The National Committee on Vital and Health Statistics, 1993

From the CENTERS FOR DISEASE CONTROL AND PREVENTION/National Center for Health Statistics

U.S. DEPARTMENT OF HEALTH AND HUMAN SERVICES
Public Health Service
Centers for Disease Control and Prevention
National Center for Health Statistics

The National Committee on Vital and Health Statistics, 1993

ncvhs

U.S. DEPARTMENT OF HEALTH AND HUMAN SERVICES
Public Health Service
Centers for Disease Control and Prevention
National Center for Health Statistics

Hyattsville, Maryland
May 1994

National Committee on Vital & Health Statistics

JUDITH MILLER JONES
CHAIR

GAIL F. FISHER, Ph.D.
EXECUTIVE SECRETARY

The Honorable Donna E. Shalala, Ph.D.
Secretary, Department of Health
and Human Services
Washington, D.C. 20201

Dear Secretary Shalala:

I am pleased to transmit to you the 1993 Annual Report of the National Committee on Vital and Health Statistics (NCVHS), as required by the Committee's Charter.

In 1993 the Committee completed major reports on improving classification of health care services and procedures in the United States and on facilitating state and local capacity to use data for assessment, policy development and assurance. Both reports are included in the appendixes. The Committee also made recommendations on long-term care statistics, hospital discharge data, and mental health statistics for children.

In my Foreword to the report, I have attempted to lay out some of the challenges facing the Department and the country in defining a health information infrastructure that will support health care delivery and health policy development into the next century.

Building on its 45-year history, the National Committee looks forward to continuing to work with you, the Public Health Service, and the Health Care Financing Administration in addressing these important issues.

Sincerely yours,

Judith Miller Jones

Judith Miller Jones
Chair

• 6525 BELCREST ROAD • RM. 1100 • HYATTSVILLE, MD 20782 • (301) 436-7050 •

Foreword

Issues surrounding the collection, analysis, and dissemination of health data have moved to a very high level on the national political agenda. Much of this is the result of the Clinton Administration introducing a plan for health care reform that is comprehensive and far-reaching, and in significant ways is data-driven. Other reform bills have been introduced that also signal important changes in the way health care would be financed and delivered and have equally strong data implications.

In this context the National Committee on Vital and Health Statistics (NCVHS) has prepared its annual report. This report is in compliance with our charge under the Public Health Service Act to advise and report to the Secretary of the Department of Health and Human Services (DHHS) on data-related activities and concerns on: 1) policies and plans in developing major national systems of health data collection; 2) coordination of Federal health data requirements; and 3) efforts to establish standards to assure quality in the collection, processing, and analysis of health statistics and epidemiological data.

Since 1949 the Committee's responsibilities and activities have grown significantly as data concerns have assumed ever-increasing importance to the operation and assessment of the U.S. health care system. Established in response to a recommendation of the First World Health Assembly, the Committee's original purpose was foremost "...to guide and stimulate studies of technical problems in the field of vital and health statistics." NCVHS is perhaps best known for its work in developing uniform minimum data sets. These data sets established the basis for standardized reporting and the ability for many varied users to employ common data systems. In recent years NCVHS has addressed issues of health data policy that impact on decisionmaking at the national, State, and community levels and in the public and private sectors.

While NCVHS is charged to advise the Secretary of DHHS, we recognize that government data policies affect far more than the operation of government programs. With this in mind, the Committee has encouraged the various arms of government, and the data missions within each, to serve many users—within government and beyond—and wherever possible, to complement one another. A case in point is the interdependence of the Health Care Financing Administration (HCFA) and Social Security Administration (SSA) in collecting race and ethnicity data, which are critical to virtually every agency within the Department. Because facilitating greater interchange between government agencies has become such a high priority, we are especially pleased that NCVHS now has staff support from a number of DHHS agencies and official liaisons from HCFA, the Agency for Health Care Policy and Research, and the Centers for Disease Control and

Prevention's National Center for Health Statistics. Additionally, our reports to the Secretary will be reviewed simultaneously by the Assistant Secretary for Health and the Administrator of HCFA.

The Context of NCVHS Deliberations Today

Recent efforts to develop health reform proposals, and to anticipate the data consequences of any future reforms, have documented the fact that current data systems are not sufficient in a variety of ways. Despite steady improvement in the design and quality of national surveys, a good number are not conducted on a regular basis. Moreover, with limited sample sizes, factors relating to diverse population groups and smaller geographic areas frequently cannot be measured. Our fragmented, multiple-payer system, and our heterogenous population (racially, ethnically, and socioeconomically), demand greater attention to enhancing, accessing, and linking data sets in order to track health status and the health care that is available for various population groups.

While still relying on traditional national surveys, policymakers increasingly have turned to information gleaned from administrative data sets, along with special periodic surveys on utilization and expenditures, such as the National Medical Expenditure Survey. Such data proved especially useful recently when enhanced modeling capabilities were used to fashion and analyze specific proposals for health care reform. But even here, those using the models indicate that the baseline data and updates they need for good projections are lacking.

Knowledge about care delivered in hospital settings is considered fairly reliable, although often lacking in detail. However, there is virtual consensus that information on care delivered in other settings, especially private physicians' offices and managed care organizations, varies greatly in quality and availability. This is critically important because so much care is now delivered in ambulatory rather than hospital settings. It is especially troubling to policymakers at the national level who, while advocating greater coverage of primary care and preventive services and greater use of managed care arrangements, cannot be assured that they will have the means to monitor such transitions in care delivery or determine the outcome effects of such arrangements on distinct population groups.

State policymakers also have great concerns about data quality and availability. Health care reform has been gathering steam for several years, and many States are attempting to move forward on their own. Hoping to contain costs and increase coverage for the previously uninsured, including those working in small businesses, many States have adopted capitation payment methods for their Medicaid programs and in other ways are looking to restructure the marketplace for private payers. The response from insurers and providers has already been significant, and many parts of the country are now witnessing mergers and contractions in the health care industry and the formation of varied provider networks. Tracking and assessing the impact of such changes is difficult, with State and local data systems very much underfunded and underdeveloped.

For State officials the ability to assess the effectiveness of programs and expenditures under their jurisdiction, to draw comparisons with others, and to anticipate future outlays is critical. Each State Medicaid program has its own reporting system, with the use of uniform accounting and standard terminology limited. Although some State Medicaid programs provide good data, they are generally seen as incomplete and less reliable than Medicare data. Similar problems affect public health agency and community health center reporting, though it should be pointed out that in the area of mental health reporting, significant progress is being made under the Mental Health Statistics Improvement Program. Still, few if any States have the capability to look at all the programs under their jurisdiction, to monitor how people are being served, or to detect where fragmentation or duplication of services might exist, etc.

Improving the administrative data systems within the States is clearly an important goal. But NCVHS has long been concerned about the limited resources that most States have to carry out their many other data responsibilities, especially in maintaining vital records, tracking disease and other threats to health, and monitoring health status. Having studied these problems, the Committee recently transmitted to the Department a report dealing with State and local capacity to perform the core public health function of assessment and to use data for policy development and assurance. The report recommended that the Department develop and implement a strategy to establish a coordinated Federal, State, and community health statistics system to support the health policy process. In our view surveillance and assessment are just as important as delivery and billing concerns within the health statistical system; each must be given proper recognition.

Toward a Data System for the Future

NCVHS believes it essential to look at data matters and the process of reform as evolutionary endeavors. Whether a specific legislative proposal is passed this year or later, implementation will be a lengthy process and entail much deliberation. At the same time, we believe there are certain basic needs regarding a data collection and analysis infrastructure that must be recognized at the outset, not after reform has begun. These needs reflect the fact that access to medical care alone may not be sufficient to bring about improvements in health status.

Disease or dysfunction often results from forces other than disordered molecular and biochemical processes. Because much of modern medicine is still predicated on the notion of fixing such impaired processes, virtually all health professionals recognize that improving or maintaining health status involves much more than biology. Other factors of a personal, social, or psychological nature—and additional influences such as level of education, income, and racial or class status in society—help to explain individual differences in illness and dysfunction.

It is true that most health insurance policies in force, whether offered by government or in the private sector, largely limit coverage to medical services. But we expect our health statistical system to measure more than access to medical services, how well they were performed, and what ultimate impact they had. We also expect the health statistical system to help measure threats to health status, regardless of whether they originate in the water we drink or the air we breathe, in our own behaviors, or in the disarray and distress that may characterize the communities where we live. And while our proclivity may be to medicalize many problems of a health nature, we do know that not all can be solved by the intervention of clinicians alone. Our health statistical system must be capable of helping to sort out cause and effect, and to chart strategies for intervention whether these require the tools of the public health professional, the medical practitioner, experts in treating mental illness and substance abuse, or myriad others.

Some Immediate Next Steps

The Committee believes that certain data activities should be undertaken as soon as possible to facilitate whatever types of reform might be enacted. We stress, however, that most of these activities are needed regardless of whether reform occurs. Even if major reforms are not forthcoming, these actions are essential to improving the delivery of care and monitoring its impact.

Our views are based on discussions of many years, duration with providers of care in the fee-for-service sector, with leading researchers and analysts, and with officials from many agencies having varied responsibilities and programs under their jurisdiction. More recently, we have begun meeting with representatives of diverse managed care organizations. These discussions have contributed to an appreciation of the many ways in which health data are collected and used—for research, epidemiological studies, public health surveillance, quality assurance, administration, and policy purposes—and the complexities involved in using health data effectively. They also have underscored long-standing needs to improve data collection and analysis and highlighted the kinds of problems that policymakers presently encounter and will encounter as they try to evaluate the impact of reform and actually enact reform.

Seek Agreement on General Goals

First, we must seek to obtain agreement on the general goals and functions of a data infrastructure that will better meet society's medical and health care needs now and into the future. In her testimony to the Committee last year, Dr. Roz Lasker, then at the Physician Payment Review Commission and now with the Department, outlined four overall tasks of a health care data system. These are: 1) to track health care costs and utilization; 2) to assess the nature and quality of care being delivered; 3) to support efforts to improve the effectiveness and efficiency of care; and 4) to develop and apply severity and risk adjuster methods for analysis and other purposes.

In her current position, Dr. Lasker has expanded this vision to include the important, and in some cases, additional information needs of public health. If agreement on these general functions is lacking, it will be difficult to make the case for necessary funding and even more difficult to mount the kind of coordinated effort that will lead to success.

Assess Present Data Capabilities

Second, we need to understand where present data capabilities are strong and where, in light of the above needs, more work and resources are required. Dr. Lasker's testimony and that of her colleague, Dr. Kenneth Thorpe, who helped develop the Administration's modeling capability and cost estimates, compellingly described the current situation. There is fairly good information on the number and type of health care resources that exist, but relatively little information about the way they are used, especially by diverse populations and their ultimate cost. Without a way to track individuals as they enter and leave various sites of care, it is hard to identify gaps and wasteful redundancies, or the different ways that patients are treated, whether over an episode of illness or a lifetime. With few good outcomes measures, we have only limited ways of assuring that those getting services are receiving good quality care or all the benefits promised under their insurance plan.

Additional problems bedevil monitoring and analysis. Private sector data, as Dr. Thorpe noted, are especially limited in use. Because many such systems were designed to pay claims and are subscriber-based rather than patient-based, the systems do not lend themselves to longitudinal analysis. When the individual members of a population cannot be matched with claims, even the most basic questions such as expenditures per capita are difficult to address. Even though there is some common terminology, there is little uniformity in the way individuals, facilities, diseases, and treatment are coded. This lack of standardization makes it difficult to evaluate the costs of care or to study the best types of treatment and establish benchmarks of good quality.

Develop Baseline Data

Third, we must develop a good baseline assessment regarding health care access, the resources being used, and some notion of the effectiveness of care. This will be essential to judge the impact of any reforms enacted. A combination of regular and special surveys will be required for this effort, with resources committed immediately. One matter of long-standing concern to the Committee is the lack of a complete facilities inventory. Many surveys simply account for care that is delivered in licensed facilities; additional efforts are needed to identify nontraditional settings, such as continuing care retirement homes or board and care facilities. Although the Institute of Medicine recommended using person-based tracking methods to link and improve individual facility surveys, more work in this area is needed.

A matter of even greater concern is the fragility of our current surveillance infrastructure. There are more than 400 independent registries now operating, most on a voluntary basis. With resources in the States dwindling rapidly, reporting capabilities are being compromised. A better partnership between the States and the Federal Government must be established in this regard.

Provide Leadership on Data Standards

Fourth, at almost every turn, we hear calls for greater leadership on the part of the Federal Government in developing data standards, especially regarding terminology and its use. The current plethora of different forms and reporting requirements is a source of much frustration and anger among physicians, nurses, and others responsible for documenting service delivery and patient status. The vagaries of insurance coverage and different payment rules have led some (perhaps many) to feel that any code will do so long as it passes a screen and allows the patient to receive needed care or gets the bill paid in a timely manner.

To the Committee, the use of multiple coding systems is particularly problematic; even when the same classification is employed, different insurers (including Medicare intermediaries or carriers) allow payment on truncated and less descriptive versions of the code so that analysis and comparison of items are made difficult if not impossible. We also believe that reducing the reporting burden on providers is an important goal and a necessary component of obtaining better quality data. To achieve these ends, we support greater uniformity in terminology, reporting guidelines, and formats. We urge, however, that the development of standards be a broad-based participatory process, where government facilitates dialogue and is especially active in providing education and technical assistance.

As a corollary of this concern, we believe that classification and coding systems need to be evaluated periodically and in light of requirements that may be changing rapidly. During the last year, the Committee has focused considerable attention on changes needed in the coding of disease for reporting mortality and morbidity and the coding of procedures for reimbursement. It has also looked at the way data collected for payment purposes are being used either to reward efficiency or to assess and improve health status. A number of recommendations in this report result from those discussions:

- Because the *International Classification of Diseases, 9th Revision* (ICD-9) is rapidly becoming outdated and worldwide support and maintenance of the classification will terminate, and because the *International Classification of Diseases, 10th Revision* (ICD-10) represents significant improvements in coding primary care encounters, external causes of injury, mental disorders, and neoplasms, we have recommended that the Department immediately commit resources to assess the applicability of the ICD-10 for coding morbidity; to identify problem areas and make modifications, as necessary; and to develop implementation plans;
- Because the use of multiple procedure codes is confusing and inefficient, and because the *International Classification of Diseases, 9th Revision, Clinical Modification* (ICD-9-CM), Vol. III and the *Physicians' Current Procedural Terminology* (CPT) no longer have adequate room for expansion, we recommend that the Department consider facilitating development and adoption of a single system for classification of health care services and procedures, applying criteria developed by the Committee to assess the benefits to various users; and
- While the Committee concurs in the main with revisions to the Uniform Hospital Discharge Data Set (UHDDS) recommended by an Interagency Task Force, and especially with the inclusion of external cause-of-injury codes, we recommend inclusion of a few new items that will contribute to outcomes measurement and risk adjustment, as well as further study of several additional items, including ways to address the relationship between race, ethnicity, socioeconomic status, and health.

Throughout our deliberation of these matters, we have been impressed by the need to solicit the views of a wide variety of users, in government and beyond. From the comments presented to us, it is clear that government is still perceived too often as acting unilaterally, without sufficient regard for the needs of other users.

Creating a Climate for Improved Data Collection and Analysis

Developing better policies regarding the collection and use of data is essential to obtaining the kind of data needed for making better decisions. This maxim applies not only to decisionmaking in the legislative context, but in the care domain as well. Better data are needed by consumers and practitioners alike—for outreach, coordinating care delivery, and many other uses.

Until now, cost and access concerns have dominated the health reform debate, with data attendant to these issues getting the most attention. Systematic improvement in the delivery of care is also important and something that most Americans take for granted. The growing use of continuous quality improvement techniques in health care, the search for better outcome measures on the part of researchers and health professionals, and interest in health plan "report cards" all speak to this. But we question whether many people, even in the policy community, appreciate the significant data requirements that such concerns entail. As we see it, systematic improvement in health care is an information-driven human activity; without planned and organized access to data, there can be no systematic delivery and improvement of health care services.

The question then arises, how prepared are we as a society to design and build a better health statistics infrastructure? The answer is not clear. The major proposals put forth to reform the U.S. health care system embody divergent views of how to go about change and how much to rely on government policies and programs as opposed to private sector mechanisms and organizations. Most assume the availability of more and better data to operate independent purchasing entities, monitor system performance, and assure quality—though the level of detail varies and leaves many questions unanswered. Most also speak to the need for a nationally standardized health data system.

The Administration has put forth a rationale for its data collection and information strategy, describing how this would facilitate the implementation of the President's plan and allow for better tracking of use and costs, choice among plans, more analysis of appropriate care, and engender systematic improvements in delivery. But while the Administration plan has held out the benefits of collecting encounter data on a universal basis as the best way to achieve these goals, it has not yet developed the political or technical constituency to support this strategy. Nevertheless, there is growing agreement on the need for better encounter data—for defining an episode of illness, monitoring a course of care, judging the outcome of treatment, and making resource allocation decisions. Who is to be responsible for collecting, analyzing, and retaining this information, and how, are matters where consensus has not been reached.

At the same time, there has been essentially no thought or public discussion of the kind of data system that a less comprehensive or complex reform proposal might require. But regardless of the plan that Congress might enact, the kinds of questions about health care cost, use, and effectiveness now being asked by policymakers, providers, and the public are sure to intensify in the years ahead. By not making clear why we have so few answers now, we have hindered the development of a constituency for improved data collection and analysis. As the Committee sees it, demonstrating the commonality of data needs that pertain to virtually all the pending proposals is a necessary first step to building a better constituency for data, and a strategy that would help determine priorities and funding needs as well.

Promote Open and Collaborative Process

In suggesting a building-block approach or strategy to establish priorities for the short-term and beyond, NCVHS suggests that a more open and collaborative process is needed. This will make it easier to agree on time frames and the specific responsibilities of each agency in the Department, as well as other players. We are pleased that some of this work is already underway in the Department, examining data gaps identified in developing the reform proposal, retooling the various data systems for programs within the Public Health Service, and looking at Medicare's data needs as more of its beneficiaries age into or seek care from managed care entities. But we also believe that engaging in such efforts on a more collaborative basis with external users will help strengthen the constituency for all data activities and funding.

Explicate Productive Uses of Data

There are several other ways in which we believe the Department, through its attention to data needs under health reform, can contribute to improving the climate for data collection and analysis. At present, providers and the public in general have little understanding of the productive uses of data. Until this is changed, progress is likely to be slowed; the Department could play a major role by assessing such gaps in knowledge and then working to improve the general level of understanding.

To make sure that data quality improves over time, objectives must be clear. Those who contribute to data collection and analysis efforts need to be cognizant of why the data are needed and how they will be used. Mandating the reporting of data is far less effective than collaboratively collecting and analyzing data that are seen as valid and useful.

Define and Assure Data Confidentiality

Furthermore, people must have full faith that concerted and painstaking efforts will be made to use data only in the ways intended and specified. Personal privacy must be assured, with data on patients and providers maintained with the strictest confidentiality; unless there is strong belief in the capability and intent to protect data privacy and confidentiality, it is likely that the effectiveness of efforts to improve data collection and analysis will be undermined.

In many of its meetings, the Committee has deliberated the need for patient and provider identifiers in order to link records longitudinally and across treatment domains. In doing so the Committee tried to differentiate the need for access to an individually identified record from the need for access to a person-level file, but one without personal identifiers. Clearly, who should make such files and the rules governing use of linkage mechanisms need further explication. The Department has a major role to play in defining and promoting better policies to protect confidentiality of records and assure personal privacy. We believe this task must be seen as equal in importance to defining a data infrastructure itself and commensurate resources committed to it.

Conclusion

Improving the present health statistical system, even on a modest basis, will be a major undertaking. The improvement will require conceptual input from the broadest possible representation of providers and consumers of health services and health statistics. Moreover, the process by which such a dialogue takes place can be expected to have a major impact on its productivity and outcome. Again, we stress the need for Federal leadership, broad-based dialogue, and the development of clearinghouse capabilities that can facilitate standardization and education on health data needs.

The Committee hopes to lend its energy and expertise to this unprecedented reform endeavor, especially utilizing its capacity to reach out to the many users of health data in the public and private sectors. Having long espoused the need for data methods and systems that can better track the care of individuals wherever they reside and wherever they receive care, we know the importance of getting good quality data and linking files appropriately. Yet we also know how controversial and contentious such matters as universal identifiers for patients and providers can be. While we feel more strongly than ever about the need to preserve personal privacy and the confidentiality of health records, we are convinced a much improved data infrastructure is possible—one that meets the highest standards for efficient collection and information exchange as well as privacy.

A final word of caution is in order. Health care reform is not and cannot be the Department's only data-oriented concern in the coming months. Other on-going activities of government involving data collection and analysis also merit attention. Development of better coding regarding disability and rehabilitation services, integration of mental health and substance abuse reporting and analysis into the overall health data system, data issues concerning special populations, and improved collection of long-term care data are all matters that the National Committee finds need further attention. We also stand ready to assist with these efforts and encourage interested parties to lend their expertise through comments, testimony, and other means.

Judith Miller Jones
Chair, National Committee on
Vital and Health Statistics

Contents

Appendixes

Executive Summary

During 1993 the National Committee on Vital and Health Statistics (NCVHS), in its advisory capacity to the Department of Health and Human Services (DHHS), accomplished the following activities through the work of the full Committee, seven subcommittees, a work group, and several monitors:

- Held a series of discussions with policymakers within the Department to consider information needs for health reform. Emphasized the importance of uniform data standards and policies in meeting these needs.
- Completed a major report recommending development and adoption of a single system for classification of health care services and procedures to be used in all settings in which health care is delivered in the United States. Preparation of the report included extensive consultation with a wide range of organizations and individuals who have a stake in procedure classification. The report, which was transmitted to the Secretary, is contained in appendix V.
- Presented its recommendations on procedure classification at a Symposium on Coding and Classification Issues sponsored by the American Health Information Management Association.
- Transmitted to the Assistant Secretary for Health a significant report related to State and local capacity to perform the core public health function of assessment and to use data for policy development and assurance. The report was the result of 2 years of study and deliberation and recommended that the Department develop and implement a strategy to establish a coordinated Federal, State, and community health statistics system to support the health policy process. The report can be found in appendix VI.
- Developed a detailed draft report on findings and recommendations concerning long-term care data gaps and issues, bringing to closure a series of meetings to review numerous national surveys and receive testimony from a wide array of experts in the field. Several recommendations concerning planned and proposed data collection efforts that require timely action by the Department were transmitted to the Assistant Secretary for Health. The full report will be finalized for submission to the Department in early 1994.
- Responded to the report and recommendations of the Interagency Task Force on the Uniform Hospital Discharge Data Set (UHDDS), reaffirming the major recommendations included in the NCVHS Proposed Revision to the UHDDS submitted to the Assistant Secretary for Health in 1992.
- Wrote to the Assistant Secretary for Health and the Administrator of the Health Care Financing Administration (HCFA) urging that the Department dedicate the necessary

resources to determine the feasibility of implementing the 10th revision of the *International Classification of Diseases* (ICD-10) for morbidity application in the United States.

