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[**Comorbidity and dementia: improving healthcare for people with dementia. (CoDem)**]

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[**Comorbidity and dementia: improving healthcare for people with dementia**]

1. Aims and objectives

The overall aims of the study are to:

1) Explore the impact of comorbidities, for a person with dementia (PWD), on access to non-dementia services

2) Identify ways of improving integration of services for this population, reducing fragmentation and inappropriate use of care.

The research objectives are to map what is already known about comorbidity and dementia, identify how the presence of dementia impacts on access to health care and service delivery for comorbid conditions, identify barriers and facilitators to service delivery for people with dementia and comorbidities, and identify models of service delivery that are best suited to meet the needs of people with dementia who have other complex health care needs. The research questions are:

1. What is best practice/effective care for service delivery for people with dementia and a comorbid condition (i.e. diabetes, stroke and visual impairment)?
2. How does the presence of one or more comorbidities impact on access to health care and service delivery for a person with dementia, their carers and health and social care professionals?
3. What are the barriers and facilitators for service delivery for PWD and comorbidities?
4. How can current services adapt to meet the needs of PWD who have other complex health care needs?

2. Background:

Dementia is a significant and increasing public health problem. It has been estimated that over 820,000 people in the UK have dementia [1]. Although there are significant differences in the physical and cognitive effects of the different types of dementias all are progressive, involve increasing physical and mental deterioration, and lead to a sufferer becoming increasingly dependent. The number of people with dementia in the UK is set to double to 1.4 million in the next 30 years [2] with an estimated cost to the UK economy of £35 billion

by 2026 [3]. Dementia is primarily a disease of old age and it often coexists with other conditions of old age. There is evidence that people with dementia have higher levels of comorbidity than comparable populations without dementia [4]. Despite this there is very little research on the combined impact of dementia and other co-morbidities on individuals' needs and use of health care services.

A cross-sectional study in the US found that more than 60% of patients with Alzheimer's disease had three or more comorbid conditions and virtually all had at least one [5, 6], with 30% having vascular or heart disease. In addition, there is increasing evidence to support an association between Alzheimer's disease and cardiovascular risk factors such as hypertension and hypercholesterolaemia [7, 8]. It has been argued that in older age groups Alzheimer's disease should be considered as a diffuse clinical syndrome representing the gradual accumulation of multiple pathologies rather than as a discrete neuropathological entity [8]. This has implications for how people with dementia are likely to present and use different primary and secondary care services and the extent to which health care professionals are able to identify, address and incorporate a diagnosis of dementia into the care and management of other conditions.

There are different conceptualizations of comorbidity but they are based on the core concept of more than one distinct condition in an individual [9]. A UK cohort study looking at incidence of dementia and survival provides some data on prevalence of comorbid conditions such as cardiovascular disease [10]. However, this does not provide information on the impact of comorbidity on access to services. Moreover, most research has been concerned with the effect of multimorbidity on physical functioning and its measurement, with little research investigating the effect on processes of care or what constitutes 'best care' for these patients [11].

This is of concern as comorbidity amongst people with dementia presents particular challenges for primary and secondary care. Certain comorbid medical conditions may exacerbate the progression of dementia. For example, there is evidence that cognitive decline may be accelerated in older people with type 2 diabetes [12, 13]. Moreover the presence of dementia may adversely affect the clinical care of other conditions and undermine patient's abilities to self-manage chronic conditions and engage in health maintenance activities. The complicating presence of dementia can be a key factor in how patients' needs are anticipated, different specialist and emergency services are used, and

decision making about transfer to long term care (nursing homes) than is the case for patients with dementia but with no serious comorbidities.

In addition little is know about patients' perspectives. An NIHR funded review of 126 qualitative research papers on the experience of diagnosis and treatment of dementia[14] has found very little evidence relating to the experiences of people diagnosed with dementia who have an accompanying comorbid condition. In fact this group were often actively excluded from research even though it is likely that a diagnosis of dementia may affect their ability to self manage other conditions. There is a lack of research on patients views on the ways in which multiple conditions affect their health, well-being and clinical care [9].

To date, research has tended to focus on the experience of living with dementia as a single disease. This study will increase knowledge about the impact of comorbidities on people diagnosed with dementia and will determine if this population have a different experience of health care to those with similar comorbidities but without dementia. It will identify services that are effective at enabling patients with dementia and comorbidities and their carers to plan their care and will support professionals' decision making about treatment. Ultimately findings from this project have the potential to inform existing approaches to service delivery and reduce unplanned admission to secondary care or premature entry to long term care.

3. Need:

Dementia is a significant public health problem with far reaching health, social and economic impacts and the prevalence of dementia in the UK is set to rise significantly. Evidence suggests that amongst people with dementia there is a high prevalence of comorbid medical conditions and complaints [2][6] but little is known about the effects of comorbidity on processes and quality of care, patient needs, or how services are adapting to address the particular needs of this population. Dementia is often viewed as an isolated condition with little understanding of how other complex health needs might impact on patient and carer experiences or service use and provision.

Improving the organisation and delivery of services for people with dementia is a key government target [15]. A recent report from the MAGDR subgroup identified several priority topics for dementia research one of which was a need for more research addressing comorbidities, especially in relation to vascular disease, and a need to improve the physical

health of patients with dementia [16].

