

White House Announces Efforts to Accelerate Precision Medicine Initiative

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NEW YORK (GenomeWeb) – The White House unveiled today a series of commitments from dozens of government agencies, academic institutions, and various public and private sector organizations to accelerate President Barack Obama's Precision Medicine Initiative (PMI) and its goal of establishing a large-scale research cohort of individuals across the US.



"Over the course of the last year ... we've seen huge interest from the private sector, from the public sector, from the not-for-profit sector, from the medical community, and researchers," President Obama said today. Now, "a large number of other organizations are joining us in this process.

"There is a whole new set of initiatives that are going to help drive this even faster, and my hope is that this becomes the foundation ... whereby 10 years from now we can look back and say, 'We revolutionized medicine,'" he added.

The PMI was [launched](#) in early 2015 and aims to leverage advances in genomics, informatics, and health information technology to accelerate biomedical discoveries in the hopes of yielding more personalized medical treatments for patients in the US. In December, President Obama [signed](#) into law a budget agreement that earmarked \$200 million specifically for the PMI.

Among the initiative's first goals is the establishment of a voluntary national research cohort of 1 million people or more and obtain sequencing and other biological data for as many of those individuals as possible.

To that end, the White House announced that the National Institutes of Health has selected Vanderbilt University and Verily, a life sciences subsidiary of Alphabet, to oversee a pilot program evaluating the best ways to engage, enroll, and retain participants in the PMI cohort.

"We want to enable any person anywhere in the United States to be able to raise their hand and volunteer to participate," NIH Director Francis Collins said during a press briefing yesterday. "This pilot approach will allow us to learn how to create durable relationships with volunteers."

Collins noted that signing up for the PMI cohort — which is expected to take three to four years to fully assemble — will be possible either through direct enrollment via a dedicated website or phone line, or through participating healthcare provider organizations, including federally qualified health centers.

The NIH has also established a partnership with the Health Resources and Services Administration to explore how it can work with federally qualified health centers on approaches to bring underserved and underrepresented individuals, families, and communities into the PMI cohort, Collins said.

To facilitate the contribution of volunteer data, the NIH is launching a program called Sync for Science, Collins added, which will "pilot the use of open, standardized applications that will give individuals the opportunity to contribute their data to research, including for the PMI cohort."

Sync for Science will include participation by electronic health records firms Allscripts, Athenahealth, Cerner, Drchrono, Epic, and McKesson, which have committed to deploying the applications required for individuals to donate their health data directly to the PMI cohort, he said. Such technologies will enable individuals to "control and manage their data ... coordinate their care among their healthcare providers, and submit their data to researchers if they choose."

To help make the best use of genomic data gathered through the PMI, the US Food and Drug Administration has kicked off the PrecisionFDA challenge, which will use an online portal to encourage

collaboration between scientists to advance quality standards and achieve more consistent and accurate results from next-generation sequencing.

The FDA is also developing a regulatory framework "for reviewing genomic technologies that will take advantage of existing and evolving standards, evidence generated and validated by the scientific community on disease mutations, and crowdsourcing to identify the best analytical tools," Collins said.

Noting the importance of privacy and data security to the PMI, the NIH has established an institutional review board composed of advisors with expertise in mobile health technology, bioinformatics, health disparities, epidemiology, genomics, and environmental health who will provide oversight and review the research conducted in the program.

The Office of the National Coordinator for Health IT, in collaboration with the National Institute of Standards and Technology (NIST), has also committed to developing a precision medicine-specific guide to the [NIST Cybersecurity Framework](#) by the end of the year. The guide will help organizations involved in the PMI maintain a strong security strategy and prioritize participant trust.

Meantime, the White House has released for public comment a set of draft [principles](#) for data security in the PMI cohort. The document was developed through an interagency process that included input from security experts in both the private sector and academia. A final version is expected to be released in the spring.

Among the other government groups pledging support for the PMI is the Department of Veterans Affairs, which is working with the US Department of Defense to expand the Million Veteran Program — a [program](#) studying the link between genes and disease with a voluntary research cohort of more than 450,000 veteran enrollees — to include the enrollment of active duty military.

Other organizations supporting the PMI include Microsoft, which has agreed to hold large, open genomics datasets on its cloud platform at no cost; Stanford Medicine, which this year will launch a consultative pharmacogenomics practice to which physicians can refer patients with unusual drug responses or family histories of such responses; and IBM and the New York Genome Center, which will develop an open cancer data repository that includes analyses by IBM's Watson computer system.

Also participating are Foundation Medicine, which is releasing to the public a large-scale genomics dataset of common and rare pediatric diseases; Color Genomics, which has agreed to double the number of underserved individuals to whom it will offer free breast and ovarian cancer screening; Roche's Genentech, which has agreed to begin sharing summaries from certain clinical trials with study participants; and Intermountain Healthcare and Syapse, which have pledged to provide patients with direct access to their cancer genomic data including clinical data from medical records, tumor genomics, treatments, and outcomes.

The PMI "is an all-hands-on-deck operation," John Holdren, director of the White House Office of Science and Technology Policy, said during the press briefing. "We really need the participation of all of these groups to realize the potential of precision medicine."