- Jointly sponsored with the National Center for Health Statistics (NCHS) a special meeting to obtain public comments on needed revisions of the World Health Organization's (WHO) *International Classification of Impairments, Disabilities, and Handicaps* (ICIDH) for applications in the United States.
- Agreed to keep the ICIDH on the NCVHS agenda in order to be supportive of the revision process, facilitate sharing of information, and foster articulation of a U.S. approach.
- Initiated a process to receive input on possible revisions to the recommendations contained in the report on the Uniform Ambulatory Care Data Set submitted to the Department by the NCVHS and an Interagency Task Force in 1989.
- Continued efforts to encourage HCFA and the Social Security Administration to improve current and future racial and ethnic identifiers in the Medicare administrative data bases.
- Encouraged development by the NCHS Minority Health Statistics Grants Program of a summer institute on methods and materials related to minority health statistics and continued to monitor the implementation of the grants program.
- Reviewed plans by the National Institute of Mental Health (NIMH) for a child epidemiological catchment area project and provided NIMH with several recommendations concerning implementation of the project and related methodological research.
- Monitored efforts by NCHS to develop appropriate mental health status measures for the National Health Interview Survey.
- Received a briefing on issues of data access and privacy as they might impact on the ability to monitor and assess health care reform and appointed a Committee liaison for ongoing monitoring of these issues.
- Participated in a Conference on Health Records: Social Needs and Personal Privacy, sponsored by the DHHS Task Force on the Privacy of Private-Sector Health Records.
- Participated in an NCHS-sponsored Workshop on Family Data and Family Health Policy issues.
- Reviewed and provided comments on the 1992 and 1993 publications of *Health, United States.*

In 1994 the Committee will continue and expand efforts related to many of the above activities.

Activities, Accomplishments, and Future Plans of the National Committee on Vital and Health Statistics

Information needs for health reform dominated the agenda of the National Committee on Vital and Health Statistics (NCVHS) and its various subcommittees during 1993. The Department, Administration, and Congress began to focus new and increased attention on many of the issues that the NCVHS has nurtured and promoted during its 45-year history. These issues include, among others, uniform data sets and systems of classification, unique identifiers, and uniform policies on access to data, data linkage, and data confidentiality.

In 1993 the Committee pursued these and related topics by carrying out substantive activities in the following areas through its subcommittee and work group structure:

- Medical classification systems
- Long-term care statistics
- Ambulatory and hospital care statistics
- Health statistics for minority and other special populations
- Mental health statistics
- State and community health statistics
- Confidentiality

The activities, accomplishments, and future plans of the subcommittees and work group are detailed in the subsequent sections of this report. Membership lists, meeting dates, and charges for the subcommittees are included in appendix IV. The legislative authority, the charter, and the membership roster and meeting dates of the full Committee can be found in appendixes I, II, and III.

The full Committee and Executive Subcommittee gave consideration to a variety of issues raised by the subcommittees and work group during the year and also addressed several additional crosscutting topics, as described below.

Discussions With Policymakers

The full Committee had the opportunity during the year to meet with a number of departmental policymakers to explore their visions of the type of information infrastructure required for a reformed health care system. The Assistant Secretary for Health met with the Committee in June and November, and at the November meeting solicited the members' recommendations on priority health information issues for health reform. In response, the individual subcommittees identified the following issues for high priority consideration:

- Development and adoption of a single system for classification of health care services and procedures to be used in all settings in which health care is delivered in the United States, as recommended in the Committee's 1993 report to the Department on procedure classification.
- The need to move forward on evaluating, modifying, and implementing the 10th revision of the *International Classification of Diseases* (ICD-10) for morbidity purposes.
- Development of measures of chronic disability for adjusting health plan quality reports and monitoring that chronically disabled enrollees are not impacted by selection bias and underservice.
- The need to collect data for disabled people across the acute and long-term care services spectrum, including data on services that are not part of the benefit package.
- Adoption of standardized data sets with definitions and guidelines for ambulatory and hospital care encounters.
- The need for unique identifiers for patients, practitioners, and sites of care.
- Mandatory and consistent capture of racial and ethnic identifiers, using the categories collected in the decennial Census, at the time of enrollment into any future health care plan.
- Development of mechanisms for tracking racial and ethnic identifiers of providers by geographic areas.
- The need to develop specific strategies within the ongoing Federal data systems for tracking the health care received by vulnerable populations.
- Collection of data on utilization, expenditures, and financing of mental health services, similar to the kind of data collected on other health services in the National Medical Expenditure Survey.
- The need to produce child mental health prevalence data that can be extrapolated to the nation as a whole, as well as better coordination of child mental health data within DHHS and across Federal agencies.
- Access to data at the State and local level in any data systems that are developed.
- Achieving a balance between the need to assure access to critical data and the corresponding need to meet the confidentiality requirements of the individual health care consumer and provider.
- Establishment of strong penalties for people who misuse personally identified health data.

The Committee also met twice with the Deputy Assistant Secretary for Planning and Evaluation/Health, who served as the principal person coordinating data analysis for the White House Task Force on Health Care Reform. The Deputy Assistant Secretary acknowledged that public and private data sets currently are inadequate for analyzing various health reform options because they were not designed for that purpose. This has necessitated "stringing together" various data bases in order to answer fundamental policy questions. Desirable information systems identified for the future include a national data base of health care use and expenditures; a data base to support a national capacity for systematic, centralized technology assessment; and a disease surveillance system. It was noted that more information will be needed on quality of care, patient satisfaction, and health status. Finally, information must be available not only at the national level but at the State and local levels. Reviewing the wide-ranging purposes for which health data potentially will be collected, the Deputy Assistant Secretary challenged the National Committee to participate in the process of considering how the different pieces of the system should fit together and what can be learned from other State and national health data efforts about how the information can most effectively be used.

The full Committee receives regular reports on major health data activities and policies from the National Center for Health Statistics (NCHS), which provides Executive Secretary support to the NCVHS. This year, as in the past, the Committee provided comments to NCHS on the development of *Health, United States,* the Secretary's annual report on the health of the Nation. The Committee also hears regularly from the Health Care Financing Administration (HCFA) and the Agency for Health Care Policy and Research (AHCPR), both of which have principal liaisons working with the Committee and Executive Subcommittee. Staff from NCHS, HCFA, and AHCPR serve as staff on most of the NCVHS subcommittees and work group and other agencies also are represented, as appropriate.

During the November meeting, the Committee had the opportunity to meet with the Deputy Administrators of HCFA and AHCPR, who described data developments and priorities at their respective agencies. The Committee is impressed by the progress that has been made by the Department in building multipurpose health information systems and is hopeful that future health reform activities will capitalize on this experience in developing standards, data bases, registration systems, and surveys, as well as take advantage of new information technologies. While supporting innovative activities at the State level, the Committee also strongly encourages national data standards that will allow comparisons to be made between States and localities.

Childhood Immunization Initiative

The full Committee received a presentation at its June meeting on the Comprehensive Childhood Immunization Initiative from the National Immunization Program (NIP), Centers for Disease Control and Prevention. The program is proposing the establishment of State-based registries based on birth records and individual immunization data. States will be expected to transmit aggregate, not individual, data to the national level. A communications superstructure will permit State-to-State transmission of information; access to data will be limited to authorized users with appropriate confidentiality provisions. The NCVHS has offered to assist the NIP with addressing issues of confidentiality and a core data set.

International Classification of Impairments, Disabilities, and Handicaps

During the June NCVHS meeting the Committee agreed to cohost with NCHS a meeting on September 8, 1993, to receive public comment on needed revisions to the *International Classification of Impairments, Disabilities, and Handicaps* (ICIDH). The ICIDH was first published in 1980 as a supplement to the International Classification of Diseases (ICD) and is widely used in a number of Western European countries as a classification of the consequences of disease. However, its use in the United States has been very limited.

NCHS, in its capacity as the North America Collaborating Center for ICD, has taken the lead in North America in the ICIDH revision process. The public hearing was attended by approximately 60 persons, with 20 presenting comments on the applications of the ICIDH to meet U.S. needs as regards State, clinical, research, program participation, and policy purposes; evaluation of strengths and limitations of the ICIDH; and specific suggestions for needed revisions, deletions, and expansions to make the next version of the ICIDH more useful for U.S. purposes.

In response to recommendations of the Subcommittee on Medical Classification Systems, the NCVHS agreed at its November meeting to take the following steps concerning the ICIDH: advise the Secretary to create resources for a group to make recommendations in organizing U.S. input into the revision process, keep ICIDH on the Committee's agenda with the purpose of supporting the revision process and facilitating information sharing, and foster articulation of a U.S. approach to the revision process that addresses the concerns of some constituents (such as about pejorative language) and that argues for hierarchical classification.

Computer-Based Patient Records

The Committee continued to follow with interest efforts to advance computer-based patient records, receiving regular reports from an NCVHS member who also serves on the Board of the Computer-based Patient Record Institute. While recognizing that much developmental work remains, the Committee supports the efforts to achieve consensus on standards and policies that will facilitate electronic exchange of the multiple components of computerized health records.

Access to Care

The Health Care Financing Administration briefed the Committee in November on its annual reports to Congress on possible changes in access to care for Medicare beneficiaries following implementation of the new payment system for physician services. The Secretary has submitted reports in 1991, 1992, and 1993. The first two reports described how the Department would monitor the new payment system, and the most recent report included post-reform data. The current analytical approach monitors trends in the use of services before and after the Medicare fee schedule went into effect. Changes in utilization for vulnerable subgroups, such as those with low income, as well as for persons in areas with a shortage of health professionals, are monitored. Limitations of the research include the difficult and elusive nature of defining access and the lack of adequate small area studies to understand access needs and problems of particular population groups.

The 1993 report revealed that expectations for the reform in the Medicare fee schedule were realized: payment for visits and consultations increased, while payment for surgical procedures fell. Although differences in utilization for black and white beneficiaries were observed, the differences were not exacerbated by the Medicare fee schedule. Neither were there changes in the visit rates in the three big counties being monitored. The research revealed that, although the hospitalization rate for Medicare beneficiaries has been increasing for black beneficiaries, compared with white beneficiaries, there are large differences by race for various procedures. The 30-day post-admission death rate for black persons also exceeds that of white persons for almost every condition studied, despite the fact that black persons have lower rates of procedures. These differences by race are as yet largely unexplained. It was also found that use of services (for example, flu shots) is associated with differences in the presence or absence of supplementary insurance.

The Committee commended HCFA for its thoughtful and effective use of timely data to address the issues of access to care in the Medicare program. It also supported plans by the agency to link census-level data with Medicare files to study smaller areas and populations.

During the year the Committee also reviewed the recent Institute of Medicine report on *Access to Health Care in America* and plans to receive a briefing on this report in 1994.

Medical Classification Systems

During 1993 the Subcommittee on Medical Classification Systems continued its evaluation of the feasibility and desirability of a single procedure classification system. In developing its recommendations, the Subcommittee sought and received advice from a wide range of organizations and individuals who have a stake in procedure classification. In November the Subcommittee completed its review and presented its report to the National Committee on Vital and Health Statistics (NCVHS) recommending the adoption of a single procedure classification system for multiple purposes in the United States. The NCVHS approved the report, which will be sent to the Assistant Secretary for Health. In December the Subcommittee Chair made a presentation of the report to the American Health Information Management Association symposium in Washington, DC.

Recommendations

The Subcommittee made the following recommendations, which were approved by the NCVHS, in its report. The report is contained in appendix V:

- The National Committee on Vital and Health Statistics recommends development and adoption of a single system for classification of health care services and procedures to be used in all settings in which health care is delivered in the United States.
- The Secretary of the Department of Health and Human Services should assume the responsibility for the development and maintenance of a single classification system as a collaborative effort involving those who have an interest or stake in a new system.
- Development of the single procedure classification system should be given immediate priority, and implementation should be coordinated with national health reform.
- The Secretary should ensure that the system is easy to use, comprehensive, hierarchical, flexible, and serves present and future needs in the public and private sectors of health care.
- Adequate resources must be provided to support all aspects of development, implementation, evaluation, education, and maintenance.

Background

The Subcommittee on Medical Classification Systems was established in 1987 as a continuation of the Subcommittee on Disease Classification and Automated Coding of Medical Diagnoses begun in 1983. Classification systems provide health care data essential for the formulation of health policy. The NCVHS has long been committed to addressing the complex issues related to classification systems and the diversity of their application.

Current Year's Activities

During 1993 the Subcommittee held three meetings and three working sessions dedicating a substantial portion of the meetings to developing and reviewing its report to recommend that steps be taken to create a single procedure classification system for multiple purposes in the United States. Initially the Subcommittee sought information on the attributes and deficiencies of existing procedure classification systems. After input on the current situation was received from respondents in the field, the Subcommittee solicited and received feedback on its provisional recommendations for the development and implementation of a single procedure classification system. In making this recommendation, the Subcommittee evaluated substantial information indicating that the current procedure classification systems were not only structurally flawed but redundant, and should not be considered as the recommended single system. The majority of respondents were in support of a major overhaul of classification methodologies, recommending a single system with the capability to be used across health care settings by all providers. The report reflects a synthesis of most of the comments that were received.

Recognizing that important questions remain about how to proceed to a unified system and what the system should look like, the Subcommittee intends to continue its deliberations and will provide more concrete recommendations after undertaking consultations with components of the Department of Health and Human Services in the next year. The Subcommittee acknowledges that implementation of a single system should be contingent upon a proper and fully funded educational initiative preceding the adoption of a single system to support a nationwide educational program to instruct clinicians and coders in the proper documentation and coding of procedures.

The Subcommittee continued to address issues relating to the *International Classification of Diseases, 10th Revision* (ICD-10), focusing on the status and implementation of ICD-10 in the United States, with particular regard to morbidity application. To that end, the Subcommittee initiated a letter from NCVHS to the Assistant Secretary for Health and the Administrator of the Health Care Financing Administration recommending that the Department dedicate resources to determine the feasibility of implementing ICD-10 for morbidity application in the United States.

The Subcommittee also discussed issues concerning the need for a disability classification system in the United States. The Subcommittee convened two meetings to review the need for, and activities relating to, the revision of the World Health Organization (WHO) *International Classification of Impairments, Disabilities, and Handicaps* (ICIDH) and to discuss various efforts being undertaken to develop disability classification definitions for specific purposes, such as program participation, resource use, and payment purposes. Because the ICIDH crossed the interests of several subcommittees, the Subcommittee referred it back to the NCVHS to facilitate sharing of information and foster articulation of a U.S. approach.

The Subcommittee was asked by the NCVHS Chair to consider adding the *International Classification of Primary Care* (ICPC) to its work plan. Due to a possible common interest in the classification, a joint meeting with the Subcommittee on Ambulatory and Hospital Care Statistics was planned for February 1994 to receive a briefing on the classification. After the briefing, the Subcommittee will determine whether the ICPC should be added to the 1994 Work Plan.

Continuing Work Plan

The Subcommittee's work plan for 1994 will focus on the following areas:

- Evaluate and advise the Secretary on the development of components of a single procedure classification system and stimulate cooperative participation of government and nongovernment entities in this endeavor.
- Monitor activities relating to the development and improvement of classification systems for procedures in the United States.
- Continue to provide an open forum for information on the progress of *ICD-10* and its implementation.
- Monitor the development and use of derivative applications of the ICD, including specialty-specific compendia.
- Continue to monitor efforts of the Coordination and Maintenance Committee.
- Monitor the effect of annual changes in diagnosis codes on data quality and research initiatives.
- Monitor progress toward improvement of data quality and coding accuracy, systems for automated coding of medical diagnoses, and patient record documentation.
- Monitor classification issues appropriate to, and related to, health care reform initiatives.

Long-Term Care Statistics

During 1993 the Subcommittee on Long-Term Care Statistics focused its efforts on the need to improve data collection on disability and the population at risk for long-term care. The Subcommittee convened a meeting in March to receive briefings on several national surveys containing data items related to disability and long-term care. The surveys reviewed are conducted under the auspices of the National Institute on Aging, Agency for Health Care Policy and Research, Health Care Financing Administration (HCFA), and the National Center for Health Statistics. The Subcommittee developed a draft report on its findings and recommendations concerning long-term care data gaps and issues and presented it to the National Committee on Vital and Health Statistics (NCVHS) in November 1993. In addition, the report will be circulated for review by people who made presentations to the Subcommittee. The final report will contain several recommendations to improve data on long-term care and will be presented to the NCVHS in March 1994 for approval, after which it will be sent to the Assistant Secretary for Health for consideration. Because approval of the report will be delayed until March, the NCVHS approved the Subcommittee's request to send a letter to the Assistant Secretary for Health addressing the need to provide resources for several planned and proposed data collection efforts that are time sensitive.

Recommendations

The Subcommittee on Long-Term Care Statistics made the following recommendations, which were approved at the November 1993 NCVHS meeting:

- Fully fund the National Health Interview Survey Disability Supplement (phases 1 and 2, in 1994 and 1995) including the Longitudinal Study on Aging II.
- Provide the resources to support proposed data collection efforts that yield information on disabled elderly people. These include:
  - Support a caregiver survey for the 1994 National Long-Term Care Survey.
  - Support full funding for the Asset and Health Dynamics Among the Oldest Old Survey.
  - Support an oversample of people 85 years of age and over in the 1996 National Medical Expenditures Survey.
  - Support funding of the 1995 National Nursing Home Survey.

Background

The Subcommittee on Long-Term Care Statistics was formed in 1987 as a successor to the Subcommittee on Uniform Minimum Health Data Sets. In 1991 the Subcommittee revised its charge to focus on identifying the data gaps in disability, particularly as they relate to the elderly, with the view of improving the coordination and the collection of disability data for policy development.

The Subcommittee convened several meetings to identify gaps in needed data for long-term care policy and planning. As part of this process, the Subcommittee on Long-Term Care Statistics reviewed and heard presentations on the following national surveys: National Long-Term Care Survey, proposed Longitudinal Survey on Aging II, National Health Interview Survey Disability Supplement, Health and Retirement Survey, Asset and Health Dynamics Among the Oldest Old, Medicare Current Beneficiary Survey, National Medical Expenditure Survey, National Nursing Home Survey, National Home and Hospice Survey, and National Health and Nutrition Examination Survey I Epidemiologic Followup Study. As a result of these deliberations, the Subcommittee developed a report discussing some of the major long-term care data gaps and issues. The Subcommittee recognizes that data on the long-term care needs of the under 65 years of age disabled population are virtually nonexistent. More data are available on the elderly population, but important gaps remain, particularly related to use of nonmedical services and residential environments. Moreover, there is a need to improve the information base on the oldest old—a population subgroup known to be at greatest risk for long-term care—and on the elderly poor and minorities.

Current Year's Activities

In 1992 the Subcommittee had conducted a public meeting that laid the groundwork for the Subcommittee's review of the need for policy relevant data about long-term care. During 1993 the Subcommittee held two public meetings and two working sessions at which they developed a set of cross-cutting questions relating to survey content and methods to be applied to the surveys listed above. Content issues included:

- data elements collected for estimates of prevalence of disability,
- data on services used, costs of services, and methods of payment,
- effects on family and friends of providing long-term care (informal care, personal assistance), and
- socioeconomic status and other descriptors of the survey population.

Methods issues included:

- the study population and major subgroups of policy interest,
- whether longitudinal data were being collected,
- periodicity of data collection,
- the extent of proxy reporting, and
- linkage with administrative records such as Medicaid and Medicare.

In addition to differences in estimates of prevalence of disability across surveys (due, in part, to variations in question wording and the types of functioning that are assessed) there are gaps in characterizing the use of long-term care services and its associated costs. Since most surveys continue to focus on medicallyrelated care, there are serious gaps in the collection of information about residential arrangements, social service use, and the immediate living environment of disabled people.

The Subcommittee made several recommendations regarding existing and planned data collection to improve information on long-term care. Among these were to: provide full funding for the National Health Interview Survey Disability Supplement; provide resources to support proposed data collection efforts to yield information on the disabled elderly population; make national data sets more accessible to researchers by requiring all Federally supported national surveys to provide for the development of public use files and technical assistance to users; establish a departmental committee to address diversity issues in long-term care data collection efforts, including the development of a standard set of services to be assessed; and provide resources to address the absence of adequate data in long-term care at the State and local levels.

The Subcommittee will continue to monitor HCFA's efforts in exploring how common data elements can be applied across various care settings and its plans for the automation of the resident assessment data collected from the minimum data set for nursing homes. The Subcommittee responded to a Notice of Proposed Rulemaking on the resident assessment instrument, citing its concerns about the quality and reliability of the data collected from the resident assessment minimum data sets. HCFA acknowledges the need to provide safeguards to assure the quality and reliability of resident assessment data and the need to provide for confidentiality while facilitating the accessibility of data for research and policy formulation.

Continuing Work Plan

The Subcommittee intends to carry out the following work plan in 1994:

- Monitor plans for data related to health care reform as these relate to disabled people, including data intended to assess access and quality of care.
- Monitor the development of risk adjustors for use in capitated payments and premium adjustments, particularly regarding the inclusion of measures of disability.
- Explore ways to encourage development of standard or recommended data items in long-term care, especially regarding types of services used and supportive living environments.
- Continue to review the adequacy of data at the national, State, and local levels on the distribution and availability of services or providers of long-term care services.
- Continue to monitor and assess current and planned Department of Health and Human Services (DHHS) data collection efforts related to disability and long-term care.
- Monitor DHHS plans for a possible national registry of nursing home residents, including employment of the Nursing Home Resident Assessment Minimum Data Set.

- Periodically review the availability of data to track year 2000 objectives relevant to disability.
- Explore data requirements of the Americans with Disabilities Act and assess other data sets measuring prevalence and levels of disability.
- Review progress of the DHHS Coordinating Group on Disability Data and the Public Health Services Task Force on Determination of Disability.
- Participate in the Interagency Forum on Aging-Related Statistics when appropriate.

Ambulatory and Hospital Care Statistics

The Subcommittee on Ambulatory and Hospital Care Statistics was encouraged during 1993 by the growing recognition in the health reform debate of the need for uniform health data sets and standards. The Subcommittee began the year with a session on information needs for health reform and continued to focus on this broad topic throughout the year. In June the Subcommittee developed a detailed response to the report and recommendations of the Interagency Task Force on the Uniform Hospital Discharge Data Set (UHDDS), continuing to support the major recommendations included in the National Committee on Vital and Health Statistics (NCVHS) June 1992 Proposed Revision to the UHDDS. In September the Subcommittee met with managed care plans, large group practices and related organizations to explore their needs for data to conduct and assess ambulatory care. In response to these discussions, the Subcommittee revised its charge to include a short-term review of the recommended Uniform Ambulatory Care Data Set that was submitted to the Department by the NCVHS and an Interagency Task Force in 1989. The full Committee approved the Subcommittee's revised charge at its November 1993 meeting.

Recommendations

During the June 1993 meeting of the NCVHS the full Committee approved the Subcommittee on Ambulatory and Hospital Care Statistics' preliminary response to the report of the Department of Health and Human Services Interagency Task Force (ITF) on the UHDDS. The response, which was finalized and transmitted to the Assistant Secretary for Health by the NCVHS Chair in July 1993, contained the following major recommendations:

- The NCVHS continues to recommend inclusion in the revised UHDDS of two new elements and further research on several additional elements, positions not supported by the ITF. The Committee maintains that these recommendations are modest and realistic and that their adoption and testing ought to proceed immediately. Several of the elements recommended directly address issues of outcomes measurement and risk adjustment that are essential to implementation of health reform. Without this kind of information, it will be very difficult to evaluate the effectiveness of treatment over an episode of illness and over a longer course of care.
- The recommended new elements are an item on type of admission (scheduled or unscheduled) and a qualifier pertaining to the onset of each secondary diagnosis (prior to admission, not prior to admission, or uncertain).

