



The American Psychological Association (APA) is an accredited nongovernmental organization (NGO) at the United Nations. APA is the largest scientific and professional organization representing psychology in the United States, with more than 118,400 researchers, educators, clinicians, consultants, and students. Our mission is to promote the advancement, communication, and application of psychological science and knowledge to benefit society and improve lives. As a means to advance this mission, we appreciate the opportunity to submit comments to the United Nations Independent Expert on the topic of sexual orientation and gender identity (SOGI) data collection in the United States.

SOGI data collection is vital to improving the health of sexual and gender minorities (SGMs), which is fundamental to Article 12 of the International Covenant of Economic, Social, and Cultural Rights: “The right of everyone to the enjoyment of the highest attainable standard of physical and mental health.”¹

APA’s 2016 Resolution on Data about Sexual Orientation and Gender Identity² explains the importance of survey data for assessing the need for public policies that address group disparities in mental health, health, and social outcomes, as well as for evaluating the impact of these policies. The inclusion of sexual orientation and gender identity as demographic variables enables scholars, policymakers, and the general public to interpret and gain a more accurate understanding of their relationship to important health and social outcomes. For example, with the introduction of items regarding sexual and gender minority status to the 2000 U.S. Census, the country has benefited from a dramatic increase in understanding the lives and conditions of people who are in a same-sex couple household.

Based on existing data, we know that SGMs experience less access to health care and higher rates of certain diseases, such as depression, cancer, and HIV/AIDS, compared to the general population. Moreover, SGMs are more likely to be targets of violence than other groups. Accordingly, data collection is critically important to better our nation’s understanding of the life experiences of this population in order to improve their mental health, physical health, and well-being.

We would like to specifically address the Independent Expert’s questions on this topic. Some of our responses address more than one question, in which cases we have clustered the questions together.

What are the current efforts by States to increase their knowledge of the LGBT population? Specifically, are questions about sexual orientation and gender identity included in government surveys (e.g., the census, national health surveys, income and living condition surveys, or other surveys funded or mandated by the State), administrative records (e.g., birth certificates/birth registries, identity cards, school records, professional licenses, social security and public benefit records, and other government documents)?

What kinds of data can be collected by government to understand the nature and extent of violence (e.g., through statistics on LGBT-phobic hate crimes and hate speech),

discrimination, and disparities in health, education, labour, civic participation, and other important areas?

The U.S. government has made great strides in the past decade on SOGI data collection, including health, living conditions, and victimization. In 2011, the Institute of Medicine (IOM) – now the National Academy of Medicine -- recommended that the National Institutes of Health (NIH) support research to develop measures on, and include standardized questions about, sexual orientation and gender identity in all federally-funded surveys. This led to NIH convening the Sexual and Gender Minority Research Coordinating Committee in 2015 to address research activities affecting sexual and gender minority communities; NIH now has a webpage dedicated to developing methods to accurately capture and understand the health of LGBT populations: <https://dpcpsi.nih.gov/sgmro/measurement>. In 2016, the NIH National Institute on Minority Health and Health Disparities (NIMHD) designated SGMs a health disparity population, and an Office of Management and Budget report called for more representative and better-quality SOGI data.

As a result of these initiatives, under the Obama administration, 12 federal surveys and studies measured sexual orientation; seven of these also measured gender identity or transgender status. Questions on sexual orientation (SO) and/or gender identity (GI) were included in many public health surveys, such as the Behavioral Risk Factor Surveillance System (SOGI) and Youth Risk Behavior Survey (SO), the National Health Interview Survey (SO), the National Survey on Drug Use and Health (SO), and the Health Center Patient Survey (SOGI). Several other surveys collected SOGI data that examined social determinants of health, such as the National Crime Victimization Survey (SOGI), which collects data on intimate partner violence, and the National Inmate Survey (SOGI), which collects data on sexual assault in prison.³

However, this progress is being rolled back. In recent years, we have observed many federal agency actions that threaten to reverse years of progress towards enhanced SOGI data collection:

- Proposed removal of SOGI questions from the National Survey of Older Americans Act Participants by the Administration for Community Living (ACL), Department of Health and Human Services (HHS).
- Reversal of plans to add SOGI questions to the Annual Program Performance Report for Centers for Independent Living by the ACL.
- Removal of SOGI from the planned topics for the American Community Survey and the 2020 Census (the largest survey in the U.S.) by the Census Bureau, Department of Commerce.
- Reported withdrawal of official requests for inclusion of SOGI topics in the ACS and 2020 Census by the Department of Housing and Urban Development, the Department of Justice and the Environmental Protection Agency.
- Removal of SOGI data collection from the “Draft U.S. Core Data for Interoperability and Proposed Expansion Process” in January 2018, by the Office of the National Coordinator for Health Information Technology.

What safeguards are in place, and what safeguards are needed, to protect the human rights of individuals providing personal data as well as individuals collecting such data?

- *Safeguards to protect the privacy of individuals who provide data about their sexual orientation/gender identity, and the confidentiality of the data provided by these individuals.*
- *Broader statutory rules or administrative policies to insure transparency and accountability of government institutions such as statistical bodies.*

What are the risks associated with the collection and management of data on sexual orientation and gender identity and initiatives to overcome those?

APA encourages all data collection to protect the safety, dignity, and privacy of research participants who are members of stigmatized populations, including sexual and gender minorities, at all stages in the design, implementation, and dissemination of data collection.

