

Perinatal HIV Exposure Surveillance and Reporting in the United States, 2014

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Abstract

Objective: We sought to describe the current status of perinatal HIV exposure surveillance (PHES) activities and regulations in the United States and to make recommendations to strengthen PHES.

Methods: In 2014, we sent an online survey to health departments in the 50 states, District of Columbia, Puerto Rico, Virgin Islands, and 6 cities and counties (Chicago, Illinois; Houston, Texas; Los Angeles, California; New York, New York; Philadelphia, Pennsylvania; and San Francisco, California). We analyzed responses from 56 of the 59 (95%) jurisdictions.

Results: Thirty-three of 56 jurisdictions (59%) reported conducting PHES and following infants to determine their infection status. Of the 33 jurisdictions performing PHES, 28 (85%) linked maternal and infant data, but only 12 (36%) determined the HIV care status of postpartum women. Themes of respondents' recommendations for strengthening PHES centered on updating laws and regulations to support PHES, reporting all HIV test results and linking vital records with PHES data to identify and follow HIV-exposed infants, communicating with health care providers to improve reporting, training staff, and getting help from experienced jurisdictions to implement PHES.

Conclusions: Our findings indicate that data on perinatal exposure collected through the current system are inadequate to comprehensively monitor and prevent perinatal HIV exposure and transmission. Comprehensive PHES data collection and reporting are needed to sustain the progress that has been made toward lowering perinatal HIV transmission rates. We propose that minimum standards be established for perinatal HIV exposure reporting to improve the completeness, quality, and efficiency of PHES in the United States.

Keywords

HIV infections/epidemiology, perinatal surveillance, HIV surveillance

Perinatal mother-to-child human immunodeficiency virus (HIV) transmission can occur in utero, during labor and delivery, or through breastfeeding. The rate of perinatal HIV transmission has been reduced to 1% to 2% or lower in the United States and Europe^{1,2} as a result of universal HIV screening of pregnant women, maternal antiretroviral treatment, caesarean section when indicated, infant antiretroviral prophylaxis, and avoidance of breastfeeding.³ The estimated number of HIV-infected infants born in the United States was 123 in 2012 and 69 in 2013.^{4,5} These figures suggest that state and local jurisdictions may be getting closer to reaching one of the Centers for Disease Control and Prevention's (CDC's) goals: to reduce perinatally acquired HIV infections to <1 per 100 000 live births annually.⁶ However, to determine if state and local jurisdictions have reached the additional CDC goal of a perinatal HIV transmission rate <1% nationally, state and local jurisdictions need more

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Table 1. History of Centers for Disease Control and Prevention–funded perinatal HIV exposure surveillance classifications and initiatives in the United States, 1987 to 2016

Program: Time Frame	Description
Pediatric AIDS and HIV Surveillance 1987-1994	Uninfected HIV-exposed children classified as seroreverters if negative antibody test after age 18 mo ⁹
1994-2008	Uninfected HIV-exposed children classified as seroreverters if negative antibody test after age 6 mo, no other laboratory evidence of HIV infection, and did not meet AIDS case definition ¹⁰
2008-2014	HIV-exposed children classified as definitive or presumptively uninfected as early as age 4 mo depending on type of testing done ¹¹
2014-2016	Distinction between definitive and presumptive diagnoses of HIV infection in children aged <18 mo ¹²
Survey of Childbearing Women (anonymous): 1988-1994	Neonatal dried blood spots collected for routine metabolic screening tested for maternal HIV antibodies to estimate prevalence of HIV infection among women delivering infants in the United States, without linking results to identifiable people ¹³
Pediatric Spectrum of Disease study (8 US sites ⁹): 1988-2004	Funded sites reviewed newborn and pediatric medical records of enrolled perinatally HIV-exposed and HIV-infected children being prospectively followed every 6 mo. ^{14,15,a}
Enhanced Surveillance Strategies (selected states) ¹⁰ : 1993, 1995, and 1996	Birth registries and HIV/AIDS case registries matched and perinatal HIV exposure data collected to determine (1) the number of HIV-infected women diagnosed before delivery, (2) the extent to which HIV testing and zidovudine prophylaxis for perinatal HIV prevention was being implemented in clinical practice, and (3) the barriers to universal implementation of perinatal HIV testing guidelines. ^{16,b}
Enhanced Perinatal Surveillance ¹¹ : 1999-2011	Perinatal HIV surveillance data collection system established (1) to monitor implementation and evaluate outcomes of US Public Health Service recommendations to prevent perinatal HIV transmission and (2) to assess prenatal HIV counseling and testing, prenatal care and treatment, longitudinal follow-up of child's HIV status, initiation of HIV-related care, and long-term outcomes. ^{17,18,c}

