

May 4, 2020

The Honorable Mitch McConnell
Majority Leader
United States Senate
Washington, D.C. 20510

The Honorable Charles Schumer
Minority Leader
United States Senate
Washington, D.C. 20510

The Honorable Nancy Pelosi
Speaker
U.S. House of Representatives
Washington, D.C. 20515

The Honorable Kevin McCarthy
Minority Leader
U.S. House of Representatives
Washington, D.C. 20515

Dear Majority Leader McConnell, Minority Leader Schumer, Speaker Pelosi, and Minority Leader McCarthy:

In recent weeks, state and local officials have documented that communities of color are being disproportionately impacted by the COVID-19 outbreak.¹ While anyone can be at risk for infection from the novel coronavirus, in the United States many systemic inequities, discrimination, and harmful social determinants of health have led to long-standing disparities in communities of color and other populations. As a result, COVID-19 is disproportionately leading to severe illness and mortality within these communities. As organizations representing a truly diverse array of stakeholders, including consumers and patients, communities of color, faith groups, health providers, health industry and public health, we urge to you ensure the federal government has the mandate and resources to address barriers to the collection, analysis, and regular public reporting of detailed disaggregated data on individuals with COVID-19 in order to equitably respond to this crisis. Without timely data, our public health system effort cannot effectively understand this pandemic, focus the response and address our national emergency.

¹ Initial data reported by federal, state and local authorities has shown that certain racial and ethnic minority populations are disproportionately experiencing COVID-19. Data reported by the Centers for Disease Control Morbidity and Mortality Weekly Report suggests that black populations might be disproportionately affected by COVID-19 examining hospitalization rates. *See Centers for Disease Control and Prevention, Morbidity and Mortality Weekly Report March 1-30, 2020, available at <https://www.cdc.gov/mmwr/volumes/69/wr/mm6915e3.htm#F2> down.* In Michigan, African Americans make up 14.1% of the population, but represent about 40% of COVID-19 deaths. *See State of Michigan COVID-19 Data, available at https://www.michigan.gov/coronavirus/0,9753,7-406-98163_98173---,00.html.* In Arizona, American Indians represent 20% of COVID-19 deaths, but only about 5% of the state's population. *See Arizona Department of Health Services, COVID-19 Deaths in Arizona, available at <https://www.azdhs.gov/>.* In New York City, Hispanics have the highest death rate from COVID-19 at 34%, but account for 29% of the city's population. *See New York City Health, available at <https://www1.nyc.gov/assets/doh/downloads/pdf/imm/covid-19-deaths-race-ethnicity-04082020-1.pdf>.* In California, Asian Americans represent 16% of COVID-19 deaths and 15% of the state population while Native Hawaiians and Pacific Islanders make up 1.6% of cases but 0.3% of the state's population. *See California Department of Public Health COVID-19 Cases and Deaths by Race/Ethnicity, available at <https://www.cdph.ca.gov/Programs/CID/DCDC/Pages/Immunization/ncov2019.aspx>.* In Oregon and California, Pacific Islanders have case rates three times the state average. *See, Pacific Islander Center of Primary Care Excellence. (April 24, 2020) https://mk0picopce2kx432grq5.kinstacdn.com/wp-content/uploads/2020_0424-PICOPCE-COVID19-Press-Release.pdf*

We appreciate that the Centers for Disease Control and Prevention (CDC), alongside the agencies and providers that interface with patients and collect the data, is working diligently to ramp up surveillance in a moment of crisis. We acknowledge the challenges in doing so, given our antiquated public health surveillance systems and fragmented health care system. In fact, moments like these are why many of us have long called for substantive and sustained investments in our public health data infrastructure at the federal, state, tribal, territorial, and local levels. However, we also know that we cannot let vulnerable communities be overlooked because of these challenges. Congress must give CDC and the individuals and organizations that participate in the COVID-19 surveillance systems the resources needed to robustly report timely and accessible disaggregated demographic data. If reporting entities, including providers, testing laboratories and public health agencies, collect data on only aggregate populations, the elevated risk of outbreaks among smaller but particularly exposed groups will be missed.²

We request Congress require the CDC to update the COVID-19 surveillance systems to collect data on patients' race, ethnicity, sex, age, primary language, sexual orientation, disability status, gender identity, and socioeconomic status in line with federal standards, and as a threshold, comport with the standards codified by Section 4302 of the Affordable Care Act.³ We also support ensuring this data is collected and reported using all appropriate privacy standards.

Tracking demographic data for those who have been tested, infected, hospitalized, recovered, or died from COVID-19 helps the public health workforce identify groups that may have a higher likelihood to get sick and experience severe illness from COVID-19 as the pandemic progresses. It can help state, tribal and local agencies, health systems, hospitals, and health care providers invest in and direct resources to provide access to testing, health care, and social services for diverse populations with different needs. Finally, it can help policymakers prioritize and distribute resources based on anticipated need.

As organizations that are deeply concerned that this pandemic may exacerbate our nation's existing health inequities, we ask you to ensure our country has the tools it needs to effectively respond in this unprecedented crisis and assist our most vulnerable populations.

