OPTIMISING ACUTE CARE FOR PEOPLE WITH DEMENTIA: A MIXED-METHODS STUDY

Study protocol. Version 2.00 (10/11/2017)

Funder's reference number: NIHR Health Services and Delivery Research: 14/154/09

Sponsor's reference number: Imperial College London: P58012

IRAS Project Identification Number: 181811

Chief Investigator [CI] Professor. Mike Crawford

Imperial College, Hammersmith Campus

Commonwealth Building,

Du Cane Road,

London W12 0NN

E-mail: m.crawford@imperial.ac.uk

Study Coordinating Office Office B. Centre for Mental Health

7th Floor Commonwealth Building

Du Cane Road

London W12 0NN

E-mail: r.sanatinia@imperial.ac.uk

Sponsoring Institution Joint Research Compliance Office [JRCO]

Imperial College London St Marys Campus

Room 221 Medical School Building

Norfolk Place

London W2 1PG

E-mail: jointresearchoffice@imperial.ac.uk

1. SUMMARY OF RESEARCH

Concerns have repeatedly been expressed about the poor quality of inpatient care that people with dementia receive in acute hospitals. This can result in delayed discharge and increased morbidity and mortality. The National Audit of Dementia has highlighted marked variation in the quality of inpatient care that people with dementia receive across England and Wales. But very little is known about why some acute hospitals are able to provide higher quality of care to people with dementia than others.

A third round of the national audit will be conducted in 2015/16. This will report levels of carer-rated quality of care, quality of assessment of needs and average length of stay of over 10,000 people who are admitted to 215 hospitals across England and Wales. While the audit will report on quality of care provided by each hospital, it is not a research project and will not address questions about how and why some hospitals are able to provide better quality of care than others. However data gathered through the audit will provide a rich source of data that could be used to address these important questions.

We are seeking funding to conduct a secondary analysis of data from the audit to identify aspects of the organisation and delivery of services (including staffing levels, staff training, access to liaison mental health services, and other specialist services) that are associated with the quality of assessment of needs, length of admission, and carer-rated experience of quality of care that patients with dementia receive.

We will use these data to identify hospitals with marked differences in length of stay and quality of care and who have adopted different approaches to trying to improve quality of care for people with dementia. In-depth qualitative interviews will be conducted with managers, front-line staff, and service users and carers to examine if and how interventions aimed at improving quality of care for people with dementia impact on length of stay and experience of care received. We will also examine why certain quality improvements initiatives impact on length of stay and experience of care received, for whom and in what circumstances.

In collaboration with front-line clinicians, service users and commissioners we will synthesise the results of the study to make recommendations about which aspects of the organisation and delivery of acute care for people with dementia are associated with better outcomes and highlight contextual factors including aspects of organisational culture which support and impeded the delivery of effective acute care for people with dementia. Through our links with NHS England, the Welsh Government, Royal College of Nursing, British Geriatrics Society, Royal College of Physicians, Royal College of Psychiatrists, Alzheimer's Society and Age UK we will communicate the results of the study to all stakeholders including targeted messages about what services should be commissioned and steps that service providers can take steps to improve the quality of care they deliver.

2. BACKGROUND AND RATIONALE

The number of people living with dementia is increasing and it is expected that over a million people in the UK will have this condition by 2021 (Health Service Ombudsman, 2011). The number of people

with dementia who are admitted to acute hospitals is also increasing with as many as one in four beds now occupied by people with dementia (Department of Health, 2009). People with dementia spend longer in hospital than those without this condition and are more likely to be readmitted to hospital following their discharge (Holmes and House, 2000; Savaray et al 2004; King et al. 2006). Admission to a general hospital can have a detrimental effect on a person with dementia resulting from unfamiliar surroundings and disruption to daily routines as well as direct cognitive effects of physical illness leading to increased cognitive impairment (Department of Health, 2005).

Concerns have repeatedly been raised about the quality of inpatient care that people with dementia receive (Alzheimer's Society, 2009; NHS Confederation, 2010; House of Commons All-Party Parliamentary Group on Dementia, 2011; Jurgens et al. 2012). Enquiries into poorly performing hospitals have highlighted the mismanagement of frail elderly people with dementia (Francis, 2013). A recent national audit of acute inpatient care for people with dementia found that many people do not receive a comprehensive assessment of their needs and that carers are not sufficiently involved at the time of the admission or when planning for discharge from hospital (Royal College of Psychiatrists, 2013). The audit also found marked variation in the quality of care that people receive at different hospitals. For instance, while staff at some hospitals routinely involved carers in assessing the needs of patients with dementia, others rarely did (Souza et al. 2014).

The National Audit of Dementia will be repeated in 2015/16. While the aim of the audit is to highlight differences in quality of inpatient care across hospitals, we believe that the data that will be collected provide an ideal opportunity to examine which aspects of the organisation and delivery of services have an impact on the quality of care that people receive.