It has been consistently highlighted that NHS professionals who do not work in mental health have very little understanding of the needs and experiences of people with dementia or the disease trajectory and that the care needs of people with dementia are currently not being met [17] [15]. Sub-optimal systems and insufficient guidance for generalist and specialist services that encounter patients with dementia and other co-morbid conditions results in duplication of services, delays in the identification of problems and ultimately patients being admitted to hospital or transferred to long term care earlier than would be necessary. Whilst there is increasing support for the use of dementia care workers, and the value of care/case management, there is also a need to consider what kind of system based support can enable different health professionals, patients and their carers to navigate the multiple systems of care they might encounter. There is a need to explore decision making processes, understand barriers and facilitators to the development of an integrated approach to care across disease specific services and reduce inappropriate use of primary, secondary and out of hours services.

The proposed research will add to our understanding of how having dementia impacts on the management of other health conditions. It will summarise current evidence in this field and provide guidance on how services should be organised and delivered to improve quality of care for people with complex health conditions who are diagnosed with dementia. The project will inform care pathways and standard setting for the care of people with dementia and complex health needs and provide a benchmark for further research and policy guidance. It will also help to identify the kind of training and support practitioners and managers require for working with people with dementia.

This study builds on existing NIHR funded dementia research carried out by the project team on the prevalence of comorbidities in people with cognitive impairment [10, 18], epidemiological pathways for dementia [19], life expectancy for people with dementia [20, 21], the impact of comorbid conditions on cognitive impairment [12] , diagnosis and treatment in primary care [22, 23], end of life care decision making in primary care [24, 25] and the transition to becoming a person with dementia [26]. However, a recent NIHR funded review of qualitative studies conducted by members of the team [14] has revealed that whilst there is a great deal of evidence relating to the experiences of people diagnosed with dementia there is little research that has sought to capture the views of people with

dementia and their carers on the way in which multiple conditions affect their health, well-being and clinical care. Moreover whilst it is recognised that there is a need to improve the physical health of PWD [16] little is known about how the presence of dementia affects the organisation and delivery of care for this group.

4. Methods:

4.1 Conceptual framework

A mixed method approach is proposed informed by theories about continuity of care [27-29]. Dementia is a long term condition. We know from previous work that navigating the different systems of care is particularly difficult for this population, not least because they receive advice and support from health and social care and increasingly third sector providers. Processes of care may be further complicated for people with dementia and other comorbid health conditions. Theories about continuity of care provide an appropriate framework for exploring the health care experiences of people with dementia and ensure that activities that support co-production of care are identified and considered. For instance, in a previous study the examples participants gave of what ensured a good outcome were: continuity and consistency of services, timely communication and follow up between services, and appropriate, respectful delivery of service [30] . The different dimensions of continuity of care as experienced by older people with dementia and their carers can inform how we analyse service delivery from generalist providers [31].

Using continuity of care as a framework will enable us to capture the impact of living with dementia and other conditions for patients, carers and health care providers at different points of the disease trajectory , and identify how continuity may be enhanced for this vulnerable group [28]. We will use this framework to structure how we explore, identify and characterise the origins, processes (including decision making processes on treatments unrelated to dementia) and outcomes of effective management of comorbidity amongst people with dementia. Continuity of care is a complex, multi-dimensional, concept that is co-constructed arising from interactions between patients, carers and professionals [29]. It may refer to relationships between patients and practitioners, coordination across services, information transfer and coordination of care over time, and the coherent delivery of services for people with long term conditions [27]. Previous research on continuity has

identified a need to prioritise the needs of vulnerable people who are unable to negotiate their own continuity as they wish [31]. We propose to consider patient, carer and professionals experiences of the three main aspects of continuity identified by Freeman and colleagues [31]:

- Relationship continuity – refers to the continuous therapeutic relationship with one or more health professionals over time
- Management continuity – refers to processes involved in coordinating, integrating and personalising care, involving communicating both facts and judgements across team, institutional and professional boundaries, and between professional and patients;
- Informational continuity – refers to record keeping and the transfer of information, the timely availability of relevant information, and people with dementia and their carers' understanding of their condition and treatment.

The service user/carer experience is fundamental to ideas about continuity and is integral to our research. Five members of the public will be invited to join a user reference group who will be involved in the design and conduct of the study.

4.2 Research Plan

The research is undertaken in three phases (see figure 1).

In phase one to understand current knowledge on the range and type of comorbid disease amongst people with dementia, the impact of comorbidity on experiences and service use we will:

- Scope current evidence on patient need and systems and structures that exist for the care of PWD and comorbid medical conditions,
- Undertake cross sectional analysis of a population cohort database to explore health and social service use in people with a diagnosis of dementia and a comorbid medication condition.

