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Design and Implementation of the All of Us Research Program COVID-19 Participant Experience (COPE) Survey

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In response to the rapidly evolving coronavirus disease 2019 (COVID-19) pandemic, the All of Us Research Program longitudinal cohort study developed the COVID-19 Participant Experience (COPE) survey to better understand the pandemic experiences and health impacts of COVID-19 on diverse populations within the United States. Six survey versions were deployed between May 2020 and March 2021, covering mental health, loneliness, activity, substance use, and discrimination, as well as COVID-19 symptoms, testing, treatment, and vaccination. A total of 104,910 All of Us Research Program participants, of whom over 73% were from communities traditionally underrepresented in biomedical research, completed 275,201 surveys; 9,693 completed all 6 surveys. Response rates varied widely among demographic groups and were lower among participants from certain racial and ethnic minority populations, participants with low income or educational attainment, and participants with a Spanish language preference. Survey modifications improved participant response rates between the first and last surveys (13.9% to 16.1%, $P < 0.001$). This paper describes a data set with longitudinal COVID-19 survey data in a large, diverse population that will enable researchers to address important questions related to the pandemic, a data set that is of additional scientific value when combined with the program's other data sources.

COVID-19; diversity; mental health; public health; social determinants of health; social medicine; survey

Abbreviations: COPE, COVID-19 Participant Experience; COVID-19, coronavirus disease 2019; EHR, electronic health record; PHQ-9, Patient Health Questionnaire-9; SMS, short message service.

In December 2019 the global medical community was alerted about a novel virus, severe acute respiratory syndrome coronavirus 2 (SARS-CoV-2), which causes coronavirus disease 2019 (COVID-19) (1). Subsequently, the COVID-19 outbreak spread globally, transforming daily lives. Individuals quarantined in their homes or restricted their activities and social interactions over extended periods, and businesses changed their operations virtually overnight. The pandemic resulted in mental, social, and physical health impacts that devastated many individuals, families, communities, and economies (2).

In addition to posing significant risks to physical health, the COVID-19 pandemic exposed social and mental health challenges across the United States. Data collected about these challenges over the course of the unfolding pandemic could provide insight into experiences of and health impacts on diverse populations within the country. Previous surveys and studies have lacked the sampling scale needed to enable well-powered analyses, the demographic diversity necessary to understand impacts across different populations (3–5), or a longitudinal design that enables researchers to follow the full scope and impact of the pandemic over time (6).

The All of Us Research Program is a longitudinal cohort study that aims to accelerate health research and advance precision medicine by collecting and enabling the study of participant data including electronic health record (EHR) data, surveys, whole genome sequences, and more from one million or more people living in the United States (7). This program is well-positioned to respond to the research challenges posed by the COVID-19 pandemic, having enrolled more than 400,000 participants reflecting the broad diversity of the United States. Eighty-three percent of current participants belong to communities traditionally underrepresented in biomedical research, such as people of certain races, sexual and/or gender minorities, older adults, or people of lower income or education levels; 50% of current participants are from self-identified racial and ethnic minority groups (5, 8). Participants enroll into the program using a Web or mobile application, called the All of Us participant portal. There they may review videos about the program, provide their consent to participate, and agree to share their EHR data. They are then invited to complete a series of online surveys, which include information about their basic demographic characteristics, health, family health history, access to care, and other topics. Many participants also provide biological samples (blood, urine, and/or saliva) as well as physical measurements (height, weight, blood pressure, heart rate, and/or waist/hip circumference). These data are collected, deidentified, encrypted, and made available for research studies through the All of Us Research Hub.

The COVID-19 Participant Experience (COPE) survey was one such participant activity, designed to understand how experiences during the pandemic were affecting people's lives and health, and their communities' health, and how these experiences changed over time. This survey was designed to be responsive to participant feedback, contribute to pressing research questions related to the COVID-19 pandemic, and include assessments that are not commonly included in EHR data. As part of the All of Us Research Program data set, the COPE survey responses can be linked to ongoing EHR data, genomic data, physical measurements, other demographic and health surveys, and data collected from mobile devices. Combined, these resources enable contextual analyses of responses and further the All of Us Research Program data's potential to accelerate health research and medical breakthroughs pertinent to the pandemic.

METHODS

Measures

In addition to COVID-19–specific questions from the NIH Common Data Elements Repository and C-19 app (https://covid.joinzoe.com/), the first version of the COPE survey included the following validated instruments: Patient Health Questionnaire (PHQ)-9 (9), Generalized Anxiety Disorder Assessment (GAD)-7 (10), portions of the UK Biobank's Mental Health and Well-being Questionnaire (11), UCLA Loneliness Scale (12), RAND MOS Social Support Survey Instrument (13), and International Physical Activity Questionnaires (Table 1) (14). In response to feedback from community partners, operational data from the survey rollout, and the evolution of the COVID-19 pandemic, the survey was modified over time, balancing programmatic desire for increased participation rates with relevance and usability of the data for researchers (details of content and operational changes are outlined in Web Table 1, available at https://doi.org/10.1093/aje/kwad035). The strategies incorporated feedback from participants about the length of the initial COPE survey and included simplifying the survey by removing questions that showed little month-to-month variability and removing question sets to enhance survey focus. These actions resulted in reduced burden on survey participants while maintaining scientific integrity.

Six survey versions were launched with corresponding communications reminders on an approximately monthly schedule and remained active in participant portals for an average of 35.3 days (Table 2). The survey initially consisted of 105 stem questions with a total of 158 items available through branching logic. This version of the survey was used for the first 3 administrations. A major survey redesign was deployed 6 months after initial launch, in November 2020, and subsequent versions reduced the number of stem questions to 27 with a total of 75 available through branching (Table 2, Web Table 1).

Resources related to the survey content were embedded in the survey. In addition, participants who selected a nonzero response option on item 9 of the PHQ-9 assessment (denoting any suicidality) were presented a pop-up displaying resources (Web Figure 1) relevant to this risk. These were made available to participants both within the survey itself and within the participant portal.

Study population

The entire All of Us Research Program cohort was invited to complete every administration of the COPE survey provided they had completed the consent process and "The Basics" survey, a baseline questionnaire that collects general profile and demographic information (15). The All of Us Research Program cohort is composed of a voluntary, nonrepresentative sample of adults living across the United States; focus is placed on recruiting individuals from demographically diverse backgrounds. No financial incentives were provided for completion of the COPE surveys.

