Plain language protocol summary 16 March 2018

Improving the experience of care for people with dementia in hospital: Systematic review of qualitative and quantitative evidence

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Protocol Amendments:

25 April 2018 – Plain Language Protocol Summary added as Appendix 1.

Background

'Description of the condition'

The importance of the care of people with dementia in hospitals is reflected in recent government policy and initiatives around the UK [1-7] . Around 40 per cent of patients over the age of 75 who are admitted to general hospitals have dementia, with only half having a prior diagnosis [8]. Those admitted to hospital with dementia experience longer stays, greater mortality and increased risk of institutionalisation post discharge [9]. An Alzheimer's Society report based on Freedom of Information request responses from 73 trusts showed that in 2015 the average length of stay for someone over 65 in an acute hospital was 5.5 days, whereas for people with dementia it was 11.8 days [10]. Hospital services are intrinsically geared towards fast and effective responses, assessment, diagnosis, intervention and discharge. Services run on the assumption that patients will be able to express their wishes, acknowledge the needs of other patients and move through the system as required. However, for people with dementia, particularly when they are ill or have had an accident, hospital settings can be confusing, challenging and overwhelming, which can further impact their well-being and the ability to optimise their care. Furthermore, what happens in hospitals can have a profound and permanent effect on individuals and their families, not only in terms of their inpatient experience, but also their ongoing health and the decisions that are made about their future [11]. In 2011, the RCN published five principles for improving dementia care in hospital settings. These covered: staff, partnership, assessment, individualised care and environments. The principles have helped take forward a key objective of the national dementia strategy, to improve hospital care for people with dementia. Whilst these principles have been detailed and set out as a resource for those involved in care, providing effective acute care services to adults with dementia remains an important challenge [12].

'Description of the intervention'

Trying to improve the care of people with dementia while they are in hospital is an ongoing challenge for health providers and there is uncertainty about the best way to do this. Our scoping of the literature suggests that there are many potential interventions or approaches that could be important in improving the experience of being in hospital for people with dementia. For example, enhanced training and integration of specialist mental health staff has been shown to improve best practice and carer experience in the acute hospital setting [13]. Similarly, introduction of a dementia activities coordinator in an acute hospital ward has been shown to improve the experience for both the person with dementia and their families [14]. There are also initiatives that have received widespread attention such as the Alzheimer's Society's 'This is Me' tool (https://www.alzheimers.org.uk/thisisme - a simple leaflet that can help people health care professionals build a better understanding of a person with dementia when they move to a new care setting) and John's Campaign (http://www.johnscampaign.org.uk/ - a campaign to give carers the right to stay with people with dementia in hospital).

'How the intervention might work'

The complex range of factors that may impact on the experience of dementia care in hospitals has been a focus for discussion throughout the development of this application in consultations with individuals with dementia and their families/carers, healthcare professionals based both in hospitals and in the community and with the voluntary sector. Scoping of the literature identified a number of models and frameworks of dementia care [15-18]. To aid discussion we used two key models [17, 18] as a starting point to iteratively develop a comprehensive conceptual framework which attempts to describe the nature and complexity of factors which may influence the experience of hospital care for someone with dementia.

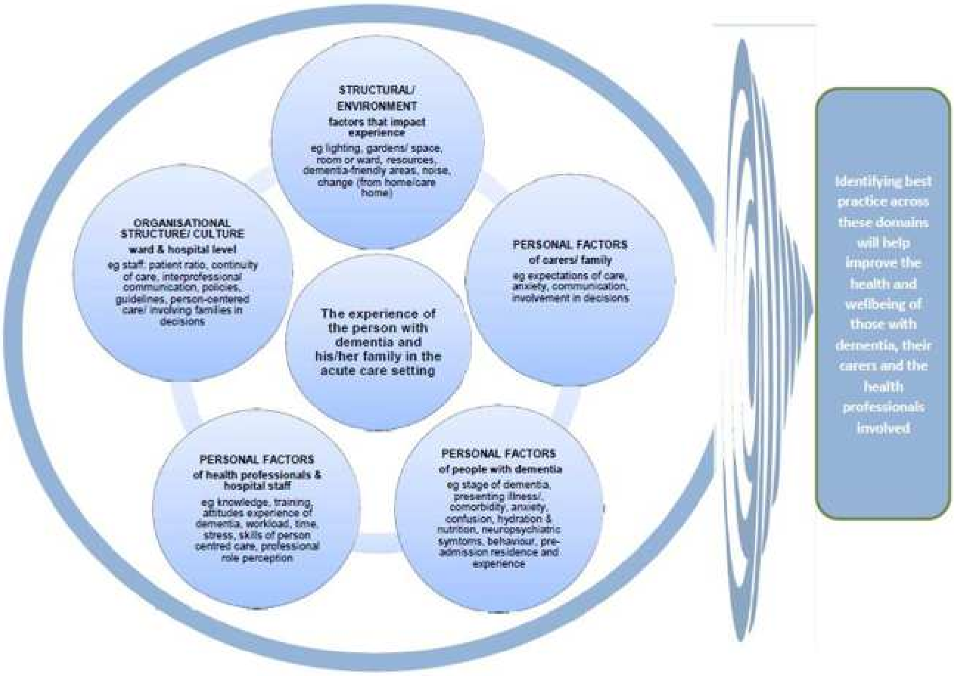

Figure 1: Conceptual framework to describe the nature and complexity of factors which may influence the experience of hospital care for someone with dementia

