# RECOMMENDATIONS FOR REVISING THE NATIONAL HIV BEHAVIORAL SURVEILLANCE CORE RESEARCH QUESTIONNAIRE FOR USE IN A FUTURE STUDY WITH TRANSGENDER WOMEN

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## EXECUTIVE SUMMARY

That National HIV Behavioral Surveillance System (NHBS) currently conducts HIV behavioral surveillance among men who have sex with men, heterosexual persons at risk of HIV infection, and people who inject drugs.[1] NHBS data are used to monitor key indicators of HIV-related risk and prevention among populations at highest risk for HIV infection.[2] CDC is anticipating the addition of another NHBS project to measure HIV-related risk and prevention behaviors among transgender women (currently denoted as NHBS-Trans). CDC has identified a need to re-develop the NHBS core questionnaire to be most appropriate for administration to transgender women.[3] We undertook a multi-phase structured survey development process to meet this need.

In the first step we worked with CDC to identify foundational principals for NHBS-Trans survey development. This process included things such as optimal survey length, relevance of topics and item design best-practices. In the second step, we worked with CDC to develop a list of initial survey domains and constructs for NHBS-Trans. We then used this information in the third step to help us focus a literature review to identify all recent publications on transgender health issues. The primary purpose of this literature review was to identify survey instruments that we could acquire and examine for suitability of items for the NHBS-Trans questionnaire. The literature review resulted in identification and collection of 170 articles and 24 individual survey instruments. These were entered into a survey item database that contained 4,256 individual survey items with detailed information (e.g., question and response wording, domain/construct, source) on each item. In the fourth step, we reviewed every item in the database, identified preferred items, and drafted survey concepts within each survey domain. These survey concepts were then reviewed by a group of 9 community advisers at 2 separate 2-hour meetings and changes/additions were incorporated into our recommendations. In the fifth step, we conducted 9 cognitive interviews of some of the newly proposed survey items with transpersons (8 transwomen and 1 transman) in 3 cities – Atlanta, San Francisco and Washington DC. The feedback from these cognitive interviews resulted in a set of proposed modifications, which were also reviewed by the community advisers at one final 2-hour meeting.

The outcomes of this process resulted in several overall recommendations regarding the NHBS-Trans survey and a full set of specific recommendations on each survey item. Our recommendation is that the NHBS-Trans survey be no greater than an average time of 1 hour. We believe this survey length is feasible to implement in the types of field sites that NHBS would likely be using for a future NHBS-Trans study. The survey should maintain as many questions from the NHBS CRQ as is feasible while addressing the specific needs for a survey with transwomen and keeping question/response option modification as minimal as necessary to address this need. Our first round of specific recommendations resulted in 295 NHBS items being kept without modification. Most of these items are in the demographics, HIV testing and care, substance use and HIV prevention domains. We also recommended keeping an additional 30 NHBS items with modifications made to better address the NHBS-Trans survey population. We recommended an additional 136 survey items for NHBS-Trans in several domains, some of which are domains with substantial modifications to items from those used in NHBS (gender identity, homelessness, sexual behavior, stigma, depression) and several that are new to NHBS (social support, medical gender

affirmation, injection of other substances, discrimination, abuse and harassment, and suicidality). Our initial recommendation included a total of 136 new items, 105 of which have been used in other studies.

The CDC reviewed our initial recommendations and returned feedback that included final decisions on items they wanted to drop and add. An in-person meeting was scheduled to discuss the sex behavior items in further detail. Our initial recommendation was to do partner by partner (PxP) loops for up to five partners. The CDC had concerns this method would take too long. Their final decision was to keep the five partner loops, but reduce the number of questions asked about each partner. Final sex behavior questions were sent by the CDC and incorporated into our second round of specific change recommendations. After receiving final CDC feedback, our final set of change recommendations includes 242 NHBS items being kept without modification, 22 NHBS items with modifications to better address the transgender population, and 144 new items.

## METHODOLOGY

### *Foundational Principles for NHBS Survey Design*

The NHBS-Trans survey recommendations are made using several foundational principles for NHBS survey designs. Overall survey length should be as short as possible to reduce participant burden and enable efficient implementation at field sites. Because there may be the need for more survey constructs to address unique physical, social and psychological issues for transgender women, it was determined that an average survey length of 45 to 60 minutes would be preferable. Where feasible, questions should exactly match or be comparable to other NHBS surveys to allow for future comparison analyses. Where new questions are recommended, the priority should be on using validated measures with transgender populations or measures that they have been previously used in other surveys of transgender persons. New survey items should also be relevant to HIV behavioral surveillance, either as direct measures of HIV risk or prevention or as likely correlates to those outcomes. Survey items should have clear timeframe delineation. Typical timeframes for NHBS are ever, in past X number of months/weeks, at last event, or current. Surveys are intended to be administered by a staff interviewer and should be designed to be spoken aloud. Surveys will be administered through computer assisted interview technology and should incorporate skip patterns to reduce interviewer/participant burden and improve data quality. Finally, all survey content should be written in plain language, explain terms where needed, use limited jargon, and be respectful of transgender participants.

### *Creation of Desired Survey Domains and Constructs*

We employed a multiple step process to create the desired survey domains and constructs that would be used as the framework for the NHBS-Trans survey design process. We first collected the survey constructs and measures from the current NHBS CRQ. We reviewed this list to determine which constructs would be kept in their entirety, which would likely require modification and which could be dropped for NHBS-Trans. During that review process, we also identified new domains and constructs that we believed were relevant to NHBS-Trans. Because of the constraints on survey length, we

also identified priority levels (1 to 3 with 1 being highest) for each construct. Those with the lowest priority would likely have either fewer items or could potentially not be included in the final recommendation. The resultant master list of desired survey domains and constructs was used during the literature and instrument review in the next 2 steps (Appendix A).

