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Service provision for older homeless people with memory problems: a mixed-methods study

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Abstract

Service provision for older homeless people with memory problems: a mixed-methods study

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Background: Early or timely recognition of dementia is a key policy goal of the National Dementia Strategy. However, older people who are homeless are not considered in this policy and practice imperative, despite their high risk of developing dementia.

Objectives and study design: This 24-month study was designed to (1) determine the prevalence of memory problems among hostel-dwelling homeless older people and the extent to which staff are aware of these problems; (2) identify help and support received, current care and support pathways; (3) explore quality of life among older homeless people with memory problems; (4) investigate service costs for older homeless people with memory problems, compared with services costs for those without; and (5) identify unmet needs or gaps in services.

Participants: Following two literature reviews to help study development, we recruited eight hostels – four in London and four in North England. From these, we first interviewed 62 older homeless people, exploring current health, lifestyle and memory. Memory assessment was also conducted with these participants. Of these participants, 47 were included in the case study groups – 23 had 'memory problems', 17 had 'no memory problems' and 7 were 'borderline'. We interviewed 43 hostel staff who were participants' key workers. We went back 3 and 6 months later to ask further about residents' support, service costs and any unmet needs.

Findings: Overall, the general system of memory assessment for this group was found to be difficult to access and not patient-centred. Older people living in hostels are likely to have several long-term conditions including mental health needs, which remain largely unacknowledged. Participants frequently reported experiences of declining abilities and hostel staff were often undertaking substantial care for residents.

Limitations: The hostels that were accessed were mainly in urban areas, and the needs of homeless people in rural areas were not specifically captured. For many residents, we were unable to access NHS data. Many hostel staff referred to this study as 'dementia' focused when introducing it to residents, which may have deterred recruitment.

Conclusions: To the best of our knowledge, no other study and no policy acknowledges hostels as 'dementia communities' or questions the appropriateness of hostel accommodation for people with dementia. Given the declining number of hostels in England, the limits of NHS engagement with this sector and growing homelessness, this group of people with dementia are under-recognised and excluded from other initiatives.

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ABSTRACT

Future work: A longitudinal study could follow hostel dwellers and outcomes. Ways of improving clinical assessment, record-keeping and treatment could be investigated. A dementia diagnosis could trigger sustained care co-ordination for this vulnerable group.

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List of abbreviations

6-CIT	Six-Item Cognitive Impairment Test	DNA	did not attend
ACE	Addenbrooke's Cognitive	GP	general practitioner
	Examination	MMSE	Mini Mental State Examination
ACE-III	Addenbrooke's Cognitive Examination III	MoCA	Montreal Cognitive Assessment
ACE-R	Addenbrooke's Cognitive	NVQ	National Vocational Qualification
7.62	Examination tool version R	QoL	quality of life
A&E	accident and emergency	SD	standard deviation
ARBD	alcohol-related brain damage	SW	support worker
CMHT	community mental health team		

Plain English summary

ffering effective support to people with memory problems or dementia and their carers is increasingly important to the NHS and the UK government. However, older people who are homeless appear to have been ignored in these changes. This 24-month study explored the extent of memory problems among older homeless people temporarily living in hostels to find out what support they received and from whom, what their quality of life was and if they had unmet needs. We also wanted to calculate the costs of the services they used. We started by reviewing the existing evidence on this subject. We then recruited eight very different hostels to our study: four in London and four in North England. In these, first we interviewed 62 of their older homeless residents, asking them about their health, lifestyle and memory, and testing their memories. Of these residents, 47 were included in the main study, with 23 in the group with 'memory problems', 17 having 'no memory problems' and 7 who were 'borderline'. We also interviewed 43 hostel staff. We went back 3 months and then 6 months later to ask what residents had done about their memory problems (if anything) and what services they were using. With their permission, we read their medical records and talked to professionals supporting them so we could work out the costs of their services. We concluded that usual memory assessment and diagnosis support services for this group are not suitable. They are not patient- or person-centred enough to meet their needs, and cannot take account of their complicated life histories or other physical and mental health conditions. Hostel residents with memory problems were often being supported by hostel staff, largely on their own. We concluded that there is little evidence that hostel settings can be effective 'dementia communities' that offer relevant, timely support.

Scientific summary

Background

There is little evidence about the circumstances and needs of older people who are homeless and have memory problems in the UK, although the subject has received some attention in the USA and Australia. Over a decade ago, audits undertaken in different parts of England suggested that 10–16% of older homeless people had 'serious memory problems' or were described as 'have memory problems/are prone to wander' (UK Coalition on Older Homelessness. *Audit of Older Homeless People September 2007: Summary of Findings*. London: Housing Learning and Improvement Network; 2007). These audits relied on staff observations, not those of mental health workers or clinical examinations; various lower age limits were applied (from 45 to 60 years); and resident profiles were unavailable. Multiple and long-standing health conditions were suggested as contributing to the problems reported: long-term alcohol misuse, untreated human immunodeficiency virus infection, vascular disease and head and chronic brain injury.

Little has been reported about problems faced by older homeless people with memory problems, the services and support they receive, and if their needs are met. This may be because they are reluctant to engage with services and difficult to assess and help because of persistent heavy drinking, or because they have behaviour that people find challenging, or other physical health problems, or because they neglect themselves. Furthermore, there is little information about the help available to homeless-sector staff working with this group, and their experiences of accessing services on their clients' behalf. Many older homeless people with memory problems are reportedly unable to live independently, and suitable long-term housing is hard to find.

We designed a 24-month study to investigate these gaps in greater detail. Four under-researched questions were identified as the study aims:

- 1. To what extent are hostel staff aware of memory problems among their older residents and their prevalence? What impact does this have on their practice or service? How do hostel staff respond to residents' memory problems?
- 2. What 'service pathways' exist for older homeless people with memory problems? What are their service experiences?
- 3. What are the gaps in service provision for such individuals, and what are the costs of providing services for them?
- 4. How do older homeless people with memory problems perceive their quality of life (QoL), and how can this be evaluated? Does this differ from that of other older people and other older homeless people? What are the implications of this for agreeing desirable outcomes from services?

Methods

Work package 1: literature reviews

The research started with two literature reviews (A and B).

Literature review A investigated the prevalence of memory problems among older homeless people. It found that previous studies of the physical and mental health of older homeless people have collected data on memory problems using varied definitions and in different ways, either as a focus or in combination with other conditions. Older homeless people in these studies were recruited from diverse settings, such as day centres, street provision, hostels and clinics. Few studies included service evaluations and trials of interventions; there were also few accounts of practice, service commissioning decisions and outcomes.

Literature review B, published in *Aging & Mental Health*, included a narrative systematic review of QoL instruments used in assessing people with dementia (all types) to assist the research team in selecting optimal measures for their aims and to address issues and life areas that are of particular importance to homeless older people (Bowling A, Rowe G, Adams S, Sands P, Samsi K, Crane M, *et al.* Quality of life in dementia: a systematically conducted narrative review of dementia-specific measurement scales. *Aging Ment Health* 2015;**19**:13–31). It noted the presence of a large body of literature in this area, but found few measures based on rigorous conceptual frameworks. Many QoL measures were based on proxy assessments rather than self-reports from people with dementia. All measures were tested on selective samples only and in just a few sites. Their general applicability remains unknown and their predictive validity is largely untested.

Study design

The study was designed in two phases: (1) a quantitative element to examine the prevalence of memory problems among older homeless people living in hostels and the extent to which homeless-sector staff are aware of and respond to these problems, and (2) a longitudinal case study phase to investigate the more specific questions related to pathways into care, services and support received and their costs, the gaps in services that existed and how these areas could be developed, and how older homeless people with memory problems perceived their QoL.

Recruitment and data collection

Ethics approval was obtained from the London and South East Research Ethics Committee in April 2014 (14/LO/09373) and fieldwork began in May 2014. Several hostels were contacted and, ultimately, eight were recruited from four main sites (Central London, South London, North East and Midlands). Details of hostel services and commissioning or funding arrangements were collected in interviews with managers. Sixty-two residents were recruited for the first phase. Once study details had been explained and informed consent had been obtained, baseline interviews were conducted, at the end of which the Six-Item Cognitive Impairment Test (6-CIT) was conducted. There were many varied challenges to recruitment and data collection, related to the way the study was introduced to study participants, to ongoing and multiple service changes in the hostel sector, and to the complex histories of the participants being recruited. A consultant psychiatrist and his staff team conducted short 20-minute Addenbrooke's Cognitive Examination III (ACE-III) assessments, or the Montreal Cognitive Assessment (MoCA) for those who found ACE-III too burdensome. In the end, 48 ACE-III assessments were conducted and one participant was administered the MoCA. Data were entered into the software SPSS version 22 (IBM Corporation, Armonk, NY, USA) and open-ended responses were entered into the software NVivo 10 (QSR International, Warrington, UK) so that categories and themes could be coded and identified. Descriptive profiles of participants were identified in interviews and using client records, including age, sex, ethnicity, education and work history, housing and homelessness history, activities and family/social contacts, income, management of everyday tasks, physical and mental health problems, head injuries, use of alcohol and drugs and service use 3 months prior to the baseline interview.

All baseline participants were allocated to one of three groups based on decisions made by the research team psychiatrist, using the cognitive assessment, and the history obtained regarding participants' lives, alcohol use and other physical and mental health conditions. The groups were 'memory problems', 'borderline' and 'no memory problems'. Follow-up interviews were conducted at 3 and 6 months with these participants and we aimed to obtain as complete a data set as possible. Fifteen participants (24%) were lost to follow-up and 47 participants were included in the case study analysis. Complementary sources of data were sought and, in total, we obtained interviews with 44 key workers, four external workers and eight hostel managers, as well undertaking analyses of hostel records of the 47 case study participants and the medical records of 30 case study participants.

We also estimated the costs of the services used and compared how these differed between those who had and those who did not have memory problems. To do so, details of the pathways of participants through different health and social care services, and the service use of each participant during the 6-month period following recruitment, were collected and documented as precisely as the available data would allow. The utilisation of a large number of services was included, and categories were informed by the Client Service Receipt Inventory. The unit costs of all services (2014–15) were obtained from validated national sources, applied to each service for each participant and summed to give a total service use per participant during the 6-month period. Summary statistics were calculated across all participants for each service use item and for groupings of services. Specific statistical tests were also conducted. The level of significance was set at a *p*-value of 0.05. Associations were also explored between service groupings and memory problems using Spearman's rank-order correlation. Ten other participant characteristics with the potential to influence service use costs were identified, and the associations between each of these characteristics and each cost grouping were explored using Spearman's rank test, the Mann–Whitney *U*-test and the Kruskal–Wallis test. All 10 variables were then included in backward stepwise regression modelling to explore the independent predictors of each cost item.

Findings

The hostels were very different in terms of their physical conditions and accessibility and the services that they offered to residents. Links with primary care and mental health services varied markedly between hostels. Some staff had substantially more sector experience than others, but high levels of staff turnover were reported. Training levels and availability varied, and differences existed in the extent to which hostel staff were permitted to access local NHS and local authority courses.

The team collected detailed demographic information, education experiences, employment history, homelessness history, physical health status, mental health status and substance misuse problems from the 62 older homeless people interviewed at baseline. Although some of those interviewed had relatively stable lives, had worked for years and had become homeless for the first time in later life, most had unsettled histories, had left school early without qualifications and subsequently had experienced long periods of unemployment, intermittent employment and homelessness. The sample tended to be 'young-elderly' homeless people, the majority being aged in their fifties, with a high prevalence of physical health problems, depression, alcohol and drug misuse problems among them. Differences in age cohorts were apparent; those in their early fifties were more likely to have left school early and to have first become homeless as teenagers or in their twenties, and were heavy drinkers and illicit drug users. Many in this group consumed superstrength lagers and beers, drinking > 50 units of alcohol per week at the time of the interview. There were differences by cluster site: those in North England were more likely to have stable histories and to have first become homeless after the age of 50 years, and to have remained in their hostels for longer periods, whereas many in the London sites had experienced homelessness intermittently or continuously since early adulthood.

It is well known that advancing age is the greatest risk factor for developing dementia, yet one of the key findings of our study is that memory problems were prevalent among large numbers of older homeless people in hostels: 47.6% of hostel residents were assessed as having memory problems, and a further 19% were deemed to be borderline. The median age of those with memory problems (groups 'memory problems' and 'borderline') was just 60.4 years. Hostel staff were relatively proficient at identifying hostel residents who were having memory difficulties. They were in regular contact with residents and were able to recognise when residents were confused or were struggling to carry out everyday activities.

We analysed the health and social care needs of the hostel residents, and their QoL and housing outcomes, drawing on information gathered over 6 months from multiple sources. We found that many older homeless people in hostels required substantial help and support to manage everyday activities of daily living and their health problems, especially those residents with memory problems. Hostel staff often provided a great deal of help to some older residents, often beyond the remit of a 'hostel worker'.

Many acted as advocates and took on roles that family members or social care staff generally provide to older people with health and support needs living in the community. In some cases, the local authority had undertaken an assessment of need and had organised a care package. In such instances, home care staff provided help to these residents; but this was not always the case, partly because of a lack of engagement of some residents with support services in conjunction with high thresholds of eligibility for local authority support, meaning that only those with very great levels of need were eligible.

We further analysed the costs of use of health and social care services, residents' unmet needs, challenges along the health and social care pathway and housing options. In terms of cost evaluation, information on service use by homeless people is rarely available, and, although this was a small sample, the data we obtained were detailed and unique. Service use data were available for 47 participants. There was variability in service use among the sample, but general practitioner services were the most frequently accessed. The median cost of service use over a 6-month period (2014–15) was £1454, but the mean was much higher than this (£2975), reflecting the small number of high users of local authority care services and in-hospital care. The proportion of the group with memory problems who had some form of mental health service use during the 6-month study was higher than that in the borderline or no memory loss groups (39%, 29% and 24%, respectively). However, the proportion of total costs accounted for by mental health services was < 5%. The reasons for the use of mental health care are not known, and may have been depression or other mental health conditions rather than memory loss. Participants with memory problems used emergency and out-of-hours services more than those without memory problems, but there was no other association between cognitive status and service use cost categories. Owing to much variability in service utilisation at the individual level, a larger sample would be required to gain definitive results. Many challenges along health and social care pathways were identified: difficulties in keeping appointments, comorbidity and alcohol problems, variability in presentation, lack of flexible dementia support and treatment, the need for residents not to be drinking at the time of assessments, inflexibility of services and the dual reluctance of services to engage with homeless people and of residents to engage with services. The lack of housing options for this vulnerable group was also highlighted.

Discussion and implications

We discuss the study findings, specifically in relation to comorbid physical health problems of the sample, histories obtained of head injuries, current and historical mental health problems, alcohol use, use of illicit drugs, literacy problems identified and varied hostel provision across all sites. We also identify the strengths and limitations of the study. Our study presents new information about older people with memory problems associated with dementia, about older hostel residents and about services for both groups. We have established baseline information and tested different methods and data collection approaches. The evidence from this study is that hostels are not suitable accommodation for people with dementia. Although some hostel staff possess skills and great competence in supporting residents for whom memory problems are having an impact on their lives and well-being, a hostel is not a long-term solution or care setting. There is a strong case for seeing hostels currently as part of the 'dementia care workforce' in the absence of suitable permanent housing or homes for these hostel residents. Likewise, there is a strong case for including hostels as part of the local housing with care economy or system and involving them in strategic planning, training and communities of practice. Local and national dementia strategies and services need to better acknowledge the existence of older homeless people with dementia, which should involve providing them with services, support and a place to call home.

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Chapter 1 Introduction

Introduction to the report

This report presents the findings of the first UK study of older homeless people living with memory problems or memory problems associated with the disabilities of dementia. It contains findings from literature reviews, and primary data collected from older people living in hostels and hostel staff supporting them. We discuss the prevalence of memory problems among older people accommodated in hostels, a form of temporary accommodation in which they have no security of tenure. We compare the services used by hostel residents with memory problems and services used by those without, using a categorisation developed for this study.

Our first three chapters follow the sequence of presenting the research questions and background to the study (see *Chapter 1*), the findings from two literature reviews (see *Chapter 2*) and the study methods (see *Chapter 3*). The next chapters report our findings: *Chapter 4* profiles the research participants and the study sites, *Chapter 5* reports our definitions and classifications of memory problems, *Chapter 6* reports hostel residents' health and social care needs and *Chapter 7* presents data on their use of health and care services. *Chapter 8* forms our discussion chapter and our final chapter (see *Chapter 9*) outlines the study's implications for service development, commissioners, providers, practice and researchers.

Background

This unique study investigated four under-researched guestion areas:

- 1. To what extent are hostel staff aware of memory problems among their older residents and their prevalence? What impact does this have on their practice or service? How do hostel staff respond to residents' memory problems?
- 2. What 'service pathways' exist for an older homeless person with memory problems? What are their experiences of these services?
- 3. What are the gaps in service provision for such individuals, and what are the costs of providing services for them?
- 4. How do older homeless people with memory problems perceive their quality of life (QoL), 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 desirable outcomes from services?

The background to the study is formed by three different domains: (1) the imperatives of dementia policy and practice, (2) equalities legislation and efforts to reduce health inequalities among older people with long-term conditions, including dementia, and (3) the impact of homelessness on older people with memory problems, including dementia, and their service needs. Little research has been conducted about the problems faced by older homeless people with memory problems (such as dementia), the services and support that they receive and the extent to which their needs are met. Our conversations with different stakeholders working in dementia services and in homelessness services as part of the development of the study proposal revealed that some older homeless people are deemed hard to engage and reluctant to work with services, and are perceived as difficult to assess and help because of persistent alcohol use. We were also told about other problems experienced by professionals in supporting homeless older people; these included accounts of distressed behaviour, complications of physical ill health, and self-neglect. We found little information about any help available to staff working with this client group in homelessness services in the UK and little research evidence about their contacts with other sectors. There were also few reported

experiences of working constructively with health and social care services. In our consultations as part of our preparation for this study, professionals from all sectors expressed a desire to gain a greater understanding of this area of practice. These discussions helped frame our study so that it would explore implications for service design through an evidence-based analysis of the barriers to diagnosis, service access, support, treatment and unmet need, and exploration of ways to address the many challenges envisaged. This study, therefore, was designed to investigate these areas. The next section provides more detail of the threefold context to the study.

Dementia

Two major policy documents have shaped dementia services and provide the background to the emerging interests in dementia recognition at patient and society levels in England: the National Dementia Strategy, superseded by the Prime Minister's Challenge on Dementia.² Both emphasise the need for earlier or more timely recognition of dementia. Commenting on the progress made under the National Dementia Strategy and the Prime Minister's Challenge, Knapp *et al.*³ reported that the provision and use of memory assessment services (sometimes referred to as memory clinics) has increased, although it is hard to detect what changes there have been and where they have occurred. The development of memory service accreditation has been slow, meaning that commissioners cannot rely on strong evidence of how best to deliver memory services. Knapp *et al.*³ added:

Local services will and should respond to local circumstances and be more person-centred, but the wide variations currently seen in staff-mix, methods of clinical assessment and provision of post-diagnostic care are unacceptable if the aim is to equalise access to diagnosis and post-diagnostic support.

P. 2. Reproduced with permission from the Policy Innovation Research Unit

Although the National Dementia Strategy¹ addressed issues of equalities, generally there has been a lack of focus on people who are homeless who have memory problems or cognitive problems that are indicative of a dementia syndrome. The Ministerial Advisory Group on Dementia Research⁴ recommended that public and professional awareness and understanding of dementia should be improved. However, whereas it made reference to caring for people with dementia at home, in hospital and in care homes, it contained no mention of those who are homeless or socially excluded from settled accommodation. It also recommended that health and social care staff working in care homes with residents who have dementia should receive appropriate training and continuous professional development, and that community mental health teams (CMHTs) working with older people should provide specialist services to care homes; however, practitioners working in homelessness services were not mentioned. The Ministerial Advisory Group on Dementia Research advised that everyone with dementia should have access to a pathway of care services, including specialist assessment, treatment, care and support, and that this pathway should be responsive to individual need and preferences. It made no reference to possible difficulties in providing care and support to older people with dementia who are homeless, or to the staff groups working with them.

Policy has also promoted broad public health and community development approaches to responses to dementia. Knapp *et al.*³ noted the considerable emphasis on improving awareness about and attitudes towards dementia through campaigns such as Dementia Friends and the development of dementia-friendly communities. Such initiatives have generally focused on people living in their own homes.⁵

Equalities

Part of the justification for a National Dementia Strategy¹ was that dementia has long been overlooked as a health problem, despite its often devastating impact in human terms and its impact on public expenditure. There have been arguments that this lack of priority reflects dementia's associations with old age and the impact of ageist beliefs and stereotypes; that the condition is stigmatised; and that there is therapeutic nihilism – or a feeling that nothing can be done.⁶ There is increasing interest in seeing dementia as needing a rights-based dimension, building on the ideas of the disability movement.^{7,8} A report from the Mental Health Foundation suggested that this would bring several benefits, such as greater legal protection and improved

service entitlement, thereby promoting cultural shifts to how dementia is perceived that will have benefits to society as well as people with dementia.⁹

Thomas and Milligan¹⁰ have argued that adapting the social model of disability to people with dementia also encourages us to think beyond the social and institutional disadvantages that may be experienced by people with dementia, and instead notice the impact this can have on the places they live. As people with dementia may lose their sense of orientation of time and space, formerly familiar places may start to seem unfamiliar or frightening to them.¹⁰ The premise that people with dementia may lose their memories of settled and familiar locations overlooks people without settled accommodation or who are unfamiliar with their present neighbourhood.

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More recently, there has been greater interest in the heterogeneity of the 'dementia population' and the possible impact of social inequalities being sustained when a person has dementia or of such inequalities being reproduced or enhanced. Research, for example, has investigated differences in service responses, such as prescriptions of 'anti-dementia' medication, by socioeconomic group,¹¹ variations in symptom recognition between ethnic groups,¹² fear of prejudice about revealing sexual orientation¹³ and gender disparities affecting women throughout the dementia trajectory.^{14,15} Concluding their literature review, Ludwin and Parker¹⁵ observed:

As we have seen throughout the material we reviewed, individuals with dementia are marked by the social locations and identities they occupied prior to diagnosis; these axes of identity may form important parts of individual sense of self. Failing to recognise them in interactions and provision of support may thus contribute to an erosion of personhood and perpetuate marginalisation.

P. 20¹⁵ Reproduced with permission from the University of York

The importance of considering equalities in respect of people who are homeless is not generally recognised, despite the very poor health and QoL of this population.¹⁶ According to the Equality and Human Rights Commission,¹⁷ this population is among the most disadvantaged groups in UK society. Although the Equality Act 2010¹⁸ provides a legal imperative to ensure that 'protected characteristics' are addressed in assessments of service impact (many of which are relevant to people with dementia²), homelessness is not readily translated into the 'characteristics' for which there is legal protection. Some advocates from the homelessness sector have suggested that the NHS Constitution instead may be an effective lever to ensure the rights of homeless people to health services.¹⁹

Housing people with dementia

There has been growing interest in the living accommodation and housing choices of people with dementia. Much has focused on how to design new accommodation and how to modify existing accommodation so that people with dementia can stay in their own homes or move to better accommodation offering choices over patterns of care and tenure.²⁰ Several organisations (e.g. the National Federation of Housing²¹) have argued that dementia-friendly housing must be an integral part of dementia care. Research has also begun to explore particular housing needs of some groups of people with dementia; for example, Lipman and Manthorpe²² investigated how social housing providers (housing associations) were beginning to respond to tenants with dementia from black and minority ethnic groups.

As Knapp *et al.*³ reported, local authorities have been encouraged to develop, in collaboration with the Homes and Communities Agency and the Greater London Authority, partnerships with housing associations (social housing providers that may offer housing and care services) and private builders to meet the needs of older people with long-term conditions, including dementia. However, the focus of such developments has been on people with dementia who already have homes, some of whom have considerable assets from home ownership and who are potentially attractive new purchasers to 'housing with care' providers.

Older homeless people

The problems and needs of older homeless people and of the effectiveness of services for them were summarised in a review article by Crane and Joly¹⁶ and the responses of statutory housing bodies by Alden.²³ There has been little research 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 USA^{24,25} (see *Chapter 2* of this report for our review of the relevant literature).

This present study used the former UK Coalition on Older Homelessness²⁶ definition of 'older' homeless people as those aged \geq 50 years, because many homeless people in their fifties have chronic health problems and disabilities normally associated with old age. Those in their fifties who are single and without dependent children are often not regarded by statutory services as 'elderly' or particularly vulnerable, meaning that these authorities' responsibilities may be fulfilled by temporary hostel placement with, increasingly, shorter stays only being permitted. Moreover, at least two-thirds of older homeless people are men in respect of whom problems have been reported if they are rehoused in care homes, which tend to be occupied predominantly by very elderly women.²⁷ Care home staff have reported difficulties in managing formerly homeless men's drinking and/or chaotic behaviour, such that some are 'evicted' from care homes,²⁷ although there is little direct evidence about this from more recent times.

The number of older homeless people is rising, as is the number of homeless people in England generally, although data quality is not sufficient to provide accurate numbers.²⁸ In 2017, Homeless Link reported a total of 36,540 bed spaces in 1253 hostels and second-stage accommodation across England. London has the greatest number of projects in total, at 183, and the most bed spaces, with 9647 beds. Reporting on the 1121 accommodation projects for single homeless people in England, Homeless Link²⁹ noted that levels of support, access and inclusion criteria varied between projects. Services that offered lower-level support tended to be for those who were homeless or in need of housing, but deemed to otherwise be capable of living independently. Some other services offered more support for those who had support needs alongside their accommodation needs, and faced many barriers to living independently.

There are expectations that hostel residents will move on from first-stage hostels (those that provide intensive support in a 24-hour hostel) to other accommodation often within 6 to 12 months.²⁹ (Stage 2 hostels involve shared accommodation and a lower level of support and stage 3 often involves a move to independent living.) Yet some older homeless people with increasing memory impairment and other vulnerabilities may remain in hostels for years, with growing frailty, as there is no suitable alternative accommodation. Most hostels are not designed or staffed to provide long-term housing or a high level of support for this client group or others. In addition, many older homeless people are reported to dislike staying in hostels, fearing intimidation and violence from younger residents.³⁰

Audits conducted over 20 years ago by homeless sector staff in Blackburn, Brighton, Cambridge, Liverpool, Oxford and Westminster²⁶ suggested that 10–16% of older homeless people known to them had 'serious memory problems' or 'have memory problems/are prone to wander'. Other reports have noted the presence of dementia among older homeless people³¹ but have not given any estimates of its prevalence. Many of such audits relied on the observations of non-clinical staff, and not on mental health workers' clinical examinations or tests; various lower age limits were applied (from 45 to 60 years); and profiles of the residents were not collected or not reported. The lack of clinical input in such audits may account for difficulties in analysing what might be contributing to the problems reported: alcohol misuse resulting in vitamin B₁₂ and folate deficiencies, for example, or untreated human immunodeficiency virus (HIV) infection, vascular disease, or chronic or long-standing brain or head injury. There is a strong association between long-standing heavy alcohol consumption and alcohol-related brain damage (ARBD) or injury.³² Moreover, studies of hostel residents of all ages have revealed multiple health needs; for example, a comprehensive survey of residents in a London hostel for homeless women collected demographic data, and information on past and present psychiatric and social morbidity and on current and premorbid cognitive functioning.³³ This reported that over half of the residents surveyed had 'severe mental illness'. The associations between poor health and homelessness are becoming better recognised. 19

Quality of life of older homeless people

The research discussed in the previous section is problem focused and does not engage with the individuals of concern and their situations. Thus, although several measures of social functioning and wider QoL have been developed for use with people with long-term mental illnesses, 34,35 their development for use with people with dementia is more recent, although there is a long history of measurement of stress and coping among family carers. Work has been undertaken to design measures that better address the social circumstances of older people who are homeless (e.g. the focus group discussions of QoL in a Canadian study included older homeless participants³⁶). These confirm the necessity of taking into account all of the social factors that this marginalisation generally brings (such as lack of family contact or meaningful activities). The QoL measures being developed in social psychiatry are embedded within a strong conceptual framework, including medical and multidimensional, holistic models of functioning,³⁷ wider health and psychosocial needs-based and life satisfaction models,34 but these generally take 'home', 'occupation' and 'social contacts' for granted. The development and use of a robust measurement of QoL among homeless people with dementia may need to take into account the literature on QoL among people with mental illness who are homeless (emphasising maintenance of stable housing, food and clothing, health and risk of victimisation³⁸), and among homeless people per se (emphasising food, shelter, necessities, respect, choice and relationships³⁹). Two particular studies have validated such scales among homeless people: Riley et al.40 used the SF-36 (Short Form Questionnaire-36 items), although this was confined to a particular subgroup of people infected with HIV who were homeless or marginally housed, whereas Auguier et al.41 used the same measure with homeless people with schizophrenia living in urban France. These highlighted the need for QoL measures to reflect the priorities of the target population, enabling better understanding of the need for any QoL instrument for those with dementia and who are homeless or 'hard to house' to reflect their own needs and priorities. The first part of the present study was therefore designed to examine the appropriateness of existing QoL instruments in reflecting the needs and priorities of this group (see *Chapter 2*).

Workplace contexts

The subsequent and major part of the present study sought to remedy, in part, the current lack of research evidence and knowledge of the extent of memory problems (used as a general term suggestive of possible dementia and to make a distinction between learning disability-related memory problems and any other mental illnesses) and service use among older homeless people resident in hostels. Other studies have investigated specific health conditions among this group (e.g. Hill *et al.*,⁴² who focused on dental problems). Little is known about how staff working in hostels are involved in identifying memory problems and steering residents into memory services, or how they manage symptoms of possible or recognised dementia among hostel residents in the current context in which dementia is a policy and practice imperative.

The hostel workforce is an under-researched group.⁴³ In England, most of those working in hostels are employed by not-for-profit or commercial organisations that provide 'temporary' accommodation for homeless people. Funding is mainly through local authority housing-related support payments (previously through the Supporting People programme) but also through other income streams and fundraising. Staffing levels in accommodation projects for single homeless people run at an average of nine full-time-equivalent staff,⁴⁴ although hostels vary greatly in resident numbers, staffing deployment and resources. Staff working in homelessness services generally undertake a range of duties but, in general, receive little continuing professional development and support compared with health-care professionals.⁴⁵ They are reported to be uncertain of their positions in local health networks,⁴⁶ yet they are considered to have much to offer health-care services locally in terms of skills and knowledge.⁴⁷ Fitzpatrick and Wygnanska⁴⁸ argued that hostel staffing and support arrangements can be even more critical to residents' QoL and future prospects than physical standards, but noted that hostel staff can be poorly qualified, often needing only a basic vocational (non-university) qualification.

Chapter summary

This chapter has located this study in the contexts of policy and practice relating to dementia and homeless older people. It has drawn attention to policy contexts of health inequalities and to the lack of knowledge about the workforce in organisations supporting older homeless people. The discussion of QoL among older homeless people highlights the general lack of information about this important matter, and draws together the contextual themes by noting the importance of this to the individuals concerned, despite difficulties in defining it. The next chapter moves to discuss previous work on this subject on which the present study draws.

Chapter 2 The literature reviewed: the prevalence of memory problems among older people who are homeless and quality of life

Introduction

The previous chapter described the overall aim of this research project as being to investigate service responses to older homeless people with memory problems (consistent with mild cognitive impairment or dementia) and the experiences of those so defined. This chapter presents findings from our two reviews of the literature to set the context for the data collected and analysed. Literature review A aimed to address objective 1 of the study by investigating the prevalence of memory problems among older homeless people. Literature review B aimed to address objective 4 of the study: how homeless people with memory problems perceive their QoL. This has been published⁴⁹ and so is briefly summarised.

There is emerging, if, at times, varied, UK evidence about the circumstances and needs of older people who are homeless and have memory problems, although, as we report below, the subject has received sustained attention in other developed countries, such as the USA, Canada and Australia. A recent paper commented that '(R)eported rates of mild and moderate cognitive impairment in older people experiencing homelessness range from 5–80%'.50 One explanation for such a vast range may be that several different interpretations of three key terms are being used, namely homelessness, older/old (usually by chronological age, which can start at 45 years) and memory problems (or disability or dementia). International comparisons are rendered even more difficult by national arrangements and terminology relating to locations, with the functions and roles of hostels, flophouses (a term mainly used in North America), shelters (North America in the main) and boarding houses (Australia and North America in the main and approximately equivalent to UK hostels) being variable or overlapping. Other national considerations include whether homeless people are covered by universal health services or systems that are based on insurance (e.g. see Brown *et al.*51). There are also differences between people who have been homeless for several years and are reaching older ages, and people who have become homeless for the first time in later life.52,53

Relatively few homeless people live long. A recent audit of mortality data concerning homeless people in East London who were registered with two specialist primary care practices⁵⁴ found that the average age at death was 47 years and concluded that most deaths were very premature and preventable. The UK Coalition on Older Homelessness²⁶ defined 'older' homeless people as those aged \geq 50 years, because many people who are homeless at this age already have long-term health problems and disabilities that are normally associated with (very) old age. In Canada, Grenier *et al.*⁵⁵ concluded that \geq 50 years would be an appropriate threshold. Similarly, Alden²³ adopted the age of \geq 50 years on the basis of evidence that poor health and 'premature ageing' are inevitably associated with 'rooflessness'.

Although official UK statistics on homelessness are acknowledged to be limited in their accuracy, 28 approximately one-fifth of homeless people living on the streets and in hostels are aged \geq 50 years (around 8% are aged \geq 60 years). 56 The audits reported in *Chapter 1* by the former UK Coalition on Older Homelessness 26 relied on the observations of staff only, and various lower age limits were applied (from 45 to 60 years), and profiles of the residents were not supplied. Around two-fifths of older homeless men and one-fifth of older homeless women have long histories of alcohol misuse, and there is a strong association between long-standing heavy alcohol consumption and brain damage or Korsakoff syndrome, which is characterised in part by short-term memory loss. 57

Little is known about the problems faced by older homeless people with memory problems, the services and support that they receive, and the extent to which their needs are met. Some are reported to be hard to engage, reluctant to work with services, and difficult to assess and help because of persistent heavy drinking or other challenges and experiences. There are the added problems among some of distressing behaviour, multiple physical health problems and self-neglect. However, Johnson and Chamberlain⁵⁸ pointed out that it is difficult to help homeless people with their mental health or other problems if they are living in substandard accommodation, such as boarding houses (as noted previously, this term is used in Australia to refer to facilities approximately equivalent to UK hostels), in which they may be at risk of violence and lack control over their environment. 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. Rather than pathologising the older homeless person, there is a perceived need, which many in the homelessness sector acknowledge,⁵⁹ to gain a greater understanding of these problems, identify the barriers to diagnosis, service access and unmet need, and find out ways in which these might be addressed in services that should be characterised by respect and dignity for older homeless people.⁶⁰

Literature review A: a scoping review of prevalence of dementia in older homeless people

Methods

Search strategy

For this scoping review of what is known about the prevalence of dementia among homeless people, we conducted a comprehensive, cross-disciplinary, systematic search of the conceptual and empirical literature across clinical and social sciences, and health, housing and social care. We searched for any type of English-language literature published or written from 1980 to the end of 2016. We included observational studies, controlled evaluations and randomised controlled trials of health and social care interventions relevant to older homeless populations with dementia or memory problems.

Process of the review

The process of the review was that two reviewers independently screened all titles and abstracts that had been retrieved for relevance; disagreements were resolved by consensus. If relevant, the full-text article or publication was obtained. The full text of obtained articles was judged to be potentially relevant by the two reviewers. A list of key questions was generated, and a pro forma (data extraction tool) was developed to address these from the included papers. These were piloted on a small number of selected papers. Owing to the few papers identified, unlike Burra *et al.*⁶¹ and Ennis *et al.*⁶² we did not adopt a critical appraisal approach to rating the quality of studies, thereby following procedures generally categorised as scoping reviews.⁶³ One key reason for this is that such an approach risks overlooking studies with small sample sizes and, thus, might exclude individual case study or whole-hostel research if the numbers of older residents were not sizeable. Ennis *et al.*⁶² considered a sample size of over 100 to be 'good', but, as discussed below, we found few studies reporting such numbers.

We identified 20 articles for inclusion in the review, after screening 260 articles retrieved from our database searches (the searches were run in May 2016). We searched English-language databases only (Web of Science, Scopus, Social Care Online, PubMed and The Cochrane Collaboration) for material published from 1980 to 2016, including 'grey' literature [Figure 1 shows the flow chart – a modified PRISMA (Preferred Reporting Items for Systematic Reviews and Meta-Analyses) diagram – for the process of literature review].

We cross-checked our findings with a recent (2014) literature review from Australia conducted by a researcher at La Trobe University,⁶⁴ in which the period 2004–14 had been searched for items from English-language literature, using the terms cognitive impairment, dementia, care needs and illness of homeless people. Chenco undertook one search for 'dementia' and 'homeless' and another for 'illness'

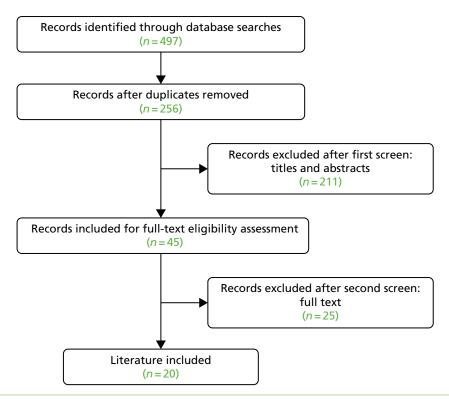


FIGURE 1 Literature review A flow chart (a modified PRISMA diagram).

and 'homeless', and then combined the findings into a single larger list.⁶⁴ This resulted in the location of 344 references, once Chenco had removed duplicates. Of these, 35 were deemed directly relevant for the purposes of Chenco's Australian review, which, as noted previously, took a much broader scope than our study by including the term 'illness'.⁶⁴ In this search of four main databases, Chenco located the following numbers of items:

- Social Services Abstracts (via ProQuest) (n = 241)
- AgeLine (via EBSCOhost) (n = 24)
- Australian Family & Society Abstracts Database (via Informit) (n = 84)
- Health & Society Database (via Informit) (n = 73).

In addition to comparing our searches with Chenco's findings,⁶⁴ we took particular account of the findings of other scoping and systematic reviews of similar subjects. In the review by Spence *et al.*,⁶⁵ for example, the following terms were searched for in the titles, abstracts and any subject heading fields: 'homeless*' or 'roofless*' or 'fixed abode*' or 'hostel*' or 'bed and breakfast*' or 'night shelter*' or 'hotel*' or 'housing benefit*' or 'street dwell*' or 'tramp' or 'tramps' or 'vagrant*' or 'vagabond*' AND 'cognit*' or 'executive function'. We did not search for the terms 'tramp' or 'vagabond', but it is interesting to note that such terms were evidently in use just over a decade ago in the UK. There are wide variations between services that provide hostel accommodation and night shelters, both internationally and in the UK and in terms of their residents or user profiles; these need to be taken into account in any comparison and are mentioned in *Findings*.

Findings

Our searches found a small number of studies covering homelessness and memory problems/deficit/dementia and *Appendix 1* contains a full table of the studies included in the second literature review. Of these studies, one of the earliest to examine these subjects in terms of prevalence was undertaken in Australia by Teeson and Buhrich.⁶⁶ Over 20 years ago, these researchers used the Mini Mental State Examination (MMSE),⁶⁷ which is still commonly used in UK dementia services, and estimated that severe memory problems affected 25% of one hostel's 65 residents, and another 40% showed signs of mild memory problems.

To establish if the high prevalence of severe memory problems was more commonly borne out in other hostels, and because no women had been included in their 1993 research, ⁶⁶ Buhrich *et al.* ⁶⁸ later conducted a broader study of homeless people, again in inner-city Sydney, NSW, Australia. Using the MMSE⁶⁷ with 204 participants (155 men and 49 women) in seven hostels, they found that 10% (20 people) had some form of memory problems. Of the 14 men with memory problems, five had severe memory problems. The six women had mild memory problems:

The prevalence of cognitive impairment among the homeless subjects in this sample was 10 percent . . . the prevalence of cognitive impairment in the general adult population is 1.7 percent . . .

Buhrich et al.68

In this study, MMSE scores of 0–17 were interpreted as indicative of severe impairment and scores of 18–23 were interpreted as mild impairment (although six people were not included in these figures as they were unable to complete the MMSE, were deaf, or could not speak English). The researchers found that people with memory problems were likely to stay in the hostel accommodation for longer than those without, postulating that this might be because 'move on' accommodation was much harder for them to find, or because their motivations to move on were compromised.⁶⁸

Measurements and assessments

Ennis *et al.* 's⁶² review found 11 studies that measured memory impairment among homeless people (of any age) using validated neuropsychiatric tools. They excluded those studies in which memory was assessed by the MMSE,⁶⁷ as they argued that this does not produce a unique score for items of memory. Eight distinct studies contained unique samples of people who were homeless, a total of 436 participants. The mean age of the studies' participants was 40.75 years and most participants were male. Most studies had been conducted in the USA. The authors commented that older homeless people were not adequately represented in the studies they reviewed (neither were women, young people or children). They suggested that studies that collect data about 'memory' problems without using validated tools are virtually impossible to compare. In respect of their findings of prevalence of memory impairment, they expressed caution in making firm estimates as there were so many variations of assessment, scoring and sample populations. They also highlighted a need for further research on traumatic brain injury, which they concluded is often misdiagnosed or mistaken for other problems. Despite their reservations about using the MMSE, and as the findings reported below show, many other researchers have used this assessment.

Other modes of assessment have explored the presence of serious mental disorders among homeless people. A systematic review (not focusing on older people) identified 29 surveys in which 5684 homeless people had participated through clinical examination or interviews using validated instruments, many of which had good participation or response rates, mostly above 70%. ⁶⁹ Inner-city Sydney, NSW, Australia, is one research site where several studies with older populations have been undertaken. For example, Rogoz *et al.*⁷⁰ found that 67% of participating homeless older people showed evidence of memory problems. Rogoz and Burke's later study of 171 older (aged \geq 45 years) homeless people in inner-city Sydney screened them for memory problems using the MMSE (taking a score of \leq 26 as indicative of memory problems), or asked them to complete a clock-drawing test, a verbal fluency test and the Trail Making Test (this was the most sensitive). ⁵⁰ This screening found that 78% (134 out of 171) were cognitively impaired, with 75% showing marked impairment of their frontal lobe functioning. This study recruited from a wide range of sources, including people living on the streets, in temporary accommodation and in marginal or shared facilities. The researchers commented that using one neuropsychological test was easy to administer and appeared acceptable.

