Chapter 3 Perinatal HIV Surveillance

3-1 General Overview

Perinatal HIV is the transmission of HIV from mother to child that may occur during pregnancy, labor and delivery or breastfeeding.[1] In the absence of intervention (i.e. antiretroviral therapy) during the prenatal or labor and delivery period, transmission rates can be 18% to 32%.[2] When non-breastfeeding women and their infants receive all recommended interventions and maternal viral suppression is achieved, transmission rates can be less than 1%.[2] The overall goal of perinatal HIV surveillance is to target and follow the progress toward maximal reduction of perinatal HIV transmission. This goal is accomplished through monitoring perinatal prevention efforts, evaluating the effectiveness of antiretroviral therapy and identifying and addressing factors that result in perinatal HIV transmission (i.e. no prenatal care, late maternal diagnosis, etc.).

Perinatal HIV surveillance data is collected using the HIV/AIDS Pediatric Case Report Form (PCRF). A PCRF is completed for all live births to HIV positive women regardless of the infant's HIV status. Infants born to HIV positive women may be classified as infected, uninfected (seroreverter) or indeterminate. A child will be considered indeterminate when the criteria for infected or uninfected are not met. *(See Chapter 7-*Appendix A*:* Revised Surveillance Case Definition for HIV Infection-United States, 2014*)* The data collected on the PCRF includes the following information: prenatal care, maternal HIV testing history, antiretroviral therapy usage for the mother and infant, prophylaxis and treatment received by the infant, appropriate follow-up care of the mother and child and other interventions relevant to the evaluation of recommended public health actions to prevent perinatal HIV transmission.

Perinatal surveillance implements additional methods of case ascertainment, including the linking of mother-infant pairs and review of supplemental medical records. Supplemental medical record reviews encompass reviewing both the mother's and child's medical records, including:

- mother's HIV clinic chart
- prenatal records
- labor and delivery records
- newborn hospital and pediatric clinic charts
- birth and death certificates; and
- laboratory reports

Supplemental medical record reviews assess testing, prenatal care, treatment and longitudinal follow-up to determine the infection status of infants, initiation of HIV-related care, and long-term outcomes. The HIV/AIDS and birth registries will be matched regularly to ensure that all mother/infant pairs are identified and identify all HIV-infected pregnant women. Where feasible, additional registry matches (i.e. birth defects and tumor registries) will be conducted to assess potential adverse outcomes of antiretroviral exposure among perinatally exposed children for short and long term effects.

HIV-exposed infants identified through perinatal surveillance will be followed up by the appropriate surveillance site every 6 months for up to 18 months or until their HIV infection status is determined. If they meet the HIV/AIDS case definition, they will continue to be followed to determine their vital status. Children found to be HIV-uninfected will be maintained in eHARS as a perinatal exposure.

3-2 Testing in Infants age <18 months born to HIV Infected Mothers

Virologic tests (i.e. HIV DNA PCR) are used to confirm HIV infection in perinatally exposed infants less than 18 months of age. Antibody tests (i.e. Western Blot) cannot be used to diagnose these infants due to the presence of maternal antibodies, therefore virologic testing is used for diagnosis of HIV infection. Virologic testing for infants should occur at ages 14 to 21 days, 1 to 2 months and at 4 to 6 months. Virologic testing should be considered at birth for infants at high risk of HIV infection.

If an infant has two or more negative virologic tests (one at age ≥2 weeks and one at age≥4 weeks) or one negative virologic test at age ≥8 weeks, they will be classified as presumptively uninfected. If an infant has two or more negative virologic tests (one at age ≥1 month and one at age≥4 months), they will be classified as definitively negative.

Beginning at age ≥6 months, antibody tests are useful in confirming HIV negative status in infants. One negative antibody test will classify the infant as presumptively uninfected and 2 or more negative antibody tests at age ≥6 months from separate specimens will definitively confirm the absence of HIV infection. Refer to the most recent Guidelines for the Use of Antiretroviral Agents in Pediatric HIV Infection available at www.aidsinfo.nih.gov for more information.

3-3 Reporting/Ownership

Each surveillance site is responsible for completing a pediatric case report form for every perinatally exposed child born within their jurisdiction. An exposure case will belong to the jurisdiction where the woman was residing at the time of birth. If the child is born outside of the country or in another state to a woman residing in Texas, any available Texas medical records will be abstracted and a pediatric case report form will be completed. If the child changes residency and the diagnosis status is updated to HIV infected or AIDS, the exposure case will change ownership to the new jurisdiction where the child resides at the time of HIV or AIDS diagnosis.

3-4 Data Collection

Data for completing pediatric case report forms will be collected from various sources including the following (as available or applicable):

a. Prenatal care records
b. Maternal HIV clinic records
c. Labor and delivery records
d. Pediatric birth records
e. Pediatric HIV medical records
f. Pediatric medical records (non-HIV clinic/provider)
g. Birth certificate
h. Death certificate
i. Health department records
j. Other records

Note that, as with the ACRF, a separate PCRF should be used for each data source.
A child should be reported into eHARS no later than 45 days after the child's date of birth. If care for either the mother or the child was received outside of the jurisdiction of residency, the surveillance site where care was received is responsible for abstracting any other pertinent information. It is the responsibility of each jurisdiction to communicate with other jurisdictions to assure all information necessary to complete the PCRF has been abstracted.

All pediatric medical records should be reviewed six weeks postpartum or later so that data on neonatal antiretroviral use, breastfeeding, etc. will be available. However, timely collection of this data is essential for identification of missed prevention opportunities, and targeting of prevention activities.

If a woman has twins or triplets, a separate PCRF is to be completed for each infant. The maternal information pertinent to each pregnancy must be included. Surveillance sites must also complete an HIV/AIDS adult case report form (ACRF) on HIV positive women delivering live-born infants.