In phase two to understand current models of service delivery, the points in the disease trajectory that pose the greatest challenges for service providers and barriers and facilitators

to access and continuity of care we will:

- Undertake in-depth interviews with PWD and a comorbid medical condition and their carers
- Undertake focus groups or interviews with clinicians involved in their care

In phase three we will bring together findings from phase one and two to:

- Map current models of care and how the presence of dementia with one or more co-morbid conditions is addressed by service providers
- Highlight interventions that support continuity and equity of access to care that can be incorporated into current models of service delivery
- Develop and refine guidance about how services should engage with people and their carers with dementia, indicators of quality that can inform commissioning of services for older people and specialty specific guidance on assessment and decision making

We propose to focus on three exemplar comorbid medical conditions, stroke, diabetes and visual impairment; all of which generally involve some form of external monitoring and require collaboration between primary and secondary care. Stroke and diabetes are chosen because they are common in older people and are thought to exacerbate or influence the progression of dementia. Moreover management of these conditions, in particular self-management, is likely to be complicated by the presence of dementia [32]. Visual impairment is also prevalent in older people [33] and may exacerbate confusion [34] . In addition, the ability to cope with visual impairment is reduced if a person also has dementia. Furthermore although it is vital that eyesight is optimal in older people with dementia, in order to maintain orientation and independence, there is a lack of uptake of services for this group with few undergoing regular eye examinations [35, 36].

4.3 Phase One

4.3.1. Scoping

The scoping study will address research question one. The research team have recently undertaken a NIHR RfPB funded systematic review of qualitative studies around patient experiences of the diagnosis and treatment of dementia. Based on the findings of this

review, we are confident that there is limited empirical evidence about the impact of co-morbidities on the experience of living with dementia. However, there is value in mapping what is known and reviewing national and local initiatives that support self-care and access to services for people with dementia that are living with other comorbid conditions. The scoping will identify existing evidence relating to: systems and structures that currently exist for the care of PWD and comorbid medical conditions, prevalence of co-morbidity amongst PWD, and experiences of PWD and their carers who have comorbid medical conditions. In addition it will identify gaps in current knowledge and evidence. The scoping will be guided by Arksey and O'Malley's six stage methodological framework [37, 38]. This includes: identifying the research question, searching for relevant studies, selecting studies, charting the data, collating, summarizing and reporting the results and consulting with stakeholders.

Identifying the research question

We will include a representative range of material that provides an overview of current knowledge and that identifies some key examples of developments in the organisation and delivery of care for people with dementia and comorbid conditions. We will include all types of literature, published and unpublished, including documents relating to current guidance and advice on meeting the health care needs of PWD and other medical conditions. The focus will be on the UK but we will draw on international literature if considered relevant to the organisation and delivery of services in the UK.

Searching for relevant studies

We will use a range of search techniques including electronic databases and lateral searches. The electronic search strategy will be developed by an experienced Information Scientist with input from the rest of the project team. Searches will include:

- Electronic databases including: Medline (PubMed), CINAHL, BNI, EMBASE, PsycInfo, DH Data, Kings Fund, Web of Science (WoS incl. SCI, SSCI, HCI), TRIP, Cochrane Library (incl. CENTRAL, CDSR, DARE, HTA), AgeInfo (Centre for policy on Ageing – UK), NTIS, SIGLE.
- Checking of reference lists from primary studies and systematic reviews (snowballing) [39]
- Citation searches using the 'Cited by' option on WoS, Google Scholar and Scopus, and the 'Related articles' option on PubMed and WoS ('Lateral Searching') [40]

- Contact with experts and those with an interest in dementia to uncover grey literature (e.g. DeNDRoN, National Library for Health Later Life Specialist Library, Alzheimer's society and For Dementia)
- Contact with disease specific charities and user groups (e.g. Stroke Association, Diabetes UK, Thomas Pocklington Trust)

Selecting studies and charting the data

Electronic search results will be downloaded into EndNote bibliographic software and, where possible, duplicates deleted. As there is evidence that two reviewers should screen records to maximize ascertainment of relevant studies [41] two reviewers (FBunn and the RA) will independently screen titles and abstracts against the predefined inclusion criteria. Full manuscripts of all potentially relevant citations will be obtained. Hard copies will then be screened independently by FBunn and the RA using a screening form with clearly defined criteria. Any disagreements will be resolved by consensus or by discussion with a third author (CG).

Data extracted will vary according to the type of material. Data from empirical studies and systematic reviews will include study type, aims/research questions, study methods, types of participants, setting and relevant outcome data (such as information on prevalence, evidence of effectiveness or patient experiences). For grey literature and reports data will include type of item (e.g. policy document, guideline, care pathway), a summary and description of service development and any evidence of evaluation.

Reporting the results

Although we do not plan to undertake formal quality assessment of included literature we will include a broad critical evaluation of the evidence. Data will be presented as a narrative and tabular summary. In addition, qualitative analysis techniques will be used to draw out common themes. Results will include a summary of current service organisation and provision and implications for policy and practice.

