

# Pre-diagnostic symptoms of young-onset dementia in the General Practice

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# PRECODE

**Prevalence REcognition and Care pathways in young Onset DEmentia**

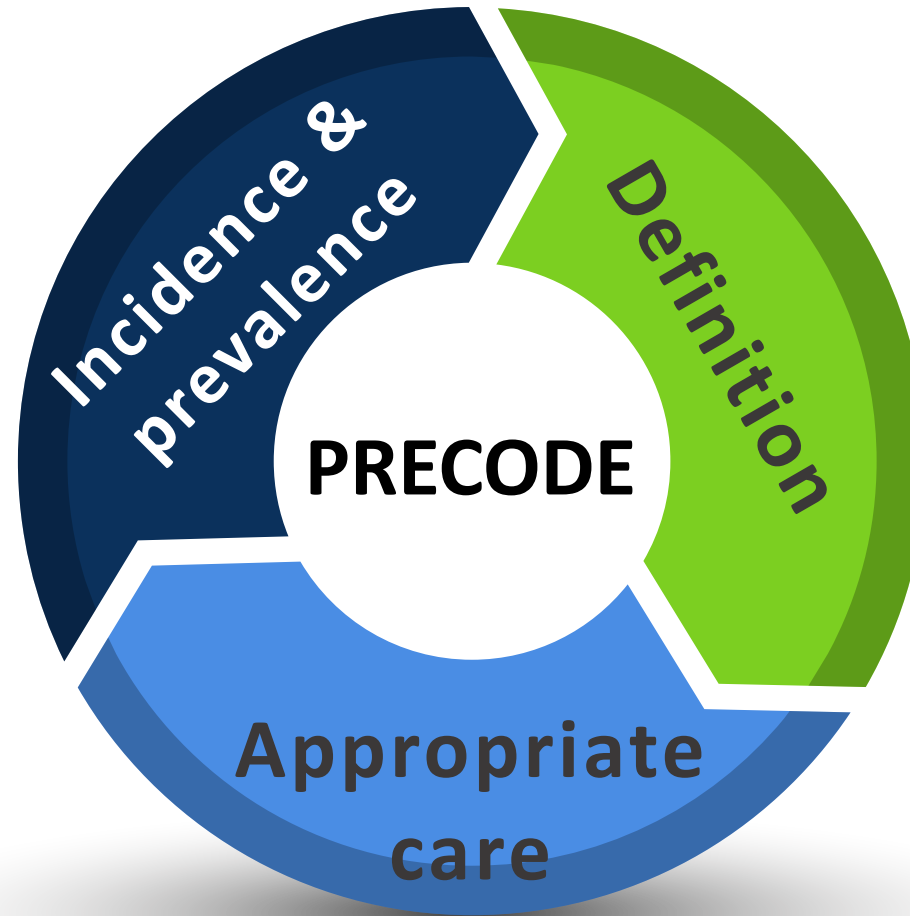
# Problem definition

## Incidence & prevalence

To create enough healthcare services for people living with young-onset dementia, it is essential to know the prevalence and incidence.

## Appropriate care

For general practitioners and occupational physicians to offer appropriate help, recognition of young-onset dementia has to be improved.

