Developing an HIV Behavioral Surveillance System for Injecting Drug Users: The National HIV Behavioral Surveillance System

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SYNOPSIS

While disease surveillance for HIV/AIDS is now widely conducted in the United States, effective HIV prevention programs rely primarily on changing behavior; therefore, behavioral data are needed to inform these programs. To achieve the goal of reducing HIV infections in the U.S., the Centers for Disease Control and Prevention, in cooperation with state and local health departments, implemented the National HIV Behavioral Surveillance System (NHBS) for injecting drug users (IDUs) in 25 selected metropolitan statistical areas (MSAs) throughout the United States in 2005. The surveillance system used respondent-driven sampling (RDS), a modified chain-referral method, to recruit IDUs for a survey measuring HIV-associated drug use and sexual risk behavior. RDS can produce population estimates for specific risk behaviors and demographic characteristics. Formative assessment activities—primarily the collection of qualitative data—provided information to better understand the IDU population and implement the surveillance activities in each city. This is the first behavioral surveillance system of its kind in the U.S. that will provide local and national data on risk for HIV and other blood-borne and sexually transmitted infections among IDUs for monitoring changes in the epidemic and prevention programs.

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Since 1981, surveillance for AIDS and HIV infection has been vital for monitoring the course of the epidemic in the United States, projecting future trends, and designing prevention programs. A program of behavioral surveillance, to complement and be integrated with case surveillance, should also monitor behaviors in populations that are not infected but are at high risk for infection.[1] Such data can be used by the Centers for Disease Control and Prevention (CDC) to identify populations needing HIV prevention services and to monitor progress toward goals in the HIV Prevention Strategic Plan.[2]

In 2002, the National HIV Behavioral Surveillance System (NHBS) was initiated to help state and local health departments establish and maintain a surveillance system to monitor selected behaviors and access to prevention services among groups at highest risk for HIV infection.[3] NHBS is conducted in rotating 12-month cycles. During the first cycle of data collection, surveillance activities focused on men who have sex with men (MSM) in 17 metropolitan statistical areas (MSAs). The focus of the second cycle was on injecting drug users (IDUs), and NHBS expanded to 25 MSAs. During the third cycle, surveillance activities will focus on heterosexuals at high risk (HET). These cycles will be repeated over time such that data are collected from any given risk group every three years. Each surveillance cycle is referred to by the group of interest: NHBS-MSM, NHBS-IDU, and NHBS-HET.

The purpose of this article is to provide an overview of the methods used in NHBS to conduct HIV behavioral surveillance among IDUs. NHBS-IDU is the first national system for behavioral surveillance among IDUs in the United States. In this article, we first briefly describe the HIV epidemic among IDUs and then describe the development of the IDU component of NHBS and preliminary information about implementation of the first NHBS-IDU cycle.

IDUs are at high risk of becoming infected with HIV and other blood-borne pathogens through sharing injection-drug equipment or by engaging in unprotected sex with infected people. Through December 2003, 14% of HIV infection cases reported from the 41 areas with confidential, name-based HIV reporting were attributed to injection drug use; an additional 4% of cases were among MSM who inject drugs (MSM-IDU); and another 4% of the cases were attributed to sex with an IDU.[4] Among AIDS cases, these proportions were, in order, 24%, 6%, and 4%. Thus, injecting drug use affects a sizeable proportion of HIV/AIDS cases in the United States.

METHODS

A number of preparatory activities preceded implementation of the NHBS-IDU surveillance cycle, including pilot studies, formative assessment (to better understand the population of interest in terms of demographic characteristics, and to identify and map locations where the target population could be reached), literature review, and expert consultation. For NHBS-IDU, the surveillance activities with the population of interest include recruitment, eligibility assessment, and administration of a behavioral survey. Data management and analysis are conducted jointly between CDC and the participating NHBS sites.

