All of Us participant perspectives on the return of value in research

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Abstract

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Conflict of Interest

The authors declare no conflict of interest.

Ethics Declaration

The study protocol was approved by the All of Us Institutional Review Board. The All of Us Institutional Review Board deemed this study exempt. Informed consent was not required as this study received a non-human subject's research determination exempt review.

Other Disclosures

The content is solely the responsibility of the authors and does not necessarily represent the official views of the National Institutes of Health.

Additional Information

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Purpose: To understand participant preferences for receiving specific types of research information, whether information preferences vary across sociodemographic groups, and the types of health providers participants could access to understand returned information.

Methods: All of Us Research Program participants completed a value of returning research information survey. Stratified sampling was implemented to enhance participant diversity and avoid noncoverage. We used weighted multivariable logistic regression to evaluate associations between the most valuable information types, access to providers, and sociodemographic variables.

Results: Participants ($N = 20,405$) were diverse in their race/ethnicity (eg, 52% were White, 18% were Hispanic/Latino or Spanish, 3% were Asian, and 20% were Black or African American). Most participants (78.6%) valued information about their risk of serious genetic diseases with available treatment. Primary care physicians, specialists, and genetic counselors were the top providers that participants could access for help understanding returned information. Information preferences and provider access varied across sociodemographic groups. For example, as income levels increased, the odds of placing value on genetic results indicating risk of serious disease with available treatment increased when compared with the lowest income levels (P value < .001).

Conclusion: Although genetic information was most valuable to participants, preferences about specific information types varied across sociodemographic groups.

Keywords

Engagement; Health equity; Participant perspectives; Precision medicine; Return of value

Introduction

Precision medicine genomics research has sparked interest in the return of biomedical study findings to participants.[1–4] Prior research in this field suggests that participants are highly interested in receiving research results because, for example, the information can inform future health care decisions.[5] Accordingly, the National Academies of Sciences, Engineering, and Medicine developed recommendations on return of results and encouraged researchers to consider participant understanding of and value placed on the type of results once returned.[6] Namely, reconceptualizing the return-of-results practice as return of value can help capture the ways participants may value different types of research information regardless of whether they are actionable.[1] Accompanying this reconceptualization is the Return of Value Conceptual Framework, which posits relationships between contextual factors, influencers of participants' values, returnable information types, and resources are needed to interpret returned information.[1]

Return of value is relevant for the National Institutes of Health's All of Us Research Program, which aims to enroll one million or more diverse participants.[7] All of Us aims to provide access to personalized information to support health and prioritizes including populations historically underrepresented in research. In 2021, All of Us developed its 5-year goals; and the fifth goal prioritizes return of value.

Although returning results is a core All of Us value and is of deep interest to researchers,[1,2] little is known about the types of research information that participants value. Indeed, prior research has largely focused on whether research results should be returned but not which specific types of information should be returned.[5] Even less is known about how these preferences for specific information types vary across sociodemographic groups. To address these knowledge gaps, All of Us data were analyzed to understand participant preferences for receiving research information and the types of health providers participants could access to help them understand this information once returned.

Materials and Methods

Study design

All of Us opened enrollment in 2018. Participants are eligible if they are 18 years old or older, live in the United States, and are able to provide informed consent.[8,9] All of Us participants provide physical measurements, biospecimens, electronic health record data, digital health data, and responses to surveys about topics, such as their sociodemographic characteristics, experiences with COVID-19, and health care access/utilization. The All of Us Institutional Review Board approved this study.

A sampled subset of participants was invited to complete a survey after enrollment. A 15-item survey was developed to understand the value All of Us participants place on receiving research information. This survey was designed based on existing literature, the Return of Value Conceptual Framework,[1] recommendations from the Precision Medicine Initiative's Working Group, and experiences of the All of Us Engagement Core.[10–15] Survey feedback was obtained from the All of Us Participant Evaluation and Assessment Board. Cognitive interviews were conducted with 11 individuals, including 4 All of Us Participant Ambassadors, to understand how respondents would interpret survey items.[16] Supplemental Files 1, 2, and 3 present survey feedback from English/Spanish speakers and the final survey, respectively.

Participants and data collection

Survey data were collected from a subset of All of Us participants between November 2020 and March 2021 via Qualtrics software (Qualtrics). Out of 333,942 All of Us participants at the time of survey, invitations were sent to 179,378 participants with the goal of receiving approximately 20,000 complete surveys. Stratifying on intersections of age, race/ethnicity, gender, sexual orientation, insurance status, annual income, preferred language, and health literacy, the sampling strategy was developed to reflect participant diversity and avoid noncoverage. Invitations were sent in 2 waves—100,674 invitations in November 2020 and 78,704 new invitations in January 2021. A total of 20,405 surveys were completed, yielding a sampling rate of 11.4%. Surveys were sent to participants via email in the participant portal and short message service. Participants were able to complete the survey in English or Spanish.

Survey items

Most valuable research information—The survey displayed a list of 14 types of health information, and participants were asked to choose up to 5 types of information from the list that they viewed as most valuable. The list included genetic information (eg, their risk for a serious disease when treatment is available) and other general types of health information (eg, medical record information). The full list is shown in Supplemental File 3. Data for each information type were coded as 0 = not selected as most valuable and 1 = selected as most valuable.

Preferred health care provider to help understand genetic information

Participants were asked to identify the types of health care providers they could access to help them understand genetic information. Examples of providers listed include a primary care physician, specialist physician, and genetic counselor. Participants were asked to "select all that apply." Each provider type was coded as 0 = not selected, 1 = selected. Participants could select that they were unsure or did not have a place to go.

