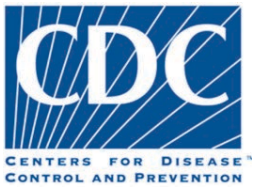
2015
FIMR/HIV Manual of Operations

Provided by:

FIMR/HIV
PREVENTION METHODOLOGY
NATIONAL
RESOURCE
CENTER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The American College of
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WOMEN'S HEALTH CARE PHYSICIANS

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CHAPTER 1:
THE FIMR/HIV PREVENTION METHODOLOGY REVIEW PROCESS

Background

There has been a remarkable decline in mother-to-child transmission of HIV in recent years. This achievement is considered one of the great public health success stories of the United States HIV/AIDS epidemic. With the early knowledge of HIV infection during pregnancy, combination antiretroviral therapy can reduce the risk of perinatal transmission to less than 1 percent and provide life-saving benefits for women. Prevention of perinatal HIV transmission and the assurance of quality HIV care remain important in many communities in the United States, especially where overall HIV prevalence remains stable or is increasing.

The Centers for Disease Control and Prevention (CDC) reports that one in four of the more than 1.1 million people living with HIV are women and only half of women diagnosed with HIV are in care. CDC also estimates that more than 8,000 women living with HIV deliver infants each year and that many cases of perinatal HIV infection "involve women who were not tested early enough in pregnancy or who did not receive prevention services."[1]

The number of cases of perinatal HIV transmission in the U.S. is low, so low that many communities go extended periods of time without a single case. This reality is a testament to the effective efforts of many public health and clinical practitioners as well as from the women living with HIV. However, the target of elimination of mother-to-child HIV transmission (EMCT) in the United States has not yet been achieved. To achieve EMCT, a reduction in approximately 100 cases each year would need to occur, and unfortunately, we are currently falling short of using all of our prevention tools, as exemplified by the following scenarios:

- Approximately 16% of people infected with HIV are unaware of their status.
- HIV testing of pregnant women remains inadequate.
- We have the technology to conduct accurate HIV testing with results in less than an hour in emergency departments and labor and delivery wards, but this technology is underutilized.
- HIV infected women who know their HIV status tend to be "in the system," but the services they receive rarely include reproductive health care including family planning.
- It is not uncommon for women with HIV infection to attain viral suppression during pregnancy only to rebound within the first year postpartum.

The bottom line is this: We have methods that can, and should, ensure that no child begins life with HIV infection and put women on track after pregnancy to remain AIDS-free long after their children become adults. The FIMR/HIV Prevention Methodology is an effective way for communities to ensure that these methods are used.

1 Centers for Disease Control and Prevention, Division of HIV/AIDS Prevention. National Center for HIV/AIDS, Viral Hepatitis, STD, and TB Prevention. *Women in HIV factsheet.* Available at: http://www.cdc.gov/hiv/risk/gender/women/facts/index.html

The goal of the FIMR/HIV Prevention Methodology (FIMR/HIV) is to improve perinatal HIV prevention and HIV care systems by using the FIMR case review and community action process.

Introduction

What FIMR/HIV is

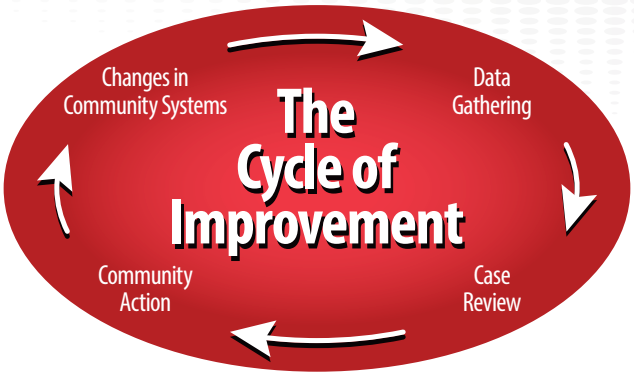
Using FIMR as a prototype, the FIMR/HIV Prevention Methodology was created to help communities identify and address missed opportunities associated with perinatal HIV exposure and transmission. To learn more about the adaptation of FIMR to FIMR/HIV, please read the FIMR/HIV Pilot Project report (**http://www.fimrhiv.org/documents/FIMRHIV.pdf**).

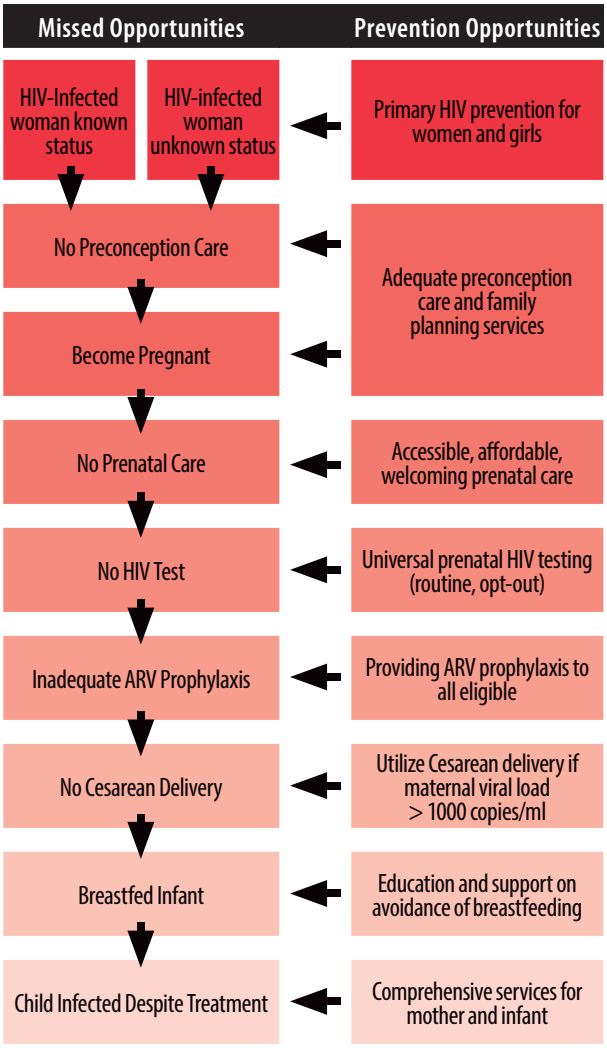
FIMR/HIV combines several processes: information gathering, case reviews and community action. First, cases are selected for review, prioritizing cases with "signals" of potential gaps in services or systems issues. In-depth information about the case is then gathered from multiple sources of data including public health and medical records. To complete the information obtained from the records, an interview is conducted with the mother living with HIV, if she agrees. During the interview, referrals for community services and resources are made available.

Next, a Case Review Team (CRT) comprised of a broad range of providers, institutions, community advocates, professional organizations, and private agencies that provide services for women, infants and families reviews a summary of the case information from the records and interview. After reviewing all of the information, the CRT identifies issues with the services the family did or did not receive and makes recommendations for improvement. A Community Action Team (CAT) that includes a diverse group of community leaders considers the CRT recommendations, then prioritizes and implements interventions to improve service systems and resources. The CAT 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.

FIMR/HIV is a continuous cycle of improvement. Review of cases is a springboard for improvement of service systems and resources for women, infants and families. The examination of new cases reveals whether previous interventions and policies were implemented successfully, whether they should be continued, or whether entirely new approaches are needed. Additionally, mechanisms to inform the CRT and CAT about the status of interventions are developed to continually monitor progress.

The FIMR Process





Report: Institute of Medicine, 1998
http://www.iom.edu/Reports/1999/Reducing-the-Odds-Preventing-Perinatal-Transmission-of-HIV-in-the-United-States.aspx

What FIMR/HIV is Not

The FIMR/HIV process is not about fault-finding or assigning blame for a perinatal HIV transmission or women being lost to care. Blame cannot be determined with the subsets of medical information that FIMR/HIV abstracts, nor should it be attempted. Comprehensive local and state professional peer review and public health and institutional quality assurance programs are already in place and respond to individual issues that need addressing on the institutional level.

The FIMR/HIV process is not about conducting original research on the causes of HIV transmission. Population-based literature exists on that subject. In addition, the information collected about individual cases may not fulfill requirements necessary to contribute to this scientific knowledge base.

Finally, FIMR/HIV is not surveillance. The data collected is not meant to be representative of the larger population of pregnant women living with HIV and their infants in a community. FIMR/HIV is a programmatic activity looking at specific cases of perinatal HIV transmission and other missed opportunities for HIV prevention for the purpose of local systems improvement.

FIMR/HIV Benefits

FIMR/HIV is an action-oriented community process that leads to improvements in health and other family services and resources for women with HIV infection and their infants. Through FIMR/HIV, diverse community members join together to become the collective experts on local service delivery systems and community resources for women with HIV infection and their infants and families. The ultimate goal of FIMR/HIV is to prevent mother-to-child transmission and to provide optimal care for women with HIV infection by:

- Identifying gaps in care and services and/or duplication of services for HIV-infected women and developing strategies to remedy systems failures
- Integrating HIV and maternal-child health services
- Increasing preconception health and family planning services for women with HIV infection

Successful FIMR/HIV programs also have the potential to develop broader public health benefits to the community, such as:

- Information about family services for women with HIV infection and their children
- Information about the effects of local health care system changes on HIV-infected mothers and their exposed infants
- A needs assessment that accurately reflects problems related to women with HIV infection
- Strengthened core public health functions and a continuous quality improvement system
- Local coalitions to build better health and social policies for women with HIV infection

Indicators of maternal and infant health status specific to HIV infection

Who Should Lead FIMR/HIV?

Successful FIMR/HIV programs are a collaboration between maternal-child health and HIV/AIDS partners within the community. Leadership may come from state and local health departments, local coalitions, such as those associated with federally sponsored programs, or local perinatal and HIV/AIDS consortia. Each has its own advantages and disadvantages. Local coalitions have the advantage of community enthusiasm and backing and knowledge of community resources and values, but they may have difficulty gaining access to institutional records and will have to spend time building alliances with large public agencies and medical centers. Programs implemented by health departments are ideal in that the support of a state or local health officer can open doors, attract the attention of other agencies, gain the endorsement of elected officials, and facilitate easier access to the records that are essential to case review. In addition, the personnel at the health department will have access to the web-based data system housed at the Centers for Disease Control and Prevention (CDC), which can enhance and simplify the implementation of the project. Members of the community may initially be wary of perceived government intrusion into sensitive and confidential medical and personal issues.

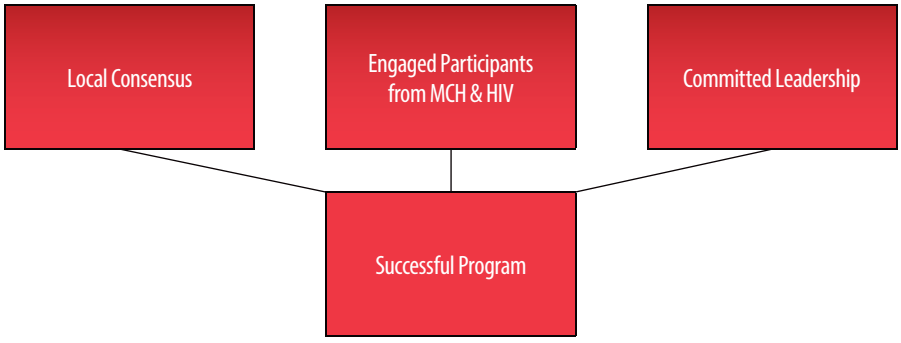
Regardless of which agency or organization implements the FIMR/HIV program, coordination and collaboration among all likely local players is crucial for the success of the program. To achieve this, program leaders will have to address any inherent institutional weaknesses.

CHAPTER 2:
LAYING THE GROUNDWORK

Introduction

Community readiness is a critical element when implementing a FIMR/HIV Prevention Methodology (FIMR/HIV) program. To be successful, an agency or organization that wants to begin FIMR/HIV should already have in place and be able to rely on 1) local consensus about the need to address issues related to HIV infection in women, especially issues related to pregnant women with HIV infection and their infants and families; 2) participation from at least some professional or community maternal-child health and HIV/AIDS coalition groups; and 3) the commitment of a few individuals who will work as a planning group to lay the groundwork upon which to build the process and motivate others to participate. The planning group typically is made up of staff from the implementing agency or organization (e.g., state or local health department or local coalition). The planning group also may include other community or professional leaders who are enthusiastic about the FIMR/HIV process and volunteer to play a role in developing the program.

Key Components of a Successful Program



This chapter focuses on the steps the planning group should take to develop the programmatic features that support FIMR/HIV. Chapter 3 describes important aspects of building community support. It should be noted that while program building and community support building appear in separate chapters for descriptive purposes, the planning group must work on these two functions concurrently (see Chapter 3).

