Using Patient Reported Outcome Measures to Assess Quality of Life in Dementia

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Country

United Kingdom

Title of project or programme

Using Patient Reported Outcome Measures to Assess Quality of Life in Dementia

Source of funding information

NIHR (PRP (03-02-04) PROMs: Dementia Care)

Total sum awarded (Euro)

€ 1,796,971

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01/06/2013

Total duration of award in years

3.5

The project/programme is most relevant to:

Alzheimer's disease & other dementias

Keywords
Research Abstract
Background: There is an increasing challenge to meet the needs of people with dementia. The government is committed to ensuring that auditing the outcome of care takes into account the views of patients and, where relevant, their lay carers. Measuring health-related quality of life (HRQL) of people with dementia is challenging as questionnaires need to be interviewer-administered, lay carers' (proxy) views are often necessary and the HRQL of carers themselves

is also a relevant consideration. Also existing measures are limited in their robustness and scores from proxies' reports cannot be substituted for patients' scores.

Aims in relation to the issue to be addressed: Using DEMQOL and DEMQOL-Proxy we aim to: adapt and improve questionnaire administration, scaling and scoring; map scores from proxy questionnaires onto those from patients so they can be substituted; determine minimally important differences; establish acceptability; evaluate cost effectiveness of collecting PROMs; map DEMQOL-U onto the generic EQ-5D.

The aims of the two evaluation studies are to: determine the effectiveness and cost-utility of memory assessment services (MAS), the association with patient characteristics, and the cost-effectiveness of different types of MAS; and establish the impact of taking patients off anti-psychotic medication on their HRQL and determine the sustainability of such changes.

Research plan and methods of investigation: The initial Development Study (Phase 1) will include sufficient methodological development to enable evaluations of the two policies to proceed (Phase 2 and 3). These will provide the data needed to complete further rigorous methodological testing in Phase 4.

 The evaluation of MAS will employ a single cohort study in which patients and lay carers are assessed on their initial attendance and 6 months later. About 80 services will recruit about 1600 patients. Clinic staff will be trained to administer HRQL questionnaires to patients. Lay carers will complete a proxy version of the questionnaire. Carers will also be asked to self-complete a questionnaire about their own HRQL and care burden. Additional clinical information on patients will be collected by staff. The absolute impact of the service will be determined by modelling different scenarios that might have occurred if the service had not been used: no change and different degrees of deterioration. The latter will be informed by the MRC Cognitive Function and Aging Studies.

 The evaluation of withdrawal of anti-psychotics will also use a single cohort design. Interviewers will administer questionnaires to about 200 patients in 20 residential care homes about their HRQL , just before anti-psychotics are discontinued and 3-6 and 12-15 months later. If a relative visits at least three times in a fortnight, they will be asked to self complete a proxy version of the same questionnaires at the same points in time. For other patients, the questionnaire will be completed by a patient advocate trained by the research team.

 Research team: The project is a collaboration between the LSHTM (health services research), Alzheimer's Society (PPI), LSE (social care and mental health economics) and NHS (old age psychiatry). The applicants have expertise in the five key areas: *clinical* (Craig Ritchie, Clive Ballard*); psychometrics*(Sarah Smith)*; policy and economics of mental health care*: (Martin Knapp);health care evaluation (Nick Black)*; patient and public involvement:* (*S*teve Dewar, Barbara Di Vita).

 Potential impact/influence on the relevant policy field, users and wider stakeholders: Provision of robust methods for the routine assessment of the HRQL of people with dementia and their lay carers will enable health and social care services to be evaluated and audited. In addition it will provide measures for the NHS Outcomes Framework and information for the public and for commissioners about local services.

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

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