TTS IMPACT

Driving health breakthroughs through diverse and accessible data

The National Institutes of Health (NIH) partnered with GSA's Federal Acquisition Services (FAS) Presidential Innovation Fellows (PIF) program within Technology Transformation Services (TTS) to develop a platform for diverse and accessible biomedical research data.

NIH'S STORY

The NIH *All of Us* Research Program works to advance individualized health care by enrolling one million or more participants to contribute their health data over many years. The program aims to reflect the diversity of the United States by including participants from groups that have been underrepresented in health research in the past, such as ethnic, rural, low socio-economic and gender and sexual minorities. By making this health data accessible to an equally diverse community of researchers via the *All of Us* Researcher Workbench in a beta "public preview" phase, this approach reflects the program's iterative and inclusive design. Sharing this data early and often allows NIH to collect useful feedback to help make the *All of Us* resource more valuable over time.

THE CHALLENGE

Enrolling and retaining participants is a challenge for longitudinal studies, and *All of Us*'s commitment to include previously underrepresented populations requires innovative approaches to build trust in the program and encourage long-term engagement.

While the *All of Us* Research Program has a clear value proposition for the research and scientific community, it needed just as compelling a value proposition for participants. Without a clear reason to enroll, it would be difficult to create lasting partnerships with participants.

KEY SHIFTS

Waiting for "perfect" → sharing early and often

Everything should be data-driven, from communications to the data platform itself

THE SOLUTION

To find a solution, NIH and TTS focused on human-centered design and data-driven communications and product strategy. Presidential Innovation Fellows (PIFs)—experts in bioinformatics, health data, and health innovation—worked with program leadership and *All of Us* consortium partners nationwide—across data, science, and communications disciplines. They developed data-driven national and regional campaign strategies to enroll the public in the *All of Us* Research Program. PIFs provided valuable program support from end to end—from giving input on nationwide communications strategy to data platform development.

Together, NIH and a PIF conducted an audit of the paid media strategy, which resulted in defining and establishing an industry benchmark that could be measured against. The audit established and measured the appropriate key performance indicators (KPIs) that provided the most information about what ads were or were not performing well and established a regular reporting mechanism.

Since the beginning, digital health technologies (DHT) have been envisioned as key sources of real-time data to integrate into the program. The program developed a "bring your own device" pilot for collecting Fitbit data from participants' devices, and PIFs have been integral to the data aspects of this effort. Recently, Apple HealthKit has been integrated, with additional DHTs planned for the future.

Additionally, PIFs worked with the Chief Medical and Scientific Officer to give feedback on the tools necessary for researchers to study the data from *All of Us* participants. With support from the *All of Us* Data and Research Center at Vanderbilt University Medical Center, researchers then began testing the initial dataset and tools in demonstration studies and conveyed the learnings to NIH about what's working and what can be improved. This culminated in the recent beta launch of the *All of Us Researcher Workbench*, which offers approved researchers access to this initial set of data and tools for analysis.

Collectively, these efforts have underscored that precision medicine research requires meticulous communications to drive awareness, trust, and engagement. In addition, *All of Us* found that, through pilots and frequent opportunities for users to share feedback, it can promote an iterative approach to platform development for biomedical research.

THE IMPACT

Currently, *All of Us* has over 270,000 participants who have completed the initial steps of the program, 80% of whom are from underrepresented backgrounds. Additionally, the *All of Us* Researcher Workbench is now live for beta testing. This data platform can help bioinformaticians and other medical/health researchers conduct studies that address health disparities affecting underrepresented populations, answering some of the hardest health questions. The program allows collecting and analyzing diverse health data to be easy and accessible.

By integrating innovation and multidomain experts, *All of Us* has launched a more robust and cross-disciplinary user-based platform. Ultimately, *All of Us* expects to provide the research community with the largest collection of genomic structural variation data, clinical data, and wearables data ever produced.

NIH is continuing to test and iterate the Researcher Workbench nationwide, expanding to worldwide access in the future. Overall, the goal is to enroll one million participants in the *All of Us* program.

DATA POINTS

270K+
participants, 80% from underrepresented backgrounds

WORK WITH US | Contact Rebecca McBride at tts-info@gsa.gov

FOCUS AREAS   Identity   Artificial Intelligence   Accelerator   Experience   Cloud   Data