Implementation of the National HIV Behavioral Surveillance Program in the United States

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Abstract

The National HIV Behavioral Surveillance program (NHBS) was established in the United States with the purpose of strengthening the national surveillance capacity to monitor the human immunodeficiency virus (HIV) epidemic, develop and implement effective HIV prevention interventions, and evaluate prevention programs. The NHBS consists of repeated cross-sectional surveys conducted systematically to monitor changes in HIV risk behaviors among three major groups at risk in the U.S.: men who have sex with men, injection drug users, and heterosexuals at risk for HIV. Since the NHBS program began in 2003, twenty-one local HIV behavioral surveillance teams have been established in Metropolitan Statistical Areas (MSAs) with the highest HIV prevalence rates. The NHBS program has demonstrated its usefulness in providing public health agencies with detailed information on populations that are at the highest risk for HIV infection in the U.S. The NHBS data is of good quality and is used on the local, state, and national levels to evaluate existing HIV prevention programs. While performing well on the collection of HIV risk behavioral data, the NHBS program needs to develop its analytical capacity. This will allow the NHBS program to monitor HIV risk behaviors better and to disseminate NHBS data analysis reports to all interested parties in a timely manner.
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Introduction

Acquired Immune Deficiency Syndrome (AIDS) surveillance began in June 1981 when the first five cases of *Pneumocystis carinii* pneumonia (PCP) were diagnosed among men who have sex with men (MSM) in Los Angeles and reported to the Centers for Disease Control and Prevention (CDC) (Berkelman, Buehler, & Dondero, 1992). Since that time, the HIV/AIDS surveillance system has been developed simultaneously with an increasing knowledge about HIV and improving methods for diagnosis and treatment of HIV infection. The 21st World Health Assembly defined *surveillance* as “the systematic collection and use of epidemiologic information for the planning, implementation, and assessment of disease control” (WHO, 1968). The current HIV/AIDS case reporting surveillance system uses disease notification as a method for collection of information in which physicians and laboratories are required to report HIV/AIDS cases to health departments. Another type of HIV/AIDS surveillance system includes seroprevalence surveys in selected sentinel populations (patients at sexually transmitted disease clinics, blood donors, newborn infants, military recruits, etc.) (Berkelman et al, 1992).

The goals of the HIV/AIDS surveillance systems are to monitor morbidity and mortality trends due to HIV infection, target prevention activities, identify individuals qualified for care, project future needs based on epidemiological trends, and establish and monitor performance indicators for HIV/AIDS programs (Colebunders & Heyward, 1990). The HIV/AIDS surveillance systems are able to detect and report most HIV/AIDS patients, measure clinical disease importance, and provide information on HIV transmission categories (WHO, 1968). Limitations to these systems exist, however. One of these limitations is a high number of “no risk reported” cases (NRR). For instance, in 2000, 33% of AIDS cases reported to CDC were
NRR (Lee, McKenna, & Janssen, 2003). Underestimation of the importance of collecting HIV related data among medical providers and lack of rapport with patients leads to non-reporting of information regarding the patients’ real risk factors for HIV transmission (WHO, 1968). In addition, the HIV/AIDS case reporting system does not accurately define levels of HIV infection among different population groups (transgenders, sex workers, etc.).

**Justification of the National HIV Behavioral Surveillance (NHBS) Program**

In spite of significant public health efforts, HIV/AIDS continues to be a serious health problem in the United States. According to CDC, 1.2 million people are living with HIV/AIDS in the U.S. today. CDC estimates that one in five people living with HIV in the U.S. is unaware of his/her HIV infection. Almost 600,000 people in the U.S. have died from AIDS since the epidemic began in 1981. Men who have sex with men (MSM), injecting drug users (IDU), and high-risk heterosexuals (HET) are the three populations at highest risk for HIV in the U.S. (CDC, 2011a).

MSM accounted for 49% of all living HIV/AIDS cases in 2008. In 2009, 61% of all new HIV infections were reported among MSM. In 2009, the largest number of new HIV cases of any group in the U.S. was among white MSM. From 2006-2009, the highest increase of new HIV cases (by 48%) was reported among young black/African American MSM (CDC, 2011b).