In a US study that explored the presence of 'geriatric syndromes' among older (age range 50–69 years) homeless people in eight homeless shelters in Boston, MA, USA, Brown *et al.*⁷¹ found that memory problems (measured by a MMSE score of \leq 24) were present among 24.3% (n = 247). Other health problems were frequently mentioned, such as incontinence (49.8%), self-reported hearing loss (29.7%), major depression (39.8%) and visual impairment (30%). Comparisons with the general population revealed a higher presence of health problems among the homeless population. Interestingly, to make such comparisons more accurate, the researchers excluded the three eligible participants who were aged

 \geq 70 years, meaning that the definition of 'older' should not always concentrate on the minimal age of this category (45 years, 50 years, and so forth) but should also enquire about other exclusion criteria on the basis of age.

In a further analysis of the data, Brown *et al.*⁵¹ explored the factors associated with 'geriatric syndromes' among older homeless adults who had participated in the data collection through interviews and physical examinations. These included assessment using the MMSE and the Trail Making Test Part B to measure executive function by the time taken to complete tasks. Joyce and Limbos²⁴ similarly used the MMSE but also used the 15-item Geriatric Depression Scale (GDS-15) among 49 users of a community-based homeless shelter for older men in Toronto, ON, Canada. Study participants were \geq 55 years of age (mean age 66.4 years) who had been homeless for an average of 8.8 [standard deviation (SD) 10.2] years. The oldest was 89 years. There was a refusal rate of 40.8%; thus, only 29 people completed the depression measures (GDS-15) and the MMSE. One person had a recorded dementia diagnosis before moving to the shelter but within 6 months of moving in another seven people had been so diagnosed (the researchers generally confirmed this) by primary health services. The researchers found a further four participants with mild impairment (MMSE score of 23–27) and one with dementia (MMSE score of \leq 22) who had not been previously diagnosed. They concluded that brief screening tools seemed to be effective in identifying memory problems (and depression) among this client group.²⁴

While focusing on ARBD among homeless hostel-dwellers (aged > 34 years, mean age 53 years) in Glasgow, Scotland, Gilchrist and Morrison⁵⁷ also collected data relating to memory problems using the Addenbrooke's Cognitive Examination (ACE). Of their sample, 82% had memory problems as measured by a score of < 88 on the ACE (the researchers estimated that ARBD affected 21%). This study helpfully describes the type of hostels participating, which ranged from large hostels for men and one for women, to a hostel with 'rapid turnover'. Similarly, in Sydney, NSW, Australia, Conroy *et al.*⁷² found that among the 50 homeless clients of one service they interviewed (average age of \geq 50 years), all had a history of alcohol abuse and early cognitive decline. They estimated that 39% had scored similarly to people with dementia in their assessments.

In a US study undertaken in California, Brown *et al.*⁷³ recruited older homeless people (aged \geq 50 years) from a variety of homelessness providers, thereby expanding the more usual recruitment source, which, as illustrated above, has often been from shelters and their sometimes transient and heterogeneous populations. They used the Modified MMSE⁷⁴ to assess cognition and defined memory problems as a score below the seventh percentile or when a participant was unable to complete the assessment.⁷³ Among their 350 participants, one-quarter (25.8%) had memory problems as measured in this study. However, Rota-Bartelink²⁵ cautioned against using the MMSE with older homeless people, despite it being easy and quick to administer. She considered it an insensitive indicator of memory problems and observed that this may account for the wide variations in detection of memory problems among homeless populations.

Summing up, a recent review of cognitive functioning among homeless people (aged \geq 18 years) located 24 studies that had tested for cognitive functioning, including performance in the MMSE, abbreviated Mental Test or ACE.⁷⁵ The authors observed many inconsistencies across the studies in terms of data collection, definitions, reporting and diagnoses. They pointed to the difficulties of determining associations between homelessness and cognition. Despite this, the authors estimated that among the adults who participated in the studies reviewed (mean age 46 years), the 'average prevalence of cognitive impairment was about 5–8 times greater than the rate of memory problems in the US population older than 70 years'.⁷⁵

However, caution is needed when generalising from this estimate, as difficulties remain in assessing whether or not cognition impairment overlaps with what might be termed dementia. In one of the few studies of homeless people (published in English) from Japan, Nishio *et al.*⁷⁶ explored the overlap between cognitive disability and mental illness in a sample of 114 people living on the streets or in a temporary residence and recruited via a support centre at mealtimes. Although ages ranged from 20 to 78 years,

84% were aged > 50 years (31 were aged 50–59 years, 33 were aged 60–69 years and 10 were aged > 70 years). Their measurements of cognitive disability covered lifelong (congenital) and acquired impairment. In this study, standardised cognitive testing, including reading, was undertaken during semistructured diagnostic interviews. Relevant to the present study was the researchers' finding of cognitive disability among 34.2% of their sample; but they concluded that half of this group's cognitive problems were not the result of congenital disability but were age related or had arisen with mental illness.⁷⁶

Summary of prevalence studies

This review first sought to determine the prevalence of older homeless people, with and without memory problems, by synthesising audits published as 'grey' literature and surveys. The literature suggests a consensus that older homeless people are more likely to have memory problems than other older people and probably more so than younger homeless people. However, there are limitations to each study, as described previously, meaning that an overall prevalence estimate is hard to determine. These complications render comparisons of prevalence near impossible. Although this may be frustrating, it is likely to be more helpful to service providers and service funders to accept that 'prevalence' will be affected by the nature of the service from which participants are recruited, their clientele, the definitions of impairment, and the measurements or tests chosen.

We also explored the range of definitions of memory problems used in these studies. Overall, the term cognitive impairment was prominent, but, as noted above, this was largely synonymous with cognitive dysfunction or cognitive deficit.²⁵ The use of the term dementia is a fairly recent addition to the literature, reflecting perhaps a more social model of dementia but also the wider user of this term in public and health services settings. Alzheimer's disease is not generally used in the existing research, possibly because the classifications of dementia were broad or simply not considered. In some discussions arising from the reviews' analyses, the term memory problems appears to be more mild than dementia, as Chenco⁶⁴ described people with dementia as a group who will need more specialised support or treatment than others with memory problems. The next section of this review discusses the literature related to service models and staffing.

Services

One point implicitly raised by Rota-Bartelink²⁵ was whether or not memory problems matter in the context of providing services to homeless people. She suggested that they do indeed matter because they affect people's ability to keep or get stable housing and to benefit from support. The person may need support to make decisions and judgements, regulate their behaviour, and build and keep social relationships. A person's ability to benefit from interventions has to take into account their cognitive abilities and disabilities. Services should beware of devising or agreeing to outcomes that do not reflect these challenges. The thesis that memory problems bring extra vulnerability was echoed in Grenier *et al.*'s⁵⁵ review, which pointed to the likely needs of older homeless people as being for safety and, by extension, the heightened vulnerabilities if a homeless person has dementia.

Two further reviews of the service needs of older homeless people were found. Stergiopoulos and Herrmann⁷⁷ noted that some researchers had concluded that older homeless people are likely to be missed by studies that recruit from large services because they are 'hidden' or do not use such services and sometimes do not access other related services, such as primary health care. The service needs in their review were mainly indicated by reports of surveys and interview-based studies that pointed to the range of problems commonly found among older people who are homeless or the 'chronically mentally ill elderly'.⁷⁷ They noted that better understanding of the events that precipitate homelessness might inform prevention measures or the pathways to homelessness. However, they also suggested that there exist 'age-specific unmet physical and mental health needs among homeless seniors, particularly among those with mobility and memory problems'.⁷⁷ They proposed that it would be helpful to think about services for all homeless people as well as those for older homeless people; the latter experience particular barriers to

accessing some services, such as physical inaccessibility, and often have a legacy of dissatisfaction with services and lack of health card identification (proof of entitlement). One concrete suggestion was that local consideration should be given to day centre programmes to engage older homeless people and to provide more acceptable and accessible assistance.

Stergiopoulos and Herrmann's study⁷⁷ was one of the few found that collected data from multiple sources, obtaining data from local health and community services in Toronto, ON, Canada, and surveying 11 hostel directors (eight responded) (in addition to completing a literature review). The directors reported that although older (aged > 65 years) male hostel residents were a very small minority of hostel users, and likely to have been homeless long term, the problems that gave rise to most concern among hostel staff were older residents' memory difficulties, verbal aggression and alcohol misuse. Fewer in number, older female hostel residents were more likely, in the directors' experiences, to have memory problems, symptoms of paranoia and depression. The directors expressed concern that overall they were not meeting older residents' memory and mobility needs.

Burra *et al.*⁶¹ systematically reviewed studies of cognitive deficits in homeless adults, and discussed their implications for services. They found that, among the studies that had administered the MMSE, between 4% and 7% of homeless people were reported as having global cognitive deficits. The consequent implications for services were thought to lie in problems with clients' adherence to treatment regimes, their difficulties following rehabilitation programmes and their lack of participation in 'training'.

Likewise, Brown *et al.*,⁷³ whose study included older homeless people living in a variety of environments, concluded that there were few differences in the mental and physical health status of older homeless people by location (temporary or rooflessness), many of whom had disproportionately high levels of long-term conditions compared with the general older population, and even when compared with older people living in poverty. These authors suggested that current service efforts in areas such as rehabilitation, environmental adaptation and addressing polypharmacy may not have much traction with older homeless people, whose key need seems to be for permanent supportive housing.

Some researchers concluded that homeless people not only need stable housing but also need support. For example, Lippmann⁷⁸ argued that older homeless people need to be able to access more of mainstream older people's (aged care in Australia) resources and funding. Van Wormer⁷⁹ similarly proposed that older homeless people need assistance with gaining and retaining housing. A review of the literature on housing options for older people⁸⁰ reported the wide spectrum of housing services, noting the importance of distinguishing between supported and supportive housing, for example the different models of shelters, and the growing evidence base for the 'housing first' approach that sees housing as a necessary preliminary for rebuilding people's lives.

For older people, it is reported to be even more difficult to provide care and resources if they are living on the streets. $^{81-83}$ O'Connell *et al.* 84 noted that diagnosing dementia is difficult 'on the streets' as assessment necessitates access to tests and the ability to take details of a person's history. In this unique longitudinal study of older homeless people in Boston, MA, USA, where the authors followed up 30 people aged \geq 60 years for 4 years, multidisciplinary teams of health professionals undertook outreach work regularly.

There have been few evaluations of services for older people with dementia or similar conditions who have been rehoused in care facilities. One of the few is of the Wicking Project in Melbourne, VIC, Australia, a model of residential care for older people with dementia and challenging behaviour arising from alcohol-related brain injury. This started in 2006, as described by Rota-Bartlink and Lipmann⁶⁰ (Lipmann is the chief executive of the provider organisation, Wintringham, a not-for-profit homeless service for people aged \geq 50 years). Using a household model with an emphasis on harm minimisation and on meeting the needs of people who 'shuffle transiently between organisations that cannot provide long-term care management solutions,' ⁶⁰ this facility offers individual care plans and specialist case management.

Findings from interviews with 50 stakeholders in Sydney, NSW, Australia, about possible best practice for older homeless people were summed up by Conroy *et al.*⁷² as suggesting the need for persistent engagement with individuals, taking a harm minimisation approach, targeting people for assessment of possible mild cognitive impairment, and improving links and referrals systems between agencies.⁷² Backer and Howard⁸⁵ had earlier noted that, although prevalence estimates of cognitive problems varied, the effects of such impairments were that older homeless people could find it difficult to access help and support or to sustain engagement with services when their housing was at risk.

Barrett *et al.*,⁸³ reporting on older homeless service provision in Florida, USA, claimed that there was an increasing need to understand and work on the different ways in which older homeless people gain access to services and the pathways designed. Unsurprisingly, perhaps, they suggested that better collaboration between services and agencies was needed.

In one of the few discussions about distressing or challenging symptoms of dementia that may be experienced in service settings supporting previously homeless older people, the homelessness provider mentioned previously, Wintringham,⁷⁸ welcomed proposals for a funding supplement to cover the extra costs needed to provide such support. It commended an approach that was 'behaviour based', although it queried whether or not the proposed assessment tool would be appropriate for people who had been homeless. Furthermore, it suggested that a wider range of staff be approved to undertake such assessments, noting that, in homelessness services, members of staff were not generally clinically qualified. It further speculated that some people's behaviour might be so challenging that a 'top-up' or an upload to the funding supplement should be considered. Such detailed considerations of cost-effectiveness and service models are rarely encountered in the literature.

Staff training and skills have been considered in some studies, although there does not appear to have been any evaluation of skills development or of training packages or workforce models. Concurring with the conclusions of other studies, 81,86,87 Rogoz et al.70 suggested that improved access and delivery of services to homeless older people with memory problems should be undertaken by specialist, multidisciplinary teams of health professionals. The skills reportedly needed were summarised as spanning the areas of outreach, assessment and multimorbidity management. In addition to advocating for more research on older homeless people following her review, Chenco⁶⁴ argued the importance of better understanding of the educational, training and resource needs of health professionals who work with homeless older people.

More specifically related to the content of clinical services, Andersen *et al.*⁸⁸ recommended screening for traumatic brain injury after finding that this seemed to explain the poor performance in cognitive testing among a sample of 34 homeless people in Canada, whose average age was 58.8 years. Further related to health services, Abdul-Hamid *et al.*⁸⁹ had earlier raised questions about whether clinical services for older homeless people should be under the responsibility of geriatricians or psychogeriatricians.

However, as reported by other commentators, some older homeless people refuse to be assessed or evaluated, and questions of competency and decision-making autonomy may forestall service engagement.⁸⁴ The legal position of having a proxy or court-appointed decision-maker is not generally addressed in most studies, although the first report of the Wicking Initiative⁶⁰ mentioned briefly that some residents had an administrator appointed to make decisions (in England and Wales this would perhaps be an appointee for benefits because other provisions of the Mental Capacity Act 2005⁹⁰ would apply only if decision capacity was substantially impaired).

Backer *et al.*,85 among others, have pointed to the need for services to prevent homelessness by addressing its causes and risk factors. The skills to follow that path are not delineated, nor is how to change service commissioning. The Wicking Initiative, discussed above, remains one of the few service examples of tertiary provision described in any detail. We do not know much about what happens over time to older homeless people in other settings who are recognised as having memory problems or a dementia. As one example of the importance of this, of the 15 older homeless people with dementia contacted by an outreach

initiative⁹¹ in the city of Tel Aviv, Israel, 11 later moved to a nursing home, with unreported outcomes. More generally, this study recommended intensive outreach and case management to effectively assist older homeless people.

Ending the 'invisibility' of memory problems among older homeless people

According to Lipmann,⁷⁸ founder and chief executive of Wintringham, Australia's largest aged care provider for homeless people, being homeless limits access to many of the supports that most other people take for granted. He argued that homeless people are often not included in support services because of their sometimes fierce independence and reluctance to push their 'rights'; in effect, they become invisible or marginalised. Likewise, he observed that homeless people do not come to the attention of 'aged care' (the term used in Australia) services and, to some extent, they also remain invisible here. Lipmann⁷⁸ acknowledged that considerable Australian government funding is provided for dementia research and services for people with dementia, but observed that little of such funding reaches homeless people with dementia. In his view, the reason for this rests on the stigma associated with homelessness and the 'fact' that homeless people do not engage with services, particularly the aged care services to which the mainstream funding is allocated. Lipmann argued that funding should be directed towards Australian welfare organisations, such as his own, that provide services to older homeless people.⁷⁸

Literature review B: how homeless people with memory problems perceive their quality of life

Although several measures of social functioning and wider QoL have been developed for use with people with long-term mental illnesses,^{34,35} their development for use with people with dementia has been slower, although stress and coping among carers have been widely studied. None appears to be relevant to the social circumstances of older people who are homeless, with all of the factors that this living situation generally brings (lack of family contact or meaningful activities, and poor health overall). This literature review⁴⁹ investigated the evidence on how older homeless people with memory problems perceive their QoL, and the potential appropriateness of existing QoL instruments in reflecting the needs and priorities of this group.

Literature review B⁴⁹ comprised a narrative systematic review and an evidence synthesis of QoL instruments used in assessing people with dementia (all types) to assist investigators and service providers in selecting the optimal measures for their aims and to specifically address issues and life areas that are of particular importance to homeless older people. It noted the presence of a large body of literature in this area (QoL and dementia), and so a narrative review and critical discussion, with tabulated evidence, were undertaken to compare the measurement properties of the QoL instruments identified, their appropriateness for assessing the QoL of homeless people with dementia, and by type and severity of dementia, and sensitivity to the type, organisation, delivery and use of health service interventions.

The objectives of this review were 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 user
- 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 the 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 the current data on the QoL of people with dementia, including homeless groups
- identify research gaps and the need for further primary research.

The findings of this review were published in 2015⁴⁹ and informed our study data collection instruments.

Chapter summary

In summary, literature review A found that studies of the physical and mental health of older people who are homeless or have experienced recent homelessness have collected data on memory problems using different definitions and in different ways either as a focus or in combination with other conditions. As a scoping review, the publications reviewed were not assessed or graded for quality, but a narrative approach has drawn attention to the key features of the studies or descriptive accounts. The review has not only identified the several varied estimates of prevalence and some debate about the most appropriate means of assessment, but, by providing details of the study populations and approaches, it offers a means of interpreting the variations.

Scoping reviews also facilitate understanding of where gaps in the evidence may lie. Notably, service evaluations and trials of interventions are few. The future of homelessness research with older people may need to shift from estimates of prevalence, as there is international consensus that older homeless people experience multiple health problems but we have far fewer data establishing what is effective in care and support or how to implement the findings. Interestingly, there are few personal accounts or qualitative studies of personal experiences and, with one exception from the Melbourne service (Wintringham), very few accounts of practice, service commissioning and outcomes. This review has set the scene for this study; *Chapter 3* presents the methods used in the research.

Chapter 3 Study methods

This chapter describes the methods used to conduct the fieldwork that was planned and undertaken to address the research objectives. The chapter begins with an explanation of what was originally planned in the study design during the preparation for the grant application in 2011, including the potential study sites identified and the proposed data collection methods for the two phases of the study. The various challenges that arose during the implementation of the study design are then discussed. The details of data sources are presented. The last section of the chapter provides accounts of the different methods of data analysis undertaken. This includes a descriptive analysis of the participants' profiles, the analysis of the cognitive assessments, an economic analysis of participants' service use and an analysis of participants' intermittent pathways through health and social care services.

The study design

The study was designed to have two distinct phases: (1) a quantitative element to examine the prevalence of memory problems among older homeless people living in hostels and the extent to which homeless-sector staff are aware of and respond to these problems, and (2) a longitudinal case study phase to investigate:

- 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 receives for cognitive problems, and the cost of these services
- how existing services can be developed to address any gaps in service provision or unmet need
- how homeless people with memory problems perceive their QoL and available support.

Phase 1 design

The first phase of the study aimed to recruit and conduct short 'screening' interviews with up to 200 older homeless people aged \geq 50 years living in hostel accommodation in England, with a maximum of 50 people in each of four diverse study sites. These were the Midlands (five hostels), Central London and South London (three hostels) and the North East of England. As noted in *Chapter 1*, we used the former UK Coalition on Older Homelessness definition of 'older' homeless people as those aged \geq 50 years.

At the time the study was being designed, managers of several hostels in the sample areas were contacted to find out if they had any residents aged ≥ 50 years and to ascertain their interest in participating in the study. There was an enthusiastic response, with the managers welcoming the need for the research as they perceived the needs of older homeless people to be growing. In the North East of England, however, the numbers of older homeless people were thought to be small in the areas approached, and, consequently, four further hostels were identified in the North East of England that potentially could supplement numbers.

The recruitment and screening interviews of older homeless people aimed to obtain a profile of each participant and an overall assessment of their problems and needs. These also aimed to enable the research team to consider whether or not a participant had any memory problems and, if so, to determine whether or not depression was an influencing factor. This enabled participants to be selected for the case study phase (phase 2). These interviews were designed using a semistructured interview schedule to collect the following information: (1) demographic factors (age, gender, ethnicity); (2) brief histories of homelessness (i.e. length of time homeless, duration of stay in present hostel); (3) previous and current employment, education, income and welfare benefits; (4) use of time and family and social contacts; (5) support received with personal care and household tasks, such as obtaining meals and personal hygiene; (6) past and current physical and mental health problems (including administration of a validated depression tool), substance misuse problems, histories of head injuries and other accidents or traumas, other diagnoses including chronic or long-term conditions, past hospitalisations, and medication and treatment; (7) concerns about memory

and support or treatment received, and administration of the MMSE; (8) the use of different health services; and (9) QoL, and hopes and plans for the future in terms of housing and support.

We were conscious that older people with memory problems and in marginal living conditions could be a vulnerable group in terms of research as well as in much of their lives. In our application for ethics approvals, we addressed the risks that they might feel obliged to co-operate in the study, might find the questions intrusive or upsetting and might have expectations of more help. Two senior researchers (MC and LJ) had considerable experience of research and practice in the homelessness sector and they supported the wider research team in fieldwork. One ethical challenge was how to acknowledge participants' time in study participation. We decided that, at the end of each interview, older homeless participants would be offered £5 to thank them for their time, either in cash or as a shopping voucher: the type of incentive was negotiated with each hostel manager.

Once participant baseline interviews were completed in each hostel, each person's key worker was contacted and invited to take part in the study. An information sheet about the study was designed for hostel workers, and workers were shown the consent form signed by the hostel resident that gave consent for the worker to be interviewed about them. Hostel workers were also required to provide written consent to be interviewed. This interview included questions on (1) the characteristics of the hostel resident; (2) how the worker assessed and planned support for the resident; (3) their perspective on any physical, mental health, substance misuse and memory problems and the support and treatment provided; (4) what assistance, prompting or supervision was provided on a day-to-day basis by hostel staff or other services; and (5) future plans for the hostel resident. If a worker suspected that the participant had memory problems, they were then asked, based on the informant interview questions in the General Practitioner assessment of Cognition (GPCOG) tool,⁹² the reasons for this, such as whether the person (1) had problems remembering things that had happened recently, (2) could not recall conversations a few days later or (3) had difficulty finding the right word or tended to use the wrong words.

To gain an understanding of the hostel staff's training and experience, a short structured questionnaire was also designed to be administered at the first interview with each practitioner. Topics were (1) current role, length of time working in the hostel and hours of work; (2) previous experience of working with homeless people; (3) other work experience; (4) training related to working with homeless people and training on supporting someone with mental health or memory problems; and (5) training that was/would be helpful in working with older hostel residents.

To collect background information about the hostel and the services it provided, an interview was also planned with the manager or senior practitioner in each hostel. An interview schedule was designed to collect information about (1) the hostel management, facilities and funding; (2) client groups and access policies; (3) tenure policies; (4) staffing levels and training available for staff; (5) help and support provided to hostel residents; and (6) characteristics of residents with memory difficulties, support provided and services available.

After the baseline interviews were completed with hostel residents and hostel staff, data were summarised so that each participant could be discussed by the research team psychiatrists to enable participants to be allocated to observation or control groups. It was initially intended that decisions regarding allocation to the observation or control group would be made with the 30 hostel residents suspected of having memory problems and a random selection of eight residents not suspected of having memory problems being invited to take part in an interview with the research psychiatrists using the Addenbrooke's Cognitive Examination tool version R (ACE-R),⁹³ which would be used to confirm the group allocation. This tool was later replaced by the Addenbrooke's Cognitive Examination III (ACE-III) following further discussion. The ACE-III is one of the most popular and commonly used cognitive tests in dementia clinics and in the assessment of other neurological disorders. It provides a sensitive, reliable, secure and easy-to-administer clinical tool to assess cognition as part of the process of assessing for dementia. The ACE-III has five subdomains, which provide a cognitive score out of a maximum of 100: (1) attention, 18 scores;

(2) memory, 26 scores; (3) fluency, 14 scores; (4) language, 26 scores; and (5) visuospatial, 16 scores. The assessment also involves asking participants if they have problems with face recognition, remembering names of people or objects, and problems with their short- or long-term memory. As with other hostel residents who participated in interviews, £5 was given for participation.

Phase 2 case study design

The 6-month longitudinal case study phase aimed to conduct case studies of 60 older homeless people – 30 with memory problems and 30 without memory problems – divided between the study sites with the samples matched on age and duration of their stay in the hostel. These 60 participants would be selected from the 200 participants recruited in phase 1. A case study methodology was chosen as it would enable an in-depth exploration of the predominant factors and challenges that staff in homelessness services face in a real-time context,⁹⁴ which can be especially useful in researching practice settings.⁹⁵

Interviews with hostel residents

The case study phase of the study involved interviews being conducted 3 and 6 months after the first 'screening' interview with the 60 hostel residents described above. In both interviews, the aim was to collect information relating to their situations during the previous 3 months. Questions covered (1) their use of time and social contacts; (2) courses, training and voluntary work undertaken; (3) contact and support received from hostel staff; (4) everyday tasks and help given; (5) changes to physical, mental health, memory, alcohol and drug use and any associated treatment or support; (6) referrals and use of health, substance misuse and other services including hospital admissions, hospital outpatient drug and alcohol detoxification and rehabilitation services, services accessed from a general practice, urgent and emergency care; and (7) help that they would have liked to have had, but did not receive.

Interviews with hostel staff

Interviews were also planned to be conducted at 3 and 6 months with hostel staff in relation to the participating hostel residents they supported. These interviews focused on the same subject areas as covered in their first interview conducted in phase 1, in particular any changes perceived by the worker in the resident's physical or mental health, substance misuse or memory problems, the services used by the resident, the support provided by hostel staff or other services and how long they spent providing this support.

It was initially proposed that information about the length of time workers spent supporting an individual could be collected using a self-completion diary sheet. This was piloted in one hostel by members of staff supporting two residents over a 2-day period. Staff were asked to document hourly any support or attention they gave these residents and how many minutes this took. This included help with finances, social activity and personal care, as well as any activities they undertook on a resident's behalf, such as arranging appointments and dealing with rent payments. However, this proved not to be a very accurate way of collecting these data, as support often involved checking on or keeping an eye on people to monitor their well-being rather than being a specific task, and, as residents often spent large amounts of time in communal areas, such 'support' was not provided to a single person. The diary element was, therefore, not pursued.

The final interview with hostel staff at 6 months contained additional questions regarding (1) effective ways of engaging with the hostel resident and any strategies or techniques used, (2) their challenges and difficulties in working with the resident and attempts to overcome the difficulties, (3) experiences of working with other agencies to support the hostel resident and (4) implications for hostel staff and other workers in helping older homeless people with similar problems.

Interviews with other support workers

To obtain as much relevant information about the support needed and provided to each participant, interviews were also planned with other workers providing support. At their 6-month interview, hostel resident participants who received support from a service such as an alcohol misuse or community mental

health team were to be asked to provide permission for the worker to be invited to take part in a semistructured interview about the support they provided. Interviews were intended to last about 45 minutes and would be digitally recorded and transcribed. The topic areas were (1) current role and experience in working with older homeless people, (2) help and support provided to the participant, (3) working arrangements with other services to provide this support, (4) challenges or difficulties in providing this support and (5) unmet needs of the participant.

Data collection from participants' hostel records

It was also planned that, following the 6-month interviews with residents, data would be collected from participants' hostel records. Information would be collected about (1) length of time in the hostel; (2) welfare benefits received and rent paid to the hostel; (3) mental and physical health conditions, substance use issues and treatment programmes; (4) medication; (5) use of different health services, including general practitioner (GP) and other health-care services, such as emergency department [accident and emergency (A&E)] use and hospital admissions; (6) frequency and duration of receipt of social care services, including domiciliary care/home care; and (7) other service use, such as voluntary services (e.g. day centres).

Data collection from participants' medical records

At the end of the case study period, data would also be requested from the medical records held by the named GP for each resident. These data would comprise all medical records for the 6-month study period, including active health problems, previous health problems, current medication, hospital admissions and discharges, responses to referrals, use of urgent care and out-of-hours services and hospital outpatient department reports.

Study implementation

This section discusses the challenges involved in implementing the study design and the responses to these.

Recruitment of study sites and participants

Ethics approval was obtained from the London and South East Research Ethics Committee in April 2014 (14/LO/09373) and fieldwork began in May 2014. Once fieldwork for phase 1 commenced, however, the recruitment plan for the study sites changed substantially in some areas. This was due to the closures of some hostels that had initially agreed to participate, and changes to the resident profiles. The team contacted many hostels, considered other areas to try to supplement numbers and attempted to identify replacement sites. A summary of the changes to the sites, the nomenclature used and the numbers of participants recruited is shown in *Table 1*.

Central London and South London

Recruitment began in May 2014 with the hostel identified during the study design period that had a large number of residents aged \geq 50 years. In this hostel, 17 residents were recruited. To supplement numbers, two additional hostels were contacted. One hostel manager met with members of the research team but later declined permission for the hostel to take part (reason unspecified). The other participated and seven out of its eight eligible residents were recruited.

The other two hostels identified in the study design stage agreed to participate. Here, 19 participants were recruited (10 in one hostel in October/November 2014 and nine in the other in February 2015).

The North East

Once recruitment began in this region in June 2014, the need for supplemental hostels became even more evident from the unexpectedly small numbers of participants. An additional hostel in the area was identified and agreed to take part; however, of the handful of other, smaller local hostels, only three became involved and, from these, only four residents were recruited: one hostel was not able to recruit

TABLE 1 Summary of recruitment of sites and participants

Original site	Other attempts to recruit to site	Total number of hostels as recruitment sites	Total number of residents recruited	Final site name
London	Also recruited from this locality	2	24	Central London
London	None	2	19	South London
North East	Tried to recruit one large hostel but it had closed. Recruited another location	3	19	North England
Midlands	Not able to recruit from initial hostel:	1		
	 attempted to create composite Midlands site, but unsuccessful attempted to create cluster in another location but able to recruit from only one locality 			
Total		8	62	

any participants. Of the four hostels that did not participate, the manager of one hostel declined to be involved, the manager of two hostels was reluctant to allow access to residents' records, and one had only a few older residents. Attempts were made to contact the two hostels previously identified in the region in 2011. One had been demolished, and the other had closed and been replaced with three smaller units with a total of 40 beds. These units either did not have any residents aged \geq 50 years or had such small numbers (one had one resident and the other had three) that it was not feasible to recruit there. Instead, a hostel in another locality participated, from which 11 residents were recruited.

The Midlands

Although three hostels were identified as suitable in one locality during the design stage of the study, once fieldwork commenced in 2014 they were found to currently have very few older hostel residents. As there were such small numbers in this locality, we looked further afield for a potential fourth site in this region. In one potential area, a hostel with > 200 beds supported many residents aged ≥ 50 years and, when visited in 2011, was very willing to participate. However, by May 2014 this hostel had closed. Residents in another hostel in the locality were being required to move from the hostel after about 3 months; therefore, it was not suitable for the study's needs. In another nearby locality, five hostels were identified in 2011 as potentially suitable; however, only one worked with homeless people aged ≥ 50 years. By 2014, this hostel was providing only short-term emergency accommodation, which also made it unsuitable for the study. Having failed to find suitable hostels in the Midlands, the potential for creating a cluster in an adjacent region was explored. In August 2014, two hostels were identified that appeared suitable initially. However, although one of these hostels had 16 residents aged \geq 50 years, the high turnover of these residents made follow-up over 6 months untenable. The hostel in the other locality had very few residents aged \geq 50 years. Finally, one hostel was contacted in another locality, which had four residents aged ≥ 50 years. All four eligible participants in this hostel were recruited in September and October 2014.

Recruiting, obtaining consent and interviewing older hostel residents

Once the initial sites had agreed to participate, three members of the research team (MC, LJ and KS) met with the site managers to further explain the study and provide information sheets for residents and staff. A few days before the team visited each hostel, hostel staff spoke to residents aged ≥ 50 years, provided them with an invitation letter and study information sheet, and sought their permission to tell the interviewers if they were interested in taking part. When the interviewers visited the hostel, residents who had expressed an interest were contacted. The researcher explained what was involved, specifically that (1) participation was voluntary and they could withdraw at any time or refuse to answer any question; (2) that they would be seen

three or four times by a researcher over the following 6 months, one of whom would be the research team psychiatrist for some questions related to memory and concentration; (3) that their consent was needed to collect information from hostel staff, their hostel records and their medical records; and (4) if they said something that indicated that they or someone else was at risk of harm, the interviewer would be obliged to take appropriate action. Permission was also sought for the researchers to make enquiries about participants' whereabouts from hostel staff, and nominated services, family or friends if they could not be contacted for future interviews.

Written consent was obtained before the first interview, with verbal consent obtained before subsequent interviews. Only hostel residents who gave informed and written consent were recruited. Participants' capacity to give informed consent was determined before each subsequent interview. It was planned that, should a participant lose capacity during the following 6 months, they would be kept in the study and, in accordance with the Mental Capacity Act 2005, a nominated consultee would be involved. This, however, was not necessary. For participants who were heavy daily drinkers of alcohol, interviews were arranged in the morning before they became intoxicated or fell asleep.

There were several challenges in recruiting residents to the study. Despite numerous visits to hostels, recruitment took much longer than planned and a greater number of older people than anticipated declined to take part. One problem was that the title of the study led to misunderstandings. Some hostels persistently referred to the study as the 'dementia study' and at times staff perceived that only people with memory problems were needed. Consequently, some residents were reluctant to take part as they felt that they did not have memory problems or dementia. Repeated efforts were made by the research team to challenge these misconceptions but it is likely that this had a negative effect on participation.

Being reliant on staff to initially speak to residents and explain the study brought other challenges. Some members of staff were very interested in the study, discussed it with residents, encouraged them to take part, and readily liaised with the research team. In other hostels it was more difficult. This was largely because of work pressures but insufficient interest in and unfamiliarity of being involved in research may have also influenced the way in which the study was explained and the extent to which residents were encouraged to take part. In one hostel in North England, only 2 out of the 16 eligible residents agreed to participate.

Practical aspects also affected when interviews could take place as the research team had to work around the shifts of hostel staff, staff handover meetings and other activities, such as resident meetings and groups run by visiting alcohol/addictions or health workers. In two hostels, members of staff were only on site until 4 p.m. so, for safety reasons, researchers could not visit after this time. Another hostel only permitted researchers to visit once per week.

Arranging and conducting interviews were also complex tasks. As outlined previously, many hostel residents were heavy consumers of alcohol and illicit drugs. On two occasions, interviews had to be completed at a second visit: one person fell asleep in their first interview and another had to attend an unexpected case review. Some participants had been homeless for many years and were vague about past details. Therefore, capturing the required information was often difficult. Some questions had to be rephrased and asked in different ways, and details needed to be checked at different points during the interview if contradictory information was provided.

Nonetheless, a total of 62 older homeless participants aged \geq 50 years were recruited to the study. Fifteen people (24%) were lost to follow-up and 47 were included in the case study analysis. Several reasons were offered as to why people either dropped out of the study or could not be followed up. These are shown in *Table 2*.

TABLE 2 Participants lost to follow-up

Reason why participant was lost to follow-up	Number of participants
Died	1
Moved to another hostel managed by different organisation; it was not feasible to follow up as this would have involved having to negotiate access and permissions again	4
Evicted/moved from hostel and contact lost	2
Relocated out of the UK	1
Went to drug and alcohol detoxification centre and then abandoned rehabilitation	1
Declined to participate further at point of ACE-III or when contacted for 3-month interview	5
Did not consent to collection of information from medical records	1

Undertaking cognitive assessments

Changes were made to the study design in relation to the various cognitive assessments undertaken in both phases of the study. In phase 1, the MMSE was replaced by the Six-Item Cognitive Impairment Test (6-CIT). This was because it was felt that the 6-CIT was more achievable to conduct as an initial screening tool, as it was shorter than the MMSE and did not involve a requirement to draw.

Although the study was designed so that only some participants would receive further cognitive assessment by the research team psychiatrists, by the time the data of the first group of residents were discussed by the research team it was apparent that recruiting up to 50 participants per site was not feasible and that it would be a challenge to obtain 60 participants for the case study phase. It was therefore decided that (1) all participants would be taken into the case study phase and (2) to ensure consistency in allocation to observation or control group, all participants would be invited for cognitive assessment. Appointments were consequently arranged with each participating hostel resident for a psychiatrist or a psychologist (RN, Tanya Walton and Elspeth Dustagheer) to conduct a short (20-minute) assessment of cognition with them where they lived. Although it was planned that the ACE-R would be used, this was replaced by the Addenbrooke's Cognitive Examination tool III (ACE-III) as copyright permissions were needed for the ACE-R.

On reviewing the first set of residents' data, the research team noted that some participants struggled to answer the 6-CIT questions about memory and concentration and therefore might struggle with the ACE-III. It was therefore proposed that the shorter Montreal Cognitive Assessment (MoCA),⁹⁶ which captures executive function of memory more succinctly, should be used with participants for whom the ACE-III could be too burdensome. This would theoretically enable all participants to undertake a cognitive assessment and reduce the number of missing data. The ACE-III was considered to still be useful for any subanalysis but the MoCA would give a good indication of whether or not an individual had memory problems. An application for a substantial amendment to ethics permissions was made and accepted at the end of July 2014. Nonetheless, 48 ACE-III assessments were conducted and the MoCA was attempted with only one participant.

Interviewing hostel staff

There were challenges in completing interviews with hostel staff. They were often very busy and found it hard to make time and, in a few cases, long-term illness meant that some could not be interviewed as planned. Consequently, on some occasions baseline questions were combined with 3-month interviews. In one hostel, members of staff were interviewed only once at 6 months. When possible, the same member of staff was interviewed each time; however, the high turnover of agency/locum staff in one hostel meant that different staff were acting as key workers for residents at baseline and at 3 and 6 months. Even when appointments with workers had been arranged, at times interviews were cancelled if there was a crisis in the hostel. Nonetheless, interviews were held with 44 hostel workers. All were recorded with consent,

transcribed and analysed thematically, and linked to any relevant resident for whom the staff member acted as a key worker (see *Data sources*).

Data sources

Extensive attempts were made to obtain a 'complete' data set that included participants' self-reports, hostel worker reports and information from hostel and medical records. However, the challenges in conducting the fieldwork explained previously meant that this was not possible in many cases. Although the majority of hostels provided full access to electronic and paper records, ensuring that all relevant information could be collected, in a few cases staff either completed the extraction themselves or acted as gatekeepers to data, making it difficult to be certain whether or not all of the relevant information had been provided.

Health centres were also difficult to contact, and, although medical records were obtained for 30 participants, nine participants' GPs did not respond to data requests, one hostel resident did not have a GP and another's GP was contacted only to find that the resident had not used the practice during this time; four practices reported that they were unable to provide the data as the resident was no longer registered with them. In one case, the hostel resident changed his GP in the last month of the case study period. Efforts were made to contact the second practice, but it did not respond. Not being able to pay general practices for the provision of data was a stated barrier to their willingness to provide data, but this did not appear to be the only factor. The different data sources and the number of participants for whom data were collected are shown in *Table 3*.

Data analysis

Descriptive analysis of the sample

Quantitative data from the interviews with hostel residents and staff were entered into a SPSS database. Open-ended responses from interviews with hostel residents and staff were entered into a NVivo database. A straightforward process of thematic analysis was applied to these responses so that categories and themes could be identified. Most of the answers related to the questions asked of participants. Drawing on the data collected in baseline interviews with hostel residents and staff, the profiles of the 62 older homeless people recruited to the study were analysed using descriptive statistics. These included age, sex, ethnicity, education and work history, housing and homelessness history, activities and family/social contacts, income, management of everyday tasks, physical and mental health problems, head injuries, use of alcohol and drugs, and use of services in the 3 months prior to baseline interview. These findings are presented in *Chapter 4*.

TABLE 3 Data sources

	Interviews (n)				
Data source	Baseline	3 months	6 months		
Older homeless people (aged \geq 50 years)	62	37	37		
Hostel staff (key workers); 43 SWs participated. Some were interviewed about more than one participant	44	15 + 4 combined with baseline questions	30 + 9 combined with baseline questions		
External workers	4: tenancy SW, alcohol worker, clinical psychologist and community mental health nurse				
Hostel managers	Interviews with manager(s)/senior staff were completed at eight hostels				
Hostel records	Data were collected from records of all 47 case study participants				
Medical records	Data were collected for 30 case study participants and partial data were collected for one participant (31 in total)				
SW, support worker.					

Analysis of cognitive assessments

The allocation of each case study participant into the observation or control group was conducted throughout the case study period once the relevant data had been collected. Although it was proposed that each participant in the case study phase would be categorised, as far as possible, as either having memory problems (suggestive of some form of dementia) or not having memory problems, it was not possible to allocate all participants precisely into these two groups. Consequently, a third group was created: those with borderline memory problems. Each case was examined by the team, with decisions regarding the allocation into each group made by the research team psychiatrist (RN) with reference to the ACE-III scores, participant self-report, hostel staff perceptions of whether or not an individual had memory problems and information obtained from participants' hostel and medical records (when available). A cut-off point of \geq 82 out of 100 was considered to categorise participants with memory problems (in clinical terms, cognitive decline). We also examined the history of declining activities of daily living for those who scored < 82 out of 100 points. Considering that many of these individuals had a history of alcohol abuse at the point of cognitive assessment, it was not possible to rely very heavily on the score from the ACE-III. To make a diagnosis of dementia in a clinical setting, a clinician usually interviews the patient, tries to gather information from family and relatives, and then reviews the person's medical record. Clinicians often use a series of biomarkers, such as blood tests, brain imaging and neuropsychiatric testing, to confirm a diagnosis. As most of that information was not available, the research team, supervised by Ramin Nilforooshan, examined the medical record and other information available for each case carefully to categorise the resident to each subcategory. These findings are presented in Chapter 5.

Economic analysis

To enable the costs of service use to be calculated, and to explore the pathways of participants through different health and social care services, the service use of each participant during the 6-month period following recruitment was collected and documented, as precisely as the available data would allow, in a Microsoft Excel® (Microsoft Corporation, Redmond, WA, USA) spreadsheet. The utilisation of a large number of services was included. Categories were informed by the Client Service Receipt Inventory, which is a well-validated and widely used instrument that captures the full range of health (primary, community, hospital A&E, outpatient and inpatient), social and voluntary sector provision. ⁹⁷ Incidences of did-not-attend (DNA) appointments were also noted.

