1	29.1
Under 15	51.8	7.6	21.4	19.3
15-19	26.6	10.22	35.3	27.8
20-24	20.5	10.4	38.5	30.7
25-29	14.3	9.8	42.5	33.5
30-34	11.1	9.4	44.0	35.4
35-39	11.4	9.1	41.4	38.2
40 or older	13.1	8.1	35.1	42.7
Mother's educational attainment [3]				
Less than high school	25.0	10.2	33.9	30.9
High school	16.7	9.6	38.2	35.5
Some college	11.4	8.7	41.1	38.5
Bachelor's degree or higher	6.7	9.2	46.7	37.5
Source of payment				
Medicaid	21.7	9.9	36.7	31.7
Private Insurance	7.3	8.9	46.2	37.5
Self-pay	34.6	13.0	33.6	18.8
Other	17.6	13.5	39.2	29.8

[1] Based on the Adequacy of Prenatal Care Utilization Index (See reference 10).

[2] Excludes data for Connecticut, New Jersey, and Rhode Island.

[3] Excludes women under 25 years of age in order to give the population a chance to complete their education.

SOURCE: NCHS, National Vital Statistics System

Behavioral Risk Factors

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Tobacco, alcohol, and illicit drug use are significant factors threatening a healthy pregnancy and the wellness of a mother and child. Reducing these risks are paramount in preventing poor birth outcomes and improving women's health. Along with these established issues, new behavioral risks, such as the use of prescription opioid pain relievers and emerging tobacco products are beginning to be defined and measured for their impact on pregnant women and infants.

PUBLIC HEALTH IMPORTANCE

Reducing behavioral risk factors is a challenging but promising strategy for preventing poor birth outcomes and improving women's health. This chapter focuses on behavioral risk factors related to substance use which, if significantly reduced, would have an immediate positive impact on the health of women and many infants in the United States. Smoking tobacco during pregnancy is a preventable cause of many adverse pregnancy outcomes including low birth weight, placental problems, preterm birth, and Sudden Infant Death Syndrome (SIDS)[1]. Alcohol consumption during pregnancy is the only cause of fetal alcohol spectrum disorders (FASDs), a set of disorders which lead to life-long cognitive disabilities and physical abnormalities in affected individuals[2]. Likewise, certain drugs, even those prescribed to women for valid medical reasons (e.g., isotretinoins, anti-epileptic drugs, oral anti-coagulants, pain relievers), and illicit drugs have teratogenic effects on the developing fetus leading to outcomes ranging from minor cognitive delays to severe birth defects[3,4]. Women planning to become pregnant can discuss options with medical professionals to transition to safer alternatives during pregnancy; however, this may not always occur, particularly if a woman experiences an unplanned pregnancy. Recently, the “opioid epidemic,” or the increased misuse of prescription pain relievers during pregnancy, has sharply increased the number of babies born with neonatal abstinence syndrome[5,6]. Substance use during the preconception and perinatal periods is associated with numerous other risk factors for poor pregnancy outcomes such as poor nutrition, domestic violence, and depression[7,8].

Primary prevention may offer the most promise for improving women’s health and reducing the number of pregnancies with substance exposure. Tobacco products, alcohol and many drugs are addictive, and cessation treatment can be complicated by pregnancy. However, while substance use is modifiable, it often co-occurs with poverty, excessive exposure to stress or trauma, and mental illness potentially necessitating assistance beyond cessation services[6]. Once physiological addiction has occurred, rehabilitation and recovery can be difficult to achieve and sustain[6]. For addicted women, treatment that integrates social services to address other factors contributing to addiction may be most successful[10,11].

The purpose of this chapter is to provide an overview of the magnitude of tobacco, alcohol, and illicit drug use among reproductive-aged women including pregnant and perinatal women in the United States, and to highlight ways that states are successfully using data to advance substance use initiatives around the time of pregnancy.

HISTORY OF DATA COLLECTION

National surveys with a focus on maternal and infant health, including surveys of behavioral risk factors, have been conducted periodically since the 1960s. The National Center for Health Statistics (NCHS) conducted the National Natality Surveys (1960s, 1972 and 1980), and later the National Maternal and Infant Health Survey (NMIHS), a natality follow-back survey similar to the current Pregnancy Risk Assessment Monitoring System (PRAMS) (1988 - 1991)[12]. Both of these surveys collected information on cigarette smoking and alcohol use before and during pregnancy. The NMIHS also collected information on illicit drug use before and during pregnancy.

CDC also monitored risk factors associated with infant mortality and poor birth outcomes (e.g., cigarette smoking before and during pregnancy) among low-income pregnant women who participated in federally funded public health programs within participating states through the Pregnancy Nutrition Surveillance

System (PNSS, 1979 - 2012)[13].

CDC SURVEILLANCE ACTIVITIES

This chapter focuses primarily on CDC surveillance systems that use surveys to collect information, as well as the National Vital Statistics System (NVSS) (Table 1). NVSS provides the nation's official statistics related to preconception and perinatal health for live births. Information on maternal and infant health is collected by states and territories as part of the official certification of live birth. CDC's National Center for Health Statistics (NCHS) collaborates with states to develop standard certificates for data collection to promote a uniform national database. Beginning with the 1989 standard version of the birth certificate (BC), information on smoking and alcohol use prior to and during pregnancy was captured[14]. The 2003 revision to the birth certificate collects information on smoking before pregnancy and during each trimester of pregnancy but does not collect information on alcohol use. States and territories transitioned from the 1989 to the 2003 birth certificate over time. All states and territories were transitioned to the 2003 version as of January 1, 2016[15].

In this chapter we have included information from one surveillance system conducted by the Substance Abuse and Mental Health Services Administration (SAMSHA). While not a CDC surveillance activity, the National Survey on Drug Use and Health (NSDUH) is one of the few surveillance systems that collects detailed information on drug use among the general population including women of reproductive age and pregnant women. A list of surveillance systems that collect data on substance use is listed in Table 1, select systems are described below.

PRAMS

In 1987, CDC's Pregnancy Risk Assessment Monitoring System (PRAMS) was initiated in five states and Washington, DC. PRAMS expanded to 40 states and New York City by 2011. PRAMS exclusively samples women who have given birth to live-born infants approximately two to six months following the birth, using the Vital Records birth certificate file as the sampling frame. Although not currently nationally representative, PRAMS estimates are representative of each participating state. PRAMS collects information on cigarette smoking, emerging tobacco products, marijuana use, prescription and illicit drug use and alcohol use in the time period surrounding pregnancy[16].

NSFG

CDC's National Survey of Family Growth (NSFG), conducted by NCHS, is a nationally and regionally representative survey (not designed to provide information at the state level). It collects comprehensive information about women's health including reproductive history and pregnancy experiences. NSFG was conducted periodically from 1973 through 2002, and regularly since 2006, with the most recent data available from 2013 through 2015. Recent versions of NSFG collect information on alcohol consumption (in the last 30 days and last 12 months) and binge drinking, cigarette smoking (current smoking, smoking in the last 12 months), and illicit drug use from all respondents. Smoking during pregnancy is collected for all reported pregnancies within the past five years among women 15-44 years of age[17]. Information is collected to assess current pregnancy status of women at the time of survey.

BRFSS

The Behavioral Risk Factor Surveillance System (BRFSS) was initiated in 1994 and is CDC's largest state-based surveillance system on health behaviors. Estimates from BRFSS represent the median prevalence from all states. BRFSS collects information on substance use behaviors among adult men and women (18 years of age or older) including cigarette smoking, use of smokeless tobacco products, marijuana and alcohol use[18]. Information is collected to assess current pregnancy status of women at the time of survey.

NHIS

The National Health Interview Survey (NHIS), initiated in 1957, annually collects information on the health status of the general population nationwide including use of tobacco products, alcohol, and cigarette smoking among adult men and women 18 years of age or older. Beginning in 2014, NHIS added questions on the use of e-cigarettes. This survey provides regional and some state estimates of these factors along with an indicator of current pregnancy status [19].

NHANES

CDC's National Health and Nutrition Examination Survey (NHANES) was initiated in the 1960s and has been conducted annually since 1999. NHANES includes pregnancy status confirmed by urine pregnancy test, although sample sizes of pregnant women within single years are small. NHANES is unique in the combined collection of biological specimens, such as tobacco metabolites and other drug metabolites along with questionnaire data. NHANES collects information on cigarette smoking and use of other tobacco products, alcohol, prescription drugs, and illicit drugs for US population 12 years and older[20].

Three additional CDC survey-based surveillance systems (NATS, NYTS, and YRBSS) collect detailed information on substance use behaviors among adults and adolescents, but do not query pregnancy status.

NATS/NYTS

The National Adult Tobacco Survey (NATS) and the National Youth Tobacco Survey (NYTS) are nationally representative surveys that annually collect detailed information on the use of cigarettes and other tobacco products, including newly emerging products, such as electronic nicotine products and hookahs[21]. NATS, however, was discontinued after 2013.

YRBSS

The Youth Risk Behavior Surveillance System (YRBSS), a state and nationally-representative surveillance system conducted biennially among in-school youth in grades 9th – 12th, collects detailed information on substance use including cigarettes, other tobacco products, alcohol, and illicit drugs[22].

NSDUH

The National Survey on Drug Use and Health (NSDUH) is a nationally-representative survey among men and women, 12 years and older administrated by the Substance Abuse and Mental Health Services Administration (SAMSHA). NSDUH collects information on use of tobacco products and alcohol, as well as detailed information on use of illicit drugs and prescription drugs[23]. NSDUH ascertains current pregnancy status of female respondents.

GENERAL FINDINGS

We compiled findings on substance use among non-pregnant reproductive-aged women (including adolescents aged 12 – 17) and pregnant and postpartum women (**Tables 2 - 4**). Estimates from PRAMS and PNSS are not nationally representative, but are taken from findings that are representative of participating states and jurisdictions.

Tobacco Use (Table 2)

Cigarette smoking

All women

- Among adult women 18 years of age and older in the general population, current smoking was reported to be 14.5% (NATS)[24] for smoking some days or every day in the past month, 15.3% (NHIS)[25] for smoking in the past 30 days, and 17.2% (BRFSS)[26] for smoking every day or some days among those having smoked ≥100 cigarettes during their lifetime.
- The NSFG[27] estimate for smoking in the past 12 months among 15 – 44-year-old women was 22.4%.
- Smoking in the three months before pregnancy was estimated to be 22.6% among women with recent live births (PRAMS[28]) and 23.3% among low-income women participating in federally-funded health programs (PNSS[29]).

Adolescents

- Estimates for cigarette smoking in the past 30 days among adolescent girls ranged from 5.5% (NSDUH)[30] to 7.9% (NYTS)[31] to 15.0% (YRBSS)[32].

Pregnant and postpartum women

- The prevalence of smoking anytime during the most recent pregnancy was 8.5% (NVSS) [33]. Smoking anytime during a pregnancy in the past five years was 11.7% (NSFG)[27], and 3rd trimester smoking was 10.2% (PRAMS) [28], 12.5% (PNSS) [29], and 15.4% (NSDUH)[30] .
- One-third (38.2%, PNSS[29]) to one-half (55.3%, PRAMS[28]) of women who reported smoking in the three months before pregnancy reported quitting by the 3rd trimester of pregnancy. Notably, 42.8% of those who quit during pregnancy relapsed to smoking postpartum (PRAMS)[34].

Smokeless tobacco use

All women

- Among the general population of adult women, smokeless tobacco use in the past 30 days was less than 1% according to BRFSS[26] and NATS[24].

Adolescents

- Among female high school students, use in the past 30 days was 1.2% (NYTS[31]) and 2.9% (YRBSS[32]).

Pregnant women

- Nationally representative data on use of smokeless tobacco among pregnant women were not collected. Prevalence of smokeless tobacco use during pregnancy in one state (Alaska) was 6% in 2012 (PRAMS)[35].

Electronic nicotine products (for example, e-cigarettes, vape pens, e-pipes, and e-hookahs)

All women

- The prevalence of using electronic nicotine products every day or some days among adult women was 1.6% (NATS)[24].

Adolescents

- Among high school girls, 11.9% reported using e-cigarettes in the past 30 days, the highest use of any single tobacco product reported by NYTS[31].

Pregnant women

- National or state level data on electronic nicotine product use among pregnant women were not available at the time this monograph was prepared but is available from select PRAMS states.

Alcohol Use (Table 3)

All women

- Any alcohol use in the past 30 days among non-pregnant women was approximately 50% according to all data sources (48.3% BRFSS[26], 43.7% NHIS[25], 56.9% NSDUH[30], and 54.1% PRAMS[23] in the three months before pregnancy for women with a live birth).

- Binge drinking (consuming four or more drinks in a two-hour time span) in the past 30 days was 23.1% for women 18 years and older (BRFSS)[26]; 31.4% for young women 18 to 25 years of age (NSDUH)[30]; and 23.1% for women with a live birth in the three months before pregnancy (PRAMS)[28].

Adolescents

- The prevalence of alcohol use in the past 30 days was 35.5% among female high school students (YRBSS)[32]; the prevalence among females aged 12–17 was 11.9% (NSDUH)[30].
- The prevalence of binge drinking was 19.6% among female high school students (YRBSS)[32] and 12.4% (NSDUH)[30] among adolescent girls 12-20 years.

Pregnant women

- Alcohol use during the third trimester of pregnancy was 9.4% among pregnant women 15 to 44 years of age (NSDUH)[30], and 7.5% for women with a recent live birth (PRAMS)[28].
- During pregnancy, the prevalence of binge drinking was 2.3% (NSDUH)[30] among women 15-44 years and 3.1% among women 18-44 years (BRFSS)[36].

Illicit Drug Use (Table 4)

All women

- Illicit drug use in the past month (including marijuana and non-medical use of psychotherapeutic drugs) for women 15–44 years of age was 11.4% (NSDUH)[30].
- Among non-pregnant women aged 18-44, 7.6% (NSDUH) [37] used marijuana in the past month.
- Use of prescription pain relievers in the past 30 days among the general population of adult women 20 years and older was 7.2% (NHANES)[38].

Adolescents

- The prevalence of illicit drug use in the past month among girls 12 to 17 years of age was 8.0% (NSDUH)[30]. The prevalence of heroin use in the past 30 days among high school girls was 1.6% and inhalant use was 10.0% (YRBSS)[32].
- The prevalence of marijuana use in the past 30 days was 6.2% among girls 12 to 17 years of age (NSDUH)[30] and 21.9% among high school girls (YRBSS)[32].
- Among adolescent girls in high school, 17.2% reported ever using prescription drugs without a

prescription (YRBSS)[32].

Pregnant women

- The prevalence of any illicit drug use was 5.4% (NSDUH)[30].
- Among pregnant women, 3.9% reported using marijuana in the past month (NSDUH)[30].
- Among women in Hawaii with a recent live birth, 2.6% reported using marijuana during pregnancy (PRAMS)[39].

USING DATA FOR ACTION

The purpose of conducting surveillance is not only to quantify the problem, but also to use the data to inform development of programs and policies to improve health. We highlight systems and clinical approaches used to address the problems of perinatal substance through data use at the local, state, and national level.

Perinatal Smoking Cessation

In 2011, Ohio had the fourth highest infant mortality rate in the United States, and the prevalence of prenatal smoking was twice the national average[40]. As a result, two of the state health priorities involved the reduction of infant mortality and tobacco use[41]. PRAMS data showed that smoking rates during pregnancy among women who recently gave birth were highest among low-income women. Women with Medicaid insurance were more than five times more likely to smoke than women without Medicaid insurance[41]. Women participating in the Special Supplemental Nutrition Program for Women, Infants, and Children (WIC) were almost three times more likely to smoke compared to non-WIC participants.

In 2006, the Ohio Partners for Smoke-Free Families initiative was established. In 2007, the initiative supported a pilot program to implement the 5A’s (Ask, Advise, Assess, Assist, and Arrange), an evidence-based smoking cessation brief intervention for pregnant women in clinical settings[42]. WIC clinics and Help Me Grow (HMG) home visiting programs in four counties were the initial pilot sites, and in 2008, the project was expanded to additional WIC clinics. Staff were trained to deliver the 5A’s brief smoking cessation intervention to pregnant smokers during clinic visits. To support implementation, a documentation form was developed for staff to record which aspects of the 5A's were covered during each client visit[43]. From 2006–2010, staff in 38 WIC clinics were trained to provide the intervention[43].

In 2012 the intervention was expanded into all Child and Family Health Services (CFHS) perinatal care clinics, and in 2013 an evaluation was conducted. The analysis used data from Ohio PNSS to assess self-reported smoking cessation behaviors of WIC participants. Rates of smoking cessation were compared among women attending the same clinic before and after the clinic staff were trained on the 5A's intervention. The evaluation suggested that training WIC clinic staff to implement the 5A's improved the odds of smoking cessation among low-income pregnant women[43].

In addition to the data analysis, in-depth stakeholder interviews with WIC and CFHS clinic staff were conducted to identify barriers and facilitators to program implementation. Stakeholder interviews revealed some challenges related to lack of self-efficacy to counsel pregnant women resistant or unable to quit smoking, and lack of resources, time, or appreciation of the potential impact of the program among already busy clinic staff[44].

In 2014, drawing on the experience and recommendations of the pilot sites, the Ohio Department of Health expanded the program to cover more clinics statewide and to include all women of reproductive age, not just pregnant women. Staff training and quality improvement was provided in CFHS prenatal clinics, Help Me Grow programs, Reproductive Health and Wellness (family planning) programs and additional WIC sites. In collaboration with the Ohio Colleges of Medicine Government Resource Center, the Ohio Department of Health developed provider toolkits. To further promote community support, the Ohio Department of Health developed and targeted a media campaign on perinatal smoking cessation messaging for four southeastern counties[41]. A contract with Ohio University was initiated to engage and train both public and private healthcare providers in those areas. The expansion was made possible by the allocation of one million dollars from the state in both 2014 and 2015 to reduce infant mortality in Ohio[41].

The availability of cessation specialists in communities was identified as a facilitator to success of public health programs implementing 5A's brief counseling. In response, the state provided funding to CFHS grantees to train staff as Certified Tobacco Treatment Specialists to implement more intensive, but complementary, programing such as BABY & ME - Tobacco Free Program.

Perinatal Alcohol Use

In 2010, the Maryland Department of Health and Mental Hygiene (DHMH) PRAMS project disseminated information on alcohol use during pregnancy to the Maryland Fetal Alcohol Spectrum Disorder Coalition (FASD) in 2010[45]. PRAMS data showed that healthcare providers in Maryland did not routinely assess alcohol consumption or counsel pregnant women about its harmful effects on infant outcomes. The Maryland FASD Coalition supported publication of the findings locally and nationally to raise awareness about the need for increased provider assessment and counseling about alcohol used before and during pregnancy. In 2010, researchers from DHMH and Johns Hopkins University authored a chapter in the book *Pregnancy and Alcohol Consumption*[46], and in February 2011, published an article on prenatal counseling related to alcohol use in *Obstetrics and Gynecology*[47]. The article was included in the approved research articles list for 2011 Annual Maintenance of Certification by the American Board of Obstetrics and Gynecology (ABOG).

In August 2011, the American College of Obstetricians and Gynecologists (ACOG) published an official Committee Opinion about Alcohol Use During Pregnancy[48]. The Maryland PRAMS Project director, a lead author on the Committee Opinion, was interviewed by *ACOG Today* about the impact of alcohol use during pregnancy. In 2012, the Maryland FASD Coalition showcased the data at a summit focused on increasing awareness among state policymakers about the prevalence of alcohol use during pregnancy, the impact, and potential solutions to address the problem.

Perinatal Drug Use

Neonatal abstinence syndrome (NAS) has increased dramatically since 2000[49], corresponding with increased prescribing of prescription pain relievers for pregnant women and others[50]. A multi-pronged approach has been undertaken to address the issue at the national, state, and local levels. Tennessee has the second highest rate of opioid prescriptions in the United States[50]. In the spring of 2012, a NAS Subcabinet Working Group was formed in Tennessee including Cabinet level representation from Public Health, Children's Services, Human Services, Mental Health and Substance Abuse Services, Medicaid (TennCare), and the Children's Cabinet[51]. One of the group's first initiatives was to propose a black box warning for use of analgesic drugs during pregnancy to the Food and Drug Administration (FDA). The FDA announced class-wide safety labeling changes for the drugs in September 2013[52].

The Prescription Safety Act of 2012 was passed in Tennessee requiring prescribers of drugs to register in the Controlled Substances Monitoring Database (CSMD)[53]. The database allows prescribers to view patients' prescriptions and assess if they are getting the same medications from other sources. In 2013, a 240% increase in database use by providers and a 50% reduction in doctor shopping (obtaining prescriptions from multiple providers) by consumers was reported [54].

Tennessee became the first state in the country to establish a public health surveillance system for NAS (2012). The system relies on hospital reporting of cases after delivery within 30 days of the diagnosis using an online system and standardized data fields. In 2013, 921 cases were reported, including information on the source of the substance that caused NAS. In 46.4% of the cases, the source of exposure was reported to be supervised opioid-replacement therapy. The surveillance system also identified the region of the state with the largest number of cases, namely the eastern portion of the state[50]. Beginning in 2012, a question on drug use during pregnancy was added to the Tennessee PRAMS survey, and these data can be analyzed in conjunction with other social and behavioral risk factors from the survey to support programmatic efforts.

In addition to these systems-level, state initiatives, a number of clinical approaches at the local level have been initiated in Tennessee. Knox County Health Department and East Tennessee Regional Health Office formed a partnership with methadone clinics to prevent unintended pregnancies by providing Depo-Provera to clients, or referring women to a local family planning clinic for long-acting reversible contraceptives (LARCs). The East Tennessee Regional Health Office, in partnership with jails in Sevier and Cocke counties, offers and provides LARCs for reproductive-aged female inmates who wish to avoid pregnancy. The multipronged approach in Tennessee is an excellent example of using data from multiple sources to address the complex array of environmental and behavioral factors that contribute to the issue of substance exposed pregnancies[51].

DATA GAPS AND LIMITATIONS

There are several key data gaps in available data that hinder understanding of the extent of substance use in the preconception period, as well as during pregnancy and postpartum. One is lack of information on drug use during pregnancy. PRAMS is the major data source for maternal experiences and behaviors around the time of pregnancy but does not routinely include information on drug use, although states may choose to add it on their own. Although several surveillance systems collect information about current pregnancy status (e.g., BRFSS, NHIS, NHANES, NSFG, and NSDUH), the sample of pregnant women may be limited in size when looking at a single year of data. Only NSDUH published estimates of substance use by pregnancy status combining several years of data[30].

Surveillance on use of emerging tobacco products (e.g., electronic cigarettes, hookahs, smokeless tobacco) during pregnancy is another data gap. While information on emerging products is included in surveillance systems that provide information for the general population (YRBSS, NATS, and NYTS), none of the systems include current pregnancy status. BRFSS queries current pregnancy status, but only collects information on use of smokeless tobacco products, and the sample size of pregnant women is limited. However, starting in 2014 NHIS added questions on electronic cigarette use, and beginning in 2016 PRAMS will also collect information on use among pregnant women. In addition, in 2015 two states (Oklahoma and Texas) added supplemental questions on electronic cigarette use to their PRAMS surveys.

Another important limitation of data related to substance use is reporting bias. In particular, use of tobacco, alcohol, and drugs are sensitive topics, especially during pregnancy, and is susceptible to underreporting due to the lack of social acceptability. NHANES and NSDUH allow questions on these topics to be confidentially self-administered by respondents using computer-assisted technology. The mailed version of the PRAMS survey is also self-administered allowing for more privacy than from a telephone or face-to-face interview. For example, PRAMS has been found to ascertain higher smoking rates before and during pregnancy than the birth certificate[55]. A number of factors may result in differences in estimates between data sources (i.e., the differences observed in the estimates for drug use among youth between NSDUH and YRBSS surveys) due to differences in survey methodology (mode of administration, populations covered, sample size)[30]. In particular, for the youth estimates, NSDUH covers the general population while YRBSS is specific to adolescents attending school.

Finally, another key gap is the lack of information among women who experience fetal loss in most data sources. Women may be surveyed as part of the general population, but there is no indicator to capture recent miscarriage, spontaneous or induced abortion, or stillbirth in the state-based surveillance systems highlighted in this chapter. NSFG obtains a full pregnancy history for all pregnancies and could be a valuable source of data on fetal loss in the context of substance use. Some information is captured by vital records systems on the fetal death certificate (limited to fetal demise after 20 weeks); however, data quality and completeness vary widely by state. Use of substances may be particularly relevant to this group, and efforts should be made to capture and report information in existing systems.

FUTURE ISSUES

Several surveillance data gaps on drug use and emerging tobacco products during pregnancy will be addressed beginning in 2015. In 2015, two states (Oklahoma and Texas) implemented a special survey supplement on PRAMS asking questions about use of electronic nicotine products during pregnancy. PRAMS will begin a new funding cycle in 2016 with the hope of expanding surveillance to all states with an interest in conducting PRAMS. In 2016, a revised version of the PRAMS questionnaire will be implemented in all participating states and will include core questions (used by all states) on use of electronic nicotine products and hookahs before and during pregnancy. In addition, optional (non-core) questions have been selected by about a quarter of the states to address smokeless tobacco use and drug use before and/or during pregnancy. Finally, a detailed PRAMS supplemental module related to marijuana and other drug use during pregnancy has been developed for future implementation.

For some of the surveillance systems that already collect detailed information on tobacco, alcohol, and drug use (NYTS and YRBSS), the addition of one to two short questions on current pregnancy status and recent pregnancy loss for females could enhance the usefulness of the systems for assessing behavioral risk factors. To address the surveillance gap related to fetal loss, CDC PRAMS will be funding states to conduct stillbirth surveillance in several pilot sites starting in 2016. Formative research on the topic and a small pilot study have already been conducted in Georgia[56]. Efforts across states to improve the quality and completeness of the fetal death record would also be important in addressing this data gap.

Analysis of data from systems that already collect information on current pregnancy status (BRFSS, NHANES, NSDUH) could increase awareness of substance use issues specific to pregnancy. Further, BRFSS and PRAMS could be valuable tools in the evaluation of state and local level efforts as both are state based. Wider reporting and dissemination of available data are essential to encourage program and policy makers to take action.

For all surveillance systems, in conjunction with collecting and publishing more data on these topics, ongoing monitoring of legislation and the regulation of emerging tobacco products, marijuana, and prescription drugs will be important. Changes in laws and regulations may influence behaviors and reveal gaps for which new data will need to be collected by surveillance systems.

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ADDITIONAL RESOURCES

- **Chronic Disease Indicators (CDI):** Online data query system for a set of surveillance indicators developed by consensus among CDC, the Council of State and Territorial Epidemiologists (CSTE), and the National Association of Chronic Disease Directors (NACDD). Available at http://www.cdc.gov/cdi/index.html
- **March of Dimes PeriStats:** Developed by the March of Dimes Perinatal Data Center; web-based queryable system unifying information about maternal and child health from a variety of data sources. Available at http://www.marchofdimes.org/peristats/Peristats.aspx
- **State Tobacco Activities Tracking and Evaluation (STATE) System:** An electronic data warehouse containing up-to-date and historical state-level data on tobacco use prevention and control. Available at http://www.cdc.gov/statesystem/.
- **WONDER Wide-ranging Online Data for Epidemiologic Research:** A menu-driven system of providing access to a wide array of public health information resources of the Centers for Disease Control and Prevention (CDC) available to public health professionals and the public at https://wonder.cdc.gov/natality.html
- **Association of State and Territorial Health Organizations (ASTHO) Maternal and Child Health (MCH) Program Successes**: Examples of case studies that address issues affecting families, women of reproductive age, infants, children, and adolescents, including those with special healthcare needs. Available at: http://www.astho.org/Programs/Maternal-and-Child-Health/.

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Table 1. Summary Characteristics of Selected National and State-Based CDC Surveillance Systems Collecting Information on Behavioral Risk Factors Among Reproductive Aged Women

			Behavioral Risk Factors	
Surveillance System/Survey	**Population**	**Data Collection Interval**	**Before Pregnancy**	**During Pregnancy**
National Vital Statistics System (birth certificate data)	All US live births	Annual	3 months prior to pregnancy	Cigarette smoking during pregnancy
National Survey of Family Growth (NSFG)	Individuals 15 – 44 years of age living in households	Periodically 1973 - 2002; continuous since 2006	Current cigarette smoking, cigarette smoking in the past 12 months; Alcohol consumption in last 30 days and last 12 months, binge drinking; Illicit drug use	Cigarette smoking during any pregnancy within the past 5 years; Pregnancy status indicator available
Pregnancy Nutrition Surveillance System (PNSS)	Pregnant women who participate in federally funded public health programs (WIC and Title V programs) in participating states/jurisdictions	Continuous, 1979 - 2012	Cigarette smoking 3 months prior to pregnancy and postpartum; Alcohol use in the 3 months before pregnancy	Cigarette smoking at time of first prenatal visit; Cigarette smoking in the last 3 months of pregnancy; Alcohol use in the last 3 months of pregnancy
Pregnancy Risk Assessment Monitoring System (PRAMS)	Women with recent live births in participating sites	Annual since 1988	Cigarette smoking in 3 months before pregnancy; Cigarette smoking postpartum (at time of survey); Alcohol use in the 3 months before pregnancy; Binge drinking in the 3 months before pregnancy	Cigarette smoking in last 3 months of pregnancy; Alcohol use in the last 3 months of pregnancy; Binge drinking in the last 3 months of pregnancy
Behavioral Risk Factor Surveillance System (BRFSS)	Adults 18 years and older	Annual since 1993	Cigarette smoking every day or some days; Smokeless tobacco every day or some days; Alcohol use in the past 30 days	Pregnancy status indicator available
National Health Interview Survey (NHIS)	Adults 18 years and older	Annual since 1957	Cigarette smoking every day or some days; Smokeless tobacco use every day or some days;	Pregnancy status indicator available

			Behavioral Risk Factors	
			Use of any other tobacco product every day or some days; Regular alcohol use (at least 12 drinks) in the past year	
National Adult Tobacco Survey (NATS)	Adults 18 years and older	Annual since 2009	Cigarette smoking every day or some days; Current use (every day or some days) of: cigars/cigarillos, tobacco pipes, electronic nicotine products, smokeless tobacco, dissolvables	NA; pregnancy status indicator not available
National Youth Tobacco Survey (NYTS)	Students, 6th-12th grades	Biennial since 1999	Cigarette smoking in the past 30 days; Use of other tobacco products in the past 30 days: cigars/cigarillos, tobacco pipes, e-cigarettes, smokeless tobacco, dissolvables	NA; pregnancy status indicator not available
Youth Risk Behavior Surveillance System (YRBSS)	Students, 9th-12th grades	Biennial since 1991	Cigarette smoking in past 30 days; Smokeless tobacco use in the past 30 days; Tobacco pipes, cigars/cigarillos use in past 30 days; Electronic tobacco product use in the past 30 days; Alcohol use in the past 30 days; chronic and binge drinking; Drug use in the past 30 days: marijuana, cocaine, heroin, inhalants, hallucinogens, synthetic marijuana; Ever use of prescription pain relievers without a prescription	NA; pregnancy status indicator not available
National Health and Nutrition Examination	Varies depending on indicator; 12 years and older	Periodic from 1979-1998; Annual since 1999	Cigarette smoking in the past 30 days; Other nicotine product use in the past 5 days	Pregnancy status indicator available

			Behavioral Risk Factors	
Survey (NHANES)	for most substance use indicators		(pipes, cigars, smokeless, gum/patch); Alcohol use in the past 30 days; Marijuana use in the past 30 days; Cocaine/crack/heroin/methamphetamine use in past 30 days; Prescription drug use in the past 30 days; Serum Cotinine (3 years and older) and Urinary Total NNAL metabolite (6 years and older)	
National Survey on Drug use and Health (NSDUH) *	Individuals 12 years and older	Annual since 1988	Cigarette smoking in the past month; Tobacco use in the past month; Current binge and heavy alcohol use; Illicit drug use in the past month; Marijuana use in the past month; Daily marijuana use in the past year and past month; Non-medical pain reliever use in the past year	Pregnancy status indicator available

*Sponsored by the Substance Abuse and Mental Health Services Administration (SAMHSA)

Table 2. Estimates of Tobacco Use Among Women from Selected Surveillance Systems/Surveys, 2011 - 2014

Indicator	All women	Adolescent girls	Pregnant women
Cigarette smoking	15.3% (NHIS, 2013)* † 17.2% (BRFSS, 2013)* † 14.5% (NATS, 2012-2013) ‡ 22.4% (NSFG, 2011 - 2013) § 22.6% (PRAMS, 2011)¶ 23.2% (PNSS, 2011)¶	15.0% (YRBSS, 2013)* 7.9% (NYTS, 2014)* 5.5% (NSDUH, 2013)*	8.5% (NVSS, 2013)¶ 11.7% (NSFG, 2011-2013) § 10.2% (PRAMS, 2011) ** 12.5% (PNSS, 2011) ** 15.4% (NSDUH, 2012-2013) **
Smoking cessation during pregnancy			55.3% (PRAMS, 2011) 38.2% (PNSS, 2011)
Smoking relapse postpartum			42.8% (PRAMS, 2011)
Smokeless tobacco use	>1% (BRFSS, 2013*†; NATS, 2012-2013‡)	1.2% (NYTS, 2014)* 2.9% (YRBSS, 2013)*	6% (Alaska PRAMS, 2012)
Electronic vapor products	1.6% (NATS, 2012-2013) ‡	11.9% (NYTS, 2014)*	

* Past 30 days or past month

† 18 years and older

‡ Every day or some days among women 18 years or older

§ Past year among 15-44 year olds

¶ 3 months before recent pregnancy

Any time during pregnancy

**Last 3 months of pregnancy or 3rd trimester

Table 3. Estimates of Alcohol Use Among Women from Selected Surveillance Systems, 2011 - 2013

Indicator	All women	Adolescent girls	Pregnant women
Alcohol use	48.3% (BRFSS, 2013)* † 43.7% (NHIS, 2013)* † 56.9% (NSDUH, 2013)* ‡ 54.1% (PRAMS, 2011) #	35.5% (YRBSS, 2013)* 11.9% (NSDUH, 2013)* ¶	9.4% (NSDUH, 2012-2013) § 7.5% (PRAMS, 2011) ††
Binge drinking #**	23.1% (BRFSS, 2013)* † 31.4% (NSDUH, 2013)* ‡ 23.1% (PRAMS, 2011) #	19.6% (YRBSS, 2013)* 12.4% (NSDUH, 2013)* ¶	2.3% (NSDUH, 2012-2013) § 3.1% (BRFSS, 2011-2013) ‡‡

*Past 30 days or past month

†18 years and older

‡ Aged 18-25

§Any time during pregnancy among women aged 15 - 44 years

¶Aged 12 – 20 years

#3 months before recent pregnancy

**Consuming 4 or more drinks in a 2-hour time span

†† Last 3 months of pregnancy or 3rd trimester

‡‡Consuming four or more drinks on an occasion at least one time in the past 30 days among pregnant women aged 18-44

Table 4. Estimates of Marijuana and Other Drug Use Among Women from Selected Surveillance Systems, 2011 - 2013

Indicator	All women	Adolescent girls	Pregnant women
Illicit drug use	11.4% (NSDUH, 2012-2013)*†	8.0% (NSDUH, 2013)* ‡	5.4% (NSDUH, 2012-2013) †
Marijuana use	7.6% (NSDUH, 2013)* §	6.2% (NSDUH, 2013)* ‡ 21.9% (YRBSS, 2013)*	3.9% (NSDUH, 2013)* †
Prescription drug use	7.2% opioid use (NHANES, 2007-2012)*	17.2% non-medical use (YRBSS, 2013)¶	

*Past 30 days or past month

† Aged 15 - 44 years

‡Aged 12 – 17 years

§Aged 18 – 44 years

¶Ever used

Pregnancy-Related Morbidity

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The quality of maternal health care is of worldwide concern, and its success is often weighed heavily on pregnancy-related mortality. With quality care drastically reducing maternal or pregnancy-related mortality rates in developed countries, new criteria are required to further define near-miss events or severe maternal morbidity that significantly impacts a woman's short- or long-term health prognosis. Expanded surveillance including pregnancy-related morbidity widens the scope of quality maternal health care.

PUBLIC HEALTH IMPORTANCE

Maternal or pregnancy-related mortality is one of the most important indicators of the quality of maternal health care, both nationally and internationally.[1] However, since maternal mortality is rare in developed countries, severe maternal morbidity (SMM) has been proposed as a supplemental indicator of the quality of maternal health care. [2] SMM and "near miss event" are often used interchangeably and have widely varying definitions. [2] Internationally, the most common definition of SMM is "an event when a woman almost died but survived through chance or as a result of adequate medical intervention received." [2] Another definition, proposed in the United States in a recent consensus document from the American College of Obstetricians and Gynecologists (ACOG) is the "unintended outcome of the process of labor and delivery that results in significant short-term or long-term consequences to a woman's health." [3]

Births with SMM often result in longer hospital stays and higher health care costs, [4] and are associated with long-term adverse outcomes for women, their newborns, and their partners. [5] Monitoring and understanding trends, developing and implementing public health programs, and/or implementing quality improvement interventions are all essential for making progress toward reducing SMM. During the last decade, *several* professional organizations (the *American College of Obstetricians and Gynecologists; the Society for Maternal-*

Fetal Medicine; the Association of Women's Health, Obstetric and Neonatal Nurses; and the American College of Nurse-Midwives) have called for developing reliable SMM surveillance. [3]

HISTORY OF DATA COLLECTION

Healthcare administrative databases usually include healthcare-related claims or hospital discharge data collected for billing, reporting, or tracking.[6] Diagnoses and procedures recorded using the *International Classification of Diseases, Ninth Revision, Clinical Modification* (ICD-9-CM) coding system and its later editions reflect the inpatient component of healthcare related to facility (hospital) costs. Although these data are not collected for research purposes, because there are no other sources of data on SMM in the United States, hospital discharge data and other secondary databases are used to monitor SMM. To address the need for surveillance of SMM at national, state, and local levels using hospital discharge data, CDC developed a standard methodology to identify pregnancy hospitalizations, along with a list of SMM indicators and their definitions.

The National Hospital Discharge Survey (NHDS) is a national probability survey of non-Federal short-stay hospitals in the United States,[7] which was conducted annually from 1965 through 2010. Initially, the NHDS was used to conduct special studies of selected complications of pregnancy (e.g., preeclampsia, placental abruption, and uterine rupture) and to evaluate trends in operative procedures for delivery in the United States. [7] During 1988 through 2007 the National Center for Health Statistics collected NHDS data from a national sample of about 500 hospitals (approximately 270,000 inpatient records), but during 2008 through 2010, the sample size was reduced to 239 hospitals.[8] Given that SMM is an index comprised of relatively rare events, the NHDS may not be the optimal data source, especially given the reduced sample size. For example, reliable measures of average length of stay and mortality could not be obtained from the NHDS for the majority of infrequent principal diagnoses, including influenza, spinal cord injuries, and acute post hemorrhagic anemia.[8]

Since 2005, CDC has used the Nationwide Inpatient Sample (NIS) for research on complications during pregnancy hospitalizations. NIS is the largest publicly available all-payer hospital inpatient care database in the United States.[9] NIS was developed through a federal/state/industry partnership and sponsored by the Agency for Healthcare Research and Quality (AHRQ). The NIS is sampled from hospitals and states that participate in the State Inpatient Databases (SID). From 1988 through 2011, NIS was a stratified sample of one-fifth of all US community hospitals selected according to five characteristics: rural/urban location; number of beds; region; teaching status; and ownership.

In addition to hospital characteristics, NIS contains up to 15 diagnosis and up to 15 procedure codes (International Classification of Diseases, Tenth Revision, Clinical Modification / Procedure Coding System (ICD-10-CM/PCS)), Diagnosis-Related Group (DRG) codes, patient demographics (age and sex), expected payer, length of stay, disposition, admission source and type, and dates of admission and discharge. [9] Researchers and public health practitioners use the NIS to track and analyze national trends in specific diseases and conditions as well as health care utilization, charges, and quality of health care. These characteristics make the NIS one of the best sources for monitoring SMM in the United States.

From 1988 to 2011, the NIS sampling frame grew from a sample of 758 hospitals and more than 5 million (25 million weighted) discharges in eight states, to a sample of 1,000 hospitals and more than 8 million (40 million weighted) in 46 states.[9] In 2014, the NIS sampling frame included more than 4,000 US community hospitals and 7 million discharges (35 million weighted) in 45 states covering more than 96 percent of the US population. [10] In addition to increasing the size of the NIS, the sampling methodology for the NIS has been updated to improve the precision and stability of estimates. Starting in 2012, a sample of one-fifth of all discharges from all US community hospitals was drawn using a more efficient self-weighting systematic design. This design ensures that every sample member of the target population was selected with the same overall probability[11] to account for patient characteristics such as diagnoses, age, and admission date. Additional changes included eliminating long-term acute care hospitals, dropping state identifiers to prevent state-level estimates, and replacing hospital identifiers with a pseudo-identifier. Finally, changes included estimating the total number of discharges in the universe by using observed State Inpatient Dataset (SID) discharge counts instead of estimated American Hospital Associations (AHA) discharge counts.[10]

Finally, state-specific files that contain all inpatient care records in participating states are available for data analysis at state level. The uniform format of the SID allows cross-state comparisons.

CDC SURVEILLANCE ACTIVITIES

Although CDC has used the NIS for research on pregnancy complications since 2005, the national and state surveillance of SMM was hindered by unavailability of standard surveillance indicators of SMM. To address this, CDC has developed methods for identifying delivery hospitalizations along with a proposed list of SMM indicators and their definitions. The process of proposing and revising SMM indicators relies on three underlying principles: 1) the proposed indicators must be measurable using state-level data that are available to the majority of states and preferably also to territories and large metropolitan areas; 2) the indicators must be based on existing evidence, previously proposed national and international conceptual models and frameworks;[12] and 3) it must be possible to reliably code the indicators using ICD-9-CM or later. When these conditions are met, indicators are considered appropriate for population level tracking, planning, and evaluation of public health interventions at the national and state level.

In this chapter and all other surveillance reports, CDC identifies delivery hospitalizations using the enhanced identification method. Using this method, the following codes are applied in a hierarchical manner: 1) outcome of delivery (ICD-9-CM diagnosis code = V27); 2) normal delivery (ICD-9-CM diagnosis code = 650); 3) diagnosis-related group (DRG) delivery codes; and 4) ICD-9-CM procedure codes for selected delivery-related procedures; in all cases abortive pregnancy outcome hospitalizations were excluded.[13] This method has been shown to improve the accuracy of identifying delivery hospitalizations, especially for women with severe morbidity. The use of this algorithm for identification of the delivery hospitalizations overcomes the limitations of other methods that underestimate the severe maternal morbidity by as much as 9% to 40%.[13] The specific ICD-9-CM codes for this enhanced method and the matching ICD-10-CM/PCS codes are listed in Appendix 1.

The original list of 25 SMM indicators was published in 2011 and incorporated three major criteria for identifying SMM:[14] 1) disease-specific criteria (i.e., eclampsia, severe pulmonary embolism) – 8 indicators; 2) management-based criteria (i.e., need for a blood transfusion or hysterectomy) – 7 indicators; and 3) organ system dysfunction-based criteria (i.e., acute renal failure, shock) – 10 indicators.

In 2015, CDC, ACOG, and the Alliance for Innovation on Maternal Health collaborated to conduct a series of reviews to make recommendations for updating the indicators. The recommendations took into account results from available validation studies, feedback from stakeholders, and the need to transition from ICD-9-

CM to ICD-10-CM/PCS. During the review process, subject-matter experts and public health practitioners were asked to provide input on the following: 1) new indicators to be added within existing categories; 2) current indicators that need to be modified; and 3) current indicators that should be removed. The updated list of ICD-9-CM indicators showing comparability with ICD-10-CM indicators is provided in Appendix 2.

Availability of SMM indicators allows CDC to use the NIS for national and state level SMM surveillance. CDC annually publishes the updated sets of SMM indicators and their rates per 10,000 delivery hospitalizations (with additional references and detailed background information) on CDC's website. [15]

GENERAL FINDINGS

Annual rates of SMM presented in this chapter were calculated using data from the NIS for 1993 to 2014, the algorithm to identify delivery hospitalizations (Appendix 1) and the list of SMM indicators (Appendix 1). Rates in this chapter are expressed per 10,000 delivery hospitalizations. Annual rates for the updated 18 SMM indicators, for selected years during 1993 to 2014, are presented in Table 1.
Rates for all types of SMM increased from 1993 to 2014, except for severe complications of anesthesia and heart failure, eclampsia, puerperal cerebrovascular disorders, and amniotic embolism. The largest relative increases (by 200% or more) were observed for acute myocardial infarction or aneurysms, blood transfusion, acute renal failure and adult respiratory distress syndrome. About 18,000 (0.5%) or 55,000 (1.4%) of all delivery hospitalizations had at least one SMM indicator in 1993 and 2014 respectively.

In 2014, blood transfusion was documented among more than 1% of all delivery hospitalizations and became the most prevalent SMM indicator (Figure 1). After blood transfusions, the most prevalent SMM indicators were hysterectomy, ventilation or temporary tracheostomy, disseminated intravascular coagulation, adult respiratory distress syndrome, and acute renal failure.

USING DATA FOR ACTION

CDC surveillance reports on SMM are the most current and reliable source for information on the epidemiology of SMM in the US, and these data can be used as benchmarks for state[16] [17] or city level analyses,[18] federal agency reports, [19] and for international comparisons among countries. [20] [21]

The list of these SMM indicators has also been successfully used for the screening of medical records of delivery hospitalizations with SMM. [22] This screening process is a part of a nationally recommended process to review cases of SMM by multidisciplinary committee to identify true cases of SMM and identify opportunities for improvement in care at the facility level. [23]

During 2013 to 2015, the National Partnership for Maternal Safety introduced several Patient Safety Bundles to guide care for maternal conditions related to SMM such as severe hypertension, obstetric hemorrhage and venous thromboembolism. The SMM indicators has the potential to be used for evaluation. [24] For example, the California Maternal Quality Care Collaborative (CMQCC), a university-based multidisciplinary and multistakeholder collaborative, used the composite SMM indicator as their primary outcome measurement. The California quality improvement guidelines on reductions in SMM was implemented among patients with hemorrhage at 99 collaborative hospitals from January 2015 to March 2016. Hospitalizations with obstetric hemorrhage were identified by ICD-9-CM and 10-CM/PCS diagnosis codes for antepartum or postpartum hemorrhage, placenta previa, abruptio placentae, or the procedure code for transfusion. In comparison to non-participating hospitals, participating hospitals reported significant reductions in the composite SMM indicator among patients with hemorrhage (20.8% vs. 1.2%). [24]

DATA GAPS AND LIMITATIONS

A number of limitations exist for using NIS for national and state level SMM surveillance. First, our initial identification of SMM during delivery hospitalizations is based solely on ICD-9-CM codes. In a recent study, the Positive Predictive Value (PPV) for SMM based solely on ICD-9-CM codes ranged from a high for hysterectomy (100%) and ventilation (92%) to a low for severe anesthesia complications (55%) and puerperal cerebrovascular disorders (55%).[25] Positive Predictive Value (PPV) was calculated as the number of true positives (where the ICD-9-CM code from billing record and clinical diagnosis from medical record agree on a positive diagnosis) divided by the sum of all positives identified from parturient billing records, which include true positives and false positives. Research has shown that when objective supportive evidence is available (e.g., laboratory values or procedure documentation), PPV values tend to be much higher than when only clinical data (e.g., signs and symptoms) are available to support the ICD-9-CM codes. [26, 27, 28] Additional factors that also may contribute to low PPV include the lack of the coder's training and/or experience, and ICD code ambiguity or omissions.

The transition from ICD-9 to ICD-10 procedure codes may present another limitation. Although, historically, a high PPV had been reported for ICD-9 procedure codes, ICD-10 procedure codes, used by healthcare providers after October 1, 2015, may have a low PPV, especially for some procedures. For example, the ICD-10-PCS guidelines for transfusion of blood product require substantially more detail, and thus, a 10-fold increase in codes over the nine ICD-9-CM codes for blood transfusions. In addition, coding of blood transfusions for in-hospital records is often defined by hospital-level policies that may allow for optional ICD-10-PCS coding for transfusions.

While the proposed list of SMM indicators is appropriate for surveillance, ICD codes do not incorporate the clinical and/or laboratory details necessary to meet specific case definitions. For example, the most common indicator of SMM, blood transfusion, does not specify the number of units transfused, which highly correlates with severity. The NIS does not contain specific codes for ICU admissions, which could be used as an additional indicator of SMM severity. To overcome these limitations, case ascertainment of SMM at the hospital level for reviewing quality of care has been proposed using two components: ICU admission and/or transfusion of ≥4 U of packed red blood cells. [24]

While marked racial-ethnic disparities in maternal morbidity and mortality have been reported in previous studies, [29, 30] up to 20% of data in the 1993 NIS was missing information on race-ethnicity. Although this percentage decreased to 6% in 2012, this missing information remains a potential bias for reporting SMM rates and ratios by race-ethnicity because it is not missing at random.[31] For example, in 2012 data on race was suppressed in California for some discharges with sensitive conditions (e.g., HIV and AIDS). In all of Louisiana and a large hospital system in Utah, no information is collected on Hispanic ethnicity.[31] Moreover, Minnesota, North Dakota, and West Virginia do not collect data on race-ethnicity.

Finally, while data on SMM during delivery and early postpartum hospitalizations (during the first six weeks after delivery) are monitored as a part of surveillance efforts, NIS does not have the capability to capture hospitalizations with late SMM (during the first year after delivery starting at seven weeks after delivery) [32] that are unlikely to be recognized and then coded as postpartum or pregnancy-associated hospitalizations. In addition, the ICD-10-CM/PCS format may be more complicated for identifying postpartum admissions than the ICD-9-CM format.

FUTURE ISSUES

Assessing the impact of the development and implementation of public health and/or quality improvement interventions to reduce SMM would not be possible without a reliable surveillance system for SMM. Hospital discharge data continue to be one of the few available data sources to track SMM, and so it is important to find opportunities to strengthen existing surveillance efforts by integrating hospital discharge data with other primary databases (pregnancy drug registries, surveys, electronic medical records, etc.) and/or secondary databases (birth certificates, death certificates, etc.). For instance, national birth certificate data on several SMMs became available beginning with data year 2016. The available SMM in birth certificate data that are not available at NIS include unplanned hysterectomy, admission to intensive care unit, and unplanned operating room procedure following delivery. Three other variables (maternal transfusion, third or fourth degree perinatal lacerations, and ruptured uterus) are available in both datasets. Thus, the availability of this information allows carrying validation studies using linked hospital discharge and administrative data and/or using these data for surveillance.

Information obtained from a facility-level review of SMM also offers a promising approach to address the current problem of growing SMM rates in the United States. In a retrospective cohort study performed by a California hospital of all delivery hospitalizations, contributing factors for improvement in care were classified into three groups: patient, provider, and system factors that contributed to SMM.[22] System contributors included policies and procedures which affected outcome, delays in transfer to a higher level of care, and communication. Provider factors included diagnosis or treatment delays, inappropriate treatment choices, and flawed management hierarchy. Patient contributing factors included: 1) patient delay in seeking health care or adhering to medical advice; 2) underlying medical or physical conditions that were suboptimally controlled during the pre-pregnancy period; and/or 3) pregnancy complications. Findings from this study indicated that 13.6% of SMM had system contributors, 78.8% had provider contributors and 28.8% had patient contributors. Identifying factors that contributed to SMM at facility level is a critical first step for Quality Improvement (QI) initiatives for reducing prevalence of SMM.

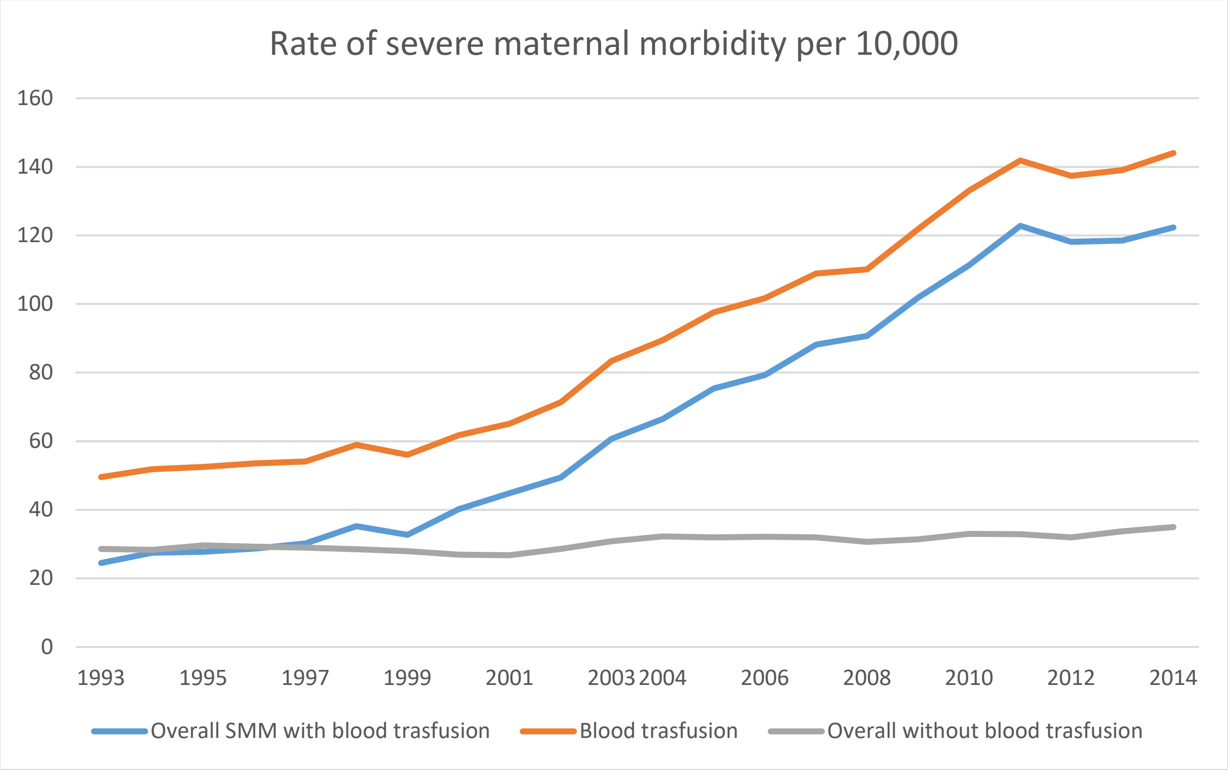
Table 1. Rates of Severe Maternal Morbidity per 10,000 delivery hospitalizations among women aged 12-55 years, by indicator, National Inpatient Sample,[2] 1993-2014, (only selected years are shown here). (N total weighted = 85,005,198).

Severe maternal morbidity indicator	Rate and 95% of confidence intervals per 10,000 delivery hospitalizations.											
	1993 N weighted = 18,386	1994	1997	1998	2001	2002	2005	2006	2009	2010	2013	2014 N weighted = 54,750	% change from 1993 to 2014
Cardiac arrest, fibrillation/conversion of cardiac rhythm	0.4 (0.1)	0.7 (0.1)	0.8 (0.1)	0.7 (0.1)	0.6 (0.1)	0.7 (0.1)	1.1 (0.1)	0.9 (0.1)	1.0 (0.1)	1.2 (0.1)	1.0 (0.1)	1.1 (0.1)	175
Acute congestive heart failure or pulmonary edema	2.6 (0.3)	3.1 (0.3)	3.7 (0.4)	3.3 (0.3)	3.3 (0.3)	3.2 (0.2)	3.8 (0.3)	3.8 (0.3)	2.9 (0.3)	2.9 (0.2)	2.7 (0.2)	2.4 (0.2)	-7.7
Adult respiratory distress syndrome	2.0 (0.2)	2.4 (0.2)	2.6 (0.2)	2.8 (0.2)	2.8 (0.2)	2.9 (0.2)	4.0 (0.2)	4.1 (0.3)	5.1 (0.3)	6.0 (0.4)	5.3 (0.3)	6.1 (0.3)	205
Acute renal failure	1.3 (0.2)	1.2 (0.1)	1.7 (0.2)	1.8 (0.2)	1.7 (0.1)	1.8 (0.2)	2.3 (0.2)	2.7 (0.2)	3.6 (0.3)	4.2 (0.3)	5.0 (0.3)	5.2 (0.3)	300
Disseminated intravascular coagulation	6.0 (0.5)	5.6 (0.4)	6.0 (0.4)	5.6 (0.4)	5.3 (0.3)	6.4 (0.4)	7.2 (0.8)	7.0 (0.7)	7.2 (0.4)	8.2 (0.5)	7.6 (0.3)	7.2 (0.3)	20
Shock	1.1 (0.1)	0.9 (0.1)	1.0 (0.1)	1.1 (0.1)	0.9 (0.1)	1.1 (0.1)	1.6 (0.2)	1.6 (0.2)	2.3 (0.2)	2.4 (0.2)	2.5 (0.2)	3.0 (0.2)	172.7
Eclampsia	4.1 (0.3)	3.7 (0.3)	3.6 (0.3)	4.0 (0.3)	4.0 (0.3)	3.8 (0.3)	4.1 (0.4)	3.5 (0.2)	3.0 (0.2)	2.6 (0.2)	2.2 (0.2)	2.0 (0.2)	-51.2
Puerperal cerebrovascular disorders	1.3 (0.2)	1.4 (0.2)	1.4 (0.2)	1.6 (0.2)	1.2 (0.1)	1.6 (0.2)	1.6 (0.1)	1.6 (0.1)	1.1 (0.1)	1.1 (0.1)	1.1 (0.1)	0.9 (0.1)	-30.8
Heart failure or arrest during surgery or procedure	0.5 (0.1)	0.7 (0.1)	0.5 (0.1)	0.6 (0.1)	0.4 (0.1)	0.6 (0.1)	0.5 (0.1)	0.8 (0.2)	0.6 (0.1)	0.5 (0.1)	0.3 (0.1)	0.3 (0.1)	-40

Acute myocardial infarction/Aneurysm	0.1 (0.0)	0.1 (0.1)	0.1 (0.1)	0.1 (0.0)	0.2 (0.1)	0.1 (0.0)	0.3 (0.1)	0.2 (0.0)	0.2 (0.1)	0.3 (0.1)	0.3 (0.1)	0.2 (0.1)	300
Air and thrombotic embolism	0.8 (0.1)	0.5 (0.1)	0.6 (0.1)	0.4 (0.1)	0.8 (0.1)	1.0 (0.1)	1.2 (0.1)	1.1 (0.1)	1.1 (0.1)	1.1 (0.1)	0.9 (0.1)	0.9 (0.1)	12.5
Amniotic fluid embolism	0.2 (0.0)	0.3 (0.1)	0.4 (0.1)	0.2 (0.1)	0.3 (0.1)	0.3 (0.1)	0.5 (0.1)	0.3 (0.1)	0.3 (0.1)	0.4 (0.1)	0.3 (0.1)	0.2 (0.1)	0
Sickle cell disease crisis	. (.)	. (.)	. (.)	. (.)	. (.)	. (.)	0.7 (0.2)	0.6 (0.1)	0.4 (0.1)	0.7 (0.1)	0.5 (0.1)	0.5 (0.1)	.
Severe anesthesia complications	2.3 (0.3)	2.1 (0.3)	1.4 (0.2)	1.5 (0.2)	1.0 (0.1)	1.0 (0.1)	0.9 (0.1)	0.8 (0.1)	0.5 (0.1)	0.5 (0.1)	0.5 (0.1)	0.3 (0.1)	-87
Sepsis	2.4 (0.3)	2.2 (0.2)	2.2 (0.2)	2.2 (0.3)	1.8 (0.2)	2.0 (0.2)	2.1 (0.2)	2.2 (0.2)	2.5 (0.2)	2.6 (0.2)	3.1 (0.2)	4.2 (0.3)	75
Hysterectomy	6.9 (0.5)	6.7 (0.4)	7.6 (0.4)	7.2 (0.4)	7.5 (0.4)	7.6 (0.4)	8.0 (0.4)	8.2 (0.5)	9.3 (0.5)	8.6 (0.5)	10.6 (0.4)	10.7 (0.4)	55.1
Ventilation/temporary tracheostomy	4.1 (0.4)	4.4 (0.3)	5.0 (0.3)	4.9 (0.3)	4.7 (0.3)	5.1 (0.3)	5.4 (0.3)	5.4 (0.3)	6.7 (0.4)	7.5 (0.5)	6.6 (0.3)	7.9 (0.4)	92.7
Blood transfusions	24.5 (2.5)	27.4 (2.1)	30.2 (2.0)	35.2 (2.1)	44.8 (2.4)	49.4 (2.7)	75.4 (5.1)	79.3 (3.7)	101.9 (4.5)	111.3 (4.9)	118.5 (2.6)	122.3 (2.9)	399.2
Overall with blood transfusions	49.5 (2.9)	51.8 (2.3)	54.1 (2.2)	59.0 (2.3)	65.1 (2.5)	71.3 (2.9)	97.6 (5.7)	101.7 (4.0)	121.9 (4.5)	133.1 (5.0)	139.0 (2.7)	144.0 (3.1)	190.9
Overall without blood transfusions	28.6 (1.4)	28.3 (1.2)	28.9 (1.2)	28.5 (1.1)	26.8 (1.0)	28.6 (1.2)	31.9 (1.6)	32.1 (1.4)	31.4 (1.1)	33.0 (1.3)	33.7 (0.9)	35.0 (0.9)	22.4

https://www.hcup-us.ahrq.gov/nisoverview.jsp

Figure 1.


Rate of severe maternal morbidity per 10,000
160
140
120
100
80
60
40
20
0
1993
1995
1997
1999
2001
2003
2004
2006
2008
2010
2012
2014
Overall SMM with blood trasfusion
Blood trasfusion
Overall without blood trasfusion

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Pregnancy-Related Mortality

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Deaths of women during pregnancy represent a major indicator of the quality of health and health care in a country. The clinical care system, as well as the public health infrastructure in the United States, has focused efforts on improving the outlook for mothers and their infants over the past several decades. Ironically, rates of maternal mortality have risen in the United States in the past 30 years. This rise primarily reflects the marked improvements in data collection and reporting at the local, state, and national levels. However, chronic disease has increased among women of reproductive age and likely impacts rates of maternal mortality. This chapter looks at past and current reporting methods and systems and sets the challenge to health officials and political systems to continue to improve pregnancy and infant health.

PUBLIC HEALTH IMPORTANCE

Maternal mortality is a major global concern and, along with infant mortality and life expectancy, one of the best measures of the quality of health and health care in a country. Although at historically low levels in most developed countries, maternal mortality remains an important public health problem in the United States.[1,2] Two recent global reports identified the United States as one of the few countries in the world in which maternal mortality increased over the last decade.[1,3] Data from CDC's Pregnancy Mortality Surveillance System (PMSS; surveillance methods and definitions described below) show that the pregnancy-related mortality ratio increased steadily from 7.2 deaths per 100,000 live births in 1987 to a high of 17.8 deaths per 100,000 live births in 2011 (Figure 1).[2,4] Despite this clear change, the reasons for the overall increase in pregnancy-related mortality are unclear. The use of computerized data linkages by states changes the way causes of death are coded (i.e., transition from ICD-9 to ICD-10 in 1999), and the addition of a set of checkboxes on the 2003 standard death certificate to indicate the temporal relationship of a woman's death to pregnancy have likely increased the numbers of pregnancy-related deaths identified as such over time.[4]

Also, many studies show that an increasing number of pregnant women in the United States have chronic health conditions, such as hypertension, diabetes, and chronic heart disease, and the presence of such conditions may put a pregnant woman at higher risk of complications of pregnancy.[5-7]

Approximately 700 pregnancy-related deaths are reported in the United States annually.[2] For every pregnancy-related death, about 80 women had severe pregnancy complications documented during their delivery hospitalization.[8] Understanding the characteristics of women who have both risk factors for pregnancy-related death and pregnancy complications is essential to developing strategies to prevent both mortality and severe morbidity associated with pregnancy complications. This understanding is especially important in addressing the most striking disparity in maternal health in the country; black women have over 3 times higher risk than white women of dying from pregnancy complications. This pattern difference has persisted for over 25 years (Figure 2).[2]

The majority of maternal deaths are preventable.[9] The National Partnership for Maternal Safety, under the umbrella of the Council on Patient Safety in Women's Health Care brings together clinicians, professional organizations, federal health agencies, and many other stakeholders in women's health to address the three most common preventable causes of maternal mortality and morbidity in the United States: obstetric hemorrhage, severe hypertensive disorders of pregnancy, and peripartum venous thromboembolism.[10,11] The National Partnership proposed an action plan designed to provide patient reference materials called "safety bundles" that address the three conditions. The bundles contain outlines of recommended protocols and materials important to safe care. Some of the contents are tailored to meet local conditions. In addition, the National Partnership advocates instituting three unit improvement bundles for obstetric services: 1) a structured approach for the recognition of early warning signs and symptoms; 2) structured internal case reviews to identify systems improvement opportunities; and 3) support tools for patients, families, and staff who must deal with an adverse pregnancy-related outcome.[11] Research has shown that when protocols and clinical policies are implemented in a systematic way, adverse maternal health outcomes can be reduced.[12,13] National pregnancy-related mortality surveillance is needed to evaluate results from such quality improvement programs and to track changes in trends in mortality over time.

HISTORY OF DATA COLLECTION

National vital statistics have served as the only national source of information on numbers, ratios, and causes of pregnancy-related deaths in the United States for many years. These data captured not only the important decline in mortality from over 800 deaths to about 7 deaths per 100,000 live births from 1900 through 1998, but also the increase in mortality since then. Whether this more recent increase is real or reflects more accurate and complete ascertainment methods (i.e., transition to using ICD-10 versus ICD-9 for cause-of-death coding in 1999; introduction of a checkbox to ascertain pregnancy/postpartum status at the time of death in 2003) is unknown (Figure 3). However, given the between-state variation in implementing the 2003 standard death certificate that includes the pregnancy check-box, the National Center for Health Statistics stopped publishing a national maternal mortality rate in 2007.[14] The beginning of the monotonic decline in pregnancy-related mortality shown in Figure 1 coincides with the introduction of penicillin in 1928, but a variety of factors have likely contributed to the subsequent substantial decline. Some possible contributing factors include higher standards of living, improved nutrition, and higher levels of sanitation. Others include improvements in hospitals and hospital deliveries, implementation of aseptic techniques, medical advances, and availability of blood transfusions.

Since 1972, CDC has conducted nationwide surveillance and investigation of abortion-related deaths based on four main sources of information: state vital statistics, state health department data, reports from state-based Maternal Mortality Review Committees, and reports from individuals.[15] In 1986, CDC began collaborating with the Maternal Mortality Special Interest Group of the American College of Obstetricians and Gynecologists (ACOG), the Association of Vital Records and Health Statistics (AVRHS), and state and local health departments to establish the comprehensive, national Pregnancy Mortality Surveillance System (PMSS). This ongoing surveillance system represents a successful collaboration among CDC and all 50 US states, New York City and Washington DC to identify and characterize maternal deaths in the United States. Information collected is presented and updated regularly on the CDC website and published as epidemiologic studies in the peer-reviewed literature.[4,2] A CDC/ACOG Maternal Mortality Study Group provides advice to CDC on an ongoing basis about the implementation of this surveillance. This study group includes representatives from CDC and other federal agencies, ACOG, state health departments, and other provider organizations with broad interest and expertise in maternal health.

State and local pregnancy mortality information has historically been obtained from state vital statistics reports and publications based on vital records linkage, review of death certificates, medical records, or from autopsy reports or reports by state-based Maternal Mortality Review Committees. About two-thirds of the states have functional Maternal Mortality Review Committees in place.[16] Largely, these multi-disciplinary committees, like PMSS, aim to identify, review, and analyze maternal deaths using core data sources (e.g., state/local vital statistics, hospital discharge records, and autopsy reports) and other available data sources (e.g., police reports, specific statewide programs).[4,16] Given that states have access to sources of information that are not available at the national level, data from state-based Maternal Mortality Review Committees are considered the "gold standard." These data and the findings of state committees can be used as justification for taking needed action.

CDC SURVEILLANCE ACTIVITIES

At the time of this monograph publication, NVSS data was not available to describe maternal deaths. More recent information is available at https://www.cdc.gov/nchs/maternal-mortality/index.htm. For this purposes of this chapter, PMSS data is described in detail.

PMSS aims to identify all pregnancy-related deaths in the United States, starting with those reported through the state vital statistics systems, and to classify causes of death more accurately into meaningful clinical categories. The CDC/ACOG Maternal Mortality Study Group introduced definitions and coding procedures for use in conducting pregnancy mortality surveillance. Two important terms and definitions that are being used by CDC, and increasingly by states and researchers, differentiate between pregnancy-associated and pregnancy-related deaths, defining them as follows:

- A **pregnancy-associated death** is the death of any woman from any cause while pregnant or within one calendar year of termination of pregnancy, regardless of the duration and whether the pregnancy is intra- or extra-uterine.
- A **pregnancy-related death** is a pregnancy-associated death resulting from: a) complications of the pregnancy itself; b) the chain of events initiated by the pregnancy that led to death; or c) aggravation of an unrelated condition by the physiologic or pharmacologic effects of the pregnancy that subsequently caused death.

These definitions differ from the definitions of maternal death per the International Classification of Diseases, 10th revision.[1] Yet, the term “pregnancy-associated death” was preferred by the study group to “maternal death” because some of these deaths might not be related to pregnancy. Moreover, since some pregnancies result in spontaneous and medically-induced abortions, ectopic pregnancies, and gestational trophoblastic neoplasia, the term “pregnancy-associated” allows for inclusion of all types of pregnancy outcomes. The CDC/ACOG definitions also extend the interval between the end of pregnancy and the death of the woman from 42 days to 1 year for case identification and review.

Case Finding and Data Collection

PMSS was designed to rely on multiple reporting sources for case identification and on multiple information sources for data collection. Use of multiple data sources is expected to improve the completeness of reporting and the accuracy of case ascertainment and to result in more accurate classification of possible associated deaths. However, the core data source for PMSS is state vital statistics. Every year, 52 reporting areas (i.e., 50 US states, New York City, and Washington, DC) are asked to submit to CDC’s Division of Reproductive Health de-identified (i.e., identity of subject not revealed) hard or electronic copies of death certificates for all deaths occurring during or within 1 year of pregnancy regardless of the cause of death or the duration of pregnancy, as well as data from matching birth or fetal death certificates.[4] Additional, although less systematic, sources of information for PMSS include reports by public health agencies, professional organizations, individual health-care providers, as well as media reports, including computerized searches of LexisNexis. To allow for accurate classification and understanding of the risk factors associated with pregnancy-related deaths, PMSS takes into account the interaction of five main factors in classifying deaths:

- The outcome of pregnancy (e.g., spontaneous or induced abortion, ectopic pregnancy, live birth).
- The method of pregnancy termination (e.g., vaginal delivery, cesarean section, dilation and curettage (D&C)).
- The time of death in relation to pregnancy termination (e.g., during pregnancy, during labor and delivery, or postpartum).
- The cause of death (e.g., hemorrhage, sepsis, embolism).
- The underlying obstetric or medical condition that precipitated the death (e.g., placenta previa, chorioamnionitis, diabetes).

Each death is reviewed to confirm that it is pregnancy-related. PMSS requires that a pregnancy-related death satisfies both temporal and causal criteria. The temporal association between the pregnancy status and death is ascertained in one of the following ways: a) presence of a selected pregnancy check box on the death certificate indicating that the woman was pregnant at the time of death or describing an interval between the end of a pregnancy and death; b) words or codes indicating a pregnancy on the death certificate; c) presence of a note indicating the duration of complications causing or events leading to death on the death certificate; or d) availability of a birth or fetal death certificate within 1 year of the woman's death. The causal association between the pregnancy status and death is based on the reported cause of death, the interval between pregnancy termination and death, and the pathophysiology of pregnancy complications. Deaths attributable to a medical condition exacerbated but not unique to pregnancy are not considered pregnancy-related if the temporal association between the pregnancy status and death is known solely from a pregnancy check box stating, "pregnant within a year." If the checkbox states, "pregnant within 42 days" or "pregnant within 90 days," the death may or may not be considered pregnancy-related depending on the cause of death and the pathophysiologic relationship between the cause and the event of pregnancy.

CDC conducts in-depth investigations beyond the review of information routinely collected from states only for deaths potentially related to induced abortions. For those cases, we request autopsy reports and hospital records of women by contacting state health departments in the states in which such cases occurred.

Classification by immediate cause of death, associated conditions, and outcome of pregnancy is made after the review of each death. PMSS differentiates between the immediate and underlying causes of death as stated on the death certificate, associated obstetrical and medical conditions or complications, and the outcome of pregnancy. For example, if a woman died of a hemorrhage that resulted from a ruptured ectopic pregnancy, the immediate cause of death would be classified as hemorrhage, the associated obstetrical condition would be classified as ruptured fallopian tube, and the outcome of pregnancy would be ectopic pregnancy. This classification scheme allows us to analyze the chain of events that led to death. For PMSS, clinically trained medical epidemiologists review all the information available for each death. They determine the cause of death, record the pregnancy outcome and associated medical conditions, along with demographic and obstetrical variables that are available in vital records. Information on pregnancy outcomes and causes of death are reviewed in duplicate to increase the consistency in their ascertainment. Cause-of-death coding is based on a 10-group classification system that allocates causes of death into the following categories: hemorrhage, infection, amniotic fluid embolism, thrombotic pulmonary or other embolism, hypertensive disorders of pregnancy, anesthesia complications, cerebrovascular accidents, cardiomyopathy, cardiovascular disease, and non-cardiovascular medical conditions. A CDC manual for data coding serves as the basis for developing the PMSS data base.

Data Analysis and Interpretation

Upon investigation of all deaths, reported data are abstracted and entered into computerized files. To ensure confidentiality, individual identifiers are removed from all records, and access to the surveillance data is restricted to CDC staff members responsible for coding and analyzing the data. All data and results of analysis are disseminated in a manner that preserves the anonymity of each individual listed in the death reports.

To facilitate comparisons and identify groups at special risk, PMSS data are used to calculate pregnancy mortality ratios. The pregnancy mortality ratio is defined as the number of pregnancy-related deaths per 100,000 live births; this is a ratio and not a rate because deaths in the numerator may not all have been associated with a live birth. However, the number of live births is accurately known, whereas the number of pregnancies (all live births, still births, induced and spontaneous abortions, ectopic pregnancies, and molar pregnancies) can only be estimated. Outcome-specific pregnancy mortality rate is defined as the number of deaths due to a pregnancy outcome per 100,000 pregnancies with the same outcome (e.g., ectopic pregnancy, induced abortion, live birth). This rate is used to determine the risk of death associated with specific pregnancy outcomes.

GENERAL FINDINGS

To draw reliable conclusions regarding specific groups of women, pregnancy outcomes, and causes of death, more complex analyses are conducted on pooled years of data. Abortion-related deaths are analyzed separately, and given the small number of reported cases each year in the United States, analyses are performed on 10 or more years of data for meaningful results. One such analysis included the period from 2006 through 2010 for pregnancy-related deaths and the 1998 through 2010 period for abortion-related deaths.[2,17]

Overall, 8,645 deaths were reported to CDC for the 2006 through 2010 period. A review of available records determined that 3,358 of these deaths were pregnancy-related. The annual pregnancy-related mortality ratio ranged from 14.5 deaths per 100,000 live births in 2007 to 17.8 deaths per 100,000 live births in 2009, and the corresponding ratio for the 2006 through 2010 period was 16.0 deaths per 100,000 live births (Figure 1). During the latter period, 40% of all pregnancy-related deaths were among non-Hispanic white women, 35.5% were among non-Hispanic black women, and 17.7% were among Hispanic women. Race/ethnicity-specific pregnancy-related mortality ratios during 2006 through 2010 were 12.0, 38.9, 11.7, and 14.2 deaths per 100,000 live births, respectively, for non-Hispanic white, non-Hispanic black, Hispanic, and women of other races. The pregnancy-related mortality ratio for non-Hispanic black was 3.2 times that for non-Hispanic white women during 2006 through 2010.[2] Pregnancy-related mortality ratios increased with maternal age for all women of all race/ethnicities, and it was among non-Hispanic black women that the interaction between age and race was highest.[2]

About 60% of all 2006 through 2010 pregnancy-related deaths occurred after live births, almost 5% occurred after still births, 3% were associated with ectopic pregnancies, and another 3% were related to abortions (induced legal and spontaneous). Around 20% of women died with the fetus still *in utero*, and the outcome of pregnancy was unknown for 10% of women whose deaths were reported.[2] The interval between the end of pregnancy and death was known for 87% of the deaths: about 23% of deaths occurred during pregnancy; 16.6% on the day of delivery or pregnancy termination; 47.5% within 41 days postpartum; and 13.5% of women died after 42 days postpartum.[2]

Seven of the 10 groups of causes of death each contributed from 9.4% to 14.6% of all pregnancy-related deaths during 2006 through 2010 (Figure 4). Cardiovascular conditions ranked first (14.6%), followed by infection (13.6%), noncardiovascular medical conditions (12.7%), cardiomyopathy (11.8%), hemorrhage (11.4%), thrombotic pulmonary or other embolism (9.6%), and hypertensive disorders of pregnancy (9.4%). Comparison of proportionate maternal mortality (i.e., percentage of all pregnancy-related deaths) by cause of death for four periods since PMSS was established (1987–1990; 1991–1997; 1998–2005; and 2006–2010) shows that the contribution of traditional causes of mortality (e.g., hemorrhage, hypertensive disorders of pregnancy, embolism, anesthesia complications) continued to decline, whereas reports of chronic medical conditions, especially cardiovascular conditions, increased over time.[2]

In the period 1998 through 2010, approximately 16.1 million induced abortions were performed in the United States; 108 women were reported to have died from abortion-related complications during this period, for a mortality rate of 0.7 deaths per 100,000 induced-abortion procedures.[17] The mortality rate increased with gestational age, from 0.3 to 6.7 deaths per 100,000 induced-abortion procedures performed at or before 8 weeks of gestational age and at 18 weeks or beyond, respectively.[17] A majority of abortion-related deaths at 13 weeks of gestation or less were associated with anesthesia complications and infection, whereas a majority of abortion-related deaths at over 13 weeks of gestation were associated with infection and hemorrhage.[17] In 20 of the 108 cases, abortion is known to have been performed as a result of a severe medical condition where continuation of the pregnancy threatened the woman's life.[17]

USING DATA FOR ACTION

Despite surveillance study limitations, the large numbers of data on deaths collected through PMSS allow for analyses and data-driven planning and actions that are not possible using only state and local data. This national PMSS surveillance system that ascertains, reviews, and analyzes maternal mortality data is needed to monitor national trends, track progress in achieving national goals, and evaluate national programs aiming to reduce maternal mortality in the country.

Results from recent quality improvement efforts demonstrated that maternal mortality can be further reduced in developed countries. In the United Kingdom, improved risk assessment of patients and adequate thromboprophylaxis led to an important decline in deaths from venous thromboembolism in recent years.[12] Clark et al., demonstrated that a policy of universal use of pneumatic compression devices for all women who underwent cesarean delivery in Hospital Corporation of America facilities resulted in a substantial decrease in postoperative deaths from pulmonary embolism, whereas a policy that involved automatic, rapid antihypertensive therapy for defined blood pressure thresholds eliminated deaths from in-hospital intracranial hemorrhage and reduced overall deaths from preeclampsia.[13] In the United States, PMSS data have been used for planning and to prioritize quality improvement efforts by the Council on Patient Safety in Women’s Health Care.[10] State perinatal quality collaboratives (PQCs), which are networks of perinatal care providers and public health professionals working to improve pregnancy outcomes for women and newborns by advancing evidence-based clinical practices and processes through continuous quality improvement, use maternal mortality and morbidity data from both state and national levels to identify care processes that need to be improved.[18] Many states currently have active PQCs, and others are being developed. CDC's Division of Reproductive Health currently funds 13 states for the State-Based PQCs Cooperative Agreement. The integration of PMSS and MMRC data inform these quality improvement initiatives. For example, from 2013 through 2014, there was a 12% reduction in severe complications among women with severe preeclampsia/eclampsia in hospitals that participated in the Preeclampsia Collaborative in California.

DATA GAPS AND LIMITATIONS

Pregnancy mortality surveillance based only on vital statistics reports has limitations as a source of numbers, ratios, and causes-of-death. However, linkages between deaths of women and either birth or fetal death records considerably aid the identification of pregnancy-related deaths and the information available for each case. Such linkages are performed by most states before they report data to the PMSS. For cases in which there is no linkage, the "pregnancy checkbox" on the death certificate may aid in case identification. However, the unequal implementation by states of the 2003 US standard death certificate that includes a pregnancy checkbox, and the checkbox format in some states being different from the recommended standard, have introduced ascertainment bias in PMSS and NVSS data. The clinical information available on death certificates is limited and the sequence of contributing and underlying cause-of-death information is often incorrectly recorded.

FUTURE ISSUES

The ultimate objective of PMSS is to contribute to the reduction of pregnancy morbidity and mortality in the United States. To reduce the health risks associated with pregnancy, we should direct our attention to reducing all morbidity associated with pregnancy. Pregnancy-related or -associated mortality is only the tip of the iceberg. CDC estimates that over 60,000 women experience severe maternal complications during delivery-related hospitalization.[8] Close partnership among CDC, ACOG, other public health agencies (local and federal), and professional organizations of clinical providers, particularly those caring for pregnant women, is needed to meet this objective.

Medical advances currently allow some women with severe medical conditions, some of which used to be contraindications for pregnancy, to carry single and multiple pregnancies to term. *In vitro* fertilization techniques allow older women, some of whom may have chronic medical conditions, to become pregnant. Thus, not surprisingly, the reported causes of pregnancy-related death have changed dramatically over time. The triad of infection, hemorrhage, and hypertensive disorders of pregnancy, which in the past accounted for more than 90% of all pregnancy-related deaths, now accounts for about one-third of such deaths.[2] Previously unreported causes of death are emerging, and currently, about half of pregnancy-related deaths involve cardiovascular, cerebrovascular, or other medical conditions that are not "traditional" causes of maternal mortality. These findings highlight the importance of active, ongoing surveillance of pregnancy-related deaths and the investigation of each death to ensure an up-to-date understanding of the rapidly changing circumstances that contribute to serious pregnancy-related morbidity and mortality. Without this detailed knowledge, public health officials will have extreme difficulty formulating strategies to achieve further reductions in pregnancy-related mortality and morbidity. Ideally, maternal death reviews should capture not only medical contributing factors, but also any other possible contributors such as quality of care, access to and use of services, socioeconomic circumstances, and behaviors during pregnancy. It is at the local and state levels that such comprehensive information can be obtained for all cases. Thus, maternal mortality surveillance that relies on multiple sources for identifying and classifying deaths should become the norm in all states. To improve the likelihood of timely action based on maternal death review findings, surveillance and review through Maternal Mortality Review Committees should be an ongoing process at all local, state, and national levels.

