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How Rural is *All of Us*? Comparing Characteristics of Rural Participants in the NIH *All of Us* Research Program to Other National Data Sources

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Abstract

Purpose: The National Institute of Health's *All of Us* Research Program represents a national effort to develop a database to advance health research, especially among individuals historically underrepresented in research, including rural populations. The purpose of this study was to describe the rural populations identified in the *All of Us* Research Program using the only rurality indicator currently available in the dataset.

Methods: Currently, the the *All of Us* Research Program provides a proxy measure of rurality that identifies participants who self-reported delaying care due to far travel distances associated with living in rural areas. Using the *All of Us* Controlled Tier Dataset v6, we compared sociodemographic and health characteristics of *All of Us* rural participants identified via this proxy to rural US residents from nationally representative data sources using chi-squared tests.

Results: 3.1% of 160,880 *All of Us* participants were rural, compared to 15–20% of US residents based on commonly accepted rural definitions. Proportionally more rural *All of Us* participants reported fair or poor health status, history of cancer, and history of heart disease (p<0.01).

Additional Contributions: The All of Us Research Program would not be possible without the partnership of its participants. **Conflict of Interest Disclosures**: None reported.

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Conclusions: The *All of Us* measure may capture a subset of underserved participants who live in rural areas and experience healthcare access barriers due to distance. Researchers who use this proxy measure to characterize rurality should interpret their findings with caution due to differences in population and health characteristics using the *All of Us* definition or rural compared to other commonly used rural definitions.

Keywords

rural; database; All of Us

INTRODUCTION

The National Institute of Health's (NIH) *All of Us* Research Program represents a national effort to develop and maintain a longitudinal research database of health, lifestyle, environmental, and genetic information from at least one million people in the United States (US).^{1, 2} As a primary objective, the *All of Us* Research Program aims to create one of the most diverse databases ever developed to advance health research. To achieve this, participants from a wide range of backgrounds and communities are recruited and enrolled.¹ To date, over 80% of *All of Us* participants represent communities historically underrepresented in medical research, and more than half identify with a racial or ethnic minority group.³

The *All of Us* Guide for Diversity and Inclusion outlines 10 diversity categories that identify US populations underrepresented in biomedical research: race and ethnicity; access to care; age; annual household income; disability; educational attainment; gender identity; sex assigned at birth; sexual orientation; and geography. Individuals who reside in rural and non-metropolitan areas (hereafter "rural") are underrepresented in biomedical research despite evidence of being no less willing to participate compared to urban residents. Consequently, rural health has been identified as a scientific gap with respect to NIH funding. The underrepresentation of rural residents in biomedical research is attributable to factors such as opportunity, awareness, and trust, 6-8 as well as time, financial, and distance constraints related to rural residents' having to travel far to research sites. 8-12

To overcome obstacles in engaging with biomedical research among rural and other populations, the *All of Us* Research Program has focused heavily on recruiting participants from populations historically underrepresented in biomedical research. 9, 13, 14 *All of Us* recruitment efforts have incorporated community-engaged strategies to engage geographically and ethnically diverse participants, 9 including use of mobile units, exhibits, and partnerships with community centers, groups, and clinics. 9, 15 In rural communities in particular, recruitment strategies have involved a focus on community partners, health professionals, and social networks. 16 However, target enrollment estimates for *All of Us* participants from rural areas are not readily available.

The *All of Us* Research Program defines geographically diverse communities as those containing "residents of established rural and non-metropolitan ZIP codes, based on the Health Resources and Services Administration (HRSA) Federal Office of Rural Health Policy (FORHP) data files."¹⁷ This approach to classifying rurality relies largely upon

Rural-Urban Commuting Area (RUCA) codes, ¹⁸ which identify rural areas based on proximity to urbanization, population density, and daily commuting patterns. ¹⁹ Despite using the FORHP definition in recruitment of rural participants, the program does not release a rurality indicator to researchers or another method to classify participant rurality using this definition. Survey data within *All of Us* may serve as a proxy to identify rural participants in this dataset.

The specific focus on rural residents as a priority population for *All of Us*, together with concerted rural recruitment efforts, presents an opportunity for rural health researchers seeking to conduct research using data from the *All of Us* Research Program. Given that nationally representative data sources suffer from small samples of rural participants, ²⁰ the *All of Us* program could serve as an important data source for advancing research that promotes equity in rural health. This is particularly important given the persistent health inequities and disparities rural residents experience such as lower life expectancies, higher burden of multiple chronic health conditions, and a higher prevalence of risk factors such as obesity and physical inactivity. ^{21–24} Contributors to poor these health outcomes among rural populations include myriad factors, such as lower access to care, socioeconomic status, and health behaviors. ²⁵ Within rural communities, it is important to also consider intersectional identities associated with health disparities. For instance, rural residents who belong to an underrepresented group may experience unique challenges and disparities in accessing healthcare services compared to their urban peers or rural residents who do not share multiple marginalized identities. ²⁶, ²⁷

The objective of this study was to describe the demographic and health characteristics of rural participants in the NIH *All of Us* Research Program database and compare them to rural US populations identified using common definitions of rurality.

