

# Learn to change and change to learn: Improving services for young-onset dementia

## Improving integrated care and support for people with young-onset dementia using participatory action research



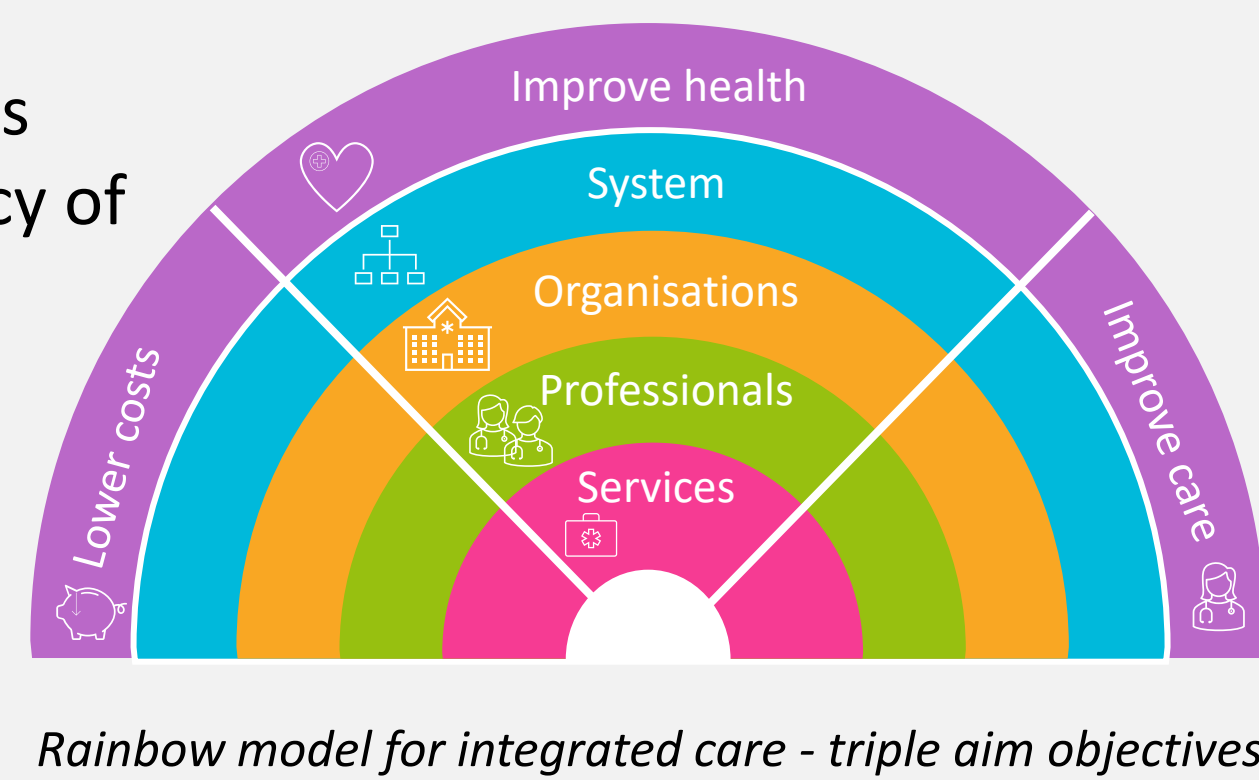
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### Background

- People with young-onset dementia (YOD) and their supporters often do **not have access** to age- and needs appropriate services.
- The goal of a (coordinated) healthcare network is **to improve** the accessibility, quality and efficiency of care and to improve patient satisfaction.
- Adopting the Triple Aim for integrated care means working towards better care and better health at lower costs. These objectives revolve around **appropriate care**.

