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Authors
Kent, Saida
Bardach, Shoshana H
Zhang, Xuan
et al.

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Public Understanding and Opinions of Genetic Research for Alzheimer's Disease

Saida Kent, B.A[1], **Shoshana H. Bardach, PhD**[2,3], **Xuan Zhang, MD, DrPH**[4], **Erin L. Abner, PhD**[2,3], **Joshua D. Grill, PhD**[4], **Gregory A. Jicha, MD, PhD**[1,2,5]

[1]University of Kentucky-College of Medicine

[2]Sanders-Brown Center on Aging University of Kentucky

[3]University of Kentucky – College of Public Health

[4]Johns Hopkins University School of Nursing

[5]University of California Irvine – Psychiatry and Human Behavior

Abstract

Background: Participants willing to provide genetic samples are needed to propel the science of Alzheimer's disease (AD) treatment and prevention forward. Limited public understanding of what AD genetic research entails and participation concerns may serve as recruitment challenges.

Objective: This study seeks to understand how well older adults understand AD genetic research and if understanding relates to concerns about participation or willingness to engage.

Methods: Surveys included a mock AD consent with corresponding knowledge and opinion questions. Surveys were mailed to participants from the University of Kentucky Alzheimer's Disease Research Center and to a list of randomly selected individuals within the same age range from a local voter registration list. Descriptive and multivariable linear regression analyses were conducted.

Results: Returned surveys (n=502) demonstrated limits in what respondents understood immediately after reading the relevant material, with mean summary knowledge scores of 74.5 out of 100. While comprehension gaps did not relate to level of concern or willingness to engage, concerns were related to willingness to engage. Concerns were greater among individuals not actively involved in research, individuals from minority groups, and those with higher levels of education.

Conclusions: Focusing on concerns specifically rather than knowledge more generally may help increase participation.

Keywords

Alzheimer's disease; Genetic research; Research participation; Concerns; Knowledge; Surveys and Questionnaires

Corresponding Author: Shoshana H. Bardach, Sanders-Brown Center on Aging, 1030 S. Broadway, Suite 5, Lexington, KY 40504, Phone: (859) 323-1331, Fax: (859) 257-4233, shbardach@uky.edu.

INTRODUCTION

Initial genetic discoveries in Alzheimer's disease (AD) began with recognition of mutations in the amyloid precursor protein, presenilin 1 and presenilin 2 as causes of autosomal dominant AD, followed by the identification of the ε4 allele of apolipoprotein E gene as a risk factor for sporadic AD. Since that time, over 20 genetic risk loci for sporadic AD has been identified [1], providing insights into molecular pathways that may be altered in AD and identifying targets for prevention and treatment. These discoveries are only possible through the involvement of large numbers of research volunteers [2].

Certain risk genes for sporadic AD can be identified through blood tests, buccal swabs, and spit kits (e.g. APOE), though this testing is typically not recommended in standard clinical care since at present these results do not provide clear clinical implications [3]. However, in the research context, genetic testing is pervasive[4] and can help identify individuals at greater risk for developing memory impairments [5]. Unfortunately, genetic testing can also introduce the potential for genetic discrimination, with potential implications for both participants and their family members [6]. AD genetic research participation decisions should be based on understanding the risks and benefits [7].

Many individuals value knowing about their personal disease risk and are frequently willing to undergo and pay for AD predictive genetic tests [8, 9]. In the research context, however, personal disease risk information often is not shared with participants [10, 11]. Additionally, certain groups are under-represented in AD genetic research, e.g. minorities and individuals with lower levels of education [8]. These same groups have a history of research mistreatment and lack of adequate consent [7] which may lead to a reluctance to participate due to concerns about privacy or use of genetic information. Concerns may be exacerbated in situations where there is uncertainty regarding what AD genetic research entails.

Prior research suggests reasonable understanding of AD genetic risk results, but suggests older adults may have more comprehension difficulties than younger adults [12]. Older adults may be more likely to see the value in biobank participation –one type of genetic research - than younger adults, but may be equally or even less likely than younger adults to report willingness to participate [13–15]. Given that older adults are typically the target population for AD prevention and treatment genetic research, there is a need for an examination of comprehension of and attitudes toward such research among older adults [16].

