Dementia UK

The full report

by 2025 one million people in the UK will have dementia

dementia costs the UK over £17 billion per year

A report to the Alzheimer's Society on the prevalence and economic cost of dementia in the UK produced by King's College London and the London School of Economics

LSE

KING'S College LONDON

Alzheimer's Society
Dementia care and research

Dementia UK

A report into the prevalence and cost of dementia prepared by the Personal Social Services Research Unit (PSSRU) at the London School of Economics and the Institute of Psychiatry at King's College London, for the Alzheimer's Society

THE FULL REPORT

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Foreword: Meeting the challenge of dementia

In 2006 the Alzheimer's Society commissioned the Personal Social Services Research Unit at the London School of Economics and the Institute of Psychiatry at King's College London to produce a report on dementia in the UK. The research team provided the most up-to-date evaluation of the numbers of people with dementia in the UK, projections on numbers of people in the future and detailed the financial cost of dementia.

I would like to congratulate the research team led by Professors Martin Knapp and Martin Prince for responding to this challenge and producing this first class piece of work. The analysis provides the most solid evidence base to date on the impact of dementia in the UK and highlights areas where more information is urgently needed. The report will be a tremendous aid to inform policy makers, service commissioners, and anyone with an interest in dementia.

It is now over a century since 1906 when German neurologist Alois Alzheimer diagnosed the disease which bears his name. What progress has been made? How much better do we understand the diseases that cause dementia? As our population ages, Alzheimer's disease and other causes of dementias are becoming ever more common and important. We urgently need to understand the impact of dementia in the UK now and in the future. This report is an attempt to answer these key questions and to inform a serious debate about how we as a society can respond to the challenges posed by dementia.

There has been significant progress since 1906, both in our scientific understanding of dementia and public awareness about the diseases which cause it.

We know more now than we ever did. We know that dementia is not a natural part of ageing and that it is caused by a variety of diseases which affect people in different ways. We also now have a range of options to treat the symptoms of dementia and to offer practical support to people with dementia and their families. However, we are a long way from fully understanding dementia and being able to offer a comprehensive response.

When the Alzheimer's Society was formed in 1979 it was a small band of committed carers who knew that people with dementia and their families needed to be offered support. That small band has developed into an army of people, working with a range of partners, committed to improving the quality of life of people affected by dementia.

As this report shows, the impact of dementia is vast. It devastates families and has a very serious impact on communities.

As our population ages the number of people with dementia will climb rapidly. Today there are 700,000 people with dementia in the UK, but that number will rise to over a million by

2025. This has the potential to overwhelm health and social care services which are already ill equipped to respond to the challenge of dementia.

This report estimates the cost of dementia at between £17 billion and £18 billion a year. The cost takes into account the value of the significant contribution made by families living with the experience of dementia.

The challenge now is to develop a more ambitious public approach to dementia. Do we as a country value the contribution made by older people throughout their lives? Do we believe that society has a responsibility to respond to the needs of families and communities faced by the challenges and opportunities of an ageing population? If the answer is yes, then an ambitious national strategy on dementia is required. We need to see political commitment at all levels to providing a range of solutions to deliver improved quality of life for people with dementia and their families.

The Alzheimer's Society is committed to an ambitious vision of working to secure a future where people with dementia and their carers can contribute fully to family and community life. We now ask others to join us to develop a more ambitious public approach to dementia and in particular are calling on government and policy makers to recognise dementia as a clinical priority by developing a National Dementia Plan.

Please read this report and consider how you can work with us to deliver a better future for people with dementia and their families.

Neil Hunt
Chief Executive

Executive summary

Overview

- This report establishes an accurate estimate of the numbers of people in the UK who currently have dementia.
- It also provides authoritative estimates for the numbers of people who will have dementia in the years up to 2051.
- The services and treatments currently provided to support people with dementia are reviewed.
- The current and future costs of dementia are estimated and recommendations for future dementia care are made.

This executive summary gives a brief overview of each chapter in the full report.

1. What is dementia?

The term 'dementia' is used to describe a collection of symptoms, including a decline in memory, reasoning and communication skills, and a gradual loss of skills needed to carry out daily activities. These symptoms are caused by structural and chemical changes in the brain as a result of physical diseases such as Alzheimer's disease.

Dementia can affect people of any age, but is most common in older people. One in six people over 80 has a form of dementia and one in 14 people over 65 has a form of dementia.

Researchers are still working to find out more about the different types of dementia, and whether any have a genetic link. It is thought that many factors, including age, genetic background, medical history and lifestyle, can combine to lead to the onset of dementia.

Dementia is a progressive condition. This means that the symptoms become more severe over time. Understanding how this progression happens can be useful in helping someone with dementia anticipate and plan for change.

Alzheimer's disease is the most common type of dementia. It changes the chemistry and structure of the brain, causing brain cells to die.

Vascular dementia is caused by strokes or small vessell disease which affect the supply of oxygen to the brain. Vascular dementia affects people in different ways. It can cause communication problems, stroke-like symptoms and acute confusion.

Frontotemporal dementia is a rare form of dementia affecting the front of the brain. It includes Pick's disease and often affects people under 65. In the early stages, the memory may remain intact, while the person's behaviours and personality change.

Dementia with Lewy bodies is caused by tiny spherical protein deposits that develop inside nerve cells in the brain. These interrupt the brain's normal functioning, affecting the person's memory, concentration and language skills.

2. New data on the prevalence of dementia

Health and social policy makers need accurate estimates of the numbers of people who currently have dementia and those who will develop it in the future.

This report uses a methodology known as the Expert Delphi Consensus to produce the best possible estimates using currently available research data. Ten leading United Kingdom (UK) and European experts systematically reviewed the evidence base and reached a consensus that:

- The prevalence of both early onset and late onset dementia increases with age, doubling with every five-year increase across the entire age range from 30 to 95-and-over.

The consensus estimates of the population prevalence of late onset dementia

Age (years)	*F (%)*	*M (%)*	*Total (%)*
65–69	1.0	1.5	1.3
70–74	2.4	3.1	2.9
75–79	6.5	5.1	5.9
80–84	13.3	10.2	12.2
85–89	22.2	16.7	20.3
90–94	29.6	27.5	28.6
95+	34.4	30.0	32.5

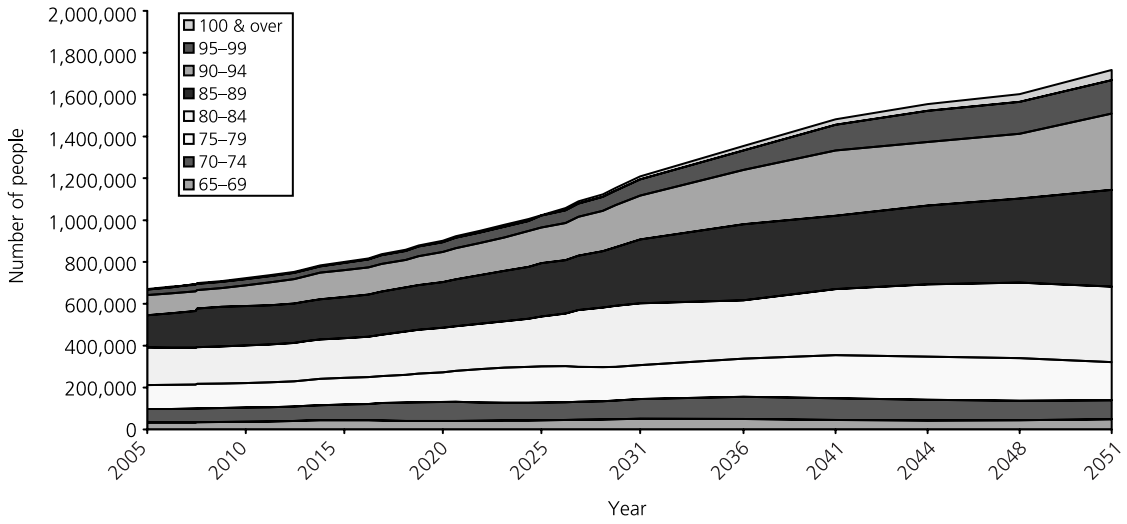
- The prevalence of early onset dementia was adjudged to be higher in men than in women for those aged 50–65, while late onset dementia was considered to be marginally more prevalent in women than in men.
- Alzheimer's disease was considered to be the dominant subtype, particularly among older people, and in women.
- Frontotemporal dementia was considered to account for a substantial proportion of early onset cases among younger men.
- The report estimates that there are 11,392 people from Black and minority ethnic (BME) groups with dementia. It is noteworthy that 6.1% of all people with dementia among BME groups are early onset, compared with only 2.2% for the UK population as a whole, reflecting the younger age profile of BME communities.
- The prevalence of dementia among people in institutions varied little by age or gender, increasing from 55.6% among those aged 65–69 to 64.8% in those aged 95 and over.

- The consensus group also generated estimates of the prevalence of dementia among all those aged 65 years and over living in EMI (elderly mentally infirm) homes (79.9%), nursing homes (66.9%) and residential care homes (52.2%).
- The proportion of deaths attributable to dementia increases steadily from 2% at age 65 to a peak of 18% at age 85–89 in men, and from 1% at age 65 to a peak of 23% at age 85–89 in women. Overall, 10% of deaths in men over 65 years, and 15% of deaths in women over 65 years are attributable to dementia. Annually, 59,685 deaths among the over 65s could have been averted if dementia were not present in the population. The majority of these deaths occurred among those aged 80–95 years. Delaying the onset of dementia by five years would halve the number of UK deaths due to dementia to 30,000 a year.

3. Number of people with dementia in the UK

We estimate that there are now 683,597 people with dementia in the UK. This represents one person in every 88 (1.1%) of the entire UK population. This is probably a very slight underestimate as it may not comprehensively include people with learning disabilities or people with dementia in NHS continuing care facilities.

The total number of people with dementia in the UK is forecast to increase to 940,110 by 2021 and 1,735,087 by 2051, an increase of 38% over the next 15 years and 154% over the next 45 years.



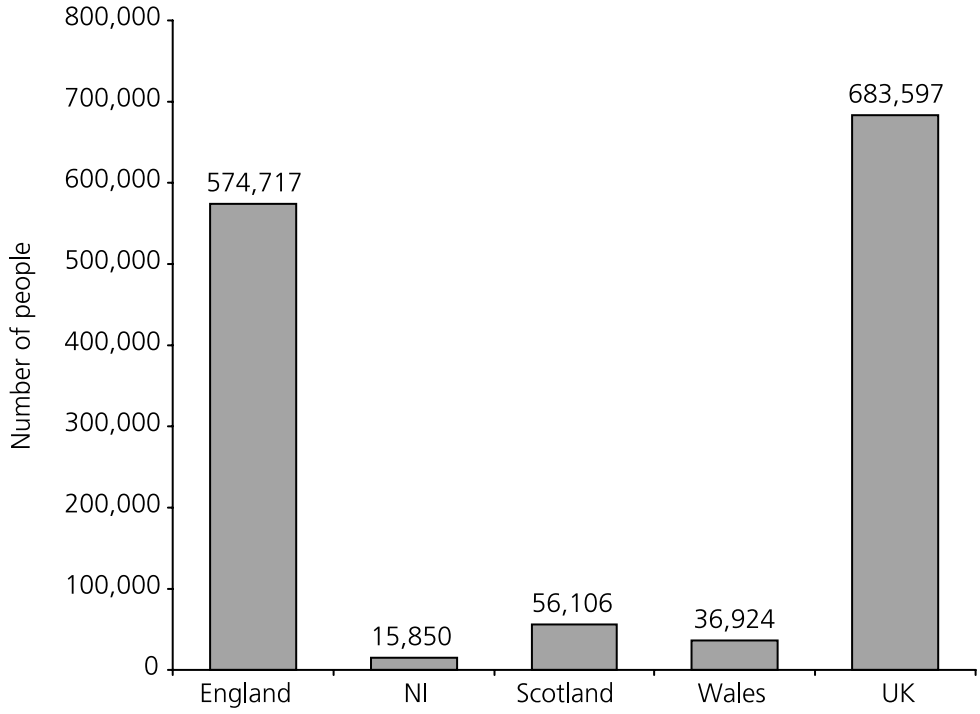
Projected number of people with late onset dementia by age group (UK)

- Early onset dementia is comparatively rare, accounting for 2.2% of all people with dementia in the UK. We estimate that there are now at least 15,034 people with early onset dementia (onset before the age of 65 years) in the UK and 668,563 people with late onset dementia (onset after the age of 65 years). However, given that data on the numbers of early onset cases are based on referrals to services, this number is likely to be an underestimate. The true figure may be up to three times higher.

- The numbers of people with late onset dementia continue to rise for each five-year age band up to the age of 80–84, and decline thereafter. Despite this, two-thirds (68%) of all people with dementia are aged 80 and over, and one sixth (17%) aged 90 or over.
- Overall we estimate that 222,925 men and 445,641 women have late onset dementia, approximately two women for every man affected. Both the higher mortality among men and the higher age-specific dementia prevalence in women contribute to the preponderance of women among the 'oldest-old' with dementia.

Dementia subtypes

- We estimate that 416,967 people with dementia (62%) have Alzheimer's disease (AD), the most common form of dementia. The next most common subtypes are vascular dementia (VaD) and mixed dementia, accounting for nearly one third (27%) of all cases.
- The distribution of subtypes is different in men and women. Alzheimer's disease is more common in women (67% in women compared with 55% in men), while vascular dementia and mixed dementias account for 31% of all cases in men and just 25% in women.



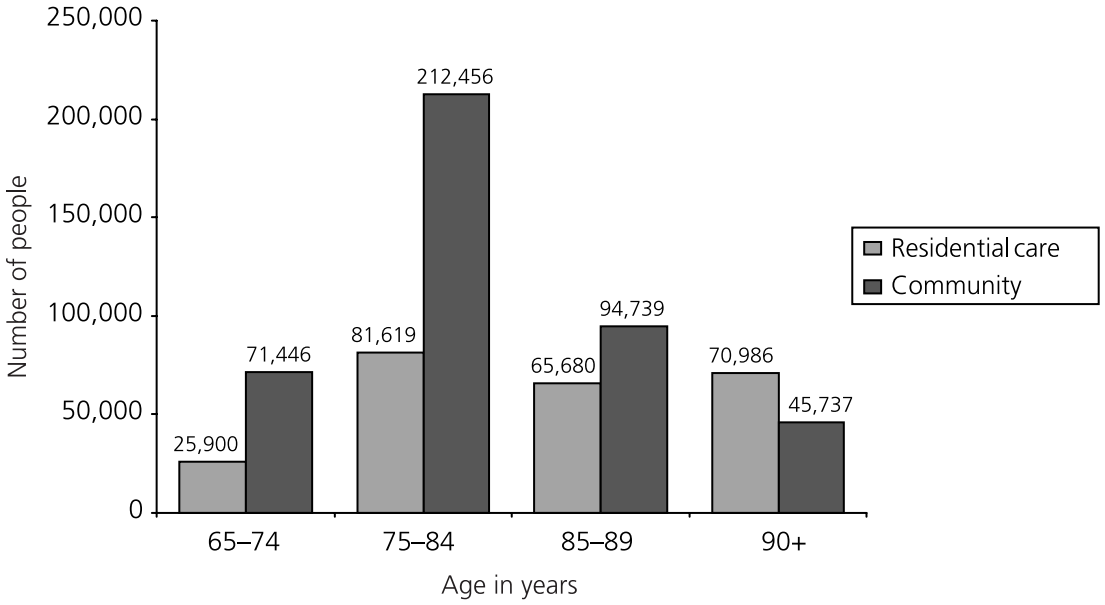
Number of people in the UK with dementia (2005)

Severity of dementia

- Among those with late onset dementia, 370,283 (55.4%) have mild dementia, 214,638 (32.1%) have moderate dementia and 83,801 (12.5%) have severe dementia.
- The proportion considered to have severe dementia increases with increasing age, from 6.3% for those aged 65 to 69 years to 23.3% for those aged 95 years and over.

Institutional care

- We estimate that 424,378 people with late onset dementia (63.5%) live in private households (the community), whereas 244,185 (36.5%) live in care homes.
- The proportion of those with dementia living in care homes rises steadily with age, from 26.6% of those aged 65–74, to 60.8% of those aged 90 and over.



Number of people in the UK with late onset dementia living in residential care and in the community

Burden of disease

Dementia is one of the main causes of disability in later life. In a wide consensus consultation for the World Health Organization's Global Burden of Disease report, disability from dementia was accorded a higher weight than that for almost any other condition, with the exception of spinal cord injury and terminal cancer. Of course, older people are particularly likely to have multiple health conditions – chronic physical diseases affecting different organ systems, coexisting with mental and cognitive disorders. Dementia, however, has a disproportionate impact on capacity for independent living. Still its global public health significance continues to be under-appreciated and misunderstood. According to the 2003 World Health Report Global Burden of Disease estimates, dementia contributed 11.2% of all years lived with disability among people aged 60 and over; more than stroke (9.5%), musculoskeletal disorders (8.9%), cardiovascular disease (5.0%) and all forms of cancer (2.4%).

Research

There have been major advances in the field of dementia research. However, public funding for dementia research lags far behind that of other serious medical conditions.

The proportion of research papers (since 2002) devoted to these chronic disorders reveals a starkly different ordering of priorities: cancer 23.5%, cardiovascular disease 17.6%, musculoskeletal disorders 6.9%, stroke 3.1% and dementia 1.4%.

4. Development of services for people with dementia

The role of the health and social care systems in meeting the multiple needs of people with dementia and their families is a key policy issue in the UK. However, the evidence base on the range of services available for people with dementia is very limited and needs significant work. In that context this chapter concentrates on:

- Informal care – unpaid care provided by family members and friends, the mainstay of dementia care in the UK.
- Financing health and social care – demographic challenges, charges, choices and independence.
- Specialist health services for people with dementia – including the role of old age psychiatry.
- Dementia assessment and care – considering diagnosis and referrals.
- Social care provision – residential and nursing care, extra care housing, community based support and mental health services.
- The state of current dementia commissioning, care and policy – services are not available for a large majority of the population to deliver the memory assessment and care services that are stipulated in government policy, yet demand is predicted to grow.

5. Mapping social service provision

Available data

Mapping local levels of social care support for people with dementia in the UK is difficult as there are no available local authority level data on service provision specific to older people with mental health problems.

This study gathered information on local levels of provision of residential and nursing care, home care and day care services to *all* older people in England, Scotland, Wales and Northern Ireland.

Findings

There were very marked variations in levels of provision, expenditure and (to a lesser extent) in unit costs across all services and in all UK countries. Variability was smallest for residential care services.

Residential care services:

UK country	*% of people over 65 supported in residential or nursing care homes*
England	2.5
Scotland	4.0
Wales	2.8
Northern Ireland	4.0

- Significantly higher proportions of older people were supported in institutions in Scotland and Northern Ireland than in England and Wales.

Home care services:

UK country	*% of people over 65 in receipt of home care services*
England	3.9
Scotland	6.9
Wales	4.3
Northern Ireland	2.4 (NB, not directly comparable figure)

Possibly as a result of the introduction of free personal care there in 2002, older people in Scotland show the highest take-up of home care services in the UK, followed by older people in Wales, England and Northern Ireland.

The highest rates of home care provision (and home care expenditure) per head of older population are concentrated in high population density areas, such as metropolitan districts and London boroughs.

Day care services:

UK country	*% of people over 65 in receipt of day care services*
England	1.7
Scotland	1.3
Wales	1.6
Northern Ireland	1.1

The levels of day care provided within each country vary widely, much more than for either of the other services explored.

Local authority expenditure

Levels of residential and home care expenditure per head of older population in local authorities in Scotland and health and social services trusts in Northern Ireland were significantly higher than levels of expenditure in English and Welsh local authorities.

Limitations of the analysis

It is important to note the contrast between the descriptive nature of the analysis presented and the complex nature of the processes from which patterns of local provision emerge. Although the interpretation of the results is helped by the availability of information on unit costs, a full understanding of the reasons behind the patterns highlighted would require considering simultaneously a significantly larger range of factors. Such analysis was beyond the scope of the present study.

6. The financial cost of dementia in the UK

Using the new prevalence estimates from this report, together with other data, we calculated the overall costs of dementia in the UK. Costs to be included were those provided by formal care agencies as well as the financial value of unpaid informal care provided by family and friends.

Costs were not available for the 2% of people with dementia under the age of 65.

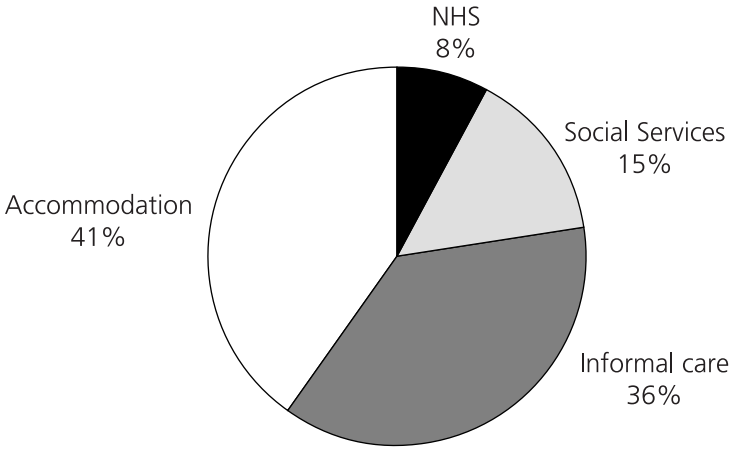
Total costs amounted to £17.03 billion per annum, or an average of £25,472 per person with late onset dementia. Accommodation accounted for 41% of the total with 36% due to informal care inputs.

The total annual cost per person with dementia in different settings is estimated as follows:

- people in the community with mild dementia – £16,689
- people in the community with moderate dementia – £25,877
- people in the community with severe dementia – £37,473
- people in care homes – £31,296.

Over a third of the total (36%) was due to informal care inputs by family members and other unpaid carers. Included in this amount is the estimated £690 million in lost income for those carers who have to give up employment or cut back their work hours. This lost employment means a loss of £123 million in taxes paid to the Exchequer.

Benefit payments are not strictly a cost (since they are transfer payments), but they are an expense to the government. Receipt of Attendance Allowance or DLA for people with dementia amounted to around £919 million per year, increasing to a total cost of about £18 billion.



Distribution of dementia service costs

7. Recommendations

1 **Make dementia a national priority**
2 **Increase funding for dementia research**
3 **Improve dementia care skills**
4 **Develop community support**
5 **Guarantee carer support packages**
6 **Hold a national debate on who pays for care**
7 **Develop comprehensive dementia care models**

Historically, a lack of attention from policy makers and service commissioners to the needs of people with dementia has led to dementia care being delivered piecemeal and in an inefficient fashion. More investment accompanied by careful planning will be needed in the years ahead in order to ensure that not only do we maximise quality of life for people with dementia and their families, but also that we do so in an efficient way with the resources available.

Despite areas of good practice, the UK's current health and social care system is characterised by a widespread failure to support people with dementia and their families. These findings have been demonstrated most recently in evidence from the Wanless report into social care (2006) and CSCI state of social care report (2007). This failure to develop services which meet the needs of people with dementia is perplexing given that dementia is a significant driver of demand for health and social care.

Dementia care is characterised by a significant lack of evidence on outcomes and the current state of service delivery. The recommendations that follow therefore contain both a series of proposals for policy development, and proposals on improving the evidence base.

Recommendation 1: Make dementia a national priority

Dementia must be made a publicly stated national health and social care priority. This must be reflected in plans for service development and public spending.

- A cross-government strategy for dementia must be developed to respond to the growing need for care from early diagnosis to end of life care.
- Dementia care and research must be prioritised in the 2007 Comprehensive Spending Review.
- Health and social care commissioners must develop local plans to support increasing numbers of people with dementia and their families.

Recommendation 2: Increase funding for dementia research

As a matter of urgency there must be a review of UK medical research funding to establish a more ambitious funding programme into the causes, prevention, cure and care of dementia.

Increasing the amount of dementia research is an urgent priority if we are to improve the treatment of people with dementia in the future, and make evidence-based plans to provide high quality care to meet the evolving needs.

Recommendation 3: Improve dementia care skills

Dementia care training should be made a core and substantial part of the training curriculum for nurses and social care staff. National Minimum Standards must be developed to include dementia specific requirements on dementia care training.

Without significant focus on improving care across health and social care, outcomes will get worse and resources will be squandered.

The current National Minimum Standards were always meant to be a starting point for good practice. Now it is time to develop stronger requirements. We must go beyond the current dementia options in the Quality and Outcomes Framework for GPs to improve the early identification, diagnosis and management of dementia by GPs.

Recommendation 4: Develop community support

People with dementia need improved home care support packages, including low-level support to retain their independence and dignity.

The number and extent of home care packages must be increased. In addition it is time to bring back home help services such as help with cleaning, shopping, DIY and gardening.

Recommendation 5: Guarantee carer support packages

Family carers must have guaranteed access to carer support. In particular:

- **psychological therapies including carer training and support groups**
- **quality respite care for people with dementia and carers.**

The current policy response to carers is very weak and needs revision. Without formal commitments to an improved package of support for carers, an increasing number will be unable to continue caring and pressures on long-term care will increase.

Recommendation 6: Hold a national debate on who pays for care

We must have a national government-backed debate on who pays for care to establish a clear and fair balance between the contributions made by the state and the individual.

We urgently require a national government-backed debate about who pays for care. The evidence is that people are willing to make a contribution towards their care if a number of conditions are satisfied. A new solution must be transparent, easy to understand and equitable. The care being paid for must also be of a good quality.

Recommendation 7: Develop comprehensive dementia care models

Develop an integrated, comprehensive range of care models for people with dementia to bridge the gap between care at home and care in a care home.

More work is needed from the public, private and voluntary sector to find good quality, cost-effective options to meet the needs of people with dementia and their families.

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CHAPTER 1

Introduction

Overview

- Dementia receives inadequate attention from policy makers in the UK.
- This report draws together information on dementia in the UK and provides answers to key questions of prevalence, the range of services and treatments provided and the costs of dementia.
- This report concludes with recommendations for dementia care.
- This introductory chapter provides a summary of what is meant by the term dementia.

1.1 Introduction

Despite its large potential impact, dementia continues to receive inadequate attention from policy makers in the UK. In part this is because policy-relevant information on prevalence, support, service consequences and costs is widely dispersed and poorly accessible. Against this background, the Alzheimer's Society commissioned research from the Institute of Psychiatry (IOP) at King's College London and the Personal Social Services Research Unit (PSSRU) which is based within the Department of Social Policy at the London School of Economics (LSE).

The objectives of the work described were to address a number of questions as they related to the UK:

- What is dementia?
- What is the prevalence of dementia?
- What services and treatments are provided to support people with dementia?
- What are the costs of dementia?
- What recommendations follow for dementia care?

1.2 Methods

The methods employed to address these questions are set out in the chapters that follow. References for all chapters are gathered together at the end of the report.

1.3 What is dementia?

The term 'dementia' is used to describe a collection of symptoms, including a decline in memory, reasoning and communication skills, and a gradual loss of skills needed to carry out daily activities. These symptoms are caused by structural and chemical changes in the brain as a result of physical diseases such as Alzheimer's disease.

Dementia can affect people of any age, but is most common in older people. One in six people over 80 has a form of dementia and one in 14 people over 65 has a form of dementia.

Dementia is a progressive condition. This means that the symptoms become more severe over time. Understanding how this progression happens can be useful in helping someone with dementia anticipate and plan for change.