Another large proportion of all reported HIV/AIDS cases was acquired through heterosexual contact. In 2009, 27% of all newly diagnosed HIV/AIDS cases were among HET. Most (85%) of the HIV/AIDS cases diagnosed among females in 2009 were attributed to heterosexual contact, as were 14% of male HIV/AIDS diagnoses. Black/African American females had the highest rate of new HIV cases among those who acquired HIV through heterosexual contact (CDC, 2011a).
HIV/AIDS cases acquired through sharing injection-drug equipment constituted 17% of living HIV cases in 2008 and 9% of new HIV infections in 2009 (CDC, 2011c). In 2009, among those IDUs newly infected with HIV, 50% were male IDUs, 22% MSM/IDUs, and 28% female IDUs. Among male IDUs, an estimated 50% were black/African American, 30% were Hispanic, and 17% were white. In comparison, among female IDUs, 54% were black/African American, 26% were white, and 18% were Hispanic (CDC, 2011c). Since the beginning of the epidemic, the proportion of cases acquired through male-to-male sexual contact increased, the proportion of IDU cases decreased, and the proportion of cases attributed to heterosexual contact remained stable (CDC, 2011a).

In 2003, CDC established the National HIV Behavioral Surveillance program (NHBS) to monitor behaviors that place people at risk for HIV infection (Lansky, Sullivan, Gallagher, & Fleming, 2007). The NHBS belongs to the second generation of HIV/AIDS surveillance because it allows a better understanding of behaviors driving the HIV epidemic and of the trends over time (UNAIDS, 2002; Lansky, Drake, DiNenno, & Lee, 2007). The NHBS is focused on subpopulations at highest risk for HIV infection. This is especially important for evaluation of risk for HIV/AIDS among racial and ethnic minority populations who comprise a majority of new HIV infections in the U.S. As noted above, during 2006–2009, over half of the new HIV/AIDS diagnoses were reported among black/African Americans and Hispanics (CDC, 2011a). Being more flexible than the HIV/AIDS case reporting surveillance system the NHBS helps to direct and evaluate local and national HIV prevention efforts in a timely manner.

**Purpose, Goals and Objectives of the NHBS Program**
The purpose of the NHBS is to monitor behaviors that place people at risk for HIV infection. The NHBS goals include:

- Assessment of the prevalence of and trends in risk behaviors and HIV testing behaviors.
- Assessment of the use of prevention services and the impact of prevention services on behaviors, with identification of prevention-service gaps and missed opportunities for prevention.
- Assessment of the prevalence of, and trends in HIV seroprevalence as well as behaviors associated with HIV serostatus.

NHBS surveillance activities focus on three groups of population at high risk of HIV: men who have sex with men (MSM), injecting drug users (IDU), and heterosexuals at risk for HIV infection (HET). The NHBS program is implemented in repeated rounds. Each round consists of three cycles. Each cycle is referred to by the group of interest: MSM, IDU, and HET. The objective for each cycle is to complete surveys with an established number of eligible participants within a timeline assigned by CDC (Gallagher, Sullivan, Lansky, & Onorato, 2007).

Twenty-one city and state public health departments are granted by CDC to participate in the NHBS program. Eligible sites represent the Metropolitan Statistical Areas (MSAs) that have the highest AIDS prevalence. While applying for the CDC NHBS grant, the potential grantee must prove their capacity to conduct NHBS activities and that the MSA has sufficient numbers of these at-risk populations (CDC, 2011d).

**The NHBS Program Sampling Methods**

For the NHBS program, two sampling methods are used: Respondent Driven Sampling (RDS) and Venue Based Sampling (VBS).
RDS is the method assigned for IDU and HET cycles. This is a chain-referral strategy that allows researchers to bring in the sample persons who might not want to be recruited by the NHBS program staff but are comfortable being recruited by a peer. RDS is characterized by several features:

- The recruitment method relies on participants to refer and recruit their peers for participation in the study and uses quotas to reduce bias from oversampling respondents within larger networks. Participants are trained to recruit their peers for the program.
- Participants receive a small financial incentive for their own participation and for recruiting others to participate (dual incentive structure).
- This method produces a final sample that stabilizes in its characteristics and is independent of the initial recruiters, or “seeds,” from which it began (referred to as reaching “equilibrium”). At the level of four to six waves, a sample is independent of the initial “seeds” (Heckathorn, 2002).
- Information gathered during sampling can provide the means for constructing a sampling frame, from which sampling probabilities can be calculated, and in turn, population estimates can be assessed for bias and the variability of these estimates can be determined.

The Venue Based Sampling Method (VBS), used for conducting MSM cycles, includes a cross-sectional survey of men who attend MSM-identified venues within an MSA. The steps of the VBS include:

- Identification of venues frequented by MSM population. Possible venues are identified during the formative research activities, while collecting data for the secondary data review, conducting focus group interviews, and conducting brief interviews at the
venue. Those venues that would yield a sufficient number of MSM attendees are included in the venue list.

- **Determination of the best time for NHBS data collection activities.** After venues are identified, the NHBS staff identifies the most suitable days and times (usually a four-hour period per day, three days per week) at each venue to interview an adequate number of participants. The NHBS staff places days and times for each venue on a list that is used later for determining sampling events for each month.

