Behavioral Surveillance Among People at Risk for HIV Infection in the U.S.: The National HIV Behavioral Surveillance System

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SYNOPSIS

The Centers for Disease Control and Prevention, in collaboration with 25 state and local health departments, began the National HIV Behavioral Surveillance System (NHBS) in 2003. The system focuses on people at risk for HIV infection and surveys the three populations at highest risk for HIV in the United States: men who have sex with men, injecting drug users, and high-risk heterosexuals. The project collects information from these three populations during rotating 12-month cycles.

Methods for recruiting participants vary for each at-risk population, but NHBS uses a standardized protocol and core questionnaire for each cycle. Participating health departments tailor their questionnaire to collect information about specific prevention programs offered in their geographic area and to address local data needs.

Data collected from NHBS will be used to describe trends in key behavioral risk indicators and evaluate current HIV prevention programs. This information in turn can be used to identify gaps in prevention services and target new prevention activities with the goal of reducing new HIV infections in the United States.

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Historically, surveillance to describe the HIV/AIDS epidemic in the United States has primarily involved case surveillance for HIV infection and AIDS, although some supplemental surveillance systems and surveys have been used to provide additional information about behaviors related to HIV infection.[1,2] Because many years may pass between the time when a person is infected with HIV and the time that HIV infection is diagnosed, case surveillance for HIV infection and AIDS does not reflect recent trends in the behaviors that fuel the epidemic. Therefore, surveillance of HIV-related behaviors is an important component of an integrated surveillance system.

In 2003, the Centers for Disease Control and Prevention (CDC), in collaboration with 25 state and local health departments, began developing a new behavioral surveillance system to measure behaviors among populations at risk for HIV infection in the United States. This article describes the rationale, methods, and uses of data from the National HIV Behavioral Surveillance System (NHBS).

BACKGROUND AND RATIONALE

HIV behavioral surveillance systems should collect data from various populations: the general population, people at risk for HIV infection, and people living with HIV infection.[3] To address the population of people at risk for HIV infection, from the mid-1990s through 2002, CDC sponsored two different surveys to measure HIV-related behaviors in at-risk people: the HIV Testing Survey (HITS) and the Young Men's Survey (YMS). HITS was a series of cross-sectional interview studies of people at high risk for acquiring HIV infection (men who have sex with men [MSM] recruited from gay bars, street-recruited injecting drug users (IDUs), and heterosexual people recruited from sexually transmitted disease [STD] clinics) conducted during five separate cycles between 1995 and 2002.[4–7] During the course of the survey, data from 22 geographic areas were collected. For each geographic area, the intended sample size was 100 each for MSM, IDU, and heterosexuals during each cycle.

The YMS was a cross-sectional, multisite, venue-based survey of men aged 15–22 conducted in seven metropolitan areas from 1994–1998.[8] Young men, most of whom were gay, were recruited from public venues within a defined geographic area frequented by gay men. These included bars, dance clubs, parks, street locations, business establishments, and social organizations. A sample size of 500 was targeted for each of the seven metropolitan health departments.

Although both of these studies were invaluable in providing behavioral information about these populations at risk, they were either time limited, not conducted in the same cities over time, or had relatively small sample sizes. These studies did not allow for the analysis of trends in consistent geographic areas over time.

The need for development of a national behavioral surveillance system for people at risk for HIV infection was articulated in both CDC's HIV Prevention Strategic Plan, and in the United Nations Joint Programme on AIDS (UNAIDS)/World Health Organization's (WHO) second generation surveillance framework.[9,10] A surveillance system to provide ongoing, systematic collection of data on behaviors related to HIV acquisition addresses CDC's strategic goal of strengthening the capacity nationwide to monitor the epidemic. Such a system is also consistent with the UNAIDS guidance on second-generation surveillance for HIV infection. The guidance strongly recommended the use of behavioral surveillance in the planning and evaluation of behavioral interventions, particularly in countries with low-level (i.e., HIV seroprevalence has not consistently exceeded 5% in any defined subpopulation) and concentrated (i.e., HIV seroprevalence below 1% in pregnant women in urban areas *and* HIV seroprevalence consistently higher than 5% in at least one defined subpopulation) epidemics.[10]

OBJECTIVES

The primary objective of NHBS is to conduct behavioral surveillance among a representative group of people at high risk for HIV infection in the United States in order to assess prevalence of and trends in: (*1*) risk behaviors for HIV infection; (*2*) HIV testing behaviors; and (*3*) exposure to, use of, and impact of HIV prevention services.

