The Role of Formative Research in the National HIV Behavioral Surveillance System

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SYNOPSIS

The National Human Immunodeficiency Virus (HIV) Behavioral Surveillance System (NHBS) is the Centers for Disease Control and Prevention's (CDC's) newest system for measuring HIV risk behaviors among three adult populations at highest risk for HIV infection in the U.S.: men who have sex with men, injecting drug users, and heterosexuals at risk of HIV infection. The system is implemented by state and local health departments in designated metropolitan statistical areas with the highest HIV/acquired immunodeficiency syndrome (AIDS) prevalence in the U.S.

Prior to implementing the behavioral surveillance survey, project sites conduct a series of formative research activities. The data collected during this preparatory phase provide contextual information about HIV risk behaviors within the study population of interest and help project sites make decisions about field operations and other logistical issues. This article describes the activities undertaken in preparation for the first round of NHBS (2003–2007) and how those activities enhanced data collection for each behavioral surveillance cycle.

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The National Human Immunodeficiency Virus (HIV) Behavioral Surveillance System (NHBS) is the Centers for Disease Control and Prevention's (CDC's) newest and most comprehensive system for measuring behaviors that place people at risk for HIV infection.[1,2] Developed in conjunction with state and local health departments from high-prevalence acquired immunodeficiency syndrome (AIDS) areas, NHBS collects information on risk behaviors, HIV testing history, and exposure to and uses of HIV prevention services among three adult populations at highest risk for HIV infection in the U.S.: men who have sex with men (MSM), injecting drug users (IDUs), and heterosexuals at risk of HIV infection (HET). The data collected through the NHBS are intended to be analyzed and disseminated both locally and nationally to help inform decisions regarding HIV prevention programs and activities.

NHBS is a community-based surveillance system in that participants are recruited from non-health-care settings within the community. In the context of NHBS, "community" is both a geographical and population construct. It refers to a physical area within a major city or epicenter of HIV, as well as to a subpopulation of people who are at high risk for HIV infection.

One of the features of this new surveillance system is that it incorporates a three-month period of formative research into the beginning of each data collection cycle. The value of conducting formative research prior to implementing epidemiologic surveys has been well-documented in the literature.[3–5] However, formative research in the context of surveillance is more rare. Most disease surveillance systems and many behavioral surveillance systems do not conduct community-based data sampling, recruitment, and data collection similar to NHBS; rather, these systems use probability samples at the national or state level to select individuals or households and have less need than NHBS to understand the community context in which participants live, interact, and engage in the behaviors of interest. For NHBS, the information collected during this preparatory phase lays the foundation for the collection of relevant behavioral surveillance data. During this period, participating health departments are expected to engage a variety of organizations, institutions, and individuals who are familiar with HIV/AIDS issues in the community.

The overall purpose of the formative research component of NHBS is to provide participating health departments with information to help them tailor this national surveillance system to their local setting. To that end, NHBS formative research activities are designed to help project sites: (*1*) describe the characteristics of their NHBS population of interest, (*2*) gain preliminary insight into the context of HIV risk behavior within the community of study, (*3*) garner the support of community stakeholders for the behavioral survey, (*4*) develop questions to measure access to local HIV prevention services, and (*5*) finalize decisions about NHBS field operations, such as the best locations and hours for data collection and the selection of appropriate interview staff (Table 1). This article describes the activities undertaken in preparation for the first round of NHBS (2003–2007) and how these activities enhanced data collection for each behavioral surveillance cycle.

BACKGROUND

Overview of the NHBS

NHBS was designed to collect information on sexual and injection drug use behaviors that are related to HIV acquisition and that are amenable to intervention through prevention programs.[1] As part of their mandate to assess the impact of HIV prevention efforts in the community, participating health departments are encouraged to collaborate with community-based organizations (CBOs) directly funded by CDC and those funded by states and cities through the community planning process for allocating HIV prevention funds.[6] NHBS data are collected in rotating annual cycles within the major city or epicenter of HIV/AIDS cases in each designated metropolitan statistical area (MSA). In the first round of NHBS, eligible awardees were health departments whose jurisdictions included the 15 MSAs with the highest AIDS prevalence in 2000.[7] However, during 2003–2004, eligibility was expanded to add the state health departments whose jurisdictions included the next 10 MSAs with the highest AIDS prevalence in states not already participating in NHBS, bringing the total number of participating project areas to 25 MSAs.[8]

To follow trends in HIV-related behaviors over time, the three NHBS study populations of interest—MSM, IDUs, and HET—are surveyed using a standardized protocol and core questionnaire once every three years. Each cycle of NHBS data collection is referred to by the population of interest: NHBS-MSM, NHBS-IDU, and NHBS-HET.