Sincerely,

Asian & Pacific Islander American Health Forum
Trust for America's Health
100 Black Men Of America, Inc.
Academic Pediatric Association
ACCESS

² A recent PolicyLink report, supported by the Robert Wood Johnson Foundation, noted that, "if public health practitioners and policymakers cannot track differences in chronic conditions or levels of treatment at a level more detailed than broad racial groups, they will lack the knowledge to act on the conditions that are leading to disparities." *Counting a Diverse Nation: Disaggregating Data on Race and Ethnicity to Advance a Culture of Health*. Policy Link. 2018, available at https://www.policylink.org/sites/default/files/Counting_a_Diverse_Nation_08_15_18.pdf.

³ Standards under Section 4302 have been promulgated by the Office of the Assistant Secretary for Planning and Evaluation. See <https://aspe.hhs.gov/basic-report/hhs-implementation-guidance-data-collection-standards-race-ethnicity-sex-primary-language-and-disability-status>.

Adhikaar
Advocates for Youth
Advocating Opportunity
AF3IRM Hawai'i
AF3IRM Sf Bay Area
African American Ministers In Action
AIDS Foundation of Chicago
Alaska Federation of Natives
Alliance for Aging Research
Allies for Independence
AlohaCare
American Academy of Pediatrics
American Academy of Physical Medicine & Rehabilitation
American Association of Birth Centers
American Association of People with Disabilities
American Association on Health and Disability
American Cancer Society Cancer Action Network
American College of Obstetricians and Gynecologists
American Congress of Rehabilitation Medicine (ACRM)
American Diabetes Association
American Federation of Teachers (AFT)
American Geriatrics Society
American Heart Association
American Holistic Nurses Credentialing Corporation
American Kidney Fund
American Lung Association
American Muslim Health Professionals
American Occupational Therapy Association
American Pediatric Society
American Physical Therapy Association
American Public Health Association
American Thoracic Society
Amplify, Inc.
Asian American Psychological Association
Asian Americans Advancing Justice - AAJC
Asian Americans Advancing Justice - Atlanta
Asian Health Services
Asian Pacific American Labor Alliance
Asian Pacific Partners for Empowerment, Advocacy and Leadership (APPEAL)
Asian Resources, Inc.
Association of Asian Pacific Community Health Organizations (AAPCHO)

Association of Maternal & Child Health Programs
Association of Medical School Pediatric Department Chairs
Association of Schools and Programs of Public Health
Association of University Centers on Disabilities
Athlete Ally
Autistic Self Advocacy Network
Bazelon Center for Mental Health Law
Big Cities Health Coalition
Biotechnology Innovation Organization
Black Women's Health Imperative
Brain Injury Association of America
Bread for the World
Breast Cancer Action
Bronx Health REACH
Bulosan Center for Filipino Studies, UC Davis
California Center For Rural Policy
California Healthy Nail Salon Collaborative
California LGBTQ Health and Human Services Network
California Pan-Ethnic Health Network
Campaign for Tobacco-Free Kids
Center for American Progress
Center for Empowering Refugees and Immigrants
Center for Law and Social Policy (CLASP)
Center for Medicare Advocacy
Center for Public Representation
CenterLink: The Community of LGBT Centers
Chinese-American Planning Council
Christopher & Dana Reeve Foundation
Chronic Sex
Church World Service
Coalition for Disability Health Equity
Coalition of Asian American Children and Families
Coalition of Labor Union Women
Colorado Alliance for Health Equity and Practice
Community Catalyst
Community Health Councils
Congregation of Our Lady of the Good Shepherd, US Provinces
Connecticut Legal Rights Project
Connecticut Legal Services, Inc.
Dia de la Mujer Latina

Disability Rights Education & Defense Fund (DREDF)
Disabled In Action of PA
DuPage Federation on Human Services Reform - Lombard, IL
Empowering Marginalized Asian Communities
Empowering Pacific Islander Communities (EPIC)
Enlace Chicago
Equal Rights Advocates
Equality California
Equality Labs
Equality North Carolina
Families USA
Family Equality
Federation of Protestant Welfare Agencies (FPWA)
Fenway Health
Fetal Alcohol Syndrome Information Network
First Focus Campaign for Children
Florida Institute for Health Innovation
Florida Legal Services, Inc.
FORGE, Inc.
Freedom Network USA
GLMA: Health Professionals Advancing LGBTQ Equality
GoFORTH.pro
Greater Hartford Legal Aid
Haitian Bridge Alliance
Hawaii Health & Harm Reduction Center
Health Resources in Action
HealthyWomen
Hep B United Philadelphia
Hep Free Hawaii
Hispanic Federation
Hispanic Health Network
Hispanics in Philanthropy
HIV Dental Alliance
HIV Medicine Association
Hmong Cultural Center of Butte County
Hmong Innovating Politics (HIP)
HopeWorks of Howard County
Human Rights Campaign
Idaho Immunization Coalition
Illinois Association of Rehabilitation Facilities
Illinois Collaboration on Youth

