

November 10, 2023

Docket #USBC-2023-0007

Submitted: via email to [acso.pra@census.gov](mailto:acso.pra@census.gov)

Re: American Community Survey SOGI Test

To whom it may concern:

The Multi-Regional Clinical Trials Center of Brigham and Women's Hospital and Harvard (MRCT Center) appreciates the opportunity to comment on the Census Bureau's ("the Bureau's") American Community Survey Sexual Orientation and Gender Identity Test ("the Test") as part of its ongoing American Community Survey Methods Panel Tests. We direct our comments below to the thoughtful survey methods proposed at [88 C.F.R. 64404](#).

The MRCT Center is a research and policy center that addresses the ethics, conduct, oversight, and regulatory environment of international, multi-site clinical trials. Founded in 2009, it is an independent convener to engage diverse stakeholders from industry, academia, patients and patient advocacy groups, non-profit organizations, and global regulatory agencies. The MRCT Center focuses on pre-competitive issues to identify challenges and to deliver ethical, actionable, and practical solutions for the global clinical trial enterprise. While the MRCT Center often collaborates and interacts with regulators around the globe, we have not discussed the comments provided here with any regulatory agency. The responsibility for this document's content rests with the MRCT Center's leadership, not with its collaborators nor with the institutions with which its authors are affiliated.<sup>1</sup>

We share your vision for bringing Sexual Orientation and Gender Identity (SOGI) data to the foreground and your enthusiasm for understanding how best to ask these questions. Only with reliable data will we be able to inform meaningful endeavors in representation and civil rights arenas, among many others. To that end, we would first like to thank the Bureau for its commitment to this endeavor and its willingness to engage the public to provide input. Second, we would like to provide our feedback and explain a few concerns on the proposal presented in the Federal Register. Below, we offer comments on some general areas of concern we would prefer to see included in the Test's fundamental design, followed by some specific questions and comments about the methodology proposed.

The collection of reliable SOGI data remains a challenge to researchers, and we applaud the Bureau's commitment to reinventing the American Community Survey (ACS) to be more

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<sup>1</sup> Brigham and Women's Hospital, Ropes and Gray LLP, Harvard Medical School, and Harvard University.

reflective of the communities it describes. Our few comments should not diminish our overarching enthusiasm for this work.

## General Comments

### *Reconsideration of the term "Test"*

While we appreciate the basis for designating the current collection of information as a "Test," we advise that the Bureau reconsider the term, particularly if the term "Test" may be used in written or oral communications with respondents or the public. The word may easily be misinterpreted, implying that the Bureau is interested in the answers to the SOGI questions that are themselves the test, not that the Bureau is conducting a data-driven exercise to understand how best to ask these questions. Particularly in the collection of sensitive and potentially stigmatizing data, any cause for misinterpretation should be eliminated.

Notwithstanding this concern, in the comments below, we use the term "Test" for clarity.

### *Privacy Concerns*

While we at the MRCT Center support the Bureau's Test on the inclusion of SOGI data in the ACS, we have serious concerns regarding the protection of individuals in historically vulnerable and marginalized communities who will be identified in non-anonymous ways as a result of this effort. According to a report from the National Academies on Science, Engineering, and Medicine (NASEM) "[Measuring Sex, Gender Identity, and Sexual Orientation.](#)"

Data collected in administrative settings are often linked to specific individuals, such as for vital statistics and other legal identification documents to establish identity. However, **these data have sometimes been used to facilitate segregation, harassment, and discrimination.** In many administrative settings, strong legal privacy protections like those in health care do not exist, so there may be specific contexts in which the collection of some of these data, such as intersex status or sex assigned at birth, may be considered invasive. For these reasons, it is especially important to establish a clear need to collect these data, **minimize the risk of data disclosure and misuse,** and allow individuals to opt out of responding. (p. 10) [emphasis added]