Abbreviation: HIV, human immunodeficiency virus.

^aPediatric Spectrum of Disease Study sites: Los Angeles County, California; New York, New York; Texas; District of Columbia; Massachusetts; North Carolina; and San Francisco, California.

^bEnhanced Surveillance Strategies states: Colorado, Indiana, Louisiana, Michigan, Missouri, New Jersey, and South Carolina.

^cThe Enhanced Perinatal Surveillance project was an extension of routine HIV surveillance activities, initially funded in 24 state and local health departments; however, by the time that the project ended in 2011, it was funded in only 15 health departments.

comprehensive data about the number of HIV-exposed infants born each year. Moreover, state and local jurisdictions need this perinatal HIV exposure surveillance (PHES) data (1) to help ensure that HIV-infected pregnant women and their infants receive appropriate interventions and (2) to identify and address gaps in care that continue to result in preventable cases of perinatally acquired HIV infection.

The process of conducting PHES involves health departments collecting, analyzing, and reporting data about infants born to HIV-infected women. Health department surveillance programs then track HIV-exposed infants until their final HIV infection status has been determined. CDC has advocated PHES, and several CDC-funded PHES initiatives and studies have played a fundamental role in the understanding and prevention of perinatal HIV transmission in the United States (Table 1). Yet, although CDC and the Council of State and Territorial Epidemiologists have recommended that states require public health reporting of all perinatal HIV exposures,⁶⁻⁸ PHES is still not a standard component of HIV surveillance activities in the United States. Furthermore, because of recent reductions in perinatal HIV transmission, CDC funding for PHES decreased over time and ended in 2011. Since 2012, public health departments have not

received any federal funding for PHES. Instead, state and local jurisdictions have had to make their own decisions about whether to fund PHES.

We conducted a national online survey of health departments in 2014 to describe the current state of PHES activities and regulations in the United States and to make recommendations that would expand and strengthen national PHES and surveillance reporting.

Methods

The Data and Surveillance Working Group of CDC's national Elimination of Mother-to-Child HIV Transmission Stakeholders Group developed an online survey using SurveyMonkey¹⁹ to gather detailed information about PHES activities (Table 2). The Stakeholders Group meets regularly to support the CDC framework for eliminating perinatal HIV transmission in the United States.⁶ We initially disseminated the survey through a Council of State and Territorial Epidemiologists electronic newsletter and then sent follow-up emails to health department HIV surveillance contacts in all 50 US states, the District of Columbia, Puerto Rico, the Virgin Islands, and 6 cities and counties that have HIV

Table 2. Questions from an online survey about perinatal HIV exposure surveillance and reporting in the United States, 2014^a**For all respondents**

1. Does your state or jurisdiction have laws or regulations regarding perinatal HIV exposure surveillance? If yes, please explain.
 - a. Laws or regulations require perinatal HIV exposure reporting.
 - b. Laws or regulations prohibit it.
 - c. Other, please explain.
2. Does your state or jurisdiction conduct perinatal HIV exposure surveillance? Yes or no.