Data were collected from several sources: participant self-report, hostel staff accounts, hostel records and medical records. When dates were recorded for specific aspects of service use, these were documented, as were the reasons for service use and outcomes. The sources of each occurrence of service use were also recorded. This allowed accounts of the same episode of service use from different sources to be cross-checked and for any discrepancies to be identified and considered. Where there were discrepancies in accounts, the most reliable source was selected. Medical records, when available, were considered to be the most accurate source, followed by hostel records, hostel staff reports and participant self-report. For example, if a hostel record showed that a resident had said that they were going to see their GP but the GP record did not have details of any contact, this would *not* have been counted as a GP contact.

The number of times each service was used was recorded for months 1–3 and for months 4–6 and subsequently amalgamated so that frequencies of use could be calculated over the full 6-month follow-up period. Frequencies of use for each service were tabulated. Some services were not used at all, or were used relatively infrequently, so groupings were created: GP and other general practice staff (nurse, care navigator) contacts in surgery, hostel or on the telephone; other primary care (i.e. chiropodist, dentist, optician); drug (including pharmacist for opiates) and alcohol services; community psychiatric/mental health nurse, counsellor, team/memory service; social care (social worker, social care allied health professionals in clinic, hostel and day centre); A&E and out-of-hours walk-in/urgent care, ambulance; hospital outpatient appointments (psychiatric and other), tests, treatments; and hospital inpatient days and stays, including intermediate care (psychiatric and other) and voluntary. In addition, all psychiatric and mental health service use was collected together in one category (community services, outpatient and inpatient) for separate consideration.

The unit costs of all services (2014–15) were obtained from validated national sources, primarily *Unit Costs of Health and Social Care 2015*⁹⁸ and *NHS Reference Costs 2014–15*, ⁹⁹ and applied to each service for each participant and summed to give a total service use per participant over the 6-month period. Summary statistics were calculated (mean, SD, median, minimum and maximum) across all participants for each service use item and for groupings of services, and overall. Proportions of zero utilisation were shown for each item. DNA (or missed) appointments were costed as if the contact had taken place, and proportions of DNA appointments were reported.

Two approaches were used to test the association between memory problems and service use costs. With costs being non-normally distributed, non-parametric tests were used. First, the Kruskal–Wallis test, a rank-based non-parametric test, was used to determine if there were statistically significant differences in the mean costs of service utilisation (each item and groupings of items) between participants grouped according to memory problems (no memory problems, borderline, and memory problems present). The Mann-Whitney U-test (a rank-based, non-parametric test for comparing only two groups) was then used for pairwise comparisons, where the Kruskal-Wallis test was significant. The level of significance was set at a p-value of 0.05. Memory problems groupings were determined by the research psychiatrist (RN), based on scores from the ACE-III (range 0-100 points, with lower scores indicating more memory problems), participant self-report, hostel staff perceptions of whether or not an individual had memory problems, and information obtained from hostel and medical records. As noted previously, it had been intended to categorise each participant as having memory problems or not, but this was not possible, so a 'borderline' category was introduced. Second, associations were explored between service groupings and memory problems as indicated solely by ACE-III scores using Spearman's rank-order correlation. As ACE-III scores were not available for all participants, and service use for some groups was low, correlations were not conducted for individual service use items.

Ten other participant characteristics with potential to influence service use costs were identified: sex, ethnicity (white British/other), literacy problems (yes/no), current (within the last 3 months) illegal drug use (yes/no), frequency of alcohol consumption (< 6–7 times per week/6–7 times per week), location (north/south, i.e. London), number of comorbidities, number of prescribed medications and number of head injuries. When more than one indicator of a particular characteristic was available (e.g. different measures of drug and alcohol use), the variable with least missing information was selected. Associations between the baseline values of each of these participant characteristics were calculated using Spearman's rank-order correlations (for pairs of continuous variables), Mann–Whitney U-tests (for continuous and categorical variables) and chi-squared or Fisher's exact tests (for pairs of categorical variables). Then the associations between each characteristic and each cost grouping were explored using Spearman's rank test (continuous variables), and Mann–Whitney U-test and Kruskal–Wallis tests (two and three or more category discrete variables, respectively). Finally, all 10 variables were included in backward stepwise regression modelling to explore independent predictors of each cost item. The decision to carry out linear modelling was driven by inspection of the cost variable. Hence, social care was excluded from the modelling exercise because of the small number of participants who accessed social care services. Logistic regression approaches were not considered suitable because of the small sample size and low proportions of participants in some categories.

Analysis of service needs and use

The service needs and use of all three case study groups were examined. Each potential 'case' was considered individually to decide whether or not there was sufficient information to understand the participant's pathway through services, and to calculate their service use. When 3-month interviews were not conducted with a participant or key worker, at the 6-month interview it was ensured that as much information was collected about the previous 6 months. In some cases it was not possible to conduct a 6-month interview with a hostel worker and/or a participant; in one hostel, for example, three participants who had lived in the hostel for almost all of the 6-month case study period could not be interviewed at 6 months as two were in hospital and one had been evicted. However, in these cases the hostel and medical records provided a clear account of what had happened and the range of services used, enabling the cases to be suitable to be

retained. In other cases in which a participant was relatively independent, hostel records held sparse information about their service use, yet hostel staff and participant self-report provided reliable data.

Chapter summary

This chapter has set out the original study design as planned prior to the submission of the grant application and then explained the challenges of implementing the design. We have shown that undertaking research with older homeless people with or without memory problems is possible, despite the continually changing landscape of homelessness services in England, and have outlined the difficulties of conducting a longitudinal study within hostels for homeless people that are supporting individuals with complex health and social care needs and in collecting data from other sources. This chapter provides detail of the adaptations made in response to the challenges of the study.

Chapter 4 Profile of hostels and their staff

This is the first chapter reporting study findings. It describes the study sites, namely the hostels that agreed to participate in the research, and the hostel staff. We have anonymised the hostels, and some details that would risk making them or their residents easily identifiable are not reported. Information reported here was collected from (1) interviews with hostel managers about the characteristics of each hostel and (2) interviews with hostel staff, namely residents' key workers.

Study sites

A total of eight study sites were included: four in the London area and four in North England. *Table 4* contains details of the sites in the London area and *Table 5* contains details of sites in North England; information was obtained in interviews with hostel managers and researcher observations and enquiries.

Sites

We outline in this chapter the salient characteristics of the hostels participating in this study. We have grouped together some identifying features, such as the exact numbers of beds, and some other details that might be easily recognisable and so compromise anonymity. We have divided the hostels into three groups for ease of reading – the Central London group (two hostels), the South London group (two hostels) and the North England group (three hostels). This does not mean that the hostels were totally representative of these geographical areas. Data from the interviews with managers are used to further set out the context of the participating hostels.

Key characteristics relevant to this study

Duration of resident stay

In this section, we report on the salient characteristics of the participating hostels. As outlined in Chapter 1, there is an increasing trend for hostels to require residents to move on 'quickly', and hence the average length of stay or maximum period of stay was of interest, in particular in noting whether or not the participating hostels made exceptions for certain residents or groups. We found considerable variation in how long residents were able to stay in each hostel. The reasons for longer stays were multifactorial, and appeared to include lack of housing options, increasing care needs, and whether or not the hostel owners/managers considered themselves as offering a 'home'. For example, in one of the London hostels (Central London hostel 1), although the maximum stay was 2 years, we were told that if a resident is not able to cope independently with their alcohol problem or is 'elderly', or 'does not fit into categories [for move on], or can't look after themselves' – or they are in 'limbo', for example not being 'ill enough for a care home' (not meeting local authority eligibility criteria), then they 'may be able to stay'. Central London hostel 2 declared a maximum 18 months' stay, whereas South London hostel 2 cited a maximum of 3-4 months but then acknowledged that this might be 'flexible'. Although still aspiring to a 2-year maximum stay, in South London hostel 3 about 15 residents had been living in the hostel for some years, and the staff reported that suitable housing with care to move them on had not been found for half of them. According to the manager:

Those on older contracts predating 3 years ago, this is generally when no other service can meet their need adequately. And, in some cases, it is when social services has come in, assessed the person, and despite very obvious high needs have deemed them as not needing another place of care. Social services know we provide a lot of support to clients here so they are happy to leave us to it, but it goes against our contract and it increases our workload when social services avoid their duty of care.

Manager, South London hostel 3

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	Hostel	Hostel				
Characteristic	Central London hostel 1	Central London hostel 2	South London hostel 1	South London hostel 2		
Drinking of alcohol permitted?	Yes, only in own room	Yes, anywhere	Yes, in bedroom, in garden, not in communal lounge rooms	Yes, in bedroom		
Number of paid staff	One manager; one assistant manager (FT); nine SWs (FT); one cleaner (FT); one drug and alcohol worker (PT); two night staff (FT); three night concierges (one FT and two PT); and two kitchen staff (PT)	One manager and one assistant manager (FT); five SWs (FT); one support assistant (FT); one cleaner (FT); one cook (FT); and two night staff (PT, agency staff)	One manager and one assistant manager (FT); 11 SWs (FT); two night support workers (FT); five cleaning/ catering staff (three FT and two PT); and two porters/security staff (FT)	One manager, two senior practitioners, one case worker, four lead SWs, four assistant SWs, three administrators, four cleaning/catering staff, two porter/night staff, one head chef, two other night workers and four trainees/apprentices Staff per shift: three management, four social workers		
Key worker status for residents	Five residents per key worker; meet once a week; action plan meeting every 3 months; look at Outcomes Star to set goals with clients	Expected to meet once every 4 weeks	Five on average (range from 3 to 6). Meet once a week or fortnight	Varies from 1 to 9 depending on seniority of role; details recorded in case files		
Life skills training	Move-on training: adult cooking groups, budgeting training	Stopped because of budget cuts	Stopped because of budget cuts	Yes – but need more volunteers to help with budgeting, cooking, employment		
Other support	Massage/reiki/alternative therapist visits weekly	Complex needs worker visits twice a week	Art workshops, gardening groups, film group, bingo night, gentle exercise classes	Activity every night, psychologists support group, therapy-based arts		
Total hostel rent (rounded to nearest £)	£267 (£242 rent plus £25 service charge)	£295 (£270 rent plus £25 service charge)	Information not provided (£35 service charge)	£270 (£230 rent plus £40 service charge)		
Funding source	100% local authority in documentation but manager not sure	50% local authority plus 50% donations/grants	Manager did not know details of funding arrangements as just started role	Local authority main source, but manager did not know specific proportions met by other agencies		
FT, full-time; PT, part-time.						

	Hostel			
Characteristic		2		4
Gender (maximum number) of occupants	Male and female (40–50)	Male only (40–50)	Male only (20–30)	Male and female (50–60)
Number and type of bedrooms	All single rooms	All single rooms	Four shared rooms, the rest all single	All single rooms; 15 en-suite rooms
Bedroom facilities	Each room has a bed, wardrobe, safe, set of drawers, sink with cupboard underneath it and curtains	Each room has a bed, bedside table, wardrobe and hand basin	Each room has a bed, bedside table, wardrobe, sink, table, chairs and kettle	Each room has a bed, wardrobe, sink and chest of drawers
Number of floors and accessibility	Four floors; no lift	Four floors; no lift	Three floors; no lift	Four floors, with lift
Disabled facilities	Nine rooms on the ground floor; one room has disabled access with a wet room, toilet and shower. Lounge and dining area are all on ground floor and accessible	None	None	Accessible toilet, pull cord ramp at front door, panic alarms around hostel
Meals included	Breakfast and evening meals only in main house. Both meals included in service charge. Resettlement home is self-catering	All three meals	Breakfast and evening meal	Breakfast and evening meal
Cooking facilities	Each landing has a kitchenette with microwave, kettle, fridge and cupboards; for quick meals rather than preparing from scratch. No cookers of any type allowed in rooms	Snack kitchen, kettle and fridge (required by local authority)	Can use kitchen, fridge, microwave and toaster	Each floor has lounge, microwave, kettle and electric hobs; one floor has a fridge
Laundry facility?	Yes	No; but service charge includes one load of washing a week done by hostel	Yes	Yes
Referral system	Minimum age 18 years; no upper age limit. Any referrals welcome: agencies, self, local authority referrals are prioritised	21 years minimum age; no upper age limit; referrals through adult social services, probation officers, self-referrals, NHS CMHT	35 years minimum age, no upper age limit; 'older drinkers' largest group, history of arson excluded; mostly through self-referrals, also mental health team and council homelessness unit	18 years minimum age, no upper age limit; all needs levels; majority mental health and substance abusers, complex needs; no formal exclusion criteria, consider referrals on case-by-case basis; referred via Housing Support Pathway

continued

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	Hostel			
Characteristic		2		4
Needs profile of residents (low, medium, high)	All	All; those with high levels of risk excluded	Medium-high	All
Tenure agreement with residents	Licence	Licence	Licence	Licence
Access times	24 hours	24 hours; 6 p.m. to 7 a.m., let in and out by staff	24 hours	24 hours; allowed two nights out per week with prior notification to staff
Drinking of alcohol permitted?	No	No	Yes, but not in communal areas	No
Number of paid staff	One manager and one programme co-ordinator (FT); five SWs (FT); one facilities manager and admin (FT); three cleaners (one FT and two PT); night staff (four FT, no security staff); two assistant support workers (FT); one chaplain; and five kitchen staff (two FT and three PT)	10 (two managers, two assistant managers, SWs, cleaner, chef, night staff) and two volunteers Staff per shift: 2–4 staff, manager always on call	Two managers, three SWs, and one catering/cleaning staff and residents help Staff per shift: five; manager on-call at night	One service manager, one programme co-ordinator, one facilities and admin, five SWs, two security staff, two assistant SWs for night shifts; and one regular volunteer Staff per shift: three managers and two SWs
Key worker status for residents	10 residents per key worker; meet once per week; review support plan every 4–6 weeks	Varies from 2 to 22 depending on seniority of role; see formally every 8 weeks, informally daily; details in case file	20 get Supporting People funding so 20 have key worker; this entails the worker seeing them daily	10–12; formal contact every 3–4 weeks, informal daily
Life skills training	A little – budgeting, cooking, rights and responsibilities of a tenancy, form-filling – in house course	None	Daily input from key worker	External agency to do budgeting, form-filling, crafts, ICT, English and maths
Other support	 Offender management team drop in to work with mix of people with alcohol and drug problems SWs work with specific residents who are ready to move on 	None	In-hostel activities: quiz, art class, photography	In-hostel activities: movie night, pool tournament, day out in summer

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Total hostel rent £178 per week (£112.35 housing £155 per week (£112.35 housing £238.99 in the main hostel (£204.47 f80 rent + f10 or f35 (includes)meals and one washing load) benefit rent + £43 service charge). benefit rent + £43 service charge). rent + £34.52 service charge). £178.83 in the resettlement house service charge For 20 clients receiving Supporting For 20 clients receiving Supporting (£157.30 rent + £21.55 service People funding, rent is £135 People funding, rent is £135 charge) Local authority 100%, top-up from Local authority 100% Funding source 80% local authority + 20% residents' Local authority Supporting People residents' charges money 33%, Housing Benefit 40%, rents Changes to funding: rest top up from charity Big drop in funding from £240 pw [per week], clients Support 1 to 1 is dropping. Not Changes to funding: now only pay £80 pw with able to spend enough time with same service being provided. individual clients. There are 10% drop in funding supported In dispute with council for last funding cuts every 3-4 years, people stream 2 years ago – 16 months, as not enough last year there were two cuts in had to do staffing restructuring, loss of staff and positions, pay service is seen as being 1 year. Have to provide same service for less money. The provided. If hostel does not win cuts and regarding tribunal regarding not getting manager [owner] won't be enhanced Housing Benefit, paying themselves next year as Staff thinner [in number]. less management will have to no funding; it's their business, resident activities, less face-torethink how hostel is run and so choosing to keep staff rather face time with residents, less than pay themselves what service is provided – even specialist activities for residents, less support, more signposting manager covers if staff are ill rather than agency staff

Quotations are from participants. FT, full-time; ICT, information and communication technology; PT, part-time; SW, support worker.

Even more variations were evident in the hostels outside London. In North England hostel 1, although there was a limit of 140 days' (4–5 months') stay, there were two long-term residents, one of whom had been living in the hostel for nearly 20 years and was said to have a mild learning disability and no close family; 'this is his home', declared the manager, who added 'when he first moved in, there would have been no pressure to move'. The other long-term resident had been living in the hostel for over a decade. In North England hostel 2, the official stay was a maximum of 24 months and we found no exceptions to this. In North England hostel 3, the maximum stay was stated to be 3 years but the manager declared being under no pressure to move residents as there was 'nowhere for them to go'. By contrast, in North England hostel 4, stays were limited to 6–12 months, with a very high turnover of residents; staff reported that they helped 'move on' 8–10 residents each month.

Housing options

Similar variations were found in the housing options open to hostel residents. The metaphor of 'fighting' with other agencies was used in a couple of London hostels to emphasise that interagency working was not always smooth-running. In Central London hostel 1, the manager reported that, of their older residents:

A few go into care [homes], especially if doubly incontinent. Few continue to remain in hostel. One is awaiting supported housing; have to fight for it. We have to fight to get them into registered care homes. It can take 1–2 years to get them in. In the meantime we get carers [care workers] in and then we see the person gradually go down. It is cheaper for them to remain here, but then sometimes if they end up in hospital we have to then say we won't take them back as their needs are too high and we have to fight not to take them back.

Manager, Central London hostel 1

South London hostel 1 reported similar tensions, here described more as a 'constant battle', in respect of the local authority adult services department (social services). Its manager explained:

This has been a big bone of contention with social services, as I explained before. They tend to view us as a care home and leave us to look after clients who get ever more frail and needy. We try and fight for nursing home placements for the most vulnerable but it doesn't always work. We had social services come in and assess our most vulnerable clients as not needing another placement when he had a carer [care worker] come in once a day, needed his food cut up, needed help feeding, was having difficulties swallowing, zero mobility, very, very vulnerable, and obviously needed nursing care that we are not trained to provide. Since I started, I have asked our commissioners to step in three times – they have spoken to the relevant head of social services and clients have been reassessed and rehoused. The one whom I mentioned before went from 'not needing any more care' to requiring the highest level of care. So it's a constant battle that we have to fight.

Manager, South London hostel 1

In Central London hostel 2, moves for older residents were more often to sheltered accommodation, but sometimes to other hostels. The manager here commented that the presence of memory problems among residents constituted a 'big stumbling block to finding appropriate housing'.

South London hostel 2, the hostel site with the highest turnover and most restricted length of stay, declared itself not suitable for those with memory problems; its manager considered that such residents would need a smaller, semi-independent service with greater support.

Central London hostel 1 reported more day-to-day working with the local authority adult services department than with the local authority housing department. The manager commented that, for its older residents:

Referrals often come via social services and alternative housing for people with memory problems is most often found through social services.

Manager, Central London hostel 1

However, in North England hostel 3, the manager considered that local cost pressures meant that rehousing for older residents was limited:

Care home costs are too high compared to hostels (£550 per week) so the local authority is reluctant to move them.

Manager, North England hostel 3

He added that some residents did not want to move to locations such as care homes because 'drinking [of alcohol] will not be allowed'. This led to an unsatisfactory situation for residents who, in his view, should not be living in hostels:

There's nothing, it's us or nothing. We try our best, not really equipped to deal with it, [we] try and help as best we can.

Manager, North England hostel 3

Experience in North England hostel 4 was that of fairly rapid turnover and most residents moved to 'own tenancy or try social housing with support, e.g. sheltered or tenancy support and any other possible support'. However, the amount of support for individuals following moves was thought to be shrinking; the manager here reported:

Due to lack of funding, [we're] looking at church-based community groups for support to plug the gap.

Manager, North England hostel 4

Support for residents with memory problems

Despite their differences in locations and policies, the accounts of hostel managers in describing the extent of support provided by some members of staff for residents with memory problems were similar, and at times such support was considerable. The manager of Central London hostel 1 reported:

We have to escort them everywhere, sometimes we have to do missing persons reports. They [residents] get upset when they realise what's going on and they get frustrated and if you speak to them about it they can get very angry with you as they don't believe you . . . If it gets very bad and we can't cope we get social services in for assessment for a care package. Some are reluctant to get help and say they are OK. We constantly have to update the risk assessment. They also have unrealistic expectations at action plan meetings. For example, one man thinks he will be able to go back to work. How they think they are is very different to what we see. Their relationship with alcohol doesn't help.

Manager, Central London hostel 1

In Central London hostel 2, substantial support could be provided inside the hostel, as the manager reported:

If they have appointments you have to keep knocking for them. They say – give me 5 minutes and then you have to go back again and again. They forget the real time. You would think your body would tell you. Not being able to do simple tasks.

Manager, Central London hostel 2

In this hostel, staff obtained appointeeship (authority to manage welfare benefits and pensions) for some residents. This indicates the high level of need among some residents in activities of daily living and also illustrates the extent of staff engagement with budgeting and money management. South London hostel 1 also reported having:

... a harm minimisation programme, which I think is unique to us. So what we do, with the voluntary agreement of clients, we hold their money, we hold their bank card and we give them a daily allowance. We also buy them and give them alcohol – this is always less than 6% (alcohol) beer or cider and give them in stages – so three times a day and two cans only. We are essentially working with them to avoid them spending all their money in one go and bingeing on potent alcohol and

harming themselves. Many feel this is controversial as we are then buying them alcohol, but we feel it reduces the risk of overuse and bingeing.

Manager, South London hostel 1

The manager of South London hostel 1 listed some of the manifestations of memory problems among its residents as confusion, forgetfulness, aggressions, falling, wandering and getting lost, and again spoke of the complexities when such behaviours were hard to differentiate from the impact of drinking; they do 'virtually everything, ensuring safety, minimising risk, try and arrange memory assessments'. A couple of residents who were 'wandering and getting lost' were supplied with wrist bands (at a cost of £20 each) by the hostel containing their identification details. Concerns about safety and adult safeguarding (protection from abuse and exploitation) were also noted in South London hostel 2, where managers reported that staff needed to be alert because certain residents were 'forgetting they are vulnerable' and that their lack of judgement meant that others took advantage of them. All of this was complicated by general difficulties in engaging with certain residents, particularly if their behaviour was challenging to staff or others or distressing, or if they were difficult to motivate or slowing down in their progress to resettlement. In North England hostel 2, the manager reported that residents with memory problems required 'more intense support, reminding appointments, time spent on routine tasks, going to appointments with them'.

Other forms of surveillance or monitoring were evident; for example, the manager of North England hostel 1 reported that staff:

[H]ad to keep a closer eye on and make sure one person had meals – but then he'd forget he had already eaten. We can't keep any medication for people we don't have any form of care provision. We do help them to get a dosette box (for pills) and remind them about meals.

Manager, North England hostel 1

However, this was exceptional as the practice in this hostel was to move such people on:

If we do get someone with memory problems, we get them moved on as quickly as we can.

Manager, North England hostel 1

North England hostel 3 similarly reported encouraging residents to eat and complete routine tasks but also efforts to maintain hygiene; as someone's poor self-care worsened, this could be accompanied by lack of motivation and energy, or, on the other hand, a resident could become non-compliant and aggressive. Several managers commented on the complications of substance misuse, which sometimes excluded people from receiving support from other services but could also mask the extent of memory problems and confusion.

Referral routes for residents with memory problems

As noted above, there were some accounts of accessing specific help for residents with memory problems, who, in addition to needing more time for support than other residents, had higher support requirements. Some needed prompting and frequent reminders, particularly in terms of managing appointments, and generally tailoring the approach to their support. The process for referral to support with memory problems was generally to advise the resident to contact their GP or to do this on their behalf:

We refer them to the GP for a referral to the memory clinic.

Manager, Central London hostel 2

However, Central London hostel 1's manager had one experience following making a referral of a resident to the local memory service, when the resident 'turned up drunk' for his appointment. In his view:

They didn't cater for homeless people. Now we refer to alcohol services and are happy about it. We also have to refer people to the continence service as well.

Manager, Central London hostel 1

Similarly, in Central London hostel 2 referrals were made to the resident's GP or alcohol services, who decided whether or not a referral for dementia assessment was needed. The difficulties of accessing help for residents who consumed large amounts of alcohol regularly were again voiced by South London hostel 1's manager, who knew that, theoretically, residents with memory problems or similar could be directly referred to the local CMHT for assessments, but for this to happen the resident needed to be sober, which the manager observed was not always possible to arrange. Likewise, North England hostel 3's manager summed up the lack of referral pathway as being again related to 'alcohol acceptability', stating more generally that there were:

No services, nothing for them. Can't be assessed in memory clinic until they're dry.

Manager, North England hostel 3

Only one out of the four North England hostels had a referral route for residents with memory problems, indicating their generally weaker links with secondary NHS services.

Primary care input

In this section, we report on the variations of primary care services' input to the hostel as summarised by the hostel managers. North England hostel 3 was an outlier, in that no input from primary care was reported by its staff or observed on our visits or in the records. Other hostels had different types and levels of engagement that varied from proactive to reactive. In the London hostels, overall, there was more regular and planned input from primary care teams to the hostels, although in Central London hostel 1 a GP surgery and a walk-in centre were also located nearby. In this hostel, a nurse from the local drug misuse service also visited weekly to undertake health assessments and to see new residents. A different model of primary health care operated in Central London hostel 2, as staff from a specialist primary care intervention for homeless people visited the hostel weekly.

A similarly separated and specific approach was evident in South London hostel 1, where there was a weekly GP visit, a weekly visit from a nurse from an integrated care pathway service, and, in addition, weekly visits from staff from a Homeless Intermediate Care Project (described by its staff as providing 'wrap around' care for the most vulnerable residents, including taking them to appointments and helping hostel staff support them). This was similar to North England hostel 2, where a weekly visit to the hostel was made by a local health outreach team; a nurse visited weekly (for 3 hours) and a nurse prescriber visited weekly for a full day. Although not part of any specialist service or new NHS configuration, the health-care practice local to South London hostel 2 held a weekly clinic (full day) in the hostel; a nurse visited weekly (for a full day) and a further specialist nurse prescriber made a weekly visit (for a full day). A similar pattern operated in North England hostel 4, where the local GP made a weekly visit, and a community nurse was described as coming in when needed. Similarly, in North England hostel 1, a local general practice held a clinic every week (lasting 3 hours) in the hostel; a nurse from a well-being team visited weekly (3 hours) to undertake hepatitis injections and apply dressings, although this seemed to be a new specialist initiative as she was not attached to a general practice.

Mental health team input

Hostels could be busy places once primary care input and other services were viewed together. In Central London hostel 1, a member of the CMHT visited weekly, and an alcohol worker visited once or sometimes twice per week. This hostel was unique in our sample in employing its own part-time drug and alcohol worker. In sharp contrast, Central London hostel 2 reported that its local CMHT was reluctant to work with the hostel because of residents' drug and alcohol problems. In its stead, a local mental health charity had been visiting regularly and had accepted self-referrals, and another voluntary sector service had formerly provided drop-in mental health support. Both had recently ceased at the time of our study. North England hostel 1 reported that it could not make direct referrals to the CMHT; these had to be made by a GP or by the local authority adult services department (social services). North England hostel 4 reported no contact with mental health services, whereas North England hostel 3 reported that a CMHT worker visited weekly or monthly, depending on the worker; its residents had often been referred to the CMHT following

their hospital A&E visits. In this hostel, a drugs or alcohol worker used to make weekly visits to the hostel but this had recently ceased following funding cuts.

Further different patterns of engagement with mental health services were evident in South London hostel 1, where some residents were 'live' cases with the local CMHT, although sobriety was required before the CMHT would engage with a resident; this was described, optimistically, as offering opportunities for residents to give up or reduce alcohol consumption. More unusually, a psychologist was available for consultations every weekday in South London hostel 2, where the local intermediate care (rehabilitation) project staff were also available daily. In this hostel, an alcohol worker ran a weekly alcohol support group, and a drugs worker visited the hostel weekly to carry out one-to-one work with some residents.

Hostel staff

Background demographics

Forty-three hostel key workers were interviewed for this study (some did not supply full demographic details). *Table 6* presents background information about them. All but two were employed full-time and worked shifts, each shift typically lasting 6 hours. Shifts changed weekly and the hours of work were not always consistent. Their job titles ranged from project worker and support worker (SW) to lead case worker, all of which incorporated many elements of the same job descriptions. Six were assistant managers, a role that SWs undertook alongside their resident caseload as key workers. In some cases, the SW was identified as having a specialist role, such as 'substance misuse worker' or 'lead worker in medication and health and support', the duties of which were in addition to their caseload.

The length of time participants had worked in their current hostel ranged from 1 month to 26 years. Twelve participants had worked in their current hostel for < 12 months, seven had worked there between 1 and 2 years and 12 had worked there for > 5 years.

Current roles and experiences

Descriptions of their roles essentially covered the same functions. Most described having a caseload of six or seven clients, for whom they provided a range of support, including supporting them with day-to-day tasks,

TABLE 6 Background characteristics of hostel staff (N = 43)

Characteristic	Hostel staff (n)
Gender	
Male	18
Female	25
Ethnicity	
White British/Irish	26
Black/African/Caribbean	6
Other	9
Age group (years)	
18–24	2
25–34	10
35–44	8
45–54	16
55–65	4

such as keeping themselves clean, tidying rooms and laundry assistance; managing money and budgeting; managing their health in terms of appointments, medication and attending to chronic problems; identifying and helping them achieve manageable goals; drawing up support plans; undertaking risk assessments; and checking on each client every day or as frequently as necessary. Such a role was often described as being the resident's key worker.

Previous roles

Eighteen SWs had not previously worked with homeless people before their current job. Their prior work experience varied; one had been a restaurant manager, another a hotel manager, one had managed laboratories, one had been a personal assistant in a technology company, one had worked in retail, two trained in nursing and one had previously worked as a designer/photographer. Three participants had started as apprentices in the homeless sector, and one as a housing officer in a local authority. The remaining participants had started work as project workers and SWs in hostels, shelters and day centres in the homelessness sector.

Training undertaken and training needs

Hostel staff described undertaking a wide range of training. Some training was described as mandatory, but several voiced enthusiasm for signing up to training as a way of developing their skills. Most appeared to be in-house training, being organised either by individual hostels themselves or by an overarching hostel provider in the not-for-profit sector. This was the case in Central London hostel 1, which ran a comprehensive mandatory training programme for all staff. This covered drug and alcohol use, key working and 'emotional intelligence'. For any staff commencing apprenticeships, there was an opportunity to take a qualification [National Vocational Qualification (NVQ) level 2] in health and social care. There was also one-off training available on 'care of the elderly' and dementia, and 'end-of-life' training. In contrast, another hostel put great reliance on being able to access local authority training covering safeguarding, managing dual diagnoses and managing complex needs.

Across the hostels, staff reported recently accessing training in adult safeguarding, working with vulnerable people, first aid, fire training, equality and diversity, risk assessment, mental health, alcohol and substance use, emotional care, health and safety, rehabilitation, debt and benefits advice, dealing with challenging behaviour (their phrase), dealing with difficult families, working with complex clients, administering medication and caseload management. Training specific to this study's focus included working with older adults, mental health, dementia training, hoarding, managing 'challenging behaviour', capacity and decision-making, and the Mental Capacity Act 2005.90

Although most participants felt that the training they required was available and accessible, when probed several identified specific areas in which more training might be helpful. Two talked about the value of more dementia-specific training, especially identifying early symptoms and supporting people with 'everyday' memory problems. One described needing more refresher courses rather than only day-long training courses. A senior member of staff in South London hostel 1 commented that training was not always available to meet the changing needs of their hostel resident profiles:

Dementia training is very hard to access and very expensive. We can't always get everyone on the course, nor is it easy or cheap to get someone to come here and deliver training. So we send someone with the understanding that they will come back and disseminate the information to the rest of us. Which is not the best way to do it! I would really like us all to have some training in managing behaviours in dementia. There are so many challenging behaviours we come across, that we can never know whether it's dementia, or their alcohol or their personality and how to deal with it. I saw this lovely clip about someone with dementia presenting with aggressive behaviour and how staff dealt with it, and it was fascinating! Wish we had access to more training like that.

Senior member of staff, South London hostel 1

There was some indication of training being carried out online as e-learning. In one North England hostel, staff accessed some courses online. In this hostel, there was particular emphasis on addictions and mental health; its managers undertook diploma courses, and other staff undertook a 2-day mental health 'first aid' course covering suicide intervention skills training, and some had completed a foundation unit in men's health to help them identify early mental health problems and self-harm and how to guide someone to the right services. However, no specialist training was accessed here that covered memory problems.

Across the hostels, 16 staff participants had obtained NVQs levels 2 and 3. The majority of these were in health and social care (nine participants), followed by mental health (three), vulnerable adults (two), promoting independence (one) and counselling (one). These had been achieved either during the course of their employment at the hostel or prior to their current role. Overall, there seemed low expectations of regular training except in the hostels that had their own in-house provision. High staff turnover clearly affected the extent to which more experienced staff could support new colleagues; this affected one North England hostel in particular, which relied more than others on what it called 'on-the-job learning'.

Chapter summary

This first chapter reporting the study findings paints a picture of the case study hostels and their residents, providing further information about the hostel staff. The physical conditions of the hostels varied, together with their accessibility and services for resident groups. Some staff had substantial experience but others were new to this area of work, reflecting the sector's high staff turnover, particularly in London. Linkages with primary care and mental health services varied considerably between hostels. This reflects others' findings that CMHTs for older people vary considerably in their engagement or outreach activities with local services. There were very wide variations in training availability, suggesting that health-care professionals should not assume that hostel staff possess high-level skills, although they should not underestimate their competence. Differences were also found in the extent to which hostel staff were permitted to access courses arranged by the local statutory sector. The background of hostel staff in front-line SW roles varied and the staffing complement of hostels could encompass staff with considerable experience as well as those new to the sector.

Important variations in the physical fabric of hostels were found, and in the support that they provided to residents. This suggests that care is needed in overestimating or underestimating services available to residents, such as cooking facilities and laundry. Accounts of needing local authority-arranged social care services to support hostel residents with their care illustrate the high level of disability or self-care needs among some residents and the difficulties of providing them with adequate care in hostel environments (such problems have recently been observed in respect of hostel residents who are at the end of life¹⁰¹). The next chapter turns to residents themselves to discuss the study findings in relation to individuals and the research team's assessments of the extent and impact of any memory problems.

Chapter 5 Profiles of the hostel residents and assessments of their memory problems

Sixty-two older homeless people were interviewed for the first phase of the fieldwork. This chapter first summarises their demographic details, education and employment history, homelessness history, and physical health, mental health and substance misuse problems. It then examines memory problems among the group as reported by the older residents interviewed and hostel staff, and presents findings from cognitive assessments undertaken by the research team's clinicians.

Demographic and background details

Age, sex and ethnicity

Among the 62 older homeless people, 24 were staying in hostels in Central London when they were first interviewed, 19 were staying in hostels in South London and 19 were staying in hostels in North England. The majority (n = 54) were men; just eight were women. One-third (34%) were aged 50–54 years, 29% were aged 55–59 years, 21% were aged 60–64 years, 8% were aged 65–69 years and 8% were aged \geq 70 years. Their ages ranged from 50 to 82 years, and the median age was 56.5 years. Hence, the sample was relatively young compared with older people generally, but was comparable with the age distribution of 'older' homeless people in Western countries. According to statistics from England, Canada and the USA, the majority of older homeless people are aged in their fifties; just 5–10% of homeless adults are in their sixties or older. There was no significant difference in age according to the cluster site of their hostel.

Most residents were white British (76%) or white Irish (8%), and 16% were from other ethnic groups. There were, however, differences among the cluster sites. All in the North England sample were white British, and most originated from the local area. By comparison, slightly fewer (71%) in the Central London cluster and just 58% in the South London one were white British. The findings are not surprising given the ethnic mix of the general population in London.

Education and employment histories

Just under half (45%) of residents said that they had an educational or vocational qualification, mainly GCSEs (General Certificates of Secondary Education), NVQs or City & Guilds certificates. Those in the North England cluster were most likely to have a qualification (68%); and those aged 50–54 years were least likely to have a qualification (29%). More than one-third of participants (37%) reported literacy difficulties, including some who had dyslexia. Reports of literacy problems were less common among the North England cluster (26%) and most common among those aged 50–54 years (48%). Several participants who reported literacy problems described the struggles that they experienced with reading and writing, including some who had left school at an early age:

I'm a bit dyslexic – have problems with writing and spelling, but not reading. I had a misspent youth. I should have gone to school but I got picked on a lot. So I'd go into school, get a mark, and then leave again.

Can't read or write – I struggle to read a sentence. Left school aged 13.

Difficulty reading. They kicked me out of school.

The employment histories of the participants varied greatly. Three-fifths (61%) said that they had been mostly employed during their adult lives, one-quarter (25%) had been 'in and out' of work, and 14% had been mostly unemployed. The last group included one man who had never been in employment. Among the 59 residents who were able to provide more detailed information, 31% had worked until they were

aged in their fifties or older, and 29% had been unemployed since aged in their twenties or thirties. Participants' types of employment also varied greatly. Using the Office for National Statistics' *Standard Occupational Classification* (2010),¹⁰² most residents (46%) had either been in skilled trades, such as painters and decorators, carpenters, chefs or similar, or they had been in elementary occupations (34%), as security guards, cleaners, postal workers, shelf fillers or similar (*Table 7*). Just one person had employment at the time of their interview.

The great variation in their employment histories is apparent from their accounts (some roles have been slightly modified to maintain anonymity):

- Worked for the civil service for 40 years, until the age of 57 years.
- Worked as a delivery man for 10 years from the age of 15 years, and then as a street cleaner for a few years. Not worked since the age of 40 years.
- Worked as a manual labourer for 16 years, then as a machine operative for 20 years, and then as a semiskilled engineer for 10 years. Retired aged 65 years.
- Worked in a supermarket filling shelves from 16 to 26 years. Not worked since.

History of homelessness

Age first homeless

The age at which residents first became homeless varied greatly. According to 54 people who were able to give details, almost one-quarter (24%) had first become homeless as teenagers or when they were aged in their twenties. By comparison, 22% had first become homeless when they were aged in their fifties and 15% were aged \geq 60 years at the time. As shown in *Table 8*, more than one-third (37%) of those aged in their early fifties had first become homeless before the age of 30 years. By contrast, most of those aged \geq 60 years had experienced late-onset homelessness; 70% had first become homeless after the age of 50 years.

The age at which residents first became homeless differed by cluster site (*Figure 2*). Almost three-fifths (59%) of those in North England first became homeless after the age of 50 years. This compares with just 39% in the South London hostels and 25% in the Central London cluster. Many in the two London sites had become homeless when they were in their thirties or forties.

TABLE 7 Participants' main or longest occupation, by age group (n = 59)

	Age group (years) (%)				
Occupational classification ^a	50–54	55–59	60–64	≥ 65	Total (%)
Skilled trades	57.9	33.3	41.7	50.0	45.8
Elementary occupations	42.1	22.2	33.3	40.0	33.9
Sales and customer services	0.0	22.2	0.0	0.0	6.8
Caring, leisure, other services	0.0	16.7	8.3	0.0	6.8
Administrative and secretarial	0.0	0.0	16.7	0.0	3.4
Process, plant and machine operatives	0.0	5.6	0.0	10.0	3.4
Number of residents	19	18	12	10	59

a Standard Occupational Classification 2010 (Office for National Statistics). 102

TABLE 8 Participants' age when they first became homeless, by age when interviewed (n = 54)

	Age when interviewed (years) (%)				
Age first homeless (years)	50–54	55–59	≥ 60	Total (%)	
≤ 19	10.5	13.3	5.0	9.3	
20–29	26.3	6.7	10.0	14.8	
30–39	26.3	13.3	10.0	16.7	
40–49	31.6	33.3	5.0	22.2	
50–59	5.3	33.3	30.0	22.2	
≥60	N/A	N/A	40.0	14.8	
Number of residents	19	15	20	54	
_					

N/A, not applicable.

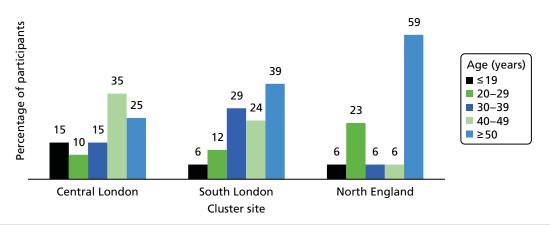


FIGURE 2 Participants' age when they first become homeless, by cluster site.

Length of time homeless

It is very difficult to collect accurate histories from homeless people about the length of time that they had been homeless, as 'homelessness' is often not a continuous state. Many frequently move between homelessness and insecure housing. For our study, collecting this information was more problematic given that some residents had memory problems, and several had moved between homelessness and insecure housing for many years. Data about the length of time homeless are drawn from residents' accounts and those of hostel staff, and from hostel records, when available. In some cases, the data refer to the *minimum time* spent homeless, as hostel records had information only about the length of time that residents had been using hostels run by that particular organisation. Therefore, the findings have to be interpreted cautiously.

Residents' length of time as homeless varied, but many had been living on the streets or in hostels continuously or intermittently for several years. Among 57 people for whom some details were available, 7% had been homeless for < 1 year, and nearly half (47%) had been homeless for > 10 years, including 21% who had been homeless for > 20 years. There were differences by cluster site. Almost one-fifth (19%) in the North England site had been homeless for < 1 year, compared with just 5% in South London and none in Central London (*Table 9*). The corresponding figures for those who had been homeless for > 10 years were 50%, 58% and 36%.

TABLE 9 Length of time homeless and in current hostel, by cluster site (n = 62)

	Cluster site (%)			
Length of time (months)	Central London	South London	North England	Total (%)
Homeless				
< 12	0.0	5.3	18.8	7.0
12–60	22.7	5.3	25.0	17.5
61–120	40.9	31.6	6.2	28.1
121–240	18.2	31.6	31.2	26.3
≥ 241	18.2	26.3	18.8	21.1
Number of residents	22	19	16	57
In current hostel				
≤6	25.0	31.6	15.8	24.2
7–12	33.3	21.1	15.8	24.2
13–24	16.7	10.5	15.8	14.5
25–60	20.8	15.8	5.3	14.5
61–120	4.2	21.1	26.3	16.1
≥ 121	0.0	0.0	21.1	6.5
Number of residents	24	19	19	62

Duration of stay in current hostel

There were variations in the length of time that residents had been staying in their current hostel. Nearly half (48%) had been in the hostel for \leq 12 months, and nearly one-quarter (23%) for > 5 years. Those in North England tended to have been in their hostel longer; nearly half of them (47%) had been so housed for > 5 years (see *Table 9*). By contrast, those in the two London clusters were more likely to have been so accommodated for \leq 12 months. These differences may partly reflect the contractual arrangements imposed on homelessness organisations by local authorities rather than the needs of homeless people. Since 2010, there have been several changes to housing and welfare policies and practice in England, and the length of stay in hostels imposed by some local authority contracts has reduced substantially. Some hostels now have maximum durations of \leq 6 months, and people are moved from one hostel to another. 103

Health and substance misuse

This section describes the health of the residents when they were first interviewed, and their use of alcohol and illegal drugs or novel psychoactive substances. It does not include memory problems, which are addressed in the following section. It draws on various sources: the accounts of the residents and hostel staff and, when available, hostel and medical records. In some instances, residents may not have mentioned or may have denied health or substance misuse problems, but the problems were clearly reported by hostel staff and/or documented in their medical records. This section, therefore, presents the 'best evidence' available.