At the time of analysis, the All of Us Research Program defined "underrepresented in biomedical research" as individuals "with inadequate access to medical care; under the age of 18 or over 65; with an annual household income at or below 200% of the federal poverty level; have less than a high-school education or equivalent; are intersex; identify as a sexual or gender minority; or live in rural or nonmetropolitan areas" (5).

The program has not begun to enroll participants under the age of 18 years. Additionally, the All of Us Research Program is currently developing metrics to calculate the number of participants with physical or mental disabilities and participants experiencing barriers to accessing care. Individuals are considered "represented in biomedical research" if they are not part of an underrepresented population as defined above.

Table 1. Instruments Included in COVID-19 Participant Experience Surveys, United States, 2020–2021

Full Instruments Deployed	Scaled Instruments Deployed	New Questions Deployed
Henry Ford Social Distancing Survey	CDC/NIH Common Data Element Bank	All of Us Research Program "The Basics" survey
Impact of Event Scale–6, based on IES-Revised	Optimism: Life Orientation Test–Revised	All of Us Research Program "Overall Health" survey
RAND Medical Outcomes Study Social Support Survey Instrument	Coronavirus Pandemic Epidemiology Consortium Tool	All of Us Research Program "Lifestyle" survey
Generalized Anxiety Disorder–7	UK Biobank Mental Health and Well-being Questionnaire	
Patient Health Questionnaire–9	Columbia COVID-19 Questionnaire	
Cohen's Perceived Stress Scale	International Physical Activity Questionnaires	
Brief Resilient Coping Scale	UCLA Loneliness Scale	
Everyday Discrimination Scale	Alcohol Use Disorders Identification Test–Concise	
	Texas Christian University Drug Screen 5	

Abbreviations: CDC, Centers for Disease Control; COVID-19, coronavirus disease 2019; IES, Impact of Event Scale; NIH, National Institutes of Health; UCLA, University of California, Los Angeles.

Completion and incompletion definitions

Completion rates were calculated as the fraction of eligible participants in each demographic category who submitted a survey, regardless of how many individual questions were answered or skipped. Participants with null values or who skipped or selected "prefer not to answer" on baseline demographic questions were excluded from the analysis for the associated category.

Surveys were considered complete if submitted via the final survey page, regardless of the quantity of survey questions answered. Incomplete COPE surveys were defined as surveys in which a participant had not clicked a "submit" button on the final page. Survey design across all 6 versions was such that after completing all survey questions, participants were prompted through 1–2 additional screens (depending on COPE version) prior to reaching a final screen, which included a "submit" button. COPE surveys did not include an explicit call to action asking participants to click the "submit" button. The additional screens provided survey respondents with a "thank you" message, mental health and COVID-related resources, and COVID-19 health insights.

Communications strategy

The survey communications strategy consisted of automated messages at the time of survey launch, including direct-to-participant emails, short message service (SMS) text messages; in-portal notifications (short alerts that participants can see when they log into their All of Us Research Program account), and push notifications (alerts sent to participants who have downloaded the All of Us Research Program app to their mobile devices). Subsequent emails, SMS, and push notifications were delivered 2 additional times throughout each survey deployment period to

Table 2. COVID-19 Participant Experience Survey Version Specifications, United States, 2020–2021

COPE Version	Survey Start Date	Survey End Date	No. of Primary Questions	Number of Questions (With Branching Logic)	No. of Days Survey Was Available	Median Completion Time (Minutes: Seconds)
May 2020	5/7/20	5/29/20	105	158	21 days	20:43
June 2020	6/2/20	6/26/20	105	129	23 days	19:53
July 2020	7/7/20	09/25/20	102	168	80 days	19:00
November 2020	10/27/20	12/3/20	27	72	37 days	8:58
December 2020	12/8/20	1/4/21	27	72	27 days	8:38
February 2021	2/9/21	3/5/21	27	75	24 days	8:58

Abbreviations: COVID-19, coronavirus disease 2019; COPE, COVID-19 Participant Experience participants who had not already completed the relevant survey. Each reminder message was spaced between 6 and 13 days from the most recent reminder message. Throughout the campaign, communications were iterated to include embedded images, targeted textual content, and participant testimonials, attempts to increase the survey completion rates.

The February COPE survey integrated 2 significant changes from previous COPE surveys. First, the survey was accessible through a link in the notifications that allowed most participants to complete the survey without having to recall login information (i.e., direct link and no login-required feature). Second, in addition to being able to complete the survey online on their own, participants were able to work with trained program staff using computer-assisted telephone interviewing, which enabled them to complete the survey over the phone instead of being dependent on digital access to the survey.

Survey and data cataloging

COPE survey concepts were cataloged according to the Observational Medical Outcomes Partnership (OMOP) data model and made publicly searchable via the online Athena repository (https://athena.ohdsi.org/). Formatted REDCap data dictionary versions of the survey instruments are also available for download through the REDCap Consortium's Shared Library (16, 17), which is freely accessible to researchers from affiliated institutions.

Statistical comparisons of response rates were made with 2-sample proportion z-tests assuming a 2-tailed distribution and carried out with Microsoft Excel, version 16 (Redmond, Washington).

RESULTS

Survey completion rates according to participant demographics

A total of 104,910 out of 342,204 eligible All of Us Research Program participants completed at least 1 COPE survey for an overall response rate of 30.7% (Table 3, Table 4). Participants from communities underrepresented in biomedical research were less likely to complete at least 1 survey (73,787 of 275,077 participants or 26.8%) than participants from communities represented in biomedical research (31,123 of 67,127 or 46.4%, $P < 0.001$). The survey was completed a total of 275,201 times by 104,910 unique participants. All 6 surveys were completed by 2,879 (4.5%) participants from communities represented in biomedical research and 6,814 (2.6%) participants from communities underrepresented in biomedical research ($P < 0.001$) (Web Figure 2). A mean of 45,867 responses were received per survey version. Overall, the proportion of participants from communities underrepresented in biomedical research was the same for those that completed at least 1 COPE survey and those that completed all 6 (70.3%).

Survey completion rates of any COPE survey were significantly lower among eligible self-identified Black (10.8%) and Latino (11.7%) participants compared with White (46.2%) participants (both $P < 0.001$); among participants with annual incomes below 200% of the individual federal poverty level (13.9%) compared with those with annual incomes above $200,000 (53.9%, $P < 0.001$); among participants who had less than high-school educations (4.5%) compared with college graduates (48.3%, $P < 0.001$); and among eligible participants preferring the Spanish language versions (8.2%), compared with eligible participants preferring the English language versions (32.1%, $P < 0.001$) of the COPE surveys (Tables 3 and 4). Completion rates across geographic lines varied, with total response rates of eligible participants ranging from 10% in Mississippi to 64% in Maine (Figure 1).