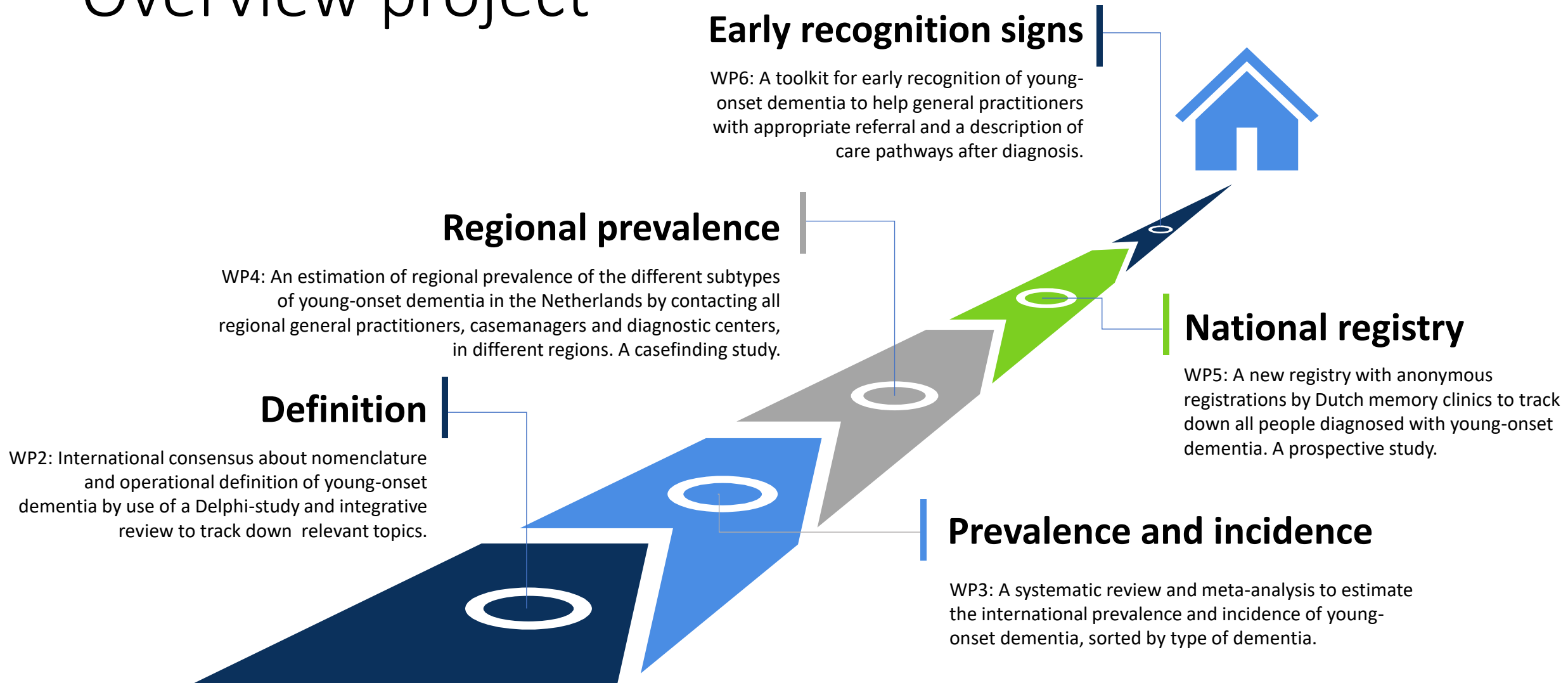


Young-onset dementia occurs in people in an active life phase. Specialized care for people living with young-onset dementia is scarce.