Residents were asked to rate their general health; 35% described it as 'good' or 'very good', 35% described it as 'fair' and 30% described it as 'bad' or 'very bad'. Interestingly, those aged in their fifties were *least* likely to describe their health as good: 43% rated it as 'bad' or 'very bad', whereas none over the age of 65 years described their health in this way. Half (50%) of those who had been homeless for \leq 5 years described their health as good or very good, compared with only 37% of those who had been homeless for > 10 years.

Most residents smoked cigarettes or other forms of tobacco, and they were much more likely than the general older population to be smokers. In 2014, just 17.7% of people in England aged 50–64 years, and 9.2% of those aged \geq 65 years, were smokers. This compares with 87% in our study.

Physical health problems

Nearly all residents (97%) had one or more physical health problems. As shown in *Table 10*, the most common problems were musculoskeletal conditions, followed by respiratory problems, eye conditions, hypertension and gastrointestinal problems. The reported figures are the minimum percentages of residents with each problem, as some people may have had conditions that they did not report, and data from their medical records were not always obtained or obtainable.

Head injuries

Three-fifths (61%) of residents reported having had a head injury, including 11% who described having had three or more such injuries. In some cases, the head injuries dated back years, but for others the injuries had occurred in recent years. Most were the result of accidents or assaults and were often linked to heavy drinking and fighting. A small percentage of residents (7%) had sustained a head injury during an epileptic seizure. The situations leading to head injuries were described by two men:

I used to be a very heavy drinker and drug taker. I'd regularly fight and fall about. One time I had an axe on my head because of a fight.

A guy knocked me out – I was away with the fairies . . . [another time] I keeled over and knocked my head when I was pissed.

Most residents who reported a head injury (88%) had received hospital treatment on at least one occasion, including 68% who were admitted into hospital. One man aged in his fifties, for example, first sustained a head injury as a teenager when he was playing rugby. He described being 'knocked out' but was not taken to hospital. As an adult, he worked on building sites and in factories, and said that he had suffered a head

TABLE 10 Physical health problems, by age when first interviewed (n = 62)

	Age group (years) (%)				
Physical health problem	50–54	55–59	60–64	<u>≥ 65</u>	Total (%)
Musculoskeletal (e.g. arthritis)	52.4	61.1	61.5	40.0	54.8
Respiratory (e.g. asthma, COPD)	19.0	55.6	61.5	40.0	41.9
Eye problems (e.g. glaucoma, cataracts)	28.6	61.1	38.5	20.0	38.7
Hypertension	33.3	44.4	30.8	40.0	37.1
Gastrointestinal (e.g. gastritis)	42.9	38.9	46.2	10.0	37.1
Blackouts, epilepsy, alcohol-induced fits	61.9	22.2	30.8	0.0	33.9
Cardiovascular disease (e.g. clots, strokes, transient ischaemic attacks)	33.3	16.7	38.5	40.0	30.6
Angina or heart disease	23.8	16.7	38.5	40.0	27.4
Liver problems (e.g. cirrhosis, hepatitis C)	38.1	16.7	30.8	40.0	27.4
Skin conditions (e.g. eczema, leg ulcers)	14.3	44.4	23.1	30.0	27.4
Renal/urinary problems	19.0	22.2	23.1	10.0	19.4
Hearing problems	9.5	16.7	23.1	20.0	16.1
Diabetes mellitus	4.8	5.6	15.4	10.0	8.1
Number of residents	21	18	13	10	62

COPD, chronic obstructive pulmonary disease.

injury on two occasions when items fell on him at work. The first time he was in his early thirties and was taken to hospital but 'sent home to rest'. The second injury occurred a few years later and he was kept in hospital for 4 days. He sustained a fourth head injury about 7–9 years ago during an epileptic seizure, and was taken to hospital but discharged the next day. He had subsequently experienced further head injuries during epileptic seizures.

Mental health problems

Nearly two-thirds (63%) of residents reported a history of mental health problems, and 44% described current mental health problems. These percentages do *not* include memory problems, which are described in *Memory problems*. When information from staff and from medical and hostel records is also considered, a higher prevalence of mental health problems was apparent: 81% of residents had a history of mental health problems, and 74% had current mental health problems.

The main problem both identified by residents and recorded by GPs was depression, sometimes accompanied by anxiety. Almost seven-tenths (69%) of residents were reported to have suffered from depression, including five people who had attempted suicide in the past. According to the medical records, two residents had been diagnosed with personality disorder, and six with schizophrenia or 'alcoholic psychosis' or 'alcohol-induced hallucinations'. One-fifth (22%) of residents described having first experienced mental health problems when they were teenagers or young adults. For some, the problems had continued over many years. Several associated the onset of mental health problems with traumas and stressful events that had taken place *before* they became homeless, such as marital or family breakdown, the death of their mother or a child, or the loss of a job:

[Mental health problems] started when I was aged 14 when I was badly beaten up at school. Was in hospital 7 months. Was bullied at school.

It was when things were all going wrong for me – marital problems, work problems. I was a heroin addict at the time as well.

So much depression – I can't forget my family . . . they were killed. When I sleep I see my mother and brothers and gran dead. I have no future.

My parents divorced when I was 15, and I was diagnosed with anxiety and depression.

Drawing on scores from the depression tool administered during the baseline interview (described in *Chapter 3*), although 54.1% of residents were assessed as having no depression, 6.6% had mild depression, 26.2% had moderate depression and 13.1% had severe depression. There were age differences. Those aged in their fifties were more likely to have moderate or severe depression than those above this age (affecting 42.9% aged 50–54 years, 58.8% aged 55–59 years, 30.8% aged 60–64 years and just 10% aged \geq 65 years). Residents living in hostels in Central London were more likely to have moderate or severe depression (52.2%) than those living in hostels in South London or North England (31.6% for both areas).

Residents with moderate or severe depression were more likely than those with mild or no depression to rate their general health as 'bad' or 'very bad' (52.1% and 13.9%, respectively), and their QoL as 'poor' or 'very poor' (34.8% and 10.8%, respectively). There were also associations between depression and alcohol and drug use. Those who drank alcohol daily or almost daily (6 days per week) were more likely to be moderately or severely depressed than those who drank less frequently or not at all (47.2% compared with 28%, respectively). Likewise, 64.7% who had used illegal drugs in the preceding 3 months were assessed as having moderate or severe depression, compared with 30.3% who had not used illegal drugs during this period [$\chi^2 = 6.03$; degrees of freedom (df) = 1; p = 0.014]. Further details of their drinking habits and use of drugs are provided in the following sections.

Alcohol use

Three-quarters (76%) of residents said that they had been a heavy drinker at some time or had had alcohol problems. This increased to 85% when reports from staff and information from medical records were included. Twenty-six residents (42%) said that they had started to drink heavily *before* the age of 20 years. Among those who had been heavy drinkers, 26% said that one of their parents had also drunk heavily, and an additional 10% said that both parents had been heavy drinkers. A history of heavy drinking was common among all age groups, but particularly prevalent among those aged 50–54 years (95% of this age group). It was also more common in the two London cluster sites, affecting 91% of participants in London, compared with 74% in North England.

When current drinking habits are examined, 13% of residents said that they did not drink alcohol and this was confirmed in hostel staff accounts. Almost three-fifths (58%), however, drank alcohol on 6 or 7 days per week (*Table 11*). Some had a few days of heavy drinking when they received their welfare benefits, followed by periods of light drinking or abstinence when they had no money. Although relatively few people drank spirits or wines, a high proportion (57%) regularly had super-strong lager (such as Tennent's, which is 9% alcohol by volume) or extra-strong beers or ciders, such as White Ace (7.5% alcohol by volume). Most people (83%) who drank alcohol daily tended to consume extra-strong beers and lagers.

It is difficult to calculate the number of units of alcohol the residents consumed each week because their drinking patterns fluctuated. Some drank spirits when they had money but consumed cheap, extra-strong lager or beer at other times. Hostel staff were also unable to say how much alcohol some residents consumed as they tended to drink either in their bedroom or away from the hostel. The average number of units of alcohol consumed by residents per week has been calculated as accurately as possible from the information they provided. Among 52 residents for whom information is available, 63.5% were regularly drinking in excess of the Department of Health and Social Care recommended weekly guidelines of no more than 14 units per week. Moreover, 48% were drinking > 50 units each week, including 25% who were drinking, on average, > 100 units per week.

TABLE 11 Current use of alcohol, by age group (n = 62)

	Age groups (years) (%)				
Use of alcohol	50–54	55–59	60–64	≥ 65	Total (%)
Frequency of drinking					
Not at all	4.8	16.7	23.1	10.0	12.9
Monthly or less	0.0	5.6	7.7	10.0	4.8
2–4 times a month	9.5	11.1	7.7	10.0	9.7
2 or 3 times a week	0.0	11.1	0.0	10.0	4.8
4 or 5 times a week	0.0	0.0	7.7	0.0	1.6
6 or 7 times a week	71.4	44.4	53.8	60.0	58.1
Binge pattern ^a	14.3	11.1	0.0	0.0	8.1
Type of alcohol ^b					
Standard beers/lagers	42.9	35.3	46.2	70.0	45.9
Super-strength beers/lagers	81.0	47.1	38.5	50.0	57.4
Spirits	14.3	17.6	7.7	30.0	16.4
Wine	4.8	11.8	23.1	0.0	9.8
Number of residents	21	18	13	10	62

a Periods of heavy drinking followed by periods of light drinking or abstinence.

b Some people reported drinking more than one type of alcohol.

Those aged in their early fifties were more likely than other age groups to drink excessively. Among those aged 50–54 years, 71% had alcohol most days and 81% consumed extra-strong beers and lagers (*Table 12*). They were also the age group most likely to be far exceeding the Department of Health and Social Care recommended weekly guidelines for alcohol consumption; 71% were consuming > 50 units of alcohol per week (see *Table 12*).

There were differences in drinking habits by cluster site. Residents in the North England cluster were less likely than those in the two London clusters to consume alcohol most days (*Table 13*). The former were significantly less likely to drink strong beers or lagers (21%, compared with 71% in Central London and 78% in South London; $\chi^2 = 15.1$; df = 2; p = 0.001). They were also less likely to exceed the Department of Health and Social Care recommended guidelines of no more than 14 units of alcohol per week ($\chi^2 = 6.7$; df = 2; p = 0.034). Residents in the Central London cluster were most likely to be drinking excessively, with nearly half (48%) drinking, on average, > 100 units each week (*Table 14*).

TABLE 12 Weekly alcohol intake, by age group

	Age groups (years) (%)				
Weekly alcohol intake (units)	50–54	55–59	60–64	≥ 65	Total (%)
> 14	82.4	60.0	45.5	55.6	63.5
>50	70.6	33.3	36.4	44.4	48.1
> 100	41.2	20.0	9.1	22.2	25.0
Number of residents	17	15	11	9	52

TABLE 13 Current use of alcohol, by cluster site (n = 62)

	Cluster site (%)			
Use of alcohol	Central London	South London	North England	Total (%)
Frequency of drinking				
Not at all	8.3	10.5	21.1	12.9
Monthly or less	4.2	0.0	10.5	4.8
2–4 times a month	4.2	5.3	21.1	9.7
2 or 3 times a week	4.2	5.3	5.3	4.8
4 or 5 times a week	4.2	0.0	0.0	1.6
6 or 7 times a week	70.8	68.4	31.6	58.1
Binge pattern ^a	4.2	10.5	10.5	8.1
Type of alcohol ^b				
Standard beers/lagers	33.3	38.9	68.4	45.9
Super-strength beers/lagers	70.8	77.8	21.1	57.4
Spirits	20.8	27.8	0.0	16.4
Wine	16.7	5.6	5.3	9.8
Number of residents	24	19	19	62

a Periods of heavy drinking followed by periods of light drinking or abstinence.

b Some people reported drinking more than one type of alcohol.

TABLE 14 Weekly alcohol intake, by cluster site (n = 52)

	Cluster site (%)			
Weekly alcohol intake (units)	Central London	South London	North England	Total (%)
> 14	76.2	73.3	37.5	63.5
> 50	57.1	60.0	25.0	48.1
> 100	47.6	13.3	6.2	25.0
Number of residents	21	15	16	52

Among residents whose weekly alcohol intake was > 14 units, three-quarters (76%) acknowledged that they had felt the need to cut down on their drinking, half (50%) had felt guilty about their drinking and most (84%) said that they had sometimes needed a drink first thing in the morning to steady their nerves or get rid of a hangover. There was no significant association between drinking excessively each week and current mental health problems. As described in the following accounts, however, a few participants believed that there was a link between their mental health problems and heavy drinking:

Something inside me doesn't want to go on . . . that's why I'm binging [drinking] more. I have made threats to kill myself. But when I'm sober I don't want to kill myself.

My depression can't stop. I've asked my GP for treatment for depression but he said I have to stop drinking first.

Use of illegal drugs

Just over half (55%) of residents said that they had used illegal drugs at some time, although many fewer (16%) reported having taken drugs during the previous 3 months. These findings increase to 57% for past drug use and 29% for drug use in the previous 3 months when reports from hostel staff are also included. Most residents who had used drugs in the previous 3 months reported having taken cannabis or crack-cocaine. Just two people said that they had taken heroin. In most cases, they had started taking drugs when they were in their teens or early twenties.

Three-quarters (76%) of residents aged in their early fifties reported a history of illegal drug use, and just over half (52%) said that they had taken drugs in the previous 3 months (*Table 15*). This age group was most likely to report this behaviour. There were also differences by cluster site. Two-thirds (67%) of Central London participants had used illegal drugs in the past, and 37.5% had taken drugs in the previous 3 months. Slightly lower figures were reported for the South London participants (57% and 28%, respectively), and even lower figures were reported for the North England cluster (47% and 21%, respectively).

TABLE 15 Use of illegal drugs, by age group

	Age group	Age group (years) (%)			
Illegal drug use	50–54	55–59	60–64	≥ 65	Total (%)
History of illegal drug use	76.2	50.0	50.0	40.0	57.4
Used illegal drugs in previous 3 months	52.4	27.8	7.7	11.1	29.5
Number of residents	21	18	12	10	61

Memory problems

At the baseline interview, all residents were asked about their memory and whether or not they were experiencing any difficulties, and the 6-CIT was administered by the researchers. Hostel staff were also interviewed and their views were sought about each resident's memory. Finally, the ACE-III was administered to all residents who consented to this by the research team's consultant psychiatrist, a psychiatric registrar or a psychologist. This section reports the findings from the various sources and examines the extent to which hostel staff identified memory problems compared with the findings of the psychiatry team.

Reports of memory problems by hostel residents

Among the 62 residents, more than half (54.8%) reported having memory difficulties, 25 (40.3%) reported no problems, and three were unsure. As shown in *Table 16*, those aged in their early fifties and early sixties were most likely to describe memory problems, and older residents aged \geq 65 years were least likely to report a problem. This may be a surprising finding in the light of the strong association of such problems with advancing age; however, caution has to be taken when interpreting these findings because of small numbers.

When the 34 residents who reported memory problems were asked how they were affected, the most common responses were:

- unable to remember appointments and other tasks (41.2%)
- unable to remember names (20.6%)
- unable to remember the day and date (17.6%)
- unable to remember yesterday's activities (14.7%)
- loses things (14.7%).

When the residents who reported memory problems were asked how long they had experienced such difficulties, 21.2% said < 1 year, 27.3% said between 1 and 5 years, 12.1% said > 5 years, and 39.4% were unable to say.

The accounts from three residents illustrate the ways in which they felt they were being affected by their poor memory:

I can go to the shops and forget what I've gone for and forgotten to take my money with me . . . small things like that.

I mislay things all the time. When I have a conversation about sport I know the answer but it's slow coming to me. I used to be able to answer immediately but now my brain is not ticking over as much.

It's [memory loss] annoying. It will stop me talking to someone as I can't recall their name and it's embarrassing.

TABLE 16 Hostel residents' reports of memory problems, by age when interviewed

	Age group (years) (%)				
Any memory problems	50–54	55–59	60–64	≥ 65	Total (%)
Yes	66.7	44.4	76.9	20.0	54.8
No	33.3	44.4	23.1	70.0	40.3
Unsure	0.0	11.1	0.0	10.0	4.8
Total number of residents	21	18	13	10	62

Reports of memory problems by hostel staff

Hostel staff were asked whether or not they believed that certain residents had memory problems and, if so, the reasons why. Information was obtained about 60 residents from their key workers (some key workers were responsible for more than one study participant). As shown in *Table 17*, hostel staff believed that nearly half (46.7%) of residents had a memory problem and that 40% of residents did not have a memory problem, and they were unsure about the remainder (13.3%). Staff in Central London were less certain about their residents than were staff in the other two cluster sites.

Members of staff gave many reasons as to why they suspected or were aware that the residents had memory problems. For example, among the residents in whom memory problems were suspected, staff said that 77.8% had difficulty remembering recent happenings and appointments, 74.1% had difficulty recalling conversations a few days later, and 37% had difficulty finding the correct words. A selection of staff's accounts illustrate this further:

He repeats himself a lot; asks everyone the same questions all the time.

He can't remember anything. Quite severe. He can't remember conversations we had 2 minutes ago. Tell him what he needs from the shop, ask him to repeat it 2 minutes later, and he can't.

He doesn't remember some things, like the other day he went out of the hostel. He could not remember this and thought he was here in the hostel all day.

Hostel staff explained that it was difficult to determine the extent to which alcohol was responsible for memory difficulties among some residents. As two workers summarised:

He often forgets what he needs to do but that could be due to alcohol. He would often ask what we had spoken about . . . but he knew when meal times were.

I give her all letters and reminders . . . is it early dementia or alcohol?

According to staff, six residents had been diagnosed as having Korsakoff syndrome, vascular dementia or alcohol-related dementia. A further six had been referred by their GP to the local memory clinic or to other services for an assessment of their memory. For some, assessments were in progress, and one resident had been initially assessed at a memory clinic but could not be assessed further because he was still drinking heavily. Another resident with memory problems was being monitored by his GP and, according to the staff, was to be referred for specialist help if his memory difficulties worsened.

Making a diagnosis of cognitive decline/dementia

The study aimed to identify individuals with memory problems. To be able to assess an individual in order to make a diagnosis of dementia or related memory problems, clinicians across different services in England follow a fairly similar care pathway. It usually starts with an individual or their family reporting concerns about the person's memory to the person's GP. After basic blood tests and initial memory

TABLE 17 Hostel staff's reports of memory problems among residents, by cluster site

	Cluster site (%)			
Any memory problems	Central London	South London	North England	Total (%)
Yes	45.5	36.8	57.9	46.7
No	27.3	57.9	36.8	40.0
Do not know	27.3	5.3	5.3	13.3
Total number of residents	22	19	19	60

assessments are carried out in primary care, the patient may be referred to secondary care services for further assessment and diagnosis. The majority of memory assessments in secondary care in England are carried out by CMHTs or at memory clinics for older adults; some of those assessments are carried out by geriatricians, neurologists and clinicians working in private centres. After a person is referred to a secondary care service, they will be seen in an outpatient department, or in their home, with the aim of gathering detailed information about their difficulties, and also collateral information will be gathered from their relatives, friends or carers.

The majority of people who are seen in memory services will be offered a type of brain imaging (computerised tomography scan or magnetic resonance imaging) to exclude a brain-occupying lesion or another reason for their cognitive presentation. Brain imaging data are helpful to confirm some dementia syndromes. Only a small percentage of those people require further imaging, such as a PET (positron emission tomography) or DaT (dopamine transporter) scan. This would usually be requested by a specialist. Almost all of those who attend a memory clinic will have memory assessment tests, and, if required, they will be referred to a neuropsychologist for further detailed memory and cognitive assessment. A simple memory assessment takes between 5 and 20 minutes to complete and a detailed assessment takes up to 3 hours. After the results of imaging and memory assessments are reviewed by clinicians, individuals with memory problems will be seen again to receive their results and possibly be given their diagnosis during the same session. The entire process may take up to 6 months to complete.

Formal assessments

In this study, it was not possible to follow the routine care pathway of the NHS to identify people with memory and cognitive difficulties; therefore, we tried to gather as much information as possible during visits and interviews with individuals and the staff from hostels. We used ACE-III as a memory test.⁹³ The tests were undertaken by the research team's consultant psychiatrist, psychiatric registrar and psychologist.

The ACE-III test has been widely used in memory clinics to assist clinicians to assess individuals' cognition. It has been validated, and the maximum score is 100 points. The cut-off point of 88 is 100% sensitive and 96% specific. There is also another cut-off point of 82 out of 100; in this case it is 93% sensitive and 100% specific for dementia. This test usually takes 20 minutes to be completed and requires a rater who has been trained to complete this memory assessment. This scale includes five subdomains, with a total maximum score of 100 points. The five domains are visuospatial (out of 16 points), attention (out of 18 points), memory (out of 26 points), fluency (out of 14 points) and language (out of 26 points).

Cognitive scores from Addenbrooke's Cognitive Examination III

Of the 62 residents interviewed at baseline, the ACE-III was completed with 42. Among those who did not complete the ACE-III, five left their hostel before it could be administered, one resident died, another could not complete it because of language difficulties, and another could not complete it because of literacy difficulties and therefore the MoCA⁹⁶ was administered to this person. The remaining 12 residents either refused to take part or were not in the hostel when the psychiatrist visited (despite several visits).

Of the 42 residents who completed the ACE-III, total scores ranged from 29 to 89 points. Just 28.6% scored \geq 80 points, and 30.9% scored < 60 points. The mean of their total ACE-III scores was 66.81 points, with a SD of 16.64 points. As shown in *Table 18*, there were differences by age group, although the findings must be treated cautiously because of small numbers. Half of those aged in their early fifties scored between 60 and 79 points, just over one-third scored \geq 80 points and just 14.3% scored 40–59 points. None in this age group scored < 40 points. By contrast, half of residents aged 55–59 scored \leq 59 points, including 10% who scored < 40 points. Those aged in their early sixties had the highest scores, and those aged \geq 65 years had the lowest scores.

TABLE 18 Hostel residents' total ACE-III scores, by age group

	Age groups				
Total ACE-III score (points)	50–54	55–59	60–64	≥ 65	Total (%)
≤39	0.0	10.0	0.0	22.2	7.1
40–59	14.3	40.0	11.1	33.3	23.8
60–79	50.0	30.0	33.3	44.4	40.5
≥80	35.7	20.0	55.6	0.0	28.6
Total number of residents	14	10	9	9	42

Classifying whether or not residents had memory problems

Owing to the small numbers of hostel residents who were interviewed at baseline, it was agreed that all who were willing and available would be included in the 'case study' element of the study. The next step was to classify residents according to whether or not they had memory problems. Several team meetings reviewed all of the data with the psychiatrist, and participants were allocated to groups according to whether or not there was enough information about them to make a judgement.

Based on all of the information, residents were assigned to one of three groups: 'memory problems', 'borderline' and 'no memory problems'. We decided to use these three groups based on the data we had after reviewing each participant's study profile, such as age, physical health problems, weekly alcohol intake and use of illegal drugs, reports and diagnoses of memory problems, and the duration of this complaint. We used these data, alongside their score on the ACE-III, to identify participants with memory problems. All data relating to individuals were reviewed by the consultant psychiatrist and his team to make sure that people were accurately placed in a subgroup. We also examined the subdomains of ACE-III scores to help us identify individuals with memory problems. We categorised each subdomain into three parts to help us analyse the data relating to individuals, before placing individuals in one of the three categories related to memory problems. Although the subcategory score of each subdomain is not validated and not tested, it has been used widely by clinicians to make decisions about an individual's memory problems based on their scores on subcategories.

We explained earlier the process and the time needed to make an accurate diagnosis of dementia through the NHS (see *Making a diagnosis of cognitive decline/dementia*). We had to adapt the system to improve the accuracy of our diagnostic criteria and it was impossible to rely on only the cut-off point of ACE-III as an inclusion or exclusion criterion for memory problems. Other factors, as explained previously, played an important role in assessing this group.

Many of the residents reported having had one or several head injuries in the past. We were not in a position to request any brain imaging for this group, and therefore we relied on the data that we had to make a decision about the cognition of these participants. One of the major problems we faced when assessing cognition was that many of these participants were under the influence of alcohol and so it was not possible to conduct a memory assessment at that point. We had to repeat some of the visits to be able to complete those assessments. Such efforts are not generally undertaken in routine NHS services in our experience.

Cognitive groups and their scoring

Based on all of the information, 23 out of the 47 case study participants were allocated to the 'memory problems' group, seven were allocated to the 'borderline' group and 17 were allocated to the 'no memory problems' group. However, only 42 residents completed the ACE-III, of whom 14 were allocated to the 'no memory problems' group (mean of their ACE-III score 83.79 points, SD 4.09 points), eight were in the 'borderline' group (mean 71 points, SD 6.78 points) and 20 were in the 'memory problems' group (mean 53.25 points, SD 12.49 points) (*Table 19*). Their scores for the subdomains are in *Table 20*. One of the residents in the borderline group was subsequently evicted from the hostel and therefore could not be included as a case study.

TABLE 19 The ACE-III scoring, by cognitive group

Cognitive group	Group (n)	Mean score (points)	SD (points)
No memory problems	14	83.79	4.098
Borderline	8	71.00	6.782
Memory problems	20	53.25	12.489
Total	42	66.81	16.643

TABLE 20 Scores for the domains of ACE-III, by cognitive group

	Cognitive group (%)			
Cognitive domain scores (points)	No memory problems	Borderline	Memory problems	Total (%)
Visuospatial				
0–8	0.0	12.5	35.0	19.0
9–12	0.0	37.5	50.0	31.0
13–16	100.0	50.0	15.0	50.0
Attention				
0–10	0.0	0.0	30.0	14.3
11–14	21.4	62.5	50.0	42.9
15–18	78.6	37.5	20.0	42.9
Memory				
0–9	0.0	0.0	60.0	28.6
10–16	35.7	62.5	40.0	42.9
17–25	64.3	37.5	0.0	28.6
Verbal fluency				
0–4	0.0	25.0	70.0	38.1
5–8	42.9	62.5	20.0	35.7
9–14	57.1	12.5	10.0	26.2
Language				
0–16	0.0	0.0	20.0	9.5
17–22	0.0	50.0	55.0	35.7
23–26	100.0	50.0	25.0	54.8
Total number of residents	14	8	20	42

Hostel staff's reports of memory problems compared with formal assessments

One of the study's objectives was to determine the extent to which hostel staff were aware of memory problems among their older hostel residents. As shown in *Table 21*, hostel staff identified memory problems for most residents who were formally assessed as having memory problems; out of 23 residents with memory problems, hostel staff identified memory problems in 70%. They were unsure for two residents, and did not identify memory problems in just five residents (22%) in whom there were memory problems in our judgement. At the same time, among 17 residents who did not have memory problems, the staff reported this correctly in 59%. Among the five residents whom the hostel staff suspected had memory problems but were found not to have memory problems by the psychiatrist, one was undergoing tests at a memory clinic, and another was a former heavy drinker and, according to the hostel staff, 'may be a little bit degenerative'.

TABLE 21 Comparison of reports of memory problems by hostel staff and formal assessments by psychiatrists

	Cognitive group (fo			
Hostel staff's reports	No impairment	Borderline	Impairment	Total (N)
Has memory problems	5	2	16	23
Does not have memory problems	10	5	5	20
Unsure	2	1	2	5
Total	17	8	23	48

Chapter summary

The backgrounds of older homeless people vary greatly, as described in this chapter. Some residents interviewed for this study had relatively stable histories, had worked for years, and became homeless for the first time in later life. Others had unsettled histories, had left school at an early age without qualifications, and had subsequently experienced long periods of unemployment and homelessness. Our sample tended to be 'young-elderly' homeless people, with the majority being aged in their fifties. Despite their relatively young age in terms of the general population, there was a high prevalence of physical ill-health, depression, and alcohol and drug problems among them. For some, mental health and substance misuse problems dated back to their teens or to early adulthood and preceded their entry into homelessness. Some associated these problems with traumas and stressful events that they had experienced as youths or young adults, while some had been raised in households in which one or both of their parents were heavy drinkers.

There were differences by age. Those aged in their early fifties tended to be particularly disadvantaged in that many had left school early without qualifications and had literacy difficulties. They were more likely than those in other age groups to have first become homeless as teenagers or when they were in their twenties, and very heavy drinking and the use of illegal drugs were characteristic of this age group. A high percentage of this age group consumed super-strength lagers and beers, drinking > 50 units of alcohol per week. By contrast, many aged in their sixties or older had worked for years and tended to have first become homeless in later life. Although several drank alcohol most days, they were less likely to drink standard-strength lagers and beers, and fewer consumed > 50 units of alcohol per week. Those in this age group were also less likely to be current illicit drug users.

There were also differences by cluster site. Those in North England were more likely to have had stable histories and to have become homeless for the first time after the age of 50 years, whereas many in the London sites had experienced homelessness intermittently or continuously since early adulthood. Heavy drinking and the consumption of super-strength alcohol were characteristic of participants in the two London clusters but less so among those in North England. Many in the latter group could be regarded as 'settled' in that they had remained in their hostel for several years.

Age is the greatest risk factor for developing dementia, and around 16% of adults in the UK experience increasing confusion or memory loss (Alzheimer's Society, 2016¹⁰⁶). This study clearly found, however, that memory problems were much more prevalent among older homeless people in the hostels participating in this study; nearly half (47.6%) of hostel residents were assessed as having memory problems, and a further 19% were deemed to be borderline. The median age for those with memory problems (memory problems or borderline) was just 60.4 years. Hostel staff were relatively proficient at identifying hostel residents who were having memory difficulties. Regular contact with residents enabled them to recognise when residents were more confused or were struggling with everyday activities. As we will discuss at the end of this report, there is perhaps a strong case for currently seeing hostel staff as part of the 'dementia care workforce'. The next chapter examines the health and social care needs of all 47 residents who were involved in the case study element of this research project.

Chapter 6 Residents' health and social care needs and quality of life

This chapter focuses on the health and social care needs of the hostel residents in the case studies, and on their QoL and housing outcomes. It draws on information gathered over 6 months (the course of the case study element). It first summarises the key characteristics of the residents with and without memory problems, and then examines their health needs and how these were met, followed by their personal and social care needs. The chapter then describes the residents' activities and how they spend their time, and their self-ratings of QoL and the factors that enhance this. Finally, their housing outcomes over the study period are summarised.

Key characteristics of the residents with and without memory problems

Thirty out of the 47 hostel residents who were included in the case studies were found to have memory difficulties (23 had memory problems and seven were borderline). All except one were men. The majority were either aged in their early fifties (33.3% were aged 50-54 years) or aged ≥ 65 years (30.0%). They were fairly evenly spread across the three cluster sites: 36.7% were in hostels in Central London, 33.3% were in hostels in South London and 30.0% were in hostels in North England. As shown in *Figure 3*, those residents with memory problems were more likely than those without to have been homeless for many years; this applied to 67% and 29%, respectively.

Those residents with memory problems were also more likely to have been in their hostel longer than those without memory difficulties. One-third (33%) with memory problems had been so housed for ≥ 5 years, compared with just 18% with no memory problems (*Figure 4*). By contrast, 53% of residents without memory problems had moved into the hostel fairly recently (within the past year). This compares with just 37% of those with memory problems.

Drawing on scores from the depression tool administered during the baseline interview, there was no difference between levels of depression and whether or not residents had memory problems. There was also no significant difference between reports of recent or past head injuries and the presence of memory problems. There was also little difference between past and present alcohol use and memory problems. Overall, 67% of residents who had ever been a heavy drinker, and 50% with no history of heavy drinking, had memory problems. A slightly higher percentage with memory problems (60.9%) currently drank on 6 or 7 days per week, compared with 47.1% with no memory problems. A slightly higher proportion of residents without memory problems had a history of illicit drug use (68.8%, compared with 52.2% with memory problems).

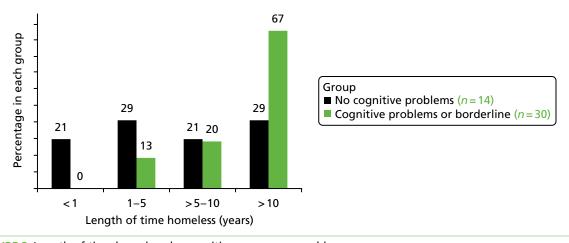


FIGURE 3 Length of time homeless, by cognitive or memory problem group.

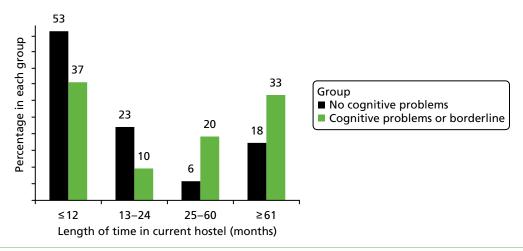


FIGURE 4 Length of time in current hostel, by cognitive or memory problem group.

Health needs

As described in the previous chapter, most residents had physical health problems, and nearly all of these people (98.2%) were receiving medication from their GP. During the 6 months of the case study period, virtually all residents (93.6%) had contact with their GP at least once, including 34% who had eight or more GP contacts. Many (59.6%) also had contact with primary care nurses or other health staff from a general practice. Similarly, a high proportion (68.1%) had contact with one or more allied health professionals such as podiatrists, dentists or opticians. During the course of the study, eight people (17%) were admitted to hospital because of physical health problems.

Almost three-quarters (73.8%) of residents in the case studies had mental health problems, and many of these received treatment (medication) from their GP. Nearly half (48.4%) also had at least one contact with mental health services during the course of the study. This included one person who was visited in the hostel by a psychiatrist from a memory clinic. Just one person was admitted to a mental health inpatient unit during the study period. One-third of residents were prescribed medication for depression, usually citalopram (Celexa®, Teva UK) or mirtazapine (Remeron®, Teva UK). When this is examined further in relation to the severity of depression scored at the baseline interview, the following groups were prescribed antidepressant medication:

- 37% without depression
- 50% with mild depression
- 38.5% with moderate depression
- 25% with severe depression.

Caution has to be taken when interpreting these findings regarding depression, as the number of residents in each group is small. For example, only four residents were in the 'severe depression' group, and only one of these was prescribed antidepressants. In addition, although several with current mild or no depression were receiving treatment, it could be that their depression had improved because of the medication.

The majority of residents who were drinking heavily or had past alcohol problems were being prescribed one or more vitamin supplements by their GP. Of those who consumed > 14 units of alcohol per week, 91.3% were prescribed vitamins. Among this group, 87% were prescribed thiamine (vitamin B₁) and 82.6% were prescribed vitamin B compound strong tablets. Ten residents also had contact with alcohol services during the study period; this included six (22.2%) out of the 21 residents who were drinking daily

or nearly every day. In some hostels, staff restricted, to some extent, the amount of alcohol that residents who were heavy drinkers could have each day, either by having a budget plan with the resident and limiting the amount of money that was handed to the person each day, or by agreeing the number of 'cans of beer' that would be given to the resident each day. The following two illustrative cases, compiled from the research records, describe the help that was given to residents with alcohol problems and the difficulties of helping some who were reluctant to stop drinking:

- Participant 201 (borderline memory problems) was reluctant to give up alcohol. His keyworker SW11 was keen for 201 to engage with alcohol services and described working very hard to change his attitude by taking the following approach: 'keep chipping away regarding alcohol use, try to get him [201] to engage with services, [I] worry for his future'. Six months later, SW11 said that the hostel staff had 'put in place a daily alcohol diary as he won't engage with professional alcohol services, we review diary monthly and will encourage him to accept professional treatment'.
- Participant 118 (no memory problems) was similarly reluctant to give up alcohol and drugs. He was supported by staff member SW19 who again was trying to encourage him to engage with drug and alcohol services, but described feeling that his job role was restricted. 'Encouragement is as far as I can go. Our work is client-centred so if [118] says no to offers of support; all I can do is to say it will affect their move on'.

Personal and social care needs

All hostels participating in this study provided older residents with basic assistance, when needed, with everyday tasks, such as bathing, washing clothes and keeping their bedrooms tidy. Some staff assisted residents with budgeting and managing money, with collecting and supervising medication and by taking them shopping to buy clothes and other essentials. The type of assistance ranged from prompting to do the domestic chore to giving a great deal of assistance with it. In some cases, residents required regular and extensive help with tasks such as bathing and managing continence, which was beyond the remit of hostel staff and the support that they could provide. Some residents had been referred to social services (adult services) and arrangements were in place for a care worker to assist with self-care and daily living activities.

As shown in *Table 22*, residents with memory problems were more likely than those without memory problems to require assistance across a range of personal and social care needs. Two-thirds with memory problems required assistance with personal hygiene and bathing, and some were occasionally incontinent (the latter was mainly associated with heavy drinking). Residents without memory problems tended to require help because of physical health and mobility problems. Overall, a relatively high proportion (36.2%) of residents received help from a care worker (organised by social services); this included 50% of those with memory problems and 11.8% of those without (see *Table 22*). In a few instances, a 'care package' was arranged but residents refused to accept help. One man, for example, regularly left the hostel when he knew that his care worker was coming to help him with bathing.

In addition to providing support with everyday self-care needs, hostel staff spent a great deal of time arranging appointments and contacting services on behalf of residents, and accompanying them to various appointments such as with the Jobcentre or the GP. In one hostel, arrangements were in place for peer advocates to escort residents to GP and hospital appointments when needed. During the study period, high percentages of both residents with and residents without memory problems received assistance from hostel staff with contacting services and with arranging and by accompanying them to appointments (*Table 23*).

TABLE 22 Requires prompting or assistance with personal and social care needs, by cognitive group

	Cognitive group (%)				
Prompting or assistance with	No memory problems	Memory problems or borderline	Total (%)		
Personal hygiene/bathing	29.4	66.7	53.2		
Managing incontinence	5.9	30.0	21.3		
Personal laundry	29.4	70.0	55.3		
Cleaning bedroom/changing bedsheets	52.9	83.3	72.3		
Budgeting/managing money	25.0	66.7	52.2		
Ordering/collecting medication	29.4	76.7	59.6		
Managing/administering medication	17.6	46.7	36.2		
Shopping for clothes and toiletries	28.6	40.7	36.6		
Has regular input from care worker (organised by social services)	11.8	50.0	36.2		
Number of residents	17	30	47		

TABLE 23 Assistance given by hostel staff during the study period with contacting services and by accompanying residents to appointments, by cognitive group

	Cognitive grou	Total (%)	
Task undertaken by hostel staff on behalf of residents	No memory Memory problems problems or borderline		
Contacted services/arranged appointments	64.3	88.9	80.5
Accompanied residents to appointments	50.0	50.0	50.0
Number of residents	17	30	47

Supporting and monitoring residents

All residents had a key worker and many hostel staff described adopting an individual or tailored approach with each resident. Over time, they became acquainted with the residents and learned how best to engage them in care and support. In some cases, this involved the staff making themselves available whenever a particular resident wanted to speak to them. In some other cases, staff sought out residents who would not seek help. For example, one man with memory problems would get anxious if too many questions were asked of him in a short period of time. Consequently, the key worker approached him gently and asked questions one at a time, sometimes over the span of a day.

The hostel staff described a need to 'keep an eye on' some residents, which applied to 34% of residents in the study (43.3% with, and 17.6% without, memory problems). It involved checking on them two or three times a day to find out how they were feeling, asking if they needed anything, and prompting them to eat or to attend to their personal hygiene or clean their room. For some residents, this was required at certain times, such as when they were intoxicated or when they appeared to be 'out of sorts' or physically unwell. In one hostel, the most vulnerable residents were allocated bedrooms near the staff office so that staff could be alerted to any problems. A few hostel residents were aware of the intensity of the support they received, and most were grateful for this. As one man described, 'the beauty of living here, you're in a bubble and you feel safe, you're under their wing, they watch out for you, you feel secure and safe'.

Activities and use of time

Residents were asked an open-ended question regarding how they spent their time. This elicited a range of responses. Many described watching television or listening to the radio, either in their own rooms or in communal areas. Several mentioned going to the shops, which was often linked to buying cigarettes and/or alcohol. A small proportion described going for walks or to the local library, or going to day centres or drop-in centres (for homeless people). Only a small number said that they liked doing activities (organised in the hostel), or reading or browsing the internet.

A high proportion of residents (72.3%) said that they were in contact with family or relatives. This included 88.2% of people without cognitive problems and 63.3% of those with memory problems. Their main contacts were with a child or a sibling, usually a sister. Many fewer, however, regularly saw a family member; just 14.9% saw at least one family member monthly or more often. Just over one-quarter (27.7%) said that they did not have any family or relatives. Those in this last group tended to be older residents (aged \geq 65 years).

The residents' comments describe their various activities and the diverse ways in which they spent time:

Reading, lot of walking. Go to nature reserves. Have freedom pass [free travel card] so go out most days . . . I like cooking so I cook upstairs [in the hostel].

Get a four-pack [four cans of beer or lager] and drink. Don't go out the hostel much. I don't use the TV room – I like to be private.

Watch telly, relax, sleep a lot. My son visits me . . . I can't go far because of my legs. I have no power in my legs anymore.

Walk to [locality] and back – that's 5 miles. See friends, go to their flats or a café or the library. Drink with friends.

Quality of life

Residents' ratings of quality of life

Residents were asked at baseline to rate their QoL; they could respond 'very good', 'good', 'neither good nor poor', 'poor' or 'very poor'. Almost half rated their QoL as 'very good' or 'good', 31.1% described it as neither good nor poor, and 20% described it as 'poor' or 'very poor' (*Table 24*). There were slight differences, however, between those with and those without memory problems (see *Table 24*). Fewer residents with memory problems were likely to say that their QoL was 'very good', although a relatively high percentage described it as 'good'. By contrast, a high proportion without memory problems rated their QoL as 'neither good nor poor'.

