

July 12, 2022

The Honorable Kathy Hochul
Governor of New York State
NYS State Capitol Building
Albany, NY 12224

Dear Governor Hochul:

On behalf of the undersigned civil rights, health care, immigrants' rights, and privacy advocates, public defenders, and health care providers, we urge you to immediately sign vaccine confidentiality and immunity passports privacy legislation, S.6541-A (Rivera)/A.7326-A (Gottfried), which passed both chambers of the legislature unanimously this month. The long overdue legislation 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 support public accommodations that choose to keep their properties safer by checking vaccination status by putting in place reasonable guardrails for immunity passports to ensure that the most vulnerable can safely use an immunity passport to participate in society.

This legislation is timely. New York has all but ended its community-based COVID mitigation strategies, such as universal masking.¹ Yet, according to the CDC, much of New York State now has high COVID-19 community levels,² and many fear a monkeypox pandemic may be on the horizon.³ Meanwhile, demand for COVID-19 vaccines is stagnating,⁴ a new round of COVID vaccines is expected in the fall,⁵ vaccines for the under-5 set finally received authorization,⁶ and vaccination rates across the state continue to

¹ See Marc Santia, *New York's Mask Mandate for Schools Ends, But Not for NYC Yet – What You Need to Know*, NBC, Mar. 2, 2022, <https://www.nbcnewyork.com/news/local/new-yorks-mask-mandate-for-schools-ends-but-not-for-nyc-yet-what-you-need-to-know/3578953/>; Emma G. Fitzsimmons, *Adams Ends Pandemic Mandates in New York City Amid Concern He Is Rushing*, N.Y. TIMES, Mar. 4, 2022, <https://www.nytimes.com/2022/03/04/nyregion/nyc-mask-vaccine-mandate.html>.

² *COVID-19 Integrated County View*, CDC COVID DATA TRACKER, https://covid.cdc.gov/covid-data-tracker/#county-view?list_select_state=New+York&data-type=CommunityLevels&null=CommunityLevels (last visited June 2, 2022).

³ See generally Daniel Victor, *What to Know About Monkeypox*, N.Y. TIMES, May 26, 2022, <https://www.nytimes.com/article/what-is-monkeypox.html>.

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

⁵ See Katherine J. Wu, *The U.S. Is About to Make a Big Gamble on Our Next COVID Winter*, THE ATLANTIC, May 13, 2022, <https://www.theatlantic.com/health/archive/2022/05/covid-vaccine-recipe-omicron-protection/629846/>.

⁶ Press Release, FDA, *Coronavirus (COVID-19) Update: FDA Authorizes Moderna and Pfizer-BioNTech COVID-19 Vaccines for Children Down to 6 Months of Age (June 17, 2022)* (<https://www.fda.gov/news-events/press-announcements/coronavirus-covid-19-update-fda-authorizes-moderna-and-pfizer-biontech-covid-19-vaccines-children>).

reflect stark racial and socioeconomic disparities.⁷ For example, only 60 percent of Black New York City residents are fully vaccinated, lagging behind every other racial demographic.⁸ The statewide data reveal similar disparities.⁹

Meanwhile, monkeypox is beginning to spread in New York, reportedly in particular among men who have sex with men. Because there are not enough monkeypox vaccine doses available, the most effective way to vaccinate for monkeypox will be “ring vaccination” where close contacts of someone who is infected receive a vaccine. As a result, receipt of a monkeypox vaccine could out a person as gay. Some men who have sex with men may be afraid to receive a monkeypox vaccination, because they fear being outed. Vaccine confidentiality will build confidence in these communities to receive monkeypox vaccinations and help stop the spread before it reaches pandemic levels.¹⁰

S.6541-A/A.7326-A eliminates barriers to vaccination in three ways: it ensures that the personal information shared with the third parties who help people sign up for vaccination is kept safe; it patches holes in the New York State Immunization Information System (NYSIIS) to prevent capricious federal overreach; and it implements key safeguards for immunity passports. Importantly, S.6541-A/A.7326-A does not require anyone to do anything, and it does not shut anything down; it simply gives people confidence to get vaccinated to help keep themselves safe.

