

**National HIV Behavioral Surveillance (NHBS)**

# **NHBS Formative Assessment Approach and Methods**



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# Table of Contents

<b>1 Introduction</b>	
1.1 Background .....	4
1.2 Formative Assessment Goals .....	4
<b>2 Staffing</b>	
2.1 Overview .....	6
2.2 Ethnographer .....	6
2.3 Project Coordinator.....	6
2.4 Project Staff.....	7
<b>3 Formative Data Collection Methods</b>	
3.1 Overview .....	8
3.2 Secondary Data Review.....	8
3.3 Primary Data Collection Methods.....	8
<b>4 Garnering Community Support</b>	
4.1 Overview .....	12
4.2 Methods of Garnering Community Support .....	12
4.2a Meetings .....	12
4.2b Collaborations .....	13
4.2c Marketing materials.....	13
4.2d Community advisory boards .....	13
<b>5 Ongoing Formative Assessment</b>	
5.1 Overview .....	15
5.2 Data Collection Methods .....	15
5.3 Data Monitoring.....	15
<b>6 Data Analysis</b>	
6.1 Overview .....	16
6.2 Rapid Data Analysis Techniques.....	16
6.2a Data collection debriefs .....	16
6.2b Identifying emerging themes.....	16
6.3 Triangulation of data.....	16
<b>7 Privacy and Institutional Review Board Procedures</b>	

## 1.1 Background

This document provides guidance on the methods for conducting formative assessment activities to inform the implementation of National HIV Behavioral Surveillance (NHBS). NHBS conducts ongoing, bio-behavioral surveys among key populations at risk for HIV infection in the U.S., including gay, bisexual and other men who have sex with men (the MSM cycle), persons who inject drugs (the PWID cycle), and heterosexually active persons at increased risk for HIV infection (the HET cycle). NHBS also conducts supplemental cycles among additional key populations. Information on the populations sampled for NHBS can be found in the respective cycle documents and the *NHBS Round 6 Model Surveillance Protocol*. NHBS is implemented across multiple project areas and using multiple sampling methods, including respondent-driven sampling (RDS) and venue-based sampling (VBS). Given the complexity of NHBS, formative assessment is critical to informing NHBS operations and garnering community support to ensure a successful implementation. The information in this document applies to all NHBS cycles and includes important considerations for staffing, formative data collection and analyses. Formative assessment activities tailored for each NHBS population are described in separate, cycle specific formative assessment manuals.

Project areas are expected to review information in the *NHBS Round 6 Model Surveillance Protocol* to understand the overall methods for NHBS prior to starting formative assessment activities. Project areas should use this document alongside cycle-specific guides to plan and implement formative assessment activities.

During formative assessment, NHBS project areas will gather information through two main approaches to data collection: 1) reviews and analyses of secondary data (e.g., HIV surveillance data) and 2) primary formative data collection (e.g., interviews with key informants). To maximize the effectiveness of these formative assessment activities, project areas should employ an iterative process; information obtained from reviewing secondary data should inform primary data collection, which should then validate or provide further insight into the findings from reviewing secondary data. Using this iterative process, project areas will be able to realize the formative assessment goals outlined below. Of particular importance, formative assessment will enable project areas to identify potential obstacles to field operations, such as participation barriers, and develop solutions to minimize or eliminate these obstacles.

## 1.2 Formative Assessment Goals

The principal goals of NHBS formative assessment are to:

- Describe HIV epidemiology and prevention efforts among populations being surveyed
- Engage community of interest
- Inform NHBS sampling and operations

Each cycle's formative assessment supplement also has specific objectives relevant to that respective population being surveyed.

## 2.1 Overview

Ideally, project staff conducting formative assessment should include an ethnographer or a researcher with close knowledge of ethnographic methods and the NHBS population, the project coordinator, and at least two additional staff members.

## 2.2 Ethnographer

Project areas may wish to hire an ethnographer to lead their formative assessment activities. If an ethnographer is hired, the principal investigator is responsible for making sure that the ethnographer's work remains focused on the NHBS formative assessment goals (**Section 1.2**). The ethnographer must understand that the purpose of the formative assessment process is to inform and guide the successful collection of NHBS data.

The ideal ethnographer has training in anthropology, sociology, or qualitative methods in public health with experience working with a range of ethnographic methods, such as observations, key informant interviews, focus groups, and brief intercept surveys. To be most effective, the ethnographer should also be familiar with the local population of interest and its various sub-populations. Ethnographers can be found through the anthropology, sociology, and public health departments of local universities and colleges, at community-based research institutes, or in the local health department.

