

December 18, 2020

LGBTQI Inclusion in COVID-19 Data Collection & Vaccination Planning

Dear Dr. Levine and Association of State and Territorial Health Officers (ASTHO) members,

We, a coalition of lesbian, gay, bisexual, transgender, queer, and intersex (LGBTQI) health policy advocates, write to encourage you to:

- incorporate attention to LGBTQI populations into your COVID-19 vaccine health equity strategies, and
- to collect and report sexual orientation and gender identity (SOGI) plus intersex data in novel coronavirus testing, COVID-19 care outcomes, and vaccine uptake.

It is vital that governments and public health experts have a clear picture of the disparate risks and impacts of the novel coronavirus on LGBTQI people to inform public health efforts. There are many reasons to believe that LGBTQI people may be disproportionately vulnerable to infection by SARS-CoV-2 and to complications should they develop COVID-19. This is especially true of our Black, Latinx and Indigenous people, our people with disabilities, and our older adults. Due to negative experiences in the health care system and high rates of medical mistrust, many LGBTQI people may be reluctant to access the vaccine when it becomes available.

Why LGBTQI people may experience disparities in COVID-19

According to a Human Rights Campaign analysis of 2018 General Social Survey data, LGBTQ people disproportionately work in jobs that are considered essential: 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. Additionally, LGBTQ people suffer economic disparities that place many in living environments that may make it harder to maintain social distancing.¹ According to 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.² LGBT people of color, bisexuals, and transgender people are more likely to be poor than other LGBT people. We also know that LGBTQ people are more likely to live in urban areas, where physical distancing measures are harder to maintain.

A recent report by the Movement Advancement Project³ highlights the disproportionate impact COVID-19 has had on LGBTQ households. As a result of COVID-19:

- 66% of LGBTQ households have had a serious financial problem versus 44% of other households;
- 64% of LGBTQ households experienced employment or wage loss, versus 45% of others; and
- 38% of LGBTQ households experienced barriers to getting care for a serious medical problem, versus 19% of others.

These problems were exacerbated for Black and Brown LGBTQ households, as examples: 95% of Black LGBTQ households experienced a serious financial problem and 61% of Latino LGBTQ households experienced employment or wage loss.

LGBTQ people are more likely to have some of the underlying health conditions that correlate with increased vulnerability to COVID-19-related health complications and fatalities. These include higher rates of cardiovascular disease, cancer, obesity, diabetes, and HIV/AIDS.⁴ A 2017 Center for American Progress survey found that 65% of LGBTQ people have chronic conditions.⁵ Lesbian and bisexual women are more likely than

heterosexual women to be overweight or obese.⁶ There is also emerging research about higher rates of sedentarism, pre-diabetes, and diabetes among LGBTQ youth, which could lead to diabetes later in life.⁷ LGBTQ older adults experience higher rates of disability than heterosexual, cisgender older adults.⁸

LGBTQ people use tobacco at rates 50% higher than the general population,^{9,10} including being more likely to vape.¹¹ They are also more likely to have other substance abuse.¹² Both smoking and vaping are known links to deleterious COVID-19 outcomes.^{13,14} Higher rates of tobacco and substance use are related to experiences of stigma, minority stress, and social anxiety. These disparities intersect with racial and ethnic health disparities. All of these conditions and risk behaviors could increase the vulnerability of LGBTQ people if they are exposed to SARS-CoV-2.

Intersex people specifically mistrust the medical community and are disproportionately at risk for COVID-19 and more likely not to seek treatment for possible infection.¹⁵

Why LGBTQI people may need extra outreach efforts to ensure vaccine uptake

LGBTQI people experience discrimination and stigma, which negatively affects physical and mental health¹⁶ and constitutes a barrier to accessing care.¹⁷ Lesbian and bisexual women¹⁸ and transgender people¹⁹ are less likely to access routine, preventive health care compared to their heterosexual and cisgender peers. LGBTQI people of color experience intersectional stigma based on race as well as sexual orientation and gender identity (SOGI).²⁰ In recent years, the federal government has enacted discriminatory religious refusal policies²¹ and removed SOGI nondiscrimination language from federal health care regulations.²²

Partly as a result of stigma and discrimination in health care, LGBTQI people, and especially LGBTQI people of color²³ and transgender people,²⁴ experience medical mistrust, which could affect the likelihood that they will know when a vaccine becomes available, know how to access it, and be willing to trust those offering the vaccine.

