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Community Support Services for People with Dementia: The Relative Costs and Benefits of Specialist and Generic Domiciliary Care Services

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Discussion Paper M245-3
September 2010
Not publicly available

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COMMUNITY SUPPORT SERVICES FOR PEOPLE WITH DEMENTIA: THE RELATIVE COSTS AND BENEFITS OF SPECIALIST AND GENERIC DOMICILIARY CARE SERVICES

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PREFACE

This work was commissioned by the Department as part of work underlying the development of the National Dementia Strategy (Department of Health, 2009). It is focused on Objective 6 of the National Dementia Strategy and is intended to contribute to the evidence base for effective community support services for people with dementia. The project is designed to address the specific concern of the Department of Health, to provide information on the economic and individual outcomes evidence for the efficacy of different models of community support to persons with dementia; and to assist in decisions concerning whether it is more cost-effective to provide specialist or generic domiciliary care services for people with dementia. In this document we have used the terms 'domiciliary care' and 'home care' interchangeably.

As a short term and modest piece of work it was clearly not possible to set up a research trial or even a more pragmatic comparison of the costs and outcomes of different approaches to the provision of home care. It was therefore decided to address the question through multiple approaches, including literature, re-examination of studies, and data collections from carers, local authorities and analysis of secondary data, each designed to shed light on the question from different sources and perspectives.

Hence there are five elements to this study. Firstly in chapter 2 is a review of the available literature which addresses the subject. Chapter 3 extracts, and where appropriate reanalyses, salient material from a number of relevant studies conducted by the PSSRU. Chapter 4 systematically analyses the preferences of carers of people with dementia for different types of home care using a discrete choice methodology. Chapter 5 is based upon interviews with local authority managers with responsibility for commissioning domiciliary care services in areas with distinctively different approaches to providing domiciliary care for older people with dementia. Chapter 6 uses national data to explore whether there are variations in patterns of admission to care homes associated with different approaches to providing domiciliary care for older people with dementia. The findings of each are reported separately and in the final chapter information from all of these is synthesised to provide guidance for commissioners.

The completion of this work has been a team effort and I am indebted to very many of my colleagues at PSSRU Manchester and Linda Davies from the Health Economics Group at the University of Manchester.

We are also grateful for the support of Simon Williams and the ADASS national older people's network; Claire Goodchild from the Department of Health for her energy and enthusiasm; the local authorities who kindly participated in the survey and subsequent interviews; and the members and organisers of the Age Concern Carers groups in Salford and Trafford who generously gave us their time.

David Challis
Director PSSRU

August 2010

CHAPTER ONE: INTRODUCTION

Domiciliary care has long been part of the fabric of the welfare state and there is historical evidence that it is the service most frequently provided to older people with dementia and that it is targeted at those who are most impaired (O'Connor et al., 1989; SSI, 1997). In the 1990s the community care reforms signalled changes in arrangements for the provision and delivery of domiciliary care. Local authorities were to become 'enabling agencies' focusing on the commissioning of services rather than their provision, domiciliary care was increasingly but not exclusively to be provided by the independent sector, with planning about its scale and content part of a new commissioning function undertaken by local authorities (Cm 849,1989). The subsequent introduction of the concept of 'Best Value' into local authority commissioning and contracting processes also influenced the relative balance of domiciliary care provided by the independent and local authority sectors and the development of specialist services. Best Value was defined as 'a duty to deliver services to clear standards - covering both quality and cost - by the most effective, economic and efficient means available.' Choice of domiciliary care provider was to be based on judgments about Best Value and optimum outcomes for individual service users, and local authorities were required to demonstrate that their contracting arrangements delivered this (Cm 4169, 1998 p113).

These principles provided an incentive for local authority domiciliary care provision to focus on specialist services such as those for older people with dementia. Another incentive for this, together with a more general requirement for their development, was provided by the Fair Access to Care Services guidance. It confirmed the duty placed on councils to have services in place to meet eligible needs, with the caveat that specialist services for groups of service users, such as older people with dementia, should be developed where there is justification for such (Department of Health, 2002a). Since then, local authorities have been required to redesign their domiciliary care services demonstrating an investment in prevention, early intervention/re-ablement, and provision of intensive care and support for those with high-level complex needs, including older people with mental health problems (Department of Health, 2008, 2009). Most recently there has been a renewed emphasis on 'jointness' in the commissioning process (Cm 7881, 2010).

This is important because dementia is recognised to pose the greatest challenge to the world's health and social care services and to individuals and families now and for the foreseeable future (Ferri et al., 2005; Prince et al., 2007). This notoriety is based on its epidemiology: the incidence and prevalence of dementia are age-related, becoming greater decade by decade beyond the early sixties and survival into these ages of greatest risk is becoming the norm (Prince, 2002). The clinical characteristics of dementia render individuals less able to care for themselves, more prone to emotional and behavioural problems and more likely to have poor physical health (Burns et al., 2005; MacKnight and Rockwood, 2001). Thus people with dementia require support from family, friends and professional health and social care agencies (National Institute for Health and Clinical Excellence and Social Care Institute for Excellence, 2006). Charitable organisations providing for and lobbying on behalf of older people and people with dementia, such as Age UK, the Alzheimer's Society and Dementia UK, also have important roles.

Dementia is a portmanteau term which subsumes a number of conditions which share core symptoms but differ in detail of presentation and prognosis according to pathology, age of onset, co-morbidity, heredity, personality, culture and social circumstance (Burns et al., 2005; Bharath et al., 2010). Thus the needs of individuals and families for help over the course of life with dementia are changeable and diverse (National Audit Office, 2007). How to anticipate and respond best to this chimera requires understanding, vision and flexibility.

The National Dementia Strategy for England and Wales reflects the importance of both clinical and more social facets of dementia care in that encourages raised awareness of the condition and early referral for assessment and diagnosis, but goes on to acknowledge that other aspects of care are influential in determining the experience of patients and carers and the economics of care (Department of Health, 2009). Optimising support for people with dementia in their own homes (Objective 6) is seen to be desirable by all. At present 94 per cent of older people in the UK live in their own homes, but 40 per cent of people with dementia are in care homes and 60 per cent will spend their final weeks in care (Knapp and Prince, 2007). Many people can experience a good life in a care home or equivalent, but most prefer home life for its quality, self-determination and economy (Challis et al., 2002a). Thus investment in models which maintain life at home and avoid relocation directly or indirectly (via a general hospital admission) will be worthwhile on several dimensions. No one model will be right in all circumstances. Careful analysis of what is known of best-fits and where to use generic or specialised teams and types of support will provide a sound source of guidance for those responsible for commissioning and delivering services and indicate the direction and capacity required of workforce development and education in all quarters. The purpose of this study is to contribute to the development of this evidence base by the synthesis of findings from previous studies, new analyses of data, and an appraisal of the current provision of domiciliary care to older people with dementia and their carers.

CHAPTER TWO: LITERATURE REVIEW

In this chapter the available literature is reviewed. The approach adopted reflected the limited time available in which to complete the review. It deliberately took a UK perspective and incorporated both peer and non peer reviewed material drawing largely on material from a literature review from a study recently completed by the Personal Social Services Research Unit at the University of Manchester. Within the overarching framework of exploring the nature of specialist and generic domiciliary care provided to people with dementia the literature review had two aims. First, the literature was examined for evidence of economic and individual outcomes of the effectiveness of different models of community support to persons with dementia. Second, it sought to inform the debate as to whether it is more cost-effective to provide specialist or generic domiciliary care services for people with dementia. After a description of the methodology adopted the findings are presented. These are described under four headings: the characteristics of literature in the sample; the extent of specialist home care provision; the efficacy and cost-effectiveness of specialist and generic domiciliary care services; and issues germane to the commissioning of specialist domiciliary care services.

Method

Two literature searches formed the basis for selection of articles for review in this study, the overall approach reflecting the short time frame for its completion. First, use was made of a literature review undertaken for a research study entitled *Recruitment and Retention of a Social Care Workforce for Older People* (Hughes et al., 2009). The report for this study was submitted to the Department of Health in 2008 and subsequently subject to peer review. This study was one of nine conducted as part of the Social Care Workforce Initiative which examined various aspects of the nature and role of the social care workforce (Department of Health, 2007). The literature review completed for this study was designed to inform both the development and reporting of the findings of a national survey of local authority commissioning and contracting arrangements. The method for the selection of the literature for this study is detailed in Box 2.1. Here the approach taken was designed to maximise the insights to be gained from the literature. Thus the primary determinant of quality was provided by the rigorous inclusion and exclusion criteria. Data was extracted by one researcher (HC) and any uncertainties discussed with another (JH). Articles included in this literature review were interrogated for evidence relating to specialist and generic domiciliary care services for older people with dementia for the present study.

Second, as the selection of the literature was undertaken in April 2008, a supplementary search was conducted to identify relevant articles published subsequently. Details of this sampling frame are summarised in Box 2.2. Due to a dearth of literature relating to services for the care of older people with dementia, we wished to be as inclusive as possible in our approach, therefore the second search incorporated both peer and non peer reviewed pieces and non-empirical as well as empirical articles. To permit the reader to make judgements about the quality of the material, in presenting the findings we draw a distinction between these different types of evidence in reporting findings. The overall process for the literature review is summarised in Figure 2.1.

Box 2.1: Sampling frame for the literature review undertaken as part of the study *Recruitment and Retention of a Social Care Workforce for Older People*

Inclusion criteria

Participants/care recipient group
Primarily older people (65+)[1]

Service
Social care or social services for older people[2] and
Community based including intermediate care and old age mental health services
(Voluntary sector could be included if social care is likely to be commissioned/purchased by lead social care agency)

Location
Completed in the UK (including Northern Ireland).

Dates
Data collected 1991 or later (The NHS and Community Care Act passed)
Published 1997 or later

Design/study type
Empirical (quantitative and qualitative) work[3] using both primary and secondary data and a variety of methodologies including case studies and national surveys.

Focus of study
Commissioning, contracting and care management arrangements for older people

Study design/nature of reference
Peer reviewed literature

Exclusion criteria

Participants/care recipient group
Adults (18-64)

Location
Non UK references

Study design/nature of reference
Individual client case studies
Book reviews
Commentaries/opinion articles
Dissertation/PhD theses
Non-peer reviewed literature

[1]Relaxation of this inclusion criterion to include all adult groups for direct payments and individual budgets due to the newness of these concepts and their centrality to the study.
[2] An operational definition of social care for older people was produced: 'Social care for older people comprises the management and provision of their care and ensuring that a coordinated approach is adopted across the local authority, the independent sector and other agencies' (adapted from Reilly et al., 2008).
[3] We only included studies that reported findings rather than theoretical or conceptual pieces. Thus, as Mays et al., (2001) stated, *"the simple test of relevance for inclusion is to specify that each reference must relate to some form of research, inquiry, investigation or study"* (p196).
Source: Hughes et al. (2009)

Box 2.2: Sampling frame for the supplementary literature review

Inclusion criteria

Participants/care recipient group
Primarily older people (65+)[1]

Service
Community based social care services for older people with dementia[2]
(Voluntary sector could be included if social care is likely to be commissioned/purchased by lead social care agency)

Location
Completed in the UK (including Northern Ireland).

Dates
Data collected 1991 or later (The NHS and Community Care Act passed)
Published 1997 or later

Design/study type
Empirical (quantitative and qualitative) work using both primary and secondary data and a variety of methodologies including case studies and national surveys.
Non-empirical pieces were included to look for evidence which supported or rebutted the empirical findings. This was scrutinised as a convenience sample from pieces published between 1997 and 2010.

Focus of study
Commissioning, contracting and care management arrangements for older people

Study design/nature of reference
Peer reviewed literature
Peer and non-peer reviewed commentaries/opinion articles

Exclusion criteria

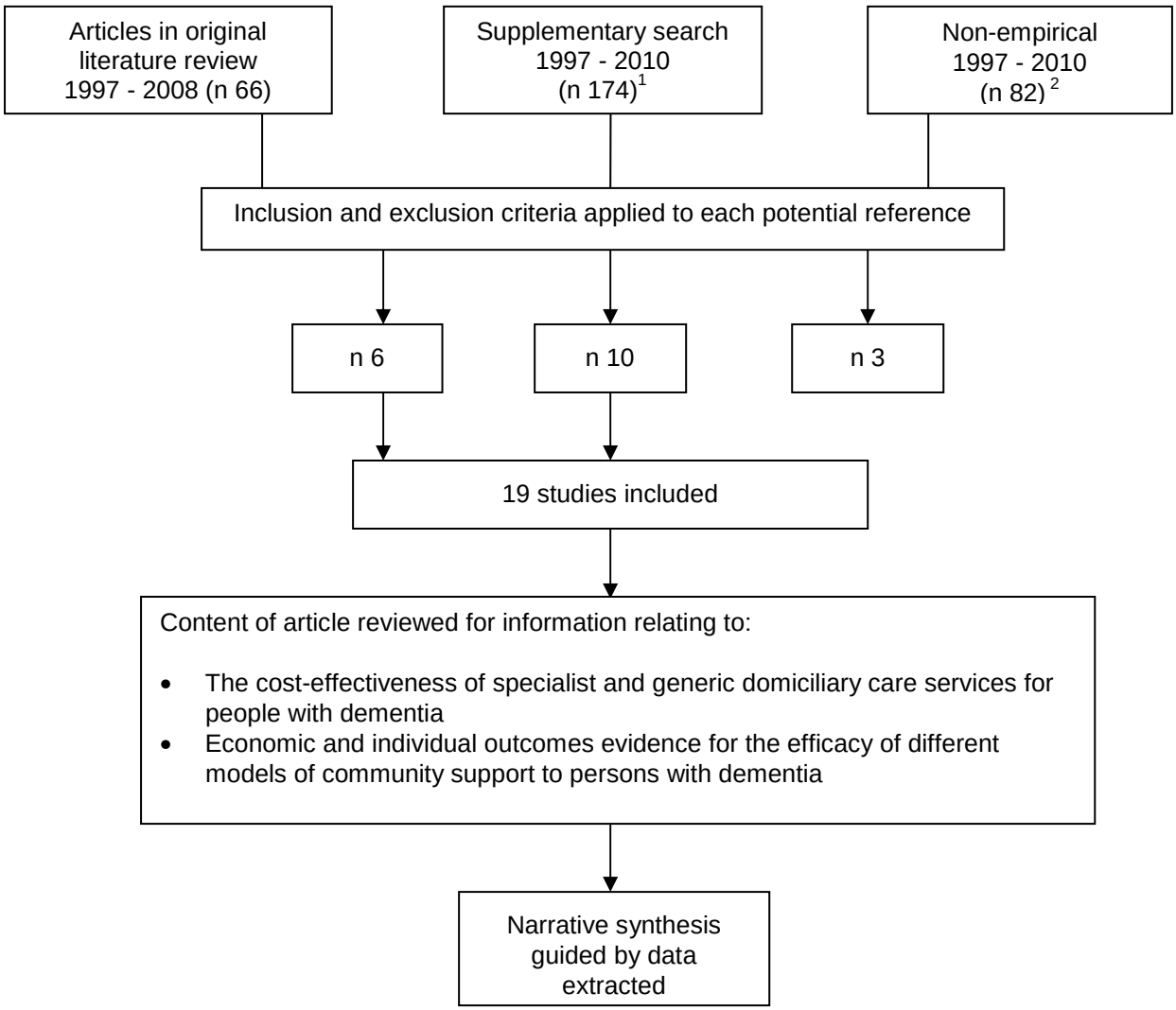
Participants/care recipient group
Adults (18-64)

Location
Non UK references

Study design/nature of reference
Individual client case studies
Book reviews
Dissertation/PhD theses
Non-peer reviewed literature for non-empirical studies

[1]Relaxation of this inclusion criteria to include all adult groups for direct payments and individual budgets due to the newness of these concepts and their centrality to the study.
[2] An operational definition of social care for older people was produced: 'Social care for older people comprises of the management and provision of their care and ensuring that a coordinated approach is adopted across the local authority, the independent sector and other agencies' (adapted from Reilly et al., 2008).

Figure 2.1: Literature review process



[1] Articles of potential relevance were identified through a key word search and reviewing titles and abstracts for relevance. These formed a selection of articles to which inclusion and exclusion criteria were then applied.
[2]This formed a convenience sample which included literature identified in the original and supplementary search.

Findings

Study characteristics

Unsurprisingly, the number of studies which addressed the question was limited as can be seen in Box 2.3. There were 19 included, involving 20 publications. These are listed in the bibliography with an asterisk (*).

Box 2.3 summarises the characteristics of the studies under consideration. The majority are specific to dementia and the remainder describe services for older people with mental health problems. The latter were included because evidence has suggested that a substantial proportion of older people with mental health problems may have dementia. For example, in a study of community mental health teams, Brown and colleagues (1996) found that nearly two fifths (38%) of referrals were diagnosed as suffering from this condition.

Box 2.3: Studies under consideration (n=19)

Peer-reviewed	18
Non peer reviewed	1
Service focus	dementia 16 old age mental health 3
Empirical	16 - qualitative 8 - quantitative 7 - mixed-methods1
Non-empirical	3

Extent of specialist home care provision

There is evidence to suggest that although specialist services for older people with dementia exist in some localities, they are often underdeveloped. Burholt and colleagues (1997) concluded that although older people with dementia received a higher level of support than those without dementia, this was less than expected given their level of impairment. McDonald and Heath (2008) reported that services for older people with dementia were under-developed in East Anglia in comparison with services for older people generally.

In terms of the responsibility for the provision of domiciliary care services, Curtice and Fraser (2000) noted that independent providers were viewed as offering useful supplementary services to those provided by the local authority, particularly where specialist services were required. However, Ware and colleagues (2001) described how the majority of independent sector providers of domiciliary care sought to offer a range of services, rather than specialise for particular groups of users, such as older people with dementia. In the opinion of Chilvers (2003), there appears generally to be a lack of specialist domiciliary care services for older people with dementia.

Efficacy and cost-effectiveness of specialist and generic domiciliary care services

It is believed that specialist rather than generic domiciliary care is more suitable for the care of older people with dementia (Chilvers, 2003). However, Venables and colleagues (2006) noted few differences in quality standards between specialist services for people with dementia and generic domiciliary care services. Nevertheless, there is evidence to suggest that the former are perceived by service users, carers, and care workers to deliver better quality care than standard services (Rothera et al., 2008). Challis et al (2002a, 2009a) found that specialist case managers with budgets supporting people with dementia saw the need to create a specialist home care support service to provide the level and content of support needed. This was cost effective for certain groups of older people with dementia (Challis et al, 2009a). Research has also demonstrated that the provision of specialist domiciliary care services for people with dementia can reduce the likelihood of requiring, or delay entry into, long-term care (Riordan and Bennett, 1998; Andrew et al., 2000). Another notable benefit of specialist domiciliary care services is that they enabled carers to care for longer (Riordan and Bennett, 1998).

This is important, as Jacobs and colleagues (2009), in a literature review relating to older people's social care services, noted that whether or not the older person has dementia, and whether or not the family carer is coping in their caring role, are two of the strongest predictors of admission to care homes. This is supported in opinion by Chilvers (2003) who wrote that specialist domiciliary care services can have an overall cost benefit even where entry to residential care is delayed only by a few months. He also argued that there may be real quality of life benefits associated with enabling people to remain at home for as long as possible.

High levels of job satisfaction amongst care workers within specialist dementia care services have been reported (Ryan et al., 2004). More generally, Chester and colleagues (2010) identified that a lower turnover of domiciliary care workers in the independent sector was associated with the contractual requirement to provide specialist training for the care of older people with dementia. This is supported in the opinion of Chilvers (2003) who argues that recruitment of staff may be easier for specialist dementia services compared to generic provision.

Commissioning specialist domiciliary care services

Moriarty (1999), in a review of policy and literature, argued that not enough is known about the levels of support that would be required to support people with dementia in their own homes. A further problem is the difficulty of identifying the number of older people with dementia, amongst service users supported by local authorities due to systems of recording and assessment. One way of identifying the care needs of the population with dementia, is detailed by Gordon and colleagues (1997). They described how a multiservice census and a stratified random sample survey were utilised to assess the care needs of the population with dementia, in order to provide locally relevant data for service planning. More generally, several researchers have also written about the benefit of involving older people with dementia, care staff, and specific ethnic groups in shaping community support for older people with mental health problems (Bamford and Bruce, 2000; Manthorpe and Alazewski, 2002; Bowes and Wilkinson, 2003; Turner et al., 2005; Tucker et al., 2007a).

Conclusion

There is a paucity of evidence to inform the debate about the relative merits of support provided to older people with dementia by generic as compared with specialist domiciliary care services. However, this literature review does reveal three findings of interest. First, few services provide solely specialist domiciliary care for people with dementia although this may be offered as a discrete service within a larger organisation. Second, judgements about the cost-effectiveness of specialist compared with generic domiciliary care are most often made in the context of a delay in the care trajectory leading to the admission of an older person with dementia to a care home. However, other factors such as carer burden influence this decision, and must be taken into account when making such judgements. Finally, routinely generated data on social care services for people with dementia is not readily available. However, such information is essential to promote informed decision making about the appropriate balance between generic and specialist domiciliary services, alongside the views of stakeholders and other factors, such as the importance of training in dementia care for domiciliary care staff.

CHAPTER 3: EVIDENCE FROM PSSRU STUDIES

The aim of this chapter is to explore the nature of specialist and generic domiciliary care provided to people with dementia using data from studies completed by the Personal Social Services Research Unit (PSSRU) at the University of Manchester since 1997. Much of the evidence presented relates to generic services, reflecting the historical and current balance of provision within the domiciliary care sector. Following a brief summary of the PSSRU studies included in this review the evidence is summarised under three headings. First, data relating to the **service context** in which both generic and specialist domiciliary care services are located is reviewed. Second, evidence relating to the **use of the domiciliary care** services is presented. Third, data to inform the service **commissioning arrangements** is summarised.

The studies

This material has been specially selected to provide a context for and inform the debate as to whether it is more cost-effective to provide specialist or generic domiciliary care services for people with dementia. It provides evidence in terms of economic and individual outcomes of the efficacy of different models of community support to persons with dementia. Both published and unpublished material is included with some reanalysis of the data conducted specifically for this synthesis of research evidence.

Findings from 10 studies reported over a thirteen year period by the PSSRU at the University of Manchester are reported below. A summary of each is included in Box 3.1. Data are derived from three sources: audit, structured interviews with service users and literature reviews, both purposive and systematic. Thus the evidence synthesised below is derived from multiple research methods. It comprises data collected at different times and places and from different people or groups; the use of more than one theoretical approach to the analysis and, in some studies, multiple methods to collect the data and multiple measurements within the same method. This is important because it is argued that the strength of the findings is increased by the triangulation of measurement approaches over time as opposed to those derived from, for example, a single methodology or even multiple methodologies, within the one study (Denzin, 1989).

The majority of this information refers to people over the age of 65 years, and hence the requirements of people with early onset dementia and their carers are not reported as fully. Evidence relates to both specialist and generic domiciliary care, with an emphasis on the latter, the most prevalent form of service provision. There is also information included, where available, about sources of care and support for older people with dementia at home other than domiciliary care. These are variously described as: generic hands-on workers, paid carers, workers whose responsibilities span health and social care, or support workers (Challis et al., 1995; 2009a; Murray, et al., 2006; Snayde and Moriarty, 2009). One of the studies reported here - *Supporting People with Dementia at Home* – is identified as an exemplar of good practice in the current national dementia strategy (Department of Health, 2009). Appendix 1 provides additional information about the 10 studies included in this

review: a brief description, a summary of the methodology and details of principal publications and the report provided to the funder.

Box 3.1: PSSRU studies

Number	Study	Time frame for data collection	Method of enquiry
1	A Systematic Evaluation of the Development and Impact of the Single Assessment Process in England: The Care Plan Study	Two: 2000 and 2005	Audit of case files
2	Care Coordination for Older People	2006	Postal questionnaire
3	Estimating the Balance of Care	1997-1998	Audit of case files
4	Mapping Specialist Dementia Services in the North West of England: Domiciliary Care	2002 2003	Postal questionnaire
5	Mapping Specialist Dementia Services in the North West of England: Professional Teams	2001-2002	Postal questionnaire
6	National Trends and Local Delivery in Old Age Mental Health Services	2008-2009	Postal questionnaire Systematic literature review
7	Recruitment and Retention of the Social Care Workforce for Older People	2008	Postal questionnaire
8	Services for Older People with Mental Health Problems: The Balance of Care in Cumbria	2003-2004	Audit of case files Balance-of-care study Purposive literature review Stakeholder consultation - questionnaire and focus group
9	Supporting People with Dementia at Home (The Lewisham intensive case management scheme)	1990-1993	Structured interviews with service users and carers
10	The Value of Specialist Clinical Assessment of Older People Prior to Placement in Care Homes	1998-2000	Structured interviews with service users and carers

Service context

In this section data are reported from five studies (numbers 4, 2, 5, 6 and 8). The evidence is summarised from three perspectives:

First, salient issues from literature reviews are considered which explore issues relating to service uptake and the extent of specialist services provided for older people with dementia within community mental health teams for older people is presented (studies 6 and 8).

Second, information relating to the structures of teams responsible for assessing and coordinating care packages for older people with dementia is presented. Data from local authorities provide a broad description of the framework (study 2) and that from community mental health teams for older people (studies 4 and 6) focus on their support to older people with dementia and also their links with domiciliary care organisations. Here there is some evidence of service development over time.

Finally the extent of domiciliary care provision for older people with dementia and how far it differs from generic provision is explored (study 5).

Together these data provide an explication of the different approaches to community support for people with dementia, an understanding of which is critical to decisions about the effectiveness of specialist and generic domiciliary care services for older people with dementia.

Findings from the literature

Study 8 - Services for Older People with Mental Health Problems: The Balance of Care in Cumbria

Here material is included from the purposive literature review conducted for this study in 2005 which supports the observation that whilst domiciliary care was a service frequently provided to older people with dementia, many who might benefit from it do not use the service, or use it only in small and often inadequate amounts (Tucker et al., 2005).

Although few studies based on representative community samples in the period after the introduction of the community care reforms were reported, the available evidence indicated that the receipt of domiciliary care services by older people with mental illness, including dementia, was higher than in the older population as a whole (Moriarty, 1999). Whilst Bennett and colleagues (1996) reported that 15 per cent of all people aged over 75 years in Great Britain received domiciliary care, two studies of people with dementia aged over 65 years reported rates of 31 per cent and 44 per cent respectively (Burholt et al., 1997; Livingston et al., 1997). However, considerable variation between the amounts of domiciliary care provided to older people with dementia in different parts of the country was also noted (Moriarty, 1999). Nevertheless a clear association between receipt of domiciliary care and older people with dementia living alone has been demonstrated (Levin et al., 1989; O'Connor et al., 1989; Webber et al., 1994).

A recurrent theme in the international research literature reviewed was that people with dementia who might benefit from services often do not use them, or use them only in small and/or inadequate amounts (Zarit et al., 1999). Historically in England this has been partly attributable to the limited availability of domiciliary care and agency constraints on its use. Often local authorities capped the cost of domiciliary care at the gross or net cost of residential care and rarely devolved budgets to care managers thereby limiting their ability to create substantial and/or innovative care packages (Sinclair et al., 1990; Askham, 1997; Audit Commission, 1997; Godfrey et al., 2000; Weiner et al., 2002). This is particularly important in meeting the special requirements of older people with dementia. Other explanations for the limited use of services made by older people with dementia have included a lack of knowledge on the part of families as to what services are available; caregiver guilt about relinquishing care of their relative; the charges made for help; and refusal of services. The latter may be in response to some of the criticisms of services noted above, or to lack of understanding on the behalf of the service user (Zarit et al., 1999; Askham, 1997).

Study 6 - National Trends and Local Delivery in Old Age Mental Health Services

Evidence is presented from a systematic literature review which examined variations in the structures and processes of community mental health teams for older people reported in the literature between 1998 and 2009. A final sample of 45 publications were included ranging from national reports and studies featuring community mental health teams for older people (n=10) to research studies and descriptions of single teams and specific practices (n=35). Overall 57 individual teams were identified in this literature (Abendstern et al., 2010).

The implicit assumption is that services provided within community mental health teams for older people are more specialised than those from outside these teams. However, the amount of evidence found in the literature which focused on the three issues discussed below is small. First the outreach role of community mental health teams for older people in supporting non-specialist services, such as domiciliary care provision, is considered. Second, the role of support workers, who may be conceived of as a substitute for specialist domiciliary care workers, within community mental health teams for older people is explored. Finally, the evidence relating to teams which included a specialist domiciliary care component is reviewed.

In 2005 the Department of Health listed advice and support to other health and social care professionals as a key function of community mental health teams for older people (Department of Health and CSIP, 2005). Eight papers make reference to such outreach work (Abendstern et al, 2006; Audit Commission, 2002; Baillon et al., 1996; Challis et al., 2002b; Coles et al., 1991; National Audit Office, 2007; Tucker et al., 2007b; 2009). However, the majority reported on support provided to care homes. There is little evidence in this literature to suggest that domiciliary care services were the recipients of any such outreach or liaison.

Moreover, it would appear that many of the teams within the studies reported in this literature did not include support workers. The National Audit Office (2007) reported that just over half of the teams surveyed by them did not have access to these workers. Aggregated data from the 35 local team studies in the current review suggested that support workers were found in about a quarter of the 57 teams considered. They included a wide range of staff from mental health support workers; physiotherapist aides; auxiliary nurses; night sitters and domiciliary care workers. Just five publications comment in some way on the availability and/or role of support workers within community mental health teams for older people. This group of staff cover a range of backgrounds and roles which, in some cases include domiciliary care (Lingard and Milne, 2004; McCrae et al., 2008; National Audit Office, 2007; Sheard and Cox, 1998; Stevenson et al., 2006).

One of the earliest community mental health teams for older people established in Cambridge in 1991 (O'Connor et al., 1991; Sheard and Cox, 1998) included both a domiciliary care organiser and domiciliary care assistants. More recently, the Enhanced Assessment and Support Team for people with dementia (Stevenson et al., 2006) included three domiciliary care workers within it who were directed by the team coordinators but received managerial supervision from within their own organisation, a local voluntary domiciliary care agency. This article offered a rare evaluation which, although focused on the work of the whole team rather than the

domiciliary care workers specifically, nevertheless, provided some evidence of a positive contribution made by the provision of domiciliary care from within the team. The findings indicated that the team's work enabled people to remain in their own home for longer than had they not been in place, whilst carers and staff who had contact with the team were largely reported as regarding its input as beneficial to the referred person.

There is also evidence that some of the few specialist teams for people with dementia have a domiciliary care component. A recent national study found that one of the six teams it reported on was dedicated for people with dementia (Healthcare Commission, 2009). Sheard and Cox (1998) reported two such teams, both in Scotland, which included domiciliary care workers. One, the Gordon team, was reported to have 'homecarers' whose role was to try to 'meet social, psychological and emotional needs but (who) are also available to provide home and personal care' (p52). The authors commented on the need to enable teams to 'act as providers of home care/support services' (p21) in order to support the provision of a high quality dementia care service from them.

Team structures

Study 2 - Care Coordination for Older People

Here data are presented from a national survey of local authorities which, as noted above, achieved a 79 per cent response rate: the data relates both to the team structure through which specialist services are provided to older people with mental health problems, including dementia, and the range of services available. Whilst the data presented below were gathered in advance of the widespread introduction of personal budgets as part of the government's personalisation agenda their continuing relevance should not be underestimated (Department of Health, 2008). The extent to which older people will wish to avail themselves of the opportunity to arrange their own care is unclear and, indeed, policy guidance has recognised that those people with complex health and social needs are likely to continue to require the assistance of a care manager to coordinate their care (Cm 6499, 2005; Glendinning et al., 2008).

The majority of respondents (61%) reported that care management for older people in touch with specialist mental health services was primarily delivered by the local authority. For the remainder, it was provided through mental health trusts, care or partnership trusts, or primary care trusts (27%, 9% and 3% respectively). However, the team setting in which the local authority provided this service varied. About half of the local authorities reported that care managers were based in multi-agency community health teams for older people (community mental health teams for older people) and specialist old age mental health teams (55% and 49% respectively). Additionally, about two-thirds (65%) reported designated specialist care manager posts for old age mental health, including dementia, within their old age care management teams. Just over half of survey respondents (54%) reported that a comprehensive assessment was completed in respect of service users with complex health and social needs, such as those associated with a diagnosis of dementia, referred to specialist old age mental health services (Challis et al., 2009b; Department of Health, 2002b).