Even if an outside researcher is hired as the ethnographer, NHBS project staff should still remain actively involved in formative assessment activities. Project staff should train the ethnographer in NHBS methodology that will be used during the cycle, more information on this is provided in **section 2.3**. The ethnographer should train project staff in the formative assessment process and its methods of data collection, and they should oversee the staff's work. The ethnographer should also provide the principal investigator and project coordinator with periodic updates on the progress of formative assessment and the findings. The ethnographer should also ensure that community connections established during formative assessment are shared with other NHBS staff who will be implementing data collection. To ensure that formative assessment activities are completed successfully and in a timely manner, the principal investigator or project coordinator should meet with the ethnographer at the beginning of the project cycle to develop a set of deliverables and a timeline for achieving them.

## 2.3 Project Coordinator

The project coordinator is responsible for reviewing secondary data to inform the local HIV epidemiology, assisting the ethnographer, and monitoring the formative assessment activities. Very importantly, the project coordinator is responsible for incorporating the formative assessment findings

into staff trainings and plans for data collection and ongoing formative activities. The project coordinator should help the ethnographer by providing them with background information on the project area, the recruitment methodology, and the HIV epidemic among the local population of interest. The project coordinator should also help the ethnographer identify and contact community partners and key informants for interviews.



If a project area does not hire an ethnographer or other outside researcher to lead its formative assessment activities, the project coordinator should assume the duties outlined for the ethnographer in **Section 2.2**.

## 2.4 Project Staff

At least two project staff should assist the ethnographer with formative assessment activities. Their responsibilities could include the following:

- Garnering community support
- Collecting secondary data for review
- Identifying and contacting community members, community organizations, and key informants to participate in interviews or focus groups
- Helping with interviews and focus groups
- Conducting observations
- Conducting brief intercept surveys
- Preparing for implementation of NHBS methodology ( i.e., RDS or VBS)

# 3

## Formative Data Collection Methods

### 3.1 Overview

Formative assessment methods include 1) secondary data review and 2) primary formative data collection through key informant interviews, focus groups, observations, and brief intercept surveys. This document provides in-depth guidance on NHBS formative assessment methods across cycles. Cycle specific requirements and deliverables are described in the cycle-specific NHBS Formative Assessment Manuals. This recorded presentation provides an overview of qualitative methods for recruitment, interviewing and data analyses. A brief description of each method commonly used as a part of NHBS formative assessment is provided below.

### 3.2 Secondary Data Review

Secondary data are data that have been previously collected by other researchers, surveillance systems, or registries. Previous NHBS cycles are key sources of data and operational information. Reviewing lessons learned from the previous cycles can help identify potential recruitment and operational barriers and solutions for overcoming them, as well as areas that need more exploration. Finally, other important secondary data sources may include reviews of local peer-recruitment or venue-based recruitment and prevention activities (e.g., HIV testing in MSM venues, peer recruitment among PWID for other surveys) among NHBS populations of interest including within health departments or local academic institutions.

Secondary data are a critical component of formative assessment because they lay the foundation for the next steps in formative assessment and provide an epidemiologic profile of the local HIV situation. Gaps in information in the secondary data will help project areas develop primary data collection plans and determine where to focus their primary data collection efforts. Project areas can also use the secondary data to identify potential collaborators, key informants within the health department and populations of interest, as well as to identify possible focus group participants. After formative assessment activities have been completed and field operations have begun, the secondary data can serve as a reference for monitoring how well participants reflect the local HIV epidemiology and the sub-populations at greatest risk for HIV infection.

### 3.3 Primary Data Collection Methods

There are several primary data collection methods that can be used to obtain data necessary for informing operations. Below are commonly used methods for NHBS. Additional detail on aims and sample data collection tools for primary data collection methods tailored to populations surveyed can be found in the cycle-specific NHBS Formative Assessment Manuals.

### **Key Informant Interviews**

Key informants are cultural and subject matter experts who can provide insight into populations of interest. For the purpose of NHBS, there are two main types of key informants: “community key informants” and “professional key informants.” Community key informants (CKIs) are members of the community or volunteers at community-based organizations (CBOs) rather than paid professionals. An example CKI in NHBS-PWID may be a client of a local syringe services program (SSP) who also exchanges syringes for others in the community who do not attend the program. An example CKI in NHBS-HET may be a long-time community resident with in-depth knowledge of the neighborhood. An example CKI in NHBS-MSM may be a Black man attending a well-known gay club who reports having sex with men as part of a brief interview. Since CKIs are interviewed on their personal time, they should receive compensation for participating in the interview. Professional key informants (PKIs) are paid staff and managers of CBOs and other public health and research organizations with knowledge of the population of interest, and are typically not entitled to compensation for their time.

