

March 15, 2019

Submitted electronically to ie-sogi@ohchr.org.

RE: Call for Input—Report of the Independent Expert on Protection against violence and discrimination based on sexual orientation and gender identity

Dear Mr. Victor Borloz-Madrigal,

We are grateful to submit input regarding this important topic on behalf of the Fenway Institute at Fenway Health. The Fenway Institute works to make life healthier for those who are lesbian, gay, bisexual, and transgender (LGBT), people living with HIV, and the larger community. We do this through research and evaluation, education and training, and policy analysis. We are the research division of Fenway Health, a federally qualified health center (FQHC) and Ryan White Part C HIV clinic in Boston, MA that serves 32,000 patients each year. About 15,000 of our patients are LGBT, and nearly 4,000 are transgender. We provide our thoughts on your questions below.

1. What are the current efforts by States to increase their knowledge of the LGBT population? Specifically, are questions about sexual orientation and gender identity (SOGI) 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)?

Currently in the United States, at least 12 federal government surveys collect data on sexual orientation, and 6 of those 12 surveys also collect data on gender identity. Of these 12 federal surveys, 10 are administered by the U.S. Department of Health and Human Services (HHS) and 2 are administered by the U.S. Department of Justice (DOJ). A table providing more information regarding these 12 surveys is included below^{1,2}:

¹ Federal Interagency Working Group on Improving Measurement of Sexual Orientation and Gender Identity in Federal Surveys. (2016, Aug). Current Measures of Sexual Orientation and Gender Identity in Federal Surveys. Retrieved from: https://nces.ed.gov/FCSM/pdf/current_measures_20160812.pdf.

² Centers for Medicare & Medicaid Services. Sexual and Gender Minority Clearinghouse. Last updated: Oct. 26, 2018. Retrieved from: <https://www.cms.gov/About-CMS/Agency-Information/OMH/resource-center/hcps-and-researchers/data-tools/sgm-clearinghouse/index.html>

Survey Name	Government Department	Survey Overview	SOGI Data
Behavioral Risk Factor Surveillance System (BRFSS)	HHS	Collects data on a wide variety of health risk behaviors and conditions	SOGI
Health Center Patient Survey (HCPS)	HHS	Collects data on delivery of care to underserved populations, how patients perceive quality of care received	SOGI
National Adult Tobacco Survey (NATS)	HHS	Collects data on tobacco use prevalence, facilitators/barriers to tobacco use, evaluation of tobacco programs	SOGI
National Health and Nutrition Examination Survey (NHANES)	HHS	Collects data on nutrition	SO only
National Health Interview Survey (NHIS)	HHS	Collects data on prevalence and distribution of illness and disability, services for such conditions	SO only
National Survey of Family Growth (NSFG)	HHS	Collects data on family life, family planning, contraception, sexual health	SO only
National Survey of Older Americans Act Participants (NSOAAP)	HHS	Collects data on health of older Americans, access to and quality of elder services programs	SO only
National Survey on Drug Use and Health (NSDUH)	HHS	Collects data on substance use prevalence, risk behaviors	SO only
Population Assessment of Tobacco and Health (PATH)	HHS	Collects data on tobacco use and health outcomes	SOGI
Youth Risk Behavior Surveillance System (YRBSS)	HHS	Collects data on health risk behaviors among youth and young adults	SO only
National Crime Victimization Survey (NCVS)	DOJ	Collects data on crime, incarceration, violence victimization, intimate partner violence	SOGI
National Inmate Survey (NIS)	DOJ	Collects data on prevalence and incidence of sexual assault in correctional facilities	SOGI

2. 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?