ADDITIONAL RESOURCES

- National Vital Statistics System Maternal Mortality Data
  https://www.cdc.gov/nchs/maternal-mortality/index.htm
- Pregnancy Mortality Surveillance System
  http://www.cdc.gov/reproductivehealth/MaternalInfantHealth/PMSS.html
- Maternal Mortality Review Committees (MMRCs)
  https://www.cdc.gov/reproductivehealth/maternal-mortality/erase-mm/index.html
  https://reviewtoaction.org/
- Severe Maternal Morbidity Measurement Algorithm
  http://www.cdc.gov/reproductivehealth/MaternalInfantHealth/SevereMaternalMorbidity.html

- Council on Patient Safety in Women's Health Care
  http://safehealthcareforeverywoman.org/
- State Perinatal Quality Collaboratives
  https://www.cdc.gov/reproductivehealth/maternalinfanthealth/pqc.htm

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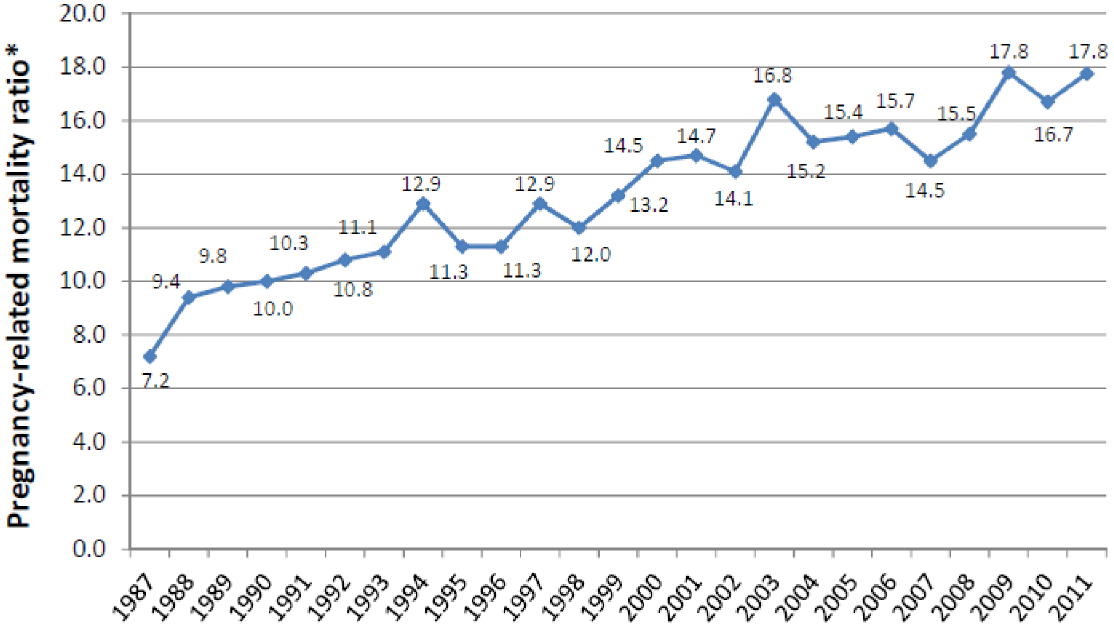
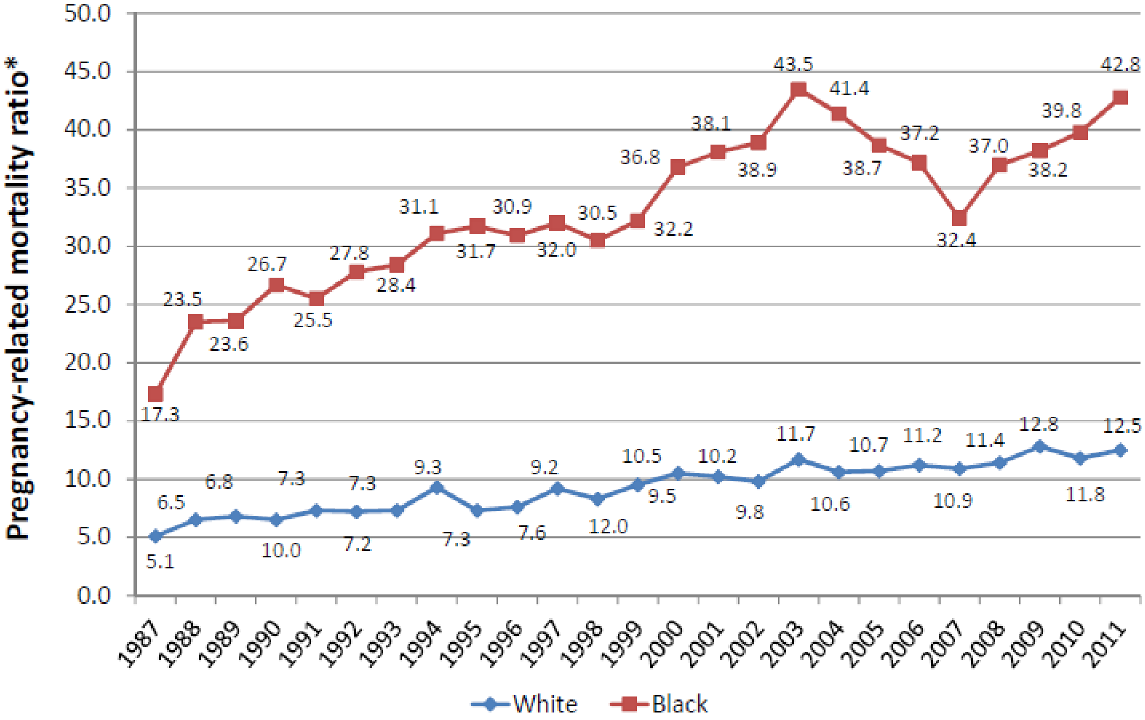
Figure 1. Trends in pregnancy-related mortality in the United States: 1987–2011



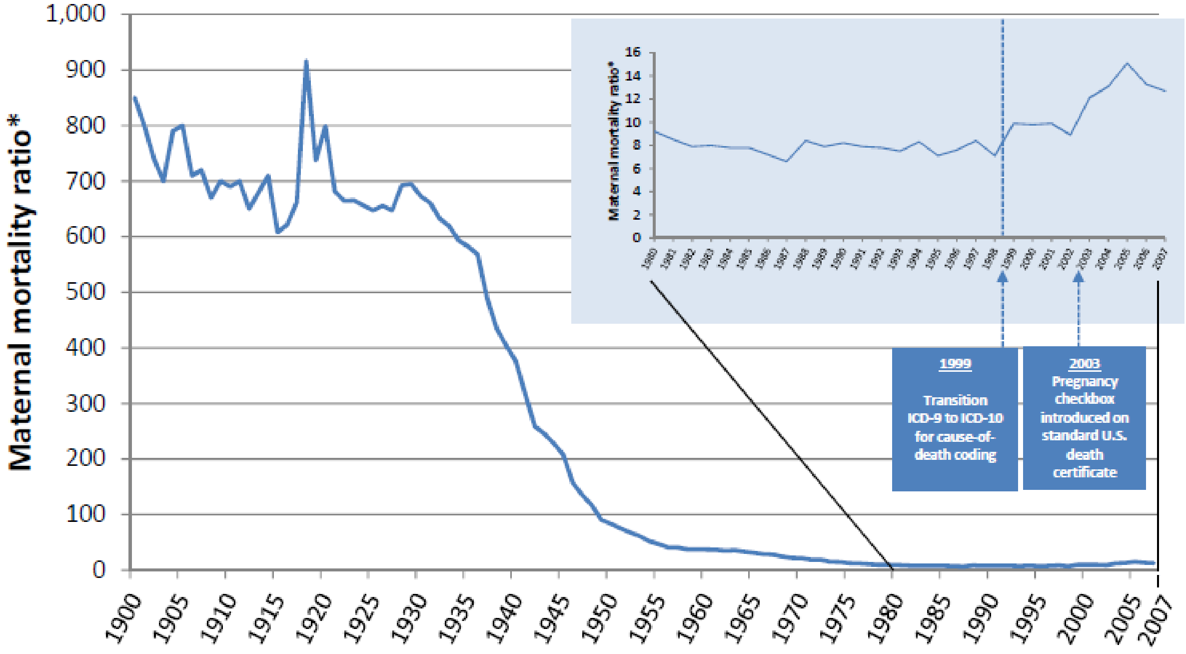
*Number of pregnancy-related deaths per 100,000 live births per year.
Data from the Pregnancy Mortality Surveillance System.

Figure 2. Trends in pregnancy-related mortality by race in the United States: 1987–2011



*Number of pregnancy-related deaths per 100,000 live births per year.
Data from the Pregnancy Mortality Surveillance System.

Figure 3. Trends in maternal mortality in the United States: 1900-2007

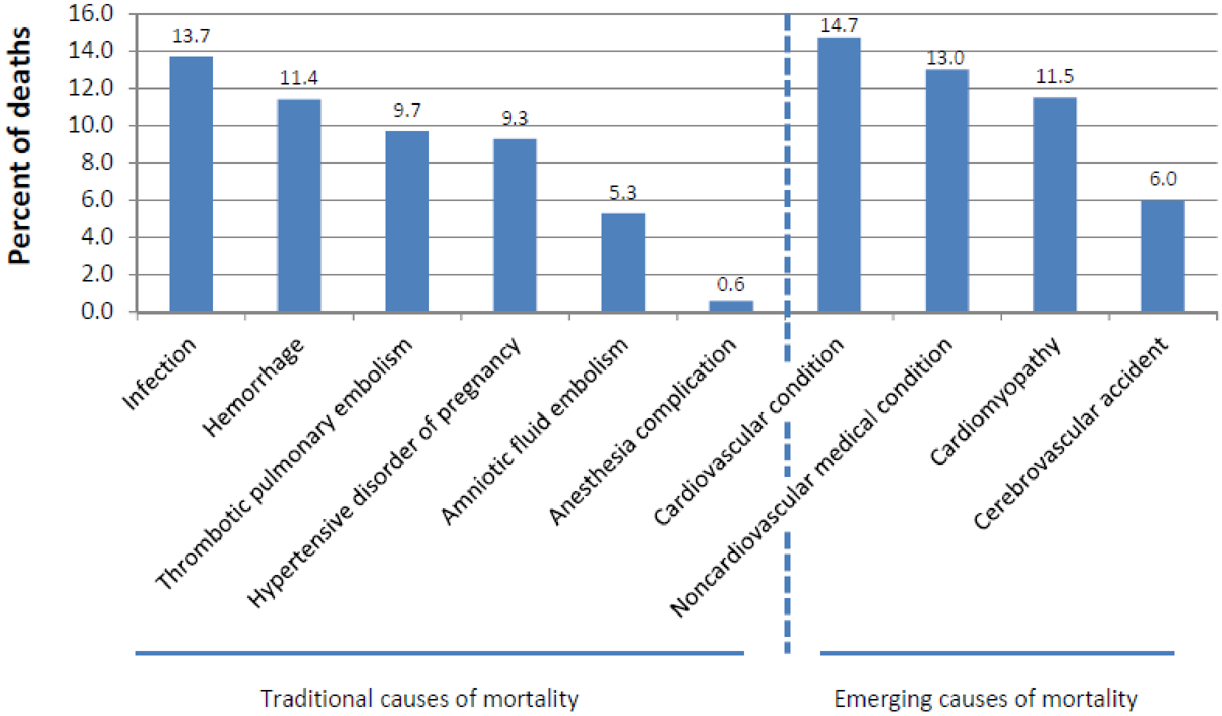


1999
Transition ICD-9 to ICD-10 for cause-of-death coding

2003
Pregnancy checkbox introduced on standard U.S. death certificate

*Number of maternal and late maternal deaths per 100,000 live births per year.
Data from the National Center for Health Statistics.

Figure 4. Cause-specific proportionate pregnancy-related mortality: United States, 2006–2011



Data from the Pregnancy Mortality Surveillance System.

Vaccine-Preventable Diseases and Vaccination of Women During the Preconception, Pregnancy, and Postpartum Periods

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Immunizations for children and adolescents in the United States have been highly successful in protecting against diseases that threatened previous generations and in fighting ever-present threats such as influenza. Now health agencies are extending their focus on vaccination to prevent diseases among the adults and in particular among women of reproductive age and pregnant women in an effort to protect their health before, during, and after pregnancy and that of their infant.

PUBLIC HEALTH IMPORTANCE

Immunization has been hailed as one of the ten great public health achievements of the 20th century playing a paramount role in the reduction of infectious disease morbidity and mortality in the United States.[1] Generally, recommended childhood and adolescent immunizations coverage is high with low racial and ethnic disparities in coverage due largely to robust private and public payment for recommended vaccines.[2,3] However, in recent years vaccine recommendations for adults, and in particular for pregnant women, have expanded and achieving high coverage in this group has proven to be challenging.[4,5]

Pregnant women are vulnerable to severe symptoms and illness due to certain vaccine-preventable diseases, including influenza. Their infants may be at increased risk of acquiring infection or suffering serious morbidity and even mortality from vaccine-preventable diseases acquired early in infancy, such as pertussis. Prevention of maternal infection during pregnancy by vaccination can reduce the risk of adverse pregnancy outcomes, including low birthweight and preterm birth. Moreover, maternal antibodies passed to the infant via the placenta can provide protection to newborns and contribute to infant survival.[4,6]

Several vaccines are recommended for adult women by the Advisory Committee on Immunization Practices (ACIP). These vaccines can be of great benefit prior to pregnancy, during pregnancy, and during the postpartum period. Inactivated influenza, as well as tetanus toxoid, reduced diphtheria toxoid, and acellular pertussis (Tdap) vaccines are recommended for administration during pregnancy. Measles, mumps, and rubella (MMR) and varicella vaccines are ideally administered prior to conception, as they are contraindicated during pregnancy. Other vaccines, like those for meningococcal disease, pneumococcal disease, and hepatitis A and B, may be used for certain age groups or women at elevated risk.[4]

Achieving high vaccination coverage among women around the time of pregnancy holds promise for improving maternal and child health.[7] Due to the benefits of vaccination for both women of reproductive age and their infants, ACIP recommendations for immunization in this population are harmonized with those of the American Academy of Pediatrics (AAP), and American Colleges of Obstetrics and Gynecology (ACOG), and American College of Nurse-Midwives (ACNM). However, achieving high levels of adult vaccination, including among pregnant women, and measuring adult vaccination coverage pose special challenges.

HISTORY OF DATA COLLECTION

National notifiable disease surveillance, in the form of congressionally authorized notification to a precursor of the US Public Health Service of diseases of outbreak potential, began in the latter half of the 19th century and evolved rapidly. By 1928 all states and the District of Columbia, Hawaii, and Puerto Rico participated in the national reporting of 29 diseases. Since the 1950s, the Council of State and Territorial Epidemiologists (CSTE) has recommended which conditions reportable at the state level should be notified to CDC. Currently, all 57 reporting jurisdictions participate in the National Notifiable Disease Surveillance System (NNDSS). Surveillance for many vaccine-preventable diseases occurs through NNDSS. Further, all states and the District of Columbia report data electronically through the National Electronic Disease Surveillance System (NEDSS). Additional systems that collect data on certain vaccine-preventable diseases include the Active Bacterial Core surveillance system (ABCs) and Enhanced Pertussis Surveillance (EPS) in the Emerging Infections Program (EIP), Viral Hepatitis Surveillance Program (VHSP), National Respiratory and Enteric Virus Surveillance System (NREVSS), Aggregate Hospitalization and Death Reporting Activity (AHDRA) for influenza, Influenza

Hospitalization Surveillance (FluSurv-NET), the Varicella Active Surveillance Project (VASP), and Rabies Surveillance Network (RSN).

The National Immunization Survey (NIS) is a family of surveys collecting nationally representative, provider-verified data to assess receipt of recommended vaccines among US children. It began in 1994 with collection of data on children aged 19 through 35 months (NIS-Child) and was expanded in 2006 to collect data on adolescents aged 13 through 17 years using similar methods (NIS-Teen). The NIS-Flu has been conducted since the 2010-2011 influenza season and measures parents' reports of their children's receipt of seasonal influenza vaccinations among children aged 6 months through 17 years. The National Flu Survey (NFS) was conducted during the 2010-2011 influenza season to measure receipt of seasonal flu shots among children and adults. The National Health Interview Survey (NHIS) also collects self-reported vaccination coverage data for adult vaccinations including tetanus-containing vaccines and influenza.[5] Other systems collect self-reported immunization coverage data among adults, including the Behavioral Risk Factor Surveillance System (BRFSS) and Pregnancy Risk Assessment Monitoring System (PRAMS). CDC also conducts a twice-annual Internet panel survey to assess vaccination coverage specifically among pregnant women, including seasonal influenza vaccination during influenza season.

Data on the safety of vaccines and vaccination are provided by three complementary systems. The Vaccine Adverse Event Reporting System (VAERS) is operated jointly by CDC and the Food and Drug Administration (FDA) and consists of passive reporting of any adverse event occurring after receipt of a vaccine. Anyone may submit a report to VAERS, including providers and the general public. The VAERS system comprises numerator data without denominators and is therefore used to identify potential safety concerns requiring further investigation but cannot identify an increased risk of adverse events. The Vaccine Safety Datalink (VSD) is a platform operated by CDC in collaboration with several managed healthcare organizations to conduct both surveillance and research. Electronic health data on the organizations' members are used to assess risk of rare and serious adverse events. Additionally, the Clinical Immunization Safety Assessment (CISA) project was established in 2001 to address vaccine safety needs not met by the VAERS and VSD systems. The CISA network of vaccine safety experts conducts expert consultation on individual vaccine adverse events as well as research on complex clinical adverse events.

To ensure that recommendations on vaccination of pregnant and postpartum women are based on consistent criteria and communicated clearly and accurately, the ACIP developed *Guidance for Vaccine Recommendations for Pregnant and Breastfeeding Women*.[8] ACIP periodically issues disease-specific recommendations for vaccination of women of childbearing age, including pregnant and postpartum women.[9-12] However, formulation of evidence-based vaccination policy for pregnant and postpartum women has been challenging due to limited data. The occurrence and complications of vaccine-preventable disease during pregnancy are not always well understood, resulting in a lack of clarity about risks and benefits of vaccination for pregnant women and fetuses.[4] This can hamper development and implementation of vaccine recommendations.[13] Additionally, surveillance systems that measure vaccination coverage among women of reproductive age, and specifically among pregnant women, are often limited in their temporal or geographic scope or provide self-reported rather than provider-verified data.

CDC SURVEILLANCE ACTIVITIES AND GENERAL FINDINGS

Although NNDSS and supplementary disease-specific surveillance systems collect demographic information on reported cases, including sex and age of affected individuals, they rarely collect information that allows for identification of currently or recently pregnant women. FluSurv-NET is unique in that it captures pregnancy status of women hospitalized for influenza. Monitoring of vaccination coverage is also a function of CDC surveillance systems and data availability on influenza and Tdap coverage has increased for reproductive age women, including those with a current or recent pregnancy. CDC surveillance systems also document where pregnant women received their flu vaccinations; their experiences with health care providers related to vaccination; their knowledge and attitudes about vaccination during pregnancy; and pregnant women's reasons for not getting vaccinated.[14] Data on the safety of vaccines in pregnant women that have become available as vaccination coverage improves and recommendations expand have been reassuring. The table at the end of this chapter summarizes highlighted surveillance systems and findings on vaccination among women of reproductive age.

Influenza

Influenza affects hundreds of thousands of United States residents annually. Immunologic changes during pregnancy are thought to place women at heightened risk for serious illness and severe complications from influenza.[15] Pregnant women are at increased risk of hospitalization with seasonal influenza compared to non-pregnant women of childbearing age.[16,17] Since 2004, use of inactivated influenza vaccines has been recommended for pregnant women in any trimester of pregnancy to protect the mother and also her infant up to six months of age.[15] In 2009, the novel influenza virus pH1N1 spread rapidly in the United States and globally. Data from the 2009 H1N1 pandemic suggested that infants born to mothers with severe pandemic influenza were more likely to have adverse outcomes, including preterm birth.[18] Severe outcomes among pregnant women infected with pH1N1 led to a renewed emphasis on the importance of maternal immunization against influenza.[19]

Comprehensive influenza surveillance is conducted by the Epidemiology and Prevention Branch in the Influenza Division of CDC to track circulation and geographic distribution of virus types, identify novel viruses, and monitor influenza-associated outpatient illness, hospitalization, and mortality. In response to the 2009 H1N1 pandemic, CDC worked closely with state and local health departments to establish methods of collecting data on pregnant women with 2009 H1N1. The FluSurv-NET system was established in the 10 EIP sites in addition to Michigan, Ohio, and Utah to conduct surveillance of laboratory-confirmed influenza hospitalizations, including the identification of pregnancy status at the time of hospitalization for influenza. CDC's Pregnancy Mortality Surveillance System (PMSS) conducts surveillance of US deaths among women during or within one year after pregnancy to identify maternal deaths and their causes. PMSS data have been used to examine pregnancy-related mortality caused by the pandemic 2009 H1N1 virus.[20,21]

Prior to 2009, influenza vaccination coverage among pregnant women was monitored through the NHIS and BRFSS.[14,22] The former is a nationally-representative, household survey on the health and demographics of non-institutionalized, civilian adults and children, while the latter monitors state-level data on health behaviors that contribute to premature morbidity and mortality. Both systems capture self-reported information on influenza immunization coverage and pregnancy status. After 2009, additional systems were established or enhanced to monitor influenza vaccination coverage.[23] Beginning with the 2009-2010 influenza season, PRAMS included supplemental questions on seasonal influenza vaccination status of women who recently had a live birth in 29 states and New York City. PRAMS continues to capture this information and is a rich source of data on maternal attitudes and experiences before, during, and shortly after pregnancy. The Internet panel survey on vaccination of pregnant women was established in the subsequent influenza season to provide mid-season and end of season estimates of vaccination coverage among pregnant women.[24] In

2012, the NHIS was also revised to improve identification of women who were pregnant during the influenza season and whether vaccination occurred before, during, or after pregnancy.

Prior to the 2009 H1N1 influenza pandemic, limited data indicated that pregnant women were vulnerable to increased risk of complications from influenza.[25] Despite recommendations from the ACIP and ACOG to vaccinate pregnant women, vaccination rates were low (14.4% in 2004).[22] During the 2009 pandemic, FluSurv-NET data demonstrated that pregnant women were more likely to be hospitalized and comprised a disproportionate number of deaths due to the H1N1 virus.[25,26] Further, PMSS data demonstrated that 2009 H1N1 influenza infection was associated with excess mortality among pregnant women compared to previous influenza seasons.[20] With increasing recognition of the risks of influenza during pregnancy, vaccination coverage increased among women of reproductive age, including pregnant women. In the 2014-15 influenza season, approximately half of pregnant women reported being vaccinated against influenza in the prior year. Vaccination rates are higher among women who reported that a health care provider recommended and offered vaccination compared with those whose provider only recommended.[24] Nevertheless, despite a goal of universal vaccination, influenza vaccination levels among pregnant women have stagnated.

Tetanus, Diphtheria, Pertussis

Tetanus and diphtheria are largely controlled in the United States due to sustained high vaccination coverage in childhood and booster doses throughout adulthood.[27] Neonatal tetanus is a risk when infants are born to unimmunized mothers and ensuring that women of reproductive age are vaccinated against tetanus is an essential strategy to achieve elimination of neonatal tetanus. While the incidence of pertussis has declined dramatically with the advent of effective vaccines, it remains among the most common vaccine-preventable diseases in the United States. Pertussis incidence in the United States reached a 50-year peak in 2012 with over 48,000 cases.[28] Pregnant women are not known to have a higher morbidity from pertussis than non-pregnant women. However, infants, especially those under age 6 months who are too young to be protected by the primary immunization series, are the group most at risk for pertussis and its complications. Prior to 2011, the ACIP recommended Tdap vaccination of postpartum women as part of a "cocooning" strategy to protect infants by vaccinating their close contacts. In 2011, the ACIP revised the strategy to protect infants too young to be vaccinated, recommending Tdap vaccination during pregnancy for women who had never received a dose of Tdap. In 2012, recognizing the short-lived nature of maternal antibodies, ACIP recommended a dose of Tdap for pregnant women during each pregnancy.[11]

Tetanus, diphtheria, and pertussis are nationally notifiable diseases and are routinely reported by all jurisdictions to NNDSS. Data on the severity of illness, patient characteristics, vaccination status, and outcome are collected for all cases. Pregnancy status of cases in adult women is not consistently collected by jurisdictions, nor is vaccination status of mothers of affected infants, and NEDSS does not allow transmittal of those data.[29] In part to fill this data gap, the Enhanced Pertussis Surveillance (EPS) system was established in the EIP network.[29] This system conducts enhanced case findings and confirmation; collects diagnostic specimens and molecular characterization of disease-causing bacterial isolates; interviews patient or caregiver to ascertain additional data, including pregnancy status and vaccination history among women of reproductive age with pertussis; and provides vaccination among mothers of infants with pertussis. EPS is also used as a platform for special studies, including identifying the source of infection in infant cases and assessing the effectiveness of maternal Tdap in preventing infant pertussis.

Data on receipt of Tdap vaccine among pregnant women are collected through the Internet panel survey of pregnant women, and in 2011, supplemental questions were added to PRAMS to allow states to assess Tdap vaccination status before, during, and after pregnancy based on self-reports of recently pregnant women.[30] The VSD sites have also assessed and confirmed Tdap coverage among their membership as part of Tdap safety assessments.

A total of 29 cases of tetanus and no cases of diphtheria were reported in the United States in 2015.[31] Only three neonatal tetanus cases were reported in the United States during 2000-2014. In contrast, thousands of cases of pertussis are reported annually in the United States.[32] The incidence of pertussis in 2014 was significantly higher for infants aged less than six months than any other age group, with 169 reported cases per 100,000 compared to a mean of 10.4 per 100,000 for all combined age groups. Infants aged less than three months accounted for the majority of 13 reported pertussis deaths in 2014.[33] Implementation of the ACIP vaccination recommended for pregnant women has occurred gradually.[11] Using 2011 PRAMS data from 16 states and New York City, it was estimated that the median percentage of women who received Tdap vaccination around the time of pregnancy was 55.7%, ranging from 38.2% in New York City to 76.6% in Nebraska, though at this time, Tdap was recommended postpartum.[30] Wide variation in Tdap vaccination coverage was identified among demographic groups with generally higher postpartum coverage for non-

Hispanic white women, those who began prenatal care in the first trimester, and those with private health insurance.[30] Among VSD sites, receipt of Tdap during pregnancy had reached 41.7% by 2013.[34]

Measles, Mumps, Rubella

Measles, mumps and rubella (MMR) vaccine is a combination vaccine that protects against three diseases, though the incidence and risks to pregnant women of these diseases differ substantially. Due to high vaccination coverage and a strong public health system to detect and respond to cases, measles was declared eliminated from the United States in 2000,[32] meaning measles and its transmission are no longer constantly present. However, measles outbreaks continue to occur with localized transmission following importation of cases from countries where measles is more common. Pregnant women may have increased risk of miscarriage if measles or mumps occur early in pregnancy, but neither infection is associated with birth defects.[35,36] In contrast, congenital rubella syndrome (CRS) can occur when non-immune pregnant women are infected with rubella. Miscarriage, stillbirth, and a wide range of birth defects can occur; the lifelong consequences of which may be profound.[35] These can include brain damage, heart defects, cataracts, and deafness. To prevent CRS, MMR vaccination is recommended before women get pregnant. Because it contains live virus, MMR should not be given during pregnancy.

Measles, mumps, and rubella are nationally notifiable diseases, and surveillance of cases from state health departments are routinely reported to NNDSS. Clinical data on the severity of illness, patient's characteristics and vaccination status, outcome, and final diagnosis are obtained for all suspected cases. CDC surveillance does not capture information on MMR vaccination coverage of postpartum women.

In 2014, the United States had 23 measles outbreaks with 667 cases of measles reported from 27 states - the largest number of cases since measles elimination in 2000.[32] The majority of cases occurred in unvaccinated persons. In 2014-2015, a large multi-state measles outbreak occurred that was linked to an amusement park in California with transmission likely introduced by an overseas traveler.[37] Although mumps is no longer common in the United States, several outbreaks occur annually, and the reported number of cases peaked at over 6,500 in 2006. Published surveillance data for these diseases do not report cases by age or pregnancy status.[32] Rubella is rare in the United States, with fewer than 10 cases reported each year, and congenital rubella syndrome has been verified as eliminated from the United States.[35]

Varicella

Chickenpox, or primary infection with varicella zoster virus, is known as a common disease of childhood. However, when it occurs during the first half of pregnancy, it can be associated with congenital varicella syndrome, and late in pregnancy or early in the postnatal period, it can cause neonatal varicella. Congenital varicella syndrome is associated with low birthweight, skin scarring, eye and brain damage, limb hypoplasia, and microcephaly. Neonatal varicella is particularly severe and can lead to death when a maternal rash appears five days prior until two days after delivery.[38] One dose of varicella vaccine was recommended for routine use in the United States in 1996, and CSTE recommended that varicella be made nationally notifiable by 2003 to monitor vaccine impact on morbidity and mortality. By 2007, two doses of varicella vaccine were recommended for routine use in children. Coverage of one dose of varicella vaccine is measured by the NIS. As of 2015, 40 states report varicella cases to CDC and 38 states conduct case-based varicella surveillance which includes standard demographic, clinical, epidemiologic data, disease severity, and vaccination status of affected persons.[39,40] It is rare for women of reproductive age to be susceptible to varicella zoster virus given the almost universal occurrence of chickenpox in persons aged less than 15 years prior to the vaccination program and the widespread use of vaccine during the past 20 years. As a result, congenital varicella syndrome and neonatal varicella are exceedingly rare.

Vaccination has resulted in substantial declines in primary varicella infection in the United States. From 2000 to 2010, in the 26 states that had adequate and consistent reporting, widespread childhood vaccination contributed to a decline in varicella incidence of 82%.[41] Indirectly benefitting from widespread vaccination were infants too young to be vaccinated, among whom infections declined by 77% from 2005-2006 to 2013-2014. By 2014, in the four states reporting varicella since the pre-vaccination period, incidence declined an average of 97%. From the end of the one-dose vaccination era of 2005-2006 to 2013-2014, the decline in varicella incidence was 85%, reflecting the impact of the two-dose vaccination program implemented in 2007.[40]

USING DATA FOR ACTION

Providers of reproductive health care are essential in implementing recommendations for vaccination during preconception, pregnancy, and the postpartum period that benefit women and infants.[4] Evidence-based recommendations are used by obstetrician-gynecologists, nurse midwives, and other providers of healthcare for women of reproductive age to understand the risks to pregnant women and their infants of vaccine-preventable diseases and the risks and benefits of vaccination. They provide information that can help providers incorporate vaccination into their routine care, increasing vaccination coverage and reducing disparities in coverage among reproductive-age women prior to conception, during pregnancy, and during the postpartum period. Data are also used to promote evidence-based communication strategies to increase acceptance of vaccination among pregnant and postpartum women.

The 2009 H1N1 influenza pandemic had a profound and lasting effect on public health surveillance, prevention, and control of vaccine-preventable diseases in women during preconception, pregnancy, and the postpartum period. It focused attention on the need for surveillance and applied research on vaccine-preventable diseases among childbearing women and the effective use of vaccines to protect mothers and their infants.[25] Surveillance of influenza disease and vaccination coverage was strengthened due to the increasing need for data to document progress in disease prevention, control, and management for women of reproductive age, including pregnant and postpartum women. Data from the 2009 pandemic have been used to inform public health policy and strategies for vaccination and treatment of pregnant women,[26] improve monitoring of disease occurrence and complications, promote increased vaccination coverage and alleviate disparities[15,24] and assess vaccine effectiveness.

Due in part to the efforts of health care providers and public health information campaigns during the 2010-2011 influenza season, immunization coverage among pregnant women more than doubled.[23] However, this is still lower than desired and sustained efforts will be needed to continue to increase maternal vaccination coverage.[25]

The 2009 pandemic also galvanized national attention to the need for emergency preparedness planning that takes into account the needs of vulnerable populations, including pregnant and postpartum women.[42] CDC's Division of Reproductive Health has developed and disseminated emergency preparedness tools, health indicators, and lessons learned[43] ensuring that the needs of pregnant and postpartum women and their infants are taken into account in national emergency preparedness exercises. During the recent Ebola epidemic, these emergency procedures were reactivated to develop and disseminate guidance for health care providers as well as monitoring and responding to maternal and child health-related Ebola inquiries received by CDC.[44,45] The Zika virus outbreak again put the issues of surveillance, prevention, and control of infectious diseases among pregnant women at the forefront of the public health response.

DATA GAPS AND LIMITATIONS

Though there are many systems to track data on vaccine-preventable diseases and vaccination among women of reproductive age, gaps remain in our ability to collect nationally representative data on these health conditions. The true burden of these diseases in pregnant and post-partum women and their infants is unknown. Data on vaccination coverage are commonly collected in sentinel systems or using self-reported rather than provider-verified vaccine receipt, so there is uncertainty about actual coverage and our ability to identify and understand the causes of disparities in vaccine coverage is limited. Collaborations, such as VSD, that maximize the use of data from large healthcare organizations are costly and resource intensive to maintain.

FUTURE ISSUES

As new vaccines are incorporated into the national immunization program, so are new specific recommendations protecting pregnant women and their infants, which are monitored by surveillance systems that track vaccine-preventable diseases as well as vaccination coverage and safety. Existing systems were modified, and new systems developed to better track disease or vaccination among pregnant women. These surveillance systems represent a breadth of methods and approaches, including passive and active data collection, sentinel and population-based systems, systems that use traditional reporting to public health authorities, and those that use complex information systems in partnership with healthcare organizations. In the future, surveillance systems must remain flexible, efficient, and timely in order to inform changes to policy and to serve as a platform to evaluate new policies.

The future will likely see expanded use of vaccinations for women of reproductive age and pregnant women to mitigate the effects of serious infectious diseases for them and their infants. Even as the recommendation for Tdap during pregnancy was expanded to include a dose during every pregnancy, the effectiveness, duration of protection, and optimal timing of vaccination remain to be determined. New vaccines are in development, including against group B streptococcus, an important cause of septicemia and meningitis in newborns, and against the respiratory syncytial virus, a common respiratory infection that puts premature infants and those with certain medical conditions at increased risk for serious morbidity, hospitalization, and death. Assessing the impact of changing vaccine recommendations, considering potential vaccination strategies in advance of licensure of new vaccines, and demonstrating the safety and effectiveness of new vaccines following licensure all require strong surveillance.

The US vaccination program is complex and extends beyond just the mechanisms to deliver vaccines. The program's success relies on provider adoption of vaccine recommendations and public confidence in vaccination. The thoughtful use of surveillance data on vaccine-preventable diseases, vaccination coverage, and vaccine safety will continue to play an integral role in the vaccination programs in the future.

Table. Surveillance Systems for Vaccine-Preventable Disease Notification and Vaccination Coverage among Women of Reproductive Age (15-49 years), including Pregnant and Postpartum Women				
Disease	**Focus of Surveillance**	**Surveillance System**	**Surveillance Approach and Content**	**Most Recently Reported Findings Regarding Women of Reproductive Age, Pregnant and Postpartum Women, or Infants**
Influenza	Disease Notification	Influenza Hospitalization Surveillance Network (FluSurv-NET)	• Surveillance of laboratory-confirmed influenza hospitalizations in 10 Emerging Infections Program sites plus Michigan, Ohio, and Utah. • Data can be subset for reproductive age women; pregnancy at the time of hospitalization can be captured.	Among reproductive-age women (15-44 years), a higher percentage of those admitted to the ICU and receiving mechanical ventilation were pregnant during the 2009 H1N1 pandemic period as compared to the preceding influenza seasons from 2005-2006 to 2008-2009.[26]
		Pregnancy Mortality Surveillance System (PMSS)	• Surveillance of US deaths among women during or within 1 year after pregnancy. • Causes of maternal deaths are identified.	Pregnancy-related mortality caused by the pandemic 2009 H1N1 virus was associated with excess mortality among pregnant women compared to previous influenza seasons.[20]
	Vaccination Coverage	National Health Interview Survey	• Annual national household survey that captures basic health and demographic data, and questions on current health topics. • Data can be subset for women who reported they were pregnant at the time of the interview, but the number of pregnant women is small.	Influenza vaccination coverage among pregnant women aged 18-44 years without any high-risk conditions was 14.4% in 2004 and did not differ statistically from non-pregnant women.[22]
		Behavioral Risk Factor Surveillance	• Stratified random-digit-dial sample of adults aged >=18 years;	Influenza vaccination coverage among pregnant women aged 18-44 years

		System (BRFSS)	captures national and state-specific vaccination coverage and place of vaccination among adults aged >=18 years. • Captures self-reported pregnancy status. Useful for capturing vaccination coverage of pregnant and non-pregnant women over time.	increased from 11.2% during the 2001-2002 flu season to 43.7% during the 2011-2012 season.[14,24].
		Internet Panel Surveys of Pregnant Women	• Nonprobability sample Internet panel survey of women aged 18-49 years who were recently pregnant; conducted annually since the 2010-2011 flu season. • Captures vaccination coverage among pregnant women. respondents and reasons for not receiving vaccines.	• During the 2014-15 influenza season, approximately half of respondents had received an influenza vaccination prior to or during pregnancy; coverage was similar to the 2013-2014; 2012-2013; and 2011-2012 seasons, but higher than found for the 2010-2011 season. • Vaccination rates were higher among women who reported that a health care provider offered and recommended the vaccination compared with those whose provider only recommended it.[24].
		Pregnancy Risk Assessment Monitoring System (PRAMS)	• State-based survey of women who had a live birth within the past 3-6 months, identified through stratified random sampling of state birth certificates from 21 states and New York City.	• Estimated median seasonal influenza vaccination coverage among women who recently had a live birth was 47.1% in the 2011-2012 season, ranging from 26.1% in Florida to 67.9% in Minnesota.

			- Included questions about seasonal and pH1N1 influenza vaccination coverage among pregnant women during the 2009-2010 and 2010-2011 flu seasons.	- Median pH1N1 coverage in 2011-2012 was 40.4% (from 21.9% in Mississippi to 63.3% in Vermont). - Influenza vaccination rates were higher among women in each state where a health care provider offered and recommended the vaccination.[47]
Tetanus, Diphtheria, Pertussis	Disease Notification	National Notifiable Diseases Surveillance System (NNDSS)	- Surveillance of cases from state health departments reported to NNDSS. - Clinical data on the severity of illness, patient's vaccination status, outcome, and final diagnosis are obtained for all suspected diphtheria cases.	- Tetanus and diphtheria are rare diseases, with 25 cases of tetanus, and 1 case of diphtheria reported in the US in 2014. Published surveillance data do not report cases by age or pregnancy status.[32] - There were 32,971 pertussis cases reported in the US in 2014. Incidence of pertussis for infants <6 months of age was significantly higher than any other age group. Vaccination status of the mother for these cases is unknown.[33].
	Vaccination Coverage	Pregnancy Risk Assessment Monitoring System (PRAMS)	- State-based survey of women who had a live birth within the past 3-6 months with women identified through stratified random sampling of state birth certificates from 16 states and New York City. - Self-reported Tdap vaccination	- In 2011, estimated median Tdap vaccination coverage among women who recently had a live birth was 55.7%, ranging from 38.2% in New York City to 76.6% in Nebraska. - There was wide variation in Tdap vaccination coverage among demographic groups, with generally

			coverage among women who delivered a live-born infant during September-December 2011.	higher postpartum coverage for non-Hispanic white women, those who began prenatal care in the first trimester, and those with private health insurance.[30]
Measles, Mumps, Rubella	Disease Notification	NNDSS, with supplemental data from National Immunization Program National Electronic Disease Surveillance System (NEDSS)	Provides electronic data on measles cases, including information on patient vaccination status, complications, importation status, and molecular epidemiology.	• In 2014, the US had a record number of 23 measles outbreaks, with a total of 667 cases of measles reported from 27 states. In 2015, the US experienced a large, multi-state measles outbreak linked to an amusement park in California. • Mumps and rubella are rare diseases in the US, with 1,223 cases of mumps reported in 2014, and 6 cases of rubella. • Published surveillance data for these diseases do not report cases by age or pregnancy status.[32]
Varicella	Disease Notification	NNDSS	• Although varicella became nationally notifiable in 1972, active sentinel surveillance was not established until 1995. • As of 2010, 31 states met CDC's criteria for adequate reporting, and 28 states reported age of varicella cases.	Between 2006 and 2010, varicella incidence among infants < 1 year declined by 44.5%. Vaccination status of the mother for these cases is unknown.[41]

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Global Maternal and Perinatal Health

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The United Nations Millennium Development Goals initiated in 1990, followed by the Sustainable Development Goals beginning in 2015, set global objectives to improve maternal and newborn health and to decrease preventable maternal and perinatal deaths. Significant strides have been made in reducing mortality rates and providing adequate healthcare for these vulnerable population groups; however, however, rates in resource-poor settings are still unacceptable. Consistent registration of vital events and public health surveillance can help stakeholders identify the depth and breadth of high-mortality countries' needs for accessible healthcare, which will further increase the survival and improved health of young children and mothers.

PUBLIC HEALTH IMPORTANCE

Globally, maternal and child survival has improved dramatically since 1990, the baseline year for the United Nations Millennium Development Goals (MDGs). From 1990 to 2015, the global maternal mortality ratio (deaths per 100,000 live births) declined by an estimated 45%. Similarly, in that time period, the global under-five years mortality rate declined 52% (from an estimated 90 to 43 deaths per 1,000 live births), and neonatal mortality fell 42% (from 33 to 19 deaths per 1,000).[1]

Despite these achievements, excess preventable mortality among mothers and children remains unacceptably high in developing countries, with highest levels concentrated in sub-Saharan Africa and Southern Asia. Together, these two regions accounted for 86% of global maternal deaths in 2013, and sub-Saharan Africa alone is estimated, in 2015, to account for approximately half of the world's deaths in children under-five years.[1] Many causes of maternal deaths in these hardest-hit regions – such as obstetric hemorrhage, obstructed labor, infection, high blood pressure, and complications of unsafe abortion – are preventable. Similarly, most child mortality is attributable to preventable causes such as pneumonia, diarrhea, and infectious diseases. Inequities in access to maternal and child health care persist, and future reductions in poor outcomes in these regions will depend on the continued scale-up of cost-effective, high-impact interventions at the population level.[1]

HISTORY OF DATA COLLECTION

The MDGs galvanized world attention on progress toward a defined set of quantitative targets, two of which focused on maternal and child health (MCH). MDG 4 established goals for reducing child mortality, and MDG 5 set targets for improving maternal health. The adoption of quantitative development indicators for MCH increased the need for reliable data to measure progress, and simultaneously underscored the longstanding challenges with data availability, timeliness, and quality, especially in countries that still lacked reliable, systematic, and sustainable data systems.

The United Nations Global Strategy for Women's and Children's Health placed reduction of maternal mortality high on the international political agenda. With the 2015 conclusion of the MDG era, a new, more comprehensive framework of 17 Sustainable Development Goals (SDGs) was adopted.[2] Reducing global maternal mortality and ending preventable deaths of newborns and children continue to top the list of health targets for SDG 3, to "Ensure healthy lives and promote well-being for all at all ages." Target 3.1 of SDG 3 is to reduce the global *maternal mortality* ratio (MMR) to less than 70 per 100,000 live births by 2030 from its 2015 level of 216 per 100,000.[3] Target 3.2 of SDG 3 is to end preventable deaths of newborns and children under five years of age, with all countries aiming to reduce neonatal mortality to at least as low as 12 per 1,000 live births and under-five mortality to at least as low as 25 per 1,000 live births. Monitoring progress toward the SDGs will require significant improvement in completeness and quality of birth and death record-keeping, Civil Registration and Vital Records Systems (CRVS), and enhancement of surveillance capacities for all nations.[4]

In recognition of the continued need to address data gaps and strengthen national statistical capacity, the UN established an Independent Expert Advisory Group on the Data Revolution for Sustainable Development. The group will focus on strategies to measure progress toward SDG targets with aims to: strengthen existing data infrastructure while harnessing new technologies; assess and fill gaps in the current production and use of statistical information; obtain more disaggregated and qualitative data to monitor inequalities; and improve the availability and use of data for policy-making and accountability.[5]

Most high-income and some middle-income countries have established CRVS systems that yield consistent and accurate information on vital events. These systems are considered the "gold standard" for collection and reporting of important demographic and health information, including continuous and complete information on births and deaths, and causes of death.[6,7] Further, most developed countries also conduct supplementary population-based surveillance to understand the major causes and underlying factors associated with maternal and perinatal deaths. Maternal death surveillance and response (MDSR) systems follow up on deaths of women within one year of pregnancy to enumerate and review deaths due to maternal causes and to understand how they can be prevented.[8] Infant mortality review systems also have been developed to investigate perinatal deaths with the aim of preventing future deaths through improving public health and clinical care.[9,10]

Low-income and a substantial number of middle-income countries still lack adequate levels of investment in data infrastructure required to establish and maintain systematic data collection that covers the country population and provides reliable data for improved accountability.[11] A 2015 global assessment of CRVS systems concluded that only modest progress had been made in the three preceding decades toward functional data collection.[12,13] Despite significant improvements in CRVS in some countries, including South Africa and Brazil, globally as of 2012, only approximately 38% of deaths for children under five and 65% of births were registered.[12,13] Moreover, accurate cause-of-death information is frequently lacking, especially for deaths that occur outside of a hospital.

Most countries with inadequate or non-existing CRVS low-scoring countries are located in the African and Asian regions. In countries that lack systematic population-based registration of births and deaths and surveillance of maternal and perinatal deaths, policy-makers and health planners have inadequate information on which to base policy and programmatic decision-making for MCH programs[11] and to assess progress.[13]

Due to diverse information needs and the lack of existing government data infrastructure in many developing countries, health information systems have frequently been driven by specific needs of donors and initiatives, and by disease-focused programs. The World Health Organization (WHO) Health Metrics Network has assessed that “country health information systems [capacity] can easily be overwhelmed by these multiple parallel information demands.”[7] Additionally, lack of population-based birth, health outcome, and mortality data in low-resource countries has caused governments, as well as multilateral organizations and bilateral donors, to rely heavily on supplemental approaches to obtain population health information, each with advantages and disadvantages. Main approaches have included: 1) reliance on population census data with supplemental data collection to identify births and maternal/perinatal deaths; 2) sentinel surveillance or population-based surveillance for vital events at sub-national levels; 3) intermittent population-based surveys and special studies; 4) Health Management Information Systems (HMIS); and 5) estimation and modelling using multiple sources of available data.

CDC SURVEILLANCE ACTIVITIES

For decades, CDC has provided scientific and technical assistance, along with capacity-building, to improve MCH data availability in developing countries. Unlike the surveillance systems maintained in collaboration with US states for domestic health activities, support to improve global MCH surveillance has focused more on providing technical assistance and mentorship for host countries to establish and/or improve their own national surveillance systems. The following section describes some of CDC's approaches to fostering MCH data improvement globally.

National Center for Health Statistics' International Statistics Program (ISP)

CDC's National Center for Health Statistics (NCHS) works through its divisions and programs to provide technical assistance to various countries on health statistics issues.[14] Approaches consist of cooperative projects and collaborative research on analytical and methodological issues, technical assistance, consultations, training, demonstrations, information exchange, and liaising with multinational agencies and organizations. In addition, NCHS sponsors and hosts international meetings and symposia, and contributes via scientific articles and lectures. NCHS's International Statistics Program (ISP) provides technical assistance for CRVS improvement to selected low- and middle-income countries worldwide. Subject matter experts train and work with countries to establish uniquely tailored strategies to improve their developing CRVS systems. Partners of ISP at CDC include: The Global Immunization Division of the Center for Global Health at CDC, The President's Emergency Plan for AIDS Relief (PEPFAR), and the Epidemiologic Intelligence Service.

Maternal and Perinatal Death Surveillance and Response (MPDSR) Activities

Health systems in low- and middle-income countries continue to face considerable challenges to measure and reduce high levels of avoidable maternal and perinatal deaths. Due to the frequent lack of infrastructure for tracking maternal mortality through community-based data collection, extensive training, monitoring, logistics, and subject-matter and analytic expertise are necessary to accomplish the goal of documenting and reviewing every maternal death, formulating appropriate actions, and monitoring the outcomes and impacts they produce.

Since the early 1990s, CDC/Division of Reproductive Health (DRH) has partnered with USAID, WHO, Ministries of Health, private donors, and non-governmental organizations to design and implement MPDSR systems. Under the leadership of WHO Department of Reproductive Health and Research, CDC/DRH has collaborated on international working groups whose missions are to improve and standardize country maternal and perinatal death surveillance. In 2012, CDC and WHO issued joint guidance to design, implement, and evaluate MDSR systems at national and subnational levels.[15] In 2016, a follow-up publication was issued which aimed to avert stillbirths and neonatal deaths through perinatal death reviews and data-based response formulation.[16] Efforts have been made to harmonize annual MPDSR reporting and to lay the groundwork for a new round of evaluation to document the status of global MPDSR implementation. Although the need for country-level MPDSR improvement remains significant relative to the resources available to these improvements, global efforts have helped to strengthen systems and harmonize data collection and dissemination.

Reproductive Age Mortality Studies (RAMOS)

Reproductive Age Mortality Studies (RAMOS) are considered among the best approaches to accurately measure maternal mortality in the absence of complete surveillance.[15] RAMOS studies involve the identification of all deaths to reproductive age women in a specific period of time, drawing on multiple sources of information. Investigation of identified deaths involves completing a “verbal autopsy” questionnaire with a family member or caregiver and ideally reviewing health facility records for the deceased. A panel of physicians reviews the verbal autopsy data to assign the probable causes of death. RAMOS studies classify maternal deaths according to the underlying cause of death, classify obstetric and non-obstetric causes, describe medical and nonmedical contributing factors, and assess the preventability of the death. RAMOS data can be used to identify needed interventions. In several countries, for example Colombia and Uganda, RAMOS has laid the foundation for maternal death surveillance.

Field Epidemiology Training Program

Since 1980, CDC's Field Epidemiology Training Program (FETP) has operated globally to train local physicians and public health professionals to establish and conduct epidemiological surveillance. FETP programs are managed by the host countries' Ministry of Health and receive technical and financial assistance from CDC to train and produce graduates trained in epidemiology and surveillance. Nearly 80% of all graduates from FETP programs around the world continue to work in public health epidemiology and surveillance programs and leadership in their home countries.[17] Originally focused primarily on communicable and outbreak-prone disease surveillance and response, FETP training has evolved to meet the changing needs of public health workforce education, incorporating non-communicable diseases and maternal and child health.

CDC's activities are carried out in partnership with other US government agencies, multilateral organizations, non-profits, and academic institutions. CDC has collaborated with WHO, USAID, and other multilateral/bilateral organizations on global initiatives to support FETP and to establish guidelines, strategies, and tools that can be applied to standardize approaches across countries as they expand and strengthen surveillance systems. Specific MCH activities, described in greater detail below, have largely focused on the development and dissemination of guidance, tools, and curricula, and strengthening host country governments' ability to gather and report reliable and consistent data, including CRVS data, maternal mortality surveillance, and most recently, perinatal mortality surveillance.

Presidential Initiatives on HIV/AIDS and Malaria

Many global MCH surveillance activities have been carried out in the context of the PEPFAR and the President's Malaria Initiative (PMI). Both PEPFAR and PMI have special areas of focus on women and children and operate in countries across the world to treat and prevent HIV/AIDS and malaria. They also provide monitoring and evaluation and surveillance mentorship and training in countries around the world – principally in African and Asian regions.[18,19] Tasked by Congress to play a leadership role in surveillance, monitoring, and evaluation for these initiatives, CDC has worked to strengthen HMIS, and to implement Demographic Surveillance Sites and surveys that monitor progress on key MCH indicators related to maternal and infant infection, prevention behaviors, and maternal and infant health outcomes.

Reproductive Health Surveys

Reproductive Health Surveys are foundational in understanding the status of maternal and child health around the globe. These are population-based reproductive health surveys that provide nationally-representative, household-level data for monitoring and evaluating a wide range of health indicators related to demographics, reproductive and maternal and child health, adolescent health, sexually transmitted infections, including HIV, and nutrition.[20] Surveys are typically conducted once every three to five years to monitor trends and evaluate the effects of interventions, and survey data often are used by national and international organizations to help develop policies, programs, and interventions to address issues and needs related to contraception. They provide the most timely and relevant data available in the absence of CRVS and strong routine surveillance systems.

USING DATA FOR ACTION

Improved MCH data collection and more complete coverage of health statistics reporting has enabled countries to strengthen data-informed decision-making to achieve improved MCH outcomes. Below are several examples that summarize general findings and demonstrate the translation of data to action in countries where CDC has provided scientific support and technical assistance for the improvement of MCH surveillance.

NCHS has partnered with Jordan, which developed and implemented a modified death notification form to improve the quality of mortality data, including cause of death and reporting. Prior to 2003, Jordan's death notification form did not comply with WHO guidelines and information was often missing, inaccurate, or incomplete. Through this collaboration, a new mortality surveillance system was implemented in 2003, and a unit for coding causes of death was established at the Ministry of Health. Jordan has continued to improve its mortality reporting system, with annual reporting since 2004; reports are now based on more than 70% of deaths. The quality of cause-of-death information has improved, with only around 6% of deaths allocated to symptoms and ill-defined causes – a substantial improvement from the percentage before 2001 of 40%. After 10 years of mortality surveillance in Jordan, the reporting has improved, and the information has been used by various health programs throughout the nation.[21]

In Cameroon, the Ministry of Health developed MPDSR national guidelines, conducted situation analyses, and evaluated existing MPDSR efforts at the community, facility, regional, and national levels. Technical assistance was provided to strengthen identification and review of maternal deaths, transmission of data to national levels, and identification of facility-based actions to reduce maternal deaths. Efforts were made to strengthen systematic investigation of deaths and improve completeness of data collection and reporting. To strengthen surveillance beyond facility level, the Ministry of Health implemented the first pilot community-based MPSDR, launched in January 2017. Following the model of MDSR, Cameroon has implemented a continuous cycle of notification, review, analysis, and response to maternal deaths

In 2012, Uganda and Zambia launched the Saving Mothers Giving Life (SMGL) Initiative. With the support of public-private partnerships, the countries sought to achieve a dramatic and rapid reduction in maternal mortality, primarily at the time of delivery and the early postpartum period. Through intensive training, capacity building, and innovative data collection approaches, MCH surveillance systems were established in selected districts of Uganda and Zambia to monitor the impact of interventions that were implemented to reduce maternal and neonatal mortality. Improved surveillance increased the countries' ability to document MCH outcomes and impact.[22] By 2015, SMGL results found a 45% and 53% decline in maternal mortality in facilities in Uganda and Zambia, respectively, with significant declines in most direct obstetric causes of mortality.[22] In Uganda, data were used to understand the relationship of maternal deaths and distance to obstetric care in one of the nation's most resource-poor regions.[22]

Data have also been used in Kigoma, western Tanzania, to implement and assess targeted interventions aimed at reducing maternal mortality. Enhanced staff training and support for emergency obstetric care was provided to facilities with high maternal death burden, which led to a reduction in maternal mortality.[23,24] In one resource-poor region, the increase of facility-based delivery rate of 11% was accompanied by a decline in maternal mortality of 18%; a spatial depiction of unmet need for obstetric care has been utilized in stakeholder decisions for resource investment toward further reduction of maternal deaths.[23,24]

The President's Malaria Initiative and PEPFAR have improved MCH data collection and surveillance efforts, which have enabled countries to tailor country-specific responses to the epidemics. In Nigeria, malaria data are essential for monitoring and evaluating impact, but paper-based systems have slowed down routine data collection and constrained timely program planning. However, implementation of the President's Malaria

Initiative included support for an updated platform for electronic data management, the District Health Information Software v2 (DHIS-2). With DHIS-2 implementation, data reporting rates from health facilities increased from 28% in 2013 to 89% in 2016. Eight other states deployed DHIS-2. Malaria data, which include MCH indicators, are now more accessible, and overall reporting rates are higher in PMI-supported states as compared to the national average.

In areas with high coverage of routine HIV testing in pregnant women, i.e., ≥80% testing uptake, WHO and PEPFAR recommend using HIV testing data among pregnant women attending antenatal care (ANC) clinics to monitor trends in HIV prevalence among pregnant women and in the general population.[25-28] HIV prevalence data for pregnant women informed prevention efforts in Thailand where, during the 1990s, 2% of pregnant women in Thailand were infected with HIV and the mother-to-child transmission (MTCT) rate was >20%. Based on data collected from prenatal care clinics with PEPFAR support, Thailand implemented maternal and child HIV prevention measures that enabled it to become the first country in Asia to eliminate MTCT of HIV and syphilis. By implementing programs that promoted condom use and HIV prevention, Thailand reduced its HIV prevalence rate in women from 2% in the mid-1990s to 0.6% in 2015. During the same period, its implementation of WHO Option B+ (lifelong antiretroviral treatment for HIV+ pregnant and breastfeeding mothers), along with a prevention of MTCT monitoring system, enabled Thailand to reduce MTCT from >20% to 1.9%. With strong host country leadership and PEPFAR/CDC technical assistance, Thailand successfully put data into action for epidemic control.[29]

DATA GAPS AND LIMITATIONS

A country's level of infrastructure development is very closely correlated to that nation's ability to support a healthy population.[13] Data infrastructure is essential to monitor and evaluate a country's progress toward global commitments for progress toward MCH targets. Nonetheless, persistent gaps in geographic coverage and completeness of data collection, registration of vital statistics and accuracy of registration, and the evaluation of programs and interventions in developing countries remain a challenge for all global health and development advancements.[13]

Robust, widely used, and efficiently functioning CRVS systems are paramount to a country's ability to plan for and implement policy surrounding issues such as maternal mortality and morbidity, family planning and access to services, child vaccination coverage, child survival, and response to infectious disease outbreaks, among many health issues related to maternal and perinatal health.[11-13,30] Additionally, epidemics such as HIV/AIDS and recurrent seasonal health concerns such as malaria – which have a direct economic impact on a country – cannot be adequately planned for and addressed without well-formed surveillance and vital statistics systems.[4,18,19,31,32]

National and local government buy-in and support to establish and maintain critical data infrastructure for MCH are essential. Inadequate funding and absent government policy has frequently challenged progress, and vertical programs have often led to the implementation of data systems in isolation from one another. Establishment of sustainable surveillance systems to monitor maternal and child health in developing countries has a direct and powerful link to their potential to grow in all aspects of the Human Development Index rankings,[11-13,31,32] including those that pertain to lasting improvement in MCH outcomes.

FUTURE ISSUES

Continued buy-in from governments and communities, facilities, and health care providers will be necessary to develop and sustain systems. Providing technical assistance to partnering countries to improve their health systems allows CDC to establish partnerships and perform valuable research. Nevertheless, the primary goal of all global health and development is that programs be ultimately country-owned and driven to achieve sustainable impact. The continued effort to improve a country's infrastructure and health systems will have a meaningful impact not only on the health of mothers and children, but also on a country's ability to provide services and approach challenges.[11-13,30] This ability and preparedness will allow for an improvement in gross domestic product, education levels, human rights provisions, environmental sustainability, quality of life, and sustainability of overall development.[4,30]

ADDITIONAL RESOURCES

- Sustainable Development Goals
  http://www.un.org/sustainabledevelopment/sustainable-development-goals/
- Field Epidemiology Training Program
  https://www.cdc.gov/globalhealth/healthprotection/fetp/index.htm
- International Statistics Program
  https://www.cdc.gov/nchs/isp/index.htm
- Maternal and Perinatal Death Surveillance and Response
  http://www.who.int/maternal_child_adolescent/epidemiology/maternal-death-surveillance/en/
- Reproductive Health Surveys

http://dhsprogram.com/
https://www.cdc.gov/reproductivehealth/global/publications/surveys/africa/kigoma-tanzania/2014-kigoma-reproductive-health-survey_tag508.pdf

- The President's Emergency Plan for AIDS Relief
  https://www.pepfar.gov/
- President's Malaria Initiative
  https://www.cdc.gov/malaria/malaria_worldwide/cdc_activities/pmi.html

- Saving Mothers Giving Life
  http://www.savingmothersgivinglife.org/

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Fetal Deaths

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Following decades of declines, fetal mortality rates have plateaued in the US over the past several years; there are now more fetal deaths than infant deaths every year. Renewed focus on the improving the quality of vital statistics fetal death data, along with expanded surveillance collaborations and enhanced emphasis on research will help to gain improved understanding into the causes and prevention of fetal death.

PUBLIC HEALTH IMPORTANCE

Fetal death is defined as the intrauterine death of a fetus at any gestational age. Having a previous pregnancy loss increases a woman's risk for having a future pregnancy loss and is an important component of a woman's pregnancy history.[1] Following decades of declines, the US fetal mortality rate has shown little recent improvement and was essentially unchanged for 2006 through 2014 at about 6.0 deaths per 1,000 births and fetal deaths.[2,3,4] In 2014, there were more fetal deaths at 20 weeks of gestation or greater (23,980) than infant deaths (23,211) in the United States.[4,5] Despite the importance of fetal death as a public health issue, much of the public concern historically surrounding reproductive loss has focused on infant mortality, due in part to a lesser knowledge of the etiology and prevention strategies for fetal mortality and the poorer quality of fetal mortality data relative to infant mortality data.[3] Over the last decade, however, there has been a growing interest in the topic both nationally and internationally.[6-19] This chapter presents key historic and current issues in fetal death surveillance in the United States. Fetal deaths at 20 weeks of gestation or more, sometimes referred to as stillbirths, will be the focus of this chapter.

HISTORY OF DATA COLLECTION

The National Vital Statistics System (NVSS) is the primary source of information on fetal deaths in the United States. Vital statistics on stillbirths (fetal deaths of 20 or greater weeks) were first collected by the Bureau of the Census in 1918. Beginning in 1922, the Bureau began annually collecting and tabulating these statistics from the states for a limited birth-registration area. All states were admitted into the birth-registration area by 1933, allowing for the national compilation of state statistics. In 1946, the responsibility for maintaining vital statistics for the entire nation moved to the Public Health Service; this responsibility has rested with CDC’s National Center for Health Statistics (NCHS) since 1960.[20]

In 1939, the newly developed US Standard Certificate of Stillbirth replaced the earlier procedure of filing both a live birth and death certificate. The certificate then underwent several revisions, before changing to the US Standard Report of Fetal Death in 1978. Information on the mother’s pregnancy history (e.g., number of live births now living/dead) has been consistently collected for fetal death over the decades, but other medical and health information was limited. Information on the cause of death has been included on the standard fetal death report since 1930, but states only began to report the information to NCHS with the 1989 report revision.

The United States adopted the World Health Organization’s (WHO) definition of fetal death in 1950:[21]

> *Death prior to the complete expulsion or extraction from its mother of a product of conception, irrespective of the duration of pregnancy; the death is indicated by the fact that after such separation, the fetus does not breathe or show any other evidence of life such as beating of the heart, pulsation of the umbilical cord, or definite movement of voluntary muscles.*

This definition was intended to emphasize the absence of signs of life at delivery regardless of gestational age. Subsequently, the 1992 revision of The Model State Vital Statistics Act and Regulations (Model Law), which serves as a model for states to use in developing their own vital records laws, further expanded this definition to add “…whether or not the umbilical cord has been cut or the placenta is attached. Heartbeats are to be distinguished from fleeting respiratory efforts or gasps.”[22] This expanded definition is continued in the most current Model Law revision for 2011.[23]

Since 1950, the term fetal death has been used to reduce confusion between the terms stillbirth, spontaneous abortion, and miscarriage.

The US Standard Report of Fetal Death is reviewed and evaluated collaboratively by NCHS and the states approximately every 10 to 15 years to help ensure that the items meet health information and administrative needs and to serve as the model for state reports.[24] Following a survey of state vital registration and statistics executives in 1994, a revision of the standard certificates and reports was recommended. A panel of expert consultants subsequently was convened to assess the 1989 report of fetal death (the most recent revision at that time) and to recommend changes. As a result of this review, many items included on the 1989 revision were dropped or modified for the 2003 revision to the US Standard Report of Fetal Death and a number of new items were added.[24] The 2003 revision includes new or modified mother's demographic items such as mother's education and mother's race (with the ability to capture multiple race data) and new or modified health items such as prenatal care, smoking status, maternal morbidities, method of delivery, and risk factors during pregnancy. The cause of death section of the report was substantively redesigned with the 2003 revision.[25] The autopsy and histological or placental examination data items were added and the structured but open-ended cause of death section was replaced with two sections with checkboxes and specify lines. The intent in changing the format was to provide more guidance on desired information while retaining flexibility to report any cause of death.[24]

The 2003 revision is being phased in over many years by the states and independent reporting areas. As of January 1, 2017, three jurisdictions, Connecticut, New York (excluding New York City) and American Samoa, had yet to transition to the 2003 revision. Most states that have transitioned conform closely to the US Standard Report of Fetal Death, but state reports may differ somewhat depending upon state specific needs or vital statistics laws.[25]

Major goals of the 2003 revision of the US Standard Report of Fetal Death were to improve data quality, expedite data collection and transmission, and to improve the standardization of data across the country. Details of this effort are described elsewhere.[24,26] Standard worksheets (the Patient's Worksheet and the Facility Worksheet) were developed to help ensure that information included on the report of fetal death is gathered from the proper sources and a comprehensive instruction manual, *Guide to Completing the Facility Worksheets for the Certificate of Live Birth and Report of Fetal Death* (2003 revision), was developed (and updated in 2016) with detailed definitions, instructions and key words to help hospital staff better report this information.[27-29]

Recent re-evaluations of items included on the 2003 US Standard Report of Fetal Death have resulted in changes to items recommended to be collected for the national NCHS fetal deaths file. In 2015, a workgroup comprised of state and NCHS representatives and subject matter experts was convened to investigate the possibility of reducing the number of data items collected to a set of items that could potentially be collected accurately.[30] As a result of the evaluation, a total of 39 items were recommended to be dropped because of poor data quality and lack of potential for improvement; lack of usefulness in adding to understanding of why the death occurred; or because of overlap and redundancy with other items on the fetal death report (i.e., between the cause of death and non-cause of death sections of the report).[30] The recommendations were accepted by NCHS and the National Association for Public Health Statistics and Information Systems (NAPHSIS) leadership, and the items have been dropped from the national fetal death data file.

CDC SURVEILLANCE ACTIVITIES

The National Vital Statistics System

The National Vital Statistics System (NVSS) is the most comprehensive source of information on fetal deaths in the United States. US fetal death registration is based on state law, and reports are filed and maintained in state vital statistics offices. Fetal mortality data from the NVSS are cooperatively produced by NCHS and state vital statistics offices under a joint agreement known as the Vital Statistics Cooperative Program. Once fetal death reports are filed and processed in jurisdiction vital statistics offices, most reporting areas send NCHS electronic files consisting of individual records. A few reporting areas still send paper copies of original fetal death reports, which are coded and keyed by NCHS. Personal identifiers are not included in the fetal death data file.

Quality control of NVSS fetal death data takes place in a number of ways. Initial review occurs at the state level and some states regularly query reports with problem data back to the original data source (typically the hospital). Fetal death data are also subject to NCHS quality control procedures at several processing stages to check for the completeness, coding validity, and consistency of data items.

National fetal mortality data are generally available about one year following the close of a data year. Detailed tables are published annually in the User Guide to the Fetal Death Public Use File,[4] as well as in periodic NCHS reports. NCHS also produces public-use data files containing individual record information on all registered fetal deaths; data for 1982-2014 are currently available. The file contents and characteristics are described in the *User Guide to the Fetal Death Public Use File* for the respective year.[4] Fetal death data will also be available in the near future in the CDC WONDER web application available at: http://wonder.cdc.gov/. Using this system, data users will be able to create their own tables using a number of different data items.

Cause-of-death analyses of fetal death are important for examining preventable risks. Although a cause of fetal death item has historically been included on the US Standard Report of Fetal Death, cause of fetal death data has not previously been released by NCHS because of concern with data quality and the lack of resources needed to adequately code cause of death. In an effort to improve the quality of 2003 revision-based cause of death data, NCHS recently revised instructions on coding, developed a system for processing cause, and assumed responsibility for coding fetal cause of death for revised reporting areas starting in 2010. Following several years of coding, evaluation, and assessment, the first NCHS report on cause of fetal death was released in October 2016. Summary findings from this report are presented in the following section;[31] a data file to include initiating cause and limited multiple cause data for selected states for the 2014 data year was released in January 2017.

The National Survey of Family Growth

Additional NCHS activities on fetal death surveillance include the National Survey of Family Growth (NSFG).[32] The NSFG serves multiple purposes as a nationally representative survey of men and women aged 15-44 years in the household population of the United States in regard to fertility, but its core purpose has always been to help explain variations in the US birth rate. Data are collected on the major, proximate determinants of fertility, which includes factors related to: sexual intercourse (primary mode of exposure to risk of pregnancy), conception (does a pregnancy occur), and pregnancy outcome (does pregnancy result in a live birth).[32] Every woman interviewed is asked if she has ever been pregnant, and if so, how many times. The survey then collects further information on each reported pregnancy, including how it ended, using the following 6 categories:

Miscarriage	1
Stillbirth	2
Abortion	3
Ectopic or tubal pregnancy	4
Live birth by Cesarean section	5
Live birth by vaginal delivery	6

Women can report multiple outcomes for each pregnancy, if they involved more than one fetus. For example, if she was carrying twins, and one was stillborn and one was born alive by vaginal delivery, she would report codes 2 and 6 for this pregnancy.

Stillbirth Surveillance 2005-2015

CDC's National Center on Birth Defects and Developmental Disabilities (NCBDDD) has initiatives to further the understanding and knowledge of stillbirths. From 2005-2015, the Center collaborated with metropolitan Atlanta and Iowa to expand their birth defects tracking systems to capture data on all stillbirths.[33] Both of these programs have provided useful information, serving as a registry for studies on factors that may increase the risk for stillbirth and as a valuable resource to help evaluate strategies to prevent stillbirths.[33] The NCBDDD funded new projects in 2016 with Arkansas and Massachusetts to gain knowledge on risk factors for stillbirths.[33] One of the goals of the studies is to be able to provide useful information on how to reduce the risk of or prevent stillbirths.[33]

The Stillbirth Collaborative Research Network

The National Institute of Child Health and Human Development also sponsors the Stillbirth Collaborative Research Network (SCRN), a major multicenter research study into the causes and prevention of fetal death.[6] SCRN, established in 2003, is currently conducting a number of ongoing studies including surveillance, case-control, and follow-up studies on stillbirth and has worked collaboratively with CDC on a number of publications on SCRN findings.[6,34-40]

Pregnancy Risk Assessment and Monitoring System (PRAMS)

PRAMS collects a wealth of information from women who have had a live birth. It is used to describe the experience of women and their babies before, during, and after pregnancy. In 2016, PRAMS funded the Utah Department of health to expand its PRAMS methods and sampling to include women who experienced a stillbirth. Utah's expanded stillbirth pilot study will provide essential data for monitoring stillbirth and related factors such as prenatal, obstetric and postpartum health care after a pregnancy loss. Information collected can fill data gaps and inform efforts to conduct stillbirth surveillance in other states.

GENERAL FINDINGS

The following findings are based on vital statistics fetal data reported by NCHS for fetal deaths occurring at 20 weeks of gestation or greater; early fetal mortality rates (fetal deaths at 20-27 weeks of gestation) and late fetal mortality (28 weeks of gestation or more) are also presented. All differences described below are statistically significant ($p<0.05$) unless otherwise noted.

The total US fetal mortality rate declined by 19% from 1990 through 2006, from 7.49 to 6.05 per 1,000 births and fetal deaths, but has been essentially stable from 2006 through 2014 (5.98 in 2014) (Figure 1). Early fetal mortality rates (20-27 weeks) fluctuated for 1990-2005 (from a low of 3.17 to a high of 3.39 per 1,000) but were down slightly for 2006-2013, from 3.10 to 3.01 (Table 1). Declines were seen in late fetal mortality (28 and greater weeks) from 1990 to 2006 (4.30 to 2.97), but the late fetal mortality rate remained stable between 2006 and 2013 (2.97 for 2006 and 2013) (Table 1). (Note that rates for 2014 are not presented for early and late fetal deaths because of the discontinuity in measures resulting from the change in gestational age measures begun for that year).

Total fetal mortality rates for non-Hispanic white, non-Hispanic black, American Indian or Alaskan Native (AIAN), Asian or Pacific Islander (API), and Hispanic women were not significantly changed between 2006 and 2014 (**Figure 2**). Accordingly, the substantial gap between non-Hispanic black and the other major race/Hispanic origin groups persisted. In 2014, the fetal mortality rate for non-Hispanic black women was 10.69 per 1,000 — more than twice the rate of non-Hispanic white (4.92), Hispanic (5.14), and API women (4.62), and 63% higher than that for AIAN women (6.55).

Data for three years are combined in Table 2 to generate more stable state-specific fetal mortality rates. For combined years 2012 through 2014, four states (Iowa, New Hampshire, New Mexico, and Vermont) had total fetal mortality rates below 4.50 per 1,000 births and fetal deaths; four states (Alabama, Georgia, Mississippi and South Carolina) had rates above 8.00. The rate for the District of Columbia was 9.97. Note, however, that differences by state should be viewed with caution because of differences in reporting requirements among states discussed in the data gaps and limitations section below.

According to a recent report based on vital statistics data for 35 states, the District of Columbia, and New York City, five broad groupings of cause of death account for about 90% of fetal deaths at 20 weeks of gestation or greater: Fetal death of unspecified cause (unspecified cause); Fetus affected by complications of placenta, cord and membranes (placenta, cord, and membrane complications); Fetus affected by maternal complications of pregnancy (maternal complications); Congenital malformations, deformations and chromosomal abnormalities; and Fetus affected by maternal conditions that may be unrelated to present pregnancy.[31] The five most commonly selected causes of fetal death are the same by race and Hispanic origin, but the order differs. Unspecified cause is the most commonly selected cause for Non-Hispanic white and Non-Hispanic black fetal deaths, whereas placental, cord, and membrane complications is the most commonly selected cause for Hispanic fetal deaths. The most commonly selected causes of fetal death also vary by birthweight. Maternal complications are relatively more of a problem for fetuses with birthweight less than 1,500 grams and 1,500-2,499 grams, while Syndrome of infant of a diabetic mother and neonatal diabetes mellitus is more common for fetuses with birthweight of 2,500-3,999 grams and especially for those weighing 4,000 grams or more.[31]

USING DATA FOR ACTION

Maternal and child health organizations have highlighted fetal death data in various initiatives to inform stakeholders. For example, the March of Dimes' Perinatal Data Center compiles and analyzes maternal and infant health data from 12 different government agencies and organizations.[41] Using fetal mortality data from the National Vital Statistics System, rates for late fetal and perinatal mortality by maternal age, race, ethnicity, state, and region are available in tabular or graphic formats for data years 2002-2006.[41] PeriStats was developed to ensure that health professionals, researchers, medical librarians, policy-makers, students, and the media have easy access to this information for fact-finding, health assessments, grant writing, policy development, lectures and presentations.[41]

The medical journal, *The Lancet*, has published two series of articles, one in 2011 and the other in 2016, on stillbirths. These series were an international effort with authors from a number of countries, such as the United States, Sweden, Egypt, Brazil, and Canada. Data from these countries, including the United States' National Vital Statistics System, were analyzed to assess the magnitude of stillbirth in both developing and developed countries and the impact of stillbirths from both the medical (cause of death) and personal perspectives (interviews with women who had experienced a stillbirth). The purpose of these series was to bring greater attention to the often-overlooked issue of stillbirths worldwide and to bring together health and policy expertise to develop strategies to prevent stillbirths and to provide better care to women and families when one occurs.[7-19]

The National Fetal and Infant Mortality Review Program (NFIMR) was established in 1990 as a joint effort between the American College of Obstetricians and Gynecologists and the Maternal and Child Health Bureau within the Health Resources and Services Administration (HRSA).[42] The purpose of this collaboration is to promote Fetal and Infant Mortality Review at the local level to evaluate, track, and work to improve service systems and community resources for women, infants, and families.[42] This includes the investigation of medical, non-medical, and systems factors that contribute to fetal and infant death at the local level.[43] As a result, local FIMR (Fetal and Infant Mortality Review) programs often have activities specifically designed for their own communities;[43] however, there is often communication and collaboration among them.[44] Through research, it has been shown that FIMR is an effective perinatal systems intervention.[42] To date, there are approximately 180 local FIMR programs across the country.[44]

One such FIMR program is the City of Milwaukee's, which has been ongoing for more than 20 years. The city has implemented a FIMR process where data on fetal deaths and infant deaths are collected from multiple sources (including vital statistics, medical and social service records, and maternal interviews) and case reviews are conducted.[45] The information gathered is then used to inform the development of new and improved programs and policies to help with the prevention of fetal and infant deaths.[45] One of the community activities focused on the FIMR recommendations is a collaborative effort between the City of Milwaukee Health Department, Madison/Dane County Public Health, the Wisconsin Department of Health Services, and the Children's Health Alliance of Wisconsin to design a FIMR database and a model statewide FIMR/CDR (Child Death Review) process.[45]

DATA GAPS AND LIMITATIONS

Reporting Requirements

From the beginning of data collection, there has been variation among the vital statistics jurisdictions in definitions and reporting requirements for fetal deaths.[46] These differences have narrowed over time, however. In 2014, all jurisdictions essentially followed the WHO/Model Law definition of fetal death outlined above. The majority of states also follow the recommended reporting requirement of fetal deaths at 20 weeks or greater or 350 grams; seven states require reporting of fetal deaths at all periods of gestation; and one state (Pennsylvania) requires reporting beginning at 16 weeks of gestation. Only one state (South Dakota) requires reporting of fetal deaths with birthweights of 500 grams or more (roughly equivalent to 22 weeks of gestation).

There is evidence that not all fetal deaths for which reporting is required are reported. Underreporting of fetal deaths is most likely to occur in the earlier part of the required reporting period for each state. Generally, states which require reporting earlier in pregnancy, i.e., that report deaths all periods of gestation or beginning at 16 weeks, have a higher percentage of all fetal deaths occurring at 20-27 weeks than those who require reporting at 20 weeks or more/350 grams or at 500 grams, suggesting states that require reporting of all fetal deaths at any gestational age are likely to have more complete reporting of fetal deaths at 20 weeks or more than those states that do not. These variations in fetal death reporting requirements and practices have implications for comparing fetal mortality rates among states and may account in part for differences in fetal mortality rates among states.[3] To ameliorate these issues, state-specific fetal mortality rates at 24 or 28 weeks or the perinatal mortality rate (fetal deaths at 28 weeks and greater and early neonatal deaths of <7 days) are often used.

Additionally, because only seven jurisdictions require reporting of fetal deaths of all ages, national information on deaths of <20 weeks are not available and NCHS bases the vast majority of its publications on deaths at 20 weeks of gestation and greater. Since the vast majority of fetal deaths occur before 20 weeks of gestation,[3] the lack of data on these fetal losses mean that we have an incomplete picture of the true magnitude of fetal mortality.

Misclassification

Fetal deaths can be misclassified as live births because of differences in the clinical interpretation or understanding of the WHO/Model Law fetal death definition.[47] To help practitioners distinguish between fetal deaths and live births in the US, the American Academy of Pediatrics publishes the NVSS definitions and reporting requirements for fetal deaths in Guidelines for Perinatal Care.[48] Classification issues occur for fetal and infant death statistics worldwide and are behind the development of perinatal mortality measures that bypass inconsistencies in classifying deaths that occur very near the time of delivery by incorporating various combinations of later fetal deaths and neonatal infant deaths.[48-51]

Item-Specific Nonresponse

In comparison with other vital statistics records, fetal death records generally have more non-stated responses for individual items. Item nonresponse in fetal death records reflects both difficulty in ascertaining early death data, such as cause of death or sex, and limitations in access to necessary information, such as hospital staff or funeral directors’ lack of access to medical charts. Additional factors contributing to item nonresponse may include the lower priority given to the fetal death system than other vital statistics systems and fewer resources available for follow-up. In general, percentages of unknown responses are higher for fetal deaths than for births, and unknown levels are higher among fetal deaths occurring earlier in the gestational period. For example, information on birthweight was missing for 7.63% of all fetal death records of 20 weeks and greater for 2014, compared with only 0.08% of birth records. Levels of missing birthweight data were also higher for fetal deaths occurring at 20-27 weeks (9.2%) compared with those occurring at 28 or more weeks of gestation (5.5%).

Unknown Cause of Fetal Death

Causes of fetal death reported, even from detailed investigations, vary because of limitations with cause-of-death information, variations in methodology, and use of multiple classifications. However, unknown cause of death consistently accounts for a large percentage of deaths.[52-57] A recent study found that a cause of death could be identified based on clinical and laboratory information alone in 24% of cases, 61% combining placental pathologic examination with clinical and laboratory information, and 74% combining autopsy findings with other assessments. These different types of examinations demonstrated a distinct benefit in establishing cause of death. However, cause remains unknown for a substantial percent of fetal deaths. The quality of information reported to vital statistics reflects the extent of care and examination given to determining the cause of death. Specialized studies define comprehensive examination protocols in an effort to maximize the information available in a standard way.[53,57] Vital statistics encompass a much broader population that is subject to various levels of examination reflecting family wishes, costs and resources available, among others.[55]

Change in Measures of Gestational Age

Because risks for poor pregnancy outcomes of fetuses differ across gestational periods, the accuracy of gestational age estimates is important to the interpretation and further analysis of these data. Prior to 2014, the gestational age of the fetus was computed by NCHS by subtracting the date of delivery from the date of last menstrual period (LMP). The obstetric estimate of gestation (OE) was used if the calculated estimate was missing, was outside of an acceptable range, or was inconsistent with reported birth weight. Due to increasing evidence of the greater validity of the OE-based data,[58] NCHS transitioned to the use of the OE as the primary measure of gestational age in 2014. The same substitution criteria noted previously for the LMP applies to the OE, with the LMP measure of gestational age being substituted when missing or inconsistent with fetal weight. While this change results in no difference in the total fetal mortality rate between the two measures, the change results in differences in the number and rate of early and late fetal deaths. That is, the early fetal mortality number and rate based on the OE is higher than the LMP-based measures whereas the late fetal mortality OE-based rate is lower. For example, the OE-based early mortality rate for 2014 was 3.16 per 1,000, compared with 2.99 for the LMP-based rate; the late fetal mortality OE rate was 2.83 compared with 3.01 for the LMP (Table 1).

FUTURE ISSUES

One of the Healthy People 2020 objectives is to "Reduce the rate of fetal deaths at 20 or more weeks of gestation to 5.6 fetal deaths per 1,000 live births and fetal deaths."[59] Given the 2014 fetal mortality rate of 5.98 per 1,000 live births and fetal deaths, a further reduction of more than 1 percent annually would be necessary to meet this goal. Further, to meet the same goal for fetal mortality among non-Hispanic black women, the 2014 rate of 10.69 per 1,000 live births and fetal deaths would need to be reduced by nearly 50 percent.

The prospects for future prevention of fetal deaths are hampered by lack of quality data on this outcome, including the fact that for many fetal deaths, the cause of death is unknown. Improvements in diagnostic methods provide the opportunity to identify cause in more cases and additional study can inform clinical management of pregnancies and the development of new prevention strategies for fetal loss.[53,55,56,60]

NCHS, in collaboration with NAPHSIS and individual states, has recently undertaken a number of efforts to improve the quality of fetal death data. These efforts include the recommendation for states to drop numerous items from vital statistics fetal death reporting in order to reduce the reporting burden on hospitals and optimally improve the quality of the remaining items on the fetal death report. Additional efforts include an updated and improved Guidebook[29] and the development of the first ever e-learning training on vital statistics birth and fetal death reporting.[61] The e-learning training is geared towards both clinical and non-clinical hospital staff and includes sections on the definitional differences between live birth and fetal death, best practices for reporting the non-cause of death medical and health information, and instructions for reporting cause of fetal death. Continuing education credits for non-clinicians, nurses and physicians are available upon successful completion of the training. These efforts, plus the expanded CDC surveillance collaborations should continue to help gain insights into the causes and prevention of fetal death.[6,33]

Table 1. Number of fetal deaths and fetal mortality rates: United States, 1990, and 1995-2014

	Fetal deaths			Fetal mortality rate[1]		
	Total[2]	20-27 weeks[3]	28 weeks or more[3]	Total[2]	20-27 weeks[3]	28 weeks or more[3]
			Obstetric estimate			
2014 [4]	23,980	12,652	11,328	5.98	3.16	2.83
			LMP-based gestation			
2014 [5]	23,999	11,948	12,051	5.98	2.99	3.01
2013 [5]	23,595	11,874	11,721	5.96	3.01	2.97
2012 [5]	24,073	12,334	11,739	6.05	3.11	2.96
2011 [5]	24,289	12,432	11,857	6.11	3.13	2.99
2010 [5]	24,258	12,388	11,870	6.03	3.09	2.96
2009 [5]	24,872	12,813	12,059	5.99	3.09	2.91
2008 [5]	26,335	13,347	12,988	6.16	3.13	3.05
2007 [5]	26,593	13,822	12,771	6.12	3.19	2.95
2006 [5]	25,972	13,270	12,702	6.05	3.10	2.97
2005 [5]	25,894	13,327	12,567	6.22	3.21	3.03
2004 [5,6]	26,001	13,068	12,933	6.28	3.17	3.14
2003 [5,6]	26,004	13,348	12,656	6.32	3.25	3.08
2002 [5]	25,943	13,072	12,871	6.41	3.24	3.19
2001 [5]	26,373	13,122	13,251	6.51	3.25	3.28
2000 [5]	27,003	13,497	13,506	6.61	3.31	3.32
1999 [5]	26,884	13,457	13,427	6.74	3.39	3.38
1998 [5]	26,702	13,229	13,473	6.73	3.35	3.41
1997 [5]	26,486	12,800	13,686	6.78	3.29	3.51
1996 [5]	27,069	12,990	14,079	6.91	3.33	3.60
1995 [5]	27,294	13,043	14,251	6.95	3.33	3.64
1990 [5]	31,386	13,427	17,959	7.49	3.22	4.30

[1] Rate is number of fetal deaths in specified group per 1,000 live births and fetal deaths.

[2] Fetal deaths with stated or presumed period of gestation of 20 weeks or more.

[3] Not stated gestational age proportionally distributed.

[4] Beginning with the 2014 data year, the obstetric estimate of gestation at delivery replaces the measure based on the date of last normal menses as the standard for measuring gestational age.

[5] Date of last normal menses was used for measuring gestational age.

[6] Rates have been revised from those published previously; see Technical notes.

NOTE: LMP refers to the date of the mother's last normal menses.

SOURCE: NCHS, National Vital Statistics System.

