

Congress of the United States
Washington, DC 20515

May 20, 2020

The Honorable Alex Azar
Secretary
Department of Health and Human Services
200 Independence Avenue, SW
Washington, D.C. 20201

Dear Secretary Azar,

We write today to urge the U.S. Department of Health and Human Services (HHS) to fulfill its commitment to its Healthy People 2020 objectives by collecting data on sexual orientation and gender identity during the coronavirus disease of 2019 (COVID-19) pandemic. The current lack of demographic data that includes sexual orientation and gender identity will make it difficult for health care providers and policymakers to clearly identify and address the prevention and treatment needs of lesbian, gay, bisexual, transgender, and queer (LGBTQ) communities and will exacerbate the challenges that these populations are already experiencing during the COVID-19 public health emergency. We strongly urge you to include information on sexual orientation and gender identity as part of any COVID-19 data collection efforts.

Congress relies on data to create better health programs, direct vital resources to communities, and better the health of all people residing in the United States. Like other marginalized groups, the LGBTQ community faces multiple health inequities.¹ With scarce demographic information available about the LGBTQ population,² it is difficult to provide quality care and solutions. In 2010, HHS created the first-ever Healthy People objectives regarding LGBTQ health data collection.³ The Healthy People objectives are science-based, ten-year national objectives for improving the health of all Americans.⁴ The Healthy People 2020 objectives recognized the need to increase the number of surveys that collect information on sexual orientation and gender identity.

Currently, the Centers for Disease Control and Prevention's (CDC) COVID-19 Case Report Form⁵ does not include questions about whether a patient identifies as LGBTQ. It is unclear if supplemental surveillance activities such as COVID-NET include these questions or if any upcoming surveys will include these questions. This omission not only contradicts the HHS

¹ <https://www.hhs.gov/sites/default/files/2016-report-with-cover.pdf>

² <https://www.americanprogress.org/issues/lgbtq-rights/reports/2016/03/15/133223/how-to-collect-data-about-lgbt-communities/>

³ <https://www.healthypeople.gov/2020/topics-objectives/topic/lesbian-gay-bisexual-and-transgender-health/objectives>

⁴ <https://www.healthypeople.gov/2020/About-Healthy-People>

⁵ <https://www.cdc.gov/coronavirus/2019-ncov/downloads/pui-form.pdf>

Healthy People 2020 objectives⁶ to improve the collection of health data on LGBTQ populations,⁷ but it also ignores the objectives of Section 4302 of the Affordable Care Act to strengthen federal data collection efforts.⁸

Data collection on sexual orientation and gender identity is an opportunity to eliminate barriers to culturally competent care. Questions about sexual orientation and gender identity allow individuals to disclose who they indeed are, if they so choose, and may allow individuals to feel safe sharing information that is relevant to their care.⁹ Inclusive and nondiscriminatory health care settings are urgently needed, as this pandemic is more likely to impact members of the LGBTQ community than the general population. According to a recent report, members of the LGBTQ community are more likely to “lack access to adequate medical care, paid medical leave, and basic necessities during the pandemic.”¹⁰ Additionally, specific health risks and conditions that disproportionately impact the LGBTQ community, such as smoking, asthma, and HIV may increase the risk of developing a severe case of COVID-19.¹¹

Collecting demographic data on sexual orientation and gender identity is increasingly common in major health surveys and public health surveillance systems, such as the CDC’s National HIV Surveillance System, Behavioral Risk Factor Surveillance System, and Youth Risk Behavior Survey. Indeed, HHS has already developed internal guidance for collecting sexual orientation and gender identity data in a uniform manner to ensure that this data can be easily aggregated into established instruments.¹² A strong and growing body of research shows that patients and providers readily understand these questions and are willing to answer them,¹³ and that asking these questions does not distress or otherwise negatively impact cisgender heterosexual patients.¹⁴

In light of the history and current prevalence of unlawful discrimination against members of the LGBTQ community in health care settings, HHS should emphasize that disclosing information about sexual orientation or gender identity is voluntary. Additionally, HHS should provide guidance to health care providers about how to ask these questions in a sensitive manner that emphasizes confidentiality.

Achieving health equity in this pandemic includes taking an equitable approach in COVID-19 surveillance systems that collect data on patients’ race, ethnicity, sex, primary language, sexual orientation, gender identity, disability status, and socioeconomic status in line with federal

⁶ <https://www.healthypeople.gov/2020/topics-objectives/topic/lesbian-gay-bisexual-and-transgender-health/objectives>

⁷ <https://www.hhs.gov/programs/topic-sites/lgbt/better-information/index.html>

⁸ <https://www.hhs.gov/sites/default/files/patient-protection.pdf>

⁹ <https://www.lgbthealtheducation.org/wp-content/uploads/2017/08/Forms-and-Policy-Brief.pdf>