### *Literature Review and Instrument Acquisition*

We conducted an exhaustive literature review to identify survey tools that have been used in studies that included transgender individuals. As a starting point for the literature review we were provided with a draft of a systematic review table from Reisner et al. submitted to the journal, The Lancet.[4] We obtained the search strategies used to identify the articles included in the Reisener evidence table and replicated these search strategies to identify any new articles that had been published since the original search was performed or articles describing a study of transgender individuals that may contain a survey instrument but that may not have met the inclusion criteria utilized by Reisner. We identified 170 relevant articles including all 116 of the articles listed in the evidence table provided by Reisner et al. plus an additional 54 articles that were not included in the evidence table. Full-length copies of all of the articles identified by our searches were obtained. Each retrieved full-length article was examined in order to identify all survey instruments that were used in the study the article described. We were able to obtain contact information for 82 unique corresponding authors and were able to retrieve 24 survey instruments. To this group of surveys obtained from the literature review, we added 3 additional surveys obtained from researchers who were conducting transgender studies/research but had not net published their findings. Every survey item on all surveys were entered into an MS-Access database to assist in review of the 4,256 individual survey items. This database allowed us to organize/search survey items by domain, construct and source. Every survey domain and construct from the desired list was represented in the surveys we were able to collect.

### *First Pass Instrument Review*

We next reviewed every survey item within each desired domain-construct and made a first pass determination of the item's relevance and suitability for further consideration. Each item reviewed was given a qualitative score: irrelevant (to NHBS-Trans survey purposes), reject (relevant but unsuitable for NHBS-Trans), modify (relevant and suitable but would require substantial modification), consider (relevant and suitable with little modification needed), or favorite (relevant, suitable and requires no/minimal modification). After this process, every survey domain and construct from the desired list was still represented in the modify, consider or favorite categories with most constructs having items in the favorite category. The one important domain that did not have favorite constructs/items was sexual behavior. The retrieved surveys used older sexual behavior constructs, many only assessing cumulative behaviors over a time period. None were able to provide the details of the current NHBS survey or were able to address the gender identity of sex partners in a way that was desired for NHBS-Trans. To address this issue, we examined another CDC survey that has implemented a partner-specific set of sexual behavior questions since 2014, the Medical Monitoring Project (MMP).[5] These

questions are administered to persons living with an HIV diagnosis, including transgender persons. Only the sexual behavior questions from MMP were considered.

***Draft Domain, Construct and Item Creation***

The desired domain and construct list was further refined based on availability of items, potential organization of constructs and estimates of survey length given the items available. For each of the desired domains and constructs we developed a questionnaire diagram/flowchart (Appendix B shows an example). This process involved reviewing the question database and the individual instruments to determine not only the desired constructs, but also their placement in the survey flow. These diagrams were then used to build the survey one domain-construct at a time using items from the database with favorite items being used preferentially and modifications to the items being made as each construct was built. Skip logic within or between constructs was also added during this process. Draft survey domains (with items, sources, modification notes, and skip logic notes) were produced for review by our community advisers (Appendix C shows an example).

***Community Advisor Input***

To ensure that the NHBS Questionnaire is sensitive to the diverse circumstances of male-to-female transgender persons (transwomen or transgender women), we assembled a group of 9 advisers – all were professionals with experience in either community organizations or healthcare for transgender persons; 8 identified as transgender; 1 was a cisgender healthcare provider for young transwomen in an NHBS city; 5 were persons of color; 8 resided in NHBS cities across all US regions; and 1 resided in another large Southern US city. Advisers met 4 times for a 2-hour web-enabled conference. We provided materials in advance of the meetings, and moderated a review and discussion of those materials. There were multiple people taking detailed notes during the call that were collated into meeting summaries. The meeting dates and content covered for each are as follows:

Meeting 1 – 1 April 2016 – Introductions, Vision and Review Survey Domains
- Introductions and Review of NHBS-Trans Survey Development Process
- NHBS Overview and Vision for Future NHBS-Trans Survey
- Review of Proposed Domains and Constructs

Meeting 2 – 19 May 2016 – Review Survey Drafts
- Gender Identity
- Medical Gender Affirmation

Meeting 3 – 26 May 2016 – Review Survey Drafts
- Sexual Behavior
- Social Support
- Stigma and Discrimination
- Mental Health
- Housing and Incarceration

Meeting 4 – 28 July 2016 – Review Cognitive Interview Findings
- Gender Identity
- Medical Gender Affirmation
- Sexual Behavior
- Stigma and Discrimination
- Social Support

***Cognitive Interviews***

A total of nine cognitive interviews were conducted at three sites, with three interviews conducted per site. The interviews were conducted in Atlanta on June 30th, San Francisco on July 6th, and Washington DC on July 22nd. Participants were recruited through local community organizations (Atlanta and San Francisco) or a primary healthcare center (Washington DC). Interested participants were screened to confirm eligibility. Appointments were set for an individual in-person interview which lasted between 1 and 1.5 hours each. The following were characteristics of the participants in the cognitive interviews:

- 8 transwomen and 1 transman
- All identified as Black or African American
- None identified as Hispanic/Latino/Latina
- All reported earning less than $20,000 annually
    - 6 reported earning less than $5,000 annually
- Participants ranged from 28 to 55 years of age

The cognitive interviews involved a subset of the proposed survey domains and constructs. These were selected based on adviser feedback regarding potential comprehension concerns or our desire to more thoroughly examine item wording, comprehension and response. Cognitive interviews were conducted using a paper version of the proposed survey items with instructions and skip patterns clearly noted. The interviewer administered the entire survey first, only answering a few clarifying questions. The interviewer then went back through the interview with the participant reviewing question and response comprehension using a set of pre-determined probes to guide the interview (Appendix D shows and example section of the interview guide). Interviews were audio-recorded and the interviewer and another staff person were taking notes. The audio-recordings were only used to verify or add to notes, were not transcribed, and will be destroyed when this project is complete. The cognitive interview protocol was approved by the Emory Institutional Review Board (Protocol #IRB00089644 – Travis Sanchez, PI).

