

CIVIL RIGHTS PRINCIPLES FOR COVID-19 VACCINE DEVELOPMENT AND DISTRIBUTION

As organizations committed to the civil and human rights of all persons in the United States, we share these principles to help guide the ongoing development and distribution of a vaccine and therapeutics for COVID-19. The impact of vaccine development and distribution on equity, economic security, health outcomes, and civil rights are critical issues facing the communities we represent. We put forward these principles to provide a framework and recommendations for civil rights and COVID-19 vaccines.

Equity must be paramount in the distribution of COVID-19 vaccines. As companies and health care entities widely distribute COVID-19 vaccines, the health and well-being of frontline and essential workers, Black, Latino, Native American, Asian American, Native Hawaiian, and Pacific Islander communities, older adults, immigrants, people with limited English proficiency, people with disabilities, and LGBTQ individuals - the communities most affected by the virus - must be prioritized. The vaccine must be provided to individuals living and working in all types of institutional and congregate settings, including jails and prisons, immigration detention facilities, nursing homes, intermediate care facilities for people with intellectual and developmental disabilities, psychiatric hospitals, assisted living facilities, board and care homes, and homeless and domestic violence shelters. Individuals who receive home and community based services (HCBS) and individuals providing those services should also be prioritized in vaccine allocation when they are unable to effectively mitigate transmission risks.

COVID-19 vaccines must be made available to all persons, regardless of their immigration status. Information about the vaccine must also be produced and provided in the maximum possible languages and formats, including plain language and screen reader accessible formats and other alternative formats needed by people with disabilities, to ensure that as many people as possible are able to receive the information and counseling needed on how to access the vaccine. This includes ensuring that materials are developed at low literacy levels, translating documents (especially those related to costs and consent for vaccination), ensuring the availability of oral interpretation services for LEP individuals, and providing communication assistance for people with disabilities at the point of vaccination.

It will also be essential that all communities have access to the resources needed to store, handle, and administer COVID-19 vaccines. This is especially critical for rural and Native American communities which often experience critical gaps in access to health care services. The ability to access the tools needed to distribute COVID-19 vaccines must not serve as a barrier to access for vulnerable communities.

As we continue to battle the COVID-19 crisis as a nation, we must provide robust funding to support all efforts around delivering COVID-19 vaccines to communities. Investments are needed to modernize and strengthen state and local immunization infrastructure, expand the

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public health workforce, including hiring and training staff to distribute the vaccine, ensure rural and underserved communities have access to all the required protective equipment necessary to give the vaccine, stand up additional vaccination sites, ensure the accessibility of vaccination sites for people with disabilities and older adults, modernize immunization information systems, and support outreach and campaigns to target hard to reach populations. Cost and access to personal protective equipment (PPE) should not be a barrier to vaccine distribution.

The process of developing, testing, and approving COVID-19 vaccines must be transparent.

As fears of politicization of the vaccine development process persist, it is more important than ever that all processes surrounding the development of the vaccine be transparent. The FDA must be allowed to operate independently and in the interest of people in our nation; the agency must take steps to avoid politicization and maintain the long-standing scientific integrity of its work. Additionally, there must be transparency on the part of pharmaceutical companies and government entities throughout the vaccine development process. This means providing the public with a clear and accessible understanding of what happens at every step of the process. Both efforts funded by Operation Warp Speed and those that are not, rely on underlying research paid for by taxpayers, and we deserve transparency. With the health and well-being of so many people in America at stake, we must not only get the vaccine right, but we must do so in a way that fosters trust in both the process and the outcomes. Transparency also increases trust in the vaccine development process, and will be critical in ensuring that people in America are willing to take COVID-19 vaccines. Transparency holds the government and companies accountable for fair and equitable processes. This includes making detailed demographic information including, at a minimum, race, ethnicity, sex, sexual orientation, gender identity, disability, primary language, and age, available for people enrolled COVID-19 vaccine trials. This also includes ensuring transparency in state plans for distribution of COVID-19 vaccines.