Survey completion rates according to survey version

The longer survey versions (May, June, and July 2020) garnered an average response rate of 12.4%, while the streamlined version in November and December 2020 and February 2021 had a 15.2% average response rate from participants. The impact of streamlining and simplification of the survey was notable: The highest response month after streamlining (February, 16.1%) had a 2.2% higher response rate than the highest response rate before streamlining (May, 13.9%, $P < 0.001$). The June survey had the lowest response rate (10.6%). For the first 3 surveys (May, June, and July 2020), median completion time ranged from 19 to 21 minutes, while for November, December, and February surveys, median completion time ranged from 8 to 9 minutes (Table 2).

A total of 113 COPE February surveys were completed using computer-assisted telephone interviewing, 102 (or 90.27%) of which were for participants from communities underrepresented in biomedical research.

Resource provision and addressing questions regarding suicidality

The pop-up displaying resources to participants with any level of suicide risk was displayed 15,571 times across all survey versions, meaning that an average of 5.5% of respondents were shown the pop-up in any survey month (Web Figure 1). Participants from sexual and/or gender minority groups as well as individuals with lower incomes had the highest suicide pop-up display rate, at above 12% for all surveys.

Incomplete survey responses

Overall, across the 6 survey versions, there were a total of 22,166 incomplete surveys. Incompletion rates were not meaningfully different between represented and underrepresented survey respondents (Web Table 2). The February survey, which incorporated the direct link and no-login-required feature, had higher numbers of both survey completions and incompletions compared with earlier versions of the survey. The number of complete surveys increased by 7.7% (from 50,993 to 54,930) between the December and February COPE surveys, and incomplete surveys increased by 380% (from 2,590 to 9,860) (Web Table 2).

Table 3. COVID-19 Participant Experience Survey Completion Rates According to Participant Demographic Characteristics, United States, May 2020 to July 2020

Representation	All of Us Full Cohort		May 2020			June 2020			July 2020			Any Summer Survey (May, June, or July)		
	No. Eligible	%	No.	Eligible	%	No.	Eligible	%	No.	Eligible	%	No.	Eligible	%
All research program participants	342,204	100	44,917	323,753	13.9	34,393	325,559	10.6	41,792	327,702	12.8	71,553	327,702	21.8
Representation														
UBR overall	275,077	80.4	30,341	261,313	11.6	23,893	262,711	9.1	28,923	264,321	10.9	49,076	264,321	18.6
RBR overall	67,127	19.6	14,576	62,440	23.3	10,500	62,848	16.7	12,869	63,381	20.3	22,477	63,381	35.5
UBR sexual orientation	35,824	10.5	4,540	33,422	13.6	3,427	33,635	10.2	4,312	33,868	12.7	7,316	33,868	21.6
UBR gender identity	15,020	4.4	1,761	14,261	12.3	1,329	14,367	9.3	1,554	14,466	10.7	2,744	14,466	19.0
UBR race/ethnicity	163,752	47.9	8,280	159,107	5.2	5,934	159,554	3.7	7,695	159,972	4.8	14,491	159,972	9.1
UBR geography	22,920	6.7	3,884	20,817	18.7	3,207	21,097	15.2	3,824	21,490	17.8	6,380	21,490	29.7
UBR education	34,260	10.0	344	33,917	1.0	247	33,948	0.7	387	33,976	1.1	697	33,976	2.1
UBR income	96,442	28.2	4,615	93,853	4.9	3,540	94,122	3.8	4,568	94,372	4.8	8,070	94,372	8.6
UBR age at consent	81,367	23.8	16,126	75,522	21.4	13,638	76,152	17.9	15,529	76,909	20.2	25,062	76,909	32.6
Age at enrollment														
18–25	26,980	7.9	1,705	25,859	6.6	1,039	25,943	4.0	1,496	26,047	5.7	2,915	26,047	11.2
26–35	52,397	15.3	4,902	49,839	9.8	3,259	50,033	6.5	4,352	50,291	8.7	8,165	50,291	16.2
36–45	50,565	14.8	5,203	47,953	10.9	3,511	48,164	7.3	4,757	48,421	9.8	8,577	48,421	17.7
46–55	61,576	18.0	6,933	58,726	11.8	5,007	59,010	8.5	6,328	59,323	10.7	11,087	59,323	18.7
56–65	73,207	21.4	10,828	69,517	15.6	8,582	69,949	12.3	10,075	70,425	14.3	16,943	70,425	24.1
66–75[a]	55,637	16.3	11,729	51,508	22.8	9,912	51,971	19.1	11,445	52,512	21.8	18,161	52,512	34.6
76–85[a]	18,941	5.5	3,345	17,620	19.0	2,843	17,741	16.0	3,058	17,916	17.1	5,223	17,916	29.2
≥86[a]	2,893	0.8	271	2,724	9.9	239	2,741	8.7	281	2,760	10.2	480	2,760	17.4
Race														
Asian[a]	10,694	3.1	1,211	10,082	12.0	821	10,144	8.1	1,074	10,190	10.5	2,016	10,190	19.8
Black or African American[a]	67,817	19.8	2,240	66,474	3.4	1,646	66,641	2.5	2,183	66,778	3.3	4,057	66,778	6.1
HLS only[a]	53,143	15.5	1,890	52,103	3.6	1,315	52,198	2.5	2,087	52,290	4.0	3,657	52,290	7.0
HLS and White[a]	4,836	1.4	611	4,500	13.6	423	4,533	9.3	672	4,561	14.7	1,024	4,561	22.5
More than 1 race[a]	12,750	3.7	1,374	12,029	11.4	1,057	12,080	8.8	926	12,143	7.6	2,166	12,143	17.8
HLS and non-White race[a]	17,627	5.2	1,721	16,702	32.0	1,292	16,765	22.5	1,156	16,842	22.0	2,737	16,842	52.1
Other race[a]	9,547	2.8	597	9,158	25.8	432	9,185	18.3	518	9,223	21.3	987	9,223	41.8

