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Evaluating the effectiveness and cost effectiveness of Dementia Care Mapping (DCM) to enable person-centred care for people with dementia and their carers

Submission date
16/01/2014

Recruitment status
No longer recruiting

Registration date
16/01/2014

Overall study status
Completed

Last Edited
02/09/2020

Condition category
Mental and Behavioural Disorders

[X] Prospectively registered
[X] Protocol
[_] Statistical analysis plan
[X] Results
[_] Individual participant data

Plain English summary of protocol

Background and study aims
At least two-thirds of people living in care homes have dementia and many become agitated or show other behaviours staff find challenging. These behaviours are often linked to poor quality care and people with these behaviours are more likely to be admitted to hospital and are often prescribed anti-psychotic drugs, which can cause harmful side effects. The UK government has prioritised research into better support for care home staff to help them deliver better care and to reduce the use of drugs. Research shows that care can be improved by tailoring each person's care to the individual, taking into account their interests, likes and life history. This is known as Person-Centred Care. Training staff in the principles of person-centred care provides them with the skills they need to prevent and support distressing behaviours. However, without extra support for staff to build on their training, these benefits soon disappear. Dementia Care Mapping (DCM) is a technique already widely used in the National Health Service (NHS) and in care homes to help staff to apply their person-centred care training to their caring role. Dementia Care Mapping involves observing the experience of care from the point of view of people with dementia and then feeding this back to staff, who use this information to look at ways they can improve care. This process is carried out every four to six months so changes can be monitored and new improvements identified. To date only one Australian study has been conducted on how effective Dementia Care Mapping is in care homes, and how it provides value for money. This study will build on the Australian study to show whether Dementia Care Mapping is effective and good value for money in care homes in the UK.

Who can participate?
People with dementia, their relatives, and care staff in 50 care homes.

What does the study involve?
Participating care homes are randomly allocated to one of two groups. Care homes in one group provide the usual care. Care homes in the other group provide the usual care and train staff to use Dementia Care Mapping. We measure the changes in residents' behaviour, resident quality

of life, the drugs residents are prescribed, the number of NHS services needed for residents, changes in the numbers and types of negative events (for example admission to hospital, falls), how staff feel about their job and the quality of their communication with residents. We look at these things at the start of the study, after 6 months and after 16 months. The study also measures how staff feel about their job and the number of staff resignations and sickness.

What are the possible benefits and risks of participating?
This study could improve care for people living in care homes in the future, but we cannot say that participants will definitely experience an improvement. The same would be true if you were not part of the study. Participants will be taking part in an important research study that could improve care for people living in care homes. We do not expect there will be any risks in taking part.

Where is the study run from?
University of Leeds (UK)

When is the study starting and how long is it expected to run for?
Care home recruitment: June 2014 to December 2015
Participant recruitment and follow-up: July 2014 to May 2017
Trial results: January 2018

Who is funding the study?
Health Technology Assessment Programme (UK)

Who is the main contact?
Amanda Lilley-Kelly
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Contact information

Type(s)
Scientific

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Additional identifiers

Protocol serial number
HTA 11/15/13

Study information

Scientific Title
Evaluating the effectiveness and cost effectiveness of Dementia Care Mapping (DCM) to enable person-centred care for people with dementia and their carers: a cluster randomised controlled trial in care homes (DCM EPIC trial)

Acronym
The DCM EPIC study 1.0

Study objectives
To evaluate the clinical and cost-effectiveness of Dementia Care Mapping (DCM) in addition to Usual Care (UC) versus UC alone for people with dementia living in care homes in England.

More details can be found at: http://www.nets.nihr.ac.uk/projects/hta/111513
Protocol can be found at: http://www.nets.nihr.ac.uk/__data/assets/pdf_file/0008/113948/PRO-11-15-13.pdf

CTRU – http://medhealth.leeds.ac.uk/info/415/older_people/1750/dcm_epic
Bradford – http://www.bradford.ac.uk/health/dementia/research/epic/

Ethics approval required
Old ethics approval format

Ethics approval(s)
Yorkshire & The Humber – Bradford Leeds Research Ethics Committee, 14/02/2013, ref: 13/YH/0016

Study design
Randomised; Interventional; Design type: Process of Care

Primary study design
Interventional

Study type(s)
Treatment

Health condition(s) or problem(s) studied
Topic: Dementias and Neurodegenerative Diseases Research Network; Subtopic: Dementia; Disease: Dementia

Interventions
Dementia Care Mapping, This is a cluster randomised trial and randomisation will be at the care-home level. Care homes will be randomised to Usual Care, or Usual Care plus Dementia Care Mapping.

