Full title: Service provision for older people who are homeless and have memory problems

Aims and objectives

The overall aim of this research project is to investigate and improve service provision for older homeless people with memory problems (consistent with mild memory problems [MCI] or dementia). In homelessness services, the term ‘memory problems’ is generally used to refer to memory problems or dementia.

The objectives are to investigate:
- the prevalence of memory problems amongst older homeless people living in hostels and extent to which homeless sector staff are aware of and respond to cognitive problems, such as dementia, amongst their service users
- the pathways by which older homeless people with suspected cognitive problems are referred to memory assessment services, the services and support that this user group currently receives for cognitive problems, the cost of these services
- how existing services can be developed to address any gaps in service provision or unmet need, and
- how homeless people with memory problems perceive their quality of life and available support.

Specific research questions are:

Awareness: To what extent are homeless sector staff aware of memory problems among their older clients? How does this impact on their practice or service? How are homeless sector staff able to respond to memory problems among their clients?

Service pathways: What ‘service pathways’ exist for an older homeless person with memory problems to be referred to appropriate memory assessment services, and thence to appropriate support? What are their experiences of these services?

Unmet need: What are the gaps in service provision for such individuals, and what are the costs of providing services for them?

Perception of quality of life: How do older homeless people with memory problems perceive their quality of life, and how can this be evaluated? Does this differ from other older people and other older homeless people? What are the implications of this for agreeing outcomes from services?

Background

There is very little evidence in the UK about the circumstances and needs of older people who are homeless and have memory problems, although the subject has received some attention in other developed countries such as the United States (Joyce and Limbos 2009) and Australia (Rota-Bartelink 2006; Rota-Bartelink and Lipmann 2007). The UK Coalition on Older Homelessness defines ‘older’ homeless people as those aged 50 or more years, because many in their fifties have chronic health problems and disabilities normally associated with old age. Approximately one-fifth of homeless people on the streets and in hostels are aged 50 or more years (around 8% are aged 60+ years). Audits undertaken since 2006 in Blackburn, Brighton, Cambridge, Liverpool, Oxford and Westminster by homeless sector staff suggest that 10-16% of older homeless people have ‘serious memory problems’ or ‘have memory problems / are prone to wander’. All audits have relied on the observations of staff, not those of mental health workers or clinical examinations or tests; various lower age limits have been applied (from 45 to 60 years); and profiles of the clients are unavailable. A number of issues may contribute to the problems reported – alcohol abuse resulting in B-12 vitamin and folate deficiencies, untreated HIV, vascular disease, head injury and chronic brain injury. Around two-fifths of older homeless men and one-
fifth of homeless women have long histories of alcohol abuse, and there is a strong association between long-standing heavy alcohol consumption and Korsakoff’s syndrome, which is characterized by loss of short-term memory.

Little is known about the problems faced by older homeless people with cognitive impairment, the services and support that they receive, and the extent to which their needs are met. Some are hard to engage, reluctant to work with services, and are difficult to assess and help because of persistent heavy drinking. There are also added problems of challenging behaviour, physical health problems, and self-neglect. There is little information about the help available to homeless sector staff working with this group, and their knowledge and experiences of accessing health and social care services. So there is a need, which is acknowledged by the sector, to gain a greater understanding of these issues, identify the barriers to diagnosis, service access and unmet need, and ways these might be addressed.

Many older homeless people with memory problems are unable to live independently, and homeless sector staff struggle to find suitable long-term housing for them. Some therefore remain in hostels for years. Those in their 50s are often not regarded by statutory services as ‘elderly’. Moreover, at least two-thirds of older homeless people are men and problems have arisen when they have been re-housed in care homes, which tend to be occupied predominantly by very elderly women (Crane and Warnes 2007). Care home staff find it difficult to manage these residents’ drinking and/or chaotic behaviour and some are evicted. This study will examine the care ‘pathways’ for older homeless people with cognitive impairment, the help and support that they receive and their unmet needs, the factors that facilitate and create barriers to achieving effective and acceptable support, and the costs of providing services to the group.

Additionally, although several measures of social functioning and wider quality of life have been developed for use with people with chronic mental illnesses (Bowling 2001; Thornicroft and Tansella 1996), their development for use with people with dementia has been slower, although there is a long history of measurement of stress and coping among carers. None appear to be relevant to the social circumstances of older people who are homeless with all the factors that this social status generally brings (lack of family contact or meaningful activities). Moreover, and in contrast to most other clinical specialties, the quality of life measures developed in social psychiatry have been clearly embedded within a strong conceptual framework, including medical and multi-dimensional, holistic models of functioning (WHO 2001), wider health and psycho-social needs-based and life satisfaction models (Bowling 2001) that take ‘home’, ‘occupation’, ‘social contacts’ for granted. The robust measurement of Quality of Life (QoL) among homeless people with dementia has also been neglected, although there is a literature on QoL among people with mental illness who are homeless (emphasising maintenance of stable housing, food and clothing, health and risk of victimisation; Sullivan et al. 2000), and among homeless people per se (emphasising food, shelter, necessities, respect, choice, relationships; Russell et al. 2005). Just as QoL measures generally need to reflect the priorities of the target population, a QoL instrument for those with dementia and who are homeless or ‘hard-to-house’, must reflect their own needs and priorities. It is uncertain whether current measures address these issues. The first part of the study will examine how older homeless people with memory problems perceive their QoL, and the appropriateness of existing QoL instruments in reflecting the needs and priorities of this client group.

The second part of the study will focus on the current lack of research evidence and knowledge on the extent of the problem of memory problems and service access amongst older homeless people. Other studies have focused on other health conditions amongst this group (e.g. Hill et al., 2011 who have focused on dental problems). Hostel staff are likely to play a key role in identifying problems and steering clients into services, but they may not be trained or aware to recognize the indications of memory problems / dementia or know what services are available or how to trigger them. This study addresses this gap in understanding of memory problems amongst older homeless people and seeks to improve service provision for this marginalized group. It is a partnership between a research team with a range of complementary skills and experiences in
the NHS and beyond and a major homelessness service, St Mungo’s, who will ensure that the study is grounded in service user needs and priorities and that findings are relevant to practice.

