

# Building bridges between research, practice and policy in young-onset dementia

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# What's in a name?

- Young-onset dementia (YOD) denotes those individuals with dementia symptom onset prior to age 65
- Over 250 possible causes of young-onset dementia
- Clear definition and reliable prevalence estimates necessary for research as well as for arranging healthcare services


Received: 31 October 2021 | Accepted: 3 February 2022

DOI: 10.1002/gps.5691

## RESEARCH ARTICLE

International Journal of  
Geriatric Psychiatry WILEY

## Provisional consensus on the nomenclature and operational definition of dementia at a young age, a Delphi study

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### Abstract

**Objectives:** Dementia at a young age differs from late onset dementia in pathology and care needs. This requires further research to improve the understanding of this group, support and service provision. Aim of current study is to reach consensus on the terminology and operational definition (i.e., age-related criteria and possible causes) of dementia at a young age, to aid further research.

**Methods:** A classical Delphi technique was used to transform opinions into group consensus by using an online survey. In three rounds statements regarding (1)

# Prevalence and incidence of YOD

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.12973

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

# Time to diagnosis in YOD

- 3.4 – 5.5 year delay in diagnosis \*
- High impact on family as a whole
- Causing delay in initiation of appropriate care and support
- Impacts on family members' view of healthcare professionals

(\*Chiari et al., 2022; Draper et al., 2016; Kvello-Alme, Brathen, White, & Sando, 2021; Loi et al., 2020; van Vliet et al., 2013)

# Time to diagnosis in YOD

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- High impact on family as a whole
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## Caused by:

- Atypical presentation first symptoms and course
- Large heterogeneity of possible underlying causes
- Low prevalence of dementia in younger individuals
- Other more likely explanations for symptoms given the low age

(\*Chiari et al., 2022; Draper et al., 2016; Kvello-Alme, Brathen, White, & Sando, 2021; Loi et al., 2020; van Vliet et al., 2013)

# Dementia healthcare in the Netherlands

- 300.000 people living with dementia in the Netherlands
- Regional dementia networks
- Approximately 120.000 beds in nursing homes, but not only for people with dementia
- 14.000 – 17.000 people with dementia onset before age 65
- Mainstream services focus on dementia in old age and regularly do not have a family system approach



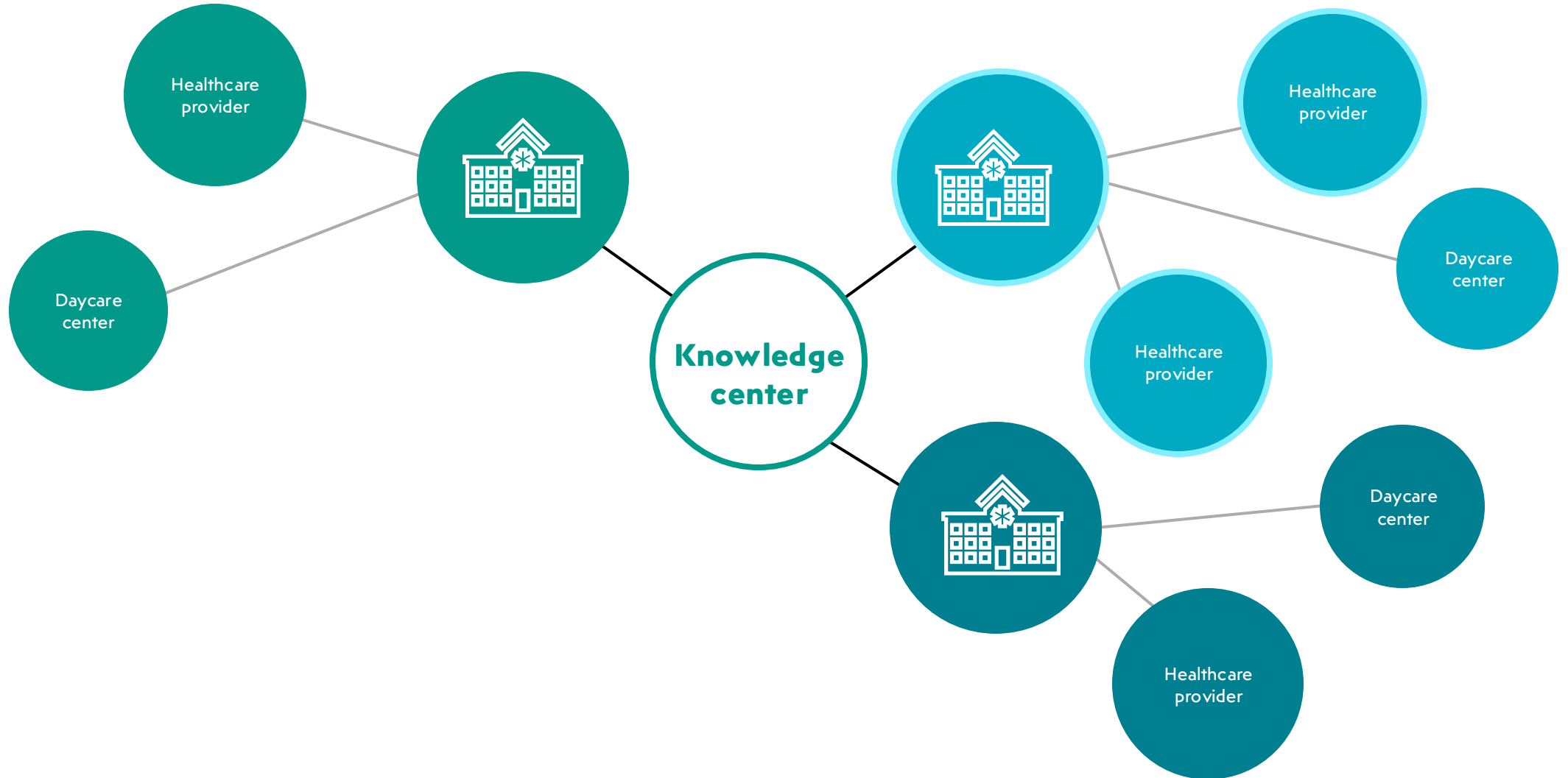
Provide people with young-onset dementia and their relatives with those things they need to live well with dementia and prepare themselves for what lies ahead.