These behaviors can be assessed across geographic areas and over time. The focus of NHBS is on behaviors directly related to transmission and those that are amenable to intervention through prevention programs. The explicit ability to identify gaps in HIV prevention services is a unique aspect of NHBS.

The data collected through this data system are intended to be analyzed and disseminated locally and nationally to help inform decisions regarding HIV prevention programs and activities. Additionally, the data collected from NHBS could be used to identify priority areas for further in-depth research studies.

METHODS

Selection of populations

Groups chosen for inclusion in behavioral surveillance should be those in which the potential contribution to the spread of HIV in the community is greatest. In the United States, three groups have been most heavily impacted by the HIV/AIDS epidemic: men who have sex with men (MSM), injecting drug users (IDUs), and people who acquired their HIV infection through heterosexual contact with an infected partner. Cumulatively 55% of AIDS cases reported through 2003 are attributed to male-to-male sex, 21% are attributed to IDU, and 6% are attributed to heterosexual transmission. In more recent years, heterosexuals have been increasingly impacted by HIV. The estimated proportion of AIDS cases diagnosed between 2000 and 2003 in heterosexuals was 15%.[11] Heterosexual transmission accounts for the majority of diagnosed cases of HIV and AIDS among women in the U.S. Accordingly, NHBS was designed to conduct behavioral surveillance among these three at-risk populations: MSM, IDU, and heterosexuals at risk for HIV infection (HET).

Selection of geographic areas

In the U.S., HIV is primarily an epidemic that affects urban areas. Eighty-two percent of AIDS cases reported in 2002 resided in metropolitan statistical areas (MSAs) with populations of 500,000 or more.[11] An additional 10% of reported AIDS cases resided in metropolitan areas with a population of 50,000 to 499,999; the remaining 8% lived in rural areas at the time of their diagnosis. For this reason, we chose to focus our NHBS efforts in the metropolitan areas with the largest burden of HIV disease. NHBS sites comprise the state and local health departments representing 25 MSAs with high AIDS prevalence at the end of 2000. As shown in Figure 1, the geographic areas covered by NHBS include most major metropolitan areas in the United States. Approximately 60% of the AIDS cases cumulatively reported through 2003 reside in these 25 metropolitan areas.[11]

Surveillance system design

The overall strategy for NHBS involves conducting rotating 12-month cycles of surveillance among the three populations at highest risk for HIV in the selected MSAs. In order to follow trends over time in HIV-related behaviors, these same three populations—MSM, IDU, and HET—will be surveyed repeatedly in the same MSAs. Once the third cycle of NHBS has been completed in heterosexuals, the next cycle in MSM will begin. Thus, surveillance data will be collected in the same high-risk population every three years. Since studies have shown that many of the HIV-related behaviors of interest do not change rapidly, due to the difficulties in effecting and sustaining behavior change, this frequency for data collection should be

Figure 1. National HIV Behavioral Surveillance System (NHBS) sites

adequate to measure any significant behavior change that occurs over time.[12–14]

Because of differences among these populations, particularly with regard to where they congregate, we anticipated using different sampling methods in each. Several guiding principles determined the selection of methods chosen to conduct surveillance in the three populations. These principles included the selection of methods that would (*1*) result in the most representative samples possible of the three populations; (*2*) be feasible for implementation in the heterogeneous areas included in the surveillance system; and (*3*) allow for consistent recruitment of the targeted number of respondents during the 12-month cycle across MSAs and across NHBS cycles. The selection of appropriate methods to recruit representative participants in the three populations was made difficult by the fact that population-based samples of these groups are not feasible since they cannot be easily identified or enumerated. For the MSM cycle of NHBS, a previously described sampling method called venue-based time-space sampling was used.[15,16] Venue-based time-space sampling uses systematic methods to enumerate attendees and then pick a representative sample for interview from each selected venue. For the IDU cycle of NHBS, respondent-driven sampling (RDS), a method used for sampling hidden populations, was used.[17,18] RDS is a modified form of chain-referral sampling with a mathematical system for weighting the sample to compensate for its not having been drawn randomly. Selected individuals or "seeds" are interviewed and refer individuals they know, who then refer those they know (and so on) to be interviewed. Because no single method to efficiently recruit a representative sample of heterosexuals at risk has been identified, the initial cycle of NHBS in this population will conduct a pilot study, using both venue-based sampling and RDS, to determine the most optimal sampling strategy.[19]

Implementation strategies

Our overall strategy was to design a surveillance system that would be simple and flexible enough to be implemented by state and local health departments with varying degrees of infrastructure and expertise; sustainability over time was also an important factor. Implementation of our strategy involved partners at state and local health departments from the earliest stages of the project. Funded areas were asked to provide critical feedback on the proposed recruitment methods and the questionnaire in order to improve feasibility and sustainability. In turn, in many of the participating geographic areas, state and local health departments elicited the support of local community planning groups and key community organizations.