For jurisdictions that do not conduct perinatal HIV exposure surveillance

1. What are the reasons for not conducting perinatal HIV exposure surveillance?
 - a. Laws or regulations require perinatal HIV exposure reporting.
 - b. Laws or regulations prohibit it.
 - c. Cost is prohibitive or lack of funding.
 - d. Too complex.
 - e. Other.
2. Do you think the implementation of perinatal HIV exposure surveillance would be beneficial to your jurisdiction? Yes, possibly, no, or unsure/don't know.
3. If resources and/or assistance were made available, would your jurisdiction consider conducting perinatal HIV exposure surveillance? Yes or no. If yes, please explain.

For jurisdictions that do conduct perinatal HIV exposure surveillance

1. When did your jurisdiction initiate perinatal HIV exposure reporting?
2. How does your jurisdiction identify HIV-exposed infants?
3. Does your jurisdiction follow HIV-exposed infants to determine HIV infection status? Yes or no. If yes, how?
4. Is your jurisdiction able to connect infant cases to their mother's case report? Yes or no. If yes, what methods do you use?
5. Does your jurisdiction have a mechanism in place to determine the care status of postpartum women with HIV? Yes or no. If yes, what methods do you use?
6. What data collection tools does your jurisdiction use?
7. What databases does your jurisdiction use?
8. How does your jurisdiction disseminate perinatal surveillance data?
9. What are your jurisdiction's technical assistance needs in the dissemination of perinatal surveillance data?

Abbreviation: HIV, human immunodeficiency virus.

^aOnline survey disseminated to 59 HIV surveillance contacts in health departments directly funded for HIV surveillance by the Centers for Disease Control and Prevention, including all 50 US states, District of Columbia, Puerto Rico, the Virgin Islands, and 6 cities and counties (Chicago, Illinois; Houston, Texas; Los Angeles, California; New York, New York; Philadelphia, Pennsylvania; and San Francisco, California), via the Council of State and Territorial Epidemiologists newsletter and email.

surveillance activities directly funded by CDC (Chicago, Illinois; Houston, Texas; Los Angeles, California; New York, New York; Philadelphia, Pennsylvania; and San Francisco, California). To encourage survey participation, we informed respondents that findings would be presented in aggregate and that no individual jurisdictional findings would be released.

All 59 state, territorial, and city surveillance jurisdictions responded between April and August 2014. We excluded 3 surveys from analyses because of inconsistent responses or missing data, which resulted in a 95% response rate. The final sample of 56 jurisdictions represented 51 states or territories and 5 cities or counties. We conducted descriptive data analyses using Microsoft Excel and SAS version 9.4.²⁰ The survey was reviewed and approved as nonhuman subjects research by the Institutional Review Board at Rutgers, The State University of New Jersey.

Results

Laws and Regulations for PHES and Reporting

Of the 56 jurisdictions, 28 (50%) indicated having laws or regulations for PHES, 25 (45%) reported having no such laws

or regulations, and 3 (5%) were unsure. Of the 28 jurisdictions with laws or regulations, 27 required perinatal HIV exposure reporting. One jurisdiction prohibited exposure reporting as part of public health surveillance but conducted PHES at selected facilities with institutional review board approval. Five jurisdictions noted that their laws were vague or did not mention perinatal HIV exposure reporting. Two jurisdictions indicated that they received information about perinatal HIV exposures from required laboratory reporting or through voluntary passive reporting from health care providers.

Jurisdictions With PHES

Of the 56 responding jurisdictions, 33 (59%) conducted PHES, including 28 of the 51 (55%) responding state or territorial jurisdictions and all 5 responding city or county jurisdictions. Of the 33 jurisdictions performing PHES, 27 (82%) reported conducting PHES >5 years before the survey, and 2 (6%) jurisdictions reported initiating PHES within 3 years of the survey (Table 3).