Study 4 - Mapping Specialist Dementia Services in the North West of England: Professional Teams

Fifty two teams completed and returned questionnaires for this study, reflecting 59 per cent of teams contacted. Two findings are of note in this context. First, a distinction was made between multidisciplinary and single discipline teams. Two thirds of the teams (67%, n=35) described themselves as multidisciplinary teams, of which about half (49%, n=17) included both health and social care professionals. People with dementia made up around half (49%) of caseloads overall, with a slightly higher percentage in multidisciplinary teams (51%) compared with single discipline teams (45%), although this difference was not statistically significant. Sixty nine per cent of teams reported having no age boundary for people with dementia, suggesting that a proportion of those with dementia supported by these teams could have been adults under the age of 65 – although no further data were available on this issue.

Second, respondents were asked to identify the percentage of people with dementia on their team's caseload who were in receipt of some form of domiciliary care. Whilst almost half (49%) of the caseloads of these teams comprised people with dementia and just over half (56%) were in receipt of domiciliary care, no information was gathered about the nature or extent of this provision and the degree of overlap between these two findings (Abendstern et al., 2005, 2006; special analysis).

Study 5 - National Trends and Local Delivery in Old Age Mental Health Services

Evidence is presented in this section from a postal survey of community mental health teams for older people**.** It aimed to identify and examine variation in community mental health teams for older people's organisation and delivery across England, and achieved an 88 per cent response rate. It provides additional information about two issues identified in the literature review: the incidence and role of support workers and the provision of outreach services to domiciliary care providers. Each is addressed in turn using specially commissioned analysis for this report. The survey identified significantly higher levels of access to support workers as compared to earlier work identified in the literature review. Eighty seven per cent of respondents reported having support workers as core team members whilst just five per cent of teams had no access at all to this staff group. Furthermore, 15 per cent of teams noted unfilled vacancies for support workers suggesting that even greater numbers were being sought. In addition, many identified other support-level staff in a direct caring role, including team members employed by voluntary agencies (such as the Alzheimer's Society) and a small number identified explicitly as 'home care workers'. Although not systematically collected, data provided in free-text form also identified a number of teams that were integrated with other allied services providing specialist support to people at home. These services, such as intensive home treatment teams and/or crisis resolution services, often shared resources and staffing with the community mental health teams for older people.

The survey also identified a wide range of formal and informal outreach and liaison work undertaken by community mental health teams for older people, including those to domiciliary care providers as well as care homes and day centres (Table 3.1). Two thirds of teams (66%) reported providing some outreach specifically to domiciliary care providers, but this was less commonly provided than that to care

homes or day centres (93% and 77% respectively). Other than general liaison work, the most commonly reported function to each service sector was education or training. Less common was for teams to operate a link worker system. Most, however, also reported other specialist liaison or outreach services provided by the NHS trust which complemented (or substituted) those provided by the community mental health teams for older people. Overall, the level of support provided to domiciliary care providers was less than that accorded to other service sectors (Wilberforce et al., 2010; special analyses).

Table 3.1: Proportion of teams providing support activities (n=365)[1]

Service sector	Open clinics %	Link workers %	Case finding %	Education or training %	General liaison work %
Care homes	6	34	12	61	50
Day centres	<0.5	22	8	36	51
Domiciliary care providers	<0.5	9	<0.5	32	45

[1]Excludes 3% of teams that provided no outreach functions
Source: special analysis

Domiciliary care provision

Study 4 - Mapping Specialist Dementia Services in the North West of England: Domiciliary Care

Here data are presented from a survey of 282 domiciliary care services for older people with dementia in the North West of England which achieved a response rate of 46 per cent. Identified services were defined as 'specialist' insofar as all or part of each service was dedicated to providing care for people with dementia, although the service might not necessarily have regarded itself as a specialist dementia service *per se.* In terms of the characteristics of service users a wide definition of dementia was adopted (Spicker and Gordon, 1997). As in the classic study by Levin and colleagues (1989), the term was used to describe those who suffered from dementia or were confused, though they might not have had a formal diagnosis of dementia. Emphasis was thus placed on the presenting pattern of needs of the older person, rather than a formal diagnosis. First, the service types represented in the sample are described. Second, the characteristics of the specialist and generic services and their recipients are examined. Finally, differences between the two service types are reported in terms of ten standards of practice, each of which comprised between one and 10 quality indicators. These related to three domains: service delivery and care process (systematic assessment and flexibility); service content (individuality, culturally appropriate care and management practices); and service quality (integration, care worker good practice, carer involvement, staff training and contents of briefing documents). A total of 53 indicators were employed in this analysis. To place these findings in a wider context some findings derived from a more recent survey conducted by the National Mental Health Development Unit are also reported.

All services included in the sample had a specialist element focusing on dementia care, but in many this constituted part of a larger service providing generic domiciliary care to older people. Respondents were therefore asked to state the

main function of the service. Table 3.2 shows that domiciliary care services most commonly stated that they were generic in nature (58%). Only a small proportion (9%) regarded themselves as a specialist service for people with dementia. There were 15 'other' services all of which provided domiciliary care in addition to the service they stated as their primary function. These comprised: one home visiting service; one early dementia service; one befriending service for people with dementia; one social services adult placement service; one specialist supported living service; one nursing and care agency; one specialist day care service; one befriending service for people with dementia; one home visiting service; one crisis response service; one sitting service; and four unspecified domiciliary care/community support services.

Table 3.2: Domiciliary care service types - main function of service (n=113)

Type of service	n	**%**
Generic domiciliary care service	65	58
Specialist domiciliary care service for people with dementia	10	9
Specialist domiciliary care service for other groups	8	7
Carer oriented services	15	13
Other	15	13

Source: Venables et al., 2005

Table 3.3 below shows the characteristics of the domiciliary care services in the sample and their service users. The mean proportion of people with dementia per service was approximately one-third, and just over one-quarter of those were regarded by respondents as being severe cases of dementia. Most service users received more than six visits per week. All current service users had dementia in just under two-fifths of services (17%). Generic services tended to have a greater capacity than specialist services, and, as would be expected, specialist services provided for a greater proportion of people with dementia. Similarly, it was more likely for all current service users to have dementia in specialist services than in generic services. Whilst there were more specialist services with above 60 per cent of service users who suffered from dementia than generic services, there were similar proportions of people regarded by respondents as having severe dementia in both types of service. Surprisingly, however, a greater proportion of service users in generic services than specialist services received relatively intense input consisting of six or more visits per week.

Table 3.3: Home care service and user characteristics

	Generic service n=65	**Specialist service** n=10	**Test statistic**	**All services** n=113
Number of service users per service *mean (standard deviation)*	180 (139.9)	49 (48.6)	U=104.0 *p*<.001	140 (131.4)
Proportion of service users with dementia per service *% (mean)*	27 (49)	62 (31)	U=67.0, *p*<.001	32 (45)
More than 60% of service users suffer from dementia or are confused *n (%)*	5 (8)	8 (80)	χ^2=34.13 *p*<.0001	22 (19)
Percentage of service users with severe dementia (of those with dementia) *mean (standard deviation)*	24 (23)	35 (27)	ns	28 (25)
Proportion of service users with dementia who receive 6 or more visits per week *%*	78	48	U=30.0 *p*<.05	76
All current service users have dementia *n (%)*	2 (3)	6 (60)	χ^2=29.47 *p*<.0001	19 (17)

Source: Venables et al., 2006

It was anticipated that specialist domiciliary care services for people with dementia would provide higher standards of care than generic services, based on the indicators utilised by the study. However, there were only significant differences between the two service types on two of the ten standards assessed: flexibility and user-centred practice. With regard to the flexibility standard, it was generic services that appeared to provide the higher quality care.

The three indicators which comprised the flexibility standard were: 24 hour service provided; live-in service provided; and twenty four hour, seven days per week service. It may be that since generic services tended to be larger organisations, this permitted greater flexibility through increased resources and economies of scale. Nevertheless, this finding is of considerable importance in view of the longstanding requirement to provide flexible services for older people with dementia which has most recently been expressed in the 'personalisation agenda' within adult social care services which has as one of its principal requirements that services are tailored to individual needs (Audit Commission 2000; 2002; Department of Health, 2003; 2008).

In contrast, specialist services scored more highly than generic services on the user-centred practice standard, reflecting the fact that a greater proportion provided sessions using memory or life story wallets (Bourgeois and Mason, 1996). Other differences related to single indicators rather than summary scores for the standards used by the study. Perhaps the most important of these related to the practice of keeping briefing documents (a written record of key events and activities) in the service user's home (Department of Health, 2003; Social Policy Research Unit, 2000)**.** Only one specialist service had adopted this practice, compared to more than four-fifths of generic services (86%). All other comparisons were non-significant.

However, since specialist domiciliary care services for people with dementia tended to be smaller and it was more likely for all of their service users to have dementia, it is possible that they were able to provide a degree of increased familiarity and continuity in terms of care provision. This was not an indicator measured by the

study *per se*, but is of considerable importance in the provision of a high quality service due to the intimate nature of domiciliary care (Edelbalk et al., 1995; Godfrey et al., 2000). Furthermore, specialist services were more likely to have close links with other services in terms of shared accommodation and management than generic domiciliary care services, although the difference in overall scores on the integration standard failed to reach significance. Challis and colleagues (2002a) have suggested that the benefits would be greatest where specialist services were co-located or integrated with community mental health teams (Venables et al., 2005; 2006).

Subsequently two of the principal findings from this study - that the concept of specialist domiciliary care for people with dementia is ill defined, rendering it difficult to quantify the amount of such provision; and that, however defined, specialist domiciliary care for older people with dementia is not widely available - have been confirmed in further research, albeit with a range of definitions of generic and specialist provision. As part of a comprehensive audit of specialist mental health services, including those for older people, data on these two forms of domiciliary care services for the latter were sought. Specialist domiciliary care services were defined as provided by support workers having specialist training and/or expertise in older people's mental health. Conversely generic domiciliary care services were defined as those which provided services to all older people with social care needs and whose staff had mental health training. A total of 209 such domiciliary care services were identified. Over three-quarters (76%) were classified as generic and just under two-fifths (18%) as specialist. The remainder (7%) were not classified. Referral to specialist domiciliary care provision as compared with a generic service was more likely to be via a specialist mental health service (42% and 17% respectively). The former were more likely than generic services to accept service users whose needs were defined as being of critical (63% and 36% respectively) or at substantial risk (94% and 48%). Furthermore specialist domiciliary care services were more likely to have smaller caseloads (a mean of 86 compared with 115 per service) (National Mental Health Development Unit, 2008; personal communication).

By matching the postcode of the service to local authorities, it was estimated that 30 local authorities had access to a specialist domiciliary care service for older people with mental health problems, including dementia, and that the generic services as defined by the National Mental Health Development Unit were located in 41 local authorities (special analysis). However, there are important limitations relating to the data overall that must be considered when interpreting the findings. First, the subjective nature of the classification of service types, particularly the definition of generic, may have led to inconsistent reporting across England. This may explain the concentration of such services within a small number of local authorities. Second, and related to this, little is known about the comprehensiveness of the data collection in identifying all relevant services. Third, other potential analyses, such as investigating staff composition of such services, which may have helped to confirm the validity of the broad findings from the National Mental Health Development Unit reported above, were not possible because of high rates of missing data.

Service use

In this section findings are presented from four studies (numbers 1, 8, 9 and 10). In the first two (studies 1 and 8) the findings are derived from audits of care plans from case files held within local authority adult social care services. They relate to the use of generic domiciliary care by service users displaying evidence of cognitive impairment. The first study (number 1) was conducted in three local authorities and the second in a single authority. Both cohorts included service users known to community mental health teams and in study 8 data from this source provided a discrete comparison group. Overall, the broad similarity in the source of the data for these two studies outweighs their differences and should be borne in mind when comparing the findings from the two studies. The other two studies reported in this section (numbers 9 and 10) describe findings derived from interviews with older people and their carers. In study 10 data is provided on the use of generic domiciliary care services by both service users with dementia and those without evidence of cognitive impairment. However, study 9 provides evidence relating to the use of both generic and specialist domiciliary care, referred to in the study as the 'paid helper service', by older people with a formal diagnosis of dementia. An important element of both is that they contain details of the costs of service provision. Together the four studies demonstrate the centrality of domiciliary care in the support of older people with dementia at home and both the importance of generic provision and the complementary role which may be provided by specialist domiciliary care services.

Care plans

Study 1- A Systematic Evaluation of the Development and Impact of the Single Assessment Process in England

This study involved an audit of case files of older people in receipt of care management at two time periods in 2000 and 2005 (n=144 and n=145). Information recorded included evidence of cognitive impairment (defined as severely or moderately impaired) and behavioural problems (defined as wandering, physical/verbal abuse or antisocial acts but excluding depression). Problem behaviours to some extent could reflect those occurring in the later stages of dementia-type illnesses (Department of Health, 2009 p15). There was an increase in the proportion of older people with evidence of cognitive impairment receiving assistance from adult social care services, increasing from 41 per cent in 2000 to 52 per cent in 2005, although this was not statistically significant and may represent improved recording. Similarly, there appeared to be little change in the proportion of older people exhibiting problem behaviour, around 20 per cent at each time frame (Sutcliffe et al., 2008). This suggests that these levels remained stable over time, and that around one fifth of older people supported by community-based services exhibited challenging behaviours, often associated with dementia.

There was significantly less provision of generic domiciliary care, services from the local authority, but more independent sector domiciliary care; however, this was not commensurate with the reduction in local authority provision (Challis et al., 2006). This suggests an overall reduction in domiciliary care provision, with independent

sector organisations substituting to some extent for that previously provided by the local authority.

Presence of cognitive impairment was not associated with receipt of generic domiciliary care, with similar levels of provision for those with or without evidence of cognitive impairment at each time frame. Further analysis of the data revealed that high intensity of domiciliary care services (more than seven domiciliary care visits weekly) was not associated with cognitive impairment. Thus, receipt of generic domiciliary care and intensity of receipt did not appear to be related to service users' levels of cognitive impairment (special analysis).

Study 8 - Services for Older People with Mental Health Problems: The Balance of Care in Cumbria

Data from this study has permitted an exploration of the link between the mental state of an older person and their receipt of help - personal care, meals and domestic assistance - in their own homes. Such assistance is typically provided by domiciliary care services, either the local authority or independent sector organisations. Case files from two sources have been examined: those of community mental health teams for older people based in a NHS mental health trust and those of the local authority adult social care services in the same geographical area. In the subsequent analysis the presence of dementia was determined by either a diagnosis of organic mental illness for patients of the community mental health teams for older people or by the Minimum Data Set Cognitive Performance Scale (Morris et al., 1994) for local authority service users.

For 79 patients of the community mental health teams for older people data were available about both their broad diagnostic category and their receipt of domiciliary care. Those with a diagnosis of an organic mental illness (n=44) – often dementia - received an average of 5.4 hours domiciliary care per week. In comparison patients with a dual diagnosis of organic and functional mental illness (n=7) received 6.2 hours per week. A picture of more intensive provision emerged when the same analysis was conducted in respect of only those patients who were in receipt of domiciliary care. In these circumstances patients with a diagnosis of an organic mental illness (n=23) received an average of 10.4 hours domiciliary care per week. In comparison patients with a dual diagnosis of organic and functional mental illness (n=5) received 8.6 hours per week.

Data in respect of the MDS CPS and receipt of domiciliary care were available in respect of 202 local authority service users. The pattern of service receipt was similar to that noted for patients of the community mental health teams for older people with a higher level of service when the same analysis was conducted for only those patients who were in receipt of domiciliary care as demonstrated in Table 3.4. This also reveals that the greater the level of cognitive impairment the more domiciliary care was received by the service user.

Table 3.4: Cognitive impairment of service users and receipt of domiciliary care

MDS CPS rating[1]	Mean frequency of domiciliary care (hours per week)	
	All service users (n=202)	Service users in receipt of domiciliary care (n=120)
Relatively intact	5.7 (118)	9.5 (71)
Mild impairment	6.3 (34)	9.0 (24)
Moderate impairment	6.1 (36)	12.2 (18)
Severe impairment	7.1 (14)	14.1 (7)

[1]Morris et al., 1994
Source: special analysis

To complement the data presented above findings from another part of the study relating to a cohort of admissions to acute inpatient care and admissions to care homes were examined to explore the care needs of older people with dementia living in the community. This is clearly more speculative and is based on the premise that if the infrastructure to support older people with dementia in the community was more developed some of these admissions could have been prevented. Nevertheless, the data presented below suggest that difficult behaviour associated with some forms of dementia and an absence of sufficient care at home precipitated the admission of older people with dementia to hospital or a care home. The evidence for this is derived from two sources. First, data on 26 admissions to an acute mental health inpatient ward of older people with a diagnosis of an organic mental illness. In 11 instances a 'breakdown of care' contributed to the admission. This might suggest that this is a group the formal community services find particularly difficult to support as currently resourced and organised, a hypothesis to which further weight is lent by the five instances in which concerns about medication contributed to the need for inpatient care. Second, data on 125 care home entrants who, according to the MDS CPS, had at least mild cognitive impairment. This revealed that almost two thirds (65%) displayed challenging behaviour; whilst only just over a half (55%) received help with personal care; just under a half (43%) assistance with the provision of meals; and a quarter domestic assistance including shopping (special analysis).

Service user and carer outcomes

Study 10 - The Value of Specialist Clinical Assessment of Older People Prior to Placement in Care Homes

For this sample, 256 older people in receipt of social and health care services, 59 (23%) had dementia and 181 (71%) did not with 16 (6%) having insufficient data relating to the assessment of cognitive impairment. Of these cases, similar proportions, 24 (41%) people with dementia and 80 (44%) without, received generic domiciliary care services. The average number of hours of domiciliary care received by those with dementia (63 hours over six months) was not significantly different from those without (55 hours). Thus, the mean six-monthly cost of domiciliary care for those with dementia (at 2000/01 prices) was £709 as opposed to £607 for those without. For the carers of those receiving domiciliary care, mean carer costs over six months were £790 for those with dementia as opposed to £246 for those without. However, although apparently higher as simple averages, this difference was not significant after taking into account the skewed distributions of costs and the fact that

more people with dementia had died at the end of the six-month study period (carer costs 'per week alive', for example, were broadly similar, £19 and £14 respectively).

From this base of similar levels of expenditure on generic domiciliary care services, outcomes for those with dementia who were receiving domiciliary care during this study period were examined at six months. In respect of one important service outcome, that of service satisfaction (Larsen et al., 1979), average levels of satisfaction, between those with dementia and those without, were similar and were towards the 'good' or 'mostly satisfied' end of the scale. Those with dementia receiving generic domiciliary care services were broadly as satisfied as those not receiving them. This included aspects such as the quality of the service, whether users received the amount and kind of service they wanted, whether it met their needs, and whether it helped them to deal more effectively with their problems. Self-rated health (Ware et al., 1993), often elicited through proxy carer responses, was also broadly similar between those with and without dementia, on average in the region of 'fair' to 'good'. Again, those with dementia receiving domiciliary care rated their health as broadly similar to those not receiving domiciliary care. Objective quality of life, in terms of the home, leisure, relationships and opportunities (Ager, 1993) was also broadly similar in those with dementia, whether they received domiciliary care or not. Behavioural functioning (the CAPE Behaviour Rating Scale; Pattie and Gilleard, 1979), however, was significantly worse in those with dementia; this finding may be expected and is probably something which domiciliary care services *per se* are not designed to impact upon. Behaviour was rated similarly for those people with dementia receiving domiciliary care and those not.

Overall, therefore, the costs of generic domiciliary care services for dementia in one local authority were broadly similar to those of older people referred more generally for assessment who did not have dementia. Benefits of generic domiciliary care were also broadly similar in terms of satisfaction, self-rated health and quality of life. Behavioural functioning was understandably worse for people with dementia but did not differ for those people with dementia who received generic domiciliary care services as against those who did not. (Challis et al., 2004; Clarkson et al., 2006; special analysis)

Study 9 - Supporting People with Dementia at Home

This study (known as the Lewisham intensive case management scheme) provides evidence relating to economic and individual outcomes to inform the debate about the efficacy of different models of community support to persons with dementia. A group of older people with dementia in receipt of intensive care management (experimental group n=45) were compared with a similar group receiving statutory care services (control group n=50). A specialist paid helper service - which could also be described as a specialist domiciliary care service - provided an additional flexible service to those in the experimental group. Paid helpers completed a wide range of tasks to assist in household activities, personal care, social needs including companionship for older people and their carers. In terms of paid carer input, for every hour of care provided by an informal carer 3.5 hours of paid care were provided. This compared to 1.6 hours of paid care for the control group. Risk factors which might prompt care home admission (carer distress, service user activities of daily living, behavioural problems, health and home environment) were

rated by researchers as present in equal proportions in each group at referral. However by 6 months there was a significantly greater reduction in these factors among those in the experimental group, and maintained over 12 months, thus reducing the risk of placement. In terms of continued community tenure, differences emerged between groups after the second year of the scheme, with half (51%) of the experimental group and a third (33%) of the control group remaining at home, showing a positive effect of the scheme. This reduced rate of placement applied equally to those living alone, and those living with a carer. Furthermore, of those assessed as having 'severe dementia' (Organic Brain Score of 6+, Gurland et al., 1977), there was also a significant difference between the two groups in respect of destinational outcome, with those in the control group being almost twice as likely to be admitted to a care home, suggesting that the scheme was successful in providing care for people with severe cognitive impairment.

In terms of service user outcomes, there was a reduction in most areas of unmet need in the experimental group, in particular daytime company for the older person. The proportion of service users with identified needs in areas of personal care such as washing, dressing and help going to bed, declined more in the experimental group reflecting difficulties for existing services in responding to these. However there was a significant reduction in indicators of need associated with activities of daily living for the experimental group particularly in relation to 'rising and retiring' underlining the capacity of the paid helper scheme to provide care outside regular working hours. At 6 months those in the experimental group were significantly more satisfied with their home environment compared to the control group, however, there were no differences in levels of depression, or in the frequency of service user activities in the home.

With regard to outcomes for carers, a significant reduction was seen at twelve months in the level of informal carer input in terms of number of hours caring, for those in the experimental group, indicating a reduction in the physical burden of caring. Carers in each group completed the Malaise Inventory, a measure of psychological and somatic health. There were no differences apparent at 6 months, however by twelve months scores were significantly lower for carers in the experimental group indicating lower levels of stress. Furthermore, there were no differences in scores for carers who lived apart from the older person with dementia, but co-resident carers in the experimental group had significantly lower scores after twelve months than those in the control group. There did not appear to be any differences between the carers in either group in relation to carer strain or overall life burden at either time frame (Challis et al., 2009a).

This study also provided data to inform the debate as to whether it might be cost-effective to provide specialist or generic domiciliary care services for people with dementia. Overall, the costs of health and social care services were significantly higher for the experimental group (n=43) compared to the control group (n=43) mainly accounted for by: domiciliary care in the form of the paid helper service (a specialist home support provision) and consequently significantly greater number of domiciliary care hours per week; costs of extra professional visits including case management; and acute hospital care. The control group received more respite care away from home. The experimental group also received private domiciliary care demonstrating the ability of care managers to use services more flexibly. In respect

of the contribution of carers, there were higher costs associated with caring for those in the control group although the difference was not significant. Further analysis indicated that the main element of this cost was the time involved in caring. There was also a higher cost to society incurred by the experimental group, the majority of this cost accruing to local authority social care services. This higher cost was offset to some extent by lower costs incurred by carers in the experimental group as a result of receiving the case management service. The balance of costs between carers and services highlights the extent to which the scheme was able to benefit carers in terms of service provision, cost reduction and outcomes.

A number of factors associated with variations in costs were examined. Analyses showed that community care package costs were higher in both groups where there was evidence of deterioration in behaviour. A single diagnosis of Alzheimer-type dementia was associated with lower agency and societal costs in the experimental group, suggesting that greater complexity of psychiatric need required more intervention. Although support of female service users incurred higher agency and societal costs in both groups, this may be explained by lower costs for male service users the majority of whom lived with female carers. The presence of a carer reduced care package costs in each group whilst a carer's desire for placement of their relative raised agency costs in both (Challis et al., 2009a).

Service commissioning

In this section data is reported from five studies (numbers 2, 3, 5, 7 and 8). Two studies (numbers 2 and 7) describe local authority commissioning arrangements for domiciliary care services with findings related to those focussing on older people with dementia highlighted. Together they provide a summary of current arrangements with regard to domiciliary care and other services which provided support to older people, including those with dementia, living at home. In the context of the present study this is important information because it provides an insight into the nature of assistance described by the overarching term 'domiciliary care' and forms of assistance which might complement or substitute for it – whether a specialist or generic service. Furthermore, it provides the context for micro level commissioning, the means by which the components of a care plan are determined by either a care manager or, with the introduction of personal budgets, the service user or their agent (Department of Health, 2008). A balance-of-care approach provides the framework for data from a further two studies (numbers 3 and 8). Such studies are typically used to inform strategic planning processes in health and social care. Their value is that they provide data to facilitate consideration of whether the existing use of resources between locations of care is 'optimal' and in which of these locations any increase or reduction of resources should be made (Hughes and Challis, 2004). Here data are presented which focus on the needs of people with cognitive impairment and particular attention is paid to the nature of the domiciliary care provided in the analysis. Finally in this section stakeholder views on domiciliary care services for older people with dementia are explored. Findings from study 5 are specific to domiciliary care and were provided by managers of community mental health teams. In contrast study 8 places priorities for the development of domiciliary care in the wider context of services to support older people with mental health problems in the community and is derived from the views of multiple stakeholders.

Commissioning arrangements

Study 7- Recruitment and Retention of the Social Care Workforce for Older People

Here data are provided from a national survey of local authorities which obtained a 73 per cent response rate (n =109) following two waves of data collection (Hughes et al., 2009; 2010). Information was obtained relating to the commissioning of generic and specialist domiciliary care services for older people with mental health problems and the inclusion of specialist dementia training either as part of their contract with independent sector providers or as a requirement for their in-house domiciliary care provision.

Around four-fifths (78%) of local authorities reported that the care of older people with mental health problems was a focus of their overall independent sector domiciliary care provision. This was compared to just over half (56%) of authorities who reported this to be a focus of their in-house service. Two-fifths of authorities (41%) reported a focus on old age mental health in both sectors. With regard to specialist domiciliary care provision for older people with mental health problems, just under a quarter (24%) of local authorities reported that they commissioned such a service. Around a third (32%) of local authorities reported that they commissioned specialist domiciliary care workers as part of a jointly commissioned old age mental health service. These findings suggest that, whilst some local authorities may consider themselves to have a specific focus within their domiciliary care services on the needs of older people with mental health problems, they may not necessarily do this by commissioning specialist provision for this group.

Two findings from this study are of note in respect of specialist dementia training for domiciliary care workers. First, over four-fifths (87%) of local authorities provided dementia care training for staff within their in-house service with just under two-thirds (62%) making this available to those working in the independent sector. Second, just under half (47%) reported that specified specialist dementia training was one of their requirements in their contracts with independent providers. Interestingly, subsequent analysis based on data from this study found that this indicator was associated with lower turnover of domiciliary care workers (Chester et al., 2010a). Information relating to local authority training provision, including that relating to the care of older people with dementia, also formed part of the basis for identifying different approaches to commissioning and contracting social care services for older people (Chester et al., 2010b).

Study 2- Care Coordination for Older People

The findings from this survey of local authorities, which achieved a 79 per cent response rate, complement those described above in the sense that they provide information on the commissioning of old age mental health services and the range of support which is potentially available to support older people with dementia in their own homes.

In terms of the range of social care services available to support older people, including those with dementia, this study revealed that in most local authorities generic domiciliary care was available through both in-house and independent sector

providers for the provision of personal care (90% and 92% respectively). In a similar proportion older people were also able to use direct payments, the forerunner of personal budgets, to purchase personal care from the independent sector (Department of Health, 2008). It is also notable that for both older people and their carers, services such as shopping and housework were more likely to be purchased by this means than arranged by local authority care managers as part of a care plan. Short breaks and other forms of respite care which may complement or substitute for domiciliary care could be sourced through either type of funding, but were more likely to be provided for older people than as part of a care plan to support their carers.

About half of the respondents to the questionnaire (52%) reported that their local authority jointly commissioned old age mental health services, and just over half of these (27%) involved the employment of 'generic hands-on workers', paid care workers whose responsibilities span health and social care. It is possible that these staff may provide an alternative or complementary source of support to older people with dementia living in their own homes to that available from a either a generic or a specialist domiciliary care service. Less than a fifth of local authorities (17%) reported that old age mental health services were delivered through a single organisation responsible for the provision of health and social care such as a care trust (Challis et al., 2009b; Xie et al., 2010).

Balance-of-care

Study 8 - Services for Older People with Mental Health Problems: The Balance of Care in Cumbria

Some of the findings from that part of the study which employed a balance-of-care approach are reported here. In this practitioners were asked to identify for which groups of older people with dementia care at home was a feasible alternative to admission to a care home or hospital. Additionally they were asked to specify the care they would require from community based services to achieve this, from which the cost compared to admission to a care home place or an acute inpatient bed was calculated. This provides a perspective on future service development from frontline staff, derived from individual patient/service user characteristics and circumstances, which complements the observations detailed above in the previous section from team managers. It is based on costed care plans, the components of which were agreed by those currently responsible for the care of such people in local authority adult social care services and community mental health teams for older people working together in small groups. In Table 3.5 evidence is provided of the costs of care at home compared with care home or acute inpatient admission. It is derived from information extracted from the costed care plans estimated for the four case types with dementia for whom care at home was perceived feasible.

Table 3.5: Older people with dementia – care at home versus care home or acute inpatient admission

Care home entrants with the potential for diversion			
Characteristics of case types	**Weekly residential cost per user (gross)[1] £**	**Weekly community cost per user to social services (gross)[1] £**	**Weekly community cost per user to health services[1] £**
Female, no carer dependent, cognitively impaired	325	138	70
Female, carer, medium dependency, cognitive impairment	377	292	-
Inpatient admissions with the potential for diversion			
Characteristics of case types	**Daily inpatient cost* £**	**Daily community cost per user to social services (gross)* £**	**Daily community cost per user to health services* £**
Female, no carer, risk of accidental self-harm / self-neglect	196	-	25
Male, carer, non-specific concerns	196	12	9

[1]2003/04 costs
*Source: Tucker et al., 2008

Several points are of note in the context of this enquiry which seeks to explore the relative importance of specialist and generic domiciliary care provided to people with dementia. The two case types for which care at home was adjudged to be a viable alternative to admission to long-term care accounted for approximately nine per cent of all admissions within the local authority in which the study was conducted over a 6 month period. In the construction of the care plan there was an assumption that the specified amount of domiciliary care would be available, together with day care tailored to the needs of older people with dementia and the input of community support workers. Analysis of these care plans revealed that domiciliary care was not envisaged as being from a specialist provider and that it would be complemented by specialist services for older people with dementia: day care provided by the local authority and community support workers funded by the NHS. This vision of effective community support for older people with dementia is not dissimilar from that identified as an exemplar of good practice in the current national dementia strategy (Department of Health, 2009) some findings from which are summarised above (*Supporting People with Dementia at Home).* This model of service provision is one in which generic domiciliary care is complemented by specialist community based support for older people with dementia.

The two case types for which care at home was adjudged to be a viable alternative to admission to hospital accounted for approximately 10 per cent of all admissions to hospital in which the study was conducted over a six month period. The care plans constructed to permit the older persons with dementia to receive appropriate care at home were primarily resourced from within the community mental health team, and, in particular, community mental health nurses, occupational therapists and community support workers. It is interesting to note that neither of these care plans included domiciliary care. In the one case where social care costs were prescribed

these were for day care one day per week and a regular programme of residential respite care. However, the involvement of community support workers (funded by the NHS), might be an alternative to the provision of specialist domiciliary care as part of a care plan constructed as an alternative to an acute inpatient admission. Overall these findings suggest that, in the area in which the study was conducted, practitioners deem generic domiciliary care as appropriate to meet the needs of older people with dementia at home if specialist support is available from community support workers. Furthermore, the role of the latter becomes particularly important if the older person with dementia is at risk of hospitalisation, suggesting that their involvement is appropriate if the patient/service user has care needs as a consequence of their dementia rather than those simply associated with the loss of the ability to perform tasks associated with, for example, food preparation and personal care.

