

# **National HIV Behavioral Surveillance: Transgender Women (NHBS-Trans)**

## **FORMATIVE ASSESSMENT MANUAL**



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

# Acknowledgements

This Formative Assessment Manual for the National HIV Behavioral Surveillance (NHBS) system was written by staff of the Behavioral Surveillance Team, Behavioral and Clinical Surveillance Branch (BCSB), Division of HIV/AIDS, National Center for HIV/AIDS, Viral Hepatitis, STD, and TB Prevention (NCHHSTP), Centers for Disease Control and Prevention (CDC).

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## Contacts

### Corresponding Author:

Kathryn Lee, MPH

Epidemiologist

Centers for Disease Control and Prevention

1600 Clifton Rd, Mailstop E-46

Atlanta, Georgia 30329

Telephone: (404) 639-6110; E-mail: [klee3@cdc.gov](mailto:klee3@cdc.gov)

### Contributing Authors:

Alexandra Balaji, PhD

Kate Doyle, MPH

Teresa Finlayson, PhD, MPH

Evelyn Olansky, MPH

Taylor Robbins, MPH

Cyprian Wejnert, PhD

### General NHBS Inquiries:

Cyprian Wejnert, PhD

Acting Team Lead, Behavioral Surveillance Team

Centers for Disease Control and Prevention

1600 Clifton Rd, Mailstop E-46

Atlanta, Georgia 30329

Telephone: (404) 639-6055; E-mail: [cwejnert@cdc.gov](mailto:cwejnert@cdc.gov)

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# 1 Introduction

## 1.1 Overview

The purpose of this manual is to inform the formative assessment phase of the transgender women (or trans women) cycle of the National HIV Behavioral Surveillance system (NHBS-Trans). This cycle will identify and enroll trans women participants, defined as those assigned male sex at birth, but identify as women or as transgender women, in order to monitor behavioral risks, prevention usage, and HIV prevalence in this population.

Formative assessment is the process by which researchers or public health practitioners define a community of interest, determine how to access that community, and describe the attributes of the community that are relevant to a specific public health issue. For NHBS-Trans, formative assessment will lay the foundation needed to conduct behavioral surveillance and measure HIV prevalence among trans women (the population of interest). The information gathered during formative assessment will enable project sites to gain an understanding of the different sub-populations of trans women and how they are networked, tailor field operations to their local settings, and identify and address any barriers to operations. These efforts will help project sites obtain a sample that reflects the diversity of the local population of trans women and enroll the target number of eligible participants. Throughout this manual, the population of interest for this NHBS cycle (i.e., trans women) is referred to as the “target population.”

The key to successfully conducting both formative assessment activities and field operations is establishing and maintaining strong relationships with members of the community, as well as stakeholders within the community, including trans women organizations, and those who provide health, prevention, and social services to the community. Accordingly, formative assessment should not focus solely on data collection, it should focus on community outreach as well. It will be of particular importance for project sites to establish relationships early on with organizations that serve trans women in order to build trust and to allow for better access to this population.

## 1.2 Formative Assessment Goals

The principal goals of NHBS-Trans formative assessment are to:

- **Garner the support of the community and its stakeholders.**
- **Identify and describe the sub-populations that exist within the local community of trans women in the metropolitan statistical area (MSA).**
  - Identify and describe the characteristics of trans women within each sub-population and interactions between various groups. Mapping of networks

may be necessary in order to appropriately plan for respondent-driven sampling (RDS) and seed selection.

- Describe and map specific settings that are relevant to the community, including safe havens, community centers, service providers, etc.
- **Investigate structural and contextual factors that may affect HIV acquisition in the local trans women population.**
- **Characterize the relationship between the trans women community and the larger MSA.**
- **Obtain information needed for conducting field operations** (e.g., accessible field site location(s), ideal hours of operation, appropriate incentives).
- **Identify potential barriers to recruitment and participation, and develop solutions to address them.**
- **Identify and recruit appropriate staff to serve as interviewers during data collection.**
- **Develop local questions of interest and identify any city-specific terminology.**
- **Develop a plan to monitor field operations and participant enrollment.**

### ***1.3 Institutional Review Board Procedures***

The Centers for Disease Control and Prevention (CDC) has conducted an administrative review of the NHBS-Trans protocol, including an assessment of its human subjects protections, and has determined that NHBS-Trans is surveillance and not research. Because of this non-research determination, review and approval of the NHBS-Trans protocol by the CDC Institutional Review Board (IRB) is not required. Project sites should note, however, that CDC's non-research determination for NHBS-Trans does *not* supersede local policies and procedures for human subjects protection. These local policies may require project sites to submit the NHBS-Trans protocol to their local IRB(s) for an expedited or full review. Even if local IRB(s) determine that NHBS-Trans is not research, project sites may still want to submit the NHBS-Trans protocol for local IRB review and approval since many scientific journals will not publish findings from projects that have not been reviewed by an IRB.

Because formative assessment interviews involve engagement with human subjects, project sites should obtain informed consent from individuals participating in these activities. **Appendices A, B, and C** of the *National HIV Behavioral Surveillance among Transgender Women Model Surveillance Protocol* contain model formative assessment consent forms that project sites can customize for local use. As with all NHBS data, formative assessment data must be collected anonymously. Therefore, interviews should never be video- or audio-taped. To further protect the anonymity of those interviewed, project sites 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 *National HIV Behavioral Surveillance NHBS-Trans Formative Assessment Manual*

*among Transgender Women Model Surveillance Protocol* contains a model waiver of documentation form that can be modified for local use.



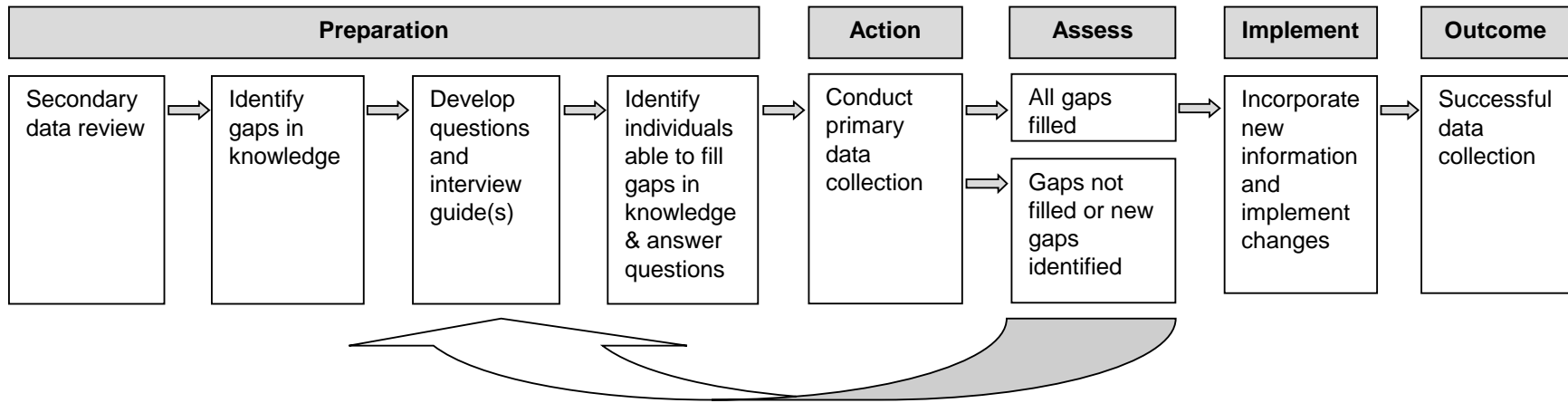
Because discussions with health department staff are not considered engagement with human subjects, project sites can gather formative information from these staff without IRB approval. For example, project sites could meet with health department staff to begin formative assessment activities and identify appropriate sources of information.

## **1.4 Formative Assessment Process**

During formative assessment, project sites will gather information through secondary data review and primary data collection. To maximize the effectiveness of these formative assessment activities, project sites should employ an iterative process (**Figure 1**); information obtained from the secondary data review should inform primary data collection, which should then validate or provide further insight into the findings from the secondary data review. Using this iterative process, project sites will be able to realize the formative assessment objectives outlined in **Section 1.2**.