Identification of HIV-Exposed Infants. Of the 33 jurisdictions conducting PHES, HIV-exposed infants were identified from

Table 3. Details of HIV exposure surveillance activities reported by health departments in 33 jurisdictions that conducted perinatal HIV exposure surveillance and reporting, United States, 2014^a

Perinatal HIV Exposure Surveillance Activities	Jurisdictions (n = 33), No. ^b (%)
When did your jurisdiction initiate perinatal HIV exposure reporting?	
Within the last 12 mo	1 (3)
1-3 y ago	1 (3)
3-5 y ago	4 (12)
>5 y ago	27 (82)
What methods are used to identify HIV-exposed infants?	
Laboratory reports	30 (91)
Reports from health care providers	25 (76)
HIV, specialty clinic, or other adult providers	21 (64)
Pediatric providers	20 (61)
Obstetricians/gynecologists	9 (27)
Other medical providers	9 (27)
Birth hospital reports	20 (61)
Vital statistics (birth registry matches)	16 (48)
Newborn testing	13 (39)
How is the infant's HIV infection status determined?	
Laboratory reporting	27 (82)
Medical record review	20 (61)
Other	4 (12)
Not specified	4 (12)
Is your jurisdiction able to link an infant's case report to the mother's case report?	
Can link all infants	21 (64)
Can link some infants	7 (21)
Can link only HIV-infected infants	3 (9)
Cannot link infants	1 (3)
Missing response	1 (3)
Does your jurisdiction have a mechanism to determine the HIV care status of postpartum women?	
Yes	12 (36)
No	21 (64)
What mechanisms are used to determine the HIV care status of postpartum women?	
Laboratory reporting	8 (24)
Medical record review	5 (15)
Other	5 (15)
Not specified	1 (3)
Do not follow women postpartum	21 (63)
What data collection tools are used for perinatal HIV exposure reporting?	
Pediatric Case Report Form	30 (91)
Adult Case Report Form	14 (42)
Perinatal HIV Exposure Report Form	7 (21)
Enhanced Perinatal Surveillance form	5 (15)
Jurisdiction-created tool	8 (24)
What databases are used for perinatal HIV exposure data?	
Enhanced HIV/AIDS Reporting System	31 (94)
Enhanced Perinatal Surveillance System	4 (12)
Other database	12 (36)
How are perinatal HIV exposure data disseminated?	
Epidemiologic profile	19 (58)
Larger surveillance annual report	16 (48)
National and international conferences	6 (18)
State and local presentations	4 (12)
Perinatal annual report	4 (12)
Website	4 (12)
Peer-reviewed journals	3 (9)
Perinatal data are not reported	4 (12)
Missing response	3 (9)

Abbreviation: HIV, human immunodeficiency virus.

^aActivities reported by 33 jurisdictions that conducted perinatal HIV exposure surveillance, in an online survey disseminated to 59 HIV surveillance contacts in health departments directly funded for HIV surveillance by the Centers for Disease Control and Prevention, including all 50 US states, District of Columbia, Puerto Rico, Virgin Islands, and 6 cities and counties (Chicago, Illinois; Houston, Texas; Los Angeles, CA; New York City; Philadelphia, PA; and San Francisco, CA).

^bNumbers do not total to 33, because respondents could choose >1 option.

laboratory results reported to surveillance by 30 (91%) jurisdictions, from health care provider reports by 25 (76%) jurisdictions, from birth hospital reports by 20 (61%) jurisdictions, from results of matches between HIV surveillance records and vital statistics birth records by 16 (48%) jurisdictions, and from newborn testing or screening results by 13 (39%) jurisdictions (Table 3). Other sources for identifying HIV-exposed infants included hospital pharmacy records, a state outreach program, and Centers for Medicare & Medicaid Services partner reports. Of the 33 jurisdictions, 31 (94%) used multiple sources of information to identify HIV-exposed infants: 23 used ≥ 4 information sources, 2 used 3 information sources, 6 used 2 information sources, and 2 used 1 information source.

