

# Supplementary Material

## Pre-Diagnostic Symptoms of Young-Onset Dementia in the General Practice up to Five Years Before Diagnosis

### Supplementary Method 1. Power analysis/sample size calculation

Using G-Power, a sample size calculation was performed a priori to obtain the sample size needed for this study. For this, different scenarios were assessed. In all scenarios alpha is set on 0.05, and the power was set at 0.8. Also, a normal distribution was assumed.

	Expected minimal OR	Proportion of patients with symptoms	Sample size needed in each group (x2 for controls)
Scenario 1	2.0	0.3	92
Scenario 2	2.0	0.6	84
Scenario 3	1.5	0.3	242
Scenario 4	1.5	0.6	215

Based on previous research, ORs can range significantly depending on the type of symptoms studied. It is difficult to calculate the needed sample size a priori. Sample sizes for several scenarios were therefore calculated. Scenario 2 was deemed most probable since previous research in elderly people with dementia found very high ORs, with increasing proportion of patients with symptoms over the 5 years before diagnosis.

## **Supplementary Method 2. ICPC categories**

A: General and unspecified

B: Blood, blood forming organs and immune mechanism

D: Digestive

F: Eye

H: Ear

K: Cardiovascular

L: Musculoskeletal

N: Neurological

P: Psychological

R: Respiratory

S: Skin

T: Metabolic, endocrine, nutrition

U: Urinary

W: Pregnancy, family planning

X: Female genital

Y: Male genital

Z: Social

### Supplementary Method 3. Categories of symptoms

#### A: cognitive symptoms

Amnesia, forgetfulness, confusion (either mentioned by caregivers, noticed by the GP, or categorized based on the patient's story), cognitive decline, orientation problems, language problems, problems with logical thinking, loss of decorum

#### B: affective symptoms

Fatigue, irritability, anxiety, sleep related problems, depressive mood, being upset, loss of initiative, loss of interest, crying, complaining, sadness, hyperventilation, mood changes, suicidal ideation

#### C: behavioral symptoms

Restlessness, delusions/hallucinations, aggression/agitation, changes in character, suspicion

#### D: vascular symptoms

Chest pains, loss of speech, temporary paralysis, continuous paralysis, loss of strength, thick tongue

