

# **Bringing palliative care for dementia patients into agreement with their wishes and needs: development and evaluation of Decidem**

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What are the effects of Decidem on the proportion of patients whose needs and wishes are known and respected, on patient and family caregiver outcomes and on healthcare costs?

|                             |                       |
|-----------------------------|-----------------------|
| <b>Ethische beoordeling</b> | Positief advies       |
| <b>Status</b>               | Werving gestart       |
| <b>Type aandoening</b>      | -                     |
| <b>Onderzoekstype</b>       | Interventie onderzoek |

## **Samenvatting**

### **ID**

NL-OMON21291

### **Bron**

NTR

### **Verkorte titel**

Decidem

### **Aandoening**

Dementia, primary care, family physician, advance care planning, shared decision making  
Dementie, eerstelijnsgezondheids zorg, huisarts, gezamenlijke besluitvorming

### **Ondersteuning**

**Primaire sponsor:** IQ-Healthcare; Radboudumc; nijmegen, the Netherlands

**Overige ondersteuning:** Zonmw

### **Onderzoeksproduct en/of interventie**

## **Uitkomstmaten**

### **Primaire uitkomstmaten**

The primary outcome on care level is the proportion of patients whose needs and wishes are known and respected.

## **Toelichting onderzoek**

### **Achtergrond van het onderzoek**

Patients with dementia have limited access to palliative care. At the end of their lives, aggressive and unwanted interventions like resuscitation and hospitalization regularly take place. Physical symptoms in patients such as pain or dyspnea and neuropsychiatric symptoms and depression in both patients and family caregivers are often undertreated. This threatens the quality of life of dementia patients and their family caregivers. Palliative care can bring actual care into agreement with patients' and caregivers' needs and wishes. Therefore an innovative intervention in dementia care combining the strengths of advance care planning (ACP) and shared decision making (SDM) called Decidem will be developed. The research aim of this project is to evaluate its effects on care, patients and caregivers, and costs. We hypothesize that Decidem will bring actual care into agreement with patients' and caregivers' wishes/preferences and needs. This patient-centered, personalized intervention may increase their satisfaction with care, decrease caregivers' burden and increase quality of life. Decrease of under- and over treatment, of hospitalizations and of unplanned visits may reduce costs.

### **Doel van het onderzoek**

What are the effects of Decidem on the proportion of patients whose needs and wishes are known and respected, on patient and family caregiver outcomes and on healthcare costs?

### **Onderzoeksopzet**

baseline measurements at timepoint 0

Followup measurements after three months for resource utilization

End measurements after 6 months

### **Onderzoeksproduct en/of interventie**

Education of the general practitioner (and practice nurse) in advance care planning and shared decision making for community dwelling elderly who live at home or in a home for the elderly

## **Contactpersonen**

### **Publiek**

Praktijk voor Acupunctuur, De Meern

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### **Wetenschappelijk**

Praktijk voor Acupunctuur, De Meern

M. Vernooij  
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The Netherlands  
030-6620846/0613610558

## **Deelname eisen**

### **Belangrijkste voorwaarden om deel te mogen nemen (Inclusiecriteria)**

Dementia diagnosis

In care of a general practitioner

Living at home or in a home for the elderly

65 years old

## **Belangrijkste redenen om niet deel te kunnen nemen (Exclusiecriteria)**

No dementia diagnosis

Not in care of a general practitioner

Not living at home or in a home for the elderly

Younger than 65 years

## **Onderzoeksopzet**

### **Opzet**

|                  |                       |
|------------------|-----------------------|
| Type:            | Interventie onderzoek |
| Onderzoeksmodel: | Anders                |
| Toewijzing:      | Gerandomiseerd        |
| Blinding:        | Enkelblind            |
| Controle:        | Geneesmiddel          |

### **Deelname**

|                         |                      |
|-------------------------|----------------------|
| Nederland               |                      |
| Status:                 | Werving gestart      |
| (Verwachte) startdatum: | 01-01-2016           |
| Aantal proefpersonen:   | 150                  |
| Type:                   | Verwachte startdatum |

## **Ethische beoordeling**

|                 |                  |
|-----------------|------------------|
| Positief advies |                  |
| Datum:          | 08-03-2016       |
| Soort:          | Eerste indiening |

# Registraties

## Opgevolgd door onderstaande (mogelijk meer actuele) registratie

Geen registraties gevonden.

## Andere (mogelijk minder actuele) registraties in dit register

Geen registraties gevonden.

## In overige registers

| Register       | ID                      |
|----------------|-------------------------|
| NTR-new        | NL4909                  |
| NTR-old        | NTR5773                 |
| Ander register | Zonmw : 70-73305-98-420 |

# Resultaten