In the United States, the Uniform Crime Reporting Program of the Federal Bureau of Investigation (FBI) collects and reports on hate crime data. For each hate crime report, law enforcement is required to indicate at least one bias motivation for the offense. Sexual orientation bias and gender identity bias are both included as options for the motivating bias for hate crime reports. Using this data it is possible to better understand the nature and extent of violence, especially hate crime violence, against LGBT Americans. For example, in 2014, 18.6% of reported hate crimes in America were perpetrated on the basis of the victim's sexual orientation, and 1.8% were perpetrated on the basis of the victim's gender identity.³ Taken together, hate crimes motivated by sexual orientation and gender identity bias comprised more than one fifth of all reported hate crimes in America in 2014. Analysis of this data has also shown that LGBT Americans are more likely to be targets of hate crimes than any other minority group.⁴

The Bureau of Justice Statistics (BJS), under the U.S. Department of Justice, collects, analyzes, publishes, and disseminates data on crime, criminal offenders, victims of crime, and the operation of the justice systems at all levels of government. BJS has collected and reported data showing disproportionate rates of sexual assault in state prisons against gay and bisexual men⁵ and transgender women.⁶

The federal government has also promoted the collection of SOGI data in healthcare settings to better understand and address health disparities. For example, the Centers for Medicare & Medicaid Services encouraged SOGI data collection in their 2015 Equity Plan for Improving Quality in Medicare.⁷ The Health Resources and Services Administration Bureau of Primary Healthcare requires health centers to report on

³ Federal Bureau of Investigation. Uniform Crime Reports: 2014 Hate Crime Statistics. Retrieved from: <https://www.fbi.gov/about-us/cjis/ucr/hate-crime/2014>

⁴ Park H, Mykhyalyshyn I. (2016, Jun 16). L.G.B.T. People Are More Likely to Be Targets of Hate Crimes Than Any Other Minority Group. *The New York Times*.

⁵ Beck AJ, Johnson C. (2012, May). Sexual victimization reported by former state prisoners, 2008. U.S. Department of Justice, Office of Justice Programs, Bureau of Justice Statistics. <http://www.bjs.gov/content/pub/pdf/svrfsp08.pdf>

⁶ Beck A. (2014). *Sexual victimization in prisons and jails reported by inmates, 2011-12. Supplemental tables: Prevalence of sexual victimization among transgender adult inmates*. Washington DC: U.S. Department of Justice, Office of Justice Programs, Bureau of Justice Statistics. http://www.bjs.gov/content/pub/pdf/svpjri1112_st.pdf

⁷ Centers for Medicare & Medicaid Services Office of Minority Health. (2015). The CMS Equity Plan for Improving Quality in Medicare. Retrieved from: https://www.cms.gov/About-CMS/Agency-Information/OMH/OMH_Dwnld-CMS_EquityPlanforMedicare_090615.pdf

SOGI data for their 18 million patients.⁸ The Meaningful Use Incentive Program, now called Promoting Interoperability, requires that certified Electronic Health Records systems have data fields to collect SOGI data.⁹

Surveys that ask about SOGI and health outcomes and risk behaviors are useful for understanding LGBT health disparities. For example, the Behavioral Risk Factor Surveillance System (BRFSS) and the Youth Risk Behavior Surveillance System (YRBSS) are two federally funded surveys administered in most states. These surveys provide data on a wide variety of health-related measures, such as health status, risk behaviors, victimization, and behavioral health. The BRFSS includes a module to collect SOGI data that most states now use, and the YRBSS collects data on SO, while some states have expanded their YRBSS to also collect GI data. The BRFSS has revealed disparities in HIV diagnoses among adolescent men who have sex with men, especially within communities of color.¹⁰ Data from the YRBSS has shown disparities in suicide ideation and attempt among LGB youth compared to heterosexual youth.¹¹ Inclusion of SOGI questions on these government health surveys was necessary to understand these disparities.

3. 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? This question includes the following:
 - a. 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.
 - b. Broader statutory rules or administrative policies to insure transparency and accountability of government institutions such as statistical bodies.

