

# **National HIV Behavioral Surveillance System (NHBS)**

**Injection Drug Users (IDU)  
and  
Heterosexuals at Increased Risk for HIV (HET)**

## **Formative Research Manual**



**Behavioral Surveillance Team  
NCHHSTP/DHAP/BCSB**

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# 1 Introduction

## 1.1 Overview

The purpose of the National HIV Behavioral Surveillance System's (NHBS) formative research process is to identify and address barriers to successful implementation of NHBS surveillance activities. This is accomplished by thoroughly investigating relevant issues among the target population in the metropolitan statistical area (MSA). As Respondent Driven Sampling (RDS) is the sampling and recruitment strategy for injection drug users (IDUs) and heterosexuals at increased risk for HIV (HET), an excellent understanding of the target population's social networks (i.e., who associates with whom in regards to age, race/ethnic group, geographic area) is critical. During the HET cycle, a thorough understanding of individuals and neighborhoods of low socio-economic status (SES) in the MSA is also important in order to effectively recruit eligible participants.

Successful implementation of both NHBS formative research and surveillance activities is dependent upon establishing and maintaining excellent relationships in the MSA. In particular, building relationships with community members, the target population, health and social services, and prevention providers that work with the target population is critically important.

## 1.2 Goals

NHBS formative research goals are to:

- Garner the support of the community and its stakeholders
- Define the characteristics of the target population
- Investigate the social and demographic characteristics of target population and their HIV-related behavior
- Identify potential “seeds”, or initial recruits, for RDS
- Obtain information on the major networks of the target population in the Division or MSA and identify social networks with potentially high homophily (the tendency for individuals to associate with others similar to themselves).
- **(HET only)** Identification of high-risk areas (HRAs)
- Identify strategies for reaching the target population for data collection (e.g., areas where the target population can be reached, community and neighborhood organizations that serve the population, and individuals that are knowledgeable about and have access to the population)
- Obtain information relevant to field logistics (e.g., appropriate locations and hours of operation for field site(s), whether appointment systems are feasible, and ideal attributes of project staff)
- Develop questions of local interest for HIV prevention
- Monitor the ongoing implementation of surveillance activities

### 1.3 Institutional Review Board Procedures

All project sites must receive approval(s) from their local Institutional Review Board(s) (IRB) prior to implementing formative research activities that involve the engagement with human subjects. To protect the anonymity of those interviewed, consent to participate should only be provided verbally by participants and interviews should not be video- or audio-taped. Each project site should follow local requirements regarding informed consent procedures. The NHBS-IDU/HET Model Protocol provides model consent forms for formative research and guidance for modifications (Chapter 9). After IRB approval is received for NHBS activities, final CDC Project Officer approval must be obtained before project sites begin interviews with human subjects.

### 1.4 NBHS Formative Research Process and Timeline

Formative research activities are completed over a period of approximately 3 months preceding the implementation of surveillance activities. Formative research is an iterative process (Figure 1), thus information obtained from the secondary data review informs primary data collection which then validates or provides further insight to the secondary data review findings. Through this process, participation barriers and challenges should be identified, solutions should be investigated, and strategies should be implemented to minimize or remove potential negative impact upon data collection.

Figure 2 illustrates the suggested flow for conducting formative research. This diagram illustrates how to identify potential sources for primary data collection and how each piece of information should inform subsequent information gathering. Briefly, the formative research process starts with a review of published and unpublished secondary data which is used to develop a plan for primary data collection. Typically, primary data collection begins with interviews with the health department staff as they can provide a general overview of the community, HIV epidemic, and target population as well as names of additional contacts for interviews.

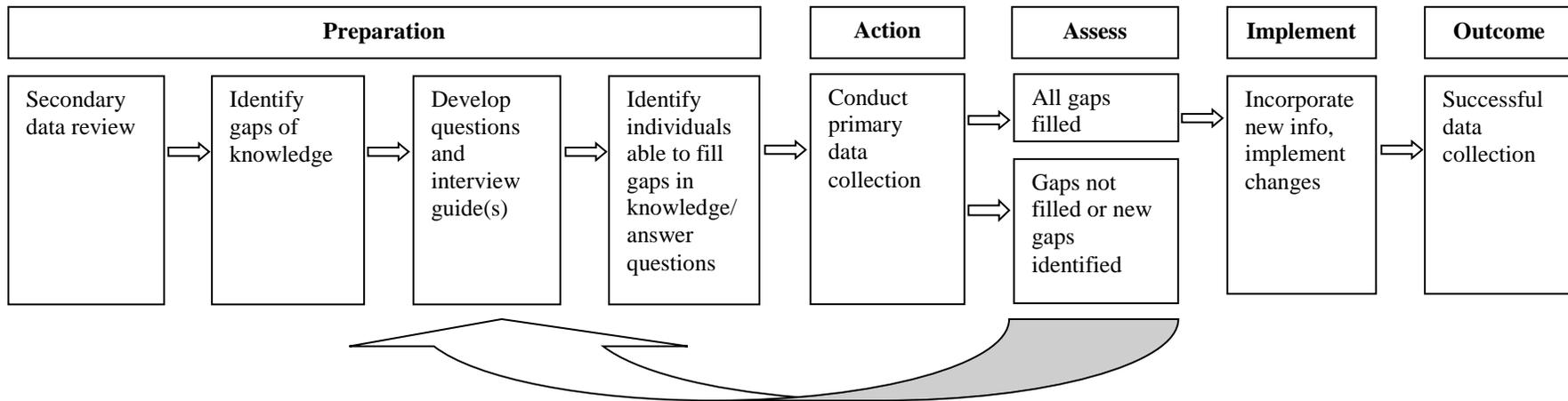
Whenever meeting with an individual or group, it is helpful to keep the following objectives of the NHBS formative research process in mind as multiple outcomes can be achieved during one meeting:

- Garner support for NHBS activities
- Learn about the target population
- Ask for referrals for others to be interviewed that can provide insight into the community
- Ask for referrals for potential ‘seeds’ (initial recruits)
- Request data if available
- Request input for local questions

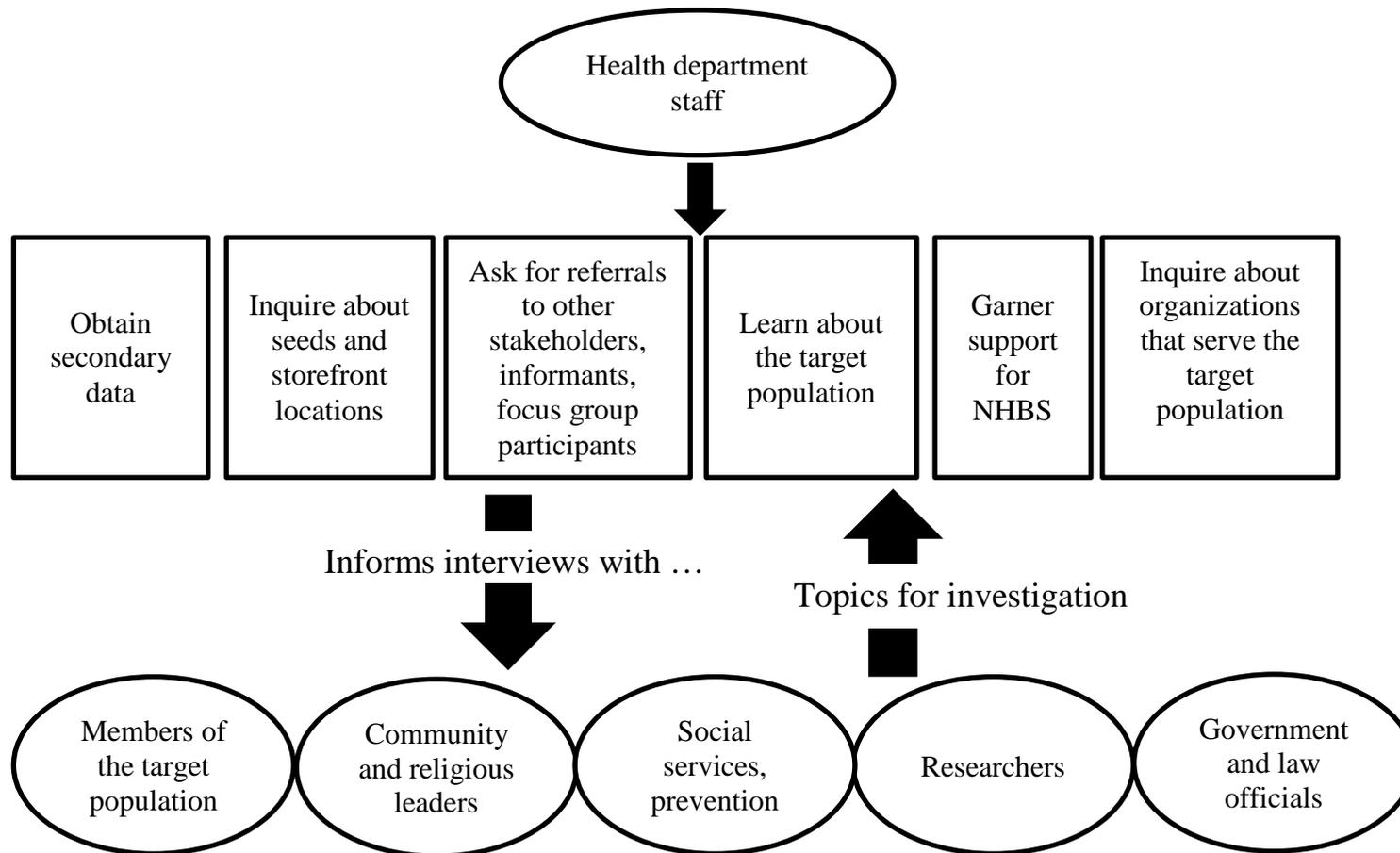
The end product of the formative research process is a series of reports. These reports are described in Chapter 3. The timeline for the reports is shown below:

<b>Report</b>	<b>Due to project officer</b>	<b>Feedback due to site</b>
Secondary Data Report	4th Friday in February	Approximately 1 week later
<b>(HET only)</b> HRA and Maps Report	1 <sup>st</sup> Friday in March	Approximately 1 week later
Primary Data Report	Draft: Six weeks after either IRB approval or approval of Secondary Data Report by the Project Officer, whichever is later.  Final report: 2 weeks after receiving feedback	Approximately 2 weeks later

**Figure 1. The iterative process of formative research**



**Figure 2. Suggested flow for formative research**



## **2 Staffing**

### **2.1 Overview**

Project staff conducting formative research should ideally include an ethnographer, the project coordinator, and a minimum of two additional project staff. During the HET cycle, at least one staff member should have at least one year of experience using Geographic Information Systems (GIS) software which is necessary to identify high-risk areas for infection (HRA).

### **2.2 Ethnographer**

Project sites are strongly encouraged to hire an ethnographer to guide their formative research activities. An ethnographer is a researcher who has been trained in an approach that places emphasis on the collection of data in their natural environment (Schensul & LeCompte, 1999). One of the strengths of an ethnographer's approach to data collection is the attention paid to the context in which particular social phenomena occur and the use of multiple data sources and methods to confirm information gathered. The ethnographer should understand that the purpose of the formative research process is to inform and guide the successful implementation of NHBS data collection including identifying barriers, investigating possible solutions, and ensuring that the project staff has a solid understanding of the target population and community prior to the start of surveillance activities.

The ideal ethnographer is an individual with either masters- or doctoral-level training in anthropology or sociology with experience working with a range of ethnographic methods as well as the cycle's target population (Schensul & LeCompte, 1999; Stimson et al., 2003). Ethnographers may be identified through anthropology or sociology departments at local universities and community colleges, community-based research institutes, or local health departments.

When an outside researcher is hired to lead the formative activities, the project staff is expected to remain closely involved with the activities. The ethnographer should train and oversee project staff in formative research methods and data collection activities. The ethnographer should also provide periodic updates on the process and findings to the staff. It is recommended that a timeline for deliverables be developed between the principal investigator or project coordinator and the ethnographer to ensure that successful project completion occurs in a timely manner.

### **2.3 Project Coordinator**

The project coordinator is responsible for conducting the secondary data review, facilitating the work of the ethnographer, and monitoring and/or supervising the formative research activities. The project coordinator should assist the ethnographer in identifying and contacting community stakeholders and potential interviewees as well as provide the ethnographer with the necessary background information on the MSA, the target population, and RDS methodology. Finally, the

project coordinator is responsible for incorporating the formative research findings into project staff trainings to ensure successful surveillance implementation.