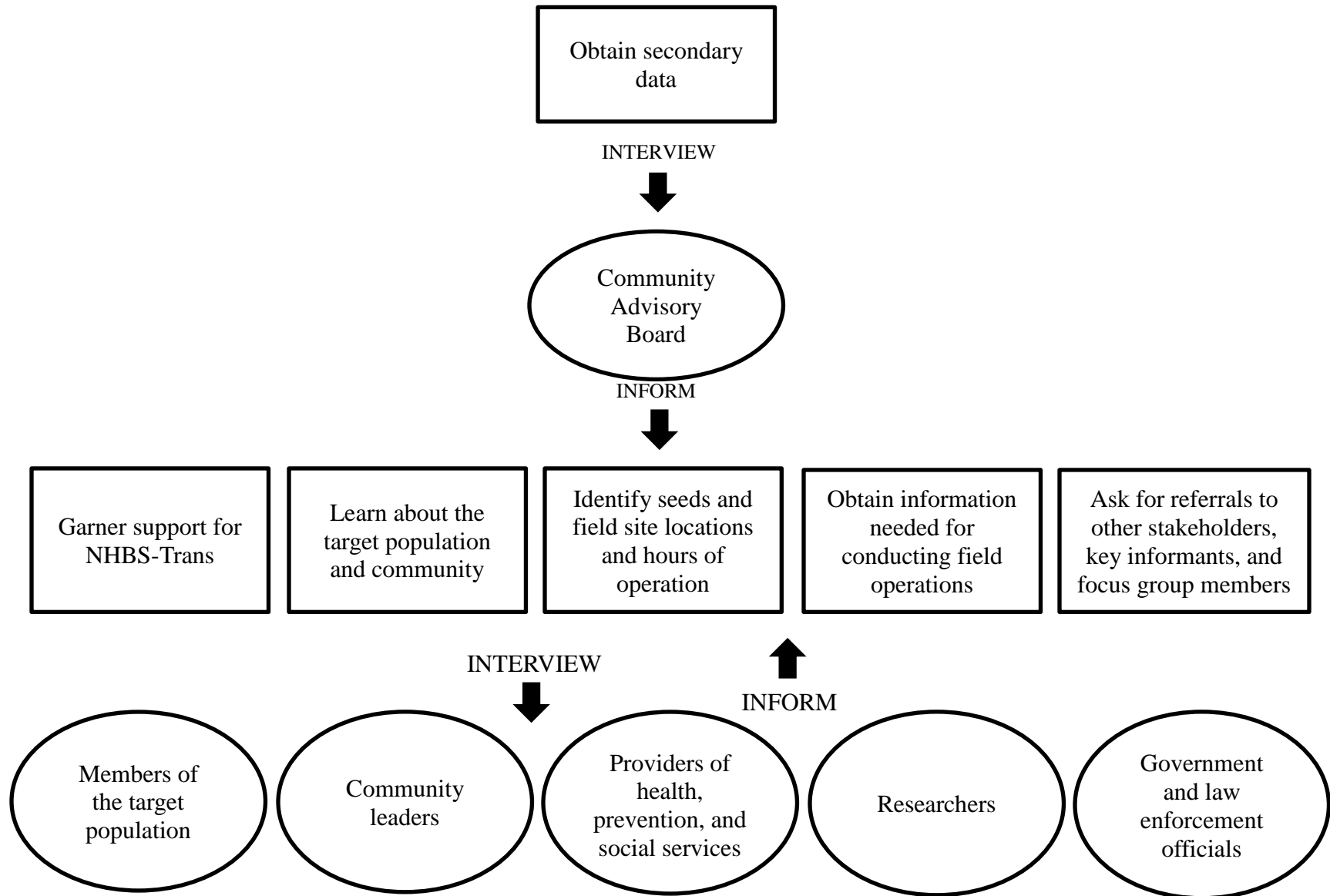
**Figure 2** illustrates the suggested work flow for conducting formative assessment activities. The figure also shows possible sources of information for primary data collection and indicates how the information gathered from each source can inform the collection of subsequent information. In brief, the formative assessment process starts with a review of published and unpublished secondary data which is used to describe the target population and develop a plan for primary data collection. This plan serves as a blueprint for obtaining information from primary sources. The initial source of data is usually health department staff. Interviews with staff members can provide a general overview of the target population and the HIV epidemic in this population, as well as provide the names of additional sources of information. Primary data collection then continues with interviews with these other sources in a feedback loop – the information gathered from one source informs the collection of subsequent information and identifies additional sources of information. The process ends when sufficient data have been collected to address all relevant gaps in information.

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





**Figure 2. Suggested work flow for formative assessment activities**



It is helpful for staff to keep all goals of formative assessment in mind when meeting with individuals or groups. Formative assessment staff should always be prepared to:

- Garner support for NHBS-Trans activities.
- Learn about the target population and community.
- Ask for referrals to others who can be interviewed about the target population and community.
- Ask for referrals for potential “seeds” (initial recruits).
- Learn about accessible field site locations and ideal hours of operation.
- Request available data.
- Request input for local questions.

### ***1.5 Formative Assessment Timeline and Documents***

Project sites will conduct formative assessment over a period of approximately 7 months preceding the start of field operations. To help plan and manage the formative assessment activities, project sites will be required to develop an Implementation Timeline for completing the various activities. The products of the formative assessment process are the Secondary Data Report, Primary Data Report, and Ongoing Formative Assessment Report. These documents, along with the Implementation Timeline, are described in greater detail in this manual.

## 2 Staffing

### 2.1 Overview

Ideally, project staff conducting formative assessment should include an ethnographer or a project coordinator with close knowledge of ethnographic methods and the target population and at least two additional staff members. Where appropriate, a single staff member may serve as both an ethnographer and project coordinator. To the extent possible, it is recommended to identify members of the target population who will be involved in the formative assessment process.

### 2.2 Ethnographer

Project sites may wish to hire an ethnographer to coordinate their formative assessment activities. An ethnographer is a researcher who has been trained to collect data in their natural environment, placing an emphasis on the context in which particular social phenomena occur. Another strength of an ethnographer's approach to data collection is the use of multiple data sources and methods to confirm the information gathered. If an ethnographer is hired, the principal investigator is responsible for making sure that the ethnographer's work remains focused on the NHBS-Trans 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-Trans data.

The ideal ethnographer has either masters- or doctoral-level training in anthropology or sociology with experience working with a range of ethnographic methods, such as observations, key informant interviews, and focus groups. To be most effective, the ethnographer should also be familiar with the local population of trans women and the various sub-populations. Ethnographers can be found through the anthropology or sociology departments of local universities and colleges, at community-based research institutes, or in the local health department. If an ideal candidate as described above cannot be located, sites may wish to hire a project coordinator who is familiar with the local population of trans women and the various sub-populations. Regardless of title, the ethnographer or project coordinator should have experience working with a range of ethnographic methods, such as observations, key informant interviews and focus groups.

The ethnographer should train other project staff in the formative assessment process and methods of data collection, and they should oversee the staff's work, in collaboration with the principal investigator. The ethnographer should also provide the principal investigator and relevant project staff with periodic updates on the progress of formative assessment and the findings. To ensure that formative assessment activities are completed successfully and in a timely manner, the ethnographer should be directly involved in the development of the implementation timeline, described in greater detail in Section 4.1.

### **2.3 Project Staff**

The ethnographer or staff member who will direct activities should be provided with staff to assist in the various aspects of the formative assessment. Staff members would also ideally be familiar with the local population of trans women and the various sub-populations. Formative assessment staff responsibilities could include:

- Garnering community support.
- Collecting information for the secondary data review.
- Identifying and contacting community members and stakeholders for potential involvement in a community advisory board.
- Assisting with interviews and focus groups.
- Identifying potential field site locations.
- Identifying and interviewing potential seeds.

### **2.4 Additional Considerations**

Project sites may find it is necessary to provide cultural competency training for NHBS-Trans staff prior to interacting with the target population. This may be especially true if a majority of the staff have little to no prior experience in working with the trans women population. Cultural competency training could cover topics such as the differences between sex assigned at birth, sexual orientation, gender identity and gender expression. It could also explore respectful terminology and how to be an ally to the community. Project sites may seek out collaborators at local organizations to provide this training. Whenever possible, such training should be conducted by a member of the local trans women population. Any cultural competency training should be grounded in insight garnered from direct engagement with the target population, as expertise garnered indirectly from research may be insufficient to describe the specific needs of the local target population.

In working with the target population, it is important for project staff to recognize that not all trans women have shared the same life experience. It is also important for project staff to not make assumptions about the gender identity of community members and stakeholders involved in formative assessment. It is recommended for staff to be aware of preferred gender pronouns when collecting data; asking and correctly using someone's preferred gender pronoun is an easy and direct way of showing respect and setting the tone for a constructive conversation. By disregarding the pronoun that someone prefers to use, it sends a sign of invalidation and can lead to further misunderstandings. A simple way to establish correct pronoun usage is to ask, "Can you tell me which pronoun you use for yourself?" Moreover, project sites should encourage staff to avoid assumptions about other aspects of the lives of trans women, including group membership, desire for or stage of transition, and outness.

Whenever possible, trans women should be hired as staff. Hiring trans women as project staff can introduce valuable intuition and needed insight into the planning and implementation process,

where a staff without transgender representation must rely solely on its CAB and formative work. In participant-facing roles, trans women staff can reduce or eliminate barriers to project participation, such as distrust for organizations affiliated with city or state governments perceived as unwelcoming of trans women, or the perception that this project may be exploitative to local trans women.

