2021 – 2022 Legislative Memorandum

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

Position: SUPPORT

We all share the fervent desire to safely re-open our state, and, indeed, New York is rapidly marching toward re-opening. All New Yorkers ages 12 and older are now vaccine eligible,¹ and there will soon be sufficient vaccine supply for all adults in the United States.² Meanwhile, Governor Cuomo has announced that immunity passports will play a key role in reducing capacity limits at public gatherings.³ Yet, demand for 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/S.6541 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.

Statewide, 73.2% of people who have received at least one vaccine dose are white although white people make up only 70.4% of New York’s population. By contrast, only

11.1% of vaccine recipients are Black, although Black people make up 17.3% of New York’s population. 15.9% of vaccine recipients are Hispanic or Latino when 18% of New Yorkers are Hispanic or Latino. New York City's more granular data reveals similarly stark disparities. While 84% of the majority white Upper East Side/Lenox Hill neighborhood and 90% of TriBeCa have received at least one vaccine dose, only 35% of the majority Black and Brown Canarsie, 37% of Brownsville, and 38% of Wakefield have received at least one dose. There are many reasons for these disparities and much work that New York must do to increase vaccine equity. A.7326/S.6541 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.

**A.7326/S.6541 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. 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.

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

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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/5e6fd0a65abc5f238ea48t/602b288efc7f027b652f7129/1613441167335/ Vaccine+Equity+Sign-on+Letter+2-11-21.pdf).
10 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.”).
social security numbers, driver’s license numbers, or passport numbers.”

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. 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. This means that the protections above could disappear at any time.

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, are disproportionately likely to suffer from COVID-19. 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. This is also true of religious enclaves, such as New York’s Hasidic community, which has also been ravaged by COVID-19, still harbors deep distrust of the public health system and government, and feels singled out for pandemic-related enforcement.

A.7326/S.6541 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 law.

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12 Id. at 2.
13 Id. at 9.
17 Khiara M. Bridges, Implicit Bias and Racial Disparities in Health Care, 43 ABA HUMAN RIGHTS MAGAZINE (2018).
18 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.”).
DUA or requires another problematic DUA in the future by permitting our state IIS to share only de-identified information with the federal government 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/S.6541 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.\(^{21}\) 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.\(^{22}\) 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/S.6541 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, opt-in 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, opt-in consent.

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

Once people are vaccinated, the expectation is that they will have to show proof of vaccination (or a negative COVID-19 test) – often through an immunity passport – in order to attend public gatherings. Indeed, after May 19, venues will be able to avoid any

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\(^{22}\) Id.
remaining capacity limits by requiring proof of vaccination or a recent negative COVID test from all attendees.\textsuperscript{23}

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 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.\textsuperscript{24}

A.7326/S.6541 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/S.6541 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 reopening depends on it.
