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Perspective

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National health information technology priorities for research: A policy and development agenda

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ABSTRACT

The growth of digitized health data presents exciting opportunities to leverage the health information technology (IT) infrastructure for advancing biomedical and health services research. However, challenges impede use of those resources effectively and at scale to improve outcomes. The Office of the National Coordinator for Health Information Technology (ONC) led a collaborative effort to identify challenges, priorities, and actions to leverage health IT and electronic health data for research. Specifically, ONC led a review of relevant literature and programs, key informant interviews, and a stakeholder workshop to identify electronic health data and health IT infrastructure gaps. This effort resulted in the National Health IT Priorities for Research: A Policy and Development Agenda, which articulates an optimized health information ecosystem for scientific discovery. This article outlines 9 priorities and recommended actions to be implemented in collaboration with the research and informatics communities for realizing this vision.

Key words: health information technology, research, policy, development, federal government

REALIZING BETTER RESEARCH WITH HEALTH INFORMATION TECHNOLOGY

Widespread adoption of electronic health record (EHR) systems and consumer electronics has resulted in large volumes of electronic health-related data.[1–4] This has created opportunities for researchers to leverage the capabilities of an evolving digital architecture. However, progress remains slow because of challenges with both the data and the health information technology (IT) infrastructure that support research uses. Specific challenges include ensuring data quality and consistency,[5,6] establishing governance structures and policies for appropriate access to data,[7–9] inconsistencies across the technical architecture that limit the development of shared tools and services,[10] and lack of understanding about how individuals and organizations want to contribute to and utilize data within the infrastructure.[11]

Understanding these challenges and addressing them is critical to accelerate scientific discovery and improve outcomes without burdening researchers, providers, and patients. Accordingly, the Office of the National Coordinator for Health Information Technology (ONC) led a collaborative project to identify and address those challenges. Specifically, ONC led a review of relevant literature, programs, and initiatives and conducted discussions with key informants. The results of the review and interviews informed a workshop in which federal and private industry stakeholders identified key health IT infrastructure gaps that should be addressed to improve scientific discovery and application. ONC publicly presented draft findings at 2 American Medical Informatics Association (AMIA) conferences and further refined the content based on attendee feedback. This article summarizes the priorities, related strategies, and actions needed to advance the priorities identified through this effort.

HEALTH IT PRIORITIES FOR RESEARCH AND SUPPORTING STRATEGIES

The review, key informant interviews, and workshop led to a vision of a health IT infrastructure that supports alignment between the

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clinical and research ecosystems so research can happen more quickly and effectively. The resulting National Health IT Priorities for Research: A Policy and Development Agenda (the Agenda) has 2 overarching goals: (1) leverage high-quality electronic health data for research and (2) advance a health IT infrastructure to support research.[12] The Agenda includes 9 priorities, which are listed in Table 1. Each priority includes 1 or more supporting strategies, each of which identifies a specific need that currently exists within the research community.

Priority 1: Improve data quality at the point of capture

For use in research, data must be accurate and precise.[13] Metadata are particularly important.[14] The quality of data must be balanced against the needs of users who generate the data. Strategies needed include coordination of a multistakeholder effort to identify high-priority metadata elements, development of metadata standards, and adoption and use of data and metadata standards.

Priority 2: Increase data harmonization to enable research uses

Common data models allow for analysis of differing datasets by converting them into a common format, yet harmonizing those models remains a challenge.[15,16] Existing data models, such as the Observational Health Data Sciences and Informatics[17] Observational Medical Outcomes Partnership,[18] and the Patient-Centered Outcomes Research Institute's National Patient-Centered Clinical Research Network common data models,[19] should be reconciled to the extent possible. There have been some efforts to do this,[15,16] but future progress in research depends on success in data harmonization. Strategies to achieve this include increasing support for development and use of existing data models, as well as incented collaboration between developers and stewards of data models.