This study seeks to understand how well older adults understand AD genetic research when presented with descriptive information mirroring the content of a research consent form and whether certain factors relate to understanding. To enhance generalizability, both current (University of Kentucky AD Center (UKADC) participants) and potential (Voter registration list (VRL)) older research participants were surveyed. This manuscript also explores how understanding relates to concerns about participation and willingness to engage. We hypothesized that older adults would have gaps in their understanding of AD genetic research and that these gaps would relate to concerns about genetic research and willingness to engage.

MATERIAL AND METHODS

Study design.

A paper survey was distributed by mail, including a study description and a postage-paid return envelope. UKADC participants had previously expressed preference for mail communication rather than email communication; email addresses were also largely unavailable for UKADC participants and were completely unavailable for the VRL participants. Accordingly, we used postal mail to distribute the survey to both groups. The cover letter included all elements of informed consent; no formal documentation of consent was required. Surveys were mailed and returned between June 2016 and August 2016.

Participants

Two groups were surveyed. First, volunteers (n=594) enrolled in the UKADC longitudinal cohort with Clinical Dementia Ratings global scores of 0 or 0.5, representing no or questionable memory and thinking problems, were surveyed [17, 18]. In addition, the UKADC manages a list from 2010 of registered voters in Fayette County Kentucky who indicated a willingness to be contacted for aging-related research, not AD research specifically. After the UKADC list was generated, summary statistics on age, sex, race, and educational attainment were computed. Using those results, the VRL was randomly sampled (n=608) within the age range of UKADC participants to get the groups as similar as possible (Table 1).

Instrument

The survey began with the Quality of Informed Consent (QUIC), a valid and reliable measure of participants' understanding of clinical trials, modified to focus on AD genetic research [19]. The survey had seven sections, each beginning with a short paragraph from a standard genetic research consent form followed by a series of questions (paragraphs available by request to the corresponding author). Each paragraph included answers to the knowledge comprehension questions that immediately followed. The seven sections were: purpose of genetic research (5 questions); risks of genetic research (6 questions); genetic data storage and access (8 questions): results information sharing (6 questions); the right to withdraw and ability to destroy samples (3 questions); future research participation based on genetic results (6 questions) and types of genetic research (5 questions). Each question used a five-point Likert scale (strongly agree to strongly disagree) (See Tables 2–4). Questions assessed comprehension of the material just presented, concerns about privacy or use of genetic material, and willingness to get involved in research. Both the cover letter and the first page of the survey specifically indicated the focus was on AD genetic research. Throughout the survey, the context for all questions was genetic research in the area of AD. While not all individual questions explicitly mentioned AD, the survey repeatedly referenced this focal area. For instance, the first section, which focused on the purpose of genetic research, provided the following paragraph prior to the questions:

SECTION 1: What is the purpose of genetic research?

The purpose of the study is to collect and store blood samples and health information to learn about the role genes play in health and disease, specifically

about the development of Alzheimer's disease. Results of these genetic studies may reveal information about you and your family members' risk for Alzheimer's disease.

As can be seen in this excerpt, while some of the language refers to genetic research more broadly, the accompanying text orients respondents to the focus on Alzheimer's disease. Basic demographic information (age, sex, race, education, and marital status) was collected. A preliminary validation of the survey was conducted with several individuals in the research clinic to make sure that the items were understood and that responses were appropriate to the questions asked.

To ensure readability and applicability, the content was matched to current consent form templates from the University of Kentucky Institutional Review Board (IRB) website and existing consents for AD clinical trials. While no formal psychometric testing of the survey was conducted, a team of interdisciplinary investigators, including neurologists, neuropsychologists, social workers, and gerontologists, reviewed the survey iteratively to ensure face validity and readability.

