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Testimony of Allie Bohm On Behalf of the New York Civil Liberties Union Before the New York City Council Committees on Health and Hospitals Regarding Oversight – COVID-19 Vaccine

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The New York Civil Liberties Union (NYCLU) is grateful for the opportunity to submit the following testimony regarding oversight of the COVID-19 vaccine. The NYCLU, the New York State affiliate of the American Civil Liberties Union, is a not-for-profit, nonpartisan organization with eight offices across the state and over 180,000 members and supporters. The NYCLU defends and promotes the fundamental principles and values embodied in the Bill of Rights, the U.S. Constitution, and the New York Constitution through an integrated program of litigation, legislative advocacy, public education, and community organizing.

The U.S. has long pinned its hopes on emerging from the coronavirus pandemic on the development and distribution of an effective vaccine. And, with COVID-19 vaccine companies concluding phase 3 studies on two vaccines, reporting over 90% effectiveness at stemming coronavirus symptoms in adults, and submitting applications for emergency use authorization to the FDA, many New Yorkers are beginning to hope that we will soon put the pandemic behind us. Still, 24% of New Yorkers statewide say they are unlikely to take a

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¹ E.g. David Paul, Wall Street's Rosy Scenario is About to Come Crashing Down, MEDIUM, July 21, 2020, https://davidapaul.medium.com/wall-streets-rosy-scenario-is-about-to-come-crashin-46d96880dfca; cf. Waiting for a vaccine fairy is for children, not leaders, SUNDAY INDEPENDENT, Oct. 18, 2020, https://www.pressreader.com/ireland/sunday-independent-ireland/20201018/282282437780731.

² The vaccine candidates were not tested for their efficacy at preventing transmission of COVID-19. *Vaccine may not stop virus transmission, says Moderna chief scientist*, THE STRAITS TIMES, Nov. 27, 2020, https://www.straitstimes.com/world/vaccine-may-not-stop-virus-transmission-says-moderna-chief-scientist.

³ Press Release, Pfizer, Pfizer and BioNTech Conclude Phase 3 Study of COVID-19 Vaccine Candidate, Meeting All Primary Efficacy Endpoints (Nov. 18, 2020) (https://www.pfizer.com/news/press-release/press-release-detail/pfizer-and-biontech-conclude-phase-3-study-covid-19-vaccine); Press Release, Moderna, Moderna Announces Primary Efficacy Analysis in Phase 3 COVE Study for Its COVID-19 Vaccine Candidate and Filing Today with U.S. FDA for Emergency Use Authorization (Nov. 30, 2020) (https://investors.modernatx.com/news-releases/news-release-details/moderna-announces-primary-efficacy-analysis-phase-3-cove-study).

coronavirus vaccine.⁴ And even for those who seek to be vaccinated, many challenges remain. The City Council must do everything in its power to ensure not only that all New Yorkers who want to be vaccinated can get the COVID-19 vaccine, but also that all New Yorkers both are and feel safe doing so. This testimony will articulate three challenges the City Council must keep front of mind: vaccine confidentiality, vaccine distribution mechanisms, and equitable, culturally competent vaccine distribution.

Vaccine Confidentiality

The federal government is conditioning distribution of any COVID-19 vaccine to a state on that state's signing a data sharing agreement⁵ that commits to provide the federal government with a wealth of personal information about each vaccine recipient, including, but not limited to, name, address, date of birth, and identification number.⁶ The sweeping nature of this data sharing agreement is unprecedented.

Although the federal Centers for Disease Control (CDC) run other vaccination programs and infectious disease surveillance programs, patients' personally identifiable information typically remains with state or local departments of health. This is true, for example, when it comes to information collected to inform the federal government's response to the other pandemic we have faced in our lifetimes: the national HIV surveillance program.

What is more, the data sharing agreement is explicit that the CDC and the federal Department of Health and Human Services (HHS) can share vaccine recipients' information

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⁴ Jimmy Vielkind, Nearly a Quarter of New Yorkers Say They Won't Take Covid-19 Vaccine, Wall Street J., Nov. 24, 2020, https://www.wsj.com/articles/nearly-a-quarter-of-new-yorkers-say-they-wont-take-covid-19-vaccine-11606213801. Even health care workers are hesitant to be vaccinated. Pien Huang, Some Health Care Workers are Wary of Getting COVID-19 Vaccines, NPR, Dec. 1, 2020, https://www.npr.org/sections/health-shots/2020/12/01/940158684/some-health-care-workers-are-wary-of-getting-covid-19-vaccines. This wariness persists even though widespread vaccination will be critical to stem the pandemic. Josh Michaud & Jen Kates, The Dangers of Vaccine Disillusionment, FOREIGN AFFAIRS, Dec. 2, 2020, https://www.foreignaffairs.com/articles/united-states/2020-12-02/dangers-vaccine-disillusionment.