Pilot studies

A variety of methods exist for sampling hidden populations.[5] Population-based random sampling of IDU is generally precluded by an inability to reliably enumerate them and develop a sampling frame. Recruitment methods commonly used by those working with IDUs include snowball sampling,[6,8] targeted sampling,[9,10] and respondent-driven sampling (RDS).[11,12] Most of these methods have been used within the context of research studies to collect epidemiological data or to evaluate prevention activities targeted to drug users. However, there is little empirical evidence assessing the feasibility of these methods or the ability of these sampling strategies to result in a representative sample of IDUs for behavioral surveillance (i.e., in a way that is replicable over time and systematic across multiple sites).[13] Because no other large-scale behavioral surveillance activity among IDUs had been performed in the U.S., pilot studies were planned for a small number of cities to determine the best method to identify, recruit, and interview IDUs in the 25 NHBS MSAs.

To identify appropriate recruitment and sampling methods for the pilot studies, CDC sponsored a consultation in 2002 that included the NHBS principal investigators, representatives from CDC, and experts in IDU research methods. During this consultation, four methods were considered: venue-based sampling (in jail or needle-exchange programs); purely qualitative, ethnographic data collection; targeted sampling (TS); and RDS. The venue-based methods were rejected due to biases in who would be included in the sample. People found in jail and needle-exchange users tended to differ from those not in jail or those who do not use needle-exchange programs; also, not all NHBS jurisdictions have legal needle-exchange programs. Regarding the purely ethnographic method, ethnographic experts with IDU study backgrounds were available in most areas and could do rapid assessments for relatively

little cost; these rapid assessments would provide a foundation for other sampling methods but would not be adequate on their own for surveillance purposes. Ultimately, two methods were selected for pilot testing: RDS and TS. These methods were implemented in four NHBS cities: Detroit, Houston, New Orleans, and New York City. The first three cities conducted a test of both methods; New York City only piloted RDS.

Three criteria were identified on which to compare the two methods to select a single method to use for NHBS in the 25 MSAs: representativeness, efficacy, and feasibility. Representativeness was defined as a sampling method's ability to produce a sample that resembled the population from which it was drawn. Although not used in the strict sense of the word, the evaluation considered the extent to which each method could produce a sample that would resemble what was known about the underlying IDU population in each MSA, based on the formative assessment activities, in terms of demographics and drug-use indicators. The data obtained through formative assessment generally represents a comprehensive picture of IDUs in each MSA, and thus was used to compare against the sample characteristics. Efficacy was defined as the ability to achieve at least 500 interviews in nine months and within budget. Feasibility was considered in terms of how well the sampling method could be implemented in a standardized way in 25 large, urban areas.

The target sample size for the pilot studies was 200 IDUs: 100 recruited through RDS and 100 recruited through TS.[14] Data were collected during a period of approximately eight weeks. Findings from the three pilots of both methods and the RDS pilot study conducted in New York City[15] were presented at a meeting of the NHBS principal investigators, followed by a discussion about the methods. The major points raised during these presentations and discussions, leading to the decision to use RDS as the method for conducting NHBS-IDU, are presented in Figure 1.

Formative assessment

Formative assessment was conducted to help local staff-NHBS-IDU understand the attributes of the IDU population in their MSA. The goals of the formative assessment were to ensure that, during the behavioral surveillance cycle, an adequate number of IDUs would be recruited and interviewed, and that the sample obtained during the surveillance cycle would resemble the broader IDU community. Experience conducting research on IDU populations indicates that recruit-

Figure 1. Summary of pilot study results comparing RDS and TS for the NHBS-IDU cycle

Criteria	*Discussion*
Representativeness	RDS resulted in a more diverse sample than TS by race and drug of choice. There were no differences in samples by age, sex risk, or drug treatment history.
	Adherence to RDS protocol is easier than TS protocol for project staff (not making decisions about who to approach).
	RDS is better able to capture IDUs not out in the open and to penetrate networks that TS might not (due to peer referral vs. outsider recruitment).
	RDS has the ability to calculate population estimates; TS does not.
Efficiency/cost	TS was less efficient due to the number of people necessary to approach to obtain 500 completed interviews; in RDS, participants do the recruiting and know where/when to find IDUs. RDS costs were higher than TS costs due to the need for a storefront and laptop to manage coupons.
	Incentive costs were comparable (many participants did not return for RDS recruiter reward).
Sample accrual per city during eight-week pilot	TS: 72–140 completed interviews RDS: 50–116 completed interviews
Feasibility	Use of storefronts for RDS was more desirable than field-based recruiting for TS due to more control over hours of operation and concerns about staff safety.
	Formative assessment for TS is complex and resource-intensive; RDS requires less formative work prior to survey implementation.