# This implicates:

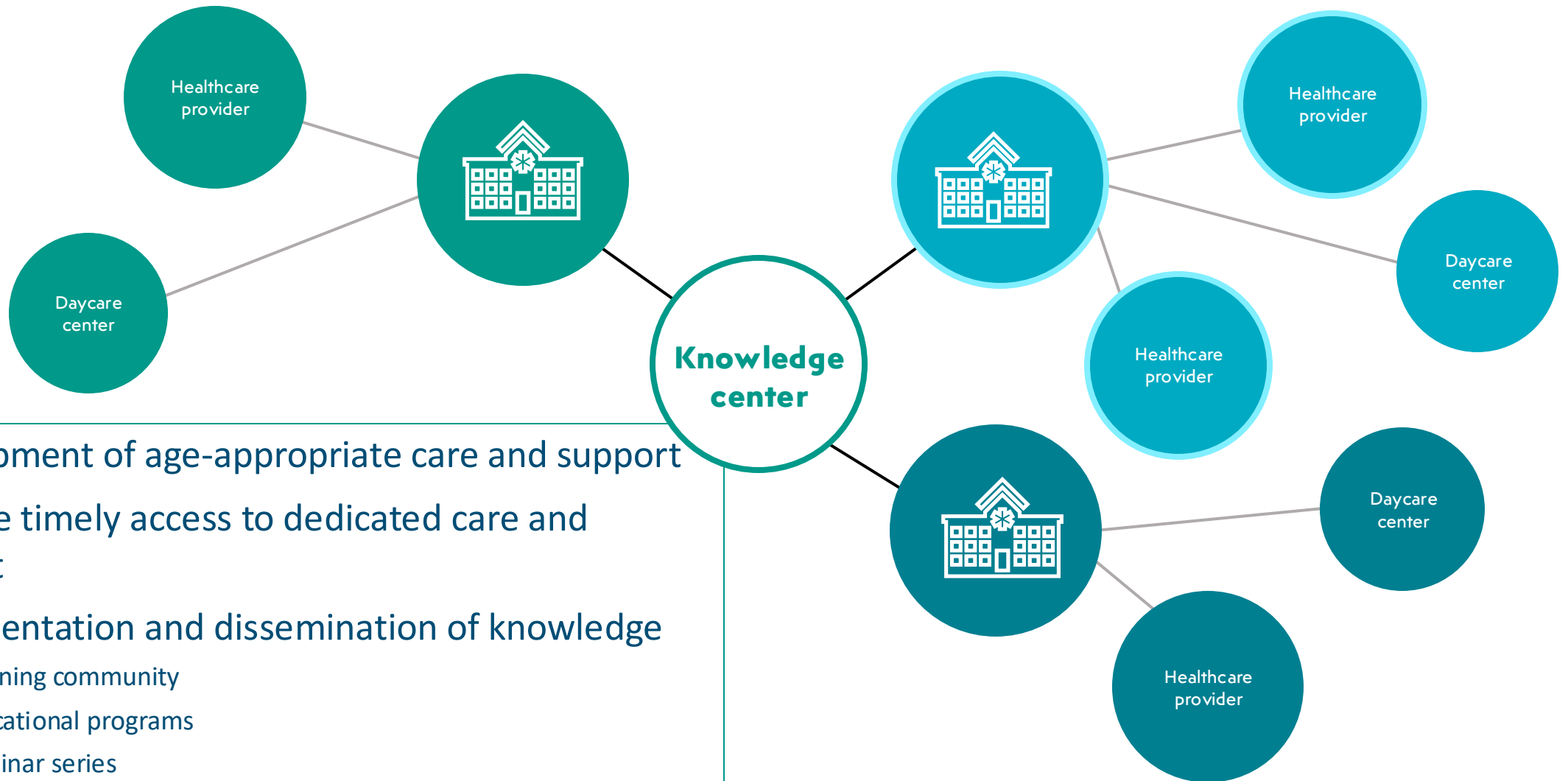
- The need for a timely diagnosis
- Knowledge about support needs
- Knowledge how to best address these needs and implications for service design
- People must have access to age-appropriate care and support
- Healthcare professionals should be equipped to support people living with young-onset dementia
- Knowledge on how to embed YOD specific services into the existing healthcare system



# Hub and spoke approach:



# Hub and spoke approach:



- Development of age-appropriate care and support
- Improve timely access to dedicated care and support
- Implementation and dissemination of knowledge
  - Learning community
  - Educational programs
  - Webinar series

# Where it al began...



Founding young-onset  
dementia steering  
group



2004

2006

2013

2015

2017

2018

2020

2021

2023

2026

# A first step to fill the vast knowledge gap...

**NeedYD**

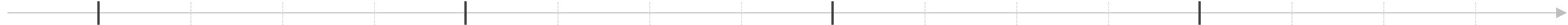
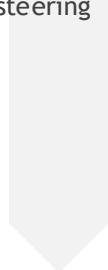
study