Determination of Infant HIV Infection Status. All 33 jurisdictions that reported conducting PHES followed HIV-exposed infants to determine their final HIV infection status: 27 (82%) used laboratory reporting, 20 (61%) used medical record reviews, and 4 (12%) did not specify the information source. Other reported sources of infant HIV infection status information included Healthy Start, Centers for Medicare & Medicaid Services partners, medical providers, and other jurisdiction-specific programs or resources.

Linking Infants and Mothers. Of the 33 jurisdictions that reported conducting PHES, 31 (94%) reported being able to link the case reports of infants and mothers, 1 jurisdiction was unable to link infants to their mothers, and 1 jurisdiction did not respond to the question. Of the 33 jurisdictions, 21 (64%) linked all infants to their mothers, 7 (21%) linked some infants to their mothers, and 3 (9%) linked only HIV-infected infants to their mothers (Table 3). Barriers preventing the linkage of mother-infant pairs included infant adoption name changes and information gaps (eg, no pregnancy outcome data).

HIV Care for Postpartum Women. Of the 33 jurisdictions that reported conducting PHES, 12 could determine if postpartum women were receiving HIV care through laboratory reporting (in 8 jurisdictions) and/or medical record review (in 5 jurisdictions). Other sources used to make this determination were case managers, care staff members, care databases, state electronic data surveillance systems, and the Perinatal HIV Exposure Reporting (PHER) form.

Data Collection Tools and Databases for Reporting PHES. Of the 33 jurisdictions that reported conducting PHES, 30 (91%) used the CDC Pediatric HIV Confidential Case Report Form to collect perinatal surveillance data, and 18 (55%) used ≥ 2 data collection tools: the Adult HIV Confidential Case Report Form, Enhanced Perinatal Surveillance form (used previously for the CDC-funded Enhanced Perinatal Surveillance project), and the PHER form. In addition, 8 jurisdictions reported using locally created jurisdiction-specific data collection tools that included electronic laboratory reporting, fetal infant mortality review for HIV chart

reviews, state electronic data surveillance systems, and local reporting forms based on PHER and Enhanced Perinatal Surveillance forms.

For storing PHES data, all 33 jurisdictions used either the CDC Enhanced HIV/AIDS Reporting System (eHARS), the Enhanced Perinatal Surveillance System databases, or both. Although 31 (94%) jurisdictions reported using eHARS, only 7 jurisdictions reported completing the PHER form. Completion of the PHER form within the eHARS database is required to transfer perinatal HIV exposure data to CDC. In addition, 12 jurisdictions reported using other databases to track surveillance activities, including sexually transmitted disease information systems,²¹ jurisdiction-created databases, or Excel spreadsheets.

Dissemination of PHES Data. Of the 33 jurisdictions conducting PHES, 19 reported and disseminated PHES data in their HIV epidemiologic profiles²², 16 did so in their annual HIV surveillance reports, 4 jurisdictions used a perinatal annual report, 3 jurisdictions shared data in presentations, 4 jurisdictions shared data in publications, 4 jurisdictions did not report perinatal HIV exposure data, and 3 jurisdictions did not respond to the question (Table 3). For the dissemination process, 14 jurisdictions identified at least 1 technical assistance need. Of these, 13 noted the need for standardized SAS programs, 11 noted the need for report templates, and 7 noted the need for cross-jurisdictional analyses.

Recommendations for Perinatal HIV Exposure Reporting. Of the 33 jurisdictions conducting PHES, 18 provided recommendations for perinatal HIV exposure reporting. The common themes of these recommendations centered on reporting all HIV test results, needing laws and regulations, building relationships with health care providers, training staff members, linking vital records with eHARS data, and getting help from more experienced jurisdictions.