- **Determination of the sampling events for a given month.** Every month the NHBS staff randomly selects days and times for conducting a sampling event in randomly selected venues. A sampling event is a single visit to the venue to conduct NHBS data collection activities.

- **Selection and recruitment of men at the sampling event.** After arrival at the venue, the NHBS staff establishes boundaries for recruiting potential participants. During the sampling event, the staff enumerates, approaches, recruits, and interviews eligible men who entered this area and who agreed to participate in the NHBS program (MacKellar, Gallagher, Finlayson, Sanchez, Lansky, & Sullivan, 2007).

**Recruitment and Sample Size**

During each cycle, every NHBS site should complete at least 500 interviews with people at risk for HIV. Criteria for participants to enroll in the NHBS cycle include age (18 years of age and older), residency in the given MSA, and presence of HIV risk behavior specific for the current NHBS cycle (MSM, IDU, or HET). The national sample size of nearly 12,500 provides adequate statistical power and precision to evaluate HIV risk behaviors among the population (Gallagher et al, 2007).
Formative Research Activities

The NHBS staff conducts formative research work to gain insight into the context of HIV risk behavior within certain settings and among sub-populations in the MSA. Formative research work allows the NHBS staff to create a surveillance system that is culturally appropriate for the local community while being consistent with the national NHBS protocol (Allen, Finlayson, Abdul-Quader, & Lansky, 2009). Usually formative assessment activities are completed over a three-month period that precedes the implementation of the NHBS data collection activities. The formative assessment activities include:

- A review of secondary data within the MSA.
- Collection of qualitative data.
- Identification of local prevention programs (Allen et al, 2009).

Secondary Data Review: The NHBS staff reviews secondary data sources including Counseling, Testing, and Referral Services data, along with HIV/AIDS surveillance data, HIV disease epidemiologic profiles, HIV prevention plans, and funding from community-based studies. These data allow analyzing the pattern of HIV/AIDS among the cycle-specific HIV risk group and documenting what is known about their HIV risk behaviors within the MSA.

Collection of qualitative data includes the group of methods usually applied in qualitative and ethnographic studies of health: key informant interviews, focus group interviews, brief intercept surveys, observations, and ethnographic mapping.

Community leaders, owners of local businesses, outreach workers, and researchers who are familiar with local populations at risk are called key informants. They serve as “cultural experts,” offering insight into the context of HIV risk behaviors within the local population. A diverse group of key informants should be interviewed to accurately reflect the characteristics of
populations at risk in the MSA. They should be able to contribute to understanding how best to approach potential participants, find initial participants for the “peer-recruitment process” (in IDU and HET cycles), and identify problems that the NHBS staff may encounter while working in the field (S. Schensul, J. Schensul, & LeComte, 1999; Allen, et al, 2009).

Focus groups conduct interviews with several individuals at one time and provide information about general topics of interest (e.g., drug use among local community members, the accessibility of HIV prevention services, location of favorite MSM venues, etc.). Information collected through these interviews is used to validate and explore findings from the secondary data review or the other formative research activities (Allen et al, 2009).

The NHBS staff conducts observations in locations related to NHBS activities. Observation relies exclusively on what can be seen through the eyes of the researcher. The NHBS program staff member (usually an ethnographer) observes what is happening “on-the-ground” and provides the program with knowledge relevant to populations at risk. That includes characteristics of settings, people, activities, signs, events, time, goals, and networks (Stimson, Donoghoe, Fitch, Rhodes, & Ball, 2003).

A street intercept survey involves collecting information about topics relevant to NHBS from individuals in key locations (e.g., men near or in venues frequented by MSMs). The NHBS staff conducts a very brief survey on the street where the person is intercepted. The street intercept surveys are used to identify venues where MSM can be recruited for participation in NHBS and the best days and time for conducting NHBS events. In addition, the street intercept surveys are used to disseminate information about the NHBS program to people in the community, to ask members of the community about possible barriers to the program, and to gather support in the community to participate in the NHBS survey (Allen et al, 2009).
The ethnographic mapping method is used by the NHBS staff to illustrate information about areas where high-risk behaviors occur (IDU cycles) or areas where potential NHBS participants can be accessed and recruited (MSM cycles) (Schensul, LeComte, Trotter, Cromley, & Singer, 1999; Allen et al, 2009).

Identification of local prevention programs. The NHBS staff creates a list of the organizations receiving CDC funds to conduct local HIV prevention programs or services in the MSA. Upon completion of this list, the NHBS sites develop local prevention questions. The purpose of the local prevention questions is to receive information about the use of local HIV/STD prevention programs, assess the association between self-reported utilization of prevention services and HIV risk among a cycle-specific population risk group, and define missed opportunities for prevention (Allen et al, 2009).