Sociodemographic variables

At initial enrollment, All of Us asks participants to self-identify their sociodemographic information (age, race, ethnicity, gender, sexual orientation, education level, annual household income, and language preference, English or Spanish).[17] Sociodemographic data from All of Us initial enrolment surveys were linked with responses to the return of value survey. Health literacy was assessed using the Brief Health Literacy Screening tool; scores range from 0 to 15.[18,19] Health literacy scores of 0 to 5 were categorized as low, scores of 6 to 10 as medium, and scores of 11 to 15 as high.

Data analysis

A sampled subset of All of Us participants were invited to complete the survey. To allow generalization of the results to the total All of Us population, survey weights were calculated for each participant based on the number and demographics of respondents in the All of Us population. Weights were further adjusted to account for individual question completeness; 2 separate χ^2 survey weightings were derived based on missingness for the 2 survey questions (ie, the most valuable information and provider access for help understanding genetic information) assuming that data were missing at random conditioning on the demographic information among respondents.[20] All analyses were conducted using weighted survey results to represent the total All of Us population.

The sampled weighted cohort is described using means and standard deviations for continuous variables and count and percentages for categorical variables. To report descriptive statistics for the overall All of Us population, the probability-weighted method was used to estimate proportions regarding participant feedback about the most valuable information types and preferred providers for facilitating the understanding of genetic information. Marginal sociodemographic differences in perspectives were assessed separately regarding the most valuable types of health information and preferred providers using weighted χ^2 tests for race/ethnicity, gender, education, income, sexual orientation,

health literacy, and preferred language for completing the survey. We used weighted multivariable logistic regression models to evaluate the adjusted associations between demographic variables and responses to the survey questions. Because participants could provide multiple answers to both survey questions, we analyzed each answer and applied the Bonferroni correction to adjust for the multiple comparison conducted for the 22 binary outcomes. A 2-sided P value less than .002 was considered statistically significant. Analyses were conducted using the survey package in R 4.2.0 and Stata version 15.1.

Role of the funding sources

The funding sources had no role in the execution, analyses, data interpretation, or decision to submit results for this study.

Results

Weighted sociodemographic characteristics for sampled participants

A total of $N = 20,405$ individuals responded to the survey and were included in analyses. The weighted mean age of participants was 55.3 years. Adjusting for sampling weights, the survey represents a population in which 52% were White, 18% were Hispanic/Latino or Spanish, 20% were Black or African American, 3% were Asian, 3% identified as more than 1 race or ethnicity, and about 1% identified as American Indian or Alaska Native. Approximately 20% of participants had a high school or less education level. About 32% of participants had an annual household income of $24,999 or less (Table 1).

Most valuable types of health information

Tables 2 and 3 present weighted participant responses about the most valuable types of health information across sociodemographic groups for genetic information and other types of health information. Most participants (78.6%) indicated that it would be most valuable to receive genetic/DNA information about their risk for a serious disease when treatment is available. Over 50% of participants indicated that receiving DNA information about how they might respond to certain medications was most valuable. Out of the 14 information types listed in the survey, the top 5 most valued information types included genetic data (Table 2). The percentage of participants who selected "most valuable" for many types of genetic/DNA information increased with education level and annual household income. Nearly 80% of participants with high health literacy and who completed the survey in English thought that having information about their risk for a serious disease when treatment is available was most valuable. However, under 60% of participants with low/medium health literacy and who completed the survey in Spanish thought that this same information was most valuable. Less than 70% of participants who identified as American Indian/Alaska Native or Black thought that having information about their risk for a serious disease when treatment is available was most valuable (Table 2). About 40% of participants who identified as American Indian or Alaska Native, Black or African American, and Native Hawaiian or other Pacific Islander most valued receiving their medical record information. These results are numerically presented in Table 3 and visually presented in Supplemental Figures 1–7.

As income and education levels increased, the odds of placing value on genetic results indicating risk of serious or nonserious disease when treatment is available increased when compared with the lowest income and education levels (Figure 1). The odds of valuing information on serious disease with available treatment were 2.34 (*P* value < .001) times higher for the highest income group compared with the lowest, and 2.26 (*P* value < .001) times higher for the most educated group compared with the least. The odds of finding genetic heterozygote information valuable were much higher for participants who identified as heterosexual/straight compared with those who identified as gay (5.5), lesbian (2.9), or bisexual (1.4) (all *P* values < .001). The odds of placing the most value on All of Us survey responses were much higher for those with the lowest level of education compared with those with some college experience or greater. Those who completed the Spanish language version had higher odds of valuing genetic heterozygote information and the risk of a nonserious disease with no available treatment. Those who completed the survey in English had higher odds of valuing environmental marker lab tests, raw genetic data, and the risk of serious disease with treatment available.

Access to providers to facilitate understanding of genetic information

The top 3 provider types that participants reported being able to access for help understanding genetic information were a primary care physician (74.6%), specialist physician (61.5%), and genetic counselor (45.4%). The percentage of participants who reported having access to these 3 provider types increased along with increasing education and income levels. The opposite pattern occurred for access to community health center providers; as education and income increased, smaller percentages of participants reported access to this provider type (Table 4). A greater percentage of participants with less than high school education reported not having a place to go for help when compared with those with an advanced degree (8.5% versus 2.0%). Only 26.8% of participants with low health literacy and 29.0% of participants who took the survey in Spanish could access a genetic counselor, but over 45% participants with high health literacy and who took the survey in English could access a genetic counselor. Also, a smaller percentage of those who completed the survey in Spanish could access a primary care or specialist provider compared with those who completed the survey in English (Table 4). Supplemental Figures 8 to 14 visually showcase participant access to provider types across sociodemographic groups.