Consulting with stakeholders

The final stage of the scoping will involve the presentation and discussion of preliminary findings from the scoping to key stakeholders (including practitioners, voluntary sector

representatives and user representatives) and the user reference group. The purpose of consulting with stakeholders in this way is to elicit additional information, test emergent findings, provide perspectives and meaning to the scoping and inform the next stage of the research [37, 38]. In addition it will ensure that the discussion and dissemination of the findings are directly informed by the priorities and interests of clinicians, people with dementia, family carers and their representatives. The applicants have used this strategy successfully in previous studies [14]

4.3.2 Secondary data analysis

Phase one of the study addresses research question two through analysis of large population based cohorts of older people. Data from the MRC Cognitive Function and Ageing Studies (CFAS & CFASII) will be used to estimate the prevalence of the target comorbid medical conditions (stroke, diabetes, and visual impairment) amongst people with incident (CFAS) or prevalent (CFASII) dementia. Service use associated with the presence of dementia and the target comorbidities (diabetes, stoke, visual impairment) will be estimated.

This work compliments previous research using CFAS [18, 42]. Professor Brayne is the PI of the Cognitive Function and Ageing Studies and will ensure this research builds on the on-going CFAS research involving Fiona Matthews (MRC Biostatistics Unit), Carol Jagger (Newcastle), Adelina Comas-Herrera (LSE) and Raphael Wittenberg (LSE).

Sample

CFAS and CFASII are large population based studies of people aged 65 years and over living in the community, including institutions (www.cfas.ac.uk). The CFAS sample (N=13,004) was selected from general practice records in five geographically diverse centres: the cities of Newcastle, Nottingham and Oxford; and rural Cambridgeshire and Gwynedd. CFASII builds on the original study, recruiting around 7,500 individuals born before 1942 from three of the original centres (Newcastle, Nottingham and Cambridgeshire). CFASII wave 1 data collection is now complete for two centres. Data for all three centres will be available for analysis before the start of the study.

Data collection

Data are collected by interviewer administered questionnaires using computer assisted

direct data entry. In about 20% an informant interview is conducted for the refinement of study diagnosis and to provide essential proxy information where respondents are unable to answer questions. Data includes information on cognitive and physical function, health status and receipt of health and social services. Cognitive function is assessed by the MMSE, and dementia diagnosis is based on the Geriatric Mental State Automated Geriatric Examination Assisted Taxonomy (GMS AGECAT). The presence of chronic disease, including diabetes and stroke, is based on self-report and visual impairment is assessed by an interviewer administered vision test. Receipt of health and social services, as well as special housing is assessed by retrospective questions on use of services. For CFAS this data was collected in 2004/6 (wave C10) and for CFASII is collected at baseline. In collaboration with Adelina Comas-Herrera (LSE), service costs for CFASII are being ascertained and will be available for analysis in 2013.

Analysis

For the purpose of this study the CFAS and CFASII cohorts will be grouped as dementia or no dementia based on the AMS AGECAT. For each grouping the age standardised prevalence of the target comorbidities will be calculated. Incident dementia is available for CFAS, allowing for the assessment of service use in those with target comorbidities following the onset of dementia. For CFASII all analysis is cross-sectional and based on prevalent dementia at the baseline assessment. Findings from CFASII will compliment CFAS and provide insight into possible intergenerational differences.

Analysis will consider the retrospective use of health and local authority services over the past four weeks (e.g. visit from or to: home help, physiotherapy, occupational therapy, G.P., day centre, day hospital, social worker, meals on wheels etc.), and the number of inpatient and outpatient hospital visits over the past three months. Where appropriate linear, logistic or Poisson regression will be employed. All analyses will control for confounding factors such as age, sex and place of residence. Sensitivity analysis examining findings across age groups, sex and centre will be undertaken to ensure the robustness of the findings.

4.4 Phase Two- Focus Groups and interviews

Phase two addresses research questions two and three through in-depth semi-structured interviews with service users with a long-term condition and focus groups or interviews with

staff that organise and deliver care in a range of different specialities. This will include:

a) People diagnosed with dementia that have at least one of our target non dementia specific health related problems (e.g. stroke, diabetes, visual impairment)

b) Family/unpaid carers of people with dementia and one of our target non dementia specific health related problems

c) Clinicians in both primary and secondary care who organise and deliver care for people with stroke, diabetes and visual impairment

Sampling

Participants will be recruited from two geographical regions. One will be the area covered by North Thames DeNDRoN (including London boroughs north of the Thames, South Bedfordshire, Hertfordshire and Essex) and the other the North East of England (Newcastle). It is anticipated that 15-25 interviews will be carried out per site with people with dementia and their family carers. In addition we aim to conduct a total of six focus groups across the sites to capture the different experiences of primary and specialist service professionals.

People with dementia and family carers

We will purposively sample to capture our specified comorbid conditions and a range of experience along the dementia pathway. For site one (run via University of Hertfordshire) participants will be recruited via the North Thames Dementia Registry (DemReg) and through local memory clinics in Hertfordshire and Bedfordshire where the team have good links with consultants that run local memory services. Using DemReg has been shown to significantly improve recruitment of people with dementia compared to more traditional channels [43]. In addition we have a cohort of dementia interested and research ready practices identified via the Evidem Study. This list will be updated through East of England PCRN. In Newcastle participants will be recruited via GP practices and via the North East DeNDRoN patient list. Participating GP practice(s) will be recruited via the local Primary Care Research Network who has a critical mass of research ready practices. Once a GP practice has agreed to take part, eligible patient participants will be identified from the practice QOF registers for the relevant long term illnesses (i.e. dementia, diabetes); this list will be screened by one of the

practice GPs to exclude those meeting the exclusion criteria.