## **2.4 Project Staff**

At least two project staff should assist the ethnographer with formative research activities. Their participation could include the following activities: identifying individuals who are community stakeholders or those who could serve as key informants, participants in focus groups, or potential seeds; assisting with interviews or focus groups; or conducting street intercept surveys or observations.

### 3 Formative Research Reports

#### 3.1 Overview

During the formative research process, project sites are required to submit reports to their Project Officer: the Secondary Data Report, High-Risk Area (HRA) and Maps Report (*HET only*), and the Primary Data Report. These reports serve as the basis from which project sites, in consultation with CDC, tailor the implementation of the NHBS to their local area to ensure acceptability and success.

The formative research reports are structured by round. An NHBS round is one rotation of NHBS-MSM, NHBS-IDU, and NHBS-HET. As shown below, during year 1 of a round (NHBS-MSM), sites are responsible for writing the Core and Population-Specific documents, but for subsequent years, sites are responsible for writing a new Population-Specific document but the Core Document only needs to be updated.

Project Officer approval of the Secondary Data Report must be received before formative research primary data collection activities begin. If a situation arises where it is important to start primary data collection prior to approval of the Secondary Data Report and IRB approval has been received, discuss with your Project Officer about possible options. Finally, all formative reports must be completed with Project Officer approval before any surveillance activities can begin.

Year	Secondary Data Report			HRA and Maps Report <i>(HET only)</i>	Primary Data Report
	Core	Population-specific	Primary Data Collection Plan		
1 (MSM)	√	√	√		√
2 (IDU)	Update only	√	√		√
3 (HET)	Update only	√	√	√	√

When completing each report, it is important to present the data and **interpret the findings** from the perspective of how this information provides greater understanding of the MSA and target population to ensure successful data collection. When barriers are identified, possible solutions should also be included. See the example below for how details about the weather were interpreted to provide insight regarding the weather’s impact upon data collection:

*“The summer and fall months are generally characterized with frequent but light rain which has proven only a moderate constraint on interviewing when we are at our mobile van location. When this occurs, we provide umbrellas to participants waiting outside the van as well as the option to wait in a nearby building until their interview time.”*

## 3.2 Secondary Data Report

The secondary data report is comprised of three parts: (1) the Core Document describes the general characteristics of the MSA, (2) the Population-specific Document describes the target population, and (3) the Primary Data Collection Plan describes the project site's plans for conducting primary formative research activities based upon the findings from the Core and Population-specific Documents. All data sources should be referenced. When relevant, references should include a description of how the study's data were collected, who collected it and when. See Chapter 4 for information how to conduct a secondary data review.

### Completing the Core Document

The Core Document investigates the MSA's structural/contextual factors, demographic characteristics, and HIV epidemic. This document is written during Year 1 of each round. During Years 2 and 3, it only needs to be updated. The Core Document should be included in each year's Secondary Data Report with documentation regarding what has been updated. See the suggested example below of how to incorporate updated information to the Core Document during subsequent cycles:

*(From Year 1) "... While the city is home to many universities, it also has high rates of illiteracy and high school dropout rates. Only 20 percent of MSA residents have college degrees. (Workforce Investment Board, 2007)."*

*IDU update: In 2010, it was reported that the percent of college degree holders had dropped to 15% in the MSA (Workforce Investment Board, 2010)."*

**Part 1: Structural and Contextual Factors in the MSA (2-4 pages):** The first part of the Core Document is a narrative that summarizes the structural and contextual factors in the MSA. The inclusion of sub-headers is suggested to help identify each section. Structural and contextual factors of interest include:

- Geographic region
- Weather
- Housing (specifically, as it related to the target population)
- Education and literacy
- Socio-economic status/poverty
- Sex work
- Laws that may impact HIV transmission or prevention (e.g., HIV testing laws, laws related to injection drug use and sex work, criminalization of HIV transmission)
- Stigma and discrimination toward high-risk groups
- Stigma and discrimination toward individuals diagnosed with HIV
- Neighborhood violence/gangs/drug presence as it relates to data collection
- Prevention and support efforts for HIV and substance use
- Other factors that could impact successful data collection

**Part 2: Demographics of the MSA (1-2 pages + Table 1):** The second part of the Core Document provides information about the demographic make-up of the MSA. Complete Table 1 and summarize findings. Feel free to add additional demographic categories that are important to the MSA.

**Part 3: Demographics of the HIV Epidemic in the MSA (1 page + Table 2):** The third part of the Core Document focuses on identifying demographic characteristics of persons diagnosed with HIV infection. Complete Table 2 using HIV/AIDS Reporting Systems (HARS) data and summarize the findings. Data should include HIV and AIDS cases that were reported to HARS through December 2012 and should be restricted to those cases that were newly diagnosed with HIV between January 2007 and December 2011. (*Note:* AIDS cases should be selected by the date of HIV diagnosis; not the date of AIDS diagnosis.) Cases that do not have a known HIV transmission category should be adjusted using the multiple imputation (MI) method developed by CDC’s HIV Incidence and Case Surveillance Branch (HICSB). A SAS program that applies the MI method to HARS data (Site Projects v1.1 [EP MI]) and a user guidance document (Guide\_to\_Multiple\_Imputation\_20091209.pdf) can be downloaded from the “Core Surveillance” folder in HICSB’s SharePoint. Any questions regarding the MI SAS program should be directed to the CDC Division of HIV/AIDS Prevention (DHAP) Informatics Customer Support at 1-877-659-7725 or [DHAPSupport@cdc.gov](mailto:DHAPSupport@cdc.gov).

In table 2, project sites should select the geographic variable, such as county, neighborhood, or zip code, which they believe will be most helpful for describing the distribution of HIV cases in their locality. In addition, socioeconomic characteristics, like education and income, should be reported if these data are collected as part of the local HARS.



Reminder: When summarizing each part, explain how each finding may impact data collection and/or guide formative research. Also, discuss gaps in knowledge and barriers identified and how they may be overcome.

## **Completing the Population-specific Document**

This component of the Secondary Data Report provides detailed information about the MSA’s HIV epidemic among the cycle’s target population, either heterosexuals at increased risk or injection drug users.

**Part 1: Overview of HIV/AIDS Epidemic Among the Target Population (1 page or less + Table 3 and 4):** The first part of the Population-specific Document is an overview of HIV/AIDS diagnoses among the target population by key demographic characteristics. This summary should also include information about: 1) which sub-groups of the target population comprise the largest proportions of HIV diagnoses (HARS data), and 2) which sub-groups of the target population are disproportionately affected by HIV (this can be determined by a high HIV prevalence in previous NHBS cycles or a large percentage of HIV diagnoses in HARS data). This helps to determine which populations are of the highest priority for the cycle.

The source of data for Table 3 should be the same as that described for Table 2 above. The data should also be restricted to cases that have the HIV transmission category of the target population (i.e., IDU or heterosexual contact).

**(IDU only)** HIV risk for MSM-IDUs may be different from other IDUs. If the MSM-IDUs population is relevant to HIV epidemic in the MSA, also include MSM-IDUs case data.

**Part 2: Demographics of Target Population in Previous NHBS Cycle(s) (1-2 pages + Table 5):** The second part of the Population-specific Document is a summary of the demographic characteristics of the target population recruited in previous NHBS cycles. Summarize findings with an emphasis on comparing the demographics of the target population's HIV epidemic (Tables 3 and 4) with the population enrolled during previous cycles. Also, discuss any sub-populations that are impacted by the HIV epidemic but not adequately represented in previous NHBS cycles.

**(IDU only)** Include MSM-IDU data if it is relevant to the MSA's HIV epidemic.

**Part 3: Summary of Research about the Target Population in the MSA (2-4 pages):** The third part of the Population-specific Document is a summary of relevant research studies conducted among the target population in the MSA such as HIV risk behaviors, social and sexual networks, sub-populations, geographic concentrations of the target population, or issues of local concern among the target population. Interpret lessons learned as well as gaps in knowledge and barriers identified and how these were overcome.



Reminder: When summarizing each part, explain how findings may impact data collection and/or guide formative research. Also, discuss gaps in knowledge and barriers identified and how they may be overcome.

## **Completing the Primary Data Collection Plan**

Based upon the findings of the secondary data review, a plan for formative research activities is to be developed. It is the responsibility of the project staff to identify the best ethnographic methods to obtain the necessary information and saturate their knowledge of the MSA and target population as it relates to successful data collection. Primary data collection can occur by using a variety of methods such as: key informant interviews, focus groups, observations, street intercept surveys, and systematic social observations (Appendix A). Appendix B provides a list of possible topics and questions to be considered for investigation.

### **The Primary Data Collection Plan (1-2 pages)**

The primary data collection plan should explain how each of the following activities will occur, building on the findings from the secondary data report. For each finding and gap in knowledge identified in the secondary data report, explain how primary data will be collected (e.g., focus groups, key informant interviews) to gather more information, designation of responsibility, and

timeline for completion. The Primary Data Collection Plan should include the following information:

- Identify steps for garnering community support
- Summarize the topics and populations that require investigation (gaps in knowledge and data) in order to effectively implement NHBS data collection
- **(HET only)** Identify steps to complete the HRA maps and report
- Outline steps to identify and recruit seeds, determine field site locations and operating hours

**TABLE 1. Selected characteristics of general adult population in metropolitan statistical area--  
City, Date  
(Data source: U.S. Census)\***

	Female n (%)	Male n (%)	Total N (%)
<b>Metropolitan population</b>			
<b>CHARACTERISTIC</b>			
<b>Race/Ethnicity</b>			
American Indian/Alaska Native			
Asian			
Native Hawaiian/Pacific Islander			
Black			
Hispanic/Latino			
White			
Other			
<b>Age group (yrs)**</b>			
18 – 19			
20 – 24			
25 – 29			
30 – 34			
35 – 39			
40 – 44			
45 – 49			
50 – 59			
≥60			
<b>Highest level of education completed**</b>			
< High school			
High school diploma or equivalent			
Some college or technical degree			
College degree or post-graduate education			
<b>Annual household income**</b>			
0 to \$19,999			
\$20,000 to \$39,999			
\$40,000 to \$74,999			
\$75,000 or more			
<b>Poverty status</b>			
At or below poverty limit			
Above poverty limit			
<b>Health insurance (if available)</b>			
None			
Private only			
Public only			
Other			
<b>Employment Status (if available)</b>			
Employed full-time			
Employed part-time			
Unemployed			
Disabled			
Full-time student			
Other			

**Note:** Reported proportions are column percentages

\*Indicate data source(s) used in final report

\*\*Categories may be adjusted as necessary based on data source or distribution of data

**TABLE 2. Number and percentage of new HIV diagnoses among adults by selected characteristics in metropolitan statistical area--City, Date (Data source: HARS)**

<b>CHARACTERISTIC</b>	<b>Female n (%)</b>	<b>Male n (%)</b>	<b>Total N (%)</b>
<b>Race/Ethnicity</b>			
American Indian/Alaska Native			
Asian			
Native Hawaiian/Pacific Islander			
Black			
Hispanic/Latino			
White			
Other			
<b>Age group (yrs)</b>			
18 – 19			
20 – 24			
25 – 29			
30 – 34			
35 – 39			
40 – 44			
45 – 49			
50 – 59			
≥60			
<b>Highest level of education completed*§</b>			
< High school			
High school diploma or equivalent			
Some college or technical degree			
College degree or post-graduate education			
<b>Annual household income<sup>§</sup></b>			
0 to \$19,999			
\$20,000 to \$39,999			
\$40,000 to \$74,999			
\$75,000 or more			
<b>Mode of Transmission/Exposure category</b>			
Male-to-male sexual contact			
Injection drug use (IDU)			
Heterosexual contact			
Male-to-male sexual contact and IDU			
Other			
<b>Geographic Variable (optional)</b>			
Category 1			
Category 2			
Category 3			
Etc			
<b>Country of birth (if relevant and/or available)</b>			
United States			
Other			
<b>TOTAL</b>			

**Note:** Reported proportions are column percentages

\*If applicable

§Categories may be adjusted as necessary

**TABLE 3. Number and percentage of new HIV diagnoses among the target population by selected characteristics in metropolitan statistical area--City, Date  
(Data source: HARS)**

<b>CHARACTERISTIC</b>	<b>Female^ n (%)</b>	<b>Male^ n (%)</b>	<b>Total (%)</b>
<b>Race/Ethnicity</b>			
American Indian/Alaska Native			
Asian			
Native Hawaiian/Pacific Islander			
Black			
Hispanic/Latino			
White			
Other			
<b>Age group (yrs) §</b>			
18 – 19			
20 – 24			
25 – 29			
30 – 34			
35 – 39			
40 – 44			
45 – 49			
50 – 59			
≥60			
<b>Highest level of education completed*§</b>			
< High school			
High school diploma or equivalent			
Some college or technical degree			
College degree or post-graduate education			
<b>Annual household income§</b>			
0 to \$19,999			
\$20,000 to \$39,999			
\$40,000 to \$74,999			
\$75,000 or more			
<b>Country of birth (if relevant)</b>			
United States			
Other			
<b>Geographic Variable (optional)</b>			
Category 1			
Category 2			
Category 3			
Etc			
<b>TOTAL</b>			

**Note:** Reported proportions are column percentages

\*If applicable

§Categories may be adjusted as necessary

^For small cell sizes, site may not want to stratify by gender. In this case, report number and percentage of HIV cases by gender characteristics.