METHODS

In this cross-sectional comparison study, we sought to identify and compare rural adult (aged >18 years) participants in the *All of Us* Research Program to rural residents sampled from the general US population. The *All of Us* Controlled Tier Dataset (v6) presently does not grant access to any variable (e.g., county, ZIP code) that would allow researchers to characterize a participants' residential location as rural vs. urban. However, *All of Us* participants complete surveys as a component of their participation in the program, and the following question from the Healthcare Access and Utilization Survey was available to identify those residing in rural areas: "Have you delayed getting care for any of the following reasons in the past 12 months? You live in a rural area where distance to the healthcare provider is too far." Response options were "yes," "no," or "don't know." Participants who did not complete the survey or answer this question were excluded, as were participants who responded "don't know."

The proportion of *All of Us* participants identified as rural were compared to the proportion of rural US residents classified using the following common definitions of rurality: Frontier and Remote (FAR) Area Codes,²⁹ Rural-Urban Continuum Codes (RUCC),³⁰ Urban Influence Codes (UIC),³¹ RUCA codes,¹⁸ and the FORHP definition.³² Estimates

of the proportion of the US population classified as rural were obtained from Mueller, et al.³³ Additionally, the US Census Bureau rurality definition (based on the 2010 Census), which classifies areas outside of urban clusters or urbanized areas as rural,³⁴ was utilized. Population estimates for the Census Bureau measure were obtained from the American Community Survey (ACS) Demographic and Housing Estimates 5-Year Estimates Data Profiles from 2021.³⁵ Demographic characteristics reported by rural *All of Us* participants were compared to US rural residents using the US Census definitions of rurality.³⁶

Demographic characteristics of rural participants obtained using the *All of Us* Researcher Workbench cohort builder included race (white, black/African American, Asian, or more than one race), ethnicity (not Hispanic, Hispanic), and sex (female, male). Self-reported health status and health history included the following measures classified dichotomously (yes, no): fair or poor health status, history of cancer, and history of heart disease. Two self-reported measures healthcare access were also obtained: delay or non-receipt of dental care due to cost (yes, no) or delay or non-receipt of medical care due to cost (yes, no). These data were obtained from the Basics Survey (demographics) and Overall Health Survey (health status) completed upon enrollment in *All of Us*, and the Personal Medical History Survey (cancer, heart disease history) and Healthcare Access and Utilization Survey (healthcare access) completed 90 days after enrollment.³⁷ Health status, health history, and healthcare access measures reported by rural *All of Us* participants were compared to health status data obtained from the 2019 National Health Interview Survey (NHIS) for non-metropolitan populations for all measures.

Proportions of rural All of Us participants across each category of demographic characteristics, health status, or healthcare access were compared to US rural populations using chi-squared tests in Stata/MP v15.0. The level for statistical significance was set at α =0.05. The Washington State University Office of Research Assurances determined that the project does not meet the criteria for human subjects research and is exempt from the need for institutional review board review.

RESULTS

Among the 160,880 participants who answered the survey question utilized as a proxy for rurality, 4,940 participants answered "yes", amounting to 3.1% rural participants in the *All of Us* Research Program. This proportion is similar to the 4.0% of US residents identified as rural using FAR area codes (Figure 1). However, the *All of Us* rural proportion is much smaller than the rural US population proportion for other definitions of rurality (range: 15.0–19.4%).

The demographic characteristics of *All of Us* rural participants differed significantly from national estimates of rural populations (Table 1; p<0.01 for all comparisons). Among *All of Us* rural participants, 13.9% identified as Black/African American, which is twice as many identified in the US population using the 2021 ACS definition of rurality. Similarly, twice as many *All of Us* rural participants identified as Hispanic than rural US populations. The *All of Us* rural participants were 70.2% female, compared to 49.2% of the rural US population (Table 1).

The prevalence of health conditions and challenges in accessing healthcare services varied significantly between *All of Us* rural participants and national estimates of rural populations (Table 2; p<0.01 for all comparisons). The proportions of *All of Us* rural participants reporting fair or poor health status, or history of cancer were significantly higher than national prevalence estimates, and proportionally more rural *All of Us* participants reported a history of heart disease (11.0%) compared to the US rural population (6.7%). The proportion of people facing a delay or non-receipt of healthcare (dental or medical) due to cost was significantly lower among *All of Us* rural participants compared to US rural populations reporting to the NHIS (Table 2).