Participating patients will be asked whether they receive any significant help from an informal carer, and if so the patient's permission will be sought to invite the carer for interview. Potentially eligible participants (PWD and/or their carers) will be approached initially via an invitation letter from DeNDRoN or from an appropriate gatekeeper (such as their GP or clinicians at participating memory clinics). Invitation letters will be accompanied by an information sheet. Those expressing an interest in participating will be given the opportunity to discuss the study further, either with the CI Dr Frances Bunn or with either of the Research Fellows undertaking interviews (Dr Anne-Marie Burn at UH, TBA at Newcastle).

Inclusion criteria for people with dementia and their family carers

- A range of experiences along the dementia pathway
- Aim to recruit similar numbers of each of our target conditions of stroke, diabetes and visual impairment (between 5-9 interviews for each group at each geographical location)
- We will include people who have more than one comorbidity (e.g. stroke and heart disease) as long as one of the comorbidities is one of our target conditions
- Any type of dementia but excluding MCI
- A confirmed diagnosis of dementia or taking dementia medication
- Stroke – confirmed diagnosis from secondary care (regardless of aetiology)
- Diabetes – confirmed diagnosis of type I or type II
- Visual impairment – defined as being registered blind or partially sighted or having a secondary care diagnosis of a condition that leads to visual impairment. For example, cataracts, macular degeneration
- Interviews may be paired (person with dementia and their carer) or with the person with dementia or carer alone

Exclusion criteria

- Unable to speak English
- Terminally ill or on the palliative care register

Arrangements for interviews

Interview participants will be contacted by one of the research team (Frances Bunn or Ann-Marie Burn at UH, Research Fellow at Newcastle (TBA) with details of the time of the interview. It is anticipated that most interviews will take place in the participants own home. However, if participants prefer, or it is more convenient for them, then some may be interviewed in other locations such as participating memory clinics. Participants will be informed that they will receive a £10 voucher in appreciation of their time and that, where appropriate, that their travel expenses will be reimbursed. Participants will be rung on the day of the interview to remind them about the interview and to check that it is still convenient. The interviews with people with dementia will be carried out by Dr Frances Bunn and Dr Anne-Marie Burn in the south and East of England and by a Research Fellow (TBA) in the North East of England. Dr Bunn has previous experience carrying out research with older people who find consent and participation in research difficult because of problems with cognition and confusion. CRIPACC (UH) and The Institute for Health & Society (Newcastle University) have lone worker policies which will be followed as appropriate.

Clinicians

Individuals recruited to the focus groups will be purposively sampled to capture a range of experience and interest, in primary and secondary care, in providing care for patients with stroke, diabetes and visual impairment. This will include General Practitioners with specialist interests in long-term conditions, secondary care doctors at consultant or senior registrar level specialising in the care of people with stroke, diabetes or visual impairment, and clinical nurse specialists/therapists or practice nurses responsible for the management of people with long-term conditions e.g. diabetes. We will strenuously seek to include people who do not have dementia as an interest within their generalist area. Focus groups will be conducted in the clinical setting and will aim to maximise participation from a range of professionals involved in either the provision of disease specific care or primary care. The research team are well connected to engage the participation of clinicians, with links to a number of hospitals including University College London, The Whittington, Royal Free, The Luton and Dunstable, The Lister (Stevenage), and North Tyneside Hospital. All focus groups will have at least two facilitators and senior members of the team will be involved in recruitment and leading focus groups/interviewing. It is envisaged that the strong clinical networks of the team will facilitate recruitment for focus groups, however, if key informants cannot attend a focus group then face to face or telephone interviews will be conducted

instead.

Data collection

The focus of the data collection is to identify characteristics of services that respond appropriately to patient and carer needs, positive and negative examples of patient care, areas where patient needs are not met, and barriers and facilitators to effective service provision for people with dementia and a comorbid condition. It will also enable us to explore how the presence of dementia impacts on clinical decision making processes. Different interview schedules/focus group prompts will be designed for use with patients, carers and clinicians and according to the comorbidity involved. Interview and focus group schedules will be guided by literature from the scoping study and consultation with members of the user reference group. Interviews will be taped and transcribed.

Analysis

Qualitative data analysis drawing on thematic content analysis [44] will enable key features of patient, carer and clinicians experiences to be elicited from the data. The different characteristics of continuity of care will be used as an organising framework and we will use a constant comparison method to look for similarities and differences between patients, carers and clinicians; between different conditions; and between different geographical sites and sources of recruitment. Two researchers will independently scrutinize transcripts (RAs and FB/CG) and emerging themes will be labelled with codes. They will then compare codes with discrepancies resolved by discussion [45]. Emerging themes will be discussed with the user reference group. Results of the studies will be entered into NVivo software for qualitative data analysis.

4.5. Phase Three – Development of guidance for service organisation and delivery

In the final phase of the study the results from the scoping, secondary data analysis and interviews will be used to describe current models of care and the impact of comorbidities on the receipt of non-dementia services. A framework driven by ideas about continuity of care will be used to organise and synthesise findings from the scoping, secondary data analysis, and interviews and focus groups. A deliverable from stage three will be a mapping

of the key clinical decision making points for people with dementia and comorbid conditions along the dementia trajectory. We will develop practical guidance about how services can be organised and delivered for people with dementia and comorbid medical conditions. LRobinson was a clinical expert who helped develop the GP dementia commissioning kits and it is anticipated that this study will provide evidence that can refine or build upon current guidance.

