

Transgender HIV Behavioral Survey

**OMB 0920-0794
EXPIRED 12/31/2010**

May 16, 2011

Contact Information:

Teresa Finlayson, PhD MPH
Behavioral and Clinical Surveillance Branch
Division of HIV/AIDS Prevention
National Center for HIV/AIDS, Viral Hepatitis, STD, and TB Prevention
Centers for Disease Control and Prevention
1600 Clifton Road (MS E-46)
Atlanta, GA 30333
Voice: 404.639.2083
Fax: 404 639 8640
Email: TFinlayson@cdc.gov

Transgender HIV Behavioral Survey

0920-0794

TABLE OF CONTENTS

SECTION

B. Collection of Information Involving statistical Methods

1. Respondent Universe and Sampling Methods
2. Procedures for the Collection of Information
3. Methods to Maximize Response Rates and Deal with Nonresponse
4. Test of Procedures or Methods to Be Undertaken
5. Individuals Consulted on Statistical Aspects and Individuals Collecting and/or Analyzing Data

LIST OF ATTACHMENTS

Attachment Number	Document Description
1	Public Health Service Act
2	60-day Federal Register Notice
3a	Eligibility Screener
3b	Behavioral Assessment
3c	Recruiter Debriefing
3d	Interview Flashcards
3e	Spanish Translation
4	Response to Public Comments
5	CDC Security and confidentiality forms
6	Assurance of Confidentiality for HIV/AIDS Surveillance Data
7	Model consent form
8	Project determination
9	Changes to the Eligibility Screener text
10	Changes to the Behavioral Assessment text
11	Model coupon
12	Recruiter training script
13	Process monitoring reports

B. Statistical Methods

1. Respondent Universe and Sampling Methods

The respondent universe for the Transgender HIV Behavioral Survey (THBS) will be male-to-female transgender individuals living in up to five selected metropolitan statistical areas (MSA). The five selected MSA will be from those where the National HIV Behavioral Surveillance (NHBS) system is currently conducted (see Section B5 for a list of all the NHBS-eligible public health jurisdictions). The five MSA will be selected from among the MSA conducting NHBS for several reasons: First, the NHBS system is conducted in metropolitan statistical areas (MSA) experiencing the largest burden of HIV disease, which is determined by the cumulative AIDS cases; Second, these MSA tend to be large urban areas and transgender populations in many urban areas tend to be well-connected with each other; Third, THBS data can be used to complement NHBS data in a description of the local HIV epidemic within the MSA; and Fourth, because these MSA conduct NHBS there is an infrastructure for conducting a similar HIV behavioral surveys in place within the MSA.

Transgender populations chosen for inclusion in THBS are those at greatest risk for becoming infected with HIV: persons who were assigned a male sex at birth. In addition to residence in the jurisdictions, eligibility criteria include: being age 15 years or older; being a resident of the MSA; having a male sex assigned at birth; identifying as a woman, transgender, or some gender other than male; being able to complete the interview in English or Spanish; and not having previously participated in the THBS survey in the past year.

Proposed funding will allow up to 5 NHBS-eligible public health jurisdictions to conduct THBS. Each funded jurisdiction will have a minimum sample size of 200 eligible respondents for a total of 1,000 eligible respondents, if the maximum of five health departments are funded.

Sampling Methods

Statistical methods will not be used to select respondents for this project. The selection of appropriate sampling methods to recruit transgender persons for a behavioral survey is complicated by the fact that population-based samples of this group are not feasible as persons cannot be easily identified as transgender or enumerated for sampling purposes. 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. In addition, because of the stigma associated being transgender, a transgender identity may not be disclosed. Therefore, a sampling method was selected that could best reach hidden populations, allow for standardized recruitment of at least 200 transgender persons from each MSA, and be easily implemented in any of the MSA eligible for conducting the survey. The best methods for recruiting hidden populations into a behavioral survey are targeted sampling (Watters & Biernacki, 1989) and respondent-driven sampling. Targeted sampling requires targeting geographic areas or venues frequented by the hidden population. As few cities have venues or geographic areas frequented by transgender persons, targeted sampling is not feasible for THBS.