We have deliberately used the word "memory problems and cognitive impairment" rather than “dementia” or “Alzheimer’s disease” or “Korsakoff’s syndrome” in order to be as inclusive of participants as possible. We are especially keen to include those who may not have received a diagnosis of dementia as yet; yet whose level of cognition may be suggestive of this or MCI. As our study is an exploratory one, aiming to chart service pathways, one of the first in this population – this inclusive definition will be necessary. It is our experience that if a discussion is held with hostels using the term ‘dementia’ that they do not see this applicable to residents. However, if this is pursued, then terms like memory problems, associated with age, begin to elicit greater interest and recognition. Hostel staff have informed us that they do indeed encounter people whose abilities to self-care and who are ‘declining’ or becoming frail’.

We have taken the advice of medical clinicians and service providers about the terminology and their views of the potential for multi-morbidity (e.g. mental illness and/or dementia). Their advice has been that memory problems are the ‘workable’ definition. Dr Phil Timms comments from his clinical practice that the main issue is likely to be a range of memory impairments in this population – often, but not only, due to chronic use of alcohol and that age-related memory problems are being encountered. This range of memory impairments will present similar management challenges in these environments, whatever the underlying pathology. In terms of service provision, the defining factor/problem to be managed is memory or declining abilities, not (in most cases) its original cause. Improving dementia services by identifying the possible challenges, presented by homeless people accessing their support will be our aspiration. Similarly, dementia services will need to meet requirements for equitable and accessible provision. Our study will identify some potential barriers and means to address these. This should enable care or patient pathways for this group to be optimal.

Need

**Health and social care need:** The number of people with dementia and the numbers of homeless people are rising (Fitzpatrick et al. 2011). There is a continuing need for the development of high quality services that reflect the experiences and expectations of people with complex and marginalised lives.

**Expressed need for research:** The Ministerial Advisory Group on Dementia (MAGDR) report recommends that public and professional awareness and understanding of dementia should be improved. It refers to caring for people with dementia at home, and in hospital and care homes, but there is no mention of those who are homeless and socially-excluded. This study will seek the opinions of older homeless people with memory problems about their support needs to inform policy and ensure that the aspirations of the National Dementia Strategy are inclusive of people who are often marginalised.

**Sustained interest and intent:** Hostels provide ‘temporary’ accommodation for homeless people, are principally funded through the Supporting People programme, and there is an assumption that residents will move on within two years. Yet some older homeless people with memory impairment and other vulnerabilities remain in hostels for years as there is no suitable alternative accommodation. Hostels are not designed or staffed to provide long-term housing and a high level of support for this client group. In addition, many older homeless people dislike staying in hostels, through fear of intimidation and violence from younger residents (Crane 1999). The study will provide guidance to aid commissioners in the development of effective support for this client group.

**Capacity to generate new knowledge and skills:** The MAGDR report recommends that all people with dementia should have access to a pathway of care services, including specialist assessment, treatment, care and support that are responsive to the personal needs and preferences of each individual. It also recommends that health and social care staff working in
care homes with people who have dementia should receive appropriate training and continuous professional development, and that older people’s community mental health teams should provide specialist services in care homes. There is no recognition of the particular difficulties of providing care and support to older people with memory problems who are homeless. Many are hard-to-engage, resist offers of help from homeless sector staff and other agencies, and are without family for support. This research is needed to help homeless sector staff find ways to support older homeless people with memory problems on a day-to-day basis, and ‘manage’ possible challenging behaviour. It will provide new evidence and guidance for practitioners in dementia services and in housing services about the help and support that are needed for this client group, and about practices that are effective.

**Generalisable findings and prospects for change:** Although qualitative research is not generalisable in the statistical sense of the word, this mixed-methods study has the scope to influence policy and practice across the UK. By conducting research in three diverse sites, we aim to provide evidence of common concerns and to tease out implications for policy and practice at a generalisable level.

**Building on existing work:** This project builds on Crane’s pioneering work on the problems and needs of older homeless people, and of the effectiveness of services for them (Crane 1999; Crane and Warnes 2002, 2005, 2007; Crane et al., 2005; Crane et al. 2010; Crane and Joly 2011), a recent ESRC multiple exclusion homelessness study (Cornes, Manthorpe, Joly et al. 2011); on-going research into mental capacity and decision-making (Samsi et al., 2011; Manthorpe and Samsi, 2009); QoL and outcome measures (Banerjee, Samsi et al. 2009; Bowling 2005; Bowling 2009); resiliency and QoL in dementia (Samsi 2010); transitions in dementia assessment (Manthorpe, Samsi et al. 2011) and will combine expertise in the field of dementia care to improve health, housing and social care services for a marginalized group.

**Methods**

In order to address the four research questions, this study incorporates three Work Packages (WP):

**WP1: Narrative systematic review (Months 1 to 6)**

In order to address objective 1 (prevalence of memory problems amongst older homeless people) and objective 4 (how homeless people with memory problems perceive their quality of life), we will begin by undertaking two narrative reviews in each of these areas.

The first will investigate evidence of the prevalence of memory problems among older people who are homeless. There is limited literature in this area, but as the numbers of older homeless people are set to increase, this is potentially a growing problem. This brief review will take the form of a scoping exercise that will inform the prevalence study being conducted in WP2.

The objectives of this review are to:

- Determine prevalence of older homeless people, with and without cognitive impairment, by synthesising audits and surveys.
- Explore the range of definitions of memory problems used in these studies.
- Determine if studies have conducted service use evaluation for this marginalized group and to explore barriers and facilitators to uptake of services and support.

