

## **Transgender HIV Behavioral Survey**

### **Supporting Statement Part B**

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## 2/4/2021Transgender HIV Behavioral Survey

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## **B. Statistical Methods**

### **1. Respondent Universe and Sampling Methods**

The respondent universe for the Transgender HIV Behavioral Survey (THBS) will be transgender individuals living in metropolitan statistical areas (MSA) with the largest burden of HIV disease. The sites are chosen for the following reasons: First, HIV is primarily an epidemic that affects the urban areas in the United States. Second, transgender populations are concentrated in many urban areas. Third, state and local health departments are currently funded to conduct the National HIV Behavioral Surveillance (NHBS) system in many of these MSA and have the infrastructure and experience for conducting the THBS pilot. However, because the purpose of THBS is to pilot a behavioral survey among transgender persons that will eventually be integrated into NHBS, funding for the THBS pilot will be limited to four state and local health departments currently funded to conduct NHBS in the MSA (see Section B5 for a list).

The respondents providing information for the proposed project are transgender persons residing in the MSA where the project is conducted. Transgender populations chosen for inclusion in THBS are those in which the potential contribution to the spread of HIV in the community is greatest: African American and Latino persons who were assigned a male sex at birth. Basic eligibility criteria include: being age 15 years or older; being a resident of the MSA; having a male sex assigned at birth; identifying, living or presenting as a woman; being able to complete the interview in English; and not having previously participated in the THBS survey.

Each of the 4 funded project areas will have a minimum sample size of 100 eligible respondents for a total of 400 eligible respondents.

#### Sampling Methods

The methods for THBS were chosen based on consultations with sampling methodologists, persons with expertise conducting research or behavioral surveys within transgender populations, and public health practitioners who provide services to these populations, as described in Section A8. The selection of appropriate methods to recruit representative samples of transgender persons is complicated by the fact that population-based samples of these groups are not feasible as they cannot be easily identified as transgender persons or enumerated for sampling purposes. Several guiding principles determined the selection of methods to conduct this survey. These principles included the selection of methods that would 1) result in the most representative sample possible, 2) be feasible for implementation in the heterogeneous areas eligible for conducting the survey, and 3) allow for standardized recruitment of at least 100 transgender persons.

THBS will use respondent-driven sampling (RDS). These methods have demonstrated ability to recruit hidden populations (Abdul-Quader, 2006; Diaz, 2001; Heckathorn, Semaan et al., 2002; Magnani, 2005; Mansergh, 2006; McFarland, 2001; Ramirez-Valles, 2005; Semaan, 2002; Wang, 2004), including transgender persons (Clements-Noelle, 2001).

RDS will be used to recruit participants. RDS is a chain-referral sampling strategy similar to snowball sampling. It starts with a limited number of “seeds” who are chosen by referrals from people who know the local transgender population well, or through outreach to areas where transgender persons can be found. Seeds complete the survey (eligibility screener and survey) and then are asked to recruit a specified number (usually between 3 and 5) of transgender persons they know who meet the eligibility criteria for THBS. These persons, in turn, complete the survey and are asked to recruit others. This recruitment process continues until the sample size has been reached. Participants receive incentives for participating in the survey as well as for recruiting others. By starting with a small number of seeds, limiting the number of individuals each participant can recruit, and allowing a significant number of recruitment waves to occur, the distribution of the final sample begins to resemble the underlying eligible population living in the project area and is unbiased by the characteristics of the seeds (Heckathorn, 1997; Heckathorn, 2002).

#### Sample size

About 100 eligible people will be recruited and interviewed in each project area. The sample size of 100 participants per project area was determined based upon other studies that used RDS to recruit respondents and advice from statistical consultants. A minimum sample size of 100 is needed to ensure that RDS methodology works well at recruiting the underlying population of interest and develop adequate estimates of key participant characteristics. The characteristics to be examined include those shown in the table below. The numbers in the table are based on estimates from other studies of transgender populations.

<u>Characteristic</u>	<u># of Respondents</u>
<u>Race/Ethnicity</u>	
Hispanic	200
Black	200
<u>Age</u>	
15-17 years of age	40
18 – 34 years of age	200
35 years and older	160

<u>HIV status</u>	
HIV positive	111
HIV negative or unknown	289
 TOTAL	 400

#### Expected response rates

In RDS, it is expected that one-half to two-thirds of the coupons given to recruiters are returned by potential participants (Heckathorn, 2002; Johnston, 2006; Ramirez-Valles, 2005; Stormer, 2006; Wang, 2004; Yeka, 2006). A benefit of peer-driven sampling is that recruiters are told, generally speaking, what the eligibility criteria are in order that they can recruit eligible participants. Response rates using RDS are expected to be between 69% and 77%. The response rates will be monitored closely during data collection. Efforts to maximize response rates are described in Section B3. If expected response rates are not reached, non-response bias will be assessed to improve the piloted methods. Further details and calculations are provided in Section B3 below.