**TABLE 4. Prevalence\* of HIV among the target population in previous NHBS cycles and other relevant local studies by selected characteristics in metropolitan statistical area--City, Date**

CHARACTERISTIC	NHBS-Round 1†	NHBS-Round 2	Study 2 (Optional)	Study 3 (Optional)
	No.‡ (prevalence)	No. (prevalence)	No. (prevalence)	No. (prevalence)
<b>Gender</b>				
Male				
Female				
<b>Race/Ethnicity</b>				
American Indian/Alaska Native				
Asian				
Native Hawaiian/Pacific Islander				
Black				
Hispanic/Latino				
White				
Other				
<b>Age group (yrs)§</b>				
18 – 19				
20 – 24				
25 – 29				
30 – 34				
35 – 39				
40 – 44				
45 – 49				
50 – 59				
≥60				
<b>Highest level of education completed</b>				
< High school				
High school diploma or equivalent				
Some college or technical degree				
College degree or post-graduate education				
<b>Annual household income§</b>				
0 to \$19,999				
\$20,000 to \$39,999				
\$40,000 to \$74,999				
\$75,000 or more				
<b>Country of birth (if relevant)</b>				
United States				
Other				
<b>TOTAL</b>				

**Note:** Reported proportions are row percentages

\* Prevalence of HIV cases should include all individuals with a valid HIV positive result in the numerator and all with a valid HIV test in the denominator

†If applicable

‡ No. indicates the total number of individuals in the study in each demographic category.

§Categories may be adjusted as necessary

**TABLE 5. Selected characteristics of the target population in previous NHBS cycles in metropolitan statistical area--City, Date**

<b>CHARACTERISTIC</b>	<b>NHBS-Round 1* n (%)</b>	<b>NHBS-Round 2 n (%)</b>
<b>Gender</b>		
Male		
Female		
<b>Race/Ethnicity</b>		
American Indian/Alaska Native		
Asian		
Native Hawaiian/Pacific Islander		
Black		
Hispanic/Latino		
White		
Other		
<b>Age group (yrs)</b>		
18 – 19		
20 – 24		
25 – 29		
30 – 34		
35 – 39		
40 – 44		
45 – 49		
50 – 59		
≥60		
<b>Highest level of education completed</b>		
< High school		
High school diploma or equivalent		
Some college or technical degree		
College degree or post-graduate education		
<b>Annual household income</b>		
0 to \$19,999		
\$20,000 to \$39,999		
\$40,000 to \$74,999		
\$75,000 or more		
<b>Health insurance</b>		
None		
Private only		
Public only		
Other		
<b>Employment Status</b>		
Employed full-time		
Employed part-time		
Unemployed		
Disabled		
Full-time student		
Other		
<b>Total</b>		

\*If applicable

### 3.3 *(HET only)* HRA and Maps Report

HRAs are low-income areas within an MSA or division where heterosexuals are expected to be at greater risk of HIV infection compared to other areas of the MSA. For NHBS-HET, HRAs are defined as the 25% of census tracts in the MSA or division that have the highest proportion of residents who live below the Census Bureau's poverty threshold. Project sites should create maps of their HRAs and other relevant information to determine the best locations for field sites and to identify neighborhoods where seeds can be recruited. The HRA and Maps Report (1-2 pages) summarizes the findings from the analysis of these maps and describes how this information will be used for project operations.

The HRA and Maps Report should detail the following information:

- Total number of census tracts in the MSA or division
- Number of census tracts that are HRAs
- Among the HRA census tracts, the median, minimum and maximum poverty rates (proportion of residents living below the Census Bureau's poverty threshold)

The HRA and Maps Report should also include the following maps:

- HRA maps (required)
- Race/ethnicity maps (required)
- HIV case surveillance maps (strongly recommended)
- NHBS-HET maps (strongly recommended)

The methods for creating the maps are described in detail in Section 6.6 of this document.



Reminder: The HRA and Maps Report should include an explanation of how findings from the HRA mapping exercise may impact field site locations and seed selection. Include a discussion of potential barriers identified and how they may be overcome.

### 3.4 Primary Data Report

#### **Part 1 (0.5 pages): Introduction**

Provide an overview of how the formative research activities were conducted. This includes describing the staff who conducted the research activities (e.g., whether an ethnographer was hired and their qualifications, the role of the local project staff in conducting these activities), how long the formative research activities took to complete, who analyzed the data, and other relevant methods issues not addressed below.

#### **Part 2 (5-7 pages): Garnering the support of community stakeholders**

**Methods:** Describe methods used to identify stakeholders and obtain their support, particularly those from important sub-populations and groups under-represented in previous cycles of NHBS. Provide a list of the types of community stakeholders interviewed and topics discussed related to garnering support.

**Summary of Findings:** Describe the main findings relating to the acceptability and promotion of NHBS in the community. Discuss challenges identified and solutions recommended. Any recommended solutions that cannot be implemented should include an explanation about the reasons/barriers that prevent adopting such solutions.

**Part 3 (6-8 pages): Learning about the target population**

**Methods:** Describe methods used to identify and recruit individuals to be interviewed, particularly those from important sub-population and/or groups under-represented in previous cycles of NHBS. Describe how data were collected (e.g., focus groups, key informant interviews, observations), and provide the topics investigated.

**Summary of Findings:** Provide demographic information about those interviewed (i.e., age, race/ethnicity, gender, etc.). Describe the main findings related to the (1) local culture and social networks of the target population, (2) gaps in knowledge identified in the secondary data review that needed to be addressed, (3) recruitment barriers, and (4) logistics such as seed identification and recruitment, field site specifications, incentives, eligibility screening. List challenges identified and describe recommended solutions regarding how best to ensure successful data collection. Any recommended solutions that cannot be implemented should include an explanation about the reasons/barriers that prevent adopting such solutions.

**Part 4 (up to 1 page): Plans for ongoing formative research**

Describe issues identified that will require ongoing formative research activities during data collection. For each issue identified, explain how ongoing formative research will be conducted, designate a responsible party, and include a proposed timeline for activities.

## 4 Conducting a Secondary Data Review

### 4.1 Overview

The secondary data review is critical to the successful implementation of NHBS as it (1) characterizes the extent and patterns of HIV infection among the MSA's target population, (2) documents what is known about the target population's HIV risk behaviors, (3) identifies potential collaborators within the health department and community, (4) identifies gaps in knowledge related to the target population, (5) identifies potential recruitment barriers, and (6) helps assess whether the demographics of the current cycle's participants match the demographics of the MSA's target population (once the cycle's data collection begins).

The resulting secondary data report also provides guidance for the ethnographer regarding where to focus formative research efforts, potential key informants and focus group participants, and topics for discussion during data collection. It is important to remember that each piece of information should inform subsequent information gathering.

### 4.2 Sources of Data

#### Previous NHBS Cycles

The first step should be to review the secondary data report from the previous corresponding cycle to assess relevant information and contacts.

Sites with the capacity to conduct RDSAT analysis from previous cycles are strongly encouraged to look at homophily statistics and affiliation matrixes to identify which sub-populations were more insular than others. Homophily and affiliation measure the extent to which individuals with a given characteristic recruit individuals with the same characteristic (homophily) or some other characteristic (affiliation) beyond what is expected based on the relative number of individuals with that characteristic. Accounting for the relative number of people with a given characteristic is important. For example, if the given characteristic is birth month and we see that people born in March recruited other people born in March in only 1/12<sup>th</sup> of their recruitments and we did not account for relative number of people, we might incorrectly conclude the people born in March avoid each other because they only were recruited 1/12 of the time. In actuality, when we account for the relative number of people, we find that birth month recruitment does not matter in recruitment because people born in March only make up 1/12<sup>th</sup> of the population.

The affiliation matrix, which includes the homophily statistic along the diagonal is useful for understanding the network structure of your population and determining field site logistics, seed selection, and what to expect during recruitment (see the RDSAT User's Manual for how to generate the affiliation matrix). In the affiliation matrix, a positive number means individuals with the Row characteristic frequently recruited individuals with the Column characteristic; a negative number means individuals with the Row characteristic rarely recruited individuals with the Column characteristic; and a number near zero means the characteristic is not associated with recruitment. Below are some examples of affiliation matrices and how they can help guide seed selection and field site location. The affiliation matrix should be produced for sample

demographics, such as race/ethnicity, age, drug of choice, gender, geography or other characteristics thought to segment the population of interest into separate communities.

Looking at the example of RDSAT output below, each group refers to a variable outcome (i.e. characteristic). In this example, the groups represent racial categories of the variable `_racecat` (1 = white; 2 = black; 3 = Hispanics). Then the affiliation matrix shows that whites (Group 1) preferentially recruited other whites (Group 1) as signified by the top left cell (0.309). Similarly, whites avoided blacks (Group 2) as signified by the next cell to the right (-0.416).

**Example 1:**

Affiliation Matrix:					
	Group 1	Group 2	Group 3		<code>_racecat</code>
Group 1	0.309	-0.416	-0.444	Group 1	{ 1 }
Group 2	-0.322	0.433	-0.482	Group 2	{ 2 }
Group 3	-0.283	-0.425	0.375	Group 3	{ 3 }

In this example each group has positive homophily, evidenced by positive values along the diagonal. This signifies that each group frequently recruits individuals who share the same characteristics. In addition, each group rarely recruits members of other groups, evidenced by negative values in the non-diagonal cells. Taken together, this signifies that there is little cross recruitment between these groups. Therefore, there should be at least one seed from each of these groups to facilitate recruitment of all groups.

**Example 2:**

Affiliation Matrix:			
	Group 1	Group 2	Group 3
Group 1	0.309	0.012	0.031
Group 2	0.021	0.433	0.005
Group 3	0.044	0.002	0.375

In this example each group has positive homophily, but the non-diagonal values are near zero. This pattern signifies that, while recruitment favors similar individuals, cross-group recruitment does occur. In this example, it would be good idea to have at least one seed from each group, however it is not critical to obtaining a diverse sample if other factors prevent it.

**Example 3:**

Affiliation Matrix:			
	Group 1	Group 2	Group 3
Group 1	0.309	0.311	-0.332
Group 2	0.412	0.433	-0.478
Group 3	-0.412	-0.366	0.375

In this example, all three groups have positive homophily as before. However, Groups 1 and 2 frequently recruit each other, while Group 3 rarely recruits Groups 1 or 2. In this case it is important to have at least one seed from Group 3 and at least one seed from Group 1 or Group 2. Since Groups 1 and 2 frequently recruit each other, it is not necessary to have seeds from both groups (but it doesn't hurt).

**Example 4:**

**Affiliation Matrix:**

	Group 1	Group 2	Group 3
Group 1	0.002	0.012	0.034
Group 2	0.096	0.122	-0.049
Group 3	-0.012	-0.111	0.104

In this example, all affiliation is near zero. This means that recruitment patterns were not associated with these characteristics. This is a null result, meaning that this result does not need to be taken into account when deciding field site location, picking seeds, or making decisions regarding these characteristics.

Network patterns may influence optimal field site location if they are geographically patterned. For example, if an important subset of the population does not interact with other groups and is geographically concentrated in a given area, it may be important to have an interview location easily accessible to that population. When choosing interview locations, it is important to consider what factors (network related or otherwise) may act as a barrier to participation for certain subgroups of the population.

Project Officers can assist in the interpretation of the affiliation matrix results.

**External Data Sources**

**Health departments:** State and local health departments have HIV and AIDS case surveillance data, epidemiological profiles, and HIV prevention plans. The HIV/AIDS Surveillance Report contains information about AIDS and HIV case reports, including data by MSA, mode of exposure to HIV, sex, race/ethnicity, age group. This information is helpful for understanding how the target population is affected by the HIV epidemic as well as the communities where they live and/or engage in high-risk behaviors. Local health department(s) can also provide information regarding sexually transmitted diseases and hepatitis in the community, HIV testing services, and prevention and treatment programs available to the target population.

