

Introduction

- Minority representation particularly among older adults, is lacking in research. Older adults may have negative beliefs about research and its purposes^{1,3}
- Older, minority adults may distrust researchers and fear mistreatment^{1,2,3}
- Many measures are now in place to protect vulnerable research participants, especially after historical breaches in research ethics. However, AA participants remain vulnerable to exploitation due to lack of knowledge about research protection measures³
- Understanding factors that promote and reduce minority participation in research is important to address participation gap among minorities³

Methods

- Participants:** 106 diverse adults were recruited as part of an educational intervention. We present baseline data here.
- Design:** cross sectional, 2 cohort groups
- Compared attitudes and beliefs about research between African Americans (AA) and White (Non-Hispanic) participants using a questionnaire
- Statistical Analysis:** Descriptive Statistics and Logistic Regression performed in SPSS



Table 1: Participant Attitudes and Beliefs towards Research Questionnaire (PABRQ)

- Q1: Familiarity with informed consent processes?** (1-5; 1= Not at all; 5=Very)
- Q2: Familiarity with research subject protection measures?** (1-5; 1= None; 5= Very)
- Q3: Yes/no: Were you ever asked to participate in research?**
- Q4: Yes/no: Have you ever participated in research?**
- Q5: Attitude toward research with human participants?** (1-5; 1=Negative; 5=Very Positive)
- Q6: Attitude towards participating in research yourself?** (1-3; 1 = Negative; 3 = Positive)
- Q7: Attitude towards someone in family/ close friend participating in human research?** (1-3; 1 = Negative; 3 = Positive)
- Q8: Attitude towards random assignment?** (1-3; 1 = Negative; 3 = Positive)
- Q9: Opinion of participants being assigned to treatment vs. non-treatment?** (1-3; 1 = Negative; 3 = Positive)
- Q10 Necessary to examine "new" drugs using science/experiments before they are implemented?** (1-4; 1=Never, 4=Always)
- Q11 (A-E): To scientists, how important is finding treatments? Helping patients? Minimizing total expenses in treatment? Promoting own career? Increasing knowledge generally? Wishing to increase general knowledge?** (1-4; 1=Not Important; 4=Very Important)

Results

Table 2: Characteristics of the Sample

	Total N=106 Mean ±SD/ N(%)	AA N=46 Mean ±SD/ N(%)	White N=60 Mean ±SD/ N(%)	P-Value
Age ¹	74 ± 11	68 ± 9	78 ± 10	<0.001*
Years of Education ¹	15.8 ± 2	15.2 ± 2	16.2 ± 2	0.017*
Number of Comorbidities ¹	2.8 ± 2	2.7 ± 2	2.8 ± 2	0.864
Number of Medications ¹	3.6 ± 3	2.9 ± 3	4.1 ± 4	0.086
Number of Falls in Past Year ¹	0.8 ± 3	0.5 ± 2	1 ± 3	0.351
Sex [^] , n (%)				0.049*
Female	76 (72)	38 (83)	38 (63)	
Male	30 (28)	8 (17)	22 (37)	
Occupational Status [^] , n (%)				0.158
Employed	21 (20)	8 (18)	13 (22)	
Homemaker	4 (4)	0 (0)	4 (7)	
Not Employed	79 (76)	37 (82)	42 (71)	
Assistive Device Use [^] , n (%)				0.052
No	69 (66)	35 (78)	34 (58)	
Yes	35 (34)	10 (22)	25 (42)	

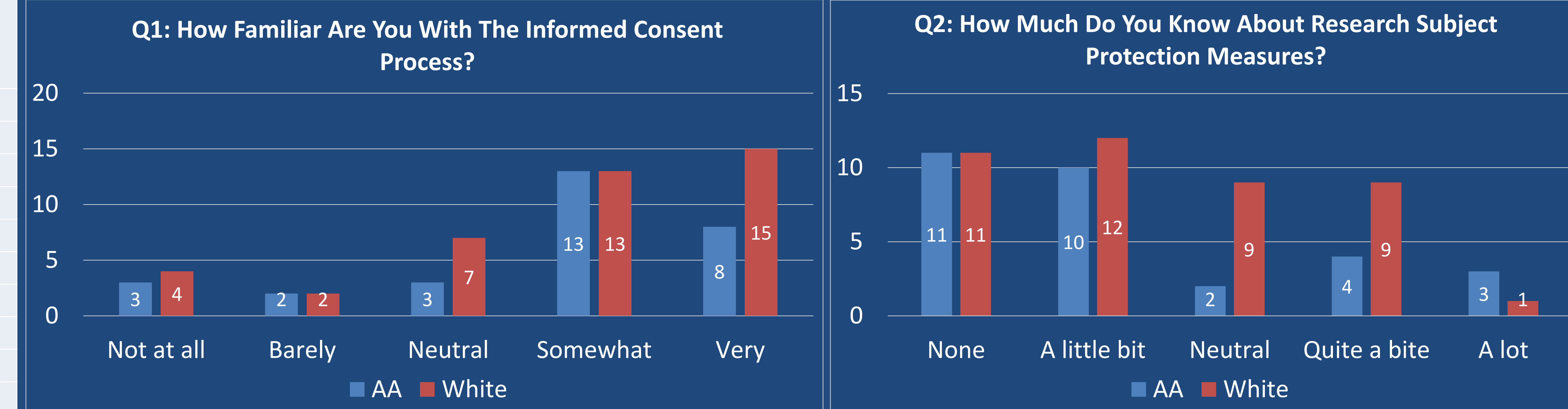
*Sig. at α=0.05 level; ¹Two-tailed, independent t-tests were used for continuous variables, comparing AA and White groups; [^] Chi-square tests or Fisher's exact tests were used for categorical variables