There were differences by age groups in ratings of QoL, although the figures must be treated cautiously because of the small numbers in each age group. Those aged ≥ 65 years were most optimistic and four-fifths described their life as 'good' or 'very good' (*Figure 5*). Residents aged 50–59 years were most likely to describe their QoL as 'neither good nor poor'. Those who were depressed were less likely than those who were not depressed to rate their QoL in positive terms. Among those with depression, 27.8% described their QoL as 'good' or 'very good' and 33% described it as 'poor' or 'very poor'. The corresponding figures for those without depression were 62.9% and 11.1%. There were also marked differences in relation to whether or not they were drinking heavily. As shown in *Figure 6*, those who were drinking very heavily (≥ 50 units of alcohol per week) were less likely to be optimistic about their QoL.

TABLE 24 Rating of QoL, by cognitive group

	Cognitive group (%)		
Rating	No memory problems	Memory problems or borderline	Total (%)
Very good	17.6	7.1	11.1
Good	17.6	50.0	37.8
Neither good nor poor	47.1	21.4	31.1
Poor	11.8	17.9	15.6
Very poor	5.9	3.6	4.4
Number of residents	17	28	45

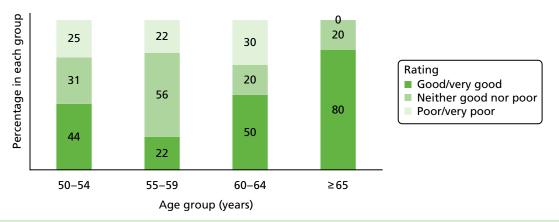


FIGURE 5 Residents' ratings of QoL, by age group.

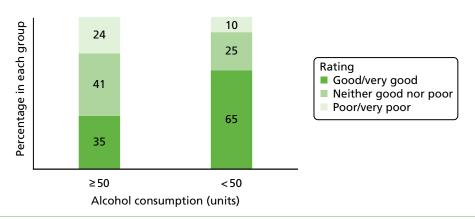


FIGURE 6 Residents' ratings of QoL, by weekly alcohol consumption.

Factors contributing to quality of life

When asked what factors contributed to their QoL, most residents described one or more factor. However, 19% were unable to answer or could not identify anything that added quality to their life. This included 17.6% of those without memory problems and 20.1% with memory problems (or who were borderline). There were large differences between those with and those without memory problems in relation to their responses about the factors that gave quality to their life (*Table 25*). The residents without memory problems were most likely to identify being healthy and engaging in various activities, such as reading, watching television and going for walks, as important factors in enhancing their QoL. By contrast, those with memory problems were most likely to say that socialising with other hostel residents and drinking alcohol were the most important factors.

TABLE 25 Factors contributing to QoL, by cognitive group

	Cognitive group (%)		
Factor	No memory problems	Memory problems or borderline	Total (%)
Socialising with friends/other residents	5.9	20.1	15.2
Being healthy and able to get up in the morning	29.4	6.9	15.2
Watching television, listening to music	17.6	10.3	13.0
Going out/going for walks	23.5	6.9	13.0
Reading, activities in the hostel	17.6	6.9	10.9
Drinking alcohol	0.0	13.8	8.7
Family contact	5.9	6.9	6.5
Feeling confident/trusted/happy	5.9	6.9	6.5
Hope and plans for the future	5.9	3.4	4.3
Having somewhere to stay/the hostel	5.9	3.4	4.3
Number of residents	17	30	47

The following accounts are examples of activities that residents said added to their QoL:

Able to get out and about. Chat with people. Make a fuss of people's dogs. Chat to shopkeepers and people on the streets.

'Borderline' group

I love music. I used to write songs and lyrics and I used to be in a band. I like being creative and doing paintings. I've done several courses at college.

'No memory problems' group

Don't know. Going to the pub.

'Memory problems' group

Factors that would improve quality of life

When the residents were asked what factors would improve their QoL, there were again differences depending on whether or not they had memory problems. The most commonly reported factor by far, in both groups, was being rehoused and moving out of the hostel (*Table 26*). Overall, 34.9% of residents identified this, including 58.8% of those without memory problems. Those residents without memory problems also mentioned having more money, getting a job and having better health as important factors. Those with memory problems identified having more money, having better health and stopping drinking or using drugs as important factors. Only a small proportion in both groups (4.7% overall) said that more contact with family and relatives would improve their QoL.

Housing outcomes during the study period

Most residents remained in their present hostel during the study period (*Table 27*). A few were rehoused, taking up their own tenancy; these tended to be residents without memory problems. One person with memory problems was also rehoused in a tenancy but was unable to cope and moved back to the hostel. Although, as described in the previous section, many residents wanted to move on from their hostel, the majority would require accommodation with flexible levels of support. The lack of suitable alternative housing options was evident. This is discussed further in *Chapter 7*.

TABLE 26 Factors that would improve QoL, by cognitive group

	Cognitive group (%)		
Factor	No memory problems	Memory problems or borderline	Total (%)
Moving/being rehoused	58.8	19.2	34.9
More money	23.5	11.5	16.3
Better health	11.8	11.5	11.6
Getting a job	11.8	7.7	9.3
Stop drinking/using drugs	0.0	11.5	7.0
More contact with family/relatives	5.9	3.8	4.7
Going on holiday/travelling	5.9	3.8	4.7
Number of residents	17	30	47

TABLE 27 Housing outcomes over the study period, by cognitive group

	Cognitive group (%)		
Housing outcome	No memory problems	Memory problems or borderline	Total (%)
Remained in original hostel	76.5	90.0	85.1
Moved to another hostel	5.9	0.0	2.1
Rehoused in own tenancy	17.6	0.0	6.4
Other ^a	0.0	10.0	6.4
Number of residents	17	30	47

a One person was evicted from the hostel, another was admitted to hospital and then transferred to an intermediate care unit and the third person was rehoused in a tenancy but could not cope and moved back to the original hostel.

Chapter summary

This chapter has summarised the health and social care needs of the hostel residents who agreed to provide us with this information, and their self-ratings of QoL. It has revealed that many older homeless people in hostels require substantial help and support to manage their everyday needs and health problems. This was particularly the case for people with memory problems. It has illustrated how hostel staff often provide considerable support to some older residents, which is beyond the traditional remit of a 'hostel worker' in a homeless setting. They were acting as advocates and taking on the role that family members or social care staff generally provide to older people with health and support needs living in the community. For some residents, the local authority had undertaken an assessment and organised a care package, mainly personal care delivered by a home care agency. This was not always the case, however, partly as a result of the lack of engagement of some residents with support services and the high threshold for local authority support. The challenges identified in this study of helping older homeless people to access health and social care services, and their unmet needs, are addressed in the next chapter.

Chapter 7 Cost of services, unmet needs and challenges in providing services

This chapter draws on the context provided in *Chapter 6* regarding the health and social care needs of hostel residents. It presents findings that cover four main topics: (1) costs of the use of health and social care services, (2) hostel staff's reports of residents' unmet needs, (3) challenges along the health and social care pathway and (4) housing options.

Costs of the use of health and social care services

This section reports on the data collected about service utilisation and the calculation of costs of provisions. The relationships between participant characteristics and costs are explored.

Sample for the economic analysis

The analysis of costs was based on complete cases. Data on service use were available for 47 (75.8%) out of the 62 study participants.

Frequency of service use

Data were recorded for a large number of services, many of which were used by small proportions of the participants (see *Appendix 2*). GP services were the most frequently accessed. Non-attendance at GP appointments was > 15%, and it was 44% for appointments with allied health professionals (see *Appendix 3*). *Table 28* presents frequency of service use data.

TABLE 28 Frequency of use of services during a 6-month period

Service groupings: number of	Frequency of	f use, <i>n</i> (%)				
participants who had	Never used	1–3 times	4–7 times	8–15 times	16-30 times	≥ 31 times
Contacts with a GP	3 (6.4)	14 (29.8)	14 (29.8)	12 (25.5)	3 (6.4)	1 (2.1)
Contacts with other GP staff (nurse, care navigator)	19 (40.4)	21 (44.7)	5 (10.6)	1 (2.1)	0 (0.0)	1 (2.1)
Contacts with other primary care (chiropodist, dentist, optician) ^a	15 (31.9)	20 (42.6)	9 (19.2)	3 (6.4)	0 (0.0)	0 (0.0)
Contacts with community psychiatric/mental health services	35 (74.5)	8 (17.0)	1 (2.1)	3 (6.4)	0 (0.0)	0 (0.0)
Alcohol and drug service contacts	29 (61.7)	8 (17.0)	4 (8.5)	3 (6.4)	2 (4.3)	1 (2.1)
Community pharmacist contacts (supervision of opiate substitute)	45 (95.7)	0 (0.0)	0 (0.0)	0 (0.0)	0 (0.0)	2 (4.3)
Contacts with social care services (AHP, social worker)	31 (66.0)	14 (29.8)	2 (4.3)	0 (0.0)	0 (0.0)	0 (0.0)
Social services funded carer visiting at hostel	30 (63.8)	0 (0.0)	0 (0.0)	1 (2.1)	2 (4.3)	14 (29.8)
Half days at AHP centre	46 (97.9)	1 (2.1)	0 (0.0)	0 (0.0)	0 (0.0)	0 (0.0)
Full days at AHP centre	42 (89.4)	1 (2.1)	0 (0.0)	0 (0.0)	2 (4.3)	2 (4.3)
Contacts with emergency and out-of-hours services	25 (53.2)	13 (27.7)	5 (10.6)	4 (8.5)	0 (0.0)	0 (0.0)
Hospital outpatient consultations and treatments/tests	15 (31.9)	17 (36.2)	8 (17.0)	7 (14.9)	0 (0.0)	0 (0.0)

continued

TABLE 28 Frequency of use of services during a 6-month period (continued)

Service groupings: number of	Frequency o	f use, <i>n</i> (%)				
participants who had	Never used	1–3 times	4–7 times	8-15 times	16-30 times	≥ 31 times
Days as a hospital inpatient (includes day and intermediate care)	38 (80.8)	4 (8.5)	2 (4.3)	0 (0.0)	2 (4.3)	1 (2.1)
Admissions, in-hospital stay (psychiatric)	46 (97.9)	1 (2.1)	0 (0.0)	0 (0.0)	0 (0.0)	0 (0.0)
Admissions, in-hospital stay (non-psychiatric)	39 (83.0)	8 (17.0)	0 (0.0)	0 (0.0)	0 (0.0)	0 (0.0)
Contacts with voluntary helper	41 (87.2)	3 (6.4)	2 (4.3)	1 (2.1)	0 (0.0)	0 (0.0)
Contacts with all psychiatric services ^b	32 (68.1)	10 (21.3)	2 (4.3)	3 (4.3)	0 (0.0)	0 (0.0)

AHP, allied health professional.

When services were grouped (*Table 29*), 94% of participants had appointments for contact with a GP during the 6-month period, 60% had appointments with other general practice staff, 68% had a hospital outpatient appointment, 47% had used emergency or out-of-hours services, 38% had used alcohol and drug services and 32% had had contact with any psychiatric or secondary mental health service (such as a member of a CMHT).

TABLE 29 Per-participant costs of services during a 6-month period

	ing months 0–6						
Service	Mean	Median	% of non-zeros	SD	Interquartile range	Minimum	Maximum
GP contacts	324.43	220.00	93.6	262.81	132–468.50	0.00	990.00
Other GP staff contacts	67.00	14.50	59.6	263.77	0–43.50	0.00	1816.30
Other primary services (chiropodist, dentist, optician)	98.29	63.90	68.1	110.78	0–160	0.00	440.40
Psychiatric/mental health services	56.60	0.00	25.5	129.84	0–42	0.00	546.00
Alcohol and drug services	442.64	0.00	38.3	1055.83	0–244	0.00	4603.56
Social care services	775.95	19.00	51.1	1337.19	0–1086	0.00	5824.00
Emergency and out-of-hours services	175.60	0.00	46.8	317.88	0–225.59	0.00	1381.95
Hospital outpatient services	285.03	118.00	68.1	366.43	0–485.84	0.00	1416.00
Hospital inpatient services	738.36	0.00	19.1	2382.44	0–0	0.00	11,083.56
Voluntary helper	11.49	0.00	12.8	37.70	0–0	0.00	200.00
All services	2975.39	1454.50	0.0	3300.16	631.86–1454.50	163.90	13,280.92
All psychiatric services ^a	128.06	0.00	31.9	403.47	0–118	0.00	2646.00

a All psychiatric services: sum of all contacts with psychiatric/mental health services, psychiatric hospital outpatient consultations and psychiatric hospital inpatient stays.

a 40% saw a chiropodist, 40% saw an optician and 13% saw a dentist during the 6-month period.

b All psychiatric services: sum of all contacts with psychiatric/mental health services, psychiatric hospital outpatient consultations and psychiatric hospital inpatient stays.

Service use costs

The cost for each service for each participant was calculated by applying 2014/15 unit costs (see *Appendix 2*) to utilisation data, including for appointments that were not attended. Summary statistics for the service groupings are shown in *Table 30*. All participants incurred a cost from at least one service group. The mean (median) cost during the 6-month period was £2975 (£14,550), of which £128 (£0) was for psychiatric services; however, there is considerable variability between participants, as shown by the SDs and ranges. The most costly grouping (means of > £700 for the 6 months) were social care services, owing to 12 participants having a care worker making frequent visits to the hostel to provide personal care and support to specific residents (five participants had daily visits and seven had several visits per week), and in-hospital stays (one day case, one psychiatric/mental health stay, and nine non-psychiatric stays including one participant having two hospital episodes). The next most costly items were alcohol and drug services (mean £443) and GPs (mean £324).

Associations between memory problems and service use costs

When all services were considered individually, there was only one significant difference in costs between participants in whom memory problems were present, participants who were borderline and participants in whom memory problems were not present. This was for the visiting home care workers, for which all costs were incurred by participants with memory problems either present or borderline (data not shown). When comparisons were conducted for groups of services, the costs for people without memory problems were significantly higher than those for people in whom memory problems were present or borderline for other GP services (i.e. nurses, care navigators in general practices), but not for any other service grouping (see *Appendix 4*). The difference in service patterns between memory problem groups should not be interpreted as identifying specific impact of memory problems, as the three groups of homeless people also differ in a number of other characteristics.

There were 41 participants who had undergone cognitive testing with the ACE-III (range 0–100 points, with lower scores indicating worse cognition). The mean ACE-III score was 65.76 points (SD 16.85, median 66, interquartile range 29–81.5 points). There were significant correlations between the ACE-III scores and costs of three groups of services. Higher costs of GP services and emergency and out-of-hours services were associated with lower scores; higher costs of other GP services (nurses, care navigators) were associated with higher scores. There was no significant association between all GP services (GPs and other practice staff together) or any other cost grouping, or total costs, and cognition as measured by ACE-III scores (see *Table 30*).

Associations between participant characteristics and costs

Tests of association between participant characteristics revealed significant (positive) correlations between number of named medications and number of comorbidities and number of head injuries reported by participants. Illegal or illicit drug use in the previous 3 months was also associated with more head injuries. Location in London, rather than North England, was associated with non-white British ethnicity and more frequent alcohol consumption (see *Appendix 5*).

Associations between costs and other participant characteristics (sociodemographic and medical) revealed that higher total costs were associated with location in London, and having more comorbidities and more prescribed medications; higher psychiatric costs were associated with more head injuries. Higher costs of all GP services were associated with being in London, more alcohol use, and having more comorbidities, prescribed medications and head injuries. Hospital stays were associated with more comorbidities and prescribed medications. Out-of-hours costs were associated with number of medications and number of head injuries (*Table 31*).

Backward stepwise regression modelling was used to explore the independent predictors of each category of costs. Characteristics describing participants were entered into the models and the least significant were removed one by one (if a p-value > 0.1). Sex (gender) was excluded from the analysis because of an underlying relationship with location (there were only five women in the sample, four of

TABLE 30 Associations between service use costs and ACE-III scores (n = 41 participants)

		Service use cost										
Service group cost	Total cost		Other GP	All GP	Other primary ^a	Psychiatric/mental health	Alcohol and drugs	Social care	Emergency and out of hours	Hospital outpatient	Hospital inpatient	All psychiatric ^b
Spearman's coefficient	-0.150	-0.34	0.344	-0.159	-0.062	-0.011	0.061	-0.145	-0.339	-0.143	-0.051	-0.043
<i>p</i> -value	0.349	0.03	0.028	0.320	0.699	0.946	0.706	0.365	0.03	0.371	0.75	0.789
Association	Not significant	Worse cognition = higher costs	Worse cognition = lower costs	Not significant	Not significant	Not significant	Not significant	Not significant	Worse cognition = higher costs	Not significant	Not significant	Not significant

The ACE-III is scored 0–100 points, with lower scores meaning worse cognition (more memory problems).

a Chiropodist, dentist, optician.

b All psychiatric services: sum of all contacts with psychiatric/mental health services, psychiatric hospital outpatient consultations and psychiatric hospital inpatient stays.

TABLE 31 Associations between service use costs and other participant characteristics

	Type of service										
Sociodemographic characteristic	All services	GP and other GP staff	Other primary	Psychiatric/ mental health	Alcohol and drug	Social care	Emergency, out of hours	Hospital outpatient	Hospital inpatient	All psychiatric	
Sex											
Male $(n = 42)$, median (mean)	1441.64 (2819.51)	274.93 (381.87)	63.90 (102.60)	0 (63.33)	0 (354.06)	0 (665.43)	0 (176.70)	116.50 (236.88)	0 (826.26)	0 (132.07)	
Female $(n = 5)$, median (mean)	5709.09 (4284.77)	431.90 (471.78)	0 (62.08)	0 (0)	488 (1186.72)	1064 (1704.30)	140.59 (166.35)	625 (689.53)	0 (0)	0 (94.40)	
Mann–Whitney <i>p</i> -value	0.228	0.409	0.336	0.319	0.202	0.058	0.242	0.049	0.449	0.725	
Age when first intervi	ewed ($n = 47$); m	ean 59.3 years, media	n 57 years								
Spearman's coefficient	-0.068	-0.192	0.087	-0.156	-0.048	0.145	-0.17	-0.053	0.029	-0.143	
<i>p</i> -value	0.650	0.197	0.562	0.296	0.75	0.332	0.254	0.721	0.848	0.337	
Ethnicity											
White British $(n = 37)$, median (mean)	1675.77 (3245.84)	290.50 (406.34)	63.90 (102.21)	0 (58.27)	0 (401.45)	41 (834.26)	0 (190.44)	118 (312.82)	0 (925.99)	0 (149.05)	
Other $(n = 10)$, median (mean)	1290.77 (1974.74)	306.90 (336.31)	63.90 (83.77)	0 (50.40)	61 (595.06)	0 (560.20)	49.50 (120.68)	27.50 (182.20)	0 (44.13)	0 (50.40)	
Mann–Whitney <i>p</i> -value	0.465	0.908	0.99	0.828	0.53	0.274	0.949	0.117	0.53	0.888	
iteracy problems											
No $(n = 31)$, median (mean)	1539.29 (3034.90)	290.50 (376.35)	63.90 (98.52)	0 (65.71)	0 (495.02)	41 (798.69)	0 (149.04)	118 (275.26)	0 (765.99)	0 (166.45)	
Yes $(n = 16)$, median (mean)	1441.64 (2860.09)	332.03 (420.65)	83.90 (97.84)	0 (38.94)	0 (341.16)	0 (731.88)	49.50 (227.06)	118 (303.97)	0 (684.84)	0 (53.69)	
Mann–Whitney <i>p</i> -value	0.686	0.406	0.493	0.792	0.355	0.676	0.387	0.681	0.883	0.408	

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TABLE 31 Associations between service use costs and other participant characteristics (continued)

Sociodemographic characteristic	Type of service									
	All services	GP and other GP staff	Other primary	Psychiatric/ mental health	Alcohol and drug	Social care	Emergency, out of hours	Hospital outpatient	Hospital inpatient	All psychiatric ^a
Number of comorbidi	ties ($n = 47$); mea	n 5.3, median 5								
Spearman's coefficient	0.403	0.294	0.239	0.181	0.286	0.104	0.235	0.136	0.287	0.1
<i>p</i> -value	0.005	0.045	0.106	0.224	0.051	0.487	0.111	0.362	0.05	0.503
Number of named me	edications ($n = 47$); mean 7.4, median 5								
Spearman's coefficient	0.516	0.607	-0.127	0.284	0.323	0.228	0.502	0.357	0.327	0.172
<i>p</i> -value	> 0.0005	> 0.0005	0.395	0.053	0.027	0.124	> 0.0005	0.014	0.025	0.249
Total number of head	injuries ($n = 47$);	mean 1.4, median 1								
Spearman's coefficient	0.156	0.319	0.115	0.44	0.142	-0.202	0.357	-0.019	0.028	0.322
<i>p</i> -value	0.294	0.029	0.44	0.002	0.34	0.174	0.014	0.898	0.853	0.027
Illegal drug use in the	previous 3 mont	hs								
No $(n = 32)$, median (mean)	1165.63 (2632.63)	237.15 (312.40)	63.90 (115.53)	0 (47.25)	0 (346.97)	31.50 (637.83)	0 (102.72)	118 (324.62)	0 (725.70)	0 (148.53)
Yes $(n = 15)$, median (mean)	2819.20 (3706.61)	381.05 (540.85)	40 (61.50)	0 (76.53)	122 (646.74)	0 (1070.60)	198 (331.08)	115 (200.59)	0 (765.37)	0 (84.40)
Mann–Whitney <i>p</i> -value	0.193	0.132	0.170	0.800	0.155	0.923	0.042	0.377	0.561	0.679
How often participant	drinks alcohol									
< 6 times/week $(n = 19)$, median (mean)	1429.60 (1875.14)	176 (253.12)	127.80 (133.44)	0 (62.45)	0 (319.61)	0 (608.45)	0 (85.71)	88.56 (258.29)	0 (150.92)	0 (105.92)
6 or 7 times/week $(n = 28)$, median (mean)	1631.23 (3721.99)	406.48 (485.29)	45.65 (74.44)	0 (52.53)	61 (526.13)	31.50 (889.61)	99 (236.59)	118 (303.18)	0 (1136.99)	0 (143.09)

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Sociodemographic characteristic	Type of service									
	All services	GP and other GP staff	Other primary	Psychiatric/ mental health	Alcohol and drug	Social care	Emergency, out of hours	Hospital outpatient	Hospital inpatient	All psychiatric ^a
Mann–Whitney <i>p</i> -value	0.146	0.008	0.057	0.966	0.094	0.426	0.112	0.284	0.57	0.564
Location										
South England (London) ($n = 32$), median (mean)	2038.53 (3641.99)	317.53 (436.83)	40 (80.58)	0 (66.39)	0 (596.35)	98.50 (882.36)	99 (207.24)	118 (304.53)	0 (1050.85)	0 (149.23)
North England $(n = 15)$, median (mean)	921 (1553.32)	146.50 (294.60)	80 (136.07)	0 (35.70)	0 (114.73)	0 (548.93)	0 (108.10)	88.56 (243.44)	0 (71.73)	0 (82.90)
Mann–Whitney <i>p</i> -value	0.015	0.004	0.063	0.216	0.064	0.104	0.008	0.561	0.397	0.629

a All psychiatric services: sum of all contacts with psychiatric/mental health services, psychiatric hospital outpatient consultations and psychiatric hospital inpatient stays.

whom were in the south of England). Final models are shown in *Table 32*. The number of medications was an important predictor of several cost categories. Memory problems were a significant factor in predicting emergency and out-of-hours care, but not any other cost category. Over one-third (37.5%) of the total service use cost (which does not include the cost of prescribed medications) was explained by number of comorbidities and number of prescribed medications. Each extra prescribed medication that a participant reported added £309 to the 6-month service use costs; each additional comorbidity added £393.

Hostel staff's reports of residents' unmet needs

During each interview, hostel staff were asked whether or not the resident they were being interviewed about had any unmet needs. Their responses were combined during the 6-month study period so that any unmet need during this time could be identified. Out of the 47 case study participants, 35 (74%) were considered to have one or more unmet needs. *Table 33* shows the distribution by cognitive group.

Table 33 shows that while almost four-fifths of those with memory problems had unmet needs from the perspective of hostel staff, there were also high levels of reported unmet need among residents with no memory problems. The types of unmet need were then categorised into six broad groups, relating to mental ill health or memory problems, physical health needs, alcohol problems, drug problems, social, welfare or housing needs, and personal care needs. These findings are shown in *Table 34*.

Nineteen residents were reported by hostel staff to have unmet social, welfare benefit or housing needs. In many cases, staff felt that residents would benefit from more social activities, including befriending services, social support and opportunities to get out of the hostel periodically. There were various reports as follows:

He is isolated and needs a befriender. I've also tried to get him more involved in social activities to reduce isolation.

A befriender would be nice to come sit with him and talk to him.

With more support he could have used the swimming baths more.

Going to a day centre . . . would benefit him hugely to get out and meet other people.

He likes to venture out, supported day trips would be good.

Although the role of hostel staff included helping people to manage their finances, there were occasions when this remained an unmet need, particularly when the need was more complex, as in the following quotation:

He [needs] . . . support for budget of his finances – we are fighting to get appointeeship, but there are many hoops to go through.

Some hostel staff felt that residents needed more suitable accommodation, as shown in the following quotation:

[He needs] more suitable housing. Should be somewhere where staff have more time to prompt and try and stimulate his brain.

TABLE 32 Predictors of costs: results of regression modelling (final models)

		Unstandardised	Standardised	Significance			
Cost category	Variable	coefficients	coefficients	<i>p</i> -value	^a Adjusted <i>R</i> ²	Durbin–Watson ^b	ANOVA <i>p</i> -value ^c
Total cost of all services	(Constant)	-1380.899		0.157	0.375	2.091	< 0.0005
	Number of comorbidities	392.662	0.280	0.045			
	Number of different named medications	308.521	0.443	0.002			
Total cost of all GP	(Constant)	0.629		0.994	0.315	2.186	< 0.0005
services	Number of different named medications	28.631	0.399	0.003			
	Illegal drug use in previous 3 months (1 = yes)	226.926	0.315	0.013			
	How often drink alcohol (1 = at least 6 or 7 times a week)	178.589	0.261	0.042			
Total cost of community	(Constant)	0.680		0.974	0.273	1.780	< 0.0005
psychiatric/mental health services	Total number of head injuries	39.819	0.538	< 0.0005			
Total cost of emergency	(Constant)	-209.792		0.031	0.297	1.995	< 0.0005
and out-of-hours services	Memory problems (1 = yes, including borderline)	196.768	0.301	0.021			
	Illegal drug use in previous 3 months (1 = yes)	265.673	0.394	0.003			
	Number of different named medications	23.231	0.346	0.008			
Total cost of hospital	(Constant)	29.831		0.743	0.181	1.737	0.002
outpatient services	Number of different named medications	34.467	0.445	0.002			
Total cost of hospital	(Constant)	-937.603		0.117	0.185	2.486	0.002
inpatient services	Number of different named medications	226.352	0.450	0.002			
Total cost of all psychiatric	(Constant)	-242.318		0.078	0.150	1.927	0.004
services	Number of comorbidities	70.193	0.410	0.004			

a Adjusted R^2 shows amount of variation in dependent variable explained by the predictor variables.

b The Durbin-Watson statistic measures autocorrelation in the residuals, range 0-4 with value close to 2 optimal.

c ANOVA p-value shows how significant the final model is for predicting the dependent variable.

Models for drug and alcohol service costs and social service costs had no significant predictors. Model for other primary care costs is not reported as it combines chiropodist, dentist and optician.

TABLE 33 Hostel staff reports of residents' unmet needs, by cognitive group

	Cognitive group (formal assessment), n (%)					
Hostel staff report	No memory problems	Borderline	Memory problems	Total (n)		
Has unmet needs	12 (70.6)	5 (71.4)	18 (78.3)	35		
Does not have unmet needs	5 (29.4)	2 (28.6)	5 (21.7)	12		
Total (N)	17	7	23	47		

TABLE 34 Hostel staff reports of residents' unmet needs, by type of need

Cognitive group (formal assessment) (n)						
No memory problems	Borderline	Memory problems	Total (n)			
1	0	2	3			
6	3	8	17			
5	1	8	14			
2	1	2	5			
5	3	11	19			
0	0	5	5			
19	8	36	63			
	No memory problems 1 6 5 2 5 0	No memory problems Borderline 1 0 6 3 5 1 2 1 5 3 0 0	No memory problems Borderline Memory problems 1 0 2 6 3 8 5 1 8 2 1 2 5 3 11 0 0 5			

a Some residents had more than one unmet need.

Seventeen residents were reported to have unmet mental health or memory needs, and 14 had unmet alcohol needs. These were often closely associated, as shown in the following examples:

He needs more dementia support. He needs more support to stay off the alcohol so he can get dementia support.

He needs help with his mental health, his Korsakoff and in being seen by the memory clinic. [Also had unmet alcohol needs.]

Counselling – going to approach it with him when he has less alcohol, he might be more open to it.

Hostel staff reported three main reasons why residents did not receive the help they needed (for some, there was more than one reason why they did not receive help). Lack of engagement was reported as a problem for just over half of hostel residents whose needs were not met (54.3%). Eleven (31.4%) were not receiving help as they were deemed not eligible to receive the support, although for some this was disputed by hostel staff. Ten residents (28.6%) were not receiving help as either the type of service they needed did not exist or the service was unavailable as it was not the type of service offered by the hostel they were staying in.

When this is considered by cognitive group, although lack of engagement was evident in both those with and those without memory problems, this suggests that factors other than cognition affected engagement.

Hostel workers provided many examples illustrating non-engagement, as described in the following comments about individual residents:

He didn't attend appointments with the counsellor.

No willingness to do anything. He'll agree to things but won't take them up.

He refused help for his drinking.

He refuses help [with his drinking and cannabis use].

He denies his hygiene is neglected. He does not engage with carers. He lets the carer clean his room, but nothing else.

He was referred to a dementia group, which he went to once and didn't go to again.

He refuses to engage with mental health services and refused to fill in the form to claim PIP [Personal Independence Payment – welfare benefit].

Refuses help. There is nothing out there for him until he has sorted out his drinking.

He won't engage or is too intoxicated to engage. He only engages when he needs something.

He doesn't want to go to any social activities, he can't be bothered.

The second reason residents did not receive the help hostel staff felt that they needed was because they were not deemed eligible by services external to the hostel. Ongoing alcohol and/or illicit drug use was one reason services would not accept referrals. Mental health services, in particular, were reported as not being able to work with some people because of their substance use, as shown in the following four examples:

[He] had drug and alcohol problems – [he was] not able to be referred to counselling as the drug and alcohol team felt it was due to alcohol and so he didn't get the counselling.

He needs psychological input due to his entrenched lifestyle, crime, homelessness and drug use for a number of years but it is not offered to that kind of client group. Deal with drug use first, then mental health later.

The alcohol services say they cannot work with him due to his Korsakoff's – he can't retain information. He is just left. He'll just go from hostel to hostel. He has been thrown from one service to another. He is lost in the system. Services don't take him seriously . . . they are just waiting for him to get worse and only when he is very bad will they get him into a care home. I thought counselling would help but the GP said it wouldn't as he needs to be able to remember what has been said in order for counselling to be of any help. There is nothing I can do until he addresses his alcohol issues. His memory is getting worse every day.

He needs a mental health or dementia assessment, but they won't see him as [he is] drinking.

Some residents underwent assessment during the study period to assess their eligibility for local authority-funded social care packages of support with activities of daily living. In contrast to those who received support with personal care, the outcome of such assessments did not always lead to a care package being provided. One resident, for example, was referred to social services for help with cleaning his room and doing laundry, but on the day of assessment he presented himself as clean and tidy and was in a good mood.

The consequence was the social worker said that he did not need help. In North England, two residents underwent an assessment period of several weeks to determine their eligibility for domiciliary social care at the hostel. At the end of the study period, hostel staff reported that the care package had been withdrawn because hostel staff were not on site 24 hours per day and the hostel was not considered safe for care workers to visit residents when staff were not on site. Other unmet needs relating to eligibility included residents who were reported to be ineligible for sheltered housing or care home accommodation because they were too young.

The final reason residents were not able to have their needs met was the lack of particular services, or the inability of the hostel they were staying in to provide specific support. In Central London, for example, staff felt that the care needs of one resident were becoming too high to manage. Elsewhere in London, another person's specific cultural needs (for worship) could not be met as there were no nearby services he could access.

Limitations of the hostel staff role and the amount of time they could spend with individual residents also had an impact on their ability to provide help. One resident was believed to be potentially able to benefit from access to a day centre; however, staff were unable to accompany him to and from the centre. Similarly, another worker felt that although it would be positive for the resident they supported to go out, their part-time hours limited what they could do. Other barriers to receipt of help included that some alcohol services delivered their support through group work only rather than through the one-to-one support preferred by residents.

This section has shown that there were unmet needs across all cognitive groups. Although hostel staff and other workers provided significant support to residents, the limitations of hostel workers' roles and the criteria for service access by external agencies, alongside the reluctance of some residents to engage in addressing their needs, all contributed to challenges in ensuring that hostel residents were able to access the help they needed.

Challenges along the health and social care pathway

Two main challenges were identified along the health and social care pathway: (1) identifying memory problems and getting a diagnosis and (2) challenges in making referrals to health and social care services.

Challenges in identifying memory problems and getting a diagnosis

As presented in *Chapter 5*, there were discrepancies between the reports of residents about their memory problems and hostel staff's perception of these. Some residents were aware of their memory problems; for example, participant 110 described their problems thus: 'I put it down to my head getting old'. Participant 122 acknowledged:

Some days I wake up and I don't know what day it is when I've been on a binge. So I have to go and buy a newspaper to find out what day it is. It's when I've had too much booze.

Qualitative responses may shed some light on these discrepancies. Residents described a number of everyday tasks for which they received help from hostel staff, including budgeting, arranging appointments, prompting, and assisting with hygiene and self-care tasks. Some of this assistance may have supported hostel residents who, if living independently, would have otherwise struggled to cope.

'Prompting' was often cited by many hostel staff as the support they provided to some residents who were able to complete daily tasks fairly independently, but might forget to do them. In the case of participant 207 (borderline), for example, hostel staff maintained his daily diary of appointments, details of his

medication regime and 'things coming up' that needed attending to. His key worker, SW14, said about participant 207 that 'he couldn't live on his own; he would forget to eat, or run out of clean clothes, etcetera. He would forget what day it is', indicating the extent of participant 207's problems with activities of daily living.

Participant 207 was himself aware of the help he was getting in supporting what may have otherwise manifested as memory problems:

If I was not living here [in hostel], it [his memory problems] would be serious; but I am living here so it's not that serious as I've got help.

He referred to the hostel as 'my home', was very satisfied with the support he received from hostel staff, and described this support as just 'assistance' and not 'care'.

Some staff felt that it was not always evident why residents needed prompting. In the case of participant 109 (borderline memory problems), his key worker, SW06, thought that he had early memory problems, which, combined with alcohol, resulted in his needing a great deal of prompting. SW06 described his view of participant 109:

Yes [he has] memory difficulties. A little. Because he's drinking alcohol. Forgets laundry loads – hard to know why. We prompt him to do things because of hygiene and his drinking, not memory problems.

Difficulties in keeping appointments

In cases in which older homeless residents had moderated their alcohol drinking and hostel staff had managed to get an appointment for an older homeless resident who was willing to engage with services, another challenge arose in that the residents sometimes found it difficult to keep their appointments. The level of support hostel staff were able to offer residents with appointments varied between hostels as previously mentioned (see *Table 23*); some staff were able to remind and prompt residents about appointments and others were able to accompany a resident to an appointment to ensure that they arrived, while in other hostels residents were assumed to be able to manage their appointments independently. In one hostel, peer workers from a local charity volunteered to take residents to hospital appointments. There were several reports that residents struggled with follow-up appointments and, even after appointments had been made, some changed their minds about attending.

At times, hostel staff could make the case or advocate for residents who found it difficult to make appointments, and rearrange their missed appointments or accompany them to a fresh appointment. This could be possible after negotiations with some agencies, such as the NHS or local authority. However, two residents described the serious consequences of missing appointments or failing to arrive punctually at social security offices (Department of Work and Pensions or Jobcentres), which had affected their incomes.

However, it often was hard for staff to rearrange missed appointments, especially if this happened on a regular basis. Indeed, if residents had other health conditions in addition to the presenting problem, it made it doubly hard to find the time to reschedule another appointment. Hostels in the study had varying relationships with local primary care practices. In some hostels, staff were able to discuss residents frequently with GPs for support. While appointments with primary care professionals were usually local, or, in the case of two hostels, doctors and nurses routinely ran clinics in the hostels, only some hostels had staff or volunteers able to accompany residents to hospital appointments. This would often take several hours and staff did not always feel that it was possible for them to be spared from the hostel.

Comorbidity and alcohol problems

A significant theme discussed by hostel staff was the inability to tell whether a resident's memory problems were attributable to their drinking alcohol or to growing problems with cognition or memory. Such uncertainties were illustrated in the case of participant 101 (borderline), whose key worker, SW05, was asked whether or not the participant had memory problems, and responded:

I don't know. He often forgets what he needs to do, but that could be due to alcohol. He would often ask what we had spoken about. He knew when meal times were. He would sometimes ask about when he had an appointment.

The amount of support hostel staff provided to some residents may have also masked the level of memory problems among some residents.

Variability in presentation

Another challenge encountered by hostel staff when referring a resident to the NHS in respect of memory problems or confusion was the variability in how these presented themselves. A new health problem could manifest itself quite suddenly among some. In one instance reported, a resident keen to seek medical attention for a health condition was happy for staff to call an ambulance, but changed their mind about leaving the hostel once the ambulance arrived. In relation to memory problems, staff member SW04 felt that they had encountered several difficulties with getting an assessment appointment for participant 104 (memory problems), whom he suspected had memory problems:

I think he has memory problems – I'd have a conversation with him and he couldn't remember what I'd said 5 minutes later. Yet he let the GP do a memory test on him and the GP said he was OK.

This had not reassured the staff member, who continued to be concerned about the resident:

But he does appear to have memory problems but then he remembers something – I can't put two and two together. I wonder if it's linked to his drinking and falling?

One resident [105 (memory problems)], who, in the view of the hostel staff, required a great deal of support from them, was in an atypically positive mood when interviewed in this research study at baseline. He stated that during a recent visit from the social worker to review his case, he had inflated his abilities to manage independently, and declined the care package offered. Responsibility for continuing to look after this resident therefore continued to fall on hostel staff. The researcher noted in her visit to the hostel:

Staff were managing most everyday tasks for 105, either by doing them themselves or by needing to prompt him. 105 had been told he had borderline Korsakoff and (staff member) SW09 was struggling to get another appointment to see if it had progressed, as he suspected. SW09 had contacted social services as 105 needed a care worker to help with budgeting and benefits, cleaning his room, doing his laundry and assisting with bathing. 105, in his interview, said he did all of these tasks independently. The staff member reported '(105) Was referred to social services but he was in a good mood the day the social worker came to do an assessment. He was clean and tidy. The social worker said he did not need it'.

Researcher field notes

Completing a full memory assessment and giving a diagnosis could present challenges for several parties, as SW08 said about participant 108 (memory problems):

He disappeared for one night in April and when he came back to the hostel he couldn't remember where he'd been. I went with him to the GP for a memory test but he covered up – said he could remember and we shouldn't worry.

The staff member added:

[The health team] tried to assess (when 108 first came to hostel) but 108 was rude and stopped the interview. They [managed to diagnose him] with dementia but could not do a proper assessment as he would not engage.

Lack of flexible dementia support and treatment

Alongside the difficulty of assessing a resident with problems such as memory loss or decreasing ability to function independently was the added problem of accepting and taking prescribed medication for some, and resident acceptance of other therapeutic options. Participant 123 had apparently received a diagnosis of alcohol-related dementia but refused to engage with services for any further help. SW24 said about this participant:

[He] Refuses help. Refuses to go to memory clinic and refuses to take thiamine [vitamin B_1].

Abstaining from alcohol in order to be prescribed medication added another layer of complexity to the challenges encountered in providing care and treatment for older hostel residents. This was illustrated in one case in which the resident's dementia had been acknowledged several years previously, as noted by the researcher:

SW23 said about participant 111 (memory problems): '[He was] diagnosed with dementia many years ago. They won't prescribe medication to him till he has abstained from alcohol for at least six months.' Adding 'He managed to abstain for a good long time once, but gave up just before the six months were up, so he's on no medication at all now'.

Researcher field notes

Hostel staff also highlighted the lack of dementia-specific therapeutic options and the lack of reviews of residents with dementia. In respect of the case of participant 111 mentioned above, who was atypical in having had his dementia diagnosed some years previously, there was general concern about whether or not suitable support could be provided to people in his position:

He [participant 111] needs more dementia support . . . He was referred to a dementia group, which he went to once and didn't go to again. I feel like that should be offered to him again . . . He refused it the first time, but I wish more was being done to review his condition and to see how his memory is doing. Because it's getting worse, but nothing is being done about it.

Staff member SW23

Challenges in making referrals to health and social care services

Many challenges were described by staff in several of the hostels concerning local referral systems to health and social care services for hostel residents whom staff felt needed more support. These ranged from the requirement to not be drinking at the time of assessments, how the personalised approach adopted by hostel support staff did not seem possible to replicate in formal services, the refusal of older residents to engage with services and services' refusals to engage with residents.

Requirement to not be drinking at the time of assessments

Just over half of all case study participants with memory problems drank alcohol. Patterns of drinking, the amount of alcohol, and the strength of alcohol consumed varied among them. All of the hostels included in the study allowed residents to drink alcohol in communal areas. Some hostels also allowed residents to drink in their own rooms. Most hostel staff described their residents' drinking habits as a significant impediment to receiving support from the NHS and local authority adult services. Staff described some residents as often falling into dangerous cycles of addiction, spending their daily or weekly allowance on alcohol as soon as they received money, and then having no resources or needing to beg for alcohol by the end of the week. Local GP services were reluctant to refer people to memory clinics, as memory clinics

require those attending to be dry (i.e. to not drinking alcohol) for 3 months before presenting for any assessments related to their increasing or apparent problems with cognitive functioning. Hostel staff often said that this was difficult or impossible for some residents to achieve.

Several hostel residents appeared not to wish to reduce the amount of alcohol they were consuming. During interviews, although some residents talked of wanting to reduce or give up alcohol, their key worker sometimes reported the opposite perspective. One interviewer noted in her field notes:

Interview with SW30 about their participant 202 (memory problems): '[Hostel alcohol worker] talks to 202 about other agencies that help regarding alcohol; 202 agrees just to shut [the worker] up and then afterwards says he has no problem with alcohol'.