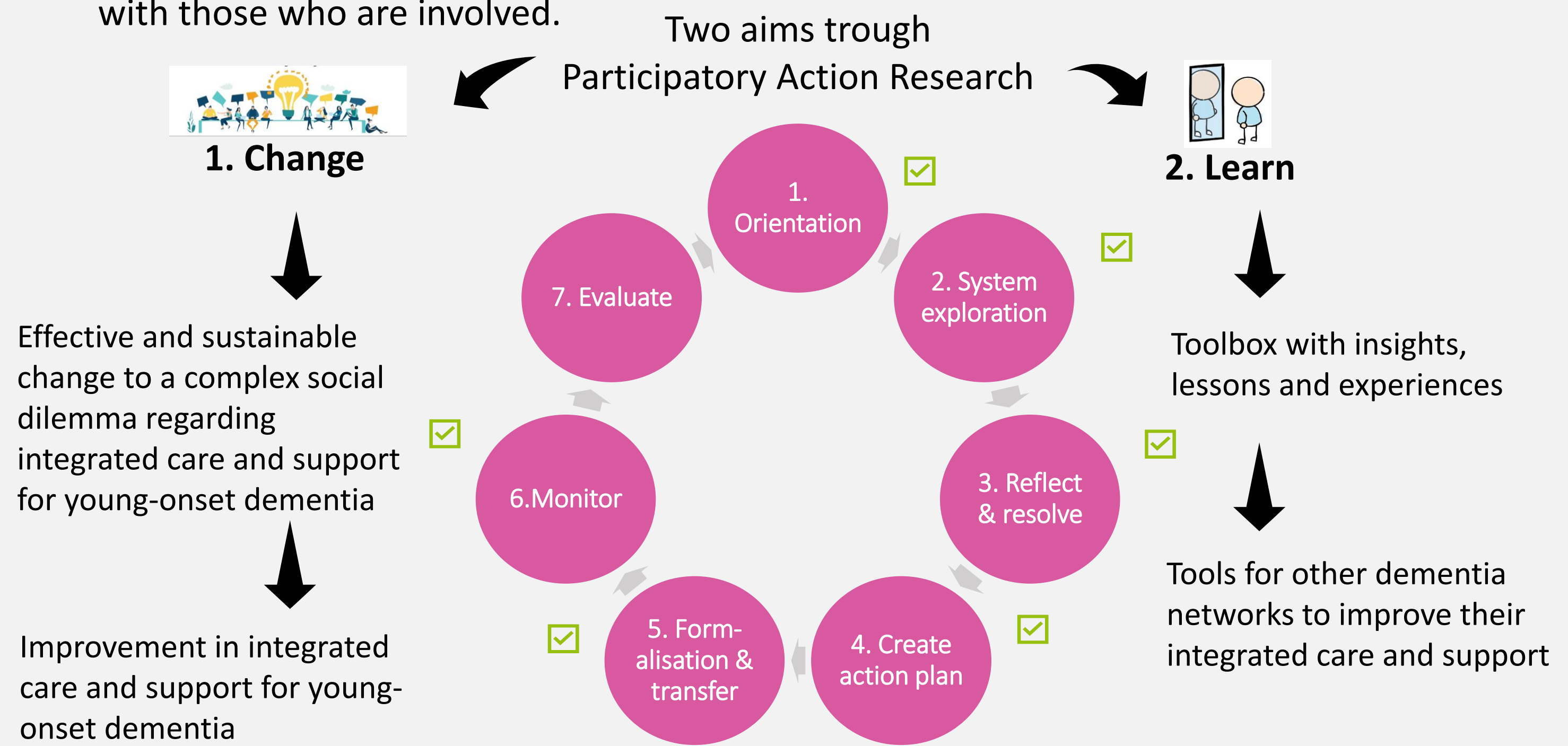


### Aim

To increase the access to age- and needs appropriate services by improving integrated care and support.

### Participatory Action Research (PAR)

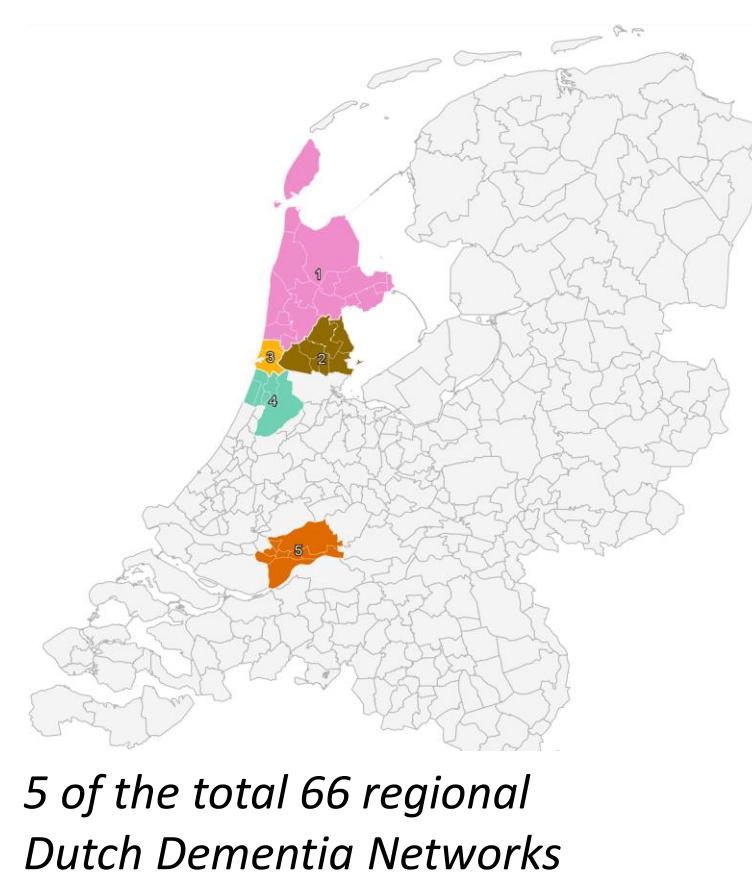
- PAR is a method to understand and address complex practical dilemmas in collaboration with those who are involved.



