Health Data Sharing to Improve Collaborative Care

August 2021

Whole-Patient Care and Data Sharing

During the past decade, health systems have increasingly recognized the value of integrated continuums of care through close collaboration among multiple providers. Caring for the "whole person"—from assessment/diagnosis through multiple stages of treatment, recovery, and other needed supports—is possible only if the individual's history, medications, treatment plan, and other relevant information are shared in a standardized and timely fashion across multiple provider and payer organizations.

Emerging Approaches to Health Data: "Patient First"

As person-centered practices take hold in health systems, there have been parallel changes in how health data is viewed by policymakers and healthcare providers. Whereas earlier approaches to protected health information (PHI) focused on enforcing security and preventing unwanted access, there's been a recent shift to protecting the rights of individuals to access and control their own health data. There's increasing awareness that the individual is the owner of their health data while providers and payers are "data stewards" rather than owners.

Recent Policy Changes: Easier Access, New Data Protection Technologies

There are changes to health data protection regulations that align with the "patient first" principle by facilitating individuals' access to their health data and increasing ease of access by multiple providers collaborating on or coordinating an individual's care. In addition to individuals' rights to access their own PHI, new regulations also give individuals the right to authorize disclosure of their data to specific organizations under most circumstances. These provisions necessitate easily accessible IT solutions that prevent unwanted access while upholding privacy and informed consent. The following are important policy changes in this direction:

The 21st Century CURES Act final rule calls for increased transparency and easier data access by patients, hospitals, provider organizations, and payers through an innovative data security IT environment.

HIPAA Privacy Rule revisions brought changes to allow disclosure of PHI to case managers, care coordinators, community-based organizations, and social service agencies.

The Interoperability and Patient Access final rule issued in 2020 by the Centers for Medicare & Medicaid Services (CMS) provides a roadmap for easing access to health data for patients, providers, and payers by enhancing compatibility across multiple health data systems.

Sharing Behavioral Health Data

Health information related to substance use disorders has special privacy protection regulations and strict consent procedures due to the potential criminal justice implications of substance use. These are articulated in the regulations labeled 42 CFR, Part 2 (Confidentiality of Substance Use Disorder Patient Records). In response to the opioid epidemic, these regulations were recently revised to facilitate care coordination across multiple providers while continuing to protect confidentiality. HIPAA Privacy Rule revisions also include special provisions for behavioral health providers to access and disclose health data in the best interest of the individual and to prevent or reduce harm to individuals with substance use disorders and serious mental illness.

Benefits of Data Sharing

In addition to facilitating crisis responses, empowering patients and families, and improving care through better coordination and collaboration, data sharing streamlines services and reduces costs. For example, a report by the American Hospital Association found that, *"fully interoperable health information…reduces costs in time and resources for patients and insurers by avoiding duplicative services, as well as for clinical and administrative staff by devoting fewer hours to these tasks"* **(p. 4).**

Success Story from an Area Agency

CICOA Aging & In-Home Solutions, an Indiana Area Agency on Aging, established a mutually beneficial data sharing agreement with the Indiana Health Information Exchange (IHIE). Now, Indiana's hospitals and other healthcare providers are able to share patient information with a social service provider, enhancing their ability to provide timely transition services for their discharged patients. Furthermore, access to real-time health information allows CICOA staff to provide supportive services in a timely fashion when one of their clients is admitted to the ER, reducing the risk of preventable complications resulting in re-hospitalization.

Timely response to service requests makes an impact on clients' health and wellbeing. For example, when CICOA quickly intervenes in the care of individuals who are at risk for falls, an area of great interest to their healthcare partners, the fall rate among these individuals drops from 25% to 5%.

Partnership with IHIE has also increased CICOA's community outreach capacity. The Director of Health Care Collaborations said that before the connection, "a 20% contact rate was considered good. Today, … we have a contact rate as high as 70% or 80%."

Technological Advances Facilitating Data Sharing

The biggest barriers to sharing PHI have been the strict privacy rules and the different ways that various agencies designed their data systems to meet privacy regulations. The multiple data platforms used by different health systems—and by different agencies *within* the same system—are difficult and costly to harmonize in a manner that allows for data to freely travel across agencies. This has resulted in "information silos" that hinder collaboration among providers and payers through the entire continuum of services and supports that an individual receives. The past decade witnessed initiatives, supported by multiple federal agencies, to break health information silos through scalable, affordable IT strategies, including those described in the following list.

❖ **The Direct Project**: This is an effort launched in 2010 to specify a simple, secure, scalable, standards-based way for participants to send authenticated, encrypted health information directly to known, trusted recipients over the internet. It makes the exchange of secure information among trusted partners as easy as sending an email, with security that meets federal regulations. Interested providers can get involved by contacting the project's community of practice for implementers.

❖ **Application Programming Interfaces** (API): These are applications that function as "translators" to help different software programs communicate with one another. They have been an important feature in online transaction applications since the 1990s. Their use in health data sharing is a recent development, following the formulation of standard privacy protection criteria in line with federal PHI regulations, specifically for these applications. The use of APIs in health data systems, provided they comply with these criteria, is now supported and encouraged by federal regulators. ONC and CMS have adopted API certification criteria for electronic health records to help enable access to health information for clinical and patient-facing uses. This technology has made it possible for communities to establish Health Information Exchanges (HIE), such as the San Diego system. Federally certified APIs for PHI sharing are commercially available.

Additional Resources

❖ ONC's *Health IT Playbook* addresses many questions that a provider might have about data sharing
❖ CONNECT is an open-source software and user community for secure, electronic health data exchange among healthcare providers, insurers, government agencies, and consumer services
❖ The Network for Public Health Law provides legal information for community health organizations on health-related topics that include information security and data sharing. They offer webinars, toolkits, trainings, and an online Legal Assistance Library