2.1 Third round of the National Audit of Dementia

The National Audit of Dementia reports on the quality of care that people with dementia receive from acute hospitals in England and Wales. The audit is part of the National Audit Programme which is funded by Health Quality Improvement Partnership on behalf of the NHS England and the Welsh Government. Following two successful rounds of the audit in 2011 and 2013 (Royal College of Psychiatrists, 2011; Royal College of Psychiatrists, 2013), a third round of the audit will start in January 2015. Following a review of data collection tools and a pilot study, data will be gathered from all 215 acute hospitals in England and Wales in the spring of 2016. The National Audit of Dementia is designed to provide a source of comparative data on the quality of acute inpatient care provided to people with dementia. Data are collected on key standards of care which are derived from national guidelines produced by the National Institute for Health and Care Excellence and recommendations of professional and service user organisations. These standards focus on key areas of organisation and delivery of service and the process and outcomes of care including; governance arrangements, assessment of patient needs, nutrition, information and communication, physical environment, staff training and discharge processes and planning (Royal College of Psychiatrists, 2011; Royal College of Psychiatrists, 2013). Data for the audit are collected a retrospective audit of case notes of a consecutive sample of people discharged from the hospital who have an ICD-10 diagnosis of dementia. These data are supplemented by surveys of managers, carers and staff. Data from the audit are published in a national report which provides an overview of the quality of acute inpatient care that people with dementia receive at NHS services in England and Wales. Each hospital that takes part in the audit also receives a local report which provides a summary of the performance of that hospital benchmarked against the performance of other acute hospitals. Data

from local reports are used by managers and clinicians to identify areas of poor performance and used to develop local action plans aimed at improving standards of care in the hospital. Local reports are also made available to commissioners, patients and carers and to statutory bodies include the Care Quality Commission.

The third round of the National Audit of Dementia will generate transparent benchmarked data for each hospital in England and Wales to be used by local commissioners, providers and users of services to identify poor performance and support efforts to improve the quality of care they provide. However the audit is <u>not</u> a research project and it is not designed or funded to generate or test hypotheses about how inpatient services could be organised and delivered to provide better care to people with dementia.

2.2 Factors that may influence quality of care that people with dementia receive

Concerns about poor health outcomes and negative experiences of inpatient care among people with dementia have promoted the development of a range of different policies and practices aimed at improving the quality of care that people receive. These efforts include better training for staff (Gandesha et al. 2012), deployment of specialist nurses (Elliot & Adams, 2011; Griffiths et al. 2012) and expansion of mental health liaison teams (Holmes et al. 2003) and specialist units (Lai et al. 2009; Arthur et al. 2010; Goldberg et al. 2013).

Data from the first two rounds of the National Audit of Dementia show that there is considerable variation in the extent to which these policies and practices have been adopted by acute hospitals in England and Wales (Royal College of Psychiatrists, 2013). For instance, some hospitals can access support from older adult mental health liaison teams 24 hours a day, while others have limited input during working hours from general psychiatric liaison teams. Some employ specialist dementia nurses, but most do not. Other hospitals have implemented new processes for working collaboratively with carers of people with dementia which are not widely used throughout the NHS. Heterogeneity in the organisation and delivery of services for people with dementia across England and Wales increases the opportunity to use data from the audit to identify aspects of the process of care that impact on patient outcomes.

2.3 Why is this research needed now?

Dementia is a government and service priority (Department of Health, 2009; Welsh Assembly Government, 2011; Department of Health, 2012). People with dementia have a right to receive high quality compassionate care when they are in hospital (Department of Health, 2013a). But quality of care that many people with dementia receive in general hospitals is poor (Royal College of Psychiatrists, 2013). Failure to assess and respond to the needs of inpatients with dementia can lead to longer length of admission and poor health outcomes (Sampson et al. 2009; Mukadam & Sampson, 2011). Identifying ways that some hospitals use to avoid lengthy admissions and improve the quality of care they provide has the potential to improve the effectiveness of NHS care as a whole.

In recent years efforts have been made to improve the quality of acute care that people with dementia receive. While studies based in single wards or hospitals have shown that it may be possible to improve patient and carer experience (Goldberg et al. 2013) and physical and mental health outcomes (Ellis et al. 2011; Lai at el. 2012), we have very little understanding of the impact of

efforts to improve quality of care at a national level and there is a pressing need to understand why some hospitals deliver more effective care to people with dementia than others.

As the proportion of people who are admitted to general hospitals who have dementia increases the cost of care associated with longer admissions will also rise. At a time of financial constraint within the NHS there is a pressing need to understand why some general hospitals provide better quality care and shorter average length of stay for people with dementia than others. This study aims to address this need.

