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Assessing Gender Identity and Sex in Diverse Low, Middle, and High-Income Settings: Findings from a WHO/HRP Consultative Process

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Short Summary: We convened a multi-disciplinary group to discuss a sexual and reproductive health instrument in diverse settings. This note describes the development of items focused on gender identity and sex.

Abstract

Obtaining detailed data on gender identity and sex in population-based sexual health studies is important. We convened a group to develop consensus survey items. We identified two items to capture data on gender identity and sex that can be used in diverse settings.

The 2019 Kenya Population and Housing Census included a survey item that specifically focused on gender identity, becoming one of the first population surveys in Africa to capture this critical information. Survey items on gender identity and sex have been revised in many countries recently (1) in order to better reflect the lived experiences and identities of all people. Obtaining detailed data on gender identity and sex is particularly important in population-based sexual and reproductive health surveys, where more complete information can help inform relevant health services. However, few population-based studies look beyond a gender (man/woman) or sex (male/female) binary when collecting data. Including measures which step beyond this binary in sexual and reproductive health surveys and all population and health surveys more broadly can help to improve awareness of and health services for all people, including non-cisgender populations (2).

Despite the importance of understanding both gender identity and sex, many general health survey items and policies continue to conflate the concepts (1, 3). The WHO working definition of sex is "the biological characteristics that define humans as female or male. While these sets of biological characteristics are not mutually exclusive, as there are individuals who possess both, they tend to differentiate humans as males and females."(4) The WHO working definition of gender is "characteristics of women, men, girls, and boys that are social constructed. This includes norms, behaviours, and roles associated with being a woman, man, girl or boy, as well as relationships with each other."(5) Most survey items about gender identity and sex have been tailored for high-income country participants in resource-rich settings, with many variations.(6-8) Survey items on gender identity and sex that can be used in diverse settings, including low and middle-income countries (LMICs), are critical for multi-country population-based surveys and

multi-country comparisons. However, there is a lack of international guidance on asking about gender identity and sex. In partnership with the World Health Organization's Department of Sexual and Reproductive Health and Research, which includes the UNDP/UNFPA/UNICEF/WHO/World Bank Special Programme of Research, Development and Research Training in Human Reproduction (WHO/HRP), our team convened a community-engaged process to develop a comprehensive sexual and reproductive health survey instrument for use in diverse settings, including LMICs. The purpose of this note is to describe the gender identity and sex survey items that resulted from this multi-stakeholder process.

Methods

The purpose of the WHO/HRP consultative process was to solicit elements (entire survey instruments, domains, and individual items) to inform the development of a sexual and reproductive health survey instrument that could be used in diverse settings. More details of the consultative process are elsewhere.(9) Briefly, the iterative process included a crowdsourcing open call, a participatory hackathon, and an adapted Delphi method (Supplemental content 1). Crowdsourcing open calls have a group of individuals attempt to solve all or part of a problem, then share solutions back with the community.(10) Hackathons are a multi-step process that bring together diverse individuals to solve a problem.(11) We used these approaches because they allowed us to engage larger groups of individuals, provide mechanisms for accountability, and increase feedback from larger groups.

These participatory processes allowed us to obtain feedback from diverse individuals from around the world. At the open call stage, a total of 59/175 contributions were from people in

LMICs, covering all WHO geographic regions. At the open call judging stage, 11/12 judges had experience leading sexual or reproductive health studies in LMICs. At the hackathon, a total of 22/35 participants were from LMICs. Our hackathon included researchers from countries where non-binary individuals and non-cis gender populations are stigmatized.(9) A stepwise process involving three rounds of online surveys and an adapted Delphi method was used to achieve consensus. The final output included a brief consensus statement and sexual and reproductive health survey instrument intended for population-based surveys. This was shared in a manuscript, announced by the HRP, field tested in some countries, and will be field tested in 20 total countries.

Results

There was intensive discussion about how best to frame gender identity and sex in diverse settings. The final survey instrument proposed a set of two survey items on gender identity and sex (Box 1). These two items preserved the distinction between the individual concepts, expanded responses options, and moved beyond traditional sex and gender binaries. We propose that the two items can be used in diverse settings.