The odds of specialist physician access were 1.98, 1.97, and 1.64 times higher for gay, lesbian, and bisexual participants (all *P* values < .001), respectively, compared with heterosexual/straight respondents, whereas the respective odds were 2.07, 2.60, and 1.59 times higher (all *P* values < .001) for genetic counselor access. Those in the highest 2 income levels reported higher odds of having access to a specialist physician compared with the lowest income level, and White respondents had higher odds compared with Hispanic and Asian respondents for access to this provider type (Supplemental Figure 15).

Discussion

We surveyed over 20,000 All of Us participants about the return of value in research. The top 5 most valued information types were information about genetic risk for serious

disease when treatment is available, pharmacogenetics, genetic risk for serious disease when treatment is unavailable, genetic ancestry, and risk for being a genetic heterozygote. Our findings echo previous literature suggesting that receiving genetic information is highly valuable to research participants, providing them an avenue to assess personal utility of results for themselves and their families.[21–23] Our study provides new insights about the specific types of genetic data participants find most valuable and how these preferences vary across diverse sociodemographic populations. Considerable variation appeared in perspectives about the most valuable information types within sociodemographic groups. Information about genetic risk for serious disease when treatment is available was selected as the most valuable by the greatest percentage of participants in the overall sample (78.6%); yet, there were notable differences in the value of this information within sociodemographic groups. Nearly 90% of participants with an advanced degree perceived this type of information was most valuable compared with 52% of participants with less than a high school education. Likewise, participants with high health literacy who preferred English had a 20% higher preference for this information compared with those with low health literacy preferring Spanish. It is possible that individuals with higher education or socioeconomic status place greater value on receiving information about genetic risk for serious disease when treatment is available because of increased access to resources needed to act on these results. Relatedly, prior research suggests populations with lower socioeconomic status may place higher value on health-related topics that have an immediate impact on their life compared with genetic information that may pose future risk.[24] A similar relationship may exist with health literacy and preferred language because those with lower health literacy and who prefer Spanish may face additional barriers accessing resources needed to act on genetic results. Accordingly, initiatives are needed to ensure that individuals with fewer resources receive results that matter most to them and can access help to understand how these results may affect health outcomes.

There are also consistent differences in the proportion of participants who placed value on serious diseases with and without treatments. As a whole, the average proportion of respondents who valued information on serious diseases with a treatment was 30% higher than diseases with no treatment. Although information on diseases with no treatments was still increasingly valued as education and income levels increased, the association was much weaker. The difference between the lowest and highest income levels was just 7% for diseases without a treatment compared with a 35% difference if there was a treatment. Similarly, only a 4% difference existed between the highest and lowest education levels for diseases without a treatment compared with a 25% difference for treatable diseases. Differences also existed between racial groups. People identifying as Asian or Native Hawaiian or other Pacific Islanders saw declines over 30% for untreatable diseases compared with treatable ones, whereas Hispanic and Black or African American respondents had declines less than 18%. A reason may be that participants as a whole saw considerably less value in learning about conditions over which they had no control, which appears to have been more pronounced among certain racial and ethnic groups. Removing the treatment ability from the disease information also removed the association between income and education level, indicating that lack of resources may have played a lesser role for untreatable diseases.

Variation also appeared in preferences for receiving information types not considered highly valuable by the overall sample. Around 40% of participants who identified as American Indian or Alaska Native, Black or African American, or Native Hawaiian or other Pacific Islander thought receiving information about their medical records was most valuable compared with 25% in the overall sample. This result may reflect racial and ethnic inequities in use of and access to electronic patient portals, which is an increasingly common way for patients to access their clinical medical records.[25,26] Accordingly, returning medical record information, especially to populations from minoritized racial and ethnic groups who express interest in receiving this information, may represent an important strategy for reducing inequities in access to personal health information. Pairing returned medical record information with support from primary care or other providers to help participants understand this information may have the most impact. Overall, our findings suggest researchers should not presume information types reported as low value among most study participants are also of low value to racially and ethnically diverse participants.

Primary care physicians, specialist physicians, and genetic counselors were the top 3 provider types that participants reported having access to for support to help them understand and use the information they receive.[6] Access to these 3 provider types generally increased with increasing education and annual income levels. About three-quarters of participants overall reported having access to a primary care provider, but only 60% of participants with less than a high school education and half of participants who completed the survey in Spanish could access a primary care provider. These results correspond to prior research suggesting that individuals with lower education levels and limited English proficiency experience greater barriers to accessing health care in the US.[27,28] Additionally, genetic counselors may be uniquely positioned to help participants gain value from returned genetic results.[29] About 45% of participants overall could access a genetic counselor for help interpreting results, but fewer than 25% of participants with less than a high school education could access a genetic counselor. These results suggest that policies are needed to increase access to health providers who can help patients understand returned results, especially for patients with lower education levels and who speak Spanish as a preferred language. It may also be beneficial to support programs that increase access to providers with similar expertise at community health centers—a location that our results suggest may be more accessible among participants with lower income levels and who prefer Spanish. These providers should be prepared to present findings in a way that is comprehendible and demonstrate benefit, whether now or distally. Ideally, researchers will connect participants with providers who have the expertise necessary to explain returned information (eg, genetic counselors may be most appropriate for genetic information, whereas primary care or specialist providers may be most appropriate for medical record information).

Aligning with participant priorities to present findings in a comprehendible and useful way, All of Us is providing a genetic counseling resource to participants who have certain genetic findings. All of Us held listening sessions before enrolling its first participant, and community participants expressed the importance of ensuring that study participants who received genetic results were also provided with resources and tools to discuss the research results and understand any clinical implications of their results. Subsequently, All of Us partnered with Color (a genetic testing support service) and the All of Us Genetic

Counseling Resource. Resources are also available to participants in the program through the regional medical centers, Federally Qualified Health Centers, Veteran's Administration, and other places that can provide a medical home (eg, primary care providers). The All of Us program took additional steps to provide resources to Color to ensure that each participant who received an actionable finding had access to a genetic counselor. To address issues of inequity potentially arising from limited access to follow-up testing, the program also provides a free clinical confirmatory test through Color for all participants who request one. Additionally, Color provides tools that participants can use to discuss their findings with their medical team and family members. Future programs should consider identifying the needed resources to support the interpretation of research versus clinical findings and to address inequities in access to care by ensuring participants have awareness of and access to genetic counseling resources.