3. AIMS AND OBJECTIVES

The overall aim is to identify aspects of the organisation and delivery of general hospital acute care that are associated with better quality care and shorter length of stay for people with dementia and to understand how the way that hospitals and wards are organised influences the quality of care that people receive. The study has been designed to generate information that can be used by policymakers, commissioners, managers, clinicians and service users to improve the quality of NHS care that patients currently receive.

To meet this aim our objectives are:

- 1. To identify features of wards and hospitals that are associated with higher quality of assessment, shorter length of admission, and better carer-rated experience of care.
- 2. To understand how aspects of organisational form and function impact on the quality of care that people with dementia receive.
- 3. To examine how contextual factors including organisational culture can support and impede the delivery of effective care.
- 4. To synthesise data on factors that improve quality of care for people with dementia and how these are best delivered in order to make recommendations for commissioners, providers and users of acute inpatient services about the optimal organisation and delivery of services for people with dementia.

4. RESEARCH PLAN

4.1 Study design

A mixed methods study with two work-packages: a secondary analysis of data from the third round of the National Audit of Dementia (work-package one), followed by nested comparative case studies of hospitals and wards that provide the most and least effective care (work-package two). This 'sequential' approach to mixed methods research has been recommended as a means of understanding the significance of quantitative associations between interventions and outcomes and has been used to develop a better understanding of how and in what circumstances positive outcomes of interventions can be delivered (Crawford et al. 2002; Creswell, 2003). Prior to starting these work packages we will complete a scoping literature review. We will identify extant literature published in the last 20 years which has examined quality of inpatient care for people with dementia and focus on reports which describe initiatives aimed at improving quality of care. We will identify relevant literature through searching bibliographic databases, contact with experts in the field and

by searching reference lists of key papers. A narrative synthesis of this material will help us ensure that the plans for the study take account of what is already known about this topic and help us interpret the results of the study in the context of previous research.

4.2 Work-package one: Secondary analysis of data from the third round of the National Audit of Dementia

No new data will be collected in work-package one. Instead, we will use existing data to examine associations between the organisation and delivery of services and patient outcomes. Data will be analysed for all patients in the audit and among sub-groups of patients with three tracer conditions which will be selected following a preliminary inspection of audit data. Work-package one will require a multi-level approach to take account of clustering of patients in hospitals. It will also involve sensitivity analyses to take account of patient deaths. None of these analyses would be possible without the modest resources we are requesting to complete work-package one.

Study setting

The setting for the study is acute hospitals in England and Wales. We will analyse data collected from all acute hospitals that that take part in the third round of the National Audit of Dementia. 210 (98% of the 215 acute hospitals in England and Wales) took part in the second round of the audit and participation in the third round of the audit is expected to exceed this. In addition to analysing data on all people in the audit we will conduct a sub-group analysis of people presenting with three 'tracer' conditions. Tracer conditions are specific health problems that can help pinpoint the strengths and weaknesses of a particular medical setting or practice and allow more precise estimates of association between practice and outcomes by reducing confounding resulting from differences in case mix across study sites.

We will select three tracer conditions for this study using established principles (Kessner & Kalk, 1973) and following consultation with co-applicants and collaborators including front-line clinicians and service users. Our criteria for selecting tracer conditions are that they should be prevalent among people admitted to acute hospitals with dementia, they should be relatively easy to diagnose (and therefore recorded accurately by hospitals at the time when audit data are collected), and have an impact on length of admission or quality if care that people receive. At this stage our three candidate conditions are hip fracture, myocardial infarction and pneumonia. These conditions are prevalent among people admitted to general hospitals with dementia (Alzheimer's Society, 2009; Sampson et al. 2009) and represent those with relatively long (hip fracture) and short (pneumonia) admissions (Alzheimer's Society, 2009). We will use data collected during the pilot phase of the audit to examine the prevalence of these conditions in the audit sample and how consistently they are recorded across different hospitals.

Sampling

Each hospital that takes part in the audit will submit anonymised data on demographic and clinical characteristics of a consecutive sample of at least 50 people who are admitted to the hospital and identified has having dementia. Patients in England are identified as having dementia through the

national CQUIN (Commissioning for quality and innovation) (NHS England, 2014) and in Wales through the 'Intelligent Target' (NHS Wales, 2014).

Process and outcome measures

We will obtain patient-level data on demographic and clinical characteristics of patients (age, gender, presenting complaint) together with information about the type of ward(s) where the patient was treated and hospital-level data on aspects of the organisation and delivery of care that may influence the quality of care that people receive, including:

- Staffing levels (number of full-time equivalent staff per ward at each hospital)
- Staff training (availability and uptake of training in assessment and treatment of people with dementia by both clinical and non-clinical staff)
- Access to liaison mental health teams (including provision of specialist older adult mental health liaison services, whether the service is based on site or off site, composition of the team and hours during which it operates)
- Deployment of specialist dementia nurses (including dementia champions and admiral nurses, and the numbers, grades and caseload sizes)
- Care pathways (whether the trust has developed and implemented a care pathway for people with dementia and appointed a senior clinician for overseeing its implementation)
- Involvement of the Trust Board in reviewing quality of care for people with dementia (including whether there is a Board member who has overall responsibility for care for people with dementia).

