

MEMO IN SUPPORT

Vaccine Confidentiality and Immunity Passports Privacy A.7326-A (Gottfried) / S.6541-A (Rivera)

May 2021

The undersigned civil rights, health care, and privacy advocates, public defenders, and health care providers urge legislators to co-sponsor and immediately pass vaccine confidentiality and immunity passports privacy legislation, A.7326-A (Gottfried)/S.6541-A (Rivera). The bill will break down barriers to vaccination by ensuring that individuals' personal information is kept safe throughout the vaccination process and that information shared to receive a vaccine cannot be used to criminalize or deport anyone or to take their children away. It will also ensure that the most vulnerable are not cut off from society by putting in place reasonable guardrails for immunity passports.

Privacy Protections for Information Shared with Vaccine Navigators and Vaccine Providers and Protections Against Information Sharing with Police and Immigration Authorities

On the front end, the bill tightens the rules for vaccine navigators, the third parties that help people sign-up for vaccine appointments. The bill:

- Ensures that when people provide personal information to obtain a vaccine, that information is used only for vaccine administration purposes – to schedule vaccine appointments, send reminders about appointments, or arrange transportation to appointments – absent affirmative, opt-in consent from the person to whom the information pertains.
- Imposes the same requirements on vaccine providers that keep vaccine recipients' information outside of medical records.
- Recognizes that many vaccine navigators are community-based organizations that use vaccine sign-up to reach people in need and channel them into other services and maintains their ability to do this crucial work with the individual's affirmative, opt-in consent.
- Ensures that vaccine recipients' information stays truly confidential by requiring vaccine navigators and providers to adhere to security standards for storing that information.
- Makes vaccine recipients' information inadmissible in judicial and administrative proceedings. This is important because many individuals simply

will not obtain a vaccine if they believe that the personal information they provide in order to make an appointment will be used to criminalize or deport them.

Protections Against Sharing Immunization Information System Information with Police and Immigration Authorities

On the back end, the bill enhances the existing protections for vaccine recipient information in our state Immunization Information System (IIS). The bill:

- Makes sure IIS information cannot be used to criminalize or deport anyone or to take anyone’s children away by making IIS information inadmissible in judicial and administrative actions and proceedings.
- Ensures that New York only shares IIS information with other states’ and tribes’ immunization registries for purposes that are consistent with New York’s law and New York’s protections.
- Permits the state to share de-identified IIS information with the federal government – codifying public health best practice¹ and protecting New Yorkers from any future capricious federal demands.²

¹ See, e.g., *Statistics Center*, CENTERS FOR DISEASE CONTROL AND PREVENTION, <https://www.cdc.gov/hiv/statistics/index.html> (“CDC’s National HIV Surveillance System is the primary source for monitoring HIV trends in the United States. CDC funds and assists state and local health departments to collect the information. Health departments report de-identified data to CDC so that information from around the country can be analyzed to determine who is being affected and why.”).

² In November 2020, the federal government informed states it would condition distribution of COVID-19 vaccine on each state’s signing a data use agreement (DUA) that committed to provide the federal government with a wealth of personal information about each vaccine recipient, including name, address, date of birth, and identification number. The sweeping scope of this agreement was unprecedented. C.D.C, COVID-19 VACCINATION PROGRAM INTERIM PLAYBOOK FOR OPERATIONS 63–64 (Oct. 29, 2020); *c.f.* *Statistics Center*, C.D.C, <https://www.cdc.gov/hiv/statistics/index.html> (“Health departments report de-identified data to CDC.”). This DUA was explicit that the CDC and the federal HHS could share vaccine recipients’ information with “other federal partners,” which could include ICE, the FBI, or DHS; this too was without precedent. Data Use and Sharing Agreement to Support the United States Government’s COVID-19 Emergency Response Jurisdiction Immunization and Vaccine Administration Data Agreement (Nov. 9, 2020) (on file with the author); *c.f.* *National Immunization Surveys*, CENTERS FOR DISEASE CONTROL AND PREVENTION, <https://www.cdc.gov/vaccines/imz-managers/nis/confidentiality.html> (“It is against federal law for us to give your name or any other information that could identify you to anyone, including the President, Congress, National Security Agency, Department of Homeland Security, Internal Revenue Service, Immigration and Naturalization Service, or welfare agencies for any reason.”).

At the urging of advocates, the CDC did roll back the most egregious parts of the DUA weeks later. The new DUA is clear that vaccine recipient information will not be used “for any civil or criminal prosecution or enforcement, including, but not limited to, immigration enforcement, against such individuals whose information is shared pursuant to this DUA.” It is also explicit that the federal government “will not seek social security numbers, driver’s license numbers, or passport numbers.” Data Use and Sharing Agreement to Support the United States Government’s COVID-19 Emergency

Safeguards for Immunity Passports

Because immunity passports rely on presenting proof of medical information in order to gain entry to public places, left unchecked, they could track immense amounts of information about where New Yorkers spend their time, who they spend their time with, and their health status. This sort of pervasive tracking will land on certain communities differently. It is a particular risk for those who, whether for fear of deportation, criminalization, or any other reason, may be afraid to share personal information with the government or private companies. A world where immunity passports serve as gatekeepers for many aspects of society will also pose particular challenges for the medically contraindicated, who cannot receive vaccines for health reasons, and for those who do not have, cannot afford, or do not know how to use a sophisticated smartphone – a group that disproportionately includes individuals who are elderly, disabled, or low-income.³ A.7326-A/S.6541-A:

- Prevents immunity passports from becoming universal tracking devices by ensuring that every business or governmental service that requires the use of an immunity passport regularly deletes any personal information it collects and that no personal information is transmitted back to the immunity passport developer.
- Ensures that developers collect only the minimal amount of information required to ascertain that someone has, in fact, been vaccinated or received a negative test.
- Requires that any entity that requires proof of vaccination or a negative test accepts an analog option so that those who do not have or do not know how to use a smartphone are not cutoff from society.
- Requires the Department of Health to promulgate regulations to ensure that the medically contraindicated are not left out of post-COVID reopening.