The second will be a narrative systematic review and evidence synthesis of quality of life (QoL) instruments used in assessing people with dementia (all types), to assist investigators and service providers to select the optimal measures for their aims and to specifically address issues and life areas that are of particular importance to homeless older people. There is a large body of literature in this area and a narrative review and critical discussion, with tabulated evidence, is required in order to compare measurement properties of QoL instruments identified, their appropriateness for assessing the QoL of homeless people with dementia, and by type and
severity of dementia, sensitivity to the type, organization, delivery and use of health service interventions.

The objectives of the systematic reviews are to:

- Assess the scope and domains included in the QoL measures, theoretical and conceptual frameworks, and the extent of user involvement in their development, by type of users
- Assess their sensitivity to different models and settings of care, the process, organisation, delivery and take-up, and outcomes of services (including service skill-mix and voluntary sector interventions).
- Assess how perceived QoL influences decisions about the care of people with dementia, including homeless groups.
- Identify factors that affect reported QoL, and QoL outcomes of people with dementia, including among homeless groups.
- Examine the relevance of existing dementia QoL measures, and their appropriateness, in relation to people who are/have been homeless.
- Summarise current data on the QoL of people with dementia, including homeless groups.
- Identify research gaps and the need for further primary research.

**Search strategy**

A comprehensive, cross-disciplinary, systematic search of the conceptual and empirical literature on both topics will be conducted, across clinical and social sciences, and health, housing and social care. There will be no age restrictions, no dwelling restrictions, and we will search for any type of literature published or written since 1966 (to current date of search). These can include observational studies, controlled evaluations and randomised controlled trials of health and social service interventions.

We will search the following databases for relevant literature from inception to current search month/year: Allied and Complementary Medicine (AMED), Applied Social Sciences Index and Abstracts (ASSIA), BNI, Cochrane Database of Systematic Reviews (CDSR), Cochrane Central Register of Controlled Trials (CCRCT), Cumulative Index to Nursing and Allied Health Literature (CINAHL), EMBASE, Intute (Social Sciences, and Medicine), MEDLINE, PsycINFO, Science Citation Index, SCOPUS, Sociological Abstracts, Web of Science and Web of Knowledge. The Social Care Institute of Excellence (SCIE) and Health Technology Assessment websites will also be searched.

The following databases will also be examined to retrieve any unpublished or grey literature: Index to Theses, Dissertations and Theses, System for Information on the Grey Literature (OpenSIGLE). Contacts with experts will be made to identify remaining grey literature.

**Process of review**

The process for both reviews will be roughly the same. Two independent reviewers will screen all titles and abstracts retrieved for relevance to the study aims; disagreements will be resolved by consensus. If relevance criteria are met, then the full text article will be obtained. The full text of obtained articles will be judged to be potentially relevant by two independent reviewers. For both reviews, a list of key questions will be generated, and a pro-forma will be developed to address these from the included papers. These will be piloted on 30 of the selected papers. Checklists will be used for assessing the psychometric properties, and methodological quality of the selected studies.

Full text copies of all papers considered to be potentially eligible will be obtained. Any disagreement will be resolved by discussion between the reviewers and a member of the team with experience of systematic reviewing. Authors of primary studies will be contacted for clarification if necessary. The quality of included studies will also be assessed independently by two reviewers, by completing a risk of bias table. Data extraction will be completed independently by two reviewers using a standard data extraction form. Any discrepancies in quality ratings or
items of data extraction will be resolved by discussion with a member of the team with experience of systematic reviewing.

For the second narrative review, psychometric properties of identified measures will be identified and assessed using gold standard criteria (Streiner and Norman, 2003) as used by Fitzpatrick, Bowling et al. (2007) in their reviews of PROMS in selected chronic conditions (physical health), and Smith et al. (2005) in their overview and development of their quality of life scale in dementia (DEMQOL). A panel of users will be convened in order to assess, with the applicants, the appropriateness of the most robust measures for people who are homeless, and to identify any missing areas. Findings from the reviews will be early products of this study.

**WP2: Memory problems among older hostel residents and staff’s awareness of the problems**

This WP will address objective 1 by examining the extent of memory problems among older hostel residents, the staff’s awareness of the problems, and the actions that are taken when such problems are recognised. The study will be carried out at four diverse sites in different areas of England: Blackburn, Cambridge, Lambeth in South London and Westminster in Central London. As noted earlier, audits were undertaken in some of these sites by homeless sector staff in 2006 and growing numbers of older homeless people identified locally. This research will therefore build on this earlier work. There has been enthusiastic response from the relevant hostel managers in the study areas, who welcome the need for the research as they perceive needs to be growing. In order to protect confidentiality, the names of the hostels are not provided here and will be anonymised in the study, but all have agreed to participate in the research. In London, three large hostels will participate: run by St Mungo’s, Thames Reach, and the Salvation Army. We have interest and support for this study from local health colleagues (see letter from Dr Ginny Wright of Imperial College Healthcare NHS Trust). In Blackburn, the hostels are run by the Ashley Foundation and the Salvation Army (see letter of support from Dr Kaiser of Pennine Care NHS Trust). In Cambridge, the hostels are run by Cambridge Cyrennians and local secondary mental health services and the NIHR research translation network have indicated their wish to assist with this study (see letters of support from Dr Denning and Professor Holland). Professor Bhugra (see letter) has indicated the support of the Royal College of Psychiatrists.

WP2 will involve the following steps:

**Interviews with older homeless people**

A maximum of 50 older people in each of the four study sites will be interviewed – sampling will take place if this number is exceeded. Participants will be identified by hostel staff who will discuss the study with them briefly, and seek their permission to pass their name to the interviewers. The interviewer will then explain the study to them in detail and seek their written consent to participate. An accessible Information Sheet about the study will be produced and given to potential participants. This will explain the purpose of the study and what their involvement would entail. Only those who give informed consent will be interviewed. The consent form will also seek their permission to collect information from hostel staff about whether they believe the participant has memory problems. This will not be a condition, however, of their involvement in the study. The older hostel residents will be given £5 for their time. [A policy for Payment for Participation (attachment 3) will be followed.]