## **2. Procedures for the Collection of Information**

### Main steps in data collection

THBS collects data through a computer-assisted questionnaire. The complexity of the eligibility screener and the behavioral questionnaire—with skip patterns and logic checks—necessitates a computer-assisted interview. The eligibility screener is a computer-assisted personal interview (CAPI) administered by a trained interviewer. External consultants suggested that this was a better approach because transgender respondents would be more forgiving of the way eligibility screener items were worded if they were delivered by a computer rather than a person. Using an interviewer to administer the eligibility screener will also allow time for THBS staff to establish rapport with the respondent. RDS should be more successful as a recruitment method when respondents feel comfortable referring their peers to the study staff. However, to improve the likelihood of reporting sensitive behaviors (e.g., sexual behaviors and drug use) in the behavioral questionnaire, this questionnaire is conducted without an interviewer using an audio, computer-assisted, self interview (ACASI).

Persons who receive a coupon (Attachment 8) to participate in THBS using RDS will be asked to make an appointment to take the survey; walk-in hours are usually available (determined locally). When a potential respondent comes to the field site, their coupon will be assessed to ensure it is valid, using the Coupon Manager program described in Section A3. Once the coupon is validated, the interviewer will explain to the potential participant that they are being asked to participate in a health survey, that they will be screened for eligibility first, and that not all persons will be eligible. All persons with a

valid coupon will be administered the eligibility screener using a computer-assisted interview (Attachment 3). If the person is not eligible, he or she will be thanked for their time and interest in the project but will not be given the behavioral questionnaire or asked to recruit others. If eligible, the interviewer will obtain informed consent by reading the consent form and obtaining oral agreement to participate (Attachment 6). After obtaining consent, the interviewer instructs the participant on how to complete the computer-assisted behavioral questionnaire on the laptop computer; the participant will then complete the audio, computer-assisted, self interview (ACASI) (Attachment 3). At the end of the ACASI questionnaire the computer will prompt the participant to get the interviewer. The interviewer will ask the participant a few brief questions that are at the end of the ACASI program to assess the questionnaire items in the survey. After this respondent debriefing at the end of the behavioral questionnaire, the interviewer will close the participant's behavioral questionnaire on the computer.

After the THBS behavioral questionnaire is completed, the interviewer will ask the participant if she would be willing to recruit other participants for a small incentive. After a brief training on the recruitment process (Attachment 9), those who agree to recruit their peers will be given three coded, non-replicable coupons (Attachment 8). The participant will be told to give one coupon to each of 3 peers meeting the eligibility criteria. Each coupon will have the local THBS project name and location(s) printed on it with a brief explanation of the project. The code on the coupon will be linked to 1) the Survey ID of the participant the coupon is issued to (i.e., the recruiter) and 2) the Survey ID of the participant returning the coupon (i.e., the recruit). The coupon information is entered and stored in the Coupon Manager program. After receiving coupons and recruiter training, the participant is paid their incentives and given instructions about returning for the recruitment rewards. This ends the data collection procedures for THBS using RDS.

### Quality Control

Data quality is ensured by use of computer-assisted interviewing, interviewer training and monitoring, site visits, and data editing. Computer-assisted interviewing improves data quality in several ways:

- a) Interviewer errors are reduced because interviewers do not have to follow complex routing instructions; the computer does it for them.
- b) Respondent errors are also reduced. Consistency checks are programmed into the questionnaire so that inconsistent answers or out of range values can be corrected or explained while the interview is in progress.
- c) Use of computer-assisted interviewing also reduces coding and coding errors, which makes it possible to prepare the data for analysis faster and more accurately.

A multi-day training of local field staff will occur prior to implementation of data collection. This training will cover general interviewing skills, the sampling and recruitment protocol, and a question-by-question review of the survey to ensure interviewers understand the purpose of each question and how the interviewer-administered eligibility screener should be read and coded in the computer. Interviewers will have opportunities to practice administering the eligibility screener as well as going through the ACASI questionnaire. The training will also address interviewer integrity, underscoring the importance of collecting quality data and the consequences of inappropriate behaviors, including falsification of data. The training will cover how to provide technical assistance to respondents who have problems with the ACASI questionnaire.