¹⁰ https://assets2.hrc.org/files/assets/resources/COVID19-IssueBrief-032020-FINAL.pdf?_ga=2.82806741.2106152923.1588019826-1116669267.1513872092

¹¹ https://assets2.hrc.org/files/assets/resources/COVID19-IssueBrief-032020-FINAL.pdf?_ga=2.82806741.2106152923.1588019826-1116669267.1513872092

¹² <https://www.hhs.gov/sites/default/files/2016-report-with-cover.pdf>

¹³ <https://www.ncbi.nlm.nih.gov/pubmed/30630837>

¹⁴ <https://www.ncbi.nlm.nih.gov/pmc/articles/PMC6153164/>

standards. The fact remains that we know little about the social and economic circumstances of the LGBTQ population at large. For these reasons, we believe that it is critical for the federal government to work with states and localities to provide disaggregated data on sexual orientation, gender identity, and other demographic characteristics when reporting COVID-19 tests, cases, and fatalities to the CDC.

Accordingly, we request that HHS undertake the following actions and address the status of any such actions in response no later than June 3, 2020:

- Create a plan to integrate sexual orientation and gender identity data variables into COVID-19 surveillance systems.
- Share guidance with health care providers about why data on sexual orientation and gender identity is essential, and best practices for asking patients to disclose this information voluntarily.
- Take steps to ensure that federally run health facilities collect data on sexual orientation and gender identity, including Veterans Administration hospitals and the National Institutes of Health Clinical Center.
- Share guidance with state health departments on how and why to include sexual orientation and gender identity data in their own COVID-19 surveillance efforts.
- Explain how HHS will document and report on the impact of COVID-19 on LGBTQ communities.
- Explain HHS' outreach to LGBTQ communities and organizations about the COVID-19 pandemic to date, including which offices in HHS are responsible for and have undertaken this outreach.
- Reach out to national, state, and local LGBTQ organizations to collect community concerns and opportunities related to the impact of the COVID-19 pandemic on LGBTQ health.

Given the exponential spread of COVID-19 in the United States, we urge you to create and implement the tools to collect data about our most vulnerable populations during these unprecedented times. Thank you for your attention to this critical matter.