- The elements recommended for further research, with possible adoption at a later time, are a socioeconomic indicator (that is, a patient's years of education completed), voluntary reporting of whether one of the secondary diagnoses was the primary diagnosis (for example, the one chiefly responsible for the major part of the patient's hospital length of stay), and modification of inpatient coding guidelines to discourage coding of "probable," "suspected," or "questionable" diagnoses as if they were established.

In several other cases the Committee modified its 1992 recommendations to conform with the ITF report, although only one new element, birth weight of newborn, was eliminated from its original report. The Committee's full recommendations on a revised UHDDS are contained in the NCVHS 1992 annual report.

Background

The Subcommittee on Ambulatory Care Statistics was formed at the June 1987 NCVHS meeting as a direct outgrowth of the Subcommittee on Statistical Aspects of Physician Payment Systems, which had begun as a work group in 1984. In June 1989 the Subcommittee and an Interagency Task Force completed work on a revised Uniform Ambulatory Care Data Set. At the November 1989 NCVHS meeting the Subcommittee amended its charge and changed its name to the Subcommittee on Ambulatory and Hospital Care Statistics to reflect an expanded focus on hospital care data.

Current Year's Activities

The Subcommittee held meetings on January 28, April 15, and September 22, 1993, as well as working sessions during full Committee meetings. On each of these occasions, updates were received on the work of the Interagency Task Force on the UHDDS, which the Subcommittee closely followed. The Subcommittee found considerable common ground between its earlier work and that of the ITF and welcomed the ITF support for adding total charges and a separate element for external cause-of-injury coding (E-coding) to the UHDDS. The Subcommittee also continued to follow the implementation, beginning on October 1, 1993, of the revised uniform bill for hospitals (UB-92), which includes a separate, labeled field to accommodate E-coding for injury patients.

The Subcommittee's first meeting on January 28 was held when interest in the possibility of comprehensive health reform already was high. The Subcommittee received two presentations on information needs for health reform, with reports from the outgoing and incoming administrations. Each stressed the importance of adequate information for policymakers to monitor and evaluate the performance of the health care system, for health professionals to assess and improve the management of health care, and for consumers and purchasers to choose providers based on the quality and cost of services. Particular attention was called to the paucity of information on severity of illness, functional status and health outcomes, and the general need for better data from the ambulatory care sector. In tracking access to care and quality of care, the importance of having information on the impact of policies on the most vulnerable populations was noted. The speakers concluded that data will need to come from multiple sources, in addition to claims data, and must be selective, limited in magnitude, clinically meaningful, useful, accurate, verifiable, standardized, and comparable.

The January Subcommittee meeting agenda also included a presentation from the Health Care Financing Administration (HCFA) on data quality and future directions for the Uniform Clinical Data Set (UCDS). The presenter reported that a decision about whether the UCDS system is ready for national implementation will be made in October 1994; the Subcommittee offered to review and provide advice concerning this forthcoming judgment, as well as regarding the use of the UCDS base for applications beyond the Peer Review Organizations. This offer was welcomed, noting that HCFA criteria for adoption will include data reliability of approximately 90 percent, efficiency, usefulness, and improvement over the current manual system.

In April HCFA staff and contractor's presented to the Subcommittee an overview of research on Ambulatory Patient Groups (APG's) and implications for policy development. Staff explained that HCFA began conducting research several years ago to define the product being purchased in ambulatory care in a manner similar to Diagnosis Related Groups (DRG's) for inpatient care. In addition to developing a classification system, HCFA chose New York State for demonstration of a payment system because of the State's infrastructure and experience in this area. It was noted that one result of past Congressional directives is that there are now 11 different ways in which hospital outpatient services are reimbursed under Medicare. Next steps in APG research include refinement in some of the medical areas, particularly rehabilitation, mental health services, and chemotherapy, and additional work on defining settings, outliers, the scope of global payments, and episodes. The aim is to create a tool that can be used in clinical, cost, and policy contexts. A report to Congress being prepared by HCFA describes an APG approach for a prospective payment system for surgical procedures and radiology and laboratory services. Research in the other areas is continuing. Again, the Subcommittee asked to be kept informed on the APG research and developments and offered to provide assistance, as needed. Particular interest was mentioned in identifying documentation and validity issues in collecting and analyzing ambulatory care data and in attempting to define a core ambulatory care data set.

The September 22 Subcommittee meeting was devoted to a stimulating and informative discussion of types of data required to conduct and evaluate ambulatory care, with a special focus on managed care plans and large group practices. Physicians and other health care professionals were asked to discuss the types of data currently collected in their plans or practices; how the data are used; what problems are confronted; and what additional data are needed or would be useful on an encounter basis, in enrollment or provider files, and through surveys. Representatives from the National Committee on Quality Assurance (NCQA), Group Health Association, American Group Practice Association, and the Medicaid Coordinated Care Office provided perspectives on multiplan analyses.

It was observed that data capabilities differ considerably depending upon the type of plan and payment mechanism (typically, fully capitated plans have not collected and automated detailed encounter data); however, all the discussants reported that there is increasing interest in capturing more information on ambulatory care encounters for internal management, risk adjustment, and quality assurance as well as external reporting. While frequently the data are collected manually and aggregated for reporting purposes, there is definite movement toward improving the underlying encounter data. In addition to the more standard information on the patient, provider, place and time of service, diagnosis or chief complaint, and services rendered, interest was expressed in improving encounter and longitudinal data on health status and functional status, health outcomes, patient satisfaction, socioeconomic status, and episodes of care. All the discussants supported unique patient and provider identifiers and standardized data definitions and classification systems. Mixed results were reported with patient completion of health status and risk factor questionnaires. Presenters stated it was essential for physicians and other health care providers to be involved in defining data needs and to find the information collected useful in the care process; further, adequate resources must be committed for data collection and analysis.

Common data collection in managed care plans is being encouraged by collaborative development under NCQA of the Health Plan Employer Data and Information Set (HEDIS), the purpose of which is to identify a uniform set of performance measures and other information to aid large employers in their purchasing decisions. The HEDIS includes at least 60 performance measures covering quality, access, satisfaction, resource utilization, and financial stability and viability, with specification as to how data should be compiled. In addition to being a set of uniform reporting standards, the measures will be incorporated into a report card. Current HEDIS plans do not include accumulating encounter-level data in a central source. The Subcommittee reiterated its support for core or minimum data sets, getting the maximum return on investments in data gathering, and in seeing that data are used effectively.

Following the September meeting the Subcommittee developed a revised charge and work plan that identified the UHDDS and Uniform Ambulatory Care Data Set (UACDS) as critical building blocks for health reform, acknowledged work already completed on the UHDDS, initiated outreach to multiple constituencies around review of the revised 1989 UACDS, and strengthened collaborative activities with public and private sector organizations around data standards, research, and policy issues.

Continuing Work Plan

The Subcommittee will pursue the following work plan in 1994:

- Review the 1989 UACDS and draft departmental revisions and the current HCFA 1500 elements and definitions.
- Circulate letter to Subcommittee mailing list soliciting feedback on the adequacy of the proposed UACDS and the HCFA 1500 for obtaining information needed on ambulatory care encounters.
- Hold Subcommittee meeting in early 1994 to obtain testimony from selected respondents to the Subcommittee letter.
- Prepare draft Subcommittee report for consideration at March 1994 NCVHS meeting.
- Finalize recommendations at June 1994 NCVHS meeting.

- Continue to work with the Department on finalizing recommendations for a revised UHDDS that will reconcile differences between the NCVHS and Interagency Task Force reports.
- Pursue, as time permits, other areas within its charge concerning information needs for health reform and development of data standards.

Health Statistics for Minority and Other Special Populations

During 1993 the Subcommittee on Health Statistics for Minority and Other Special Populations continued in its efforts to encourage the Health Care Financing Administration (HCFA) and the Social Security Administration (SSA) to improve current and future racial and ethnic identifiers in the Medicare administrative data bases. The Subcommittee completed a draft report and recommendations regarding this issue for submission to the full Committee in 1994. The Subcommittee began a review of Federal agency practices regarding the collection of racial and ethnic data, beginning with presentations by personnel from the U.S. Bureau of the Census. The Subcommittee continues to monitor the implementation of the National Center for Health Statistics (NCHS) Minority Health Statistics Grants Program and to support data-related minority health activities of the Department of Health and Human Services Office of Minority Health.

Background

The Subcommittee on Minority Health Statistics was established by the National Committee on Vital Health Statistics (NCVHS) in 1986 after the Secretary's Task Force on Black and Minority Health noted the inadequacy of data on minority populations and identified a need to improve and fully utilize available sources of data.

The Subcommittee recognized the need to expand its focus to include other groups such as the medically indigent, whose health status and health care utilization patterns required special attention that could not be addressed adequately through current data systems. To reflect this expanded focus, the Subcommittee's name was changed in November 1989 to the Subcommittee on Health Statistics for Minority and Other Special Populations.

Current Year's Activities

The Subcommittee held one meeting and three working sessions during 1993 with a continuing main focus on efforts to improve data on the race and ethnicity of current and future Medicare beneficiaries. The original emphasis of the Subcommittee's inquiry (that began in 1986) was to identify a mechanism through which health researchers could gain access to Medicare data with enhanced racial and ethnic identifiers. The Social Security application file is the source of race and ethnicity for important administrative data sets, including Medicare data. For persons who applied for a social security number (SSN) before 1980, only distinctions between the white population and all other races were recorded. The Subcommittee has held several meetings with the HCFA and SSA to explore whether additional information available to SSA could be provided to HCFA for updating race and ethnicity on Medicare files. During the course of its investigation in 1992, the Subcommittee discovered that recent changes in the application process have resulted in the loss of all racial and ethnic information for a substantial proportion of new applicants. For over 90 percent of infants born in the United States, the information for the issuance of an SSN is collected in the hospital, as part of the birth registration process. The States pass this information on to SSA, and an SSN is issued for the child.

This new process is probably more efficient and inexpensive than the traditional application process and increases the likelihood that the nation's children will have SSN's to meet new reporting requirements of the Internal Revenue Service (IRS). The IRS currently requires the reporting of the SSN for any person 1 year or older who is claimed as a dependent. States collect racial and ethnic identification of the parents on the birth certificate, but under most State laws it is confidential information. Racial and ethnic information is still collected during the SSN application process for persons who apply at an SSA office. However, even in this context, the provision of this information is clearly stated as voluntary.

Based on information the Subcommittee gathered in 1993 from representatives of SSA and HCFA and from NCHS staff who work with the State vital statistics programs, the Subcommittee explored possible solutions to the problems outlined above, that is, the need for: 1) enhancement of racial and ethnic data available for current Medicare beneficiaries, and 2) creation of mechanisms that will ensure collection and dissemination of adequate racial and ethnic data for future Medicare beneficiaries. The Subcommittee has completed a draft report with recommendations regarding the improvement of current and future racial and ethnic identifiers in the Medicare administrative data bases for submission to the full Committee in 1994.

The Subcommittee began a review of Federal agency practices regarding the collection of racial and ethnic data. Ongoing and expected demographic changes in the U.S. population have increased Federal awareness that the collection of racial and ethnic information in Federal statistics programs must be critically examined. Beginning with presentations by personnel from the U.S. Bureau of the Census and including presentations by experts who have been involved in conferences and workshops designed to address these issues, the Subcommittee continued its effort to keep abreast of methodological and substantive advances directly affecting the collection and dissemination of minority health statistics. In early 1994 the Subcommittee plans to initiate discussions with the Office of Civil Rights about the Department of Health and Human Services' needs for racial and ethnic information.

The Subcommittee continues to monitor the implementation of the NCHS Minority Health Statistics Grants Program. As extremely limited funds were available for new grants in fiscal year 1993, Subcommittee members encouraged the development of a summer training program for minority health researchers with funds not already committed to existing grants. As a result, the NCHS Minority Health Statistics Grants Program has funded the School of Public Health at the University of North Carolina, at Chapel Hill, to develop plans for a summer institute on methods and materials related to minority health statistics. A 1-week course will be previewed in the summer of 1994 at the University of Michigan School of Public Health summer session in epidemiology.

Through regular interaction with staff from the Department of Health and Human Services' Office of Minority Health, the Subcommittee continues to support its data-related minority health activities.

Continuing Work Plan

- Submit to the full Committee a final report and recommendations regarding efforts to improve current and future data on race and ethnicity in the Medicare administrative databases.
- Continue to monitor the NCHS reauthorization provisions with regard to the mandate to improve minority health statistics and the grants program to public and nonprofit entities for the conduct and/or analysis of special surveys and methodological studies on the health of racial and ethnic populations.
- Maintain liaison with the Department's working groups established to identify data needs within the Department for health care utilization and expenditures information.
- Meet periodically with the Office of Minority Health and collaborating agencies.
- Continue to explore minority data collection in other Federal agencies and to keep abreast of methodological advances in public and private research endeavors that have implications for Subcommittee activity.
- Consider the potential effects of health care reform for minority and other special populations and the implications of health care reform for data-related activities involving these populations.

Mental Health Statistics

In 1993 the Subcommittee on Mental Health Statistics conducted its 4th year of activities. The Subcommittee continued to pursue key objectives: to achieve the integration of priority mental health topics into national health care surveys; to serve as a forum for mental health statistical concerns within the Department of Health and Human Services; and to provide liaison with other committees and activities concerned with data on mental health epidemiology, services, and clients, within and outside of the Department. A primary focus for the Subcommittee in 1993 was the continued progress of the National Center for Health Statistics (NCHS) in integrating mental health measures into the general health measures of the National Health Interview Survey (NHIS). The Subcommittee held a special 2-day meeting in July 1993 to focus on further identifying and developing the statistical field for mentally ill children and adolescents. At the November meeting of the National Committee on Vital and Health Statistics (NCVHS), the NCVHS endorsed the Subcommittee's recommendations for the Child Epidemiological Catchment Area Project; these recommendations were transmitted to the National Institute of Mental Health (NIMH), which has responsibility for the project. In addition, the Subcommittee has placed emphasis on the inclusion of mental health measures in drug abuse, alcoholism, and various disability surveys.

Recommendations

In a November 1993 letter to the NIMH, the Subcommittee expressed strong support and enthusiasm for the proposed Child Epidemiological Catchment Area project. The letter, which had been endorsed by the full NCVHS at its November 3–5, 1993, meeting, included several recommendations concerning implementation of the project and related methodological research. The highest priority recommendations were as follows:

- In addition to the local sites proposed by NIMH, it would also be important to conduct a survey of a national probability sample of the U.S. population. The national sample would bolster the community studies in significant ways, as well as add critical data that will not be available from community sites.
- The local and national surveys should provide adequate attention to high risk inner-city populations.

Background

The Subcommittee on Mental Health Statistics was formed during 1990 because of concern that the separation of statistical efforts in the areas of physical and mental health limits the ability to monitor changes in the health status of the American population.

In 1991 the Subcommittee prepared a report on incorporating mental health status measures in national surveys and commended the NCHS for initiating steps to include appropriate measures in the NHIS. During 1992 the Subcommittee collaborated with NCHS in developing appropriate mental health status measures for the NHIS.

Current Year's Activities

In 1993 the Subcommittee on Mental Health Statistics held four meetings to continue pursuing activities initiated earlier, with an emphasis on the further identification and development of disability measures for mentally ill persons and development of the statistical field for mentally ill children and adolescents; and on the inclusion of mental health measures in drug abuse, alcoholism, and various disability surveys.

Members of the group also explored facilitating development of a system-wide data collection effort with adequate funding support and dissemination to health care policymakers with appropriate technical assistance.

The Subcommittee was briefed on the various survey and data collection efforts of the Substance Abuse and Mental Health Services Administration (SAMHSA). This included indepth presentations on the mental health statistics program and the national reporting program. Further specifics were addressed with discussions of the Drug Survey—mental illness component and new measures for services outcomes by NIMH and the Center for Mental Health Services, SAMHSA staff.

The group also heard from Dr. Ronald Kessler, University of Michigan, who provided expert, comprehensive testimony on the use of mental health measures within the NHIS.

Attention was additionally directed at an examination of children's mental health data collection activities within the government. These subjects were addressed at a special 2-day symposium in July with presentations by key people from other Federal agencies. Focus was placed on epidemiological and services data on meeting the needs of mentally ill children and youth and an inventory compilation of baseline data before health care reform. This included exploring the status of epidemiological, service, and client statistics on children; the content, scope, and data integration gaps; future objectives of developing the statistical field for mentally ill children and adolescents; and NIMH plans for the Child Epidemiological Catchment Area study.

Continuing Work Plan

In 1994 the Subcommittee will continue to pursue unfinished activities initiated in 1993. Particular attention will be given to:

- Continuing support for tabulation of databases.
- Continuing development of mental health items in existing surveys and studies.
- Contributing directly to the development of child mental health treatment guidelines and indirectly to population prevention and outcome measures.

- Establishing a working group on mental health statistics in conjunction with the Interagency Forum on Aging-Related Statistics and the Interagency Forum on Child and Family Statistics.
- Ensuring the adequate coverage of mental health issues in data plans developed for the health care reform initiative.

State and Community Health Statistics

During 1993 the Subcommittee on State and Community Health Statistics continued to address the availability of health and health care data at the State and community levels. The Subcommittee issued a report addressing State and community data needs, statistical capacity, and other relevant issues. The report was accepted by the full Committee at its June 1993 meeting and transmitted to the Assistant Secretary for Health.

Recommendations

The report of the Subcommittee on State and Community Health Statistics, presented in appendix VI, includes the following recommendations:

- The Department of Health and Human Services should develop and implement a strategy to establish a coordinated Federal, State, and community health statistics system to support the health policy process. The Secretary should establish a task force to pursue this strategy.
- The Department should implement a process to assure that all Departmental administrative health data sets have the capacity to provide statistics for assessment, policy development, and assurance. In addition, these data sets should be constructed in a manner that will permit linkage to other relevant data sets for statistical and health services research purposes.
- The Department should take the necessary steps to, whenever possible, develop national data systems that are established in a way that will produce, at a minimum, State-level estimates. Regardless of the purpose for which the data are collected, all Federal health data systems should include uniform geocoded identifiers that will allow for their use at the State and community levels.
- Every State health agency should have the capacity to perform the functions of a State Center for Health Statistics. These functions include coordination among State health programs to assure that needed data are available to users, as well as data collection, processing, analysis, dissemination, technical assistance to users, and research and development. The Secretary should review, revise, adopt, and implement the Guidelines for State Cooperative Health Statistics Systems Agencies.
- The Department should take steps to strengthen the capacity of State health agencies to act as a resource for the data necessary for State and community assessment, to provide technical assistance in the analysis of those data, and to develop and implement mechanisms for transmitting data to the Department.

- The Department, working through the State health agencies, should develop mechanisms to locate and support staff that can work with communities to develop the assessment programs in local health jurisdictions.
- The Department should provide leadership in developing model-based estimation techniques to provide indicators in the absence of actual State and/or community level data. States and communities should be encouraged to use these techniques where appropriate.
- The Secretary should involve the National Committee on Vital and Health Statistics (NCVHS) in the efforts to evaluate the Health Status Indicators for State and community use and to consider potential additions and/or deletions from the set.

Background

The Subcommittee on State and Community Health Statistics was established by the NCVHS as a work group in 1990 after review and consideration of the health statistics implications of the Institute of Medicine report on the Future of Public Health and the Nation's Health Objectives for the year 2000. It was elevated to a subcommittee in March 1991. Health assessment and surveillance are two of the necessary functions of public health departments. Although assessment is needed at all levels of government, it is at the local or community level where public health issues are identified and solutions effected. Past experience has indicated that at the State and community levels, statistics, statistical methodology, and the resources needed to conduct assessment and surveillance are inadequate.

Current Year's Activities

The Subcommittee met on February 19 and April 21, 1993 to consider testimony and draft its report. Subsequent to the presentation of the report at the June meeting of the full Committee, the Subcommittee met on September 21 and November 4 to receive updates on various topics, including the implications of health care reform for State and community data.

Continuing Work Plan

During 1994 the Subcommittee will:

- Gather information on the availability and need for data on long-term care at the State and community level.
- Gather information on the availability and need for data on mental health and disability at the State and community level.
- Gather information on State and community ability to address data needs related to health care reform, including the monitoring of health outcomes.
- Initiate preparation of a draft report summarizing its findings on these topics.
- Continue to monitor progress towards achieving the year 2000 objectives, including the review and monitoring of the annual *Healthy People 2000 Review.*

Confidentiality

In January 1993 the National Committee transmitted to the Assistant Secretary for Health the Report of the Work Group on Confidentiality. This report, which had been presented to the full Committee at the November 1992 meeting and was accepted with minor modifications, is contained in the appendix of the National Committee on Vital Health Statistics (NCVHS) 1992 annual report. The report recommended continuation of the Work Group as a monitor, continued support for a unique personal identifier, and ongoing commitment to represent need for solutions to data access and confidentiality issues. The completion of this report fulfilled the tasks assigned to the Work Group. At the June 1993 meeting the full Committee recommended that the Work Group take on a monitoring function for the near future.

Background

The Work Group on Confidentiality was established at the March 1991 meeting of the full NCVHS with a charge to the group being approved at the June 1991 meeting of the full Committee. The two major objectives for 1991–92 were:

- The explication of current public policy issues surrounding the release and disclosure of data
- The development of a strategic approach to the long-term management of these critical issues.

The Work Group was formed as a result of discussions regarding issues related to the tabulation and publication of health data, including vital statistics data, and the production of public-use data tapes. An additional concern was the need to provide researchers with the optimal amount of data while still maintaining its confidentiality. During an early Work Group conference call, it became clear that other interagency, interdepartmental, and National Academy of Sciences work underway on confidentiality and privacy may be informative but will not necessarily address the broad questions of concern to the National Committee. The consensus of the group was that the NCVHS is in a unique position to assist specific agencies in their deliberations and to heighten awareness of the advantages of proactive policy positions on data linkage, access, security, and the role of the social security number or other unique identifiers.

Current Year's Activities

In January 1993 the National Committee transmitted to the Assistant Secretary for Health the Report of the Work Group on Confidentiality. This report had been presented to the full

Committee at the November 1992 meeting and was accepted with minor modifications. The completion of this report fulfilled the tasks assigned to the Work Group. No additional meetings of the work group were held in the winter or spring of 1993.

During the March 1993 meeting, David Flaherty, Ph.D., privacy advocate and Visiting Scholar at the Woodrow Wilson Center, addressed issues of data access and privacy as they might impact on the ability to monitor and assess health care reform. Dr. Flaherty stated that he regards the provision of adequate privacy and data protection measures for health and medical information as the most pressing privacy issue facing the U.S. today. He expressed strong concern about the profiling of patient data over a lifetime, noting the concept in the French data protection law of "the right to be forgotten." Dr. Flaherty also discussed the problem of unauthorized disclosure of personal information.

By the culmination of 2-years' activities by the Work Group, it was obvious that there were many groups in Washington, DC, and throughout the country working on issues of personal privacy and confidentiality of health data. The Work Group had not identified any additional unique issues to be brought to the table but was seen as a valuable resource in monitoring and reacting to the suggestions of others. At the June 1993 meeting the full Committee recommended that the Work Group take on a monitoring function for the near future. Because of the importance of the subject matter, it was recommended that one National Committee member be appointed as confidentiality monitor or liaison and that staff continue to follow the issues and keep the liaison informed of critical activities. Through the liaison, the Committee will be following the issues and commenting when a specific topic needs to be addressed.