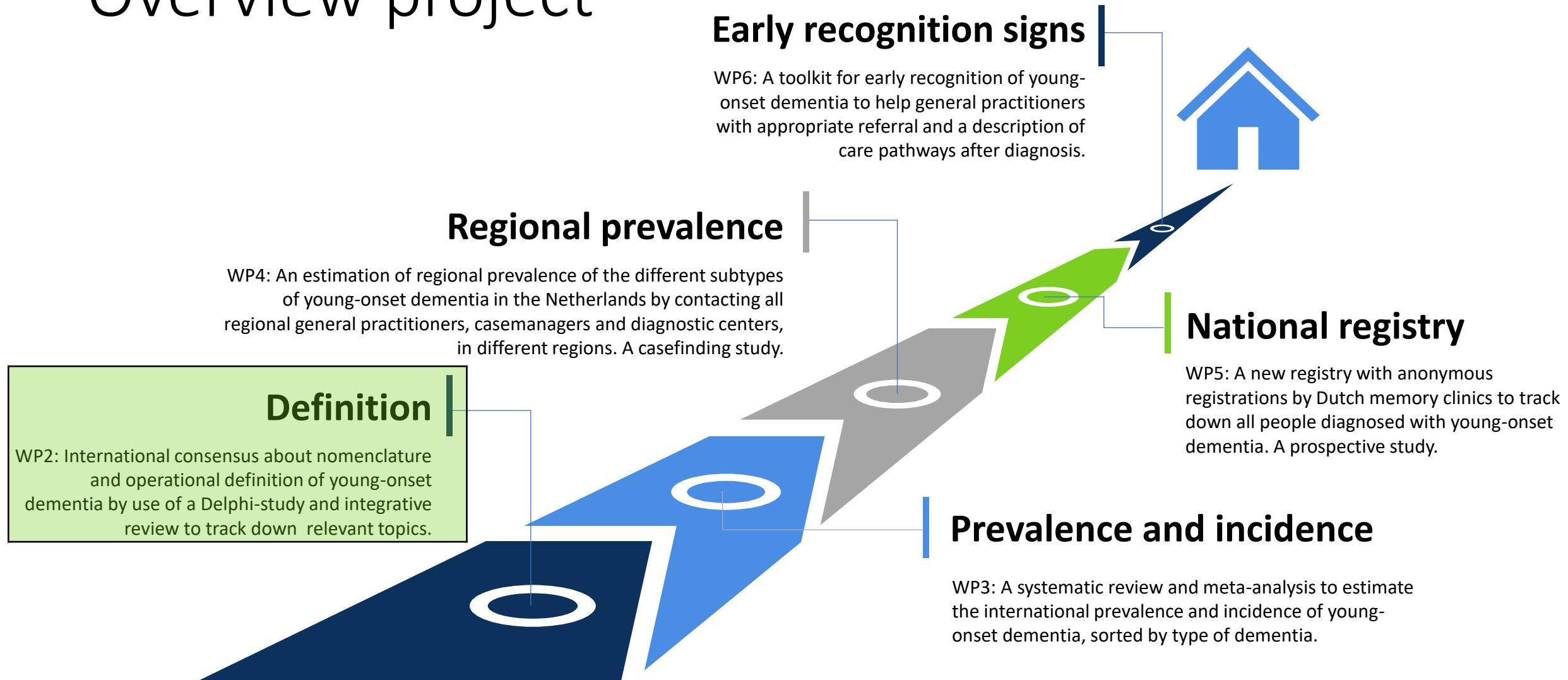
## Definition

To be able to study the prevalence and incidence of young-onset dementia, the definition of this concept has to be clear and universal.

