

**U.S. DEPARTMENT OF HEALTH AND HUMAN SERVICES
COVID-19 HEALTH EQUITY TASK FORCE**

2nd MEETING (Virtual)

April 9, 2021

Members Present

Marcella Nunez-Smith, MD, MHS (Chair)
Mayra Alvarez, MHA
James Hildreth, PhD, MD
Andrew Imparato, JD
Victor Joseph
Joneigh Khaldun, MD, MPH, FACEP
Octavio Martinez, MD, MPH, MBA, FAPA
Tim Putnam, DHA, EMS
Vincent Toranzo
Mary Turner, RN
Homer Venters, MD
Bobby Watts, MPH, MS
Haeyoung Yoon, JD

Members Absent

None

Federal Ex-Officio

Jessica Cardichon, JD, EdD

Federal Staff

Minh Wendt, PhD, Designated Federal Officer, Office of Minority Health
Martha Okafor, PhD, Executive Director, Office of the Assistant Secretary of Health

Invited Presenters

Rachel Levine, MD, Assistant Secretary for Health, Department of Health and Human Services
Xavier Becerra, JD, Secretary, Department of Health and Human Services
Samantha Artiga, MHSA, Vice President and Director, Racial Equity and Health Policy, Kaiser Family Foundation
Nadia Islam, PhD, MS, Associate Professor, Department of Population Health, New York University Grossman School of Medicine
Kara Ayers, PhD, Associated Director, University of Cincinnati Center for Excellence in Developmental Disabilities

Call to Order, Welcome and Introductions

Minh Wendt, PhD

Designated Federal Officer, Office of Minority Health

Dr. Wendt opened the second meeting of the COVID-19 Health Equity Task Force (HETF) by welcoming the HETF chair and members as well as the invited speakers. She reminded attendees that the meeting was open to the public and that American Sign Language interpreters were available for the meeting.

Opening Remarks

Marcella Nunez-Smith, MD, MHS

Chair, COVID-19 Health Equity Task Force

Dr. Nunez-Smith introduced the meeting by stating its objective: to discuss interim recommendations on equitable vaccine access and acceptance. She underscored the following: (1) the importance of promoting recommendations that seek transformative change against the backdrop of increased rates of hate crimes and preexisting inequities that have been highlighted by the pandemic; (2) the critical role of policy in meeting the needs of individuals impacted by hate-fueled violence and long-lasting health and social inequities; and (3) the need to serve communities that have been minoritized, marginalized, and medically underserved.

Despite the approval of three COVID-19 vaccines, the benefits of these discoveries have been uneven. Race and place, historical drivers of opportunity, have been correlated with vaccination rates to date. Individuals of color and individuals in underserved and at-risk zip codes have been vaccinated at lower rates. These individuals are further harmed by the lack of data to show the inequities of distribution. Equity requires intention from governments, scientists, and communities to address barriers to equitable vaccination (e.g., transportation, supply, trust).

Dr. Nunez-Smith noted that the task force's four subcommittees developed interim recommendations for consideration and modification to best achieve an equitable response to the COVID-19 pandemic. She added that, although the recommendations focus on currently eligible age groups, HETF expects unique challenges to emerge at the national level regarding equitable distribution of the COVID-19 vaccine to pediatric populations.

After Dr. Nunez-Smith's opening remarks, Dr. Wendt performed a roll call of the HETF members.

Updates from HHS

Rachel Levine, MD

Assistant Secretary for Health, HHS

Dr. Levine greeted the HETF members and thanked them for working toward the mitigation of health inequities as well as the prevention of future inequities. She noted that the past year has been challenging mentally and physically, especially for communities hit hardest by the pandemic. She emphasized the importance of identifying those communities' questions and concerns about the vaccine and working to answer them. She reiterated the importance of the

HETF's recommendations to ensure that no one is left behind in the COVID-19 vaccination efforts and that all Americans have health care security and access.

Updates from HHS

Xavier Becerra, JD
Secretary of HHS

Mr. Becerra expressed excitement at the qualifications and capabilities of the experts assembled to tackle health equity challenges on assignment from President Joseph R. Biden. He quoted Frederick Douglass' famous line, "it is easier to build strong children than to repair broken men." He noted that the HETF will help to build stronger children and a stronger America, by ensuring fair access to resources to combat COVID-19 and by reducing barriers to equitable health care access. Mr. Becerra concluded by emphasizing that equity will be at the heart of the U.S. Department of Health and Human Services (HHS) mission as long as he serves as the Secretary and that HETF should aim high, push hard, and work together to meet their mission.

Introductions of Members

HETF members briefly introduced themselves, summarized their backgrounds, and highlighted any experiences relevant to the charge of the HETF.

Ms. Mayra Alvarez, President of The Children's Partnership, brings to the HETF her experience working with children and with a Latinx community that has been disproportionately affected by the pandemic, as well as her perspective as an immigrant and as a daughter of immigrants.

Dr. James Hildreth is President and Chief Executive Officer of Meharry Medical College, the nation's largest private, independent, historically black academic health sciences center. Dr. Hildreth brings his experience as an immunologist and a leader of equity in health care access for disadvantaged communities.

Mr. Andrew Imparato, a disability rights lawyer and the Executive Director of Disability Rights California, brings his experience as a disability lawyer and as an advocate for the elderly and the disabled. As an individual diagnosed with bipolar disorder, he can also provide insight into the pandemic's impact on individuals who struggle with mental health.

Mr. Victor Joseph, former Tanana Chiefs Conference Chief/Chairman (March 2014-October 2020), brings his experience as a former Chief of Native communities in Tanana to provide his perspective on the challenges faced by the American Indian and Alaska Native communities.

Dr. Joneigh Khaldun, Chief Medical Executive for the State of Michigan and the Chief Deputy Director for Health in the Michigan Department of Health and Human Services, brings her perspective as an emergency medical physician working on the frontlines of Michigan's response to the COVID-19 pandemic.

Dr. Octavio Martinez, Executive Director of the Hogg Foundation for Mental Health at The University of Texas at Austin, brings his experience as a psychiatrist concentrating on the mental

health impact of the pandemic, as well as his perspective as a trained minority health policy expert seeking to eliminate work force disparities and address social and political determinants of health.

Dr. Tim Putnam, President and CEO of Margaret Mary Health and a former emergency medical technician (EMT), brings his experience as the head of a rural hospital dealing with the challenges of the COVID-19 pandemic.

Mr. Vincent Toranzo, State Secretary of the Florida Association of Student Councils, brings his perspective as a student who works with his local government, advocating for the safety of students and foster children across the state of Florida, as well as his direct experience with the challenges that COVID-19 poses for Latinx Americans.

Ms. Mary Turner, an intensive care unit (ICU) nurse at North Memorial Medical Center and President of the Minnesota Nurses Association union, brings her perspective as a nurse working on the frontlines of the COVID-19 pandemic.

Dr. Homer Venters, a physician and epidemiologist working at the intersection of incarceration, health, and human rights, brings his experience helping incarcerated populations to cope with the challenges of COVID-19.

Mr. Bobby Watts, CEO of the National Health Care for the Homeless Council, brings his experience working with homeless Americans for the past 30 years, including during the pandemic, as well as a perspective gleaned from working with clinicians who treat homeless patients.

Ms. Haeyoung Yoon, Senior Policy Director at the National Domestic Workers Alliance, brings 20 years of experience working with low-wage immigrant workers, who during the pandemic were largely labeled as essential workers but still face economic challenges of caring for themselves and their families.

Panel Presentations

Three invited speakers, Ms. Samantha Artiga, Dr. Nadia Islam, and Dr. Kara Ayers, presented on the challenges and barriers to an equitable COVID-19 vaccination response, as well as strategies for overcoming them. The presentations were followed by a brief discussion period.

Equity in COVID-19 Vaccinations: Understanding and Addressing Gaps

Samantha Artiga, MHSA

Vice President and Director, Racial Equity and Health Policy, Kaiser Family Foundation

Ms. Artiga presented the findings of the Kaiser Family Foundation (KFF) highlighting COVID-19 vaccination gaps and efforts to address those gaps. Ms. Artiga presented data illustrating the uneven impacts of the pandemic. For example, individuals of color are more likely to be infected by, hospitalized for, or die from COVID-19 than their white counterparts, and are more likely to experience negative mental health and financial impacts from COVID-19. She emphasized the

importance of not seeking vaccine equality (proportional distribution of vaccine to everyone) but focusing on vaccine equity (preferential access to vaccines for those most affected).

Thus far, those individuals most impacted by the pandemic, both by race and place, have been least likely to be vaccinated. KFF analysis of state-reported vaccination data shows that, among states reporting racial and ethnic vaccine data, Black and Hispanic populations are receiving disproportionately small numbers of vaccines given their numbers of cases and deaths, as well as their populations. KFF also studied vaccination rates at the county level and found that counties with higher social vulnerability index scores and larger proportions of people who are of color, living in poverty, or uninsured had lower rates of vaccination compared to counties with lower social vulnerability index scores and smaller proportions of people who are of color, living in poverty, or uninsured. KFF surveys also found that individuals identifying as LGBT have been disproportionately affected by the pandemic but struggle to gain access to vaccines despite their receptiveness to vaccination campaigns. These data suggest that the main driver of low vaccination rates is lack of access, not lack of willingness.

Ms. Artiga emphasized that underlying inequities create uneven barriers to COVID-19 vaccine access. These inequities include limited resources to navigate the online sign-up process, limited transportation options, less flexibility in schedules, high uninsured rates and less connection to the health care system, lack of information, linguistic barriers, confusion about eligibility, fears of potential impacts on immigration status, and difficulty providing proof of identity or residence.

Ms. Artiga highlighted emerging strategies for addressing disparities in COVID-19 vaccinations, including the following: making more doses available and locating more clinics in harder hit and underserved communities; prioritizing vaccine appointments or eligibility for target groups or areas; providing alternative sign-up options for people without internet access; collaborating with and supporting community-based organizations and health centers; minimizing information and documentation requirements; launching focused outreach and communications campaigns; and collecting, reporting, and utilizing data to measure against and work toward equity goals. She emphasized that, beyond reducing barriers, governments and providers must increase access to information to address questions and concerns. This information must be made available through trusted messengers. To that end, KFF and Black Coalition Against COVID developed a national campaign called “The Conversation: #BetweenUsAboutUs” to provide credible and accessible information through Black health care workers. KFF is working toward developing a similar campaign for Latinx and Spanish-speaking communities.

Ms. Artiga concluded by emphasizing the importance of prioritizing equity in COVID-19 vaccinations as the rollout continues, and of collecting comprehensive high-quality data; mitigating disproportionate impacts of the pandemic on people of color and other underserved groups; reaching high vaccination rates across individuals and communities; addressing inequities built into underlying systems and structures; and supporting efforts that build upon existing community resources and strengths.

Achieving Health Equity for Asian American and Native Hawaiian and Pacific Islander Communities: If Not Now, When?

Nadia Islam, PhD

Associate Professor, Department of Population Health, New York University Grossman School of Medicine

Dr. Islam began her presentation by identifying two distinct but mutually reinforcing myths about Asian Americans: that they are a model minority as well as a perpetual foreigner. The latter myth was further perpetuated at the outset of the COVID-19 pandemic when the media began to use phrases such as “Wuhan virus” or “Chinese virus.” These negative stereotypes have resulted in increased anti-Asian xenophobia and hate crimes across the United States, with nearly 2 million Asian Americans experiencing anti-Asian hate since the onset of COVID-19. Dr. Islam noted that this hate is driven by and results in lack of data equity within and across Asian Americans.

False understandings of Asian Americans are perpetuated by the fact that the single category of “Asian Americans” includes 30 subgroups. For example, when aggregated together, 50 percent of Asian Americans have a bachelor’s degree or higher. However, there is a range in bachelor’s degree attainment across different Asian American subgroups, ranging from 11 percent of Tongan and Laotian individuals to 75 percent of Taiwanese individuals. In fact, most Asian American subgroups are below the national average in degree attainment, as well as in other key social determinants of health such as poverty and English language proficiency. However, because of the aggregated data, the health care needs of these communities remain widely misunderstood.

Dr. Islam stressed that invisibility due to aggregate data is killing Asian Americans, who are often not included in national efforts or outreach projects for COVID-19. Dr. Islam also presented data illustrating that although vaccine uptake appears high among Asian Americans, the lack of disaggregated data makes it difficult to track exact uptake numbers. Dr. Islam noted that race and ethnicity data are missing from national- and local-level reporting. She explained that missing data are particularly challenging for Asian Americans and Native Hawaiians and Pacific Islanders because studies have demonstrated that these groups are more likely to be impacted by COVID-19 and misclassified in data collection.

However, one issue that has affected all Asian Americans is the xenophobia that has led to individuals fearing for their safety. One way to combat this safety issue is to engage trusted messengers and gatekeepers in the community in the form of community health workers (CHWs) and community-based organizations (CBOs). Dr. Islam presented two examples of CHWs in New York City that are providing individuals with access to necessary health care services, mitigating fear, and providing social and mental health support.

Based on these findings, Dr. Islam presented three key recommendations:

1. All states should collect, analyze, and report disaggregated data, including separating Asian Americans from Native Hawaiian and Pacific Islanders and disaggregating Asian American subgroups.

2. Governments and providers should prioritize language access for Asian American and Native Hawaiian and Pacific Islander communities across COVID-19 efforts.
3. Governments and providers should provide direct financial support to CBOs and CHWs to facilitate safe access to COVID-19-related services for Asian American and Native Hawaiian and Pacific Islanders.

Equitable Vaccine Access for People with Disabilities

Kara Ayers, PhD

Associate Director, University of Cincinnati for Excellence in Developmental Disabilities

Dr. Ayers highlighted the importance of each state's University Centers for Excellence in Developmental Disabilities Education, Research, and Service (UCEDD) as important sources of disability data. People with disabilities are a heterogeneous group that is difficult for researchers to define. They may have mobility, cognition, independent living, hearing, vision, or self-care disabilities. Yet people with disabilities are not a small population, with 26 percent of adults in the United States having some type of disability. When viewed at a county level, there are higher concentrations of people living with disabilities in historically underserved areas, with concentrations in the South and across Appalachia.

The heterogeneity of disabilities and individuals in this community necessitates a varied approach to increasing vaccine accessibility for all. Beyond their medical needs, people with disabilities are more likely to live in poverty than those without disabilities and be multiply marginalized by race, ethnicity, or sexual orientation. Additionally, one-third of people with disabilities had no regular access to a health care provider before the emergence of COVID-19; and while most states have relied on the Intellectual or Developmental Disabilities (IDD) agencies to reach this population, only 20 percent of people with disabilities are served by these agencies.

Dr. Ayers noted that, in a study of 64 million Americans, people with disabilities were 3.5 times more likely to be diagnosed with COVID-19, and from 2 to 3 times more likely to die from it, than people without disabilities. She emphasized that these findings are not explained by worse health outcomes, but instead by inequitable treatment influenced by ableism that devalues the lives of individuals with disabilities.

One major factor creating inequities for people with disabilities is the lack of consistent data collection, particularly disability status for people infected with or hospitalized for, or who have died from, COVID-19. In response to these inequities, Johns Hopkins University partnered with the Center for Dignity in Healthcare for People with Disabilities to develop a COVID-19 Vaccine Disability Prioritization Dashboard. The dashboard is updated weekly and includes tracking caregiver access to vaccines and data visualization, as well as a report of the accessibility problems identified on all states' and organizations' vaccine registration sites.

Dr. Ayers noted that equitable vaccine distribution requires science, data, and policy. While ethics are often at the forefront of policy and decision making for equity, the field of ethics has a history of ableism. Based on these issues, Dr. Ayers emphasized that vaccine plans must consider people with disabilities who live in the community (i.e., not at care facilities); people

who are and are not connected to IDD agencies or other state services; access needs for people with disabilities at vaccination sites; barriers before, during, and after registration; and pediatric distribution. Dr. Ayers noted that best practices for equitable vaccination of people with disabilities must include accessible websites for information and registration; self-attestation; provider involvement; phone registration; transportation consideration; and other creative solutions developed in partnership with the disability community. Dr. Ayers concluded by emphasizing that people with disabilities need better representation, better data collection, equitable hospital care, and support to live in the community.