At the November 1993 meeting the National Committee discussed the importance of privacy and confidentiality issues with Health Reform activities. Staff was requested to monitor congressional hearings on these issues and to discuss with Department staff the need or desire to have the Secretary, Department of Health and Human Services (DHHS), discuss data privacy and confidentiality at Congressional hearings.

During the year the Work Group Chair, NCVHS members, or key staff also attended the following meetings:

The Conference on Health Records: Social Needs and Personal Privacy, sponsored by the DHHS Task Force on the Privacy of Private-Sector Health Records.

The Annual Confidentiality Symposium held in Washington, DC, sponsored by the American Health Information Management Association.

Privacy and confidentiality sessions and meetings at the 1993 Annual Meeting of the American Statistical Association; San Francisco, CA.

Designing Privacy in Computer Systems for Health Care Information, a workshop sponsored by the Office of Technology Assessment.

The 1993 Annual Meeting of the American Society of Law, Medicine and Ethics; Arlington, VA.

The Conference on Clinical Technologies, Emerging Systems to Improve Mental Health Outcomes; Cambridge, MA.

The 1993 Drug Information Association Workshop, "Drug Utilization Review;" Arlington, VA.

The Conference on The 1993 Louis Harris-Equifax Health Information Privacy Survey, cosponsored by the American Health Information Management Association, in cooperation with the U.S. Office of Consumer Affairs.

The Annual Meeting of the American Public Health Association; San Francisco, CA.

The Annual Meeting of the National Association of Health Data Organizations; Washington, DC.

Continuing Work Plan

The Confidentiality liaison intends to carry out the following work plan in 1994:

- Encourage the Secretary to take a proactive stance in the health care reform debate with regard to the need for a balance between privacy and confidentiality and legitimate access to data for health services research and policy formulation.
- Monitor the current national activities related to data sharing, unique identifiers, privacy, and confidentiality issues.
- Assist NCVHS subcommittees in areas related to data sharing, confidentiality, and unique identifiers.

Appendix I.
Legislative Authority for the National Committee on Vital and Health Statistics From the Public Health Service Act

Section 306, subsection (k) of Public Health Service Act

(1) There is established in the Office of the Secretary a committee to be known as the National Committee on Vital and Health Statistics (hereinafter in this subsection, referred to as the "Committee") which shall consist of sixteen members.

(2) The members of the Committee shall be appointed by the Secretary from among persons who have distinguished themselves in the fields of health statistics, health planning, epidemiology, and the provision of health services. Except as provided in subparagraph (B), members of the Committee shall be appointed for terms of four years.

(3) Members of the Committee shall be compensated in accordance with section 208(c).

(4) It shall be the function of the Committee to assist and advise the Secretary—

  (A) to delineate statistical problems bearing on health and health services which are of national or international interest;

  (B) to stimulate studies of such problems by other organizations and agencies whenever possible or to make investigations of such problems through subcommittees;

  (C) to determine, approve, and revise the terms, definitions, classifications, and guidelines for assessing health status and health services, their distribution and costs, for use (i) within the Department of Health and Human Services, (ii) by all programs administered or funded by the Secretary, including the Federal-State-local cooperative health statistics system referred to in subsection (e), and (iii) to the extent possible as determined by the head of the agency involved, by the Veterans' Administration, the Department of Defense, and other Federal agencies concerned with health and health services;

  (D) with respect to the design of and approval of health statistical and health information systems concerned with the collection, processing, and tabulation of health statistics within the Department of Health and Human Services, with respect to the Cooperative Health Statistics System established under subsection (e), and with respect to the standardized means for the collection of health information and statistics to be established by the Secretary under subsection (j)(i);

  (E) to review and comment on findings and proposals developed by other organizations and agencies and to make recommendations for their adoption or implementation by local, State, national, or international agencies;

  (F) to cooperate with national committees of other countries and with the World Health Organization and other national agencies in the studies of problems of mutual interest; and

(G) to issue an annual report on the state of the Nation's health, its health services, their costs and distributions, and to make proposals for improvement of the Nation's health statistics and health information systems.

(5) In carrying out health statistical activities under this part, the Secretary shall consult with, and seek the advice of, the Committee and other appropriate professional advisory groups.

Appendix II. Charter

THE SECRETARY OF HEALTH AND HUMAN SERVICES
WASHINGTON, D.C. 20201

CHARTER

NATIONAL COMMITTEE ON VITAL AND HEALTH STATISTICS

PURPOSE

The Secretary is charged under Section 306(k) of the Public Health Service Act, as amended, 42 U.S.C. 242k(k), with the responsibility to collect, analyze, and disseminate national statistics on vital events; the extent and nature of illness and disability of the population of the United States; the impact of illness and disability of the population on the economy of the United States, and on other aspects of the well-being of its population; environmental, social, and other health hazards; determinants of health; health resources and the supply of services by health institutions; utilization of health care; health-care costs and financing; family formation, growth, and dissolution; to undertake research, demonstrations, and evaluations respecting new or improved methods for obtaining current data on the matters referred to above; to undertake epidemiological research, demonstrations, and evaluations on such matters; to provide selected technical assistance to State and local jurisdictions; to coordinate health statistical and epidemiological activities of the Department; and to engage in cooperative endeavors with other countries to foster research consultation and training programs in statistical activities.

This committee shall provide advice, consultation, and assistance and make recommendations to the Secretary through the Assistant Secretary for Health on policies and plans in developing major national systems of health data collection in the Department, on coordination of Federal health data requirements, and on analysis over a wide range of questions relating to general health problems of the population, health-care resources, the use of health-care services and health-care financing and expenditures. In these matters, the Committee shall consult with the Health Care Financing Administration and other components of the Department, other Federal entities, and non-Federal organizations as appropriate.

AUTHORITY

Section 306(k) of the Public Health Service Act, as amended, 42 U.S.C. 242k(k). The Committee is governed by provisions of Public Law 92-463 (5 U.S.C. App. 2) which sets forth standards for the formation and use of advisory committees.

FUNCTION

It shall be the function of the Committee to assist and advise the Secretary:

(A) to delineate statistical problems bearing on health and health services which are of national or international interest;

(B) to stimulate studies of such problems by other organizations and agencies whenever possible or to make investigations of such problems through subcommittees;

(C) to determine, approve and revise the terms, definitions, classifications, and guidelines for assessing health status and health services, their distribution and costs, for use:
(i) within the Department of Health and Human Services;
(ii) by all programs administered or funded by the Secretary;
and (iii) to the extent possible as determined by the head of the agency involved, by the Department of Veterans Affairs, the Department of Defense, and other Federal agencies concerned with health and health services;

(D) with respect to the design of and approval of health statistical and health information systems concerned with collection, processing, and tabulation of health statistics within the Department of Health and Human Services, and with respect to the standardized means for the collection of health information and statistics to be established by the Secretary under subsection (j)(i);

(E) to review and comment on findings and proposals developed by other organizations and agencies and to make recommendations for their adoption or implementation by local, State, national, or international agencies;

(F) to cooperate with national committees of other countries and with the World Health Organization and other national agencies in the studies of problems of mutual interest;

(G) in the development of a report on the state of the Nation's health, its health services, their costs and distributions, to make proposals for improvement of the Nation's health statistics and health information systems, at such intervals as may be required by the Congress;

(H) in establishing standards to assure the quality of health statistical and epidemiological data collection, processing, and analysis; and

(I) with respect to data on the effects of the environment on health.

STRUCTURE

The Committee shall consist of 16 members, including the Chair. The members of the Committee shall be appointed by the Secretary from among persons who have distinguished themselves in the fields of health statistics, health planning, epidemiology, and the provision of health services. The Secretary shall appoint the Chair for a one-year period, renewable at the discretion of the Secretary.

Members shall be invited to serve for overlapping four-year terms. Terms of more than two years are contingent upon the renewal of the Committee by appropriate action prior to its termination. Any member appointed to fill a vacancy occurring prior to expiration of the term for which their predecessor was appointed shall be appointed only for the remainder of such term. A member may serve after the expiration of their term until a successor has been appointed.

Subcommittees composed of members of the parent Committee may be established to provide the Committee with background study and proposals for consideration and action. The Chair shall appoint members from the parent Committee to the subcommittees and designate a Chair for each subcommittee. The Chair shall appoint ad hoc subcommittees, composed solely of members of the parent Committee, as necessary to address specific issues for consideration. The subcommittees shall make their recommendations to the parent Committee. Timely notification of the subcommittees and ad hoc subcommittees, including charges and membership, shall be made in writing to the Department Committee Management Officer by the Executive Secretary of the Committee.

Management and support services shall be provided by the National Center for Health Statistics, Centers for Disease Control.

MEETINGS

Meetings shall be held not less than annually at the call of the Chair with the advance approval of a Government official, who shall also approve the agenda. A Government official shall be present at all meetings.

Meetings of the subcommittees shall be held at the call of the Chair with the advance approval of a Government official, who shall also approve the agenda. A Government official shall be present at all subcommittee meetings. All subcommittees shall report their findings to the Committee.

Meetings shall be open to the public except as determined otherwise by the Secretary; notice of all meetings shall be given to the public.

Meetings shall be conducted, and records of the proceedings kept, as required by the applicable laws and departmental regulations.

COMPENSATION

Members who are not full-time Federal employees shall be paid at the rate of $188 per day, plus per diem and travel expenses in accordance with the Standard Government Travel Regulations.

ANNUAL COST ESTIMATE

Estimated annual cost for operating the Committee, including compensation and travel expenses for members but excluding staff support, is $147,723. Estimated annual man-years of staff support required is 2.5, at an estimated annual cost of $133,650.

REPORTS

An annual report shall be submitted to the Secretary through the Assistant Secretary for Health, not later than January 31 of each year, which shall contain as a minimum a list of members and their business addresses, the Committee's functions, dates and places of meetings, and a summary of committee activities and recommendations made during the fiscal year. A copy of the report shall be provided to the Department Committee Management Officer.

TERMINATION DATE

The duration of the National Committee on Vital and Health Statistics is continuing, and a new charter shall be filed no later than July 23, 1994, the date of the expiration of the next two-year period following the date of the statute establishing this advisory committee, in accordance with Section 14(b)(2) of Public Law 92-463.

APPROVED:

JUL 23 1992

Date

Louis W. Sullivan

Louis W. Sullivan, M.D.
Secretary

Appendix III.
Roster of the National Committee on Vital and Health Statistics

Department of Health and Human Services
Office of the Assistant Secretary for Health

Chair

Judith Miller Jones (1996)
Director
National Health Policy Forum
2021 K Street, NW., Suite 800
Washington, DC 20006

Executive Secretary

Gail F. Fisher, Ph.D.
Associate Director, Office of
Planning and Extramural Programs
National Center for Health Statistics
6525 Belcrest Road
Hyattsville, MD 20782

Current Membership

(Date Appointment Expires)

John T. Ashley, M.D. (1994)
Associate Vice President
University of Virginia
Health Sciences Center
Box 236, Jefferson Park Avenue
Charlottesville, VA 22908

William F. Bridgers, M.D. (1994)
2221 English Village Lane
Birmingham, AL 35223

Nancy L. Cannon, Ph.D. (1993)
315 Lincoln Street
Lexington, MA 02173

Paul Y. Ertel, M.D. (1994)
Clinical Professor
University of Michigan, Pediatrics
Applied Medical Data
400 Maynard Street, Suite 11A
Ann Arbor, MI 48104

Donna Ganzer (1995)
Vice President
Health Care Management and
Patient Services
American Hospital Association
840 North Lake Shore Drive
Chicago, IL 60611

Judith D. Kasper, Ph.D. (1996)
Associate Professor
Department of Health Policy
and Management
The Johns Hopkins University
Room 689 Hampton House
624 North Broadway
Baltimore, MD 21205–1901

Sister Irene V. Kraus (1993)
President and CEO
Sacred Heart Hospital
5151 North 9th Avenue
P.O. Box 2700
Pensacola, FL 32513–2700

Carlos A. Moreno, M.D. (1994)
Associate Professor
Department of Family Practice
University of Texas Health Science
Center at San Antonio
7703 Floyd Curl Drive
San Antonio, TX 78284

Byron C. Pevehouse, M.D. (1995)
135 Mountain Spring Avenue
San Francisco, CA 94114–2119

Bruce Steinwald (1995)
Vice President
Health Technology Associates
Columbia Square
555 Thirteenth Street, NW.
Washington, DC 20004–1109

James W. Thompson, M.D. (1996)
Associate Professor of Psychiatry
University of Maryland at Baltimore
School of Medicine
IPHB, 645 West Redwood Street
Baltimore, MD 21201

George H. Van Amburg (1993)
State Registrar and Chief
Office of the State Registrar
and Center for Health Statistics
Michigan Department of Public Health
4323 North Logan Street, Box 30195
Lansing, MI 48909

Thomas T.H. Wan, Ph.D. (1995)
Professor and Chair
Department of Health Administration
Medical College of Virginia
Virginia Commonwealth University
520 North End 12th Street, Box 203
Richmond, VA 23298–0203

David R. Williams, Ph.D. (1996)
Associate Research Scientist
Associate Professor of Sociology
Institute for Social Research
University of Michigan
P.O. Box 1248
Ann Arbor, MI 48106

Nicholas Zill, Ph.D. (1996)
Vice President
Westat, Inc.
1650 Research Boulevard
Rockville, MD 20850–3129

Meeting Dates

All meetings held in Washington, DC

March 9–11, 1993
June 8–10, 1993
November 3–5, 1993

Appendix IV. Subcommittees of the National Committee on Vital and Health Statistics, Rosters, Meeting Dates, and Charges

Executive Subcommittee

Current Roster

Chair

Judith Miller Jones (1996)
Director
National Health Policy Forum
2021 K Street, NW., Suite 800
Washington, DC 20006

Paul Y. Ertel, M.D. (1994)
Clinical Professor
University of Michigan, Pediatrics
Applied Medical Data
400 Maynard Street, Suite 11A
Ann Arbor, MI 48104

Judith D. Kasper, Ph.D. (1996)
Associate Professor
Department of Health Policy
and Management
The Johns Hopkins University
Room 689 Hampton House
624 North Broadway
Baltimore, MD 21205–1901

Bruce Steinwald (1995)
Vice President
Health Technology Associates
Columbia Square
555 Thirteenth Street, NW.
Washington, DC 20004–1109

George H. Van Amburg (1993)
State Registrar and Chief
Office of the State Registrar
and Center for Health Statistics
Michigan Department of Public Health
4323 North Logan Street, Box 30195
Lansing, MI 48909

Ex Officio

Gail F. Fisher, Ph.D.
Executive Secretary
National Committee on Vital and
Health Statistics
6525 Belcrest Road
Hyattsville, MD 20782

Staff

Jack Anderson, NCHS
Marjorie S. Greenberg, NCHS
Thomas S. Vissman, NCHS

Robert Moore, HCFA

Harvey A. Schwartz, Ph.D., AHCPR

Meeting Dates

Meetings held in Washington, DC

January 11, 1993 (Conference Call)
April 14, 1993
September 8, 1993

Meetings held in Shepherdstown, WV

April 25–27, 1993

Functions and Process for the Executive Subcommittee, NCVHS

Background

At the November 8, 1985, meeting of the NCVHS, based upon the recommendations of the Ad-hoc Subcommittee on Policy and Directions, there was established an Executive Subcommittee of the NCVHS.

Purpose

The Executive Subcommittee was established to assist the Chairman, NCVHS, in administering the activities of the NCVHS to facilitate and expedite accomplishment of policies determined by the full Committee, and in providing liaison with governmental and nongovernmental organizations. The functions and procedures governing the Executive Subcommittee are subject to approval and modification by the full Committee.

Composition

The Chairman of the NCVHS is the Chairman of the Executive Subcommittee. Additionally, the Chairman, NCVHS, shall appoint, subject to ratification of the full Committee, three members to the Executive Subcommittee on an annual basis, with the option of reappointment, if appropriate. When appropriate, the three members will be selected one member each from those who have 1, 2, or 3 years remaining in their terms of appointment to the NCVHS. The NCVHS Executive Secretary, or designee, will be an ex officio member of the Executive Subcommittee.

Functions

Specific responsibilities of the Executive Subcommittee are to:

- Identify and recommend issues for full Committee and subcommittee attention.
- Develop Committee agendas, with a view towards planning several agendas in advance.
- Develop annual NCVHS Report.
- Coordinate and facilitate subcommittee activities.
- Advise National Center for Health Statistics (NCHS) or other appropriate agency on allocation of annual NCVHS budget and on resource needs for future years.
- Conduct other business delegated to it by the full Committee.

Procedures and Process

The Executive Subcommittee is empowered to act between full Committee meetings on those activities delegated to the Subcommittee, their actions subject to ratification by the full Committee.

Specific activities include:

1. In interim periods between the full Committee meetings of the NCVHS, the Executive Subcommittee will monitor, through telephone calls, mail, and/or meetings, the progress of work and other activities relevant to the current approved

program of the full Committee. Working with staff and subcommittee Chairmen, activities will be facilitated, and problems and issues identified and resolved to accomplish the planned program.

2. The Executive Subcommittee will review work plans developed by the subcommittees and make recommendations to the full Committee.
3. The Subcommittee may confer with Chairmen of other subcommittees or with others to consider particular problems or issues impacting on the work of the full Committee. These may include senior personnel in the Department and other public and private agencies with interest in considerations appropriate to the responsibilities of the Committee.
4. Minutes of any meetings of the Subcommittee will be prepared and mailed to the full Committee membership and/or presented at the next full Committee meeting. If work progresses by mechanisms other than meetings, appropriate reports will be made to the full Committee membership.
5. The Chairman of the NCVHS or designee will report on the activities of the Subcommittee at each full meeting. This report will include an outline of the areas of concern of the Subcommittee and proposed plans for subsequent followup and activity.
6. In unusual events where some actions, previously not approved by the Committee, may be required by the NCVHS and a meeting has not been scheduled, the Subcommittee may consider alternatives and make recommendations to the full Committee by mail or telephone. With concurrence, approved actions may be taken by the Chairman or other formally appointed representatives of the Committee.
7. In the absence of the Chairman at an Executive Subcommittee or full Committee meeting, the Executive Subcommittee member with the most seniority on the NCVHS would act as Chairman.

Subcommittee on Medical Classification Systems

Current Roster

Chair

Bruce Steinwald (1995)
Vice President
Health Technology Associates
Columbia Square
555 Thirteenth Street, NW.
Washington, DC 20004–1109

Paul Y. Ertel, M.D. (1994)
Clinical Professor
University of Michigan, Pediatrics
Applied Medical Data
400 Maynard Street, Suite 11A
Ann Arbor, MI 48104

Donna Ganzer (1995)
Vice President
Health Care Management and
Patient Services
American Hospital Association
840 North Lake Shore Drive
Chicago, IL 60611

Byron C. Pevehouse, M.D. (1995)
135 Mountain Spring Avenue
San Francisco, CA 94114–2119

James W. Thompson, M.D. (1996)
Associate Professor of Psychiatry
University of Maryland at Baltimore
School of Medicine
IPHB, 645 West Redwood Street
Baltimore, MD 21201

Staff

Lynnette Araki, NCHS
Perrianne Lurie, M.D., NCHS
Sue Meads, NCHS

Patricia Brooks, HCFA

Kathleen A. Weis, Dr.P.H., AHCPR

Meeting Dates

Meetings held in Washington, DC

January 27, 1993
March 10, 1993 (Working Session)
April 1, 1993
June 9, 1993 (Working Session)
September 9, 1993
November 4, 1993 (Working Session)

Charge to the Subcommittee on Medical Classification Systems

It shall be the charge to this Subcommittee to monitor, evaluate, and formulate recommendations as appropriate in the following areas:

- The progress of decisions regarding *International Classification of Diseases, 10th Revision* (ICD-10) with particular attention to the feasibility of development and necessity of an International Classification of Diseases, 10th Revision, Clinical Modification (ICD-10-CM), including alternative mechanisms and suggested time tables for a clinical modification.
- The progress towards implementation of ICD-10 including ongoing dissemination of information; the development and dissemination of educational materials; the implementation of operational systems and programs to serve the whole of the user community, providers (physicians, hospitals, ambulatory care), payers, researchers, etc.

- The development and use of derivative applications of the ICD, including specialty-specific compendia.
- The continuing process of the ICD-9-CM Coordination and Maintenance Committee and related activities since they are expected to serve as the prototype for ongoing maintenance of ICD-10, including national and international activities.
- The progress of activities relating to the development and improvement of classification systems for procedures in the United States.
- The ongoing refinement of Diagnosis Related Groups (DRG's), including non-Medicare applications.
- The progress towards improvement of data quality and coding accuracy, systems for automated coding of medical diagnoses, and patient record documentation.

Subcommittee on Long-Term Care Statistics

Current Roster

Chair

Judith D. Kasper, Ph.D. (1996)
Associate Professor
Department of Health Policy
and Management
The Johns Hopkins University
Room 689 Hampton House
624 North Broadway
Baltimore, MD 21205–1901

William F. Bridgers, M.D. (1994)
2221 English Village Lane
Birmingham, AL 35223

Nancy L. Cannon, Ph.D. (1993)
315 Lincoln Street
Lexington, MA 02173

Judith Miller Jones (1996)
Director
National Health Policy Forum
2021 K Street, NW., Suite 800
Washington, DC 20006

Thomas T.H. Wan, Ph.D. (1995)
Professor and Chair
Department of Health Administration
Medical College of Virginia
Virginia Commonwealth University
Box 203
Richmond, VA 23298-0203

Staff

Lynnette Araki, NCHS
Evelyn Mathis, NCHS

Marvin Feuerberg, Ph.D., HCFA
Judith Sangl, Sc.D., HCFA

Mary Waid, HCFA

Meeting Dates

Meetings held in Washington, DC

March 1–2, 1993
June 10, 1993 (Working Session)
September 20, 1993
November 4, 1993 (Working Session)

Charge to Subcommittee on Long-Term Care Statistics

The multifaceted universe of chronic or long-term care of interest to the Subcommittee consists of those therapeutic and preventive health services and social and personal services required to compensate for or preclude losses in independent functioning resulting from physical or cognitive impairments. These services take place in a wide range of institutional, community, and residential settings, are provided by various kinds of professionals as well as lay persons, are paid for by a number of Federal, State, and local public and private sources, and sometimes are provided without compensation. All of these factors make consideration of data adequacy a complex undertaking.

There is a link between disability and long-term care, and the causes of disability are varied: developmental, injury-related, chronic disease-related including mental health conditions, related to aging or frailty, or to conditions secondary to a primary disability. Disabilities often dictate the need for assistance in the activities of daily living (ADL's) or instrumental ADL's (IADL's). However, care of the disabled or those at risk in the disabling process is not limited to that resulting from ADL and IADL limitations; it requires a complete and integrated system of longitudinal care.