Study 3 - Estimating the Balance of Care

As part of an earlier balance of care study a comparison was made between a group of people admitted to care homes form the community and a group of people who were supported at home by an intensive care management service, coordinating a range of services typically including a substantial amount of domiciliary care, in the same area (Challis et al., 2002c; Challis and Hughes, 2002). As Table 3.6 demonstrates a greater proportion of those with severe cognitive impairment received assistance at home from the intensive care management service compared with those who entered long-term care from the community. It is also noteworthy that those who were in receipt of intensive case management had higher levels of physical dependency compared with those admitted to care homes. This provides additional evidence of the capacity of intensive care management to support vulnerable older people in their own homes. However, more recent research has demonstrated that only a minority of adult social care services have an intensive care management service focusing exclusively on older people at a high level of risk or with high needs, circumstances particularly associated with older people with dementia living alone in the community (Challis et al. 2009a).

Table 3.6: Comparison of the characteristics of older people admitted to long-term care from the community and those in receipt of intensive care management

	Case type	
	Admissions to long-term care from the community n=90 (%)	Receipt of intensive care management at home n=32 (%)
Cognitive status[1]		
Intact or mild impairment (MDS CPS 0-3)	72 (80)	20 (62)
Severe impairment (MDS CPS 4-6)	18 (20)	12 (38)
Dependency[2]		
High dependence (Barthel 0-8)	16 (18)	19 (59)
Moderate dependence (Barthel 9-11)	22 (24)	7 (22)
Low dependence (Barthel 12+)	52 (58)	6 (19)
Chi-squared test: Cognitive impairment: χ^2= 3.89 P<0.05 Dependency: χ^2=20.24. P<0,001		

[1]MDS CPS (Morris et al., 1994)
[2] Barthel Index (Mahoney and Barthel, 1965)
Source: Challis and Hughes, 2002

Stakeholder views on service development

Study 5 - Mapping Specialist Dementia Services in the North West of England: Professional Teams

As noted above, this study comprised a postal questionnaire distributed to community based teams providing care to older people with dementia in England and elicited a 59 per cent response rate (52 teams). Respondents were asked to note any serious gaps in services for people with dementia that they were aware of in their area. They were provided with a list of services including domiciliary care and asked to provide further details of the identified gaps. Almost two-fifths of respondents (39%) reported a serious shortage of domiciliary care provision. A smaller number provided further details. These are listed in Box 3.2 below and clearly demonstrate the importance attached to dementia care being supplied by workers with specialist knowledge of the condition. There were also a number of comments relating to the lack of services in general for people with young onset dementia. These are listed in Box 3.3 and demonstrate an absence of services – not just domiciliary care for this group of people (Abendstern et al., 2005; special analysis).

Box 3.2: Comments relating to lack of specialist home care services for people with dementia

- Home care is not always given due to the person with dementia stating they can manage and the social services assessing not understanding
- Home care do not have specialist skills
- Home care limited by budgets
- Limited number of specialist services – home care
- More specialised home care needed
- Insufficient home care – inflexible/time limited / task oriented
- Home carers need training and coping strategies
- Expert home care staff with people in own homes is limited
- Very little specialist dementia care with residential care and none in home care

Source: Abendstern special analysis

Box 3.3: Comments relating to lack of services for people with young onset dementia

- All (services) are deficient within our area for clients with early onset dementia
- Younger people with dementia services poor
- Need for coordinated services for younger people
- There is currently no facility for younger people with dementia
- (Lack of) early onset dementia services
- No local services for those with younger onset dementia which are appropriate

Source: Abendstern special analysis

Study 8 - Services for Older People with Mental Health Problems: The Balance of Care in Cumbria

In the context of stakeholder views on service development this study provides data from two sources. First, conclusions are presented from an extensive consultation with staff – social workers, community and hospital based nurses, general practitioners and old age psychiatrists – and carers and older people with dementia, which relate to domiciliary care arrangements. These are summarised in Table 3.7 below. Services for younger people with dementia were identified as requiring development. Overall, stakeholders expressed satisfaction with domiciliary care provision in their area, which at the time the consultation took place was what we have described as a generic service in this study.

Table 3.7: Stakeholder views on domiciliary care arrangements

• Over three quarters of general practitioners stated that domiciliary care services for older people with mental health problems were fully / mostly available (n=88, 76%).
• Over three quarters of social services staff stated that domiciliary care services for older people with mental health problems were fully / mostly available (n=17, 76%).
• Over half of specialist mental health staff stated that domiciliary care services for older people with mental health problems were fully / mostly available (n=19, 53%).
• General practitioners, social services staff, specialist mental health staff and carers and older people did **not** identify the development of domiciliary care services as an area for future development when asked to select three from a list of 21 services.
• Social services staff, specialist mental health staff and carers and older people did identify specialist services for younger people with dementia (which may include domiciliary care) as an area for future development when asked to select three from a list of 21 services.

Source: Tucker et al., 2005

Conclusion

In this section the principal findings from the 10 studies conducted by the PSSRU at the University of Manchester are synthesised. The narrative follows a similar structure to that of the chapter. First, observations relating to the service context in which specialist and generic domiciliary care services are located are presented. Second, the evidence relating to the use of the domiciliary care services by older people with dementia is reviewed with particular emphasis on the data available relating to the cost-effectiveness of generic and specialist provision. Finally, data relating to service commissioning arrangements are critically appraised. In the final chapter of this report these conclusions will be reviewed alongside those of the literature review (chapter one) and the appraisal of the current state of service provision described in chapters four, five and six.

The broad review of the service context at the beginning of this chapter provides some important contextual information to inform decisions about whether it is more cost-effective to provide specialist or generic domiciliary care services for people with dementia. One of the most important conclusions is that definitions of specialist domiciliary care vary and some generic services have a specialist component providing care to older people with dementia. Equally, whilst specialist domiciliary care services are often targeted on service users exposed to high levels of risk and may take referrals only from a specialist team, they often do not cater solely for older people with dementia. Thus it is important to develop a clear specification for the service. Research has demonstrated that specialist domiciliary care services solely for older people with dementia are likely to be more user centred in their practice and to have better links with community mental health teams for older people. On the other hand, generic services which had a specialist element focusing on dementia care provided more intensive help and demonstrated greater flexibility in terms of service availability. The paradox of this is that older people with dementia require all four of these features, with the flexibility component particularly allied to the goal of personalisation in adult social care services (Department of Health, 2008).

Historically, support planning for older people with dementia as part of the care management process has largely been undertaken by care managers or their equivalents in either single discipline or multidisciplinary specialist old age mental health teams. However, some care managers specialising in this work are based in local authority old age teams. Whilst most of these staff continue to be employed by the local authority, a substantial minority are now employed by NHS trusts. Since older people with dementia typically have complex needs it is likely that even with the advent of personal budgets support planning will continue to be undertaken by care managers (Cm 6499, 2005). Furthermore, within care management other research evidence has demonstrated that links with service providers, which permit people to have intensive support at home and choice in its content are associated with positive outcomes (Challis, 2003). Thus the location of these staff and their links with specialist provision – however it is defined – are considerations to be taken into account in the development of an overarching service framework for specialist domiciliary care for older people. The studies reviewed in this chapter provide some interesting insights into how community mental health teams for older people might forge this relationship. First, there is some evidence of staff from these teams providing support to domiciliary care providers as part of their outreach service as

recommended in policy guidance (Department of Health, 2001). Alternatively domiciliary care workers may be based in community mental health teams for older people and work exclusively with service users known to the team. A variant on this approach is for a specialist domiciliary care service (i.e. a domiciliary care organiser and domiciliary care workers) to be a part of a community mental health team. As noted above, even in these circumstances it would be rare for such a service to focus solely on the needs of people with dementia. Such considerations must, however, be viewed in the context of the contribution of support workers in community mental health teams and the potential of role overlap between the two staff groups.

With regard to service use, audits of care plans over time have demonstrated that generic domiciliary care services provide assistance to a substantial number of service users with dementia with some evidence that the level of support offered increases with the severity of the condition. Moreover, a study of service user outcomes has demonstrated that this can be provided at a similar cost to that received by older people who are cognitively intact and that the benefits are similar in terms of satisfaction, self-rated health and quality of life. There is, however, some evidence from analysis of data relating to admissions to care homes or an acute mental health inpatient ward for older people that difficult behaviours often associated with the later stages of dementia-type illnesses are precipitating factors. One possible conclusion might be that on occasions this group of people require a level of support in the community that is not available from a generic domiciliary care service. This would suggest that specialist domiciliary care services should be targeted on older people with severe dementia and or co-morbidities associated with either physical or functional mental illness. There is also evidence that the joint provision of support by both generic and specialist domiciliary care services can reduce the risk of admission to a care home, particularly for older people with severe dementia. Indeed, such arrangements produced improved outcomes for both older people with dementia and their carers compared with a similar cohort of service users who did not have access to a support from a specialist domiciliary care service. These observations provide the context to inform decisions about the relative costs of generic and specialist domiciliary care.

Whilst extrapolating evidence of the cost-effectiveness of specialist domiciliary care for older people with dementia is not easy, the PSSRU study identified as an exemplar of good practice in the current national dementia strategy provides some insights (study 9). First, the cost of using specialist domiciliary care supporting older people with dementia at home seemed to be higher than assistance solely provided by a generic organisation. It is therefore important that judgements about the cost-effectiveness of the services are made in the context of its receipt by services users with similar levels of need. Hence, as noted above, specialist domiciliary care must be targeted on those with severe needs and/or co-morbidities and its cost-effectiveness judged in respect of service users with these characteristics. Second, the time frame over which judgements of cost-effectiveness are made is also important. Typically the cost of care at home is compared with admission to long-term care and, for this to have a resonance, judgements must be made over a substantial period. For example, in study 9, differences in the rate of admission to care homes between service users with access to the equivalent of a specialist domiciliary care service and those with a generic service were only apparent after

they had received the support for more than one year. Third, it is axiomatic that the apportionment of the additional cost will be borne by the agency responsible for the provision of specialist domiciliary care. In the study described above it was ascribed to the local authority who took responsibility for the paid helper service which was in effect a specialist domiciliary care service. On the other hand, if community support workers provided a service equivalent to that provided by staff from a specialist domiciliary care provider, it is not inconceivable that the cost of it would be ascribed to the NHS. Finally, study 9 demonstrated reduced costs to carers where the older person received assistance from the specialist domiciliary care service, demonstrating the transfer of cost from the informal care sector to the formal sector. This balance of costs between the formal and the informal care sectors is one which must be addressed in the context of the cost-effectiveness of dementia care.

In terms of service commissioning, it is relevant to note that most domiciliary care provided for older people with dementia is provided by generic rather than specialist organisations. However, these providers are often required to demonstrate within the commissioning and contracting process that they can address the requirements of older people with dementia. There is also some evidence that within the commissioning process specialist training for those providing direct care for older people with dementia is recognised, reflecting the stakeholder perspective that training for this staff group is important . The provision of specialist domiciliary care services for older people with dementia is most likely to be provided as a consequence of a joint commissioning strategy for old age mental health services. However, there is rarely a single provider for this. An alternative service configuration is the provision of specialist support workers within an old age mental health team providing support to older people with dementia together with home care workers employed by a generic service provider. More generally, a lack of appropriate services for people with early onset dementia was noted.

Domiciliary care is only one of a range of services required to support older people with dementia and their carers at home and contributes to the service mix in a care plan. For carers particularly the provision of respite services is important. It is particularly important that, whether sourced from a generic or specialist provider, domiciliary care is available in sufficient quantity to provide for the multiple needs of older people with dementia. More generally whilst generic domiciliary care services typically focus on the provision of personal care, service users and carers also value help with housework and shopping. Thus, greater diversification of services may be required from generic domiciliary care providers with the increasing use of personal budgets by service users and their carers. Irrespective of who is responsible for the support plans for older people with dementia the range of services they require to enable them to continue to live in their own homes is considerable. Nevertheless, there is evidence that with this support, coordinated by a case manager often referred to as ‘intensive care management’, older people with dementia can be maintained in their own homes (Challis et al., 2002a; 2009a; Challis, 2003).

CHAPTER 4: THE VALUES AND PREFERENCES OF CARERS OF PEOPLE WITH DEMENTIA: A DISCRETE CHOICE EXPERIMENT

This element of the investigation in particular was intended to focus on one of the main objectives of the study, to provide *individual outcomes evidence for the efficacy of different models of community support to persons with dementia*. Given the short time period for the study and the aim of providing up to date evidence, it was not possible, as is established practice, to investigate outcomes through interviews with samples of service users using standard research measures. An alternative, presented here, was to seek the views of carers on the different characteristics, or attributes, of home care services for people with dementia. These characteristics were those where, from the literature, variation could be expected between generic home care services and those designated as more specialist. This exercise therefore aimed to provide evidence of the value carers place on particular attributes of home care services. This used a Discrete Choice Experiment (DCE) to elicit and model their choices.

DCEs have been used previously in health care as a way of eliciting patients' preferences for particular attributes (or characteristics) of health care and their choices as to which they would prefer, bearing in mind that these attributes may often conflict. There will often be a trade off, for example, between attributes such as continuity of care (seeing the same staff member) and cost or waiting time for a service (Ryan et al., 2001). Patients are asked to choose between sets of hypothetical scenarios describing a service in terms of various characteristics and levels, such as different costs or different opening times of services (Hall et al., 2004). Their choices from each of a series of these choice 'sets' are modelled using regression analysis, to determine the relative importance of characteristics, the trade-off between them (and if a cost variable is included this can be interpreted as their marginal willingness to pay for particular characteristics) and the overall benefit for alternative ways of providing a service (Ryan et al., 2001).

There have been limited applications of DCEs in social care. Ryan et al. (2006) used the approach to estimate older people's preferences to design an outcome measure for social care. Nieboer and colleagues (2010) modelled preferences for various attributes of long-term care services in the general population. Hall et al. (2007) used a DCE to elicit carers' preferences in terminal illness. All these applications stress the benefits of initial qualitative investigations to determine sets of attributes, and levels for these, before the presentation of scenarios from which modelling and data analysis are derived. In the present study, a DCE offered a credible means of obtaining carers' preferences for different aspects of specialist home care for people with dementia, which reflected features derived from the literature and that were also grounded in the real world of carers' experiences. Such a method enables the choices faced by carers to be clarified, for instance between greater availability or specific training of home care workers and cost or a waiting period for service.

Methods

Both Lancsar and Louviere (2008) and Douglas et al. (2005) outline the stages of a DCE: identifying attributes; assigning levels to each attribute; designing the choice

sets; presenting them to respondents as questionnaires; and analysing their responses using regression analysis. The reporting of this element of the study follows these stages and the approach adopted, with supporting information, is introduced at each stage. A final stage, after the experiment itself had been conducted, was a qualitative review by groups of carers of people with dementia who offered their comments on the method and also on their experiences of home care provided within their areas.

Identifying attributes

Given that little is known about the precise attributes of specialist as opposed to generic home care services for people with dementia, these were identified through a number of sources. Previous studies from the earlier literature review (see chapter two) were first used to identify a number of characteristics of specialist versus more generic services (Venables et al., 2006; Rothera et al., 2008). Information from these was supplemented by the views of carer representatives, local authority commissioners and carers themselves in two focus groups specially convened for this study (with seven participants each) run in North West England. These participants identified salient issues in terms of the provision of home care for people with dementia and how different attributes characterising more specialist provision were differentially valued. As the DCE literature suggests, such attributes should show real world validity, reflect a range of features available and be capable of being traded off (Turner et al., 2007). That is, they should be at several levels to permit the person to form a compromise between positive and negative aspects (for example the potentially higher cost of specialist provision as against greater personal contact or training).

These consultations resulted in a list of features of home care services, specifically for people with dementia, that were described as important, higher degrees of which have been viewed as characterising specialist home care. This list reflected some attributes that were more salient to commissioners of services, such as whether documents specific to the assessment of the person with dementia were left in people's homes. Items such as this were omitted after a review by two of the researchers in the team concluded that carers might not be expected to have information on such aspects. The final list of features resulted in seven attributes of home care services that might be expected to vary from generic to specialist services and for which carers may have some knowledge as the service is provided (Table 4.1).

Assigning levels to each attribute

Levels of each attribute in the experiment were assigned to reflect values of generic home care and the likely values if more specialist home care was introduced. These levels and the coding for them for the regression analysis are described in Table 4.1. The levels were chosen to be realistic and plausible in the real world when presenting them to carers as choices. It was decided to assign all seven of the chosen attributes to three levels for each, so as to permit a sufficiently wide range of levels and for non-categorical attributes (for example waiting times) to be as evenly spaced as possible to assist estimation, as recommended in the literature (Lancsar and Louviere, 2008).

Table 4.1: Attributes and levels in the carers DCE

Attributes	Levels		
1. Home care workers use life story or memory wallets[1]	Not at all	To some extent	Fully
2. There is a waiting list for this service[2]	No waiting list	5 weeks	10 weeks
3. Home care workers are available[1]	Day time only Mon-Fri	Night time Mon-Fri also if required	Weekends also if required
4. Respite opportunities for carers[1]	Not provided	Limited respite service	Full respite service for weekends and longer periods
5. The home care worker visiting[1]	Can be a different person each time	Varies from time to time	Is the same person each time
6. The cost of this service is[2]	£140 per week	£170 per week	£200 per week
7. Home care workers have additional training in dementia care[1]	No training	Some training	Full training

[1] Attributes coded as dummy variables
[2] Attributes take numerical value

Most of the attributes were assigned three categorical levels (for example 'not at all', 'to some extent', 'fully'). These were entered in regression analysis (below) as dummy coded variables (taking a value of 1 if that level was present in a chosen scenario and 0 if not). However, two of the attributes, waiting time and cost, were given numerical values. These were assigned realistically, taking into account the context as presented to carers in the real world, drawing on the initial consultations. For the cost attribute, numerical values were chosen from real unit costs of home care in England. The average unit cost of home care of £14 per hour, taken from the Dementia UK report (Knapp et al., 2007), was chosen as the first level, assuming an average duration of care as being 10 hours per week for generic home care for someone with dementia (therefore, £140 per week). For the second level, this average cost was raised by one standard deviation on the distribution of unit costs taken from the Key Indicators Graphical System (PAF indicator B17) again assuming an average duration of 10 hours per week. For the third level, this unit cost was raised by two standard deviations from the average and applied to the assumption of 10 hours per week. Allowing some levels, such as cost, to take a numerical value permitted marginal rates of substitution of other attributes to be calculated, for instance the carer's willingness to pay.

Designing the choice sets

In order to model choices and determine the most important preferences of carers, the attributes and levels chosen needed to be presented as choice sets; that is, combinations of attributes at different levels where each carer could be offered a choice between hypothetical scenarios. These combinations, or choice profiles, are deliberately mixed to allow trade-offs and realistic choices to be made. With seven attributes, as here, with three levels for each, the total of all possible combinations would be 2,187 (3^7) (Lancsar and Louviere, 2008). Such a number would be unmanageable to use in practice and therefore this was reduced to a 'fractional factorial' design; a sample from the full factorial number of possible combinations that, nevertheless, allows all effects of interest to be estimated. The software from Burgess (2007) was used to calculate an optimal number of choice sets based on the number of attributes and levels, with a choice between two scenarios in each set. A main effects linear model was assumed and the calculation resulted in a design of 18 choice sets with two scenarios in each set. This design was 100% efficient compared to an optimally efficient design using two scenario options in each choice set. The design resulted in sets of orthogonal scenarios (the absence of multicollinearity between scenarios) (Ryan et al., 2001).

Presenting choices to respondents as questionnaires

The survey element of a DCE involves presenting the choice scenarios to a sample of respondents, allowing these to be coded and used in an analysis of which attributes are most important relative to each other. The choice sets, once designed as above, were presented in the form of questionnaires to groups of carers at three separate meetings arranged through local Age Concern representatives. These took place in June 2010 and participants in these groups were all carers of people with dementia who had received home care services. Two of the meetings had been arranged specifically to carry out the DCE whilst a further group completed this task at one of their regular meetings. All had been informed of the study and had been

invited to take part in advance of the meeting. Further details about the study were given before the start of the exercise and each participant was also given a project outline explaining the study and its objectives. The sample was a convenience sample and thus was dependent on the number of carers who attended these meetings. A sample of twenty-eight carers was achieved. The DCE literature discusses appropriate sample sizes of respondents in order to model choices and provide reliable estimates. Turner and colleagues (2007) recommend 50 individuals to estimate interactions, for example between respondent characteristics and attributes. In this study we employed the sample size calculations of Hensher and colleagues (2005). With a choice experiment of 18 choice sets, a sample of 85 was required to detect changes at a 5% significance level at 90% power. However, there is some debate that a minimum sample size of 20 is sufficient; given there are multiple observations for each individual (Lancsar and Louviere, 2008).

The carers were asked to imagine two options for a home care service being available to their relative/person for whom they cared, in the form of scenarios with a mix of levels for each attribute. In order to ground their decision concerning the cost attribute, they were asked to imagine having a budget to pay for care. This budget was set at £230 per week reflecting the average weekly cost of social care for older people receiving an Individual Budget (Glendinning et al., 2008). They were asked to complete each of the scenarios by ticking a box (A or B) for the one they preferred, bearing in mind the mix of levels of each attribute. A team of four researchers were present at each group meeting to assist should any participant have required help on any aspect of the questionnaire. An example of one of these discrete choices (from the set of 18) is given in Figure 4.1. In addition, at the end of the questionnaire, respondents were asked to rate each of the attributes used in the choice sets (from 1 considered most important to 7 the least important). This technique has been used as a reliability check on the choices made in DCEs and the attributes that seem to have had the most bearing on these choices.

Figure 4.1: Example of a choice question (one of 18)

Question 2
Imagine being offered these options for a home care service for your relative/person for whom you care today and that you had a budget of £230 per week to pay for care.
Please tick the box for the option you prefer more (A or B)

	Option A	Option B
Home care workers use life story or memory wallets	To some extent	Fully
There is a waiting list for this service of:	5 weeks	10 weeks
Home care workers are available:	Night time Mon-Fri if required	Weekends if required
Respite opportunities for carers	Limited respite service	Full respite service for weekends and longer periods
The home care worker visiting:	Varies from time to time	Is the same person each time
The cost of this service is:	£170 per week	£200 per week
Home care workers have additional training in dementia care	No training	Some training
Which service do you prefer? (*Tick <u>one</u>*)	☐	☐

A number of other questions were also included in the questionnaire to elicit the characteristics and also health status of carers, factors that may influence preferences (Turner et al., 2007). Thus, age, sex, ethnic group and employment status were included. Health status was measured by the EQ-5D (EuroQol) measure (EuroQol Group, 1990). Each respondent's ratings on the EQ-5D descriptive system (the five dimensions of mobility, self-care, usual activities, pain/discomfort and anxiety/depression) were converted from the five digit health state scoring to a single summary index by applying the formula for value weights for the UK population (Dolan, 1997; Szende, 2007).

Analysing responses using regression analysis

Each carer's choice from each scenario contains two alternatives (option A and B) and these were presented 18 times with different levels of each attribute. There were therefore multiple observations for each respondent. DCEs model these observations according to a utility model whereby the utility (U) for each of i individuals is given by:

$$(1) \qquad U_{isj} = x'_{isj}\beta + e_{isj}$$

Where j alternatives are repeated under s scenarios; x'_{isj} is a vector of observed variables (attributes), relating to alternative j in scenario s; β is a vector of

coefficients for these variables; and e_{isj} are error or disturbance terms. The specified model adopted here was the multinomial logit, for when the dependent variable in question is nominal (in this case, the choice between A and B in each choice set). Where coefficients are significant (at p = 0.10) then this indicates their impact on the probability of choosing an alternative (in other words, the influence of the attribute on a preference for one option over another). The sign of the coefficient indicates the level which respondents preferred (for example a negative sign for lower levels of an attribute). The coefficients themselves indicate the change in utility, or value, for carers of a unit change in the particular attribute concerned. For those attributes taking categorical units of measurement (such as home care workers' availability) then coefficients indicate the change in utility of one level in relation to the base case – designated here as characterising more generic home care. For availability, for example, this would be the utility in moving from having a home care worker available Monday-Friday to having one available night times also if required. For attributes taking a numerical value, coefficients indicate the change according to the defined unit of measurement. In the case of waiting time, therefore, this would be the value of a 1 week change in waiting time; for cost, the value of a £1 change.

Response data from the questionnaire were analysed in STATA. A general to specific approach to the modelling was used following Ryan and colleagues (2001). Hence, a general model first of all included all attributes as part of the design of the experiment. The specific model then included only those attributes significant at the 10% level. From equation (1) the following findings were evaluated:

- The relative importance of each attribute (as indicated by the size, direction and significance of the coefficients β).
- The trade-offs that occurred between these attributes for carers. This trade off – the rate at which one unit of an attribute is given up for an increase in another – is calculated by the ratio of particular coefficients. One in particular was calculated, that of attributes in relation to cost, from which could be calculated individuals' marginal willingness to pay (WTP), given by the ratio of the coefficient β of the particular attribute in question to that of the cost attribute.

Findings

Circumstances of carers

Twenty-eight carers completed the choice surveys and their characteristics are shown in Table 4.2. The sample was mostly of white British ethnic origin with around three quarters being female. Around a quarter of carers were engaged in paid work in some capacity as well as caring for their relatives. The health of the carers taking part, shown by the summary score on the EQ-5D, was on average poorer than for primary care consulters (a mean of 0.81; Turner et al., 2007) and for UK normal population samples (a mean of 0.91; Myers and Wilks, 1999).

Table 4.2: Characteristics of carers completing the choice experiment

Characteristics	
Sex, female (%)	75
Age, mean years	66
Ethnic origin, proportion white British (%)	96
Employment status[1]	
Not employed due to caring or family (%)	19
Not employed because of health problems (%)	8
Full-time employment (%)	12
Part-time employment (%)	12
Unpaid or voluntary employment (%)	12
Retired (%)	39
Health status, average EQ-5D score[2]	0.69

[1] Does not sum to 100% due to rounding.
[2] The score quoted is anchored by the points 1 (full health) and 0 (death).

Regression results: carer preferences

Table 4.3 presents estimated coefficients with associated standard errors and p-values for the regression equation. Based on the coding described in Table 4.1, the positive signs of the coefficients indicate that carers preferred a home care service where there was full use of life story or memory wallets compared to one where these were used only to some extent or not at all. There was also a preference for home care workers being available at the weekends as well as day and night time and for a limited or full respite service being in place. Carers also indicated a preference for having the same care worker providing care each time. The findings also indicate a preference for care being provided by a care worker with full or some training in the care of older people with dementia, compared to none. There was little difference in the coefficients for each of these categories suggesting that whilst carers felt some training was preferable, care workers did not always need to be fully trained. Overall, the most important attributes of home care services, as judged by carers, were having the same care worker providing care each time and having some or full training in the care of older people with dementia.

Perhaps surprisingly the results from the analysis suggested that higher cost was preferred to lower cost. However, since the coefficient was non-significant this impact is difficult to discern reliably. It may be that due to the low sample size and random error the impact of cost on the choices made was not faithfully represented in the analysis. The impact of waiting time was also non-significant but had an effect in the expected, negative, direction (carers preferred a lower waiting time for receiving home care).

Although non-significant, the cost coefficient was used alongside others in the model to calculate the marginal WTP for particular attributes. These calculations are therefore presented here as indicative figures. They express what carers would be willing to pay for a discrete change in a level of a particular attribute, thus giving an

indication of what attributes they consider most important (Nieboer et al., 2010). These figures suggest that the most important attribute in carers' considerations was whether their relative received the same home care worker each time, for which they would be willing to pay £233 per week. In contrast, the use of memory wallets by home care workers was relatively less valued; carers willing to pay £66 per week for this service.

A comparison of these findings with those of the ranking exercise that carers were also asked to complete suggest that these findings have some reliability as the home care worker visiting and home care workers having additional training in dementia care were ranked as most important. Cost and waiting time by comparison were less important (Table 4.4).

Table 4.3: Regression results from discrete choice experiment

Attributes	General model		Specific model		
	Coefficient (SE)	p	Coefficient (SE)	p	Marginal willingness to pay £
Use life story or memory wallets – to some extent	0.149 (0.139)	0.287	-	-	
Use life story or memory wallets – fully	0.263 (0.138)	0.056	0.198 (0.118)	0.094	66
Waiting time	-0.016 (0.014)	0.240	-	-	
Home care workers availability – night time	0.105 (0.139)	0.451	-	-	
Home care workers availability – weekends	0.314 (0.138)	0.023	0.267 (0.120)	0.026	89
Respite opportunities – limited respite service	0.357 (0.139)	0.010	0.348 (0.137)	0.011	116
Respite opportunities – full respite service	0.468 (0.138)	0.001	0.461 (0.138)	0.001	154
Home care worker – varies from time to time	0.245 (0.141)	0.081	0.236 (0.138)	0.087	79
Home care worker – is the same person each time	0.696 (0.138)	0.000	0.699 (0.138)	0.000	233
Cost	0.003 (0.002)	0.210	-	-	
Training in dementia care – some training	0.650 (0.142)	0.000	0.649 (0.141)	0.000	216
Training in dementia care – full training	0.661 (0.137)	0.000	0.655 (0.137)	0.000	218
No. of individuals	28		28		
No. of observations	1000		1000		
Pseudo R^2	0.12		0.11		
Log-likelihood	-305.308		-307.665		

Table 4.4: Results from prioritisation exercise

		Score for attribute			
	N	Minimum	Maximum	Mean	Std. Deviation
The home care worker visiting	22	1	7	3.0	2.2
Home care workers additional training in dementia care	22	1	7	3.2	2.0
Home care workers availability	22	2	7	3.4	1.3
Respite opportunities for carers	22	1	7	4.4	1.9
The cost of the service	22	1	7	4.4	1.9
Waiting list for this service	22	1	7	4.6	1.7
Home care workers use life story or memory wallets	22	1	7	5.0	2.1

1=most important, 7=least important

Qualitative review: carers' experiences of home care services

After completion of the choice survey, carers were given an opportunity to remark more generally on the design of the questionnaire and also to offer their experiences and opinions of home care provided to their relatives/people for whom they cared in their local areas. Over and above the presentation of this for general interest, carers' opinions were useful in order to highlight particular issues that may be allied with estimates from the data analysis. What follows is a short review of their discussions.

All the carers made the general comment that the survey seemed to encapsulate the difficult choices that sometimes had to be made between aspects of a service, particularly between more personal elements, seen as very important, and elements such as costs. On average, the questionnaires took 35-40 minutes to complete. Most found no problem in completing the scenarios although some requested additional information about some of the attributes (the use of memory wallets being one). Participants in one of the groups in particular were very interested and sometimes critical of respite care (for their relatives with dementia) provided in their local area and did not have experience of home care services offering carers a respite period also. However, in contrast, another group focused on respite periods offered specifically to them as carers, whilst home care workers stayed with their relative. Thus, a wide range of issues and opinions were elicited with a general feeling from carers that the attributes included in the experiment gave a realistic picture of the current situation regarding provision and the difficult choices that often had to be made.

Carers viewed the developments in more specialist home care as encouraging but some were of the opinion that the way home care services were 'badged' in terms of the terms used was largely immaterial; what mattered to them were the personal qualities of the home care worker and whether they had what could be referred to as 'clinical nous'. That is recognition, on the part of the home care worker, that the person with dementia may have particular needs for protection as well as a need to be approached sensitively and in a 'person-centred' manner. For example, some of the carers stated quite vociferously that home care workers as part of a generic service, in their experience, had often offered the person with dementia a choice as to meals or whether to bathe but had taken their responses at face value. The workers, in the view of carers, had not recognised that there may be a particular style of communicating with the person with dementia so as to elicit reliable opinions but also to manage necessary (and sometimes life maintaining) tasks. Three carers in particular spoke of situations in which their relatives were left without a meal or a wash because the home care worker had offered a direct choice to the person rather than being sensitive to the particular nuances and expressions that could be viewed as characteristic of the condition. The effect of this was to leave the person in need. Many of the carers thought that specialist training in dementia care could address these difficulties and felt that home care workers should have the same approach to communication and eliciting reliable responses from the person with dementia as those of specialist nurses.