**SUMMARY OF COMMUNITY ADVISER FEEDBACK**

During review of the survey development procedure and proposed domains/constructs, the advisers provided the following feedback. Advisers supported the use of the NHBS-Trans term for internal references to the study. During discussion of survey domains and constructs the advisers requested that we add questions related to migration to large

urban centers for trans-related reasons such as safety or accessing better health services. These questions are being proposed as part of the demographics domain. Advisers also specifically requested that intersex condition be considered in developing survey constructs. Intersex was added as a gender identity, as a birth gender and as a diagnosed medical condition. Advisers wanted to ensure that we were including all transwomen, even those who may not identify as such. This was particularly true for those who identify as women or some other gender. The proposed gender identity and birth sex questions address this issue for survey eligibility. Advisers suggested that the survey be implemented in English and Spanish since some cities have substantial populations of Hispanic/LatinX transwomen. Advisers suggested having constructs related to meeting of basic needs such as food and shelter. We propose an expanded section on homelessness and have added 2 questions on food insecurity. Advisers recommended that mental health and suicidality be higher priority for survey creation. We are recommending that those domains be included and that the depression index be expanded to the CESD-10 from the one currently in use by NHBS (K-6). Advisers recommended that we try to balance the survey domains with more positively-framed constructs such as wellbeing and support. We recommended a construct measuring social support.

During review of survey drafts, advisers provided the following feedback. Advisers recommended that we make the gender identity question a choose all that apply. There was also discussion of who should be eligible for the study based on gender identity, birth sex and intersex diagnosis. It was recommended that we focus study eligibility on those who are transwomen identified or are female identified but not female at birth. Though this may miss some sub-populations of transwomen who only identify as some other gender, that group may be small. The age of gender identity development was first proposed as multiple items, but through adviser feedback and cognitive interviewing was refined to just one item regarding age at which a participant felt that their sense of gender didn't match their body or appearance. Though this concept of "match" or "didn't match" was recommended for this question and the introduction to the medical gender affirmation questions, it was not recommended for use throughout the medical gender affirmation questions as was originally proposed. Instead, the advisers preferred to refer to these treatments as being "used for gender transition or affirmation" more generally. Advisers had few other comments on the medical gender affirmation domain/constructs, mostly related to the types of hormones commonly used and sources for hormones and needles. Advisers suggested wording changes and less focus on silicone injection for the other injected substances section that were incorporated into our recommendations. For the sexual behavior questions, advisers were mainly concerned with being able to adequately capture whether exchange sex had occurred and the contexts around exchange sex. They recommended that a total number of sex partners be added for the 12 month period as a large number of sex partners could be a proxy for exchange sex (in addition to the partner-specific questions). Advisers recommended that we simplify the social support questions by reducing the number of groups we ask about. They also were concerned regarding the original (and cognitively tested) question set that asked about anticipated future support from those who had not yet been disclosed to. Advisers recommended (after cognitive testing results were shared) that we provide a larger scope/definition for the social support construct, suggesting that we include terms such

as “accepting” in our definition. In the original reviewed survey constructs, we included multiple questions that were attempting to attribute discrimination or mental health outcomes to being transgender. These proposed constructs produced substantial discussion from advisers regarding the proper wording and the types of attribution. We are recommending that we only include structural level discrimination on NHBS-Trans as these measures are likely more objective and may be more related to accessibility of services – these would be specific experiences of discrimination related to homeless shelters, housing, employment, healthcare, restrooms, and other public accommodations.

## SUMMARY OF COGNITIVE INTERVIEW FEEDBACK

All participants gave positive feedback about the survey, voicing their appreciation that this topic is being researched. Some participants expressed embarrassment regarding the more personal and sensitive questions regarding the number of sex partners. We found that these concerns could be addressed by assuring the participants that they did not have to answer any questions that made them feel uncomfortable. Overall, we found that the participants were well-versed in issues related to the transgender community, and for the most part were able to understand the various types of gender identity, sexual identity, and sexual intercourse definitions referenced throughout the survey. It is important to note, however, that this may be a product of our sample, which was recruited via advocacy organizations in the three cities.

With regard to the survey as a whole, the cognitive interviews provided a number of important insights. Each interview lasted about 45 minutes, meaning that with the additional material that was not tested in this round of interviewing, the full survey will be quite long. Based on this, we recommend that the survey be trimmed wherever it is possible to do so without loss of understanding or quality. In addition, some participants had difficultly comprehending some of the more complex questions, so we suggest to edit these by simplifying the wording and even providing definitions for some of the more technical terms used. Finally, transitions between topics in the current version are rather abrupt and may benefit from some added text to aid the flow of the interview.

*Gender Identity*

During the screening and interview processes, we encountered significant misunderstanding of the question regarding a diagnosis of a “medically recognized intersex condition,” which some participants interpreted as being diagnosed with a sexually transmitted disease. In addition to this confusion, the inclusion of a question about intersex diagnosis in the eligibility criteria allowed a transman to be screened into the survey. Based on this, if included in the final survey, any questions including the term “intersex” may require additional explanation.