S.6541-A/A.7326-A ensures that the personal information shared with the third parties who help people sign up for vaccination is kept safe.

Vaccine navigators, the third parties that help people sign-up up for vaccination appointments, are not health care providers, which means that they are not covered by HIPAA or Public Health Law 18, and because we have no consumer privacy law in New York State or nationally, at present, these entities are free to do whatever they want with the personal information shared with them. Anecdotal evidence demonstrates that these entities collect a wide range of information from vaccine recipients, with some navigators collecting no information at all and other navigators requiring scans of Social Security cards.

⁷ *Vaccine Demographic Data*, NEW YORK STATE, <https://covid19vaccine.health.ny.gov/vaccine-demographic-data> (last visited June 2, 2022); see also *NYC Vaccination Coverage, by Zip Code*, NYC HEALTH, <https://www1.nyc.gov/site/doh/covid/covid-19-data-vaccines.page> (last visited July 11, 2022).

⁸ *Vaccination by Demographic Group*, NYC HEALTH COVID-19: DATA, <https://www1.nyc.gov/site/doh/covid/covid-19-data-vaccines.page> (last visited July 11, 2022).

⁹ *New York State COVID-19 Vaccination Demographics: Race & Ethnicity*, NEW YORK STATE COVID-19 DEMOGRAPHIC VACCINATION DATA, <https://coronavirus.health.ny.gov/demographic-vaccination-data> (last visited July 11, 2022).

¹⁰ See generally James Krellenstein, Joseph Osmundson, & Keletso Makofane, *To Fight Monkeypox, Remember the Lessons of Covid and H.I.V.*, N.Y. TIMES, May 29, 2022, <https://www.nytimes.com/2022/05/29/opinion/monkeypox-covid-and-hiv.html>.

Similarly, some large chain pharmacies that offer vaccines require would-be recipients to sign-up for bonus card accounts in order to make a vaccine appointment.¹¹ Because bonus card information is not medical information, there are also no meaningful restrictions on how pharmacies can use it.¹²

Pervasive information collection without adequate safeguards may chill the most vulnerable from receiving vaccines. This is particularly true for Black, Brown, and immigrant communities, who, due to a toxic cocktail of socioeconomic factors, physical environment, and inferior access to health care,¹³ are disproportionately likely to suffer from COVID-19.¹⁴ They are also disproportionately likely to be alienated from and distrustful of our health care system because of the racial biases that pervade that system.¹⁵ This is also true of religious enclaves, such as New York's Hasidic community, which has also been ravaged by COVID-19,¹⁶ still harbors deep distrust of the public health system and government,¹⁷ and feels singled out for pandemic-related enforcement.¹⁸

S.6541-A/A.7326-A will ameliorate this problem by putting in place reasonable privacy protections for non-medical personal information shared in order to receive a vaccine. It will ensure that such information is used only for vaccine administration purposes – to schedule vaccine appointments, send reminders about appointments, arrange transportation to appointments, or for accountability to a health department that contracted with a vaccine

¹¹ Sara Morrison, *You got a vaccine. Walgreens got your data*, VOX RECODE, Mar. 4, 2021, <https://www.vox.com/recode/22310281/covid-vaccine-walgreens-cvs-rite-aid-walmart-data>.

¹² *Id.*

¹³ *NCHHSTP Social Determinants of Health*, CENTERS FOR DISEASE CONTROL, <https://www.cdc.gov/nchhstp/socialdeterminants/index.html> (last visited May 14, 2020); see also Ibram X. Kendi, *Stop Blaming Black People for Dying of the CoronaVirus*, ATLANTIC, Apr. 14, 2020, <https://www.theatlantic.com/ideas/archive/2020/04/race-and-blame/609946/>.