Table 2. Total number of fetal deaths at 20 weeks of gestation or more and fetal mortality rates: United States and each state, 2012-2014

State	Number of fetal deaths	Fetal mortality rate [1]
Total	71,648	6.00
Alabama	1,576	8.87
Alaska	188	5.49
Arizona	1,503	5.77
Arkansas[2]	764	6.62
California	7,677	5.09
Colorado[3]	1,042	5.29
Connecticut	546	4.99
Delaware	191	5.78
District of Columbia	284	9.97
Florida	4,652	7.12
Georgia[3]	3,326	8.46
Hawaii[3]	313	5.51
Idaho	334	4.87
Illinois	2,852	5.97
Indiana	1,500	5.95
Iowa	530	4.49
Kansas	576	4.84
Kentucky	1,087	6.44
Louisiana	915	4.78
Maine	174	4.53
Maryland	1,678	7.61
Massachusetts	1,007	4.64
Michigan	1,746	5.09
Minnesota	1,076	5.15
Mississippi	1,103	9.42
Missouri	1,225	5.39
Montana	169	4.56
Nebraska	441	5.56
Nevada	671	6.30
New Hampshire	161	4.33
New Jersey	2,082	6.67
New Mexico[4]	269	3.37
New York (including New York City)[3]	5,248	7.27
North Carolina	2,462	6.80
North Dakota	186	5.77
Ohio	2,678	6.38
Oklahoma	819	5.11
Oregon	694	5.09

Pennsylvania	2,725	6.36
Rhode Island[3]	196	5.98
South Carolina	1,458	8.43
South Dakota	217	5.89
Tennessee	1,783	7.31
Texas	5,674	4.83
Utah	843	5.46
Vermont	76	4.18
Virginia[3]	1,904	6.13
Washington	1,553	5.88
West Virginia	301	4.84
Wisconsin	1,051	5.20
Wyoming	122	5.30

[1] Rate per 1,000 live births and specified fetal death

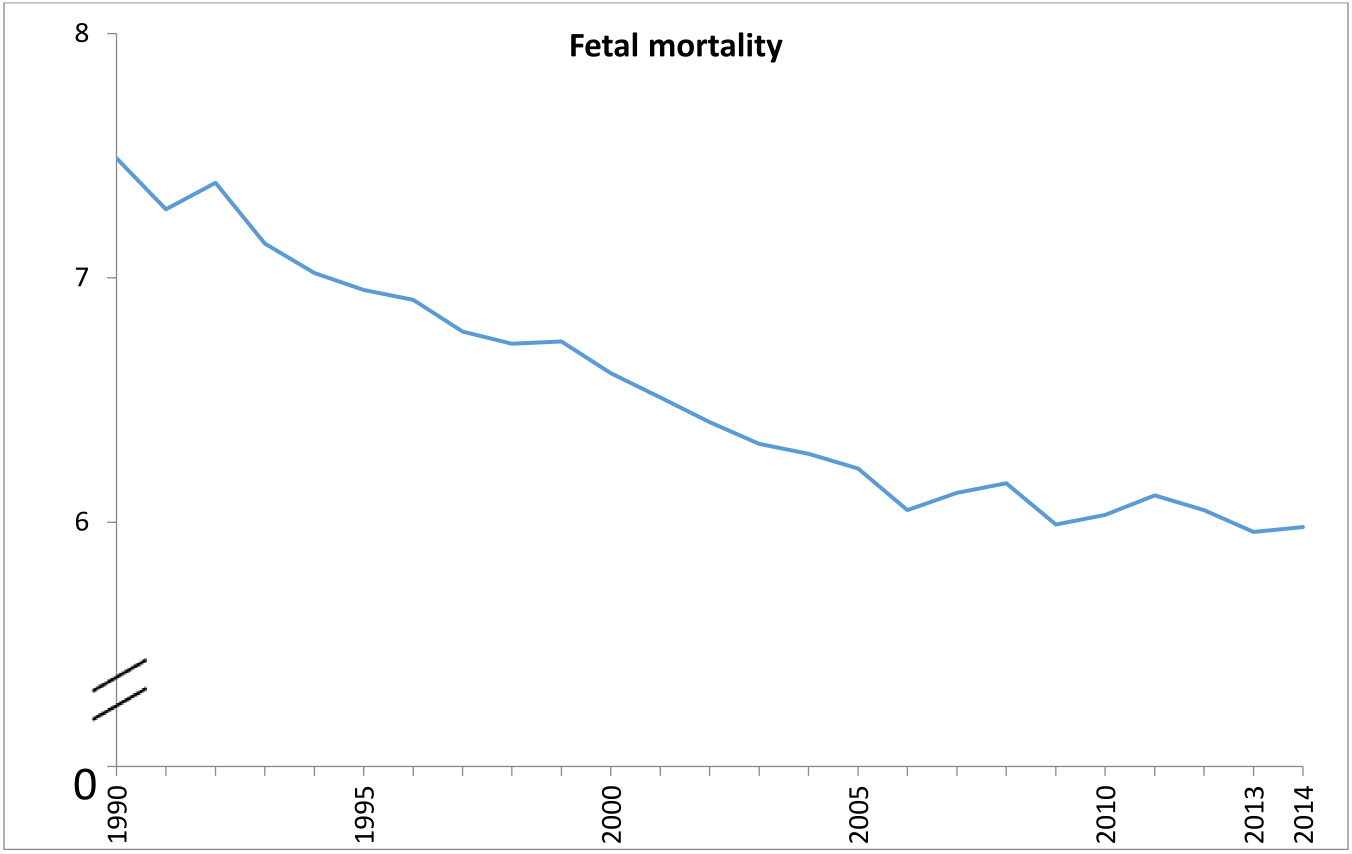
[2] Beginning in 2014, state law required reporting of fetal deaths of 350 grams or greater, and if weight is unknown, 20 completed weeks of gestation or more. Formerly, state law required the reporting of fetal deaths of all periods of gestation.

[3] State law requires the reporting of fetal deaths of all periods of gestation.

[4] Beginning in 2014, state law required reporting of fetal deaths of 20 weeks gestation or greater, or if gestational age is unknown when the fetus weighs not less than 350 grams. Formerly, state law required the reporting of fetal deaths with a weight of 500 grams or more.

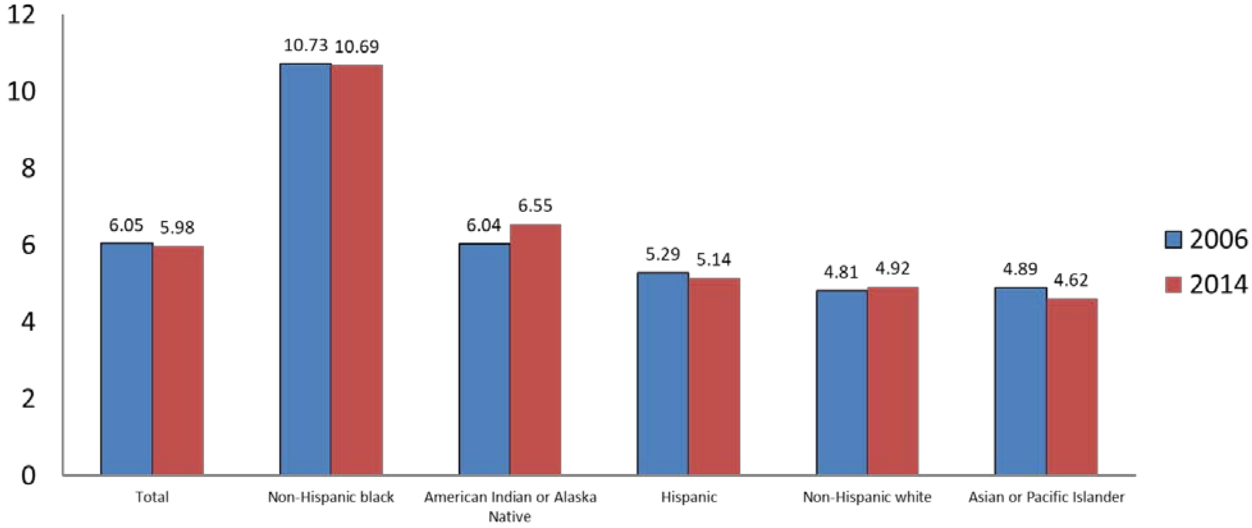
SOURCE: NCHS, National Vital Statistics System.

Figure 1. Fetal mortality rate: United States, 1990-2014



NOTES: Fetal mortality rates are the number of fetal deaths at 20 weeks of gestation or more per 1,000 live births and fetal deaths. Beginning with the 2014 data year, the obstetric estimate of gestation at delivery replaces the measure based on the date of last normal menses as the standard for measuring gestational age.
SOURCE: NCHS, National Vital Statistics System.

Figure 2. Fetal mortality rates by race and Hispanic origin of mother: United States, 2006 and 2014



NOTE: No difference between 2006 and 2014 for any group was statistically significant at $p<0.05$.
SOURCE: NCHS; National Vital Statistics System.

ADDITIONAL RESOURCES

- Stillbirth Collaborative Research Network https://www.nichd.nih.gov/research/supported/Pages/scrn.aspx
- CDC's Stillbirth Activities https://www.cdc.gov/ncbddd/stillbirth/activities.html

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Infant Health

Infant Health Commentary

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Improving infant health requires a multi-faceted approach that includes preventive services, screening programs, novel intervention strategies, and accurate and timely surveillance systems. Infant health encompasses breastfeeding, newborn screening, birth defects, preterm birth, low birth weight, and infant death to mention a few. The death of an infant is one of the most tragic events a family can experience. For the past several decades, infant mortality has served as an indicator of the health and well-being of families, communities and nations because many of the same biological, social, economic, and environmental risks that contribute to infant death also affect the health of populations. The decline in the infant mortality rate (IMR) in the United States during 1935-2000[1] — from 55.7 to 6.9 per 1,000 live births — is considered one of the 20th century's great public health victories[2]. However, IMR plateaued during 2000-2005[3], and with the 2013 rate of 6.0 per 1,000 live births, the United States lags behind 28 other developed countries[4]. Of great concern is the widening IMR racial/ethnic gap within the United States. While all racial/ethnic groups experienced steep declines in IMR over the past century, IMR for whites declined faster than for blacks, driving the black/white IMR gap from 58% in 1935[1] to 119% in 2013[4].

The US rate of preterm birth, a major contributor to infant death, has increased in recent years, ranking 19th among selected European countries with a rate of 9.8% in 2010[3]. When compared to Sweden, 39% of the excess infant mortality in the United States was due to the higher percentage of preterm births. However, 47% of the difference was due to higher mortality among infants born full term[3]. Sudden unexpected infant death (SUID) accounts for 15% of all infant deaths in the United States[5]. During 2010-2013, SUID mortality rates were higher for American Indian/Alaska Native (190.5 per 100,000) and non-Hispanic black (171.8) infants compared to non-Hispanic white infants (84.4). SUID rates were lowest among Hispanic (50.8) and Asian/Pacific Islander infants (34.7).

As maternal and child health (MCH) leaders, we have a professional obligation to elucidate why the United States, one of the wealthiest countries in the world, has such a high IMR and such stark racial/ethnic disparities in both preterm delivery and IMRs. As we rethink our approach to reducing IMR and improving infant health, particularly using innovative approaches such as the infant mortality Collaborative Improvement and Innovation Network (CoIIN) model, new data collection and surveillance systems that capture relevant and timely information become increasingly relevant. The 12-Point Plan[6] to "close the black-white gap in birth outcomes," is an excellent framework highlighting the need to improve health care services in poor and minority communities and to address inequities over the life course. Yet much of the data necessary to monitor and evaluate this framework are not available. For instance, states lack the capacity to track parental leave and early child care usage, which affect infant feeding, sleep practices and quality of care.

State-level, population-based surveillance systems play a crucial role in identifying, classifying and characterizing birth defects, a major cause of infant mortality. This includes detecting disparities in birth defects prevalence and survival, identifying new exposure risks prior to and during pregnancy, and predicting long-term medical and educational needs and associated costs. As the age of mothers at first birth increases across the country, more are using assisted reproductive technologies (ART) and medications, with known (preterm birth) and unknown risks to health outcomes[7] . Environmental exposures such as air pollution and water contamination, health behaviors like diet and exercise, and emerging infections including arboviruses, also require widespread, active surveillance to ascertain the associated risks of birth defects. The ability of states to rapidly share standardized data will help identify harmful exposures quickly, and increase opportunities for effective and timely interventions.

Linkage of surveillance data with other datasets such as inpatient, outpatient and emergency department discharges, substance abuse treatment, Early Intervention (EI), WIC, birth defects, claims (Medicaid and All

Payers Claims Databases) have been conducted in a few states including Massachusetts, Michigan, and Florida. These linkages have improved our ability to examine the effect of maternal health before pregnancy and prenatal exposures on birth outcomes and infant and child health. With support from CDC, Massachusetts developed its Pregnancy to Early Life Longitudinal (PELL) data system, a linkage of delivery and hospital discharge records for both mothers and infants. The linkage of PELL with ART clinic outcome data provided a unique, innovative, and crucial platform for studies of the impact of ART on subsequent infant health outcomes, including enrollment into EI programs[8,9]. Through increased use of electronic health information, states will increase capacity to link data from different sources.

Another area of opportunity for future surveillance is standardizing and utilizing measures of exposure to racism in order to discern its effects over the life course and across generations. The Life Course Indicators developed by the Association of Maternal and Child Health Programs, provide a set of standardized measures available to all states to use the life course approach to improve maternal and child health[10]. The National Survey of Children’s Health (NSCH) and the Pregnancy Risk Assessment Monitoring System (PRAMS) collect information on discrimination, as well as measures of community advantage including safety, social cohesion, and the built environment.

Although PRAMS data also provide important information on infant safe sleep practices (SSP), more “real time” data are needed to monitor the effectiveness of safe infant sleep initiatives taking place throughout the country. Maternal report of infant sleep practices during the birth hospitalization would help determine whether hospitals are integrating SSP into routine newborn care. In addition, data on sleep practices in child care facilities would provide more encompassing data on practices of caregivers. Despite the American Academy of Pediatrics (AAP) Task Force on SIDS recommendation that clinically stable preterm infants be placed supine by 32 weeks postmenstrual age[11], an analysis of PRAMS data (2007-2010) in Massachusetts demonstrated that late preterm infants (34-36 weeks gestation) were less likely to be placed in supine sleep position after hospital discharge. Moreover, 14% of late preterm and term infants were sleeping on an adult bed with another person[12]. These findings highlight the need to standardize parent education and the infant sleep environment in hospital settings. Massachusetts developed the neonatal intensive care unit (NICU) Safe Sleep Collaborative, with the overall goal of increasing the use of SSP among high risk infants discharged from NICUs.

The objective of Newborn Hearing Screening (NHS) programs is for all babies with permanent congenital hearing loss (PHL) to receive EI services aimed at avoiding speech/language and psychosocial delays. With legislation governing screening in the birth hospital, most states achieve nearly 100% documented screening rates. However, tracking the progress of the approximately 2.5% of babies who do not pass the NHS through diagnostic testing and EI referral/enrollment remains a challenge. Indeed, in 2013, state loss-to-follow-up rates for diagnosis ranged 4.1-79.4%. Those Early Hearing Detection and Intervention Information Systems that are linked to vital statistics and birth defects registries, EI databases, and school records form the ideal that CDC funding is helping states to work toward. Some programs already incorporate some of these elements and thus, cannot only estimate PHL prevalence and ensure proper follow-up, but also investigate PHL outcomes and evaluate the benefits of EI and school programs.

Massachusetts currently utilizes the CDC Breastfeeding Report Card to monitor trends and progress toward Healthy People 2020 breastfeeding benchmarks, as well as to provide annual updates to medical providers regarding the status of breastfeeding outcomes in the state. Massachusetts also uses PRAMS to monitor breastfeeding exclusivity and duration and allows analysis by WIC participation. The now discontinued Pediatric Nutrition Surveillance System allowed WIC programs to compare their performance against other states, as well as local agencies within states. The Maternity Practices in Infant Nutrition and Care report is an excellent tool that can be used in quality improvement initiatives with birth hospitals to improve maternity care practices related to breastfeeding.

In sum, to optimize health and developmental outcomes and give all children an equal opportunity to reach their full potential, it is important to invest in MCH programs, surveillance data capacity, and quality improvement activities. Relevant, accurate, and timely data are needed to inform programs and policy.

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Breastfeeding

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Breastfeeding is recognized globally for providing protection against infant mortality and morbidity. Despite being the recommended form of nutrition for most infants, a surveillance system focused solely on breastfeeding practices (and rates) in the United States does not exist. To monitor trends in breastfeeding practices in the United States, adaptions have been made to existing surveillance systems. Continued enhancement in breastfeeding surveillance is needed to better inform efforts to improve breastfeeding practices.

PUBLIC HEALTH IMPORTANCE

Breastfeeding plays an important role in the growth and development of infants (aged <1 year).[1-4] Globally, breastfeeding is the recommended form of nutrition for most infants.[2, 4-6] In the United States, the American Academy of Pediatrics (AAP) recommends infants be exclusively breastfed for about the first six months of life, and that breastfeeding continues for at least the first year, with the introduction of nutrient-rich complementary foods when the infant is about six months old.[2] Exclusive breastfeeding occurs when the infant receives only human milk and no other liquids (e.g., formula, water, glucose water, juice, cow's milk, or other fluids) or foods except vitamin and mineral supplements or medications (e.g., medications in liquid form, vitamin D, iron).[2, 7] In this chapter, "breastfeeding" includes human milk delivered directly from the breast, or expressed by hand or using a breast pump and delivered to the child through another method (e.g., bottle, tube feeding, spoon, cup).

The health advantages associated with breastfeeding have received increasing attention in the United States, particularly since the inclusion of breastfeeding objectivesin Healthy People 2010 and the release of the Surgeon General's Call to Action to Support Breastfeeding (Call to Action) in 2011.[8-9] Specifically, Healthy

People 2010 breastfeeding objectives called for increasing the proportion of mothers in the United States who ever breastfed, continued breastfeeding to 6 months and 1 year, and those who breastfed exclusively through 3 and 6 months, respectively.[9] Breastfeeding provides protection against morbidity and mortality for mothers and their infants.[1-2] Evidence has shown breastfeeding is protective against breast and ovarian cancer;[10-11] mothers who breastfeed longer than 12 months have a 7% lower relative risk of breast cancer[1-2, 10] and a 30% lower relative risk of ovarian cancer.[1-2, 11] In addition, emerging evidence indicates breastfeeding may also be protective against heart disease.[12] Thus, breastfeeding may help protect mothers from two of the leading causes of morbidity and mortality in women – cancer and heart disease.[13-14]

Human milk meets the unique nutritional needs of infants, facilitates optimal growth and development, and protects against adverse health outcomes.[1-4] For infants, breastfeeding is associated with a lower risk of diarrhea, respiratory infections, asthma, and ear infections, all of which are contributors to hospitalization.[1-2] Breastfed infants have a lower risk of sudden infant death syndrome, the third leading cause of infant mortality in the United States.[2, 15-16] The health advantages of breastfeeding are especially critical for infants born preterm (<37 completed weeks gestation),[2] who have increased vulnerability to adverse health outcomes, such as necrotizing enterocolitis (NEC: the most prevalent gastrointestinal disease among preterm infants) and hospital-acquired infections, two leading causes of infant morbidity and mortality.[2, 16-18]

Currently, there is no surveillance system that focuses solely on breastfeeding outcomes (i.e., initiation, duration, exclusivity, and intensity) among US infants; however, several systems collect breastfeeding data as an extension of other surveillance goals.[19] This chapter will focus on surveillance systems implemented by the Centers for Disease Control and Prevention (CDC) that include breastfeeding rate and breastfeeding-related maternity care practice. Specific focus is placed on surveillance systems that use breastfeeding data from medical records, such as the US Standard Certificates of Live Birth (birth certificate); or with recall periods of less than three years, including the National Immunization Survey-Child (NIS-Child), Pregnancy Risk Assessment Monitoring System (PRAMS), and the Maternity Practices in Infant Nutrition and Care Survey (mPINC).

HISTORY OF DATA COLLECTION

In November 1999, CDC convened a meeting to assess existing and potential surveillance systems for monitoring breastfeeding practices in the US and afterward released a report, which included recommendations for future breastfeeding surveillance.[19] When Healthy People 2010 was released in January 2000, the only source of national breastfeeding surveillance data was information collected by a manufacturer of infant formula, the Ross Laboraties Mothers Survey.[19] Concerns about a potential conflict of interest in using formula manufacturer data to track breastfeeding practices pointed to the need for public-sourced data on breastfeeding practices.[19] CDC highlighted the lack of a national surveillance system from the public sector and included the following recommendations:[19]

- Justify the need for additional resources to build a comprehensive national system;
- Add questions on breastfeeding incidence, duration, and exclusivity to the National Immunization Survey-Child;
- Ensure that breastfeeding questions on national surveys are consistent;
- Encourage state use of the optional breastfeeding questions in CDC's Pregnancy Risk Assessment Monitoring System to supplement the core measures.

Healthy People 2010 breastfeeding objectives were updated and expanded with the 2010 release of the Healthy People 2020 objectives, which underwent further revision in 2012.[9, 20] In addition to the original Healthy People 2010 breastfeeding objectives, the Healthy People 2020 breastfeeding objectives include increasing the proportion of employers that have worksite lactation support programs and reducing the proportion of breastfed newborns who receive formula supplementation within the first 2 days of life.[9, 20]

In response to recommendations from the CDC breastfeeding surveillance meeting,[19] questions on breastfeeding incidence, duration, and exclusivity were added to NIS-Child in 2001.[21] NIS-Child collects data on a nationally representative sample of households from all states; the District of Columbia; and designated local areas in Illinois, New York, Pennsylvania, and Texas.[22] CDC uses data from NIS-Child to calculate estimates of the prevalence of any and exclusive breastfeeding.[23]

During July 2001 through December 2002, breastfeeding questions were implemented among a sample of NIS-Child participants; beginning in January 2003, all respondents were asked the breastfeeding questions.[24] In 2004, the NIS-Child question on exclusive breastfeeding was modified to include water among the list of items other than breast milk (i.e., formula, juice, cow's milk, *water*, sugar water, solid foods, or anything else) that a mother may have fed her child. In 2006, CDC reframed breastfeeding duration and breastfeeding exclusivity questions in NIS-Child to ask the child's age when each practice ended (Table 1). In addition, the breastfeeding exclusivity question was split to ask separately about the age of the child when he/she was first fed: 1) formula and 2) something other than breast milk or formula (Table 1).[24] As a result, estimates of exclusive breastfeeding were substantially lower; thus, NIS-Child data users are cautioned against including pre-2006 data in reports on trends in exclusive breastfeeding.[24]

CDC uses NIS-Child breastfeeding data to derive national and state breastfeeding rates for the CDC Breastfeeding Report Card, which was released annually from 2007–2014, then biennially as of 2016.[25] Annual breastfeeding rates are available through the CDC *Breastfeeding* website.[23]

Before breastfeeding questions were added to NIS-Child, CDC assessed data on breastfeeding initiation and duration collected through the Pediatric Nutrition Surveillance System (PedNSS) and the Pregnancy Nutrition Surveillance System (PNSS).[26] PedNSS data were collected among children who visited public health clinics for routine health care, nutrition education, and supplemental foods. PNSS collected prenatal and early postpartum data on nutritional (including breastfeeding initiation) and behavioral risk factors related to infant mortality and adverse birth outcomes among low-income women enrolled in public health programs, most commonly the Special Supplemental Nutrition Program for Women, Infants, and Children (WIC).[26]

The composition of contributors participating in PedNSS and PNSS varied while the systems were operational, and not all contributors collected breastfeeding data. Although PedNSS and PNSS data were not representative of the US overall, both systems allowed for national, state, and county-level estimates of breastfeeding behaviors among WIC participants. CDC discontinued PedNSS and PNSS in 2012[27] due to overlap with the WIC Participant and Program Characteristics (WIC PC) survey, which is administered and analyzed by the US Department of Agriculture.[28]

The 2003 revision of the birth certificate included the first-ever addition of any measure of breastfeeding.[29] As of 2016, breastfeeding data were available from the birth certificate for all states (except California and Michigan), the District of Columbia, Guam, Puerto Rico, the US Virgin Islands, and the Northern Marianas.[30] Timing of the adoption of the 2003 birth certificate has varied by state;[31] consequently, national data on breastfeeding are not available and trends are limited.[30] However, the birth certificate allows for analysis of breastfeeding initiation among subpopulations, by detailed gestational age, and by state.

Originating in 1987, PRAMS provides surveillance of maternal experiences and behaviors before, during, and shortly after pregnancy, and includes data on breastfeeding initiation, duration, and exclusivity, as well as breastfeeding-related maternity care practices.[32] PRAMS is currently in its eighth phase, and has undergone revision over time, including changes to breastfeeding measures, which it began collecting from a few states during the 1990s (Phase 2).[32] As of 2018, PRAMS collects data from 47 participating states, New York City, the District of Columbia, Puerto Rico, and the Great Plains Tribal Chairmen's Health Board.[32] PRAMS also collects behavioral and sociodemographic data resulting in a rich dataset that can be used to improve understanding of influences on breastfeeding.

Initiated in 2007, mPINC, a national census of maternity care practices and policies, is conducted biennially, representing all states, the District of Columbia, Puerto Rico, and Island Territories.[33-34] The mPINC survey was developed in response to recommendations from an expert panel, which noted the lack of surveillance data on maternity care facilities in the United States.[33] In contrast to individual-level maternity care practice data collected by PRAMS, mPINC focuses on facility-level data and is completed by a facility representative(s).[32-33]

CDC SURVEILLANCE ACTIVITIES

Breastfeeding Rates

A comparison of questions measuring breastfeeding practices for each surveillance system is presented in Table 1.

National Immunization Survey-Child (NIS-Child)

CDC conducts NIS-Child with the primary purpose of collecting data on vaccination coverage among children aged 19-35 months in the United States.[35] Random-digit dialing is used to identify US households with an age-eligible child.[35] NIS-Child is conducted by a landline or cell phone interview with the child's parent or legal guardian.[35] Due to the increasing prevalence of cell phone use, in 2011 NIS-Child included a cell phone sample in addition to a landline sample; currently, participants are randomly sampled from both landline and cell phone numbers (i.e., dual-frame sampling).[22, 35] The inclusion of a cell phone sample had a minimal effect on national breastfeeding initiation and exclusivity rates, but a slightly larger effect on breastfeeding duration at the national level. Researchers caution against making rate comparisons between current dual-frame birth-year estimates and more recent landline estimates (e.g., 2007 and 2008) when cell phone-only households were increasing, but cell phone sampling had not begun.[35-36]

Breastfeeding data collected by NIS-Child are presented by birth cohort and include data from multiple survey years.[22-25] NIS-Child is the only nationally representative source of breastfeeding data and has been used since 2007 to assess Healthy People breastfeeding objectives.[9, 20]

US Standard Certificate of Live Birth, 2003 Revision

Using infant and maternal medical records, a maternity care facility representative completes the US Standard Certificate of Live Birth within five days of infant delivery.[29, 37] Breastfeeding is assessed using one dichotomous variable, "breastfed at discharge."[29] Despite question wording, the period assessed includes the time from infant birth to discharge from the facility.[29] Breastfeeding in this context includes infant receipt of human milk or colostrum, regardless of infant formula exposure; in the absence of human milk receipt, breastfeeding includes maternal establishment of or attempt to establish her milk supply (Table 2).[29]

Pregnancy Risk Assessment Monitoring System (PRAMS)

PRAMS, a collaboration between state health departments and CDC, consists of a "core" questionnaire (questions that all participating sites are required to include) and "standard" or optional questions that sites can add to their site-specific survey.[32, 38] Breastfeeding initiation and duration questions are core questions, whereas breastfeeding exclusivity questions have been standard questions since 2012.[32, 38]

PRAMS samples mothers from states' birth certificates between two and six months postpartum.[32] Each sampled mother receives a mailed questionnaire; non-respondent mothers receive up to two additional mailed questionnaires and are followed up by telephone if they do not return a questionnaire by mail.[32] To maximize response rates, sites provide mothers with a small incentive/reward, such as a prepaid gift card,[32, 39-40] but data collection attempts cease 95 days after the initial questionnaire is mailed.[32] PRAMS data are linked to birth certificate data, and select birth certificate indicators are available in the PRAMS dataset.[32]

Breastfeeding Maternity Care Practices

Pregnancy Risk Assessment Monitoring System (PRAMS)

PRAMS sites can include the optional, standard maternity care practice questions in their surveys. The questions assess breastfeeding-related maternity care that mothers report receiving during hospitalization for infant delivery,[32, 38] and correspond with many elements of the *Ten Steps to Successful Breastfeeding (Ten Steps)*, which are evidence-based maternity care practices that are supportive of breastfeeding.[34, 41-42] Only mothers who report ever breastfeeding are directed to complete these questions; consequently, data on the maternity care experiences of women who never breastfed are unavailable.

Maternity Practices in Infant Nutrition Care Survey (mPINC)

The mPINC survey collects data on seven domains of maternity care to obtain information about the typical care provided by hospitals and birth centers to healthy term newborns and their mothers. The assessed maternity practices are characterized by the following domains: 1) Labor and Delivery Care, 2) Feeding of Breastfed Infants, 3) Breastfeeding Assistance, 4) Contact between Mother and Infant, 5) Facility Discharge Care, 6) Staff Training, and 7) Structural and Organizational Aspects of Care Delivery.[34] Elements within each domain have been linked to the *Ten Steps*[34, 41-42] (Table 3). A representative of the maternity care facility who is knowledgeable about the facility's breastfeeding-related policies and practices completes mPINC, often in consultation with other knowledgeable facility staff (e.g., those who work in labor and delivery, the newborn nursery, and other areas where newborns receive care in the hospital).[34] CDC then analyzes mPINC data and develops facility-specific and state-specific reports as well as web tables with aggregate, national data.[34] The mPINC survey is scored on a scale of 0 to 100, with a higher score indicating better maternity care practices and policies that support breastfeeding.[34] Each participating facility receives a report on their total score, subscores on each domain, and information about how their scores compare to the United States overall, their state, and comparably sized facilities.[34]

GENERAL FINDINGS

Breastfeeding Rates

National Immunization Survey-Child (NIS-Child)

NIS-Child data have demonstrated consistent progress toward Healthy People 2020 targets.[9, 20, 23-24, 43] The most current available data for children born in 2014 show breastfeeding initiation is high (81.1%); however, breastfeeding duration and exclusivity rates remain low (Table 4).[43] While the number of states that have met Healthy People 2020 breastfeeding targets is increasing (Table 5), variability by state and race/ethnicity persists, pointing to the need for continued monitoring of breastfeeding outcomes.[43]

US Standard Certificate of Live Birth, 2003 Revision

In 2016, most infants were breastfed at discharge from the maternity care facility (84.7%).[30] Analysts should note that although use of birth certificate data is appropriate to assess some state trends, it is not appropriate to use to assess national trends in breastfeeding due to the variability in the number of states using the 2003 birth certificate from year to year.[30]

Pregnancy Risk Assessment Monitoring System (PRAMS)

Analyses of 2015 PRAMS breastfeeding data from 34 sites indicate that among PRAMS respondents, 87.1% initiated breastfeeding and 65.6% breastfed (any amount) at least 8 weeks.[45] Of note, like many surveillance systems that collect data from individuals, PRAMS has experienced declining response rates over time.[46-50] As a result, PRAMS lowered the response rate criterion for sites to be included in publicly available data.[48] Thus the composition of states that meet the response rate threshold varies annually, which is important for researchers to consider when planning analyses of PRAMS data to assess trends in breastfeeding practices.[48]

Breastfeeding Maternity Care Practices

Pregnancy Risk Assessment Monitoring System (PRAMS)

Results from questions used to assess maternity care practices are unavailable publicly but can be requested through the PRAMS proposal process.[48] An advantage of PRAMS maternity practices data is that it allows associations between mothers' breastfeeding outcomes and maternity practices received to be evaluated.

Maternity Practices in Infant Nutrition Care Survey (mPINC)

Scores for mPINC indicators that align with the *Ten Steps* have increased from 2007 to 2015; however, variability in the level of progress is evident (Table 6).[34, 51] Most indicators within the domains saw an improvement in scores between 2007 and 2015.[34, 51] Indicators with scores that improved by 15 or more percentage points from 2007 to 2015 included: having a comprehensive "model" breastfeeding policy (11.7% to 32.4%); annually assessing staff competency in breastfeeding management and support (44.6% to 59.9%); initiating breastfeeding within one hour of uncomplicated vaginal births (43.5% to 69.3%); having most (≥90%) mother-infant dyads together in the same room at least 23 hours per day (30.8% to 54.7%); and ensuring <10% of healthy term infants are given pacifiers by hospital staff (25.5% to 52.4%).[34, 51] Some indicators, however, improved by less than 7 percentage points, perhaps most notably: ensuring <10% of healthy term breastfed infants are supplemented with formula, glucose water, or water (20.6% to 27.0%); and routinely providing new mothers with a postpartum follow-up visit and referrals to community breastfeeding support services (26.8% to 33.7%).[34, 51] Overall, the increasing mPINC scores suggest that US maternity care facilities are making wide-scale systematic changes to better support breastfeeding.

USING DATA FOR ACTION

Public-sourced surveillance of breastfeeding rates and maternity care practices provides data on national performance on Healthy People breastfeeding objectives.[8-9, 20, 34] Breastfeeding surveillance has been instrumental in informing policy decisions and implementation of interventions to promote AAP breastfeeding recommendations and the *Ten Steps.*[2, 42] Select examples of breastfeeding surveillance data in action are highlighted below.

In 2007, baseline breastfeeding surveillance data from NIS-Child highlighted low breastfeeding duration and exclusivity rates in the United States.[9, 20] Over time, NIS-Child data highlighted that although progress had been made, a number of breastfeeding objectives had not been achieved, and pointed to the need for systems-level interventions to improve breastfeeding practices.[9, 20] In response, changes to improve promotion and support of breastfeeding have been made at the national, state, and local levels, as well as throughout hospitals across the country.

At the national and state levels, judiciary acts have been proposed and passed to help make breastfeeding an easier option.[52] When women return to work or school, breastfeeding often declines due to increasing time demands and lack of a space for breastfeeding or milk expression.[8] In response to low breastfeeding exclusivity and duration rates, legislation was enacted in 2010 that included a two-part requirement for employers to 1) provide reasonable break time and 2) a place, other than a bathroom, for employees to express breast milk.[52]

In 2011, the Surgeon General released the Call to Action, highlighting the legislation and lack of supportive breastfeeding environments in the workplace, in addition to 19 other actions that individuals, clinicians, employers, researchers, communities, states, and the federal government could take to support breastfeeding.[8] Continued breastfeeding surveillance data can be used to assess whether policies and interventions implemented at the national or state level have the intended effect on breastfeeding outcomes (i.e., breastfeeding rates and maternity care practices).

The longevity of mothers' breastfeeding experiences is often predicted by the type and level of support they receive in the maternity care facility.[53] Supportive maternity care practices can be instrumental in facilitating breastfeeding while hospitalized and continuation after discharge.[53] "Action 7" from the Call to Action encourages maternity care facilities throughout the United States to ensure they are providing care that is supportive of breastfeeding.[8] Prior to mPINC, national and state-level assessments of maternity care practices were limited.[33]

Implementation of mPINC highlighted gaps in hospitals' support of breastfeeding. Further, mPINC scores have informed quality improvement projects in maternity care facilities and can be used as a tool by individual hospitals to work toward becoming designated as Baby-Friendly.[33] From 2011 to 2015, CDC funded Best Fed Beginnings, a national quality improvement initiative, which worked with 89 hospitals to achieve the Baby-Friendly designation.[54] Currently, CDC funds EMPower Breastfeeding: Enhancing Maternity Practices (EMPower), which aims to increase the number of US Baby-Friendly hospitals and to identify best practices to help hospitals become Baby-Friendly.[54] Launched in 2014, the EMPower initiative partners provide technical assistance and training to teams from 93 hospitals in 24 states to implement the *Ten Steps* to become a Baby-Friendly facility.[55] The mPINC scores provide individual facilities, states, and the nation with information to assess adherence to evidence-based, breastfeeding-related maternity care and monitor progress following additions, changes, or continuation of breastfeeding-related maternity care practices.[33]

DATA GAPS AND LIMITATIONS

Breastfeeding surveillance is often reliant on the ability to add breastfeeding-related questions to existing surveillance systems, and the current number of breastfeeding-related questions is relatively limited.[22, 29, 32] Further, variability in question wording and differences in recall period for each surveillance system makes it challenging to compare breastfeeding outcomes across systems.

While breastfeeding-related questions in existing surveillance efforts can assess initiation, duration, and exclusivity, they are unable to delineate the intensity of breastfeeding (i.e., the proportion of an infant's milk diet that comprises human milk), mode of feeding human milk (i.e., breast vs. bottle or other medium), and source of human milk (i.e., mother's own milk vs. donor human milk). In addition, assessment of environmental and policy support for breastfeeding are currently limited to hospital settings despite efforts to improve support in other settings (e.g., workplace).

The intensity of breastfeeding has important implications for maternal, infant, and child health outcomes. Current surveillance system measures of breastfeeding do not allow for easy assessment of associations and dose-response relationships between different intensities or amounts of human milk and maternal, infant, and child health outcomes. Understanding the relationship between breastfeeding intensity and health outcomes is critical for informing breastfeeding-related policy and program implementation.

FUTURE ISSUES

Feeding human milk at the breast has been linked to increased ability of infants to self-regulate intake.[2, 56] In contrast, infants fed human milk (or formula) via a bottle have been found to be more likely to empty the bottle and consume in excess compared to infants fed at the breast, suggesting poorer self-regulation.[57, 58] Increased volume consumed of human milk (or formula) may have an impact on weight gain trajectories during infancy.[57, 58] Excessive weight gain in infancy may have potential adverse long-term health consequences.[1, 2] Additional data on the role of breastfeeding mode (human milk delivered directly from the breast versus delivered to the child through another method (e.g. bottle, tube feeding, soon, cup) is warranted.

Individual studies have shown that infants born preterm have different feeding experiences than healthy, term infants.[59-60] Compared with term infants, those born preterm tend to have higher rates of comorbidities that may benefit from human milk receipt, but have lower rates of human milk consumption.[17, 61-61] Early gestational age (e.g., infants born preterm) can have a significant effect on infants' abilities to feed directly at the breast due to underdevelopment of coordination and swallowing reflexes, as well as gut development.[60] Additionally, mothers who give birth to preterm infants may experience delayed milk production and secretion (i.e., lactogenesis), which can be detrimental to their ability to breastfeed.[63] While NIS-Child presents data on breastfeeding, data on infant gestational age are not collected; therefore, results cannot be reported by infant gestational age.[22] Published, nationally representative data on breastfeeding rates by gestational age would be valuable in informing maternity care practices, as the breastfeeding support needs of mothers giving birth to preterm infants may differ from those of mothers giving birth to healthy term infants. For example, mothers who give birth to very preterm (<34 weeks gestation) infants must initiate milk expression (pumping) and continue expressing milk for an extended period before their infant is able to attempt to feed directly at the breast;[63] to succeed in doing so often requires skilled support.

Among preterm infants, use of donor human milk when mothers are unable to provide their own human milk may be increasing,[64] but it is challenging to know for certain because current CDC surveillance systems do not capture adequate information about donor milk use.[33] While donor milk use has been shown to be beneficial compared with the use of formula among preterm infants, use of mother's own human milk is recommended when possible.[2] To optimize infant health, understanding the prevalence, availability, and barriers to donor milk use among preterm and other infants is important for identifying target action areas.

Despite progress in breastfeeding surveillance over the past two decades, continued improvement is needed.[9, 20] Better understanding the role of societal structures that impact breastfeeding such as workplace leave policies will better identify a fuller suite of tools to improve breastfeeding practices and outcomes. This may be especially salient to women with traditionally lower rates of breastfeeding and may help serve to close the gap in breastfeeding disparities.[65]

ADDITIONAL RESOURCES

- CDC Breastfeeding Website

  https://www.cdc.gov/breastfeeding/

- CDC mPINC Survey

  https://www.cdc.gov/breastfeeding/data/mpinc/

- CDC NIS Website

  https://www.cdc.gov/vaccines/imz-managers/nis/

- CDC PRAMS Website

  https://www.cdc.gov/prams/index.htm

- Surgeon General’s Call to Action to Support Breastfeeding

  https://www.surgeongeneral.gov/library/calls/breastfeeding/

- Baby-Friendly USA

  https://www.babyfriendlyusa.org/

- Office on Women’s Health, US Department of Health and Human Services

  https://www.womenshealth.gov/breastfeeding/

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Table 1. Comparison of Breastfeeding Questions by Surveillance System

	Breastfeeding Initiation	**Breastfeeding Duration**	**Breastfeeding Exclusivity**
National Immunization Survey-Child (NIS-Child); 2006 – present (24)	Was [child's name] ever breastfed?	How old was [child's name] when [child's name] completely stopped breastfeeding or being fed breast milk?	How old was [child's name] when (he/she) was first fed formula? This next question is about the first thing that [child] was given other than breastmilk or formula. Please include juice, cow's milk, sugar water, baby food, or anything else that [child] may have been given, even water. How old was [child's name] when (he/she) was first fed anything other than breastmilk or formula?
U.S. Standard Certificate of Live Birth (29, 30)	Is the infant being breastfed at discharge?	None	None
Pregnancy Risk Assessment Monitoring System (PRAMS) (32)	Did you ever breastfeed or pump breast milk to feed your new baby, even for a short period of time?	Are you currently breastfeeding or feeding pumped milk to your baby? How many weeks or months did you breastfeed or pump breast milk to feed your baby?	How old was your new baby the first time he or she drank liquids other than breast milk (such as formula, water, juice, tea, or cow's milk)?* How old was your new baby the first time he or she ate food (such as baby cereal, baby food, or any other food)?*

*PRAMS questions on breastfeeding exclusivity are applicable only to states that implemented the standard questionnaire in addition to the core questionnaire.

Table 2. Certificate of live birth definitions of “breastfed at discharge” and instructions for completing the certificate (29)

Information on whether the infant was receiving breast milk or colostrum during the period between birth and discharge from the hospital.

Breastfeeding refers to the establishment of breast milk through the action of breastfeeding or pumping (expressing).

Include any attempt to establish breast milk production during the period between birth and discharge from the hospital.

Include if the infant received formula in addition to being breastfed.

Does not include the intent to breastfeed.

Check “yes” if the infant was breastfed at any time before being discharged from the hospital.

Check “no” if the infant was not breastfed before being discharged from the hospital.

Table 3. The *Ten Steps to Successful Breastfeeding* and Corresponding Indicators from the CDC mPINC Survey (34, 41)

Ten Steps to Successful Breastfeeding*[†]	Corresponding mPINC Indicators
1. Have a written breastfeeding policy that is routinely communicated to all health care staff	Model breastfeeding policy: Hospital has a written breastfeeding policy that includes 10 model policy elements[§]
2. Train all health care staff in skills necessary to implement this policy	Staff competency assessment: Nurses/birth attendants are assessed for competency in basic breastfeeding management and support at least once per year
3. Inform all pregnant women about the benefits and management of breastfeeding	Prenatal breastfeeding education: Breastfeeding education is included as a routine element of prenatal classes
4. Help mothers initiate breastfeeding within an hour of birth	Early initiation of breastfeeding: ≥90% of healthy full-term breastfed infants initiate breastfeeding within one hour of uncomplicated vaginal birth
5. Show mothers how to breastfeed, and how to maintain lactation even if they should be separated from their infants	Teach breastfeeding techniques: ≥90% of mothers who are breastfeeding or intend to breastfeed are taught breastfeeding techniques (e.g. positioning, how to express milk, etc.)
6. Give breastfeeding newborn infants no food or drink other than breastmilk unless medically indicated	Limited use of breastfeeding supplements: <10% of healthy full-term breastfed infants are supplemented with formula, glucose water, or water
7. Practice rooming in – that is, allow mothers and infants to remain together 24 hours per day	Rooming-in: ≥90% of healthy full-term infants, regardless of feeding method, remain with their mother for at least 23 hours per day during the hospital stay
8. Encourage breastfeeding on demand	Teach feeding cues: ≥90% of mothers are taught to recognize and respond to infant feeding cues instead of feeding on a set schedule
9. Give no artificial teats or pacifiers to breastfeeding infants	Limited use of pacifiers: <10% of healthy full-term breastfed infants are given pacifiers by maternity care staff
10. Foster the establishment of breastfeeding support groups and refer mothers to them on discharge from the hospital or clinic	Post-discharge support: Hospital routinely provides 3 modes of post-discharge support to breastfeeding mothers: physical contact, active reaching out, and referrals[¶]

*These are the Ten Steps to Successful Breastfeeding as implemented by Baby-Friendly USA. In the U.S., these are the same as the WHO/UNICEF Ten Steps to Successful Breastfeeding except for Step 4, which in the U.S. says mothers should initiate breastfeeding within one hour of birth, compared to thirty minutes elsewhere.

[†] In April 2018, WHO/UNICEF released updated Ten Steps to Successful Breastfeeding: http://www.who.int/nutrition/bfhi/ten-steps/en/

[§] Model policy elements are 1) in-service training, 2) prenatal breastfeeding classes, 3) asking about mothers' feeding plans, 4) initiating breastfeeding within one hour of uncomplicated vaginal birth, 5) initiating breastfeeding after recovery for uncomplicated cesarean sections and/or showing mothers how to express milk and maintain lactation if separated from infant, 6) giving only breast milk to breastfed infants, 7) rooming-in 24 hours per day, 8) breastfeeding on demand, 9) no pacifier use by breastfed infants, 10) referral of mothers with breastfeeding problems and/or referral of mothers to appropriate breastfeeding resources at discharge.

[¶] Physical contact: home visit, hospital postpartum follow-up visit; Active reaching out: follow-up phone call to patient after discharge; Referrals: hospital phone number to call, hospital-based support group, other breastfeeding support group, lactation consultant/specialist, WIC, outpatient clinic.

Table taken from “Indicators on the Ten Steps to Successful Breastfeeding” available at https://www.cdc.gov/breastfeeding/data/mpinc/results-tables.htm

Table 4. Comparisons of Healthy People 2020 Targets, Baseline Measures, and Most Current Breastfeeding Rates – United States (20, 43)

Healthy People 2020 Breastfeeding Indicators	Healthy People 2020 Target (%)	Healthy People 2020 Baseline (Children Born in 2006) (%)	Current US Breastfeeding Rates (Children Born in 2014) (%)
Ever breastfed	81.9	74.0	81.1
Breastfed 6 months	60.6	43.5	51.8
Breastfed 12 months	34.1	22.7	30.7
Exclusively breastfed 3 months	46.2	33.6	44.4
Exclusively breastfed 6 months	25.5	14.1	22.3

Table 5. Number of States* Meeting the Healthy People 2020 Breastfeeding Objectives among children born in 2010 and 2014

Healthy People 2020 Breastfeeding Indicators	Number of States That Met Healthy People 2020 Targets	
	Children Born in 2010†	Children Born in 2014‡
Ever breastfed	16	29
Breastfed 6 months	8	12
Breastfed 12 months	7	19
Exclusively breastfed 3 months	9	22
Exclusively breastfed 6 months	3	18

* Includes Puerto Rico

† Source for breastfeeding data on children born in 2010 derived from CDC 2013 Breastfeeding Report Card (44).

‡ Source for breastfeeding data on children born in 2014 derived from CDC 2016 Breastfeeding Report Card (43).

Table 6. Average mPINC Scores*, Overall and by Domain – United States, 2007—2015

mPINC Indicator	Year (Number of Respondent Maternity Facilities[†])				
	2007 (N=2,687)	2009 (N=2,666)	2011 (N=2,742)	2013 (N=2,667)	2015 (N=2,582)
Total Score	63	65	70	75	79
Labor & Delivery Care	59	63	70	80	85
Feeding of Breastfed Infants	76	78	81	84	86
Breastfeeding Assistance	79	81	84	86	89
Mother/Infant Contact	67	71	74	79	83
Discharge Care	40	43	49	62	68
Staff Training	51	51	57	62	64
Structural & Organizational Aspects of Care	66	69	71	74	77

*The mPINC survey is scored on a scale of 0 to 100, with a higher score indicating implementation of maternity practices that support breastfeeding, aligning with the *"Ten Steps."* Each domain subscore is computed by taking an average of scores for the questions comprising the domain. The total mPINC score is the average of the seven domain scores (34).

[†] The number of hospitals and birth centers that responded to the mPINC survey.

Screening of Newborns

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The systematic screening of newborns in the United States has continued to improve substantially over the past 50 years. Serious problems such as profound hearing loss are being identified soon after birth for many infants, and this early screening allows for appropriate interventions to be targeted at the babies before the defect has had an irreversible negative impact of the infant's future academic and social development. Local jurisdictions play a major role in this screening and follow-up intervention strategy. Efforts are under way to connect public health and clinical services by leveraging advances in health information technology.

PUBLIC HEALTH IMPORTANCE

Screening of newborns (designated NBS) is conducted in the United States as a nationwide system in which more than 98% of the almost 4 million infants born each year are screened soon after birth for one or more congenital conditions, and if any of the screen results are positive, the newborns are referred for clinical or early intervention services. NBS includes both laboratory testing for various disorders using dried blood spots collected on filter paper cards and point-of-care screening, usually conducted at the place of birth. The US Department of Health and Human Services (HHS) has established a Recommended Uniform Screening Panel (RUSP) that as of February 2016 included 34 core disorders that all states are recommended to screen for[1]. Two of those involve point-of-care screening (i.e., congenital hearing loss and critical congenital heart disease), and the remaining disorders are detected through laboratory analysis of dried blood spot specimens. States and other jurisdictions define their own screening policies, including deciding which disorders to include in state-defined screening panels, although most follow the RUSP. In 2009, approximately 12,500 infants were diagnosed with disorders following the screening they received as newborns, including more than 5,000 with congenital hearing loss[2,3].

NBS systems are critical to effective public health practice, but screening per se does not improve outcomes. It is the receipt of timely and effective interventions following screening and diagnosis that results in improved health and developmental outcomes. Public health programs can take actions to assure that the ultimate purpose of NBS is fulfilled, including short-term and intermediate monitoring of delivery screening by program staff, follow-up to diagnosis, and referral to services. Long-term follow-up of health outcomes, such as developmental milestones and academic performance, is also important to demonstrate the public health impact of NBS. If public health programs are to meet these objectives, the process must make use of data systems for collecting information on screening and diagnostic assessments and, ideally, reports of the receipt of services and outcomes. CDC supports surveillance and data system activities related to screening newborns through funding and technical assistance, which is the focus of this chapter.

Congenital hearing loss affects one to three of every 1,000 live born infants in the United States [4].Without detection and early intervention, hearing loss can have a negative impact on a child's development, including delayed speech, language, social, and emotional development[5,6]. To address this public health issue, each US jurisdiction (n = 59: 50 US states, the District of Columbia, the Commonwealth of Puerto Rico, the US Virgin Islands, the Commonwealth of the Northern Marianna Islands, American Samoa, Guam, the Federated States of Micronesia, the Republic of the Marshall Islands, and the Republic of Palau) has established an Early Hearing Detection and Intervention (EHDI) program. As of 2015 a total of 43 jurisdictions had passed statutes or regulatory guidance related to identifying infants who are deaf or hard of hearing (DHH)[7].These programs are working to ensure that all US newborns are screened for hearing loss, receive follow-up diagnostic audiologic testing if they do not pass screening, and obtain early intervention services if diagnosed as DHH. A CDC analysis in 2007 found that rates of screening newborns for hearing loss were substantially higher in states with legislation that either requires or promotes hearing screening[8].

The early identification of infants with who are DHH is endorsed by the Joint Committee on Infant Hearing (JCIH), whose members include multiple national professional and advocacy organizations[9]. Screening of newborns for hearing loss has also been recommended by the US Preventive Services Task Force (Grade B recommendation) and included in the HHS RUSP[1,10]. The recommended national benchmarks for the EHDI process, which are supported by the JCIH, include hearing screening for infants at no later than 1 month of age, diagnostic testing no later than at 3 months of age (for those infants who did not pass the hearing screening), and enrollment into an early intervention service no later than at 6 months of age (for those identified with a permanent hearing loss). Progress towards these benchmarks is measured by the *Healthy People 2020* Objective ENT-VSL-1. In addition, three EHDI-related quality measures, initially endorsed by the National Quality Forum (NQF) in 2011, were re-endorsed by the NQF in November 2015[11,12].

HISTORY OF DATA COLLECTION

Data related to screening newborns for hearing loss and follow-up were initially collected by the Directors of Speech and Hearing Programs in State Health Welfare Agencies (DSHPSHWA), which is a national organization that promotes public health programs that target the diagnosis and treatment for communication disorders. DSHPSHWA convened a task force in 1995 to begin development of a standardized data set that could be collected by states. As part of this effort, CDC collaborated with DSHPSHWA to develop a list of EHDI data items, which were included in a paper-based survey that was sent annually from 1999 through 2004 to representatives of jurisdictional EHDI programs. The original version of the survey included seven questions, whereas later versions included 15 questions. To minimize collection burden, the survey requested only aggregate data and allowed estimated information to be reported if actual data were not available. At the request of DSHPSHWA, CDC assisted in the analysis of these survey data and made summaries available on the CDC web site (www.cdc.gov/ncbddd/hearingloss/documents/1999-2004_dshpshwa-summary.pdf). DSHPSHWA retired the survey after the collection of data for calendar year 2004.

To obtain more complete data, the CDC EHDI program, in collaboration with DSHPSHWA Health Resources and Services Administration (HRSA), and jurisdictional EHDI programs, developed the Hearing Screening and Follow-up Survey (HSFS), which can be found on the CDC EHDI website (www.cdc.gov/ncbddd/hearingloss/ehdi-data.html). This voluntary survey is approved for use by the Federal Office of Management and Budget (OMB) and serves as the primary national source of EHDI-related data. It has been used to gather aggregate-level data for years 2005 through 2013 and is intended to be used to gather data for 2014 and beyond. The HSFS is sent to jurisdictional EHDI programs annually and gathers standardized data about the hearing screening, diagnostic, and intervention status of all births that occurred in a jurisdiction. To help ensure accuracy, jurisdictions are instructed to report only non-estimated data for this variable.

CDC SURVEILLANCE ACTIVITIES

To support the early identification of infants who are DHH, CDC has provided funding to assist jurisdictions in developing and implementing EHDI tracking and surveillance systems, commonly referred to as EHDI Information Systems (EHDI-IS). These systems serve as a key tool in efforts by jurisdictional EHDI programs to ensure that all infants are screened for hearing loss and receive recommended follow-up diagnostic and early intervention services. Although the design and capabilities of these systems vary, each of the 52 jurisdictions currently funded by CDC now has an EHDI-IS in place to help ensure the provision and documentation of hearing screening, and diagnostic and intervention services. Jurisdictions also use their EHDI-IS to analyze and report data to stakeholders, including CDC, by generating summaries from the individual-level data within these systems.

Most CDC surveillance activities associated with EHDI are based on the HSFS, which is sent to the coordinator of each jurisdiction’s EHDI program requesting aggregate-level data. The survey consists of three separate parts. Part 1 requests information about the number of infants screened, diagnosed with permanent hearing loss, and enrolled in early intervention. Data are also collected about reasons infants did not receive recommended services if none were documented. Part 2 requests configuration (bilateral or unilateral), type (sensorineural, conductive, mixed, auditory neuropathy and unknown) and severity (mild, moderate, severe, profound, and unknown) data for all infants diagnosed with permanent hearing loss. Part 3 requests aggregate demographic data (e.g., infant’s sex, maternal age at the birth of this infant, race, ethnicity, and education) for selected items reported in Part 1. Data are collected annually, and there is an intentional delay in the collection (i.e., data for year 2013 were collected in January 2015). This delay is necessary because infants born in December of the given reporting year need adequate time to complete the EHDI process, which may include diagnostic testing and enrollment in appropriate intervention.

To help ensure reported data are complete, the HSFS uses a series of automated error checks to verify that the screening, diagnostic, and intervention status of each birth that occurred in the jurisdiction is reported. For example, if a jurisdiction reports 1,000 births, the screening status (e.g., screened, not screened, unknown) of all 1,000 newborns has to be accounted for before the survey can be completed. The HSFS defines births that have occurred as the birth of any infant that is born within the reporting period, in the reporting jurisdiction, including those born in military facilities, even if the infant's family resides in another jurisdiction. When a jurisdiction is unable to provide the status of an infant, they are asked to provide a reason why the evaluation of that infant could not be documented and reported. A detailed explanation document that defines each data element on the HSFS is available to jurisdictions from CDC, as shown below. Summaries of the data collected using the HSFS are available online at: www.cdc.gov/ncbddd/hearingloss/ehdi-data.html.

GENERAL FINDINGS

Data from jurisdictions that responded to the HSFS for calendar year 2013 show that an average of 97% (n=3,805,631) of all newborns were documented as having been screened for hearing loss in 2013, with 91% (n=3,490,133) of the infants having been screened before the benchmark of 1 month of age. Of those who did not pass the final hearing screening (n=61,653), 59% completed recommended follow-up diagnostic testing, with 69% (n=21,904) of the infants receiving a diagnosis before the benchmark of 3 months of age. Diagnosis includes confirmation of "permanent hearing loss" or "no identified hearing loss." Of the infants that did not pass the screening procedure in the 2013 cohort, an average of 10% (n=5,246) were diagnosed with permanent hearing loss. The prevalence of confirmed permanent hearing loss was 1.5 per 1,000 newborns screened. Of the infants identified with a permanent hearing loss, an average of 63% (n=3,486) were enrolled in and started receiving early intervention, with 69% (n=2,397 enrolled before the benchmark of 6 months of age. Enrollment in early intervention for the HSFS is defined as the infant having a signed (by the EI (Early Intervention) Provider and a parent or guardian) Individualized Family Services Plan, which is a written plan of care for infants and toddlers with a developmental delay or disability. This plan is in accord with Part C of the Individuals with Disabilities Education Act[13]. Reports for surveillance years between 2005 through 2014 that summarize progress in meeting benchmarks, as shown by the EHDI data, have been published by CDC and are available online[14,15].

Although sustained progress has been made, jurisdictions still face challenges in ensuring that all infants are documented as receiving recommended follow-up diagnostic testing and/or intervention services. In calendar year 2013, jurisdictions reported 32% (n=17,181) of infants that did not pass the hearing screening were either lost to follow-up (LFU) or lost to documentation (LTD) for diagnosis. Of those identified with hearing loss, 24%

(n = 1,334) of infants were LFU/LTD for enrollment in intervention. Since it is difficult for jurisdictions to distinguish between cases of LFU and cases of LTD, these data are reported by CDC as a combined rate. A common reason for LFU is created when parents do not follow through on obtaining the recommended services for their child. A common reason for programs not being able to document the receipt of follow-up is created when providers do not submit documentation of the results of diagnostic testing and/or intervention enrollment status to the appropriate jurisdiction. Also, infants born to non-residents of a given jurisdiction may be more difficult to track.

USING DATA FOR ACTION

Although more than 95% of infants born in the United States are being consistently screened for hearing loss, screening alone is not enough to ensure that infants who are DHH can fully develop their communication, language, and social skills. Diagnostic testing is necessary to confirm whether a hearing loss is present when an infant does not pass the screening as a newborn. In 2005, which was the first year CDC collected data using the HSFS, jurisdictions used data captured by their EHDI-IS to report progress toward the early identification of infants who are DHH. The data for 2005 indicated that 64% (n=38,411) of infants that did not pass the hearing screening were LFU/LTD because there was no documentation that they had received recommended diagnostic follow-up testing. To raise awareness among jurisdictions and address this issue CDC highlighted findings about LFU/LTD in presentations and publications, and collaborated with national partners[14-19].

Jurisdictions responded to these findings in several ways. First, jurisdictional EHDI programs analyzed data within their EHDI-IS to identify gaps in the data and potential reasons and factors related to LFU/LTD. In some cases, CDC staff provided technical assistance in the analysis of the data and discussed ways to improve data standardization. This outreach involved, first, clarifying the requirements needed to consider a parent “unresponsive,” which is one of the categories used by CDC to determine the LFU/LTD rate. Second, jurisdictions reviewed their follow-up protocols and data reporting policies. Third, jurisdictions actively engaged hospitals, providers, and other stakeholders to identify ways to assure and document that recommended follow-up services had been provided.

CDC engaged with and supported initiatives by national partners, including HRSA and the American Academy of Pediatrics (AAP). HRSA’s Maternal and Child Health Bureau funded an extensive quality improvement collaborative between 2006 and 2013 where EHDI programs developed strategies specific to their jurisdiction to decrease rates of LFU/LTD. CDC supported this effort by providing assistance in the collection and analysis of data that were used to help assess jurisdictional progress during the collaborative. The collaborative led to the development of several strategies to help improve the provision of follow-up services, such as having birth hospitals make follow-up appointments for infants not passing the screening and calling families to remind them about upcoming appointments[20,21]. CDC collaborated with AAP by providing input into developing their educational materials for physicians to deal with LTD in the client's primary care provider's office, and presenting to pediatricians about the importance of follow-up services among infants not passing the hearing screening[22]. CDC also collaborated with an EHDI Data Committee, which includes representatives from jurisdictional EHDI programs, to refine the HSFS. This collaboration resulted in several updates to the HSFS, including the addition of new data fields and clarification of data definitions related to LFU/LTD. These changes have helped to improve the completeness and standardization of the data being collected from jurisdictions.

The percentage of infants who were referred and not documented to have received recommended follow-up diagnostic testing has been steadily decreasing since 2006. The percent LFU/LTD in 2006 was 48% compared to 32% in 2013. During this same period, the percentage of infants documented as diagnosed with a permanent hearing loss each year increased from 5% to 10% among those not passing their final hearing screening[13].

DATA GAPS AND LIMITATIONS

The data gathered through the HSFS are subject to at least five main limitations. First, because the HSFS is a voluntary survey, some jurisdictions either did not respond to CDC requests to complete and submit it or were only able to provide limited data in one or more reporting years. As a result, there were differences in the number of jurisdictions reporting data to CDC each year (range: 48-57). Its use has increased, since the response rate for the 2013 HSFS was 97%, an improvement from the 83% rate in the initial years of the HSFS. Second, the data reported only reflect those services that infants were documented to have received. Because reporting of hearing screening for newborns and follow-up data are not required in all jurisdictions, it is possible for a jurisdiction to have a higher percentage of infants receiving diagnostic and early intervention services (and therefore lower rates of LFU/LTD) than was reported. Third, variations between jurisdictions in the percentage of children diagnosed with permanent hearing loss could result from either differences among jurisdictions in screening and diagnostic protocols or differences in the underlying prevalence of congenital hearing loss. Fourth, while definitions for each item in the HSFS have been established and technical assistance is provided on an ongoing basis, it is possible that jurisdictions may complete the survey in ways that lack consistency in at least some elements of this voluntary data reporting. Such differences can impact the comparability of the data that are reported. Fifth, although jurisdictions are supposed to report the total number of births that occurred in their jurisdiction, there may be some underreporting due to home births not necessarily being consistently reported to every EHDI program.

Although surveillance related to infant hearing loss has steadily improved, several challenges remain. First, the nature of the data that are captured by each jurisdiction varies. For example, some jurisdictions routinely capture and record detailed demographic data about each infant while others do not. Second, there are variations between each jurisdiction's EHDI-IS, with some being advanced systems integrated with other public health information systems that support online data reporting; others are standalone systems that rely on manual data entry. This variation has resulted in differences in the completeness and quality of data captured across the United States. Third, the availability of epidemiologic and statistical support is often limited in jurisdictions, which has impacted the ability of EHDI programs to conduct detailed analysis of the data that are being captured, and thus limit their ability to have their data collection efforts inform and improve public health practice in their state.

FUTURE ISSUES

Identifying ways to further improve the completeness and standardization of EHDI-related data is an important component of ensuring all DHH infants are identified early. Since 2007, CDC has worked to connect public health and clinical services by leveraging advances in health information technology. The CDC EHDI program has worked with the National Library of Medicine, Health Level 7 International, and the Integrating Healthcare Enterprise to establish standard guidelines aimed at improving the electronic reporting and exchange of information with electronic health records. In addition, to ensure that consistent, high-quality performance measurement information is publicly available, CDC developed a series of quality measures. These measures have been endorsed by the NQF[12]. All these national efforts are aimed at improving the epidemiological understanding and early identification of children with hearing loss, linkage to follow-up services, and the surveillance of their progress and outcomes.

ADDITIONAL RESOURCES

- Annual results from the Hearing Screening and Follow-up Survey (HSFS) www.cdc.gov/ncbddd/hearingloss/ehdi-data.html.
- EHDI Data Analysis and Statistical Hub (DASH) www.cdc.gov/ncbddd/hearingloss/ehdi-data.html.

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Surveillance for Birth Defects

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Birth defects are important to monitor at a population level given the significant contributions of birth defects to infant death, medical and social costs, and life-long disabilities and morbidities. Although the first surveillance system in the United States was established in 1929 to monitor babies born with birth defects in New Jersey, most systems in the United States were not developed until more recent decades. Progress has been made in identifying, understanding, and managing birth defects. Survival rates among children with birth defects in the United States continue to improve, although disparities in various population groups and in different geographic locations continue to exist. Not only do birth defects take a toll on families, but they also represent a substantial economic cost to society. The major causes of birth defects have not yet been identified and work in this area is ongoing. Moreover, a better understanding is needed of health care uses as well as the health and social needs of these children across their lifespan.

PUBLIC HEALTH IMPORTANCE

Birth defects are common, costly, and critical conditions that affect one in 33 infants and cause one in five infant deaths in the United States.[1,2] They are defined as conditions that: a) result from a malformation, deformation, or disruption in one or more parts of the body, a chromosomal abnormality, or a known clinical syndrome; b) are present at birth; and c) have a serious, adverse effect on health, development, or functional ability.[1] To better understand the impact of birth defects and health outcomes of individuals with birth defects, ongoing population-based surveillance systems have been established to monitor birth defects, form a foundation for determining and characterizing risks and causes, and evaluate prevention and intervention activities.

Some birth defects disproportionately affect certain racial or ethnic groups. Racial/ethnic disparities were suggested in 57% of the 46 major birth defects examined from a population-based, active case-finding ascertainment system in the metropolitan Atlanta, Georgia area.[3] Furthermore, Canfield and colleagues reported a significantly higher prevalence among American Indians or Alaska Natives than among non-Hispanic whites using data from multi-state population-based surveillance systems.[4]

Survival for US children with birth defects continues to improve, although disparities continue to persist, with much larger racial/ethnic disparities in survival than the pattern for birth prevalence indicates. Wang and colleagues reported an increase in the overall probability of survival from about 78% to 89% over a 25-year survival period (birth years 1983 through 2006).[5] However, the overall survival probability was less than 60% for children who have birth defects as well as very low birth weight (≤ 1500 g), regardless of gestational age at birth. In addition, racial/ethnic differences in survival and mortality risk for children ages 0 to 8 years with birth defects have been documented.[6] The black-white disparities in mortality risk were observed across different conditions and widened in childhood for several congenital heart defects (CHDs). When considering contextual factors, the greatest mortality risk among infants with CHDs has been associated with residing in communities in the most disadvantaged population areas in terms of poverty, low education level, and low-paying parental operator or laborer occupations.[7]

Children with birth defects are at an increased risk for comorbidities and life-long disabilities. Decouflé and colleagues reported that a child with a birth defect was eight times more likely than a child without a birth defect to have a serious developmental disability.[8]

The economic costs of caring for children with birth defects are high. The estimated annual cost for birth defect-associated hospitalizations in the United States was $22.9 billion in 2013.[9] Furthermore, this does not take into consideration non-hospitalization costs associated with treatment, management, and life-long care of individuals with birth defects and their families.

In addition to the need for more accurate and specific characterization of birth defects, much work remains in successful efforts to understand their causes. Most birth defects have unknown causes, but progress has been made to better understand some of the risk factors, such as maternal diabetes and obesity, maternal opioid medication use, and maternal smoking.[10] Most recently, a causal link was established between maternal Zika virus infection and microcephaly and other serious brain anomalies.[11] Accelerating work to identify risk factors for birth defects will help translate the findings into effective prevention strategies.

HISTORY OF DATA COLLECTION

The first population-based surveillance system in the United States was established to monitor babies born with birth defects in the state of New Jersey in 1929.[12] This system was developed to link children with birth defects to medical and social services. The development of similar surveillance systems across the United States did not expand substantially until the 1970s and 1980s, when systems began to proliferate as a result of concerns over environmental exposures such as thalidomide and the environmental toxins discovered during the New York Love Canal landfill incident. The number of state population-based surveillance programs grew from three in the early 1970s to 28 by the early 1990s.[12] Additional clusters of birth defects associated with environmental concerns, such as a cluster of anencephaly in a border region of Texas, as well as a need for data-driven prevention and intervention strategies, have served as an impetus for the development of additional state surveillance programs.

Nationally, support for population-based surveillance for birth defects led to the passage of the Birth Defects Prevention Act of 1998 (PL 105-168).[13] This act directed the Centers for Disease Control and Prevention (CDC) to: a) collect, analyze, and make data on births defects available; b) operate regional centers for the conduct of applied epidemiological research on the prevention of such defects; and c) provide information and education to the public on the prevention of such defects. The act further directed CDC to encourage states to establish or improve surveillance programs for birth defects and to establish and maintain a national clearinghouse to collect and disseminate information on birth defects, including prevention strategies to apply before these defects occur. The subsequent Children's Health Act of 2000 (PL 106-310) directed CDC to continue its birth-defects-related surveillance, research and information dissemination activities.[14]

The number of states that collect data on birth defects has continued to grow since 2000. Currently, 43 states have established population-based birth defects surveillance programs that use various data-collection methods.[15]

CDC SURVEILLANCE ACTIVITIES

In 1967, CDC established the Metropolitan Atlanta Congenital Defects Program (MACDP) in collaboration with Emory University and the Georgia Mental Health Institute.[16] MACDP pioneered a more accurate method of gathering data on birth defects that uses specially trained collectors to abstract information from medical records at birthing facilities and involves review of potential case information by a clinician. This active case-finding method has served as a model for birth defects surveillance systems in the United States and around the world. MACDP has also been a training ground for birth defects surveillance and analytic methods, epidemiologic studies, and clinical expertise for almost five decades. For example, CDC created a more detailed coding scheme to more accurately capture information on birth defects that expanded the International Classification of Diseases, 9th Revision, Clinical Modification (ICD-9-CM) coding system. With the transition to ICD-10-CM on October 1, 2015, CDC has developed a new expanded coding scheme based on the ICD-10-CM structure.

CDC provides technical support and funding for population-based birth defects surveillance in the United States. CDC began providing funding support to state surveillance programs in the 1990s to bolster state capacity to conduct ongoing, population-based birth defects surveillance and to use the data to: monitor the impact of birth defects on the community; implement and evaluate prevention strategies; and identify gaps and refer families to medical and social services.

Using the infrastructure of population-based birth defects surveillance systems, in 1993 CDC began conducting applied epidemiologic research to examine modifiable risk factors for birth defects through a pilot risk-factor study in three sites - California, Iowa, and Metropolitan Atlanta. In 1997, CDC expanded the etiologic research using cases identified from population-based birth defects surveillance programs in 10 states. These CDC-funded Centers for Birth Defects Research and Prevention (CBDRP) participated in one of the largest case-control studies of birth defects called the National Birth Defects Prevention Study (NBDPS) and also conducted center-specific research projects of local interest.[17] Briefly, the NBDPS collected data from 1998 through 2013 on pregnancies between October 1997 and December 2011. Cases included all pregnancy outcomes (live births, fetal deaths, and induced terminations) and were identified through birth defects surveillance programs in Arkansas, California, Georgia, Iowa, Massachusetts, New Jersey, New York, North Carolina, Texas, and Utah. Controls were live-born infants without major birth defects identified from the same geographic regions and time periods as the case patients. Over 44,000 women participated in the NBDPS. Beginning with the 2014 birth cohort, the CBDRP transitioned to a new phase of the study called the Birth Defects Study to Evaluate Pregnancy exposureS (BD-STEPS) in seven states (Arkansas, California, Georgia, Iowa, Massachusetts, New York, and North Carolina).[18] The BD-STEPS is further examining promising findings from the NBDPS and examining emerging risk factors for birth defects.

As part of the Birth Defects Prevention Act of 1998, CDC was also directed to establish and maintain a national clearinghouse on birth defects. This was carried out with the creation of the National Birth Defects Prevention Network (NBDPN) through the joint efforts of CDC, state birth defects programs, and the March of Dimes. Through this collaboration, major initiatives have included production of an annual data report with state-level data for over 45 major birth defects, development of guidelines for conducting birth defects surveillance, establishment of national standards on birth defects data quality, and expansion of multi-state collaborative epidemiologic studies on birth defects.[19-21] CDC has served as a data repository for a number of multi-state epidemiologic collaborations, results from which have been used to document increasing trends in gastroschisis; race/ethnicity disparities for a number of birth defects, especially among Native Americans; and survival outcomes for children with major birth defects.[4,6,22]

CDC has also worked with the NBDPN to evaluate prevention strategies. Since 1999, CDC has collected quarterly data on the prevalence of neural tube defects (NTDs) from over 20 states (representing about one-half of the US live-birth population) to monitor the trend in NTDs before and after mandatory folic acid fortification of enriched cereal grains in the United States.[23,24] The estimated cost savings associated with folic acid fortification from the societal perspective is around $400-$600 million annually.[25] Additionally, CDC is working with the NBDPN and state programs to collect data to monitor *Healthy People 2020* national measures on birth defects, such as the prevalence of anencephaly and spina bifida and survival of infants born with Down syndrome.

CDC is developing a clearer understanding of survival and health outcomes of children born with birth defects through linking population-based birth defects surveillance data with health service outcome data sets. For example, linkages to administrative databases that collect information regarding: hospitalizations (e.g., hospital discharge data sets), comorbidities, medical costs, education, surgical information (e.g., the Society for Thoracic Surgeon (STS) database), and insurance (e.g., state Medicaid claims) can help in efforts to examine health status, costs, and disparities associated with birth defects.

GENERAL FINDINGS

National Prevalence Estimates

Estimates of the prevalence of birth defects in the United States are critical in planning for public health research as well as for the health-care and educational needs of children with birth defects. In 2006, the first "national estimates" for 21 major birth defects were published based on data from 11 state surveillance programs with active case-finding methods.[26] The national estimates were updated and expanded to include birth defects data from 14 state programs in 2010 using pooled state surveillance data; these estimates showed a range from 0.72 per 10,000 live births for common truncus to 13.56 per 10,000 live births for Down syndrome when adjusted for maternal race and ethnicity.[27] Although only state programs that were able to confirm all cases were included in these estimates, variation can be seen in the reported prevalence of specific defects across the states. State-specific prevalence data for the 14 programs used to estimate the national prevalence are presented in Figure 1 (adapted from Parker et al. 2010).[27]

Trends in Prevalence

The overall prevalence of major birth defects in the United States remained relatively stable during the period of 1978-2005.[1] This stability in the overall prevalence of major birth defects was consistent with the stability in prevalence observed for many individual defects.[16] However, the prevalences of certain birth defects, such as CHDs and gastroschisis, have changed over time.

Congenital Heart Defects

Congenital heart defects are conditions present at birth that cause problems in the structure of the heart and are the most common birth defects in the United States. MACDP data from 1968 through 1997 show that the occurrence of CHDs nearly tripled in Metropolitan Atlanta during that time.[28] A follow-up study observed a continued increase in the overall prevalence of CHDs from 1978 through 2005, largely driven by increases in ventricular septal defect, atrial septal defect, and valvar pulmonic stenosis. This rise probably did not reflect an actual increase in the underlying prevalence but rather an increased rate of diagnosis of the conditions as a result of echocardiography use, which enhances the ability to detect small, less-severe lesions.[16] The prevalence of the most severe phenotypes (i.e., defects requiring surgical or catheterization intervention within the first year of life) remained relatively stable.[29]

Gastroschisis

Gastroschisis, a defect in which the intestines and other abdominal organs develop outside the abdominal wall of the fetus, has had an unexplained increase in prevalence in the United States and worldwide over the last several decades.[22,30] Using pooled data from 15 population-based, state-level, birth defects surveillance programs, a near doubling of the prevalence was observed (from 2.32 per 10,000 to 4.42 per 10,000 live births) from 1995 through 2005. A recent update confirmed that the prevalence of this serious defect continues to increase, primarily among mothers younger than 20 years.[31] Recognized maternal risk factors for gastroschisis include young age and low body mass index, both atypical risk factors for major birth defects.[32] Concerted efforts continue to monitor this condition and better understand the risk factors.

Racial/Ethnic Disparities in Prevalence

It is critical to document variation in the prevalence of birth defects among racial/ethnic sub-populations in order to explore possible variations in diagnosis, case ascertainment, health care use, or risk factors specific to certain sub groups. In 2014, a published report of the largest study to examine associations between race/ethnicity and 27 specific birth defects in the United States used pooled data from 12 states.[4] With over 13.5 million births from 1999 through 2007, Canfield and colleagues were able to examine less-studied groups – American Indians/Alaska Natives, Cubans, and Asian subgroups. As shown in Table 1, significantly higher prevalences of anotia/microtia, cleft lip, trisomy 18, encephalocele, and limb deficiencies were observed among American Indians/Alaska Natives; whereas Cubans and Asians, especially Chinese and Asian Indians, generally had prevalences of many defects comparable to or lower than those for non-Hispanic whites.

USING DATA FOR ACTION

Birth defects surveillance data have been used to uncover disparities in prevalence and burden; investigate risk factors; understand patterns of use of health services and health and educational outcomes; document infant and child survival; and evaluate policy interventions.

Investigation of Risk Factors

Birth defects surveillance data form the foundation from which the Centers for Birth Defects Research and Prevention (CBDRP) have selected their cases for the large, population-based, case-control studies of modifiable risk factors for birth defects conducted in the United States. This massive effort includes the National Birth Defects Prevention Study (NBDPS; birth years 1997-2011) and the Birth Defects Study to Evaluate Pregnancy ExposureS (BD-STEPS; birth years 2014 - present).[33,34] The NBDPS has made important contributions to our knowledge of the risk for birth defects associated with chronic conditions, such as pre-gestational diabetes and obesity; occupational exposures, such as pesticides and solvents; environmental hazards, such as air pollution; lifestyle factors, such as smoking and illicit drug use; and medications, such as antidepressants, opioid analgesics, and antibiotics.[35-46] BD-STEPS extends the NBDPS by continuing to collect data on risk factors that were assessed in NBDPS and expands the NBDPS by collecting more detailed information as well as information on new potential risk factors, such as selected medications and stress.

Population-based birth defect surveillance programs have also contributed important data to support the relationship between congenital Zika virus infection and select anomalies. Data from surveillance programs were used to calculate the baseline prevalence of birth defects consistent with those observed with congenital Zika virus infection during the pre-Zika years (2.86 per 1,000 live births).[47] The proportion of Zika virus-associated birth defects among pregnancies with laboratory evidence of Zika virus infection was approximately 20 times higher than the baseline prevalence for these birth defects (approximately 30 times higher in brain abnormalities and/or microcephaly).[48] Surveillance data have been and remain an important resource to further explore the effects of congenital Zika infection.

Infant and Child Survival

The linkage of data from population-based birth defects surveillance to state death certificates and the National Death Index has provided information on both short- and long-term survival of children with birth defects. There have been several studies on the survival of infants with birth defects that draw on individual state population-based birth defects surveillance data.[49-53] The use of pooled data from several surveillance systems was, until recently, limited to a few studies of individual defects.[54,56] In a 2015 study from the NBDPN, data from 12 population-based birth defects surveillance programs in the United States covering about 39% of US live births during the study period were pooled to estimate infant and child survival for 21 birth defect subtypes by race/ethnicity.[6] For most birth defects studied, survival rates were lower for babies born to non-Hispanic black and Hispanic mothers than the rates for babies born to non-Hispanic white mothers. Children with hypoplastic left heart syndrome had the lowest chance of survival in the age group 0 through 8 years when compared with children with any other birth defects studied. Children born with spina bifida, cleft palate, cleft lip with or without cleft palate, pyloric stenosis, gastroschisis, or Down syndrome had the highest infant survival rates; those for all groups were greater than 90%.[6]

Referral to Services

Birth defects surveillance programs can provide an important mechanism in the public health system to ensure that children with birth defects are identified and referred to appropriate specialized care and interventions in a timely manner. These population-based surveillance registries of infants with birth defects can be linked to local public health programs and service providers, such as Early Intervention and Children with Special Health Care Needs programs, to ensure that children are systematically identified and linked to reduce gaps in referrals. In 2003, Farel and colleagues reported that about 40% of state birth defects surveillance programs had identification and referral systems in place.[57] An updated NBDPN survey in 2011 of operational state surveillance programs showed that about half of the programs have a system in place that routinely identifies and refers children to services (unpublished data). In a Colorado survey of parents of children receiving referral services, about 65% of survey respondents said that they learned of services, resources, or developmental screening through the state program, and about one quarter of the survey respondents indicated receipt of services or developmental screening as a result of program contact.[58]

Health Services Use and Costs

Birth defects surveillance data traditionally lack measures of the level and type of use of health services and associated costs; however, linkages with other data sets (e.g., inpatient, outpatient and emergency department discharges as well as Medicaid/Children's Health Insurance Program claims) can be conducted, and analyses of such linked data have led to important gains in knowledge. For example, the Massachusetts Pregnancy to Early Life Longitudinal (PELL) Data System has routinely linked its state birth defects surveillance data with vital records and the maternal delivery hospital records and, for long-term trends, to all subsequent hospitalizations of a child with a reported birth defect. Analyses of PELL data on health services use and costs have been published for Down syndrome and craniofacial malformations.[59,60] At least two states, California and North Carolina, have linked their birth defects surveillance data to Medicaid claims and have documented the costs of birth defects among Medicaid-enrolled populations.[60,61] The Florida Birth Defects Registry has longitudinally linked its surveillance data with hospital discharge data. Publications that use these linked data have contributed to knowledge about the costs of caring for infants and children with selected birth defects, such as orofacial clefts and spina bifida, and the amount of time and distance families travel to receive care for children with selected conditions.[63-65] Also, cost-effectiveness analyses have been conducted for public health interventions, such as newborn screening for critical congenital heart defects (CCHDs). CCHDs are congenital heart defects that lead to abnormally low levels of oxygen in the blood and require intervention within the first year of life. A recent publication on the costs associated with detection and treatment for CCHDs was used for a subsequent cost-effectiveness analysis of universal newborn pulse oximetry screening for CCHDs.[65,67]

Educational Outcomes

As medical and surgical technology improves, and children born with birth defects are living longer, understanding the long-term outcomes, including educational outcomes and quality of life of children born with birth defects, have become an increasingly important area of inquiry. Population-based birth defects surveillance systems have been a data source for this type of investigation. Recently, Knight and colleagues analyzed data on academic outcomes (e.g., letter grades, school days missed, and academic retention) from a follow-up survey of parents of children born with orofacial clefts in North Carolina in 1996 through 2002 (ascertained from the state's birth defects surveillance data) and a sample of parents of controls (matched infants born without birth defects in North Carolina during the same time period).[68] Parents of children with clefts reported more developmental disabilities and hearing and speech problems among their children than did parents of the control children. In addition, children with clefts were also more likely than unaffected children to receive lower grades and miss more school days.[68] An alternative to conducting a follow-up survey of families is a data linkage approach. MACDP has successfully linked to a special education database to investigate the use of special education services by children born with selected birth defects, such as CHDs.[69]

Policy Evaluation

Use of birth defects surveillance data to document the impact of a policy intervention is critically important. Beginning in 1998, the United States mandated fortification of enriched cereal grain products with 140 μg of folic acid per 100 g of cereal.[70] Immediately after mandatory fortification, the birth prevalence of neural tube defects (NTDs) declined. Recent data from 19 population-based birth defects surveillance programs in the United States, covering the years 1999 through 2011, were used to examine the long-term impact of fortifying cereal with folic acid.[23] After the initial decrease in the prevalence of NTDs during the post-fortification period, rates of occurrence have remained relatively stable. The number of births that occur annually without NTDs that would otherwise have been expected to occur, on the basis of previous patterns, is about 1,300 or a total of about 15,000 prevented since 1999. This intervention has also yielded a cost savings around $400 - $600 million annually.[25]

DATA GAPS AND LIMITATIONS

The United States does not have a national population-based surveillance system to accurately monitor birth defects but relies instead on state programs. Given limited and sometimes fluctuating resources at the federal and state levels, state programs differ in case ascertainment approaches and vary in terms of timeliness, completeness, and accuracy of data. Variations in case-finding approaches and utilization can be limitations in pooling datasets.

CDC has worked with the NBDPN to develop guidelines with detailed clinical case definitions for major birth defects. However, state programs may differ in applying the recommended steps and therefore, in the criteria and level of clinical information collected. For example, some programs that are only able to collect birth defect information from administrative datasets may lack clinical details needed to classify specific conditions. Also, the availability of clinical specialists, such as clinical geneticists, helps programs to accurately interpret clinical case information. However, only about half of US state-level birth defects programs use clinical reviewers.[15]

Although population-based surveillance programs attempt to capture all cases within their catchment areas, under-ascertainment of non-live birth cases can occur. Cragan and Gilboa found about a 7% increase in total defect prevalence when prenatally diagnosed defects were included, but the increase was greater than 50% for selected defects, such as anencephaly and chromosomal conditions.[71]

Although population-based birth defects surveillance programs focus on capturing all cases diagnosed within the first year of life (and into childhood for some programs), the lack of longitudinal follow-up cohort data makes it difficult to determine the impact of birth defects across individuals' lifespans. Data linkage of birth defects surveillance systems with other datasets is offering opportunities to overcome this data limitation. In a 2012 survey of state population-based birth defects programs, about 30% of the programs indicated an ability to access or link to health-care services data during the first year of life and only 14% could follow-up beyond the first year of life.[15]

FUTURE ISSUES

Electronic Medical Records

As medical records move from paper to electronic formats, birth defects surveillance programs need to adapt their approaches to accessing, collecting, transmitting, and sharing information. Remote access to electronic data has become more common for state programs, which can translate to cost savings in travel time and/or improved timeliness of, access to, and processing of data. However, it can be difficult to access and work with electronic medical data because data systems vary from hospital to hospital. Work is under way to develop standard messaging so that public health programs and clinical databases can communicate with each other either directly or through health information exchanges. Staying abreast of rapidly changing technology, with limited resources and lack of skilled staff who understand information systems, will be challenging for surveillance programs. Collective efforts are needed to ensure that surveillance programs have adaptive systems to capitalize on potential efficiencies.

Data Access

Birth defects surveillance programs rely on legislation and/or public health authorities to access and efficiently use data. As such, programs need to be consistent with the interests and agendas of their authorities in order to continually show public health benefit and advocate for improvements in surveillance practice that ensure efficiency. For example, the Illinois program was able to update its regulations to allow remote access to birth defects data, where available.