*Age of Gender Identity*

The two questions regarding the age at which participants first became aware of their gender identity raised some concerns. Question 7 asks about the age at which “you first became aware that how you felt about your gender was different from what others expected” (focusing on awareness of the mismatch between the social expectation for their gender vs. how they felt about it) while Question 8 asks about the age at which “you first became aware that your own sense of your gender did not match your body or physical appearance” (focusing on the mismatch between the physical appearance of

their body vs. sense of their gender). Some participants gave the same age for the two questions, suggesting some difficulty in understanding the difference in the intent of the two questions. Most participants were able to understand the intent of Question 8 more readily than the intent for Question 7. CDC may consider combining the two questions, or only asking one of the two questions.

*Gender Identity on Official Records*

Findings from the cognitive interviews point to the need for some clarification about the meaning of having official records "match your gender identity." Participants expressed some confusion and gave differing answers based on whether they interpreted this to mean having a name listed that matched their gender identity, having the gender marker (M/F) match this, or even having their picture reflect their current appearance.

*Medical Gender Affirmation*

The cognitive interviews also revealed differing interpretations of the concept of "transitioning," and these different interpretations impacted their answers to the questions in this section. Clarification here regarding the definition of "transitioning" would help reduce this variance. Additionally, the range of responses and experiences possible for Question 16, "why is medical gender transition important to you?," may be too complex to capture for this question. Some respondents had difficulty identifying with the response options because they are framed as fixing a negative in their opinion, whereas they did not feel that anything was inherently "wrong" prior to transition. A common response was "I wanted my body to match how I felt," or some version thereof.

*Sexual Identity*

Our participants had some trouble differentiating between gender identity and sexual identity in this section, especially with regard to the gender identity of the people they are attracted to. A number of participants noted, for instance, that they are attracted to "heterosexual men," when the response choices were based on gender identify (e.g. cis (non-trans) men, trans men, trans women, etc.). Some of this confusion may be avoided with the addition of some transition material between this section and the previous one, highlighting the difference between gender identity and sexual identity.

*Sexual Behavior Questions, Partner-by-Partner, and Other Sex Questions*

The current order of the questions asks about specific partners in detail before moving on to other sex partners more generally. This format caused some confusion among cognitive interview participants – asking the more general sex questions first could help avoid this. Participants also had an inconsistent understanding of what it means to use a condom "for the whole time." Some participants interpreted using a condom the whole time as using a condom for all their sex experiences, as opposed to using it for the entirety of the sex act. The phrase using a condom "for the whole time" may need some clarification.

*Discrimination*

We found that participants did not indicate much experience with discrimination during the survey, but in later probing many of them described instances of verbal slights or social exclusion. Participants seem to interpret 'discrimination' in its formal legal sense: something that they might file a legal complaint about, and a negative event explicitly tied to their gender identity. Clarification about the meaning of 'discrimination' may be needed to capture these instances of verbal slights or social exclusions. The response options referring to "hide your gender identity" probes on a specific reaction to

discrimination (hiding it); however, a respondent could experience discrimination without feeling that she had to hide her gender identity. We suggest rewording to capture work-related or school-related discrimination more generally. For brevity, CDC may also want to consider asking about whether respondents experienced discrimination generally, then ask about whether they experience discrimination in particular settings (school, work, etc.)

*Community Stigma*

Participants provided generally positive responses to questions about community stigma. It is possible that our participants or even the transgender community as a whole have a generally higher threshold for discrimination and stigmatization, explaining our findings in these two realms.

*Gender Identity Disclosure, Social Support, and Expected Social Support*

This is a rather long section, thus consolidation of these questions by combining answer options, not differentiating between groups, or even using a single question to capture the general support that transwomen receive may help cut down the total length of the interview. In addition, some participants brought up the fact that they did not care about whether certain groups (e.g., coworkers) support them, as they simply wanted to be treated "like everyone else." Based on this, a term other than "support" (e.g. "respect") may be more applicable for the questions about these groups.

## SURVEY DESIGN AND CONTENT RECOMMENDATIONS

Our recommendation is that the NHBS-Trans survey be no greater than an average time of 1 hour. We believe this survey length is feasible to implement in the types of field sites that NHBS would likely be using for a future NHBS-Trans study. The survey should maintain as many questions from the NHBS CRQ as is feasible while addressing the specific needs for a survey with transwomen. These needs often result in additional survey domains-constructs, hence the increased survey length over previous NHBS survey versions. We believe our recommendations will produce a final survey of this average length. If average survey length is greater than 1 hour, we may propose removing constructs or items, or may recommend randomizing participants to question subsets. Randomization to subsets allows for a shorter overall survey time, while still collecting needed data albeit from a smaller number of participants. The recommended survey domains and constructs are included in the following table. The order of the domains and constructs in the table is also the recommended order for the survey. Appendix E contains a detailed set of recommendations including question and response wording, sources, modifications, feedback from the advisers and cognitive interviews, and an item-specific rationale.

