



## HIV Perinatal Program Guidance

Division of HIV/AIDS Prevention  
Centers for Disease Control and Prevention

Version 1.0  
July 2017

## **Overview**

Perinatal HIV surveillance and prevention programs, including the testing of pregnant women and treatment for those who are infected, have resulted in dramatic declines in the number of children infected with HIV. A large proportion of pregnancies among women with HIV infection now occur after HIV has been diagnosed, emphasizing the importance of linking to and retention in care of women with HIV, whether pregnant or not pregnant. Even though testing and treatment are universally recommended, there continues to be perinatal HIV transmission in the United States each year. These infections are due to missed opportunities for prevention, most often a lack of detection of HIV infection in pregnant women or a lack of adequate preconception care (e.g., adequate therapy and pregnancy planning for women with HIV infection). Continued efforts are needed to ensure that all women and their providers know their HIV status as early as possible in pregnancy.

Perinatal HIV surveillance and prevention activities with HIV exposure reporting and perinatal services coordination is an integrated approach to advancing the progress toward perinatal elimination goals. The approach combines broad population-based surveillance and HIV testing efforts in women and children with perinatal HIV exposure reporting, provision of perinatal HIV services coordination and continuous quality improvement of services in the most affected jurisdictions.

## **Summary of Activities**

The following perinatal HIV prevention and surveillance activities are covered under PS18-1802.

### **Required activities in all jurisdictions:**

1. Prenatal HIV testing of all pregnant women according to CDC recommendations
2. Case surveillance activities for women and children <13 years of age with diagnosed HIV infection
3. Annual matching of HIV-infected women reported to surveillance to the state birth registry, where laws and regulations allow
4. Analysis and dissemination of data on HIV-infected women of childbearing age, perinatal HIV exposures as determined from matching with the birth registry, and HIV-infected infants

### **Required activities in a subset of jurisdictions:**

5. Perinatal HIV Exposure Reporting (PHER), where laws and regulations allow
6. Perinatal HIV Services Coordination (PHSC) to address local issues that lead to missed perinatal HIV surveillance and prevention opportunities
7. Case review and community action using the FIMR-HIV Prevention Methodology

CDC strongly recommends that all jurisdictions conduct Perinatal HIV Exposure Reporting (PHER), Perinatal HIV Services Coordination (PHSC), and case review and community action using the FIMR-HIV Prevention Methodology, regardless of disease burden. To achieve perinatal elimination goals and maximize provision of services for mothers and infants, 16 areas will be required to participate in activities 5 – 7, described below.

The following 16 jurisdictions are required to conduct activities 5 – 7: California (excluding Los Angeles County and San Francisco), Delaware, The District of Columbia, Florida, Georgia, Houston, Louisiana, Maryland, Mississippi, New Jersey, New York City, North Carolina, Philadelphia, Puerto Rico, South Carolina, and Texas (excluding Houston). These jurisdictions were identified as having  $\geq 3,000$  females aged 15-44 years living with diagnosed HIV infection at year-end 2014 or a rate of  $\geq 200$  females living with diagnosed HIV infection at year-end 2014 per 100,000 females aged 15-44 years. Grantees may conduct these activities within the entire jurisdiction or within the MSA, city, or facilities where the grantee deems the problem to be most significant.

Because HIV exposure reporting and perinatal services coordination may involve coordinated efforts statewide, states with directly funded jurisdictions that meet the prevalence threshold should also consider conducting activities 5 – 7.

Jurisdictions that do not meet the morbidity threshold may opt out of participating in activities 5 – 7 by providing a justification in their application. Jurisdictions with state or local regulations that prohibit exposure reporting may opt out of participating in activity 5 (PHER) by providing a justification in their application.