During the data collection period, field staff will be monitored by their supervisor or other management staff. Approximately 10% of each interviewer's eligibility screening survey will be monitored. Feedback will be provided for areas of improvement or incorrect implementation of the protocol. Also, during the data collection period, CDC will closely monitor the recruitment process in each project area. Supervisors will provide feedback on ways to help improve response rates.

CDC will conduct at least one site visit to each of the four project area during data collection. The purpose of the site visit is to monitor adherence to the THBS protocol, observe the eligibility screening interviews, and obtain feedback on study procedures.

In addition to the checks provided through the computer-assisted interview program, editing of the data will be performed by CDC, performing extensive checks of the quality of the data files. Monthly processing allows for identification of errors in programs or procedures.

### **3. Methods to Maximize Response Rates and Deal with Non-response**

#### Response rate calculations

Previous studies using RDS find that one-half to two-thirds of coupons given to recruiters are returned by potential participants (Heckathorn, 2002; Johnston, 2006; Ramirez-Valles, 2005; Stormer, 2006; Wang, 2004; Yeka, 2006). Thus the sample size does not, in practice, accrue exponentially as the design suggests. However, one of the benefits of peer-driven sampling is that recruiters are told, in general terms, what the eligibility criteria are so that they can recruit eligible participants. Thus, it is expected that at least 90% of those returning with a coupon will be eligible (Ramirez-Valles, 2004). In addition, survey completion rates among those found eligible is generally high. Generally, persons who are eligible and not interested in doing the survey will not return with the coupon.

The response rate calculations based on 100 completed surveys and using the estimated outcomes noted above result in response rates of 69 – 77%. The unweighted response rate calculations were done using the methods provided in the document “Standards and Guidelines for Statistical Surveys” distributed in September 2006 by OMB. For THBS, the response rate calculations were based on 100 completed surveys or cases (C) and using the estimated outcomes:

- Number of eligible and interview completed (c) = 100
- Number of eligible and not interviewed (e) = 0
- Number of ineligible (out of scope) (i) = 10 (based upon 90% eligibility)
- Number of unable to determine eligibility (u) = 33 to 50

Unweighted response rates are calculated by the formula:  $RR = C/[c+e+x(u)]$ , where  $x = (c+e)/(c+e+i)$  or .9. The unweighted response rate calculated by this formula assuming 67% coupon return rate is  $100/[100+0+0.9(33)]$  or  $100/130$  or 77%. The unweighted response rate calculated by this formula assuming 50% coupon return rate is  $100/[100+0+0.9(50)]$  or  $100/145$  or 69%.

Expectations for more standard survey methods—such as use of probability sampling and response rates in excess of 80%—cannot be applied to THBS for multiple reasons. Given that the populations targeted by THBS are considered hard to reach, either because their behaviors are illegal or not socially normative, there is no “gold standard” probability sampling method that can be used. The peer-referral sampling methods used in THBS were developed precisely to reach these populations and our projected response rates are within the range of those achieved in previous studies. Bias in the samples can be evaluated; weighting methods for RDS also help adjust for bias in the sampling strategies. Despite the limitations, the expected response rates for THBS will be adequate for the purposes of evaluating the eligibility screener, questionnaire content, and the survey method.

#### Methods to maximize response rates

Refusal rates for THBS are adversely affected by the anonymous nature of the survey (no follow-up contacts) and the sensitive nature of the questions. Aspects of the recruitment methods can also adversely affect response rates; however, these methods also offer ways to maximize response rates, as described below. Monitoring of response rates will be done through conference calls on a weekly basis with each grantee and monthly with all grantees together, offering the opportunity to share strategies for improving response rates. In addition, recruitment statistics and sample demographics will be reported to CDC on a weekly and monthly basis, respectively (Attachment 10).

Research indicates that incentives help raise response rates for long, sensitive, in-person surveys (Kulka, 1995). Incentives are useful for groups that are hard to interview, including those for whom conventional means of motivation may not work, including



disenfranchised populations such as those who are targeted for THBS. In addition, these other populations at risk for HIV infection (particularly MSM and IDU) are often surveyed and incentives for survey participation are the norm. Therefore, the use of incentives for THBS is critical to achieving acceptable response rates.

Because RDS is a peer-referral mechanism, the field staff has little control over sampling methods and sample accrual, other than the recruitment of seeds. One advantage of RDS, however, is that peer referral and endorsement of the project are likely to have a positive impact on participation rates. To maximize coupon return rates, peer recruiters are trained on how to recruit their peers and given important information about the study (Attachment 9). The dual incentive structure (i.e., providing incentives to recruiters for successful peer referral) also helps to maximize response rates. Field site logistics may also maximize response rates; field sites will be located in areas that are easy to get to by public transportation and hours of operation will be set to meet the needs and schedules of the population of interest.

