

# **Improving the decision making process with older people living with frailty and their caregivers about location of care**

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of Shared Decision Making in Primary Care

3<sup>rd</sup> Annual TVN Conference on Improving Care for the Frail Elderly  
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# Team members

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## Caregivers

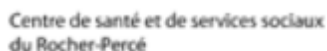
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- **Lise Roy**

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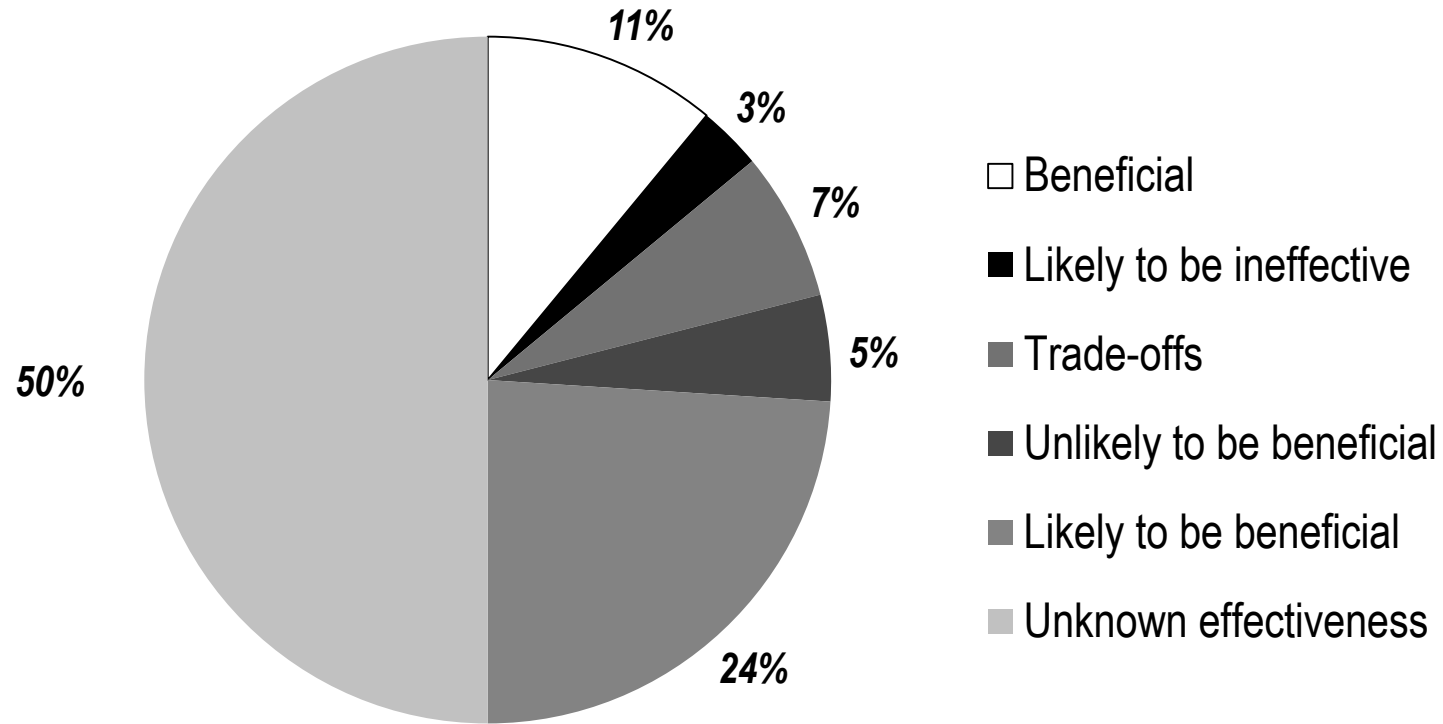




# Shared Decision Making

# ▶ Most decisions occur in the grey zone

Lomas & Lavis 1996



Benefits of 3000 health interventions  
Editorial team of BMJ *Clinical Evidence*