Conclusions

This element of the wider study aimed to elicit and systematically evaluate the preferences of carers of people with dementia with the aim of offering more individual outcomes evidence of the value of specialist as against generic home care. Carers – as those who could recount intimate personal experience of the services received – occupy a prime position in evaluating service models and evidence as to their benefits. It was not possible in the time and financial envelope available for the wider study to elicit and evaluate the views of people with dementia themselves. However, future work could investigate this, using methods similar to those described here. Nevertheless, the DCE method employed here does offer some unique advantages, taken in consort with other evidence from other parts of the wider study. First, it is possible from examination of the individual estimates provided through the regression analysis to assess the importance of individual preferences for home care services. Second, the method allows us to quantify how those intimately concerned with the day to day care of persons with dementia may trade off aspects of home support. In the real world of service delivery, aspects seen as indicative of more specialist provision (more personalised care or enhanced training for example) have often to be compromised in relation to other aspects such as higher costs or waiting periods for service. The policy question here is therefore: which aspects of home support for people with dementia do members of the public, intimately acquainted with the delivery of this care, consider to be most important? The experiment conducted here, with a mixture of qualitative review and quantitative analysis, makes it possible to gain insight into the real choices faced by those providing daily care of those with dementia and the attributes judged to be a priority, taken in the round. As such, it can also offer evidence for commissioners, especially in light of the stated wish to now derive commissioning intelligence from patient or user related outcomes measurement (Cm 7881, 2010).

The results detailed here, in terms of their broad direction, were generally in line with expectations. For example, the more personal aspects of home care and wider availability, characteristics that have been signalled as part of a model of specialist home support (Rothera et al., 2008) were in the positive direction. Across the sample, carers preferred home care workers to be available at the weekends if required not just weekdays; even a limited respite service was preferred to none at all but one including weekends and longer periods was preferred to a partial one; relational continuity (Turner et al., 2007), in terms of seeing the same worker each time, stood out as preferred above other forms of contact; and even limited training in dementia was viewed as more valuable than none. However, less expected were the findings related to waiting time and cost. Although a waiting time period has been described as necessary in more specialist provision (Rothera et al., 2008) and in this study was estimated as being in the expected direction (i.e. a negative value denoting that respondents preferred lower waiting times if asked to choose between options), it was non-significant in the model. Thus, a waiting period was judged as having no impact on the likelihood of choosing a preferred model of home care, everything else being equal. Cost too was non-significant. That is, the higher costs that may be associated with specialist provision did not impact on carers judgements regarding their preferences for home support. In this study, therefore, personal contact with the worker in the context of an on-going relationship, their availability at

times to suit the demands on carers and opportunities for carers to take a break were viewed as more important.

The finding that the use of life story or memory wallets by home care workers was also just significant is of substantive interest. Such a characteristic has been suggested to be an indicator of individuality in approach and indicative of more specialist services (Venables et al., 2006). In the limited studies that are available (Bourgeois and Mason, 1996), it has also been viewed as leading to more enhanced outcomes in terms of improved communication on the part of the person with dementia, comprising an increase in factual statements and a lessening of ambiguous or unintelligible speech and reduced perseverance, or repeated utterances (Kovach, 1997). However, one reason for the impact of this attribute on carers' choices only just reaching statistical significance may have been that this aspect was not familiar to some respondents and was not always provided as part of a home care service. Although some had knowledge of this practice, others did ask for clarification of it despite all attributes being explained before administration of the questionnaires. The practice may therefore not have been sufficiently grounded in carers' experiences when asked to choose options from the scenarios. A further reason for its limited impact, however, may simply have been that the practice was not valued as highly as other aspects. This conclusion has tentative support from the early consultations to design the attributes used in the DCE. One carer representative in particular had voiced the opinion that the practice was largely immaterial in providing a quality home care service for people with dementia; more important were the personal qualities of the home care worker, aspects which are, to an extent, subjective and difficult to measure. However, the practice was considered to have some impact as part of carers' judgements. Clearly, there is scope for more work on memory aids and associated practices in the context of service delivery, perhaps in a wider range of settings with larger samples (for example, Bourgeois and Mason, 1996 studied only four people with dementia in a day care setting; McPherson et al., 2001, only five people).

There are inevitably limitations to this study. The sample size was at the lower end of that calculated to be the minimum necessary to detect significant impact, and this may explain the non-significance of some of the findings, such as that relating to cost. Further work would also be valuable to explore perceptions of the relative worth of different forms of service in relation to different symptom profiles. However, in the time available for this study, the sample of carers, albeit limited, was that which was available at the time for consultation. Future work is planned, extending this experiment to more groups of carers of people with dementia which will increase the robustness of the findings. This work will be reported separately. Further potential limitations to the study involve the DCE method itself. First, the data collected are based around what individuals say they would choose in hypothetical situations. This may not correspond to what they would actually do if offered the choice (here, that between the generic home care usually provided and more specialist provision). However, the qualitative review with carers concerning actual provision did tend to concur with their judgements on the choice survey so increasing confidence in the findings. Second, the method only evaluates the set of attributes chosen as part of the study design and it is possible that, if other attributes were added, then this would change the results in a different direction. However, again, the attributes included were those most salient to carers' concerns elicited from our

initial consultations. Within these limitations, therefore, the study does offer credible evidence of the value carers place on different aspects of home care thought to be indicative of more specialist provision.

CHAPTER 5: LOCAL AUTHORITY DOMICILIARY CARE ARRANGEMENTS FOR PEOPLE WITH DEMENTIA

This part of the study was conducted to provide data on existing domiciliary care arrangements for people with dementia in a way that could be useful to local authority commissioners. As part of the wider proposal it sought to first of all describe arrangements. More specifically, through a cluster analysis procedure, this element of the study was intended to describe different models of community support for people with dementia and the relative mix of specialist and generic home care available in authorities. Using this clustering technique, a sample of authorities was then identified exhibiting these different mixes of generic/specialist home care across England. Local authority commissioners of home care within these authorities were subsequently interviewed to collect information on: a description of specialist home care, where provided – the range of providers, access routes, number of hours commissioned and contracts; the quality of home care provision according to a range of indicators; and costs. The aim here was to provide an evidence base concerning specialist provision: a description of its prevalence, mix, quality and costs in relation, where possible, to generic home care for people with dementia.

This chapter therefore first describes the cluster analysis procedure and provides evidence of different models of community support before moving on to describe the use of a telephone interview schedule to provide further evidence regarding specialist and generic home care provision for people with dementia: a description of the current mix of arrangements; provision against a range of quality indicators; and relative costs.

Typology of domiciliary care arrangements

Method

The aim of the typology was to describe different organisational characteristics using a combined dataset assembled using data from two existing national postal surveys already completed by PSSRU Manchester. These were: a survey of commissioning, contracting and care management arrangements (Hughes et al., 2009) where data were collected from local authorities with social services responsibilities in a postal survey in 2008 and a survey of community mental health teams for older people conducted in 2008/09 (Challis et al., 2009c) which collected details of their organisational and working arrangements. A look-up table (MIMAS, 2010) was utilised to match postcodes of community mental health teams for older people to local authority boundaries to enable this to be linked to the local authority data with the local authority as the unit of analysis. A subset of data from the combined dataset was used to construct the typology.

Six variables were selected for consideration which related specifically to services for older people with mental health problems or dementia and these are detailed in Table 5.1. Informed by exploratory analysis, a consideration of their substantive importance, and capacity to discriminate between local authorities, four were selected in order to represent four areas of activity: commissioning; joint commissioning; contract specification and service provision/delivery. These were used to identify generic and specialist domiciliary care provision, including that jointly

commissioned with the NHS. The two remaining indicators were retained, but were considered to be useful descriptors, rather than clustering variables.

Findings

A hierarchical cluster analysis was performed in SPSS (SPSS, 2006) to categorise local authorities using these indicators with authorities included only if they had complete data for all four. This identified the number of clusters of local authorities present in the data by using a measure of similarity to link those local authorities most like each other. A variety of different methods were compared before obtaining a final cluster solution (Everitt, 1993; Campbell, 2002). The wards method was used, together with the squared Euclidean distance as a measure of similarity (Campbell, 2002). The cluster analysis identified four different approaches to the provision of home care for older people with mental health problems/dementia, and features of these are presented in Table 5.1 below. This provides details of the proportion of local authorities in the sample contained within each cluster, together with information about how all the local authorities in England with responsibilities for social services would distribute across the clusters, assuming that the obtained sample is representative. It also details the number of local authorities in each cluster with each characteristic. The greater the proportion of local authorities with each attribute, the more likely it can be said it is a feature of that cluster's arrangements.

Cluster One's defining feature is that they jointly commission specialist home care with health. Some authorities within this group specify training for care of people with dementia in contracting with independent home care providers and some may regard old age mental health as one explicit focus of home care services across sectors. This cluster appears to provide some evidence of commissioning specialist services although this may only be done in conjunction with health.

In contrast, some authorities in ***Cluster Two*** have a specific focus on old age mental health in domiciliary care. However, none commission or jointly commission specialist services. Also, there is no requirement for specialist dementia care training in contracts with independent home care providers. This suggests that this cluster may generally only commission generic home care provision although they may maintain a specific focus on old age mental health in their home care services through other means (for example through less formal arrangements).

All authorities in ***Cluster Three*** specify dementia care training in contracts with independent home care providers but for the most part do not commission or jointly commission specifically for old age mental health/dementia services. They do not generally regard their home care services as having an explicit focus on old age mental health across sectors. Authorities falling within this cluster therefore may tend to have generic rather than specialist home care provision although they may require providers to ensure their staff are trained to care for older people with dementia.

In contrast, few authorities in ***Cluster Four*** specify specialist training for the care of older people with dementia in their contracts with independent home care providers. However, all commission specialist domiciliary provision for older people with mental

health problems or dementia and some do this jointly with health. Some regard old age mental health care to be an explicit focus of domiciliary care services. Overall, this suggests that this cluster has arrangements for commissioning specialist home care and this is not done exclusively with health.

Table 5.1 also indicates that there is a significant difference between clusters with respect to three out of the four clustering variables which supports the idea that these clusters may represent different approaches to the organisation of services for older people with mental health problems/dementia. Box 5.1 summarises the domiciliary care arrangements for dementia care derived from the cluster analysis. Further confirmation is given in Box 5.2, which explores how four authorities from different clusters compare with respect to these indicators. These were selected as they were examples of the most typical of that group, defined as those authorities exhibiting the modal (i.e. most frequently evident) combination of characteristics in that group. Box 5.2 explores (as in Chester et al., 2010) how the typology might exhibit features of an ideal type.

Box 5.1: Categorisation of local authorities in commissioning and provision of domiciliary care in old age mental health care (n=93)

Group 1: local authorities *who jointly commission specialist domiciliary care services* with health, with many also stipulating dementia specific training as a contractual requirement, and also have an explicit focus on old age mental health in service provision (26%).

Group 2: local authorities who have *mainly generic domiciliary care provision* but some of whom also have a specific focus on older people with mental health problems in service provision (26%).

Group 3: local authorities who *maintain a specialist focus through contractual requirements in respect of training a*nd additionally commission specialist services or have an explicit focus in service provision on old age mental health services. Joint commissioning with health for specialist domiciliary care services was not a feature of this group (31%).

Group 4: local authorities who display *multiple approaches to commissioning and providing specialist domiciliary care*. All commission specialist services for older people with mental health problems. A substantial number jointly commission specialist domiciliary care services with health and also have an explicit focus on old age mental health in service provision. A sizeable minority also stipulate dementia specific training as a contractual requirement (17%).

Table 5.1: Features of four different approaches to the organisation of home care for older people with mental health problems/dementia (n=93)

`		No. (%) with feature by cluster			
		1	2	3	4
Domain of activity - indicator	Commissioning -commission specialist home care for older people with mental health problems/dementia, n (%)[1]	0 (0)	0 (0)	6 (21)	16 (100)
	Joint commissioning -jointly commission with health specialist home care for older people with mental health problems, n (%)[1]	24 (100)	0 (0)	0 (0)	7 (44)
	Contract specification - training for the care of people with dementia specified in contracting with independent home care providers, n (%)[1]	11 (46)	0 (0)	29 (100)	4 (25)
	Service provision/delivery - explicit focus on old age mental health in home care (%)	10 (42)	9 (38)	10 (34)	7 (44)
	Number (%) of sample in cluster	24 (26)	24 (26)	29 (31)	16 (17)
	Number (%) of all local authorities in cluster	39 (26)	39 (26)	46 (31)	25 (17)
Further descriptors	Local authority has community mental health team that liaises/supports home care providers in relation to education or training (n=86) [1]	13(59)	7 (32)	17 (65)	11 (69)
	Dementia care training provided to care workers regardless of sector of employment (n=87) [1]	19 (83)	10 (48)	(17) 63	7 (44)

[1]Statistically significant difference between clusters (at 10% level) as determined through use of Chi-square/Cramers V test.

Box 5.2: Comparison of the cluster profiles of four local authorities

	Local authority A from cluster 1	Local authority B from cluster 2	Local authority C from cluster 3	Local authority D from cluster 4
Commissioning -commission specialist home care for older people with mental health problems/dementia	No	No	No	Yes
Joint commissioning -jointly commission with health specialist home care for older people with mental health problems	Yes	No	No	No
Contract specification - training for the care of people with dementia specified in contracting with independent home care providers	No	No	Yes	No
Service provision/delivery - explicit focus on old age mental health in home care	No	No	No	No

Box 5.3: Characteristics of ideal type applied to emergent typology

Ideal type[1]	Typology of organisational arrangements for home care services for older people with mental health problems/dementia
• Selection of characteristics to adequately describe the phenomena under investigation.	• Secondary analysis of existing datasets and selection of indicators created for the construction of the typology (Table 5.1). These were selected as they specifically related to services for older people with mental health problems/dementia.
• Description of current arrangements derived from historical patterns.	• Variables were selected to represent four areas of activity: commissioning; joint commissioning; contract specification; and service delivery.
• Reformulations of the typology to achieve the best interpretation of the data.	• Hierarchical cluster analysis was used to identify the number of clusters present in the data. A variety of different methods were compared before the final selection.
	• Examples of individual local authorities confirmed that clusters differed with respect to the indicators (Box 5. 1). The identification of clusters of local authorities confirmed the validity of the indicators (Table 5.1).
• Production of conceptual tools to provide an interpretative scheme	• Four clusters were identified and the characteristics of each were documented in terms of the proportion of local authorities within each cluster possessing each attribute (Table 5.1).
• Interpretation to be both understandable and valid.	• Statistical tests confirmed that the clusters were significantly different with respect to three out of the four clustering variables (Table 5.1).
• Heuristic in its purpose permitting the same phenomena to be identified by others.	• This framework can be used in a number of ways. It can be applied to all English local authorities. Within the research it served as a sampling frame for subsequent fieldwork (Table 5.1).

[1] Psathas, 2005

In summary, this procedure identified four groupings of local authorities that offered different models of community support for people with dementia. Within each group there was a different mix of specialist and generic provision according to areas of activity: commissioning; joint commissioning with health; contract specification; and service delivery. Broadly speaking, group two authorities represented more generic home care provision for people with dementia but in all groups there was a specialist element where home support specifically for people with dementia was concerned (for example, through training or by having a specific focus on mental health problems). The second element to this part of the study, detailed below, sought to describe more fully these different arrangements through telephone interviews with

local authority commissioners representing authorities with different mixes of specialist and generic home care provision.

Survey of local authority commissioners

Method

The analysis employed a telephone interview schedule (see Appendix 2), which was constructed to describe current provision, offer judgements of its quality and elicit costs of specialist in relation to generic provision.

Questionnaire development

The interview schedule had three elements. The first of these was a description of current provision. This was intended to add breadth to the existing evidence regarding the provision of specialist home care for people with dementia, which is sparse. Domains of enquiry were drawn from the earlier literature review. They included the current mix between specialist and generic provision, an outline of current providers (for example, local authority, independent or NHS providers) and their numbers, access arrangements, the nature of contracts and number of hours provided. Definitions of specialist provision were taken from respondents themselves. That is, it was left to commissioners to describe whether certain services were designated as 'specialist' in their authority and no judgements were made by the researchers conducting the interviews.

The second element related to indicators of quality in home care provision. This was intended to elicit evidence of quality standards for specialist home care and consisted of items selected from an existing tool which identified differences in service delivery, content and quality between generic and specialist home care services (Venables et al., 2006). These quality indicators included: systematic assessment, flexibility, individuality, cultural appropriacy, management practices, integration, care worker practice, carer involvement, training and document quality. A subset of 12 of these was selected for measurement in the telephone interviews with local authorities. The choice was mediated by three factors: the views of a stakeholder advisory group which included older people, representatives of older people's groups and employee representatives (Hughes et al., 2009); a consideration of what was possible to capture/operationalise in a telephone survey of local authorities; and their relevance in the current policy and practice context (informed by chapters two and three of this report. These were developed through a series of questions designed to capture each of the above constructs and the 12 indicators are listed in Box 5.4.

Box 5.4: Indicators of quality in home care

Assessment and review of user circumstances

- Users' abilities and needs assessed
- Planned reviews undertaken
- Risk assessment for user is conducted

Individualised care

- Client need
- Client preferences
- Culturally appropriate personal care: language for example translated leaflets
- Culturally appropriate food for example specific dietary requirements
- Memory/life story wallets

Service components

- Seven days a week availability
- 24-hour service availability
- Whether new provider staff receive an induction
- Assistance by local authority to providers in training 'hands on' staff in dementia care

The third element related to the cost of specialist home care provision in relation to generic provision. Here data were necessary to describe the costs of provision so as to offer evidence of the cost-effectiveness of specialist home care in tandem with other evidence collected in the study as a whole (principally from the national data set analysis, in Chapter 6). Costs here were collected via a 'top down' variant of the traditional approach to costing services, where usually user-level data are available on each person accessing a service (McCrone et al., 1994; Challis et al., 2004). This form of data was not available in this study so, instead, local authority commissioners were asked about their price per hour of home care for both specialist and generic services. Other national data available on the cost per hour of home care across all local authorities (Knapp et al. 2007) were used to supplement the data collected here concerning overall provision across England.

Data collection

The work was given the full endorsement of the ADASS National Older People's Network who met on the 11 June 2010. From a database of all local authority Directors of Social Services, we derived a sample of authorities to contact for the telephone survey. A quota sample of authorities who were representative of each of the four cluster groups identified in the previous analysis were contacted, through the Director of Social Services, to obtain the name and contact details (email/telephone) of the relevant person to whom enquiries concerning the commissioning of home care services could be directed. An appointment was then made to administer the questionnaire over the telephone. If an authority refused to take part or was non-contactable then researchers contacted the next authority on the list of those authorities representative of each cluster group.

In the time available, the aim was to conduct approximately 20 interviews across authorities broadly representative of each of the four cluster groups identified earlier. Overall, the intention in analysing these data from local authority commissioners was *not* to provide a statistical comparison between the four groups. The groups, as identified above, did differ according to their mix of specialist/generic home care

provision. However, as already stated, all groups contained authorities with an element of what could be termed 'specialist' provision. Moreover, not all authorities in each of the groups exhibited all the activities characteristic of that group. The four cluster groups were therefore seen, in general, as representative of the range of models of home care for people with dementia rather than being viewed as a focus for comparison. Thus, the aim of the analysis reported below was to describe more fully than hitherto the characteristics, quality and costs of specialist home care when compared with generic provision, taking into account this range of approaches. It was recognised that this method, owing to the time and resources available, resulted in a non-probability sample of local commissioners and therefore the findings derived from the survey would be descriptive and indicative rather than fully representative of the national picture.

Findings

Overall, 21 authorities were interviewed regarding their home care provision specifically for people with dementia. Where authorities were unsure of the answer to specific questions owing to information being unavailable, these responses were coded as missing. The findings are presented below in order, moving from descriptions of the sample and services to quality standards and then cost.

Descriptions of specialist home care

Table 5.2, below, shows data describing various aspects of home care provision in the local authorities and more generally, describes the sample used in the analysis. A large proportion of the authorities (nearly 40%) from which data were derived were contained in our group four cluster (a focus of which was the commissioning of specialist home care). However, local commissioners representing each of our cluster groups were interviewed. There was also a mix of types of authorities in the sample with around a third being from metropolitan districts. The sample therefore represented a broad mix of sizes and types of authorities across different regions of England.

Most of the authorities, according to their own definitions of the service, were currently commissioning *predominantly* 'generic' home care for people with dementia. Only four authorities in our sample described their home care provision as predominantly specialist in nature with three authorities describing a mix of provision across the authority. In this latter respect, for example, one authority described specialist provision as being located within an 'in house' specialist mental health service although people with dementia were served also by usual generic home care services. Another authority described a situation in which there was one specialist service provider, through the local Alzheimer's Society, providing for only one district within the authority; generic home care was commissioned for the rest of the authority. Furthermore, an example from one authority confirmed that definitions of specialist providers of home support may require further elucidation. This authority commissioned home care to people with dementia that was also available generally to all older people, so this was defined as basically generic. However, amongst these, there were providers with experience of providing home care to people with dementia as part of their usual service. For those authorities where a specialist model predominated, arrangements ranged from an 'in-house' specialist home care service for people with dementia, through to a partnership arrangement

between an in-house re-ablement service contracted from care providers in intermediate care, to an independent sector specialist provider.

Table 5.2: Description of home care provision for people with dementia (n=21) [1]

Descriptors		
Cluster groups of authorities, n (%)		
Group 1	5	(24)
Group 2	3	(14)
Group 3	5	(24)
Group 4	8	(38)
Type of authority, n (%)		
Metropolitan district	7	(33)
Shire county	6	(29)
Unitary authority	5	(24)
London borough	3	(14)
Home care for people with dementia is provided by:		
Predominantly generic, n (%)	14	(67)
Predominantly specialist, n (%)	4	(19)
A mix of generic/specialist, n (%)	3	(14)
No. of home care providers contracted with providing for those with dementia, mean (range)	25	(1-60)
No. of home care providers designated as 'specialist', mean (range)	1	(1-4)
No. of hours of home care commissioned for people with dementia – general, mean (range)	8,294[2]	(300-25,300)
No. of hours of home care commissioned for people with dementia – 'specialist', mean (range)	745[2]	(8-4,000)

[1]Averages are derived only from the number of respondents answering specific questions (i.e. missing values are omitted from calculations)
[2]In previous financial year.

There was a wide range in the numbers of separate providers of home care in authorities that were providing care at some point to people with dementia; most of these providers were generic, providing home care to the general population of older people also. However, only a small proportion of these were designated as 'specialist'. On average, over 8,000 hours of home care were commissioned in the last financial year for people with dementia, this mostly relating to generic home care services. Information was often unavailable on total hours commissioned and for specifically specialist services this was a much lower number, around 700 hours commissioned. Thus, specialist services represented, on average, around 9% of the total hours commissioned by authorities for people with dementia.

On the whole, the interface between the local authority and home care providers of specialist home care was managed through a block contract (in seven cases) with a 'call off' arrangement (where the price per hour is specified in advance and paid when the service is provided) and a 'spot' contract (with the price agreed and paid when service is provided) following a close second (in five cases). Specialist home support, where designated as being available, was accessed usually through local authority social care. However, in five cases, access could be through an NHS

specialist mental health service with one representative stating that specialist home care could be accessed via self-referral.

Quality standards

Some interest was shown by the local authority representatives taking part in the survey in the quality indicators used as part of the telephone interview schedule. Table 5.3 offers evidence from the respondents as to a range of quality indicators of specialist provision. Local commissioners in 16 (76%) authorities in our sample signalled that home care providers were required to make an assessment of the user's abilities or needs (in contrast to say, social workers completing their assessment before service was purchased). Interestingly, this aspect and also whether home care staff participated in planned reviews of service users was present in some authorities where it was designated that generic rather than specialist home care predominated. Less prevalent, however, was the presence of attributes denoting more individualised care, such as whether written documents kept in users' homes contained information on their needs or reasons for service, or whether arrangements were made for culturally appropriate personal care/dietary requirements, or if life story/memory wallets were used. In terms of service components, 14 (67%) authorities signalled that their home care providers were required to give an induction to 'hands on' care staff regarding the care of people with dementia; this was the case for some authorities who designated their provision as predominantly generic as well as those stating that they contracted with specialist providers. Similarly, in terms of the availability of home support, although fewer authorities than for other aspects said that providers were required to be available seven days a week, this attribute was also shared by some who commissioned predominantly generic as well as specialist services. Interestingly, representatives from only two authorities said that, as part of their contractual requirements, providers would be required to be available for 24 hour 'round the clock' care. Both these authorities were ones in which specialist home care was designated to predominate.

Table 5.3: Quality indicators of home care provision for people with dementia (n=21)

Descriptors	N	%
Assessment and review of user circumstances		
Home care providers required to complete assessment of users' abilities/needs	16	76
Home care staff participate in planned reviews of service user	16	76
Home care providers required to complete risk assessment of users	17	81
Individualised care		
Written documents contain information on users' needs/problems/reasons for service	7	33
Written documents contain information of users' preferences/special needs	7	33
Home care providers required to make arrangements for culturally appropriate personal care	5	24
Home care providers required to make arrangements for culturally appropriate food	6	28
Home care providers employ life story/memory wallets	6	28
Service components		
Providers available seven days a week	8	38
Providers available 24 hours	2	9
Home care providers required to provide induction for 'hands on' care staff	14	67
Assistance given to home care providers by local authority to train 'hands on' care staff in working with people with dementia	6	28

Commissioners were given the opportunity at the end of the interview to offer any additional comments and some were particularly apposite to the original research brief for this study. Some authorities, although not currently commissioning from specialist providers were hoping to do so in the near future. Others, whilst not currently purchasing care from providers designated formally as specialist, were still of the opinion that a good standard of care was being provided specifically to people with dementia. One representative in an authority commissioning predominantly generic services for people with dementia said:

> "Whilst we don't buy from designated specialist services [we] do support generic providers with enhancement, mostly through mental health services which is [a] joint [venture] between the local authority and health. If a person requires specialist care by [a] specialist team we have got major initiatives, for example telecare and assistive technology to maintain the person with dementia at home. Dementia is a very broad spectrum, at one end somebody may need 24/7 care and at the other [a] 55 year old may forget where he put his glasses a minute ago. Specialist services should be the last resort not the first. It's about personalisation/normalisation; only a specialist service when [someone] really needs it, not a (specialist) service operating in a certain way to stick people in – needs led not service led…[There are] problems/issues with specialist services, for example [if] somebody needs 24/7 care this could be done by telecare; not somebody physically being there 24/7."

Similarly, another representative stated:

> "Our service provision is basically generic; [we] try to match the best providers with experience"

Such views would seem to suggest that the formal definition of what constitutes a specialist home support service for people with dementia requires greater clarification. It would appear that good care conforming to a number of quality standards, such as those above, can be provided by services that are broadly generic in nature. In contrast, designated specialist home care may offer an enhanced service and was seen by those authorities commissioning it as worthwhile. However, the development of such specialist providers required, in the view of one respondent, "significant capability building" but it was also stated that "the challenge is to also equip generic providers as they will be working with dementia sufferers and their carers". Such views add complexity and detail to the original aim behind this part of the study: to provide additional evidence about specialist care and its differential value from usually provided generic care.

Costs of specialist versus generic provision

Local commissioners were asked what the current price per hour of home care was for those people with dementia for both generic and specialist provision (where available). Table 5.4 shows the costs, in this sense, of specialist as against generic home care across the authorities. Included too are figures for overall provision derived from the total population of local authorities (n=150) from national data (Knapp et al., 2007) with which to compare our figures as a test of representativeness.

Table 5.4: Costs of specialist versus generic home care for people with dementia[1]

	Specialist provision (survey)	Generic provision (survey)	Overall provision (national figures)[2]
Cost per hour of home care, Mean (range)	16.23 (12.51-23)	13.27 (11.11-16.24)	14.10 (9.2-25.9)

[1] In £, 2009/10 prices
[2] Knapp et al. (2007)

Although the costs of specialist domiciliary care appeared higher than generic, an average of £16 per hour against £13 per hour, there was a considerable degree of overlap in the costs of different types of home care between different local authorities. Hence, a cost of £16 per hour could represent either a generic or specialist domiciliary care service in some local authorities. Overall, the figures from our survey respondents were within the range of overall costs derived from national figures. The cost variation appeared to represent variations in the commissioning and contracting processes in different local authorities.

Conclusions

The survey material described in this part of the study showed a range of approaches to domiciliary care arrangements specifically for people with dementia. Four broad groupings of local authorities were identified along a number of variables reflecting different elements of specialist provision. This analysis showed the complexities underlying the original research question. The definition and elaboration of variations in the types of home care for people with dementia, and their particular content, is a prerequisite for further study which looks at patterns of complementarity and substitution between forms of home care and identifying the optimal mix. Rather than being a case of simply judging the impacts of specialist *versus* generic provision in the home support of people with dementia, there are a range of models of support available. It appears more likely that local authorities in England are characterised by having a mix of approaches with different degrees of specialism/genericism in their dementia home care. For example, some authorities may have designated their provision as 'specialist' along the lines of some of the elements used in the clustering employed here (specialist training or commissioning for example) but they may nevertheless share some attributes associated with generic provision (for example, similar costs or achieving similar levels on quality indicators). Moreover, other authorities who may not have designated their home care provision as 'specialist' may still share some attributes (particularly quality indicators) which could be argued to be associated with specialist provision. Thus, the evidence from the survey material here offers a description of the extent of specialist provision, as defined by local authority commissioners themselves. The precise definition of what is meant by specialist home care for people with dementia requires further elucidation since its attributes and modes of operation will tend to vary and share commonalities with more generic home care usually commissioned for older people as a whole. For these reasons, the descriptions of local authority commissioning approaches given here should be treated as further contemporaneous evidence, building on the models identified through our cluster analysis. Assessing the impact of specialist as opposed to generic provision for people with dementia is therefore difficult. However, a start is made in the following chapter where the associations between our cluster groups highlighting different types of domiciliary arrangements and a measure of outcome, national admissions to care homes, are explored. The findings in the previous chapter examining the discrete choice experiment involving carers of people with dementia are also important.

Box 5.5 below, outlines some of the key messages from this part of the study that are of relevance to local authority commissioners and others. These summary points are elucidated further in the conclusions at the end of this report where their relevance to other areas of the wider study is drawn out.

Box 5.5: Key findings - local authority domiciliary care arrangements for people with dementia

- Four broad groupings of local authorities in England were identified that exhibited different mixes of and approaches to specialist and generic home care provision.
- 'Specialist' home support requires greater precision in definition: for example, within a model of home care where generic provision was the predominant focus, some authorities still provided a specific focus on old age mental health or dementia (through perhaps training or experience). It may be that certain quality attributes, such as the availability of 24 hour care, mark out specialist provision in contrast to generic home care.
- Although nearly half of local authorities commission some form of specialist home care for people with dementia, the more specialist forms are only evident in a minority of places. Furthermore, specialist domiciliary care is only a very small component of the overall domiciliary care used by people with dementia.
- The number of providers of specialist home care for people with dementia is currently small with only about nine per cent of total hours commissioned being from specialist providers.
- The picture on a range of quality indicators of specialist provision is mixed. More prevalent were attributes concerned with assessment of abilities/needs by providers and whether they took part in planned reviews. Less prevalent were aspects related to more individualised care such as culturally appropriate practice or the use of life story/memory wallets. However, some of these attributes were also shared by generic home support services. The issue is one of good practice and appropriate care rather than whether providers are formally designated as specialist or generic.
- The costs of specialist home care appear on average higher than generic, an average of £16 per hour against £13 per hour. However, there was a considerable degree of overlap; at £16 per hour, a home care service could be one designated as generic or specialist.