Researchers are still working to find out more about the different types of dementia, and whether any have a genetic link. It is thought that many factors, including age, genetic background, medical history and lifestyle, can combine to lead to the onset of dementia.

There are very many underlying causes. Alzheimer's disease, which is characterised by the build up of deposits in the brain known as amyloid plaques and neurofibrillary tangles, is the commonest, accounting for one half to three-quarters of all people with the disease. Vascular dementia is diagnosed when the brain's blood circulation is repeatedly disrupted by strokes or other blood vessel pathology leading to significant accumulated damage to brain tissue and function. The distinction between Alzheimer's disease and vascular dementia has been called into question, as it is common for people to develop both conditions simultaneously, particularly over the age of 80. Vascular damage may be a co-actor accelerating the onset of clinically significant symptoms in people with Alzheimer's disease.

There are a few rare causes of dementia that may be treated effectively by timely medical or surgical intervention – these include deficiencies of thyroid hormone, vitamin B12 and folic acid. For the most part, altering the progressive course of the disorder is unfortunately not possible. However treating the symptoms of dementia and offering appropriate support services can make a significant difference to the lives of people with dementia and their caregivers.

The main risk factor for most forms of dementia is advanced age, with prevalence roughly doubling every five years over the age of 65. Onset before this age is known as young or early onset dementia, it is very unusual and, in the case of Alzheimer's disease, often suggests a genetic cause. When early onset Alzheimer's disease runs strongly in families then single gene mutations at one of three loci (Beta amyloid precursor protein, presenilin1 and presenilin2) account for most of these cases. For late onset Alzheimer's disease both environmental (lifestyle) and genetic factors are important. Having a common genetic polymorphism, the apolipoprotein E (apoE) gene Q4 allele greatly increases the risk of going on to suffer from dementia; up to 25% of the population has one or two copies of this polymorphism (Saunders et al 1993, Nalbantoglu et al 1994). However, it is not uncommon for one identical twin to suffer from dementia, and the other not.

This implies a strong influence of the environment (Breitner et al 1995). Evidence from cross-sectional and case–control studies suggest associations between Alzheimer's disease and limited education (Ott et al 1995) and head injury (Mortimer et al 1991, Mayeux et al 1995), which, however, are only partly supported by longitudinal (follow-up) studies (Stern et al 1994). Depression has been shown to be a risk factor in short-term longitudinal studies, but this may be because depression is an early presenting symptom, rather than a cause of dementia (Devanand et al 1996). Recent research suggests that vascular disease and vascular risk factors predispose to Alzheimer's disease as well as to vascular dementia (Hofman et al 1997). Smoking seems to increase the risk for Alzheimer's disease as well as vascular dementia (Ott et al 1998). Long-term follow-up studies show that high blood pressure (Skoog et al 1996, Kivipelto et al 2001) and high cholesterol levels (Kivipelto et al 2001) in middle age each increase the risk of going on to develop Alzheimer's disease in later life. Reports from epidemiological studies of protective effects of certain prescribed medication such as non-steroidal anti-inflammatory drugs, anti-hypertensives and cholesterol lowering therapies, are now being investigated in randomised controlled trials.

The importance of diagnosis

Early diagnosis is helpful so that the person with dementia and any carers can be better equipped to deal with the disease and to know what to expect. A diagnosis is the first step towards planning for the future. There is no simple test to make a diagnosis. The diagnosis of dementia is made by taking a careful account of the person's problems from a close relative or friend, together with an examination of the person's physical and mental state, supported by investigations such as neuropsychological testing, blood tests and brain scans as appropriate. It is important to exclude other conditions or illnesses that cause memory loss, including depression, alcohol problems and some physical illnesses with organic brain effects. For the purpose of making a diagnosis, clinicians focus in their assessments upon impairment in memory and other cognitive functions, and loss of independent living skills. For carers and, arguably, for people with dementia, it is the behavioural and psychological symptoms (BPSD) linked to dementia that are most relevant. Nearly all studies indicate that BPSD are an important cause of strain on caregivers. They are a common reason for institutionalisation, as the family's coping reserves become exhausted. Problem behaviours may include agitation, aggression, calling out repeatedly, sleep disturbance (day night reversal), wandering and apathy. Common psychological symptoms include anxiety, depression, delusions and hallucinations. BPSD occur most commonly in the middle stage of dementia.

Currently, there are no treatments available that cure, or even alter the progressive course of dementia, although numerous new therapies are being investigated in various stages of clinical trials. Evidence-based, symptomatic treatments are available for cognitive impairment (the anticholinesterase drugs), and psychological symptoms including depression, anxiety, delusions and hallucinations. Non-drug interventions are often highly effective, and should generally be the first choice when managing behavioural problems. Carers can be *educated* about dementia, countering lack of understanding and awareness about the nature of the problems faced. They can also be *trained* to manage better most of the common behavioural symptoms, in such a way that their frequency and/or the strain experienced by the carer is reduced. Above all, the person with dementia and the family carers need to be *supported* over the longer term. The person with dementia needs to be treated at all times with patience and respect for their dignity and personhood. The carer

needs unconditional support and understanding – their needs should also be determined and attended to.

Dementia is one of the main causes of disability in later life. In a wide consensus consultation for the World Health Organisation's Global Burden of Disease report, disability from dementia was accorded a higher weight than that for almost any other condition, with the exception of spinal cord injury and terminal cancer. Of course, older people are particularly likely to have multiple health conditions – chronic physical diseases affecting different organ systems, coexisting with mental and cognitive disorders. Dementia, however, has a disproportionate impact on capacity for independent living. Still its global public health significance continues to be underappreciated, and misunderstood. According to the 2003 World Health Report Global Burden of Disease estimates, dementia contributed 11.2% of all years lived with disability among people aged 60 and over; more than stroke (9.5%), musculoskeletal disorders (8.9%), cardiovascular disease (5.0%) and all forms of cancer (2.4%). The proportion of research papers (since 2002) devoted to these chronic disorders reveals a starkly different ordering of priorities; cancer 23.5%, cardiovascular disease 17.6%, musculoskeletal disorders 6.9%, stroke 3.1% and dementia 1.4%.

The way each person experiences dementia, and the rate of their decline, will depend on many factors – not just on which type of dementia they have, but also on their physical make-up, their emotional resilience and the support that is available to them. Typically symptoms will include:

- Loss of memory – for example, forgetting the way home from the shops, or being unable to remember names and places.
- Mood changes – this happens particularly when the parts of the brain which control emotion are affected by disease. People with dementia may feel sad, angry or frightened as a result.
- Communication problems – a decline in the ability to talk, read and write.

Dementia subtypes

There are different types of dementia caused by different diseases of the brain. Because these diseases affect the brain in different ways, they produce different symptoms. Some of the most common forms of dementia are listed below.

Alzheimer's disease is the most common type of dementia. It changes the chemistry and structure of the brain, causing brain cells to die.

In the early stages of Alzheimer's, the person's behaviours may change in very small ways. They may start forgetting things or repeating themselves more often than usual, for example. At first people often attribute these symptoms to factors such as ageing, stress or bereavement.

In the middle stages of Alzheimer's, the person may need reminders to carry out activities of daily living such as eating, dressing or using the toilet. The person's memory will get worse, and they may have difficulty recognising familiar people or places.

Over time, the person will become increasingly dependent on others for help. They are likely to experience severe memory loss and become increasingly frail. They may have difficulty with eating, swallowing, continence and experience loss of communication skills such as speech.

Vascular dementia is caused by strokes or small vessell disease which affect the supply of oxygen to the brain. Vascular dementia affects people in different ways. It can cause communication problems, stroke-like symptoms and acute confusion.

The symptoms that a person experiences as a result of a stroke depend on which part of the brain has been damaged. For example, if the damaged area is responsible for movement of a limb, paralysis may occur. If the part of the brain damaged is responsible for speech, the person may have problems communicating.

When vascular dementia is caused by a single stroke, it is called single-infarct dementia. Vascular dementia is more commonly caused by a series of small strokes. These can be so tiny that the person may not notice any symptoms or the symptoms may be only temporary. This is called multi-infarct dementia.

Vascular dementia progresses in a similar way to Alzheimer's disease, but progression is often 'stepped' rather than gradual, declining suddenly as the person has a new stroke. Progression of vascular dementia may be slowed through the control of underlying risk factors such as blood pressure.

Frontotemporal dementia is a rare form of dementia affecting the front of the brain. It includes Pick's disease and often affects people under 65. In the early stages, the memory may remain intact, while the person's behaviours and personality change.

In the early stages of frontotemporal dementia, the person is less likely to become forgetful than in Alzheimer's disease. Instead their behaviour can change quite dramatically. For example, they may seem more selfish or unfeeling than usual or sexually uninhibited. The later stages are very similar to Alzheimer's disease.

Dementia with Lewy bodies is caused by tiny spherical protein deposits that develop inside nerve cells in the brain. These interrupt the brain's normal functioning, affecting the person's memory, concentration and language skills.

This type of dementia has symptoms similar to those of Parkinson's disease, such as tremors and slowness of movement. The person may also experience hallucinations. The progression of this condition can be confusing for carers, as the person's abilities may fluctuate.

The international context

Dementia and Alzheimer's disease have been reliably identified in all countries, cultures and races in which systematic research has been carried out. However, levels of awareness vary enormously. In 2005, Alzheimer's Disease International commissioned a panel of experts to review all available epidemiological data and reach a consensus estimate of prevalence in each world region, and numbers of people affected. Evidence from well-conducted, representative epidemiological surveys was lacking in many regions. The panel estimated that 24.3 million people have dementia today, with 4.6 million new cases of dementia annually (one new case every 7 seconds) (Ferri et al 2005). Numbers of people affected will double every 20 years to 81.1 million by 2040.

Most people with dementia live in developing countries, 60% in 2001 rising to 71% by 2040. Rates of increase are not uniform; numbers in developed countries are forecast to increase by 100% between 2001 and 2040, but by more than 300% in India, China and their south Asian and western Pacific neighbours. Long-term studies from Sweden and the USA suggest that the age-specific prevalence of dementia has not changed over the last 30 or

40 years. Whatever the explanation for the current discrepancy between prevalence in developed and developing countries, it seems probable that as patterns of morbidity and mortality converge with those of the developed west, then dementia prevalence levels will do likewise, leading to an increased burden of dementia in poorer countries.

1.4 Structure of the report

- Chapter 2 describes the Delphi consensus approach used to arrive at new prevalence estimates for the UK.
- Chapter 3 gives the estimated numbers of people with dementia, broken down by various subgroups.
- Chapter 4 sets out the policy, funding and organisational contexts for dementia care in the UK, including an account of the development of old age mental health services.
- Chapter 5 describes the new UK-wide mapping of key service data relating to the support of older people with dementia.
- Chapter 6 sets out the costs of dementia.
- Chapter 7 offers recommendations built on the evidence base set out in earlier chapters.

CHAPTER 2

The Expert Delphi Consensus on the prevalence of dementia in the UK

Overview

- This report uses a methodology known as the Expert Delphi Consensus to produce the best estimates to date of the prevalence of dementia in the UK using currently available research data.
- The prevalence of both early onset and late onset dementia increases with age, doubling with every five-year increase across the entire age
- The prevalence of early onset dementia appears to be higher in men than in women for those aged 50–65, while in later life, late onset dementia was considered to be marginally more prevalent in women than in men.
- Alzheimer's disease is the dominant subtype, particularly at older ages, and among women, whereas frontotemporal dementia accounts for a substantial proportion of early onset cases among younger men.
- The prevalence of dementia in institutions varied little by age or gender, increasing from 55.6% among those aged 65–69 to 64.8% in those aged 95 and over.
- Estimates of the prevalence of dementia among all those aged 65 years and over living in EMI (elderly mentally infirm) homes was 79.9%; nursing homes 66.9% and residential care homes 52.2%.

2.1 Background

Accurate estimates of the numbers of people with dementia provide an authoritative and consistent foundation for health and social policy making, as well as assisting national Alzheimer's Associations in their task of raising awareness of the challenge to be faced by this and future generations.

Estimates of the numbers of people with dementia are made by applying a prevalence estimate (the proportion of people affected) to the numbers of people in any given population. Prevalence estimates are obtained from population-based epidemiological surveys. Many previous estimates have been 'rough and ready'. Some are based on only one epidemiological study and most do not take account of all relevant evidence (Ferri et al 2005). Others fail to account properly for the variation in prevalence by age, gender and region. For its estimate of the numbers of people with dementia in the UK, the Alzheimer's Society

did consult the available research literature, and applied age-specific prevalence rates of 0.1% for all those aged 40–64 years, 2% for all those aged 65–69, 5% for those aged 70–79 years and 20% for those aged 80 and over. Using this method, which did not take into account the effect of age, and did not consider the effect of gender on prevalence, they estimated 775,000 people with dementia in 2001, of whom 18,000 would be aged under 65 years.

A more comprehensive approach necessitates a systematic review of all relevant studies, and synthesising the evidence into a single consensus estimate of likely prevalence. Such an approach (known as Delphi consensus) was recently used by a group of researchers commissioned by Alzheimer's Disease International to study the prevalence of dementia in each world region (Ferri et al 2005); they estimated 24 million people worldwide have dementia, of whom 741,000 live in the UK.

We have now carried out a detailed Delphi consensus exercise to estimate the current prevalence and numbers of people with dementia in the UK. Delphi consensus is a useful method for making estimates where an evidence base exists but data are incomplete, scanty or otherwise imperfect. The essence of the method is deriving quantitative estimates through the qualitative assessment of research evidence. It is an interactive process of consensus. Experts first make estimates independently, which are then aggregated and fed back anonymously so that they may review them in the light of group-wide choices. Our expert consensus group comprised 10 senior academics. Six of them had previously been involved in population-based dementia research in the UK, two were international (European) experts, and two were UK-based clinical and health services researchers.

The experts addressed three main areas:

1 The prevalence of dementia
   - The population prevalence of late onset dementia in the UK (for those aged 65 and over).
   - The population prevalence of early onset dementia in the UK (onset before the age of 65).
   - The prevalence of dementia among those living in care homes.
2 The relative frequency of dementia subtypes – the proportion of dementia cases that would fall into different diagnostic subtype categories.
3 The severity of dementia – the proportion of dementia cases that could be considered to be mild, moderate and severe.

This is an improvement upon previous UK estimates in five main respects. It generates consensus estimates of prevalence based on a systematic review of the whole relevant research evidence base. It uses age- (within five-year bands from 30 to 95 and over) and gender-specific prevalence to estimate numbers, allowing more precisely for the effects of these important determinants. It extends the evidence-based estimation of numbers of people with dementia to include early onset cases. It enables an estimate of the numbers of people with dementia living in care homes, and in the community. It facilitates estimation of the economic costs associated with dementia, which are driven largely by the fixed costs of institutional care and (for those living in the community) by the severity of dementia.

2.2 Method

The evidence base

We summarised the available research evidence, to assist the group in making their judgements. There were three stages. First, we carried out a systematic review of the relevant UK literature, since 1981, using the Medline and Psychlit databases. Copies of the papers were obtained and read to see if they were eligible for inclusion. The main inclusion criteria were that there should be a clinical dementia diagnostic outcome, and that the study should be population-based, or in the case of institutions should have a clear sampling frame. Next, a draft list of papers was circulated to the expert consensus group to see if any had been missed. A final list of eligible papers was drawn up. Each study was carefully examined and a detailed document synthesising the research evidence was sent to each expert. This contained details on the methodology (setting, sample size, one- or two-phase survey, appropriateness of the procedures used for two-phase design, response rates for first and second phases, diagnostic criteria). The document also contained a table summarising the age-specific or age/gender-specific prevalence estimates from each eligible study. The 95% confidence intervals were included where they were given in the paper, or could be calculated from information provided. Cleusa Ferri, Martin Prince and Emiliano Albanese highlighted any apparent methodological deficiencies. Information regarding excluded studies (with reasons for exclusion) was also provided. The evidence base is summarised below in Results, Section 2.3.

Delphi consensus procedure

Each expert reviewed the document synthesising the research evidence and was then asked to give their own estimates for each of the following parameters:

1 The population prevalence of late onset dementia (%) by gender and age (five-year bands from 65 to 94 years, and 95 years and over).

2 The population prevalence of early onset dementia (per 100,000) by gender and age (five-year bands from 30 to 64 years; also for all those aged 45–64 years).

3 The prevalence of dementia among older people living in care homes

- for care homes in general the prevalence of dementia (%) by gender and age (five-year bands from 65 to 94 years and 95 years and over; also for all those aged 65 years and over);
- for each of the three main types of care homes – residential care, nursing home care and EMI care facilities – the prevalence of dementia for all those aged 65 years and over, by gender.

4 The proportion of dementia cases in the general population that might be attributed to the major subtypes: Alzheimer's disease, vascular dementia, mixed, dementia with Lewy bodies, frontotemporal dementia, dementia with Parkinson's disease and 'other dementia' by gender and age (five-year bands from 30 to 94 and 95-and-over).

The experts could make brief comments justifying their estimates.

The estimates for each parameter were entered into spreadsheets. Individual responses were anonymised so that the experts could identify their own responses but not those of

others. The group response was summarised as the mean prevalence or proportion estimate. These spreadsheets were then returned to the members of the panel who, in the second round, were invited to reconsider, in the light of their colleagues' responses, both their estimates and their comments explaining the basis of their decision. If they chose to alter their estimates, they were then able to see the impact of this change upon the group mean.

Analysis

The levels of agreement between participants in the first and second round of the exercise were assessed using a statistical device known as intra-class correlation coefficient (ICC) within age groups. The mean prevalence estimate and its standard deviation were calculated for each age and gender group.

2.3 Results

Population prevalence of late onset dementia

Six eligible population-based studies were identified (see Table 2.1) (O'Connor et al 1989, Brayne and Calloway 1989, Livingston et al 1990, Clarke et al 1991, Saunders et al 1993, MRC CFAS 1998). We excluded two studies that did not include a clinical dementia outcome (Lindesay 1990, Clarke et al 1986), and one that only assessed screen positive cases in the second phase, with a high non-response rate (Stevens et al 2000). Four of the eligible studies were conducted in the 1980s, and two in the early 1990s. Some of the studies were limited by their relatively small sample size (Brayne and Calloway 1989, Livingston et al 1990), or because only the oldest old (O'Connor et al 1989, Brayne and Calloway 1989, Clarke et al 1991) or women were sampled (Brayne and Calloway 1989). In terms both of sample size and scope the evidence base is dominated by the Medical Research Council Cognitive Function and Ageing Study (Saunders et al 1993, MRC CFAS 1998). This study was set up with funding from the MRC and the Department of Health specifically to provide generalisable estimates for policy-making and planning. MRC CFAS fieldwork was carried out in urban (Liverpool, Newcastle, Nottingham, Oxford) and rural (Cambridgeshire and Gwynedd) settings. Other surveys sampled from much smaller single catchment areas in Cambridge (O'Connor et al 1989), rural Cambridgeshire (Brayne and Calloway 1989), London (Gospel Oak) (Livingston et al 1990) and Melton Mowbray (Clarke et al 1991).

Most studies used two phase designs with an initial screening assessment, followed by a second phase definitive diagnostic assessment – for all but one of these studies (Livingston et al 1990), screen negatives were also sampled and weighting back carried out appropriately. All of the population-based studies included older people living in institutions within the study catchment areas. None reported separate prevalence estimates for community dwelling older people (those not living in care homes). Only the MRC-CFAS study reported prevalence among those living in care homes (Matthews and Dening 2002) (see also below).

The dementia diagnostic outcome for the earlier surveys (O'Connor et al 1989, Brayne and Calloway 1989, Clarke et al 1991) was derived from the CAMDEX interview (comprising a mental state examination, medical and psychiatric history, cognitive testing, physical examination and an informant interview). CAMDEX diagnoses were made clinically with all

Table 2.1 Population-based studies of late onset dementia

Study	*Setting*	*Sampling*	*Design (screening assessment)*	*Number and proportion responding*		*Outcome*	*Severity*	*Diagnosis*
				Phase 1	*Phase 2*			
O'Connor et al (1989)	Cambridge City	All aged 75+. GP age/sex registers	Two phase (MMSE)	2311 (90%)	481 (82%)	CAMDEX dementia	Mild/Moderate/ Severe (cognitive test)	SDAT (Alzheimer's), VAD (Vascular) according to CAMDEX
Brayne and Calloway (1989)	East Cambridgeshire	Women aged 70–79. GP age/ sex registers	One phase	365 (89%)		CAMDEX dementia	Mild/Mild to moderate/ Moderate/ Moderate to Severe/Severe (CAMDEX)	SDAT, multi-infarct dementia, mixed, other
Livingston et al (1990)	Gospel Oak, London	All women 60+ and men 65+. Doorknocked register	Two phase (SHORT-CARE)	813 (87%)	48 (80%)	'Clinical dementia diagnosis' guided by GMS	No information	Alzheimer's (NINCDS-ADRDA), Multi-infarct (Hachinski score); Mixed and Reversible dementia
Clarke et al (1991)	Melton Mowbray	All aged 75+. GP age/sex registers	Two phase (MMSE)	1579 (83%)	438 (84%)	CAMDEX	Minimal, Mild, Moderate, Severe according to the CAMDEX	No information
Saunders et al (1993)	Liverpool (linked to MRC-CFAS study, below)	All aged 65+. GP age/sex registers. Oversampling of older old	One phase	5222 (87%)		GMS/AGECAT 'organic' case	No information	No information
MRC-CFAS (1998)	Cambridge, Gwynedd, Newcastle, Nottingham and Oxford.	All aged 65+. GP age/sex registers. Oversampling of 75+	Two phase (GMS/AGECAT organicity, MMSE and age)	13,009 (80%)	2622 (83%)	GMS/AGECAT 'organic' case	No information	No information

available information using criteria that map quite closely to the clinical ICD10 criteria. MRC CFAS used the Geriatric Mental State and its AGECAT computerised algorithm to generate diagnoses. GMS does not cover all of the criteria required for a clinical dementia diagnosis (lacking for example an informant interview) but has nevertheless been validated against the criterion of DSM dementia (Schaub et al 2003, Ames et al 1994, Copeland 1990). Because of some limitations in the UK evidence base, we also presented to the consensus panel the prevalence of dementia derived from two meta-analyses of European surveys; one of 12 studies carried out between 1980–1990 (Hofman et al 1991) (including three UK surveys also eligible for our review (O'Connor et al 1989, Brayne and Calloway 1989, Livingston et al 1990)), and the other of 11 studies carried out in the 1990s (Lobo et al 2000) (including two UK surveys also eligible for our review (Clarke et al 1991, Saunders et al 1993)).

The selected studies provided, for the most part, fairly consistent age-specific estimates of the prevalence of dementia (Figure 2.1). As expected, the prevalence of dementia rises exponentially with age. The Gospel Oak study (Livingston et al 1990) is excluded from this figure as it only provided gender-specific prevalence for two broad age bands, those aged 65 to 80 and 81 and over.

The MRC CFAS investigators addressed specifically the issue of regional variation of dementia prevalence across the five sites and urban and rural settings covered in their survey (MRC CFAS 1998). They found no evidence to support significant regional variation in dementia prevalence or Mini Mental State Examination score distributions (MRC CFAS 1998).

The studies that were of sufficient size to provide fairly precise age- and gender-specific prevalence estimates mostly suggested a slightly higher prevalence of dementia among women, particularly in the older age groups (see Figure 2.2).

The means of the age- and gender-specific prevalence rates for late onset dementia from the expert consensus group are given in Table 2.2.

These can be seen to be broadly consistent with those previously used by the Alzheimer's Society, with those used for European regions in the ADI/Lancet estimates, with the estimates from the EURODEM meta-analysis, and with the estimates from the five centres involved in the MRC CFAS UK survey (Table 2.3).

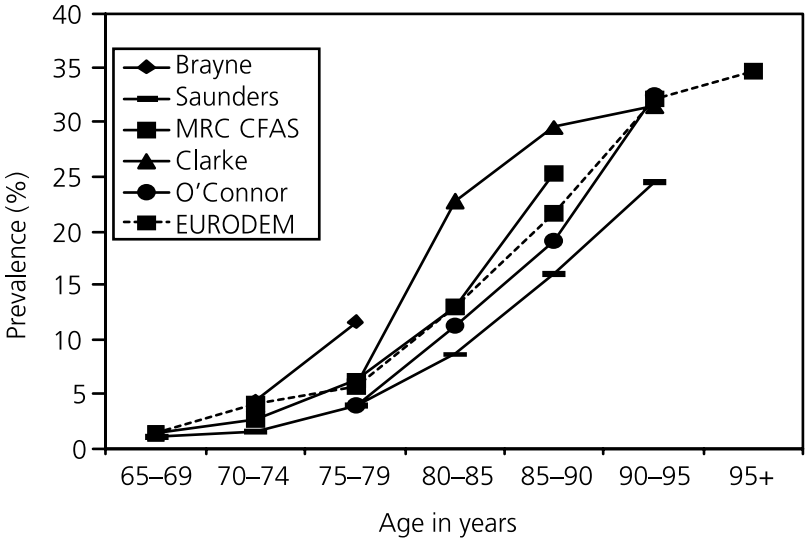


Figure 2.1 Prevalence of late onset dementia by age – relevant UK and European studies

Table 2.2 The consensus estimates of the population prevalence (%) of late onset dementia

Age in years	*F*	*M*	*Total*
65–69	1.0	1.5	1.3
70–74	2.4	3.1	2.9
75–79	6.5	5.1	5.9
80–84	13.3	10.2	12.2
85–89	22.2	16.7	20.3
90–94	29.6	27.5	28.6
95+	34.4	30.0	32.5

Table 2.3 Comparison of current consensus estimates for the prevalence (%) of late onset dementia with others used previously to estimate numbers of people with dementia in the UK

Age in years	*65–69*	*70–74*	*75–79*	*80–84*	*85–89*	*90–94*	*95+*
Consensus estimates from literature review							
Current UK consensus	**1.3**	**2.9**	**5.9**	**12.2**	**20.3**	**28.6**	**32.5**
ADI/Lancet consensus (Europe)	1.5	3.6	6.0	12.2	24.8		
Alzheimer's Society estimates	2.0	5.0		20.0			
Estimates from key surveys							
EURODEM meta-analysis	1.4	4.1	5.7	13	21.6	32.2	34.7
MRC CFAS	1.5	2.6	6.3	13	25.3		

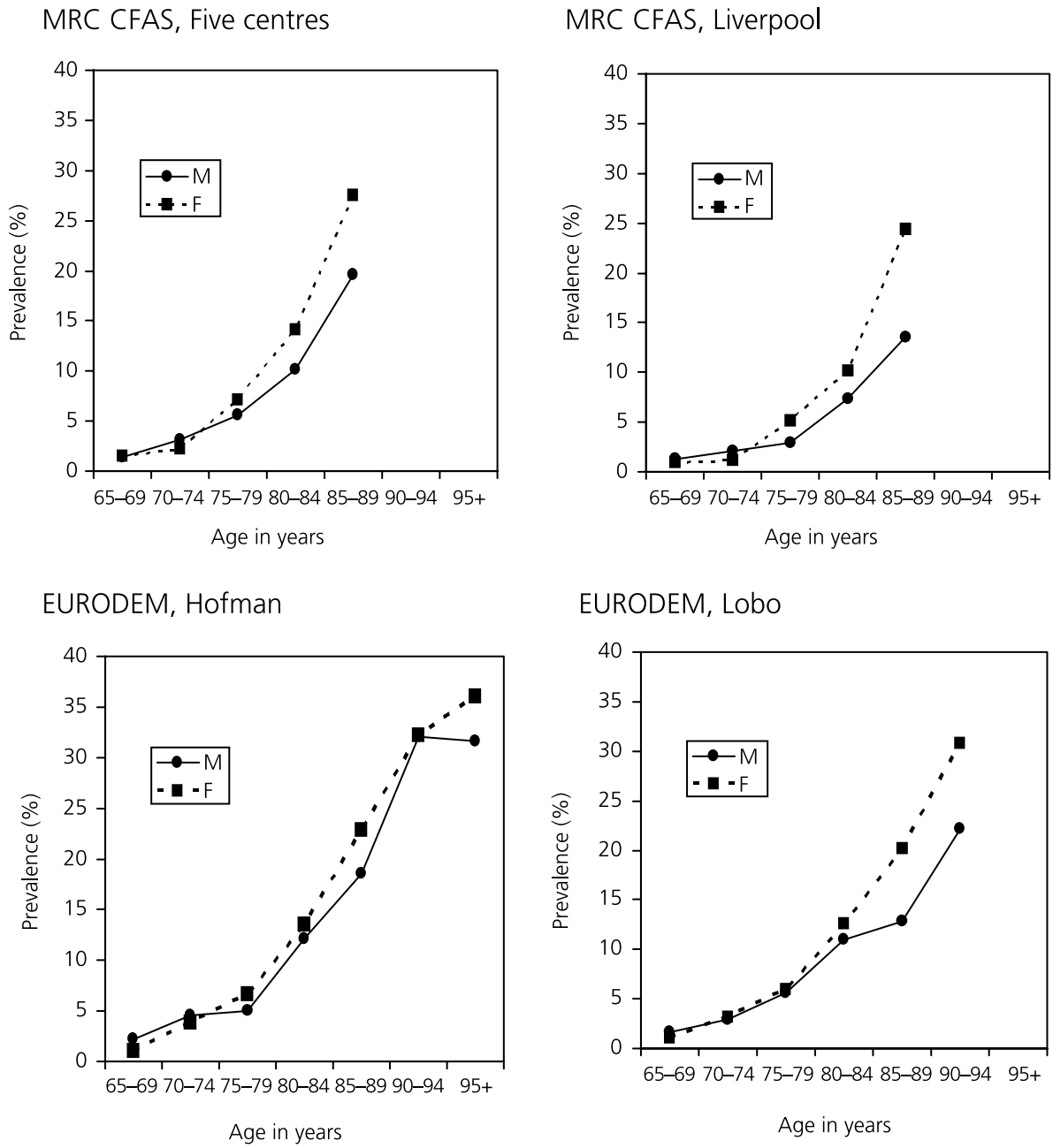


Figure 2.2 Population-based studies reporting on the prevalence of late onset dementia by age and gender

Source: MRC CFAS 1998, Saunders et al 1993, Hofman et al 1991, Lobo et al 2000

The population prevalence of early onset dementia

Early onset dementia is a rare condition and, as such, no population-based surveys have been carried out into the prevalence of the condition in the UK. Huge sample sizes would be required to do so with any precision. Instead, researchers typically report the prevalence calculated as the number of cases known to local service providers divided by the total local population as enumerated in the census. The underlying assumption is that all of those with early onset dementia seek help early in the disease course. Given that this will not always be the case, there will be a general tendency for such studies to underestimate the true prevalence of dementia.