Discussion

Ms. Turner asked Dr. Islam to elaborate on the need to increase the number of public health nurses and health care professionals in addition to CHWs in the health care process, given the continued need to ensure the highest standard of care for people. Dr. Islam emphasized that CHWs are meant to complement the other members of the health care work force by providing a bridge from community settings to care systems. CHWs serve as trusted messengers because they have the lived experience of the community and the experience of the health care setting, providing contextualization for other health care workers. Dr. Islam noted that CHWs are not meant to replace the health care workers (e.g., nurses).

Mr. Imperato asked Dr. Ayers whether data exist to investigate the intersection between disabilities and racial and ethnic minorities (e.g., Black and Latinx populations). Dr. Ayers responded that no existing data source demonstrates this intersectionality. She emphasized that there are valid and varied reasons for distrust of health care among people of color with disabilities. For this reason, a trusted messenger is needed to ensure that equitable health care systems gain the trust of individuals in need. In addition, these individuals need to self-advocate, seeking answers to the COVID-19 and vaccine questions they may have.

Dr. Martinez asked presenters to address the health economic impact of incomplete, aggregated data. Ms. Artiga noted that all Americans suffer from the fragmentation of knowledge and the inefficient outbreak responses that result from health inequities. Dr. Ayers explained that when advocacy organizations for specific groups suffering from health inequities asked their state governments for dedicated resources to help those groups, state governments required those organizations to provide data to prove the existence of those health inequities. However, because those data are not collected by the state itself, advocacy organizations had to begin to gather their own data, which meant that those organizations that already had disproportionate resources were most able to secure additional funding from the state. Dr. Ayers also noted the importance of grassroots organizations and their ability to collect and assess data much faster than state and federal organizations. Dr. Islam stressed that governments must listen to providers, especially community providers, who see the negative effects of inequitable resource allocation.

Ms. Alvarez asked Ms. Artiga whether, in addition to building on previously successful efforts, novel opportunities were identified to increase vaccine access for marginalized communities. Ms. Artiga emphasized that the key is not to insert new people into the communities to create trust, but to rely on individuals and places within communities that are trusted and may not have already been leveraged (e.g., barbershops, CBOs).

In response to a question from Dr. Putnam, Dr. Ayers explained that individuals may have a variety of reasons for not having a primary care physician (e.g., care divided across specialties, changing health care needs). She suggested that although vaccination by primary care providers may meet the needs of individuals who cannot attend mass vaccination sites (e.g., sensory issues at mass vaccination sites for individuals with autism) that this solution will only address the needs of some individuals.

Subcommittee Presentations

Dr. Okafor introduced the four HETF subcommittees: Communications and Collaboration; Data, Analytics, and Research; Healthcare Access and Quality; and Structural Drivers and Xenophobia. Since the last HETF meeting, the subcommittees were tasked with identifying interim recommendations regarding equitable vaccine access and acceptance.

Each subcommittee invited subject matter experts to its meetings to assist with developing these interim recommendations, which spanned four broad themes: (1) mandating data collection, harmonization, and integrity; (2) increasing vaccine and health care confidence; (3) engaging marginalized communities; and (4) improving vaccine accessibility. Subcommittee chairs each presented their interim recommendations, which will be further refined to produce a final set of recommendations for the HETF to present to President Biden.

Communications and Collaboration Subcommittee

Mayra Alvarez, MHA

The Communications and Collaboration Subcommittee's charge was to explore how issues related to communications and collaborations within federal, state, and local partners can contribute to a more equitable vaccine rollout. The Subcommittee formulated three problem statements. First, federal, state, and local communication strategies about the vaccine are not reaching marginalized communities effectively. Second, structural barriers, including inadequate access to information, transportation, the internet, language-appropriate materials, health care, and in-home services and supports, hinder marginalized communities' access to vaccines. Third, public health infrastructure often lacks the knowledge and relationships necessary to engage with marginalized communities in a culturally and linguistically responsive manner and build trust in the vaccine deployment.

To address the first problem statement, the Communications and Collaborations Subcommittee presented the following interim recommendations:

1. The federal government should lead a coordinated, multi-pronged vaccine education, outreach, and communications campaign.
2. The federal government should provide clear guidance to states and localities on vaccine outreach protocols and identification of high-risk populations, and critical locations for deployment, including community health centers, public libraries, schools, and childcare centers.
3. The federal government should operate a coordinated clearinghouse on vaccine eligibility, access, and allocation across the country.

4. The federal government should host regular, monthly calls with various stakeholder groups on vaccine access and allocation.
5. The White House should identify opportunities to draw public attention to the pandemic emergency, such as inclusion of COVID-19-related information in the President's weekly address; weekly fireside chat between the President and various pandemic response leaders (both within the government and with state and community leaders); and a Cabinet-wide meeting on the public health emergency and opportunities to respond.

To address the second problem statement, the Communications and Collaborations Subcommittee presented the following interim recommendations:

1. Federal departments should strengthen collaboration with CBOs by providing robust funding for CBOs to reach marginalized communities and address access barriers to the vaccine, while requiring grantees to help amplify a Federal Government coordinated communications campaign.
2. In the short term, federal departments should provide clear standards on best practices for reaching marginalized communities, including ways to eliminate structural barriers, and do so in partnership with trusted national partners with state and local reach.
3. The federal government, through interdepartmental collaboration and in partnership with private industry, should host a series of televised, local town halls, utilizing agency initiatives that are known and trusted.
4. Federally supported vaccination sites should be expanded in partnership with local leaders and grassroots organizations in order to be most effective, leveraging parallel vaccination programs and centering the leadership of community partners.
5. Federal civil rights enforcement agencies should provide clear guidance and oversight to ensure that vaccine deployment is fully accessible to people with disabilities and people who need access in languages other than English.

To address the third problem statement, the Communications and Collaborations Subcommittee presented the following interim recommendations:

1. Departments should engage in a coordinated effort to fund CHWs across health, housing, agriculture, nutrition, childcare, and other programs, to support short-term COVID-19 deployment and response.
2. Over the long term, the federal government should commit to identifying a sustainable career pathway, classification structure, and scope of work that provides CHWs the support they need to be necessary partners in the work of achieving healthy communities.
3. In the short term, the federal government should provide guidance on working with community leaders, including community health workers, Promotoras, independent living centers, and other disability service providers, to support state and local health departments in their efforts to better reach marginalized communities, including providing examples of successful programs or initiatives.
4. In the short term, the federal government should leverage and mobilize its networks of regional partners.
5. The federal government should coordinate with relevant associations (ASTHO, NACCHO, NGA) to distribute information and leverage its coordinated communications campaign while also strengthening knowledge of who are trusted providers and

expanding the number of community members available to distribute vaccines to marginalized communities.

6. The federal government should require and invest in state-specific vaccine distribution registry sites in every state to assist municipal governments, hospitals and clinical providers, community health centers, regional centers, and other eligible administrators in achieving the logistics of equitable vaccine allocation.

Dr. Martinez highlighted the importance of the trusted voices such as certified peer specialists, who play a key role as both messengers and individuals with lived experience serving on clinical teams.

Discussion

Dr. Cardichon noted that as schools prepare for students to return to in-person learning, governments and organizations are considering engagement strategies that can rebuild trust and reengage families with support, meals, and nutrition education; she stressed that COVID-19 infection, safety, and vaccination information could be included in these packages. Dr. Cardichon also asked the HETF members to consider the importance of building relationships with community partners that extend beyond COVID-19 so that these new partnerships can be leveraged to address other inequities or health crises in the future.

Mr. Imperato endorsed the recommendation to hold a Cabinet meeting focused on vaccine inequities, noting that different federal agencies have different community connections and that these connections could be leveraged jointly to reach more populations.

Regarding the first recommendation associated with the first problem statement, Mr. Joseph suggested that the multi-pronged campaign should also be “culturally appropriate” because that will be a key factor in reaching many populations. He also noted that during a recent meeting of tribal leaders, speakers noted that one component of vaccine hesitancy is brand hesitancy. He concluded by adding that Alaska is a strong example of successful collaboration between government and community organizations to improve vaccine dissemination.

Ms. Turner expressed concern that, while CHWs serve as a trusted and important voice, the recommendations need to more clearly define the role of such workers in the vaccine dissemination plan.

Data, Analytics, and Research Subcommittee

Joneigh Khaldun, MD, MPH, FACEP

The Data, Analytics, and Research Subcommittee’s charge was to explore how addressing issues related to collection, sharing, and use of data can improve the current COVID-19 response and drive equity for health care services overall. The Subcommittee formulated two problem statements. First, a lack of robust and consistent demographic data on COVID-19 cases, morbidity, deaths, and vaccinations hinders the ability to develop and implement strategies to protect marginalized populations. Second, there is a lack of interoperability, integrity, and compliance across data systems.

To address the first problem statement, the Data, Analytics, and Research Subcommittee presented the following interim recommendations:

1. The federal government should mandate that states, tribes and tribal epidemiology centers, territories, and local health departments collect and report on a comprehensive set of standardized equity-focused demographic data elements pertaining to COVID-19 testing, hospitalizations, deaths, congregate setting (including homeless shelters, jails and prisons), type of employment, and vaccinations to support strategies to protect minoritized, marginalized, and underserved populations.
2. The federal government should develop a COVID-19 equity dashboard that tracks key disaggregated metrics across states, tribes, territories, and local governments that include data on testing, treatment, and vaccinations. The federal government should share best and promising practice guidance on how these data can be shared appropriately between states, tribes, territories, local governments, and health care providers to ensure proper understanding of the virus spread and its impact on different communities.
3. State, tribal, and local health departments should leverage existing sources of quantitative and qualitative data, including Emergency Medical Services, Medicaid, state and local community health assessments, and hospital community health needs assessments, in guiding outreach and vaccination strategies as well as understanding the impact of COVID-19 on marginalized populations. Incomplete data should not prevent health authorities from prioritizing groups that have increased risks associated with their underlying health conditions or other risk factors.

To address the second problem statement, the Data, Analytics, and Research Subcommittee presented the following interim recommendation: The federal government should provide funding/incentives for hospitals, community health centers, and state, tribal, and local health departments to update data systems, in alignment with the CDC Data Modernization Initiative, in order to assure interoperability and automatic electronic lab reporting of a robust set of standardized demographic data elements.

Discussion

Mr. Joseph explained that a challenge for reaching vaccine equity is that to serve all minority populations, the HETF will need to create a set of recommendations that considers the varied needs of different minority populations. For example, American Indian and Alaska Natives face unique data collection and sharing barriers because of the Indian Health Improvement Act, which was permanently reauthorized in 2010. The Act defined 12 tribal epidemiology centers (TECs) as public health authorities for the purpose of Health Insurance Portability and Accountability Act (HIPAA) privacy, which has the effect of inhibiting data sharing. Due to these restrictions, the TECs cannot conduct public health surveillance, limiting the ability to make evidence-based recommendations and changes. The Indian Health Service (IHS) consequently developed the following set of recommendations: HHS must implement a policy that directs all HHS agencies and employees to share data freely with TECs; IHS should be instructed to provide direct access to electronic health data systems for all TECs; and HHS should include specific requirements for real-time, line-level data sharing with TECs. Mr. Joseph strongly encouraged the HETF to consider either generalizing or otherwise incorporating the recommendations into its final set of recommendations.

Dr. Venters noted that individuals in jail are another community affected by the lack of data regarding COVID-19 infection, hospitalization, and death rates, emphasizing that although nonprofits and other nongovernmental organizations have created strong data resources, the existence of these resources do not absolve the government of its responsibility to collect and disseminate complete and accurate health care data.

Mr. Imperato emphasized the difficulty of identifying disabilities as a unique challenge to collecting accurate disability data. He noted that it can be expensive for data collection surveys to ask all the necessary questions to identify individuals with disabilities. The Subcommittee has discussed this issue Dr. Andrew Houtenville, professor of economics and research director at the Institute of Disability at the University of New Hampshire, who suggested collecting meaningful population data on individuals with disabilities using the largest sample size possible. Expanding on this advice, the Subcommittee will continue to work with Dr. Houtenville to formulate an exact recommendation.

Healthcare Access and Quality Subcommittee

Tim Putnam, DHA, EMS

The Healthcare Access and Quality Subcommittee's charge was to explore how issues related to health care access and quality drive inequities. The Subcommittee formulated four problem statements. First, many marginalized groups lack access to vaccines due to location, transportation, internet access, distribution reprioritization, language, and other barriers. Politicization in some states has hindered the prioritization identified by the best scientific recommendations and has further marginalized these groups. Second, adults and children who generally lacked access to health care prior to the pandemic have been disenfranchised for testing, treatment, and vaccination. Third, the vaccination process is not being led or delivered by people that vulnerable populations trust. Fourth, states and localities are not assuring appropriate allocation of vaccine and medical resources to the groups most in need. It has been clear that affluent people (with transportation resources, flexible schedules, and internet access) have gained access to vaccinations and testing before more vulnerable and needy populations have.

To address the first problem statement, the Healthcare Access and Quality Subcommittee presented the following interim recommendations:

1. Federal, state, territorial, and tribal governments should partner with local health care institutions, community organizations, and other trusted sources to promote vaccine awareness and uptake within local communities, with particular attention to institutions and organizations that serve communities that have borne the brunt of COVID-19 exposure, illness, and death.
2. Federal, state, territorial, and tribal governments should prioritize vaccine distribution, testing, and treatment to adults and children in medically-underserved populations and those who face mobility, geographic, or other barriers to receiving the vaccine.
3. Federal, state, territorial, and tribal governments should simplify registration procedures.
4. The federal government should ensure access to broadband and telehealth services in medically underserved communities, including rural and tribal communities.

To address the second problem statement, the Healthcare Access and Quality Subcommittee presented the following interim recommendations:

1. The federal government should engage with employers to provide paid time off for employees to receive the vaccine or accompany loved ones/dependents and allow up to two days paid time off for individuals experiencing significant side effects.
2. Completely remove all insurance/billing barriers for people receiving and administering the vaccine.

To address the third problem statement, the Healthcare Access and Quality Subcommittee presented the following interim recommendations:

1. The federal government should deploy the Reserve Corps and Public Health Service Corps to communities that lack necessary staff upon their request.
2. Continue to expand the number of health care professionals who can be trained to provide vaccinations safely and effectively.
3. Support communities with mobile services upon their request.
4. Assign CHWs the role of screening for social determinants of health while people are waiting to get vaccines at the community health centers, safety net providers, and other health care organizations administering vaccines.
5. As vaccine supply increases and age groups expand for adults and children, provide vaccines to all physician offices and health care agencies that are capable and willing to safely vaccinate with priority given to providers who serve minoritized and marginalized populations.

To address the fourth problem statement, the Healthcare Access and Quality Subcommittee presented the following interim recommendations:

1. The federal government should strongly recommend states not prohibit priority groups identified by the Advisory Committee on Immunization Practices (ACIP) from receiving vaccines. Federal guidelines from ACIP regarding vaccine administration are based on scientific data and knowledge. We recognize that the ACIP priority groups are not a comprehensive list and that states and territories have the rights to adjust priority groups based on the local situation.
2. Utilize credible data (i.e., zip code data) to prioritize vaccine allocation and distribution to support localities that have historically low life expectancy, greater COVID-19 mortality, and high rates of economic hardship.
3. States should have set-aside allotments of vaccines for providers to vaccinate hard-to-reach populations, such as the incarcerated, migrant workers, etc.
4. The federal government should provide additional vaccines or other incentive to states that collect data and hit or exceed equity targets based on collection and reporting of equity data (e.g., race/ethnicity/housing status/language, etc.).

Discussion

Mr. Toranzo voiced his support for the recommendations drafted in response to the first problem statement. He focused on the second recommendation, regarding vaccine access in hard-to-reach communities, and the strategies to use established mobile medical services, establish testing and vaccination sites close to public transportation, and ensure hours of operation are accessible to all. He added that the politicization of the pandemic in multiple states has promoted an unwillingness to widely provide vaccines, disproportionately affecting hard-to-reach

communities. He emphasized that the lack of prioritization of vaccine rollouts leaves members of affected communities feeling like second class citizens of their respective states.

Mr. Watts suggested two amendments to the recommendations responding to the fourth problem statement. He expressed concern that the recommendations require too much decision making at the local level and pushed for enhancing equity and effective public health response at the federal level. He cited issues in Michigan and Texas with local or state governments blocking equitable access to vaccines and testing. For this reason, Mr. Watts recommended that the federal government reduce the ability of states or local authorities to deviate from the ACIP recommendations without adequate public health data to justify deviation. Mr. Watts also suggested strengthening the third recommendation to recommend that administrations set aside vaccines for specific populations and provide them directly to the health providers serving those populations, as opposed to providing them to the states.