Analysis

Summary scores of the modified QUIC were calculated for knowledge comprehension, concerns about privacy and use of genetic material, and willingness to engage according to established procedures [19]. We separated privacy and genetic concerns to tease out the nature of concerns. Privacy items focused explicitly on privacy concerns whereas genetic concerns focused on issues related to preferences for sharing and use of genetic materials; we interpreted expressions of a preference for restricted use of genetic information as genetic concerns. Correct answers, endorsement of concern, and positive attitude answers were assigned a score of 100. Incorrect, lack of concern, and negative attitude answers were assigned a score of 0. "Not Sure" was assigned a score of 50, because it is preferred that participants recognize areas of uncertainty rather than be certain of false beliefs. To mirror the established QUIC analysis procedures, responses of "Strongly agree" and "Agree" were given the same score, as were responses of "Strongly disagree" and "Disagree". Unanswered questions were not scored. Summary scores were then calculated by adding the scores for each item and dividing by the number of non-missing items (See Tables 2–4). The resulting summary scores range from 0 to 100. The items for knowledge, concerns, and privacy were all predetermined in the questionnaire design phase and scoring procedures followed the QUIC guidelines, with higher scores representing greater comprehension, more positive attitudes, and greater endorsement of concerns. All survey questions are included in one of the tables, with each table representing responses that measure one of the measured constructs: knowledge comprehension (Table 2), concerns about privacy and use of genetic material (Table 3), and willingness to engage (Table 4).

Descriptive statistics were used to compare the UKADC and VRL groups. To assess potential nonresponse bias, respondents were compared to non-respondents within each group in regard to age, sex, education, and race using unpaired *t* test for age and chi-square for the remaining variables. Multivariable linear regression was used to assess the association between summary scores and respondent group, adjusting for education (college

and above vs. no college), marital status (married vs. unmarried), race (white vs. non-white), sex (male vs. female), and age. Analyses for willingness also controlled for summary knowledge score. Analyses were performed in SAS 9.4® and statistical significance was set at 0.05. *Ethics.* Approval for this research was received from the University of Kentucky IRB.

3. RESULTS

Respondents

Fourteen UKADC surveys and 123 VRL surveys were returned due to a change in address or death of the recipient. A total of 502 surveys were received, including 329 (56.7%) UKADC participants and 173 (34.7%) VRL participants.

UKADC respondents had higher education (71.7% college education vs. 58.2%, p=.001) and were less frequently from a minority racial group (8.8% vs. 17.9%, p=.04) compared to UKADC non-respondents. VRL respondents were younger (mean age = 79.3 vs. 80.7, p=.007) and less frequently from a minority racial group (9.2% vs. 17.0%, p=.048), compared to VRL non-respondents. No other differences were observed between respondents and non-respondents in either group.

The mean age of the overall sample was 78.8 years; 57.8% were female, and 58.6% were currently married (Table 1). Participants were highly educated, 68.3% had at least a college degree. Most were white. The research group was significantly more likely to have a college education or higher (72.4%) than the VRL group (60.5%, p=.023).

Knowledge of genetic research

Overall, limitations in understanding the complexity of AD genetic research were identified, with mean summary unadjusted knowledge scores of 74.5 out of 100. Summary knowledge scores did not differ between the research and VRL groups (adjusted mean difference = −0.7 points, 95% CI −3.0 to 1.7, p=0.57).

There were several areas where responses demonstrated knowledge comprehension gaps (Table 2) including areas of genetic testing and beliefs about personal benefit. Nearly half of respondents failed to understand that confidentiality could be compromised based on genetic information. More than a third of respondents did not understand that their genetic information could be shared, and 43% did not recognize that their genetic information and samples may not always be destroyed if they withdraw. Regarding comprehension gaps in the area of personal benefit, most respondents failed to understand that there are instances where they cannot get personal genetic results. Nearly a third of participants thought that the main goal of genetic research was to help them directly (with an additional quarter of participants being unsure). Many respondents (52%) thought that they would be informed about their own risk for AD, and 53% thought that they would be contacted if their genes showed any disease risk factors.

Based on the multivariable regression analysis, several socio-demographic factors were associated with knowledge summary scores. Participants with less than a college education

had an adjusted mean summary knowledge score of 66.9, compared to 73.0 for those with at least a college education (adjusted mean difference = 6.1, 95% CI 3.6 to 8.5, p<0.001). Non-white respondents had an adjusted mean summary knowledge score of 66.14 vs. 73.71 of white respondents, p=0.0001. In addition, for each additional year of age, respondents scored 0.30 points lower (95% CI −0.5 to −0.2, p<0.001) on the QUIC summary knowledge score, p=.0008. There were no significant associations between sex or marital status and knowledge scores.