⁵ 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).

⁶ See Centers for Disease Control and Prevention, COVID-19 Vaccination Program Interim Playbook for Operations 63 – 64 (Oc. 29, 2020).

⁷ E.g. Statistics Center, CENTERS FOR DISEASE CONTROL AND PREVENTION, https://www.cdc.gov/hiv/statistics/index.html (last visited Dec. 2, 2020) ("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.").

with "other federal partners," which could include Immigration and Customs Enforcement (ICE), the FBI, or the Department of Homeland Security (DHS). This too is without precedent. ¹⁰ 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, ¹¹ are disproportionately likely to suffer from COVID-19. ¹² 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. ¹³ This is also true of religious enclaves, such as New York City's Hasidic community, which has also been ravaged by COVID-19, ¹⁴ still harbors deep distrust of the public health system and government after last year's bruising battle over the repeal of religious exemptions for vaccines, ¹⁵ and feels singled out for pandemic-related enforcement. ¹⁶

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⁹ 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).

¹⁰ E.g. National Immunization Surveys, CENTERS FOR DISEASE CONTROL AND PREVENTION, https://www.cdc.gov/vaccines/imz-managers/nis/confidentiality.html (last visited Dec. 2, 2020) ("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.")

¹¹ 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/.

¹² 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.

¹³ Khiara M. Bridges, *Implicit Bias and Racial Disparities in Health Care*, 43 ABA HUMAN RIGHTS MAGAZINE (2018).

¹⁴ 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-Jewishneighborhoods.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.").

¹⁵ 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.

¹⁶ 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.

Councilmembers must be careful to avoid spreading confusion and fear about the risks of information sharing so as not to exacerbate a chilling effect. At the same time, City Council must do everything it can to ensure that New York does not share troves of vaccine recipients' personal information with the federal government and that, where information is shared, it remains with the federal health agencies. This advocacy should include reevaluating and strengthening, where necessary, the protections for the Citywide Immunization Registry, as well as pressuring state and federal lawmakers to adopt policies that protect vaccine recipients' personal information, because information shared to respond to a public health crisis should not be used to criminalize or deport people.

Vaccine Distribution Mechanisms

The federal government has also announced that it will use the traditional private health infrastructure that delivers the flu vaccine – major pharmacy chains, doctors' offices, and hospitals – to distribute COVID-19 vaccines. ¹⁷ Unfortunately, the traditional private health infrastructure does not serve all communities equally. In fact – and, unsurprisingly, given that the pandemic has disproportionately impacted New York City's lower income neighborhoods that are home to a high percentage of essential workers and individuals who cannot work from home ¹⁸ – this network is woefully inadequate in the neighborhoods hardest hit by COVID-19. For example, Manhattan has nearly *four times* as many traditional vaccination sites as the Bronx – despite comparable borough populations. ¹⁹ Particularly galling, there is only *one* lonely vaccination site in East Elmhurst, Queens ²⁰ – which is home to more than 23,000 people. ²¹

The paucity of traditional vaccination sites in the lower income communities that have been devastated by the pandemic is likely to be exacerbated by the extremely cold storage required for the two leading vaccine candidates. Pfizer's vaccine must be stored at -70 degrees Celsius and will go bad if not injected within five days of thawing. 22 Moderna's vaccine must be stored at -20 degrees Celsius, although it remains stable for 30 days at 2-8 degrees Celsius. 23 Extreme cold storage and transport procedures ("cold chains") are

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¹⁷ Press Release, Gov. Andrew Cuomo, Audio & Rush Transcript: Governor Cuomo Updates New Yorkers on State's Progress During COVID-19 Pandemic (Nov. 2, 2020) (https://www.governor.ny.gov/news/audio-rush-transcript-governor-cuomo-updates-new-yorkers-states-progress-during-covid-19-18).