Two studies of this type were considered eligible (Table 2.4), one carried out in Cambridgeshire (Ratnavalli et al 2002), and the other in four London boroughs (Harvey et al 2003). In the London study, 50% of cases were reconfirmed by independent research diagnostic interview. Four studies were excluded; two provided incidence rates (McGonigal et al 1993) or rate ratios only (Whalley et al 1995), one the prevalence of AD subtype only (Newens 1993), and the other did not calculate population prevalence (Woodburn and Johnstone 1999).

For the London study the prevalence of early onset dementia is given by gender and in five-year age bands. Findings are summarised in Figure 2.3. The prevalence for all those aged 45 to 64 was for males 120/100,000 in London and 101/10,000 in Cambridgeshire; and for females 77/100,000 in London and 61/100,000 in Cambridgeshire. There was thus a clear general tendency, in late middle age, for the prevalence of early onset dementia to be higher among men than among women. As with late onset dementia, the prevalence of dementia increases exponentially with increasing age.

The means of the prevalences from the expert consensus group for early onset dementia are given in Table 2.5.

For early onset dementia, as with late onset dementia, the consensus was that prevalence increased exponentially with increasing age, roughly doubling every five years. However, there is a discontinuity in this smooth exponential increase, in that the early onset prevalence for those aged 60–64 years is 156/100,000, or 0.16%, whereas the late onset prevalence for the next five-year age band (those aged 65–69) was 1.3%, nearly nine times higher. This may be artificial, arising from the underestimation of population prevalence in the early onset studies because of their method of ascertaining cases from service contact only.

Table 2.4 Population-based studies of the prevalence of early onset dementia

Study	*Setting*	*Total population*	*Case ascertainment*	*Outcome*	*Subtype*
Harvey et al (2003)	London Boroughs: Kensington and Chelsea, Westminster, Hillingdon	Base population: 240,766 aged 30–64 Dementia cases: 130	1. All local GPs, psychiatrists, old age psychiatrists, neurologists, geriatricians 2. Social services, voluntary organisations, community care facilities 3. Hospital information systems	DSM IV dementia	AD (NINCDS/ADRDA), VaD (NINDS/AIREN), dementia with Lewy bodies, frontotemporal dementia, alcohol related dementia, other
Ratnavalli et al (2002)	Cambridge City, East and South Cambridgeshire	Base population: 72,815 aged 45–64 Dementia cases: 108	1. all GPs, psychiatrists, clinical psychology, 2. Community care teams, nursing homes, voluntary services 3. Hospital-based specialist dementia services, inpatient hospital records	DSM IV dementia	AD (NINCDS/ADRDA), VaD (NINDS/AIREN), dementia with Lewy bodies, frontotemporal dementia, alcoholic dementia, Parkinson's dementia, progressive supranuclear palsy, multisystems atrophy.

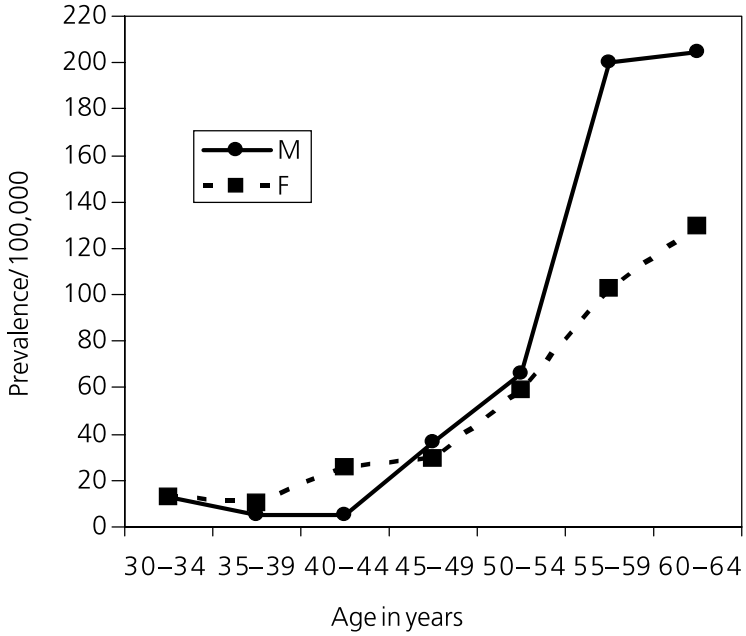


Figure 2.3 The prevalence of early onset dementia in London
Source: Harvey et al (2003)

Table 2.5 The consensus estimates of the population prevalence (per 100,000) of early onset dementia

Age in years	*F*	*M*	*Total*
30–34	9.5	8.9	9.4
35–39	9.3	6.3	7.7
40–44	19.6	8.1	14.0
45–49	27.3	31.8	30.4
50–54	55.1	62.7	58.3
55–59	97.1	179.5	136.8
60–64	118.0	198.9	155.7
45–64	66.2	99.5	84.7

The prevalence of dementia among those living in care homes

We could only identify three studies specifically examining the prevalence of dementia among those living in UK care homes (Table 2.6). One gave the prevalence of dementia among the subgroup of the 571 MRC CFAS study participants living in institutions at the time of interview (Matthews and Dening 2002), another was a survey of a representative sample of 'non-EMI' (elderly mentally infirm) nursing homes in the South Thames region (Macdonald et al 2002), and the third a survey of diagnoses upon admission of all residents of BUPA care homes in the UK (Bowman et al 2004). The MRC CFAS was a one-phase survey using GMS/AGECAT to generate dementia diagnosis. Four studies were excluded because they did not provide a clinical dementia diagnostic outcome, only assessing cognitive impairment or behavioural disturbance (Jagger et al 1997, Challis et al 2000, Netten et al 2001, Margallo-Lana et al, 2001).

In MRC CFAS the prevalence of dementia among those living in care homes did not vary appreciably by age or gender, being 50% for those aged 65–74, 58% for those aged 75–84

Table 2.6 Studies of the prevalence of dementia in care homes

Study	*Setting*	*Total population*	*Case ascertainment*	*Outcome*
Matthews and Dening (2002)	All MRC CFAS participants (aged 65 and over) living in institutional care establishments in the five catchment area sites (Cambridgeshire, Gwynedd, Newcastle, Nottingham, Oxford)	571	Two phase survey; screening using GMS/AGECAT organicity, MMSE and age to screen, and definitive diagnosis using GMS/AGECAT	GMS/AGECAT
Macdonald et al (2002)	Probability sample of non-EMI nursing homes in south-east England and probability sample of residents	445 (phase 1) 61 (phase 2)	Two phase survey; screening using MMSE and definitive diagnosis using GMS/AGECAT	GMS/AGECAT
Bowman et al (2004)	All 224 residential and nursing homes in BUPA's UK portfolio	15,483	Census form distributed to care home staff	'AD or other dementia' listed among reasons for admission

years and 56% for those aged 85 and over. There were non-significant differences in the prevalence according to care home setting: 72% in nursing homes, 51% in council residential care and 58% in private residential care. The prevalence of dementia in the nursing homes in SE England was 74%. The prevalence of recorded diagnoses in the BUPA census was 31% in residential care, and 38% in nursing homes, probably reflecting low levels of staff awareness (given that unlike the other two studies there was no direct evaluation of the residents).

Given the limitations of the evidence base, we asked the consensus group only to provide estimates for late onset dementia among residents of institutions in the UK. These are given in Table 2.7. The consensus group also generated estimates of the prevalence of dementia among all those aged 65 years and over living in EMI homes (79.9%), nursing homes (66.2%) and residential care homes (50.1%).

Table 2.7 The consensus estimates of the prevalence (%) of late onset dementia among residents of care homes

Age in years	*F*	*M*	*Total*
65–69	59.9	56.1	55.1
70–74	59.9	55.4	55.4
75–79	62.9	55.7	57.9
80–84	66.1	56.9	61.6
85–89	65.9	62.7	62.9
90–94	66.9	64.3	63.9
95+	67.6	62.9	66.4

The severity of dementia

Three of the six population-based studies of late onset dementia included information about dementia severity (O'Connor et al 1989, Brayne and Calloway 1989, Clarke et al 1991). These used CAMDEX severity ratings, incorporating information on cognitive decline, change in activities and interests, social behaviour and personality. These provide limited data on severity by age, but not by gender. None of the studies of early onset dementia, or of dementia in institutions, include estimates of prevalence by severity. For the consensus estimates we defined severity according to three levels *Mild, Moderate* and *Severe*. These descriptors are used both in the CAMDEX and CDR severity classifications, and can be considered to be roughly equivalent across the two systems. The CAMDEX *minimal dementia* rating has been shown to be equivalent to that of *questionable dementia* in the CDR system and was therefore excluded.

Given the limitations of the evidence base, we asked only our consensus group to estimate proportions of late onset dementia that could be considered to be mild, moderate and severe. The consensus was that the proportion considered to have severe dementia increased from 6.2% at 65–69 years to 24.2% for those aged 95 years and over (Figure 2.4).

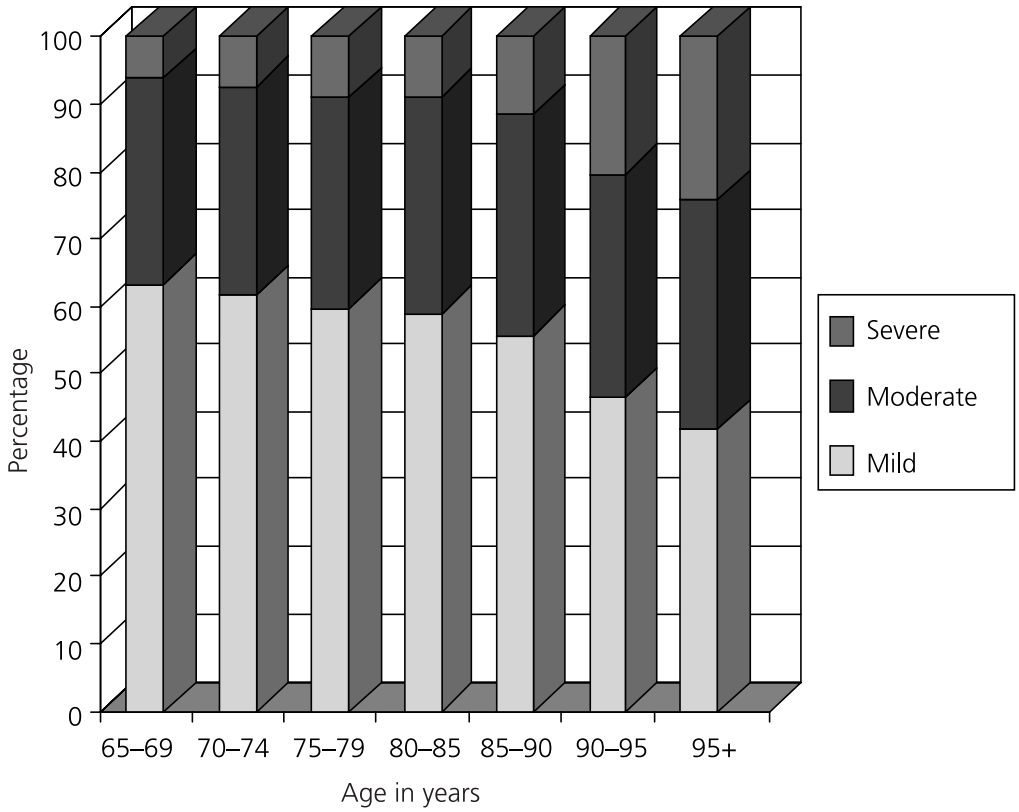


Figure 2.4 The consensus of the proportion (%) of cases of dementia in the population that are mild, moderate and severe

Dementia subtypes

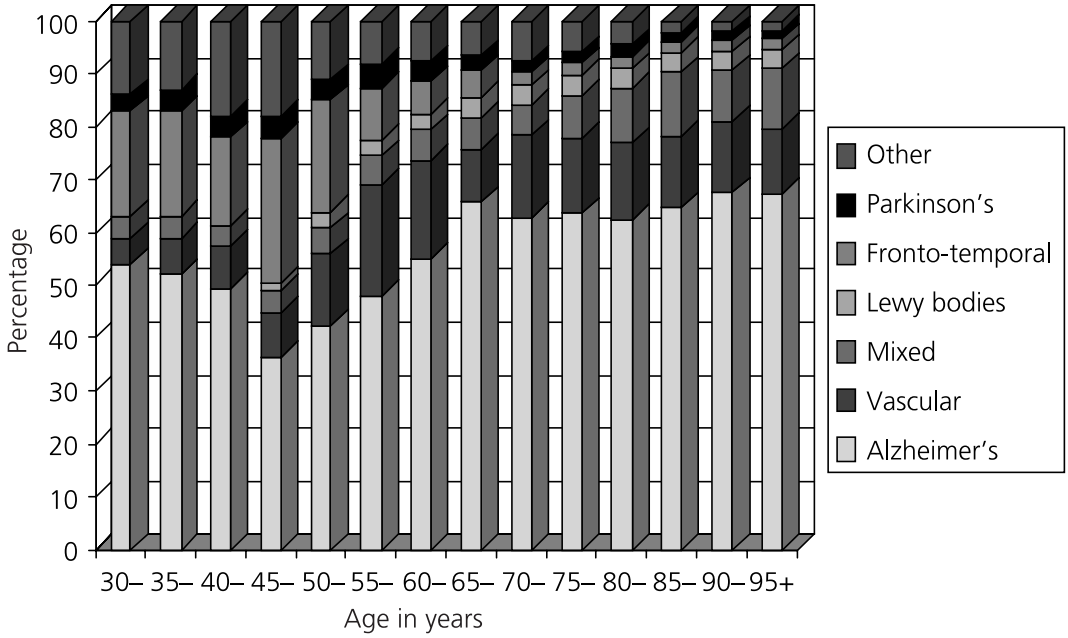
Three of the six population-based studies of late onset dementia included information on subtype diagnoses (O'Connor et al 1989, Brayne and Calloway 1989, Clarke et al 1991). These were carried out in the late 1980s or early 1990s and hence were restricted to Alzheimer's disease, vascular or mixed dementia and 'other'. Only the EURODEM meta-

analysis of studies in the 1990s provided gender- as well as age-specific proportions with AD and VaD. In that study, while the proportion with AD among females remained constant at around 70% across the age range from 65 to 90 and over, among men the proportion increased progressively from 38% among those aged 65–69 to 80% in those over 90 years of age. Only the more recent Islington study (Stevens et al 2002), excluded from the evidence base for overall dementia prevalence, provided information on the relative frequency of a wider range of subtypes: AD (41%), VaD (32%), dementia in Parkinson's disease (3%), frontotemporal dementia (3%) and dementia with Lewy bodies (8%); however, these proportions were only provided for all ages and both genders combined. Both early onset dementia studies included detailed information on the full range of dementia subtypes, based upon specialist dementia clinic work ups (Ratnavalli et al 2002, Harvey et al 2003). Two further studies (McGonigal et al 1993, Newens et al 1991), excluded from the evidence base for overall dementia prevalence, provided limited information on the relative frequency of AD, VaD and mixed dementia. None of the studies of dementia in institutions included information on dementia subtype diagnosis.

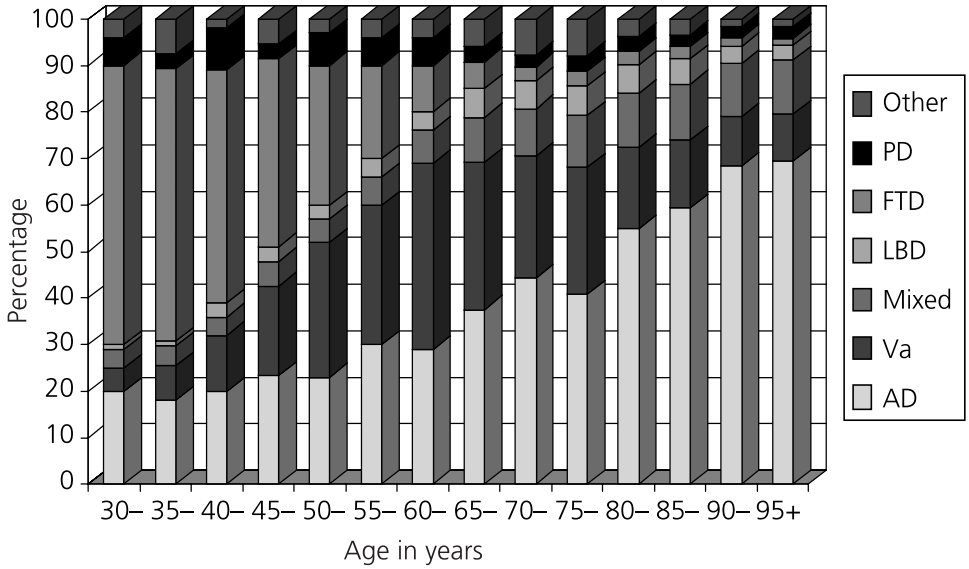
Estimates of the proportion of dementia cases attributable to different subtypes need to be interpreted with some caution. Clinico-pathological correlational studies examine the agreement between the diagnosis made in life, and the pathology evident in the brain post-mortem. These have tended to indicate that mixed pathologies are much more common than 'pure' – this is particularly true for Alzheimer's disease and vascular dementia, and AD and dementia with Lewy bodies (DLB) (Neuropathology Group of the Medical Research Council Cognitive Function and Ageing Study 2001). In one large case series of over 1000 post-mortems (Jellinger 2006), while 86% of all those with dementia had AD related pathology, only 43% had pure AD. 26% had mixed AD and cerebrovascular pathology and 10% had AD with cortical Lewy bodies. Findings were similar for those who had been given a clinical diagnosis of AD. 'Pure' vascular dementia was comparatively rare (7.3%). Uncommon subtypes of dementia – frontotemporal dementia, Creuzfeldt-Jakob and Huntington's disease – tended to be misdiagnosed in life as AD.

It is difficult, particularly in community-based epidemiological studies, to gather all of the necessary information for accurate subtype diagnosis. Even then, the evidence from neuro-pathological studies challenges the notion that individuals with dementia can be neatly categorised into particular discrete subtypes. Therefore, the consensus estimates of the proportion of cases accounted for by Alzheimer's disease, vascular dementia, mixed dementia, dementia with Lewy bodies, Parkinson's dementia, frontotemporal dementia and other dementias are perhaps best seen merely as tentative estimates of the relative prominence of these different pathologies, in men and women with dementia, at different ages (Figure 2.5a and b).

a) Women



b) Men



Figures 2.5a and 2.5b The consensus estimates of the proportion of all dementia cases accounted for by different dementia subtypes, by age and gender

2.4 Limitations

Some limitations to these estimates should be noted.

The population-based studies that inform the estimates of population prevalence were carried out between 1986 and 1993. No new epidemiological studies of the prevalence of dementia have been carried out in the UK over the last 15 years. We cannot be certain that the age- and gender-specific prevalence rates derived from these studies would have remained stable over time. Changes in incidence (perhaps linked to improvements in diet and cardiovascular health) and survival with dementia (improved medical and social care) are both possible.

Prevalence estimates derived from surveys sampling from relatively small catchment area sites may not be generalisable to the whole of the UK. Against this, there is marked consistency in reported prevalence across the studies, and between the UK and other European studies that are included in the EURODEM meta-analyses.

All UK studies have reported the population prevalence for dementia, including those living in institutions and those living in the community. The density of institutions within the particular catchment areas studied will have an impact on overall population prevalence. Relatively few studies provided information on dementia severity and there is an indication that compared to census data, people within care facilities are under represented in those studies. This may have led to an underestimate of the proportion of people living with more severe, relative to mild and moderate dementia. While there are separate estimates of the prevalence of dementia within institutions, there are no estimates of the prevalence of dementia among those living in the community.

Studies of early onset dementia are limited to those that derive the numerator for the prevalence estimate from those in contact with local services. This is likely to have led to an underestimate of prevalence and numbers affected in the age range 30–64 years. There is an indication that ascertainment of numbers of those with dementia and learning difficulties may have been particularly inefficient.

There are very few studies of the prevalence of dementia in care homes. The limited sampling frames mean that we cannot be confident that estimates derived from these studies will generalise to the institutional settings in the UK as a whole. There is limited information on the prevalence of dementia in different levels of care (residential care, nursing home and EMI) and none of the studies focus specifically upon NHS continuing care facilities. Again, there are no recent studies of dementia prevalence in care homes. Changes in care provision and in criteria for banding may well have led to changes in prevalence over time.

There is very limited information available from representative population-based studies regarding the use of health and social services by people with dementia, and their informal care. Again, these parameters would be expected to change over time given changes in policy, legislation and level of provision.

2.5 Conclusions

We have successfully generated expert consensus estimates of dementia prevalence based on a systematic review of the whole relevant research evidence base. We have allowed more precisely than before for the effects of age and gender on prevalence. We have extended the evidence-based estimation of numbers of people with dementia to include early onset cases and enabled the estimation of the numbers of people with dementia living in care homes, and in the community.

CHAPTER 3

Number of people with dementia in the UK

Overview

- The prevalence figures described in the previous chapter were applied to UK population estimates to produce estimates of the numbers of people with dementia in the UK.
- We estimate that there are now 683,597 people with dementia in the UK. This represents one person in every 88 (1.1%) of the entire UK population.
- Numbers of people with dementia in the UK are forecast to increase to 940,110 by 2021 and 1,735,087 by 2051, an increase of 38% over the next 15 years and 154% over the next 45 years.
- Further estimates are given for the numbers of people with young and late onset dementia; different subtypes of dementia; levels of severity of dementia and differences between genders.
- We estimate that 424,378 people with late onset dementia (63.5%) live in private households in the community, whereas 244,185 (36.5%) live in some form of institutional care setting.
- The methodology used to make these estimates is described and discussed.

3.1 Calculation methods

The prevalence figures described in the previous chapter were applied to estimates of population numbers for the UK. Mid-year population estimates for 2005 were obtained from the National Statistics website for England and Wales (www.statistics.gov.uk), the Scottish census results website (www.scrol.gov.uk) and the Northern Ireland census data site (www.nisranew.nisra.gov.uk). Separate estimates were obtained for men and women, for the age bands specified in the consensus exercise, and for those from Black and minority ethnic groups.

Applying the first set of prevalence estimates (for all people with dementia) to these figures gave us the total number of people with dementia.

Separate prevalence estimates were made for people living in care homes (by age group and gender). These estimates were applied to the numbers of people (again by age group and gender) living in care homes. These data were obtained from the NOMIS website for England and Wales which gives official labour market statistics (www.nomisweb.co.uk) and the aforementioned website for Scottish census data. These numbers were then adjusted to reflect the increase in population between 2001 and 2005. The proportion of people with dementia living in care homes could then be computed, and this proportion was applied to the total number of people with dementia in Northern Ireland in order to estimate the numbers in care homes in that country (care home numbers were not available at the time of the analysis for Northern Ireland).

The number of people with dementia living in care homes was subtracted from the total number in the population to estimate the number living in the community, and the associated age- and gender-specific prevalence of dementia in the community-dwelling population. These prevalences were applied to each local authority (or equivalent) area in England, Wales, Scotland and NI and added to the number of people with dementia living in care homes for each area. This allows us to examine local variations taking into account age differences as well as differences in the supply of care home places.

It should be noted that there is some uncertainty regarding the total numbers of persons living in supported accommodation. The census returns (care home residents in 2005) should, in principle, provide an accurate estimate. However, the Laing and Buisson market survey database (Laing and Buisson Publications 2005) suggests higher numbers. Assuming 91.1% occupancy, they calculated 477,315 residents in all, of whom 108,646 lived in EMI homes and 368,669 in non-EMI homes.

Projections of numbers of people with dementia were made by applying the population prevalence rates to projected population estimates for the years 2005 through to 2051. The latter were obtained from the Government Actuary's Department (www.gad.gov.uk).

3.2 Number of people with dementia in the UK

We estimate that there are now 683,597 people with dementia in the UK. This represents one in every 88 (1.1%) of the entire UK population.

Eighty-four per cent of those with dementia live in England, 8% in Scotland, 5% in Wales and 2% in Northern Ireland (see Figure 3.1, p. 24).

3.3 Projected increases in the number of people with dementia in the UK

The number of people with dementia in the UK is forecast to increase to 940,110 by 2021 and 1,735,087 by 2051, an increase of 38% over the next 15 years and 154% over the next 45 years.