Table continues

Table 3. Continued

Representation	All of Us Full Cohort		May 2020			June 2020			July 2020			Any Summer Survey (May, June, or July)		
	No. Eligible	%	No.	Eligible	%	No.	Eligible	%	No.	Eligible	%	No.	Eligible	%
Unset, skip, or prefer not to answer	6,175	1.8	499	5,664	8.8	382	5,705	6.7	503	5,751	8.7	862	5,751	15.0
White	172,365	50.4	36,148	159,070	22.7	28,082	160,388	17.5	33,599	162,067	20.7	56,213	162,067	34.7
Sex assigned at birth														
Female	207,317	60.6	29,366	195,836	15.0	22,224	196,995	11.3	27,491	198,325	13.9	47,062	198,325	23.7
Male	130,432	38.1	15,274	123,642	12.4	11,946	124,269	9.6	14,003	125,059	11.2	24,000	125,059	19.2
Unset, intersex[a], none of these describe me[a], skip, or prefer not to answer	4,455	1.3	277	4,275	18.5	223	4,295	13.5	298	4,318	22.3	491	4,318	32.9
Gender identity														
Man	129,882	38.0	15,174	123,151	12.3	11,869	123,776	9.6	13,912	124,566	11.2	23,858	124,566	19.2
Nonbinary[a]	1,119	0.3	211	994	21.2	149	1,005	14.8	202	1,015	19.9	330	1,015	32.5
Transgender[a]	1,031	0.3	190	924	20.6	144	927	15.5	191	937	20.4	301	937	32.1
Unset, skip, none of these describe me[a], or prefer not to answer	4,158	1.2	264	3,978	20.0	220	3,997	15.3	296	4,010	22.9	486	4,010	35.9
Woman	206,014	60.2	29,078	194,706	14.9	22,011	195,854	11.2	27,191	197,174	13.8	46,578	197,174	23.6
Sexual orientation														
Bisexual[a]	12,221	3.6	1,618	11,208	14.4	1,211	11,301	10.7	1,584	11,384	13.9	2,672	11,384	23.5
Gay[a]	7,853	2.3	1,293	7,302	17.7	987	7,347	13.4	1,184	7,410	16.0	1,994	7,410	26.9
Lesbian[a]	4,275	1.2	701	3,979	17.6	512	4,004	12.8	641	4,038	15.9	1,096	4,038	27.1
None of these describe me, and I'd like to see additional options[a]	7,102	2.1	721	6,705	10.8	532	6,736	7.9	672	6,771	9.9	1,164	6,771	17.2
Straight, i.e., not gay or lesbian	301,298	88.0	40,144	285,402	14.1	30,784	286,980	10.7	37,245	288,876	12.9	63,805	288,876	22.1
Unset, skip, or prefer not to answer	9,455	2.8	440	9,157	4.8	367	9,191	4.0	466	9,223	5.1	822	9,223	8.9

Table continues

Table 3. Continued

Representation	All of Us Full Cohort		May 2020			June 2020			July 2020			Any Summer Survey (May, June, or July)		
	No. Eligible	%	No.	Eligible	%	No.	Eligible	%	No.	Eligible	%	No.	Eligible	%
Income, $														
<10,000[a]	53,928	15.8	1,438	52,957	2.7	1,058	53,060	2.0	1,469	53,141	2.8	2,697	53,141	5.1
10,000–24,999[a]	42,514	12.4	3,177	40,896	7.8	2,482	41,062	6.0	3,099	41,231	7.5	5,373	41,231	13.0
25,000–34,999	24,801	7.2	2,749	23,559	11.7	2,142	23,675	9.0	2,714	23,793	11.4	4,543	23,793	19.1
35,000–49,999	26,599	7.8	4,033	24,871	16.2	3,138	25,030	12.5	3,859	25,238	15.3	6,556	25,238	26.0
50,000–74,999	34,618	10.1	6,838	31,870	21.5	5,270	32,148	16.4	6,438	32,523	19.8	10,805	32,523	33.2
75,000–99,999	26,320	7.7	6,019	24,009	25.1	4,657	24,225	19.2	5,593	24,526	22.8	9,431	24,526	38.5
100,000–149,999	32,116	9.4	8,076	29,173	27.7	6,392	29,475	21.7	7,364	29,842	24.7	12,456	29,842	41.7
150,000–199,999	14,688	4.3	3,900	13,304	29.3	2,832	13,445	21.1	3,499	13,603	25.7	5,936	13,603	43.6
≥200,000	20,035	5.9	5,171	18,270	28.3	3,768	18,431	20.4	4,464	18,622	24.0	7,873	18,622	42.3
Unset, skip, or prefer not to answer	66,585	19.5	3,516	64,844	5.4	2,654	65,008	4.1	3,293	65,183	5.1	5,883	65,183	9.0
Education														
Never attended school or only attended kindergarten[a]	523	0.2	<20	519		<20	519		<20	519		<20	519	
Grades 1–4 (primary)[a]	2,974	0.9	<20	2,958		<20	2,960		<20		2,960	<20	2,960	
Grades 5–8 (middle school)[a]	8,010	2.3	73	7,941	0.9	52	7,948	0.7	79	7,952	1.0	142	7,952	1.8
Grades 9–11 (Some high school)[a]	22,753	6.6	260	22,499	1.2	191	22,521	0.8	295	22,545	1.3	531	22,545	2.4
Grade 12 or GED (high-school graduate)	68,818	20.1	2,931	67,120	4.4	2,282	67,293	3.4	2,821	67,473	4.2	5,072	67,473	7.5
Some college, associate's degree or technical school	87,928	25.7	9,791	83,220	11.8	7,431	83,701	8.9	9,521	84,223	11.3	16,155	84,223	19.2
College 4 years or more (college graduate)	73,879	21.6	14,237	68,426	20.8	10,892	68,958	15.8	12,979	69,582	18.7	22,417	69,582	32.2
Advanced degree (master's, doctorate, etc.)	69,332	20.3	17,368	63,321	27.4	13,371	63,889	20.9	15,838	64,657	24.5	26,786	64,657	41.4
Unset, skip, or prefer not to answer	7,987	2.3	246	7,749	3.2	170	7,770	2.2	246	7,791	3.2	426	7,791	5.5
Primary language														
English	321,952	94.1	44,532	303,665	14.7	34,114	305,443	11.2	41,312	307,574	13.4	70,736	307,574	23.0
Spanish	20,251	5.9	385	20,088	1.9	279	20,116	1.4	479	20,128	2.4	816	20,128	4.1

Abbreviations: COVID-19, coronavirus disease 2019; GED, General Educational Development; HLS, Hispanic, Latino, or Spanish; RBR, represented in biomedical research; UBR, underrepresented in biomedical research.