**Local research:** A literature review of local studies among the target population may also help characterize the local epidemic and identify researchers to interview as part of the formative research process

**Data resources:** Tables 7 and 8 provide information on a variety of data sources.

**(IDU only)** Other data sources useful in characterizing local injection drug use include drug arrests and drug treatment data. Drug treatment data sources can provide characteristics of those entering treatment including types of drugs used and modes of administration.

**Table 7. Potential data sources for secondary data review for NHBS-IDU**

DATA SOURCES	DESCRIPTION	DATA CONTENTS	WEB LINK
<b><i>National Institute of Drug Abuse (NIDA)</i></b>			
Community Epidemiology Work Group (CEWG) reports	A synthesis of available data describing the epidemiology of drug abuse for both the country and participating metropolitan areas. Data comprising these reports are presented by local researchers at national NIDA meetings.	Drug abuse indicator data, findings from surveys, and other quantitative information compiled from local, State, and Federal sources. Data are enhanced with qualitative information obtained from ethnographic research, focus groups, and other community-based sources. The participant list may provide the names of local experts on drug abuse.	<a href="http://www.drugabuse.gov/about/organization/CEWG/CEWGHome.html">http://www.drugabuse.gov/about/organization/CEWG/CEWGHome.html</a>
<b><i>Substance Abuse and Mental Health Services Administration (SAMHSA)</i></b>			
National Household Survey on Drug Use and Health (NHSDUH, formerly known as NHSDA)	Annual survey of prevalence, patterns and consequences of drug and alcohol use and abuse in the general U.S. civilian non-institutionalized population age 12 and over	Demographic and drug use data among individuals.	<a href="http://www.oas.samhsa.gov/nhsda.htm">http://www.oas.samhsa.gov/nhsda.htm</a>
Treatment Episode Data Set (TEDS)	Information collected by States from local alcohol and drug abuse treatment facilities characterizing the admissions to alcohol and drug treatment.	Demographic and drug history information about individuals admitted to treatment; changes in treatment admissions.	<a href="http://wwwdasis.samhsa.gov/webt/NewMapv1.htm">http://wwwdasis.samhsa.gov/webt/NewMapv1.htm</a>
Drug Abuse Warning Network (DAWN) reports	A national surveillance system that monitors trends in drug-related emergency department visits and medical examiners reports of drug-related deaths.	Characteristics of cases of drug overdose, as well as other complications of drug abuse.	<a href="http://www.oas.samhsa.gov/dasis.htm">http://www.oas.samhsa.gov/dasis.htm</a>
Substance Abuse Treatment locator	Searchable database of drug and alcohol abuse treatment programs in the US;	Location of the programs in a map of the city as well as general information about each program	<a href="http://findtreatment.samhsa.gov/facilitylocator/doc.htm">http://findtreatment.samhsa.gov/facilitylocator/doc.htm</a>
<b><i>National Institute of Justice (NIJ)</i></b>			
Arrestee Drug Abuse Monitoring (ADAM) Program	Survey & Urine testing of booked arrestees in 27 cities	Drug use, markets, & treatment	<a href="http://www.nij.gov/topics/drugs/markets/adam">http://www.nij.gov/topics/drugs/markets/adam</a>

**Table 8. Potential data sources for secondary data review for NHBS-HET**

DATA SOURCES	DESCRIPTION	DATA CONTENTS	WEB LINK
Behavioral Risk Factor Surveillance System (BRFSS)	BRFSS is an ongoing data collection program administered and supported by the Division of Adult and Community Health, National Center for Chronic Disease Prevention and Health Promotion, CDC. It is a comprehensive state-based surveillance system that tracks major health risks among Americans.	Questions include HIV/AIDS, sexual behavior, alcohol, and women's health. Additional questions are added to the core by each state. The data available on HIV pertain mostly to testing. Participants are not asked about HIV infection status.	<a href="http://www.cdc.gov/brfss">http://www.cdc.gov/brfss</a>
National Survey of Family Growth (NSFG)	The National Survey of Family Growth (NSFG) is conducted by the National Center for Health Statistics (NCHS). It is an area probability sample that represents the civilian non-institutionalized population of the United States, 15-44 years of age.	Separate questionnaire for men and women; pregnancy, contraceptive history, family planning asked of women; number of sex partners, marital history and 'desires and intentions for future children' asked for men. The survey sample is designed to produce national data, not estimates for individual States. They can approximate the HET sampling frame by selecting cases based on NHBS income and education eligibility criteria.	<a href="http://www.cdc.gov/nchs/nsfg.htm">http://www.cdc.gov/nchs/nsfg.htm</a>
Census	Census data can be broken down, for many variables, at the city, MSA, or census tract level.	Census data should be used to characterize the socio-demographic characteristics of the MSA. Information is limited to socio-demographic data.	<a href="http://www.census.gov">http://www.census.gov</a>
Epi Profile	The Community Planning Groups in each state develop a Comprehensive HIV Prevention Plan, which analyzes epidemiological data in order to ensure that resources are appropriately directed to the populations and communities in need.	Specific data on heterosexuals at risk of HIV infection and HIV-infected heterosexuals may be obtained. This would include behavioral, drug use, and demographic information on the population.	Refer to state surveillance coordinator, or prevention program coordinator of the state health department for links to the Epi profile.

**(Continued) Table 8. Potential data sources for secondary data review for NHBS-HET**

<b>DATA SOURCES</b>	<b>DESCRIPTION</b>	<b>DATA CONTENTS</b>	<b>WEB LINK</b>
HIV/AIDS Surveillance Report	The HIV/AIDS Surveillance Report contains tabular and graphic information about U.S. AIDS and HIV case reports, including data by state, MSA, mode of exposure to HIV, sex, race/ethnicity, age group, vital status, and case definition category. It is published annually by the Division of HIV/AIDS Prevention, National Center for HIV, Viral Hepatitis, STD, and TB Prevention, Centers for Disease Control and Prevention (CDC).	The annual HIV Surveillance Report provides an overview on the current epidemiology of HIV disease in the United States and dependent areas. Data are analyzed by CDC and then displayed by age, race, sex, risk factor, and jurisdiction (where appropriate). Data on HIV infection (not AIDS) should be interpreted with caution. HIV surveillance reports may not be representative of all persons infected with HIV because not all infected persons have been tested. Many HIV-reporting states offer anonymous HIV testing; the results of anonymous tests are not reported to the confidential name-based HIV registries of state and local health departments.	<a href="http://www.cdc.gov/hiv/topics/surveillance/resources/reports/index.htm">http://www.cdc.gov/hiv/topics/surveillance/resources/reports/index.htm</a>  Refer to state surveillance coordinator, or prevention program coordinator of the state health department for links to the local surveillance report data.

## 5 Garnering Community Support

### 5.1 Overview

The success of each cycle is largely dependent upon obtaining support from the community and its stakeholders to ensure that NHBS is accepted once surveillance activities begin.

Community stakeholders should come from a variety of backgrounds, affiliations, and interests with diverse and sometimes contradictory opinions about the target population and the broader community. Despite their diversity, stakeholders can be mobilized to provide support for NHBS because of their knowledge of and influence among the target population. Stakeholders may include individuals from the following local groups or organizations:

- HIV prevention outreach programs
- Community health workers/outreach workers/social workers
- Non-profit organizations
- Researchers
- Government officials
- Law enforcement representatives
- Community leaders
- Religious leaders
- Business owners
- Media

#### *(IDU only)*

- Injection drug users
- Substance abuse and treatment programs
- Needle exchange programs
- Drug counselors

#### *(HET only)*

- Residents of high-risk areas for HIV infection

Possible ways to identify community stakeholders include, but are not limited to, soliciting names from the following:

- Staff from health departments and other prevention/service agencies
- Key informants or focus group participants
- Individuals who participate in street intercept surveys..

### 5.2 Approaches to garnering community support

Once stakeholders have been identified, a number of strategies for garnering community support should be considered. Appendix B includes possible topics of discussion that may help facilitate community input and support.

## **Meetings**

Holding a series of formal and informal meetings with stakeholders throughout the community provides an opportunity to introduce the project, its goals, and past successes; introduce the staff; share the project logo to increase recognition; answer questions; discuss possible field site locations and hours of operation; and provide contact information for future questions or concerns about the study. When meetings involve multiple community stakeholders, it should be held in neutral and easily accessible locations at convenient dates and times.

A formal meeting could be a structured public meeting with an outlined agenda and presentation about the current cycle and its past successes. An informal meeting may be an advertised drop-in gathering with less structure and more one-on-one discussions.

## **Distribution of informational NHBS materials**

Another means for garnering community support is to develop and distribute informational materials throughout the cycle. Local events, such as community service days and health fairs, are opportunities for project staff to talk to residents about NHBS and become known throughout the community in an ongoing manner.

## **Community Advisory Board**

Convening a community advisory board (CAB) is a good way to garner community support. A CAB consists of stakeholders who agree to meet as a group with NHBS investigators to discuss issues pertinent to the particular cycle and to represent the point of view of the target community. CAB members could include local researchers, health department officials, social service/prevention/outreach workers, current and former members of the target population, individuals who became HIV infected through the cycle's transmission mode, local elected officials, etc.

Benefits of assembling a CAB include gaining the shared knowledge of the community as it relates to the target population, HIV, and current cycle; sharing NHBS information, findings, and analyses; and developing relationships with people who ideally will become invested in NHBS and serve as ambassadors for promoting the study in the community. Sites that elect to assemble a CAB should plan to meet with their CAB on a regular basis (e.g. monthly).

## **5.3 Communicating the purpose of NHBS to stakeholders**

It is important for NHBS investigators to communicate the purpose of NHBS with relevant stakeholders and how the target population is defined. Project staff should emphasize that data collected are intended to shed light on the disparities facing the target population in order to better serve their health needs and decrease rates of HIV in their communities. Project staff should also seek input about the potential difficulties with implementing data collection within the target population.

**(HET only)** Communicating how the target population is defined may be especially important during the HET cycle as the NHBS definition may vary from how other individuals and researchers define heterosexuals at increased risk of HIV infection. NHBS investigators should

explain the background of NHBS-HET, including the pilot cycle which guided the selection of the recruitment method, and the analyses that led to the current target population definition. Information can be found in the NHBS-IDU/HET Protocol (Section 1.5), the MMWR entitled, “Characteristics Associated with HIV Infection Among Heterosexuals in Urban Areas with High AIDS Prevalence --- 24 Cities, United States, 2006—2007”, and the publication “Piloting a system for behavioral surveillance among heterosexuals at increased risk of HIV in the United States” (DiNenno et al, 2012). Below you can find suggested language for these discussions:

The NHBS-HET pilot study done in 2006-2007 was conducted to better define “Heterosexuals at high risk of HIV infection” and evaluate the best method to recruit them into the survey. Our analysis was based on more than 18,000 interviews conducted among persons in cities with high AIDS prevalence across the United States. Following an investigation of the performance of predictor variables for heterosexuals with newly diagnosed HIV infection, we determined that the definition of a heterosexual at increased risk would to focus on persons with low SES.

The pilot study analysis was an important step in the effort to better conceptualize heterosexual risk of HIV. Earlier research on the topic defined heterosexuals at risk solely on the basis of high risk sexual behavior, such as sex with multiple partners. Results from the NHBS pilot study shift this focus from risky behaviors to at-risk communities by emphasizing the role of social factors – specifically, low SES - in which individuals exist and behaviors occur.

## **6 Collecting Primary Data**

### **6.1 Overview**

Depending on the needs identified as part of the secondary data review, primary data collection can occur in a variety of ways, such as key informant interviews, focus groups, observations, street intercept surveys, and systematic social observations. An explanation of each method is detailed in Appendix A.

### **6.2 Triangulation of Data**

Many qualitative researchers triangulate their data to confirm results and ensure completeness of data collection. “Triangulation” refers to cross-checking findings by using multiple data collection methods, data sources, investigators or theoretical perspectives (Denzin, 1978; Mays and Pope, 1995). Qualitative research that relies on only one data collection method is subject to errors associated with that single method (Patton, 1990).

One way to triangulate formative research data is to use at least two different data collection methods (e.g. observations, focus groups, key informant interviews). It is unlikely that completely consistent findings will be achieved from using different methods (Patton, 1990); however conflicting results may indicate the need for collecting some additional data to better understand the findings. Another approach is to compare data from different sources about the same topic.