Laying the groundwork for FIMR/HIV usually takes about 6–8 months, although some communities may require less or more time. Programs will need to:

- Identify the community/geographic area of focus
- Identify community resources/assets
- Determine the type and number of cases to be reviewed
- Determine FIMR/HIV's relationship to other types of sentinel event review
- Identify and address legal and institutional issues related to the review (e.g. IRB review)
- Establish systems to maintain confidentiality and anonymity
- Establish a system to identify cases
- Select data collection and processing methods
- Identify costs and funding sources
- Designate the program co-leads
- Formalize policies and procedures
- Build in opportunities for initial and on-going training

While the planning group needs to accomplish all of the tasks listed above, the order in which they need to be addressed may vary from community to community. Some communities may already have accomplished one or more of these activities before the planning group begins its work.

Pre-Implementation Tasks

Identifying the Community or Geographic Area of Focus

Some small programs, such as those implemented by local HIV/AIDS organizations, will already have a defined geographic area. However, larger state programs will need to identify areas, such as cities or counties or areas within them, with highest HIV prevalence and incidence among women of childbearing age or where cases of perinatal HIV transmission are occurring.

Some suggested questions to ask the health department are:

- How many babies are diagnosed with HIV infection in your community annually?
- How many HIV-exposed babies are born in your community annually?
- Does your community offer repeat third trimester HIV testing?
- Are pregnant women offered HIV tests when they present in the emergency room?
- How many HIV positive women of reproductive age are in your community and what proportion are in care and are virally suppressed?
- Where do children receive pediatric HIV care?

The responses provided to these questions will assess the needs in your community and gaps in what data you need.

After viewing surveillance and other available data, the planning group might consider other broad indicators, including rates of women with no prenatal care, rates of HIV testing in pregnancy, data from HIV testing performed in third trimester or at delivery, poverty rates, HIV incidence and prevalence in the target geography, as well as data from social services, education, child care, employment, housing, transportation and other areas. These additional indicators could also be broken down to show differences according to age, race, ethnicity, parity or education/ income.

A geographic area for a FIMR/HIV program should be a true community that will assume local ownership of the program and has the will to create change for women with HIV infection. Some questions to be considered when defining the community are:[2]

- How should the geographic area comprising the FIMR/ HIV community be defined? Will it include an entire city, county or perinatal region, health department jurisdiction,

2 Wise PH, Wulff LM, editors. A manual for fetal and infant mortality review. Washington (DC): American College of Obstetricians and Gynecologists: 1992. Section 3:2

state, only those zip codes or census tracts with the most adverse outcomes, or will a cross-section of the community be represented?

- Is the community defined in a way that will translate into local ownership, accountability and pride?
- How many HIV-infected women of childbearing age are there in the community?
- How many pregnant women with HIV deliver annually?

Identifying Community Resources/Assets

Many FIMR/HIV programs compile a directory of current health and social services and resources. This is a valuable source of information for the FIMR/HIV teams as they begin their reviews and an essential tool for the maternal interviewer who will use the directory to make referrals for the mothers who are interviewed. Perinatal networks or coalitions, a community health worker program or the local health department may already have developed such a list.

Choosing Program Co-leads

The lead agency will designate FIMR/HIV co-leads. The co-leads assume the responsibility for the tasks related to planning FIMR/HIV as well as the ongoing day-to-day management of the program. The co-leads prepare or oversee preparation of the case summaries that the CRT reviews, schedules all meetings of the CRT and CAT, and drafts minutes of these meetings. The FIMR/HIV co-leads will supervise the FIMR/HIV staff who abstract case information and interview mothers, keeping a close eye to see that these activities are completed in a timely fashion. In smaller FIMR/HIV programs, the co-leads may also pitch in to abstract some or all of the records or conduct some of the home interviews.

Determining the Type and Number of Cases to be Reviewed

It is important to take into account the number of cases that a team can review in a year's time. A well-run case review team (one that has been meeting for six months or so and is a fully functioning group) will generally review an average of 2-3 cases in a two-hour CRT meeting. Team meetings are usually held every other month, or as necessary, to review the target number of cases. Some jurisdictions review a larger number of cases on a quarterly basis. There has been a wide range of cases reviewed by FIMR/HIV programs, with some programs reviewing up to 20 cases in a year once they were established.

Sites are responsible for reviewing an adequate number of cases annually to identify systemic issues within their community. The number of cases may vary based on the number of women with HIV giving birth in a community and a site's capacity.

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

A priority assessment will assist sites in selecting cases for review that are likely to illustrate potential gaps in maternal HIV care and the prevention of perinatal HIV. Cases in which the infant has been diagnosed with HIV infection or had at least one positive virologic test must be reviewed. The following are examples of other issues prioritized for assessment:

- late maternal HIV diagnosis
- lack of or inadequate prenatal care
- lack of or inadequate maternal HIV treatment or viral suppression
- short inter-pregnancy interval
- no maternal postpartum care visit within 12 weeks
- mother was born outside the United States
- mother experienced prolonged hospitalization (greater than 7 days) during pregnancy
- mother was perinatally infected with HIV or has a co-infection of syphilis, gonorrhea, hepatitis B or C
- mother has experienced homelessness, mental illness, chemical dependency or substance abuse

A sample image of the priority assessment form is on the following page. The priority assessment can be found on the FIMR/HIV National Resource Center website **(www.fimrhiv.org)**.

Identifying Legal and Institutional Issues Related to the Review

Immunity

The laws and regulations relevant to the FIMR (and FIMR/HIV) process are found primarily in state rather than local or federal laws. All states have laws that afford immunity to those who participate in certain types of reviews. Because these laws vary enormously from state to state, it is very important to check specific state laws as part of the FIMR/HIV planning process. Attorneys affiliated with state or local health organizations are useful resources to help structure the review process to maximize available legal protection.

Immunity means that records pertaining to a particular case under review, as well as the minutes of the CRT meeting and other written records, cannot be subpoenaed or brought to court. In some instances, the FIMR process specifically may be named in the state law. More often, the FIMR (and FIMR/HIV) process may be included under general terms such as "professional review," "peer review," "quality assurance", or "public health research." Protection from testifying usually is extended to individuals on the CRT and project staff.

Additionally, immunity usually means that written information about cases is not discoverable through state laws or the federal Freedom of Information Act (FOIA), a law that gives any private citizen or organization the right to request written information on a particular topic from local, state, or federal governments. In the past, print and other media representatives have mistakenly thought that they could use the FOIA to access FIMR information; however, based on the experience of FIMR programs, being informed that the FOIA does not apply usually closes the discussion and there are no further attempts to access FIMR records.

While situations requiring protection are rare, all FIMR/HIV programs should seek protection as a necessary precaution and as an important reassurance for professionals serving on the CRT. Also, to be on the safe side, cases with pending or expected litigation should be avoided.

Access to records

When planning a FIMR/HIV program, it is important to make sure that all available laws related to accessing medical records and vital statistics are found and interpreted by state or local health department attorneys. Most laws that provide immunity for reviewers and the review team written records also allow access to medical records.

In addition, many states have other regulations that permit access to medical and vital statistics records for "investigations for the benefit of the health of the public" or comparable purposes. Vital statistics data are housed in local city and county health departments. Therefore, a FIMR/HIV program sponsored by the local health department would probably have an easier time accessing records.

Some FIMR/HIV programs access medical records through the federal Health Insurance Portability and Accountability Act (HIPAA).[3] HIPAA permits a covered entity, such as a hospital, to disclose protected health information to a "public health authority" for certain public health activities.

A covered entity may disclose protected health information without authorization from the individual to "[a] public health authority that is authorized by law to collect or receive such information for the purpose of preventing or controlling disease, injury, or disability, including, but not limited to, the reporting of disease, injury, vital events such as birth or death, and the conduct of public health surveillance, public health investigations, and public health interventions."

Many of the activities related to FIMR/HIV programs may fall within the purview of HIPAA public health disclosures. However, this permitted disclosure applies only to FIMR/HIV programs that are sponsored by public health agencies or that are acting under a grant of authority from or contract with a public health agency. Disclosures to FIMR/HIV programs that are acting under the auspices of a public health agency should be permissible

Sample of the Priority Assessment

✓YES	Criteria for Priority Case Review *Case Definition:HIV-infected woman with exposed infant or fetus ≥ 24 weeks gestation*
☐	1. The infant has been diagnosed positive for HIV or had at least one positive virologic test – MUST BE REVIEWED
☐	2. Delivery within the last 24 months
☐	3. Case includes fetal, infant, and/or maternal death. Please indicate: ☐ Fetal Death ☐ Infant Death ☐ Maternal Death
☐	4. Woman was under the age of 21 years at the time of delivery
☐	5. Woman was born outside the U.S.
☐	6. The woman received late prenatal care, e.g. started in 3rd trimester (≥28 weeks gestation) OR the woman did not receive prenatal care
☐	7. Woman experienced prolonged hospitalization (greater than 7 days) during pregancy
☐	8. There is no HIV viral load information for the woman available for the last 3 months of pregnancy
☐	9. The woman received a late HIV diagnosis, i.e. during third trimester, during labor/delivery, or during postpartum period
☐	10. The woman had a detectable HIV viral load at the time of delivery OR viral load was unknown at the time of delivery

3 American College of Obstetricians and Gynecologists, National Fetal and Infant Moretality Review Program; The fetal and infant mortality review process: the HIPAA privacy regulations. Washington (DC):ACOG; 2003

under the federal privacy rule. However, it is important to remember that HIPAA does not preempt any state law that requires reporting of disease or injury, child abuse, birth or death, or the conduct of public health surveillance, investigation, or intervention.

If it is not possible to access medical records under the auspices of state law or federal HIPAA regulations, records usually may be obtained if the mother signs a consent form to release her records and those of her infant. The planning committee will need to develop a release form that the mother can sign. This form should be reviewed and approved by state or local attorneys.

All information gathered should adhere to the CDC's National Center for HIV/AIDS, Viral Hepatitis, STD and TB Prevention Data Security and Confidentiality Guidelines. These guidelines establish standards of data protection programs should have in place to ensure the secure collection, storage, and use of data while maintaining confidentiality. This will be discussed further in the "Establishing systems to maintain confidentiality and anonymity" section of this chapter.

Consent for Maternal Interview

It is essential to have a legally valid consent for the maternal (or other family member) interview. All respondents should understand prior to the interview the reasons for collecting the information, the potential risks and benefits, and steps being taken to protect their confidentiality. Typically, this information is included on the consent form. The interviewer should witness and co-sign the form to document that the mother has been informed about these provisions and understands them. The maternal interview consent form (in English, French, Spanish, and Creole) can be found on the FIMR/HIV National Resource Center website **(www.fimrhiv.org)**.

Institutional Review Boards

Some hospitals, universities, and other agencies have Institutional Review Boards (IRBs) whose purpose is to review all research proposals that are generated by the institution in order to ensure that 1) the research question and study design are valid and 2) that any "human subjects" (people who may participate in the study) are not harmed. The FIMR/HIV process is not research. Nevertheless, some sponsoring agencies still may require that FIMR/HIV programs be cleared through their IRB process and some hospitals may require IRB approval before a program is allowed to access medical records.

Having to apply for IRB approval may seem like a paradox, given that the FIMR/HIV is a continuous quality improvement process for the community and is not research. However, since data abstraction and maternal interviews are part of the FIMR/HIV process, it may be helpful to have a discussion with or provide written information to the IRB to explain why FIMR/HIV is not a research project and should not be subject to the full review board process. It may also be possible to get expedited review.

The Centers for Disease Control and Prevention (CDC) has generated guidelines for describing attributes of public health research and non-research. The FIMR/HIV process was examined against the criteria in these guidelines and was determined to be a non-research project. This information may be helpful to assist IRBs to understand the true public health focus of the FIMR/HIV process. This statement can be found on the FIMR/HIV National Resource Center website (www.fimrhiv.org).

During project years 2009-2012, about one-half of all FIMR/HIV programs had to go through the IRB process. This process takes time and effort and involves both a written response to a lengthy set of questions about the program and possibly one or two formal meetings with members of the Board. Many IRBs meet only quarterly, so it's possible that 6–9 months could elapse before approval can be obtained. If a program knows that it must pass the IRB approval process, it's important to get placed on their meeting agenda as soon as possible. Here are some general tips in dealing with IRBs:

- Be aware that FIMR/HIV might be unique among types of proposals the IRB has reviewed
- Be prepared to briefly describe the underlying purpose of FIMR/HIV (i.e., continuous quality improvement versus research), but only do so if it's requested. Too much information shared about FIMR/HIV during the actual IRB process may confuse the Board and extend the approval process
- Respond promptly to written and oral questions from the IRB
- Answer only the questions asked; do not volunteer extra information
- Seek advice; try to recruit a colleague who has already gone through the IRB process and knows Board members

Assistance and examples of IRB applications can be found on the FIMR/HIV National Resource Center website **(www.fimrhiv.org)**.