Rates of increase in the number of people with dementia are not symmetrical across the range of ages of those affected. Since we have assumed that the age- and gender-specific prevalence of dementia will not vary over time, the projected increases are driven entirely by demographic ageing, that is the relatively large increase in the numbers of older people, who are most at risk from dementia. This effect is illustrated in Figure 3.2. The increases

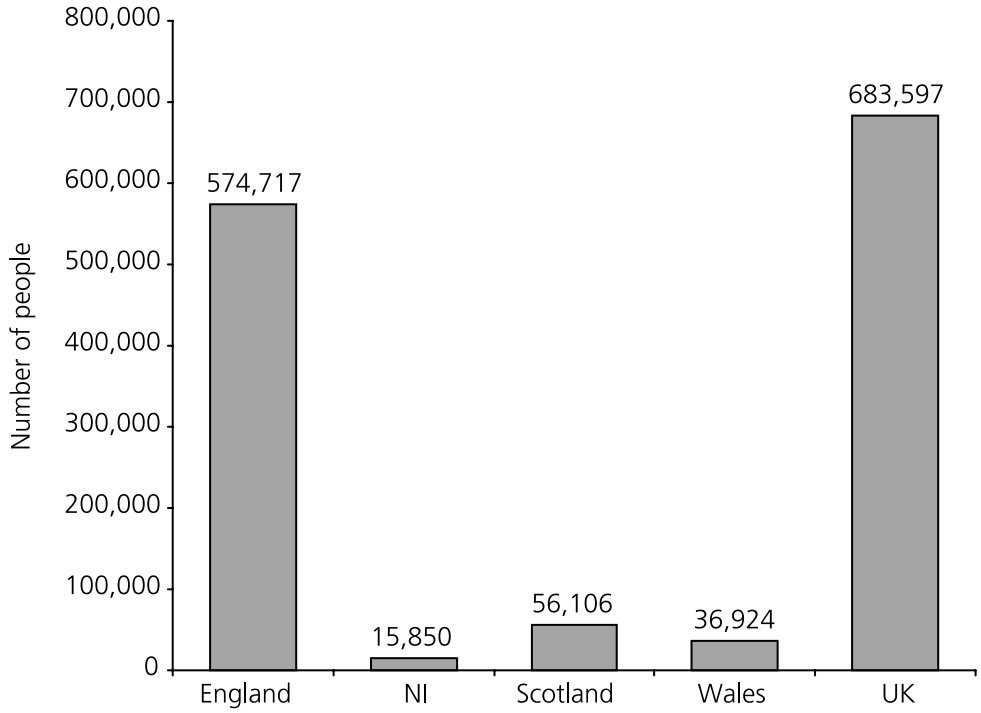


Figure 3.1 Number of people in the UK with dementia (2005)

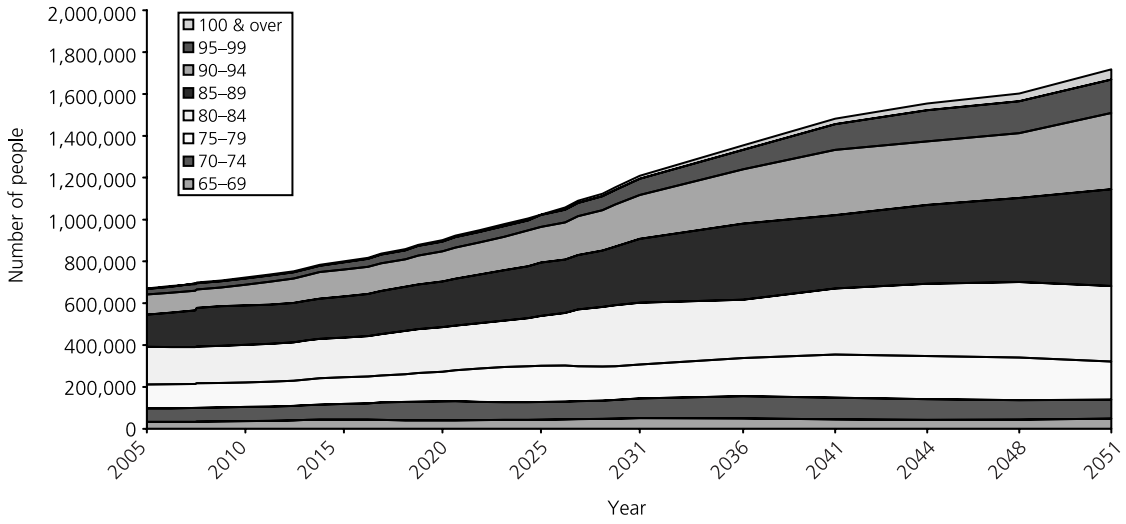


Figure 3.2 Projected increases in the number of people with dementia in the UK, by age group (2005–2051)

in the numbers of people with dementia under 80 years of age will be relatively small. Numbers of people with early onset dementia are projected to remain relatively stable over time (see pp. 27–8).

Numbers of men and women with dementia are projected to increase at a similar rate (see Figure 3.3).

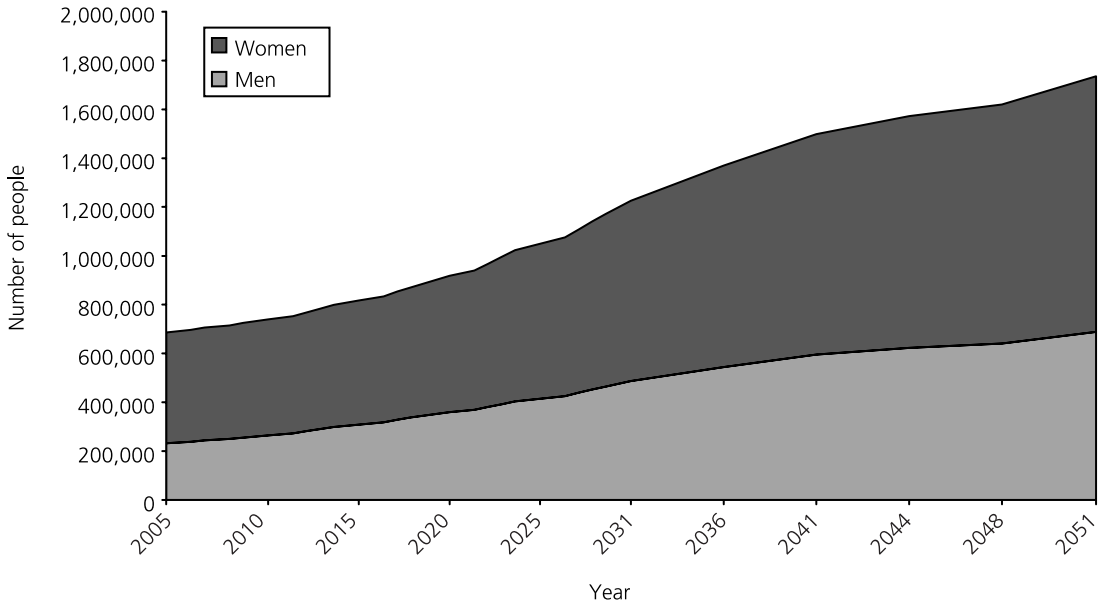


Figure 3.3 Projected increases in the number of people with dementia in the UK, by gender (2005–2051)

3.4 Regional variation

We have estimated the numbers of people with dementia for each local authority, primary care trust (or equivalent) and parliamentary constituency. Detailed results are provided in an appendix published separately to this report.

Figure 3.4 summarises the regional variation in the prevalence of dementia, by local authority. We have chosen to display variation in the whole population prevalence of dementia (1.1% for the whole of the UK) as this serves to illustrate the impact both of different age distributions and different densities of institutions (residential care and nursing homes) on the relative frequency of people with dementia within each local authority. Local authorities with larger proportions of older inhabitants, and with a higher relative density of institutional places will tend to have a higher whole population prevalence of dementia.

Figure 3.4 indicates considerable variation in the whole population prevalence of dementia from 0.51% (Newham) to 2.09% (Torbay). In general, the whole population prevalence is higher in rural and coastal local authorities, and lower in urban and metropolitan authorities. This regional variation will have an impact upon the adequacy of local funding to meet the health and social care needs of people with dementia. Apart from the higher proportion of people with dementia, rural authorities with their dispersed populations may face increased costs and logistical difficulties in providing home-based care in the community.

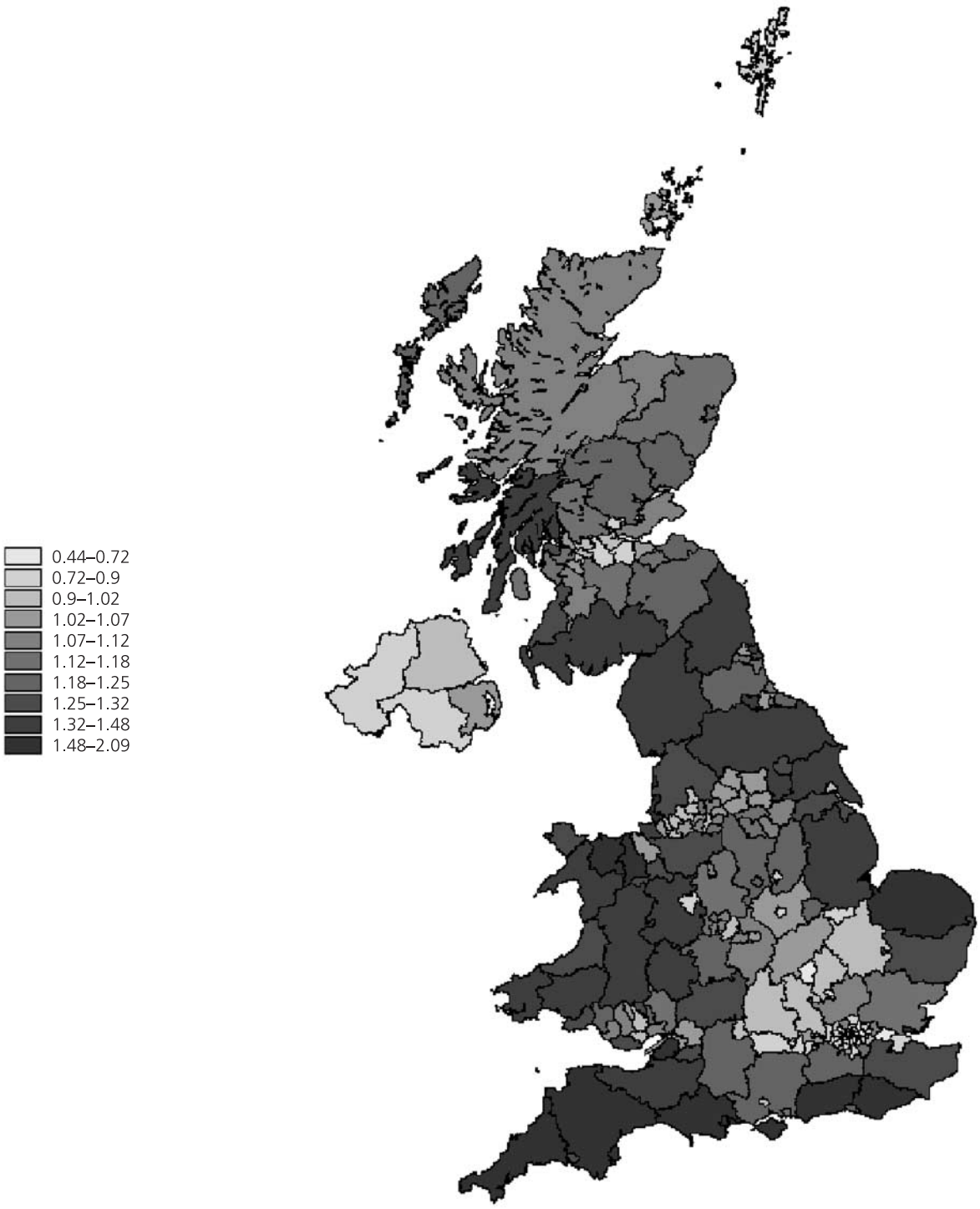


Figure 3.4 Regional variation in the prevalence of dementia by local authority

3.5 Early onset dementia

We estimate that there are now at least 15,034 people with early onset dementia (onset before the age of 65 years) in the UK. This is likely to be an underestimate by up to three times given that estimates are based on referrals of younger people to services which significantly underestimate the numbers.

Early onset dementia is comparatively rare, accounting for 2.2% of all people with dementia in the UK.

Eighty-three per cent of people with early onset dementia live in England, 9% in Scotland, 5% in Wales and 3% in Northern Ireland.

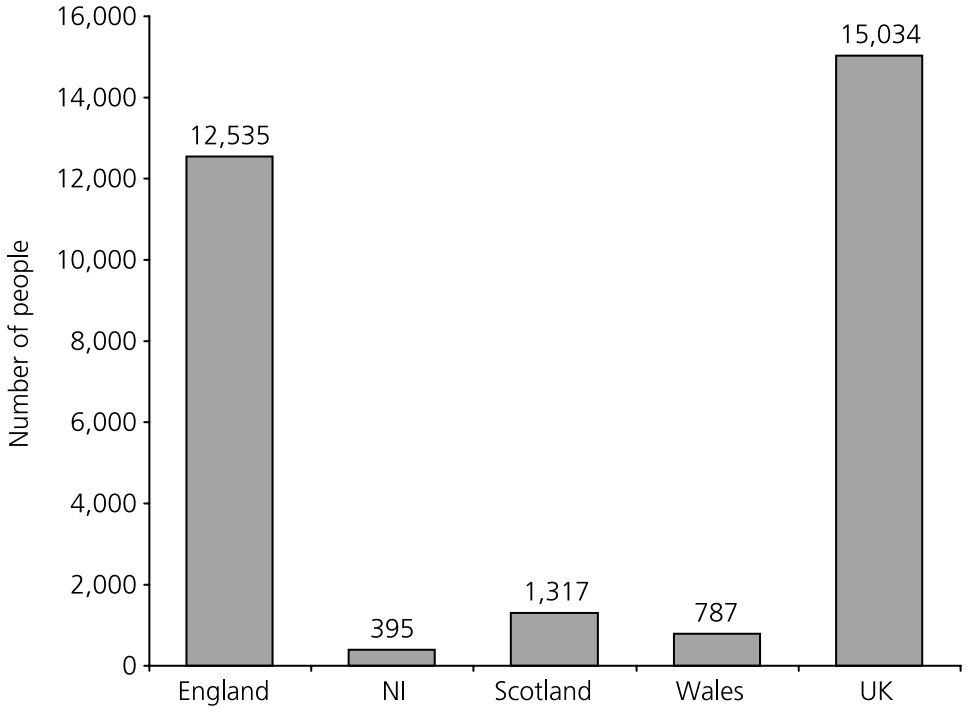


Figure 3.5 Number of people in the UK with early onset dementia (2005)

3.6 Projected increases in the number of people with early onset dementia

Numbers of people with early onset dementia in the UK will increase to 17,279 by 2021 and 17,584 by 2051, an increase of just 17% over the next 45 years.

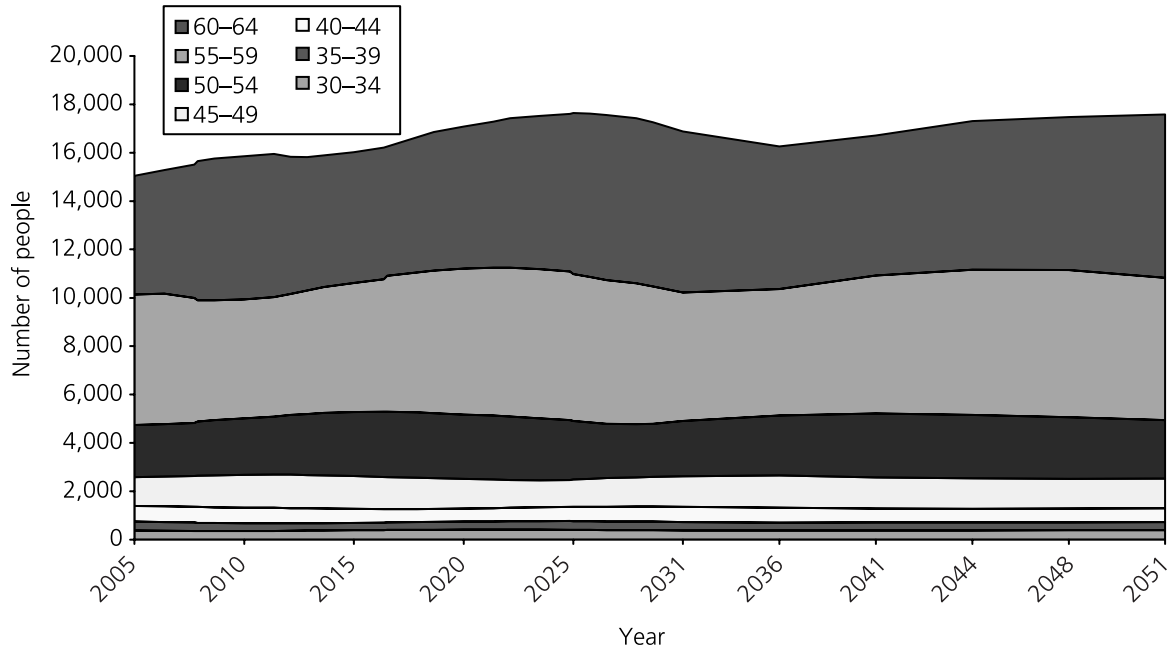


Figure 3.6 Projected increases in the number of people in the UK with early onset dementia, by age group (2005–2051)

3.7 Number of people with early onset dementia, by age and gender

The number of people with early onset dementia increases sharply with age. Two-thirds (68%) of all cases are aged 55 and over.

Among this larger middle-aged group of people with early onset dementia, males predominate over females with a M:F gender ratio of 1.7 to 1. Overall we estimate 8,771 men and 6,261 women in the UK have early onset dementia, a M:F gender ratio of 1.4 to 1.

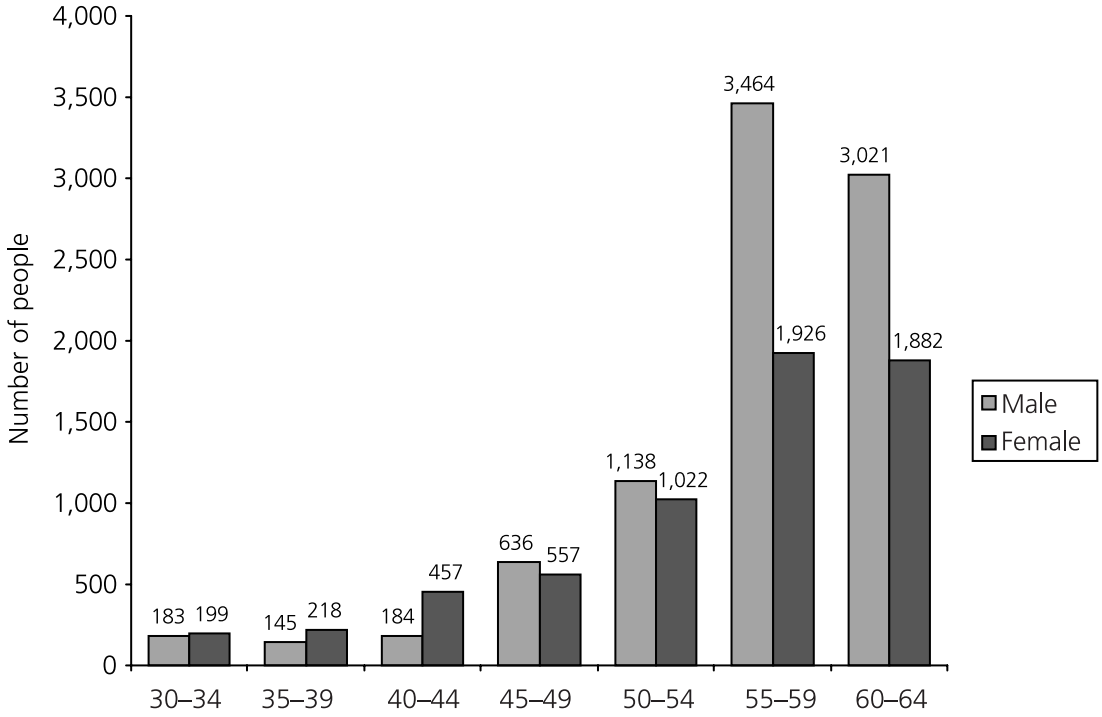


Figure 3.7 Number of people in the UK with early onset dementia by age and gender (2005)

3.8 Late onset dementia

We estimate that there are now 668,563 people with late onset dementia (onset after the age of 65 years) in the UK.

Late onset dementia accounts for 97.8% of all people with dementia in the UK.

Eighty-three per cent of people with late onset dementia live in England, 8% in Scotland, 5% in Wales and 2% in Northern Ireland.

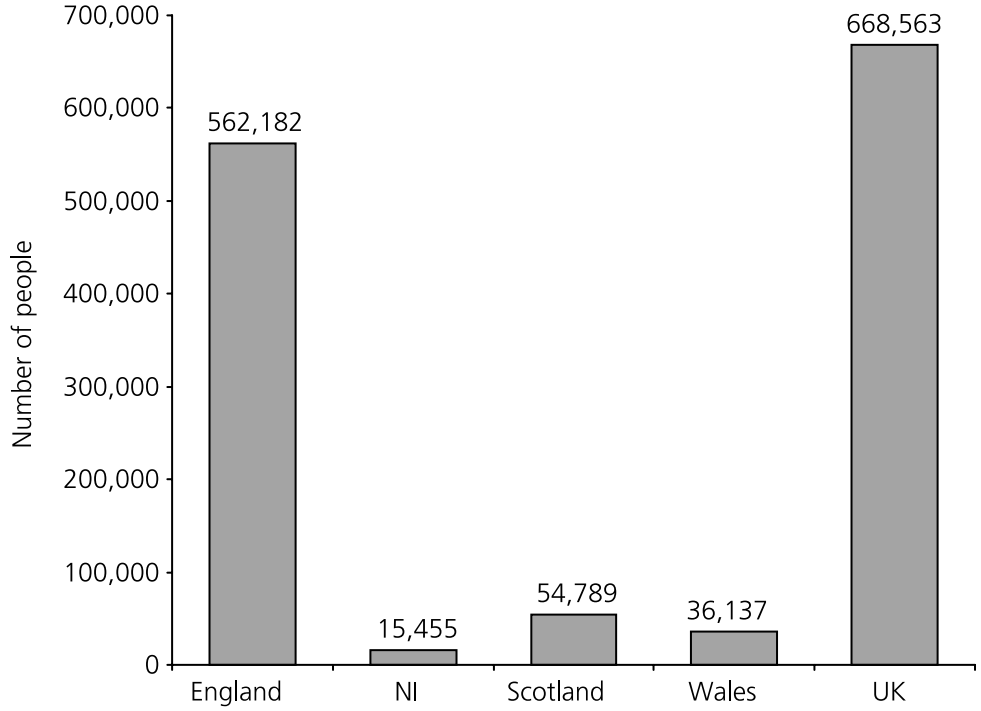


Figure 3.8 Number of people in the UK with late onset dementia (2005)

3.9 Projected increases in the number of people with late onset dementia

The number of people with late onset dementia in the UK will increase to 922,831 by 2021 and to 1,717,503 by 2051, an increase of 156% over the next 45 years.

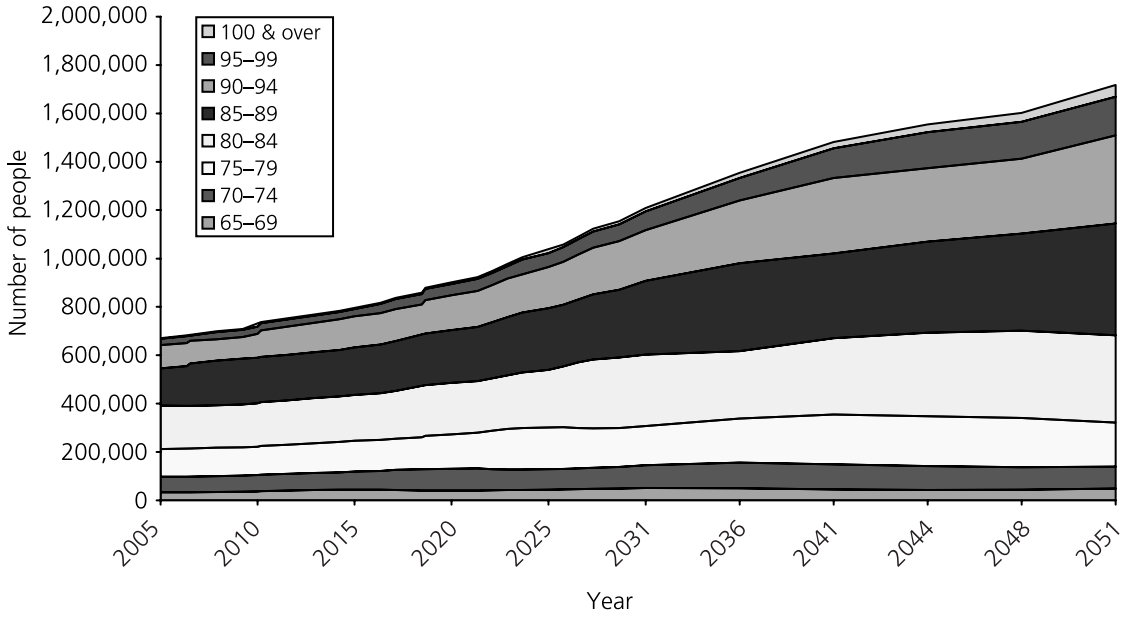


Figure 3.9 Projected increases in the number of people with late onset dementia in the UK (2005–2051)

3.10 Number of people with late onset dementia, by age and gender

The number of people with late onset dementia continues to rise for each five-year age band up to the age of 80–84. For both genders, numbers decline thereafter. The reason for this distribution is that while the age-specific prevalence (the proportion affected within each age band) was considered by the expert consensus panel to increase exponentially with increasing age, the number of people in these older age groups declines progressively because of increasing mortality. Despite this, two-thirds (68%) of all people with dementia are aged 80 and over, and one sixth (17%) aged 90 or over.

Overall we estimate that 222,925 men and 445,641 women have late onset dementia, approximately two women for every man affected. At older ages mortality is higher in men than in women. Both the higher mortality among men and the higher age-specific dementia prevalence in women contribute to the preponderance of women among the 'oldest-old' with dementia (see Figure 3.10). The male to female gender ratio is 1.4 to 1 at age 65–69 years, falling to 0.2 to 1 (five women for every man affected) for those aged 95 and over.