Public Health Interventions and Infrastructure Adaptability

Birth defects surveillance programs need to ensure that the data collected can be used to address community needs and critical public health concerns. CDC was able to pool data to examine the prevalence of NTDs before and after mandatory folic acid fortification. With the addition of CCHDs to the newborn recommended uniform screening panel, state programs are being asked to evaluate the impact of this public health intervention. Evaluation activities that birth defects programs can help address include examining the extent of babies with CCHD who might not have been screened or those with false negative screens, as well as costs, use of services, and health outcomes among children with CCHDs. Finally, as public health threats emerge, birth defects programs need infrastructure adaptability and unprecedented collaborations among different public health groups. Gilboa and colleagues highlight the need for a joint, coordinated effort between pregnancy surveillance and birth defects surveillance as an essential part of the Zika virus response and in future emergent threats to maternal and child health.[72]

ADDITIONAL RESOURCES

- Guidelines for Conducting Birth Defects Surveillance Manual
  http://www.nbdpn.org/birth_defects_surveillance_gui.php
- CDC Birth Defects Surveillance Program: Metropolitan Atlanta Congenital Defects Program (MACDP)
  http://www.cdc.gov/ncbddd/birthdefects/MACDP.html
- CDC-funded state population-based surveillance programs

http://www.cdc.gov/ncbddd/birthdefects/states/index.html

- CDC-funded population-based Zika-related birth defects surveillance programs https://www.cdc.gov/zika/reporting/birth-defects.html
- Centers for Birth Defects Research and Prevention (CBDRP) http://www.cdc.gov/ncbddd/birthdefects/cbdrp.html
- CDC birth defects surveillance tools and resources http://www.cdc.gov/ncbddd/birthdefects/research-tools.html
- National Birth Defects Prevention Network (NBDPN) http://www.nbdpn.org/

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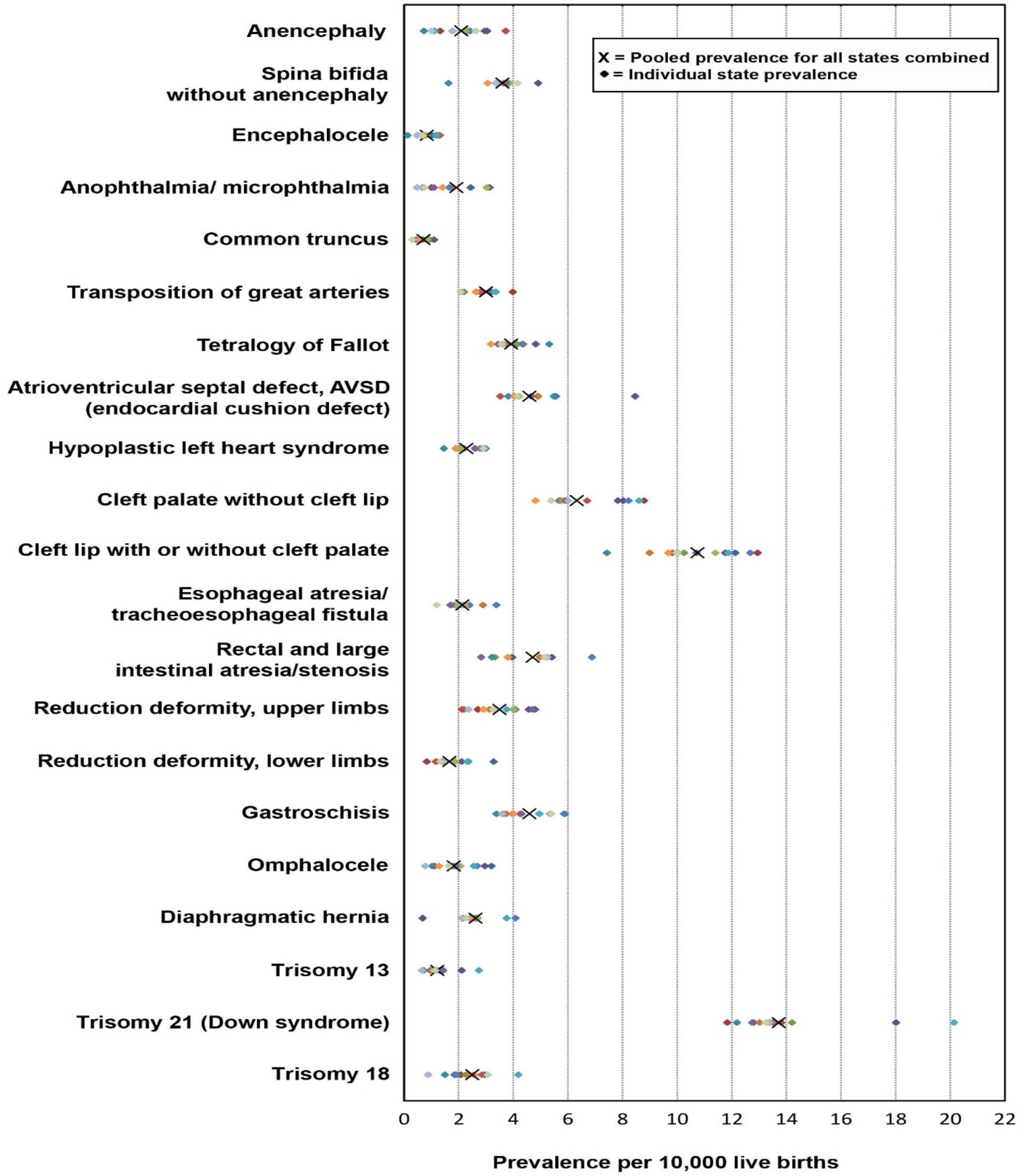
Figure 1: State-specific and pooled prevalence for selected defects from 14 surveillance programs, United States, 2004–2006*.



*Adapted from Parker SE, et al. Updated national birth prevalence estimates for selected birth defects in the United States, 2004-2006. *Birth Defects Res A Clin Mol Teratol.* 2010;88(12):1008-1016.

Table 1: Adjusted prevalence ratios for major birth defects among maternal racial/ethnic groups and selected Asian and Hispanic sub-groups in the United States, relative to non-Hispanic whites, 1999-2007[a].

Birth Defect	**Main Racial/Ethnic Groups**				**Selected Asian Subgroups**	
	NH Black	**Hisp**	**NH Asian**	**NH Am Ind**	**Chin**	**Filp**
Anencephalus	1.1	↑ **1.6**	1.1	1.3	0.5	0.9
Spina bifida without anencephalus	↓ **0.9**	↑ **1.2**	↓ **0.4**	1.2	↓ **0.4**	↓ **0.3**
Encephalocele	↑ **1.8**	↑ **1.5**	0.8	↑ **2.1**	0.3	0.9
Anotia/microtia	↓ **0.7**	↑ **2.4**	↑ **1.4**	↑ **4.0**	↑ **2.1**	↑ **1.9**
Common truncus	1.1	1.0	↓ **0.3**	1.7	0.2	0.5
Transposition of great arteries	↓ **0.8**	0.9	1.0	1.0	↓ **0.6**	0.9
Tetralogy of Fallot	↑ **1.2**	0.9	1.1	1.2	0.7	1.4
Atrioventricular septal defect[b]	↑ **1.3**	↓ **0.9**	↓ **0.7**	0.9	↓ **0.6**	↓ **0.5**
Atrioventricular septal defect w/out DS[b]	↑ **1.4**	1.0	0.9	1.2	1.2	0.4
Aortic valve stenosis	↓ **0.5**	↓ **0.8**	↓ **0.6**	0.8	↓ **0.3**	0.6
Hypoplastic left heart	1.1	↓ **0.9**	↓ **0.5**	0.8	0.5	↓ **0.4**
Coarctation of the aorta	↓ **0.8**	↓ **0.9**	↓ **0.6**	1.1	↓ **0.4**	0.8
Cleft palate w/out cleft lip	↓ **0.7**	↓ **0.8**	0.9	1.0	1.1	1.3
Cleft lip +/- cleft palate	↓ **0.6**	1.0	↓ **0.9**	↑ **1.9**	0.8	1.2
Esophageal atresia	↓ **0.8**	↓ **0.9**	↓ **0.6**	1.1	↓ **0.5**	↓ **0.2**
Pyloric stenosis[b]	↓ **0.4**	↓ **0.9**	↓ **0.3**	↓ **0.8**	↓ **0.2**	↓ **0.2**
Rectal and large intestinal atresia[b]	↓ **0.9**	↑ **1.1**	1.0	0.9	1.0	0.9
Hypospadias[b,c]	↓ **0.8**	↓ **0.5**	↓ **0.6**	↓ **0.6**	↓ **0.5**	↓ **0.7**
Upper limb deficiency	1.0	1.0	↓ **0.7**	↑ **1.5**	0.7	0.6
Lower limb deficiency	↑ **1.2**	1.0	↓ **0.7**	↑ **1.9**	0.7	0.9
Total limb deficiency	1.1	1.0	↓ **0.7**	↑ **1.5**	↓ **0.6**	0.7
Diaphragmatic hernia	0.9	1.1	0.9	1.3	0.8	1.1
Gastroschisis[d]	↓ **0.6**	1.0	↓ **0.6**	↑ **1.4**	↓ **0.2**	1.1
Omphalocele[e]	↑ **1.4**	1.0	↓ **0.6**	0.9	0.8	0.8
Down syndrome	1.0	↑ **1.4**	↓ **0.8**	1.2	↓ **0.5**	1.2
Trisomy 13	↑ **1.4**	1.1	0.9	1.2	0.9	1.3
Trisomy 18	↑ **1.7**	↑ **1.2**	0.9	↑ **1.9**	0.6	1.2
Significant Results by aPR Magnitude:[a]						
# Significantly Elevated aPRs (P<0.05):	8	7	1	8	1	1
# Markedly Elevated (aPRs≥1.5; P<0.05):	2	3	0	7	1	1
# Significantly Lower aPRs (P<0.05):	12	8	16	2	11	6
# Markedly Lower (aPRs<0.7; P<0.05):	4	1	10	1	11	5

Abbreviations: aPR, adjusted prevalence ratios; +/-, with or without; Hisp, Hispanic; NH, non-Hispanic; Asian, non-Hispanic Asian/Pacific Islander; Am Ind, non-Hispanic American Indian/Alaska Native; Chin, Chinese; Filp, Filipino; Kor, Korean; As Ind, Asian Indian; Viet,Vietnamese; Mex, Mexican; PR, Puerto Rican; Cub, Cuban; Note: Adjusted prevalence ratios in bold if significantly elevated (↑) or significantly lower (↓)

[a] Adjusted for maternal age and U.S. state of residence, relative to non-Hispanic whites. Rounded to 1 decimal.

[b] Arizona data excludes years 2005-2007.

[c] Among male deliveries

[d] Excludes Michigan data.

[e] Excludes Florida and Michigan data.

*Adapted from Canfield MA, et al. The association between race/ethnicity and major birth defects in the United States, 1999-2007. *Am J Public Health.* 2014;104(9):e14-23.

Gestational Age of the Newborn – Preterm Birth

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Nearly ten percent of infants born in the United States are delivered preterm or at a gestational age of less than 37 completed weeks. While the rate of preterm birth declined steadily from 2007 to 2014, rates for more recent years have been on the rise, causing renewed concerns on the impact of the greater risk of health and developmental problems for these infants. Birth certificate data, with which these trends can be assessed for the country as a whole and by characteristics such as maternal age, race and ethnicity, are of key importance in measuring preterm birth impact.

PUBLIC HEALTH IMPORTANCE

Gestational age is strongly associated with the short and long-term health of the newborn. In general, the shorter the length of the pregnancy, the greater the risk of a poor outcome.[1,2] Historically, the most common gestational age measure used is the percentage of infants born preterm or at less than 37 completed weeks of gestation. This measure, commonly referred to as the preterm birth rate, is a leading indicator of infant health in the US and across the world.[1,3,4] Approximately 380,000 infants, or nearly one in ten, are born preterm in the US every year.[5] Preterm infants are at greater risk of early death than those born later in pregnancy - more than a third of all infant deaths are estimated to be preterm-related.[2] Infants delivered preterm can also suffer numerous health and developmental problems.[3,6] The preterm category can be further sub-divided into: extremely preterm (less than 28 weeks); very preterm (28 through 31 weeks); and moderately preterm (32 through 36 weeks). Moderate preterm birth is often further split to focus on late preterm birth (34 through 36 weeks). Although infants born at the earliest ages suffer the greatest risk of morbidity and mortality, those born late preterm comprise the larger number of births and experience more complications than those born at term.[7,8] The poorer outcomes of infants delivered early term (37 and 38 weeks) compared with those delivered at full term (39 and 40 weeks) is also now recognized.[9,10]

Despite important strides in reducing infant morbidity and mortality in the US, preterm birth rates rose during the last three decades from the early 1980s through 2006.[5] Over the next decade, rates declined, but recent data indicate that the downward trend in preterm rates has abated (Figure 1).[5,11] Also, the persistent disparities in rates of preterm birth by race and Hispanic origin are of import, with non-Hispanic black mothers consistently about 50% more likely to give birth prior to 37 weeks than non-Hispanic white and Asian or Pacific Islander (API) women (Figure 2).[5,12]

The causes of preterm birth can be multi-faceted. Preterm delivery can occur as the result of the spontaneous onset of labor or labor that is provider induced. Although in nearly half of all cases, the cause of early delivery is unknown, maternal risk factors for spontaneous labor include previous preterm delivery, younger or older maternal age, short inter-pregnancy interval, low body-mass index, and multi-fetal pregnancy among other causes.[1,13] Non-spontaneous preterm deliveries occur as the result of obstetrical intervention, i.e., induction of labor or cesarean delivery prior to 37 weeks and can be medically (for the health of the mother or the infant) or non-medically indicated (e.g., errors in gestational age estimate).[1,13]

In 2003, the March of Dimes launched a national prematurity campaign calling for increased awareness of the problem of prematurity and reductions in the preterm birth rate. This effort involves funding research and supporting legislation to improve care for mothers and newborns.[14] The March of Dimes initiative “Healthy Babies are Worth the Wait” aims to reduce preventable preterm birth with a focus on reducing elective deliveries before 39 weeks gestation.[15]

HISTORY OF DATA COLLECTION

National Vital Statistics System (NVSS)

The National Vital Statistics System (NVSS), managed by the National Center for Health Statistics (NCHS), is the primary source of national data on gestational age. Information on the gestational age of the newborn has been included on the US Standard Certificate of Live Birth since 1930.[16] Early gestational age items (e.g., months of pregnancy; length of pregnancy in weeks; completed weeks of gestation) were replaced with the more precise “date of last normal menses” (LMP), commonly used by clinicians when combined with the date of birth, to estimate gestational age with the 1979 birth certificate revision. Beginning with the 1981 data year, NCHS introduced imputation procedures for records with missing day of LMP where the month and year are valid. Accordingly, LMP-based gestational age data are comparable from 1981 onward.

Persistent concerns with the quality of LMP-based gestational age measures (see below discussion on data gaps and limitations) led to the addition of the “clinical estimate of gestation” (CE) to the 1989 revision of the US standard certificate.[17] Detailed definitions and instructions were not developed or distributed,[17] however, and concerns with data quality (for example, that the estimate may sometimes be based on a neonatal exam rather than perinatal factors) and the lack of national reporting (California did not report the CE) precluded it from replacing the LMP as a national measure of gestational age.

The 2003 revision of the birth certificate replaced the existing CE with the similar item, the “obstetric estimate of gestational age at delivery” (OE).[18] The title of the item was changed from the clinical to the obstetric estimate of gestation to more clearly underscore that it should be based on the obstetric, not the pediatric estimate.[18] Detailed definition and instructions were developed and distributed for the OE, which, in brief, is, “The best estimate of the infant’s gestation in completed weeks based on the birth attendant’s final estimate of gestation.” For the detailed definition, see “Guide to Completing the Facility Worksheets for the Certificate of Live Birth and Report of Fetal Death.”[19] Despite the substantially more detailed definitions and instructions for the OE compared with the CE, both are recommended to be based on the attendant’s or clinician’s estimate of gestational age.[17,19] Accordingly, the two measures appear comparable[20] and are combined in natality public use files for 2003 through 2015 and where national CE/OE gestational age estimates are presented; see also data gaps and limitations section. (Note that the gradual adoption of the 2003 birth certificate revision across the country during 2003-2015 resulted in a combination of reporting of both the CE and OE among the states; national data based on the OE became available for 2016 when the revision of the 2003 birth certificate was implemented by all jurisdictions.)

Also, of import, are the consistent differences in estimates of gestational age between the CE/OE and the LMP. The CE/OE consistently results in lower levels of pre- and post-term births than the LMP and higher levels of full-term births.[21]

Pregnancy Risk Assessment Monitoring System (PRAMS)

The Pregnancy Risk Assessment Monitoring System (PRAMS) is an ongoing, population-based surveillance system project, jointly conducted by CDC and state health departments, that collects state-level data on various aspects of pregnancy and maternal health among women who have recently given birth.[22] It is designed to monitor self-reported maternal behaviors that occur before, during, and after pregnancy. Participants are sampled from each participating state's birth certificate file. Response rates for PRAMS vary by state but states must meet a minimum response rate threshold to have data released. For recent years of PRAMS, this threshold captures approximately 66% of participating states per year. The initial PRAMS was fielded in 1987 and included only six reporting areas (Indiana, Maine, Michigan, Oklahoma and West Virginia) and the District of Columbia but has recently expanded to 47 states, New York City, Puerto Rico, and the District of Columbia, representing approximately 83% of all US live births.[23] States participating in PRAMS aim to include between 1,300 and 3,400 women per year. Women from certain demographic groups are included at a higher rate to ensure there is adequate data to represent small but high-risk populations. Selected women participate in PRAMS by questionnaires sent by mail or by phone interviews. All states use standardized data collection procedures and questionnaires, which allows comparisons between states. The standardized data collection methodology is described elsewhere.[22] Each state follows the general protocol but may also customize parts of the questionnaire to be more tailored to the needs of a particular state. Because PRAMS survey data are linked to selected birth certificate data, they have served as an adjunct to NVSS data that can provide more detailed contextual information about pregnancy, birth, and the postpartum period. Gestational age information reported in PRAMS is from the NVSS. Details on PRAMS' methodology have been described previously.[22]

CDC SURVEILLANCE ACTIVITIES

NVSS

Birth certificate data from the NVSS are the primary source of information on the gestational age of the newborn in the US. The NVSS collects information on pregnancy length for essentially all births occurring in the nation each year. Information on the 2003 revision-based items, the obstetric estimate of gestational age and the date of the last normal menses are sent to the NCHS by each state and independent reporting area.

NCHS reviews and edits these data and contacts the jurisdictions for correction if irregularities are observed. Beginning with the 2014 data year, NCHS transitioned to the use of the OE as the primary measure of gestational age. National OE-based data are available from 2007 and LMP-based data from 1981. Despite the transition to the OE, NCHS will continue to make LMP-based data publicly available.

Birth certificate data can be used to examine gestational age of the newborn by a number of demographic and medical and health items on the birth certificate such as maternal age and education, previous pregnancy history, tobacco use, pregnancy risk factors (e.g., gestational diabetes, previous preterm birth), maternal body mass index and weight gain during pregnancy, timing and utilization of prenatal care, infections during pregnancy (e.g., gonorrhea), method of delivery, source of payment for the delivery, characteristics of labor and delivery (e.g., induction of labor), maternal morbidities (e.g., ruptured uterus), abnormal characteristics (e.g., NICU admission), congenital anomalies of the newborn, birthweight and plurality.[18] Additionally, use of the linked birth and infant death data file, which includes both birth certificate with death certificate information, allows for the examination of the fact, timing and cause of infant death by gestational age.[2]

PRAMS

PRAMS uses the information on gestational age of the infant from the NVSS combined with questionnaire data on several aspects of biological, medical, and contextual characteristics of women who delivered a preterm infant (data based exclusively on gestational age from the birth certificate). For example, PRAMS' questions on health conditions in the three months prior to conception or about domestic violence during pregnancy may be examined in relation to gestational age at delivery of their infant. Information from PRAMS can be used to identify high-risk groups of women and infants who may be more vulnerable to health problems and preterm birth. Similar to vital statistics, PRAMS is also used to monitor trends in maternal-child health and to measure progress towards health improvement goals, such as Healthy People. PRAMS data are also used by state and local governments to inform maternal-child health policy and for program planning and review. Examples of PRAMS questionnaire data and examples of data use for program and research purposes can be found on the PRAMS website.[22,23]

GENERAL FINDINGS

The following trend analysis is based on the OE unless otherwise stated. All changes over time and differences among groups are statistically significant ($p \leq 0.05$) unless otherwise noted.

The (LMP-based) preterm birth rate in the United States rose by more than one-third from 1981 through 2006, but then declined 11% for 2007 through 2013.[24] Both the LMP and the OE show declines in preterm birth rates from 2007 through 2014 (Figure 1 and Table 1 for OE data).[5,21,24] The trend in the preterm rate then shifted again, rising slightly (less than 1%) for 2014-2015 (from 9.57% to 9.63%);[5] the most recent data available indicate continued increases in the preterm birth rate through the third quarter of 2016 to 9.81%.[11]

Over the last two and a half decades, changes were also seen in the distribution of births at term and higher gestational ages. In brief, from 1990 through 2006, the percentage of early term births (37 and 38 weeks) rose by nearly 50%, whereas births at 40 weeks and higher declined by more than 30%.[24] From 2007 through 2014, however, the trend reversed and the percentage of early term births dropped 16%,[5] and full-term births rose 11% (Figure 2). For 2015, these patterns shifted again, and the percentage of early-term births again rose while full-term birth declined – a trend that has continued through at least the third quarter of 2016.[5,11] From the third quarter of 2015 to the third quarter of 2016, the early-term rate rose from 24.92% to 25.35%, and the full-term rate declined from 58.54% to 58.05%.

Despite improvement in preterm rates over the last several decades among each of the largest race and Hispanic origin groups,[24] large differences in the risk of preterm birth among groups persist (Figure 3). In 2015, the preterm rate for infants born to non-Hispanic black women was 13.41%, about 50% higher than that for non-Hispanic white (8.88%) and Hispanic women (9.14%).[5] The rate among infants to American Indian or Alaskan native women was also higher than those for non-Hispanic white and Hispanic women at 10.54%; the preterm rate for Asian or Pacific Islander women was the lowest of all groups at 8.63%.[5]

Preterm rates also vary widely by state. In 2015, rates ranged from less than 8% in Vermont, Oregon and New Hampshire, to more than 12% in Louisiana and Mississippi (Figure 4). From 2007 through 2014, reductions in rates were observed across much of the United States.[24]

USING DATA FOR ACTION

March of Dimes

The March of Dimes uses gestational data from the NVSS to inform, plan, and measure public health campaigns geared towards prematurity. In 2003, the March of Dimes launched a national prematurity campaign calling for increased awareness of the problem of prematurity and reductions in the preterm birth rate. This effort involves funding research and supporting legislation to improve care for mothers and newborns.[14] The March of Dimes initiative, "Healthy Babies are Worth the Wait" aims to reduce preventable preterm birth with a focus on reducing elective deliveries before 39 weeks gestation.[15] In addition, the March of Dimes develops and disseminates their annual Premature Birth Report Card ratings for each state.[25] This tool grades states on their progress towards reducing preterm birth by assigning a letter grade based on a comparison to preterm birth rates for a given state to the March of Dimes goal of 8.1% by 2020.[26] The Report Card also provides grades and information according to specific counties or boroughs within a state as well as a Disparity Index score measuring disparities in preterm birth by race and ethnicity. This allows public health practitioners at the state and local level to plan and implement interventions that are more specific to their target populations of concerns.

Strong Start for Mothers and Newborns Initiative: Effort to Reduce Early Elective Deliveries

The Strong Start for Mothers and Newborns initiative, which uses vital statistics data to inform strategies, is a joint effort among three agencies of the Department of Health and Human Services: the Centers for Medicare and Medicaid Services (CMS), the Health Resources and Services Administration (HRSA), and the Administration on Children and Families (ACF).[27] The initiative has two strategies, one being a public-private partnership to promote awareness of the potential problems with early elective deliveries prior to 39 weeks gestation, and the second is to provide funding opportunities to research institutions to examine prenatal care models that are aimed at reducing low birthweight and preterm birth among Medicaid recipients. These models include home visitation, group prenatal care, and enhanced prenatal care at birthing centers and maternity care homes.[28]

Perinatal Quality Collaboratives

Perinatal Quality Collaboratives (PQCs) are networks of perinatal healthcare providers and public health professionals who strive towards improving maternal and perinatal health outcomes by supporting evidence-based clinical practices and processes.[29,30] These networks focus their efforts on quality improvement of several factors related to maternal and infant health outcomes including early elective deliveries and prematurity prevention. The Ohio Perinatal Quality Collaborative (OPQC) is one such collaborative. To reduce preterm birth and improve its preterm birth and infant mortality rankings (Ohio ranks 44th in infant mortality and 35th in prematurity among all states), the OPQC has undertaken efforts such as the Progesterone Project which aims to reduce preterm and very preterm births by 10% through increased screening and treatment to identify pregnant women who may benefit from progesterone therapy to prevent preterm birth.[30] Several PQCs in other states have focused efforts on improving data quality and accuracy reported in the state birth vital statistics system, including the encouragement of the use of standardizing definitions and reducing the number of reported missing or ‘unknown’ values. Several PQC objectives, including the reduction of unnecessary scheduled births from 37 to 39 weeks, rely on tracking of vital statistics data.

DATA GAPS AND LIMITATIONS

A main strength of NVSS gestational age data are their availability for approximately four million US births each year. These large numbers, combined with additional information available from the birth certificate, allow for the analysis of smaller population groups (e.g., American Indian or Alaskan Native) and of less frequently occurring factors (e.g., birth resulting from the use of assisted reproductive therapies) typically unavailable in survey data. These data do, however, have notable gaps and limitations.

The Quality of LMP-Based Gestational Age Data

The primary gaps and limitations with vital statistics gestational age data are quality, especially LMP-based data, and the discontinuity in trends resulting from the change to the use of the OE. As noted, gestational age data based on the date of the LMP and the date of birth was the standard measure used by NCHS from 1981 through 2013.[21] Concerns regarding the quality of LMP-based gestational age data were long standing and included unacceptable levels of missing dates (especially the date of the LMP), imperfect maternal recall, misinterpretation of bleeding early in pregnancy, irregular menstrual cycles, digit preference, and data entry errors.[31-33] These errors resulted in a bimodal birthweight distribution for preterm births representing implausibly high birthweight for gestational age combinations[34,35] and gestational age misclassification, especially at pre-and post- term.[36,37,38]

The Quality of the Clinical Estimate of Gestation

The quality of the alternative measure of gestational age, the clinical estimate, added to the 1989 revision of the US Standard Certificate of Live Birth was also an issue, especially during the initial years of data collection.[39] Although levels of missing information for the CE were comparatively low, early estimates showed a marked peak in the distribution at precisely 40 weeks.[39] Although the quality of CE data improved over time,[39] the lack of detailed definitions and instructions, and the lack of national reporting (California did not report the CE), precluded the CE from being used as a national measure of gestational age prior to 2007.[18,40]

The Clinical/Obstetric Estimate compared with the LMP

During the 2000s studies evaluating the CE and the OE demonstrated greater validity for these measures compared with the LMP. That is, results routinely showed higher consistency between the OE/CE-based estimates and birthweight[35] and better agreement between the OE/CE based estimates and estimates of gestational age based on early ultrasound (considered the gold standard) compared with those based on the LMP.[36,37,41] Although the OE was added to the 2003 birth certificate revision, the certificate change was implemented slowly across the country resulting in a combination of CE and OE data for the nation through 2015 (heretofore referred to as the CE/OE). Agreement was also closer between the CE/OE-based estimates and gestational ages for births conceived using assisted reproductive technology for which dates of conception were well-documented.[38] Studies indicate high to moderate agreement between the OE reporting on the birth certificate, information which is recommended to be gathered from the hospital medical records, and information on best estimates of gestational age and estimated delivery dates in hospital medical records.[42] Analyses also indicate that the CE/OE result in similar gestational age estimates[43] and given the strong evidence for the greater validity of the CE/OE compared with the LMP and the availability of national data for the CE/OE, NCHS transitioned to the use of the CE/OE-based measure beginning with 2014.[21]

Differences between the LMP and Obstetric Estimates in Gestational Age Distributions

The CE/OE and the LMP result in substantially different estimates of pregnancy length (Table 2). The CE/OE results in lower levels of preterm and post-term births than the LMP and higher levels of full-term births.[21] These differences are seen consistently in national data and are also generally observed by state data.[21] The CE/OE also results in higher preterm and post-term infant mortality risk compared with the LMP.[21] These differences indicate that the LMP overestimated preterm birth rates and underestimated the risk of death for newborns delivered preterm and post-term.[21] For example, the 2015 CE/OE-based preterm birth rate is 9.63% compared with the LMP-based rate of 11.29% (Table 2); the 2013 infant mortality rate at 34-36 weeks was 7.23 per 1,000 births based on the LMP compared with 8.54 when based on the CE/OE.[21] The LMP date continues to be reported by all states, however, and NCHS will continue to make available LMP-based gestational age estimates accessible for as long as needed. In sum, although national gestational age LMP data are available from 1981 onward, more reliable data based on CE/OE are available only from 2007 resulting in a discontinuity in trends in important gestational age measures such as rates of preterm birth.

While the literature demonstrates that the OE is an improved measure of gestational age over the LMP, the OE also has limitations. An unpublished study based on interviews with 25 hospital staff responsible for collecting and/or entering OE information for the birth certificate found incorrect rounding procedures (i.e., rounding to the nearest whole number in lieu of rounding down to completed weeks).[44] Another recent study comparing birth certificate OE data with information from hospital medical records (EDD/best obstetric estimates) for two states found exact agreement in weeks between the OE and hospital records to be high in one state, but only moderate in another.[42] Lastly, another study found that sensitivity between preterm rates (i.e., combined weeks less than 37 weeks, not exact weeks) based on the OE and those calculated from the EDD (considered the best obstetric estimate) were excellent in one jurisdiction, but moderate in another.[43]

FUTURE ISSUES

Efforts are underway to improve the quality of vital statistic gestational age data across the country. The first e-learning course on the importance of and best practices for reporting birth certificate and report of fetal death information, “Applying Best Practices for Reporting Medical and Health Information on the Birth Certificate,” was released in October of 2016.[45] The course was developed by NCHS in collaboration with the

National Association for Public Health Statistics and Information Systems which represents the vital statistics jurisdictions, individual representatives of the vital statistics jurisdictions, and clinical experts. The new training includes instructions for reporting the OE and links to the updated “Guide to Completing the Facility Worksheets for the Certificate of Live Birth and Report of Fetal Death” (Facility Guidebook).[19] The Facility Guidebook has been updated and expanded to include more detailed instructions for the OE and to ensure consistency with ACOG’s ReVITALize Obstetric Data Definitions for establishing the estimated due date.[46] The e-learning training was developed for physicians, nurses, and non-clinical staff at hospitals or free-standing birthing centers who are responsible for completing the medical and health information for the birth certificate or report of fetal death and includes continuing education and certificates of completion for clinical and non-clinical staff.

The training is being promulgated across the country by the vital statistics jurisdictions and by provider organizations such as ACOG.[47] NCHS is also fielding studies to evaluate the effectiveness of the new training and any impact it may have on changes to hospital reporting practices. It is hoped that the training and expanded use of the Facility Guidebook will lead to further improvements in the quality of vital statistics gestational age data.

Health services research can be used to better understand the implications of clinical guidance, receipt of healthcare services and healthcare utilization and cost related to preterm birth. Future studies will be needed to examine the validity of the OE and its concordance with the best estimate of gestational age recorded in electronic medical records, hospital discharge and administrative claims data. Linkages between vital statistics and these data sources can help better understand their validity for analysis, as well as provide a more robust surveillance, research and quality improvement initiative evaluation.

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Table 1. Preterm birth rates by race and Hispanic origin of the mother: United States, 2007-2015

Year	Preterm 1			
	All races 2	Non-Hispanic		Hispanic 4
		White 3	Black 3	
	Percent			
2015	9.63	8.88	13.41	9.14
2014	9.57	8.91	13.23	9.03
2013	9.62	8.94	13.25	9.08
2012	9.76	9.13	13.48	9.09
2011	9.81	9.21	13.54	9.02
2010	9.98	9.41	13.81	9.09
2009	10.07	9.50	14.05	9.12
2008	10.36	9.81	14.38	9.38
2007	10.44	9.90	14.71	9.35

1 Births of less than 37 completed weeks of gestation based on the obstetric estimate of gestation.

2 Includes races other than white and black and origin not stated.

3 Race and Hispanic origin are reported separately on birth certificates. Persons of Hispanic origin may be of any race. Race categories are consistent with 1977 Office of Management and Budget standards. Forty-nine states and the District of Columbia reported multiple-race data for 2015 that were bridged to single-race categories for comparability with other states; see "Technical Notes." Multiple-race reporting areas vary for 2003-2015; see "Technical Notes."

4 Includes all persons of Hispanic origin of any race.

Table 2. Percent distribution of OE and LMP-based gestational age categories: United States, 2015

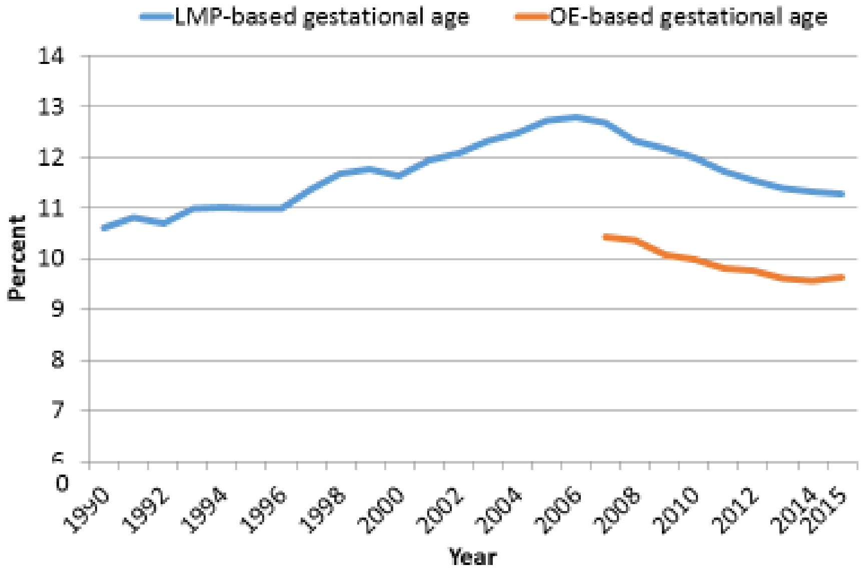
Gestational age [1]	OE [2]	LMP [3]
Under 28 weeks	0.68	0.72
28-31 weeks	0.91	1.18
32-33 weeks	1.17	1.47
34-36 weeks	6.87	7.93
Total under 37 weeks	9.63	11.29
37-38 weeks	24.99	24.82
39-40 weeks	58.47	50.01
41 weeks	6.51	8.6
42 and higher weeks	0.4	5.28

[1] Completed weeks of gestation.

[2] Based on the obstetric estimate of gestation.

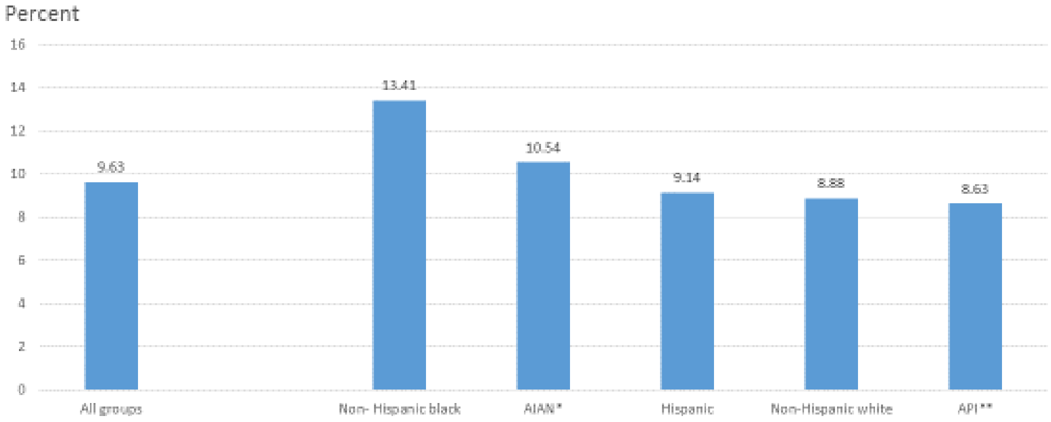
[3] Based on the date of the last normal menses.

Figure 1. Preterm birth rates: United States, 1990-2015



NOTES: LMP-based are based on the Last Normal Menses; OE-based are based on the Obstetric Estimate of gestational age. National OE-based data are not available prior to 2007. Source: CDC/NCHS, National Vital Statistics System

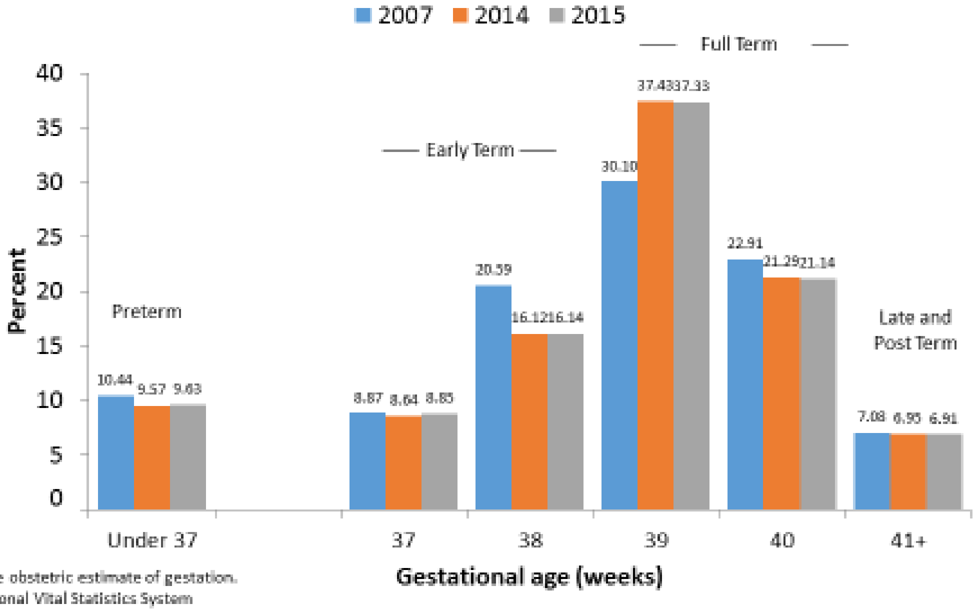
Figure 2. Preterm birth rates by race and Hispanic origin of mother: United States, 2015



NOTE: Based on the obstetric estimate of gestation. Data for AIAN and API women include those of Hispanic origin.
Source: NCHS, National Vital Statistics System

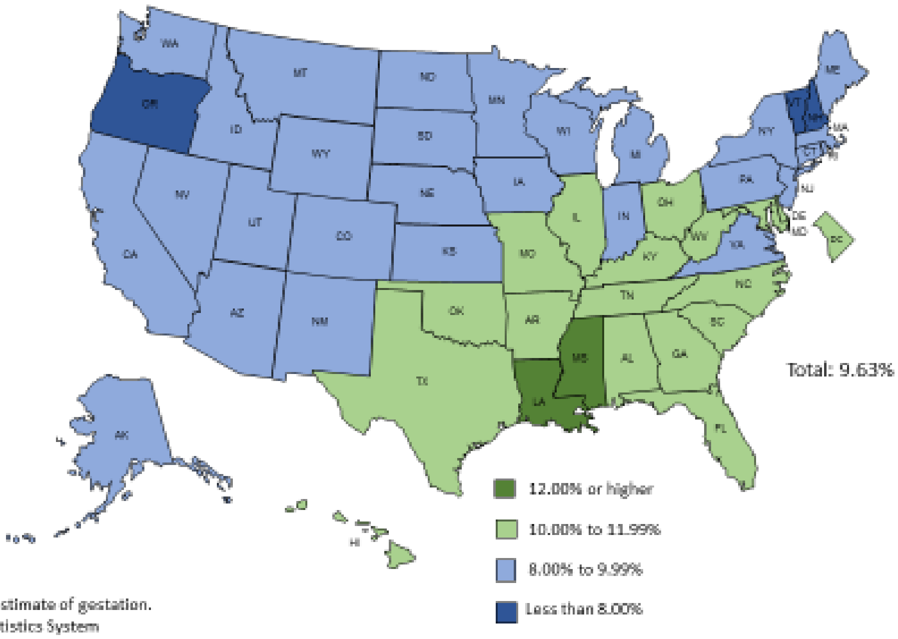
*American Indian or Alaskan Native
**Asian or Pacific Islander

Figure 3. Distribution of births by gestational age: 2007, 2014 and 2015



NOTE: Based on the obstetric estimate of gestation.
Source: NCHS, National Vital Statistics System

Figure 4. Preterm birth rates by state of residence: United States, 2015



NOTES: Based on the obstetric estimate of gestation.
Source: NCHS, National Vital Statistics System

Low Birth Weight and Small for Gestational Age Infants

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Low birth weight in newborns is of such importance as a primary public health concern that the World Health Organization set a goal of globally reducing low birth weight by 30% by 2025. This aggressive approach requires multiple strategies and collaboration among many different levels (individual, family, community, state, regional, and national) of public health action, including targeting modifiable prenatal risk factors and addressing life course, environmental, and social determinants of birth weight.

PUBLIC HEALTH IMPORTANCE

How much a baby weighs at birth is of interest to not only the parents and other family members but also to our communities, states, and nation. Compromised fetal growth is associated with both short- and long-term health effects, including increased risks of mortality, morbidity, developmental delay and disabilities, and cognitive disorders.[1-8] There are also associations with increased risk for chronic disease later in life for both the infant and mother.[1,2] Many children who are born too small have increased needs for medical care and other supportive services, leading to increased economic, family, and societal costs. Low birth weight (LBW), defined as birth weight (BWT) less than 2500 grams (g), is a primary public health indicator for population-based studies of fetal growth. There have been decades of public health focus on the primary prevention of LBW globally, nationally, and locally.

Recognizing the problem of LBW, the World Health Organization (WHO) set a goal in 2012 to reduce LBW rates by 30% globally by 2025.[9] Rates of LBW vary internationally with estimates of approximately 28% in Southeast Asia, 13% in sub-Saharan Africa, and 9% in Latin America.[9] These estimates are likely conservative, because many infants are not routinely weighed at birth in under-resourced areas.[10] Differences in whether early, very small infants who die within minutes of delivery are included in vital statistic registrations may confound both international and intra-national comparisons.[11]

In the United States (US), the Healthy People 2020 (HP2020) Maternal Infant Child Health objective 8.1 is to reduce the national LBW rate to 7.8%.[12] Objective 8.2 is to reduce very low birth weight (VLBW, <1500g) to 1.4%.[12] In 2016, the national rates of LBW and VLBW were 8.17% and 1.40%, respectively[13] (Figure 1). Rates were below the 2020 LBW goal for non-Hispanic white (NHW) and Hispanic mothers but not non-Hispanic black (NHB), American Indian Alaska Native (AIAN), and Asian-Pacific Islander (API) mothers. Rates were below the 2020 VLBW goal for all groups except NHB and AIAN mothers. NHB mothers have consistently higher rates of LBW and VLBW compared to other racial/ethnic groups in the United States.

Table 1 provides data on the rate of LBW by selected characteristics and risk factors, as available from the 2016 public-use natality dataset.[13]

HISTORY OF DATA COLLECTION

Low Birth Weight

The use of <2500g as the definition of LBW originated with Arvo Yippo, a Finnish pediatrician, in 1919 and was used to distinguish preterm and term infants.[4] Thus, LBW was considered a marker of prematurity and, at that time, preterm birth (PTB) was defined as <2500g BWT. It is thought 2500g was selected as the cut-point because it corresponded to 5 pounds, 8 ounces, allowing simple conversion between metric and avoirdupois measurement systems.[4] This definition was supported by WHO in 1948 as an indicator for vital statistics, public health campaigns, and public policy.[4]

It is now recognized that there are two pathways to LBW. Infants may be too small because they were born too early or because their *in-utero* growth was restricted. Thus, PTB (now defined as <37 completed weeks of gestation) and LBW are not equivalent − preterm infants are not necessarily LBW and term infants may be LBW. In the United States in 2016, over half (58%) of preterm infants were LBW whereas 2.8% of term infants were LBW. Over two-thirds (69%) of LBW infants were preterm.[13]

While LBW is a marker for increased risk of adverse health events, not all LBW infants have poor outcomes. Attempts at improved risk assessment for subsequent poor health or death associated with LBW have led to use of subcategories of absolute weight, such as VLBW, moderately low birth weight (MLBW, 1500-2499g), or extremely low BWT (<1000g). Term LBW has also been used as an indicator of compromised fetal growth, independent of the effects of prematurity. There are also relative assessments of BWT in consideration of the full distribution of gestational age at delivery.

Small for Gestational Age

Similar to anthropometric assessment of child weight for height at a specific age, relative assessments of BWT based on weight distributions at each gestation week have been used to identify compromised growth.[1] In 1967, two pediatricians from Colorado, Frederick C. Battaglia and Lula O. Lubchenco, coined the term “small for gestational age” (SGA) in consideration of expected norms of fetal growth at each completed week of gestation.[14] Over time, terminology on perinatal growth restriction has been inconsistent in scientific literature with terms such as SGA; “fetal growth restriction,” “intrauterine growth restriction,” and “intrauterine growth retardation” are often applied interchangeably to both fetuses and newborns.[1,15] To standardize terminology and distinguish between assessment of growth during gestation and at birth, the American College of Obstetrics and Gynecology defined “fetal growth restriction” as a *fetus* with an *estimated fetal weight* of <10th percentile for gestational age and “SGA” as an *infant* with a *birth weight* of <10th percentile for gestational age.[15]

The definition of SGA as less than the 10th percentile of the BWT distribution at a gestation week distinguishes this indicator from the LBW definition of <2500g – the two indicators are not equivalent. If an SGA infant has a BWT above 2500g, it is not an LBW infant. Similarly, if a LBW infant is above the 10th percentile for its gestational age, it is not an SGA infant. If an infant weighs less than 2500g, and this weight is below the 10th percentile for its gestational age, then the infant is both LBW and SGA.

As with LBW, the use of SGA as an indicator for subsequent health risks is problematic. It does not differentiate infants who are born small because of a pathological process, which limits fetal growth potential, from infants who are constitutionally small yet who have achieved potential (such as infants born to small mothers).[1,3,16,17] It is also important to note that for population level surveillance, SGA incorporates gestational age and birthweight, but other indicators are important for clinical considerations and the pathology of SGA such as head circumference. Pathological growth restriction (e.g. vascular constriction in utero) has been associated with a greater risk of adverse outcomes compared to constitutional smallness. Lower thresholds, such as the 3rd or 5th percentiles instead of the 10th, have been used to increase the probability of distinguishing pathological growth restriction from constitutional smallness.[1,3,17] However, a concern is that as this threshold is changed along the growth continuum, rates of sensitivity, specificity, false positives and false negatives will change.[18]

Divisions by gestational age have been used to distinguish SGA subtypes, with early preterm SGA associated with pathological smallness and term SGA associated with constitutional smallness.[19] However, these distinctions are not absolute. The percentages of pathological and constitutional SGA are influenced by population characteristics, maternal and fetal risks, and clinical care.[1]

Birth Weight Reference or Standard

Assessing the incidence of SGA depends on both accurate assessment of gestational age and construction or use of a weight-for-gestational-age population *reference* or normative *standard*.[1,3] A weight *reference* is descriptive and includes birth weights from both low- and high-risk pregnancies with normal and adverse outcomes in a population. A reference is population specific and comparative. It requires large, representative sample sizes. Use of a reference indicates an infant's BWT relative to the BWT distribution of the population from which the reference is constructed.

In contrast, a weight *standard* is prescriptive and includes BWT from normal, low risk, uncomplicated pregnancies. Observations with risk factors that affect fetal growth are excluded. A standard indicates how an infant/fetus *should* grow. A standard is not population-specific and is independent of changing population characteristics. Use of a weight standard enables comparison of an infant's BWT with that expected in a normally grown infant. Fetal growth standards based on longitudinal ultrasound estimates of fetal weight for US and for international populations were published recently.[20-22]

Population surveillance of SGA has predominantly used BWT references from cross-sectional studies of live births, assuming BWT at a specific gestational week has a normal distribution and is representative of all fetuses at that week. Many contemporary US references exclude pregnancies with implausible BWT (values outside of valid ranges of birth weight for gestational age based on last menstrual period) but generally include pregnancies with maternal or fetal complications.[23-29] References may be restricted by plurality or stratified by sex because of the differences in growth patterns and mortality risks between male and female fetuses.

The use of cross-sectional BWT data for construction of a reference may lead to biased assessment of SGA.[1,3,30] Fetuses *in utero* at a specific gestational age are unrepresented in the construction of a reference. This is a problem for identifying preterm SGA because the weights of fetuses at that gestational age, but who do not deliver until a later gestational age, are not included. These weights are necessary to have a more normal distribution at each week. Because reference distributions include births from pregnancies with complications that may affect BWT and lead to PTB, the SGA threshold is lower in a reference than in a standard. This leads to under-diagnosis of preterm SGA in a reference compared to a standard.[1,30]

Customized Standard

Customized weight standards were developed to improve identification of growth restriction in preterm and term pregnancies.[1,3,31] Customized standards use regression modeling to calculate optimal BWT according to ultrasound-based fetal weight standards from term pregnancies, adjusted for plurality and maternal variables (height, weight, parity, race, and ethnicity). Infant sex may also be an adjustment factor. Observations with risk factors that may influence BWT, such as PTB, smoking, and maternal morbidities, are excluded. A growth-based proportionality statistical function is used to predict expected weight potential at all gestational ages and to calculate percentiles. This approach eliminates using only PTB in the development of a standard at <37 weeks' gestation.

Customized standards are used in clinical assessment of *in utero* growth and in studies of perinatal outcomes, leading to improved identification of preterm infants at increased risk for adverse outcomes and term births at lower risk.[1] Customized standards may also identify compromised growth in infants who are above the 10th percentile.[1]

Other Assessments of BWT and SGA

Other measures, including Z-scores, qualitative scores, and medical coding, have been used to assess BWT in descriptive or analytic studies.[32,33] A *Z*-score is calculated by transforming an observed BWT into a unit of standard deviation (SD) based on the mean (expected) of the weight distribution [(Observed – Expected)/SD = Z-score]. Z-scores may be calculated after stratification by gestational week, race/ethnicity, or other factors.

Use of qualitative scores based on the mother's assessment of BWT, such as "very small", "smaller than average", and "average" or "very below", "below average", "average," and "above average" are used in the Demographic and Health Surveys and the Multiple Indicator Cluster Surveys in countries where many infants are not routinely weighed at delivery.[34-36] An algorithm and statistical weighting using these assessments and measured BWT data are then used to estimate LBW prevalence.[34,37]

There are medical codes related to BWT in the International Classification of Diseases, Ninth and Tenth Revisions, Clinical Modification (ICD-9-CM and ICD-10-CM). In the ICD-9-CM, slow fetal growth and fetal malnutrition are coded in the 764 range and short gestation and low BWT are coded in the 765 range. In the ICD-10-CM, these codes are P05 and P07, respectively.[38,39] The ICD-9-CM codes were used to examine recent trends in term SGA infants in the United States using the Nationwide Inpatient Sample.[40]

CDC SURVEILLANCE ACTIVITIES

The National Vital Statistics System

In the United States, BWT, as a record of fetal mass at delivery, is recorded on the Standard Certificate of Live Birth and compiled by state and territory vital registration departments for all infants born in the United States. Birth certificate data are sent to the National Center for Health Statistics (NCHS), via the National Vital Statistics System, and published in annual reports and public-use natality datasets. The use of a common birth certificate promotes uniformity and comparability. BWT has been consistently available on multiple versions of the US birth certificate since 1949 and its measurement has not changed over time. BWT in the natality datasets has excellent accuracy and reporting with less than 0.1% of live birth records missing BWT in 2016.[13,41]

Weight at delivery is also included on the Standard Fetal Death certificate; however, reporting is less complete than in the birth certificate. In 2015, weight at delivery was missing for 7.3% of fetal deaths with a gestational age of 20 weeks or greater. Among those with a reported weight, 65% were VLBW; 81% were LBW.[42]

Annual summaries of all births occurring in the United States are now available about nine months following the data period. Users may download NCHS public use data files and documentation.[13] The National Bureau of Economic Research provides downloadable input statements for software applications.[43] Searchable data are available in CDC Wonder and the March of Dimes PeriStats.[44,45] The natality file is also linked to the infant death file enabling analyses of relationships between BWT and infant mortality.

Pregnancy Risk Assessment Monitoring System (PRAMS)

State-based birth certificates provide the sampling frame for the Pregnancy Risk Assessment Monitoring System (PRAMS), and most states oversample LBW infants.[46] PRAMS collects information on maternal behaviors and experiences, such as barriers to prenatal care, preconception care, and psychosocial stress and support. The BWT variable is included in the state-specific PRAMS datasets allowing studies of the associations of LBW and PRAMS-specific variables.

Reproductive Health Surveys and the Demographic and Health Surveys

CDC supported Reproductive Health Surveys and the Demographic and Health Surveys, which include data on BWT, in select developing countries.[35,47] A statistic compiler for data from these surveys is located at http://www.statcompiler.com/.

GENERAL FINDINGS

Geographic Variation

In the United States, 21 states met the HP2020 goal of reducing LBW to 7.8% in 2015; 33 states met the HP2020 VLBW goal of 1.4% in 2015 (Figure 2a and 2b).[48-50] The highest rates of LBW and VLBW generally occurred among states in the southeast.

Trends

In the United States, LBW rates for all births increased from 6.97% to 8.26% between 1990 and 2006, then declined to 8.00% in 2014, and then increased to 8.17% in 2016 (Figure 3). Similar trends are evident, but to a lesser extent, in the VLBW trend between 1990 and 2013; however, the VLBW rate has remained stable at 1.40% between 2014 and 2016. The singleton LBW rate was increased between 5.90% in 1990 to 6.49% in

2006, then decreased to 6.24% in 2014, and then increased to 6.44% in 2016. The VLBW trend for singletons parallels the VLBW trend for all births.[13,48]

Variations in LBW trends are observed when racial/ethnic-specific trends for all births are examined (Figure 4). For AIAN mothers, LBW rates increased from 6.13% in 1990 to 7.91% in 2016. For Hispanic mothers, the LBW rate increased from 6.06% in 1990 to 6.99% in 2006, then remained relatively stable until 2012 (6.97%), and then increased to 7.32% in 2016.

For NHW, API, and NHB mothers, there are varying periods of increases and decreases in LBW rates over time. For NHW mothers, LBW rates increased from 5.61% in 1990 to 7.32% in 2006, then declined to 6.93% in 2015, and increased to 6.99% in 2016. For API mothers, the LBW rate increased from 6.42% in 1990 to 8.50% in 2010, then decreased to 8.08% in 2014, and then increased to 8.39% in 2016.

The LBW rate for NHB mothers is greater than the rates for the other race/ethnicity groups and displays a different trend pattern. For NHB mothers, LBW rates decreased 13.32% in 1990 to 13.07% in 2001, a time when LBW rates were increasing in other groups. The LBW rate for NHB mothers then increased to 13.97% in 2006, decreased to 13.06% in 2013, and then increased to 13.53% in 2016. Thus, while all groups have had an increase in LBW rates between 2014 and 2015, the increase started in 2013 for NHB mothers.

The reasons for these trends are not well understood but may be related to changes in plurality, maternal demographics and morbidity, smoking, prenatal care and obstetric intervention, body mass index, weight gain, and PTB rates.[51-56] For example, a “fetal shift,” which occurs when a small, at-risk fetus is delivered live via medical intervention (to reduce fetal death risk), may be increasing the observed VLBW and LBW rates.[57]

Risk Factors

Risk factors for LBW and for SGA are similar. Both have multiple-level, complex, inter-connected risk factors involving the placenta, fetus, and mother.[1,4,16,17] These include demographic, behavioral, biologic, health care, environmental, and social factors (Table 2). A specific etiology is often difficult to identify. The risk factors for LBW and SGA are also similar to those for PTB, because PTB is a risk factor for LBW.

Race/Ethnicity

A striking feature of perinatal epidemiology is the persistent two-fold difference in LBW rates for NHB infants compared to other groups (Figures 1 and 4). This disparity occurs over decades of monitoring and intervention. The disparity has slightly narrowed in recent years because of a decrease in the LBW rate among NHB mothers and an increase in the other groups. API infants also have LBW rates, especially term LBW rates, which are greater than the national average (Figure 1). This may be because of smaller maternal body size in this population although other factors may also be important.[58,59]

Plurality

The plurality of a pregnancy is a strong risk factor for LBW. In 2016, over 55% of twins were LBW compared to 6% of singletons[13] (Figure 5). Rates of LBW were over 95% for triplets and higher-order multiple births. Rates of VLBW also increase with plurality – over 37% of triplet and 77% of quadruplets or higher births were VLBW.[13] Because of the association between plurality and BWT, most epidemiologic studies examining other risk factors for LBW restrict analyses to singleton births.

Other Factors

Other factors consistently associated with increased risk of LBW or SGA include tobacco and other substance use, teen or older mothers, low socioeconomic status (SES), nutritional factors (low pregnancy weight gain, low maternal body mass index, undernutrition), short height, parity, previous LBW or PTB delivery, short inter-pregnancy intervals, inadequate prenatal care, placental disorders, maternal and fetal infections, maternal chronic diseases, genetics (maternal or fetal), birth defects, and select medications.[1,4,16,17]

There are conflicting epidemiologic associations for environmental toxins, including lead, air pollutants (such as environmental tobacco smoke, particulate matter, and polycyclic aromatic hydrocarbons), phthalates, polychlorinated biphenyls, perfluorinated compounds, arsenic, benzene, herbicides, bisphenol A, and dioxins.[60] These chemicals may act as teratogens or disrupt maternal and placental physiology.

USING DATA FOR ACTION

Over the past decades, numerous initiatives have sought to reduce LBW and SGA rates, often as part of infant mortality reduction programs. These initiatives include policy, social, clinical and individual actions, such as Medicaid expansion, the Special Supplemental Nutrition Program for Women, Infants, and Children (WIC), Healthy Start, home visiting and case management, social support, enhanced clinical services, teen pregnancy prevention and family planning, preconception and inter-pregnancy care, nutrition counseling, and smoking cessation.[51,61-73] Initiatives include strategic actions that are important across the reproductive life cycle and not solely in prenatal care (Table 2).

Many state and local health agencies have LBW prevention initiatives that monitor trends and disparities and provide action items across the agency and state. For example, a public/private partnership in the state of Georgia works to reduce LBW births using strategies to improve preconception health including: reducing smoking, unintended pregnancy, and chronic health conditions; improving nutritional status and access to and quality of health care; and achieving optimal birth spacing.[74]

The state of Colorado identified inadequate weight gain and smoking as modifiable risk factors for LBW by using population attributable risk analyses of natality data.[75] Colorado then developed multiple interventions to address these risks. They developed social marketing campaigns, increased tobacco taxation, enacted a Clean Indoor Air Act, expanded Medicaid tobacco cessation medication benefits, developed a “Baby and Me Tobacco Free” program, developed smoking cessation clinical guidelines for pregnant and postpartum women, tailored QuitLine counseling for pregnant women, and developed educational materials for consumers, providers, and local agencies on appropriate weight gain during pregnancy. Program evaluations were conducted through the perspectives of LBW risk reduction.[76] The health department outlined specific objectives for what providers, policy makers, payers, and women themselves could each do to improve smoking cessation and adequate weight gain.

There are many case-management, social support, and home visiting programs targeting high LBW rates in states and communities.[63,77-80] One example is the Community Health Access Project in Richmond County, Ohio, which used natality data to identify census tracts with high LBW rates.[81] Pregnant at-risk women living in those tracts then participated in a non-randomized intervention to address social factors and health care access and use. The intervention used a “Pathways Community HUB Model” with local community health workers as care coordinators for case management. The intervention included identification of problems directly and indirectly affecting patient health status, desired positive outcomes, barriers, and evidenced-based action steps. When compared to a matched control birth (non-participant), there was a 65% lower estimated risk of LBW among mothers who completed the intervention.

The Association of Maternal and Child Health Programs Life Course Metrics project has SGA as an indicator (Community Well-Being, item LC-11), because it is a consequence of pre-pregnancy health and social factors and may have life-long consequences for the infant.[82] Life Course Metrics are utilized by state and local health departments to evaluate maternal and child health programs.

LBW is an indicator in the Medicaid Children’s Health Insurance Program (CHIP) Core Set of measures to assess health care quality because of the increased LBW risk among infants born to women of low SES.[83] Because Medicaid covers a large proportion of US births, analyses of natality and Medicaid linked datasets at the state level are important tools to monitor trends and disparities and to target intervention activities.[84]

DATA GAPS AND LIMITATIONS

The quality of vital statistics birth weight data is generally considered to be excellent.[41] However, one potential data quality issue related to measurement should be noted. Although reporting of birth weight measured in grams is recommended, weight may be recorded on the birth certificate in either grams or pounds/ounces. The conversion of measurements recorded in pounds/ounces to grams may lead to discrepancies, depending on the precision of the conversion factor.

There are several data issues with SGA. It is not available in vital statistics without additional calculations. There is no consensus on which standard, reference, or customized distributions should be used in surveillance of SGA. It is unresolved as to whether maternal race/ethnicity, parity, infant sex, or other factors are important in the construction of distributions.

Because the obstetric estimate became the default measure used for gestational age in US natality data in 2014, new calculations of reference distributions are needed.[85] The weights of fetal deaths are also not included in reference distributions. There is a lack of precision in identifying infants at increased risk for adverse health outcomes. There is no consensus in perinatal epidemiology on whether there is a single average birthweight distribution or if there are normal variations in distributions, according to population subgroups, leading to varying definitions of high and low risk.[1,3] It is unclear whether population differences in BWT distributions are because of normal biological variation or the result of epigenetic and/or antepartum factors.

While vital statistics form the basis for the ongoing surveillance of LBW, they are not designed to answer specific epidemiologic or clinical research questions.[86] Many risk factors that may help assess trends and disparities, such as social determinants of health and environmental factors, are not available in natality data. Nor are the effects of emerging protective or risk factors for LBW and SGA, such as group prenatal care, antepartum depression, or use of prescription drugs (e.g., selective serotonin reuptake inhibitors, opioids).[87-91] Linkages to other datasets, such as hospital discharge, census data, or environmental records, analyses of PRAMS data or clinical data, or analyses of other cohort or case-control studies are required.

FUTURE ISSUES

Because of its reliability, consistency, and ease in measurement over time, vital statistics BWT data remains an important indicator of infant health. The natality files are the sole source of this data for the United States

annually. As of 2016, the HP2020 goal to reduce the US LBW rate to 7.8% was unmet. Nationally, the LBW rate increased in both 2015 and 2016, moving further away from the goal. Achieving this goal requires further reductions in the two determinants of LBW – PTB and SGA. Unfortunately, PTB rates also increased in 2015 and 2016. Understanding why these rates are increasing will be important for reversing the trends.
Multiple strategies and collaboration among many different levels (individual, family, community, state, regional, and national) of public health action are necessary to reduce LBW rates and disparities. Interventions targeting modifiable risk factors, such as smoking, preconception health and maternal morbidity, nutritional status, unintended pregnancy, and access to health care, need to be available to all mothers at risk of having a LBW infant. Reduction of racial/ethnic disparities in LBW rates requires addressing risks on both individual- and population-levels. This includes consideration of life course, preconception, antenatal, postpartum, intergenerational, environmental, and social determinants of health. Relatively little is understood about how these factors affect birth weight distributions in disadvantaged populations. Evaluation is critical to ascertain which prevention components reduce LBW and SGA in population subgroups and in what risk contexts.[51,71]

ADDITIONAL RESOURCES

- CDC Wonder
  http://wonder.cdc.gov/natality.html
- NCHS National Vital Statistics System
  https://www.cdc.gov/nchs/nvss/index.htm
- NCHS vital statistics public use datasets http://www.cdc.gov/nchs/data_access/vitalstatsonline.htm
- National Bureau of Economic Research Vital Statistics
  http://www.nber.org/data/vital-statistics-natality-data.html
- Pregnancy Risk Assessment Monitoring System
  http://www.cdc.gov/prams/
- March of Dimes PeriStats
  http://www.marchofdimes.org/peristats/Peristats.aspx

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Table 1: Prevalence of low birth weight (LBW) among selected characteristics and risk factors available on the natality public use file, United States, 2016[a]

	LBW Rate (%)
Overall	8.17
Characteristics	
Singleton birth	
Yes	6.44
No	56.65
Maternal race/ethnicity	
Non-Hispanic white	6.99
Non-Hispanic black	13.53
Hispanic	7.32
American Indian Alaska Native	7.91
Asian Pacific Islander	8.39
Maternal age (years)	
<20	9.90
20 - 24	8.51
25 - 29	7.56
30 - 34	7.52
35 - 39	8.83
≥ 40	11.52
Maternal education	
No high school diploma	9.59
High school diploma	9.13
Some college but no degree	8.34
Associate degree	7.67
Bachelor’s degree	6.61
Master’s degree	6.89
Doctoral or professional degree	6.95
Delivery payment method	
Medicaid	9.52
Private insurance	7.11
Self-pay	6.93
Other	7.79
WIC[b]	8.96
Cigarette smoking	
Yes	13.74

	LBW Rate (%)
No	7.71
Maternal nativity status	
Born in United States	8.39
Born elsewhere	7.38
Prenatal care in first trimester	
Yes	7.69
No	8.97
Parity[c]	
Primiparity	8.74
Low	7.15
High	9.82
Maternal body mass index	
Underweight (<18.5)	12.39
Normal (18.5 – 24.9)	7.88
Overweight (25.0 – 29.9)	7.49
Obese I (30.0 – 34.9)	8.02
Obese II (35.0 – 39.9)	8.43
Obese III (≥ 40.0)	9.12
Pregnancy weight gain	
Within IOM guidelines[d]	7.50
Below IOM guidelines	12.74
Above IOM guidelines	6.13
Gestational Age (weeks)	
<37	57.57
≥ 37	2.78
Delivery method	
Vaginal	5.80
Cesarean	13.20
Infant Sex	
Female	8.86
Male	7.51
Congenital anomaly	26.17
Maternal morbidity	
Chronic hypertension	19.81

	LBW Rate (%)
Gestation hypertension	19.85
Eclampsia[e]	34.79
Pre-pregnancy diabetes	13.95
Gestational diabetes	8.98
Previous preterm birth	21.08
Infertility treatment[f]	23.06
Fertility enhancing drugs[f]	21.62
Assisted reproductive technology[f]	24.67

[a] See National Center for Health Statistics[13]

[b] WIC is the Special Supplemental Nutrition Program for Women, Infants, and Children

[c] See Parker.[92] High parity is defined as three or more previous births to mothers age 24 and younger or four or more previous births to mothers age 25 and older. Low parity is defined as all other multiparity.

[d] IOM Institute of Medicine.[93]

[e] Eclampsia is reported by 48 states and the District of Columbia. This represents 96.5% of births in 2016.[13]

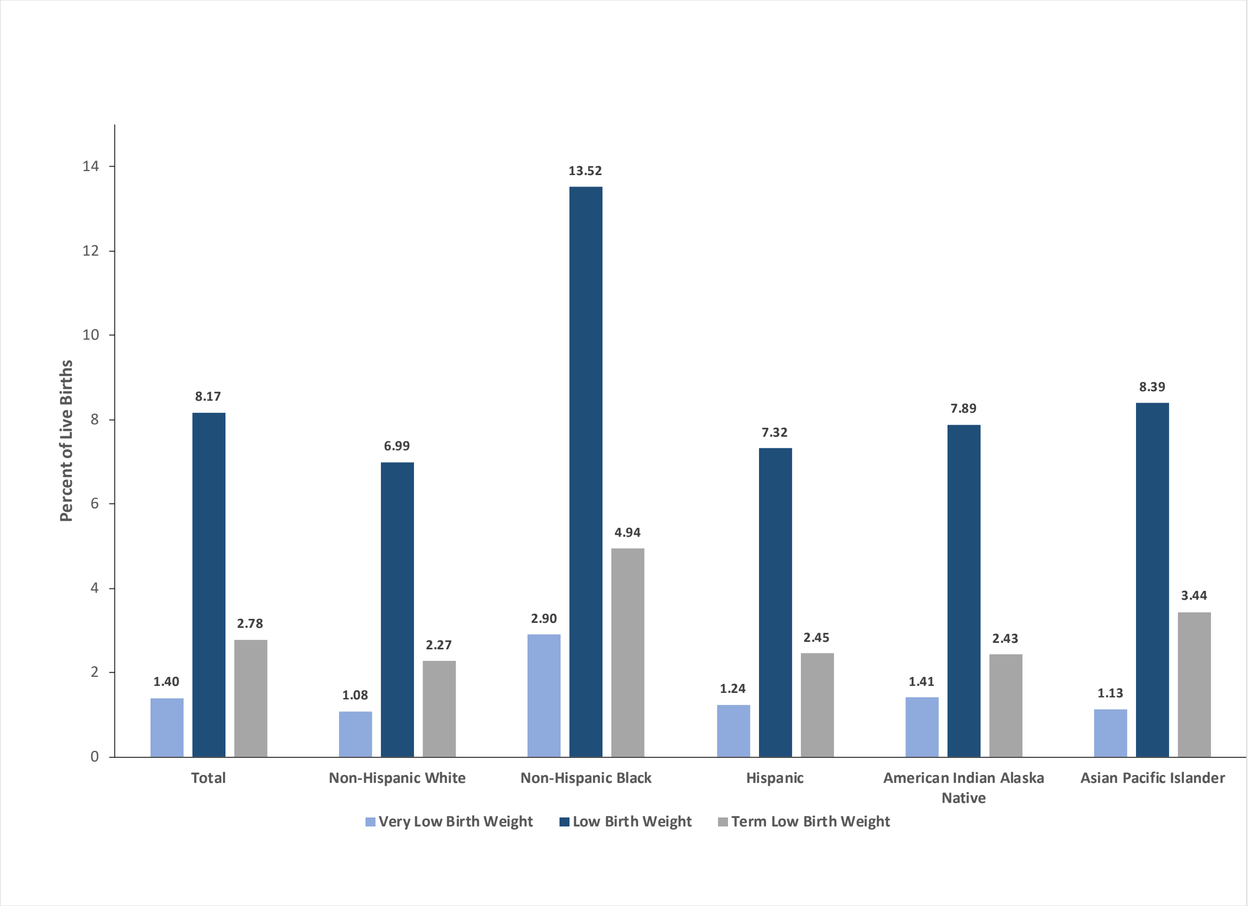
[f] Type of infertility treatment is reported by 47 states and the District of Columbia. This represents 96.2% of births in 2016.[13]

Table 2: Action strategies to improve low birth weight rates

Preconception and inter-pregnancy	**Prenatal**
Preconception care	Risk-appropriate regular prenatal care
Improve nutritional status	Improve nutritional status
Optimize body mass index	Adequate weight gain
Stop smoking and use of illicit drugs	Stop smoking and use of illicit drugs
Family planning	Access to WIC[a] if eligible
Identify and treat existing medical conditions	Identify and treat pregnancy-related condition
Single embryo transfer	Reduce elective early delivery
Reduce and manage stress	Reduce and manage stress
Address mental health issues	Address mental health issues
Increase social support	Increase social support
Reduce toxin exposures	Reduce toxin exposures
Address social determinants	Address social determinants
Health education	Health education
Access to Medicaid or insurance coverage	Access to Medicaid or insurance coverage

[a] WIC is the Special Supplemental Nutrition Program for Women, Infants, and Children

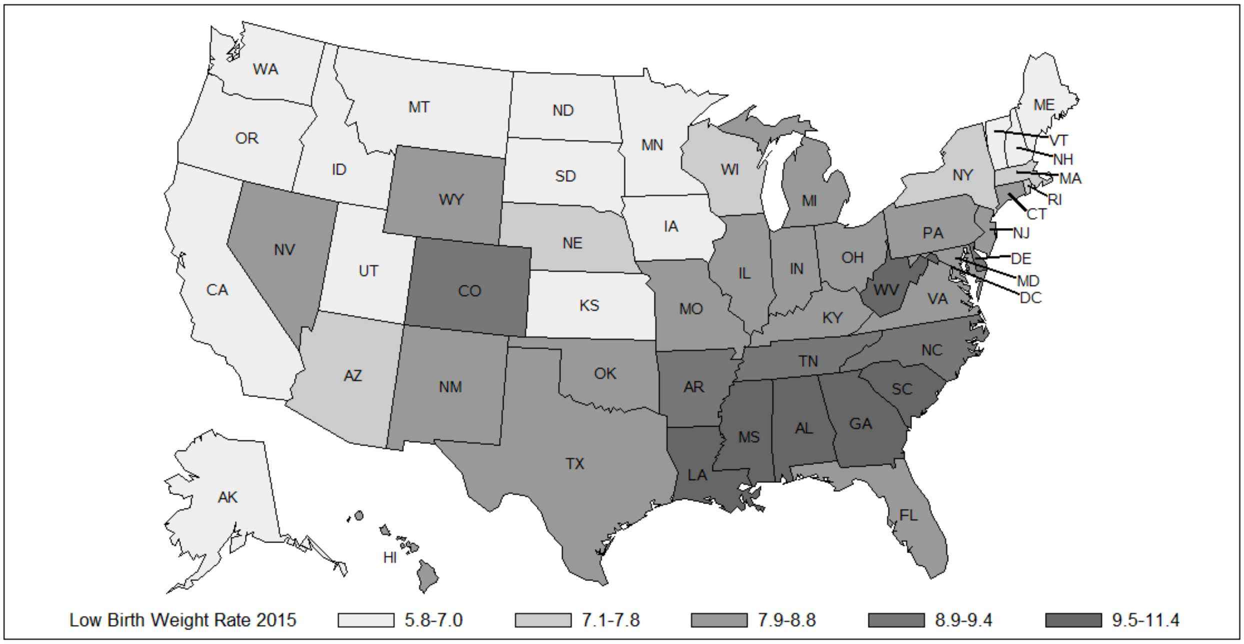
Figure 1. Very low, low, and term low birth weight rates (%) – all births, by maternal race/ethnicity, United States, 2016



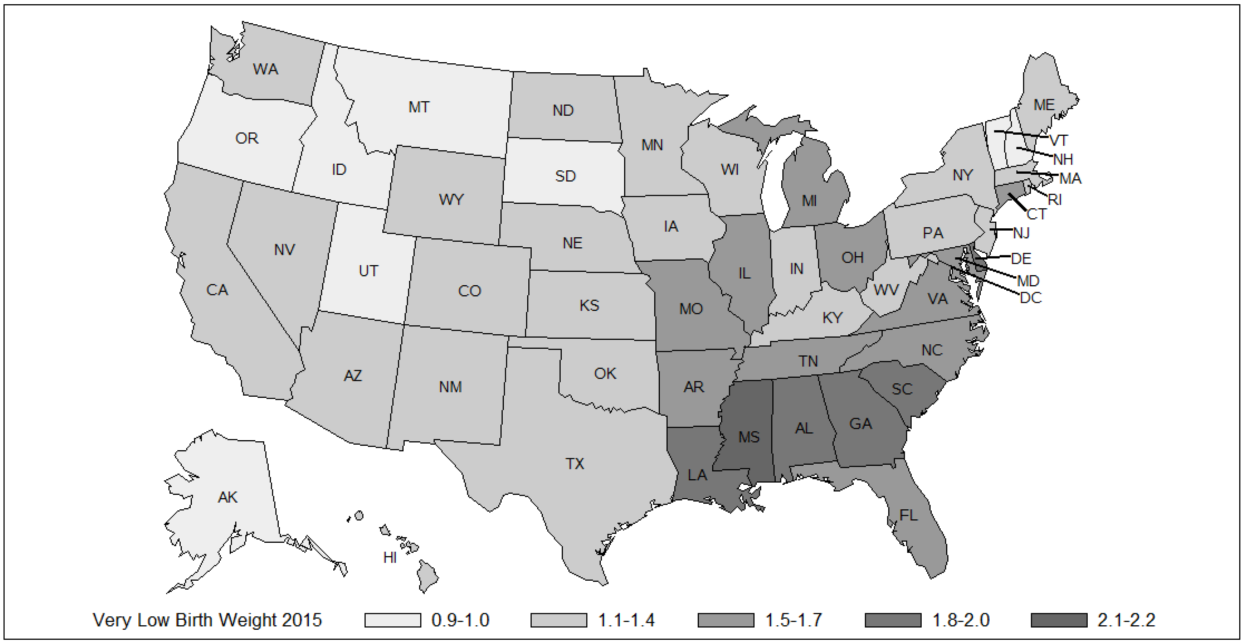
Source: National Center for Health Statistics public use natality data, 2016.[13]

Figure 2a-b: Low and very low birth weight rates (%): all births, by state, United States, 2015

a. Low birth weight

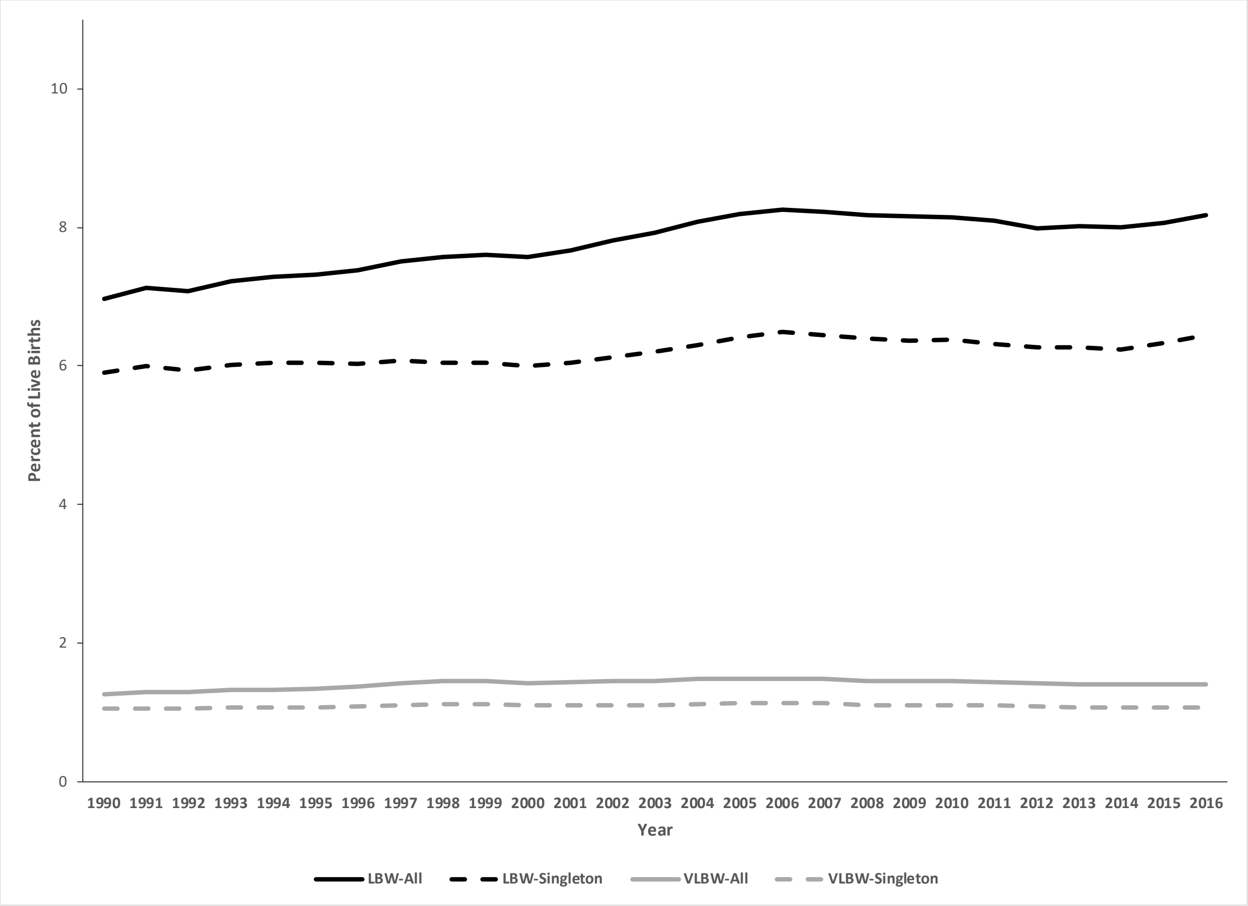


b: Very low birth weight



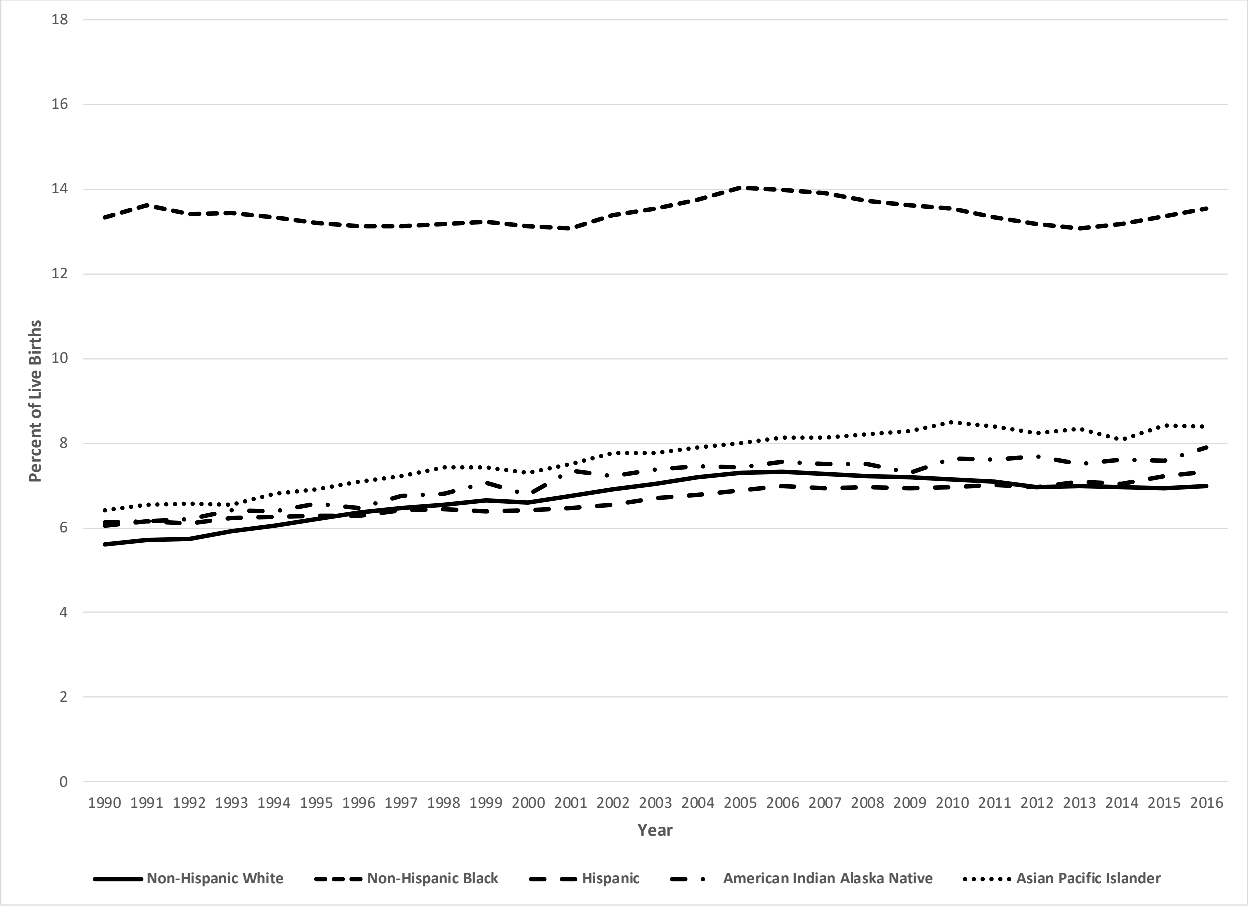
Source: National Center for Health Statistics natality data, 2015.[48]

Figure 3. Trends in low and very low birth weight rates (%) – all and singleton births, United States, 1990 – 2016



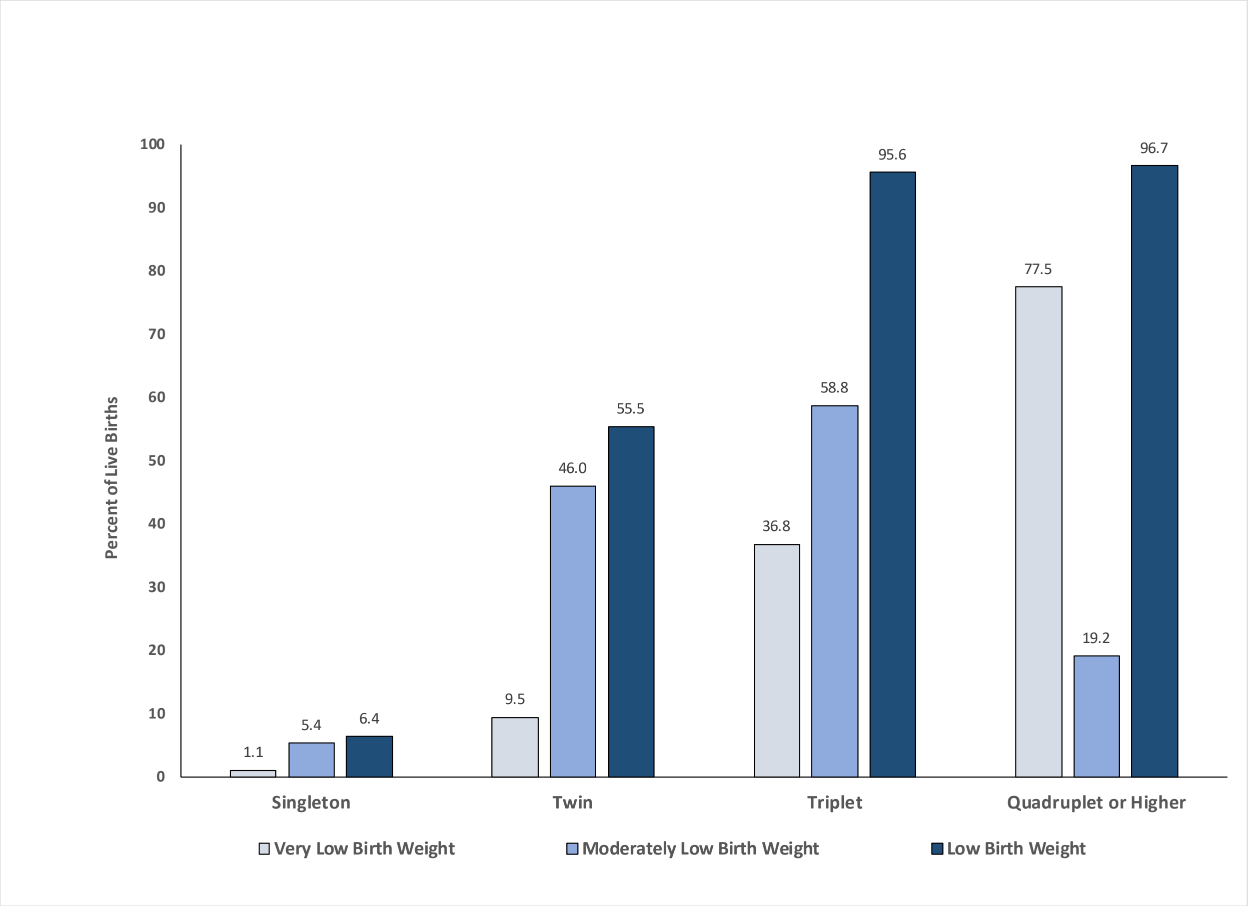
Source: National Center for Health Statistics public use natality data, 2016.[13]

Figure 4. Trends in low birth weight rates (%), by maternal race/ethnicity, United States, 1990 – 2016



Source: National Center for Health Statistics public use natality data.[13,48]

Figure 5. Very low, moderately low, and low birth weight rates (%), by plurality, United States, 2016.