Confirmatory conference using nominal group technique

The findings from phases one and two of the study will be presented to, and discussed with, key stakeholders at a confirmatory conference. Up to twenty-five participants will be invited to the meeting including clinicians and service user representatives who took part in focus groups or interviews, practitioners specialising in the care of people with dementia, service managers and commissioners and representatives from the third sector involved in supporting people with dementia (e.g. Alzheimer's Society, Carers in Herts) or people with our target comorbid conditions of Stroke, Diabetes and visual impairment (e.g. The Stroke Association, Diabetes UK, Thomas Pocklington Trust). The purpose of consulting with stakeholders in this way is to validate the findings, and assist in the development of guidance. The meeting will begin with a presentation from the research team that draws on the synthesised findings from our study and also any other relevant NIHR portfolio studies. The presentation will cover: what is known about the impact of dementia on receipt of non-dementia health services, barriers and facilitators to service delivery for people with dementia and comorbidities, and evidence around best practice/ effective care for service delivery for people with dementia and a comorbid medical condition. This will be followed by group discussion on the implications of the findings.

To structure the discussion and rank the importance of the findings and their relevance for service improvement and delivery we propose using a nominal group technique [46, 47]. Participants will be split into small groups facilitated by a member of the project team. Discussions will be recorded by an observer taking detailed notes and by audiotape. The facilitator will direct the discussion and focus attention on achieving a common understanding of the questions and their answers.

Discussions will be guided by our conceptual framework of continuity. This will include:

- Relationship continuity (including who is/who should be the main coordinator of care

for a person with dementia and a comorbid condition)

- Management continuity (who is the most appropriate main care manager responsible for detection of significant changes in functional status)
- Informational continuity (how should information be transferred between different health and social care professionals and how should information be given to patient and carer)

Based on the evidence presented participants will also be asked to consider:

- Priorities for the organisation and delivery of care for people with dementia and comorbid conditions.
- How the identified organisational and individual barriers to continuity and service delivery for people with dementia and comorbidities can be addressed
- Potential facilitators
- If there are any key issues missed by the research team

5. Contribution of existing research:

Although there is increasing recognition of the limitations of a pathology led approach for people with dementia [5] there is limited evidence to inform commissioners and providers of services as to the extent and impact of comorbidities on health care provision for PWD. This proposal will enable commissioners and service providers to make informed decisions about how best to develop services for PWD who have co-morbid medical conditions.

The rationale underpinning the proposed project is that for many people the presence of dementia may not always be the main problem but that it can complicate the management of other health needs. In addition, some comorbid medical conditions can influence the progression of dementia. The study will employ a mixed methods approach including: a scoping of current evidence; analysis of a pre-existing research-based UK dataset (CFAS – The Cognitive Function and Ageing Studies) and in-depth interviews with health care professionals and patients and their carers. This will enable us to answer questions about quality and processes of care, and how systems of care should be organised to provide care for people with dementia (PWD) and comorbid medical conditions.

This is an already well-established team of collaborators demonstrated by existing NIHR

funded research on improving the quality of community-based dementia care. Research includes the transition to becoming a person with dementia (SDO Manthorpe & Robinson, RfPB Bunn, Goodman, Brayne, Robinson, Rait), dementia care in the community (Programme Grant Iliffe, Goodman, Rait), supporting people in community setting with complex health and social care needs (SDO Goodman), collaborative care approaches to dementia care (NIHR HTA Robinson & Manthorpe), preventing avoidable hospital admissions (HTA Downs, Robinson), dementia advisors and peer support (DoH Robinson), development of a dementia risk algorithm (NIHR School for Primary Care Research Rait), cognitive function and ageing (MRC CFAS studies Brayne), and advance care planning in dementia (RfPB Robinson). In addition, the project is in line with the aims of the Cambridge NIHR Collaboration for Leadership in Applied Research and Care (CLAHRC) which is focused on mental health and would provide support for the analysis of the CFAS databases.

The study team includes researchers with a proven track record of collaboration with lay people and interest groups. The research team have developed extensive links with service users (including people with dementia and their carers), specialist service providers and relevant charities such as The Alzheimer's Society and Carers in Hertfordshire. These networks are a key resource and will be involved in the design and conduct of the study and dissemination of the findings.

A comprehensive dissemination strategy will be developed to ensure project results are made available in appropriate ways to all potential audiences. There will be an emphasis on producing information that can be used directly by NHS staff and managers to improve service delivery and organisation for people with dementia and co-morbid conditions. Senior clinical academics (LR, GR) will lead on the development of, and dissemination strategy for, practical guidance for health care professionals on the management of comorbid illness in people with dementia.

Research outputs and dissemination

Project results will be disseminated via a number of routes including published reports, peer review papers, stakeholder meetings, voluntary organisations and professional and research networks. The format of published outputs will include full detailed reports and shorter summary documents aimed at policy makers, practitioners, and patients and their families.