RDS = respondent-driven sampling

TS = targeted sampling

NHBS = National HIV Behavioral Surveillance System

IDU = injecting drug user

ment success depends on how easy it is for individuals to access the location where the survey will take place. Therefore, formative assessment provided vital information on locations where field sites should be set up for data collection and areas where IDUs could be reached and recruited to begin the peer-recruitment process central to RDS methods. The formative assessment was comprised of multiple activities, including secondary data review, key informant interviews, focus group interviews, observations, and mapping key drug-use indicators in the community. Formative assessment activities primarily occurred prior to the survey implementation, but continued throughout the cycle.[16] RDS is enhanced by formative assessment activities because they allow investigators to better understand the community and build trust within the population of interest.[17,18]

RDS recruitment procedures

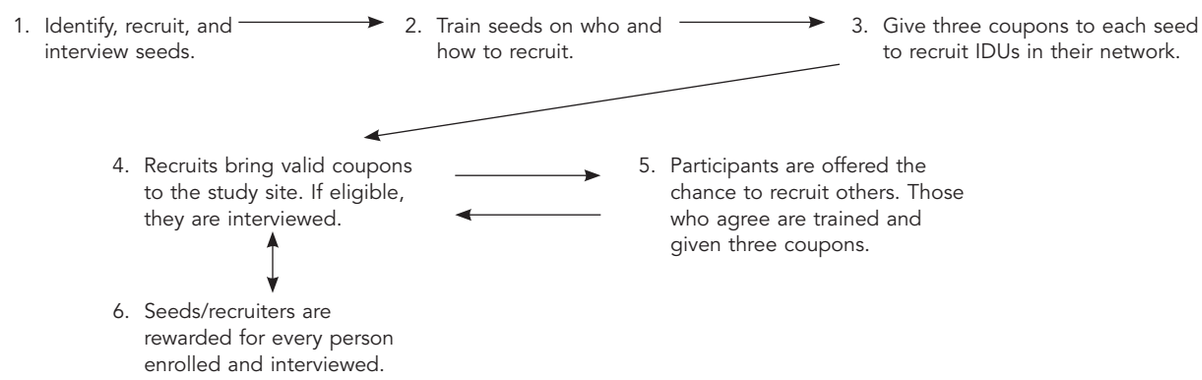
RDS is a modified chain-referral strategy similar to snowball sampling. RDS starts with a limited number of "seeds," who are chosen by referrals from people who know the local IDU community well, or through outreach to areas identified through the formative assessment. Seeds are the starting point for chain-referral sampling. These seeds complete an interview, and are then asked to recruit a specified number of people they know who also inject drugs (i.e., individuals in their network). The specified number of people to refer is small—usually three to five—and generally is the same for all participants throughout the sampling period. Participants are compensated for interview time and for recruiting others; this dual-incentive structure is unique to RDS. The overall RDS recruitment procedures are shown in Figure 2. Although it is a relatively new sampling strategy, these RDS procedures have been used to recruit various groups of drug users[19–21] and MSM.[18]

A theoretical limitation of chain-referral sampling is that selection of initial participants can influence the composition of the final sample given that individuals differentially recruit others like themselves (referred to as homophily). However, by starting with a small number of seeds, limiting the number of individuals that each participant can recruit, and allowing a significant number of recruitment waves to occur, the distribution of the sample begins to resemble that of the underlying population (referred to as equilibrium). Heckathorn suggests that, based on the probability that people recruit others who are unlike themselves, approximately six referral waves can produce a sample that resembles the underlying population of IDUs within a geographic area on major demographic characteristics (e.g., race, age, gender). As a result, the final sample is unbiased by the selection of seeds.[11,12]

Seed selection. Seeds should be dynamic individuals who are knowledgeable about their IDU community, who know other IDUs, and to whom many IDUs within the community come for information. When individuals with these traits are selected as seeds, they are more likely to encourage others to participate and to provide support for the project in the community. Selecting such seeds speeds the growth of recruitment chains (i.e., waves), which in turn increases the likelihood of obtaining a sample that resembles the underlying IDU population.[18]

