

Juliana M. Ison, BA¹; Elizabeth W. Karlson, MD, MS^{2,3,4}; Jonathan D. Jackson, PhD^{1,3,4};
Alexander Hille, BS^{4,5}; Cheryl McCloud, BS^{4,6}; Meg Bor, BBA^{4,5};
Guohai Zhou, PhD^{2,3,4}; Cheryl R. Clark, MD, ScD^{2,3,4}

Purpose: Enhancing the bidirectional benefit of precision medicine research infrastructure may advance equity in research participation for diverse groups. This study explores the use of research infrastructure to provide human-centered COVID-19 resources to participants as a part of their research participation.

Design: The *All of Us* New England (AoUNE) consortium research team developed standardized check-in telephone calls to ask participants about their well-being and share COVID-19 resources.

Participants: A total of 20,559 participants in the AoUNE consortium received a COVID-19 check-in call.

Methods: Research assistants called participants during March-April 2020, distributed COVID-19 resources to interested participants, and subsequently rated call tone.

Results: Of the total cohort participants called, 8,512 (41%) spoke with a research team member. The majority of calls were rated as positive or neutral; only 3% rated as negative. African American and Black as well as Hispanic populations requested COVID-19 resources at higher rates than other groups.

Conclusion: Calls made to AoUNE participants were received positively by diverse groups. These findings may have implications for participant-centered engagement strategies in precision medicine research. *Ethn Dis.* 2021;31(3):407-410; doi:10.18865/ed.31.3.407

Keywords: Population Health; Health Disparities; Precision Medicine; Community Engagement

INTRODUCTION

Diversity in precision medicine (PM) research is a principal goal of the National Institutes of Health *All of Us* Research Program.¹⁻³ Historically, engaging populations who are underrepresented in biomedical research (UBR) has required expressions of care toward participants who are uncommon in traditional biomedical research paradigms.⁴ Research traditions that promote social distance between study staff and participants may be unable to overcome a legacy of systemic racism and ensure benefits of research accrue to UBR participants.⁵

The COVID-19 pandemic highlighted several inequities faced by UBR populations who participate in PM research.⁶ Threats to basic human needs—including unemployment, food insecurity, perceived stress, and lack of COVID-19 prevention information—disproportionately affect the health of UBR populations as well as the secondary issue of re-

search participation.⁷ Using research infrastructure to “check-in” with participants may allow study staff to provide service and build caring connections with participants as part of the bidirectional benefit of research.⁴ In this context, the *All of Us* New England (AoUNE) consortium researchers used standardized check-in telephone calls for the sole purpose of asking AoUNE participants about their well-being and sharing COVID-19 resources.

METHODS

Methods for recruitment of *All of Us* Research Program participants have been previously described.³ The AoUNE began enrolling *All of Us* Research Program participants in May 2018 through community health centers and in-patient hospitals affiliated with a large academic medical center and a large safety-net academic medical center in Boston, Massachusetts, as well

¹ CARE Research Center, Massachusetts General Hospital, Boston, MA

² Brigham and Women’s Hospital, Boston, MA

³ Harvard Medical School, Boston, MA

⁴ All of Us New England, Cambridge, MA

⁵ Massachusetts General Hospital, Boston, MA

⁶ Boston Medical Center, Boston, MA

Address correspondence to Cheryl R. Clark, MD, ScD, crclark@bwh.harvard.edu

as through the national NIH *All of Us* Research Program study website. As of February 2020, 20,559 study participants were enrolled by AoUNE staff.

During the peak of the COVID-19 pandemic between March 2020 and April 2020, research assistants (RAs) phoned all study participants enrolled by AoUNE staff. Three attempts were made to reach each participant. RAs documented the outcome of each call (whether participants were reached for a conversation, or whether there was no answer). When the RA reached a

participant, the RA recorded a rating of each conversation according to the RA's perception of the call tone as positive, neutral, or negative. RAs were equipped with COVID-19 prevention resources from the Centers for Disease Control and Prevention, and local information related to mental health, housing instability, and food insecurity to provide to participants who requested these materials. All data were collected via REDCap surveys during the calls; requests for COVID-19 information were described by demographic

characteristics. Ordinal logistic regression odds ratios (OR) were conducted using version 4.0 of the statistical analysis software R to examine demographic characteristics associated with RA perceptions of positive call tone as well as COVID-19 resource requests.

