

Health IT Leadership Roundtable: Future of Interoperability and Secure Consumer Access to Health Care Data

Executive Summary

Health care clinicians, hospitals, health plans, and consumer advocates all agree – patients should have access to meaningful and actionable health information.

Patients' health information may include medical history, tests performed, family history, and diagnoses and services rendered – information that is critical to enabling more informed patient and clinician health care decision-making, thereby improving quality of care and health outcomes.

However, patients and their clinicians often face challenges in accessing timely and meaningful information that they can use, while also maintaining the privacy and security of this information.

With this in mind, in January 2020, a wide range of organizations representing clinicians, hospitals, health plans, technology companies, and consumer advocates joined together to jointly host a *Leadership Roundtable on the Future of Interoperability and Secure Consumer Access to Health Data* (the Roundtable).

The Roundtable sought to provide an opportunity for a diverse set of patients, policymakers, and organizations to find common ground in identifying ongoing patient health information access and interoperability challenges and solutions to those challenges.

This White Paper seeks to summarize many of the key conversations and perspectives raised during the Roundtable event, and recommendations for moving forward. The White Paper: (1) describes the current consumer health information access environment, including recent regulatory efforts to advance consumer access to personal health information through third party applications; (2) highlights efforts to standardize and make available meaningful and actionable health care data; and (3) outlines legislative and regulatory barriers to information sharing in the health care system as identified by the Roundtable.

Key recommendations resulting from the Roundtable discussions include:

- **Education and Engagement**
 - *Administrative, Private Sector* - Create materials to help clinicians and patients better understand the Health Information Portability and Accountability Act (HIPAA), including the Privacy Rule, the delineation between HIPAA and non-HIPAA-covered entities, and notice and consent policies.
- **Privacy and Security**
 - *Administrative* - Establish a public-private partnership to review privacy and security policies for third-party apps and create a Star-rating, or some other indicator, of their commitment to privacy and security of patients' information.

Health IT Leadership Roundtable Host Committee

AMERICAN ACADEMY OF FAMILY
PHYSICIANS

AMERICAN COLLEGE OF PHYSICIANS

AMERICAN HEALTH INFORMATION
MANAGEMENT ASSOCIATION

AMERICAN HEART ASSOCIATION

AMERICAN HOSPITAL ASSOCIATION

AMERICAN MEDICAL INFORMATICS
ASSOCIATION

BLUE CROSS BLUE SHIELD ASSOCIATION

COLLEGE OF HEALTHCARE INFORMATION
MANAGEMENT EXECUTIVES

CONSUMER TECHNOLOGY ASSOCIATION

FEDERATION OF AMERICAN HOSPITALS

NATIONAL PARTNERSHIP FOR WOMEN &
FAMILIES

PREMIER HEALTHCARE ALLIANCE

- *Legislative* - Establish a data privacy structure that ensures health data is protected regardless of whether it is covered by HIPAA, aligning privacy and security rules where possible.
- *Legislative* - Create stronger compliance and government enforcement mechanisms for entities not subject to HIPAA and adequate funding for such mechanisms.
- *Data Sharing and Interoperability*
 - *Private-Sector* – Support for bidirectional information sharing built on a foundation of robust data integrity that would allow patients to add to their health record.
 - *Legislative/Administrative* – Strengthen consumer discrimination protections related to downstream or secondary uses of data.
 - *Legislative/Administrative* – Dedicate funding to support standards development by the private-sector for priority data elements and use cases.