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Comment from National LGBT Cancer Network

Submitter Information

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General Comment

The National LGBT Cancer Network would like to submit a comment on the proposed measurement changes for the National Quitline Data Warehouse.

First, let it be known that the National LGBT Cancer Network is CDC-funded to run one of the eight tobacco and cancer disparity networks, the one on LGBTQ persons. In this capacity we serve as subject matter experts on the topics of LGBTQ tobacco and cancer impacts. A large part of our work is to provide technical assistance on these points to state or federal governmental entities. The author of these specific comments, Dr. Scout, has worked in this capacity for over a dozen years. Over these years, Dr. Scout has also been a subject matter expert on measurement strategies for the sexual orientation and gender identity (SOGI) populations, including testing measures for MN state quitlines, working with National Jewish Quitline and the North American Quitline Consortium to further enhance measures, as a co-chair of the Williams Institute Gender Identity in US Surveillance (GenIUSS) workgroup and more recently as a presenter on SOGI data collection at the Behavioral Risk Factor Surveillance System annual meeting. Our organization has led or co-signed numerous recent letters related to SOGI + intersex data collection, including those to the White House, National Association of Insurance Commissioners, U.S. Senate, U.S. Census Household Pulse Survey, and the HHS Assistant Secretary of Health. We are also members of the Federal LGBTQI Health Policy Roundtable, and as such work closely with a large group of federal organizations to best convey best strategies for policy changes to federal entities.

We strongly support the addition of better measurement strategies for LGBTQ populations in the National Quitline Data Warehouse. As was clearly outlined in the 2011 Institute of Medicine report on LGBT health and newer research continues to support, the disproportionate impact of tobacco on the LGBTQ populations is profound. By most recent MMWR report, we have tobacco use rates 45% higher than the general population. In order to eliminate this disparity, we must measure and monitor access to the quitlines by this population.

In following information coming out of the current convening of the National Academies of Science, Engineering, and Medicine workgroup on SOGI measurement, we would however recommend some minor changes to the question wording.

Ask about gender identity first.

The CDC's recommendation and the recommendation of leading LGBTQI+ researchers and analysts is that gender identity be asked first, before sex assigned at birth. Asking gender identity first reflects the importance of gender in the lived experiences of all people, both transgender and cisgender.

Allow respondents to select all that apply for gender identity, and include a free-text answer option for gender identity.

The option to mark more than one answer choice has not been universally implemented on federal, national-scale U.S. data collections; however, some recent federal and academic data collections, including the National Institutes of Health (NIH) All of Us Research Program and the PRIDE Study, have included this feature. Studies and reviews of gender identity questions have found that, for some gender minority individuals, "male" and "female" are not mutually exclusive from "transgender" or "another gender identity." A recent study using focus groups and cognitive interviews among sexual and gender minority participants identified the need to allow participants to select more than one answer choice with a "select all that apply" prompt. The ability to select all that apply and inclusion of the answer choice of "Another gender identity (specify)" both clarifies the question is asking about gender identity and provides a write-in option for those who do not find a suitable choice among those provided. These question features are also in line with recently published statistical data collection standards published by the New Zealand government. (If you would like to see more citations to support this, please reference a letter submitted to CMS at this link:

https://docs.google.com/document/d/1xHfWIFF2iYG2w0_CsNfcY9vhgWAGaGSlaV6UdSRT6QE/edit.

Specifically, we recommend the following design for the "two-step" question:

Gender:

What is your gender? Please select all that apply.

1. Male
2. Female
3. Transgender
4. Another gender (please specify): _____

Sex assigned at birth:

What sex were you assigned at birth, on your original birth certificate?

1. Male
2. Female
3. Something else (please specify): _____
4. Prefer not to say

Additionally, in keeping with NIH precedent, we would also strongly urge you to consider measuring intersex status as well on quitline intake. Information on best measures for this can be found at this link: <https://interactadvocates.org/intersex-data-collection/>.

Thank you for the commitment to these improvements.