Many older LGBTQI people experience medical mistrust because when they were coming of age the medical establishment pathologized same-sex behavior and gender diversity. Many sexual and gender minority individuals were subjected to shock therapy or lobotomies, or were committed to psychiatric institutions with the support of mainstream medicine and psychiatry.²⁵

Intersex people also often have challenging relationships with the health care system. Many have experienced medical trauma related to medically unnecessary cosmetic surgeries conducted without their consent, and unnecessary and objectifying medical examinations.²⁶ Many experience minority stress related to nondisclosure and concerns related to disclosure of their intersex status.²⁷ In a recent study on intersex adults in the U.S., over 43% of participants rated their physical health as fair/poor and 53% reported fair/poor mental health. Prevalent health diagnoses included depression, anxiety, arthritis, and hypertension, with significant differences by age. Nearly a third reported difficulty with everyday tasks and over half reported serious difficulties with cognitive tasks.²⁸

Public health authorities and health care providers should conduct affirmative outreach and enlist trusted community leaders to promote vaccination in Black and Native American communities, immigrant communities, LGBTQI communities, and other communities in which medical mistrust is high.

The need for sexual orientation and gender identity data collection in the COVID-19 pandemic

In order to know if LGBTQI people are accessing the vaccine, health systems need to systematically collect and report sexual orientation and gender identity (SOGI) plus intersex data in real time in relation to COVID-19

vaccination. This would be consistent with the CDC's recommendations for 10 essential public health services.²⁹

Are LGBTQI people more likely to develop complications from COVID-19? Are they more likely to die? Are LGBTQI Black people most at risk? What about LGBTQI older adults and long-term survivors living with HIV in the U.S., most of whom are LGBTQI? These are critically important questions. We need our public health response system to systematically collect SOGI plus intersex data to understand if LGBTQI people face increased risks of acquiring the novel coronavirus, how LGBTQI people are experiencing COVID-19, and how LGBTQI disparities intersect with racial and ethnic disparities in COVID-19 risks and outcomes.

This data will help ensure that prevention efforts, testing, and care services are effectively meeting the needs of LGBTQI people.

SOGI plus intersex data collection would be consistent with a decade of federal initiatives

Over the past decade, a number of federal agencies and initiatives have encouraged SOGI plus intersex data collection in health care settings, including:

- Healthy People 2020, our nation's health promotion and prevention strategy, makes promoting SOGI data collection to help understand and eliminate disparities a key priority.³⁰
- The 2011 Institute of Medicine Report on LGBT Health called for SOGI questions to be included in the Meaningful Use Program (a CMS/ONC-led incentive program to promote the shift to Electronic Health Records) and added to more health and demographic surveys.³¹
- In 2015, ONC adopted SOGI standards as required fields in the “demographics” section of the 2015 Edition Base Electronic Health Record (EHR) Definition certification criteria, making SOGI part of all Certified Electronic Health Record Technology (CEHRT) products.³¹
- SOGI data have also been included in the Interoperability Standards Advisory since it was first published in 2015.³² SOGI standards have achieved steadily increasing and high levels of maturity and adoption since 2015, as reflected in the 2020 reference edition of ONC's Interoperability Standards Advisory.³³
- In 2015 the Centers for Medicare and Medicaid Services encouraged the collection and use of SOGI data to improve quality of care in their *CMS Equity Plan for Medicare Beneficiaries*.³¹

In addition to these government agency actions, in 2011 the Joint Commission called for SOGI data collection.³⁴ The American Medical Association (2017)³⁵ and other professional associations have adopted formal positions supporting SOGI data collection in health care.

Health centers are collecting, reporting, and using SOGI data to improve quality of care and our understanding of LGBTQ disparities. An increasing number of hospitals and private practices are as well. Inclusion of SOGI data in Electronic Health Records is the industry norm.

Several states are taking the lead on SOGI data collection in the COVID-19 pandemic, including Pennsylvania, California,³⁶ Rhode Island, and the District of Columbia.³⁷ California is requiring all health care providers and labs to collect and report to the state health department SOGI data in COVID-19 cases and other reportable diseases. The Massachusetts Department of Public Health is adding SOGI fields to the Mass. Virtual Epidemiologic Network (MAVEN), and is on the verge of releasing SOGI data standards.

Based on many years of experience collecting and using patient SOGI data in Electronic Health Records (EHRs), advocating for inclusion of SOGI in national health IT systems, and training health centers and other

organizations in how to collect and use SOGI to improve quality of care, the Fenway Institute recommends the following SOGI questions:

Sexual orientation

Do you think of yourself as (Check one):

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

Gender identity

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

- Female
- Male
- Transgender Woman/Transgender Female
- Transgender Man/Transgender Male
- Other* (e.g. non-binary, genderqueer, gender-diverse, or gender fluid). Please specify _____.
- Choose not to disclose

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

- Male
- Female

**You may replace the term “other” on patient-facing forms with the term that is most affirming for the communities you serve (e.g. “something else” or “additional category”).*