Instead, THBS will use respondent-driven sampling (RDS). This method has 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 is a chain-referral sampling strategy similar to snowball sampling. It starts with a limited number of initial recruits or “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 are recruited to complete the eligibility screener. If they are eligible, they are asked to complete the behavioral assessment, and then to recruit up to 5 transgender persons they know who meet the eligibility criteria for THBS. If they agree to be a peer recruiter, they are given up to 5 coupons to provide to their peer recruits (**see Attachment 11**). These recruits, in turn, will come into the field site to be screened for eligibility and if eligible, complete the behavioral assessment and be asked to recruit others. This recruitment process continues until the sample size has been reached. Respondents receive incentives for participating in the behavioral assessment as well as rewards for recruiting others. 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, is expected to lead to a final sample that resembles 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 200 eligible persons will be recruited and interviewed from each MSA. The sample size of 200 participants from each MSA is based on the availability of funds, experience from the previously approved pilot data collection, other studies that have used RDS to recruit respondents, and advice from statistical consultants. A sample size of 200 is expected to allow for a sufficient number of waves from the initial recruit to result in a final sample that has diverse characteristics and no longer resembles the initial recruit in terms of race/ethnicity or age but the race and age in the broader transgender community. The expected distribution of respondents according to these characteristics is indicated in table B1 below. Although this data collection does not use probability sampling, if we assume that RDS is half as efficient as a simple random sample (Salganick, 2006), a sample size of 200 participants per site would allow local areas to estimate a proportion of 50% with precision of roughly 7% for the outcome of interest (e.g., the proportion of eligible participants who engage in unprotected anal sex or who have never been tested for HIV). Assuming that these data are a probability sample, the larger national sample of 1,000 respondents should provide adequate power and precision to evaluate most behaviors of interest overall and by the major demographic variables shown below in Table B1. The numbers in the table are based on experience from conducting the previously approved pilot data collection and other similar RDS studies. The expected sample is likely to have a higher proportion of Black and Hispanic participants than white participants and a small percentage participants will be either Asian or some other racial group. In addition, a large percentage of the participants will be over the age of 35 years and small proportion will be below the age of 18.

Expected response rates

A benefit of the peer-driven sampling conducted in RDS (Heckathorn, 2002; Johnston, 2006; Ramirez-Valles, 2005; Stormer, 2006; Wang, 2004; Yeka, 2006) is that recruiters are told, generally speaking, what the eligibility criteria are in order that they can recruit eligible participants. For this reason, response rates for the proposed data collection are expected to be high, approximately 90%. Results from the previously approved pilot data collection support this expected response rate. Further details and calculations are provided in Table B1 below. 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 recruitment. Further details and calculations are provided in Section B3 below.

In the previously approved pilot data collection, a total of 238 persons were recruited to participate in the pilot data collection. All 238 were screened and completed the pilot’s eligibility screener; 230 (97%), of the 238 screened, were eligible; 228 (96%), of the 238 screened, were subsequently interviewed. These figures varied slightly across the three MSA: the total screened (Range: 59-106); the total number of interviews completed (Range: 59-102); and the percentage of persons were screened who completed an interview (Range: 92-100%). Of the 230 persons who were eligible and completed the behavioral assessment, 206 (90%) were given coupons to recruit their peers.

Table B1: Expected Response Rates and Sample Size, NHBS*

Characteristic	Persons referred by peer recruiters completing the screener	Eligible Transgender persons completing the behavioral assessment	Peer recruiter completing the recruiter debriefing
TOTAL	1,100	1,000	500
Hispanic	300	275	138
Black	550	500	250
White	200	180	90
Other	50	45	22
15-17	200	180	90
18 – 34 years of age	400	365	183
35 years and older	500	455	227

* Based on experience from the pilot and other similar RDS studies, participation and recruiter rates tend not to differ across race and age. Therefore, the expected numbers of participants completing the screener, behavioral assessment, and recruiter debriefing are not expected to vary by race or age.

