



Nurse Angela Richard, left, draws blood from Chum Prom of Rhode Island for the All of Us research project, an initiative to build a database for researchers to study. JONNY WILLIAMS/THE PROVIDENCE JOURNAL

Building a diverse DNA database relies on trust

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PROVIDENCE, Rhode Island – Chum Prom, a Cambodian immigrant who has lived in Rhode Island since 1996, didn't even wince when nurse Angela Richard slid a needle into her right arm.

A mother of eight, Prom has likely had her fair share of encounters with needles. But this was the first time she was getting blood drawn for a DNA test.

It wasn't curiosity about her ancestry that drove her to do it. For that matter, she could have turned to the many online services that offer DNA testing. In fact, the reason behind her decision sat right next to her: her youngest son.

She said she did it to help “find the right medicine to cure the next generation.”

Prom is one of more than 880 Rhode Islanders who have signed up to participate in the All of Us Research Program, an initiative of the National Institutes of Health to build a sprawling database for researchers to study.

It's a monumental effort – with 817,000 participants across the U.S. so far – that began in May 2018. The goal, said Brave de la Cruz, a tour manager for NIH's mobile All of Us initiative, is to build a databank that is representative of the country's diverse population.

The executive director of the National LGBT Cancer Network and an adviser to the All of Us initiative, who uses the mononym Scout, said research has often overlooked minorities. Historically, research has skewed toward white men and overlooked women, LGBTQ+ people, and racial and other minorities.

“This is the exact type of research that particularly underrepresented populations have always wanted,” Scout said of the All of Us initiative.

Minnkyong Lee, deputy chief engagement officer for All of Us, stressed the importance of having diversity in the data that is gathered for research.

“If people who look like you are not included, then the outcomes from that data set ... won't really benefit directly and go back to your communities,” Lee said.

A problem that has resulted from the lack of research diversity is mistrust of science, stemming as far back as the infamous Tuskegee syphilis study, where researchers observed Black men who were ill with the disease without offering treatment, although it had become widely available.

To overcome this legacy, All of Us is partnering with trusted community organizations. Recently, its mobile unit visited the Center for Southeast Asians in Providence, where volunteers and staff walked participants through the registration process and took blood, saliva and urine samples.

“Research should move at the speed of trust,” Lee said, emphasizing the importance of partnering with local trusted community-based groups.

Most of the benefits of participating in the research program are likely to be seen in the long term – perhaps in the form of new treatments designed for specific population groups or better understanding of how disease works among particular communities.

Lee said that with nearly a quarter of a million whole genome sequences, the All of Us databank is the largest genomic dataset in existence, though not all of the research is genome-based.