

US seeking 1 million for massive study of DNA, health habits

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In this Aug. 7, 2017, file photo, Stephanie Richurk, a nurse at the University of Pittsburgh Medical Center, sorts blood samples collected from participants in the "All of Us" research program in Pittsburgh. The National Institutes of Health announced on Tuesday, May 1, 2018, that it will open nationwide enrollment and is seeking 1 million volunteers to share their DNA and medical records. (AP Photo/Dake Kang, File)

Wanted: A million people willing to share their DNA and 10 years of



health habits, big and small, for science.

On Sunday, the U.S. government will open nationwide enrollment for an ambitious experiment: If they can build a large enough database comparing the genetics, lifestyles and environments of people from all walks of life, researchers hope to learn why some escape illness and others don't, and better customize ways to prevent and treat disease.

"A national adventure that is going to transform medical care," is how Dr. Francis Collins, director of the National Institutes of Health, describes his agency's All of Us Research Program.

Congress has authorized \$1.45 billion over 10 years for the project. It all hinges on whether enough people around the country will sign up, either online or through participating health centers.

There's already interest: More than 25,000 people got early entry to the project over the past year through an invitation-only pilot test run by participating universities and health providers.

WHY STUDY SO MANY?

Most of today's medical care is based on what happened to the average person in short studies of a few hundred or thousand patients with a specific health condition.

And most people who volunteer for those studies are white, leaving questions about the best care for people of different races.

"One-size-fits-all is far from an optimal strategy," Collins said Tuesday in announcing enrollment for All of Us.

The project involves "precision medicine," using traits that make us



unique to forecast and treat disease. Learning enough to individualize care requires studying a massive number of participants: The healthy and not-so-healthy, young and old, rural and urban, blue-collar and whitecollar—and people of all races and ethnicities.

For now, participants must be at least 18. Next year, the study will open to children, too.

While there are other big "biobanks" of genetic data from at least 100,000 people, the NIH project aims to be the largest and most diverse of its kind. At least half of the participants must be from groups traditionally under-represented in medical research, Collins stressed.

GENES AREN'T THE WHOLE STORY

Sure, what genes you harbor can raise your risk for various diseases. But other factors can increase or reduce some genetic risks.

So first volunteers will share electronic health records and blood samples, and answer periodic questionnaires about their diet, sleep, environmental exposures and other lifestyle factors. They might wear fitness trackers and other sensors.

And later this year they'll start undergoing genetic testing, initially to look for so-called "variants" in DNA that affect disease risk, similar to what some private companies now sell, Collins said. Fully mapping the genetic code is too pricey now for a million people, but that more comprehensive approach eventually will be used with some participants, too.

Among the first lessons Collins hopes to learn is about resilience: Why do some people stay healthy despite smoking or pollution or poor nutrition?



"We have no idea how those people escape those odds," he said.

LEARN YOUR RESULTS

Unlike with most medical studies, participants can choose to see their own test results and share them with their physician long before the study reaches any big-picture conclusions. A caution: There are still many questions about how best to use the results of genetic tests. Still, "we will try to help their doctors sort through what it means," Collins said.

One result that might bring a quick benefit: Genetic variants can signal who is prone to side effects from more than 100 drugs, information that could be used to prescribe a safer drug if only their doctors knew, Collins added.

PROTECTING PRIVACY

The privacy of DNA databases made headlines last week when investigators used a free genealogy website to track down a suspected California serial killer. That's pretty different than the security under which medical DNA must be handled.

NIH said it has taken as many steps as possible to safeguard against would-be hackers. Volunteers' medical data is stripped of identifying information and replaced with a code. Only scientists meeting specific security requirements will be cleared to study the data. NIH also said federal "certificates of confidentiality" prohibit disclosure to law enforcement.

Privacy wasn't a worry for Michelle McNeely, 41, an early participant at Dallas' Baylor Scot & White Health System. She underwent breast cancer treatment in 2016 and considers taking part in All of Us a way to



give back.

"If they can use my genes and someone's genes in California and someone's genes in New York to find some common ground, to help discover some cure—they can use my genes all day long," McNeely said.

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