

Health IT Standards Committee

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



Precision Medicine Initiative Update

Joint Health IT Committee Meeting

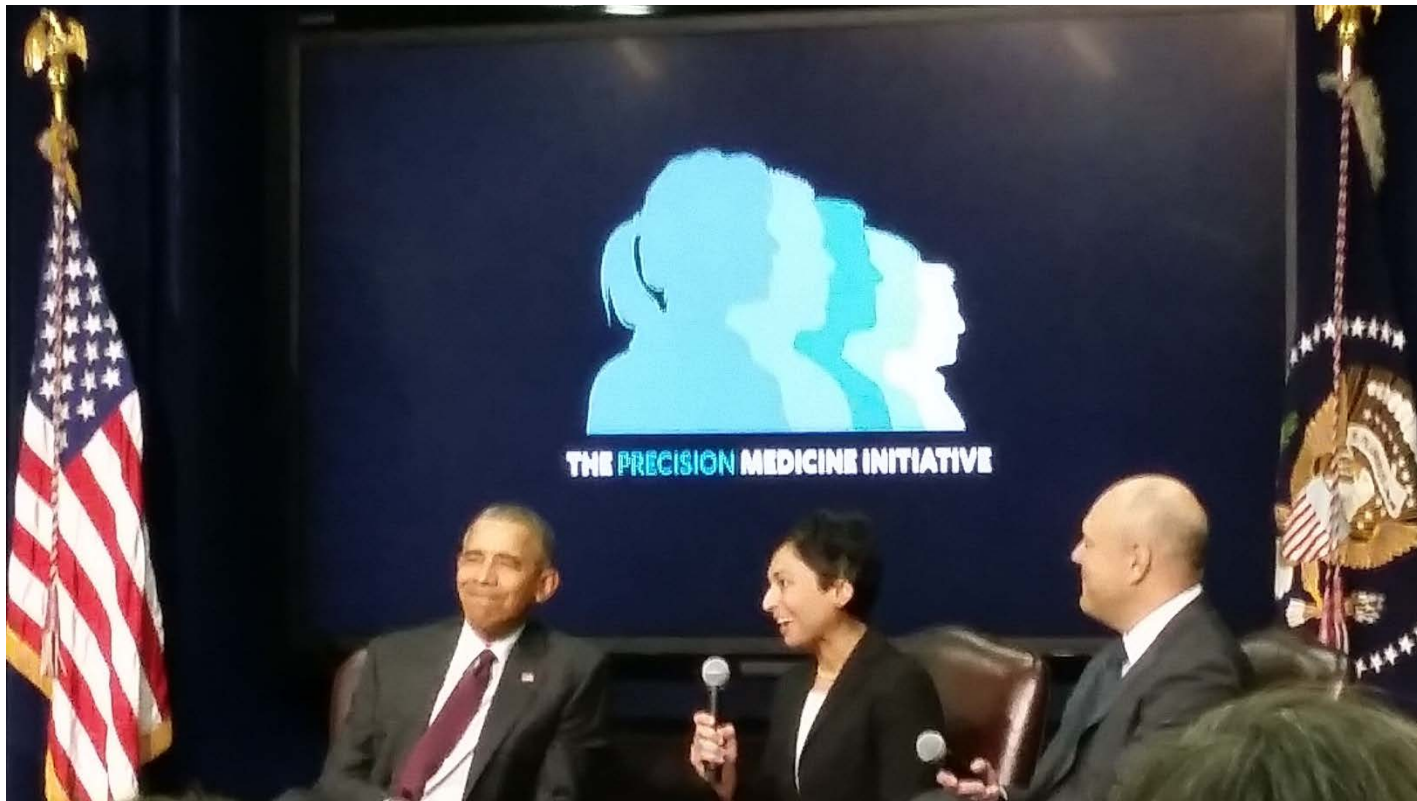
March 10, 2016

P. Jon White, MD, Deputy National Coordinator for Health IT

Precision Medicine Initiative Summit



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



We don't want... data just trapped. So if I... voluntarily I want to join with other people... and donate our data to help accelerate cures, I've got to be able to work with the electronic health record... to make sure that I can do that easily.

-President Barack Obama, Feb. 25, 2016

New Federal Investments and Actions



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

- The National Institutes of Health announces an award to Vanderbilt University in collaboration with Verily (formerly Google Life Sciences) to launch the first phase of the Precision Medicine Initiative Cohort, which will lay the foundation for a national community of 1 million or more U.S. volunteers who will partner with researchers, share data, and engage in research to transform our understanding of health and disease through precision medicine.
- The National Institutes of Health, in collaboration with the Office of the National Coordinator for Health IT, will coordinate “Sync for Science” pilots through an open standards development process with several electronic health record developers. The lessons learned will inform efforts to scale individual data access and donation for precision medicine research, and could be used to support implementation of consumer-mediated data access across the healthcare industry.



- PMI Data Security Policy Principles & Framework:
[https://www.whitehouse.gov/sites/whitehouse.gov/files/documents/PMI Security Principles and Framework FINAL 022516.pdf](https://www.whitehouse.gov/sites/whitehouse.gov/files/documents/PMI_Security_Principles_and_Framework_FINAL_022516.pdf)
 - Public comment form (30 day period):
<https://www.whitehouse.gov/webform/precision-medicine-initiative-draft-data-security-policy-principles-and-framework>
- OCR HIPAA Guidance on fees, third party access
 - Blog: <http://www.hhs.gov/blog/2016/02/25/new-hipaa-guidance-accessing-health-information-fees-copies.html>
 - FAQs: <http://www.hhs.gov/hipaa/for-professionals/privacy/guidance/access/index.html#newlyreleasedfaqs>



- 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



- Will test multiple promising approaches for individual participants to contribute their EHR data to the PMI cohort
 - Will provide data and experience to decide how to extend API-based contribution of data to all or a subset of individually-enrolling participants
 - Furthers administration objectives to support interoperability patient access via APIs
 - Supports ongoing standards development work for FHIR and OAuth 2