Important limitations should be noted. First, this was a cross-sectional survey. Results reflect perspectives at a single time point. Second, All of Us only recruits participants in the United States. Participants in other countries may have different perspectives regarding return of value.[30] Third, because All of Us is not a representative sample of the US population, the analysis incorporated sampling weights to reflect the All of Us cohort from which participants were sampled and invited to complete the survey, rather than to represent the entire US population.

A key strength of this study is our sampling strategy, which focused on surveying participants from diverse sociodemographic groups. Of note, our sampling rate was 11.4%, which was not entirely unexpected as previous research has found significant differences in response rates across diverse sociodemographic groups.[31] The diverse participant sample also facilitated a data analysis approach in which we did not combine participants from multiple historically minoritized identities into single categories. This approach allowed us to conduct a novel analysis of perspectives for receiving health-related information across a diverse sample of participants, traditionally underrepresented in research. Although respondents were diverse in their self-identified race/ethnicity, results should not be interpreted to represent the views of everyone across diverse racial/ethnic groups or diverse Tribal Nations. Also, our study focused on the return of value for individual study participants. Future research is needed to understand return of value to communities. Future research is also needed to apply intersectionality theory[32] to examine how intersecting systems of oppression affect return of value perspectives for populations who have been historically marginalized at multiple intersections (eg, individuals who identify with a historically marginalized racial, ethnic, and/or sexual orientation group who also have low education, income, and/or health literacy). Examining intersecting barriers to care is an important call for future research that applies intersectionality theory to conduct such investigations.

Conclusion

Although genetic information was most valuable to participants, preferences about specific information types varied across sociodemographic groups. Researchers should not assume that participant preferences for receiving research results are uniform within diverse study

populations. Future work is needed to ensure that all research participants receive results they find valuable and understandable, and to identify other information of value that research participants want to receive in addition to genetic health information.

Supplementary Material

Refer to Web version on PubMed Central for supplementary material.

Acknowledgments

Data Availability

The authors will make relevant anonymized survey data available to collaborators external to their team on email request, assuming that they can make appropriate arrangements to safeguard any sensitive information participants might have revealed in the course of the survey and ensure that collaborators receiving data are able to adhere to the expressed preferences and concerns of the researchers and participant partners involved in governance of this project. In accordance with All of Us policies, row-level participant data for this study will not be made available to individuals who were not involved in the study.

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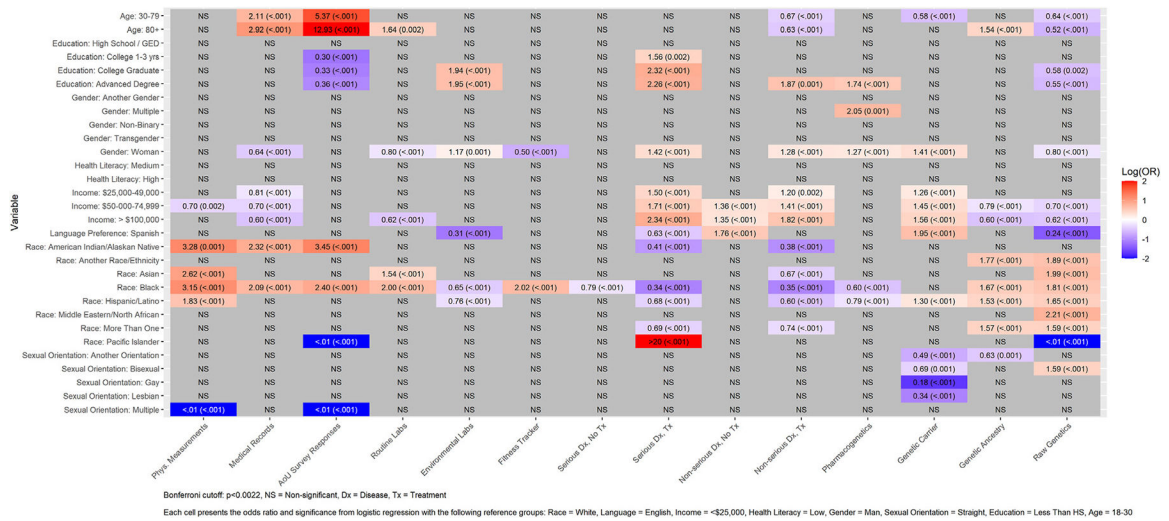
Figure 1.
Weighted logistic regression results: Most valuable types of information to All of Us participants.

Table 1

Weighted sociodemographic characteristics of sampled participants (*N* = 20,405)

Characteristic	*N* or Mean	% or SD
Age (years)		
Mean, SD (Range 18–97 years)	55.3	±16.7
Race and ethnicity		
American Indian or Alaska Native	231	1.1
Another race or ethnicity	204	1.0
Asian	631	3.1
Black, African American, or African	4036	19.8
Hispanic, Latino, or Spanish	3605	17.7
Native Hawaiian or other Pacific Islander	24	0.1
Middle Eastern or North African	115	0.6
More than one race or ethnicity	545	2.7
White	10,679	52.3
Missing	335	1.6
Gender identity		
Another gender	33	0.2
Man	7757	38.0
Multiple gender identities	99	0.5
Nonbinary	44	0.2
Transgender	26	0.1
Woman	12,268	60.1
Missing	179	0.9
Education		
<High School	1105	5.4
High school/GED	2893	14.2
College 1–3 y	5455	26.7
College graduate	5437	26.6
Advanced degree	5192	25.4
Missing	324	1.6
Annual household income (US dollars)		
$24,999	5422	26.6
$25,000-$49,999	3197	15.7
$50,000-$99,999	3861	18.9
$100,000	4318	21.2
Missing	3607	17.7
Sexual orientation		
Another sexual orientation	429	2.1
Bisexual	740	3.6
Gay	733	3.6
Lesbian	251	1.2