One key tension is that familiarity with non-binary response options (e.g. intersex persons for the 'sex' question, as well as numerous gender identities outside of cisgender men/women) can vary widely across countries and within segments of any country's population. Additionally, some gender identities with longstanding cultural or social traditions may not be recognized outside a specific country or culture. For example, the term *hijra* is a non-binary gender identity, which can include transgender and intersex persons, which is officially recognized as a third gender in

India and several other countries in the region. As a response-option in a survey, however, it would not be recognized outside of this region.

For our global survey instrument, we opted for a broader third option for gender identity. We intentionally avoided the use of an "Other" gender response to avoid further entrenching the concept of a gender binary, which could further marginalize many people who identify as something other than cisgender man or woman.(12) When implemented, researchers can include locally-recognized, non-derogatory gender identities. These should be done with appropriate consultation around appropriate terminology as well as field testing.

Discussion

Our multi-stakeholder process identified gender identity and sex items that are inclusive and could potentially be used in a broad spectrum of settings. The community-engaged, iterative process included robust input from researchers around the world who were familiar with local norms and gender research. This WHO/HRP consultative process breaks new ground in using participatory methods to inform the development of a multi-country survey instrument. The resulting items have already been used by researchers in Kenya, Malaysia, China and other countries as part of a multi-country COVID-19 survey (13). Two points are worth highlighting.

First, the participatory process allowed us to identify some of our own gender biases, resulting in a more inclusive survey instrument. Despite a substantive and technical interest in more inclusive surveys, heteronormative language is deeply entrenched in our thinking and our language. There is a delicate balance to be inclusive of populations with a long history of being overlooked and

marginalized, while at the same time maintaining comprehension and applicability across a wide variety of global communities and cultures. This consultative process suggests that such a compromise is possible.

Second, prominent local variations in terminologies revealed the complexity of gender identity and sex. Identifying appropriate survey items is important to capture this nuance. Survey instruments that conflate gender identity and sex may be upsetting and cause distress. Similarly, reduction of gender to a binary construct could re-affirm conventional gender and sex stereotypes that are social determinants of illness (7).

This study has several limitations. First, this is only a single brief survey instrument and there is a need for a longer survey instrument. Second, we did not have a comparator arm to assess the crowdsourcing consensus approach, underlining the need for more research. Finally, data from ongoing field testing has yet to be incorporated.

However, our proposed survey items are not meant to be an ultimate and static solution, but a starting point for more dialogue between researchers and local communities to adequately reflect gender identity and sex in the local context. Further research is needed to clarify these important points and ensure that population-based sexual health surveys capture appropriate data on gender identity and sex.

Box 1. Two brief items to assess gender identity and sex in sexual and reproductive health surveys for use in diverse settings. The entire survey instrument is in a supplement to the main paper.(9)

1. At birth, were you described as….?

   a. Male
   b. Female
   c. Intersex, undetermined, or another sex

2. Today, do you think of yourself as…?

   a. Man/boy
   b. Woman/girl
   c. In another way (please specify)

Contributors

All authors wrote components, edited the manuscript and approved the final draft. All authors confirm that they have contributed to this article and met the following three requirements: (a) they made significant contributions to the conception, design and implementation; (b) they drafted or revised the article for intellectual content; and (c) gave final approval of the submitted article.

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Competing interests

The authors declare that they have no conflict of interests.

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Supplemental Material 1. Consensus process methods

We used a three-stage adapted Delphi process to achieve consensus. Each stage of the Delphi process incorporated feedback from a group of individuals and iteratively revised the survey instrument and related implementation considerations. Participants completed a brief survey instrument that included five-point Likert items (strongly agree to strongly disagree) associated with key components of the survey instrument. Data from the first stage were discussed as a group at the hackathon event. The second round of the survey was administered and discussed at the hackathon event. The third and final survey was organized by email. Dissent was encouraged at all stages in order to make the survey instrument stronger. Items that achieved 100% agreement were graded as "U" (unanimous), 90-99% agreement was graded as "A", 80-89% agreement was graded as "B", and items with less than 80% agreement were not included.