2. Procedures for the Collection of Information

Main steps in data collection

All eligibility screening and interviews will be conducted by trained project staff. Participation in the project is voluntary. Respondents may refuse to participate at all or in part. Respondents may refuse to answer questions or stop participation at any time without penalty. The approved Project Determination Form (**Attachment 8**) indicates that because CDC is not directly engaged with human subjects in connection with this project, the protocol will not be reviewed by CDC's IRB. Each participating health department will be required to obtain IRB approval prior to data collection.

Respondent Driven Sampling (RDS) procedures which are described in section B1 will be used to recruit eligible male-to-female transgender persons for data collection. Persons who receive a coupon (**Attachment 11**) to participate in THBS will be asked to make an appointment to be screened for eligibility and if eligible, to complete the behavioral assessment, although they may also have the option to present without an appointment during certain hours (determined locally). When a potential respondent presents with a coupon at a THBS field site, the coupon will be assessed to ensure that it is valid, using the Coupon Manager program described in Section A3. After the coupon is validated, a trained interviewer will explain to the potential participant that she is being invited to participate in a health survey, that she will be screened for eligibility first, and that not all persons will be eligible. The number on the valid coupon will become the survey ID used to link data from each of the data collection instruments. All persons with valid coupons will be administered the eligibility screener using an electronic interview application on a handheld computer (screening questions are listed in **Attachment 3a**). Persons who present to the field staff at the office without a valid coupon will not be allowed to participate in the behavioral assessment.

If the person is not eligible, she will be thanked for her time and interest in the project but will not be asked to participate in the behavioral assessment or to recruit others. The interviewer will obtain informed consent from eligible persons by reading the consent form and obtaining oral agreement to participate (**Attachment 7**). During the consent process, the behavioral assessment and HIV testing components are described and the person must indicate which of these components, if any, she agrees to participate in. Informed consent will be obtained by having the interviewer read the consent script and indicating on the handheld computer whether the person being recruited provided verbal consent.

After obtaining consent, the interviewer will administer the behavioral assessment (**Attachment 3b**), again using an electronic application on a handheld computer. For the previously approved pilot data collection, the interview was only available in English, but for this information collection request, the interview will be available in both English and Spanish. (**Attachment 3e**) HIV testing was not conducted in the previously approved pilot data collection; testing was added to this information collection request. Specimens for HIV testing will be collected from persons who consent to testing. Persons recruited may elect to participate in the behavioral assessment and not to participate in HIV testing. Persons who refuse the behavioral assessment will not be offered HIV testing.

After the THBS behavioral assessment is completed, the interviewer will ask the participant if she would be willing to recruit other participants for a small token of appreciation. After a brief training on the recruitment process (**Attachment 12**), those who agree to recruit their peers will be given up to five coded, non-replicable coupons (**Attachment 11**). The participant will be told to give each coupon to a peer 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 number on each coupon will be linked to 1) the Survey ID of the participant given the coupon to her recruit peers (i.e., the peer recruiter) and 2) the Survey ID of each participant returning the coupon (i.e., each recruit). The participant will be asked a series of questions to create a unique recruiter ID (see section A.1 for specific questions) and the field staff record any physical marks or characteristics of the participant. These data help the local field staff identify the person as the peer recruiter and locate their record in the coupon database. This information as well as the number of each coupon given to the peer recruiter is entered and stored in the coupon manager program. After receiving coupons and recruiter training, the participant is given a token of appreciation for participating in the survey and given instructions about returning for her recruitment tokens of appreciation. In the coupon database, the field staff will also indicate in the record of the participant's recruiter that the coupon was successfully returned by an eligible peer. This notation is important so that the participant's recruiter can receive a token of appreciation for recruiting the participant into the survey.

