

# Shared decision making in mild to moderate dementia.

<https://neurodegenerationresearch.eu/survey/shared-decision-making-in-mild-to-moderate-dementia/>

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### Country

United Kingdom

## Title of project or programme

Shared decision making in mild to moderate dementia.

## Source of funding information

NIHR (RfPB Competition 17 - London)

## Total sum awarded (Euro)

€ 342,475

## Start date of award

01/04/2014

## Total duration of award in years

3.0

## The project/programme is most relevant to:

Alzheimer's disease & other dementias

## Keywords

### Research Abstract

Shared decision making has been shown to improve therapeutic alliance, treatment adherence, self-care and overall treatment outcomes<sup>1</sup>. However, in a condition such as dementia, which affects judgment and rational thinking, the involvement of a patient in making decisions may become increasingly difficult. Nonetheless, there is evidence that patients in the early stages of dementia prefer to participate in shared decisions<sup>2</sup>. This is perhaps understandable given that

key life-changing decisions often need to be made. The NICE guidelines for dementia state that patient involvement in decisions should be maximized. In addition, the guidelines make provisions for advance directives and lasting power of attorney covering health decisions. The early stages of dementia thus provide a window of opportunity to put these provisions in place for the future. However, there has been no research into the communication that takes place between professionals, patients and carers when making decisions in clinical practice.

### Aim:

The aim of this project is to provide evidence on how to implement shared decision making in practice in mild to moderate dementia.

### *Research Questions:*

- 1) What are patients' and carers' preferences for, and experiences of, involvement in decision making?
- 2) How does the level of involvement of patients with mild to moderate dementia and their carers in shared decision-making vary depending on the decision?
- 3) What types of clinician communication facilitate shared decision making with patients and carers?

### Plan of Investigation:

*Sample size:* 15 psychiatrists, 75 patients (5 patients from each psychiatrist to limit cluster effects) and 75 carers, will be recruited in Memory Clinics and other outpatient settings across NHS trusts. We will focus on secondary care as this is where decisions on management are frequently made. Patients will have a diagnosis of mild or moderate dementia with a Mini Mental State Examination score of 16 or above or other classification used in the clinical setting.

*Data collection and analysis:* Patient and carer preferences for involvement in decision making will be assessed. Naturally occurring consultations involving the patient, carer and clinician(s) will be video recorded. Patient and carer satisfaction with decision making will be assessed after the consultation. Semi-structured interviews will be held with patients and carers. The interviews will address topics such as patient autonomy, positive and negative experiences of involvement in decisions, capacity to make decisions, obstacles to and facilitators of involvement. Focus groups with health care professionals will explore their experiences including challenges in

involving patients and carers and strategies to overcome these within the constraints of practice.

The consultations will be rated using the OPTION<sup>3</sup> scale to quantify level of shared decision making. They will also be analysed using conversation analysis to identify communicative strategies that facilitate decision-making with patients and carers, particularly when patients and carers may have different preferences and views. The interviews and focus groups will be analysed using thematic analysis to identify high-level categories and subsequently themes. The statistical association between (i) preferences and level of shared decision making and (ii) level of shared decision making and patient and carer satisfaction will be analysed.

Summary of potential benefits to patients and NHS:

This study will benefit 0.75 million people with dementia, their carers and health care professionals in the NHS. Rather than identifying ideals for practice, we will identify evidence on how to involve patients and carers in decision making, within the constraints of busy everyday practice, different types of decisions and balancing different patient and carer preferences. This evidence will be an essential step to develop guidelines for clinical practice to improve patient and carer experiences and outcomes.

**Lay Summary**

**Further information available at:**

**Types:**

Investments > €500k

**Member States:**

United Kingdom

**Diseases:**

Alzheimer's disease & other dementias

**Years:**

2016

**Database Categories:**

N/A

**Database Tags:**

N/A