**Barriers and Facilitators to Expanding the NHBS to Conduct HIV Behavioral Surveillance Among Transgender Women (NHBS-Trans)**

**#0920-NEW**

NEW Information Collection Request

**Section B: Supporting Statement**

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## 1. Respondent Universe and Sampling Methods

NHBS-Trans is a pilot study intended to assess the feasibility of a survey and supporting data collection methodologies to obtain data on HIV risk behaviors, gaps and barriers to services, and other experiences of transgender (TG) women within racial and ethnic minority populations in 9 U.S. cities with high burden of HIV. Grantees funded to participate in the National HIV Behavioral Surveillance System (NHBS, OMB# 0920-0770, exp. 5/31/2020) applied to participate in the NHBS-Trans pilot study. Application were ranked and 7 were selected for funding.

- Atlanta, GA (grantee: Georgia Department of Public Health)
- Los Angeles, CA (grantee: Los Angeles County Department of Health)
- San Francisco, CA (grantee: San Francisco Department of Public Health)
- New Orleans, LA (grantee: Louisiana Office of Public Health)
- New York City, NY (grantee: New York City Department of Health and Mental Hygiene)
- Seattle, WA (grantee: Washington State Department of Health)
- Philadelphia, PA (grantee: Philadelphia Department of Public Health)

Two additional NHBS grantees will participate in this project as self-funded sites.

- Dallas, TX
- Washington, D.C.

NHBS-Trans is not intended to yield representative data about transgender women, but may provide data about best practices for sampling transgender women across multiple cities.

Over two years, staff in health departments participating in NHBS will implement respondent-driven sampling (RDS) to recruit until they meet their quota of 200 participants meeting the inclusion criteria listed below. Through an informed consent process, selected persons will be asked to participate in an interview. After completing the interview, respondents will be offered free HIV and STD testing.

### Selection of Respondents

#### *Participant inclusion criteria*

A screening interview will be used to assess whether each respondent meets inclusion criteria. Respondents are eligible to complete the NHBS-Trans interview if they:

- Present a valid NHBS-Trans coupon
- Have not previously participated in NHBS-Trans
- Live in the participating MSA or Division
- Are 18 years of age or older*
- Identify as a woman, identify as a transgender woman, or identify as anything other than exclusively male/man
- Were listed as male sex at birth, or listed as Intersex/ambiguous sex at birth

and

- Are able to complete the interview in English or Spanish

*NHBS is a surveillance system of the HIV risk behaviors of adults in the United States, and the methods are designed to recruit an adult population (OMB# 0920-0770, exp. 5/31/2020). Surveillance systems, such as the Youth Risk Behavior Surveillance System (YRBSS) are more appropriate to understand the risk behaviors of minors in the United States.

Expected response rates

A benefit of the peer-driven sampling conducted in RDS (Heckathorn, 2002; Johnston, Sabin, Hien & Houng 2006; Ramirez-Valles, Heckathorn, Vazquez, Diaz & Carlson, 2005; Stormer, Tun & Guli et al. 2006; Wang, Carlson, Falck, Siegal & Li, 2004; Yeka, Maibani-Michie, Karon, Lemp & Janssen, 2006) is that recruiters are told, generally speaking, what the eligibility criteria are in order that they can recruit eligible participants. For this reason, RDS response rates for the NHBS-Trans project are expected to be approximately 90%. Results from NHBS focused on other populations to date support this expected response rate (OMB# 0920-0770, exp. 5/31/2020). Further details and calculations are provided in Table B2 below:

Table B2: Expected Response Rates and Sample Size over Two Years of Data Collection, NHBS*

| | **Transgender Cycle** | | |
|---|---|---|---|
| | **Screened** | **Participants** | **Recruiters** |
| TOTAL | 1,980 | 1,800 | 1,800 |
| | | | |
| Hispanic | 594 | 540 | 540 |
| Black | 990 | 900 | 900 |

| | | | |
|---|---|---|---|
| White | 198 | 180 | 180 |
| Other | 198 | 180 | 180 |
| | | | |
| Transgender Women | 1,800 | 1,800 | 1,800 |
| Not Transgender Women | 180 | 0 | 0 |
| | | | |
| 18–34 years of age | 396 | 360 | 360 |
| 35 years and older | 1,584 | 1,440 | 1,440 |

* Based on experience from NHBS, participation rates tend not to differ across race, age and gender categories. Therefore, the expected numbers of participants by race, age, and gender have the same frequency distribution as the numbers screened by race, age, and gender.