Eligibility criteria and sampling methods for NHBS vary by cycle and have been described in detail elsewhere.[9–11] In brief, all NHBS cycles have four eligibility criteria in common: participants must (*1*) be at least 18 years of age, (*2*) live in the MSA, (*3*) be able to complete the interview in English or Spanish, and (*4*) have not previously completed an NHBS interview during that cycle. There are also eligibility criteria that are

specific to each NBHS cycle. For the first NHBS-MSM cycle, eligible participants were individuals who met the four criteria previously mentioned and were born male. Participants were recruited through time-space sampling in venues (e.g., bars, parks, and bookstores) frequented by MSM. Eligible participants for NHBS-IDU were male or female IDUs who met the four criteria previously mentioned and had injected drugs in the past 12 months. NHBS-IDU participants were recruited using respondent-driven sampling (RDS), a modified chain-referral method in which those recruited for interviews recruit their peers in turn.

Eligible participants for NHBS-HET were adult males or females who met the four previously mentioned criteria and (*1*) had a physical or social connection to a high-risk area (HRA)—a geographic area with high rates of heterosexually acquired HIV infection and poverty—(*2*) had had vaginal or anal sex with a person of the opposite sex in the past 12 months, (*3*) were not transgender, and (*4*) were not older than 50 years of age. The first cycle of NHBS-HET was a pilot study of two methods. Fifteen of the 25 project areas recruited heterosexual adults through RDS. The remaining 10 project areas recruited heterosexual adults through time-space sampling in venues located within HRAs.

METHODS

The formative research component for NHBS consists of three activities: (*1*) a review of secondary data, (*2*) the collection of qualitative data, and (*3*) the identification of organizations that provide HIV prevention programs and services within the NHBS study area. Guidance for conducting NHBS formative research activities is provided by CDC as part of the protocol for each NHBS cycle.

NHBS formative research is an iterative process: knowledge about the study population builds on information collected during each of the formative research components described hereafter. Ongoing review of the data throughout the formative research process helps project sites identify gaps in knowledge and determine if there is a need to collect additional information. When necessary, initial assumptions or conclusions are revised, such as changes in the number or type of venues to be included on a project site's sampling frame or the location and number of neighborhoods from which a project site will recruit its initial RDS seeds.

Upon completion of their formative research activities, project sites compile their findings into a series of short reports that they send to CDC. These reports serve as the basis from which the sites, in consultation with CDC, finalize decisions about how best to tailor the behavioral survey and field operations to the community of study.

Review of secondary data

The purpose of the secondary data review is to use existing data (published and unpublished) to help characterize the pattern of HIV/AIDS among the population of interest, document what is known about their risk behaviors, and define the geographic area from which the NHBS sample will be drawn. As part of their secondary data review, project sites examine a minimum of three HIV-specific data sources: their HIV/AIDS case surveillance data, HIV counseling and testing data, and the HIV/AIDS epidemiologic profile. This latter document describes the impact of HIV/AIDS on an area in terms of its sociodemographic, geographic, behavioral, and clinical characteristics.[12] Project sites also compile a list of community resources (e.g., social organizations, media outlets, local businesses) that serve the NHBS study population.

As part of their secondary data review for the NHBS-MSM cycle, project sites conducted a review of local gay and bisexual publications and online resources to identify venues that are frequented by MSM in the project area (e.g., clubs, restaurants, businesses, bars, social organizations, social functions).[9] Additional components of the secondary data review for the NHBS-IDU cycle included a review of national, state, and local resources on the types and methods of illicit drug use, geographic locations of drug activity and drug arrests, and drug treatment programs in the project area.[10] As part of their secondary data review for the NHBS-HET cycle, project sites examined the geographic dispersion of heterosexual AIDS cases within the MSA to better understand where to target their recruitment efforts.[11]

In addition to describing the attributes of populations at highest risk for HIV within their MSA, the review of existing secondary data helps project sites identify any gaps in knowledge about the study population of interest. The review of secondary data, in essence, serves as the starting point from which project sites make initial decisions about the type of qualitative formative research data they will need to collect.