Concerns about privacy and use of genetic information

Concerns about privacy and use of genetic information were low (Tables 1 and 3). In analysis adjusted for respondent group, age, education, race, sex, and marital status, neither privacy concerns nor genetic concerns were related to summary knowledge scores. Based on the regression analysis, there were no significant relationships between any of the demographic variables, including respondent group, and summary privacy concern scores (Global F test p=0.37). For concerns about genetic materials, respondent group, education, and race were all significantly related to genetic concern summary scores. VRL participants were significantly more concerned about use of genetic material than research participants (mean genetic concern score = 36.2 vs. 31.2, 95% CI for adjusted mean difference = 0.3 to 9.7, p=0.04). Non-white participants were significantly more concerned about use of genetic material than white participants (mean genetic concern score = 40.6 vs. 26.7, 95% CI for adjusted mean difference = 6.1 to 21.6, p<0.001). Those with a college or higher education had more concerns about genetic information than those with less than a college education (mean genetic concern score = 37.08 vs. 30.22, 95% CI for adjusted mean difference = 2.0 to 11.7, p= 0.006).

Willingness to participate in genetic research

Overall willingness to participate in genetic research for AD was high, with no single item achieving less than majority agreement (Table 1). Willingness scores and summary knowledge scores were not related when controlling for respondent group, age, education, race, sex, and marital status. Based on the regression analysis, none of the demographic variables examined, including respondent group, were related to willingness summary scores. Willingness to participate was inversely related both to concerns about genetics (Pearson correlation = −.212, p <.001) and concerns about privacy (Pearson correlation = − . 216, p <.001).

4. DISCUSSION

This study explored understanding and acceptance of genetic research for AD among older adults with varying degrees of research engagement. Both current and potential older adult research participants had gaps in their understanding of AD genetic research. While the QUIC does not provide clear guidelines of what is considered a “good” score, a score of 74.5 immediately after viewing the material clearly demonstrated suboptimal knowledge and is slightly lower than scores found with other instances of the QUIC [20, 21]. Consistent with prior research exploring knowledge of genetics, comprehension gaps were greater among those with less education, older individuals, and those of non-white racial groups

[22]. These factors should alert researchers of the need for extra time during the consent process to ensure all information is fully understood. Teach-back techniques are often used to confirm capacity when a researcher is uncertain about a participant's comprehension [23]. Given the complexity of AD genetic research, perhaps this should be done for all participants in key areas where misunderstandings are more common, such as those highlighted in this study. While ensuring fully informed consent might not necessarily increase participation, ensuring a common understanding at the outset may help avoid any potential loses in trust or future research willingness. This might occur if a negative outcome is experienced that was not even recognized as a possibility or a positive anticipated result is not realized.

In our study, there were comprehension gaps, but concerns were relatively low. Comprehension gaps were most notable in the areas of genetic testing and results and beliefs about personal benefit. Gaps in understanding of genetic testing may have implications for concerns. Concerns may be lower if participants do not fully understand the potential for confidentiality to be compromised, genetic information to be shared, and samples to remain even if they withdraw. Such misunderstanding may be caused by the terminology or language used. For example, in the biomedical community, the definition of clinical utility may be relatively narrow compared to the public's perception. Additionally varying perceptions of the treatability of AD may compound this confusion [24]. While low concern is encouraging for research engagement, information should be conveyed in an easily understandable way to ensure participants make informed decisions. For example, participants seemed to interpret the goal of research as to help them directly, many believing they would receive information about their own risk for AD and be contacted if their genes showed any disease risk factors. While participation in a research study may provide some personal benefit and on occasion provide personal disease risk information, in many instances this is not the case. Special care should be taken with terminology and language selected to help ensure clear expectations. Researchers may want to clarify with potential participants their goals for joining a study to ensure that their goals are aligned with their research involvement and to evaluate risks and benefits [25].