# SDM steps

1. Define problem/identify decision to be made
2. Present options (including watchful waiting)
3. Discuss potential benefits/risks (probabilistic nature of evidence)
4. Identify patient values/preferences
5. Explore patient ability
6. Present recommendations
7. Check understanding
8. Make/defer decision & arrange for follow-up

# Quality/optimal decision

Is congruent

With the  
best  
available  
evidence  
and what an  
informed  
patient  
values

Choice





ELSEVIER

Contents lists available at ScienceDirect

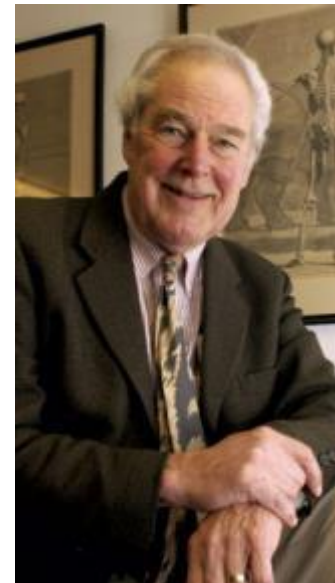
## Health Policy

journal homepage: [www.elsevier.com/locate/healthpol](http://www.elsevier.com/locate/healthpol)



### Editorial

Geographic variation in health care—A special issue on the 40th anniversary of “Small area variation in health care delivery”





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## Conference



Following a small gathering of health professionals, scientists, and others in early 2012, it was decided to initiate and plan an international conference, the first of which took place at The Dartmouth Institute, [September 10-12, 2013](#). A second conference hosted by the Centre for Evidence-Based Medicine, at the University of Oxford, UK took place [September 15-17, 2014](#) and [Preventing Overdiagnosis 2015](#) is held at the National Institutes of Health, National Cancer Institute, Bethesda, Maryland, US. September 1-3.

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# Informed consent





# **Interprofessional Shared Decision Making**

# Research program 2007- ongoing



Stacey D, Legare F, Pouliot S, Kryworuchko J, Dunn S. Shared decision making models to inform an interprofessional perspective on decision making: a **theory analysis**. Patient Educ Couns 2010;80:164-72.

Legare F, Stacey D, Gagnon S, et al. Validating a **conceptual model** for an inter-professional approach to shared decision making: a mixed methods study. J Eval Clin Pract 2011;17:554-64.

Legare F, Stacey D, Briere N, et al. Healthcare providers' intentions to engage in an interprofessional approach to shared decision-making in home care programs: **A mixed methods study**. J Interprof Care 2013.

Legare F, Stacey D, Briere N, et al. An interprofessional approach to shared decision making: an **exploratory case study** with family caregivers of one IP home care team. BMC Geriatr 2014;14:83.

Stacey D, Briere N, Robitaille H, Fraser K, Desroches S, Legare F. A systematic process for creating and appraising **clinical vignettes** to illustrate interprofessional shared decision making. J Interprof Care 2014;28:453-9.





# IP-SDM in the context of home care

# Introduction

- One of the toughest decisions that older people living with frailty face is the decision to remain at home or to move to another location
- Caregivers and interprofessional home care teams play an important role in this highly preference-sensitive decision
- Thus an interprofessional approach to shared decision making (IP-SDM) may be helpful

# Pilot trial

- In 2010, we piloted a new multifaceted intervention (training and decision aid) with two interprofessional (IP) home care teams in Quebec City and Edmonton to help older people living with frailty and their caregivers make decisions about location of care
- But we had not yet evaluated its impact on clinical practices or on older people living with frailty and their caregivers

