

# Public Perceptions of Presymptomatic Testing for Alzheimer Disease

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## Abstract

**Objective:** To explore the self-expressed desire for, envisioned reaction to, and basic understanding of presymptomatic Alzheimer disease (AD)—related genetic and biomarker tests.

**Patients and Methods:** The Alzheimer's Prevention Registry is an online community of people at least 18 years of age who are interested in AD prevention research for purely informational purposes or to be considered for possible research participation in future studies. Information about presymptomatic testing and an online multiple choice format survey were posted from November 1, 2012, through June 20, 2013, on the registry website.

**Results:** Of 4036 respondents, 80.8% (3195/3952) wanted genetic testing if paid by insurance and 58.7% (2261/3851) if it would cost them at least \$100. A total of 80.2% (3112/3879) wanted biomarker testing. If at high risk for AD, 90.5% (3478/3841) endorsed that they would "pursue a healthier lifestyle," but 11.6% (427/3706) endorsed "seriously consider suicide." The implication of a positive genetic test result was incorrectly understood by 13.1% (500/3812) and 32.6% (1255/3848) failed to view a positive biomarker test result as evidence of increased risk for or the presence of AD.

**Conclusion:** Despite efforts to increase public awareness of AD, our survey results suggest that greater education of the public is needed. Interested patients should probably undergo psychological screening to identify those at high risk of adverse psychological outcomes, and disclosure of presymptomatic test results should be anchored to tangible constructive action plans, such as healthy lifestyle changes, long-term care planning, and, when available and appropriate, participation in research trials.

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The proper role for presymptomatic genetic and biomarker tests marketed directly to consumers is not clear, yet the practice is increasing and may find a ready customer base among those concerned about their risk for Alzheimer disease (AD). There are risks attendant to such tests,<sup>1</sup> and presymptomatic screening for AD is of particular concern because AD is prevalent and lacks effective prevention therapy (the implicit purpose of presymptomatic testing). Hence, the number of people potentially seeking such testing is likely to be high even though there are still no proven disease-modifying interventions to offer those disclosed to be at high risk or to harbor early-stage AD. Insights gained regarding the effects of apolipoprotein E (*APOE*) genotype disclosure (the most prevalent genetic risk factor for AD<sup>2,3</sup>) derive primarily from the Risk Evaluation and Education for Alzheimer's Disease (REVEAL) study, a carefully executed entry into the

impending world of personalized medicine that focused on a small subset of carefully screened and counseled research participants whose main message has been interpreted to be that disclosure can be given safely.<sup>4</sup> Such screening and follow-up are unlikely to accompany widespread clinical practice, however, and do not routinely accompany direct-to-consumer marketing. There remains, therefore, a need to explore the perspectives of unscreened and unsheltered individuals who are likely to seek presymptomatic testing for AD to better prepare health care practitioners and policymakers to anticipate and address the questions and consequences that may arise from this rapidly growing practice. To address this, we administered a questionnaire through an online website dedicated to AD to specifically assess the following: (1) the desire for preclinical testing in the absence of effective interventions, (2) possible reactions to such information, and (3)



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how well the results of such testing would be understood.

## METHODS

### Development of the Questionnaire

To develop this survey, we conducted a 2-part interview. In part 1, a total of 20 members of the Arizona APOE cohort<sup>5</sup> were initially interviewed with open-ended questions to get a sense of what features of presymptomatic AD testing seemed most relevant to them (for example, whether they thought any form of predictive testing for AD was appropriate, if so how they would like to see such testing offered, and how they might handle such information if it were disclosed to them). This cohort is composed of cognitively healthy residents of Maricopa County, Arizona, who have undergone genetic screening for APOE (the results of which have not been disclosed to them) and who undergo longitudinal neuropsychological and related testing every 1 to 2 years.

Guided by their responses, in part 2 an information sheet that described presymptomatic biomarker and genetic testing and a self-completed questionnaire was provided by a genetics counselor (K.S.H.) to 12 different members of this cohort whose verbatim responses were transcribed and analyzed. A final draft of the questionnaire composed of yes/no and multiple choice questions that addressed demographic characteristics, genetic testing, biomarker testing, and possible reactions to such information was then posted on the Alzheimer's Prevention Registry website. A copy of the questionnaire is included in the [Supplemental Appendix](#), available online at <http://www.mayoclinicproceedings.org>.

### Study Population

The Alzheimer's Prevention Initiative<sup>6</sup> launched the online Alzheimer's Prevention Registry in 2012. This registry is an online community of people at least 18 years of age who are interested in AD prevention research for purely informational purposes or to be considered for possible research participation in future studies. The survey was posted on the Alzheimer's Prevention Registry website ([www.endALZnow.org](http://www.endALZnow.org)) and was completed online by visitors who registered with this website. If a survey was completed once by a registrant, it was no longer available

after that. The survey was posted and offered to all registry members from November 1, 2012, through June 30, 2013. To complete the survey, respondents must first accept the website terms and conditions which allows for completion of website-associated questionnaires, including this survey. All parts of this study were approved by the Mayo Clinic and Western Institutional Review Board.

### Statistical Analyses

Descriptive statistics included unpaired *t* tests (2-tailed) for continuous data and  $\chi^2$  tests for categorical data. Continuous data were summarized as mean  $\pm$  SD and categorical variables as frequency. Univariate regression of responses to questions regarding perceptions of, desire for, and reactions to presymptomatic testing, as well as responses to 2 basic questions on the understanding of presymptomatic testing, was performed for 8 demographic variables (age, sex, years of formal education, self-reported racial/ethnic background, previous or current role as a caregiver for a patient with dementia, first-degree relative with dementia, total number of family members known to have/had dementia, and whether current residence is within same geographic region as where respondent was raised). Multivariate regressions of all 8 demographic variables were then performed from which odds ratios (ORs) and 95% CIs were calculated.

## RESULTS

There were 4036 website respondents, with a mean  $\pm$  SD age of 58.0 $\pm$ 12.2 years and a mean  $\pm$  SD educational level of 16.1 $\pm$ 3.9 years (95.0% [3828 out of 4030] were high school graduates and 66.2% [2668 out of 4030] were college graduates). A total of 82.1% (3316 out of 4038) were women, of whom 61.3% (2423 out of 3952) reported a first-degree relative with dementia (Table 1). A total of 78.3% (2414 out of 3083) perceived themselves to be at higher than average risk for AD. In a multivariate analysis (Table 2; see [Supplemental Table](#), available online at <http://www.mayoclinicproceedings.org>, for univariate analyses and specific sample sizes for each analysis), younger age (OR, 0.95 per year; 95% CI, 0.93-0.96; *P*<.001), male sex (OR, 2.4; 95% CI, 1.27-4.60; *P*=.007), having a first-degree relative with dementia (OR, 12.76; 95%

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