One way triangulation can provide greater understanding of the MSA’s HIV epidemic is by comparing quantitative data, for example, from the health department- to qualitative data collected from members of the target population. For example, if quantitative data show that men 35 years of age and older are the heaviest drug users but findings from the qualitative interviews identify younger men ( 20-25 years of age) as the heaviest users, then both findings will need additional investigation as well as constant monitoring during data collection.

### **6.3 Understanding the Target Population’s Social Networks**

Understanding the target population’s social networks is critical to understanding how sampling is likely to proceed and how to implement an optimum recruitment strategy. In one city, the entire population may frequently interact as a single community. In a second city, the same population may form two separate communities that rarely, if ever, interact with each other. In the second city, NHBS staff would need to recruit seeds from both communities and make sure that the field site is equally accessible to each community, perhaps by selecting two field locations so that each community has easy access to one of the field sites. On the other hand, the resources of the first city would be better spent on other implementation issues.

Knowledge of the target population’s social networks can be improved throughout the formative research process. Project staff can investigate social networks by analyzing the affiliation matrixes from previous cycles, by asking key informants about characteristics of their social connections, or by asking key informants if they travel to other parts of the city or utilize certain resources. Geography can also play an important role in shaping social networks. If segments of

the target population are geographically separated, assessing whether they would have opportunities to meet and interact will help determine their likelihood of social interaction. For example, two geographically separated communities will be more likely to interact (and therefore recruit each other) if they share the same means of obtaining goods and services. If members of each community can meet all their needs within the community, they are less likely to meet or associate with individuals outside their community.

## 6.4 Identifying and Recruiting Seeds

There are multiple criteria to consider when identifying seeds (see NHBS-IDU/HET Protocol, Chapter 4). Ideal seeds are dynamic individuals who are knowledgeable about and well connected to the target population; reflect the major sub-populations and social networks that contribute most significantly to the HIV epidemic; and have a vested interest in the target population. As seeds are the initial recruiters for the surveillance activities, it is important that they are highly motivated to encourage others to participate and provide support for the project. Selecting appropriate seeds accelerates recruitment, promotes longer recruitment chains, and helps reduce bias in the sample. During formative research, project sites should determine the relevant demographic and geographic factors of important sub-populations and social networks from which seeds should be chosen.

Seed identification can occur during data collection (e.g. key informant interviews, focus group, street intercept surveys). After explaining the seed criteria, interviewees can be asked if they are interested in being a seed or if they can refer other potential seeds to the project staff.



Reminder: NHBS is anonymous and project sites *cannot* retain contact lists of potential seeds during formative research. Rather, project staff should distribute NHBS contact information to potential seeds and ask them to contact the staff at some future date.

## 6.5 Field Site Logistics

NHBS surveillance activities for IDU and HET are conducted at fixed field sites (a term referring to a van location or office). It is essential for project sites to determine the most appropriate locations for field sites as well as anticipate participant barriers to accessing such locations. Specifically, sites need to consider the following questions:

- **Is the field site accessible, appropriate, and safe for the target population?** Investigate what barriers could keep the target population or specific sub-population from coming to the field site. Investigate whether the area (residents, local businesses, law enforcement, etc.) is accepting of the target population and the presence of a study that recruits the target population. Field sites must also be in a safe environment for the participants and project staff.

It is also not appropriate for a field site to be located in facilities that primarily or exclusively provide a specific service to the target population, such as medical/mental health care, HIV/STD testing, care or prevention, or drug prevention/treatment. Settings that primarily provide social services to the target population are also not suitable. Based on previous RDS

studies, it is likely that this could result in a biased sample of those who frequent such places rather than from the target population's personal network. Multi-service facilities that provide a vast array of services could be considered for a field site as it is not likely that the sample would become biased toward people who receive any one particular service.

- **What is the appropriate number of field sites?** There needs to be a sufficient number of field sites for NHBS to be accessible to the target populations; however, operating too many field sites may decrease the chance of cross-recruitment. In extreme cases, this could result in completely separate RDS samples, which are challenging to analyze. Experience from previous NHBS cycles and other RDS studies suggest that it is preferable to operate as few field sites as necessary to reach the sub-populations that are most important to the HIV epidemic in the MSA or division.
- **What are appropriate logistics for field site operations?** Inquire with the target population about ideal hours of operation and whether an appointment or walk-in system would be preferred. It is recommended that a field site be open outside normal business hours at least one day per week to accommodate population members who work or are busy during that time.
- **Are special accommodations necessary?** A field site should meet the needs of the participants. For instance, if formative research identifies that a high number of participants may bring children with them when they come for their interview, the field site should consider having an area assigned for children while their caretaker is completing the interview and HIV testing.

## 6.6 *(HET only)* Identifying High Risk Areas and Creating Maps

As described in Section 3.3, HRAs are defined as the 25% of census tracts in a project site's MSA or division that have the highest proportion of residents who live below the Census Bureau's poverty threshold. HRAs are used to determine the best locations for field sites, as well as to identify neighborhoods where seeds can be recruited.

### **HRA Maps (Required)**

Project sites should identify and map their HRAs using a geographic information system (GIS) mapping software, such as ArcGIS. Most health departments provide GIS services, but if these services are not available, project sites can use Epi Map, a GIS module included in Epi Info 7. Although Epi Map has limited capabilities, it is easy to use and can be downloaded for free with Epi Info 7 from <http://wwwn.cdc.gov/epiinfo/7/index.htm>. Instructions for using Epi Map are contained in *NHBS-HET3 Epi Info Maps Guidance* (provided separately).

CDC will provide project sites with the poverty data needed to create and map their HRAs. The data will come from the 2007-2011 American Community Survey (ACS) and will include the poverty rate (proportion of residents living below the poverty threshold) for each census tract in the project site's MSA or division. Project sites will then have to order the data by poverty rate (from the census tract with the highest poverty rate to the tract with the lowest rate) and select

the 25% of tracts that have the highest poverty rates. These census tracts will constitute their HRAs.

Projects sites should produce at least two HRA maps: one showing the entire MSA or division and the other showing the principal city where project operations will be conducted. Multiple maps of the principal city may be necessary if it is large and cannot be depicted on a single map. Additional instructions for creating the HRA maps are listed below:

1. Title the maps with the name of the project site (e.g., Atlanta) and the type of map (e.g., HRA Map of the Principal City).
2. Indicate the total number of census tracts in the MSA or division and the number of census tracts that are HRAs.
3. Clearly mark census tract boundaries.
4. Color census tracts that are HRAs blue and color tracts that are *not* HRAs white.
5. Divide HRA census tracts into terciles (3 groups), quartiles (4 groups), or quintiles (5 groups) based on their poverty rates. Color the tracts in each group with a different shade of blue and grade the shades of blue using the lightest shade for HRA census tracts that are in the group with the lowest poverty rates and the darkest shade for those that are in the group with the highest poverty rates. Include a legend showing the range of poverty rates in each group and the corresponding shade of blue. When deciding how many groups to select, consider the number of HRA census tracts in the MSA or division, the range of poverty rates in the HRA census tracts, and how well the various color gradations can be viewed on the maps.
6. Add a simple hatch or symbol to census tracts with <200 residents to mark these tracts. Poverty rates in census tracts with few residents can be easily skewed too high or too low and should be viewed cautiously.
7. Include any important explanatory notes at the bottom of the map.
8. Save the maps as .pdf files or insert copies in the HRA and Maps Report.

### **Race/Ethnicity Maps (Required)**

To help ensure that field site locations are readily accessible to the racial and ethnic sub-populations most affected by the local HIV epidemic among heterosexuals, project sites should supplement their HRA maps with maps showing the proportion of residents in each census tract who are black or Hispanic. Because both these racial and ethnic sub-populations are disproportionately impacted by the HIV epidemic among heterosexuals at the national level, it is likely that they will be disproportionately impacted at the local level as well. However, if one of these racial and ethnic sub-populations is not impacted locally, project sites may request permission from their CDC project officer to not produce a map for that sub-population. The data needed to create the race/ethnicity maps will be provided by CDC and, like the poverty data used

in the HRA maps, will come from the 2007-2011 ACS. The ACS data for the black sub-population will be restricted solely to non-Hispanic blacks.

Unless instructed otherwise by their CDC project officer, projects sites should produce two race/ethnicity maps of their principal cities: one showing the proportion of residents in each census tract who are black and the other showing the proportion who are Hispanic. More than one map may be required for each racial and ethnic sub-population if the principal city is too large to fit on a single map. Additional instructions for creating the race/ethnicity maps are listed below:

1. Title the maps with the name of the project site and the type of map.
2. Clearly mark census tract boundaries.
3. On the map for the black sub-population, color census tracts with black residents red and color tracts *without* black residents white; and on the map for the Hispanic sub-population, color census tracts with Hispanic residents green and color tracts *without* Hispanic residents white. Project sites with large black or Hispanic sub-populations could also color census tracts with small proportions of black or Hispanic residents white. For example, on the map for blacks, they could color census tracts with  $\geq 10\%$  black residents red and color tracts with  $< 10\%$  black residents white.
4. Divide census tracts into terciles (3 groups), quartiles (4 groups), or quintiles (5 groups) based on the proportion of residents who are black or Hispanic. Color the tracts in each group with a different shade of red on the map for the black sub-population or green on the map for the Hispanic sub-population. Grade the shades of red or green using the lightest shade for census tracts that are in the group with the lowest proportion of residents who belong to the racial/ethnic sub-population and the darkest shade for those that are in the group with the highest proportion. Include a legend showing the range of proportions in each group and the corresponding shade of red or green. When deciding how many groups to select, consider the number of census tracts in the principal city, the range of proportions of black or Hispanic residents, and how well the various color gradations can be viewed on the maps.
5. Add a simple hatch or symbol to census tracts with  $< 200$  residents to mark these tracts. Proportions in census tracts with few residents can be easily skewed too high or too low and should be viewed cautiously.
6. Include any important explanatory notes at the bottom of the map.
7. Save the maps as .pdf files or insert copies in the HRA and Maps Report.

In addition to the HRA and race/ethnicity maps, project sites may choose to create another set of maps which overlay the race/ethnicity data on the HRA maps. For example, on an HRA map, census tracts with the highest proportion of residents who are black or Hispanic could be marked with a hatch, symbol, or bold border. Project sites may also produce maps of any other racial or ethnic sub-populations that they consider to be important to the local HIV epidemic among heterosexuals.

## HIV Case Surveillance Maps (Strongly Recommended)

CDC strongly recommends that project sites map their heterosexual HIV and AIDS cases to identify those areas of their principal cities most heavily impacted by the HIV epidemic among heterosexuals. This information will help project sites determine the optimal areas for locating field sites and recruiting seeds.

Project sites should obtain the data needed to create the HIV case surveillance maps from their local HARS. The data should be the same as that used in Table 3 of the Secondary Data Report. It should include HIV and AIDS cases that were reported to HARS through December 2012 and should be restricted to those cases that were newly diagnosed with HIV between January 2007 and December 2011. (*Note:* AIDS cases should be selected by the date of HIV diagnosis; not the date of AIDS diagnosis.) The data should also be restricted to cases that have an HIV transmission category of “heterosexual contact.” Cases that do not have a known HIV transmission category should be adjusted using the multiple imputation (MI) method described previously in Section 3.2. If possible, the data should exclude cases whose residence address is a hospital, jail, HIV counseling and testing site, or other facility where people are routinely tested for HIV. Including such cases would skew the geographic distribution of new HIV diagnoses to areas that contain these facilities. If the cases cannot be excluded, project sites should indicate the locations of the facilities on their HIV case surveillance maps using symbols. Providing this information will help prevent misinterpretation of the data on the maps.

Project sites should *not* geocode their HARS data specifically for creating their HIV case surveillance maps. If the data are already geocoded, project sites can map their cases by census tract; but if they are not already geocoded, project sites should map their cases by zip code. Lastly, since the objective of the HIV case surveillance maps is to identify areas in the principal city where new HIV diagnoses (and presumably, new HIV infections) are concentrated, project sites should present counts of new HIV diagnoses on their maps and *not* rates of new diagnoses.