Collection of qualitative data

Previous qualitative studies have offered valuable insight into the range of behaviors that put people at risk for HIV infection, as well as the social, economic, and cultural contexts that shape those behaviors.[13–18] Qualitative data collection can also be of value within

a national HIV behavioral surveillance system. To that end, a central component of CDC's guidance on NHBS formative research activities is the collection of qualitative data, using an array of methods common to many qualitative and ethnographic studies of health: key informant interviews, focus group interviews, brief intercept surveys, observation, and ethnographic mapping.[19–24]

During the first cycle of NHBS-MSM, CDC recommended three qualitative data collection methods: key informant interviews, brief intercept surveys, and observations in venues frequented by MSM.[9] For the NHBS-IDU and NHBS-HET cycles, CDC expanded its recommendations to include focus group interviews and ethnographic mapping. It was at this point that CDC also began strongly recommending that project sites hire an ethnographer to oversee and guide all aspects of qualitative data collection and analysis. Brief summaries of CDC's guidance regarding NHBS qualitative data collection activities and their relevance within each NHBS cycle follow.

Key informant interviews. A key informant is an individual who is knowledgeable about the study population or topic of interest. Also referred to in the literature as "cultural experts," key informants can come from different populations or groups in the community, including members of the study population of interest, service providers, law enforcement, and community leaders.[24,25] Although a key informant may not know everything there is to know about the context of HIV risk behavior within a particular community, a good key informant will have a deep understanding of particular domains of interest. As noted in Schensul et al.:

> Effective key informants are individuals who have broad knowledge of the research setting or deep knowledge of an important aspect of the research. . . . Most often they 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.[25]

CDC encourages NHBS project sites to use the format of the key informant interview to explore the range of HIV risk behaviors and issues among MSM, IDUs, and HET in the local communities. Such information may include the make-up of their social networks, their interaction with different sectors of society, and the various locales where risk behaviors take place or are initiated. The information collected during interviews with key informants can also provide insight into indicators of HIV risk specific to the NHBS study area.

During the NHBS-MSM cycle, key informant interviews provided information about the different subpopulations of MSM in the community as well as

Figure. Outcomes of formative research for the NHBS by data collection activity

Formative research outcome	*Data collection activity*
1. Describe the characteristics of the NHBS study population of interest.	Review of secondary data Interviews with key informants Focus group interviews Brief street intercepts Ethnographic mapping
2. Understand the context of HIV risk behavior within the NHBS study area.	Review of secondary data Interviews with key informants Focus group interviews Observations
3. Garner the support of community members.	Interviews with key informants Focus group interviews
4. Develop questions to measure access to local HIV prevention services.	Review of secondary data Interviews with key informants Focus group interviews
5. Finalize NHBS study logistics.	Interviews with key informants Focus group interviews Brief street intercepts Observations Ethnographic mapping

NHBS = National HIV Behavioral Surveillance System

HIV = human immunodeficiency virus

venues where MSM meet and socialize. In addition to helping project staff identify popular bars and dance clubs where large numbers of NHBS-MSM participants might be recruited, key informants in some project areas also suggested that staff consider smaller recruitment venues, such as gay-identified social clubs and organizations. Although attendance at these venues was often lower than would be found at a bar or dance club, recruitment at these venues helped increase the diversity of the NHBS-MSM sample.

For the NHBS-IDU cycle, interviews with key informants provided project staff with insight into the characteristics of the social and injecting networks of IDUs, descriptions of drug-trafficking activities within a particular area, and the various locations where study participants could be reached and recruited. This latter information was particularly useful in helping project sites find the initial participants to start off the peer-recruitment process used during the NHBS-IDU cycle.[10]

For the NHBS-HET cycle, interviews with key informants helped project sites identify community leaders and other relevant stakeholders in the community whose support of the project was considered to be crucial to its success. Subsequent interviews with these stakeholders provided project staff with information about how best to promote NHBS in the community and garner the support of other community members for NHBS. During all NHBS cycles, project staff used the format of the key informant interview to help identify local HIV prevention programs that provided services to high-risk populations within the study area.

Focus group interviews. Focus group interviews are conducted with several individuals at a time, under the direction of a moderator. This interview format can provide quick information about general topics of interest or location-specific issues about which little is known.[23,27,28] NHBS project sites are encouraged to use the format of the focus group interview to explore group opinions or community norms about specific behaviors and practices and to help identify location-specific issues. Information collected through this format can also be used to validate other formative research findings.