When a participant returns for her token of appreciation, she will be asked questions to determine how many coupons she distributed, if anyone refused the coupons, the race or ethnicity of the persons refusing coupons, and the reasons for refusal (**Attachment 3c**). This information will be stored in a spreadsheet kept separate from, but linked to the eligibility screener and behavioral assessment data by the survey ID.

THBS data will not be collected any more frequently than every 3 years, because NHBS grantees will be funded for THBS and THBS must be coordinated with NHBS data collection (OMB 0920-0770 exp 03/31/2011). NHBS data are collected for six months in sequential annual cycles from three populations at increased risk for HIV infection: men who have sex with men; injection drug users; and heterosexuals at increased risk for infection. NHBS data collection in each of these three populations is completed every three years. Collection of data from transgender persons for THBS will take place during one of the NHBS cycles, after active data collection and before the next annual cycle begins.

Quality Control

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 the need to enter data post data collection, which makes it possible to prepare the data for analysis faster and more accurately.

In addition, data quality is ensured through, interviewer training and monitoring (including observation of interviews), and data editing. A multi-day training of local field staff will occur prior to 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 that interviewers understand the purpose of each question and how the interviewer-administered eligibility screener, behavioral assessment questionnaire, and recruiter debriefing questions should be read and recorded in the computer. During the training, interviewers will have opportunities to practice administering the eligibility screener, behavioral assessment questionnaire, and recruiter debriefing questions. The training will also address interviewer integrity, underscoring the importance of collecting quality data and the consequences of inappropriate behaviors, including falsification of data.

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 and behavioral assessment interviews will be observed. Feedback is provided for areas of improvement and in cases of incorrect implementation of the protocol. Monitoring also includes recruitment training procedures.

During the data collection period, CDC will closely monitor the recruitment process in each project area. Also, CDC staff will conduct at least one site visit to each of the funded areas during data collection. The purpose of this visit will be to monitor adherence to the THBS protocol, observe the interviews, and elicit feedback on study procedures. CDC will also convene weekly conference calls with the project areas to address any issues with the data collection application and discuss administration of the behavioral assessment specifically and the project in general.

In addition to the checks provided through the electronic interview application, CDC will perform extensive checks of the quality of the data. Monthly processing will allow for prompt identification of errors in programs or procedures. The data collection instruments will not collect specific identifiers (e.g., name, address, social security number). Also, the data collection instruments are only electronic; no paper instruments are used to collect THBS data.

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 persons recruited by their peers for THBS will present for eligibility (Heckathorn, 2002; Johnston, 2006; Ramirez-Valles, 2005; Stormer, 2006; Wang, 2004; Yeka, 2006). In the previously approved pilot data collection, data were not collected to determine how many of the persons recruited by their peers presented for eligibility. Because recruiters are instructed to invite participation of their peers who meet the general eligibility criteria, it is expected that at least 90% of those presenting at the field site for

eligibility screening will be eligible (Ramirez-Valles, 2005). In addition, survey completion rates among those found eligible is generally high because those who have taken the initiative to present for eligibility screening are motivated to participate. Generally, persons who are eligible and not interested in doing the survey will not return with the coupon.

Expected response rate calculations are presented below. These calculations were done using the methods provided in the document “Standards and Guidelines for Statistical Surveys,” OMB, September 2006. The response rate calculations were based on 200 completed surveys or cases (C) and using the following estimated outcomes based on the previously approved pilot data collection:

- Number of eligibles with interview completed (c) = 200
- Number of eligibles not interviewed (e) = 0
- Number of ineligible (out of scope) (i) = 21 (based upon 90% eligibility)
- Number unable to determine eligibility (u) = 66

Expected (unweighted) response rates were calculated according to the formula: $RR = \frac{c}{c+e+x(u)}$, where $x = \frac{(c+e)}{(c+e+i)}$ or $\frac{(200+0)}{(200+0+21)}=0.90$. The unweighted response rate calculated by this formula assuming two-thirds of coupons are returned (67% coupon return rate) is $\frac{200}{[200+0+0.90(66)]}$ or $\frac{200}{259}$ or 77%.