Please be mindful that trans women hired as project staff may also need training, particularly in the areas of boundary-setting and self-care. Peer staff, or staff members who belong to the target population, may be uniquely vulnerable to experiencing secondary traumatic stress. In engaging with trans women participants, peer staff may be exposed to traumatic stories with which they strongly identify, from trans women with whom they feel a deep emotional investment. Project management should be particularly conscientious of transgender peer staff's needs in this regard, and work proactively to prevent and mitigate burnout, enable sustainable boundary-setting, and to assuage potential feelings of guilt that peer staff cannot do more for their target population peers.

## 3 Garnering community support

### 3.1 Overview

The success of NHBS-Trans will depend largely on a project site's ability to garner support from both key stakeholders and members of the broader trans women community. Greater community acceptance of NHBS-Trans will result in a higher rate of participation in the survey and greater willingness to overcome barriers that may arise during data collection. To have the most impact, project sites should elicit support from a wide variety of stakeholders. Stakeholders should have diverse backgrounds and they should represent different trans women sub-populations, especially those sub-populations at greatest risk of HIV infection and those whom formative assessment indicates may risk being underrepresented during data collection.

Examples of stakeholders include the following:

- Staff of community-based organizations (CBOs) that provide services to trans women
  - These could be organizations that provide services only to trans women or LGBTQ organizations who may not specifically focus efforts on trans women but are inclusive of trans women.
- Providers of HIV and STD prevention/treatment services to trans women
  - Similar to community-based organizations, some service providers may be exclusive to trans women, others may serve the general population but also serve trans women.
- Providers of transgender-affirming medical care
- Local researchers whose work focuses on trans women
  - Researchers may be affiliated with local academic institutions or located within the health department.
- Members of established community advisory boards
- Political leaders and government officials
  - Local municipalities may have an advisory council or commission in place to advise city leaders on issues facing trans women.
- Police and law enforcement officials
  - Each project area may have a special unit or task force responsible for improving relationships with the trans community or the greater LGBTQ community (e.g. <http://www1.nyc.gov/site/nypd/bureaus/administrative/lgbt-outreach.page>).
- Staff of substance abuse treatment programs
- Staff of syringe exchange programs
- Staff of legal aid groups
- Staff of advocacy organizations
- Correctional staff
- Staff of homeless shelters

When garnering support from stakeholders, project sites should explain the goals and objectives of NHBS-Trans and describe its data collection methods. Project sites should emphasize that the key objective of NHBS-Trans is to understand HIV and other health disparities in the target population in order to better serve their health needs and to guide the development and implementation of high impact HIV prevention programs. It may be helpful to provide written materials such as a brochure or fact sheet so stakeholders may be able to learn more about NHBS-Trans and share with others. Project sites should also be prepared to provide information about the content of the survey instrument.

It is important that project sites explain to community stakeholders how NHBS defines trans women because this definition may differ from other individuals' and researchers' definition of the population. It is important to explain the purpose for the survey as well, as some stakeholders may feel that there are 'more urgent' needs than HIV prevention.

In general, the ideal stakeholders are trans women, and stakeholders who are not trans women should only be pursued when their expertise cannot be obtained from a member of the local trans women community. Additionally, avoid selecting stakeholders whose participation could deter the participation of local trans women. In some cases, communities of trans women may report antagonistic relationships with certain CBOs, police representatives, city or state officials, offices, agencies or staff. In such cases, take care to avoid selecting stakeholders who are perceived as antagonistic to local trans women.

### **3.2 Rationale**

Garnering the support of stakeholders that serve and represent trans women and from the community itself is very important for the success of NHBS-Trans. This is true for several reasons:

- Working with trans women-focused organizations will help project staff gain the trust of members of the community.
- Gaining buy-in from stakeholders and members of the community can ensure that the project is relevant to and respectful of their needs.
- Stakeholders who are familiar with the local trans women community can provide the necessary orientation to the size and structure of the community as a whole.
- Organizations can help project staff identify potential community key informants and focus group participants, especially hard-to-reach sub-populations.
- Stakeholders can assist in identifying members of the community who should be hired as project staff.
- Stakeholders can assist in identifying geographic areas that will be safe for data collection activities.
- Involving the organizations that serve trans women can also help identify priority topics of local interest to address with local questions.

- Working closely with the community from the start will help ensure that the findings of NHBS-Trans are well received and used. Stakeholders will be able to provide guidance on effective ways of sharing information with the community and organizations could potentially serve as vehicles of data dissemination.
- Failure to establish these connections could result in the community of trans women viewing the survey as a process that is *about them without involving them*.

Project sites should keep in mind that established organizations that represent or serve trans women may not represent *all* trans women and should strive to reach out to trans women in all segments of the community. Project sites may find that trans women organizations may be wary of interacting with health department staff, depending on previous experiences. It will be important to explain why this survey is important for trans women. Historically, some organizations have felt that these types of behavioral health surveys gather data on trans women but rarely share these data back with the community or result in direct benefit to the community. Project sites should have consistent messaging to address these concerns and also be prepared to explain why the specific city was chosen to participate.

It is intended for the implementation of NHBS-Trans to utilize a method of community-based participatory research (CBPR). This approach involves members of the community, stakeholders, and project staff working together in the development and implementation of the project and sharing in the ownership of the success and outcomes. The benefits of CBPR are numerous and can increase the impact of NHBS-Trans on the communities in which data are collected. In CBPR, the involvement of communities and stakeholders affirms the importance of the experiential knowledge they bring to the table, builds trust, and establishes a partnership for the project. It also highlights the need for project staff to have a deep understanding of the social and contextual factors influencing the community in which the project will be conducted. These collaborations should result in increased relevance of the findings and improved approaches of data to action.

As such, it is important for project staff to highlight the ways in which stakeholders and members of the community have been involved in the development of project protocols and survey instruments, as well as the plans for their involvement during formative assessment and data collection. This will reaffirm that NHBS-Trans is *not* a “project about us without us”.

### ***3.3 Methods of Garnering Community Support***

#### **3.3.1 Community Advisory Board**

Greater community acceptance of NHBS-Trans activities will result in higher participation in the survey. To have the most impact, project sites shall assemble a community advisory board (CAB) comprised of members of the community and other key stakeholders, such as those listed in Section 3.1, who are familiar with the local target population. As stated in Section 3.1, sites should take



care to ensure that no member of the CAB is perceived as antagonistic to local trans women. In particular, representatives from seemingly relevant organizations (CBOs, city officials and police representatives) may be poor choices for CAB membership if they do not identify as trans women, and especially if they are perceived as antagonistic to local trans women.

Project staff should recruit members of the community and stakeholders to join the CAB for the duration of the NHBS-Trans project period. During the initial invitation, project staff should introduce NHBS-Trans, describe its objectives, and outline the expectations for the CAB members. The CAB will meet periodically during formative assessment to discuss findings and evaluate next steps. CAB meetings should continue during data collection to identify obstacles that may arise while in the field and develop strategies to overcome them. CAB meetings can convene on a regular schedule or an as-needed basis. Project sites should determine if in-person attendance for CAB meetings is more effective or if conference calls are suitable.

Similar to the involvement of community stakeholders, there are many potential benefits of the ongoing support of a CAB, including:

- A network of people involved in the development of the project who are invested in the outcomes and can assist with speedbumps that may occur during data collection.
- Members who can become ambassadors for NHBS-Trans in the target community and provide access to other stakeholders.
- The ability to foster stronger relationships between the health department and community stakeholders.
- Strengthen connections between organizations to encourage collaboration and positive community relations.

### **3.3.2 Other meetings with stakeholders**

One-time meetings with other community stakeholders who are not associated with the CAB provide an opportunity for project sites to give an overview of NHBS-Trans, describe its objectives, introduce staff members, share the project logo to increase brand recognition, answer questions, and address any concerns. Meetings can be one-on-one or involve multiple stakeholders. When meeting with multiple stakeholders, project sites may want to conduct a more structured meeting with an agenda. To maximize participation at these meetings, project sites should hold them in easily accessible locations at convenient times. CAB members may be able to provide advice about locations appropriate for these meetings.

When coordinating in-person or phone meetings between multiple stakeholders or CAB members, please consider the dynamics and history between potential attendees and the organizations they represent. If the purpose of a meeting is, for example, to seek information pertaining to the identification of locations where trans women engage in exchange sex or illicit drug use, the

presence of law enforcement representatives may dissuade the full participation and forthrightness of trans women stakeholders.

Project sites can also hold public meetings with the broader community or conduct community outreach at special events, such as health fairs. In addition, whenever project sites interview key informants or conduct focus groups, described in greater detail in Section 6.3, they should use those meetings to garner support for the project as well.

### **3.3.3 Marketing materials**

Project sites should create a logo and marketing materials, like informational flyers or posters, to identify the project and promote community awareness of it. The logos and marketing should be culturally appropriate and respectful of the target population. During primary data collection, staff should test sample logos and marketing materials to identify those that would be most appealing to potential participants. Marketing materials would then be distributed to and displayed by community partners who are willing to assist in promoting the project. For example, flyers could be hung at community-based organizations that serve trans women, or in the offices of clinicians with trans women patients. Community members and stakeholders should also be asked about the most effective marketing strategies for reaching the local target population.