Our framework shows that a range of factors may play a role, relating to i) the person with dementia and his/her family (e.g., stage of dementia, expectations of care, presence of delirium, carer stress); ii) the healthcare professionals involved (knowledge about dementia, pressures on time, perceptions of professional role and responsibilities); iii) organisational factors at ward (type of ward, emphasis on person-centred care) or hospital level (staff turnover, leadership, local policies) and iv) the environment (lighting, resources).

'Why it is important to do this review'

We believe that this topic is relevant and topical for the following reasons:

1. Improving the experience of care for people in the hospital setting with dementia is among the Alzheimer's Society's top priorities for dementia research, and improving the understanding of the best way to do this was the fifth highest priority in the recent James Lind Alliance Priority Setting Partnership with the Alzheimer's Society [19].

2. Improving the experience of hospital care was the most significant issue for carers of people with dementia in a recent focus group we held with Alzheimer Society Research Network members.

3. Discussions with local healthcare providers have highlighted this issue as a priority and this is demonstrated by the size of our team and the range of clinical expertise and experience of those who are keen to be involved both as co-applicants and as collaborators.

In order to improve the experience of hospital care, it is necessary to understand the issues faced by those with dementia and their carers in this complex setting, to identify effective best practices in this area and establish what the critical factors are which promote or hinder best practice. The proposed work would benefit current hospital care practice, resulting in better care for those with dementia and support for those involved in their care, as well as highlighting areas in which we have limited understanding of how to achieve best practice. This project will constitute the first comprehensive set of systematic reviews to fully focus on the experience of persons with hospital care for people with dementia.

While the evidence for the effectiveness of some of the potentially relevant interventions has been researched and reviewed, some of the reviews do not focus solely on the hospital setting [20, 21] and others have not used robust systematic methods [22, 23]. We are aware of a review protocol [24] registered in 2015 that aims to summarise the evidence for the non-pharmacological care and management of older people with cognitive impairment in general hospitals but have been unable to identify any publications arising from it. Our systematic review will enable us to collate all the relevant evidence on all potentially useful initiatives, those that have received attention and those that are less well known. We will also be bringing together the views and perceptions of the experience of care from people both giving and receiving that care and the evidence on the effectiveness and cost-effectiveness of interventions to improve the experience of care within a logic model and nesting the evidence within the real-world experience of individuals currently working in the hospital setting. By doing this, we will be able to compare evidence for different approaches in different contexts, to highlight gaps in the evidence and to identify factors that may influence the effectiveness and implementation of interventions. All of this information, will enable us to co-produce plans that can facilitate effective practice change.

Expert Advisory Group

To identify the focus of this project, we held a focus group comprised of individuals with lived experience of caring for people with dementia and discussed a variety of potential research ideas. The topic of improving the experience of care for people with dementia in the acute hospital setting was something that the group felt passionately about. Two individuals from the group, Sue Lawrence and Julia Burton (members of the Alzheimer's Society Research Network) agreed to be part of our Expert Advisory Group and have provided feedback on the development of the protocol.

Sue Lawrence and Julia Burton will be joined in the Expert Advisory Group by people with experiences of providing and commissioning care to those with dementia, either in the hospital setting or in transition from other settings. These people are: Di Walker, (Assistant Director of Nursing (Community) for the Northern Devon Healthcare NHS Trust), Tina Naldrett (Director of Patient Services, HospiceCare), Jenny Richards (Joint Commissioning Manager for the Partnerships Directorate of Northern, Eastern & Western Devon Clinical Commissioning Group & Social Care Commissioning for Devon County Council), Martyn Rogers (Director of AgeUK, Exeter), George Coxon (care home owner), Sarah Black (South West Ambulance Service NHS Foundation Trust) and Jo Gajtkowska (South West Academic Health Sciences Network).

The Expert Advisory Group will be involved in all stages of the project. Involvement will include a) refining research questions, b) developing and refining the search strategy, c) finalising search terms/sources, d) clarifying the definition of interventions/approaches to care, e) examining the results of included papers, f) considering the emerging findings and discussing implications for the overarching synthesis, g) drafting plain English summaries and h) reviewing drafts of manuscripts & the final report.

We aim to meet on four occasions; between meetings we will maintain contact via email/telephone conference call.

Objectives

1. To bring together studies which have explored the experience of care for people with dementia in hospital from the perspectives of the people giving and receiving care.