Characteristic	N or Mean	% or SD
Multiple sexual orientations	31	0.2
Heterosexual/straight	17,744	87.0
Missing	476	2.3
Health literacy		
Low (score 0–5)	297	1.5
Medium (score 6–10)	2782	13.6
High (score 11–15)	17,326	84.9
Preferred language		
English	19,183	94.0
Spanish	1222	6.0

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Table 2

Weighted All of Us participant perspectives on the most valuable types of genetic information across sociodemographic groups[a,b]

Characteristic	Serious Dx, Tx Available	Pharmacogenetics	Serious Dx, No Tx Available	Genetic Ancestry	Genetic Carrier	Nonserious Dx, Tx Available	Raw Genetic Data	Nonserious Dx, No Tx Available
Sample overall (weighted)								
Overall	78.6 (13,276)	53.2 (8985)	49.9 (8428)	49.7 (8394)	48.4 (8175)	39.9 (6739)	18.4 (3108)	16.1 (2719)
Race and ethnicity[c]								
American Indian/Alaskan Native	65.4 (<20)[d]	44.2 (<20)	47.6 (<20)	54.8 (<20)	41.7 (<20)	19.7 (<20)	20.9 (<20)	7.2 (<20)
Another Race or Ethnicity	83.3 (<20)	61.1 (<20)	46.0 (<20)	55.7 (<20)	50.7 (<20)	39.8 (<20)	22.4 (<20)	12.1 (<20)
Asian	86.0 (<20)	58.6 (<20)	55.3 (<20)	36.6 (<20)	51.7 (<20)	44.2 (<20)	23.3 (<20)	16.6 (<20)
Black	60.3 (2013)	40.5 (1352)	42.1 (1405)	59.8 (1996)	40.7 (1359)	20.0 (668)	27.9 (931)	11.7 (391)
Hispanic/Latino	70.2 (2092)	49.6 (1478)	55.1 (1642)	57.9 (1726)	58.2 (1735)	30.8 (918)	20.2 (602)	18.1 (540)
Middle Eastern/North African	86.0 (<20)	59.0 (<20)	56.0 (<20)	38.3 (<20)	53.3 (<20)	50.9 (<20)	26.1 (<20)	16.4 (<20)
More than One Race or Ethnicity	79.0 (<20)	51.7 (<20)	49.2 (<20)	56.2 (<20)	49.6 (<20)	39.1 (<20)	22.9 (<20)	15.0 (<20)
Pacific Islander	100.0 (<20)	53.5 (<20)	33.8 (<20)	52.1 (<20)	29.6 (<20)	29.6 (<20)	18.3 (<20)	11.2 (<20)
White	87.8 (7768)	58.7 (5193)	50.9 (4503)	43.5 (3848)	47.7 (4220)	50.5 (4468)	13.6 (1203)	17.4 (1539)
Gender identity								
Another gender	87.5 (<20)	70.2 (<20)	67.4 (<20)	37.6 (<20)	29.8 (<20)	49.8 (<20)	15.0 (<20)	29.8 (<20)
Man	75.4 (4842)	49.7 (3191)	48.7 (3127)	47.9 (3076)	41.2 (2646)	36.7 (2357)	19.9 (1278)	16.3 (1047)
Multiple gender identities	84.1 (<20)	68.9 (<20)	55.4 (<20)	37.0 (<20)	31.1 (<20)	48.1 (<20)	16.3 (<20)	13.1 (<20)
Nonbinary	90.7 (<20)	67.8 (<20)	61.9 (<20)	36.4 (<20)	25.4 (<20)	56.8 (<20)	29.7 (<20)	22.0 (<20)
Transgender	70.7 (<20)	54.6 (<20)	49.9 (<20)	55.1 (<20)	19.5 (<20)	42.1 (<20)	35.0 (<20)	28.4 (<20)
Woman	80.5 (8174)	55.2 (5605)	50.5 (5128)	51.0 (5178)	53.2 (5402)	41.8 (4244)	17.5 (1777)	15.9 (1614)
Education								
< High school	51.9 (414)	39.3 (313)	47.9 (382)	52.9 (422)	50.0 (399)	21.7 (173)	27.3 (218)	14.0 (112)
High school/GED	61.1 (1313)	44.6 (958)	42.6 (915)	55.6 (1195)	47.9 (1029)	24.8 (533)	21.9 (471)	12.7 (273)
College 1–3 yrs	74.8 (3462)	48.1 (2226)	49.5 (2291)	56.2 (2601)	49.3 (2282)	32.7 (1514)	21.7 (1004)	14.8 (685)
College Graduate	85.8 (3969)	55.9 (2586)	52.5 (2429)	47.9 (2216)	48.1 (2225)	45.4 (2100)	16.6 (768)	17.7 (819)