Similarly, hostel staff reported several residents being referred to detoxification services and agreeing to accept help to cut back on drinking, but then refusing to go when the time of the appointment came round:

When staff member SW21 signed up participant 112 (borderline) to a drug and alcohol service he recalled that: '[121] agreed and signed the paperwork, but then he refused to go. After three Did-Not-Attends, they took him off their books. He said he liked drinking. He didn't think it affected him and had no intention to change'.

Similarly, staff member SW04 said about participant 104 (memory problems):

The first year here (I) was doing some good work with [104]. I got [him] a detox in place [treatment for detoxification], got the money for it, he initially agreed, but then refused when a place became available. He's too attached to this place; he wants to live here forever.

Even if a resident had willingly signed up to and then attended one therapy or detoxification session, it did not always mean that they were willing to go through with the recommendations of giving up and abstaining from alcohol. Staff member SW34 said about participant 133:

She attends the weekly support group [for alcohol] but doesn't really want to stop drinking. So it feels like she comes more for the socialising.

Inflexibility of services

It was evident from interviews that almost all hostel staff endeavoured to support their residents through as personal an approach as possible and that personalising support was a dominant motive in describing their interventions and the purpose of the service. For instance, staff member SW30 said of participant 202 (memory problems) that he did not 'do official', and that he had to be approached in a friendly, non-threatening manner. His key worker, SW30, chose to phrase things in a jocular way to engage him. Similarly, staff member SW09 said about participant 101 that he was simply unable to attend appointments 'first thing' in the morning. Health services, he acknowledged, were not traditionally ready to engage with patients in such roundabout ways or have sufficient flexibility of timing. Seeing patients at a predesignated appointment was described as generally the way in which residents were responded to, and it was evident that many hostel staff felt that many older homeless residents were likely to be dismissed by local health services if they failed to attend.

Some residents described the format of the therapy or other support sessions on offer as one that did not appeal to them. For instance, most of the alcohol support services appeared to offer group sessions, which participant 210 (no memory problems) said he did not like. No other services, such as one-on-one sessions, were available in the locality, as noted by staff member SW03, who commented in relation to participant 210:

He doesn't want to do group work and that's what you have to do at alcohol support.

Practitioners working in the local NHS secondary mental health services were also encouraging participant 210 to enrol for 'detox', but unsuccessfully. It was not clear if this reluctance was related to participant 210's increasing memory problems or if there was another reason behind his wish to avoid group sessions.

Reluctance of services to engage with homeless clients

Several staff talked about the difficulties they experienced in getting local authority adult services and staff from other agencies to engage with the hostel and its residents. Staff member SW32 reported contacting adult services about resettlement for participant 132 (borderline) and estimated that he had made 10–15 telephone calls to various officers, followed by additional repeat calls, and had been speaking to five or six different people about this resident. The manager of another hostel felt that the reluctance of services to address the needs of homeless people living in hostels was perhaps because residents were not perceived as requiring urgent care or because they were not seen as particularly vulnerable because they were being looked after in the hostel.

In some cases, when local authority adult services had been called and an assessment appointment had been made for a resident, a care package did not always follow as the resident did not meet the eligibility criterion of having sufficiently high unmet needs for care and support. In other cases, as with participant 108, a local authority-funded care package had been put in place but the resident kept refusing access to the care workers when they visited. Eventually the service was withdrawn, leaving hostel staff with the responsibility of supporting the resident. Key worker SW08 said:

I send e-mails to the social worker but she never replies; he has had three social workers, it's been a nightmare. It makes the process slow as we have to start all the way from the beginning again. I put 108 through the social services panel (to agree to fund the care package) and they agreed to the home care . . . he's (over 80) years old. Now agreed he cannot live independently. He was supposed to be in this hostel for just 10 days but social services just left him here.

Similarly, staff member SW05 made several efforts to get an assessment for participant 107 (memory problems), who needed increasing help with his personal care:

It was hard to get the personal care worker set up. It took 4–5 months to sort it out as I had to make a strong case. I got fed up. The social services' older persons unit didn't want to do anything. I had to provide lots of evidence about his needs. We had got to the stage where he didn't do anything.

There was very little mention of regular communication with local adult services' departments, more a sense of individual residents being referred to them for assessment, which resulted sometimes in a care plan and services and sometimes in an assessment that concluded that the person did not have eligible care needs. Residents' needs for information and advice about care appeared to be met by hostel staff. As with participant 107, hostel staff felt that it was their responsibility to pass on information to adult services and other bodies; at one level this seemed to be because they held valuable information and were a credible source, and in other cases it seemed to be because the resident was not able to convey the details of their own circumstances accurately for reasons that included their confusion, memory loss and sometimes misuse of substances such as alcohol.

Reluctance of residents to engage with services

A further challenge encountered by hostel staff in referring older homeless residents with suspected memory problems for assessment or support was the reluctance of residents to engage with health and other services. Reasons reported ranged from apathy and a lack of motivation to seek help to an active distrust of services and professionals.

A general sense of apathy and distrust of formal services was apparent in interviews with several older hostel residents. Some older homeless residents described 'hating' the hostel, resenting hostel staff and generally having no trust in authority or professionals working in health and care services. In some instances, such feelings were more muted and were evident only when the reluctance to go to services was revealed. For example, staff member SW42 felt that participant 123 (no memory problems) made 'empty promises' that he did not keep and would lie about attending appointments that he had deliberately missed. Similarly, staff member SW21 said that participant 112 (borderline) would say 'all right' to suggestions but then consistently find excuses to not follow them through.

In some cases, when hostel staff had tried to encourage a resident to engage with health and social care services to get more appropriate support, they reported that the resident had not been interested and had disregarded their encouragement. Some hostel staff felt that they understood why residents were behaving this way and were willing to work around this lack of engagement and distrust. Many staff considered that some residents' drinking patterns were often reflective of a troubled past and a long-standing chaotic lifestyle. In respect of participant 201 (discussed previously), his key worker noted that this resident suffered from low self-esteem and had problems with anger management; as a result, in the key worker's view, he refused to cut down on drink or engage with services. Staff in this hostel worked hard to reinforce the messages to him about the risks of his alcohol use and described their general approach as being to 'keep chipping away regarding alcohol use, try to get him to engage with services, worry for his future'. By 6 months, staff member SW11 said that the staff had:

put in place a daily alcohol diary as he won't engage with professional alcohol services, we review diary monthly and will encourage him to accept professional treatment.

Some residents were openly reluctant to try cutting down their alcohol use, citing their experiences with different abstaining services over the years and how none had worked for them. Participant 137 (no memory problems) acknowledged:

There is an alcohol counsellor here but I don't go — I've done all that before and it didn't work. Been to a hundred AA [Alcoholics Anonymous] meetings and it didn't help.

Similarly, participant 113 (no memory problems) said that he 'didn't go back to drug and alcohol programme as I didn't like the other people in the group'. He revealed, 'I don't trust the GP, they are not very helpful', adding:

Doctor told me to sort out some anger management issues I had, but I told them I don't need it – only when I'm drunk.

Anger and challenging behaviour were described by staff in relation to several hostel residents and some of these residents also acknowledged that they could become angry in situations they found threatening. For example, participant 101 (borderline) routinely refused to engage with health services to help him reduce his alcohol use, yet he blamed all his outbursts and challenging behaviour on drink and his irritable bowel syndrome. Staff member SW09 described being supportive of participant 101's irritable bowel syndrome, but said of his behaviour:

I wanted him to engage with a counsellor. He'd say yes and then didn't engage. X was a really good worker and was very firm with clients. But they closed 101's case. He'd put it down to anxiety. We are not paid to be abused.

Case study

It is challenging to identify trends in service pathways when each participant's 'patient journey' has been complex, with many repeat referrals and rescheduled appointments, and no trajectory has been straightforward. We therefore adopted a case study methodology for the next part of this chapter to provide an illustrative example of service pathway or patient journey through care encountered by this group of participants. Case studies are not generalisable, but are typical and representative of the experiences of other participants in some form or another. This case study was presented to and discussed by the study advisory group, and their views and feedback are also presented.

Case study of 'John' (name anonymised)

Background

John was in his early sixties and had lived in the hostel for 18 months when he was first interviewed. His first homelessness experience had been in his early thirties and he had spent at least 12 of these years sleeping rough. He had no contact with his family. He was interviewed twice by the research team and his key worker was also interviewed twice. We also obtained information about John's health and social care needs from hostel records and medical records. For the purposes of the study, an ACE-III memory test had been completed with John by the research psychiatrist.

Perception of memory problems

John reported that he did not have any concerns about his memory. However, while the memory test was being conducted, he said that he had some issues with short- and long-term memory. Staff reports were, however, different. The key worker reported that John knew that he was experiencing memory problems and had started to leave himself reminder notes. He had problems remembering recent events and would forget to take his medication if staff did not give it to him. He also forgot his resolve to drink lower-strength alcohol and that he had given up drinking fortified wine. He would worry about, and repeatedly ask about, appointments, as he struggled to retain information. His key worker felt that his problems had become worse over the 6 months.

Memory assessment by research team

On the 6-CIT, John scored 15 out of 28 points. On the ACE-III, he scored 48 out of 100 points, with the following subscores:

- attention, 10 out of 18 points
- memory, 14 out of 26 points
- fluency, 1 out of 14 points
- language, 17 out of 26 points
- visuospatial, 6 out of 16 points.

He was allocated to the 'memory problems' group.

Memory support

John reported not seeing anyone about his memory; however, staff felt that his symptoms reflected an early stage of Korsakoff syndrome. However, his medical records noted that John had 'dementia in Alzheimer's disease, atypical or mixed type (mixed type = vascular and alcohol related)', corroborated by a head scan.

Support from hostel staff

John was provided a range of support from hostel staff, including prompting to get meals, and budgeting (they held his money and had an agreement that he would get £10 per day); a member of staff checked on him twice per shift (three shifts per day); ordered, collected and gave him his medication; reminded him about his appointments and gave him a notebook to write things down; and bought him clothing when needed. Care workers from the local authority also supported John by helping with personal hygiene twice

per day, changing incontinence pads, laundry, cleaning his room and changing bed clothes when needed; they visited for 14 hours per week.

Health and social care use over 6 months

Table 35 details some of the health and social care services John used during the study period (excluding home care). This includes the number of times a specific service was used during the 6-month period.

Challenges in providing/obtaining support as reported by hostel staff

Over time, John's physical health problems deteriorated and his memory and mobility worsened. John's support needs were proving too high for the hostel and during the 6 months of the study hostel staff tried to find a suitable care home for him. John visited several housing schemes where he could still drink alcohol but turned them all down. The local funding panel of adult services decided that his needs were being met and that he could stay in the hostel. He continued to refuse help even when very unwell. After the study period ended, we learned that he had been admitted to hospital for several months and then moved to a care home, but only after the hostel refused to have him back.

Feedback from study advisory group members (anonymised to preserve confidentiality) Member 1 expressed surprise at how much service input John had received. He that said it was atypical of what a lot of other hostels and services would provide, and he was impressed by how hard the hostel had worked towards getting the right kind of care for John. Member 2 agreed with this view and also

speculated that, were John living in his own home, placement in a care home would have taken place a lot sooner, as a Best Interests Assessment would have taken place and a placement would have been deemed necessary. Member 2 also said that mental health services had not been involved in John's care at all, atypical for any client who lived in the community.

Member 3 also said how she could see that funding would have been an issue, as those living in their own homes as owner-occupiers had greater access to money, making it easier for them to access and receive services. Member 4 concurred and said that adaptations to the home would perhaps have been the first starting point, which is unlikely to happen in a hostel.

TABLE 35 Health and social care use over study period by John (anonymised)

Service	Number of times used during 6-month period
GP: home visit	2
GP: telephone call with worker	8
GP: seen at general practice	2 (includes 1 DNA)
Nurse: seen at general practice	1
District nurse visit at hostel	4
Out-of-hours GP visit to hostel	2
NHS 111 service	1
Ambulance service	3
Chiropody	3
Outpatient investigations (with hostel worker)	3
Outpatient appointments (with hostel worker)	4
Other	3 (TB screening; social worker; memory service)
TB, tuberculosis.	

Member 5 remarked on how individual decision-making had meant that John was able to make unwise decisions, such as refusing to move to a care home even if it was better for him to do so.

Both the advisory group chairperson and member 3 discussed the level of staff involvement and that there appeared to be far greater tolerance of challenging or distressing behaviour by hostel staff than by care home staff. Discussion ensued regarding whether or not this was because the hostel was a large provider, which meant that staff were available to accompany residents to hospital appointments and care home visits (as in the case of John). Member 1 considered this to be atypical, as a specific charity at this hostel had been set up for this very reason, namely to take hostel residents to necessary appointments.

Member 2 remarked that it would be interesting to find out how John was doing in the care home. Was he using fewer services, as care homes generally provide some services anyway (e.g. chiropody)? Had his health and cognition stabilised? The researchers said that it was not possible to follow up this individual in this study, but that it might be a good idea for future studies to compare hostel service use and outcomes with care home service use and outcomes.

The advisory group discussed how John's outcomes might have been different had he received different services. If John had been referred by a GP, member 2 thought that he would have been given less time at a memory clinic. At a memory clinic assessment, he would have been given 5 minutes of 'cajoling' to participate in the assessment and then the clinician would have left to see the next patient. The research clinician, on the other hand, was thought to have made more effort and spent more time in carrying out an assessment with him. Member 5 remarked that this was worrying, as some residents may be more reticent to engage with, and maybe be in even greater need of, services.

This case example also highlighted how different services had to work effectively together to provide care for John. Member 1 wondered whether or not 'bad' care in hostels where services were not so good would have been highlighted in our study. The research team reassured him that 'bad' care would have been reported and that there was no evidence of negligence or very poor services in the fieldwork, something the research team would have reported and dealt with immediately.

Member 2 thought that it was common, as in John's case, for someone to be dropped off at A&E and for hospital services to be forced to take over their care and find a placement for them. Thus, whereas care home managers might have refused to take a client who drinks, a hospital might have been able to have arranged for his detoxification and then been able to place him in a care home.

Lack of appropriate housing options

Chapter 4 describes how long residents were able to stay in each of the hostels in the study. In several cases, hostel staff described the problems they encountered in terms of finding somewhere appropriate for residents to move to following their hostel stay. For residents who were alcohol dependent, staff thought that care homes were unsuitable, even if funding for a care home place had been agreed by the local authority and if the care home had agreed to accept the person. Similarly, other long-term care settings, such as sheltered housing or extra care, were not generally an option, as staff predicted that many residents were unlikely to cope independently because of their alcohol dependence, learning difficulties and/or behaviour or lifestyle. In some cases, the problems of agreeing funding and then finding a placement for a resident limited the range of options that were deemed feasible.

The example of participant 203 (memory problems) illustrates the lack of housing and care options for older people with a history of homelessness combined with deteriorating health and increasing memory problems. Participant 203 also had learning disabilities, and, although at the time of data collection he was managing daily self-care tasks independently, he had never lived on his own or managed a budget. Left to live in a flat on his own, staff were certain that he would not cope. Sheltered housing was seen to provide

too little support, and a care home would have provided too much in terms of restricting the lifestyle he chose; therefore, there seemed to be nowhere for him to go.

In respect of one of the few female residents who participated in this study, participant 133 (memory problems), SW34 said:

Ideally, we would like some sheltered accommodation for her. The biggest barrier to that will be her drinking, and that she can't manage money or shopping or cooking on her own. So the options of where she can move on to are limited. She wants to move, she's 'maxed out' on the 2 years she should be living here, but we're being realistic about what is and isn't possible. We talk about her moving on a lot – but we're trying to make smaller steps towards independence, as finding suitable accommodation for her is going to be tricky.

This cautious approach from hostel staff indicated how such discussions were sometimes 'in-house' and did not involve NHS or other public bodies. As with other residents who were 'overstaying' their allotted time in a hostel, there were particular concerns that alcohol use and misuse significantly reduced their likelihood of finding other forms of accommodation.

Some staff and residents described very specific needs that affected the type of accommodation required if a move from the hostel was being considered; for example, participant 201 (borderline) described himself as having very specific needs, as he had a history of seizures:

A warden-aided flat near my current hostel so I can pop back in and see friends and staff. It'll need to be warden-aided.

Staff member SW14 described the very specific needs of participant 207 (borderline) as being for 'specialist supported housing – with cognitive therapy, 24-hour staff support, more hands-on support, such as being taken out shopping when needed' – but explained that 'he's too well for nursing care and independent living is not suitable'. This view of a care home with nursing as being for people with physical health needs and other complex needs for care and support was not always voiced in relation to how these care homes often catered for older and frailer people. However, it was frequently mentioned that the age bracket of care home residents did not always fit with older homeless people.

For example, staff member SW28 felt quite strongly that accommodating young and older residents together in the same hostel was not a good idea because there were 'different attitudes, falling out, older people were brought up to show respect and don't get it back'. He added that the older residents were 'open to financial abuse [in these environments]'.

Another staff member, SW13, also felt that residents such as participant 209 (no memory problems) were at risk of exploitation and that this person needed to be in 'his own flat, maybe sheltered with older people, not younger people as they could take advantage of him'. The language of adult safeguarding services was not generally used by hostel staff, but they were aware of the vulnerability of some older residents to exploitation from some younger residents or others in their social circles.

Life skills and independence

Some residents with borderline memory problems were supported by hostel staff and managed to live mostly independently, with many of their everyday needs for care and support met in a relatively informal way. However, once individuals left the hostel and moved to more independent living situations or sheltered accommodation, this low-level but continuous support was not always available. In the case of participant 129 (memory problems), for example, staff member SW39 observed that in the hostel:

Here he's [participant 129] fine and managing OK – but for moving-on purposes, he will need a carer [care worker], who sees him at least once a day for medication and self-care.

The hostel worker thought that this would be an unlikely development.

Similarly, staff member SW04 said about participant 104 (memory problems):

He's been here [in the hostel] over the allotted time. I'd like to see him in a care home where he gets the support he needs. I need help from social services with this. He's been allowed to stay on here because the manager wants him to have a positive move on. The level of support he needs will take money and that's the problem. If he was put in a flat he wouldn't last – he has no life skills. It's difficult to prove his case – I've sent in medical assessments to X housing options but they say he doesn't fit the criteria.

In this case, the hostel was able to continue to support participant 104 but this appeared to rely on the goodwill of the manager and of the hostel's ability to be able to secure funding for participant 104 even though he did not meet the criteria set out in the hostel's funding contract. This was not the only example of hostels 'holding' residents who they thought would deteriorate substantially if they moved on to locations that proved unable to support them.

Residents being reluctant to move

Staff in several hostels reported finding it difficult to engage residents and to encourage them to move from their present location. Several explanations were provided for such reluctance. For example, participant 108 (memory problems) could not find housing that was acceptable to him or suitable for his needs. Staff member SW08 said that this was not for want of effort; indeed, he had accompanied participant 108 to at least five locations to view potential new accommodation. However, each was rejected with the following reasons:

One place was in [the area] but was too far away; another was nice but the waiting list was too long; another was [name of house] but he didn't like it. Also another in [name of area] but it was too independent. Also [name of house]. Nothing has worked out.

Although some of these reasons could be linked to the participant's possible fear of not managing in more independent living and of being some distance away from his support or social networks, they were not as firmly linked to declining functional ability as in the case of participant 106. Here, hostel staff described their great and continuing difficulties in finding appropriate housing for him to move on to. *Box 1* summarises what happened to participant 106 (memory problems).

Chapter summary

This chapter has provided the opportunity to consider individual residents in the context of the data previously presented. As might have been expected, the variety of hostels means that there is unlikely to be a 'typical older hostel resident'. Common among many of the accounts reported above, and others that are similar but not illustrated, was the lack of suitable housing with care options for this vulnerable group. Access to other services in the community could be complicated or limited by thresholds or rules that meant that these older people were not deemed suitable for or potentially responsive to support. The situation of social care staff coming to hostels to provide care and support has not generally been conveyed in the UK literature on social care or on homelessness.

BOX 1 The declining ability of a hostel to support one resident (participant 106)

Throughout 2015, participant 106 was shown round other hostels with a SW (who was not from the hostel he was staying in), but he declined to consider these alternatives, saying:

They have sent me to see a lot of hostels not suitable for me. One said you can drink three cans [of beer] a day – it's not much. One place didn't have a lift. One was in [X area], another in [street name far away]. I've seen most and refused them. I had my reasons for each one.

The specific difficulties for staff seeking to move 106 were his needs for nursing care, which hostel staff were finding increasingly difficult to provide. The hostel staff said that their referral of participant 106 to local authority adult services had not worked, and one voiced some anger at this rejection:

He needed more care. I referred him to the review panel for a place in a registered care home and they turned him down. We were concerned about him not being able to leave the building quickly enough if there was a fire . . . But the panel thought he was OK to stay here. They said we should put a fire extinguisher in his room – but that was not the point.

Eventually, participant 106 was admitted to hospital, which resulted in his condition deteriorating further. His SW described the difficulties of not being adequately supported by NHS staff:

When he went into hospital, we had to decline him coming back here. We suggested he went instead to the hospital discharge unit that was downstairs at the time. His needs were too high for the hospital discharge place. I had one or two calls from the hospital saying they were ready to discharge him. He was in hospital for 3–4 months. We weren't trying to get rid of him. We were ready to argue it out and the hospital was told to sort it out.

Chapter 8 Discussion

n this chapter, we discuss the study's main findings. We note the limitations and strengths of this study. We have referred to the multiple sources of evidence – from residents, from staff and from medical records – as providing the 'best evidence' available. Such evidence will provide a baseline for other studies and service development. Although the focus of this study is on England, in many developed countries the single homeless population is ageing and increasing numbers of older people are homeless. Just under half (23/47; 49%) of those in our sample for whom substantial data were collected had 'memory problems' and a further 15% (7/47) were considered 'borderline'. Their cognitive status had not generally been collected previously.

Homelessness is described as a 'silent killer', the average age of death among UK homeless people being 47 years. ^{54,107} Therefore, many do not live long enough for memory problems to emerge or be identified. This present study took place at a time when homelessness and rough sleeping were of great and increasing policy concern in the UK. Owing to a multitude of reasons, in 2015/16 local authorities in England responded to the threat of, or to actual, homelessness among 327,390 households (254,320 households in 2009/10). The situation of single homeless people, particularly older people, is caught up in these wider trends, and in the gaps between housing need and affordable housing supply.²⁷ Although none of this present study's participants was currently rough sleeping, several had done so during earlier episodes of homelessness (see *Chapter 4*). Today's rough sleepers may be future hostel residents; others will not survive.¹⁰⁸ Homelessness among older people is increasing internationally,¹⁰⁹ offering new challenges to health and social care services that have traditionally focused on community-dwelling (i.e. housed) older people and now need to address the shifting age profile of homeless people.

The Homelessness Reduction Act 2017¹¹⁰ has placed further responsibilities on local authorities to help prevent homelessness (its main provisions amend Part VII of the Housing Act 1996¹¹¹). They are mandated to take reasonable steps to help secure accommodation for any eligible person who is homeless. The impact of this Act on hostel residents' health and well-being will need to be ascertained.

Internationally, the subject of homelessness and ageing is being argued as representing a challenge to services,⁷³ and specific attention to homelessness and dementia has been evident in Australia, building on the Chenco review⁶⁴ and informed by consultations with front-line homelessness services and advocacy organisations. The discussion paper from Wintringham offered a variety of reasons why homeless people fail to access dementia assessment pathways.¹¹² Similar to our findings, this organisation pointed out that homelessness services staff often have to act on clients' behalf yet they are not being supported in this work by wider health agencies.

The next section draws on our study's findings that should be set in this context of dementia pathways, both the explorations of a person's memory problems and the pathways or their access to appropriate care, accommodation and services.

Physical health problems

Although the focus of our study was on memory problems, the extent of physical health problems among the hostel residents participating in this study was substantial, and this is likely to have been under-reported. A recent US study of older people (aged \geq 50 years) who were homeless summarised their findings as that the homeless group experienced health and disability problems that were generally experienced by people who were 20 years their senior.⁷³ The sample group in our study had at least one long-term condition. Participating hostels were not generally well equipped to support people whose health was in decline and whose disabilities were likely to worsen and accelerate if not well controlled. Some hostels were more accessible (in terms of physical facilities and adaptations) than others but overall

they faced challenges in accommodating residents with increasing needs for care and long-term health problems. Our data on the physical conditions of hostels add considerably to the picture of what is available to residents and the wide variety of living conditions. Overall, the implications of this for our study research question about 'pathways' are that memory problems may be one among many health-related problems facing older hostel residents and that pathways are not necessarily helpful if they are disease specific.

Sight and hearing problems may mask early or mild symptoms of memory problems, and they were commonly reported. This has implications for the provision of information, for the keeping of appointments and for the mode of assessments, and, of course, for the physical fabric of hostels and their accessibility. Hostels without or with very limited key worker systems appeared to find it especially difficult to respond to residents with multiple problems covering physical and mental health, and their contacts with local health and care services appeared to be more tenuous. Furthermore, hostels without key workers were not generally equipped with good records of residents' physical health problems. The presence of key workers should not be presumed by other professionals external to a hostel.

Head injuries

Our findings of the level and extent of head injury among older hostel residents in this study have implications for any assessments of cognition as well as longer term effects of such injuries. It is likely that among this group not all head injuries had been reported to NHS professionals or were on patient records. Among hostel staff, their knowledge of residents' head injuries was partial; thus, their role as possible informants in assessments or monitoring would be limited, although better than no-one.

Mental health problems

Chapter 6 reported that nearly three-quarters of case study participants had a history of mental health problems and three-quarters had current mental health problems, particularly depression. Here, our study design of combining data from hostel residents and from staff interviews, hostel and medical records was particularly helpful. For example, the staff reports and hostel/medical records showed much higher percentages (81% from medical records vs. 63% self-reports) of a history of mental health problems than were found in self-reports. Using a depression tool, as described in Chapter 4, enabled us to ascertain current details of the extent and severity of depression among residents. Not surprisingly, depression was associated with poor physical health. There were also associations between depression and excessive alcohol use and the use of illicit substances.

Homeless Link's audit¹⁹ of > 2500 homeless people found that the proportion of homeless people with mental health problems (45%) was nearly twice that among the general population (approximately 25%). Most significantly, the audit found that just over one-third (36%) had depression (compared with 3% of the general population) with further higher rates of bipolar disorder, personality disorder, schizophrenia and post-traumatic stress disorder. Such findings are in line with this present study's data.

Mental health and well-being are prominent in the government's recent Homelessness Prevention Programme. The development of Social Impact Bonds is intended to support a group who are described as the most complex and entrenched, namely rough sleepers, including personalised mental health support. Older hostel residents may no longer be rough sleepers but are likely to have survived these experiences and share many of their characteristics.

Alcohol use

Heavy alcohol use is not unusual among people who have a history of homelessness or are currently homeless, particularly men.¹⁹ Similarly, the high weekly alcohol intake among the residents who participated in this study

(see *Chapter 4*) indicates that heavy drinking is not unusual; indeed, one-quarter of the 52 hostel residents who provided details of their alcohol consumption were consuming > 100 units of alcohol each week. Alcohol use varied by hostel, particularly as some hostels permitted drinking on their premises. There are implications for memory assessment and other services from these data. First, assessments that require patients to be sober or abstinent for a period may exclude certain groups from their services. Second, regularly high levels of alcohol consumption may mean that certain times of day are best for professional assessments and conversations (and for researchers). Some days of the week may be better than others for accessing individuals who drink heavily or 'binge drink' after receiving their welfare benefits. Third, the researchers asked questions carefully to elicit ideas about what was being drunk and, methodologically, this collected a more accurate picture of consumption than just numbers of drinks. Finally, it is not easy to calculate what individuals drink; in this study we relied on self-reports. Hostel staff admitted that they did not know too much about the amounts being drunk; indeed, several residents informed us that they consumed their alcoholic beverages outside the hostel.

Use of illicit drugs

The growth in number of older drug users and the ageing of 'baby boomers', whose rates of illicit drug use are higher than those of previous older cohorts, combined with improved health care for drug users so that they are living longer, all need to be taken into account as relevant changes to the practice and service contexts.¹⁹

We relied on self-reports and staff reports about illicit drug use in this study. Although of course there are limits to this, our findings suggested that many hostel residents have a history of drug misuse (in this study over half) and that some (nearly one-third in this study) still regularly consume drugs (see *Chapter 6*). Among our participants, this consumption was mainly of cannabis and crack-cocaine; these were long-standing patterns of behaviour. The implications of this for memory assessment are similar to those in respect of alcohol consumption; behaviour and responses to tests may be affected by substance use. Similarly, staff working in hostels may not have accurate information about residents' substance use.

Literacy problems

We noted in *Physical health problems* that sight and hearing problems may affect communication. The level of literacy among some hostel residents is also relevant. Literacy problems were, of course, long-standing; more than one-third reported such problems (see *Chapter 5*). Unsettled early lives and leaving formal education at an early age to move to unskilled work or unemployment were characteristic of some residents. The impact of this on dementia pathways was that hostel staff often acted for these residents in communication with health and care services, 'proving their case' and making exceptions about moving residents on, and accompanying them to appointments and to 'move on' possibilities. Not all hostels were able to provide this level of support.

The next section focuses on the hostels and the wider systems in which the difficulties of following routine care pathways to identify people with memory problems or cognitive difficulties were prominent.

Hostel provision

Our study focused on people aged \geq 50 years who were living in hostels; in other jurisdictions this population might be described as 'provisionally sheltered'. The case study approach of this study revealed the wide variety of UK hostels and also their risks of non-sustainability. Whereas large not-for-profit hostels have a range of services and contracts with statutory sectors and appear more organisationally resilient, smaller and single-ownership hostels are highly vulnerable to changes in their external environment and also to the decisions made by owners about sustainability. The differences

encountered, as reported in *Chapter 4*, reflect this heterogeneity and this too affected their resident group. In one hostel, for example, some residents were 'settled' as they had lived there for many years. However, this situation may not continue, and so the attention being given by the social care sector to risks of care home closures¹¹⁴ and resident resettlement could be expanded to other provision such as hostels.

Hostel staff were generally helpful and engaged in the study, and freely gave their time and views in the context of being busy and sometimes short-staffed. There is a risk of bias in that those hostels that participated in this study may have been exceptional. These risks were mitigated by the research team explaining that this was an independent study and that data would be confidential and not reported to commissioners. High staff turnover is common in social care services;115 the extent of it in homelessness services should be acknowledged in interagency communications as well as in research. Completing a diary was not feasible, not only because staff were busy but also because communal facilities meant that 'checking' or monitoring was done in relation to several residents and could not be easily linked to individuals. Hostel staff's descriptions of 'prompting' residents may seem an easy task but our interviews revealed that this work was skilled in making such assistance acceptable and not disempowering. The range of support in hostels was potentially extensive (see Tables 4 and 5). However, laundry and cleaning provision varied, budgeting assistance was infrequent, and collection or management of medication was provided in some hostels but not in others. Each of these activities was identified and interrogated in this study, providing a rich set of data about hostel provision and experiences. The expositions of these multiple differences highlighted the value of data collected from meticulously conducted semistructured interviews and structured survey questions.

In our interviews with hostel staff, several expressed a wish for more training and this may be a reflection of the high levels of resident need that they are encountering. As noted, whereas some hostel staff had relevant skills and training in mental health, other staff lacked such experience. Almost all acknowledged that some hostel residents were not trusting of other professionals or lacked motivation to seek further involvement in services. For some of the most disabled residents, the extent to which hostel workers acted as their advocates was substantial. The mixed presentation of hostel residents, with multiple problems and apparent reluctance to access support, further complicated interagency networking.

It is important to stress, however, that the hostel residents were homeless and that housing (for many this needed to be accompanied by care of some form) was a primary need. This is particularly the case at a time when the length of hostel stays is becoming shorter, when hostels are vulnerable to closure or to having to accept residents with multiple needs, and when wider system pressures are evident, such as increased pressure on hospital beds. 116 Although much has been said about social care being at a 'tipping point' 116 and that local authority funding is declining, 117 provision in the homelessness sector for people who have care and support needs is similarly affected by instability and resource limitations. Despite the best efforts of their staff, on the basis of our findings hostels are not suitable accommodation for older homeless people with memory problems. As we shall highlight in the implications of this study, suitable, accessible and acceptable long-term accommodation needs to be available; our literature review identified some examples of care homes run by homelessness-sector organisations for older homeless people with memory problems, some of whom are heavy drinkers. Such a model could be developed in England, and the current context of moves to more integrated care might foster such developments.

It is seemed inappropriate for older homeless people with memory problems and often comorbid or other long-term conditions to be in hostels with transient resident populations, young and middle-aged drug or alcohol misusers or other residents in troubled circumstances. Some of the 'checking' tasks carried out by hostel staff were protective and risk managing in intent. Although older homeless people generally do not like living in hostels with younger people – they may feel or be threatened and intimidated – in other circumstances this work would be seen as addressing safeguarding concerns. As a recent report from St Mungo's¹¹⁸ suggested, homeless people on the streets are at risk of harm, including violent attacks; thus, safety and well-being in hostels also need to be addressed as safeguarding matters when adults have care and support needs under the Care Act 2014¹¹⁹ and are unable to protect themselves.

There is currently strong emphasis on a policy of only short stays in hostels for all age groups.⁴⁴ This rests on a belief that hostels are not suitable accommodation other than for a short period. Older homeless people with memory problems are probably more difficult to rehouse than others and, as our study found, sometimes remain in hostels because of a lack of suitable accommodation (see *Chapter 7*). This is not an argument for them staying in hostels. As gerontological researchers such as Grenier *et al.*¹²⁰ have argued, homelessness in later life may newly occur or, for some, may have been experienced on several occasions. An implication of our study is that 'older homelessness' needs to be part of local strategic thinking for public services.

Strengths and limitations of the study

To our knowledge, this is the first study of cognitive problems, dementia and older homeless people in the UK. We were able to assess clinically the extent of memory problems among a sample of hostel residents, using a test (ACE-III) that appeared to work well in not being too intrusive, time-consuming or onerous (48 such assessments were conducted). We were able to adjust our study to categorise residents into three rather than two groups for analysis according to their memory problems (memory problems, no memory problems and 'borderline'). Our work on unit costs broke new ground in linking (or attempting to link) sources of self-report, hostel staff accounts, medical and hostel records. Medications were not included in the costing data and no comparison was made of service use and costs with another comparator group (e.g. non-homeless or long-term care residents). Despite the challenges of interviewing hostel residents, out of 62 participants at baseline, 37 were interviewed at 3 months and 37 were interviewed at 6 months. Only six residents declined to participate further in the study for reasons other than being unavailable, moving away or relocation. Over half of those interviewed (25 out of 47) considered that they had difficulties with or concerns about their memory. Notably, we acquired data on the impact of this on their everyday life but also on their ability to provide information about themselves; a total of 18 residents were not able but perhaps not willing to tell the research team if they had stayed in a hostel prior to their current stay. Among participants in this study, most spent their days in the hostel with visits to shops their most frequent outing, and made very limited use of day centres or drop-in facilities. In many ways, several were living a life that was close to living in a long-term care facility, except that community contact was possibly even more restricted and that care quality inspection, regulation and monitoring are absent from the hostel sector.

Finally, in terms of the strengths of this study, the assistance of an study advisory group from different perspectives, including people with experience of homelessness, offered insights and deepened understanding. The group was involved in discussions of the research design, decisions following recruitment challenges and dissemination. Those with lived experience of homelessness were involved as full members of this group and made very insightful comments; for example, it was on their advice that we collected data not only on how much alcohol might be consumed by study participants but also on the type of alcohol. They drew attention to the low cost of super-strength alcohol, such as lager or cider. As older people with lived experience, they were very helpful in the study; sadly, one member died during the study. Representatives from the homelessness service provider St Mungo's and from the Alzheimer's Society who attended the Advisory Group have agreed to actively help with study dissemination.

There are, of course, several limitations to this study. We accessed hostels in urban environments and the needs and circumstances of rural homeless people were not addressed, important though these are. 121 We were not able to access NHS data for several residents, although for some this was understandable as contact had ceased or been temporary. In any future study we would seek funding for incentivising of GPs and would collect data on medication prescription and use (and on over-the-counter medications). We took care not to refer to this as the 'dementia' study, but this is how this study became known to hostel staff and residents; this may have affected not only recruitment (see *Chapter 3*) but also responses. We have previously noted the volatility of hostel provision in some areas and unpredictability in their contractual arrangements. There were fewer contacts with other professionals than we anticipated, bearing in mind the level of need for care and support of the hostel residents. We further noted in our

review of the literature that there is little on social care provision for homeless people, and that much of the earlier evidence of the outcomes of their moves to care homes focused on the problems for care homes and is now dated.²⁷ These gaps in the evidence base remain. Few studies and other literature have identified that older homeless people may experience inequities of provision, ageist and discriminatory behaviours and systems, and that their human rights are hard to uphold in settings such as hostels.

Our work on service use also broke new ground. Information on the service use of homeless people is rarely available and not triangulated with different reports of what is taken up. This was a small sample of older homeless people, but the information was meticulously collected. Much variability in service use was found among the sample. The median cost of service use over the 6-month period was £1454, but the mean was much higher than this (£2975), reflecting a small number of high users of social care services and inpatient care.

One of the original aims of this study was to compare access to services of older homeless people with memory problems with that of their peers without memory problems. Just under half (49%) of the sample for whom service use was available had memory problems, and a further 15% were considered borderline. The proportion of the group with memory problems (the 'cognitively impaired' group) who had used some form of psychiatric or mental health service during the 6-month study was higher than for those in the borderline or no memory problems groups (39%, 29% and 24%, respectively). However, the proportion of total costs accounted for by psychiatric or mental health services was < 5%. Moreover, the reason for accessing psychiatric or mental health care is not known, and it may have been for depression or another psychiatric morbidity rather than for memory problems. Contact with the memory assessment services was recorded for only one participant (a hostel visit). For many participants, it was only through the research project that cognitive status was assessed. Without any formal diagnosis before the study, it is perhaps to be expected that there is little evidence of memory service input.

Participants with memory problems (the memory problems group) used NHS emergency and out-of-hours services more than did those without such problems, but there was no other association between cognitive status and service use cost categories. However, there was much variability in service utilisation at the individual level and a larger sample would be required to gain definitive results.

A limitation of the study noted previously is that medications were not included in the costing study. More generally, the lack of a comparison group means that it is not possible to comment on the extent to which the service utilisation of homeless people differs from that of the non-homeless population.

The final chapter of this study outlines the implications of our study.

Chapter 9 Implications

The previous chapters have reported unique data in the UK context that we have used to construct a set of implications for four main audiences: commissioners, providers, practitioners and researchers. We also frame these implications for the attention of the wider dementia stakeholder community, and in the context of equalities in mental health services and services for older people, particularly those who are disadvantaged socially. Although some of the implications overlap, they are a unique set of implications coming from the analysis of the experiences of people who are homeless, some of whom have received a diagnosis of dementia and some who have not, and of those who support them as practitioners and managers in homelessness services.

Early or timely recognition of dementia was a key policy goal of the National Dementia Strategy.¹ Older people who are homeless were not considered in this policy and practice imperative despite their risk factors. Indeed, we identified barriers to their assessment for possible memory problems. Overall, the system of memory assessment is not only far from patient-centred for this group but also largely inaccessible. Older people living in hostels are very likely to have several long-term conditions, including mental health needs. Thus, the issues arising for people with possible dementia who are homeless may be similar to those for other older people but they may also be experienced to a greater degree and cover different aspects of life and well-being. Experiences of declining cognitive abilities were reported in this study, and some people with a diagnosis of dementia were living in hostels. To the best of our knowledge, no other study and no policy document acknowledges these as 'dementia communities'.

These confounding effects of dementia and homelessness may need to be investigated further so that health care, social care and housing support practices can be better tailored to support older homeless people. Although undertaking interviews with older hostel residents, and in particular those consuming a large amount of alcohol, could take several attempts, our study showed that psychiatric assessments can be conducted; however, it may be more productive for parts of assessments to be conducted at a hostel rather than at a memory service. It is interesting that several hostel staff were able to determine which residents had suspected memory problems (although there were also several 'false positives') and this suggests that their role as informants is potentially significant and may partially compensate for a lack of family informants. In this context, the following implications are drawn out for the consideration of different groups.

Implications

In this section we outline some of the emerging implications from this study.

Implications for the consideration of commissioners

- There is a need for local strategies to create and agree a plan(s) for the support of older homeless residents in hostels, which should be undertaken in partnership with the hostel staff. This might be usefully informed by public health expertise. Such specific planning and anticipation of need will help to ensure that current reactive care is part of a co-ordinated plan. Local work on integration may be the vehicle for such developments, but only if older homeless people are identified as a priority.
- Are hostels providing another form of 'housing with care' in the local health and care economy? The implications of our findings that some hostel residents have substantial care and support needs merits exploration of whether or not the use of such terminology might help integrate funding and provide better continuity of care and support. Furthermore, the closure of a hostel or change to its contracted funding arrangements may have substantial implications for older residents with high or growing support needs. Our study suggests that hostel provision might be encompassed in the

- new market shaping responsibilities of local authorities under the Care Act 2014¹¹⁹ and its wider responsibilities for local citizens' well-being.
- We suggest that local health and care agencies' training and education be welcoming to hostel staff. Such shared learning might also forge greater contact between hostel staff and statutory services to the benefit of their shared clients or residents.