In addition to these individuals' characteristics, diversity among the group of seeds should be considered in terms of demographic characteristics,

Figure 2. RDS recruitment methods



RDS = respondent-driven sampling
IDU = injecting drug user

geographic factors, and type(s) of drugs used. It is important that seeds are diverse with respect to factors that most strongly determine the formation of social ties, such as race/ethnicity, gender, age, proximity (residence, workplace), and, in this instance, drug-use patterns. Choosing a diverse set of seeds in this manner can help make the sampling operations (time and field costs) more efficient. For NHBS-IDU, seeds were identified to represent various networks in each MSA as defined by race, gender, age, location within the MSA, and drug of choice.

Participant recruitment of other participants. After the interview with the seed is completed, the interviewer asks the seed if s/he is willing to recruit other participants for a small incentive. After a brief training on the recruitment process, those who agree to recruit are given three coded, non-replicable coupons. These recruiters are told to give one coupon each to people in their networks. The code number on the coupon is linked to the participant to whom the coupon was issued (i.e., the recruiter) and the participant returning the coupon (i.e., the recruit). People who receive a coupon bring it to the field site to complete an interview, if they are eligible. After the interview is completed, participants go through the same process as the seeds: asked to recruit others, provided training, and given three coded coupons. The process of recruitment continues until a desired sample size is reached or the study period ends.

Screening for eligibility

The standard eligibility criteria for all cycles of NHBS are that respondents must be 18 years of age or older and live in the MSA (determined, in most areas, by county of residence). Other eligibility criteria are that the participant must be able to complete the screener and the interview in English or Spanish and not previously have completed an interview for the current cycle.

Additional criteria were deemed necessary for the IDU cycle, so an eligibility screener was developed (Figure 3). Ethnographers and other staff from NHBS sites with expertise working with IDUs helped develop the screening tool and guidance for interviewers.

One eligibility criterion specific to the NHBS-IDU was having injected drugs in the past 12 months. Although this time period is longer than many IDU studies, it was chosen for several reasons:

- It permits analyses by time period of last injection (e.g., comparing those who last injected three, six, and 12 months ago) to determine differences in risk behavior.
- It provides an increased likelihood of recruiting at least 500 IDUs in each NHBS-IDU project area.
- It is the referent time frame for most NHBS survey questions.
- It is the same eligibility time frame used in NHBS-MSM, which will permit comparisons across cycles.

Figure 3. Eligibility criteria for NHBS-IDU

1. All potential participants should be asked every question.
2. To be eligible, each participant must meet the following criteria:
   - Aged 18 years or older
   - Lives in the participating MSA
   - Has not previously completed an interview for NHBS-IDU
   - Able to complete the interview in English or Spanish
   - Has injected drugs (drugs that have not been prescribed) within the past 12 months
   - Has either . . .
     — Physical evidence of recent injection (fresh track marks, scabs, or abscesses)
     OR
     — Knowledge of drug preparation, injection, and needles and syringes

NHBS-IDU = National HIV Behavioral Surveillance–Injecting Drug Users

MSA = metropolitan statistical area

As part of the screener, participants were asked to show where they inject. Interviewers examined these areas and determined if there was physical evidence of recent injection. Additional assessment of eligibility was necessary to screen in those who had not injected recently enough to have physical evidence of injection (e.g., fresh track marks) but had injected in the past 12 months, and to screen out those who used drugs but did not inject. Therefore, participants were asked to describe how they prepared their drugs for injection, how they injected, and the needles they used. Key points interviewers were listening for in the responses included the following: how respondents mixed drugs (e.g., with water [heroin] or lemon juice [crack cocaine]); whether and how drugs were cooked prior to injection; how participants "tied off" and injected; and the size and color of syringes the participants used. Interviewers were trained to determine if the participant's description was adequate for eligibility when no evidence of recent injection was available.

In addition to questions assessing these factors, the eligibility screener also included "distracter" questions, asking about behaviors such as use of alcohol, tobacco, and other non-injection drugs. The reason for including these distracters was to prevent participants from

learning the criteria and then coaching those they recruit to give the correct answers to get into the study and earn the incentives and rewards.