Child Abuse Reporting Laws

All states have laws that require physicians, nurses, social workers, teachers and other health and human service professionals to report suspected child abuse and neglect. These statutes all confer immunity from civil and criminal prosecution upon those reporting. The FIMR/HIV program is bound by these requirements.

Experience from FIMR/HIV programs indicates that having to report abuse or neglect is extremely rare. As stated earlier, cases with pending or expected litigation should be avoided. Additionally, it is unlikely that a mother will invite an interviewer into her home if there is an ongoing abuse problem involving other children or family members. It is important that program staff understand abuse reporting requirements in the event that the maternal interviewer observes abuse or neglect in the home or the case review itself leads the team to suspect abuse or neglect. **The maternal interviewer who observes or suspects abuse or neglect in the home must report it.** If the case review uncovers suspected abuse or neglect, it is the program director's responsibility to report it to the appropriate agency. Each geographic area may have a different reporting system, and the specific local reporting method should be determined before case reviews begin.

Establishing Systems to Maintain Confidentiality and Anonymity

Because FIMR/HIV is collecting HIV/AIDS related information about cases, each FIMR/HIV project is required to adhere to the CDC's National Center for HIV/AIDS, Viral Hepatitis, STD and TB Prevention Data Security and Confidentiality Guidelines. These guidelines establish standards of data protection programs should have in place to ensure the secure collection, storage, and use of data while maintaining confidentiality.

Preserving the privacy of all involved parties is of paramount importance to FIMR/HIV programs. Local providers and institutions will not participate in the process or provide records for review without assurance that all information will be kept confidential. The planning group needs to be aware that the following information must be kept confidential:

- Names, dates of birth, addresses, telephone numbers, email addresses, and other contact information for participants
- Names, addresses, telephone numbers, email addresses, and any other information that would identify providers (individuals, hospitals, clinics, etc.)
- Any documents that contain the name or medical record number for participants
- Completed medical record abstraction forms

Ten Guiding Principles for Data Collection, Storage, Sharing and Use to Ensure Security and Confidentiality[4]	
1.	Public health data should be acquired, used, disclosed, and stored for legitimate public health purposes.
2.	Programs should collect the minimum amount of personally identifiable information necessary to conduct public health activities.
3.	Programs should have strong policies to protect the privacy and security of personally identifiable data.
4.	Data collection and use policies should reflect respect for the rights of individuals and community groups and minimize undue burden.
5.	Programs should have policies and procedures to ensure the quality of any data they collect or use.
6.	Programs have the obligation to use and disseminate summary data to relevant stakeholders in a timely manner.
7.	Programs should share data for legitimate public health purposes and may establish data-use agreements to facilitate sharing data in a timely manner.
8.	Public health data should be maintained in a secure environment and transmitted through secure methods.
9.	Minimize the number of persons and entities granted access to identifiable data.
10.	Program officials should be active, responsible stewards of public health data.

4 Centers for Disease Control and Prevention, Division of HIV/AIDS Prevention. National Center for HIV/AIDS, Viral Hepatitis, STD, and TB Prevention. *Data Security and Confidentiality Guidelines for HIV, Viral Hepatitis, Sexually Transmitted Disease, and Tuberculosis Programs.* Available at: http://www.cdc.gov/nchhstp/programintegration/docs/PCSIDataSecurityGuidelines.pdf

- Completed maternal interview forms
- Any other forms or papers containing individual case information
- Case summaries, including de-identified case summaries
- Any other documents with descriptions sufficient to identify the case

All hard copy case documents must be clearly marked "Confidential" and kept in a locked file cabinet. Case summaries must be de-identified and destroyed after the case is reviewed, along with all case documents. If state law permits document shredding, a shredder dedicated to the FIMR/HIV program is a worthwhile investment. After the case is reviewed by the case review team, all paper records of the case should be shredded, if the state law permits. Any records that link the FIMR/HIV case number to a family's name should also be destroyed. For more information on how data entered into the FIMR/HIV data system can be used and stored, please see Chapter 8.

FIMR/HIV staff and case review team members' knowledge about the facts of the cases also is confidential. Discussion of cases should only be behind closed doors, and then only for the purpose of developing better insight into the problems presented in a specific case. An example pledge of confidentiality form is available on the National Resource Center website **(www.fimrhiv.org)**.

The potential for harm to program participants and to the program itself is great if confidential information is not properly contained. Staff should always err on the conservative side if unsure about how to treat a document. Being overly cautious about confidentiality is best. In one jurisdiction, charts are reviewed on-site and information is entered directly onto forms stored on a secure website, eliminating the need for carrying around sensitive information.

In summary, the FIMR/HIV process must be confidential at every level:

- All abstracted medical records, maternal interviews, and elated records are stored in locked files
- All identifiers (e.g., patient names, dates of birth, provider names, hospitals or clinic sites) are deleted from the abstracted records and maternal interviews
- Case review summaries are anonymous
- All case review team members must sign a pledge of confidentiality at each meeting that prohibits them from discussing review specifics outside the team meetings (see forms)
- The confidentiality of reviews is protected by relevant state statutes

As the planning group is laying the groundwork for a new FIMR/HIV program they may be asked to respond to professional or institutional concerns that the reviews could result in censure of providers or institutions. The planning group needs to continue to stress the strict confidentiality of the model and review the safeguards provided above. Providers and institutions need to be reminded that the abstracted information is de-identified. It is unlikely that providers or institutions could be connected to actual cases, and in that unlikely event, such information usually is categorized as hearsay and would not be admissible in any type of legal action.

Establishing a System to Identify Cases

All FIMR/HIV programs need to develop a timely system to identify perinatal HIV exposure and transmission cases well before they have begun case reviews and interviews. It is important to identify cases in a timely fashion in order to 1) ensure that the mother can be found and asked to participate in the interview; 2) begin the process of abstraction of medical records; and 3) ensure a timely review of cases by the case review team.

There are a number of ways FIMR/HIV programs have identified cases, including:

- Referrals through local hospital or other HIV case management programs;
- Through health department surveillance; and,
- Referrals from HIV care providers, high-risk OB clinics, and pediatric HIV care providers.

Selecting Data Collection and Process Methods

The primary objective of the FIMR/HIV process is to identify and address systems factors contributing to missed opportunities for perinatal HIV prevention and treatment. The information gathered will create a narrative summary of what happened in each case. To facilitate this process, standardized data collection forms have been developed, revised, and updated based on the experiences of the pilot projects and existing FIMR/HIV programs. These forms were developed to collect a wide range of information that enables the process to capture the uniqueness of each case, while at the same time maintaining structure and consistency. In addition, a CDC-developed FIMR/HIV web-based data system allows sites to: store de-identified

case information in a secure, password protected location; compile case information into customizable and printable reports to share at CRT and CAT meetings; and run analyses of site level data. Sites are strongly encouraged to use this system and can modify the reports to fit local needs. These data collection forms and link to the database can be found on the FIMR/HIV National Resource Center website (**www.fimrhiv.org**).

Identifying Costs and Funding Sources

The most frequently needed resources for FIMR/HIV relate to the collection, review and reporting of information. These include, in descending order of cost and importance: dedicated staff time (for medical record abstraction, maternal interviews and overall program coordination), clerical services, space, duplicating, printing and mailing, and food for meetings.

One approach to estimate the cost of the FIMR/HIV program is to calculate the percent of full time equivalent (FTE) staff salary needed for the FIMR/HIV co-lead position. The FIMR/HIV co-lead position usually ranges from .05 to .15 FTE, often with generous in-kind contributions. This cost will vary by state and county salary scales.

Funding sources for FIMR/HIV programs vary. While many programs have benefited from seed money from federal or private sources, these temporary, one-time-only funds are intended to help communities get started and to develop long-term local support. For long-term implementation, some programs are funded by their state or local health department HIV prevention funds, while others are using money from the Title V Maternal and Child Health Program or funds from the Ryan White HIV/AIDS Program.

Regardless of the original funding sources, successful local FIMR/HIVs are increasingly savvy and resourceful. They are able to build a variety of local partnerships and find creative short-term and long-term funding to sustain their efforts, such as:

- Non-profit organizations (e.g., March of Dimes; Healthy Mothers, Healthy Babies Coalitions) may provide space and equipment and printing costs.
- Businesses may provide direct support as well as space, equipment and printing costs. One program receives donations of free food from local restaurants for the case review team meeting.
- Private local foundations may be willing to provide start-up funds for staff salaries.

Formalizing Policies and Procedures

During the planning process, the planning group should begin to keep a written record of the emerging policies and procedures for conducting the FIMR/HIV program. These guidelines will be the program's detailed description and road map. The guidelines will evolve and expand as the program grows, and should be revised on an annual basis to reflect the most current policies. This will be even more important if two or more agencies implement the program jointly. A table of contents of written policies and procedures may include, but is not limited to:

- Written description of the program mission statement, goals and objectives
- Job descriptions (e.g., director, coordinator, interviewer, abstractor)
- Case review team (CRT) and community action team (CAT) responsibilities
- CRT and CAT rosters
- CRT and CAT meeting format
- Methods for obtaining consent
- Methods for maintaining confidentiality
- Methods for finding cases
- System to select and prioritize cases
- Methods for finding and contacting mothers
- Methods for conducting maternal interviews
- Methods for conducting medical records abstraction
- Forms used by the program

All of these forms and sample job descriptions can be found at the FIMR/HIV National Resource Center (**www.fimrhiv.org**).

CHAPTER 3:
BUILDING THE CASE REVIEW AND COMMUNITY ACTION TEAMS

Introduction

The FIMR/HIV planning group must recruit case review team (CRT) members, and community action team (CAT) members to represent a broad spectrum of the community. Team members should include policy makers, representatives from organizations and professional groups, as well as consumer and advocacy groups.

This chapter describes important aspects of building community support and collaboration for FIMR/HIV. Chapter 2 focuses on the steps the planning group should take to develop the programmatic features that lay the groundwork for the program. Please note that while these two sets of activities appear in separate chapters for descriptive purposes, the planning group should work on them concurrently. Building community support and collaboration for FIMR/HIV and developing its programmatic features usually takes 6-8 months.

Selecting the Right People to Get the Job Done

Choosing the right mix of individuals to serve on the FIMR/HIV CRT and CAT is crucial to the success of the program and requires careful planning. According to experts in building community alliances, and echoed by the experiences of many traditional FIMR programs, membership should include individuals who will bring diversity, influence, commitment, and consumer participation to the table.[5]

Diversity requires that both the CRT and the CAT memberships represent a wide array of personal and professional knowledge, expertise and experience, the ethnic and cultural diversity in the community, and a broad, creative range of organizations including some who may not have been included in traditional maternal and child health or HIV/AIDS consortia. Choosing members who exemplify multi-cultural partnership, family/consumer-community service agency partnership, multi-agency partnership and public health-private provider partnership is vital to building FIMR/HIV team diversity.

It can be expected that the different opinions brought to the table by such a diverse membership may make for some lively and at times even divisive team meeting discussions, especially during the first year of the project. However, this type of group interaction is a positive sign because it paves the way for establishing the common ground of understanding that is critical to FIMR/HIV review and action and adds team sensitivity to the many cultural values, attitudes and beliefs in the community. Finally, this diverse membership on the CRT and CAT team membership sets a community standard of cooperation and mutual respect that should be a model for individual team members, their respective organizations and the community as a whole.

Influence refers to policy makers, institutional and professional leaders, and/or organizational spokespersons who have the power to make decisions for and mobilize fiscal and programmatic resources on behalf of their constituencies, agencies or organizations. Team members with influence will usually be the leaders in charge of a specific agency, organization, an elected official, or a high level staff member clearly entitled to represent them and make decisions. Some examples of these types of team members would be a director of a local HIV/AIDS treatment facility, a local HIV planning council member, a supervisor of a maternal and child health program at a local health department, a representative from the perinatal network system, a Title X representative and/or a chief of OB/GYN or Infectious Diseases at a local hospital.

Commitment refers to a team member's proven track record of putting what is good for women, infants and families before what is expected or convenient for his or her own organization or professional interest. Commitment means that the member already has demonstrated the ability to act as an advocate or champion for improvement in systems even when deeply-rooted and long-standing policies or interests oppose such change. However, not all team members come to the table as proven community advocates; mobilizing this spirit of commitment, especially among new or younger community members, is one of the overall benefits of active participation in the FIMR/HIV process.

Consumer participation should be an integral part of the FIMR/HIV process from the beginning. In general, consumers are individuals who live in the community chosen for FIMR/HIV and use its services and resources. Some FIMR/HIV programs have used peer leaders and consumers at HIV care centers on

5 Melaville AI, Blank MJ. Together we can: A guide for crafting a profamily system of education and human services. Washington (DC): U.S. Government Printing Office; 1993

both their CRT and CAT. These participants bring an important voice to the discussions of how to improve care and services to women and families across all systems.