Project sites should produce at least one map showing the number of new HIV diagnoses in each census tract or zip code of their principal city. Multiple maps of the principal city may be necessary if it is large and cannot be depicted on a single map. Additional instructions for creating the HIV case surveillance maps are listed below:

1. Title the maps with the name of the project site and the type of map.
2. Indicate the total number of new HIV diagnoses among heterosexuals in the principal city during 2007-2011 and the number and proportion of these new HIV diagnoses that are included on the map.
3. Clearly mark census tract or zip code boundaries.
4. Color census tracts or zip codes that have new HIV diagnoses orange and color tracts or zip codes that do *not* have any new diagnoses white.
5. Divide census tracts or zip codes into terciles (3 groups), quartiles (4 groups), or quintiles (5 groups) based on the number of new HIV diagnoses. Color the tracts or zip codes in each group with a different shade of orange and grade the shades of orange

using the lightest shade for census tracts or zip codes that are in the group with the smallest number of new HIV diagnoses and the darkest shade for those that are in the group with the largest number. Include a legend showing the range of numbers in each group and the corresponding shade of orange. When deciding how many groups to select, consider the number of census tracts or zip codes in the principal city, the range of numbers of new HIV diagnoses, and how well the various color gradations can be viewed on the map. Moreover, ensure that the group with the smallest number of new HIV diagnoses does not violate the local data release policy. For example, if a project site's local data release policy prohibits the release of HARS data stratified in groups of <3 cases, the group with the smallest number of new HIV diagnoses must have an upper bound of at least 3 new diagnoses. The group with the smallest number of new HIV diagnoses could thus have a range of 1–3, 1–4, 1–5, and so on; but it could not include just 1 or have a range of 1–2.

6. If mapping by census tract, add a simple hatch or symbol to census tracts with <200 residents to mark these tracts. This will highlight census tracts that are likely to have few or no new HIV diagnoses.
7. Include any important explanatory notes at the bottom of the map.
8. Save the maps as .pdf files or insert copies in the HRA and Maps Report.

In addition to the HRA and HIV case surveillance maps, project sites may choose to create another set of maps which overlay HARS data on the HRA maps. For example, on an HRA map, census tracts with the largest number of new HIV diagnoses could be marked with a hatch, symbol, or bold border. Similarly, project sites may also create a set of maps which overlay HARS data on the race/ethnicity maps.

### **NHBS-HET Maps (Strongly Recommended)**

To assess the geographic diversity of participants in prior NHBS-HET cycles, CDC strongly recommends that project sites map the census tract of residence for participants in the previous NHBS-HET cycle. By comparing these maps with the HRA, race/ethnicity, and HIV case surveillance maps, project sites can determine how well participants have represented communities at greatest risk of HIV infection. This comparison will either validate a project site's choice of locations for its field sites in the previous cycle or demonstrate the need to more effectively identify locations in the current cycle.

Project sites should use the data from the prior NHBS-HET cycle to create their NHBS-HET maps. Data should be restricted to participants who were eligible and completed an interview (variable COMPLETE= 1). It is not necessary for project sites to “clean” their NHBS-HET census tract data; they can just map whichever data can be successfully matched to a valid census tract number. Project sites should produce at least one map showing the number of NHBS-HET participants in each census tract of their principal city. Multiple maps of the principal city may be necessary if it is large and cannot be depicted on a single map. Additional instructions for creating the NHBS-HET maps are listed below:

1. Title the maps with the name of the project site and the type of map.

2. Indicate the total number of NHBS-HET participants who were eligible and completed an interview, as well as the number and proportion of these participants whose census tract of residence could be matched and mapped to a valid census tract.
3. Clearly mark census tract boundaries.
4. Color census tracts that have NHBS-HET participants purple and color tracts that do *not* have any participants white.
5. Divide census tracts into terciles (3 groups), quartiles (4 groups), or quintiles (5 groups) based on the number of NHBS-HET participants. Color the tracts in each group with a different shade of purple and grade the shades of purple using the lightest shade for census tracts that are in the group with the smallest number of participants and the darkest shade for those that are in the group with the largest number. Include a legend showing the range of numbers in each group and the corresponding shade of purple. When deciding how many groups to select, consider the number of census tracts in the principal city, the range of numbers of participants, and how well the various color gradations can be viewed on the map. Furthermore, ensure that the group with the smallest number of participants does not violate the local data release policy.
6. Identify the locations of field sites using a symbol.
7. Add a simple hatch or symbol to census tracts with <200 residents to mark these tracts. This will highlight census tracts that are likely to have few or no participants.
8. Include any important explanatory notes at the bottom of the map.
9. Save the maps as .pdf files or insert copies in the HRA and Maps Report.

If project sites wish, they may create maps showing sub-populations of NHBS-HET participants, such as a map of black participants or a map of Hispanic participants. As described previously for the other maps, project sites may also choose to overlay their NHBS-HET data. For example, on an HRA map, census tracts with the largest number of participants could be marked with a hatch, symbol, or bold border.



Reminder: Please refer to Section 3.3 for guidance on analyzing the various maps and summarizing the findings in the HRA and Maps Report. The report should include an explanation of how findings from the maps analysis could impact the locations of field sites and the selection of seeds. It should also discuss how the locations of field sites could present potential barriers to participation and identify how these barriers could be overcome. For example, if Hispanics are disproportionately impacted by the HIV epidemic in a project site, but they were underrepresented among participants in the previous NHBS-HET cycle, the project site could use its race/ethnicity map for the Hispanic sub-population to determine the best location for a field site that is readily accessible to Hispanics.

## 7 Ongoing Formative Research

### 7.1 Overview

Project sites are expected to conduct ongoing formative research throughout the cycle to ensure successful implementation of data collection. Ongoing formative research serves to monitor key indicators such as participation barriers, coupon distribution, social network diversity, sample characteristics, recruitment schemes, and the effectiveness of seeds and recruitment chains. Information collected helps project staff to improve project activities. When a site identifies a potential problem, project staff should discuss it with their CDC Project Officer and develop a plan to alleviate the problem and/or modify field operations.

Ongoing formative research will primarily be conducted by existing staff members: project coordinator, field supervisor, interviewers, and data managers. Sites may want to retain the services of an ethnographer. Additional information about procedures for conducting ongoing formative research will be provided in the NHBS-IDU/HET Operations Manual.

### 7.2 Methods

Ongoing formative research involves gathering additional information to address concerns identified from reviewing the process monitoring reports, feedback from the project staff, or other sources. This process consists of a combination of quantitative and qualitative data collection methods. All sites are expected to analyze demographic and enrollment data. When problems are identified through data monitoring, it might be necessary to conduct further formative research to gain a better insight into the problem. Sites are also expected to make observations inside and outside of the field site on a regular basis to document such things as coupon distribution to individuals who do not appear to be part of the recruiter's network, participation barriers, wait time and its impact on enrollment.

### 7.3 Factors to be monitored

Field sites are expected to monitor factors that could affect the validity of data, cause potential harm to participants, and site-specific needs. Information collected during ongoing formative research activities will help project staff better understand participation barriers and recruitment schemes so that local procedures can be developed and implemented to improve project activities. Additional details will be provided in the NHBS IDU-HET Operations Manual on how to use this information.

Examples of factors to monitor include:

- Enrollment numbers by demographics (age, race/ethnicity, and other relevant characteristics)
- Changes in enrollment (unexpected decreases or increases)
- Effectiveness of seeds and recruitment chains using Net Draw
- Effectiveness of eligibility screener
- Potential concerns about respondents' eligibility

- Missed appointments
- Recruitment of “strangers”/recruitment schemes
- Participation barriers
- Coercion
- Coupon distribution and redemption patterns
- **(IDU only)** Percentage of potential participants without physical signs of injecting drug use

## 8 References

- DiNenno E A, Oster A M, Sionean C, Denning P, and Lansky A. Piloting a System for Behavioral Surveillance among Heterosexuals at Increased Risk of HIV in the United States (2012). *Open AIDS J*, 6:169-76.
- Centers for Disease Control and Prevention. Characteristics Associated with HIV Infection among Heterosexuals in Urban Areas with High AIDS Prevalence -- 24 Cities, United States, 2006—2007. <http://www.cdc.gov/mmwr/preview/mmwrhtml/mm6031a1.htm>; published August 12, 2011.
- Denzin NK (1978). *The Research Act: A Theoretical Introduction to Sociological Methods*. New York, NY: McGraw-Hill.
- Kreuger RA, Casey MA (2000). *Focus Groups: A practical guide for applied research* (3rd ed.). Thousand Oaks, CA: Sage Publications.
- Mays N, Pope C (1995). Qualitative research: Rigour and qualitative research. *BMJ*, 311(6997):109-112.
- Patton MQ (1990). *Qualitative Evaluation and Research Methods*. Newbury Park, CA: Sage Publications.
- Schensul J J, LeCompte MD, eds. (1999). *The Ethnographer's Toolkit* (Vols. 1-7). Walnut Creek, CA: Altamira Press. (For content of specific volumes, go to <http://www.altamirapress.com>)
- Stimson GV, Donoghoe MC, Fitch C, Rhodes TJ (2003). *Rapid Assessment and Response Technical Guide*. World Health Organization (Department of Child and Adolescent Health and Development, and Department of HIV/AIDS). Geneva. <http://www.who.int/docstore/hiv/Core/Index.html>.

## Additional Resources

- Centers for Disease Control and Prevention (CDC). *International Rapid Assessment, Response and Evaluation Curriculum. Draft Trainer's Manual, 2004*.
- Hughes D DuMont K (1993). Using focus groups to facilitate culturally anchored research. *American Journal of Community Psychology*, 21(6) p: 775 – 806.
- Koester, SK (1994). The context of risk: Ethnographic contributions to the study of drug use and HIV. In: *The Context of HIV Risk Among Drug Users and Their Sexual Partners*. RJ Batties, Z Slobada, WC Grace, eds. NIDA Research Monograph 143. NIH Publication No. 94-3750.
- LeCompte MD, Schensul, JJ (1999). *Designing and Conducting Ethnographic Research*. In: *The Ethnographer's Toolkit, Vol. 1.*; JJ Schensul, MD LeCompte, eds. Walnut Creek, CA: Altamira Press.
- Marshall PL, Singer M, Clatts MC (1999). *Integrating Cultural, Observational, and Epidemiological Approaches in the Prevention of Drug Abuse and HIV/AIDS*. NIH Publication No. 99-4565, National Institute on Drug Abuse.
- Morgan DL, Krueger RA, King JA (1998). *The Focus Group Kit* (Vols. 1-6). Thousand Oaks, CA: Sage Publications.

- The data collection toolbox available at the UCSF Center for AIDS Prevention Studies website: <http://caps.ucsf.edu/uploads/pubs/manuals/pdf/GQBA.pdf>
- The Rapid Assessment and Response Technical Guide section available at the World Health Organization website: <http://www.who.int/docstore/hiv/Core/Contents.html>

## Appendix A Primary Data Collection Methods

### Overview

Based upon the secondary data review, the project staff should develop a plan for formative research activities to address the identified gaps in knowledge, determine sub-populations and topics that need further investigation, and guide the selection of individuals to be interviewed. Sites should solicit information from a diverse group of individuals to accurately reflect the characteristics of the target population, including the sub-groups of the target population's community who are at greatest risk of HIV infection (Schensul et al., 1999; University of Illinois, 2006).

Primary data collection can utilize a variety of methods including key informant interviews, focus groups, observations, street intercept surveys, and systematic social observations (Kreuger and Casey 2000; Lambert et al. 1995; Power 2002; Schensul and LeCompte 1999; Scrimshaw et al. 1991; Stimson et al. 2003; Needle et al. 2002; Trotter et al. 2001). **It is the responsibility of the project staff to identify the most appropriate ethnographic methods to obtain the necessary information about the MSA and the target population to guide a successful data collection.**

Ethnographic methods, such as key informant and focus group interviews, can provide guidance for the following:

#### Operations

- Identify locations, days and times potential participants are willing to be interviewed for behavioral surveillance data collection
- Explore options for resolving operational issues which may be problematic during data collection, such as coupon distribution, appointment systems vs. walk-in structure, recruitment schemes, challenges with peer recruitment
- Identify vocabulary used by local residents or target population to talk about HIV, sex behaviors, condoms, drugs, drug paraphernalia, and other key concepts related to the local culture
- **(IDU only)** Identify information for the eligibility screener such as local drug preparation and injection techniques, injection equipment, and price of drugs

#### Community Support

- Gain information about how or whether different communities in the MSA interact with each other (e.g. communities in different geographic locations in the city, communities with different racial compositions)
- Learn about gender and age dynamics in communities and how they may impact peer-recruitment
- Identify HIV prevention agencies or programs in the community
- Identify priority topics of concern in communities that could be explored with local questions

#### Target Population

- Identify barriers to working with the target population

- Explore HIV testing knowledge and/or stigma among the target population
- Identify social norms among the target population
- Identify organizations that serve the target population
- Identify key individuals that are knowledgeable about and have access to the target population in the community

**(IDU only)**

- Explore the extent of drug use and identify the major drugs used by IDUs in the MSA
- Identify locations where IDUs congregate
- Identify the main IDU networks in the MSA
- Identify any differences in drug-using networks by demographic characteristics of the members of the networks (e.g. gender, race, ethnicity, age)

A list of possible topics and questions to explore are presented in Appendix B. Project sites are encouraged to use these example questions and/or adapt as needed, and to share ideas for formative research questions with other project areas.