Dr. Hildreth emphasized the importance of expanding the pool of individuals qualified to administer vaccinations in order to meet the need for vaccinating the American population. He added that qualified individuals should also represent the populations being served at vaccination sites.

Ms. Turner expressed concerns with the focus on telehealth in the recommendations. She emphasized that many aspects of health care, including vaccination, cannot occur via telehealth. She also expressed concern that reliance on telehealth may close clinics and hospitals, particularly in rural and minority communities, reducing the ability for people to receive necessary in-person care.

Mr. Joseph responded to Ms. Turner's comments, emphasizing that in Alaska, many small, rural communities rely heavily on telehealth. He noted that many communities are served by health aids, who are required to be monitored by a supervisor. He added that without the telehealth services, many health aids would be unable to complete their jobs and many rural Alaskans would be unable to receive regular health care services (e.g., follow-up for vaccinated individuals experiencing side effects from the vaccine).

Structural Drivers and Xenophobia Subcommittee

Haeyoung Yoon, JD

The Structural Drivers and Xenophobia Subcommittee's charge was to explore how structural drivers and xenophobia perpetuate inequities and how to address related barriers. The Structural Drivers and Xenophobia Subcommittee identified two problem statements. First, the COVID-19 pandemic has laid bare our nation's long-standing structural inequities, revealing that individuals and communities hit hardest by COVID-19 also experience structural barriers to accessing vaccinations. Second, xenophobia, racism, and anti-Asian violence are nothing new, but a wave of incidents of hate against Asians, Asian Americans, and Pacific Islanders (AAPI) has risen in the midst of the COVID-19 pandemic.

To address the first problem statement, the Structural Drivers and Xenophobia Subcommittee presented the following interim recommendations:

1. Diversify federal, state, city, tribal and territorially supported vaccine registration and appointments. Support states, cities, territories, as well as federally supported vaccination sites, to require and offer other mechanisms, in addition to on-line appointments, for the public to sign up for vaccinations.
2. Localize venues to bring vaccines closer to communities, particularly underserved communities. In partnership with the local and state governments, create as many venues as needed in communities and settings that people trust for quick and efficient vaccination.
3. Identify targeted equity populations. States and cities should be required to provide a menu of options for appropriate documentation for individuals to prove identity and eligibility.
4. Coordinate deployments of Corps support with communities and state and local governments.
5. Invest in paid sick leave to encourage uptake of vaccines.
6. Prohibit vaccination being made a condition of employment when workers are unable to obtain the vaccine; and require that any vaccination passport system must be developed with equity at the center.
7. The federal government must ensure that structural barriers that effectively prevent or hinder individuals from getting vaccinated are removed.
8. Address climate conditions by considering alternate allocation strategies in geographically isolated communities.

To address the second problem statement, the Structural Drivers and Xenophobia Subcommittee presented the following interim recommendations:

1. Work with relevant federal agencies and local and state governments to ensure there are community-centered solutions to target and reach AAPI communities to access vaccines.
2. Create effective vaccines distribution infrastructure. Ensure a more equitable and targeted approach to vaccine allocation and distribution support, especially to the Pacific Islander communities that have less local vaccination distribution infrastructure.
3. The federal government should collaborate with other relevant federal agencies and stakeholders to collect and disaggregate data on Asian, Asian American, Native Hawaiian, and Pacific Islander in terms of COVID-19 cases, deaths, socio-economic and health impact of the pandemic, and vaccination rate.

Mr. Joseph was invited to discuss factors regarding global warming and impacts of climate change. He noted that many coastal and river communities have been affected by erosion, which harms infrastructure (e.g., sewer, water, electric, communications) and may require communities to relocate the infrastructure or relocate the community at large. Global warming also has an impact on transportation of vaccines, as well as of people from rural areas to vaccination clinics amidst changing weather patterns. Some rural areas in Alaska fly residents into Fairbanks to stay overnight in a hotel for vaccination.

Discussion

Dr. Martinez emphasized that a cross-systems approach with federal partners is critical to address structural drivers and social determinants of health. He noted that graded funding is needed at the community level to promote flexibility and creativity to implement key changes.

Ms. Turner voiced her opposition to the concept of vaccine passports. She noted that she is concerned that vaccine passports will allow employers to remove access to personal protective equipment for health care providers or otherwise encourage unsafe work and travel practices despite the need for continued safe practices post-vaccination.

Interim Recommendations Vote

Dr. Nunez-Smith introduced the voting phase for HETF members to vote on each set of interim recommendations and whether the recommendations should move forward to the next stage for refinement. Dr. Nunez-Smith opened the floor for consideration for the following interim recommendations:

- Communications and Collaboration Subcommittee recommendations,
- Data, Analytics, and Research Subcommittee recommendations,
- Healthcare Access and Quality Subcommittee recommendations, and
- Structural Drivers and Xenophobia Subcommittee recommendations.

Each recommendation received a motion to approve that was seconded. Motion carried with majority vote to approve. All four sets of interim recommendations will return to their subcommittees with the friendly amendments noted in the discussion sections above and revisions considered by the relevant subcommittee.

Public Comments

Sean Cahill, Adjunct Associate Professor of the Practice, Health Law, Policy, & Management, Fenway Institute

Hello, Madam Chair and Task Force members. I am Sean Cahill from the Fenway Institute in Boston. I am speaking on behalf of the LGBTQI federal health policy round table. We encouraged the Biden-Harris administration to issue federal guidance requiring the collection and reporting of data on sexual orientation, gender identity, and intersex status, or SOGI, in COVID-19 testing, care, and vaccination. First, sexual and gender minority people, or SGM people, may be more vulnerable to infection with the novel coronavirus. SGM people are nearly twice as likely to work in frontline jobs like food and retail services. Many live in urban areas where social distancing is difficult. SGM people are more likely to be low income. A recent survey found that SGM people of color were more likely than straight cisgender people of color to test positive for COVID-19 and twice as likely to test positive as SGM white people. Second, SGM people are more likely to have chronic conditions, such as diabetes, cardiovascular disease, and asthma, and risk factors like smoking, vaping, and substance use disorder that may put them at risk for complications from COVID-19. Third, sexual minority women, transgender people, and SGM people of color are less likely to access routine preventive care, and this may inhibit their ability to access COVID-19 testing, care, and vaccination. SGM people must be included in vaccine dissemination plans, and SOGI data must be collected to ensure equitable vaccine uptake. SGM people experience medical mistrust, which can affect willingness to get the vaccine. A recent analysis in the *Journal of Vaccine* found that Black and Native American men who have sex with men were less willing to get vaccinated than white and Asian American MSM. Federal requirements to collect SOGI data could come from CDC or somewhere else in HHS. The CDC COVID-19 case report form needs to add SOGI questions and change its current

sex question. Right now the sex response options are male, female, other, and unknown, and these are not affirming. We also ask that the National COVID Cohort Collaborative add SOGI to its COVID-19 warehouse data dictionary. Currently this collaborative does not allow for research on SGM populations' experiences with COVID-19. In the midst of the worst global pandemic of our lifetimes, our federal government and most state governments are not collecting and reporting SOGI data so that we know how COVID-19 is affecting SGM people, including people of color and elders. I am heartened by Dr. Khaldun's presentation today and hope to work with the task force and the Data, Analytics, and Research Subcommittee, to help address this important data equity issue. Thank you very much.

Bonnielin Swenor, Director, Johns Hopkins University Disability Health Research Center

My name is Bonnielin Swenor, I am the director of the Johns Hopkins University Disability Health Research Center. I lead the COVID-19 vaccine dashboard for people with disabilities that Dr. Kara Ayers discussed, and my center is working as fast as possible to continue to expand that resource. My comment intends to elevate some lessons learned from that dashboard project about how persistent gaps in disability data have widened health inequities, including in the vaccine rollout during the pandemic for the disability community. The disability community has historically been excluded from many data collection opportunities, perpetuating gaps in evidence and creating formidable barriers in health equity for people with all types of disabilities. As we say at my center, who counts depends on who counts. These deep disability data gaps have impacted COVID-19 tracking efforts, and I ask the task force to consider the following to support efforts to surveil and address COVID-19 and related inequities for the disability community. One, ensure disability is included in all national and state surveys and public health data systems. Current data gaps have prevented us from being able to track the impact of COVID-19 on people with disabilities and continues to limit us from identifying and addressing the structural and accessibility barriers to achieving vaccine equity for disabled people. Two, to collect disability data at all health care interactions. While data on age, race, ethnicity, and gender identity are routinely collected in medical records, disability is not assessed. This information is necessary to track COVID-19 outcomes and vaccine rates for people with disabilities and without this information efforts to achieve vaccine equity will remain inadequate. Three, to ensure disability data allows for the examination of intersecting identities. Health equity efforts, including efforts to track gaps in the vaccine rollout cannot ignore the intersectionality between disability and race, ethnicity, gender identity, sexual orientation, geographic location, and other groups. But without robust and disaggregated disability data at state and national levels this is impossible. And four, funding the development of disability data infrastructure, disability research, and supporting the inclusion of the disability community in these efforts is needed. Without resources our work cannot move forward, and vaccine gaps and health inequities within the disability community will go underrecognized and unaddressed. Leading this COVID dashboard has taught me that we must reexamine how we approach disability research and related public health efforts. Filling gaps in disability data cannot wait. This work requires innovation, multidisciplinary collaboration, and must start meaningful partnerships with the disability community and should ensure that resulting information is shared back with the community and made accessible to people with disabilities. During the pandemic the absence of disability data has often been interpreted as absence of risk or inequity, and as a result the disability community has been excluded from many pandemic

response efforts. That must change. Data is powerful, and my hope is that this task force will work to close these critical disability data gaps and support the creation of better disability data infrastructure, which is a necessary and essential step to advancing health equity for the disability community both during the pandemic and beyond. Thank you.

Harald Schmidt, Assistant Professor of Medical Ethics & Health Policy, University of Pennsylvania

My name is Harald Schmidt. I'm an assistant professor of medical ethics and health policy at the University of Pennsylvania. I want to congratulate the chair, the task force members, and the staff for everything you've done so far. I continue to be in awe of your energy and relentless focus. It is really inspiring. I am also grateful for the opportunity to provide some brief comments now and I would like to raise three points. The first, allocating in ways that recognizes disadvantage needs to continue as we near vaccines for all. Second, states and cities with lower average vaccination rates and above average shares of disadvantaged communities need particular attention as we transition to this next phase. Third, ID requirements must not be barriers to particularly vulnerable populations. First, on allocating in ways that recognize disadvantage, in a little over a week, states will open vaccine eligibility to all residents. But disadvantages and vulnerability still matter. The general population is not a uniform group. Many can safely wait a little longer, but many others cannot. If we switch from one day to the next from structured and mostly equitable to first-come-first serve, we will undoubtedly be successful at vaccinating a large number of people, but for equity and public health it is key to make sure that vulnerable groups are not pushed aside by other population groups that may be just as impatient as everybody else to get a vaccine, but are far less vulnerable. Many more disadvantaged groups, including larger shares of people of color, are at the ends of their abilities to withstand economic shock from the pandemic and receiving a vaccine is far more urgent for them than for the better off. Using a disadvantage index such as the CDC Social Vulnerability Index that the National Academies suggested should be used in all phases including the general population remains critical. Our most recent review of states' use of indices found that by the end of March we now have 37 jurisdictions and the majority of states (34 states) use a disadvantage index. It is not too late for universal adoption, and it would likely be helpful if the task force were to urge all jurisdictions to explore how they can use disadvantage indices for planning dispensing sites locations, outreach and communication, increasing allocations, and monitoring and adjusting allocations. Then we need to recognize that not all states are equal as they open the gates. While all states are the same in being asked to open eligibility on April 19, all states are not the same in their vaccine uptake rates and they are not the same in their shares of disadvantaged populations. So opening vaccines to all should be to the benefit of all, but given where we are it is not clear that it will be. What this means is that for equity in public health, we need to pay particular attention to states and cities with below average vaccination rates and above average shares of disadvantaged communities as opening in such situations will very likely make it harder for more disadvantaged groups to receive vaccines. We need to be able to monitor and swiftly adjust if needed access, communication, outreach, and allocations in such states, and not see all states as starting from the same situation because they are not. The equity dashboard mentioned earlier seems highly promising. Finally, ID requirements must not be barriers to particularly vulnerable populations. As Ms. Artiga noted earlier, a particularly vulnerable group are immigrants, both documented and undocumented. Thanks to the chilling

effects of the public charge rule, many immigrants are understandably, even if wrongly, concerned about seeking the vaccine. And when they do try to register, seeing that they are asked to provide ID and insurance will turn off many. States including New Jersey, Wisconsin, Illinois, and North Carolina recognized this in allocation plans and prescribed that insurance and ID must not be required. Yet, for example in North Carolina, some counties do require ID, so there is an urgent need to correct such misalignment. In addition, states should enable vaccines with no questions asked. With that, I thank you for the opportunity to share these comments and your outstanding work, and I will follow-up with written comments too.

Pilar Whitaker, Council for the Economic Justice Project at the Lawyers; Committee for Civil Rights Under Law

Good afternoon, my name is Pilar Whitaker and I serve as council at the Lawyers Committee for Civil Rights Under Law. Over the past year we have analyzed federal data collection directives and tracked demographic data published by the states and federal government. Based on this, we recommend that HHS and CDC align their data reporting guidance for labs, hospitals, and vaccine providers with the 2011 HHS data standards. Those standards include 14 different racial and 5 different ethnic subgroups. This is compared to just 5 racial and 2 ethnic subgroups currently tracked. The department can absolutely accomplish this using express authority under section 4302 of the Affordable Care Act. Revised guidance must also require the reporting of primary language and disability status, as well as other demographic points that correlate with social vulnerabilities. Such data points can include employment, housing, and insurance status as well as sexual orientation and gender identity. As you are all aware, President Biden has now issued two executive orders noting the importance of complete disaggregated data and ensuring an equitable pandemic response. Calls for disaggregated health data are not new. In 1985, HHS similarly noted “data must be disaggregated by race and ethnicity, providing major detail within major ethnic groups, such as Hispanics.” Now, 40 years later, the federal government’s failure to collect disaggregated data is inexcusable. In the three months since President Biden’s executive order, there has not been a single revision to COVID-19 data reporting requirements. HHS has failed to apply its 2011 data collection standards to any COVID-19 data collection efforts, despite its statutory authority to do so. Also, there is no federal directive requiring data reflecting, in the President’s words, “those living at the margins of our economy.” Our analysis also revealed differences between government data collection tools such as case report forms and V-Safe and reporting requirements for providers. When coupled with the lack of data infrastructure and education at the provider level, these factors have resulted in woefully incomplete race and ethnicity data. I ask you today to issue recommendations on data and reporting collection requirements. Lives are at stake. First, HHS and CDC must issue guidance clarifying that labs, hospitals, and vaccine providers must collect disaggregated race and ethnicity data in accordance with 2011 HHS standards. Two, HHS guidance must direct these providers to report data in each of the following categories: primary language, disability status, sexual orientation, gender, gender identity, employment status, pregnancy status, housing status, insurance type, and income. Finally, HHS and CDC should ensure that all data collected at the federal level through case report forms, V-Safe, and FEMA-run vaccination sites mirror these data categories. The Lawyers Committee will be issuing a report that will expound upon these and other issues in the coming days. We appreciate the task force taking on these absolutely critical health equity issues.

Elena Ong, President and CEO of the Asian & Pacific Islander Caucus for Public Health

Hi, I am honored to have the opportunity to read a summary of a United Against Racism letter that was signed by more than 100 leaders from the American Indian, Asian American, Black, Disability, Latinx, LGBTQ, Native Hawaiian and Pacific Islanders, White, and/or women's communities to show solidarity with Asian Americans. We must understand the killings of six Asian American women in context. Exactly one year ago, the phrase "China virus" went viral and serial tweets fueled xenophobic racism and led to deadly discrimination. Since 2020, Asians globally and domestically have been experiencing two epidemics: COVID-19 and xenophobic racism. Asian Americans have been verbally harassed and physically attacked. Customers have stopped patronizing Asian-operated businesses, and many were forced to close. Many Asian Americans suffer from extremely high unemployment rates. Stigmatized, murdered, blamed, and shamed, Asian Americans went into hiding. Many were deterred from anti-Asian hate from reporting race and ethnicity. Statistics were made invisible when Asian and Pacific Islanders were lumped into the same category data were not collected by the level of disaggregation necessary to address the true impact of COVID-19 on Filipinx and other groups. The dearth of linguistically and culturally incompetent outreach may have also contributed to COVID-19 undertesting. Unusually low COVID-19 case rates and unusually high COVID-19 case fatality rates without a proportionally higher reported COVID-19 case rates, Asian Americans were left out of equitable vaccine prioritization. Will they be left out of further vaccination? So today we are at a critical flashpoint. The hate toll is at 3,800 and rising. While we encourage the community to report incidents of hate and language barriers, we also must protect Asian Americans and ensure their access to vaccines. We applaud President Biden for issuing the memorandum condemning and combating racism and xenophobia and urging Congress to pass hate crime legislation. We look forward to working with elected officials and administrators to ensure that resources are prioritized to protect communities from racism. We stand united against racism and other "isms" because no one is safe until we are all safe from racism, xenophobia, poverty, ablism, homophobia, homelessness. And I recommend intersecting U.S. Department of Justice civil rights recommendations with President Biden's memos, particularly item 1 on hate crimes, item 6 on non-English languages, and item 7 on data to ensure equitable outcomes. I also recommend real-time transparent data to get the vaccine to those experiencing access barriers. Thank you very much.