[a] Underrepresented in biomedical research groups.

Table 4. COVID-19 Participant Experience Survey Completion Rates According to Participant Demographic Characteristics, United States, November 2020 to February 2021

Representation	November 2020			December 2020			February 2021			Any Survey Version			All Survey Versions		
	No.	Eligible	%	No.	Eligible	%	No.	Eligible	%	No.	Eligible	%	No.	Eligible	%
All research program participants	48,314	335,019	14.4	50,841	337,325	15.1	54,944	342,204	16.1	104,910	342,204	30.7	9,693	327,702	3.0
Representation															
UBR overall	33,708	269,727	12.5	35,615	271,467	13.1	40,270	275,077	14.6	73,787	275,077	26.8	6,814	264,321	2.6
RBR overall	14,606	65,292	22.4	15,226	65,858	23.1	14,674	67,127	21.9	31,123	67,127	46.4	2,879	63,381	4.5
UBR sexual orientation	4,816	34,871	13.8	5,199	35,190	14.8	5,439	35,824	15.2	10,877	35,824	30.4	976	33,868	2.9
UBR gender identity	1,655	14,744	11.2	1,840	14,844	12.4	1,924	15,020	12.8	3,962	15,020	26.4	352	14,466	2.4
UBR race/ethnicity	8,476	161,806	5.2	9,114	162,450	5.6	11,216	163,752	6.8	23,829	163,752	14.6	1,182	159,972	0.7
UBR geography	4,303	22,203	19.4	4,533	22,463	20.2	4,948	22,920	21.6	9,221	22,920	40.2	873	21,490	4.1
UBR education	447	34,087	1.3	426	34,156	1.2	791	34,260	2.3	1,535	34,260	4.5	39	33,976	0.1
UBR income	5,082	95,413	5.3	5,532	95,756	5.8	6,609	96,442	6.9	13,388	96,442	13.9	810	94,372	0.9
UBR age at consent	19,360	79,119	24.5	20,142	79,827	25.2	23,290	81,367	28.6	36,724	81,367	45.1	4,475	76,909	5.8
Age at enrollment[a]															
18–25	1,413	26,495	5.3	1,540	26,672	5.8	1,523	26,980	5.6	4,332	26,980	16.1	184	26,047	0.7
26–35	4,315	51,381	8.4	4,573	51,702	8.8	4,573	52,397	8.7	11,775	52,397	22.5	716	50,291	1.4
36–45	4,965	49,525	10.0	5,305	49,861	10.6	5,350	50,565	10.6	12,709	50,565	25.1	755	48,421	1.6
46–55	7,112	60,469	11.8	7,498	60,819	12.3	7,785	61,576	12.6	16,383	61,576	26.6	1,234	59,323	2.1
56–65	12,038	71,829	16.8	12,723	72,274	17.6	13,462	73,207	18.4	24,677	73,207	33.7	2,557	70,425	3.6
66–75[b]	14,096	54,060	26.1	14,627	54,567	26.8	16,415	55,637	29.5	26,186	55,637	47.1	3,341	52,512	6.4
76–85[b]	4,005	18,421	21.7	4,208	18,574	22.7	5,319	18,941	28.1	8,042	18,941	42.5	853	17,916	4.8
≥86[b]	369	2,832	13.0	366	2,849	12.8	516	2,893	17.8	804	2,893	27.8	53	2,760	1.9
Race[c]															
Asian[b]	1,091	10,464	10.4	1,130	10,533	10.7	1,245	10,694	11.6	2,902	10,694	27.1	211	10,190	2.1
Black or African American[b]	2,516	67,320	3.7	2,699	67,490	4.0	3,594	67,817	5.3	7,297	67,817	10.8	328	66,778	0.5
HLS only[b]	1,945	52,677	3.7	2,064	52,821	3.9	2,816	53,143	5.3	6,214	53,143	11.7	221	52,290	0.4
HLS and White[b]	622	4,681	13.3	645	4,729	13.6	697	4,836	14.4	1,471	4,836	30.4	124	4,561	2.7
More than 1 race[b]	1,403	12,433	11.3	1,557	12,550	12.4	1,670	12,750	13.1	3,418	12,750	26.8	183	12,143	1.5

Table continues

Table 4. Continued

Representation	November 2020			December 2020			February 2021			Any Survey Version			All Survey Versions		
	No.	Eligible	%	No.	Eligible	%	No.	Eligible	%	No.	Eligible	%	No.	Eligible	%
HLS and non-White race[b]	1,690	17,224	28.2	1,905	17,367	32.7	2,091	17,627	37.3	4,329	17,627	24.6	209	16,842	3.1
Other race[b]	604	9,352	25.6	666	9,422	27.1	764	9,547	30.2	1,600	9,547	64.3	88	9,223	3.8
Unset, skip, or prefer not to answer	602	5,951	10.1	654	6,027	10.9	804	6,175	13.0	1,452	6,175	23.5	89	5,751	1.5
White	39,244	167,350	23.5	41,078	168,936	24.3	42,933	172,365	24.9	79,645	172,365	46.2	8,423	162,067	5.2
Sex assigned at birth															
Female	31,216	202,930	15.4	32,854	204,354	16.1	35,379	207,317	17.1	68,788	207,317	33.2	5,988	198,325	3.0
Male	16,759	127,693	13.1	17,595	128,549	13.7	19,137	130,432	14.7	35,310	130,432	27.1	3,650	125,059	2.9
Unset, intersex[b], none of these describe me[a], skip, or prefer not to answer	339	4,396	20.9	392	4,422	29.5	428	4,455	26.8	812	4,455	51.0	55	4,318	5.1
Gender identity															
Man	16,661	127,172	13.1	17,498	128,022	13.7	19,035	129,882	14.7	35,093	129,882	27.0	3,632	124,566	2.9
Nonbinary[b]	202	1,070	18.9	219	1,086	20.2	238	1,119	21.3	495	1,119	44.2	47	1,015	4.6
Transgender[b]	178	996	17.9	189	1,008	18.8	204	1,031	19.8	410	1,031	39.8	50	937	5.3
Unset, skip, none of these describe me[b], or prefer not to answer	326	4,092	23.9	371	4,115	27.1	413	4,158	24.6	794	4,158	51.3	53	4,010	4.8
Woman	30,947	201,689	15.3	32,564	203,094	16.0	35,054	206,014	17.0	68,118	206,014	33.1	5,911	197,174	3.0
Sexual orientation															
Bisexual[b]	1,654	11,818	14.0	1,802	11,952	15.1	1,872	12,221	15.3	3,942	12,221	32.3	321	11,384	2.8
Gay[a]	1,421	7,647	18.6	1,526	7,713	19.8	1,521	7,853	19.4	2,929	7,853	37.3	321	7,410	4.3
Lesbian[b]	753	4,157	18.1	778	4,191	18.6	803	4,275	18.8	1,565	4,275	36.6	146	4,038	3.6
None of these describe me[a]	704	6,927	10.2	791	6,991	11.3	871	7,102	12.3	1,765	7,102	24.9	145	6,771	2.1
Straight, i.e., not gay or lesbian	43,243	295,128	14.7	45,363	297,087	15.3	49,172	301,298	16.3	93,342	301,298	31.0	8,685	288,876	3.0
Unset, skip, or prefer not to answer	539	9,342	5.8	581	9,391	6.2	705	9,455	7.5	1,367	9,455	14.5	75	9,223	0.8

