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Political Ideology and Participation in Clinical Studies

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Abstract

Background—Americans' confidence in science varies based on their political ideology. This ideological divide has potentially important effects on citizens' engagement with and participation in clinical studies of Alzheimer Disease (AD).

Methods—A probability sample of 1583 Americans was surveyed about their willingness to participate in longitudinal AD research and about their political attitudes. These survey results were compared with a survey of 382 participants in a longitudinal AD study at the Knight Alzheimer Disease Research Center (Knight ADRC).

Results—Among Americans, more conservative ideology decreases willingness to participate in a hypothetical longitudinal cohort study of AD both directly and through its negative effect on confidence in science. The Knight ADRC study participants expressed more liberal ideology and greater confidence in science than Americans in general. Of the survey respondents opposed to participation, over a quarter changed to neutral or positive if the study returned their research results to them.

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Conclusions and Relevance—Clinical studies of AD are likely biased toward participants who are more liberal and have higher confidence in science than the general population. This recruitment bias may be reduced by lowering the trust demanded of participants through measures such as returning research results to participants.

Keywords

Political Ideology; Confidence in Science; and Participation in Alzheimer Disease Research Studies

1. Introduction

The conduct and efficacy of medical research depends on public commitment to science. Public funding and public policies governing research set limits on the scope and process of medical inquiry. Perhaps most directly, research involving human subjects often relies critically on voluntary public participation. The demands on volunteers can be quite substantial, as seen in issues with recruitment for large prospective longitudinal cohort studies and for clinical trials.^{1,2,3}

We investigate one important obstacle to successful recruitment for clinical studies conducted in the United States: the wide ideological divergence in Americans' confidence in the scientific community. Political ideology reflects fundamental political values and is relatively stable, providing a general structure from which one derives attitudes toward social, economic, and political institutions and public policies.^{4,5,6} Americans with a conservative political ideology gradually lost confidence in the scientific community over the last thirty years and now express significantly less trust in science than do liberals.^{7,8,9} If this ideological divide in trust affects public participation in medical studies, many study cohorts are likely biased ideologically. Moreover, given that political ideology is correlated with important health behaviors (e.g., smoking) and health outcomes, this bias—if unaddressed—could substantially limit the generalizability of study findings.^{10, 11, 12}

We examine how this ideological divide relates to study participation in the context of prospective longitudinal cohort studies for Alzheimer disease (AD). AD investigators rely heavily on longitudinal clinical research for the development of treatments and prevention strategies. Currently, AD studies are recruiting over 70,000 volunteers for 150 active trials in North America.¹³ The demand on participants for these trials is often high, as they may include frequent cognitive testing, neuroimaging studies, lumbar puncture to obtain cerebrospinal fluid, and collection of information about their daily function from family members. With few exceptions, volunteers are not informed about their individual performance. Participation in these studies therefore involves an important element of trust in researchers. The ideological divide in trust in science could therefore influence the decision to participate in these longitudinal studies.

2. Methods

2.1 Participants

Mass survey respondents are a probability sample of 1583 adult US citizens in June 2014 through the American Panel Survey (TAPS), a monthly on-line panel survey conducted by Knowledge Networks for the Weidenbaum Center at Washington University in St. Louis. The analysis uses a weighting strategy that ensures the sample is representative of the U.S. adult population.¹⁴ The TAPS survey was reviewed and deemed exempt by the Washington University Institutional Review Board.

We compare the TAPS survey responses with those of cognitively normal participants (n=412) in longitudinal studies at Washington University's Knight Alzheimer Disease Research Center (Knight ADRC) surveyed between June 2013 and February 2016.¹⁵ All participants were invited to participate in a paper and pencil survey at their regularly scheduled annual visits. At these visits, participants undergo blood draw for genetic testing, cognitive evaluations, and assessments of self-reported health and psychological changes. Individuals selected for this study also completed lumbar puncture for AD biomarker assessment. Written informed consent was obtained from all participants and the study was approved by the Washington University Human Research Protection Office. A small number (n=30) of Knight ADRC participants failed to complete the survey. Those who failed to complete the survey were similar to those who completed the survey with regard to age, sex, and average years of education (some college).