In addition to the above activities, the NHBS staff identifies potential community stakeholders by using information collected from state and city public health officials. Once the key stakeholders have been identified, the NHBS staff holds meetings to provide community stakeholders with opportunities to learn more about the NHBS program. Written materials describing the goals and objectives of the NHBS are distributed within communities where the NHBS program is implemented. The formative research work benefits the program with knowledge about how to make the NHBS activities successful while operating in the local community. During key informant interviews, street intercept surveys, and focus groups, the NHBS staff identifies an appropriate location for NHBS activities, days/hours of operation, size of incentives for participants, and characteristics of the staff that would be most important for conducting interviews.
The NHBS staff also conducts ongoing formative research when data collection starts in order to monitor the quality of the data collection process. For MSM cycles, quality assurance indicators include monitoring of eligibility, suitability, and availability of the venues for the NHBS activities. Ongoing formative research activity in IDU and HET cycles monitors enrollment rates, effectiveness of initial recruiters (“seeds”), respondents’ eligibility, and the distribution of participation coupons.

**Data Collection Tools**

Each NHBS site uses the standard core questionnaire for all NHBS cycles. The core questionnaire covers the following areas: demographic information, sexual behaviors, alcohol and drug use history, HIV testing experiences, health conditions, and the use of prevention services. Cycle-specific questions are added to the core questionnaire to collect in-depth information about HIV risk behavior specific to the given cycle (MSM, IDU, or HET) (Gallagher et al, 2007). In addition to core and cycle-specific questions, each NHBS site develops local prevention questions to evaluate the participants’ access to and use of local HIV prevention services (Allen et al, 2009).

**HIV Testing**

The testing component of NHBS is voluntary. All NHBS participants are offered an anonymous HIV test. Those who agree to participate in the testing component of NHBS are provided with information about testing for HIV. HIV test results are returned to participants by a trained counselor during a scheduled counseling visit or shortly after the time of testing if a rapid test is used. The purpose of testing is to estimate HIV prevalence among NHBS program participants.
Operation of the NHBS Program

For MSM cycles of NHBS, when the venue-based sampling (VBS) method is used, the NHBS staff conducts a cross-sectional survey of MSM who attend venues within the MSA. VBS sampling activities include creating a list of MSM-identified venues through formative research. The list is used to produce monthly sampling frames of venues and venue-specific day/time periods that are expected to provide an adequate number of eligible participants. The NHBS staff randomly selects venues and day-time periods from the list of MSM-identified venues. During recruitment events, the NHBS staff counts venue attendees and then selects a representative sample for interview from each selected venue (Gallagher et al, 2007). Potential participants among venue attendees are approached, interviewed, and offered testing for HIV.

For IDU and HET cycles, when the respondent-driven sampling (RDS) method is applied, a limited number of initial recruiters (“seeds”) are identified through formative research. “Seeds” begin the peer-referral process by referring to NHBS one to five individuals they know. Those who are referred by recruiters visit the NHBS storefront where the NHBS staff screens them for eligibility (Lansky et al, 2007). Eligible participants take the survey and are offered an HIV test.

Participants receive a small stipend for participation in NHBS activities. This includes incentives for completing the survey and if the participant was tested for HIV. In addition, participants who recruit their peers into the NHBS program are compensated a small incentive for each eligible person they recruit (Lansky et al, 2007).

The NHBS data are collected electronically by using handheld computers. Data are transferred from handheld computers to a desktop computer of the NHBS data manager who
transfers it weekly to CDC. The CDC NHBS staff reviews and standardizes data from all participating sites. Standardized data are analyzed on the local and CDC levels.

On the local level, the NHBS data are used for creating ad hoc reports, information letters, and epidemiologic profiles. These data are released to community planning groups, health care professionals, and the general public. The local HIV prevention programs use NHBS information for planning and evaluating HIV prevention strategies and services. The CDC NHBS staff presents the NHBS data analysis in morbidity and mortality weekly reports, public health journals, and in meetings and conferences held by CDC. The NHBS data were used for creation of the CDC HIV Prevention Strategic Plan and the Healthy People 2020 document.

Building the NHBS Team

Participation in the program requires all NHBS staff to apply high ethical standards, commitment, and professionalism. While working in the field with the continuously changing environment, the NHBS staff must meet their deadlines and produce each year at least 500 interviews with people at high risk for HIV. The implementation of the NHBS program requires a collective work and the main task for leaders of the program should be building a team.

