7 ways to expand diversity in precision medicine research

JAN 30, 2020

Sara Berg, MS
Senior News Writer

Ethnic and racial minority populations in the U.S. have a long history of being mistreated by the health care system, researchers and the government. The resulting mistrust can pose a challenge for researchers seeking to understand the biology of complex traits, as well as for physicians interested in delivering personalized care to diverse patients. Diversity in precision medicine research is crucial for understanding genetic differences that shape so many health outcomes and potential treatments.

Learn what physicians and health systems can do to advance precision medicine research and build rapport and trust to increase minority participation in critical research.

Genetics and precision medicine have become increasingly important in effective patient care. Through its partnerships and research, the AMA is advancing the ethical implementation of precision medicine.

About 10% of the world’s population is of European ancestry. However, this population accounts for 78% of genetic study participants. The National Institutes of Health’s All of Us Research Program aims to address this disparity in medical research by enrolling 1 million or more participants to gather data on a wide variety of health conditions.

The AMA has partnered with the All of Us program, which aims to enable a new era of medicine through research, technology, and policies that empower patients, researchers and providers to work together to develop individualized care. This program is intended to gain better insights into the biological, environmental and behavioral influences on disease to enhance prevention and treatment.

The AMA Ed Hub™ module, “All of Us Research Program: Informing the Future of Health Care,” is enduring material and designated by the AMA for a maximum of 0.75 AMA PRA Category 1 Credit™?

Learn more about AMA CME accreditation.
There are currently more than 320,000 *All of Us* participants, with about 250,000 having completed the initial steps of the program. Nationwide, more than 50% of *All of Us* participants are members of racial or ethnic minority groups. And in Illinois, more than 80% are from groups that have traditionally been underrepresented in biomedical research.

Joyce Ho, PhD, is a research assistant professor and lead investigator for the *All of Us* Research Program at Northwestern University Feinberg School of Medicine in Chicago. Ho shared how she and her colleagues in Illinois are engaging a diverse pool of participants, and offered advice for how physicians can help.

**Begin the conversation**

“We’re on track to build a sample of 1 million or more participants in the next five years or so,” said Ho, adding that Illinois has more than 26,000 participants in the *All of Us* program to date. The Illinois Precision Medicine Consortium, which includes the University of Illinois, University of Chicago, Rush University Medical Center, NorthShore University Health System, and Cook County Health, is also in the lead nationally for how diverse their participant pool is.

“The effort that’s needed to reach diverse populations is something that we were prepared to put in,” she said. “We understood just from the history of research in this country—especially with underrepresented populations—that it’s not just, ‘Hey, here’s a consent form, please read it and we know you will participate.’”

Instead, trust must be built through providing honest and accurate answers to patients’ questions about precision medicine, the privacy and security of patients’ data, and more.

“That are all concepts that, regardless of how much you know about biomedical research, or whether you have participated in studies, you deserve a thorough explanation,” said Ho.

Learn how to answer patients’ top five questions about the *All of Us* Research Program.

**View participants as partners**

The actions of past medical researchers have earned much distrust in minority communities, making it crucial to treat these diverse populations as partners.

“Nationally, even at the beginning of designing the *All of Us* Research Program—because we know that we have this goal of building a diverse research database—we made sure that participants are
our partners,” said Ho.

Participants from all walks of life should be included and valued in the design of the program. Everyone plays a major role.

**Collaborate with communities**

The National Institutes of Health and its *All of Us* Research Program partners conducted focus groups to look at “everything from participating in research to concepts about precision medicine and sharing data,” said Ho. “There’s a lot of work ... that we put in to understand how we can really build this resource in a way that includes what different communities want so that we really can benefit the health of people who are living in this country.”

One of the most important ways that *All of Us* Research Program researchers in Illinois have approached this program is in the collaboration of community organizations, health systems and participants. *All of Us* Research Program investigators in Illinois have decades of experience working with diverse communities in biomedical research.

**Go mobile**

Transportation is often a barrier to working with underrepresented communities. It can prevent patients from receiving the health care they need. In Illinois, though, mobile clinical research units have allowed researchers to better reach these communities.

Researchers drive these research vehicles containing exam rooms to different communities to engage people about the program. They also leverage long-standing relationships with area churches, community organizations and clinics to engage community members.

“That breaks down a lot of the barriers with transportation that happens in many of the communities here in Chicago,” said Ho. “It really makes a big difference in terms of being able to reach this community.”

**Don’t rush things**

Engagement is key in creating a diverse community of participants for precision medicine and biomedical research.
“When we go out to talk to folks, we don’t immediately ask people to participate. A lot of times, we just have great conversations with people about biomedical research,” said Ho. “A lot of times we are addressing a potential mistrust that has very reasonably existed in different communities.”

For example, the University of Chicago has developed curriculum aimed at addressing mistrust, biomedical research and importance of research inclusion, especially among the African American community.

“Our teams develop different engagement tools and strategies to reach communities that have been underrepresented in research,” she said, adding that it goes beyond talking to someone for five or 10 minutes before they participate.

Instead, “it is multiple conversations over time, and letting participants know that we aim to return health information back to them and perhaps in the future, they might decide to participate,” said Ho.

And once participants have shared their information, it is important to reiterate that there will be a waiting period.

“One of the challenges is to really explain to participants this is a long-term program and it really takes a lot of time and patience for us to be able to return the value back to you that you deserve,” she said.

Create awareness and trust

“One of the missions of the program is not just building 1 million people and collecting all this data. It’s just to have substantive conversations with people about the importance of inclusion in biomedical research to build awareness,” she said.

By creating awareness around precision medicine and building trust within these communities, it is paving the way for future conversations.

“Even if they’re being approached by another research group, they’ll have a little more trust and understanding about why participation and representation is so important,” said Ho.

Illinois All of Us researchers also have a community participant advisory board that provides feedback on the program. Together they discuss additional ways to engage Illinois communities.

These meetings cover items such as how to “provide clinically relevant information to participants, which is one of the hallmarks of the program,” Ho said. “We’re not just grabbing the data. We’re also planning to return information back to participants.”

URL: https://www.ama-assn.org/delivering-care/precision-medicine/7-ways-expand-diversity-precision-medicine-research

Copyright 1995 - 2021 American Medical Association. All rights reserved.
Emphasize data security

Not only does the program have a 1-million-person database to build, but they need to have an infrastructure that is ready to process the volume of data and biosamples, while also prioritizing data security and privacy.

“Our program spends a lot of resources building as secure of a data system as possible,” said Ho, adding that there is also “a whole pipeline of generating genomic data and clinically relevant data to return to participants.”

“Many people are wondering about the security and privacy of the data, so we need to not just build a very secure system, but be able to explain to people what the risks might be so that people can make an informed decision,” she said.

One way that the All of Us program is building a robust research resource, is to include EHR data from participants. However, it is important for participants and physicians to know that the data is securely shared—all personal identifiable information is removed.

Data collected will be connected to other data types such as self-reported information, which includes health background and behaviors, as well as medical history, physical measurements and data gleaned from biosamples.

“There’s a wide variety of longitudinal data we’re collecting from participants. Through a research data portal that the program is building, researchers will eventually be able to access data and samples to accelerate medical discoveries for diverse populations. That’s powerful,” said Ho.