

Web Material

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

Claire E. Schulkey, Tamara R. Litwin, Genevieve Ellsworth, Heather Sansbury, Brian K. Ahmedani, Karmel W. Choi, Robert Cronin, Yasmin Kloth, Alan W. Ashbeck, Scott Sutherland, Brandy Mapes, Mark Begale, Geeta Bhat, Paula King, Kayla Marginean, Keri Ann Wolfe, Aymone Kouame, Carmina Raquel, Francis Ratsimbazafy, Zach Bornemeier, Kyle Neumeier, Rubin Baskir, Kelly A. Gebo, Joshua Denny, Jordan W. Smoller, and Holly A. Garriock

Table of Contents

Web Figures	2-3
Web Figure 1: Suicide Pop-up Resources	2
Web Figure 2: Total COPE Surveys Completed by Unique Participants	3
Web Tables	4-7
Web Table 1: COPE Survey Content Modifications by Version (2020-2021)	4
Web Table 2: COPE Survey Incompletions (2020-2021)	5
Web Table 3: List of Resources Included with COPE (2020-2021)	6-7

Web Figures

Web Figure 1: Suicide Pop-up Resources

[← Back](#)

[Cancel](#)

If this is how you feel, think about getting help. There are people who can help 24/7.



[Text the Crisis Text Line at 741741](#)

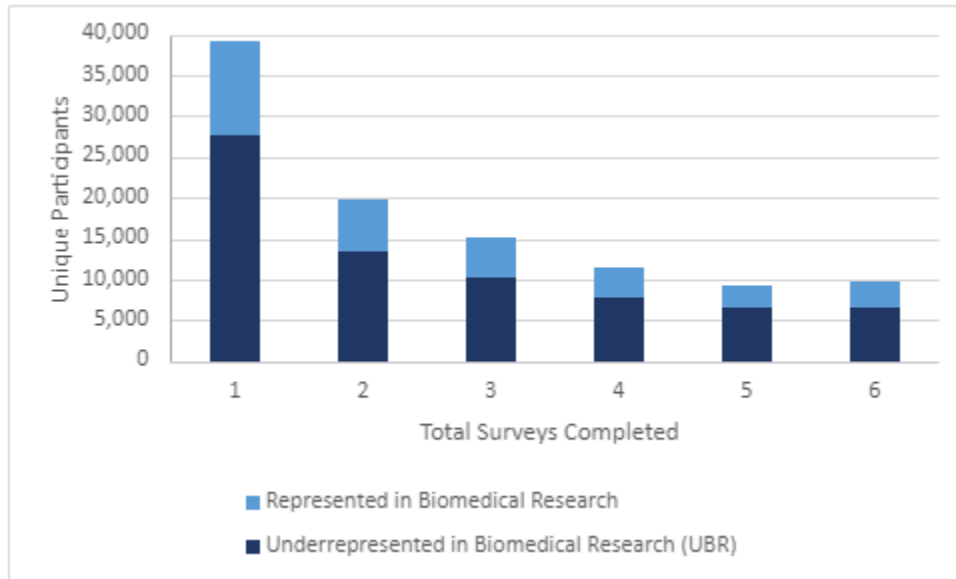


[Call the National Suicide Prevention Lifeline at 1-800-273-8255](#)

NEXT

Web Figure 1: Suicide Pop-up Resources. Given the challenging times in which the COPE survey was deployed and the inclusion of suicide assessment questions, the above resources for the Crisis Text Line and National Suicide Prevention Lifeline were presented to participants who responded anything other than 'Not at all' to the following question: *Over the last two weeks, how often have you been bothered by the following problem: Thoughts that you would be better off dead or hurting yourself in some way.* Answer choices were *Not at all, several days, more than half the days, nearly every day.* Resources were displayed during the PHQ-9 assessment for select participants and at the end of the survey for all participants.

Web Figure 2: Total COPE Surveys Completed by Unique Participants



Web Figure 2: Total COPE Surveys Completed by Unique Participants. Each completed survey total represents a subset of unique participants (e.g., those who have completed 6 surveys are not included in the total of those who have completed 5). 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. The largest subset of participants completed a single COPE survey, and over 65,000 participants completed between 2-6 total COPE surveys, providing valuable longitudinal insights into evolving experiences and perspectives over time.