2. To determine the key characteristics, components and processes that should be included when caring for people with dementia in hospital.
3. Where adequate data are available, to determine the effectiveness of interventions aiming to improve the experience of care of people with dementia, their families and hospital staff.
4. To convene a series of consensus meetings with people with dementia, their families and friends, representatives from acute and community hospitals, commissioners of services, ambulance trusts, the voluntary sector and care homes to discuss what the findings mean for clinical practice and service provision leading to the co-production of plans for service change.

Research Questions

1. What is the experience of people with dementia and their families of receiving care in a hospital setting?
2. What is the experience of hospital staff of caring for people with dementia?
3. What evidence is available to inform on the most effective and cost-effective ways to improve the experience of care for people with dementia in hospital?
4. What is the impact of such interventions on the health and wellbeing of the hospital staff and the families and informal carers of those with dementia?
5. Which factors are important in the successful delivery of approaches to improve the experience of care?

Methods

We will conduct two qualitative evidence syntheses to address Research Questions 1, 2 and 5. The review approaches below are structured using the SPIDER tool [25].

The first synthesis will address Research Question 1 and Research Question 2:

> *Research Question 1: What is the experience of people with dementia and their families / carers of receiving care in hospital?*
>
> *Research Question 2: What is the experience of hospital staff caring for people with dementia?*

Evidence from this review may also contribute to understanding Research Question 5:

> *Research Question 5: Which factors are important in the successful delivery of approaches to improve the experience of care?*

Through understanding the experiences and perceptions of people with dementia and their families/carers receiving care in hospital and those of the hospital staff providing the care, we will develop an understanding of the challenges for service provision for this group.

The second, will address Research Question 5.

> *Research Question 5: Which factors are important in the successful delivery of approaches to improve the experience of care?*

Through understanding how existing interventions are perceived and experienced, we will develop an understanding of the factors that may help or hinder success of such interventions.

We will also conduct a quantitative evidence synthesis to address Research Question 3 and Research Question 4. Approaches below are structured around the PICO format.

Research Question 3: What evidence is available to inform on the most effective and cost-effective ways to improve the experience of care for people with dementia in hospital?

Research Question 4: What is the impact of such interventions on the health and wellbeing of the hospital staff and the families and informal carers of those with dementia?

Eligibility Criteria

Inclusion Criteria – Qualitative Studies

Sample: For the first synthesis we will seek research with:

i) People with dementia,

ii) Their families and carers and,

iii) Hospital staff providing care.

Phenomenon of Interest: Experiences and perceptions of providing and receiving care in hospital.

Design: Any recognised method of qualitative data collection, including interviews, focus groups and observational techniques. This may be stand-alone qualitative research, or reported as part of a mixed methods intervention evaluation. We will include process and outcome evaluations.

Evaluation: i) Attitudes, experiences, perceptions and understanding of people with dementia.

ii) Attitudes, experiences, perceptions and understanding of the families and carers of people with dementia.

iii) Attitudes, experiences, perceptions and understandings of hospital staff who have provided care to people with dementia and who have supported families and carers.

Research type: Qualitative research which focuses on the experience of care in hospital for people with dementia, their families and carers and the hospital staff providing the care.

For the second synthesis we will seek research with:

Sample:

i) People with dementia,

ii) Their families and carers and,

iii) Hospital staff providing care.

Phenomenon of Interest: Experiences and perceptions of providing and receiving interventions to improve the experience of care in hospital.

Design: Any recognised method of qualitative data collection, including interviews, focus groups and observational techniques. This may be stand-alone qualitative research, or reported as part of a mixed methods intervention evaluation. We will include process and outcome evaluations.

Evaluation: i) Attitudes, experiences, perceptions and understanding of people with dementia who have experienced interventions to improve the experience of care in hospital.

ii) Attitudes, experiences, perceptions and understanding of the families and carers of people with dementia who have experienced interventions to improve the experience of care in hospital.

iii) Attitudes, experiences, perceptions and understandings of hospital staff who have delivered interventions to improve the experience of care for people with dementia and their families and carers.

Research type: Qualitative research and process evaluations related to specific interventions aimed at improving the experience of care for people with dementia and their families/carers in hospital. We will carefully seek to identify qualitative research which is associated with the programmes included in the effectiveness review, through targeted searches for 'sibling' studies though will not be confined to these.

Language and date restrictions: No date restrictions will be applied. Translation of non-English language qualitative papers is complex due to the risk of misinterpreting information on attitudes and experiences, therefore only papers published in English will be included.

Location: Only studies from OECD countries will be included. Consideration will be given to the degree of transferability of findings from non-UK settings to the NHS context.

Inclusion Criteria – Quantitative Studies

Population: People with dementia, their families and carers and hospital staff providing care, considering a NHS and social care perspective alongside a wider societal perspective.

Intervention: Any intervention, delivered to people with dementia and/or their families and carers which aims to improve the experience of care in hospital.

Interventions delivered to hospital staff will be included if they report outcomes relating to the experience of care for people with dementia and/or their families and carers.