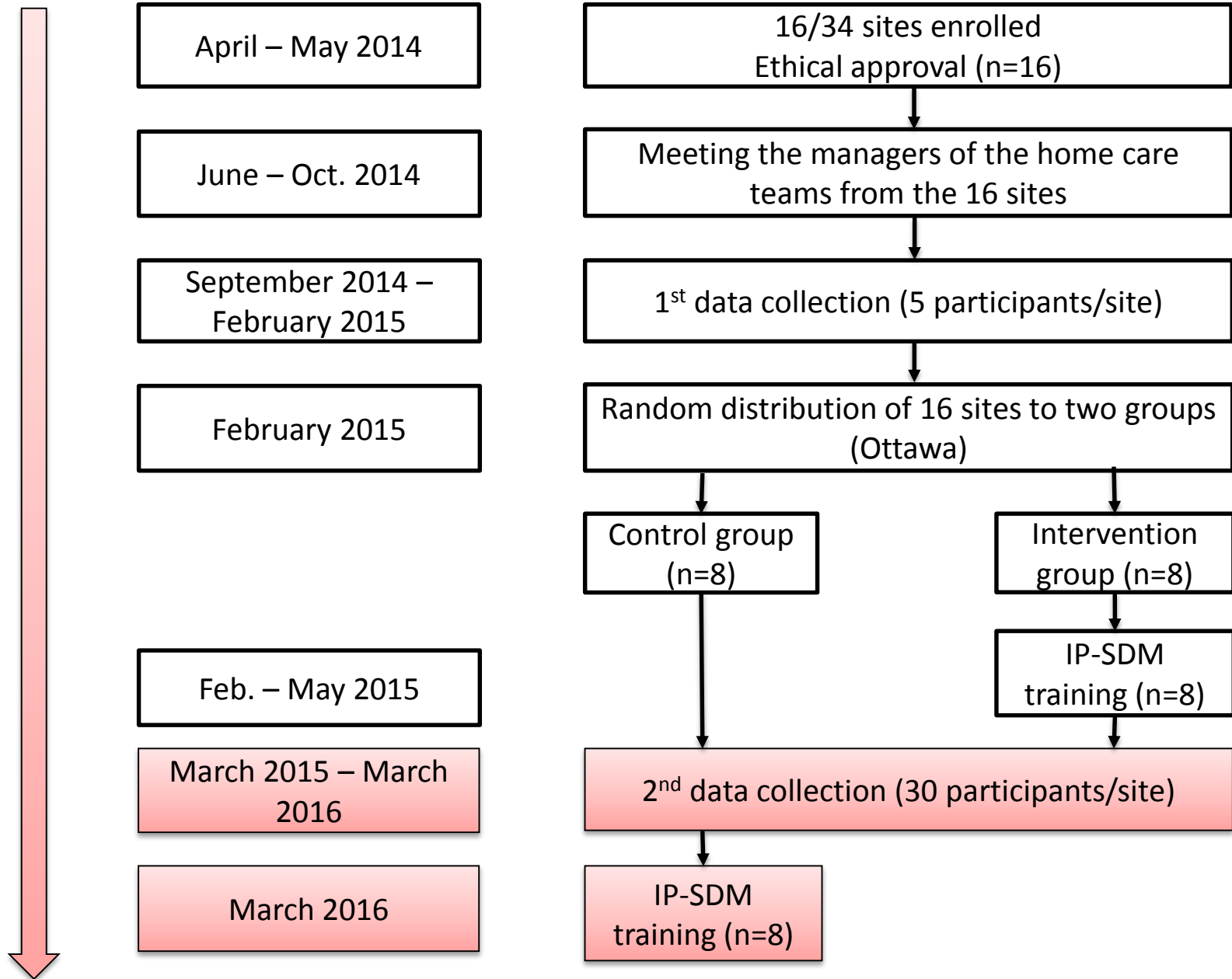
# 2014 - 2016 Cluster Randomized Trial

|   |  |
|---|--|
| P | Older people living with frailty and their caregivers  |
| I | IP-SDM training for home care teams with a decision support guide  |
| C | Usual care   |
| O | Engagement of older people living with frailty and their caregivers in the decision-making process concerning location of care |





# Study design



# Eligibility criteria (1)

- Participants

- Home care teams

- Involved in healthcare for eligible frail elderly people

- Elders

- $\geq 65$  years
    - Have made a decision about relocating
    - Able to read, understand and write in French or English and to give informed consent