Jurisdictions Without PHES

Reasons for Not Conducting PHES. All 23 of the 56 jurisdictions (41%) that reported not conducting PHES were state or territorial jurisdictions. Reasons for not conducting PHES included prohibitive costs or lack of funding (16 jurisdictions), too few exposures (9 jurisdictions), laws or regulations prohibiting perinatal exposure reporting (1 jurisdiction), and the high complexity of PHES (1 jurisdiction).

Implementation of PHES. Of the 23 jurisdictions that reported not conducting PHES, 16 thought that PHES implementation would be beneficial or possibly beneficial, 5 did not think that it would be beneficial, and 2 were unsure. Of the 16 jurisdictions that thought it would be beneficial or possibly beneficial, 15 reported that they would consider implementing PHES if resources and assistance were made available.

Discussion

To our knowledge, this study is the first to describe the scope of PHES in the United States and its territories. In 2014, 48% of responding jurisdictions reported laws or regulations requiring perinatal HIV exposure reporting, and 59% reported conducting PHES and following infants to determine their infection status. Almost all of these jurisdictions were also able to link the case reports of infants and mothers (which may enhance assessments of individual cases and perinatal HIV prevention programs) and to disseminate their PHES data, but only about one-third of jurisdictions were able to determine if postpartum women were receiving HIV care.

Because of recent progress in preventing perinatal HIV transmission, the performance and dissemination of PHES has received less attention since funding for PHES in 2011. Despite the efficacy of existing prevention methods, however, new cases of perinatally acquired HIV infection still occur. A retrospective review of 27 HIV-infected infants born between 2005 and 2012 and receiving care at a pediatric HIV clinic in Georgia found widespread missed opportunities for preventing perinatal HIV transmission.²³ These missed opportunities reflected multiple system failures in prenatal care, HIV testing, antiretroviral therapy during pregnancy, intrapartum zidovudine treatment, caesarean section when indicated, and infant antiretroviral prophylaxis. We noted that gaps in the perinatal HIV exposure reporting system contributed to failures to identify opportunities for perinatal HIV prevention, resulting in avoidable occurrences of perinatal HIV transmission. Similar missed opportunities have been reported in other jurisdictions, demonstrating that tracking only perinatal HIV transmissions is not sensitive enough to detect emerging issues until after an outbreak has occurred.^{24,25} A review of Enhanced Perinatal Surveillance System data from 15 jurisdictions during birth years 2005 through 2008 found that 52.6% of all births to HIV-infected women involved at least 1 missed prevention opportunity, despite a perinatal HIV transmission rate of 2.2%.²⁶ Moreover, the scope of the problem is large: a 2011 publication estimated that 8700 HIV-infected women delivered infants in 2006, up 30% from 2000, although more up-to-date data are needed.²⁷

Furthermore, costs need to be considered in the context of the discounted average lifetime cost for care of a person with HIV infection, which is estimated at \$253 000 to \$402 000.²⁸ PHES provides data for timely identification of HIV-exposed infants and about missed opportunities, and these data can be used locally to improve prevention systems and reduce health care disparities. PHES data can also help to address remaining questions about the long-term health effects of infant exposure to HIV infection and antiretroviral medications.^{3,29,30}

After evaluating the 2014 survey data (including recommendations from survey respondents), we discussed the results with the Elimination of Mother-to-Child HIV

Transmission Data and Surveillance Working Group in 2015-2016 and used this discussion to begin formulating recommendations intended to expand and strengthen perinatal HIV exposure reporting and surveillance programs. Our recommendations address such topics as updating reporting laws and regulations, linking vital records with eHARS data, reporting all HIV test results, providing trained staff members and technical assistance, identifying mother-infant pairs for Data to Care activities, and reporting data to CDC (Table 4). Data to Care is a new public health strategy that aims to use HIV surveillance data to identify HIV-diagnosed people not in care, to link them to care, and to support the HIV continuum of care.³¹