Comparators: Any control or comparator.

Outcomes: Any outcome describing the experience of or outcome of care.

Economic outcomes will be collected from any study (whether ostensibly an effectiveness study/RCT, an observational study, a cost/outcome analysis or an economic evaluation) that reports on the costs or resource implications or related consequences/benefits for the included interventions and comparators. For example, changes in informal care, frequency of service use or numbers of referrals will be included as economic outcomes, and better support an integrated assessment of effectiveness and cost-effectiveness.

To help to inform Research Question 3 we will include data from process evaluations conducted alongside included RCTs.

Study design: As this review aims to establish whether interventions are effective or not, we will aim to include randomised controlled trials where available. However, our scoping suggests that evidence from randomised controlled trials may not be available for all the relevant interventions we have identified. We will therefore include all quantitative study designs reporting comparative data prioritising evidence from more robust study designs in the synthesis where possible.

For the assessment of cost effectiveness, we will include economic analyses and comparative cost studies of interventions meeting the inclusion criteria.

Language: No language restrictions will be applied.

Date: No date restrictions will be applied.

Setting/location: Any hospital setting, including the process of transition into and out of hospital. No restriction but consideration will be given to the degree of transferability of findings from non-UK settings to the NHS context.

Identification of the evidence

The search methods will include extensive database searching and supplementary searching including forwards and backwards citation chasing, hand-searching of any key journals identified during the search process and additional searching on topic specific websites (if applicable). There will be a particular focus on grey literature to reflect the potential for unpublished reports and documents describing relevant interventions.

Database Searches: A search strategy will be developed by an information specialist (MR) in collaboration with the co-applicants and Project Advisory Group to ensure that all relevant key terms are covered. The strategy will be extensively tested in our suggested portfolio of resources. The strategy will use both controlled headings (e.g. MeSH) and free-text searching. Terms will be grouped according to three concepts:

- dementia terms (e.g. dementia, Alzheimer's, cognitive impairment)
- setting terms (e.g. hospital, acute care, ward)
- outcome terms (e.g. experience, "quality of care", patient centred, comfort, dignity, satisfaction, dissatisfaction)

We will not use study design terms in the search, allowing us to perform one search across the databases that will retrieve both quantitative and qualitative research.

We have carried out extensive scoping to establish the volume and nature of this literature. We anticipate a screening load of around 10,000 records in total with an approximate 80/20 split between qualitative and quantitative research. The scoping study also informs our focus on supplementary searches to identify grey literature.

Based on our scoping searches, we propose to search the following databases:

- MEDLINE including MEDLINE in-process (via OvidSp)
- EMBASE (via OvidSp)
- PsycINFO (via OvidSp)
- Cochrane Database of Systematic Reviews (via the Cochrane Library)
- CENTRAL (via the Cochrane Library)
- DARE (via the Cochrane Library)
- HTA database (via the Cochrane Library)
- NHS EED (via the Cochrane Library)
- CINAHL (via EBSCOhost)
- Social Policy and Practice (via OvidSp)
- ProQuest Theses and Dissertations
- British Nursing Index (via ProQuest)
- HMIC (via OvidSp)
- Conference Proceedings Citation Index (via Web of Science)
- Social Science Citation Index (via Web of Science)

Supplementary searches: The citation lists of included references will be checked and forwards citation chasing (identifying where included references have been cited) will be carried out using Web of Science, Scopus and Google Scholar. Any journals that are identified as being particularly pertinent in the field will be hand-searched. Targeted searches to identify "sibling" studies (process evaluations, economic studies and qualitative research) associated with included trials and based on trial names and first and last authors will also be conducted.

Grey literature: To identify grey literature we will:

- Search databases that are rich sources of grey literature (e.g. HMIC and SPP) including dissertations/theses (PTDG) and conference abstracts (Web of Science),
- Use the CHAIN network to identify reports,
- Utilise contacts identified through the Project Advisory Group,
- Contact hospital dementia leads identified in the searches for additional information and details of useful further contacts using a snowballing technique,
- Search grey literature websites (e.g. OpenGrey http://www.opengrey.eu/ and Grey Literature Report (http://www.greylit.org/) and the British Library catalogue.

All references identified by the searches will be exported into EndNote X7 prior to de-duplication and screening.

The searches will be recorded using PRISMA guidelines [26]. This will include the list of databases searched, recording of the date searched and the strategies used for each database.

Study selection

Qualitative studies

References obtained through the search strategies will be uploaded into reference management software (Endnote X7). Assessment for inclusion will be undertaken initially at title and/or abstract level by two researchers independently. Where the research methods used or type of initiative evaluated are not clear from the abstract, assessment will be based upon reading of the full paper. The full text of any potentially includable papers will be obtained. Full text screening will be done separately for each qualitative review and examined by two reviewers independently. Any disagreement or uncertainty will be resolved through discussion with a third member of the review team as necessary.