Short interviews will be conducted, with consent, with older homeless people (aged 50+ years) in the participating hostels, to collect background information and assess their levels of memory loss / cognitive impairment. Through discussion with staff, and a sample of clients, a semi-structured questionnaire will be designed to collect details from participants on: (i) demographic factors (age, gender, ethnicity); (ii) brief histories of homelessness, i.e. length of time homeless, duration of stay in present hostel; and (iii) past and current health and substance misuse problems, including histories of head injuries and other accidents / traumas, other known diagnoses, including chronic conditions, past hospitalisations.
The researcher will then administer the Mini-Mental State Examination (MMSE) to each participant. This instrument is widely used by lay researchers (i.e. those not medically trained) and all the researchers in this study are familiar with the use of this. This is considered a reliable screening instrument and is used routinely in clinical practice and in research to screen for cognitive impairment. Based on the advice of applicant Dr Phil Timms and discussion with his clinical colleagues, a cut-off score of 25 (out of a total of 30) will be used to suggest the presence of cognitive impairment.

**Interviews with hostel managers**

Semi-structured interviews will be conducted with the hostel managers in each study sites. Using an Interview Schedule, generic information will be collected about what the hostel does / does not do about identifying people with memory problems, daily practices and possible referrals. We will ask them about the number, profiles and turnover of hostel residents and staff, and intensity of keyworking; support sought for or by those with cognitive impairment; and any unmet needs of this user group. Additionally, we will seek information about the bigger picture of finances, resources and policies by exploring funding sources for the service and payment options available to clients. All data will be stored in a folder marked “WP2 Service policy review”.

**Interviews with hostel workers**

Information will also be collected from designated hostel workers about their ratings of whether the older people who are interviewed have memory problems and their reasons for believing this (these details will only be collected for the older people who consented to this). These interviews will include:; (ii) number of older residents whom staff believe have memory problems by rating the possibility of their having cognitive impairment; factors that lead them to reach this conclusion will also be explored; (iii) what help and support staff and other hostel residents provide to such people, and the feasibility and difficulties of this; and (vi) the training, support and professional development of staff in relation to older people with memory problems, and views of their strengths and limits. Informed consent from the staff to participate will be obtained, and interviews will be recorded and transcribed.

**Interviews with consultant psychiatrist**

In each of the study sites, Dr Phil Timms (consultant psychiatrist) will interview a total of 38 older homeless people across all four sites (10 in Blackburn, 10 in Cambridge, 9 in Lambeth, 9 in Westminster). Of these, it is estimated that 30 will be those identified by researchers as having potential memory problems (8 in Blackburn, 8 in Cambridge, 7 in Lambeth, 7 in Westminster). The remaining eight will include a randomly selected sample of those ascertained by the interviewers as not having cognitive impairment. Dr Timms will review all participants’ hostel records, conduct cognitive testing, confirm as far as possible the presence or absence of cognitive impairment, and identify any confounding diagnoses which might have implications for use of services. He will be ‘blinded’ to whether or not participants have suspected memory problems. The aim is to compare the accuracy of hostel staff perceptions of whether a client has memory problems vs. MMSE scores vs. expert judgement (using a similar methodology to Morrell et al., 2011).

**Data analysis for WP2**

Quantitative data from the interviews with older homeless people and with staff will be entered into a SPSS database. The qualitative data analysis software N-Vivo 7 (QSR International, 2002) will be used to process the open-ended responses, code the data and identify themes in an efficient and systematic manner, borrowing on the principles of framework analysis (Pope et al., 2000). While some qualitative research (e.g. grounded theory) tends to be inductive, approaches such as framework analysis enable qualitative methods to be used for deductive pre-specified research questions as well (Pope et al., 2000). All transcripts will be independently scrutinized by KS, MC, LJ and JM to identify emerging themes, develop a thematic framework and draw out interpretations and other commonalities.

The quantitative analyses will examine MMSE scores among older homeless people by factors such as age, prolonged heavy drinking, and histories of homelessness. Comparisons will be
made between hostel staff’s perception of memory problems and the findings of the research team, taking into account factors such as age, alcohol problems, length of time in hostel, and the MMSE scores. The research team has experience of conducting statistical analyses, but we have access to a Unit statistician, if necessary. Other variables of interest in the recognition of memory problems will be: the number of hostel residents and staff; the intensity of keyworking; and staff training/professional development. The factors identified by staff which led to them successfully recognising or suspecting memory problems will be elucidated during qualitative interviews.

Although study numbers appear limited for a full-scale epidemiological study, we would like to reiterate this is a pilot study which will indicate the methodology we will need to employ for WP3. Given the challenges of research with this population, in this setting, and limited resources, it seems reasonable to test the situation with a small number of hostels and their residents. We aim to learn from the methodology and strongly feel that, depending on our findings, a larger scale epidemiological study can be developed, which at this stage is too ambitious. We are aiming for our study findings to be as representative of the population as possible by situating our sites in three of the areas where audits have indicated the presence of older homeless people with memory problems: Blackburn, Cambridge, Westminster.

WP3: Services received by older homeless people with memory problems and costs

This WP addresses objectives 2, 3 and 4 of this study, by exploring service use, unmet need and service user perspectives. WP3 adopts a longitudinal case comparative approach, the purpose of which is to determine in detail the health, housing and social care services, and other support received by older homeless people with cognitive impairment, compared to other homeless people without cognitive impairment. ‘Service pathways’ for both groups will be charted and the costs of providing will be calculated and compared over a six month period.

Study population: We will undertake case studies of 30 older homeless people with memory problems divided between the study sites (henceforth, referred to as observation group, OG). Only those confirmed by Dr Timms in WP2 as having memory problems will be included. Case studies will also be undertaken of 30 older homeless people without memory problems (henceforth, referred to as comparison group, CG). The samples will be matched on the basis of age and duration of homelessness. WP2 will inform the selection of people for the case studies.