Closing Remarks and Next Steps

Marcella Nunez-Smith, MD, MHS

Dr. Nunez-Smith thanked the HETF members, speakers, public commenters, and American Sign Language interpreters for making the second HETF meeting a success. She also thanked the HETF subcommittee members for all of their interim recommendations, and noted that the four subcommittees will continue to refine them in advance of the next HETF meeting.

Appendix A. Written Public Comments

Cathy St. Pierre

I come to make these comments as someone who falls into multiple groups having a serious interest in the progress and effectiveness of this effort to mitigate health inequities among underserved and vulnerable populations.

I am a person

-living with disabilities

who, prior to becoming unable to work more than a few hours a week,

-conducted primary research into identifying and measuring drivers of vaccine uptake (during the H1N1 pandemic of 2009/2010) and who, for over 25 years,

-designed and implemented strategic marketing communications in both commercial organizations and at health-related research centers at Boston University and Harvard Medical School.

The major topics and themes from the HETF Fireside Chat and the EO that I'll be addressing include: the need for data; race and place; media and messaging; trust in vaccine, health providers, and other key influencers; implementation and operationalization. My comments include miscellaneous suggestions and an overview and specifics of value to be gained from the findings and products associated with the above-mentioned study on identifying and measuring drivers of vaccine uptake.

The need for data was noted as a challenge in both the Fireside Chat and the Executive Order, e.g., strengthening equity data collection, utilizing a place-based approach; understanding barriers that have restricted access to preventive measures and treatment. Also described was an aim to develop short-term and longer-term recommendations to address data shortfalls and to be better prepared to respond in the future.

Data Collection: strengthening equity data collection through a place-based approach; implementation and operationalization

- 1) GOTVax I recently learned about this effort from a medical student in Boston who considered this effort to be an effective novel approach to reaching underserved populations. I believe that the methodology would also work for data collection among those populations. The effort "is committed to helping bring vaccines to those in our communities who are most in need" by conducting "vaccine outreach leveraging electoral campaign strategies. (See GOTVax.org)
- 2) Speaking for those who have disabilities, a variation on a place-based approach would be to reach people while they are at doctor's appointments. I know that in the past I was approached in waiting rooms at Brigham and Women's Hospital about participating in research (of course, keeping in mind the adjustments needing to be made for social distancing). While a sample of convenience, data can be gained while waiting for doctor's appointments.
- 3) For possible adaptation: The model of how pharmaceutical companies have collaborating sites at hospitals or other health care offices may serve to be replicated in the service of data collection.

Data about Race, Research from 2010/2011 identifying drivers of vaccine uptake

4) The dataset. “Hispanics were .241 times as likely to get the shot for H1N1 as whites.” The 2010/2011 research on identifying drivers of vaccine uptake I conducted has produced this and other findings that have not been widely disseminated. This is because it was shortly after this point that my health issues began to prevent me from pursuing additional work with this research. I am making the dataset used to produce these findings available for others to use and continue analysis. There are still many of the relationships surrounding Race/Ethnicity that need to be analyzed relative to their influence in taking the H1N1 vaccine. (See ACHA presentation in the bibliography for finding noted above along with other findings. Contact stpierre@bu.edu to request a copy of the dataset.)

Understanding barriers that have restricted access to preventive measures and treatment; building trust; identifying influencers; determining appropriate messaging

a. Utilization of the current dataset for the 2010/2011 H1N1 vaccination. Barriers and facilitators of vaccine uptake can be measured against the variable Race/Ethnicity toward the outcome of taking the H1N1 vaccine in the existing dataset. The 2010/2011 research study features a 23-item validated scale based on the Health Belief Model that includes many of the factors that were described as needing understanding in order to address concerns of building trust and determining appropriate messaging and key influencers. These scale factors include:

- Perceived Threat of the Disease,
- Perceived Benefits of Vaccination,
- Perceived Barriers to Vaccination,
- Peer Influence,
- Parental Influence, and
- Perception of Health Services.

It may be surprising that Parental Influence was still seen to be significant among college students. A finding like is highly actionable, as are many of the other findings (see Bibliography for access to products of the 2010/2011 Research described)

b. To facilitate speedy development of well-constructed data collection instruments in other studies focused on identifying and measuring barriers to uptake as well as other factors affecting vaccine uptake, I suggest reviewing the validated scale that developed in the 2010/2011 Research I conducted to identify drivers of vaccine uptake. I am making that scale available for use. The Single-Event Vaccination (SEV) validated scale and the specific items making up each of the constructs are described in a peer-reviewed article in a journal published by George Washington University. To address a multiple dose vaccination, a construct for Perceived Self-Efficacy should be added to the SEV in order to measure and isolate the influence of one’s perception of agency in being able to get/take something more than a single shot. (see bibliography for access to the article)

c. In that article, there is also a table showing which particular variables showed as significant in influencing the choice to take the H1N1 vaccine at a univariate level. For deeper analyses, a slide deck and presentation at a national conference describes those variables that showed significant at a multivariate level.

d. The importance of using a validated scale in order to achieve the collection of robust data is well-explained in the article by Boateng, et al. (see bibliography for access to the article and to the Scale)

e. The 70-item web questionnaire that was part of the 2010/2011 Research that is available could be readily repurposed for community colleges and other institutions of higher education that are already likely to have answered the concern of having access to the internet. Those underserved populations who have not could be reached out to using the techniques described in the GOTVax effort noted above.

Long-term recommendations to address data shortfalls; be better prepared for the future; best practices

Usable data is findable data. The HETF would be well-served to have a website that houses datasets, articles, and best practices. This speaks to the need of being more ready in the future to respond to pandemics. This repository could include techniques in data collection, data sets and successful best practices. Examples of online repositories include the Cochrane Library (Cochrane.org) and the Campbell Collaboration (campbellcollaboration.org)

I think the lack of reference to lessons learned from the 2009-2010 H1N1 pandemic indicates that not much of the knowledge gained has been accessed. One example is from the American College Health Association (ACHA) Annual Meeting in 2011 which had a track focused on H1N1 vaccine delivery and health communications. I sat in on a woman who presented about her university's success in achieving high rates of vaccination because of how they did their distribution. Even the ACHA no longer has those presentation available on their website.

However, piles of information alone without assistance is like an attic with so much in it that it's hard to find what is needed. In addition to excellent user interface design, such a Repository could have dedicated human resources to assist those in search of data or best practices. In the field of clinical and translational science, there were/are Research Navigators who have as their job to listen to the needs of an individual and to point them in a right direction; much like excellent librarians do.

In addition, I suggest making part of any grant funding for supporting data collection for these equity topics require that the dataset and its products, e.g., abstracts to articles, be shared to the Repository.

Vaccination Implementation and operationalization, place-based approach, pharmacy deserts
Among those underserved populations who may have difficulty in accessing the location of there is the compounded concern of being able to get to the shot for a second time. Consider then the distribution of the J&J vaccine being prioritized among those people for whom access to the vaccine is a challenge.

During the Fireside Chat, mention was made that some organizations are giving people time off to get the vaccine. This is an excellent example of how a study finding can be made actionable. In the 2010/2011 Research, the factor Finding the Time to Get the Shot was found to be significant in multivariate analysis against the outcome Took the Shot for H1N1.

Creative partnerships with commercial organizations could include those with organizations that already have an infrastructure that can meet some of the existing challenges. For example, the use

of ice cream trucks as traveling pop-up vaccination centers (of course, providing that the temperature tolerances are acceptable). Or once a vaccine that is stable at room temperature, partnering with organizations such as Coca-Cola that have ubiquitous distribution of their product so that vaccine distribution can reach “pharmacy deserts”.

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I invite review and utilization of the 2010/2011 Research on identifying and measuring drivers of vaccine uptake that are housed on my LinkedIn page at <https://www.linkedin.com/in/cathystpierre/>

Cathy Piazza St. Pierre
MS, Applied Research in Communication
Boston University

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Brian Vamstad, Regulatory Affairs and Payment Policy, Public Affairs, Allina Health

RE: Comments for the COVID-19 Health Equity Task Force

Dear Dr. Marcella Nunez-Smith, Chair, and Members of the COVID-19 Health Equity Task Force: On behalf of Allina Health, we are writing to provide comments to the COVID-19 Health Equity Task Force. We appreciate the opportunity to share our perspective and experience with serving our communities during this pandemic. We also provide some recommendations to help engage and provide access through health equity strategies and tactics within our communities for consideration by the Task Force.

Allina Health is dedicated to the prevention and treatment of illness and enhancing the greater health of individuals, families, and communities throughout Minnesota and western Wisconsin. As a not-for-profit health care system, Allina Health cares for patients from beginning to end-of-life through our 90+ clinics, 11 hospitals, 15 pharmacies, specialty care centers and specialty medical services providing home care, senior transitions, hospice care, and emergency medical transportation services.

Background

The COVID-19 Health Equity Task Force was established by President Biden under Executive Order 13995. The Task Force is charged with developing a set of recommendations to the Coordinator of the COVID-19 Response and Counselor to the President for mitigating the health inequities caused or exacerbated by the COVID-19 pandemic and for preventing such inequities in the future. The Task Force shall submit a final report addressing any ongoing health inequities faced by COVID-19 survivors that may merit a public health response, describing the factors that contributed to disparities in COVID-19 outcomes, and recommending actions to combat such disparities in future pandemic responses.

COVID-19 Vaccine Outreach

The pandemic has heightened health disparities throughout our nation and heightened awareness to the historic and systemic inequities our underrepresented patients face. Recognizing and addressing vaccine hesitancy is vital to ensuring inoculations throughout our diverse communities. In Minnesota, recent data indicates disparities in vaccine distribution and uptake. Black people make up 6% of the state's population but only 3.5% of its vaccine recipients. Additionally, Black Minnesota residents comprise more than double the COVID-19 deaths than white residents when adjusted for average ages. Furthermore, Hispanic and Multiracial groups also lag behind White populations in vaccine uptake across all adults in Minnesota¹ while accounting for substantially higher COVID-19 case rates.²

Faced with a history of mistreatment from medical researchers and involuntary subjugation of medical practices, many in the Black communities remain apprehensive of vaccines and medical studies. At Allina Health, we are starting our approach with an understanding of this hesitancy. By providing points of access to communities identifying as Black, Indigenous, and people of color (BIPOC) for vaccination, we offer opportunities to discuss the vaccine, answer questions, and help alleviate safety concerns.³ Tailoring care for our patients in ways that help support their needs and desires is the bedrock of improving health equity to support healthy communities. At Allina Health,

we are using data to drive outreach within our communities. Our East Lake Clinic is an example of providing access to medical care and vaccines in low income neighborhoods. This clinic remains a critical access point for health care and our vaccine distribution plan.

As part of our outreach strategy, we recently offered a temporary “pop-up” community vaccine clinic, focusing on lower income, culturally diverse, and underserved people in the Phillips neighborhoods of Minneapolis. By using zip codes to build an outreach tool to invite eligible individuals to sign up for an appointment, and maximizing accessibility and turnout by hosting this event on a weekend, we were able to provide more than 800 vaccines in a single day. This event offered us an opportunity to learn from our communities that may be hesitant to take the vaccine or lacked easy access to health care services like vaccinations, while providing education and reassurance about safety to defeat this pandemic to community members. We are now applying these learnings, and planning additional community vaccine clinics throughout our service region, focusing on underserved communities.

To support our patients with complex care needs, we’ve mobilized outreach services with patient scheduling, community vaccine clinics, and door-to-door outreach. Allina Health patients with disabilities were offered the opportunity to schedule a vaccine appointment at one of our locations. In addition, Allina Health is targeting outreach to people with disabilities and their primary caregivers who reside in the targeted geographies for our free community COVID-19 vaccine events. We are reaching out directly to our clients/patients and working through our disability community partners to schedule appointments and offer support with addressing other barriers such as transportation.

Furthermore, our Complex Care program is a home-based, primary care initiative that focuses on improving management of health to help prevent unnecessary trips to the clinic or hospital. Our skilled care team specialized in providing comprehensive coordinated care for older adults with complex health care needs. Our care team addresses one’s whole being—mind, body, spirit, and community—so patients can maintain independence for as long as possible. Through this initiative, we are performing COVID-19 vaccine “house calls” to patients who may be homebound or have disabilities.⁴ This program has been part of our broader efforts to support vaccine equity for those with disabilities throughout our community.

Recommendations

As the task force develops recommendations for a successful vaccine roll out, we recommend the following action steps based on our experience:

- Integrate health equity strategies throughout vaccine distribution planning. Ensure a health equity lens is used in all facets of distribution.
- Provide education and resources to address hesitancy. Listen and learn about concerns and provide resources to answer questions about the vaccine in multiple languages and cultural competencies. Providing resources in languages our communities understand is important to connect with them and discuss their concerns.
- Focus distribution on underserved communities and areas with high rates of COVID-19 infections. Communities of color have been disproportionately impacted by COVID-19. Efforts should be made to prioritize vaccine distribution to underserved communities, individuals with disabilities, and those with higher-than-average case rates.
- Promote and provide resources for mobile or “pop-up” vaccine clinics. To ensure access for our

communities, provide resources and funding to support mobile methods of vaccine administration that provide easy access for those without means of transportation. The speed of vaccines cannot compromise goals of health equity, even when current demands for vaccines far exceed current supply. Bringing vaccines to our patients is instrumental to widespread inoculation uptake.

- Leverage existing community partnerships to bring vaccines to underserved communities. Our community partners have been instrumental in helping to reach out to individuals and families affected by COVID-19. Leveraging existing community programs and stakeholders can help reach those with barriers to receiving health care services. Successfully connecting with underserved communities helps care professionals to understand values, beliefs and how to reach those who face obstacles to being vaccinated.

- Collect data, learn, and engage. While vaccine distribution is moving forward quickly and rapidly increasing, it is important to continuously collect public health data to inform ongoing strategies and outreach planning to reach communities across the country.

Conclusion

On behalf of Allina Health, we greatly appreciate the focus from Health and Human Services on vaccine distribution and outreach through a lens of health equity. Successfully defeating this pandemic requires thoughtful planning, coordination, and outreach to those unable to obtain care or who may have hesitancy in taking the vaccine. We ask the Task Force to consider our recommendations in drafting the plan for HHS to implement as soon as possible.

Allina Health is committed to health equity during and beyond the Public Health Emergency. Please feel free to reach out to us with any questions or to learn more about how Allina Health is supporting health equity efforts during our vaccine outreach and how it can be applied to communities across the country.

Sincerely,
Vivian Anugwom, MS
Program Manager, Health Equity
Allina Health
vivian.anugwom@allina.com

1 Minnesota Department of Health, Vaccine Data, Race and Ethnicity, <https://mn.gov/covid19/vaccine/data/index.jsp>, updated March 21, 2021.

2 Minnesota Department of Health, COVID-19 Data by Race/Ethnicity, <https://mn.gov/covid19/vaccine/data/index.jsp> accessed April 1, 2021.

