

2021 – 2022 Updated Legislative Memorandum

Subject: Relates to protecting the confidentiality of vaccine information A.7326-A (Gottfried) / S.6541-A (Rivera)

Position: SUPPORT

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 and vaccination rates across the state reflect stark racial and socioeconomic disparities.⁵ 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 both *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 NYCLU strongly supports this legislation and urges its immediate passage.

Although both the City and State have made strides toward increasing vaccination across all demographics and narrowing the gap between Black and white vaccination rates, there are still persistent disparities. For example, only 60 percent of Black New York City residents are fully vaccinated, lagging behind every other racial demographic.⁶ The

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 *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 June 2, 2022).

⁶ *Vaccination by Demographic Group*, NYC HEALTH COVID-19: DATA, <https://www1.nyc.gov/site/doh/covid/covid-19-data-vaccines.page> (last visited June 2, 2022).

statewide data reveal similar disparities.⁷ There are many reasons for these disparities and much work that New York must do to increase vaccine equity.⁸ A.7326-A/S.6541-A addresses one piece of this puzzle by knocking down barriers for those who, whether for fear of deportation, criminalization, losing custody of their children, or any other reason, may be afraid to share intimate information with the government or private companies.

Meanwhile, monkeypox is beginning to spread in New York, particularly 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 stop the spread before it reaches pandemic levels.⁹

A.7326-A/S.6541-A enhances protections for information in our state Immunization Information System (IIS) and prevents capricious federal overreach.

In November 2020, the federal government told 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.¹⁰ 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.¹¹

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.”

⁷ *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 June 2, 2022).

⁸ *See generally* Letter from the COVID-19 Working Group to Dr. Howard Zucker, Commissioner, New York State Dep’t of Health, Dr. Dave Chokshi, Commissioner, New York City Dep’t of Health & Mental Hygiene, & Dr. Mitchell Katz, President & CEO, New York City Health + Hospitals (Feb. 12, 2021) (<https://static1.squarespace.com/static/5e6fd0a65abcc54f238eae48/t/602b288efcff027e852f7129/1613441167335/Vaccine+Equity+Sign-on+Letter+2-11-21.pdf>).

⁹ *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>.

¹⁰ 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.”).

¹¹ 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.”).

It is also explicit that the federal government “will not seek social security numbers, driver’s license numbers, or passport numbers.”¹² But the DUA continues to require states to share vaccine recipients’ 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.¹³ 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.¹⁴ This means that the protections above could disappear at any time.¹⁵

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 Black, Brown, and immigrant communities, who, due to a toxic cocktail of socioeconomic factors, physical environment, and inferior access to health care,¹⁶ are disproportionately likely to suffer from COVID-19.¹⁷ 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.¹⁸ This is also true of religious enclaves, such as New York’s Hasidic community, which has also been ravaged by COVID-19,¹⁹ still harbors deep distrust of the public health system and government,²⁰ and feels singled out for pandemic-related enforcement.²¹

¹² 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>.

¹³ *Id.* at 2.

¹⁴ *Id.* at 9.

¹⁵ 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).

¹⁶ 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/>.

¹⁷ *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>.

¹⁸ Khiara M. Bridges, *Implicit Bias and Racial Disparities in Health Care*, 43 ABA HUMAN RIGHTS MAGAZINE (2018).

¹⁹ 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.”).

²⁰ 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>.

²¹ 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>.

A.7326-A/S.6541-A plugs 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 our state IIS 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 making sure that 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.

A.7326-A/S.6541-A ensures information shared with vaccine navigators and vaccine providers is kept safe and cannot be used to criminalize or deport anyone.

Vaccine navigators, the third parties that help individuals sign-up up for vaccination slots, are not always health care providers, which means that they are not always covered by HIPAA or Section 18 of the New York Public Health Law. 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 asking for scans of social security cards. Meanwhile, some vaccine providers, like Walgreens, require would-be vaccine recipients to sign-up for bonus card accounts in order to register for a vaccine appointment.²² Because bonus card information is collected and kept separately from vaccine recipients' medical records, there are no meaningful restrictions on how vaccine providers use that information.²³ Pervasive information collection without adequate safeguards may chill the most vulnerable from receiving vaccines. 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 or private companies.

A.7326-A/S.6541-A will ameliorate this problem by ensuring that personal information provided to obtain a vaccine is used only for vaccine administration purposes – to schedule vaccine appointments, send reminders about appointments, or arrange transportation to appointments – absent affirmative consent from the person to whom the information pertains. And, it will make vaccine recipients' information inadmissible in judicial and administrative proceedings, because no one should be criminalized or deported for getting 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.

A.7326-A/S.6541-A imposes important safeguards for immunity passports.

Once people are vaccinated, the expectation is that they may have 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

²² 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>.

²³ *Id.*

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 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.²⁴

A.7326-A/S.6541-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 not similarly left out. 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 judicial and administrative actions and proceedings. Finally, the bill will limit immunity passports to the current COVID-19 crisis and ensure that they do not become universal health trackers.

The end of the COVID-19 pandemic cannot come soon enough, and we must make sure that all New York communities emerge from the pandemic. A.7326-A/S.6541-A 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. The NYCLU strongly supports the bill and urges its immediate passage. A safe and just return to normal depends on it.

²⁴ 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>.