Source: National Center for Health Statistics public use natality data, 2016.[13]

Infant Mortality

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Infant mortality is a key indicator of the health of a nation, state, or community. While the infant mortality rate in the United States has declined rapidly for much of the 20th century, declines in infant mortality have not kept pace with declines with other high-income countries. Addressing the leading causes of infant death are a key strategy to improve outcomes. Data linkages provide the most robust data to inform action.

PUBLIC HEALTH IMPORTANCE

Infant mortality is a key indicator of the health of a nation, state, or community. It has been, and continues to be. associated with a variety of factors such as quality and access to medical care, maternal health, socioeconomic conditions, and public health practices.[1–5] The US infant mortality rate has declined more than sixteen-fold since the beginning of the 20th century, from an estimated 97.30 infant deaths per 1,000 live births in 1900[6] to 5.82 deaths per 1,000 live births in 2014.[7]

Infant mortality declined rapidly during the 20th century and into the early part of the 21st century; however, rates of decline were slower from 1950 through 1964 and 1981 through 1990 with increases in 2001 and 2007 (Figure 1). Despite these improvements, the issue of infant mortality remains substantial. In 2014, 23,215 infants died before their first birthday, and it continues to be an important public health issue.[7]

Declines in infant mortality in the United States have not kept pace with declines in European and some Asian countries. In 2013, there were approximately two dozen countries with infant mortality rates lower than the United States.[8] The US infant mortality rate of 5.98 (rounded to 6 in Figure 2) per 1,000 live births was greater than three times that of Finland and Japan. Within the United States, large disparities in the risk of infant death persist among racial and ethnic groups. For example, in 2013 the infant mortality rate for infants of non-Hispanic black mothers was 2.2 times the rate for non-Hispanic whites.[5]

HISTORY OF DATA COLLECTION

The primary source of infant mortality statistics for the United States is the National Vital Statistics System. Through this system, vital events (births, deaths, and fetal deaths) occurring in the United States and territories each year are registered; the data are then reviewed, processed and made available to the public. Infant deaths, those who die in the first year of life, comprise a subset of the approximate 2.6 million deaths registered on death certificates each year.[9]

There were periodic precursors, but in 1900 the US Bureau of the Census began collecting mortality statistics annually for a death registration area of ten states, the District of Columbia, and several cities. The death registration area gradually expanded and, by 1933, included the entire United States. In 1946, the responsibility for providing vital statistics was given to the Public Health Service.[10] For over 60 years, vital statistics have been a part of CDC's National Center for Health Statistics (NCHS).

CDC SURVEILLANCE ACTIVITIES

National Vital Statistics System

Mortality Data

Mortality data from the National Vital Statistics System (NVSS) are cooperatively produced by NCHS and state vital statistics offices under the Vital Statistics Cooperative Program. The basic source of mortality information is the death certificate. US death registration is a state function; death certificates are filed and maintained in state vital statistics offices according to legal requirements. The NVSS includes reporting from all states, as well as New York City, the District of Columbia, Puerto Rico, Guam, Virgin Islands, Northern Mariana Islands, and American Samoa.

Information is provided on the number of infant deaths by various characteristics of the decedent including age, sex, race and ethnic origin, and cause of death. These data also form the numerator when computing infant mortality rates. Data on the number of live births, used as the denominator for infant mortality rates, are also provided through the National Vital Statistics Program in a manner similar to that described for mortality data.

The US Standard Certificate of Death has been revised approximately once every 10 to 15 years in collaboration with the states, NCHS, other federal agencies, and subject-matter experts.[11] The current certificate, revised in 2003, was adopted by 46 states and the District of Columbia in 2014. The information on the death certificate is provided by two groups of persons: 1) the certifying physician, medical examiner, or coroner; and 2) the funeral director. The certifying physician, medical examiner, or coroner certifies the causes of death.[12,13] The funeral director provides the demographic information (e.g., age, race, sex) and files the certificate with the state vital statistics office.[14] Coverage of death certificate reporting is universal because state laws require death certificates for disposition of bodies, and the certificates are often needed for legal purposes, including estate settlement.

In addition to making periodic revisions to the US Standard Certificates, NCHS promotes uniformity in the collection and processing of vital statistics data in a number of ways, such as in the development of detailed specifications for death registration systems and training for collecting cause of death. NCHS has also facilitated the most recent *Model State Vital Statistics Act and Regulations*[15] to help states develop and revise their vital statistics laws. In addition, NCHS offers training and technical assistance to state vital statistics offices to enhance their capabilities.[16,17] NCHS has coded cause of death information for the state vital statistics offices according to standard procedures since the 2011 data year.

Mortality data are subject to NCHS quality-control procedures at several processing stages to check for completeness, individual item code validity, and consistency among data items. First, NCHS may check problems or inconsistencies against available original source information and correct them, if possible. Second, lists of problems or inconsistencies are returned to the states for information and corrective action. Third, NCHS routinely reviews records that previously have been more challenging to process or code to assess if any correction is needed. Fourth, NCHS codes a quality control sample of records and compares the sample with previously coded data to assess the accuracy of coding. Fifth, numbers of deaths are compared between the current and previous years' data for each county in the United States and for all cause-of-death categories.

Data problems are investigated as to possible source (e.g., system, coding, or reporting) and potential resolutions are sought. Sixth, counts and percentages of records with impossible or out-of-range codes are also reviewed and compared with previous years' patterns. Finally, invalid or inconsistent values may be modified or assigned as unknowns according to written procedures, and selected missing items may be imputed.[9,18]

Final Infant Mortality Data

Final infant mortality data from the death certificate within the National Vital Statistics System are generally available about one year after the close of a data year. These data are published annually in NCHS National Vital Statistics reports.[9,19-21] NCHS also produces public-use data files containing individual-record information on all registered deaths occurring since 1968. The file, file contents, and file characteristics are all available for free download on the NCHS web site.[22] Lastly, there are a couple of tools to assist the public in creating tables using the data including CDC Wonder.[23]

Linked Birth and Infant Death Data

The primary tools used to understand and analyze infant mortality in the United States are the linked birth and infant death data sets. In the linked file the information from the death certificate is linked to information from the birth certificate for each infant under one year of age who died in the 50 states, the District of Columbia, Puerto Rico, the Virgin Islands, and Guam. The purpose of the linkage is to use the many additional variables available from the birth certificate to conduct more detailed analyses of infant mortality patterns. This includes infant mortality data by race and Hispanic origin of the mother, birthweight, period of gestation, sex of infant, plurality, maternal age, live birth order, marital status, mother's place of birth, maternal smoking during pregnancy, age at death, and underlying cause of death.[5] Information on all of the approximately 4 million live births in the United States each year is also included in the data set to enable researchers to compare deaths with survivors and to facilitate the computation of rates.

Period and Cohort Linked Files

The NCHS creates both a period and cohort linked birth and infant death file. From 1983 through 1991, NCHS produced linked files in a birth cohort format only.[22] Beginning with 1995 data, linked files are produced first using a period format and later the cohort format. The period linked file contains a numerator file that consists of all infant deaths occurring in one year that have been linked to their corresponding birth certificates, whether the birth occurred in the year before or in the same year.[5] The birth cohort linked file contains a numerator file that consists of all infant deaths to babies born in a single year whether the death occurred in that year or the next. Beginning with 1995 data, the period linked file is the basis for all published NCHS linked file statistics.

For all years, a record weight is added to the file to compensate for infant deaths that could not be linked to their corresponding birth certificate. In 2013, 99.0% of records were linked and thus, 1.0% of infant deaths were not linked.[5] Cohort linked files are available for 1983–1991 and 1995-2010 and the period files for 1995-2013 data.[22] Data presented here from the period linked file are from the most recent year available (2013).

GENERAL FINDINGS

Trends

The infant mortality rate in the United States declined rapidly during much of the 20th century. In 1900, about 1 in 10 infants died within the first year of life,[6] compared with about 1 in 145 infants' deaths in 2000.[23] The infant mortality rate declined rapidly from 1900 through 1950; by 1950, the rate of 28.59 infant deaths per 1,000 live births was less than one third the rate in 1900. However, from 1950 through 1964, the decline in the infant mortality rate slowed markedly to average 1% per year. From 1965 through 1981, the infant mortality rate again declined rapidly, by an average of 4.5% per year from 24.70 to 11.93. However, from 1981 through 1989, the rate of decline slowed markedly to an average 2.5% per year. Between 1990 and 2000, the infant mortality rate decreased a total of 25% to 6.89 per 1,000 (in more recent years the IMR is measured with two decimal places).[24,25] From 2000 through 2013, the rates declined an additional 13% to 5.96 per 1,000.[5]

Leading Causes of Infant Death

In 2013, the five leading causes of infant death were congenital malformations, disorders relating to short gestation and low birthweight, newborn affected by maternal complications of pregnancy, sudden infant death syndrome, and accidents (Table 1). Together, these five causes accounted for over half (57%) of all infant deaths. The first five leading causes of death were the same for infants of non-Hispanic black and non-Hispanic white mothers, although their rank order differed. The leading cause of death for infants of non-Hispanic black mothers was disorders relating to short gestation and low birthweight.[5]

Preterm-Related Causes of Death and Sudden Unexpected Infant Deaths

Two supplemental cause-of-death groupings have been developed to more fully examine infant deaths associated with preterm birth and sudden death. The first, "preterm-related causes," includes causes if 75% or more of infants whose deaths were attributed to that cause were born at less than 37 weeks of gestation, and the cause of death was a direct consequence of preterm birth based on a clinical evaluation and review of the literature.[26,27] In 2013, 8,470 out of a total of 23,446 infant deaths (36.1%) in the United States were estimated to be preterm-related. The second grouping, "Sudden Unexpected Infant Deaths (SUID)," was developed in response to variations over time and among those who complete death certificates in how sudden unexpected infant deaths are reported on death certificates.[28,29] The SUID category combines different codes that may have captured these deaths over time. In 2013, there were 3,422 SUIDs in the United States, comprising 14.6% of all infant deaths in that year.

Period of Gestation and Birthweight

The gestational age of an infant is perhaps the most important predictor of his or her survival and subsequent health. Infants born too small or too soon have a greater risk of death and both short-term and long-term disability compared with those born at full term (39–40 weeks of gestation).[30-36] The percentage of preterm births has been linked to variations in infant mortality rates per 1,000 live births among countries.[37] Because of their much greater risk of death, preterm infants have a large impact on the US infant mortality rate. Infant mortality rates are highest for very preterm (less than 32 weeks) infants, and the risk decreases sharply with increasing gestational age[31,35] (Table 2). Although mortality falls with increasing gestational age, even infants born only a few weeks early have a substantially increased risk of death and disability when compared with term infants.[38-41]

Birthweight is also an important predictor of infant health. It is closely associated with, but does not exactly correspond with, the period of gestation. Infant mortality rates are highest for the smallest infants and decrease as birthweight increases. Because of their much higher mortality rates, infants born at the lowest birthweights have a substantial impact on overall infant mortality rates (Table 2).

The large variations by race and Hispanic-origin in both the percent born preterm and births at low birthweight mean that some racial/ethnic groups are disproportionately impacted by the high infant mortality rates for preterm and low birthweight infants.[5]

Racial and Ethnic Differences

In the United States, infant mortality rates vary substantially by race and ethnicity. Mortality rates are highest for the infants of non-Hispanic black, American Indian or Alaska Native (AIAN), and Puerto Rican mothers, and they are lowest for the infants of Cuban and Asian or Pacific Islander mothers (Table 2).

In 2013, the infant mortality rate for infants of non-Hispanic black mothers was 2.2 times the rate for non-Hispanic whites and this disparity, of at least twice the rate, has been observed for decades.[5]

Risk Factors

The probability of death varies markedly according to the risk factors of the mother, the infant, and the pregnancy. Maternal and family characteristics that influence infant mortality include age, marital status, family income, and access to medical care. Infant and pregnancy related variables include period of gestation, birthweight, birth order, sex of the infant, and plurality.

In examining the relationships between some of the most important of these variables and infant mortality, note that differentials in infant mortality rates for each variable are unadjusted for the possible effects of other variables. Often, women with one risk factor have other risk factors as well. For example, while teenaged mothers are at a higher risk of infant mortality, they are also more likely to be unmarried and of a low-income status, both of which are additional risk factors.

Infant mortality rates exhibit a curvilinear relationship with the age of the mother, with infants of teenaged mothers and mothers over 40 years of age having a substantially higher risk of death than mothers aged 20–39 years (Table 2). For 2013, the infant mortality rate was 8.52 per 1,000 live births for mothers less than 20 years of age, compared with 5.59 for mothers aged 25 through 29 years and 4.87 for mothers aged 30 through 34 years. For mothers aged 40 through 54 years, the rate was 7.77.[5] Biological factors may contribute to the elevated mortality risks for infants born to teenaged and older mothers.

Infants born to unmarried mothers are also at an elevated risk of death. In 2013, infant mortality rates for the infants of unmarried mothers (7.96 per 1,000 live births) were 1.7 times those for the infants of married mothers (4.60)[5] (Table 2). This ratio was also 1.7 for non-Hispanic white mothers but 1.3 for unmarried non-Hispanic black mothers. Overall, 29% of infants of non-Hispanic white mothers and 71% of non-Hispanic black mothers were born to unmarried mothers.[5]

Infants born from multi-fetal pregnancies are also at an elevated risk of death. For 2013, the infant mortality rate was 5.24 for single births compared with 25.84 for multiple births (Table 2). Multiple pregnancies can lead to an accentuation of maternal risks and complications associated with pregnancy.[42-44] Infants from multiple pregnancies are also much more likely to be born with low birthweight or at preterm gestational ages.[45-47]

Geographic Variations

Substantial geographic variation in infant mortality has been observed in the United States. A greater than twofold difference is seen between the highest and the lowest state-specific infant mortality rates. In 2013, Mississippi had the highest infant mortality rate (9.60 per 1,000 live births) and Massachusetts had the lowest (4.18)[5] (Figure 3). Some of these differences relate to differences in states' demographics.

USING DATA FOR ACTION

Vital statistics infant mortality data are used extensively by state and local health departments to track numbers and rates of infant death for states, cities, counties, and other geographic areas. Major changes in numbers of deaths, in rates, or in the cause-of-death profile of a region can give clues as to whether efforts to lower infant mortality are having or not having an expected impact.

Many states and local jurisdictions with high infant mortality rates have active programs to lower their rates. Vital statistics data provides reliable measurement of current infant mortality levels and the populations most affected. One example is Mississippi, which currently has the highest rate of infant mortality in the United States.[5] To lower the rate of infant death and other birth outcomes, they have developed a program titled, "Perinatal Health: Improving Birth Outcomes in Mississippi".[45] The purpose of this program is to lower rates of infant mortality as well as preterm birth, low birthweight, and maternal mortality. One important element of their effort is to determine trends in infant mortality and risk factors for negative birth outcomes among Mississippi women. These data give them an ongoing measurement of trends in these outcomes in the state and whether the programs are having a positive impact.

The Collaborative Improvement & Innovation Network (CoIIN) to Reduce Infant Mortality is a public-private partnership to improve birth outcomes and lower infant mortality at the national, state, and local level.[48] Members of this network learn from one another as well as national experts, share best practices, and track progress toward shared benchmarks. Using vital statistics data is a critical component of their efforts and assists in keeping track of current trends.

DATA GAPS AND LIMITATIONS

The overall measurement of infant mortality is considered to be robust in the United States. The legal necessity of completing a birth and death certificate helps to ensure that infant death data collected by states are complete and that the National Center for Health Statistics (NCHS) reports the full population of infant deaths each year.

For the past decade NCHS has been unable to link around 1% of infant death records to a birth certificate. With the overall number of infant deaths decreasing, so has the number unlinked. In 2013, there were 223 unlinked records which was 1.0% of infant deaths.[5] Linked birth and infant death data files include a weight to bring the analysis of the linked file up to 100%.

There are some items collected on the birth certificate that are considered to be underreported. Please see the chapters on *Pregnancy in Adolescents*, *Prenatal Care*, and *Preterm Births* for a discussion of these items. Additional issues are discussed elsewhere.[46,47]

From the death certificates of infants, the primary focus is the reporting of the cause of death. Few studies focus on the validity of cause-of-death information for infants, although the validity of cause-of-death data, in general, has been discussed extensively elsewhere.[49-51] In 2014, an autopsy was reported as done for 30.8% of infant deaths compared to 7.5% of deaths at other ages.[23] The much higher autopsy rate would suggest that the quality of cause-of-death certification for infants would be at least as good as that for persons at other ages. Research on the subject of sudden unexplained infant death has found shifts among a small group of codes to which such deaths are classified and explored a variety of factors that may be responsible including diagnostic and terminological shifts.[52]

FUTURE ISSUES

The national Healthy People objective for the year 2020 relating to infant mortality is to reduce the infant mortality rate to 6.0 per 1,000 live births.[53] This objective was first achieved in 2012 for the nation but not for all race and ethnic groups.[5] In 2013, two groups had rates higher than 6.0: non-Hispanic black (11.1 per 1,000) and American Indian or Alaska Native (AIAN) (7.6 per 1,000). The infant mortality rate for infants of AIAN mothers would need to decline an average of 3.5% each year, from 2014 through 2020, to attain the 2020 objective. Achieving the 2020 objective for infants of non-Hispanic black mothers would require an average annual decline of over 8% each year. Average annual sustained declines of this magnitude have not been observed in the past decade.[5] Special attention will be required to identify the drivers of racial and ethnic inequities in infant death, including the role of the social determinants of health and the context in which women give birth.

The gestational age of the newborn has been identified as an important factor in the cause of infant mortality.[30,31,35,37] The percentage of births born preterm had been declining in the United States[47] but a recent report suggests an uptick for 2015, the first since 2007.[54] Future improvements in infant mortality levels may be influenced by changes in the incidence of preterm birth.

Approaches to preventing infant mortality include universal access to quality prenatal care, substance abuse counseling and treatment, as well as medical interventions.[45,55-56] There has been some success and there are current efforts to continue on this path.[57-58] Although improvements in perinatal medicine have lowered the infant mortality rate, there is a growing recognition that non-clinical factors play a substantial role. Better identifying, addressing and evaluating mitigation of social factors that influence infant death can out the US on a trajectory of more rapidly reducing this tragic outcome.

ADDITIONAL RESOURCES

- The NCHS Birth Data

  http://www.cdc.gov/nchs/births.htm
- The NCHS Linked Birth and Infant Death Data

  http://www.cdc.gov/nchs/linked.htm
- The NCHS Mortality Data

  http://www.cdc.gov/nchs/deaths.htm
- The CDC's Division of Reproductive Health http://www.cdc.gov/reproductivehealth/index.html
- The March of Dimes

  http://www.marchofdimes.org/

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Table 1. Infant deaths and mortality rates for the five leading causes of infant death: United States, 2013 linked file

[Rates per 1,000 live births in specified group]

Cause of death (Based on the Tenth Revision, International Classification of Diseases, 1992)	Rank	Number	Rate
All causes		23,446	5.96
Congenital malformations, deformations, and chromosomal abnormalities (Q00-Q99)	1	4,778	1.21
Disorders related to short gestation and low birth weight, not elsewhere classified (P07)	2	4,213	1.07
Newborn affected by maternal complications of pregnancy (P01)	3	1,597	0.41
Sudden infant death syndrome (R95)	4	1,561	0.40
Accidents (unintentional injuries) (V01-X59)	5	1,150	0.29

Source: National Vital Statistics System, NCHS, CDC

Table 2: Infant mortality rates by selected characteristics: United States, 2013

Total	5.96
Non-Hispanic white	5.06
Non-Hispanic black	11.11
American Indian or Alaska Native/1	7.61
Asian or Pacific Islander	4.07
Mexican	4.90
Puerto Rican	5.93
Cuban	3.02
Central and South American	4.30
Age at death	
Total neonatal	4.04
Early neonatal (< 7 days)	3.28
Late neonatal (7-27 days)	0.76
Postneonatal	1.92
Sex	
Male	6.51
Female	5.39

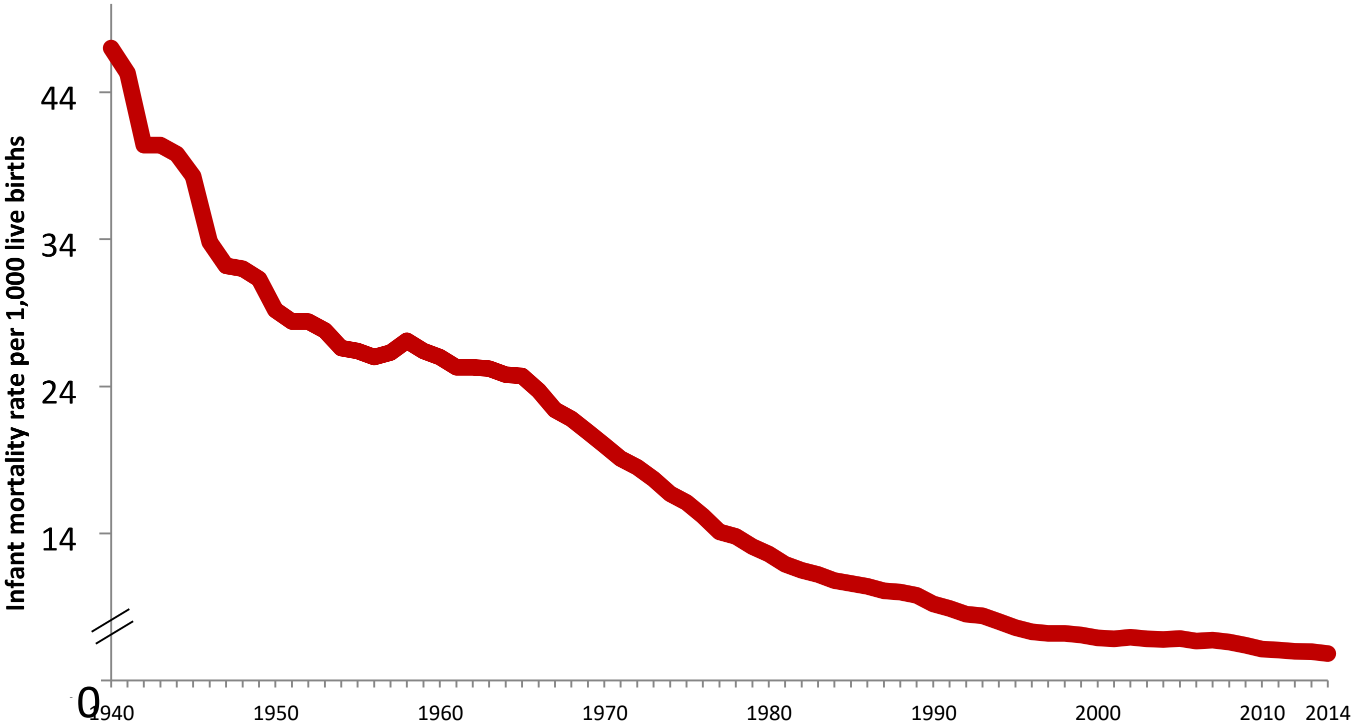
Plurality	
Single births	5.24
Plural births	25.84
Birthweight	
Less than 2,500 grams	50.26
Less than 1,500 grams	219.56
1,500-2,499 grams	13.41
2,500 grams or more	2.05
Period of gestation	
Less than 37 weeks	34.76
Less than 32 weeks	163.71
32-33 weeks	16.02
34-36 weeks	7.23
37-41 weeks	2.19
37-38 weeks	3.01
39-40 weeks	1.85
41 weeks	1.80
42 weeks or more	2.39

Age of mother	
<20 years	8.52
20-24 years	7.00
25-29 years	5.59
30-34 years	4.87
35-39 years	5.35
40-54 years	7.77
Live-birth order	
1	6.02
2	5.14
3	5.84
4	6.73
5 or more	9.11
Marital status	
Married	4.60
Unmarried	7.96

1/ Includes Aleuts and Eskimos.

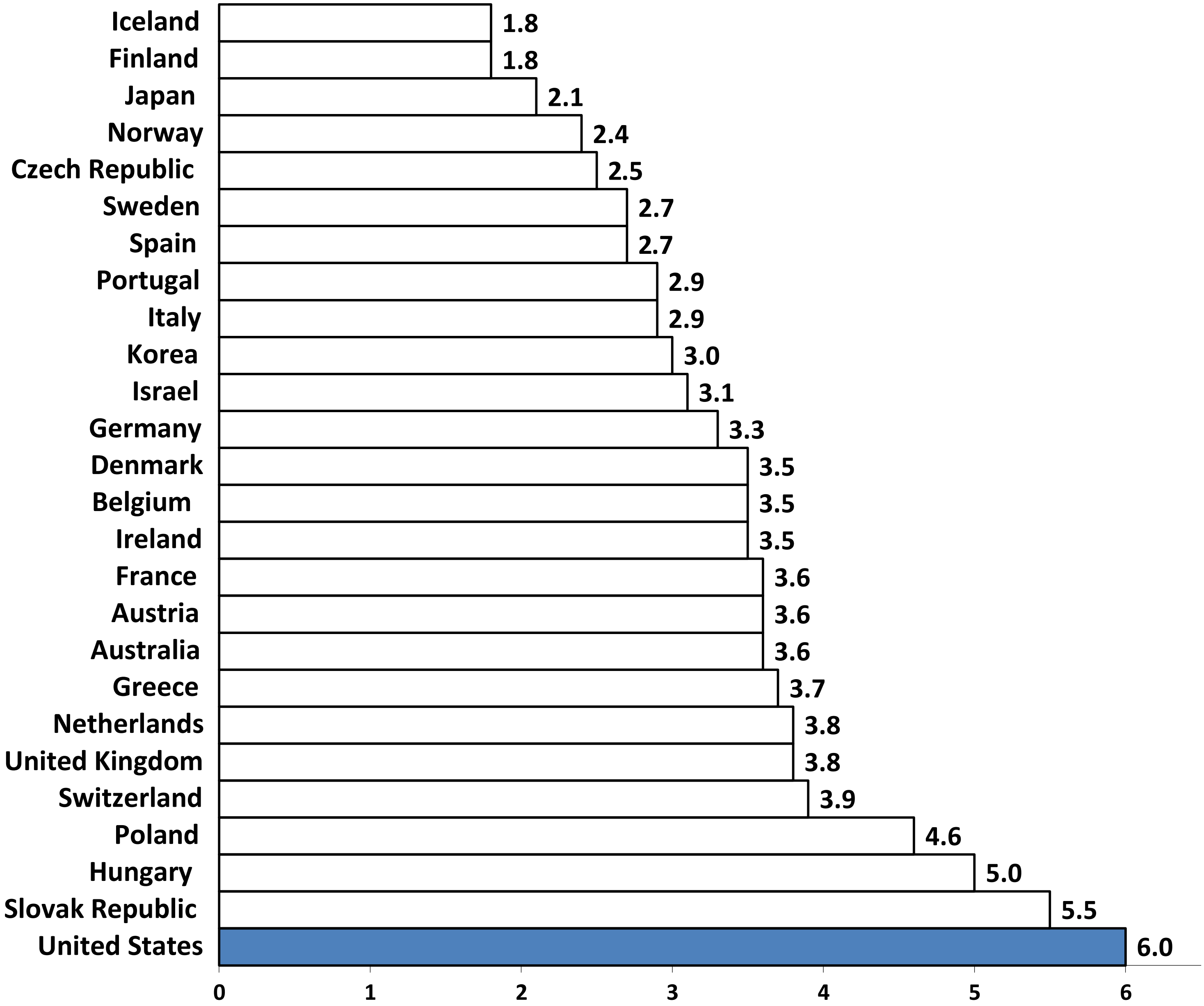
Source: National Vital Statistics System, NCHS, CDC

Figure 1. Infant mortality rate: United States, 1940-2014



Source: National Vital Statistics System, NCHS, CDC.

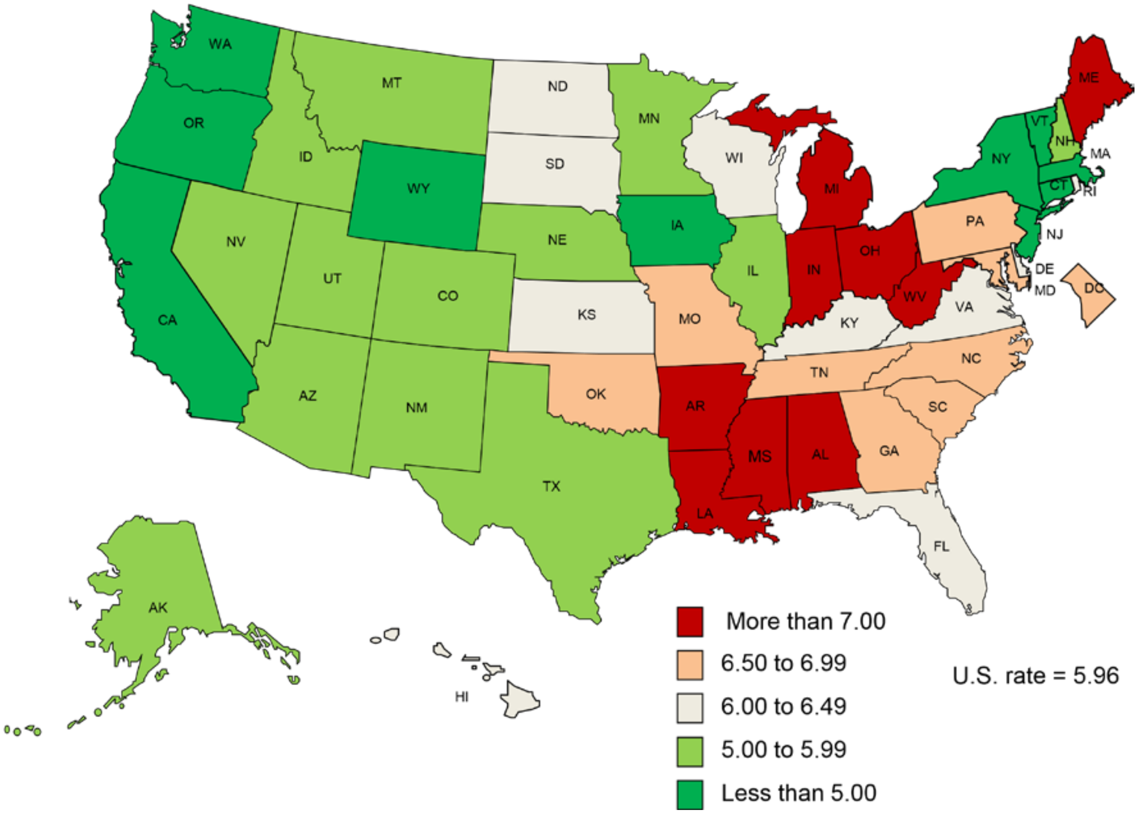
Figure 2. Infant mortality rates, selected OECD countries, 2013



Rate per 1,000 live births

Source: Organization for Economic Cooperation and Development (OECD) data base.

Figure 3. Infant mortality rates by State, 2013



Source: National Vital Statistics System, NCHS, CDC

Sudden Unexpected Infant Death (SUID) and Safe Sleep

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The condition generally referred to as "sudden unexpected infant death (SUID), " which has recently been expanded in definition to include deaths associated with infants during sleep, accounts for about 15% of all infant deaths in the United States each year. Medico-legal investigations are conducted for these deaths to try to determine cause and to further identify risk factors and therefore, to develop interventions that can lead to prevention of this source of infant mortality. This chapter discusses numerous strategies for intervention and suggest ways in which state and local health authorities can assist their communities in combating this important health problem.

PUBLIC HEALTH IMPORTANCE

Annually, about 3,500 US infants younger than one year die suddenly and unexpectedly, representing about 15% (about 1 in 7) of all infant deaths.[1,2] We often refer to these deaths as sudden unexpected infant deaths (SUIDs), or more recently as, sleep-related infant deaths, since many occur while sleeping in potentially hazardous environments in the presence of risk factors for asphyxiation.[1,2] The cause of SUID is only confirmed through medico-legal investigation and may remain unexplained even after such an investigation.[1]

Definitions of the Major Types of SUID

The three most frequently reported SUID types are sudden infant death syndrome (SIDS), unknown cause, and accidental suffocation and strangulation in bed (ASSB).[3] Definitions of SUID types vary, and there are no universally accepted criteria for determining cause of death.[4,5] In general, however, SUID types can be defined as follows.

SIDS is a diagnosis of exclusion (i.e., a cause reached by eliminating other causes as an explanation of death). SIDS is defined as the sudden death of an infant (<1 year old) that cannot be explained after a thorough case investigation.[6] A thorough investigation includes an examination of the death scene, a review of the clinical history, and an autopsy and allows the death certifier to consider other explanations for the death. SIDS is the leading cause of death in infants from 1 up to 12 months old.[7]

Unknown cause may be used to classify a sudden death of an infant (less than 1 year old) that cannot be explained. Deaths may be unexplained because a thorough case investigation was not conducted or because the cause could not be determined with certainty.[5] Without a thorough investigation, the death certifier cannot fully explore other causes that might explain the death.

ASSB includes deaths that the certifier attributes to accidental (or unintentional) suffocation by the following mechanisms:[8]

- Suffocation by soft bedding — such as a pillow or waterbed mattress.
- Overlay — when another person rolls on top of or against an infant while sleeping.
- Wedging or entrapment — when an infant is wedged between two objects such as a mattress and wall, bed frame, or other furniture.
- Strangulation — when an infant's head and neck become caught between crib railings.

Among injury deaths in infants, ASSB is the most frequently reported cause.[7] ASSB is potentially preventable when infants are provided a sleeping environment free of suffocation hazards.

Because many SUIDs are unwitnessed events, it can be difficult to determine cause. Even after a thorough investigation, it is difficult to distinguish SIDS from other sleep-related infant deaths, such as overlay or suffocation in soft bedding. No anatomic or physiologic markers for suffocation or SIDS exist. For example, an observed overlay may be considered an explained suffocation, but when these deaths are not witnessed, autopsy tests cannot determine with certainty that suffocation was the cause of death. Although death certifiers often classify these unwitnessed or unobserved deaths as SIDS, many certifiers are now classifying these deaths as unknown cause or as ASSB.[3]

In reviewing death records, we find that the SUID types (SIDS, unknown cause, and ASSB) share similar sociodemographic characteristics, which suggests a similar underlying etiology.[3,9] For example, deaths coded as SIDS, unknown cause, and ASSB are characterized by a similar distribution of race/ethnicity, sex, and age at death, i.e., occurs more often among non-Hispanic blacks and American Indians/Alaskan Natives, among males, and among infants 2-3 months old.[3,10]

Risk factors for SIDS and other SUID

We do not know what causes SIDS, but several SIDS risks factors have been identified,[11] but if these known risk factors are eliminated, the risk of SIDS and perhaps of other sleep-related infant deaths may also be lowered.[12] Table 1 describes modifiable and non-modifiable risk and protective factors for SIDS. Some of these factors (especially those related to sleeping environments) are also mechanisms that have been attributed to ASSB. Studies to identify modifiable risk factors for ASSB or other accidental suffocation deaths have not been conducted, but by eliminating the mechanisms causing suffocation, deaths can be prevented.

Strategies to Promote Safe Sleep and Reduce SIDS and Other SUID

Because most cases of SUIDs occur in sleep environments, promoting safe sleep has become a national priority. In 1992, the American Academy of Pediatrics (AAP) issued recommendations that encourage safe sleep; these recommendations were last modified in 2011.[12-14] Promoting safe sleep for interventions aimed at reducing US infant mortality, including, the Safe-to-Sleep campaign (formerly Back-to-Sleep) (https://www.nichd.nih.gov/sts/Pages/default.aspx); the Collaborative Improvement & Innovation Network (CoIIN) (http://www.nichq.org/childrens-health/infant-health/coiin-to-reduce-infant-mortality); and the National Action Partnership to Promote Safe Sleep (NAPPSS -- http://nappss.org/about.php). Reducing the rate of SIDS and other SUID is also a Healthy People 2020 (HP2020) objective. The HP2020 objectives also call attention to racial and ethnic disparities in SIDS rates.[15]

HISTORY OF DATA COLLECTION

Distinguishing unexplained infant deaths, including SIDS and ASSB

SUID typically occurs during sleep and is not witnessed by a caregiver. Distinguishing death by suffocation from SIDS or some unexplained natural cause remains as controversial a topic today as it did a century ago. In 1944, Abramson[16] used vital records to show a substantial increase in infant deaths attributable to accidental mechanical suffocation from the 1930s to the 1940s. He further reported that most suffocations resulted from smothering that occurred when the infant was lying face down. Woolley refuted Abramson's findings based on his experiments, testing the suffocation hypothesis by covering infants' faces with layers of blankets.[18] He observed that the infants he studied could extricate themselves from potentially asphyxiating situations. Woolly refuted suffocation as an explanation of death because he believed that suffocation, as a cause-of-death determination, “instilled guilt and self-incrimination in parents.” In 1947, Werne and Garrow,[17] published a case-series analysis from sudden infant death investigations that included autopsies.[19] The authors concluded that although many of the cases were certified as accidental mechanical suffocation, autopsy findings could not confirm that this was in fact the cause of death. Debate about evidence for accidental suffocation continues today as biological markers to confirm suffocation have not yet been identified.

Defining SIDS

In 1969, forensic pathologist, Bruce Beckwith and other attendees at an international conference about the causes of sudden deaths in infants defined Sudden Infant Death Syndrome (SIDS) as “the sudden death of an infant or young child, which is unexpected by history, and in which a thorough post-mortem examination fails to demonstrate an adequate cause for death.”[18,19] Having the term SIDS to describe these unexpected and unexplained infant deaths helped call attention to the fact that SIDS was a leading cause of infant death. In addition, recognizing SIDS as a cause of death helped support grieving families and reduce parental guilt and blame. Since 1969, the SIDS definition has not changed substantially and remains a diagnosis of exclusion. In 1991, a requirement of a death-scene investigation was added to the SIDS definition.[6] This was the impetus for CDC’s Sudden Unexplained Infant Death Investigation Reporting Form (SUIDIRF), guidelines, and training materials for death-scene investigation.[20-24]

The National Center for Health Statistics' (NCHS) National Vital Statistics System (NVSS) has monitored annual rates and trends in cause-specific mortality among infants using death certificates and has assigned codes based on the *International Classification of Diseases (ICD).*[25] ICD classifications and codes are a standardized and internationally accepted system developed by the World Health Organization (WHO) to promote comparison of mortality statistics across countries.

ICD version 8 (ICD-8) was introduced in 1965. Because a SIDS code did not exist (it had not been defined), most SIDS (i.e., cases for which cause of death was unknown or unexplained) were classified under the ICD-8 code 795-Sudden death, cause unknown.[26] To monitor data on the SIDS incidence more accurately, NCHS introduced SIDS as a cause of death in 1975 and modified the ICD-8 code to 795.0 to represent SIDS. Following NCHS's example, ICD-9 in 1978 included 798.0, the SIDS code. In 1999, WHO released ICD-10 codes, with SIDS (R95) retained as an official cause of death. The use of ICD-10 codes continues today.

In 1992, CDC's *Morbidity and Mortality Weekly Report (MMWR)* reported US SIDS rates for the first time.[27] In 1996, another MMWR showed that annual rates of SIDS had declined more rapidly from 1990-1994 than from 1983-1989.[28] The more dramatic decline was attributed to the promotion of non-prone sleep that occurred with the introduction of the 1992 AAP safe sleep recommendations and the Back-to-Sleep campaign.[13,31]

With national efforts aimed at reducing SIDS and promoting safe sleep in the 1980s and early 1990s, it became important to measure the prevalence of risk factors for SIDS and accidental suffocation. The National Infant Sleep Position Study (NISP), conducted from 1992-2010, was an annual telephone survey of nighttime-caregivers of infants (less than 8 months) funded by National Institutes of Child Health and Human Development. The survey asked caregivers about infants' sleep practices (e.g., sleep position, place of sleeping, use of bedding, and bed sharing) and receipt of infant-sleep-position recommendations from health-care providers.[29] Over the NISP study years, the prevalence of non-prone sleep position[30] and the use of potentially hazardous bedding in the sleeping environment declined, but the prevalence of bed-sharing increased. Although the prevalence of some risk factors declined, the earlier observed practices remain relatively common, and especially high among some minority racial and ethnic populations.[33-35]

CDC SURVEILLANCE ACTIVITIES

Surveillance data about SUID and practices about safe sleep for infants are currently available in three CDC population-based systems: the NVSS, the Sudden Unexpected Infant Death (SUID) Case Registry, and the Pregnancy Risk Assessment Monitoring System (PRAMS). For NVSS, NCHS contracts with 50 States, two cities (Washington, DC and New York City), and five territories (Puerto Rico, the Virgin Islands, Guam, American Samoa, and the Commonwealth of the Northern Mariana Islands) to collect and disseminate national vital statistics using common procedures and standards. The NVSS data sets most often used in SUID surveillance are the mortality files, birth files, and the linked-birth and infant death files.

The NVSS mortality data sets are derived from the US Standard Certificate of Death and provide demographic, geographic, and cause-of-death information.[31] These data provide the numerator for use in calculation of infant mortality rates. Similarly, the NVSS birth data sets are derived from the US Standard Certificate of Live Birth. In addition to demographic and geographic information, the natality files contain information on birth outcomes (e.g., gestational age at birth, and congenital anomalies), mothers' pregnancy history, and delivery and postpartum characteristics. Data from the birth files are the usual source for denominator data in the calculation of infant mortality rates.

The NVSS linked birth and infant death files contain information from the death certificate linked to information from the birth certificate for each infant (less than 1 year old) who dies in the United States or its territories.[32] Quality assurance evaluations show that data on maternal race and ethnicity in the birth files are more accurate than the race and ethnicity data in the mortality files. Using the linked files allows not only for the calculation of cause-specific infant mortality rates, but also allows for calculation of mortality rates by sociodemographic characteristics (e.g., race/ethnicity, maternal age, maternal education), prenatal exposures (e.g., maternal smoking) and birth outcomes (e.g., pre-term birth).

The SUID Case Registry, launched in 2009, aims to improve population-based surveillance of SUID by supplementing vital records data with additional existing data from other sources. Through cooperative agreements, CDC assists Registry awardees in compiling more comprehensive information about the circumstances associated with SUID cases, as well as information about death-scene investigation and autopsy components. This level of data goes beyond the scope of vital records and hence, can provide a richer data set to improve knowledge about cause-specific SUID trends and characteristics. Details about the surveillance system described elsewhere.[33] Briefly, the SUID Case Registry builds upon the National Center for the Review and Prevention of Child Deaths (NCRPCD) program and its case reporting system.[34] The NCRPCD works with multidisciplinary child death review (CDR) programs at local and state levels. Although every state and the District of Columbia has a CDR program, these programs vary in their composition of teams, level of state support, administrative leadership, supporting legislation, and types of deaths reviewed. The commonality is that all CDR teams meet regularly and share medical, legal, and social data sources to discuss the circumstances and events surrounding cases. Review findings help guide prevention strategies. Following review, many states enter findings into the NCRPCD case reporting system. For the SUID Case Registry grantees, CDC provides technical assistance and resources to improve data quality (case ascertainment, timeliness, and data completeness).

CDC and its awardees use the SUID Case Registry surveillance data to monitor trends in SUID-specific mortality. In addition, they use data for program planning and evaluation, modifying public health practice and policy for state maternal and child health programs, and encouraging more consistent medico-legal investigation practices. In addition, the SUID Case Registry grantees monitor risk factors associated with SUIDs, which allows for the development of targeted prevention and intervention strategies and improvement in systems of care for families.

In 2015, CDC and the National Institutes of Health launched the Sudden Death in the Young (SDY) Case Registry. The SDY Case Registry builds on the SUID Case Registry by expanding the surveillance population of children up to 19 years of age who die suddenly and unexpectedly. Hence, infants who die suddenly and unexpectedly are also captured in the SDY Registry. In addition to reviews from CDR teams, the SDY Case Registry includes information from an advanced child-death case review where pediatric cardiologists, epileptologists, forensic pathologists, and other specialists discuss and categorize cases that are potentially cardiac or neurologically related. The SDY Case Registry also collects a blood sample for future research that might help explain the etiology of these often unexplained deaths of children.

PRAMS collects state-specific, population-based data on maternal attitudes and experiences before, during, and shortly after pregnancy (http://www.cdc.gov/prams/) involving a sample of women who have recently had a live birth and includes information on infant sleep practices and environments.[35] Data collection procedures and instruments are standardized allowing for comparisons among states. In 2015, 40 states and New York City participated in PRAMS, representing approximately 78% of all US live births.

PRAMS data can be used to identify groups of women and infants at high risk of health problems; to monitor changes in health indicators, including unintended pregnancy, prenatal care, breastfeeding, smoking, drinking, and infant health; and to measure progress toward goals in improving the health of mothers and infants. Questions about sleep-related behavior have been included in PRAMS since 2000 and provide surveillance data for key Title V and Healthy People 2020 performance indicators.

GENERAL FINDINGS

In 2015, SIDS comprised less than half (43%) of all SUIDs in the US; ASSB and "unknown cause" comprised 32% and 25% of SUIDs, respectively.[41,2] The mortality rates of these SUID subtypes have changed substantially from 1990 through 2015 (**Figure 1**). SIDS rates declined considerably from 130.3 deaths per 100,000 live births in 1990 to 39.4 deaths per 100,000 live births in 2015. Although SIDS has declined by more than 50% since the 1990s, the magnitude of the decline has been less since 1999. In contrast, ASSB rates increased beginning in 1998 and reached the highest rate of 23.1 deaths per 100,000 live births in 2015. The "unknown cause" rates remained relatively stable from 1990 through 1998, but have been slowly increasing since 1998. In 2015, the unknown cause rate was 30.1 per 100,000 live births.

Despite the shift in SUID-specific mortality rates, SIDS and the combined SUID mortality rate declined considerably following the release of the AAPs' safe sleep recommendations in 1992 and the initiation of the Back-to-Sleep campaign in 1994.[32] After the release of the Sudden Unexplained Infant Death Investigation Reporting Form in 1996,[20] the decline in SIDS appears to be explained by a shift in reporting, i.e., an increase in mortality rates for ASSB and unknown causes, especially for 1999 through 2001.[22,5] The combined SUID death rate has remained stable since 2001, although it decreased slightly from 2009 through 2011 (Figure 1).[36,42]

As is the case with many indicators of infant health, substantial racial/ethnic disparities exist for SUIDs. From 2010 through 2013, SUID mortality rates per 100,000 live births for American Indian/Alaska Native (190.5) and non-Hispanic black infants (171.8) were more than twice those of non-Hispanic white infants (84.4) (Figure 2). SUID rates per 100,000 live births were lowest among Hispanic infants (50.8) and Asian/Pacific Islander infants

(34.7). The pattern of racial/ethnic disparities observed in these most recently available data have been consistent for the last 20 years.

PRAMS provides the only multi-state surveillance data that can be used to measure sleep-related behaviors among live infants and their caregivers in the United States. For example, the percentage of mothers who reported that they most often lay their babies on their backs for sleep increased from 61% in 2000 (19 states reporting) to 78% in 2011 (26 states reporting). The percentage of babies reported to have usually shared a sleep surface with another person decreased from 27% in 2000 (7 states reporting) to 19% in 2011 (14 states reporting). Although the numbers of states with available data on infant sleep behaviors varies from one year to the next, the standardized sampling, data collection, cleaning, and weighting procedures should result in comparable data among states. Representativeness of the participating states and generalizability to the United States remain a limitation of the PRAMS survey. In 2016, PRAMS began to collect new and improved variables related to safe sleep (Table 2). Previously, only questions about sleep position was collected for all PRAMS states. In 2016, all states had questions about sleep position, sleep place, shared sleep surface, and soft objects in the sleep environment. This is critical, as NISP has been discontinued.

USING DATA FOR ACTION

CDC grantees increasingly use SUID Case Registry and PRAMS surveillance data to support and improve their infant health programs. Below we highlight a few states that have successfully used their SUID Case Registry and PRAMS data to inform new strategies and interventions aimed at reducing infant mortality.[43]

From 2008 through 2012, Colorado, a SUID Case Registry grantee, identified 284 child deaths that occurred in sleep environments that were potentially hazardous. All cases were associated with risk factors for SIDS or other sleep-related infant deaths (e.g., use of soft bedding such as pillows, blankets and bumpers; putting the infant to sleep on his or her side or stomach; or not using a firm sleep surface). Of all deaths, 5.3% occurred in child-care settings. Most (87%) of these child-care associated deaths occurred in licensed child-care homes, and 87% of caregivers were licensed child-care workers. To address these findings, the Colorado grantee worked with its state Infant Safe Sleep Partnership and recommended modifications to child-care licensing requirements and regulations. Addtionally, the grantee engaged stakeholders to generate support and determine the feasibility of these recommendations. These activities resulted in changes to the Colorado Department of Human Services' rules regulating licensed child-care facilities.

Hawaii uses its PRAMS data to drive infant safe sleep promotion activities (http://www.cdc.gov/prams/state-success-stories/hawaii.html). For 2009 through 2010, PRAMS data show about one-quarter (24.3%) of infants were most often placed to sleep in the non-supine position, one-third (33.9%) "always" or "often" shared a sleep surface with someone else, and nearly two-thirds (65.8%) usually slept in potentially hazardous bedding. In 2012, the Hawaii Healthy Mothers Healthy Babies Coalition (HMHB) included PRAMS prevalence estimates of infant sleep practices in a grant application for the CJ Foundation for SIDS (now known as CJ First Candle). In 2013, this SIDS organization awarded Hawaii HMHB $5,000 to incorporate comprehensive, family-oriented safe sleep education into the Hawaii Cribs for Kids Program. By 2015, the educational program's popularity led to its expansion from the island of Oahu to include the island of Maui.

In another example, Michigan has demonstrated multiple instances of data driving action and policy changes related to safe sleep using both their PRAMS and SUID Case Registry data. SUID Case Registry data revealed that nearly one-third of the 560 infant sleep-related deaths (from 2010 through 2013) involved a shared sleep surface. Moreover, a PRAMS analysis showed that safe sleep behaviors had not noticeably improved from 2001 through 2008 (i.e., the prevalence of back sleeping remained at about 75% for all infants and at 50% for black infants). This data proved valuable in developing several grant proposals that subsequently were funded. Using grant funds, Michigan implemented a nurse practice model for hospitals to promote infant safe sleep, revised childcare licensure rules to reflect AAP safe sleep recommendations, developed educational materials (including brochures, posters and DVDs) for pediatric and obstetrician office settings, and implemented the Direct on Scene Education (DOSE) program (http://hmhbbroward.org/dose/) in Emergency Medical Services/Fire Departments. DOSE uses first responders to educate caregivers. When responding to emergency calls, DOSE-trained first responders call attention to and remove potentially hazardous items (i.e., those associated with SIDS and accidental suffocation) from sleep environments for infants. In addition, Michigan passed the Infant Safe Sleep Act in 2014, a law requiring that Michigan birthing hospitals (n=~85) provide safe sleep education to all new parents.

DATA GAPS AND LIMITATIONS

Lack of Standardized Practices for Case Investigation

Accurate and consistent reporting of surveillance trends are hampered by the lack of standardized practices for death-scene investigation and autopsy.[36] CDC has developed guidelines,[20,22] a reporting form, and a training curriculum for the investigation of SUID.[22-26] Since 2006, more than 23,000 medical examiners, coroners, law enforcement personnel, first responders, and child advocates have been trained to conduct comprehensive infant-death investigations.[45] In addition, several states have mandated SUID investigation training and the use of the SUIDIRF.[46] Notwithstanding, scene investigation and autopsy practices continue to vary across jurisdictions.[47]

Lack of Standardized Reporting Practices for Determining Cause of Death

The ability to monitor SUID trends accurately and consistently also depends on the reporting practices of those who provide documentation about cases of SUID (e.g., medical examiners, coroners, and forensic pathologists). Since 1999, many deaths that were once classified as SIDS are now being classified as “unknown cause” and ASSB.[5,48] This diagnostic shift is well documented and may be attributed in part to certifier preference, more complete information from death-scene investigation about the role of the infant sleep environment at the time of death, and the influence of child-death review teams.[5,9] Because of the difficulty in distinguishing these causes and the variation in reporting, the 2013 infant mortality statistics report recognized SUID by combining ICD-10 codes R95, R99, and W75 as a new category grouping for the annual infant mortality report.[1]

Lack of Study Power

Designing analytical studies that examine new risk factors for SIDS and other sleep-related infant deaths is a challenge. The relatively small number of SIDS and other sleep-related infant deaths that occur annually, together with classification issues and the ethics of prospective studies, limit the ability to conduct sufficiently powered analytical studies to identify new risk or protective factors. The association between bed sharing and SIDS, especially among infants who breast-feed, remains controversial. However, the small number of SIDS cases does not allow us to design studies to elucidate this association.

FUTURE ISSUES

The lack of standardized practices for the investigation and reporting of SUID hamper research and the evaluation of trends. Medical examiners, coroners, public health practitioners, and clinical researchers continue to collaborate on improving standardized practices.

To maximize the usefulness of SUID data for surveillance, clinical, and research purposes, several activities may be considered. First, more states adopting the SUID Case Registry model would further improve data quality and representativeness. With an expanded Registry, more states might use the standardized classification system to categorize SUID cases and thereby, improve monitoring of cause-specific SUID trends. Second, researchers can use the SUID Case Registry to identify cases for future descriptive and etiologic studies. Finally, improving the representativeness and continuity of state-level PRAMS data will improve our understanding of state and national trends in safe-sleep practices.

Additional Resources

- US Vital Statistics Data Available Online: http://www.cdc.gov/nchs/data_access/Vitalstatsonline.htm
- CDC Wonder (Wide-ranging Online Data for Epidemiologic Research): http://wonder.cdc.gov/
- PRAMS: http://www.cdc.gov/prams/
- NISP: https://www.nichd.nih.gov/research/supported/Pages/nisp.aspx
- National Center for the Review and Prevention of Child Deaths: https://www.childdeathreview.org/
- The Child Death Review Case Reporting System: (https://www.childdeathreview.org/resources/national-cdr-case-reporting-system/)

Table 1. Modifiable and non-modifiable risk factors and protective factors for SIDS[11]

Modifiable risk factors

- **Prone/side sleep position**
- **Soft sleep surface***
- **Excess bedding, soft sleep surface and stuffed animals***
- **Loose bedding, including pillows and quilts***
- **Bed sharing***
- **Smoking: maternal/prenatal and environmental**
- **Overheating**
- **Late or no prenatal care**
- **Alcohol and other substance abuse exposure prenatally by mother**

Non-modifiable risk factors

- **Young maternal age**
- **Prematurity and low birthweight**
- **Male infant sex**
- **African American infant race**
- **Native American infant race**

Protective factors

- **Breast feeding**
- **Pacifier use**

*Some mechanisms causing accidental suffocation are the same as SIDS risk factors.

American Academy of Pediatrics Task Force on Sudden Infant Death Syndrome. SIDS and Other Sleep-Related Infant Deaths: Expansion of Recommenations for a Safe Infant Sleeping Environment. *Pediatrics.* 2011.

Table 2. Safe Infant Sleep Questions Added to the Core Pregnancy Risk Assessment Monitoring System (PRAMS) Survey Instrument Beginning in 2016

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1. **In which *one* position do you *most often* lay your baby down to sleep now?** Check ONE answer
    - ☐ On his or her side
    - ☐ On his or her back
    - ☐ On his or her stomach

2. **In the *past 2 weeks*, how often has your new baby slept alone in his or her own crib or bed?**
    - ☐ Always ➔ Go to Next Question
    - ☐ Often
    - ☐ Sometimes
    - ☐ Rarely
    - ☐ Never

Insertion point for standard question(s): Who does your new baby usually sleep with? Check ALL that apply: ☐Me, ☐My husband or partner, ☐Someone else: Please tell us: ________________.

3. **When your new baby sleeps alone, is his or her crib or bed in the same room where *you* sleep??**
    - ☐ No
    - ☐ Yes

4. **Please tell us how your new baby *most often* slept in the *past 2 weeks*.** For each item, check **No** if it doesn't *usually* apply to your baby or **Yes** if it does.

		No	Yes
a)	In a crib, bassinet, or pack and play	☐	☐
b)	On a twin or larger mattress or bed	☐	☐
c)	On a couch, sofa, or armchair	☐	☐
d)	In an infant car seat or swing	☐	☐
e)	With a blanket	☐	☐
f)	With toys, cushions, or pillows, including nursing pillows	☐	☐
g)	With crib bumper pads (mesh or non-mesh)	☐	☐

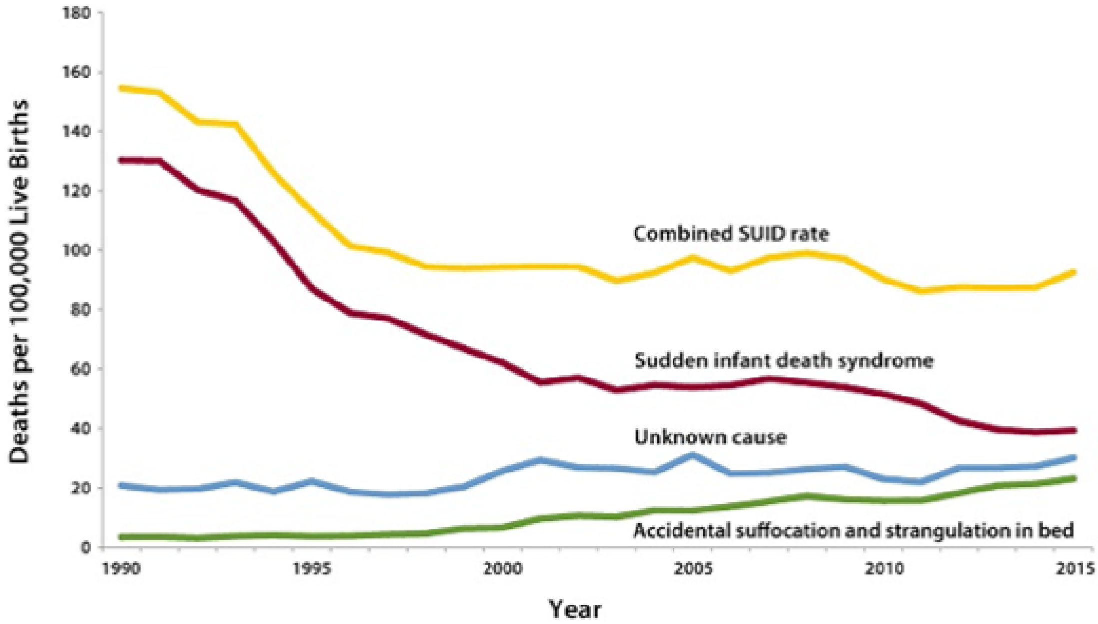
h) In a sleep sack	☐	☐

5. **Did a *doctor, nurse, or other health care worker* tell you any of the following things?** For each thing, check **No** if they did not tell you, or **Yes** if they did

	No	**Yes**
a. Place my baby on his or her back to sleep	☐	☐
b. Place my baby to sleep in a crib, bassinet or pack and play	☐	☐
c. Place my baby's crib or bed in my room	☐	☐
d. What things should and should not go in bed with my baby	☐	☐

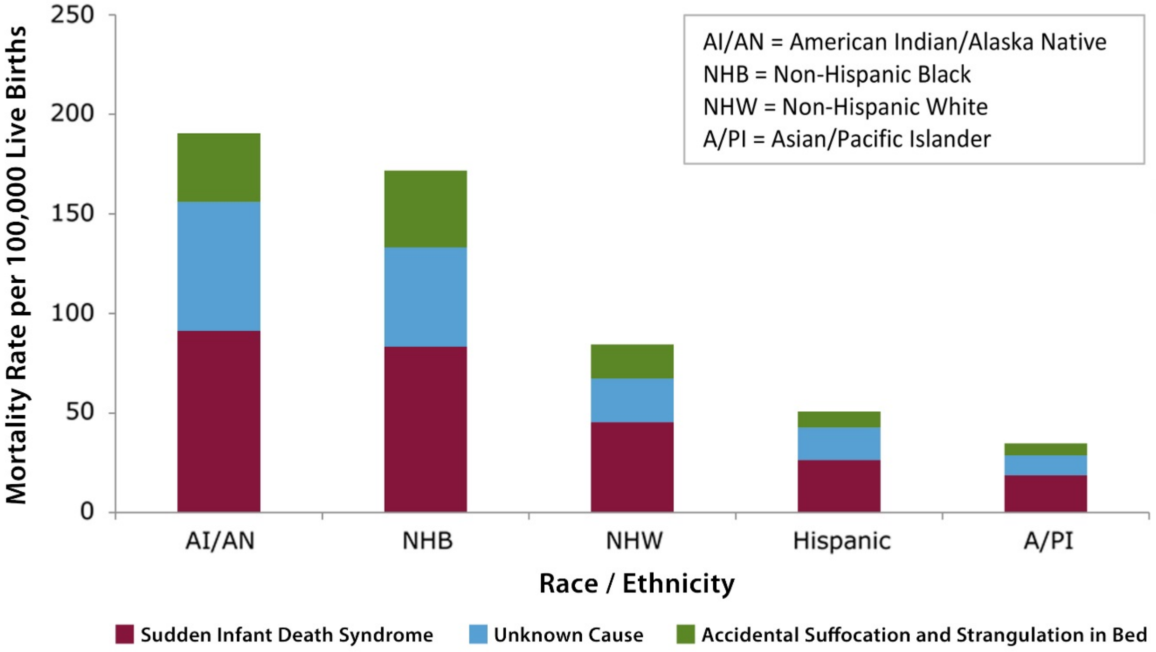
SOURCE: CDC/ Division of Reproductive Health, National Center for Chronic Disease Prevention and Health Promotion. http://www.cdc.gov/PRAMS/Questionnaire.htm

Figure 1. Trends in Sudden Unexpected Infant Death (SUID) by Cause, United States from 1990 through 2015.



SOURCE: CDC/NCHS, National Vital Statistics System, Compressed Mortality File. Figure duplicated from http://www.cdc.gov/sids/data.htm.

Figure 2. Sudden Unexpected Infant Death by Race/Ethnicity, United States from 2010 through 2013.



SOURCE: CDC/NCHS, National Vital Statistics System, Period Linked Birth/Infant Death Data. Figure duplicated from http://www.cdc.gov/sids/data.htm.

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Child Health

Commentary on Child Health

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The first five years of life are a pivotal time for laying the foundation for a lifetime of well-being. This critical period of physical, cognitive, social, and emotional development is a key lever of influence for population-level health.[1] Further, it is important that we recognize this time as a tremendous opportunity to prevent disease as well as assure children's exposure to nurturing and stimulating environments that provide safe and clean air, water, food and housing that help children to thrive and reach their full health and development potential.

One of the greatest public health successes integral to building a foundation that is free of infectious disease has been the implementation of effective immunization programs. In the United States, the widespread use of vaccines is often credited, rightly so, for significant declines in morbidity and mortality. In addition to the health benefits, US immunization programs have accrued significant cost savings.[2] Vaccinations for illnesses such as measles, mumps, and rubella (MMR) have made these diseases significantly rarer in the community. In addition to the prevention of acute infections and their proximate complications, vaccines have taken on a significant role in preserving health beyond the early years into adolescence and adulthood.

However, other challenges to health and development remain. Unintentional injuries remain a leading cause of morbidity and mortality. Among children birth to nine years of age, unintentional injuries are the leading cause of death, and non-fatal injuries have not shown a steady, marked decline.[3,4,5] Even when surviving childhood injury, the aftermath can be devastating with cascading and costly impacts for the injured child, parents, family members, and others. Further, this impact bears the greatest burden on communities suffering the most significant social and economic challenges.

Using data to identify causes and mechanisms of fatal and non-fatal injuries, such as suffocation, fire/burns, poisoning, maltreatment, and motor vehicle collisions, inform efforts to improve child safety. This straightforward approach has guided lifesaving interventions such as: child safety seats, child-resistant medicine bottles and cigarette lighters, smoke alarms, and mandatory child abuse reporting.[6] The foundations of childhood health and development also encompass exposure to safe and health-promoting physical and social environments.

Collecting, analyzing and disseminating environmental health data is essential to developing policies and programs, enacting legislation, and promulgating regulations that prevent exposure to hazardous conditions, and promote healthy environments. Some of these data are available nationally on the Center for Disease Control and Prevention’s National Environmental Public Health Tracking Network (Tracking Network), a tool that provides health, exposure and hazard information and data from a range of national, state and local sources. Twenty-five states and New York City participate in the Tracking Network. In NYC, the Environment Health and Data Portal integrates data from a variety of sources to present user-friendly information about outdoor air and weather, the built environment, pests and pesticide use, food and drink, water, and environmental sustainability.[7] Users can customize a dataset or download curated neighborhood reports, making the data hyperlocal. These are not the only useful data systems at our disposal for tracking and assessing childhood well-being.

Other national tracking systems include CDC’s National Health and Nutrition Examination Survey (NHANES) and the Youth Risk Behavior Surveillance System (YRBS), which are incredibly important sources of information for identifying trends and illuminating risk factors that contribute to leading causes of morbidity and mortality among children and youth. For example, overweight and obesity have emerged as serious risk factors for chronic diseases for which addressing dietary behaviors in the first five years of life can be a valuable prevention strategy. In NYC, these data have been the driver for myriad policies, programs, and allocation of resources. However, for some areas of child health, the lack of data inhibits efforts to serve children.

Surveillance systems can be a rich source of data regarding developmental delays or disabilities in children over the age of three years, and in particular, among eight-year-old school-age children. However, neither of CDC's primary surveillance activities, the Metropolitan Atlanta Developmental Disabilities Surveillance Program (MADDSP) nor the Autism and Developmental Disabilities Monitoring (ADDM), include the population of children ages birth to three years, although many developmental disabilities emerge during this time period. In fact, approximately 13% of children ages 9 through 24 months have developmental delays that are likely to render them eligible to receive services through their state's Early Intervention Program (EIP).[8] However, it is estimated that only 3% of children ages birth to three years old with developmental disabilities actually receive EIP services annually.[9]

In NYC, approximately 30,000 children are referred to the EIP each year. Over the past seven years, there has been an increase in the number of children with autism spectrum disorder (ASD) in the program; however, without population-level prevalence data, it is challenging to determine whether there has been a true increase in ASD among children ages birth to three years old or whether there is merely an increase in the proportion of children with ASD who are referred to the EIP. This absence of data complicates the evaluation of therapies and outcomes in this population and, in so doing, restricts planning for effective service delivery, policy development, as well as community outreach and education.

In summary, investments in timely surveillance of child health and development data are critical for taking action to improve population health, human capital and wellbeing across the life course. Existing surveillance systems are valuable and can be even more effective by capturing developmental data. These data are critical to designing and implementing the most effective interventions and public health systems of care.

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Childhood Vaccine-Preventable Diseases

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The universal use of vaccines to prevent and control infectious diseases is one of the world's great public health achievements. While vaccines have significantly reduced morbidity and mortality among children, maintaining surveillance for the safety and effectiveness of vaccines and the occurrence of vaccine-preventable diseases is critical to ensure that vaccines remain available and accessible.

PUBLIC HEALTH IMPORTANCE

Vaccines are one of the most effective preventive health care interventions, and the prevention and control of infectious disease through vaccination is one of the great achievements of public health.[1, 2] Vaccination has resulted in the eradication of smallpox from the globe and eliminated endemic polio and measles from the Western hemisphere. In the United States, the eight vaccines routinely recommended prior to 1980 had reduced the incidence and deaths caused by each vaccine-preventable disease by more than 92% and 99% by 2006, respectively.[3] Vaccination also results in substantial cost savings for the healthcare system and society. Each year, vaccination prevents approximately 42,000 early deaths and 20 million cases of disease in the United States and saves $13.5 billion in direct costs and $68.8 billion in societal costs.[2] Recommendations for vaccination in the United States are made at the federal level. The Food and Drug Administration (FDA), an agency of the US Department of Health and Human Services (HHS), is responsible for regulating vaccines. The Advisory Committee on Immunization Practices (ACIP) is a group of medical and public health experts convened by HHS to make recommendations on the use of licensed vaccines to prevent and control disease domestically. Numerous sources of data inform the development of recommendations including clinical trial data on vaccine efficacy and safety, surveillance data on disease burden, and observational studies of vaccine effectiveness. In order to optimize recommendations, ACIP experts consider the appropriate age for vaccination, number of doses, timing, and precautions and contraindications for licensed vaccines. The ACIP works closely with other federal agencies, such as FDA and the National Institutes of Health (NIH), and professional organizations that are engaged in healthcare and the provision of vaccines, such as the American Academy of Pediatrics (AAP) and American Academy of Family Physicians (AAFP), in order to harmonize recommendations and understand their broader impact on the healthcare delivery system. The ACIP meets three times a year, and its recommendations are reviewed by the Director of CDC. Accepted recommendations are published in CDC's Morbidity and Mortality Weekly Report (MMWR).

The US childhood vaccination program is a partnership among federal, state, and local government, industry, healthcare providers, and insurers that strives to deliver universal, on-time vaccination to all of America's children, without regard to a family's ability to pay. The program achieves high coverage with recommended childhood vaccines and has eliminated or dramatically reduced racial and ethnic disparities in coverage.[4-6] The surveillance systems that track vaccine-preventable diseases, vaccination coverage, and vaccine safety are foundational elements of the vaccination program.

HISTORY OF DATA COLLECTION

Disease surveillance in the United States has evolved into a complex system of laws, policies, information systems, and human resources collaborating to detect, track, and ultimately prevent conditions of public health significance. In many ways, actual or anticipated public health threats have driven this evolution and led to the systems currently in place to monitor the impact and safety of the vaccination program and inform vaccination policy.

In the latter half of the 19th century, communicable disease reporting emerged as a means to support quarantine measures to prevent the importation and spread of diseases such as cholera, smallpox, and plague. Communicable disease reporting expanded over subsequent years to include collection of reports from domestic jurisdictions and standardized notification systems. By 1912, the first annual Summary of Notifiable Diseases was published in conjunction with the US Public Health Service (PHS), compiling data on 10 diseases reported in 19 states in addition to Hawaii and the District of Columbia.[7] In the 1950s, state and territorial epidemiologists convened to establish the national notifiable diseases list, and, since that time, the Council of

State and Territorial Epidemiologists (CSTE) has had responsibility for defining and recommending diseases and conditions that are reportable in states and notifiable to CDC.

The Cutter Polio Incident was a defining event in the history of vaccine-preventable disease surveillance, making clear the value of near real-time data in response to a public health emergency.[8] On April 25, 1955, shortly after implementation of the polio vaccination program, a vaccinated infant with polio was identified in Chicago.[9] Five additional cases were reported the following day in California, all among children who had received inactivated vaccine from the same manufacturer. Within two days, following consultation with federal epidemiologists, virologists, and public health administrators, the Surgeon General of the PHS requested recall of the implicated vaccine. On the following day, he directed establishment of the Poliomyelitis Surveillance Unit within the Communicable Disease Center. This unit directed all State and Territorial Health Officers to designate a State Poliomyelitis Reporting Officer charged with ascertaining cases of polio among vaccinated individuals, and subsequently cases among contacts of vaccines, and reporting them to CDC. Beginning May 1, 1955, daily polio surveillance reports were disseminated. In addition to evaluation of cases in real time, production and testing procedures were reviewed at all manufacturing facilities. With increasing certainty, the vaccine-associated polio cases were linked primarily to one manufacturer. The efforts of CDC, including timely collection, analysis, and dissemination of polio surveillance data, were critical to the rapid resumption of the vaccination program and ultimately to the elimination of polio from the western hemisphere.

CDC SURVEILLANCE ACTIVITIES

National Notifiable Disease Surveillance System

Surveillance for most vaccine-preventable diseases occurs through the National Notifiable Disease Surveillance System (NNDSS). All jurisdictions conduct surveillance for communicable and other diseases including vaccine-preventable diseases, with 52 jurisdictions (all states, New York City, and the District of Columbia) transmitting data electronically through NNDSS. Case ascertainment and investigation data are used at the local and state level to monitor disease occurrence and to detect and respond to public health threats. At the national level, surveillance data for vaccine-preventable disease are critical in monitoring the effectiveness of the vaccination program. Each year, a National Summary of Notifiable Diseases is published, which summarizes the current epidemiology and notable recent developments in the occurrence and prevention of diseases tracked by NNDSS.

Other Data Systems

Several systems that are complementary to NNDSS also monitor trends in the burden of vaccine-preventable diseases. The Active Bacterial Core surveillance system (ABCs) of the Emerging Infections Program (EIP) is an active, laboratory- and population-based surveillance system for invasive bacterial diseases of public health importance. The Enhanced Pertussis Surveillance (EPS) also builds on the EIP platform, a collaboration between state public health departments, academic partners, and CDC. The Influenza Hospitalization Surveillance (FluSurv-NET) system was established in the 10 EIP sites plus Michigan, Ohio, and Utah to conduct surveillance of laboratory-confirmed influenza hospitalizations. Similar to the ABCs system, the National Respiratory and Enteric Virus Surveillance System (NREVSS) is a laboratory-based system that monitors circulation of important viral pathogens including rotavirus. The Viral Hepatitis Surveillance Program (VHSP) supplements NNDSS data with additional information on clinical features, risk factors, and laboratory confirmation for cases of Hepatitis A, B, and C. From 1995 through 2010, the Varicella Active Surveillance Project (VASP) monitored population-based varicella rates and monitored vaccine impact in two large metropolitan jurisdictions, but since then efforts have been made to improve case-based surveillance through NNDSS.

National Immunization Survey

In the early 1990s, in response to widespread measles outbreaks associated with diminished vaccine coverage, the National Immunization Survey (NIS) was authorized. The first survey data were collected in 1994, and CDC now conducts three surveys to monitor vaccination coverage among children aged 19-35 months, 13-17 years, and influenza vaccination among children aged 6 months through 17 years. The surveys collect data in all 50 states, the District of Columbia, and select local areas and territories using random digit dialing samples that include cell phones and landlines. Vaccination coverage estimates are based on provider-verified reports with the exception of influenza vaccination; to improve timeliness of seasonal influenza vaccination coverage, parental report is used. These surveys yield national vaccination coverage data that can also be analyzed at the state and local level.

Immunization Information Systems

Immunization information systems (IIS), commonly known as immunization registries, came into widespread use in the 1990s as computerized databases that allowed participating providers to record and access a confidential record of all vaccinations received by children residing in a given jurisdiction. They can improve patient care by allowing confirmation of timely vaccination across different providers and practice locations, facilitate recognition of under-immunization, and reduce missed opportunities for vaccination. They have expanded to incorporate systems for reminders and recall of patients for immunization and support for provider decision making about immunization eligibility. They also can assist medical practices in managing vaccine inventory and tracking of quality care measures.[10] Some systems allow parents and caregivers to access a "shot record" for their child. Public health authorities can use registry data to track community- and provider-level vaccine coverage, including assessing school- and community-level vaccine coverage, and they have served as useful sources of data in evaluations of the vaccine program and vaccine effectiveness.[11, 12] In 2012, CDC developed a strategic plan for IIS in response to challenges that had arisen from reliance on disparate sources of funding to maintain IIS, absence of uniform policies for interstate exchange of data, and an increasing need to integrate IIS with electronic health record systems. The plan continues to evolve, but maintains a vision of making "real-time, consolidated immunization data and services for all ages available for authorized clinical, administrative, and public health users and consumers anytime, anywhere."[13]

Vaccine Adverse Event Reporting

During the 1970s and 1980s, a number of cases of neurologic manifestations were reported among children who had received whole-cell pertussis vaccination. Although no causal association was established, several instances of permanent disability in children were widely publicized.[14] The ensuing controversy led to an increase in vaccine injury-related lawsuits in the United States and, in some countries, led to loss of public confidence in vaccination, declining vaccination coverage, and resurgence of pertussis.[15] Manufacturers began to withdraw their products from the market, endangering the vaccine supply. In response, the National Childhood Vaccine Injury Act (NCVIA) was passed and signed into law in 1986.[16] Important provisions of NCVIA included the establishment of the National Vaccine Injury Compensation Program, a no-fault system for compensating claims of vaccine-related injury or death, and the establishment of the Vaccine Adverse Event Reporting System (VAERS).

VAERS is one of the three complementary systems by which HHS conducts surveillance for adverse events associated with licensed vaccines. While NCVIA mandates the reporting of certain adverse events, VAERS accepts reports from anyone on any adverse event that may be related to vaccination. Data from VAERS can identify an unusual pattern of occurrence of adverse events in place or time; however, it is not useful for identifying an excess risk or causality because it consists of numerator data without denominators.[16] Because of this limitation, the Vaccine Safety Datalink (VSD) was established in 1990. The VSD is a collaboration between CDC and several large managed healthcare organizations that prospectively compiles data on vaccination history, patient characteristics, and health outcomes among members. While VAERS can be considered a “hypothesis-generating” system, VSD is used to test hypotheses regarding excess risk and causality of adverse events associated with vaccination. The third system, the Clinical Immunization Safety Assessment project, was established in 2001 and provides expert consultation on individual cases of adverse events, as well as a platform for research into the causes and prevention of adverse events.

GENERAL FINDINGS

Vaccine Coverage

Vaccination coverage among children in the United States has been sustained at high levels for many years.[5] Among children aged 19 through 35 months during 2014-2015, the Healthy People 2020 vaccination targets were met for four vaccines, including poliovirus vaccine, the hepatitis B series, MMR, and varicella vaccines. Targets were not met for DTaP, the Hib series, PCV, hepatitis A, the hepatitis B birth dose, and rotavirus vaccines, as well as the combined seven-vaccine series. Less than 1% of children in the United States receive no vaccines. Though racial and ethnic differences in vaccine coverage have been reduced, children living below the federal poverty level have lower coverage for almost all vaccines in the childhood series, and coverage levels for individual vaccines vary substantially by state.

Tetanus, Diphtheria, and Pertussis

Pertussis is a highly contagious bacterial respiratory infection commonly known as whooping cough. Prior to the advent of childhood vaccination, pertussis was a greater killer of children in the United States than measles and polio combined.[17] With the introduction of killed, whole-cell pertussis vaccines during the 1940s and subsequent implementation of near universal childhood vaccination with acellular pertussis vaccines, the incidence of pertussis dropped 99%, reaching a nadir of 1,010 reported cases in 1976.[3, 17] However, since the early 2000s, the incidence of pertussis has trended upwards. A large epidemic of pertussis occurred in 2004 with a substantial burden of disease among adolescents, leading to the introduction in 2006 of a tetanus and reduced dose diphtheria and acellular pertussis (Tdap) vaccine dose at age 11 or 12 years.[18] Large pertussis epidemics also occurred in 2010 and 2012.[11, 17, 19] The incidence and morbidity from pertussis are greatest among infants, and the majority of the 10 to 30 deaths reported each year occur in this age group (annual case-fatality rate 0.04% to 0.1%).[20]

Pertussis is reportable in all jurisdictions, and case notifications are sent to CDC through NNDSS. To facilitate understanding of pertussis epidemiology, from 1979 through the 1990s, the Supplemental Pertussis Surveillance System collected additional information on cases including vaccination history, certain clinical features and complications, laboratory confirmation, and treatment. This supplemental data collection was gradually incorporated into routine NNDSS electronic reporting. Beginning in 2011, CDC collaborated with six states within the Emerging Infections Program network of health departments and academic institutions to establish the Enhanced Pertussis Surveillance System (EPS).[21] The EPS system builds on the NNDSS infrastructure and collects additional demographic, clinical, and epidemiologic variables, more thorough case ascertainment, and more complete data collection. It also has a component of improved bacteriologic and molecular confirmation of cases. The objectives of EPS are to describe the epidemiology of pertussis including age-specific incidence, monitor characteristics of disease-causing strains, and serve as a platform for studies of vaccine effectiveness and other prevention and control measures.

Tetanus is different from other vaccine-preventable diseases in that it is not transmitted from person to person, but is caused when tetanus bacteria normally found in soil enter the body through breaks in the skin. Tetanus causes muscle spasm or tightening, often occurring first in the jaw muscles, giving rise to the common name for tetanus, “lockjaw.” Diphtheria is a bacterial respiratory infection that can cause severe cardiac and neurologic complications. Both tetanus and diphtheria are toxin-mediated diseases, and the vaccines against them are highly effective. Tetanus and diphtheria are largely controlled due to near universal childhood vaccination and booster doses throughout adulthood. Neonatal tetanus is a risk in children born to unvaccinated mothers, however, hospital births greatly reduce the risk of exposure to tetanus spores. Since 2000, only three cases of neonatal tetanus have been reported to CDC.

Measles, Mumps, and Rubella

Measles is a highly contagious viral infection characterized by fever, runny nose, cough, red eyes, and sore throat, followed by rash that spreads over the whole body. While measles most often resolves without complications, pneumonia can occur and is the most common cause of death from measles. Encephalitis, or swelling of the brain, may lead to permanent deafness or intellectual disability. Even before measles vaccine introduction in the early 1960s, public health professionals advocated for the elimination of measles due to its high burden of morbidity and mortality.[22] The United States set a goal in 1978 to eliminate endemic measles by 1982. This goal was not achieved, and a resurgence of measles among school-aged children in the late 1980s ultimately resulted in recommendation of a second dose of measles-containing vaccine prior to school entry. Achieving and maintaining high coverage with two doses of measles, mumps and rubella (MMR) vaccine ultimately led to the declaration of elimination of endemic measles transmission in the United States in 2000.

Surveillance for measles, mumps, and rubella occurs through NNDSS, with routine collection of data on clinical severity, patient characteristics, vaccination status, and outcome. All cases of measles should be investigated to prevent secondary transmission. Though endemic measles is eliminated in the Americas, it remains common in much of the world and Europe has experienced large outbreaks in recent years. Imported cases can lead to secondary cases and local transmission when susceptible persons are exposed, and clusters and outbreaks in the United States have been associated with introduction into communities with groups of unvaccinated children. In 2014, 23 measles outbreaks occurred in the United States, including one large outbreak occurring primarily among unvaccinated Amish communities which resulted in 383 cases.[23]

Mumps is a contagious viral disease that causes swollen salivary glands. Since vaccination was recommended beginning in 1967, there has been a 99% reduction in the burden of disease.[3] Outbreaks remain numerous each year, however, and a large number of cases can result.[24] Outbreaks often occur on college campuses, where the degree of close contact and behaviors that result in exposure can promote spread.[25] High two-dose vaccination coverage is thought to help limit the size and duration of mumps outbreaks; however, recently a third dose has been recommended in outbreaks among college students with high two-dose coverage and found to be effective.[25, 26]

Rubella, commonly known as "German measles," is a contagious virus that causes fever and rash. Disease may be mild, and infection can be asymptomatic. Rubella was declared eliminated from the United States in 2004.[27] Fewer than ten cases are reported each year, with no evidence of endemic transmission.[23, 27]

Newer Vaccines

Certain bacteria that commonly cause disease of the respiratory tract, like ear infections or pneumonia, can also cause more severe and invasive disease, like bloodstream infection or meningitis. These include Neisseria meningitidis, Streptococcus pneumoniae, and Haemophilus influenzae. Once common causes of serious disease and death in young children, these bacteria were prime targets for vaccine development. However, these bacteria are covered by protective capsules to which children under two years of age have immature immune responses.[28, 29] Vaccination with capsule alone is insufficient to produce protection, but connecting the capsule to a protein, known as conjugation, can improve the immune response in young children. Conjugate vaccines to Haemophilus influenzae type b (Hib) and multiple serotype of Streptococcus pneumoniae (PCV) are routinely recommended for children. Following introduction of Hib conjugate vaccines in the late 1980s, the annual incidence of invasive Hib disease in children aged less than five years declined by 99%, to less than 1 per 100,000.28 The first pneumococcal conjugate vaccine protected against 7 serotypes (PCV7) and was recommended in 2000 and, by 2008, the incidence of invasive pneumococcal disease in children aged less than five years had been reduced from approximately 99 to 21 per 100,000, a 79% reduction.30 In 2010, PCV13 was introduced and recommended. The use and evaluation of Hib and PCV vaccines are discussed in more detail below.