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

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 12**) indicates that because NHBS-Trans is ”non-research,” the protocol will not be reviewed by CDC’s IRB. Each participating health department will be required to obtain approval for this project from their IRB as required by their local review and approval processes and federal regulations before data collection.

Respondent driven sampling (RDS) will be used to recruit participants. Persons who receive a coupon (developed locally) to participate in NHBS-Trans will be asked to make an appointment to participate in the interview; walk-in hours are usually available (determined locally). When a potential respondent comes to the field site, their coupon is assessed to ensure it is valid, using the Coupon Manager application described in Section A3. After the coupon is validated, the potential respondent is invited to be screened for eligibility; the informed consent process will be initiated with eligible persons. During the consent process, each component of the project is described and the eligible person must indicate which component(s), if any, they agree to participate in. These include: 1) participating in the NHBS-Trans interview; 2) HIV testing; 3) other diagnostic testing (offered in some but not all MSAs); and 4) storing leftover serum. Informed

consent will be obtained by having the interviewer read the consent script and indicating on the portable computer whether the person being recruited provided verbal consent. After consent is obtained, the interview will be conducted; testing will be performed for those who consent, after the interview has been completed. Persons recruited may elect to participate in the interview and not to participate in the testing. Persons who refuse the interview will not be offered HIV or other diagnostic testing. Persons who present to the field staff at the office without a valid coupon will not be allowed to participate, but those who want to receive an HIV test will be accommodated as resources allow.

After the NHBS-Trans interview and testing are completed, the interviewer asks the participant if they would be willing to recruit other participants, an activity for which a small incentive (approximately $10; see Section A9) will be given. After a brief training on the recruitment process, those who agree to recruit their peers are given up to 5 coded, non-replicable coupons. The participant is told to give one coupon to each of between 1 - 5 peers (determined locally) meeting the eligibility criteria. Each coupon has the local NHBS project name and location(s) printed on it with a brief explanation of the project. The code on the coupon is 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 application. After receiving coupons and recruiter training, the participant is provided the incentive and given instructions about returning for an additional incentive after distributing a coupon(s).

When a participant returns for her incentive, she will be asked questions to determine how many coupons were distributed, if anyone refused the coupons, the race or ethnicity of the persons refusing coupons, and the reasons for refusal. This information will be stored in a password-protected database kept separate from, but linked to the eligibility screener and interview data by the survey ID. Race and ethnicity are commonly associated with many health outcomes in the U.S. Understanding if there are systematic patterns in coupon refusal provides information about potential bias and nonresponse in the sampling process.

Mechanisms for returning test results to participants are determined locally; if necessary follow-up appointments are set before the participant leaves the field site or field office location.

Persons who consent to participate in the interview will be administered a structured questionnaire. The questionnaire collects self-reported demographics, sexual behavior, drug use, HIV testing

history, sexually transmitted infection diagnosis, and exposure and access to HIV prevention services from all respondents. The interview instrument will be programmed into QDS and will be administered face-to-face using portable computers.

The portable computers for data collection and laptop computers for use with Coupon Manager and for data storage after each recruitment event will be password protected and the data on them will be encrypted using standard, 128-bit encryption software. No personal identifiers will be collected or included with responses to the interview. The interview is expected to take approximately 40 minutes for the Transgender cycle (excluding eligibility screening).

Respondents will receive HIV prevention materials after the interview and referrals to local HIV prevention and care services, if requested.

Quality Control

Data quality is ensured by the 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 the routing 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 with fewer errors.

A multi-day interviewer training will occur before the start of data collection. This training covers general interviewing skills, sampling and recruitment protocols, and a question-by-question review of the questionnaire to ensure interviewers understand the purpose of each question and how it should be read and coded in the portable computer. Interviewers have opportunities to practice administering the questionnaire during the training. The training also addresses interviewer integrity, underscoring the importance of collecting quality data and the consequences of inappropriate behaviors, including falsification of data. Project staff are also trained on how to conduct recruitment procedures, such as approaching participants and training participants to recruit their peers into the study.

During the data collection period, interviewers are monitored by the field supervisors or other management staff. Approximately 10% of each interviewer’s interviews are monitored. Feedback is provided for areas of improvement and in cases of incorrect implementation of the

protocol. Monitoring of respondent-driven sampling also includes recruitment procedures. Supervisors provide feedback on ways to help improve response rates.

