

OPINION

# Privacy, equity, and efficiency in vaccine distribution

Every American has the right to get vaccinated against COVID-19 without any cost and without giving up their privacy.

By **Ramesh Raskar** Updated December 23, 2020, 3:00 a.m.



Pharmacist Ann Nguyen prepares a dosage from the first shipment of the Pfizer COVID-19 vaccine to be administered at the Lemuel Shattuck Hospital in Boston, Dec. 18. NICOLAUS CZARNECKI/POOL

COVID-19 has [killed more than 319,000 Americans](#) and hurt millions more economically. Now we are embarking on the single largest public health initiative ever undertaken in this country: the vaccination of more than [328 million people](#).

The speed of the development of effective vaccines has been remarkable. The next challenge is to make sure that the vaccines get out safely and broadly.

Large-scale adoption of vaccines will depend on everyone's confidence and participation. However, the nation is at risk of losing many people's trust by asking them to give up too much of their personal information to get a vaccination. Every American has the right to get vaccinated without any cost and without giving up their privacy.

The novelty of COVID-19 vaccine platforms as well as the urgent need for global vaccine distribution have required the development of untested distribution pipelines and tracking and monitoring systems. Large-scale data collection can be enormously effective in determining whether health outcomes are equal across diverse population groups and within areas of differing health, socioeconomic, cultural, and ethnic backgrounds. Data can also be used to monitor vaccination rates among different populations, something that might inform health policy across geographic regions. However, the current data systems being developed for COVID-19 vaccine

distribution overstep privacy boundaries and may inspire fear and mistrust in the public.

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Systems such as the [Centers for Disease Control's Vaccine Management System](#) and the [Vaccine Adverse Events Reporting System](#) are centralized digital solutions for vaccine administration. These platforms collect massive amounts of individual information and monitor nearly every step in the vaccine administration pipeline. This results in the ability to quickly identify any complications in vaccine distribution and the comprehensive collection of all data that might be useful in analyzing the long-term efficacy of COVID-19 vaccines.

However, these systems store large volumes of what's called personally identifiable information, including name, birthdate, address, demographic background, medical history, and insurance information in a centralized

way. In some cases, strict data privacy guidelines have not been vetted for such systems. In other cases, these guidelines have not been adequately explained to the public. Even if proper data security measures are implemented, there is the potential for data breaches. This, coupled with the perceived invasive nature of these centralized solutions, has the potential to discourage COVID-19 vaccination, especially among already marginalized and vulnerable communities.

There is an alternative to these centralized systems. Technology exists to build decentralized data management and computing systems that put individual users in control of their own information while also allowing for analysis and insights based on active user consent. It would achieve the same monitoring needs of the centralized systems being proposed today while also preserving user privacy by storing personally identifiable information on an individual's personal device. Furthermore, mobile apps provide users with control over their own information and can serve as a single platform for user vaccination reminders, education, immunity verification, and adverse event reporting.

Not everyone has a smartphone, but a decentralized system can also work for people without them. They could use paper-based, bar-coded credentials that could be generated on a computer and printed or handed out at the time of vaccination. The user-centric nature of this approach ensures that there is no need for a central registry and no sensitive data to secure.

By effectively communicating the privacy benefits of decentralized data collection and anonymized data reporting, mobile apps might diminish barriers to vaccination that exist due to privacy concerns. Placing an emphasis on individual health outcomes and user experience could enable apps to be a source of education, hopefully increasing adherence to multi-dose vaccine regimens and public health guidelines. Mobile apps and decentralized solutions could also preserve user privacy while providing a powerful platform for vaccine distribution and monitoring.

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