Priority 3: Improve access to interoperable electronic health data

Access to interoperable electronic health data is key for advancing research.[20–23] The current approach to improved interoperability is through standards-based application programming interfaces (APIs), enabling patients and providers to access and share health data for a variety of purposes, such as research. For example, Sync for Science (S4S),[24] a public–private collaboration that began in 2016, developed a simplified, scalable, and secure way for individuals to share their clinical data with research and consumer health applications (apps) of their choice via the Health Level Seven International® Substitutable Medical Apps, Reusable Technology on Fast Healthcare Interoperability Resources® (FHIR®) API.[25] One goal of S4S was to lower the barriers for health IT developers to participate in a mobile app ecosystem. IT firms such as Apple, Google, and Microsoft have leveraged the same API standard as S4S to enable sharing of health data.[26–28] Experience with publicly available APIs will drive incremental improvement of API standards. While this trend will enable data sharing for a variety of end users and purposes, documentation regarding schema and technical specifications underlying health IT systems may be needed for researchers to understand, integrate, and analyze data from open APIs.

Priority 4: Improve services for efficient data storage and discovery

The historical trend in research is for exponential growth in data volume.[29] There is increased interest in migrating large health and health-related data to cloud-based environments.[30,31] This allows for increased storage capabilities and access to cloud-based computing and other computational tools and resources while also reducing the need for localized physical data centers. This supports the research use case by providing secure, scalable, rapidly available storage and computation infrastructure.[31] The National Institutes of Health's (NIH) *All of Us* Research Program leverages the cloud for storing data, as well as creating an interactive web-based platform that includes a Jupyter Notebook environment so researchers and citizen scientists can explore the data and test hypotheses.[32,33] Moving forward, research projects should prepare and implement standards-based plans for storage and access to research data that are interoperable with other information systems.

Priority 5: Integrate emerging health and health-related data sources

As discovery of causal factors in health progresses, science will identify previously unknown or unstudied data elements. Examples include omics data, social media data, imaging data, patient-generated health data, and social determinants of health.[4,34–38] Environmental and location data could further inform our understanding of how our surroundings affect our health.[34] Health IT systems should support an infrastructure and underlying standards that can integrate and link to novel data elements.

Priority 6: Improve methods and tools to support data aggregation

Presently, many steps involved in aggregating data from multiple sources are often done manually by researchers, and this curation is not standardized or replicable at scale, or across multiple institutions. Future areas of focus to achieve advanced aggregation functionality include patient matching, data use agreement management, data curation, and more convenient analytic methods and tools.[39]

Priority 7: Develop tools and functions to support research

Current resources are not optimized to facilitate critical research activities. Advanced functions will support consent management of personal data for research and improve processes such as recruitment, enrollment, randomization, and data de-identification.[40,41] Advanced analytic tools and approaches (eg, deep learning, machine learning, split-learning algorithms) are showing promise in extracting information from large datasets or de-identifying data.[42–45] Such tools have the potential to spur to new methods for improving study designs and more rapid, pragmatic trials.

Priority 8: Leverage health IT systems to increase education and participation

Potential participants are not involved in research because of barriers such as lack of awareness of available studies,[46,47] effort required to participate,[48–50] and lack of trust in the research community.[51–54] Approaches that support better education, engagement, and participation about or in research are coming into use,[55,56] but further work is needed to pursue infrastructure improvements enabling and incenting participation from a diverse patient population.