CHAPTER 6: EXPLORING ASSOCIATIONS BETWEEN TYPES OF DOMICILIARY CARE AND ADMISSIONS TO CARE HOMES

In this part of the study national secondary data sets were analysed to compare the numbers of older people with dementia admitted to care homes across England, over time, for local authorities with different models of specialist and generic domiciliary care (identified through the earlier cluster analysis discussed in chapter five). This essentially compared authorities on the different typologies identified in terms of one of the principal outcomes used to justify investment in community-based support: a reduction of admissions to long-term care homes (Department of Health, 2009). The purpose of this analysis was to determine whether groups of authorities, with degrees of attributes characterising more specialist home care provision for people with dementia, would admit fewer people to care homes. It was surmised that this would be one indication of the possible effectiveness of specialist home care for this group of older people.

Method

The analysis employed performance data from the Key Indicators Graphical System (KIGS) (www.drfoster.co.uk/localgovernment/kigs.asp), so as to calculate the number of admissions of people with dementia to care homes and also, in subsequent analysis, to employ other indicators to control for factors such as need, the supply of care home places, and local health provider behaviour.

Estimating the number of admissions for older people with dementia

Calculation of the estimated number of admissions of older people with dementia to care homes employed the performance indicator PAF C72: 'the numbers of older people admitted permanently to residential or nursing home care per 10,000 population aged 65 and over'. These figures, until recently, have been collected on an annual basis by the inspecting body for social care services in order to assess the performance of individual local authorities in priority outcome areas. The data includes all admissions to care, both nursing and residential care and include those older people suffering from dementia and those not.

To provide an approximate figure for the number of these admissions to permanent care in which the person has dementia, estimates of the prevalence of dementia in care homes were required. The Dementia UK report (Knapp et al., 2007) provided estimates split by type of care home; 50 per cent of those in residential care and 66 per cent of those in nursing home care having dementia. These estimates measure the proportion of residents with dementia and not the proportion of new admissions to care, as measured by the PAF C72 indicator. Therefore, when applying these proportions to the national data available, there will be some margin of error. However, this will be mitigated by the fact that the local authority is the unit of analysis here and so any such error may be assumed to be distributed more or less equally across all authorities.

In order to apply these estimates to the admissions data the proportion of admissions to each type of care (residential care home and nursing care) was required. Two sets of estimates were used here. First, Netten and colleagues

(2001a) give approximate figures of the proportion of all admissions to each type of care home in England as 54 per cent and 46 per cent to residential and nursing home care respectively. Second, data available from the Dr Foster website also provides some indication of this split of admissions between types of care home. The KIGS data provide separate measures of raw numbers of admissions of those aged 65 or over to residential care and to nursing care per 1,000 population aged 75 and over, by local authority. These data were then used to calculate the proportion of admissions to each care type for each local authority by allying these measures to population and age figures.

By calculating the proportion of admissions to nursing care and residential care, using the estimates provided by Netten and colleagues. (2001a) and the data provided by the KIGS, and then applying these to the PAF C72 data, the dementia prevalence estimates from the Dementia UK report were then employed to estimate the number of admissions of older people with dementia, for each local authority, to nursing care homes, to residential care homes and to all care homes.

Descriptive comparisons: number of admissions by cluster group

The above figures for numbers of admissions were first of all compared across the cluster groups of authorities identified earlier in this study. This comparison was initially done visually by plotting admissions by each local authority across three years, 2005-06, 2006-07 and 2007-08. The average (mean) number of admissions was also plotted across authorities in each of the four groups. It will be remembered that the groups following the cluster analysis earlier varied on dimensions of specialist home care, focusing on specialist and joint commissioning, training in dementia care specified in contracts and an explicit focus on old age mental health. Box 6.1 provides summary descriptions of the four groups.

Box 6.1: Categorisation of local authorities in commissioning and provision of domiciliary care in old age mental health care (n=93)

Group 1: local authorities *who jointly commission specialist domiciliary care services* with health, with many also stipulating dementia specific training as a contractual requirement, and also have an explicit focus on old age mental health in service provision (26%).

Group 2: local authorities who have *mainly generic domiciliary care provision* but some of whom also have a specific focus on older people with mental health problems in service provision (26%).

Group 3: local authorities who *maintain a specialist focus through contractual requirements in respect of training a*nd additionally commission specialist services or have an explicit focus in service provision on old age mental health services. Joint commissioning with health for specialist domiciliary care services was not a feature of this group (31%).

Group 4: local authorities who display *multiple approaches to commissioning and providing specialist domiciliary care*. All commission specialist services for older people with mental health problems. A substantial number jointly commission specialist domiciliary care services with health and also have an explicit focus on old age mental health in service provision. A sizeable minority also stipulate dementia specific training as a contractual requirement (17%).

It was determined that the hypothesis to be explored in these initial descriptive comparisons was therefore that group two authorities, as characterising more generic home care, would show an increased number of admissions compared to the other groups. The rationale behind this was that those groups in which authorities provided a greater mix of more 'specialist' home care would be more successful at supporting older people with dementia at home leading to a reduced number of admissions in comparison with the more 'generic' group. This hypothesis was tested in subsequent analysis by comparing the average number of care home admissions across the cluster groups using one way ANOVA and independent t tests comparing group two authorities with each of the other groups. The rate of admissions across the three years was also explored by investigating the average percentage change in admissions across authorities using one way ANOVA. The 5 per cent significance level was chosen in all analyses.

Analytical comparisons: predicted number of admissions by cluster group

Examination of the potential impact of models of home care for people with dementia on care home admissions needed to move beyond the above descriptive comparisons. This is because there are a number of confounding factors, many outside the direct control of local authorities, which influence whether older people enter care homes (Clarkson et al., 2005). These factors include the needs or demands of users (such as their dependency and level of functioning), the effect of factors influencing the decision making process (such as at the point of hospital discharge), and system factors (such as the supply of care home places and the availability of domiciliary care). Such factors will tend to vary across local authorities and so estimating the influence of one factor of interest (for example the type of home care) on admissions will need to take these other factors into account. The established way of doing this is through regression analysis, in which the influence of several factors on admissions to care homes is modelled to produce estimates of the average expected number of admissions taking into account these other influences. This will tend to produce a fairer comparison across authorities.

Through a series of regression models, the relationship between the numbers of permanent admissions of older people with dementia to care homes and type of home care was explored. All models explored the influence of cluster group membership controlling for other influencing factors. This type of analysis follows that of epidemiological enquires where the phenomenon of interest (here admissions to care homes of those with dementia) is modelled controlling for the presence of other factors as potential confounding effects (McNamee, 2005). These independent control variables need not reach statistical significance but are left in the model to allow for estimation of 'exposure' to the factor of interest whilst allowing for other multiple influences. In this case, a selection of explanatory variables to control for deprivation, need, health care inputs (hospital admissions) and supply of services were added as potential confounding factors. These models enabled the predicted number of admissions, on average, by cluster group to be calculated, allowing comparisons to be made between the type of home care available (extent to which it is generic or specialist) and admissions to care homes. This exercise was undertaken twice, once with the dependent variable measuring admissions estimated via the use of KIGS data, and then again with estimates derived from

Netten and colleagues (2001a). The variables considered in these analyses are summarised in Box 6.2.

Box 6.2: Variables under consideration

Dependent variables • Estimated number of admissions of older people with dementia to care homes (KIGS) 2007/08 • Estimated number of admissions of older people with dementia to care homes (Netten et al.) 2007/08 • Percentage change in estimated number of admissions of older people with dementia to care homes (KIGS) from 2005/06 to 2007/08 • Percentage change in estimated number of admissions of older people with dementia to care homes (Netten et al.) from 2005/06 to 2007/08
Independent (explanatory) variables • Cluster group membership (reference category = 'group 2' 'generic home care') • Dementia prevalence (within the local authority area) • Receipt of key social security benefits • Receipt of Attendance Allowance • Receipt of Income Support • Numbers of older people living alone • Numbers of older people living in rented accommodation • Deprivation concentration • Social care expenditure (Formula Spending Share) • Number of care home places • Number of home care agencies • Number of admissions of older people to hospital

Model construction was guided not only by consideration of variables to include, selected from those above, based on the literature and the investigators' professional knowledge, but also by statistical considerations such as the results of diagnostic tests and correlations. In terms of the variables chosen as characterising important influences on the number of care home admissions, these were selected from those above after initial analyses tested for correlations and contribution to the variance explained. Box 6.3 describes the variables chosen in the models with the rationale for their inclusion and their expected relationships to admissions. Second, to inform statistical considerations of model fit, bivariate correlations were undertaken to identify possible relationships between the two dependent variables and all other independent variables. In addition to displaying the possible contribution of these factors to explain variation in admissions of older people with dementia to care homes, correlations between pairs of explanatory variables allow considerations regarding the issue of collinearity to be made. The existence of collinearity between independent variables poses problems for model fit and interpretation and can lead to unstable models, for instance unreliable parameter estimates (Greene, 1993; Nelson et al., 2004). The bivariate correlations are displayed in the Appendix, Table A3.1.

Box 6.3: Regression models – description and rationale supporting selection of explanatory variables

Description	Rationale	Expected relationship with dementia admissions
Percent of older people with dementia [1]	A prevalence measure indicating the potential need for services (Campbell et al., 1983).	A higher number of people with dementia will mean that more people may require assistance and so greater numbers of people with dementia may be admitted to care homes
Number of pensioners in receipt of attendance allowance per 1,000 aged 65 and over [2]	A proxy measure of need and social deprivation (Scott et al., 2001)	Higher numbers indicates a population income deprived and with greater needs, therefore requiring greater input from services and may be less likely to care themselves in their own homes.
Number of pensioners in receipt of income support per 1,000 aged 65 and over [2]	A proxy measure of deprivation (Scott et al., 2001)	Higher proportions of pensioners in receipt of benefits (a measure of low income) may require more input from services.
Percent of older people living alone [2]	A proxy measure of need for services (Bebbington and Davies, 1980)	Older people living alone may be more likely to be admitted to care as they require a greater degree of input from social care services.
Percent of households with at least one pensioner living in rented accommodation [2]	A proxy measure of need (Grundy and Glaser, 1997)	Higher number in rented accommodation may indicate higher levels of deprivation and needs therefore resulting in higher demands on services. The relative insecurity of rented accommodation may also influence the numbers admitted to care on a permanent basis.
Indices of Deprivation: Local Concentration Score [2]	A measure of the extent to which local socio-economic deprivation is geographically concentrated in pockets within a local authority's most deprived areas rather than being spread evenly (Lang et al., 2008).	A high score indicates that local authorities may need to deliver higher levels of care to a large number of people in a small concentrated area. In deprived areas the need for service delivery may be higher.
Admissions to hospital aged 65 and over per 10,000 aged 65+ [2]	An indicator of health need but also health provider behaviour and demands from hospital discharge	More older people admitted to hospital may indicate a greater need for services and also increased referrals for assessment at discharge.
Number of care home places per 10,000 population aged 65 and over [2]	An indicator of supply regarding potential care home placement (Netten et al., 2001b)	Authorities with fewer care home places available may be less likely to admit to care homes.

[1] Dementia UK (Knapp et al., 2007)
[2] Key Indicators Graphical System.

Several models were considered and the details of these are set out in the Appendix, in Box A3.1. In each, we sought the best statistical explanation of the variations in care home admissions for older people with dementia, given the average impact, across authorities, of differences in needs, outputs and other influences. These models were tested for issues of multicollinearity and degree of statistical explanation before final models were chosen.

'Performance' comparisons: authorities lying outside of average expected performance

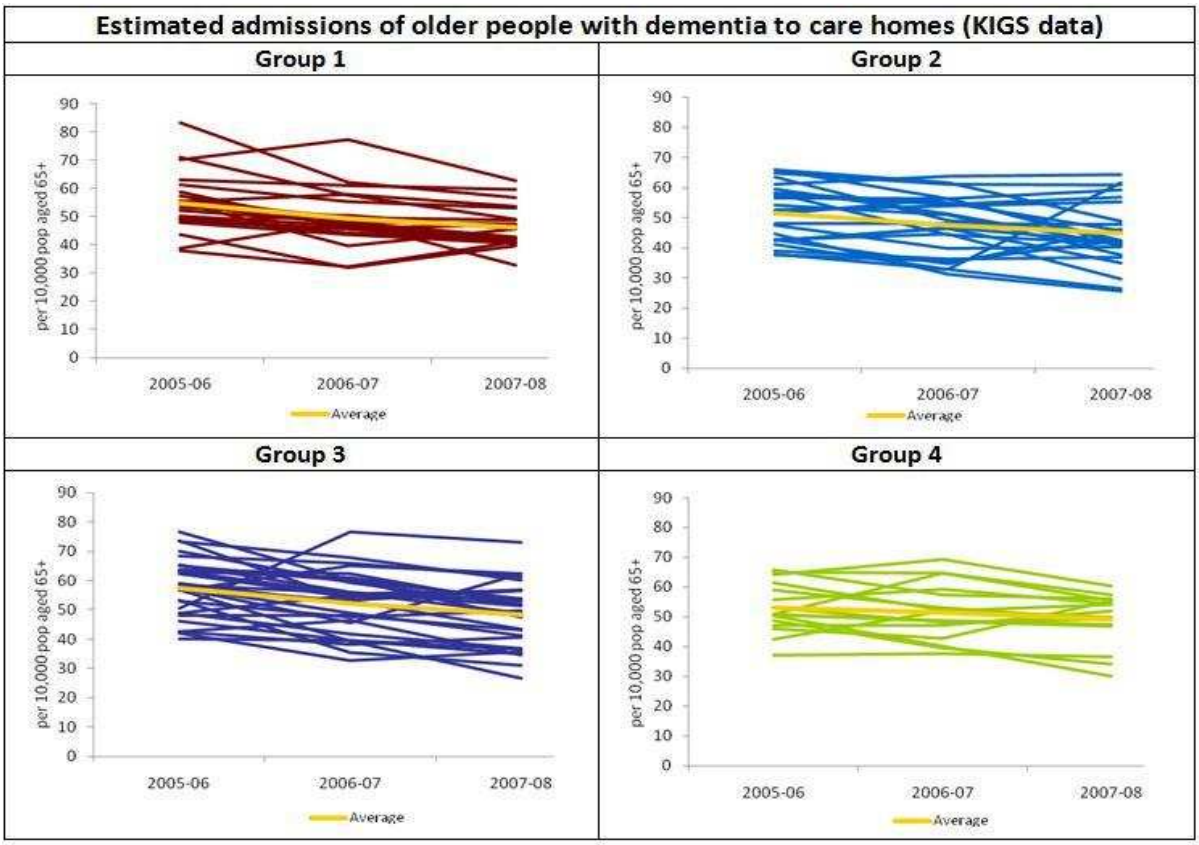
A further way to view the influence of the model of home care adopted in authorities and its potential influence on care home admissions for older people with dementia is to draw on performance measurement methods (Levitt and Joyce, 1987; Clarkson and Challis, 2006). Here, the results from the regression models were used but, instead of employing the coefficients for each authority group to estimate their influence on admissions, the models were run with the control variables only and subsequently individual authorities (and the group to which they belonged) were identified that fell outside a designated range. The regression models operate a standard of 'average expected performance' in terms of care home admissions (shown by the regression line fitted to the data) against which each local authority can be compared. By comparing in this way, we can consider whether particular authorities admit more or fewer older people with dementia to care homes than we would expect, given the conditions under which they operate. The designated range adopted here was measured against the residuals from the regression equation (the difference between actual and expected numbers of admissions). In order to rank authorities against this, a statistical criterion was adopted on the distribution of residuals of above or below two standard errors (a measure of the 'spread' of the residuals). This follows that, with a normal distribution of residuals, we would expect 95 per cent of authorities to have actual admissions within twice the standard error of the regression equation (Levitt and Joyce, 1987, p.118). This analysis was used to test the proposition that those authorities who admitted more older people with dementia than expected would tend to be from group 2 (generic home care).

Findings

The results of the analyses detailed above were broadly similar in terms of the figures chosen to estimate the number of care home admissions for those with dementia. For this reason and because the KIGS data are based on more up to date figures, the following findings are presented using KIGS data only. However, findings employing the earlier Netten et al. (2001a) data are detailed in the Appendix (Figure A3.1). Similarly, the findings detailing the numbers of admissions by types of home (residential and nursing care) were broadly similar in terms of trends. The findings of all analyses below therefore relate to care homes as a whole.

Descriptive comparisons: number of admissions by cluster group

Figure 6.1: Comparisons of admissions to care homes for older people with dementia for individual authorities by cluster group



Note: N = 93

Figure 6.1 shows the number of care home admissions of older people with dementia by individual local authority (unlabelled) split by cluster group. The average (mean) number of admissions is also shown by group. This figure demonstrates that although some individual local authorities differed in terms of their trajectories with respect to care home admissions across the three years, there was a general fall in admissions over time in each group. This reiterates a more general trend that has been ongoing in England and which is perceived to be a reflection of the success by which local authorities have supported older people at home (Clarkson et al., 2009). Across the authorities in each cluster group the average trend was also for a reduction in admissions that was similar in each group. In fact, as Table 6.1 shows, both the average figures for number of admissions and trends in terms of percentage change were not significantly different across the cluster groups. Data across the three years studied (2005/06 to 2007/08) show that, on average, the rate of reduction in admissions was slower in the predominantly 'generic' group 2 authorities (a reduction of 13% compared to 15%) but, again, this difference was not statistically significant ($F = 0.93$; $p = 0.43$).

Table 6.1: Average number of admissions of older people with dementia to care homes by cluster group

Authority cluster	Mean KIGS estimates			Percentage change KIGS Estimates		
	2005/06	2006/07	2007/08	2005/06 – 2006/07	2006/07 – 2007/08	2005/06 – 2007/08
Group 1	54.77	49.47	46.29	-9.7	-6.4	-15.5
Group 2	51.43	47.60	44.69	-7.4	-6.1	-13.1
Group 3	57.37	52.27	48.37	-8.9	-7.5	-15.7
Group 4	53.01	51.55	49.26	-9.7	-6.4	-15.5

All figures NS across groups (p> 0.05)

Analytical comparisons: predicted number of admissions by cluster group

Table 6.2 presents the results from the regression analyses examining the numbers of admissions for older people with dementia by cluster group, controlling for other factors in the authorities concerned. The coefficients (estimates) of the influence of authority group (using group 2 'generic' home care as the reference category) and other factors, their individual statistical significance and the degree of variance (R^2) explained by the model are all shown. The series of models presented here each show the influence of group membership on admissions to care homes and employ the specification 'model 4' (see Appendix, Box A3.1). The models are each specified similarly, other than they employ different variables characterising need or deprivation at the local authority level (percentage of older people living alone versus deprivation concentration).

As can be seen by these models, there was no significant influence of group membership (type of home care) on the dependent variable, the number of admissions of older people with dementia to care homes. The factors that did influence admissions, on average across authorities, were those of deprivation (model A, table 6.2), need (living alone, model B, table 6.2) and supply (number of care home places, model B, table 6.2). The overall trend in these findings remained the same if the reference category for the grouping variable was changed to that of group 4 (specialist), with the non-significant finding of group and the significance of deprivation, need and supply remaining. The models explained around 20 per cent of the variation in care home admissions for those with dementia across English local authorities.

The explanatory variables described here were also applied to the dependent variable of percentage change in admissions over the three year period. These models only explained a small amount of the variance in the changes in admissions over time (R^2 range 0.03 to 0.10).

Table 6.2: Regression analysis – predicted number of admissions of older people with dementia to care homes

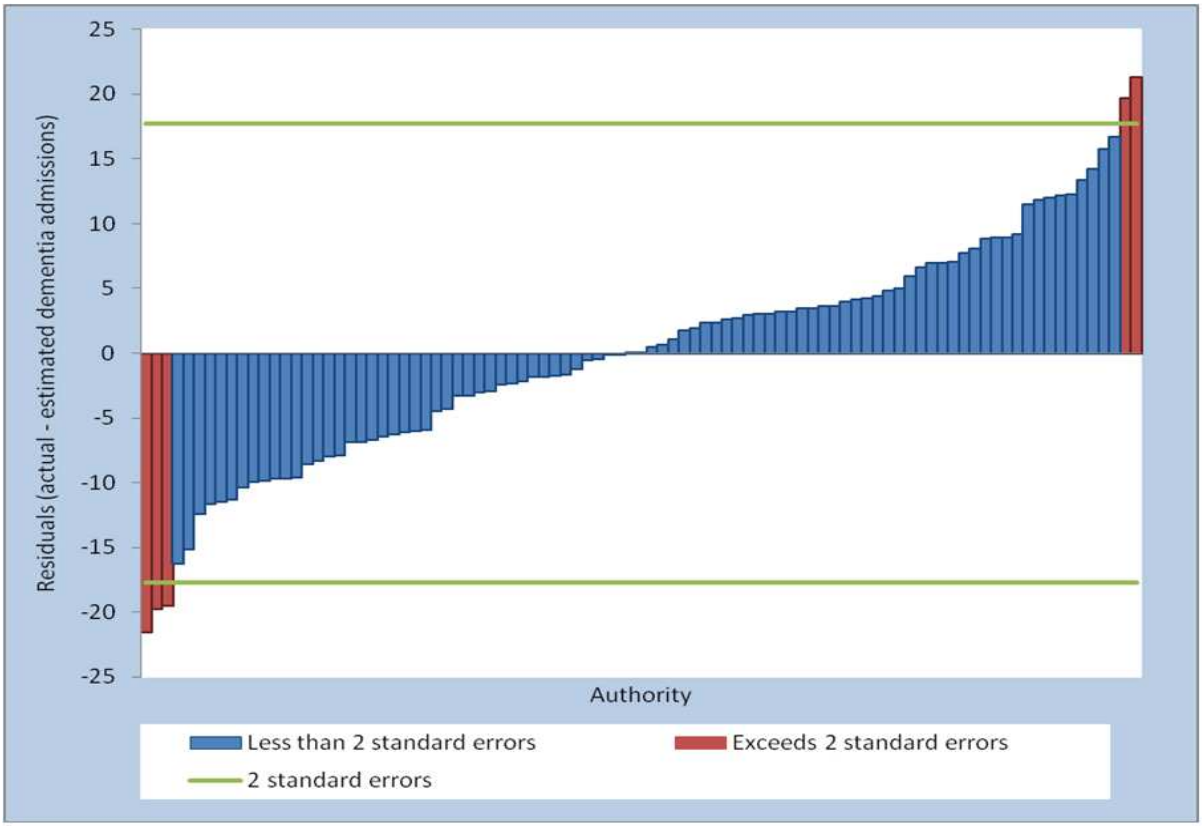
Variables	***Model A***			***Model B***		
	Coefficient (β)	SE	P	Coefficient (β)	SE	P
Constant	17.51	8.65	0.05	1.27	10.24	0.90
Group 1[1]	-0.22	2.65	0.93	0.69	2.57	0.79
Group 3 [1]	1.48	2.58	0.57	2.74	2.46	0.27
Group 4 [1]	2.23	2.95	0.45	3.32	2.84	0.25
Number of care home places	0.11	0.007	0.13	0.02	0.007	0.003
Number of admissions to hospital	0.00	0.002	0.85	0.00	0.001	0.89
Deprivation concentration	0.001	0.00	0.002	-	-	-
Percentage of older people living alone	-	-	-	0.96	0.25	<0.001
R^2	0.20			0.24		

[1] Reference category = group 2 (‘generic’) authorities; N = 93

'Performance' comparisons: authorities lying outside of average expected performance

Figure 6.2a and 6.2b highlight particular authorities, with their group numbers, measured against the residuals from the regression equations above**.** That is, authorities for England as a whole are measured against a model of average expected performance, taking into account the factors above; those who admit significantly more or fewer older people to care homes are signalled as worthy of further investigation.

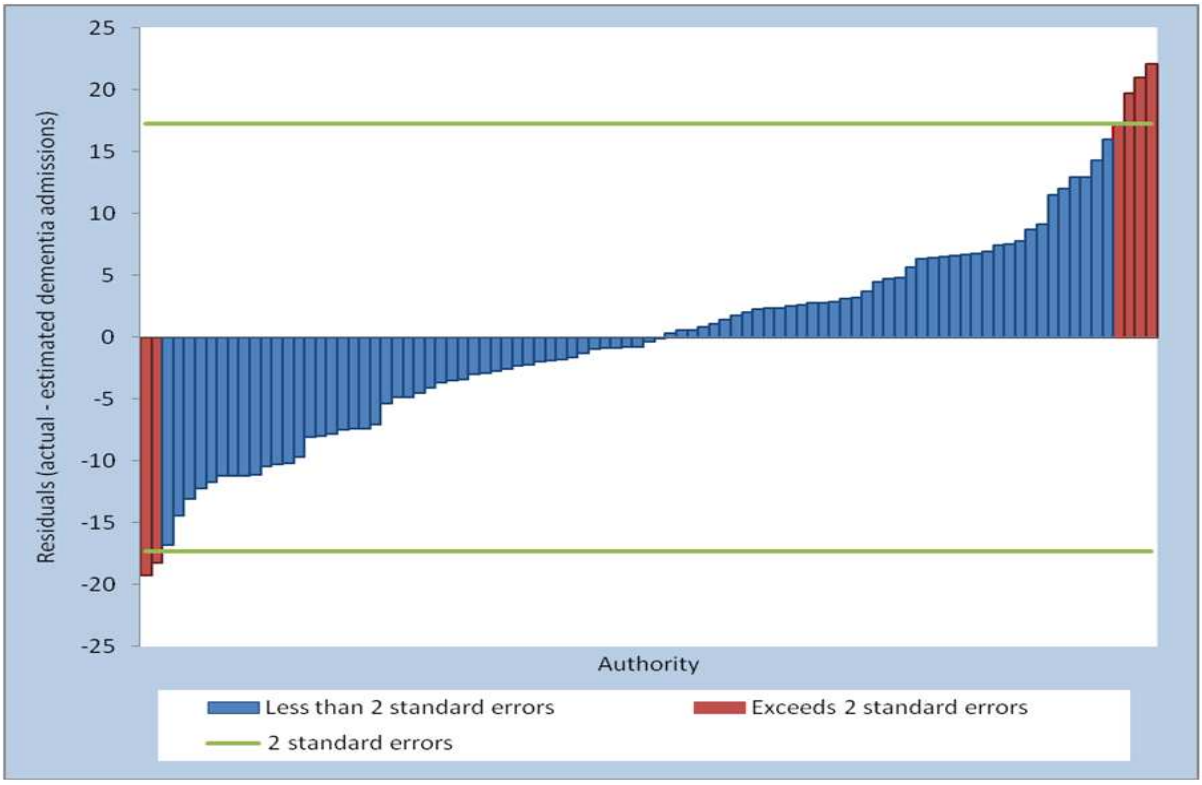
Figure 6.2a: Estimated admissions of older people with dementia to care homes – residual values from regression model A



Explanatory variables: admissions to hospital, care home places, deprivation concentration); N = 93
+ 2 Standard errors (cluster group membership) – (2), (3)
- 2 Standard errors (cluster group membership) – (2), (3), (2)

Using the model with deprivation as an independent variable characterising need (model A) resulted in two authorities performing particularly poorly (admitting more older people with dementia than expected). These authorities were in groups 2 and 3. However, two group 2 authorities also performed well (admitted fewer people than expected).

Figure 6.2b: Estimated admissions of older people with dementia to care home – residual values from regression model B



Explanatory variables: admissions to hospital, care home places, older people living alone; N = 93.
+ 2 Standard errors (cluster group membership) - (4), (2), (2), (3)
- 2 Standard errors (cluster group membership) - (3), (2)

Using the model with living alone as an independent variable characterising need (model B) resulted in four authorities performing relatively poorly (admitting more people than expected). Two of these were group two (generic) authorities but also two were more specialist (groups three and four). Similarly, of the authorities performing relatively well (admitting fewer people than expected) one was from group two and one from group three.

Conclusions

The analyses presented in this element of the study were intended to assess the extent to which more specialist home care, identified using the cluster groups of authorities identified earlier, would result in fewer admissions to care homes for older people with dementia. The findings were that all groups of authorities had experienced a reduction in care home admissions over time. There were, however, no significant relationships between the type and mix of home care and the number of care home admissions of older people with dementia. Given the small scale of specialist domiciliary care, this is perhaps unsurprising. This finding was repeated controlling for several factors likely to influence authorities' decisions to admit older people to care homes. Factors relating to need and the supply of care home places across authorities were, on average, more important and significant than the type of home care provision. Investigation of particular authorities falling outside a range of expected admissions showed, again, that there was no one to one relationship between the type of home care in authorities and their ability to maintain older people with dementia at home.

Chapter 7: Lessons for Commissioning Domiciliary Care for People with Dementia

Assessing the evidence about different forms of domiciliary care for people with dementia and their carers presents a number of challenges. These include the many different ways in which domiciliary care has been conceptualised within the literature and the fact that much of the relevant work has been undertaken in the United States where not only is terminology different, but so too is the way in which health and social care is organised (Donaghy, 1999; Tester, 1999; Godfrey et al., 2000). Moreover, in the UK some issues do not seem to have been addressed at all, including whether the provision of domestic support for people who are less dependent has any effect on their subsequent need for services (Godfrey et al., 2000). Methodologically there are concerns about the identification of people with dementia from local authority information systems (Moriarty, 1999; SSI, 1997) and small sample sizes (Donaghy, 1999) and sources of bias in sample selection. Sometimes, practical and ethical reasons have made it difficult to employ randomised designs (Challis and Darton, 1990). Furthermore there is a problem with the contemporariness of some of the evidence as some of the studies cited were published in the 1980s prior to the community care reforms of the 1990s and we know relatively little about the specific effects of the subsequent changes in commissioning and purchasing activity. Finally there are questions about the measures of effectiveness employed. Whilst the majority of studies have looked at the extent to which the provision of domiciliary care services may prevent or delay the need for institutionalisation, or its effect on carer burden, there are concerns about the appropriateness of these as primary outcomes (Baldock, 1997; Zarit et al., 1999). There has, for example, been very little consideration of the impact of such services on the wellbeing of the person with dementia. This may in part be due to the problems of measuring this (Donaghy, 1999); although an alternative explanation is that carers are perceived to be the primary beneficiaries of services for people with dementia. Indeed there is an ongoing debate about whether formal services should focus on meeting the needs of older people or carers – whether these are substitutes or complementary – although either way it would seem important to document the outcomes for both parties (Moriarty, 1999; Zarit et al., 1999).

Assessing the evidence base in relation to the provision of specialist and generic domiciliary care for people with dementia requires clear definitions of both target population and of service content. Neither is unproblematic. In terms of social care utilisation, identifying the numbers of people with dementia in contact with services is not easy. Many individuals with cognitive impairment will not have received a formal diagnosis (Levin et al., 1989) and as noted, often cognitive impairment is poorly recorded in social care record systems. Thus managers are reliant only on the identified general care needs of people receiving support to guide service commissioning rather than specific information on those with dementia. Much greater clarity of definition of specialist domiciliary care is also required. One of the most important conclusions from the review of PSSRU studies was that definitions of specialist domiciliary care vary and some generic services have a specialist component providing care to older people with dementia. This finding was confirmed in the survey of those currently responsible for commissioning domiciliary care. The latter also highlighted the complexity of current service arrangements with evidence of overlap between specialist and generic providers in terms of their target population and specialist domiciliary care often only available in part of a local authority. Thus the development of different service specifications for generic

domiciliary care and specialist domiciliary care for older people with dementia is a challenge for commissioners. Measures such as severity of needs or indeed the stage of dementia are not necessarily helpful in this context As a consequence service specifications and contracts often focus on the form of care required by the service user and the skills of the staff providing them, with the latter often being reflected in the provision of specialist training.

In the rest of this chapter the lessons from this study are organised under five headings which reflect key attributes relevant to the decision to commission different types of domiciliary care for people with dementia. These are: Quality; Intensity; Service mix; Service linkages; and Costs and Effectiveness.

Quality

Overall this study demonstrated the importance of quality as a key dimension in the provision of domiciliary care for older people with dementia. In the work undertaken with carers it was clear that they particularly valued continuity of care and training of staff. These were areas of care they were willing to pay more for. They also valued wider availability of weekend support and more personalised approaches to support, exemplified in activities such as life history work. Interestingly one aspect of quality likely to be derived from training was seen as particularly important, that of what we have described as "clinical nous" – an understanding of dementia and its manifestations so as to make appropriate responses and judgements more likely. Hence staff quality and capacity to comprehend particular needs of and ways to relate to people with dementia were identified as crucial, perhaps provided through training and on the job experience with good role models. However, it did not seem that these facets of quality were necessarily present in one type of service or another.

