Carer and patient-led development of recommendations for people with dementia returning home from hospital: understanding what is important

https://neurodegenerationresearch.eu/survey/carer-and-patient-led-development-of-recommendations-for-people-with-dementia-returning-home-from-hospital-understanding-what-is-important/

Principal Investigators

Dr Carole Mockford

Institution

University Hospitals Coventry and Warwickshire NHS Trust

Contact information of lead PI
Country

United Kingdom

Title of project or programme

Carer and patient-led development of recommendations for people with dementia returning home from hospital: understanding what is important

Source of funding information

NIHR (RfPB Competition 20 - West Midlands)

Total sum awarded (Euro)

€ 302,178

Start date of award

01/04/2014

Total duration of award in years

2.0

The project/programme is most relevant to:

Alzheimer's disease & other dementias

Keywords
Research Abstract

Improving care services for people with dementia and their carers is vital as we know that that increasing longevity means that the numbers of people with dementia in the UK will more than double by 2051. Recent reports strongly suggest that hospital discharge may not be so straightforward for someone with dementia and their carer and have found major gaps in the hospital discharge process including a rush to discharge (RCN 2011), delays in care packages (DH 2010) and ignoring the wishes and ability of the carer to cope (HQIP 2010). This can lead to re-admission to hospital or costly premature, and often permanent, admission to a care home (DH 2010). There is very little evidence documenting carer and patient perspectives of health and social care services during and after hospital discharge (Glasby et al 2004) and a paucity of evidence showing good outcomes (ADASS 2010).

Using the experiences of health and social care professionals, and informal carers and patients with dementia, this study asks what is working well for informal carers and patients with dementia after hospital discharge and what needs improving to enable a smooth and appropriately supported transition to care at home.

Aims of the project:

1. To develop carer and patient-led recommendations for services to enable smooth transition for people with dementia from hospital care to home care.
2. To explore the experiences of carers and people with dementia of service provision from hospital discharge, at 6 weeks (when free intermediate care stops), and 12 weeks post-discharge, what works well and what can be improved.
3. To assess the enablers and barriers to providing good discharge planning by health and social care professionals, including the availability and uptake of services.
4. To ascertain the involvement of carers and people with dementia in decision-making around service provision at and after hospital discharge.

Up to 30 carers and patients will keep diaries of their experiences as and when they are able to during the study, they will be interviewed at hospital discharge, 6 weeks (when free intermediate care ceases) and 12 weeks post discharge about their experiences of service provision. Health and social care staff from two NHS trusts involved in hospital discharge planning will be interviewed once. A carer and patient focus group will be convened to discuss the findings from the data and recommendations will be developed and later discussed with health and social care staff for feedback, as an iterative process. Carers, as co-researchers, will conduct the interviews with the support of the lead researcher, assist with analysis and final dissemination of the findings and recommendations e.g to staff involved in hospital discharge planning. A project advisory team consisting of service users, health and social care professionals and academics will oversee the project with a view to reviewing progress and achievement of milestones.

Potential benefits to patients and the NHS include:

i. Improving person-centred care and individualised services

ii. Improving patient and carer experiences of hospital to home care

iii. Improving carer experience, which may delay or prevent early entry to long term care of the person with dementia, which will reduce costs to the NHS

iv. Informing the training for those involved in hospital discharge planning for people with dementia and their carers

v. Informing the NHS what is important to families at a vulnerable time from their own perspective particularly the availability and uptake of services by families, what works well and what could be improved

vi. Informing the NHS of the experiences of health and social care services when trying to provide a seamless service and the perceived enablers and barriers at hospital discharge.

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