2.2. Survey Instrument

We included survey questions regarding AD study participation in the June 2014 mass opinion survey—The American Panel Survey (TAPS). The TAPS survey included respondents' self-reported socio-economic and demographic characteristics (including self-reported race), respondents' answers to a standard battery of questions concerning economic and political issues, and our module of questions regarding confidence in political and social institutions and participation in medical research. Our module included a vignette regarding an AD research study comparable to the character and burden of participating in the Knight ADRC longitudinal studies. We also included conventional measures of confidence in science and political ideology and employed them in surveys of both the TAPS and the Knight ADRC respondents.

Political Ideology—Respondents were asked, "In terms of your political views, do you think of yourself as:" and presented with a 7-point Likert scale. The options were very conservative, conservative, slightly conservative, moderate, slightly liberal, liberal, very liberal, and "don't know". The 111 respondents who indicated "don't know" were presented with a follow-up question, "If you had to choose, would you consider yourself a liberal or conservative?". Responses of "liberal" or "conservative" were coded as "slightly liberal" or "slightly conservative" on the original 7-point scale. The remaining 18 respondents who refused to answer were dropped from the analysis. The responses were recoded so that the variable ranges from 0 (very conservative) to 6 (very liberal). The Knight ADRC respondents answered a similar survey question about their ideology with the same 7-point

response scale. Because the Knight ADRC survey did not include a follow-up question, the 17 responses of “don’t know” were assigned to categories using multiple imputation. The 18 Knight ADRC respondents who refused to answer were dropped from the analysis.

Confidence in the Scientific Community and Other Institutions—Respondents were asked, “As for the people running each of these professions and institutions, would you say you have a great deal of confidence, quite a lot of confidence, only some confidence, or very little confidence in them?” with reference to the following institutions and professions: the press, the television news, the Supreme Court, the scientific community, Congress, and the military. The responses were on a 4-point Likert scale coded so that the variable ranges from 0 (very little confidence) to 3 (great deal of confidence). For the “scientific community”, 22 respondents refused to answer the question and were eliminated from the analysis. The same survey question was asked of Knight ADRC study participants. Twenty-two participants refused to answer and were eliminated from the analysis.

We used the TAPS responses in reference to the other institutions/professions to create a measure of each respondent’s general confidence in institutions. Specifically, we estimated a one-factor model of responses to these questions using principal factors analysis. All items were positively related to the single factor and the eigenvalues (factor 1=1.93; factor 2=0.29) strongly supported a single-factor model. We then generated factor scores for TAPS respondents, with higher scores indicating higher general confidence in institutions. Fifty-six respondents refused to answer one or more of these questions and were excluded from the analysis.

Willingness to Participate in Alzheimer Disease Study—TAPS Survey respondents were presented with the following vignette describing the research study:

Some healthy people join research studies about Alzheimer disease. Such studies often involve a 2-3 hour interview at a medical center where the person tells their medical history, completes tests of memory and thinking, and has a physical examination. These interviews and test are repeated every year, for 10 or more years. Information from these and other tests, such as a brain scan (MRI) and a spinal tap, help researchers better understand Alzheimer disease so that better treatments can be developed. The test results are kept confidential and are not typically shared with the study participants.

They were then asked whether they agreed or disagreed with two statements. The first statement was “I would be willing to join such a study about Alzheimer disease.” The response options were on a 5-point Likert scale: strongly agree, agree, neutral, disagree, strongly disagree. Eighteen respondents refused to answer this question and were eliminated from the analysis. The responses were coded so that the variable ranges from 0 (strongly disagree) to 4 (strongly agree). The second statement was “I would be willing to join such a study about Alzheimer disease, but only if I learn my test results.” The response options and coding were the same as for the first statement. We excluded the 23 respondents who refused to answer this question.

Given that the questions were asked in order, we expect the answer to the first question to anchor the responses to the second (e.g., the stipulation can only increase willingness above the level indicated in response to the first question). Thus, by comparing responses to the two questions, we can identify how important that stipulation is to the respondent's willingness to participate in such a study. Accordingly, we created a variable for the change in willingness due to learning test results by subtracting respondent answers to the first question from their responses to the second question.