## SUMMARY OF CDC FEEDBACK

Final recommendations include CDC's input about what should be in the final CRQ. The following are the key points that the CDC requested be implemented in the CRQ:

- Reduced number of questions regarding homelessness
- Removed questions about gender listed on identification and records
- Modified social support questions to use the Multi-dimensional Scale of Perceived Social Support
- Reduced number of partner by partner (P x P) questions

- Added questions regarding sexual behavior in the past 12 months
- Replaced CESD-10 questions with K6 questions in mental health section
- Reduced number of questions abuse and harassment

| Order | Survey Domain | Construct | Source | Rationale |
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| 1 | Eligibility | Age | NHBS CRQ 4 | Kept NHBS CRQ 4 Item |
| 2 | Eligibility | NHBS previous participant | NHBS CRQ 4 | Kept NHBS CRQ 4 Item |
| 3 | Eligibility | NHBS city residency | NHBS CRQ 4 | Kept NHBS CRQ 4 Item |
| 4 | Eligibility | Birth sex | Fenway Health Patient Survey[6] | Birth sex allows determination of whether those who are no transwoman-identified would be considered transwomen for the study (female identity and male/intersex at birth). |
| 5 | Eligibility | Gender identity | Fenway Health Patient Survey Cahill, 2014 #126} | Gender identity construct is central to NHBS-Trans study |
| 6 | Eligibility | English proficiency | NHBS CRQ 4 | Kept NHBS CRQ 4 Item |
| 7 | Eligibility | Spanish proficiency | NHBS CRQ 4 | Kept NHBS CRQ 4 Item |
| 8 | Eligibility | County of residence | NHBS CRQ 4 | Kept NHBS CRQ 4 Item |
| 6 | RDS | RDS coupon source | NHBS CRQ 4 | Kept NHBS CRQ 4 Item |
| 7 | RDS | RDS network size | NHBS CRQ 4 | Kept NHBS CRQ 4 Item |
| 8 | Demographics | Race and ethnicity | NHBS CRQ 4 | Kept NHBS CRQ 4 Item |
| 9 | Demographics | Nativity | NHBS CRQ 4 | Kept NHBS CRQ 4 Item |
| 10 | Demographics | Languages spoken at home | NHBS CRQ 4 | Kept NHBS CRQ 4 Item |
| 11 | Demographics | Marital status | NHBS CRQ 4 | Kept NHBS CRQ 4 Item |
| 12 | Demographics | Education | NHBS CRQ 4 | Kept NHBS CRQ 4 Item |
| 13 | Demographics | Employment | NHBS CRQ 4 | Kept NHBS CRQ 4 Item |

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| | | and income | | |
| 14 | Demographics | Food insecurity | USDA Food Insecurity Definitions[7] | Food insecurity is a measure of SES, may be more common in LGBT populations and may impact ability to engage in other health/prevention services. |
| 15 | Demographics | Homelessness in past 12 months | NHBS CRQ 4 | Kept NHBS CRQ 4 Item |
| 16 | Demographics | Number of homeless episodes in past 12 months | Atlanta Homeless Youth Count and Needs Assessment[8] | Construct provides more detailed information on homelessness, which is a critical social issue for transwomen. |
| 17 | Demographics | Number of homeless nights past 12 months | Atlanta Homeless Youth Count and Needs Assessment[8] | Construct provides more detailed information on homelessness, which is a critical social issue for transwomen. |
| 18 | Demographics | Duration of current homelessness | Transgender Veteran Survey[10] | Measure of severity of current homelessness. |
| 19 | Demographics | Currently homeless | NHBS CRQ 4 | Kept NHBS CRQ 4 Item |
| 20 | Demographics | Refused access to homeless shelter in past 12 months | TransPULSE Provincial Survey[9] | Measure of structural discrimination for homeless transwomen. |
| 21 | Demographics | Trans-related reasons for relocating to NHBS city | New | Added at the request of Advisers. Related to discrimination and access of health services. |
| 131 | Demographics | 2011 DHHS standard for disability status | NHBS CRQ 4 | Kept NHBS CRQ 4 Item |
| 22 | Healthcare access | Health insurance | NHBS CRQ 4 | Kept NHBS CRQ 4 Item |
| 23 | Healthcare access | Usual source of care | NHBS CRQ 4 | Kept NHBS CRQ 4 Item |
| 24 | Healthcare access | Healthcare provider visit in past 12 months | NHBS CRQ 4 | Kept NHBS CRQ 4 Item |
| 25 | Healthcare | HIV tested at | NHBS CRQ 4 | Kept NHBS CRQ 4 Item |

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| | access | HCP visit | | |
| 26 | Healthcare access | Unmet need for HCP | NHBS CRQ 4 | Kept NHBS CRQ 4 Item |
| 27 | Healthcare access | HCP comfortable talking to about trans-issues | CDC recommended addition | |
| 28 | Gender identity | Age of gender identity development | TransPULSE Provincial Survey 2009[9] | May be related to gender congruence and mental health. |
| 29 | Gender identity | Gender congruence scale | Gender Congruence Scale[11] | Related to mental health. |
| 30 | Gender identity | Gender identity perceived social support | MSPSS from Zimet, et al[12] | Social support as a resiliency measure. May be protective for adverse health outcomes. |
| 31 | Medical gender affirmation | Ever used hormones | Form 311--Los Angeles Transgender Health Survey[13] | Gateway construct for this hormone use. |
| 32 | Medical gender affirmation | Want hormones | CDC recommended addition | |
| 33 | Medical gender affirmation | Health insurance for gender transition | CDC recommended addition | |
| 34 | Medical gender affirmation | Age of initiation of medical gender transition | TransPULSE Provincial Survey[9] | May be related to gender congruence and mental health. |
| 35 | Medical gender affirmation | Use of hormones in past 12 months | Form 311--Los Angeles Transgender Health Survey[13] | Gateway construct for unsafe hormone injection. |
| 36 | Medical gender affirmation | Source of hormones in past 12 months | TransPULSE Provincial Survey[9] | Sources other than HCP may pose health risks. |
| 37 | Medical gender affirmation | Types of hormones past 12 months | CDC recommended addition | |

