Advancing Gender Equity in Health Research Through Innovative Engagement and Inclusion: The All of Us Research Program

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INTRODUCTION

• The All of Us Research Program is a longitudinal study seeking to engage one million or more participants across different ages, racial and ethnic identities, and regions of the country.
• All of Us has invested in intentional engagement with participant and researcher communities to ensure diversity in gender identity, sexual orientation, socioeconomic status, education, and health status with the aim to address health inequities including those regarding gender.
• The All of Us dataset, which includes more than 80% populations underrepresented in biomedical research (UBR), is available through the All of Us Researcher Workbench. It provides unprecedented opportunities for a wide range of studies to understand how biological, behavioral, and environmental factors influence health and a broad range of diseases and conditions.

METHODS

• All of Us works with a network of Community Engagement Partners to foster trusted relationships and mitigate the lack of inclusion of women and gender minorities in research.
• Our engagement partners conduct a wide range of activities, including engaging and facilitating enrollment and retention of UBR communities and contributing to the body of knowledge supporting the science of community engagement.
• Participants respond to surveys spanning a variety of topics, including demographics, lifestyle, health history, and social determinants of health, and may be asked to provide samples of blood, urine, and/or saliva for lab and DNA tests.
• Partners also engage researchers from diverse backgrounds to utilize this diverse array of All of Us data.

Figure 1. All of Us Researcher Engagement Partners

CONCLUSION

• The All of Us Research Program is building one of the nation’s largest research platforms to transform the future of health by providing researchers with expansive and diverse health data from one million or more participants, including populations historically UBR.

• The participant diversity in All of Us coupled with multi-dimensional data types including electronic health records, bio-samples and bioassays, whole genome sequencing, surveys, physical measurements, and mobile health data, in addition to our engagement with diverse researchers can ultimately reduce existing gender inequities in health research.

• Select Publications in Women’s Health:
  o Prevalence, Comorbidity, and Sociodemographic Correlates of Psychiatric Disorders Reported in the All of Us Research Program. Barr Peter B, et al. JAMA psychiatry 2022 0 0.
  o Predictive Analytics for Glaucoma Using Data From the All of Us Research Program. Baxter Sally L, et al. American journal of ophthalmology 2021 0 0. 74-86
  o Racial, ethnic, and gender differences in obesity and body fat distribution: An All of Us Research Program demonstration project. Karnes Jason H, et al. PloS one 2021 0 0. (8) e0255583

• Visit the All of Us Researcher Workbench

Register to be an All of Us Researcher: allof-us.org/Register

RESULTS

• As of June 2022, All of Us enrolled more than 510,000 participants with 372,380 participants providing their demographic information through survey questions. Of these participants, 221,500 self-identify as woman, 33,780 self-identify as sexual and gender minorities (SGM), and 1,160 self-identify as transgender (Table 1).
• As of September 2022, there are more than 3,100 registered researchers on the All of Us Researcher Workbench; 1,430 of whom self-identify as woman and 39 self-identify as SGM (Table 1).
• Of the 2,493 projects on the Researcher Workbench research projects directory, there are 85 projects focused on “women”, 17 projects on “transgender”, and 11 projects on “SGM” (as of September 14, 2022).
• Researcher Workbench Project Highlights:
  o Disparities in Cervical Cancer Screening among Hispanic women. Tong Han Chung, Linh Nguyen - University of Texas Health Science Center
  o HIV Risk of Black Behaviorally Bisexual Women, DaJaneil McCree - University of Michigan
  o Protective Factors for Sexual Minority Women’s Mental Health during COVID-19, Kristie Seelman - Georgia State University

Table 1. Sexual Orientation and Gender Identity of All of Us participants and researchers

<table>
<thead>
<tr>
<th>Demographic</th>
<th>Responses (n)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Total Participant Survey Responses</td>
<td>372,380</td>
</tr>
<tr>
<td>Woman</td>
<td>221,500</td>
</tr>
<tr>
<td>Sexual and Gender Minority (SGM)</td>
<td>33,780</td>
</tr>
<tr>
<td>Transgender</td>
<td>1,160</td>
</tr>
<tr>
<td>Total Registered Researchers</td>
<td>3,129</td>
</tr>
<tr>
<td>Woman</td>
<td>1,430</td>
</tr>
<tr>
<td>SGM</td>
<td>39</td>
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</tbody>
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