Characteristic	Serious Dx, Tx Available	Pharmacogenetics	Serious Dx, No Tx Available	Genetic Ancestry	Genetic Carrier	Nonserious Dx, Tx Available	Raw Genetic Data	Nonserious Dx, No Tx Available
Advanced Degree	88.8 (3966)	62.4 (2787)	51.8 (2314)	41.2 (1840)	47.5 (2122)	52.7 (2354)	13.6 (607)	17.9 (800)
Annual household income								
$24,999	65.0 (2898)	45.6 (2033)	46.7 (2082)	58.6 (2613)	43.1 (1922)	27.3 (1217)	24.8 (1106)	13.4 (597)
$25,000-$49,999	82.3 (2175)	54.1 (1430)	50.1 (1324)	52.5 (1387)	49.5 (1308)	39.5 (1044)	20.1 (531)	16.1 (425)
$50,000-$99,999	86.9 (2795)	57.4 (1846)	51.1 (1644)	46.6 (1499)	50.7 (1631)	47.3 (1521)	14.3 (460)	18.2 (585)
$100,000	91.6 (3313)	60.6 (2192)	53.7 (1942)	37.1 (1342)	51.8 (1873)	56.7 (2050)	11.9 (430)	18.4 (665)
Sexual orientation								
Another sexual orientation	72.1 (252)	48.3 (169)	48.0 (168)	39.6 (138)	32.1 (112)	43.7 (153)	15.2 (53)	17.0 (59)
Bisexual	77.1 (<20)	54.3 (<20)	51.6 (<20)	50.4 (<20)	42.7 (<20)	39.5 (<20)	29.9 (<20)	17.4 (<20)
Gay	73.9 (463)	56.0 (351)	53.9 (338)	54.4 (341)	12.7 (80)	41.8 (262)	21.6 (135)	20.1 (126)
Lesbian	82.0 (<20)	57.8 (<20)	51.6 (<20)	51.4 (<20)	27.1 (<20)	43.1 (<20)	19.9 (<20)	13.5 (<20)
Multiple sexual orientations	69.9 (<20)	43.7 (<20)	61.6 (<20)	50.5 (<20)	44.7 (<20)	26.0 (<20)	49.9 (<20)	26.9 (<20)
Heterosexual/straight	79.3 (11,646)	53.0 (7784)	49.7 (7299)	49.7 (7299)	51.0 (7490)	40.0 (5874)	17.7 (2599)	15.9 (2335)
Health literacy								
Low	56.9 (<20)	37.2 (<20)	46.3 (<20)	47.7 (<20)	35.3 (<20)	30.6 (<20)	26.1 (<20)	12.4 (<20)
Medium	59.4 (1305)	44.1 (969)	45.7 (1004)	53.4 (1173)	44.2 (971)	23.7 (521)	24.0 (527)	13.3 (292)
High	81.9 (11,826)	54.9 (7927)	50.6 (7306)	49.2 (7104)	49.2 (7104)	42.5 (6137)	17.4 (2512)	16.6 (2397)
Preferred language								
English	80.0 (12,702)	53.3 (8463)	49.3 (7828)	49.3 (7828)	47.3 (7510)	40.8 (6478)	19.0 (3017)	15.8 (2509)
Spanish	57.5 (582)	50.9 (515)	59.3 (600)	56.2 (569)	65.9 (667)	26.4 (267)	8.3 (84)	21.1 (214)

Dx, diagnosis, *Tx*, treatment.

[a] Data presented in Tables 2 and 3 were collected as part of a single survey question but are shown in 2 separate tables for ease of interpretation.

[b] Data shown are weighted results to allow for generalization to the entire All of Us population and are not raw statistics.

[c] Results should not be interpreted to represent the views of everyone across diverse Tribal Nations or diverse racial/ethnic groups.

[d] Because of All of Us privacy policies, any participant row containing a count of less than 20 must be hidden and marked as "<20."

Table 3

Weighted All of Us participant perspectives on the most valuable types of general health information across sociodemographic groups[a,b]

Characteristic	Results of Environmental Marker Labs	Medical Records	Results of Routine Labs	Physical Measurements	All of Us Survey Responses	Fitness Tracker Data
Sample overall (weighted)						
Overall	35.1 (5928)	24.6 (4155)	22.8 (3851)	6.7 (1132)	4.8 (811)	4.4 (743)
Race and ethnicity[c]						
American Indian/Alaskan Native	40.6 (<20)[d]	38.1 (<20)	38.1 (<20)	11.7 (<20)	10.8 (<20)	7.3 (<20)
Another race	38.5 (<20)	22.5 (<20)	15.3 (<20)	3.3 (<20)	4.4 (<20)	3.7 (<20)
Asian	37.6 (<20)	21.3 (<20)	21.4 (<20)	8.4 (<20)	3.4 (<20)	3.9 (<20)
Black	27.9 (931)	39.5 (1319)	35.9 (1198)	14.2 (474)	9.1 (304)	7.6 (254)
Hispanic/Latino	25.2 (751)	24.1 (718)	25.1 (748)	8.8 (262)	5.6 (167)	3.9 (116)
Middle Eastern/North African	28.9 (<20)	13.1 (<20)	17.7 (<20)	7.0 (<20)	3.3 (<20)	3.6 (<20)
More than one race or ethnicity	40.1 (<20)	23.4 (<20)	20.0 (<20)	4.3 (<20)	3.0 (<20)	3.4 (<20)
Pacific Islander	47.9 (<20)	40.8 (<20)	35.2 (<20)	5.6 (<20)	18.3 (<20)	5.6 (<20)
White	40.5 (3583)	19.3 (1707)	17.2 (1522)	3.3 (292)	3.0 (265)	3.5 (310)
Gender identity						
Another gender	40.1 (<20)	20.1 (<20)	12.5 (<20)	2.5 (<20)	2.5 (<20)	2.5 (<20)
Man	34.1 (2190)	29.8 (1914)	25.9 (1663)	8.3 (533)	5.8 (372)	6.3 (405)
Multiple gender identities	48.8 (<20)	16.8 (<20)	19.7 (<20)	5.6 (<20)	4.8 (<20)	3.3 (<20)
Nonbinary	47.5 (<20)	13.6 (<20)	10.2 (<20)	0.8 (<20)	1.7 (<20)	2.5 (<20)
Transgender	30.7 (<20)	20.7 (<20)	20.6 (<20)	8.1 (<20)	11.1 (<20)	1.8 (<20)
Woman	35.5 (3604)	21.4 (2173)	20.9 (2122)	5.8 (589)	4.2 (426)	3.3 (335)
Education						
<High school	18.9 (151)	34.4 (274)	36.7 (292)	12.3 (98)	14.4 (115)	6.3 (50)
High school/GED	27.6 (593)	34.5 (741)	33.2 (713)	12.8 (275)	8.9 (191)	7.2 (155)
College 1–3 Years	31.4 (1453)	28.6 (1324)	26.3 (1217)	7.6 (352)	4.2 (194)	3.9 (181)
College Graduate	39.1 (1809)	21.4 (990)	18.6 (860)	4.7 (217)	3.3 (153)	4.4 (204)
Advanced Degree	41.6 (1858)	17.1 (764)	15.8 (706)	4.0 (179)	3.3 (147)	3.6 (161)
Annual household income						
$24,999	28.5 (1271)	33.4 (1489)	30.1 (1342)	10.4 (464)	6.8 (303)	6.3 (281)