First prospective cohort study on course and characteristics



kenniscentrum  
Dementie op Jonge Leeftijd

Founding young-onset dementia steering group



2004

2006

2013

2015

2017

2018

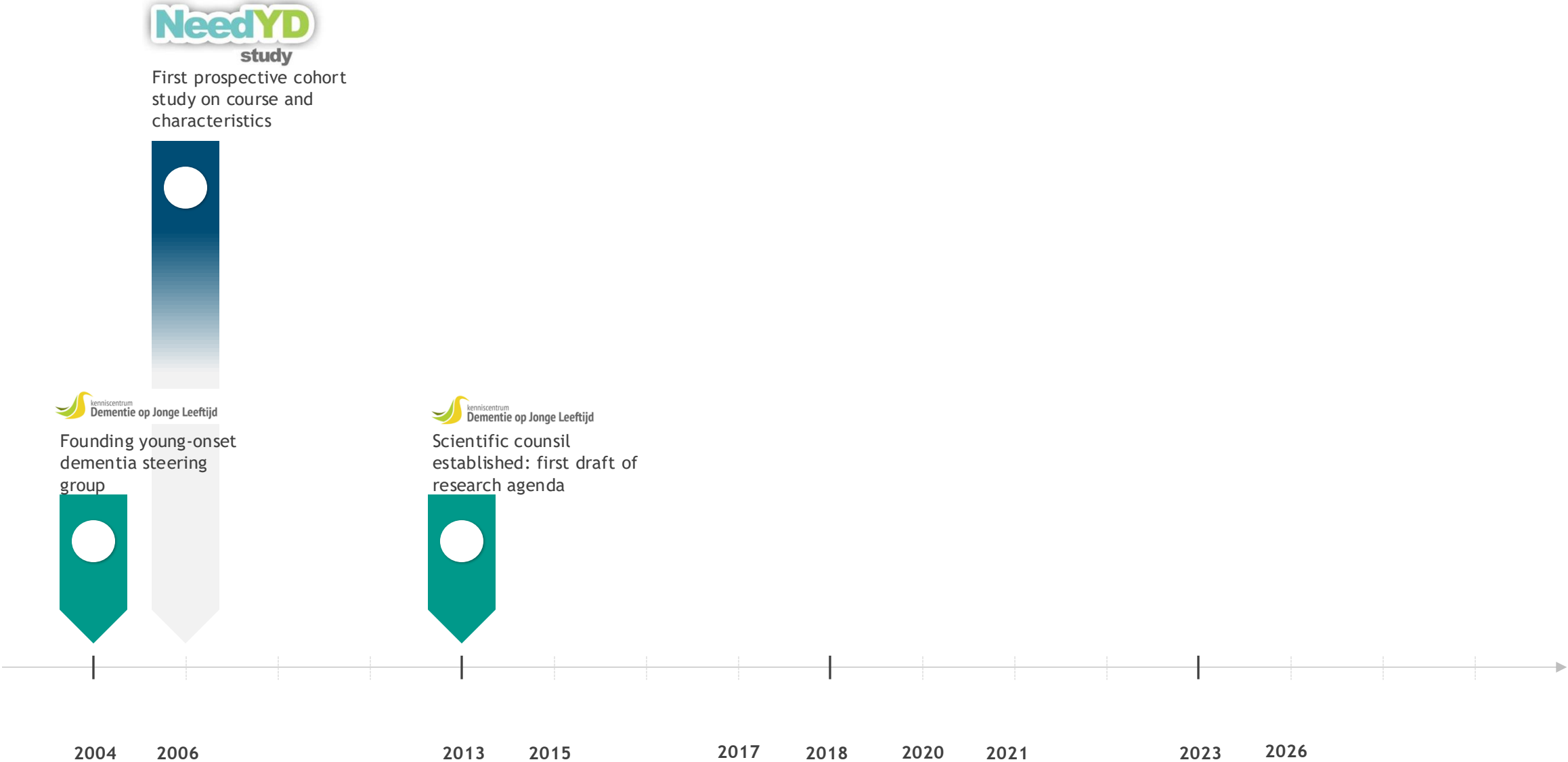
2020

2021

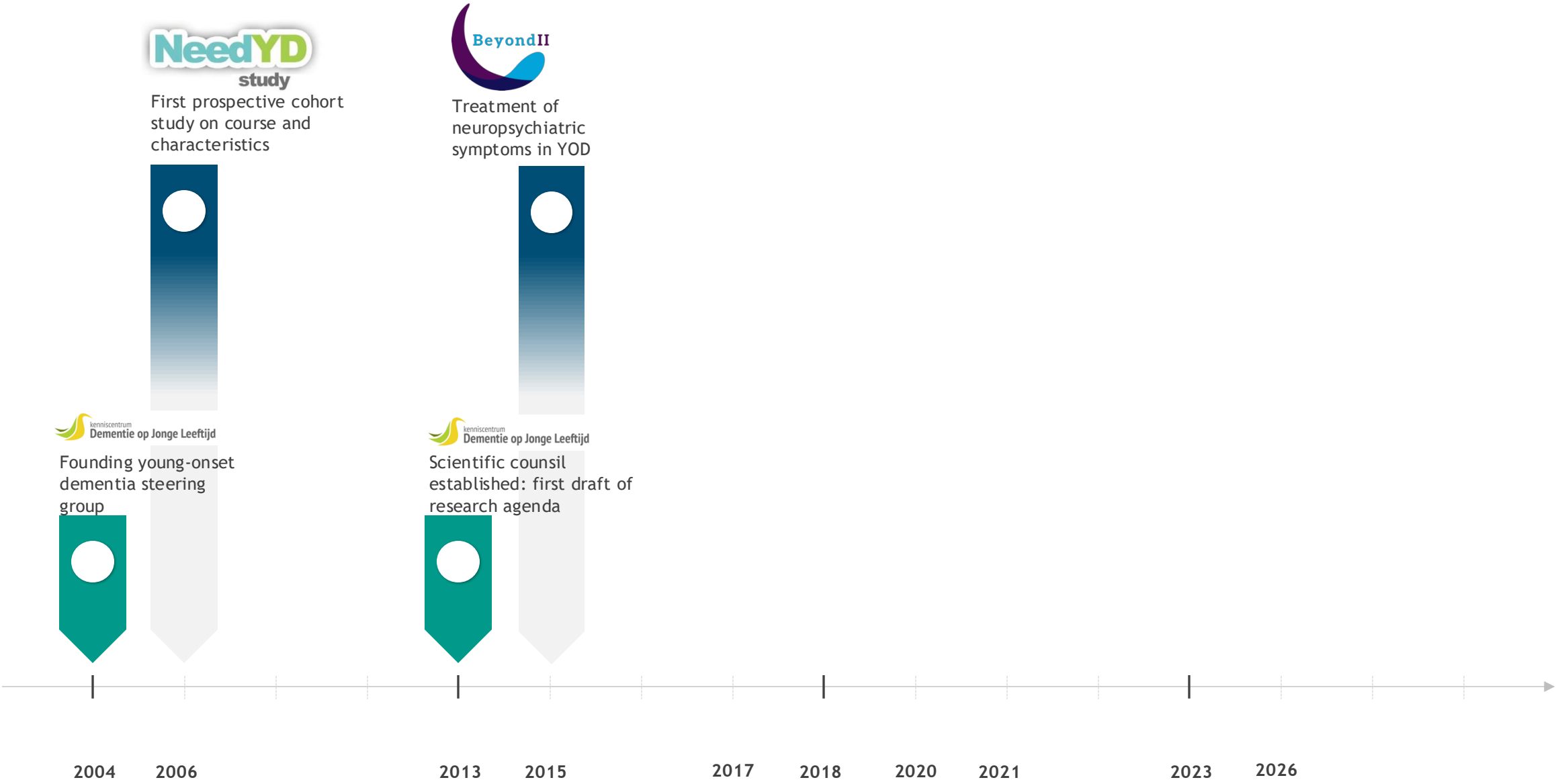
2023

2026

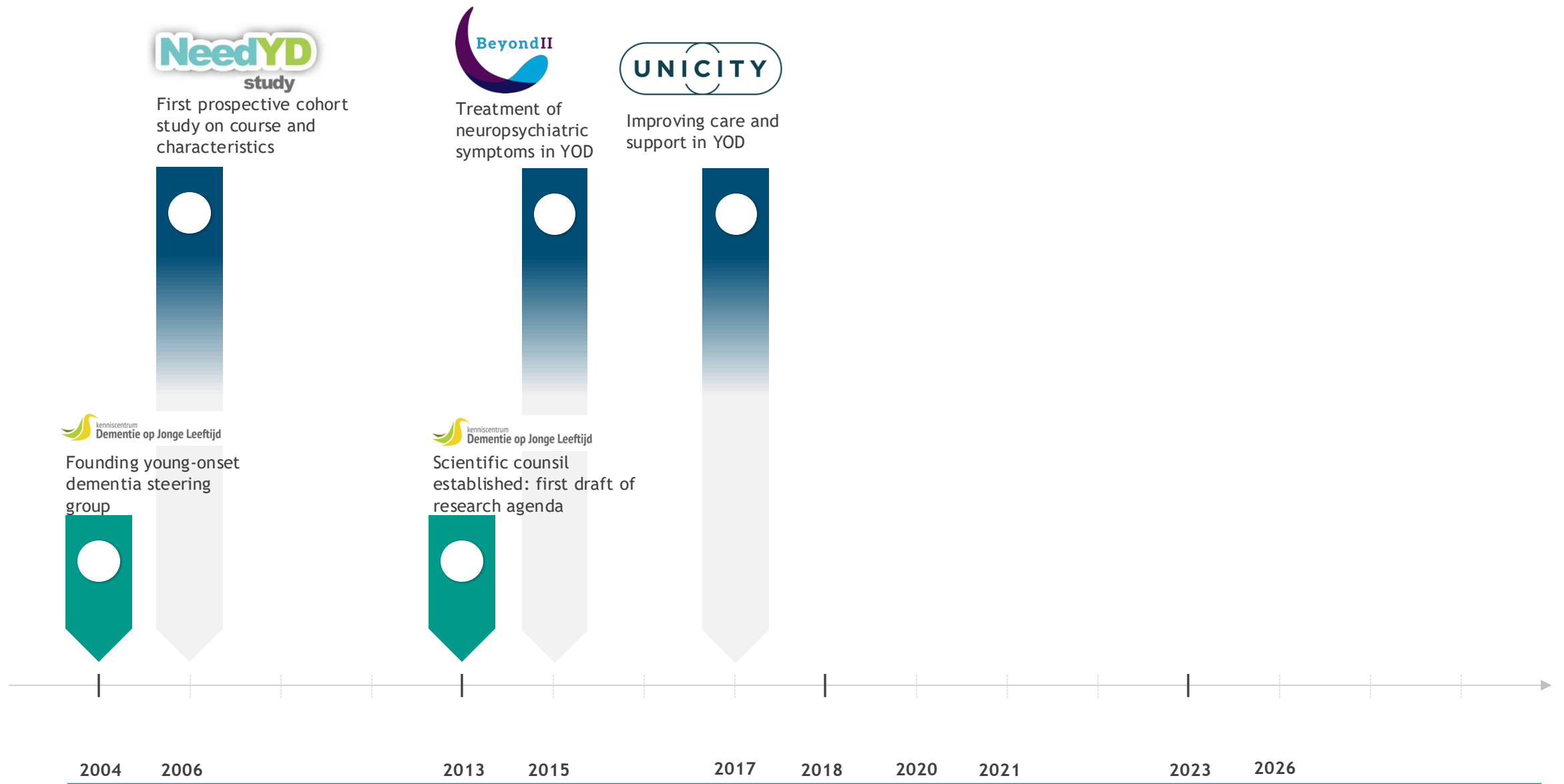
# The importance of combining research with practice...