Quantitative studies

Inclusion and exclusion criteria will be applied to the title and abstract of each identified citation independently by two reviewers with disagreements being settled by discussion with a third. The full text will be obtained for papers that appear to meet the criteria and those for which a decision is not possible based on the information contained within the title and abstract alone. The full text of each paper will be assessed independently for inclusion by two reviewers. A PRISMA-style flowchart will be produced to detail the study selection process and reasons for exclusion of each full-text paper will be reported.

Data Extraction

Qualitative studies

Details of the studies' methods and findings will be extracted into a pre-designed and piloted data extraction form. The extraction of data will be conducted by two reviewers independently, and reconciled by discussion. Involvement of more than one reviewer in the extraction of qualitative research allows for alternative readings of the findings to be explored. To facilitate analysis and synthesis, included papers will be uploaded into NVIVO for coding.

Quantitative studies

A standardised, piloted data extraction form will be used to collect data from each included paper. Data extraction will be performed by one reviewer and checked by a second, with disagreements being settled through discussion with a third.

Quality Appraisal

Qualitative studies

We will use the Wallace checklist for quality assessment checklist [27]. The checklist will be supplemented by critical reading of each study. The quality of studies will be independently quality assessed by two reviewers. Any disagreement will be resolved by consensus and if necessary a third reviewer will be consulted. We also anticipate, however, that the value of each study will be judged through its contribution to the synthesis [28, 29].

Quantitative studies

We will use the EPHPP tool [30] to critically appraise all included papers that assess the effectiveness of interventions as this allows critical appraisal of different quantitative study designs according to the same metric. Cost effectiveness papers will be critically assessed using the CHEERS framework [31]. Quality assessment will be performed independently by two reviewers, with recourse to a third in case of disagreement. Where insufficient detail is provided in the published paper to adequately assess the risk of bias, authors will be contacted and asked to provide additional information.

Data Synthesis

Qualitative studies

Precise methods of synthesis will be determined in response to the nature of the findings in the identified studies. Preliminary analysis will involve reading and re-reading the findings of included papers, in order to consolidate understandings of the themes and concepts and their relations within and between studies. A structured summary for each paper will also be produced which will aid discussion of the emerging synthesis amongst the review team. Key findings, quotes and concepts will be coded in NVIVO to aid analysis. We will initially code deductively, using the conceptual framework to understand how people experience care in hospital. However we will also be open to new ideas and concepts and will code inductively to accommodate these.

Assuming sufficient conceptual data is available, we will undertake a meta-ethnography [28, 32]. The aim of meta-ethnography is to identify where similar themes and concepts from different papers refer to the same concepts (congruent synthesis) or identify opposing findings (refutational synthesis), this process is referred to as 'translation'. Study concepts may also be linked to create a 'line of argument', developing ideas across more than one study. The context of the findings will also be considered in relation to the methods used to collect them and any theories that either drive the research or are produced by it [33]. Such elements may help to explain similarities and differences between study reports. This may be particularly useful in identifying where experiences are generic, and where they are condition specific.

If findings are more descriptive, we will conduct a thematic synthesis. Where the evidence base consists of a mixture of more and less conceptual analyses, it may be necessary to thematically analyse the more descriptive papers first, before incorporating these into a meta-ethnography. This approach has been successfully used by members of the team in a previous, complex qualitative synthesis[34]. In the same review, we found that initial synthesis of similar viewpoints (for example, people with dementia, families and carers) was helpful, prior to juxtaposing these experiences and perceptions in an overarching synthesis. We plan to take a similar approach here.

Ongoing discussions within the broader team and with our stakeholder group will ensure that we develop a coherent picture of the body of relevant research.

Quantitative studies

Data will be tabulated and discussed narratively in the first instance. Data tables for the effectiveness studies will include details of the intervention type and content, the setting and the provider, sample characteristics of the included population and the type of outcomes measured. Studies will be grouped by comparator, by intervention and/or by co-morbidity if appropriate. The conceptual framework will be used to consider other potential subgroups relating to different factors addressed in the intervention.

The methods and findings from included economic evaluations will be summarised in a tabular format, noting the type of evaluation carried out, the setting and perspective. Details of the sources of data and structural approaches of any decision analytic models used to synthesise data for the economic evaluations will be noted. Findings will be synthesised in a narrative review (i.e. we will not quantitatively synthesise summary measures of inputs to economic evaluation) which will pay particular regard to issues relating to generalisability of findings to the UK.

For the effectiveness studies, we anticipate that meta-analysis will not be possible across all interventions. We will therefore primarily employ methods of narrative synthesis as described by Popay and colleagues [66]. For outcomes/interventions where data allow, meta-analysis will be used to estimate summary measures of effect on relevant outcomes, based on data from intention to treat analyses in contributing studies. If data allow, we will explore the impact of study quality factors (e.g. control for potential confounding factors) using meta-regression and we will explore sub-group analyses by age, intervention and common intervention and delivery components. If meta-analysis is conducted it will be carried out using random effects models, using Review Manager and R software. Heterogeneity will be explored through consideration of the study populations, methods and interventions by visualisation of results and, in statistical terms, by the chi-squared ($\chi 2$) test for heterogeneity and I-squared (I^2) statistic and, where possible, using meta-regression.