## Key Informant Interviews

*“Effective key informants are individuals who have broad knowledge of the research setting or deep knowledge of an important aspect of the research.” (The Ethnographer's Toolkit)*

*“[Key informants] have gained their knowledge by virtue of their position and experience in the community, their established networks of relationships, their ability to express themselves orally, and their broad understanding of their community.” (Schensul et al. 1999)*

Key informants are cultural and subject matter experts that can provide insight on the target population’s HIV-related behavior, potential barriers to recruitment and successful data collection. Interviewing several key informants allows for a cross-checking of information and helps ensure its validity and reliability (Schensul et al., 1999). The interview guide for key informant interviews should be semi-structured allowing for detailed and in-depth discussions.

In the context of NHBS, we identify two types of informants: key informants and community key informants. This distinction was created to accommodate individuals that can receive compensation for participating in the formative research activities (community key informants) and individuals that cannot (key informants). Each site is to determine whether individuals are key informants or community key informants. The table below provides guidance on the distinction between these two groups.

<b>Suggested Distinction Between Key and Community Key Informants</b>	
<b>Key Informants</b>	<b>Community Key Informants</b>
<ul style="list-style-type: none"> <li>• Staff of prevention and treatment programs</li> <li>• Community outreach workers</li> <li>• Community health workers</li> <li>• Representative from community based organizations</li> <li>• Law enforcement representatives/local police</li> <li>• Staff working for federally funded social service programs (e.g. WIC, unemployment office) <b>(HET only)</b></li> </ul>	<ul style="list-style-type: none"> <li>• Current and former target population members</li> <li>• Clients of prevention and treatment programs</li> <li>• Community leaders</li> <li>• Local researchers familiar with the target population</li> <li>• Individuals who acquired HIV through the cycle's transmission mode</li> <li>• Drug dealers <b>(IDU only)</b></li> <li>• Residents of HRAs <b>(HET only)</b></li> <li>• Commercial sex workers <b>(HET only)</b></li> <li>• HIV discordant couples <b>(HET only)</b></li> </ul>

## Focus Groups

*“Group interviews are interactive; members are encouraged to express their opinions and to dialogue about them with one another.” (The Ethnographer's Tool Kit)*

Focus groups are conducted with six to 12 individuals under the direction of a moderator (Kreuger and Casey 2000). Focus groups are particularly helpful in gaining insight into commonly held perceptions within the target population and eliciting information on community norms and assumptions. Due to their interactive nature, they typically produce information different from that obtained during other data collection methods. Information collected can be used to validate findings or explore issues expressed during other formative research activities.

The moderator's role is to promote interaction between members of the group and assure that the discussion remains on topic. Having a skilled moderator is critical to having a successful focus group. Project sites should also have a skilled note taker at each focus group as audio- or video-taping is not allowed. Typically, focus groups last from 1 1/2 to 2 hours. Groups with less than six people may have a tendency to lose energy while groups with more than 12 people may make it difficult for everyone to participate. The interview guide for focus groups should be semi-structured allowing for detailed and in-depth discussions.

Participants should be recruited from within the MSA and may include community stakeholders and leaders, staff from organizations that serve at-risk populations, and community residents. Focus groups should be divided into small groups of similar individuals. For example, focus groups can be created based on age, gender, race/ethnicity, role in the larger target community, or HIV status. It is important that focus groups provide a comfortable and trustworthy environment for all participants.

## Observations

*“The most natural and obvious way for observers to collect data is to simply watch, listen, and record what is happening around them.” (Rapid Assessment and Response Technical Guide)*

Observations build upon information gathered from other data sources and rely solely on what is seen by the researcher (Schensul et al., 1999; Trotter et al., 2001). Observations include counting, census-taking, and ethnographic mapping. Ethnographers can advise which would be most useful based upon site-specific needs. Observations can provide insight into the behavior of the target population, issues related to field sites, or a specific topic of interest. Observations can occur in settings such as neighborhoods, service organizations, parks, or high drug activity areas. For example, if a particular community center may be a possible location for a field site, observations may be conducted at the location to learn about high traffic times, safety considerations, accessibility, and whether it is an appropriate environment for the target population.

The table below outlines eight important aspects to keep in mind when conducting observations:

<b>Eight Aspects of Observations</b> (Stimson et al., 2003)	
Settings	Where is the location? Time? Physical layout? Objects present?
People	What types of people are present? How old are they? Why are they there?
Activities	What is going on? What are the people doing?
Signs	Are there clues that provide evidence about meanings and behaviors?
Events	Is this a regular occurrence or special event (e.g. meeting or disagreement)?
Time	In what order are things happening? Is there a reason for this?
Goals	What are the people trying to accomplish?
Networks	How do the people seem to know one another? Is it social or related to a type of business? Do the relationships change over time?

Observations can also provide insight related to:

### **(IDU only)**

- Contextual information about the nature of drug activity in particular neighborhoods (e.g. Where are drugs being sold? Is drug activity hidden or out in the open?)
- Interactions between different groups of drug-using networks (e.g. between men and women or different racial groups)

### **(HET only)**

Interactions between different demographic sub-groups in low income neighborhoods in the MSA

## Street Intercept Surveys

Street intercept surveys are informal discussions about topics relevant to NHBS with individuals in key locations throughout the MSA. These surveys are an easy and useful method of soliciting spontaneous input on such topics as community support and feasibility of NHBS. Street

intercepts also offer the opportunity to disseminate relevant information about the study (e.g. project purpose, anonymity of responses, the benefits for the community) and may be a way to identify potential key informant or focus group participants.

Surveys should be no longer than five minutes and are typically conducted where the person is intercepted. During the intercept, consider collecting basic demographic or geographic information (e.g., age, ethnicity/race, and zip code/neighborhood) so responses can be stratified if needed. Consent is not needed for street intercepts and compensation is not provided.

## **(HET only) Systematic Social Observations**

The method of combining observations and street intercepts is called systematic social observation and is a standardized approach for directly observing the physical, social, and economic characteristics of neighborhoods. Systematic social observations can also be used to confirm that census tract data are still relevant and accurate for neighborhoods with high rates of poverty. The data for HET are intercensal estimates of poverty; they are not Census data, and so it is important to ensure that areas are in fact “poverty areas”. Project sites do not need to conduct systematic social observation in each census tract identified as a HRA, but may choose to do so in some census tracts where there are some questions about whether the data are reflective of poverty areas. Systematic social observation is also useful for understanding the target population and garnering community support for NHBS-HET.

This information may help project sites identify targeted community programs and appropriate storefront locations. Sites interested in using this method should discuss it with their Project Officer before proceeding. It is important to note that information gathered through this process should not be used to exclude a census tract from the list of HRAs or to include a census tract that was previously not listed as an HRA.

A number of studies have shown that neighborhood physical disorder is a valid proxy for poverty areas. These indicators of physical disorder are used in the systematic social observation techniques described below. An example of a study that used observation of neighborhood physical disorder as a proxy for poverty and its relationship with STDs is by Cohen et al. (2000) on neighborhood conditions and gonorrhea rates in New Orleans neighborhoods. They created a “broken window” index, or a measure of neighborhood deterioration. The broken window index includes things such as rating the quality of physical structures (both residential and non-residential), garbage accumulation, graffiti, abandoned cars, billboards and signs, and the general upkeep of non-structures (such as parks, open spaces, and institutional properties).

The study found that the broken window index was more strongly associated with STD rates in the neighborhoods. For NHBS-HET, neighborhood physical disorder may be used to better understand which census tracts are in poverty, or to gain contextual information about these neighborhoods.

## **Step 1: Setting up to Observe an Area**

For the purposes of systematic social observation, census tracts may be too large of a geographic unit to study. It may be useful to break down the census tracts into block groups for sampling and observation at the neighborhood level.

An observation checklist has been created for this task and is included later in this appendix. Within each block group, the observational unit for which the checklist instrument will be used is the street segment – a length of street between cross streets. One checklist will be used for each sampled street segment.

To conduct the actual observations of street segments, staff can choose to either conduct a “windshield survey” by staying in the automobile to make observations or to make observations on foot. A windshield survey can cover more area in limited time, but there is less visibility because you are not as able to gain a good “360 degree” view, and there is less interaction with the physical surroundings.

In some neighborhoods, observation from a slow-moving vehicle can draw suspicion and negative perception by residents. Getting out of the vehicles allows neighborhood residents to approach and ask questions. Which of these methods you follow will depend on the personal preference and comfort level of project staff as well as time and weather considerations.

For each census tract in which you are verifying poverty rates, it may be helpful to break it down into block groups for sampling street segments and reflecting the physical condition of neighborhoods. You should be able to do this in GIS and create maps that will help you to sample street segments in a way that covers neighborhood variability.

Within each block group, include all commercial and institutional street segments in your sample. Census tracts chosen for the observations are based on residence of the target population, and will be mostly residential. Because commercial/institutional street segments should be a relatively small proportion of the total, you should complete an observation checklist for each. For the residential street segments, because the data from observation won't be analyzed statistically it is not necessary to select a sample via any type of randomization. Estimate the total number of residential street segments in the block group, using the GIS map, and determine 25%. Then select that number of residential street segments on the map, trying to distribute them around the block group in order to sample most areas of the neighborhood. You can then use the map to find and conduct observation on those street segments.

## **Step 2: Systematic Observation Checklist**

The sample systematic observation checklist included in this chapter contains indicators for a number of different variables. For each street segment you will mark which type of segment it is (residential or commercial). If it is a residential street segment, you will indicate the type(s) of housing found on that segment.

For both commercial and residential street segments, you will mark what you see in terms of the broken window index indicators: graffiti, garbage accumulation, condition of structures

(including actual broken windows), abandoned or burned buildings, abandoned cars, the presence or absence of sidewalks and street lamps.

For commercial street segments, you will mark all of the types of commercial institutions you see. Whether a commercial zone has a bank branch, or whether it has check cashing services instead, is an indicator of socioeconomic and demographic factors. The same is often true for whether there is a supermarket or chain grocery store, or whether there are only convenience stores. The presence of sit-down restaurants relative to fast food outlets is also an indicator of neighborhood quality. Although the economy has created an issue of closed businesses even in some better neighborhoods, it is still important to look for closed or abandoned stores and malls.

### **Step 3: Talking to Key Informants**

Even the best systematic observation will not tell you everything about a neighborhood. You may be able to verify whether the neighborhood seems to match the poverty rate calculated from the intercensal data estimates, but only in a cross-sectional “snapshot.” To learn more about how the neighborhood is either improving or declining, you may want to talk with people from the neighborhood that have a knowledgeable, un-biased, and longitudinal perspective, such as a community leader, real estate broker or agent with experience in the neighborhood (and who is not just a booster but willing to give an unvarnished opinion), law enforcement representative with experience in the neighborhood, or local government representative like a city council representative or alderman.

As always, make sure you have IRB approval before talking to anyone for purposes of NHBS-HET.

To start the interview, you will want to introduce the purpose of the project and what you’re trying to accomplish. Then show the informant the hard-copy map of the census tract, so that he or she knows exactly the area you’re discussing. Then ask the small list of questions about how the neighborhood has changed over the past 10 years (sample questions are provided in this appendix). Try to get an impression of how the neighborhood compares currently to how it was 10 years ago, and how it is changing currently.

### **Step 4: Analyzing the Data**

Even though the techniques described here are not a true “ethnography,” staff should take an ethnographic approach. That is, data collection and analysis are a somewhat iterative process. The data collection itself should be systematic, in order to provide uniformity across data collectors and across sites, but the decisions about what the data “mean” are qualitative. For example, a commercial district with a bank branch, supermarket, and functioning storefronts is most likely not a high-risk disordered area, even if there is some garbage and a little graffiti. Along with your judgment about the observation data, you can use what you learn from interviews to triangulate your analysis. It is probably best if you conduct the interview(s) after you complete observation, so that you can use the interview to confirm or counter your impressions, and to put the impressions from observation in context. As stated above, project areas are encouraged to employ the services of a trained ethnographer to analyze this data.