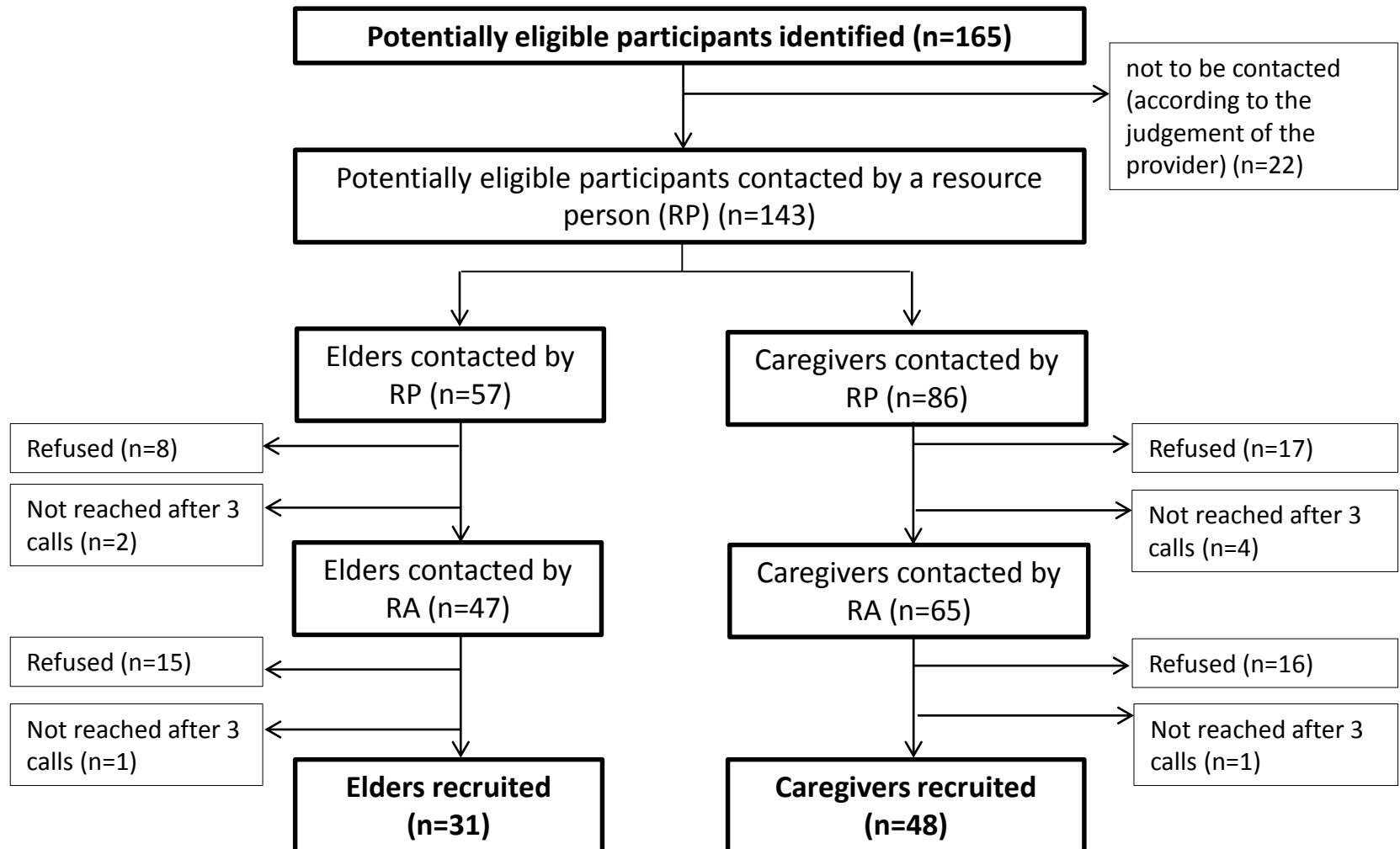
# Eligibility criteria (2)

## ■ Participants

### – Caregivers

- Have made a decision about relocating an elder with cognitive impairment
- Are able to read, understand and write in French or English and to give informed consent
- Were referred by a member of the home care team enrolled in the study