Before logos and marketing materials are printed and distributed, they must be reviewed by the local program review panel, the local CAB, and the project site's CDC project officer, and approvals must be obtained. Of particular importance, project sites should not include the CDC logo or name on any of their marketing materials.

### **3.3.4 Facebook and social media**

During formative assessment, project sites should investigate which social media platforms are most likely to reach the target population. If project sites wish to use Facebook to market NHBS-Trans, they should create a Facebook Page. With a Facebook Page, project sites can control privacy settings and ensure that the page adheres to local policies regarding content and the handling of user comments. Project sites should note that NHBS-Trans-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 review panel, the local CAB, and the project site'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: [www.cdc.gov/SocialMedia/Tools/guidelines](http://www.cdc.gov/SocialMedia/Tools/guidelines).

## 4 Formative Assessment Overview

As part of the formative assessment process, project sites are required to submit four documents to their CDC project officer: 1) the Implementation Timeline, 2) the Secondary Data Report, 3) the Primary Data Report, and 4) the Ongoing Formative Assessment Plan. The purpose and content of each of these documents is described in subsequent chapters and submission deadlines are shown in Table 1 below.

Table 1. Formative assessment deliverables.

| Document  | Due to CDC Project Officer  | Feedback Due to Site   |
|---|---|--|
| Implementation Timeline                                   | <i>Draft:</i> By Friday, December 29 <sup>th</sup> , 2017<br><i>Final:</i> 1 week after receiving feedback from the CDC project officer   | Approximately 1 week after submission to the CDC project officer |
| Secondary Data Report                                     | <i>Draft:</i> By Friday, December 29 <sup>th</sup> , 2017<br><i>Final:</i> 1 week after receiving feedback from the CDC project officer   | Approximately 1 week after submission to the CDC project officer |
| Primary Data Report and Ongoing Formative Assessment Plan | <i>Draft:</i> 5 months after the CDC project officer has approved the Secondary Data Report (including the Primary Data Collection Plan) <i>or</i> 5 months after local IRB approval has been received, whichever is later<br><i>Final:</i> 2 weeks after receiving feedback from the CDC project officer | Approximately 1 week after submission to the CDC project officer |

After the formative assessment documents have been submitted, the CDC project officer will review and provide feedback to the project site and the project site will be responsible for revising the documents to address any concerns. In these reports, project sites should not merely recount the information they have collected during formative assessment; they must also interpret the findings and explain how the findings will be used to guide operations.

### 4.1 Implementation Timeline

The Implementation Timeline will help project sites plan and manage formative assessment activities and other activities conducted in preparation for field operations. By completing these tasks on schedule, project sites should be prepared for initiation of data collection in 2018.

**Appendix A** of this manual contains a model Implementation Timeline that project sites can customize for local use. The timeline should show the period when tasks will be performed and the dates when they will be completed. The following items should be included on the timeline:

- IRB package
- Formative assessment staff hiring and training
- Secondary data review and report
- Identification of Community Advisory Board
- Primary data collection and report
- Ongoing formative assessment report
- Local questionnaire development
- Field site identification
- Interviewer hiring and training
- Acquisition of incentives and supplies
- Seed identification and recruitment
- Operations Checklist
- Start of survey data collection

The timeline should also include any other tasks that may impact formative assessment or preparation for field operations. If the timeline has to be modified after it has been submitted, project sites should discuss the needed changes with their CDC project officer and send a revised timeline.

## **5 Secondary Data Review**

### **5.1 Overview**

Secondary data are data that have been previously collected by other researchers, surveillance systems, or registries. Secondary data also refers to data that have been collected via trans-friendly organizations. News reports found online or elsewhere may also form part of secondary data. The secondary data review is critical as it 1) characterizes what information is publicly available regarding the trans women community in the MSA, 2) documents sources of data on trans women, and 3) identifies gaps in knowledge related to trans women.

Secondary data form the basis of a project site's formative assessment activities, including who to recruit for CAB membership and sub-populations of trans women to recruit for focus group participation. Gaps in knowledge about the local community will be identified and will lead to formulation of questions to ask during primary data collection. This process will be iterative; primary data findings may prompt project sites go back to secondary data review. Findings from the secondary data review will be summarized in the secondary data report. After formative assessment activities have been completed and field operations have begun, the secondary data report can serve as a reference for monitoring how well the sample reflects the local target population.

### **5.2 Secondary Data Report**

The Secondary Data Report summarizes the findings from the secondary data review and is composed of three sections: 1) the Description of the Target Population, which describes the general characteristics of trans women residing in the principal city of the funded MSA or MSA Division and describes factors that may influence the lives of trans women in the principal city; 2) the Description of the Community, which identifies organizations that serve the community and resources available, along with key stakeholders; and 3) the Primary Data Collection Plan and Interview Guide, which outlines the project site's plans for collecting primary data during the second phase of formative assessment. Possible sources of secondary data are listed in Section 5.3 of this manual.

Project sites should structure the Secondary Data Report according to the following outline:

- I. Target Population**
  - a. Description of target population**
  - b. Local structural and contextual factors**
  - c. HIV prevalence**
- II. Description of the Community**
  - a. Organizations that serve the community**
  - b. Resources available**
- III. Primary Data Collection Plan and Interview Guide**

Project sites should use the titles provided in the outline to label each section of the report. References should be provided for all data sources included in the report. Each section of the report is described in further detail below.

### **5.2.1 Target population**

Project sites should provide an overview of trans women residing in the principal city of the funded MSA or MSA Division.

#### ***Description of the target population***

In this section, project sites should report known demographics of the trans women community, including age and race/ethnicity, and any available data which report on the local population size estimates. Project sites should identify neighborhoods in which trans women live and/or congregate and describe sub-populations of trans women that may exist within the larger community.

#### ***Local structural and contextual factors***

In this section, project sites should describe structural and contextual factors that may influence the lives of trans women in the principal city. This can include things like:

- Housing availability
- Employment opportunities
- Poverty and homelessness
- Stigma and discrimination toward gender minorities
- Stigma and discrimination toward persons living with HIV
- Violence
- Law enforcement and incarceration, including state and local policies and standard operating procedures for interactions with trans women
- Laws affecting transgender individuals (e.g., access to gender-specific spaces, such as locker rooms and bathrooms, marriage rights, anti-discrimination protection, prisoner detention and healthcare)
  - Project sites should investigate legislation that is being presented on a state and local level, even if it does not pass, to depict the political environment in which trans women are living
- Sex work

Beyond the structural and contextual factors listed here, project sites should be sure to highlight other relevant findings that were revealed during the review of secondary data. This could include the results of other data collection or research efforts, or instances where trans women have been in the news, etc.

### ***HIV prevalence among trans women***

This section provides detailed information about the HIV epidemic among the target population in the principal city. Project sites should analyze HIV case data from their HIV Surveillance System. The data should be restricted to those HIV cases that were reported through December 2016 and were newly diagnosed between January 2011 and December 2015. Project sites should gain a clear understanding of the way in which transgender cases were captured in the HIV Surveillance System during this time frame, describe any reclassification that may occur and the challenges that may exist in the reporting of accurate data. To gain the most accurate information, NHBS-Trans staff should identify which staff members within the health department have previous experience with or expertise about this population.

Project sites should present case data using HIV Surveillance System data and describe the findings. To show the geographic distribution of HIV cases in their locality, project sites should include a geographic variable, such as county, district, or neighborhood, if available. They may select whichever geographic variable they believe would be most helpful. Socioeconomic characteristics, like education and income, should be included as well if these data are collected in the local surveillance system. If project sites wish, they have the option of including additional tables of HIV surveillance data, like a table of trends in HIV diagnoses or a table of recent HIV diagnoses. Tables such as these could help project sites identify emerging trends in the HIV epidemic. Project sites should also explore other sources of HIV case data within the health department, like an Epi Profile.

### **5.2.2 Description of the community**

Beyond the description of the trans women that make up the local population, it is necessary to describe the system of support that is in place within the MSA.

#### ***Organizations that serve the community***

Project sites should identify all organizations that serve the community of trans women. This should include various types of service organizations, including those that provide general healthcare, gender-affirming healthcare, HIV care, support resources, etc. Engagement with trans-led and trans-focused organizations should be prioritized over organizations that are not exclusively trans-serving. However, this search should be inclusive of LGBTQ organizations and women's organizations, not only organizations whose sole focus is the trans women community.

Other places of significance for the trans women community should be identified and described, including social venues, safe havens, places of worship, sex strolls and the house ball community. Project sites should also provide context for the importance of these key places and if they serve a particular purpose for specific sub-populations of trans women. These places do not necessarily need to have a brick-and-mortar locale; key places could exist online. For example, an online forum could provide trans women with information about legal support or housing resources. For those

organizations with brick-and-mortar locations, or those key places with distinct geographic areas, project sites should create a map depicting these places of significance for the trans women community.

During the identification of organizations and other key places, project sites should also identify and name key stakeholders who are important to the community. These are individuals who could serve as gatekeepers to the community and have an understanding of the lives of trans women in their respective MSA. This list will assist project sites in identifying those who should be approached for potential CAB membership.

