

## Attachment 3 – Summary of Changes

### National HIV Behavioral Surveillance among Transgender Women (NHBS-Trans) Summary of Changes to Data Collection Instruments

#### 1) Eligibility Screener, Attachments 5a & 6a

- Modified date of birth to include MM/DD/YYYY rather than MM/YYYY; the previous method increased challenges in de-duplication of data and identification of previous participants. (ES1)
- Modified assessment of previous project participation to include a 1-year recall period. (ES2)
- Modified response options for question of current gender identity. The following responses were added: trans feminine, trans masculine, and non-binary. These modifications were made to reflect most common write-in responses obtained in 2019-2020 and to reduce burden on interviewers. (ES3)

#### 2) Behavioral Assessment, Attachments 5b & 6b

- Emerging priorities in HIV prevention – The following changes were necessary to ensure NHBS-Trans continues to collect the most relevant HIV-associated behavioral data:
  - o Discrimination: Moved, added and/or modified 18 questions. This includes 3 questions capturing housing/shelter-related discrimination, 5 questions on employment and employment-related discrimination, 6 questions on healthcare-related discrimination, and 4 questions about discrimination in public. A subset of the added questions measures the experience of discrimination EVER where previously experience of discrimination was only measured in the past 12 months. Experiences that occurred more than 12 months ago may continue to affect current attitudes, beliefs, and behaviors.
  - o Gender Affirmation: The previously approved section on Gender Identity was updated to reflect a more holistic, all-encompassing experience of gender affirmation. Research has identified a link between the experience of gender affirmation and HIV risk behaviors. 9 questions were added to capture the support received from immediate family members, 4 questions were added about correct pronoun usage, 3 questions were added about name and gender on legal documents, and 5 questions were added about personal experiences with gender expression. 12 questions in the previous instrument were modified and reduced to 9 questions to capture an individual's support system and 12 questions were deleted due to negative feedback received during the 2019-2020 data collection. In the Medical Gender Affirmation section, a question was added about insurance coverage for preferred hormones as insufficient coverage may be a barrier in gender affirmation.
  - o PrEP: The HIV prevention landscape has changed significantly in recent years with increased emphasis on Pre-Exposure Prophylaxis (PrEP). Added 8 questions measuring stages along the prevention continuum for HIV-negative persons focusing on PrEP access, current use, and adherence. Deleted 3 questions assessing use of PrEP for 2 or more consecutive months as it is no longer required to distinguish PEP from PrEP use, and 2 questions assessing non-daily PrEP use and 1 assessing sources of PrEP due to low variability.
  - o Other testing: Added 7 questions to measure testing and treatment for other sexually transmitted conditions including hepatitis C, chlamydia, gonorrhea, and syphilis.
- Deletion of lower priority items – Every question in the Behavioral Assessment was reviewed for quality and content value. Items measuring repetitive or low priority content were removed from the assessment.

- o Deleted 42 questions assessing behaviors with and characteristics of participants' recent sex partners. The level of detail from these questions is not necessary to collect in NHBS-Trans. In addition, questions about frequency of sex proved difficult for participants to answer.
  - Deleted 15 questions about the 2<sup>nd</sup>-to-last sex partner.
  - Deleted 15 questions about the 3<sup>rd</sup>-to-last sex partner.
  - Deleted 9 questions assessing the frequency of sex with the last partner.
  - Deleted 3 questions assessing partner initials to help participants accurately report partner-specific behaviors and characteristics. These items are no longer necessary, as participants will no longer be asked to recall partner specific information for more than 1 recent sex partner.
- o Deleted 8 questions determined to yield low priority data, data with insufficient variability to conduct meaningful analysis, or the measure had low internal consistency.
  - Frequency of new, sterile needle during injection of non-hormonal, gender-affirming substances
  - Gender identity and sex assigned at birth of most recent sex partner
  - Frequency of binge drinking
  - The experience of being hooked on painkillers before initiation of injection
  - Number of times tested for HIV in past 2 years
  - 2 questions on partner services after first HIV-positive test
  - HIV testing while incarcerated in past 12 months
- Measurement improvements – Modifications were made to items with potential to yield higher quality or more directly relevant data based on lessons learned from previous NHBS data collections and analyses.
  - o Modified 1 introductory statement (INTRO\_NS2) and 2 questions (NS2, NS2CONFa) to reduce cognitive burden when determining size of personal network.
  - o Added 3 questions (DM5-DM7) to capture a broader experience of unstable housing as recent evidence indicates effect on HIV prevention and transmission.
  - o Modified 1 question assessing household income (DM14) adding one response option to accommodate relevant income categories in areas with higher cost of living. Wording of this item was also modified to clarify the recall period.
  - o Modified 1 question (GA1) to reflect more appropriate wording for transgender people.
  - o Modified section on gender affirming surgeries to include a wider range of procedures and injection of substances other than hormones. The introductory statement was modified, 4 questions were modified, and 3 questions were moved. 6 questions were deleted because specificity of which surgeries have occurred or are desired is not necessary.
  - o 3 questions were added in the Sexual Behavior section to obtain information on relevant anatomy. The responses to these questions will allow for skip patterns to tailor the remainder of the section for a specific participant. This change was prompted by feedback from participants in 2019-2020.
  - o In the Sexual Behavior section, 9 questions were added and the introductory statement was modified to allow for respondents to provide preferred terms instead of standard anatomical terms for use when discussing sexual behavior. This option resulted in the modification of 24 subsequent questions to incorporate these preferred terms.