Survey administration and content

Survey data were collected by interviewers using a handheld computer. An algorithm, programmed into the computer, was used to determine which participants were eligible. For those determined to be eligible, consent to participate was obtained.

The survey included questions to measure the size and characteristics (gender, race) of the participant's network. Networks were defined as people the respondent knew who injected drugs and whom he/she had seen in the past six months. Network information is needed to calculate population-based estimates of behavior using RDS-specific analysis software.

The NHBS core questions assess the participant's drug use and sexual behavior, HIV testing history, and access to and use of HIV prevention services. Most risk behavior questions have a referent time period of the 12 months prior to the interview. For the IDU cycle, additional questions were included on the survey to assess the self-reported hepatitis C virus infection status of the participants and their sex- and drug-sharing partners, and exposure to HIV prevention services or materials specific to injectors (e.g., receipt of free sterile needles or other injection equipment).

When recruiters returned for their recruitment incentive, they were asked a short series of questions about their recruitment experience. These questions focused on the number of coupons given out and the characteristics of people who refused coupons (gender, race, and reason for refusal) to measure nonresponse.

Data management

NHBS-IDU data were collected electronically to eliminate the need for subsequent data entry from paper forms and to minimize the possibility of data-entry errors. The two software programs used to collect and manage data electronically were RDS Coupon Manager (RDSCM) version 2.0[22] and Questionnaire Development System (QDS™).[23]

RDSCM tracked coupon distribution and payments to recruiters. The link between the recruiter and his/her recruits was made in RDSCM by matching the code number on coupons. An identifying code was used to verify a recruiter's identity for payment purposes. That code was created by using part of the following information: the recruiter's last name, his/her mother's maiden name, and the recruiter's month and year of birth, gender, and race. The unique identifier was only stored within RDSCM and was not linked to survey data. RDSCM was also used to collect the nonresponse data from recruiters.

QDS was used to collect and manage the NHBS-IDU eligibility and survey data, as well as to develop a program that interviewers used to administer the interview electronically on handheld computers. Logic checks and skip patterns were included in the program to help prevent data entry errors. Data collected on the handheld computers were transferred to a desktop computer, and QDS was also used to maintain the interview records in a single file, called a "warehouse," where incomplete and duplicate records could be identified and resolved. Data were sent from the NHBS sites to CDC monthly during the survey period; staff at CDC reviewed the data and provided standardization, where needed, for comparability across sites. Data can be exported from QDS to a variety of statistical software packages for analysis.

Analytical and statistical methods

The sampling frame for RDS is based on specific information collected from participants, including:

- Who recruited whom (tracked in RDSCM)
- The relationship of the participant to the recruiter. The RDS population estimates are based on an assumption that the recruiter and the participant know each other.
- The participant's personal network size (i.e., how many injectors they know). The network size information from individuals is used to estimate the average network size by different sample characteristics (e.g., by gender, race/ethnicity, drug of choice, etc.).

From this frame, sampling probabilities can be calculated and, in turn, population estimates can be assessed for bias and the variability of these estimates can be determined.[18,24] To calculate the population estimates derived from RDS, several sources of bias are taken into account: the differences in effective recruitment across groups (those more effective at recruitment would be overrepresented in the sample); homophily (groups that are more insular would be overrepresented because it is more difficult to break out of those groups); and the network size (groups with larger networks would be overrepresented because more recruitment paths lead to their members). These analyses can be conducted using RDS Analysis Tool (RDSAT), a custom program designed specifically to analyze RDS datasets by calculating recruitment matrices (copyright: Douglas Heckathorn; download from: http://www.respondentdrivensampling.org). Details

on the theory behind and calculation of population estimates are available elsewhere.[11,24] It is important to evaluate whether the theoretical assumptions of RDS are met in the actual samples achieved.[25]

EARLY IMPLEMENTATION OF NHBS-IDU

Formative assessment began in late 2004 but primarily occurred from January through April 2005. The first sites began recruitment using RDS in May 2005.

Seed selection

The NHBS-IDU protocol recommended the use of eight to 10 seeds to begin RDS. In each city, seeds were recruited from a variety of racial/ethnic groups; however, across the 25 NHBS-IDU sites, seeds were predominantly male and African American. Most sites focused seed recruitment among heroin injectors but also included seeds who injected speedballs and, in smaller numbers, those who injected methamphetamines.