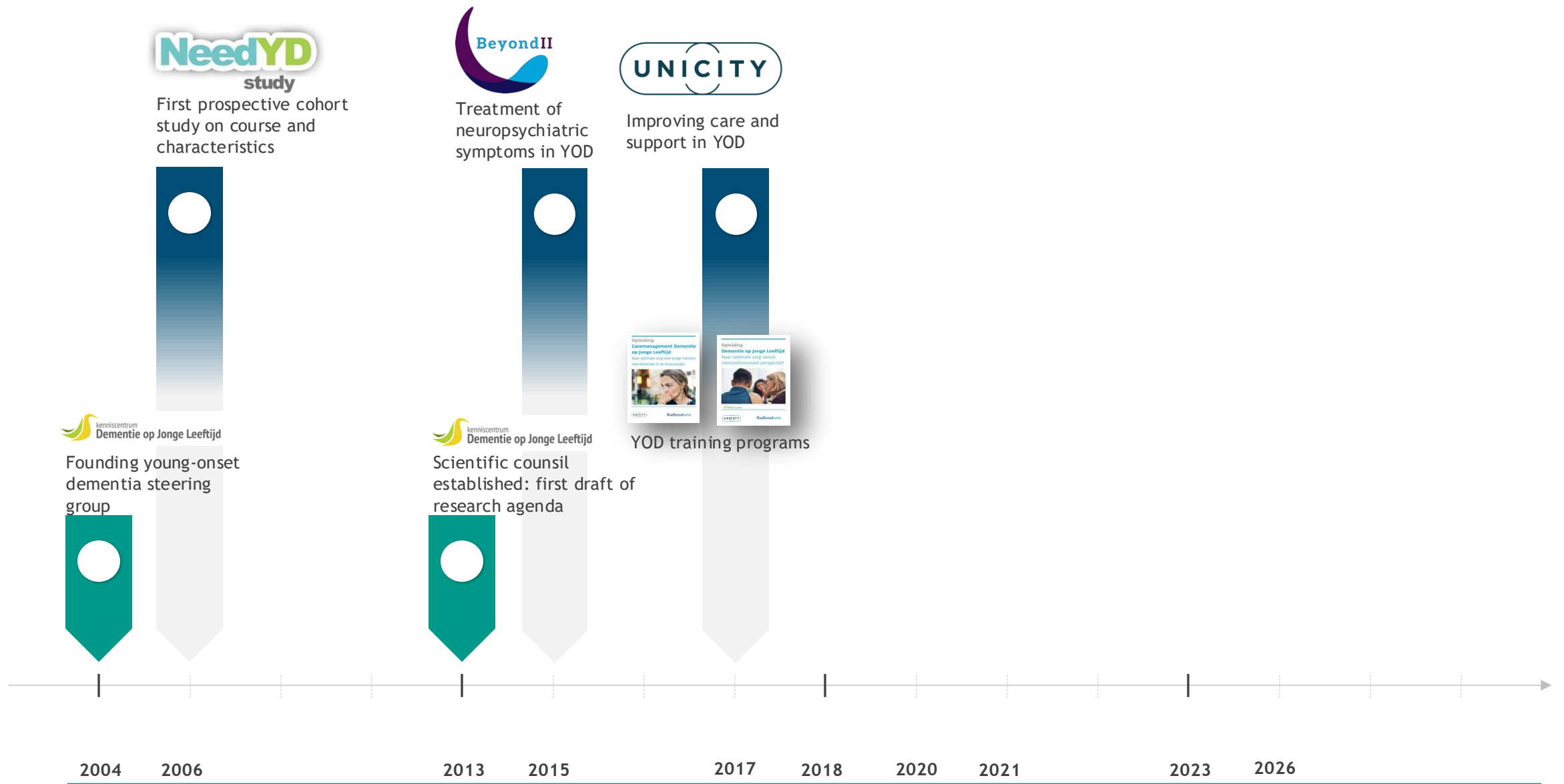
# Addressing research questions from clinical practice...