Implications for the consideration of practitioners

- We do not know what social care staff supporting older hostel residents with or without memory problems find to be the most effective and acceptable elements of their practice. This study suggests that they may have a wider role in 'bridging' the different sectors, or at least their managers being able to communicate with other professionals if a care plan is not working well. As with hostel staff who are key workers, we do not know if and how care workers are engaged in care planning and anticipatory care. The implications of this study are that home care workers who provide care and support to hostel residents are potentially underused as a monitoring system, particularly in hostels without key worker systems.
- Living alone with dementia but not on one's own is a situation highlighted by this study. People who are living alone or are isolated are not generally thought of as living in a congregate environment such as a hostel. However, increasing frailty and the needs of other residents may affect socialisation within a hostel. Hostel residents themselves and those who work with them may have relevant insight into the needs of people who are used to being on their own and person-centred experiences of how to help support be accessible and acceptable. These could be usefully explored by other practice communities working with older people who are lonely or unwillingly isolated. The implication of this study is that societal commitment to reducing the loneliness and isolation of older people should be inclusive of older people who have a history of homelessness.
- The practice evidence about the relative merits and benefits of different resources and supports for homeless people wishing to sustain their abilities and memory is thin. Memory support, environmental modifications and technology are variously suggested and appreciated among some people with dementia. A stronger evidence base for these in diverse settings might be developed so that health-care practitioners can better support people who are not usually seen as benefiting from them, such as older homeless people.
- This study found that many hostel staff would like more training. This is a broad topic; but in respect
 of ageing and memory problems, evidence of most effective and cost-effective ways to support older
 residents could be collated into good practice guidelines that could underpin training. Training resources
 for practitioners could be developed by the homelessness sector with the support of dementia practice
 communities.
- For clinical practice this study has identified several barriers to memory assessment that could be addressed by flexibility in terms of appointments, assessment practices and liaison with hostel staff. Records of individual health status and history are not always complete among people with histories of homelessness. One important implication of this study is that the presence of head injury or a history of trauma may merit particular consideration in assessments, but that records of such an injury may not be available or may not have been taken. Another clinical implication is our finding of high levels of depression among residents. Although this was being treated in some residents, its presence may merit greater preventative efforts, taking a public health approach.

Implications for the consideration of hostels

- Hostel staff are a key resource, and many were informed, supportive and committed to resident
 well-being. Providers may wish to encourage and assist them to access local training and practice
 development opportunities.
- Key working was a very effective way of supporting residents with high-level needs in hostels and some key workers undertook case management roles. Not all hostels run their service with key workers and their managers or owners may wish to consider this staffing arrangement.

- Hostel staff and hostel records may be the main sources of information about some residents. Practice varies widely in terms of record keeping and how such records are maintained. Hostels facing difficulties in this activity should work with partners in local authorities and health services to seek assistance so that such valuable data are not lost. The implication of this study's finding that hostels may close quickly means that there is substantial risk of unique information about residents being lost. For those with memory problems, this is of great concern to future person-centred care that takes a life history approach.
- Hostels are not traditionally seen as dementia communities; but this research shows that they are supporting people with such conditions, diagnosed or not. The difficulties faced by hostels supporting people with memory problems are substantial and are compounded at a system level by demands for short stays and resettlement. Even those hostels whose facilities are more suitable for people with physical health conditions are not the optimal environment for living well with dementia. The implication of this study is that hostel providers will need to continue to advocate for their residents to move to more appropriate accommodation in general and that the appropriateness of this takes into account declining cognition or memory problems. Hostel providers may wish to build up local alliances or to join dementia community initiatives to improve the lives of their residents with memory problems and to supplement their advocacy on residents' behalf.

Implications for the consideration of the research community

- Multiple research methods were used in this study. Not surprisingly, interviews were more productive than questionnaires or surveys among people whose recall levels might fluctuate. Our interviews with older homeless people seemed to be encouraging of discussion and facilitated recall in some instances; however, they were only partially successful (see *Chapter 3*) in providing factual information. A few records were incomplete or partial; as noted above, these could cover clinical histories but sometimes chronologies or biographies. Research with older homeless people needs more time and resource than is the case with other homeless people, and compared with studies of other housed older people with or without dementia. Further longitudinal research would be helpful in considering ways to support older homeless people with memory problems across the trajectory of multiple conditions and challenges.
- The funders of research are in a strong position to enable researchers to accommodate the efforts of data collection and may have a helpful role in the developing of researcher capacity to work in this sector when investigating health and social care questions, especially those related to addressing inequalities. The building up of experience of research participation in hostels, particularly those that are small and not part of larger charitable bodies, could be part of this capacity building. There are risks of bias in recruiting only from large hostels or day centres whose funders or central offices are committed to research but even in such locations this needs to be fostered locally. The professional or service backgrounds of researchers in homelessness studies assist greatly in understanding the subject, the approach and communications; if they are not available, then greater preparation and induction will be needed. An expert advisory group is strongly recommended, including people with lived experience of homelessness. Such capacity could be fostered and funded.

Conclusion

Our study has presented new information about the lives and circumstances of older people with memory problems, about older hostel residents and about services for both groups. We have established baseline information and tested out different methods and data collection approaches. On the basis of the evidence, the implication of this study is that hostels are not suitable accommodation for older people with memory problems, such as those associated with dementia. Nevertheless, the study found much evidence of the skills and competence among some hostel staff who provided support to residents for whom memory problems were having a negative impact on their lives and well-being. Inequalities of support for people with dementia or memory problems include the exclusion of some older people from a place to call home and the security that this brings.

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Contributions of authors

Professor Jill Manthorpe (Professor of Social Work) was chief investigator, designed the study, reviewed the background literature, provided supervisory support and co-wrote the report.

Dr Kritika Samsi (Research Fellow) was co-investigator, conducted recruitment, data collection and data analysis, and co-wrote the report.

Dr Louise Joly (Research Fellow) designed the study and the interview documents, conducted recruitment, data collection and data analysis, and co-wrote the report.

Dr Maureen Crane (Reader in Applied Social Research) was co-investigator, designed the study and interview documents, conducted recruitment, data collection and data analysis, and co-wrote the report.

Professor Heather Gage (Professor of Health Economics) was co-investigator and conducted the economic aspects of the study; for this, she developed study instruments, conducted the analysis and wrote the relevant chapter.

Professor Ann Bowling (Visiting Professor in Health Sciences) was co-investigator and conducted the systematic review for the study; for this, she designed the review, conducted the searches, analysed the data and co-wrote the relevant chapter.

Dr Ramin Nilforooshan (Consultant Psychiatrist) designed the clinical investigations of the study, identified suitable cognitive instruments, conducted assessments with his colleagues, analysed the relevant data and co-wrote the relevant chapter.

Publications

Manthorpe J, Samsi K, Crane M, Joly L, Timms P, Gage H, et al. Dementia & homelessness: starting to make the links. *Journal of Dementia Care* 2013;**21**:39.

Bowling A, Rowe G, Adams S, Sands P, Samsi K, Crane M, et al. Quality of life in dementia: a systematically conducted narrative review of dementia-specific measurement scales. Aging and Ment Health 2015;19:13–31.

Data-sharing statement

All data requests should be submitted to the corresponding author for consideration. Access to available anonymised data may be granted following review.

Patient data

This work uses data provided by patients and collected by the NHS as part of their care and support. Using patient data is vital to improve health and care for everyone. There is huge potential to make better use of information from people's patient records, to understand more about disease, develop new treatments, monitor safety, and plan NHS services. Patient data should be kept safe and secure, to protect everyone's privacy, and it's important that there are safeguards to make sure that it is stored and used responsibly. Everyone should be able to find out about how patient data are used. #datasaveslives You can find out more about the background to this citation here: https://understandingpatientdata.org.uk/data-citation.

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Appendix 1 Table summarising the 20 items included in the second literature review

Author(s), year	Country	Methods	Study aims	Study population	Findings/content
Abdul-Hamid <i>et al.</i> , ⁸⁹ 1998	International	Literature review using three databases	To identify the needs of 'elderly graduates' (defined as people who started using mental health services before the age of 65 years and continue to do so) and models and methods of services they use	'Elderly graduates' and their needs assessments	The review concluded that the needs of the 'elderly graduates' of mental health/psychiatric services are under-researched; this particularly applied to nursing home residents but also to the homeless. Questions that require further research have been highlighted
Andersen <i>et al.</i> , ⁸⁸ 2014	Canada	Quantitative and qualitative	To examine cognitive performance among a sample and compare cognitive performance between those with and those without traumatic brain injury; using qualitative methods to explore their situations	Sample of men (aged \geq 18 years) from a residential unit – an urban homeless shelter ($n = 34$)	A history of TBI was associated with generally poorer cognitive performance in the study sample. Improved awareness of TBI and cognitive dysfunction among service providers is recommended
Backer and Howard, ⁸⁵ 2007	USA	Literature review and discussion paper	To examine the forms of cognitive impairment and how many homeless people are cognitively impaired	N/A	More research is needed to document the prevalence of cognitive impairment among people who are homeless and at risk of homelessness, about the origins and severity of their impairments, and about the consequences of these impairments for the effectiveness of the service process
Barak and Cohen, ⁹¹ 2003	Israel	Examination of all elderly homeless people in Tel Aviv by a psychiatrist over a 10-year period	To characterise the 'new' homeless – defined as non-'skid row'	Over a 10-year period each homeless person aged ≥ 65 years was assessed by a psychiatrist (old number = 98; general homeless population number = 2567)	The main conclusion is that the 'new' elderly homeless are typically male and suffering from frequent psychiatric morbidity and physical comorbidity. Of the 44 who were diagnosed with a psychiatric disorder, 15 had dementia

APPENDIX 1

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Author(s), year	Country	Methods	Study aims	Study population	Findings/content
Brown <i>et al.</i> , ⁷¹ 2012	USA	Cross-sectional. 247 homeless people (aged 50–69 years) interviewed and examined. Known as project MUSE	To determine prevalence of common geriatric syndromes in a sample of older homeless adults and compare these with population-based cohorts	Population drawn from homeless facilities for single adults aged ≥ 50 years in Boston, MA	Cognitive impairment present in 24.3% of participants. Geriatric syndromes that are potentially amenable to treatment are common in older homeless adults, and are experienced at higher rates than in the general older population
Brown <i>et al.</i> , ⁵¹ 2013	USA	Used multivariable regression models to estimate association of individuals' characteristics with number of 'geriatric syndromes'. Geriatric syndromes included falls, cognitive impairment, frailty, major depression, sensory impairment and urinary incontinence. Data had been collected in in-person interviews and physical examinations	To extend previous work describing prevalence of geriatric syndromes in cohort of 250 homeless people aged ≥ 50 years	As in Brown et al., 71 recruited from eight shelters (six emergency, five transitional, five day centres) in Boston, MA, serving single adults aged \geq 50 years (of 387 eligible, 250 were recruited)	A higher total number of 'geriatric syndromes' was associated with having less than a high school education, medical comorbidities (diabetes mellitus and arthritis), alcohol and drug use problems, and difficulty performing one or more activities of daily living. Average MMSE score of 26; 61% scored < 24 in MMSE, indicating impairment. Overall high number of geriatric syndromes (e.g. falls in past year 53.4%; 41.6% mobility impaired; 49.1% sensory impairment)
Brown <i>et al.</i> , ⁷³ 2017	USA	Interviews with 350 homeless adults aged ≥ 50 years	As only a minimum of homeless adults stay in shelters, the prevalence of geriatric conditions among older homeless people in other environments is unknown; this study aimed to address this gap	Older homeless people in Oakland, CA, were recruited by population-based sampling from unsheltered locations; shelters/ hostels; intermittent stayers with family/friends; and renters who were recently homeless	A total of 25.8% of interviewees had cognitive impairment. Geriatric conditions were common among older homeless adults living in diverse environments, and the prevalence of these conditions was higher than that seen in housed adults who are 20 years older
Buhrich <i>et al.</i> , ⁶⁸ 2000	Australia	204 homeless adults were interviewed and assessed using the MMSE	To assess the prevalence of cognitive impairment among a cohort of homeless men and women in inner Sydney, NSW	A cohort of homeless men and women ($n = 155/n = 49$) were selected randomly from larger hostels in Sydney and assessed	10% of sample showed evidence of cognitive impairment (prevalence of cognitive impairment in general adult population is 1.7%)

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Author(s), year	Country	Methods	Study aims	Study population	Findings/content
Conroy <i>et al.</i> , ⁷² 2013	Australia	Data were collected on physical/ mental health, alcohol use and acquired brain injury. Used MoCA and PRMQ and interviews with 11 key stakeholders	To conduct a pilot study to examine needs of older homeless people with a history of problematic alcohol use and cognitive decline	50 people (aged ≥ 45 years) (39 male) who had been homeless within past 6 months were interviewed. Recruited from a centre and a clinic. Stakeholders were providers and professionals	Prevalence of mild cognitive impairment among the sample was high (i.e. 77%)
Depp <i>et al.</i> , ⁷⁵ 2015	US-based review of international literature	Literature review; items located through PubMed and PsycInfo from 1980 to 2013	To estimate frequency of cognitive impairment among homeless populations	Found 24 studies measuring cognition in homeless adults	Among the 24 studies, there are indications that cognitive impairment is common among homeless adults and may be a 'transdiagnostic' problem. Average prevalence of cognitive impairment was about 5–8 times greater than the rate of cognitive impairment in the US population aged > 70 years (mean age across the samples was 46.1 years). Notes lack of data on women and the 'unsheltered' population
Ennis <i>et al.</i> , ⁶² 2015	Canadian-based review of the international literature	Systematic review using MEDLINE and CINAHL (excluded studies only using MMSE assessment)	To systematically review literature on memory deficits among homeless people to gain better understanding of their nature, causes and prevalence	All age groups studied. Notes that of 11 studies the mean age of participants was 40–75 years (the range 30–58 years = mean)	Identifies 11 studies of memory deficits among people who are homeless and of all adult ages. Across the studies, memory deficits were common among the samples of homeless persons studied. However, conclusions difficult to draw because of variation in measures used to assess
Gilchrist and Morrison, ⁵⁷ 2005	Scotland	Used ACE to assess prevalence of ARBD in hostel-stayers	To assess prevalence of ARBD among homeless people staying in hostels	Survey of 266 homeless people staying in hostels in Glasgow (Scotland). Mean age 53 years (95% CI 51 to 54 years)	82% of sample had cognitive impairment. Prevalence of ARBD was 21%. Hostel-dwellers were aged ≥ 34 years
Joyce and Limbos, ²⁴ 2009	Canada	Cross-sectional study; used MMSE and Geriatric Depression Scale	To describe occurrence of mental health problems and cognitive impairment in a group of older homeless men and how clinical examination and screening in a shelter context might help with their identification	49 homeless men aged ≥ 55 years in a homeless shelter in Toronto, ON	Of the 29 men who were assessed, 37.9% had cognitive impairment

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Author(s), year	Country	Methods	Study aims	Study population	Findings/content
Nishio <i>et al.</i> , ⁷⁶ 2015	Japan	Semistructured interviews conducted by psychiatrists. Wechsler Adult Intelligence Scale used to diagnose intellectual/ cognitive disability	To comprehensively address the prevalence of mental illness and cognitive disability and their overlap in a homeless population in Nagoya (fourth largest city in Japan)	114 homeless people, 84% aged > 50 years (age range 20–78 years; mean 44 years), were assessed in Nagoya. Recruited in co-operation with local support centre that had proposed the study with other voluntary sector providers. An earlier study had reported high prevalence of mental illness, cognitive disability and their overlap but was limited to 18 participants	34.2% of whole sample demonstrated cognitive disability (for half this was likely to be congenital; for the other half this had come later in life); 42% had mental illness. This is much higher than in the general population. Some of the cognitively impaired group did not seem likely to take up support leading to leaving their homeless life. High rates of smoking, drinking alcohol and gambling were noted relative to participants' limited incomes
Rogoz and Burke, ⁵⁰ 2016	Australia	Screening for cognitive impairment with MMSE	To determine prevalence and characteristics of cognitive impairment in older homeless people in inner Sydney	144 men and 27 women aged 45–93 years were screened; those with MMSE scores of ≤ 26 undertook a semistructured interview	78% of sample manifested cognitive impairment
Rota-Bartelink, ²⁵ 2009	Australia	Evidence review in homelessness sector journal mentioning the ongoing Wicking Project in Melbourne, VIC	To explore the influence of cognitive capacity on the efficacy of early intervention and prevention strategies among older homeless people	General homelessness with focus on experience of Melbourne services	General account of significance of cognitive impairment among homeless people, appropriate instruments for assessing it and strategies for supporting people with it
Rota-Bartelink and Lipmann, ⁶⁰ 2010	Australia	Description of intervention (the Wicking Project, a specialist residential care project using a psychosocial model of care) with older people with alcohol-related brain injury and associated complex behaviours	Outlines the aim of the Wicking Project: to provide services with opportunity to develop and trial a specialist service for older homeless men and women aged ≥ 50 years. Sets out service values and operating processes (e.g. rules of the residential care facility)	Descriptive report of the residential model used in the Wicking Project (in Melbourne) and its clientele	Discussion of the synthesis, design and key features of the Wintringham model. Mentions that Wicking trial was completed in 2009

Author(s), year	Country	Methods	Study aims	Study population	Findings/content
Stergiopoulos and Herrmann, ⁷⁷ 2003	International review and survey in Canada	Literature review using MEDLINE, AgeLine and PsycINFO; survey of directors of shelters in Toronto, ON; analysis of shelter-use data for Toronto		Survey of 11 hostel directors (eight responses) seeking information of reasons for clients' shelter use, problem behaviours and mental health needs. Reporting of data and some secondary data analysis of shelter usage completed from 1997 (start of this data collection)	Studies reviewed indicate high prevalence of mood and psychotic disorders and cognitive impairment among older homeless people. Service use data showed that about 2% of Toronto's shelter users are aged ≥ 65 years (= about 450 people annually). Homeless older people are most vulnerable of shelter users. Geriatric psychiatrists should play a more active role with this population
Stergiopoulos <i>et al.</i> , ¹²² 2015	Canada	Assessment of 1500 homeless adults enrolled in the At Home/ Chez Soi study (homeless people with mental illness) who provided neuropsychological, sociodemographic and clinical information. Analysis using linear regression to examine factors associated with neurocognitive performance	To characterise neurocognitive performance of large sample of homeless people with mental illness using a battery of tests and to test hypothesis that psychosis, alcohol abuse/ dependence, history of traumatic brain injury and longer homeless would be associated with greater neurocognitive deficits	Sample recruited from a multisite (five sites across Canada) randomised controlled trial of a Housing First intervention in Canada. Mean age of sample was 41 years (SD 10.9 years). 67.3% were male; 31.8% were female	Overall, 72% of participants demonstrated neurocognitive impairment and 71% experienced problems with verbal learning and 67% with recall; 38% experienced problems with executive functioning
Teesson and Buhrich, ⁶⁶ 1993	Australia	Cognitive assessment of hostel residents, one-quarter of whom were randomly selected and asked to complete the MMSE and a schizophrenia assessment	To establish prevalence of cognitive impairment in a representative sample of residents of a large refuge for homeless men in Sydney	In the sample from the hostel containing 450 beds for male residents, 185 completed the MMSE	Of the sample residents, 28% $(n = 18)$ had severe cognitive impairment (mean age 57 years, SD 10.7 years) and 13% $(n = 10)$ had mild cognitive impairment (mean age 59 years, SD 7.8 years). The mean age of the cognitively impaired group was 55 years

CI, confidence interval; CINAHL, Cumulative Index to Nursing and Allied Health Literature; N/A, not applicable; PRMQ, Prospective and Retrospective Memory Questionnaire; TBI, traumatic brain injury.

Appendix 2 Unit costs used in the costing analysis

TABLE 36 Unit costs used in the costing analysis from *Unit Costs of Health and Social Care 2015*98 and *NHS Reference Costs 2014*–1599

Service	Unit cost (£)	Source	
Visit GP at surgery	44/visit	PSSRU ⁹⁸ section 10.8b, general practitioner – unit costs – £44 per patient contact lasting 11.7 minutes, length of a consultation at surgery	
See GP at hostel	70.75/visit	PSSRU ⁹⁸ sections 10.8a and 10.8b, general practitioner – cost elements a unit costs, respectively – £225 per hour of patient contact for 11.4 minut length of a home visit consultation, plus £140 per hour of General Medic Services activity for 12 minutes, average travel time per home visit	
Speak to GP over telephone	27/call	PSSRU ⁹⁸ section 10.8b, general practitioner – unit costs – £27 per telephone consultation lasting 7.1 minutes	
Visit nurse (non-psychiatric) at surgery	14.50/visit	PSSRU ⁹⁸ section 10.6, nurse (GP practice) – £56 per hour of face-to-face contact lasting 15.5 minutes, duration of surgery consultation	
See nurse (non-psychiatric) at hostel	27.30/visit	$PSSRU^{98}$ section 10.1, community nurse – £67 per hour of patient-related work lasting 15.5 minutes, assumed consultation length, plus £50 per hour lasting 12 minutes, assumed travel time	
Speak to nurse (non-psychiatric) over telephone	7.90/call	PSSRU ⁹⁸ section 10.1, community nurse – £67 per hour of patient-related work lasting 7.1 minutes, assumed consultation length	
See nurse (psychiatric) at hostel	45.50/visit	PSSRU 98 section 10.2, nurse (mental health) – £75 per hour of face-to-face contact lasting 30 minutes, assumed consultation length, plus £40 per hour lasting 12 minutes, assumed travel time	
Use care navigator at GP practice	14.50/use	PSSRU ⁹⁸ section 10.6, nurse (GP practice) – £56 per hour of face-to-face contact lasting a duration of 15.5 minutes	
Use health trainer at GP practice	14.50/use	PSSRU ⁹⁸ section 10.6, nurse (GP practice) – £56 per hour of face-to-face contact lasting a duration of 15.5 minutes	
Visit AHP clinic	19/visit	PSSRU 98 section 13.2, hospital occupational therapist – £38 per hour with an assumed consultation length of 30 minutes	
See AHP at hostel	22/visit	PSSRU ⁹⁸ section 11.5, community occupational therapist (local authority) – £44 per hour lasting an assumed consultation length of 30 minutes	
Use AHP day centre (half-days)	28/half day	PSSRU 98 section 2.4, local authority social services day care for people with mental health problems – £28 per client session lasting 3.5 hours	
Use AHP day centre (full days)	56/day	PSSRU 98 section 2.4, local authority social services day care for people with mental health problems – £28 per client session lasting 3.5 hours, assume a full day lasts 7 hours	
Visit walk-in clinic	85/visit	NHS Reference Costs ⁹⁹ – service code T02NA, currency code VB11Z (emergency medicine, no investigation with no significant treatment). Use national average unit cost of £85	
Visit urgent care centre	85/visit	NHS Reference Costs ⁹⁹ – service code T02NA, currency code VB11Z (emergency medicine, no investigation with no significant treatment). Use national average unit cost of £85	
Visit A&E but not admitted	140.59/visit	NHS Reference Costs ⁹⁹ – total outpatient attendances, service code 180 (A&E). Use 'total' unit cost of £140.69	

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TABLE 36 Unit costs used in the costing analysis from *Unit Costs of Health and Social Care 2015*98 and *NHS Reference Costs 2014–15*99 (continued)

Service	Unit cost (£)	Source
In-hospital stay (non-psychiatric)	NHS Reference stays. If the st dividing the n over the trim	e Costs ⁹⁹ – non-elective (admitted via A&E) and elective (otherwise) long ay was at or below the trim point, a cost per day was applied, calculated by ational average unit cost by the average length of stay (days). If the stay was point, the 'spell cost' (national average unit cost) was used plus an excess for each day beyond the trim point. For specific costs, see <i>Table 38</i>
In-hospital stay (psychiatric)		e Costs ⁹⁹ – mental-health-care clusters – unit cost per occupied bed-day. osts refer to <i>Table 38</i>
Day cases in hospital	704/day case	PSSRU ⁹⁸ section 7.1, NHS reference costs for hospital services – national average of day cases, weighted average of all stays (£704)
Use intermediate care unit (post hospital discharge)	119/day	NHS Reference Costs 99 – service code IC, currency code IC01 (intermediate care, crisis response and early discharge services). Use national average unit cost of £119
Attend outpatient consultation (non-psychiatric)	118/visit	PSSRU ⁹⁸ section 7.1, <i>NHS Reference Costs</i> ⁹⁹ for hospital services – national average of consultant-led outpatient attendances (£118)
Attend outpatient consultation (psychiatric)	118/visit	PSSRU ⁹⁸ section 7.1, <i>NHS Reference Costs</i> ⁹⁹ for hospital services – national average of consultant-led outpatient attendances (£118)
Have outpatient treatment	See <i>Table 37</i>	
Have outpatient test		
Use ambulance	99/use	PSSRU ⁹⁸ section 7.1, <i>NHS Reference Costs</i> ⁹⁹ for hospital services – national average of all ambulance services (£99)
Attend alcohol services	122/visit	PSSRU ⁹⁸ section 2.1, <i>NHS Reference Costs</i> ⁹⁹ for mental health services – mean of alcohol services – community (per care contact) (£122)
Attend alcohol/drug services	123/visit	PSSRU ⁹⁸ section 2.1, <i>NHS Reference Costs</i> ⁹⁹ for mental health services – combination of alcohol (£122) and drug (£124) services
Attend drug services	124/visit	PSSRU ⁹⁸ section 2.1, <i>NHS Reference Costs</i> ⁹⁹ for mental health services – mean of drug services – community (per care contact) (£124)
Use community pharmacist (for supervised opiate substitute)	7.58/visit	PSSRU ⁹⁸ section 10.7, advanced nurse (similar salaries ^b) – £91 per hour of client contact with an assumed visit duration of 5 minutes
Use social worker	39.50/use	PSSRU ⁹⁸ section 11.2, social worker (adult services) – £79 per hour of client-related work lasting 30 minutes, assumed duration
Have carer visit hostel, arranged by social services	12/visit	PSSRU ⁹⁸ section 11.6, home care worker – £24 per hour weekday of face-to-face contact, assuming 30 minutes duration per visit
Visit dentist	51.30/visit	PSSRU ⁹⁸ section 10.12, NHS dental charges – band 2 treatment (£51.30)
Visit chiropodist	40/visit	NHS Reference Costs ⁹⁹ – service code AHP, currency code A09A (Podiatrist, Tier 1, General Podiatry). Use national average unit cost of £40
Visit optician	63.90/visit	NHS Reference Costs ⁹⁹ – total outpatient attendances, service code 130 (ophthalmology). Use non-consultant unit cost of £63.91
Use community mental health services crisis team	189/use	PSSRU 98 section 12.3, crisis resolution team for adults with mental health problems – mean average cost for a crisis resolution team per team contact (£189)
Receive counselling	42/use	PSSRU ⁹⁸ section 12.1, NHS CMHT for older people with mental health problems – £42 per hour per team member where duration of a visit is 60 minutes
Use older people's mental health team	42/use	PSSRU ⁹⁸ section 12.1, NHS CMHT for older people with mental health problems – £42 per hour per team member where duration of a visit is 60 minutes

TABLE 36 Unit costs used in the costing analysis from *Unit Costs of Health and Social Care 2015*98 and *NHS Reference Costs 2014*–1599 (continued)

Service	Unit cost (£)	Source
Use memory service visiting at hostel	42/use	PSSRU ⁹⁸ section 12.1, NHS CMHT for older people with mental health problems – £42 per hour per team member where duration of a visit is 60 minutes
Phone out-of-hours call handler	7/call	PSSRU ⁹⁸ section 7.1, <i>NHS Reference Costs</i> ⁹⁹ for hospital services – national average of calls within ambulance services (£7)
Phone NHS 111	7/call	PSSRU ⁹⁸ section 7.1, <i>NHS Reference Costs</i> ⁹⁹ for hospital services – national average of calls within ambulance services (£7)
Have voluntary helper as advocate for health appointments	20/use	$PSSRU^{98}$ section 10.5, clinical support worker nursing (community) – £20 per hour with an assumed duration of 60 minutes

AHP, allied health professional; HRG, Healthcare Resource Group; PSSRU, Personal Social Services Research Unit.

Sources: Unit Costs of Health and Social Care 201598 and NHS Reference Costs 2014–15.99

TABLE 37 Unit costs of outpatient treatment/test

Outpatient treatment/test	Unit cost (£)	Directory	Description
Treatment			
Diabetes mellitus prevention group	111.19	Total Outpatient Attendances – Service code 307	Diabetic medicine – non-consultant
Dysport® (Galderma Laboratories) injections, Botulinum toxin clinic	133.98	Total Outpatient Attendances – Service code 400	Neurology – non-consultant
Laser treatment to hair on face	78.94	Total Outpatient Attendances – Service code 160	Plastic surgery – non-consultant
Cast fitted to fractured leg	92.47	Total Outpatient Attendances – Service code 110	Trauma and orthopaedics – non-consultant
Cardiac rehabilitation	60.68	Total Outpatient Attendances – Service code 327	Cardiac rehabilitation – non-consultant nt
Cardiac dietary advice	93.05	Total Outpatient Attendances – Service code 327	Cardiac rehabilitation – consultant led
Cardiac exercise programme	60.68	Total Outpatient Attendances – Service code 327	Cardiac rehabilitation – non-consultant
Fitted leg brace	92.47	Total Outpatient Attendances – Service code 110	Trauma and orthopaedics – non-consultant
Fitting of shoes, orthotics	129.57	Total Outpatient Attendances – Service code 658	Orthotics – consultant led
Collecting shoes from orthotics	112.04	Total Outpatient Attendances – Service code 658	Orthotics – non-consultant
			continued

a Trim points obtained from HRG4+ 2014/15 Reference Costs Grouper – HRG4+ Trimpoints – Health and Social Care Information Centre. 123

b Advanced nurse salary: £38,332. Community pharmacist salary: PayScale¹²⁴ gives a median of £34,791 and Net Salary Calculator¹²⁵ gives an average of £37,645.

TABLE 37 Unit costs of outpatient treatment/test (continued)

	Heit				
Outpatient treatment/test	Unit cost (£)	Directory	Description		
Test					
Abdominal aortic screening (ultrasound)	55	Diagnostic Imaging – Department code IMAGOP – Currency Code RD40Z	Ultrasound scan with duration of < 20 minutes, without contrast (duration and contrast assumed) – national average		
Blood test	3.46	Total Other Currencies – Currency code DAPS08	Phlebotomy – 'total' unit cost		
Chest X-ray	17	Non Consultant Led – Currency code WF01D	Service code 811 – interventional radiology – national average unit cost		
CT scan	93	Diagnostic Imaging – Department code IMAGOP – Currency Code RD20A	CT scan of one area, without contrast, ≥ 19 years (contrast assumed) – national average		
MRI scan	137	Diagnostic Imaging – Department code IMAGOP – Currency code RD01A	MRI scan of one area, without contrast, ≥ 19 years (contrast assumed) – national average		
Bronchoscopy	98	Outpatient Procedures – Service code 120 – Currency code DZ69A	Diagnostic bronchoscopy, ≥ 19 years – national average		
Retinopathy screening	117	Outpatient Procedures – Service code 130 – Currency code BZ89A	Digital retinal photography, ≥ 19 years – national average		
Abdomen ultrasound	60	Diagnostic Imaging – Department code IMAGOP – Currency code RD42Z	Ultrasound scan with duration of ≥ 20 minutes, without contrast (duration and contrast assumed) – national average		
Bladder ultrasound	55	Diagnostic Imaging – Department code IMAGOP – Currency Code RD40Z	Ultrasound scan with duration of < 20 minutes, without contrast (duration and contrast assumed) – national average		
Testicle ultrasound	55	Diagnostic Imaging – Department code IMAGOP – Currency Code RD40Z	Ultrasound Scan with duration of < 20 minutes, without contrast (duration and contrast assumed) – national average		
Eye slit lamp screening	88.56	Total Outpatient Attendances – Service code 662	Service description optometry – 'total' unit cost		
Flexible cystoscopy	167	Outpatient Procedures – Service code 100 – Currency code LB72A	Diagnostic flexible cystoscopy, ≥ 19 years – national average		
OCT of maculae (eye)	35ª				
Leg ultrasound to check for DVT	61	Diagnostic Imaging – Department code IMAGOP – Currency code RD43Z	Ultrasound scan with duration of ≥ 20 minutes, with contrast (duration and contrast assumed) – national average		
Endoscopy	223	Outpatient Procedures – Service code 100 – Currency code FZ42A	Wireless capsule endoscopy, \geq 19 years – national average		
Breast ultrasound (gynaecomastia)	60	Diagnostic Imaging – Department code IMAGOP – Currency code RD42Z	Ultrasound scan with duration of ≥ 20 minutes, without contrast (duration and contrast assumed) – national average		
X-ray of hip and knee	17	Non Consultant Led – Currency code WF01D	Service code 811 – interventional radiology – national average unit cost		
Mammogram	33.98	Total HRG – Currency code WH15Z	Special screening, examinations or other genetic disorders – 'total' unit cost		

CT, computerised tomography; DVT, deep-vein thrombosis; HRG, Healthcare Resource Group; MRI, magnetic resonance imaging; OCT, optical coherence tomography.

a Source is C4 SightCare. 126

Source: NHS Reference Costs 2014–15.99

TABLE 38 Unit costs of elective and non-elective long stays and mental health care clusters

In-hospital stay	Further description	Currency description (code)	Cost per day (spell) (£) ^a
Non-elective			
Epigastric bleeding	Following recent alcohol binge	Gastrointestinal bleed without interventions – average of all CC scores (FZ38M-FZ38P)	406.94
COPD exacerbation		COPD of bronchitis, without Interventions – average of all CC scores (DZ65F-DZ65J)	373.83
Admitted to HDU	Participant shouting at receptionist, police involved	Admission related to social factors without interventions – average of all CC scores (WH17B-WH17C)	430.43
Transient ischaemic attack		Transient ischaemic attack – average of all CC scores (AA29C-AA29F)	434.35
Thrombus	Acute cholecystitis	Deep-vein thrombosis – average of all CC scores (YQ51A-YQ51E)	253.91 (2763)
Seizure	From alcohol withdrawal	Muscular, balance, cranial or peripheral nerve disorders, epilepsy or head injury, with CC score 0–2 (AA26H)	441.33
COPD exacerbation and congestive cardiac failure		COPD or bronchitis, without Interventions – average of all CC scores (DZ65F–DZ65J)/heart failure or shock– average of all CC scores (EB03A–EB03E) (average taken of both)	388.49
Scabies and cellulitis		Skin disorders without Interventions – average of all CC scores (JD07E-JD07K)	382.31
Elective			
Respiratory unit	Respiratory failure	Respiratory failure without interventions – average of all CC scores (DZ27S-DZ27U)	634.15
Fractured leg/ankle	Problem related to the fracture	Foot fracture without interventions – average of all CC scores (HE31D-HE31G)	371.93
Psychiatric			
Psychiatric hospital		Cluster 03: non-psychotic (moderate severity) (MHCC03)	345

COPD, chronic obstructive pulmonary disease; HDU, high-dependency unit.

Source: NHS Reference Costs 2014–15 – Elective and Non-Elective Long Stays and Mental Health Care Clusters.99

a The cost per day values are inlier costs unless a spell cost is given, in which case the cost per day value is an excess bed-day cost.

Appendix 3 Frequency of use of services over a 6-month period

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Memory service visiting at hostel

46 (97.9)

1 (2.1)

0 (0.0)

0(0.0)

0.0)

0.0)

0.0)

0 (0.0)

		Number o	of times, n (%)						
Service group	Number of	0	1	2–4	5–10	11–25	26–75	76–150	≥ 151	Notes ^a
Alcohol and drugs	Bookings made for alcohol services	35 (74.5)	4 (8.5)	4 (8.5)	1 (2.1)	1 (2.1)	2 (4.3)	0 (0.0)	0 (0.0)	1.0% were DNAs
	Bookings made for alcohol/drug services	43 (91.5)	2 (4.3)	0 (0.0)	1 (2.1)	1 (2.1)	0 (0.0)	0 (0.0)	0 (0.0)	10.5% were DNAs
	Contacts with drug services	45 (95.7)	0 (0.0)	0 (0.0)	0 (0.0)	1 (2.1)	1 (2.1)	0 (0.0)	0 (0.0)	
	Community pharmacist (opiate substitute)	45 (95.7)	0 (0.0)	0 (0.0)	0 (0.0)	0 (0.0)	0 (0.0)	1 (2.1)	1 (2.1)	
Social care	Appointments made with AHP at clinic	41 (87.2)	4 (8.5)	2 (4.3)	0 (0.0)	0 (0.0)	0 (0.0)	0 (0.0)	0 (0.0)	44.4% were DNAs
	Contacts with AHP at hostel	44 (93.6)	2 (4.3)	1 (2.1)	0 (0.0)	0 (0.0)	0 (0.0)	0 (0.0)	0 (0.0)	
	Social worker/care manager	39 (83.0)	4 (8.5)	3 (6.4)	1 (2.1)	0 (0.0)	0 (0.0)	0 (0.0)	0 (0.0)	
	Social service carer visiting at hostel (hours)	30 (63.8)	0 (0.0)	0 (0.0)	0 (0.0)	1 (2.1)	7 (14.9)	4 (8.5)	5 (10.6)	
	Half day at AHP centre	46 (97.9)	0 (0.0)	1 (2.1)	0 (0.0)	0 (0.0)	0 (0.0)	0 (0.0)	0 (0.0)	
	Full day at AHP centre	42 (89.4)	1 (2.1)	0 (0.0)	0 (0.0)	1 (2.1)	2 (4.3)	1 (2.1)	0 (0.0)	
Emergency and out of	Walk-in clinic visit	43 (91.5)	4 (8.5)	0 (0.0)	0 (0.0)	0 (0.0)	0 (0.0)	0 (0.0)	0 (0.0)	
hours	Urgent care centre visit	46 (97.9)	1 (2.1)	0 (0.0)	0 (0.0)	0 (0.0)	0 (0.0)	0 (0.0)	0 (0.0)	
	A&E but not admitted	35 (74.5)	6 (12.8)	5 (10.6)	1 (2.1)	0 (0.0)	0 (0.0)	0 (0.0)	0 (0.0)	
	Ambulance trips	30 (63.8)	7 (14.9)	7 (14.9)	3 (6.4)	0 (0.0)	0 (0.0)	0 (0.0)	0 (0.0)	
	Out-of-hours call handler	41 (87.2)	5 (10.6)	1 (2.1)	0 (0.0)	0 (0.0)	0 (0.0)	0 (0.0)	0 (0.0)	
	NHS 111 service	41 (87.2)	5 (10.6)	1 (2.1)	0 (0.0)	0 (0.0)	0 (0.0)	0 (0.0)	0 (0.0)	
Hospital outpatient	Non-psychiatric OP consultations made	25 (53.2)	7 (14.9)	11 (23.4)	3 (6.4)	1 (2.1)	0 (0.0)	0 (0.0)	0 (0.0)	27.1% were DNAs
	Attendances to psychiatric OP consultation	42 (89.4)	4 (8.5)	1 (2.1)	0 (0.0)	0 (0.0)	0 (0.0)	0 (0.0)	0 (0.0)	
	OP treatment	40 (85.1)	2 (4.3)	4 (8.5)	1 (2.1)	0 (0.0)	0 (0.0)	0 (0.0)	0 (0.0)	
	OP test appointments made	31 (66.0)	6 (12.8)	9 (19.2)	1 (2.1)	0 (0.0)	0 (0.0)	0 (0.0)	0 (0.0)	15.8% were DNAs

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AHP, allied health professional; OP, outpatient.

a The percentage of *all* appointments/visits made that ended up being DNA – 'accompany' refers to non-psychiatric nurses accompanying patients to hospital and 'elsewhere' refers to when a participant went to counselling outside the hostel.

Appendix 4 Associations between service use costs and cognitive impairment grouping

		Cost (£) of s	ervices per	participant in	months 1–6		Kruskal–\	Wallis test	Mann–Whitney	<i>U</i> -test
Service	Cognitive impairment group	Quartile 1	Median	Quartile 3	n (%) zeroª	Mean	<i>p</i> -value	Ranking ^b	None vs. (borderline and present)	(None and borderline) vs. present
GP services	None	79.50	212.25	330.88	2 (11.8)	225.10	0.191	N/A	0.071	0.139
	Borderline	132	212.50	912.75	0 (0)	397.96				
	Present	132	331	610	1 (4.3)	375.47				
Other GP staff contacts	None	7.25	54.60	85.85	4 (23.5)	153.28	0.012 ^c	None	0.006	0.212
	Borderline	0	0	27.30	5 (71.4)	7.80		> borderline, present ^c	None	
	Present	0	14.50	29	10 (43.5)	21.25			> borderline and present ^c	
Other primary (chiropodist,	None	0	63.90	163.90	5 (29.4)	107.10	0.888	N/A	0.875	0.845
dentist, optician)	Borderline	0	40	120	2 (28.6)	86.64				
	Present	0	80	183.90	8 (34.8)	95.32				
Psychiatric/mental health	None	0	0	0	14 (82.4)	30.88	0.650	N/A	0.355	0.462
services	Borderline	0	0	126	5 (71.4)	51				
	Present	0	0	42	16 (69.6)	77.30				
Alcohol and drugs services	None	0	0	612.50	9 (52.9)	443.33	0.406	N/A	0.249	0.189
	Borderline	0	0	244	4 (57.1)	662.43				
	Present	0	0	122	16 (69.6)	375.24				
Social care services	None	0	0	1120.50	10 (58.8)	912.15	0.706	N/A	0.423	0.455
	Borderline	0	22	1086	3 (42.9)	528.50				
	Present	0	331	1131.50	10 (43.5)	750.59				
Emergency and out-of-hours	None	0	0	106	12 (70.6)	59.75	0.158	N/A	0.059	0.101
services	Borderline	0	0	732.77	4 (57.1)	290.96				
	Present	0	99	345.59	9 (39.1)	226.12				

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		Cost (£) of s	ervices per	participant in	months 1–6		Kruskal–\	Wallis test	Mann–Whitney	<i>U</i> -test
Service	Cognitive impairment group	Quartile 1	Median	Quartile 3	n (%) zeroª	Mean	<i>p</i> -value	Ranking ^b	None vs. (borderline and present)	(None and borderline) vs. present
Hospital outpatient services	None	0	67.96	301.92	8 (47.1)	257.35	0.286	N/A	0.215	0.803
	Borderline	55	472	690.94	1 (14.3)	431.08				
	Present	0	118	510	6 (26.1)	261.04				
Hospital inpatient services	None	0	0	0	15 (88.2)	194.71	0.174	N/A	0.342	0.698
	Borderline	0	0	9951.38	4 (57.1)	3058.12				
	Present	0	0	0	19 (82.6)	434.18				
All services	None	485.53	1173.75	3923.67	0 (0)	2389.54	0.312	N/A	0.288	0.966
	Borderline	905.80	2907.86	12,231.90	0 (0)	5520.21				
	Present	831.30	1546.05	4321.92	0 (0)	2633.90				
All psychiatric services ^d	None	0	0	63	13 (76.5)	58.65	0.683	N/A	0.414	0.418
	Borderline	0	0	126	5 (71.4)	396				
	Present	0	0	118	14 (60.9)	97.83				

N/A, not applicable.

a n (%) of participants who did not use the service at all over 6 months.

