Health IT Leadership Roundtable:

Future of Interoperability and Secure Consumer Access to Health Care Data

MARCH 2020

o - 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.

o Create stronger compliance and government enforcement mechanisms for entities not subject to HIPAA and adequate funding for such mechanisms.

o Support for bidirectional information sharing built on a foundation of robust data integrity that would allow patients to add to their health record.

o Strengthen consumer discrimination protections related to downstream or secondary uses of data.

o Dedicate funding to support standards development by the private-sector for priority data elements and use cases.

Introduction

The health care system is rapidly evolving. New medical innovations, treatments, and technologies   as well as reforms to health care payment and delivery systems   are changing the ways consumers interact with their clinicians and receive care.

The health care system is increasingly reliant on the exchange and transfer of data, allowing researchers to better understand the effectiveness of new treatments or medical devices; clinicians to obtain greater

s on a clinical care team; researchers to access and analyze data to address increasingly complex issues; and for patients to gain access to their health care infor64q0.12 0 612 792 reW*ħBT/F1 11.04 Tf1 0 0 1 4090.06 2.59a to address increasingly c 50

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patient choices regarding the

However, several studies have discussed challenges in patient access and use of their online records, citing cumbersome or difficult to use tools, incorrect information with little ability to modify, and inconsistent access to information   as well as concerns about privacy and security of information.[8,9] Surveys have also found that patients are interested in more robust functionality and features of online access.[10] Although ONC found that only three percent of patients who accessed their online medical records in 2017 transmitted their health record information to a service or app,[11] many believe that open-access APIs will encourage the development of many more choices and tools for patients to access and engage with their health care information via mobile applications (apps).

Privacy and Security Concerns

Third party apps, wearable fitness trackers, and social media platforms have become a common part of modern life. In 2018, half of smartphone or tablet owners had health or wellness apps, such as Apple Health or Google Fit, which were commonly used to track progress towards a health-related goal.[12] Consumers are also beginning to take advantage of apps to download and transport their medical records.[13]

Apps and other digital tools provide consumers with convenient, informative and innovative tools to track, store, and share their health care information. But such tools also present a new challenge in protecting patient data privacy. Most apps are not covered by HIPAA, and therefore do not have to abide by the same privacy and security rules as covered entities such as health plans, clinicians, and hospitals. Health information collected by a non-covered app, as well as HIPAA-protected PHI shared by a covered entity with a non-covered app at a patient   direction, may not be protected once the information has been transmitted or a non-covered app on a consumer device.

While some clinicians and hospitals already provide patients with access to their health care information through mobile health apps, the interoperability, patient access and information blocking rules proposed by ONC and the Centers for Medicare & Medicaid Services (CMS) are poised to greatly expand consumer

Development of Data Standards

Data standardization efforts help to promote the exchange of usable and actionable information for patients, providers, clinicians, and other stakeholders in the health care system. Data and interoperability standards offer health IT developers, EHR vendors, and health care entities a foundation to exchange data
\ V # -upon methods for connecting systems together.

Gaps and Challenges in Standards Development

While FHIR-based or other standards-based APIs will help to accelerate health care information sharing, other challenges persist in developing, standardizing, integrating, and translating data so that it is meaningful and actionable.

For instance, while there are many mechanisms in place to design new use cases and standards, the process for developing, testing, and scaling standards takes time and resources. Several Roundtable panelists noted concern that unless there is a sufficient business case and funding to develop use cases in a timely manner, there may be gaps in interoperability of information.

Another challenge raised during the Roundtable was the applicability of interoperability and data sharing across the continuum of care and outside of the health care setting. It is important to close gaps in care not only through real time clinical data access and exchange at the point of care by integrating claims, clinical, lab, and pharmacy data, and also to ensure that post-acute and other types of settings beyond acute and ambulatory ones are able to appropriately contribute to and access patient health information.

Additionally, it would be helpful to be able to include non-clinical data that might inform health care and treatment that is collected by health apps or other tools, or housed in other systems. One panelist called essentially, a longitudinal record of clinical and non-clinical data that can be used to inform decision-

Use and Translation of Meaningful Data

To achieve widespread interoperability and patient access to health care information, we need both a shared set of comprehensive and adopted standards, as well as tools that will interpret data and present them to consumers, providers and clinicians in ways that are meaningful and actionable. Consumers make more informed choices and demonstrate greater comprehension when health care information is presented in less complex ways.[31] And, according to a recent survey, 82 percent of adults want their health care information delivered in a way that is more concise and simpler to understand.[32]

Expand patient education and engagement so that consumers understand their health information

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APPENDIX A

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to encourage hospitals and other health care clinicians to adopt electronic health records (EHRs). The Act significantly increased the rate of adoption of EHRs in hospitals and in clinician offices.

Importantly, HITECH also included provisions related to privacy and security of health information

Proposes definitions related to the practice of information blocking, as well as seven categories of reasonable and necessary practices that would not be considered to constitute information blocking: (1) promoting the privacy of EHI, (2) preventing harm, (3) promoting the security of EHI, (4) recovering costs reasonably incurred, (5) responding to requests that are infeasible, (6) licensing of interoperability elements on reasonable and non-discriminatory terms, and (7) maintaining and improving health IT performance.

Other Administration Initiatives to Promote Patient Access to Health Information

Additionally, beyond the CMS and ONC proposed patient access and interoperability rules, the Administration has spearheaded several other key initiatives to promote greater sharing of and access to health care information.

MyHealthEData   An overarching initiative that intends
and use of their health care data while keeping it safe and secure. Having timely electronic access to health information makes it easier for people to make more informed decisions about their health   [38]

Blue Button 2.0   Launched as part of the MyHealthEData Initiative, Blue Button is an API that contains four years of Medicare Part A, B, and D information for 53 million Medicare beneficiaries.[39]

Beneficiary Claims Data API - The Beneficiary Claims Data API (BCDA) enables Accountable Care Organizations (ACOs) participating in the Shared Savings Program to retrieve Medicare Part A, Part B, and Part D claims data for their prospectively assigned or assignable beneficiaries. This includes Medicare claims data for instances in which beneficiaries receive care outside of the ACO, allowing a full picture of patient care.[40]

Data at the Point of Care Pilot - Data at the Point of Care is a pilot API program that enables healthcare providers to deliver high quality care directly to Medicare beneficiaries by making a pat   U   u
be accessed in the existing workflow and without logging into another application or portal.[41]

Trusted Exchange Framework and Common Agreement   The 21st Century Cures Act also required HHS to establish a national framework and common agreement for the trusted exchange of health information. ONC is currently in the process of implementation.[42]

OCR Patient Access Initiative - HHS Office of Civil Rights (OCR), which has enforcement authority
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without being overcharged   o   o   \ #k
two enforcement actions and settlements.[43],[44]

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