3 Jeremy Olson, “Officials say it's 'time to play catch-up' on race gap as vaccine access widens,” Star Tribune, March 15, 2021, <https://www.startribune.com/officials-say-it-s-time-to-play-catch-up-on-race-gap-as-vaccine-access-widens/600034724/> accessed March 25, 2021

4 Jennifer Hoff, “Doctors go door-to-door to ensure homebound patients get vaccinated as eligibility expands,” KARE 11, March 26, 2021, <https://www.kare11.com/article/news/health/coronavirus/doctors-go-door-to-door-ensure-homebound-patients-get-vaccinated/89-787deaa2-4056-407e-880f-e085cd215b85>

Nina Bihani, Department of Psychiatry, Wayne State University, Detroit Medical Center

I am a psychiatry resident in Detroit. I would like to express my concerns that our nation is not prioritizing many important and marginalized people with schizophrenia and intellectual and developmental disability (IDD) during our vaccine rollout. I am writing to request that these conditions be added to the CDC's list of underlying conditions for increased COVID-19 vaccine prioritization.

A few months ago, the inpatient psychiatric unit I was working at had an outbreak of COVID-19, and we had to discharge several patients before they completed their treatment. Further, much of the staff on the unit also fell sick. Luckily, there were no serious illnesses and most people involved did not need to be hospitalized. This psychiatric unit was part of the Veterans Affairs system, and many of these patients had schizophrenia-spectrum conditions that placed them at high risk for COVID-19 mortality.

I have a brother with IDD. He has displayed remarkable resilience over the last year, as he has adapted to the new rules of the pandemic. However, he struggles to understand and follow social distancing rules, which places him at higher risk than he already has due to his disability. My family has caregivers for him that come into our home, which further increases his risk. This has been a scary time for my family as we grapple with ensuring my brother has the supports he needs without putting his wellbeing at risk.

People with intellectual and developmental disabilities are among those at highest risk for mortality due to COVID-19--three times higher risk than those without IDD. Complications from and death rates due to COVID-19 for people with IDD are disproportionately higher when compared to people without IDD. Mortality rates have been cited to be up to 15% in individuals with IDD. Some reports state that people with IDD are four times more likely to contract COVID-19 and 2.5 times more likely to die from it. Although IDD is not part of the official CDC list of underlying conditions, it should be. The data supports the dire need that people with IDD have for the vaccine as do many professional medical and scientific societies. In fact, Tennessee recently became the first state to prioritize patients with IDD in their vaccine distribution, because the data so strongly supports this population's needs for protection.

Similarly, new data is showing that people with schizophrenia and other thought disorders have an independent risk of COVID-19 mortality, with about three times the higher mortality risk. This data is particularly concerning because it shows that after age, schizophrenia is the second highest risk factor for death from COVID-19. This is compounded by a well-documented phenomenon that people with schizophrenia have a reduced lifespan, with average life expectancy up to 25 years less than the general public. Finally, people with schizophrenia often experience neurocognitive decline as part of the progression of the disorder, which can create increased need for accessibility. Schizophrenia is also not listed as an underlying condition by the CDC, but it also should be. Although each disease and disorder have different pathology, the big picture outcome is the same: people with disabilities have a higher risk of death during this pandemic.

I know that the vaccine supply is highly limited, but people with IDD and people with schizophrenia are dependent on others on a daily basis. They depend on family caregivers and direct support professionals who come into their homes to assist them with activities of daily living that they cannot complete on their own. Or they often live in group homes and other congregate

settings. They do not have the luxury to socially distance because they need to interact with others for survival.

My request of the HHS Taskforce on Health Equity is simple: please include developmental disabilities and schizophrenia on the list of underlying conditions and empower local communities to improve accessibility to the vaccine for these patients. I commend the CDC for including Down Syndrome on the list, and as a physician, I understand that not every condition can be listed. However, listing one developmental disability, and not others, causes unnecessary distinctions within the disability community. Similarly, excluding schizophrenia perpetuates mental health stigma that has persisted in our society, and in medicine, for far too long. I request that you add developmental disability and schizophrenia to the list with haste, and provide communities with extra resources to ensure there is increased outreach and accessibility measures in place for those living with these conditions. This is an opportunity to save the lives of people who are far too often marginalized. As a physician, I took an oath to do no harm, and leaving these patients behind is causing immeasurable harm throughout our nation.

Molly Burgdorf, Rights Policy at The Arc

Dear COVID-19 Health Equity Task Force:

Thank you for the COVID-19 Health Equity Task Force Meeting on April 9, 2021. We appreciate the chance to offer input on the impact of COVID-19 on people with Intellectual and Developmental Disabilities (IDD), and on equitable vaccine access specifically. The Arc is the largest national community-based organization advocating for people with intellectual and developmental disabilities (IDD) and serving them and their families. We are encouraged by the increasing vaccine supply and distribution efforts. The widespread use of a safe and effective vaccine will be essential to curb the deadly COVID-19 pandemic that has already had such a deadly toll on so many, including too many people with IDD and their families. We also wish to express support for the comments from Dr. Kara Ayers, and we applaud the Task Force for including her presentation in the agenda.

Vaccine distribution and allocation must be done in a safe, nondiscriminatory, and equitable manner. It's critical that any vaccine distribution plan take into consideration the needs of people with disabilities and direct support workers, no matter where they live or work, and the toll the pandemic has taken in these communities. People with disabilities, along with the people who provide the services and supports that we rely on, must be appropriately prioritized.

Eligibility

Data indicates that that people with IDD who contract coronavirus die at sharply higher rates than the general population. People with IDD also have a higher incidence of other conditions that may put them at elevated risk for severe COVID-19 illness, including higher rates of obesity and other chronic conditions (e.g., cardiovascular disease and diabetes) than the general population. Experts including the National Council on Disability and the American Academy of Developmental

Medicine & Dentistry have advocated that vaccine allocation frameworks should put people with IDD at high priority. Thus far, the CDC has not included these conditions on the list of people with “certain underlying medical conditions” who are at increased risk for severe illness from the virus that is being used by states to set their vaccine priorities (with the significant exception that people with Down Syndrome are identified as being at increased risk).

Though the CDC indicates that dementia or other neurological conditions “can make you more likely to get severely ill from COVID-19,” it is not clear whether or how that should be applied to people who fall within the functional definitions of having an intellectual or developmental disability. Uncertainty and lack of clarity in vaccine prioritization and allocation has fostered fear, confusion and frustration as states have implemented and revised their vaccine allocation plans. Without adequate information and transparency, people with disabilities and their families face an ongoing burden to navigate a complex and periodically changing vaccine process. At minimum, vaccine allocation and distribution plans must also include people with IDD who are not served by state IDD agencies.

Accessibility

We must ensure that both the information people need and how it’s distributed are accessible, and comply with federal guidance and civil rights laws. Information about the vaccine and how to get it must be communicated in plain language and provided where people will see it, including people with low technology literacy or without convenient online access. Accessibility also includes effective and equitable distribution, such as safe transportation options to vaccination sites, particularly for people who do not drive; a clear and navigable process to request necessary accommodations; and flexible options for vaccinating people who may not be able to travel to a vaccine site.

Other Systemic Issues

Overall, additional research and data collection efforts are needed to understand the impacts of COVID-19 on people with disabilities, communities of color, and people who live at the intersection of marginalized identities.

In addition to the vaccine-related issues, we remain focused on addressing the disproportionately heavy toll that people with IDD, their families and caregivers have faced in this health crisis. The COVID-19 pandemic has exposed just how dangerous institutions and nursing homes are for people with disabilities, and how important access to home and community-based services are for health, safety, and overall well-being. We continue to call for measures including dedicated, robust funding for Medicaid home and community-based services, and paid leave for all caregivers.

As Dr. Ayers indicated, people with IDD are not expendable. We look forward to working with you to address and eliminate inequitable treatment, and ensure that people with IDD have equal access to timely, high quality, appropriate health care that meets their individual needs.

Thank you for considering this information. For additional questions or further discussion, please contact Julie Ward, ward@thearc.org or Molly Burgdorf at burgdorf@thearc.org.

Kathleen Jaeger, Health and Wellness Strategy, Policy, & Patient Advocacy President, NACDS Foundation

The National Association of Chain Drug Stores (NACDS) would like to extend our tremendous appreciation to the Task Force for your leadership in executing the Biden-Harris Administration's National COVID-19 Strategy, placing equity at the very core of the nation's response and recovery efforts amid the current pandemic and beyond. We applaud the Task Force's keen focus to put forth interim recommendations aimed at improving data standardization, advancing vaccine confidence, increasing engagement of marginalized communities, and improving vaccine accessibility. Pharmacies, too, are dedicated to these initiatives via their participating in state and federal vaccination programs, including the Federal Retail Pharmacy Program.

As an example, early in the COVID-19 vaccination campaign, pharmacies experienced first-hand the challenges arising from inconsistent data reporting requirements across state vaccine registries and within various state COVID-19 vaccine programs, which often conflicted with federal data reporting requirements. Pharmacies have advocated for more harmonious reporting systems to remove undue burdens on vaccine providers, and most importantly, to enhance the quality and utility of data being collected in order to improve vaccination efforts. In many cases, operational updates and pharmacy system refinements were required to accommodate new data elements across various states. However, disparate data reporting requirements continue to pose operational challenges, ultimately leading to data gaps, and underscoring the need for standardized data reporting.

In addition to standardizing data reporting, pharmacies are committed to the Task Force's goals to advance vaccine confidence, increase engagement of marginalized communities, and improve vaccine accessibility. To that end, retail pharmacies are honored to continue to serve as key partners in the equitable COVID-19 vaccination rollout, helping to provide vaccine access points in communities who need them most – from the largest U.S. cities to the smallest rural communities. For example, with 45% of pharmacies participating in the Federal Retail Pharmacy Program located in the hardest hit neighborhoods across the country, pharmacies are particularly well positioned to help ensure equitable access to vaccines and other healthcare services, including COVID-19 testing, screening and linkage to care for chronic diseases such as diabetes and hypertension, in addition to screening for and helping to address social determinants of health.

As the COVID-19 vaccination campaign continues, pharmacies are engaging within the communities they serve to provide ongoing education, outreach, and communications to help overcome vaccine hesitancy and address systemic and longstanding barriers to care, while in parallel, offering additional COVID-19 vaccine access points at nearly 40,000 pharmacies within the Federal Retail Pharmacy Program, and at additional pharmacies through direct partnerships with jurisdictions. In fact, the Federal Retail Pharmacy Program is central to the President's directive to provide 90% of Americans with COVID-19 vaccine access within 5 miles of where they live by April 19th.

Because pharmacies are close to home and integrated members of the communities they serve, pharmacies develop a strong understanding of the local social, economic, and cultural dynamics. These relationships and understanding help cultivate meaningful conversations about vaccines and other healthcare needs, allowing pharmacies to answer questions, dispel myths, and foster shared decision making. As a result, pharmacies can help alleviate vaccine hesitancy and increase the

uptake of vaccines by addressing confidence and complacency in trusted and conveniently accessible locations. In fact, pharmacists continue to receive high trust ratings from the public and importantly, 66% of Black Americans and 72% of Hispanics trust pharmacists to provide a COVID-19 vaccine, according to a survey conducted by Morning Consult and commissioned by the National Association of Chain Drug Stores (NACDS).

Further, pharmacies have more than a decade of vaccination experience that can be utilized to better reach marginalized communities. In fact, pharmacies are leveraging their experience to help reach those who have been hardest hit by the pandemic and are facing the greatest barriers to receiving COVID-19 vaccines. For example, pharmacies are partnering with schools, community leaders, and faith-based organizations, collaborating with ride-share companies, deploying mobile vaccination units, meeting people where they are – even going door-to-door – transcending community outreach strategies that work well for flu shots, offering appointment times well into the evening hours and on weekends, and working to overcome disparities in technology access.

Also, while mass vaccination efforts are an important part of the nation’s overall strategy to defeat COVID-19, evidence suggests that across races and ethnicities, Americans would prefer to obtain their COVID-19 vaccinations in a pharmacy rather than in a large venue such as a stadium, and from pharmacy staff rather than from a member of the military, for example. As trusted members of their communities and one of the most easily accessible healthcare providers, pharmacies are able to help address the specialized needs of those with limited mobility, for example, such as the elderly or persons with disabilities, who may be unable to navigate large mass vaccination clinics or stand in line for long periods of time. A keen example of this comes from early accounts of the Federal Retail Pharmacy Program wherein many individuals are opting to receive their 2nd COVID-19 vaccine dose from local, trusted, and easy-to-access retail pharmacies, rather than returning to a mass vaccination clinic or another venue.

In summary, community pharmacies are committed to advancing equity in all aspects of care amid the COVID-19 pandemic and beyond, in lockstep with the work of the Task Force. NACDS applauds the hard work of the Task Force to advance interim recommendations presented at the April 9th meeting, and we welcome the opportunity to be a partner and resource as these recommendations are finalized and implemented. We appreciate your ongoing leadership and dedication to advance health equity for the nation.

Denny Chan, Equity and Racial Justice Advocacy, Justice in Aging

We believe it is critical for the TF to continue to encourage vaccine distribution models that center meeting people where they’re at and leveraging trusting messengers. In many areas of the country, vaccination rates among older adults of color continue to lag compared to white older adults. Although it is wonderful that community health centers and other models may help with outreach to communities of color more broadly, older adults of color tend to receive care elsewhere. We believe that the TF must champion distribution models that involve working with senior centers and other aging service providers. These are absolutely critical.

The recent rise in Anti-Asian hate hits Asian American older adults in unique ways. A number of recent incidents have targeted Asian American older adults who may be perceived as easy targets by virtue of their age and race. We at Justice in Aging believe that Asian American older adults

cannot be expected to get their vaccines with any sense of urgency if they fear for their safety. We call on the TF and relevant subcommittees to meet with aging and disability advocates who work directly with Asian American older adults to anchor their recommendations to the lived experiences of Asian American older adults and their unique needs.

Finally, I want to reiterate the importance of data. Only two states out of fifty are reporting out vaccination rates among race and age. We strongly support all recommendations that move more states to report this intersectional data publicly so we can better target outreach and education efforts for older adults of color. We also support additional recommendations by today's speakers regarding disaggregated AAPI data and data regarding people with disabilities. These steps are absolutely necessary in order to achieve true health equity.



Harald Schmidt, PhD
Assistant Professor, Department of Medical Ethics and Health Policy
Research Associate, Center for Health Incentives and Behavioral Economics
Senior Scholar, Leonard Davis Institute of Health Economics

Health Equity Task Force
Office of Minority Health
Tower Oaks Building
1101 Wootton Parkway
Suite 100
Rockville, MD 20852

Philadelphia, April 20, 2021

Dear Dr. Nunez Smith and members and staff of the Health Equity Task Force,

Public comment – improving equity in vaccine (and ventilator) allocation

I am writing to congratulate the chair, the Task Force members, and the staff for everything you have done so far, and for your inspiring energy and relentless focus.

I would also like to thank you for the opportunity to provide a brief oral comments at the April meeting of the Task Force, and am following up here with a written version and references to relevant sources, regarding 1) the need to continue to allocate vaccines in ways that recognizes disadvantage, 2) the importance of paying particular attention to states and cities with below average vaccination rates, and above average shares of disadvantaged communities, and 3) to ensure that ID requirements do not become vaccination barriers for particularly vulnerable populations, especially in states that have already formally committed to reducing such barriers. Further to earlier correspondence, I would also like to 4) draw the Task Force’s attention to an important recent study quantifying the extent of inequity arising from ventilator allocation policy, which is of central relevance to the planned work on Crisis Standards of Care (this point was not included in my oral comments).

Allocating vaccines in ways that recognizes disadvantage through disadvantage indices and other place-based measures

On April 19, 2021, all US residents became eligible for vaccines. But disadvantage and vulnerability still matter. The general population is not a uniform group. Many can safely wait a little longer—but many cannot. For equity and public health, it is imperative that that more vulnerable groups are not pushed aside by population groups who may be as impatient as everyone to get a vaccine—but are far less vulnerable.

Many more disadvantaged groups, including disproportionately larger shares of disadvantaged communities of color, are at the end of their abilities to withstand the economic shock of the pandemic, and receiving a vaccine is far more urgent for them than for more privileged groups.¹

Using a disadvantage index such as the CDC’s Social Vulnerability Index, that the National Academies of Science, Engineering and Medicine recommended should be used in all allocation phases—that is: including the general population—remains critical.

In an update of our earlier study,² our most recent review of states’ use of disadvantage indices and Zip-code-based prioritizations found that by the end of March, there are now have 37 jurisdictions (and the majority of states, N=34) that use a disadvantage index, see the enclosed copy here (note that at the time of submission of this letter, the manuscript had just been accepted for publication by *Nature Medicine* and that the final published version may differ as a result of further editing).