Expectations of 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,” probability sampling methods cannot 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 measuring the extent to which various sub-populations recruit other sub-populations. For example, how likely were Latino recruiters to recruit a black participant and vice versa. Such calculations are possible via the coupon management system, which tracks who recruited whom, as well as information gathered during the interview process on the size and composition of participants’ social networks. Despite the limitations, the expected response rates for THBS are expected to be adequate for the purposes of describing risk behaviors of transgender persons and understanding the prevention efforts needed in the local transgender community.

Methods to maximize response rates

Response rates for THBS may be affected adversely by the anonymous nature of the survey (no follow-up contacts by project staff are possible) and the sensitive nature of the questions. 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 13**).

Research indicates that providing remuneration to respondents helps raise response rates for long, sensitive, in-person surveys (Kulka, 1995). Remuneration is also useful for groups that are hard to reach, including those for whom conventional means of motivation may not work, such as disenfranchised populations like those who are recruited for THBS. Other populations at risk for HIV infection (particularly MSM and IDU) are often surveyed and remuneration is the norm (Thiede, 2001; MacKellar, 1996, 2005). Research has also shown that remuneration is effective at increasing response rates among female residents in minority zip codes (Whiteman, 2003) and African American participants in a community-based health promotion program (Halbert et al., 2010). A meta-analysis of 95 studies published between January 1999 and April 2005 describing methods of increasing minority enrollment and retention in research studies found that incentives enhanced retention among this group (Yancy et al., 2006). Providing remuneration to THBS respondents is critical to achieve 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 to recruit their peers and given important information about the study (**Attachment 12**). Peer recruiters may help improve response rates by providing credibility and legitimacy for the survey among peers. In addition, peers recruits may be more willing to participate when recruited by a peer (versus a researcher). Peer recruiters are able to follow up with their recruits to see if they have completed the survey. The “dual-incentive” structure (i.e., providing payments to recruiters for each successful recruit) also helps to maximize response rates. Convenient location of field sites and hours of operation may also maximize response rates; field sites will be located in areas that are easy to access by public transportation and hours of operation will be set to meet the needs and schedules of the population of interest.

Prior to conducting THBS, the field staff in each participating area will review existing data sources to determine the characteristics (e.g., race, ethnicity, age, geographic location) of the local transgender community. The field staff will also obtain input on the survey from local stakeholders and members of the local transgender community. This input will help the local staff avoid barriers to participation of transgender persons in the data collection.

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 from RDS, each peer recruiter returning to the field site will be asked, using the recruiter debriefing instrument (**Attachment 3c**) whether anyone refused a coupon, why they refused, and the race of those who refused. This information will be collected using a laptop computer. Following up with recruiters has improved return rates in other studies implementing RDS (Draus, 2005; Ramirez-Valles, 2005). However, due to the anonymous nature of THBS, participants cannot be re-contacted by field staff. So field staff, cannot actively encourage peer recruiters to distribute coupons or ask the recruiters to report on coupon refusals. Instead, when a THBS recruiter returns to the field site, the field staff will remind recruiters to encourage any recruits who have not yet presented for eligibility screening to do so.

In addition, peer recruiters will be debriefed about their recruitment efforts when they return to the field site for their recruiter rewards (see **attachment 3c**) as described above. This information will be used to understand if certain racial groups are not responding or if persons are not responding for a particular reason.

Recruitment will be monitored through on-going data reports generated weekly and monthly from the data submitted to CDC. These reports will be used to monitor the seed recruitment, the characteristics of seeds, general recruitment (i.e., recruitment of non-seed participants), the characteristics of the resulting sample, the number and length of recruitment chains, the number of recruiters who returned for rewards, the number of coupons distributed to recruiters, the number of persons who present with a coupon for eligibility screening, the number of persons refusing coupons, the race/ethnicity of those refusing coupons, and the reason coupons were refused. The field staff and CDC will use the data in these reports to identify problems with recruitment. Comparing data from the sample characteristics report with the information gathered from local data sources and stakeholders about the local transgender community will be used to identify characteristics of transgender persons not responding to the survey. When a problem with response or recruitment arises during data collection, field staff will be instructed to consult with local stakeholders and members of the transgender community to identify solutions to the problem.