Our recommendations start with a focus on the need to review, clarify, and update local laws and regulations to support the identification of HIV-exposed infants through reporting mechanisms that involve laboratories, health care providers, and/or active data collection. Currently, jurisdictional laws and regulations can be difficult to access and understand. The lack of clarity of these laws and regulations may result in underreporting from laboratories and health care providers, who may otherwise be willing to report. We recommend that revised regulations explicitly require the reporting of all negative HIV test results for infants and young children. Our recommendations are supported by the fact that in 2013, CDC recommended that all jurisdictions update laws, regulations, or policies to support the reporting of all HIV-related test results to their HIV surveillance programs.³²

We also recommend that a national PHES system be implemented. CDC should recommend surveillance activities for all jurisdictions, regardless of disease burden. The initial scope of activities may need to be limited, given the lack of direct funding support. However, program costs that substantially limit data collection will likely result in the incomplete identification of HIV exposures and infant HIV infections, creating a roadblock to developing a comprehensive surveillance program. Consequently, in areas where disease burden is high, restoration of CDC prevention funding or leveraging of other resources (eg, the Ryan White HIV/AIDS program) may be necessary to support these surveillance activities.

We propose that minimum standards be established for perinatal HIV exposure reporting, including matching surveillance to vital statistics birth records, reporting complete HIV laboratory results, reporting all data to CDC, and using perinatal HIV exposure reporting in Data to Care activities. To control costs and reduce demands on staff member time, these minimum standards should be set so that the required amount of data for reporting is limited, laboratory reporting can be done electronically, and technical assistance (eg, standardized computer programs) can be provided. Use of electronic laboratory reporting as the central approach to HIV exposure surveillance would reduce but not eliminate demands on staff member time. For example, staff member follow-up may still be needed to determine why a child is being tested or to ensure complete reporting by laboratories,

Table 4. Author recommendations^a to expand and strengthen perinatal HIV exposure surveillance and reporting in the United States, 2014

Recommendation	Rationale
Review and update HIV reporting laws and regulations to include requirements for perinatal HIV exposure.	Health care providers, laboratories, and health departments may not report HIV-exposed infants, because laws are unclear or prohibit perinatal exposure reporting or because reporting is optional.
Match Enhanced HIV/AIDS Reporting System and vital statistics birth records to identify perinatal HIV exposures that occurred after mother's HIV diagnosis or up to 1 mo after birth of infant.	Matching with mother's name, date of birth, and/or social security number provides a mechanism to assess completeness of perinatal HIV exposure reporting. Matching can determine lower-bound estimate of number of perinatal HIV exposures in jurisdictions that have low morbidity or do not conduct active follow-up of exposures.
Implement complete laboratory reporting for HIV, including all nucleic acid diagnostic tests conducted, to determine HIV-exposed infant's infection status. ^{33,b}	Laboratory reporting provides a mechanism to determine the infection status of HIV-exposed infants electronically, without active reporting by health care providers or medical record review. CD4 and viral load data can also identify all cases of HIV infection in women of childbearing age so that matching with vital statistics birth registries is complete.
Provide trained staff members and technical assistance from the Centers for Disease Control and Prevention and jurisdictions with experience to support perinatal HIV exposure reporting.	Perinatal HIV surveillance reporting requires a different skill set and knowledge level than adult HIV case reporting.
Report perinatal HIV exposure data to the Centers for Disease Control and Prevention.	National-level reporting provides data that can be used to assess progress and disparities in perinatal HIV transmission, as well as data needed for cross-jurisdictional technical assistance and discussion.
Use HIV exposure surveillance data to identify mother-infant pairs for Data to Care ³¹ activities in designated jurisdictions.	Provides mechanism to include vulnerable women and infants in services that focus on closing gaps in the HIV continuum of care and improving patient outcomes.

Abbreviation: HIV, human immunodeficiency virus.

^aWe discussed survey results with the Data and Surveillance Working Group of the Centers for Disease Control and Prevention's national Elimination of Mother-to-Child HIV Transmission Stakeholders Group and used this discussion and suggestions from survey respondents to formulate recommendations.

