

# US Adults' Likelihood to Participate in Dementia Prevention Clinical Trials: Results from the National Poll on Healthy Aging

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## Abstract

**Background:** Recruitment to dementia prevention clinical trials is challenging, and participants are not representative of US adults at risk. To inform future recruitment strategies, the field needs a better understanding of public attitudes toward dementia prevention research.

**Method:** We analyzed data from a subset of respondents to the University of Michigan National Poll on Healthy Aging (October 2018 wave), ages 50-64, who completed a supplementary poll on dementia and brain health. Our primary outcome was likelihood to participate in a dementia prevention clinical trial (collapsed into very/somewhat likely versus not likely). Logistic regression models were used to examine associations between sociodemographic and dementia-related factors (e.g., family history) and likelihood to participate. Among respondents not likely to participate, we examined frequency of reasons endorsed, stratified by age, sex, and race/ethnicity.

**Result:** Among 1,028 respondents, 44% reported being at least somewhat likely (12% very likely) to participate in a dementia prevention trial. In adjusted analyses, there were no differences in likelihood to participate by sociodemographic characteristics. Factors associated with higher likelihood to participate were higher perceived likelihood to develop dementia [adjusted OR, 2.04 (95% CI, 1.53, 2.72)], family history of dementia [adjusted OR, 1.89 (95% CI, 1.38, 2.57)], and having discussed dementia prevention with a doctor [adjusted OR, 2.31 (95% CI, 1.20, 4.44)]. Among the 570 respondents not likely to participate, 38% did not want to be a guinea pig, 24% did not think dementia would affect them, 22% thought there would be too high a chance for harm, 16% indicated it would take too much time, and 5% reported fear of learning information about oneself. Compared to females, males more frequently endorsed that dementia would not affect them (28% versus 20%;  $p = 0.03$ ). No other differences among demographic groups were observed.

**Conclusion:** In this study, perceived risk of dementia, family history, and discussion of prevention with a doctor were associated with likelihood to participate in a dementia prevention clinical trial, whereas sociodemographic factors including race/ethnicity were not. This suggests that campaigns focused on dementia risk and prevention may be effective tools to improve enrollment rates, regardless of target community.

**Table 1. Characteristics of Survey Respondents (n=1,028<sup>a</sup>)**

<b>Sociodemographic Characteristics</b>	<b>No. (%)</b>
<b>Age category</b>	
50 to 54	305 (29.7)
55 to 59	393 (38.2)
60 to 64	330 (32.1)
<b>Sex</b>	
Male	506 (49.2)
Female	522 (50.8)
<b>Race and ethnicity</b>	
Non-Hispanic White	762 (74.1)
Non-Hispanic Black	93 (9.1)
Hispanic	101 (9.8)
Other <sup>b</sup>	72 (7.0)
<b>Educational status</b>	
High school or less	342 (33.3)
Some college	340 (33.1)
Bachelor's degree or higher	346 (33.7)
<b>Household income</b>	
Less than \$30,000	151 (14.7)
\$30,000 to \$59,999	194 (18.9)
\$60,000 or greater	683 (66.4)
<b>Employment status</b>	
Working	732 (71.2)
Retired or not working	296 (28.8)
<b>Marital status</b>	
Married or partnered	740 (72.0)
Not married or partnered	288 (28.0)
<b>Dementia-Related Characteristics</b>	
<b>Subjective memory rating</b>	
Slightly or much worse than when I was younger	681 (66.4)
As good as when I was younger	344 (33.6)
<b>Perceived likelihood to develop dementia</b>	
Very or somewhat likely	497 (48.8)
Not likely	522 (51.2)
<b>Family history of dementia</b>	
Yes	364 (35.5)
No or don't know	662 (64.5)
<b>Dementia caregiver experience</b>	
Yes	191 (18.6)
No	837 (81.4)
<b>Discussed dementia prevention with doctor</b>	
Yes	55 (5.4)
No	969 (94.6)

a. Missing data on individual survey items ranged from n=0 to n=9

b. Respondents self-reported "Other, Non-Hispanic" or "2+ Races, Non-Hispanic"