While prior research suggests many individuals can distinguish hopes for benefit from expectations of benefit, not all research participants are able to do so [26]. Misperceptions of personal benefit may have implications for participant retention; individuals who engage with false perceptions of feedback may be more likely to withdraw when they fail to get anticipated feedback. With the complexity involved in genetic research and the prospect of incidental findings, informed consent should be explicit about research results (primary and incidental) and whether and when participants may receive personal information [27].

Disclosure of genetic results is an issue that is hotly debated by research communities and ethicists [28]. Consistent with our findings that participants desire disease risk information, previous research also suggests that a majority of participants favor knowing their genetic test results, are psychologically able to deal with such information, and that such knowledge may even serve as an incentive for research participation [29–31]. While there are logistical and ethical challenges that can result from sharing genetic results [32], the research community should work towards finding a balance between the complexity involved with

sharing individualized results and the benefits of disclosure for maintaining trust and giving a sense of involvement and reciprocity. While some efficiency may be lost and costs accrued by incorporating a disclosure process [33], recruitment challenges may be somewhat ameliorated over time as research becomes more participant-centered.

While no significant relationship between comprehension and concerns was found, concerns were related to education, respondent group, and race. Surprisingly, those with higher levels of education had greater levels of concern. Perhaps individuals with more education are more aware of the potential – both good and bad – of genetic information and therefore have more concern. Those with lower levels of education had more comprehension difficulties, but fewer concerns regarding genetic information. This raises the unwelcome possibility that individuals with lower levels of education may have knowledge gaps that pose challenges to fully comprehending potential risks [34].

Similarly, the finding that minorities had a greater level of concern than White participants is in line with numerous studies that indicate higher levels of mistrust of health research and researchers among minority populations [35, 36]. This mistrust may stem from various sources, including a history of research mistreatment and misuse of genetic information, e.g. the prominent case of Henrietta Lacks. The current findings may provide some insight into approaches for addressing lower rates of minority participation in genetic research [37] including educational efforts accompanied by efforts to build relationships and address mistrust and research concerns [38]. While not all concerns can be fully addressed, efforts to communicate research safeguards may need to be strengthened. Some of these efforts may be more successful if information comes from sources potential participants already are familiar with and trust and respect, such as healthcare providers [39]. Greater transparency about the use and sharing of genetic information may also help alleviate some concerns. With the alleviation of some concerns, hopefully barriers will be reduced and participation among minorities might increase. It is important to note that some concerns stem directly from the research, whereas others may relate to broader issues regarding trust in researchers and institutions [40]. Addressing these factors may require broader efforts including the development of innovative partnerships between research entities and community organizations [41].

Another unanticipated finding in our study was that participants' were generally unconcerned with drug companies obtaining their data or with researchers making a profit from their genetic information without sharing these profits. Of note, however, over 20% of respondents replied "Not sure" to these items, suggesting the possibility that upon further reflection concerns may be somewhat greater or that this may be a more nuanced issue than previously recognized. Perhaps those who see the benefits of these instances of sharing are those who are generally more trusting of the research process and may be less concerned with how their information is shared. This question will require further attention in the future to ensure respect for participants' autonomy.

Willingness to participate generally was very high across all groups, consistent with previous research showing generally positive attitudes towards genetic research [42]. This finding was also somewhat expected given that the participants surveyed were either already

involved in AD research or had previously expressed a willingness to be contacted for aging research. However, given that many of the VRL participants were research naïve and likely had not previously considered AD genetic testing, the high willingness observed is still noteworthy. Given respondents' receptivity to the idea of AD genetic research, greater promotion of opportunities in general may increase participation. Prior research has suggested one of the major barriers to participation is simply never being asked [39]. Additionally, the finding that knowledge and willingness were not significantly related, but that willingness was inversely related to concerns, suggests that research willingness may be influenced more by comfort with research engagement than by knowledge per se [31]. Directly addressing concerns and highlighting the benefits and value of participation, rather than broader research education efforts, may be key to increasing public participation. Future research will need to explore whether these same strategies are appropriate for those who have not previously demonstrated any research interest.