Research outputs will include a research summary for use across the NHS, publication of

each component of the research in relevant peer review journals and conference and seminar papers. Dissemination will be through relevant professional groups (including the British Geriatrics Society and the Dementia Alliance) and through local and national research networks (specifically topic networks for Dementia, diabetes, and stroke and local speciality groups including ophthalmology and Age and Ageing). CGoodman is chair, East of England PCRN, CGoodman, GRait, CBrayne, LRobinson are all members of DENDRON (Dementias and Neurodegenerative Disease Research Network), LRobinson is chair of DeNDRoN Primary Care Clinical Studies Group, GRait is primary care lead for North Thames DeNDRoN, CBrayne is lead for Public Health for the Cambridge and Peterborough CLAHRC, the primary goal of CLAHRC is the translation of research evidence into practice.

Results will also be disseminated through user representative networks such as the Alzheimer's Society and Age UK. In addition, we will use local research and clinical meetings such as CRIPACC's AgeNet research group which has a wide local membership and attracts an audience of older people, voluntary sector representatives, staff from health and social care and academics.

LR and GR will lead on both the development of, and dissemination strategy for, practical guidance for health care professionals on the management of co-morbid illness in people with dementia. This will be facilitated through her role as RCGP Clinical Champion for Ageing and her primary care leadership in relevant national organisations such as the Dementia Alliance and British Geriatrics Society.

Specific outputs include:

SDO Project reports

Six monthly interim reports and full final project report

Peer review journal papers

We envisage that a number of peer review journal papers will result from the study. We will aim to publish these papers in practitioner orientated and academic journals in the field of general practice, nursing and general medicine. Planned papers are:

Findings of scoping from phase 1 (month 11-12)

CFASI – service use in target comorbidities following the onset of dementia (month 9)

CFAS II – service use in target comorbidities with prevalent dementia, with comparison of change from CFASI (month 18)

Findings of interviews and focus groups in phase 2 (month 24)

Final findings and implications for practice (month 32)

Other published outputs

There will be a number of other published outputs aimed at disseminating the final results of the study to patients and their family members, practitioners and policy makers. These are:

Policy briefing

Summary of guidance on good practice

Information sheets for people with dementia and their carers. This will involve condition specific sheets covering our three tracer conditions. These leaflets will be developed in conjunction with our lay panel and representatives from relevant voluntary sector organisations.

Knowledge mobilisation activities for policy makers/practitioners

Year 1 – Stakeholder meeting to present and discuss findings of Scoping

Year 2 – Stakeholder dissemination event. This will serve the dual purpose of disseminating results from phase 1, and preliminary findings from phase 2, and ensuring that the study team receive feedback from key stakeholders. The team have links to an extensive network of general and specialist practitioner groups and these will be used to recruit participants for a stakeholder event.

Year 3 – Confirmatory conference with practitioners and policy makers. In order to increase the reach of the conference we propose to use online access, webcam technology and interactive support for questions and answers. This technology has been used successfully in a recently completed study to involve external participants in a validation event.

Knowledge mobilisation through professional and research networks

The team have extensive practice and research networks (listed above) that will be used for the mobilisation and dissemination of knowledge. For example, CLAHRC will be used as a vehicle for assisting with dissemination to clinical commissioning groups, local policy makers and practitioners. In addition to these we would work to share our findings with the RCGP

who have listed multi-morbidity as a key clinical priority. The RCGP will be appointing a Clinical Champion in Dementia in February 2012 and we will work with them to disseminate our findings as appropriate. We would also work to disseminate our findings to clinical commissioning groups through the Department of Health and through dementia champions in secondary care and to the NICE Dementia Guideline development group in order that there are available for future updates of NICE guidance.

6. Plan of Investigation:

- Pre-grant: May 2012-end August 2012: Establish reference and advisory groups, advertise for and recruit research assistant for UH (scoping and interviews) and Cambridge (secondary data analysis). Begin process for ethical and R&D approval.
- Month 1 (September 2012): Finalise protocols for scoping and analysis of CFAS
- Month 2-3 (October, November 2012): Undertake electronic and lateral database searches for scoping and screen records for inclusion, begin CFAS analysis
- Month 4-6 (December-February 2012): Extract data for scoping, develop patient information materials and interview schedules, submit application for ethical and R&D approval
- Months 7-9 (March-May 2013): Data analysis scoping, prepare CFAS1 paper for submission to journal
- Months 10-11 (June-July 2013) – Stakeholder meeting to disseminate and discuss results of scoping, prepare final scoping report and paper for submission to journal, begin analysis of CFAS II (including incorporation of CFASII service cost data)
- Month 11 (July, 2012): Recruit Newcastle RA. Liaise with organisations and individuals involved in recruitment
- Months 12-18 (August – February 2014): Recruitment and interviews/focus groups
- Months 16-18 (December-February 2013) : Prepare CFASII paper for submission to journal
- Months 19-22 (March -June 2014) – Analysis of interviews & focus groups, organise and run stakeholder dissemination event
- Months 23, 24 (July, August 2014): Write up results of interviews/FG and prepare paper for submission to journal
- Month 25-27 (September-November 2014): Synthesis of data from scoping,

secondary data analysis and interviews

- Month 27-30 (November 2014-February 2015): Organise and run confirmatory conference, opportunity for stakeholder feedback. develop guidance
- Months 30-32 (February-April 2015): Prepare final report, prepare paper for submission to journal and disseminate findings

