FIMR/HIV PREVENTION METHODOLOGY PROTOCOL

Goal: *To improve perinatal HIV prevention systems by using the FIMR case review and community action process.*

This FIMR/HIV Prevention Methodology Protocol describes how participating sites will conduct their work based on five project pillars. Each participating community will need to determine specific details for each step of this protocol, taking into account specific community factors, organizations, and people necessary to carry out the work. The protocol will be updated as needed based upon continued evaluation of the experience in the pilot sites and the experiences of new communities implementing the methodology.

Technical assistance from City**M**at**CH**, the College/NFIMR and CDC in the form of teleconferences, site visits and an in-person training will be made available to sites implementing the FIMR/HIV Prevention Methodology. Additionally, sites will have access to resources on the City**M**at**CH** website (fimrhiv.citymatch.org).

1) Case Identification

For this methodology, a case is defined as, "HIV-exposed infant/fetus ≥ 24 weeks gestation and < 24 months of age at the time of the review"

To identify cases in accordance with the definition presented above, sites should build relationships with delivery hospitals in their communities. This will facilitate the primary case identification strategy, which requests that hospital employees contact FIMR/HIV staff when women with HIV infection present for delivery. Two supplemental case identification strategies have been developed:

- Develop relationships with HIV case managers and prenatal care providers who will contact FIMR/HIV staff when pregnant women with HIV infection are identified.
- Regular review of existing HIV and disease surveillance programs (e.g., HIV/AIDS Reporting System, Enhanced Perinatal Surveillance, etc) by FIMR/HIV staff to identify missed cases.

Sites are responsible for reviewing between 25-35 cases annually. A priority assessment developed during the pilot will assist sites in selecting cases for review that are likely to illustrate potential gaps in the prevention of perinatal HIV. Issues prioritized for assessment include identification of the infant as HIV infected, late maternal HIV diagnosis in the prenatal period, lack of or inadequate prenatal care, lack of maternal HIV treatment or poor viral suppression during pregnancy or lack of administration of antiretroviral prophylaxis during labor and delivery.

2) Data Abstraction

Sites will attempt to collect information from the birth certificate and the following medical records: Maternal HIV care, prenatal care, labor and delivery care, newborn care, post-partum/reproductive health care, and pediatric care (birth – 6 months). Data abstraction forms have been developed for each of these sources.

Results from the pilot project indicate that information obtained from the following four sources were the most essential: prenatal care records, labor and delivery records, pediatric care records, and maternal interview. Data from these sources permitted participants to compile complete case information that led to a high quality case review. Completion of these four data abstraction forms should be a priority for data abstractors.

3) Maternal Interview

Each site will make concerted efforts to interview the mother using the Maternal Interview Abstraction Form.

Signed consent from the mother should be obtained prior to interview. Site staff must pursue contact with a woman as soon as possible after a positive HIV screening test in order to solicit consent; however, FIMR/HIV staff should wait to conduct the interview until the diagnosis of HIV infection is confirmed. To increase the percentage of interviews conducted, sites must attempt to complete an initial interview as early as possible. Not all relevant information will be available from the mother at an early interview date (e.g., whether the infant received the entire 6-week antiretroviral regimen, the infant's infection status, etc.). Therefore, a follow-up interview should be attempted at a later time (e.g., after three months after delivery). The location and method of each Maternal Interview should be negotiated with the woman in order to best accommodate her needs and life situation.

4) Case Review Team (CRT)

Each site must convene a Case Review Team (CRT) that includes a broad range of professional organizations, institutions, and public and private agencies (e.g., clinical care providers, health clinics, welfare agencies, educational institutions, and advocacy groups) that provide services and resources for women, infants and families. The CRT should represent the diverse ethnic and cultural groups in the community and should include representatives with expertise in maternal and child health as well as HIV infection, care and prevention.

- **The purpose of the CRT:** Review all information gathered for each case; identify systems issues and make recommendations for improvement to the Community Action Team

In the review of cases, deliberations should be guided by the FIMR CRT Summary Questions (i.e. What economic, health service systems, community resources or personal factors helped this family? Did the family receive the services and resources that they needed? What are the local service delivery issues that the case highlights? Are there gaps in the system or community resources? Can more responsive community resources or service delivery systems be designed? What should they look like?).

The frequency of CRT meetings, along with their precise structure and processes, should be decided by each community in order to best tailor the work to the specific needs and circumstances of participants.

5) Community Action Team (CAT)

Each site must convene a Community Action Team (CAT) that is composed of two types of members: those with the political will and fiscal resources to create large-scale systems change and those who can define community perspectives on how best to create the desired change in the community. The CAT should include representatives with influence over maternal and child health systems as well as HIV prevention and care systems. In general, CRT and CAT membership will not include the same people, as too much overlap in membership could result in individuals being overburdened. However, each community can determine the composition that is most effective and relevant to their situation.

- **The purpose of the CAT:** Initiate systems change based on CRT findings and recommendations.

As with the CRTs, the frequency of CAT meetings, along with their precise structure and processes, must be decided by each community in order to best tailor the work to the specific needs and circumstances of participants.

About Confidentiality

All FIMR/HIV sites must maintain confidentiality throughout each of the five steps.

- All identifying information (patient name, provider name and hospital/clinic site) must be removed.
- All institution, provider and family identifiers must be removed.
- Case review meetings must be closed to the public and protected from subpoena or legal discovery by appropriate federal, state, and local statutes.
- All Case Review Team members must sign a pledge of confidentiality which prohibits them from discussing reviews outside of team meetings.
- All information collected from medical records and the maternal interviews must be stored in a secured, locked location and destroyed after the case review.