^bTests include HIV RNA and DNA polymerase chain reaction (assays and related RNA qualitative or quantitative assays).

including submission of negative test results. However, when all CD4 and HIV viral load results are reported, public health agencies can use the data to better monitor the engagement in care and the treatment outcomes of HIV-infected infants and postpartum women.

The financial outlay for implementing these minimum standards would be balanced by the cost-effectiveness of using PHES data to improve clinical care. As part of this process, we recommend a focus on building good relationships and effective collaborations with health care providers (eg, through presentations about the importance of PHES), which would promote better reporting, strengthen PHES data quality, and improve the quality of clinical care.

We recommend that eHARS data and vital statistics birth records be matched so that maternal HIV status and infant HIV exposure can be identified. This matching would enable jurisdictions to assess the completeness of their perinatal HIV exposure reporting. Accurate information about the number of perinatal HIV exposures is needed to calculate perinatal HIV transmission rates. Currently, this information is not available at the local or national level, preventing complete assessment of progress toward the goal of reducing or eliminating mother-to-child HIV transmission.

Furthermore, we recommend that jurisdictions enter data into eHARS as a way to report all perinatal HIV exposure data to CDC. Data from all jurisdictions are needed to obtain

a complete picture of perinatal HIV care in the United States, encompassing pregnant women and their infants and including those who are HIV exposed and those who are HIV infected. Currently, national perinatal HIV surveillance is limited to reporting about infants with perinatally acquired HIV infection. A more complete national database may help identify trends in the number and service needs of HIV-infected pregnant women and their infants, including disparities in perinatal HIV transmission outcomes, which may not be apparent at the state and territorial levels.

We also recommend that jurisdictions conducting Data to Care activities include pregnant women and mother-infant pairs who are identified through perinatal exposure reporting. This recommendation is supported by reports documenting low antiretroviral adherence rates and substantially higher risk of loss to follow-up in women during the postpartum period.³⁴⁻³⁶ Perinatal HIV exposure data could be used to identify these postpartum women in need of services, support their adherence to medication, and retain them in care. This recommendation is further supported by the important role that sustained viral suppression from the time of conception has in preventing perinatal HIV transmission.³⁷ Additionally, Data to Care activities could even be used to identify infants whose HIV status remains indeterminate, locate them and their parents, and link them to appropriate services.

Limitations

This study had several limitations. First, because precise definitions of PHES and perinatal HIV exposure reporting were not included in the survey, we classified jurisdictions as conducting PHES only when they reported following infants to determine HIV infection status. This method could have biased our results. Second, the use of an anonymous online survey precluded our ability to follow up and clarify responses, which could have resulted in less reliable data. For example, some respondents may have reported past rather than current activities. Third, we were unable to control who responded to the survey, and data accuracy may have been influenced by the respondents' levels of knowledge. However, by collaborating with the Council of State and Territorial Epidemiologists, we increased the likelihood that the survey would reach respondents with a high level of knowledge of their surveillance programs.

Conclusions

Although CDC and Council of State and Territorial Epidemiologists have recommended that states require public health department collection and reporting of all perinatal HIV exposure data, we found that these data were not collected and reported by all jurisdictions in the United States. These findings indicate that perinatal exposure data collected in 2014 were inadequate to comprehensively monitor and prevent perinatal HIV exposure and transmission. Given that no new funding sources for PHES have been made available, this situation has not likely improved to the current day. Although the United States may be close to reaching CDC perinatal HIV transmission rate goals, more comprehensive PHES data collection and reporting are needed to maintain progress and avoid losing ground. Among other recommendations, we propose that minimum standards be established for perinatal HIV exposure reporting by all jurisdictions to improve the completeness, quality, and efficiency of PHES in the United States. Additional work may be needed to examine the cost-effectiveness of this proposal in jurisdictions with high and low HIV morbidity.

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