Race: Black/African American—In both surveys, respondents were asked to choose one or more categories from a list to indicate the race they consider themselves. We created a dummy variable coded 1 for respondents who indicated “Black or African American” and coded 0 otherwise. Seventeen TAPS respondents were eliminated due to missing data on this question.

Level of Education—Respondents were asked “What is the highest level of school you have completed?” and presented with fifteen ordinal options ranging from “no formal education” (1) to “Doctorate degree” (15). Two respondents refused to answer and were eliminated from analysis. In the Knight ADRC survey, respondents reported the number of years of schooling.

Age—We use the self-reported year of birth (TAPS respondents) and the full birthdate (Knight ADRC study subjects) to calculate the age at time of survey. In the TAPS survey, 27 respondents did not report their year of birth and were eliminated from the analysis.

2.3. Statistical Methods and Analysis

The descriptive statistics, difference in proportions tests, multiple imputation, and regression analyses were executed with STATA 14.0. The STATA *svy* suite for survey weighted data was used for the TAPS survey data. The mediation analysis was conducted with the “medeff” function in STATA.¹⁶ This function provides estimates of mediated effects with robust (Huber/White/sandwich) standard errors and accommodates weighted survey data and continuous and binary outcome variables.

3. Results

TAPS survey respondents varied considerably in their political ideology and confidence in science (Table 1). Although the modal respondent was an ideological moderate, most respondents identified as at least slightly conservative (44%) or liberal (31%). A large share (45%) of respondents had only some or very little confidence in the scientific community. Respondents were widely divided in their willingness to participate, with almost half expressing some willingness to participate. Overall, 33% agreed and 16% strongly agreed with the statement that they would be willing to join the hypothetical study. Figure 1 presents the path diagram of the direct and mediated effect of political ideology on willingness to participate.¹⁷ Consistent with past studies, political ideology positively predicted confidence in science. Political ideology was also positively related to willingness to participate in research studies. Trust in science had a positive and statistically significant effect on participation, mediating the effect of ideology. For example, a change from very

conservative to very liberal ideology had an adjusted average causal mediation effect (ACME) of 0.20 (95% CI: 0.09 to 0.33), an average direct effect of 0.35 (95% CI: 0.03 to 0.67) and a total effect of 0.55 (95% CI: 0.23 to 0.87). Over a third of the effect of ideology (36%, 95% CI: 0.23 to 0.87) was mediated. These relationships survived the inclusion of controls for several potential confounding factors: African-American race, level of education, age and general level of confidence in institutions.

In addition to the TAPS survey involving hypothetical participation in an AD study, we examined attitudes among older adults enrolled in an actual AD study at the Knight ADRC. Knight ADRC participants and TAPS survey respondents were similar in terms of racial composition and average education levels (see Table 1). The TAPS respondents reported on average at least some college education, while the Knight ADRC participants reported on average almost 16 years of education. In addition, the Knight ADRC participants were substantially older than the TAPS respondents (see Table 1). Consequently, we compared the Knight ADRC participants with both the full set of TAPS respondents and with an older subset over 60 years of age for each of the main analyses.

Figure 2 shows that Knight ADRC participants reported more liberal and less conservative ideology than the US general public, as indicated by the TAPS survey results. The Knight ADRC study participants were almost 50% more liberal than were the TAPS respondents ($p < .01$, two-tailed test). Furthermore, the subset of TAPS respondents who were very willing to participate in the hypothetical study were much more liberal than the full sample of TAPS respondents and very similar in ideology to that of the Knight ADRC participants. We found no statistical difference in the proportion of respondents who identified as liberal in the TAPS subset (40%) and the proportion who identified as liberal among the Knight ADRC participants (44%, $p > 0.28$, two-tailed test).

These same relationships hold when we compare the Knight ADRC study subjects with the TAPS respondents over 60 years of age. Knight ADRC study subjects were more liberal than the full set of older TAPS respondents ($p < .01$, two-tailed test). Furthermore, among older respondents who reported that they were very willing to participate in a hypothetical AD study, the proportion expressing a liberal ideology (42%) was nearly identical that of the Knight ADRC study subjects (44%) ($p > 0.68$, two-tailed test).

