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Disparities in Response to the All of Us Research Program COVID-19 Participant Experience (COPE) Survey

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Commentary

Background

The "All of Us Research Program" (AoURP), launched by the National Institutes of Health (NIH), is a nationwide initiative that aims to build one of the most diverse and comprehensive biobanks in history. The program prioritizes recruiting individuals from underrepresented biomedical research populations, defined as those with limited access to healthcare, lower income, less education, or living in rural areas. By collecting data from over one million volunteers from all population groups, the program seeks to accelerate medical research breakthroughs and enable personalized prevention, treatment, and care. Designed as a longitudinal cohort study, AoURP collects several types of data, including survey responses, electronic health records, surveys, biological samples such as blood and urine, and DNA and other genomics data, and supports subsequent analyses of the data by broad researchers through the All of Us Research Hub [1]. This initiative is exceptionally ambitious in its pursuit of diverse and widespread data that can be applied across various populations so that the data it collected is geographically, medically, and demographically diverse. As of 2024, the project has enrolled over 800,000 participants, with 80% of them from underrepresented communities in biomedical research and 570,000 fully enrolled (*All of Us Website)*. The program's database continues to grow slowly, getting close to its one-million goal, and providing critical insights into health disparities and personalized care.

Toward a More Representative AoURP

However, human variability presents inherent challenges in achieving universally applicable results. Many research articles surrounding the All of Us project have reported representation gaps, racial and demographic disparities in participating populations, external influences like COVID-19, and barriers to healthcare access [2-4]. For instance, some papers highlight how certain minority groups remain underrepresented despite major efforts of AoURP to ensure inclusivity [5], while others emphasize the importance of improving data accuracy and completeness across different regions [6].

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The coronavirus disease 2019 (COVID-19) pandemic, caused by severe acute respiratory syndrome coronavirus 2 (SARS-CoV-2), emerging in December 2019, led to lockdowns in the United States on March 15, 2020, to prevent further spread of the pandemic, which continued for several months to a year depending on the states, regions, occupations, and other factors. To investigate how COVID-19 leads to different pandemic experiences and health impacts in diverse populations over time, the AoURP took advantage of its database of over 400,000 participants at the time and rapidly developed and executed a series of six longitudinal COVID-19 Participant Experience (COPE) surveys, spanning from May 2020 to March 2021, collecting data on participant's health, anxiety, well-being, loneliness, physical activity, and so on.

A study recently reported the design and implementation of the COPE surveys [7]. The COPE surveys were open to every AoURP participant who had completed the consent process and the baseline "Basics" survey. While AoURP does not yet include participants under 18, it has high representation across various demographics, including those with disabilities and healthcare access challenges. The COPE surveys underwent six iterations between May 2020 and March 2021. Over time, the surveys were simplified to enhance participant engagement and reduce response burden. Initial surveys featured over 100 questions, while later versions shortened the content to 27 core items, focusing on health, mental well-being, and social support. Updates reflected participant feedback and pandemic developments while maintaining scientific integrity. Participants were invited to complete the surveys via automated emails, text messages, in-portal notifications, and push alerts, with reminders sent every 6-13 days. Communications included images, testimonials, and direct links to the surveys, enabling completion without requiring login credentials- a low barrier of entry. Later surveys introduced phone-based options with trained staff to increase accessibility for those without digital access [7]. These tailored strategies aimed to improve survey completion rates and inclusivity.

AoURP Survey Completion Rates by Population Groups

In the study, the authors reported that the survey completion rates varied significantly across age groups (Figure 1A) [7]. Completion rates steadily increased with age, peaking among participants aged 66-75, while younger adults (18-25 years) completed surveys at much lower rates. This trend may reflect differences in health priorities, with older participants potentially valuing health more or feeling a greater sense of public health responsibility. Conversely, the sharp decline in completion rates for participants aged 76-85 and 86+ could be attributed to age-related challenges, such as cognitive or health limitations, or difficulties with technology.

It was also found that educational attainment influenced survey completion (Figure 1B). Participants with a college degree or higher were more likely to complete the surveys than those with a high school diploma or less, potentially reflecting greater comfort with survey participation or increased awareness of public health research. During the pandemic crisis, interestingly, participants with higher educational attainment appeared to be the most disrupted, demonstrating a bigger drop in completion rates, the cause of which requires further analyses of the COPE survey data.

Survey completion rates also varied notably across income groups (Figure 1C). Lower-income participants (< $10,000) consistently exhibited lower completion rates compared to higher-income groups (> $150,000 and ≥ $200,000). Participants earning $150,000 or more were among the most likely to respond throughout the survey period, surpassing those earning more than $200,000 who might have been too busy at work to fill out surveys. This trend underscores structural inequities that may limit survey accessibility for lower-income populations. The trends suggest that higher-income individuals might have greater access to resources or motivation to complete the surveys.

Not surprisingly, racial disparities were evident in completion rates (Figure 1D). White participants, in general, had higher completion rates compared with minority groups, such as African Americans and Asians. Structural barriers, including digital access, cultural differences, or social norms in survey engagement, may have contributed to these disparities. However, we noticed significant differences among the 3 Hispanic, Latino, or Spanish (HLS) subgroups. Hispanic, Latino, or Spanish (HLS) & non-white participants responded much more than HLS & White and HLS-only participants. Yet, due to the lack of clear definitions of the HLS subgroups in the original paper, further interpretation was not possible [7].