Bringing the consumer perspectives into the FIMR/HIV process is essential to broadening the knowledge base and creativity of the teams and greatly enhances the character of the actions that will be developed and implemented. Because FIMR/HIV team membership requires active participation in divergent and occasionally heated group meetings, consumers who already have some experience in community advocacy groups seem better able to cope with those dynamics and actively join in the discussions. Members may be recruited from hospital or health center community advisory boards, faith-based organizations, civic groups, tenant groups, advocacy groups, and community development organizations. In order to ensure community representation, the planning group should make a special effort to identify and address any barriers (e.g., transportation, child care, etc.) that may make it difficult for community members to participate.

Characteristics of a Successful Team

DIVERSITY	• Adds sensitivity to cultural values, attitudes, and beliefs in the community • Sets community standard of cooperation & mutual respect
INFLUENCE	• Power to make decisions & mobilize fiscal and programmatic resources
COMMITMENT	• Act as an advocate/champion for improvement in systems • Proven track record of putting what is good for women, infants and families first before what is convenient or expected
CONSUMERS	• Essential to broadening knowledge base & creativity of teams • Enhances character of the actions that will be developed and implemented

Choosing Case Review and Community Action Team Members

CRT Members

Some community stakeholders will be more appropriate participants on the CRT. CRT members should represent consumers as well as professionals. Some examples include:

- Local health department (including HIV data expert) staff
- Primary and tertiary care institutions
- Obstetric and pediatric providers
- HIV/ID clinicians
- Hospital administrators
- Medicaid supervisors
- WIC program nutritionists
- Family planning services providers
- Health educators
- Community health workers
- Ryan White Program providers
- Substance abuse providers
- Child protective services professionals
- Women's correctional services professionals
- Mental health ptrofessionals

Ideally, a successful CRT will have no less than 15 members.

When developing the CRT, it will often be helpful to identify existing groups or committees in a community that have similar focus areas to FIMR/HIV (e.g. MCH, HIV). One FIMR/HIV program used their existing FIMR case review team (which included a wide variety of agencies providing MCH and social services) and added infectious disease experts to create their FIMR/HIV case review team. Another FIMR/HIV program that was starting from scratch used a wide variety of HIV providers and support services and then added representation from MCH and other social service agencies (e.g. someone from the Department of Children and Family Services).

CAT Members

Other individuals and agencies/organizations will collaborate to implement change through the CAT. The CAT is composed of two types of members: 1) those with the political will and fiscal resources to create large-scale system change and 2) members who can define a community perspective on how best to create the desired change in the community.

Here are some example agencies/individuals represented in a FIMR/HIV CAT:

- Medical Director – Ob/Gyn
- MCH Director
- HIV prevention services manager
- HIV surveillance manager
- Executive director of AIDS/HIV service program
- Mental health/substance abuse program director
- Ryan White program manager
- Perinatal Prevention Workgroup for HIV (e.g. AETC, pediatrician, epidemiologist, HIV prevention, Office of Drug Control Policy, surveillance)
- WIC
- March of Dimes
- Area director for family services
- Perinatal services director
- Hospital risk-management specialist

Many communities already have a functioning group or perinatal initiative that has the characteristics necessary to fulfill the role of the CAT. This includes entities such as a prenatal/perinatal regional consortium, a community advisory board, a Healthy Mothers, Healthy Babies Coalition, or a consortium for a federal Healthy Start project. One important lesson learned from FIMR and FIMR/HIV programs is that it is important not to form a new and distinct FIMR CAT unless no other comparable group exists in the community or the group is working to capacity.

Identifying & Recruiting Members

When developing a preliminary list of potential FIMR/HIV CRT and CAT members, it may be useful to consider the following questions:

1. Does the list include a broad-based, multi-partner array of agencies and individuals?
2. Does the list include consumer advocates that represent the diverse ethnic and cultural make-up of the community?
3. Are there sufficient members with the desired level of influence and administrative responsibility included in both teams?

To keep team size manageable, it may be useful to look for potential members who "wear two hats" and represent more than one constituency or point of view. Examples: a practicing obstetrician who also heads a local medical society or a pediatrician who provides well-baby care in a public health clinic.

After potential CRT and CAT members have been identified, the planning group should begin to recruit key members. As these members come on board, they can use their influence and connections to recruit other potential members and partners. When approaching potential members, the planning group should be prepared with the following information:

Understand the organization's mission or purpose and any current issues the organization is facing

Communicate specific ways the organization might assist the FIMR/HIV program and know which team (CRT or CAT) the member would best serve

Describe the purpose and objectives of the FIMR/HIV process in simple terms

Explain why the community would benefit from the FIMR/HIV process and how the process would specifically benefit the organization's mission or purpose

Reinforce the rigorous confidentiality of the FIMR/HIV process and be able to address any specific issues of concern

Facilitate a candid discussion about the potential member's view of the FIMR/HIV process and be able to respond to specific questions or concerns

The FIMR/HIV National Resource Center has developed sample invitation letters to solicit participation on the CRT and CAT. Also, the FIMR/HIV National Resource Center website can provide a great way to market the methodology and help explain the steps in the FIMR/HIV process **(www.fimrhiv.org)**.

CHAPTER 4:
ABSTRACTING MEDICAL RECORDS AND CONDUCTING THE MATERNAL INTERVIEW

Introduction

Once the program development is complete and community support is ensured, the sponsoring agency should begin identifying agency staff that will be responsible for abstracting medical and related records and conducting home interviews. Basic descriptions of the roles of the medical record abstractor and home interviewer are presented in this chapter.

Additional information about these two essential FIMR/HIV responsibilities can be found at www.fimrhiv.org, including sample job descriptions for each position.

You can also find detailed references for each new home interviewer included in the Fetal and Infant Mortality Review: A Guide for Home Interviewers (2003)[6] and a webcast titled FIMR Home Interviewing at www.nfimr.org.

Practical experience suggests that people most likely to thrive in the labor intensive and emotionally challenging roles of FIMR/HIV staff include professionals and paraprofessionals, especially community residents, who:

- Are flexible and creative
- Are team players
- Are self-motivated and self-select to work on the FIMR/HIV program

- Have experience in the maternal and child public health sector or in HIV/AIDS work
- Genuinely appreciate the cultural diversity of the community and the assets and strengths of families
- Understand and respect community values

Abstracting Medical Records

Medical records abstraction is a core component of FIMR/HIV. Abstractors should have sufficient experience with obstetric, pediatric care, and HIV care so as to be able to understand the information they abstract. Generally, nurses are well-equipped to conduct FIMR/HIV abstractions. Physicians, social workers and other public health professionals, such as surveillance staff, have also been used by various programs.

The abstraction process takes time and information from one record may uncover another source of information for the mother or infant not previously identified. Initially, abstractors will concentrate on the birth certificates, hospital records for delivery, HIV care records, newborn assessment or newborn intensive care, prenatal records and any additional records related to HIV care. For complete HIV treatment and prenatal and pediatric information, additional data may need to be obtained from private providers, as well as public health clinics, community case management providers, emergency room visits and other sources.

Obtaining access to records

Prior to beginning records abstraction, the FIMR/HIV planning committee will have established the method for obtaining access to medical records. This process may have entailed 1) making sure that there are state statutes to allow access to records, 2) complying with HIPAA regulations, and 3) going

6 Shaefer J, Noell D, McClain M. Fetal and infant mortality review: A guide for home interviews. American College of Obstetricicans and Gynecologists, National Fetal and Infant Mortality Review Program; Washington (DC): ACOG; 2003

through the hospital's IRB process or establishing some other type of agreement between the sponsoring agency and the hospital. Also, each institution's medical records staff will want information about the FIMR/HIV program, such as who will be examining the records, how many records are expected to be involved, and how often the abstractor will be coming to the hospital.

It is important for the abstractor to establish good working relationships with the medical records staff of each setting where records will be abstracted. Medical records staff may also want to examine the abstraction forms. Follow-up meetings with administrators and medical records directors may also be necessary. Taking time to lay the groundwork with the medical records staff will pay off in long-term cooperation. The abstractor should also make the program's year-end written report available to hospital staff. One site uses a general letter of introduction from the department of health to explain the purpose and intent of the abstraction process and the letter is sent in advance of the abstraction appointment.

Records from private providers may be more difficult to obtain. Release of information from private providers is voluntary and usually not covered in the state laws that allow for release of hospital records. A letter about the program and a sample of the abstraction form may dispel any fears and encourage participation from private providers. Also, it is important to identify which office staff the abstractor will be contacting to request medical information. Physicians' schedules are hectic, and it is likely the office manager or nurse will be the gatekeeper of the records. The fewer number of office staff involved in the requests the better. Keeping a confidential communication sheet with the record to note the names and titles of staff in each office with whom the abstractor talks is a good way to keep track of case contacts and communication.

While abstracting medical records for FIMR/HIV, it is useful and important to also collect information on the adult and pediatric HIV surveillance case report forms and provide them to the HIV surveillance staff in the health department.

Procedures and tips for abstracting records

1. Call hospital(s) to arrange to review records. Be sure to agree upon a time to examine the records. The record room usually will be able to pull the requested record within 24–72 hours.
2. Assemble a packet for each case containing the appropriate abstraction forms and case identification information for the mother and infant (names and dates of birth), as well as the relevant HIV surveillance report forms.
3. Identifying information should be stored in a locked file and carried in a locked car for the trip to and from the hospital. Each abstraction form should contain only the case number; no identifying information should be written on the forms.
4. Review records only in designated areas of the hospital. Do not photocopy any portion of the record.
5. Determine if additional records should be requested from private providers' offices or other facilities.
6. Contact private providers to arrange to review records.
7. Document pertinent laboratory results.
8. Circle discrepancies in information to keep track of differences.
9. Record any supporting information that will help in writing the case summary.
10. Keep a record of barriers encountered during abstracting, such as access difficulties, discrepancies in documentation, illegibility, and lost records.

How long does abstracting take?

It is difficult to calculate the exact time to abstract a FIMR/HIV case. Some cases are more involved than others, and in some cases records may be missing. Records for some cases will be available in a single location, while in other cases the records may be in various locations and additional travel time will be required. In general, a typical case takes 2-4 hours, although beginning abstractors will need extra time to become comfortable with the forms.

Obtaining additional information on a case

Additional information, other than from the interview and medical records, can be important in developing a case summary. Most commonly, additional information comes from social services agencies, including those that administer Medicaid, WIC and other benefits, and child welfare. Speaking with HIV care and other health providers, where appropriate, may provide more details not documented in the medical records.

Social services agencies and other public health programs

Agencies that administer programs such as Medicaid, WIC and food stamps are important to FIMR/HIV in determining whether the people who should be receiving such services are in fact getting them. Records from such programs can point out the barriers that families face while trying to establish eligibility and receive assistance. These records also point out duplication of services or efforts, or cases where providers are over-burdened with paperwork or other tasks.

Other public health agencies, such as family planning, public health nursing and infectious disease programs should be approached for information when necessary. Information from these agencies can be used to determine whether services are reaching those in need, and for identifying barriers to receiving services. This is of course critically important when looking at the care and treatment of a mother and/or infant for HIV services. Privacy and confidentiality must be observed with these agency records as well.

Conducting Maternal Interviews

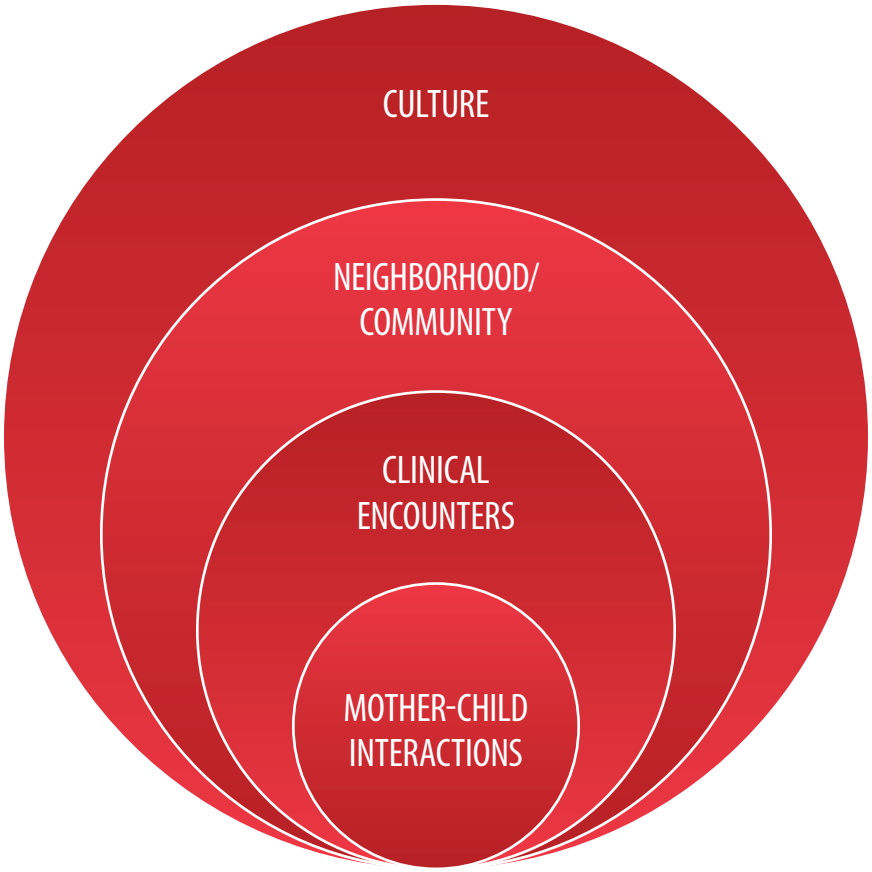
As in the traditional FIMR, the cornerstone of FIMR/HIV is the maternal interview. The maternal interview provides the mother's perspective and allows her to tell her story in her own words. The information obtained in the interview is often not found in health records. FIMR/HIV team members report that the maternal interview provides some of the most valuable information in the review.

