

Health IT Standards Committee

A Public Advisory Body on Health Information Technology to the National Coordinator for Health IT



Precision Medicine Task Force

HITSC Update

August 26, 2015

Leslie Kelly Hall, Co-Chair

Jon White, Co-Chair

Precision Medicine Task Force Membership



Health IT Standards Committee
A Public Advisory Body on Health Information Technology
to the National Coordinator for Health IT

Member	Organization
Co-Chairs	
Leslie Kelly Hall	Healthwise
Jon White	ONC / Agency for Healthcare Research and Quality (AHRQ)
Members	
Mary Barton	National Committee for Quality Assurance (NCQA)
Lisa Gallagher	Healthcare Information and Management Systems Society (HIMSS)
David McCallie, Jr.	Cerner Corporation
Andrey Ostrovsky	Care at Hand
Eric Rose	Intelligent Medical Objects
Andrew Wiesenthal	Deloitte Consulting, LLP
Federal Ex Officio	
James Breeling	Veterans Health Administration (VHA)
Josh Denny	National Institutes of Health (NIH)
Christina Heide	HHS Office for Civil Rights (OCR)
Betsy Humphreys	National Library of Medicine (NLM)
Mitra Rocca	Food and Drug Administration (FDA)
Invited Guests	
Mina Hsiang	United States Digital Service (USDS) / Office of Management and Budget (OMB)
Claudia Williams	White House Office of Science & Technology Policy
ONC Staff	
Maya Uppaluru	ONC – Federal Staff Lead
Debbie Bucci	ONC - Technical Advisor

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 treatments.





To advance data standards that support precision medicine, address relevant privacy policies, and advance innovation, PMI will:

- Work with ONC's Federal Advisory Committee Task Force on PMI to recommend:
 - Existing standards that are ready to use now support PMI
 - Existing standards that may be able to support PMI but require further pilot testing
 - Gaps in available data standards to support PMI
- Recommend standards to support privacy and security of participant data, as well as standards that support a participant-driven approach to data contribution
- Identify opportunities for innovative collaboration around pilots and testing of standards that support health IT interoperability for research



- Identify opportunities for innovative collaboration around pilots and testing of standards that support health IT interoperability for precision medicine
- Recommend existing standards that are currently ready to support PMI
- Identify emerging standards and reference implementations that may require further pilot testing in order to support PMI
- Identify gaps in available data standards related to PMI

Precision Medicine Task Force Workplan

8/19/15



Health IT Standards Committee
A Public Advisory Body on Health Information Technology
to the National Coordinator for Health IT

	Meetings	Task
✓	July 17, 2015 11:00 am - 1:30 pm ET Kick-off Meeting	<ul style="list-style-type: none">• Review charge, work plan• Overview of the Precision Medicine Initiative - White House Office of Science & Technology Policy & National Institutes of Health
✓	Wednesday July 29, 2015 1:30 - 3:00 pm ET	<ul style="list-style-type: none">• Presentations from experts - 23andMe; NIH Precision Medicine Workshop; Institute of Medicine Genomics Roundtable
✓	Wednesday August 5, 2015 12:00 - 1:30 pm ET	<ul style="list-style-type: none">• Presentations from experts - Intel Corporation; Intermountain Healthcare; National Library of Medicine
✓	Wednesday August 19, 2015 12:00 - 1:30 pm ET	<ul style="list-style-type: none">• Presentations from experts<ul style="list-style-type: none">○ Duke Me Tree Project○ eMerge Network○ New York Genome Center○ Sage Bionetworks
	Monday August 31, 2015 12:00 - 1:30 pm ET	<ul style="list-style-type: none">• Develop preliminary recommendations
	Thursday September 10, 2015 1:30 - 3:00 pm ET	<ul style="list-style-type: none">• Finalize recommendations to HITSC
	September 22, 2015 – HITSC Meeting	<ul style="list-style-type: none">• Present final recommendations



Focus

- The exchange of genomic and phenomic data among:
 - Patients/Participants
 - EHRs
 - Researchers
 - Testing labs (for both research and clinical care)

Questions for Presenters

- What is the key problem or set of problems your organization is attempting to solve?
- What is the minimum interoperable data set of genome and phenome data for these data exchanges?
- Are there standards that can support this movement today?
- What gaps are there and what is needed in the future?



- White House Office of Science & Technology Policy and National Institutes of Health
- 23andMe
- IOM Genomics Roundtable
- Intel Corporation
- Intermountain Healthcare
- National Library of Medicine
- Duke
- Sage Bionetworks
- eMERGE
- New York Genome Center



Major challenges and topics:

- Patient access and return of study results
- Electronic consent
- Privacy, security, and de-identification of data
- Minimum set of EHR/clinical data needed to support scientific inquiry
- Representation of genomic and family history data in the EHR for primary care and how to implement clinical decision support, pharmacogenomics
- Use of APIs for patient access and data exchange
- Data storage and transportation



- Hearings are completed, now developing recommendations
- Alignment with NIH ACD Work Group recommendations process
- Initial recommendations will be presented at HITSC meeting on Sept 22
- More detailed recommendations later this winter



Q&A