

Supplemental Appendix

A. General background

1. How old are you?
2. Are you a man or a woman?
3. How many years of formal education have you had?
4. What is your general occupational background (choose 1): laborer, manager, professional, self-employed, homemaker
5. In what region of the country were you raised?
6. In what region of the country do you now reside?
7. What is your zip code?
8. Do you believe yourself to be at higher than average risk for developing Alzheimer's disease?
9. Which do you believe yourself to be highest risk for (choose one): Alzheimers' disease, heart attack, stroke, cancer
10. Which are you most fearful of developing (choose one): Alzheimer's disease, heart attack, stroke, cancer
11. Have you yourself been told you have mild cognitive impairment (MCI), Alzheimer's disease or any other form of dementia?

B. Genetic Testing

Possessing certain genes (such as the APOE4 gene) can increase our risk for Alzheimer's disease, but having such a gene does not mean a person has the disease at the specific time they are tested. We are born with our genes, so the gene test results will be the same whether we are newborn or 80 years old. The following questions apply to people with no definite symptoms of memory loss or diagnosis of Alzheimer's disease, and assume the average age of onset of Alzheimer's disease to be after age 70 years (with increasing risk the older we become).

1. Do/did you have a parent, brother, or sister with Alzheimer's disease?
2. How many blood relatives do you know of who had/have Alzheimer's disease?
3. Would you describe yourself as predominantly
 - a. Latino
 - b. African-American
 - c. Asian
 - d. American Indian/Pacific Islander
 - e. Caucasian
4. Assuming we have no cure or way to slow its onset and progression, do you believe it is important for you to have genetic testing to determine your relative lifetime risk for Alzheimer's disease?
5. If you had the opportunity to undergo genetic testing for Alzheimer's disease that was covered by your insurance (no out of pocket cost to you), would you want it?
6. If you had the opportunity to undergo genetic testing for Alzheimer's disease that was NOT covered by your insurance (out of pocket cost to you of at least \$100), would you want it?
7. If you had genetic testing as part of a research study in which disclosure of results was optional:

- a. would you want to know the results
 - b. would you want your doctor (or anyone else) to know the results?
8. If you knew you carried the APOE e4 gene, would you tell
- a. your spouse
 - b. your children
 - c. your friends
 - d. your brothers and sisters
 - e. your lawyer
9. If disclosure of genetic information was required for participation in a research study to test whether a new drug could prevent Alzheimer's disease symptoms, would you be willing to have that information disclosed to you in order to participate?
10. If you were to learn you were at high risk for Alzheimer's disease based on your genetic test results would you:
- a. begin a healthier lifestyle (for example, low fat diet, regular exercise)
 - b. obtain long term care insurance (assuming you do not already have it)
 - c. spend all your money to obtain or do the things you always wanted
 - d. seriously consider suicide

C. Biomarker Tests.

Alzheimer's disease can sometimes be detected years before the onset of any symptoms with "biomarker tests." It is not known however, how long after a biomarker test becomes positive that symptoms will emerge (some people live for many years with no significant symptoms of Alzheimer's disease). The two that are currently available are PET scans and spinal tap based tests (measuring the levels of Alzheimer related proteins abeta-amyloid and tau). The following questions apply to people with no definite symptoms of memory loss or diagnosis of Alzheimer's disease, and assume the average age of onset of Alzheimer's disease to be after age 70 years (with increasing risk the older we become).

1. Would you want to have a biomarker test to determine if you might have Alzheimer's disease years before you developed any symptoms even if there was no known effective treatment at that stage?
2. If you were potentially interested in participating in a research study to test a new drug's ability to prevent the development of Alzheimer's disease symptoms would you be willing to undergo
 - a. a PET scan only?
 - b. a spinal tap only?
 - c. both a PET scan and a spinal tap?
3. If you had biomarker evidence of possible Alzheimer's disease but were uncertain how many years from now symptoms would develop, would you tell
 - a. your spouse
 - b. your children
 - c. your friends
 - d. your brothers and sisters
 - e. your lawyer
4. If you were to learn you had presymptomatic Alzheimer's disease based on your biomarker test results would you:

- a. begin a healthier lifestyle (for example, low fat diet, regular exercise)
- b. obtain long term care insurance (assuming you do not already have it)
- c. spend all your money to obtain or do the things you always wanted
- d. seriously consider suicide

D. Quiz

The following is purely fictional. Any resemblance to any person living or dead is unintentional and coincidental.

1. Mr. Jones is a 60 year old man in generally good health, and with no symptoms of memory loss or other cognitive or emotional problems. Both of his parents died with Alzheimer's disease: mother was 78 and father was 82 at the time of death. Mr. Jones is concerned about his risk for Alzheimer's disease. His doctor performs a genetic test for APOE4 that comes back "positive." Which of the following is the correct interpretation of this result:

- a. Mr. Jones has Alzheimer's disease now despite his lack of symptoms
- b. Mr. Jones is at higher risk for developing Alzheimer's disease in the future compared to someone with a negative result
- c. Neither of the above is correct
- d. Both of the above are correct

2. Mrs. Smith is a 71 year old woman in generally good health. She feels her memory has slipped a little, but is not sure whether it is any worse than her friends' of a similar age. However, because both of her parents died in their 70's with Alzheimer's disease she decided to enroll in a research study to determine whether an experimental drug might prevent her from developing further memory loss in the future. As part of the study procedures she underwent a PET scan and a spinal tap that were both "abnormal." Her genetic test (APOE4) however was negative. Which of the following is the correct interpretation of these results:

- a. Mrs. Smith has Alzheimer's disease now despite her minimal symptoms
- b. Mrs. Smith does not have Alzheimer's disease now but is at higher risk for developing it in the future
- c. Neither of the above is correct
- d. Both of the above are correct