In earlier work examining the quality of domiciliary care, on the majority of standards there was no difference between generic and specialist provision. On only two indicators of the 10 standards employed were there differences: generic services scored higher on the flexibility standard whilst specialist services scored higher on that relating to individuality or user centred practice (Venables et al., 2006). In this context flexibility was defined as wider availability around the clock, providing live in support where needed and offering the capacity to respond differentially and more individually as required to the needs of older people with dementia. Such flexibility of response has always been critical to meeting the needs of frail older people and particularly those with dementia and is currently expressed in the personalisation agenda within adult social care services. Interestingly it was a feature of generic rather than of specialist services, possibly related to economies of scale, since several sources indicated that specialist services tended to be of smaller size. However, there is obviously a trade-off between this and the importance of continuity and familiarity, sometimes associated with the smaller specialist provision, which was clearly valued by carers in the present study.

This evidence provided four domains of quality relevant to the decision as to whether to employ specialist or generic domiciliary care. These quality indicators were:

- *Individuality (or user centred practice)* – practices such as use of memory wallets, culturally appropriate care;

- *Dementia specific training for staff* – whether at the induction stage or specific subsequent training (Hughes et al., 2008);
- *Continuity of care* – support from the same care worker; and
- *Flexibility of response* – care available at different times of the day and at weekends; offering live in support where needed; possible 24 hour care and the capacity to respond differentially and more individually as required to the needs of older people with dementia.

It appeared that these attributes may be provided by both generic and specialist domiciliary care services for people with dementia, albeit with different emphases. Most people with dementia receive care from generic domiciliary care services. Yet there is evidence that in certain situations specialist domiciliary care is of benefit to older people with dementia and their carers. Indeed, in providing appropriate levels of support it may be that quality of support is provided not by one or the other approach alone but rather as joint contributors to a support plan. This is discussed further in more detail below.

Intensity

Clearly the starting point for a comparison of the relative value of specialist or generic domiciliary care has to be the extent to which each addresses the requirements of people with dementia and their families. A number of studies in this report have indicated that the intensity of provision of support, in terms of the amount and frequency, is crucial. This is not a new message (Isaacs et al., 1972). The evidence also suggests that intensity of support is more likely to be delivered by generic domiciliary care services which are generally larger organisations. However, assistance from both types of domiciliary care may be appropriate for an individual in certain circumstances.

Intensity of domiciliary care support aligned with intensive case management has enabled people with dementia to retain their residential independence longer and enabled people to remain at home with greater levels of cognitive impairment than many who enter care homes lacking such support. This indicates the importance of the case manager role, whether undertaken by a nurse or social worker, in coordinating and integrating two types of domiciliary care with other services. Clearly, since the evidence from the intensive case management studies indicates that what people with dementia need is care tailored to their circumstances, features of quality need to be combined with intensity of support (Challis et al, 2009a).

Service mix – complementarity and substitution

Earlier it was noted that generic services can and do provide domiciliary care to large numbers of people with dementia and that there are differences in intensity and quality between the two forms of domiciliary care. However, no differences were evident in terms of admissions to care homes between local authorities with different approaches to commissioning domiciliary care for people with dementia. Nonetheless, there appeared to be different functions attributable to the different forms of domiciliary care. One possible hypothesis would be to link this observation to different phases of dementia, with perhaps the emphasis being upon specialist provision in the early stage and mixed provision in the later stages. It has been demonstrated that both generic and specialist domiciliary care services may operate jointly as complementary parts of a care plan. In such circumstances specialist

services were primarily oriented towards specific needs associated with the condition, such as behaviour, and more generic domiciliary care was focused more on the loss of Activities of Daily Living (such as toileting and dressing) and Instrumental Activities of Daily Living (such as meal preparation and managing affairs) (Challis et al., 2009a). In this example specialist paid domiciliary care workers supported by case managers within a community mental health team were funded by the local authority in addition to support from generic domiciliary care services. Other examples of linking domiciliary care for people with dementia to community mental health teams for older people have also been found, although such arrangements appear to be the exception rather than the norm.

More generally commissioning and service development cannot take place in a vacuum; decisions on the relative balance of specialist and generic provision need to take place in the context of existing service configurations within both health and social care, as noted by respondents to our telephone survey. This inevitably raises a series of issues about the degree of complementarity and substitution between generic and more specialist forms of domiciliary care as well as between domiciliary care and other service support. This is evident in a number of settings. For example, there is the opportunity for substitution between support workers in mental health teams, whose numbers have increased in recent years, and domiciliary care support workers. More generally, in the empirical work undertaken for this study, carers placed a high valuation on complementary services to domiciliary care, particularly citing respite care.

It is likely that a number of features of the commissioning process will influence the service mix and thus the development of specialist domiciliary care alongside generic provision. At the local authority level, it was observed that patterns of commissioning domiciliary care for older people with mental health needs (including dementia) appeared to vary markedly. In terms of commissioning and contracting arrangements three factors, all of which were evident in earlier studies appeared important. These were: the presence of joint commissioning for old age mental health services; the commissioning of specialist domiciliary care services for older people with mental health needs; and specification of specialist dementia training within the contracting process. Each one of these arrangements was only present in a minority of authorities and they served to distinctly group local authority patterns of provision. Further work would usefully unravel the local rationales for these very different patterns of commissioning of what is a key element of support for older people with mental health needs, identify the extent to which they reflect different local wider care system logics, and identify their possible costs and benefits.

Service linkages

It was previously noted that to consider the virtues of specialist and generic domiciliary care for people with dementia outside of the wider service context in a locality is unhelpful. Staff with responsibility for assessment and support planning are placed in a wide variety of organisational and team structures, ranging from social care settings, primary care mental health settings to community mental health teams for older people. Thus service users and carers may receive different services and levels and types of support. A further difficulty arises from the fact that linkages between community mental health teams for older people and domiciliary care services are often poorly developed despite this being specified in the service model in the *National Service Framework for Older People* (DH 2001).

It could, be argued that one distinguishing feature of a specialist as distinct from a generic domiciliary care service is most likely to be its relationship to other services providing support to older people with dementia. For example in the intensive case management scheme which provided support for people with dementia, specialist domiciliary care workers were based within the community mental health team for older people from whom they received their referrals (Challis et al. 2009a). Similarly, current service provision may include short term reablement services specifically for people with dementia, thereby offering another example of how the target population may be defined by the service sector – intermediate care – in which it is located.

Costs and effectiveness

The evidence for differences in costs between the different forms of domiciliary care for people with dementia appeared limited. In terms of unit cost, whilst, on average, specialist domiciliary care was slightly more expensive than generic this is not always the case. Specialist domiciliary care was not always more expensive than generic provision and there was considerable overlap between the costs of providing these types of support across local authorities. Furthermore, the problem of accurate costing was marked in services where specialisation was partial, taking the form of certain staff being responsible for supporting people with dementia due to their experience, but not reflected in average cost pricing approaches.

Overall, in terms of differential impact of different types of domiciliary care for people with dementia, it would seem that there are more subtle effects to be identified through varied impact on different sub groups or needs of people with dementia (early/later stage); different types of needs (behaviour or help with activities of daily living); and provision of different types of support (delivery of more therapeutic or practical support). There was little evidence of differential effects at the authority level with regard to the effect of specialist or generic forms of domiciliary care using national data. If the outcome in terms of maintaining people out of a care home setting is considered then all local authorities appear to have become better at this over recent periods. The particular mix of generic and more specialist provision that may exist appeared to have no significant bearing on authorities' ability to maintain older people at home; more important are factors such as the capacity of authorities, in terms of the numbers of care home places they provide, and the particular level of need in a local area.

With regard to cost effectiveness there are several different sources of evidence. In one of the PSSRU balance of care simulation models, generic domiciliary care was prescribed as a means of providing a cost effective alternative to care home support for people with dementia. Furthermore, in an evaluation of community based services for vulnerable older people for whom a care home placement was probable, which included both people with dementia and those who were cognitively intact, costs, satisfaction, and quality of life levels associated with receiving generic home care services for people with dementia and people who were cognitively intact were relatively similar. This might be used to infer that the cost effectiveness of generic domiciliary care was relatively similar for both groups. The case management intervention for people with dementia which used both specialist and generic domiciliary care services found that this combination was cost effective in terms of meeting the needs of carers (Challis et al., 2009a).

An indirect measure of cost-effectiveness is users' and/or carers' preferences, expressed in monetary terms as an expression of value. In our carers' experiment, the most important attribute of a domiciliary care service delivered to people with dementia, from the carers' perspective, was continuity in terms of the same worker visiting. As noted above carers were willing to pay a premium for this aspect whereas other attributes were viewed as less important. Training of domiciliary care workers came a close second in this respect and importantly, even some dementia-specific training was viewed as valuable in comparison to none. Neither attribute is the exclusive preserve of specialist or generic provision.

Conclusions

In terms of guidance for commissioners, the findings could be seen to suggest that it is 'not what you do but the way that you do it'. That is, it does not particularly matter in terms of effectiveness whether domiciliary care for people with dementia is organised on a 'specialist' or 'generic' basis; thus form is of less significance than content. What matters most is whether the service conforms to good practice or quality standards for dementia care, and the evidence here suggests that both generic and specialist providers may often offer such features. Whilst specialist domiciliary care was valued by commissioners where it was available, despite a slightly higher unit cost, it may be the case that sufficiently good care can be commissioned from generic providers if efforts are made, through training or experience, to provide domiciliary care that fulfils some of the key criteria for good quality support. Therefore, it is these criteria that require specification and thus the definition of 'specialist' support requires further formal definition, perhaps building on the evidence contained throughout this report. However, there were indications that certain people with dementia do require specialist support, for example people with behavioural problems associated with dementia, which could not reasonably be expected to come from generic domiciliary care. A logical corollary of this is that specialist support might also benefit those with early onset dementia as well as those where behavioural problems are acute. Whether or not this assistance comes from support workers based within a community mental health team for older people or a specialist domiciliary care provider is a decision for local service commissioners.

In an earlier paper, Challis and Ferlie (1988) stated that 'specialism' in social work should be viewed as an aspect that 'seeks to develop a distinctive but circumscribed knowledge base through immersion in a limited field of practice in which general and particular expertise can be applied to the benefit of vulnerable people'. If this is the case, translated to our present purposes, specialist domiciliary care for people with dementia may be delivered in a variety of ways, not necessarily dependent on the structure and organisation of the provider. It is the knowledge, experience, attitudes and values of home support providers which can facilitate appropriate care and support for people with dementia, as noted in the Norwegian Dementia Plan (Engedal, 2010). Not only 'specialist' but also generic services, offered to most older people who require support, are capable of providing such expertise. It is therefore not necessarily the case that 'specialist' care is better than generic care; it all depends on the content and nature of this care. It would seem that for the future, as part of commissioning decisions in respect of services for people with dementia, the need is to define more precisely what we mean by specialist provision, and where it fits in the care pathway, and for it to be understood as part of a range of support for this target population.

REFERENCES

* included in the literature review

Abendstern, M., Harrington, V., Brand, C., Tucker, S., Wilberforce, M. and Challis, D. (2010) Community Mental Health Teams for Older People: Structures, Processes and Out comes. A Systematic Literature Review, Discussion Paper M243, Personal Social Services Research Unit, University of Manchester at Manchester.

Abendstern, M., Reilly, S., Challis, D., Hughes, J. and Venables, D. (2005) Professional Community Based Teams for Older People with Dementia in the North West of England, Discussion Paper M069, Personal Social Services Research Unit, University of Manchester at Manchester.

Abendstern, M., Reilly, S., Hughes, J., Venables, D. and Challis, D. (2006) Levels of integration and specialisation within professional community teams for people with dementia, *International Journal of Geriatric Psychiatry*, 21, 77-85.

Ager, A. (1993) The Life experiences Checklist: 1. Applications in staff training and programme. *Mental Handicap*, 21, 7-9.

*Andrew, T., Moriarty, J., Levin, E. and Webb, S. (2000) Outcome of referral to social services departments for people with cognitive impairment, *International Journal of Geriatric Psychiatry*, 15, 406-414.

Askham, J. (1997) Supporting elderly people and informal carers at home, in I.J. Norman and S. Redfern (eds), *Mental Health Care for Elderly People,* Edinburgh, Churchill Livingstone.

Audit Commission (1997) *The Coming of Age: Improving Care Services for Older People,* London, Audit Commission.

Audit Commission (2000) *Forget Me Not: Mental Health Services for Older People,* Portsmouth, Holbrooks.

Audit Commission England (2002) *Forget Me Not: Developing Mental Health Services for Older People in England,* London, Audit Commission.

Baillon, S., Neville, P. and Broome, C. (1996) A survey of the relationship between CMHTs and residential homes for the elderly, *International Journal of Geriatric Psychiatry,* 11, 807-811.

*Bamford, C. and Bruce, E. (2000) Defining the outcomes of community care: the perspectives of older people with dementia and their carers, *Ageing and Society*, 20, 5, 543-570.

Bebbington, A.C. and Davies, B. (1980) Territorial need indicators: a new approach. Part II. The personal social services for the elderly. *Journal of Social Policy*, 9, 433-462.

Bennett, N., Jarvis, L., Rowlands, O., Singleton, N. and Haselden, L. (1996) *Living in Britain: Results from the 1994 General Household Survey,* London, HMSO.

Bharath, S., Shaji, K. and Jolley, D. (2010) Course and outcome of dementia, in N. Kar, D. Jolley and B. Misra (eds), *Handbook of Dementia,* second edition Hyderabad, Paras.

*Bowes, A. and Wilkinson, H. (2003) 'We didn't know it would get that bad': South Asian experiences of dementia and the service response, *Health and Social Care in the Community*, 11, 5, 387-396.

Brown, P., Challis, D. and von Abendorff, R. (1996) The work of a community mental health for the elderly: referrals, caseloads, contact history and outcomes, *International Journal of Geriatric Psychiatry*, 11, 29-39.

Burgess, L. (2007) Discrete choice experiments [computer software], Department of Mathematical Sciences, University of Technology, Sydney, http://crsu.science.uts.edu.au/choice/.

*Burholt, V., Wenger, G.C. and Scott, A. (1997). Dementia, disability and contact with formal services: a comparison of dementia sufferers and non-sufferers in rural and urban settings, *Health and Social Care in the Community*, 5, 6, 384-397.

Burns, A., O'Brien, J. and Ames, D. (2005) *Dementia,* third edition, London, Hodder Arnold.

Campbell, A. J., McCosh, M., Reinken, J. and Allan, C. (2003) Dementia in old age and the need for services. *Age and Ageing,* 12, 11-16.

Campbell, M. (2002) *Cluster Analysis: CCSR Short Course Notes*, Manchester, Mimas.

Challis, D. (2003) Achieving co-ordinated and integrated care among long term care services: the role of care management, in J. Brodsky, J. Habib, and M. Hirschfeld (eds) *Key Policy Issues in Long Term Care*, Geneva, World Health Organisation.

Challis, D. and Ferlie, E. (1988) The Myth of Generic Practice: Specialisation in Social Work, *Journal of Social Policy,* 17, 1, 1-22.

Challis, D., Darton, R., Johnson, L., Stone, M. and Traske, K. (1995) *Care Management and Health Care of Older People: The Darlington Community Care Project*, Aldershot, Arena.

Challis, D. and Hughes, J. (2002) Frail older people at the margins of care: some recent research findings, *British Journal of Psychiatry*, 180, 126-130.

*Challis, D., von Abendorff, R., Brown, P., Chesterman, J. and Hughes, J. (2002a) Care management, dementia care and specialist mental health services, *International Journal of Geriatric Psychiatry,* 17, 4, 315-325.

Challis D., Reilly S., Hughes J. , Burns A., Gilchrist H. and Wlison K. (2002b) Policy, organisation and practice of specialist old age psychiatry in England, *International Journal of Geriatric Psychiatry,* 17, 11, 1018-1026.

Challis, D., Chesterman, J., Luckett, R., Stewart, K. and Chessum, R. (2002c) *Care Management in Social and Primary Health Care. The Gateshead Community Care Scheme,* Aldershot, Ashgate.

Challis, D., Clarkson, P., Williamson, J., Hughes, J., Venables, D., Burns, A. and Weinberg, A. (2004) The value of specialist clinical assessment of older people prior to entry to care homes, *Age and Ageing,* 33, 1, 25-34.

Challis, D., Sutcliffe, C., Hughes, J., Abendstern, M. and Clarkson, P. (2006) A Systematic Evaluation of the Development and Impact of the Single Assessment Process in England. Stage II- Impact of the SAP form the perspective of multiple stakeholders, Volume I – The Care Plan Study, Discussion paper M145, Personal Social Services Research Unit, University of Manchester.

*Challis, D., Sutcliffe, C., Hughes, J., von Abendorff, R., Brown, P., and Chesterman, J. (2009a) *Supporting People with Dementia at Home: Challenges and Opportunities for the 21st Century,* Surrey, Ashgate.

Challis, D., Hughes, J., Sutcliffe, C. and Xie, C. (2009b) Care Coordination Arrangements for Older People, Discussion Paper M216, Personal Social Services Research Unit, Manchester, University of Manchester.

Challis, D., Abendstern, M., Brand, C., Harrington, V., Tucker, S. and Wilberforce, M. (2009c) *How Does Your Team Work? An Investigation of Joint Working and Integration within Community Mental Health Teams for Older People,* Discussion Paper M 213. Personal Social Services Research Unit, Manchester, University of Manchester.

Chester, H., Hughes, J. and Challis, D. (2010a) Commissioning social care for older people: influencing service delivery, Discussion Paper M242, Personal Social Services Research Unit, University of Manchester at Manchester.

Chester, H., Hughes, J. and Challis, D. (2010b) Patterns of commissioning, contracting and care management in social care services for older people in England, *British Journal of Social Work*, doi:10.1093/bjsw/bcq044.

*Chilvers, D. (2003) The case for specialist home care for people with dementia, *Journal of Dementia Care*, 11, 1, 20-21.

Clarkson, P., Hughes, J. and Challis, D. (2005) The potential impact of changes in public funding for residential and nursing home care in the United Kingdom: the Residential Allowance. *Ageing and Society*, 25, 159-180.

Clarkson, P. and Challis, D. (2006) Performance measurement in social care: a comparison of efficiency measurement methods. *Social Policy & Society*, 5, 4, 461-477.

Clarkson, P., Davies, S., Challis, D., Donnelly, M. and Beech, R. (2009) Has social care performance in England improved? An analysis of performance ratings across social services organisations, *Policy Studies*, 30, 1-20.

Clarkson, P., Venables, D., Hughes, J., Burns, A. and Challis, D. (2006) Integrated specialist assessment of older people and predictors of care home admission, *Psychological Medicine,* 36, 1011-21.

Cm 849 (1989) *Caring for People: Community Care in the Next Decade and Beyond*, London, HMSO.

Cm 4169 (1998) Modernising Social Services. Promoting Independence, Improving Protection, Raising Standards, London, The Stationery Office.

Cm 6499 (2005) *Independence, Well-being and Choice Our Vision for the Future of Social Care for Adults in England,* London, The Stationery Office.

Cm 7881 (2010) *Equity and Excellence: Liberating the NHS*. London: The Stationery Office Limited.

Coles, R., von Abendorff, R. and Herzberg, J. (1991) The impact of a new community mental health team on an inner city psychogeriatric service, *International Journal of Geriatric Psychiatry,* 6, 31-39.

*Curtice, L. and Fraser, F. (2000) The domiciliary care market in Scotland: quasi-markets revisited, *Health and Social Care in the Community*, 8, 4, 260-268.

Denzin, N.K. (1989) *The Research Act: A Theoretical Introduction to Sociological Methods*, third edition, Prentice Hall, Englewood Cliffs, New Jersey.

Department of Health (2001) *Modern Standards and Service Models: National Service Framework for Older People*, Department of Health, London.

Department of Health (2002a) *Fair Access to Care Services. Guidance on Eligibility for Adult Social care,* LAC (2002)13, London, Department of Health.

Department of Health (2002b) *Guidance on the Single Assessment Process for Older People*, HSC2002/001: LAC (2002) 1, London, Department of Health.

Department of Health (2003) *Domiciliary Care: National Minimum Standards – Regulations,* London, The Stationary Office.

Department of Health (2007) *Social Care Workforce Research Initiative,* http://www.dh.gov.uk/prod_consum_dh/groups/dh_digitalassets/documents/digitalasset/dh_090353.pdf accessed 2010

Department of Health (2008) *Transforming Social Care,* LAC (DH) (2008) 1, London, Department of Health.

Department of Health (2009) *Living Well with Dementia: A National Dementia Strategy*, London Department of Health.

Department of Health and Care Services Improvement Partnership (2005) *Everybody's Business. Integrated Mental Health Services for Older Adults: A Service Development Guide,* London, Department of Health.

Dolan P (1997) Modeling valuations for EuroQol health states. *Medical Care*, 35, 1095-1108.

Douglas, H.R., Normand, C.E., Higginson, I.J. and Goodwin, D.M. (2005) A new approach to eliciting patients' preferences for palliative day care: The choice experiment method. *Journal of Pain and Symptom Management,* 29, 5, 435-445.

Edelbalk, P.G., Samuelsson, G., & Ingvad, B. (1995), How elderly people rank order the quality characteristics of a home service, *Ageing and Society*, 15, 83-102.

Engedal, K. (2010) The Norwegian Dementia Plan 2015 - 'making most of the good days', *International Journal of Geriatric Psy*chiatry, 25, 928–930.

EuroQol Group (1990) EuroQol — a new facility for the measurement of health related quality of life. *Health Policy*, 16, 199-208.

Everitt, B.S. (1993) *Cluster Analysis*, 3rd edn., New York: Halsted Press.

Ferri, C.P., Prince, M., Brayne, C., Brodaty, H., Fratiglioni, L., Ganguli, M., Hall, K., Hasgawa, K., Hendie, H., Huang, Y., Jorm, A., Mathers, C., Menezes. P., Rimmer, E. and Scazufca, M. for Alzheimer's Disease International (2005) Global prevalence of dementia: a Delphi consensus study, *The Lancet,* 366, 2112-2117.

Glendinning, C., Challis, D., Fernández, J.L., Jacobs, S., Jones, K., Knapp, M., Manthorpe, J., Moran, N., Netten, A., Stevens, M. and Wilberforce, M. (2008) *Evaluation of the Individual Budgets Pilot Programme*. Social Policy Research Unit, University of York/ Personal Social Services Research Unit, Universities of Manchester, London School of Economics and Kent/ Social Care Workforce Research Unit, King's College London.

Godfrey, M., Randal, T., Long, A. and Grant, M. (2000) Review of Effectiveness and Outcomes: Home Care, Centre for Evidence-Based Social Services, University of Exeter at Exeter.

*Gordon, D., Carter, H. and Shonagh, S. (1997) Profiling the care needs of the population with dementia: a survey in central Scotland, *International Journal of Geriatric Psychiatry*, 12, 7, 753-759.

Greene, W. (1993) *Econometric Analysis*. New Jersey: Prentice Hall.

Grundy, E. and Glaser, K. (1997) Trends in, and transitions to, institutional residence among older people in England and Wales, 1971 to 1991. *Journal of Epidemiology and Community Health,* 51*,* 531.

Gurland, B., Kuriansky, J., Sharpe, L., Simon, R., Stiller, P. and Birkett, P.L. (1977) The comprehensive assessment and referral evaluation (CARE) - rationale, development and reliability, *International Journal of Ageing and Human Development*, 8, 1, 9-42.

Hall, J., Kenny, P. and Hossain, I. (2007) The provision of informal care in terminal illness: an analysis of carers' needs using a discrete choice experiment. *CHERE Working Paper 2007/12*. Sydney: Centre for Health Economics Research and Evaluation Faculty of Business University of Technology, Sydney.

Hall, J., Viney, R., Haas, M. and Louviere, J. (2004) Using stated preference discrete choice modelling to evaluate health care programs. *Journal of Business Research*, 57, 1026-1032.

Healthcare Commission (2009) *Equality in Later Life. A National Study of Older People's Mental Health Services,* London, Commission for Health Care Audit and Inspection.

Hensher, D.A., Rose, J.M. and Greene, W.H. (2005) *Applied Choice Analysis: A Primer*. Cambridge: Cambridge University Press.

Hughes, J. and Challis, D. (2004) Frail older people - margins of care, *Reviews in Clinical Gerontology,* 14, 2, 155-64.

Hughes, J., Bagley, H.J., Reilly, S, Burns, A.S. and Challis, D.J. (2008). Care staff working with people with dementia: Training, knowledge and confidence. *Dementia*, 7, 227-238.

Hughes, J., Chester, H. and Challis, D. (2009) Recruitment and Retention of a Social Care Workforce for Older People, Discussion Paper M193/2, Personal Social Services Research Unit, University of Manchester at Manchester.

Hughes, J., Chester, H. and Challis, D. (2010) Domiciliary care services for older people: fit for purpose? Discussion Paper M241, Personal Social Services Research Unit, University of Manchester at Manchester.

Isaacs, B., Livingstone, M. and Neville, Y. (1972) *Survival of the unfittest : a study of geriatric patients in Glasgow*, London: Routledge and Kegan Paul.

*Jacobs, S., Xie, C., Reilly, S., Hughes, J. and Challis, D. (2009) Modernising social care services for older people: Scoping the United Kingdom evidence base, *Ageing and Society*, 29, 4, 497-538.

Knapp, M., Prince, M., Albanese, E., Banerjee, S., Dhanasiri, S., Fernandez, J.L., Ferri, C., McCrone, P., Snell, T. and Stewart, R. (2007) *Dementia UK*. London: PSSRU, London School of Economics and the Institute of Psychiatry, London, for the Alzheimer's Society.

Kovach, C.R. (1997) *Late-Stage Dementia Care: A Basic Guide*. London: Taylor and Francis.

Lancsar, E. and Louviere, J. (2008) Conducting Discrete Choice Experiments to inform healthcare decision making: A user's guide. *PharmacoEconomics*, 26, 8, 661-677.

Lang, I.A., Llewellyn, D.J., Langa, K.M., Wallace, R.B., Huppert, F.A. and Melzer, D. (2008) Neighbourhood deprivation, individual socioeconomic status, and cognitive function in older people: analyses from the English longitudinal study of ageing. *Journal of the American Geriatrics Society*, 56, 191-198.

Larsen, D.L., Attkisson, C.C., Hargreaves, W.A. and Nguyen, T.D. (1979) Assessment of client/patient satisfaction: Development of a general scale. *Evaluation and Program Planning*, 2, 197-207.

Levin, E., Sinclair, I. and Gorbach, P. (1989) *Families, Services and Confusion in Old Age,* Aldershot, Avebury.

Levitt, M.S. and Joyce, M.A.S. (1987) *The Growth and Efficiency of Public Spending.* Cambridge: Cambridge University Press.

Lin, F.J. (2008) Solving multicollinearity in the process of fitting regression models using the nested estimate procedure. *Quality & Quantity*, 42, 417-426.

Lingard J. and Milne A. (2004) *Integrating Older People's Mental Health Services: Community Mental Health Teams for Older People: A Commentary and Resource Document,* London, Department of Health.

Livingston, G., Manela, M. and Katona, C. (1997) Cost of community care for older people, *British Journal of Psychiatry,* 171, 1, 56-69.

MacKnight. C. and Rockwood, K. (2001) Use of the Chronic Disease Score to measure co-morbidity in the Canadian study of Healthy Ageing, *International Psychogeriatrics,* 13, Supplement 1 137-142.

Mahoney, F.I. and Barthel, D.W. (1965) Functional evaluation: the Barthel Index, *Maryland State Medical Journal,* 14, 61-65.

*Manthorpe, J and Alaszewski, H. (2002) Listening to the dementia workforce: local providers' perceptions of dementia services, *Quality in Ageing - Policy Practice and Research*, 3, 2, 22-29.

McCrae, N., Banerjee, S., Murray, J., Prior, S. and Silverman, M. (2008) An extra pair of hands? A case of the introduction of support workers in community mental health teams for older adults, *Journal of Nursing Management,* 16, 734-743.

McCrone, P., Beecham, J., and Knapp, M. (1994) Community psychiatric nurse teams: cost-effectiveness of intensive support versus generic care, *British Journal of Psychiatry*, 165, 218–221.

*McDonald, A. and Heath, B. (2008) Developing services for people with dementia: Findings from research in a rural area, *Quality in Ageing - Policy, Practice and Research*, 9, 4, 9-18.

McNamee R. (2005) Regression modelling and other methods to control confounding. *Occupational and Environmental Medicine*, 62, 500-506.

McPherson, A., Furniss, F.G., Sdogati, C., Cesaroni, F., Tartaglini, B. and Lindesay, J. (2001) Effects of individualized memory aids on the conversation of persons with severe dementia: A pilot study, *Aging & Mental Health*, 5, 289-294.

MIMAS (2010) GeoConvert http://geoconvert.mimas.ac.uk/ [accessed 30/04/2010]

*Moriarty, J. (1999) Use of community and long-term care by people with dementia in the UK: a review of some issues in service provision and carer and user preferences, *Aging and Mental Health,* 3, 4, 311–319.

Morris,J., Fries, B., Mehr, D., Hawes, C., Phillips, C., Mor, V. and Lipsitz, L. (1994) MDS Cognitive Performance Scale, Journals of Gerontology, 49, 4, 174-182.

Murray, A., Shepherd, G., Onyett, S. and Muijen, M. (2006) *More than a Friend: The Role of Support Workers in Community Mental Health Services*, London, The Sainsbury Centre for Mental Health.

Myers, C. and Wilks, D. (1999) Comparison of Euroqol EQ-5D and SF-36 in patients with chronic fatigue syndrome. *Quality of Life Research*, 8, 9-16.

National Audit Office (2007) *Improving Services and Support for People with Dementia*, London, The Stationery Office.

National Institute for Health and Clinical Excellence and Social Care Institute for Excellence (2006) Dementia: supporting people with dementia and their carers in health and social care, *National Clinical Guideline number 42,* London, National Institute for Health and Clinical Excellence.

National Mental Health Development Unit (2008) *Combined Mapping Framework,* http://www.mhcombinedmap.org/ accessed 2009.

Nelson, T., Fernandez, J.L., Livingston, G., Knapp, M. and Katona, C. (2004) Does diagnosis determine delivery? The Islington study of older people's needs and health care costs. *Psychological Medicine*, 34, 147-155.

Netten, A., Darton, R., Bebbington, A. and Brown, P. (2001b) Residential or nursing home care? The appropriateness of placement decisions. *Ageing and Society,* 21, 3-23.

Netten, A., Darton, R., Bebbington, A., Forder, J., Brown, P. and Mummery, K. (2001a) Residential and nursing home care of elderly people with cognitive impairment: prevalence, mortality and costs. *Aging and Mental Health*, 5, 1, 14-22.

Nieboer, A.P., Koolman, X. and Stolk, E.A. (2010) Preferences for long-term care services: Willingness to pay estimates derived from a discrete choice experiment. *Social Science and Medicine*, 70, 1317–1325.

O'Connor, D., Pollitt, P., Brook, C. and Reiss, B. (1989) The distribution of services to demented elderly people living in the community, *International Journal of Geriatric Psychiatry,* 4,6, 339-344.

O'Connor, D., Pollitt, P., Brook, C., Reiss, B. and Roth, M. (1991) Does early intervention reduce the number of elderly people with dementia admitted to institutions for long term care? *British Medical Journal,* 302, 871-875.

Pattie, A.H. and Gilleard, C.J. (1979) *Manual of the Clifton Assessment Procedures for the Elderly (CAPE),* Sevenoaks, Hodder and Stoughton Educational.

Prince M. (2002) Epidemiology, in R. Jacoby and C. Oppenheimer (eds), *Psychiatry in the Elderly,* third edition, Oxford, Oxford University Press.

Prince, M., Livingston, G. and Katona, C. (2007) Mental health care for the elderly in low-income countries: a health system approach, *World Psychiatry,* 6, 5-13.