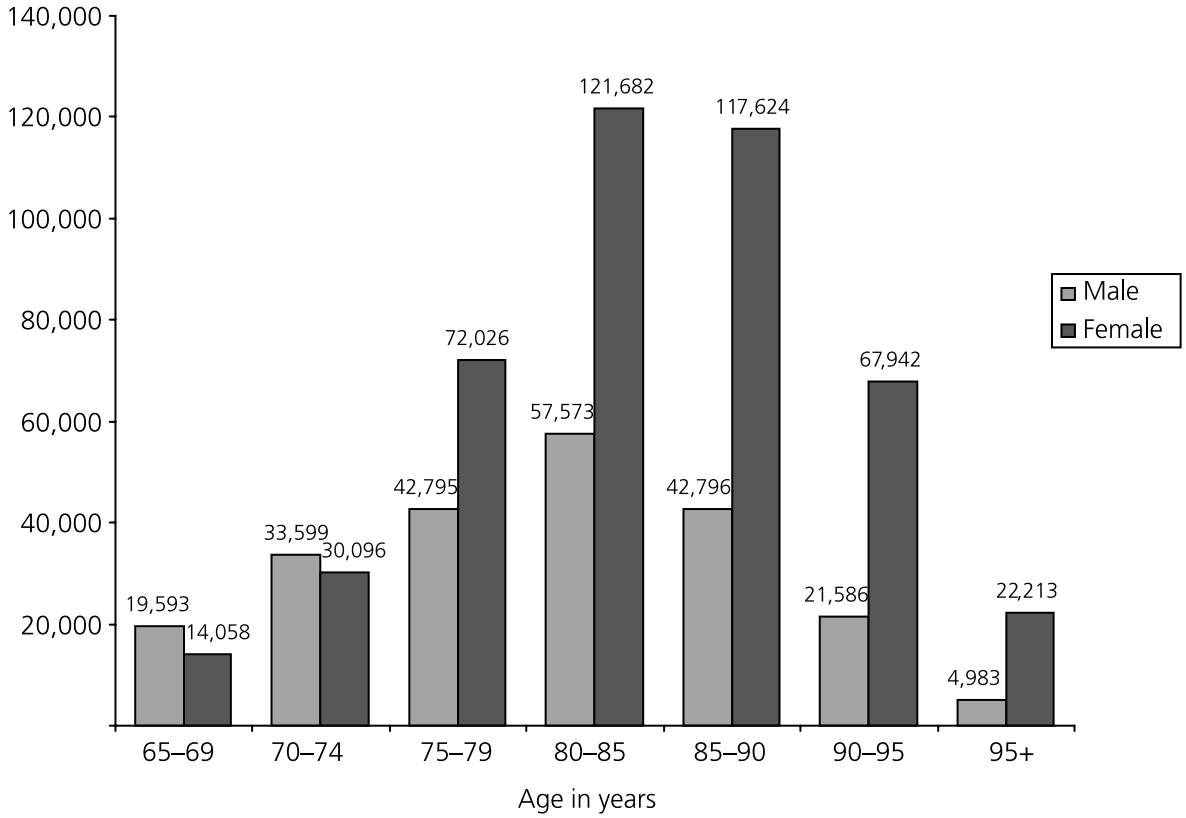


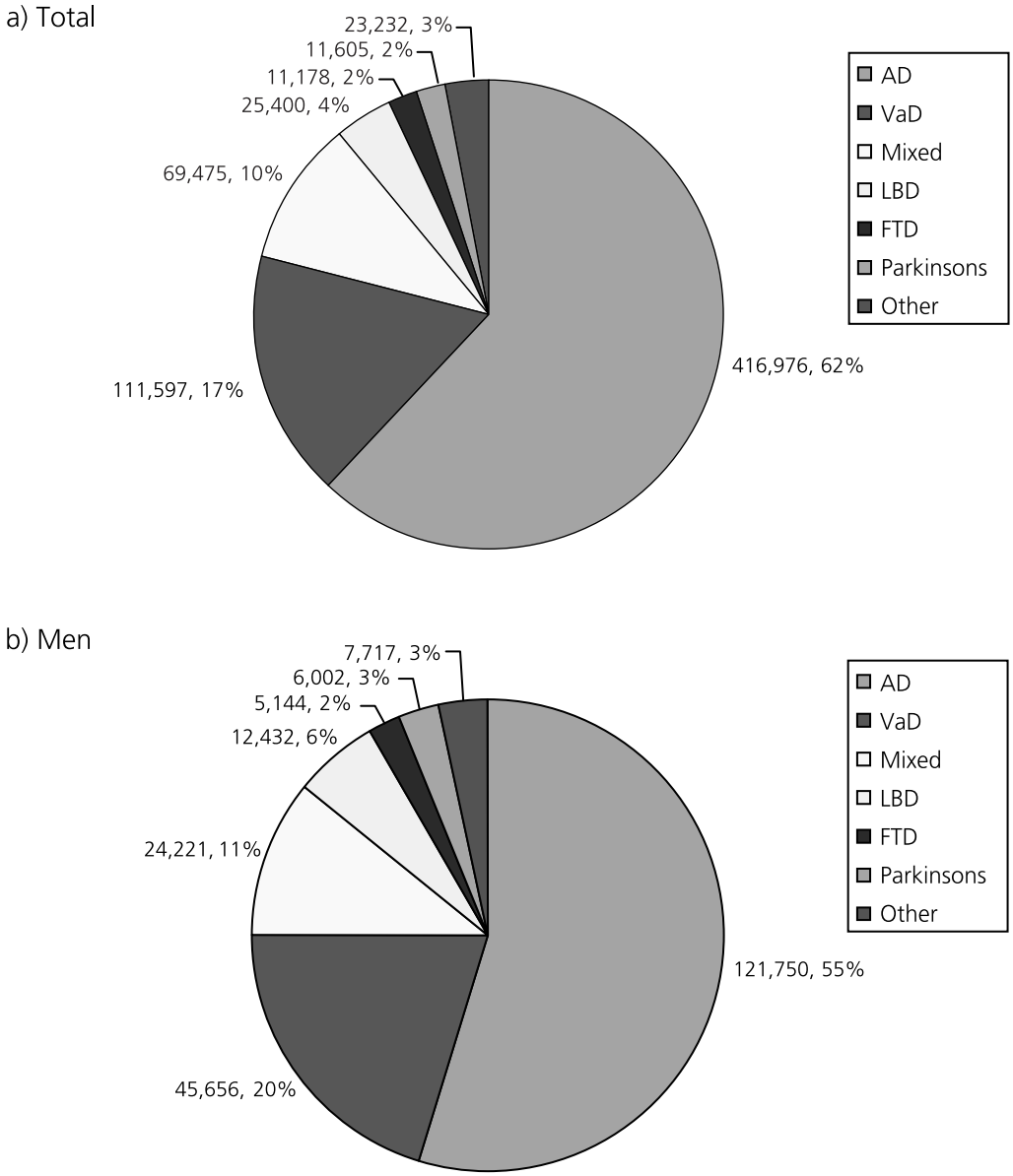
Figure 3.10 Number of people in the UK with late onset dementia by age and gender (2005)

3.11 Dementia subtype

We estimate that nearly two-thirds (62%) of all people with dementia in the UK, 416,967 in all, have Alzheimer's disease (AD), the most common form of dementia. The next most common subtypes are vascular dementia (VaD) and mixed (vascular dementia and

Alzheimer's disease) dementia, together accounting for over one quarter (27%) of all cases. In order of relative frequency dementia with Lewy bodies, frontotemporal dementia and Parkinson's dementia together account for 8% of all cases.

The distribution of subtypes is different in men and women; Alzheimer's disease is more common in women (67% in women compared with 55% in men), while vascular dementia and mixed dementias account for 31% of all cases in men and just 25% in women.



c) Women

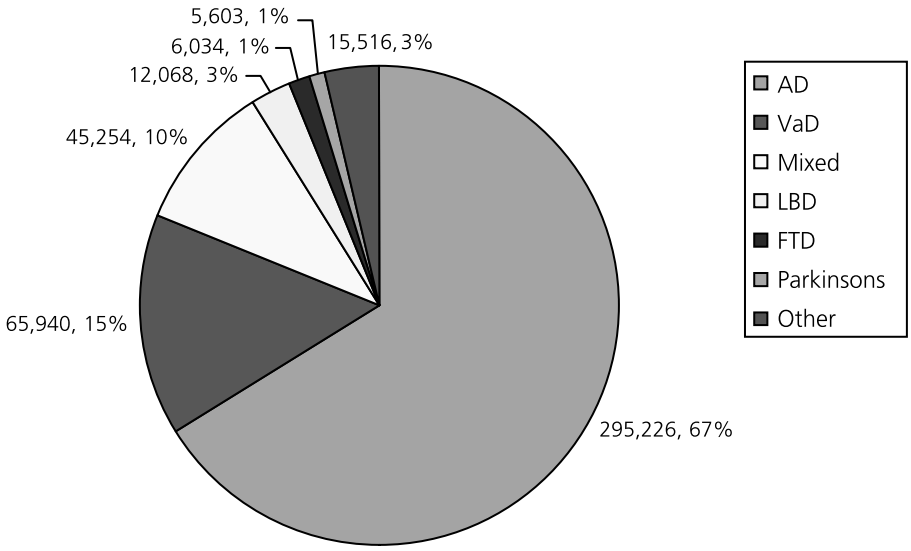


Figure 3.11a, b and c Number and percentage of people in the UK with dementia by subtype and gender

3.12 Severity of dementia

For those with late onset dementia, we estimate that 370,283 (55.4%) have mild dementia, 214,638 (32.1%) have moderate dementia and 83,801 (12.5%) have severe dementia. The proportion considered to have severe dementia increases with increasing age, from 6.3% for those aged 65 to 69 years to 23.3% for those aged 95 years and over.

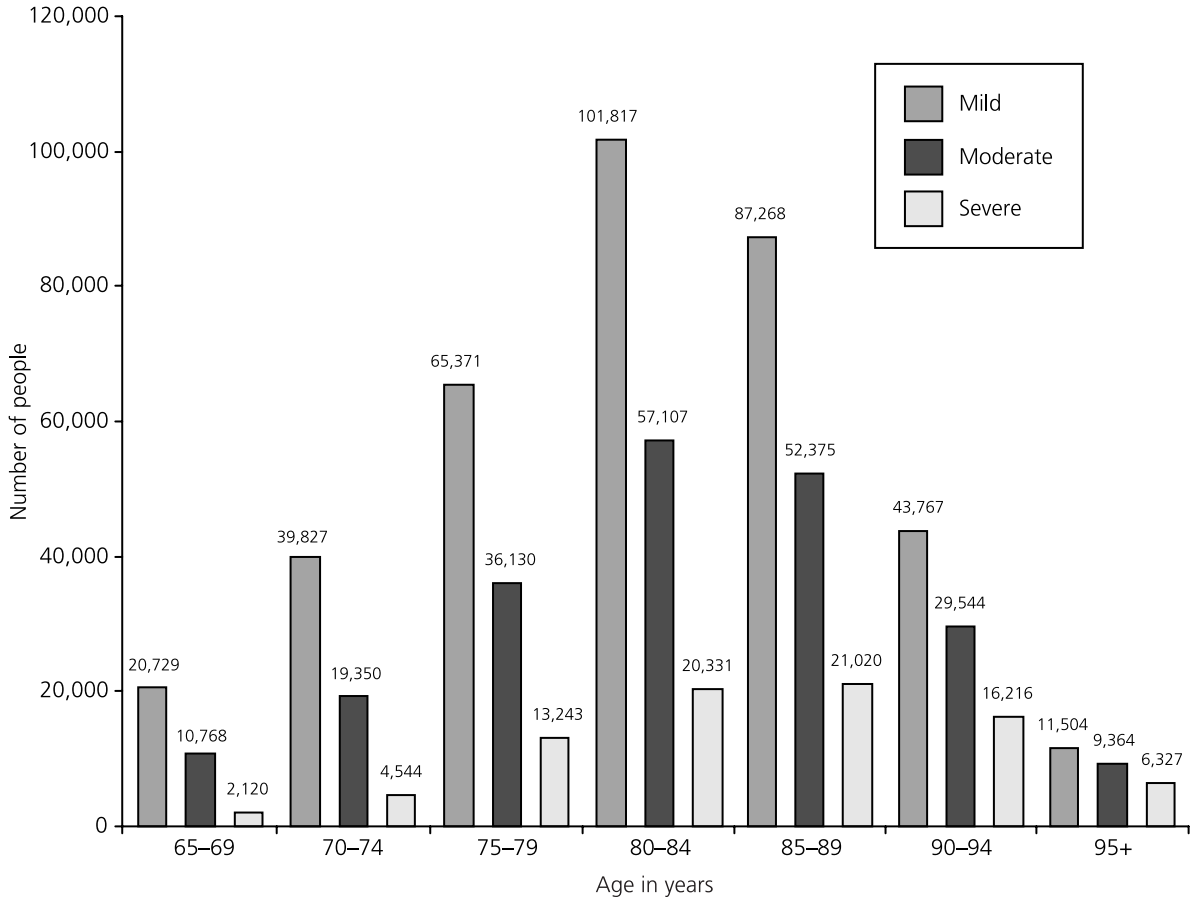


Figure 3.12 Number of people in UK with late onset dementia by level of severity and age group

3.13 Residential status

We estimate that 424,378 people with late onset dementia live in private households (the community), whereas 244,185 live in some form of care home. Overall, therefore, nearly two-thirds (63.5%) of people with dementia live in their own homes and just over one third (36.5%) live in a care home (Figure 3.13).

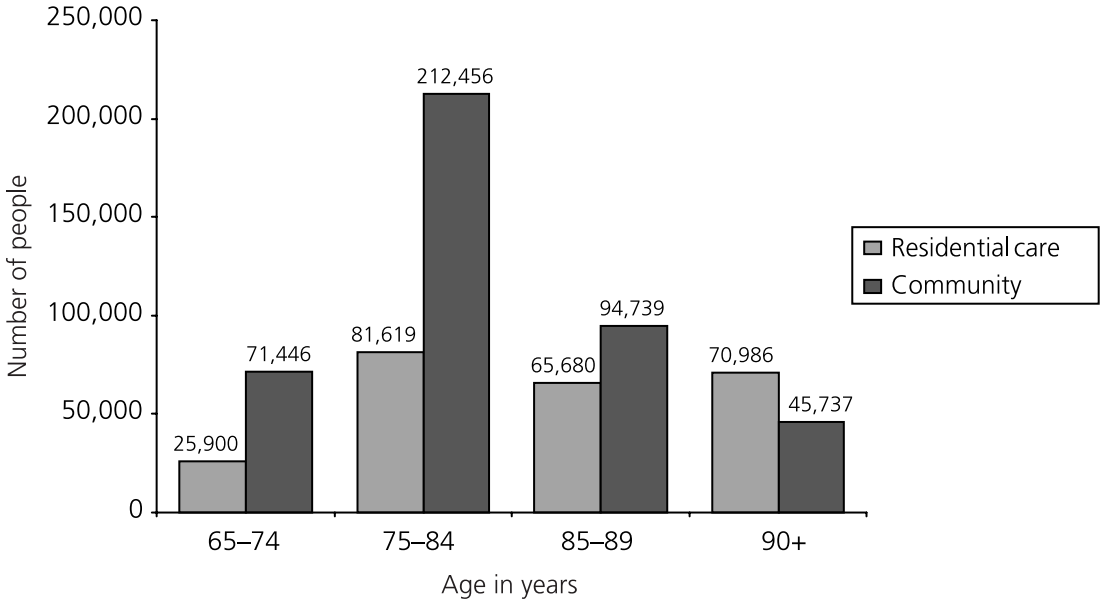


Figure 3.13 Number of people in the UK with late onset dementia living in residential care and in the community

The proportion of those with dementia living in care homes rises with age, from 26.6% of those aged 65–74, to 27.8% of those aged 75–84, to 40.9% of those aged 85–89, to 60.8% of those aged 90 and over. This is understandable in the context of

(a) the greater severity of dementia, in general, among the oldest old (see Figure 3.14), and

(b) the relative paucity of informal support among older people, who are more likely to have been widowed, and to have lost many of their friends through bereavement.

Given the importance of the topic, there has been surprisingly little research in the UK into factors predicting institutionalisation among people with dementia. One small longitudinal study found a 20-fold increased risk among those without a co-resident caregiver. The same study also found that people with behavioural and psychological symptoms of dementia were more likely to be placed in residential care (Banerjee et al 2003). A study in the Netherlands (de Vugt et al 2005) suggested that it was the caregiver response to behavioural symptoms, rather than the symptoms themselves that predicted the break-down of home-based care arrangements. The largest longitudinal study to date, from the USA (Yaffe et al 2002), found that patient-related factors (ethnicity, severity of cognitive impairment, disability and behavioural symptoms) and caregiver factors (older age and caregiver strain) were implicated.

It should be noted that our estimates of the total numbers of people with dementia living in care homes, and of the proportion living in these settings are substantially lower than a recently published estimate (Macdonald and Cooper 2006) of 368,000 older residents with dementia, accounting for 54% of all those with dementia. While Macdonald applies a slightly higher prevalence estimate for institutional care, the discrepancy arises mainly because of the larger number of institutional care residents suggested by the Laing and Buisson market report survey (Laing and Buisson Publications 2005) compared with the more conservative census figures used in this report.

3.14 Ethnicity

Table 3.1 summarises the estimated number of people from Black and minority ethnic groups (BME) with early onset and late onset dementia in 2004. We have no specific estimates of the prevalence of dementia in ethnic minority groups in the UK, and have therefore assumed that this would be the same as for the UK population as a whole. The total of 11,392 people from black and minority ethnic groups with dementia represents 1.7% of all people with dementia in the UK. It is noteworthy that 6.1% of all people with dementia among BME groups are early onset, compared with only 2.2% for the UK population as a whole.

Table 3.1 Number of people with early onset and late onset dementia from Black and minority ethnic groups

	Early onset	*Late onset*	*Total*
NI	2	43	45
Wales	10	185	195
England	699	10,693	11,392
Scotland	15	213	228
UK	726	11,134	11,860

There are as yet no accurate projections available for the future size of the BME population in the UK, by age and gender. We were, therefore, not able to calculate projected increases in the numbers of people with dementia within these groups. However, we can predict, with confidence, that the increases will be much larger in relative terms than for the UK population as a whole. The number of older people and the number of people with dementia will rise especially quickly in several minority ethnic groups as first generation migrants from the 1950s to the 1970s age into the age groups most at risk for dementia. Figure 3.14 (taken from ONS 2001 survey data) illustrates the current preponderance

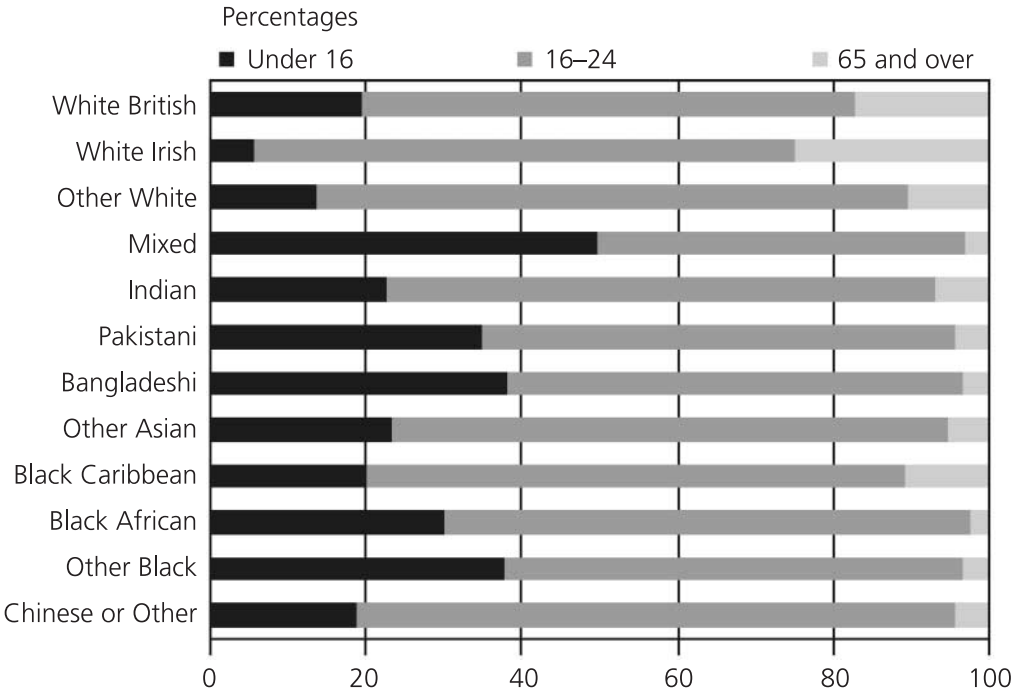


Figure 3.14 The age distribution of BME groups in the UK (2001 census)

of middle aged, compared with older aged persons among Indian, Black Caribbean Black African and Chinese minority ethnic groups.

3.15 Mortality

Dementia shortens the lives of those who develop the condition. One of the best studies in the field (Fitzpatrick et al 2005) estimated median survival with Alzheimer's disease at 7.1 years (95% confidence intervals, 6.7–7.5 years) and for vascular dementia 3.9 years (3.5–4.2 years). Evidently, there is much individual variability around these median estimates. The contribution of dementia to mortality is difficult to assess, as people with dementia often have one or more comorbid health conditions that may or may not be related to the dementia process, and which themselves may hasten death. Death certificates are acknowledged to be an imperfect source of information on dementia-related mortality. An alternative is to use a probabilistic approach, based upon empirical findings from epidemiological studies of the increased risk of mortality associated with dementia. The EURODEM incidence studies reported a constant relative risk of 2.38 up to age 89, declining to 1.80 in females and 1.60 in males over the age of 90. The population attributable risk fraction (PARF) is the proportion of the outcome (in this case death) that could be averted if the risk exposure (dementia) could be removed from the population. The PARF is calculated using the formula

$$PARF = p\,(RR - 1)/[p\,(RR - 1) + 1]$$

(where p is the population prevalence of dementia, and RR is the relative risk for mortality, as above)

for each age and gender stratum, and these proportions are then applied to the total number of deaths in England, Scotland and Wales within this age and gender group.

The findings from these analyses are summarised in Table 3.2. The proportion of deaths attributable to dementia increases steadily from 2% at age 65 to a peak of 18% at age 85–89 in men, and from 1% at age 65 to a peak of 23% at age 85–89 in women. Overall, 10% of deaths in men over 65 years, and 15% of deaths in women are attributable to

Table 3.2 Total deaths (England, Scotland and Wales) for 2005, and the proportion and number of deaths theoretically attributable to dementia

	Males			*Females*			*All*
Age group	*Total deaths (for the year 2005)*	*PARF (proportion of deaths attributed to dementia)*	*Number of deaths annually attributed to dementia*	*Total deaths (for the year 2005)*	*PARF (proportion of deaths attributed to dementia)*	*Number of deaths annually attributed to dementia*	*Number of deaths annually attributed to dementia*
65–69	23,993	0.02	487	16,492	0.01	224	711
70–74	33,369	0.03	896	24,322	0.03	811	1,707
75–79	43,826	0.07	2,934	38,911	0.08	3,158	6,092
80–84	49,648	0.12	6,179	57,101	0.15	8,799	14,978
85–89	34,325	0.18	6,335	54,495	0.23	12,736	19,071
90–94	19,494	0.14	2,735	46,408	0.19	8,813	11,548
95+	5,500	0.15	825	22,647	0.21	4,753	5,578
Total	210,155	0.10	20,391	260,376	0.15	39,294	59,685

dementia. If dementia were removed from the population 59,685 deaths annually among the over 65s may have been averted. The majority of these deaths occurred among those aged 80–95 years.

A more realistically achievable model would be one in which the onset of dementia might be delayed on average by 5 years, by a combination of improvements in public health (cardiovascular risk factor reduction and diet) and specific preventive treatments. This would halve the prevalence of dementia in each five year age band, and, in principle, halve the numbers of death attributed here to dementia – saving nearly 30,000 lives annually.

3.16 Research

There has been a steady growth, worldwide, in ISI listed publications relating to dementia, from a low base in the early 1980s to the near 7000 publications in 2004 (see Figure 3.15 below).

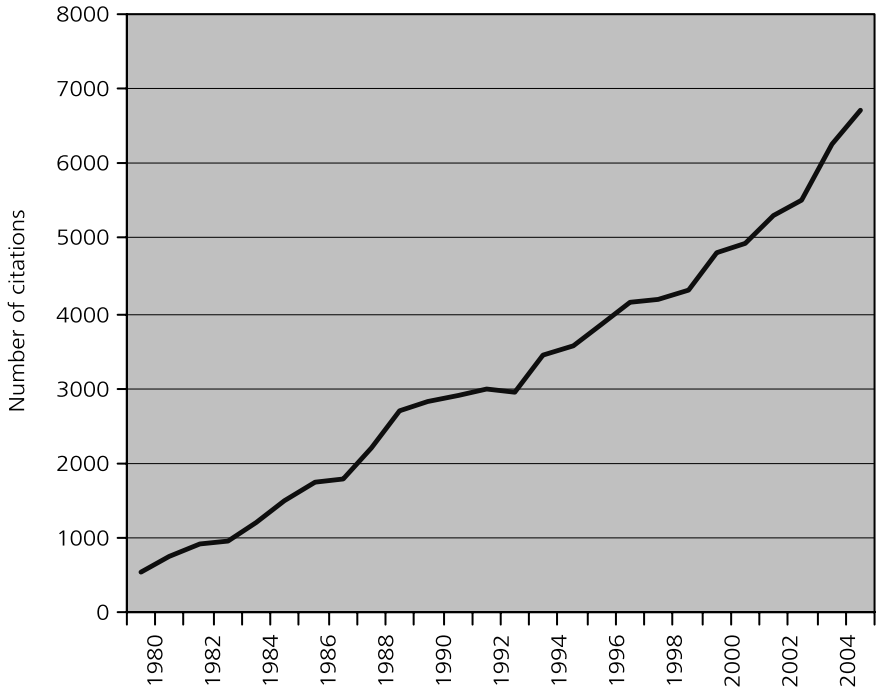


Figure 3.15 Growth in annual citations (worldwide) for publications relating to dementia

In the field of dementia research, UK biomedicine performs creditably well with respect to overseas-based research groups, particularly those in the USA, when the relative size of the countries' populations is taken into account (see Figure 3.16).

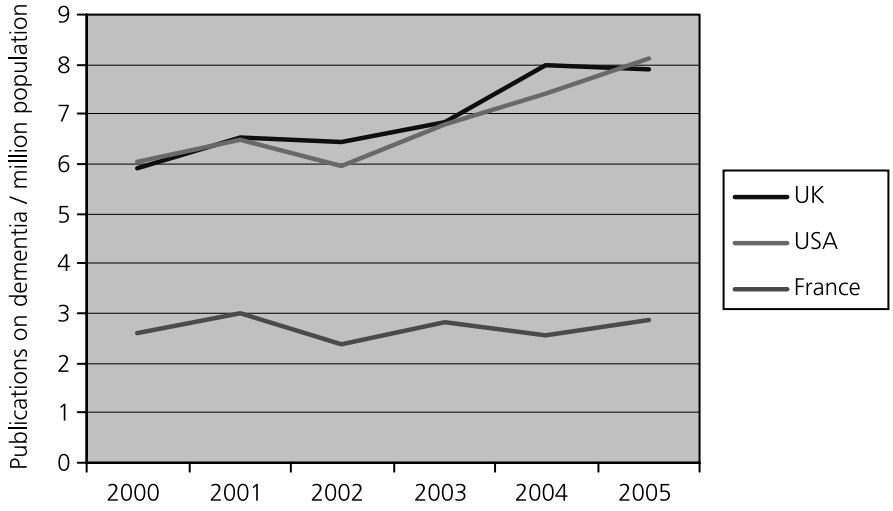


Figure 3.16 Number of publications on dementia per million people in the UK, USA and France

Funding for dementia research

Exact figures on research funding for dementia are difficult to come by. However, Professor Simon Lovestone (personal communication) recently made the following estimates, by contacting research funders and examining publicly available information on grant awards:

- Dementia-specific non-governmental organisations (the charitable sector) provide similar levels of support for dementia research in the UK and the USA. Thus the £1.5 million pounds per annum provided by the UK Alzheimer's Society, coupled with the £2 million provided by the Alzheimer's Research Trust (5.8 pence per UK citizen), compares favourably with the US$20 million per annum provided by the US Alzheimer's Association (3.7 pence per US citizen).
- Public funding for dementia research reveals gross disparities, with the National Institute of Health in the USA providing US$375 million in 1999 (66 pence per US citizen) compared with the average of £6.7m per annum granted by the UK Medical Research Council and £2.6m per annum provided by the Department of Health for the five years between 1997 and 2002 (a total of £9.3m per annum or 15 pence per UK citizen).