We encourage the Bureau to address concerns over respondents' privacy in advance of collecting any data. In the current political climate, one in which a reported [586 anti-trans bills have been introduced nationwide this year alone](#), the collection of non-anonymous data of this sort – effectively creating a government-run database of information that includes the address, ages, and sexual orientation and gender identity of household members – simply *must* coincide

with robust privacy protections to ensure the safety of individuals, households, and communities. Unlike in surveys where individuals self-report and should have the option to opt-out of answering questions on sexual orientation and gender identity, which is one minimum form of privacy protection, in the case of this Test, individuals that are reported on by proxy do not have the option to opt-out of information about their sexual orientation or gender identity being given. In the well-intended spirit of the Bureau's endeavor, we recommend the Bureau carefully consider, clarify, and communicate how respondents' and household members' privacy will be protected, the potential for disclosure/misuse minimized, and how any inappropriate or unapproved uses of these data will be penalized/prosecuted before proceeding with the Test. Further, we recommend that the process of this clarification involve LGBTQIA+ leaders at the community, state, and federal levels so that their views on the appropriate types and level of protections are respected and that this important Test is not wrongly delayed.

## Methodological Comments

### *Sex assigned at birth*

We support the Bureau's proposal to omit language regarding a respondent's "original birth certificate" and agree that many respondents may not have or may not have access to their original birth certificates. However, the language proposed in the section, "What sex was <Name> assigned at birth? *Mark (X) ONE box*" does not state what the pro forma response options would be. The paragraph refers to male/female and addresses some issues with the "X" designation, but it does not explain what the choices will be.

Our concern in this regard stems from the inference that responses would conform to the traditional, but outdated, concept of binary biological sex, despite the increased frequency and visibility of individuals assigned "intersex" at birth. (See e.g., [Moseson et al, 2020](#).) We recommend inclusion within the language of the proposal itself the selectable variable options available to respondents when answering the question referenced above to support the collection of more comprehensive, more reliable, and more accurate SOGI data.

Furthermore, we recommend testing the inclusion of "intersex" as one of those variables in "sex assigned at birth," potentially in a sub-sample of the surveys. We recognize that NASEM's report explained, "Available research on specific language is too limited for the panel to offer definitive recommendations on the exact terminology to use in the measurement of intersex status." (p. 145). However, the National Science and Technology Council Subcommittee on Sexual Orientation, Gender Identity, and Variations in Sex Characteristics (SOGI) Data Subcommittee on Equitable Data stated in the report "[Federal Evidence Agenda on LGBTQIA+ Equity](#)" that "Some commenters recommended further question development and testing on how to ask questions about intersex populations and people with variations in sex

characteristics... [and] consistently made clear that these areas of future research – along with continued testing of SOGI questions to account for evolving terminology – should not delay the Federal Government’s progress on including SOGI data collection on surveys and forms.” (p. 13) Therefore, this Test seems like an opportune time to further question development on how to ask questions about intersex populations and people with variations in sex characteristics, which may begin to reduce the stigma and harmful segregation of intersex individuals.

Thus, will the “Mark [X] one box” choices be “Male / Female / Intersex or X / Other / Do not know / Prefer not to answer” or some other choice? Will the order of choices start with male first? Please note, particularly given the intention to permit proxy respondents, “Do not know” is an important additional choice.

#### *Age of respondents and current gender*

The proposed question regarding current gender indicates that this question will be asked “only of people who are 15 and older,” while the survey methodology later states, “For half of the reinterview sample, we will reinterview the sample respondent as the original interview, for the other half we will reinterview another adult member of the household.” First, we would like to ask for clarification whether only adults (i.e., those age 18 or older) will be allowed to act as the [proxy] respondent for the household, and thus whether those individuals in the household aged 15-17 would ever be able to provide information from their perspective about themselves or other household members. Further, if the “of” in the statement “asked only of people who are 15 and older,” does actually mean [by proxy] *about* people who are 15 and older and not to people who are 15 and older, will it be clear to the proxy adult respondents that they should not answer, respond to, or seek to gather information on the gender questions for individuals in the household who are under 15 years of age?

The proposal also lists a series of responses that will be made available to respondents regarding an individual’s current gender but does not define those terms or indicate methodologically whether definitions will be made available to respondents. Given the dynamic nature of gender vocabulary, interpretation of this question and comparisons of the responses over time will be challenging unless definitions are included. While we appreciate how challenging providing culturally appropriate definitions may be, the utility of collecting this information depends upon common definitions of the data elements.