Limitations

This study's main limitation is generalizability. While the UKADC response rate was 56.7%, the VRL response rate was 34.5%. Although somewhat anticipated by the lack of an active relationship with the VRL group, this response rate raises questions about the generalizability of the VRL responses to the Kentucky older adult population. The possibility for nonresponse bias, where respondents may be more knowledgeable and positive about AD genetic research than non-respondents, exists. The sample's limited diversity and high educational attainment also limit generalizability. While relatively low, the number of minority participants was in line with Kentucky demographics [43]. The VRL members had previously expressed a willingness to be contacted about research; accordingly research willingness is likely higher than among the general public. Differences between respondents and non-respondents also suggest that respondents could potentially be more comfortable with the concept of AD genetic research than non-respondents. Accordingly, while this study likely overestimates AD-related genetic research willingness of older adults from the general public, the findings regarding comprehension gaps and the role of concerns remain essential for consideration when designing future outreach and recruitment efforts, where these gaps and concerns will likely be even greater.

Another limitation lies in the hypothetical nature of the research. Real-world concerns and engagement decisions may differ from hypothetical assessments. Research engagement may also relate to factors beyond the individual that were not assessed, such as lack of access to institutions conducting AD genetic research, lack of/limited racial and cultural diversity among research investigators and staff, and time and travel challenges involved in research participation. Future research should move from hypothetical willingness to actual research engagement.

In this study participants completed the survey in isolation with no one immediately available for questions or clarification. Research consent processes are interactive and allow for opportunities for dialogue and clarification. Our intention was not to mirror a consent process, but rather, to gain insight into understanding and views of AD genetic research. Most of the public never gets to the point of discussing a research consent form, and even for

those who do, initial review often occurs prior to coming in for the actual consent process; accordingly investigating public understanding and attitudes without the benefit of active researcher interaction is important

CONCLUSION

Despite the noted limitations, this study shows that older adults recognize the importance of genetic research. Extra efforts to bring awareness of research participation opportunities to the public and to assuage fears about the use of genetic information should be made to capitalize on this interest. As new and emerging genetic discoveries continue, we should remain cognizant of the public's attitudes and beliefs and ensure that outreach materials and research design choices reflect community wishes and expectations, especially as efforts to increase participation among vulnerable and under-represented populations continue. In the future, we will also explore knowledge, concern, and research willingness across older adults who have not previously expressed any research interest.

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Table 1.

Demographic characteristics and unadjusted mean summary scores

Characteristic	All Subjects (N=502)	Research Participants (n=329)	VRL Participants (n=173)	P Value
Age (mean ± SD)	78.8±6.6	78.5±7.2	79.3±5.3	0.21
Sex				
Male	212 (42.2)	132 (40.1)	80 (46.2)	0.19
Female	290 (57.8)	197 (59.9)	93 (53.8)	
Education				
No College	158 (31.7)	90 (27.6)	68 (39.5)	0.02
College	340 (68.3)	236 (72.4)	104 (60.5)	
Race				
Non-white	45 (9.0)	29 (8.8)	16 (9.3)	0.88
White	456 (91.0)	299 (91.2)	157 (90.7)	
Marital status				
No	206 (41.4)	135 (41.2)	71 (41.8)	0.90
Yes	292 (58.6)	193 (58.8)	99 (58.2)	
QUIC Summary Knowledge	74.5±13.1	75.1±12.8	73.2±13.7	0.12
Summary Privacy Concerns	30.88±31.97	29.63±31.99	33.33±31.88	0.23
Summary Genetic Concerns	28.78±25.53	27.31±25.20	31.61±26.00	0.07
Summary Willingness Score	89.81±15.14	90.50±14.31	88.49±16.57	0.16

Abbreviations: QUIC, Quality of Informed Consent. All summary scores have a maximum value of 100, with higher scores indicating higher knowledge, higher concerns, and higher willingness.