The interviewer conveys the mother's story through the case summary presented to the case review team (CRT). Through them, the voice of the mother reaches the community at large. The mother's information allows team members to gauge the extent to which services and community resources for women with HIV infection are available, accessible, and culturally appropriate. Team members can more readily identify areas of deficiency or inequality in service delivery systems for women with HIV infection and can begin to address these problems more effectively.

The intent of the FIMR/HIV maternal interview is to:

- Learn about the mother's clinical and social experiences before, during and after pregnancy
- Learn about the infant's care at delivery, in addition to general medical care and HIV care during the first six months of life
- Mother's report of child's health status
- Identify community assets and deficits that affected the mother's life during the pregnancy and after the birth of her infant
- Accurately summarize and convey the mother's story of her encounters with local service systems to the community through the FIMR/HIV case review
- Assess the family's needs and provide culturally appropriate referrals for health and social service needs

Areas Explored During the Maternal Interview



The FIMR/HIV interviewer

Training in the FIMR/HIV process, which includes interviewing and active listening techniques and cultural competency, is necessary before the first interview is scheduled. It is also essential to have knowledge of community resources and the ability to make a wide variety of referrals. The interviewer must be familiar with the cultural and ethnic groups in the community and be comfortable with home visiting.

The FIMR/HIV interviewer must be committed to maintaining strict confidentiality. Case information must be kept anonymous. Information about the mother, the baby, caregivers, and institutions that provide services to mother and baby cannot be discussed with colleagues. Locating mothers without divulging the purpose of the visit to others can be challenging, but it's important that the mother trust that the interviewer will protect her privacy. The FIMR/HIV program recommends interviewing mothers privately and separately from other family members.

The FIMR/HIV National Resource Center has developed a standardized home interview form to collect information about the mother's employment and living situation, her preconception and postpartum health information, her general prenatal care, her HIV care before, during, and after her pregnancy, her nutrition and other health habits, the delivery of the baby, information about her other children, information on the biological father, to whom she has disclosed her HIV status, any social services she received, life changes and social supports, and the child's health and HIV care.

Who should be interviewed?

The mother, if available and provides consent is interviewed because it is her experience and perspective can best inform recommendations for systems improvement. She is most likely the primary caretaker of the infant and can relate her unique experiences associated with pregnancy, labor and delivery, her postpartum health, and care of the infant, as well as the degree of satisfaction with the care that she and her baby received during that time. Because the highly personal and sensitive questions contained in the home interview concern information that the mother may not wish to divulge to anyone else, most FIMR/HIV programs interview the mother privately and separately from other members of the family.

Qualifications of the interviewer

Maternal interviewers usually are paid staff or paid sub-contractors. Most FIMR/HIV interviewers are appropriately trained public health nurses or social workers with extensive experience in general maternal-child health and/or perinatal HIV. Regardless of the interviewer's background, the right personal qualities are important. Mothers relate well to an interviewer who is sympathetic, mature, warm, sincere, non-judgmental, and interested.

Training the interviewer

Most FIMR/HIVs may link with an experienced FIMR program interviewer in their community/state to learn more about the interview process. Some FIMR/HIV sites may also want to speak to an interviewer at an established FIMR/HIV site. Role-playing the home visit and interview is important in any training sessions. Content areas that should be addressed include how to:[7]

- Contact and engage women
- Prepare to conduct the interview, including obtaining consent
- Provide support during the interview, including referrals to services and resources
- Listen and record, do not interpret
- Conduct a standardized interview including eliciting responses with open-ended and close-ended questions
- Maintain confidentiality (see below)
- Recognize public health and safety codes related to home visiting and pertinent reporting requirements
- Handle difficult encounters and recognize personal safety issues and when to conclude or omit an encounter
- Conduct a home assessment and refer for needed services

The FIMR/HIV National Resource Center can connect a new interviewer with an experienced FIMR/HIV interviewer. The Resource Center also has maternal interview training materials available for sites to download (**www.fimrhiv.org**).

7 Material in this section was originally prepared by Dani Noell, ARNP, MSN, Florida State Pregnancy Associated Mortality Review abstractor, FIMR coordinator and former medical record abstractor of the Broward County, FL Healthy Mothers/Healthy Babies Program.

Maintaining Confidentiality

The process of locating mothers requires maintaining strict confidentiality because the mother might be living with people whom she does not wish to reveal her experiences or HIV status. To avoid inadvertently revealing private information to anyone, the home interviewer should not mention the FIMR/HIV review by name or describe the purpose of the interview to others in the household or to neighbors. If the mother is not home, interviewers have asked neighbors or apartment managers when she might be home. The interviewer should only say something general, such as: "I am _____ from the county health department. I am conducting a state-wide Department of Health survey and I would like to know when (person to be interviewed) will be at home." For the same reasons, any mailings to the families should not include the name "FIMR/HIV Prevention Methodology program".[8]

Locating mothers

Locating mothers can be difficult. Some women move frequently because of poverty, unemployment, and/or unstable housing and do not leave forwarding information. Vital records usually have the mother's address, but not her phone number. If a woman has moved, the interviewer may be able to locate her by contacting family members, neighbors, landlords, the post office, or utility companies. The interviewer should gather as much information as possible from these other sources before setting out to visit the mother. However, when contacting any of these sources, the interviewer must remember to not mention the specific purpose of the interview. A detailed local map, a GPS, and a cell phone for emergencies are important tools for the interviewer.

Ensuring the safety of the home interviewer in her travels is an important issue that should be addressed before interviews begin. Networking with the local health department or home health agency that does the most home visiting in the community where FIMR/HIV operates will provide some practical insights into the safety of individual neighborhoods. Disease Intervention Specialists from health departments are also good resources and can often serve as interviewers. Safety is a relative issue and each community must identify local problems that put the home interviewer at risk.

How long does a home interview take?

The answer to this question depends on how long it takes for the mother to tell her story, and how long it takes to complete the standardized questionnaire provided by the National Resource Center. Some mothers have much to say and many questions to ask as the home interviewer may be the first and only person that the mother has had an opportunity to talk about her experiences. It is safe to say that the whole interview process probably takes an average 1½-3 hours and may be done in one or two visits.

The interviewing process

When the interviewer greets the mother, she should introduce herself, tell the mother which agency she is from, and show her official identification. The mother should be fully informed about the FIMR/HIV process and the significance of her participation. The interviewer should emphasize the extent of the privacy and confidentiality offered by the program. If the mother agrees to participate, the interviewer should review the consent form with her and obtain her signature. The maternal interview consent form can be found on the National Resource Center website, www.fimrhiv.org. The interviewer should assure the mother that she can decline to answer questions and may terminate the interview at any time without fear of loss of any current or future services.

The best way to start an interview is to ask the mother to describe in her own words how she and the child are doing since the delivery. When the mother has completed her initial comments, the interviewer may proceed with the questionnaire. Throughout the interview, the interviewer should call the child by his/her name, if given.

The interviewer must adapt to the mother's environment, whether it's her home or some other location. The manner in which the interviewer is received and the way the interviewer responds to the mother influences the tone of the entire visit. A mother will be especially sensitive to any hint of criticism about her health, lifestyle habits or parenting skills. Unless there is a present danger to health or safety, any criticism should be avoided. The interviewer should be understanding and neutral, avoiding any expression of surprise, pleasure, approval or disapproval at any answer or comment.[9] Developing a "value-neutral therapeutic" interviewing technique will require some experience and skill.

When the interview is completed, the interviewer should thank the mother for her participation and give her the opportunity to relate any feelings or comments she may have about the interview process. Any immediate health or safety crises (e.g., no heat in winter, no food available, critical health problems for mother, baby, or other children), should be addressed. Any other referrals that the family needs or wants may be given at that time or in a follow-up visit or conversation.

Providing "tokens of appreciation"

Nearly all FIMR/HIV projects offer an incentive or a "token of appreciation" to women for agreeing to participate in the interview. These items are usually a gift card of about $50 and/or a gift package of diapers and other useful items. It is likely that agencies, such as health departments, have limits on the amount that can be offered or the type of incentive or other rules. Project sites should clarify if and what kind of incentives may be offered to participants.

8 Shaefer J, Noell D, McClain M. Fetal and infant mortality review: A guide for home interviewers. American College of Obstetricians and Gynecologists, National Fetal and Infant Mortality Review Program; Washington (DC): ACOG; 2003

9 1988 national maternal and infact health survey: Field representative's manual. Washington (DC): United States Department of Commerce, Burearu of the Census; 1988

How to handle home interview refusals

If the mother is reluctant to participate, the interviewer may try the following:[10]

- Explain that the program aims to complete interviews for as many mothers as possible to assure that the most complete information about services and resources in the community are documented.
- Explain that the information gathered from the interview will be used to look at ways to improve health and community services for pregnant women with HIV infection and their families. Also reiterate that her name will not be written on the interview and will be kept confidential.
- Ask the mother to begin the interview and answer one or two sample questions. Assure her that she is free to stop the interview at any time and that she can refuse to answer any questions that she thinks are too sensitive. Many times this approach encourages the mother to provide most of the information needed for the interview
- Offer to contact her in a few days or weeks to revisit the mother's decision to not participate.

10 1988 national maternal and infact health survey: Field representative's manual. Washington (DC): United States Department of Commerce, Burearu of the Census; 1988

CHAPTER 5:
BASIC TEAM BUILDING AND GROUP PROCESS CONCEPTS FOR FIMR/HIV PROGRAMS

FIMR/HIV programs conduct their business and create community change through a series of ongoing CRT and CAT meetings. Each meeting usually lasts from 2–3 hours but may vary by site. The quality and productivity of these discussions can make or break a FIMR/HIV program. To keep team members engaged, FIMR/HIV meetings must be well-run and efficient. These meetings must also result in action. This chapter discusses some basic content about group process that may be useful for FIMR/HIV programs to know.

Leadership

FIMR/HIV meetings require competent leaders who are responsible for meeting productivity and success. Each and every team member must also pledge to do their part to make meetings effective.

Leaders of the FIMR/HIV CRT and CAT come from many backgrounds, including but not limited to city government officials, county executives, HIV/AIDS health professionals, obstetricians/gynecologists, neonatologists, maternal and child health professionals, community advocates, substance abuse and mental health professionals, and child welfare staff, to name a few.

Team Functions

The main work of the FIMR/HIV teams is to review cases, make recommendations, and take recommendations to action. However, team members must realize that there is more to meetings than these tasks and that team work also involves process and maintenance functions that require time, energy, and hard work.

Resolving Conflict

While some FIMR/HIV team members dislike conflict, some disagreement is to be expected during early meetings. FIMR/HIV programs make a deliberate effort to bring together diverse, energetic community agency directors and community leaders as well as outspoken community advocates and families. These members are bound to have different priorities and raise different points of view. Initially, they may not agree about which community actions are most needed. This is not necessarily a bad development— a lack of conflict may mean that the group does not represent enough diverse opinions to have meaningful dialogue. FIMR/HIV communities benefit when membership is diverse and when the tone is set that all members are equal, free to voice their opinions, and can disagree with others on the team. Diverse teams are able to identify significant health and service system issues and are able to develop a range of high quality, community-sensitive, and culturally relevant actions to address these problems. Keep in mind that it is important to establish meeting ground rules, including appropriate ways to handle disagreement.

Compromise

Experienced FIMR/HIV team members are skilled at using compromise to move recommendations to action and should decide at the outset how they will reach agreement on controversial or sensitive actions. Plans for community action probably will not promote the opinions of any one faction and are more likely to reflect compromise among differing points of view. Compromise encourages diverse, multi-professional, and multi-cultural team members to reach a satisfactory, workable plan for the community's benefit.

Rewarding FIMR/HIV Team Members

FIMR/HIV programs should recognize and celebrate the work of their CRT and CAT members. Team members are volunteers and the ability to make meaningful change is dependent on their continued enthusiasm and support. Showing appreciation of team members is key to keeping them engaged in the process. Another approach is to celebrate positive actions: some group time should be dedicated to fun and affirmation of the strengths in the community. Another way to honor the work of team volunteers is to publicly acknowledge team work to the community at large, such as presenting team members with a certificate of participation that can be displayed in their offices.