# 1st data collection (5 participants/site)



| Characteristic of participants n (%) | Seniors (n=31) | Caregivers (n=48) |
|--------------------------------------|----------------|-------------------|
| <b>Age (year) mean (SD)</b>          | 84 (7.5)       | 67 (13.0)         |
| <b>Female</b>                        | 26 (83.9)      | 34 (70.8)         |
| <b>Status</b>                        |                |                   |
| Single                               | 1 (3.2)        | 6 (12.5)          |
| Married                              | 6 (19.4)       | 30 (62.5)         |
| Separated/Divorced                   | 3 (9.7)        | 9 (18.8)          |
| Widower                              | 21 (67.7)      | 3 (6.3)           |
| <b>Employment status</b>             |                |                   |
| Full time                            | -              | 10 (20.8)         |
| Part time                            | -              | 3 (6.3)           |
| Retirement                           | -              | 27 (56.3)         |
| Home                                 | -              | 7 (14.6)          |
| Other                                | -              | 1 (2.1)           |
| <b>Education level</b>               |                |                   |
| Primary                              | 20 (64.5)      | 9 (18.8)          |
| Secondary                            | 4 (12.9)       | 12 (25.0)         |
| Post-secondary                       | 7 (22.6)       | 25 (52.1)         |
| Other                                | 0 (0.0)        | 2 (4.2)           |

| <b>Choice characteristics n (%)</b>           | <b>Seniors (n=31)</b> | <b>Caregivers (n=48)</b> |
|---|-----------------------|--------------------------|
| <b>Preference about the location of care</b>  |                       |                          |
| Stay at home                                  | 20 (64.6)             | 33 (68.7)                |
| Move to a private care facility               | 7 (22.6)              | 9 (18.8)                 |
| Move to a public care facility                | 2 (6.5)               | 1 (2.1)                  |
| Other   | 2 (6.5)               | 3 (6.3)                  |
| Missing                                       | 0 (0.0)               | 2 (4.2)                  |
| <b>Choice made about the location of care</b> |                       |                          |
| Stay at home                                  | 10 (32.2)             | 17 (35.4)                |
| Move to a private care facility               | 18 (58.1)             | 12 (25.0)                |
| Move to a public care facility                | 1 (3.2)               | 16 (33.3)                |
| Other   | 2 (6.5)               | 2 (4.2)                  |
| Missing                                       | 0 (0.0)               | 1 (2.1)                  |

| Characteristics of the decision making process n (%)                 | Seniors (n=31)     | Caregivers (n=48)  |
|--|--------------------|--------------------|
| <b>Assumed role in the decision-making</b>                           |                    |                    |
| I made the decision  | 19 (61.3)          | 9 (18.8)           |
| I made the decision after considering my providers' opinions         | 7 (22.6)           | 18 (37.5)          |
| My providers and I shared the responsibility for the decision making | 3 (9.7)            | 7 (14.6)           |
| My providers made the decision after considering my opinion          | 2 (6.5)            | 14 (29.2)          |
| My providers made the decision                                       | 0 (0.0)            | 0 (0.0)            |
| <b>Decisional conflict</b>   |                    |                    |
| DCS, mean (SD)   | 24.7 (20.1)        | 31.7 (23.7)        |
| DCS <25  | 17 (54.8)          | 18 (37.5)          |
| DCS ≥25  | 14 (45.2)          | 26 (54.2)          |
| Missing  | 0 (0.0)            | 4 (8.3)            |
| <b>Decisional regret, mean (SD)</b>                                  | <b>19.2 (22.7)</b> | <b>15.2 (19.0)</b> |

# Intervention

## Elders/caregivers

## Providers

- Decision guide (DG):  
“To get the care and services I need, should I stay in my home or move?”

