

THE OPPORTUNITY PROJECT

FDA DIAGNOSTIC DATA EXCHANGE 2023 SPRINT PROBLEM STATEMENT

Empowering Consumers (Patients) Through Knowledge of Privacy and Security Regarding Their Health Data

U.S. Food and Drug Administration (FDA)

THE CHALLENGE – New modes of testing and care delivery rely in part on patients to input and share health data to provide a complete picture to those using population-level data. Yet patients may have questions and concerns regarding the safety, security, and utility of sharing their health information. We challenge sprint teams to create tools and digital resources that increase clarity, transparency, and autonomy regarding health privacy and security in order to empower patients to understand, own, use, and voluntarily share diagnostic data with greater confidence.

THE PROBLEM – Patient education and patient privacy are important pillars of healthcare delivery, and they are considered to be two key responsibilities of the healthcare provider. Taking time to counsel patients helps build trust and has been shown to be an important driver of behavior change. Empowering patients to realize they are in control of their health data likewise helps strengthen that trust, especially when it comes to sharing personal health data. The COVID-19 pandemic served as a powerful reminder that effective patient education and empowerment can fall outside of the traditional doctor-patient relationship, and that achieving these goals can be especially challenging in uncertain times.

THE OPPORTUNITY – A patient's experience with the health system can impact their willingness to become an active participant not only in their own health, but also in the health of their community. With this in mind, education and simple tools for privacy management that prioritize patient autonomy and informed consent throughout the patient's healthcare journey are needed. With the ability to understand and easily access, utilize, and share relevant data with appropriate privacy criteria, patients can become active players in the effective response to public health challenges.

VISION FOR SPRINT OUTCOMES – This TOP sprint will empower consumers (patients) to easily access, utilize, and share relevant data with appropriate privacy criteria for the coordination of an effective response to public health challenges.

TARGET END USERS – Patients/consumers; health and patient advocacy organizations; healthcare providers; consumer protection organizations.

RELATED DATA SETS

- ↳ [COVID-19 Case Surveillance Public Use Data](#) – Centers for Disease Control and Prevention
- ↳ [Census Household Pulse Survey](#) – U.S. Census Bureau
- ↳ [DOT Cyber Security Assessment Management](#) – Department of Transportation
- ↳ [Cybersecurity and Privacy Reference Tool](#) – National Institute of Standards and Technology
- ↳ [NIH COVID-19 Research Resources](#) – National Institutes of Health

- ↳ [Open-Access Data and Computational Resources to Address COVID-19](#) - National Institutes of Health
- ↳ [CDC/ATSDR Social Vulnerability Index](#) - Centers for Disease Control and Prevention

EXECUTIVE CHAMPION

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