Sincerely,

/s/ Robert Menendez
Robert Menendez
United State Senator

/s/ Tammy Baldwin
Tammy Baldwin
United States Senator

/s/ Raúl M. Grijalva
Raúl M. Grijalva
Member of Congress

/s/ Sherrod Brown
Sherrod Brown
United State Senator

/s/ Edward J. Markey
Edward J. Markey
United States Senator

/s/ Bernard Sanders
Bernard Sanders
United States Senator

/s/ Richard Blumenthal
Richard Blumenthal
United States Senator

/s/ Catherine Cortez Masto
Catherine Cortez Masto
United States Senator

/s/ Sheldon Whitehouse
Sheldon Whitehouse
United States Senator

/s/ Robert P. Casey, Jr.
Robert P. Casey, Jr.
United States Senator

/s/ Kirsten Gillibrand
Kirsten Gillibrand
United States Senator

/s/ Kamala D. Harris
Kamala D. Harris
United States Senator

/s/ Richard J. Durbin
Richard J. Durbin
United States Senator

/s/ Elizabeth Warren
Elizabeth Warren
United States Senator

/s/ Cory A. Booker
Cory A. Booker
United States Senator

/s/ Tina Smith
Tina Smith
United States Senator

/s/ Amy Klobuchar
Amy Klobuchar
United States Senator

/s/ Mazie K. Hirono
Mazie K. Hirono
United States Senator

/s/ Jacky Rosen
Jacky Rosen
United States Senator

/s/ Jack Reed
Jack Reed
United States Senator

/s/ Jeffrey A. Merkley
Jeffrey A. Merkley
United States Senator

/s/ Colin Z. Allred
Colin Z. Allred
Member of Congress

/s/ Alma S. Adams, Ph.D.
Alma S. Adams, Ph.D.
Member of Congress

/s/ Karen Bass
Karen Bass
Member of Congress

/s/ Earl Blumenauer
Earl Blumenauer
Member of Congress

/s/ Lisa Blunt Rochester
Lisa Blunt Rochester
Member of Congress

/s/ Suzanne Bonamici
Suzanne Bonamici
Member of Congress

/s/ Tony Cárdenas
Tony Cárdenas
Member of Congress

/s/ Ed Case
Ed Case
Member of Congress

/s/ David N. Cicilline
David N. Cicilline
Member of Congress

/s/ Gilbert R. Cisneros, Jr.
Gilbert R. Cisneros, Jr.
Member of Congress

/s/ Yvette D. Clarke
Yvette D. Clarke
Member of Congress

/s/ J. Luis Correa
J. Luis Correa
Member of Congress

/s/ TJ Cox
TJ Cox
Member of Congress

/s/ Jason Crow
Jason Crow
Member of Congress

/s/ Susan A. Davis
Susan A. Davis
Member of Congress

/s/ Madeleine Dean
Madeleine Dean
Member of Congress

/s/ Peter A. DeFazio
Peter A. DeFazio
Member of Congress

/s/ Eliot L. Engel
Eliot L. Engel
Member of Congress

/s/ Veronica Escobar
Veronica Escobar
Member of Congress

/s/ Adriano Espaillat
Adriano Espaillat
Member of Congress

/s/ Bill Foster
Bill Foster
Member of Congress

/s/ Jesús G. "Chuy" García
Jesús G. "Chuy" García
Member of Congress

/s/ Sylvia R. Garcia
Sylvia R. Garcia
Member of Congress

/s/ Alcee L. Hastings
Alcee L. Hastings
Member of Congress

/s/ Jahana Hayes
Jahana Hayes
Member of Congress

/s/ Pramila Jayapal
Pramila Jayapal
Member of Congress

/s/ Eddie Bernice Johnson
Eddie Bernice Johnson
Member of Congress

/s/ Joseph P. Kennedy, III
Joseph P. Kennedy, III
Member of Congress

/s/ Ro Khanna
Ro Khanna
Member of Congress

/s/ John B. Larson
John B. Larson
Member of Congress

/s/ Barbara Lee
Barbara Lee
Member of Congress

/s/ Zoe Lofgren
Zoe Lofgren
Member of Congress

/s/ Alan Lowenthal
Alan Lowenthal
Member of Congress

/s/ Carolyn B. Maloney
Carolyn B. Maloney
Member of Congress

/s/ Sean Patrick Maloney
Sean Patrick Maloney
Member of Congress

/s/ A. Donald McEachin
A. Donald McEachin
Member of Congress

/s/ James P. McGovern
James P. McGovern
Member of Congress

/s/ Grace Meng
Grace Meng
Member of Congress

/s/ Debbie Mucarsel-Powell
Debbie Mucarsel-Powell
Member of Congress

/s/ Eleanor H. Norton
Eleanor H. Norton
Member of Congress

/s/ Alexandria Ocasio-Cortez
Alexandria Ocasio-Cortez
Member of Congress

/s/ Ilhan Omar
Ilhan Omar
Member of Congress

/s/ Jimmy Panetta
Jimmy Panetta
Member of Congress

/s/ Chris Pappas
Chris Pappas
Member of Congress

/s/ Chellie Pingree
Chellie Pingree
Member of Congress

/s/ Mark Pocan
Mark Pocan
Member of Congress

/s/ Ayanna Pressley
Ayanna Pressley
Member of Congress

/s/ Mike Quigley
Mike Quigley
Member of Congress

/s/ Jamie Raskin
Jamie Raskin
Member of Congress

/s/ Lucille Roybal-Allard
Lucille Roybal-Allard
Member of Congress

/s/ Linda T. Sánchez
Linda T. Sánchez
Member of Congress

/s/ Albio Sires
Albio Sires
Member of Congress

/s/ Adam Smith
Adam Smith
Member of Congress

/s/ Darren Soto
Darren Soto
Member of Congress

/s/ Jackie Speier
Jackie Speier
Member of Congress

/s/ Tom Suozzi
Tom Suozzi
Member of Congress

/s/ Mark Takano
Mark Takano
Member of Congress

/s/ Lori Trahan
Lori Trahan
Member of Congress

/s/ David Trone
David Trone
Member of Congress

/s/ Lauren Underwood
Lauren Underwood
Member of Congress

/s/ Katie Porter
Katie Porter
Member of Congress

/s/ Ted W. Lieu
Ted W. Lieu
Member of Congress

/s/ Juan Vargas
Juan Vargas
Member of Congress

/s/ Lucy McBath
Lucy McBath
Member of Congress

/s/ Jimmy Gomez
Jimmy Gomez
Member of Congress

/s/ Bonnie Watson Coleman
Bonnie Watson Coleman
Member of Congress

/s/ Julia Brownley
Julia Brownley
Member of Congress

/s/ Harley Rouda
Harley Rouda
Member of Congress

/s/ Dina Titus
Dina Titus
Member of Congress

/s/ Henry C. "Hank" Johnson, Jr
Henry C. "Hank" Johnson, Jr
Member of Congress

/s/ Donna E. Shalala
Donna E. Shalala
Member of Congress

/s/ Gregory W. Meeks
Gregory W. Meeks
Member of Congress

/s/ Danny K. Davis
Danny K. Davis
Member of Congress

/s/ José E. Serrano
José E. Serrano
Member of Congress

/s/ Nydia M. Velázquez
Nydia M. Velázquez
Member of Congress

/s/ Deb Haaland
Deb Haaland
Member of Congress

/s/ Rashida Tlaib
Rashida Tlaib
Member of Congress

/s/ Jennifer Wexton
Jennifer Wexton
Member of Congress

/s/ Judy Chu
Judy Chu
Member of Congress

/s/ Kathleen M. Rice
Kathleen M. Rice
Member of Congress