#### Assessing non-response bias

The use of an eligibility screener will allow comparison of the demographic and eligibility-related behavioral data on those who are eligible and ineligible. To assess non-response bias in RDS, the number of those who are offered a coupon and refused will be tracked, by asking recruiters whether anyone had refused a coupon, why they refused, and demographic characteristics of the refusers. Due to the anonymous nature of THBS, participants cannot be re-contacted to encourage them to give out coupons nor have the recruiters come in to report on coupon refusals; following up with participants has improved coupon return rates in other studies (Draus, 2005; Ramirez-Valles, 2005). Those recruiters who do come in and have not had all their recruits come in will be reminded to encourage them to do so.

#### Generalizability

The statistical theory upon which RDS is based suggests that if peer recruitment proceeds through a sufficiently large number of waves, the composition of the sample will stabilize, becoming independent of the seeds from which recruitment began, and thereby overcoming any bias the nonrandom choice of seeds may have introduced (Heckathorn, 1997; Heckathorn, 2002). This stable sample composition is termed the “equilibrium.” Experience with RDS indicates that equilibrium can be achieved in approximately 6 waves. Another factor that has an impact on how quickly equilibrium can be reached is called “homophily.” This refers to the degree of insularity, or in-group preference for recruitment. The more insular a group, the more likely they are to recruit others like themselves and it would take more waves to reach equilibrium. Having a diverse set of seeds will help ensure diversity of networks with regards to their degree of insularity included in the initial waves.

The sampling frame for RDS is created during the sampling process. The frame is based on specific information collected from participants regarding who recruited them and their network size. Recruitment is tracked by the use of coupons; recruiters can be linked to those they have successfully recruited using the Coupon Manager software. Information on who recruited whom is used to calculate cross-group recruitment proportions. The participant's personal network size is based on how many people they know who fit the eligibility criteria for the project.

To calculate the population estimates and variances derived from RDS, several sources of bias are taken into account: 1) the differences in effective recruitment across groups (those more effective at recruitment would be overrepresented in the sample); 2) homophily (groups that are more insular would be overrepresented because it is more difficult to "break out" of those groups; and 3) the network size (groups with larger networks would be overrepresented because more recruitment paths lead to their members). The population estimates derived from RDS are applicable to the underlying eligible transgender population.

#### Evaluation

CDC will conduct an evaluation of the questionnaire and survey methods during implementation and at the conclusion of data collection. This evaluation will encompass survey procedures and results. Relevant findings from these evaluations will be incorporated into the design of future THBS data collection. Specific findings related to analysis of the data collected will be made available to users of the data.

#### **4. Test of Procedures or Methods to be Undertaken**

The data collection instruments were developed using questions from previous CDC surveillance projects, and external consultants (Attachment 4). Most questions comprising the data collection instruments have been previously tested and used. Prior to implementation in the field, CDC staff will test the skip patterns and responses both electronically and using paper versions of the data collection instruments. CDC staff will also conduct mock interviews of other CDC staff using laptop computers.

#### **5. Individuals Consulted on Statistical Aspects and Individuals Collecting and/or Analyzing Data**

Drs. Lillian Lin, Chris Johnson, and Doug Heckathorn were consulted about the statistical aspects of the project, including the sampling strategy, analytic methods for examining the objectives, and sample size.

Subcontractors to Research Triangle Institute.

Funding for THBS is expected to occur during the third quarter of FY08 through contracts. The request for proposals will have eligibility limited to the directly funded city health departments containing the following Divisions of Metropolitan Statistical Areas (MSA): Los Angeles, CA (Los Angeles Division); San Francisco, CA (San Francisco Division); Chicago, IL (Chicago Division); New York City, NY (New York Division); Philadelphia, PA (Philadelphia Division); Houston, TX ; and the State health departments containing the following MSA or Divisions: San Diego, CA; Denver, CO; Washington DC (Washington Division); Miami, FL (Miami Division); Atlanta, GA; New Orleans, LA; Boston, MA (Boston Division); Baltimore, MD; Detroit, MI; St. Louis, MO; New York City (Newark Division and Nassau Division); San Juan, PR; Dallas, TX (Dallas Division); VA; Seattle, WA (Seattle Division). The actual grantees will be determined depending on available funds and evaluation of the funding proposals.

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