RESULTS

A total of 20,559 AoUNE participants received a COVID-19 check-in call, and 8,512 (41%) participants

Table 1. Call tone results from check-in calls with *All of Us* research program participants from the New England Consortium

Participant Characteristics	Call Tone, n (%)				Adjusted odds ratio (95% CI)	P ^a
	Positive, n=6167	Neutral, n=1973	Negative, n=262	No response, n=12157		
Age, yrs.						
18–39	1305 (25)	528 (10)	40 (1)	3351 (64)	Reference	
40–59	1875 (27)	609 (9)	73 (1)	4477 (64)	1.23 (1.07 - 1.41)	.003
60+	2987 (36)	836 (10)	149 (2)	4329 (52)	1.28 (1.12 - 1.46)	<.001
Race and ethnicity						
Non-Hispanic White	3855 (32)	175 (1)	1165 (10)	6975 (57)	Reference	
Non-Hispanic Asian	169 (30)	4 (1)	75 (13)	324 (57)	.84 (.63 - 1.12)	.24
Non-Hispanic Black	671 (24)	30 (1)	240 (9)	1847 (66)	1.08 (.91 - 1.29)	.39
Hispanic (any race)	1005 (31)	34 (1)	327 (10)	1905 (58)	1.07 (.88 - 1.29)	.52
Other race/ethnicity	467 (27)	19 (1)	166 (9)	1106 (63)	.97 (.80 - 1.18)	.76
Sex						
Female	3749 (32)	1090 (9)	156 (1)	6663 (57)	Reference	
Male	2347 (27)	858 (10)	100 (1)	5268 (61)	.83 (.75 - .92)	<.001
Missing	71 (22)	25 (8)	6 (2)	226 (69)	-	
Language						
English	5637 (30)	243 (1)	1826 (10)	11325 (60)	Reference	
Spanish	530 (35)	19 (1)	146 (10)	831 (54)	1.39 (1.08 - 1.80)	.012
Missing	0 (0)	0 (0)	1 (50)	1 (50)	-	
Education						
Advanced degree	1881 (35)	69 (1)	546 (10)	2880 (54)	Reference	
College graduate	1566 (33)	53 (1)	465 (10)	2619 (56)	.98 (.86 - 1.13)	.79
Some college	1231 (31)	51 (1)	374 (9)	2332 (58)	.88 (.76 - 1.02)	.09
High school graduate	877 (22)	59 (2)	348 (9)	2636 (67)	.64 (.54 - .75)	<.001
< High School	495 (25)	25 (1)	195 (10)	1301 (65)	.58 (.46 - .72)	<.001
Missing	117 (21)	5 (1)	45 (8)	389 (70)	-	

a. P-value cutoffs for estimating statistical significance are based on the Bonferroni correction: .05/2=.025 for age (2 comparisons), .05 for gender (1 comparison), .05/4=.0125 for race (4 comparisons), .05/4=.0125 for education (4 comparisons).

spoke with an RA. Calls reached a diverse group of participants. Of all 8,512 participants reached, 4,003 calls (47%) took place with participants aged ≥60 years. Where race/ethnicity was specified, 5,225 calls (61%) were with non-Hispanic White participants, 1,382 calls (16%) were with Hispanic participants of any race, 991 calls (12%) were with non-Hispanic Black/African American participants, and 323 calls (4%) were with non-Hispanic Asian participants. With respect to binary sex assigned at birth, 3,353 (39%) of those reached were male. The preferred language of those reached was English; 702 (8%)

participants reported Spanish as their preferred language. The educational attainment of participants was diverse: 733 calls (9%) were with participants with less than high school education, 1,317 (15%) calls were with high school graduates, 1,686 (20%) had some college education, 2,100 (25%) were college graduates, 2,505 (29%) had advanced degrees, and 171 (2%) had unknown education status (descriptive data not shown in tables).