Recent initiatives give cause for optimism

- In 2006 the Department of Health announced the launch of seven new Local Research Networks in England (Dementias and Neurodegenerative Diseases Research Network – DeNDRoN) with £3 million per annum to coordinate and deliver research studies which focus on the prevention, diagnosis and treatment of Alzheimer's disease, Huntington's disease, Parkinson's disease and motor neurone disease. The new Local Research Networks, part of the UK Clinical Research Network, are made up of regionally based, collaborative groups in NHS Trusts, Primary Care Trusts, Hospitals and Universities managed within each host organisation.
- The NHS Health Technology Assessment programme has recently funded randomised controlled trials of the effectiveness of antidepressant treatment for depression in dementia (£1.5 million), befriending by trained lay workers of dementia caregivers (£638,000), a systematic review of non-pharmacological interventions for wandering (£125,000) and the development of a quality of life in dementia scale – DEMQOL (£323,000)

However, although these initatives give some cause for optimism they amount to only another 9p per UK citizen, leaving UK public funding three times lower than in the USA.

UK achievements in dementia research

Despite the low levels of funding, British science has contributed significantly to the understanding of basic biological processes in dementia and Alzheimer's disease. Discoveries include:

- formulation of the amyloid cascade hypothesis (Hardy and Higgins 1992)
- first autosomal dominant gene for Alzheimer's disease (Chartier Harlin et al 1991)
- linkage to chromosome 10 (Kehoe et al 1999, Myers et al 2000)
- a link between head injury, amyloid cascade and APOE genotype (Graham et al 1999, Horsburgh et al 2000)
- the role of alpha secretase
- finding AD is a cholinergic disorder (Wilcock et al 1983, Francis et al 1985)
- demonstration of Tau as a constituent of tangles (Anderton et al 1982)
- showing GSK-3 is the predominant Tau kinase (Hanger et al 1992, Lovestone et al 1994)
- discovery and description of dementia with Lewy bodies (Gibb et al 1987, Byrne et al 1989) and demonstration of a-synuclein as the Lewy body protein (Spillantini et al 1997)
- defining symptoms of frontotemporal dementia and variants (Neary et al 1998).

UK scientists working abroad have also made major contributions:

- finding the second autosomal dominant AD gene (Sherrington et al 1995)
- finding the gene for FTDP-17 (Hutton et al 1998)
- developing mouse models of AD (Holcomb et al 1998).

The MRC CFAS epidemiological study is one of the UK's largest longitudinal studies of dementia incidence, with over 13,000 participants aged 65 and over interviewed at baseline in 1991 in five centres in England and Wales. The study monitored 3,145 survivors between 1991 and 2001. The aims of the study included:

- to estimate the prevalence and incidence of cognitive decline and dementia and the range of variation of those two measures throughout England and Wales;
- to determine the natural history of dementia, in particular the rate of progression of cognitive decline including the distribution of the interval between the identification of cognitive impairment and death;
- to evaluate the degree of disability associated with cognitive decline and the service needs this disability generates.

The study was a result of strategic investment by the UK Medical Research Council and the Department of Health to provide a resource for policymaking and planning. The investment has been successful with 28 peer-reviewed publications covering dementia prevalence and incidence, risk factors, service utilization and economic cost.

3.17 Conclusions

The estimate of the total number of people with dementia in the UK provided in this report (683,597) is somewhat more conservative than that previously calculated by the Alzheimer's Society (775,000 in 2001), and than that estimated for the UK by Alzheimer's Disease International (ADI) in an earlier consensus exercise (741,000 aged 60 and over in 2005). We are however confident that the estimate in this report provides the *best* current basis for policymaking and planning, based as it is upon a systematic review and expert consensus synthesis of the entire relevant UK research evidence base. The earlier Alzheimer's Society figures allowed only approximately for the effect of age, and did not apply separate prevalence figures for men and women. The ADI figures were derived by applying the expert consensus age-specific prevalence figures for the European region as a whole to the UK population.

The estimates for the number of people with early onset dementia (15,034) were derived from studies that relied upon service contacts for ascertainment of cases. These will almost certainly have led to an underestimation of prevalence and numbers, given any delay between the onset of a clinically diagnosable syndrome and help-seeking. The discontinuity between the otherwise smooth exponential increase in the prevalence of dementia between the age range covered by the early onset studies (30–64 years) and the late onset studies (65 years and over) suggests that the extent of the underestimation may be as much as threefold.

We are not aware of any previous reliable UK-wide estimates of the proportion, or numbers of dementia cases accounted for by different subtypes. The estimates provided here are therefore unique.

The UK MRC CFAS study estimated from the five regional centres included in their sampling frame that 34% (95% CI 30%–39%) of people with dementia lived in care homes (Matthews and Dening 2002). This figure is very close to the 36.5% that we have estimated in this report. The Canadian Study of Health and Ageing (1994) is, to date, the only nationally representative survey of dementia to have sampled separately private households and institutional care settings. After weighting back, the evidence was that approximately one half of all those with dementia lived in institutional settings. While the Canadian health and social care systems are somewhat different from those in the UK, the disparity between these estimates and ours do suggest the possibility that our figure may be an underestimate.

Need for more research

There is a clear need for more descriptive epidemiological research into dementia in the UK.

Ideally, we need a UK-wide representative survey of older people with separate sampling frames for private households and care homes, that includes all members of society including those with learning disability. This survey would estimate the prevalence of dementia in

the community, and in different types of care home using current clinical diagnostic criteria (DSM IV or ICD10). The survey would include a comprehensive assessment of formal and informal care receipts, to allow accurate estimations of cost of illness, and to monitor access to and uptake of health and social services.

The survey should be repeated at regular intervals, using comparable methodology in order to assess trends over time: in the prevalence of dementia and in formal and informal care arrangements.

A survey meeting most of these requirements, the Great Britain National Psychiatric Morbidity Survey, was carried out in 1995, 2000 and 2006, commissioned and funded by the UK Government. The first survey was limited to those aged 16–64 years. The upper age range was extended to 74 years in 2000 and there was no upper age limit in the 2006 survey. There is no oversampling of older adults. Despite the inclusion of older adults, dementia assessment is limited to a brief cognitive screening test, the TICS-m, similar to the MMSE. The survey includes a second phase element in which those screened as likely to have serious (but low prevalence) mental disorders, for example psychosis, and a random sample of those screening negative, receive a more detailed clinical diagnostic assessment. Dementia is not yet among the conditions prioritised in this way.

CHAPTER 4

Service development

Overview

The role of the health and social care systems in meeting the multiple needs of people with dementia and their families is a key policy issue in the UK. This chapter provides a commentary on the development of services for people with dementia and considers the following:

- Informal care – unpaid care provided by family members and friends, the mainstay of dementia care in the UK.
- Financing health and social care – demographic challenges, charges, choices and independence.
- Specialist health services for people with dementia – the role of old age psychiatry.
- Dementia assessment and care – diagnosis and referrals.
- Social care provision – residential and nursing care, extra care housing, community-based support and mental health services.
- The state of current dementia commissioning, care and policy – services are not available for a large majority of the population to deliver the memory assessment and care services that are stipulated in government policy, yet demand is predicted to grow.

4.1 Introduction

Many people with dementia and their families have multiple needs, which can be identified, assessed and addressed by more than one agency or sector. In particular people with dementia may receive support from both or either of the health and social care systems. Differences between the finance arrangements and responsibilities, eligibility and ways of accessing health and social care services can be a source of both confusion and distress. An added complication is that the support and care needed by people with dementia and their families could be delivered by government, private or voluntary organisations. However, most support and care is not provided through structured organisations but by individuals, whether unpaid family members, other unpaid caregivers or, increasingly, by individuals employed under direct payment or individual budget arrangements. The need to support family and other unpaid carers, and the opportunities to increase choice and control

through devolution of responsibility for commissioning services are important aspects of current provision for people with dementia in the UK.

In this chapter we describe the development and organisation of services for people with dementia and for their families. First we look at family and other informal caregivers for people with dementia (Section 4.2). We then offer a brief summary of the financing structure for services, including the growth of consumer-directed arrangements (Section 4.3). The next few sections consider the development of old age mental health services primarily within the NHS (Sections 4.4 to 4.7), and then look at social care services and their development (Section 4.8). A final section summarises the current state of commissioning in dementia care and policy.

4.2 Informal care

Using data from the General Household Survey (1998/99), Pickard et al (2001) estimated that 53% of people aged 65 or over with 'dependency problems' were supported by unpaid carers only, 34% received both informal and formal care, 9% received formal care only and 3% were unsupported. The Audit Commission (2004) estimated that there were four million carers in England, about one million of whom provide more than 50 hours a week of care. Most are of working age.

Legislation and guidance in the UK over the last two decades has considerably improved the (potential) support for carers (Secretary of State for Health 2000, National Assembly for Wales 2000, Audit Commission 2004), but the Audit Commission's view was that the government's aspirations for carers of older people were not being realised in practice for the majority.

The Audit Commission identified a number of 'failings', including poor early identification of carers, failure to refer them to social services or the voluntary sector for support and guidance, unsystematic approaches to the provision of information and advice, and a lack of clear points of contact for carers in need of urgent help or advice. They also pointed to limited availability of appropriate support services at crucial times (such as at night or at weekends) or when the person being cared for is being discharged from hospital.

A particular issue for dementia care is that the pool of potential family caregivers is being affected by changing demographic patterns, shifts in family composition, labour force participation and increased geographical mobility (Moise et al 2004, Comas et al 2007). Projections of the future costs of long-term care are sensitive to assumptions made about the future supply of informal care.

A great many studies have pointed to the effects of caring on carers (e.g. the review by Pickard 2004). Many carers gain satisfaction from their role, however there are also negative aspects to caregiving. For example, there is plenty of evidence that poor carer health is particularly associated with supporting older people with cognitive impairment (Morris et al 1988, Moise et al 2004). Schneider et al (1999) pointed to the 'high level of burden and mental distress in spouse carers for people with Alzheimer's disease' (p.652). They made recommendations for better primary and secondary prevention of this burden by addressing the clinical needs of people with dementia, changes in public attitudes and education to reduce the negative social reactions to the illness, better economic support for carers, and recognition of the particular needs of higher risk groups, such as younger spouse carers. Livingston et al (1996) reported a high prevalence of depression among the carers of older people

with depression, dementia or physical disability living in community settings, although MRC CFAS (2002) found that caregivers' psychological well-being did not deteriorate over a two-year period in the cases of carers of older people with mental health problems. Buck et al (1997) investigated the extent and correlates of psychological distress among carers: stress was higher when the older person being cared for had more behavioural problems.

Another widely documented effect of caring is the reduced opportunity that carers have to work and earn an income. For example, Evandrou (1995) found that men and women who provide 20 or more hours per week of informal care have earnings from employment that are 25% lower than the earnings of employed non-carers. Indeed, caring has a lifetime impact on earnings and other income (Evandrou and Falkingham 1995). Glendinning (1992) concluded that the health status of the care recipient was the most important influence on decisions over changes in labour force participation by the informal carer. The MRC CFAS study found that 15% of informal carers of people with dementia had altered their employment arrangements: 9% of them had reduced their hours of work and 6% had changed their hours of work without reducing them. One fifth of carers of pre-statutory retirement age had given up work altogether. Half of those of pre-statutory retirement age who were not working claimed that caring was the main reason for not seeking paid employment.

Our discussion of formal care service arrangements must be seen against this backdrop of informal care.

4.3 Financing arrangements and funding devolution

The National Health Service is funded out of centrally collected general taxation, is universally available, and is mainly free from user charges. In contrast, social care services are funded from central and local taxation, routed through local authorities (since 1993), and are subject to user charges (personal care is means-tested in England, Wales and Northern Ireland, but not in Scotland).

A nationally applicable means test for residential care takes account of an individual user's income and assets, although there is a 'disregard' for the initial period of care, and if these assets exceed a prescribed capital limit then charges are levied.

Charges for home care, day care and a range of other services are set by local authorities. There is substantial tension about where dementia services should sit in relation to the boundary between NHS services (free at point of use) and social care (means-tested). A few years ago the Audit Commission (2002) described wide variations in the extent of NHS funding of continuing care for older people with mental health problems, and the problem persists.

Financing long-term care

There has been an ongoing debate about the extent to which long-term care should be financed publicly in the UK. The key recommendation of the Royal Commission (Royal Commission, 1999) was that the costs of nursing and personal care should be financed out of general taxation by the state, without a means-test. The means-test for nursing care for nursing homes in England was removed, while all other costs of care remained subject to means-testing (Secretary of State for Health 2000). The National Assembly for Wales and the Northern Ireland Assembly adopted similar decisions, but the Scottish Executive

decided to make personal and nursing care free of charge, both in people's own homes or in care homes (Care Development Group 2001). As we shall see in Chapter 5, there are quite marked differences in social care costs and patterns of provision between different parts of the UK.

There have been calls to make personal care free to all, for example by the Institute for Public Policy Research (IPPR) (Brooks et al 2002). A recent report by the Joseph Rowntree Foundation (2006) argued for fundamental reform of the long-term care financing system, and made suggestions for improvements.

The recent Wanless Review of Social Care (Wanless at al 2006) recommended increased expenditure on social care for older people and a radical change to the financing system. The review team have proposed a non-means-tested entitlement to social care, with government meeting two-thirds of the cost of the care package, and the remainder of the costs being met half by the user and half by the government, that is, with government meeting five-sixths of the costs if the user agrees to meet one sixth.

Direct payments

The 1990 NHS and Community Care Act encouraged individual flexibility and devolved budgets (to case/care managers), but real progress has been made only comparatively recently (Knapp 2007). Direct payments (transfers of social care funding to individuals to spend on a range of services to meet their personal care needs) were only extended to older people in 2000. It is now mandatory for local authorities to offer direct payments to all 'suitable' users, and national performance monitoring systems monitor the numbers of people who receive them.

The roll out of direct payments to social care users has been slow – certainly disappointingly slow to central government, and noticeably slower outside England (Davey et al 2007). In particular, the most recent Department of Health statistics show that less than 1% of older people supported by English authorities are in receipt of direct payments, and that for disabled people the proportion is only around 7%. Several reasons have been suggested for the slow take-up (Perri 6 2005; Fernandez et al 2007), including ignorance of their availability, resistance among those who have responsibility for implementation (because of risk-aversion, conservatism or fear of loss of control), vested interests within the provider community, scarcity of suitable people to work as personal assistants, the perception that the monetary value of a direct payment is too small, lack of availability of local community groups or support organisations, concerns about the burden of legal and administrative responsibility, and concerns about the vulnerability of individuals to financial exploitation. Not surprisingly, there are very wide variations in both rate of take-up and level of support by different user groups and between local authorities, linked to a number of need, policy, political and other characteristics of area (Fernandez et al 2007). The supply of informal care is influential too, with direct payments take-up being lower in areas with a higher proportion of the local population providing informal care.

Individual budgets

More recently, more adventurously, and certainly with more attendant risks, is the piloting of *individual budgets.* This programme has been heralded as the centrepiece of ambitions to 'modernise' social care in England (Glendinning et al 2006), with individual budgets currently being piloted in 13 English local authorities. They bring together the resources

to which an individual is eligible from (among other funding streams) local authority adult social care budgets, community equipment, housing adaptations, housing-related support through the Supporting People programme, the Independent Living Fund and Access to Work from the Department for Work and Pensions. An individual who is assessed as eligible for one or more of these forms of support is told the total amount available from these sources, and can then decide how to use their allocated resources to meet their personal care or other needs. The process is transparent, hands much more control to the individual budget holder, and clearly seeks to promote real, operational choice. The pilot programme is currently being evaluated (Manthorpe et al 2007, Glendinning et al 2006). To date few people with dementia have been offered individual budgets, although this is expected to change over the next year.

4.4 Specialist health services for people with dementia

People with dementia are part of the caseload of all medical specialties with the possible exception of paediatrics and obstetrics. This is because dementia is predominantly a disorder of later life and with increasing age come other disorders requiring consultation and intervention. Dementia is a common disorder and so is routinely dealt with by primary care. In addition, dementia itself complicates the management and rehabilitation of all other disorders, so people with dementia have longer stay lengths in hospital and more readmissions than their peers without dementia.

In the UK the lead specialty that has evolved to diagnose and treat people with dementia is old age psychiatry. However even within the UK, diagnosis and treatment might also be carried out by a geriatrician (e.g. if there is concomitant acute physical illness requiring admission to a general hospital), a neurologist, adult psychiatry, liaison psychiatry, neuropsychiatry (e.g. where the person is relatively young) or a GP (where the GP has a particular skill or interest in the area).

Although families provide the majority of care received by people with dementia professional health care can be vital to the individual with dementia and their family. A lack of diagnosis means a lack of specific treatment and care for dementia. Diagnosis is the gateway for care. Despite excellent development work there remains a widespread reticence amongst GPs to make the diagnosis in primary care (Vernooj-Drassen et al 2005).

4.5 Historical development of specialist health services

In 1949 Felix Post opened the first geriatric unit in a psychiatric hospital at the Bethlem Royal Hospital (Post 2002). Some day hospital provision for older people was developed in the 1950s and 1960s (Farndale 1961, Hilton 2005). In 1963 the service at Severalls Hospital in Essex introduced emergency home assessment using an old ambulance whose interventions included providing coal, candles and soap as well as medication (Whitehead 1970), encapsulating the pragmatic approach that old age psychiatry has had from the start. The first comprehensive old age psychiatric service was probably that working from Goodmayes Hospital in east London (Arie 1970). Its underpinning principles were:

- ease of accessibility;
- flexibility;

- assessments being made at the patient's home;
- management of the patient in close cooperation with GPs and other interested parties.

This comprehensive model of service, with its strong community focus, remains the basis for old age psychiatric services provided in the UK and, through the evangelism of Professor Tom Arie and his many trainees, in a large number of other countries across the world.

It is UK policy that all areas should have a specialist old age psychiatry service and data held by the Royal College of Psychiatrists' faculty of old age psychiatry suggest that is now the case. These posts are now mostly filled by doctors working full time in old age psychiatry rather than being split between old age and general psychiatry (Banerjee et al 1993). However, there remain posts which are poorly resourced with unsustainably large catchment areas and workloads (Jolley and Benbow 1997). In 1996 20% of old age psychiatric consultant posts in south London were either vacant or filled by a locum (Philpot and Banerjee 1997).

4.6 Community assessment and treatment in old age psychiatry

The traditional model of old age psychiatric service delivery combines first assessment either at home following a GP request for a consultant domiciliary visit or more rarely in an out-patient clinic. Follow-up may then be by further consultant home visits, out-patient attendance or CPN. Out-patient assessment and follow-up may be problematic in elderly populations for reasons which include:

- difficulty assessing the patient's true level of functioning without seeing them in their own home;
- the need to assess risk in the patient's own environment;
- the value of being able to inspect the home;
- difficulties or unwillingness of patients to attend clinics due to disability, cognitive impairment or lack of insight;
- transporting people with dementia to unfamiliar surroundings may exacerbate disorientation and behavioural disturbance and so compromise the assessment;
- decreased access to information (e.g. medicine bottles and district nursing or social service notes) and informants such as neighbours.

For these reasons many services have almost entirely done away with hospital-based, clinic or GP practice-based outpatient assessment and follow-up, or reserve it for select groups of patients.

4.7 Dementia assessment and care

The interface between primary health care and old age psychiatric services with respect to people with dementia continues to be clouded by the lack of generally agreed criteria for referral. This has resulted in a lack of clarity about what can and should be done by and in primary care, and what is required from, and is the responsibility of, old age psychiatry

(Downs 1996). There is marked variation in GPs' skills in diagnosing and managing dementia (O'Connor et al 1988, Philp and Young 1988). There is considerable heterogeneity of need in dementia. The people with dementia who are referred to old age psychiatry include those where: the diagnosis is difficult; there is associated psychopathology such as depression or psychosis; there is dangerous or severely disturbed behaviour such as violence, wandering or sexual disinhibition; there is severe carer strain; and where other agencies such as social services have asked the GP to request an assessment for their own needs. This is however only a small proportion of people with dementia and current models of service provision may be seen to be failing to meet the needs of the majority of people with dementia with only 15–20% ever having contact with specialist services (Holmes et al 1995).

It is therefore possible to identify two main streams in dementia care: a 'serious mental illness' stream and an 'early intervention' stream. The 'serious mental illness' stream includes people with severe and complex disorders where there are high levels of risk and comorbidity. These individuals require the resources and skills of old age psychiatric community mental health teams and many will find their way to such care. This stream is skewed to those with higher levels of severity. In the 'early intervention' stream there is early and often uncomplicated disorder with the possibility of early intervention and therefore the greatest possibility of the prevention of future harm, risk and cost for the patient, their carers and services (Gaugler et al 2005). This group has less likelihood of access to care.

With advances in public expectation and in psychological, social and biological treatments in dementia, services are already under pressure from increasing numbers of new referrals from the 'early intervention' stream (Banerjee 2001). The health service is therefore faced with how to meet this challenge: by replicating existing services ('more of the same') or by generating new models of service delivery and service redesign. One approach has been the establishment of memory clinics (Lindesay et al 2002, Phipps et al 2002), but their services are inconsistent and their reach limited at present (Moise et al 2004).

4.8 Social care services

Many of the needs of older people with dementia stem from deterioration in their health and are usually met appropriately by health care services. Other needs are better met by social services, but the boundaries between the two are sometimes hard to draw and potentially have implications for access and level of care, and for the balance of funding. However, the most important 'provider sector' is the informal one, as noted earlier, and the availability of support from families, neighbours and community groups heavily influences the level and type of need for formal care.

Balance of care

A major theme in long-term care for the past two decades has been to shift the balance of care away from institutional forms of care towards community or home care. Discussions on the appropriate balance of care have included arguments about relative effectiveness (for whom is residential care more effective, and when?), relative cost (both in total and to various agencies, especially health and social care) and user and family preferences (themselves influenced by factors such as perceptions of quality, availability of informal care,

cultural expectations with regard to family obligations and personal cost). We provide the most recent statistics on care home provision across the UK in Chapter 5.

Residential care

Residential care services for older people grew rapidly during the 1980s for a number of reasons: demographic change, the liberal social security environment (with no needs assessment of residents), the general business-supporting climate engendered by the Conservative governments, and the boom in the property market making investment in physical capital a sound one. But in recent years, this trend has been reversed. England has experienced a greater fall in the number of care homes than other parts of the UK, and particularly in the number of private residential homes, although it is interesting that the immediate years after the 1990 Act saw a slowing, but not a reversal, in the rate of growth of care home provision. During this period many local authorities were looking to close some of their in-house provision, but in fact many facilities were transferred to the private and voluntary sectors (Wistow et al 1994 chapter 7, Kendall et al 2002). There was also difficulty countering the strong influences of the inherited patterns of (supply-induced) demand (Audit Commission 1997). Today, as a result of a faster rate of home closure than anticipated, some areas face shortages of care home accommodation.

Provision of residential and nursing home care has in fact changed considerably in a number of respects, with a rapid growth of private sector market share (particularly of larger corporate providers) and a fall in public sector in-house provision. Average home size has been increasing, now about 34 beds per home in England. Care home closures have been disproportionately common among small homes and those with a positive social environment. They have arisen because fees paid by local authorities do not always cover costs (exacerbated by rising dependency levels and rising standards) and staff recruitment can be difficult. One consequence of these (unplanned) closures has been to leave some areas with under-capacity, particularly in nursing homes and other facilities offering specialist care for older people with mental health problems (SSI 2003, Netten et al 2002). The availability of care home places has demonstrably important impacts on delayed discharges from hospital (Fernandez and Forder 2002).

Quality of care in residential and nursing homes has been a concern for many decades. Standards have improved, of course, in response to inspection and contractual requirements as well as competition, although more could clearly be achieved. For example, the Audit Commission (2002) found that the physical environments in which respite and hospital services were provided were unsuitable for older people with mental health problems in over a third of the areas examined in the course of their audit, and that specialist settings – where they were available – had 'consistently good quality physical environments' in only half the areas (p. 32). A number of initiatives have been taken to improve care home standards, working through purchaser–provider contracts and monitoring, performance reviews, inspections, audits, Best Value reviews and, of course, national regulatory standards.

There have always been marked variations within the constituent countries of the UK in relation to many of these charted features of care homes. For example, the Audit Commission (1986) noted that there were heavier concentrations of private sector care homes in the south of England and in larger conurbations, particularly on the coast, where there already existed suitable housing stock for conversion. The SSI (2003) pointed to marked regional variations in admissions.

Extra care housing

A significant change in the service portfolio for older people over recent years has been the development of 'extra care housing as an alternative to long-term care and as a community focus for intermediate care schemes' (SSI 2003 p.7). Earlier manifestations of these services were called 'very sheltered housing' and 'housing and care' schemes. Retirement communities can come within this category (e.g. see Croucher et al 2003 on Hartrigg Oaks in York). Most extra care housing is provided by the social rented sector (local authorities or registered social landlords). Many local initiatives in England are linked to the Supporting People programme, which replaced the previously fragmented funding arrangements for housing and care arrangements and was intended to overcome legal restrictions on the use of housing benefit for care services. The underlying aim was the promotion of independence through unregistered rather than registered accommodation, in a consistent and fair manner – with mixed success (Griffiths 2000).

Home care

One reason for the recent reversal of 50 years of per capita and then absolute growth in residential, nursing home and long-stay hospital provision was the growing provision of community-based support. However, rather bigger influences on the scale of care home provision came from outside the social care system, including the broader economic environment.

There are no statistics on the *overall* size of the home care market, and the (potentially large) privately funded sector is currently neither registered nor regulated. Looking at publicly supported home care in England, it is clear that there has been:

- very significant growth in the volume of home care hours purchased by local authorities;
- a fall in the number of people supported;
- changes in service range and orientation (e.g. more short-duration, weekend, out-of-hours and dependency-contingent care packages); and
- very rapid growth of the market share of the independent sectors.

Considerably fewer households are now receiving home care services than a few years ago, but those that do are receiving a much more intensive package of support. Generally, these are the people with greater needs. In 1993 in England, for example, 38% of households in receipt of home care had only one visit of two hours or less in duration, compared with 15% in 2003 (Department of Health 2004). Many of these people will now be purchasing home care services privately: the proportion has increased considerably (Pickard et al 2001). With the virtual disappearance of (publicly supported) low-level home care the burden falling on families has clearly increased. Another consequence is that people tend to be admitted to care homes when already quite dependent, including at later stages of dementia. Carer-related factors are common reasons for admission to care homes. Another consequence is that a high proportion of residents in care homes and other highly staffed congregate care settings today will have dementia.

In contrast with these trends in England, the number of home care contact hours for older people in Wales has decreased in recent years, as has the number of people aged 65 or over receiving home care in Northern Ireland. The independent sector also appears to provide a

much lower proportion of home care in Wales than in England. In terms of the intensity of home care provision, there are broadly similar proportions of home care recipients receiving over 10 hours per week of care in Wales and England.

There is little evidence on the quality of home care services, but user satisfaction levels are often rather low (Netten et al 2004). Underlying problems include staff recruitment and retention difficulties, under-developed relationships with providers (see above), a poorly trained workforce, and a recent tendency to keep prices low, thereby threatening quality. There have been moves towards registration and national regulation of care standards only quite recently.