Associations between these factors and three dependent measures will be examined. These are;

a) Carer-rated quality of care

As part of the audit a paid or family carer will be asked to rate the quality of care that each patient received using a validated measure of carer experience. The measure focuses on carer involvement at the time of admission and discharge and the overall experience of the quality of care that the patient received. The measure generates a total score on a continuous scale from 0 (low carer rated quality) to 100 (high carer-rated quality of care).

b) Quality of assessment of patient needs

Data from clinical records will be used to assess the quality of assessment that each patient receives (Souza et al. 2014). The measure is based on five components of the quality of assessment of patients with dementia (nutritional state, completion of a structured assessment of functioning, assessment of cognitive state, assessment of pain and evidence of a carer being involved in the assessment) which are based on NICE guidelines (2006) and recommendations of the British Geriatrics Society (2010). They have been shown to be linked with length of stay and likelihood of early readmission of people with dementia (Ellis & Langhorne, 2005; Ellis et al. 2011). For each patient we will generate a score on an ordinal categorical variable indicating the total number of components of assessment that were made (from 0 to 5).

c) Length of admission to hospital

During the audit the length of admission of each patient will be recorded. In addition to this we will obtain data on average length of stay for people with dementia from the Health and Social Information Care (HSIC). This will be based on data for each hospital for the 12 months prior to the

case note audit and carer survey (i.e. May 2015 to April 2016). In addition to calculating mean length of stay among all those identified as having dementia through the audit, we will calculate mean length of stay for those with the three tracer conditions.

Data collection

All data for work-package one will be collected during the third round of the National Audit of Dementia. Methods for data collection will be based on this which were used successfully during the previous two rounds of the audit and will be refined and tested in a pilot phase of the audit which will be completed in 2015. Data from the organisational checklist, audit of clinical records, staff survey and carer survey will be gathered in the first half of 2016. As in previous rounds of the audit, data on aspects of the organisation and delivery of care for people with dementia will be gathered from senior managers at each hospital using an 'organisational checklist'. Data cleaning will be conducted by members of the audit team prior to the start of work-package one.

Data analysis

We will use a univariate tests to explore the relationships between dependent variables (carer-rated quality of care, quality of assessment of needs and average length of stay) and patient-level (age, gender, presenting complaint), type of ward, and hospital level (staffing levels, staff training, access to liaison mental health services, deployment of specialist dementia nurses, involvement of the Trust Board) explanatory variables. Further exploratory analysis will be performed to look at different combinations of these exploratory variables that could best explain the dependent variables.

Given the clustered structure of the data (patients within hospitals), the final analysis will be carried out using Hierarchical Models (Snijders & Bosker R, 1999; Hox, 2002). Traditional regression methods are not appropriate because they assume independent observations. For instance, measurements taken from the same hospital can no longer be assumed to be independent, i.e., they are correlated. Hierarchical Models take this into account to draw valid statistical inferences (Goldstein, 1995).

Through hierarchical modelling it will be possible to compare hospitals in terms of patient outcomes. This will be achieved by testing cross-level interactions which combine the effects of explanatory variables at the patient and hospital level. Interactions between explanatory variables within each level will also be tested. Outcome measures such as length of stay are usually skewed so transformation of data on length of stay is likely to be required.

Analyses will initially be conducted on the total sample of people admitted with dementia, including those who died whilst in hospital. The analyses will then be repeated for sensitivity, excluding those who died. Finally the statistical analysis will be repeated in a sub- sample of patients who presented with one of the three tracer conditions.

All data will be analysed using statistical packages STATA (version 13) and SAS 9.3. Results of the analysis will be used to identify case study sites for work-package two and to help us build theory of how the organisation and delivery of services can impact on the quality of acute in-patient care that people with dementia receive.

4.3 Work-package two: Realistic evaluation of the delivery of acute care for people with dementia

We propose to conduct a 'Realistic evaluation' (Pawson & Tilley, 1997) of the delivery of acute care for people with dementia. Realist research design employs no one standard 'formula', other than producing a clear theory of program mechanisms, contexts and outcomes, and then using

appropriate empirical measures and comparisons (ibid, 83-115). We think that the most effective approach for this study will be to use case study design in the context of the theoretical framework of Realistic Evaluation. The selection of hospitals, methods and research questions will be theory-driven; that is, driven by the applicants' theory for how interventions for improving dementia care bring about change in this setting, and about how organisational culture shapes the response of hospital staff. The theory will be framed in terms of propositions about how mechanisms are fired in acute hospital contexts to produce good outcomes such as positive carer-rated experiences of care. It will be developed, tested and refined over the course of the study.