NHBS project sites have used focus group interviews to solicit input on a variety of HIV-related issues, such as the range of risk behaviors within the study population of interest, the vocabulary associated with specific HIV risk behaviors, the accessibility of HIV prevention services within the NHBS study area, how best to achieve community buy-in for the behavioral survey, and how to successfully recruit individuals from the NHBS study population of interest. NHBS project sites have also used the focus group format to solicit community input on issues directly related to study logistics.

This latter use of focus group discussions was particularly salient during the NHBS-HET cycle. In contrast with the NHBS-MSM and NHBS-IDU cycles, NHBS-HET took place among a study population that had very little experience participating in HIV research studies. Focus group discussions with men and women highlighted a variety of logistical issues project sites needed to consider for their field operations. These included the provision of child care for participants who were mothers of young children, hours of field operations that were flexible enough to accommodate varied work schedules, appropriate levels of compensation for study participants, and the cultural characteristics to consider when hiring project interviewers.

Brief intercept surveys. A brief intercept survey involves asking individuals who are encountered in or near the NHBS sampling area about issues that are relevant to the specific NHBS cycle. The survey is rapid (5 minutes maximum) and is typically conducted on the street.[26] One advantage of this method is that it is quick and easy to do, although it provides little opportunity to probe or ask follow-up questions.

During the NHBS-MSM and NHBS-HET cycles, the brief intercept survey was used to solicit the spontaneous input of community members about locations of venues where MSM and heterosexual adults could be recruited to participate in the behavioral survey. Once those venues were identified, project sites conducted additional brief intercept surveys with venue patrons to assess their characteristics in terms of eligibility for and willingness to participate in the behavioral survey. Some RDS sites also used the format of the brief street survey to elicit quick information about neighborhood demographics or to identify members in the community whose buy-in for the project might be essential for its success.

Observations. Unlike the information gleaned from key informant or focus group interviews, observation relies solely on what is seen by the researcher.[25,26] Being there and observing what is happening "on the ground" can provide project staff with important insights into the context of HIV risk behaviors among the study population. NHBS guidance for conducting observations recommends that project sites incorporate the eight aspects of observations identified by Stimson et al.: settings, people, activities, signs, events, time, goals, and networks.[23]

Observations are conducted in a variety of locations that are relevant to NHBS activities within specific

communities or among particular at-risk populations. These may include observations to gauge the presence of drug activity in particular neighborhoods, the visibility of HIV prevention services, or the flow of clientele at venues being considered for inclusion into the sampling frame. During the NHBS-MSM and NHBS-HET cycles, observations within venues (e.g., bars, barber shops, beauty salons, retail outlets, street intersections) helped project sites identify those venues most likely to yield a sufficient number of study participants. As part of their preparation for the NHBS-IDU cycle, project sites conducted observations in different neighborhood settings to obtain firsthand information about the areas and hours of highest drug activity. This information helped them determine where best to set up field sites so that they would be accessible to the largest number of potential NHBS-IDU participants.

Ethnographic mapping. Ethnographic mapping involves the use of simple graphics or maps to visually convey information about the environment of a study area.[23,29] Within the context of NHBS, CDC recommends that project sites map the physical and social environment of HIV risk behavior within the NHBS study area. This includes mapping areas where high-risk behaviors occur or areas in the community where members of the study population can be accessed and recruited. During the NHBS-IDU cycle, project sites used this method to map areas of high drug activity within the NHBS study area. For the NHBS-HET cycle, some project sites used this method to illustrate the physical location of venues on their sampling frame.

Identification of local prevention programs

The third component of NHBS formative research activities provides information about HIV prevention programs operating within the project area. Project sites compile a comprehensive list of federally and non-federally funded programs that provide HIV prevention services within the NHBS project area. In compiling their list, project sites meet with HIV prevention staff from the local health department to get information about the HIV prevention programs or services they provide within the project area. This includes identifying programs that receive CDC funds to conduct local HIV prevention programs or services in the local geographic area and collecting information about the amount of CDC funds budgeted to that organization, program, or service. Project sites are also encouraged to meet with members of the Community Planning Group to get their input into which programs are believed to have the greatest exposure among the NHBS population of interest and why.