Prior to the implementation of each cycle of NHBS, formative research is conducted to identify the demographic characteristics of the at-risk population, identify possible venues for recruitment of participants, and ensure that the prevention questions included in the questionnaire are relevant to local prevention activities.

Recruitment and sample size

During each cycle of the survey, at least 500 people 18 years of age or older who are residents of the MSA are recruited and interviewed from the appropriate high-risk group. We based this sample size of 500 enrollees per geographic area on financial and feasibility considerations. A sample size of 500 participants per site should allow local areas to estimate a proportion of 50% (e.g., the proportion of men who reported unprotected anal intercourse in YMS) with fairly good precision (roughly ± 5%). The larger national sample of approximately 12,500 respondents per cycle should provide adequate power and precision to evaluate most behaviors of interest.

Questionnaire domains

Areas participating in NHBS use the same core questionnaire for all cycles of the survey. The questionnaire will collect information about demographics, sexual behavior, injection and non-injection drug use, HIV testing, and exposure to and use of prevention services (see Figure 2). Cycle-specific questions may be added to address the data needs for each target population.

In addition to the core questions, each participating health department includes a series of questions to evaluate the participants' access to and use of local HIV prevention programs. The objectives of these questions are to: (*1*) monitor the exposure to and use of local HIV/STD prevention programs or activities; (*2*) assess the association between self-reported utilization of prevention services and indicators of HIV risk; (*3*) characterize missed opportunities for prevention; and (*4*) complement current data collected for monitoring and evaluating CDC-funded HIV prevention programs.

The interview is conducted by trained public health personnel and administered with a handheld personal computer. The use of handheld computers to administer the survey improves the data quality and the efficiency of data collection, entry, and editing.[20]

To maximize the response rate, the interview is anonymous and relatively short (30 minutes). People

Figure 2. Information collected as part of core questionnaire, National HIV Behavioral Surveillance System (NHBS)

Domain/category	*Data elements collected*
Demographics	Project area, venue ID, age, years of formal education, residency, duration of residence in geographic area, race, ethnicity, sexual identity, country of birth, current living situation, current health insurance, history of homelessness, history of incarceration
Sexual behaviors	Number of male and female sex partners in the past 12 months, unprotected intercourse in past 12 months by partner type (main/casual/exchange), characteristics of last sexual encounter and partner-by-partner type (main/casual/exchange), degree of "outness"
Injection drug use	Lifetime history of drug use, age at first injection, date of most recent injection, place for acquisition of needles, types of drugs injected, use of needle-exchange programs, needle sharing, using bleach to clean shared syringes, sharing of cookers/containers/waters, use of shooting galleries, characteristics of needle-sharing partners, use of drug treatment programs
Non-injection drug use	Use of illicit drugs in past 12 months, types of non-injection drugs used, high during sex, use of erectile dysfunction drugs
HIV testing	Testing history, result of most recent HIV test, reasons for not getting test results, type of HIV test (anonymous/confidential), place of most recent HIV test, type of HIV test (rapid/standard), reasons for not being tested, date and time of first HIV positive test, use of partner notification
Medical care (for HIV positives)	Seen by health-care provider for HIV infection, reasons for not accessing health care, reasons for delaying access to health care, history of antiretroviral use
Medical history	History of STDs and STD testing, history of hepatitis, history of hepatitis vaccination
Assessment of prevention activities	Receipt and use of condoms, use of individual-level intervention, use of small group-level interventions, name of organizations sponsoring interventions

who agree to participate are given a small stipend once the interview has been completed.

Human subjects considerations

Public health surveillance systems collect data that are intended to be used for the purposes of disease control and evaluation of public health prevention efforts; the intent of the data collection and analysis is not to create generalizable knowledge. Accordingly, CDC has determined that the collection of behavioral surveillance data represents a non-research activity, and therefore, review by the CDC Institutional Review Board (IRB) was not required. In some local NHBS sites, IRB review was conducted pursuant to local human subjects determinations.

USES AND INTERPRETATION OF DATA

Data collected from behavioral surveillance should be used for public health action. Ideally, the data will be used at both the national and local levels to determine trends in key behavioral indicators over time and monitor progress toward the goals of CDC's HIV Prevention Strategic Plan.[9] Key behavioral indicators include, but are not limited to, the proportions of people who had unprotected intercourse in the past 12 months or had multiple sex partners in the past 12 months, or injected drugs or shared needles in the past 12 months.

