

To: Biden Harris Admin. COVID-19 Health Equity Task Force
From: Sean Cahill, PhD, Director of Health Policy Research
Date: May 20, 2021
Re: Sexual orientation and gender identity (SOGI) data collection
and reporting in COVID-19 testing, care and vaccination

Hello Madame Chair and Task Force members. I am Sean Cahill, Director of Health Policy Research at The Fenway Institute and Affiliate Associate Clinical Professor of Health Sciences at Northeastern University. I am also a member of the LGBTQI Federal Health Policy Roundtable.

We encourage the Biden-Harris Administration to issue federal guidance requiring the collection and reporting of data on sexual orientation, gender identity, and intersex status (SOGI) in COVID-19 testing, care and vaccination.

On April 9 I spoke to the Task Force as to why this is important. Today I focus on specific actions we hope the Administration can take to support SOGI data collection and reporting.

First, the need for guidance. To our knowledge five states and the District of Columbia are currently collecting SOGI data, usually in COVID-19 testing. We encourage the Department of Health and Human Services to issue guidance requiring the collection of voluntary SOGI data, in COVID-19 testing and vaccination. These data should be reported out on a regular basis in COVID-19 surveillance data so that we understand what is happening within the LGBTQI+ community, and within specific populations, such as among Black LGBTQI+ individuals and older LGBTQI+ individuals.

We recommend specific questions that have been developed and used in the health center network for many years now. They are listed in the testimony that I am submitting in writing to the Task Force (See Appendix A).

The CDC COVID-19 case report form should add these SOGI questions and change its sex question. Right now the sex question response options on that form are “male, female, other, unknown.”¹ The current response options are not affirming, and miss an opportunity to understand how this pandemic is affecting LGBTQI people.

Second, we request that the Office of the National Coordinator of Health Information Technology, or ONC, require that HL7 add SOGI fields to enable exchange of these data between clinical and reporting systems. This would also encourage the health care sector, laboratories, and the health IT industry to make collection and use of SOGI data a standard practice.

Third, we request that the National COVID Cohort Collaborative, a project of the National Center for Advancing Translational Sciences, add SOGI to its COVID-19 Clinical Data Warehouse Data Dictionary. This would allow collaborators to “contribute and use COVID-19 clinical data to answer critical research questions to address the pandemic,” and would allow researchers to examine “associations between COVID-19 patient outcomes and social determinants of health.”² By not including SOGI, the National COVID Cohort Collaborative does not allow for research on LGBTQI populations’ experiences with COVID-19.

Fourth, we also request that COVID-NET, a network of 100 large hospitals meant to represent the US population, collect and report SOGI in COVID-19 care, testing and vaccination.

Fifth, we ask HHS to ensure that LGBTQI+ people are included in vaccination outreach activities. We are especially concerned about medical mistrust among LGBTQI+ people of color, older adults, transgender people, and intersex people.

¹ <https://www.cdc.gov/coronavirus/2019-ncov/downloads/pui-form.pdf>

² <https://ncats.nih.gov/n3c>

Finally, broader than COVID-19 but related to COVID-19, we ask the Task Force and the Biden-Harris Administration to ensure that the CDC's Data Modernization Initiative, funded by \$500 million in funding from the CARES Act, prioritizes increasing and improving SOGI data collection in public health surveillance.

Thank you for your attention to these matters. We look forward to partnering with you to make SOGI data collection and reporting in COVID-19 happen as soon as possible.

My contact information: scahill@fenwayhealth.org, 646-761-6639

Appendix: How to ask SOGI and intersex questions

Sexual orientation³

Do you think of yourself as (Check one):

- Straight or heterosexual
- Lesbian, gay, or homosexual
- Bisexual
- Additional category (e.g. queer, pansexual, asexual). Please specify _____.
- Don't know
- Choose not to disclose

Gender identity⁴

What is your current gender identity? (Check all that apply):

- Female
- Male
- Transgender Woman/Transgender Female
- Transgender Man/Transgender Male
- Additional category (e.g. non-binary, genderqueer, gender-diverse, or gender fluid).

³ Adapted from <https://www.lgbtqiahealtheducation.org/courses/collecting-sexual-orientation-and-gender-identity-sogi-data-fall-2020/>

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Please specify _____.

Choose not to disclose

What sex were you assigned at birth? (Check one):

Male

Female

These questions and response options were developed by the National LGBTQIA+ Health Education Center and approved by the Bureau of Primary Health Care at HRSA for use with the Health Center Program.⁵ These terms collect data that can be used to populate the Health Center Program's Uniform Data System.⁶ They are also only slightly different from the minimal standards adopted by the Office of the National Coordinator of Health Information Technology in 2015,⁷ based on research that the Fenway Institute and the Center for American Progress conducted with health center patients in South Carolina, Maryland, Chicago and Boston.⁸

Additionally, in order to effectively identify and include the intersex community the above questions alone are not enough. In consultation

⁵ National LGBTQIA+ Health Education Center (2020). *Ready, set, go! A guide for collecting data on sexual orientation and gender identity*. Updated 2020. Page 5.

https://www.lgbtqihealtheducation.org/wp-content/uploads/2018/03/TFIE-47_Updates-2020-to-Ready-Set-Go-publication_6.29.20.pdf

⁶ HRSA Health Center Program. *Uniform Data System: Reporting Instructions for the 2019 Health Center Program*. http://bphcdata.net/docs/uds_rep_instr.pdf

⁷ Department of Health and Human Services, Office of the Secretary: 45 CFR Part 170, RIN 0991-AB93. 2015 Edition Health Information Technology (Health IT) Certification Criteria, 2015 Edition Based Electronic Health Record (EHR) Definition, and ONC Health IT Certification Program Modifications. Pages 495-497. Released October 6, 2015. Accessed October 16, 2020. Available at <https://s3.amazonaws.com/public-inspection.federalregister.gov/2015-25597.pdf> Cited in Cahill S, Baker K, Deutsch M, Keatley J, Makadon H. (2016). Inclusion of sexual orientation and gender identity in Stage 3 Meaningful Use guidelines a huge step forward for LGBT health. *LGBT Health*. 2016 Apr;3(2):100-2.

⁸ Cahill S, Singal R, Grasso C, King D, Mayer K, Baker K, Makadon H. Do ask, do tell: high levels of acceptability by patients of routine collection of sexual orientation and gender identity data in four diverse American community health centers. *PLoS One*. 2014 Sep 8;9(9):e107104.

with the Williams Institute, interACT recommends the inclusion of specific additional questions⁹ about intersex status such as:

Were you born with a variation in your physical sex characteristics? (This is sometimes called being intersex or having a Difference in Sex Development (DSD).)

- No
- Yes, my chromosomes, genitals, reproductive organs, or hormone functions were observed to be different from the typical male/female binary at birth and/or I have been diagnosed with an intersex variation or Difference of Sex Development
- I don't know

⁹ *Intersex Data Collection: Your Guide to Question Design*. interACT: Advocates for Intersex Youth. Published August 24, 2020. Accessed December 17, 2020. <https://interactadvocates.org/intersex-data-collection/>