Katzenbach and Smith (1994) defined a team as a small number of people with complementary skills who are committed to a common purpose, performance goals, and approach for which they hold themselves mutually accountable (Katzenbach & Smith, 1994). The team members who possess multiple skills (for instance, a field supervisor who can substitute as an interviewer, or an HIV tester who can combine testing and counseling skills) will contribute to the success of the project. Their mix of skills and knowledge makes it possible to respond to numerous challenges that confront the team during the implementation of the NHBS program. Common goals shared by all team members along with self-management helps NHBS
team members to establish communication and solve real-time problems in a timely manner. The team becomes flexible and adaptive for any challenge (Katzenbach & Smith, 1994). NHBS team members, working in different and often dangerous environments enhance development of trust and confidence in each other’s capabilities. Highly motivated team members perform better and make the NHBS program successful.

The role of the leader is to help the team establish its goals and its methods of working (Fischetti, 1998). The team leader should motivate his/her team to face the multiple challenges that the team will face during the NHBS program implementation, and mobilize the team to do adaptive work, such as evolution of values, development of new practices, and the revision of priorities (Williams, 2005).

**Consideration of Human Subjects**

The NHBS staff places the highest priority on human subjects’ protection and ethics while conducting program activities. The NHBS branch of CDC and each site participating in the NHBS annually submit their protocols to the appropriate Institutional Review Board (IRB) and receive IRB approval for conducting NHBS activities.

Participation in an NHBS survey involves minimal risk to participants. NHBS survey participants and those who are interviewed for formative research purposes must give their informed consent before taking part in the NHBS program. Risk of participating in the NHBS program includes possible discomfort to those whose risks for HIV infection are not fully recognized. Another risk is that, although privacy of participants is protected to the greatest extent, some acquaintances may recognize those respondents who enter field-site locations and who choose to participate. The risks of participating in the HIV testing component of NHBS are
minimal and include those associated with loss of anonymity, drawing blood, and returning test
results.

Benefits from participating in the NHBS include gaining knowledge about a participant’s
own risks for HIV infection, discussion with trained staff about how to reduce those risks,
learning about local HIV prevention services, and receiving prevention materials. They also
benefit from referral to local programs, support groups and health care providers, as well as
obtaining free HIV testing. Literature sources strongly support the contention that participation
in the HIV-related behavioral studies reduces risk behaviors (Oulett, 2008). The NHBS program
benefits local communities by assisting prevention planners to better direct HIV prevention
efforts.

As a component of HIV/AIDS surveillance, the National HIV Behavioral Surveillance
(NHBS) data are protected by the Assurance of Confidentiality {Section 308(d) of the Public
Health Service Act, 42 U.S.C.242 m (d)}. This assurance prohibits the disclosure of any
information that could be used directly or indirectly to identify individuals. Participation in the
NHBS survey is anonymous and voluntary. Participants are not required to provide their names
or other personal identifiers. Participant names are not included in any NHBS data collection
instruments or systems. Each NHBS participant receives a unique Survey ID number that is used
to label his/her data. Recruiters in IDU cycles, where the RDS method is used, are asked to
create a recruiter ID. In addition, the NHBS staff notes physical marks (scars, tattoos, etc.) on
the survey participant. This information links coupon numbers between recruiters and recruited
participants. When recruiters return to receive reimbursement for recruitment, they are asked to
provide their recruiter ID and staff verified physical marks. These methods ensure that recruiter
incentives are given to the correct person (Lansky & Mastro, 2008).
Specimens, lab slips, and questionnaires are linked using the Survey ID number and the interview date. No personal identifiers can be written or affixed to the test results and lab slips. Transfer files containing the NHBS data are encrypted and transmitted to CDC via a secured network. The NHBS program staff exercises great caution in public release of numerical, small cell data that could directly or indirectly lead to a participant’s identification.

Participants are reimbursed with small incentives for completing the NHBS survey and HIV testing. In addition, those who recruit other participants for IDU and HET cycles where the RDS method is used, also receive a minimal remuneration. The modest amount of money paid for participation in NHBS activities is unlikely to cause a negative effect for the study participants. For instance, Festinger et al., (2005) stated that drug users reported that incentives received for participation in the study were used to pay for personal and household needs, transportation, debts, etc. The same study demonstrated that the moderate amount of remuneration was not associated with rates of drug use (Festinger, Marlowe, Dugosh, Mastro, Lee et al, 2005).

**NHBS Program Usefulness**

The NHBS program exists for a relatively short time period and collects data about each risk group (MSM, IDU, and HET) only during the two cycles. Therefore, at this point in time, NHBS is not a mature enough system to describe trends in development of the HIV disease epidemic. However, data collected by the NHBS program does present a detailed snapshot of the population that is at highest risk for HIV infection in the U.S.