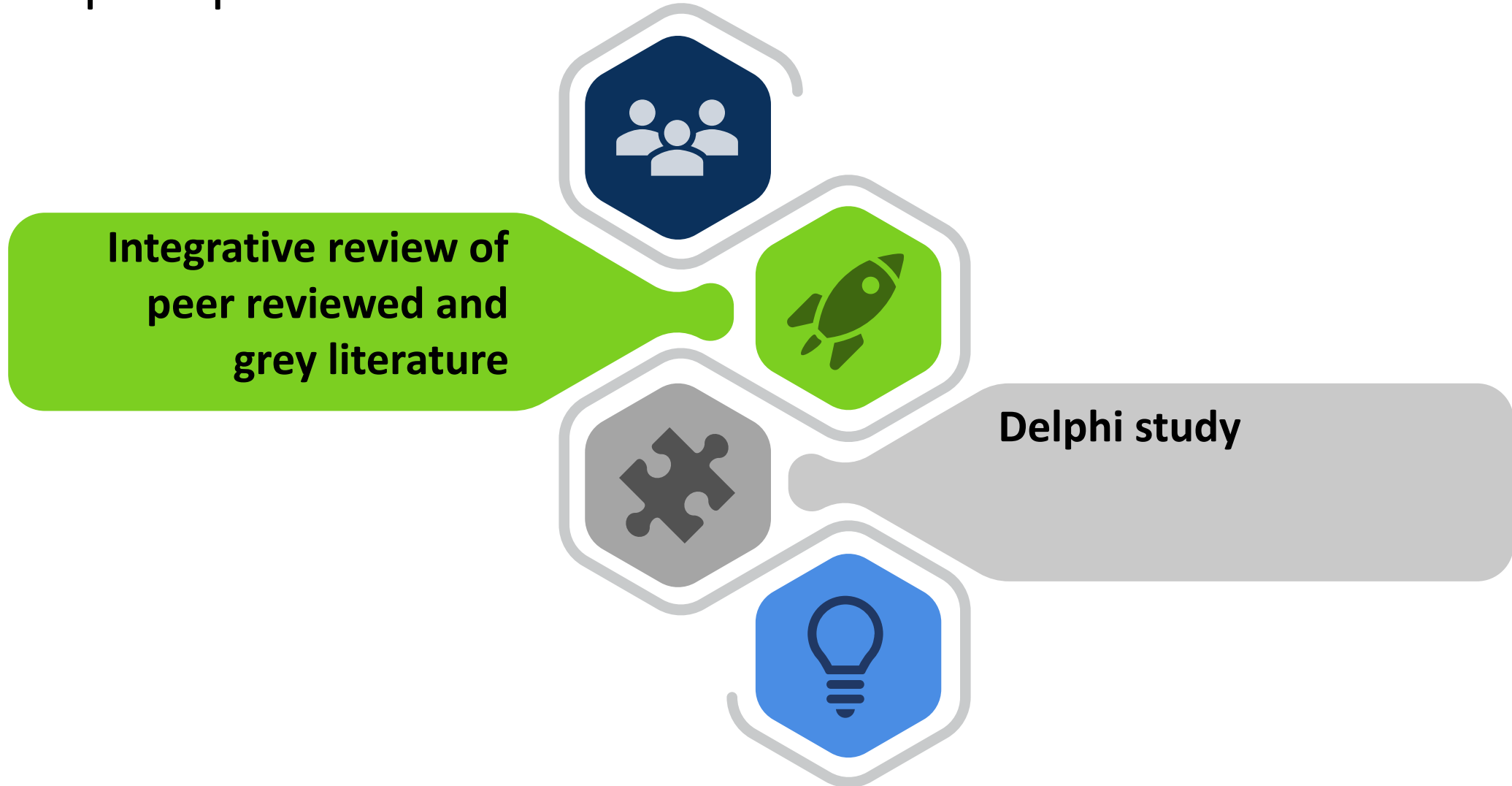
# Overview project



# Overview project



# Delphi procedure

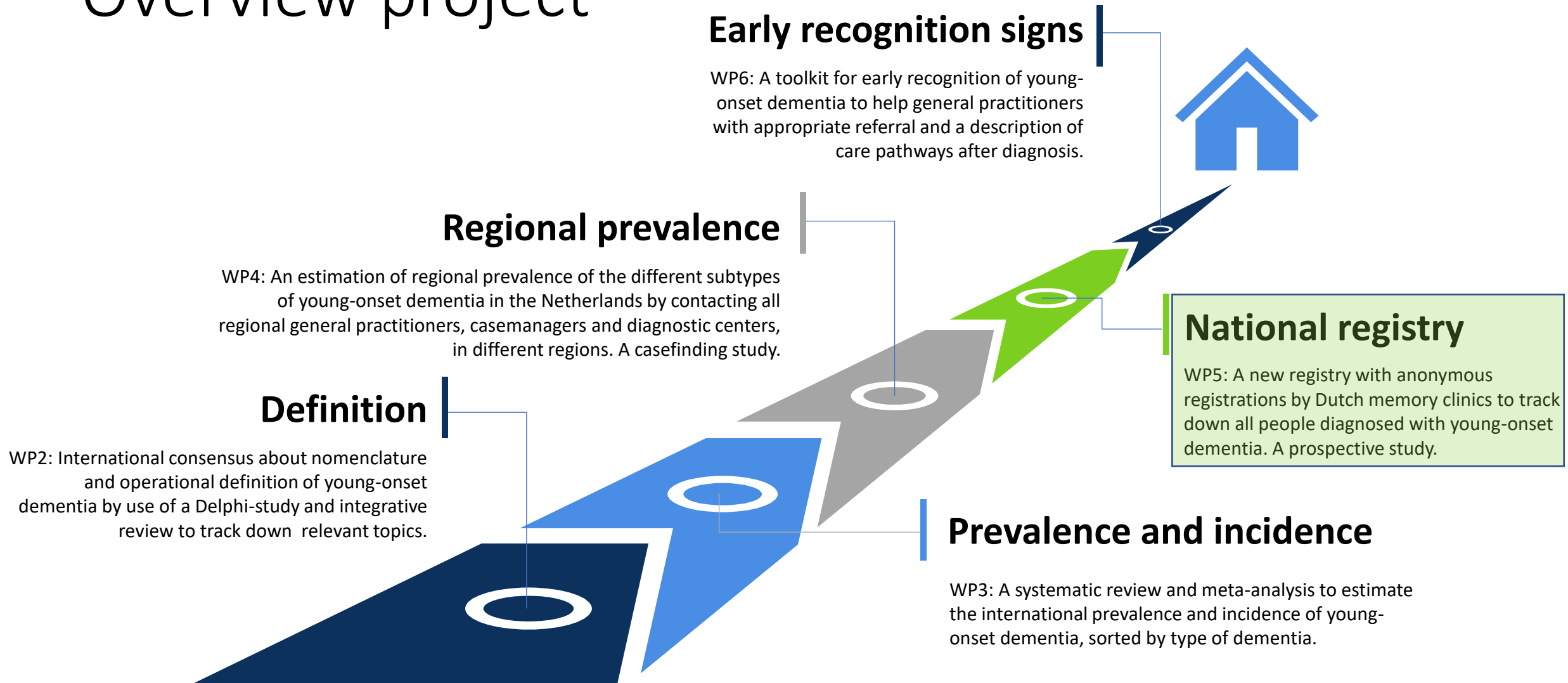


# Results

- Consensus is reached for a preferred term: *young-onset dementia*.
- A moderate level of agreement is reached to prefer the *age of 65 at symptom onset* as cut-off age.