It is often helpful for project areas to start primary data collection by interviewing key informants with more general information to gain an overall understanding of the population, and then moving to sources with more in-depth information to address any issues that remain unclear or are of particular importance locally. In addition, to help ensure the reliability and validity of the data, project areas should interview several key informants and cross-check the information they provide.

The *NHBS Round 6 Model Surveillance Protocol* provides model consent forms for both types of key informants that can be modified for local use.

### **Focus Groups**

Focus groups are small group discussions facilitated by a moderator. They are especially helpful for gaining insight into commonly held perceptions within the populations of interest and for eliciting information on community norms. Focus groups can also be used to confirm formative assessment findings or to explore findings in greater depth. Due to their interactive nature, focus groups often yield information that is different from the information gathered with other data collection methods.

A skilled moderator is critical to the success of a focus group. The moderator’s role is to promote interaction between members of the group and to make sure that the discussion remains on topic. Because a focus group cannot be audio- or video-taped, a note taker is needed to record the discussion. Typically, a focus group lasts from 1½ to 2 hours and has 6 to 12 members. Groups with fewer than 6 members tend to lose energy while those with more than 12 members may not allow everyone to participate fully. As with CKIs, focus group participants participating outside of their professional capacity should be compensated for their time. Focus groups should ideally take place in-person rather than virtually.

Focus group participants should be recruited from within the project area and can include the population’s members and community leaders, as well as staff from CBOs that serve the population. To facilitate a free and open discussion, focus groups should be composed of members with similar demographic characteristics. For example, focus groups could be organized based on age, race/ethnicity, or HIV status. It is also important for focus groups to provide a comfortable and trusting environment for all who participate.

## Observations

Unlike information collected from interviews, observations rely solely on what is seen by the observer. They can be used to both validate and build on information gathered through other data sources. Observations can provide insight into the behavior of the population, issues related to field sites, or a specific topic of interest. Observations can occur in settings such as neighborhoods, service organizations, parks, or SSPs, sometimes referred to as syringe exchange programs, and high drug activity areas. For example, if a particular community center is being considered as a possible field site, observations can be conducted at the community center to learn about accessibility, safety, and appropriateness. Observations are of particular importance for VBS as they are essential for properly assessing potential MSM venues for eligibility and accessibility. For example, by observing a venue's attendees and layout, project areas can determine the level of attendance at the venue, the demographic characteristics of the venue attendees, and the logistics and safety of conducting field operations at the venue.

Researchers have identified eight aspects of observations that can help guide project staff when conducting observations. These aspects have been adapted for NHBS and are summarized in **Table 1**.

**Table 1. Aspects of observations**

Domain	Description
Settings	Where does the observation take place? When? What is the physical layout?
People	What types of people are present? How old are they? What is their race/ethnicity? How many are present?
Activities	What is going on? What are the people doing?
Events	Is this a regular occurrence or is it a special event?
Signs	Are there clues that provide evidence about meanings and behaviors?
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 present seem to know one another? Is it social or related to a type of business? Do the relationships change over time?

Adopted from: Stimson GV, Fitch C, Rhodes T (1998). The rapid assessment and response guide on injecting drug use. World Health Organization Substance Abuse Department. (Available [here](#))

## Brief Intercept Surveys

Brief intercept surveys (BIS) are very short surveys that focus on a few key topics, like assessing network size, gauging interest in participating in NHBS, or identifying MSM venues. They can be open- or close-ended and should not take more than five minutes to administer. If project areas need additional

information on specific sub-populations or communities, they can target their BIS to these groups. Consent is not needed for BIS, and compensation should not be provided.

## 4

# Garnering Community Support

## 4.1 Overview

The success of NHBS will depend largely on a project area's ability to garner support from the community, as well as the broader population of interest. Greater community acceptance of NHBS will result in a higher rate of participation in the survey. To have the most impact, project areas should elicit support from a wide variety of community members and organizations. Community partners should have diverse backgrounds and they should represent different sub-populations of interest, especially those sub-populations most impacted by the HIV epidemic and those underrepresented in previous cycles (e.g., young persons in NHBS-PWID, Hispanic/Latino people in NHBS-HET, and Black men in NHBS-MSM).