It is still not too late to universalize the adoption of place-based disadvantage indices, and it would be helpful if the Task Force urged all jurisdictions to explore how they can use such measures for improving equity in planning the location of dispensing sites, outreach and communication strategies, increased allocations and shares of vaccination appointments, as well as continued monitoring and adjusting of vaccine allocations, as needed.

Recognizing that not all states are equal, as vaccine eligibility has become universal

All states are in the same position in having been asked to open vaccine eligibility by April 19, 2021. But all states are *not* the same in their vaccine uptake rates, and are *not* the same in their shares of disadvantaged populations (see Table S1 in Appendix 2 of the enclosed study).

Opening vaccines to all should be to the benefit of all—but given where we are, it is not clear that it will be. For equity and public health, it is therefore critical to pay particular attention to states and cities with below average vaccination rates, and above average shares of disadvantaged communities, as opening up eligibility in such situations will very likely make it harder for more disadvantaged groups to receive vaccines.

Jurisdictions therefore need to be able to monitor closely, and adjust swiftly, if needed, access, communication, outreach and allocations in such states and cities. It is fallacious to simply see all jurisdictions as starting from the same situation—because they are not (the equity data dashboard that was mentioned during the Task Force’s April meeting seems highly promising in this regard).

ID requirements must not be barriers for particularly vulnerable populations

As was mentioned in Samantha Artiga’s presentation at the Task Force’s April meeting, a particularly vulnerable group when it comes to vaccine access are immigrants, both documented and undocumented groups. Due to the chilling effects of the Public Charge rule, many immigrants are understandably, (even if wrongly) concerned about seeking a vaccine. And where they do try to register, seeing that they are asked to provide ID and insurance is known to have deterrent effect. States including New Jersey, Wisconsin, Illinois, and North Carolina recognize this in their allocation plans, and prescribe that ID and insurance must not be required. Yet, for example, in NC, Onslow County *does* require ID—so there is an urgent need to correct such misalignment, and instruct county health departments to not deviate from higher-level policy.³ Further, jurisdictions that have not yet taken steps to enable vaccines with ‘no questions asked’ should do so as a matter of priority (as a public health researcher, and in light of the two points made above, I recognize, of course, that this proposal creates a dilemma, since, to optimize

equitable allocation, it would be desirable to have as key data on each person receiving a vaccine, including, for example, accurate home address and Zip code, which are helpful for an accurate understanding of vaccination coverage by SVI or other indices. However, the proposal is not to abolish *all* information gathering, but to establish and implement frameworks that enable vaccinations in ways that does not start out with onerous ID requirements, including verification through official documents—see North Carolina’s approach as a starting point³).

Addendum: Ventilator rationing/Crisis Standard of Care guidance

While, for all the obvious reasons, equitable vaccine allocation remains a particularly pressing priority, I also wanted to make sure that the Task Force is aware of an important recent study relating to equitable ventilator rationing.

Hopefully, we can continue to avoid the need to ration ventilators, as seems to have been the case so far (though, due to a regrettable lack of transparency, it also appears unclear whether it is possible to know this with absolute certainty). But the need for actual rationing should not be the only reason to consider what equitable frameworks should look like. There is a not insubstantial risk that a comprehensive stock taking is deferred, or never occurs, due to other priorities. The fact that the national Covid strategy charged the Task Force with developing federal guidance on Crisis Standards of Care (including ventilator rationing) is therefore especially welcome.

An important study the Task Force should consider as part of its deliberations is by Dr. Deepshikha Ashana and colleagues, which, based on data on more than 100,000 patients, found that:

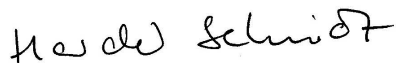
“81.6% of Black patients included in lower priority crisis standard of care categories, and 9.4% of all Black patients, were erroneously excluded from receiving the highest prioritization. The SOFA score without creatinine reduced racial miscalibration. Conclusions: Using SOFA in crisis standards of care may lead to racial disparities in resource allocation. More equitable mortality prediction scores are needed.”

The question of what form, exactly, more equitable prediction scores should look like is far from trivial, similar to the broader question of how the SOFA score should be considered in triage frameworks. However, what is clear is we cannot simply leave current models in place.

We cannot be sure that these frameworks will not be used again during the current pandemic; they might be seen as templates to be adapted for future pandemics; and uncorrected, historians of medicine might interpret them as expressing an uncontroversial consensus, when—as evident in light of the Ashana et al. study—it is clear that these models compound the disparate impact that the pandemic has had on, particularly, more disadvantaged Black residents, and constructive proposal to mitigate their impact have been made.⁴ on all three counts, the Task Force’s guidance will hence be critical.

If there would be anything that you would like to discuss further, please feel free to reach out via schmidth@upenn.edu.

Sincerely,



Harald Schmidt, PhD

References

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**WHITE HOUSE COVID-19 HEALTH EQUITY TASK FORCE MEETING OF APRIL 9,
2021
PUBLIC COMMENT BY ELENA ONG, PHN, MS**

COVIDnomics
Satcher Health Leadership Institute Health Equity Task Force Advisor
Asian American & NHPI COVID-19 Policy & Research Team Member
American Public Health Association* Past Executive Board Member
California Commission for Women & Girls* Past Vice Chair
theongpartnership@gmail.com

I thank the White House COVID-19 Health Equity Task Force for addressing the **3 Rs of rescue, recovery and re-imagination, because I believe in an open, inclusive and equitable America.** I co-wrote this letter for your March 26 meeting and the National Day of Asian American Action. It was signed by more than 100 leaders from the American Indian, Asian American, Black, Disability, Latinx, LGBTQIA+, Native Hawaiian, Pacific Islander, White, and/or Women's communities. We believe in **"do no harm."** **"No one is safe, until we are all safe"** from racism, xenophobia, sexism, homophobia, able-ism, poverty & homelessness. We stand

UNITED AGAINST RACISM

Our hearts go out to the loved ones of eight people brutally murdered in Atlanta on March 16. We must understand the killings - of six Asian women - in context. For exactly a year ago, the phrase "China Virus" went viral. That serial tweet fueled "xenophobic racism" and led to "deadly discrimination."

Since 2020, Asians, globally and domestically, have been experiencing two epidemics – COVID-19 and xenophobic racism. Asian Americans have been [verbally harassed](#) and [physically attacked](#). When customers stopped patronizing Asian-operated businesses, many [were forced to close](#). Many Asian Americans suffer from extremely high [unemployment rates](#). Stigmatized, blamed and shamed, Asian Americans [went into hiding](#). [Statistics were "hidden"](#) when Asians & Pacific Islanders were lumped into the same category. Data were not collected by the level of disaggregation necessary to address the [true impact of COVID-19 on Filipinx](#) and other groups. The dearth of linguistic- and culturally-competent outreach may have also contributed to COVID-19 undertesting. There were unusually low COVID-19 case rates and unusually high COVID-19 [case fatality rates](#). Without a proportionately higher "recorded" COVID-19 case rate, Asian Americans were left out of [equitable vaccine prioritization](#).

Today, we are at a critical flash point. The hate toll is 3,800 and rising. While we encourage the community to report incidents of [hate](#) and [language barriers](#), we must protect and "do no harm."

We applaud President Biden for issuing the [Memorandum Condemning and Combating Racism & Xenophobia](#), and urging Congress to pass [hate crime legislation](#). We look forward to working with elected officials and administrators to ensure that resources are prioritized to protect communities from racism.

The original letter, with complete text, was signed,

We stand united against racism.

**Organizations are listed for identification purposes only, and do not imply organizational endorsement.*

Sefa Aina, Associate Dean and Director, Draper Center for Community Partnerships at Pomona College; Board Chair, Empowering Pacific Islander Communities (EPIC);*and former Vice Chair, President Obama's Commission on Asian American and Pacific Islander Affairs*

Randall Akee, PhD, Associate Professor of American Indian Studies and Public Policy, UCLA*

Jose Pietro Aparicio, MD, MPH. President, Latino Caucus for Public Health in Affiliation with APHA*

Maria Rosario Araneta, PhD, MPH, Professor of Epidemiology, UC San Diego*, and NIH Advisory Council Member for the National Institute on Minority Health and Health Disparities (2015-19)*

Mona AuYoung, PhD, MS, MPH*

Sameena Azhar, PhD, LCSW, MPH, Assistant Professor, Fordham University Graduate School of Social Service*

Adrian Matias Bacong, PhD Candidate, UCLA Fielding School of Public Health*

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Planned Parenthood Federation of America, Inc.

April 1, 2021

VIA ELECTRONIC SUBMISSION

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Chair, COVID-19 Health Equity Task Force
Office of Minority Health
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RE: PPFA’s Written Testimony for COVID-19 Equity Task Force Meeting

Dear Dr. Nunez-Smith and Secretary Becerra:

Planned Parenthood Federation of America (Planned Parenthood) submits these comments in response to the COVID-19 Equity Task Force’s invitation for public comment during its postponed virtual meeting originally on Friday April th. As a trusted health care provider, Planned Parenthood takes every opportunity to weigh in on policy proposals that impact the communities served by our affiliates across the country.

Planned Parenthood is the nation’s leading sexual and reproductive health care provider and advocate, as well as a trusted nonprofit source of primary and preventive care for people of all genders across the United States. Each year, Planned Parenthood’s hundreds of health centers provide affordable birth control, lifesaving cancer screenings, testing and treatment for sexually transmitted infections (STIs), vaccines, and other essential care to 2.4 million patients. One in

five women in the United States has visited a Planned Parenthood health center and nearly two-thirds of our patient base identifies as a person of color. Over 75 percent of Planned Parenthood patients have incomes at or below 150% of the federal poverty level. Further, fifty-seven percent (57%) of Planned Parenthood health centers are located in rural or medically underserved areas.¹

Given the impact of this pandemic on patients and staff, and the scope of our services and expertise, Planned Parenthood welcomes this opportunity to provide input for ways we can mitigate the harmful impact of COVID-19 pandemic on our patients and advocates.

¹*The Irreplaceable Role of Planned Parenthood Health Centers*, Planned Parenthood (Jan. 2020), available at https://www.plannedparenthood.org/uploads/files_public/d2/a3/d2a3053e-237d-4e28-a1ac-7c4f43b6e238/191230-irreplaceable-role-factsheet-p01.pdf.

I. The COVID-19 Has Exacerbated Existing Disparities in Sexual and Reproductive Health Care

The COVID-19 pandemic has exacerbated the existing health disparities in our country and around the world. Not only has it placed a significant burden on our health care system writ large, but it has also caused a sharp decrease in access to vital sexual and reproductive health care. In fact, one in three women have cancelled or delayed an appointment for sexual and reproductive health during the pandemic.² This translates to less women receiving contraceptive counseling, STI screenings and testing, wellness exams and other essential care during the pandemic. Alarming, this includes Black and Latinx women who already experience significant reproductive health disparities, such as high rates of maternal mortality,³ cervical and breast cancer related-deaths,⁴ and severe complications caused by untreated STI infections.⁵ Below are notable impacts of the COVID-19 pandemic on reproductive care.

- **Unintended Pregnancy:** In a recent survey, it was found that nearly 30 percent of women had concerns over accessing reproductive health care during the pandemic and 27 percent of women expressed concerns over accessing contraception.⁶ This is leading to a slight increase in unintended pregnancy rates during the PHE. Further, Because of limits on in-person health care visits, the COVID-19 pandemic has created an added barrier to accessing safe abortion. The Food and Drug Administration's Risk Evaluation and Mitigation Strategies (REMS) restrictions on mifepristone have created unnecessary barriers for providers aiming to minimize in-person interactions, for the safety of themselves and their patients, resulting in many women delaying abortion care. Given the disproportionate burden of COVID-19 on Black, Latinx, and Indigenous patients, the in-person requirement for Mifepristone will result in additional and unnecessary exposure risks for communities already at higher risk of experiencing COVID-19.
- **HIV/STIs:** Lesbian, Gay, Bisexual, Transgender, Queer (LGBTQ+) and Black communities are the populations at the highest risk for STI and HIV infections, but the least likely to receive screenings and treatment.⁷ A recent survey found that 83% of STI programs are deferring STI services and 62% cannot maintain their HIV and syphilis caseloads.⁸ Additionally, 60% of clinics are experiencing reduced capacity to treat STIs.⁹ Black, Indigenous, and people of color (BIPOC) and LGBTQ+ individuals are shouldering the brunt of the decline in HIV/STI services. For

² Ibid.

³ *Racial and Ethnic Disparities Continue in Pregnancy-Related Deaths*, Centers for Disease Control & Prevention (Last reviewed Sep. 2020), available at <https://www.cdc.gov/media/releases/2019/p0905-racial-ethnic-disparities-pregnancy-deaths.html>.

⁴ *Hysterectomy-Corrected Cervical Cancer Mortality Rates Reveal a Larger Racial Disparity in the United States*, Amer. Cancer Society (Jan. 23, 2017), available at <https://acsjournals.onlinelibrary.wiley.com/doi/full/10.1002/cncr.30507>.

⁵ Murray Horwitz et al. *Trends and Disparities in Sexual and Reproductive Health Behaviors and Service Use Among Young Adult Women (Aged 18-25) in the United States, 2002-2015*. American Journal of Public Health (May 12, 2018) available at <https://ajph.aphapublications.org/doi/10.2105/AJPH.2018.304556>.

⁶ *Early Impacts of the COVID-19 Pandemic: Findings from the 2020 Guttmacher Survey of Reproductive Health Experiences*, Guttmacher Institute (Jun. 2020), available at

https://www.guttmacher.org/report/early-impacts-covid-19-pandemic-findings-2020-guttmacher-survey-reproductive-health?clid=CjwKCAjAq8f-BRBtEiwAGr3DgcDi-RTJfqJoPMaRBdieUO3TacJ7s5SbA0ew-svWi5Klh67Tt6dJORoCxXOOAvD_BwE

⁷ *STD Health Equity*, Centers for Disease Control and Prevention (last reviewed Mar. 2, 2020, available at <https://www.cdc.gov/std/health-disparities/default.htm>).

⁸ *COVID-19& the State of the STD Field*, National Coalition of STD Directors, (May 2020) https://www.ncsddc.org/wp-content/uploads/2020/05/STD-Field-Survey-Report-Final_5.12.20.pdf.

⁹ Ibid

example, recent study that surveyed gay and bisexual men found that over one third of survey participants reported that COVID-19 had prevented them from being tested for HIV or STI's.¹⁰

- **Breast/Cervical Cancer Screenings:** Breast and cervical cancers are leading causes of death among Black and Latinx women of reproductive age. While early detection can be lifesaving, barriers to accessing regular cervical and breast cancer screenings and treatment make women of color significantly more likely to die from these highly treatable diseases compared to non-Hispanic white women.¹¹ One study found that breast cancer screenings dropped 63% and cervical cancer screenings dropped 67%. This can lead to later stage diagnosis with a higher chance of a poorer prognosis.¹²

Planned Parenthood urges the Taskforce to uphold their commitment to advancing health equity by expanding access to essential sexual and reproductive health care services and work with other agencies to equip family planning providers with the resources and capabilities required to continue to serve patients most in need.

ii. **Sexual and Reproductive Health Care Providers Are Vital to COVID-19 Testing and Vaccination Efforts**

The COVID-19 virus has claimed over a half a million lives thus far, and left many with COVID-19 related long-term health consequences. It has elevated some of our starkest inequities in the health care system, as Black, Latinx, and Indigenous people are more likely to be hospitalized and nearly three times more likely to die from COVID-19.¹³ This could be, in part, because Black and Latinx communities report higherrates of forgoing care, particularly during the pandemic.¹⁴

For many people — especially BIPOC and LGBTQ communities — any health decisions must take into account the rightful mistrust of a systemically racist medical industry whose legacy of abuse still haunts many communities. According to recent data, 27% of adults, including 35% of Black respondents, are not confident in a potential vaccine and one in 4 Hispanic adults say they will “probably not get it” or “definitely not get it”.¹⁵ Another survey in Colorado found that 17% of respondents who identified as LGBTQ were hesitant to get the vaccine, in comparison to only 9% of non-LGBTQ participants.¹⁶

¹⁰ Rob Stephenson et al., *Sex in the Time of COVID-19: Results of an Online Survey of Gay, Bisexual and Other Men Who Have Sex with Men's Experience of Sex and HIV Prevention During the US COVID-19 Epidemic*, *J. of AIDS & Behavior* (2020), available at <https://link.springer.com/article/10.1007/s10461-020-03024-8>.