Clinical trials must include representation from diverse communities in order to ensure vaccine efficacy and trust in the process. It is crucial that data about the vaccine reflect the effectiveness and potential side effects for people in all racial and ethnic groups. However, people of color and members of certain ethnic groups are consistently and significantly underrepresented in certain phases of clinical research and overrepresented in others. Despite national efforts to address the longstanding lack of representation in clinical trials, challenges persist. With limited guidance around the levels of diversity in clinical trials, it is difficult to know whether current and forthcoming COVID-19 vaccines will be equally safe and effective for all communities. As efforts continue to develop COVID-19 vaccines, it is critical that diverse populations be included in representative numbers in every stage of clinical trials and as part of future vaccine safety and monitoring efforts. In addition to the benefits around understanding efficacy, diversity in clinical trials also inspires more trust in a vaccine.

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Communities must be engaged in COVID-19 vaccine distribution processes to provide education and address vaccine hesitancy in communities of color. As discussed, long-standing challenges related to historical and continued discrimination, lack of consent, and medical racism have left many communities of color distrustful of vaccines and of the health care system. Addressing vaccine hesitancy is critical to ensuring that communities of color, who have been hit hardest by the virus, are prioritized for preventive treatment. While the Tuskegee syphilis study is one of the more notorious incidents of medical abuse that cultivated mistrust of medical institutions specifically for African American communities, the history of medical and research abuse of communities of color goes far beyond that incident. The lack of trust and hesitancy that communities of color, specifically Black, Latino, Native American, Asian American, Native Hawaiian, and Pacific Islander communities, and the disability community, experience around vaccinations is reinforced by systemic racism in our health care system and discriminatory events that continue to this day. Immigrants may also have deep distrust in government institutions due to both their own history and fear of enforcement in the United States. Given the potential for hesitancy to rapidly undermine vaccination coverage in certain communities, it is important that entities responsible for the distribution of COVID-19 vaccines immediately take steps to understand and address the extent and nature of hesitancy at a local level, on a continuing basis.

As we grapple with the realities of COVID-19 vaccine distribution, it is imperative that private and public agencies develop culturally and linguistically competent strategies to build trust and increase acceptance and demand for vaccinations, including but not limited to, targeting investments in community-based organizations, not only as partners in public education but also to ensure regular, transparent responses to concerns around the distribution and safety of the vaccine. Communication and education are key to combating hesitancy and this must include collaboration with and leadership by community partners and trusted health care providers.

Robust data collection around vaccine development and distribution must be an instrumental part of our nation's COVID-19 response. Since the beginning of the COVID-19 pandemic, data has been key in helping us understand how communities have been impacted by the virus and, subsequently, which communities we will need to prioritize in our response to the virus. Throughout the clinical trial phases of vaccine development, we have seen how data helps us understand which communities have been involved in clinical trials and the vetting of the vaccine, and which communities have been underrepresented during development. Now, as we enter the vaccination stage of the pandemic, data can be used to help track progress in the fight against COVID-19. As populations begin to be vaccinated, data on vaccinations should be analyzed to help us identify gaps and understand how to rectify them.

Additionally, we must ensure that data collected around COVID-19 is maintained safely and securely by the appropriate entities. No data should be collected beyond what is necessary for demographic reporting and for follow-up on additional doses, if needed. Strict standards must be developed to ensure no data collection can be used for immigration enforcement or other

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negative actions impacting vaccine recipients. These standards must be clear and communicated to vaccine recipients to combat vaccine hesitancy that could result from data collection. In addition, actions must be taken to restore trust in the federal government, such as repealing the public charge rules.

Once COVID-19 vaccines have been authorized or approved by the FDA, they must be free and accessible for all people. Cost or access to health care or insurance should not be a barrier to anyone seeking to get vaccinated against COVID-19. The virus has disproportionately impacted low-income individuals, including many essential workers who are more likely to be Black, Latino, Indigenous, Asian American, Native Hawaiian, or Pacific Islander. There are also already significant barriers to accessing health care for many depending on their proximity to health care services, previous experiences with health care (including discrimination, income, and insurance status), and immigration status. If people cannot afford the vaccine, highly impacted communities are less likely to achieve community immunity and face the potential of prolonged high COVID-19 infection rates. The cost of the vaccine and its administration should not be an added deterrence to inoculation, especially for communities most highly impacted by the virus. At the same time, we must ensure adequate reimbursement is available to providers for both vaccine administration and educational counseling. This reimbursement process must be equitable and available to providers treating all patients, including undocumented immigrants.

Strenuous efforts must be employed before any discussion of a vaccine mandate.