When participants were reached for conversations, 6,167 (72%) conversations were perceived by RAs as having a positive tone, 1,973 (23%) were perceived as neutral and only 262 (3%) as

negative. Male sex (OR .83, P<.001) and lower educational attainment (OR .58, P<.001), but not race or ethnicity, were inversely associated with positive RA perceptions of the call. Older age (OR 1.28, P<.001) and Spanish language (OR 1.39, P=.01) were associated with positive call tone. (Table 1)

Trends in requests for resources varied by demographic group. Thirty-one percent of Black participants (n=291) requested COVID-19 resources compared with 30% of Hispanic/Latinx (n= 410) and 10% of White participants (n=516). Thirty-eight percent of participants phoned in Spanish (n= 265) requested COVID-19 materials

Table 2. Requests for COVID-19 resources from check-in calls with All of Us research program participants from the New England Consortium

Participant Characteristics	Requested COVID-19 Resources, n (%)			Adjusted odds ratio (95% CI) for COVID-19 Resources	P ^a
	Yes, N=1382	No, N=6990	No response, N=1218)		
Age, yrs.					
18–39	286 (5)	1578 (30)	3360 (64)	Reference	
40–59	550 (8)	2001 (28)	4483 (64)	1.03 (1.01 - 1.06)	.003
60+	546 (7)	3411 (41)	4344 (52)	1.01 (.99 - 1.03)	.427
Race and Ethnicity					
Non-Hispanic White	516 (4)	4661 (38)	6993 (57)	Reference	
Non-Hispanic Asian	23 (4)	222 (39)	327 (57)	1.01 (.96 - 1.06)	.746
Non-Hispanic Black	291 (10)	648 (23)	1849 (66)	1.18 (1.15 - 1.22)	<.001
Hispanic (any race)	410 (13)	951 (29)	1910 (58)	1.09 (1.06 - 1.12)	<.001
Other race/ethnicity	142 (8)	508 (29)	1108 (63)	1.10 (1.07 - 1.13)	<.001
Sex					
Female	880 (8)	4096 (35)	6682 (57)	Reference	
Male	479 (6)	2815 (33)	5279 (62)	.99 (.97 - 1.00)	.124
Missing	23 (7)	79 (24)	226 (69)	-	
Language					
English	1117 (6)	6560 (34)	11354 (60)	Reference	
Spanish	265 (17)	429 (28)	832 (55)	1.15 (1.10 - 1.20)	<.001
Missing	0 (0)	1 (50)	1 (50)	-	
Education					
Advanced degree	218 (4)	2270 (42)	2888 (54)	Reference	
College graduate	242 (5)	1833 (39)	2628 (56)	1.02 (.99 - 1.04)	.138
Some college	320 (8)	1332 (33)	2336 (59)	1.06 (1.04 - 1.09)	<.001
High school graduate	313 (8)	966 (25)	2641 (67)	1.08 (1.05 - 1.11)	<.001
< High School	236(12)	476 (24)	1304 (65)	1.09 (1.06 - 1.13)	<.001
Missing	53 (10)	113 (20)	390 (70)	-	

a. P-value cutoffs for estimating statistical significance are based on the Bonferroni correction: .05/2=.025 for age (2 comparisons), .05 for gender (1 comparison), .05/4=.0125 for race (4 comparisons), .05/4=.0125 for education (4 comparisons).

compared with 15% phoned in English (N= 1,117). A socioeconomic gradient was observed by educational attainment, where 33% of participants (n=236) who did not complete high school requested COVID-19 resources compared with 9% of individuals with advanced degrees (n=218). Adults aged 40-59 years requested COVID-19 resources more frequently than younger adults (OR 1.03, P=.003). Non-Hispanic Black/African American race (OR 1.18, P<.001), Hispanic ethnicity (OR 1.09, P<.001), and Other/not-specified race/ethnicity (OR 1.10, P<.001), as well as Spanish language (OR 1.15, P<.001) and lower educational attainment (OR 1.09, P<.001) were all associated with requests for COVID-19 resources. (Table 2)

DISCUSSION

In our check-in calls, RAs perceived calls as predominantly positively received. Importantly, UBR participants requested COVID-19 resources more frequently, suggesting a potential benefit of this type of call to these groups. Engaging in frequent contact with participants is an important method of study retention in longitudinal research.⁴ To our knowledge, our study is unique in using study infrastructure to provide participant check-in calls unrelated to measurable study outcomes for the purpose of enhancing the bidirectional benefit of research participation.