Table continues

Table 4. Continued

Representation	November 2020			December 2020			February 2021			Any Survey Version			All Survey Versions		
	No.	Eligible	%	No.	Eligible	%	No.	Eligible	%	No.	Eligible	%	No.	Eligible	%
Income, $															
<10,000[a]	1,578	53,498	2.9	1,732	53,640	3.2	2,137	53,928	4.0	4,695	53,928	8.7	200	53,141	0.4
10,000–24,999[a]	3,504	41,915	8.4	3,800	42,116	9.0	4,472	42,514	10.5	8,693	42,514	20.4	610	41,231	1.5
25,000–34,999	3,013	24,288	12.4	3,185	24,462	13.0	3,609	24,801	14.6	6,959	24,801	28.1	597	23,793	2.5
35,000–49,999	4,384	25,912	16.9	4,570	26,128	17.5	5,217	26,599	19.6	9,673	26,599	36.4	868	25,238	3.4
50,000–74,999	7,417	33,607	22.1	7,790	33,931	23.0	8,390	34,618	24.2	15,565	34,618	45.0	1,579	32,523	4.9
75,000–99,999	6,485	25,473	25.5	6,822	25,751	26.5	7,185	26,320	27.3	13,372	26,320	50.8	1,380	24,526	5.6
100,000–149,999	8,667	30,985	28.0	9,134	31,333	29.2	9,191	32,116	28.6	17,363	32,116	54.1	1,867	29,842	6.3
150,000–199,999	4,064	14,135	28.8	4,238	14,279	29.7	4,207	14,688	28.6	8,146	14,688	55.5	863	13,603	6.3
≥200,000	5,322	19,366	27.5	5,461	19,584	27.9	5,360	20,035	26.8	10,799	20,035	53.9	1,086	18,622	5.8
Unset, skip, or prefer not to answer	3,880	65,840	5.9	4,109	66,101	6.2	5,176	66,585	7.8	9,645	66,585	14.5	643	65,183	1.0
Education															
Never attended school or only attended kindergarten[b]	<20	521		<20	521		<20	523		<20	523		<20	519	
Grades 1–4 (primary)[a]	<20	2,967		<20	2,970		51	2,974	1.7	80	2,974	2.7	<20	2,960	
Grades 5–8 (middle school)[b]	100	7,972	1.3	84	7,989	1.1	210	8,010	2.6	368	8,010	4.6	<20	7,952	
Grades 9–11 (some high school)[b]	332	22,627	1.5	332	22,676	1.5	526	22,753	2.3	1,080	22,753	4.7	31	22,545	0.1
Grade 12 or GED (high-school graduate)	3,335	68,097	4.9	3,518	68,359	5.1	4,392	68,818	6.4	8,562	68,818	12.4	536	67,473	0.8

Table continues

Table 4. Continued

Representation	November 2020			December 2020			February 2021			Any Survey Version			All Survey Versions		
	No.	**Eligible**	**%**	**No.**	**Eligible**	**%**	**No.**	**Eligible**	**%**	**No.**	**Eligible**	**%**	**No.**	**Eligible**	**%**
Some college, associate's degree or technical school	10,685	85,992	12.4	11,466	86,605	13.2	12,906	87,928	14.7	24,861	87,928	28.3	1,966	84,223	2.3
College 4 years or more (college graduate)	14,849	71,818	20.7	15,799	72,473	21.8	16,489	73,879	22.3	31,871	73,879	43.1	3,056	69,582	4.4
Advanced degree (master's, doctorate, etc.)	18,671	67,134	27.8	19,320	67,801	28.5	19,972	69,332	28.8	37,323	69,332	53.8	4,051	64,657	6.3
Unset, skip, or prefer not to answer	327	7,891	4.1	312	7,931	3.9	394	7,987	4.9	758	7,987	9.5	45	7,791	0.6
Primary language[d]															
English	47,912	314,825	15.2	50,429	317,114	15.9	54,049	321,952	16.8	103,244	321,952	32.1	9,656	307,574	3.1
Spanish	402	20,193	2.0	412	20,210	2.0	895	20,251	4.4	1,665	20,251	8.2	37	20,128	0.2

Abbreviations: COVID-19, coronavirus disease 2019; GED, General Educational Development; HLS, Hispanic, Latino, or Spanish; RBR, represented in biomedical research; UBR, underrepresented in biomedical research.

[a] Total number of participants in the age category does not sum to the total participant number because it was pulled from the data resource at a later date after which 8 participants had withdrawn from the program.

[b] Underrepresented in biomedical research groups.

[c] Participants are counted in more than 1 category resulting in a sum greater than the total number of participants.

[d] Total number of participants in the language category does not sum to the total participant number because it was pulled from the data resource at a later date after which a single participant had withdrawn from the program.