# The importance of a solid infrastructure...

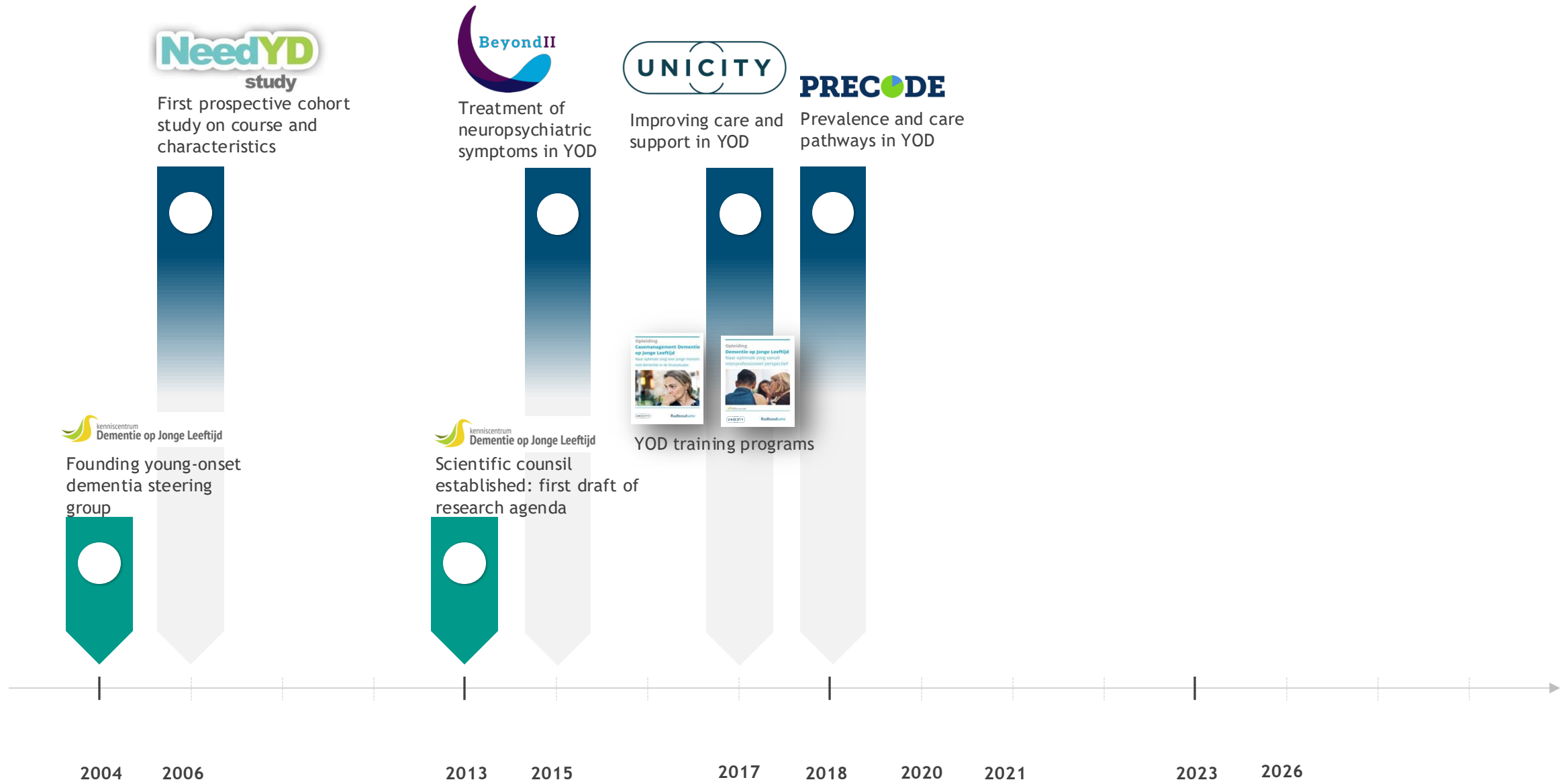


# The importance of a solid infrastructure...

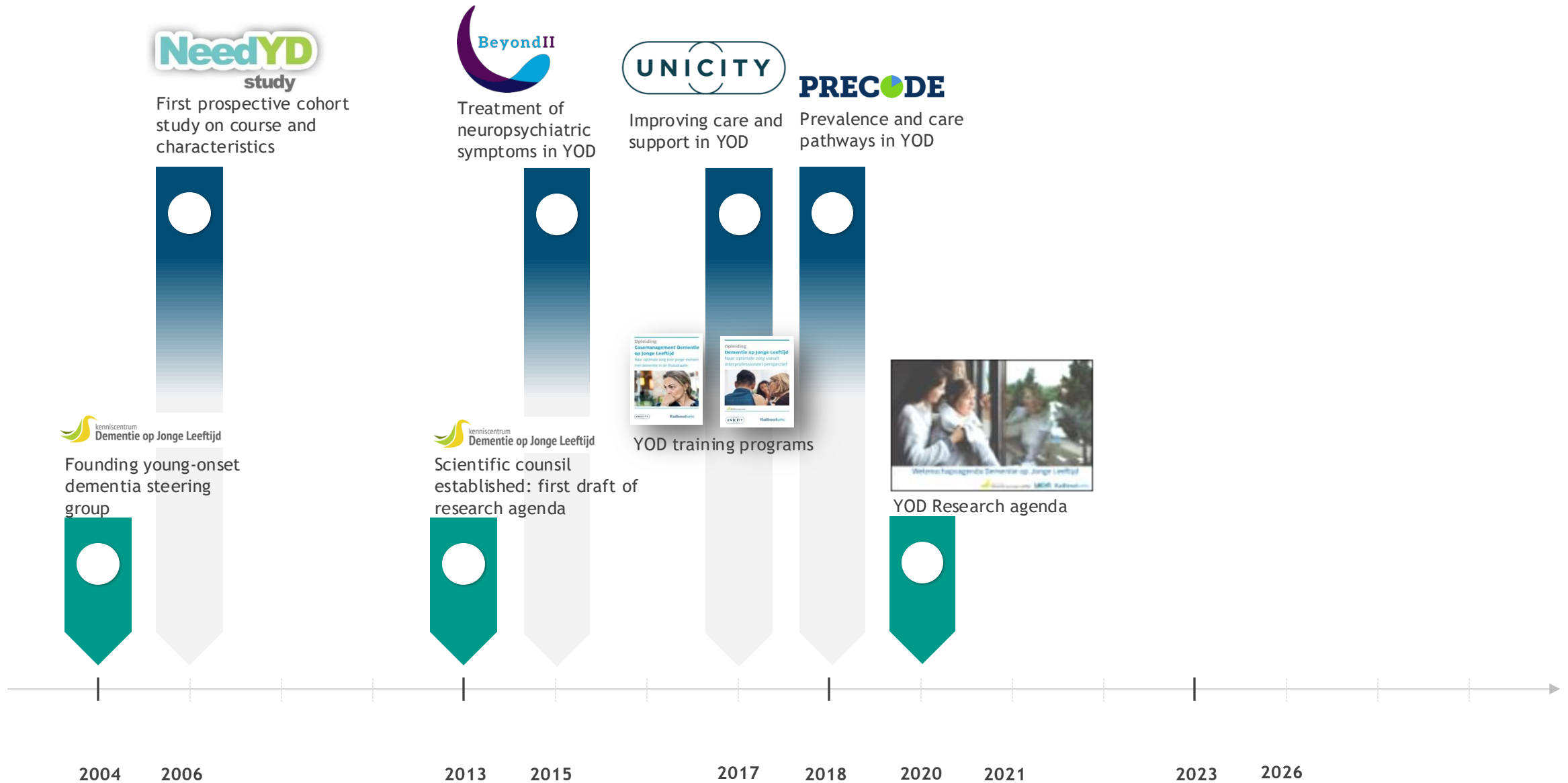