DISCUSSION

To date, the only approach to classifying rurality among *All of Us* participants is via a self-reported survey question that defines rurality as participants' geographic residence where the distance to the healthcare provider is too far and contributes to delay in getting medical care. This question only captures participants who delayed care due to geographic distance and does not sufficiently identify rural residents who traveled far for healthcare without access delay or rural residents who accessed healthcare nearby. While the NIH *All of Us* Research Program is not intended to be nationally representative, differences in characteristics of rural residents using this proxy measure in the *All of Us* data compared to common rurality classification schemes shed little light as to an accurate representation of rural in the database. Researchers who use *All of Us* to study rural health should consider the validity of this proxy for rurality relative to their specific inquiry, and note the limitations in their dissemination of findings.

Only 3.1% of All of Us participants indicated they resided in a rural area where distance to the healthcare provider was too far. Because this database lacks an objective geographic measure (e.g., ZIP code) or rurality classification (e.g., RUCA codes), it is not possible to determine what proportion of All of Us participants actually resided in rural areas and perceived they resided too far from care. Although distance to care is particularly a barrier for residents of of small rural areas, many residents of urban, suburban, and large rural areas also perceive distance to care as a healthcare access barrier albeit at smaller proportions compared to residents of small rural areas.³⁸ A participant's tolerance of distance traveled for healthcare may also vary by provider type (i.e., primary care vs. specialist care), and type of healthcare provider was not specified in the All of Us survey question. It should be noted, however, that rural residents may be more accepting than urban residents to drive long distances for healthcare, ³⁹ likely as an artifact of being accustomed to having fewer healthcare options in their direct vicinity. It is possible, therefore, that the measure currently used within All of Us may be subject to low sensitivity, such that it falsely classifies truly rural residents as non-rural because they are generally less likely to self-identify as residing too far from healthcare.

Although we cannot accurately determine if a respondent lives in a rural area using this proxy measure in the All of Us data, evidence suggests that the perception of living in a rural area has implications for understanding rural-urban health disparities. Relatively recent evidence shows there is low agreement (kappa = 0.33) between RUCA codes and perceived

rurality, and this discordance raises important questions about the concept of rurality and the various factors that affect health outcomes. 40 Similar research conducted among pharmacists in North Carolina has shown that fewer than half of pharmacists who perceive working in a rural workplace are in a RUCA-designated rural area. 41 This discordance between perceived rurality and rurality based on commonly used measures has been attributed to perceptions people have about their environments and available resources. 40, 41 This explanation is plausible in light of our findings, as perceived rurality was based on distance to receiving healthcare. Should geographic measures, such as county or ZIP code, remain unavailable to All of Us researchers, inclusion of recently developed measures of rural perception or identity⁴² will advance rural health research within the All of Us ecosystem. In addition, All of Us should also consider revising the current question used to determine rurality to avoid conflating delay in receiving healthcare with rurality. Given the existing constraints in defining rurality within the NIH All of Us dataset, this study is first to conduct any analyses focused on the characteristics of rural participants and lays the groundwork for future research to refine how All of Us ensures that rural populations are represented in health research.

Rural participants identified via the proxy measure within the NIH *All of Us* Research Program differed significantly from rural US residents identified using common rurality definitions. One limitation to note is that the national estimates for rural populations by race or ethnicity were based on all ages, not only adults aged 18 years and over. We do not, however, believe the adult esitmates would differ markedly from the estimates reported for all ages in this study. Additionally, certain rurality classification schemes may underor over-estimate rural populations, ⁴³ as shown in Figure 1, with rural residents comprising from 4.0% to 19.4% of the US population. This is important to note, given the comparisons of *All of Us* rural participant characteristics to national rural populations reported in this manuscript.

The unique focus of *All of Us* on recruiting underserved and historically underrepresented populations likely plays a role in this study's findings. Based on the current proxy measure of rurality available within *All of Us*, rural participants in *All of Us* are specifically identified as those who face barriers to healthcare access due to distance from a provider. This definition may drive the finding that rural participants in *All of Us* appear to have poorer health status and experience diminished access to care compared the rural US population described from other data sources. Yet, this study also revealed that less than one third of the identified *All of Us* rural participants were male, despite the fact that rural men, especially those of color, experience disparities in healthcare access and health outcomes. Future *All of Us* efforts recruitment efforts should focus on connecting with rural men, especially rural men from diverse populations, to increase awareness and engagement in the future. The *All of Us* database is nonetheless valuable in its diversity, especially that it captures a diverse population of rural participants. Future rural health research efforts using *All of Us* should account for the uniquely diverse population therein.