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). (“Waves” are defined as generations of recruits stemming from a seed, i.e., from recruitment efforts of the persons the seed directly recruited and from the recruitment efforts of those the seed’s recruits recruited, etc.) This stable sample composition is termed the “equilibrium.” Experience with RDS indicates that equilibrium can be achieved in approximately 6 waves. In the pilot data collection, the number of waves of recruitment varied (range: 6-9 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 insularity implies a greater number of waves to reach equilibrium. In the pilot data collection, racial homophily – which can also be described as the measure of persons’ preferences to recruit only those who are like themselves racially ranged from .1 to .8 (or 10 to 80%) across sites, meaning that 10 to 80% of the recruiters, recruited only persons of their same race or ethnicity, while the remaining percentage (90-20% across sites) recruited at random regardless of race. The pilot data collection was limited to only African American and Latino persons; the external consultants involved with data collection explained that these two racial and ethnic groups sometimes do not interact socially, which means that they would be less likely to recruit from the other racial group. Since the proposed data collection will not be limited to these two racial/ethnic groups, recruiters will be able to recruit from a wider, more racially diverse network and equilibrium may be reached sooner. The age homophily ranged from .1 to .5 (or 10-50%) across sites, which

means 10 to 50% across sites of the persons less than 30 years in age recruited persons of a similar age versus persons 30 years or older. Overall, the homophily estimates for the pilot are within the anticipated bounds reported in other studies using RDS methods. Having a diverse set of seeds (according to race/ethnicity and age) will help ensure diversity of networks which is expected to minimize the insularity of the sample.

With the RDS method, the sampling frame is initially the social networks of the seeds, with the social networks of successive waves of peer recruiters added. This frame can be described by information collected from participants regarding who recruited them and information about the sizes of recruiters' social networks. 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, as described above. The participant's social network size is defined as how many people they know who fit the eligibility criteria for the project. In the previously approved pilot data collection, the median social network size reported was 15 and the first and third quartiles were 6 and 30.

4. Test of Procedures or Methods to be Undertaken

The feasibility of using RDS methods to recruit transgender persons into a behavioral survey were examined using data from the previously approved pilot data collection. Overall, 97% of the 238 persons screened for eligibility were eligible; 99% of the 230 eligible agreed to participate. When using RDS methods, the number of interviews conducted each week should increase steadily over time. However, in the previously approved pilot data collection, recruitment did not steadily increase as expected in some of the participating sites. Homophily estimates for race and age were also reviewed and are presented above in section B3. This information was presented to the external consultants involved with the previously approved pilot data collection. Overall, RDS appeared feasible for recruiting transgender persons into the behavioral assessment. However, the methods needed to include more time to conduct additional formative research in the local transgender community prior to data collection to identify initial recruits and barriers to participation (e.g., field site location, unfamiliarity with the project in the community, insular demographic groups). The proposed data collection includes this change.

The data collection instruments were developed using questions from previous CDC surveillance projects, such as the Medical Monitoring Project (MMP) (OMB 0920-0740, exp. 5/31/2012) and the National Behavioral Surveillance System (OMB No. 0920-0770, exp. 03/31/2011). External consultants helped develop and refine the data collection instruments (See Table 8.A. in Supporting Statement, Part A for a list of consultants). In addition, questions from the eligibility screener and behavioral assessment used in the previously approved pilot data collection were evaluated by examining the number of respondents who either refused or reported not knowing the answer. Also in the previously approved pilot data collection, each respondent completing the behavioral assessment instrument was asked to provide feedback on the questionnaire. The questions for which at least 3 respondents either refused or reported not knowing the answer and the respondent feedback on the questionnaire were reviewed with external consultants who were involved in the pilot data collection. Changes were made in the instruments based on this review

(See **Attachment 9 and 10** for changes). Prior to implementation in the field, CDC staff will test the skip patterns and responses of the data collection instruments. CDC staff will also conduct mock interviews of their CDC colleagues using the electronic interview application loaded onto handheld computers.