 ¹⁸ See Joseph Goldstein, 1.5 Million Antibody Tests Show What Parts of N.Y.C. Were Hit Hardest, N.Y.
 TIMES, Aug. 19, 2020, https://www.nytimes.com/2020/08/19/nyregion/new-york-city-antibody-test.html.
 ¹⁹ Flu Vaccine, NYC, https://a816-healthpsi.nyc.gov/NYCHealthMap/ (last visited Dec. 2, 2020).
 ²⁰ Id.

²¹ U.S. Census Bureau, Census 2010, Table PL-P5 NTA: Total Population Per Acre New York City Neighborhood Tabulation Areas.

²² Deep-Freeze Challenge Makes Pfizer's Shot a Vaccine for the Rich, BLOOMBERG, Nov. 10, 2020, https://www.bloomberg.com/news/articles/2020-11-10/deep-freeze-challenge-makes-pfizer-s-shot-a-vaccine-for-the-rich.

²³ Press Release, Moderna, Moderna Announces Longer Shelf Life for its COVID-19 Vaccine Candidate at Refrigerated Temperatures (Nov. 16, 2020) (https://investors.modernatx.com/news-releases/news-release-details/moderna-announces-longer-shelf-life-its-covid-19-vaccine).

expensive, and to ensure that the early vaccine candidates are not solely options for the rich, appropriate cold chains will need to be established throughout the City.²⁴

The City Council must do everything in its power to ensure that the vaccine reaches all of our communities and to make sure that individuals do not have to traverse the city to receive vaccines, but rather can be vaccinated – without substantial wait times – within their neighborhoods. This should include partnering with community-based organizations to establish additional vaccination sites that are local, culturally competent, and linguistically inclusive. The City should also ensure free and accessible transportation to existing vaccination sites, as well as guarantee job-protected time off work to get vaccinated, where necessary. And, the City should engage in a culturally competent and linguistically inclusive public education campaign to ensure that all of our communities know where they can receive vaccines.

Equitable, Culturally Competent Vaccine Distribution

Questions of vaccine distribution are likely to arise imminently. Earlier this week, Governor Cuomo announced that New York's first vaccine delivery, expected on December 15, will include enough doses for 170,000 New Yorkers statewide. New York will have the unenviable task of deciding who to prioritize for vaccination, among many groups and individuals with compelling needs: health care workers; those working at and those living in congregate settings, including the elderly and the disabled, as well as those working at and those detained in prisons and jails; essential workers of all stripes, including teachers and other school staff, grocery store and pharmacy workers, and bus drivers and subway conductors, among others; those with pre-existing medical conditions; those whose racial, ethnic, and socioeconomic circumstances heighten their vulnerability; and the list goes on. Second

It is imperative that New York prioritize those with the most need and that, within the prioritized groups, vaccines be distributed on an equitable basis. The City must also develop a mechanism for distributing vaccines to those for whom traditional identification documents

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²⁴ Deep-Freeze Challenge Makes Pfizer's Shot a Vaccine for the Rich, BLOOMBERG, Nov. 10, 2020, https://www.bloomberg.com/news/articles/2020-11-10/deep-freeze-challenge-makes-pfizer-s-shot-a-vaccine-for-the-rich.

²⁵ Press Release, Gov. Andrew Cuomo, Governor Cuomo Announces State to Receive Initial Delivery of COVID-19 Vaccine Doses for 170,000 New Yorkers (Dec. 2, 2020) (https://www.governor.ny.gov/news/governor-cuomo-announces-state-receive-initial-delivery-covid-19-vaccine-doses-170000-new).

²⁶ The CDC's Advisory Committee on Immunization Practices has recommended that health care workers and adults living in long-term care facilities receive the first vaccines, although this recommendation is not binding on the states, and the initial batch of vaccines will be insufficient to fully vaccinate these two populations. See Jon Cohen, CDC advisory panel takes first shot at prioritizing who gets the first shots of COVID-19 vaccines, SCIENCE, Dec. 1, 2020, https://www.sciencemag.org/news/2020/12/cdc-advisory-panel-takes-first-shot-prioritizing-who-gets-first-shots-covid-19-vaccines.

present a problem, including undocumented individuals.²⁷ At a minimum, vaccination sites must accept a broad range of identity documents, including foreign IDs and documents besides photo identification, such as utility bills. The City must also establish ways for individuals who lack such documents to receive vaccines, because many low-income individuals and people experiencing homelessness do not have identification documents.²⁸

