ONC Strategizes Health Data, IT Infrastructure Improvements for Research

The plan aims to leverage quality electronic health data and advance an IT architecture.

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Mon, 02/24/2020 - 11:35

The Office of National Coordinator for Health IT released Monday a strategy to better leverage health IT and data in research activities over the next three to five years.
The strategy, known as the National Health IT Priorities for Research, states that despite the growing adoption of electronic health records and boom in health data availability, challenges around data quality and consistency, data access policies and governance, limited research tool development and inconsistencies across technical architectures make capitalizing on health IT and data for research difficult.

ONC reviewed research documents, interviewed relevant experts on EHRs and best health IT architecture for supporting research, and also held a workshop in July 2018 to identify these challenges. Through this work, ONC also found that a lack of opportunities for the use of health IT infrastructure for research, tools for researchers to learn how to use and share standardized EHR data and a slew of other obstacles.

To overcome these challenges, ONC drafted in its agenda two overall goals — to leverage high-quality electronic health data for research and to advance a health IT infrastructure to support research. Under these two goals are nine priorities, which ONC will enforce over the next three to five years.

The first goal focuses on optimizing high-quality health data for research amid preexisting complications of lack of data standards and data compatibility for research. The three priorities include:

- **Improve data quality at the point of capture** by identifying developed standards that capture more information about data points at time of capture and promoting the adoption and use of current and emerging data and metadata standards to improve data quality for care and research.
- **Increase data harmonization to enable research uses** by supporting the development and use of existing common data models to transform and analyze data for research uses, as well as identifying cooperative opportunities to improve understanding of research data use in accordance with privacy and security safeguards.
- **Improve access to interoperable electronic health data** by ensuring that “health IT systems provide sufficient documentation about their data models and technical specifications to develop shared tools for acquiring clinical data from those systems.”
While these priorities will help ONC create standards for and the security and interoperability of health data, the following support the second goal of developing a research-ready health IT architecture. The priorities under this goal are to:

- **Improve services for efficient data storage and discovery** by “making advanced computational capacity and storage available to researchers to reduce redundant data collection efforts.”

- **Integrate emerging health and health-related data sources** by supporting the functionality within health IT architectures to link research-relevant data sources outside the patient care realm with EHR data and supporting processes of standardizing new data concepts.

- **Improve methods and tools to support data aggregation** with the ability to match individuals to different sources of data, the development of tools to manage data use agreements across organizations efficiently and develop the ability to manage data across distributed sources.

- **Develop tools and functions to support research** with support for easier consent management for research and expanding tools for both supporting research processes and indexing systems to identify and recruit potential patient groups for different studies.

- **Leverage health IT systems to increase education and participation** by developing health IT tools that realize value for patients and providers in research participation, pursuing infrastructure improvements that enable diverse patient participation in research and expanding research opportunities beyond large health systems.

- **Accelerate integration of knowledge at point of care** by advancing new ways to accelerate digitization of evidence into computable knowledge and developing tools to translate computable knowledge at the point of care supporting patients and providers.

To act upon these priorities, ONC said that it will require the collaboration of federal, industry, academic and research organizations both in health care and IT. They will work on education and communication efforts, policy development, tools and services access and development, research and evaluation activities, as well as standards development.
Overall, ONC hopes this plan will lead to reliable, high-quality and standardized health data.

“In the ideal state, electronic health data will have high reliability and validity,” the report says. “These data will be in standardized formats and will include the necessary metadata to understand where, why, how and by whom they were collected. The data will also be available to researchers using common models for consolidating and securely transmitting the information.”

Further, ONC aims for a health IT infrastructure that can support a variety of research functions in a secure manner — a platform that will let researchers, providers and patients understand where data is stored and how it is used.

“The health IT infrastructure will have services to locate data stored across various sources and tools that support needed research functions, including aggregating data from multiple internal and external sources and incorporating robust methods of identifying patients and matching them across systems to ensure adherence to the necessary privacy and security procedures,” the report says.