We note limitations in our approach. Fifty-nine percent of participants could not be reached after three attempts. Further investigation should explore other methods of “check-ins”

tailored to meet participant needs equitably.^{8,9} Additionally, the unprecedented circumstance of the start of the COVID-19 pandemic may have created a context in which study participants, particularly UBR participants, may have appreciated calls from a trusted source with the sole purpose of providing information regarding available resources. Future research should address other circumstances during which participants may appreciate outreach, including occasions (birthdays, national holidays) that are well-documented in literature.⁹

CONCLUSION

Our findings suggest research infrastructure can be used to express care and human connection with study participants with benefits to UBR populations. Still, check-in calls do not immediately address roots of systemic racism. Consequently, future research should investigate whether demonstrations of care by researchers shift perceptions of the utility and benefits of research for UBR participants, and potentially, for researchers who provide this care.

ACKNOWLEDGMENTS

This Brief Report was made possible by the engagement of our research participants and the tireless efforts of team members across the *All of Us* New England Research Program Consortium, especially Natalie Boutin and Carolina J. Stamoulos. A special thank you to everyone involved.

CONFLICT OF INTEREST

No conflicts of interest to report.

AUTHOR CONTRIBUTIONS

Research concept and design: Ison, Karlson, Jackson, McCloud, Bor, Clark; Acquisition of data: Karlson, Hille; Data analysis and

interpretation: Ison, Jackson, Hille, McCloud, Bor, Zhou, Clark; Manuscript draft: Ison, Karlson, Jackson, Hille, McCloud, Zhou, Clark; Statistical expertise: Karlson, Zhou, Clark; Acquisition of funding: Karlson; Administrative: Ison, Jackson, Hille, McCloud, Bor, Clark; Supervision: Jackson, Clark

REFERENCES

1. Booker CL, Harding S, Benzeval M. A systematic review of the effect of retention methods in population-based cohort studies. *BMC Public Health*. 2011;11(1):249. <https://doi.org/10.1186/1471-2458-11-249> PMID:21504610
2. George S, Duran N, Norris K. A systematic review of barriers and facilitators to minority research participation among African Americans, Latinos, Asian Americans, and Pacific Islanders. *Am J Public Health*. 2014;104(2):e16-e31. <https://doi.org/10.2105/AJPH.2013.301706> PMID:24328648
3. All of Us Research Program Investigators. The ‘All of Us’ research program. *N Engl J Med*. 2019;318:668-676.
4. Abshire M, Dinglas VD, Cajita MIA, Eakin MN, Needham DM, Himmelfarb CD. Participant retention practices in longitudinal clinical research studies with high retention rates. *BMC Med Res Methodol*. 2017;17(1):30. <https://doi.org/10.1186/s12874-017-0310-z> PMID:28219336
5. Sixsmith J, Boneham M, Goldring JE. Accessing the community: gaining insider perspectives from the outside. *Qual Health Res*. 2003;13(4):578-589. <https://doi.org/10.1177/1049732302250759> PMID:12703418
6. Yancy CW. COVID-19 and African Americans. *JAMA*. 2020;323(19):1891-1892. <https://doi.org/10.1001/jama.2020.6548> PMID:32293639
7. Steinman MA, Perry L, Perissinotto CM. Meeting the care needs of older adults isolated at home during the COVID-19 pandemic. *JAMA Intern Med*. 2020;180(6):819-820. <https://doi.org/10.1001/jamainternmed.2020.1661> PMID:32297903
8. Edwards P, Roberts I, Clarke M, et al. Increasing response rates to postal questionnaires: systematic review. *BMJ*. 2002;324(7347):1183. <https://doi.org/10.1136/bmj.324.7347.1183> PMID:12016181
9. Yancey AK, Ortega AN, Kumanyika SK. Effective recruitment and retention of minority research participants. *Annu Rev Public Health*. 2006;27(1):1-28. <https://doi.org/10.1146/annurev.publhealth.27.021405.102113> PMID:16533107