Examples of community partners include the following:

- Staff of community-based organizations (CBOs)
- Providers of HIV and STD prevention and treatment services to the population of interest
- Members of community advisory boards
- Researchers whose work focuses on the population
- Political leaders and government officials
- Police and law enforcement officials
- Leaders of local MSM community
- MSM venue owners and managers
- Persons who inject drugs
- Members of the LGBTQIA media
- Staff of substance abuse treatment and recovery programs
- Staff of syringe exchange programs
- Local LGBTQIA Chamber of Commerce and Bar Owners' Associations

When garnering community support, project areas should explain the goals and objectives of NHBS and describe its data collection methods, and prior findings (e.g., sharing locally developed fact sheets and data products). Project areas should emphasize that the key objective of NHBS is to understand HIV and other health disparities in the population *in order* to better serve their health needs and to guide the development and implementation of high-impact HIV prevention programs for them.

## 4.2 Methods of Garnering Community Support

### 4.2a Meetings

Meetings with community partners provide an opportunity for project areas to explain the project, describe its goals, introduce staff members, share the project logo to increase brand recognition, and answer questions. Meetings can be one-on-one or involve multiple partners, and may include public meetings (e.g., at a local community center or CBO) and can be in-person or remote. These meetings are also an excellent forum for presenting findings from previous NHBS cycles, demonstrating how NHBS

data are used to develop and evaluate local policies and programs, and identifying and assessing important topics for local questions in the upcoming cycle. These meetings can also serve as a jump off to PKI interviews which are described above (**section 3.3**). By involving community partners in the development of local questions, project areas can gain valuable knowledge and community insight, while giving community partners a vested interest in the success of NHBS. As a result, community partners may become more likely to support and promote the project.

#### **4.2b Collaborations**

Project areas should collaborate with other health department programs, CBOs, and academic institutions that conduct HIV prevention outreach and research among the NHBS population of interest. Project areas should meet with the managers of these organizations and programs to explain NHBS goals and objectives, the population sampled, the overall methods and field operations, and discuss the opportunity to collaborate to provide appropriate referrals to health and social programs. These collaborations foster cooperation and positive community relations.

#### **4.2c Marketing materials**

Project areas should create a logo and marketing materials, like informational flyers or posters, to identify the project and promote community awareness. During formative data collection, community partners, and members of the population should be asked about the types of logos and marketing materials that would be most appealing to potential participants. They should also be asked about the most effective marketing strategies for reaching the local population.

The logos and marketing materials developed by project areas should be culturally appropriate and respectful of the population of interest. Before logos and marketing materials are printed and distributed, they must be reviewed by the project area's CDC project officer, and approvals must be obtained. Note that project areas should not include the CDC logo or name on any of their marketing materials.

##### *Social media*

If project areas wish to use Facebook or other social networking sites to market NHBS, they should create project accounts and pages. With social media accounts (e.g., Facebook page, Instagram account, or TikTok account), project areas can control privacy settings and ensure that the page adheres to local policies regarding content and the handling of user comments. Project areas should note that NHBS-related content posted on social media sites should be treated the same as all other NHBS marketing materials; the content must be reviewed by the local program and the project area's CDC project officer, and it should not display the CDC logo or name. Information from CDC on social media tools, guidelines, and best practices for public health can be found at:

<http://www.cdc.gov/socialmedia/tools/guidelines/index.html>.

#### **4.2d Community advisory boards**

Another means of garnering support for NHBS is through meetings with health department community advisory boards (CABs), such as the local HIV prevention planning group or HIV care consortium. CAB members already have vested interest in the health department's public health activities, and thus, would be ideal allies for NHBS. Project areas could introduce the project to their CABs, describe its goals,

and present findings from previous cycles. CAB members, in turn, could become ambassadors for promoting the project in the community of interest and they could provide access to other community partners. Depending on their experience and expertise, CAB members may also be able to provide technical assistance and advice to project areas. If the health department does not have a CAB, project areas can form an NHBS CAB composed of local community members. There may be cycle-specific needs that require developing a CAB.

## 5

# Ongoing Formative Assessment

### 5.1 Overview

Ongoing formative assessment is the collection and examination of additional quantitative and qualitative data to improve field operations and ensure the successful recruitment and enrollment of participants. Project areas should conduct ongoing formative assessment throughout the survey data collection period to maintain community support, identify and address barriers to survey participation, and monitor participant enrollment and demographic characteristics. Project areas do not have to hire additional staff to conduct ongoing formative assessment. They can use their existing staff, including the project coordinator, field supervisor, interviewers, and data manager. Project areas will receive further guidance on conducting ongoing formative assessment in the cycle-specific NHBS Operations Manuals.