These distinctions between the Knight ADRC participants and the TAPS survey respondents generally apply to confidence in science as well (Figure 3). The Knight ADRC study participants reported relatively high levels of trust in science, particularly when compared to the full sample of TAPS respondents. A higher proportion of Knight ADRC participants expressed a great deal of confidence in science (24%) than in the full set of TAPS respondents (17%) ($p < .01$, two-tailed test). Furthermore, the proportion expressing a great deal of confidence among the subset of TAPS respondents most willing to participate in the hypothetical study (26%) was not statistically different from that of the Knight ADRC participants (24%) ($p > 0.57$, two-tailed test).

We found the same pattern when we compared the Knight ADRC participants with an older subset of TAPS respondents. The proportion of all TAPS respondents over 60 years old with

a great deal of confidence in science (15%) was significantly lower than in the Knight ADRC group (24%) ($p < .01$, two-tailed test). Among older respondents who reported that they are very willing to participate in an AD study, the proportion with a great deal of confidence increased to (31%), which is not statistically different than the proportion in the Knight ADRC group (24%) ($p > 0.16$, two-tailed test).

For a large proportion (40%) of TAPS respondents, interest in participation differed depending on whether study participants would learn their study results. About half (19%) of those respondents recorded a positive change, indicating they were more likely to participate with the stipulation “only if I learned my test results”. Of the respondents who were negatively predisposed toward participation without the stipulation, 27% abandoned their opposition to participation if the study stipulated they would learn their test results. Moreover, almost one-fifth of those originally opposed to participation changed to agreement with participation when the study stipulated learning test results.

The magnitude of the change in willingness due to sharing test results differed with political ideology. The per cent of conservatives (22%) with positive changes was greater than that of liberals (15%), indicating that learning test results from the study was more salient to the participation of conservatives than it was for participation of liberals. This effect of ideology was both direct and mediated through confidence in science (Figure 4). As ideology became more conservative, respondents were more likely to change to participation with the stipulation that test results are shared. Trust in science had a negative and statistically significant effect, mediating the effect of ideology. For example, a change from very conservative to very liberal ideology had an adjusted average causal mediation effect (ACME) -0.13 (95% CI: -0.23 to -0.05), an average direct effect of -0.35 (95% CI: -0.65 to -0.06) and a total effect of -0.49 (95% CI: -0.79 to -0.18). The mediated portion of the ideological effect was 28% (95% CI: 17% to 76%). These relationships held in the presence of controls for African-American race, level of education, age, and general level of confidence in institutions.

4. Discussion

The ideological divide among Americans in their trust in science has important implications for the recruitment and representativeness (external validity) of prospective longitudinal research studies. Almost half (49%) of survey respondents were willing to participate in a longitudinal AD study, which is generally consistent with the past results showing fairly broad willingness to participate in hypothetical longitudinal studies.^{1,18} However, conservative Americans were less willing to participate than liberals and this ideological difference was mediated by their confidence in the scientific community. Furthermore, this divide in participation appears to affect participation in actual longitudinal research studies, not simply survey responses about hypothetical ones. Participants in an actual study of the type described in the vignette, the Knight ADRC study group, express comparable political ideology and confidence in science to the subset of TAPS respondents who were most willing to participate in the hypothetical study. Moreover, similar to this subset of TAPS respondents, the Knight ADRC study participants are significantly more liberal and express much greater confidence in the scientific community than does the general US public. This

is also true for an older subset of TAPS respondents with a similar age distribution to that of the Knight ADRC group (Table 1) and to that of many dementia studies.¹⁹

These findings should inform the development of study recruitment practices, public outreach programs and policies regarding the disclosure of test results to research participants. Because ideological differences are associated with important differences in health behaviors and health outcomes, disregarding ideological bias in the recruitment of study subjects can pose a significant constraint on the external validity of longitudinal studies and clinical trials.^{10, 11, 12} This problem can be addressed in at least two ways. First, and most concretely, studies can be designed to limit or reduce the level of trust required of participants. For example, when test results are kept from study subjects, they must trust that the study administrators will evaluate and act upon clinically relevant or otherwise important findings in the best interest of the participant. We found that this sort of concern likely affects willingness to participate in studies, as willingness among conservatives increased if the study results were shared with study participants. Of course, sharing test results requires careful implementation, as it may adversely affect the study or the study participants.^{20, 21} Nevertheless, disclosing test results is an example of study design attributes that may lower the trust demanded of study participants.

