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Insights of Precision Medicine Initiative's All of Us Research Program in Mississippi

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Insights of Precision Medicine Initiative's "All of Us Research Program" in Mississippi

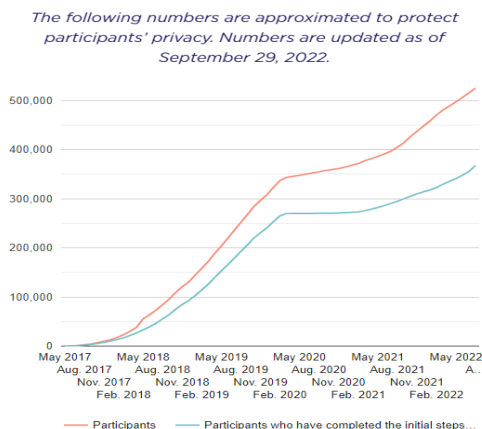
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Background

The *All of Us* Research Program finds its roots within former President Obama's precision medicine initiatives, namely the CURES ACT, which was passed in 2016. The motivation behind this unprecedented health initiative was to finally devote resources dedicated to ending diseases such as cancer and Alzheimer's, while also ending opioid addiction, and giving researchers the tools, they need to do it. "Bringing doctors and data together" was one of President Obama's identifiable pathways to better treatment for all Americans – treatment that works specifically for the individual (obamawhitehouse.archives.org, 2016). The *All of Us* Research Program is sponsored by the National Institutes of Health (NIH) and aims to enroll at least 1 million participants nationwide during the 10-year study. This program launched in May 2017 with a recruitment model that is based on patient sourcing at Academic Health Institutions and partnerships with community health organizations. This program uniquely returns data to the participants at intervals during their participation, and it also houses data available to researchers in a cloud-based environment (Ramirez, et al, 2022). Not only does this enhance the participant experience by giving participants health information, but it also provides a rich research environment and allows for collaborative research theories to develop through its multi-dimensional functionality. The *All of Us* Research Program came to Mississippi through its relationship with the University of Alabama-at Birmingham (UAB). As the primary awardee for the Southern Consortium of the national *All of Us* Program, UAB oversees the planning and implementation of the research programs across several southern academic medical centers. The University of Mississippi Medical Center (UMMC) has been a sub-awardee of the program since 2018 and is the only healthcare provider organization in the state offering *All of Us* participation. UMMC has enrolled 2,122 participants to date with a goal to enroll at least 640 more by the end of June 2023. Below are the national numbers of enrollment since the program's inception in 2017.

Figure 1

Growth of *All of Us* participants nationwide since the launch of the program in 2017



Note: Taken from www.researchallofus.org/data-tools/data-snapshots/. Copyright 2022 by the National Institutes of Health: All of Us Research Program.

The Enrollment and Retention Process

Recruitment in Mississippi involves a dynamic approach to community engagement. Mississippi's predominantly rural landscape requires that a population study is one brought to the people, even if the hub of *All of Us* recruitment is located on the campus of UMMC in Jackson. The UMMC *All of Us* team faces the challenge of reaching the population with limited resources, but partnerships with community organizations and other non-profits have provided an avenue to reach those areas of the state where health information and resources are often scarce. The *All of Us* enrollment process requires three separate consents and several more surveys prior to biospecimen collection. While it is an all-digital process, it can seem overwhelming for a first interaction, and many are hesitant to commit to the time it takes to complete.

Opportunities for Partnership

Mississippi *All of Us* has found that success lies in creating a dialogue with interested participants about the study, prior to offering the complete enrollment opportunity. Education about the history of the program, advantages to the participant in the form of health reports, and emphasis on the partnership between participants and the program are critical to participant-to-enrollee conversion. Scheduling educational presentations are an opportunity to share all key information, allow for questions, and build trust and relationship with the community. Providing the educational information to a captive audience or at a public community event, then returning to offer full enrollment, is a predictable model that yields enrollment. Having a presence at community events aimed at wellness and health also plays a pivotal role in engaging with potential participants and creating awareness of the program. Building relationships with local partners, particularly non-profits and healthcare facilities, is critical in rural areas, considering over half of the state's population are rural residents (ruralhealthinformation.org, 2022). Beyond the digital completion of the consents and surveys, biospecimen collection is a requirement of the study. *All of Us* Mississippi team has two locations with which to conduct these visits: UMMC Rehab Building on the UMMC Campus and the Jackson Medical Mall. These options are convenient for those in the immediate area, but the team actively seeks

