Improving Access to Interoperable Data for Research

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Abstract

Widespread adoption of electronic health record (EHR) systems and consumer electronics has resulted in large volumes of health-related data potentially available for research.\textsuperscript{1,2} However, realizing the value of these data for research has been slow due to challenges in both the data and the health information technology (IT) infrastructure that supports it.\textsuperscript{1} This panel will discuss efforts by the Office of the National Coordinator for Health Information Technology (ONC) to guide the development of a future health IT infrastructure that supports use of electronic health data for research. This work addresses three objectives: (1) articulate a vision for an ideal health information ecosystem that supports research; (2) identify stakeholders’ priorities needed to address challenges within the current ecosystem; and, (3) propose a Policy and Development Agenda that will contribute to realizing an ideal health information ecosystem in which both the health IT infrastructure and the data it supports are optimized.

Introduction

The Office of the National Coordinator for Health Information Technology (ONC) Chief Scientist Division (CSD), responsible for developing and evaluating ONC’s overall scientific efforts and activities, recently completed an effort to understand and define the work needed to advance the nation’s health IT infrastructure over the next 3 to 5 years in support of innovative biomedical and health services research.

ONC’s vision is for a health IT infrastructure that supports alignment between the clinical and research ecosystems enabling faster, better, and easier access to data for research. The future health IT infrastructure will: (1) facilitate capture of highly reliable and valid data; (2) ensure the data are standardized and interoperable; (3) make available tools to aggregate and configure data from multiple sources; (4) incorporate robust methods of identifying patients and matching them across systems to ensure adherence to the necessary privacy and security procedures, and (5) support the capability to return this information to the point of care for actionable use.

ONC identified policy and development priorities to address health IT infrastructure gaps and challenges to achieve its vision that support easier access to high-quality data and broaden opportunities for research participation. Activities needed to address the gaps and challenges were compiled into an action agenda organized into the following areas: improve the health IT architecture, enhance standards development, advance governance, and support people and processes to advance biomedical and health services research through education and communications efforts.

Improving the Health IT Infrastructure for Research

The health IT infrastructure – which encompasses technical architecture and standards, governance, and policies to enable interoperability – must also support researchers by providing appropriate access to data that can be used to conduct research that will lead to better treatments and improved care.\textsuperscript{3,4} The health IT infrastructure must also support the translation of point-of-care health tools into improvements in patient and provider experiences.\textsuperscript{5} The policy and development agenda identifies eight priorities one or more associated calls to action to achieve two key areas of the vision:

- Easier Access to High Quality Data: (1) Improve data quality at the point of capture, (2) Improve data federation and storage services, (3) Improve data aggregation tools, (4) Improve access to interoperable data, and (5) Improve knowledge sharing solutions
- Broaden Opportunities for Research Participation: (6) Increase transparency and incentives, (7), Improve recruitment processes, and (8) Improve consent management processes

The panelists will discuss the action agenda, which includes a set of activities in the area of collaboration, demonstration and pilots, education and communications, policy levers, access to tools and services, research and evaluation, standards, and tool development. The panelists will discuss each action agenda component and describe the policy and/or development action(s) needed along with the activities, collaborators, and timeline that are critical.
to achieve each component of the action agenda. Panelists will also discuss barriers both experienced and anticipated to achieving these priorities and provide examples of how institutional and infrastructure challenges are considered and addressed to facilitate research.

**Panel Objectives and Presenters**

Panelists will discuss the policy and development agenda including priorities for improved access and use of high-quality data. These include improving data quality at the point of capture, data federation and storage services, data aggregation tools, and access to interoperable data, knowledge sharing solutions. Panelists will present national priorities related to providing opportunities for research participation, such as: increasing transparency and initiatives, improving patient recruitment, and improving consent management.

Mr. Kevin Chaney, a Senior Program Manager at ONC within the Chief Scientist Division, will moderate the panel.

Dr. Teresa Zayas-Cabán, is the Chief Scientist at ONC and her division leads ONC’s scientific and evaluation efforts including PCOR, precision medicine programs, and Leading Edge Acceleration Projects (LEAP) in Health IT. Dr. Zayas-Cabán will provide an overview of ONC’s research priorities.

Dr. Jon White recently served as the Deputy National Coordinator for Health IT at ONC and provided leadership support for development of ONC’s research priorities. He is currently the Associate Chief of Staff of Research at the Salt Lake Veterans Affairs (VA) Medical Center and will offer national and VA perspectives on health IT data and infrastructure needs to support research.

**Panel Discussion Questions**

- What health IT architecture improvements are essential to make advance computational capacity and storage available to researchers?
- What activities are needed to advance standards-based mechanisms to find and identify data or link research-relevant data sources outside the patient care setting with EHR data?
- What standards gaps should be prioritized and what barriers exist to resolving the widest gaps?
- What governance and policy levers can help researchers better understand the data models within EHR and health IT systems?
- How can research opportunities using EHR data be expanded beyond large health systems and ensure diversity of research study participants (such as organizations that serve underserved communities and vulnerable populations)?

**Panel Learning Objectives**

- Participants will gain a better understanding of industry stakeholder perspectives regarding national health IT priorities to support research.
- Participants will learn the challenges within the current health IT data ecosystem that hinder the ability to effectively use health IT data for research.
- Participants will learn the policy and development actions for specific stakeholders that can improve the ability of health IT to advance research.
- Participants will be able to identify the activities relevant to them to participate and engage in to advance national health IT priorities to advance research.

**Conclusion**

Over the last decade, the health IT infrastructure has largely supported the capture, access, and exchange of standards-based health information at the point of care. However, additional solutions, standards, and governance is needed to support the effective use of health information to improve care through clinical research and patient-reported outcomes research. ONC has developed a forward-looking Policy and Development Agenda to enhance and expand the needed health IT infrastructure for effective research and improved care delivery.

**Statement of Participation**

Each of the panelists and the moderator have confirmed that they will participate if this submission is accepted, at the assigned timeslot during the Informatics Summit.
References