Detailed case studies will be conducted in up to eight hospitals. Realistic evaluation can be used to test theory for how change occurs (if the evaluators already have some fairly well-developed theory) or formulate and develop theory through a more exploratory approach (ibid). At this beginning stage of the project, we expect our theory to be only moderately well developed, so after testing the theory in an initial six-month phase of fieldwork in four hospitals, we will seek to fine-tune it in a second six-month phase of fieldwork in up to four additional hospitals (explained further below).

Sampling

We will select case study sites from among those participating in the National Audit of Dementia. Their selection will be determined by what, theoretically, are the **best and worst contextual conditions to trigger the mechanisms that result in good quality care** for people with dementia. To identify these conditions, the applicants will at the start of the project develop a preliminary theory for change, based on (a) the research and evaluation literature (e.g. Brooker et al, 2014), (b) results of data analysed in work-package one, (c) existing theory; specifically, diffusion of innovation theory (Greenhalgh et al, 2004) which seeks to explain how, why, and at what rate new ideas and technology spread through organisations, and the normalization process model (May et al, 2007) which asks what people do to make a complex intervention workable, and to integrate it into everyday practice. We propose that the **best case contextual conditions** for delivering good quality acute care for people with dementia would include key components in the organisation and delivery of care discussed under work-package 1 (above), such as adequate staffing levels and access to liaison mental health services, as well as the deployment of a specialist dementia care nurse and evidence for innovative practices. Further, we define **good performance or 'outcome'** in realistic evaluation terms, as: comparatively positive carer-rated experiences of care plus shorter admissions.

Length of admission is an important 'outcome' because of cost implications. We think there is likely to be a complex relationship between service organisation and delivery, experience of care and length of stay, so hospitals will be carefully chosen for detailed case study analysis on the basis of their capacity to (a) provide insights into this relationship, and (b) provide a better understanding of what works for whom under what circumstances.

To select the first four hospitals for detailed case study, we will use data from work-package one on organisation and delivery of services and patient outcomes. Using these data we will 'shortlist' 16 hospitals for inclusion in the study, half operating under best case contextual conditions and half under worst case contextual conditions. Hospitals with differing performance levels will be included. We will then review additional data sources, such as Care Quality Commission reports, and undertake telephone interviews with key stakeholders identified by local audit leads, before selecting four exemplars:

<u>Case A:</u> best-case-scenario hospital with comparatively good outcomes (i.e. positive carer-rated experiences of care and shorter admissions)

<u>Case B:</u> best-case-scenario hospital with comparatively poor outcomes

Case C: worst-case-scenario hospital with comparatively good outcomes

<u>Case D:</u> worst-case-scenario hospital with comparatively poor outcomes

After data collected from these hospitals have been subjected to an interim analysis we will purposively sample up to four additional hospitals for case study analysis. We discuss this further below.

Data collection

A researcher trained in realistic evaluation will visit each site over a period of up to four weeks, under the supervision of a senior researcher with expertise in qualitative case study methods (coapplicant Dr Quirk). Informed by lessons from earlier qualitative research about how improvement programmes work (Health Foundation, 2013) ethnographic techniques will be used to observe the culture and behaviour related to the delivery of acute care to people with dementia. The researcher will collect data via participant observation and in-depth individual interviews with consenting stakeholders. Documentary evidence will also be gathered.

In-depth interviews will be conducted using a topic guide that will be drafted by the study team and presented to the Project Advisory Group and the Patient and Carer Reference Group for comments. It is expected that up to 12 stakeholders from each site would be interviewed. With consent, the interviews will be digitally recorded and transcribed. Observations, e.g. of the delivery of acute care, will be subject to participants' verbal consent. Handwritten notes will be made during these events and subsequently typed up as field notes.

Data will be collected from the first four hospitals over a period of six months. Following this the evaluation team will spend three months undertaking a computer-assisted interim analysis of the data. They will then purposively select up to four additional hospitals based on new criteria that emerge from the interim analysis. For example, the first four case studies may flag up certain mechanisms as having a particularly influential role in preventing delayed discharge, in which case we would be able to select additional hospitals in which such mechanisms were present in order to explore their function in more depth. Data from these hospitals will be collected using participant observation and in-depth interviews using a modified topic guide over a further six-month period. This process can be summarised as follows:

- Phase 1 data collection in first 4 hospitals (6 months)
- Computer assisted interim analysis (3 months)
- Phase 2 data collection in up to 4 additional hospitals (6 months)
 Hospitals purposively sampled for the purpose of fine-tuning theory

Data analysis

Qualitative data will be transcribed and analysed from a 'realistic' perspective. The analysis and write-up will focus on the relationship between service organisation and delivery, experience of care and length of stay, and will address questions such as:

- why are certain change mechanisms triggered in some contexts but not in others of a similar nature
- what hinders hospitals operating under best case contextual conditions from performing as well as other similar hospitals
- how do hospitals operating under worst case contextual conditions manage to deliver good quality care.