Second, and more long-term, the medical and scientific community can work to increase confidence in science. Political ideology, as conventionally understood, is fairly stable and difficult to manipulate.^{4,5,6} But its connection to confidence in the scientific community is a potential target for improvement. Scientists and researchers are generally seen as highly competent but not particularly warm or trustworthy.²² In particular, efforts by researchers to communicate uncertainty and impartiality in reporting scientific findings can enhance trust.^{22,23,24} Targeting such messages at conservative audiences may reduce the ideological divide in willingness to participate.

The current study has several limitations. First, the TAPS survey design (e.g., the use of self-reported ideology and confidence in science and a hypothetical AD study vignette) to assess the political basis for participation may, at least in part, fail to capture actual behavioral choice about participation. Nevertheless, this concern is mitigated by the favorable comparison of ideology and trust in science between the TAPS survey respondents willing to participate in the hypothetical AD study and participants in the Knight ADRC. Second, the TAPS survey was conducted on-line with a national sample, while the Knight ADRC survey involved primarily residents of the St. Louis area and a paper-and-pencil survey. We were unable to control for these design features and thus cannot rule out that they may account for some of the observed differences across the surveys. Third, this study addressed participation in only a longitudinal AD study. Such AD studies are common and continue to recruit significant number of participants. However, whether confidence in science and political ideology affect other forms of participation in clinical research is an open question.

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Figure 1.

Note: The values in the figure represent standardized regression coefficients. The value in parentheses is for the total effect of political ideology, which was estimated in the equation without confidence in science. ** $p < .01$, two-tailed test; * $p < .05$, two-tailed test.

Figure 2.

Note: The TAPS (very willing) subset consists of TAPS survey respondents who answered “strongly agree” in response to the survey question about their willingness to participate in the longitudinal research study of Alzheimer disease. The three categories of political ideology were constructed by combining the ideologically related responses to the 7-point Likert scale used in the survey question. For example, responses of 0-2 (very conservative, conservative, and slightly conservative) comprise the ‘conservative’ category.

Figure 3.

Note: The TAPS (very willing) subset consists of TAPS survey respondents who answered “strongly agree” in response to the survey question about their willingness to participate in the longitudinal research study of Alzheimer disease.

Figure 4.

Note: The values in the figure represent standardized regression coefficients. The value in parentheses is for the total effect of political ideology, which was estimated in the equation without confidence in science. ** $p < .01$, two-tailed test; * $p < .05$, two-tailed test.

Table 1

Descriptive statistics

Characteristic	N	Mean	Standard Deviation
<i>TAPS survey respondents:</i>			
Political Ideology (conservative-liberal)	1565	2.75	1.63
Confidence in Science	1561	1.61	0.89
Confidence in Institutions (factor score)	1527	0.01	0.92
Level of Education (categories)	1573	10.30	2.14
Black/African American	1581	0.11	0.31
Age	1556	48.81	16.96
Willingness to Participate	1568	2.41	1.07
Change in Willingness to Participate	1560	-0.09	1.02
<i>TAPS survey respondents over 60 years old:</i>			
Political Ideology (conservative-liberal)	607	2.70	1.68
Confidence in Science	605	1.70	0.81
Level of Education (categories)	611	10.44	2.22
Black/African American	613	0.07	0.26
Age	613	70.61	7.39
Willingness to Participate	606	2.27	1.09
<i>Knight ADRC study participants:</i>			
Political Ideology (conservative-liberal)	364	3.22	1.62
Confidence in Science	360	2.09	0.63
Years of Education	382	15.95	2.55
Black/African American	382	0.16	0.36
Age	382	73.42	8.65