# Sample Systematic Observation Checklist for Neighborhoods

Date: \_\_\_\_\_

Rater ID: \_\_\_\_\_

Start time: \_\_\_\_\_ End time: \_\_\_\_\_

Census Tract \_\_\_\_\_

Block Group \_\_\_\_\_

Street Name \_\_\_\_\_

Street Segment \_\_\_\_\_

## 1. TYPE OF Zone

- Residential
- Commercial
- Industrial

## 2. TYPE OF STREET SEGMENT

- Major thoroughfare/busy street
- Moderately busy thoroughfare
- Side street
- One-way street
- Cul-de-sac street
- Dead-end street

## RESIDENTIAL LAND USE TYPES

### 3. RESIDENTIAL TYPES (check all that apply)

- None (skip to #5)
- Single-family detached dwellings
- Multiple occupancy (2–6 units)
- Apartment building (7 or more units)
- Housing authority projects
- Trailer home/mobile home
- New construction
- Renovation

### 4. MAIN RESIDENTIAL TYPE (check one)

- Single-family detached dwellings
- Multiple occupancy (2–6 units)
- Apartment building (7 or more units)
- Housing authority projects
- Trailer home/mobile home
- New construction
- Renovation

**[Skip to #13 for more residential indicators]**

**[Skip to #18 for more nonresidential]**

## NONRESIDENTIAL LAND USE TYPES

### 5. NONRESIDENTIAL TYPE

- Retail (strip mall)
- Retail (indoor mall)
- Retail (storefront)
- Manufacturing
- Professional offices
- Warehouse

### 6. INSTITUTIONAL

- Fire station
- Police station
- Courthouse
- Government office
- Library
- Parking lot

### 7. SCHOOLS/CHILD CARE

- Daycare centers
- Public school (primary-secondary)
- Technical school
- Colleges/universities
- Private school

### 8. FOOD

- Convenience stores
- Fast-food/takeout places
- Restaurants
- Supermarket/grocery stores
- Liquor stores

### 8. FINANCIAL SERVICES

- Banks
- Check-cashing service
- Tax refund service

### 10. USED GOODS SALES

- Pawn shop
- Second-hand stores

### 11. RECREATION

- Bars
- Movie theater
- Recreational center
- Sex entertainment shops
- Video games/pool/bowling

### 12. RELIGIOUS

- Cemetery
- Church/religious center
- Funeral home

**RESIDENTIAL PHYSICAL CONDITION**

**13. OVERALL CONDITION OF MOST RESIDENTIAL UNITS**

- Excellent
- Good condition/well kept
- Fair condition
- Poor/deteriorated condition
- Mixed condition (extreme differences)

**14. \_\_\_\_\_ NUMBER OF RESIDENTIAL UNITS**

**15. \_\_\_\_\_ NUMBER OF FOR SALE OR FOR RENT SIGNS**

**16. \_\_\_\_\_ NUMBER WITH FORECLOSURE/BANK-OWNED SIGNS**

**17. \_\_\_\_\_ NUMBER OF BURNED, BOARDED UP, OR ABANDONED**

**NONRESIDENTIAL PHYSICAL CONDITION**

**18. OVERALL CONDITION OF MOST OF THE BUILDINGS**

- Excellent
- Good condition/well kept
- Fair condition
- Poor/deteriorated condition
- Mixed condition (extreme differences)

**19. PROPORTION WITH SECURITY BARS/GRATING**

- None
- Less than one-third
- One-third to one-half
- More than half

**20. PROPORTION OF BURNED, BOARDED UP, OR ABANDONED**

- None
- Less than one-third
- One-third to one-half
- More than half

**PUBLIC SPACE: RESIDENTIAL AND NONRESIDENTIAL**

**21. GENERAL CONDITION OF PUBLIC SPACE**

- Good
- Fair
- Poor
- Mixed

**22. PROPORTION OF LAND THAT IS VACANT/UNDERDEVELOPED**

- None
- Less than one-third
- One-third to one-half
- More than half

**23. OVERALL CONDITION OF UNDERDEVELOPED PROPERTY**

- Good
- Fair
- Poor (illegal dumping)

**24. AMOUNT OF LITTER**

- None
- A little
- A moderate amount
- A considerable amount

**25. TYPE(S) OF LITTER (select all that apply)**

- Paper, cans/bottles nonalcoholic
- Cans/bottles alcoholic
- Drug paraphernalia
- Furniture
- Tires
- Clothing items
- Appliances
- Abandoned vehicles
- Other \_\_\_\_\_

**26. AMOUNT OF GRAFFITI**

- None
- A little
- A moderate amount
- A considerable amount

## Sample Neighborhood Knowledge Questionnaire

Hi, I'm \_\_\_\_\_ from the \_\_\_\_\_ Health Department. We're doing a project to help improve the health of people living in neighborhoods, and we're going around and doing observations and talking to people who know about the communities where we're working. We especially want to learn about how particular neighborhoods have changed over the past 5 or 10 years, either by improving or getting worse. We would like to talk with you because [give reason]. Anything you tell us will be strictly confidential. We will not share your name with anybody and will not connect what you say with your name in any documents or reports. You don't have to answer anything you don't want to, and you can decide to end the conversation at any time. Your opinion is valuable to us in our efforts to improve the public's health, and anything you can share about the neighborhood is greatly appreciated.

[Record what role the person fills in the neighborhood (e.g., community leader, police, business person)]

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- 1) Do you think you have knowledge about how things have changed or stayed the same in this neighborhood over the past 5 or 10 years? Yes No [If no, ask if he/she can recommend somebody who would have this kind of knowledge.]  
Let me show you this map just to make sure we're talking about the same area. [Show the map of census tract.]
- 2) Do you live in this neighborhood? Yes No
- 3) [If business person, police, etc.] How long have you (been a police officer) (owned a business) (sold real estate) (been a community leader) in this neighborhood? \_\_\_\_\_
- 4) Over the past 10 years [5 years if that is the extent of their knowledge], how would you say the neighborhood has changed?  
\_\_\_\_ Improved a lot  
\_\_\_\_ Improved a little bit  
\_\_\_\_ Stayed the same  
\_\_\_\_ Gotten somewhat worse  
\_\_\_\_ Gotten much worse
- 5) How would you describe the changes that you have seen happen in this neighborhood over the past 10 [5] years? [Probe for poverty, crime, drug-selling and use, other risky behaviors, physical conditions, real estate market, business conditions.]
- 6) Is there anything else you can tell me that might help me understand poverty in this neighborhood and how it might influence drug use, crime, or other risky behaviors that happen here?
- 7) Who else do you think I should talk to who will have a perspective on how the neighborhood has changed over the past 10 [or 5] years? \_\_\_\_\_

Thank you very much for taking the time to talk to me about the neighborhood. We are hoping that our efforts will help prevent illness in the city, and your input is very helpful. [Give business card.] Please feel free to contact me if you have any questions or additional input.

## Appendix B Sample Questions for Key Informant Interviews and Focus Groups

Findings from the secondary data review and discussions with the Project Officer should aid in determining appropriate topics and questions for investigation. Project sites are invited to use these topics and questions if helpful based upon site-specific needs. Sites are also encouraged to develop their own questions and share questions with other sites.



Reminder: When using these questions during an interview, please replace the term ‘target population’ with ‘IDUs in the community’ or ‘residents of the community’ according to the appropriate cycle.

### Operations

#### *Field site locations and operations*

- Are you familiar with an appropriate meeting space (e.g. office space, building, neighborhood location) to the conduct the study?
- We’re thinking of using <x> as a study site. Would potential participants feel comfortable going there to do an interview? If not, why not?
- Is <x> study site accessible to potential participants? Is it safe for participants and project staff?
- What kinds of barriers could keep potential participants from coming to <x> study site for an interview? What could we do to make it easier for people to come to this site?
- What neighborhoods and organizations in the city are friendly/unfriendly to the target population?
- Should we set up an appointment system for study participants, or do you think they would rather walk in during office hours?
- What days of the week/time of day would be best for our office hours?

#### *Incentives*

- We will give eligible participants an incentive for completing a survey that will take approximately an hour to complete and for taking an HIV test. What would be appropriate incentive amounts?
- What form of incentive (cash, Visa gift card, retail gift card, etc.) would be most valuable to participants in our study?
- If we use (cash/visa card/store card) as an incentive, what problems might we encounter?

#### *Staffing*

- What criteria should we consider when hiring project staff?
- What are the characteristics of the ideal interviewer for this project?

*Names of local public health insurance programs (to aid interviewers in coding type of insurance during survey implementation)*

- What are the names of the public health insurance programs available locally? Are there abbreviations or “street names” for these programs?

## Learning about the Community and Garnering Support

### *Identifying advocates for NHBS*

- Who are key individuals knowledgeable about and have access to the target population?
- Who are key people and groups that advocate for issues affecting the target population?
  - Which have the strongest ties to the target population? To the sub-groups?
- Who are key people and groups that could advocate for NHBS activities?
  - What are the best ways for NHBS to gain acceptance of stakeholders and community members of the target population? (e.g., CAB meeting, social marketing, one-on-one meetings)
  - Who could help us work with the target population?
- Do you know of any people, meetings, and/or activities in the community that would help us advocate for NHBS?
- What NHBS findings would be beneficial to you/your organization?
  - What are key topics related to HIV risk and/or prevention among the target population that you would suggest being explored with local questions?

## Learning about the Target Population

### *Demographics and social networks*

- What are the different demographics of the target populations and/or sub-populations (i.e. by race or ethnicity/gender/geographic location [for IDU: type of drug injected])?
  - What makes them different from each other?
  - What are the gender and age dynamics in communities and how could they impact peer- recruitment?
  - How does network size vary among groups?
  - Which of these populations/networks have the largest impact on HIV prevalence in the MSA?
  - How can we reach each group/network? Who are the gatekeepers?
  - What specific groups within the target population do we need to focus on?
- How do the different networks interact with one another?
  - For networks that don’t interact, why not?
- How could the demographics and social networks of the target population affect the successful implementation of NHBS?
  - How can these barriers be overcome?

### *Behaviors, social norms and perceptions*

- What vocabulary is used by local residents to think and talk about HIV, sex behaviors, condoms, and other key concepts related to HIV risk and prevention in the local culture?
- What are the social norms among the target population (e.g. relationships between men and women; interactions between younger and older people; [for IDU]:the influence of the drug culture in communities]).

- How could these potentially impact recruitment?
- What are the perceptions about HIV infection and/or HIV testing held by the target population?
  - Are people knowledgeable of how HIV infections occur?
  - Are people knowledgeable about how to reduce their risks of infection?
    - What are the barriers to risk reduction?
  - Are people aware of their serostatus?
    - Among those not, are they interested in knowing?
  - Is there stigma or fear about being tested?
  - What are the barriers to being tested?
- How could the behaviors, social norms, and/or perceptions of the target population affect the successful implementation of NHBS?
  - How can these barriers be overcome?

*Issues related to working with the target population*

- What challenges have you encountered when working with the target population (e.g. trust, participation rates, testing, incentives, community support)?
  - Can you offer any solutions or ways to overcome these challenges?
- What should NHBS do to foster trust among the target population?
  - Does the target population perceive researchers, or other community outsiders, differently?
    - If so, how should we foster trust in both groups?
- In general, what are the challenges facing the target population that could impact data collection?
  - Can you offer any solutions or ways to overcome these challenges?
- What do you think will be barriers to NHBS survey participation and/or HIV testing for potential participants?
- What are HIV prevention challenges experienced by the target population?
  - What are potential solutions to such challenges?
- How could issues related to working with the target population affect the successful implementation of NHBS?
  - How can these barriers be overcome?

*Use and extent of prevention services available for target population; gaps in services*

- What types of HIV prevention services and programs are available and/or used by the target population in the community?
  - What are the prevention priorities for local services and programs?
  - Where do people go for these services?
  - To what extent are services used by the target population?
  - What are the service needs of the target community?

***(IDU only)***

General

- What is the extent of drug use in the MSA?
- What are the major injection and non-injection drugs used by IDUs in the MSA?
- Where do IDUs congregate, where does drug activity occur, and where are needles obtained?

- What is the vocabulary used by IDUs to think and talk about drugs, drug paraphernalia, and other key concepts related to the local drug culture;

#### Prevention-related

- What types of drug treatment programs are available in the community?
- Do syringe exchange programs operate in the MSA? If so where?
- What are the (local and state) laws prohibiting or permitting syringe exchange in the MSA?

#### Survey-related

- What criteria should we use to determine if someone injects drugs or not? What physical signs could we look for?
- How is <drug type> prepared for injection? How is it injected?