When collecting sensitive information like SOGI, there should be policies and procedures in place that ensure that privacy and confidentiality are maintained at all times. For example, in the U.S., the Health Insurance Portability and Accountability Act of 1996 (HIPAA) sets forth policies and procedures to assure that the health information of individuals is protected and kept confidential while allowing the flow

⁸ Health Resources and Services Administration Bureau of Primary Care. (2016). Uniform Data System Reporting Instructions: For use to submit Calendar Year 2016 UDS Data. Retrieved from: <https://bphc.hrsa.gov/sites/default/files/bphc/datareporting/reporting/2016udsreportingmanual.pdf>

⁹ U.S. Department of Health and Human Services. (2015). 2015 Edition Health Information Technology (Health IT) Certification Criteria, 2015 Edition Base Electronic Health Record (EHR) Definition, and ONC Health IT Certification Program Modifications. Retrieved from: <https://s3.amazonaws.com/public-inspection.federalregister.gov/2015-25597.pdf>

¹⁰ Ocfemia MC, Dunville R, Zhang T, Barrios LC, & Oster AM. (2018). HIV Diagnoses Among Persons Aged 13–29 Years — United States, 2010–2014. *Morbidity and Mortality Weekly Report*, 67, 212–215.

¹¹ Kann L, McManus T, Harris W, et al. (2018). Youth Risk Behavior Surveillance – United States, 2017. *Morbidity and Mortality Weekly report Surveillance Summary*, 67(8).

of important health information necessary to provide high quality care. Oftentimes, it is necessary to collect very sensitive information from patients, including SOGI, in order to provide the best quality of care, so it is imperative that privacy and confidentiality are ensured so that patients are comfortable sharing sensitive information in a healthcare setting. Healthcare organizations that are regulated by HIPAA must have protocol in place for the collection, storage, and transfer of information so as to protect the privacy and confidentiality of patients.¹² Surveys that collect SOGI data can be made anonymous, or if that is not possible, when the data is stored and managed, it can be de-identified with specific policies in place about who is able to access the identified data.

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

The risks associated with collection of SOGI data are similar to the risks associated with collection of other sensitive information, in that collecting the data from some individuals may be uncomfortable or hostile. Those who collect SOGI data should be trained in LGBT cultural competency, and should also have a good understanding of why the questions are being asked, how the information will be used, and how privacy and confidentiality will be protected. Free online trainings for how to collect SOGI data and LGBT cultural competency can be found at the National LGBT Health Education Center website.¹³

In terms of managing the collected SOGI data, one major risk that should be accounted for is the risk of security or privacy breaches. There should be a set protocol in place for how to store, manage, and transfer the SOGI data so as to ensure that the information stays confidential. There should also be policies in place that regulate who is allowed to see identified and de-identified data and for what purposes. Unintentional sharing of SOGI data can lead to outing an individual as LGBT, which can in turn result in immediate danger, harm, and distress. This is especially the case in countries where same-sex behavior and/or transgender identity is criminalized. However, even in countries that do not criminalize same-sex behavior or transgender identity, outing can still be a serious danger and serious precautions should still be taken to keep this information confidential.

5. Are there circumstances where data collection is ill-advised, such as in countries that criminalize same-sex behavior or where particular government agencies have

¹² U.S. Department of Health and Human Services. Summary of the HIPAA Privacy Rule. Last updated: Jul 26, 2013. Retrieved from: <https://www.hhs.gov/hipaa/for-professionals/privacy/laws-regulations/index.html>

¹³ <https://www.lgbthealtheducation.org/>

demonstrated a cause for concern regarding their treatment of issues related to sexual orientation and gender identity?