Table 2:

Alzheimer's Genetics Quality of Informed Consent (QUIC) Comprehension Items in Ascending Order of Comprehension (Higher Scores Reflect Greater Comprehension)*

Question	Strongly Agree	Agree	Not sure	Disagree	Strongly Disagree	Missing	QUIC Item Score Mean (SD)
Genetic studies will inform me about my risk for Alzheimer's disease	100 (19.9)	159 (31.7)	187 (37.3)	**41 (8.2)**	**10 (2.0)**	5 (1.0)	29.07 (33.52)
I will be contacted if during the research testing, my genes show any disease risk factors.	58 (11.6)	205 (40.8)	80 (15.9)	**108 (21.5)**	**34 (6.8)**	17 (3.4)	37.53 (44.00)
The main goal of genetic research is to help me directly	59 (11.8)	99 (19.7)	122 (24.3)	**164 (32.7)**	**48 (9.6)**	10 (2.0)	55.49 (43.06)
If I withdraw from the study, all of my genetic information and samples containing my genetic information will be destroyed	32 (6.4)	101 (20.1)	84 (16.7)	**171 (34.1)**	**102 (20.3)**	12 (2.4)	64.29 (43.26)
No one will ever be able to find out who I am, based on my genetic information	39 (7.8)	82 (16.3)	101 (20.1)	**184 (36.7)**	**80 (15.9)**	16 (3.2)	64.71 (42.04)
There is always a way to get my results from research studies if I want them	18 (3.6)	57 (11.4)	185 (36.9)	**153 (30.5)**	**68 (13.5)**	21 (4.2)	65.18 (36.21)
If my sample is identified there is a federal law (GINA) that protects me from discrimination	**79 (15.7)**	**223 (44.4)**	108 (21.5)	56 (11.2)	22 (4.4)	14 (2.8)	72.95 (37.21)
Others not directly connected to the study will have access to my genetic information	**62 (12.4)**	**246 (49.0)**	100 (19.9)	56 (11.2)	25 (5.0)	13 (2.6)	73.21 (38.12)
There is a possibility that my genetic sample could be identified	**51 (10.2)**	**265 (52.8)**	103 (20.5)	45 (9.0)	25 (5.0)	13 (2.6)	75.15 (36.65)
The researchers taking my DNA sample will be the only ones to use my genetic information	26 (5.2)	41 (8.2)	107 (21.3)	**201 (40.0)**	**113 (22.5)**	14 (2.8)	75.31 (36.25)
I can decide to not be told any results of my genetic testing	**57 (11.4)**	**256 (51.0)**	100 (19.9)	43 (8.6)	15 (3.0)	31 (6.2)	77.07 (35.20)
The GINA law may not completely protect my privacy and confidentiality	**79 (15.7)**	**254 (50.6)**	118 (23.5)	21 (4.2)	18 (3.6)	12 (2.4)	80.00 (31.62)
Research that examines all of my genetic information involves the greatest risk that the information could be linked back to me or my family	**85 (16.9)**	**221 (44.0)**	88 (17.5)	24 (4.8)	1 (0.2)	83 (16.5)	83.53 (29.20)
I will be contacted if during the research testing, the results show I have a high risk factor for a disease that currently has available treatment	**113 (22.5)**	**279 (55.6)**	60 (12.0)	23 (4.6)	9 (1.8)	18 (3.6)	87.19 (28.44)
If I withdraw from the study, some of my genetic information already shared will continue to be used	**142 (28.3)**	**298 (59.4)**	38 (7.6)	12 (2.4)	1 (0.2)	11 (2.2)	93.48 (20.41)
Genetic research may entail varying levels of genetic information being collected depending on the study	**118 (23.5)**	**324 (64.5)**	36 (7.2)	2 (0.4)	6 (1.2)	16 (3.2)	94.65 (17.94)
Genetic studies will help researchers' find genes associated with higher and/or lower risk for Alzheimer's disease	**252 (50.2)**	**211 (42.0)**	31 (6.2)	4 (0.8)	1 (0.2)	3 (0.6)	95.90 (15.45)
My genetic information could be used for multiple research studies.	**174 (34.7)**	**285 (56.8)**	24 (4.8)	4 (0.8)	4 (0.8)	11 (2.2)	95.93 (16.40)

Question	Strongly Agree	Agree	Not sure	Disagree	Strongly Disagree	Missing	QUIC Item Score Mean (SD)
The main goal of genetic research is to help others in the future	**330 (65.7)**	**152 (30.3)**	8 (1.6)	5 (1.0)	2 (0.4)	5 (1.0)	97.79 (13.29)

*Note, in some AD genetic studies the correct answer for these questions could differ based on study design. The answers identified as correct above were the accurate answers based on the information in the summary paragraphs provided to participants. Bolded cells refer to correct responses.