As WP3 adopts a case-study approach, the sample size (30+30) is adequate for this purpose. Findings will not be seen as definite in themselves, but as indicative of the methodology required to support a larger cost-analysis study. At this pilot study stage, a case study methodology is appropriate as it will enable us to explore in-depth the predominant factors and challenges that staff in these services face within a real-time context (Yin, 1999). A case study approach can be especially useful in researching practice settings (Crabtree and Miller, 1999).

Recruitment: The study will be explained in detail to the participants, including its (short) longitudinal nature, and their informed consent to be involved will be obtained. This will include permission to collect information from their hostel manager or project worker, from other agencies providing support, and from hostel records. Because of the need for comprehensive and reliable data, only those who give consent for information to be collected from hostel staff and elsewhere will be included in this part of the study. Once again, the consent form will explicitly state that should there be any urgent personal, service or safeguarding need identified during the interview not already known to hostel staff, the research team will share this information with the hostel manager/project worker or GP. They will be offered an incentive payment of £5 at each interview. We have now developed a Consent protocol which highlights that people unable to consent at follow up interviews will not be automatically excluded from the study. Instead, a consultee will be identified who will be able to inform us regarding whether or not the individual should remain a part of the study. We have done this to reflect the principles of the Mental Capacity Act 2005 and so as to not marginalise those without capacity to consent.
Research methods: Using semi-structured questionnaires, information will be collected from the OG and CG individuals at baseline, after three months, and after six months about:
   i. their problems and needs;
   ii. help and support that they currently receive and from whom;
   iii. referrals and use of health, substance misuse and other services since last interview (at baseline, 3 and 6 month interviews);
   iv. how they spend their time, social contacts, and their perceptions of their quality of life (informed by WP1);
   v. help to achieve the outcomes they would like but do not currently receive; and
   vi. their hopes for the future in terms of housing and support.

The questionnaires will be piloted and revised accordingly. The MMSE will also be administered at three and six months.

The Client Service Receipt Inventory will be customized for the collection of this information. This is a well validated and widely used instrument that captures the full range of health, social and voluntary sector provision (Chisholm et al. 2000). Prior to use, the questionnaire will be piloted with six people from the St Mungo's service user group and revised accordingly.

Maintaining contact over time: Each person will be followed up over six months. If they move, contact will be maintained at the new address. The research team has a great deal of experience in conducting longitudinal research with homeless people, and it is relatively easy to keep in contact with older homeless people than other age groups. They are not highly transient and tend to remain in the same accommodation. Moreover, any planned move will generally be with the support of their keyworker or resettlement worker - thus obtaining their new address should be straightforward. Crane successfully maintained contact with older homeless people for 24 months during a longitudinal study of their resettlement (Crane and Warnes 2002). Crane, Joly and Coward have considerable experience in tracking homeless people who have had unplanned moves from their accommodation or who are more difficult to contact. In the recent FOR-HOME study (Crane, Warnes and Coward, 2011), 400 homeless people of all ages were followed up after being resettled for 18 months. Among the 56 respondents aged 50+ years, contact was lost with only 5%. This was achieved through a diligent tracking system and through persistence, flexibility and collaboration in arranging interviews. Moreover, in London, the CHAIN database allows the movements of homeless people with experience of rough sleeping to be traced as hostel staff have access to this.

Other data sources: Interviews with the OG and CG will be supplemented at each wave by (i) interviews with the hostel manager or their keyworker; (ii) interviews with other providers involved in the individuals’ support; (iii) hostel case records. At final follow-up, GP case records will be accessed. Details will be collected about:
   i. staff perceptions of individuals’ problems and needs;
   ii. types of help currently being received within the hostel and externally, frequency of this help, and from whom;
   iii. use, since last interview, of health, substance misuse and other services, such as day centres;
   iv. referrals to other services and outcomes;
   vi. the behaviour of the person and their willingness to accept help; and
   vii. unmet needs and reasons for these.

Data analysis for WP3: The analyses in WP3 will concentrate on the problems of older homeless people with memory problems, and the support that is required and provided over time. Changes over the six months will be analysed in relation to memory problems (MMSE scores), support needs, contact with services, and help received. Pathways into services will be traced. Service-delivery factors influencing the provision of support will be examined, including the hostel staff’s capacity and skills to meet the needs of the client group; the availability and accessibility of local services for the client group; and the willingness of local statutory services to offer help to certain groups with memory problems, such as homeless people, heavy drinkers and people aged in their fifties. Personal factors influencing the provision of support and the person’s willingness to accept help will also be examined, including age, duration of homelessness,
physical health problems, alcohol problems, social contacts, perceptions of quality of life and hopes for the future.

Differences in the amount and type of service contact will be compared between older homeless people with and without memory problems. Health and social care services used by people in the OC and CG will be converted to costs using nationally validated data on unit costs (Curtis, 2010), and information from local financial/commissioning managers. Regression modelling will be used to explore the main cost drivers, including the presence (or not) of memory problems and background factors. Dummy variables to represent sites will be used to explore location-specific influences.

**Outputs:**
The research team will work jointly with St Mungo’s to develop strategies to maximize long-lasting impact on policy and practice, which will continue even after the grant period.

Throughout the study we will be engaging actively with members of our Advisory Group, which we have detailed in the section entitled *Contribution to collective research effort and research utilization*. During the phase of data analysis, we will conduct a systematic consultation of the views of our Advisory Group, homelessness staff, health and social care staff, our Department of Health representative, and of St Mungo’s ‘Outside In’ peer support group. We will also conduct one workshop in each of the hostels where we collected data for study participants to be given the opportunity to hear our findings and express their interpretations of it. Any recommendations for policy and practice that are discussed will be recorded. Any new information that emerges will be incorporated into the findings.

We intend to disseminate findings throughout the course of our project in a number of ways. We will aim for wide readership of our publications and audience at our seminars and, therefore, will target academic as well as practice journals and conferences.