- o To capture higher quality data about oral sex behaviors, 1 question about oral sex (giving or receiving) was split into 2 questions, 1 about giving oral sex, and 1 about receiving oral sex. Differentiating oral sex directionality enables more accurate surveillance of disease transmission risk related to oral sex.
  - o 1 question was added to detect non-penetrative sex behaviors. This change was prompted by feedback from participants in 2019-2020.
  - o The question series on exchange sex was updated to reflect current subject area knowledge; the definition of exchange sex was broadened to include other types of trade that may have not been captured previously. This expansion resulted in the modification of 3 questions. 5 questions were added to measure items of exchange and risk behavior with exchange partners; 3 questions were deleted.
  - o Added 3 questions to more accurately capture condom use at last sex.
  - o Added 4 questions assessing sexual partner behaviors to more accurately measure risk for HIV.
  - o Modified 2 questions measuring injection history.
  - o Response options for 2 questions updating list of injection drugs.
  - o Added 1 question assessing drug sharing behaviors.
  - o Modified the question set on Non-injection drugs to obtain frequency data rather than dichotomous (Y/N) data.
  - o Added 'not applicable' response options in drug treatment section to more accurately capture experience of participants.
  - o Modified question format of home HIV testing to Y/N rather than frequency.
  - o Modified response options for result of most recent viral load test to more accurately align with clinical thresholds for viral suppression.
- Clarity, repetitive language, and interview flow - The changes listed below do not affect the scope or content of the questions; they also do not affect the time burden of NHBS-Trans for participants. However, they are intended to improve the overall participant experience and the quality of data by improving clarity and flow of the interview process.
    - o Modified 3 Introductory statements (INTRO\_CORE, INTRO\_MG1, INTRO\_ID1)
    - o Modified 2 questions capturing consent (CN1, CN4)
    - o Moved 1 Introductory statement (INTRO\_DM1) and 5 questions about homelessness (DM1-DM4, DM9) to capture the experience of homelessness prior to questions about household income.
    - o Modified 4 questions (MG1a, MG1b, MG2, MG4) to reduce repetitive language.
    - o Modified order of questions in Non-Injection Drugs section to reduce burden on participants who only use marijuana and no other non-injection drugs.
    - o Modified 1 question on location of first positive test (HT7a).
    - o Added an introductory statement (INTRO\_MH2a) to prepare participant for questions on thoughts of suicide.
    - o Modified 2 questions (AH1, AH2) to reduce repetitive language.
    - o Modified 1 question on forced sex (AH4).

Supporting documentation for changes:

1. National HIV Behavioral Surveillance (NHBS); OMB #0920-0770, exp. 01/31/2023
2. Medical Monitoring Project (MMP); OMB #0920-0740, exp. 05/31/2024
3. Injection Drug Use Surveillance Project (IDU-SP); OMB #0920-1325, exp. 02/29/2024
4. [Sevelius JM, Chakravarty D, Dilworth SE, Rebchook G, Neilands TB. Gender Affirmation through Correct Pronoun Usage: Development and Validation of the Transgender Women's Importance of Pronouns \(TW-IP\) Scale. Int J Environ Res Public Health. 2020;17\(24\):9525. Published 2020 Dec 19. doi:10.3390/ijerph17249525](#)
5. [Corina Lelutiu-Weinberger, Devin English & Priyadharshiny Sandanapitchai \(2020\) The Roles of Gender Affirmation and Discrimination in the Resilience of Transgender Individuals in the US, Behavioral Medicine, 46:3-4, 175-188, DOI: 10.1080/08964289.2020.1725414](#)
6. [Wilson EC, Garofalo R, Harris RD, Herrick A, Martinez M, Martinez J, Belzer M; Transgender Advisory Committee and the Adolescent Medicine Trials Network for HIV/AIDS Interventions. Transgender female youth and sex work: HIV risk and a comparison of life factors related to engagement in sex work. AIDS Behav. 2009 Oct;13\(5\):902-13. doi: 10.1007/s10461-008-9508-8. Epub 2009 Feb 6. PMID: 19199022; PMCID: PMC2756328.](#)
7. [Moseson H, Lunn MR, Katz A, Fix L, Durden M, Stoeffler A, et al. \(2020\) Development of an affirming and customizable electronic survey of sexual and reproductive health experiences for transgender and gender nonbinary people. PLoS ONE 15\(5\): e0232154. https://doi.org/10.1371/journal.pone.0232154](#)
8. [Sevelius, J.M.; Chakravarty, D.; Dilworth, S.E.; Rebchook, G.; Neilands, T.B. Measuring Satisfaction and Comfort with Gender Identity and Gender Expression among Transgender Women: Development and Validation of the Psychological Gender Affirmation Scale. Int. J. Environ. Res. Public Health 2021, 18, 3298.](#)