### 5.2 Data Collection Methods

Project areas should always begin with the least labor-intensive and time-consuming methods (e.g., reviews of recruitment and enrollment data, observations, and informal conversations with participants and field staff) and then, if simpler methods do not yield results, they should proceed to more labor-intensive and time-consuming methods (e.g., key informant interviews, brief intercept surveys, and focus groups). For example, project areas may conduct exit interviews with participants as a means of better understand any issues relating to recruitment or participant experiences during the survey. Exit interviews are brief open-ended interviews that take place after all survey data collection is complete and participants have been checked-out. Project areas can use the same methods outlined above in addition to recruitment monitoring reports described in the cycle-specific NHBS Operations Manual. Whenever sites identify an operational or enrollment problem using ongoing formative research, they should discuss the problem with their CDC Project Officer and develop a plan to resolve it.

### 5.3 Data Monitoring

Project areas should continuously monitor their operations and corresponding data. Each cycle requires a unique set of elements that should be monitored. Detailed information on data monitoring can be found in the cycle-specific NHBS Operations Manuals and Formative Assessment Manuals.

## 6.1 Overview

Following data collection, project areas will need to rapidly analyze data. For qualitative data, these analyses require a specific approach. Below is some information on approaches areas can use in analyzing their formative and ongoing formative data rigorously and rapidly to inform NHBS operations.

## 6.2 Rapid Data Analysis Techniques

As project areas collect primary data there are several approaches they can use to succinctly analyze data rapidly to inform operations. Several analytic tools and software are available to help organize and analyze data (e.g., Nvivo, Atlas.ti, MAXQDA), but project areas do not have to use these tools to effectively analyze data. Below are some methods that can be employed throughout data collection.

### 6.2a Data collection debriefs

Following each episode of data collection, for example following an in-depth interview or a venue/field observations, conduct a structured debrief among formative assessment staff. The debrief should identify key emerging themes based on your notes or information collected and summarize those findings. For example, following an in-depth interview with a CKI, the interviewer and note taker should meet to discuss the information shared by the participant. Prior to the interview, identify key topics to debrief on and then type notes while the interviewer and note taker meet to discuss the interview. Debriefs should be shared back with the larger formative assessment team so everyone is aware of the emerging findings and data collection plans.

### 6.2b Identifying emerging themes

Debriefs can be used to inform a larger discussion about the key ideas and reoccurring themes that are emerging across interviews. After conducting several interviews, focus groups, observations, or BSIs, you can reflect on the key themes that emerged from each debrief. You can even organize these themes into a matrix to review different themes. When you begin to see the same themes repeat, it likely means you have reached saturation or the point where you are not hearing new information, which indicates you can stop collecting data.

## 6.3 Triangulation of data

“Triangulation” means cross-checking findings by using multiple data sources, data collection methods, or investigators. Since formative assessment that relies on only one data source or collection method is subject to the errors associated with that source or approach, triangulation helps to validate the results and ensure that the information is complete. One way project areas can triangulate their formative assessment data is to compare information on the same topic that has been obtained from different

data sources (e.g., discussions about HIV stigma across several PKIs). Another strategy is to use at least two different data collection methods (e.g., key informant interviews, focus groups, observations, or BIS). Lastly, project areas should always compare the findings from their primary and secondary data reviews; this is essential for the success of formative assessment.



When triangulating information with a variety of data sources and collection methods, project areas may obtain some inconsistent findings. If this occurs, they should collect additional data to resolve these discrepancies and better understand the results.

## 7 Privacy and Institutional Review Board Procedures

Key informant and focus group interviews involve engagement with human subjects; therefore, project areas should obtain informed consent from individuals participating in these activities. Appendices A, B, and C of the *NHBS Round 6 Model Surveillance Protocol* contains model formative assessment consent forms that project areas can customize for local use. To further protect the privacy of those interviewed, project areas that are required to submit the NHBS protocol to their local IRB(s) should request a waiver of documentation of informed consent from their IRB(s) so that consent can be obtained verbally. Appendix N of the *NHBS Round 6 Model Surveillance Protocol* contains a model waiver of documentation form that can be modified for local use.

Interviews should never be video- or audio-recorded. PKIs are often known to project area staff along with their contact information. However, project staff should always obtain consent to store any of their contact information. CKIs are not required to provide their names or other personal identifiers as a condition for participation. For CKI convenience or benefit, they can provide contact information to project staff on a voluntary basis. For example, informants may provide a phone number for phone text reminders of interview appointments. Provision of contact information is optional; project areas can offer anonymous alternatives to achieve cycle objectives. If collected, contact information must be maintained separately from all NHBS data and destroyed immediately upon completion of its intended use. Contact information should only be available to local staff and will not be submitted to CDC.