For instance, those who were interviewed in MSM favored venues (66% were recruited in bars or dance clubs) in 21 U.S. MSAs during the 2008 MSM cycle were mostly white. Seventy-six percent of the participants reported having more than one male sex partner during one year
before the interview. Unprotected anal intercourse with a main male partner was reported by 37% of the participants and with a casual partner by 25% participants. Forty-six percent of the respondents reported non-injection drug use during the past year. Thirty-eight percent used marijuana, 18% cocaine, 13% poppers (amyl nitrate), and 11% ecstasy. Sixty-two percent of respondents had been tested for HIV during the past year, 51% percent had received a hepatitis vaccination, 35% had been screened for syphilis during the past year, and only 18% had participated in an individual- or group-level HIV behavioral intervention (CDC, 2011d).

According to the CDC HIV Prevention Strategic Plan, the number of new HIV infections in the U.S. could be reduced through:

- Decreasing the number of persons at high risk for HIV infection.
- Increasing the proportion of HIV-infected persons who know they are infected.
- Increasing the proportion of HIV-infected persons who receive prevention services and are linked to appropriate care and treatment.
- Strengthening the capacity nationwide to monitor the epidemic, develop and implement effective HIV prevention interventions, and evaluate prevention programs (CDC, 2007).

The NHBS data demonstrate in-depth the situation with HIV testing for populations at risk for HIV and provide HIV prevention programs with indicators for strategies to be used to increase the number of people at risk for HIV who know their status. A significant number of NHBS program participants were not screened for HIV during the year prior to their participation in the program and did not know the HIV status of their recent sexual partner. The main reason for not having an HIV test was the participant’s perception that he/she was at low risk of HIV infection or the fear of testing positive. The reasons provided by NHBS participants
for not being tested can be used for modifying HIV testing procedures and making HIV testing more acceptable for those who are at risk. Another way to increase HIV testing rates for populations at risk for HIV is to educate medical providers about the importance of HIV testing for these populations. For instance, CDC recommends that MSM be screened for HIV at least once a year. According to NHBS data, only 26% of those who were tested during the previous year reported their medical provider’s office as the most recent place of HIV testing (CDC, 2011d). The analysis of NHBS data demonstrates that MSM who had ever disclosed male-male sex relationships to medical providers were more likely have been tested for HIV (Bernstein, Liu, & Begier, 2008). Thus, the NHBS data analysis assists in assessing HIV testing programs efforts and shows ways on how to make these programs more effective.

The NHBS data also allow identifying demographic characteristics and risk behaviors and designing behavioral intervention. For example, collecting data on risk behaviors among black/African Americans (who have the fastest-growing rate of new HIV infections) allows for developing community-based programs to provide HIV prevention services in communities at increased risk for HIV infection. Data collected through NHBS are used to document the accessibility and use of prevention services, for instance, by comparison of the use of sterile needles between MSAs with a needle-exchange program, and MSAs without an exchange program (Lansky et al, 2007).

**Effectiveness and Efficiency**

Effectiveness is an ability of the system to accomplish a purpose and produce the expected result. In accordance with established goals, the NHBS program is able to collect information on HIV risk behaviors and to provide directions for prevention interventions. The
NHBS program demonstrated its effectiveness by meeting its objective of collecting an average of 10,000 interviews with people at risk for HIV each year.

The efficiency of the NHBS program can be improved. To make the NHBS program more efficient, it might consider extending the grant period to ten years. Currently, CDC changes the program participants every three to five years. This means that each 3-5-year period the new participating site starts building the local NHBS structure from zero by purchasing new equipment, hiring and training staff, obtaining a vehicle for field activities, etc. Extending the grant period would allow avoiding unnecessary expenses and make the program more cost efficient. In addition, a longer standing team is more efficient because the staff would become more skilled and experienced over time.

Simplicity

The simplicity of a public health surveillance system refers both to its structure and ease of operation (CDC, 2001). The NHBS branch of CDC made significant efforts to make the structure of the NHBS program simple and easy to maintain. Data collection methods, project procedures, and key documents (protocols, formative research manual, core questionnaire, consent forms, etc.) are kept the same from one cycle to another (Gallagher et al, 2007).

CDC releases information on any update and trains the NHBS site’s staff as needed. However, the large number of participating sites makes the NHBS program somewhat difficult to implement because of different organizational structures, financial resources, and political environments of these agencies.