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| 38 | Medical gender affirmation | Source of needles for hormone injection in past 12 months | Form 311--Los Angeles Transgender Health Survey[13] | Sources of needles for hormone injection other than HCP may pose health risks. |
| 39 | Medical gender affirmation | Sharing of needles for injected hormones in past 12 months | NHBS CRQ 4 | Modified NHBS CRQ 4 Item. Modified to be about needles used to inject hormones that may pose health risks. |
| 40 | Medical gender affirmation | Ever had gender affirmation surgery | Form 311--Los Angeles Transgender Health Survey[13] | May be related to gender congruence and mental health. |
| 41 | Medical gender affirmation | Want surgery for gender affirmation | CDC recommended addition | |
| 42 | Medical gender affirmation | Age first surgery for gender affirmation | CDC recommended addition | |
| 43 | Medical gender affirmation | Types of gender affirmation surgery | TransPULSE Provincial Survey 2009[9] | May be related to gender congruence and mental health. Genital surgery used in skip logic for sexual behavior questions and may pose health risks. |
| 44 | Other injections | Ever injected other substances for gender affirmation | Transgender Empowerment and Community Health[14] | Gateway question to recent other substance injection. Unsafe injection of other substances such as silicone may pose health risks. |
| 45 | Other injections | Injected other substance for gender affirmation in past 12 months | Transgender Empowerment and Community Health[14] | Gateway question to recent other substance injection. Unsafe injection of other substances such as silicone may pose health risks. |
| 46 | Other injections | Who gave the injections | CDC recommended addition | |
| 47 | Other injections | Sterile needles for | CDC recommended addition | |

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| | | other substances for gender affirmation | | |
| 48 | Cumulative sexual behavior | Oral, vaginal or anal sex in past 12 months | Transgender Empowerment and Community Health[14] | Gateway question to cumulative sex behaviors. Not gender-specific since those questions have to be administered partner-by-partner. |
| 49 | Cumulative sexual behavior | Vaginal sex by type (any, insertive, receptive) | CDC recommended addition | Based on modification to NHBS CRQ item |
| 50 | Cumulative sexual behavior | Anal sex by type (any, insertive, receptive) | CDC recommended addition | Based on modification to NHBS CRQ item |
| 51 | Cumulative sexual behavior | Only oral sex | CDC recommended addition | Based on modification to NHBS CRQ item |
| 52 | Cumulative sexual behavior | Age at first sex | NHBS CRQ 4 | Modified NHBS CRQ 4 Item. Modified to make gender non-specific. |
| 53 | Cumulative sexual behavior | Number of sex partners in past 12 months | CDC recommended addition | Cumulative sexual risk indicator |
| 54 | Cumulative sexual behavior | Exchange sex, past 12 months | CDC recommended addition | Based on modification to NHBS CRQ item |
| 55 | Cumulative sexual behavior | Condom use during role-sex types in past 12 months | CDC recommended addition | cumulative sexual risk indicators by condomless insertive and receptive vaginal and anal sex. |
| 56 | Cumulative sexual behavior | Number of main partners | CDC recommended addition | Based on modification to NHBS CRQ item |
| 57 | Cumulative sexual behavior | Number of anal sex partners in past 12 months | CDC recommended addition | Based on modification to NHBS CRQ item |

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| 58 | Cumulative sexual behavior | Ways found exchange sex | CDC recommended addition | Based on modification to NHBS CRQ item |
| 59 | Cumulative sexual behavior | Money earned per month from exchange sex | CDC recommended addition | Based on modification to NHBS CRQ item |
| 60 | Partner characteristics | Partner, gender identity | Fenway Health Patient Survey[6] | Gender identity construct of sex partners necessary to address potential for participants partners to be transpersons. |
| 61 | Partner characteristics | Partner, birth sex | Fenway Health Patient Survey[6] | Birth sex construct of sex partners necessary to address potential for participants partners to be transpersons. |
| 62 | Partner characteristics | Partner, age categories | NHBS CRQ 4 | Kept NHBS CRQ 4 Item |
| 63 | Partner characteristics | Partner, race/ethnicity | NHBS CRQ 4 | Kept NHBS CRQ 4 Item |
| 64 | Partner characteristics | Partner, main or casual | NHBS CRQ 4 | Kept NHBS CRQ 4 Item |
| 65 | Partner characteristics | Partner, length of relationship | NHBS CRQ 4 | Kept NHBS CRQ 4 Item |
| 66 | Partner risk behaviors | Partner, concurrent sex partner during relationship | NHBS CRQ 4 | Kept NHBS CRQ 4 Item |
| 67 | Partner sexual behaviors | Partner, exchange sex at last sex | NHBS CRQ 4 | Kept NHBS CRQ 4 Item |
| 68 | Partner sexual behaviors | Partner, sex by role and type in past 12 months | Medical Monitoring Project[5] | Partner sexual risk indicators by insertive and receptive vaginal and anal sex. |
| 69 | Partner sexual behaviors | Partner, condom use during role-sex types in past 12 months | Medical Monitoring Project[5] | Partner sexual risk indicators by condomless insertive and receptive vaginal and anal sex. |
| 70 | Partner sexual | Partner, | NHBS CRQ 4 | Kept NHBS CRQ 4 Item |

