



The Office of the National Coordinator for
Health Information Technology

PRECISION MEDICINE FOR EVERYONE

HIMSS Innovation Preconference Symposium | February 19, 2017

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Agenda

- About ONC
- Precision Medicine Overview & Updates
- *All of Us* Research Program
- ONC Activities
 - » Sync for Science (S4S)
 - » S4S Privacy & Security
 - » Sync for Genes (S4Genes)
- Engagement
- Q&A





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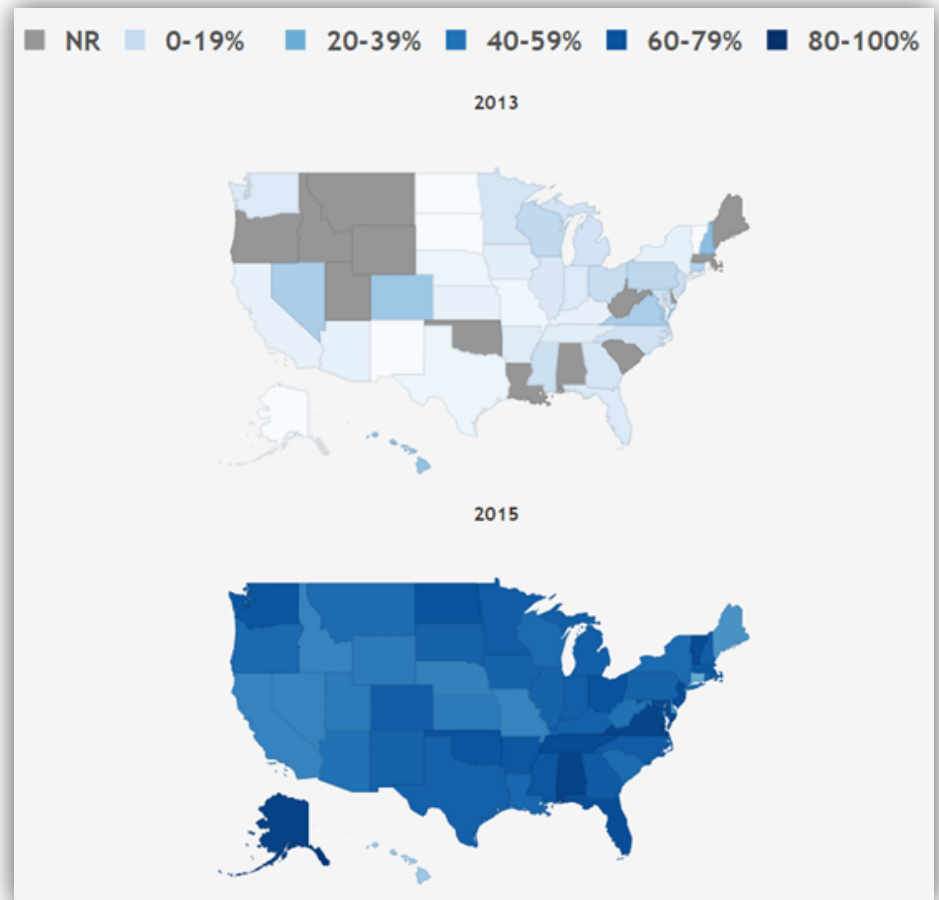
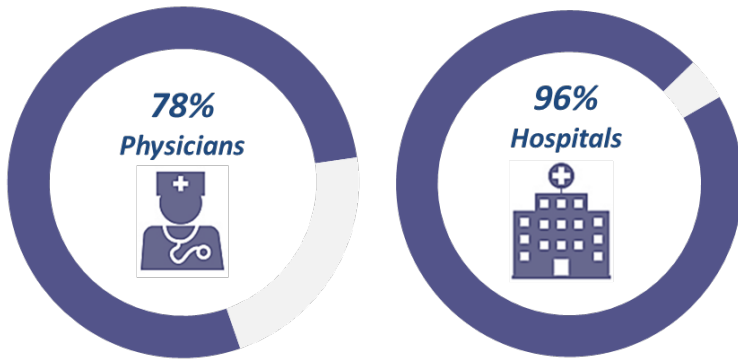
- ✓ Promote the widespread adoption of standardized and certified health IT
- ✓ Facilitate the secure use and exchange of interoperable health information
- ✓ Foster the delivery of safe, high-quality care