Hospital–community balance

One major concern across the UK is the inappropriately high use of in-patient hospital services by older people. In-patient care has fallen since 1990, although not as fast as hoped. Delayed discharges from hospital are problematic to policy makers because they waste resources: they are both inefficient and inequitable. They are also problematic to individual older people because they confine them to longer stays in hospital than they or their families would wish. Analyses have corroborated the view that provision of social care services (both community- and institution-based) can significantly reduce delayed discharge rates. Local resource levels and input prices matter significantly. A number of national and local initiatives have been set up to reduce inappropriate in-patient bed use.

Unmet mental health needs

There is no shortage of evidence from various parts of the UK that mental health remains one of most prevalent of unmet needs for older people (e.g. Department of Health 2001, Girling et al 1995, Holmes et al 1995, Social Services Inspectorate 1997, MRC CFAS 1999). Depression is especially overlooked, among both people with dementia and without. Clarification is needed of the role of social care staff in dementia assessment and support services (Manthorpe et al 2004). Recognition of the mental health needs of older people from Black and minority ethnic groups may be lower than in the white population (Lloyd 1993, Abas 1996; but see Odutoye and Shah 1999, Livingstone et al 2002). Adamson (2001) found limited knowledge of dementia among families of South Asian and African/Caribbean descent, which could cause difficulties in the planning of community-based services. Gaining a better understanding of the mental health needs of minority ethnic communities has been stated as a policy aim in Wales and England (Welsh Assembly Government 2003, Social Services Inspectorate 2003). It is also worrying that older people in receipt of home care services or living in care homes have unrecognised and unmet mental and other health needs (e.g. see Banerjee and MacDonald 1996, Barodawala et al 2001, Bagley et al 2000). Generally, targeting of services has been seen as poor for older people with mental health problems.

When the Audit Commission followed up their 2000 report on mental health services for older people, *Forget Me Not*, they still found many areas in England without specialist teams for older people with mental health problems (and see Mitchell 2001), and many teams did not have all the recommended core professions represented. Respite care was hard to access, day hospital services were not available in more than half the areas surveyed, and only a third of the areas had jointly agreed assessment and care management procedures. Almost a quarter of all areas studied had no clear service goals or plans. The physical environments in which respite and hospital services were provided were unsuit-

able for older people with mental health problems in over a third of the areas, and specialist settings – where available – had 'consistently good quality physical environments' in only half the areas. As noted above, specialist dementia services have developed in various ways across the UK, as set out above, including special care units for dementia patients.

The voluntary sector provides a range of innovative services for people with dementia and their carers, as well as advocacy, self help, information and training – across all parts of the UK. For example, the Alzheimer's Society provides helplines and support for carers, runs quality day and home care, funds medical and scientific research and gives financial help to families in need. Dementia Voice works to promote service development and best practice in dementia care.

One of the major organisational and resource challenges in dementia care is to coordinate the funding of services in ways that are effective, cost-effective and fair. Cost shifting and 'problem dumping' between agencies will not help individuals or families, but recognition of economic symbiosis could help decision makers fashion improved responses to needs through pooled budgets, jointly commissioned programmes and other 'whole system' initiatives.

4.9 Variation in service provision in England and Wales – a case study of the prescription of anti-dementia medication

In order to investigate variation in service provision we obtained data from IMS, a medical information service, on the number of prescriptions for anti-dementia medication that had been made in the year October 2005–September 2006. These data are commercially available and are derived from the activity of 50% of the pharmacies in England and Wales, representing some 90% of all UK prescribing.

There are limitations to the data: they record numbers of prescriptions, not the numbers of individuals receiving treatment. Prescriptions may be for a short or a long period, and one individual is likely to receive many prescriptions in a year. However, the data also have strengths. They are independently gathered and their 90% coverage is actually better than the response rates in epidemiological studies. The data are also up-to-date and available by PCT (or local health board in Wales), reflecting current practice and commissioning and its variation. While the prescription durations will vary, when taken over a year these variations should even out across areas. This enables a comparison of the intensity of activity between PCTs. Finally, we have to ask: what else is there available with which to compare services nationally? Nationwide mapping of the availability of and spend on services of the sort generated for working age adults is not yet available for older people's mental health services; there is an absolute lack of data in this area with which to look at service variation. Consequently, the use of a marker such as anti-dementia medication must be considered reasonable if it throws light on this neglected area.

In these analyses we have taken the IMS data on all four anti-dementia medications added together and divided these on a PCT basis by the projections of numbers of people with dementia derived from the figures presented in Chapter 3 above. These data provide a unique opportunity to compare level of activity in different areas. The number of prescriptions per person with dementia is presented in Figure 4.1 and these data are mapped onto the UK in Figure 4.2, p. 55. For a full list of the data in Figure 4.1 please see Table A1.2 at the beginning of the appendices.

The most striking finding of these analyses is the very high level of variation between PCTs,

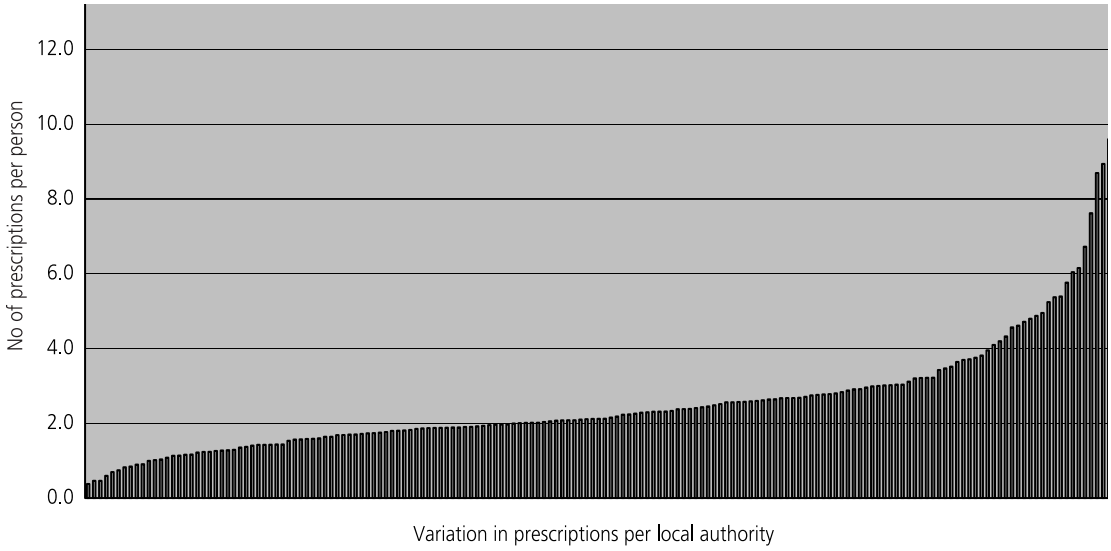


Figure 4.1 Variation in prescriptions per local authority. Number of prescriptions of dementia drugs per local authority per person with dementia, October 2005–September 2006

even in similar geographical and socio-demographic areas. There is an absolute variation in activity from 12.0 prescriptions per year in Knowsley to 0.4 in West Berkshire, representing a 30-fold difference in activity. Around 75% of the PCTs have an activity level between 1.0 and 4.0 but this still represents a three-fold variation, which is very high for what should be a core element of health provision. This activity variation is not explicable in terms of the numbers of people with dementia since these are rates per person with dementia.

There are many possible reasons for the variation seen and further research is needed to understand in detail why these variations occur. It would be interesting for example to compare these data with the forthcoming National Audit Office national study of service provision. However, it is extremely unlikely that technical issues or local prescribing methods could generate the spread of activity seen. What these data are likely to reflect is that there is major variation in the assessment and treatment services provided to people with dementia across the UK. This variation is likely to be related directly to the number of services commissioned to meet the needs of people with dementia. The data presented here therefore suggest strongly that there is a major element of 'postcode commissioning' going on in the UK, affecting the extent to which people's needs are met depending on an accident of residence rather than need.

4.10 The state of current dementia commissioning, care and policy

Mental health forms the subject of Standard 7 of the National Service Framework for Older People (NSF-OP, DH 2000). It specifies the need for comprehensive specialist OPMH services and is explicit about the need to identify and treat people with dementia early in their illness as well as providing high quality health and social care across dementia severity. However, as we have seen, evidence has been accumulating that suggests a failure of services for older people with mental disorders. The Audit Commission's (AC) *Forget Me Not* (2000) and *Forget Me Not 2002* (2002) reports identified multiple areas for service improvement. In 2003 the national inspection reports by the Social Services Inspectorate (SSI) *Improving Older People's Services: an overview of performance* and the Commission

Figure 4.2 Map showing variation in services for people with dementia 2005–06

for Health Improvement (CHI) *What CHI has found in mental health trusts* reported deficiencies in the commissioning and delivery of OPMH services (CHI 2003a).

The CHI (2003b) investigation into matters arising from care on Rowan Ward found similar local circumstances and systemic problems to its 2000 investigations into abuse of older people at the North Lakeland Healthcare NHS Trust. In 2005, the national review of older people's services by Healthcare Commission/AC and the Commission for Social Care Inspection (CSCI) found that commissioning and delivery of OPMH services were still causing for concern and required additional work. This was confirmed in National Directors' reviews in 2004 (Louis Appleby: *The National Service Framework for Mental Health – Five Years On*, and Ian Philp: *Better Health in Old Age*). Both highlighted the fact that mental health in older people required particular attention. *Living Well in Later Life*, the HC/CSCI/AC 2006 review of older people's services, highlights the difficulties faced by OPMH services. While it found that explicit age discrimination had declined in general since the publication of the older people's NSF, but OPMH services were an exception whereby differential investment 'the organisational division between mental health services for adults of working age and older people has resulted in the development of an unfair system. . .'.

The clearest policy guidance on the provision and commissioning of specialist OPMH services is included in *Everybody's Business*. This service development guide for integrated mental health services for older adults was published by the Care Services Improvement Partnership (CSIP) in 2005 with a particular emphasis on informing the commissioning of OPMH services. In essence, this gives direction to the broad positive statements of the NSF-OP. The content of *Everybody's Business* has been endorsed by the 2006 White Paper on community services *Our Health, Our Care, Our Say* and the 2006 NICE/SCIE guideline on the treatment and care of people with dementia in health and social care. This again stresses the need for early identification and intervention in dementia and an effective response across the range of severity and complexity in dementia.

The fundamental challenge is that at present it may be the case that less than a quarter of people with dementia come into contact with old age psychiatry services at any time in their illness (Holmes et al 1997). Services are not available for a large majority of the population to deliver the memory assessment and care services that are stipulated in *Everybody's Business*. Currently demand has been managed by health purchasers not providing funding for service development and services continuing to act reactively. With the publication of definitive statements on the content and value of good quality care, such as the NICE Clinical Guideline, and positive changes in public attitudes and understanding of dementia, demand can be predicted to grow. This is a profound challenge for both service providers and commissioners.

CHAPTER 5

Mapping social service provision

Overview

- Mapping local levels of social care support for people with dementia in the UK is difficult as there are no available local authority level data on service provision specific to people with mental health problems.
- This study gathered information on local levels of provision of residential and nursing care, home care and day care services to *all* older people in England, Scotland, Wales and Northern Ireland.
- The figures presented provide a good picture of differences between local patterns of service provision in the UK, however they have limitations in terms of explaining the reasons for such patterns.

5.1 Introduction

This chapter describes variation in the provision of residential care, home care and day care for older people in England, Scotland, Wales and Northern Ireland. We present information on numbers of recipients as well as the levels of expenditure, unit costs and intensity of provision for home and residential care.

5.2 Features of the data

Specificity of the data

Although a significant proportion of older people in receipt of social care services have dementia, there are no data on social care provision specifically for them. Rather, the data available relates to *all* older people in receipt of publicly-funded social care services.

The extent to which the data presented reflects accurately the provision of services for older people with dementia depends therefore on the degree to which such services are targeted at them. This is likely to be particularly the case for residential care services given the significance of cognitive impairment as a risk factor for institutionalisation (Davies et al 2000, Wanless et al 2006). For example, data from the Evaluating Community Care for Elderly People (ECCEP) study suggested that in 1995, approximately 49% and 36% of users of day care and home care services suffered from mild and severe cognitive

impairment, respectively (Davies et al 2000). These rates are likely to have increased significantly by now, because of increased targeting of social care services on the neediest users since.

Comparability of the indicators across countries

In this study we collected data from each of the four countries in the UK. However, the methodology used for deriving the indicators differs for each nation. For instance, no data on home care could be found for Northern Ireland. Instead, data could be identified on 'domiciliary care'. It is difficult to judge the extent and likely impact of differences of this kind, but they may help to explain some of the evident disparities.

Because the indicators for individual countries may not be comparable they are generally presented as separate figures. However, we do present a number of UK maps (excluding Northern Ireland, due to a lack of relevant boundary data), which compare patterns of provision across countries.

Descriptive nature of the results

The data presented provide a good picture of differences between local patterns of service provision in the UK, however it has limitations in terms of explaining the reasons for such patterns. A whole range of factors within and outside the control of local policy makers – such as levels of need, differences in socio-economic factors, local supply factors, local deprivation and other influences – are likely to explain local levels of provision. We have explored these associations in previous work (e.g Forder and Fernandez 2005, 2006, 2007, Fernandez et al 2007).

The evidence on unit cost patterns provided help with the interpretation of the expenditure and service provision patterns. However, determining why a particular authority appears to provide significantly more services, for instance, requires a multivariate analysis beyond the scope of this report.

5.3 Residential care provision

A summary of our findings of the provision of services in each of the four UK countries follows. Further details can be found in the four appendices to this report. Tables and figures prefixed with 5. can be found in this chapter. Tables and figures prefixed E are in the appendix for England, those with an N in the appendix for Northern Ireland, S denotes the appendix for Scotland, and W the appendix for Wales.

England

There is fourfold variation in the proportion of older people supported in residential and nursing care by local councils in England, with the range running from 1.3% in Wokingham to 4.8% in Kingston-upon-Hull. On average, 2.5% of older people in England are supported in residential or nursing care homes. See Figure E2, Table E1 and Table 5.1.

There is a clear divide between the higher rates of provision in the North of England, particularly in some of the metropolitan authorities, and the lower rates in most of the south of England. Some London boroughs also appear to support above average proportions of older people in institutional care (see Figure E1).

Table 5.1 Local authority service provision and unit cost indicators, England

	England average	*Obs*	*Std. Dev.*	*Min*	*Max*
Proportion of population over 65 living in CSSR and registered staffed care homes, 2005 (%)	2.5	149	0.7	1.3	4.8
Expenditure on residential and nursing care for older people per head of population over 65, 2004–05	578.3	150	151.6	333.6	1,273.5
Unit cost of residential and nursing care for older people, 2004–05 (£ per person per week)	410.5	147	66.4	300.6	697.3
Proportion of older people receiving home care, 2006 (%)	3.9	149	1.8	1.5	13.2
Expenditure on home care for older people per head of population over 65, 2004–05 (£)	214.4	150	102.6	62.0	758.9
Unit cost of home care for all recipients, 2004–05 (£ per hour)	14.1	150	2.7	9.2	25.9
Average weekly home care package for older people, 2004–05 (hours)	8.1	150	2.3	1.9	16.5
Proportion of older people receiving day care, 2004–05 (%)	1.7	145	0.7	0.1	4.1

The distribution of residential care expenditure per head of older population is even more concentrated on metropolitan counties and London boroughs than levels of service provision. This pattern reflects higher unit costs for residential services in such authorities (see Figure E3 and Table E2).

There is a significant 'London effect' on unit costs, with the cost of residential care highest in London boroughs, and decreasing proportionately as the distance from London increases (see Figure E3). Overall the average weekly cost of residential care in English local authorities varies over twofold from £300 in Knowsley to £697 in Lewisham.

Scotland

There is a smaller variability in the rate of provision of residential care per head of older population in Scotland than in England (see Figure S2 and Table S1). On average, approximately 4% of older people are supported in institutions in Scotland, a significantly higher rate than in England (see Table 5.2). The range of provision varies from 2.5% in Orkney Islands to 5.0% in South Lanarkshire.

Levels of residential care expenditure per head of older population show a larger degree of local variability (see Table S2 and Figure S4), as indicated by the steeply declining values of the distribution shown in Figure S4. There is approximately a threefold difference between the maximum expenditure level of £1,171 in Eilean Siar and the minimum value recorded of £374 for South Ayrshire.[1] The average residential care expenditure per older person in Scotland is, at £778, approximately 33% higher than in England.

[1] The values for Glasgow City and South Lanarkshire, which were significantly below the Scottish minimum expenditure figure presented, were excluded from the analysis because of concerns over data quality. It is also worth noting that the Scottish Executive is currently carrying out a review of the residential care expenditure estimates for all local authorities, because of concerns over differences in local data collection methodologies.

Table 5.2 Local authority service provision and unit cost indicators, Scotland

	Scotland average	*Obs*	*Std. Dev.*	*Min*	*Max*
Proportion of population over 65 living in care homes, 2005 (%)	4.0	32	0.6	2.5	5.0
Expenditure on residential and nursing care for older people per head of population over 65, 2004–05 (£)	777.6	30	201.2	373.5	1,171.1
Average charge for residential and nursing care for older people, per person per week, 2004–05 (£)	448.3	32	59.3	390.0	621.0
Proportion of older people receiving home care, 2006 (%)	6.9	32	2.3	4.1	14.2
Expenditure on home care for older people per head of population over 65, 2005–06 (£)	424.8	32	163.9	186.8	1,093.6
Average weekly home care package for older people, 2005 (hours)	7.4	32	1.7	3.6	10.3
Proportion of older people receiving day care, 2005 (%)	1.3	32	0.9	0.4	4.8

Except in four local authorities with average charges significantly in excess of £500 per week (Orkney Islands, Shetland Islands, Eilean Siar and City of Edinburgh), the average charge in all Scottish authorities ranges between £400 and £500 per week. The distribution of average weekly charge in care homes for older people by local authority, the closest reliable estimate to a residential care unit cost figure for Scotland, is depicted in Figure S5, Figure S6 and Table S3.[2]

Wales

There is a moderate degree of variability in the proportion of older people supported in residential care in Wales (see Figure W2 and Table W1). Figures range from between 2.1% for Monmouthshire and 3.3% for Gwynedd, with an average estimate for the whole of Wales of 2.8% (see Table 5.3). This figure is close to the 2.5% for England and below the 4.0% recorded in Scotland.

The spatial distribution of residential care provision and expenditure in Wales (see Figures W1 and W3) appears to follow broadly similar patterns. In contrast, the spatial distribution of unit costs appears to be quite different (see Figure W5). Interestingly, Cardiff records one of the lowest unit costs for residential care in the whole of Wales, at £335 per week. Relative to England and Scotland, there appears to be less variability in unit costs in Wales, with the range of values observed extending between £297 in Conwy and £455 in Pembrokeshire.

[2] The residential care charge indicator from which the estimates were derived was defined as the average of the mean expenditure per client supported in local authority homes and the mean charge for older people in privately provided care, weighted by the relative number of residents in the two sectors.

Table 5.3 Local authority service provision and unit cost indicators, Wales

	Wales average	*Obs*	*Std. Dev.*	*Min*	*Max*
Proportion of population over 65 supported in residential care homes or nursing homes, 2004–05 (%)	2.8	22	0.4	2.1	3.3
Residential and nursing care expenditure for older people per head of population over 65, 2004–05 (£)	571.6	22	79.0	443.7	725.2
Unit cost of residential and nursing care for older people, per person per week, 2004–05 (£)	389.3	22	40.0	296.5	454.5
Proportion of older people receiving home care, 2004–05 (%)	4.3	22	1.1	2.4	6.9
Expenditure on home care for older people per head of population over 65, 2004–05 (£)	265.6	22	63.3	159.9	399.0
Unit cost of home care for older people*, 2004–05 (£ per hour)	17.6	22	5.5	11.4	27.4
Average weekly home care package for older people, 2004 (hours)	8.0	22	1.7	6.0	12.5
Proportion of older people receiving day care, 2004–05 (%)	1.6	22	0.8	0.3	3.2

Northern Ireland

With an average of 4% of older people being supported in institutions, Northern Ireland shares (together with Scotland) the highest average rate of utilisation of residential care services per head of older population of the four UK countries. At the individual health and social services trust (HSST) level, the values ranged between 3.1% in South & East Belfast and 5.2% in North & West Belfast (Table 5.4).

Table 5.4 Health and Social Services Trust service provision and unit cost indicators, Northern Ireland

	Northern Ireland average	*Obs*	*Std. Dev.*	*Min*	*Max*
Proportion of population over 65 living in care homes, 2004–05 (%)	4.0	11	0.7	3.1	5.2
Expenditure on residential and nursing care for older people per head of population over 65, 2004–05 (£)	949.9	11	128.8	735.6	1,252.0
Unit cost of residential and nursing care for older people, 2004–05 (£ per person per week	461.3	11	36.4	408.8	526.5
Proportion of older people receiving domiciliary care, 2005 (%)	2.4	11	0.8	1.3	3.8
Expenditure on domiciliary care for older people per head of population over 65, 2004–05 (£)	440.7	11	127.8	328.9	715.2
Unit cost of domiciliary care for all recipients, 2004–05 (£ per hour)	11.3	11	1.6	8.6	13.6
Proportion of older people receiving day care, 2005 (%)	1.1	11	0.6	0.0	2.0

Not surprisingly, the distribution of residential care expenditure per head of older population is very similar to that of residential care per head of older population. South & East Belfast and North & West Belfast again show the lowest and highest levels recorded, respectively.

Out of the four UK countries, Northern Ireland health and social services trusts (HSSTs) show the smallest degree of heterogeneity in local unit costs of residential care, which vary between £409 in Craigavon & Banbridge and £527 in Sperrin Lakeland. However, to some extent at least, the smaller range of values in Northern Ireland is the product of the smaller number of local units of observation.

5.4 Home care provision

England

The average proportion of older people in receipt of home care in England is, at 3.9%, significantly greater than the proportion supported in care homes (see Table 5.1). There is a sevenfold difference between the minimum and maximum rates of homecare provision in England (1.8% in Herts and 13.2% in Tower Hamlets, respectively, see Figure E8). Geographically, the highest rates of provision per head of older population are concentrated in high population density areas, such as metropolitan districts and London boroughs (see Figure E9).

Higher levels of home care expenditure per head of older population also appear to be clustered around high population density areas, and many London areas appear situated in the top decile of the distribution (see Figure E11 and Table E6). The degree of variability, however, is much more extreme than for the indicator of home care provision. Hence, Table E8 and Figure E12 show a sixfold difference between the £610 per older person home care investment in Islington and the £101 expenditure level in Dorset.[3]

Hourly home care unit costs in England are less variable than expenditure or provision levels, and ranges between £9.20 per hour in Sefton and £22.10 in Windsor & Maidenhead (see Figure E14 and Table E7). Figure E13 shows that the spatial distribution of home care unit costs is different from the distribution of home care expenditure and home care provision rates.

The average number of hours of home care per week per recipient in England has increased significantly in recent years. It is estimated at 8.1 hours for 2004–05, but this is still below the 10 hours per week defined by the Department of Health as an intensive care package (see Table 5.1). As for other indicators, Table E8 and Figure E16 show very significant variability in the intensity of provision per recipient, with values ranging between 3.7 hours per week per recipient in Barnsley to the very high 16.5 hours per week in Coventry.

Scotland

The proportion of older people receiving home care in Scotland, at 6.9%, is higher than the value for England, a finding likely to be related to the impact of the introduction of free

[3] The values for Isles of Scilly and City of London are not quoted because of their untypical characteristics, which make them outliers with respect to most aspects of social care provision in England.

personal care in Scotland in 2002 (see Table 5.2). As in England, the rate of provision in Scotland varies significantly between Scottish local authorities (see Figure S8 and Table S4). The minimum value, 4.1% in Perth & Kinross, is over three times lower than the maximum value, 14.2% in the Shetland Islands.

The distribution of home care expenditures per older population (see Figure S9 and Table S5) shows a cluster of three very high spending authorities, which spend in excess of £740 per person per year. Spending amongst the rest of Scottish authorities showed moderate variability, and ranged between £187 in East Renfrewshire to £505 in Argyll & Bute. Notably, the average rate of home care expenditure per older population in Scotland is, at £425, over twice the level recorded for England. This differential is largely explained by the much greater proportion of older people receiving home care in Scotland.

Surprisingly given the higher levels of expenditure, average care packages in Scotland in fact cost slightly less than English care packages (see Table 5.2, Table S6, Figure S11 and Figure S12). Due to problems with the reliability of data, no information could be provided on unit costs of home care in Scotland.

Wales

The proportion of older people receiving home care services in Wales at 4.3% is slightly higher than in England and significantly lower than in Scotland. Overall, the distribution indicates a three-fold variation in the rates of provision between local authorities (see Figure W8 and Table W4). The differences in the spatial distribution of the rates of provision and expenditure per head of older population (see Figure W1 and Figure W3 respectively) are explained by differences in unit costs and differences in the average intensity of care packages between local authorities (see Figure W12 and Figure W14, respectively).

The higher home care unit costs in Wales relative to other UK countries (£17.6 per hour on average) could be due to higher levels of in-house provision. These high unit costs explain why, despite lower numbers of recipients per head of older population and similar levels of average care package intensity, the Welsh home care expenditure rate per head of older people exceeds England's by approximately 24%.

Northern Ireland

It is difficult to compare the patterns for provision of home care in Northern Ireland against those in other UK countries as only data relating to domiciliary care could be identified. Nevertheless, assuming that the number of recipients of domiciliary care should at least equal if not exceed those of home care services, the proportion of older people in receipt of domiciliary care support in Northern Ireland appears very low at 2.4%, against 4.3% in Wales, 6.9% in Scotland and 3.9% in England.

As for residential care services, Northern Ireland patterns of provision appear to vary less than in the rest of the UK, partly because of the smaller number of areas.

5.5 Day care provision

Much smaller proportions of older people receive day care services than either home care or residential and nursing care (see Tables 5.1 to 5.4). The proportion of older people in

receipt of day care services ranges between averages of 1.1% in Northern Ireland, 1.3% in Scotland, 1.6% in Wales and 1.7% in England.

Rates of provision within each constituent country vary widely, much more than for either of the other services explored. In England, the highest rates of provision are concentrated in the north of the country and some London boroughs (see Figure E15). Strikingly, the proportion of older people receiving day care services varies from 0.1% in Bath & North East Somerset to 4.1% in Kingston-upon-Thames (see Figure E19 and Table E9). Regional differences in the distribution of voluntary sector organisations may help to explain such variations in the provision of day care services (references to be added).

Similar ranges of provision are also found in Scotland and Wales, varying between 0.4 and 4.8 and 0.3 and 3.2, respectively.

5.6 Comparisons of indicators across countries

Limitations in comparability

The data presented in this chapter are intended to show equivalent indicators for each of the four countries in the UK. While this facilitates the comparison of data across countries, it should be noted that inconsistencies in the methods of data collection employed from country to country could have an effect upon the reliability of such an assessment. Activity and expenditure rates are generally reported as annual figures, however in some cases indicators are based on data collected during a sample week or at the close of a financial year. Equally, the level of exactitude in recorded data varies between countries, most notably in the case of care package intensity: data recorded by range will provide less accurate an indicator than those collected as actual values.