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| | behaviors | number of times anal sex (by type) | | |
| 71 | Partner sexual behaviors | Partner, sex role and type at last sex | Medical Monitoring Project[5] | Partner sexual risk indicators by insertive and receptive vaginal and anal sex. |
| 72 | Partner HIV status | Partner, knowledge of partner HIV status at last sex | NHBS CRQ 4 | Kept NHBS CRQ 4 Item |
| 73 | Partner HIV status | Partner, partner HIV status at last sex | NHBS CRQ 4 | Kept NHBS CRQ 4 Item |
| 74 | Partner HIV prevention | Partner, used ARVs (HIV+ partner) | American Men's Internet Survey[16] | Measure can be used to determine risk from condomless sex. |
| 75 | Partner HIV prevention | Partner, suppressed VL (HIV+ partner) | American Men's Internet Survey[16] | Measure can be used to determine risk from condomless sex. |
| 76 | Partner HIV prevention | Partner, used PrEP (HIV- partner) | American Men's Internet Survey[16] | Measure can be used to determine risk from condomless sex. |
| 77 | Alcohol use | Drank any alcohol in past 30 days | NHBS CRQ 4 | Kept NHBS CRQ 4 Item |
| 78 | Alcohol use | Binge drank alcohol in past 30 days | NHBS CRQ 4 | Kept NHBS CRQ 4 Item |
| 79 | Alcohol use | Intensity of drinking alcohol in past 30 days | NHBS CRQ 4 | Kept NHBS CRQ 4 Item |
| 80 | Injection of illicit drugs | Ever injected | NHBS CRQ 4 | Kept NHBS CRQ 4 Item |
| 81 | Injection of illicit drugs | Age at first injection | NHBS CRQ 4 | Kept NHBS CRQ 4 Item |
| 82 | Injection of illicit drugs | Time since last injection | NHBS CRQ 4 | Kept NHBS CRQ 4 Item |
| 83 | Injection of illicit drugs | Frequency of injection of specific drugs in past 12 | NHBS CRQ 4 | Kept NHBS CRQ 4 Item |

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| | | months | | |
| 84 | Injection of illicit drugs | Drug injected most often in past 12 months | NHBS CRQ 4 | Kept NHBS CRQ 4 Item |
| 85 | Injection of illicit drugs | Source of needles in past 12 months | NHBS CRQ 4 | Kept NHBS CRQ 4 Item |
| 86 | Non-injection illicit drugs | Used non-injection drugs in past 12 months | NHBS CRQ 4 | Kept NHBS CRQ 4 Item |
| 87 | Non-injection illicit drugs | Which non-injection drugs used in past 12 months | NHBS CRQ 4 | Kept NHBS CRQ 4 Item |
| 88 | Alcohol and drug treatment | Participated in alcohol or drug treatment in past 12 months | NHBS CRQ 4 | Kept NHBS CRQ 4 Item |
| 89 | Alcohol and drug treatment | Had unmet need for alcohol or drug treatment in past 12 months | NHBS CRQ 4 | Kept NHBS CRQ 4 Item |
| 90 | HIV testing experiences | Ever HIV tested | NHBS CRQ 4 | Kept NHBS CRQ 4 Item |
| 91 | HIV testing experiences | Ever testing positive for HIV | NHBS CRQ 4 | Kept NHBS CRQ 4 Item |
| 92 | HIV testing experiences | Times tested for HIV in past 2 years | NHBS CRQ 4 | Kept NHBS CRQ 4 Item |
| 93 | HIV testing experiences | Date of most recent HIV test | NHBS CRQ 4 | Kept NHBS CRQ 4 Item |
| 94 | HIV testing experiences | Location of most recent HIV test | NHBS CRQ 4 | Kept NHBS CRQ 4 Item |

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| 95 | HIV testing experiences | Result of most recent HIV test | NHBS CRQ 4 | Kept NHBS CRQ 4 Item |
| 96 | HIV testing experiences | Used a home test in past 12 months | NHBS CRQ 4 | Kept NHBS CRQ 4 Item |
| 97 | HIV testing experiences | Main reason not tested in past 12 months | NHBS CRQ 4 | Kept NHBS CRQ 4 Item |
| 98 | HIV testing experiences | Date of first positive HIV test | NHBS CRQ 4 | Kept NHBS CRQ 4 Item |
| 99 | HIV testing experiences | Location of first positive HIV test | NHBS CRQ 4 | Kept NHBS CRQ 4 Item |
| 100 | HIV testing experiences | Partner services after first positive HIV test | NHBS CRQ 4 | Kept NHBS CRQ 4 Item |
| 101 | HIV testing experiences | Referred to HIV care after first positive HIV test | NHBS CRQ 4 | Kept NHBS CRQ 4 Item |
| 102 | HIV testing experiences | Ever tested HIV negative before first positive HIV test | NHBS CRQ 4 | Kept NHBS CRQ 4 Item |
| 103 | HIV testing experiences | Date of last negative HIV test before first positive HIV test | NHBS CRQ 4 | Kept NHBS CRQ 4 Item |
| 104 | HIV testing experiences | Times tested HIV negative in the 2 years before first positive test | NHBS CRQ 4 | Kept NHBS CRQ 4 Item |
| 105 | HIV care | Ever received HIV care | NHBS CRQ 4 | Kept NHBS CRQ 4 Item |
| 106 | HIV care | Date of first HIV care visit | NHBS CRQ 4 | Kept NHBS CRQ 4 Item |
| 107 | HIV care | Main reason for delayed or | NHBS CRQ 4 | Kept NHBS CRQ 4 Item |