Strategies to ensure widespread vaccination uptake must be rooted in the principles above. Given the distrust and vaccine hesitancy that exist, every effort must be made to ensure education with trusted messengers to promote voluntary vaccination. We should work to prevent situations where an individual may be coerced into taking the vaccine as a condition of employment. This is especially important given the lack of diversity in clinical trials and subsequent concern about how a vaccine might affect certain communities. Hinging employment and economic security on whether a person has been vaccinated may exacerbate existing economic and health disparities and every effort should be taken to avoid or to mitigate any negative, unintended consequences of a vaccine mandate.

Preparing for the future. For years, public health infrastructure in America has been underfunded and has failed to serve the most vulnerable people in our nation. The COVID-19 pandemic has exposed critical, long-standing deficiencies in our nation's health care system. In order to meet the needs around COVID-19 vaccine development and distribution, we must ensure that our health care system is adequately financed to last for future generations. This planning goes beyond immediate funding needs, and should be forward-looking to include dedicated funding for community-based organizations, researchers, federal agencies, and state and local governments. Preparing for the future also means making changes now that help to improve health outcomes for all. This includes the need to address diversity in clinical trials in

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the long term to ensure that vulnerable communities are represented in every stage of the process.

This pandemic has laid bare some of the most jarring inequities in this nation. As we work to reign in the impacts of the COVID-19 pandemic, we must aspire toward outcomes that protect the health, well-being, and livelihood of all people in America. Every step of this effort is an opportunity to dismantle historic disparities that exist for marginalized communities within our health care system. It is critical that we seize this opportunity and work to build a health care system that works for the most vulnerable in our nation.

Signatories (as of 12/9/20):

The Leadership Conference on Civil and Human Rights
ACCESS

African American Ministers In Action

Alianza Nacional de Campesinas

American Atheists

American Humanist Association

American-Arab Anti-Discrimination Committee (ADC)

Americans for Democratic Action (ADA)

Amnesty International USA

Asian & Pacific Islander American Health Forum

Asian Americans Advancing Justice – AAJC

Asian Pacific American Labor Alliance, AFL-CIO

Association of Asian Pacific Community Health Organizations (AAPCHO)

Autistic Self Advocacy Network

Bazelon Center for Mental Health Law

Black Alliance for Just Immigration

Black Women's Health Imperative

Center for Disability Rights

Center for Law and Social Policy (CLASP)

Center for Public Representation

Church of the Brethren, Office of Peacebuilding and Policy

Clearinghouse on Women's Issues

Community Change Action and Fair Immigration Reform Movement (FIRM)

Disability Rights Education and Defense Fund (DREDF)

Empowering Pacific Islander Communities (EPIC)

End Citizens United / Let America Vote Action Fund

Fair Count

Farmworker Justice

Feminist Majority Foundation

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Government Information Watch
Hindu American Foundation
Hispanic Federation
Human Rights Campaign
Immigrant Legal Resource Center
Impact Fund
Institute for Intellectual Property and Social Justice
Japanese American Citizens League
Justice in Aging
Labor Council for Latin American Advancement
Lambda Legal
Lawyers for Good Government (L4GG)
Lawyers' Committee for Civil Rights Under Law
League of United Latin American Citizens (LULAC)
League of Women Voters of the United States
Matthew Shepard Foundation
NAACP
National Asian Pacific American Families Against Substance Abuse (NAPAFASA)
National Association of Human Rights Workers
National Center for Parent Leadership, Advocacy, and Community Empowerment (National PLACE)
National Center for Transgender Equality
National Coalition for the Homeless
National Disability Rights Network (NDRN)
National Down Syndrome Congress
National Education Association
National Employment Law Project
National Equality Action Team (NEAT)
National Health Law Program
National Hispanic Media Coalition
National Immigration Law Center
National Network for Arab American Communities
National Urban League
NHMC
Oxfam America
Pacific Islands Primary Care Association
Planned Parenthood Federation of America
Prison Policy Initiative
Public Citizen
Public Justice
Service Employees International Union (SEIU)

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South Asian Americans Leading Together (SAALT)
South Asian Network
South Asian Public Health Association (SAPHA)
Southeast Asia Resource Action Center (SEARAC)
SPLC Action Fund
The Arc of the United States
The United Methodist Church - General Board of Church and Society
The Workers Circle
UFCW
Union for Reform Judaism
UNITED SIKHS
Workplace Fairness