¹⁴ *Fatalities*, NYS DEP'T OF HEALTH, <https://covid19tracker.health.ny.gov/views/NYS-COVID19-Tracker/NYSDOHCOVID-19Tracker-Fatalities?%3Aembed=yes&%3Atoolbar=no&%3Atabs=n> (last visited May 26, 2020); see also *The Color of Coronavirus: COVID-19 Deaths By Race And Ethnicity in the U.S.*, AMP RESEARCH LAB, May 20, 2020, <https://www.apmresearchlab.org/covid/deaths-by-race>; John Eligon, Audra D.S. Burch, Dionne Searcey, & Richard A. Oppel Jr., *Black Americans Face Alarming Rates of Coronavirus Infection in Some States*, N.Y. TIMES, Apr. 14, 2020, <https://www.nytimes.com/2020/04/07/us/coronavirus-race.html>.

¹⁵ Khiara M. Bridges, *Implicit Bias and Racial Disparities in Health Care*, 43 ABA HUMAN RIGHTS MAGAZINE (2018).

¹⁶ Joseph Goldstein, *N.Y.C. Warns About Rising Virus Cases in Hasidic Neighborhoods*, N.Y. TIMES, Sept. 22, 2020, <https://www.nytimes.com/2020/09/22/nyregion/coronavirus-Orthodox-Jewish-neighborhoods.html> (“In late April, roughly 700 members of New York City’s Hasidic community were believed to have been killed by the disease, and few families have been spared . . . In some areas with significant Hasidic populations, more than 40 percent of people being tested were found to have antibodies.”).

¹⁷ See Bobby Allyn, *New York Ends Religious Exemptions For Required Vaccines*, NPR, June 13, 2019, <https://www.npr.org/2019/06/13/732501865/new-york-advances-bill-ending-religious-exemptions-for-vaccines-amid-health-cris>.

¹⁸ Liam Stack & Joseph Goldstein, *New York Threatens Orthodox Jewish Areas With Lockdown Over Virus*, N.Y. TIMES, Sept. 25, 2020, <https://www.nytimes.com/2020/09/25/nyregion/coronavirus-orthodox-jewish-communities.html>.

navigator – absent affirmative consent from the person to whom the information pertains. It will also make this information inadmissible in most judicial and administrative proceedings,¹⁹ because no one should be criminalized or deported for signing up to receive a vaccine to stop a public health crisis.

Importantly, the bill 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. It maintains their ability to do this crucial work with the individual’s affirmative consent. The bill is also careful not to disrupt existing relationships between individuals and vaccine navigators.

S.6541-A/A.7326-A patches holes in NYSIIS to prevent capricious federal overreach.

When COVID-19 vaccines first arrived, the federal government conditioned distribution of vaccines 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.²⁰ 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.²¹

At advocates’ and states’ urging, the CDC rolled back the most egregious parts of the DUA weeks later.²² But the DUA continues to require states to share vaccine recipients’

¹⁹ The legislation does permit the use of personal information, following in camera review, in investigations, prosecutions, and defense of computer tampering or billing fraud related to vaccine records, fraudulent statements related to an individual’s vaccination status, an act of violence or attempted violence at a vaccination site or a vaccine navigator’s business, medical malpractice, and professional discipline. A.7326-A/S.6541-A § 6(2)(c)(4), 2021-2022 Reg. Sess. (N.Y. 2022).

²⁰ 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.”).

²¹ 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.”).

²² Data Use and Sharing Agreement to Support the United States Government’s COVID-19 Emergency 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> (committing in an appendix 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” and that the federal government “will not seek social security numbers, driver’s license numbers, or passport numbers.”).

identifiable information with the federal government 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.²³ Further, it continues to permit the federal government to unilaterally change relevant sections of the DUA with mere notice to the states, without opportunity to agree or disagree to the changes.²⁴ This means that the current federal protections could disappear at any time.²⁵

Any number of people are likely to be chilled from receiving vaccines if they believe their personal information will be shared broadly within the federal government. This is particularly true for those who, whether for fear of deportation, criminalization, or any other reason, may be afraid to share personal information with the government.

