

June 19, 2020

Office of the United Nations High Commissioner for Human Rights, United Nations Office at Geneva, CH 1211 Geneva 10, Switzerland

Submitted via email to registry@ohchr.org

RE: Call for input to a thematic report: The impact of COVID-19 on the human rights of LGBTQ persons, communities and/or populations

The Fenway Institute at Fenway Health would like to provide comment to inform the Independent Expert's report on the impact of COVID-19 on the human rights of LGBTQ persons, communities and/or populations. Fenway Health is a federally qualified health center in Boston, Massachusetts that serves approximately 32,000 patients each year, about half of whom identify as LGBTQ. In order to best understand the impact of the COVID-19 pandemic on LGBTQ people's health outcomes and access to resources, one critical step that we have recommended to our local and state governments as well as to the United States government is requiring the systematic collection and reporting of sexual orientation and gender identity (SOGI) data of individuals tested for or diagnosed with COVID-19.

Previous research indicates that LGBTQ people in the United States may be disproportionately vulnerable to infection by the novel coronavirus. According to a recent Human Rights Campaign [analysis](#) of 2018 General Social Survey data, LGBTQ people disproportionately work in jobs that are considered "essential" in the United States: 40% work in restaurants/food services, health care, education, and retail, compared to 22% of non-LGBTQ individuals. They may therefore be more likely to be exposed to the coronavirus because they are unable to work from home. Additionally, LGBTQ people suffer economic disparities that place many in living environments that may make it harder to maintain social distancing. According to [research](#) by the Williams Institute at UCLA School of Law, 22% of LGBT people in the U.S. are poor, compared to 16% of straight cisgender people. We also know that LGBTQ people are more likely to live in urban areas, where physical distancing measures are harder to maintain.

Previous research also shows that LGBTQ people are more likely to have underlying health conditions that correlate with increased vulnerability to COVID-19-related health complications and fatalities. For example, a 2017 Center for American Progress [survey](#) found that 65% of LGBTQ people have a pre-existing health condition, such as diabetes, asthma, heart disease, and HIV. Research also shows that LGBTQ people across the age spectrum are more likely to [smoke](#) and [vape](#), and to have [substance use disorders](#). All of these pre-existing health conditions and risk behaviors could increase the vulnerability of LGBTQ people to COVID-19-related complications and fatalities.

Even though we have research that indicates that LGBTQ people in the United States may be disproportionately vulnerable to infection and complications from COVID-19, without

systematic collection and reporting of SOGI data of individuals tested for and diagnosed with COVID-19, we cannot understand the actual impact of the COVID-19 pandemic on LGBTQ people's health outcomes and access to resources. For these reasons, we have recommended that both our federal and our state government begin to systematically collect and report sexual orientation and gender identity (SOGI) data in real time in relation to COVID-19.

In order to facilitate LGBT people's access to health care in the United States, including COVID-19 testing and care, we have also recommended that the federal government ensure that nondiscrimination provisions related to healthcare, especially in relation to the provision of COVID-19 services and resources, explicitly include both sexual orientation and gender identity. [Research](#) shows that LGBTQ people in America experience discrimination in accessing healthcare. This discrimination correlates with poorer health outcomes for LGBTQ people, and it causes LGBTQ people to avoid accessing necessary and preventative [healthcare](#). During a global pandemic, it is of the utmost importance to ensure that LGBTQ people feel safe accessing healthcare and disclosing their sexual orientation and gender identity.

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 United States, 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 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. 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. Unintentional sharing of SOGI data can lead to outing an individual, which can in turn result in immediate danger, harm, and distress. People collecting the data should be trained in LGBTQ cultural competency.

It is important to note that it could be very difficult and potentially dangerous to collect this data in countries that criminalize same-sex behavior and transgender identity. Under conditions of such extreme prejudice and stigma, it could be 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 men](#) and [transgender women](#)¹⁶ 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.

In order to best understand the disparate impact of the COVID-19 pandemic on LGBTQ people, it is imperative to systematically collect SOGI data on those tested and diagnosed with COVID-19, and report these data in real time. In order to facilitate the collection of this data, it is essential that nondiscrimination provisions are inclusive of sexual orientation and gender

identity, and that those collecting the data are following strict privacy guidelines and informed about LGBTQ cultural competency. If you have any questions, feel free to reach out to me at twang@fenwayhealth.org.

Sincerely,

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