Flexibility

The NHBS program is flexible enough to adapt to significant changes, as needed. For example, in 2007 the NHBS sites conducted the supplementary Partner Study project that
included collection data on 100 minority female residents of a given MSA and their sexual partners (Michigan Department of Community Health, 2011). By adding a small amount of additional time and funds the NHBS staff held Partner Study data collection simultaneously with the major program activities.

**Acceptability**

Acceptability refers to the willingness of persons and organizations to participate in the surveillance system. The NHBS program was widely accepted by the local health departments’ staff, community based organizations, and local population. The formative research activities allowed the NHBS staff to introduce the program to the MSAs residents and gain support from them.

The local NHBS staff, recruited from local public health professionals, demonstrated a high level of commitment to the program and willingness to participate. The NHBS team worked closely with CDC on maintaining participation rates, interview completion rates, and timeliness of data reporting on the appropriate levels.

**Quality of NHBS Data**

The quality of the NHBS data is controlled on each step of the NHBS program implementation. The quality assurance started with intensive training of all NHBS staff on formative research, sampling, recruitment, and data collection procedures. Before conducting interviews with NHBS participants, each NHBS site is required to submit and receive approval of the formative research report that includes information relevant to potential participants and field logistics. Use of handheld computers helps eliminate subsequent data entry procedures and connected with it, possible data entry errors. The computer program installed in handheld computers includes logic checks and skip patterns, helping to prevent data entry errors. Data are
transferred from handheld computers to a desktop computer where all incomplete or duplicate records are resolved by the local NHBS data manager. CDC monitors the quality of data by using indicators specific to each sampling method. The NHBS sites’ staff submits data to CDC on a monthly basis. Any discrepancies are resolved before the data is accepted by CDC (MacKellar et al, 2007) (Lansky et al, 2007).

**The NHBS as a Part of the International HIV Behavioral Surveillance System**

Repeated overtime, cross-sectional surveys focus on country-specific populations at risk for HIV. For instance, in Zambia, a country among those with the highest prevalence of HIV, the Behavioral Surveillance System (BSS) collected information from long-distance truck drivers, uniformed personnel, and female sex workers (FHI, 2003a; FHI, 2003b). In Thailand, BSS data collection activities were focused on female sex workers, IDU, transgenders, and migrant males (Mills et al, 1997). In Albania, IDU and MSM populations, as well as the Roma ethnicity group, were a center of interest for the local BSS project (FHI, 2006). Although national HIV behavioral surveillance programs data contain country-specific information, analysis of these data is beneficial for understanding the HIV pandemic from a regional perspective and can be used by other countries in the region to highlight problem areas and identify appropriate intervention measures. Globally, HIV behavioral surveillance programs allow identifying the populations that are most vulnerable for HIV, including MSM, IDU, and transgenders. This information can be used for developing universal intervention programs that could work successfully in various countries. Because of cultural and economic similarities, Canada and the U.S. HIV behavioral surveillance programs can share their findings and develop common HIV prevention programs that benefit populations at risk in both countries (Choudhri, Lydon-Hassen, Hennink, & Millson, 2004). The U.S. NHBS program also can use the
experience of other countries in collecting HIV risk behavioral information among subpopulations that are vulnerable for HIV, such as transgenders and female sex workers. In addition, the NHBS should screen its participants, not only for HIV, but also for hepatitis C and syphilis like BSS systems in other countries do.

**Limitations**

In spite of the thoughtful design, intensive formative research work, and consultations with experts, the NHBS has several limitations. 1) The data collected through the NHBS activities are self-reported, therefore it can include under- and/or over-reporting of behaviors that are difficult to determine. 2) Information collected by 25 NHBS sites represents risk behaviors in corresponding MSAs but may not apply to behaviors among populations at risk throughout the U.S. 3) CDC used high AIDS prevalence as a criterion when selecting MSAs to participate in the NHBS program. However, in some regions with low AIDS prevalence, risk behaviors are notably high. Including some low-prevalence sites in the NHBS program could help identifying MSAs where future epidemics can occur (Lansky et al, 2007). 4).The respondent driven sampling is a relatively new method and requires continuous quality assurance to verify that representative samples of IDU and HET populations are obtained.

Since the beginning of the NHBS program, CDC and participating sites met numerous challenges. Some of these were resolved and others continue to exist. For instance, the Institutional Review Board approval process in some health departments can take place over several months and cause a delay in implementation of the NHBS data collection activities. Another challenge is a low analytic capacity demonstrated by the NHBS program. For example, in 2007, the NHBS staff conducted a cycle focused on the HET population. In conjunction with this, a supplementary Partner Study project was conducted that focused on HIV risk behaviors.
among minority females and their sexual partners. However, a detailed analysis of both Partner Study project and HET cycle data on the national level still has not been introduced to the public health community. Attracting analysts with RDS analysis experience to the NHBS program, and training of the existing NHBS staff on NHBS data analysis, are considered first steps in strengthening the NHBS analytic capacity.