Dementia Care Mapping (Intervention Arm Only)
Dementia Care Mapping (DCM) is an observational tool designed to assess quality of care in

formal dementia care settings. It is grounded in the philosophy of person centred care and was designed to be used in a series of developmental evaluations over time. Through a process of; Follow Up Length: 16 month(s); Study Entry : Registration only

Intervention Type
Other

Phase
Phase III

Primary outcome(s)
Cohen Mansfield Agitation Inventory (CMAI); Timepoint(s): Baseline, 6 and 16 months

Key secondary outcome(s))
1. DEMQoL Proxy; Timepoint(s): Baseline, 6 and 16 months
2. EuroQol Group (EQ-5D); Timepoint(s): Baseline, 6 and 16 months
3. Neuropsychiatric Inventory (NPI-NH); Timepoint(s): To investigate if the intervention is effective in reducing Behaviours Staff find Challenging
4. Pittsburgh Agitation Scale; Timepoint(s): Baseline, 6 and 16 months

Completion date
01/12/2017

Eligibility

Key inclusion criteria
Current inclusion criteria as of 30/06/2016:
Care homes:
1. Have a minimum of 24 permanent residents
2. Have 60%+ permanent residents with dementia based on a formal diagnosis or Functional Assessment Staging of Alzheimers Disease (FAST) (score of 4+) rated with the home manager or another experienced member of staff
3. Have a manager or nominated person agreeing to sign up to the trial protocol as research lead for the duration of the project, based on appropriate discussions and permissions
4. Agree to release staff for DCM training and subsequent mapping processes
5. Be within catchment area

Residents will be recruited at baseline (pre-randomisation) and 16 months post randomisation, as part of the open cohort design.
Residents meeting all of the following criteria at screening will be eligible for this trial:
1. Be a permanent resident within the care home defined as a person residing in the care home and not present for receipt of for respite or 5-day- care
2. Have a formal diagnosis of dementia or score 4+ on the Functional Assessment Staging of Alzheimer’s Disease (FAST) [87] rated with the home manager or another experienced member of staff
3. Be appropriately consented (in accordance with Mental Capacity Act and clinical trials guidance on informed consent)
4. Have an allocated member of staff willing to provide proxy data.
5. Have sufficient proficiency in English to contribute to the data collection required for the research.

Note that residents will NOT be excluded if they lack capacity to consent. Guidance on consent where persons lack capacity will be followed for residents assessed to lack capacity.

Staff meeting both of the following criteria will be eligible to provide data on the staff measures for this trial:
1. Be a permanent, contracted, agency or bank member of staff at data collection
2. Have sufficient proficiency in English to contribute to data collection required for the research.

To be eligible to provide proxy data (i.e, Quality of Life) on a resident, carers must meet both of the following criteria:
1. Visit the care home on a regular basis over the past month (i.e. usually at least once per fortnight) and be available during the week of data collection
2. Be appropriately consented

To be eligible to provide proxy data on a resident, staff must meet all of the following criteria:
1. Be a permanent or contracted member of staff
2. Know the resident well, as assessed by their key worker status and/or the judgement of the home manager
3. Indicate their willingness to providing data for the study by returning the Staff Screening Questionnaire (SSQ)

To be eligible to be a mapper on the trial staff must meet all of the following criteria
1. Be a permanent or contracted member of staff
2. Be appropriately consented

Previous inclusion criteria:
Care homes:
1. Have a minimum of 24 permanent residents
2. Have 60%+ permanent residents with dementia based on a formal diagnosis or Functional Assessment Staging of Alzheimers Disease (FAST) (score of 4+) rated with the home manager or another experienced member of staff
3. Have a manager or nominated person agreeing to sign up to the trial protocol as research lead for the duration of the project, based on appropriate discussions and permissions
4. Agree to release staff for DCM training and subsequent mapping processes
5. Be within catchment area

Residents meeting all of the following criteria at screening will be eligible for this trial:
1. Be a permanent resident within the care home defined as a person residing in the care home and not present for receipt of for respite or 5-day- care
2. Have a formal diagnosis of dementia or score 4+ on the Functional Assessment Staging of Alzheimers Disease (FAST) [87] rated with the home manager or another experienced member of staff
3. Be appropriately consented (in accordance with Mental Capacity Act and clinical trials guidance on informed consent)

Note that residents will NOT be excluded if they lack capacity to consent. Guidance on consent where persons lack capacity will be followed for residents assessed to lack capacity.