Chickenpox, or infection with varicella zoster virus, is a common disease of childhood. One dose of varicella vaccine was recommended for routine use in the United States in 1996, and CSTE recommended that varicella be notifiable nationally by 2003 to monitor vaccine impact on morbidity and mortality.[31] Though the incidence of varicella declined dramatically following implementation of the vaccination program, outbreaks continued. By 2007, two doses were recommended for routine use in children. As of 2015, 40 states report varicella cases to CDC and 38 states conduct case-based varicella surveillance which includes standard demographic, clinical, epidemiologic data, disease severity, and vaccination status of affected persons.[32, 33] From the period before two-doses were recommended (2005-2006) through 2013-2014, nationwide varicella declined by 85%, and by 97% in the four states that have consistently reported varicella cases since before implementation of the varicella vaccination program (1993-1995 through 2013-2014). Substantial declines also occurred in varicella-related hospitalizations and the number of varicella outbreaks, and vaccinated children with varicella had milder disease than those unvaccinated.[34]

Hepatitis is inflammation of the liver, most commonly caused by viral infection. Among the various forms of viral hepatitis, those caused by Hepatitis A, B, and C virus are most common, and hepatitis A and B are vaccine-preventable. Hepatitis B can cause chronic infection and liver disease, which in turn can lead to hepatocellular carcinoma. All states collect and report basic information on cases of acute viral hepatitis through NNDSS, and some states collect additional information on laboratory testing, clinical course, and exposures.[35] Effective vaccines against hepatitis A and B became available in 1995 and 1981, respectively. The initial recommendation for vaccination of children against hepatitis A was made for children aged two years and greater who resided in communities with increased incidence as part of an incremental strategy to improve hepatitis A control.[36, 37] This recommendation led to a 92% decline in incidence from 1995 through 2007, from 12.0 to 1.0 per 100,000.[35] Subsequently, the recommendation was updated to include universal vaccination of children aged one year and greater.[38] The incidence of hepatitis A was 0.4 per 100,000 in 2014.[23] Vaccination against hepatitis B was first implemented in 1982, and since that time, vaccination has become a cornerstone of a strategy to eliminate hepatitis B transmission in the United States.[39] An important aspect of this strategy is universal vaccination of infants, recommended since 1991, to prevent infection in childhood and ultimately in adolescents and adults. Vaccination of children begins with a dose at birth, and coverage is currently comparable to other vaccines given in childhood. During 1990 through 2007, the incidence of new hepatitis B infections declined 85%, from 8.5 to 1.5 cases per 100,000.35 In 2014, 2,791 new cases of hepatitis B were reported, though actual cases are estimated to be 6.5 times more frequent than reported cases.[23, 40]

Rotavirus is the most common cause of severe gastroenteritis in infants and young children, and prior to vaccination, infection was essentially universal by age five.[41] Although deaths caused by rotavirus were uncommon in the United States, over 400,000 doctor visits, from 205,000 to 272,000 emergency department visits, and between 55,000 to 70,000 hospitalizations annually were attributable to rotavirus, with peak incidence during the "rotavirus season" in summer months. Infant rotavirus vaccination was first recommended in 2006. The NREVSS comprises a network of laboratories that report weekly to CDC the aggregate number of rotavirus tests they perform and the number positive.4[2] It is a simple, timely system used to monitor the burden of rotavirus by indirectly measuring testing and detection. During 2011 and 2012, the rotavirus season threshold was never crossed, and the 2010 season was eight weeks shorter than usual. Further the number of rotavirus tests performed declined by 28% to 36% each season, while the proportion of positive results declined by 74% to 90% each season after vaccination compared to before, indicating a substantial decline in rotavirus disease following vaccine implementation.

Vaccination of Older Children and Adolescents

Though it is beyond the scope of this chapter to cover in depth, vaccination is also recommended for older children, pre-teens, and teenagers.[43] Influenza vaccine is recommended annually, beginning at six months of age. Routine vaccination at age 11 to 12 years is recommended to protect against tetanus, diphtheria, and pertussis (Tdap), human papillomavirus, a cause of cervical cancer, and Neisseria meningitidis serogroups A, C, W, and Y, a cause of meningitis and other serious bacterial infections.

USING DATA FOR ACTION

Despite a long-standing vaccination program and high coverage, the epidemiology of pertussis changed dramatically beginning in the 2000s, and surveillance data were used in numerous ways to understand this resurgence and to formulate and evaluate additional prevention and control strategies. A large pertussis epidemic in 2004-2005 was characterized by a high incidence of disease among adolescents, and this changing epidemiology led to a recommendation in 2006 for Tdap at age 11-12 years.[18] The early direct impact of the Tdap booster dose in reducing adolescent disease was demonstrated using NNDSS data; however, the anticipated additional benefit of reducing disease in infants by reducing transmission was not demonstrated.[44] Though cases declined with increasing adolescent vaccination coverage, epidemics again occurred in 2010 and 2012, with high incidence among fully vaccinated children and adolescents.[17] Subsequent studies suggested that waning of vaccine-induced immunity was likely playing a large role in the resurgence of pertussis, potentially exacerbated by the switch from whole-cell to acellular vaccines during the 1990s.[44, 45] California experienced its largest pertussis epidemic in over 60 years in 2010, notable for 10 fatal cases in infants.19 In the context of limited ability to prevent or control epidemics through further vaccination, public health officials focused on ways to prevent morbidity and mortality in infants. Surveillance data were used to assess the potential impact of a maternal vaccination strategy versus a "cocooning" strategy of vaccinating close contacts of infants.[46] The favorable impact of vaccinating pregnant women to prevent pertussis led ACIP to recommend this strategy. Surveillance and vaccination coverage data were also used to model the potential impact of recommending a second Tdap dose for adolescents, but the limited impact and unfavorable cost-effectiveness results led ACIP not to recommend this strategy.[47] Enhanced Pertussis Surveillance data have been used to assess the changing source of transmission to infants as the age-specific incidence of pertussis has changed, and further support the recommendation to vaccinate pregnant women to help protect their infants.[48]

Data from the EIP network and its ABCs surveillance system for invasive bacterial pathogens have been used extensively to develop and evaluate recommendations for several new vaccines, including pneumococcal, meningococcal, and Haemophilus influenzae type b conjugate vaccines. Streptococcus pneumoniae is a major cause of invasive disease, including meningitis and bloodstream infections, in the United States; however, it is not reportable in all jurisdictions.[49] The ABCs system was established coincident with the development of pneumococcal conjugate vaccine to establish baseline rates of invasive pneumococcal disease, understand the serotypes causing disease, and evaluate vaccine effectiveness. Subsequent to introduction of the 7-valent pneumococcal conjugate vaccine in 2000, ABCs data demonstrated a reduction of disease in young children, the target group for vaccination, as well as among adults through a reduction in transmission, commonly referred to as herd protection.[50] Further reductions were demonstrated following the transition to 13-valent vaccine in 2010.[51] The EIP network also serves as a platform for conducting vaccine effectiveness studies, mathematical modeling of disease prevention strategies, tracking the occurrence of antimicrobial resistance, and monitoring for the occurrence of "replacement disease" with non-vaccine pneumococcal serotypes.

DATA GAPS AND LIMITATIONS

The childhood vaccination program and the surveillance systems that support it are largely mature. Over time, data gaps that have emerged have been ameliorated with the addition of complementary systems, and systems strengthened to overcome limitations. However, systems that rely on medical providers to report cases often have incomplete sensitivity.[52] Registries can have gaps when providers choose not to participate. Further, each system or type of system has its own limitations. Passive systems may undercount high-incidence diseases like pertussis or viral hepatitis.[18, 53] Active, population-based systems may require substantial resource investments to achieve near complete reporting or obtain nationally-representative statistics.[5, 54, 55] The greatest challenge occurs when changes in disease epidemiology or licensure of new vaccines requires expansion of the scope of a surveillance system or the implementation of a novel system.[21, 56]

FUTURE ISSUES

The NNDSS is used to conduct surveillance for over 100 conditions, and though data are transmitted electronically, it relies on outdated electronic messaging standards. In response to the rapid proliferation of health data such as laboratory testing results, the expansion of electronic medical record systems, and the evolution in technology of data exchange standards, CDC has embarked on the NNDSS Modernization Initiative (NMI), a multi-year process to increase the capacity and interoperability of the nation's public health surveillance infrastructure. The NMI aims to build new electronic messaging systems and improve the effectiveness of data transfer. This should reduce the need for manual data entry or recoding, improving data usability and timeliness. By 2016, ten states were transmitting data using the new standards.[57] Efforts are also being made to standardize data structure and content and harmonize common data elements across diseases. The NMI is part of a larger strategic initiative to work with state and local health agency partners to improve surveillance systems that includes improving electronic laboratory reporting. Electronic reporting of laboratory results for communicable diseases from healthcare facilities to public health agencies can accelerate reporting and improve data validity and completeness. These efforts to modernize electronic messaging and data transmittal within NNDSS are taking place in the broader context of efforts by CDC to implement shared information technology services, develop the technical capacity of the surveillance workforce, and harness healthcare information technology systems to improve electronic case reporting.

As has been described in this chapter, vaccines are among the most successful public health interventions ever developed. High levels of vaccination are needed to maintain protection in a population, and as recent outbreaks have underscored, diseases like measles transmitted readily when unvaccinated persons are exposed.[58] Some children cannot be vaccinated because of certain health conditions, others have been vaccinated but may not have had a protective immune response, and still others are too young to be vaccinated. Some children are unvaccinated by parental choice, and geographic clustering of vaccine refusal has been noted, further exacerbating the risk of vaccine-preventable disease outbreaks in these areas.[59] To maintain high childhood immunization rates, confidence in vaccines and vaccination must be maintained. Vaccine confidence has been defined as the "trust that parents or healthcare providers have in the immunizations recommended by the ACIP, in the providers who administer vaccines, and in the processes that lead to vaccine licensure and the recommended vaccination schedule."[60] Parental trust in healthcare providers, effective communication, provider endorsement of vaccination, and social norms all play a role in fostering vaccine confidence. In the future, robust systems and validated tools to measure vaccine confidence at the individual and community level could further the goal of universal vaccination.

ADDITIONAL RESOURCES

- CDC "Pink Book"
  https://www.cdc.gov/vaccines/pubs/pinkbook/index.html
- CDC Vaccine Information Statements
  https://www.cdc.gov/vaccines/hcp/vis/index.html
- HHS Vaccine Adverse Events Reporting System
  https://vaers.hhs.gov/

- CDC National Notifiable Disease Surveillance System
  https://wwwn.cdc.gov/nndss/
- ACIP
  https://www.cdc.gov/vaccines/acip/index.html
- CDC Immunization Schedule for Children and Adolescents
  https://www.cdc.gov/vaccines/schedules/hcp/child-adolescent.html
- The Immunization Action Coalition
  http://immunize.org/
- CDC National Immunization Surveys
  https://www.cdc.gov/vaccines/imz-managers/nis/about.html

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Unintentional Injuries and Violence Among Children (0-9 Years Old)

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Despite local and national efforts to focus on the preventable health problem of unintentional and intentional injuries to children, injury and violence continue to be the leading cause of death for young people in the United States. Prevention of injury is extremely important because of short- and long-term consequences to the child, family, and even society. Data from a large number of sources are being used by health officials, law-enforcement services, and other concerned groups and individuals to define causes and provide interventions for this vulnerable population group.

PUBLIC HEALTH IMPORTANCE

While death rates in the United States from injury and violence among children 0 through 9 years of age have declined by almost 25% since 1999, injury and violence remain the leading cause of death for US young people[1]. Injuries can be unintentional or violence-related. “Unintentional” refers to injuries not deliberately inflicted, regardless of whether inflicted by oneself or by another person. “Violence” refers to the use of physical force by one or more persons with the intent of causing harm to another person or to oneself. Children under the age of 10 years are particularly vulnerable since they are dependent on their parents, guardians, caregivers, and society for protection.

Prevention is extremely important because of short- and long-term consequences to the child, family, and even society[2]. Injured children may experience emotional effects, altered growth and development, time lost from school, and time away from family and peers. Additionally, parents and families who care for an injured child can experience difficulty maintaining normal work and general schedules, which can affect those family members' mental and physical health and finances[3].

Injuries are predictable, preventable, and controllable. As is the case with other diseases, the public health problem of unintentional and intentional injuries involving young children can be addressed through the use of strong surveillance data and systems.

HISTORY OF DATA COLLECTION

Injury and violence surveillance data historically have been used in several ways. Surveillance is used to describe the magnitude of injuries in a population and to monitor trends over time of a given type of injury relative to other types of injuries and health conditions and within the general population or in special populations. This approach can help direct priorities for injury research. Additionally, surveillance can identify new injury problems or emerging issues. For children, this may involve new consumer products, changes to existing products, or new exposures to other hazards. Lastly, strong injury surveillance systems can support the evaluation of interventions and prevention efforts.

Mortality Data

A number of data sources and data systems are used for the surveillance of fatal injuries among children. These include systems run by CDC and other federal- and state-level agencies.

The main source of data on injury deaths in the United States is the National Vital Statistics System (NVSS: http://www.cdc.gov/nchs/nvss.htm), a data-collection system managed by CDC's National Center for Health Statistics (NCHS). Since 1999, these data have been coded using the *International Classification of Disease – 10th revision (ICD-10),* with mechanism and cause of injury based on ICD-10 external cause of injury codes.

Medical examiner and coroner systems can offer additional information that is not always included on a death certificate. For example, these records may include details on alcohol and drug involvement, description of injuries involved, and a narrative on the circumstances surrounding the injury event and death. Although these systems are run at the state level, CDC will collaborate with state health departments and use these systems on specific investigations and local public health issues.

The National Highway Traffic Safety Administration (NHTSA) runs the Fatality Analysis Reporting System (FARS), which is a census of fatal traffic crashes within the 50 states, the District of Columbia, and Puerto Rico. States report data to NHTSA through a cooperative agreement using several local data sources such as police accident reports, state highway department data, vital statistics, hospital medical records, and emergency medical services reports. Data elements characterize the crash, the vehicles, and the people involved. Because FARS and other NHTSA-run data systems include more information on the circumstances of the crashes, which are critical to determining what prevention measures should be applied, CDC uses these data and partners with NHTSA often.

Morbidity Data

Deaths only represent the most severe injuries that occur. Understanding the types and number of non-fatal injuries among children helps local and national health officials have a clearer understanding of the overall burden non-fatal injuries represent to society.

Hospital discharge records capture morbidity data on injuries that are severe enough to warrant hospitalization. The National Hospital Discharge Survey (run by the CDC's NCHS) and the Healthcare Cost and Utilization Project-National Inpatient Sample (HCUP-NIS, run by the Agency for Healthcare Research and Quality) both provide national estimates of hospitalizations.

Trauma registries are used primarily to understand the quality of trauma care and outcomes, but can also be used for injury surveillance. The National Trauma Data Bank is the largest aggregation of US trauma registry data. Participation is voluntary, but 746 facilities contributed data in 2015[4].

Data on outpatient care are available through several systems. Estimates for emergency department visits for injuries are available through the National Electronic Injury Surveillance System-All Injury Program (NEISS-AIP; see section below on CDC surveillance activities), NCHS's National Hospital Ambulatory Medical Care Survey (NHAMCS), and HCUP-Nationwide Emergency Department Sample (NEDS). The National Ambulatory Medical Care Survey (NAMCS) is a sample of visits to office-based physicians who are primarily engaged in direct patient care.

Other key morbidity data systems include NHTSA's National Accident Sampling System (NASS). NASS has two parts: the Crashworthiness Data System (CDS) and the General Estimates System (GES). Both systems select cases from police accident reports, with CDS data focused on identifying potential improvements in vehicle design, and GES data focused on assessing the size of the problem and tracking trends. These are critical systems because they complement CDC data with information not routinely available from health-care facilities.

CDC SURVEILLANCE ACTIVITIES

In addition to the systems listed in the sections above, CDC's National Center for Injury Prevention and Control (NCIPC) and other programs at CDC conduct numerous surveillance activities and maintain data systems that include children and adolescents.

NEISS-AIP (http://www.cdc.gov/ncipc/wisqars/nonfatal/datasources.htm) provides information about the causes of nonfatal injuries that are seen in a nationally representative sample of US hospital emergency departments. All injury-related cases seen in participating hospitals are included in NEISS-AIP, and data are weighted to create national estimates. NEISS-AIP is a collaboration between CDC and the Consumer Product Safety Commission (CPSC), with the first full year of data collection having occurred during the All Injury Program in 2001; however, CPSC has been supporting the NEISS system (only product-related injuries) since the late 1970s. These systems include data on children as well as older age groups.

Several NEISS Special Studies collect additional information on specific injuries. For example, special studies on work-related injuries, adverse drug events, self-inflicted violence, assaults, and firearms are ongoing. Non-CDC agencies also lead NEISS special studies on poisonings and motor vehicle traffic crashes involving children.

The National Violent Death Reporting System (NVDRS: http://www.cdc.gov/ViolencePrevention/NVDRS/) is an active, state-based surveillance system that collects information on all violent deaths (e.g., child maltreatment homicides, intimate partner homicides, suicides) in all settings and among all ages. Data are collected from three primary sources: death certificates, coroner/medical examiner records, and law enforcement reports. Linked data represent a unique strength of NVDRS and provides detailed information about the circumstances and precipitating factors of violent deaths, which can strengthen prevention activities. NVDRS was created in 2002, and in 2015, 32 states participated in NVDRS.

The National Intimate Partner and Sexual Violence Survey (NISVS: http://www.cdc.gov/violenceprevention/nisvs/) is a nationally representative, random digit dial telephone survey, which assesses experiences of intimate partner violence, sexual violence, and stalking among adult women and men in the United States. Although respondents are adults, the survey collects lifetime prevalence data, as well as the age at the time of first victimization. Some NISVS respondents report their first victimization was as children or adolescents. NISVS data collection is ongoing since data collection began in 2010.

Violence Against Children Surveys (VACS: http://www.cdc.gov/violenceprevention/vacs/) measure physical, emotional, and sexual violence against children in low- and middle-income countries. VACS surveys are nationally representative household surveys of children and young adults age 13 through 24 years. VACS surveys have been conducted in over 11 countries since 2007 and multiple new surveys are planned every year.

GENERAL FINDINGS

According to 2014 NVSS data, injuries resulted in 4,009 deaths among US children under the age of 10 years, for a death rate of 9.92 per 100,000 population. This represents a decrease from 5,207 deaths or 13.10 per 100,000 in 1999. Injuries accounted for about 41% of deaths among children ages 1 through 4 years, and 36% of deaths among those 5 through 9 years old during 2014[1]. Among children less than 1 year old, unintentional injuries ranked as the fifth leading cause of death in 2014 (see Table 1), with almost 1,000 babies dying as a result of suffocation (see Table 2). For children 1 through 9 years of age, unintentional injuries were the leading cause of death. For this age group, the most common causes of injury deaths were motor vehicle traffic crashes, drowning, and homicide[1].

Table 1. Ten leading causes of death* among children, by age group – United States, 2014

	Age Groups (years)		
Rank	<1	1-4	5-9
1	Congenital Anomalies 4,746	Unintentional Injuries 1,216	Unintentional Injuries 730
2	Short Gestation 4,173	Congenital Anomalies 399	Malignant Neoplasms 436
3	Maternal Pregnancy Complications 1,574	Homicide 364	Congenital Anomalies 192
4	SIDS 1,545	Malignant Neoplasms 321	Homicide 123
5	Unintentional Injury 1,161	Heart Disease 149	Heart Disease 69
6	Placenta Cord Membranes 965	Influenza & Pneumonia 109	Chronic Lower Respiratory Disease 68
7	Bacterial Sepsis 544	Chronic Lower Respiratory Disease 53	Influenza & Pneumonia 57
8	Respiratory Distress 460	Septicemia 53	Cerebrovascular Disease 45
9	Circulatory System Disease 444	Benign Neoplasms 38	Benign Neoplasms 36
10	Neonatal Hemorrhage 441	Perinatal Period 38	Septicemia 33

* Cause and number of deaths are represented in each cell.
Data Source: National Center for Health Statistics (NCHS), National Vital Statistics System

Table 2. Leading causes of injury-related death among children, by age and sex – United States, 2014

	Numbers (and rate*) of injuries								
	< 1 year			1-4 years			5-9 years		
	Males	Females	Total	Males	Females	Total	Males	Females	Total
All Injury	853 (42.27)	634 (32.84)	1,487 (37.66)	983 (12.08)	661 (8.48)	1,644 (10.32)	543 (5.18)	335 (3.34)	878 (4.28)
Suffocation	613 (30.38)	444 (23.00)	1,057 (26.77)	96 (1.18)	55 (0.71)	151 (0.95)	29 (0.28)	26 (0.26)	55 (0.27)
Homicide	144 (7.14)	105 (5.44)	249 (6.31)	196 (2.41)	168 (2.16)	364 (2.29)	61 (0.58)	62 (0.62)	123 (0.60)
MV Traffic	34 (1.68)	27 (1.40)	61 (1.54)	161 (1.98)	132 (1.69)	293 (1.84)	192 (1.83)	153 (1.52)	345 (1.68)
Drowning	15 (0.74**)	18 (0.93**)	33 (0.84)	270 (3.32)	137 (1.76)	407 (2.56)	101 (0.96)	29 (0.29)	130 (0.63)
Fire/Burn	9 (0.45**)	9 (0.47**)	18 (0.46**)	82 (1.01)	51 (0.65)	133 (0.83)	48 (0.46)	29 (0.29)	77 (0.38)
Firearms	3 (0.15**)	4 (0.21**)	7 (0.18**)	41 (0.50)	30 (0.39)	71 (0.45)	42 (0.40)	33 (0.33)	75 (0.37)

* Rates per 100,000 population; categories may not be mutually exclusive.

** Rates based on 20 or fewer deaths may be unstable.

Data Source: National Center for Health Statistics (NCHS), National Vital Statistics System.

Children are also subject to non-fatal injuries that require medical treatment. According to NEISS-AIP data in 2013, almost 3.8 million children 0 through 9 years of age were treated and released from an emergency department for an injury in the United States[1]. Additionally, among those seen in an emergency department for an injury, over 123,000 were hospitalized or transferred to other facilities for further care. The most common causes of nonfatal injury among children in this age group were falls, being struck by or against (i.e., patient was hit, crushed or struck by a another human, animal, or inanimate object), and bites and stings. For both fatal and non-fatal injuries, rates and numbers of injuries were higher for boys than for girls[1].

USING DATA FOR ACTION

CDC used data from a NEISS Special Study, National Electronic Injury Surveillance System-Cooperative Adverse Drug Event Surveillance (NEISS-CADES) project, to understand the problem of unintentional medication overdoses among children[5]. They found that unintentional ingestions and medication dosing errors were two common problems that led to emergency department visits for medication overdose, particularly among young children. In response, CDC initiated a public-private partnership, the PROTECT Initiative, to examine the available data, brainstorm priorities and strategies for intervention, and evaluate progress toward prevention[6]. Guided by national data, the PROTECT Initiative’s three-pronged approach focuses on a) improving medication safety packaging to prevent unintentional ingestions; b) standardizing medication labels and dosing to reduce errors; and c) improving safe medicine storage practices. As a result, flow restrictors that limit how much medicine can be removed are now incorporated into bottles of infants’ acetaminophen and other liquid medicines; dosing instructions and devices have been standardized for infant and children's over-the-counter medicines; and safe practices for using and storing medicines are regularly shared through the "Up and Away and Out of Sight" campaign.

The effectiveness of child safety seats and booster seats has been well documented, including legislation requiring mandatory use[7-10]. However, state policies vary in their coverage with several states requiring booster seat use until only age 5 or 6[11]. Children typically do not fit properly in a seat belt at these ages. One analysis assessed whether booster seat coverage for ages 7 and 8 was effective in reducing crash injury among these children[12]. The authors of this chapter analyzed police crash data from Missouri, North Carolina, Pennsylvania, Wisconsin and Wyoming before and after coverage. Police crash data are a key data source for the previously described national systems run by NHTSA; however, states typically use local data to evaluate their prevention strategies. Results of our multi-state study demonstrated that amending laws to cover children ages 7 or 8 increased the use of child safety seats, increased rear seating position (safer location in a crash), and decreased injuries, including fatal and incapacitating injuries, among children covered under the law.

California has been funded by CDC to implement Essentials for Childhood, which is a framework for preventing child abuse and neglect[13]. The second goal area for Essentials for Childhood is to use data to inform prevention action. As such, California used Adverse Childhood Experiences (ACE) data from their Behavioral Risk Factor Surveillance System (BRFSS) to better understand the issue in their state[14]. BRFSS is an ongoing telephone survey of adults ages 18 years and above. Data regarding health-related risk behaviors and events are collected at the state level. The ACE study questions are included in an optional BRFSS module, which asked respondents to retrospectively report on experiences of child abuse and other forms of family challenges (e.g., having a parent with a mental illness or substance use issue) that they may have experienced before the age of 18. CDC does not currently provide direct funding to implement the ACE module, but the questions are available for states to use and over 30 states and the District of Columbia have collected this information to date.

California presented ACE data on the prevalence of early adversity like child abuse in their state to their legislature and its related impact on child development and achievement, health, and wellness across the life course. In response, California banned suspensions from school for young children because of "willful defiance," recognizing that keeping young children in school can help buffer their early experiences of adversity and can help them to achieve their maximal health and life potential.

DATA GAPS AND LIMITATIONS

In general, comprehensive information on the circumstances surrounding why an injury occurred is not available in most systems. This information can inform the development of prevention strategies. For younger children, this is particularly important since the actions and behaviors of parents or caregivers can increase risk.

For national systems, the collection, compilation, and review of injury data systems can be complex and time consuming, and it may take several years before high quality data are available for analysis. This lack of timely data hinders the field's ability for program evaluation, identification of emerging issues, and quick data-driven responses.

For many injury surveillance systems, rates are calculated with population denominators. While this can be useful to make some comparisons, this is not always the ideal way to understand populations at risk. For example, the number of injuries related to specific sports will depend on participation rates, which can vary by age, sex, and geographic region. This information is not readily available at the national level, so estimated injury rates per population should be interpreted with caution.

Most of the systems described here provide national level data and estimates, but injury and violence incidence vary by geographic region. States, counties, and cities are best informed with data from their communities, not always by national data. Data at the sub-national level are not always available or accessible by federal agencies. Most states collect hospital inpatient data, mainly for administrative and management purposes, but fewer have emergency department data. Furthermore, definitions, completeness, and quality can vary across states, which make combining data challenging.

FUTURE ISSUES

In the upcoming years and decades, several issues will affect injury and violence surveillance systems for children. On October 1, 2015, health-care delivery organizations began coding their morbidity patient information using the *International Classification of Diseases, Tenth Revision, Clinical Modification (ICD-10-CM)*. The new framework improves on the 9th Revision in several ways including expanding injury codes, creating combination diagnosis/symptom codes to reduce the number of codes needed to fully describe a condition, and adding information relevant to ambulatory and managed care encounters. At this point, the impact of this new coding framework is unclear. When ICD-10-CM coded data become available, there will need to be a comprehensive assessment to understand how this affects reporting of injury cases and external causes.

There are new opportunities to expand how injury and violence data are collected, including opportunities to explore non-traditional sources of data. The development of electronic medical record (EMR) systems in the United States could transform the implementation of surveillance systems that rely on health care data. There is the potential to dramatically improve the efficiency and timeliness of data collection and access. Data from telemedicine and web-based outlets such as Google searches, Facebook, and Twitter could provide quick and useful findings on factors related to injury and violence.

There will be advances in technology-driven approaches to survey data collection. Face to face or telephone-based interviews may be replaced or supplemented with web-based surveys, panels, and applications. These new approaches could automate the process, which would reduce the time needed and remove human error and inconsistencies. This is most applicable to teenagers and young adults who are more likely to directly participate in surveys, and applies to all areas of public health, not just injuries and violence.

ADDITIONAL RESOURCES

- NCIPC maintains an inventory of national injury data systems (http://www.cdc.gov/injury/wisqars/InventoryInjuryDataSys.html). This list includes numerous federal data systems that provide nationwide injury-related data. Each data system is listed along with the lead agencies and associated web sites. This list is updated periodically by NCIPC and can help injury and violence practitioners and researchers identify available datasets of interest. Many systems can be accessed online or allow for full datasets to be downloaded for offline analyses.

- NCIPC developed and maintains WISQARS (Web-based Injury Statistics Query and Reporting System) https://www.cdc.gov/injury/WISQARS. WISQARS is a free interactive online database that includes modules on fatal injury data from death certificates, nonfatal injury data from emergency department visits, violent deaths, cost of injury reports, and fatal injury mapping. These modules are updated with new data as they become available. Researchers, the media, public health professionals, and the public can use WISQARS to learn more about unintentional and violence-related injury in the United States.

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Environmental Hazards

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Environmental hazards found in the air, water, soil and other media are affecting health in adults and children worldwide, contributing to chronic illnesses and affecting quality of life. Through CDC surveillance systems and partnerships with local, state, and other federal agencies, data are collected and analyzed to study the associations between exposure and adverse health outcomes to provide evidence to help reduce the impact of environmental hazards.

PUBLIC HEALTH IMPORTANCE

Environmental factors play an important role in human health. These factors represent a broad spectrum of exposures and hazards such as chemical and physical agents, biological toxins found in air, water, soil, and other environmental media. All humans are affected in some way by these environmental factors in their daily lives when outdoors and indoors, at work, at home or at play. In the United States, environmental factors have been associated with many of the leading causes of death including the five leading causes for 2013 and 2014: diseases of the heart, malignant neoplasms, chronic lower respiratory diseases, unintentional injuries, and cerebrovascular diseases (Xu et al., 2013; Kochanek et al., 2014). A similar trend is observed globally and, according to the World Health Organization (WHO), an estimated 12.6 million deaths each year are attributable to unhealthy environments and environmental risk factors (WHO, 2016). Environmental hazards can also have profound effects on the health and well-being of children. Worldwide, around three million children under the age of five die due to environment-related diseases each year (WHO, 2016). Aside from this devastating loss of life, environmental hazards can have additional impacts on quality of life.

The progression by which environmental factors or agents can lead to an adverse health outcome is best illustrated by the "hazard-exposure-outcome axis" conceptual model described by Thacker et al., (1996, Figure 1). The conceptual model highlights the key steps necessary to identify agents that may develop into adverse outcomes. For each step, it is therefore important to conduct surveillance to assess the presence and distribution of an environmental factor or agent and its potential human health effects.

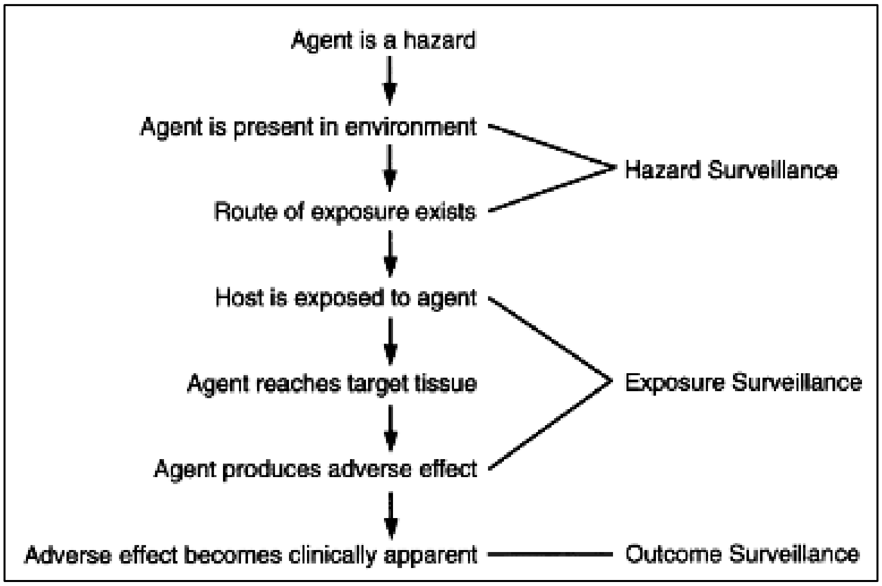
More specifically, hazard surveillance involves the assessment of the occurrence, distribution, and trends in levels of hazards responsible for disease and injury, such as specific air pollutants. Historically, the type and methods of hazard data collection have often been developed for and guided by enforcement activities and not specifically designed for public health surveillance. For example, the US Environmental Protection Agency (EPA) collects specific data to assess compliance with the federal drinking water standards; however, the benefit of this data for environmental health surveillance can be limited because the data can vary depending on the consistency of collection protocols and may not be available unless the maximum contaminant levels are exceeded (McGeehin et al., 2004).

Exposure surveillance involves the monitoring of individuals or populations for the presence of an environmental agent after they have come into contact with it but possibly before any clinically apparent effects (Wegman et al., 1992). For example, data collected by the EPA air quality monitoring network, that was established to monitor compliance with their National Ambient Air Quality Standards, can be linked in individual addresses to estimate human exposure to specific air pollutants. Another approach that more accurately represents direct exposure to hazardous agents is through biological monitoring ("biomonitoring") of the amounts of a specific chemical or biological agent or a related chemical or biological indicator ("biomarker") in the human body (Pirkle et al., 1995; Calafat, et al., 2006).

The last surveillance component in the Thacker model is the monitoring of health outcomes which represents more traditional public health surveillance efforts similar to those conducted for infectious diseases and, more recently, including noninfectious disease and condition surveillance. Examples include disease registries and administrative data systems, such as hospital discharge data. Environmentally related outcome surveillance is the monitoring of adverse health effects of environmental hazards and exposures after they have become clinically apparent. There has been a growing effort to follow chronic diseases with suspected links to an environmental etiology such as asthma and other respiratory diseases, neurological diseases (e.g., Parkinson's disease) and cancers (e.g., bladder, liver). The effect of an environmental hazard on individual health is influenced by multiple factors including the dose of the hazard, the duration of exposure, exposure route, and individual factors (e.g., age, genetics, health status).

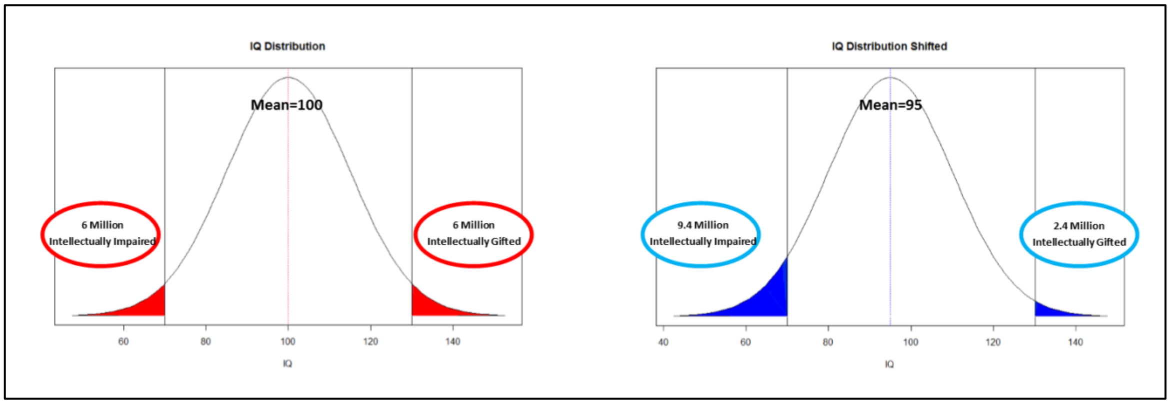
Conducting surveillance of hazards, exposures, and relevant outcomes is critical to environmental public health prevention and practice. In this context, the conceptual model of Thacker et al., (1996, Figure 1) is an important framework to apply to assess the hazard present in an environment, understand the population exposed to the agent, and the potential role of the agent in developing clinically apparent adverse health effects. The national surveillance systems and surveys implemented by the National Center for Environmental Health at the Centers for Disease Control and Prevention are paramount to our understanding of environmental exposures temporally and spatially. For this chapter, three national surveillance systems that monitor children's exposure to environmental hazards, exposures, and related health outcomes are described.

Figure 1. Hazard-exposure-outcome axis conceptual model described by Thacker et al., (1996).



Conducting surveillance is also integral to understanding the effect that the environmental factors may have on vulnerable populations, such as children. The public health importance of monitoring human exposure to environmental hazards at the population level can be illustrated using the example of childhood lead exposure. In an international-pooled analysis of children, a blood lead level between 2.4 and 10 µg/dL was associated with a decrease in intelligence quotient (IQ) of 3.9 (95% CI 2.5-5.3) points (Lanphear et al., 2005). This small change in IQ may be difficult to appreciate in an individual and may seem inconsequential. However, the effects of such a deficit are illustrated in Figure 2 which depicts two standard normal (bell curve) distributions for IQ. As shown below, when average IQ (defined as mean=100 in the panel on the left) of a population is shifted only 5 points lower (defined as mean=95 in the panel on the right), there's a 57% increase in the intellectually impaired population and a corresponding decrease in the intellectually gifted population (Weiss, 1997).

Figure 2. Illustration of the potential effects of exposure to environmental hazards at the population level using the example of blood lead and children's IQ (Weiss, 1997).



Children are highly susceptible to adverse effects associated with many environmental exposures (NIEHS, 2016). Childhood is a time of rapid growth and development that is marked by changes in organ system functioning including: metabolic capabilities, physical size, and behaviors that can dramatically modify the effects of environmental toxins (Ginsberg et al., 2004). Examples of how children are at increased risk of adverse effects from exposure to environmental hazards are:

- Children eat more food, drink more water, and breathe more air per kilogram (kg) of bodyweight than adults, resulting in greater exposure per kg to toxic substances (EPA, 1996).
- Children have physiologic differences compared to adults and these differences can affect absorption, distribution, metabolism, and elimination of toxicants (Ginsberg et al., 2004)
- Children exhibit hand-to-mouth and hand-to-object behaviors, greatly increasing the risk of exposure to toxicants via ingestion (ATSDR, 2013).

Additionally, across the lifespan, individuals experience several "critical windows of vulnerability" – periods during which exposure to a toxic substance can have a more detrimental effect than if the exposure had occurred at another time – and these critical windows often occur during specific stages of early development (Nijland et al., 2008). Several such windows occur during early childhood and adolescence which corresponds with the concept of "developmental origins of adult disease" (Barker, 2004). This concept suggests that toxic exposures during early development (both pre- and post-natally) can have profound effects on health status later in life which is an active area of research and public health interest (Heindel et al., 2017).

Children's health, as it relates to the environment, has been a rapidly growing topic of research and discussion in recent years. Since the 1994 publication of *From Data to Action,* the number of articles published yearly on the topic of children's environmental health has increased from 431 in 1994 to 3,018 in 2016. Historically, children's environmental health research has focused primarily on the effects of exposures to toxic metals including lead, mercury, and arsenic and second-hand tobacco smoke. In recent years, this focus has expanded to include synthetic compounds, such as polychlorinated biphenyls (PCBs), per- and poly-fluorinated alkyl substances (PFAS), and other environmental chemicals that are emerging as potential health threats. With thousands of chemicals produced and used in commerce today, in addition to the various known pollutants and toxins in the environment, it is nearly impossible to know exactly how many substances we are used to at a given time or to assess potential health effects specific to each of them. Moreover, it is difficult to ascertain how these chemicals will impact children's health; however, research into these questions is ongoing and important to public health. Environmental public health surveillance is an important source of information to help answer some of these critical questions (Macdonald et al., 1996).

HISTORY OF DATA COLLECTION

National Health and Nutrition Examination Survey (NHANES)

The National Health Survey Act, passed in 1956, provided the legislative authorization for a continual survey to provide current statistical data on the amount, distribution, and effects of illness and disability in the United States. To fulfill the purposes of this act, it was recognized that data collection would involve at least three sources: 1) the people themselves by direct interview; 2) clinical tests, measurements, and physical examinations on sample persons; and 3) places where persons received medical care such as hospitals, clinics, and doctors' offices. The National Health Examination Survey (NHES) was conducted by the National Center for Health Statistics in three parts between 1959 and 1962: NHES I focused on adults (ages 18-79 years); NHES II focused on children (ages 6-11 years); and NHES III focused on youth (ages 12-17 years). In the early 1970s, this survey system became known as the National Health and Nutrition Examination Survey (NHANES) and is still conducted today. Initially conducted in multi-year cycles (e.g., 1971-74, 1976-80, and 1988-94) (CDC, 2011a), NHANES became a continuous survey in 1999, sampling the US population annually and releasing data in two-year cycles. The sampling plan follows a complex, stratified, multistage, probability-cluster design to select a representative sample of the civilian, noninstitutionalized population in the United States based on age, sex, and race/ethnicity.

NHANES collects information about a wide range of health-related behaviors, performs physical examinations, and collects samples for laboratory tests. The NHANES protocol includes a standardized physical examination in a mobile examination center. As part of the examination component, blood is obtained by venipuncture from participants aged 1 year and older, and urine specimens are collected from participants aged 6 years and older (3 years and older after 2014). NHANES data from children have been used to assess growth and development (e.g., age-specific growth charts) and to evaluate selected biochemical indicators of nutritional status. Additional information on the design and conduct of the NHANES survey is available at http://www.cdc.gov/nchs/nhanes.htm. NHANES data including interview, physical examination, and laboratory results are publicly available from the NHANES website.

Environmental chemicals are measured in whole blood, serum, or urine specimens collected as part of the examination component of NHANES. The participant ages for which a chemical is measured varies by chemical group, in part because of limitations in the amount of blood that can be drawn from young children and due to the feasibility of collecting urine from non-toilet trained children. Most of the environmental chemicals are measured in randomly selected subsamples within specific age groups. The subsamples are designed so that the results will be representative of the US population.

Most NHANES datasets are publicly available and can be used to examine trends in chemical exposures over time, associations between levels of chemicals in the general population or subgroups with dietary, demographic, lifestyle, and other data collected during the examination or interviews. Health outcome data are mostly self-reported and limited in nature. To preserve the privacy and confidentiality of survey participants, NHANES does not provide any geographic or residential information in the public-use data files. Researchers who wish to gain access to this and other potentially identifiable data must submit a detailed proposal for the intended analysis and, if the proposal is approved, the data analysis can only be conducted at one of the Research Data Center locations under NCHS supervision.

Since 1976, NHANES has measured blood lead in the US population, and this exposure surveillance data has played a large role in regulations and public health interventions to decrease sources of lead in the environment (Annest et al., 1983). NHANES continues to measure blood lead levels in a representative sample of the US population, including adults and children. Other environmental chemical measurements were added in 1999. Because of difficulties obtaining specimens from young children, fewer chemicals are measured in children compared to adults; however, measurements of blood lead levels and cotinine (a marker of tobacco smoke exposure) in children have been very useful to examine population trends over time and assess the effectiveness of exposure reduction efforts on a population basis.

Childhood Blood Lead Levels

The Lead Contamination Control Act of 1988 authorized CDC to initiate efforts to eliminate childhood lead poisoning in the United States by supporting state and local agencies to develop comprehensive Childhood Lead Poisoning Prevention Programs (CLPPPs). The purpose of these programs is to identify and monitor children at increased risk for lead exposure through enhancing blood lead screening efforts, ensuring referral for medical and environmental intervention for lead exposed children, and providing education about childhood lead poisoning prevention (MMWR, 1992). In February 1991, the Department of Health and Human Services announced its *Strategic Plan for the Elimination of Childhood Lead Exposure* (HHS, 1991). Surveillance of blood lead levels in children was a key component of the plan. A blood lead test is currently the best way to identify and monitor children's exposure to lead. From 1991 to 2012, according to a widely-adopted CDC policy, children were identified as having a blood lead "level of concern" if a laboratory blood lead test result indicated 10 or more micrograms per deciliter (µg/dl) of lead in blood. This threshold value was recommended as the "action level" to prompt public health action by state or local health departments for individual case management and follow-up activities (CDC, 1991). However, more recent scientific evidence supports the concept that there is no safe blood lead level as even small amounts of lead can be harmful to a child's developing brain (Schwartz, 1994; Lanphear et al., 2005). Additionally, continuous analyses of US population-based NHANES data show blood lead levels decreasing over time. In 2012, CDC's former Advisory Committee on Childhood Lead Poisoning Prevention (ACCLPP) recommended elimination of the term "level of concern" and shift its priorities to primary prevention (ACCLPP, 2012). ACCLPP also recommended using a reference value based on the estimated 97.5 percentile of the blood lead distribution among children aged 1–5 years calculated from two 4-year cycles of NHANES data. At that time, a blood lead "reference value" of 5 µg/dL was established to define when a child is exposed to higher levels of lead than the general population of children in the US.

Surveillance of children's blood lead levels provides information on how well we are protecting children from exposure to lead and also provides critical information needed to identify and care for those children who are already exposed. State and local lead poisoning prevention programs initiate public health actions at varying blood lead levels based on applicable state/local laws and regulations as well as available resources. Case management for elevated blood lead levels involves follow-up testing, parental education and counseling, and may include such activities as home visits to investigate the potential sources of exposure in a child's environment and medical interventions, depending on the level of the blood lead test result (AAP, 2016). Blood lead screening and surveillance data also provide the foundation for targeting prevention activities to high risk areas.

CDC's Childhood Lead Poisoning Prevention Program began collecting surveillance data on blood lead levels in children less than 16 years of age in 1995 (Pertowski, 1994). Also in 1995, the Council of State and Territorial Epidemiologists (CSTE) designated elevated blood lead levels as the first noninfectious condition to be notifiable at the national level. Notifiable diseases and conditions are reportable to CDC on a voluntary basis for nationwide aggregation and monitoring (https://wwwn.cdc.gov/nndss/data-collection.html). A key component for surveillance of blood lead levels is a law or regulation at the state-level requiring that laboratories report all blood lead test results to the state health department (Pertowski, 1994).

Environmental Public Health Tracking

In 2000, The Pew Environmental Health Commission released a report on the state of environmental health in the United States calling for the creation of a coordinated public health system to improve response to environmental threats (Pew, 2000). The report described that the environmental public health system was fragmented and neglected. At that time, no systems existed at the state or national level to track many of the exposures and health effects that may be related to environmental hazards. In addition, most existing local health department tracking systems were not organized into a network, making it difficult to identify and monitor associations or to extrapolate findings on a larger scale. One of the recommendations made by the report was to establish a national environmental public health tracking network to link information on environmentally related diseases, human exposures, and environmental hazards. The information from this tracking network would be used to respond to and help reduce the burden of these diseases on the nation's population (McGeehin et al., 2004).

Most of the public health surveillance in place at that time focused on infectious diseases. A more comprehensive national approach to collect and analyze noninfectious disease data and the integration with environmental hazard monitoring and exposure data was therefore needed (Macdonald et al., 1996). Healthy People 2000 established objective 11.16 to establish and monitor plans to "define and track sentinel environmental diseases including: asthma, heatstroke, hypothermia, heavy metal poisoning, pesticide poisoning, carbon monoxide poisoning, acute chemical poisoning, and methemoglobinemia in at least 35 states." By the time Healthy People 2010 objectives were being developed, at least 51 jurisdictions had surveillance activities occurring for at least one of 12 environmental conditions (CDC, unpublished data, 1998), but these efforts were largely unfunded.

The Environmental Public Health Tracking Program ("Tracking Program") was formed at CDC in 2002, when Congress authorized funding with a goal of developing a nationwide network of integrated health and environmental data that can help inform actions to improve the health of communities. The Tracking Program now represents a large network of people and information systems that deliver a core set of health, exposure, and hazards data, information summaries, and tools to enable data analysis and visualization. The Tracking Program currently includes funded partners from 25 states and one city and includes collaboration with academic and other federal partner agencies.

Following the Thacker model (Figure 1), the Tracking Program – in collaboration with federal, state, and local partners – collects, integrates, analyzes, interprets, and distributes data from environmental hazard monitoring, human exposure surveillance, and health outcomes surveillance. The data are collected from multiple sources and disseminated through a publicly available, Web-based network for exploration and visualization. This National Environmental Public Health Tracking Network ("Tracking Network") is the cornerstone of the Tracking Program. In addition to a Tracking Network at the national level, funded partners are also tasked to operate a tracking program and develop a tracking network at the state and local levels. Public health officials and practitioners have used data from the tracking networks to identify trends and community needs as well as to inform, improve, or evaluate interventions, policies, and programs designed to prevent or reduce the impact of environmental hazards on health. Currently, data related to children's exposures range from information about the outdoor environments to exposure biomonitoring data and health outcomes including measures of asthma, cancer, and developmental disabilities.

CDC SURVEILLANCE ACTIVITIES

NHANES and The National Report on Human Exposure to Environmental Chemicals

CDC's Division of Laboratory Sciences in the National Center for Environmental Health conducts activities to monitor human exposure to environmental chemicals including measurements on the NHANES biological specimens. These measurements in human samples, referred to as biomonitoring, of specific chemicals or their metabolites are compiled in CDC's *National Report on Human Exposure to Environmental Chemicals* (the *Report*). The *Fourth Report* released in 2009 has been updated periodically as *Updated Tables*. Each *Updated Tables* is cumulative so that the earlier as well as the most recent data are included. Nationally representative biomonitoring data are provided in table format (available at: www.cdc.gov/exposurereport). For each chemical, a data table displays descriptive statistics (e.g., geometric means, selected percentiles) by category (total population, age group, sex, and race/ethnicity) for each NHANES two-year survey cycle. The most recent *Updated Tables, January 2017* provided data for more than 300 environmental chemicals, some of which have been measured since 1999.

Examples of some environmental chemicals, biological specimens in which they are measured, and ages of children tested are shown in Table 1. As mentioned previously, biomonitoring data in children are notably limited by the difficulties in collecting specimens from younger children.

Table 1. Some Environmental Chemicals Measured in Children by NHANES.

Chemical Group (with Examples)	**Biological Specimen**	**Ages**
Secondhand Tobacco Smoke (Cotinine)	serum	≥3 years
Personal Care & Consumer Products & Metabolites (Bisphenol A, Triclosan, Benzophenone-3, Parabens)	urine	≥6 years[1]
Insect Repellent (Diethyltoluamide [DEET] and Metabolites)	urine	≥6 years[1]
Organophosphorus Pesticide Metabolites (Diazinon, Malathion, Chlorpyrifos, and others)	urine	≥6 years[1]
Pyrethroid Insecticide Metabolites	urine	≥6 years[1]
Blood Metals (Cadmium, Lead, Manganese, Mercury, Selenium)	whole blood	≥6 years
Urine Metals (Arsenic, Cadmium, Lead, Mercury, and others)	urine	≥6 years[1]
Phthalate Metabolites	urine	≥6 years[1]
Perfluoro- and Polyfluorinated Alkyl Substances [PFAS, previously called PFCs] (PFOS, PFOA, and others)	serum	≥12 years
Phytoestrogens and Metabolites	urine	≥6 years
Polycyclic Aromatic Hydrocarbon [PAH] Metabolites	urine	≥6 years[1]
Flame Retardants (Polybrominated Diphenyl Ethers [PBDE])	serum	≥12 years
Polychlorinated Biphenyl Compounds [PCB]	serum	≥12 years
Dioxins, Furans, and Chlorinated Persistent Pesticides	serum	≥12 years
Volatile Organic Compounds (Benzene, Toluene, Xylene, and others) Volatile Organic Compound metabolites	whole blood urine	≥12 years ≥6 years[1]

[1] Beginning in 2015, urine specimens were collected on children aged 3 years and older

The purpose of the *Report* and *Updated Tables* is to provide unique exposure information to scientists, physicians, and health officials to help prevent exposure to some environmental chemicals. Because it provides ongoing assessment of nationally representative biomonitoring data, the *Report* and *Updated Tables* is a surveillance tool that can help detect, diagnose, treat, and prevent harmful environmental chemical exposures. The exposure information has several specific public health uses:

- To determine which chemicals get into Americans and at what concentrations.
- To establish reference ranges that can be used to determine whether a person or group has an unusually high exposure. This information is especially helpful to identify population groups that merit further assessment of exposure sources or health effects.
- For chemicals with a known toxicity level, to determine the prevalence of people with levels above those toxicity levels.
- To determine whether exposure levels are higher among potentially vulnerable groups, such as certain racial/ethnic groups, pregnant women, and children.
- To track, over time, trends in levels of exposure of the population.
- To assess the effectiveness of public health efforts to reduce exposure of Americans to specific chemicals.
- To set priorities for research on human health effects.

In some cases, chemicals are no longer measured but have data that are included in the *Updated Tables* for historic purposes, for example: several fungicides and organophosphate pesticides; carbamate pesticides; and the herbicide atrazine.

Childhood Blood Lead Surveillance (CBLS) System

The CDC Childhood Lead Poisoning Prevention Program compiles blood lead surveillance data for children less than 16 years of age into a national Childhood Blood Lead Surveillance (CBLS) system. More information is available at: https://www.cdc.gov/nceh/lead/data/index.htm. CBLS is currently composed of data from 35 funded state and local health departments that report a common set of required variables to CDC on a quarterly basis (CDC, 2016b). States that are not funded by CDC can also send data on the same set of required variables on a voluntary basis for inclusion in CBLS. The core set of required variables, developed by

CDC in collaboration with state partners, includes child-specific information on demographics, blood lead test results, and other information. The surveillance system was designed not only to provide ongoing collection and tracking of children's blood lead levels, but also to provide the opportunity to: identify and confirm cases of elevated blood lead levels (BLLs), ensure appropriate medical management, and investigate and remediate lead hazards in the child's home environment.

State and local childhood blood lead surveillance systems are passive surveillance systems that rely on healthcare provider-initiated testing and BLL test results reported by private and public laboratories. Mandatory laboratory reporting of all blood lead test results is an essential element of successful state-based childhood lead surveillance systems. Blood lead reporting requirements are set by each state and vary across jurisdictions; by 2002, a total of 29 states mandated reporting of all BLLs. In states where all blood lead level test results are not reportable, there is no denominator data available to understand the extent of testing rates or to accurately estimate prevalence of blood lead levels greater than the reference value.

CDC publishes CBLS surveillance summaries describing trends in children's BLLs to help understand the burden of childhood lead exposure in the US. For example, from 1997 to 2001, there was a sharp decrease in the number of children with BLLs ≥10µg/dL with a continued decrease until 2008 when stabilization occurred. By 2010, CBLS was also monitoring children with BLLs ≥5µg/dL which have also shown a consistent decline (CDC, 2003; CDC, 2016b). It is important to note that the CLPPPs were defunded by Congress in 2012 and much of the existing surveillance infrastructure was lost; funding was restored in 2014 and the number of children being tested for lead exposure is once again on the increase as program infrastructure is reestablished.

National Environmental Public Health Tracking Network

CDC's National Environmental Public Health Tracking Program emphasizes the dissemination of actionable data to public health practitioners, policymakers, and communities. The Tracking Program's National Environmental Public Health Tracking Network ("Tracking Network"), is a web-based data and information system. CDC first launched the national Tracking Network in 2009 (https://ephtracking.cdc.gov/showHome.action) along with tracking networks in 16 states and New York City, becoming the first surveillance system to offer environmental data and public health data in a single, integrated repository. The Tracking Network continues to collect standardized data provided by national, state, and local partners and currently includes 21 health outcomes, environmental hazards, exposures, and other risk factors including air quality, asthma, birth defects, cancer, chronic obstructive pulmonary disease, community water, developmental disabilities, heart disease, heat stress illness, pesticide exposures, populations and vulnerabilities, and reproductive and birth outcomes.

A primary goal of the Tracking Network is to allow the exploration of data on demographics, environments, and health effects. A main feature of the Tracking Network is to allow a user to explore trends and possible associations between environmental and health data. Environmental and health experts from states, cities, and other agencies helped CDC develop the indicators and measures in the Tracking Network. These decisions were based on many factors including priorities for state and local health departments, priorities for CDC, the strength of scientific evidence, and whether or not data were available for a particular topic. Since inception, there has been enormous progress in the amount and types of data collected with great effort placed on validating and integrating available data to be used meaningfully by diverse users. The Tracking Program has grown and adapted to the changing public health landscape in response to the needs of a broader audience, including public health practitioners, researchers, consumers, and community members.

Data on the Tracking Network can be visualized using the Data Explorer via our public web-based network by year and geography, and data on children can be visualized separately for some of the measures. The data can also be used to: 1) describe temporal and spatial trends in disease and potential environmental exposures; 2) identify populations most affected; 3) generate hypotheses about associations between health and environmental exposures; and 4) develop, guide, and assess the environmental public health policies and interventions aimed at reducing or eliminating health outcomes associated with environmental factors.

In addition to the Data Explorer, there are multiple tools and features on the Tracking Network for data visualization including “Info by Location,” a tool that provides data in infographic form, downloadable datasets, communications tools, and an Application Program Interface (API).

GENERAL FINDINGS

Each of the CDC Surveillance Systems for children’s environmental health described above has its own set of strengths, weaknesses, and intended uses (Table 2).

Table 2. Summary of Data Characteristics: CDC Systems for Children's Environmental Health Surveillance.

Characteristic	**Data System**		
	NHANES	**CBLS**	**EPHT**
Data Steward	Division of Laboratory Sciences	Childhood Lead Poisoning Prevention Program	Environmental Health Tracking Program
Year Collection Initiated	1976	1995	2002
Population	Stratified, multistage, probability-cluster design survey of US adults and children.	US children <16 years of age from various locations using a combination of universal and targeted screening approaches.	US adults and children captured in environmental hazard, human exposure, and health effects datasets.
Source of Data	NCHS, National Health and Nutrition Examination Survey.	State and local health departments.	National, state, and local health and environmental agencies.
Types of Data	300+ environmental chemicals or their metabolites.	Child-specific blood lead levels and relevant medical and environmental follow-up data.	21 health outcomes, environmental hazards, exposures, and other risk factors. Health data from sources such as: administrative datasets, vital records, national surveys, registries. Environmental data from sources such as: USEPA air monitoring datasets, state- and local-level water quality data, meteorological datasets.
Strengths	Nationally-representative sample of the civilian, noninstitutionalized population in the	Population-based electronic reporting of child-specific laboratory test results linked to	Provides a national repository for storing and linking environmental hazard, exposure,

	United States based on age, sex, and race/ethnicity.	individual factors and follow-up actions; allows for analysis at local level (county, zip code, census tract).	and health outcome data, as well as other risk factors.
Weaknesses	Not statistically reliable in subsample analysis with small numbers; unavailable for analysis below regional level.	Not generalizable to the US population or comparable across locations due to variations in testing and reporting requirements.	Limited data available at the individual level for purposes of follow-up of environmentally-related conditions.
Intended Uses	Estimates of exposure to a large number of environmental chemicals for US population and certain subgroups.	Identify high risk geographic areas; case management and monitor trends at state and local level; assess program objectives; inform policy makers.	Publicly available web-based network for visualization and exploration of links between hazards, exposures, and health outcomes.

NHANES measures hundreds of chemicals in various biological matrices and is an invaluable tool for showing trends in environmental health data for the entire US population, including both children and adults. This nationally representative survey system provides important information on the distributions of human exposure to environmental chemicals in the US population over time. The information can be used to establish reference levels for exposure to environmental hazards, such as lead, which will be discussed further in the “Using Data for Action” section. However, NHANES does not provide statistical estimates for smaller geographic areas or specific populations. Because NHANES was developed to provide a representative survey sample of the US population, these data are therefore not useful to examine exposure at the local level or to identify areas at high risk of exposure in the US.

Surveillance systems designed to collect and analyze data on specific exposures or conditions can be used to monitor trends at the local level and identify areas (“hot spots”) at high risk of exposure. For example, the CBLS system was developed to establish a national repository for state and local data used to identify and monitor individual cases of childhood lead exposure. CBLS is based on electronic reporting of blood lead levels linked to child-specific demographic and follow-up information. Due to differences in testing and reporting requirements at the state and local levels, however, these data cannot be used to estimate national prevalence or to compare across locations.

The National Environmental Public Health Tracking Network provides a national repository for storing and linking environmental hazard, exposure, and health outcome data, as well as other risk factors that may be used to improve human health. It is a tool that provides a publicly available web-based portal for visualization and exploration of links between hazards, exposures, and health outcomes. Data and tools may be used for visualization and exploration of links between hazards, exposures, and health outcomes. Limited data are available, however, at the individual level for purposes of follow-up of environmentally-related conditions.

USING DATA FOR ACTION

NHANES

Data generated from the National Exposure Report biomonitoring efforts, in collaboration with NHANES, have been used effectively to assess the impacts of multiple public health policies implemented to reduce the US population to numerous environmental chemicals.

- ***Blood Lead Levels***

  Over the past forty years, blood lead levels in the US population have declined dramatically due to the elimination of lead from gasoline, paints, and other consumer products. NHANES blood lead data collected over several decades has documented the effectiveness of these policies (Brown & Margolis, 2012). In addition, NHANES help to establish important risk factors for elevated blood lead levels in US children including: race/ethnicity (non-Hispanic black and Mexican-American), housing age (pre-1946 and pre-1973), and poverty level (family income at or below poverty income ratio). This information can be used to identify areas that may be at higher risk for exposure due to the prevalence of these known risk factors. Blood lead levels from NHANES are currently used to assess progress towards the Healthy People 2020 Goals to: 1) reduce blood lead levels in children aged 1–5 years; and 2) reduce the mean blood lead levels in children (https://www.healthypeople.gov/2020/data-search/). For example, the HP2020 target for mean blood lead in children (1.6 µg/dL) was met in 2005-06 when NHANES found mean blood lead in children equal to 1.5 µg/dL; in 2011-12, the mean blood lead in children was equal to 1.0 µg/dL. The HP2020 target for blood lead levels in children (5.2 µg/dL) was met in 2009-2012 when NHANES found the 97.5 percentile in children ages 1–5 years equal to 4.3 µg/dL.

- ***Serum Cotinine***

  Serum cotinine, a metabolite of nicotine, is found in cigarette smokers and non-smokers exposed to secondhand smoke (SHS). Measurement of cotinine levels in human tissues provides irrefutable evidence that non-smokers can be exposed to the many harmful chemicals in tobacco smoke. Since 1988, NHANES has reported serum cotinine results in the US population ages 3 years and older. These data were used to demonstrate that a serum concentration below 10 ng/mL indicates SHS exposure (Pirkle et al., 1996) and that SHS exposure was widespread in the US population. In addition to studies of serum cotinine in vulnerable non-smoker populations (e.g., children, pregnant women), population-based data from NHANES was used to support regulations and policies to eliminate smoking in public places and to demonstrate effectiveness of these interventions. As work and public places have banned smoking, serum cotinine in non-smokers has dramatically declined, but children and adolescents have relatively higher levels of serum cotinine (Pirkle et al., 2006).

- ***Phthalates***

  Phthalates are a group of chemicals with widespread use as plasticizers, solvents, fragrances, and adhesives in paints, personal care products, pharmaceuticals, and industrial plastics. Phthalates undergo limited human metabolism and the urinary metabolites can be measured to assess human exposure. Since 1999, various phthalate metabolites measured in NHANES have provided evidence of widespread human exposure. These data, along with animal and other human studies, led to concerns that children may be particularly vulnerable to the potential adverse health effects. One result was that the Consumer Products Safety Commission (CPSC) convened an advisory panel that ultimately recommended banning several phthalates from children’s toys and child care articles (CHAP, 2014).

Lead Poisoning Prevention

Forty years ago, more than 99% of the US population had elevated blood lead levels by today’s standards (>5 µg/dL). The Lead Contamination Control Act of 1988 had a tremendous impact on public health because it supported the creation of childhood lead poisoning prevention programs to identify, monitor, and respond to cases of elevated blood lead levels in US children. Between 1991 and 2006, the percent of US children ages 1 to 5 years old with blood lead levels >10 µg/dL fell from 4.4% to 0.6%. We can attribute much of this remarkable public health success to many of CDC’s efforts including supporting state and local health departments to develop prevention and surveillance programs to identify and monitor where children are most likely to be exposed to dangerous levels of lead, developing safe renovation guidelines, and educating parents, the general public, and health care providers. Some examples of recent success stories include:

- ***New York City***
  In New York City, over 300,000 children under 6 years of age are tested annually. Since 2010, the number of children with blood lead levels at or above the 5 micrograms per deciliter (µg/dL) has decreased from 13,000 children in 2010 to 6,000 children in 2014. The lead surveillance program used small-area analyses to identify neighborhoods with higher blood lead levels. Within one neighborhood with a high rate of lead poisoning, the vast majority of children with the highest blood lead levels resided in an area home to a large Hasidic Jewish community. The lead program collaborated with local political and religious leaders and worked with trusted community based organizations to increase awareness about childhood lead poisoning prevention and all information was translated into Yiddish.

- ***Rhode Island***
  In 2011, four core cities in Rhode Island reported having three times the number of children with elevated blood lead levels ≥10 µg/dL compared to other Rhode Island cities and towns. An estimated 80% of Rhode Island homes were built before 1978 and likely contain lead-based paint hazards which can create lead dust hazards during renovations to these homes. Rhode Island implemented the US EPA's 2010 Lead-Based Paint Renovation, Repair and Painting (RRP) Rule that requires workers to be certified and trained in the use of lead-safe work practices, and requires renovation, repair, and painting firms to be licensed by the department of health. Following the first full year of the program, there were 225 fewer children in Rhode Island with elevated blood levels and 180 cases of RRP violations were prosecuted for failure to obtain lead-safe certificates for rental units.

- ***Louisiana***
  Louisiana state data demonstrated that some children attending Women and Infants Special Nutrition Projects (WIC clinics) do not receive routine health prevention services, and therefore are unlikely to receive blood lead testing at a medical clinic. The Louisiana lead program partnered with a New Orleans area WIC clinic to increase lead testing rates of children in Louisiana and to determine the percent of children tested during WIC clinic visits who had blood lead levels ≥5 µg/dL. By matching WIC

client lists with surveillance data, the program demonstrated that WIC clinics are an efficient way to screen high-risk children who would not otherwise be tested. The program ensured blood lead testing for 1,395 children, 81% of whom had never had a previous test and has expanded to include WIC clinics in other high-risk areas of the state.

- ***Washington***

  The Washington State Lead Poisoning Prevention Program convened an expert panel to develop risk-based childhood lead screening recommendations for use by clinicians in the state. The Program partnered with the Refugee Health Program to screen all refugee children between 6 months and 16 years of age as part of the refugee resettlement program. Over a three-year period from 2013 to 2016, they screened 3,275 children. Fourteen percent of the refugee children screened had elevated blood lead levels and 3% with blood lead levels greater than 10 µg/dL. These children were then able to be linked to appropriate follow-up services.

Tracking Network

Data, expertise, technical infrastructure, and other tracking resources have enabled the Environmental Public Health Tracking Network to provide public health practitioners and policy makers at the state and local levels a unique platform of health and environment data. They have been able to use the national, state, and local tracking networks to help assess trends in specific health outcomes, such as increased asthma and children's lead poisoning rates or areas where individuals may be at risk for consuming contaminated drinking water. Use of these data help inform over 400 documented public health actions by our state and local partners of which several are described below. A complete list of success stories can be found here: https://www.cdc.gov/nceh/tracking/successstories.htm.

- ***Oregon***

  Radon is the second leading cause of lung cancer and is the leading environmental cause of cancer deaths in the US. Radon is a colorless, odorless, tasteless radioactive gas; testing is the only way to know if radon levels are high in a building or home. The Oregon Tracking Program and partners developed maps showing radon hazards for areas smaller than counties and used these maps to support public education to encourage in-home radon testing. They published the radon maps on the health department's web pages and on Oregon Tracking's Facebook page. They also sent news releases to media outlets announcing the maps and providing information about radon testing. Media coverage about the maps helped raise public awareness of radon hazards and encourage radon testing. Following the coverage, monthly average visits to the Radon Program's web pages tripled. Data from the American Lung Association of Oregon showed that, within three days of the media coverage, they sold more radon test kits online than they did in the entire year of 2012.

- ***Maine***

  Maine has one of the highest rates of asthma in the country. Maine often has elevated levels of ozone and particulate matter, two common air pollutants that can exacerbate asthma symptoms and trigger asthma attacks. Maine's Tracking Program linked outdoor ozone data with asthma-related emergency department visit data. Using this data, scientists can estimate ozone-related asthma cases both in a community and statewide. The tracking program used this data to identify Mainers who are at high risk for ozone-related asthma exacerbations and shared information to health care professionals to better target people who are most at risk.

- ***Minnesota***

  The Minnesota Tracking Program maintains data on secondhand smoke among nonsmokers for the state. Tracking staff analyzed state data to determine if Freedom to Breathe legislation, passed in 2007, helped reduce residents' exposures to secondhand smoke. Tracking staff found that since 2007 children's exposure to secondhand smoke decreased by 20% and adults' exposures decreased by 25%. Freedom to Breathe legislation remains in place because the tracking program demonstrated that the legislation was associated with a decrease in exposures to secondhand smoke and because there is strong support to keep the smoking bans in Minnesota. In addition, tobacco prevention programs and others have been able to use the tracking data to plan more effective smoking cessation and awareness activities.

- ***Vermont***

  Vermont has one of the highest rates of Lyme disease in the country. Being able to track where ticks are living is one way to monitor how their range may be changing. Because Vermont’s tick surveillance activities involve sampling only a few locations a few times per year, data about the locations and timing of high tick activity are limited. To help improve tick monitoring, the Vermont Tracking Program, in partnership with CDC’s Climate and Health Program, developed a “crowd-sourced” web application called the Tick Tracker. The Tick Tracker can be used by anyone to record tick sightings anywhere in the state and submit reports to the health department. In as little as a minute, they can add the sightings to an online map of Vermont. The map shows where people may need to take extra steps to prevent tick bites when spending time outdoors. Along with the map, the site has links to information about tick-borne diseases and preventing tick bites. The Tick Tracker has been an important new tool in helping educate Vermonters about tick-borne diseases.

DATA GAPS AND LIMITATIONS

Children’s environmental health surveillance activities have provided much needed information to identify geographic areas and vulnerable populations at high risk of exposure to a small number of environmental hazards. More information is needed to fill gaps in our scientific understanding of the effects of environmental hazards on children’s health. Additional research is needed to address knowledge gaps and data needs in children’s environmental health. However, a main limitation of research related to environmental hazards is that it is unethical to purposefully expose children and others to hazardous substances. There will likely never be double-blind, randomized controlled trials to investigate the causal associations between environmental hazards and health effects in humans. Most environmental epidemiology studies, therefore, are observational in nature and designed to address a specific hypothesis or hypotheses.

Children’s environmental health surveillance can fill a critical need for information about this vulnerable population group. Free-living populations are exposed to numerous chemicals and substances simultaneously. Surveillance data can be used to describe the magnitude of the problem, identify populations at high-risk of exposure, and monitor trends over time. Surveillance data can also be used to generate hypotheses about suspected associations between hazards in the environment, potential for human exposure, and observed health outcomes. Combined with data from environmental hazard monitoring, this information can be used to target remediation efforts to areas of greatest need. Finally, data are needed to evaluate prevention efforts and inform health care providers, policy makers, and the general public about the need for attention to these issues.

FUTURE ISSUES

Emerging contaminants, characterized by a perceived, potential, or real threat to human health or the environment or by a lack of published health standards (EPA, 2016), present a challenge for public health surveillance and research on children's health. A newly emerging chemical or material may have insufficient evidence to determine human health effects for several reasons. Analytical methods and limits of detection may be limited or unavailable to detect low levels of human exposure. Many environmental toxicants are ubiquitous and pervasive leading to ongoing exposures to multiple chemicals simultaneously. Furthermore, health effects from exposures may take years or decades to become clinically symptomatic, making it difficult to identify an association between exposure and effect. Thus, it may be difficult to attribute a given health outcome to one specific substance. The precautionary principle implies that there is a responsibility to protect the public from harm even in the absence of data; however, US policy makers typically require substantial scientific evidence to justify decisions even where there is a plausible risk. Surveillance of environmental hazards, human exposures, and relevant health outcomes, including development of laboratory and data processing methods, requires an investment of substantial time and resources. Progress made over the past 20 years indicates that the investment is paying off with advances in information technology, data science, analytic methods, and information sharing. These advances provide a growing opportunity to enhance surveillance. In 2014, CDC initiated a strategy for programs across the agency to harmonize many common data elements, standardize data content and structure, and build new electronic messaging systems that allow more timely and effective data transfer. There has also been progress on electronic laboratory reporting through increased collaboration with commercial laboratories, state public health agencies, and other national partners. Work continues to improve efforts to facilitate the sharing of data from the local level to CDC, while also protecting the confidentiality of individual data.

There are numerous Healthy People 2020 initiatives on environmental health (https://www.healthypeople.gov/2020/topics-objectives/topic/environmental-health) (ODPHP, 2016). A number of these goals are related to children's environmental health including:

- Reduce exposure to selected environmental chemicals in the population, as measured by blood and urine concentrations of the substances or their metabolites.
- Reduce the number of US homes that are found to have lead-based paint or related hazards.

- Increase the proportion of persons living in pre-1978 housing that has been tested for the presence of lead-based paint or related hazards.
- Increase the proportion of the nation's elementary, middle, and high schools that have official school policies and engage in practices that promote a healthy and safe physical school environment.
- Reduce indoor allergen levels.
- Minimize the risks to human health and the environment posed by hazardous sites.
- Reduce blood lead levels in children.
- Reduce air toxic emissions to decrease the risk of adverse health effects caused by mobile, area, and major sources of airborne toxics.
- Reduce pesticide exposures that result in visits to a health care facility.

These public health initiatives, in tandem with ongoing research on related issues, are working to improve children's environmental health for future generations.

ADDITIONAL RESOURCES

- CDC's National Report on Human Exposure to Environmental Chemicals
  http://www.cdc.gov/exposurereport/
- CDC's Childhood Lead Poisoning Prevention Program
  http://www.cdc.gov/nceh/lead/
- CDC's Environmental Public Health Tracking Program
  https://ephtracking.cdc.gov/showHome.action

- World Health Organization (WHO) Global Plan of Action for Children's Health and the Environment
  http://www.who.int/ceh/en/

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Childhood Nutrition

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Nutrition's impact on the physical and mental development of children and adolescents is a worldwide concern. Childhood obesity, elevated blood pressure, high cholesterol, abnormal glucose tolerance, and iron deficiency are only some of the conditions that track into adulthood due to poor nutrition. The National Health and Nutrition Examination Survey (NHANES) and Youth Risk Behavior Surveillance System (YRBSS) are two tools in assessing nutritional guidelines and program development in the United States to educate and facilitate good nutrition for children of all ages and population groups.

PUBLIC HEALTH IMPORTANCE

Nutrition has an impact on physical and mental growth as well as development of children and adolescents[1]. Extremes, either too much or too little, can have negative impacts[2]. For example, caloric intake that exceeds need related to growth, development, and physical activity can lead to obesity[3]. Childhood obesity tracks to adulthood[4]. In addition, it can lead to immediate consequences such as elevated blood pressure, high cholesterol, and abnormal glucose tolerance[5]. Not enough of a particular nutrient can put children at risk, too. Iron deficiency, the most common form of nutritional deficiency worldwide, can lead to developmental delay and cognitive impairment among young children[6,7].

HISTORY OF DATA COLLECTION

The nutritional status of children and adolescents is assessed through physical size and growth (anthropometry), self- or proxy-reported dietary intake, and biochemical indicators (e.g., serum vitamin D, serum total body iron, or urinary iodine). CDC monitors the nutritional status of US youth using two existing surveillance systems: the National Health and Nutrition Examination Survey (NHANES) and the Youth Risk Behavior Surveillance System (YRBSS). A third surveillance system, the Pediatric Nutrition Surveillance System (PedNSS), monitored the nutritional status of children who participated in federal nutrition programs; however, this system was retired in 2012.

The School Health Policies and Practices Study (SHPPS) is a national survey periodically conducted to assess school health policies and practices at the state, district, school, and classroom levels. SHPPS tracks policy and program support of nutrition services, such as school breakfasts and lunches. This chapter will focus on individual-level surveillance and therefore, no additional information about SHPPS will be provided.

This chapter will provide a brief nutrition related background on NHANES and YRBSS, and present previously published select findings on anthropometry, dietary intake, and nutritional biochemical indicators for US children and adolescents. NHANES provides national estimates, which can be used to monitor trends over time and can provide detailed information about the food and nutrient intake of children. YRBSS tracks several key nutritional indicators at different levels: national, state and local. The majority of nutritional surveillance data at the national level comes from NHANES.

CDC SURVEILLANCE ACTIVITIES

National Health and Nutrition Examination Survey (NHANES)

The goals of NHANES are to monitor the nation’s health and nutritional status. NHANES has its roots in the 1960s with the National Health Examination Surveys (NHES I in 1960–1962 covering adults 18-79 years; NHES II in 1963–1965 covering children 6-11 years; and NHES III in 1966–1970 covering adolescents 12-17 years). In the early 1970s, the topic of nutrition was added to the survey and the first National Health and Nutrition

Examination Survey was conducted, covering individuals 1-74 years (NHANES I in 1971–1974). NHANES II was conducted in 1976–1980 and included individuals 6 months to 74 years and NHANES III in 1988–1994 on all individuals 2 months and older. Beginning in 1999, NHANES became continuous, annually examining a nationally representative sample of about 5,000 persons of all ages [8].

NHANES is conducted by the National Center of Health Statistics (NCHS). Data collection includes an in-home interview and a standardized physical exam which includes laboratory testing in a mobile examination center (MEC). NHANES uses a complex, multistage probability sampling design to select participants who are representative of the civilian, non-institutionalized US population, including infants, children and adolescents[9]. Particular subgroups are oversampled in different cycles to increase the reliability and precision of health status estimates in these populations[10,11]. The unweighted examined response rate for youth aged 1-19 years ranged from 81% in 1999-2000 to 75% in 2013-2014[12]. NHANES releases data every two years on roughly 3,800 children aged 1-19 years.

The nutritional data collected in NHANES include anthropometry, 24-hour dietary recall interviews, and nutritional biochemistries. The anthropometry component includes standardized measurements of height, weight and length among other measures. The 24-hour dietary recalls, also referred to as the "What We Eat in America" component of NHANES, are collected by trained interviewers. Two recalls are conducted, first during the visit to the MEC and second by phone interview 3 to 10 days later, using a computer-assisted dietary interview system with standardized probes (the USDA's Automated Multiple-Pass Method[13]). These interviews capture the quantity and type of food consumed in the 24-hour period from midnight to midnight prior to the interview. Total nutrient intakes from the foods and beverages consumed during the 24-hour period are calculated using the USDA's Food and Nutrient Database for Dietary Studies[14].

The biological samples collected in NHANES vary by survey cycle depending on research priorities, feasibility and available funding. They may include, or have included in the past, blood, urine, hair and saliva and are used to address research needs relevant to specific age and sex groups[15-17]. Table 1 provides a summary of select nutrition biochemistries collected in NHANES for children aged 1-19 years by survey cycle since 1999.

Youth Risk Behavior Survey (YRBS)

YRBS is the main component of the larger surveillance system (Youth Risk Behavior Surveillance System:

YRBSS). Developed in 1990, the surveillance system was designed to describe the prevalence of health-risk behaviors among youth; assess trends in health-risk behaviors over time; provide comparable national, state, territorial, tribe and local data; and evaluate and improve health-related policies and programs. The surveillance system monitors six types of health-risk behaviors including one related to nutrition, unhealthy dietary behaviors.

YRBS is conducted by CDC biennially and provides data representative of students in grades 9-12 attending US high schools[18]. Two types of surveys are conducted: a national survey and separate state/local surveys. The dietary behaviors monitored include: not consuming fruit, vegetables or milk; soft drink, sports drink, and water consumption; and not eating breakfast. In addition, self-reported height and weight are collected to monitor obesity prevalence.

YRBS questionnaires are self-administered, and students record their answers on a computer-scannable questionnaire booklet. The survey focuses on health behaviors in the seven days prior to conducting the questionnaire. Since 2013, education or health agencies in all 50 states are eligible to receive funding to conduct a YRBS to provide state level estimates. In 2015 overall response rate for the national survey was 60% and the response rate by state ranged from 60% to 84% [19]. Certain state, territorial, and local agencies and tribal governments also conduct a separate survey among middle school students by using a modified YRBS questionnaire designed specifically for the reading and comprehension skills of students in this age group[20].

GENERAL FINDINGS

Anthropometry

In children and adolescents, body measures such as weight, height and length are compared to distributions from a reference population (usually a growth chart) of the same age and sex to assess growth. There are many growth charts available. In the United States, CDC recommends the use of the World Health Organization (WHO) growth charts, which are based on optimal growth patterns for assessing weight and recumbent length in infants and toddlers from birth to 24 months of age. The 2000 CDC growth charts, which are based on the general US population in 1960-1994, are recommended for assessing weight, height and body mass index (BMI) in children and adolescents 2-19 years of age[21].

In infants and toddlers birth to 24 months of age, low weight-for-age (i.e., underweight), low weight-for-recumbent length (i.e., wasting) and low recumbent length-for-age (i.e., stunting) are defined based on the cut point of -2 z-scores (standard deviations, corresponding to 2.3rd percentile) on the sex-specific WHO growth charts. High weight-for-recumbent length (i.e., excess weight) is defined based on the cut point of +2 z-scores (97.7th percentile). In children and adolescents aged 2-19 years, the 5th and 95th percentiles on the sex-specific CDC BMI-for-age growth charts are used to define underweight and obesity. Outside of surveillance purposes, growth charts can be used to determine abnormal growth in a clinical or research setting based on patterns of growth over time.

Table 2 shows the percentage of US infants and toddlers below and above the WHO cut points. In 2013-2014, 8.1% of US infants and toddlers (birth to 24 months of age) had high weight-for-recumbent length (excess weight)[22]. In 2013-2014, 3.4% of infants and toddlers birth to 24 months had low recumbent length-for-age (stunting), nearly 1% had low weight-for-age (underweight), and about 1% had low weight-for-recumbent length (wasting)[23].

Both NHANES and YRBS provide estimates of weight status; however, national estimates of obesity from YRBS and NHANES are not directly comparable. YRBS includes self-reported weight and height, whereas NHANES has standardized protocols for measuring weight and height by trained technicians. Self-reported weight and height results in lower estimates of obesity because weight is often under reported and height is over reported[24].

National estimates of underweight[25] and obesity[26] among children and adolescents 2-19 years of age from NHANES data are shown in Tables 3-5. In 2013-2014, 3.8% of US children and adolescents were underweight (Table 3). The prevalence of obesity was 17.2% (Table 4). Significant race and Hispanic origin disparities in obesity prevalence are evident (Table 5): among boys in 2013-2014, the prevalence of obesity is lower in non-Hispanic Asian youth (12.1%) compared to non-Hispanic white (15.9%), non-Hispanic black (16.8%), and Hispanic youth (20.6%)[27]. The pattern is somewhat different in girls. Similar to boys, the prevalence of obesity in 2013-2014 is lower among non-Hispanic Asian youth (5.0%) compared to other groups, but unlike boys, the prevalence of obesity is lower among non-Hispanic white girls (14.6%) compared to non-Hispanic black (20.9%) and Hispanic girls (22.1%).

State-level estimates of obesity from YRBS highlight differences based on locality. Among 9th-12th grade students in 2015, the obesity prevalence (students who were ≥95th percentile for body mass index, based on sex- and age-specific reference data from the 2000 CDC growth charts) was highest in Mississippi (18.9%) and lowest in Montana (10.3%)[19].

Dietary Intake

The foods and beverages consumed by an individual are referred to as an eating pattern by the 2015-2020 Dietary Guidelines for Americans. The pattern may be more predictive of health and disease rather than a particular food or nutrient[28]. Eating patterns highlight the food and beverage components that are part of a healthy diet, and they emphasize the fact that people eat foods, not nutrients. The Healthy US – Style Eating Pattern encourages the consumption of food components that promote overall health and help prevent chronic disease[28]. For example, omega-3 fatty acids found in seafood are important in brain development[29]; so seafood consumption is associated with a healthy eating pattern. Likewise, nut consumption is associated with a healthy pattern because nuts are a vegetarian source of protein and another source of omega-3 fatty acids, which also provide essential minerals and fiber[30]. Solid fats (those solid at room temperature), in comparison to oils (those liquid at room temperature), contain more saturated and/or *trans* fats. These compounds tend to raise low density lipoproteins (LDL levels or "bad" cholesterol) in the blood. High levels of LDL may increase the risk for heart disease[31]. For these reasons, choosing oils over solid fats is encouraged in the Dietary Guidelines[28].

Data from NHANES are routinely used to assess how the diet of Americans compares to the Dietary Guidelines for Americans. The eating patterns of the US population estimated using NHANES data from 2007-2010 have been compared to the 2015-2020 Dietary Guidelines for Americans [28].

The 2015-2020 guidelines provide ranges of consumption based on age, sex and activity level. Figure 1 summarizes how dietary intake of US children and adolescents compares to the Dietary Guidelines. Intakes fall below, at, or above the recommendation or limit. For example, sodium has an upper limit that usual consumption should fall below, because high intakes of sodium are associated with higher systolic blood pressure[32]. Fruits and vegetables have a lower limit that usual consumption should be above, because they are rich sources of nutrients like potassium, folate, fiber, vitamins A, C and K and are traditionally under consumed[28,33,34]. Diets high in fruits and vegetables are also associated with a reduced risk of chronic disease in adults[35-37]. As seen in Figure 1, gray boxes represent the intake of foods and nutrients that meet the US Dietary Guidelines; blue boxes represent foods and nutrients where intake is below the guidelines; and yellow boxes represent foods and nutrients where intake is above the guidelines.

The data show that for the majority of food and food groups, consumption patterns of US children and adolescents are not in alignment with the Dietary Guidelines[28]. Consumption was generally below the guidelines for vegetables, fruits, dairy, whole grains, seafood and oils, yet above the guidelines for refined grains, solid fats, added sugars, saturated fats and sodium[28]. Total grains and proteins were the only foods or nutrients that children and adolescents consumed in accordance with the Dietary Guidelines.