Sites then use the information they collect to develop a spreadsheet of local HIV prevention organizations with the following information: (*1*) name of the organization, (*2*) amount of CDC funds the organization receives annually, (*3*) HIV prevention programs or services the organization provides, (*4*) demographics of the targeted population, and (*5*) names of those programs that specifically target the NHBS population. Additional criteria for inclusion on the list are that those prevention programs provide several types of HIV-related services and have been ongoing for several years.

Upon completion of this list, project sites use a template provided by CDC to create a set of local questions to measure survey respondents' exposure to these HIV prevention programs. Project sites can develop a set of questions for up to 10 programs from the list. In selecting which programs to include, project sites are encouraged to give priority to those that receive HIV prevention funds directly or indirectly from CDC. In addition to helping NHBS project sites monitor exposure to local HIV prevention activities, the information gathered through these questions helps project sites characterize missed opportunities for prevention. These local prevention questions are meant to complement those on the NHBS survey that measure participants' exposure to and use of three specific types of HIV prevention interventions: (*1*) provision of information, (*2*) counseling and skills building, and (*3*) provision of prevention supplies.[30]

Ongoing collection of qualitative data. Although project sites conduct most of the NHBS formative research activities prior to implementation of the behavioral survey, the collection of qualitative data does not end once the behavioral survey begins. Ongoing collection of qualitative data is vital to the project's success in that it can alert project sites to any changes in the NHBS study area that may have a bearing on the implementation of the study. For the NHBS-IDU cycle, this included identification of the emergence of new injection drugs of choice, new subpopulations of IDUs, or the presence of recent police activity in the area that might affect the recruitment of new participants. For the NHBS-MSM and NHBS-HET cycles, the ongoing collection of qualitative data provides project sites with up-to-date information on the eligibility, suitability, and availability of the venues on their sampling frame. It also provides an opportunity to identify new venues. To keep abreast of these and similar changes, CDC recommends that project sites collect additional qualitative data every 12 to 14 weeks.

DISCUSSION

The NHBS formative research activities described in this article yield practical information for surveillance operations as well as contextual information for understanding HIV risk in these populations and geographic areas. Formative research data allow each project site to design a surveillance system that is culturally appropriate and locally relevant while remaining consistent with the core elements of the national NHBS protocol.

One of the strengths of this model is that it involves the use of an array of qualitative data collection methods. In addition to providing project sites with different methods to cross-check and verify the information they collect, having several methods to choose from gives project sites the flexibility of selecting the method that may be best suited to a given situation, such as exploring sensitive topics or conducting interviews at particular locations. Moreover, because the methods used to collect qualitative data are inherently interactive, they can serve as important mechanisms by which local NHBS staff get out into the community and gain visibility for the NHBS project. Achieving visibility for the project can be critical in determining people's willingness to participate once the behavioral survey gets underway.

As with any new data collection system, a number of valuable lessons for improving the formative research component of this behavioral survey were learned along the way. During the NHBS-MSM cycle, qualitative data collection activities were primarily focused on identifying venues in the community where MSM could be recruited. However, beginning with the NHBS-IDU cycle, formative research guidance emphasized the importance of collecting preliminary information about HIV risk behaviors among members of the study population of interest and about the cultural, social, and economic contexts in which those behaviors occurred. For the NHBS-HET cycle, a separate activity to help project sites identify and elicit the support of community stakeholders was added to the list of formative research activities, as was the recommendation that project sites hire an ethnographer to guide all aspects of qualitative data collection, including analyzing the information collected and writing the ethnography report.

Valuable lessons for improving CDC's guidance to project sites were also learned. During the first round of NHBS, CDC did not provide training in qualitative data collection methods. It was assumed that such training, if needed, would be conducted at the local level by the project site's ethnographer. Instead, while the majority of project sites worked with an ethnographer, most ethnographers were hired on a part-time basis for very limited data collection tasks; very few were directly involved in training local staff. CDC is currently working with NHBS project sites to address these challenges and improve the quality of formative research data collected in future NHBS cycles.

CONCLUSION

Much has been written about the value of incorporating both qualitative and quantitative data collection methods into public health research.[31–36] This article highlights the benefits of such an approach when the data collected are used to inform the implementation of the NHBS. In addition to providing project sites with information about a host of issues associated with HIV risk behaviors within their study area, the data collected during this preparatory period of fieldwork help project sites make decisions about field operations and other logistical issues related to the NHBS project area.

The findings and conclusions in this article are those of the authors and do not necessarily represent the views of the Centers for Disease Control and Prevention.

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