FIMR/HIV Over Time

Membership

What happens to team membership over time? Some core team members will stay involved with the program over the long haul. Other FIMR/HIV team members can be expected to move out of the community, take new positions, retire or choose other volunteer activities. Recruitment of new, dynamic members is always critical to sustaining FIMR/HIV action.

Ongoing process

FIMR/HIV programs should not be discouraged when an identified problem is not fully addressed in a single stroke. Just as in the traditional FIMR, the FIMR/HIV process is a type of continuous quality improvement (CQI) that frequently occurs incrementally. Actions accomplished in one year often become the basis for building improvements down the road.

Benefits for FIMR/HIV Team Members

Enhanced interaction among FIMR/HIV team members in the community is a valuable by-product of the methodology. When a diverse group of people come together in a team, they build both professional and personal relationships while compiling in-depth information about the community. This information brings team members together, encourages new ways of thinking about the community, enhances respect and understanding of cultures different from their own, and generates fresh partnerships to create innovative resources and service systems. By virtue of coming together and learning about the community, the FIMR/HIV team builds unique, local partnerships that can last a lifetime and creates opportunities for community-strengthening outcomes.

CHAPTER 6:
ROLE OF THE CASE REVIEW TEAM (CRT)

The case review team (CRT) reviews and analyzes the information collected in the maternal interview and medical record data abstractions. The CRT processes the information and summarizes findings to create recommendations to improve the community's service delivery systems and community resources.

The process for case review should reflect the FIMR/HIV program's mission, and success depends on the team's commitment to this purpose. Continued success also depends on the team leader's ability to keep the team focused on the work that needs to be accomplished while engendering a spirit of team pride and ownership for the work that team members do through the program to benefit their community.

What CRTs Can Accomplish

The overall goal of the FIMR/HIV is to enhance the health and well-being of women living with HIV infection, their infants, and their families. This may be accomplished by improving the service systems and community resources available to them. Specific actions that relate to this goal include the following:

Review cases

The case review process is a distinguishing characteristic of the FIMR (and FIMR/HIV) methodology. Involving individuals from many disciplines and aspects of the community makes the case review findings and opinions especially valuable. When the CRT discovers information about the way community resources and services are provided to a pregnant woman with HIV infection, it can be the basis for creative problem-solving to improve overall health and related service delivery systems within the community. Discoveries can include sentinel events, trends, and incidental findings.

Sentinel incidents

Mother-to-child HIV transmission (MCT) is a sentinel event that in many instances could have been prevented. While MCT is relatively rare (about 200 cases annually in the U.S.), when it does occur, it can alert the community to problems or situations with services or resources for women with HIV infection that need prompt attention. The FIMR/HIV case review process identifies and presents the problems and issues clearly and often suggests a solution.

Trends

Over the course of time, several cases will identify similar problems or situations. Taken together, the cases will better illustrate a particular problem than if a single case were to be presented. For example, some FIMR/HIV sites have found issues with HIV testing (e.g. multiple hospitals in an area not doing HIV testing of pregnant women in emergency departments) or a lack of provider education on treating HIV positive pregnant women (e.g. a consistent lack of understanding about most current HIV care guidelines).

Incidental findings

Incidental findings are problems or issues uncovered by the FIMR/HIV process that are not necessarily part of the case review process. For example, during early program development, staff or team members may discover gaps in service delivery systems that should be addressed. For example, through case reviews in one community it was discovered that routine prenatal screening for domestic violence was not being done. In another community it was discovered that mothers were not being offered contraception education and prescriptions at hospital discharge. While these two findings might not be directly related to mother-to-child HIV transmission, they expose other gaps in services for all women living in these communities.

Develop initial recommendations for eventual action

The core of the FIMR/HIV process is: 1) a careful, thorough study of every case by the CRT to determine the adequacy of local systems of care and community resources for women with HIV infection, their infants and their families and 2) to make recommendations for their improvement. While a preliminary discussion of recommendations occurs at each case review session, recommendations are not finalized at that time. The team should be encouraged to think creatively and not be limited by feasibility.

The FIMR/HIV co-leads usually provide a brief update on the reviews at the CAT quarterly or semi-annual meetings. This brief update usually includes information about the process, e.g., number of meetings held in the time period and number of cases reviewed.

The FIMR/HIV co-leads will have kept a record of findings and recommendations. These findings should be presented to the CRT quarterly. After reviewing the findings, the CRT must identify and prioritize the major trends that require systems change. Team members should select 6–10 of the most important trends as recommendations to be sent to the CAT, selecting a mix of long-term (more than one year), short-term

(less than one year), and immediate actions. Refining and overseeing the implementation of recommendations is the job of the CAT and will be discussed in Chapter 7.

New FIMR/HIV programs often do not convene the CAT until year two of the project and the first set of recommendations will be presented at that time. However, once the CAT is up and running, recommendations from the CRT may be forwarded as often as the CAT meets (typically quarterly).

Taking action
Findings from review of cases may prompt CRT members to initiate some actions individually or jointly with other members and their organizations.

Individual. Many CRT members are powerful members at their own agencies or organizations and are in a position to stimulate or make changes in communications, availability of services, and access in the community. As cases are reviewed, a member may recognize a barrier or gap in services in his or her own agency and personally act as the agent of change.

Caution: Any specific information about FIMR/HIV case reviews or CRT proceedings that pertain to issues identified by a specific agency always remain confidential and cannot be shared by the team member as a rationale for encouraging his or her agency's system change.

Interagency or Joint Interventions. Sometimes case reviews point out a simple problem that rallies some or all of the CRT members to develop a limited action together. It is important for CRT members to consider what the overall community outcome of their decisions could be and to advise the CAT of their actions. The CAT can then consider whether to expand the scope of this intervention to other service providers or agencies.

What FIMR/HIV Case Review Does Not Do

FIMR/HIV case review is not about fault-finding or assigning blame. Blame cannot be determined with the subsets of medical information that are abstracted through this program. Comprehensive local and state professional peer review and public health and institutional quality assurance programs already are in place for the purposes of holding individual professionals and health care organizations accountable to adhere to practice standards.

CRT Orientation

It takes time for the individuals on the team to develop a process by which they can work together. Members of new CRTs (or new members of established teams) will need time 1) to become acquainted with the FIMR/HIV program goals and objectives, 2) to become familiar with the case summary format, and 3) to become comfortable with each other. Team leaders should plan at least one orientation meeting before introducing cases. Activities for this meeting should include the following:

- Give each team member an information packet, including a brief description of the FIMR/HIV program; program mission statement; FIMR/HIV staff and CRT rosters; a CAT roster if available; sample case summaries and forms; useful articles and other literature; a community resource guide if available; and a glossary of technical terms. Present these materials in a binder so that additional material may be added later.
- Have team members introduce themselves individually, telling their personal and professional backgrounds and current positions.
- Explain the need for absolute confidentiality and review the confidentiality protocol; members should sign and return their confidentiality oaths at this and at every meeting (see Chapter 2).
- Review the specific objectives of the FIMR/HIV case reviews and describe how these objectives will be carried out by the team.
- Describe how case information is collected and summarized.
- Review the roles of the CRT in developing recommendations and taking limited individual actions.
- Explain the relationship of the CRT to the CAT, and the process for sending the CRT's recommendations to the CAT and subsequent community action.

Once the CRT understands its role, the team should establish their operating ground rules, such as:

- Where, when and how often will the team meet?
- How will team members share responsibilities?
- What happens if a disagreement or problem arises?
- How will the CRT make its decisions?

Some of this may take place later after the team has been guided through a few reviews by the team leader.

An example CRT orientation meeting agenda template can be found on the FIMR/HIV National Resource Center website **(www.fimrhiv.org)**.

CRT Meetings

Preparing for subsequent CRT meetings

Summaries of 2-5 cases that include information from birth certificates, hospital records, outpatient records, related social services records and the maternal interview, if available, are prepared by FIMR/HIV abstractors or co-leads prior to the meeting. Using a case summary as opposed to actual medical records is essential to the FIMR/HIV process because it allows the program to organize and de-identify the information.

A case review summary can be generated from the FIMR/HIV web-based data system, which will organize data entered into the system from the medical record abstraction forms and the interview. The FIMR/HIV staff member preparing the summary, usually the co-lead or abstractor, will have the opportunity to write a brief case synopsis and include it in the case summary. The following information is an example of what the case summary will include, although the content of the summary will vary depending on what medical records are available for abstraction and whether or not an interview is completed:

- Clinical HIV care provided to the mother before, during and after pregnancy and to her baby during the first 6 months of life.
- Medical record information of the mother related to prenatal, delivery and postpartum care, in addition to general medical care. General care of the infant, such as well-baby visits and immunizations, are also included in the case summary.
- Living situation including financial difficulties, unstable housing and number of people living with the mother during pregnancy.
- Services or community resources the woman was known to have received or not received. If the family had obvious need for particular services, were referrals made? If referrals were given were they followed up? Were any particular reasons known why the family did not receive services?
- Stressful situations, social support, disclosure and trouble accessing care and services experienced by the mother.
- Any events that are relevant to the case, such as subsequent pregnancies, changes in the family, resolution of problems identified in the case, etc.

Remind the CRT members not to make copies of the summaries. If the summaries are mailed electronically prior to the CRT meeting, the e-mail should be marked "confidential" and formatted so that the e-mail may not be forwarded to anyone else. The team members should also be instructed not to share the downloaded e-mail document with anyone else, and the document itself should also be marked "confidential."

At the end of the meeting, all paper copies of the cases and case summaries reviewed should be collected from team members and shredded. Immediately after the meeting, any e-mailed cases should be retracted and deleted.

Conducting subsequent meetings

FIMR/HIV staff will coordinate and schedule all CRT meetings and prepare case summaries. If team members have received the case review summaries in advance of the meeting, they are responsible for bringing the summaries to the meeting. Some programs will wait until the meeting to distribute case summaries. In either situation, each team member must read and sign the confidentiality form before the cases are presented.

The FIMR/HIV co-leads usually present each case summary for discussion at the first few meetings. Subsequently, this responsibility may rotate among members, with assignments being made in advance. Case abstractors may also present the case. A discussion of the case follows the presentation. Programs typically allow 30–45 minutes for each case discussion, but the time frame may vary. Sites may use the FIMR/HIV CRT Deliberations form provided by the National Resource Center to guide discussion and document system gaps and weaknesses. Discussion points should include, but are not limited to:

- Did the mother and infant receive the appropriate clinical HIV testing and care?
- Did the mother and infant receive all the social services or community resources that they needed?
- Were the systems and services culturally and linguistically appropriate?
- What system gaps related to care, treatment, social services, and prevention and treatment are apparent or suggested by this case? Are there duplication of service systems?
- What does this case tell us about how families are able to access existing local services, care, and resources?

This discussion allows the team to develop a list of all possible issues related to the case. Identified issues should be recorded for all to see, such as on a white board or flip chart. Initially, this list may include as many as 10–12 suggestions for community improvement. If possible, the list should be narrowed to the three or four most important issues. This will facilitate the development of future recommendations and action plans that are based on the most important findings identified from cases over time. Issues identified with a case and recommendations can be recorded on the CRT Deliberations form and entered into the data system. This process can be done for all cases and will help projects track how many times a system issue or gap is identified across cases and record recommendations sent to the CAT.

FIMR/HIV CRT members need to accomplish a lot during each meeting. The average meeting is approximately two hours long and 2–3 cases will be reviewed. Prolonged discussion about any one case may hinder progress. Therefore, it is the team leader's responsibility to keep an eye on the clock and keep the discussion moving.

Most FIMR/HIV programs ask that the medical record data abstractor and the maternal interviewer participate in all meetings and be prepared to answer questions about issues that are not included in the case summaries or for clarification. FIMR/HIV program staff should be mindful of the need for strict confidentiality when called upon to provide additional information about a case and be careful not to divulge any information that might identify the patients, providers or institutions.

At the end of the meeting, all copies of the de-identified case summaries are to be collected by program staff and shredded. Program staff is responsible for preparing the minutes of the meeting in a timely fashion (within two weeks).

Meeting minutes and preparing recommendations

Meeting minutes are crucial to the process, as they summarize the decisions made by the CRT. The FIMR/HIV CRT Deliberations form can be used to document issues and decisions made by the CRT. Again a caution: When meeting minutes are being prepared, care should be taken to preserve the anonymity of the cases as well as the anonymity of comments and suggestions from individual team members. FIMR/HIV program staff will use these minutes to prepare a summary of cumulative CRT findings to present to team members on a regular basis, usually quarterly. These findings form the justification for recommendations. Keep in mind that it is equally useful to identify community assets as well as it is to determine systems gaps.