A.7326-A/S.6541-A patches the holes in our state law and ensures that New Yorkers' personal information will remain protected even if the federal government changes the current DUA or requires another problematic DUA in the future by permitting NYSIIS to share only de-identified information with the federal government, unless the CDC agrees in writing not to share personally identifiable information with other federal agencies, and by making sure that NYSIIS information cannot be used to criminalize or deport anyone or to take anyone's children away by making NYSIIS information inadmissible in most judicial and administrative actions and proceedings.^{26,27}

S.6541-A/A.7326-A implements key safeguards for immunity passports.

One way that public accommodations and governmental entities have sought to safely reopen in pandemic times is to require people to show proof of vaccination (or a negative COVID-19 test) – often through an immunity passport – in order to attend public gatherings.

Because immunity passports rely on presenting proof of medical information to gain entry to public places, left unchecked, they could track immense amounts of information about where New Yorkers spend their time, with whom, and their health status. This sort of pervasive tracking will impact different communities differently. It is a particular risk for those who, whether for fear of deportation, criminalization, or any other reason, may be

²³ *Id.* at 2.

²⁴ *Id.* at 9.

²⁵ *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).

²⁶ The legislation does permit the use of personal information, following in camera review, in investigations, prosecutions, and defense of computer tampering or billing fraud related to vaccine records, fraudulent statements related to an individual's vaccination status, an act of violence or attempted violence at a vaccination site or a vaccine navigator's business, medical malpractice, and professional discipline. A.7326-A/S.6541-A § 3(d)(i), 2021-2022 Reg. Sess. (N.Y. 2022).

²⁷ Importantly, the legislation ensures that the Office of Children and Families, as well as local social services districts, will continue to have access to NYSIIS information for the young people in their custody. A.7326-A/S.6541-A § 3(d)(ii), 2021-2022 Reg. Sess. (N.Y. 2022).

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 people who are elderly, disabled, or low-income.²⁸

S.6541-A/A.7326-A will prevent 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. It will also require that any business or governmental service 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 cut off from society. And, it will require the Department of Health to promulgate regulations to ensure that the medically contraindicated are reasonably accommodated. Most importantly, it will ensure that immunity passport information cannot be used to criminalize or deport anyone or to take away anyone’s children by making immunity passport information inadmissible in most judicial and administrative actions and proceedings.²⁹ Finally, the bill will limit immunity passports to the current COVID-19 crisis and ensure that they do not become universal health trackers.

* * *

S.6541-A/A.7326-A is a sensible measure that will remove barriers to vaccination and ensure that immunity passports do not disproportionately cut off the most vulnerable – those who have suffered most during the pandemic – from society. Please sign it into law immediately. A safe and just return to normalcy depends on it.

Sincerely,

The Bronx Defenders
Brooklyn Defender Services
Callen-Lorde Community Health Center
Consumer Federation of America
Electronic Frontier Foundation
Housing Works
Immigrant Defense Project
Latino Commission on AIDS

²⁸ 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>.

²⁹ The legislation does permit the use of personal information, following in camera review, in investigations, prosecutions, and defense of computer tampering or fraudulent statements related to an individual’s vaccination status. A.7326-A/S.6541-A § 8(4)(c), 2021-2022 Reg. Sess. (N.Y. 2022).

The Legal Action Center
National Black Leadership Commission on AIDS, Inc.
Neighborhood Defender Service of Harlem
Network for Long COVID Justice / Strategies for High Impact
New York Civil Liberties Union
New York Immigration Coalition
NY Statewide Peer Network
Physicians for a National Health Program – NY Metro Chapter
Primary Care Development Corporation
Surveillance Technology Oversight Project
Treatment Action Group
Women Together Global Inc.