The Subcommittee's charge is to describe and assess the adequacy of statistical information on needs, access, utilization, effectiveness, financing, and eligibility for long-term care as broadly defined. Projections suggest that this challenge will become greater in the years just ahead; as the baby boom generation ages and mortality rates continue to fall, the number of older persons will increase. The prevalence of some chronic, debilitating conditions and comorbidities will increase, and the complexities of assuring equitable and effective financial and geographic access to appropriate care will expand. An increasing capability for therapeutic and preventive intervention technologies and strategies such as deinstitutionalizing many with disabilities may lead to further fragmentation of services and their financing, further complicating data adequacy. The work plan of this Subcommittee will need to evolve in response to all of these factors; this will be a multi-year undertaking.

Subcommittee on Ambulatory and Hospital Care Statistics

Current Roster

Chair

John T. Ashley, M.D. (1994)
Associate Vice President
University of Virginia
Health Sciences Center
Box 236, Jefferson Park Avenue
Charlottesville, VA 22908

Paul Y. Ertel, M.D. (1994)
Clinical Professor
University of Michigan, Pediatrics
Applied Medical Data
400 Maynard Street, Suite 11A
Ann Arbor, MI 48104

Donna Ganzer (1995)
Vice President
Health Care Management and
Patient Services
American Hospital Association
840 North Lake Shore Drive
Chicago, IL 60611

Judith Miller Jones (1996)
Director
National Health Policy Forum
2021 K Street, NW., Suite 800
Washington, DC 20006

Byron C. Pevehouse, M.D. (1995)
135 Mountain Spring Avenue
San Francisco, CA 94114–2119

George H. Van Amburg (1993)
State Registrar and Chief
Office of the State Registrar
and Center for Health Statistics
Michigan Department of Public Health
4323 North Logan Street, Box 30195
Lansing, MI 48909

Staff

Marjorie S. Greenberg, NCHS
Catherine Burt, Ed.D., NCHS
Linda Lawrence, NCHS

William Sobaski, HCFA

Roxanne Andrews, Ph.D., AHCPR
Judy Ball, Ph.D., AHCPR

Meeting Dates

Meetings held in Washington, DC

January 28, 1993
March 10, 1993 (Working Session)
April 15, 1993
June 9, 1993
September 22, 1993 (Working Session)
November 4, 1993 (Working Session)

Charge to Subcommittee on Ambulatory and Hospital Care Statistics

1. Monitor the responses within DHHS to the Proposed Revision to the Uniform Hospital Discharge Data Set (UHDDS), which was submitted to the Assistant Secretary for Health by the NCVHS in June 1992, and the subsequent NCVHS response to the report of the Interagency Task Force on the UHDDS. Follow the process within the Department for reconciling the two sets of recommendations and promulgating a revised UHDDS.

2. Monitor the responses within DHHS to the final report on the Uniform Ambulatory Care Data Set (UACDS), which was submitted to the Assistant Secretary for Health by the NCVHS and the Interagency Task Force on the UACDS in June 1989.
3. Review the recommendations contained in the 1989 Uniform Ambulatory Care Data Set and any subsequent revisions under consideration by the Office of the Assistant Secretary for Health, in light of the proposed revisions to the UHDDS and information needs for health reform. Examine needs for enrollment and encounter data and consider the extent to which additional testimony or input is indicated from other government agencies, the research community, and the private sector. Conduct this review, to the extent possible, in cooperation with departmental committees and work groups responsible for developing and reviewing uniform health data standards.
4. Review the efforts of the Uniform Claim Form Task Force (for the HCFA 1500), the National Uniform Billing Committee (for the UB-92), the American National Standards Institute Healthcare Informatics Standards Planning Panel, and the Computer-Based Patient Record Institute to seek greater standardization of the data sets, definitions, classification systems, forms and electronic formats for collecting and sharing ambulatory and hospital care data.
5. Review and contribute to the work of the Department and the private sector in developing and promoting standards for electronic receipt and transmission of health insurance information and for an automated patient medical record.
6. Provide continuing liaison with the Health Care Financing Administration (HCFA), the National Center for Health Statistics (NCHS), the Agency for Health Care Policy and Research (AHCPR), and other relevant agencies concerning data systems and research and demonstration projects pertaining to patient-provider encounters.
7. Follow data systems development and related activities by receiving periodic updates, responding to developments, and, where appropriate, framing recommendations concerning their future course. Among those activities for which data policy, data coordination, and data quality issues will be reviewed are a) progress towards implementing the Medicare Transaction System, b) status of the revision of the HCFA 1500, c) status of the implementation of the UB-92, d) progress towards implementation by the Medicare program of the unique physician identification number (UPIN), e) status of research and demonstration projects on prospective payment methodologies for ambulatory care, f) Medicaid data development, g) status of the evaluation and modification of the external cause-of-injury coding system, h) development of the National Health Care Survey components for ambulatory and hospital care, and i) development of the National Practitioner Data Bank.
8. Consider and make recommendations concerning the needs for data to inform the discussion of various health care reform proposals, to establish a minimum baseline, to identify key indicators for tracking health status and health care, and to monitor the impact of reform proposals as they are implemented. This will include looking at the capability of health care delivery systems, including managed care systems, to provide the desired data.
9. Review emerging and projected quality and outcomes of care activities for relevance to existing data systems and implications for revisions to those systems. Examine data quality issues related to measurement of the effectiveness and quality of care. Provide liaison with HCFA and Public Health Service (PHS) on these types of activities.

Subcommittee on Health Statistics for Minority and Other Special Populations

Current Roster

Chair

Carlos A. Moreno, M.D. (1994)
Associate Professor
Department of Family Practice
University of Texas Health Science
Center at San Antonio
7703 Floyd Curl Drive
San Antonio, TX 78284

Sister Irene V. Kraus (1993)
President and CEO
Sacred Heart Hospital
5151 North 9th Avenue,
P.O. Box 2700
Pensacola, FL 32513–2700

Thomas T.H. Wan, Ph.D. (1995)
Professor and Chair
Department of Health Administration
Medical College of Virginia
Virginia Commonwealth University
520 North End 12th Street, Box 203
Richmond, VA 23298–0203

David R. Williams, Ph.D. (1996)
Associate Research Scientist
Associate Professor of Sociology
Institute for Social Research
University of Michigan
P.O. Box 1248
Ann Arbor, MI 48106

Staff

P. Ellen Parsons, Ph.D., NCHS
Diane Makuc, Ph.D., NCHS
Patricia M. Golden, NCHS

Frank Emerson, HCFA

Harvey A. Schwartz, Ph.D., AHCPR

Meeting Dates

Meetings held in Washington, DC

February 9–10, 1993
March 10, 1993 (Working Session)
June 8–9, 1993 (Working Sessions)
November 4, 1993 (Working Session)

Charge to Subcommittee on Health Statistics for Minority and Other Special Populations

Recognizing the importance to the Department of Health and Human Services of collecting and disseminating valid and reliable health data on minority and other special populations, it shall be the Subcommittee's charge to:

1. Review and make recommendations on the uniformity and adequacy of the collection, analysis, and dissemination of minority health data.
2. Work with and support the Office of Minority Health and collaborating offices in their data-related minority health activities.
3. Examine health data issues related to the medically indigent, including the medically underserved, uninsured, and underinsured to determine whether DHHS systems adequately address these issues, and make recommendations.

Subcommittee on Mental Health Statistics

Current Roster

Chair

Nicholas Zill, Ph.D. (1996)
Vice President
Westat, Inc.
1650 Research Boulevard
Rockville, MD 20850–3129

Nancy L. Cannon, Ph.D. (1993)
315 Lincoln Street
Lexington, MA 02173

Judith D. Kasper, Ph.D. (1996)
Associate Professor
Department of Health Policy and Management
The Johns Hopkins University
Room 689 Hampton House
624 North Broadway
Baltimore, MD 21205–1901

James W. Thompson, M.D. (1996)
Associate Professor of Psychiatry
University of Maryland at Baltimore School of Medicine
IPHB, 645 West Redwood Street
Baltimore, MD 21201

Thomas T.H. Wan, Ph.D. (1995)
Professor and Chair
Department of Health Administration
Medical College of Virginia
Virginia Commonwealth University
520 North End 12th Street, Box 203
Richmond, VA 23298–0203

David R. Williams, Ph.D. (1996)
Associate Research Scientist
Associate Professor of Sociology
Institute for Social Research
University of Michigan
P.O. Box 1248
Ann Arbor, MI 48106

Staff

Ronald Manderscheid, Ph.D., SAMHSA

Peggy Barker, NCHS

Regina Walker, HCFA

Shirley Clark, AHCPR

Meeting Dates

Meetings held in Washington, DC

February 16, 1993
May 11, 1993
July 6–7, 1993
October 19, 1993

Charge to Subcommittee on Mental Health Statistics

The Subcommittee will serve to identify important mental health statistical issues for the full Committee and to facilitate the integration of general health and mental health statistical systems. More specifically, it will

1. Identify major gaps in mental health statistics;
2. Explore the feasibility of filling existing gaps with ongoing data collection efforts; to explore how ongoing efforts might be supplemented;

3. Examine areas of measurement development necessary to meet national goals or priorities;
4. Work with PHS and other DHHS agencies to identify areas of needed initiatives and opportunities for coordination of efforts and to bring in other relevant Federal agencies;
5. Examine how major data sources (for example, Medicare and Medicaid data) can be used to help meet mental health data needs;
6. Explore opportunities for data linkage relevant to data bases collected by NCHS, HCFA, and other Federal agencies;
7. Increase the availability, quality, and utility of data dealing with mental illness including the provision of public-use data tapes; and
8. Coordinate the NCVHS review of the biennial publication, *Mental Health, United States.*

Committee on State and Community Health Statistics

Current Roster

Chair

George H. Van Amburg (1993)
State Registrar and Chief
Office of the State Registrar and
Center for Health Statistics
Michigan Department of Public Health
P.O. Box 30195
Lansing, MI 48909

John T. Ashley, M.D. (1994)
Associate Vice President
University of Virginia
Health Sciences Center
Box 236, Jefferson Park Avenue
Charlottesville, VA 22908

William F. Bridgers, M.D. (1994)
2221 English Village Lane
Birmingham, AL 35223

Sister Irene V. Kraus (1993)
President and CEO
Sacred Heart Hospital
5151 North 9th Avenue,
P.O. Box 2700
Pensacola, FL 32513–2700

Nicholas Zill, Ph.D. (1996)
Vice President
Westat, Inc.
1650 Research Boulevard
Rockville, MD 20850–3129

Staff

Mary Anne Freedman, NCHS

Kathleen A. Weis, Dr.P.H., AHCPR

Meeting Dates

Meetings held in Washington, DC

February 18, 1993
April 21, 1993
September 21, 1993
November 4, 1993 (Working Session)

Charge to Subcommittee on State and Community Health Statistics

Background

The Institute of Medicine Report *The Future of Public Health* identifies health assessment as one of the necessary core functions of public health departments (1). To quote from the report:

> *The Committee recommends that every public health agency regularly and systematically collect, assemble, analyze, and make available information on the health of the community, including statistics on health status, community health needs, and epidemiologic and other studies of health problems.*

Health assessment is necessary at all levels of government. However, it is at the local or community level where public health issues are identified and solutions effected.

Unfortunately, the resources (people, money, accepted methodologies, and statistics) to conduct such assessments at the community level are often inadequate.

Healthy People 2000, the year 2000 health objectives, underscores the need for assessment at the community level. Priority area 22, Surveillance and Data Systems, addresses the public health problems and evaluates solutions (2). NCHS, as lead agency for implementing priority area 22, must work with public and private agencies to track the objectives, identify data gaps, and build statistical capacity at the State and local levels. As the year 2000 process proceeds, many of the general concerns related to community health assessment will become focal points of year 2000 initiatives.

The process of setting the year 2000 objectives has brought together many individuals and organizations from the public and private sectors. These groups will be instrumental in implementing intervention strategies and evaluating success toward meeting the objective targets. The NCVHS has the opportunity to complement these activities by utilizing its broad advisory role to assist the Public Health Service in policy development related to data availability and need.

The charge of the Subcommittee shall be to:

1. Monitor progress toward achieving the year 2000 health objectives 22.1–22.7.
2. Work with NCHS, other Federal and State agencies, appropriate private agencies, and other subcommittees of the NCVHS to review and identify gaps in current health statistics including social, environmental, mental health, social economic, health care, and disease statistics.
3. Review efforts to link national, State, and local data sets including data collected and compiled by the private sector for use in evaluating the effectiveness of disease and injury prevention and therapeutic intervention strategies.
4. Participate with other groups in a process to recommend any necessary action to improve the comparability and compatibility of health statistics collected and published through various government and private agencies.
5. Identify and review current alternative methodological approaches to community health assessment.
6. Review and monitor the annual *Prevention Profile* that will appear in *Health, United States* throughout the 1990's.

References

1. Institute of Medicine. The future of public health. Washington: National Academy Press. 1988.
2. U.S. Department of Health and Human Services. Healthy people 2000: National health promotion and disease prevention objectives. Washington: Public Health Service. 1990.

Work Group on Confidentiality

Current Roster

Chair and Monitor

James W. Thompson, M.D. (1996)
Associate Professor of Psychiatry
University of Maryland at Baltimore
School of Medicine
IPHB, 645 West Redwood Street
Baltimore, MD 21201

Meeting Dates

Meetings held in Washington, DC

March 10, 1993 (Working Session)

Staff

Mary A. Moien, NCHS

Glenn Martin, HCFA

Harvey A. Schwartz, Ph.D., AHCPR

Charge to Work Group on Confidentiality

The Work Group on Confidentiality had two objectives for 1991–92: 1) the explication of current public policy issues surrounding the release and disclosure of data and, 2) the development of a strategic approach to the long-term management of these critical issues. In setting a course of the Work Group, the basic assumption was that the National Committee members have a common goal. Health care data should be made available to researchers and policy analysts (at the appropriate levels of disaggregation), *with* the correct safeguards in place to protect confidentiality.

Background

The Work Group on Confidentiality was formed as a result of discussion during the March 1991 meeting of the National Committee. The members of the Work Group held a conference call in May. In the discussion, it became clear that other interagency and interdepartmental and National Academy of Sciences work underway on confidentiality and privacy may be informative but will not necessarily address the broad questions of concern to the National Committee. The consensus of the group was that the NCVHS is in a unique position to assist specific agencies in their deliberations, and to heighten awareness of the advantages of proactive policy positions on data linkage, access, security, and the role of the social security number or other unique identifier.

Appendix V. Recommendations for a Single Procedure Classification System, November 1993

Summary and Recommendations

In its capacity as advisor to the Secretary of Health and Human Services, the National Committee on Vital Health Statistics (NCVHS) has for years been concerned with the manner in which patient classification systems contribute to health data. The Medical Classification Subcommittee of NCVHS is charged with the responsibility of identifying circumstances when evolving health data needs create requirements for changes in classification systems or processes for system maintenance and updating. Classification systems play a crucial role in nearly all uses of health data, including reimbursement, outcomes research, and program evaluation. If such systems are deficient, the uses of health data are inevitably compromised.

This report concerns the systems used in the United States for classifying medical and related services and procedures. The Committee has evaluated substantial information over a long period indicating that existing systems are structurally flawed and wastefully redundant. Over the past year, the Subcommittee sought advice from a wide range of organizations and individuals who have a stake in procedure classification. Although there was considerable diversity of opinion on priorities and potential solutions to the current situation, there was also consistent support for the concept of moving as quickly as possible to a single, unified system. It is largely on the basis of this support that the Subcommittee advised the full Committee that the need for action was evident.

A combination of forces make movement to a single system timely. First, existing systems are increasingly limited in their ability to meet the evolving needs for procedure classification. The growing requirements to classify new procedures and to more fully describe preventive and primary care services, for example, have outstripped the capacities of existing systems. Specifically, we are running out of code numbers in each of the existing systems. Also, the two systems (*International Classification of Diseases, 9th edition, Clinical Modification* and *Physicians' Current Procedural Terminology)* cannot be combined or crosswalked, and neither can be "fixed" without a complete overhaul (that is, creating a new classification).

Second, existing systems are incapable of permitting recent advances in information technology to create the data bases necessary to evaluate an increasingly complicated health care technology. The need to evaluate health care on the basis of health outcomes demands data that describe the full range of services provided for treatment of given illnesses and conditions. Continued use of existing procedure classification systems presents a serious obstacle to accomplishing this goal.

Third, and most important, the health care reform movement presents a window of opportunity and an intensified need to consolidate procedure classification. Health care reform will require substantial retooling of health care data systems. Reform of procedure classification can be accomplished as part of this retooling effort, rather than as a completely separate endeavor. New health care financing and delivery systems that are created through health care reform will require monitoring to evaluate their effects and data to design improvements. This need is evident regardless of whether the significant reforms are enacted at the Federal, State, or private sector level.

For these reasons, as explained in greater detail below, the NCVHS is recommending to the Secretary of Health and Human Services that immediate steps be taken to create a single procedure classification system for multiple purposes in the United States. The Committee believes that the social benefits of this action would outweigh the social costs, and that the time is right to implement a change of this magnitude. Despite our conviction that this is the proper course, however, the Committee recognizes that important questions remain about how to proceed to a unified system and what precisely the system should look like. The Committee, therefore, intends to continue its deliberations on this issue and provide more concrete recommendations and consultations with components of Department of Health and Human Services (DHHS) and the private sector over the coming months.

Recommendations

- The National Committee on Vital and Health Statistics recommends development and adoption of a single system for classification of health care services and procedures to be used in all settings in which health care is delivered in the United States.
- The Secretary of the Department of Health and Human Services should assume the responsibility for the development and maintenance of a single classification system as a collaborative effort involving those who have an interest or stake in a new system.
- Development of the single procedure classification system should be given immediate priority, and implementation should be coordinated with national health reform.
- The Secretary should ensure that the system is easy to use, comprehensive, hierarchical, flexible, and serves present and future needs in the public and private sectors of health care.
- Adequate resources must be provided to support all aspects of development, implementation, evaluation, education, and maintenance.

Background

Two major classification systems are used to code medical procedures in the United States volume 3 of the *International Classification of Diseases, 9th edition, Clinical Modification* (ICD-9-CM) was developed in the United States to classify procedures performed during inpatient hospital stays. The *Physicians' Current Procedural Terminology* (CPT) system was developed by the American Medical Association (AMA) to classify procedures performed by physicians in inpatient and ambulatory settings. The two classifications have widely differing conceptual foundations, maintenance and updating systems, advantages, and limitations. Payment and other considerations require both classifications to be coded when the patient is hospitalized. The two systems are sufficiently different that they cannot be "crosswalked" on a code to code basis.

Both systems are used for multiple purposes, including research and payment. The ICD-9-CM system, for example, is integral to the creation of Diagnosis Related Groups (DRG's), which are used for payment under the Medicare Prospective Payment System. The CPT system is the core of the Health Care Financing Administration (HCFA) Common Procedure Coding System (HCPCS), which is used for Medicare reimbursement of noninstitutional providers of health services. Non-CPT components of HCPCS are used for many nonphysician-provided services.

Having two systems for coding procedures is costly for providers of care, who frequently must code both systems for the same services. It is also unproductive for research and administrative purposes to have two systems because care delivered for episodes of illness cannot always be tracked across different provider settings. However, it is costly to change; the two systems are widely used and replacement with a consolidated single system would be disruptive and expensive. Even though few would agree that the present dual system is ideal, there will be considerable resistance to movement to a single system, because of transitional costs and other factors.

Despite these costs, interest in a unified classification system is widespread. Congressman Fortney "Pete" Stark, for example, introduced a bill (H.R. 1255) in the 103rd Congress that would require the development of a "single uniform coding system for diagnostic and procedure codes." Although this provision is part of a program to reduce fraud and abuse in the Medicare program, and the bill apparently has been tabled in favor of incorporation into the larger health care reform legislative initiative, it is indicative of congressional interest in rationalizing procedure classification.

NCVHS has monitored medical procedure classification for over a decade. The Committee recommended moving to a single procedure classification system in 1986. In 1993 the Committee believes that the need to consolidate procedure classification is even more compelling. The NCVHS Subcommittee on Medical Classification Systems undertook anew a review of procedure classification beginning in 1992. The Subcommittee sought advice from a wide range of organizations and individuals who have a stake in procedure classification.

Initially, we sought information on the attributes and deficiencies of existing procedure classification systems. Second, we solicited feedback on the Subcommittee's provisional recommendations for the development and implementation of a single system. Information on persons and organizations responding to the Subcommittee's inquiries appears on pp. 71–75.

Most of the individuals who provided detailed information to the Subcommittee, particularly those who use procedure classification systems or represent system users, expressed frustration at the current state of procedure classification in the United States. They were frustrated by the deficiencies of each system and by the necessity of coding both systems, sometimes on the same cases. Although it is not possible to provide an exhaustive list of system deficiencies, some of the frequently cited problems with ICD-9-CM (volume 3) and CPT are shown in exhibit 1. These problems were culled from correspondence and from minutes of Subcommittee meetings.

The ICD-9-CM system is seen by many respondents as the better one of the two at meeting criteria for a "good" classification, such as a hierarchical structure, but woefully lacking in specificity and detail. The CPT system is more detailed, but narrowly oriented to physicians' services and poorly structured as a classification system. Both systems share many deficiencies, such as lack of space for expansion, overlapping codes, and inconsistent use of terminology. Most of the system critics did not believe that either system is "fixable" for the long term, and therefore neither system should be viewed as a potential candidate for becoming the single classification for all-purpose usage in the United States.

Certain advantages of the two systems were also pointed out. The structure established by the American Medical Association to update the CPT represents a serious effort to maintain currency with technological advancement. The broad-based foundation of the ICD-9-CM system in the international disease classification community was also seen as a positive attribute. None of these advantages, however, emerged as a sufficient justification to prefer one system over the other.

In the summer of 1993 a draft of the Subcommittee's report and recommendations was sent to a mailing list of organizations and individuals having a stake in procedure classification and its potential reform. Twenty-eight written responses from individuals representing themselves or constituent organizations were received. Respondent positions on the need for moving toward a single system of procedure classification, as articulated by the Subcommittee in its draft report, are summarized in exhibit 2.

The results of this inquiry are striking because positions adopted by respondents tend to be determined by their discipline or the type of organization they represent. All of the health information management respondents, including coders in the field, were in favor of moving to a single system. In contrast, nearly all physicians or representatives of medical organizations oppose this position. Allied (nonphysician) health occupations favored moving to a unified system, provided that their constituents were represented in system design and implementation issues. Responses of other organizations, such as government agencies and insurance organizations, were mixed.

These responses do not constitute a representative sample of all who might be affected by procedure classification or its overhaul. Nevertheless, the responses appear to provide a consistent message that should be recognized when procedure classification reform proceeds further. Medical organizations, probably because of their control of the CPT updating process through the auspices of the American Medical Association, tend not to see a need for change. Other types of organizations do see this need because of the deficiencies in the current systems and because of the perceived lack of representation in

Exhibit 1: Commonly Cited Flaws of ICD-9-CM and CPT-4 Procedure Classification Systems

Both Classifications

- lack of space for expansion
- overlapping and duplicative codes
- inconsistent and noncurrent use of terminology
- lack of codes for preventive services

ICD-9-CM (volume 3)

- insufficient specificity and detail
- insufficient structure to capture new technology

CPT-4

- nonhierarchical structure
- physician service orientation (not multidisciplinary)
- poorly defined, nondiscrete coding categories, with variable coding detail

Exhibit 2: Position on Moving to a Single Procedure Classification System by Respondent Type[1]

Type of Respondent	*Pro*	*Con*	*Neutral*[2]	*Total*
Health Information Management	7	0	0	7
Medical Organizations and Clinicians	1	8	0	9
Allied Health Professionals	4	0	0	4
Others	4	1	3	8
Total	16	9	3	28

[1] Based on written responses to the Subcommittee's second mailing soliciting comments on the draft report and recommendations.
[2] No position stated.

the maintenance and control of procedure classification. Careful planning of the participation of stakeholders in the design, implementation, and maintenance of a new system will be required.