- A full report (with executive summary) which summarises the study’s findings: the prevalence of memory problems among older homeless people and the characteristics of those affected; existing evidence of barriers and facilitators to accessing services; the awareness of homeless sector staff of memory problems among their clients and actions taken when problems are suspected; the services received by the client group and their appropriateness; service needs and quality of life as perceived by the client group; and staff’s perceptions of unmet needs and services required. (This will provide new evidence about a marginalised group of people with dementia or whom may be accessing memory assessment services).
- A review of quality of life instruments and their suitability for homeless people, and the development of a unique QoL instrument appropriate for older homeless people with memory problems.
- A practice guide for homeless sector staff on recognising potential memory problems among older homeless people, their service needs, and responding to these needs, including referrals to services.
- A practice guide for primary healthcare staff about the distinct problems and needs of older people with memory problems who are homeless, and ways of meeting their needs.
- A resource guide for commissioners about the services used by and needed for this client group and costs of providing these services.

During the lifetime of the project, we will attend and contribute to practice and service-user networks with which we are already engaged. These include: Homeless LINK, Crisis, Making Research Count, NIHR School of Social Care Research, Alzheimer’s Society’s, Journal of Dementia Care and the Dementia Congress.

We will also attend a minimum of 5 conferences over the course of the study, including dementia and Alzheimer’s disease conferences, health services research conferences and others related to
homelessness. We will aim for these to be at local, national and international levels. We will ensure that our own annual Older People’s Conference includes material from this study.

For the NIHR SDO programme, in addition to the Final Report (and an Executive Summary) which we will produce at the end of month 24, we will also produce 2 interim reports at months 8 and 16 to keep the programme up to date with our progress. These will be advertised on our own unit website and a downloadable link will be sent around to all participating hostels and homelessness networks. Copies of the report and the summary will be sent to relevant government departments, including the Communities and Local Government, Department of Health, the Ministerial Working Group on homelessness, the Ministerial Advisory Group on Dementia and the All-Party Parliamentary Group on Dementia. We will offer to conduct presentations at relevant homelessness agencies and services, such as St Mungo’s, Shelter, Salvation Army, Homeless Link and the Chartered Institute of Housing.

Project summary

Little is known about the problems faced by older people who are homeless and have cognitive impairment, how this is recognized and responded to, the services and support they receive, and the extent to which their needs are met. This research will investigate these issues.

Specific research questions will explore:
1. The extent to which hostel staff are aware of memory problems amongst their clients
2. The support and services received by older homeless people with cognitive impairment, the costs of these and the identification of any unmet need
3. The service pathways for this group as they are referred, assessed and diagnosed with memory problems and their experiences of these services
4. The perception of quality of life amongst this group and how this can be evaluated

The study will be carried out in four diverse study sites: Blackburn, Cambridge, and the London boroughs of Lambeth and Westminster. We define older in this population as over 50 years of age (as recommended by the UK Coalition on Older Homeless).

The study is designed in 3 work packages (WP). The first is a systematic investigation of the literature. The first of these will examine what is known about the prevalence of memory problems amongst older homeless people and their access to services and support. The second will be an evidence review of the use of quality of life measures in dementia and to identify suitable outcome measures for a specific population of older homeless people with memory problems. Outputs will add to the evidence base in this field, will aid the development of relevant outcome measures and will inform WP3 which will explore this subject with older homeless people with memory problems themselves.

WP2 will explore the extent of awareness of homeless sector staff in recognizing and identifying memory problems amongst their older homeless clients. We will also explore staff response to identification of cognitive impairment, in order to understand service pathways for this client group. We will conduct assessments with 50 older people in each site, in order to assess the prevailing levels of cognitive impairment. This will be followed by a confirmatory cognitive assessment by a consultant psychiatrist familiar with this client group of seven older people with cognitive impairment. Discrepancies amongst cognitive assessments will be discussed with the relevant project worker and the research team will add to the data in this WP2. Principles of framework analysis will be applied to qualitative interview data.

WP3 will adopt a mixed methods case study approach, as it will follow 30 older people with memory problems and 30 people without cognitive impairment, over four sites for 6 months. Interviews will be conducted at baseline, 3 months and 6 months. Through hostel staff interviews, hostel case records and records from GPs and other service providers, we will determine the services and support both groups received, and the costs of providing these services. Details will
be collected at the start of this work-package. Older homeless persons themselves will also be interviewed to gather their perspectives on their problems, needs, services received, aspirations, and quality of life. The comparative group will help establish the additional services (if any) accessed by those with cognitive impairment, and enable the comparison of costs of services used within and between groups.

Outputs from the study will include practice guides for health and homelessness practitioners, and a resource guide for commissioners about the services used by and needed for older homeless people with memory problems and costs. Only older homeless people who give informed consent will be included in the study. While this could exclude those with serious memory problems who are unable to give informed consent, it is unlikely that this would apply to many older hostel residents (by virtue of the tenancy contract in a hostel, residents require a degree of independence). If the situation does arise, information will be collected from hostel staff about the provision of services to the client group. The research team is diverse and highly-skilled to carry out this study of a marginalised group. People with expertise in dementia and health and social care research have come together with those who have expertise in the homelessness field.

The costs of the research cover staff salaries, the use of freelance specialist interviewers, travel to the study sites, and incentive payments for older homeless people who participate. A small amount is requested for hosting the Advisory Groups, and for the dissemination work, including conference presentations.