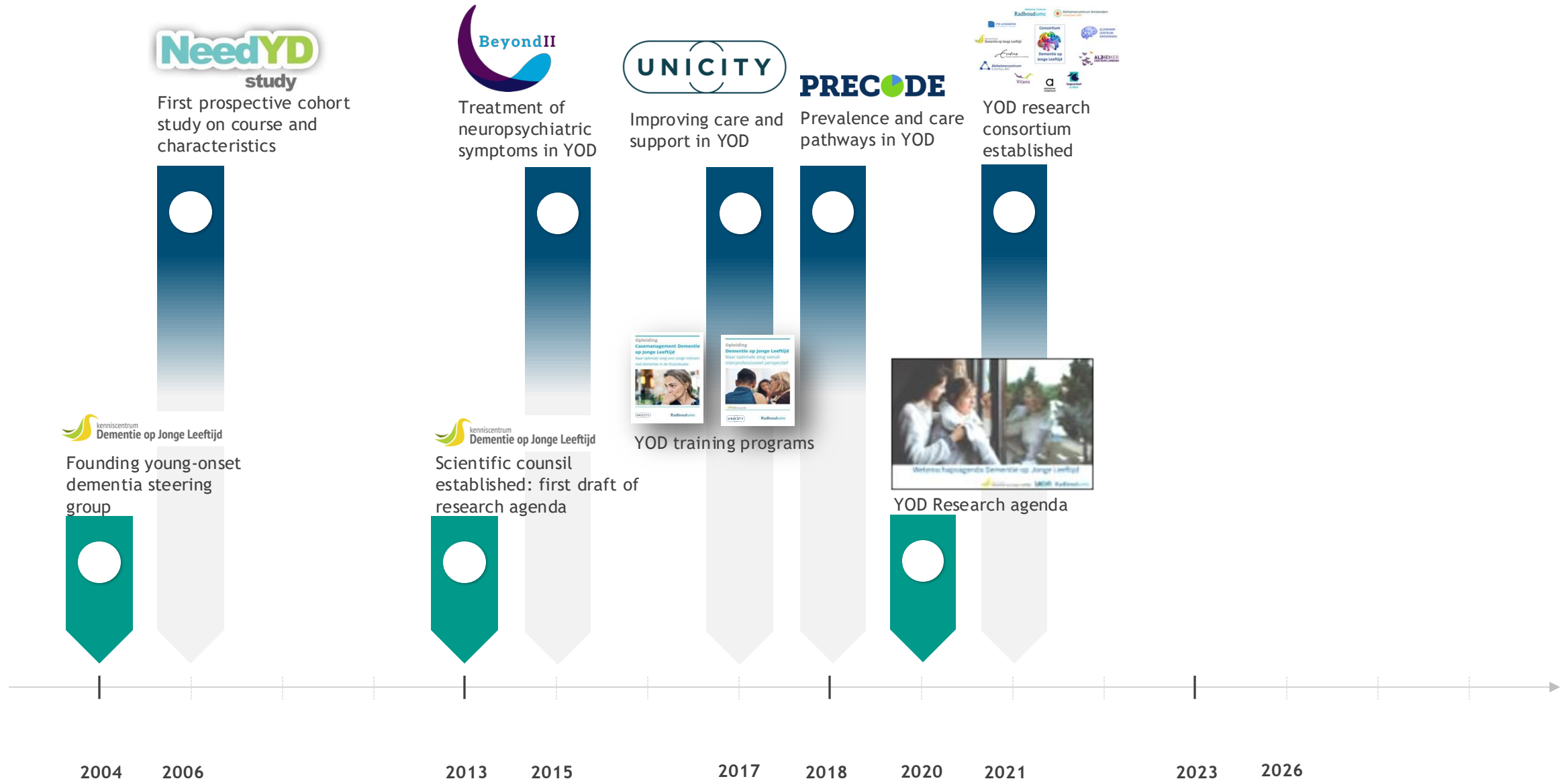
# What does the name young-onset dementia imply...?



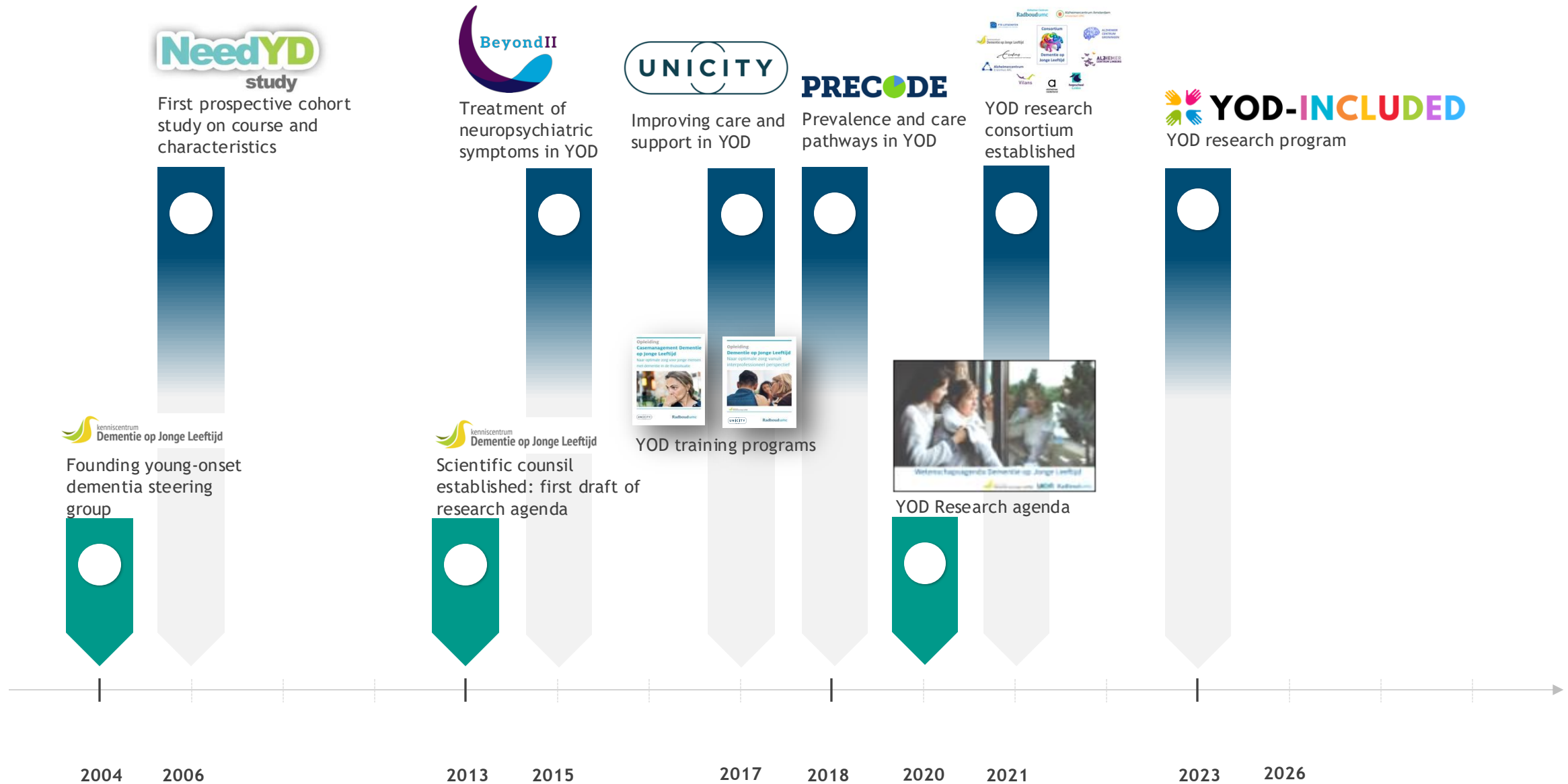
# Establish focus...