Psathas, G. (2005) 'The ideal type in Weber and Schutz', in Endress, M., Psathas, G. and Nasu, H. (eds), *Explorations of the Life-World*, Dordrecht: Springer.

*Riordan, J.M. and Bennett, A.V. (1998) An evaluation of an augmented domiciliary service to older people with dementia and their carers, *Aging and Mental Health*, 2, 2, 137-143.

*Rothera, I., Jones, R., Harwood, R., Avery, A., Fisher, K., James, V., Shaw, I. and Waite, J. (2008) An evaluation of a specialist multiagency home support service for older people with dementia using qualitative methods, *International Journal of Geriatric Psychiatry*, 23, 65-72.

Ryan, M., Bate, A., Eastmond, C.J. and Ludbrook, A. (2001) Use of discrete choice experiments to elicit preferences. *Quality in Health Care*, 10 (Suppl I), i55-i60.

Ryan M, Netten A, Skatun D, Smith P.(2006) Using discrete choice experiments to estimate a preference-based measure of outcome-an application to social care for older people. *Journal of Health Economics* 25, 5, 927-44.

*Ryan, T., Nolan, M., Enderby, P., Reid, D. (2004) Part of the family: sources of job satisfaction amongst a group of community-based dementia care workers, *Health and Social Care in the Community* 12, 2, 111-18.

Scott, A., Evandrou, M., Falkingham, J. and Rake, K. (2001) Going into residential care: evidence from the BHPS 1991-1999. *ESRC SAGE Research Group Discussion Paper No 5*, March.

Sheard, D. and Cox, S. (1998) Teams, Multidisciplinary and Interprofessional Working and Dementia, Stirling, The Dementia Services Development Centre, University of Stirling at Stirling.

Sinclair, I., Parker, R., Leat, D. and Williams, J. (1990) *The Kaleidoscope of Care: A Review of Research on Welfare Provision for Elderly People,* London, HMSO.

Snayde, F. and Moriarty, J. (2009) Person-centred home care for people with dementia: developing a specialist service in and ethically diverse community, *Dementia*, 8.1.148-152.

Social Policy Research Unit (2000) *Briefing Home Care Staff about Older People's Individual Needs,* Research Works November 5263-5330, Social Policy Research Unit, York, University of York.

Social Services Inspectorate (1997) *At Home with Dementia: Inspection of Services for Older People with Dementia in the Community*, London, Department of Health.

Spicker, P. and Gordon, D.S. (1997) *Planning for the Needs of People with Dementia: The Development of a Profile for Use in Local Services,* Aldershot, Avebury.

SPSS (2006), *SPSS Base 15.0 User's Guide*, USA, SPSS Inc

Stevenson, G., Ewing, H., Herschell, J. and Keith, D. (2006) An enhanced assessment and support team (EAST) for dementing elders - review of a Scottish regional initiative, *Journal of Mental Health,* 2, 251-258.

Sutcliffe, C., Hughes, J., Abendstern, M., Clarkson, P. and Challis, D. (2008) Developing multidisciplinary assessment – exploring the evidence from a social care perspective, *International Journal of Geriatric Psychiatry*, 23, 1297-1305.

Szende, A., Oppe, M. and Devlin, N. (2007) *EQ-5D Valuation Sets: An Inventory, Comparative Review and Users' Guide*. Rotterdam: EuroQol Foundation/Springer.

Tucker, S., Hughes, J. and Challis, D. with Burns, A. (2005) Services for Older People with Mental Health Problems: The Balance of Care in Cumbria, Discussion Paper M106, Personal Social Services Research Unit, Manchester, University of Manchester.

*Tucker, S., Hughes, J., Scott, J., and Challis, D. and Burns, A. (2007a) Commissioning services for older people with mental health problems: is there a shared vision? *Journal of Integrated Care*, 15, 2, 3-12.

Tucker, S., Baldwin, R., Hughes, J., Benbow, S., Barker, A., Burns, A. and Challis, D. (2007b) Old age mental health services in England: Implementing the National Service Framework for Older People, *International Journal of Geriatric Psychiatry,* 3, 211-217.

Tucker, S., Hughes, J., Burns, A. and Challis, D. (2008) The balance of care – reconfiguring services for older people with mental health problems, *Aging and Mental Health,* 12, 1, 81-91.

Tucker, S., Baldwin, R., Hughes, J., Benbow, S., Barker, A., Burns, A. and Challis, D. (2009) Integrating mental health services for older people in England - from rhetoric to reality, *Journal of Interprofessional Care,* 23, 341-354.

Turner, D., Tarrant, C., Windridge, K., Bryan, S., Boulton, M., Freeman, G. and Baker, R. (2007) Do patients value continuity of care in general practice? An investigation using stated preference discrete choice experiments. *Journal of Health Services Research & Policy*, 12, 132-137

*Turner, S., Christie, A. and Haworth, E. (2005) South Asian and white older people and dementia: a qualitative study of knowledge and attitudes, *Diversity in Health and Social Care,* 2, 3, 197-209.

Venables, D., Reilly, S., Challis, D., Hughes, J. and Abendstern, M. (2005) Home Care Services for Older People with Dementia in the North West of England, Discussion Paper M097, Personal Social Services Research Unit, University of Manchester at Manchester.

*Venables, D., Reilly, S., Challis, D., Hughes, J. and Abendstern, M. (2006) Standards of care in home care services: a comparison of specialist and generic services for older people with dementia, *Aging and Mental Health*, 10, 2, 187-194.

Ware, J.E., Snow, K.K., Kosinski, M. and Gandek, B. (1993) *SF-36 Health Survey: Manual and Interpretation Guide*. Boston, MA: The Health Institute, New England Medical Centre.

*Ware, P., Matosevic, T., Forder, J., Hardy, B., Kendall, J., Knapp, M. and Wistow, G. (2001) Movement and change: independent sector domiciliary care providers between 1995 and 1999, *Health and Social Care in the Community*, 9, 6, 334-340.

Webber, P.A., Fox, P. and Burnette, D. (1994) Living alone with Alzheimer's disease: Effects on health and social service utilization patterns, *Gerontologist,* 34, 1, 8-14.

Weiner, K., Stewart, K., Hughes, J., Challis, D. and Darton, R. (2002) Care management arrangements for older people in England: key areas of variation in a national study, *Ageing and Society* 22, 4, 419-439.

Wilberforce, M., Harrington, V., Brand, C., Tucker, S., Abendstern, M. and Challis, D. (2010) Towards integrated community mental health teams for older people in England: progress and new insights, *International Journal of Geriatric Psychiatry,* DOI: 10.1002/gps.2517.

Xie, C., Hughes, J., Sutcliffe, C., Chester, H. and Challis, D. (2010) Personalisation in Social Care Services for Older People: Findings from a National Survey of English Local Authorities, Discussion Paper M240, Personal Social Services Research Unit, University of Manchester at Manchester.

Zarit, S.H., Gaugler, J.E. and Jarrott, S.E. (1999) Useful services for families: research findings and directions, *International Journal of Geriatric Psychiatry,* 14, 3, 165-181.

APPENDIX 1: PSSRU STUDIES CONDUCTED AT THE UNIVERSITY OF MANCHESTER

In this appendix the studies included in chapter 3 are summarised. Additionally, selected publications to date from them are listed. This includes some not referred to in the main body of the text. The order in which the studies are described replicates that of Box 3.1.

Number	Study	Time frame for data collection	Method of enquiry
1	A Systematic Evaluation of the Development and Impact of the Single Assessment Process in England	Two: 2000 and 2005	Audit of case files

This research was designed to provide an evaluation of the development and implementation of an assessment procedure for older people, the Single Assessment Process (SAP) in England, which was introduced in 2002. It was intended to avoid duplication in assessments and promote a standardised approach across health and social care. The care plan study was designed to explore how assessment processes for older people changed following the introduction of the SAP and consequently, the extent to which care packages were more closely aligned to needs.

The study utilised information collected from an audit of case files in three local authorities at two time frames, permitting a comparison of pre- and post-SAP implementation. On both occasions, information about care packages received by service users was obtained from case files of older people receiving community support and meeting the following selection criteria. They were required to have: received an assessment and a care plan and were eligible for review; received local authority purchased or provided domiciliary or day care for at least two weeks; and were the responsibility of a team providing long-term care.

Information extracted from case files covered a number of domains: living situation of service users; level of physical dependency; cognitive function; multidisciplinary assessments; social care and health care provision; and measures of quality. Assessment and service information was taken from the most recent assessment or review and the care plan which related to this. There were 144 case files included in the 2000 sample and 145 in the 2005 sample.

Publications

Abendstern, M., Hughes, J., Clarkson, P., Sutcliffe, C., Wilson, K. and Challis, D. (2010) 'We need to talk': communication between primary care trusts and other health and social care agencies following the introduction of the Single Assessment Process for older people in England, *Journal of Primary Health Care Research and Development,* 11, 61-71.

Abendstern, M., Clarkson, P., Challis, D., Hughes, J. and Sutcliffe, C. (2008) Implementing the Single Assessment Process for older people in England: lessons from the literature, *Research Policy and Planning,* 26, 1, 15-32.

Clarkson, P., Abendstern, M., Sutcliffe, C., Hughes, J. and Challis, D. (2009) Reliability of needs assessments in the community care of older people: impact of the Single Assessment Process in England, *Journal of Public Health*, 31, 521-529.

Sutcliffe, C., Hughes, J., Abendstern, M., Clarkson, P. and Challis, D. (2008) Developing multidisciplinary assessment – exploring the evidence from a social care perspective, *International Journal of Geriatric Psychiatry,* 23, 1297-1305*.*

Report to funder

Sutcliffe, C., Hughes, J., Abendstern, M., Clarkson, P., and Challis, D. (2006) A Systematic Evaluation of the Development and Impact of the Single Assessment Process in England: Care Plan Study Authority Reports, Discussion Paper M140, Personal Social Services Research Unit, University of Manchester at Manchester.

Number	Study	Time frame for data collection	Method of enquiry
2	Care Coordination for Older People	2006	Postal questionnaire

The information presented is extracted from a postal survey of local authority older people's services in England, part of a research programme entitled *'Coordinated Care, Care Management, Service Integration and Partnerships'.*

The purpose of the programme is to identify emerging patterns of care coordination for older people. The questionnaire was derived from previous studies, incorporating subsequent developments in policy and practice. It covered services for physically frail people and those with mental health problems aged 65 and over. The domains covered by this questionnaire were: background information; care management objectives; organisational arrangements; the process of care management; mental health services for older people; management information; and service development.

Questionnaires were sent to 149 English councils with social services responsibilities at the beginning of 2006, for completion by officers with a lead responsibility for older people's services. One hundred and nineteen completed questionnaires were returned by August 2006, giving a response rate of 80 per cent.

Publication

Sutcliffe, C.; Hughes, J.; Chester, H.; Xie, C. and Challis, D. (2010) Changing patterns of care coordination within old-age services in England**,** *Care Management Journals*, 11, 3,157-69.

Report to funder

Challis, D., Hughes, J., Sutcliffe, C. and Xie, C. (2009) Care Coordination Arrangements for Older People, Discussion Paper M216, Personal Social Services Research Unit, University of Manchester at Manchester.

Number	Study	Time frame for data collection	Method of enquiry
3	Estimating the Balance of Care	1997-1998	Audit of case files

The aim of this study was to estimate the cost and feasibility of shifting the balance of care from residential and nursing home care to community support for older people in Gateshead.

The research strategy had five components. First, the collection of data on admission to long term care. Second, this data was compared with national findings. Third, cases which were most likely to be admitted to care in Gateshead were categorised. Fourth, local practitioners and managers were involved in an expert panel exercise to estimate the cost of community care packages for people hitherto placed in long term care. Finally, a projection of the data in order to estimate the cost of alternative care arrangements in Gateshead was undertaken.

The data in chapter three refers to a small part of the study in which data in respect of cases within the main study cohort who were admitted to long-term care from the community were compared with cases in receipt of assistance from the Community Care Scheme at a particular point in time (23 April 1997). The latter was derived from an early pilot care management scheme operational in part of the authority prior to the implementation of the community care legislation and which still provided additional support at home to that available from the local authority home care service, the major provider of domiciliary care. It is also relevant to note that the study cohort was almost three times as large as the cohort from the Community Care Scheme and the data were collected over a nine-month period.

Publication

Challis, D. and Hughes, J. (2002) Frail older people at the margins of care: some recent research findings, *British Journal of Psychiatry,* 180, 126-30.

Report to funder

Challis, D., McNiven, F., Hughes, J., Darton, R., Stewart, K. and Evans, S. Estimating the Balance of Care in Gateshead Discussion Paper M021, Personal Social Services Research Unit, University of Manchester at Manchester.

Number	Study	Time frame for data collection	Method of enquiry
4	Mapping Specialist Dementia Services in the North West of England: Domiciliary Care	2002 2003	Postal questionnaire

The information presented is extracted from a postal survey of domiciliary care services. The study formed part of the larger research project undertaken to identify and describe a range of four types of specialist dementia services in the North West of England.

The services identified were ‘specialist’ services insofar as all or part of each service was dedicated to providing care for people with dementia, although the service might not necessarily have regarded itself as a specialist dementia service *per se*. A broad definition of dementia was adopted that encapsulated both those formally diagnosed with dementia and also those who could be described as ‘confused’, by service providers. The aims of this part of the project were to: identify and describe domiciliary care services that had a specialist focus on dementia care; assess the

quality of care provided in these facilities; and compare the type and quality of care provided by the different forms of home care service identified. The questionnaire was developed through a review of the literature, particular attention was paid to evidence that related to the provision of effective home care. The domains covered by it were: service user characteristics; service description; capacity; personnel; and person focused care.

Questionnaires were sent 282 domiciliary care services in the North West of England identified by means of a screening questionnaire sent to key personnel in the NHS Trusts, Health Authorities, Social Services Departments and voluntary organisations in the North West of England in 2002. One hundred and fifty five responses were received. Ten services formally refused, and 32 were excluded: 29 services did not provide care for people with dementia, and 3 were excluded on the basis of data quality. The final sample size was therefore 113, giving a response rate 46 per cent.

Publication

Venables, D., Reilly, S., Challis, D., Hughes, J. and Abendstern, M. (2006) Standards of care in home care services: a comparison of specialist and generic services for older people with dementia, *Aging and Mental Health,* 10, 2, 187-94.

Report to funder

Venables, D., Reilly, S., Challis, D., Hughes, J. and Abendstern, M. (2005) Home care services for older people with dementia in the North West of England, PSSRU Discussion Paper M097, Personal Social Services Research Unit, University of Manchester at Manchester.

Number	Study	Time frame for data collection	Method of enquiry
5	Mapping Specialist Dementia Services in the North West of England: Professional Teams	2001-2002	Postal questionnaire

The information presented is extracted from a postal survey of professional community based teams for older people with dementia in the North West of England. This study also formed part of the larger research project undertaken to identify and describe a range of four types of specialist dementia services in the North West of England.

'Specialist' services were defined as resources that were provided exclusively or that had part of them dedicated specifically for older people with dementia and/or their carers. The same as in broad definition of dementia was adopted as that described above in study four. In this part of the project the aims were to identify and describe professional community teams for people with dementia and to capture variations in standards and capacity. The questionnaire was developed through reviewing the relevant literature, in particular evidence about the most recent models of service provision and standards of care. The domains covered by it were: service description; service users and team workload; personnel; training; person focused care; service available for informal carers; links with other services; and service development

Questionnaires were sent 88 to the professional community teams in the North West England previously identified by managers in the NHS and local authority social services departments as providing some level of care to people with dementia in 2001 for completion by team managers. Fifty two completed questionnaires were returned by 2002, giving a response rate of 59 per cent.

Publication

Abendstern, M., Reilly, S., Hughes, J., Venables, D. and Challis, D. (2006) Levels of integration and specialisation within professional community teams for people with dementia. *International Journal of Geriatric Psychiatry*, 21, 77-85.

Report to funder

Abendstern, M., Reilly, S., Challis, D., Hughes, J. and Venables, D. (2005) Professional community based teams for older people with dementia in the North West of England, Discussion Paper M069, Personal Social Services Research Unit, University of Manchester at Manchester.

Number	Study	Time frame for data collection	Method of enquiry
6	National Trends and Local Delivery in Old Age Mental Health Services	2008-2009	Postal questionnaire Systematic literature review

The information presented is extracted from two sources: a national survey of community mental health teams for older people and a systematic literature review. Both are part of a research programme entitled *'National Trends and Local Delivery in Old Age Mental Health Services'*.

The purpose of the programme was to address the need for better evidence on the most appropriate and cost-effective ways to care for older people with mental health problems. The questionnaire was informed by the findings from study four and the literature and subsequent developments in policy and practice. It covered the range of functions undertaken by community mental health teams for older people. The domains covered by this questionnaire were: background information; team members; the team's processes; liaison and wider support; and service development.

Questionnaires were sent to 429 community mental health teams for older people in England in 2008 for completion by a team member (ideally the team manager or coordinator). Three hundred and seventy six completed questionnaires were returned by March 2008, giving a response rate of 88 per cent.

The systematic review described both how the structure and processes of community mental health teams for older people in the UK varied – over time and place - and the impact of different practices on service user, staff, and service outcomes. The definition of these teams followed that of the Royal College of Psychiatrists. It comprised community teams with at least two professional disciplines and which provide specialist assessment, treatment and care to older people (over 65) with mental health problems, the majority of whom are living in their own homes. Included studies needed to describe or evaluate at least one aspect of a team's structure, organisation and operation

Searches produced a final sample of 45 published articles and reports. Seven of these reported outcome data that compared different community mental health teams approaches as opposed to comparing community mental health teams practice with 'traditional' ways of working. The overall sample contained 28 full research articles, six short reports of empirical studies, seven UK reports and four journal articles which directly reported practice rather than research findings of the latter. A number of *a priori* concepts and themes were used to 'interrogate' the literature to establish the position each paper and issue in relation to key indicators of relevance to practice today. These included: evidence of change over time and enduring issues: the nature and extent of integrated structures and practices; support for people with dementia; the nature of professional roles; the provision of outreach services; and issues of widening access and appropriate targeting.

Publication

Wilberforce, M., Harrington, V. Brand, C., Tucker, S., Abendstern, M., and Challis, D. (2010) Towards integrated community mental health teams for older people in England: progress and new insights, *International Journal of Geriatric Psychiatry,* DOI: 10.1002/gps.2517.

Report to funder

Abendstern, M., Harrington, V., Brand, C., Tucker, S., Wilberforce, M. and Challis, D. (2010) Community Mental Health Teams for Older People: Structures, Processes and Out comes. A Systematic Literature Review, Discussion Paper M243, Personal Social Services Research Unit, University of Manchester at Manchester [not publicly available].

Number	Study	Time frame for data collection	Method of enquiry
7	Recruitment and Retention of the Social Care Workforce for Older People	2008	Postal questionnaire

The information presented is extracted from a postal survey of local authority commissioning and contracting arrangements older people's services in England, part of a of three-phase study entitled *'Recruitment and Retention of a Social care Workforce for Older People'*.

The aim of the first phase was to identify and categorise different approaches to commissioning and contracting within local authorities with respect to services for older people. The development of the questionnaire was informed by both meetings held with social services commissioners in two local authorities and also by a relevant, purposive review of literature and policy. The domains covered by this questionnaire were: background information; commissioning; contracting – domiciliary care services; contracting – residential/nursing home care; and commissioning within care management arrangements.

Questionnaires were sent to 149 English councils with social services responsibilities in 2008, for completion by officers with a lead responsibility for older people's services Information was collected in two waves. The first collected data to construct a typology of local authorities care management arrangements, commissioning and contracting practice across domiciliary and residential care services. This was used to inform the selection of sites for subsequent phases of the study. Subsequently, non respondents were contacted again in a second wave to provide a larger dataset with which to appraise the overall state of service provision. In total, 110 local authorities returned completed questionnaires, giving a final response rate of 74 per cent.

Publication

Chester, H. Hughes, J. and Challis, D., (2010) Patterns of commissioning, contracting and care management in social care services for older people in England, *British Journal of Social Work*, doi: 10.1093/bjsw/bcq044

Report to funder

Hughes, J., Chester, H. and Challis, D. (2008) Recruitment and Retention of a Social care Workforce for Older People, Discussion Paper M193-2, Personal Social Services Research Unit, University of Manchester at Manchester.

Number	Study	Time frame for data collection	Method of enquiry
8	Services for Older People with Mental Health Problems: The Balance of Care in Cumbria	2003-2004	Audit of case files Balance-of-care study Purposive literature review Stakeholder consultation - questionnaire and focus group

The information presented is extracted from four sources: an audit of case files; a balance-of-care study; a purposive literature review; and a stakeholder consultation. All are part of a research study entitled *'Services for Older People with Mental health Problems: The Balance of Care in Cumbria'*. This purpose of the study was to evaluate the provision of services for older people with mental health problems in North Cumbria and to provide data to inform local commissioners' decisions about the mix of services needed for this client group, underpinning future strategic planning. Case files were in respect of four groups of older people with mental health problems were audited. Data collection arrangements for each group are summarised in the box below. From each case file data was extracted about the sociodemographic, functional and service receipt characteristics of the patients / services users.

Box A1.1: Audit of case files: data collection arrangements

Population of interest	Inclusion / exclusion criteria	Approach to sampling	Time frame and information source	Sample size
Admissions to acute mental health inpatient beds	All people admitted to the Trust's acute admissions wards for older people excepting those admitted for planned respite	Six month series of consecutive admissions	September 2003 - February 2004. Information provided by nominated ward staff	69
Admissions to residential and nursing homes who had mental health problems	All people admitted to a care home with social service's assistance by the older people's teams, excepting those admitted for planned respite	Six month series of consecutive admissions	July 2003 - January 2004. Information provided by service user's care co-ordinator	144
Older people with mental health problems on the community caseloads of social services staff	Service users aged 65+ on the caseloads of the older people's teams who were not long- term residents of residential, nursing or NHS inpatient accommodation	One in 12 systematic random sample from a computer-generated list of users organised by staff member (allocated cases) and 1 in 20 by team (unallocated)	Sample taken 3rd November 2003. Information provided by team members	309
Older people on the caseloads of community mental health staff	Clients on the caseloads of community mental health nurses or community support workers in the older people's service	One in six systematic random sample from a clinician-generated list of clients organised by practitioner and stratified by broad diagnostic group	Sample taken 10th November 2003. Information provided by team members	122

The balance-of-care study was designed to explore the desirability and feasibility of changing the existing balance of services and considered whether the needs of a certain proportion of those older people with mental health problems who presently receive inpatient care or enter a care home in North Cumbria could be more appropriately met in other settings. It comprised four stages and was conducted between 2004 and 2005. In the first five variables were used to produce a number of representative case studies/vignettes of older people with mental health problems admitted to care homes. These were: the source of admission; the presence of a significant informal carer; gender; the presence or absence of behaviours known to be difficult for carers to cope with; and a measure of dependency. Similarly four variables were used to produce a number of representative case studies/vignettes of older people admitted to acute mental health inpatient beds. These were: the presence of a significant informal carer; the presence of a primarily organic or functional mental illness; whether the admission was at least in part for assessment of the client's future care needs; and a hierarchy of risk / concern.

Alternative ways of meeting the needs of the people depicted in the above vignettes were explored in a series of workshops in the second stage. At the first staff from the specialist mental health service including the four consultant psychiatrists, managers and ward-based nurses were asked to read the inpatient vignettes and to indicate whether they believed that it was completely, possibly or not appropriate to admit each of the clients described to an acute mental health inpatient bed. Subsequently an independent expert panel with experience in the community care of older people with mental health problems then used the respective services

highlighted to create a weekly care plan for each client. At two further workshops a mixture of community mental health nurses and social workers who predominantly worked with older people were invited to two further workshops. Working in multidisciplinary teams they were given care home vignettes and asked to create packages of care that would enable these clients to remain in the community. Finally, in workshops comprising a mixture of older people, carers and their representatives a similar series of tasks to that undertaken by professional staff, appropriately modified, was undertaken. These findings complemented those of professional staff, acting as a reality check. The packages of care that practitioners believed would enable those older people who are currently admitted to a care home or inpatient bed to remain at home were then costed. Wherever possible these were sourced from local agencies.

In the third stage the selected care plans for the care home entrants were then submitted to the independent expert panel referred to above. The panel was asked to act as gatekeeper for access to social services resources and to decide whether it was prepared to fund the proposed community care packages, mirroring local decision-making processes. A parallel exercise constructed a hierarchy of appropriateness for the inpatient admissions based on the perspectives of the specialist mental health staff, with each case type scored according to the number and mix of practitioners who believed their admission to be completely or possibly appropriate.

Finally in the fourth stage a sensitivity analysis of the potential for the agencies in North Cumbria to shift the balance of care for older people with mental health problems i.e. to provide more community-based care as an alternative for care currently provided in residential or hospital settings was underatken. In essence this explored the resource implications of caring for different combinations of those care home and inpatient case types thought to have most potential for diversion from institutional to community care

This literature review for this study was undertaken to ascertain what is known about the effective provision of services for older people with mental health problems. Thus it did not attempt to provide an exhaustive analysis of the vast body of work concerned with individual therapies or treatments, but rather concentrate on the way in which individual service elements, or their organisation, might facilitate better outcomes for both service users and their carers, as well as for providers. It was thus deliberately selective in terms of the client group who form the focus of the discussion and in its orientation towards the ways in which their care might be provided.

The stakeholder consultation employed a series of questionnaires and was conducted between 2004 and 2005. A postal questionnaire was sent to all GPs within the three participating primary care trusts. This was designed to ascertain their perspectives of the services currently provided for older people with mental health problems and their priorities for future development. Subsequently attendees at the workshops held in respect of the balance-of –care study, specialist mental health staff, social services staff, older people, carers and their representatives, were invited to complete suitably modified versions of the same proforma. Whilst such convenience samples do not produce representative findings, they provided a quick and easy way of getting a feel for the issues perceived to be most important.

Publications

Tucker, S., Hughes, J., Sutcliffe, C. and Challis, D. (2008) Care management for older people with mental health problems: from evidence to practice, *Australian Health Review*, 32, 2, 210-22.

Tucker, S., Hughes, J., Burns, A. and Challis, D. (2008) The balance of care – reconfiguring services for older people with mental health problems, *Aging and Mental Health,* 12, 1, 81-91.

Tucker, S., Hughes, J., Scott, J., Challis, D. and Burns A. (2007) Commissioning services for older people with mental health problems: is there a shared vision? *Journal of Integrated Care*, 15, 2, 3-13.

Report to funder

Tucker, S., Hughes, J, and Challis, D. with Burns, A. (2005) Services for Older People with Mental Health Problems: The Balance of Care in Cumbria, Discussion Paper M106, Personal Social Services Research Unit, University of Manchester at Manchester.

Number	Study	Time frame for data collection	Method of enquiry
9	Supporting People with Dementia at Home (The Lewisham intensive case management scheme)	1990-1993	Structured interviews with service users and carers

The aim of this study was to evaluate a model of intensive case management which provided specialist community-based care to frail older people with dementia at risk of admission to long-term care. It was conducted in the period immediately before the introduction of the community care reforms in 1993 which introduced care management arrangements for all older people receiving an assessment from local authority adult social care services. A quasi-experimental design was used whereby individuals in one community mental health team for older people with mental health problems received care management and were compared to those in a similar setting without such a service. Equivalent cases were identified in each team by using similar criteria - a diagnosis of dementia; needs unmet by existing services; and at risk of care home admission. Eligible older people and their carers were interviewed at uptake and at six and 12 months using a range of indicators including quality of care, quality of life, well-being; and aspects of needs. Interviews were also conducted with key informants in the service provision process.

Case managers based in multidisciplinary teams were given control over a devolved budget and were responsible for coordinating long-term support. They maintained structured care plans using a specifically designed tool, and service use and costs data were also tracked throughout the study period. Cost information was collected in relation to: health and social care agencies; older people and their carers; and society as a whole. A paid helper service was developed for those receiving care management to complement the domiciliary care service and provide greater flexibility and availability of care.

Forty five cases were recruited to the experimental group and 50 to the control group and 43 matched pairs, created using variables associated with outcome, were analysed.

Publications

Challis, D., Sutcliffe, C., Hughes, J., von Abendorff, R., Brown, P. and Chesterman, J, (2009) *Supporting People with Dementia at Home: Challenges and Opportunities for the 21st Century,* Aldershot: Ashgate.

Challis, D., von Abendorff, R., Brown, P., Chesterman, J. and Hughes, J. (2002) Care management, dementia care and specialist mental health services: an evaluation, *International Journal of Geriatric Psychiatry,* 17, 4, 315-25.

Challis, D., von Abendorff, R., Brown, P. and Chesterman, J. (1997) Care management and dementia: an evaluation of the Lewisham Intensive Case Management Scheme, in S. Hunter (ed.) *Dementia. Challenges and New Directions*, London, Jessica Kingsley Publishers.

Number	Study	Time frame for data collection	Method of enquiry
10	The Value of Specialist Clinical Assessment of Older People Prior to Placement in Care Homes	1998-2000	Structured interviews with service users and carers

The objective of the study was to ascertain the value of employing a specialist clinician's contribution to the community care assessment of older people prior to care home entry. It was a randomised controlled trial of the effects of these enhanced assessments versus the usual community care assessment undertaken by care managers.

Two hundred and fifty six older people at risk of care home entry were randomly allocated to either a control group, who received the usual care management assessment, or to an experimental group who, in addition, received a clinical assessment by a geriatrician or old age psychiatrist. The value of the additional assessment was evaluated by an analysis of clinical recommendations, questionnaires eliciting the views of stakeholders and research interviews with older people and their carers at initial assessment and six months. Data on service use and costs over six months and on destination at six and 12 months were also collected.

Publications

Challis, D., Clarkson, P., Williamson, J., Hughes, J., Venables, D., Burns, A. and Weinberg, A. (2004) The value of specialist clinical assessment of older people prior to entry to care homes, *Age and Ageing,* 33, 1, 25-34.

Clarkson, P., Venables, D., Hughes, J., Burns, A. and Challis, D. (2006) Integrated specialist assessment of older people and predictors of care home admission, *Psychological Medicine,* 36, 1011-21.

Venables, D., Clarkson, P., Hughes, J., Burns, A. and Challis, D. (2006) Specialist clinical assessment of vulnerable older people: outcomes for carers from a randomised controlled trial, *Ageing and Society, 26, 6, 867-82.*

Weinberg, A., Williamson, J., Challis, D. and Hughes, J. (2003) What do care managers do? a study of modern working practice in older people's services, *British Journal of Social Work,* 33, 901-19.

Report to funder

Challis, D., Clarkson, P., Williamson, J., Hughes, J., Burns, A., Venables, D. and Weinberg, A. (2002) The Value of Specialist Assessment of Older People Prior to Placement in Care Homes, Discussion Paper M043, Personal Social Services Research Unit, University of Manchester at Manchester

APPENDIX 2: LOCAL AUTHORITY COMMISSIONERS - TELEPHONE INTERVIEW SCHEDULE

PERSONAL SOCIAL SERVICES RESEARCH UNIT

Dementia Home Care Project

Telephone Interview Schedule

Date of interview _____

Respondent's Name _____

Job Title _____

Telephone Number _____

Email address _____

Authority/CSSR name _____

RESEARCH QUESTION

What are the characteristics, quality and costs of different models of home support (home care) for people with dementia?

