National Health IT Priorities for Research: A Policy and Development Agenda

Health Information Technology Advisory Committee (HITAC)

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At the Intersection Between Research and Care Delivery

- Develop and evaluate ONC's scientific efforts and activities

- Recommend scientific policy to the National Coordinator

- Promote and lead activities that spur innovation, support patient-centered outcomes research, and advance precision medicine

https://www.healthit.gov/topic/scientific-initiatives

ONC Chief Scientist Division: Recent Activities

- LEAP in Health IT Special Emphasis Notice
  - Area 2: Cutting Edge Health IT Tools for Scaling Health Research
  - https://www.healthit.gov/topic/onc-funding-opportunities/leading-edge-acceleration-projects-leap-health-information

- Precision Medicine Initiative
  - Sync for Genes Phase 2 Final Report: https://www.healthit.gov/topic/sync-genes
  - Blog post series: https://healthit.gov/topic/precision-medicine

- Patient-Centered Outcomes Research
  - Patient-Reported Outcomes through Health IT final report: https://www.healthit.gov/topic/scientific-initiatives/pcor/patient-reported-outcomes-through-healthit-pro
  - Web page refresh: http://healthit.gov/pcor

Health IT is Foundational to Research

- Enormous array of data will require new thinking and pathways for storing, accessing, and analyzing the information.

- Success will require portable electronic health information that is actively exchanged among health care providers, researchers, and individuals.

Advancing Health Data and the IT Infrastructure for Research into the 21st Century

- Increased availability of electronic health data for research

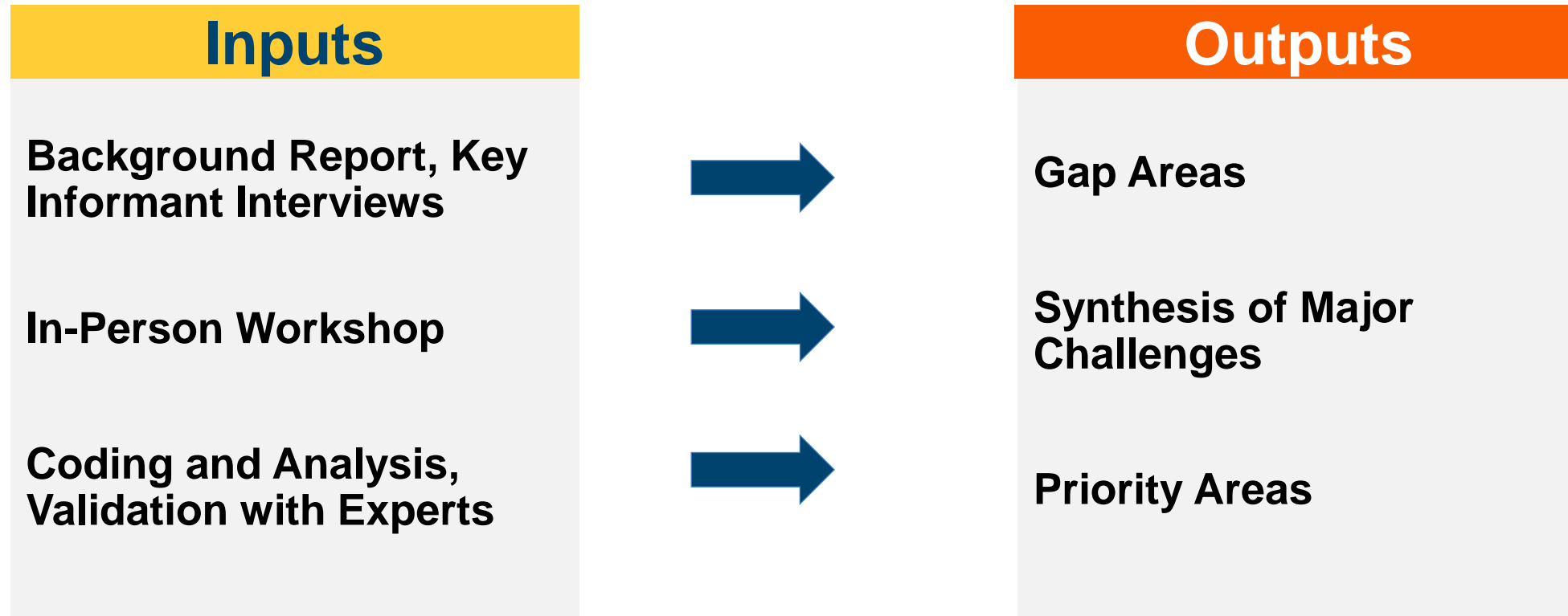- Challenges to leveraging those data and the health IT infrastructure for research remain