# Overview project

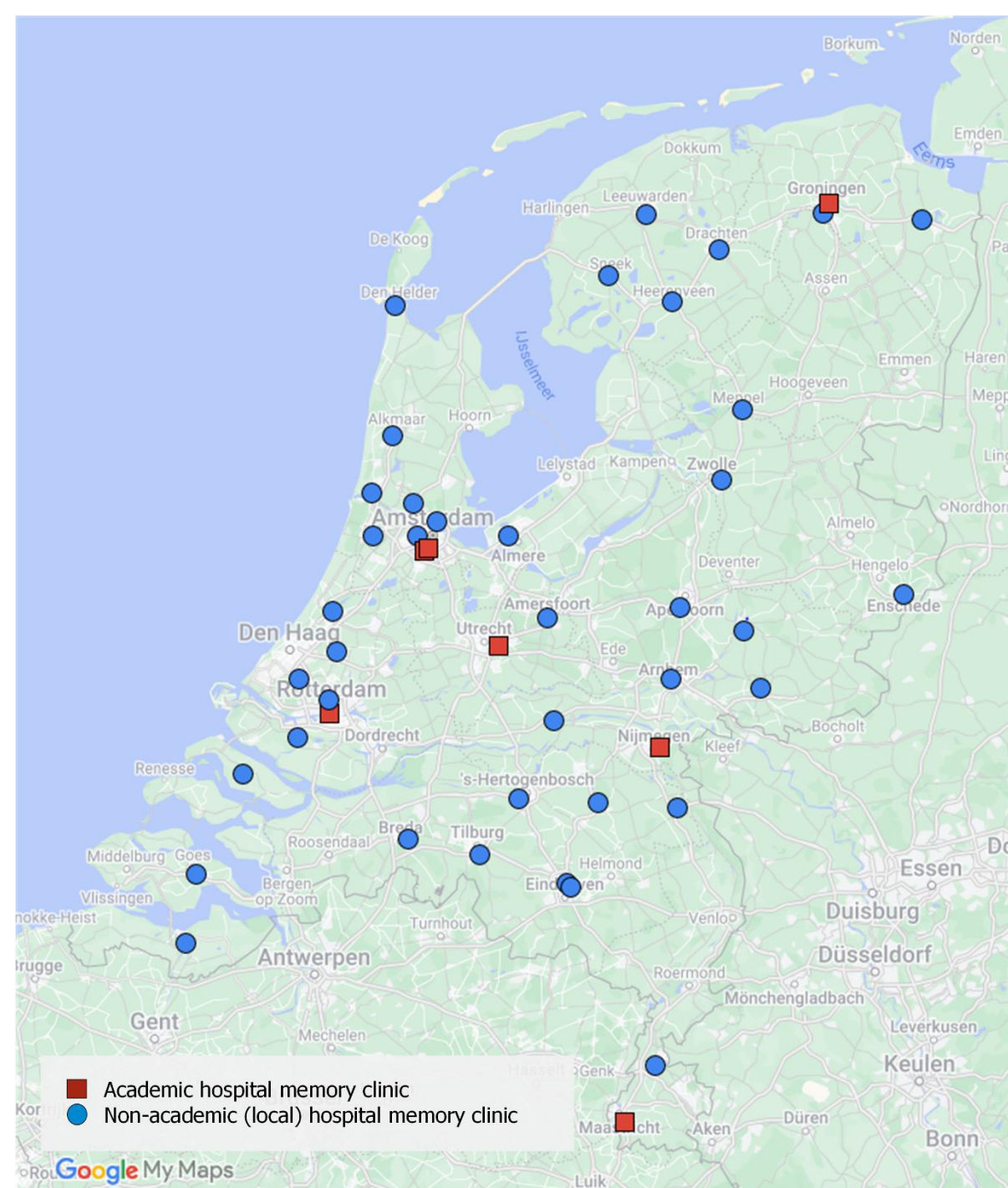




# Participating memory clinics

**Total: 47 clinics**

- 7 academic centers
- 40 peripheral centers

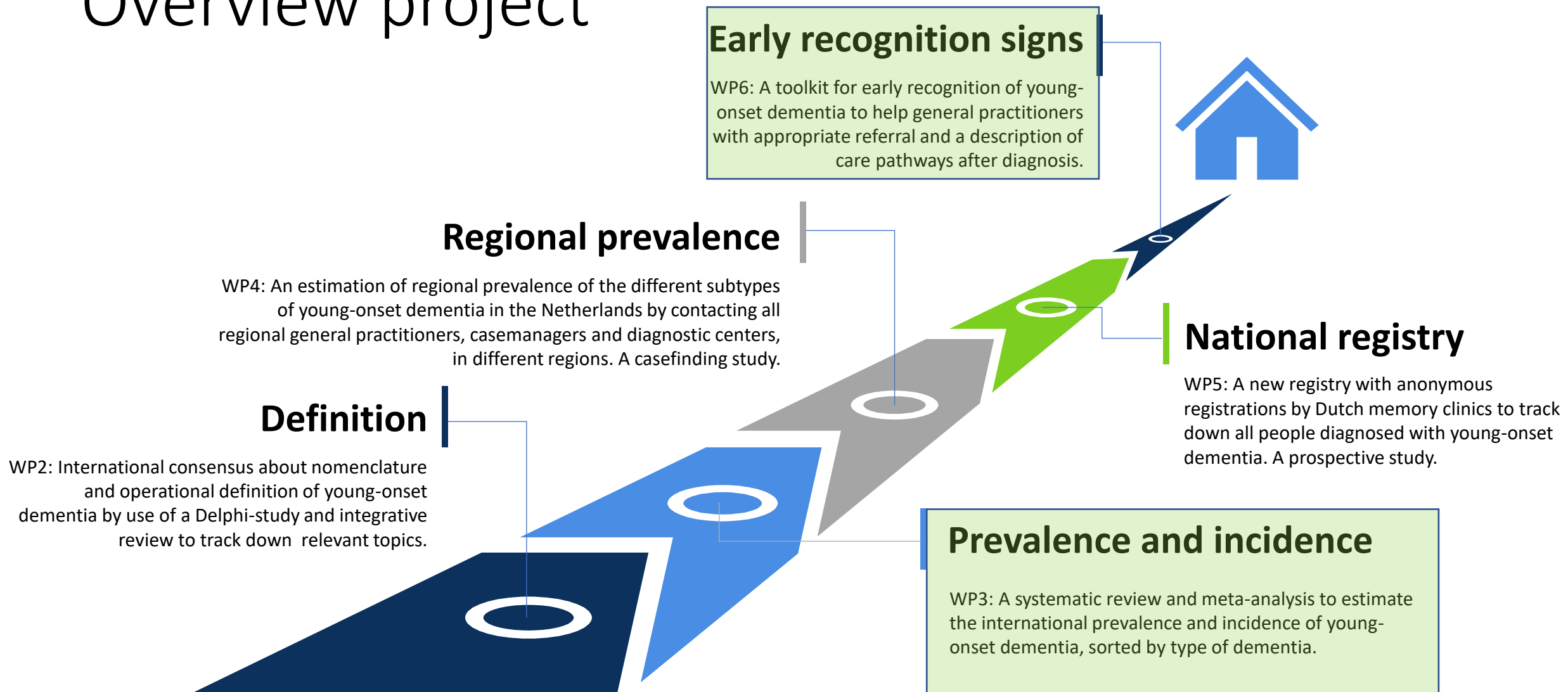


# Baseline characteristics (n=711)

|                                 | <b>Total group<br/>(N=711)</b> |
|---------------------------------|--------------------------------|
| <b>Sex, female</b>              | 371(52%)                       |
| <b>Age at diagnosis, y</b>      | 62±5.8                         |
| <b>Caucasian</b>                | 590(83%)                       |
| <b>Education, y</b>             | 10±3.4                         |
| <b>Living situation</b>         |                                |
| Living alone                    | 146(22%)                       |
| With spouse, without children   | 396(61%)                       |
| With spouse and children        | 86(13%)                        |
| With children, without spouse   | 12(2%)                         |
| Sheltered/nursing home          | 14(2%)                         |
| <b>Marital status</b>           |                                |
| Unmarried                       | 66(10%)                        |
| Married/registered relationship | 504(74%)                       |
| Widow/widower                   | 29(4%)                         |
| Divorced                        | 66(10%)                        |
| Living (apart) together         | 6(1%)                          |
| <b>Included by</b>              |                                |
| Local memory clinic             | 279(39%)                       |
| Academic hospital               | 432(61%)                       |