The data will be subjected to thematic analysis (Joffe, 2012) aided by N-VIVO software. The researcher will meet regularly with the evaluation team throughout the fieldwork to share and reflect on what has been observed, which will feed into theory building.

4.4 Synthesis of data from work package one and two

We will conduct an interpretive synthesis of findings from work package one and two (Dixon-Woods et al. 2005). We will integrate information derived from quantitative associations from work package one with mainly qualitative data on mechanisms, contexts and outcomes of policies and practice aimed at improving quality of inpatient care for people with dementia from work package two. Preliminary findings from data synthesis will be discussed among study applicants and presented to members of the Project Advisory Group and the Patient and Carer Reference Group. We will use feedback from members of these groups to help interpret study findings and make recommendations for commissioners, providers and users of acute inpatient services about the optimal organisation and delivery of services for people with dementia.

5. PLAN OF INVESTIGATION AND TIMETABLE

-6 to 0 months (unfunded preparatory phase)

Preparation of ethics application, employ main researcher, apply for adoption by CRN.

0-6 months (funded set-up phase)

Scoping literature review

Work-package one: Clean data for data analysis, finalise statistical analysis plan.

Work-package two: Refine topic guides for qualitative interviews.

Work-package one (7-12 months)

Undertake quantitative analysis, identify aspects of organisation and delivery of acute services that are associated with better patient outcomes, and identify aspects of dementia care requiring focused observation in work-package two.

Work-package two (7-24 months)

Undertake case studies, site visits, key informant interviews, interviews with front-line staff and observation of practice. Draw also on results of work-package one for theory building after first phase of data collection. Identify aspects of organisational culture, context and delivery that are

associated with better patient outcomes, and factors that promote and hinder the delivery of high quality acute care to people with dementia.

Report writing and dissemination (25-30 months)

Synthesise data from the two work-packages, use feedback from clinicians, commissioners and users of services to use these to develop conclusions and recommendations for organisation and delivery of care. Prepare final project report, summaries of research findings for service users, providers and commissioners. Plan and deliver webinars. Prepare papers for publication in peer-review journals.

6. ETHICS APPROVAL

6.1 Work-package one

During the development phase of the audit we will seek guidance from the Confidentiality Advisory Group at the Health Research Authority on whether our plans for data collection, reporting and secondary analysis of the audit data require us to apply for Section 251 approval. Recent correspondence with the Health Research Authority on plans for conducting and analysing data from other national audits suggest that this should not be required as details that make individual patients identifiable will not be requested, and any coding applied within the hospital necessary to link or generate carer surveys is not considered to be identifiable data. However we will apply for Section 251 approval if advised to do so.

Confidentiality of individual respondents will also be assured through supplying secure password protected platform or sealed envelope response options; presentation of aggregate data in reports and removing any potentially identifiable comments or detail prior to reporting.

6.2 Work-package two

We will apply for ethics approval for collecting data for work-package two. Data collection will only begin once national and site-specific approval has been granted. All clinicians, managers, patients and carers will be provided with written and verbal information about the study before being asked to decide whether they are willing to take part in the project. Only those people who are willing and able to provide written informed consent will be interviewed.

7. REFERENCES

Alzheimer's Society (2009) *Counting the cost. Caring for people with dementia on hospital wards.* London: Alzheimer's Society.

Arthur A, Wilson E, Hale J et al. (2010) *Environments for Care at End of Life: Evaluation of The King's Fund Enhancing the Healing Environment Programme*. University of Nottingham: Nottingham. http://www.kingsfund.org.uk/sites/files/kf/Kings-Fund-Improving-Patient-Experience-Environments-Care-End-of-Life-Programme-2008-2010.pdf

British Geriatrics Society. (2010) Comprehensive assessment of the frail older patient in hospital. London: British Geriatrics Society.

http://www.bgs.org.uk/index.php/topresources/publicationfind/goodpractice/195-gpgcgassessment

Brooker D, Milosovic S, Evans S, Carter C, Bruce M, Thompson R (2014) *RCN Development Programme: Transforming Dementia Care in Hospitals. Evaluation Report*. Worcester: University of Worcester & Royal College of Nursing.

Crawford MJ, Weaver T, Rutter D, Sensky T, Tyrer P (2002) Evaluating new treatments in psychiatry: the potential value of combining qualitative and quantitative research methods. *International Review of Psychiatry* **14**, 6-11.

Creswell JW (2003) *Research design. Qualitative, quantitative, and mixed methods approaches.* Second edition. London: Sage Publications.