National Health Information Technology (IT) Priorities for Research:

A Policy and Development Agenda

https://healthit.gov/research-agenda

Methodology

Inputs		Outputs
Background Report, Key Informant Interviews	➡	**Gap Areas**
In-Person Workshop	➡	**Synthesis of Major Challenges**
Coding and Analysis, Validation with Experts	➡	**Priority Areas**

Health IT Infrastructure Gaps

- Adaptability of the health IT infrastructure

- Ability to produce data for research

- Functionality needed for research

- Data aggregation across multiple platforms

- Advancement of patient engagement in research

- Realizing a transparent and scalable architecture
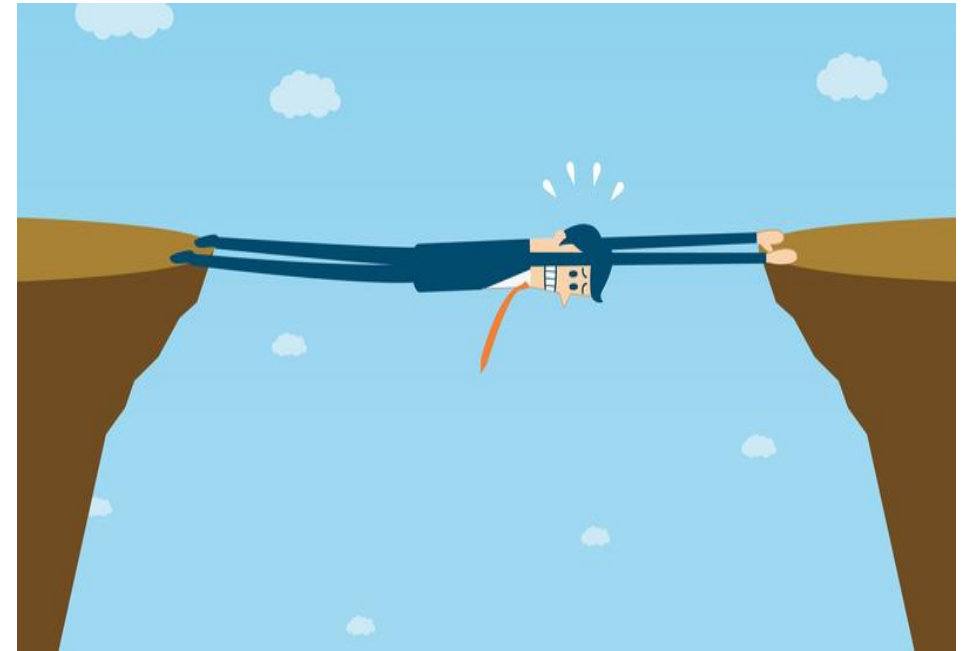
Challenges Identified

- Transparent and interoperable health-related data

- Tools that allow use, interaction with, and sharing of standardized EHR data

- Solutions to enable aggregation across multiple, non-EHR-based data sources

- Functional solutions for patient matching and identity management

- Consent management necessary for data sharing in research

- Research opportunities for those traditionally been underserved or underutilized in research participation

- Opportunities to encourage dialogue and education on the use of the health IT infrastructure for research

The Vision

Health IT infrastructure that supports alignment between the clinical and research ecosystems so research can happen more quickly and effectively.

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Agenda Goals and Associated Priority Areas

Goal 1: Leverage High-Quality Electronic Health Data for Research

- Improve Data Quality at the Point of Capture

- Increase Data Harmonization to Enable Research Uses

- Improve Access to Interoperable Electronic Health Data

Goal 2: Advance a Health IT Infrastructure to Support Research

- Improve Services for Efficient Data Storage and Discovery

- Integrate Emerging Health and Health-Related Data Sources

- Improve Methods and Tools to Support Data Aggregation

- Develop Tools and Functions to Support Research

- Leverage Health IT Systems to Increase Education and Participation

- Accelerate Integration of Knowledge at the Point of Care

Goal 1: Leveraging High-Quality Electronic Health Data for Research

Priority 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

Goal 1: Leveraging High-Quality Electronic Health Data for Research

Priority 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

Goal 1: Leveraging High-Quality Electronic Health Data for Research

🎯 Priority 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

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Goal 2: Advancing a Health IT Infrastructure to Support Research