Table 1. Agenda priorities, supporting strategies, and selected actions

Priorities	Supporting Strategies	Sample Actions
1. Improve data quality at the point of capture	Identify and develop metadata standards that capture more information about a given data point at the time of capture Promote the adoption and use of current and emerging data and metadata standards to improve data quality for care and research	Coordinate a multistakeholder effort to identify high-priority metadata elements Incent advancement of new data concepts and metadata elements Test emerging data and metadata elements through pilot or demonstration projects
2. Increase data harmonization to enable research uses	Increase support for the development and use of existing common data models to transform and analyze data for research purposes Identify collaborative opportunities to improve understanding regarding research data use and reuse in accordance with established privacy and security safeguards	Create incentives for researchers to use and share common data models Investigate the utility and funding of a national centralized "research workbench"
3. Improve access to interoperable electronic health data	Ensure health IT systems provide sufficient documentation about their data models and technical specifications to develop shared tools for acquiring clinical data from those systems	Require certified systems to share relevant technical specifications to understand data representation Encourage health IT developers to enable access to API specifications by other systems Test effectiveness of data model publication
4. Improve services for efficient data storage and discovery	Realize efficiencies by making advanced computational capacity and storage available to researchers to reduce redundant data collection efforts	Establish low-cost access for researchers to needed computational and data-related tools and services Pilot use of novel methods for identifying data and making data discoverable
5. Integrate emerging health and health-related data sources	Support functionality within the health IT architecture to link research-relevant data sources outside the patient care setting with EHR data Provide support for accelerating the process of standardizing new data concepts while working to update current standards	Standardize taxonomies and methods for data collection across a wide variety of settings and purposes Continue standardizing data elements needed to enable precision medicine and advance biosurveillance and postmarketing surveillance Develop and disseminate tools and applications that improve data quality for research Support rapid consensus-based standardization of data concepts
6. Improve methods and tools to support data aggregation	Improve the ability to match individuals to different sources of data Develop tools to efficiently manage data use agreements across organizations Develop functionalities needed to manage data across distributed sources, including to identify redundancy; account for updates to data and metadata; and analyze data in different formats	Establish performance measures of participant matching to accelerate private industry matching solutions Investigate the ability to manage data use agreements between parties electronically Support shared services for de-duplication of records and management of updates to data and metadata
7. Develop tools and functions to support research	Support easier consent management for research Develop additional tools to support research processes such as recruitment, enrollment, randomization, and Health Insurance Portability and Accountability Act–compliant de-identification Investigate and expand tools that index, search, and query systems to identify and recruit possible patient cohorts for a given study as well as easily extract data about participants	Determine the authority needed to identify a trusted eConsent management organization Identify the functionalities desired in an eConsent system and for the management of relevant information Investigate infrastructure requirements and standards needed for consent managements systems Test advancements of tools for de-identification and identification of research cohorts Investigate indexing and query functions within distributed data networks to identify any gaps and challenges Develop and support indexing and query tools
8. Leverage health IT systems to increase education and participation	Develop health IT tools that deliver value for providers and patients to participate in research Pursue infrastructure improvements that enable participation from a diverse patient population Expand research opportunities beyond large health systems	Assess effective methods to add value for patients who participate in research Support research on evidence-based methods for delivering information to patients Support workforce development and capacity-building programs Make using the health IT infrastructure for research more accessible
9. Accelerate integration of knowledge at the point of care	Advance new methods to accelerate the digitization of evidence into computable knowledge Develop tools to support the translation of computable knowledge at the point of care supporting providers and patients	Support digital knowledge that is standardized and scalable across the architecture Incent researchers to develop digital knowledge from evidence-based findings Investigate bidirectional API-based clinical decision support tools

API: application programming interface; EHR: electronic health record; IT: information technology.

Priority 9: Accelerate integration of knowledge at the point of care

Gaps between new knowledge and its integration at the point of care are widespread.[57] The rate at which new knowledge is expected to be generated, both by traditional research and new care delivery approaches such as precision medicine, will continue to outpace its integration and use if infrastructure and capabilities are not harnessed properly.[58,59] Ongoing digitization of evidence needs to be complemented by integration and implementation of this information into clinical care, for example using CDS Hooks[60] or other API tools.

ACTIONS NEEDED TO REALIZE THE AGENDA

The priorities and supporting strategies identified above reflect ONC's support for scientific discovery. The Agenda also identifies actions, some of which are listed in Table 1, needed to advance the priorities. These actions can be implemented using a variety of mechanisms, such as collaborations, demonstrations and pilot projects, the development of standards, leveraging health IT to improve education and communication regarding research, policy levers, continued support for research and evaluation within the health informatics community, tool development, and wider access to tools and services. Implementing these actions will require engaging a wide variety of stakeholders, including educational institutions, federal partners, foundations, healthcare provider organizations, health IT developers, the IT sector, patient advocacy groups, payors, researchers, research funding organizations, and standards development organizations.