Health IT Progress

Patient Engagement

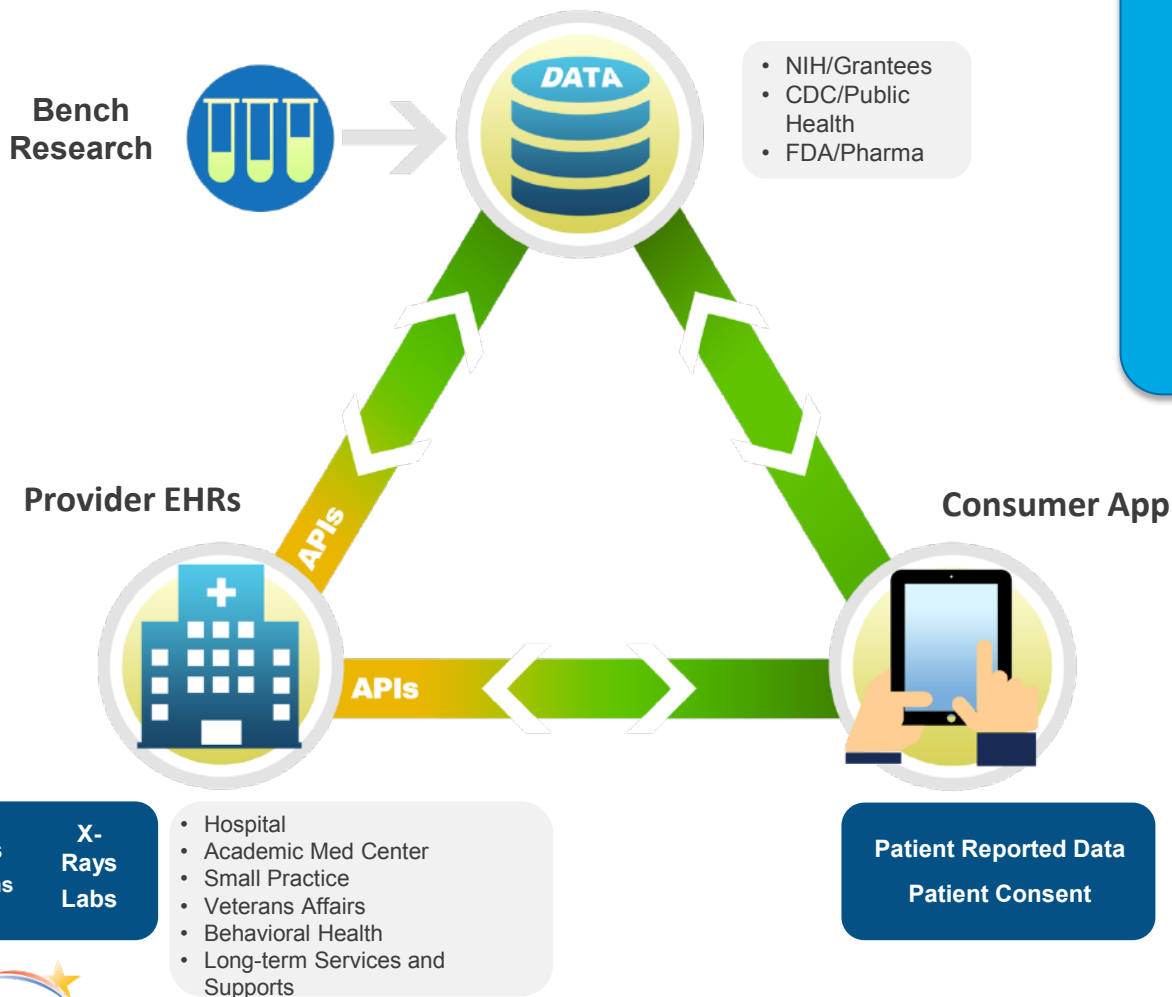
Hospitals that allow patients to view, download, and transmit data

Use of Certified Health IT



Vision for Learning Health Data Ecosystem

Research and Public Health Databases



From Vision to Action

The *Federal Health IT Strategic Plan*, *Shared Nationwide Interoperability Roadmap*, and *Near Term Health IT Strategy* are all designed to advance this overarching vision

What is Precision Medicine?

Precision Medicine Initiative (PMI) mission statement:

To enable a new era of medicine through research, technology, and policies that empower patients, researchers, and providers to work together toward development of individualized care.



- NOT one size fits all
- Gives medical professionals new and enhanced resources
- An **all-of-government** initiative

<https://www.nih.gov/research-training/allofus-research-program>

The *All of Us* Research Program

All of Us will engage a group of **1 million or more** U.S. research participants:



Lay the scientific foundation

Identify new ways to treat and prevent disease



Test whether mobile devices can encourage healthy behaviors

Develop the right drug for the right person at the right dose



<https://www.nih.gov/allofus-research-program>

All of Us Research Program: Updates

\$130 million in funding
in 2016...



...to 10 new projects

21st Century Cures
strengthened provides PMI
with expanded resources



Recruiting participants beginning this year

PMI: What is ONC's role?



Accelerate innovative collaboration around pilots and testing of standards that support health IT interoperability for research



Adopt policies and standards to support privacy and security of cohort participant data



Advance standards that support a participant-driven approach to patient data contribution

In 2016, ONC launched three separate but related projects assisting in making the vision of the *All of Us* Research Program a reality:

» Sync for Science (S4S)

» S4S Privacy and Security

» Sync for Genes

Sync for Science (S4S)

- Launched February 2016 to make it **easy** and **safe** for patients to share EHR data with researchers

TEN DATA TYPES INCLUDE:

- » demographics
- » medications
- » laboratory results
- » problems
- » procedures
- » vitals
- » immunizations
- » smoking
- » allergies
- » documents



- **Expect pilot testing to begin May 2017**

<https://www.healthit.gov/buzz-blog/health-innovation/nih-and-onc-launch-the-sync-for-science-pilot/syncfor.science>

Project Goals

- Evaluate if S4S pilots **implement appropriate privacy and security principles**
- Understand what are the necessary and appropriate **privacy and security safeguards**
- Share **best practices**
- **PMI Security Implementation Guide**

» <http://healthit.gov/pmiguide>



Privacy and Trust Principles

Provide guidance for PMI activities regarding:

- Governance
- Transparency
- Participant empowerment
- Respect for participant preferences
- Data sharing, access, and use
- Data quality and integrity



Sync for Genes

- **Allows for the sharing of genomic data in a consistent and usable way**
- **Five pilot groups testing enhancements to the HL7 Clinical Genomics Workgroup Group suite of standard**
 - » **Pilot Participants to be announced soon!**

www.sync4genes.org

Engagement

- **A set of core values is guiding its development and implementation:**
 - » Participation is open to all
 - » Participants reflect the rich diversity of the U.S.
 - » Participants are partners
 - » Participants have access to their information
 - » Data will be accessed broadly for research purposes
 - » Security and privacy will be of highest importance
 - » The program will be a catalyst for positive change in research
- Visit <https://www.nih.gov/allofus-research-program/announcements> to stay up-to-date on the *All of Us*SM Research Program



Questions?





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