

# Informal caregiver involvement in innovative home care projects in Belgium

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## Background

### Innovative home care projects in Belgium

#### “protocol 3” (2009-2013)

- ✓ Bottom-up approach
- ✓ Aim: delay institutionalization of frail elderly

#### Why is informal caregiver involvement important?

- ✓ Impact on caregiver burden, quality of care, ...

### Research question

To what extent do the protocol 3 projects involve the informal caregivers?

## Methods

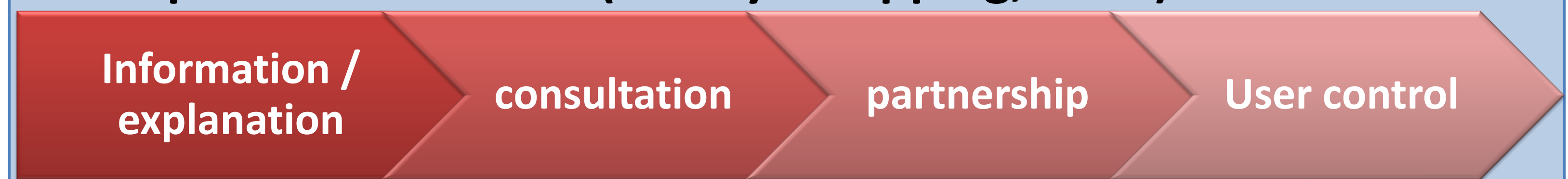
### Data sources:

- ✓ applications + yearly questionnaires + interviews + focus groups

### Qualitative descriptive analysis:

- ✓ communication between professionals and informal caregivers
- ✓ decision-making process

### Participation continuum (Hickey & Kipping, 1998)



## Preliminary results

### ✓ Communication:

- Importance of a relationship of trust
- Subjective feeling of professionals: Effect of ‘relationship of trust’ on accuracy of Zarit-scores

### ✓ Decision-making process:

- Informal caregiver is not always involved or key person
- Depends on complexity/urgency of care situation

### ✓ Participation continuum:

- Dynamic: at some points in the course of a service provision a higher level of participation is desirable (e.g. at intake)

Quote: “I involve the informal caregivers especially when I am looking for the right tool because they know the clients best. It is appreciated that you do not say *here is your tool*, but that you really consult with them.”  
(*occupational therapist*)



Quote: “It is with the informal caregiver that arrangements about the care for the frail older person can be made. The informal caregiver is treated as a partner and not as a patient.”  
(*nurse in night care project*)

## Discussion

### ✓ For now: only 1 side of the story: professionals view

- To match with informal caregiver point of view (questionnaire)
- To match with frail elderly / informal caregiver outcomes (e.g. interRAI HC and Zarit)

### ✓ Importance of in-depth qualitative data

- To explain why the informal caregiver is or is not involved



Reference: Hickey, G. and Kipping, C. (1998), *Exploring the concept of user involvement in mental health through a participation continuum. Journal of Clinical Nursing, 7: 83–88.*