Web Tables

Web Table 1. COPE Survey Content Modifications by Version (2020-2021)

COPE Version	Survey Content Revisions from Previous Version
May 2020	Baseline survey developed (105 stem questions)
June 2020	<ul style="list-style-type: none"> • Revised time to reflect completion time data from May • Updated COVID-19 symptoms • Changed reporting to minutes only for physical activity • Added some forecasting of future questions • Added bolding and other formatting changes to improve readability • Made mental health support resources available outside of portal (in addition to at end of survey)
July 2020	<ul style="list-style-type: none"> • Removed flu testing item
November 2020	<ul style="list-style-type: none"> • Length reduced to 27 stem questions, with decreased completion time <ul style="list-style-type: none"> ○ Focused on COVID-19-specific symptoms, testing, treatment, community mitigation practices, vaccine perceptions, blood type, access to health care ○ Removed survey domains including most of mental health (except Patient Health Questionnaire-2 + Questionnaire-9 and Generalized Anxiety Disorder 2), substance use, physical activity, social support, discrimination, coping/resilience, perceived stress, optimism • Focused on Return of Value <ul style="list-style-type: none"> ○ Increased visibility of resources ○ Updated suicide prevention hotline resource ○ Incorporated participant testimonials ○ Enhanced several communication tactics • Added Tooltip i.e., “why is this important” for each section of survey • Implemented Auto Save functionality for survey • Added item to report flu vaccination and a follow-up item on intent to receive one
December 2020	<ul style="list-style-type: none"> • No changes from November
February 2021	<ul style="list-style-type: none"> • Added COVID-19 vaccination questions • Included direct email link (no login needed) • Enabled Computer Assisted Telephone Interviewing availability for some participants

Web Table 1. COPE Survey Content Modifications by Version

COPE survey content was revised for every new survey period. The greatest number of revisions occurred between the July and November 2020 surveys, encompassing a significant streamlining of the survey and improvements in user experience and return of value.

Web Table 2: COPE Survey Incompletions (2020-2021)

COPE version	May	June	July	November	December	February
Completions	44890	34386	41760	48295	50993	54930
Incompletions (total)	2124	1021	3776	2795	2590	9860
Percent started but did not complete	4.52%	2.88%	8.29%	5.47%	4.83%	15.22%

Web Table 2. COPE Survey Incompletions

Number of surveys completed, started but not completed, and percent of surveys started which were not completed. Incomplete surveys are defined as any surveys in which a participant did not click the *submit* button. Incomplete survey data are not currently available to researchers, though the program is actively working to include them in the *All of Us* Research Program dataset.

Web Table 3. List of Resources Included with COPE (2020-2021)

English	Spanish
If you or someone you care about needs help:	Si usted o alguien que conoce necesita ayuda:
To learn more about COVID-19: https://www.cdc.gov	Para aprender más acerca del coronavirus (COVID-19):
Disaster Distress Helpline: · 1-800-985-5990 (press 2 for Spanish), or · Text TalkWithUs for English or Hablanos for Spanish to 66746 · Spanish speakers from Puerto Rico can text Hablanos to 1-787-339-2663.	La línea de ayuda para los afectados por catástrofe (The Disaster Distress Helpline): 1-800-985-5990 (presione 2 para español), o envíe un mensaje de texto a 66746. Los hispanohablantes en Puerto Rico pueden enviar en mensaje de texto a 1-787-339-2663.
National Suicide Prevention Lifeline: · 1-800-273-TALK (8255) for English, · 1-888-628-9454 for Spanish, or · Lifeline Crisis Chat https://suicidepreventionlifeline.org/talk-to-someone-now/	Red Nacional de Prevención del Suicidio: 1-888-628-9454 para español, 1-800-273-8255 para inglés
National Domestic Violence Hotline: · 1-800-799-7233 or · Text LOVEIS to 22522	Línea Nacional de Violencia Doméstica: 1-800-799-7233 o envíe un mensaje de texto con LOVEIS a 22522
National Child Abuse Hotline: · 1-800-4AChild (1-800-422-4453) or · Text to 1-800-422-4453	La Línea Directa de Abuso Childhelp Nacional de Niños: (1-800-422-4453) or text 1-800-422-4453
National Sexual Assault Hotline: · 1-800-656-HOPE (4673) or · Online Chat at https://hotline.rainn.org/online	La Línea de Ayuda Nacional Online del Asalto Sexual: 1-800-656-4673 o hable en vivo por Internet
The Eldercare Locator: · 1-800-677-1116	The Eldercare Locator (Buscador de cuidados para personas de la tercera edad): 1-800-677-1116, Solicite hablar con un operador que hable español. Los operadores que hablan español están disponibles de lunes a viernes de 9 a.m. a 8 p.m.
Veterans Crisis Line: · 1-800-273-TALK (8255) or · Crisis Chat at https://www.veteranscrisisline.net/get-help/chat or Text to 8388255	
NIMH Getting Help page: https://www.nimh.nih.gov/health/find-help/index.shtml	Recibe ayuda en salud mental: https://espanol.mentalhealth.gov/pida-ayuda
For more information on mental health topics and research:	Para más información acerca de temas de salud mental e investigación:

https://www.nimh.nih.gov/health/index.shtml	cientifica: https://www.nimh.nih.gov/health/publications/espanol/spanish-listing.shtml
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Web Table 3. List of Resources Included with COPE. The above text and links to resources were provided to participants during and/or after the COPE survey.