To respondents:
"We are trying to find out what sorts of home care provision you have specifically for people with dementia and about its characteristics." "We use the phrase 'specialist home care' to describe provision exclusively for this group of people"

GENERAL

1. In your authority, how is home care for people with dementia provided? (tick one only)

- **a) Predominantly generic services (services available to all older people)** ☐
- **b) Predominantly specialist services (for those specifically with dementia)** ☐
- **c) A mix of the above** ☐

2. Who provides specialist home care to people with dementia? (tick all that apply)

- **a. Local authority ('in house')** ☐
- **b. independent sector** ☐
- **c. NHS. If so specify Trust** _____ ☐
- **d. Other** ☐
- **e. N/A No designated 'specialist' home care** ☐

3a. How many home care providers do you contract with for older people with dementia? (write in number/estimate)

If a. (above) ☐

If b. (above) ☐

3b. How many of these home care providers provide designated 'specialist' home care for people with dementia? (write in number/estimate)

If a. (above) ☐

If b. (above) ☐

4. How are specialist home care services for older people with dementia accessed?

a. Local authority adult social care ☐

b. NHS Specialist mental health service ☐

c. Self-referral ☐

d. N/A No designated 'specialist' home care ☐

e. Other, please specify: ☐

_____

_____

_____

5a. In general, how many hours of home care for older people with dementia did you commission from home care providers in the last contracting period? (Please write in number/estimates)

☐

In the (√):

a. **Last week**
b. **Last month**
c. **Current financial year**
d. **Previous financial year**
e. **Last contracting period, please specify: from** _____ **to** _____

5b. How many hours of <u>specialist</u> home care for older people with dementia did you commission from home care providers in the last contracting period? (Please write in number/estimates)

☐

In the (√):

f. **Last week**
g. **Last month**
h. **Current financial year**
i. **Previous financial year**
j. **Last contracting period, please specify: from** _____ **to** _____

6. In your contracts with home care providers, what is your price per hour of home care? (Please write in number)

In general	☐
'Specialist' for Dementia (where appropriate)	☐

7. On the whole, how is the interface between the local authority and home care providers who provide specialist home care for older people with dementia managed? (tick one only, only read brackets if respondent unclear as to what options mean)

- **a. Block Contract (payment for pre-determined no. of hours clients)** ☐
- **b. Call off (price per hour specified in advance; paid when service provided)** ☐
- **c. Spot (price agreed and paid when service is provided)** ☐
- **d. Cost and volume (guaranteed block purchase of hours + option to purchase additional)** ☐
- **e. Grant (general payment not linked to particular client or amount of service)** ☐
- **f. Service level agreement** ☐
- **g. Other, please specify** ☐
- **h. N/A No designated 'specialist' home care** ☐

QUALITY

8. Are providers of specialist home care for older people with dementia required to provide an induction for 'hands on' care staff, as part of the contractual arrangement?

Yes	☐
No	☐
N/A No designated 'specialist home care'	☐

a) If yes, do you require a specific component of this induction to focus on caring for people with dementia?

Yes	☐
No	☐

b) If yes, how long do you require this to be?

a.	**5 minutes**	☐
b.	**10- 15 minutes**	☐
c.	**about 30 minutes**	☐
d.	**about 1 hour**	☐
e.	**more than 1 hour**	☐
f.	**other (please specify)……**	☐
g.	**Not known**	☐

9. Do you provide any of the following types of assistance to providers of specialist home care for people with dementia to train their 'hands on' care staff to care for people with this condition (in addition to any induction)? [tick all that apply]

- **a) Direct training provided by the local authority** ☐
- **b) Commission training from training organisation** ☐
- **c) Training grant/loan to home care provider** ☐
- **d) Specific monies for this training paid to home care provider as part of contract** ☐
- **e) Other assistance (please specify) _____** ☐

10. Are specialist home care providers for people with dementia required to complete an assessment in respect of the following, as part of their contractual arrangements?

- **a. Risk to the user / patient in their home** ☐
- **b. Health and safety requirements for staff in the user / patient's home environment** ☐
- **c. The users abilities/ needs** ☐

11. Do you require as part of your contractual arrangements with providers of specialist home care for people with dementia, written briefing documents that are kept in users' homes?

- **Yes** ☐
- **No** ☐
- **N/A No designated 'specialist home care'** ☐

If yes, do they contain the following information on the older person: [tick all that apply]

- **a. Client's needs /problems/reasons for service** ☐
- **b. Preferences /special needs /requests** ☐
- **c. History /life story** ☐
- **d. A profile of a client's expected abilities for daily living tasks** ☐
- **e. Changes /specific goals to work towards** ☐
- **f. Changes in client to watch out for** ☐
- **g. Changes in users/carers circumstances, health, physical condition, care needs** ☐
- **h. Other information to assist consistent provision of care** ☐

12. Do staff employed in specialist home care services for older people with dementia participate in planned reviews of each service user?

- **Yes** ☐
- **No** ☐
- **N/A No designated 'specialist home care'** ☐

a) If yes, how often are they required to undertake this task?

- **a. Monthly** ☐
- **b. Two monthly** ☐
- **c. Three monthly** ☐

d. Every four or five months ☐

e. Six monthly ☐

f. 12 monthly ☐

g. Other (please specify) …… ☐

h. Not known ☐

b) If yes, how is this review conducted?

Meeting convened by care co-ordinators ☐

Informal discussion with care co-ordinator ☐

Completion of written report for care co-ordinator ☐

Other (please specify)_____ ☐

_____

13. Do providers of specialist home care for people with dementia employ any of the following methods or approaches in the care of service users? (Tick all that apply)

Memory/life story wallets/ files ☐

Policy of no uniforms for staff ☐

Special liaison with police service ☐

Other (please describe) ☐

N/A No designated 'specialist home care' ☐

14. Are specialist home care providers for people with dementia required to be available (tick all that apply)

a. Day time Monday-Friday ☐

b. Evenings Monday-Friday ☐

c. Night time Monday - Friday ☐

d. Weekends ☐

N/A No designated 'specialist home care' ☐

15. As part of their contractual requirement, are providers of specialist home care for people with dementia required to provide, if necessary:

a. 24 hour services i.e. round the clock care provided by several workers on a shift basis ☐

b. Live in services i.e. carer lives, either permanently or temporarily, in home of service user. (Exclude informal carer arrangements with relatives or friends.) ☐

N/A No designated 'specialist home care' ☐

16. Are providers of specialist home care for people with dementia required as part of the contractual arrangements, to make any of the following special arrangements for people from ethnic minority groups? (tick all that apply)

Personal care	☐
Language resources e.g. translated leaflets, staff skills, interpreter service	☐
Food - diet / storage/ preparation /cooking e.g. catering for specific dietary requirements	☐
Religious observation / spirituality e.g. providing services at appropriate times	☐
N/A No designated 'specialist home care'	☐

Comments

Do you have any comments on the provision of home care to people with dementia?
Would you like to elaborate on any questions you have answered?
Would you like to raise any other issues?

THANK YOU

APPENDIX 3: EXPLORING ASSOCIATIONS BETWEEN TYPES OF DOMICILIARY CARE AND ADMISSIONS TO CARE HOMES -SUPPLEMENTARY DATA

Table A3.1: Bivariate correlations between possible explanatory and dependent variables

		Est aged 65+ admitted to care per 10,000 aged 65+ with dementia (KIGS)	Est aged 65+ admitted care per 10,000 aged 65+ with dementia (Netten)	% aged 65+ with dementia	Older people in receipt of attendance allowance per 1,000 aged 65+	Pensioners receiving income support per 1000 pensioners	% pensioners receiving Key Benefits who receive Retirement Pension only	% aged 65+ living alone	% household with at least one pensioner living in rented accommodation	Number of care home place per 10,000 pop aged 65+	Number of home care agencies available per 10,000 pop aged 65+	Deprivation Concentration	Total FSS per capita
Est aged 65+ admitted to care per 10,000 aged 65+ with dementia (KIGS)	Pearson Correlation	1	.888**	.226**	.312**	.193*	-.258**	.132	.056	.281**	-.063	.327**	.072
	Sig. (2-tailed)		.000	.006	.000	.019	.002	.109	.496	.001	.443	.000	.387
Est aged 65+ admitted care per 10,000 aged 65+ with dementia (Netten)	Pearson Correlation	.888**	1	.311**	.299**	.168*	-.245**	.056	-.013	.369**	-.117	.348**	.018
	Sig. (2-tailed)	.000		.000	.000	.041	.003	.501	.873	.000	.158	.000	.832
% aged 65+ with dementia	Pearson Correlation	.226**	.311**	1	.081	-.249**	.165*	-.199*	-.446**	.761**	-.182*	.046	-.221**
	Sig. (2-tailed)	.006	.000		.323	.002	.044	.015	.000	.000	.026	.579	.007
Older people in receipt of attendance allowance per 1,000 aged 65+	Pearson Correlation	.312**	.299**	.081	1	.462**	-.705**	.044	.137	.232**	.195*	.585**	-.047
	Sig. (2-tailed)	.000	.000	.323		.000	.000	.590	.095	.004	.017	.000	.571
Pensioners receiving income support per 1000 pensioners	Pearson Correlation	.193*	.168*	-.249**	.462**	1	-.687**	.326**	.623**	-.005	.559**	.711**	.121
	Sig. (2-tailed)	.019	.041	.002	.000		.000	.000	.000	.948	.000	.000	.143
% pensioners receiving Key Benefits who receive Retirement Pension only	Pearson Correlation	-.258**	-.245**	.165*	-.705**	-.687**	1	-.495**	-.651**	-.055	-.208*	-.783**	-.109
	Sig. (2-tailed)	.002	.003	.044	.000	.000		.000	.000	.506	.011	.000	.187
% aged 65+ living alone	Pearson Correlation	.132	.056	-.199*	.044	.326**	-.495**	1	.774**	-.311**	.201*	.404**	.560**
	Sig. (2-tailed)	.109	.501	.015	.590	.000	.000		.000	.000	.014	.000	.000
% household with at least one pensioner living in rented accommodation	Pearson Correlation	.056	-.013	-.446**	.137	.623**	-.651**	.774**	1	-.360**	.334**	.418**	.358**
	Sig. (2-tailed)	.496	.873	.000	.095	.000	.000	.000		.000	.000	.000	.000
Number of care home place per 10,000 pop aged 65+	Pearson Correlation	.281**	.369**	.761**	.232**	-.005	-.055	-.311**	-.360**	1	-.147	.169*	-.386**
	Sig. (2-tailed)	.001	.000	.000	.004	.948	.506	.000	.000		.074	.039	.000
Number of home care agencies available per 10,000 pop aged 65+	Pearson Correlation	-.063	-.117	-.182*	.195*	.559**	-.208*	.201*	.334**	-.147	1	.162*	.245**
	Sig. (2-tailed)	.443	.158	.026	.017	.000	.011	.014	.000	.074		.049	.003
Deprivation Concentration	Pearson Correlation	.327**	.348**	.046	.585**	.711**	-.783**	.404**	.418**	.169*	.162*	1	.075
	Sig. (2-tailed)	.000	.000	.579	.000	.000	.000	.000	.000	.039	.049		.364
Total FSS per capita	Pearson Correlation	.072	.018	-.221**	-.047	.121	-.109	.560**	.358**	-.386**	.245**	.075	1
	Sig. (2-tailed)	.387	.832	.007	.571	.143	.187	.000	.000	.000	.003	.364	

** Correlation is significant at the 0.01 level (2-tailed).
* Correlation is significant at the 0.05 level (2-tailed).

Box A3.1: Specification of regression models – influences on numbers of admissions to care homes of older people with dementia

Dependent variables
Estimated admissions of older people with dementia to care homes (KIGS) 2007/08
Estimated admissions of older people with dementia to care homes (Netten et al.) 2007/08

Model 1

Explanatory variables:
Group membership 1, 3, 4 (group 2 as reference category)
Number of care home places
Dementia prevalence
Deprivation/need measure (one of the following included; attendance allowance, income support, key benefits, living alone, rented accommodation, deprivation concentration)

Collinearity statistics (Tolerance Factor and Variance Inflation Factor (VIF)) supported the assumptions of non collinearity. All variables in each model achieved a Tolerance Factor of >0.1and a VIF of <10. R^2 ranged from 0.09 to 0.19 (KIGS) and from 0.2 to 0.26 (Netten et al.).

Model 2

Explanatory variables:
All possible explanatory variables were ranked in term of their correlation with the dependent variable. Each variable was then added to the model in turn following the nested estimate procedure recommended by Lin (2008). Group membership was added to all models (group 2 as reference category).
Variables were therefore added to the discrete regression models in the following series:

KIGS Estimates:
Deprivation concentration
Attendance allowance
Number of care home places
Key benefits
Dementia prevalence

Netten Estimates:
Number of care home places
Deprivation concentration
Dementia prevalence
Attendance allowance
Key benefits

Collinearity statistics relating to Tolerance Factor and VIF supported the assumptions of non collinearity. All variables in each model achieved a Tolerance Factor of >0.1and a VIF of <10. R^2 ranged from 0.18 to 0.23 (KIGS) and 0.15 to 0.27 (Netten et al.).

Box A3.1: Specification of regression models continued - models – influences on numbers of admissions to care homes of older people with dementia (continued)

Modelling KIGS Estimates
Inclusion of the variable key benefits to models raised issues regarding collinearity. In further models all variables were included but with the variable key benefits removed; this reduced issues around collinearity.

Modelling Netten Estimates
Inclusion of the variable dementia prevalence and those variables added subsequently to the model raised issues regarding collinearity. In further models variables were included but with the variable dementia prevalence removed; this reduced issues around collinearity.

Model 3

This model replicates the process used in Model 1. However, due to inter-correlations between dementia prevalence and other explanatory measures, this series of models omits this variable.

Explanatory variables:
Group membership 1, 3, 4 (group 2 as reference category)
Number of care home places
Deprivation/need measure (one of the following included; attendance allowance, income support, key benefits, living alone, rented accommodation, deprivation concentration)

In all models the collinearity statistics relating to Tolerance Factor and VIF supported the assumptions of non-collinearity. All variables in each model achieved a Tolerance Factor of >0.1and a VIF of <10. R^2 ranged from 0.11 to 0.24 (KIGS) and 0.19 to 0.24 (Netten et al.).

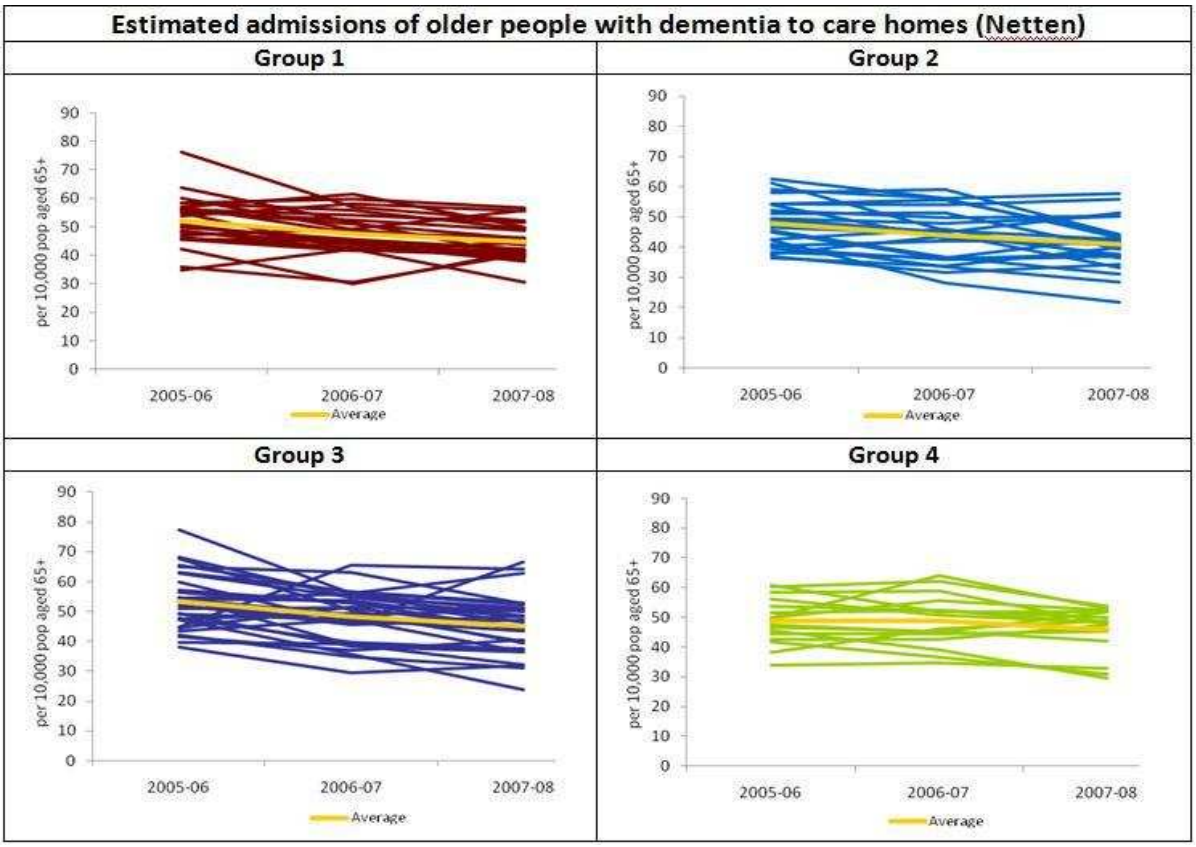
Model 4

These models as previously, also omit dementia prevalence. The variable measuring admissions to hospital is included.

Explanatory variables:
Group membership 1, 3, 4 (group 2 as reference category)
Number of care home places
Deprivation/need measure (one of following included; living alone, concentration)
Admissions to hospital

Again, the collinearity statistics relating to Tolerance Factor and VIF supported the assumptions of non-collinearity. R^2 ranged from 0.14 to 0.24 (KIGS) and 0.19 to 0.20 (Netten et al.).

Figure A3.1: Comparisons of admissions to care homes for older people with dementia for individual authorities by cluster group (using Netten et al. 2001)



APPENDIX 4: Carers Discrete Choice Schedule

Dementia Home Care Study

Questionnaire

Background Information

Firstly we would like to ask some questions about you. These details will be kept confidential. If you do not wish to answer some of the questions you do not have to.

What is your sex?

- Male ☐
- Female ☐

What is your date of birth (or age)? _____

What is your ethnic group?

White

- UK ☐
- Irish ☐
- Other European ☐
- Other ☐

Black

- Caribbean ☐
- African ☐
- Other ☐

Asian

- Indian ☐
- Pakistani ☐
- Bangladeshi ☐
- Chinese ☐
- Other ☐

What is your employment status? Please tick one box that best describes your employment today

- Employee, full time (more than 30 hours/week) ☐
- Employee, part time (less than 30 hours/week) ☐
- Full time education or employment training ☐
- Unpaid or voluntary employment ☐
- Not in employment because of health problems ☐
- Not in employment and looking after family or home ☐
- Not in employment due to retirement ☐
- Not in employment and seeking work ☐

Could we ask how you view your current health? By placing a tick in at least one box in each of the groups below, please indicate which statements best describe your own health today.

Mobility:

I have no problems in walking about	
I have some problems in walking about	
I am confined to bed	

Self-care:

I have no problems with self-care	
I have some problems washing or dressing myself	
I am unable to wash or dress myself	

Usual activities (*e.g.* work, study, housework, family or leisure):

I have no problems with performing my usual activities	
I have some problems with performing my usual activities	
I am unable to perform my usual activities	

Pain/discomfort:

I have no pain or discomfort	
I have moderate pain or discomfort	
I have extreme pain or discomfort	

Anxiety/Depression:

I am not anxious or depressed	
I am moderately anxious or depressed	
I am extremely anxious or depressed	

Choice questions

We are interested in what your views would be of different home care services. These questions ask you to compare descriptions of different types of home care services for people with dementia. We ask that you select which you prefer by ticking a box to indicate your choice. There are 18 of these questions and then a question at the end asking you to rate the descriptions. Please just tick to state your view; there are no right or wrong answers.

Question 1

We ask that you imagine being offered these options for a home care service for your relative/person for whom you care today and that you had a budget of £230 per week to pay for care.

Please tick the box for the option you prefer more (A or B)

	Option A	**Option B**
Home care workers use life story or memory wallets	Not at all	To some extent
There is a waiting list for this service of:	No waiting list	5 weeks
Home care workers are available:	Day time only Monday-Friday	Night time Mon-Fri if required
Respite opportunities for carers	Not provided	Limited respite service
The home care worker visiting:	Can be a different person each time	Varies from time to time
The cost of this service is:	£140 per week	£170 per week
Home care workers have additional training in dementia care	No training	Some training
Which service do you prefer? (*Tick <u>one</u>*)	❑	❑

Question 2
Again, imagine being offered these options for a home care service for your relative/person for whom you care today and that you had a budget of £230 per week to pay for care.

Please tick the box for the option you prefer more (A or B)

	Option A	**Option B**
Home care workers use life story or memory wallets	To some extent	Fully
There is a waiting list for this service of:	5 weeks	10 weeks
Home care workers are available:	Night time Mon-Fri if required	Weekends if required
Respite opportunities for carers	Limited respite service	Full respite service for weekends and longer periods
The home care worker visiting:	Varies from time to time	Is the same person each time
The cost of this service is:	£170 per week	£200 per week
Home care workers have additional training in dementia care	No training	Some training
Which service do you prefer? (*Tick <u>one</u>)*	❑	❑

Question 3
Again, imagine being offered these options for a home care service for your relative/person for whom you care today and that you had a budget of £230 per week to pay for care.

Please tick the box for the option you prefer more (A or B)

	Option A	**Option B**
Home care workers use life story or memory wallets	Fully	Not at all
There is a waiting list for this service of:	10 weeks	No waiting list
Home care workers are available:	Weekends if required	Day time only Monday-Friday
Respite opportunities for carers	Full respite service for weekends and longer periods	Not provided
The home care worker visiting:	Is the same person each time	Can be a different person each time
The cost of this service is:	£200 per week	£140 per week
Home care workers have additional training in dementia care	No training	Some training
Which service do you prefer? (*Tick one*)	❑	❑

Question 4

Again, imagine being offered these options for a home care service for your relative/person for whom you care today and that you had a budget of £230 per week to pay for care.

Please tick the box for the option you prefer more (A or B)

	Option A	**Option B**
Home care workers use life story or memory wallets	Not at all	To some extent
There is a waiting list for this service of:	No waiting list	5 weeks
Home care workers are available:	Night time Mon-Fri if required	Weekends if required
Respite opportunities for carers	Full respite service for weekends and longer periods	Not provided
The home care worker visiting:	Varies from time to time	Is the same person each time
The cost of this service is:	£200 per week	£140 per week
Home care workers have additional training in dementia care	No training	Some training
Which service do you prefer? (*Tick <u>one</u>)*	❑	❑

Question 5

Again, imagine being offered these options for a home care service for your relative/person for whom you care today and that you had a budget of £230 per week to pay for care.

Please tick the box for the option you prefer more (A or B)

	Option A	**Option B**
Home care workers use life story or memory wallets	To some extent	Fully
There is a waiting list for this service of:	5 weeks	10 weeks
Home care workers are available:	Weekends if required	Day time only Mon-Fri
Respite opportunities for carers	Not provided	Limited respite service
The home care worker visiting:	Is the same person each time	Can be a different person each time
The cost of this service is:	£140 per week	£170 per week
Home care workers have additional training in dementia care	No training	Some training
Which service do you prefer? (*Tick <u>one</u>)*	☐	☐

Question 6

Again, imagine being offered these options for a home care service for your relative/person for whom you care today and that you had a budget of £230 per week to pay for care.

Please tick the box for the option you prefer more (A or B)

	Option A	**Option B**
Home care workers use life story or memory wallets	Fully	Not at all
There is a waiting list for this service of:	10 weeks	No waiting list
Home care workers are available:	Day time only Mon-Fri	Night time Mon-Fri if required
Respite opportunities for carers	Limited respite service	Full respite service for weekends and longer periods
The home care worker visiting:	Can be a different person each time	Varies from time to time
The cost of this service is:	£170 per week	£200 per week
Home care workers have additional training in dementia care	No training	Some training
Which service do you prefer? (*Tick one*)	☐	☐

Question 7

Again, imagine being offered these options for a home care service for your relative/person for whom you care today and that you had a budget of £230 per week to pay for care.

Please tick the box for the option you prefer more (A or B)

	Option A	**Option B**
Home care workers use life story or memory wallets	Not at all	To some extent
There is a waiting list for this service of:	5 weeks	10 weeks
Home care workers are available:	Day time only Mon-Fri	Night time Mon-Fri if required
Respite opportunities for carers	Full respite service for weekends and longer periods	Not provided
The home care worker visiting:	Is the same person each time	Can be a different person each time
The cost of this service is:	£170 per week	£200 per week
Home care workers have additional training in dementia care	Some training	Full training
Which service do you prefer? (*Tick one*)	❑	❑

Question 8

Again, imagine being offered these options for a home care service for your relative/person for whom you care today and that you had a budget of £230 per week to pay for care.

Please tick the box for the option you prefer more (A or B)

	Option A	**Option B**
Home care workers use life story or memory wallets	To some extent	Fully
There is a waiting list for this service of:	10 weeks	No waiting list
Home care workers are available:	Night time Mon-Fri if required	Weekends if required
Respite opportunities for carers	Not provided	Limited respite service
The home care worker visiting:	Can be a different person each time	Varies from time to time
The cost of this service is:	£200 per week	£140 per week
Home care workers have additional training in dementia care	Some training	Full training
Which service do you prefer? (*Tick <u>one</u>*)	☐	☐

Question 9

Again, imagine being offered these options for a home care service for your relative/person for whom you care today and that you had a budget of £230 per week to pay for care.

Please tick the box for the option you prefer more (A or B)

	Option A	**Option B**
Home care workers use life story or memory wallets	Fully	Not at all
There is a waiting list for this service of:	No waiting list	5 weeks
Home care workers are available:	Weekends if required	Day time only Mon-Fri
Respite opportunities for carers	Limited respite service	Full respite service for weekends and longer periods
The home care worker visiting:	Varies from time to time	Is the same person each time
The cost of this service is:	£140 per week	£170 per week
Home care workers have additional training in dementia care	Some training	Full training
Which service do you prefer? (*Tick <u>one</u>*)	☐	☐

Question 10

Again, imagine being offered these options for a home care service for your relative/person for whom you care today and that you had a budget of £230 per week to pay for care.

Please tick the box for the option you prefer more (A or B)

	Option A	**Option B**
Home care workers use life story or memory wallets	Not at all	To some extent
There is a waiting list for this service of:	10 weeks	No waiting list
Home care workers are available:	Weekends if required	Day time only Mon-Fri
Respite opportunities for carers	Not provided	Limited respite service
The home care worker visiting:	Varies from time to time	Is the same person each time
The cost of this service is:	£170 per week	£200 per week
Home care workers have additional training in dementia care	Some training	Full training
Which service do you prefer? (*Tick <u>one</u>*)	☐	☐

Question 11

Again, imagine being offered these options for a home care service for your relative/person for whom you care today and that you had a budget of £230 per week to pay for care.

Please tick the box for the option you prefer more (A or B)

	Option A	**Option B**
Home care workers use life story or memory wallets	To some extent	Fully
There is a waiting list for this service of:	No waiting list	5 weeks
Home care workers are available:	Day time only Mon-Fri	Night time Mon-Fri if required
Respite opportunities for carers	Limited respite service	Full respite service for weekends and longer periods
The home care worker visiting:	Is the same person each time	Can be a different person each time
The cost of this service is:	£200 per week	£140 per week
Home care workers have additional training in dementia care	Some training	Full training
Which service do you prefer? (*Tick one*)	❑	❑

Question 12
Again, imagine being offered these options for a home care service for your relative/person for whom you care today and that you had a budget of £230 per week to pay for care.

Please tick the box for the option you prefer more (A or B)

	Option A	**Option B**
Home care workers use life story or memory wallets	Fully	Not at all
There is a waiting list for this service of:	5 weeks	10 weeks
Home care workers are available:	Night time Mon-Fri if required	Weekends if required
Respite opportunities for carers	Full respite service for weekends and longer periods	Not provided
The home care worker visiting:	Can be a different person each time	Varies from time to time
The cost of this service is:	£140 per week	£170 per week
Home care workers have additional training in dementia care	Some training	Full training
Which service do you prefer? (*Tick one*)	❑	❑

Question 13

Again, imagine being offered these options for a home care service for your relative/person for whom you care today and that you had a budget of £230 per week to pay for care.

Please tick the box for the option you prefer more (A or B)

	Option A	**Option B**
Home care workers use life story or memory wallets	Not at all	To some extent
There is a waiting list for this service of:	5 weeks	10 weeks
Home care workers are available:	Weekends if required	Day time only Mon-Fri
Respite opportunities for carers	Limited respite service	Full respite service for weekends and longer periods
The home care worker visiting:	Can be a different person each time	Varies from time to time
The cost of this service is:	£200 per week	£140 per week
Home care workers have additional training in dementia care	Full training	No training
Which service do you prefer? (*Tick <u>one</u>*)	☐	☐

Question 14

Again, imagine being offered these options for a home care service for your relative/person for whom you care today and that you had a budget of £230 per week to pay for care.

Please tick the box for the option you prefer more (A or B)

	Option A	**Option B**
Home care workers use life story or memory wallets	To some extent	Fully
There is a waiting list for this service of:	10 weeks	No waiting list
Home care workers are available:	Day time only Mon-Fri	Night time Mon-Fri if required
Respite opportunities for carers	Full respite service for weekends and longer periods	Not provided
The home care worker visiting:	Varies from time to time	Is the same person each time
The cost of this service is:	£140 per week	£170 per week
Home care workers have additional training in dementia care	Full training	No training
Which service do you prefer? (*Tick <u>one</u>*)	☐	☐

Question 15
Again, imagine being offered these options for a home care service for your relative/person for whom you care today and that you had a budget of £230 per week to pay for care.

Please tick the box for the option you prefer more (A or B)

	Option A	**Option B**
Home care workers use life story or memory wallets	Fully	Not at all
There is a waiting list for this service of:	No waiting list	5 weeks
Home care workers are available:	Night time Mon-Fri if required	Weekends if required
Respite opportunities for carers	Not provided	Limited respite service
The home care worker visiting:	Is the same person each time	Can be a different person each time
The cost of this service is:	£170 per week	£200 per week
Home care workers have additional training in dementia care	Full training	No training
Which service do you prefer? (*Tick <u>one</u>*)	☐	☐

Question 16
Again, imagine being offered these options for a home care service for your relative/person for whom you care today and that you had a budget of £230 per week to pay for care.

Please tick the box for the option you prefer more (A or B)

	Option A	**Option B**
Home care workers use life story or memory wallets	Not at all	To some extent
There is a waiting list for this service of:	10 weeks	No waiting list
Home care workers are available:	Night time Mon-Fri if required	Weekends if required
Respite opportunities for carers	Limited respite service	Full respite service for weekends and longer periods
The home care worker visiting:	Is the same person each time	Can be a different person each time
The cost of this service is:	£140 per week	£170 per week
Home care workers have additional training in dementia care	Full training	No training
Which service do you prefer? (*Tick <u>one</u>)*	❑	❑

Question 17

Again, imagine being offered these options for a home care service for your relative/person for whom you care today and that you had a budget of £230 per week to pay for care.

Please tick the box for the option you prefer more (A or B)

	Option A	**Option B**
Home care workers use life story or memory wallets	To some extent	Fully
There is a waiting list for this service of:	No waiting list	5 weeks
Home care workers are available:	Weekends if required	Day time only Mon-Fri
Respite opportunities for carers	Full respite service for weekends and longer periods	Not provided
The home care worker visiting:	Can be a different person each time	Varies from time to time
The cost of this service is:	£170 per week	£200 per week
Home care workers have additional training in dementia care	Full training	No training
Which service do you prefer? (*Tick <u>one</u>*)	☐	☐

Question 18

Again, imagine being offered these options for a home care service for your relative/person for whom you care today and that you had a budget of £230 per week to pay for care.

Please tick the box for the option you prefer more (A or B)

	Option A	**Option B**
Home care workers use life story or memory wallets	Fully	Not at all
There is a waiting list for this service of:	5 weeks	10 weeks
Home care workers are available:	Day time only Mon-Fri	Night time Mon-Fri if required
Respite opportunities for carers	Not provided	Limited respite service
The home care worker visiting:	Varies from time to time	Is the same person each time
The cost of this service is:	£200 per week	£140 per week
Home care workers have additional training in dementia care	Full training	No training
Which service do you prefer? (*Tick <u>one</u>*)	❑	❑

Question 19

We would now like you to consider all 7 characteristics that described the options you've just completed. Please rank each characteristic in order of importance to you, from 1 (the characteristic you think is the most important) to 7 (the characteristic you think is the least important)

Characteristic	Rank
Home care workers use life story or memory wallets	
Waiting list for this service	
Home care workers availability	
Respite opportunities for carers	
The home care worker visiting	
The cost of the service	
Home care workers additional training in dementia care	

Thank you for your help and taking the time to complete this questionnaire