Table 3: Performance On PABRQ Between Groups¹

Beliefs Question ²	Analysis Grouping	AA N (%)	White N (%)	OR	95 % CL	P-value
Q1	3,4,5 vs. 1,2	5 (17) vs. 24 (83)	6 (15) vs. 35 (85)	0.9	(0.2, 4.7)	0.91
Q2	3,4,5 vs. 1,2	21 (70) vs. 9 (30)	23 (55) vs. 19 (45)	0.5	(0.1,1.4)	0.17
Q3	Yes vs. No	21 (68) vs. 10 (32)	26 (63) vs. 15 (37)	0.5	(0.2,1.7)	0.29
Q4	Yes vs. No	16 (53) vs. 14 (47)	23 (56) vs. 18 (44)	0.9	(0.3, 2.8)	0.89
Q5	4,5 vs. 3	8 (26) vs. 23 (74)	6 (14) vs. 36 (86)	0.5	(0.1, 1.7)	0.25
Q6	3 vs.2	29 (94) vs. 2 (6)	39 (95) vs. 2 (5)	1.0	(0.1, 11.9)	1.00
Q7	3 vs. 2	28 (90) vs. 3 (10)	37 (90) vs. 4 (10)	0.8	(0.1, 5.2)	0.86
Q8	3 vs. 2	22 (71) vs. 9 (29)	23 (56) vs. 18 (44)	0.7	(0.2, 2.1)	0.52
Q9	3 vs. 2, 1	18 (58) vs. 13 (42)	24 (57) vs. 18 (43)	1.1	(0.4, 3.3)	0.86
Q10	4 vs. 1,2,3	9 (29) vs. 22 (71)	13 (31) vs. 29 (69)	1.9	(0.6, 6.6)	0.31
Q11A	4 vs. 3	24 (77) vs. 7 (23)	36 (86) vs. 6 (14)	0.8	(0.2, 3.3)	0.78
Q11B	4 vs. 2, 3	24 (77) vs. 7 (23)	31 (74) vs. 11 (26)	0.6	(0.2, 2.0)	0.43
Q11C	4 vs. 1, 2, 3	12 (39) vs. 19 (61)	12 (29) vs. 30 (71)	0.6	(0.2, 1.9)	0.41
Q11D	3,4 vs. 1,2	52 (16) vs. 15 (48)	16 (38) vs. 26 (62)	0.6	(0.2, 1.7)	0.32
Q11E	4 vs. 2, 3	24 (77) vs. 7 (23)	26 (60) vs. 17 (40)	0.2	(0.1, 0.8)	0.03*

Frequency of different characteristics may vary, and percentages may not be equal to 100% because of missing data*Sig. at α=0.05 level; ¹Logistic regression controlling for age, sex, and education compared OR of AA and White participants; ²For each question, there is a range of answers that participants can choose from. Answers have been dichotomized.

Results



- Beliefs Q1: Although not statistically significant, it appears that White participants were, on average, more familiar with the informed consent process than were AA participants
- Beliefs Q2 : Despite historical breaches in research ethics impacting racial and ethnic minorities, African American participants were 8 times more likely to be unaware of research subject protection measures
- Beliefs Q11E: More AA positively believed that scientists desired to increase general scientific knowledge than Whites. This may stem from AA's gaps in knowledge about scientific concepts, due to underrepresentation in STEM workforce.
- Both groups were equally likely to have participated in research in the past

Conclusion

Due to lack of familiarity with the informed consent process and protections measures, African American participants may be more vulnerable to exploitation during human subjects' research as well as in clinical settings. However, both groups in our sample had similar attitudes and beliefs towards participating in research.

Relevance of Findings to Participant Care

- Explanation of participant /patient protection measures should be integrated into the recruitment
- Researchers and care providers should be aware of increased vulnerability and potential knowledge gaps regarding human subjects' protections among minority participants/ patients
- Researchers and care providers should cultivate trusting relationships with minority participants by providing patients/participants opportunities to ask questions
- Increased knowledge about rights and legal protections could allow participants/patients to advocate for themselves more effectively in research studies and in clinical settings

References

- Perkins M, Hart A, Dillard R, Wincek R, Jones D, Hackney ME. A Formative Qualitative Evaluation to Inform Implementation of a Research Participation Enhancement and Advocacy Training Program for Diverse Seniors: The DREAMS Program. *Journal of Applied Gerontology*, 2017
- Miller, K. J., Siddarth, P., Gaines, J. M., Parrish, J. M., Ercoli, L. M., Marx, K., Ronch, J., Pilgram, B., Burke, K., Barczak, N., Babcock, B., & Small, G. W. (2012). The memory fitness program: Cognitive effects of a healthy aging intervention. *The American Journal of Geriatric Psychiatry: Official Journal of the American Association for Geriatric Psychiatry*, 20(6), 514–523. <https://doi.org/10.1097/JGP.0b013e318227f821>
- Shah A, Macauley C, Ni L, Bay AA, Hackney ME. The Relationship Between Attitudes about Research and Health Literacy among African American and White (Non-Hispanic) Community Dwelling Older Adults. *Journal of Racial and Ethnic Health Disparities*, 2021.

Acknowledgements: This project conducted with support from grant 1099-EU from the Patient Centered Outcomes Research Institute (PCORI) and grant A01 from the National Parkinson Foundation.