Benefits and Costs of a Single Procedure Classification System

The Subcommittee discussed the pros and cons of recommending a single procedure classification system, continuation of the present situation with multiple classification systems, or some third alternative. After reviewing feedback from the field, the Subcommittee decided that a single procedure classification system is by far the preferred option.

Pursuing the development of a single procedure classification system will provide a unique opportunity to develop a refined system by retaining strengths and eliminating weaknesses of existing and tested systems. The Subcommittee recognizes that the cost of developing a single classification system is significant, but it also believes that the cost of *NOT* developing a single system would ultimately be more costly and harmful to the health care industry and to patients.

In the United States medical procedure classification is used for reimbursement and is also used for outcome evaluation. Adoption of a single coding scheme will facilitate development of integrated systems for procedure reimbursement in managed care and other settings. Better integration of data from inpatient and outpatient settings will improve the ability of researchers to develop diagnosis and procedure relationship studies, epidemiological studies, and statistical evaluation.

Conversion to a new system is ultimately less costly than maintenance and training on dual systems, which significantly add to the administrative burden. Current emphasis on streamlining administrative processes to reduce health care costs provides an opportunity for leadership directed to widespread adoption of automated patient records, hastening the abandonment of primitive computer systems, software, and paper forms.

In attempting to identify the benefits and costs of a single procedure classification system, the Subcommittee looked at potential effects on patients, providers, payers, and the research community.

Effect on Industry

The introduction of a new classification system will affect all levels of the health care industry. Long-term effects of a single procedure classification system can be categorized into the following areas: reimbursement, automation, and administrative and regulatory costs.

Reimbursement— A single procedure classification system will improve payment processing because reimbursement will be simplified by reducing the need to use dual systems for insurers who reimburse for services using CPT and ICD-9-CM volume 3 for physician procedures and hospital-based services. However, claims histories will have to be developed if no cross reference is available.

Intangible benefits would include less frustration on the part of coders and billers trying to use two systems. If the procedure classification system is tied to reimbursement, inpatient coding and documentation would be enhanced. Coders and billers could work together to improve the quality of their data instead of experiencing the competitiveness and fragmentation of different health care groups using different coding systems.

Automation— There is no doubt that the initial costs of converting to a new coding system will be significant. The largest cost will be in converting computer software used in the health care industry, especially if the new system differs dramatically from the currently used coding schemes. Industry costs for upgrading or altering computer systems (hardware and software) will be substantial. But it will be a one-time conversion of the coding system.

There will be a need to translate existing codes to the new system and a need for increased computer processing and storage. Validity of codes, data retrieval, crosswalks, and transition validity checks will be necessary. Sites where data are collected, processed, and analyzed will have to undergo modifications and behavioral changes by providers, payers, and researchers.

In the long run, however, it is reasonable to assume that it will be less costly to convert to a single coding system than it would be to continue indefinitely absorbing the costs to maintain training and education in ICD-9-CM and CPT. Automation might slow the reimbursement process initially but, once established, will facilitate reporting and paying.

Administrative and regulatory costs— For providers and insurers, a single system will reduce administrative costs of providing and maintaining data in two different systems. It will eliminate the need for multiple documentation, thereby reducing the amount of paper work needed to support different systems and improving claims processing. By providing a standardized vocabulary, a single procedure classification system will permit uniform communication among health professionals across health care settings and will facilitate utilization review.

Proponents of the present dual classification systems feel that increased administrative costs to initiate the system do not justify the problems incurred when other systems are already in place and could be improved to work better. For instance, maintenance mechanisms are in place in the CPT system for a physician consensus process. Timeliness with HCFA statutory regulatory requirements are in place. To meet the demands of allied health professionals who used the HCFA HCPCS based on the CPT, the AMA has organized a second Advisory Committee with representatives from major limited licensed practitioner groups. Major reservations have been expressed by others about the proprietary nature of the CPT and the role of the AMA in the maintenance of a system that is widely used for public purposes.

A new classification system will require a revision of all DRG's, Resource-Based Relative Value Scale (RBRVS) relative value units, and Ambulatory Patient Groups (APG's). Additional revisions of Uniform Bill-92 (UB-92) and HCFA 1500 forms, tumor registry abstracts, Medicare code editors, DRG groupers, and all automated encoders will be necessary. State Medicaid programs will require major changes and the Federal share of State costs would probably be significant. Many forms will have to be redesigned and printed and coding manuals revised.

Effect on Health Care Delivery

A single procedure classification system will expedite development of treatment profiles associated with various configuration of demographic profiles and medical conditions across health care settings. A single system would aid in the development of needed improvements in medical record keeping, especially when combined with automation of medical records. Current physician documentation is often incomplete and abbreviated. An explicit structure will improve terminology and provide clarity and accuracy. This would facilitate understanding by entry level coders as well. Ultimately, complete documentation will help in the provision of improved health care to the patient.

Comparability of Data Across All Settings and Over Time

A single system for all health care settings will improve retrospective analysis and projections of cost and utilization and enhance analytic capability regarding episodes of care and provider practice habits. It will also allow better integration of data from inpatient and outpatient settings and the eventual merging of coding of all systems.

The Subcommittee recommends that the new coding structure be hierarchical, that is, data coded with the new system may be aggregated according to a predetermined structure. The Subcommittee feels such a structure will permit aggregation of clinical data for small area analysis to:

- detect patterns of over or under use,
- monitor outcomes,
- detect fraud,
- monitor archaic or ineffective procedures,
- distinguish clinical objectives of diagnostic, preventive, and therapeutic interventions,
- detect excessive device failure rates, and
- provide early warning of unacceptable procedural risks.

Coding is only as good as the patient source data available to coders who have to use the system. Initially, all parties will need cross reference data from the old to new system, including major software conversion. There could be an interruption of longitudinal data trends and comparability of longitudinal studies may be affected. There will be a need to develop a conversion system to cross-reference between pre- and post-crossover periods so that researchers can understand the new system and how it correlates to data already collected from existing systems.

Record Keeping and Data Retrieval

A single procedure classification system would facilitate the standardization of data collection and processing systems and reduce redundancy in data bases. The integrity of the data bank will improve with less complexity of computer applications. It would improve the environment for developing a standard electronic data collection system, thus, accelerating movement toward electronic patient records. With an automated system, data elements independent of classification can be collected easily for research and administrative purposes.

Most users do not need a complex detailed system. Office-based physicians may find new training costs especially burdensome in smaller practices but eventually the cost of data reporting would decrease and accuracy will improve with increasing familiarity of classification. Finally, a single procedure classification system will foster cooperation between coders and billers to improve the quality of data.

Maintenance and Training

Development and maintenance of the data processing system will be simplified, owing to the ease of a single system for reference. Revisions will be easier to maintain. A coordination and maintenance mechanism representing the public and private sectors needs to be established to oversee revisions to the classification system. It will be necessary to establish and staff a clearinghouse to provide end users with technical advice on the use of the system, validation of proper code assignments, and a forum to address common complaints.

Initial training costs will be high for health information managers, physicians and other health practitioners, payers, and researchers. Major industry investment in training and hiring more personnel will be required. But it is unrealistic to expect hospitals to bear all the costs for training and implementation. A Federally mandated system should include a provision for a national training initiative. Overall, less training time will be needed once the new system is in place and users' familiarity with the new system improves. A single system will simplify ongoing training at facilities.

An additional side benefit could be the provision of career paths and ladders for experienced coding personnel, encouraging more people into the profession.

Characteristics of a Procedure Classification

The Subcommittee observed that the new system should be centered on the patient rather than on the needs of the institution. A procedure classification system should have the capability of capturing a procedure that can be used with other data elements for other purposes. Inherent in the recommendation is the need to agree upon a common definition of procedure classification boundaries.

Potential uses of data from procedure classification include:

- patient care evaluation
- program or systems management
- reimbursement
- effectiveness or outcome assessment
- health services and epidemiological research and trends

- policy development
- ability to make national or international comparisons

A single procedure classification system should facilitate data retrieval and analysis (see exhibit 3). The organization of the classification must be systematic and meaningful and should relieve users of the burden of assigning meanings and associations imposed by entity coding. Insignificant procedures should not be included ("omit code" notes in index).

A procedure classification system should have a hierarchical structure so that data from individual codes may be aggregated into increasingly larger groups of procedures. Each code number should have a unique definition that does not change over time. The system must be flexible enough to incorporate new techniques, technologies, and types of procedures. It must be comprehensive enough to include a place for every type of procedure used in all settings and by all provider groups. The categories must be discrete (that is, no overlap is permitted).

The system should be easy to use. This can be accomplished through standardization of definitions and terminology, and by adequate annotations in the tabular list and extensive and consistent indexing. The same procedure should be coded the same way regardless of the site or provider of care.

The system must be multi-axial in order to accommodate procedures performed on different body systems, using different techniques and technologies. It should be limited to the classification of procedures and should not attempt to incorporate diagnoses or other elements found elsewhere in the medical record.

Process to Establish a Single Procedure Classification System

The process of implementing a classification system should enunciate global issues concerning the applicability of a procedure classification system. Further, in highlighting these issues, it is necessary to identify the entities or major players responsible for addressing them. The global issues are as follows:

- clarity of the purpose(s) of the classification;
- criteria for its design components, auditable evaluation mechanisms, flexibility, and ability to incorporate new techniques;
- long range ramifications of implementation;
- maintenance mechanisms to update periodically;
- the need for cross-walks from ICD-9-CM (volume 3) and CPT to the new system for comparability of data over time, ease of implementation, etc.;
- multiple applications of a new procedure classification system, which distinguish between financial and reimbursement issues and statistical and epidemiological research issues; and,
- if feasible, tandem implementation with ICD-10 to minimize impact upon users of the classification.

Exhibit 3: An Outline of the Characteristics of a Procedure Classification System

I. Hierarchical structure
  A. ability to aggregate data from individual codes into larger categories
  B. each code has unique definition forever—not reused

II. Expandability
  A. flexibility to incorporate new procedures and technologies ("empty" code numbers)
  B. mechanisms for periodic updating
  C. code expansion must not disrupt systematic code structures

III. Comprehensive
  A. provides not otherwise specified (NOS) and not elsewhere classified (NEC) categories so that all possible procedures can be classified somewhere
  B. includes all types of procedures
    1. diagnostic, therapeutic, and preventive procedures
    2. invasive, noninvasive (including counseling, evaluation, and management)
  C. applicability to all settings and types of providers

IV. Nonoverlapping
  A. each procedure (or component of a procedure) is assigned to only one code

V. Ease of use
  A. standardization of definitions and terminology
  B. adequate indexing and annotation for all users (physicians and nonphysicians)

VI. Setting and provider neutrality
  A. same code regardless of who or where procedure is performed
  B. discourage "turf battles"

VII. Multi-axial
  A. body system(s) affected
  B. technology used
  C. techniques or approaches used
  D. physiological effect or pharmacologic properties
  E. characteristics or composition of implant

VIII. Limited to classification of procedures
  A. should not include diagnostic information
  B. other data elements (such as age) should be elsewhere in the record

Development

The fundamental needs of a system that can serve multiple users (providers, payers, and researchers) across settings must be considered by assessing, as thoroughly as possible, benefits and costs of moving to a single classification system. Early on the components for a single classification system, including the political feasibility of the components, should be identified. Consideration of the necessary level of coding specificity, computer requirements, capacity and support for data collection, quality of data, and uses of information in all systems must also be made.

A major concern is the effect a new classification system would have on the human infrastructure (that is, the impact on health information managers, physicians and other providers, hospital administrators, third party payers, and researchers). There is a large range of abilities among coders (health information managers) and, depending upon its complexity, a new classification system may require sophistication that exceeds the abilities of health information managers accustomed to the current systems. Providers of services, especially physicians, may have to change the way they document procedures. This may require increased interaction between physicians and coders, particularly during the implementation phase.

Hospital administrators and third party payers will be affected because reimbursement mechanisms such as DRG's, relative value units, APG's, etc., will have to be revised to account for coding changes. Simple crosswalks between the old and new systems probably will not suffice or be possible.

A determination of the type of information necessary for a national data base to conduct trend analyses should be made. For instance, researchers may have to develop new groups of old codes to allow analyses of groups of procedures rather than individual procedure codes. Translations will be necessary for certain key procedures to continue longitudinal trends.

Careful consideration should be given to ensure that the classification system does not inadvertently create incentives for the performance of one type of procedure over another (for example, by providing more detailed classification for invasive procedures than for noninvasive procedures). The new procedure classification system must also provide interspecialty balance. Procedures performed by specialists and providers other than physicians should be coded in a similar fashion to avoid reimbursement and evaluation discrepancies.

A single procedure classification system must be comprehensive and include all types of diagnostic, therapeutic, and preventive procedures across health care settings and for different types of providers. Accommodation must be made to include invasive procedures and noninvasive types of procedures, such as counseling, evaluation, and management of patients. This implies a need to reevaluate what is meant by "procedure."

Implementation

Natural and future constraints in implementing the new system should be recognized. Adequate lead time to implement the new system is paramount.

Field testing— It will be necessary to set up several demonstration projects to evaluate the costs, benefits, and impact of a new procedure coding system. The classification should be rigorously tested for validity and reliability by an independent agency employing real users with various levels of skill and experience in all settings in which the classification will be used. Results from the testing should be used to modify the classification and guidelines as necessary.

Training needs— Training needs for health information managers, physicians, third party payers, researchers, and others who will have to learn to use the new system must be accommodated. Training should be coordinated so that the same information is provided uniformly across sites and regions. Involving potential users in the development process will allow provider associations to assure that on-the-job training is accomplished.

Organizations such as the AMA, AHA (American Hospital Association), and AHIMA (American Health Information Management Association) as well as the Federal Government must identify resources to provide training for end users. The Federal Government should support the development and preparation of training packages.

A major "Train the Trainer" program should be developed and supported by the Federal Government and the health care industry. Training can be accomplished by training representatives of professional associations and societies. These members will train members of their profession at national, regional, State, and local meetings to develop informational networks and continuity of training efforts. Specialty societies can provide training to physicians as part of their continuing medical education program during their national membership meetings. Time should also be allocated to train key personnel in each health care setting who will be responsible for training others in their facilities.

Transition— Crosswalks between ICD-9-CM (volume 3) and the new system and CPT and the new system need to be developed. The feasibility of this must be investigated given the impossibility of developing a crosswalk between ICD and CPT. Software conversion programs will be needed, as well as increased computer processing and storage capacities.

An official source of crosswalk information should be in place before any change is implemented, and the identification of this source should be well publicized to all users. Responses to inquiries must be timely to ensure the integrity of the new classification coding system. Quality controls should be established to monitor the systems during the transition period and periodically to ensure conformity to the new system.

Maintenance

The implementation process must provide for a public forum to discuss maintenance issues and changes to the system similar to the role played by the ICD-9-CM Coordination and Maintenance Committee. As a central source, the functions of such a coordination and maintenance entity will be to:

- serve as a formal mechanism for maintenance of the system,
- serve as an official organ to inform users of revisions and updates,
- receive recommendations for revisions,

- make decisions about the grey areas ("appropriate exclusions"), and
- widely disseminate information on how the maintenance system operates and how to gain access to it.

Evaluation

The ability to code procedures accurately and consistently is paramount in evaluating a new system. If providers are to code accurately, clarity of procedure definitions is essential. The quality of the data will be high and statistics retrieved from them will accurately reflect the care that was provided.

Evaluating a new system will require extensive testing and revision. At a minimum, the new system will have to be able to provide the types of data provided by the current systems. Intensive initial auditing will be required to determine how coding and data entry quality might have changed. Data analyzed under the new coding scheme will need to be compared with previous analysis to determine if any changes were attributable to the coding change itself or to actual systemic changes. Pilot auditing with automated medical records systems would be an efficient means of analyzing the data under both systems.

Ongoing monitoring in areas of quality assurance and utilization review by peer groups, third party payers, and other purchasers of care need to be established. Other monitoring mechanisms include: software edits, reabstraction, peer review organization (PRO) studies and audits to ensure coding data quality and quality of medical records documentation, and linking computerized medical records into on-line quality or utilization review.

Maintaining the validity of the system needs to be a cooperative effort involving those who perform the procedures reflected in the data, those who use the system to collect the data, and those who use the data to analyze health care issues and trends.

Conclusion

By virtue of being able to respond to changes in the clinical environment, the single procedure classification system should possess utility as a statistical classification and an administrative tool. There is a general resistance to altering the existing systems except where changes are considered necessary to reflect current clinical trends. Because of multiple deficiencies, however, the current systems are badly in need of overhaul and consolidation. Pressure for change derives not only from end users who must contend with these deficiencies, but also from political forces that must address major health care reform. As the health care reform movement progresses, reliance on administrative data sets will increase. The Committee notes, however, that these data sets currently do not permit the ability to track patients through the system as they enter and leave various care settings over the course of an illness or over a longer time. Reform measures adopted at all levels will require this tracking ability to evaluate the appropriateness and effectiveness of care received.

The scope of services covered by a single procedure classification system is not specified in this report. It seems clear that it should be broader than hospital and physician office-based provider services, the focus of current coding systems. On the other hand, there is a broad range of services, such as social services, housing, and some public health functions, that contribute to the health and well-being of the population but may not be appropriate to include in a classification system. Therefore, defining what is meant by "procedure" is a crucial initial task of developing a unified system.

The Committee realizes that recognition of the necessity for the development and implementation of a single procedure classification system is only the first step in a difficult and time consuming process of reform. Public and private sector resources will be required to achieve a successful and timely solution to the issues enumerated above. The Committee will continue its work in this area to provide more specific advice in system design and implementation alternatives and a forum where the stakeholders in procedure classification reform may present information and express their views.

National Committee on Vital & Health Statistics

JUDITH MILLER JONES
CHAIR

GAIL F. FISHER, Ph.D
EXECUTIVE SECRETARY

SEP 29 1992

Dear Colleague:

The Subcommittee on Medical Classification Systems of the National Committee on Vital and Health Statistics met last April to discuss the procedure classification system developed by 3M/HIS as part of a Health Care Financing Administration (HCFA) contract. The discussion was most fruitful and generated several thought provoking ideas about a new procedure classification. Among the issues discussed was the need to identify the benefits, both tangible and intangible, of instituting a single procedure classification system.

To continue the dialogue further on whether a single procedure classification system is feasible and desired, the Subcommittee has developed a list of questions (see enclosure) pertaining to the purposes and criteria of such a system. We would like to contribute substantively to the discussion on the feasibility of a single procedure classification system. Thus, because of your expertise and interest in classification systems, we are soliciting your input to the discussion. The Subcommittee plans to synthesize the information received with a view towards making a policy recommendation on this issue to the Department of Health and Human Services.

If you are willing and able to contribute, please comment in writing to Lynnette Araki, National Center for Health Statistics, 6525 Belcrest Road, Room 1100, Hyattsville, MD 20782. You may not be able to comment on all of the questions on the attached list. Nevertheless, we would be very interested in your views in areas where you feel qualified to comment. Please send your response no later than **October 16, 1992.**

Thank you in advance for your thoughtful response.

Sincerely yours,

Bruce Steinwald, Chairman
Subcommittee on Medical
Classifications Systems

Enclosure

• 6525 BELCREST ROAD • RM. 1100 • HYATTSVILLE, MD 20782 • (301) 436-7050 •

Subcommittee on Medical Classifications Systems Questions Regarding Benefits of a Single Procedure Classification System

- What should be the objectives of a new procedure classification system?
- What are the elements that must be provided for if such a system is developed to accommodate all settings? What is the appropriate level of detail of such a system?
- What are tangible benefits of obtaining data from a single procedure classification system? What are some of the intangible benefits of such a system?
- What are the costs of changing procedure classifications systems?
- What will be the impact of a new classification system on medical records personnel, physicians, third party payers, researchers, etc.?
- How should training needs be planned for, including costs of providing training? Who should pay for training?
- Can current available documentation in medical records support the detail required? If not, how much modification would be necessary to improve the quality of information recorded in, and collected from, the medical records?
- Would automated medical records help or hinder implementation of the new system?
- What will be the impact of a new classification system on computer systems?
- What would be necessary to make the transition from the current system to a new system, and how would comparability of data be assured?
- What are the necessary components for evaluating a new system? (Issues to be addressed would include, among others, the quality of data entry, data retrieval, and data analysis.) What types of ongoing monitoring would be needed to ensure the quality and accessibility of the data?
- What procedure system(s) do you use now? What are its (their) positive and negative aspects?
- What other issues are important in considering a single procedure classification system?

National Committee on Vital and Health Statistics
Subcommittee on Medical Classification Systems

The following is a list of respondents who replied to the Subcommittee's first mailing to the field soliciting input on the feasibility and desirability of adopting a single procedure classification system. While this report incorporates some of the comments from respondents who were either in support of, or against, the adoption of a single procedure classification system, it does not reflect all of the opinions expressed by respondents.

Responses to First Mailing

Organization	Correspondent
Blue Cross Blue Shield Association Chicago, IL	Bonnie Balkin Consultant
Blue Cross Blue Shield Association of the National Capital Area Washington, DC	Marian Wordsworth Assistant to the Vice President Health Care Finance
Blue Cross Blue Shield Association Chicago, IL	Charles B. Clayman, M.D. Medical Consultant
Health Insurance Association of America Washington, DC	Thomas D. Musco Director of Statistics
Kaiser Permanente Medical Care Program Hospitals and Planning Oakland, CA	Susan B. Willner, R.R.A. Regional Data Quality Coordinator Vicky Howe, A.R.T. Regional Coding Specialist
St. Vincent Hospital and Health Care Center Indianapolis, IN	Londa Bechert Manager, Medical Record Department
American Nurses Association School of Nursing Georgetown University Washington, DC	Virginia Saba, Ed.D, R.N., F.A.A.N. Member, ANA Steering Committee on Data Bases to Support Clinical Nursing Practice
American Medical Association Chicago, IL	James S. Todd, M.D. Executive Vice President
American Physical Therapy Association Alexandria, VA	Francis Mallon, Esq. Associate Executive Vice President Professional Relations
Center for Orthopaedic & Sports Medicine Care Owings Mills, MD	Melvin M. Friedman, M.D.
American Speech-Language-Hearing Assn. Rockville, MD	Steven C. White, Ph.D. Director, Healthcare Financing Division
American Optometric Association Alexandria, VA	John W. Lahr, O.D. Chairman, Subcommittee on Coding
American College of Nuclear Physicians Washington, DC	August Miale, M.D. Robert Henkin, M.D. Kristen Morris, Director of Government Relations
Applied Medical Data, Inc. Ann Arbor, MI	Paul Y. Ertel, M.D.

Responses to First Mailing—Con.

