



**Comments of the World Privacy Forum
Regarding the CDC COVID-19 Vaccination Program Provider Requirements**

**CDC Advisory Committee on Immunization Practices (ACIP) Meeting
August 13, 2021
Docket No. CDC-2021-0084
*via Regulations.gov***

Chair Lee and members of the committee, thank you for the opportunity to participate in the ACIP meeting today. I am the founder and Executive Director of the World Privacy Forum. WPF is a public interest research group, and we have focused on privacy and data governance of complex ecosystems for more than two decades. A major focus of our work includes issues regarding health data ecosystems, their governance, and attendant privacy interests.

We have two points today.

I. WPF supports the prohibition of the use of vaccine recipient data for commercial marketing purposes

The World Privacy Forum fully supports the CDC *COVID-19 Vaccination Program Provider Requirements*, published May 18, 2021. These requirements specifically prohibit the use of vaccination data for commercial marketing purposes. We were very pleased to see these prohibitions put in place. They were warranted, and are important for ensuring patient trust in the public health data ecosystem.

Specifically, the May 2021 CDC *Vaccination Program Provider Requirements* asserts that **COVID-19 vaccination registration information and vaccine administration data** is

prohibited for commercial marketing purposes or other non-allowable purposes. Following is the complete text of the CDC May 18, 2021 requirements regarding the marketing restriction:

“Use of Vaccine Recipient Data for Commercial Marketing Purposes Prohibited

Notwithstanding uses or disclosures otherwise allowed by law, providers are prohibited from using or disclosing data collected from vaccine recipients for and through the CDC COVID-19 Vaccination Program for commercial marketing purposes or for any other purpose not allowed under this updated provision of the COVID-19 Vaccination Provider Agreement. Such data include COVID-19 vaccination registration information and vaccine administration data. These data are collected solely for the purposes of the CDC COVID-19 Vaccination Program and must be maintained in a manner that protects the integrity of the CDC COVID-19 Vaccination Program by only being used or disclosed for the purposes of the COVID-19 Vaccination Program and other limited purposes that promote public health, advance positive patient outcomes, and promote health equity.

This prohibition is not intended to limit communications by health care providers to vaccine recipients with whom the provider has an existing relationship prior to contact about COVID-19 vaccination.

The following are not included in the above prohibition:

- Communications regarding receipt of a second dose, or potential booster dose(s), of COVID-19 vaccine
- Communications to vaccine recipient for public health purposes
- Communications to vaccine recipients involving pharmacy or clinical services of the provider, personalized to the vaccine recipient’s medical needs, even if those services are not directly related to COVID-19 vaccination
- Availability of other vaccines (e.g., shingles, pneumococcal conjugate, seasonal influenza, routine childhood vaccines)
- Clinical emails
- Disease screening services
- Communications about the availability of programs to manage particular health conditions (e.g., asthma, diabetes, heart disease)

In addition, de-identified, aggregate datasets can be used by providers and shared with other partners for public health, population health, and health equity purposes.

Communications with COVID-19 vaccine recipients involving the store component of any pharmacy or other provider participating in the CDC

COVID-19 Vaccination Program are considered prohibited commercial marketing. For example, text, e-mail, mail, or other communications to COVID-19 vaccine recipients about products on sale in the store are prohibited as commercial marketing.

COVID-19 vaccination registration information and vaccine administration data collected in the course of participation in the CDC COVID-19 Vaccination Program cannot be sold, for direct or indirect remuneration, even with permission of the vaccine recipient.”

<https://www.cdc.gov/vaccines/covid-19/vaccination-provider-support.html>
(5/18/21).

We note that standard HIPAA rules already prohibit providers from using patient data for commercial purposes. We emphasize the importance of the CDC requirement that expressly prohibits a merchant operating a HIPAA hybrid entity (e.g., a supermarket with a pharmacy) from using any vaccination information for any purpose outside the hybrid entity. This is an important aspect of the prohibition, and we support it.

There must be no leakage of COVID-19 public health data into marketing systems. There is now, after many years of HIPAA implementation, a reasonable expectation of privacy in COVID-19 data ecosystems. Very few individuals understand the labyrinthine rules regarding HIPAA-covered ecosystems and public health ecosystems. The May 2021 Vaccination Program Provider Requirements are an important component in ensuring there are protections in place in our current emergency situation.

We note that the World Privacy Forum has some concerns with the breadth of some of the HIPAA waivers for COVID, which complicate the issue of what privacy rules are operative under HIPAA during a health emergency. This is something that should be addressed in due course. A report on that subject is on our website. <https://www.worldprivacyforum.org/2020/09/covid-19-and-hipaa/>

II. Extend the prohibition on the use of vaccine recipient data for commercial marketing purposes to vaccine credentialing systems

We urge the committee to ensure that the same prohibitions for commercial marketing uses of vaccine recipient data will also be required when the data is utilized in vaccine credentialing systems (proof of vaccination). We see significant potential risks for the commercial use of patient registration and vaccination data due to the sheer number of credentialing systems in development across complex public-private pathways.

We note that when proof of vaccination status is no longer voluntary then the calculus for privacy changes. Yesterday, the city of San Francisco announced mandatory proof of full vaccination in certain indoor venues. It is still unknown how many cities, schools, or workplaces

will require proof of vaccination status. There are rapid developments in COVID-19 vaccine data systems, such as the buildout of the Vaccine Administration Management System (VAMS), the upgrading of the Immunization Information System (IIS), and now a new ecosystem of vaccine credentialing subsystems. There should be no place or opportunity in this new ecosystem for the commercial marketing use of vaccine recipient data.

To conclude, we support the work of the CDC and this committee to protect patient privacy interests and the integrity of public health data. We request and urge the committee to extend the same protections to vaccine recipient data as it starts to move into the rapidly developing ecosystems of multiple vaccine credentialing and proof of vaccine tools and apps.

There is much to be said in how credential systems should operate. This committee has the ability to make the most important statement of all about this ecosystem: that the data of those who have been vaccinated is protected, and credentialing systems utilizing that data are prohibited from utilizing that data for commercial marketing or other unauthorized purposes.

Thank you for the opportunity to participate today. I welcome your questions.

Respectfully,

Pam Dixon,
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