Characteristic	Results of Environmental Marker Labs	Medical Records	Results of Routine Labs	Physical Measurements	All of Us Survey Responses	Fitness Tracker Data
$25,000-$49,999	35.7 (943)	23.6 (624)	21.9 (579)	5.4 (143)	3.6 (95)	3.4 (90)
$50,000-$99,999	39.9 (1283)	19.9 (640)	18.9 (608)	3.9 (125)	3.1 (100)	4.3 (138)
$100,000	42.5 (1537)	15.8 (571)	13.7 (495)	3.2 (116)	2.9 (105)	3.2 (116)
Sexual orientation						
Another sexual orientation	40.6 (142)	29.5 (103)	26.5 (93)	10.2 (36)	11.7 (41)	5.7 (20)
Bisexual	38.8 (<20)	21.5 (<20)	16.6 (<20)	7.9 (<20)	2.9 (<20)	3.7 (<20)
Gay	39.4 (247)	30.8 (193)	25.5 (160)	9.2 (58)	4.7 (29)	5.8 (36)
Lesbian	46.6 (<20)	22.7 (<20)	19.4 (<20)	4.7 (<20)	3.0 (<20)	3.6 (<20)
Multiple sexual orientations	48.6 (<20)	17.7 (<20)	42.9 (<20)	0.0 (<20)	0.0 (<20)	3.7 (<20)
Heterosexual/straight	34.5 (5067)	24.3 (3569)	22.7 (3334)	6.4 (940)	4.7 (690)	4.4 (646)
Health literacy						
Low	27.7 (<20)	33.8 (<20)	41.7 (<20)	12.4 (<20)	7.8 (<20)	6.6 (<20)
Medium	28.5 (626)	35.3 (776)	33.2 (729)	12.8 (281)	9.8 (215)	7.4 (163)
High	36.2 (5227)	22.8 (3292)	20.9 (3018)	5.7 (823)	4.0 (578)	3.9 (563)
Preferred language						
English	36.4 (5780)	24.5 (3890)	22.3 (3541)	6.4 (1016)	4.5 (715)	4.5 (715)
Spanish	13.6 (138)	25.9 (262)	31.5 (319)	11.6 (117)	9.9 (100)	3.9 (39)

[a] Data presented in Tables 2 and 3 were collected as part of a single survey question but are shown in 2 separate tables for ease of interpretation.

[b] Data shown are weighted results to allow for generalization to the entire All of Us population and are not raw statistics.

[c] Results should not be interpreted to represent the views of everyone across diverse Tribal Nations or diverse racial/ethnic groups.

[d] Because of All of Us privacy policies, any participant row containing a count of less than 20 must be hidden and marked as "<20."

Table 4

Provider types All of Us participants can access for help understanding genetic information across sociodemographic groups, weighted results[a]