### ***Resources available***

Once organizations who serve the community have been identified, project sites should collect information regarding which services are available to trans women. This can include resources like:

- Medical services, including transgender-affirming care
- HIV prevention and treatment
- Support groups
- Mental Health
- Substance abuse treatment
- Housing assistance
- Employment assistance/job placement services
- Legal assistance

Project sites should include services that are provided by state and local health departments.

### **5.2.3 Primary data collection plan and interview guide**

Based on the findings from their secondary data review and the gaps in information identified, project sites should develop a plan for primary data collection. Project sites should summarize the additional information they need to obtain during the second phase of formative assessment and describe the methods they will use to collect the data, such as key informant interviews, focus groups, and observations. Project sites should also include their interview guides for key informant interviews and focus groups. **Chapter 6** of this manual describes the objectives of primary data collection and **Appendix B** contains example interview questions that project sites can use to develop their own interview guides.

## **5.3 Sources of Data**

Project sites should use both internal and external sources of secondary data.



### **5.3.1 Internal sources of data**

Internal sources of data are research projects, surveillance systems, and registries available within the health department.

#### ***NHBS***

Project sites should begin the secondary data collection process by reviewing their NHBS survey and HIV testing data from previous IDU cycles. In reviewing previous formative research reports, project sites should abstract any information about trans women that may have been collected in prior IDU cycles. Participation by trans women in previous IDU cycles has been low in most NHBS sites, so data must be interpreted with caution.

#### ***Other internal sources***

Other sources of data within the health department are HIV counseling, testing, and referral databases and sexually transmitted disease (STD) and hepatitis surveillance systems. The health department's HIV Epi Profile may also contain useful information. In addition, health department HIV prevention staff or outreach workers may have listings of the locations or collaborations where interventions are conducted for trans women.

### **5.3.2 External sources of data**

Project sites will need to rely on a variety of external sources of data. Project sites should attempt to focus on sources of data that contain information that is specific to their MSA or state.

#### ***Publications and reports***

Published data from outside the health department on trans women sex can include:

- Published journal articles
- Reports from public and private researchers and organizations

Publications can be found through literature searches (e.g., [www.ncbi.nlm.nih.gov/pubmed](http://www.ncbi.nlm.nih.gov/pubmed)) and internet searches (e.g., [google.com](http://google.com) or [scholar.google.com/](http://scholar.google.com/)). Moreover, the authors of these publications could serve as project collaborators or key informants. Note that while some researchers and academics may not focus explicitly on trans women, those who work with LGBTQ communities may have knowledge useful to NHBS-Trans. While you may be successful in identifying published journal articles and reports specific to your project area, gaining a thorough understanding of the national conversation of health issues affecting trans women will also provide context for a greater perspective on your local trans community. Such sources of information include The Center of Excellence for Transgender Health ([www.transhealth.ucsf.edu/](http://www.transhealth.ucsf.edu/)) and The World Professional Association for Transgender Health ([www.wpath.org/](http://www.wpath.org/)).

#### ***Other online information***

Project sites can find a great deal of information online in order to gain an understanding of the trans women community in their MSA. There may be online resources and forums specific to a

city (e.g. <http://www.transgeorgia.org/Home>, <https://www1.nyc.gov/site/doh/health/health-topics/transgender-resources.page>), as well as national websites that provide information on a city-level (e.g. <https://radremedy.org/>, etc.). Project sites can find local trans women community resources online by searching the internet with the term “trans community resources < project area name>”.

Accessing websites that trans women use to communicate and socialize with other trans women can be another useful method for gaining information about the local community, to characterize their online behavior and to understand how the community networks with each other. Online resources can be used to help people make contact with other people who are interested in similar activities, events, and/or social organizations. In addition, social media platforms such as Facebook and Twitter are used to communicate trans-community specific information, and NHBS-Trans project staff should search for local Facebook pages as well as follow local organizations on Twitter to keep abreast of any local trans-specific events and information. In addition, people utilize the internet for a wide variety of purposes other than social networking, such as searching for HIV information and/or support groups, event promotion, online dating, and sex seeking.

To be comprehensive in your search strategy, it may be necessary to be inclusive of the larger LGBTQ community rather than focusing solely on online resources specifically tailored for trans individuals. Depending on the local context, project sites should also consider doing online research in other languages such as Spanish or other locally relevant languages in order to gain a more complete understanding of the trans women community in the MSA.

## **6 Primary data collection**

### **6.1 Overview**

Primary data are data that the project staff will collect themselves as part of the formative assessment process. Despite a different method of collection, primary data can fulfill many of the same objectives as secondary data, provide context for the findings from the secondary data review and fill in gaps in knowledge that were revealed during the secondary data review. Primary data can be used to further describe the target population, along with its sub-populations, and to characterize various aspects of the community within the MSA. They can also be used to anticipate barriers to participation in the survey and obstacles to field operations.

The process of collecting primary data is particularly useful in garnering community support for NHBS-Trans and informing stakeholders about plans for data collection. Moreover, primary data are useful for collecting in-depth information to guide the implementation of the RDS methodology, such as collecting data on peer networks, characteristics of effective seeds, and optimal field site logistics.

Findings from the primary data review are summarized in the primary data report.

### **6.2 Primary Data Report**

The Primary Data Report summarizes the findings from primary data collection and is composed of six sections which are listed below. Methods used in primary data collection are listed in Section 6.3 of this manual.

Project sites should structure the Primary Data Report according to the following outline:

- I. Methods**
- II. Garnering Community Support for NHBS-Trans**
- III. Review of SDR Findings**
  - a. Target population**
  - b. Description of community**
- IV. Project Preparation**
- V. Barriers to Participation in NHBS-Trans**
- VI. Data Dissemination**

Each section of the Primary Data Report is described in more detail below.

#### **6.2.1 Methods**

This section summarizes the methods used to collect primary data. Project sites should describe the roles of staff members who gathered information and conducted interviews, report the methods

used to collect the data (e.g., key informant interviews, focus groups, observations), and describe the characteristics of those interviewed.

- Approximate age
- Race/ethnicity
- Connection to the trans women community
- Organization (if applicable)
- Other pertinent characteristics

Project sites should differentiate between those who were interviewed as key informants or focus group members. They should also note whether an individual provided information specifically on a sub-population of trans women (e.g. trans women who engage in sex work, Latinx trans women). Note that individuals can provide information on more than one sub-population. When reporting the characteristics of those interviewed, project sites may find it helpful to present the data in a table or set of tables.

### **6.2.2 Garnering community support for NHBS-Trans**

Project sites should describe their efforts to obtain support from both the community stakeholders and the broader target population during primary data collection. Project sites should discuss how different stakeholders, including the CAB members, have assisted in connecting project staff with trans women and what input they have provided on the project. The discussion should also include marketing strategies and materials recommended by the primary data sources and indicate which strategies will be adopted for NHBS-Trans. If any obstacles to garnering community support are identified, project sites should explain how these obstacles will be overcome for the remainder of the project.

Project sites should also describe the extent to which they think the organizations involved in primary data collection represent the different sub-populations within the target population and what can be done to address the gaps in coverage. Project sites should describe how they will continue to promote NHBS-Trans among different sub-populations during data collection activities, in particular, sub-populations that have been identified as those who may be hard to reach during data collection.

### **6.2.3 Review of SDR findings**

In this section, project sites should revisit the findings from the secondary data review and update information as necessary. Moreover, project sites should provide additional perspectives uncovered during primary data collection, as described below.

#### ***Target population***

Project sites should revisit the characteristics of the target population reported in the secondary data report and update as necessary, including information on age, race/ethnicity, and local

population size estimates. Project sites should also confirm the reported information about sub-populations and if primary data collection revealed the existence of other sub-populations that were not identified during secondary data review. For each sub-population identified, project sites should discuss their findings regarding network characteristics, including size, characteristics, and membership. Project sites should also interpret their findings on the feasibility of recruiting trans women from different sub-populations. Furthermore, project sites should explain whether primary data suggest that certain sub-populations may be at higher risk for HIV infection and whether some sub-populations will be prioritized during data collection, and why. Project sites should also explore how different sub-populations of trans women interact with each other. This information is critical to understanding how RDS sampling is likely to proceed and how recruitment can be optimized to enroll a representative sample of participants.

Similarly, project sites should include relevant information regarding community perceptions of structural and contextual factors within the MSA. Pertinent factors are listed in Section 5.2.1. Project sites should particularly investigate perceptions of HIV in the community, both from community members and clinicians who treat trans women.

Primary data collection is also a good opportunity to gather information on local terminology related to the community of trans women. For example, terms associated with gender identity may be well-known in one city but not another, or used among one sub-population but not another. Project sites may even find that there are sensitivities around certain terminology that is commonly used in other cities. This information will help guide project sites on what clarifying terms to use during interactions with participants or in local questions. Examples of the kinds of questions project sites can ask to assess local language are provided in Appendix B.