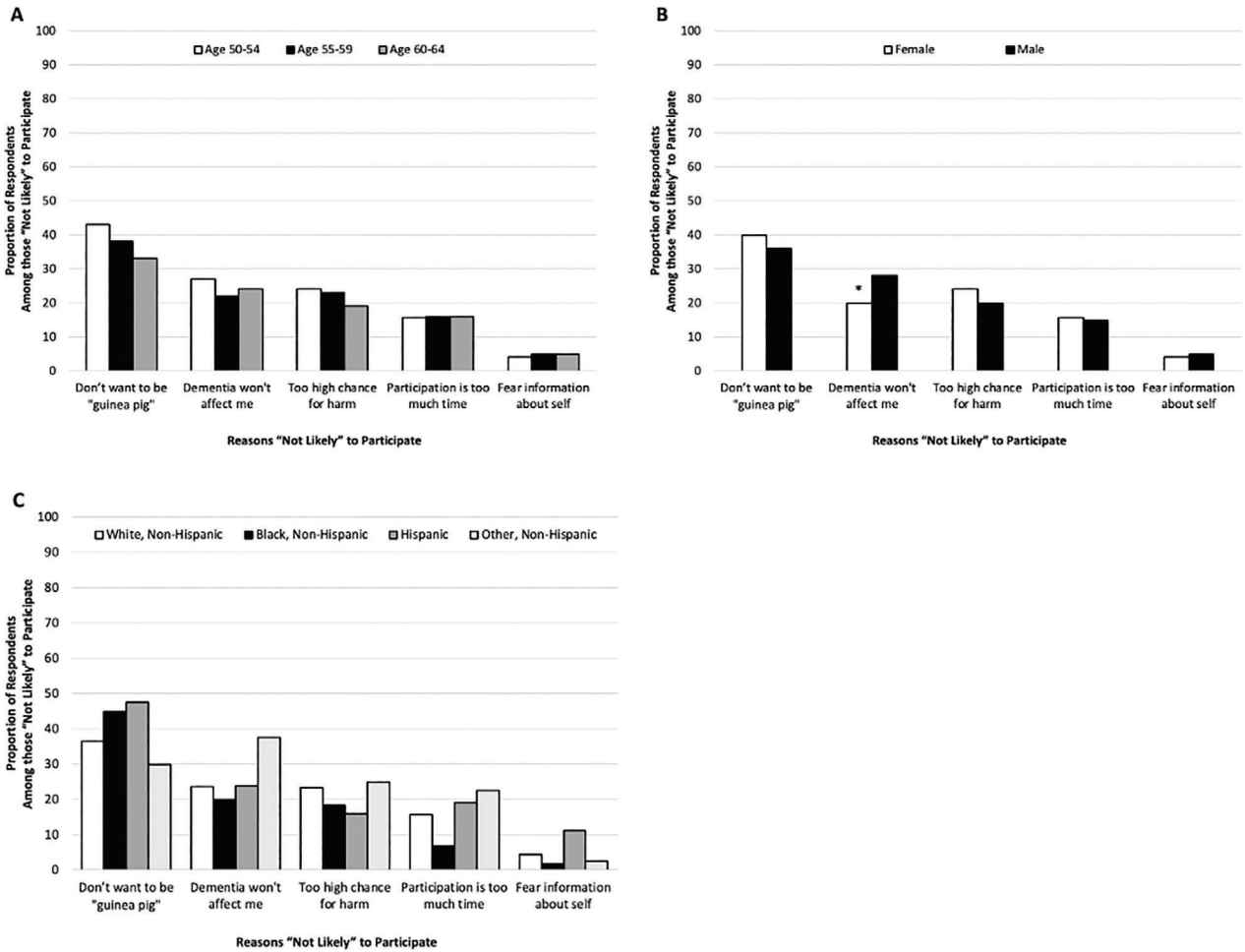
**Table 2. Associations with “Very” or “Somewhat Likely” to Participate in a Dementia Prevention Trial**

Sociodemographic Characteristics	Odds Ratios (95% CI) <sup>a</sup>	
	Unadjusted	Adjusted <sup>b</sup>
<b>Age category</b>		
50 to 54	1.00 (reference)	1.00 (reference)
55 to 59	1.16 (0.86, 1.57)	0.98 (0.71, 1.37)
60 to 64	1.29 (0.94, 1.77)	1.01 (0.71, 1.44)
<b>Sex</b>		
Male	1.00 (reference)	1.00 (reference)
Female	1.25 (0.98, 1.60)	1.07 (0.81, 1.40)
<b>Race and ethnicity</b>		
Non-Hispanic White	1.00 (reference)	1.00 (reference)
Non-Hispanic Black	<b>0.61 (0.39, 0.97)*</b>	0.66 (0.41, 1.09)
Hispanic	0.70 (0.45, 1.07)	0.76 (0.48, 1.20)
Other	0.92 (0.57, 1.50)	1.06 (0.62, 1.79)
<b>Educational status</b>		
High school or less	1.00 (reference)	1.00 (reference)
Some college	1.12 (0.83, 1.51)	1.08 (0.77, 1.51)
Bachelor’s degree or higher	0.92 (0.68, 1.25)	0.90 (0.63, 1.29)
<b>Household income</b>		
Less than \$30,000	1.00 (reference)	1.00 (reference)
\$30,000 to \$59,999	0.92 (0.60, 1.41)	0.92 (0.57, 1.49)
\$60,000 or greater	0.77 (0.54, 1.10)	0.76 (0.48, 1.19)
<b>Employment status</b>		
Working	0.84 (0.64, 1.10)	0.96 (0.70, 1.31)
Retired or not working	1.00 (reference)	1.00 (reference)
<b>Marital status</b>		
Married or partnered	1.06 (0.80, 1.40)	1.19 (0.86, 1.66)
Not married or partnered	1.00 (reference)	1.00 (reference)
<b>Dementia-Related Characteristics</b>		
<b>Subjective memory rating</b>		
Slightly or much worse than when I was younger	<b>1.63 (1.25, 2.13)**</b>	1.31 (0.98, 1.76)
As good as when I was younger	1.00 (reference)	1.00 (reference)
<b>Perceived likelihood to develop dementia</b>		
Very or somewhat likely	<b>2.95 (2.28, 3.82)**</b>	<b>2.04 (1.53, 2.72)**</b>
Not likely	1.00 (reference)	1.00 (reference)
<b>Family history of dementia</b>		
Yes	<b>2.79 (2.15, 3.64)**</b>	<b>1.89 (1.38, 2.57)**</b>
No or don’t know	1.00 (reference)	1.00 (reference)
<b>Dementia caregiver experience</b>		
Yes	<b>2.52 (1.82, 3.48)**</b>	1.40 (0.96, 2.04)
No	1.00 (reference)	1.00 (reference)
<b>Discussed dementia prevention with doctor</b>		
Yes	<b>3.47 (1.89, 6.39)**</b>	<b>2.31 (1.20, 4.44)*</b>
No	1.00 (reference)	1.00 (reference)

a. Abbreviation: Confidence Interval

b. Adjusted for all factors in table

\* p-value < 0.05; \*\* p-value < 0.001



**Figure 1. Reasons "Not Likely" to Participate in a Dementia Prevention Trial by (A) Age, (B) Sex, and (C) Race/Ethnicity**

\* Chi-square p-value < 0.05