Across all demographic groups, there was a drastic drop in the survey completion rate in the June 2020 survey. This decline was likely attributable to pandemic-induced stress, economic uncertainties, and limited digital engagement due to shifting priorities. Federal shutdowns and social distancing measures may have also impeded communication efforts with participants. Despite these challenges, the program observed an overall increase in completion rates by February 2021, suggesting adaptive strategies and participant resilience. It is also possible that the changes in survey structure during the latter half of the year proved to be effective in increasing completion rates.

Comparisons

The disparities observed in the COPE surveys, such as lower response rates among younger adults, lower-income groups, and racial minorities, parallel the underrepresentation of rural populations in the AoURP dataset. Both studies highlight systemic barriers to participation, whether through digital access issues, as seen with rural participants, or structural inequities like income and education levels that affected COPE survey completion. Interestingly, while rural participants in AoURP reported worse health outcomes, such as higher rates of chronic conditions, their health priorities may differ from those of urban populations, potentially mirroring the lower survey

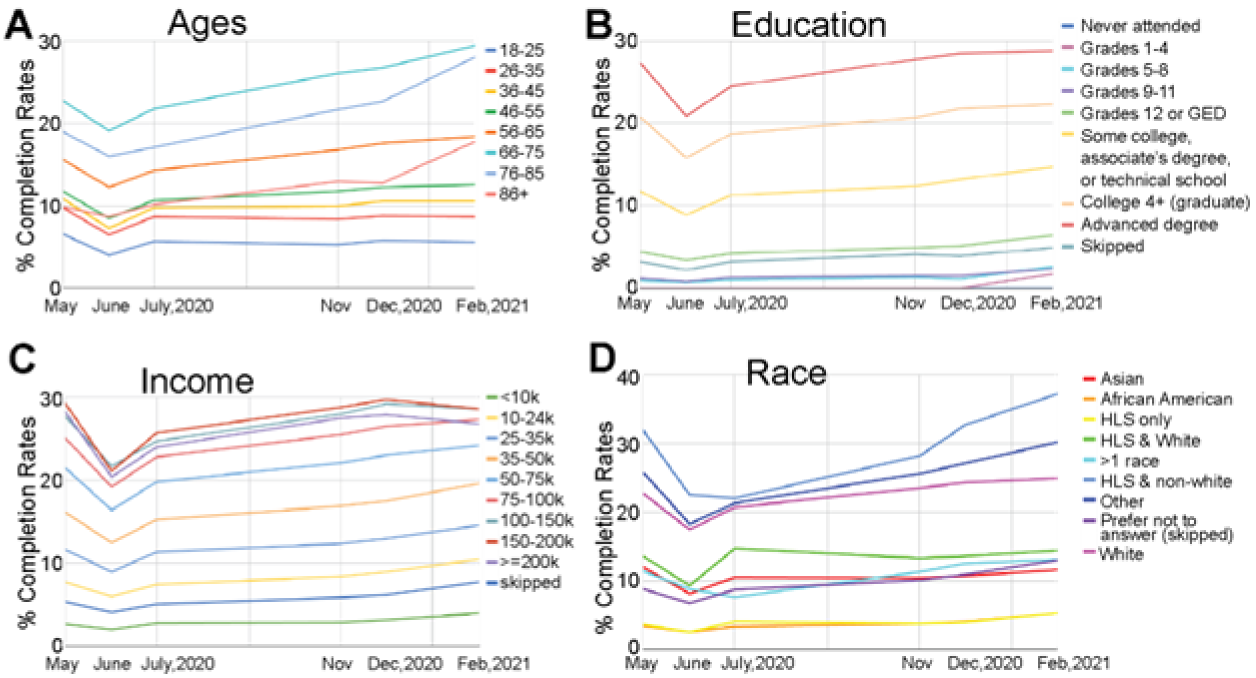

Figure 1. Reanalysis of the COPE Survey Completion Rates over time in May, June, July, November, and December 2020 and February 2021 Surveys, according to participant demographic characteristics, such as age (**A**), education (**B**), income (**C**), and race (**D**) [7].

engagement among younger, healthier individuals in COPE. These parallels suggest that the program faces common challenges in engaging diverse groups, whether due to geographic isolation, socioeconomic status, or demographic characteristics and underscores the need for adaptive strategies that account for the various barriers faced by each group.

A valuable perspective is offered in the study on demographic differences in willingness to share electronic health records (EHRs) within the AoURP, which provides insights that complement findings from the COPE surveys. While the COPE surveys emphasized disparities in survey completion across age, income, and race, the study on EHR data sharing pinpointed a higher likelihood of younger, female, and more educated participants declining access [4]. Interestingly, while racial minorities were underrepresented in the COPE survey responses, race and ethnicity were not significantly linked to decisions about EHR sharing. These findings suggest that while socioeconomic and technological factors impact both survey participation and data sharing, concerns about privacy and trust may disproportionately affect willingness to share sensitive information, such as electronic health records or survey completion rates. It is an interesting perspective in understanding the nuances of human behavior, showing how trust, privacy concerns, and demographic factors all influence decisions about sharing sensitive information, whether in surveys or electronic health records.

Conclusion

In summary, this study demonstrated the successful longitudinal recruitment of a large number of diverse participants to the COPE survey in a very short time, empowered by the All of Us Research Program, its infrastructure, and databases. Despite the disparity of response rates across demographic groups, the data collected in the COPE surveys will enable researchers to investigate how the pandemic differentially affects diverse populations and their health status across the United States. Additionally, the findings highlight the need for future research aimed at improving response rates among underrepresented groups, ensuring the All of Us Research Program achieves its goals of diversity and inclusivity in research.

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