In addition to the automated checks provided through the computer-assisted interview program, editing of the data is performed by CDC following extensive checking of the quality of the data files. Monthly processing allows for identification of errors in the data sets (such as incorrect identification codes or in correct coding of other critical data elements) or incorrect local data management procedures. CDC regularly convenes conference calls with the project areas and the CDC contractor to address any issues with the data collection application and discuss administration of the interview specifically and the project in general.

NHBS-Trans interview instruments will not collect specific identifiers (e.g., name, address, social security number). Data are collected electronically; no paper instruments are used to collect data.

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

Response Rate Calculations

*Respondent-driven sampling*

Previous studies using RDS find that one-half to two-thirds of persons recruited by their peers will present for eligibility screening (Heckathorn, 2002; Johnston, Sabin, Hien & Houng 2006; Ramirez-Valles, Heckathorn, Vazquez, Diaz & Carlson, 2005; Stormer, Tun & Guli et al. 2006; Wang, Carlson, Falck, Siegal & Li, 2005; Yeka, Maibani-Michie, Karon, Lemp & Janssen, 2006). 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 et al., 2005). In addition, response rates among those found eligible are 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 participating in the interview will not make the effort to come to the field office with the coupon.

The peer-referral sampling methods that will be used for NHBS-Trans were developed precisely to reach hard-to-reach populations for which a sampling frame does not exist, and the expected response rates for NHBS-Trans are within the range of those achieved in other studies using these non-probability sampling methods (MacKellar, Valleroy, Karon, Lemp & Janssen 1996; Thiede, Romero, Bordelon, Hagan & Murril, 2001).

Methods to maximize response rates

Response rates for NHBS-Trans may be adversely affected by the anonymous nature of the survey (no follow-up contacts by project staff are possible) and the sensitive nature of the questions. However, monitoring of response rates will be done through conference calls on a weekly basis with each project area and monthly with all project areas together, offering the opportunity to share strategies for improving response rates. Recruitment statistics and sample demographics will be reported to CDC on a weekly and monthly basis, respectively.

Research indicates that providing a incentive to respondents helps raise response rates for sensitive, in-person surveys (Kulka, 1995). A incentive 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 recruited for NHBS-Trans (Thiede et al., 2001; MacKellar et al., 1996). Research has shown that financial tokens of appreciation are effective at increasing response rates among female residents in minority zip codes (Whiteman, Langenberg, Kjerulff, McCarter & Flaws, 2003) and among African American participants in a community-based health promotion program (Halberti, Kumanyika & Bowman 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 tokens of appreciation enhanced retention among this group (Yancy, Ortega & Kumanyika, 2006). Providing a incentive to NHBS-Trans respondents is critical to achieve acceptable response rates.

Incentives have been shown to be effective for promoting participation and reducing nonresponse in similar data collections that involve hidden populations or collect sensitive information. Specifically, incentives are used in CDC’s National HIV Behavioral Surveillance (NHBS)(OMB 0920-0770, exp. 5/31/2020) which collects highly sensitive information from three at risk populations- men who have sex with men, persons who inject drugs, and heterosexuals at high risk for HIV. The current data collection utilizes the NHBS infrastructure, including sampling methods and questionnaire, applied to a different high-risk population – transgender women. A previous data collection, using similar methods, focused on transgender women (Transgender HIV Behavioral Survey (OMB 0920-0794 exp. 12/31/2010) also utilized incentives. Finally, the Medical Monitoring Project (OMB 0920-0740, exp. 6/30/2021), which collects sensitive information from HIV-positive persons, also utilizes incentives to reduce nonresponse. Further information on the need for incentives in data collections focused on high populations or collecting sensitive information is provided in sectionA.1.

*Respondent-driven sampling*

Because RDS is a peer-referral mechanism, the field staff has little control over sampling methods and sample accrual, other than through the recruitment of seeds. One advantage of RDS, however, is that peer referral, which implies endorsement or at least acceptance of the project by a peer, is likely to have a positive impact on response rates. To maximize the effectiveness of peer recruiting, training is provided to recruiters. Peer recruiters may help improve response rates by providing credibility and legitimacy for the project in the target population. In addition, persons recruited by a peer may be more willing to participate than if they had been recruited by someone unknown to them. In this anonymous survey in which multiple contacts by staff to boost response rates are not possible, peer recruiters are not so constrained (because they are recruiting persons known to them) and are able to follow up with those they have referred to the project to provide reminders to participate. The incentive provision structure (i.e., providing additional incentives to recruiters when they successfully recruit an eligible participant) 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 NHBS-Trans, 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 population. The field staff will also obtain input on the logistics of data collection from local stakeholders and members of the local transgender community. This input will help the local staff identify the most appropriate hours of operation for the field sites and avoid barriers to participation of persons in the data collection. This information may be of use to future projects seeking to access this population.