Priority 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

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Goal 2: Advancing a Health IT Infrastructure to Support Research

Priority 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

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Goal 2: Advancing a Health IT Infrastructure to Support Research

Priority 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

Goal 2: Advancing a Health IT Infrastructure to Support Research

Priority 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 HIPAA-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

Goal 2: Advancing a Health IT Infrastructure to Support Research

Priority 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

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# Goal 2: Advancing a Health IT Infrastructure to Support Research

Priority 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

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Achieving the Agenda's vision would support:

- the pursuit of more complex research questions,

- the development of more rapid and reliable discoveries about health and healthcare to improve outcomes,

- and the engagement of a broader, more representative population in research participation.

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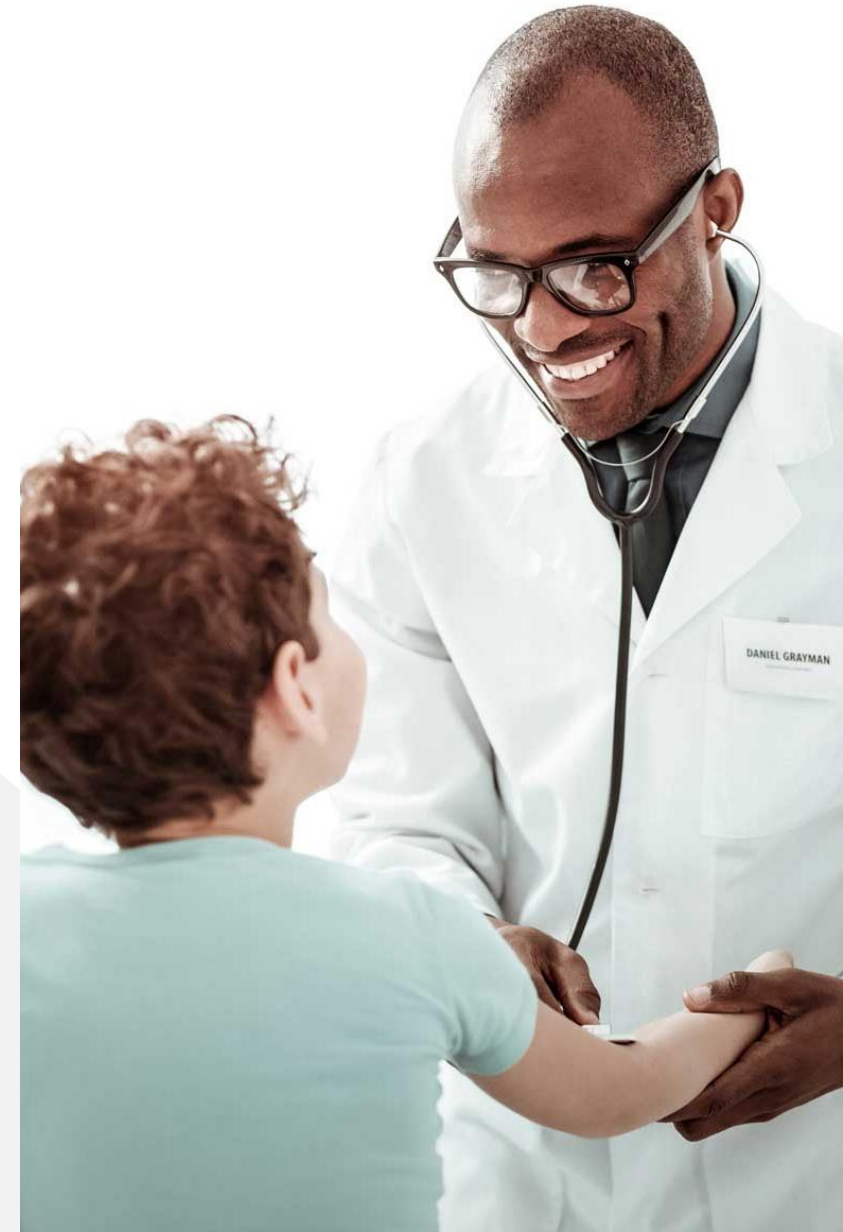
Advancing the Agenda to Address Research Agency Priorities

- ONC's Role

- Alignment between priorities and other agencies' data and infrastructure needs

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Thank you!

For more information visit:

https://healthit.gov/research-agenda

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