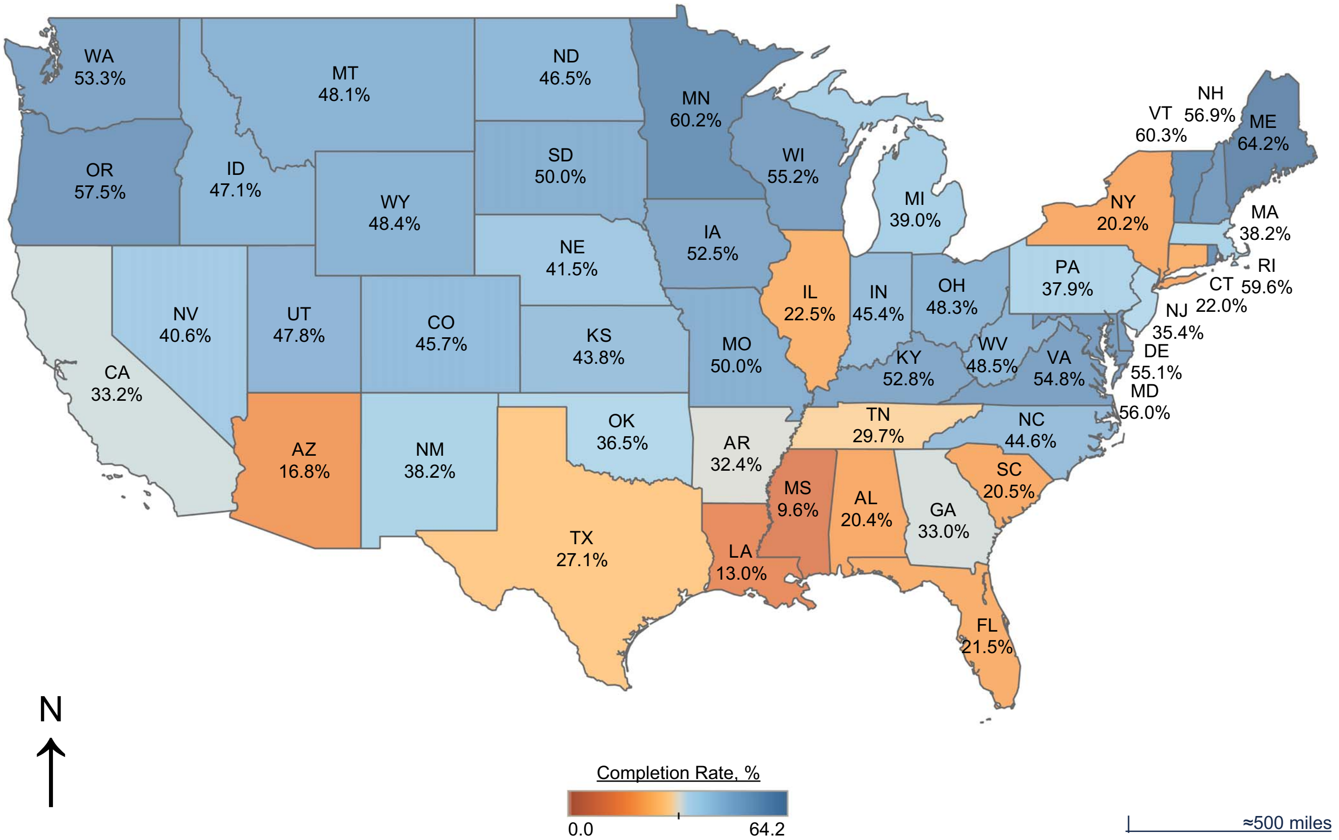

Figure 1. COVID-19 Participant Experience (COPE) survey completion according to state, 2020–2022. COPE survey completion rates varied widely, ranging from 9.6% (Mississippi) to 64.2% (Maine) and showing large regional differences. COVID-19, coronavirus disease 2019.

DISCUSSION

The COPE survey represents the All of Us Research Program's first longitudinal survey data collection effort and first data on COVID-19, mental health, and social determinants of health (15). The COPE survey and accompanying analysis represent important steps in understanding the impact of the COVID-19 pandemic in general, and specifically among individuals from communities underrepresented in biomedical research. The COPE survey adds elements to the All of Us Research Program's data set that could significantly affect health outcomes but are not typically captured in EHR data. These data, along with accompanying program data, are currently available to the research community through the All of Us Researcher Workbench (https://www.researchallofus.org/).

The COPE survey efforts provided insight into the effect of survey modifications on survey completions at scale and across diverse populations. While the general trend was increased survey completions for each iteration of the COPE survey after the second survey, disparities in response rates among demographic groups remained regardless of survey content or implementation changes. It is important to note that a systematic scientific approach to increasing survey completions among disparate populations was not the goal of the COPE survey. Instead, small iterative changes were made to improve the participant experience over time while maintaining the scientific integrity of the overall COPE assessment survey. Some of the changes (e.g., shortening the survey, enhancing email communications, implementing direct links) appeared to increase overall survey completion rates, whereas other changes (location of resources, explicitness of "submit" button) generated unanticipated consequences, such as increased numbers of incomplete survey responses. Computer-assisted telephone interviewing interactions were a pilot method for the program; the relatively small number of completions (113/59,944, or 0.2% of February responders) cannot be credited for the significant increase in COPE February response rates. However, because some participants prefer the telephonic method, the All of Us Research Program has expanded the use of this method for other program surveys.

Given the urgency and emergent nature of the COVID-19 pandemic, the COPE survey was conceived, designed, and administered rapidly. Programmatic prioritization of COPE survey development in response to the surging pandemic enabled streamlining of the regulatory processes and empowered the COPE survey development team in its rapid action. As a result, the timeline from development to survey rollout was markedly shorter than it was for past All of Us

Research Program surveys, spanning just over 1 month from concept approval to first survey deployment.

Due to the program's desire to swiftly respond to the evolving pandemic, some risks were accepted during the development of the COPE survey. Primarily, cognitive and user testing were done only on subsections of the survey, not on the survey as a whole. The program held multiple listening sessions with participants, community partners, and frontline staff, although due to the shortened development timeline for the survey not all recommendations from these listening sessions could be implemented. Finally, while the COPE survey incorporated previously validated scales when possible and was consistent with the NIH Common Data Elements repository (https://cde.nlm.nih.gov/home), not all survey items were validated prior to the survey launch.

One consistent element across all COPE survey deployments was the inclusion of a set of resources available to participants. Given the challenging times in which the COPE survey was deployed and the inclusion of suicide assessment questions, the team deemed it necessary to provide support for those in need. Resources were presented based on a conditional response during the PHQ-9 assessment for select participants, and again at the end of the survey for all participants (Web Table 3). This represents a well-balanced approach and a comprehensive method for supporting participants in a digital manner when asking questions related to suicide.