Immunization Action Coalition
In Our Own Voice: National Black Women's Reproductive Justice Agenda
Indiana Immunization Coalition
Indivisible
Infectious Diseases Society of America
Inter University Program on Latino Research
International Community Health Services
Japanese American Citizens League
Johnson & Johnson
Justice in Aging
Kansas Appleseed Center for Law and Justice
Keep the Promise Coalition
Kentucky Equal Justice Center
Khmer Girls in Action
Korean Community Center of the East Bay
Labor Council for Latin American Advancement (LCLAA)
Lakeshore Foundation
Latino Coalition for a Healthy CA
Latino Commission on AIDS
LatinoJustice PRLDEF
Lawyers' Committee for Civil Rights Under Law
League of United Latin American Citizens (LULAC)
Legal Aid & Defender Association, Inc.
Legal Aid at Work
Legal Council for Health Justice
LGBT Technology Partnership & Institute
Lupus and Allied Diseases Association, Inc.
MANA, A National Latina Organization
March of Dimes
Mid-City CAN (Community Advocacy Network)
Ministerial Health Fellowship
Mississippi Center for Justice
Mixteco/Indígena Community Organizing Project (MICOP)
Modern Military Association of America
MomsRising
Movement Advancement Project
Muslim Caucus of America
NAACP
National Association of County Behavioral Health & Developmental Disability Directors
National Association for Rural Mental Health
NASTAD

National Advocacy Center of the Sisters of the Good Shepherd
National Alliance on Mental Illness
National Asian Pacific American Women's Forum (NAPAWF)
National Association of Chronic Disease Directors
National Association of Community Health Centers
National Association of Community Health Workers
National Association of Councils on Developmental Disabilities
National Association of Hispanic Nurses
National Association of Pediatric Nurse Practitioners
National Association of Rehabilitation Research and Training Centers
National Association of Social Workers
National Association of Social Workers, CT Chapter
National Association of State Head Injury Administrators
National Black Nurses Association
National Center for Lesbian Rights
National Center for Parent Leadership, Advocacy, & Community Empowerment (National PLACE)
National Center for Transgender Equality
National Coalition of Ethnic Minority Nurse Association s
National Community Action Partnership
National Council of Asian Pacific Americans
National Council of Asian Pacific Islander Physicians
National Council of Jewish Women
National Disability Rights Netork
National Employment Law Project
National Equality Action Team
National Harm Reduction Coalition
National Health Care for the Homeless Council
National Health Law Program
National Hispanic Council on Aging
National Immigration Law Center
National Indian Council on Aging
National Institute for Reproductive Health (NIRH)
National Latina Institute for Reproductive Justice
National Latinx Psychological Association
National League for Nursing
National LGBT Cancer Network
National Medical Association.
National Minority Quality Forum
National Network for Immigrant and Refugee Rights
National Organization for Women
National Partnership for Women & Families

National Patient Advocate Foundation
National Puerto Rican Agenda
National REACH Coalition
National Urban League
National Women's Health Network
National Women's Law Center
National Working Positive Coalition
Nebraska Appleseed
Network for Environmental & Economic Responsibility of United Church of Christ
OCA - Asian Pacific American Advocates
OutCenter of Southwest Michigan
PA ADAPT
Papa Ola Lōkahi
Partnership for Inclusive Disaster Strategies
Pediatric Policy Council
People For the American Way
PFLAG National
Pharmaceutical Research and Manufacturers of America
Physicians for Reproductive Health
Planned Parenthood Federation of America
Poligon Education Fund
Poverty & Race Research Action Council
Power to Decide
Prevention Institute
Pride at Work
Public Advocacy for Kids (PAK)
Public Justice Center
Raising Women's Voices for the Health Care We Need
RespectAbility
RESULTS
Revolutionary Love Project
Rian Immigrant Center
SAGE: Advocacy and Services for LGBT Elders
SC Appleseed Legal Justice Center
Service Employees International Union
Services, Immigrant Rights & Education Network (SIREN)
SHK Global Health
Shriver Center on Poverty Law
Sikh American Legal Defense and Education Fund (SALDEF)
Silver State Equality-Nevada
Society for Pediatric Research

Society for Public Health Education
South Asian Americans Leading Together (SAALT)
South Asian Public Health Association (SAPHA)
Southeast Asia Resource Action Center
Southern New England Conference of the United Church of Christ
Tennessee Justice Center
The Arc of Illinois
The Arc of the United States
The Fresno Center
The Gerontological Society of America
The Health Trust
The Immunization Partnership
The Latino Coalition
The Leadership Conference on Civil and Human Rights
The National Puerto Rican Chamber of Commerce
The New York Academy of Medicine
The Praxis Project
The Trevor Project
The Wall Las Memorias Project
UCLA Center for Health Policy Research
UnidosUS
Union for Reform Judaism
United Spinal Association
United States Hispanic Leadership Inst
Universal Health Care Action Network of Ohio
URGE: Unite for Reproductive & Gender Equity
UsAgainstAlzheimer's
Vermont Legal Aid, Inc,
We All Rise
Western Center on Law & Poverty
Whitman-Walker Health and Whitman-Walker Institute
WithinReach
WomenHeart: The National Coalition for Women with Heart Disease
Young Invincibles
ZERO TO THREE