**Conclusions and Recommendations**

The NHBS is the first large-scale behavioral surveillance system in the U.S. that was created to provide ongoing monitoring of the behaviors of people at increased risk for HIV infection. Since 2003, CDC, in collaboration with local and state public health agencies, built the NHBS structure that is useful, effective, flexible, acceptable, and provides high-quality data.

Two main directions of HIV prevention – HIV screening and behavior change interventions – need to be used to target the most affected populations and make a major impact on the HIV epidemic. Individuals at high risk for HIV need to have easy access to HIV testing. Those who live in economically deprived communities with high HIV prevalence should have easy access to free HIV testing. Local health departments can use mobile units to provide residents of these communities with HIV Counseling, Testing and Referral (CTR) services. In addition, HIV screening activities can be conducted near venues where, according to NHBS information, people at risk for HIV gather.

Health providers play an important role in offering HIV testing to the MSM population. Lack of disclosure of patients’ sexual orientation and sexual behavior history to medical providers significantly decreases the likelihood that appropriate health services are recommended to MSM patients. Therefore, appropriate recommendations should be developed for medical
providers on disclosing their patients’ sexual orientation along with recommendations for preventive/diagnostic health care services.

Developing responsible behaviors among those who are at risk for HIV is not an easy task. It is a long process that requires efforts from all interested parties. Reducing the risk in sexual behavior through the increased use of condoms has always been the goal of HIV prevention services. It is well known how highly influential is fashion, modern music, etc. on young, sexually active people. Developing a new line of condoms with special designs popular among different youth groups could increase the use of condoms among them.

One of the possible options to help those MSM who developed sexual addiction could use the assistance of a professional psychologist to deal with this addiction. A pilot project on psychological assistance to these individuals could be established in MSAs with high HIV prevalence among the MSM population.

For IDUs who cannot change their behaviors and continue injecting drugs, the needle exchange programs (NEP) continue to be the major prevention strategy. Although eight federal reports showed that needle exchange programs decreased HIV and hepatitis B and C, in 2009, Congress voted to extend a ban on federal funding of NEP. The public health community should work closely with legislators to reverse this decision.

The NHBS program as a part of HIV prevention efforts can also be improved. One of the opportunities to make the NHBS program better is to develop ongoing relationships with the local community. Currently, the NHBS staff is required to gain the local community support only for the time when the staff works in the field. In my opinion, relationships with residents and leaders of affected communities should be developed continuously. The local residents will benefit from information on HIV risk behaviors that are specific to their community. The local
analysis of NHBS data can be used by community based organizations and local HIV prevention services for grant applications, prevention activities evaluation, etc. Strong relationships with local community members will make future NHBS activities conducted in this community more successful.

I also think that interactions between NHBS and staff in local and state agencies should be improved. Attracting epidemiologists from the state agencies and university public health schools could benefit the NHBS program with analysis of NHBS data. The joint project could be implemented with the state mental health department when conducting an IDU cycle of NHBS. While using the mental health specialists as the important source of information for conducting formative research work on injection drug users, the NHBS staff could develop collaborations through sharing IDU data and working on its analysis.

In addition, the local NHBS team should be proactive in building relationships with local health department staff. This collaboration could be mutually beneficial for both organizations. For instance, the local health department can assist the NHBS program with sending HIV testers to participate in field activities and the NHBS team can provide the local health department with data on populations at risk for HIV.

Another opportunity to improve the NHBS program is to develop its analytical capacity and increase the timeliness of spreading information. To improve the situation on the local level, CDC can develop regular training activities and materials for local and state public health agencies and the NHBS staff. In the current financial situation, the CDC NHBS branch may benefit by attracting professionals from other state and federal CDC agencies for collaborative opportunities.
Another important component of the NHBS program - dissemination of information - also needs to be improved. Detailed analysis of each NHBS cycle findings should be disseminated to all interested parties in a timely manner.

In conclusion, the NBHS system has played an important role for almost a decade in strengthening the country’s capacity to monitor the HIV epidemic, develop important prevention strategies, and evaluate prevention initiatives. It has given local health officials specific, useful information on high-risk HIV populations and excellent quality data for evaluation of HIV prevention programs. These functions and roles have been extremely valuable, however, it is time for leadership to extend this system's analytical capacity and increase the frequency and effectiveness of dissemination of the excellent information it obtains in order for its full potential to be reached and realizing its greatest possibilities for ameliorating the HIV epidemic in the US both within and beyond MSA’s.
References


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