### **Activity-specific Guidance**

1. **Prenatal HIV testing of all pregnant women according to CDC recommendations.** Continued efforts are needed to ensure that all women know their HIV status as early as possible in pregnancy.
  - Grantees shall promote routine, early HIV screening for all pregnant women, according to current CDC recommendations (Revised Recommendations for HIV Testing of Adults, Adolescents, and Pregnant Women in Health-Care Settings, 2006, available at: [http://www.cdc.gov/mmwr/preview/mmwrhtml/rr5514a1.htm?s\\_cid](http://www.cdc.gov/mmwr/preview/mmwrhtml/rr5514a1.htm?s_cid)).
  - Grantees shall work to promote universal HIV screening for all of their pregnant patients early in prenatal care as well as repeat HIV testing during third trimester and expedited HIV testing during labor as indicated.
  - Grantees shall monitor performance based on the indicators outlined in the Evaluation Performance and Measurement Plan (EPMP).
2. **Case surveillance activities.** Routine case surveillance activities include the collection of data on women and children <13 years of age with diagnosed HIV infection. Most cases of perinatal HIV infection are associated with missed opportunities for antiretroviral prophylaxis during pregnancy, labor and delivery or the neonatal period. Timely case finding, as well as partnerships with HIV prevention services and case management during pregnancy can reduce the number of missed opportunities and the number of perinatally acquired HIV infections.
  - Grantees shall conduct activities according to the Pediatric HIV Surveillance Chapter of the Technical Guidance for Surveillance Programs.
3. **Annual matching of HIV-infected women reported to surveillance to the state birth registry.** A match of state HIV surveillance data and birth records will help to determine the number of births to women with HIV infection (i.e., the size of the population for whom perinatal interventions are necessary).
  - Grantees shall conduct activities according to the Pediatric HIV Surveillance Chapter of the Technical Guidance for Surveillance Programs.
4. **Analysis and dissemination of data on HIV-infected women of childbearing age, perinatal HIV exposures, and HIV-infected infants.** Data on HIV-infected women of childbearing age, perinatal HIV exposures as determined by matching to birth registries, and HIV-infected infants should be routinely analyzed and included in routine surveillance publications and reports.
  - Grantees shall conduct activities according to the Pediatric HIV Surveillance Chapter of the Technical Guidance for Surveillance Programs.
5. **Perinatal HIV Exposure Reporting (PHER).** Perinatal exposure reporting for infants <18 months of age differs from reporting of pediatric cases of HIV infection among children <13 years of age, as infants exposed to HIV may or may not be infected with HIV. Example activities include longitudinal follow-up of perinatally HIV-exposed infants every 6 months until 18 months of age (or until HIV infection status is determined) and medical record review of mother-infant pairs to ascertain relevant data. Active reporting

should also be established with laboratories, pediatric clinics, delivery hospitals, and HIV clinics to receive test results on exposed infants, including all positive and negative HIV virologic test results.

- Grantees shall conduct activities according to the Pediatric HIV Surveillance Chapter of the Technical Guidance for Surveillance Programs.

**6. Perinatal HIV Services Coordination (PHSC) to address local issues that lead to missed perinatal HIV surveillance and prevention opportunities.**

Perinatal HIV services coordination (PHSC) activities include: real-time case-finding (HIV infections among pregnant women, pregnancies in women known to have HIV infection), care coordination (therapy for women, and, for the infant, prophylaxis or treatment for infants who acquire HIV), data reporting to surveillance, case review and community action using the FIMR-HIV Prevention Methodology (see below), and preconception care (PCC) for women and men with HIV infection. This approach recognizes the vital importance of assuring proper care of adults with HIV infection, and attention to the reproductive lives of these individuals.

Methods to detect cases of pregnancy in women with HIV infection include, but are not limited to: lab-based reporting of pregnancy in HIV-infected women, lab-based reporting of HIV infection among pregnant women; frequent direct contact with prenatal care providers, perinatal hotlines, surveillance data, relationships with substance abuse treatment, family planning and other providers. Recognition for the first time at or after delivery that an infant has been exposed to HIV should warrant an investigation by PHSC or the FIMR-HIV process.