The burden of the COVID-19 pandemic has disproportionately fallen on persons belonging to racial and ethnic minority groups (18), on individuals with low levels of income and education (19), and on sexual and gender minority communities (20), all of whom are often underrepresented in biomedical research. This survey successfully collected data from these demographic groups, which can be combined with EHR data, genomics, and data collected from mobile devices within the All of Us Researcher Workbench. Compared with other large longitudinal studies and surveys, COPE survey respondents represent a significantly more diverse population. For example, the Framingham Heart Study consists of predominantly White participants, leading to known racial and ethnic disparities in predictive capabilities (4). Similarly, the Nurses' Health Study includes women, with self-identified racial and ethnic minorities comprising 14% of respondents (21), and the UK Biobank is less than 5% non-White (22).

COPE survey respondents were not demographically representative of the All of Us Research Program cohort overall, being more frequently White and older, with higher levels of income and education. Similar patterns in survey completion rates by demographic category have been seen in other surveys completed by All of Us Research Program participants. Notably, survey completion patterns for other postenrollment surveys mirror those of the COPE survey (56.2% response rates in secondary surveys from participants belonging to communities well represented in biomedical research vs. 33.3% response rates in secondary surveys from participants belonging to communities traditionally underrepresented in biomedical research) (15). However, these other surveys were largely completed before the pandemic, with different timing and communications strategies. While not directly comparable, lower response rates from certain underrepresented communities are commonly observed in patient surveys (23, 24) and might be affected by a variety of factors for different individuals and groups, including justified distrust of the medical establishment, divided attention due to competing priorities and concerns, lack of access to stable internet, or lower internet literacy. Programmatic outreach and retention strategies must address the challenges faced by underrepresented communities in order to lower barriers to completion and improve equitable access. Additionally, the COVID-19 pandemic may have created unique disproportionate barriers to survey completion, such as lack of time or interest due to life stressors such as loss of employment, essential-worker status, lack of childcare, lack of stable housing, and COVID-19-related illness, among others (25). The All of Us Research Program data set does not currently include detailed data on occupation, which is likely correlated with COVID-19–related risks and behaviors and may be considered a strong unmeasured confounder. The All of Us Research Program intends to collect occupational history in the future, enabling future data releases to include participant occupation history.

Highly differential survey response rates among demographic groups indicate that COPE survey results may not be generalizable to the full All of Us Research Program cohort or US population. Response rate disparities are compounded among cross-tabulations of multiple demographic categories (data not shown but available in the All of Us Researcher Workbench). The application of appropriate weighting would reduce but not remove the impact of this nonresponse bias due to the inability to correct for unmeasured factors. Researchers using COPE data in the All of Us Researcher Workbench will need to apply appropriate statistical techniques to manage missingness and bias. When conducted with appropriate caution, descriptive analysis leading to the development of research questions for future studies may be the most obvious use case for COPE survey data. Causal analyses require particular attention to understanding the limitations of the COPE data set, although the All of Us Research Program is well positioned to support researchers in this process. Research support is offered in the All of Us Researcher Workbench through educational resources (written documentation, videos, tutorials, interactive forums); sample, tutorial, and example notebooks; virtual office hours offering 1:1 support from data scientists; and a review board of experienced scientists and statisticians available to review workbooks for potential bias or stigmatizing research. As of this publication, a demonstration project led by a team of experienced researchers using COPE survey data was completed, and a tutorial notebook guiding users through analysis is being made available to researchers. Demonstration projects are intended to provide an example of minimally biased, high-integrity research and methods for less experienced researchers. Additionally, external resources are available to help researchers understand and apply techniques to appropriately handle selection bias and to conduct bias analysis or other techniques (26–28). The longitudinal complexity of the data and strong temporal trends in COVID-19 risk and associated health behaviors admittedly require rigorous analytical treatment and acknowledgement of limitations by researchers using the data set.

Survey completion strategies we found to be successful in the COPE survey and plan to retain for future surveys include sending direct, no-login-required links from email and SMS messages; reducing survey length; incorporating testimonials and personal stories as part of the messaging platform; and working across the All of Us Research Program consortium to build national-to-local outreach in ways that are integrated into the larger communications strategy. Many of these strategies were suggested by community partners and participants during listening sessions specific to the COPE survey.

Regarding incomplete surveys, we hypothesize that aspects of the user experience design, such as the positioning of resource pages prior to the "submit" screen to accommodate the direct link functionality, affected and perhaps increased "functionally complete" incomplete survey rates (incomplete surveys where participants had responded to all survey questions but had not clicked the final "submit" button). An improved survey design would be to present resources and "thank you" pages after completion of the last question.

Insights into what factors—biological, environmental, and social, among others—might make individuals more vulnerable or more resilient in periods of increased and prolonged stress such as during a pandemic are limited due to the relative infrequency of pandemics as well as the logistical and technical challenges associated with studying these emergent situations. Responding to the historic crisis posed by the COVID-19 pandemic, the All of Us Research Program swiftly developed and deployed COPE surveys to provide participants with an opportunity to share their experiences. Data regarding these experiences can also be combined with additional programmatic data such as genetics, EHR data, and other survey responses.

The COPE survey represents a successful survey implementation and iteration to collect longitudinal data and to improve response rates across a large and diverse cohort, offering lessons to other groups proposing similar surveys. A total of 65,339 participants filled out the COPE survey at least twice (9,693 filling out all 6), providing a substantial longitudinal data set spanning 10 months following the initial emergence of SARS-CoV-2 in the United States. The deployment timeline and midstream pause enabled assessment of longitudinal effects within the survey cohort, developed and enacted strategies to increase the number of responses, and assessed the effectiveness of survey and communications changes for increasing the number and diversity of participant responses. Efforts to reduce completion bias in future All of Us Research Program surveys include focused communications, outreach, and accessibility improvements.

In addition to being the first longitudinal survey deployed by the All of Us Research Program, the COPE surveys represent the first significant contribution of participant data on COVID-19 pandemic experiences, mental health, and social determinants of health. As the program evolves, its aim is to enhance and increase the prevalence of data on mental health and social determinants of health that participants may share. These contributions will build an increasingly robust data set, one generated by a diverse cohort of participant partners that is available to researchers as a foundation for future medical breakthroughs.

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COPE survey materials and data are available to researchers through the All of Us Research Hub, which contains publicly accessible English language versions of the survey questions, source instrumentation, and aggregate response data for each of the survey versions (https://databrowser.researchallofus.org/survey/covid-19-participant-experience). Row-level response data was made available to registered researchers through the Researcher

Workbench on the All of Us Research Hub beginning in November 2020, accompanied by reference materials and virtual quality-assurance sessions. Data refreshes will add additional response data to the Researcher Workbench over time. As of August 2021, the survey codebook has been downloaded 191 times in English and 24 times in Spanish across all versions.

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