Successful implementation of the priorities will require both continuing current and developing new collaborations across stakeholders on relevant initiatives, whether in the pursuit of coordinated prioritization of standards development and adoption or using the combined leverage of multiagency incentives and prioritization. Advancing priorities may also require use of policy levers, such as rulemaking on EHR certification criteria, NIH research funding policies, or the Food and Drug Administration (FDA) drug and device approval process. Several federal agencies are already making relevant policy changes. For example, NIH recently issued a notice encouraging funded investigators to use FHIR for research,[61] FDA's recently released Technology Modernization Action Plan prioritizes interoperability and the use of APIs and standards,[62] and the Veterans Health Administration will be implementing certified health IT nationwide over the next several years.[63] In addition, development activities for tools, platforms, or other resources are needed to advance priorities listed in the Agenda. An important category for engagement of the private sector is demonstration or pilot projects.

Specifically, ONC is already working to implement actions across several priority areas through its programs and policies in collaboration with stakeholders. ONC actively collaborates with NIH's *All of Us* Research Program and standards development organizations to develop, pilot, and advance standardized data sharing (eg, clinical, genomic, social determinants of health, patient-generated health data) for both research and clinical care.[64] ONC's Leading Edge Acceleration Projects in Health IT program is an example of ONC's ability to fund projects that seek to overcome challenges that inhibit the development, use, or advancement of well-designed, interoperable health IT affecting care and research.[65] Leading Edge Acceleration Projects in Health IT awardees are furthering progress of key actions under priority areas 3, 7, 8, and 9. They are working to expand the scale and utility of population-level data-focused APIs, advance clinical knowledge at the point of care, standardize and implement scalable FHIR consent resources, and develop enhanced patient engagement technologies for care and research.

In 2019, ONC released a notice of proposed rulemaking that would require certified health IT products to support the export of electronic health information for both a single patient and for multiple patients in a defined population through APIs.[22] The proposed rule also replaces the definition of the common clinical data set standard with the U.S. Core Data for Interoperability. U.S. Core Data for Interoperability Version 1 includes updated versions of vocabulary standard code sets, address and phone number, pediatric vital signs, provenance data elements, and clinical notes including discharge summary note, history and physical, progress note, consultation note, imagined narrative, laboratory report narrative, pathology report narrative, and procedures note. This proposed rule will advance interoperability by addressing factors that create barriers to the standardized sharing of electronic health data and limit patients', caregivers', and providers' ability to access health information. In particular, the requirements will support improvements in patient matching, the development of a longitudinal record, access to information for research purposes, and the inclusion of standardized metadata information about how data were collected. ONC expects to continue its standards development activities to address areas of high priority for research.

FUTURE DIRECTIONS

The increased volume of electronic health data and the investment made in a health IT infrastructure over the past decade have created unprecedented opportunities for research, as well as related activities such as biosurveillance, drug development, and postmarketing surveillance. While there have been notable improvements in the availability of health care–related data and the health IT infrastructure supporting it, challenges regarding data quality and management remain, as does a need for better tools to facilitate research. The Agenda describes a path to a health information ecosystem that can accelerate research and represents a vision shared across several contributing federal agencies.

There are a variety of high-impact activities that can improve standards for how data are captured, what is known about those data, the formats used to aggregate data, and how the data are transmitted. The development of new tools and the speed at which they are developed will increase as researchers in the health services and biomedical research fields collaborate more closely with health IT developers and informatics experts. Importantly, the ability to leverage the health IT infrastructure to enable faster and better communication with patients participating in research will have a profound influence on engagement with the research community. ONC and federal partners such as NIH, FDA, and VHA will continue to collaborate with key stakeholders on broad strategies modernizing our nation's health IT infrastructure to enable research and discovery.

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AUTHOR CONTRIBUTIONS

TZ-C and KJC led the development of the agenda through a series of coordinated activities gathering stakeholder input, and DWR provided executive leadership as well as critical appraisal and input to the agenda. TZ-C and KJC led drafting of the article. All 3 authors revised the article critically and provided intellectual content, and approved the final version for submission. The order of authors listed in the manuscript has been approved by all authors.

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CONFLICT OF INTEREST STATEMENT

None declared.

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