NHBS is also intended to provide information about whether or not the combined prevention efforts in the surveyed community are having an impact on behaviors that fuel the epidemic. Although data collected from behavioral surveillance cannot be a substitute for formal HIV prevention program evaluation, it can supplement that information by identifying whether or not HIV prevention programs are reaching and being used by their intended audiences. Because formal HIV program evaluation only collects information on those who have received the services provided, NHBS is necessary to identify gaps in access to these services. NHBS can help to identify those people who did not have access to these prevention programs or those who may have initially participated in these programs, but dropped out due to dissatisfaction.

CHALLENGES TO IMPLEMENTATION

As with any surveillance system, one of the biggest challenges with NHBS was to develop a system that is simple, flexible, acceptable, timely, and representative and provides high-quality data.[21] Designing and implementing the system was complicated by the heteroge-

neity of NHBS MSAs, and the need to retain common approaches and questionnaire domains among the participating areas and over time.

At the local level, the rotating nature of the surveillance system to cover three different at-risk populations means making a "switch" to a different target group and a different sampling and recruitment methodology for each cycle. This may require retraining project staff or assigning new staff to ensure that staff has appropriate expertise in working with a specific at-risk population or surveillance method.

Finally, reaching the targeted sample size (500) may be difficult in certain geographic areas during certain cycles. Sites were selected for inclusion in NHBS based on their total number of people living with AIDS at the end of 2000. Therefore, recruiting 500 people from certain subpopulations in some urban areas may be difficult, particularly if the local epidemic suggests a small number of high-risk people in one subpopulation (e.g., MSM).

LIMITATIONS

Because of the cross-sectional nature of NHBS, we are unable to infer causal relationships between demographic factors and HIV risk or testing behaviors or the impact of prevention programs on behavior change. As a surveillance system, NHBS was designed to monitor key risk behaviors over time. It was not intended to explain the multiple complex factors that affect a person's willingness to participate in preventative or risk behaviors. These contextual issues are best addressed by more focused research.

Although the information gathered through NHBS will be helpful in designing and evaluating HIV prevention programs, it provides only one piece of the information needed to develop effective HIV prevention programs. Additional information about factors impacting access to prevention services should be obtained from key informants in at-risk and affected communities.

Further, NHBS participants may not be representative of all at-risk people in the U.S. The goal of the project is to produce data that are as representative as possible of at-risk people in the participating cities. Therefore, these data cannot be extrapolated to smaller cities or rural communities or to groups that were not surveyed.

NHBS data are self-reported and therefore may be subject to certain biases.[22] Because respondents are asked about sexual or drug-use behaviors that may be perceived as "undesirable" or are illegal, behavioral surveillance data are especially prone to social desirability bias. However, because the interview is anonymous and respondents are assured of the confidentiality of their responses, this bias is most likely minimized.

Finally, NHBS may have limited ability to detect small behavior changes in a local area. A sample size of 500 local participants per cycle would allow local health departments to detect a 9% change in behavior, if the prevalence of the behavior in one group is approximately 50%. Nonetheless, the large combined sample size from all sites should provide adequate power and precision to evaluate most behaviors of interest at the national level.

FUTURE DIRECTIONS

Over time, NHBS must be able to address the changing HIV epidemic in the U.S. Although changes can and should be made as ways to improve the system are identified or as information needs change, these will need to be made with consideration for how they could impact interpretation of trends over time.

NHBS will be evaluated after the initial MSM, IDU, and HET cycles. These evaluations will include the following areas: (*1*) surveillance evaluation to assess characteristics of surveillance system (timely, flexible, acceptable, and sustainable); (*2*) evaluation of the representativeness of the samples obtained by the chosen methods; (*3*) informatics evaluation to determine if the system's software and hardware meet public health standards; and (*4*) program evaluation to ensure that the system is meeting its objectives and the needs of participating sites. Based on the results of these evaluations, changes to the design and methods of the system will be considered.

NHBS will serve as a powerful, consistent, and ongoing source of behavioral data for the three populations at highest risk for acquiring HIV in the United States: MSM, IDU, and heterosexuals at risk. The widespread geographic coverage of the surveillance system to include areas with the highest HIV morbidity means that the data collected are likely to accurately reflect the behaviors of people at increased risk for HIV infection nationally. As a result, the information gathered by NHBS will be critical in the targeting of future HIV prevention programs throughout the United States.

The authors regretfully report that Ida Maria Onorato, co-author and mentor, died on May 31, 2006. This article is dedicated to her memory and to her exceptional contributions to the field of public health.

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