- SDM online tutorial (1h30)
- Workshop (3h30):
  - IP-SDM approach
    - ✓ Observation grid (video)
    - ✓ Video
    - ✓ IP-SDM model
  - Decision guide
    - ✓ Presentation page by page
  - Role play
    - ✓ Decision guide use and the IP-SDM model

Materiel available in both French and English

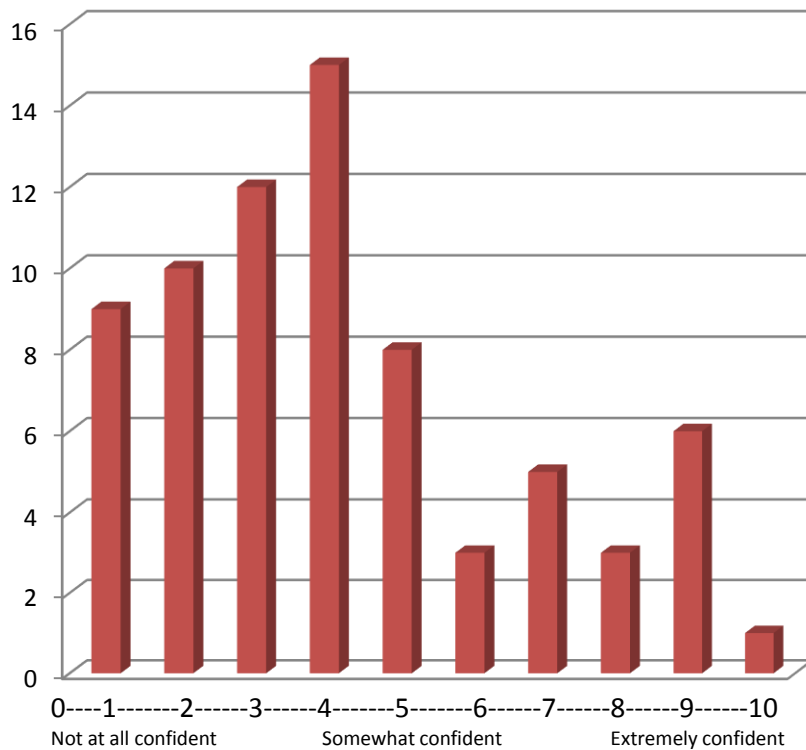


# What has the home care team told us so far?

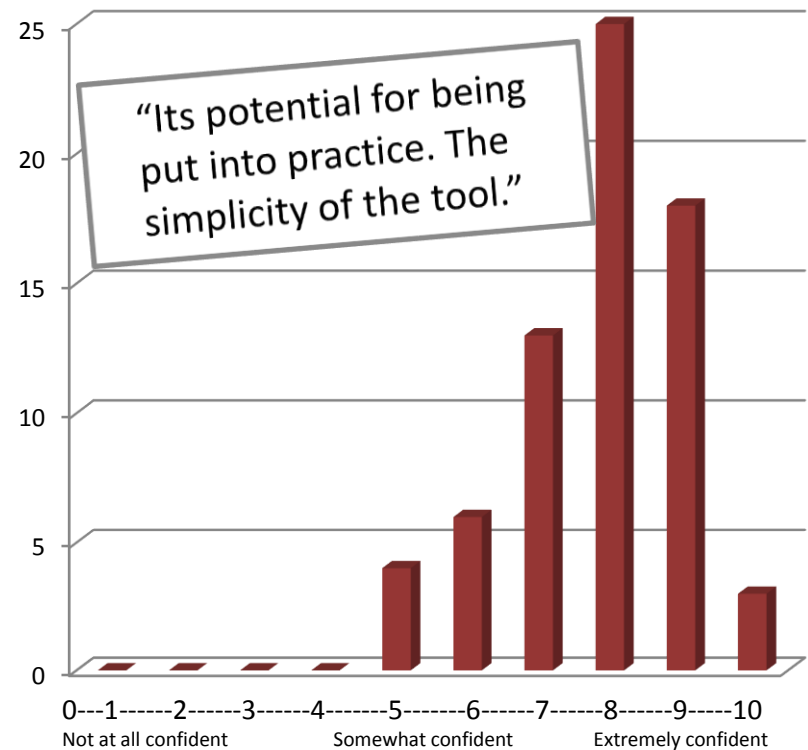


# Confidence in using the decision aid

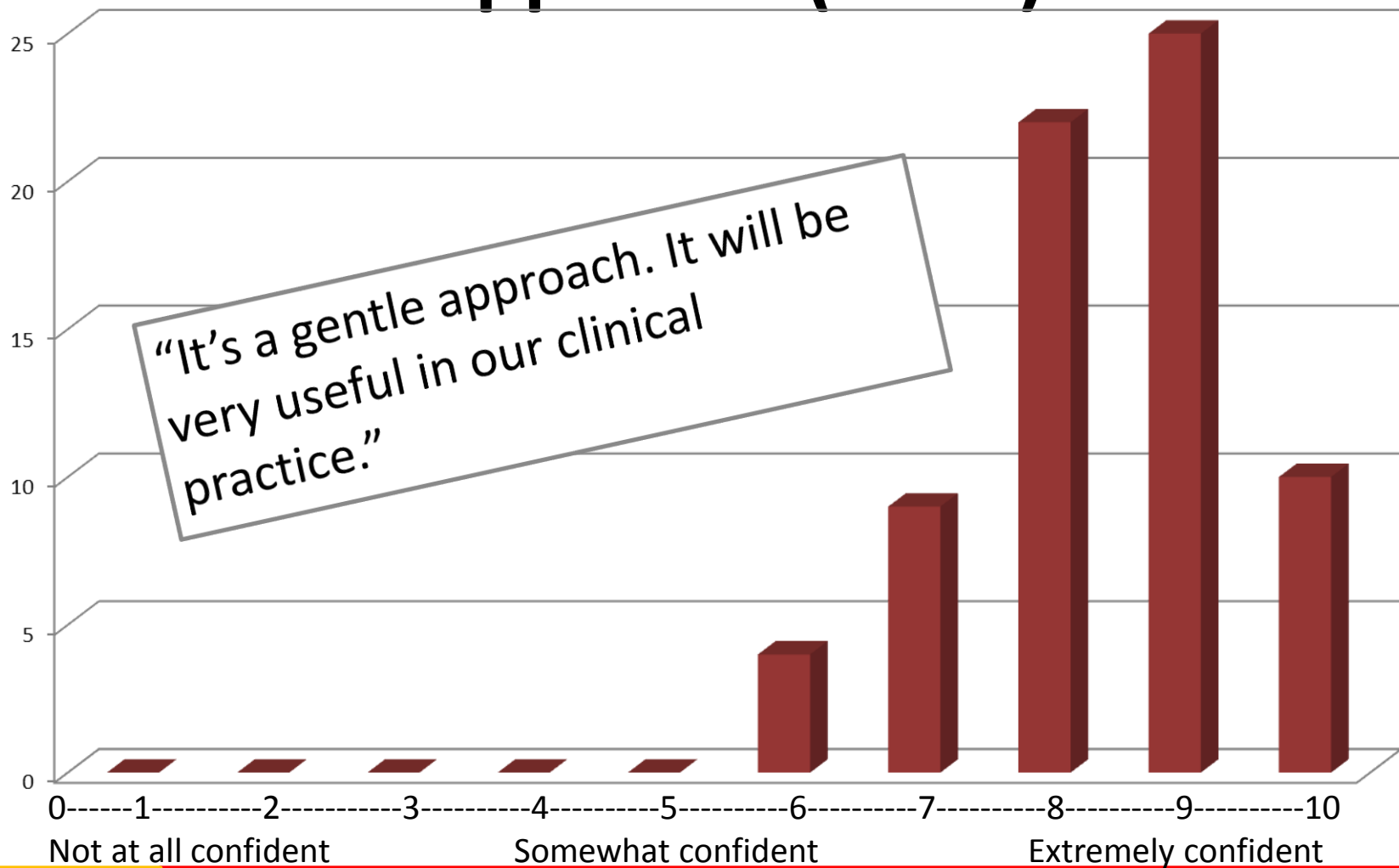
Before the training (n=72)



