

May 4, 2020

Secretary Alex Azar  
Department of Health and Human Services  
200 Independence Avenue SW  
Washington, DC 20201

Dear Secretary Azar,

In recent weeks, state and local officials have documented that communities of color are being disproportionately impacted by the COVID-19 outbreak.<sup>1</sup> 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. Therefore, 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 the Department of Health and Human Services to address barriers to the collection, analysis and regular public reporting of detailed disaggregated demographic data on individuals with COVID-19 in order to equitably respond to this crisis. Without timely data, our public health system cannot effectively understand this pandemic, focus the response and address our national emergency.

We appreciate that the 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. We urge the Department to

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<sup>1</sup> 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](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](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>.

empower the individuals and organizations that participate in the COVID-19 surveillance systems 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.<sup>2</sup>

In particular, we request that the Department 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.<sup>3</sup> We also support ensuring this data are collected and reported using all appropriate privacy standards.

Tracking demographic data for those who have been tested, infected, hospitalized, recovered, and 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, healthcare, 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.

Sincerely,

Asian & Pacific Islander American Health Forum  
Trust for America's Health  
100 Black Men Of America, Inc.  
Academic Pediatric Association  
ACCESS  
Adhikaar  
Advocates for Youth  
Advocating Opportunity  
AF3IRM Hawai'i  
AF3IRM Sf Bay Area

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<sup>2</sup> 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](https://www.policylink.org/sites/default/files/Counting_a_Diverse_Nation_08_15_18.pdf).

<sup>3</sup> 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>.

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  
Bazon 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 (For HHS - First Focus on 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

Cc: The Honorable Dr. Robert Redfield, Director, Centers for Disease Control and Prevention  
The Honorable Seema Verma, Administrator, Centers for Medicare and Medicaid  
Services