

# Supplementary Material

## Attitudes of family members and caregivers regarding Alzheimer’s disease pre-symptomatic screening

### STROBE Statement—Checklist of items that should be included in reports of cross-sectional studies

	Item No	Recommendation	Page No
<b>Title and abstract</b>	1	(a) Indicate the study’s design with a commonly used term in the title or the abstract	1
		(b) Provide in the abstract an informative and balanced summary of what was done and what was found	2
<b>Introduction</b>			
Background/rationale	2	Explain the scientific background and rationale for the investigation being reported	3
Objectives	3	State-specific objectives, including any prespecified hypotheses	5
<b>Methods</b>			
Study design	4	Present key elements of study design early in the paper	6
Setting	5	Describe the setting, locations, and relevant dates, including periods of recruitment, exposure, follow-up, and data collection	6
Participants	6	(a) Give the eligibility criteria, and the sources and methods of selection of participants	6
Variables	7	Clearly define all outcomes, exposures, predictors, potential confounders, and effect modifiers. Give diagnostic criteria, if applicable	9-12
Data sources/measurement	8*	For each variable of interest, give sources of data and details of methods of assessment (measurement). Describe comparability of assessment methods if there is more than one group	7
Bias	9	Describe any efforts to address potential sources of bias	6
Study size	10	Explain how the study size was arrived at	6
Quantitative variables	11	Explain how quantitative variables were handled in the analyses. If applicable, describe which groupings were chosen and why	6,7,8
Statistical methods	12	(a) Describe all statistical methods, including those used to control for confounding	8
		(b) Describe any methods used to examine subgroups and interactions	8
		(c) Explain how missing data were addressed	n.a.
		(d) If applicable, describe analytical methods taking	n.a.

		account of sampling strategy	
		(e) Describe any sensitivity analyses	n.a.
<b>Results</b>			
Participants	13*	(a) Report numbers of individuals at each stage of study—e.g., numbers potentially eligible, examined for eligibility, confirmed eligible, included in the study, completing follow-up, and analyzed	6
		(b) Give reasons for non-participation at each stage	n.a.
		(c) Consider use of a flow diagram	n.a.
Descriptive data	14*	(a) Give characteristics of study participants (e.g., demographic, clinical, social) and information on exposures and potential confounders	9
		(b) Indicate number of participants with missing data for each variable of interest	n.a.
Outcome data	15*	Report numbers of outcome events or summary measures	9-12
Main results	16	(a) Give unadjusted estimates and, if applicable, confounder-adjusted estimates and their precision (e.g., 95% confidence interval). Make clear which confounders were adjusted for and why they were included	n.a.
		(b) Report category boundaries when continuous variables were categorized	9-12
		(c) If relevant, consider translating estimates of relative risk into absolute risk for a meaningful time period	n.a.
Other analyses	17	Report other analyses done—e.g., analyses of subgroups and interactions, and sensitivity analyses	11,12
<b>Discussion</b>			
Key results	18	Summarize key results with reference to study objectives	12
Limitations	19	Discuss limitations of the study, taking into account sources of potential bias or imprecision. Discuss both direction and magnitude of any potential bias	19,20
Interpretation	20	Give a cautious overall interpretation of results considering objectives, limitations, multiplicity of analyses, results from similar studies, and other relevant evidence	12-19
Generalizability	21	Discuss the generalizability (external validity) of the study results	19
<b>Other information</b>			
Funding	22	Give the source of funding and the role of the funders for the present study and, if applicable, for the original study on which the present article is based	21

\*Give information separately for exposed and unexposed groups.

**Supplementary Table 1**

<b>Health Status</b>				
		<b>N</b>	<b>Mean</b>	<b>Std. Deviation</b>
<b>Perceived harms of testing</b>	Excellent	32	22.18	6.50
	Very good	93	23.29	6.44
	Good	65	21.83	6.34
	Fair	14	20.00	7.73
	Bad	7	24.57	10.69
	Total	211	22.49	6.68
<b>Acceptance of testing</b>	Excellent	32	20.18	4.05
	Very good	94	18.61	4.24
	Good	65	20.50	3.60
	Fair	15	20.13	4.96
	Bad	7	18.14	4.91
	Total	213	19.52	4.16
<b>Perceived benefits of testing</b>	Excellent	32	23.87	3.24
	Very good	94	23.20	3.05
	Good	65	22.50	3.31
	Fair	15	22.46	3.77
	Bad	7	21.71	5.37
	Total	213	22.99	3.31
<b>Need for knowledge</b>	Excellent	32	18.25	2.42
	Very good	94	18.18	1.83
	Good	65	18.09	1.95
	Fair	15	18.00	1.85
	Bad	7	18.28	1.88
	Total	213	18.15	1.95
<b>ANOVA results</b>				
	<b>F</b>	<b>Df (Between Groups)</b>	<b>Df (Within Groups)</b>	<b>p</b>
<b>Perceived Harms of Testing</b>	1.17	4	206	0.3
<b>Acceptance of Testing</b>	2.57	4	208	0.04
<b>Perceived Benefits of Testing</b>	1.37	4	208	0.25
<b>Need for Knowledge</b>	0.07	4	208	0.99

