

# Survey shows broad support for national precision medicine study

August 17 2016

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In a recent survey designed to measure public attitudes about the Precision Medicine Initiative (PMI) Cohort Program, a majority of respondents expressed willingness to participate in the nationwide research effort. The findings were published online in *PLOS ONE* by a team of National Institutes of Health researchers.

The PMI Cohort Program is a landmark longitudinal research effort that aims to engage 1 million or more U.S. participants to improve our ability to prevent and treat disease based on individual differences in lifestyle, environment and genetics. Participants will be invited to contribute a range of data about themselves via questionnaires, [electronic health records](#) and mobile or wearable devices. They will also undergo a baseline physical evaluation and provide blood and urine samples for analysis. These data, protected by essential privacy and security safeguards, will comprise a valuable national resource for researchers and citizen scientists studying a range of health conditions. NIH anticipates launching the PMI Cohort Program in phases, beginning later this year.

"We are excited about engaging participants in this historic research effort," said Kathy L. Hudson, Ph.D., NIH Deputy Director for Science, Outreach and Policy and a study author. "These [survey results](#) are extremely promising—they show that after people learn about the PMI Cohort Program, they're supportive, and they recognize the value in taking part."

The study authors analyzed responses of 2,601 people, selected randomly from a representative sample of the U.S. population. The survey, offered in English and in Spanish, included questions to gauge public interest in the program and to learn about individuals' preferences concerning data collection, data sharing and involvement in various aspects of the program.

After reading a short description of the PMI Cohort Program, 79 percent of the respondents expressed support for the program, and 54 percent said they would definitely or probably participate if asked. This level of support was fairly constant across racial and ethnic groups as well as other demographic categories.

"The survey findings do not support the idea that people from communities that have historically been understudied in research are not interested in participating in this cohort. In contrast, in each demographic group . . . , at least 1 in 11 people (9 percent) said they would definitely participate if asked, would donate blood, and would take part for at least 10 years," the authors wrote.

Some groups showed a slightly higher or lower interest in participation. Higher percentages of younger people, college-educated people, and those who identified as lesbian, gay, bisexual, or transgender (LGBT) reported a willingness to take part. Those with fewer years of education and those ages 60 and above were less inclined to join.

"These survey results suggest that people from all walks of life will be interested in the cohort program," said Dave Kaufman, Ph.D., lead author and a program director at NIH's National Human Genome Research Institute. "But it may take some more thought and effort to engage older people and those with fewer years of education. These results were helpful in identifying areas where the PMI Cohort Program may want to focus outreach efforts, beyond the communities that have

been historically underrepresented in research."

Other notable findings from the study included the following:

- Respondents expressed high rates of willingness to share many types of personal data, such as blood samples (73 percent), genetic information (76 percent), a family medical history (77 percent), soil and water samples from their home (83 percent) and data on their lifestyle, diet and exercise (84 percent). In contrast, of those with social media accounts, only 43 percent said they would share social media information.
- In considering the value of various incentives for participation, 90 percent of respondents felt it was important to receive information about their health. When asked what types of information they would like, 75 percent wanted lab results (such as cholesterol and blood sugar levels), 75 percent wanted genetic information, 68 percent wanted a copy of their medical records and 60 percent wanted information about other research studies relevant to their health.
- Seventy-six percent of respondents agreed that "research participants and researchers should be equal partners in the study." In particular, respondents felt that it was important for participants to help decide what kinds of research are appropriate, what to do with study results and what research questions to answer.

The authors cautioned against using these initial results to predict specific enrollment figures for the PMI Cohort Program, noting that the people who chose to respond to this survey may view research more favorably than the general population.

They also emphasized that retention would be an important element of the program's success, as well as enrollment.

"To sustain participants' commitment over the long term, researchers must continue working as part of the study communities," said Dr. Kaufman. "Participants offer terrific ideas and insights when researchers earn their trust."

**More information:** *PLOS ONE*, [DOI: 10.1371/journal.pone.0160461](https://doi.org/10.1371/journal.pone.0160461)

Provided by National Institutes of Health

Citation: Survey shows broad support for national precision medicine study (2016, August 17)  
retrieved 9 April 2024 from  
<https://medicalxpress.com/news/2016-08-survey-broad-national-precision-medicine.html>

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