### ***Description of the community***

Project sites should validate the list of organizations and resources that was created from the secondary data review. Further, conversations with members of the community and stakeholders should evaluate the quality of the resources available in the community, and barriers and facilitators of accessing these resources. These conversations should also highlight the unmet needs of the community and areas where resource improvement is necessary. The map depicting places of significance for the trans women community should be updated as well.

## **6.2.4 Project preparation**

This section should describe the findings related to the implementation of NHBS-Trans data collection in the MSA.

### ***Field site locations***

Field operations for NHBS-Trans are conducted at fixed field sites, like a storefront location or a mobile unit parked at a fixed location. Project sites must select field sites that are readily accessible

and suitable to all members of the target population. The locations of field sites should not create a barrier to participation for any sub-populations. Not all field site locations will necessarily be suitable for all sub-populations but project sites should attempt to identify at least one location that will work for each group.

Project sites should investigate whether there are any barriers that would keep the target population or specific sub-populations from coming to the field site. For example, can all members of the target population easily access the field site using public transportation? Is the site ADA compliant? Project sites should determine if the community (e.g., residents, local businesses, law enforcement) around the field site is accepting and welcoming of the target population and NHBS-Trans activities. A field site must also be safe for both the participants and the project staff.

Contrary to what is advised for other NHBS cycles, settings that primarily provide social services to trans women would be suitable. This is because recruiting trans women could prove to be challenging and if project sites establish a field site in a place that is already familiar, it may facilitate recruitment. However, keep in mind that some potential participants may not feel comfortable attending a location that is specifically transgender-identified, such as a CBO that specifically serves the transgender community out of concern that they could be identified, or “outed”, whereas other participants may seek out attendance at this type of location because it is viewed as a safe space that they may be familiar with.

While there should be a sufficient number of field sites so that all members of the target population have access to a field site, there should not be so many field sites that the chance of cross-recruitment of participants between field sites is negligible. When there is no cross-recruitment of participants between field sites, separate RDS samples are generated at each field site, which presents analysis challenges. Based on experience from previous NHBS cycles and other RDS studies, project sites should operate as few field sites as are necessary. Fewer field sites will also reduce the amount of time that a potential participant would have to wait for an appointment at a location that is convenient and/or comfortable for their attendance.

### ***Hours of operation***

Project sites should ask members of the target population which days and hours of operation would be most convenient for them to go to the field site for an interview. For example, is it important for members of the target population to have the option of participating in data collection outside of normal business hours, either in the evenings or early mornings? Would it be critical for at least one field site to have availability on the weekend? Project sites should also determine whether members of the target population would prefer to set up appointments to be interviewed or to walk-in to be interviewed anytime during operating hours, or a combination of both methods.

### ***Incentives***

As described in the *NHBS Round 4 Model Surveillance Protocol, Trans Edition*, incentives are provided to participants for their participation in the survey and the HIV test. After completion of the survey and testing procedures, some participants will be asked to recruit other participants for which they will receive an additional incentive. For other NHBS cycles, project sites have used things like cash, VISA gift cards, or retail gift cards. Project sites should explore during primary data collection the type and amount of incentive appropriate for NHBS-Trans.

### ***Seed characteristics***

There are multiple criteria to consider when identifying seeds in RDS (see **Chapter 4** of the *National HIV Behavioral Surveillance among Transgender Women Model Surveillance Protocol*). Ideal seeds are dynamic individuals who are extremely knowledgeable about the target population, well-connected to it, and understand the importance of the success of the project. They should also have network ties to the major sub-populations in the project area. Since seeds are the initial recruiters in RDS, it is essential that they are highly motivated to provide support for the project, spread the word that data collection is beginning, and encourage others to participate. Selecting effective and well-connected seeds facilitates recruitment, promotes longer recruitment chains, and helps reduce bias in the sample.

Taken together, all the information that project sites gather on the community of trans women such as sub-populations, geographical distribution, and peer networks forms the basis for deciding how many initial recruits, or seeds, are required and the optimal characteristics of those seeds. Project sites should discuss how their findings will impact the number and characteristics of seeds needed to ensure the successful recruitment of a diverse sample of participants. They should then describe how many seeds will be needed, from which sub-populations they will be recruited and other important characteristics, and their method of recruitment.

Seed recruitment can occur during primary data collection (e.g. key informant interviews, focus groups). After explaining the study and how participation will work, interviewees can be asked if they are interested in being a seed or if they can refer other potential seeds to project staff. Remember, the NHBS-Trans survey is anonymous. Project sites should keep this in mind when establishing procedures to contact seeds identified during formative assessment. Project sites can consider providing their contact information to the potential seeds and asking the seeds to contact them at some future date, or working with local CBOs that can identify and refer potential seeds.

### ***Recruiter training***

As mentioned earlier, select participants will be asked to recruit other trans women to participate. Formative assessment provides an opportunity to explore the recruitment messaging with members of the community to determine their understanding of what they are being asked, how they think they would go about finding others to recruit, and if there are barriers to recruitment. It is important to consider messaging with a range of trans women who are members of various sub-populations.

For example, project sites may find that trans women of different races or gender identities do not respond to the same messaging. Ultimately, project sites will want to identify the messaging that will motivate members of the community to participate in NHBS-Trans and in turn, become effective recruiters. Project sites can consider allowing coupons to be sent by email or MMS and should explore how trans women perceive this.

### ***Other considerations***

Project sites should identify what additional considerations to make the field site a welcoming environment where participants feel comfortable while maintaining anonymity. This could include considerations to make participation more appealing to the community, such as computers with internet access, or areas to relax.

Project sites should also investigate what interviewer characteristics would be well-received by members of the community. Project sites should explore the importance of having members of the community employed as interviewers as well as staff characteristics or behavior that would deter someone from participating. The interaction between the interviewer and the participant can affect the overall impression of the project and influence the likelihood that a participant will recruit their friends.

Each project site should explore appropriate referrals that can be provided to participants after completing the survey and HIV test. These referrals can be for a variety of services, including HIV prevention, health care, and social services. Those interviewed during primary data collection can provide input on what referrals would be valuable to the community and which organizations have a strong reputation in working with the trans women community.

### **6.2.5 Barriers to participation**

Project sites should explore potential barriers to recruitment and survey participation for the target population. Project sites should also describe any factors that may adversely affect their ability to effectively conduct field operations or enroll a diverse sample of participants. Examples include safety concerns at field sites, or logistical barriers to blood-based or rapid HIV testing. Additionally, barriers may exist that hamper the ability to recruit a sample using respondent-driven sampling, such as small network sizes, resistance to in-person participation, or lack of trust from the community.

For each barrier identified, project sites should describe how they plan to overcome that obstacle during data collection. If there are potential barriers that cannot be resolved, project sites should explain why the barriers are insurmountable.

Participation barriers may include those that may be unique to a specific sub-population. For example, primary data collection may reveal that the proposed incentive level may not provide sufficient motivation for participation by trans women with high socioeconomic status.



Additionally, project sites may find that optimal hours of operation for trans women who exchange sex are only in the early morning and there may be participation barriers if the only field site hours are planned for mid-day/early evening.

### **6.2.6 Data dissemination**

As one of the central tenets of community-based participatory research, plans for use and dissemination of NHBS-Trans data should be explored before data collection even begins. In discussions with community members and key stakeholders, project sites should identify organizations that will partner in efforts to share findings and investigate the most effective ways of disseminating results to the broader community.

Project sites should also identify topic areas of local interest that are not included in the core survey instrument. Each project site is able to add up to ten minutes of additional questions to be administered to participants at the conclusion of the core survey. Collaboration with stakeholders to understand current gaps in knowledge and what kind of data are needed will ensure important information will be collected and utilized by the community.

## **6.3 Data Collection Methods**

For primary data collection, project sites can use a variety of qualitative and quantitative methods, such as key informant interviews, focus groups, and observations. Project sites should choose methods which will be most effective at obtaining the information necessary to understand the local target population.

To protect the anonymity of key informants and focus group participants, interviews and discussions cannot be audio- or video-recorded. In addition, because key informant interviews and focus groups involve engagement with human subjects, project sites should obtain informed consent from individuals participating in these activities. **Appendices A, B, and C** of the *National HIV Behavioral Surveillance among Transgender Women Model Surveillance Protocol* contain key informant and focus group consent forms that project sites can customize for local use. Model interview guides in **Appendix B** are also available to develop site-specific interview guides. During interviews, a guide can help keep the conversation on topic while still allowing for the free and open exchange of ideas.

### **6.3.1 Key informant interviews**

Key informants are cultural and subject matter experts that can provide insight into the target population. According to Schensul et al. (1999):

*[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.*

Some key informants have broad-based knowledge of the target population and will be able to provide general information on a variety of subjects, whereas others have more focused knowledge and will be able to provide in-depth information on a specific subject or sub-population. It is often helpful for project sites to start primary data collection by using sources with more general information to gain an overall understanding of the target population, and then graduate 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 sites should interview several key informants and cross-check the information they provide.

