An Open Letter to Health Leaders:

In the 1950s and 1960s, brave, pioneering LGBTQI+ advocates such as Barbara Gittings, Marsha P. Johnson, Frank Kameny, and Sylvia Rivera took great personal risks to break the oppressive silence around human sexuality and end our invisibility. In the 1980s, ACT-UP protested government inaction regarding HIV/AIDS with the slogan “Silence = Death.” This Pride month, we, a group of lesbian, gay, bisexual, transgender, queer, and intersex (LGBTQI+) health serving organizations and our allies, again call for an end to oppressive silence and invisibility in public health. We urgently call for routine collection and reporting on sexual orientation, gender identity, and variations in sex characteristics (also known as intersex status) (SOGISC) whenever demographic health data are collected.

We know almost nothing about COVID-19’s impacts on LGBTQI+ communities. We have a dearth of data on the impact of heart disease, cancer, tobacco use, diabetes, substance use, and any number of vital health issues on LGBTQI+ people. And we have almost no population-based data on intersex populations in the US. We need to be collecting voluntary SOGISC data from patients throughout every level of our health system. The failure of health institutions to routinely collect SOGISC data puts us at risk.

Thus SOGISC should be collected in the following places:
- Every electronic health record;
- Every insurance application;
- All research studies;
- All clinical trials;
- All health laboratory tests;
- Across all public health surveillance: including surveys, disease, and mortality reporting; this can be addressed via the $500 million CDC Data Modernization Initiative;
- Across COVID-NET, a network of 100 large hospitals reporting on COVID-19 care; and
- As required measures on the Behavioral Risk Factor Surveillance System, where the optional SOGI module used by 40 states provides the largest source of health data on LGBT people today.

We have years of experience in collecting information from our LGBTQI+ patients and colleagues, as do many health systems, local and state agencies, and their counterparts in many nations around the world. Here is a set of measures that have been widely tested and are currently being recommended by community experts. Funding is needed to test enhanced measures but the value of adding tested measures immediately has been amply demonstrated.

We are heartened by the increasing number of organizations recognizing Pride month but we want to be very clear: if you truly value our lives, collect our data.
Signor list:

National LGBT Cancer Network
National Black Justice Coalition
Equality Federation
CenterLink: The Community of LGBT Centers
National Center for Transgender Equality
National LGBTQ Task Force
The Trevor Project
Transgender Law Center
Whitman Walker Institute
Transhealth Northampton
interACT: Advocates for Intersex Youth
Movement Advancement Project
Center for American Progress
Howard Brown Health

1Hood Power
African American Office of Gay Concerns
AIDS Foundation Chicago
AIDS Resource Alliance
Alaskans Together For Equality
Alder Health Services
All Under One Roof LGBT Advocates of Southeastern Idaho
American Trans Resource Hub
Arizona Trans Youth and Parent Organization
Association of Transgender Health Nurses
Atlanta Pride Committee
Aunt Rita's Foundation
BiNet USA
Boston Bisexual Women's Network
Bradbury-Sullivan LGBT Community Center
Brooklyn Community Pride Center
California LGBTQ Health and Human Services Network
CAMP Rehoboth Community Center
CANDLE

Cascade AIDS Project
Center for Black Equity
Center for Law and Social Policy (CLASP)
Center for LGBTQ Economic Advancement & Research (CLEAR)
Center on Halsted
Centre LGBTQ Support Network
Charlotte Transgender Healthcare Group
COLAGE
Community Catalyst
Compass LGBTQ Community Center
CRUX LGBTQIA+ Climbing
DBGM, Inc.
Dolan Research International, LLC
EDIT Program, Northwestern Institute for Sexual and Gender Minority Health and Wellbeing (ISGMH)
ENC - Equality NC
Equality California
Equality Florida
Equality Illinois
Equality Michigan
Equality Nevada
Equality New Mexico

Equality Ohio
Equality Texas
Equality Utah
Erie City Mayor's LGBTQIA+ Advisory Council
Erie County Democratic Party
LGBTQIA+ Caucus
Erie Gay News
Fair Wisconsin
Fairness Campaign
FORGE, Inc.
Garden State Equality
Gay City: Seattle's LGBTQ Center
GenderNexus
Georgia Equality
Georgians for a Healthy Future
GLAA
Great Lakes Bay Pride
Guilford Green Foundation & LGBTQ center
Health Equity Alliance for LGBTQ+ New Mexicans
Henderson Equality Center
HIV Medicine Association
Hugh Lane Wellness Foundation
Identity
Indiana Youth Group (IYG)
Interfaith Voices for Reproductive Justice (IVRJ)
Justice in Aging
Lancaster LGBTQ+ Coalition
Legacy Community Health
LGBT Center of Greater Reading
LGBT Community Center of Greater Cleveland
LGBT Elder Initiative
LGBT Technology Partnership & Institute
LGBT+ Center Orlando
LGBTQ Center of Bay County
LGBTQ Center of Bay County Lighthouse Foundation
Live Out Loud
Lyon-Martin Health Services
Massachusetts Transgender Political Coalition
MassEquality
Mazzoni Center
Medical Students for Choice
Modern Military Association of America
National Black Justice Coalition
National Center for Lesbian Rights
National Equality Action Team (NEAT)
National Health Law Program
National Working Positive Coalition
New York Transgender Advocacy Group
NJ LGBTQ Democrats
NWPA Pride Alliance
Oklahomans for Equality
Dennis R Neill Equality Center
One Colorado
ONE Community
one-n-ten
Onslow County LGBTQ+ Community Center
Out and Equal
Out Boulder County
OUT MetroWest
Out To Innovate
OutCenter of Southwest Michigan
OutFront Kalamazoo
Outright Vermont
Parity Pennsylvania Equality Project, Inc.
PFLAG Greensburg
PFY - Long Island Crisis Center
PGH Equality Center
Phoenix Pride
Pizza Klatch
Pride Action Tank
Pride at Work
Pride Center of Staten Island
Pride Center San Antonio
Pride Community Services Organization
PROMO
Rainbow Rose Center
Rescue I The Behavior Change Agency
Resource Center
Ricky's Pride
Rockland County Pride Center
Sacramento LGBT Community Center
Safeguarding American Values for Everyone (SAVE)
SAGE Metro Detroit
San Diego LGBT Community Center
Secular AZ
Silver State Equality
SOJOURN
Southwest Center
The Center on Colfax
The Charlotte Transgender Healthcare Group
The Cranky Queer Guide to Chronic Illness
The DC Center for the LGBT Community
The Frederick Center
The LGBTQ Center Long Beach
The LGBTQ Community Center of Southern Nevada
The Montrose Center
The Pride Center at Equality Park
The Pride Center of New Jersey
The TransLatin@ Coalition
Trans Empowerment Project
TransFamily Support Services
Transgender Education Network of Texas (TENT)
Transgender Resource Center of New Mexico
TransOhio
TriVersity - The Pride Center
True Colors United
University of Nevada, Las Vegas
Vivent Health
Washington AIDS Partnership
Washington County Gay Straight Alliance, Inc.
Waves Ahead and SAGE Puerto Rico
Waves Ahead Puerto Rico
Wellness AIDS Services, Inc.
William Way LGBT Community Center
Woodhull Freedom Foundation
Zebra Coalition