Department of Health (2005) Everybody's business: integrated mental health services for older adults. A service development guide. London: Department of Health.

Department of Health (2009) Living well with dementia: A national dementia strategy. Putting people first. London: Department of Health.

Department of Health (2010) *Improving quality of care for people with dementia in general hospitals.* London: Department of Health.

Department of Health (2012) *Prime Minister's challenge on dementia: Delivering major improvements in dementia care and research by 2015.* London: Department of Health.

Department of Health (2013) a *Improving care for people with dementia* https://www.gov.uk/government/policies/improving-care-for-people-with-dementia

Department of Health (2013) b The NHS Outcomes Framework 2014 to 2015. London: Department of Health https://www.gov.uk/government/publications/

Dixon-Woods M, Agarwal S, Jones D, Young B, Sutton A (2005) Synthesising qualitative and quantitative evidence: a review of possible methods. *Journal of Health Services Research & Policy*, **10**, 45-53.

Elliot R, Adams J. (2011) The creation of a dementia nurse specialist role in an acute general hospital. *Journal of Psychiatric & Mental Health Nursing* **18**, 648-652.

Ellis G, Langhorne P. (2007) Comprehensive geriatric assessment for older hospital patients. *British Medical Bulletin*, **71**, 45-59.

Ellis G, Whitehead M, Robinson D, O'Neill D, Langhorne P. (2011) Comprehensive geriatric assessment for older adults admitted to hospital: meta-analysis of randomised controlled trials. *BMJ* **343**, 6553.

Francis Q (2013) Mid Staffordshire NHS Foundation Trust public inquiry. Final Report. Available at: http://www.midstaffspublicinquiry.com/report.

Gandesha A, Souza R, Chaplin R, Hood C (2012). Adequacy of training in dementia care for acute hospital staff. *Nursing Older People.* **24**, 26–31.

Gladman J, Porock D, Griffiths A, et al. (2012) *Care of older people with cognitive impairment in general hospitals*. HS&DR final report, Vol. 08/1809/227.

Goldberg SE, Bradshaw LE, Kearney FC, et al. (2013) Care in specialist medical and mental health unit compared with standard care for older people with cognitive impairment admitted to general hospital: randomised controlled trial (NIHR TEAM trial). *British Medical Journal*, **347**, 4132.

Goldstein H. (1995) Multilevel Statistical Models. London: Edward Arnold.

Greenhalgh T, Robert G, MacFarlane F, et al. (2004) Diffusion of innovations in service organizations: systematic review and recommendations. Milbank Quarterly, **82**, 581-629.

Griffiths P, Bridges J, Sheldon H, Bartlett R, Hunt K (2013) *Scoping the role of the dementia nurse specialist in acute care*. University of Southampton Centre for Innovation and Leadership in Health Sciences: http://eprints.soton.ac.uk/id/eprint/349714

Hannan R, Thompson R, Worthington A, Rooney P (2013) *The Triangle of Care Carers Included: A Guide to Best Practice for Dementia Care*. London: Carers Trust & Royal College of Nursing.

Health Foundation (2013) *Lining Up: How do improvement programmes work?* London: Health Foundation.

Health Service Ombudsman (2011) Care and compassion? Report of the health service ombudsman on ten investigations into NHS care of older people. London: The Stationery Office.

Holmes J, Bentley K, Cameron I (2003) A UK survey of psychiatric services for older people in general hospitals. *International Journal of Geriatric Psychiatry* **18**, 716-21.

Holmes J, House A. (2000) Psychiatric illness predicts poor outcome after surgery for hip fracture: A prospective cohort study. *Psychological Medicine*, **30**, 921–929.

House of Commons All-Party Parliamentary Group on Dementia (2011). The £20 billion question: an enquiry into improving lives through cost-effective dementia services. London: The Stationary Office.

Hox J. (2002) *Multilevel Analysis: Techniques and Applications*. Mahwah, Lawrence Erlbaum Associates.

James Lind Alliance (2013) *Priority Setting Partnership in Dementia*. Available at: http://www.lindalliance.org/DementiaPSP.asp

Joffe H. (2011) *Thematic analysis*. (In: D. Harper, A.R. Thompson (Eds.), Qualitative methods in mental health and psychotherapy. A guide for students and practitioners). Chichester, Wiley. pp. 209–223.

Jurgens FJ, Clissett P, Gladman JRF, et al. (2012) Why are family carers of people with dementia so dissatisfied with general hospital care? A qualitative study. *BMC Geriatrics*, **12**, 1–19.

Kessner DM, Kalk CE. (1973). A strategy for evaluating health services. Washington DC: Institute of Medicine, pp. 1 – 28.

King, B., Jones, C. and Brand, C. (2006) Relationship between dementia and length of stay of general medical patients admitted to acute care. *Australasian Journal on Ageing*, **25**, 20–23.