Organization	Correspondent
George Washington University Medical Center Washington, DC	William R. Felts, M.D., M.A.C.R., F.A.C.M.I Professor of Medicine McLean, VA
Beth Israel Hospital Boston, MA	Lisa I. Iezzoni, M.D., M.S.
	Vergil Slee, M.D. Brevard, NC
Health Management Information Center Des Moines, IA	Michael J. Gerzema Contractor to Iowa Health Data Commission
GMIS Cost Containment Solutions Malvern, PA	Thomas C. Hartwell, R.R.A., C.C.S. Medical Support Representative
St. Anthony Publishing Alexandria, VA	Paul H. Hubbard Director, External Affairs
Commission on Professional and Hospital Activities Ann Arbor, MI	Marjorie Zernott Director, Classification Development
HCIA Ann Arbor, MI	Nancy Ramirez Medical Systems Specialist Health Care Management Systems
	Arden W. Forrey, Ph.D. Chair, ASTM E31.13 and Working Group on Standards AACC LIS Division Seattle, WA
Faye Brown Consultants Rio Rancho, NM	Faye Brown, R.R.A.
National Center for Health Statistics Hyattsville, MD	Amy Blum, R.R.A.
National Center for Health Statistics Hyattsville, MD	Sue Meads, R.R.A. Chief, Morbidity Classification Branch
Agency for Health Care Policy and Research Rockville, MD	Donald Goldstone, M.D. Director, Center for Intramural Research
Iowa Health Data Commission Des Moines, IA	Charles M. Palmer Chairperson
Colorado Health Data Commission	Paul Abel
Florida Healthcare Purchasing Cooperative, Inc. Tallahassee, FL	Dian Kahn
California Office of Statewide Health Planning and Development Sacramento, CA	Andra Zach, R.R.A. Medical Record Consultant
Canadian Center for Health Information Ottawa, Canada	John W. Coombs Acting Director

National Committee on Vital & Health Statistics

JUDITH MILLER JONES
CHAIR

GAIL F. FISHER, Ph.D.
EXECUTIVE SECRETARY

June 30, 1993

Dear Colleague:

Last year the Subcommittee on Medical Classification Systems of the National Committee on Vital and Health Statistics (NCVHS) requested your input regarding the feasibility and desirability of a single procedure classification system. The Subcommittee received many substantive thoughts on the issue from those of you whose work involves the use of the classification systems.

In addition, the Subcommittee also held several meetings over the course of the year to discuss many of the issues related to whether or not a single procedure classification system is feasible. We have tentatively decided that a single system is both feasible and desirable, but we need your continued advice. Enclosed is a draft report recommending the development and adoption of a single procedure classification system. This report will be finalized and submitted to the NCVHS for adoption and transmittal to the Secretary of the Department of Health and Human Services through the Assistant Secretary for Health.

At this time, the Subcommittee respectfully requests your further input into the process by reviewing the draft report and commenting on its contents. In particular, we ask you to react to the recommendations and to the characteristics of a single procedure classification. Additional comments on the rest of the report, including identification of issues which have not been addressed, are welcome.

If you are willing and able to contribute, please comment in writing to Ms. Lynnette Araki, National Center for Health Statistics, 6525 Belcrest Road, Room 1100, Hyattsville, MD 20782. Please send your response no later than July 30, 1993.

Thank you in advance for your thoughtful response.

Sincerely yours,

Bruce Steinwald, Chairman
Subcommittee on Medical Classification Systems

Enclosure

• 6525 BELCREST ROAD • RM. 1100 • HYATTSVILLE, MD 20782 • (301) 436-7050 •

National Committee on Vital and Health Statistics
Subcommittee on Medical Classification Systems

The following is a list of respondents who replied to the Subcommittee's second mailing to the field soliciting input on the feasibility and desirability of adopting a single procedure classification system. While this report incorporates some of the comments from respondents who were either in support of, or against, the adoption of a single procedure classification system, it does not reflect all of the opinions expressed by respondents.

Responses to Second Mailing

Organization	Correspondent
GMIS Cost Containment Solutions Malvern, PA	Thomas C. Hartwell, R.R.A., C.C.S. Medical Support Representative
American Health Information Management Association Chicago, IL	Margaret Amatayakul, R.R.A., C.C.S. Associate Executive Director
	Mary L. Reichley, A.R.T. DRG Consultant for Laguna Medical Systems
California Health Information Association Fresno, CA	Claudine L. DeFazio, R.R.A. President
Laguna Medical Systems Laguna Beach, CA	Elizabeth A. Duggan, A.R.T.
MetriCor Louisville, KY	Martha Brown, R.R.A. Manager, Health Information Analysis
American Physical Therapy Association Alexandria, VA	Francis J. Mallon, Esq. Senior Vice President/General Counsel Health Policy and Practice
American Nurses Association Washington, DC	Virginia Trotter Betts, J.D., M.S.N, R.N. President
	Arden W. Forrey, Ph.D. Chair, ASTM E-31.13 and AACC-LISD Standards Working Group Seattle, WA
Mayo Clinic Rochester, MN	Karel M. Weigel, R.R.A.
American Psychological Association Washington, DC	Russ Newman, Ph.D., J.D. Executive Director for Professional Practice
American Optometric Association Alexandria, VA	John W. Lahr, O.D. Chairman, Subcommittee on Coding
American Academy of Neurology Minneapolis, MN	Laura B. Powers, M.D. Medical Economics and Management Subcommittee
American College of Nuclear Physicians Washington, DC Society of Nuclear Medicine Washington, DC	Terence Beven, M.D. CPT Advisory Committee Representative Kenneth McKusick, M.D. CPT Advisory Committee Representative

Responses to Second Mailing—Con.

Organization	Correspondent
The Atrium Richmond, VA	Nelson G. Richards, M.D., F.A.C.P.
The George Washington University Washington, DC	William R. Felts, M.D., M.A.C.R., F.A.C.M.I Professor Emeritus of Medicine McLean, VA
American Psychiatric Association Washington, DC	Melvin Sabshin, M.D. Medical Director
American Academy of Dermatology Schaumburg, IL	Mark V. Dahl, M.D. President
American College of Radiology Reston, VA	Gary W. Price Senior Director, Government Relations
American Medical Association Chicago, IL	James S. Todd, M.D. Executive Vice President
	Vergil Slee, M.D. Brevard, North Carolina
Health Insurance Association of America Washington, DC	Thomas D. Musco Director of Statistics
Blue Cross Blue Shield of the National Capital Area Washington, DC	Marian H. Wordsworth Assistant to the Vice President Health Care Finance
Health Care Finance Commission Augusta, ME	Rebecca E. Symes Acting Director, Division of Research and Data Management
Health Care Financing Administration Baltimore, MD	Charles Booth Director, Office of Payment Policy
Agency for Health Care Policy and Research Rockville, MD	Harvey A. Schwartz, Ph.D.
Lion Associates Cambridge, MA	Joanna Lion, Ph.D.
National Health Policy Forum Washington, DC	Don Zimmerman, Ph.D.

Appendix VI.
Report of the Subcommittee on State and Community Health Statistics, June 1993

Executive Summary

The National Committee on Vital and Health Statistics' Subcommittee on State and Community Health Statistics is charged with investigating issues related to State and local capacity to perform the core public health function of assessment and to use data for policy development and assurance. This report presents findings and recommendations resulting from the Subcommittee's recent work.

Findings

The Subcommittee finds that health data for State and community assessment and policy development are limited. While government collects and maintains considerable information about the health of Americans, there is little coordination of health statistics to support the health policy process at any level of government. Furthermore, despite the need for comparable data across jurisdictions, systems created to produce national data often cannot be used to produce State and/or community estimates. In addition, a lack of comparability among various State-specific systems often makes interstate comparisons difficult. A further constraint is that confidentiality policies may restrict access to data.

Community assessment is the foundation of local public health. However, local health departments typically lack the resources to obtain, analyze, interpret, and use data for policy development and community assessment and are dependent on State health agencies for data and analytic assistance.

State Centers for Health Statistics were established within State government agencies as focal points for State and community health data. However, these Centers are often not adequately staffed or funded to actively pursue broad-based assessment programs at the State or community level. In some cases the Centers may be housed in State administrative agencies that inhibit their ability to function as a resource for State and community health agencies.

Recommendations

1. The Department of Health and Human Services should develop and implement a strategy to establish a coordinated Federal, State, and community health statistics system to support the health policy process. The Secretary should establish a task force to pursue this strategy.

2. The Department should implement a process to assure that all Departmental administrative health data sets have the capacity to provide statistics for assessment, policy development, and assurance. In addition, these data sets should be constructed in a manner that will permit linkage to other relevant data sets for statistical and health services research purposes.
3. The Department should take the necessary steps to, whenever possible, develop national data systems that are established in a way that will produce, at a minimum, State level estimates. Regardless of the purpose for which the data are collected, all Federal health data systems should include uniform geocoded identifiers that will allow for their use at the State and community levels.
4. Every State health agency should have the capacity to perform the functions of a State Center for Health Statistics. These functions include coordination among State health programs to assure that needed data are available to users, as well as data collection, processing, analysis, dissemination, technical assistance to users, and research and development. The Secretary should review, revise, adopt, and implement the Guidelines for State Cooperative Health Statistics Systems Agencies.
5. The Department should take steps to strengthen the capacity of State health agencies to act as a resource for the data necessary for State and community assessment, to provide technical assistance in the analysis of those data, and to develop and implement mechanisms for transmitting data to the Department.
6. The Department, working through the State health agencies, should develop mechanisms to locate and support staff that can work with communities to develop the assessment programs in local health jurisdictions.
7. The Department should provide leadership in developing model-based estimation techniques to provide indicators in the absence of actual State and/or community level data. States and communities should be encouraged to use these techniques where appropriate.
8. The Secretary should involve the National Committee on Vital and Health Statistics in the efforts to evaluate the Health Status Indicators for State and community use and to consider potential additions and/or deletions from the set.

Introduction

In November 1990 the National Committee on Vital and Health Statistics (NCVHS) created the Work Group on Community Health Statistics to investigate issues related to data needs at the community level. The Work Group's preliminary investigations led the Committee to believe that this area warranted ongoing attention. In March 1991 the Committee changed the Work Group to a subcommittee and renamed it the Subcommittee on State and Community Health Statistics. The new Subcommittee was charged with:

(1) Monitoring progress toward achieving the year 2000 objectives 22.1–22.7;

(2) working with the National Center for Health Statistics (NCHS), other Federal and State agencies, appropriate private agencies, and other subcommittees of the NCVHS to review and identify gaps in current health statistics...;

(3) reviewing efforts to link national, State, and local data sets...for use in evaluating the effectiveness of disease and injury prevention and therapeutic intervention strategies;

(4) participating...in a process to recommend any necessary action to improve the comparability and compatibility of health statistics collected and published through various government and private agencies;

(5) identifying and reviewing current alternative methodological approaches to community health assessment; and

(6) reviewing and monitoring the annual *Prevention Profile...in Health United States* throughout the 1990's.

Over the past 2 years, the Subcommittee met seven times, heard testimony from numerous public health and other professionals, synthesized this input through the expertise of its members, and developed the recommendations presented in this report. The roster of Subcommittee members is given on page 88.

Background

Throughout its deliberations, the Subcommittee repeatedly used two documents *(The Future of Public Health,* (1) and *Healthy People 2000, National Health Promotion and Disease Prevention Objectives* (2) to provide a framework for its findings and recommendations.

The Future of Public Health— In 1989 the Institute of Medicine's (IOM) Committee on the Future of Public Health published its landmark report. The IOM Committee looked at all aspects of public health and made observations about the strengths, weaknesses, and needs for reform in the Nation's public health infrastructure.

The IOM Committee defined the mission of public health as "fulfilling society's interest in assuring conditions in which people can be healthy" and noted that governmental public health agencies have a unique role in this mission: "to see to it that vital elements are in place and that the mission is adequately addressed (1)."

Government's role in fulfilling this mission is especially important at the State and community levels. The IOM Committee stated that "States are and must be the central force in public health. They bear primary public sector responsibility for health (1)." Regarding community responsibility, the IOM Committee avers that "no citizen from any community, no matter how small or remote, should be without identifiable and realistic access to the benefits of public health protection, which is possible only through a local component of the public health delivery system (1)."

The IOM Committee identified three core public health functions: assessment, policy development, and assurance. Regarding assessment, the report recommends that:

"Every public health agency regularly and systematically collect, assemble, analyze, and make available information on the health of the community, including statistics on health status, community health needs, and epidemiologic and other studies of health problems. Not every agency is large enough to conduct these activities directly; intergovernmental and interagency cooperation is essential. Nevertheless each agency bears the responsibility for seeing that the assessment function is fulfilled. This basic function of public health cannot be delegated (1)."

This finding has implications for the current work. It means that Federal and State government share an obligation to provide data and analytic assistance to enable local health agencies to fulfill their assessment function. A major portion of the Subcommittee's work has been focused on this issue.

Healthy People 2000—The process of generating the year 2000 health objectives took place during the same period that the IOM committee was developing its report. The *Healthy People 2000* effort is intended to improve the health of Americans by the end of the decade. It includes over 500 measurable objectives and subobjectives laid out in 22 priority areas that span the spectrum of public health.

The objectives have three major characteristics: they are constructed to be measurable, there must be a reasonable opportunity for achieving them, and the data to measure progress toward the objectives must be available or obtainable with a reasonable amount of effort. Priority area 22, Surveillance and Data Systems, speaks to the need for an infrastructure spanning the national, State, and local levels to track the objectives and to identify and evaluate emerging public health issues. There are seven objectives in priority area 22 (figure 1). Of these, five objectives deal directly with needed improvements in State and local assessment capacity.

Figure 1. *Healthy People 2000* Area 22: Surveillance and Data Systems

22.1 Develop a set of health status indicators appropriate for Federal, State, and local health agencies and establish use of the set in at least 40 States.

22.2 Identify, and create where necessary, national data sources to measure progress toward each of the year 2000 national health objectives.

> 22.2a Identify, and create where necessary, State level data for at least two-thirds of the objectives in at least 35 States.

22.3 Develop and disseminate among Federal, State, and local agencies procedures for collecting comparable data for each of the year 2000 national health objectives and incorporate these into Public Health Service data collection systems.

22.4 Develop and implement a national process to identify significant gaps in the Nation's disease prevention and health promotion data, including data for racial and ethnic minorities, people with low incomes, and people with disabilities, and establish mechanisms to meet these needs.

22.5 Implement in all States periodic analysis and publication of data needed to measure progress toward objectives for at least 10 priority areas of the national health objectives.

22.5a Implement in 25 States periodic analysis and publication of State progress toward the national objectives for each racial or ethnic group that makes up at least 10 percent of the State population.

22.6 Expand in all States systems for the transfer of health information related to the national health objectives among Federal, State, and local agencies.

22.7 Achieve timely release of national surveillance and survey data needed by health professionals and agencies to measure progress toward the national health objectives.

Other Issues—Other external issues permeating the Subcommittee's discussions deserve mention:

- **Health care reform.** This issue dominates much of the current activity in the health field and will affect the way health services are delivered. It will increase the demands for information from Federal, State, and local agencies. There will be a need to restructure systems for data collection, analysis, and dissemination to provide measures of services, costs, outcomes, and quality. At the same time, there will be a need to find mechanisms to incorporate surveillance data into the health care arena.
- **Confidentiality of health data.** There are statutory and policy restrictions that limit access to some health data sets, particularly those items that identify individuals and/or institutions. It is important to balance these restrictions with the need for information from the data sets.
- **Advances in information technology.** Emerging technologies are changing the ways that data are collected and used. For example, the implementation of the electronic patient record will provide new opportunities to more easily obtain data on issues such as service delivery and costs. These changes will also have major impacts on the quality and timeliness of data. Access to electronic data will raise additional confidentiality concerns.
- **Accountability at the State and local levels.** Many States and localities collect data on health services, particularly inpatient and high technology services, but have inadequate data on health status and health risks in the general population. In addition, there are insufficient data on ambulatory care services, long-term care, access to health care, and health care resources. There are increased pressures, from Congress and elsewhere, for States to be able to link services, especially for those targeted to vulnerable population groups, to outcomes.

Subcommittee Findings

Topics considered by the Subcommittee cover a wide range of public health issues. The Subcommittee received testimony about Federal initiatives and programs through presentations by representatives of the Centers for Disease Control and Prevention (CDC) and the Health Care Financing Administration (HCFA). The Subcommittee also considered issues of importance to State and local health agencies including variations in the organization of statistical services at the State and local levels. The Public Health Foundation, the National Association of County Health Officials, and the U.S. Conference of Local Health Officers were among the presenters on this topic, as were directors of individual State statistics programs. The Subcommittee learned about private sector activities designed to influence the statistical capacity of States and communities through discussion with organizations such as the Robert Wood Johnson Foundation.

Several issues that influence the Nation's public health statistical system, especially at the State and local levels, emerged from this testimony and Subcommittee discussion. These issues are reflected in these findings.

- The Federal Government collects and maintains considerable information about the health of Americans. National data bases address topics such as health status, health behaviors, risks and attitudes, the availability and use of health care resources, and the cost of health care services. Despite the extent of these data, there is little coordination of national health statistics to support the health policy process. This lack of coordination is also evident at the State and community level. As a result, State and local capacity to use data for assessment, policy development, assurance, and evaluation is limited.
- There are two major types of data systems at all levels of government: *administrative* systems and *statistical* systems. Administrative data systems are usually tied to program management and use (for example, the Medicaid system). They are primarily financial in nature. The Subcommittee found that Federal as well as State and local use of administrative data for health policy purposes is problematic. Statistical data systems are created primarily to gather information about a given population or other group. Examples include the National Health Interview Survey and various disease registries. Depending on the reason for which they were developed, statistical systems may also be inadequate for policy development purposes.
- Comparable data are needed at the national, State, and local levels to enable analyses across and among jurisdictions. However, systems created to produce national data often cannot be used for producing estimates for States and/or communities. This constraint applies to administrative and statistical systems. Administrative systems often have limitations and restrictions that preclude their use for small area analysis. Furthermore, many do not have the necessary geographic identifiers for small area analysis. The designs and sample sizes of national statistical systems are often insufficient to produce State and/or local estimates.
- Federal data systems often include only the geographic detail needed to serve Federal agency purposes, thus limiting the utility of these data systems for State and community analyses. In addition, there are no consistent standards for geocoding to the State and community levels; comparable geocoding across all health data systems does not exist.
- There are numerous State-specific systems that all collect health-related data, but are not consistent across States. For example, Medicaid, a Federally mandated system, is composed of multiple State data systems with different formats and definitions. The lack of consistency among these systems make interstate comparisons difficult, if not impossible, and may not always permit the aggregation of State data to obtain national totals. In addition, data access issues and confidentiality policies and statutes play a significant role in the availability and use of these data at the community level.
- Federal agencies have initiated and funded State-based health data systems. Because these are often housed in specific public health programs, the systems have not been

organized in ways that support State and local assessment and policy development capabilities. (The CDC Behavioral Risk Factor Surveillance System is one example.) On the positive side, these systems do encourage the collection of comparable information across States.

- State Centers for Health Statistics were established to be focal points for issues related to health data within the States. During the late 1970's and the 1980's efforts were made to obtain official State designation for these Centers, either through legislation or executive order. In 1980 the Public Health Service developed proposed guidelines for the characteristics, authority, statistical mission, and functions of State Centers for Health Statistics (pp.89–95). These guidelines were published in the Federal Register (3). However, the guidelines were not adopted as regulations by the Public Health Service, although they have served as a model for some States to follow in setting up a comprehensive health statistics program.

All 50 States have designated State Centers for Health Statistics, but with varying results. The testimony received by the Subcommittee revealed that State Centers have diverse capabilities, ranges of authority, and placements within State government. Although in most States the State Center is a part of the Health Agency, in some the Center is located in a Human Resources agency, or, in one case, in the Budget and Control Board. In a few States, the State Center plays a major role in the development of information needed for assessment, policy development, and assurance. At the other end of the spectrum, there are a number of State Centers whose function is limited to the tabulation and analysis of vital statistics.

- State and local health agencies expend considerable resources to provide program specific data in response to reporting requirements tied to Federal funding sources. (Some of these reporting systems are congressionally mandated.) A large portion of these data have limited use to States and communities for meeting policy development and assurance functions.
- Community assessment is the foundation of local public health. At least five community-based assessment models (for example, Assessment Protocol for Excellence in Public Health (APEX-PH) are available for use by local health agencies in developing priorities and obtaining community support (4). These tools can be extremely useful to a local health agency. However, the local health department is often unable to obtain the data needed to undertake a community assessment either because of lack of sufficient resources or for the reasons described above.
- Methodologies for developing State and community level statistics from national or regional data are available. Some model-based estimates use specific demographic classes to estimate the health parameters of an unsampled population. This type of model is preferable to other estimation techniques that do not account for differences among local areas. It should be recognized that model-based estimates are no substitutes for State and local estimates based on appropriately collected local data. Also, there are concerns about the acceptance of these estimates by policy makers and the public. To use these techniques successfully, the health agency must be willing to devote some effort to providing explanations of and support for the technique.

- In 1991 CDC fostered development of a consensus set of Health Status Indicators in response to Objective 22.1 of *Healthy People 2000* (5). Because of difficulties in obtaining these data at local levels, the indicators do not include measures of risk or morbidity. Since their establishment, CDC has undertaken several efforts to encourage use of the indicators at the State and local levels. A recent survey of State health departments found that all of the 46 responding States were using at least some of the indicators and most (75 percent) were providing related data to their local health departments. Several of the indicators (for example, children in poverty) were being used infrequently. Data availability was the reason States gave for not monitoring these indicators (6). CDC has reconvened Committee 22.1 to evaluate the appropriateness of the indicators and potentially to refine them.

Recommendations

Based on its findings, the Subcommittee on State and Community Health Statistics concludes that the National Committee on Vital and Health Statistics should make the following recommendations to the Secretary of the Department of Health and Human Services.

1. **The Department of Health and Human Services should develop and implement a strategy to establish a coordinated Federal, State, and community health statistics system to support the health policy process. The Secretary should establish a task force to pursue this strategy.**

- The system should include the following data sets in order to carry out the functions of assessment and policy development: vital statistics, inpatient hospital utilization, ambulatory care, long-term care, incidence and prevalence of disease and disability, health care resources, health care costs and expenditures, demographic profiles of populations served, access to basic health care and preventive services, health risk behaviors and attitudes, and environmental health risks.
- The task force should address mechanisms for providing leadership and assuring the resources to States in the implementation and utilization of data systems for assessment, policy development, and assurance at the State and community levels.
- The task force should also address the issue of program specific Federal reporting requirements imposed on States and communities. Efforts should be made to streamline these requirements to avoid duplication, coordinate requests for data among Federal agencies, and make the reporting process more efficient and relevant so that useful feedback is provided to States and communities.
- The task force should include representation from appropriate Federal agencies, as well as State and local public health agencies, and, include health statistics professionals at all levels of government.

2. **The Department should implement a process to assure that all Departmental administrative health data sets have the capacity to provide statistics for assessment, policy development, and assurance. These data sets should be constructed in a manner that will permit linkage to other relevant data sets for statistical and health services research purposes.**

- Administrative data systems should include a set of core data elements with common definitions. These elements should be established through the coordinated system (recommendation 1) taking into consideration the needs of the Department and other interested parties. Core data elements should be those deemed essential for policy development and data set linkage.
- Hospital inpatient data systems are based on the billing form in a fee for service system. Capitated systems do not generally report data on health problems, services, and charges now recorded on billings. Methods are needed to assure that person-oriented health data important for the policy process are available under all health care options.