Contribution to collective research effort and research utilisation

There will be active collaboration with key stakeholder groups through the formation of a National Advisory Group, and a Local Advisory Group in each of the three study areas (Blackburn, Cambridge and London). They will include health and social services staff; homeless sector service-providers and front-line staff; other voluntary sector staff working with or on behalf of homeless people such as the UK Coalition on Older Homelessness and Homeless link (the national voluntary organisation that supports homeless sector service-providers); older people with dementia; and academic and professional advisors involved in the field (see letters of support from the Alzheimer’s Society, Mental Health Foundation, Greater London Forum for Older People, Housing 21 and Royal College of Psychiatrists). Each Advisory Group will meet twice during the study (at the start and at the reporting / dissemination-planning stage). In between meetings they will be consulted about: content of information sheets, study protocols and web summaries, interview questions, interpretation of findings, dissemination routes and strategies. The Local Advisory Groups will specifically address issues such as the availability of services locally for the study group, and health, housing and social services arrangements in the area. Discussions with key stakeholders will also be noted (with permission) and used where appropriate (with permission). The study will produce full and summary reports for SDO, with allied materials for health, social care and homeless sector staff, in formats that can be used for front-line work and continuing professional development (we have support from SCIE for such activity and will seek use of their web-based professionally accessible formats). The research team has experience in producing such materials for a range of professionals, including nurses, doctors, social care and homeless sector staff. We will engage directly with local provider organisations to ensure that our findings have impact on the development of local services through presentations and joint consultation meetings. We will also engage with service commissioners locally to produce a template for use when developing service maps outlining sources of support for people with memory problems and early-stage dementia. Findings will be written up for peer-reviewed academic journals (in gerontology, clinical psychology, health service policy, nursing, old age psychiatry, primary care, and social work / social care, housing studies) and service-oriented versions will be sent to relevant professional publications. Presentations will be made at health, housing, social care and professional conferences – locally, nationally, and internationally.
Plan of investigation and timetable

The study will last 24 months and the work packages are divided in the following manner:

Brief timetable:
Months 1-6 = design of instruments, ethics approval, and literature review
Months 7-9 = WP2
Months 10-18 = WP3
Months 19-24 = analysis and reporting.

<table>
<thead>
<tr>
<th>Detailed timetable</th>
<th></th>
</tr>
</thead>
<tbody>
<tr>
<td>April 2012 to Sept 2012</td>
<td>Design of questionnaires, Interview Schedules, consent forms and information sheets for WP2 and WP3 Application to relevant Ethics committee and for R&amp;D approvals WP1 = Systematic review</td>
</tr>
<tr>
<td>Oct 2012 to Dec 2012</td>
<td>WP2 = Cognitive assessments by researchers WP2 = Cognitive assessments by Dr Timms WP2 = First round of data analysis</td>
</tr>
<tr>
<td>Jan 2013 to March 2013</td>
<td>WP3 = Identification of OG and CG WP3 = Baseline interviews</td>
</tr>
<tr>
<td>April 2013 to June 2013</td>
<td>WP3 = Follow up three-monthly interviews (Time 2)</td>
</tr>
<tr>
<td>July 2013 to Sept 2013</td>
<td>WP3 = Data analysis for Time 2 interviews WP3 = Follow up six-monthly interviews (Time 3)</td>
</tr>
<tr>
<td>Oct 2013 to Dec 2013</td>
<td>WP3 = Data analysis of Time 3 interviews</td>
</tr>
<tr>
<td>Jan 2014 to March 2014</td>
<td>Writing up and dissemination of all three Work Packages</td>
</tr>
</tbody>
</table>

Approval by ethics and research governance committees

We will begin the process of applying to the relevant Research Ethics Committee as soon as funding has been approved by SDO. We envisage, from previous experience (SDO project: 08/1809/229), that this could take between six to nine months and have specifically designed WP1 to not need ethical approval. Moreover, this time will also be spent developing interview schedules, data collection tools and pro-formas required. Prof Bowling will contribute to the development of questions about QoL to include in the interview schedules, in order that we can prepare materials for the Ethics Committee. These will be refined as the study progresses and the findings of the systematic narrative review emerge.

When applying for ethical approval (and in the conduct of the study), we foresee the following four issues or challenges:

Issues relating to the specific service user group

Concerns may be expressed that recruiting, obtaining consent and interviewing this specific client group may be problematic as they are likely to be transient, alcohol misusers and behave erratically. Following them over time may also be challenging. However, our experience (MC, LJ, SC) and advice (from PC and PT) suggests that this is not likely to be the case. The study is relatively short-term and the study population is unlikely to experience change of address during this time. This also means that relationships with hostel staff will be strong and there will be staff...
who will be familiar with the most best way to engage individuals and involve them in the study. Moreover, for those participants using alcohol, researchers will endeavour to find the most suitable time of day for interviews. The research team will also work closely with hostel staff to ensure that the interviews and data gathering are carried out with minimum disruption to the service. Our recent evaluation of a London hostel achieved this (Crane et al 2011).

**Obtaining informed consent**

All participants will be provided with detailed information about the study and invited to participate. They will be told that the study is about memory problems among older homeless people, the help that they receive, and services that are effective or needed. We will emphasise that the information they give us will be kept confidential and held only by the research team. We will also tell them that if they share any information that suggests that their situation is life-threatening, abusive or may place others at risk of harm, we will be obliged to tell their keyworker or project worker and possibly their GP about this. We will also tell them that they are free to withdraw from the study at any point. We will then answer any questions they may have and, if they are willing for the interview to proceed, we will ask them to sign a consent form. Only those who have understood the nature of the study and what their involvement will entail will be included. By virtue of being in a hostel, which requires residents to have some degree of independence, it is unlikely that we will meet people with such severe memory problems/cognitive impairment who would be unable to give informed consent however, if this is suspected the provisions of the Mental Capacity Act will be applied.

In WP3, we will follow the same procedure to obtain consent from both the Observation Group and the Comparison Group. In this case, during the consent procedures at baseline, we will inform all residents that the study is likely to last six months and ask their approval to remain involved, but emphasise that we will seek their permission at each stage. If a person is unwilling for us to collect information from hostel staff and other sources about the help they have received, then they will not be included in this part of the study.

**Absence of family member to act as consultee**

Participants in this study are highly likely to lack the continued presence or availability of a family member, thereby making it difficult to obtain permissions or views and other information from a consultee. Therefore, we will only include people who are able to consent for themselves. As most people will be in the early stages of cognitive impairment, we do not foresee this as a potential problem for recruitment or retention of participations.