**Supplementary Table 2**

<b>Depression</b>				
		<b>N</b>	<b>Mean</b>	<b>Std. Deviation</b>
<b>Perceived Harms of Testing</b>	Happy	108	24.23	6.32
	Sometimes depressed feelings	93	21.25	6.54
	Depressed most of the times	10	15.30	4.37
	Total	211	22.49	6.68
<b>Acceptance of Testing</b>	Happy	109	19.20	4.05
	Sometimes depressed feelings	93	19.78	4.31
	Depressed most of the times	11	20.45	4.00
	Total	213	19.52	4.16
<b>Perceived Harms of Testing</b>	Happy	109	23.31	3.40
	Sometimes depressed feelings	93	22.75	3.19
	Depressed most of the times	11	21.81	3.28
	Total	213	22.99	3.31
<b>Need for Knowledge</b>	Happy	109	18.00	1.94
	Sometimes depressed feelings	93	18.24	2.01
	Depressed most of the times	11	18.90	1.30
	Total	213	18.15	1.95
<b>ANOVA results</b>				
	<b>F</b>	<b>Df (Between Group)</b>	<b>Df (Within Group)</b>	<b>p</b>
<b>Perceived Harms of Testing</b>	12.2	2	208	0.00
<b>Acceptance of Testing</b>	0.78	2	210	0.45
<b>Perceived Benefits of Testing</b>	1.14	2	210	0.23
<b>Need for Knowledge</b>	1.26	2	210	0.28

**Supplementary Table 3**

<b>Anxiety</b>				
		<b>N</b>	<b>Mean</b>	<b>Std. Deviation</b>
<b>Perceived harms of testing</b>	Never anxious	8	30.75	8.86
	Sometimes anxious	135	23.37	5.81
	Anxious most of the times	57	20.42	7.00
	Always anxious	11	16.54	5.18
	Total	211	22.49	6.68
<b>Acceptance of testing</b>	Never anxious	8	18.62	3.42
	Sometimes anxious	136	19.54	3.96
	Anxious most of the times	58	19.34	4.68
	Always anxious	11	20.81	4.40
	Total	213	19.52	4.16
<b>Perceived benefits of testing</b>	Never anxious	8	23.50	4.40
	Sometimes anxious	136	23.05	3.22
	Anxious most of the times	58	22.75	3.26
	Always anxious	11	23.00	4.19
	Total	213	22.99	3.31
<b>Need for knowledge</b>	Never anxious	8	17.62	2.13
	Sometimes anxious	136	18.00	1.90
	Anxious most of the times	58	18.36	2.07
	Always anxious	11	19.36	1.28
	Total	213	18.15	1.95
<b>ANOVA results</b>				
	<b>F</b>	<b>Df (Between Group)</b>	<b>Df (Within Group)</b>	<b>p</b>
<b>Perceived Harms of Testing</b>	10.9	3	207	0.00
<b>Acceptance of Testing</b>	0.51	3	209	0.67
<b>Perceived Benefits of Testing</b>	0.17	3	209	0.91
<b>Need for Knowledge</b>	2.13	3	209	0.09

# **“Perceptions regarding pRE-symptomatic Alzheimer’s Disease Screening” (PRE-ADS) Questionnaire**

## **Sociodemographic questions and the questionnaire of the 25 items**

### **INTRODUCTION PART**

#### *Demographic data*

#### **Sex**

Male

Female

#### **Age**

20-30 / 31-40 / 41-50 / 51-60 / 61-70 / 71-80 / 81-90

#### **Education**

PhD/Post-doc

Post graduate’s studies

Graduate studies

Higher education

Primary school

Without education

#### **Marital status**

Married

Unmarried

Divorced

Widower

In relationship

#### **Working status**

Public sector employee

Private employee

Freelancer

Seasonal employee

Unemployed

Student

Retired

#### **Residence**

Thessaloniki

Athens

In another big city in Greece

Village/ Province of Greece/Island

Abroad

*Please choose one answer to each of the following questions.*

**Health status**

Do you consider that your health status is:

1. Excellent
2. Very good
3. Good
4. Fair
5. Bad

Do you think that you are usually:

1. I am happy most of the time / without depression
2. Sometimes I have depressed feelings
3. I feel depressed most of the time
4. I suffer from severe depression

Do you think that your level of anxiety or distress is:

1. I am never anxious or I feel distressed
2. Sometimes I feel anxious or distress
3. I feel anxious or distressed most of the time
4. I always feel anxious or distressed

**Concerns about getting Alzheimer's Disease**

- I believe that I am at a higher risk of getting Alzheimer's disease.
- I believe that I'll develop AD.
- I think that I have more problems with my memory than others in my age.
- I am not concerned if I will get AD.

**Beliefs about the treatment of Alzheimer's Disease**

- I don't believe that a treatment for AD is currently available.
- I believe an effective treatment for AD will be available in the next 5 years.
- I believe that there is a treatment for AD.
- I don't know if there is a treatment for AD.

**Prior experience with Alzheimer's disease (AD)**

Do you have a family history of AD? Yes / No

If yes, please choose one answer to the following questions

1. What's your family's relationship with the person with AD? Grandparent, Parent, Sibling, Aunt / Uncle
2. How many people in your family (including previous generations) suffered from AD?
3. In how many different generations do you have a relative with AD? One, two, three, four.

4. What's the age of the younger relative with AD symptoms? 55-60, 60-65, 65-70, >70

Are you a caregiver of a person with AD? Yes / No

If yes, please choose one answer to the following questions

1. The person that I care for, is: my grandparent, my parent, my sibling, my aunt/ uncle, my spouse, a friend, other?
2. What's the stage of dementia of the person you care for? 1°, 2°, 3°, 4°
3. For how many years you care for? 1-3, 3-5, more than 5
4. For how many hours per week are you in your caring role? 3-7, 7-15, all day
5. Did you choose to be a caregiver? Yes/No

If no, please answer the question

Do you know any person with dementia? Yes/No

Have you ever been tested or screened for an increased risk of AD? Yes / No

If yes, this screening included:

1. short questionnaire/ assessment testing
2. genetic testing, with blood sample
3. Magnetic Resonance Imaging (MRI) or PET-scan
4. using biomarkers of pathophysiology (including A $\beta$  protein, tau protein).

## **MAIN PART OF THE QUESTIONNAIRE**

(Each item is rated on a 5-point Likert scale including “strongly agree”, “agree”, “I don't know”, “disagree”, and “strongly disagree”)

### **Acceptance of dementia screening and the need for knowledge**

*Please, choose if you agree or disagree with the following statements*

1. I would like to know if I am at higher risk than others for developing AD.
2. I would like to be tested for the presence of AD on a regular basis with a short questionnaire.
3. I would like to get a genetic testing with blood sample in order to find if I am at a higher risk for AD.
4. I would like to be tested for the presence of AD on a regular basis with pictures of my head or brain (CT-scan or MRI).
5. I would like to be tested for the presence of AD on a regular basis with the use of biomarkers in cerebrospinal fluid (A $\beta$  amyloid, t-protein).
6. In order to decide to be tested for the presence of AD, I would need more information and details.
7. If I was informed that I am at a higher risk of AD, I would like to discuss it further and to get advice from a doctor or another health professional expert in this field.
8. If I was informed that I am at a higher risk of AD, I would like to meet a health professional, expert on genetics, in order to discuss my feelings and my thoughts



### **Motivations and barriers of AD biomarkers testing**

*If you were informed that you are at a higher risk of developing AD, to what extent you would prefer to do the following statements. (select an answer).*

9. My family will suffer from the additional costs of my care
10. My family will suffer emotionally
11. I feel that I would be overwhelmed by mental pain
12. I feel that I would be overwhelmed by intense anxiety
13. I would improve my quality of life
14. I will be motivated to stay abreast of new developments in AD treatment and prevention
15. My family would suffer financially
16. My family would suffer emotionally
17. My family would have a better chance to take care of me
18. I think that others will treat me in a different way
19. I would be depressed
20. I would be anxious
21. I would give up on life
22. I would have more time to plan my future
23. I would have more time to talk with my family about my health care
24. I would have more time to talk with my family about my finances
25. I would be motivated to have a healthier lifestyle (physical exercise, diet, vitamins, cognitive stimulation, stop smoking)

\* Each statement begins with the “If I was informed that I am in a higher risk of AD...”