Given the possibility that the identity of respondents could be compromised in population-based surveys, it is essential that researchers develop safeguards in their methodology to prevent this occurrence. For example, when conducting research with adolescents, it is recommended that questions regarding sexual orientation not be placed in demographics sections, particularly if this section is placed at the beginning of the instrument, thus making it easier to see how someone else responds, violating privacy. Moreover, minors should be notified that in some instances their gender data field cannot be hidden from their guardians.

In the event that transgender identity is collected in a clinical setting for minors and is documented in the clinical notes, best practices, such as the ones recently approved by the Health Commission of the San Francisco Department of Public Health, are to consider the local Minor Consent Policies in place. (See Best Practice for Asking Questions about Sexual Orientation on Surveys by SMART⁴ and the San Francisco Department of Public Health Sex & Gender Guidelines⁵ for additional recommendations for safeguards to ensure privacy and anonymity.)

It is also important to consider the developmental appropriateness of asking SOGI questions of participants and the feasibility of gaining full consent from vulnerable populations.

Are there circumstances where data collection is ill-advised, such as in countries that criminalize same-sex behavior or where particular government agencies have demonstrated a cause for concern regarding their treatment of issues related to sexual orientation and gender identity?

Although 193 countries signed onto the Sustainable Development Goals and UN 2030 agenda to leave no one behind and protect the rights of all, SGMs were not mentioned explicitly in the document. In many parts of the world, it is dangerous to be an SGM. According to the United Nations High Commissioner for Human Rights, in 2015, “at least 76 States retain laws that are used to criminalize and harass people on the basis of sexual orientation and gender identity or expression, including laws criminalizing consensual, adult same-sex relationships.”⁶ In some states, such conduct may even result in the death penalty. In nations such as these, data must be collected extremely carefully, and results interpreted with caution due to participants’ fear of repercussions.

When States engage in data gathering activity, to what extent is civil society able to meaningfully participate in the design and implementation of these programs? This question includes the following:

- ***Do states have policies that guide the process of civil society participation national statistical programs and other State efforts to increase knowledge about LGBT populations?***
- ***Does civil society have the capacity, in terms of expertise and technical knowledge, to meaningfully participate in State efforts to gather data?***
- ***What constitutes meaningful participation in this area?***

Civil society should be afforded opportunities for meaningful participation in national-level data-gathering activities. Engagement early in planning processes helps with acceptance of data collection activities, particularly where information is asked of populations facing stigma or discrimination, such as SGMs.

States may require entities funded to collect data on SGMs to demonstrate they have incorporated meaningful community engagement into their decision-making. One model of meaningful community engagement is the Community Advisory Board. A Community Advisory Board is a group of community members or stakeholders representing the local population(s) impacted by the data collection that works in close collaboration with those institutions responsible for collecting the data. If the formation of official advisory bodies is not feasible, states may convene periodic consultation meetings with members of the SGM community and other interested stakeholders. These consultations could include opportunities for national statistical programs to obtain input into data collection planning and dissemination of findings.

Does the lack of a global classification scheme carry risks that data will not be useful for international comparisons or will not accurately reflect the identities and lived realities of local populations?

Data need not be universal to be valuable. Data collection by individual states would benefit those states and SGMs living within them.

Data collection, including language, should be specific to cultures and languages in order to accurately reflect the identities and lived realities of local populations. For example, in 2011, the government of Nepal attempted to utilize a census in which respondents had the option of choosing “Male,” “Female,” or “Third Gender.” However, the effort was not successful, partly because large proportions of the gender minority population did not identify with the term “third gender.” Subsequent research determined that the use of culturally specific terms such as “Methi” and “Kothi” would have increased the accuracy of the census.⁷

Over time, we hope that researchers will discover ways to compare international data, even in the absence of uniformity of classification systems.

Thank you for the opportunity to provide our input on these questions. If we may provide any further information, please contact Dr. Rashmi Jaipul, APA’s United Nations NGO Main Representative, at rashmijaipal@gmail.com.

¹ International Covenant on Economic, Social, and Cultural Rights. United Nations General Assembly. 16 December, 1966. Retrieved from <https://www.ohchr.org/en/professionalinterest/pages/cescr.aspx/>.

² American Psychological Association. (2016). *Resolution on Data about Sexual Orientation and Gender Identity*. Retrieved from <https://www.apa.org/about/policy/data-sexual-orientation>

³ <https://fenwayhealth.org/wp-content/uploads/The-Fenway-Institute-Trump-Pence-Administration-One-Year-Report.pdf>

⁴ SMART (Sexual Minority Assessment Research Team). (2009). *Best practices for asking questions about sexual orientation on surveys*. Retrieved from The Williams Institute website: <http://williamsinstitute.law.ucla.edu/wp-content/uploads/SMART-FINAL-Nov-2009.pdf>

⁵ San Francisco Department of Public Health. (2014). *Sex and gender guidelines: Principles for collecting, coding, and reporting identity data*. San Francisco, CA: Author. Retrieved from https://www.sfdph.org/dph/files/PoliciesProcedures/COM5_SexGenderGuidelines.pdf.

⁶ Report of the Office of the United Nations High Commissioner for Human Rights. (2015). *Discrimination and violence against individuals based on their sexual orientation and gender identity*.

⁷ Park, A. (2016). *Reachable: Data collection methods for sexual orientation and gender identity*. Report prepared in conjunction with a presentation at a civil society event during the sixtieth session of the United Nations Commission on the Status of Women. Retrieved from <https://williamsinstitute.law.ucla.edu/wp-content/uploads/Reachable-Data-collection-methods-for-sexual-orientation-gender-identity-March-2016.pdf>.