Some key informants may be members of the target population or volunteers at CBOs rather than paid professionals. These key informants are referred to as “community key informants”. Since community key informants are interviewed on their personal time, they may receive compensation for participating in the interview. Usually, paid staff who are interviewed in their professional capacities are not entitled to compensation for their time. Project sites should decide whether or not each of their key informants is a community key informant and is entitled to compensation. The *National HIV Behavioral Surveillance among Transgender Women Model Surveillance Protocol* has sample consent forms for both types of key informants (**Appendix A** for key informants and **Appendix B** for community key informants).

### **6.3.2 Focus groups**

Focus groups are interviews conducted with a group of individuals under the direction of a moderator. They are especially helpful for gaining insight into commonly held perceptions within the target population and for eliciting information on community norms. Focus groups can also be used to confirm other 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. As there are many topics to cover in primary data collection, it may not be feasible to discuss all topics during every focus group. The moderator must be prepared to prioritize the conversation and change topic if necessary.

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 community key informants, focus group participants should be compensated for their time.

Focus group participants should be recruited from within the project area. Focus groups can also be done with community leaders, and stakeholders, as well as staff from CBOs that serve the target

population. To facilitate a free and open discussion and to gain a better understanding of various sub-populations, focus groups should be composed of members with similar characteristics. For example, one focus group could be populated with Latinx trans women. Another focus group may contain trans women who exchange sex. It is important for focus groups to provide a comfortable and trusting environment for all who participate.

CAB members and other stakeholders may be especially crucial in facilitating the recruitment of trans women for focus group participation. Members of the community who are unfamiliar with NHBS-Trans may be weary to attend the focus group and a CAB member or stakeholder could serve as a gatekeeper to help build trust between project staff and focus group participants.

### 6.3.3 Observations

Unlike information collected from interviews, observations rely solely on what is seen by the researcher. Observations can be used to both validate and build on information gathered through other data sources. 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, parks, or service organizations. Observations can also provide insight related to the way in which different sub-populations of trans women interact with each other, if at all.

Stimson has identified aspects of observations that can help guide project staff when conducting observations (Stimson et al, 1998). These aspects have been adapted for NHBS-Trans and are summarized in **Table 2**.

**Table 2. Aspects of observations**

|            |   |
|------------|---|
| 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? |
|----------|---|

#### **6.4 Note-taking**

Because interviews and discussions cannot be audio- or video-recorded, it is recommended that a designated staff member take detailed notes (including direct quotes when possible) during each focus group session and key informant interview and that sufficient time is allowed after each interview session for additional notes and debriefing. During the debriefing session, the interviewer and note taker should write down additional notes and feedback and review any emerging topics that need to be further explored in subsequent interviews. This thorough notetaking and debriefing after each interview session will ensure that sufficient data is documented in lieu of audio- or video-recording to allow for analyses and publications of the qualitative findings from the formative assessment process. Documenting interview information from multiple participants during a focus group may be more challenging, therefore project sites may assign two note takers for focus groups sessions.

#### **6.5 Triangulation of Data**

“Triangulation” means cross-checking formative assessment findings by using multiple data sources, data collection methods, or investigators. Since formative assessment, especially qualitative assessment, that relies on only one data source or collection method is subject to the errors associated with that approach, many researchers triangulate their data to validate the results and ensure that the information is complete. One way project sites can triangulate their formative assessment data is to compare information on the same topic that has been obtained from different data sources. Another strategy is to use at least two different data collection methods (e.g., key informant interviews, focus groups, or observations).

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

## 7 Ongoing Formative Assessment

### 7.1 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 sites 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 sites 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.

### 7.2 Data Collection Methods

To conduct ongoing formative assessment, project sites should employ many of the same methods they used during formative assessment. These include data reviews, observations, interviews, and focus groups. Project sites 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 and focus groups). Whenever project sites identify an operational or enrollment problem using ongoing formative assessment, they should discuss the problem with their CDC project officer and develop a plan to resolve it. Plans to address operational and enrollment problems can also be shared with the CAB for additional feedback.

### 7.3 Data Monitoring

Project sites should continuously monitor their recruitment, coupon distribution and demographic data to assess field operations and participant enrollment. Some specific problems that can be identified with these data include the following:

- **Enrollment.** Low or declining participant enrollment may be the first sign of a barrier to recruitment and survey participation. Project sites should evaluate strategies to improve participant enrollment, such as adding new seeds, changing the number of coupons, or strengthening recruiter training.
- **Coupon Distribution.** A low proportion of distributed coupons that are returned indicates a barrier to survey participation, and thus, should be evaluated further to identify the cause and to develop a solution. The number of coupons circulating in the community may also help project sites manage differential coupon distribution and the phasing out of coupons at the end of the project cycle. Software such as NetDraw may be used to assess the effectiveness of seeds and recruitment patterns and waves.
- **Demographics.** Sub-populations will become underrepresented among enrollees when there is a participation barrier among that sub-population. Recruitment of sub-

populations that formative assessment indicates may be particularly hard to reach should be closely monitored and barriers to participation should be further evaluated and addressed early in the recruitment process. Project sites should monitor the sample with regards to demographic data such as race/ethnicity and age.

#### ***7.4 Ongoing Formative Assessment Plan***

In the Ongoing Formative Assessment Plan, project sites should briefly describe how they will conduct the needed formative assessment activities. They should also indicate which staff members will carry out the activities.

## 8 Appendix A: Implementation timeline

A model Implementation Timeline is shown below. The form can be modified using the Excel file named **Appendix A – Model Implementation Timeline.xlsx**.

[Project Site] NHBS-Trans Implementation Timeline

| Task                                     | Due Date | 2017    |          |          | 2018    |          |       |       |     |      |
|--|----------|---------|----------|----------|---------|----------|-------|-------|-----|------|
|  |          | October | November | December | January | February | March | April | May | June |
| Develop Implementation Timeline          |          |         |          |          |         |          |       |       |     |      |
| Submit Implementation Timeline           |          |         |          |          |         |          |       |       |     |      |
| Prepare IRB package                      |          |         |          |          |         |          |       |       |     |      |
| Submit IRB package                       |          |         |          |          |         |          |       |       |     |      |
| Obtain IRB approval                      |          |         |          |          |         |          |       |       |     |      |
| Review secondary data                    |          |         |          |          |         |          |       |       |     |      |
| Write Secondary Data Report              |          |         |          |          |         |          |       |       |     |      |
| Recruit CAB members                      |          |         |          |          |         |          |       |       |     |      |
| Hold CAB kick-off meeting                |          |         |          |          |         |          |       |       |     |      |
| Collect primary data                     |          |         |          |          |         |          |       |       |     |      |
| Write Primary Data Report                |          |         |          |          |         |          |       |       |     |      |
| Submit Primary Data Report               |          |         |          |          |         |          |       |       |     |      |
| Write Ongoing Formative Assessment Plan  |          |         |          |          |         |          |       |       |     |      |
| Submit Ongoing Formative Assessment Plan |          |         |          |          |         |          |       |       |     |      |
| Develop local questions                  |          |         |          |          |         |          |       |       |     |      |
| Identify field site locations            |          |         |          |          |         |          |       |       |     |      |
| Hire field staff                         |          |         |          |          |         |          |       |       |     |      |
| Train field staff                        |          |         |          |          |         |          |       |       |     |      |
| Obtain incentives                        |          |         |          |          |         |          |       |       |     |      |
| Obtain testing/other supplies            |          |         |          |          |         |          |       |       |     |      |
| Complete Operations Checklist            |          |         |          |          |         |          |       |       |     |      |
| Submit Operations Checklist              |          |         |          |          |         |          |       |       |     |      |
| Start survey data collection             |          |         |          |          |         |          |       |       |     |      |

## 9 Appendix B: Formative Research Topics and Interview Questions

Below is a list of model formative assessment topics and interview questions that project sites can use to develop interview guides. Project sites should adapt the questions to the type of interview being conducted and to the background of the individual(s) being interviewed. Some questions may be more appropriate for key informants and service providers, where others may be better suited for community members or focus groups. Project sites should be aware of comprehension level when developing more tailored guides. Project sites can also modify the questions to focus on trans women sub-populations, like young trans women or racial and ethnic minority trans women.

The example interview questions use the term trans women. When interviewing community members and other non-professionals, project sites should replace this term with another locally-acceptable term as necessary.

Before interviewing each primary data source, project sites should briefly describe NHBS-Trans, including the respondent-driven sampling (RDS) method and the process of recruiting trans women to participate in the project.

### B.1 Community Description

- How would you describe the make-up of the trans women community in *[project area]*?
  - What are the demographics characteristics of trans women (e.g., by age, race/ethnicity)?
  - What terms do you hear trans women in *[project area]* use to refer to their gender identity? Which of these terms are positive? Which terms are negative?
    - Are there any terms which are acceptable for some people to use, but unacceptable from other people? What are some of those terms, and who can or can't use them?
- What are the various sub-populations, such as Black, White, Hispanic, young, old, sex workers, other sub-populations?
  - What are the interactions between these sub-populations?
  - Are there sub-populations that don't interact with other trans sub-populations?
  - Are there some groups that are isolated?
  - Is there a lot of interaction between the sub-populations?
- A person's "peer network" is defined as the set of people whom the participant knows from the trans women community in *[project area]* and whom they have seen in the past 30 days.
  - What are the typical sizes of trans women's peer networks?
  - About how many transgender women do you interact with on a monthly basis?