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

Drs. Lillian Lin, Chris Johnson, Cyprian Wejnert, 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.

Grantees

State and local health departments are funded to conduct THBS through a cooperative agreement. Their role as a grantee is to collect the data. Data collected by the health department and its agents belong to that health department. The grantee is responsible for analyzing their data. After completing the data collection, the grantees will be debriefed by CDC to obtain input on improving future data collection.

When funds become available, funding for THBS will be provided through the cooperative agreement used to fund state and local health departments to conduct the National HIV Behavioral Surveillance system. Eligibility for submitting request for proposals in this cooperative agreement is 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 grantees will be determined depending on available funds, AIDS prevalence, and evaluation of the funding proposals.

CDC Project Staff

CDC is not directly engaged with collecting data from human subjects for THBS. However, CDC Project Staff below designed the data collection and will train health department staff in data collection methods, monitor the progress of recruitment by health department staff, as well as analyze the national data.

All CDC project staff can be reached at the following addresses and phone number:

Behavioral and Clinical Surveillance Branch
Division of HIV/AIDS Prevention
Centers for Disease Control and Prevention
1600 Clifton Rd, NE
MS E-46
Atlanta, GA 30333
Phone: (404) 639-2090

Kristina Bowles, MPH
Project officer
Email: KBowles@cdc.gov

Melissa Cribbin, MPH
Project officer
Email: MCribbin@cdc.gov

Paul Denning, MD, MPH
Project officer
Email: PDenning@cdc.gov

Elizabeth DiNenno, PhD
Project officer
Email: EDiNenno@cdc.gov

Rick Dulin
Public health analyst
Email: Rdulin@cdc.gov

Teresa Finlayson, MPH, PhD
Project officer
Email: TFinlayson@cdc.gov

Kathy Hageman, MPH
Project officer
Email: KHageman@cdc.gov

Nevin Krishna, MPH
Public health analyst
Email: HBX0@cdc.gov

Tricia Martin, MPH
Project officer
Email: THall1@cdc.gov

Isa Miles, MPH
Project officer
Email: IMiles@cdc.gov

Alexa Oster, MD
Project officer
Email: AOSter@cdc.gov

Catlainn Sionean, PhD
Project officer
Email: CSionean@cdc.gov

Amanda Smith, MPH
Project officer
Email: ASmith3@cdc.gov

References

- Abdul-Quader A, Heckathorn D, McKnight C et al. Effectiveness of respondent-driven sampling for recruiting drug users in New York City: Findings from a pilot study. *Journal of Urban Health* 2006; 83(3):459-476.
- Clements-Noelle, K., Marx, R., Guzman, R., & Katz, M. HIV prevalence, risk behaviors, health care use, and mental health status of transgender persons: Implications for public health interventions. *American Journal of Public Health* 2001, 91:915-921.
- Diaz RM, Ayala G, Bein E, Henne J, Marin BV. The impact of homophobia, poverty, and racism on the mental health of gay and bisexual Latino men: Findings from 3 US cities. *American Journal of Public Health* 2001; 91(6):927-932.
- Draus P, Siegal H, Carlson R, Falck R, Wang J. Cracking the cornfields: Recruiting illicit stimulant drug users in rural Ohio. *The Sociological Quarterly* 2005; 46:165-189.
- Halbert CH, Kumanyika S, Bowman M, Bellamy SL, Briggs V, Brown S, Bryant B, Delmont E, Johnson JC, Purnell J, Rogers R, and Weathers B. Participation Rates and representativeness of African Americans recruited to a health care program. *Health education research* 2010; 25(1):6-13.
- Heckathorn D. Respondent-driven sampling: a new approach to the study of hidden populations. *Social Problems* 1997; 44(2):174-199.
- Heckathorn D. Respondent-driven sampling II: Deriving valid population estimates from chain-referral samples of hidden populations. *Social Problems* 2002; 49(1):11-34.
- Heckathorn D, Semaan S, Broadhead R, Hughes, J. Extensions of respondent-driven sampling: a new approach to the study of injection drug users aged 18-25. *AIDS and Behavior* 2002; 6(1):55-67.
- Johnston LG, Sabin K, Mai Thu Hien, Phame Thi Houg. Assessment of respondent driven sampling for recruiting female sex workers in two Vietnamese cities: Reaching the unseen sex worker. *Journal of Urban Health* 2006; 83(7):i16-i28.
- Kulka R. The use of incentives to survey "hard to reach" respondents: a brief review of empirical research and current research practice. *Seminar on New Directions in Statistical Methodology*, 1995 #23, 256-289. 1995. FCSM Statistical Policy Working Papers.
- Magnani R, Sabin K, Saidel T, Heckathorn D. Review of sampling hard-to-reach and hidden populations for HIV surveillance. *AIDS* 2005; 19(Suppl 2):S67-S72.