Moreover, it is imperative that everyone who receives a vaccine has first given voluntary, informed consent.²⁹ The initial vaccines will be distributed under the FDA's Emergency Use Authorization (EUA), which means that the FDA will release the vaccine "without all of the evidence that would fully establish its effectiveness and safety" and without reviewing – or having access to – all of the information and evidence that it typically would before approving a drug, device, or test in the normal course.³⁰

Many, particularly in the Black community, remember the Tuskegee syphilis study – when, in the 1930s, the U.S. government studied the trajectory of untreated syphilis in hundreds of Black men, both concealing the nature of their research and withholding effective treatment after one had been identified – as well as surgical experimentation on enslaved people. To individuals who still face stark disparities in the U.S. health care system, Tuskegee feels ever-present. Black patients suffering from appendicitis, broken bones, and other serious conditions are less likely to be offered painkillers than white patients, and in 2016

 $^{^{\}rm 27}$ Despite IDNYC and Green Light, ID requirements continue to present unique challenges for undocumented people.

²⁸ See Brennan Ctr. for Justice, Citizens Without Proof: A Survey of Americans' Possession of Documentary Proof of Citizenship and Photo Identification 3 (Nov. 2006),

https://www.brennancenter.org/sites/default/files/legacy/d/download_file_39242.pdf ("At least 15 percent of voting-age American citizens earning less than \$35,000 per year do not have a valid government-issued photo ID."); NAT;L LAW CTR. ON HOMELESSNESS & POVERTY, PHOTO IDENTIFICATION BARRIERS FACED BY HOMELESS PERSONS: THE IMPACT OF SEPTEMBER 11 13 (Apr. 2004) ("A total of 10.7% of clients lacked photo identification.").

²⁹ It is not clear that consent can ever be truly voluntary when an individual is incarcerated, though incarcerated populations are among both the highest risk and the least likely to have access to adequate medical care. *Cf.* Camila Strassle, E. Jardas, Jorge Ochoa, Benjamin E. Berkman, Marion Danis, Annette Rid, & Holly A. Taylor, *Covid-19 Vaccine Trials and Incarcerated People – The Ethics of Inclusion*, 383 N. ENGL. J. MED. 1897 (2020).

³⁰ Joshua Sharfstein, MD, *What Is Emergency Use Authorization?*, JOHNS HOPKINS BLOOMBERG SCHOOL OF PUBLIC HEALTH, Oct. 20, 2020, https://www.jhsph.edu/covid-19/articles/what-is-emergency-use-authorization.html.

³¹ Peter Jamison, *Anti-vaccination leaders fuel [B]lack mistrust of medical establishment as covid-19 kills people of color*, WASH. PO., July 17, 2020, https://www.washingtonpost.com/dc-md-va/2020/07/17/black-anti-vaccine-coronavirus-tuskegee-syphilis/?hpid=hp_hp-banner-main_black-antivax-940am%3Ahomepage%2Fstory-ans.

³² Khiara M. Bridges, *Implicit Bias and Racial Disparities in Health Care*, 43 ABA HUMAN RIGHTS MAGAZINE (2018).

³³ Peter Jamison, *Anti-vaccination leaders fuel [B]lack mistrust of medical establishment as covid-19 kills people of color*, WASH. PO., July 17, 2020, https://www.washingtonpost.com/dc-md-va/2020/07/17/black-anti-vaccine-coronavirus-tuskegee-syphilis/?hpid=hp_hp-banner-main_black-antivax-940am%3Ahomepage%2Fstory-ans.

researchers found that half of white medical students surveyed "were willing to entertain one or more false statements about biological differences based on race, such as the notion that African Americans have less-sensitive nerve endings than whites." ³⁴ In fact, COVID-19 researchers are using a cell line that originated from Henrietta Lacks, a Black woman whose cells were harvested without her knowledge and consent. And, although research done with so-called HeLa cells "underpin[] much of modern medicine . . . [n]one of the biotechnology or other companies that profited from her cells passed any money back to her family." ³⁵

Indigenous Americans, too, have survived "significant unethical research and medical care" since colonization.³⁶ Latinx New Yorkers remember that between the 1930s and the 1970s, approximately one-third of Puerto Rican women and girls were forcibly sterilized.³⁷ This history feels strikingly present as immigrants detained in ICE facilities in Georgia this year report forced hysterectomies.³⁸ Against this backdrop, it is no wonder that some communities are skeptical of vaccines, particularly if pushed too forcefully upon them when the vaccine is experimental and new.³⁹ Getting New Yorkers to take this vaccine will require planning, care, and sensitivity to these concerns.