- How long have most trans women you know lived in the area?
- Are there any neighborhoods in *[project area]* where trans women hang out and live?
  - Where are these neighborhoods located?
- What is the income status of trans women in *[project area]*?
- What are the opportunities for employment for trans women in *[project area]*?
- What is housing availability like for trans women in *[project area]*?
  - Are you aware of any shared living environments for trans women?
    - How common is this?
- What kind of relationship do trans women have with the local police in *[project area]*?
- What are the perceptions of HIV testing in the trans women community?
  - Is there stigma or fear about being tested?
- What are the perceptions of HIV-positive persons in the trans women community?
  - Is there stigma or fear about disclosing an HIV-positive status?

## Resources

- Where do trans women go for health services? Services like primary care, mental health and support services, hormone therapy, or other things.
  - Are these places specifically for trans women?
  - Do you feel there is sufficient access to health services for trans women in *[project area]*?
  - What are the barriers for seeking out health services? (e.g., lack of insurance, negative experiences in the past, provider lack of knowledge)
- Where do trans women go for HIV care and treatment services?
  - Are these places specifically for trans women?
  - Do you feel there is sufficient access to HIV care and treatment services for trans women in *[project area]*?
  - What are the barriers for seeking out HIV care and treatment services? (lack of insurance, negative experiences in the past, provider lack of knowledge, etc.)
- Are there HIV prevention services available in *[project area]*?
  - Have you heard of PrEP? PrEP is pre-exposure prophylaxis to prevent HIV. It is a daily pill that people who do not have HIV can take to reduce the risk of getting HIV. Do you know where you can get PrEP in *[project area]*?
- Does your organization collect any data on the trans women that you serve? Are you able to share any information or reports with me today? (demographics, risk behaviors, population size, etc.)

## B.2 Garnering Community Support

Project sites can modify these questions for local use to identify trans women stakeholders, develop marketing materials, and establish collaborations with other programs or organizations that provide health care and social services to members of the community.

## Identifying stakeholders

- Who are the leaders of the trans women community?
  - Do they represent any specific sub-populations?
  - If yes: What sub-populations do they represent?
- Which key individuals or organizations provide services to the trans women community?
- Which key individuals or organizations advocate for issues affecting the trans women community? (e.g., gatekeepers, stakeholders)
- What is the best way for us to gain support for our survey from the trans women community?
- What is the best way for us to gain support from *[specific sub-population]* trans women?
- What is the best way for us to gain support from community leaders, service providers, and advocates?
- What are your thoughts on ways that we could promote our study among the transgender community?

## How to use the data

- What survey findings would be beneficial to you or your organization?
- Are there any key topics that we should explore with local questions?
  - Are there any important topics we should explore with local questions that could help with the development or evaluation of policies or programs?
- Who would be interested in learning the findings from our survey?

## Developing marketing materials

- Which marketing strategies (e.g., flyers, posters, media, social media) would be most effective at reaching the trans women community?
  - Which marketing strategies would be most effective at reaching *[specific sub-population]* trans women?
- Which marketing messages would be most effective at encouraging trans women to participate in our survey?
  - Which marketing messages would be most effective at encouraging *[specific sub-population]* trans women to participate in our survey?
- Where would marketing efforts be most effective? (e.g., specific brick-and-mortar locations, specific websites or social media outlets)

## Establishing collaborations

- Does your program or organization provide health care or social services to the trans women community?
  - What services are provided?
  - Please tell me about the trans women who access these services?
  - How many trans women access your services?

- How can we collaborate so that appropriate referrals are given to participants in our survey?
- Is your program or organization currently conducting research among *[trans women/specific sub-population]* in *[project area]*?
- Do you know of other institutions or individuals who have conducted or are currently conducting research among *[trans women/specific sub-population]* in *[project area]*? Please list them:
- Would you be able to accompany us to *[specific location]* to connect with trans women there and help us gain their trust?

### **B.3 Identifying and Addressing Barriers to Survey Participation**

Project sites can modify these questions for local use to identify barriers to survey participation, HIV testing, and if applicable, sexually transmitted infection (STI) testing. Whenever a primary data source identifies a barrier to survey participation, project sites should follow-up and ask the source to propose a solution to overcome that barrier.

#### **General**

- What are the barriers to trans women participating in our survey?
  - What suggestions do you have for overcoming these barriers?
- Would trans women be willing to recruit their friends to take the survey?
  - What would it take for trans women to be willing to recruit their friends?
  - What would be an appropriate incentive for recruiting friends?
- Are there any barriers to survey participation that are specific to trans women sub-populations (e.g. young trans women or racial and ethnic minority trans women)?
  - What suggestions do you have for overcoming these barriers?
- What challenges have you encountered when working with the trans women community (e.g., trust, HIV testing, incentive type or amount, community support)?
  - How do you think these challenges will affect the success of our survey?
  - What suggestions do you have for overcoming these challenges?
- How can we foster trust among the trans women community?
- Does the trans women community perceive researchers or other community outsiders differently?
- How do trans women perceive the local health department? Do they view them as advocates or with suspicion?
- How can we motivate trans women to participate in our survey?

#### **HIV testing, blood specimen storage, and additional testing**

- Would trans women avoid participating in the survey if HIV testing is offered?
  - What are the barriers to using *[testing method]* HIV tests?

- What suggestions do you have for overcoming barriers to HIV testing among trans women?/ What – if anything – can we do to make women less concerned about taking the test as part of our survey?
- If a participant tested HIV-positive as part of this study, how willing would she be to speak to a medical professional about treatment options?
  - Who/what are some of the most trusted providers of HIV medical care for trans women in *[project area]*?
- In addition to the HIV test, we plan on collecting blood specimens for storage for future tests, such as tests for HIV viral load, recent HIV infection, and antiretroviral drugs. Blood specimens will be collected with a fingerstick and saved on a card. Results from any future tests will not be returned to participants.
  - How will the trans women community perceive blood specimen storage for future tests?
  - Will trans women be willing to provide blood specimens for storage for future tests?
    - If no: How can we encourage trans women to provide blood specimens for storage for future tests? What would be required for trans women to feel comfortable providing blood specimens for future tests?

## **B.4 Exploring Field Operations**

Project sites can modify these questions for local use to ensure successful field operations by identifying acceptable incentives for the survey and HIV test; determining ideal staff characteristics; developing the most effective recruitment messages; and identifying which local prevention, health care, and social services are available for making referrals and linkages to care.

### **Seeds**

- What would be the best way to identify seeds who can refer others into the study for each of the identified sub-populations?

### **Incentives**

- We will give eligible participants an incentive for completing the survey and another incentive for taking the HIV test. The survey takes approximately 45 minutes to complete and the HIV test takes 20 minutes. What would appropriate incentive amounts be for each?
- What type of incentive, like cash, Visa gift cards, or retail gift cards would be most desirable to the trans women who participate in our survey?

### **Staffing**

- What criteria should we consider when hiring survey staff to work with the trans women community?

- What are the characteristics of the ideal interviewer for this project?

### **Field site locations and hours of operations**

- Do you know of an appropriate meeting space (e.g. office space, building, neighborhood location) to conduct this survey in *[project area]*?
- We're thinking of using *[x]* as a survey site.
  - Would *[trans women/specific sub-population]* feel comfortable going there to do an interview? If not, why?
  - Is *[x]* survey site accessible to *[trans women/specific sub-population]*?
  - Is it safe for participants and project staff?
  - Is the area friendly/unfriendly to *[trans women/specific sub-population]*?
  - What kinds of barriers could keep *[trans women/specific sub-population]* from coming to *[x]* survey site for an interview?
  - What could we do to make it easier or more appealing for *[trans women/specific sub-population]* to come to this site?
- What days of the week/time of day would be best for our office hours for the *[trans women/specific sub-population]*?
  - Are there trans women we would be missing by using these office hours?
- Should we set up an appointment system for survey participants, or do you think they would prefer to walk-in during office hours?

### **Local prevention and social services**

- We provide referrals to our survey participants for a variety of HIV prevention, health care, and social services. What HIV prevention, health care, or social service information would be most helpful to provide to trans women?
- We also provide linkage to HIV care and treatment services. For participants who test positive for HIV, where would trans women feel comfortable going for HIV care and treatment?
- What other type of referrals would be beneficial for trans women in *[project area]*?

### **Names of local public health insurance programs**

- Information on health insurance programs is collected to help interviewers code the types of public health insurance reported by participants.
- What are the names of the public health insurance programs that are available in *[project area]*?
- Are there acronyms or “street names” for these programs?

### **Additional stakeholders**

- Would you be able to connect us with one or more trans women from *[sub-population]* in order for us to do a community key informant interview with them or invite them to a focus group?