YRBS collects information on unhealthy dietary behaviors but not the exact amount of food and beverages consumed, which prohibits direct comparison against the Dietary Guidelines. Unless a specific state is referenced, YRBS results below refer to estimates generated from the national survey. Results from YRBS 2015 showed that nationwide, 63.3% of students in 9th-12th grades ate fruit or consumed 100% fruit juice one or more times per day in the previous week. This prevalence ranged from 67.7% in California to 49.0% in Mississippi in state surveys. Nationally, 61.0% of students reported eating a vegetable one or more times per day in the previous week (including green salad, carrots, potatoes [excluding French fries, fried potatoes or potato chips], or other vegetables), and the prevalence ranged from 72.3% in Vermont to 46.7% in South Carolina. Approximately, 20.4% of students reported having consumed a can, bottle or glass of soda (not including a diet version) one or more times a day ranging from 11.9% in Connecticut to 32.4% in Kentucky[19].

Biochemical indicators

Biochemical indicators can provide estimates of the nutrient status of the US population. CDC's Division of Laboratory Sciences at the National Center for Environmental Health conducted and published the laboratory analyses of nutritional biochemical indicators collected by NHANES. The first report in the series contains information on 27 biochemical indicators from all or part of the four-year period from 1999 through 2002[38]. The second report contains information on 58 biochemical indicators collected during all or part of the four-year period from 2003-2006[39]. The third report in the series is currently under production. Not all biochemical indicators are collected in every survey cycle; new indicators are added and others discontinued. Table 1 presents a schedule of collection for nutritional biochemical indicators collected in NHANES that are of concern for children and adolescents. Previously published findings are presented below on iodine, iron status, and vitamin D. National estimates of iron status (total body iron and anemia) and vitamin D have been published for 2007-2010. Although newer data on vitamin D have been collected in NHANES, they have not been publicly released and were not available for analysis at the time of this publication. No newer data have been collected to estimate total body iron. NHANES currently collects biochemical indicators to estimate anemia and urinary iodine; however, published estimates are only available through 2007-2010.

Iodine

Iodine is essential for the synthesis of thyroid hormone which directs normal growth, development and metabolism throughout the life cycle[40]. Iodine deficiency can cause severe and irreversible consequences depending on the timing and duration of deficiency. Deficiency in pregnancy can cause miscarriage, stillbirth, congenital abnormalities and in early infancy, mental retardation[41]. Given the action of iodine, women of child-bearing age and children are at greatest risk of iodine insufficiency. WHO defines nutrition iodine sufficiency for a population by median urinary iodine (UI) concentrations:

- Excessive iodine intake, ≥ 300 µg/L
- More than adequate intake, 200–299 µg/L
- Adequate intake, 100–199 µg/L
- Mild iodine deficiency, 50–99 µg/L
- Moderate iodine deficiency, 20–49 µg/L
- Severe iodine deficiency <20 µg/L[40].

In NHANES 2009-2010, the median UI for children 6-11 years old was 213 µg/L (95% CI 188-234) and for adolescents 12-19 years, 131 µg/L (95% CI 112-151)[42]. However, the US population median for persons six years and older was significantly lower in NHANES 2009-2010 (144 µg/L [95% CI 132-154][42] compared with NHANES 2007-2008 (164 µg/L[95% CI 154-173])[43]. The most recently published estimates on iodine are from 2009-2010; however, NHANES continues to collect this indicator, and more recent data from 2013-2014 have been publicly released but were not available at the time of our publication.

Iron

Iron, a critical mineral in the body, plays key roles to ensure adequate oxygen transport throughout the body[6]. Iron deficiency (ID) is the most common nutrient deficiency worldwide and affects large numbers of young children and women of childbearing age[44]. ID and iron deficiency anemia (IDA) are associated with altered mental and motor development for children; cognitive and behavioral alterations for mothers[45,46]; and reduced work capacity for individuals and populations hampering national development[44]. Severe ID can lead to IDA, a significant contributor to child mortality[47] and maternal death[48].

NHANES fulfills a key surveillance role by monitoring the prevalence of ID in vulnerable populations in the United States. ID is defined as body iron <0 mg/kg[49]. The prevalence of ID among children aged 1-2 years was 13.5% (95% CI: 9.8, 17.2) and 3.7% (95% CI: 1.9, 5.5) among children aged 3-5 years in NHANES 2007-2010[50]. These estimates are similar to those from NHANES 2003–2006, which also used body iron model to define ID[49]. Iron status, as determined by the total body model (utilizing serum ferritin and serum transferrin receptors) has not been measured in NHANES since the 2009-2010 survey cycle; however, these measures cycled back into the survey beginning in the 2015-2016 cycle.

Anemia can be caused by a variety of factors including ID[51] and is defined as hemoglobin (Hb) <11.0 g/d, or hematocrit (Hct) <32.9% for children aged 6 months to 2 years, and Hb <11.1 g/dL, or Hct <33.0% for children aged 2–5 years. In 2007-2010 3.2% of US children aged 1-5 years were anemic based on NHANES data[50].NHANES currently collects hemoglobin and hematocrit for monitoring anemia; however, no new reports using more recent data have been published.

Vitamin D

The primary functions of vitamin D are to ensure adequate absorption of calcium and phosphorus from the intestine and to regulate bone mineralization[6]. Serum concentrations of 25-Hydroxyvitamin D ((OH)D) are the best indicator of vitamin D status, as they reflect the sum of endogenously produced vitamin D (i.e., synthesized within the body through actions in the skin, liver and kidney) and exogenously consumed vitamin D (i.e., obtained through eating foods)[52]. Vitamin D deficiency can cause suboptimal bone mineralization. A serum of 25(OH)D concentration less than 30 nmol/L is associated with an increased risk of developing rickets in infants and children and osteomalacia in adults and is, therefore, considered vitamin D deficiency. Concentrations of serum 25(OH)D greater than or equal to 30, but less than 50 nmol/L, are considered inadequate for bone and overall health; while >125 nmol/L is thought to be linked with adverse effects and is considered toxic[53]. Vitamin D toxicity can result from consuming too much vitamin D (excess sun exposure will not result in vitamin D toxicity). Vitamin D toxicity can cause a variety of symptoms, such as anorexia, weight loss, increased urination of dilute urine, heart arrhythmias and calcification (accumulation of calcium salts in body tissues)[52].

Data from NHANES 2007-2010 show that the prevalence of vitamin D deficiency among children is low; however, there is variation by race and Hispanic origin. During this time period, nearly 1% of children aged 1-11 years and almost 6% of children aged 12-19 years were at risk of vitamin D deficiency. Among children aged 1-11 years, 0.8% of Hispanic, 3.2% of non-Hispanic black, and <1% of non-Hispanic white children were at risk for vitamin D deficiency. Among older children aged 12-19 years, 6.7% of Hispanic, 25% of non-Hispanic black, and 1% of non-Hispanic white youth were vitamin D deficient[54].

Overall, about 10% of children aged 1-11 years and 25% of adolescents aged 12-19 years were at risk of vitamin D inadequacy or vitamin D deficiency (serum 25(OH)D <50 nmol/L). Variations by race and Hispanic origin among children 1-11 years were large: 13% of Hispanic, 29% non-Hispanic black and 3% non-Hispanic white children were at risk of vitamin D inadequacy or vitamin D deficiency. In comparison, variations by race and Hispanic origin for adolescences aged 12-19 years were striking: 41%, 70% and 8% of Hispanic, non-Hispanic black and non-Hispanic white adolescents were at risk of vitamin D inadequacy or vitamin D deficiency. Approximately 2% of children and adolescents have serum 25(OH)D values that are >125 nmol/L, (Figures 2 and 3)[54]. As of this publication, NHANES collects biochemistries to monitor vitamin D status; however, data from 2011-2012 onwards were not publicly released and available for analysis. Therefore, the estimates presented here based on NHANES 2007-2010 are the most recent years that have been collected, released and published.

DATA GAPS AND LIMITATIONS

NHANES sample sizes are relatively small so it is not possible to produce stable estimates for all subgroups within a single two-year survey cycle. For example, the sample size of breastfeeding infants (birth-12 months) in a two-year cycle of NHANES is only about 130 infants. Survey years can be combined but it may still be difficult to provide estimates by race and Hispanic origin. Similar issues arise with surveys such as the Youth Risk Behavior Survey where ensuring adequate response to produce sufficient sample sizes to generate state-level estimates can be challenging.

Surveillance systems also require significant resources. Faced with limited time and resources, prioritization means that some components may rotate in and out of active data collection. For example, vitamin A/E/carotenoids have not been measured in NHANES since 2005-2006[55]. Moreover, because NHANES samples are relatively small, two years of data collection are recommended for computing national estimates and data are generally released about nine months after collection.

Challenges exist with the collection of dietary intake. Measurement error (e.g., recall bias, respondent fatigue, within-person variability, social desirability bias) is present regardless of whether or not the survey uses 24-hour recall (NHANES) or food frequency questionnaires (YRBS) to assess dietary intake[6]. Self-reported dietary intakes are also associated with underreporting of energy intake, particularly among overweight and obese persons and women[56]. NHANES also faces the challenge of maintaining a current nutrient data base, so the participants' reported intake is as close as possible to a true representation of what was actually consumed.

USING DATA FOR ACTION

Nutrition surveillance systems provide public health professionals with key resources to monitor the nutritional status of the population and evaluate the impact of nutrition programs. Surveillance systems are used to assess anthropometric measures in the population including inadequate and excess dietary intake, and whether the nutritional status of individuals or subgroups need improvement. Trend data are valuable for assessing the effectiveness of public health efforts to improve the diet and nutritional status of the US population over time.

NHANES anthropometric data on infants, children, and adolescents were used to create pediatric growth charts. The 1977 National Center for Health Statistics growth charts, based on data collected from NHANES in the 1970s, were widely used by pediatricians and researchers to monitor growth. In 2000, updated CDC growth charts were released that included data from more recent NHANES surveys. These charts are widely used by clinicians to monitor growth and by researchers to calculate population estimates of obesity, overweight and normal weight in US children and adolescents ≥ 2 years of age[57].

Dietary data from NHANES are used to evaluate how closely the US population follows the Dietary Guidelines. Every five years, a committee comprised of outside experts convenes to consider the current scientific and medical knowledge regarding nutrition in order to provide recommendations to the government about healthy eating. Representatives from the Department of Agriculture and the Department of Health and Human Services develop a policy document from these recommendations to help policymakers design and implement US nutrition programs. The 8th edition of these guidelines (Dietary Guidelines for Americans 2015-2020) evaluated eating patterns in the US population using NHANES 2007-2010[28]. These national dietary estimates were used to assess whether different subgroups were meeting national guidelines[28]. NHANES data are also a source for many of the nutrition and weight status objectives in Healthy People 2020, a science-based set of 10-year national objectives for improving the health of all Americans[58].

Dietary data from NHANES have helped inform the development of national-level policies. For instance, NHANES data have been used to estimate sources of sodium intake among infants and toddlers[59] and to monitor total sodium intake among infants and preschool children[60], school-aged children[61], and adults[62,63] in the United States. These estimates were used in efforts to reduce the amount of sodium in various products children consume[64,65]. Additionally, the United States Department of Agriculture (USDA) used the information in setting updated standards for the amount of sodium in school meals[66].

Data from NHANES have also been used to estimate the impact of changes in the food supply on the health of Americans. In April 2016, the U.S. Food and Drug Administration (FDA) announced approval of manufacturers fortifying corn masa flour with folic acid to help reduce the risk of neural tube defects (serious birth defects of the brain, spine, and spinal cord)[67]. This decision stemmed from the use of NHANES data to estimate the additional amount of folic acid that the US population and specific subgroups, such as reproductive age women, would consume if corn masa flour were fortified with folic acid[68-70]. Data from NHANES and other sources were also used to estimate the impact of folic acid fortification of corn masa flour on the number of neural tube defects that could be averted, especially among the most vulnerable populations, which includes Hispanic women, women taking antiepileptic medication, and those who are obese or have diabetes[71].

Using state-based estimates from YRBS, state profiles have been developed that include statistics on the prevalence of adolescent behaviors and health outcomes such as obesity and dietary behaviors[72]. These profiles can be used by program and policy makers to monitor state-programs, justify the provision of support for activities addressing these issues, and leverage partners to continue programmatic and policy efforts addressing areas of need.

In summary, data from NHANES and YRBS provide essential information about the nutritional status of US children and adolescents. NHANES, in particular, allows CDC to monitor the nutritional status of youth using physical measurements and biomarkers. Both NHANES and YRBS are adaptable and can be modified to meet changing public health nutrition priorities.

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Table 1. Select nutritional biochemistries collected in children 1-19 years by NHANES survey cycle 1999-2014[1,2]

	Age	1999/00	2001/02	2003/04	2005/06	2007/08	2009/10	2011/12	2013/14
Markers of iron status									
Ferritin	1 y and over[3]	▨	▨	Note A	Note A	Note A	Note A		
Erythrocyte protoporphyrin	1 y and over[3]	▨	▨	Note B	Note B				
TIBC/transferrin saturation	1 y and over[3]	▨	▨	Note B	Note B				
Transferrin receptors	1-5 y, females 12-19 y			▨	▨	▨	▨		
Minerals									
Iodine[4]	1/3 sample 6 y and over[3]	Note C	▨	▨	▨	Note C	▨	▨	▨
Iron	1 y and over[3]	▨	▨	Note B	Note B				
Copper/Zinc	1/3 sample 6 y and over[3]							▨	▨
Selenium	3-11 y[3]	▨	Note D					Note E	Note E
Vitamins									
A/E/carotenoids	3 y and over[3]	▨	▨	Note E	Note E				
B-6	1 y and over			▨	▨	▨	▨		
B-12	3 y and over[3]	▨	▨	Note F	Note F				
C	6 y and over			▨	▨				
D	6 y and over[3]	Note G	Note G	Note G	Note G	Note G	Note G	Note G	Note G
Folate, RBC	3 y and overr[3]	▨	▨	Note F	Note F	Note F	Note F	Note F	Note F
Folate, serum	3 y and over[3]	▨	▨	Note F	Note F	Note F	Note F	Note F	Note F

1 Shaded boxes indicate that measure was collected, non-shaded boxes indicate measure was not collected. Notes detail changes in the measure.

2 Minerals and vitamins identified in serum blood sample, unless otherwise noted.

3 Except where noted otherwise.

4 Urine Sample.

A: Aged 1-5 year and females aged 12-19 years.

B: Aged 3-5 year and females aged 12-19 years.

C: Data collection began in 2000 and was a full sample in 2007-2008 only.

D: Selenium ended in 2001.

E: Aged 6 years and over.

F: Aged 1 year and over.

G: Vitamin D began in 2000; in 2003-2012, vitamin D was conducted on study participants aged 1 year and over.

NOTES: Blood sample, unless noted otherwise. Total iron binding capacity(TIBC).

SOURCE: National Health and Nutrition Examination Survey, 1999-2014.

Table 2. High weight-for-recumbent length (excess weight), low weight-for-recumbent length (wasting), low recumbent length-for-age (stunting) and low weight-for-age (underweight) among infants and children, birth to 24 months: United States, 1999-2000 through 2013-2014

	High weight-for-recumbent length (Excess weight)	Low weight-for-recumbent length (Wasting)	Low recumbent length-for-age (Stunting)	Low weight-for-age (Underweight)
Survey period	WHO growth charts[1] Percent(SE)	WHO growth charts[2] Percent(SE)	WHO growth charts[3] Percent(SE)	WHO growth charts[4] Percent(SE)
1999-2000	9.2 (1.3)	0.4 (0.3)	4.9 (1.1)	1.6 (0.8)
2001-2002	7.8 (1.1)	0.7 (0.5)	3.3 (0.7)	0.8 (0.3)
2003-2004	8.5 (1.2)	1.1 (0.6)	3.9 (1.1)	2.5 (0.8)
2005-2006	7.1 (1.0)	1.7 (0.6)	2.1 (0.8)	1.2 (0.5)
2007-2008	8.8 (1.0)	1.2 (0.5)	3.8 (0.7)	1.4 (0.5)
2009-2010	8.6 (1.3)	0.3 (0.2)	3.3 (0.7)	1.1 (0.3)
2011-2012	7.1 (1.3)	0.9 (0.4)	3.2 (1.1)	0.4 (0.2)
2013-2014	8.1 (1.2)	0.9 (0.6)	3.4 (0.7)	0.8 (0.5)

1 Weight-for-recumbent length >= 97.7th percentile (+2 standard deviations) of the sex-specific WHO growth standards

2 Weight-for-recumbent length <2.3 percentile (-2 standard deviations) on the sex-specific WHO growth standards

3 Recumbent length-for age <2.3 percentile (+2 standard deviations) on the sex-specific WHO growth standards

4 Weight-for-age <2.3 percentile (-2 standard deviations) on the sex-specific WHO growth standards

SOURCE: National Health and Nutrition Examination Survey; Fryar et al NCHS health estats, see reference 22 and 23.

Table 3. Prevalence of underweight among children and adolescents aged 2-19 years by sex: United States, 1999-2000 through 2013-2014

Survey period	All Percent(SE)	Boys Percent(SE)	Girls Percent(SE)
1999-2000	4.2 (0.4)	4.9 (0.9)	3.5 (0.7)
2001-2002	3.4 (0.3)	3.7 (0.5)	3.1 (0.4)
2003-2004	3.2 (0.3)	3.6 (0.4)	2.9 (0.5)
2005-2006	3.2 (0.4)	3.7 (0.7)	2.7 (0.4)
2007-2008	3.7 (0.4)	3.8 (0.8)	3.6 (0.4)
2009-2010	3.3 (0.4)	3.3 (0.5)	3.4 (0.5)
2011-2012	3.5 (0.5)	4.2 (1.1)	2.8 (0.5)
2013-2014	3.8 (0.4)	3.6 (0.6)	4.0 (0.5)

NOTES: Pregnant females were excluded from analysis. Obesity: body mass index (BMI) was calculated as weight in kilograms divided by height in meters squared, rounded to one decimal place. Obesity in children and adolescents was defined as a BMI of greater than or equal to the age- and sex-specific 95th percentile of the 2000 CDC growth charts.
SOURCE: CDC/NCHS, National Health and Nutrition Examination Surveys (NHANES); Fryar et al NCHS estat. July 2016.

Table 4. Prevalence of obesity among children and adolescents aged 2-19 years by sex: United States, 1999-2000 through 2013-2014

Survey period	All Percent(SE)	Boys Percent(SE)	Girls Percent(SE)
1999–2000	13.9 (0.9)	14.0 (1.2)	13.8 (1.1)
2001–2002	15.4 (0.9)	16.4 (1.0)	14.3 (1.3)
2003–2004	17.1 (1.3)	18.2 (1.5)	16.0 (1.4)
2005–2006	15.4 (1.4)	15.9 (1.5)	14.9 (1.6)
2007–2008	16.8 (1.3)	17.7 (1.4)	15.9 (1.5)
2009–2010	16.9 (0.7)	18.6 (1.1)	15.0 (0.8)
2011–2012	16.9 (1.0)	16.7 (1.4)	17.2 (1.2)
2013–2014	17.2 (1.1)	17.2 (1.3)	17.1 (1.6)

NOTES: Excludes pregnant females. Obesity: body mass index (BMI) was calculated as weight in kilograms divided by height in meters squared, rounded to one decimal place. Obesity in children and adolescents was defined as a BMI of greater than or equal to the age- and sex-specific 95th percentile of the 2000 CDC growth charts
SOURCE: CDC/NCHS, National Health and Nutrition Examination Survey; Fryar et al NCHS Health estat. July 2016.

Table 5. Prevalence of obesity among children and adolescents aged 2-19 years by sex and race and Hispanic origin: United States, 1999-2000 through 2013-2014

	Non-Hispanic white	Non-Hispanic black	Non-Hispanic Asian	Hispanic[1]	Mexican American
Boys					
1999-2000	10.9 (1.5)	16.4 (1.2)	---	---	23.5 (1.5)
2001-2002	15 (1.5)	15.5 (1.3)	---	---	22.0 (1.3)
2003-2004	17.8 (2.2)	16.4 (1.5)	---	---	22.0 (1.6)
2005-2006	13.4 (1.9)	18.3 (1.3)	---	---	24.3 (2.7)
2007-2008	15.6 (1.9)	17.3 (2.2)	---	24.5 (1.7)	24.9 (2.3)
2009-2010	16.1 (1.8)	24.3 (2.8)	---	23.4 (1.4)	24.0 (1.7)
2011-2012	12.6 (2.4)	19.9 (1.1)	11.5 (2.1)	24.1 (1.4)	24.2 (1.5)
2013-2014	15.9 (2.0)	16.8 (1.9)	12.1 (3.0)	20.6 (2.0)	19.5 (2.1)
Girls					
1999-2000	11.1 (1.8)	21.4 (1.4)	---	---	16.8 (1.9)
2001-2002	12.7 (1.9)	19.5 (1.3)	---	---	17.0 (1.9)
2003-2004	14.9 (1.9)	23.8 (1.4)	---	---	16.1 (2.3)
2005-2006	12.2 (2.2)	24.4 (2.2)	---	---	20.6 (1.6)
2007-2008	14.9 (2.5)	22.8 (2.4)	---	17.3 (1.7)	16.6 (2.5)
2009-2010	11.7 (1.1)	24.3 (2.6)	---	18.9 (1.8)	18.2 (2.5)
2011-2012	15.6 (2.1)	20.5 (3.1)	*5.6 (2.4)	20.6 (1.5)	21.1 (1.7)
2013-2014	14.6 (2.8)	20.9 (1.6)	5.0 (1.0)	22.1 (2.1)	24.2 (2.8)

1 Includes Mexican American persons.

--- Data not available.

*Estimate has a relative standard error greater than 40% and should be used with caution because it does not meet standards of reliability or precision.

NOTES: Excludes pregnant females. Obesity: body mass index (BMI) was calculated as weight in kilograms divided by height in meters squared, rounded to one decimal place. Obesity in children and adolescents was defined as a BMI of greater than or equal to the age- and sex-specific 95th percentile of the 2000 CDC growth charts

SOURCE: CDC/NCHS, National Health and Nutrition Examination Survey; Fryar et al NCHS Health estat July 2016.

Figure 1. Mean usual intake of select foods and nutrients in comparison to Dietary Guidelines Recommendations, US youth aged 1-18 years by sex and age, 2007-2010

	Males				**Females**			
	1 to 3	*4 to 8*	*9 to 13*	*14 to 18*	*1 to 3*	*4 to 8*	*9 to 13*	*14 to 18*
Vegetables	🟦	🟦	🟦	🟦	🟦	🟦	🟦	🟦
Dark green vegetables	🟦	🟦	🟦	🟦	🟦	🟦	🟦	🟦
Red and orange vegetables	🟦	🟦	🟦	🟦	🟦	🟦	🟦	🟦
Legumes (beans and peas)	▒	🟦	🟦	🟦	▒	🟦	▒	🟦
Starchy vegetables	🟦	🟦	🟦	🟦	🟦	🟦	🟦	🟦
Other vegetables	🟦	🟦	🟦	🟦	🟦	🟦	🟦	🟦
Fruits	▒	▒	🟦	🟦	▒	▒	🟦	🟦
Total grains	▒	▒	🟨	▒	▒	▒	▒	▒
Whole grain	🟦	🟦	🟦	🟦	🟦	🟦	🟦	🟦
Refined grains	🟨	🟨	🟨	🟨	🟨	🟨	🟨	🟨
Dairy	▒	🟦	▒	🟦	▒	🟦	▒	🟦
Protein foods	▒	▒	▒	▒	▒	▒	▒	🟦
Meats, poultry, and eggs	▒	▒	▒	🟨	▒	▒	▒	▒
Seafood	🟦	🟦	🟦	🟦	🟦	🟦	🟦	🟦
Nuts, seeds and soy products	▒	▒	▒	🟦	▒	▒	▒	🟦
Oils and solid fats:								
Oils	🟦	🟦	🟦	🟦	🟦	🟦	▒	🟦
Solid fats	🟨	🟨	🟨	▒	🟨	🟨	🟨	🟨
Other dietary components:								
Added sugars	🟨	🟨	🟨	🟨	🟨	🟨	🟨	🟨
Saturated fats	🟨	🟨	🟨	🟨	🟨	🟨	🟨	🟨
Sodium	🟨	🟨	🟨	🟨	🟨	🟨	🟨	🟨

KEY:

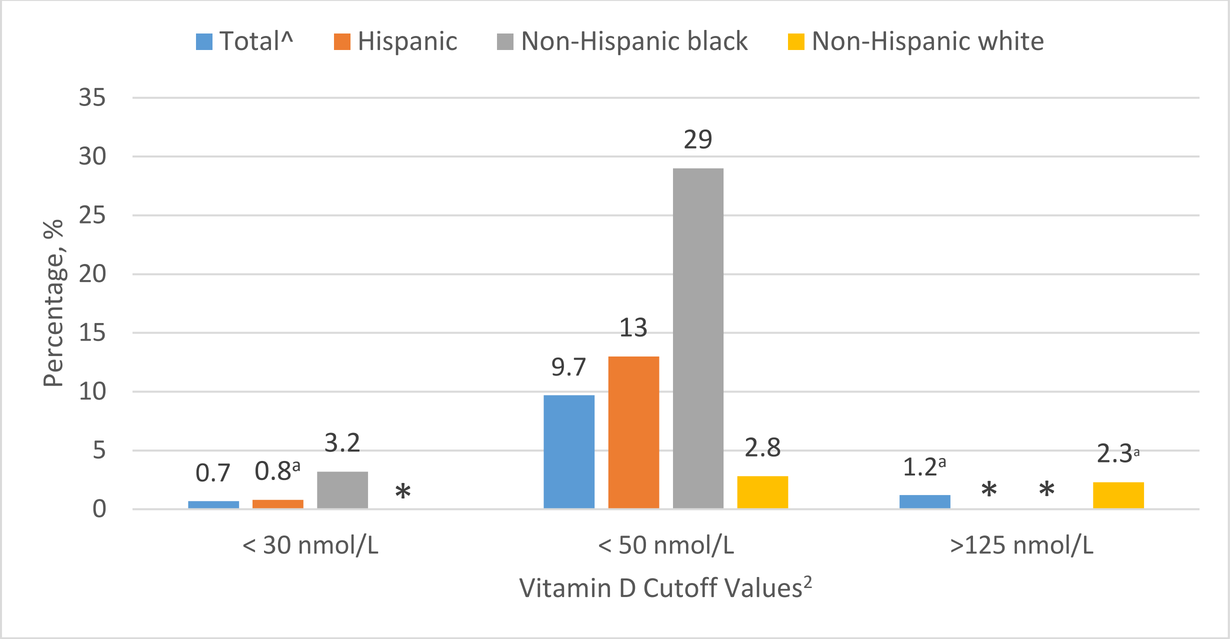
Blue = below recommendation

Yellow = above recommendation

Gray = met recommendation

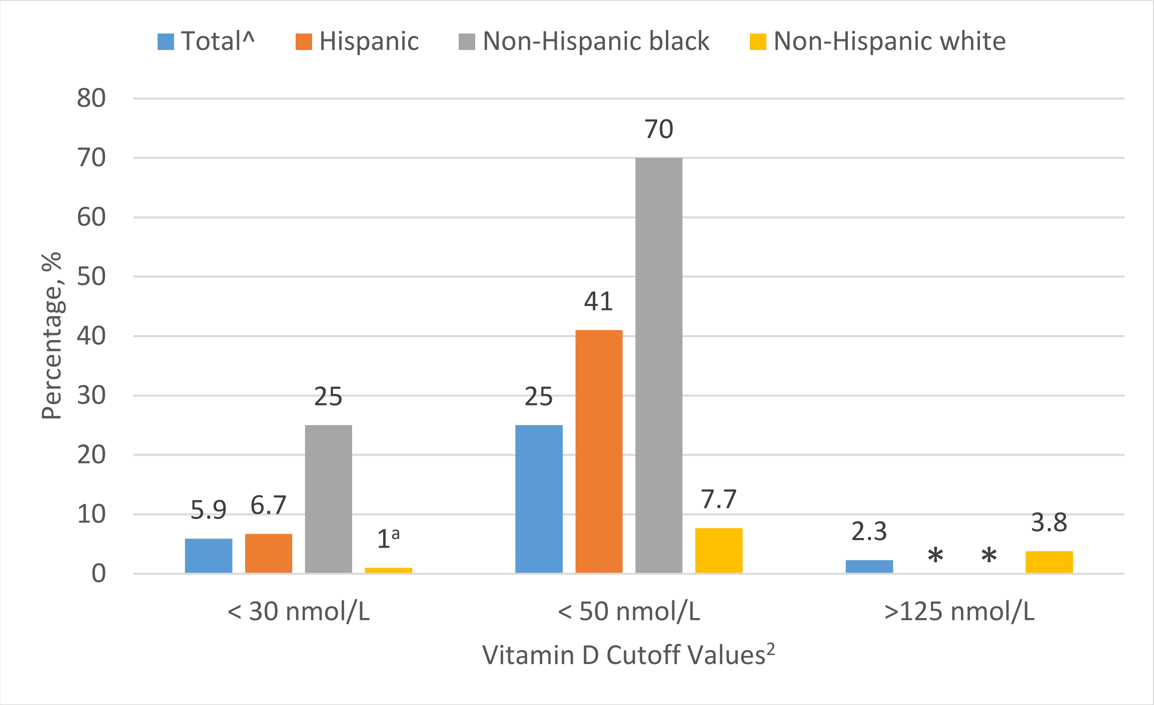
Source: National Health and Nutrition Examination Survey; Dietary Guidelines for Americans 2015-2020. Reference 28.

Figure 2. Prevalence of vitamin D concentrations at various cutoff values, stratified by race and Hispanic origin among children aged 1-11 years, NHANES 2007-2010[1]



1 Estimates are weighted percentages.
2 Cutoff values defined by the Institute of Medicine Dietary Reference Intake Report. Reference 53.
a 30% ≤ relative SE < 40%
* Estimate suppressed, relative SE ≥ 40%
^ Estimates for "other" race group (persons with multiethnic background) are not shown but are included in total estimates. The Hispanic subgroup represents the sum of Mexican-American and other Hispanic ethnicities.
SOURCE: Schleicher RL et al. 2016

Figure 3. Prevalence of vitamin D concentrations at various cutoff values, stratified by race and Hispanic origin among children aged 12-19 years, NHANES 2007-2010[1]



1 Estimates are weighted percentages.
2 Cutoff values defined by the Institute of Medicine Dietary Reference Intake Report. Reference 53.
a 30% ≤ relative SE < 40%
* Estimate suppressed, relative SE ≥ 40%
^ Estimates for "other" race group (persons with multiethnic background) are not shown but are included in total estimates. The Hispanic subgroup represents the sum of Mexican-American and other Hispanic ethnicities.
SOURCE: Schleicher RL et al. 2016

DEVELOPMENTAL DISABILITIES

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Developmental disabilities (DDs) represent a broad group of conditions attributable to a physical or mental impairment which are often accompanied by functional limitations requiring life-long and interdisciplinary supports. Overall, an estimated 15% of children in the United States have at least one developmental disability with significant associated lifetime costs in the billions of dollars. Early identification and intervention can provide meaningful improvements in daily functioning and social participation in children with developmental delays and disabilities. Surveillance data are necessary to monitor the frequency, characteristics, and trajectory of prevalence in order to inform resource needs for children with DDs as they mature into young adulthood.

PUBLIC HEALTH IMPORTANCE

Developmental disabilities (DDs) are a group of chronic conditions attributable to a physical or mental impairment resulting in functional limitations that often require life-long coordinated, interdisciplinary services and supports.[1] Overall, an estimated 15% of children in the United States have at least one DD, with estimated lifetime economic costs for intellectual disability, cerebral palsy, hearing loss, and vision impairment totaling approximately $51.2 billion, $11.5 billion, $2.6 billion and $1.9 billion, respectively, for persons born in 2000, based on 2003 dollars.[2-3] The lifetime cost associated with having one of these DDs is substantial and has implications for the affected individual, family, and society. Although many children with DDs are identified at school-age, the consequences of DDs are often life-long underscoring the public health importance of understanding developmental disabilities across the lifespan. Early identification and intervention of specific DDs may result in meaningful improvements in functioning and social participation.[4] Prevalence data are quantifying the magnitude and trajectory of resource needs for school-age children with DDs as they mature into young adulthood.

HISTORY OF DATA COLLECTION

Developmental disabilities are usually identified during early childhood, when limitations in response to developmental, educational and societal expectations become apparent. As such, identification requires that information be obtained from data sources within a community, including parents, usually months to years after birth. With the goal of providing timely data, it is generally acknowledged that population screening followed by diagnostic assessment of all children to determine prevalence is too costly and time-consuming for an ongoing public health surveillance system.[5] Data collection on DDs in the United States uses two overarching methods: a) ongoing population-based multiple-source surveillance through the Metropolitan Atlanta Developmental Disabilities Surveillance Program (MADDSP) and Autism and Developmental Disabilities Monitoring (ADDM) Network; and b) national surveys through the National Health Interview Survey (NHIS), National Survey of Children with Special Health Care Needs (NSCSHCN), and National Survey of Children's Health (NSCH).

MADDSP began in 1991 as a scientifically robust, yet feasible model for public health surveillance, building upon experience gained in the 1980s through an earlier study of DDs (Metropolitan Atlanta Developmental Disabilities Study, MADDS).[6] As a result of the Children's Health Act of 2000, CDC was funded to replicate the MADDSP model across multiple US communities through the ADDM Network. Since the 1980s, nationally representative survey data collected based on parental reports have included questions about DDs in an effort to determine the prevalence of these conditions among children. Examples include the NHIS, NSCSHCN, and NSCH. National surveys have reported prevalence estimates that are similar to those obtained by the ADDM Network's ongoing population-based surveillance efforts. Survey data serve as a complement to more in-depth data collection on populations of children across the United States. All three national surveys examine a variety of resource and medical needs of children and young adults with developmental disabilities.[7-9] Population-based surveillance of health conditions provides the most complete and unbiased data to describe the magnitude and characteristics of the problem, provide the basis for generating hypotheses for understanding risk and protective factors and possible causes, and contribute to policy and prevention strategies. Thus, the focus of this chapter is on CDC's active surveillance programs.

CDC SURVEILLANCE ACTIVITIES

Metropolitan Atlanta Developmental Disabilities Surveillance Program (MADDSP)

The overarching purpose of MADDSP is two-fold: a) to provide regular and systematic monitoring of the prevalence of selected developmental disabilities according to various demographic, maternal, and child characteristics; and b) to provide a framework and data base for conducting studies of children with the selected conditions. MADDSP is a record-based surveillance system which relies on access to records within education, health, and service agencies (e.g., public schools, state health clinics and diagnostic centers, hospitals, and other providers for children with developmental disabilities [DDs]) to identify cases and ensure unduplicated case counting (Figure 1). Case ascertainment of MADDSP's five selected DDs -- autism spectrum disorder (ASD), intellectual disability (ID), cerebral palsy (CP), hearing loss (HL) and vision impairment (VI) -- include screening of records by trained staff to confirm age and residency requirements and for specific DD indicators. These indicators include qualifying test results for ID, HL, or VI; behavioral or diagnostic descriptions indicating possible ASD; and physical or diagnostic findings consistent with CP. Once detailed information is abstracted from records of eligible children, information from multiple sources is consolidated into a single composite record for a given child. The composite records for ASD and CP are systematically reviewed by trained clinical research reviewers to determine final case status. Ongoing quality checks are conducted to ensure reliability across clinical research reviewers and field abstractors. Further details of the MADDSP methodology (Appendix I) have been described elsewhere.[10] MADDSP functions as a public health authority in accordance with its data source agreements and meets applicable privacy/confidentiality requirements under 45 CFR 46.[11] MADDSP is deemed public health practice by the Centers for Disease Control and Prevention's Institutional Review Board.

From 1991 through 994 MADDSP monitored CP, HL, ID, and VI among 3- to 10-year-old children and added ASD in 1996. Examination of the 3- through 10-year age range afforded the ability to understand how prevalence of each DD varied by age and, in conjunction with other analyses, provided evidence to support restriction of the ascertainment age to the peak age of 8 years. Given the resource intensive addition of ASD to MADDSP surveillance, MADDSP has focused on 8-year-old children, reporting estimates in 1996 and every other calendar year since 2000 for CP, HL, ID and VI, and ASD. MADDSP has monitored the prevalence of these five DDs in the same five central counties of metropolitan Atlanta, Georgia (Clayton, Cobb, DeKalb, Fulton, and Gwinnett) using the same methods.

Surveillance is conducted every other calendar year to provide cross-sectional prevalence estimates. MADDSP traditionally reports period prevalence as the number of 8-year-old children with a given DD divided by the number of 8-year-old children in the corresponding population. MADDSP's geographic and methodologic consistency over time has provided a unique strength in evaluating prevalence trends. Each surveillance year, MADDSP data are linked to additional external datasets including birth and death certificates, birth defects surveillance data, data from newborn screening, and census files to conduct additional analyses examining, for example, risk factors and co-occurring conditions.

Autism and Developmental Disabilities Monitoring (ADDM) Network

Established in response to the Children's Health Act of 2000 (Public Law 106–310), the ADDM Network comprises universities and health departments funded under a competitive, cooperative agreement with CDC to conduct surveillance of ASD and either ID or CP. All sites funded under this cooperative agreement adhere to the MADDSP methodology (Figure 1 and Appendix I). MADDSP represents the CDC ADDM site in Georgia. Children 8 years old are the focus of core surveillance activities, although up to half of ADDM sites receive additional funding to monitor ASD among 4-year-olds. Each site's geographic surveillance area must contain a minimum population of 20,000 8-year-old children, according to the most recent decennial or postcensal population estimates. All ADDM Network sites maintain active agreements to access children's evaluation records at health data sources, and most sites are also permitted to access education records in part or in all of their geographic surveillance area.

The ADDM Network's first surveillance year (2000) entailed the funding of cooperative agreements with five partner organizations. By 2002, 14 sites were conducting ASD surveillance using the common methodology. As of 2016, three additional cycles of ADDM funding have been initiated, which included 10 sites during 2006 to 2010, 11 sites during 2010 to 2014, and 10 sites for the current cycle 2015 to 2018. In addition to the historically used Diagnostic Statistical Manual of Mental Disorders Fourth Edition-Text Revision (DSM-IV-TR)-based case definition, the current funding cycle will develop and implement methods for case determination based on the DSM-Fifth Edition (DSM-5) criteria for ASD.[12-13] Each ADDM site links their surveillance data to birth certificates and is encouraged to link to additional external datasets such as done with MADDSP.

GENERAL FINDINGS

MADDSP

Findings from the first MADDSP prevalence report, its inaugural 1991 surveillance year, reported estimates among 3- through 10-year-olds of 8.0 per 1,000 for ID, 2.4 per 1,000 for CP, 1.1 per 1,000 for HL and 0.8 per 1,000 for VI.[14] Prevalence varied by age, race/ethnicity, sex, and severity of DDs. The first ASD prevalence for metropolitan Atlanta reflected the 1996 surveillance year and was an estimated 3.4 per 1,000 3- through 10-year-olds with the highest estimate among 8-year-olds of 4.7 per 1,000.[15] In 2015, CDC reported data that reflected trends in the five MADDSP DDs since the inception of the program; 1991-2010 (Figure 2).[16] Across the 20-year reporting period, prevalence estimates of ID and HL were stable, and there were slight increases in the prevalence of VI. For the greater part of the two decades, 1993 through 2010, the prevalence of CP prevalence was stable. Significant increases of 9.3% per year from 1996-2010 were observed in ASD prevalence with a 269% increase from 4.2 per 1,000 8-year-old children in 1996 to 15.5 per 1,000 in 2010. Similar increases in ASD prevalence were observed across all sex, racial/ethnic, and levels of cognitive functioning. Interestingly, while the prevalence from 2000-2010 of ASD with and without co-occurring ID increased significantly by an average of 6.6% and 9.6% per year, respectively, the prevalence of ID overall and that of ID without ASD were stable. One of MADDSP's strengths is its use of objective intelligence quotient (IQ) information to ascertain children with ID. As a result, MADDSP was the first US surveillance program to assess concurrent changes in the prevalence of ID and ASD over time.

The heterogeneity of MADDSP's population and the strength of monitoring five DDs have afforded CDC the ability to examine disparities in prevalence by population demographics and co-occurring DDs. In metropolitan Atlanta, prevalence estimates of ID and CP have been consistently higher among black non-Hispanic children than white non-Hispanic and Hispanic children.[17] Conversely, the prevalence of ASD has been higher among white non-Hispanic than black non-Hispanic and Hispanic children over time. When racial/ethnic disparities in community identification of ASD were examined, after adjusting for sex and socioeconomic status (SES), white non-Hispanic children were more likely to receive any ASD diagnoses whereas black non-Hispanic children were more likely to receive only the most severe diagnoses, potentially preventing or delaying intervention and receipt of services.[17] Using MADDSP data, Kancherla et al., examined the co-occurrence of VI, HL and ASD demonstrating that about 7% of children with VI and 6% of children with HL also had ASD.[18] With respect to early identification, children with VI were diagnosed with ASD later than those without VI (6 years and 7 months compared with 4 years and 8 months, respectively). By contrast, children with HL and ASD were evaluated by a community provider earlier than children who had ASD without HL (3 years and 4 months compared with 4 years and 2 months, respectively), but were diagnosed at about the same age as their peers without HL. These findings highlight the need for continued awareness and professional education, particularly concerning milder ASDs in minority groups and co-occurring visual, hearing and behavioral impairments. These data also underscore the need for development of screening and diagnostic tools for children with multiple DDs.

Linkage with birth certificate and birth defects data have afforded MADDSP the ability to examine risk factors for DDs such as birth weight, gestational age, co-occurring birth defects, as well as trends in birth prevalence. Data from the 1996 surveillance year (1981 through 1993 births) reported that ASD prevalence among children born low birthweight (<2500 grams) or very preterm (<33 weeks gestation) was lower than that of children with MADDSP's other DDs.[19] Nevertheless, after adjustment for multiplicity, parity, child's gender, presence of birth defects, maternal factors, and child's age, ASD prevalence was significantly higher among those born low birth weight than normal birth weight [odds ratio (OR): 2.3 95% Confidence Interval (CI): 1.3, 4.1]. Although not as strong a risk factor as it is for ID, CP, HL or VI, having a low birth weight places an infant at increased risk for ASD as well. When MADDSP data were linked to birth defects surveillance data, approximately 7% of children with a major birth defect had a serious DD compared with 0.9% of children with no major birth defect [prevalence ratio (PR): 8.3 (95% CI 7.6-9.0)] with increasing PR as DD severity increased.[20] These findings suggest possible early prenatal origins of select DDs.

Recent findings that examined trends in the birth prevalence of CP by birth weight and gestational age demonstrated that CP birth prevalence has been stable between children born in 1985 through 2002, both overall and across all birthweight and gestational age categories.[21] Although these data support that improved neonatal survival of infants born too early or too small does not appear to be resulting in an increase in CP prevalence, overall declines in CP prevalence are also not apparent. Of note, the prevalence of CP among children with co-occurring moderate to profound ID decreased approximately 2.6% annually among children born from 1985 through 2002, suggesting that advances in obstetric and neonatal care may be contributing to a decrease in more severely affected children with CP.

ADDM

The earliest reports from the ADDM Network provided ASD prevalence estimates from six sites for the 2000 surveillance year and from 14 sites for the 2002 surveillance year. Combined data from all sites in each respective surveillance year indicated that ASD prevalence estimates among 8-year-olds were similar for both years: 6.7 per 1,000 in 2000 (range: 4.5–9.9) and 6.6 per 1,000 in 2002 (range: 3.3–10.6).[22-23] A subsequent ADDM Network report provided data on ASD prevalence among 8-year-olds for 2004 (8 sites) and 2006 (11 sites). When data from all sites were combined, overall ASD prevalence was 8.0 per 1,000 in 2004 (range: 4.6–9.8) and 9.0 per 1,000 in 2006 (range: 4.2–12.1).[24] The 2008 surveillance year ADDM Network report (14 sites) estimated a combined ASD prevalence of 11.3 per 1,000 children aged 8 years (range: 4.8–21.2).[25] Comparison of the 2008 findings with those for previous surveillance years showed an increase in ASD prevalence of approximately 23% compared with the 2006 estimates and 78% compared with 2002. The largest increases from 2002 to 2008 were noted among Hispanic children, black non-Hispanic children, and children without co-occurring ID. The ADDM Network's most recently published ASD prevalence estimate for 2012 surveillance year (14 sites) was 14.6 per 1,000 children 8 years old which was comparable to the 2010 surveillance year estimate of 14.7 per 1,000.[26-27] This recent and rapid increase in ASD prevalence underscores the importance of continuing surveillance to monitor trends in the population and the need for continued expansion of research into risk factors, etiology, and effective interventions.

In addition to its biannual prevalence reports, data collected by the ADDM Network have provided the ability to examine various risk factors for ASD and further our understanding of the epidemiology of CP. ADDM data were used to model the possible contributions of perinatal risk factors including prematurity, low birth weight, multiple birth, cesarean delivery, breech presentation, and assisted reproductive technology, on the increase in ASD prevalence. These analyses found that none of these risk factors had sufficient baseline prevalence, change in prevalence over time, and magnitude of association with ASD to have significantly influenced the observed increase in ASD prevalence.[28] Examination of the role of socioeconomic status demonstrated that ASD prevalence increased with higher socioeconomic status, suggestive of possible SES disparities in access to services for children with ASD and the related ascertainment bias; PR of 0.70 (95% CI 0.64, 0.76) for low to medium SES and 1.25 (95% CI 1.16, 1.35) for high to medium SES.[29] In the 2002 surveillance year, two sites joined MADDSP's efforts in monitoring the prevalence and characteristics of CP. The ADDM CP Network expanded with an additional CP site in 2006 and has produced four joint prevalence reports to date (2002-2008).[30-33] CP prevalence ranged from 3.6 per 1,000 (95% CI: 3.1, 4.4) in 2002 to 3.1 (95% CI: 2.8, 3.4) in 2008. ADDM CP Network data have consistently shown higher prevalence among males compared with females and among black non-Hispanic compared with white non-Hispanic children. Additional analyses using these data have demonstrated that this racial disparity was only present among children with severe gross motor impairment; this disparity persisted across gestational ages.[34] In addition, maternal education appeared to independently affect CP risk and adjustment for maternal education did not fully explain the existing racial disparities in CP prevalence in the United States.[35] Collectively, these results highlight the need for more research on risk factors for ASD and CP and further investigation into the role and impact of racial/ethnic and socioeconomic disparities.

USING DATA FOR ACTION

Over the past two decades, data from MADDSP and ADDM have been used to address a broad spectrum of public health issues ranging from evaluation of the timing of identification and receipt of services for children with ASD to examination of neurodevelopmental outcomes of children who screen positive on newborn screening. Both MADDSP and ADDM data are used to evaluate three Healthy People 2020 Maternal, Infant, and Child Health (MICH) objectives focused on: a) improving the occurrence of developmental screening and timing of evaluation and receipt of services among children with ASD (MICH.29), and b) reducing the proportion of children with CP born low birth weight (MICH.27) as well as reducing the proportion of children who screen positive on a newborn screen who require special education services (MICH.26).[36] MICH.29 is comprised of three sub-objectives focusing on screening, evaluation and receipt of special services using data from the NSCH, ADDM and MADDSP, respectively. While overall, the proportions of toddlers screened for ASD and other DDs have increased from 22.6% (2007) to 38% (2011-2012), the proportion of children with ASD who had their first evaluation by 36 months or were receiving special services by 48 months has been unchanged across four ADDM cohorts: 2006, 2008, 2010 and 2012 (see Figure 3). No differences were observed in the proportion of toddlers screened among white non-Hispanic, black non-Hispanic and Hispanic children, yet lower proportions of black non-Hispanic and Hispanic children with ASD received their first evaluation by 36 months compared with white non-Hispanic children. These data highlight the need for continued efforts to improve professional awareness and training for developmental screening and evaluation as well as greater accessibility and continuity between medical and education settings with a specific focus on improvements within minority populations. To this end, CDC partnered with ADDM communities to host community engagement events with key stakeholders to identify barriers to and opportunities for improvements in early identification and access to services for all children with ASD with a specific focus on reducing racial/ethnic disparities.

CDC's surveillance efforts have been unique in their ability to provide empiric support for conducting universal newborn hearing screening as well as the consequent developmental outcomes among children with confirmed newborn screen conditions. In the late 1990s, MADDSP data reported that the median earliest age at documented identification for moderate to profound, bilateral HL was on average 2.9 years ranging from 2.4 years for children with severe to profound HL to 3.6 for moderate HL.[37] These data helped serve as the impetus for Universal Newborn Hearing Screening implemented in every state nationwide since 1999. MADDSP linkages and special studies as well as utilization of the entirety of special education data received from the metropolitan Atlanta special education systems for MADDSP (Special Education Database of Metropolitan Atlanta, SEDMA) have demonstrated an increased likelihood of developmental disabilities and receipt of special education services among children with congenital heart defects, orofacial clefts and those with positive newborn screens who are subsequently confirmed with a metabolic or endocrine disorder.[38-40] Findings from one of these efforts, in particular, supported the clinical concern of a relationship between children with *duarte galactosemia* and speech and language impairment, underscoring the need for further examination of the length of monitoring and intervention for children with this milder variant of *galactosemia.*[41] Together these findings underscore the need for early evaluation and identification of neurodevelopment issues among children with life-long conditions identified at or around the time of birth.

DATA GAPS AND LIMITATIONS

CDC's population-based surveillance programs for DDs have many advantages over other methods for obtaining prevalence and describing the characteristics of children with DDs. The ADDM Network's multiple-source methodology provides more complete case ascertainment compared with single source administrative datasets which rely on either a specific diagnosis or special education eligibility. In addition, the use of consistent methods and objective test scores and behavioral descriptions for case determination is an additional strength. However, there are several areas for improvement and enhancement. First, since clinical evaluation is the "gold standard" for identifying ASD (based on behaviors) and CP (based on neurological findings), clinical validation provides data for key measures for evaluating surveillance programs, i.e., sensitivity, specificity, positive predictive value, and negative predictive value. An evaluation of MADDSP published in 2010 found that sensitivity was 60%, determining that MADDSP prevalence for ASD in metro Atlanta was conservative.[42] As the prevalence and characteristics of the children identified through surveillance have changed over time, a contemporary validation study would be informative. Because MADDSP and ADDM rely on the availability and completeness of information in source records, this information will likely improve in the future when the conversion to electronic medical records is complete. Whereas CDC's ongoing population-based surveillance provides the best estimate of the prevalence of ASD and other DDs in multiple communities across the United States, with rich information about the children and families, the sample size, especially for CP, is limited for examining some important issues within smaller subgroups, such as for refined birth-weight groups and assessment of trends over time.[21] Expansion of the ADDM Network to include additional sites would provide larger samples to examine some of these important public health questions. Due to ADDM's competitive application process, sites were not chosen for their representativeness of the US population, as such MADDSP and ADDM data are limited in their generalizability. As CDC surveillance for DDs has expanded to include younger children through the Early ADDM Network, challenges with data linkages such as early intervention service information have become apparent.[43] Working with these systems will become increasingly important as surveillance expands beyond school-age children with the goal of identifying children closer to the time of exposures contributing to the development of the DDs.

As the literature continues to report benefits of intervention for children with DDs, especially younger children, it is becoming increasingly important to capture this information and evaluate the type and frequency of interventions in order to develop a more complete picture of the developmental trajectory, cost, and effect of intervention on long-term outcomes.[44] With a reported prevalence of ASD of between 1% and 2%, there is growing concern about the transition of these children to adulthood and medical, vocational, and social service systems are beginning to be impacted by the large number of young adults with ASD. From a public health perspective, extending surveillance of children as they age in order to capture the myriad of transition issues is essential.

FUTURE ISSUES

With the adoption of the DSM-5 in 2013, there is a question about the impact of the revised ASD diagnostic criteria on prevalence. Historically, a correlation between ASD diagnostic criteria and the prevalence of ASD has been demonstrated, with broadening of criteria leading to higher prevalence estimates.[45] It has been projected that ASD prevalence will be lower using DSM-5, but this has yet to be quantified in the population. The ADDM Network in an ideal position to evaluate the impact of changing diagnostic criteria on the measured prevalence of ASD with empirical data over the next several study years. ADDM Network ASD cases will be identified using DSM-IV-TR and DSM-5 criteria, with comparison anticipated for the 2014 and 2016 surveillance years.

MADDSP and ADDM data have been critical to our understanding of racial/ethnic and SES disparities in the prevalence of a number of DDs.[17,28,33,34] However, understanding why these disparities exist, and why disparities in conditions such as CP and ID persist despite public health efforts to improve maternal, perinatal and neonatal care, remains one of the biggest challenges in the field. As we know more about prevention of post neonatal causes of DDs (e.g., infection, injury), we should be more aggressive in our efforts to lower their prevalence from known preventable causes. Yet, our limited understanding of the prevention of congenital causes and risk factors for DDs warrants future focus and priority.

ADDITIONAL RESOURCES

- National Health Interview Survey
  http://www.cdc.gov/nchs/nhis.htm
- National Survey on Children's Health
  http://www.cdc.gov/nchs/slaits/nsch.htm
- National Survey on Children with Special Health Care Needs: http://www.cdc.gov/nchs/slaits/cshcn.htm
- Autism and Developmental Disabilities Monitoring Network:
  http://www.cdc.gov/ncbddd/autism/addm.html
- Metropolitan Atlanta Developmental Disabilities Surveillance Program:
  http://www.cdc.gov/ncbddd/developmentaldisabilities/maddsp.html
- Learn the Signs Act Early
  http://www.cdc.gov/ncbddd/actearly/index.html

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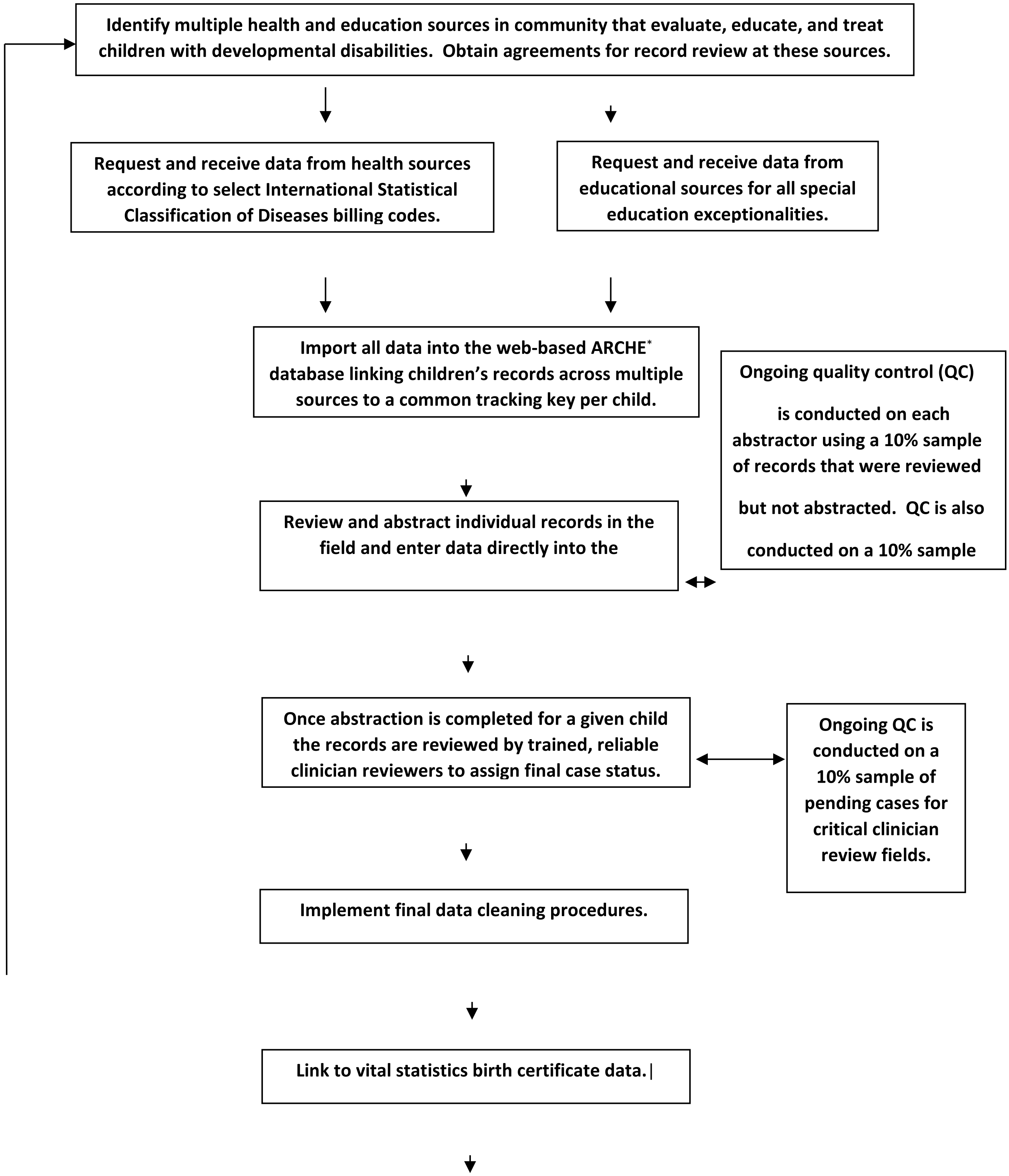
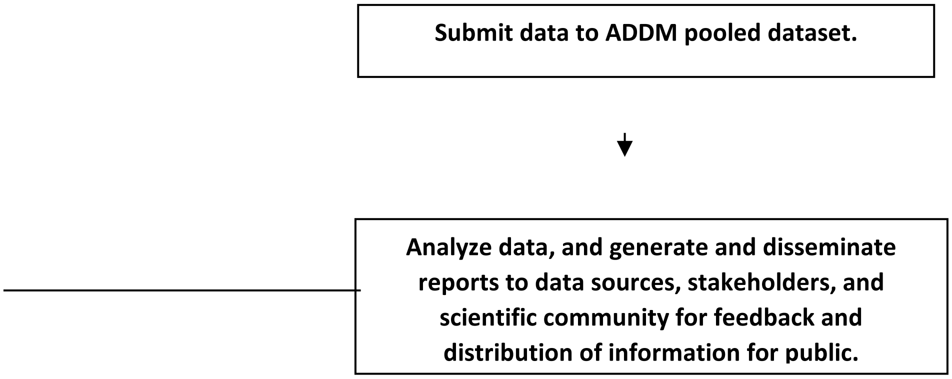
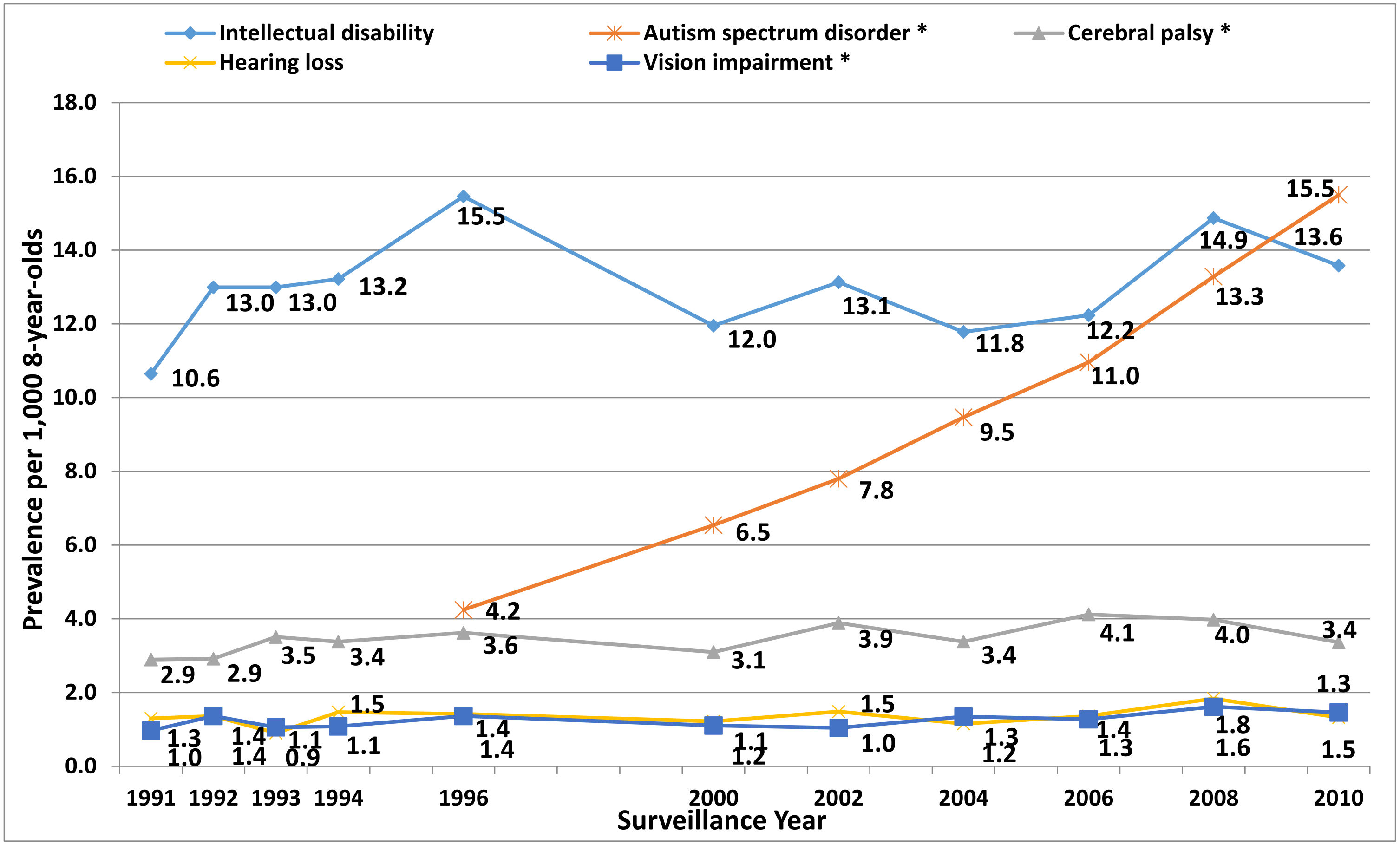
Figure 1. Flowchart for Metropolitan Atlanta Developmental Disabilities Surveillance Program (MADDSP) and Autism and Developmental Disabilities Monitoring (ADDM) Network Surveillance Methodology, 2000-2010.





|All sites conducting CP surveillance are conducting linkage of cases with vital statistics death certificates. If feasible, other sites also conducted this death certificate linkage.

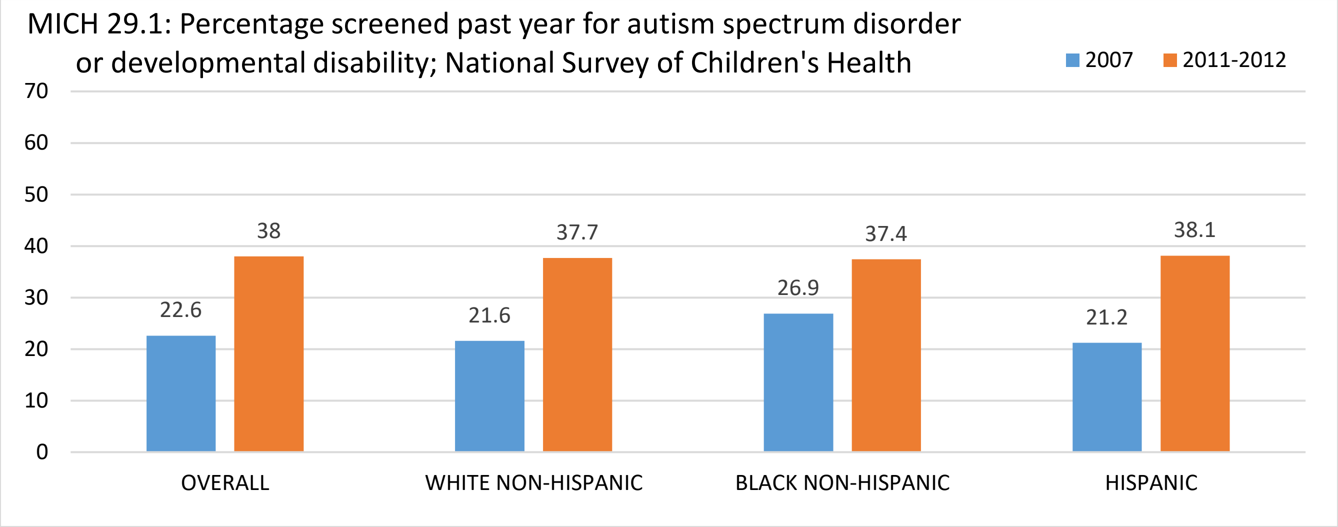
Figure 2. Trends in prevalence of five developmental disabilities, Metropolitan Atlanta^, Georgia, 1991-2010.

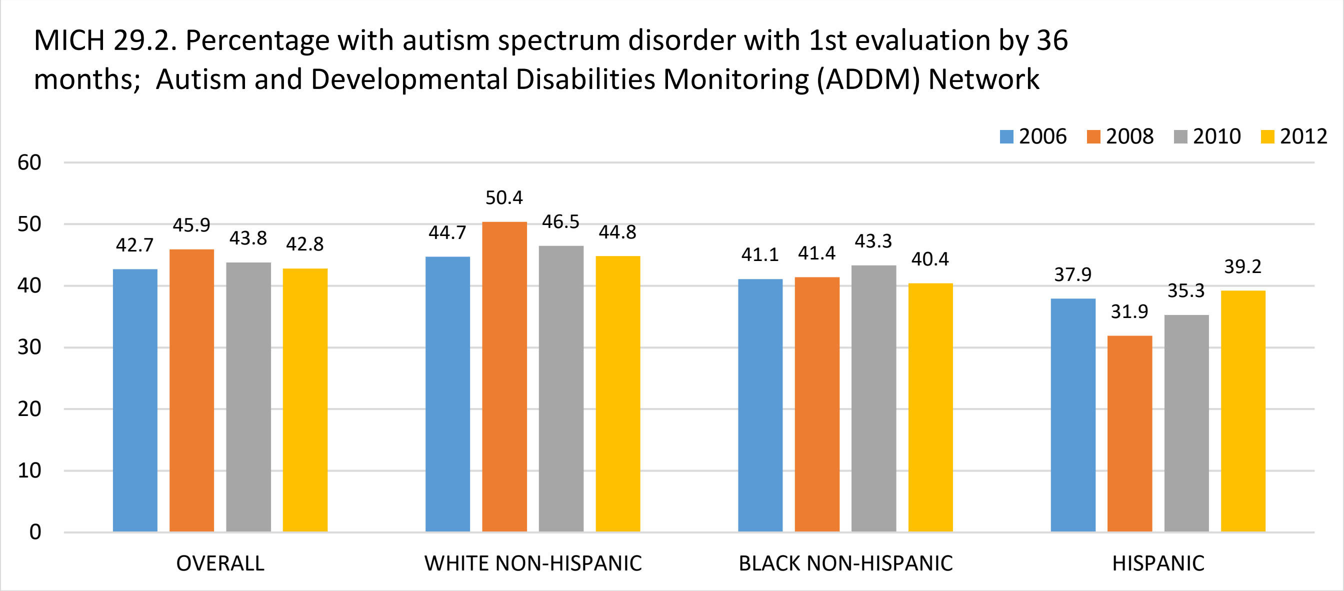


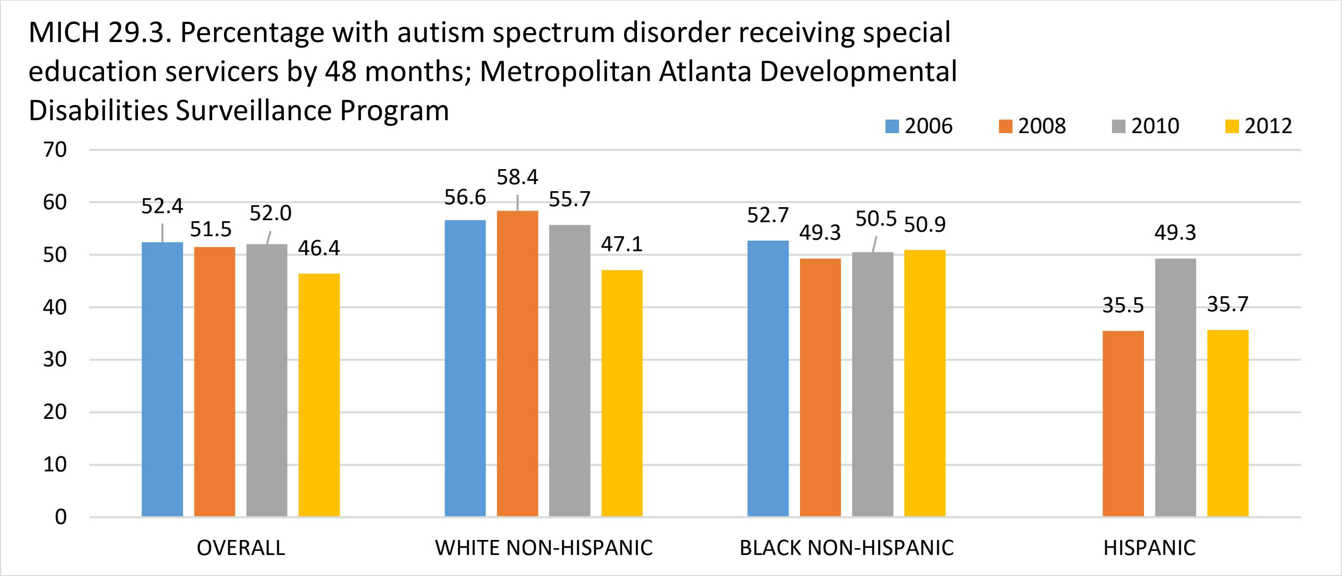
^Clayton, Cobb, DeKalb, Fulton, and Gwinnett.

*Negative binominal and Poisson regression were used to model assumed linear trends in the observed prevalence estimates. Model selection was determined using chi-square Goodness of Fit test results (p>0.05).[16]

Figure 3. Healthy People 2020 Objectives for Maternal Infant and Child Health (MICH) 29


MICH 29.1: Percentage screened past year for autism spectrum disorder or developmental disability; National Survey of Children's Health


MICH 29.2. Percentage with autism spectrum disorder with 1st evaluation by 36 months; Autism and Developmental Disabilities Monitoring (ADDM) Network


MICH 29.3. Percentage with autism spectrum disorder receiving special education servicers by 48 months; Metropolitan Atlanta Developmental Disabilities Surveillance Program

Adolescent Health

Commentary on Adolescent Health

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Adolescence and young adulthood are an important developmental period with crucial biological, cognitive, emotional, and social changes. The American Academy of Pediatrics (AAP),[1] World Health Organization,[2] the Society for Adolescent Health and Medicine,[3] the American Academy of Family Physicians,[4] and the American College of Obstetricians and Gynecologists[5] each endorse guidance pertaining to the health needs of adolescents and young adults. Ongoing public heath surveillance among adolescents supports the delivery of clinical services to address behaviors that lead to detrimental health problems. The experiences and behaviors during the adolescent period often set the trajectory for trajectory for lifelong health.[6,7]

The utility of comprehensive surveillance of adolescents has been well documented since the 1990s using the Center for Disease Control (CDC) Youth Risk Behavior Surveillance System (YRBSS) as the gauge for adolescent well being. In 1991, CDC conducted the first national school-based YRBSS.[8] It has been performed biennially during odd-numbered years among nationally representative samples of U.S. high school students. The target population comprises all public and private school students in grades 9-12 in the 50 states and the District of Columbia. The YRBSS incorporates six broad categories: 1) behavior that results in unintentional injuries and violence; 2) tobacco use; 3) use of alcohol and other drugs; 4) sexual behavior that contributes to unintended pregnancy and sexually transmitted infections (STI), including HIV infection; 5) dietary behaviors that result in disease; and 6) physical inactivity. YRBSS enable public health professionals, educators, policy makers, and researchers to monitor the prevalence of health-risk behaviors among youth.

In addition, YRBSS provide critical data on subpopulations of youths. For example, it has been noted that sexual minority and transgender youth, are at higher risk of mental health problems, including depression and suicidality, altered body image, and substance abuse.[9] In 2016, YRBSS expanded to include questions to identify sexual minority youth.[10] Sexual minority students have a higher prevalence of many of the health-risk behaviors measured by YRBSS as compared with nonsexual minority students. Because of these expanded surveillance programs, state and national programs are responding to their needs.

Teen pregnancy rates in the United States are higher than that of other high-income nations, yet there has been a downward trend in recent years with annual record lows.[11] Multiple factors, including reductions in sexual activity and the increase in use of long-acting reversible contraception, have contributed to these declines.[12] However, racial and ethnic disparities persist.[11] Adolescent birth is associated with delays in educational and career success for adolescents.[13] Moreover, pregnant teenagers are more likely to seek medical care later, putting them at risk of pregnancy-related health problems such as higher rates of preterm birth and infant mortality.[14] Community wide initiatives that integrate evidence based programs coupled with increase in access to youth-friendly reproductive health services show promise as a strategy to work with communities to address high rates of teen pregnancy and reduce disparities.[15]

Most of the mortality during adolescence is attributable to unintentional injuries, suicide, and homicide. Approximately 79% of all unintentional injury deaths among adolescents are attributable to injuries related to motor vehicle crashes.[16] Injury related deaths in adolescents, including homicide and suicide, and are often influenced using alcohol and illicit substances.[17]. There is an interplay between many risk factors for poor outcomes among adolescents including poor school performance, bullying, involvement in the juvenile justice system, substance abuse, and high-risk sexual behaviors. Overarching strategies such as positive youth development and encouraging parental engagement can help mitigate many of these intermingling factors.[18]

More adolescent patients are presenting with chronic medical illness as survival rates improve for some conditions such as congenital heart disease, while others such as increases in obesity, reflect ongoing societal challenges.[19] We know that integrating adolescent-centered approaches into existing state and local systems of care, many of which are funded with Title V Maternal and Child Health Block Grants, has the potential to bolster opportunities for optimal development and care of teens.

Opportunities for improvement in clinical care exist. According to the National Ambulatory Medical Care Survey and the National Hospital Ambulatory Medical Care Survey, only 39% of adolescents received any type of preventive counseling during ambulatory visits.[20] There needs to be an increase in evidence based recommended screening and counseling for adolescents, while supporting best practices such as confidentiality protections. When considering the health challenges to adolescents, it is imperative to take into account not only the clinical context, but also the social and ecologic factors (e.g., socioeconomic status, family composition, parental education and engagement, neighborhood and school environment, religion, earlier childhood trauma and toxic stress, and access to health care). Cultural humility and competence are also key for adolescent health practitioners, according to the US Census, the current population of adolescents is more diverse than the adult population, and this trend is predicted to continue in the foreseeable future.[21]

In this DATA to ACTION report, three chapters in this section highlight the needs of the adolescent population. These chapters also reflect that through the combined efforts of the medical organizations that care for children, adolescents and young adults as well the concerted efforts of the public health stakeholders to continuously monitor this population through robust surveillance systems, our adolescents and young adults can lead healthy and productive lives best prepared to reach their full potential.

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Youth Risk Behavior

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America's youth practice behaviors that may compromise their health and result in injury and death. CDC partners with state and local health and education agencies to assess behaviors such as sexual activity; tobacco, alcohol, and other drug use; and poor nutrition that impact their ability to be academically successful and live healthy, productive lives into adulthood.

PUBLIC HEALTH IMPORTANCE

In the United States, 71% of all deaths among youth and young adults aged 10-24 years result from four causes: motor vehicle crashes (23%); other unintentional injuries (17%); suicide (17%); and homicide (14%).[1] A considerable amount of acute and chronic morbidity also results from these causes.

Excessive alcohol consumption is responsible for more than 4,300 deaths among youth under age 21 in the United States each year[2] and underage drinking cost the United States $24.3 billion in 2010.[3] About 90% of the alcohol consumed by youth under age 21 occurs while binge drinking and the risk of alcohol-attributable harms (e.g., motor vehicle crashes) increases with the amount of alcohol consumed.[4] Alcohol use is a factor in about one-third of all traffic-related deaths[5] and is often a contributing factor in homicides and suicides. The use of alcohol and other drugs also contributes to many important social problems - including family problems, crime, poor school performance, and lost economic productivity - that are not reflected in vital statistics.[6]

Among youth aged 15-19 years, substantial morbidity and social problems also result from the estimated 273,105 births;[7] 451,208 cases of chlamydia, gonorrhea, and syphilis;[8] and 1,828 cases of human immunodeficiency virus (HIV)[9] reported annually. Young persons aged 13-24 years accounted for an estimated 22% of all new diagnoses of HIV in the United States in 2014.[10]

Finally, among adults aged ≥25 years, 54% of all deaths in the United States result from just two causes: cardiovascular disease (31%) and cancer (23%).[1] Cardiovascular disease and cancer are also related to an enormous amount of acute and chronic morbidity and are often caused by health behaviors usually initiated and established during youth.

This review of the leading causes of mortality and morbidity among youths and adults indicates that nearly all contributing behaviors can be assigned to one of six broad categories: 1) behavior that results in unintentional injuries and violence; 2) tobacco use; 3) use of alcohol and other drugs; 4) sexual behavior that contributes to unintended pregnancy and sexually transmitted infections (STI), including HIV infection; 5) dietary behaviors that result in disease; and 6) physical inactivity. These behaviors are both interrelated and preventable. Population-based data on these behaviors at the national, state, and local levels can help monitor the effectiveness of public health interventions designed to protect and promote the health of youth nationwide.

HISTORY OF DATA COLLECTION

In 1988 CDC began developing the Youth Risk Behavior Surveillance System (YRBSS)[11] to 1) focus the nation on specific behaviors that cause the most important health problems among youths; 2) assess whether these behaviors increase, decrease, or remain the same over time; and 3) provide comparable data among national, state, and local samples of youths. A panel of experts was established for each of the six broad categories of behaviors listed in the above paragraph. Each panel was asked to identify the highest priority risk behaviors in each category and to develop survey questions to measure this behavior. These panels consisted of scientific experts from relevant federal agencies, scientists from outside the federal government, representatives of state and local health and education agencies, and survey research specialists and subject matter experts from throughout CDC. Because students would have a class period of about 45 minutes to complete the questionnaire covering all six categories of behaviors, each panel was asked to identify only the highest priority behaviors and to suggest a limited number of questions to measure the prevalence of these behaviors.

The first version of the YRBSS questionnaire was completed in October 1989 and was reviewed at a national conference by representatives of each state department of education and 16 local departments of education. Survey research specialists also provided comments and suggestions on that version of the questionnaire. Following this conference, the questionnaire was revised, and a second version was completed in November

1989. This questionnaire was used the following spring to generate data from national, state, and large urban school district samples of students in grades 9-12. This questionnaire also was sent to the Questionnaire Design Research Laboratory at the National Center for Health Statistics at CDC for four waves of laboratory and field-testing with high school students. A review of student responses led to the development of recommendations to improve the wording of questions, set recall periods, and identify response categories. The field tests sought to identify survey conditions that could be expected to encourage students to be honest in answering survey questions.

A core and a national questionnaire are now reviewed and amended prior to each survey cycle to best meet the needs of participating states, large urban school districts, territories, and tribal governments as well as CDC and its partners. The core questionnaire is the starting point for all state, large urban school district, territory, and tribal government Youth Risk Behavior Survey (YRBS) questionnaires. The national questionnaire is used for the national YRBS and always contains the entire core questionnaire plus eight to ten additional questions of particular interest to CDC or its partners. The 2017 core questionnaire contains 89 multiple-choice questions and the 2017 national questionnaire contains 99 multiple-choice questions. Both questionnaires are self-administered and have about a grade-7 reading level. In addition to measuring the six categories of health-risk behaviors, they also include questions to assess self-reported height and weight, HIV testing, asthma, sleep, dental health, grades in school, and sexual minority status. The national questionnaire also includes questions on sun exposure and food allergies. A standard computer-scannable bubble sheet is used to record responses. Skip patterns are not included in the questionnaires to help ensure that students do not lose their place on the answer sheet when recording responses and to prevent students from looking at other youths' answer sheets to detect a pattern of blank responses that might identify the risk behavior of those students.

Over time, both the quality and quantity of YRBSS data have improved. During the 1991 cycle, just 26 states and 11 large urban school districts conducted a YRBS and only 35% of the states and 64% of the districts obtained an overall response rate (i.e., school response rate x student response rate) high enough (60% is the threshold established by CDC) to generate weighted data. During the 2015 cycle, 47 states and 21 large urban school districts conducted a YRBS and 79% of states and 90% of districts had weighted data. In addition, a small number of territories and tribal governments conduct YRBS's occasionally as well.

CDC SURVEILLANCE ACTIVITIES

The YRBSS currently has two complementary components conducted among high school students as mentioned above: 1) national surveys, and 2) state, large urban school district, territorial, and tribal government surveys. The YRBSS also includes additional surveys conducted by CDC:

- A middle school survey conducted by interested states, territories, tribal governments, and large urban school districts.[12]
- A 2010 study to measure physical activity and nutrition-related behaviors and determinants of these behaviors among a nationally representative sample of high school students (http://www.cdc.gov/healthyyouth/data/yrbs/nypans.htm).
- A series of methods studies conducted in 1992, 2000, 2002, 2004, and 2008 to improve the quality and interpretation of the YRBSS data.[13-22]
- The National Alternative High School Youth Risk Behavior Survey conducted in 1998 among a representative sample of almost 9,000 students in alternative high schools.[23]
- The National College Health Risk Behavior Survey conducted in 1995 among a representative sample of about 5,000 undergraduate students.[24]

National Surveys

In spring 1991, CDC conducted the first national school-based YRBS, which has been conducted biennially during odd-numbered years since then, among nationally representative samples of US high school students. The target population comprises all public and private school students in grades 9-12 in the 50 states and the District of Columbia. The national YRBS uses a three-stage cluster sample design with oversampling of black and Hispanic students. At the first stage, primary sampling units (PSU) consisting of large-sized counties or groups of smaller, adjacent counties are selected with probability proportional to enrollment size of schools within the PSU. Schools are then selected with probability proportional to enrollment size and then classes are randomly selected in each sampled school. All students in sampled classes are eligible to participate. The average sample size is approximately 14,400.

State, Large Urban School District, Territorial, and Tribal Government Surveys

Since 1990, CDC has provided funding and extensive technical support to state, large urban school district, territorial, and tribal government education and health agencies to conduct a YRBS among representative samples of students in grades 9-12 in their jurisdiction. The target population in most sites is public schools, but some states also elect to include private schools. These surveys typically employ a two-stage, cluster sample design. Schools are selected with probability proportional to enrollment size and then classes are randomly selected in each sampled school. All students in sampled classes are eligible to participate. The average sample size is 2,600 though these sample sizes range from approximately 1,100 to more than 53,000. Each participating agency starts with the same core questionnaire that may be modified by adding, deleting, or modifying questions to meet local needs. To help improve the quality of the surveys and increase the usefulness of the data, CDC provides several types of technical assistance to funded agencies. For example, CDC has developed a *Handbook for Conducting Youth Risk Behavior Surveys* to help state and local agencies plan surveys; obtain clearance; select schools, classes, and students; contact or notify parents about the surveys; conduct surveys; prepare data for analysis; and report survey results. CDC also offers a two-day intensive YRBS training for survey coordinators, monthly YRBS newsletters, specialized products such as videos to explain class sampling and data preparation, a YRBS listserv for YRBS coordinators to exchange ideas and share successful strategies, a secure survey technical assistance website that provides technical resources and access to survey reports and data sets, and one-on-one technical support available via email or telephone. CDC provides data analysis services that include scanning answer sheets and cleaning, editing, weighting, and analyzing data. Standard procedures are used to help make results comparable across sites. CDC generates a detailed technical report for each survey and can help agencies interpret, apply, and disseminate results. The data generated from these surveys remain the property of the agency conducting the survey.

GENERAL FINDINGS

Results from the 2015 national YRBS[25] indicated that many high school students are engaged in priority health-risk behaviors associated with the leading causes of death among persons aged 10–24 years in the United States. During the 30 days before the nationwide survey of high school students:

- 41.5% of the 61.3% who drove a car or other vehicle had texted or emailed while driving.
- 32.8% had drunk alcohol.

- 21.7% had used marijuana.

During the 12 months before the survey:

- 15.5% had been electronically bullied.
- 20.2% had been bullied on school property.
- 8.6% had attempted suicide.

Many high school students are engaged in sexual risk behaviors that contribute to unintended pregnancies and STI, including HIV infection. Nationwide, 41.2% of students had ever had sexual intercourse; 30.1% had had sexual intercourse during the three months before the survey (i.e., currently sexually active); and 11.5% had had sexual intercourse with four or more persons during their life. Among currently sexually active students, 56.9% had used a condom during their last sexual intercourse.

Results from the 2015 national YRBS also indicate many high school students are engaged in behaviors associated with chronic diseases, such as cardiovascular disease, cancer, and diabetes. During the 30 days before the survey, 10.8% of high school students had smoked cigarettes and 7.3% had used smokeless tobacco. During the seven days before the survey, 5.2% of high school students had not eaten fruit or had not drunk 100% fruit juices and 6.7% had not eaten vegetables. More than one-third (41.7%) had played video or computer games or used a computer for something that was not school work for three or more hours per day on an average school day.

USING DATA FOR ACTION

YRBSS data are used to describe health-risk behaviors among high school students and to compare how health-risk behaviors vary among subpopulations of students. They assess trends in health-risk behaviors over time; monitor progress toward achieving 20 national health objectives[26] and other indicators of the success of public health policies, programs, and other interventions[27, 28]; develop, assess, and improve health-related policies, programs, and practices; support development of policies and legislation designed to improve the health of youth; and advocate for increased resources for school and community health programs.

Alaska used their YRBS data to monitor the frequency of soda and other sugar-sweetened beverage consumption among high school students. A new Sugary Drinks Public Education media campaign was specifically designed to reduce the frequency with which these beverages are consumed and the Alaska YRBS is among the data sources used to assess the impact of this campaign.