Eligibility screener

After the first few sites had been conducting surveys for about four weeks, interviewers solicited feedback on how well the eligibility screener was working. These sites reported the following:

- Enough participants reported either that they had never injected drugs or that they had injected more than 12 months ago to assure that these criteria had not been "leaked" to potential participants.
- Participants were able to show physical signs of injection and interviewers were able to distinguish recent marks from older marks.
- Interviewers were able to elicit enough information from participants about their injection practices to determine these descriptions as adequate or inadequate for the purposes of eligibility.

DISCUSSION

Methodological challenges of NHBS-IDU

Before NHBS, RDS had been used in smaller-scale intervention studies, behavioral surveys, or tests of the method's validity; NHBS-IDU was the first large-scale, multisite implementation of RDS for behavioral surveillance purposes. Implementing RDS on a broad scale, such as for NHBS, provides challenges in terms of standardizing operations both across the 25 MSAs and across years of surveillance. Evaluation of RDS will be important to assess the extent to which the sample resembles what is known about the underlying population of IDUs. Data collected from IDUs recruited through RDS could be compared to sample characteristics and risk behaviors of similar IDU populations recruited through other methods. The use of robust, computationally intensive analysis methods recently developed for active set adaptive sampling will be investigated for NHBS-IDU. These methods have been applied to certain dynamic sampling strategies that rely on information available about the current sample to compute a sampling probability for the next member of the sample.[26,27]

Limitations

Despite comprehensive literature reviews, consultation with experts, and thoughtful design consideration, NHBS-IDU has limitations that should be acknowledged. First, like other NHBS cycles, all NHBS-IDU data are self-reported; underreporting or overreporting of behaviors is possible yet difficult to ascertain. Second, the findings apply only to IDUs in the 25 participating MSAs; behaviors among IDUs in these MSAs may not be representative of the behaviors among IDUs throughout the United States.

The NHBS MSAs were chosen based on high AIDS prevalence.[3] Therefore, NHBS-IDU is likely to provide excellent data on behaviors in MSAs where prevention programs are needed to curtail ongoing HIV transmission. However, in some regions, HIV risk behaviors are highly prevalent even though HIV prevalence is low.[28] Therefore, the inclusion of some low-prevalence sites would be needed to identify MSAs where future epidemics could occur; an effort similar in principle to the rapid behavioral assessments conducted among MSM in medium- and low-morbidity areas of the United States could be adapted for IDUs.[29]

The benefits of RDS include the ability to attain a sample independent of its origins (i.e., the seeds) and the ability to adjust estimates for bias in the sample.[18,21] Although RDS is relatively new, and future studies describing its use in a variety of settings are needed, the studies conducted to date suggest that this method is at least as effective and perhaps better than other sampling methods for obtaining representative samples of hidden populations such as IDUs.[5,13,25]

Application of the data

NHBS-IDU data can be used in the 25 participating project areas as a baseline measure of risk behavior for comparison over time, with future cycles on key indicators measured in the NHBS core survey, such as prevalence of sharing equipment and use of drug treatment. The data can also be used to better understand the current epidemic among IDUs, such as changes

in drugs of choice and examining the extent to which IDUs are also at risk of acquiring HIV through sex and transmitting it to their non-injecting sex partners.[30,31]

Information collected through NHBS-IDU—both in the formative assessment and the survey—can be used to document the availability and use of HIV prevention services targeted to IDUs. This information can, in turn, be compared across cities; for example, the use of clean, sterile needles can be compared in cities with and without needle-exchange programs. Coupled with HIV surveillance data, trends in access to and utilization of prevention services can be compared with trends in HIV prevalence and incidence.

SUMMARY

NHBS-IDU is the first large-scale, behavioral surveillance system of its kind in the United States that will provide local and national data on risk for HIV and other blood-borne and sexually transmitted infections among IDUs for monitoring changes in the epidemic and prevention programs. Although the population can be challenging to reach, the use of RDS holds promise for reaching a broad array of IDU networks and providing population-based estimates of risk behaviors. Data from NHBS will be used to monitor changes in behaviors among IDUs in the United States who are at high risk for HIV infection, and better tailor prevention services for this population.

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