<u>Assessing Non-Response Bias</u>

The use of an eligibility screener will allow comparison of the demographic and eligibility-related behavioral data among 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 whether anyone refused a coupon (invitation to participate), why they refused, and the race/ethnicity of those who refused. This information will be collected using a laptop computer. Following up with recruiters has improved rates of participation in other studies implementing RDS

(Draus, Siegal, Carlson, Falck & Wang, 2005; Ramirez-Valles et al., 2005). However, due to the anonymous nature of NHBS-Trans, participants cannot be re-contacted by field staff. Nor can field staff initiate contact to encourage peer recruiters to distribute coupons or to ask the recruiters to report on refusals. However, when an NHBS peer recruiter initiates contact with project staff, such as when a peer recruiter returns to the field site for incentives, 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 incentives as described above. This information will be used to understand if certain racial (or ethnic) 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. For NHBS-Trans, in which respondent-driven sampling will be used, reports will monitor the seed recruitment, the characteristics of seeds, general recruitment (i.e., participation rate among seeds and non-seeds who present for screening and are eligible), the characteristics of the resulting sample, the number and length of recruitment chains, the number of recruiters who returned for incentives, 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 at-risk populations will be used to identify subgroups of the target population whom the data collection may be missing. 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 local target populations to identify solutions to the problem.

Generalizability

Data collected during NHBS-Trans are for pilot testing and evaluation purposes. The data may not be generalizable to any broader population.

**4. Tests of Procedures or Methods to be Undertaken**

The data collection instruments were developed using questions from previous CDC surveillance projects, such as the Medical Monitoring Project (MMP) (OMB 0920-0740, exp. 6/30/2021), the Transgender

Behavioral Surveillance System (OMB No. 0920-0794, exp. 12/31/2010) the Behavioral Assessment and Rapid Testing project (BART) (OMB No. 0920-0883, exp. 4/30/2014), and the National HIV Behavioral Surveillance System (NHBS, OMB No. 0920-0770, exp. 5/31/2020). External consultants helped develop and refine the specific RDS methods. NHBS has used many questions included in the eligibility screener and interview instruments since 2008.

The NHBS core instrument was reviewed by external contractors with Transgender survey design expertise. The contractor conducted a literature review to identify all Transgender specific surveys or survey items. All identified, publically available items were considered for inclusion based on expert review and relevance to HIV. A community advisory board (CAB) made up of less than 9 national Transgender experts representing all regions of the U.S. provided feedback on the items and content. New and potentially challenging items were cognitively tested by 8 Transgender women recruited from 3 U.S. cities. All persons gave positive feedback about the survey, voicing their appreciation that this population is being researched. Some participants expressed embarrassment regarding the more personal and sensitive questions regarding the number of sex partners. In the final survey instrument, it is reiterated that participants do not have to answer any questions that make them feel uncomfortable. Overall, participants were well-versed in issues related to the transgender community, and were able to understand the various types of gender identity, sexual identity, and sexual intercourse definitions referenced throughout the survey. The hidden stigmatized nature of Transgender women prevented recruitment of more participants for the CAB and cognitive testing. Identities of CAB and cognitive testing participants were intentionally withheld from with CDC. The consultants suggested modifications to the standard NHBS survey to increase the acceptability of the survey with this population, as well as additional sections and questions from other surveys designed to capture experiences unique to transgender lives. The report describing the methodology, findings and recommendations of the consultants are included in this package (**Attachment 8)**.

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 portable computers. OMB will be informed of any changes to data collection procedures or instruments as quickly as possible.

For a cross-walk of NHBS-Trans project aims and variables, see **Attachment 14**.

**5. Individuals Consulted on Statistical Aspects**

Consultants on Statistical Aspects

The following individuals consulted on statistical aspects only. They are not involved in collecting or analyzing the data

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**Individuals Collecting and/or Analyzing Data**

CDC is not directly engaged with human subjects during data collection. However, CDC Project Staff below will train health department staff in data collection methods, monitor the progress of recruitment by health department staff, and analyze the data.

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

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