Additionally, the proposal describes a “more concise” version of the question on current gender that will be employed in the “proxy version” of the Test but does not elaborate on how the wording would change under these circumstances. We propose amending the language (i) to reflect more clearly the reality that questions on current gender during the Test may be directed to individuals or their proxies, (ii) to indicate whether definitions of responses will be provided to respondents and, if so, what those definitions will be, and (iii) to include the “more

concise” wording mentioned with respect to the proxy version of the question, so that the public can provide more concrete comments on the proposed Test.

### *Current gender verification*

The proposal describes a verification process to be included in the Test for those occasions when an individual’s responses to “sex assigned at birth” and “current gender” do not “match.” We appreciate the Bureau’s proposal to include this verification process irrespective of the responses to the questions as a necessary step to validate proxy responses. However, the use of the phrase “do not match” appears to imply that the gender identity of a non-cisgendered individual is somehow discordant. In an effort to gather robust, inclusive, and accurate SOGI data, we recommend reconsideration of the terminology.

### *Sexual orientation*

As above with the gender identity question, the language of the proposal should clearly indicate the age threshold of the potential household [proxy] respondent and confirm that the proxy respondent will only answer, respond to, or seek to gather information on sexual orientation for individuals in the household who are 15 years of age or older. Similarly, the proposed question on sexual orientation offers several responses but does not indicate whether or how those terms will be defined for survey respondents. Beyond the similar methodological concerns between this question and the one above on gender identity, the Bureau has proposed additional methods specific to this question about which we have concerns. First, the Test proposes to omit “I don’t know” as a viable response to the question on sexual identity to “minimize nonresponse and increase data quality.” However, we recognize that individuals of any age, but especially those as young as 15 years old, may not know their sexual orientation. Further, sexual orientation will evolve and change, prompting the question of how often this survey will be conducted. We believe that providing the option “I don’t know” will increase data quality over potentially forcing a response that may not be reflective of the truth about an individual. Lastly, for this question, the Test proposes to create a means by which in-person respondents may answer this question via flash card to “help address [the] sensitivity” that may arise in interviewer-led circumstances, but the proposal does not indicate how this process will work or how the process would ameliorate any of the concerns surrounding the sensitivity of the subject matter.

### *Reinterview*

The Test also proposes to reinterview respondents as a means to compare the reliability of the proxy-reported responses against the self-reported responses. However, the language of the proposal does not appear to connect directly to this objective, as it is unclear when/how the survey will obtain self-reported responses to sexual orientation and gender identity questions.

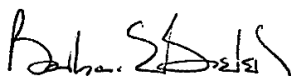
The proposed reinterview process would involve revisiting the initial survey respondents or “another adult member of the household.” If the people in the household that are LGBTQIA+ were not the initial survey respondent or “another adult member of the household” that was selected in the alternate sample for re-interview, how could they self-report responses to compare to the proxy responses? And if household members will self-report at reinterview to compare against proxy responses, how will privacy of the self-reporter be protected (Even from household members)? The proposal’s intent to assess self-reported data aims to address a much-needed area of concern regarding data integrity, but a more detailed and targeted method by which the Test would gather self-reported data for the purposes of benchmarking the reliability of proxy-reported data is needed.

### *Conclusion*

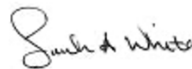
We appreciate the opportunity to comment on this proposal. It is a difficult and nuanced undertaking, and we value the Bureau’s commitment to improving the integrity of the data it gathers. We believe the Test as proposed represents an important first step toward gathering robust and reliable demographic SOGI data, and we hope to be able to contribute and provide comments to an updated proposal from the Bureau. We would also welcome the opportunity to work directly with you to bring this vision for a 21<sup>st</sup> century ACS to fruition safely and ethically.

Please feel free to contact the MRCT Center ([bbierer@bwh.harvard.edu](mailto:bbierer@bwh.harvard.edu) or [sawhite@bwh.harvard.edu](mailto:sawhite@bwh.harvard.edu)) if we can be helpful or if you wish to discuss.

Respectfully submitted,



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