CONCLUSIONS

The only measure that can be used to determine rurality in the NIH *All of Us* database does not appear to adequately identify rural residents in the US. One reason for this is that the rurality measure only identifies residents whose healthcare access has been impacted by their residence. This measure should not be used to identify rural residents; although, it may be a helpful indicator of rural underserved participants. In order to conduct rural health research within *All of Us*, geographic indicators that align with common and widely accepted methods of defining rural should be integrated within their platform. Researchers who rely on the current *All of Us* measure for determining rurality should interpret their findings with caution due to the differences in population and health characteristics between the current measure compared to other measures.

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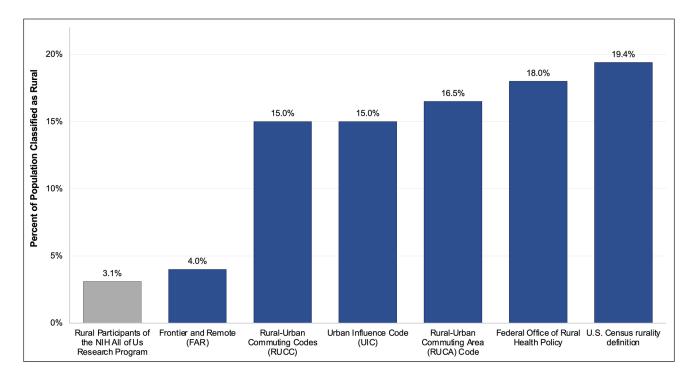


Figure 1. Percentage of rural participants in the NIH *All of Us* Research Program compared to rural residents identified using various rurality classification schemes in the United States.^{33, 35} *Note:* Population estimates by rurality classification scheme were obtained from Mueller, et al.,³³ with the exception of the U.S. Census rurality definition, which was obtained from the American Community Survey, 2021 (5-year estimates).³⁵

Table 1.Demographic characteristics of *All of Us* rural participants and rural US residents.

	All of Us rural participants ^a	2021 ACS rural residents b
Race		
White	62.6%	84.9%
Black/African American	13.9%	6.0%
Asian	1.5%	1.3%
More than one race	1.9%	4.3%
Ethnicity		
Not Hispanic	78.1%	92.5%
Hispanic	14.8%	7.5%
Sex		
Female	70.2%	49.2%
Male	24.5%	50.8%

Abbreviations: ACS, American Community Survey

^aRural All of Us participants were identified as those who responded "Yes" to the following question in the Healthcare Access and Utilization Survey: "Have you delayed getting care for any of the following reasons in the past 12 months? You live in a rural area where distance to the healthcare provider is too far." Estimates of the proportion of rural All of Us participants (aged >18 years) (N = 160,880) across categories were obtained from the Basics Survey.

^bRural US residents were identified using the US Census definition, which classifies rural as any location outside a Census-defined urban area (based on Census 2010 data). ³⁶, ⁴⁶ Estimates of rural US residents (N = 64.0 million) obtained from American Community Survey, 2021 5-Year Estimate Subject Table DP05. ³⁵ Adult (aged >18 years) estimates reported by sex; for race and ethnicity, reported estimates reflect all ages.

Table 2.

Health status and healthcare access experience among rural All of Us participants versus the rural US population.

	All of Us rural participants ^a	US rural population
Health status		
Fair or poor health status b	41.9%	14.1%
Health history		
History of cancer b	14.5%	7.3%
History of heart disease b	11.0%	6.7%
Healthcare access		,
Delay or non-receipt of dental care due to $\cos b$	20.3%	41.4%
Delay or non-receipt of medical care due to $\cos t^{b,c}$	14.4%	41.1%

^aRural *All of Us* participants were identified as those who responded "Yes" to the following question in the Healthcare Access and Utilization Survey: "Have you delayed getting care for any of the following reasons in the past 12 months? You live in a rural area where distance to the healthcare provider is too far." Estimates of the proportion of rural *All of Us* participants (aged >18 years) across categories were obtained from the Overall Health Survey (Health Status), Personal Medical History Survey (Cancer, Heart Disease History), and Healthcare Access and Utilization Survey (Healthcare Access).

^bUS rural population estimates (aged >18 years) obtained from the National Health Interview Survey (NHIS), 2019 (rural respondents are those who reside outside of a metropolitan statistical area). ⁴⁷

^cType of medical care received not specified.