Unfortunately, throughout the pandemic response, both the City and state have failed to prioritize cultural and linguistic competence and meaningful community engagement – to all of our detriments. ⁴⁰ The City must do better this time. It must work with community members and community-based organizations to engage all New Yorkers in the vaccination effort. Just as community members have been more effective at convincing their neighbors to

³⁴ Id · Sandhya Samasha

³⁴ Id.; Sandhya Somashekhar, The disturbing reason some African American patients may be undertreated for pain, WASH. Po., Apr. 5, 2016, https://www.washingtonpost.com/news/to-your-health/wp/2016/04/04/do-blacks-feel-less-pain-than-whites-their-doctors-may-think-so/.

³⁵ Henrietta Lacks: science must right a historical wrong, NATURE, Sept. 1, 2020, https://www.nature.com/articles/d41586-020-02494-z.

³⁶ See Felicia Schanche Hodge, No Meaningful Apology for American Indian Unethical Research Abuses, 22 ETHICS & BEHAVIOR 431 (2012).

³⁷ Katherine Andrews, *The Dark History of Forced Sterilization of Latina Women*, UNIV. OF PITTSBURGH, Oct. 30, 2017, https://www.panoramas.pitt.edu/health-and-society/dark-history-forced-sterilization-latina-women.

³⁸ Caitlin Dickerson, Seth Freed Wessler, & Miriam Jordan, *Immigrants Say They Were Pressured Into Unneeded Surgeries*, N.Y. TIMES, Sept. 29, 2020, https://www.nytimes.com/2020/09/29/us/ice-hysterectomies-surgeries-georgia.html.

³⁹ E.g. Desi Rodriguez-Lonebear, PhD (@native4data), Twitter (Nov. 25, 2020), https://twitter.com/native4data/status/1331818437211955204. Nearly half of Black people in the U.S. say they will avoid a vaccine "even if scientists deem it safe and it is available for free," and 40% of Hispanic adults expressed skepticism about getting vaccinated while "two-thirds of white people said they would definitely or probably get vaccinated." Press Release, Kaiser Family Foundation & The Undefeated, New Nationwide Poll by the Kaiser Family Foundation and The Undefeated Reveals Distrust of the Health Care System Among Black Americans (Oct. 13, 2020) (https://www.kff.org/racial-equity-and-health-policy/press-release/new-nationwide-poll-by-the-kaiser-family-foundation-and-the-undefeated-reveals-distrust-of-the-health-care-system-among-black-americans/).

 $^{^{40}}$ See generally NYCLU, TESTIMONY BEFORE THE NEW YORK CITY COUNCIL COMMITTEES ON HEALTH AND HOSPITALS REGARDING OVERSIGHT OF NYC'S COVID-19 TESTING AND CONTACT TRACING PROGRAM, PART II (2020).

wear masks and adhere to social distancing, 41 community members and organizations are more likely than outsiders to know how to convince their neighbors to get vaccinated.

In addition, as long as there are not enough vaccines to go around, New York City must eschew any temptation to make vaccination a pre-requisite for employment, education, ⁴² housing, or public accommodations. Such a requirement could worsen New York's existing racial, disability, and economic disparities. ⁴³ In addition, some individuals may never be able to be vaccinated because of medical counterindications. These individuals must be able to continue to participate in society. As New York City adapts its policies to the changing realities of the pandemic, it must maximize adherence to the best public health practices and to equity.

The NYCLU thanks the Committees for the opportunity to provide testimony and for their consideration of this critically important issue.

⁴¹ Ashley Southall, *Police Face Backlash Over Virus Rules. Enter 'Violence Interrupters.'*, N.Y. TIMES, May 22, 2020, https://www.nytimes.com/2020/05/22/nyregion/Coronavirus-social-distancing-violence-interrupters.html.

⁴² COVID-19 vaccines have not yet even been tested on young people. Denise Grady, *Moderna Plans to Begin Testing Its Coronavirus Vaccine in Children*, N.Y. TIMES, Dec. 2, 2020, https://www.nytimes.com/2020/12/02/health/Covid-Moderna-vaccine-children.html.

⁴³ Cf. Esha Bhandari & ReNika Moore, Coronavirus 'Immunity Passports' are not the Answer, ACLU, May 18, 2020, https://www.aclu.org/news/privacy-technology/coronavirus-immunity-passports-are-not-the-answer/.