Overarching synthesis

We will take the synthesised quantitative and qualitative research findings and bring them together using a logic model approach. A logic model is a summary diagram which maps out conjectured links between interventions and anticipated outcomes and seeks to uncover the theories of change or logic underpinning pathways from interventions to outcomes. The Expert Advisory Group will be involved at all stages (in face to face meetings, telephone calls and via email) in contributing to the interpretation of the findings and in the development of the logic model. In previous complex reviews [35], the use of diagrammatical representation of the study findings has proved invaluable as a communication aid and in facilitating discussion between stakeholders from differing perspectives.

Quality of the evidence

We will use GRADE and CERQual to assess the quality of the body of evidence for each outcome, and to draw conclusions about the quality of evidence within the text of the review. GRADE will be used to assess confidence in the quantitative evidence [36] and CERQual will be used to assess confidence in the findings in the qualitative evidence [37].

Dissemination

The focus of our multi-faceted dissemination strategy is on reaching those involved in the care of people with dementia in hospital settings; voluntary sector organisations, academics; policy makers; and people with dementia, their families and carers. We will work closely with the Expert Advisory Group to develop and deliver a dissemination strategy that is appropriate to the findings and for different target audiences.

At the heart of the strategy will be a series of regional consensus meetings with providers, commissioners and recipients of services to discuss the findings in the context of existing services. We will utilise the formal and informal networks of the research team and the Expert Advisory Group (e.g. via Special Interest Groups of the British Geriatrics Society and the British Psychological Society, the Alzheimer's Society, the Academic Health Sciences Networks, NHS Strategic Clinical Networks, ENRICH and the CLAHRCs) to convene meetings that maximise efficiency and attendance. The aim of these meetings will be to co-produce plans for service change.

We will also use our networks to communicate the findings using a variety of methods e.g. face-to-face, by phone and email, via newsletters or social media, to ensure that we reach as many relevant people and groups as possible with findings in appropriate formats for each. Plain-language summaries will be co-produced and offered as written summaries and short video clips or podcasts that can be distributed via social media or embedded on websites. With the advice of Project Advisory Group members we will develop a list of potential contacts including popular internet information sources and social media. We will disseminate summaries to clinicians via email discussion groups and relevant organisations.

We will identify opportunities to present our findings at meetings and conferences that include both dementia and hospital care audiences and voluntary agencies and support groups involved with dementia care. Likely meetings include, but are not limited to, British Geriatric Society Special Interest Group meetings and regional NHS Strategic Clinical Network meetings (which bring together commissioners and providers of dementia care).

We expect the outputs from this project to be:

- plans for service change to improve the experience of care for people with dementia in hospital, their families and hospital staff,
- all relevant findings presented as plain language summaries in multiple formats to enable easy access for all those for whom this research is relevant and,
- a minimum of three high-quality scholarly papers, the pre-publication versions of which will be made available without cost to enable access for all.

By including providers, commissioners and recipients of services as partners in the research at all stages we aim to produce plans for service change that are evidence based, relevant and feasible.

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Contribution of authors

JTC, RA, MR and DL were involved in the idea for the review and the design of the review methods. MR designed the search strategy in consultation with RA, JTC, DL, LC, DR, AH, CO and DC. JTC drafted the protocol; RA and MR devised the conceptual framework. All authors contributed to and edited the protocol. RA, JTC and MR will be involved in screening the titles and abstracts, extracting and synthesising the data. All authors will be involved in the interpretation of the data and will contribute to the drafting and editing of the manuscript.

Declarations of Interest

None.

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Caring about Care

Improving the experience of care for people with dementia in hospital

This document is our plain language protocol summary (PLPS). A protocol is like a map that explains how researchers intend to achieve their aims for an upcoming project. The PLPS helps anyone interested in this project to understand the process of research without all the detail normally included in published protocols.

Where will this information be available?

This plain language protocol summary (PLPS) will sit with the published academic protocol on our website (http://clahrc-peninsula.nihr.ac.uk/research/caring-about-care), on the NIHR website (https://www.journalslibrary.nihr.ac.uk/programmes/hsdr/165252/#/), on PROSPERO (https://www.crd.york.ac.uk/PROSPERO/display_record.php?RecordID=86013), and will be a document for team members with a non-research background to refer to throughout the project.

What is this research about?

Hospital services are geared towards fast and effective responses: assessment, diagnosis, intervention and discharge. Services run on the assumption that patients will be able to express their wishes, acknowledge the needs of other patients, and move through the system as required.