PHSC activities can also be directed toward women after pregnancy. Adherence to medical visits and in taking medications may decline in some women during the post-partum period. These women may have disease progression and/or increases in viral load, which can in turn encourage development of resistance or increase the risk of HIV transmission to partners. Ascertaining HIV status of the partners of these women is important, since heterosexual males have the longest time from infection to diagnosis. By monitoring viral loads in all infected women of childbearing age, programs can also identify additional women (e.g., beyond the post-partum period) who may be out of care, and link and or engage them in care.

- Grantees shall conduct real time case-finding (detection) of HIV-infected pregnant women and exposed infants. Exposures should be identified prior to birth to allow time for appropriate intervention. This activity must also include identification of pregnancy among women known to be HIV-infected.
- Grantees shall conduct data to care activities including linkage to care for HIV-infected women (prenatally and postnatally) and HIV-exposed infants using perinatal exposure data and laboratory data.
  - Grantees shall assure linkage to comprehensive care (including preconception care) and track health outcomes.
  - Grantees shall develop approaches for working with women’s clinicians, birthing hospitals and pediatricians to identify women whose children are (or were) at exceptional risk for HIV infection and notify those providers about prophylaxis and treatment options for women.
  - Grantees shall develop approaches for working with women’s clinicians, birthing hospitals and pediatricians to identify children who are (or were) at exceptional risk for HIV infection and notify those providers about prophylaxis and treatment options for infants and children.
  - Grantees shall assure HIV-infected women of childbearing age are referred to contraceptive/family planning and preconception care services before and between pregnancies. At a minimum, grantees shall incorporate information on preconception care into interactions with providers.

- Grantees shall assist providers with monitoring viral suppression in their patients using surveillance data.
- Grantees shall conduct linkage to other services as appropriate (e.g., psychosocial, clinical, and drug treatment programs) for HIV-infected women and their infants.
  - Grantees shall assure that women are referred to appropriate clinical and psychosocial services to optimize their own health and to prevent perinatal HIV transmission.
  - Grantees shall assure that infants and children with HIV infection are referred to appropriate clinical and psychosocial services to optimize their own health.
- Grantees shall monitor performance based on the indicators outlined in the Evaluation Performance and Measurement Plan (EPMP).

**7. Case Review and Community Action Using the FIMR-HIV Prevention Methodology.** The FIMR-HIV Prevention Methodology is used to review cases of perinatal transmission or cases in which key perinatal HIV prevention opportunities were missed. The reviews involve in-depth medical record abstraction and interviews of women. The data collected are summarized and presented to a multi-disciplinary case review team (CRT) to identify recommendations for improvement. Recommendations are shared with a community action team (CAT) that chooses among recommendations and chooses strategies to improve the perinatal and HIV care for women and infants. This constitutes a continuous quality improvement process that has been in use in some areas since 2005 and shown to be a low-cost way to attain rich information and to improve systems.

- Grantees shall conduct sentinel event case review to address local systems issues that lead to missed prevention opportunities by using the FIMR-HIV Prevention Methodology (available at: <http://www.fimrhiv.org/>). Eligible cases must include at minimum mother-infant pairs in which the infant is perinatally infected and should also include mother-infant pairs in which mother received no prenatal care, mother was not diagnosed with HIV prior to labor and cases in which mothers and infants did not receive ART during the prenatal, intrapartum and neonatal periods. Other cases may be included based on data at the local level, if desired. This methodology involves:
  - Comprehensive, multidisciplinary review of selected cases based on data from medical records and maternal interviews.
  - Identification of systems failures and actions to address factors contributing to these failures.
  - Development and implementation of strategies to address missed opportunities for prevention. A manual of operations is available at: [http://www.fimrhiv.org/documents/2015\\_FIMRHIV\\_Manual\\_of\\_Operations.pdf](http://www.fimrhiv.org/documents/2015_FIMRHIV_Manual_of_Operations.pdf)
- Grantees shall monitor performance based on the indicators outlined in the Evaluation Performance and Measurement Plan (EPMP).