7. Ethical Issues:

Ethical approval for the interviews will be obtained via IRAS. We anticipate that the study will be adopted by East of England, and Northumberland, Tyne and Wear PCRNs and North Thames and North East DeNDRoN who will assist in obtaining R&D approval. As the interview schedules will be shaped by findings from the scoping study we will be unable to apply for ethics and R&D approval before the study begins. However, much of the preparatory work for ethics and R&D will be done before the study begins so that an application can be submitted as soon as interview schedules are ready. We anticipate we will have gathered enough information from the scoping to be able to apply for ethics approval in month six; allowing six months for ethical and R&D approval before recruitment for the interviews is scheduled to begin.

Ethical issues

As some of the participants will have a degree of cognitive impairment, careful consideration needs to be given to the consent process. Before interviews begin researchers will explain the purpose of the study, checking the participants understand this and can communicate their decision either verbally or written. Researchers will be guided by a checklist for assessing capacity to participate in research published by The British Psychological Society [48]. In instances where people with dementia are judged to lack capacity to consent we will interview their carer only. Interviewers will be sensitive to the cognitive abilities of participants with dementia and will alter questions or interview schedules as necessary.

The Research Fellows at both the University of Hertfordshire and at Newcastle University will have experience of undertaking field work with vulnerable older people, including those with dementia. Both institutions have a track record in undertaking research with frail and vulnerable populations including those who lack mental capacity and have a recognised

expertise in this area [25, 49]. The design of the study ensures that senior staff will be closely involved in data collection and supervision of data collection.

We will nevertheless ensure that all researchers undertaking fieldwork will undergo Good Clinical Practice Training and Training on the Mental Capacity Act and Assessment of Capacity. Both courses are offered via CLRNs and are regularly available. In addition supervision and support for research assistants will be provided by Professor Claire Goodman and Dr Frances Bunn at the University of Hertfordshire and by Professor Louise Robinson at Newcastle. They have previous experience of interviewing this patient group, supervising researchers working in this area, and are aware of issues around capacity and consent.

Confidentiality

All information about participants will be kept confidential and they will not be identifiable in any written reports. Their name will only appear on the consent form they sign. However, if during the interview with patients and their carer's, issues are raised that relate to a serious compromise of patient safety and care, the researchers will be obliged with the participant's full knowledge to take appropriate action. This will be made clear in the relevant Participant Information Sheet. A protocol for establishing and dealing with bad practice will be followed by the research team.

Data will be stored on University of Hertfordshire and Newcastle University computers conforming to data protection regulations. Only the research team will have access to the data. Data generated from the study will be kept for 5 years in locked University data archive premises.

8. Project Management:

Dr Bunn is PI and will act as project manager. We propose to employ three part time research assistants one at UH (Dr Anne-Marie Burn), one at Cambridge (TBA) and one at Newcastle (TBA). Dr Bunn will be responsible for supervising Dr Burn and liaising with the other applicants and other RAs employed on the project. She will meet weekly with the RF employed at UH and will hold regular team meetings with the research assistants employed at Newcastle and Cambridge (either face to face or via telephone). Dr Sam Norton and Professor Brayne will be responsible for supervision of the RA at Cambridge and Professor

Robinson for the RA at Newcastle. The project team will meet (face to face or via teleconference) every 8-12 weeks.

The project will be overseen by an Advisory Group. As well as members of the project team the advisory group will include: Professor Murna Downs (Professor in Dementia Studies), Ms Wendy Ward a dementia liaison nurse, a representative with the Alzheimer's society (TBA), Ms Heather Maggs a member of the UH Public Involvement in Research Group and a former dementia carer, Dr Kunle Ashaye a consultant in Old Age Psychiatry, Dr Declan O'kane a Stroke Physician and Dr Catherine Dennison the R&D manager for the Thomas Pocklington Trust. The advisory group will meet three to four times during the course of the study and its purpose will be to guide the research, monitor its progress, comment on emerging findings and support dissemination.

9. Service users/public involvement:

A well-established Public Involvement in Research Group (PIRG) at the University of Hertfordshire has a broad membership of service users and carers. A member of this group (Heather Maggs a former dementia carer) has commented on the research proposal and will collaborate with the team throughout the project. She, and another member of the public will be invited to join the project advisory group. As members of the advisory group they will have the opportunity to comment on research methods and study documents (including patient information sheets) and be involved in interpreting and disseminating the review findings.

In addition, we will invite members of the public to join a study user reference group. This group will be involved in the design and conduct of the research including: guiding the development of the interview schedule, guiding and challenging our interpretation of the qualitative findings, facilitating understanding of the implications for continuity from a service user perspective and advising on the dissemination process. It is envisaged that we would hold three user reference group meetings over the course of the project and that members of the user reference group would also be invited to attend the stakeholder meeting in phase one and the confirmatory conference in phase three.

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