However, for people with dementia, particularly when they are ill or have had an accident, hospital settings can be confusing, challenging and overwhelming. This can further impact their well-being and the ability to optimise their care. Furthermore, what happens in hospitals can have a profound and permanent effect on individuals and their families – not only in terms of their inpatient experience – but also their ongoing health, and the decisions that are made about their future.

What are we trying to find out?

1. What are the experiences of care for people with dementia in hospital, their families and the staff caring for them?

2. What changes to healthcare services in hospital will best improve these experiences of care?

We will answer these questions by combining findings from existing studies – this is called a *systematic review*. We then want to use this information to improve hospital care. Working alongside the people who will use this research is important throughout the *Caring about Care* study, but it is particularly important during the final stage of the research, when the findings will be widely shared. We want to work together with the people who will use this research to understand and communicate the findings in a form that is accessible and meaningful.

What is involved in doing a systematic review?

Combining the findings from all existing studies is called 'systematic review'. It is 'systematic' because:

- It will include all information about the chosen topic, not just information individuals think important;
- The quality of the studies is assessed;
- It is reported clearly enough so that someone else would be able to conduct the review in the same way.

We expect to find studies in which researchers have interviewed health care professionals, people with dementia and their carers about their experiences of being in hospital (qualitative research) and studies in which the effects of efforts to improve the experience of care in hospital for people with dementia have been measured (quantitative research).

How will we do the systematic review?

We've included a list of the full team on Page 5 of this document. The day to day review tasks will be completed by Ruth, Hannah, Becca, Morwenna and Jo. They will meet weekly to discuss progress. Researchers with expertise in statistics (Sue), health economics (Colin), qualitative research (Darren), nursing (Dave) and dementia (Linda, David and Iain) and clinicians with experience of caring for people with dementia in hospital (Colm, Debbie and Anthony) will join those meetings when there are specific issues to discuss and will also be available to provide advice by email. We also have the benefit of an Expert Advisory Group with experience in many other aspects of dementia care. We will meet with the Expert Advisory Group on four occasions during the project.

The different stages of a systematic review are shown in Figure 1. In the following sections we describe each stage and what we hope it will achieve. We also highlight where the people in the team with real-world experience of these issues can help.

How did we come up with the question?

The idea for the *Caring about Care* project started at a South West Network Meeting for Alzheimer's Research UK. Researchers, practitioners and carers talked about what was needed most to improve things for people with dementia. The questions they came up with formed the foundation for this study. A number of people from that group went on to recruit others to complete gaps in expertise, forming an Expert Advisory Group (EAG) that includes former carers, healthcare practitioners, care home staff and researchers with methodological and dementia expertise. Together they designed the research project detailed below. The group successfully applied for funding from the Health Service and Delivery Research Programme of the National Institute of Health Research, which was granted in 2017.

The protocol

A protocol acts as a map that researchers write before they begin a project that then guides their work. Our draft protocol was shared at the first Whole Team Meeting held in February 2018 for comments. The final protocol can be found here.

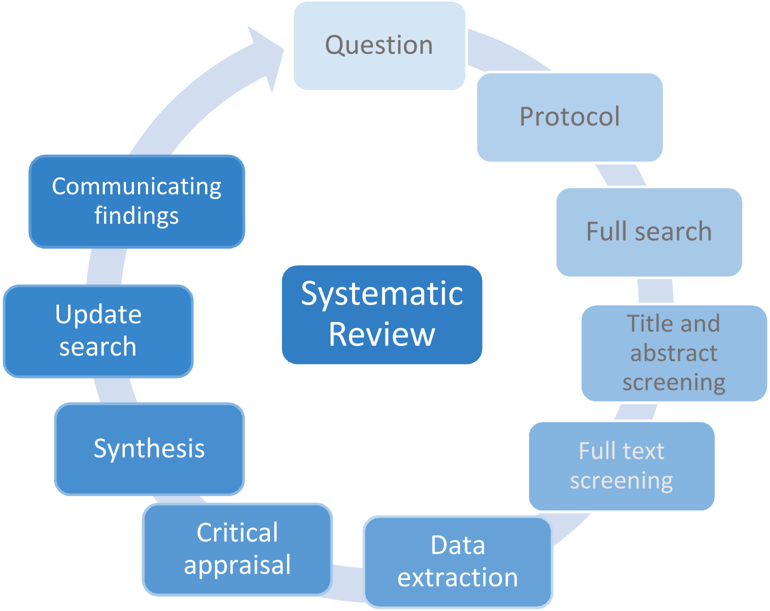

Figure 1. *The process of doing a systematic review.*

Full search

From our background reading, and by asking for ideas during our first Whole Team Meeting, our Information Specialist (Morwenna) will compile terms that relate to dementia, hospital settings, and the experience of care. Morwenna will then run a search of academic databases to identify studies that include these terms in their titles and abstracts. We will also look for research referred to in the studies we have already found, and ask the experts in Dementia on our team about any research we have missed.