Table 3:

Alzheimer's genetics Quality of Informed Consent (QUIC) Privacy and genetic items survey responses.

Question	Construct	Strongly Agree	Agree	Not sure	Disagree	Strongly Disagree	Missing	Item Score
		N (%)	N (%)	N (%)	N (%)	N (%)	N (%)	Mean (SD)
I am concerned about the privacy and confidentiality of my genetic information	P	**29 (5.8)**	**163 (32.5)**	63 (12.5)	167 (33.3)	63 (12.5)	17 (3.4)	46.08 (46.52)
Concerns about privacy would prevent me from participating in genetic research	P	**8 (1.6)**	**25 (5.0)**	91 (18.1)	229 (45.6)	136 (27.1)	13 (2.6)	16.05 (29.73)
I am okay with my genetic information being shared without my direct involvement.	G	89 (17.7)	270 (53.8)	77 (15.3)	**31 (6.2)**	**18 (3.6)**	17 (3.4)	18.04 (32.92)
I would prefer to have my genetic information "open access" to allow maximal use of my genetic information for Alzheimer's research.	G	114 (22.7)	217 (43.2)	79 (15.7)	**53 (10.6)**	**24 (4.8)**	15 (3.0)	23.92 (37.64)
I would prefer to have my genetic information "restricted access" to allow only NIH approved researchers to use my genetic information for Alzheimer's research.	G	**45 (9.0)**	**153 (30.5)**	67 (13.3)	179 (35.7)	41 (8.2)	17 (3.4)	47.73 (46.41)
I am okay with the researchers sharing my genetic information with "for-profit" drug companies.	G	43 (8.6)	177 (35.3)	117 (23.3)	**94 (18.7)**	**59 (11.8)**	12 (2.4)	43.16 (43.13)
I am okay with researchers making a profit from my genetic information without receiving any profits myself.	G	47 (9.4)	219 (43.6)	104 (20.7)	**70 (13.9)**	**47 (9.4)**	15 (3.0)	34.70 (41.66)
Once I provide genetic samples I would like them to be used indefinitely to maximize their utility.	G	178 (35.5)	254 (50.6)	47 (9.4)	**8 (1.6)**	**6 (1.2)**	9 (1.8)	7.61 (2.57)

Note: Bold items reflect responses that indicate concerns with privacy or use genetic information.

P = Privacy Concerns

G = Genetic Concerns

Table 4:

Alzheimer's genetics Quality of Informed Consent (QUIC) Willingness items survey responses

Question	Strongly Agree	Agree	Not sure	Disagree	Strongly Disagree	Missing	Item Score
	N (%)	N (%)	N (%)	N (%)	N (%)	N (%)	Mean (SD)
It is important to participate in genetic research.	**269 (53.6)**	**194 (38.6)**	27 (5.4)	5 (1.0)	2 (0.4)	5 (1.0)	95.88 (16.13)
I would like to be presented with an opportunity to participate in an experimental medication trial if I were at high risk for developing Alzheimer's disease.	**156 (31.1)**	**230 (45.8)**	78 (15.5)	15 (3.0)	5 (1.0)	18 (3.6)	87.81 (25.86)
I would prefer not to be contacted for future research based on my genetic information.	7 (1.4)	28 (5.6)	61 (12.2)	**248 (49.4)**	**138 (27.5)**	20 (4.0)	86.41 (29.32)
Researchers should not knowingly withhold information about promising studies for which I may be eligible.	**119 (23.7)**	**278 (55.4)**	54 (10.8)	18 (3.6)	11 (2.2)	22 (4.4)	88.33 (27.40)
I would be willing to submit my genetic information to a registry to help match me to Alzheimer's disease research studies based on my genetic information.	**132 (26.3)**	**279 (55.6)**	55 (11.0)	12 (2.4)	3 (0.6)	21 (4.2)	91.16 (22.82)

Note: Bolded responses reflect positive attitudes towards/a willingness to participate in AD genetic research.