¹¹ *Cervical Cancer Deaths per 100,000 Women by Race/Ethnicity*, Kaiser Family Foundation (2021), available at <https://www.kff.org/other/state-indicator/cervical-cancer-death-rate-by-re/?currentTimeframe=0&sortModel=%7B%22collId%22:%22Location%22,%22sort%22:%22asc%22%7D>

¹² Christopher Mast & Alejandro Munoz del Rio, *Delayed Cancer Screenings—A Second Look*, Epic Health Research Network (July 17, 2020) available at <https://www.ehrn.org/articles/delayed-cancer-screenings-a-second-look/>.

¹³ *Risk for COVID-19 Infection, Hospitalization, and Death By Race/Ethnicity*, Centers for Disease Control and Prevention (Feb. 2021), available at <https://www.cdc.gov/coronavirus/2019-ncov/covid-data/investigations-discovery/hospitalization-death-by-race-ethnicity.html>

¹⁴ The Urban Institute's Coronavirus Tracking Survey found that Black adults reported being more likely than white or Latinx adults to delay or forgo care. Additionally, 76% of all adults who delayed or went without care had one or more chronic health conditions, including diabetes, hypertension, cancer or mental health disorders.

¹⁵ Audrey Kearney et al., *Vaccine Hesitancy Among Hispanic Adults*, Kaiser Family Foundation (Jan 14, 2021), available at <https://www.kff.org/coronavirus-covid-19/poll-finding/vaccine-hesitancy-among-hispanic-adults/>

¹⁶ *COVID-19 LGBT Survey Results*, Our Boulder County (Jan. 20, 2021), available at <https://static1.squarespace.com/static/5b10b6968ab722b1af17a9ca/t/6018839a3abddf20f4af6223/1612219291979/COVID+LGBT+%2B+Survey+Report+FINAL+1-20-21+for+release.pdf>

For many communities with mistrust of medical providers, safety-net providers, and specifically, reproductive health providers, have become the most trusted source of care. In particular, many women of reproductive age place great trust in their reproductive health providers. In fact, one study found that women rate their family planning providers as higher than general practitioners on a number of measures, including listening, cultural understanding, and shared decision-making. Black women specifically responded as most likely to rate their reproductive health providers favorably in contrast to their general practitioners.¹⁷ Furthermore, another study found that an estimated 40% of patients rely on their family planning clinic as their only source of health care.¹⁸

In order to address vaccine and testing hesitancy among communities of color and LGBTQ communities, COVID-19 public health information, vaccinations and testing must come from trusted health care providers. As you develop your report and recommendations, Planned Parenthood urges the Taskforce to consider the vital role sexual and reproductive health providers play as a trusted messenger and vital support network for patients in need of COVID-19 testing, vaccinations and medical information.

Given the devastating effects of COVID-19 on the lives of people across the globe, the development and distribution of a vaccine, shoring up public health infrastructure, and ensuring barriers to care and services for communities most impacted, are of paramount importance. Planned Parenthood applauds the COVID-19 Equity Task Force for developing a set of recommendations for mitigating the health inequities caused or exacerbated by COVID-19. We encourage the Task Force committee to put forward policy recommendations that are fully inclusive of sexual and reproductive health care needs as part of the larger public health infrastructure and safety net system.

Respectfully submitted,



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¹⁷ *Women + OB/GYN Providers*, Planned Parenthood (Nov. 2013), available at

http://www.plannedparenthood.org/files/4914/0656/5723/PPEA_OBGYN_Report.FINAL.pdf.

¹⁸ Jennifer Frost et al., *Specialized Family Planning Clinics in the United States: Why Women Choose Them and Their Role in Meeting Women's Health Care Need*, Guttmacher Institute (2012), available at

<https://www.guttmacher.org/sites/default/files/pdfs/pubs/journals/j.whi.2012.09.002.pdf>.



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**Meeting of the COVID-19 Health Equity Task Force
Statement of Pilar Whitaker
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Lawyers' Committee for Civil Rights Under Law**

Thank you Task Force members. My name is Pilar Whitaker and I am Counsel at the Lawyers' Committee for Civil Rights Under Law. We are a non-partisan racial justice organization with the unique mission of mobilizing lawyers across the country to provide critical pro bono support to advance the cause of civil rights. Founded in 1963 at the request of former President John F. Kennedy, we work to protect and defend the civil rights of Black people and other communities of color across our nation.

Over the past year, we have analyzed federal data collection directives, tracked demographic data published by the states, and advocated for the dissemination of race and ethnicity data that is broken down into specific sub-groups. It is abundantly clear that neither the states nor the federal government collect demographic data that helps mitigate the glaring COVID-19 racial health disparities. As discussed in detail below, the United States Department of Health and Human Services ("HHS") and the Centers for Disease Control and Prevention ("CDC") must revise their data reporting guidance to require labs and hospitals to report race and ethnicity data that is broken down into specific sub-groups. Specifically, HHS must align its COVID-19 data reporting requirements with the 2011 HHS demographic data standards pursuant to its authority under Section 4302 of the Affordable Care Act. The 2011 standards disaggregates racial categories into 14 different subgroups, and five subgroups for ethnicity, inclusive of country of origin because, according to HHS, the collection of more granulated data "is important for documenting

and tracking health disparities.”ⁱ Current COVID-19 data reporting requirements only track five categories for race and just two for ethnicity. Guidance must also require the reporting of primary language and disability status, as well as other demographic points that correspond with social vulnerabilities.

Data is the Cornerstone of an Equitable Pandemic Response

To address the pandemic’s disproportionate impact upon communities of color, President Biden issued an Executive Order titled Ensuring an Equitable Pandemic Response and Recovery on January 21, 2021—his second day in office. The Executive Order notes:

[T]he lack of complete data, disaggregated by race and ethnicity, on COVID-19 infection, hospitalization, and mortality rates, as well as underlying health and social vulnerabilities, has further hampered efforts to ensure an equitable pandemic response. Other communities, often obscured in the data, are also disproportionately affected by COVID-19, including sexual and gender minority groups, those living with disabilities, and those living at the margins of our economy.ⁱⁱ

The Executive Order further established this Task Force, which has been charged with the responsibility of “develop[ing] recommendations for expediting data collection for communities of color and other underserved populations and identifying data sources, proxies, or indices that would enable development of short-term targets for pandemic-related actions for such communities and populations.”ⁱⁱⁱ However, we note that calls for disaggregated race and ethnic health data are not new. In 1985, the HHS Task Force on Black and Minority Health similarly recommended that “[d]ata should be disaggregated by race and ethnicity, providing detail within major ethnic groups such as Hispanics.”^{iv} Nearly 40-years later, HHS and the CDC have failed to collect appropriately disaggregated health data in COVID-19 surveillance. It is crucial that this Task Force act immediately on its charge to improving data collection. Lives are at stake.

HHS and the CDC Must Issue Stronger Demographic Data Collection Guidance

The health inequities President Biden highlighted in his Executive Order are unrelenting. One year into the coronavirus pandemic, people of color still face hospitalization rates up 2.4 times that of white people and mortality rates up to 3.7 times greater than white people.^v Despite loud calls for equitable vaccine distribution, communities of color continue to receive the vaccine at significantly lower rates than white people.^{vi} Nationally, Black people represent just 7.9% of vaccinated individuals, even though they comprise 13% of the population.^{vii}

Notwithstanding these inequities, in the three months since President Biden's January Executive Order, there has not been a single revision to either HHS or CDC data reporting requirements. Those requirements, therefore, continue to fall short of what's needed to develop an equitable pandemic response. For example, HHS has failed to apply its most detailed race and ethnic demographic data collection standards—the 2011 HHS Data Standards promulgated pursuant to its authority under Section 4302 of the Affordable Care Act—to any COVID-19 data collection efforts. At minimum, labs, hospitals, and vaccine providers should be required to report the race, ethnicity, primary language and disability status of COVID-19 patients and vaccine recipients in accordance with the 2011 HHS Standards. Similarly, CDC's own data collection tools, such as Case Report Forms and vaccine safety tracking platform, V-Safe fail to track this information as well. Moreover, data gathered by governmental tools (such as the CDC Case Report Forms) do not align with the federal data reporting requirements for labs and hospitals. For example, the CDC Case Report Form collects data on housing status, primary language, disability status, and pregnancy status.^{viii} However, HHS does not require this same information from labs and hospitals.^{ix} All of the above factors, when coupled with a lack of federal support for data

infrastructure and education at the provider level, have resulted in woefully incomplete demographic data, specifically along the lines of race and ethnicity.

Additionally, disjointed federal demographic data collection efforts are reflected at the state level. The Lawyers' Committee conducted a survey of the demographic data collected and published by all 50 states (and the District of Columbia) and our survey revealed that, as of March 2021: (1) no two states publish the same demographic data; (2) almost none of the states publish race and ethnicity data disaggregated into country of origin subgroups; and (3) only some states publish demographic or socioeconomic data beyond race and ethnicity, such as employment type, disability status, sexual orientation, housing status, and insurance status.^x It is also clear that some public health jurisdictions report certain demographic information (such as pregnancy status or primary language) to the CDC via the Case Report Form, but do not publish this information on their COVID-19 dashboards, rendering it inaccessible by the general public.^{xi}

Equitable Data Collection Recommendations

Ultimately, there is little alignment between: (1) the data collection practices called for by President Biden; (2) existing federal data reporting requirements; and (3) data that is actually reported or published. We therefore recommend HHS and the CDC take the following steps to ensure the collection of data that helps mitigate disparities and lessen health inequities:

- HHS should issue guidance clarifying that all race, ethnicity, primary language, and disability data be collected in accordance with the 2011 HHS Data Standards, pursuant to its express authority under Section 4302 of the Affordable Care Act.
- HHS should issue guidance directing labs, hospitals, and vaccine providers to collect, report, and publish demographic data in each of the following categories: (1) sexual orientation; (2) gender/gender identity; (3) co-morbidities; (4) employment status/type; (5) pregnancy status; (6) housing status; (7) type of insurance; and (8) income.

- The CDC should update its Case Report Forms that include sufficient space for demographic data collection. These forms should collect, at minimum, the fourteen race and five ethnicity categories specified by the 2011 HHS Data Standards, pursuant to HHS's authority under Section 4302 standards. The forms should also provide space for collecting the remaining demographic categories specified above.
- HHS and the CDC should ensure that all data collected directly at the federal level through programs, such as V-Safe and FEMA-run vaccination sites mirror the 2011 HHS Data standards for public health surveys, pursuant to its express authority under Section 4302 of the Affordable Care Act.
- HHS should issue guidance directing labs and hospitals to collect COVID-19 healthcare and health outcome data in each of the following categories: (1) COVID-19 tests administered; (2) hospitalization rates; and (3) ICU admissions.
- HHS should disseminate clear data and privacy standards—that are both culturally competent, and accessible to low literacy and non-English speaking people—to assure patients that demographic data will never be used in a way other than specified public health purposes.
- HHS should work to ensure that providers, hospitals, testing facilities, public health departments and all other relevant entities have the technical capability of collecting, transmitting and reporting these demographic categories. This may include the provision of grants and technical assistance for improving technology and data infrastructure.
- HHS and other relevant governmental agencies should ensure that all Health IT systems can collect detailed demographic data that are in line with the standards developed by the Office of the National Coordinator for Health IT and that systems are interoperable.
- In conjunction with state and local public health departments, HHS and/or the CDC should provide training to health care providers on data collection practices. The outcomes of this training should be to increase the rates at which providers collect demographic data and the quality of that data, as well as to develop strategies for overcoming hesitancies communities may have in providing demographic information.
- The CDC must provide technological support to allow states to publish data daily on COVID-19 dashboards in a manner that is easily accessible by the public, and that is also language accessible.

Conclusion

In the coming weeks the Lawyers' Committee will release a report that: (1) discusses our analysis of federal regulations; (2) details the results of our nationwide survey of publicly released demographic data related to the pandemic; and (3) issues recommendations for equitable data collection. The need for complete and disaggregated data is necessary to develop public health strategies. We therefore urge the Task Force to adopt these recommendations immediately, as they are vital to ensuring equitable data collection practices at both the federal and state level.

ⁱ “HHS Implementation Guidance on Data Collection Standards for Race, Ethnicity, Sex, Primary Language, and Disability Status.” ASPE, Department of Health and Human Services, 21 Feb. 2017, aspe.hhs.gov/basic-report/hhs-implementation-guidance-data-collection-standards-race-ethnicity-sex-primary-language-and-disability-status.

ⁱⁱ Executive Order. No. 13995, 86 F.R. 7193, (Jan. 21, 2021), <https://www.federalregister.gov/documents/2021/01/26/2021-01852/ensuring-an-equitable-pandemic-response-and-recovery>

ⁱⁱⁱ *Id.*

^{iv} U.S. Department of Health and Human Services (1985). Report of the Secretary's Task Force on Black & Minority Health, p. 184. www.minorityhealth.hhs.gov/assets/pdf/checked/1/ANDERSON.pdf.

^v “Risk for COVID-19 Infection, Hospitalization, and Death By Race/Ethnicity.” Centers for Disease Control and Prevention, Centers for Disease Control and Prevention, 12 Mar. 2021, www.cdc.gov/coronavirus/2019-ncov/covid-data/investigations-discovery/hospitalization-death-by-race-ethnicity.html.

^{vi} “Demographic Characteristics of People Receiving COVID-19 Vaccinations in the United States.” CDC COVID Data Tracker, Centers for Disease Control and Prevention, covid.cdc.gov/covid-data-tracker/#vaccination-demographic. Accessed 9 Apr. 2021.

^{vii} *Id.*

^{viii} “Human Infection with Coronavirus Disease 2019 (COVID-19) Surveillance Worksheet.” Centers for Disease Control and Prevention, <https://www.cdc.gov/coronavirus/2019-ncov/downloads/php/COVID19-Worksheet-CSV-annotated-2020Jan15.pdf>. (Updated 15 Jan. 2021.)

^{ix} “How to Report COVID-19 Laboratory Data” Centers for Disease Control and Prevention, 26 Dec. 2020, www.cdc.gov/coronavirus/2019-ncov/lab/reporting-lab-data.html#what-to-report. Updated 26 Jan. 2021.

^x The survey captures only the data categories that states publicly report on their online COVID-19 dashboards as of March 2021. It also takes into account data included in state-published daily/weekly status summaries, if available. Data that was available only in its raw form, however, was not considered. Of course, states may collect and report data to the CDC that they do not publish online.

^{xi} For example, only the state of Tennessee publishes COVID-19 pregnancy data, although the CDC had been gathering this information from state and local public health jurisdictions via its Case Report Form for one year.



Recommendations for Improving
Access to & Acceptance of
COVID-19 Vaccinations
April 1, 2021

1. Online/web-based design and functionality barriers

- **Issue:** State COVID-19 vaccine information can be siloed, requiring vaccine eligibility surveys to be completed before proceeding to general tabs of resources and other information (FAQs, vaccine locations, etc.) that should be upfront and transparent. For those visiting the website multiple times or on behalf of another individual, this type of obstacle will discourage many from continuing.
 - **Recommendation:** Elevate available resources on national and state-based vaccine pages and try to streamline as much as possible into a single landing page, as opposed to multiple websites with partial information.

2. Phone and intake training/support

- **Issue #1:** An abundance of hotlines, only partial assistance available per number. Based on our experience, the people staffing these hotlines are not always assisting individuals in making appointments, or helping to schedule transportation to appointments (if needed), which is a missed opportunity.
- **Issue #2:** Frontline intake customer service representatives (CSRs) staffing these hotlines sometimes learn of the latest vaccine distribution plan updates only after consumers are calling to ask for or about that new level of service. It bottlenecks delivery of care and information.
- **Recommendations:**
 - It's perfectly fine to have multiple hotlines, however, these numbers should not only be prominently displayed on every website possible, but they should also be clear in letting individuals know they can speak w/ someone on the phone who can assist them in scheduling their appointment, or helping them to schedule transportation to their vaccine appointment.
 - Train hotline staff to assist individuals in scheduling vaccine appointments. After helping them find available vaccine locations, a good prompt would be, "Are you able to schedule yourself an appointment online or would you like assistance?".
 - Any time there is a development in the distribution of vaccines - new phase announcement, new locations announcement, etc. - frontline CSRs should receive this information beforehand.

3. Clear messaging about required documents and no OOP costs

- **Issue:** Some vaccine locations are simply posting notices that say insurance and ID are required, which is both incorrect and discourages many individuals from getting the vaccine.
- **Recommendations:**
 - All messaging in advertisements, on websites, and at vaccination sites should clearly indicate what information/documentation IS required and what information IS NOT required. Kentucky's [Cabinet for Health & Family Services "checklist" doc](#) with live links is a fantastic example of what this can look like. This sort of information should

be prominently displayed, specific to each state but also on a federal level, and include a statement that the vaccine is FREE with NO out-of-pocket costs.