Title and abstract screening

The full search will return a list of titles and abstracts that are potentially relevant to the review. Ruth, Hannah, Morwenna and Becca (and any members of the wider team who want to be involved), will screen each title and abstract found during the full search to decide if it is relevant or not. Two different people will screen each entry, make a decision, and then compare answers. If they disagree, they will discuss their decisions and will ask another member of the team (Becca or Jo) to help if necessary.

Full text screening

Because titles and abstracts don’t include all the relevant information about a study – they just give a brief overview – we will need to find the full publication for all the papers that look like they might be useful. The same process as for title and abstract screening is repeated at full text screening – two people make a decision about whether a paper should be included or not in the review, then compare answers. Where they disagree they discuss why or why not the study should be included to make a decision. If they can’t agree, they will ask Becca or Jo to help.

Data extraction

‘Data extraction’ refers to the process of compiling all the information from each included study that is relevant to the review. Ruth and Hannah will do this part of the review. Using tables, the same information – for example, the process of recruiting participants, the characteristics of participants, methods of data collection and analysis, and findings – is recorded for each study. This makes it easier to compare studies and to see similarities and differences, as well as making it more straightforward to find information. It is also part of what makes the review 'systematic' – information is drawn from each study using the same process.

Critical appraisal

'Critical appraisal' is a process of evaluating how robust each included study is by looking at how the researchers designed and conducted their study. Ruth and Hannah will complete this phase. We will use checklists that have been accepted as sound by other systematic reviewers. Critical appraisal helps us to make judgements about the quality of each study so that we can prioritise the findings from the best studies.

Synthesis

Synthesis is the process of combining the findings from all the studies. For studies that look at whether efforts to improve the experience of care work or not (quantitative studies), the results will be described and compared, and if possible, combined, to show what kind of changes to hospital practice improve experiences of care. For studies in which researchers have interviewed health care professionals, people with dementia and their carers about their experiences of being in hospital (qualitative studies), the findings will be described and compared, and where possible, new ideas about how and why the experience of care is improved will be developed.

The input of people with real world experience of the challenges for people with dementia of being in hospital is valuable during this stage of a systematic review for helping researchers to interpret findings. First-hand knowledge of hospital practice and the experience of living with and caring for people with dementia can inform findings that may have become removed from the realities and complexities of everyday life. We have planned a Whole Team Meeting for the early part of this stage, so that we can discuss, and make sense of, the emerging findings.

Update search

About six months before the end of the study, Morwenna will run an update search to find out if any new research has been published since we conducted the first full search. The search results will be screened in the same way as before, and any new relevant studies will be added to the review.

Communicating findings

This final phase of the *Caring about Care* project is a particularly important one, because we are trying a more collaborative approach to communicate our findings. Drawing from contacts across the whole team, we plan to hold multiple events across England, where we will discuss how best to change hospital practice.

We will seek people currently involved with hospital care for people with dementia – hospital staff, charitable organisations, carers and people with dementia themselves – to ask how our findings could be used. Together we will create plans for service change that will be shared across healthcare and dementia-support networks.

How to get in touch and find out more:

Weblink: http://clahrc-peninsula.nihr.ac.uk/research/caring-about-care

Email addresses

Ruth Gwernan-Jones: R.C.Gwernan-Jones@Exeter.ac.uk

Hannah Jones: H.Jones4@Exeter.ac.uk

The *Caring about Care* team

Day-to-day research tasks

Jo Thompson-Coon - Principal Investigator
Rebecca Abbott - Senior Research Fellow
Hannah Jones - Research Fellow
Ruth Gwernan-Jones - Research Fellow
Morwenna Rogers - Information Specialist

Additional expertise

Darren Moore - qualitative research.
Iain Lang – dementia research and implementation.
David Llewellyn - dementia research; David is also a primary carer of a person with dementia.
Linda Clare – dementia research.
Sue Ball – statistics.
Colin Green – health economics.
Dave Richards – nursing and complex interventions.
Anthony Helmsley. Consultant geriatrician.
Colm Owens. Consultant old age psychiatrist.
Debbie Cheeseman. Consultant nurse for older people.

The *Caring about Care* team members who conduct day-to-day research tasks: Becca, Ruth, Morwenna and Jo

Expert Advisory Group

Sue Lawrence - experience of caring for someone with dementia; member of the Alzheimer's Society Research Network.
Julia Burton - experience of caring for someone with dementia; member of the Alzheimer's Society Research Network.
Chrissy Hussey - Consultant Admiral Nurse Dementia Lead from HospiceCare.
Dominic Hudson – Commissioning Manager, Northern, Eastern & Western Devon Clinical Commissioning Group.
Di Walker - Consultant nurse from Northern Devon Healthcare NHS Trust.
Martyn Rogers – Chief Executive AgeUK Exeter, a charity providing support to people with dementia and their carers.
George Coxon - care home owner and founder of Devon Care Kitemark.
Sarah Black – Head of Research, South West Ambulance Service Foundation Trust.
Jo Gajtkowska – Programme Manager (Improvement), South West Academic Health Science Network.