Staff meeting both of the following criteria will be eligible to provide data on the staff measures for this trial:

1. Be a permanent, contracted, agency or bank member of staff at data collection
2. Provide consent to providing data for the trial through returning the Staff Screening Questionnaire (SSQ)

To be eligible to provide proxy data (i.e, Quality of Life) on a resident, carers must meet both of the following criteria:
1. Visit the care home on a regular basis over the past month (i.e. usually at least once per fortnight) and be available during the week of data collection
2. Be appropriately consented

To be eligible to provide proxy data on a resident, staff must meet all of the following criteria:
1. Be a permanent or contracted member of staff
2. Know the resident well, as assessed by their key worker status and/or the judgement of the home manager
3. Indicate their willingness to providing data for the study by returning the Staff Screening Questionnaire (SSQ)

To be eligible to be a mapper on the trial staff must meet all of the following criteria
1. Be a permanent or contracted member of staff
2. Be appropriately consented

Healthy volunteers allowed
No

Age group
Adult

Sex
All

Total final enrolment
726

Key exclusion criteria
Care homes meeting any of the following criteria will not be eligible for this trial:
1. Be, in the view of the researchers, not suitable for inclusion due to being subject to CQC enforcement notices, admission bans or relevant moderate or major CQC compliance breaches
2. Receive other special support for specific quality concerns; such as be currently subject to or have pending, serious safeguarding issues/investigations; receiving other voluntary or compulsory admissions bans; be in receipt of local commissioning special support special support for due to quality concerns
3. Have used DCM as a practice development tool within the last 18 months prior to randomisation
4. Be taking part, have recently taken part in, or be planning to take part, in another trial that conflicts with DCM or with the data collection during the course of their involvement in DCM-EPIC

Residents meeting any of the following criteria will not be eligible for this trial:
1. Be terminally ill i.e. formally admitted to an end of life care pathway or permanently bed-bound due to late stage dementia and unable/with limited ability to clearly to communicate distress

Staff meeting any of the following criteria will not be eligible to provide data on staff measures for this trial:
1. Be acting as a personal nominee for any resident participant in the trial

Staff meeting any of the following criteria will not be eligible to provide proxy data on a resident for this trial:
1. Be acting as a personal nominee for any resident participant in the trial
2. Be a trained Dementia Care Mapper and be using DCM for the purposes of this trial

Staff meeting any of the following criteria will not be eligible to be a mapper on the trial
1. Be acting as a personal nominee for any resident participant in the trial

Date of first enrolment
01/09/2014

Date of final enrolment
01/04/2017

Locations

Countries of recruitment
United Kingdom

England

Study participating centre
University of Leeds
Leeds
United Kingdom
LS2 9JT

Sponsor information

Organisation
Leeds Beckett University (UK)

ROR
https://ror.org/02xsh5r57

Funder(s)

Funder type
Government

Funder Name
Health Technology Assessment Programme; Grant Codes: 11/15/13

Alternative Name(s)
NIHR Health Technology Assessment Programme, Health Technology Assessment (HTA), HTA

Funding Body Type
Government organisation

Funding Body Subtype
National government

Location
United Kingdom

Results and Publications

Individual participant data (IPD) sharing plan

IPD sharing plan summary

Study outputs

Output type	Details	Date created	Date added	Peer reviewed?	Patient-facing?
Results article	results	01/04/2020	11/11/2019	Yes	No
Results article	results	01/03/2020	30/03/2020	Yes	No
Results article	results	25/08/2020	02/09/2020	Yes	No
Protocol article	protocol	24/06/2016		Yes	No
HRA research summary			28/06/2023	No	No
Other publications	process evaluation	08/02/2019	29/01/2020	Yes	No
Participant information sheet	Participant information sheet	11/11/2025	11/11/2025	No	Yes
Study website	Study website	11/11/2025	11/11/2025	No	Yes