Characteristic	Primary Care Physician	Specialist Physician	Genetic Counselor	Community Health Center	Emergency Department	Unsure	Urgent Care	Don't Have a Place
Sample overall (weighted)								
Overall	74.6 (13564)	61.5 (11182)	45.4 (8255)	12.8 (2327)	10.8 (1964)	10.5 (1909)	10.4 (1891)	3.8 (691)
Race and ethnicity[b]								
American Indian/ Alaskan Native	78.3 (<20)[c]	60.6 (<20)	34.3 (<20)	20.7 (<20)	16.2 (<20)	11.5 (<20)	17.6 (<20)	1.4 (<20)
Another race or ethnicity	71.0 (<20)	59.5 (<20)	47.9 (<20)	10.3 (<20)	8.1 (<20)	14.0 (<20)	9.1 (<20)	4.1 (<20)
Asian	70.5 (397)	60.3 (340)	52.3 (295)	11.2 (63)	7.4 (42)	10.7 (60)	8.7 (49)	3.6 (20)
Black	76.3 (2742)	55.3 (1987)	38.5 (1384)	20.3 (730)	17.0 (611)	12.2 (438)	17.8 (640)	4.9 (176)
Hispanic/Latino	64.3 (2065)	50.3 (1615)	37.0 (1188)	18.8 (604)	10.3 (331)	13.8 (443)	10.2 (328)	7.5 (241)
Middle Eastern/ North African	59.1 (<20)	57.9 (<20)	46.4 (<20)	10.3 (<20)	8.6 (<20)	12.7 (<20)	9.8 (<20)	4.8 (<20)
More than one race or ethnicity	71.8 (347)	61.6 (298)	48.5 (234)	11.9 (58)	10.2 (49)	12.9 (62)	9.7 (47)	5.1 (25)
Pacific Islander	84.0 (<20)	57.0 (<20)	58.0 (<20)	26.0 (<20)	21.0 (<20)	0.0 (<20)	26 (<20)	0.0 (<20)
White	78.0 (7426)	67.7 (6445)	50.4 (4798)	8.0 (762)	8.8 (838)	8.6 (819)	7.8 (743)	2.2 (209)
Gender identity								
Another gender	66.2 (<20)	66.2 (<20)	56.4 (<20)	12.3 (<20)	4.9 (<20)	17.2 (<20)	7.4 (<20)	6.9 (<20)
Man	76.0 (5255)	61.3 (4239)	41.0 (2835)	14.6 (1010)	13.0 (899)	10.3 (712)	13.0 (899)	3.9 (270)
Multiple gender identities	75.2 (<20)	60.0 (<20)	53.9 (<20)	19.5 (<20)	7.0 (<20)	14 (<20)	7.0 (<20)	7.1 (<20)
Nonbinary	72.4 (<20)	58.5 (<20)	53.7 (<20)	10.6 (<20)	4.9 (<20)	18.7 (<20)	4.1 (<20)	6.5 (<20)
Transgender	76.0 (<20)	60.5 (<20)	63.2 (<20)	12.8 (<20)	16.5 (<20)	8.2 (<20)	14.5 (<20)	2.6 (<20)
Woman	73.8 (8065)	61.6 (6731)	48.1 (5256)	11.7 (1279)	9.4 (1027)	10.6 (1158)	8.8 (962)	3.7 (404)
Education								
<High school	60.5 (533)	39.5 (348)	23.6 (208)	25.3 (223)	13.8 (122)	17.2 (152)	14.0 (123)	8.5 (75)
High school/GED	72.6 (1761)	48.6 (1179)	30.9 (749)	19.4 (470)	15.1 (366)	14.5 (352)	15.4 (373)	5.2 (126)
College 1–3 years	75.5 (3746)	60.1 (2982)	41.7 (2069)	14.3 (709)	12.8 (635)	11.2 (556)	11.9 (590)	4.9 (243)
College graduate	77.0 (3799)	66.0 (3257)	50.0 (2467)	11.0 (543)	9.6 (474)	9.1 (449)	9.7 (479)	2.7 (133)
Advanced degree	75.2 (3555)	69.5 (3286)	56.5 (2671)	7.3 (345)	7.0 (331)	7.5 (355)	6.5 (307)	2.0 (95)

Characteristic	Primary Care Physician	Specialist Physician	Genetic Counselor	Community Health Center	Emergency Department	Unsure	Urgent Care	Don't Have a Place
Annual household income								
$24,999	72.9 (3501)	53.5 (2570)	38.5 (1849)	20.0 (961)	15.0 (720)	12.6 (605)	14.8 (711)	5.6 (269)
$25,000–$49,999	76.1 (2167)	60.2 (1714)	43.2 (1230)	12.3 (350)	10.1 (288)	11.3 (322)	9.9 (282)	3.3 (94)
$50,000–$99,999	75.9 (2633)	66.4 (2304)	50.2 (1742)	8.0 (278)	7.7 (267)	8.2 (284)	7.3 (253)	2.8 (97)
$100,000	78.0 (3019)	72.4 (2802)	57.6 (2230)	5.7 (221)	7.0 (271)	6.4 (248)	7.1 (275)	1.5 (58)
Sexual orientation								
Another sexual orientation	70.6 (270)	61.6 (236)	42.7 (164)	20.7 (79)	14.2 (54)	14.0 (54)	14.8 (57)	5.9 (23)
Bisexual	78.7 (<20)	58.8 (<20)	52.9 (<20)	18.8 (<20)	14.9 (<20)	12.4 (<20)	13.7 (<20)	2.5 (<20)
Gay	76.0 (<20)	61.4 (<20)	44.0 (<20)	15.0 (<20)	11.0 (<20)	11.5 (<20)	9.8 (<20)	2.6 (<20)
Lesbian	69.0 (<20)	59.1 (<20)	47.3 (<20)	7.3 (<20)	9.9 (<20)	10.8 (<20)	6.9 (<20)	2.4 (<20)
Multiple sexual orientations	83.7 (<20)	79.1 (<20)	66.5 (<20)	35.2 (<20)	25.2 (<20)	11.9 (<20)	29.9 (<20)	1.4 (<20)
Heterosexual/straight	74.6 (11,787)	61.8 (9765)	45.2 (7142)	12.2 (1928)	10.4 (1643)	10.2 (1612)	10.2 (1612)	3.9 (616)
Health literacy								
Low	67.3 (<20)	39.6 (<20)	26.8 (<20)	17.2 (<20)	8.3 (<20)	19.6 (<20)	7.3 (<20)	4.1 (<20)
Medium	72.1 (1738)	51.0 (1230)	31.7 (764)	20.6 (497)	16.9 (407)	14.7 (354)	15.4 (371)	5.3 (128)
High	75.2 (11,659)	63.5 (9845)	47.8 (7411)	11.5 (1783)	9.9 (1535)	9.7 (1504)	9.7 (1504)	3.6 (558)
Preferred language								
English	76.1 (13,008)	62.5 (10,683)	46.4 (7931)	11.9 (2034)	10.7 (1829)	10.2 (1743)	10.4 (1778)	3.4 (581)
Spanish	51.0 (556)	46.2 (503)	29.0 (316)	26.4 (228)	12.8 (139)	15.0 (163)	11.0 (120)	10.1 (110)

[a] Data shown are weighted results to allow for generalization to the entire All of Us population and are not raw statistics.

[b] Results should not be interpreted to represent the views of everyone across diverse Tribal Nations or diverse racial/ethnic groups.

[c] Because of All of Us privacy policies, any participant row containing a count of less than 20 must be hidden and marked as "<20."