### Methods

We use Participatory Action Research (PAR) to:

- **Make a change** and improve integrated care and support for people with YOD in two regions of the Netherlands:
  - PAR-community A – a superregional network, including the regional networks 1 – 4
  - PAR-community B – a regional network 5
- **Learn** from this process and create a toolbox with practical tools and tips for others to use.



### Members of PAR-community A



Policy advisors, director and managers of healthcare organisations, director of care farms, quality manager, healthcare professionals, representatives of welfare organisations, coordinators of dementia networks, researcher

### Members of PAR-community B



Policy advisors, healthcare professionals, coordinator of dementia network, researcher

### Preliminary results PAR-community A

**Change:** Organisation of daily activities for people with YOD and their supporters

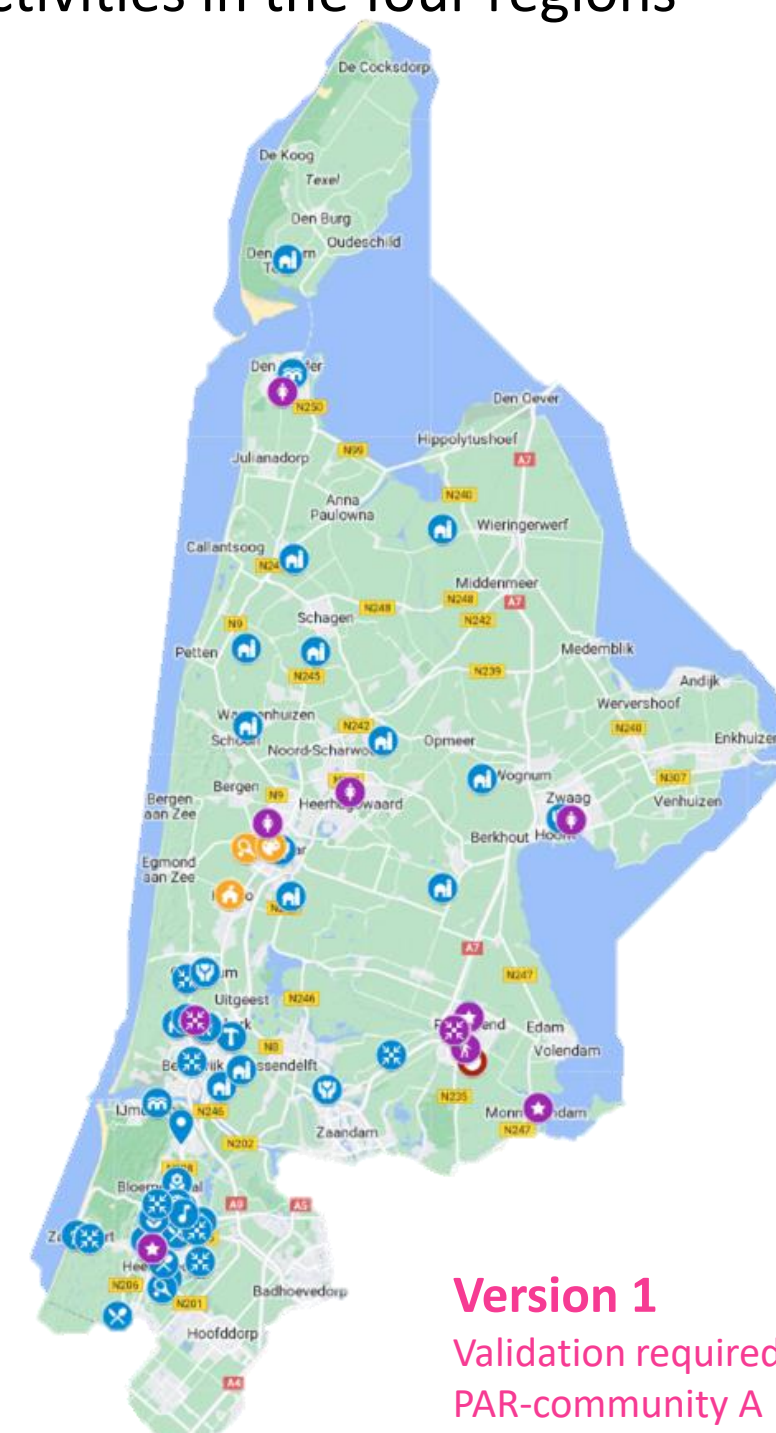
First definition of the dilemma:  
Project team

