

December 20, 2020

Submitted online at: <https://extranet.who.int/dataformv3/index.php/899588?lang=en>

RE: Call for public comment on WHO draft sexual health-related survey instrument and consensus statement

Howard Brown is the largest LGBTQ health center in the Midwest United States, serving over 38,000 patients across twelve clinic locations in Chicago, Illinois. As a federally qualified health center, Howard Brown provides comprehensive, high quality and affordable care—including primary care, behavioral health, mental health services, HIV/STI prevention, elder services and community outreach initiatives—to all of our patients, regardless of ability to pay. Howard Brown’s Center for Education, Research, and Advocacy (ERA) conducts rigorous community-based medical and behavioral research, cultivates responsive healthcare professionals, and advances policies that affirm the lives of LGBTQ people and their families. We appreciate the opportunity to provide feedback on the World Health Organization’s (WHO) draft sexual health-related survey instrument.

Howard Brown conducts a wide variety of sexual health-related public health research with LGBTQ populations. Based on our expertise, we offer the following recommendations to make the survey more inclusive of LGBTQ people and to ensure that the survey is collecting accurate data. Generally, many of these specific recommendations are related to the use of binary, hetero- and cis-normative definitions of sex. These definitions often exclude transgender and gender nonbinary (TGNB) people. Additionally, when survey questions do not make a clear distinction between sex assigned at birth and gender identity, they can be unclear and difficult to answer, especially for LGBTQ participants. Below are our specific recommendations.

Section A

- A1. If you are going to reference birth certificates or other context-specific ID documents assigned at birth, we would recommend rephrasing this question to: “What sex were you assigned on your original birth certificate?” Because some TGNB people may update their birth certificates/other ID documents, it is important to specify “original” if this question is meant to assess assigned sex at birth. Because of these complexities around ID documents, we would ideally recommend removal of reference to documents if possible and simplifying this question to: “What sex were you assigned when you were born?” We would also recommend inclusion of a response option to this question for intersex people to identify themselves.

- A5. If this question is meant to specifically assess marital status, we would recommend changing the question to: “What is your marital status?” If this question is meant to collect data on various relationships, the response options are rather limited. We would recommend adding in a response option to capture participants who are in a relationship, but not married. This is especially important for LGBTQ folks who live in locations where they cannot get married. We would also recommend including options for participants who are in non-monogamous relationships.

Section B

- For this section, and throughout the survey, skip patterns refer only to binary sex (men and women). It is unclear what question is providing the data that informs these skip patterns, and if that data is based on sex assigned at birth or on gender identity. Because there isn’t a clear distinction made between gender identity and sex assigned at birth in Section A, this survey may not capture data from every person who can become pregnant. For example, a transgender man who answers “male” for A1 would theoretically not be asked questions about being pregnant even if they had pregnancy data to report. Similarly, this survey may not capture data from every person who can impregnate another person. Rather than basing skip patterns on being a man or being a woman, which will not capture full data on pregnancy experiences and does not include all people who may take this survey, we would instead recommend replacing “men” with “people who produce sperm” and “women” with “people with uteruses.” This language is clearer and includes the people that we believe this survey is interested in hearing from about experiences being pregnant or getting someone else pregnant.
- B1. For the question, “To the best of your knowledge, how many times have you gotten a woman pregnant to date?” we would recommend saying instead: “To the best of your knowledge, how many times have you gotten another person pregnant to date?” Women are not the only people who can be pregnant, so the recommended wording is more inclusive and will produce more accurate data. We recommend this change for all the pregnancy questions in this section.
- B7. This question is confusing given question B2. We would recommend moving B7 to immediately follow B2 to clarify the distinction between age at first pregnancy and age at first delivery.
- The pregnancy section of questions in Section B ends without asking any questions relating to contraception or current fertility plans. These are important subjects to explore in a survey about sexual health.

Section C

- Like the previous section, this section just uses binary male or female language and it is unclear whether the questions are interested in sex assigned at birth or gender identity. We would recommend using language describing the body parts involved (i.e. “people with penises”) if the intent is to better understand the types of sex that participants may be having. If the intent is to better understand how the participants would identify their sexual orientation, asking a more straight forward sexual orientation question would be clearer. Consider revising C1 and C3 to clarify this.
- C6. This question should also include HIV/STI testing, pre-exposure prophylaxis (PrEP) for HIV, and post-exposure prophylaxis (PEP) for HIV as response options. Furthermore, there are several response options that include binary language that is not inclusive, and we would recommend revising these response options. For example, option b and option c for “male condom” and “female condom” could be revised instead to “external condom” and “internal condom.” Additionally, for option k, instead of “he/I withdrew,” this could be revised to “my partner/I withdrew” or simply to “withdrawal.” Similarly, for option l, “made sure it was safe time period in my/her monthly cycle” could be revised to “made sure it was safe time period in my/my partner’s monthly cycle,” or simply “made sure it was safe time period in monthly cycle.”

Section D

- D3. Rather than saying “steady relationship,” it may be more clear to instead say “long-term relationship” or “committed relationship.”
- D8. See comment for C6.
- D12 – D15. The parenthetical “(woman/man)” is unnecessary and the questions can just be ended with “...sex with someone?”

Section E

- This section is again very binary. With the understanding that this section is meant to assess a participant’s agreement or disagreement with certain societal expectations or norms around sexual health, we would recommend prefacing this sections with a short introduction that says: “We are interested in understanding how you feel about social perceptions and beliefs about sex that are rooted in binary gender norms. For E1 – E13, please read the following statements and say whether you:”

Section F

- The questions in this section that assess gender identity and sexual orientation should be asked much earlier, ideally in Section A along with the sex assigned at birth question (A1). This information will help to clarify many of the sexual behavior and practice questions that come in the following sections.
- F1. Add transgender, gender nonconforming, nonbinary, and queer as additional response options for this question. Participants should also be given the option to respond that they are not sure or do not wish to answer the question.
- F2. We would recommend adding queer as a response option to this question. We would also recommend separating the “Not sure/undecided” response option from the “Another identity not listed here” option, as these are two separate things.
- F8 – F9. These are important questions for understanding the prevalence and consequences of anti-LGBTQ discrimination. However, these survey questions are currently only asked to people based on sexual orientation. Research has shown that TGNB people experience widespread discrimination based on gender identity, and this survey should seek to capture those experiences as well. The same questions can be asked for people whose gender identity (F1) differs from their sex at birth (A1).

Thank you for the opportunity to provide comment. If you have any questions, please feel free to reach out to Tim Wang, Director of Policy and Advocacy, at timothyw@howardbrown.org.

Sincerely,

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