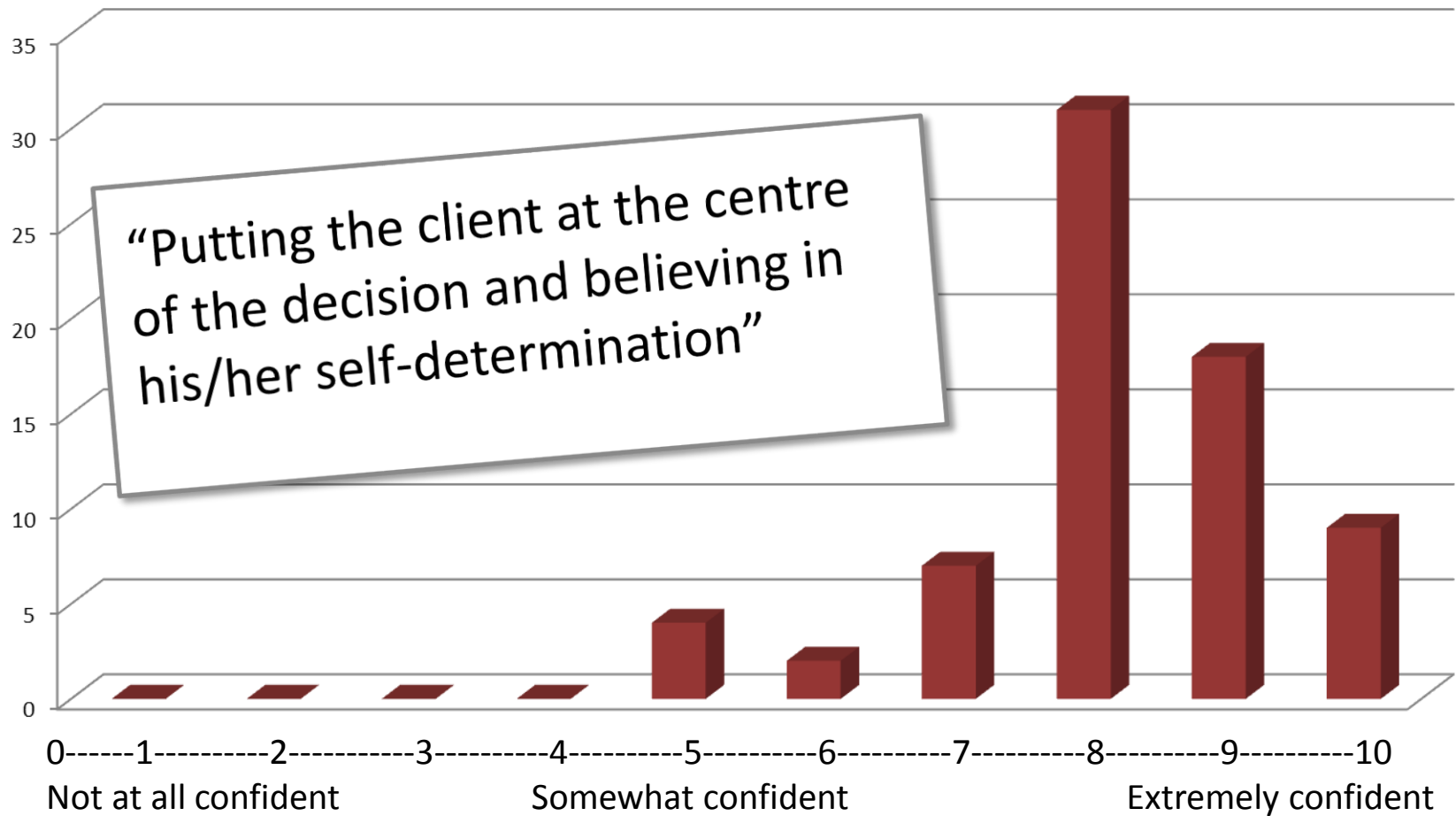
After the training (n=98)



# Confidence in adopting the IP-PDP approach (n=98)



# Confidence that this will support the elderly and their caregivers in engaging in the decision-making process (n=98)



# What we have learned so far...

- We aimed to work with stakeholders to develop a decision aid
  - Based on the responses we obtained, we developed a decision guide
- We aimed to enroll the elderly and caregivers
  - We enrolled more caregivers
- We relied on an on-site research assistant
  - Managers play a crucial role
- We planned to offer the training to a certain number of home care workers per site
  - Some sites asked us to train more workers