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| | | no entry into care | | |
| 108 | HIV care | Date of most recent HIV care visit | NHBS CRQ 4 | Kept NHBS CRQ 4 Item |
| 109 | HIV care | Main reason for not currently engaged in care | NHBS CRQ 4 | Kept NHBS CRQ 4 Item |
| 110 | HIV care | Currently taking ARVs | NHBS CRQ 4 | Kept NHBS CRQ 4 Item |
| 111 | HIV care | Main reason for not currently taking ARVs | NHBS CRQ 4 | Kept NHBS CRQ 4 Item |
| 112 | HIV care | Ever had HIV viral load | NHBS CRQ 4 | Kept NHBS CRQ 4 Item |
| 113 | HIV care | Date of most recent HIV viral load | NHBS CRQ 4 | Kept NHBS CRQ 4 Item |
| 114 | HIV care | Result of most recent HIV viral load | NHBS CRQ 4 | Kept NHBS CRQ 4 Item |
| 115 | Health Conditions | Ever tested for HCV | NHBS CRQ 4 | Kept NHBS CRQ 4 Item |
| 116 | Health Conditions | Time and location of most recent HCV test | NHBS CRQ 4 | Kept NHBS CRQ 4 Item |
| 117 | Health Conditions | Ever diagnosed with HCV | NHBS CRQ 4 | Kept NHBS CRQ 4 Item |
| 118 | Health Conditions | Treated HCV | NHBS CRQ 4 | Kept NHBS CRQ 4 Item |
| 122 | Other STDs | Ever diagnosed with herpes | NHBS CRQ 4 | Kept NHBS CRQ 4 Item |
| 123 | Other STDs | Ever diagnosed with genital warts | NHBS CRQ 4 | Kept NHBS CRQ 4 Item |
| 124 | Other STDs | Tested for STDs other than HIV in | NHBS CRQ 4 | Kept NHBS CRQ 4 Item |

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| | | past 12 months | | |
| 125 | Other STDs | Diagnosed with gonorrhea, chlamydia or syphilis in past 12 months | NHBS CRQ 4 | Kept NHBS CRQ 4 Item |
| 126 | Other STDs | Ever receive HPV vaccine | NHBS CRQ 4 | Kept NHBS CRQ 4 Item |
| 127 | Other STDs | Age at first dose of HPV vaccine | NHBS CRQ 4 | Kept NHBS CRQ 4 Item |
| 128 | Mental health | K-6 scale for symptoms of depression | K6 scale from Kessler, et al[17] | |
| 129 | Mental health | Ever suicidal thoughts or attempts | Transgender Veteran Survey[10] | Suicidality is an indicator of a serious mental health problem. |
| 130 | Discrimination | Ever fired for being trans | Transgender Empowerment and Community Health[14] | Experiences of discrimination may impact mental health or may be direct barriers to accessing needed health services. |
| 131 | Discrimination | Ever had trouble getting a job for being trans | Transgender Empowerment and Community Health[14] | Experiences of discrimination may impact mental health or may be direct barriers to accessing needed health services. |
| 132 | Discrimination | Ever denied access to gender appropriate restroom | New | Experiences of discrimination may impact mental health or may be direct barriers to accessing needed health services. |
| 133 | Discrimination | Ever denied housing or evicted for being trans | Transgender Empowerment and Community Health[14] | Experiences of discrimination may impact mental health or may be direct barriers to accessing needed health services. |
| 134 | Discrimination | Ever denied or give lower quality healthcare for being trans | Project STRONG[18] | Experiences of discrimination may impact mental health or may be direct barriers to accessing needed health services. |

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| 135 | Discrimination | Ever received poor service in public accommodations for being trans | NHBS CRQ 4 | Modify NHBS CRQ 4 to question about being transgender. |
| 136 | Abuse and harassment | Ever verbally abused or harassed for being trans | Form 311--Los Angeles Transgender Health Survey[13] | Verbal and physical abuse may impact mental health and may be barriers for participants accessing needed health services or ability to use prevention services. |
| 137 | Abuse and harassment | Ever physically abused or harassed for being trans | Form 311--Los Angeles Transgender Health Survey[13] | Verbal and physical abuse may impact mental health and may be barriers for participants accessing needed health services or ability to use prevention services. |
| 138 | Abuse and harassment | Ever forced to have sex | Multi-country LGBT stigma survey[19] | Sexual assault may be directly related to health risk or may be related to mental health and accessing other health services. |
| 139 | Incarceration | Ever incarcerated | NHBS CRQ 4 | Kept NHBS CRQ 4 Item |
| 140 | Incarceration | Incarcerated in past 12 months | NHBS CRQ 4 | Kept NHBS CRQ 4 Item |
| 141 | Incarceration | HIV tested while incarcerated in past 12 months | NHBS CRQ 4 | Kept NHBS CRQ 4 Item |
| 142 | Assessment of prevention activities | Received free condoms in past 12 months | NHBS CRQ 4 | Kept NHBS CRQ 4 Item |
| 153 | Assessment of prevention activities | Individual or group intervention in past 12 months | NHBS CRQ 4 | Kept NHBS CRQ 4 Item |
| 154 | Assessment of prevention activities | Heard of PEP | CDC recommended addition | Based on modification to NHBS CRQ item |
| 155 | Assessment of | Heard of PrEP | NHBS CRQ 4 | Kept NHBS CRQ 4 Item |

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| | prevention activities | | | |
| 156 | Assessment of prevention activities | Discussed PrEP with healthcare provider in past 12 months | NHBS CRQ 4 | Kept NHBS CRQ 4 Item |
| 157 | Assessment of prevention activities | Received PrEP prescription in past 12 months | NHBS CRQ 4 | Kept NHBS CRQ 4 Item |
| 158 | Assessment of prevention activities | Used PrEP in past 12 months | NHBS CRQ 4 | Kept NHBS CRQ 4 Item |
| 159 | Assessment of prevention activities | Perceived risk for HIV | NHBS CRQ 4 | Kept NHBS CRQ 4 Item |

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