Report to the CAT

After a number of cases are reviewed and recommendations are made, the co-lead and/or a delegation from the CRT should formally report their recommendations for action to the CAT. This report usually is an oral report with an accompanying PowerPoint presentation. Suggested components of the report may include, but are not limited to:

- Number of meetings held
- Number of cases reviewed and total number of cases
- General availability of relevant information for the cases (includes maternal interview information)
- Trends—in issues, adequacy of services relative to the cases reviewed
- Priority recommendations
- CRT members' actions

Much of this information already will have been documented in the course of developing the periodic summaries for the CRT and in the FIMR/HIV web-based data system.

The CRT should take great pride in reporting their recommendations to the CAT. This formal report is the culmination of their thorough examination and consideration of case information. Their recommendations and rationale provide a strong argument for improving services and resources for women with HIV infection, their infants, and their families.

Group Process and CRT Member Participation

Rare is the team in which every member comes to every meeting. Despite the best efforts at recruitment and motivation, the reality of professional life is that other commitments will from time to time prevent members from attending. Some FIMR/HIV programs have solved this problem by having two professionals share one team seat (e.g., two pediatricians rotate every other meeting). On the other hand, it is important to emphasize to team members that the invitation to participate in team discussions is issued to each member personally and that the member may not delegate that responsibility without prior approval.

Over the long run, team membership may change. Some members may assume other job responsibilities or move from the community. Vacant spaces on the team should be filled as quickly as possible. The impact of changing team membership is felt most on the group's ability to have a consistent process from meeting to meeting. New members need to be oriented to the process, the expected outcomes, and the mission statement. It might be helpful to have new team members observe a meeting prior to active participation. Reviewing the CRT's mission statement and objectives with new team members and maintaining consistency in the case discussion format are two ways to ensure consistency over time.

Common Questions about the CRT Process

1. What should I do when one of the review team members has been involved with the case?

   The FIMR/HIV case review includes all of the systems of care that could have been involved with a case, not just medical and social services. At each meeting, before the case summaries are presented, remind the team that if any of them were providers for a case or know who the providers were, they should not identify themselves, others, or the institutions involved. Emphasize that if they have additional information about the case or if the information has been presented incorrectly, they should refrain from identifying themselves and not give out any additional information. That team member should contact the program coordinator following the case reviews. If necessary, the case can be re-abstracted for clarification or to correct any misrepresentation. Remember, the case review may include only information found in the records or obtained through the maternal interview, not anecdotal information from team members.

2. A team member wants to know the names of all the physicians or facilities involved with the cases. What should I tell him/her?

   FIMR/HIV is a systems review, not a peer review. Cases are anonymous and provider identifiers are never on file or recorded on abstraction forms. All forms are shredded after each case review meeting. The fewer the number of program staff in possession of identifying information the better. Additionally, remind the team member that all CRT team members and FIMR/HIV program staff have signed confidentiality agreements and that the provider information cannot be divulged.

3. What should I do if a team member identifies her/himself at a meeting as involved in a case?

   Self-identification as a provider on a case under review can and does happen. If it does, stop the conversation immediately and reiterate the confidentiality standards. Do not allow any non-abstracted information to be shared and ask the person to not divulge the names of other providers.

4. In what circumstances would the name of the family or the mother in a FIMR/HIV case have to be revealed?

   There is never a reason to reveal this information to the CRT. In the case of suspected child abuse or neglect, the mother or other involved family member would have to be reported to the appropriate authorities. Individual geographic areas have different methods to accomplish this, which should be determined before case reviews begin. Mothers consenting to the interview are notified of this provision before the interview.

5. In what situations is it appropriate for a CRT member to share information about FIMR/HIV findings prior to their formal presentation to the public?

   Sometimes, review team members are stimulated by CRT discussions and elect to initiate systems change in their own institutions before recommendations are made public. However, any specific information about the FIMR/HIV case histories or proceedings of individual CRT meetings that pertain to issues identified at a particular agency are confidential and cannot be shared as the rationale to encourage the change.

CHAPTER 7:
ROLE OF THE COMMUNITY ACTION TEAM (CAT)

CAT Role

The main goal of the Community Action Team (CAT) is to initiate systems change based on the case review team findings and recommendations. The ongoing role of the CAT is to:

- Develop solutions to improve services based on case review team (CRT) recommendations
- Enhance the credibility and visibility of issues related to women, infants, and families and for people living with HIV within the broader community by informing the community about the need for these actions through presentations, media events and written reports
- Work with the community to implement interventions to improve services and resources
- Determine if the needs of the community are changing over time and decide which interventions should be added or altered to meet them
- Safeguard successful systems changes initiated by FIMR/HIV that have been implemented from being discontinued in the future
- In the course of their work, the CAT may respond to issues that are broad or politically complex, that change over time, and that require substantial time and resources to implement change

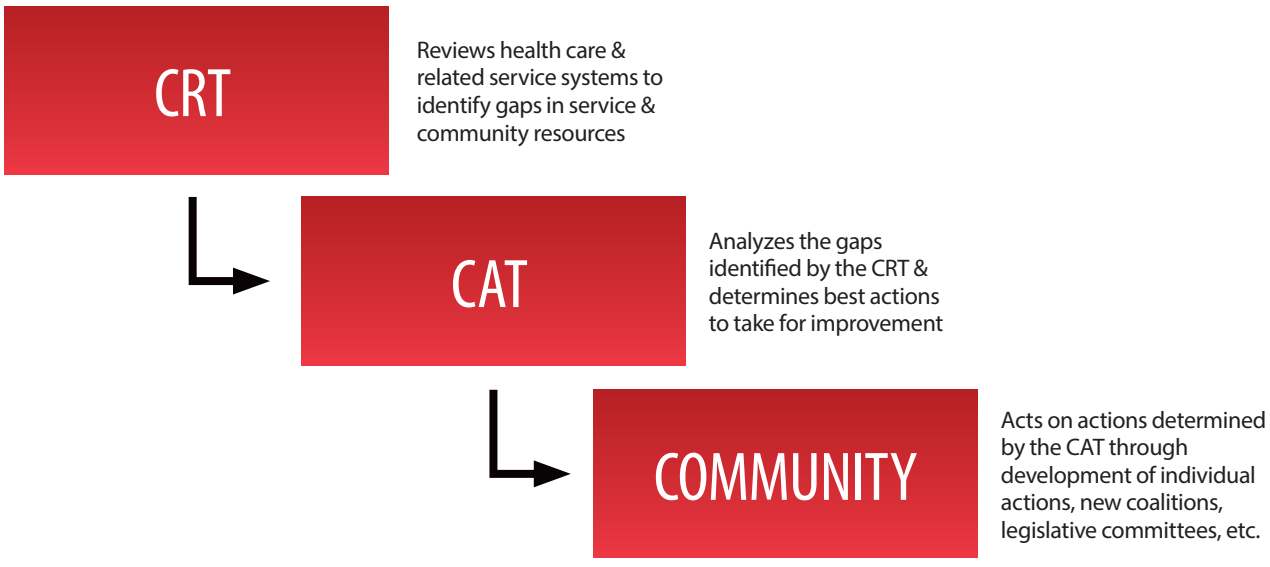
Relationships among the CRT, the CAT and the community

The relationships among the case review team, the community action team and the community are meant to be dynamic and responsive to community issues or problems. The CRT reviews health care and related service systems to determine if gaps in services or community resources exist, to document opportunities for improvement and to report findings to the CAT. For example, one CRT found that there was a recurring need in their community for ongoing case management services for women who are pregnant and have HIV. In response, the CAT helped develop an intensive case management training certificate for case managers working with high-risk pregnant women.

In response to findings reported jointly by these two groups, the broader community may act through the development of individual actions, new coalitions, legislative committees or other local organizations to improve service delivery and resources for women, infants and families.

Experience tells us that many communities already have a functioning group with the characteristics to fulfill the role of the CAT, such as a prenatal/perinatal regional consortium or a community advisory board. It may be appropriate or necessary to add a few new members from the community. The CRT reports its findings to the existing group with the

Relationship between the CRT, CAT & Community



understanding that that group would work to address the recommendations from the CRT and to facilitate change. It is important not to form a new and separate FIMR/HIV CAT unless no other comparable group exists in the community. The members would certainly overlap and be asked to do much more work. For that reason, the team members may then give less than optimal attention to FIMR/HIV.

In some communities, however, there may not be an already established group that can function as a CAT. In that case, the list in Chapter 3 is a good starting point for people who may be appropriate for a CAT. However, this is just a starting point.

Additional members may need to be invited based on the findings of the CRT and the types of service delivery systems that need to be changed. Example letters to new CAT members are available on the FIMR/HIV National Resource Center website (www.fimrhiv.org) and can be tailored to each community.

Given the strong working relationship between the CRT and the CAT, some CRT members may also be members of the CAT (e.g., Commissioner of Health, Director of Social Services, etc.). In addition, some members of the CRT may rotate onto the CAT after several years of service and vice versa.

CAT Orientation

Members of a new CAT will need time to become acquainted with the FIMR/HIV goals and objectives, to become familiar with their role and responsibilities, and to become comfortable with one another. A portion of the first team meeting should be devoted to orientation. Activities for this meeting are somewhat similar to the CRT orientation meeting and should include the following:

- Give each team member a packet of information. This should include a brief description of the FIMR/HIV program, program mission statement, FIMR/HIV staff and CRT rosters, the CAT roster, useful articles and other literature or data, a community resource guide if available and a glossary of technical terms. These materials can be presented to each member in a binder to which additional information can be added over time.
- Review the specific objectives for FIMR/HIV and describe how the CAT will carry them out. It may be a good idea to give team members information from this chapter.
- Describe how the case findings are developed by the CRT and how the CAT develops action plans based on these findings.

Translating Recommendations into Action

Following the annual receipt of recommendations from the CRT, the CAT is then responsible for ensuring that recommendations are translated into local action. The CAT must decide who will do what, when, and with what resources to improve services and resources.

To track their progress, the CAT can enter action items for their action plan in the FIMR/HIV web-based data system. The data system captures key information for documenting and monitoring progress: description of action step(s), person or agency taking the lead on the action step, timeline, resources used, status and outcome. The action plan can be updated to reflect changes in the status of an action item (e.g. in planning process, in progress).

Creating the Action Plan

The CAT works through several steps to create an action plan:

1. Develop a list of actions or interventions responsive to the issues and recommendations. This involves considering a range of actions, taking into account prior recommendations and actions, refining the CRT recommendations if necessary and/or including additional action strategies. Ideally, the plan should be:
   - Limited to a reasonable number of actions
   - Able to specify a person/agency that should be accountable for the action
   - Realistic in terms of resource requirements
   - Time-framed: short term (less than one year) or long term (more than one year)
2. Prioritize the actions as needed. Occasionally, the ideas for improvement may exceed the resources and capacity available for the year and priorities will have to be established.
3. Formulate a simple work plan for achieving the actions. In order to move forward on their priority actions the CAT also needs to determine:
   - A CAT team member/subgroup who volunteers to be responsible for overseeing the action
   - A practical means to check the ongoing status of the activity

Prioritizing FIMR/HIV actions

All CATs face the tough decision of identifying which of the many recommended actions will have priority for implementation. Ideas communities should consider in prioritizing their decisions include, but are not limited to the following:

1. *Building on Existing Initiatives.* Whenever possible, the CAT should choose actions that can build on the foundation of existing community services and resources. Building on existing initiatives helps ensure that actions can be sustained over time and that the FIMR/HIV process is integrated into the existing community infrastructure.
2. *Linking Community Action to Population-Based Information.* The process of finalizing an action plan can benefit from a review of community-specific vital statistics (population-based) information. That way, proposed actions based on case findings can be readily linked to similar problems documented in the larger population, if present.
3. *Taking Stock of the Political Reality.* CAT members must be politically astute and ready to seize all opportunities to promote their chosen actions when they emerge in the political arena. On the other hand, the CAT members might also need to ask whether proposed actions make sense in the local or state political climate and, of course, whether the answer should redirect their proposed course.
4. *Relying on Common Sense and Community Wisdom.* What if the CAT members decide that an action recommended by the CRT should be pursued even though it may be very difficult to achieve? If their local FIMR/HIV program is configured to include community legislators, leaders, services providers, advocates and consumers and is reviewing comprehensive case reviews with maternal interviews, they can be sure that they are looking at the big picture of service systems and community resources in their community. The team members should be confident that the FIMR/HIV process is an effective perinatal systems approach that can identify systems failures and instigate the appropriate actions needed to correct them.

Grouping people for action

By having the right decision-makers in the same room at the same time, the CAT could accomplish in minutes what would take an individual agency or provider weeks or even months to complete.

Other actions will be much broader in scope and may take several years to accomplish. Larger-scale activities also need to be handled more deliberately. For example, one FIMR/HIV program developed a letter to send to the state Medicaid Medical Director advocating for Medicaid coverage of long-acting reversible contraceptives at the time of delivery. This action is not something that can be easily changed at the local level and requires approval at the state-level, making it a long-term goal for the CAT.