'Currently, there are not enough adjusted daily activities for persons with young-onset dementia to their and their families distributed in the four regional networks'

Refined definition of the dilemma  
Members of PAR-community A

'Currently, daily activities for persons with young-onset dementia are:  
- Often not available  
- Not adjusted to the specific needs and lives  
- Not well distributed within regions  
- Complicated by transport issues, inflexible openings hours or stigma'

Current situation:  
Map with current available daily activities in the four regions



'We want to adjust daily activities for persons with young-onset dementia to their and their families' needs'

Ideal situation:  
What do we want as daily activities in the four regions?



What is our ideal situation?  
Data collection in progress

Legend:  
● = age-appropriate activities  
● = activities for dementia  
● = possible age-appropriate activities  
● = discontinued age-appropriate activities

**Learn:** Reflections and learned lessons at  points

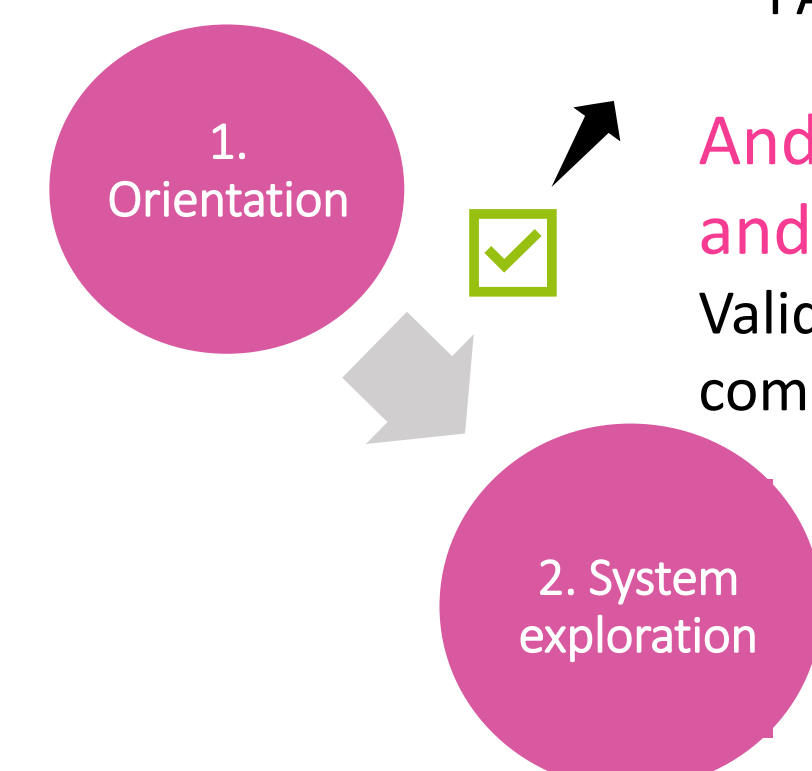
**We reflect on:**

- The action
- The result of the action
- The process of the action

**As:**

- Individuals
- Researcher and advisor
- Project leaders
- PAR-community

**And form learned lesson and tools:**  
Validated by the PAR-community



### Future results

This study will lead to:

1. A change in integrated care and support for young-onset dementia
2. Tools for other dementia networks to change



### Discussion

What would you change in this study design?  
What would you want to learn?

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