Response Jurisdiction Immunization and Vaccine Administration Data Agreement 24 (Dec. 1, 2020), <https://www.cdc.gov/vaccines/covid-19/reporting/downloads/vaccine-administration-data-agreement.pdf>. But the DUA continues to require states to share vaccine recipients' identifiable information unless they have a state law prohibiting sharing identifiable information about vaccine recipients; states with such a law may send de-identified information to the federal government. *Id.* at 2. Further, it continues to permit the federal government to unilaterally change its appendices with mere notice to the states, without opportunity to agree or disagree to the changes. *Id.* at 9. This means that the protections above could disappear at any time. *See generally* NYCLU, TESTIMONY BEFORE THE NEW YORK CITY COUNCIL COMMITTEES ON HEALTH AND HOSPITALS REGARDING OVERSIGHT – COVID-19 VACCINE DISTRIBUTION & ACCESSIBILITY IN NYC (2021).

³ *See* Allie Bohm, *Unbridled Surveillance Will Not Save Us From COVID-19*, TECH POLICY GREENHOUSE BY TECHDIRT, July 7, 2020, <https://www.techdirt.com/articles/20200706/07440844842/unbridled-surveillance-will-not-save-us-covid-19.shtml>.

- Ensures that immunity passports are limited to the current COVID-19 crisis and do not become universal health trackers.
- Makes sure that immunity passport information cannot be used to criminalize or deport anyone or to take away anyone's children by making such information inadmissible in judicial and administrative actions and proceedings.

New York is rapidly marching toward re-opening – with the expectation that immunity passports will play a key role in reducing capacity limits at public gatherings.⁴ All New Yorkers ages 12 and older are vaccine eligible,⁵ and there will soon be sufficient vaccine supply for all adults in the United States.⁶ Yet, demand for vaccines is stagnating,⁷ and vaccination rates across the state reflect stark racial and socioeconomic disparities.⁸ New York must double-down on eliminating barriers to vaccination, and it must ensure that immunity passports do not cut the most vulnerable off from participating in society. A.7326-A/S.6541-A advances these goals by ensuring that everyone is and *feels* safe sharing the personal information required to receive a vaccine and by making sure that immunity passports do not become another tool that disproportionately hurts the people who have suffered most throughout the COVID-19 pandemic.

The legislature must pass A.7326-A/S.6541-A immediately. A safe and just reopening depends on it.

Sincerely,

Access Now
African Services Committee

⁴ Press Release, New York State Gov. Andrew Cuomo, Governor Cuomo, Governor Murphy and Governor Lamont Announce Significant Easing Of COVID-19 Pandemic Restrictions on Businesses, Gatherings and Venues (May 3, 2021) (<https://www.governor.ny.gov/news/governor-cuomo-governor-murphy-and-governor-lamont-announce-significant-easing-covid-19>).

⁵ Scott Neuman, Laurel Wamsley, & Tamara Keith, *CDC Says Kids As Young As 12 Should Get The Pfizer COVID-19 Vaccine*, NPR, May 12, 2021, <https://www.npr.org/sections/coronavirus-live-updates/2021/05/12/996185305/federal-panel-recommends-coronavirus-vaccines-for-adolescents-aged-12-15>.

⁶ Shannon Caturano, *Vaccine Eligibility Expands to New Yorkers 30 and Over, All Adults on April 6*, SPECTRUM NEWS NY1, Mar. 30, 2021, <https://www.ny1.com/nyc/all-boroughs/breaking-news/2021/03/29/vaccine-eligibility-expands-to-new-yorkers-30-and-over-tomorrow--all-adults-on-april-6>.

⁷ *COVID-19: Some U.S. Vaccination Sites Will Close as Demand Drops*, NY TIMES, May 4, 2021, <https://www.nytimes.com/live/2021/04/23/world/covid-vaccine-coronavirus-cases>.

⁸ *Vaccine Demographic Data*, NEW YORK STATE, <https://covid19vaccine.health.ny.gov/vaccine-demographic-data>; see also *NYC Vaccination Coverage, by Zip Code*, NYC HEALTH, <https://www1.nyc.gov/site/doh/covid/covid-19-data-vaccines.page>.

AI for the People
The Arc New York
Bannon Consulting Services
The Bronx Defenders
Brooklyn Defender Services
Callen-Lorde Community Health Center
The Center for HIV Law and Policy
CNY HIV Care Network
Commission on the Public's Health System
Consumer Federation of America
The Cranky Queer Guide to Chronic Illness
Drug Policy Alliance
Electronic Frontier Foundation
Gender Equality New York, Inc.
Housing Works
Immigrant Defense Project
Latino Commission on AIDS
Legal Action Center
The Legal Aid Society of Westchester County
Long Term Care Community Coalition
Make the Road New York
National Black Leadership Commission on Health, Inc.
Neighborhood Defender Service
New York Civil Liberties Union
New York Immigration Coalition
New York State Nurses Association
Positive Women's Network-USA
Release Aging People in Prison/RAPP Campaign
Southern Tier AIDS Program
Treatment Action Group