3-5 Case Ascertainment

Surveillance staff must regularly contact reporting facilities and/or have an active reporting system established with delivery hospitals and clinics to identify potential HIV/AIDS perinatal exposure cases. HIV-infected women should be identified during pregnancy by surveillance staff and the infant should be followed-up until the infection status is known.

All reports of pregnant HIV positive women are to be recorded using the tracking spreadsheet provided by DSHS. When contacting health care providers (prenatal care providers, HIV care providers for pregnant women, and pediatric HIV providers) to identify HIV positive women and their infants, please notate this activity as active surveillance using the Monthly Site Activity Tool provided by DSHS.

Each surveillance site must maintain regular contact with health care practitioners from hospitals and clinics. (Providers of HIV care to pregnant women must be contacted regularly to discover if there are new HIV positive pregnant women in care and to obtain the estimated date of delivery.) Perinatal exposures may be identified through the following strategies:

- Medical record review of newly reported women of child bearing age suspected to be HIV positive;
- Communication between the surveillance sites and providers regarding women that have been previously identified as HIV positive and have since become pregnant;
- Review of laboratory results from rapid testing performed at delivery;
- Laboratory reporting of Polymerase Chain Reaction (PCR) test results for children less than 3 years of age; and
- Birth registry linkages (e.g. programs can match HIV cases in women of child-bearing age with the birth registry database annually).

1) For newly reported women of child bearing age who are identified as potential HIV positive cases prior to delivery, laboratory reports may be the primer for initiating an HIV/AIDS related surveillance investigation.

Beginning with receipt of the lab report, surveillance staff should then perform a follow-up investigation involving the review of medical records for these newly reported women. When reviewing the medical record, surveillance staff must first review the record to confirm the woman's HIV status. For women who are identified as being infected, surveillance staff must also review the medical record looking for an indication that the woman is pregnant. If the woman is determined to be pregnant, the woman's information is entered into the tracking spreadsheet (provided be DSHS), and the woman's prenatal care and HIV care is tracked until her delivery date. (Reports of known pregnant HIV infected women must be provided to DSHS on a quarterly basis.)

2.) Perinatal exposures may also be identified through active surveillance involving communication between each of the surveillance sites and providers. This regular communication will pertain to women who have been previously identified as HIV positive and have since become pregnant. Staff from each of the surveillance sites should regularly communicate with providers within their jurisdiction by telephone or a visit to the facility to determine if any births have occurred to women previously identified as HIV positive. In other cases, hospitals, obstetricians or pediatric case managers report directly to the local surveillance sites when they become aware of an HIV positive woman's pregnancy or delivery. When an HIV positive woman's pregnancy is identified prior to delivery, the women's information should again be entered into the tracking spreadsheet (provided be DSHS), and the woman's prenatal care and HIV care should be tracked until her anticipated delivery date. (Reports of known pregnant HIV infected women must be provided to DSHS on a quarterly basis.)

3.) Perinatal exposures may also be identified through review of laboratory results from testing performed at delivery. Surveillance sites may learn about a pregnancy once the women has delivered through a laboratory report if the woman tests positive at delivery or by being notified by a health practitioner that a child has been born to an HIV positive woman.

4.) Perinatal exposures may also be identified through laboratory reporting of negative Polymerase Chain Reaction (PCR) test results. Negative PCR test results for infants up to three years of age are reportable. (See Chapter 1-*Appendix A*: *Texas Reporting Rules*)

5.) And lastly, perinatal exposures may be identified through birth registry matches. A registry match between eHARS and the Vital Statistics birth registry is critical for ascertaining all possible mother/infant pairs so that data is representative of all HIV-infected pregnant women who were known to be HIV-infected during pregnancy. A registry match occurs when a woman's information in eHARS matches the maternal information on the infant's birth certificate. After conducting this match, HIV positive women who are identified to have given birth to a child that is not currently reported in eHARS, will be forwarded to the respective surveillance site for investigation. DSHS will provide each eHARS site with a report for each potential perinatal exposure identified to have been born to an HIV positive woman. After investigation, surveillance sites must submit all completed potential perinatal exposure reports to DSHS. The site will also be required to complete a pediatric case report form for each confirmed perinatal exposure within 3 months of notification from DSHS.

3-6 Follow-Up

The goal is for 85% of exposed infants born to have an HIV status determined (i.e., not be coded as indeterminate) 3 years after the birth. A child must be followed-up every six months until 18 months of age or until the child's HIV status has been determined and if they meet the HIV/AIDS case definition, will continue to be followed to determine their vital status. For indeterminate children, the PCRF should indicate if a child is under active follow-up, child moved to another state, provider is out of state, child lost to follow-up, failure to attend medical appointments, child died before status was determined, or physician has designated the child as seroreverter despite the lack of necessary tests. In cases where the physician has designated the child as a seroreverter despite the necessary tests, DSHS will contact the physician for further clarification.

References

1. Centers for Disease Control and Prevention (CDC). HIV among Pregnant Women, Infants, and Children in the United States, CDC HIV/AIDS Fact Sheet; Dated December 2012.

2. Nesheim S, Taylor A, Lampe MA, et al. A Framework for the Elimination of Perinatal Transmission of HIV in the United States. Pediatrics 2012; 130(4):1–7.

3. Panel on Antiretroviral Therapy and Medical Management of HIV-Infected Children. Guidelines for the Use of Antiretroviral Agents in Pediatric HIV Infection. Available at http://aidsinfo.nih.gov/contentfiles/lvguidelines/pediatricguidelines.pdf. Section accessed [01/20/2015] [C1-C6]