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.³⁸ These terms collect data that can be used to populate the Health Center Program’s Uniform Data System.³⁹ They are also only slightly different from the minimal standards adopted by the Office of the National Coordinator of Health Information Technology in 2015,^{40,31} 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.⁴¹ For more information please see <https://www.lgbtqiahealtheducation.org/> or email scahill@fenwayhealth.org

Additionally, in order to effectively identify and include the intersex community the above questions alone are not enough. In consultation with the Williams Institute, interACT recommends⁴² the inclusion of specific additional question 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

Thank you for considering incorporating attention to LGBTQI individuals into your vaccine distribution plan, with particular attention to addressing medical mistrust. Thank you also for considering collecting and reporting SOGI plus intersex data in SARS-CoV-2 testing, COVID-19 care outcomes, and COVID-19 vaccine uptake.

Sincerely,

Original signers:

Whitman-Walker Institute
The Fenway Institute
interACT: Advocates for Intersex Youth
Howard Brown Health
Transgender Legal Defense and Education Fund
Callen-Lorde Health Center
SAGE USA

National Center for Transgender Equality
GLMA: Health Professionals Advancing LGBTQ Equality
Transgender Law Center
Center for American Progress
Lyon-Martin Health Services
National LGBTQ Task Force
National LGBT Cancer Network

Additional signers:

Advocates for Youth
Aldee Health Services
Alliance For Full Acceptance
Atlanta Pride Committee
Billy DeFrank LGBTQ+ Community Center
Bisexual Organizing Project (BOP)
Bradbury-Sullivan LGBT Community Center
California LGBTQ Health and Human Services Network
CAMP Rehoboth Community Center
Center for American Progress
Center on Halsted
CenterLink: The Community of LGBT Centers
Chase Brexton Health Care
Compass LGBTQ Community Center
Corktown Health Center
Cortland LGBTQ Center
CrescentCare
DBGM, Inc.
Deaf Queer Resource Center
Dolan Research International, LLC
Equality California
Equality Florida
Equality North Carolina
Equitas Health Institute
Erie Gay News
Evaluation, Data Integration, and Technical Assistance (EDIT) Program
FORGE, Inc.
Gay City: Seattle's LGBTQ Center
Gay Elder Circle
Georgia Equality

GLBT Alliance
GLBTQ Legal Advocates & Defenders (GLAD)
Global Healthy Living Foundation / CreakyJoints
Greater Erie Alliance for Equality, Inc.
GRIOT Circle
Harriet Hancock Center Foundation
Health Equity Alliance for LGBTQ+ New Mexicans
Hetrick-Martin Institute
Hudson Pride Center
Hugh Lane Wellness Foundation
Human Rights Alliance Santa Fe
Human Rights Campaign
Identity, Inc
Imperial Valley LGBT Resource Center
Inside Out Youth Services
Institute for Human Identity
InterPride
Justice in Aging
Lansing Area AIDS Network (LAAN)
Legacy Community Health
LGBT Center of Greater Reading
LGBT Center of SE Wisconsin
LGBTQ Center OC
LGBTQ Center of Bay County
Long Island LGBT Center
Los Angeles LGBT Center
Mass Equality
Mazzoni Center
Modern Military Association of America
Movement Advancement Project (MAP)
National Coalition for LGBT Health

National Equality Action Team (NEAT)
National LGBTQ Task Force
New York LGBT Network
Newark LGBTQ Community Center
One Colorado
one-n-ten
Open Door Health
Out Boulder County
Out in the Open
OutCenter of Southwest Michigan
Pennsylvania Youth Congress
PFY
PGH Equality Center
Pride Center of Vermont
Pride Center of WNY
Pride Community Center, Inc
Pride Link
Pridelines
PROCEED INC.
Queens LGBT Center
QWELL Community Foundation
Rainbow Community Center of Contra
Costa County
Rainbow Rose Center
Resource Center
Rhode Island Public Health Institute
Rockland County Pride Center
Safeguarding American Values for
Everyone (SAVE)
SAGE Metro Detroit
San Francisco AIDS Foundation
San Francisco Voice & Swallowing
San Joaquin Pride Center
Seacoast Outright
Stand with Trans
SunServe
The DC Center for the LGBT Community
The Frederick Center
The Lesbian, Gay, Bisexual and
Transgender Center
The LOFT LGBTQ+ Community Center
the Montrose Center
The Sacramento LGBT Community Center
The Source LGBT+ Center
The Trevor Project
Thundermist Health Center
Transgender Education Network of Texas
(TENT)
Translatinx Network
TriVersity Center for Gender and Sexual
Diversity
U.S. People Living with HIV Caucus
Uptown Gay and Lesbian Alliance (UGLA)
Waves Ahead & SAGE Puerto Rico
William Way LGBT Community Center

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