- b Mann–Whitney *U*-tests compared the mean ranks of each group (carried out in pairs), if Kruskal–Wallis *p*-value was < 0.05.
- c 'Other GP' grouping (see Appendix 3).
- d All psychiatric services: sum of all contacts with psychiatric/mental health services, psychiatric hospital outpatient consultations and psychiatric hospital inpatient stays. Cognitive impairment groups: none, n = 17; borderline, n = 7; present, n = 23.

Appendix 5 Characteristics of 47 participants in the economic analysis and associations (*p*-values) between them

			Characteristic (p-va	alue ^a)										
Characteristic	Mean	SD	Age when first interviewed	Number of comorbidities	Total number of head injuries	Number of different medications	Sex	Ethnicity	Literacy problems	Illegal drug use	Memory problems: yes/ (borderline and no)	Memory problems: (yes and borderline)/no	Location	How often participant drinks alcohol
Age when first interviewed (years)	59.3	7.77		0.904	0.083	0.841	0.242	0.159	0.212	0.732	0.495	0.218	0.714	0.879
Number of comorbidities	5.28	2.36	0.904		0.099	< 0.0005 ^b	0.88	0.07	0.865	0.173	0.129	0.937	0.782	1
Total number of head injuries	1.4	1.75	0.083	0.099		0.015 ^b	0.167	0.075	0.169	0.024 ^b	0.629	0.406	0.054	0.238
Number of different medications	7.4	4.74	0.841	< 0.0005 ^b	0.051 ^b		0.287	0.144	0.684	0.963	0.74	0.349	0.186	0.073
Sex, male (vs. female)	42	89.4	0.242	0.88	0.167	0.287		1 ^c	1°	0.648 ^c	0.348 ^c	0.051 ^c	1 ^c	1 ^c
Ethnicity: white British (vs. other)	37	78.7	0.159	0.07	0.075	0.144	1 ^c		0.068 ^c	0.704 ^c	1 ^c	0.46 ^c	0.019 ^{b,c}	0.496 ^c
Literacy problems: yes (vs. no)	16	34.0	0.212	0.865	0.169	0.684	1 ^c	0.068 ^c		0.211	0.051	0.074	0.164	0.769
Illegal drug use in last 3 months: yes (vs. no)	15	31.9	0.732	0.173	0.024 ^b	0.963	0.648 ^c	0.704 ^c	0.211		0.831	0.305	0.742 ^c	0.968
Memory problems: yes (vs. borderline and no)	23	48.9	0.495	0.129	0.629	0.74	0.348 ^c	1°	0.051	0.831		<0.0005 ^b	0.831	0.859
Memory problems: no (vs. borderline and yes)	17	36.2	0.218	0.937	0.406	0.349	0.051 ^c	0.46 ^c	0.074	0.305	<0.0005 ^b		0.708	0.485
Location: North (vs. South/London)	15	31.9	0.714	0.782	0.054	0.186	1°	0.019 ^{b,c}	0.164	0.742 ^c	0.831	0.708		0.012 ^b
How often participant drinks alcohol: < 6 (vs. 6 or 7) times a week	19	40.4	0.879	1	0.238	0.073	1 ^c	0.496 ^c	0.769	0.968	0.859	0.485	0.012 ^b	

a Tests: Spearman's rank-order correlations between pairs of continuous variables, Mann–Whitney *U*-tests between continuous and categorical variables and chi-squared tests between pairs of categorical variables.
b 'Other GP' grouping (see *Appendix 3*).
c Fisher's exact test was used instead of the Pearson chi-squared test as there were ≥ 1 cells with an expected count of < 5 cells.

Appendix 6 Hostel resident baseline interview



NIHR HS&DR funded study

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

Hostel residents: baseline interview

VERSION 2 - 02.06.2014

To be completed by the interviewer with hostel residents

Maureen Crane, Louise Joly, Kritika Samsi and Jill Manthorpe, Social Care Workforce Research Unit, King's College London, Strand, London WC2R 2LS.

Participant ID number Participant name	
Date of interview: Interviewer's name	
Where interviewed (name of hostel)	
I'd like to start by collecting a few background details from you	
1 Sex: Male Female	
2 What is your date of birth?	
Day Year	
3 Where were you born?	
4 Where did you grow up?	
Which ethnic group or race do you identify with? SHOW CARD A	
DK	
6 Are you currently in paid work? Yes \square No \square	
IF YES, b. What are you doing and how many hours per week?	
IF NO, c. How old were you when you last worked?	
d. Are you now retired? Yes \square No \square DK \square	
7 Since you left school, have you been Mostly employed In and out of work Mostly unemployed DK	
Other	

Type of job?	How long?
Do you have difficulties reading or writing or other Yes No Don't know	r literacy problems?
IF YES, b. What are the problems?	
c. What educational and vocational qualifications, if	any, do you have?
Ask about each and tick all that apply	
GCE/GCSE 'A' Level Degree NV	Q/City and Guilds None
HOMELESSNESS HISTORY	
I'd now like to ask a few questions about your stay in this hostel.	your time homeless. Let's start
When did you move into this hostel?	DK 🗆
IF DON'T KNOW, TRY: How long have you liv	ved in this hostel?
IF IN HOSTEL LESS THAN TWO YEARS,	
b. Please tell me where else you have lived in the (Work backwards and include hostels, the street)	•
Where stayed, e.g. name of hostel, streets, own tenancy	For how long?
Immediately before moving into current hostel 1.	
2.	
How old were you when you first became homeles temporary accommodation?	s and slept on the streets or in hostels or
Since you become hemaless, where hove you cleat	or stayed, and for how long?
Since you became homeless, where have you slept	of stayed, and for now long.

USE OF TIME

I'd	like to ask you a few questions al	bout how :	you spend you	ar tim	e
13	On an average day, how do you spen	nd your time	?		
14	Do you go to any day centres or drop-	in centres?	Yes No		IF YES:
	Which centre or project? (n	name)	How often do	you go	?
15	Are you doing any courses, work-train IF YES, b. What are you doing and h		ntary work? Yes	s 🗌	No 🗌
16	Are you in contact with any family or	relatives?	Yes No L		
	IF YES, b. Please tell me about you	r contact wi	th family and rel	latives	
	Who in contact with (relationship to participant)		often sees erson	О	ther contact and frequency
	1.				
	2.				
	3.				

EVERYDAY TASKS AND SUPPORT

I'd now like to ask you a few questions about how you are managing everyday tasks such as meals, laundry and budgeting, and any support you are getting.

17	In an average week, how many days a week do you have	e a cooked meal?				
	Number of days DK					
	In an average week, how many days do you (ask	about each)				
	b. Have a meal provided by the hostel					
	c. Have take-away food					
	d. Cook a meal yourself					
	g. Where else do you get meals and how often?					
18	During the last <u>two weeks</u> , have you had any loss of app	oetite or been eating	more than usual?			
	Yes No DK					
19	What income do you receive? (earnings, types of pen.	sions, names of ben	efits)			
			,			
	Type of income	Amount	Frequency			
	Type of income 1.	Amount	· ·			
		Amount	· ·			
	<u>1.</u>	Amount	· ·			
20	1. 2.		Frequency			
20	1. 2. 3. Do you have a 'keyworker' among the hostel staff who		Frequency om time to time?			
20	1. 2. 3. Do you have a 'keyworker' among the hostel staff who	o meets with you frowker	Frequency om time to time?			
20	1. 2. 3. Do you have a 'keyworker' among the hostel staff who Yes \(\sqrt{N} \) No \(\sqrt{N} \) DK \(\sqrt{N} \) Name of keyworker	o meets with you frowker	Frequency om time to time?			

21 Please tell me about any help you receive from hostel staff, other workers, relatives or friends with \dots

Help with	Who helps you	What help do they give you?	How often?
Bathing/showering			
Getting meals			
Washing your clothes			
Cleaning your room/changing sheets			
Budgeting/managing money			
Collecting/managing medication			

HEALTH PROBLEMS

I'd now like to ask you about your health and any treatment that you are receiving

22	How would your r	ate your gene	rai neaitn?	SHOW CA	KD B	
	Very good	Good	Fair \square	Bad \square	Verv bad 🗌	DK 🗌

23	Do you smoke cigarettes or	r tobacco?	Yes	□ No □
	IF YES, b. On average	how many	do you	smoke a day?
	Cigarettes	Roll-u	ps	E-cigarettes
24	Do you have any physical	l health pro		NO OR DK, GO TO Q.25
	IF YES, b. What are the	e problems?		
	LIST WHAT PARTICI	IPANT SA	YS AI	ND THEN GO THROUGH CARD C
c.	Are you receiving any h	nelp or tre	atmen	t for your physical health problems?
	PROBE: GP, nurse, hospita	al, physioth	erapy	Yes No
	IF YES, b. Who is helpi	ing you and	what l	nelp are they giving you?
	Help from?			What help is being given
	GP	Yes	No	
	Hospital doctor	Yes	No	
	Nurse	Yes	No	
	Other (specify)	Yes	No	

25	Н	ave you ever had a head injur	y? (PROMPT: as	s a result o	f boxing	; assault;	fight
	rc	oad traffic accident; fall) Y	es □ No □	DK [
		IF YES, b. Please tell me wha	t happened and w	hen			
		What happened?	When?	What treatm	ent did yo	u have?	
	-						
	Ot	ther comments made about head in	juries				
'd		w like to ask you a few question	ons about how yo	u've been	feeling o	over	
		e last two weeks.					
26	In	the past <u>TWO WEEKS</u> , have you.	•••	Yes	No	DK	
	a.	Felt sad, low in spirits or tearful?					
	b.	Been able to enjoy things that you	ı would usually enjo	y? 🗌			
	c.	Felt low in energy or motivation?					
	d.	Had any problems getting to sleep	or sleeping too mu	ch?			
	e.	Had any thoughts that life is not v	vorth living?				
	f.	Felt negative about the future?					
	g.	Had feelings of guilt?					
	h.	Had any difficulty concentrating?					

27	Have you ever had depression, a	inxiety or oth	er mental nealth problems?
	Yes No DK] IF	NO OR DK, GO TO Q. 30
	IF YES, b. How old were you	when the pro	blems started? DK
	c. Please tell me more about	the problems	
28	Are you currently experiencing	depression, a	nxiety or other mental health problems?
	Yes No DK		
	IF YES, CONTINUE IF	NO OR DK	GO TO Q. 30
	b. Please describe the problem	ms	
29		-	from services for your mental health st, mental health team, psychologist, counsellor
	Yes No No	Unsure	
	IF YES, b. Who is helping y	ou and what	help are they giving you?
	Help from?		What help is being given
	GP	Yes No	
	Psychiatrist	Yes No	
	CPN	Yes No	
	Hostel staff	Yes No	
	Other (specify)	Yes No	

ALL PARTICIPANTS

30	• •	mory changes with age. Do you have any difficulties
	or concerns about your memory?	
	Yes No DK	
	IF YES CONTINUE IF NO	OR DK GO TO Q. 33
	b. What are the difficulties or	concerns?
	c. How long have you noticed	difficulties or been concerned?
31	How do your memory difficulties or	concerns affect your everyday life?
32	Are you receiving any help or suppor PROMPT: hostel staff; GP; mental h	
	Yes No DK	IF NO, GO TO Q. 32c
	IF YES, b. Who is helping you ar	nd what help are they giving you?
	THEN GO TO Q. 33	
	Type of worker/service	What help are you receiving?
	IF NOT RECEIVING HELP FO	R MEMORY DIFFICULTIES, ASK:
	c. Have you spoken to a doctor concerns?	r or anyone about your memory difficulties or
	Yes No DK	
	IF YES d. Who did you speak to	o and what did they say?
	OR IF NO e. Why not?	
	ALL PARTICIPANTS	

ALL PARTICIPANTS

I'd like to ask you a few questions about your memory and concentration. Interviewer: write down the answers given 33 What year is it? What month is it? I'm going to give you a name and address. After I have said it, I want you to repeat it. Remember this name and address because I'm going to ask you to tell it to me again in a few minutes: John / Smith / 42 / High Street / Bedford. Without looking at your watch or a clock, what time is it? (Interviewer: Write down the actual time?) Could you please count backwards from 20 to 1 36 Could you please say the months of the year in reverse order? 37 38 Could you please repeat the name and address I gave to you earlier **ALCOHOL AND DRUGS** I'd now like to ask you a few questions about your drinking habits and whether you take drugs 39 Have you ever been a heavy drinker or had alcohol problems? Yes No 🔲 DK 🔲 **IF YES,** b. How old were you when you started drinking heavily? c. How has your drinking affected you?

40	How often do you drink alcohol nowadays?
	CODE AS: Never Monthly or less 2-4 times a month
	2-3 times a week \square 4-5 times a week \square 6-7 times a week \square DK \square
	Other pattern
	IF HAS A DRINK: b. What do you drink on a typical day when you are drinking?
	Type of drink (note whether normal or super strength beer or lager) How many drinks
	c. How often do you have <u>six or more</u> drinks on one occasion?
	CODE AS: Never Monthly or less 2-4 times a month
	2-3 times a week \square 4-5 times a week \square 6-7 times a week \square DK \square
41	What changes, if any, have there been in your drinking habits in recent years?
12	Have you ever felt you needed to cut down on your drinking? Yes \square No \square DK \square
43	Have people annoyed you by criticising your drinking? Yes \(\sum \) No \(\sum \) DK \(\sum \)
14	Have you ever felt guilty about drinking? Yes No DK
45	Have you ever felt you needed a drink first thing in the morning to steady your nerves or to get rid of a hangover? Yes \square No \square DK \square
46	Did either of your parents drink heavily?
	Mother
	Other comments
	IF ALCOHOL PROBLEMS/DRINKS 4+ TIMES A WEEK continue IF NOT, GO

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TO Q. 48

ROMPT: from hostel staff; alcoho			
Help from?			What help is being given
Hostel staff	Yes	No	
Alcohol worker/services	Yes	No	
GP	Yes	No	
Other (specify)	Yes	No	
		IF N	CARD D IO OR DK, GO TO Q. 51 st started taking drugs?

Type of drug			Frequency
IF NOT TAKEN DRUGS	IN LAST 3 MO	ITHS,	
b. When did you last take dru	ıgs?		
c. What drugs did you use to	take?		
IF DRUG PROBLEMS/TA	AKING DRUGS	continue IF N	NOT, GO TO Q. 5
re vou receiving any heln or	support to control	ır reduce vour dru	σ-taking?
			_
are you receiving any help or ROMPT: from hostel staff; dru	ıgs worker; GP; Nar		_
	ıgs worker; GP; Nar		_
ROMPT: from hostel staff; dru	ugs worker; GP; Nar	cotics Anonymous; c	_
PROMPT: from hostel staff; dru	ugs worker; GP; Nar	cotics Anonymous; o	_
ROMPT: from hostel staff; dru Yes No DK IF YES, b. Who is helping	ugs worker; GP; Nar	cotics Anonymous; o	other
ROMPT: from hostel staff; dru Yes No DK IF YES, b. Who is helping Help from?	you and what help	cotics Anonymous; o	other
ROMPT: from hostel staff; dru Yes No DK IF YES, b. Who is helping Help from? Hostel staff	you and what help Yes No	cotics Anonymous; o	other
ROMPT: from hostel staff; dru Yes No DK IF YES, b. Who is helping Help from?	you and what help	cotics Anonymous; o	other
ROMPT: from hostel staff; dru Yes No DK IF YES, b. Who is helping Help from? Hostel staff	you and what help Yes No	cotics Anonymous; o	other

SERVICES USED

	I'd now like to ask a few questions about health services that you've used over the last three months
51	Are you registered with a GP? Yes No DK
	IF YES, b. Where is the GP practice? (name of GP and address)
	c. How many times in the <u>last three months</u> have you seen a GP from the practice?
	IF NOT REGISTERED WITH GP OR NOT SEEN GP IN LAST THREE MONTHS, ask:
52	When were you last seen by a doctor (GP or other doctor)?
	ALL PARTICIPANTS
53	Are you registered with a dentist? Yes \(\square\) No \(\square\) DK \(\square\)
	IF YES, b. Where is the dental practice? (address)
54	When were you la st seen by a dentist?
55	During the <u>last three months</u> , have you used a walk-in health centre (not GP surgery)?
	Yes \square No \square DK \square
	IF YES, b. How many times?
	c. Why did you go there?
56	During the <u>last three months</u> , have you used an A&E department at a hospital?
	Yes
	IF YES, b. How many times?
	c. Why did you go there?

	EACH ADMISSION OR		T
Where stayed ¹	Reason for admission	Date admitted/ discharged or approx. time	Length of stay (number of nights)
·	cord whether medical, surgitablets or medication? Yes		neral ward.
PROBE: by GP or	mental health services; mer r-the-counter medicines, e.	thadone or similar fro	m drugs service;
What are you taki	ing? (name if known)	Dosage and	d frequency
ER SERVICES			
	worker? Yes 🗌 1	No 🗆 DK 🗀	
Do you have a social	worker? Yes \(\sime\) 1 Id you last see your social		
Do you have a social of		worker?	
Do you have a social of FYES, b. When one. What help or suppose	did you last see your social	worker? ng you?	upport from any otl
Do you have a social of the people you have a social of the pe	did you last see your social ort is the social worker givi	worker? ng you?	upport from any otl
Do you have a social of the property of the people you workers or services?	did you last see your social ort is the social worker givi	worker? ng you? ou receiving help or s	upport from any otl
Do you have a social of the people you workers or services? FYES, b. What help	did you last see your social ort is the social worker giving or already mentioned, are your social worker giving the soci	worker? ng you? ou receiving help or s DK	upport from any otl
c. What help or supposes the people you workers or services? IF YES, b. What help is there any help or ser	did you last see your social ort is the social worker giving or already mentioned, are your support and who from?	worker? ng you? ou receiving help or s DK	upport from any otl

HOPES AND PLANS

I'd lastly like to ask you about your hopes and plans

52	What things give quality to your life – that is, makes your life good?
63	What things, if any, would improve the quality of your life?
54	Overall, how would you describe your quality of life? SHOW CARD E
	Very good Good Neither poor nor good Poor
	Very poor DK
65	Are there any plans for you to move on from this hostel?
	Yes No DK D
	IF YES b. What plans?
66	What [other] plans or hopes do you have for the next few months?
57	Are there any other comments you'd like to make?

Thank you for answering the questions. You have been very patient and helpful. In about three months' time we will get in touch to let you know whether we would like you to take part further in the study. Only a few people in each hostel will be invited to take part. Go through the Contact Details Sheet and give incentive payment

Interviewer: add any additional information provided by the participant

Appendix 7 Hostel resident case study interview at 3 and 6 months



NIHR HS&DR funded study

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

Hostel residents: case study interview

VERSION 1 - 12.02.2014

To be completed on paper by the interviewer with hostel residents at three and six months

Maureen Crane, Louise Joly, Kritika Samsi and Jill Manthorpe, Social Care Workforce Research Unit, King's College London, Strand, London WC2R 2LS.

Participant ID number Pa	articipant initials	
Date of interview:	Into	erviewer's name
Where interviewed (name of hoste	el)	
last saw you, and any help yo	ou have had from nd you that you	you have been getting on since we the hostel staff or from other can refuse to answer any question or ng you'd like to ask me?
1 We last saw you three months ago	. How have you be	een getting on since then?
USE OF TIME		
I'd like to ask you a few quest	ions about how y	ou spend your time
2 During the day, what proportion of to 0-25% 26-50% 51		
3 What do you do while in the hostel? (Probe: stay in room; use TV loung		her residents; hostel activities)
4 During the <u>last three months</u> , have yo luncheon clubs or similar?	, ,	entres, drop-in centres at churches,
Yes No IF Y	E2:	
Name of centre or project	How often?	What do you do there?

5	During the last three months, have you had contact with any family or relatives?		
	Yes No IF YES, C	ONTINUE IF NO,	GO TO Q. 7
	Who with? (relationship to participant)	How often seen person	Other contact and frequency
	1.		
ó	6 What help and support, if any, have you	u had from your family a	and relatives?
7	7 During the last <u>three months</u> , have you	had contact with people	you regard as friends or mates?
	Yes No IF NO, GO 1	го Q. 8	
	IF YES, b. What do you do together	?	
	c. What help and support, if any, hav	ve you had from your fri	ends or mates?
3	B During the <u>last three months</u> , have you w	worked or done any cou	rses, training or voluntary work?
	Yes No No		
	IF YES, b. What have you done and	how often?	
	c. In what ways, if any, have you bene	fited from this?	
)	How else do you spend your time?		

CONTACT WITH HOSTEL STAFF

I'd now like to ask you a few questions about whether you meet with hostel staff to discuss your problems and any support that you need

10	Do you have a 'keyworker' among the hostel staff who meets with you from time to time?
	Yes \square No \square IF NO, GO TO Q. 11
	IF YES, b. How often have you met your keyworker during the <u>last three months</u> ?
	c. Have you experienced any difficulties in meeting your keyworker? PROBE: out of hostel all day, staff too busy/change a lot; reluctant to see worker Yes No
	IF YES, d. What difficulties have there been?
	IF NO KEYWORKER, CONTINUE OTHERWISE GO TO Q. 12
11	Do you talk to any hostel staff about your problems and needs?
	Yes No DK D
	IF YES, b. How often?
	ALL PARTICIPANTS
12	During the <u>last three months</u> , have you had a support plan that has been drawn up between you and your keyworker or a member of the hostel staff? Yes \(\subseteq \text{No} \subseteq \text{DK} \subseteq \)
	IF YES, b. What has been in the plan?
ΕV	ERYDAY TASKS AND HELP GIVEN
	I'd nour libe to cale your a face greations about hour your are grounding arounder.
	I'd now like to ask you a few questions about how you are managing everyday tasks such as getting meals and doing laundry, and any help you've had.
13	During the <u>last three months</u> , have you been eating well? Yes \(\square \) No \(\square \)
	IF NO, b. Why is this?
14	During the <u>last three months</u> , where have you mainly been getting food and what have you been eating? <i>PROBE</i> : self-caters; meals in hostel or drop-in centre; takeaway food; sandwiches

15	During the <u>last three months</u> , have you had any difficulties obtaining food [OR
	preparing meals if self-caters]? Yes \square No \square DK \square
	IF YES, b. What difficulties have you had?
16	How do you manage shopping for things for yourself?
17	During the <u>last three months</u> , has the hostel staff helped you with shopping or done it on
	your behalf, such as buying clothes or toiletries? Yes \(\Boxed{\subset}\) No \(\Boxed{\subset}\)
	IF YES, b. What have they done?
	c. How often?
I'd	now like to ask about how you are managing with bathing and laundry
18	Are you having any difficulties using the bath or shower?
	Yes No DK D
	IF YES, b. What difficulties are you having?
19	During the <u>last three months</u> , has anyone helped you to bathe or shower?
	Yes
	IF YES, b. Who has helped you?
	c. How often?
	d. What help have they given you?
20	How do you manage with regard to washing your clothes?

21	During the last three months, has anyone helped you with washing your clothes? Yes No DK D
	IF YES, b. Who has helped you?
	c. How often?
	d. What help did they give you?
22	How do you manage with changing your bedsheets and cleaning your room?
23	During the <u>last three months</u> , has anyone helped you change your bed and clean your room? Yes No
	IF YES, b. Who has helped you?
	c. How often?
	d. What help have they given you?
	BUDGETING AND FINANCES
24	Do you have any difficulty with day-to-day budgeting and managing your money? Yes No
	IF YES, b. Why are the difficulties?
25	During the <u>last three months</u> , have you received help from anyone with budgeting and managing your money? Yes No DK D
	c. What help did they give you?
26	During the <u>last three months</u> , has anyone reminded you or helped you to sort out
	payment of your rent and service-charge? Yes \(\Boxed{\Boxes}\) No \(\Boxed{\Boxes}\) DK \(\Boxed{\Boxes}\)
	IF YES, b. Who has helped you?
	c. What help have they given you?

27	During the <u>last three months</u> , has anyone helped you sort out social security benefit
	claims or financial problems such as debts?
	Yes No DK D
	IF YES, b. Who has helped you?
c. W	hat help have they given you?
HEA	ALTH PROBLEMS
	I'd now like to ask you about your health and any treatment that you are receiving
	At your previous interview, you mentioned that you had the following physical health problems/ <i>OR</i> did not have physical health problems:
C	a. Over the <u>last three months</u> , have there been any changes in your physical health?
	Yes No DK D
IF Y	ES, b. What changes have there been?

IF PHYSICAL HEALTH PROBLEMS CONTINUE ... OTHERWISE GO TO Q. 30

IF YES, b. What tre	atment or help have you had?	ASK ABOUT EACH
Help from?	What treatment or help?	How often/no. times seen in last 3 months
GP		Do not ask here
Hospital outpatient with doctor		
Practice/district/ community nurse (not CPN)		
Physiotherapist		
Other (state who)		
At your previous intervie	w, you mentioned that you had the on or other mental health problems on the one of the other mental health problems in the other been any changes in the other been and the other been any changes in the other been and the other been any changes in the other been any changes in the other been and the other been any changes and the other been and the other be	following mental health pro

IF MENTAL HEALTH PROBLEMS CONTINUE ... OTHERWISE GO TO Q. 32

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33

IF YES, b. What trea	tment or help have you had?	ASK ABOUT EACH
Help from?	What treatment or help?	How often/no. times seen in la 3 months
GP		Do not ask here
Psychiatrist		
CPN		
Other (state who)		
ALL PARTICIPANTS		the following difficulties or con
• •	iew, you mentioned that you had? did not have any difficulties or c	· ·
	nonths, have you had any [other] o	difficulties or concerns about

How have your memory difficulties or concerns affected your everyday life?

34	During the last three months, have you received any help for your memory difficulties?
	PROMPT: hostel staff; GP; mental health worker; other
	Yes \square No \square DK \square IF NO, GO TO Q. 35
	IF YES, b. Who has helped you and what help have they given you?
	Type of worker/service What help have they given you?
	ALCOHOL AND DRUGS
	I'd now like to ask you a few questions about your use of alcohol and drugs
	over the last three months
35	At your previous interview, you mentioned that you were drinking (<i>state type of drink and frequency</i>)/ <i>OR</i> did not drink alcohol:
	a. Over the <u>last three months</u> , have there been any changes in your drinking habits?
	PROBE: frequency of drinking; types of alcohol Yes No Unsure
	IF YES, b. What changes have there been?
	ALCOHOL PROBLEMS/DRINKS 4+ DAYS A WEEK continue IF NO, GO TO Q. 37

IF YES, b. What help have	ve you had? ASK AE	BOUT EACH
Help from?	What help?	How often/no. times se in last 3 months
Hostel staff		Not applicable
Alcohol worker		
GP		Do not ask here
Other (state who)		
	have you taken any illegal drug ve you taken and how often?	
Type of drug		Frequency

IF DRUG PROBLEMS/TAKEN DRUGS IN LAST 3 MONTHS continue ... IF NO, GO TO Q. 39

IF YES, b. What help hav	e you had	l? ASK	ABOUT	EACH
Help from?		What help?		How often/no. times seen in last 3 months
Hostel staff				Not applicable
Drugs worker				
GP				Do not ask here
Other (state who)				
MEDICATION				
At your previous interview, were not taking any medica		tioned that you we	ere taking	the following medication
a. During the last three mo	onths has	your medication c	hanged?	Have you started or
stopped any tablets?				
PROBE: by GP or mental		ervices; methador edicines, e.g. pair		lar from drugs service;
muiti-vitamins: over-tne-c		canonico, cigi pan		

Pharmacist

40	Do the hostel staff look after yo	our tablets or remind you to take t	hem?
	Yes No	DK 🗌	
	IF YES, b. What help do the	ey give you?	
41	Do the hostel staff arrange or of Yes No No I	collect repeat prescriptions on you DK	ır behalf?
ОТ	HER SERVICES USED		
	now like to ask a few quest ee months	ions about other services tha	t you've used over the last
42	_	ow many times have you seen/use	
	Service	Number of times in last 3 months	Reasons for use
	General Practitioner (GP)		
	Walk-in health centre		
	Hospital A&E department		
	Hospital visit for tests e.g. blood tests, Xray		
	Ambulance service		
	Dentist		
	Chiropody		
	Optician		

Where stayed ¹	Reason f	or admission/stay		mate date discharged	Length of stay (number of nights)
If in hospital, reco	ord whethe	r medical, surgical,	psychiatric,	or general wa	ard.
Ouring the <u>last three</u>	e months, l	nave you seen a so	cial worke	r? Yes	No □ DK
EVER & Harri	many time	es have you seen th	ne social w	orker in the	last three months?
г 1 ЕЭ, D. HOW 1			ic social w	orker in the	idst till ce montilis.
·	•	•	ic social w	orner in the	iust unce months.
. What help has th	e social w	orker given you?			
. What help has th uring the <u>last three</u>	e social w months, h	orker given you? ave you used or re		o from any w	
What help has the last three ervices that we've r	e social w months, h	orker given you? ave you used or re	ceived help	o from any w	
. What help has th uring the <u>last three</u> ervices that we've r	e social w months, h not covered	orker given you? ave you used or red? SHOW	ceived help CARD G What serv	o from any w	
e. What help has the uring the last three ervices that we've recovery	e social w months, h not covered	orker given you? ave you used or red? SHOW IF YES, b.	ceived help CARD G What serv	o from any w	orkers or
e. What help has the uring the last three ervices that we've recovery	e social w months, h not covered	orker given you? ave you used or red? SHOW IF YES, b.	ceived help CARD G What serv	o from any w	orkers or
what help has the last three ervices that we've reservice (specify)	e social we months, he mot covered	orker given you? ave you used or red? SHOW IF YES, b. Number of tim	CARD G What serve	o from any wices?	orkers or
. What help has thuring the last three ervices that we've reservices (specify) Service (specify)	e social we months, he not covered No	orker given you? ave you used or red SHOW IF YES, b. Number of time	ceived help CARD G What serve	o from any wind ices? Treatment of the property of the proper	or help received
what help has the last three ervices that we've notes tha	e social we months, he not covered No	orker given you? ave you used or red SHOW IF YES, b. Number of time	Cerred to an ees; benefit	o from any wind ices? Treatment of the property of the proper	or help received

Yes No	IF YES, ASK:	
Who accompanied you?	Where to?	Number of times?
Besides what you have already men	itioned, have you received	any other help from hostel s
V N. DV		
Yes No DK		
Yes No DK DK		
IF YES , b. What help?		
IF YES , b. What help?Are there any services or help that y	you need but are not gettin	
IF YES, b. What help? Are there any services or help that y GO THROUGH CARD H	you need but are not gettin	g? , GO TO Q. 50

HOPES AND PLANS

I'd lastly like to ask you about your hopes and plans
Are there any plans for you to move on from this hostel? Yes No DK D
IF YES b. What plans?
What [other] plans or hopes do you have for the next few months?
52 Are there any other comments you'd like to make?
IF 3 MONTH INTERVIEW, SAY:
Thank you for answering the questions. You have been very patient and helpful. We would like to see you again in 3 months' time to find out how you are getting on. Check contact details and give incentive payment. IF 6 MONTH INTERVIEW, SAY: I'd lastly like to ask you a few questions about your views of the services and support you have received
53 What things, if any, do you like about living in the hostel [name hostel]
What things, if any, do you dislike about living in the hostel [name hostel]
55 What type of housing would you like to live in long-term and why?
Overall, how satisfied are you with the services and support you've received from the hostel staff?
SHOW CARD I Very Fairly Not very Not at all DK
ALL RESPONSES b. Why is this?

57	How satisfied are you with the services and support you've received from other workers [if applicable name types of workers]				
SHC	OW CARD I Very Fairly Not very Not at all DK				
ALL	RESPONSES b. Why is this?				
58	In what ways, if any, could services be changed or improved to meet your needs?				
Besides what you have already told me, are there any other comments you'd like to make about your experiences over the last few months					
	Thank you for answering the questions and sharing your experiences with				
	me. You have been very patient and helpful. We are extremely grateful that				
	you agreed to take part in the study. When the study finishes we will send				

you a booklet describing the main findings and recommendations.

Appendix 8 Hostel staff case roles and experiences



NIHR HS&DR funded study

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

Hostel staff: roles and experiences

To be completed with hostel managers / workers (when first interviewed)

Maureen Crane, Kritika Samsi, Louise Joly, and Jill Manthorpe, Social Care Workforce Research Unit, King's College London, Strand, London WC2R 2LS.

We are interested to find out about the experiences of staff who work in hostels, the security of their jobs and the opportunities available to them for training. I'd therefore like to ask you a few questions about your role, your experiences, and any training you've received. I'd just like to remind you that everything you say is confidential, and will be reported in such a way that neither you nor your organisation can be identified. You can refuse to answer any question.

Name of hostel staff member	ID
Name of hostel	Site ID
Date of interview	
Name of interviewer	

- 1. When did you start working at this hostel?
- **2.** What hours do your work?
- 3. What is your role or job title? What doesyour job involve?
- **4.** Have you previously worked with homeless people, and in what capacity? Have you previously worked in hostels and, if so, for how long?
- **5.** What other work experience do you have? Do you have any qualifications in social care or similar? If yes, what?
- 6. Have you undertaken any training on working with homeless people? If yes, what training?
- **7.** Have you undertaken any training on mental health problems or working with people who have mental health or memory problems? If yes, what training?
- **8.** Is there any training that you need or would find helpful in your work with older hostel residents? If yes, what training?

Thank you very much for your help today in answering all these questions.

Finally, we would appreciate it if you could complete a short form which collects background information about hostel staff. Just to remind you this information will be kept confidential.

Background information: hostel staff

1.	Gender Male Female	
2.	Age group 18-24	
3.	What is your ethnic group? A White English/Welsh/Scottish/Northern Irish/British Irish Any other white background	
	B Mixed/multiple ethnic groups White and Black Caribbean White and Black African White and Asian Any other mixed/multiple ethnic background	
	C Asian/Asian British Indian Pakistani Bangladeshi Chinese Any other Asian background	
	D Black/African/Caribbean/Black British African Caribbean Any other Black/African/Caribbean background	
	F Other group	

Appendix 9 Hostel manager interview



NIHR HS&DR funded study

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

Hostel manager interview

VERSION - 12.02.2014

To be completed by the interviewer with the hostel manager

Maureen Crane, Louise Joly, Kritika Samsi and Jill Manthorpe, Social Care Workforce Research Unit, King's College London, Strand, London WC2R 2LS.

APPENDIX 9

5	Is the hostel for men, women or both?
6	How many beds does the hostel have?
7	How many beds are: a. for men only? b. for women only?
	c. In single rooms d. On the ground floor
8	What facilities are in the typical bedroom? e.g. furniture, sink, ensuite
9	How many floors in the hostel are used by residents?
10	Does the hostel have a lift for residents' use? Yes No
11	What disabled facilities, if any, are available?
12	Are meals available to the residents:
	a. Breakfast
	Yes, included in service charge \square Yes, pay per meal \square No \square
	b. Cooked meal at lunch-time or evening
	Yes, included in service charge \square Yes, pay per meal \square No \square
13	What facilities, if any, are available for residents to prepare snacks/cook meals?
14	Is there a laundry for the residents' use? Yes \(\square\) No \(\square\)
15	What interview rooms are available for workers to see residents?
	CLIENT GROUPS AND ACCESS POLICIES

I'd now like to ask you a few questions about the client groups served by the hostel and access policies

16	What age restrictions are there for residents:
	minimum age (years) no minimum age restriction \Box
	maximum age (years) no maximum age restriction \square
17	How many residents do you currently have who are aged 50+ years?
18	During recent years, has there been any noticeable change in the number of
	residents aged 50+? Increased \square Decreased \square About the same \square
ı	F CHANGED, b. What do you think are the reasons for the changes?
19	Does the hostel accommodate people with (tick <u>all</u> that apply):
	low support needs \square medium support needs \square high support needs \square
20	Does the hostel target specific client groups? Yes \square No \square
	IF YES, b. Which groups? (e.g. rough sleepers; people with alcohol problems)
	What client groups, if any, are excluded from the hostel?
i	PROBE: ex-offenders; people without a local connection or not in receipt of benefits
22	Does the hostel accept self-referrals? Yes \square No \square
23	How [else] are people referred to the hostel? e.g. through local authority, street
	outreach team
TE	NURE POLICIES
24	What is the tenure agreement with the residents?
lice	nce \square assured shorthold tenancy \square no written agreement \square
oth	er

25 Can the residents enter and leave the hostel 24-hours? Yes \square No \square
IF NO, b. What are the restrictions?
26 Is the drinking of alcohol permitted on the premises? Yes No
IF YES, b. Where are the residents allowed to drink? (tick <u>all</u> that apply)
In bedroom In lounge/'wet room' In garden
27 What is the average length of stay of residents?
28 Is there a stated maximum length of stay for residents? Yes No
IF YES continue IF NO, GO TO Q. 29
b. What is this?
c. Who decided what the maximum length of stay should be?
d. Do any residents stay longer and, if so, why?
HOSTEL STAFF

I'd like to collect some details about staffing levels in the hostel and the training available to staff

29 How many paid staff are there at the hostel (not workers from external agencies)

ASK ABOUT THE FOLLOWING ...

		Type of worker	Full-time (30+ hrs per week)	Part-time (<30 hrs per week)
			Number	Number
		Manager/assistant manager		
		Case workers/support workers		
		Administrative/reception staff		
		Cleaning/catering staff		
		Porters/security staff		
		Other (specify)		
		Other (specify)		
		Other (specify)		
30	Do	olunteers regularly work at the hoste	l? Yes □, numb	er No 🗌
31	On a	average, how many managers/support	t workers are on du	ıty <u>per shift</u> during
	the	day?		
	Nun	ber of workers		
32	Wha	t staff cover do you have at night?		
33	What training is available to support staff on assessing the problems and needs of			
	resid	lents?		
	b	. Are all support staff required to atte	nd? Yes	No 🗌
34	Wha	t training is available to support staff o	on recognising mem	nory problems among
	resid	ents and working with this client grou	p?	
	b	. Are all support staff required to atte	nd? Yes	No 🗌

35 Is there any training that would be helpful for your staff that is unavailable or you
cannot access? Yes No IF NO, GO TO Q. 36
IF YES, b. What training?
c. Is it unavailable or why can you not access it?
HELP AND SUPPORT
I'd now like to ask about the help and support provided to residents
36 Do the hostel residents have a named key-worker who assesses their needs and
organises support? Yes No No
IF YES , b. How many residents does each key-worker have?
c. How often do residents see their key-worker?
IF NO KEYWORKER,
d. How are the needs of residents assessed and support organised?
37 Is a risk assessment carried out for each resident? Yes No
IF YES, b. How often?
c. Is the risk assessment documented? Yes \square No \square
38 Do the residents have written support plans/care-plans? Yes No
IF NO, b. How is the support that residents receive documented?

39	Does each resident have a case-file? Yes No	
	IF YES , b. Is the case-file record computerised? Yes ☐ No ☐	
	Is the following information recorded in the case-file?	
	c. Personal details, <i>e.g.</i> age, ethnicity, benefit claims Yes	No 🗌
	d. Background details, <i>e.g.</i> housing/employment history Yes	No 🗌
	e. Problems, support given, and contact with services Yes	No 🗌
40	Does a local GP practice(s) provide health care for residents? Yes	No 🗆
	IF YES, b. Which practice(s) and what arrangements do you have?	
	(name and address of practice; type of registration)	
41	Do primary health care doctors or nurses <u>routinely</u> visit or run clinics a	at the hostel?
	Yes No No	
	IF YES , b. Who visits and from what team/practice?	
	c. How often do they visit and when?	
IF	HEALTH CARE NOT PROVIDED BY GP OR VISITING HEAI	TH TEAM:
	d. How do residents access health care?	
AL	L MANAGERS	
42	Does a psychiatrist, CPN, or other mental health worker <u>routinely</u> visit	or run
	clinics at the hostel? Yes No	
	IF YES , b. Who visits and from what team/practice?	
	c. How often do they visit and when?	
43	How [else] do you access mental health services for the residents?	

4 Does an alcohol or drugs worker <u>routinely</u> visit the hostel to see residents?							
Alcohol worker Drugs worker Doint alcohol/drugs worker No D							
IF YES , b. Who visits and from what team/practice?							
c. How often do they visit and when?							
How [else] do you access substance misuse services for the residents?							
Is there any lifeskills training available to residents to prepare them for resettlement?							
Yes No No							
IF YES , b. What training is available?							
c. Who organises or runs the training?							
47 Are any [other] training programmes or activities organised for residents?							
Yes No No							
IF YES , b. What training or activities?							
c. Who organises or runs these?							
48 Please tell me about any other workers or services that visit the hostel and provide							
support, training or help to residents?							
Type of worker/service Frequency of visits Help given							
RESIDENTS WITH MEMORY DIFFICULTIES							
I'd now like to ask you a few questions about residents with memory							
difficulties.							

9 Do you sometimes have residents that you think might have memory difficulties?						
Yes \square No \square IF YES continue IF NO, GO TO Q. 55						
b. How do their memory difficulties manifest?						
50 What are the characteristics of the residents with memory difficulties?						
PROBE: age; alcohol problems; drug problems; other						
b. How do their problems and needs differ from those of other residents, if at all?						
Do the hostel staff provide help and support to residents with memory difficulties?						
Yes No No						
IF YES, b. What help and support do they provide?						
Do you contact any particular services if you think residents might have memory						
difficulties? Yes No No						
IF YES, b. What services?						
IF NO, b. Why not?						
53 What are the longer-term housing plans for residents with memory difficulties?						
Where do they generally move to when they leave the hostel and how is this						
organised?						
54 Is there any help or services that residents with memory difficulties require that you						
and your staff are unable to provide or obtain? Yes \square No \square						
IF YES continue IF NO, GO TO Q. 55						
b. What help or services do they need?						
c. Why are you unable to provide or obtain it?						

FUNDING

I'd now like to ask you a few questions about funding for the hostel

55	What is the <u>total</u> cost per week for a resident to stay in the hostel?						
	b. How much is the rent?						
	c. How much is the service charge?						

56 What are the main sources of funding for the hostel?

Funding source	Receives funding?		Approximate % of overall income for hostel
Local authority	Yes	No	
Residents' charges	Yes	No	
Donations	Yes	No	
Other (specify)	Yes	No	
Other (specify)	Yes	No	

In recent years, have there been any changes to the way the hostel is run or to the						
services that are provided? For example, any changes in funding, staffing levels						
or the length of stay of residents?						
Yes No IF NO, GO TO Q. 58						
IF YES, b. What changes have there been?						
c. How have the changes affected the services and support provided to residents?						
58 Are there any other comments you'd like to make about the hostel and the services						
provided?						
Thank you very much for your time and patience. The information you have						

provided is very helpful.

EME HS&DR HTA PGfAR PHR

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