There also may be situations for which the CAT creates a subcommittee of the CAT members to mobilize specific actions. An issue-specific taskforce can also be convened in instances where the issue requires expertise not available on the CAT.

Characteristics of Effective FIMR/HIV CATs

Although there is flexibility in how CATs are structured and managed, FIMR/HIV programs and their CATs that have functioned successfully for multiple years demonstrate a number of characteristics.

1. *Address a wide range of community actions.*[11] Rather than choose a single focal issue for action, existing FIMR/HIV programs can point to a wide array of issues they have identified and a comparable range of activities they have accomplished. They are flexible, capable of developing an action agenda on different fronts at the same time and able to enact plans that change over time.

   How do FIMR/HIV programs have the energy to identify so many issues and take action on numerous different fronts at once? The group motivation and passion for the betterment of woman, infants and families creates the momentum. Current FIMR/HIV leaders suggest that the interaction among diverse community participants generates ideas for action that exceed an individual provider or agency.

   Some FIMR/HIV programs also divide into subcommittees to move multiple actions forward. Subcommittees can be standing or ad hoc. Standing committees have been created to address issues that continue to confront the CAT or particular types of strategies. FIMR/HIV programs should recognize that selection of subcommittee themes, if desired, depends on the particular circumstances and issues of the community. Ad hoc committees form to undertake a specific action issue and dissolve once that issue is satisfactorily addressed.

2. *View improving services and resources as a continuing journey.* FIMR/HIV programs have come to understand that improving service systems and community resources is not a one-time job. Rather than becoming discouraged that a problem that has been identified cannot be addressed

11 American College of Obstetricians and Gynecologists, National Fetal and Infant Mortality Program. The fetal and infant mortality review (FIMR) process: A decade of lessons learned. Washington (DC): ACOG; 2000

fully in one single stroke, these programs realize that the most meaningful change frequently occurs incrementally. FIMR/HIV actions accomplished in one year often become the basis for building enhanced improvements down the road. A new FIMR/HIV action may advance and expand the previous actions.

Securing resources and saving costs

The CAT must come to the table being aware that all proposed FIMR/HIV actions will require resources. Resources can mean identifying staff, volunteers, products or services that can be leveraged for the good of the community or donated in-kind, as well as allocating existing local dollars or generating new funding sources. For each action that the CAT proposes for the community, members must think about what kind of resources are needed and where they can be secured. In these days of diminishing financial resources, it is important to ask local companies and organizations, and other entities viewed as community assets, to get involved in the action, including:

- Local March of Dimes chapters
- Networks of charitable organizations focused on communities
- HIV/AIDS service provider community
- Community-based foundations
- Pediatric and obstetric professional groups, medical societies or academic institutions
- Hospitals and MCOs
- Local businesses
- Local schools, churches, libraries and community leaders

Costs of actions/interventions are not usually borne by the FIMR/HIV program. Typically, the CAT mobilizes agency, institutional and community policies, programs, resources, capital and/or services to accomplish proposed changes.

Role of FIMR/HIV Staff

FIMR/HIV staff coordinate and schedule all CAT general meetings as well as subcommittee meetings, write the minutes in a timely fashion and assist the CAT in keeping the information in their documents current. Behind the scenes, the staff may find that they act as facilitators helping to smooth over an occasional misunderstanding between the powerful CAT members.

Recording the CAT Decisions and Progress of Actions

It is important to keep track of decisions about the CAT actions, work plan and subsequent progress. The CAT members responsible for each action can incorporate this information into the CAT form developed for FIMR/HIV. The Community Action Team Summary and Action Plan form describes the actions, responsible person/agency, timeframe, current status and outcome(s). This form can serve as a practical tool to track progress on the actions and any changes in the plan. Additionally, information from this form is part of the FIMR/HIV data system and can be used to keep track of the program's decisions, actions and outcomes.

Monitoring the Progress of FIMR/HIV Interventions

Critical to the FIMR/HIV process are the notions of assessing the status of proposed actions to ensure their implementation and securing information about system change in the community as feedback for the process. The continuous nature of the case review process provides a means for ongoing monitoring and feedback; however, it is up to the members of the CRT and CAT (with assistance from FIMR/HIV co-leads) to make this happen.

Examination of new cases over the long term by the CRT can shed light on whether a system or resource problem has been resolved, and reveal that new action has indeed been incorporated into systems of care. In the same vein, the CAT will need to check periodically on the extent to which they are able to obtain the desired information for their quarterly updates on pending actions. It is anticipated that input from the members on the CAT who represent the most important systems for women, infants and families will make this possible.

Monitoring selected actions into periodic community needs assessments (such as those conducted by the local health department) whenever possible is another strategy to track progress. In this way, the FIMR/HIV monitoring process becomes a part of the larger community assessment process.

CHAPTER 8:
THE CDC FIMR/HIV DATA SYSTEM

Purpose and Function

The primary purpose of the data system is to serve as a useful tool for sites to manage their FIMR/HIV projects. A secondary purpose is for the national FIMR/HIV partners to have access to sites' activities in order to inform broader, large scale initiatives.

The FIMR/HIV web-based data system is designed to:

- Help sites securely store the information collected in abstraction forms and maternal interviews
- Document and track outcomes from the Case Review Team (CRT) and Community Action Team (CAT) meetings
- Generate customizable reports
- Export site-specific data for analysis
- Manage data system user access and permissions

Using the Data System

The data system is housed on the CDC's server and is password protected. The CDC and the National Resource Center will work with sites to obtain access to the data system. Each FIMR/HIV site can only view and enter information for its own local project in the data system. All forms including the interview, recommendations from CRTs, and action plans from CAT meetings are programmed into the data system.

Because the data system is web-based, an abstractor can take a laptop to a health facility and enter the medical record information directly into the data system eliminating the need to use paper forms and then enter the information. However, this process may not be permitted by some institutions and/or your project's policies. Sites should discuss the possibility of using a laptop with staff and with providers and healthcare institutions before attempting to use a computer during record abstraction. It is not recommended to use a computer or laptop while conducting an interview.

Data Security

As with any project that collects sensitive information, maintaining security of the FIMR/HIV data system and the information stored must be ensured. The following is a list of details related to security for the data system:

- **User login:** Only authorized users with a valid user ID and password will be able to access the FIMR/HIV system.
- **Roles/Permissions:** Administrators will be able to grant/deny individual users permission to access certain functionalities of the FIMR/HIV system.
- **HTTPS:** The FHPM database will be hosted as an HTTPS protocol-based website. Hypertext Transfer Protocol Secure (HTTPS) is a combination of the Hypertext Transfer Protocol with the SSL/TLS protocol to provide encrypted communication and secure identification of a network web server. It is similar to the secure access provided by banks and other financial websites.
- **Hosted at CDC:** The FHPM Data System will be hosted behind CDC firewall and will be protected by CDC's security systems.
- **Remote/Central data storage:** Data entered by the user will not be stored locally in their computer. All data entered by the user will be stored in a SQL Server database which will be hosted at CDC.
- **Audit trails:** FHPM system will track the data entry operations and login operations of the users. Administrators will be able to verify the date and time on which certain operations were performed in the system.

The security measures highlighted above are in place to protect the data collected. Users of the FIMR/HIV data system should not share their passwords with anyone and should follow the security and confidentiality procedures described in Chapter 2.

Case Reports

The data system will generate a case report that organizes and compiles all data collected and entered for an individual case. This report can be used for CRT meetings and reduces the time required of FIMR/HIV staff to prepare meeting materials. Record abstraction information will be on the left side of the report and the corresponding interview questions will be on the right. For example, information on ARVs the woman took prior to pregnancy found in medical records will be displayed on the left side of the report. The mom's report of ARVs she took prior to pregnancy or reasons she was not taking ARVs will be shown right next to the medical record information on ARV use prior to pregnancy. This format allows a CRT to see what is in the medical record and how it compares with the mother's experience.

The case report includes an area for free text that will be displayed on the first page of the report for a co-lead or designated staff member to enter a case synopsis. The report can be converted into an editable format so FIMR/HIV staff can add notes or re-organize sections.

Analyzing and Using FIMR/HIV Data

Data from the data system can be exported into Excel if sites wish to run more complex analyses. A data dictionary will be made available on the National Resource Center website. While the data system is designed to help sites manage the large amount of information, FIMR/HIV projects are encouraged to share their data and findings with community leaders and at other venues, such as conferences or state-wide meetings.

The national partners have access to sites' data and will use the information to identify common issues and challenges across all FIMR/HIV sites. Viewing the information across all sites will help direct national efforts to eliminate perinatal HIV transmission. CDC and national partners can view information but cannot change or alter original entries made by sites.

Data System Administrators and Users

There are different levels of users for the data system. Each site will have a data system administrator set up by CDC and the national partners. The following briefly describes the user level and their permissions (e.g. creating new cases).

Site Administrator:
The site administrator will have a broad range of permissions to operate the data system but only for the administrator's local site. The national partners will help each site identify the best person to take on this role. Examples of permissions of the administrator include adding a new user for the site and assigning privileges for that user, resetting passwords for a user, and deleting a user from the system. The administrator can also have all of the site data manager functions (see Site Data Manager).

Data Entry User:
The data entry user can add forms, create new cases and enter data into the system. The site administrator will initially create the user account and assign any combination of privileges. The data entry user may also generate and edit reports, if assigned the privilege, and have all Site Viewer privileges (below).

Site Viewer:
The site viewer has a login and password for the data system for the local. The user can select a case and view the forms submitted for each case. The viewer can also read system generated reports. The viewer cannot edit or make changes to data entered or to forms.

Site Data Manager:
The site data manager can export data for the local site for data analysis and also access site generated reports. The site data manager may also have the privileges of the "site viewer" role.

After 6 months of inactivity the system's user account will be locked out of accessing the data system. The site administrator can unlock a returning user.

Structure of Case ID for the Data System

The case ID for the data system has between 6-9 characters. The data system will not allow duplicate case IDs. The following describes the structure of the Case IDs formatted for the data system.

Digits 1-3 are letters indicating the site. These will be assigned by the central data system.

Digits 4-5 are alpha or numeric and are free fields for each site's local use.

Digits 6-9 are enrollment numbers (each abstractor /interviewer will be assigned a block of sequential numbers, e.g., 1-100, 101-200, 201-300, etc.) and are assigned to new abstractors and interviewers as they are given data entry privileges. Only numbers are allowed in these fields.

Example: A new case is being abstracted in Newark by Jane Smith and is the first case to be entered in the data system. Each site will have letters already assigned by the data system for fields 1-3. The site decides to use abstractors' initials for the free fields 4-5. Because this is the first case being abstracted by Jane and entered into the data system, the enrollment number is 1. The site ID is NWKJD1

N	W	K	J	D	I	-	-	-
1	2	3	4	5	6	7	8	9

Summary

Detailed information and training resources on using the data system will be made available by the national partners. Sites can also contact the National Resource Center directly with questions.

CONCLUSION

In closing, the FIMR/HIV National Resource Center and its National Partners would like to remind readers that the FIMR/HIV Prevention Methodology is a continuous quality improvement process for identifying and addressing gaps in HIV and maternal and child health systems. The 2015 FIMR/HIV Manual of Operations is an important tool your community can use in the development and maintenance of your FIMR/HIV project. The FIMR/HIV National Resource Center houses not only materials for implementing the methodology, but also virtual learning modules and links to the most up-to-date resources in the area of perinatal HIV. To visit the National Resource Center, go to **www.fimrhiv.org**.

Thank you for your commitment to healthy families and a generation free of HIV!

Glossary

Case identification: "HIV-exposed infant/fetus ≥ 24 weeks gestation and < 24 months of age at the time of the review."

Case review team: Responsible for reviewing all information gathered for each case, identifying systems issues, and making recommendations for improvement.

Co-lead: Individual responsible for managing the FIMR/HIV program and associated tasks, planning, and staff supervision

Community action team: Responsible for initiating systems change based on CRT findings and recommendations

Data abstraction: Involves the review and abstraction of information from all available medical, hospital, public health and case management records.

Institutional Review Board: Agency whose purpose is to review all research proposals in order to ensure the validity and safety of the research

Maternal interview/home interview: Provides the mother's perspective and allows her to tell her story in her own words. This interview provides some of the most valuable information in the review, including prior HIV risk and information on pregnancy, labor and delivery, and postpartum care. (Please note: maternal interview and home interview can be used interchangeably.)

Priority assessment: A form used to help FIMR/HIV sites in selecting cases for review that are likely to illustrate potential gaps in maternal HIV care and the prevention of perinatal HIV

Acronyms

Case Review Team (CRT)

Community Action Team (CAT)

Fetal and Infant Mortality Review (FIMR)

Human Immunodeficiency Virus (HIV)

Infectious Diseases (ID)

Institutional Review Board (IRB)