| <b>Referring physician</b>        |          |
|-----------------------------------|----------|
| General practitioner              | 363(51%) |
| Neurologist                       | 212(30%) |
| Psychiatrist                      | 24(3%)   |
| Internal/geriatric medicine       | 58(8%)   |
| Elderly care physician            | 24(3%)   |
| Other                             | 27(4%)   |
| <b>Second opinion (%)</b>         | 268(38%) |
| <b>Screening test results</b>     |          |
| MMSE (0-30)                       | 22.0±5.1 |
| MoCA (0-30)                       | 17.7±5.4 |
| <b>Complaints at presentation</b> |          |
| Memory                            | 472(67%) |
| Language                          | 162(23%) |
| Organizing/planning               | 101(14%) |
| Attention/concentration           | 55(8%)   |
| Behavioral                        | 144(20%) |
| Other                             | 29(4%)   |
| <b>Duration of complaints</b>     |          |
| <1 year                           | 70(10%)  |
| 1-2 years ago                     | 243(35%) |
| 2-4years ago                      | 218(31%) |
| >4 years ago                      | 164(24%) |

# Overview project



# Introduction

Research

JAMA Neurology | **Original Investigation**

## Global Prevalence of Young-Onset Dementia A Systematic Review and Meta-analysis

Stevie Hendriks, MSc; Kirsten Peetoom, PhD; Christian Bakker, PhD; Wiesje M. van der Flier, PhD; Janne M. Papma, PhD; Raymond Koopmans, PhD; Frans R. J. Verhey, MD, PhD; Marjolein de Vugt, PhD; Sebastian Köhler, PhD; and the Young-Onset Dementia Epidemiology Study Group

DOI: 10.1002/ajna.12979

FEATURED ARTICLE

Alzheimer's & Dementia®  
THE JOURNAL OF THE ALZHEIMER'S ASSOCIATION

## Global incidence of young-onset dementia: A systematic review and meta-analysis

Stevie Hendriks<sup>1</sup> | Kirsten Peetoom<sup>1</sup> | Christian Bakker<sup>2,3</sup> | Raymond Koopmans<sup>2</sup> |  
Wiesje van der Flier<sup>4</sup> | Janne Papma<sup>5</sup> | Frans Verhey<sup>1</sup> | Young-Onset Dementia  
Epidemiology Study Group | Marjolein de Vugt<sup>1</sup> | Sebastian Köhler<sup>1</sup>

- Prevalence 3.9 million persons with YOD worldwide
- Incidence 370.000 new cases every year

# Introduction

Average diagnostic delay of 4.4 years before persons receive a diagnosis of YOD.

Reasons for diagnostic delay:

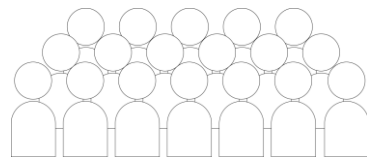
- Large heterogeneity of first symptoms
- Young age
- Misdiagnoses

Aim: to investigate how people with YOD present themselves at the General Practice (GP) up to five years before diagnosis