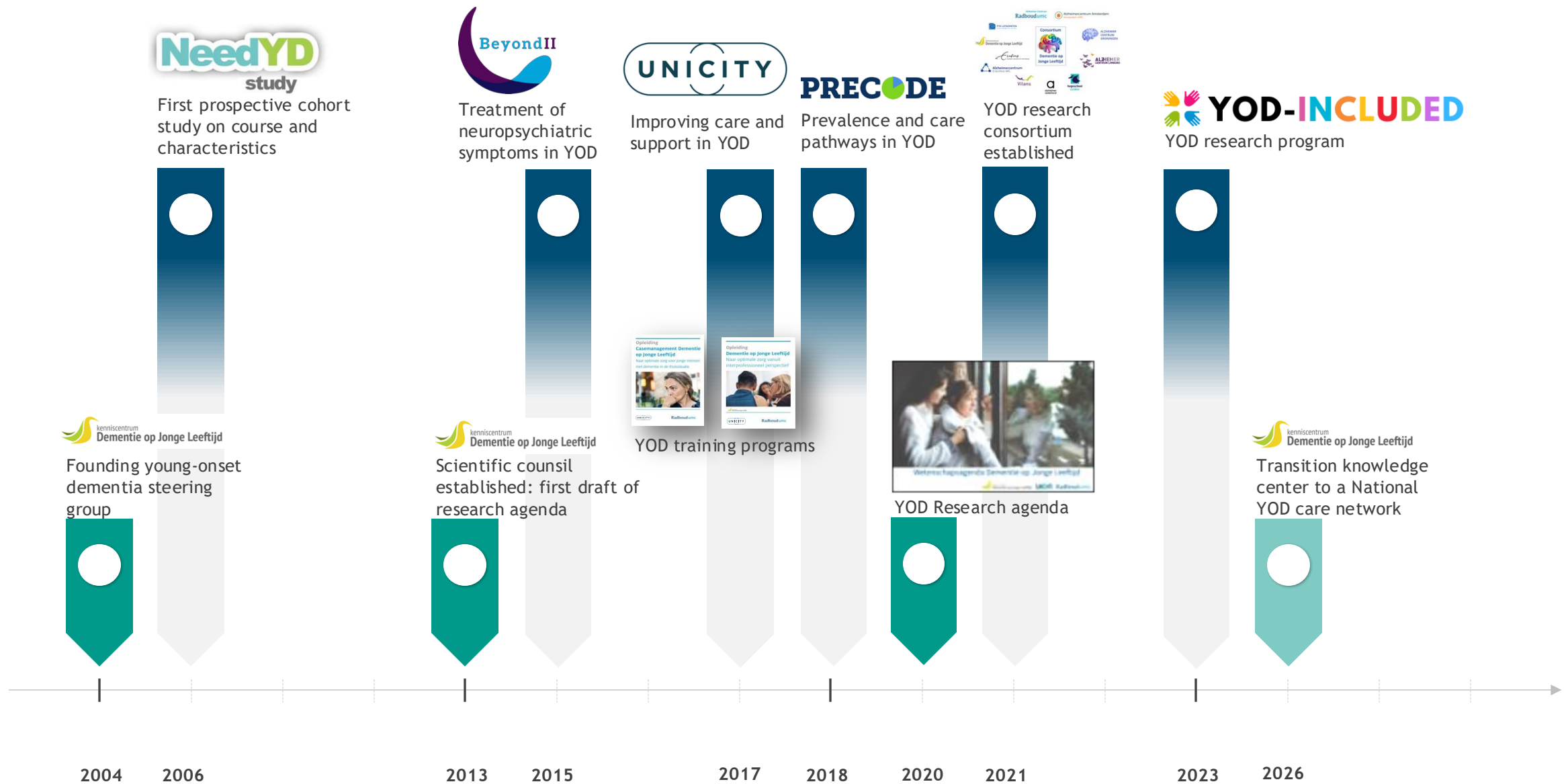
# Join forces where possible...



# Where we are currently at:



# A look at the near future:



# *focussen*

Developing the Focussen Intervention

# .focussen

Malissa Janssen

Junior researcher



Christian Bakker

Project lead



Margreet Mantel

PPI Representative



Karin Stolk

PPI Representative



Elly Prins

Expert



Annelore van Dalen

Team member



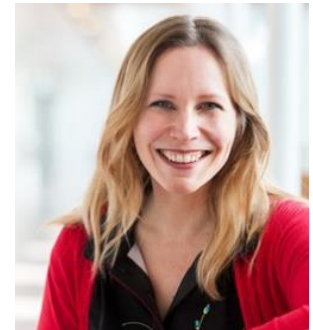
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Team member



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Team member

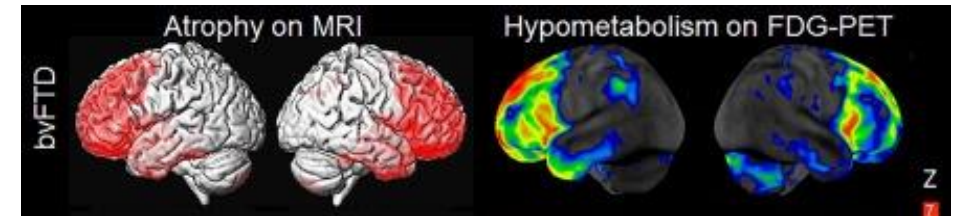


# The behavioral variant of frontotemporal dementia

Specific areas of the brain affected, causing:

- Inability to ignore internal and external stimuli
- Inability to monitor ones own behavior
- Inability to inhibit a response
- Inability to empathize

Causing all sorts of difficulties in daily life.





# de waalboog





# Evaluation of the *focussen* program: method



- Gain a better understanding why ‘Focussen’ works.
- Improve ‘Focussen’ as a method
- Perform a feasibility study
- Draft recommendations regarding implementation of the program



# Evaluation of the *focussen* program: method

After adaptation of the intervention a proces evaluation and multiple casestudy were performed

- Proces evaluation: intervention quality, implementation knowledge, effect and user satisfaction
- Multiple casestudy:

Five days (N = 6)

- A-phase: no intervention (15 min)
- B-phase: intervention (15 min)
- Extended B-fase: intervention (45 min)



Differences in Disinhibited behaviors and wellbeing A-phase, compared to B-phase

# Intervention

Disinhibited behaviors should be considered as an automatic response to internal or external stimuli, that is not inhibited.