locations around the state to provide on-site collection events, as well. Even interested participants who are located near Jackson and surrounding cities prefer this option since it is much more convenient for participation. *All of Us* emphasizes the partnership of the program by facilitating consistent communication with its participants over the life of the study. Participants are encouraged to complete any new surveys released through email notifications. *All of Us* recruitment teams use participant-provided information to track multi-modal communications with their enrolled participants. Participants are notified by email, or through push notifications on their app, when test results are ready for them to view. If results are more urgent and require phone communication, the national program will alert the participant through sensitive messaging that arranges for direct communication. Genetic resources are also available to participants at no charge following such notification.

Enrollment barriers, as with any population study, hinder the study's proliferation. Research mistrust and misinformation continue to influence the public's conceptualization of health research. Mississippi *All of Us* faces these issues often when encouraging participation. There is a hesitancy to provide samples, as well as privacy misconceptions concerning access to the Electronic Health Record (EHR), which is one of the essential consents for involvement in the program. While this information is vital to the research in terms of understanding the links in clinical data, the public is not intrinsically trustful of the process, and some do refuse consent. The *All of Us* team recognizes this gap in understanding, even anticipating the responses to all of these concerns. Education, along with relationship-building that bears trust, are the keys to reaching a skeptical public. Connecting with local organizations that already have established relationships with the community is critical to broadening awareness of the program. *All of Us* is a unique program when compared to other population surveys as it frames the enrollment as a participating partner experience. This is a longitudinal cohort study with the intention of tracking participants, along with their EHR as long as the study continues. In an effort to maintain these research "relationships", members of the *All of Us* team contact participants on a regular basis to stay connected and offer new opportunities to complete data surveys as they are released by the national program. This process is known as active retention and is a benchmark metric by which enrollment sites are measured. Passive retention refers to the collection of EHR data including billing, procedural, diagnostic codes and medication data that will ultimately connect to other data such as healthcare claims, environmental data, and national death indexes (Ramirez, et al, 2022). This unprecedented approach to data collecting requires extensive resources. Each enrollment site must allocate significant periods of time to this aspect of the program to sustain retention efforts.

All of Us in Mississippi find this component of the program to be one of the most challenging to achieve. Participants provide contact information at the time of enrollment, which invariably changes, leading to disconnected phones or email accounts. The research team has found it challenging, even with the addition of proxy information that is also provided by the participant, to adequately track all participants. Some participants simply do not care to participate in any further studies after their initial enrollment. Although participants agree at the moment of enrollment to be contacted later, it is inevitable that people reconsider, and at some point, will no longer be amenable to engaging in further communication. While teams are trained to build a trustworthy relationship with participants to set the tone for future opportunities, this is one of

the most common challenges. For this reason, it is important for teams to strategize continually regarding innovative ways to reach their participants to strengthen participation.

Conclusion

A population study of this kind is an unprecedented charge for the NIH. The promises it holds for the future of medicine, however, are unimaginable. Through the data of one million people across the United States, this diverse data set will undoubtedly allow for the advancement of biomedical research in an unprecedented time frame. Together with the use of genomic analysis, this study can provide what other population studies have previously been unable to do—identify improved, individualized therapies using this extensive database of populations with various ancestries. *All of Us* holds promises for precision medicine that could not have been actualized until now. Understanding the human gene, along with technology that can connect health data and bring it to researchers, is an innovative approach to health research, offering solutions to individualized care.

The benefits of the program are innumerable, but it does face challenges. Mississippians are undoubtedly some of the most hospitable in the nation, but when it comes to a topic such as research, they are less likely to be so acquiescent. It is incumbent upon the research team to facilitate a transparent, educational opportunity for our state's population, with an emphasis on their participation's contribution to the overall research goals. Populational studies require a unique approach to communities that rests on several foundational principles: education, trust, and humanitarianism.

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