Yes, it would be very difficult and potentially dangerous to collect this data in countries that criminalize same-sex behavior and transgender identity. In countries where same-sex consensual behavior and transgender identity are criminalized, LGBT people and people who are perceived to be LGBT already face extreme discrimination, and this discrimination contributes to negative health outcomes and worsens health disparities. Social discrimination and persecution is particularly pronounced in the former Soviet bloc countries of Eastern Europe and Central Asia, in sub-Saharan Africa, and in majority Arab and Muslim countries. Research shows that sexual minority individuals living in communities with high levels of structural stigma die an average of 12 years earlier compared to people living in more accepting communities.¹⁴ Under conditions of such extreme prejudice and stigma, it would be difficult and dangerous for people to identify as LGBT in data collection efforts.

That being said, it is still possible and often very important to collect SOGI data in countries where same-sex behavior and transgender identity are criminalized because the intense stigma can worsen health disparities. In order to collect SOGI data in more hostile environments, it is necessary to have safeguards in place to protect individuals who do disclose their identity in data collection efforts. Several research studies examining HIV disparities in gay and bisexual men¹⁵ and transgender women¹⁶ have been done all across the globe, so that research could be consulted in order to better understand what safeguards should be in place before collecting SOGI data. The 2008 United States President's Emergency Plan for AIDS Relief Reauthorization stated that one strategy for reducing HIV burden in Africa was to "evaluate the effectiveness of prevention efforts among MSM, with due consideration to stigma and risks associated with disclosure." While collecting SOGI data can be difficult and dangerous in countries where same-sex behavior and transgender identity are criminalized and highly stigmatized, if proper consideration is given to safeguards and policies that protect privacy and safety, the data can be collected and can inform important research into health disparities.

¹⁴ Hatzenbuehler ML, Bellatorre A, Lee Y, Finch BK, Muennig P, Fiscella K. 2014. "Structural stigma and all-cause mortality in sexual minority populations." *Soc Sci Med*. 103:33-41.

¹⁵ Beyrer C, Baral S, van Griensven F, et al. (2012). Global epidemiology of HIV infection in men who have sex with men. *The Lancet*, 380: 367-377.

¹⁶ Baral S, Poteat T, Stromdah S, Wirtz AL, Guadamuz TE, Beyrer C. (2013). Worldwide burden of HIV in transgender women: a systematic review and meta-analysis. *The Lancet*. 13: 214-222.

6. 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:
 - a. 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?
 - b. Does civil society have the capacity, in terms of expertise and technical knowledge, to meaningfully participate in State efforts to gather data?
 - c. What constitutes meaningful participation in this area?

Generally, changes to federal surveys, including addition or removal of SOGI questions, goes through a period of public comment where members of society and organizations are free to give feedback on the proposed changes. This feedback is then considered before implementing final changes. For example, in recent years, the U.S. federal government has proposed the rollback of SOGI data collection in national surveys. The Department of Health and Human Services released a proposed rule in 2017 to eliminate the SO question from the National Survey of Older Americans Act Participants (NSOAAP). The proposed rule was opened up to a period of public comment, and LGBT advocates and organizations were able to provide feedback to keep the question on the survey. In response to pushback against removing the SO question, the SO questions was added back onto the NSOAAP.

In addition to public comment, the general public is also able to engage with federal advisory committees and working groups in order to meaningfully participate in the design and implementation of data gathering activities. For example, under the Obama Administration, the U.S. Department of Health and Human Services created an LGBT working group which regularly consulted with community members, advocates, organizations, and stakeholders on a variety of issues related to LGBT health, including SOGI data collection.

7. 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?

Ideally, we would have a standardized SOGI measures for data collection so that researchers could readily use, transfer, and compare data. However, using standardized measures for SOGI data collection across different cultures may not yield the most useful data since concepts related to sexuality and gender can vary greatly between cultures. In order to collect accurate SOGI data that reflects the identities and lived realities of local populations, it may be better to use local and

culturally competent terminology to ask about sexuality and gender rather than a standardized list of options.

Thank you for the opportunity to provide feedback. If you have any questions, please feel free to reach out to Sean Cahill, PhD, Director of Health Policy Research at scahill@fenwayhealth.org.

Sincerely,

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