3. **The Department should take the necessary steps to, whenever possible, develop national data systems that are established in a way that will produce, at a minimum, State level estimates. Regardless of the purpose for which the data are collected, all Federal health data systems should include uniform geocoded identifiers that will allow for their use at the State and community levels.**

- The ability to use national data for State and community purposes will greatly enhance the capacity for community analyses. However, it is important to understand that not all national data sets are amenable to this purpose. Issues to be considered in the development of appropriate usage include coverage, sufficient sample size for estimates at the State and community levels, quality of the geocodes, and confidentiality.
- The Federal agency responsible for the data system should validate the information in the data set and develop and maintain a data dictionary to facilitate widespread use.
- The National Health Interview Survey will be redesigned in 1995. In developing these design modifications, the National Center for Health Statistics should be fully cognizant of the need for State and community level data and should consider methodologies that will enable States to meet these needs.

4. **Every State health agency should have the capacity to perform the functions of a State Center for Health Statistics. These functions include coordination among State health programs to assure that needed data are available to users, as well as data collection, processing, analysis, dissemination, technical assistance to users, and research and development. The Secretary should review, revise, adopt, and implement the Guidelines for State Cooperative Health Statistics Systems Agencies.**

- "Needed data" include, but are not limited to, those data sets listed in recommendation 1.
- The coordination function is an essential component of this process. It includes, as a minimum, 1) identifying health data needs and data gaps, 2) evaluating the quality of existing data, 3) seeking agreements for data sharing among multiple collection agencies (for example, State data organizations), and 4) maintaining liaison with other State, local, and national health statistics programs.
- Required State capacity includes resources (personnel, technical support services, physical facilities, and funding support) and authority (see pp. 88–95). State Centers need broad authority to collect and disseminate data as well as to protect the confidentiality of data.

5. **The Department should take steps to strengthen the capacity of State health agencies to act as a resource for the data necessary for State and community assessment, to provide technical assistance in the analysis of those data, and to develop and implement mechanisms for transmitting data to the Department.**

- The Department should support State health agencies by providing guidance and technical assistance in the areas of data collection, analysis, and interpretation of data.
- Decisions on what data should be transmitted from States to a Federal agency should be a cooperative Federal-State process.
- The Department should assist State health agencies by providing State and community estimates from national surveys and sharing data collection instruments and techniques.
- A local health agency's primary contact for data and support in the analysis and interpretation of data should be the State health agency. State health agencies should be staffed and funded at a level to enable them to provide support to the local health agencies within the State in a timely and comprehensive manner. This recommendation applies even when the local health agency is using data from a Federal source.
- Every community health agency should have access to the data sets listed in recommendation 1. These data need not be collected at the community level, nor must they be analyzed by the community. However, it is important that the local health agency obtain this information from some source to pursue its policy development and assurance functions.

6. **The Department, working through the State health agencies, should develop mechanisms to locate and support staff that can work with communities to develop the assessment programs in local health jurisdictions.**

7. **The Department should provide leadership in developing model-based estimation techniques to provide indicators in the absence of actual State and/or community level data. States and communities should be encouraged to use these techniques where appropriate.**

8. **The Secretary should involve the National Committee on Vital and Health Statistics in the efforts to evaluate the Health Status Indicators for State and community use and to consider potential additions and/or deletions from the set.**

- Potential additions include indicators of risk and morbidity (for example, nutrition and smoking).

Conclusion

This report is the culmination of the Subcommittee on State and Community Health Statistics' examination of critical issues concerning the availability and accessibility of health data at the State and community level. The Subcommittee found that Federal agencies give little consideration to State and local health policy needs in the development of national data systems. Thus, national data sets may not be amenable to State and community use for the key public health functions identified in the IOM report on *The Future of Public Health.* In the absence of Federal direction, States and communities have attempted to develop the needed data; these efforts have had varying levels of success. Unique State or community data systems often produce data that are not comparable across geopolitical boundaries.

The Subcommittee believes that the recommendations contained in this report, if pursued, will improve the content, quality, and availability of health data to support the policy process at all levels of government. We urge the National Committee on Vital and Health Statistics to forward these recommendations to the Secretary of Health and Human Services for consideration and implementation.

References

1. Institute of Medicine. The future of public health. Washington: Academy Press. 1988.
2. U.S. Department of Health and Human Services. Healthy people 2000: National health promotion and disease prevention objectives for the nation. Washington: Public Health Service. 1991.
3. Public Health Service. Designation of State cooperative health statistics system agencies: Proposed guidelines. Federal Register, 1980. 45:42, 48945–8.
4. National Association of County Health Officials. Assessment protocol for excellence in public health. Washington: Public Health Service. 1991.
5. Centers for Disease Control. Consensus set of health status indicators for the general assessment of community health status, United States. MMWR 40(27): 449–51. 1991.
6. Carson CA, Zucconi SL, Mattison DR. Assessment of the consensus set of health status indicators in the United States.Washington: American Public Health Association Annual Meeting. 1992.

Roster
National Committee on Vital and Health Statistics
Subcommittee on State and Community Health Statistics

George H. Van Amburg (1993)
Chair
State Registrar and Chief
Office of the State Registrar
and Center for Health Statistics
Michigan Department of Public Health
4323 North Logan Street, Box 30195
Lansing, MI 48909

John T. Ashley, M.D. (1994)
Associate Vice President
University of Virginia
Health Sciences Center
Box 236, Jefferson Park Avenue
Charlottesville, VA 22908

Laurence G. Branch, Ph.D. (1992)
Director of Long-term Care Research
Abt Associates Inc.
55 Wheeler Street
Cambridge, MA 02138

William F. Bridgers, M.D. (1994)
2221 English Village Lane
Birmingham, AL 35294

Sister Irene V. Kraus (1993)
President and CEO
Sacred Heart Hospital
5151 North 9th Street
P.O. Box 2700
Pensacola, FL 32513–2700

Nicholas Zill, Ph.D. (1996)
Vice President
Westat, Inc.
1650 Research Boulevard
Rockville, MD 20850–3129

Staff

Mary Anne Freedman
National Center for Health Statistics
6525 Belcrest Road
Hyattsville, MD 20782

Kathleen A. Weis, Dr. P.H.
Agency for Health Care Policy
and Research
5600 Fishers Lane
Rockville, MD 20857

Designation of State Cooperative Health Statistics System Agencies: Proposed Guidelines

Summary: In this Notice, the Office of Health Research, Statistics, and Technology proposes guidelines under Section 306(e) of the Public Health Services Act to assure that statistical activities within States participating in the Cooperative Health Statistics System produce uniform and timely data and assure appropriate access to such data.

Date: Comments must be received on or before September 22, 1980. All comments should be submitted to Dr. Gail Fisher, Associate Director for the Cooperative Health Statistics System, Room 2–63, Center Building, 3700 East-West Highway, Hyattsville, MD 20782.

All comments received will be available for public inspection and copying at the above address between the hours of 8:30 a.m. and 5:00 p.m., Monday through Friday (Federal Holidays excepted).

For Further Information Contact:

Dr. Gail F. Fisher (301) 436–7050.

Supplementary Information:

1. *Purpose.* These proposed guidelines present material to assist States in designating an agency to administer or be responsible for the administration of the statistical activities within the States under the Cooperative Health Statistics System (CHSS). They are being published for the purposes of soliciting comments from all interested parties. These guidelines include their applicability, the definition of the CHSS, the characteristics and functions expected of designated agencies, and actions required. Final guidelines will be published in the *Federal Register* and all comments will be taken into consideration in their development.

2. *Scope.* These guidelines apply to all States, the District of Columbia, and Puerto Rico. Several States have already designated CHSS agencies and a list of agencies so designated by each State is appended below.

3. *Authority.* The legislative authority for these guidelines is specifically contained in Section 306(e) of the Public Health Service act as follows:

States participating in the (Cooperative Health Statistics) System shall designate a State agency to administer or be responsible for the administration of the statistical activities within the State under the System. The Secretary, acting through the (National) Center (for Health Statistics), shall prescribe guidelines to assure that statistical activities within States participating in the System produce uniform and timely data and assure appropriate access to such data.

4. *Background.* The objective of the Cooperative Health Statistics System is to provide the initiative for assuring the availability and timeliness of a range of uniform health statistics to governmental agencies and nongovernmental organizations within and among national, State, and local geopolitical jurisdictions. Efforts were initiated more than a decade ago to translate such a cooperative system objective into a reality. The early efforts, initiated by the Federal Government within the National Center for Health Statistics, have evolved over time to encompass other Federal agencies, their State counterparts, and Federal and State legislative activity.

The objective of the System is now recognized by Federal legislation; Section 306(e) of the Public Health Service Act, cited above, formally establishing the Cooperative Health Statistics System (CHSS). The objective is the use of health information by operating through a network of health statistical units at every geopolitical level. One of the major goals of the System is to improve Federal health statistics for planning, evaluation, and budget purposes. Involved in planning and developing the system are the Health Care Financing Administration (HCFA), the Center for Disease Control (CDC), the Alcohol, Drug Abuse, and Mental Health Administration (ADAMHA), the Health Resources Administration (HRA), the Health Services Administration (HSA), and the National Center for Health Statistics (NCHS).

5. *Definition of the CHSS.* The Cooperative Health Statistics System is a national network of public and private agencies and organizations participating in cooperative efforts to produce comparable and uniform health information and statistics and to assure appropriate and continuous access to such information and statistics by multiple users at the national, State, and local levels.

It is expected that designated State Agencies will adhere to principles for operation of the CHSS which have been developed by NCHS in consideration of demonstrated problems in the design, collection, and use of health statistics.

These principles are:

- *Allow for Provider/User Input*—The System will rely on national, State, and local users and providers of health statistics for input into its design, development, and maintenance.
- *Reduce Reporting Burdens and Duplicative Data Collection*—The System will build on existing systems at each geopolitical level whenever possible to meet the needs of users and thereby minimize costly duplication of effort and respondent burden.
- *Maximize Data Application*—The System functions to promote the utility of at least minimum uniform health statistics as tools to assist in decision-making regarding health care and its delivery in the United States. The network construction of the CHSS should assure the availability of timely information as required at each geopolitical level recognizing that decision-making in health care occurs to varying degrees at all geopolitical levels.
- *Meet Multiple User Needs*—The System is organized for the sharing of at least minimum uniform data among multiple users.
- *Develop Cooperative Relationships*—The accomplishment of the System's purpose is dependent on cooperation which in many instances must be voluntarily given among geopolitical levels and the public and private sectors. The effective operation of the System can only in part be based on State and Federal legal requirements.
- *Share Costs*—Funding for the System is dependent upon sharing of the costs for its development and maintenance among the multiple sponsors and beneficiaries of the total System. While some funds will be available from Department of Health, Education, and Welfare (DHEW) for demonstration and support, funds for the total system will not be available from a central source. Each participating unit will develop and maintain multiple sources of funding.
- *Preserve Confidentiality*—The System will operate through various legal mandates and administrative policies to preserve the required and proper

confidentiality of data identifying individuals and yet assure appropriate access to such data by users.

- *Respond to Data Needs*—Designated CHSS units are encouraged to perform functions and maintain data bases in addition to those defined as a minimum for participants in the CHSS.
- *Accept Organizational Variation*—The organization of individual units of the System are not prescribed however minimal levels of function are presented. Organizational structure of a unit can encompass any one of a potential range of organizational forms. The form is not of concern to the System as long as it is structured to permit the defined level of function to be accomplished.
- *Allow Expansion of Functional Scope*—The CHSS, as any system, is dependent upon an evolutionary process for its continued growth of service. Therefore standards, principles, and programs related to the System are designed to assure minimum performance among a large number of organizational units. The System as a whole will become more advanced as the comprising units become more advanced in terms of functional scope.
- *Adopt Minimum Uniform Health Data Sets*—Minimum uniform health data are subject to specific sets of health statistics, e.g., hospital discharge statistics (including both data items and their definitions) that are needed by multiple agencies and organizations at multiple geopolitical levels. This includes all Federally-sponsored data sets that apply to State designated Agencies. Data sets will be developed in accordance with identification of multiple user needs and published. Data sets and their content items will be constructed and reviewed periodically by national, State, and local representatives, public and private, of health data providers and users. All revisions in data sets will be published after they have met criteria established by participants in the System.

6. *Functions of the CHSS.* While multiple agencies and organizations are encompassed by the CHSS at each geopolitical unit there is one unit designated at the Federal level, the National Center for Health Statistics, and one unit to be designated at each State level that will be the focal points for stimulating interest, providing coordination, serving as a clearinghouse of health statistical data, developing statistical standards, providing technical assistance, and in other ways promoting the CHSS as a national health information and statistics network.

These guidelines outline the types of functions the Federal and State CHSS units should perform. The functions these units will carry out are described below. These guidelines provide a structural foundation and are to be followed by more specific guidelines relating to health data required by multiple users at the Federal, State, and local level; standards relating to data classification systems, quality control, data analysis, and related matters.

a. *Federal Unit.* In Section 306(e) of the Public Health Service Act, Congress identified the National Center for Health Statistics as the unit at the Federal level to initiate, guide, support, and monitor the CHSS. Under the provisions of this statute several requirements are placed on the Center.

(1) To prescribe guidelines to assure that statistical activities within States participating in the System produce uniform and timely data and to assure appropriate access to such data.

(2) To coordinate the activities of Federal agencies involved in the design and implementation of the System.

(3) To undertake and support (by grant or contract) research, development, and demonstrations, and evaluations respecting the System.

(4) Make grants to and enter into contracts with State and local health agencies to assist them in meeting the costs of data collection carried out under the System.

(5) Review the statistical activities of the Department to assure that they are consistent with the System.

As the Federal unit with responsibility for the successful operation of the System, the National Center for Health Statistics will assist each designated State CHSS Agency in assuming and accomplishing its responsibilities under the System to produce uniform and timely data and assure appropriate access to such data.

b. *Other participating Federal Agencies and National Organizations.* Other Department of Health and Human Services (DHHS) components and national organizations which will participate in development of CHSS include but are not limited to the Health Care Financing Administration (Medicare, Medicaid, and PSRO data); Health Resources Administration (planning, manpower, and facility data); Health Services Administration (family planning, maternal and child health care, and community services data); Alcohol, Drug Abuse, and Mental Health Administration (facilities, manpower, and utilization data); Centers for Disease Control (communicable disease data); American Medical Association; and American Hospital Association. Participation of these Agencies in the development of the State Agency Designation program will assure that the CHSS principles will be met.

Participation of other Federal and national agencies will be voluntary and may be limited in scope to only one or a few functions in relation to the designated State Agency or NCHS. The essential function will be coordination of their data collection efforts with the appropriate level of CHSS be it with the NCHS or with the State CHSS Agency.

In turn, as partners in the CHSS, other DHHS components and national organizations conducting health statistics programs involving State and local agencies will be assured that their needs and uses of data will be fully considered by the designated State Agencies and NCHS.

c. *State CHSS Agencies.* The long-range goal of the CHSS program in relation to the State CHSS Agencies is to have in every State a designated CHSS unit having certain common characteristics and a full scope of functional capacities in active operation.

At the present time, the accomplishment of the goal of the program lies in the future. All States have some type of health statistics activity now but the functional scope of this activity and the organizational form of the agencies and/or organizations responsible for the activity vary widely. Many, but not all, States have designated Agencies. Variation in health statistics programs among States is recognized and will be accommodated in the design and implementation of the State Agency Designation program.

The immediate goal of the State CHSS program is to accomplish CHSS State Agency designation in every State and to assure that initially each designated Agency has certain minimum uniform characteristics (outlined in section 7 below) and a minimum common level of function. Conformance to these characteristics and efficient performance of these functions will assure production of uniform health information and equitable access by all legitimate users. As these goals are accomplished, State CHSS programs will be expanded to include additional characteristics and functions.

The CHSS characteristics and functions are not intended to be restricted to the present or potential health statistical activities of any individual State. Rather they have been designed to assure that among all States there is a common uniform albeit minimum CHSS program.

7. *Desired Characteristics of Designated Agencies.* To assist those responsible for deciding upon the Agency most appropriate for their State to be designated as the State CHSS Agency we are indicating below the characteristics expected of such an Agency. At the time of designation it is not expected that the Agency will possess all these characteristics. None of these characteristics should be considered mandatory but only advisory since the CHSS is a voluntary program. Funding by the Federal Government is not a prerequisite for designation.

- *Public Entity*—The State CHSS Agency will ordinarily be an organizational entity of the State government. A private nonprofit organization may be a designated State Agency if it can be considered and formally recognized as a State Agency in accordance with State constitutional or statutory authority.
- *Adequate Resources*—The State CHSS Agency should have personnel, personnel and technical support services, physical facilities, and funding support that are adequate to support at least the minimum level of function. For example, it should have the capacity to provide minimum information to multiple users, and to provide advice to them on using the data.
- *Adequate Authority*—The State CHSS Agency should have the authority necessary to collect, process, and disseminate data and to protect the confidentiality of data. For data collection and dissemination, authorities may include both government mandates and voluntary agreements with subject individuals or institutions. In the protection of confidentiality, the Agency must have policies and procedures which preclude disclosure of or unwarranted access to confidential or sensitive data. Such safeguards should include legislative authority to protect the identity of respondents, necessary measures to secure records and computer files, including staff educated in safeguarding data confidentiality.
- *Statistical Mission*—It is desirable that as the State CHSS Agency expands functions, especially in the area of analysis, that its primary function both within the State in general and to CHSS in particular be that of a multipurpose health statistics agency serving many users and their needs.

8. *Desired Functions of Designated Agencies.* The State CHSS Agency does have options in the administration of the program, namely: (1) Directly undertake functions within the State CHSS Agency, and/or (2) indirectly carry out functions by delegating authorities to other agencies or organizations through formal agreements to accomplish a function for which the agency is responsible or some portion of it. If an indirect option is elected by a State

designated Agency it is still responsible for the effective administration of all functions.

- *Coordination*—The State CHSS Agency should provide assurance to multiple agencies and organizations as to: (1) The quality and timeliness of CHSS data available within the State area, and (2) access to the data.

In carrying out the minimum function of coordination, a wide range of program-related activity is possible. Examples of activities fulfilling this function are:

(1) Identifying the needs for health data in the State, data gaps, and existing data systems that should be participating in the CHSS;

(2) Evaluating the quality of existing data for CHSS purposes;

(3) Review proposed new CHSS-related systems to assure quality of product—integrating where possible existing systems with the proposed new systems;

(4) Seeking agreements for the sharing of CHSS data among multiple collectors and/or users consistent with promises of confidentiality given to data subjects;

(5) Resolving technical and jurisdictional problems using the assistance of health leaders where necessary; and

(6) Maintaining liaison with other State, local, and national CHSS participating programs.

- *Data Collection*—The State Agency should collect at least minimum uniform health data sets gathered by: (a) Abstracting the data from a primary source record or respondent, or (b) accessing data abstracted by others data collection function either directly from primary sources. In undertaking a or indirectly, the Agency should use or build on existing systems to the extent that those systems can produce uniform, timely, and accessible CHSS data.
- *Data Processing*—The State Agency should be able to do or contract for data processing including the coding and editing of abstracted data into machine-readable form, aggregation of abstracted data according to user specifications, and preparation and exchange of data tapes among multiple users.
- *Analysis*—The State Agency should provide analyses of aggregated data (information) including graphic and tabular displays for general statistical purposes for multiple agencies and organizations. To undertake analytic functions, directly or indirectly, appropriate technical staff are required to ensure a thorough understanding of the source of the data, the collection mechanism, the processing procedures, the subject matter to which the subject is addressed, and statistical methods.
- *User Services*—The State Agency should provide health data services including information dissemination, training, and technical assistance.

In terms of *information dissemination*, the Agency should provide information to appropriate multiple users. It should adopt a publicly stated policy to provide access at least to information based on the minimum uniform health data sets in all possible forms (general-purpose publications, special studies, newsletters, etc.)—except when such access is prohibited by law or constitutes a violation of confidence established as a condition for obtaining the data.

In terms of *training*, the Agency should encourage and support the development of function-related skills of Agency employees through local universities, training institutions, and the Applied Statistics Training Institute of the National Center for Health Statistics. Training programs related to the functions of the Agency should be sponsored or endorsed by the Agency or both data providers and users. In addition to the above options, the Agency—resources permitting—should conduct their own training programs relevant to their own employees, contractor's employees, or those of other participating Agencies and organizations.

In terms of *technical assistance,* the State CHSS Agency should provide advice and consultation on request to other Agencies and organizations in the areas appropriate to the Agency's scope of functions.

- *Research and Development*—The State Agency should conduct or support research and development activities related to the Agency's functions (i.e., that is improving methods of data aggregation) and in general improving the quality of data bases by improving methods of measuring particular subjects (i.e., that population health status).

9. *Notification of Designation.* When a State designates an organization as the State CHSS Agency, the State should notify the Assistant Secretary for Health by letter of the designation. Such notification should cite the authority used by the State for designation, such as executive directive or statute. The Assistant Secretary will acknowledge the notification and forward copies of the correspondence to the Regional Health Administration.

Appendix: List of Currently Designated State CHSS Agencies as of May 14, 1980.

Arkansas—State Department of Health. Governor, 4/23/79.
California—Consortium of Three State Agencies. Governor, 2/19/80.
Colorado—Division of Health Statistics and Vital Records, Colorado Department of Health. Governor, 3/1/79.
Hawaii—Department of Health. Governor, 7/30/79.
Illinois—Department of Public Health. Governor, 11/21/79.
Indiana—Indiana State Board of Health. Governor, 4/30/79.
Kansas—Department of Health and Environment. Governor, 10/2/79.
Louisiana—Office of Health Services and Environmental Quality. Governor, 7/23/79.
Maine—Bureau of Health Planning and Development, Department of Human Services. Governor, 12/21/79.
Massachusetts—Office of State Health Planning, Department of Public Health. Governor, 11/6/79.
Michigan—Department of Public Health. Governor, 2/15/80.
Montana—Bureau of Records and Statistics, Department of Health and Environmental Sciences. Governor, 8/29/79.
New Hampshire—Bureau of Vital Records and Health Statistics, Division of Public Health Services. Legislature, 7/1/79.
New York—Office of Biostatistics, Department of Health. 2/21/79.
North Carolina—Division of Health Services, Department of Human Resources. Governor, 4/9/80.

North Dakota—Office of Statistical Services, North Dakota State Department of Health. Governor, 12/28/78.

Ohio—Ohio Department of Health. Governor, 1/3/79.

Pennsylvania—Health Data Center, Bureau of Health Systems, Pennsylvania Department of Health. Governor, 11/29/78.

Rhode Island—Rhode Island Department of Health. Governor, 1/26/79.

South Carolina—Division of Research and Statistical Services, State Budget and Control Board. 5/13/80.

South Dakota—Center for Health Statistics, Department of Health. Governor, 9/12/79.

Tennessee—Department of Health. Governor, 3/10/80.

Texas—Texas Department of Health. Governor, 2/15/79.

Vermont—Department of Health. Governor, 7/17/79.

Virginia—Bureau of Vital Records and Health Statistics, Department of Health. Governor, 5/14/80.

West Virginia—Health Statistics Center, Department of Health. Governor, 4/9/80.

Wisconsin—Bureau of Health Statistics, Department of Health and Social Services. Governor, 2/7/79.

☆ U.S. GOVERNMENT PRINTING OFFICE: 1994 - 301-049 - 814/13649

FILE

6/3/94

DHHS Publication No. (PHS) 94-1205
4-0929 (6/94)