In Kentucky, after reviewing their YRBS data on fruit and vegetable consumption, physical activity, and obesity, the Coordinated School Health Program and Kentucky Action for Healthy Kids collaborated to create Students Taking Charge projects in high schools around the state. This initiative trains high school students to assess their school's nutritional and physical activity environment, develop an action plan to improve it, implement their plan using mini-grants, and learn how to advocate for healthier school environments and policies.

Maine's YRBS data on suicide ideation and attempts were used to support the Maine Youth Suicide Prevention Project. Maine's YRBS data on suicide ideation and attempts also were used to support passage of a bill which requires the Department of Education to adopt rules on standards for schools and school administrative units for suicide prevention education and training. The training and education included suicide prevention awareness education for all personnel and more advanced suicide prevention and intervention training for at least two persons per school district.

Massachusetts used their YRBS data to describe the needs of sexual minority youth to stakeholders and to support schools in modifying their sexual health curricula and lessons to make them more inclusive of all sexual orientations and gender expressions. This resulted in the elimination of differences between the percent of sexual minority youth and all other students who ever learned about HIV in school. Additionally, YRBS data were used in a two-day training of school counselors, social workers, and nurses to help them understand the risks faced by sexual minority youth in Massachusetts and the impact that their support can have in reducing those risks.

Montana YRBS data on bullying were used to support passage of a new rule in Montana's Standards of Accreditation. The Student Protections Procedures rule requires schools to address bullying and threatening behavior in schools, on school buses, at school-sponsored activities, and online. A Bully Free Montana website (http://opi.mt.gov/Programs/TitlePrgms/SafeSchools/bully.html) and other materials were created as a result.

Montana's YRBS data on bullying also stimulated the inclusion of a bullying prevention component into their 21st Century Community Learning Center Programs,

The Tobacco Use Prevention and Control (TUPAC) Program in New Mexico and its partners regularly refer to the YRBS data for planning youth tobacco use prevention strategies. For example, TUPAC has used current cigarette use data as its primary indicator of program success. Recently, their YRBS data indicated the emergence of other tobacco product use (e.g., hookah and shisha) among youth. Consequently, current tobacco use data and hookah and shisha data from their YRBS were added as indicators of program success and TUPAC developed a campaign called "Clear the Haze" for high school students to raise awareness about the dangers of hookah use. TUPAC also analyzed their YRBS data to help plan social media campaigns aimed at preventing youth tobacco use. Further, data from their YRBS questions on current cigarette use on school property have been used by TUPAC's statewide contractor to provide school policy technical assistance and guidance to schools and districts around the state as part of the 24/7 campaign to make schools tobacco free.

Utah YRBS data on texting while driving were used to evaluate the impact of the no texting while driving law a year after it was passed to see how rates had changed. These YRBS data were also compared to Behavioral Risk Factor Surveillance System data to look for differences between youth and adults.

Wisconsin used their YRBS data on sexual minority youth in numerous reports and presentations including a disparities report as part of their Healthiest Wisconsin 2020 initiative. In addition, their YRBS data on sexual minority youth were used to support a requirement that all district grantees within the Safe and Supportive Schools Project (https://dpi.wi.gov/sspw/safe-schools/safe-and-supportive) select at least one strategy that addresses the needs of sexual minority youth. Their YRBS data also were used to support the development of an enumerated model bullying policy, and they continue to use these data to help educate districts on pupil nondiscrimination and protections provided for sexual minority students.

The Chicago Public Schools used their YRBS data on physical education attendance to demonstrate how a new physical education waiver had decreased attendance in physical education. These YRBS data were combined with data from Chicago's Department of Public Health showing that about half of all Chicago Public School students were overweight or obese and then used to support an updated, district-wide policy requiring daily physical education for all students.

The Los Angeles Unified School District used their YRBS data to support a new Los Angeles County ordinance on electronic cigarettes and vaping. Their YRBS data were presented to the Los Angeles Board of Supervisors who create policy for the City of Los Angeles and led to the passage of an ordinance to treat electronic cigarettes/vaping as a tobacco product to be banned from public spaces, bars, and restaurants. In addition, their school district policy on tobacco use for youth and adults is being changed to reflect the new city ordinance.

In Philadelphia, their YRBS data on sexual behaviors were cited along with data on the prevalence of chlamydia and gonorrhea to help persuade the Philadelphia Department of Health and the School District of Philadelphia to set up an in-school STI screening program to educate students about STIs and identify and treat chlamydia and gonorrhea among high school students.

The San Diego Unified School District used their YRBS data to identify symptoms of an unhealthy school environment, including feeling unsafe at school or on the way to or from school, feeling sad or hopeless, considering or planning suicide, or having attempted suicide among all students including sexual minority students. This spurred development of a district-wide Bullying, Harassment, and Intimidation Prohibition Policy (https://www.sandiegounified.org/schools/dingeman/bullying-harassment-and-intimidation-prohibition-policy) that complies with federal and state laws and extensively delineates the types of protections addressed.

DATA GAPS AND LIMITATIONS

Like all public health surveillance systems, the YRBSS is subject to at least several limitations. YRBSS data are self-reported, and the extent of underreporting or overreporting of behaviors cannot be determined, although methodology studies demonstrate that the data are of acceptable quality.[13-22] YRBSS data apply only to youths who attend school and, therefore, are not representative of all persons in this age group. Nationwide, in 2009, approximately 3% of persons aged 16–17 years were not enrolled in a high school program and had not completed high school.[29] Local parental permission procedures are not consistent across school-based survey sites. However, in a 2004 study, CDC demonstrated that the type of parental permission typically does not affect prevalence estimates as long as student response rates remain high.[30] State-level data are not available for all 50 states. Three states (Minnesota, Oregon, and Washington) do not participate in the YRBSS and, in every cycle, some state and local agencies do not obtain a high enough response rate to get weighted data. YRBSS addresses only those behaviors that contribute to the leading causes of morbidity and mortality among youths and adults. However, school and community interventions should focus not only on behaviors but also on the determinants of those behaviors. Self-reported height and weight is used to calculate body mass index (BMI), and therefore, YRBSS estimates of BMI tend to underestimate the prevalence of obesity and overweight.[15] Not all participating states and local agencies include all of the standard questions on their YRBS questionnaire.

FUTURE ISSUES

YRBSS is evolving constantly to meet the needs of CDC and other users of the data. The core and national questionnaires are revised before each biennial cycle to reflect the latest and most important public health issues and new survey populations periodically have been added to the system since its inception. For example, the YRBSS is a primary data source for monitoring the impact of two major CDC cooperative agreements: Promoting Adolescent Health Through School-Based HIV/STD Prevention and School-Based Surveillance (CDC-RFA-PS13-1308 - https://www.cdc.gov/healthyyouth/fundedpartners/1308/pdf/rfa-1308.pdf) and State Public Health Actions to Prevent and Control Diabetes, Heart Disease, Obesity and Associated Risk Factors and Promote School Health (CDC-RFA-DP13-1305 - https://www.cdc.gov/chronicdisease/about/state-public-health-actions.htm). This required implementation of more than 60 new sub-site surveys during the 2015 and 2017 YRBSS cycles in the schools chosen as the focus of intervention efforts for these cooperative agreements. Some states also have elected to conduct surveys at the county, region, or school district levels greatly increasing overall sample size and the resources needed for survey implementation and data processing.

In addition, two questions measuring sexual minority status (one on sexual identity and the other on sex of sexual contacts) were added for the first time to the core and national questionnaires for the 2015 YRBSS cycle. This generated landmark data on the sexual minority status and the health risk behaviors of US high school students,[31] but more needs to be done to further increase the number of states choosing to use these questions. Further research and development is also needed to create a credible question that could be used to measure gender identity among high school students as part of the YRBSS.

Finally, although web-based administration is not recommended for YRBSS at this time, CDC will continue to monitor schools' computer capacity as well as the development of innovative and cost-effective methods and technologies that can ensure students' privacy which could permit online administration of YRBS's in the near future.

ADDITIONAL RESOURCES

- For additional information about the YRBSS go to www.cdc.gov/yrbss.

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Pregnancy and Birth in Adolescents

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While the adolescent birth rate has declined 61% in the United States since 1991, it is still considerably higher than comparable European countries. Adolescent pregnancy and birth reflect and impact health risks and social determinants of health for adolescents and their children. CDC has established several surveillance systems to collect information on adolescent pregnancy, childbearing, fetal loss, abortion, and sexual experience: 1) births from the National Vital Statistics System; 2) abortions from the Abortion Surveillance System and Guttmacher Institute; and 3) fetal losses from the NSFG. The rates of the three outcomes are derived separately and then added together to obtain the pregnancy rate. Through these data and continued advances in electronic reporting and analyses, programs and initiatives can be targeted by federal, state, and local organizations for adolescents at risk.

PUBLIC HEALTH IMPORTANCE

The monitoring of adolescent pregnancy and related outcomes including adolescent births, abortions, and sexual risk behaviors can contribute to the development of policies and programs to improve the health of adolescents. In 2011, the most recent year for which pregnancy estimates are available, 574,000 female adolescents became pregnant in the United States.[1,2] In 2015, there were 229,715 births to females aged 15-19 (adolescents), with the birth rate among this age group 22.3 per 1,000 females.[3] Of those births, an estimated 75% were either unintended (occurring sooner than desired) or were not wanted at any time.[1] While there has been a historic decline in the overall adolescent birth rate since 1991 (Table 1), the current rate is still approximately 3 times that in France, Germany and Finland; 6 times that of the Netherlands; and 12 times that of South Korea,[4] indicating that further declines are possible. Substantial regional and state variation exists in the adolescent birth rate; for example, the adolescent birth rate ranges from 11.3 per 1,000 in Massachusetts to 41.5 per 1,000 in Arkansas (Table 2). Racial and ethnic disparities in adolescent birth rates also persist.[1,5] Use of local and state pregnancy and birth surveillance data can assist in identifying areas or groups at higher risk for implementation of appropriate intervention strategies.

Adolescent pregnancy and birth both reflect and impact social determinants of health such as educational, social, economic, and behavioral risks. Risks for adolescent pregnancy and birth include unprotected sex, low socioeconomic status, and low school performance. There is evidence that women who give birth as teens have decreased likelihood to finish high school, but whether that is due to the pregnancy itself or other mitigating factors associated with teen pregnancy is unclear.[6] In one study, only 51% of adolescent mothers graduated from high school or passed a general equivalency diploma (GED) test by age 22, compared to 89% of women who didn't have an adolescent birth.[7] When prior disadvantages were accounted for, these differences remain. Only 2% of women who had a birth before age 18 attained a college degree by age 30.[8] While employment opportunities for young women most likely to become adolescent mothers may be limited even if they do not have an adolescent birth, from 2009 to 2010, 48% of adolescent mothers had incomes below the poverty line,[9] 63% received some sort of public assistance in the first year after delivery,[10] and 58% received no child support.[11] In a study among African American women at age 32, those who had been adolescent mothers were twice as likely to be living in poverty, receiving welfare, and be unemployed compared to non- adolescent mothers.[12] As infants of teen mothers grow into childhood and adolescence, they are more likely to need foster care, drop out of school, be incarcerated, and become teen parents themselves.[13]

Adolescent pregnancy and birth also reflect and impact health risks for adolescents and their children. Unprotected sex is a risk factor not only for adolescent pregnancy but also for STDs.[14,15] Among adolescent mothers, no or inadequate prenatal care and complications of pregnancy are more common.[16,17] Infants born to adolescent moms are more likely to have low birthweight and be preterm;[17] these conditions place infants at risk for numerous complications, such as chronic lung disease, vision and hearing problems, cognitive delay, and increased risk of mortality. The infant mortality rate in 2014 was 8.56 per 1,000 live births among mothers aged less than 20 years, and 4.82 per 1,000 live births for women aged 30-34 years.[18]

HISTORY OF DATA COLLECTION

The surveillance of pregnancy among adolescents requires the collection of data on live births, fetal losses, and abortions. Historically, national data on these events have been collected by different organizations at different points in time. Since 1933, annual national data on live births to teenage mothers and birth rates for teens have been available from CDC's National Center for Health Statistics (NCHS). The national birth registration system, which was established in 1915 with 10 states and the District of Columbia, included all 48 states and the District of Columbia by 1933, with Alaska joining in 1959 and Hawaii in 1960.

Over the past three decades, CDC has established several additional surveillance systems for collecting information on adolescent pregnancy, childbearing, fetal loss, abortion, and sexual experience. In the late 1960s, CDC began work on reducing unintended pregnancies among teens. CDC assisted state and local family planning programs by providing them with analyses of state statistics on teenage pregnancy and evaluations of state and local teen pregnancy prevention programs. CDC published national and state pregnancy and birth data in a series of publications for federal, state, and local program planners and evaluators of family planning services.[2,3,16,17,19-26] In 1969, CDC began abortion surveillance activities to document the number and characteristics of women obtaining legal induced abortions, and in 1970, published CDC's first report on legal induced abortions. The term "legal" was used to contrast the reported abortions with illegal or self-induced procedures.[20] Since then, reports of annual abortion data have been published regularly.[27] CDC and the Alan Guttmacher Institute, an independent nonprofit research organization, each report national abortion data.[28-30] Data on the sexual attitudes and behaviors of adolescents who have ever had sexual intercourse contribute to our understanding of adolescents at risk of becoming pregnant.[31] The first surveys that measured sexual behavior among adolescent girls were the National Surveys of Young Women conducted in 1971, 1976, and 1979.[32] Since 1982, the National Survey of Family Growth (NSFG), conducted by NCHS, has collected data on these issues including pregnancy history and fetal loss from a sample of all US females aged 15 to 44 years.[33,34] NSFG data are used to produce estimates of sexual experience, pregnancy history, and contraceptive use estimates for adolescent girls and young women.[1,20,21] In addition, CDC's school-based Youth Risk Behavior Surveys, first conducted in 1990, collect information from middle and high school students concerning their sexual behaviors and other risk behaviors.[33]

CDC SURVEILLANCE ACTIVITIES

Pregnancy

Data on pregnancy rates reported by the NCHS combine information on the three possible pregnancy outcomes: 1) births from the National Vital Statistics System; 2) abortions from the Abortion Surveillance System[27] and Guttmacher Institute[34]; and 3) fetal losses from the NSFG.[33,34] The rates of the three outcomes are derived separately and then added together to obtain the pregnancy rate.[1,20,21] Pregnancy and pregnancy outcome rates by age, race and ethnicity are available.[2]

Live Birth

Birth data collected and reported by NCHS are based on 100% of the birth certificates filed with the health departments in all states and the District of Columbia. A birth certificate is filed for every birth occurring in the United States and includes information on the age, race, Hispanic origin, education and marital status of the mother and father, the pregnancy history of the mother, and other sociodemographic and health-related questions on the infant and mother. Although the completeness of reporting is high for most birth certificate items, the data quality of the items, in particular the medical and health information, may vary.[35,36]

Abortion

CDC's National Center for Chronic Disease Prevention and Health Promotion, Division of Reproductive Health (DRH) requests tabulated data from the central/state health agencies of 52 reporting areas (the 50 states, DC, and New York City) to document the number and characteristics of women obtaining legal induced abortions (see also chapter on "Legal Induced Abortion").[28] Currently, with the exception of New Hampshire, Maryland, and California, state health entities voluntarily report aggregated data. The number of states that provide data stratified by characteristics such as age and race vary.

Fetal Loss

Fetal loss data used to calculate pregnancy and fetal loss rates are based on information collected by the NSFG,[32] which includes questions on pregnancy history, pregnancy outcomes, and sociodemographic and health related questions, such as age, race, and Hispanic origin.[32] Estimates of fetal losses depend on the degree to which losses, particularly important at very early gestational ages, are detected and reported.

Population Estimates

Rates are calculated based on population counts enumerated as of April 1 for census years 1990, 2000, and 2010 and population estimates as of July 1 for all other years, which are available on the NCHS website.[38]

In 1997, the Office of Management and Budget (OMB) issued the ‘‘Revisions to the Standards for the Classification of Federal Data on Race and Ethnicity.”[38] These standards set forth the requirements used throughout the federal government for the recordkeeping, collection, and presentation of data on race and Hispanic origin and are used in the decennial censuses, population surveys, and administrative program reporting.[38] Among the changes required to the collection and reporting of race and ethnicity data, the revised standards permitted respondents to select more than one race; prior standards permitted the selection of only one race. As of the start of 2016, all states are now reporting multiple races. During the transition period, however, before multiple-race data are available for all states, it has been necessary to impute multiple-race responses to provide uniformity and comparability of data. Population estimates that have been modified to bridge estimates using multiple-race responses (permitted by the 1997 Office of Management and Budget standards) to single-race categories (consistent with the earlier 1977 OMB standards) are used to calculate rates; for detailed information on the estimates used to compute the rates, see *United States Census 2000 Population with Bridged Race Categories.*[39]

GENERAL FINDINGS

National Data – Pregnancy, Live Birth, Abortion, and Fetal Loss Rates

Adolescent pregnancy, abortion, fetal loss, and birth rates have all declined, with minor interruptions, since 1957; all recorded the lowest rates recorded in 2010 (the most data recent available), and the birth rate decreased further up to 2014 (Figure 1 and Table 1).[1,3,4,18,25] Small increases in pregnancy and birth rates occurred in 1970, 1979, 1980, 1982, 1985, 1987-1991, and 2006-2007 (Figure 1).

Pregnancy

From 1990 through 2010, the pregnancy rate among US females aged 15-19 years has decreased by one-half, from 116.8 per 1,000 to 58.9 per 1,000 (Figure 1 and Table 1). Except for 2006, there was a decline every year during this period; there were also reductions in the rate for each pregnancy outcome: births, abortions, and fetal losses. Among 15 to 17-years-old females, the pregnancy rate declined from 77.1 per 1,000 to 32.2 per 1,000 (58% decrease), and among 18 to 19-year-olds, from 167.7 per 1,000 to 96.8 per 1,000 (42%). Among non-Hispanic white, non-Hispanic black, and Hispanic females from 1990 through 2010, the pregnancy rate declined from 86.8 per 1,000 to 38.8 (55%), 232.7 to 103.4 (56%), and 167.4 to 87.7 (48%), respectively.[4] From 1990 through 2010, while the number of women aged 15-19 years rose by 23%, the number of pregnancies among adolescent females declined by 38%.

Live Birth

Birth rates have declined with minor interruptions since 1957 (Figure 1). Since 1991, the birth rate for teenagers has fallen 61%. Except for a 5% rise from 2005 through 2007, the decrease in the live birth rate has accelerated in more recent years to historic lows for all groups. While the birth rate declined 33% in the 16-year period from 1991 through 2007, it has declined 42% from 2007 through 2014. By age group, the birth rates declined for teenagers aged 15–17 years (72%) and 18–19 years (53%) from 1991 through 2014 with similar declines by age and race/ethnicity, respectively. Declines between 1991 and 2014 occurred for non-Hispanic white (43.4 to 17.3, [60%]), non-Hispanic black (118.2 to 34.9 [70%]), and Hispanic teens (104.6 to 38.0 [64%]); there were 72% declines among Asian or Pacific Islander and 68% declines among American

Indian or Alaska Native teens. The disparity between non-Hispanic whites and Hispanics or non-Hispanic blacks has also decreased.[5]

Abortion

The abortion rate for teenagers aged 15-19 years has decreased 64% since 1990, declining nearly every year (except in 2006) from 40.3 abortions per 1,000 females in 1990 to 14.7 per 1,000 females in 2010, the most recent data available.[2] The abortion rate for younger teenagers aged 15-17 years and older teenagers aged 18-19 years also declined nearly every year from 1990 to 2010, by 68% and 59%, respectively. Abortion rates declined for the three race and Hispanic origin groups for which data are available. The rate for non-Hispanic white, non-Hispanic black, and Hispanic teens aged 15-19 years were down 74%, 56%, and 61%, declining almost every year to 2010, to 8.5, 36.8, and 15.4 abortions per 1,000 females, respectively.

The teenage abortion ratio (the number of abortions per 1,000 live births among women 15–19 years of age) fell generally from 1990 to 2010, from 673 per 1,000 in 1990 to 428 in 2010. The decrease in the abortion ratio indicates that a relatively greater proportion of teenage pregnancies are ending in births. The abortion ratios for younger and older teens, and for non-Hispanic white and Hispanic teens, declined from 1990 to 2010. The abortion ratio for non-Hispanic black teens was essentially unchanged from 1990 to 2010.

Fetal Loss

From 1990-2010, the fetal loss rate among females aged 15-19 years decreased from 16.6 per 1,000 to 10.0 per 1,000, a 40% decline. The decline in fetal loss also occurred in both age groups and by race/ethnicity: for 15 to 17-year-olds from 13.0 to 6.5 (50%); 18 to 19-year-olds from 21.2 to 14.9 (30%); non-Hispanic whites from 11.6 to 6.7 (42%); non-Hispanic blacks from 33.0 to 15.1 (54%); and Hispanics from 28.1 to 16.6 per 1,000 females (41%).[4]

State Data

Pregnancy rate data by state are not available because the survey estimates for fetal loss used to calculate pregnancy rates, which is also used with birth and abortion data, are not reliable at the state level. However, birth rates are a useful proxy for pregnancy rates at the state level. In 2014, birth rates for females aged 15-19 years varied widely by state and within state by race and Hispanic origin, although race-specific data cannot be reported for all race groups in all states (Table 2).[3,6] Overall, birth rates ranged from 10.6 births per 1,000 females in Massachusetts to 39.5 births per 1,000 females in Arkansas. For most states in 2014, birth rates for Hispanics were higher than rates for the other groups (Table 2). For non-Hispanic whites, birth rates ranged from their lowest at 4.5 births per 1,000 females in New Jersey to their highest at 37.2 births per 1,000 females in West Virginia. For non-Hispanic blacks, birth rates ranged from 15.6 births per 1,000 females in Massachusetts to 52.5 births per 1,000 females in Wisconsin. For Hispanics, birth rates ranged from 20.0 births per 1,000 females in Alaska to 54.7 births per 1,000 females in Oklahoma.

From 1991 to 2014, birth rates for teenagers aged 15–19 years either declined or remained essentially unchanged for all states, with declines ranging from 33% for North Dakota to 72% for Massachusetts and 74% for the District of Columbia (Table 2).[3] During 2007 to 2014, the most recent period of accelerated decline, birth rates for teenagers aged 15–19 years continued to either decline or remain essentially unchanged for all states. Declines ranged from 18% for North Dakota to 51% for Colorado. For non-Hispanic whites, the decline in state birth rates ranged from 19% for West Virginia to 59% for Massachusetts. The decline in state birth rates for non-Hispanic blacks ranged from 32% for West Virginia to 63% for Rhode Island. For Hispanics, the decline in state birth rates ranged from 33% for Louisiana to 66% for South Carolina.

DATA GAPS AND LIMITATIONS

As noted above, the teen birth rate is often used as a proxy for examining trends in teen pregnancy. The most common pregnancy outcome is birth, and the rates of the other pregnancy outcomes often mirror the birth rate trend. Pregnancy rates, which are based on estimates, usually lag behind availability of birth data from vital records. However, there may be local or regional variations or racial/ethnic disparities in rates of pregnancy, birth, and other outcomes that are only apparent by examining each separately. When calculating abortion rates, CDC and the Guttmacher Institute use different methods (see Chapter *Legal Induced Abortion*"); the Guttmacher Institute method may have sampling errors or biases while CDC receives incomplete data.[27-30] CDC reports aggregated data reported voluntarily by states, and the Guttmacher Institute reports information directly obtained from providers, with some adjustments. CDC estimates are usually lower than the Guttmacher estimates for any given year. Since there is no national surveillance for pregnancy, interpretation of pregnancy data is requires use of multiples sources of data (births from vital statistics data, abortion data from CDC and the Guttmacher Institute, and fetal losses from NSFG). Whereas the pregnancy rate is calculated based on the entire female population aged 15-19 years, pregnancy only occurs among sexually active females, which is not the denominator used for the pregnancy rate. The pregnancy rate using the sexually active population would provide information more specific to the at-risk population.

USING DATA FOR ACTION

The Department of Health and Human Services' (HHS) Teen Pregnancy Prevention Initiative grew out of concern about national teen pregnancy and teen birth rates.[40] Using vital statistics, YRBS, and other data, states have set goals, planned, and executed policies and interventions to address teen pregnancy. States often use a mixture of local and federal funds and develop partnerships with local organizations to implement programs. Successful approaches often combine the following elements: engaging stakeholders, mobilizing the community, working with diverse communities, implementing evidence-based programs, and maximizing utilization of appropriate clinical services.[41,42] Some examples of using local data to galvanize local efforts among states include North Carolina's Teen Pregnancy Prevention Initiative,[43] the Massachusetts Alliance on Teen Pregnancy,[44] the Texas Healthy Adolescent Initiative[45] and the Texas Campaign to Prevent Teen Pregnancy;[46] among national organizations, The National Campaign to Prevent Teen and Unplanned Pregnancy uses CDC's NCHS national data for numerous briefs and for their website.[47]

FUTURE ISSUES

Anticipated improvements in surveillance methodology, expansion of surveillance activities, and technological advances are likely to help us better measure our progress in reducing teen pregnancy.

Improvements in Surveillance

A recent, major improvement to vital statistics reporting is the implementation of the 2003 revision of the US Standard Certificate of Live Birth, which was completed by all states by 2016. The revised certificate includes many new items on medical and lifestyle risk factors related to pregnancy and birth. These enhancements of medical and health data on mothers and babies expand the scope of information on pregnancy outcomes among both teenagers and adults in the United States.[2,48-52] Since 1973, NSFG has collected data on several topics related to the risk of pregnancy among women aged 15-44 years. These include the characteristics of the respondent's first sexual partner and the nature of that relationship, which may help researchers better understand adolescent sexuality and risks for pregnancy. Since 1995, information on contraceptive use (for example, at first sexual intercourse; in the last three years; with the most recent partner), along with information on formal sex education and questions on the respondent's family background, allows examination of the role these factors play in teen pregnancy. Because the NSFG oversamples teens, Hispanics, and non-Hispanic blacks, improved group-specific estimates on reproductive health topics are available.

Expansion of Surveillance Activities

With the implementation of electronic registration and reporting of birth data, and with all states reporting electronically since 2005, NCHS's release of birth data files has been expedited considerably. The 2015 preliminary birth report was released six months after the end of the data year, and the 2014 birth file was released nine months after the end of the data year, the earliest releases of these data. To further expedite the timely release of birth data, NCHS has released quarterly provisional estimates of birth and fertility rates, including birth rates for teenagers, as part of Vital Statistics Rapid Release.[53] To facilitate the dissemination of the birth data files, NCHS has utilized a number of new means and added data elements for data users to access and examine birth data. These include CDC Wonder, a product that allows users to access and examine birth and death data interactively, and making public use birth files available for download from the NCHS webpage.[54,55] CDC Wonder currently includes data for 1995 through 2014 and is expanding to include data for years prior to 1995, additional data file items, and vital statistics data files other than births and deaths.

Contributors to Teen Pregnancy Rate Decline

Advances in contraceptive technology and in emergency contraception, as well as further expansion of policies that expand health care coverage and access for contraception for teens and young adults including Medicaid Family Planning Waivers and the 2010 Affordable Care Act, have made more contraceptive options available and accessible for teens.[56] Newer contraceptive options include implants (Norplanon); IUDs (Mirena, Skyla, ParaGuard, and Loleeta); and emergency contraceptives (ParaGuard, Plan B, and Next Step). Implants and IUDs are collectively known as long-acting reversible contraception (LARC); LARC use has been increasing nationally among women of all ages, and by 2014, use increased in teens to approximately 3%.[57] LARCs are safe and appropriate contraceptive methods for most women and adolescents.[58] Increased knowledge of options and availability of contraception for teens may play a role in the recent accelerated decreases in the teen birth rate.[59] However, there is concern that initiatives to promote the most effective methods of reversible contraception, such as IUD and implants, may be associated with decrease in condom use.[15] Some declines in initiation of first sex and increased use of contraception use at first sex may also play a role in the decline in the birth rate.[60] Findings from the National Survey of Family Growth show that in 2011–2013, 44% of female teenagers and 47% of male teenagers aged 15–19 years had experienced sexual intercourse; the percentage has declined significantly, by 14% for female and 22% for male teenagers, over the past 25 years. In addition, 79% of female teenagers and 84% of male teenagers used a contraceptive method at first sexual intercourse, and this use has been increasing.[58]

Teen pregnancy remains a key marker of complex interactions between social and structural factors and sexual behaviors, and an area of significant public health concern and action. Changes in reproductive health care, contraceptive options, and sexual and protective behaviors will continue to challenge adolescent pregnancy and birth surveillance and reporting. However, continued and enhanced surveillance for teen pregnancy and birth outcomes at community, state, and national levels will provide the information needed for policy and program development.

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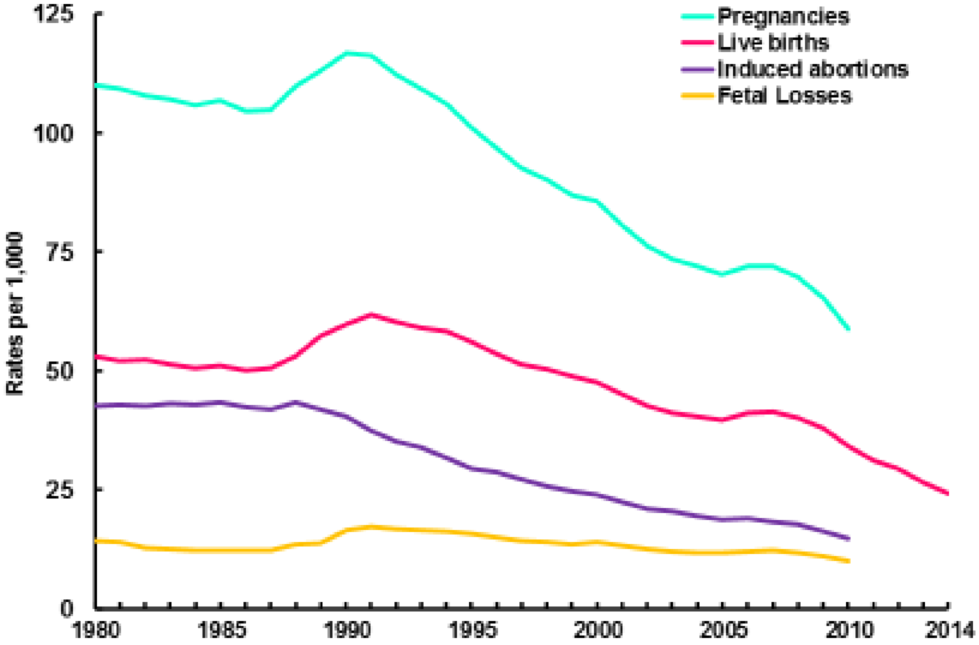
Figure 1. Pregnancy, induced-abortion, and fetal-loss rates for females 15-19 years: United States, 1990-2010, and live-birth rates for females 15-19 years: United States, 1990-2014.

Pregnancy, birth, abortion, and fetal loss rates for women aged 15–19: United States, 1980–2010, and birth rate, 2011–2014



SOURCE: National Vital Statistics System, NCHS, CDC.

Table 1. Pregnancy, induced-abortion, and fetal-loss rates for teenagers 15–17, 18-19 years, and 15-19 years, by race and Hispanic origin of mother: United States, 1990-2010, and live-birth rates for teenagers 15–17, 18-19 years, and 15-19 years, by race and Hispanic origin of mother: United States, 1990-2014

[Rates are pregnancy outcomes per 1,000 women in specified group, estimated as of April 1 for 1990, 2000, and 2010 and as of July 1 for all other years.]

Pregnancy outcome and year	All races and origins[1]			Non-Hispanic white[2]			Non-Hispanic black[2]			Hispanic[3]		
	15-19 years	15-17 years	18-19 years	15-19 years	15-17 years	18-19 years	15-19 years	15-17 years	18-19 years	15-19 years	15-17 years	18-19 years
All pregnancies												
2010	58.9	32.2	96.8	38.8	18.3	67.4	103.4	59.8	165.1	87.7	53.0	139.5
2009	65.3	36.4	106.3	42.6	20.5	73.5	113.7	67.3	179.9	100.1	61.1	158.9
2008	69.8	39.5	114.2	44.8	21.6	78.0	121.6	72.8	193.8	111.5	69.7	176.4
2007	71.9	40.6	119.6	45.9	22.3	81.3	123.5	74.4	200.9	119.9	74.1	193.3
2006	72.1	40.9	120.2	45.4	22.4	80.4	128.0	80.6	204.5	123.5	75.4	199.7
2005	70.2	40.2	116.2	44.6	21.9	79.0	122.1	75.2	197.3	122.3	76.6	193.6
2004	71.9	41.4	117.6	45.8	22.8	80.1	126.7	79.7	200.2	127.1	80.2	198.5
2003	73.6	42.9	119.9	47.7	24.2	82.9	130.9	83.7	204.3	127.5	80.6	198.4
2002	76.3	44.5	124.4	49.6	25.4	86.3	138.2	88.1	215.7	131.8	83.9	203.0
2001	80.8	47.1	130.8	52.9	27.3	91.4	148.0	94.8	228.2	137.7	87.9	209.4
2000	85.8	51.6	135.8	56.9	30.2	96.4	160.5	106.2	239.9	143.9	94.8	213.9
1999	86.9	53.1	136.6	59.0	32.4	98.2	161.9	106.4	242.9	143.2	97.0	209.6
1998	90.1	56.7	140.3	61.8	35.4	101.8	168.4	114.5	247.8	146.3	100.3	214.5

1997	92.7	59.5	144.3	64.5	37.9	106.1	174.7	121.3	257.3	147.7	102.6	215.5
1996	97.0	63.4	149.0	67.2	40.3	109.1	182.2	129.7	264.0	157.1	109.4	228.4
1995	101.1	67.4	153.4	70.6	43.0	113.7	189.6	139.4	268.4	163.3	115.5	234.2
1994	106.1	71.1	159.6	73.4	44.7	117.4	207.3	152.9	292.2	169.0	120.3	240.7
1993	109.4	72.7	164.1	75.9	46.0	120.8	219.0	161.9	305.1	170.3	117.8	247.9
1992	112.3	73.5	169.3	78.3	46.6	125.3	226.0	165.2	314.8	174.0	119.7	253.9
1991	116.4	76.1	172.1	83.8	50.1	130.4	231.8	170.5	316.0	173.7	117.4	254.3
1990	116.8	77.1	167.7	86.8	52.5	129.8	232.7	172.0	312.6	167.4	113.0	242.4
Live births												
2014	24.2	10.9	43.8	17.3	6.7	32.9	34.9	16.6	61.5	38.0	19.3	66.1
2013	26.5	12.3	47.1	18.6	7.4	35.0	39.0	18.9	67.0	41.7	22.0	70.8
2012	29.4	14.1	51.4	20.5	8.4	37.9	43.9	21.9	74.1	46.3	25.5	77.2
2011	31.3	15.4	54.1	21.7	9.0	39.9	47.3	24.6	78.8	49.6	28.0	81.5
2010	34.2	17.3	58.2	23.5	10.0	42.5	51.5	27.4	85.6	55.7	32.3	90.7
2009	37.9	19.6	64.0	25.7	11.0	46.2	56.8	31.0	93.5	63.6	37.3	103.3
2008	40.2	21.1	68.2	26.7	11.6	48.6	60.4	33.6	100.0	70.3	42.2	114.0
2007	41.5	21.7	71.7	27.2	11.9	50.4	62.0	34.6	105.2	75.3	44.4	124.7
2006	41.1	21.6	71.2	26.7	11.8	49.4	61.9	38.1	105.0	77.4	45.1	128.7
2005	39.7	21.1	68.4	26.0	11.5	48.0	59.4	34.1	100.2	76.5	45.8	124.4
2004	40.5	21.7	68.7	26.7	12.0	48.6	61.8	36.4	101.5	78.1	47.3	124.8
2003	41.1	22.2	69.6	27.4	12.4	50.0	63.7	38.2	103.4	78.4	47.6	124.8
2002	42.6	23.1	72.2	28.6	13.1	52.0	67.7	40.6	109.5	80.6	49.3	127.1
2001	45.0	24.5	75.5	30.3	14.0	54.7	73.1	44.8	115.8	84.4	51.9	131.3
2000	47.7	26.9	78.1	32.6	15.8	57.5	79.2	50.1	121.9	87.3	55.5	132.6

1999	48.8	28.2	79.1	34.1	17.1	59.4	81.0	51.7	123.9	86.8	56.9	129.5
1998	50.3	29.9	80.9	35.3	18.3	60.9	85.7	56.8	128.2	87.9	58.5	131.5
1997	51.3	31.4	82.1	36.0	19.3	62.1	88.3	60.7	131.0	89.6	61.1	132.4
1996	53.5	33.3	84.7	37.6	20.6	64.0	91.9	64.8	134.1	94.6	64.2	140.0
1995	56.0	35.5	87.7	39.3	22.0	66.2	97.2	70.4	139.2	99.3	68.3	145.4
1994	58.2	37.2	90.2	40.4	22.7	67.6	105.7	77.0	150.4	101.3	69.9	147.5
1993	59.0	37.5	91.1	40.7	22.7	67.7	110.5	81.1	154.6	101.8	68.5	151.1
1992	60.3	37.6	93.6	41.6	22.7	69.7	114.7	82.9	161.0	103.3	68.9	153.8
1991	61.8	38.6	94.0	43.3	23.6	70.5	118.2	86.1	162.2	104.6	69.2	155.4
1990	59.9	37.5	88.6	42.6	23.3	66.9	116.2	84.9	157.5	100.2	65.8	147.6
Induced abortions												
2010	14.7	8.4	23.6	8.5	4.6	14.0	36.8	22.1	57.6	15.4	8.6	25.5
2009	16.3	9.5	25.9	9.6	5.3	15.5	40.3	24.8	62.4	17.5	9.8	29.1
2008	17.8	10.4	28.6	10.4	5.7	17.0	43.4	26.7	68.2	20.1	11.7	33.2
2007	18.2	10.8	29.6	10.8	6.0	18.0	43.1	26.8	68.8	22.1	13.0	36.7
2006	18.9	11.2	30.8	11.0	6.2	18.4	45.2	28.3	72.5	22.9	13.4	38.1
2005	18.7	11.2	30.3	11.1	6.1	18.7	44.9	28.3	71.5	22.9	13.6	37.4
2004	19.5	11.6	31.3	11.4	6.3	19.0	46.4	29.6	72.6	25.7	15.1	41.7
2003	20.4	12.4	32.5	12.3	7.2	20.1	48.1	31.2	74.4	25.7	15.1	41.6
2002	21.1	12.7	33.8	12.7	7.3	21.0	50.2	32.2	78.1	27.0	16.0	43.3
2001	22.5	13.4	36.0	13.9	8.0	22.7	53.0	33.3	82.7	28.0	16.6	44.4
2000	24.0	14.5	37.7	14.8	8.5	24.1	57.4	37.3	86.8	30.3	18.4	47.3
1999	24.7	15.2	38.6	15.5	9.4	24.6	58.1	36.7	89.4	32.1	20.2	49.1

1998	25.8	16.4	40.0	16.9	10.7	26.3	58.6	38.0	89.0	33.7	21.5	51.6
1997	27.1	17.2	42.6	18.6	11.8	29.1	61.3	39.5	95.0	32.7	20.3	51.4
1996	28.6	18.6	44.0	19.3	12.6	29.8	64.1	42.4	97.9	35.7	22.9	54.9
1995	29.4	19.5	44.8	20.5	13.4	31.6	64.6	44.6	96.0	35.8	23.5	54.0
1994	31.6	21.0	47.8	21.8	14.1	33.7	71.2	49.1	105.8	39.0	26.1	58.0
1993	33.9	22.2	51.2	24.0	15.4	36.9	76.9	52.6	113.5	39.7	25.5	60.7
1992	35.2	22.9	53.3	25.3	16.0	38.9	78.6	53.5	115.2	41.6	26.8	63.3
1991	37.4	24.2	55.7	28.7	18.3	43.0	80.0	54.5	115.0	39.6	24.2	61.7
1990	40.3	26.5	57.9	32.5	21.1	46.8	83.5	57.7	117.4	39.1	24.3	59.5
Fetal losses[4]												
2010	10.0	6.5	14.9	6.7	3.7	10.9	15.1	10.3	21.9	16.6	12.1	23.2
2009	11.1	7.3	16.4	7.3	4.1	11.8	16.7	11.6	24.0	19.0	14.0	26.5
2008	11.8	7.9	17.5	7.7	4.3	12.4	17.8	12.6	25.6	21.1	15.8	29.2
2007	12.2	8.1	18.4	7.8	4.4	12.9	18.4	13.0	26.9	22.5	16.7	32.0
2006	12.1	8.1	18.3	7.7	4.4	12.6	19.1	14.3	26.9	23.1	16.9	33.0
2005	11.7	7.9	17.5	7.5	4.3	12.3	17.7	12.8	25.7	22.9	17.2	31.9
2004	11.9	8.1	17.6	7.7	4.5	12.5	18.5	13.7	26.0	23.4	17.8	32.0
2003	12.1	8.3	17.8	7.9	4.7	12.8	19.1	14.3	26.5	23.5	17.9	32.0
2002	12.6	8.7	18.5	8.3	4.9	13.3	20.3	15.2	28.1	24.2	18.5	32.6
2001	13.3	9.2	19.4	8.8	5.2	14.0	21.9	16.8	29.7	25.3	19.5	33.7
2000	14.1	10.1	20.0	9.5	5.9	14.7	23.8	18.8	31.2	26.3	20.8	34.0
1999	13.5	9.8	18.9	9.3	5.9	14.2	22.7	18.0	29.6	24.4	19.8	31.0
1998	14.0	10.4	19.4	9.6	6.4	14.6	24.1	19.7	30.7	24.8	20.3	31.4
1997	14.3	10.9	19.6	9.9	6.7	14.9	25.1	21.1	31.3	25.4	21.2	31.7

1996	15.0	11.6	20.3	10.3	7.2	15.3	26.2	22.5	32.1	26.8	22.3	33.5
1995	15.7	12.3	21.0	10.8	7.6	15.8	27.9	24.4	33.3	28.2	23.7	34.8
1994	16.3	12.9	21.6	11.2	7.9	16.2	30.4	26.8	36.0	28.7	24.3	35.3
1993	16.5	13.0	21.8	11.2	7.9	16.2	31.7	28.2	37.0	28.8	23.8	36.1
1992	16.8	13.0	22.4	11.4	7.9	16.7	32.7	28.8	38.5	29.1	23.9	36.8
1991	17.2	13.4	22.5	11.8	8.2	16.9	33.7	29.9	38.8	29.4	24.0	37.2
1990	16.6	13.0	21.2	11.6	8.1	16.0	33.0	29.5	37.7	28.1	22.9	35.3

[1] Includes live-births, induced-abortions, and fetal-losses to race and origin groups not shown separately, such as white Hispanic and black Hispanic women, and births with origin not stated.

[2] Race and Hispanic origin are reported separately on birth certificates. Persons of Hispanic origin may be of any race. Race categories are consistent with the 1977 Office of Management and Budget (OMB) standards. Forty-nine states and the District of Columbia reported multiple-race data in 2014. The multiple-race data for these states were bridged to the single-race categories of the 1977 OMB standards for comparability with other states; see reference 35. Multiple-race reporting areas vary from 2003-2014.

[3] Includes all persons of Hispanic origin of any race.

[4] Spontaneous fetal losses from recognized pregnancies of all gestational periods as estimated from reports from women in the 1995, 2002, and 2006-2010 National Surveys of Family Growth conducted by the National Center for Health Statistics. The rate of fetal loss depends on the degree to which losses at very early gestations are detected and reported. See references 1,2,31 for more information.

NOTES: Due to sample size limitations in any given year, fetal loss proportions for teenagers for 1990-2010 are based on the 1988, 1995, 2002, and 2006-2010 National Surveys of Family Growth. For information on sources and methods of estimation, see references 1,2,31.

Table 2. Birth rates for teenagers 15–19 years, by race and Hispanic origin of mother: United States and each State, 2014, and percent change in rates: United States, 2007 to 2014 and 1991 to 2014 [By place of residence. Rates are births per 1,000 women in specified group]

Area	All races and origins[1]			Non-Hispanic white[2]			Non-Hispanic black[2]			American Indian or Alaska Native[2,3]			Asian or Pacific Islander[2,3]			Hispanic[4]		
		Percent change			Percent change			Percent change			Percent change			Percent change			Percent change	
	2014	2007-2014	1991-2014	2014	2007-2014	1991-2014	2014	2007-2014	1991-2014	2014	2007-2014	1991-2014	2014	2007-2014	1991-2014	2014	2007-2014	1991-2014
U.S.	24.2	-42	-61	17.3	-36	-60	34.9	-44.0	-70.0	27.3	-45.0	-68.0	7.7	-48.0	-72.0	38.0	-50	-64
Alabama	32.0	-39	-57	28.4	-31	-50	37.3	-43.0	-66.0	16.0	†	‡	13.1	†	†	52.4	-64	†
Alaska	27.8	-35	-58	21.2	-24	-59	29.5	-48.0	-67.0	46.2	-38.0	-59.0	27.7	†	†	20.0	-65	-76
Arizona	29.9	-50	-62	17.1	-43	-68	32.7	-41.0	-76.0	38.8	-47.0	-63.0	9.4	-47.0	-66.0	42.5	-56	-66
Arkansas	39.5	-34	-50	36.4	-28	-46	50.1	-41.0	-60.0	24.8	†	-61.0	31.4	†	†	43.7	-55	-37
California	21.1	-47	-71	9.5	-43	-78	26.0	-41.0	-75.0	9.9	-47.0	-79.0	4.9	-57.0	-83.0	31.5	-51	-74
Colorado	20.3	-51	-65	12.5	-44	-69	23.8	-58.0	-81.0	16.1	-52.0	-78.0	9.7	-38.0	-72.0	37.9	-59	-68
Connecticut	11.5	-50	-71	5.0	-50	-75	19.4	-54.0	-81.0	*	‡	‡	*	‡	‡	31.4	-53	-76
Delaware	20.7	-47	-66	14.6	-40	-60	28.5	-52.0	-79.0	*	‡	‡	*	‡	‡	37.6	-60	-67
D.C.	28.4	-44	-74	*	‡	‡	41.5	-37.0	-72.0	*	‡	‡	*	‡	‡	47.7	-56	-55
Florida	22.5	-48	-67	18.2	-40	-64	33.8	-46.0	-74.0	7.5	-74.0	-87.0	5.8	-63.0	-63.0	23.3	-57	-60
Georgia	28.4	-47	-63	22.9	-41	-58	34.1	-46.0	-71.0	16.1	†	‡	8.5	-47.0	-69.0	42.5	-63	-48
Hawaii	23.1	-40	-61	17.9	-45	-53	18.0	†	-75.0	*	‡	‡	22.9	-42.0	-65.0	43.5	-49	-62
Idaho	23.2	-42	-57	19.7	-39	-60	*	‡	‡	41.7	†	-44.0	*	‡	‡	40.9	-55	-67
Illinois	22.8	-43	-65	13.3	-37	-64	44.4	-42.0	-70.0	*	‡	‡	3.2	-48.0	-74.0	33.8	-53	-66
Indiana	28.0	-35	-54	25.1	-31	-53	41.4	-44.0	-68.0	*	‡	‡	12.2	†	†	39.9	-53	-37
Iowa	19.8	-40	-53	16.1	-41	-59	41.8	-49.0	-69.0	35.3	-59.0	-62.0	11.0	†	-66.0	45.3	-49	-44
Kansas	27.6	-35	-50	21.9	-34	-53	41.2	-41.0	-69.0	21.3	†	-65.0	14.5	†	-62.0	50.0	-47	-48
Kentucky	35.3	-33	-49	35.1	-29	-46	38.7	-43.0	-66.0	*	‡	‡	13.8	†	†	41.0	-62	†
Louisiana	35.8	-35	-53	29.4	-27	-45	44.5	-41.0	-62.0	26.4	†	-54.0	14.7	†	†	47.6	-33	92
Maine	16.5	-37	-62	16.2	-36	-63	26.8	†	‡	*	‡	‡	*	‡	‡	*	‡	‡
Maryland	17.8	-48	-67	10.1	-50	-72	25.5	-49.0	-74.0	16.8	†	‡	3.9	†	-68.0	39.6	-49	†
Massachusetts	10.6	-50	-72	5.7	-59	-77	15.6	-57.0	-84.0	*	‡	‡	3.5	-74.0	-87.0	35.9	-41	-72
Michigan	21.1	-37	-64	15.6	-36	-62	42.2	-32.0	-68.0	21.5	†	-67.0	4.9	-57.0	-74.0	32.2	-54	-64
Minnesota	15.5	-44	-58	10.3	-43	-65	34.0	-51.0	-79.0	45.1	-56.0	-70.0	20.4	-52.0	-72.0	38.8	-58	-62

Mississippi	38.0	-46	-55	31.6	-41	-47	45.3	-48.0	-61.0	57.1	-44.0	-58.0	*	‡	‡	42.6	-60	‡
Missouri	27.2	-38	-58	24.0	-35	-53	42.4	-41.0	-71.0	29.1	†	-53.0	10.9	†	†	39.7	-52	-39
Montana	26.4	-25	-44	19.8	-29	-49	*	‡	‡	84.0	†	-37.0	*	‡	‡	35.7	†	-54
Nebraska	22.2	-37	-48	15.1	-35	-56	39.9	-56.0	-71.0	60.4	-48.0	-59.0	27.5	†	‡	50.4	-48	-50
Nevada	28.5	-45	-62	20.2	-35	-67	41.1	-34.0	-71.0	26.5	-42.0	-61.0	9.4	-61.0	-78.0	37.0	-56	-66
New Hampshire	11.0	-43	-67	10.8	-42	‡	*	‡	‡	*	‡	‡	*	‡	‡	20.7	-52	‡
New Jersey	13.1	-47	-68	4.5	-48	-75	25.7	-47.0	-76.0	*	‡	‡	1.4	-53.0	-81.0	29.4	-50	-64
New Mexico	37.8	-41	-52	21.1	-43	-59	26.4	-54.0	-75.0	44.7	-31.0	-52.0	*	‡	‡	45.0	-44	-55
New York	16.1	-38	-65	9.7	-34	-63	22.5	-42.0	-74.0	8.3	†	-71.0	5.6	†	-47.0	30.5	-42	-64
North Carolina	25.9	-46	-63	19.1	-42	-64	33.3	-47.0	-70.0	33.9	-38.0	-66.0	17.3	†	-44.0	45.9	-62	-48
North Dakota	23.9	-18	-33	18.7	†	-34	39.4	‡	‡	63.5	-41.0	-59.0	*	‡	‡	44.4	†	‡
Ohio	25.1	-37	-59	20.7	-36	-58	44.9	-40.0	-67.0	28.8	†	-56.0	8.2	-41.0	-45.0	39.7	-46	-51
Oklahoma	38.5	-34	-47	33.5	-31	-46	45.4	-35.0	-65.0	42.6	-44.0	-52.0	20.9	†	-45.0	54.7	-41	-39
Oregon	20.0	-42	-64	16.1	-39	-67	30.1	-34.0	-74.0	22.1	-47.0	-73.0	7.1	-44.0	-65.0	36.5	-55	-71
Pennsylvania	19.3	-37	-59	13.4	-34	-59	36.2	-45.0	-73.0	18.0	-56.0	-75.0	8.6	-41.0	-52.0	47.0	-43	-63
Rhode Island	15.8	-46	-65	9.6	-42	-71	21.2	-63.0	-86.0	*	‡	‡	*	‡	‡	39.8	-47	-63
South Carolina	28.5	-45	-61	23.6	-37	-57	35.2	-48.0	-66.0	30.3	†	‡	14.9	†	‡	43.3	-66	-28
South Dakota	26.2	-37	-45	16.3	-38	-54	35.1	‡	‡	78.6	-37.0	-49.0	*	‡	‡	42.6	-60	‡
Tennessee	33.0	-38	-56	29.2	-33	-53	43.3	-41.0	-66.0	28.0	-55.0	-68.0	14.9	-52.0	†	47.2	-65	†
Texas	37.8	-39	-52	22.4	-35	-55	37.8	-41.0	-68.0	10.1	-36.0	-79.0	6.6	-49.0	-63.0	52.4	-43	-52
Utah	19.4	-45	-60	14.5	-42	-67	24.6	-60.0	†	38.6	†	-56.0	12.3	-49.0	-65.0	43.4	-56	-57
Vermont	14.2	-32	-64	14.7	-32	-63	*	‡	‡	*	‡	‡	*	‡	‡	*	‡	‡
Virginia	18.4	-46	-66	14.6	-39	-64	25.9	-51.0	-74.0	*	‡	‡	4.6	-53.0	-69.0	32.6	-56	-46
Washington	19.1	-43	-64	14.4	-41	-69	22.5	-47.0	-77.0	34.6	-52.0	-66.0	8.5	-54.0	-67.0	39.5	-53	-67
West Virginia	36.6	-20	-37	37.2	-19	-35	34.8	-32.0	-58.0	*	‡	‡	*	‡	‡	28.8	†	‡
Wisconsin	18.0	-42	-59	11.3	-41	-62	52.5	-40.0	-71.0	36.7	-56.0	-63.0	19.1	-53.0	-73.0	38.2	-55	-58
Wyoming	30.1	-40	-45	28.2	-32	-43	*	‡	‡	46.1	-61.0	-69.0	*	‡	‡	40.1	-58	-48

Unintentional Injuries and Violence Among Adolescents (10-19 Years Old)

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Although progress has been made in lowering the rates of serious injury and death among US adolescents (10 through 19 years old), these adverse health events continue to be a substantial public health problem throughout the nation. This age group is often not aware of the level of risk associated with a particular action or of what level of skill will be required in dealing effectively with such a situation. For example, teens are more likely than older drivers to underestimate dangerous situations; in addition, teens also have the lowest rates of using seat belts of any age group of drivers in this country. Adolescents are also subject to increased risk of violence in the home, at school, and in the community. Many states are focusing on the need for legislation and regulation to protect this vulnerable population group.

PUBLIC HEALTH IMPORTANCE

Although death rates among adolescents 10 through 19 years of age have declined by over 37% since 1999, injuries continue to be a serious public health problem among youth [1]. Members of this age group are susceptible to injuries in part because they tend to participate in riskier behaviors than do their younger and older counterparts in the US population. US adolescents also tend to demonstrate poor decision-making skills compared with adults, and adolescents test boundaries as they exert their newly developing independence, which puts them even normatively at high risk[2,3]. Also implicated in higher injury rates is that an adolescent's brain and executive functions (which are thought to involve the frontal lobes of the brain and can have a major impact on our ability to perform such tasks as planning, prioritizing, organizing, paying attention to and remembering details, and controlling our emotional reactions) are not completely developed[4].

Driving a motorized vehicle, one of the hallmarks of adolescence, is particularly risky for this age group because of the combination of lack of maturity and experience. Teens are more likely than older drivers to underestimate dangerous situations or not to be able to recognize hazardous situations, and compared with other age groups, teens have the lowest rate of seat belt use[5, 6].

In addition, violence in their peer age group is another public health problem adolescents face. Youth violence can involve fighting, bullying, threats with weapons, and gang-related violence[7]. The impact of this violence goes beyond the perpetrators and victims affecting communities by increasing the cost of health care, reducing productivity, decreasing property values and disrupting social services[8].

HISTORY OF DATA COLLECTION

The history of injury and violence surveillance systems and data collection is similar for all childhood and adolescent age groups in the United States. For a summary of this history, see the chapter entitled *Unintentional Injuries and Violence among Children (0-9 Years Old)*.

CDC SURVEILLANCE ACTIVITIES

The Behavioral Risk Factor Surveillance System is a telephone survey that collects state data about US residents regarding their health-related risk behaviors, chronic health conditions, and use of preventive health-care services. Established in 1984 with 15 reporting states, at present (2016) BRFSS collects data in all 50 states as well as the District of Columbia and three US territories (American Samoa, Guam, and Puerto Rico). BRFSS data are collected by states, and the process currently involves more than 400,000 interviews of adults (i.e., people at least 18 years old) each year. This age grouping means that some data on adolescents 18 or 19 years old are collected. Several questions about injuries (e.g., falls, seat-belt use, drinking and driving) are included among the core questions, and CDC offers optional modules on sexual violence, intimate partner violence, and adverse childhood experiences (ACE).

The Youth Risk Behavior Surveillance System (YRBSS) was created in 1990 to monitor high-priority health-risk behaviors among youth in the United States. YRBSS is a school-based survey of a representative sample of 9th through 12th grade students in public and private schools. The survey occurs every two years and includes behaviors that contribute to unintentional injuries and violence.

GENERAL FINDINGS

According to 2014 National Vital Statistics System (NVSS) data, in the United States injuries are responsible for about 45% of deaths among children ages 10 through 14 years, and 72% of deaths among those 15 through 19 years[1]. In 2013, injuries caused 8,474 deaths among US adolescents, for a death rate of 20.09 per 100,000 population. This number and rate have decreased from 12,733 deaths or 31.60 per 100,000 in 1999. Among young people 10 through 14 years, unintentional injuries, suicide, and homicide rank as the first, second, and fifth leading causes of death, respectively (Table 1). For individuals 15 through 19 years of age, injury mechanisms are in the top three leading causes of death. In this oldest adolescent age group, motor vehicle traffic crashes resulted in 2,450 deaths, and firearms contributed to 88% of all homicides in this age group[1].

US adolescents suffer from non-fatal injuries that require medical treatment. In 2013, almost 4.5 million individuals 10 through 19 years old were treated and released from an emergency department for an injury in the United States. Additionally, among those seen in an emergency department for an injury, over 214,000 were hospitalized or transferred to other types of facilities for further care. The most common causes of nonfatal injury among adolescents in this age group were being “struck by or against” (i.e., injury resulting from being struck by (hit) or crushed by a human, animal, or inanimate object or force other than a vehicle or machinery), falls, overexertion, and being injured while in a motor vehicle. Being struck by or against and falls each accounted for over one million annual emergency department visits. As is the case for members of younger groups, adolescent males were generally more likely than females to be injured[1]. Leading causes of injury-related death among adolescents aged 10 through 19 years, by age and sex are included in Table 2.

USING DATA FOR ACTION

CDC's National Vital Statistics Systems show that motor vehicle crashes kill thousands of teenagers each year[1]. One of the most effective ways to prevent these deaths is through state graduated driver licensing (GDL) systems. These systems address the risks novice drivers encounter when learning to drive: for example, emphasis is placed on helping the young driver gain experience through supervised practice and appropriate feedback or avoiding higher risk driving situations by placing restrictions for young drivers on driving at night and transporting non-adult passengers[9]. However, there is substantial variability in GDL systems across states. Since 1998, there have been 158 instances of a state (some more than once) strengthening or adding provisions to their GDL requirements around minimum learner periods, minimum practice hour requirements, and nighttime or passenger restrictions[10]. These improvements have contributed to a 51% decline in the number of deaths among young drivers and their passengers in the period 2004 through 2013[11].

CDC used fatality data from 1999-2010 to explore the problem of racial and ethnic disparities in drowning by swimming venue[12]. They found large disparities among drowning rates, with rates for blacks being substantially higher than those for whites and Hispanics. The disparities were greatest for drownings that occurred in swimming pools. Drowning rates for blacks 5 through 19 years were almost 6 times those of their white and Hispanic counterparts. This is likely due to disparities in basic survival swimming skills[13,14]. These data were used to support partner outreach efforts to provide basic survival swimming skills in minority communities. Programs providing low- or no-cost lessons are available through groups such as the YMCA and are supported by programs such as USA Swimming Foundations' Make a Splash (www.usaswimmingfoundation.org). With improved basic swimming skills among minority communities, reductions in racial and ethnic disparities in drowning, especially in swimming pools, are expected.

Utah used their Violent Death Reporting System (VDRS) data to get a broader picture of domestic violence-related deaths in their state, resulting in improved identification of service needs among children affected by domestic violence. They found that among children younger than 18 years old, 147 were directly exposed to a domestic violence-related homicide (e.g., they saw it, heard it through the walls, were attacked or threatened during the incident, or discovered the body). The state's Violence and Injury Prevention Program and their multi-disciplinary Domestic Violence Fatality Review Committee used these data to inform a policy change. This change allows for the Department of Children and Family Services (DFCS) to help the children (birth through 18 years) of domestic violence-related homicide victims to receive an assessment and get access to intervention services, such as mental health. As a result, in the period 2003 through 2008, a referral to DFCS was made in 13 (46%) of the 28 intimate partner violence incidents with children in the home[15].

The prevalence of Adverse Childhood Experiences (ACEs) in Washington prompted changes in service delivery. Clark County Juvenile Court compared items from the Washington State Juvenile Assessment System and ACE data for Washington on the BRFSS with the original CDC-Kaiser ACE Study data for a more representative understanding of the prevalence and impact of ACEs for their population of adolescents (i.e., including 18- and 19-year-olds). The original ACE Study included 17,000 patients from a Kaiser Permanente's Health Appraisal Clinic in Southern California. These patients in the period 1995 through 1997 provided detailed information about their childhood experiences of abuse, neglect, and family challenges such as "parental mental health issues" or "substance use issues"[16]. The Washington comparison examined the interrelationships among such adversities and the connection to attitudes and behaviors that might have impacted school attendance. Juvenile offenders in Clark County, Washington had a high prevalence of ACEs compared with non-offenders. As such, legislators recognized that truancy offenders needed additional support to mitigate future adverse outcomes, which led to increased support of flexibility in juvenile courts. For example, probation officers can now prioritize high-ACE offenders into programs, such as Functional Family Therapy.

DATA GAPS AND LIMITATIONS

The data gaps and limitations are similar for all childhood and adolescent age groups. For a summary of these, see the chapter *Unintentional Injuries and Violence among Children (0-9 Years Old).*

FUTURE ISSUES

Future issues are similar for all childhood and adolescent age-groups. For a summary of these, see the chapter *Unintentional Injuries and Violence among Children (0-9 Years Old).*

ADDITIONAL RESOURCES

Additional resources are similar for all childhood and adolescent age-groups. For a summary of these, see the chapter *Unintentional Injuries and Violence among Children (0-9 Years Old).*

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Table 1. Ten leading causes of death* among adolescents, by age group – United States, 2014

	Age Groups (years)	
Rank	10-14	15-19
1	Unintentional Injuries 750	Unintentional Injuries 3,736
2	Suicide 425	Suicide 1,834
3	Malignant Neoplasms 416	Homicide 1,397
4	Congenital Anomalies 156	Malignant Neoplasms 612
5	Homicide 156	Heart Disease 299
6	Heart Disease 122	Congenital Anomalies 179
7	Chronic Lower Respiratory Disease 71	Influenza & Pneumonia 64
8	Cerebrovascular Disease 43	Cerebrovascular Disease 58
9	Influenza & Pneumonia 41	Chronic Lower Respiratory Disease 55
10	Benign Neoplasms 38	Septicemia 39

* Cause and number of deaths are represented in each cell
Data Source: National Center for Health Statistics (NCHS), National Vital Statistics System

Table 2. Leading causes of injury-related death among adolescents aged 10 through 19 years, by age and sex – United States, 2014

	Numbers (and rates*) of injuries						
	10-14 years				15-19 years		
	Males	Females	Total		Males	Females	Total
All Injury	905 (8.58)	456 (4.51)	1,361 (6.58)		5,409 (50.16)	1,704 (16.57)	7,113 (33.76)
MV Traffic	227 (2.15)	157 (1.55)	384 (1.86)		1,688 (15.65)	762 (7.41)	2,450 (11.63)
Firearm	231 (2.19)	76 (0.75)	307 (1.49)		1,857 (17.22)	232 (2.26)	2,089 (9.92)
Homicide	105 (1.00)	51 (0.50)	156 (0.75)		1,201 (11.14)	196 (1.91)	1,397 (6.63)
Suicide	275 (2.61)	150 (1.48)	425 (2.06)		1,404 (13.02)	430 (4.18)	1,834 (8.71)
Poisoning	20 (0.19**)	25 (0.25)	45 (0.22)		495 (4.59)	246 (2.39)	741 (3.52)
Suffocation	164 (1.55)	108 (1.07)	272 (1.32)		631 (5.85)	263 (2.56)	894 (4.24)

* Rates per 100,000 population in the designated age groups; categories may not be mutually exclusive.

** Rates based on 20 or fewer deaths may be unstable

Data Source: National Center for Health Statistics (NCHS), National Vital Statistics System

Appendices

Appendix 1. Elements and codes of enhanced delivery identification method

Element	ICD-9-CM	ICD-10-CM/PCS
Outcome of delivery	V-27	Z37X: Z370, Z371, Z372, Z373, Z374, Z3750, Z3751, Z3752, Z3753, Z3754, Z3759, Z3760, Z3761, Z3762, Z3763, Z3764, Z3769, Z377, Z379
Normal delivery	650	O80, O82
Diagnosis related group (DRG) codes	370, 774 - complicated cesarean section 371, 775 - uncomplicated cesarean section 372, 765 - complicated vaginal delivery 373, 766 - uncomplicated vaginal delivery 374, 767 - uncomplicated vaginal delivery with sterilization and/or dilatation & curettage 375, 768 - vaginal delivery with operation room procedure except sterilization and/or dilatation & curettage 370, 371, 372, 373, 374, 375 (until October 1, 2007) 774, 775, 765, 766, 767, 768 (on October 1, 2007 and after)	774, 775, 765, 766, 767, 768
Exclusions (pregnancy with abortive outcomes)	**Hydatidiform mole:** 630 **Other abnormal product of conception:** 631 **Ectopic pregnancy:** 633 **Abortion:** 632, 634, 635, 636, 637, 638, 639, 69.01, 69.51, 74.91, 75.0 **Failed labor:** 659.00, 659.03, 659.10, 659.13	O00.xx, O01.xx, O02.xx, O03.xx, O04.xx, O05.xx, O06.xx, O07.xx, O08.xx, Z33.2, O47 10A00ZZ, 10A03ZZ, 10A04ZZ, 10A07ZZ, 10A07ZX, 10A07Z6, 10A07ZW, 10A08ZZ, 10D17ZZ, 10D18ZZ

ICD-9-CM: International Classification of Diseases, Ninth Revision, Clinical Modification

ICD-10-CM: International Classification of Diseases, Tenth Revision, Clinical Modification
ICD-10- PCS: International Classification of Diseases, Tenth Revision, Procedure Coding System

ICD-10-CM/PCS codes
Delivery outcome (Secondary diagnosis)

Hospitals reimbursed under the DRG payment method are encouraged to enter all applicable diagnosis codes in the *Diagnosis Codes* fields, so the claim will reimburse at the appropriate level. The primary diagnosis should be the appropriate **Z38.0 – Z38.8** code for the birth episode.

Z370	Single live birth
Z371	Single stillbirth
Z372	Twins, both liveborn
Z373	Twins, one liveborn and one stillborn
Z374	Twins, both stillborn
Z3750	Multiple births, unspecified, all liveborn
Z3751	Triplets, all liveborn
Z3752	Quadruplets, all liveborn
Z3753	Quintuplets, all liveborn
Z3754	Sextuplets, all liveborn
Z3759	Other multiple births, all liveborn
Z3760	Multiple births, unspecified, some liveborn
Z3761	Triplets, some liveborn
Z3762	Quadruplets, some liveborn
Z3763	Quintuplets, some liveborn
Z3764	Sextuplets, some liveborn
Z3769	Other multiple births, some liveborn
Z377	Other multiple births, all stillborn
Z379	Outcome of delivery, unspecified

Examples of ICD-10-PCS code[33]
Vaginal: 10D07Z3 – 10D07Z8, 10E0XZZ

Code	Shortened description	Clinical description
10D07Z3	Extraction of Products of Conception, Mid Forceps, Via Natural or Artificial Opening	Forceps; vacuum; and breech delivery

Code	Shortened description	Clinical description
10D07Z4	Extraction of Products of Conception, Mid Forceps, Via Natural or Artificial Opening	Forceps; vacuum; and breech delivery
10D07Z5	Extraction of Products of Conception, High Forceps, Via Natural or Artificial Opening	Forceps; vacuum; and breech delivery
10D07Z6	Extraction of Products of Conception, Vacuum, Via Natural or Artificial Opening	Forceps; vacuum; and breech delivery
10D07Z7	Extraction of Products of Conception, Internal Version, Via Natural or Artificial Opening	Other procedures to assist delivery
10D07Z8	Extraction of Products of Conception, Other, Via Natural or Artificial Opening	Other procedures to assist delivery
10E0XZZ	Delivery of Products of Conception, External Approach	Other procedures to assist delivery

Cesarean deliveries: 10D00Z0-10D00Z2

10D00Z0 Extraction of Products of Conception, Classical, Open Approach

10D00Z1 Extraction of Products of Conception, Low Cervical, Open Approach

10D00Z2 Extraction of Products of Conception, Extraperitoneal, Open Approach

Induction of labor: 0U7C7ZZ, 0U7C7DZ, 10900ZC, 10903ZC, 10904ZC, 10907ZC, 10908ZC, 3E030VJ, 3E033VJ

Code	Shortened description	Clinical description
0U7C7DZ	Dilation of Cervix with Intraluminal Device, Via Natural or Artificial Opening	Cervical Dilators (Labor Induction) using mechanical methods such as a balloon, digital exam or similar approach

0U7C7ZZ	Dilation of Cervix, Via Natural or Artificial Opening	Cervical Dilators (Labor Induction) using mechanical methods such as a balloon, digital exam or similar approach
10900ZC	Drainage of Amniotic Fluid, Therapeutic from Products of Conception, Open Approach	Artificial rupture of membranes to assist delivery
10903ZC	Drainage of Amniotic Fluid, Therapeutic from Products of Conception, Percutaneous Approach	Artificial rupture of membranes to assist delivery
10904ZC	Drainage of Amniotic Fluid, Therapeutic from Products of Conception, Percutaneous Endoscopic Approach	Artificial rupture of membranes to assist delivery
10907ZC	Drainage of Amniotic Fluid, Therapeutic from Products of Conception, Via Natural or Artificial Opening	Artificial rupture of membranes to assist delivery
10908ZC	Drainage of Amniotic Fluid, Therapeutic from Products of Conception, Via Natural or Artificial Opening Endoscopic	Artificial rupture of membranes to assist delivery
3E033VJ	Introduction of Other Hormone into Peripheral Vein, Percutaneous Approach	Labor Induction with Oxytocin/Pitocin®
3E0P7GC	Introduction of other therapeutic substance into female reproductive, via natural or artificial opening	Cervical Ripening (Labor Induction) using cervical inserts or tablets with prostaglandins (e.g. Cervidil®, Prepidil®, misoprostol or similar)

More details can be found at:
https://www.cmqcc.org/sites/default/files/ICD10%20Labor%20Induction%20FINAL_8.3.16.pdf

Possible additional codes: 3E030VJ, 3E040VJ, 3E043VJ, 3E050VJ, 3E053VJ, 3E060VJ, 3E063VJ, 3E0DXGC, 3E0P7VZ

Other procedures: 0HQ9XZZ, 0KQM0ZZ, 0DQR0ZZ, 0DQP7ZZ, 0W8NXZZ

0HQ9XZZ - Repair of Perineum Skin (1st degree perinatal laceration)
0KQM0ZZ - Repair of Muscles, Open (1st + 2nd degree perinatal laceration)
0DQR0ZZ - Repair of Gastrointestinal System, Repair, Anal Sphincter, Open (2nd + 3rd degree perinatal laceration)
0DQP7ZZ - Repair Rectum, Via Natural or Artificial Opening (1st, 2nd, 3rd , + 4th degree perinatal laceration)

0W8NXZZ – Episiotomy, division of female perineum, external approach

Exclusions

Pregnancy with Abortive Outcomes: O00.xx, O01.xx, O02.xx, O03.xx, O04.xx, O05.xx, O06.xx, O07.xx, O08.xx
<u>O00</u> Ectopic pregnancy
<u>O01</u> Hydatidiform mole
<u>O02</u> Other abnormal products of conception
<u>O03</u> Spontaneous abortion
<u>O04</u> Complications following (induced) termination of pregnancy
<u>O07</u> Failed attempted termination of pregnancy
<u>O08</u> Complications following ectopic and molar pregnancy
Z33.2 - Abortion
O47 - False labor*
*To be used when the patient has Braxton Hicks contractions or patient believes that she might be in labor (but, after examination by health care provider, is not).
This code is not to be used if the patient is actually in pre-term labor, but the progress of that labor is stopped. Code selection is based on whether the false labor is occurring before or after 37 weeks gestation.

Procedures indicative of pregnancy termination: 10A00ZZ, 10A03ZZ, 10A04ZZ, 10A07ZZ, 10A07ZX, 10A07Z6, 10A07ZW, 10A08ZZ, 10D17ZZ, 10D18ZZ

ICD-9-CM	Description	ICD-10-PCS
69.01	Aspiration curettage of uterus for termination of pregnancy	10A07ZZ Abortion of Products of Conception, Via Natural or Artificial Opening
		10A08ZZ Abortion of Products of Conception, Via Natural or Artificial Opening Endoscopic
69.02	Dilation and curettage following delivery or abortion	10D17ZZ Extraction of Products of Conception, Retained, Via Natural or Artificial Opening
		10D18ZZ Extraction of Products of Conception, Retained, Via Natural or Artificial Opening Endoscopic
69.51	Aspiration curettage of uterus for termination of pregnancy	10A07ZZ Abortion of Products of Conception, Via Natural or Artificial Opening
		10A08ZZ Abortion of Products of Conception, Via Natural or Artificial Opening Endoscopic
74.91	Hysterotomy to terminate pregnancy	10A00ZZ Abortion of Products of Conception, Open Approach
		10A03ZZ Abortion of Products of Conception, Percutaneous Approach
		10A04ZZ Abortion of Products of Conception, Percutaneous Endoscopic Approach

75.0	Intra-amniotic injection for abortion	10A07ZX Abortion of Products of Conception, Abortifacient, Via Natural or Artificial Opening
		10A07Z6 Abortion of Products of Conception, Vacuum, Via Opening (Abortion of Products of Conception, Vacuum, Via Natural or Artificial Opening)
		10A07ZW Abortion of Products of Conception, Laminaria, Via Opening (Abortion of Products of Conception, Laminaria, Via Natural or Artificial Opening)

Appendix 2. Severe Morbidity Indicators and Corresponding ICD-9-CM/ICD-10-CM/PCS Codes during Delivery Hospitalizations

Severe Maternal Morbidity Indicator	DX or PR	ICD-9	ICD-10	ICD-10 short
1. Acute myocardial infarction	DX	410.xx	I21.01, I21.02, I21.09, I21.11, I21.19, I21.21, I21.29, I21.3, I21.4, I22.0, I22.1, I22.2, I22.8, I22.9	I21.xx, I22.x
2. Acute renal failure	DX	584.5, 584.6, 584.7, 584.8, 584.9, 669.3x	N17.0, N17.1, N17.2, N17.8, N17.9, O90.4	N17.x, O90.4
3. Adult respiratory distress syndrome	DX	518.5x, 518.81 518.82 518.84, 799.1	J80, J95.1, J95.2, J95.3, J95.821, J95.822, J96.00, J96.01, J96.02, J96.20, J96.21, J96.22, R09.2	J80, J95.1, J95.2, J95.3, J95.82x, J96.0x, J96.2x R09.2
4. Amniotic fluid embolism	DX	673.1x	O88.11x*, O88.12 (*childbirth*), O88.13 (*puerperium*) * *x*=1st, 2nd and 3rd trimester	O88.1x
5. Aneurysm	DX	441.xx	I71.00 – I71.03, I71.1, I71.2, I71.3, I71.4, I71.5, I71.6, I71.8, I71.9, I79.0	I71.xx* I79.0 *No I71.7 code exists, so ICD-10 list encompasses all possible I71 codes
6. Cardiac arrest/ventricular fibrillation	DX	427.41, 427.42*, 427.5 * Ventricular flutter	I46.2, I46.8, I46.9, I49.01, I49.02*, * Ventricular flutter	I46.x, I49.0x
7. Disseminated intravascular coagulation	DX	286.6, 286.9, 666.3x	D65, D68.8, D68.9, O72.3* *see comments for pregnancy related codes	D65, D68.8, D68.9, O72.3
8. Eclampsia	DX	642.6x	O15.02, O15.03, O15.1, O15.2, O15.9 O14.22 - HELLP syndrome (HELLP), second trimester, O14.23 - HELLP syndrome (HELLP), third trimester HELLP syndrome is not included currently (ranges in severity, more research is needed)	O15.0x, O15.1, O15.2, O15.9

9. Heart failure/arrest during surgery or procedure	DX	997.1	I97.120, I97.121, I97.130, I97.131	I97.12x, I97.13x
10. Puerperal cerebrovascular disorders	DX	430.xx, 431.xx, 432.xx, 433.xx, 434.xx, 436xx, 437.xx, 671.5x, 674.0x, 997.02	I60.0x-160.9, I61.0x-161.9, I62.0x, 162.1,162.9, I63.0x-163.9, I65.0x, 165.1, I65.2x, 165.8,165.9, I66.0x, 166.1x, I66.2x, 166.3, 166.8, 166.9, 167.1, 167.2, 167.3, 167.4, 167.5, 167.6, 167.7, 167.8x, 167.9, 168.0, 160.8, 168.9, O22.50, O22.51, O22.52, O22.53, I97.810, I97.811, I97.820, I97.821, O873 674.0x – no crosswalk	I60.xx-I63.xx, I65.xx-I68.xx, O225x, I97.81x, I97.82x, O873
11. Pulmonary edema / Acute heart failure	DX	518.4, 428.1, 428.0, 428.821, 428.823, 428.831, 428.833, 428.841, 428.843	J81.0, I50.1, I50.20, I50.21, I50.23, I50.30, I50.31, I50.33, I50.40, I50.41, I50.43, I50.9 (-) Add 5th character: 0=unspecified 1=acute 2=chronic 3=acute on chronic 0=unspecified – keep since it is commonly used among health care providers terminology in medical records	J81.0, I50.1, I50.20, I50.21, I50.23, I50.30, I50.31, I50.33, I50.40, I50.41, I50.43, I50.9
12. Severe anesthesia complications	DX	668.0x*, 668.1x, 668.2x	74.0, O74.1, O74.2, O74.3, O89.01,* O89.09, O89.1, O89.2 *O89.01 Aspiration – decided to keep due to difficulties of separation from “Aspiration Pneumonitis”	O74.0, O74.1 , O74.2, O74.3, O89.0x, O89.O89.2
13. Sepsis	DX	038.xx, 995.91, 995.92, 670.2x (after October 1, 2009)	O85 or T80.211A or T81.4XXA **plus** A40.0, A40.1, A40.3, A40.8, A40.9, A41.0, A41.0Z1, A41.1, A41.2, A41.3, A41.4, A41.50, A41.51, A41.52, A41.53, A41.59, A41.81, A41.89, A41.9, A32.7 **plus** severity: R65.20 (or septic shock, see indicator “Shock”)	O85 T80.211A T81.4XXA **plus** A40.x, A41.x, A32.7 **plus** R65.20

14. Shock	DX	669.1x, 785.5x, 995.0, 995.4, 998.0x	O75.1, R57.0, R57.1, R57.8, R57.9, R65.21, T78.2XXA, T88.2XXA, T88.6XXA, T81.10XA, T81.11XA, T81.19XA	O75.1, R57.x, R65.21, T78.2XXA, T88.2 XXA, T88.6 XXA, T81.10XA, T81.11XA, T81.19XA
15. Sickle cell disease with crisis	DX	282.42, 282.62, 282.64, 282.69	D57.00, D57.01, D57.02, D57.211, D57.212, D57.219, D57.411, D57.412, D57.419, D57.811, D57.812, D57.819 (5th digit: unspecified, acute chest syndrome or splenic sequestration)	D57.0x, D57.21x, D57.41x, D57.81x
16. Air and thrombotic embolism	DX	415.1x, 673.0x, 673.2x 673.3x, 673.8x	I26.01, I26.02, I26.09, I26.90, I26.92, I26.99 O88.011-O88.019, 088.02, O88.03, O88.211-O88.219, O88.22, O88.23, O88.311-O88.319, O88.32, O88.33, O88.81, O88.82, O88.83 * I26.0 - Pulmonary embolism with acute cor pulmonale (acute right ventricle heart failure)	I26.x, O88.0x, O88.2x, O88.3x, O88.8x
17. Blood transfusion	PR	99.0x	99.0x → 160 ICD-10-PCS codes **The most common** 30233H1 Transfusion of Nonautologous Whole Blood into Peripheral Vein, Percutaneous Approach 30233K1 Transfusion of Nonautologous Frozen Plasma into Peripheral Vein, Percutaneous Approach 30233L1 Transfusion of Nonautologous Fresh Plasma into Peripheral Vein, Percutaneous Approach 30233M1 Transfusion of Nonautologous Plasma Cryoprecipitate into Peripheral Vein, Percutaneous Approach 30233N1 Transfusion of Nonautologous Red Blood Cells into Peripheral Vein, Percutaneous Approach	30233 Peripheral vein, percutaneous (7th digit: x=1: nonautologous) 30240 Central Vein, open (7th digit: x=1: nonautologous) 30243 Central Vein, percutaneous (7th digit: x=1: nonautologous x=0: autologous) + Hx (whole blood) Kx (frozen plasma) Lx (fresh Plasma) Mx (plasma cryoprecipitate) Nx (red blood cells) Px (frozen Red cells) Rx (platelets)

			30233P1 Transfusion of Nonautologous Frozen Red Cells into Peripheral Vein, Percutaneous Approach 30233R1 Transfusion of Nonautologous Platelets into Peripheral Vein, Percutaneous Approach 30233T1 Transfusion of Nonautologous Fibrinogen into Peripheral Vein, Percutaneous Approach 30240H1 Transfusion of Nonautologous Whole Blood into Central vein, open approach 30240K1 Transfusion of Nonautologous Frozen Plasma into Central vein, open approach 30240L1 Transfusion of Nonautologous Fresh Plasma into Central vein, open approach 30240M1 Transfusion of Nonautologous Plasma Cryoprecipitate into Central vein, open approach 30240N1 Transfusion of Nonautologous Red Blood Cells into Central vein, open approach 30240P1 Transfusion of Nonautologous Frozen Red Cells into Central vein, open approach 30240R1 Transfusion of Nonautologous Platelets into Central vein, open approach 30240T1 Transfusion of Nonautologous Fibrinogen into Central vein, open approach 30243H1 Transfusion of Nonautologous Whole Blood into Central vein, percutaneous approach 30243K1 Transfusion of Nonautologous Frozen Plasma into Central vein, percutaneous approach	Tx (fibrinogen)

			30243L1 Transfusion of Nonautologous Fresh Plasma into Central vein, percutaneous approach 30243M1 Transfusion of Nonautologous Plasma Cryoprecipitate into Central vein, percutaneous approach 30243N1 Transfusion of Nonautologous Red Blood Cells into Central vein, percutaneous approach 30243P1 Transfusion of Nonautologous Frozen Red Cells into Central vein, percutaneous approach 30243R1 Transfusion of Nonautologous Platelets into Central vein, percutaneous approach 30243T1 Transfusion of Nonautologous Fibrinogen into Central vein, percutaneous approach 30233N0 Transfusion of Autologous Red Blood Cells into Peripheral Vein, Percutaneous Approach 30233P0 Transfusion of Autologous Frozen Red Cells into Peripheral Vein, Percutaneous Approach 30240N0 Transfusion of Autologous Red Blood Cells into Central vein, open approach 30240P0 Transfusion of Autologous Frozen Red Cells into Central vein, open approach 30243N0 Transfusion of Autologous Red Blood Cells into Central vein, percutaneous approach 30243P0 Transfusion of Autologous Frozen Red Cells into Central vein, percutaneous approach	

18. Conversion of cardiac rhythm	PR	99.6x	5A2204Z, 5A12012	5A2204Z, 5A12012
19. Hysterectomy	PR	68.3x-68.9x	0UT90ZZ, 0UT94ZZ, 0UT97ZZ, 0UT98ZZ, 0UT9FZZ	0UT90ZZ, 0UT94ZZ, 0UT97ZZ, 0UT98ZZ, 0UT9FZZ
20. Temporary tracheostomy	PR	31.1	0B110Z4, 0B110F4, 0B113Z4, 0B113F4, 0B114Z4, 0B114F4	0B11x
21. Ventilation	PR	93.90, 96.01, 96.02, 96.03, 96.05	5A1935Z, 5A1945Z, 5A1955Z	5A1935Z, 5A1945Z, 5A1955Z

More details can be found at:
http://www.cdc.gov/reproductivehealth/MaternalInfantHealth/SevereMaternalMorbidity.html
For all pregnancy related codes O00-O9A:
1. Only applicable to maternity patients aged 12 - 55 years inclusive
2. Use a code under Z3A (Z3A.20-Z3A.42) to document the exact week during the pregnancy

Appendix 3. Autism and Developmental Disabilities Monitoring (ADDM) Network and Metropolitan Atlanta Developmental Disabilities Surveillance Program (MADDSP) Surveillance Case definitions

Autism spectrum disorder (ASD): ASD case status is confirmed by applying a standardized coding scheme based on the Diagnostic and Statistical Manual of Mental Disorders, Fourth Edition, Text Revision.
Cerebral palsy (CP): CP case status is confirmed by the presence of a documented diagnosis of CP or physical findings consistent with CP at or after age 2 years.
Intellectual disability (ID): ID case status is defined as an intelligence quotient (IQ) of ≤70 on the most recently administered test of intellectual ability.
Hearing loss (HL): HL case status is defined as an unaided, measured bilateral pure tone hearing loss at frequencies of 500, 1,000, and 2,000 hertz averaging ≥40 decibels (dB), unaided in the better ear.
Vision impairment (VI): VI case status is defined as a visual acuity of 20/70 or worse in the better eye with correction.