

Attachment 13 – Summary of Changes

National HIV Behavioral Surveillance (NHBS) System Round 7 (2023-2025) Summary of Changes to Data Collection Instruments

1) Eligibility Screener, Attachments 3a & 4a (**2 items modified**):

- Opened the universe of respondents for 1 question, sex at birth, (ES8a) previously asked only in the MSM cycle. This question now will be asked in PWID and HET cycles as well to improve the accuracy with which the instrument classifies respondents as transgender.
 - The NHBS PWID and HET cycle behavioral assessments previously asked only gender identity, as interviewer feedback from the first PWID cycle (2005) and cognitive testing conducted by NCHS in 2011 indicated that members of the target populations for PWID and HET cycles conflated the concepts of sex and gender and asking both was confusing to them and led to response error. More recent cognitive studies indicate that a higher proportion of the general population is familiar with the concept of transgender identity and are able to respond accurately when asked both sex assigned at birth and gender identity, e.g., Bauer et al., 2017, Ellis et al., 2017.
- Modified wording and response options for 1 item (ES8b) assessing gender identity in order to improve measurement and meet the objectives of both the MSM cycle and HET cycle eligibility algorithms.
 - The new wording and response options are based on recommendations by subject matter experts in transgender-inclusive measures of sex/gender for population surveys (Bauer et al., 2017). The wording and response options were specifically selected to be understood and yield valid data on gender identity for cisgender as well transgender and nonbinary individuals and, when cross-classified with the response to sex assigned at birth, to distinguish sex/gender subgroups needed for MSM and HET cycle eligibility screening algorithms. Eligibility algorithms were updated to allow transgender men and men assigned male at birth who identify as nonbinary to participate in the MSM cycle and to restrict eligibility for the HET cycle to cisgender men and women.

2) Behavioral Assessment, Attachments 3b-d & 4b-d (**12 items added, 14 items deleted, 31 items modified**):

- Emerging priorities in HIV prevention - The HIV prevention landscape has changed significantly in recent years with increased emphasis on Pre-Exposure Prophylaxis (PrEP). The following changes were necessary to ensure NHBS continues to collect the most relevant HIV-associated behavioral data:
 - Measuring use of Pre-Exposure Prophylaxis (PrEP)
 - Added 5 questions measuring stages along the prevention continuum for HIV-negative persons, focusing on lifetime use (PA7a, PA7b.1, and PA7b.2 [pg. 108-109] []) last use (PA6f [pg. 107]), and on-demand use (PA6d [pg. 106]).
 - Deleted 2 questions assessing sources of PrEP (PA6h [pg.107] and PA6i [pg. 107]), due to poor data quality.
 - Deleted 1 question assessing PrEP use frequency (PA6f [pg. 106]) due to low variability.
 - Measuring sexual risk
 - Added 3 questions to improve measurement of sexual risk at last sex by accounting for partner viral load at last sex (SX36e [pg. 54]); partner PrEP use at last sex (PA8a [pg. 110]) and respondent PrEP use at last sex (PA8b [pg. 110]).

- Modified from existing sexual behavior questions asked of cis-gender participants substitute 20 questions (SX60 Through SX68e [pg. 58-65]) to assess sexual risk among transgender men (MSM cycle only). These questions will only be asked of a very small proportion of participants (estimated 1-5%) who previously were not eligible for the MSM cycle. Participants who are asked SX60-SX68e will not be asked other sexual risk questions that are asked of other participants.
 - o Measuring substance use risk
 - Added 1 question assessing access to new sterile syringes (PA2c) [pg. 104].
 - Added 1 question assessing average daily injection frequency (ID2b) [pg. 71].
 - Added 1 question assessing stimulant overdose (TX6) [pg. 86].
 - o Measuring mpox diagnosis and vaccination (MP1 and MP2 [pg. 153] - Added 2 questions related to mpox that were identified as critical data elements for the MSM population (nearly all U.S. mpox cases occurred among MSM). These items were added after the initial ICR submission. Amended documents with these additions were uploaded by CDC ICRO December 14, 2023.
 - Deletion of lower priority items – Every item in each Behavioral Assessment was reviewed for quality and content value. Items measuring repetitive or low priority content were removed from the assessment.
 - o Deleted 4 questions collecting duplicative or overly detailed information:
 - 1 question (DM4a), assessing legal marital status. This level of detail is not required for NHBS [pg. 14].
 - 1 question (HT10a), assessing date of last viral load test. This level of detail is not required for NHBS [pg. 94].
 - 2 questions (AL3m, AL3f) meant to assess binge drinking [pg. 68]. These items are very difficult for respondents to answer and the information is duplicative of another item (AL2).
 - o Deleted 7 questions assessing outcomes no longer necessary to report using NHBS data:
 - 2 questions (PA6d PA6e) assessing prescriptions for PrEP [pg. 106]
 - 2 questions (PA3a, PA3b), assessing receipt of new injection equipment [pg. 104]
 - 2 questions (ID5a, ID5b), assessing use of high dead space syringes [pg. 74-75]
 - 1 question (ID1b) about use of opioids before first injection. [pg. 70]
 - 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 12 questions (e.g., changes to question order, wording, response options, universe)
 - Modified the order and wording of 2 questions assessing any non-injection drug use and frequency of marijuana use (ND0, ND1, and ND2a) to reduce respondent burden. In MSM and HET cycles, a substantial proportion of respondents who used any non-injection drugs reported only marijuana use. [pg. 80-81]
 - Modified 2 questions assessing viral load testing and results (HT10a, HT10b) to improve participant comprehension and recall [pg. 94].
 - Limited the universe for 2 questions about HPV vaccine (HC9a, HC9B) to the MSM cycle [pg. 99].
 - Modified response options for 1 question assessing sources of new sterile syringes (PA2b) [pg. 103-104].

- Opened the universe for 1 question assessing awareness of PrEP (PA6a) to include participants who reported being HIV-positive [pg. 105].
 - Modified wording of 4 items about PrEP (PA6a, PA6b, PA6c, PA6e.1) to refer to “use of” rather than “taking” PrEP, to account for emerging, non-oral forms of PrEP [pg. 105-106].
- Clarity, repetitive language, and interview flow - Based on a review of all items in the Behavioral Assessments, 1 item was added and 2 were modified to improve clarity and interview flow. These changes do not affect the scope or content of the questions; they also do not affect the time burden of NHBS to 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 Added 1 introductory statement (INTRO_TX5) [pg. 85]
 - o Modified 2 questions
 - 1 question measuring sexual identity (DM10). An outdated term was removed from one of the response options [pg. 19].
 - 1 question assessing perceived community tolerance (SO4). A phrase was changed to use person-first language [pg. 22].

References:

Bauer GR, Braimoh J, Scheim AI, Dharma C. Transgender-inclusive measures of sex/gender for population surveys: Mixed methods evaluation and recommendations. PLoS ONE. 2017; 12(5): e0178043. <https://doi.org/10.1371/journal.pone.0178043>.

Ellis, R., M. Virgile, J. Holzberg, D.V. Nelson, J. Edgar, P. Phipps, and R. Kaplan. 2017. Assessing the feasibility of asking sexual orientation and gender identity in the Current Population Survey: Results from cognitive interviews. Washington, DC: Center for Survey Measurement, U.S. Census Bureau and Office of Survey Methods Research, Bureau of Labor Statistics. Available at: <https://www.bls.gov/osmr/researchpapers/2017/html/st170210.htm>.