**Offering remuneration for participating in research**

We will be offering £5 to all participants as remuneration for their time in participating in our research. We have referred to the guidance produced by the Research Ethics Guidebook, Department of Health and INVOLVE (www.invo.org.uk) and are aware of potential pitfalls. However, we are keen to take an inclusive approach with our research and have, therefore, set out the following principles, contained in the Payment for Participation policy that all researchers will follow:

- All participants will be offered £5 in cash for participating in an interview. This will be clearly explained during the consent process, and the money will be given to participants at the end of the interview.
- In cases where the hostel staff advise against giving a person the money directly (e.g. if the person is having support to stop or control their drinking), an agreement will be reached with the older person and the hostel staff as to how they will be remunerated.
- As participation will be one-off encounters and the amount is nominal, this will not affect an individual’s benefits.

**Project management**
Manthorpe is an experienced Chief Investigator and project manager who will provide leadership for the project. She will ensure that the study meets the requirements of ethics, research governance and the SDO/NIHR and that systems are established to maintain these requirements. She will also manage relationships with the hostels and manage and mentor Crane, Samsi, Joly and Coward. Manthorpe will also ensure that the study keeps to timescales and will monitor the budget. She will undertake some interviews and analysis and writing up of findings.

Crane will have overall management responsibility of the quantitative data generated from WP3. She will develop the analysis strategy and coordinate statistical analysis. With Samsi, she will ensure the production of reports and publications.

Samsi will have overall management responsibility of quantitative and qualitative data generated from WP2. She will generate the analysis strategy and coordinate qualitative data analysis through the use of NVivo software. Along with Crane, she will ensure the timely production of reports and relevant publications. With Manthorpe, she will ensure the effective engagement of members of the National and Local Advisory Groups.

Gage will have overall responsibility of the economics data generated from WP1 and WP3. She will manage and coordinate the analysis of the economics data and liaise with Samsi and Crane in the production of reports and publications.

Bowling will have overall responsibility of the systematic and evidence review in WP1. She will manage and coordinate the search strategy and the production of the review. She will provide expert advice in data collection and data analysis in WP3 to ensure that relevant information about QoL is obtained and analysed. She will liaise with Samsi and Crane in the production of reports and publications.

Public users/public involvement

We will use our existing links with members of the public affected by dementia that have been involved in our recent Transitions study (SDO 08/1809/220) and the NIHR EviDEM Mental Capacity Act study to act as a Local Advisory Group in London. With others who are ‘experts by experience’ in homelessness, they will act as informal members in increasing our understanding of the experience of dementia and memory problems among older homeless people. Local Advisory Groups will meet in Blackburn and Cambridge with the involvement of local stakeholders.

Additionally, homeless people from St Mungo’s ‘Outside In’ peer support group will also be involved. They will be consulted about the suitability of Quality of Life instruments for homeless people. Workshops will be helped to gather their opinions and recommendations, at the stage of developing instruments and interview topic guides, but also during dissemination. During the lifetime of the project, we will attend and contribute to practice and service-user networks with which we are already engaged. These include: Homeless LINK, Crisis, Making Research Count, NIHR School of Social Care Research, Alzheimer’s Society’s, Journal of Dementia Care and the Dementia Congress.

We also have good links with the Alzheimer’s Society (Policy advisers working on issues related to housing) and we will be engaging with them regularly in order to capture emerging policy issues that our study findings can build upon and inform regularly.

Expertise and justification of support required

Manthorpe is an NIHR Senior Investigator with 20+ years’ experience in social work / social care and applied health research focusing on older people and dementia. She is a co-investigator in the EVIDEM NIHR programme and a member of the DeNDRON primary care research network. (7% of time for the project).
Crane pioneered research in the UK into older homeless people and has conducted studies of homeless people and homeless services for 20 years. She has considerable experience in working closely with homeless sector organisations and in interviewing marginalised and hard-to-engage homeless people (40% of time). She has worked with Manthorpe and Joly on a study of an innovative hostel.

Samsi has experience of data collection and analysis in applied dementia health services and social care research. She will be involved in the study design, data collection, service user input, analysis, reporting and dissemination (50% of time).

Timms is Consultant Psychiatrist in the START team (for homeless people) and Honorary Senior Lecturer in Psychiatry, King’s College London. He will contribute as a clinician to the study design and interpretation of findings (15 days).

Bowling has a long track record in QoL assessment, measurement and review, and has conducted the psychometric assessment of QoL scales for older people. She will be responsible for the review of QoL instruments for homeless people and the development of a new QoL instrument for the client group (5% of time).

Gage is a health economist and health services researcher, and coordinator of the Health Economics Research Group at University of Surrey. She will oversee the data collection and analysis surrounding service use and costs in WP’s 2 and 3 (5% of time). A health economics researcher (TBA) will undertake the health economic analysis during the last year of the project. Gage and members of the Group have extensive experience in evaluative studies and outcome measurement involving older people in general, and people with dementia in particular. She has worked with Manthorpe on other SDO funded studies.

Cockersell has long experience in the homelessness field, and is Director of Health and Recovery at St Mungo’s (homelessness organisation in London). He will provide the study with a perspective from homeless sector organisations, and contribute to its design, execution and interpretation of findings (10% of time).

Joly is a general and district nurse who practised in a specialist homeless health-care team, before completing a PhD relating to health and homelessness. She has worked on several studies related to homelessness and social care with Manthorpe, and with Crane, and has considerable experience of recruiting and interviewing homeless people for research. She will undertake data collection in London and Cambridge and will also contribute to data analysis and project steering groups.

Coward has 10+ years’ experience in social, housing and urban regeneration research, including studies of homelessness and worked with Crane on homelessness studies. She has considerable experience of interviewing homeless people and will undertake data collection in Blackburn.

References


Ready RE, Ott BR (2003) Quality of Life measures for dementia, Health and Quality of Life Outcomes, 1, 11.


Samsi K, Manthorpe J and Rapaport P (2011) “As people get to know it more”: Experiences and expectations of the Mental Capacity Act 2005 amongst local information, advice and advocacy services, Social Policy and Society, 10(1), 41-54.