- Mansergh G, Naorat S, Jommaroeng R et al. Adaptation of venue-day-time sampling in Southeast Asia to access men who have sex with men for HIV assessment in Bangkok. *Field Methods* 2006; 18(2):135-152.
- McFarland W, Caceres C. HIV surveillance among men who have sex with men. *AIDS* 2001; 15(Supplement 3):S23-S32.
- MacKellar D, Valleroy L, Karon J, Lemp G, and Janssen, R. The Young Men's Survey: Methods for Estimating HIV Seroprevalence and Risk Factors Among Young Men Who have Sex with Men. *Public Health Reports* 1996; 3 (Suppl 1): 139-144.
- MacKellar DA, Gallagher KM, Finlayson T, Sanchez T, Lansky A, Sullivan P. Surveillance of HIV Risk and Prevention Behaviors of Men who have sex with men -- A national application of venue-based, time-space sampling. *Public Health Reports* 2005; 122 (Suppl 1): 39-47.
- Ramirez-Valles J, Heckathorn D, Vazquez R, Diaz RM, Carlson R. From networks to populations: The development and application of respondent-driven sampling among IDUs and Latino gay men. *AIDS and Behavior* 2005; 9(4):387-402.
- Salganik M. Variance estimation, design effects, and sample size calculations for respondent-driven sampling. *Journal of Urban Health* 2006; 83:98-111.
- Semaan S, Lauby J, Liebman J. Street and network sampling in evaluation studies of HIV risk-reduction interventions. *AIDS Reviews* 2002; 4:213-223.
- Stormer A, Tun W, Guli L et al. An analysis of respondent driven sampling with injection drug users (IDU) in Albania and the Russian Federation. *Journal of Urban Health* 2006; 83(7):i73-i82.
- Thiede H, Romero M, Bordelon K, Hagan H, Murrill CS. Using a jail-based survey to monitor HIV and risk behaviors among Seattle area injection drug users. *Journal of Urban Health*. 2001; 78(2):264-78.
- Wang J, Carlson R, Falck R, Siegal H, Rahman A, Li L. Respondent-driven sampling to recruit MDMA users: a methodological assessment. *Drug and Alcohol Dependence* 2005; 78(5):147-157.
- Whiteman MK, Langenberg P, Kjerulff K, McCarter R, Flaws JA. A randomized trial of incentives to improve response rates to a mailed women's health questionnaire. *Journal of Women's Health*. 2003; 12(8):821-8.
- Yancy AK, Ortega AN, Kumanyika SK. Effective recruitment and retention of minority research participants. *Annual Review of Public Health* 2006; 27:1-28.

Yeka W, Maibani-Michie G, Prybylski D, Colby D. Application of respondent driven sampling to collect baseline data on FSWs and MSM for HIV risk reduction interventions in two urban centres in Papua New Guinea. *Journal of Urban Health* 2006; 83(7):i60-i72.