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# Methods

- Research Network Family Medicine (RNFM) primary care database



150.000 patients

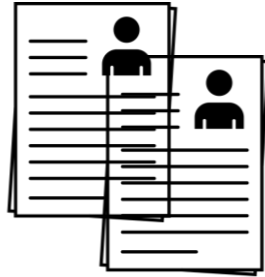


RESEARCH NETWORK FAMILY MEDICINE MAASTRICHT

# Methods



89 persons with YOD



162 controls



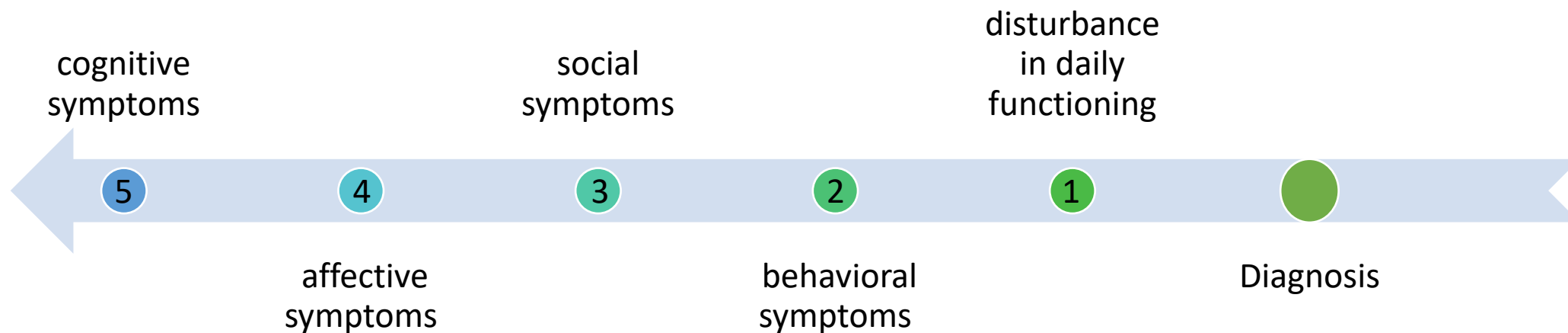
5 years



Diagnosis



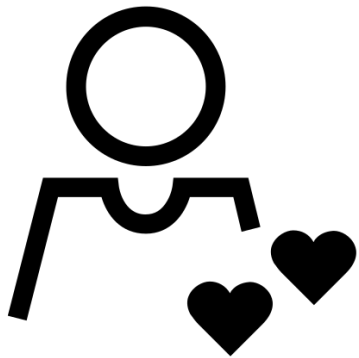
|                                   |
|-----------------------------------|
| <b>Symptom categories</b>         |
| Cognitive symptoms                |
| Affective symptoms                |
| Behavioral symptoms               |
| Vascular symptoms                 |
| Gait disturbances                 |
| Changes in weight or appetite     |
| Social symptoms                   |
| Disturbances in daily functioning |



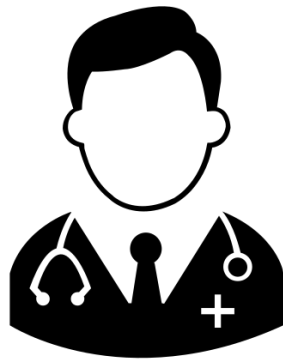
| <b>Cognitive symptoms</b> | <b>Affective symptoms</b> | <b>Social symptoms</b>  | <b>Behavioral symptoms</b> | <b>Disturbances daily functioning</b> |
|---------------------------|---------------------------|-------------------------|----------------------------|---------------------------------------|
| Forgetfulness             | Depressive mood           | Worries from caregivers | Change in character        | Overall decline in functionality      |
| Confusion                 | Anxiety                   | Work problems           | Agitation                  | Neglect                               |
| Language problems         | Being upset               | Relationship problems   | Aggression                 | Isolation                             |



# Results



Worries from caregivers



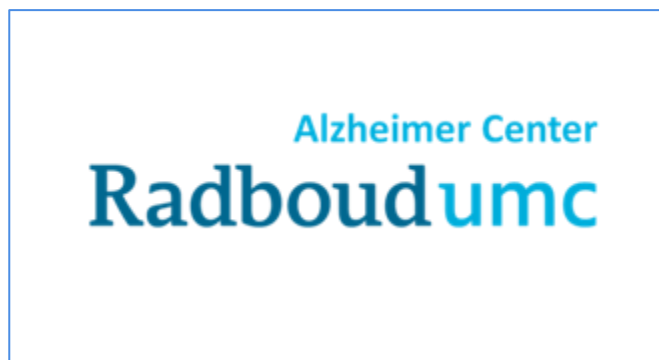
Main trigger for GP



Diagnostic follow up

# Discussion

- First indication that persons with YOD present different in the years before diagnosis
  - However, clinical relevance is limited
  - Future research:
    - Single symptoms
    - Longitudinal course of symptoms
    - Compare persons with YOD to persons with depression/burn-out
-



The PRECODE-project is part of:



**For more information:**

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<https://content.iospress.com/download/journal-of-alzheimers-disease/jad220215?id=journal-of-alzheimers-disease%2Fjad220215>

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