#### E: gait disturbances

Falls, problems with walking

#### F: changes in weight or appetite

Loss of appetite, weight changes

#### G: social symptoms

*(involves everything about interaction with others)*

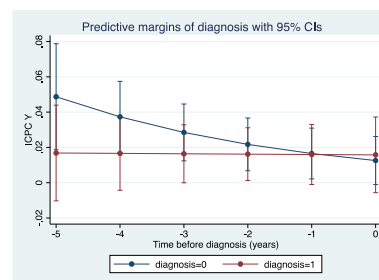
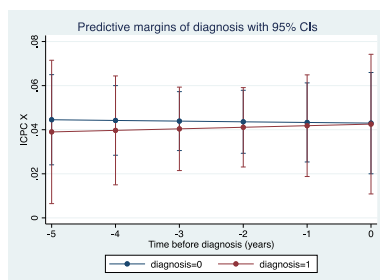
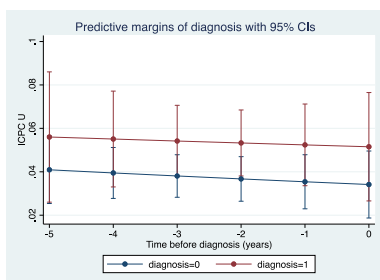
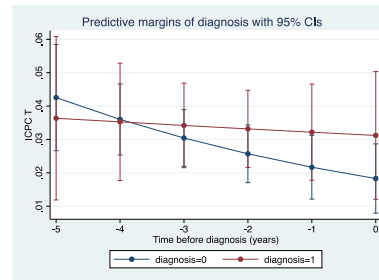
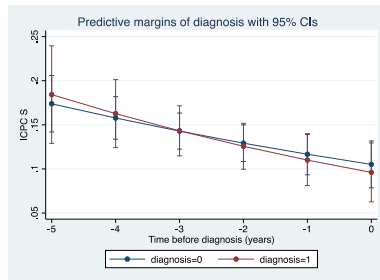
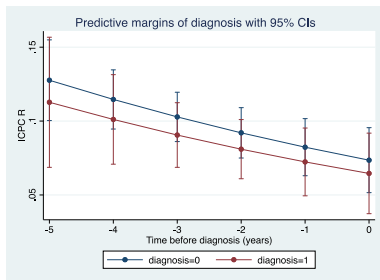
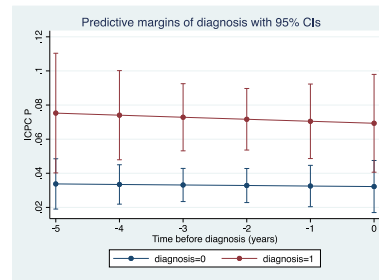
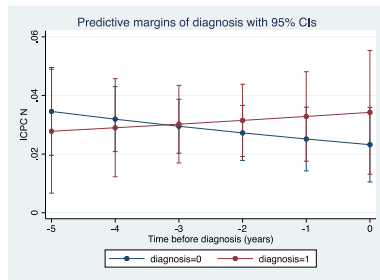
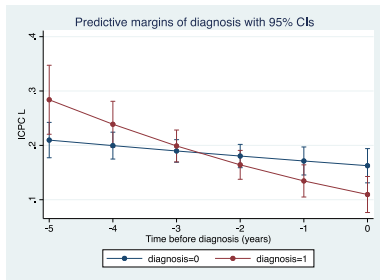
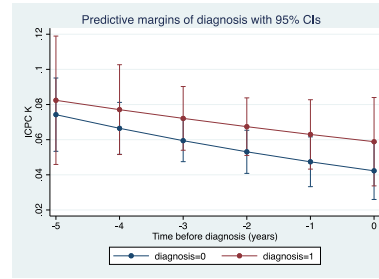
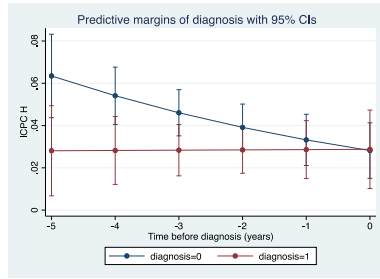
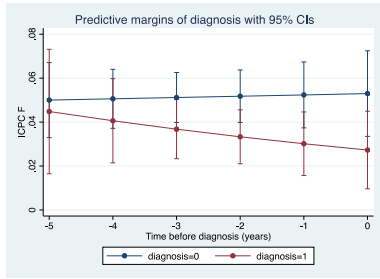
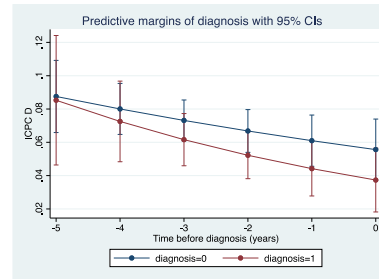
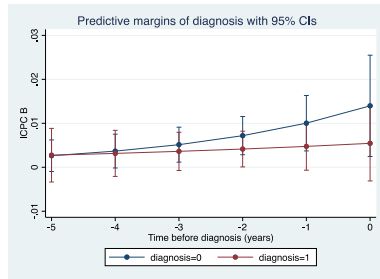
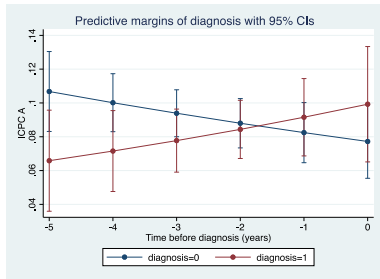
Worries from friends/family (about the cognitive changes they experience in their loved ones), job loss, work problems, relationship problems, financial problems, fear of dementia

#### H: daily functioning symptoms

*(involves everything linked to functionality of the person at home)*

Forgetting GP appointments, social isolation, neglect (in selfcare, household etc), decline in functionality (difficulties with daily routine)

# Supplementary Result 1



## Supplementary Result 2. ICPC P codes

P codes from people with YOD	P codes from controls
P01 - Feeling anxious/nervous/tense	P01 - Feeling anxious/nervous/tense
P02 - Acute stress reaction	P02 - Acute stress reaction
P03 - Feeling depressed	P03 - Feeling depressed
P04 - Feeling/behaving irritable/angry	P04 - Feeling/behaving irritable/angry
P06 - Sleep disturbance	P06 - Sleep disturbance
P15 - Chronic alcohol abuse	P07 - Sexual desire reduced
P16 - Acute alcohol abuse	P08 - Sexual fulfilment reduced
P17 - Tobacco abuse	P15 - Chronic alcohol abuse
P19 - Drug abuse	P17 - Tobacco abuse
P20 - Memory disturbance	P19 - Drug abuse
P22 - Child behavior symptom/complaint	P20 - Memory disturbance
P27 - Fear of mental disorder	P22 - Child behavior symptom/complaint
P29 - Psychological symptom/complaint other	P23 - Adolescent behavior symptom/complaint
P71 - Organic psychosis other	P29 - Psychological symptom/complaint other
P74 - Anxiety disorder/anxiety state	P74 - Anxiety disorder/anxiety state
P76 - Depressive disorder	P76 - Depressive disorder
P78 - Neuraesthesia/surmenage	P77 - Suicide/suicide attempt
P79 - Phobia/compulsive disorder	P78 - Neuraesthesia/surmenage
P80 - Personality disorder	P79 - Phobia/compulsive disorder
P85 - Mental retardation	P80 - Personality disorder
P98 - Psychosis nos/other	P99 - Psychological disorders other
P99 - Psychological disorders other	

### Supplementary Result 3. Marginal effects of symptom categories in people with YOD and their controls