- Request or require states to Issue guidance through their respective Departments of Public Health to their state's vaccines providers that insurance, a SSN, and/or government issued ID is NOT required for patients to receive a vaccine. Providers should be required to post all types of acceptable ID and information for people who are uninsured.

4. Data Collection Disclaimer

- **Issue:** Many immigrants will be reluctant to seek vaccinations if they believe their data could be shared with ICE or used against them in a Public Charge test, even though this Policy recently reverted back to 1999 standards. In Kentucky, many people are distrustful of the government for various reasons and may also be reluctant to provide the necessary information to get vaccinated - this is not an obstacle specific to Kentucky.
 - **Recommendation:** Clearly state in outreach and online materials that data collected is ONLY to follow-up with individuals and will not be shared with anyone outside of their state's Department of Public Health.

5. Accessibility

- **Issue:** Many are struggling to get vaccinated due to language, literacy, and transportation barriers. This is especially true for many of the highest risk populations of older adults and minority groups.
- **Recommendations:**
 - Websites and materials should be accessible and available in an individual's preferred language or interpreters should be made available to read the website/materials on the numerous hotlines.
 - Interpreters should be made available by request at all vaccine sites. Information about the availability of interpreters should be displayed on websites and at vaccine sites.
 - Utilize churches, multi-family public and subsidized housing as vaccination locations.
 - Consider training contact tracers, community health workers, and individuals employed in state's who have their own state-based health exchanges (e.g. in Kentucky these are "kynectors") to help with outreach to high risk groups, making appointments, and coordinating transportation.
- **Issue:** The vaccine scheduling sites (via kroger, walgreens, local health depts) are cumbersome to maneuver, especially for older individuals and those with low computer literacy. We can give you multiple examples where older Kentuckians have walked into Walgreens and Kroger stores wanting assistance and are turned away to "sign up online first".
 - **Recommendation:** Each location should either have a paper sign up option available or have employees use their workstation computers to help sign people up.

6. Other Barriers Related to Immigration

- **Issue:** Fears over deportation and the former Public Charge rule have discouraged immigrants to seek services, regardless of whether they are eligible.
- **Recommendations:**
 - Issue guidance to all vaccine providers that COVID-19 testing, treatment, and vaccines can be covered through Emergency Time-limited Medicaid. Here's an

example from Michigan:

https://www.michigan.gov/documents/mdhhs/MSA_20-75-Vaccine-New_711334_7.pdf

- Issue a public statement/post flyers that: 1) vaccines are free to all regardless of immigration status; 2) no data or personal information collected will be shared with ICE; 3) receiving a vaccine is not considered in public charge test and will not impact status; 4) DHS will not conduct enforcement operations at or near vaccine distribution sites/clinics; and 5) the public charge rule has ENDED.
 - **USCIS info:**
<https://www.uscis.gov/green-card/green-card-processes-and-procedures/public-charge>
 - **Here's a great flyer from NC:**
<https://www.ncjustice.org/publications/immigrant-rights-and-the-covid-vaccine/>

Pulling it all together, here is the information we would recommend be displayed on as many federal and states' website, provided on a flyer, and posted at all vaccine sites:

- COVID-19 vaccines are free to all *insert state* residents with or without insurance.
- Locate the vaccination site closest to you by checking *state specific map website* or by calling *state or federal hotlines*. For persons who are deaf or hard of hearing, call *equivalent state/federal hotlines*.
- Need help scheduling an appointment?" call *state/federal #* for assistance.
- Interpreters are available to assist you in scheduling an appointment and when receiving the vaccine. Call XXX to request an interpreter.
- When going to your appointment, be sure to bring your ID or other proof of state residency such as a utility bill, rental agreement, or property tax bill. You may also be asked to provide a copy of your insurance card, if you have it. **NOTE:** A government issued ID, SSN, and insurance **are not** required.
- Personal information you provide will only be used to follow-up with you. It will not be shared with anyone outside of the Kentucky Department of Public Health.
- Immigrants **do not** need to provide a SSN or other proof of documentation to get the vaccine. Getting the vaccine **will not** be used in a Public Charge test and will not have any negative impact on your chances of getting a green card. The public charge policy has ENDED.
- Vaccine providers may not share any personal information about you with ICE for immigration enforcement.



April 1, 2021

Samuel Wu
Designated Federal Officer, COVID-19 Health Equity Task Force
Office of Minority Health, Department of Health and Human Services
Tower Building, 1101 Wootton Parkway, Suite 100
Rockville, MD 20852

Dear Mr. Wu:

On behalf the National Down Syndrome Society (NDSS), the leading human rights organization for all individuals with Down syndrome, we applaud the Department of Health and Human Services Office of Minority Health for convening a meeting on equitable vaccine access and acceptance. We are writing to seek your help in focusing more federal and state attention on ensuring access to the vaccine for individuals with Down syndrome and their family members. Unfortunately, in many states, the Down syndrome community is facing many difficulties in getting vaccinated, despite the classification of Down syndrome as a high-risk condition in December 2020.¹

Our organization supports the COVID-19 Vaccine Allocation Principles outlined by the Consortium for Citizens with Disabilities (CCD), which take into consideration the needs of people with disabilities and direct care workers across settings, ensure that both the information and the means of distribution are accessible and comply with federal guidance and civil rights laws.²

Our organization also supports the recommendations of the CDC's Advisory Committee on Immunization Practices, which prioritize persons living in certain congregate living situations and with certain underlying conditions, based on the CDC's listing of who is at increased risk. Down syndrome is on that list, and many persons with Down syndrome, due to where they live or their underlying health issues, continue to need to be considered for early phase COVID-19 vaccine prioritization.

We encourage the Office of Minority Health to strengthen the message and enforcement of these Vaccine Allocation Principles and CDC recommendations as the health risks for individuals with Down syndrome are significant.

There are an estimated 210,000 Americans with Down syndrome. In addition to intellectual disability, people with Down syndrome have a variety of co-occurring medical conditions that

¹ <https://www.cdc.gov/coronavirus/2019-ncov/need-extra-precautions/people-with-medical-conditions.html#downsyndrome>

² <http://www.c-c-d.org/fichiers/CCD-Vaccine-Allocation-Principles-October-2020.pdf>

contribute to medical complexity and place them at a disproportionately increased risk of having more severe outcomes following infection with COVID-19. In addition, many adults with Down syndrome live in community-based congregate settings, such as group homes, which share many of the same risk factors as long-term care facilities where a significant portion of COVID-19 deaths have occurred.

The T21 Research Society (T21RS), an international non-profit scientific organization of researchers studying Down syndrome, recently released survey data comparing how COVID-19 is impacting people with Down syndrome versus the general population.³ The survey shows that, while in the general population the risk for poor outcomes of COVID-19 increases around 60 years, in people with Down syndrome poor outcomes become more pronounced after age 40 and is increased in these older individuals compared to the general population of similar age.⁴ In fact, the risk of death for an individual with Down syndrome after age 40 is equivalent to the risk of death for an individual without Down syndrome after the age of 80.⁵

Based on the survey results, T21RS strongly recommends that individuals with Down syndrome, particularly those over 40, and those younger than 40 with significant comorbidities, be prioritized for COVID-19 vaccination programs to limit SARS-Cov-2 infections.⁶

NDSS continues to hear from families and affiliate organizations across the country that people with Down syndrome still are not eligible to get vaccinated. Many states have gone from distributing vaccines based on the risk and need to distributing vaccines based on age, leaving much of our community behind. We have engaged with states since December on prioritizing people with Down syndrome for the vaccine, and as we hear about states not prioritizing our community, we once again engage with them to reconsider prioritizing people with Down syndrome based on their poor outcomes with COVID-19.

We are asking for your leadership and help. We urge the COVID-19 Health Equity Task Force to take swift action to ensure those with Down syndrome get prioritized appropriately across the country.

Sincerely,



Kandi Pickard
President and CEO
National Down Syndrome Society
kpickard@ndss.org

³ <https://www.t21rs.org/t21rs-statement-with-regards-to-vaccinations-for-people-with-down-syndrome-during-the-covid-19-pandemic/>

⁴ <https://www.t21rs.org/wp-content/uploads/2020/02/TT21RS-shielding-statement.pdf>

⁵ <https://www.t21rs.org/results-from-covid-19-and-down-syndrome-survey/>

⁶ <https://www.t21rs.org/wp-content/uploads/2020/02/T21RS-vaccines.pdf>

To: Biden Harris Administration COVID-19 Health Equity Task Force
From: Sean Cahill, PhD, Director of Health Policy Research
Date: April 9, 2021
Re: Sexual orientation and gender identity (SOGI) and intersex data collection and reporting in COVID-19 testing, care and vaccination

Hello Madame Chair and Task Force members. I am Sean Cahill, Director of Health Policy Research at The Fenway Institute and Affiliate Associate Clinical Professor of Health Sciences at Northeastern University. I'm speaking on behalf of the LGBTQI Federal Health Policy Roundtable.

We encourage the Biden-Harris Administration to issue federal guidance requiring the collection and reporting of data on sexual orientation, gender identity, and intersex status in COVID-19 testing, care and vaccination.

Why is this important?

First, LGBTQI people may be more vulnerable to infection with the novel coronavirus.

LGBTQ people are nearly twice as likely to work in frontline jobs like retail, food services, health care, and education.ⁱ

Many LGBTQI people live in urban areas, live in dense congregate housing, and use public transportation, where social distancing is difficult.

LGBT people are more likely to be low-income, especially bisexual women, transgender people, and people of color.ⁱⁱ

A recent Williams Institute analysis of Axios/Ipsos survey data found that LGBT people of color were more likely than straight, cisgender people of color to test positive for COVID-19, and twice as likely to test positive for COVID-19 than LGBT White people.¹

Second, LGBT people are more likely to have chronic conditions such as diabetes,ⁱⁱⁱ asthma,^{iv} obesity, and cardiovascular disease,^v and risk factors like smoking, vaping,^{vi} and substance use disorder,^{vii} that may put them at risk for complications from COVID-19.

Third, LGBTQ people experience discrimination in health care as well as in employment, housing and other settings.^{viii} This discrimination has negative physical and mental health effects, and serves as a barrier to accessing health care.^{ix} Sexual minority women, transgender people, and LGBT people of color are less likely to access routine, preventive care due to discrimination and lower rates of health insurance.^x This may inhibit their ability to access COVID-19 testing, care, and vaccination.

¹ Sears, B. Conron, K.J., & Flores, A.J. (2021). *The Impact of the Fall 2020 Surge of the COVID-19 Pandemic on LGBT Adults in the US*. Los Angeles, CA: The Williams Institute, UCLA.

LGBTQI people must be included in vaccine dissemination plans, and sexual orientation and gender identity data--SOGI data—must be collected to ensure equitable vaccine uptake.^{xi} LGBTQI people experience medical mistrust, which could affect willingness to get the vaccine.

Many older people experience medical mistrust because in their youth the medical establishment pathologized same-sex behavior and gender diversity, subjecting them to shock therapy or worse.^{xii}

Intersex people mistrust the medical community due to abuses many experience in childhood and adulthood.^{xiii}

A recent analysis in the journal *Vaccine* found that Black and Native American men who have sex with men were less willing than White and Latino MSM to get vaccinated for COVID-19, while Asian American MSM were more likely to get vaccinated.^{xiv}

The Biden-Harris Administration should issue federal guidance that, at a minimum, encourages SOGI + intersex data collection and reporting in COVID-19 testing, care and vaccination uptake. This could come from CDC or somewhere else in HHS. The CDC COVID-19 case report form needs to add SOGI questions and change its sex question. Right now the sex question response options on that form are “male, female, other, unknown.”^{xv} These are not affirming, and miss an opportunity to understand how this pandemic is affecting LGBTQI people.

It is also imperative that the National COVID Cohort Collaborative (N3C), a project of the National Center for Advancing Translational Sciences, add SOGI + intersex to its COVID-19 Clinical Data Warehouse Data Dictionary. By not including SOGI + intersex, N3C does not allow for research on LGBTQI populations’ experiences with COVID-19.

In the midst of the worst global pandemic of our lifetimes, our federal government and most state governments are not collecting and reporting SOGI data so that we know how COVID-19 is affecting LGBTQI people, including LGBTQI people of color and elders. Given the Biden-Harris Administration’s commitment to LGBTQI equality and health equity, we hope that the Biden Harris Administration will issue federal guidance soon. I am heartened by Dr. Khaldun’s presentation today. We hope to work with the Task Force and the Data, Analytics and Research Committee to help address this important data equity issue.

Thank you.

ⁱ Whittington C, Hadfield K, Calderón C. *The lives and livelihoods of many in the LGBTQ community are at risk amidst COVID-19 crisis*. Washington, DC: Human Rights Campaign. 2020. Available at: <https://www.hrc.org/resources/the-lives-and-livelihoods-of-many-in-the-lgbtq-community-are-at-risk-amidst>

ⁱⁱ Badgett MVL, Choi SK, Wilson BDM (2019, Oct.). *LGBT Poverty in the United States: A Study of Differences Between Sexual Orientation and Gender Identity Groups*. Los Angeles, CA: UCLA School of Law, The Williams Institute. <https://williamsinstitute.law.ucla.edu/wp-content/uploads/National-LGBT-Poverty-Oct-2019.pdf>

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- iii Beach LB, Elasy TA, Gonzales G. Prevalence of Self-Reported Diabetes by Sexual Orientation: Results from the 2014 Behavioral Risk Factor Surveillance System. *LGBT Health*. 2018 Feb/Mar;5(2):121-130.
- iv Karen I. Fredriksen-Goldsen, Hyun-Jun Kim, Chengshi Shui, and Amanda E. B. Bryan, 2017: [Chronic Health Conditions and Key Health Indicators Among Lesbian, Gay, and Bisexual Older US Adults, 2013–2014](#). *American Journal of Public Health* 107, 1332_1338.
- v Fredriksen-Goldsen KI, Kim H-J, Emler CA, et al. *The Aging and Health Report: Disparities and Resilience Among Lesbian, Gay, Bisexual, and Transgender Older Adults*. Seattle: University of Washington; 2011.
- vi McCabe SE, Matthews AK, Lee JGL, Veliz P, Hughes TL, Boyd CJ. Tobacco use and sexual orientation in a national cross-sectional study: age, race/ethnicity, and sexual identity–attraction differences. *Am J Prev Med*. 2018;54(6):736–745.
- vii National Institute on Drug Abuse (no date; accessed March 23, 2021). Substance use and SUDs in LGBTQ* populations. <https://www.drugabuse.gov/drug-topics/substance-use-suds-in-lgbtq-populations>
- viii Ahmed Mirza, Shabab and Rooney, Caitlin (2018). *Discrimination Prevents LGBTQ People from Accessing Health Care*. Washington, DC: Center for American Progress.
- ix Reisner SL, White Hughto JM, Dunham E, Heflin K, Begenyi JB, Coffey-Esquivel J, Cahill S (2015). Legal protections in public accommodations settings: A critical public health issue for transgender and gender nonconforming people. *Milbank Quarterly*. 1-32.
- x American Cancer Society. 2020. *Cancer Facts for Lesbian and Bisexual Women*. <https://www.cancer.org/healthy/find-cancer-early/womens-health/cancer-facts-for-lesbians-and-bisexual-women.html#:~:text=Studies%20suggest%20that%20some%20lesbian,and%20cervical%20cancer%20screening%20tests>.
- xi <https://fenwayhealth.org/wp-content/uploads/12.18.20-LGBTQI-Data-Vaccination-Letter.pdf>
- xii Blakemore E. (no date). Gay Conversion Therapy’s Disturbing 19th-Century Origins. HISTORY. Accessed December 17, 2020. <https://www.history.com/news/gay-conversion-therapy-origins-19th-century>
- xiii *Covid-19 Survey Report*. OII Europe. Published December 9, 2020. Accessed December 17, 2020. <https://oii europe.org/covid-19-survey-report/>
- xiv Teixeira da Silva D, Biello K, Lin WY, et al. COVID-19 Vaccine Acceptance among an Online Sample of Sexual and Gender Minority Men and Transgender Women. *Vaccines* 2021, 9, 204.
- xv <https://www.cdc.gov/coronavirus/2019-ncov/downloads/pui-form.pdf>