Lai CKY, Yeung JHM, Mok V, Chi I. (2009) *Special care units for dementia individuals with behavioural problems*. Cochrane Database of Systematic Reviews. No. 4.

May C, Finch T., Mair F. et al. (2007) Understanding the implementation of complex interventions in health care: the normalization process model. *BMC Health Services Research*, **7**, 148-155.

Mukadam N, Sampson E (2011) A systematic review of the prevalence, associations and outcomes of dementia in older general hospital inpatients. *International Psychogeriatrics*, **23**, 344-55.

NHS Confederation. (2010) Acute awareness: improving hospital care for people with dementia. London: NHS Confederation.

NHS England. (2014) *Commissioning for quality and innovation (CQUIN): 2014/15 guidance*. London, NHS England. http://www.england.nhs.uk/wp-content/uploads/2014/02/sc-cquin-guid.pdf

NHS Wales (2014) 1000 Lives Improvement: The Quality Improvement Guide (The Improving Quality Together Edition). Cardiff: 1000 Lives Improvement.

http://www.1000livesplus.wales.nhs.uk/sitesplus/documents/1011/Quality%20Improvement%20Guide%20-%203rd%20edition%20%28IQT%29%20WEB.pdf

National Institute for Health and Clinical Excellence (2006) *Dementia: Supporting people with dementia and their carers in health and social care.* http://www.nice.org.uk/guidance/cg42

National Institute for Health and Clinical Excellence and Social Care Institute for Excellence (2006) Clinical guideline 42. Supporting people with dementia and their carers in health and social care. London: National Clinical Guideline Centre.

National Institute for Health and Clinical Excellence (2010) a *Dementia quality standard*. http://www.nice.org.uk/Guidance/qs1

National Institute for Health and Clinical Excellence (2010) b *Delirium: Diagnosis, prevention and management* http://www.nice.org.uk/guidance/cg103

Page S, Hope K. (2013) Towards new ways of working in dementia: Perceptions of specialist dementia care nurses about their own level of knowledge, competence and unmet educational needs. *Journal of Psychiatric and Mental Health Nursing*. **20,** 549-556.

Pawson R, Tilley, N. (1997) Realistic Evaluation. London: Sage.

Royal College of Psychiatrists (2011) *Report of the National Audit of Dementia Care in General Hospitals*. London: Healthcare Quality Improvement Partnership.

Royal College of Psychiatrists (2013) *National Audit of Dementia care in general hospitals 2012-13:* Second round audit report and update. London: Healthcare Quality Improvement Partnership.

Sampson E, Blanchard MR, Jones L, Tookman A, King M. (2009) Dementia in the acute hospital: Prospective cohort study of prevalence and mortality. *The British Journal of Psychiatry*, **195**, 61-66.

Savaray S, Kaplowitz M, Kurek J, et al. (2004). How do delirium and dementia increase length of stay of elderly general medical patients? *Psychosomatics*, **45**, 235–242.

Snijders T, Bosker R. (1999) *Multilevel Analysis: An introduction to basic and advanced multilevel modelling*. London: Sage Publications.

Souza R, Gandesha A, Hood C, Chaplin R, Young J, Crome P, Crawford MJ. (2014) Quality of care for people with dementia in general hospitals: national cross-sectional study of patient assessment. *Clinical Medicine* **14**, 490-494.

Welsh Assembly Government (2011) *National dementia vision for Wales*. http://www.Wales.Nhs.Uk/healthtopics/conditions/dementia

8. FLOW DIAGRAM

Preparatory phase

- Scoping literature review
- Obtain Sect 251 approval for work-package one and REC approval for work-package two

Work package one (Secondary analysis of audit data)

- Multilevel analysis of process and outcomes of care among >10,000 people with dementia who are admitted to 215 hospitals across England and Wales
- Identify aspects of organisational and delivery of care that are associated with higher quality care and shorter length of stay
- Identify higher and poorer performing hospitals for initial case study sites and aspects of dementia care requiring focused enquiry in work-package two

Work package two (Qualitative case studies)

- Four nested comparative case studies in exemplar hospitals (best/worst-case policies and practices with comparatively good/poor outcomes)
- Develop theory of how interventions, policies, culture and practice influence the quality of acute inpatient care that people with dementia receive
- Up to four additional case studies at purposively sampled hospitals to fine-tune the theory

Synthesise and disseminate study findings

- Interpretative synthesis of findings from work package one and two with input from Project Advisory Group and Patient and Carer Reference Group
- Develop and disseminate recommendations for commissioners, users and providers of acute inpatient services on the optimal organisation and delivery of care for people with dementia
- Develop and disseminate recommendations about factors that support and impeded the
 effective implementation of policies, practices and interventions that are associated with
 higher quality acute inpatient care for people with dementia