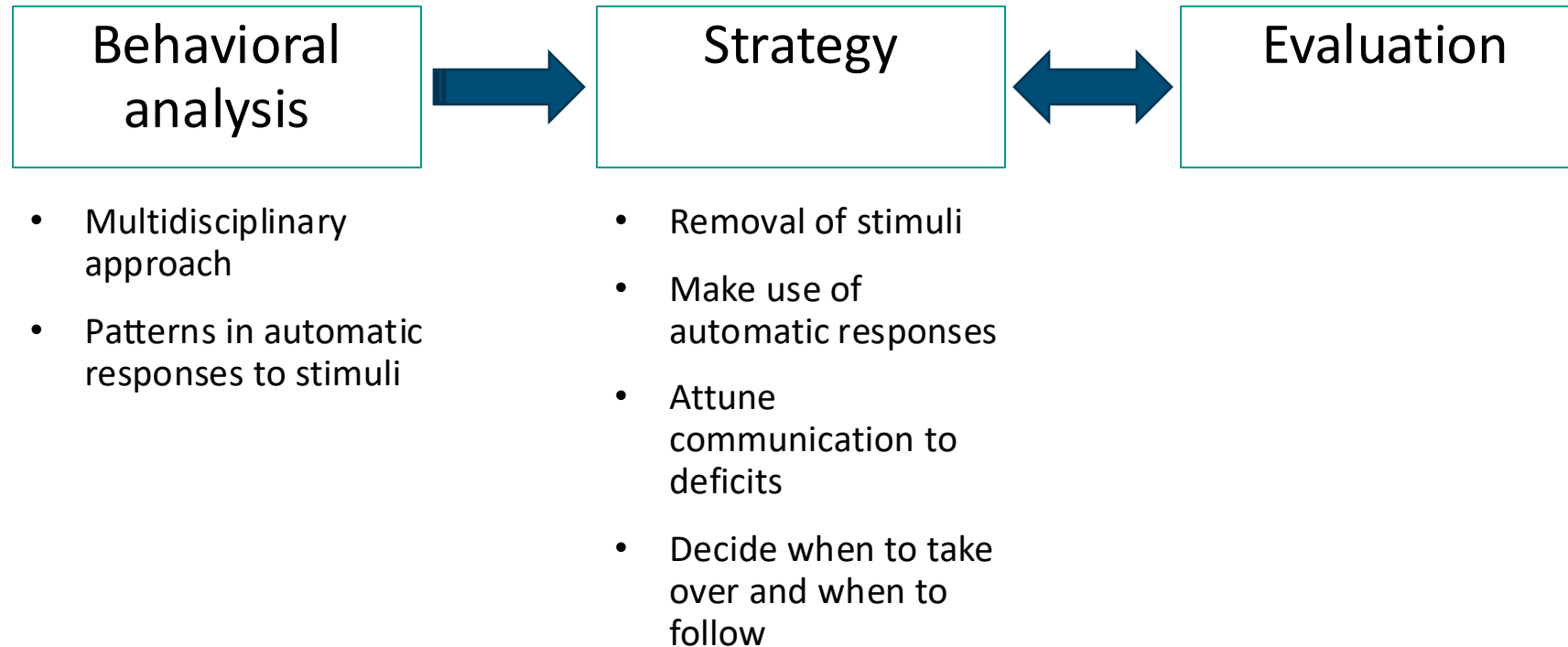
# Intervention

Disinhibited behaviors should be considered as an automatic response to internal or external stimuli, that is not inhibited.

Compensate for or take over cognitive functions that are 'broken'

- Know when to 'steer' and when to 'follow' the person with FTD
- Filter or remove stimuli that evoke an unwanted automatic response
- Shift focus to stimuli that evoke an automatic response that is acceptable
- Only communicate what is necessary to achieve the response we want
- Make use of the environment and 'focus activities'

# Intervention

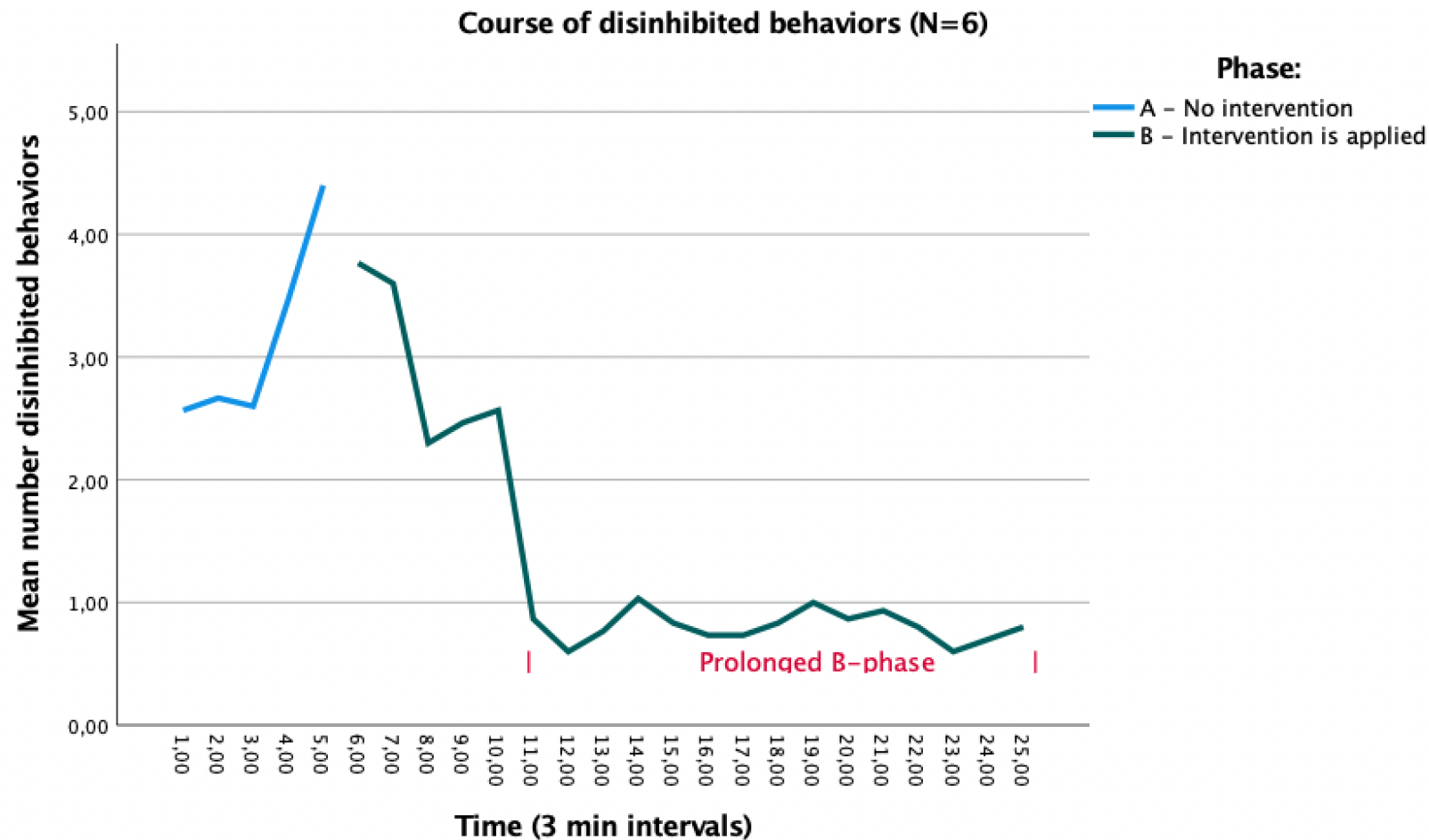


# Evaluation of the *focussen* program: results

- Steps of the intervention could be performed as planned
- Better equipped to deal with disinhibited behaviors
- Shift in focus from behavioral problems to positive interaction with person with FTD
- Disinhibited behaviors are still there, but frequency and severity were reduced
- Wellbeing in residents with FTD improved
- Method could be easily incorporated into existing working methods
- Challenging for some team members, because existing ideas about 'what is good dementia care' had to be changed
- Respondents would highly recommend the intervention to other organisations caring for people with FTD



# Evaluation of the *focussen* program: results



# Conclusions....

- ✓ Disinhibition in the behavioral variant of frontotemporal dementia can be regarded as automatic responses to stimuli that are not inhibited
- ✓ A strategy to manage these behaviors from this perspective seems to work and health care professionals feel more equipped because of the focussen program
- ✓ We should evaluate the focussen program on a larger scale whether or not there is a lasting effect
- ✓ We should look into using the program for the management of disinhibition seen in other types of dementia



# Some thoughts....

- ✓ When thinking about developing services and support in YOD research can help
- ✓ Establishing an infrastructure in which care and research are embedded has helped in the Netherlands (and may also help elsewhere)
- ✓ In research: look at what is already there in clinical practice and built on that
- ✓ In clinical practice: a YOD learning community at the national level will help improve implementation, innovation and acceptability of new things (e.g. interventions, insights)



# Contact & information

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