Indicators for Northern Ireland have not been included in this section. A lack of boundary data corresponding to HSS Trusts meant that data from Northern Ireland could not be illustrated as a thematic map. Moreover, the paucity of information specific to older people and lack of consistency with terminology used in datasets from England, Scotland and Wales would make inter-country comparisons far less appropriate in this instance. The indicators covered below also exclude unit costs, because of the heterogeneity of methodologies employed by countries to calculate these.

Residential care

As Figure 5.1 shows, the proportion of older people in care homes is notably higher in Scotland (4.0% on average) than England or Wales (2.5% and 2.8% on average, respectively). Indeed, the average figure in Scotland exceeds the proportion recorded in all but four local authorities in England.

Greater variation is evident amongst authorities in England than either of its neighbours, although this in itself is not entirely revealing given the number of authorities it contains (150 in England, compared with 32 in Scotland and 22 in Wales).

The average expenditure per head of population over 65 on residential and nursing care homes for older people is highest in Scotland at £778.00 per week, as might be expected given the high proportions of older people supported in institutions. Although to a lesser extent than for community services, the introduction of free personal and nursing care in 2002 may have played a part in increasing residential care expenditure in Scotland relative

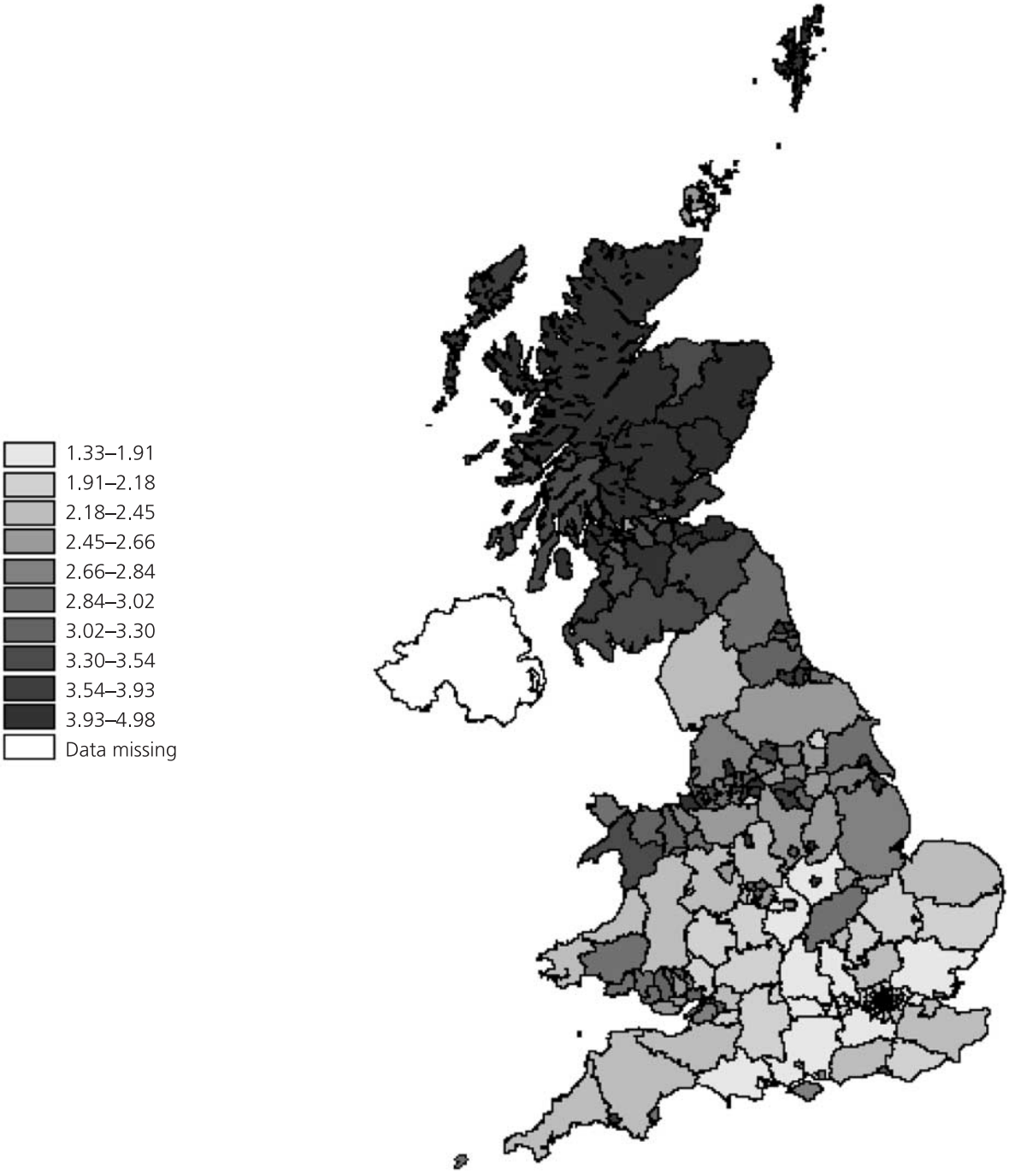


Figure 5.1 Spatial distribution (deciles) of the proportion of population over 65 living in care homes, UK 2004–05 (%)

to other countries (see Figure 5.2). Overall, the Wanless enquiry estimated free personal care would lead to increases in care costs for older people of around 10% (Wanless 2006).

In both England and Scotland, levels of expenditure amongst authorities appear to vary broadly in keeping with levels of supported residents, whereas in Wales such a correlation

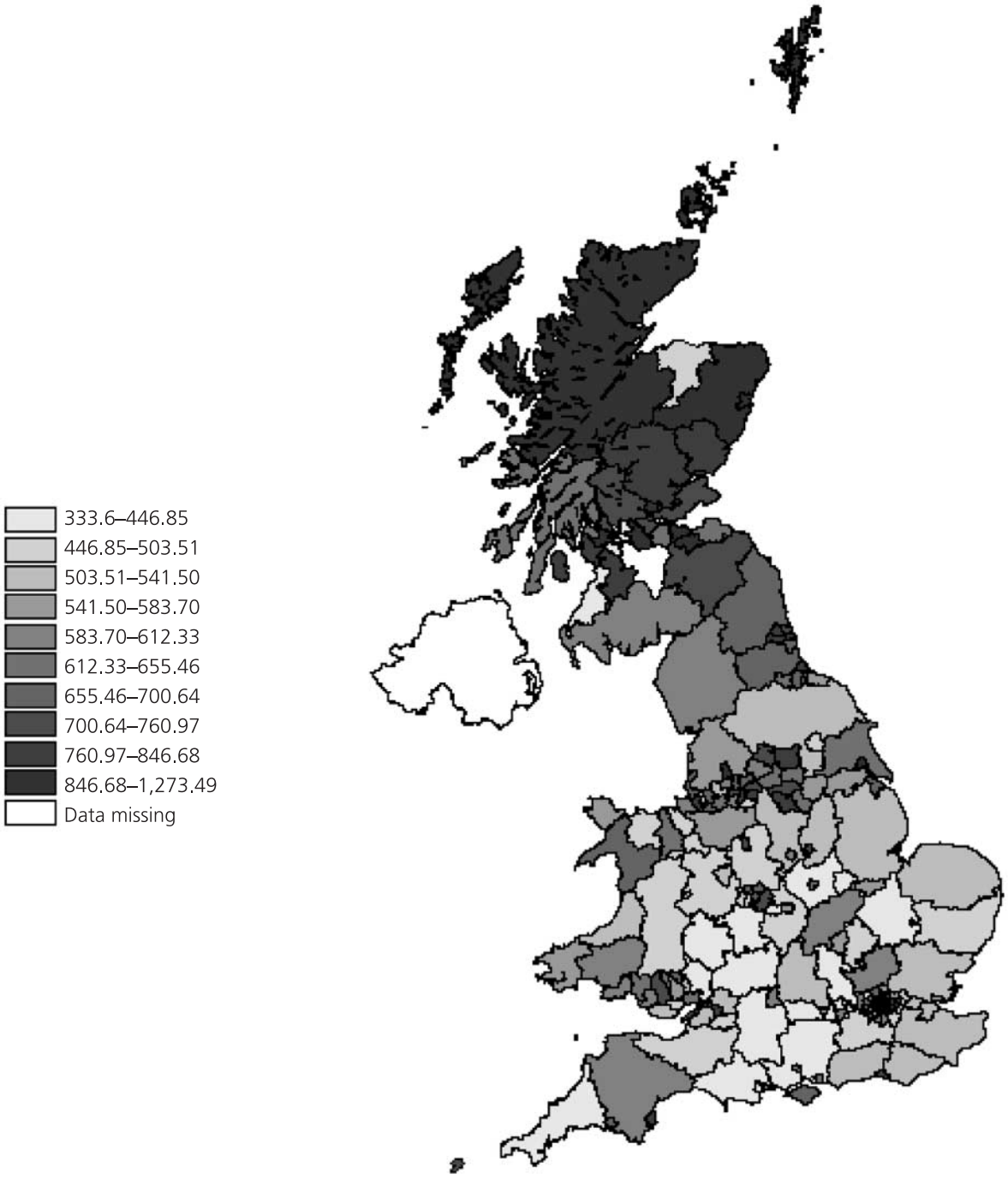


Figure 5.2 Spatial distribution (deciles) of the expenditure on residential and nursing care for older people per head of population over 65, UK 2004–05 (£)
Excludes data for Glasgow city and South Lanarkshire

is less evident. The highest rate of expenditure on residential and nursing care for older people per head of population over 65 (£1273) is recorded in Islington. In general London boroughs accounted for 73% of English authorities in the top decile of expenditure per capita.

Home care

As was found for residential services, the proportion of older people in receipt of home care is highest on average in Scotland, where 6.9% of the population over 65 received home care, as opposed to 3.9% and 4.3% in England and Wales, respectively (see Figure 5.3 and

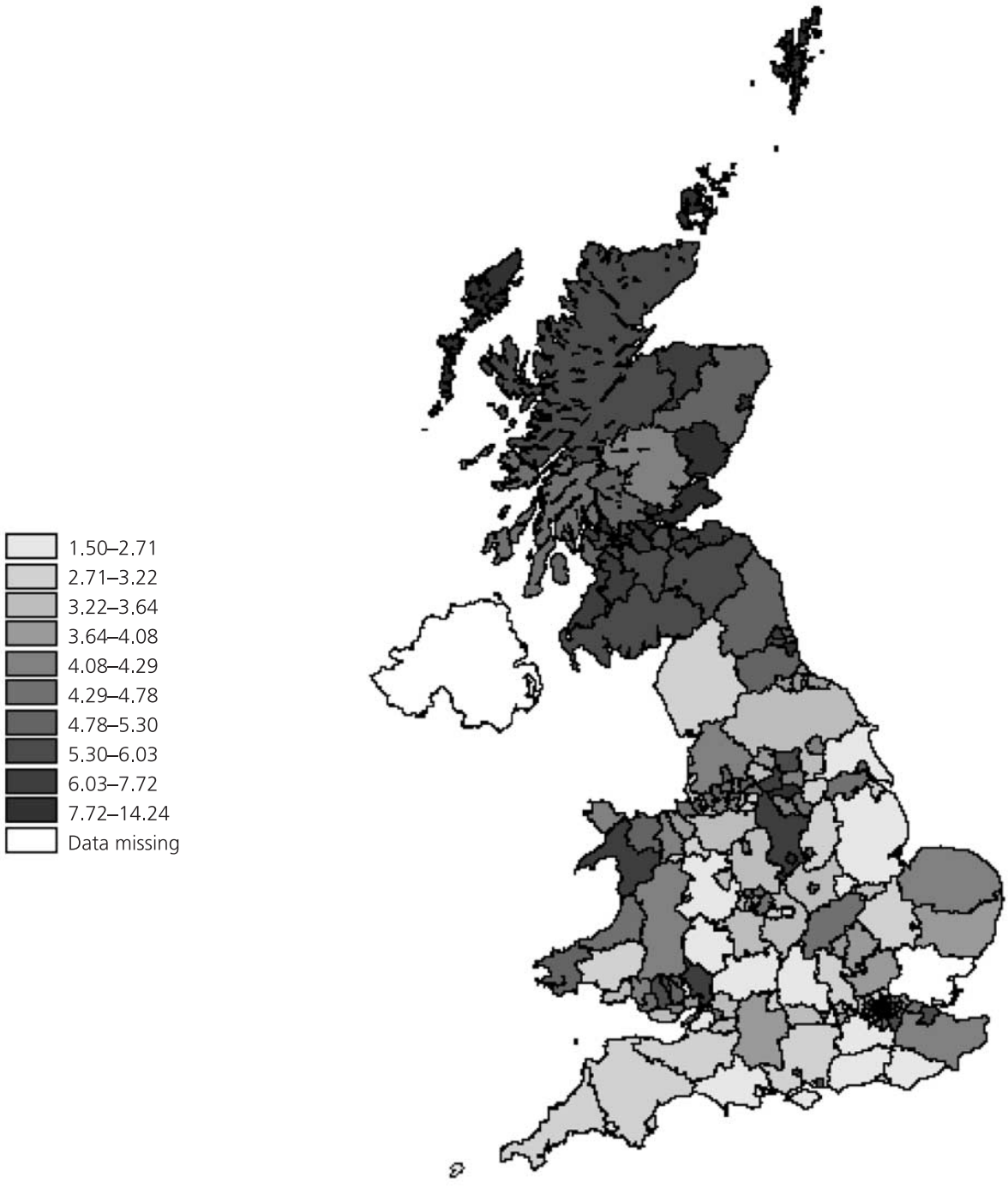


Figure 5.3 Spatial distribution (deciles) of the proportion of population over 65 receiving home care, UK 2004–05 (%). Data for Scotland relate to 2005–06

Table 5.3). Again, the introduction of free personal care is likely to have contributed to raising demand for home care in Scotland.

The receipt of home care varied by a similar magnitude amongst authorities in England and Scotland, from 1.5% to 13.2% in England and 4.0% to 14.2% in Scotland. The proportion of older people in receipt of such services ranged from 2.4% to 6.9% in Wales.

Expenditure per capita on home care (Figure 5.4) varied significantly between the countries.

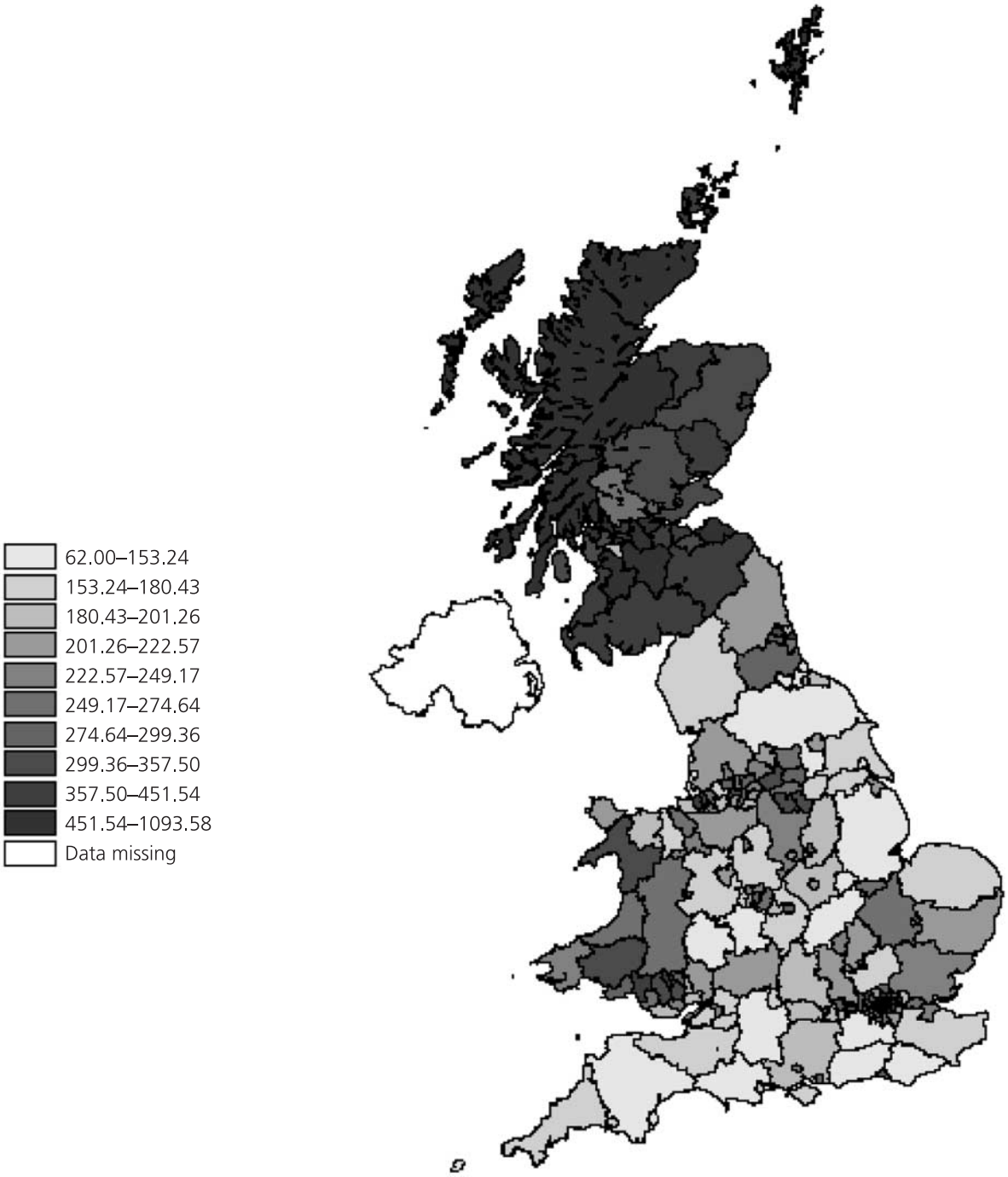


Figure 5.4 Spatial distribution (deciles) of the expenditure on home care for older people per head of population over 65, UK 2004–05 (£). Data for Scotland relate to 2005–06

England had the lowest average expenditure levels, at £214 per head of population over 65 in England, followed by £266 in Wales and £425 in Scotland. While activity levels amongst authorities were notably lower than those in England and Scotland, the prevalence of local authority-provided care services in many Welsh authorities may go some way to explaining the relatively high levels of expenditure reported.

There are large variations in the provision of home care services in England, Scotland and Wales (see Figure 5.5). West Scotland, northwest England and the West and East

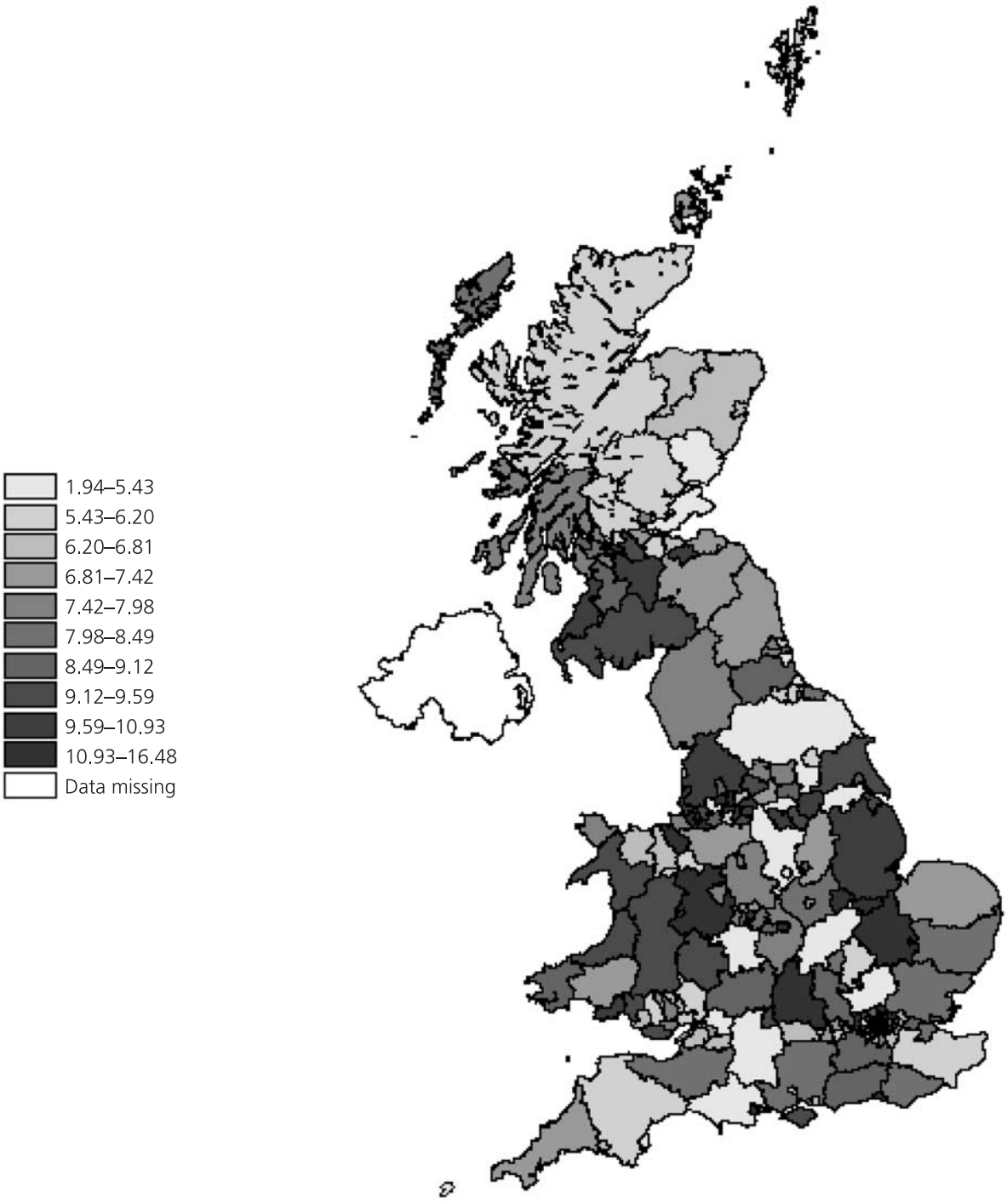


Figure 5.5 Spatial distribution (deciles) of the average weekly home care package for older people, UK (hours)

Midlands all provided the larger weekly home care packages, although intensity varies amongst neighbouring English authorities. While Wales has relatively few areas in which the average home care package counts as 'intensive' (more than 10 hours of home care per week), it also has a comparatively high minimum average package of care (6.0 hours per week on average in Monmouthshire, compared with 1.9 hours per week in the Isles of Scilly

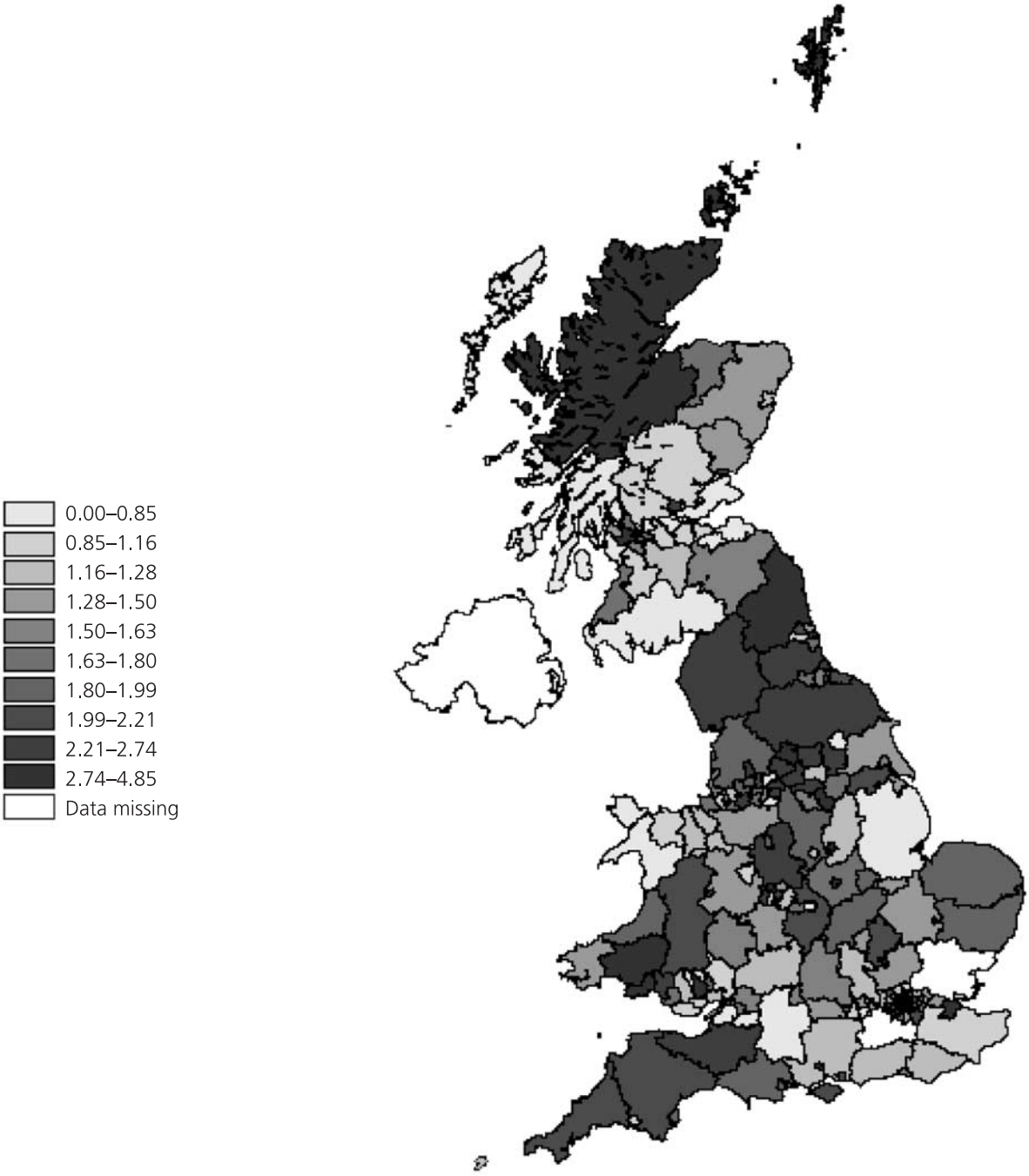


Figure 5.6 Spatial distribution (deciles) of the proportion of older people receiving day care, UK 2004–05 (%). Excludes data from Birmingham, Essex, Surrey, City of London, Isles of Scilly

(the next lowest is Barnsley with 3.7 hours) in England and 3.6 hours per week in Angus in Scotland. Again, the fact that Wales contains notably fewer authorities will account for this result to some extent – the average home care package at 8.0 hours per week in Wales being close to the average of 8.1 hours per week in England and 7.4 hours per week in Scotland.

Day care

As Figure 5.6 shows, the highest levels of day care are in the Scottish Highlands, The north and southeast of England and Mid Wales. While the area with the highest average proportion of older people receiving day care is in Scotland (4.8% in the Shetland Islands), the average proportion was higher both in England and Wales (1.7% and 1.6% respectively), compared with 1.3% in Scotland. At the lower end of the range, figures indicate that only 0.1% of the population receive day care in Bath & northeast Somerset, 0.4% in Midlothian and 0.3% in Gwynedd.

CHAPTER 6

The financial cost of dementia in the UK

6.1 Introduction

Establishing the costs associated with dementia is a complex process because, as with any chronic debilitating illness, there are facets of costs that can be justifiably included or excluded. Previous UK cost-of-illness studies, which we briefly summarise to introduce our own new estimates, have used a range of methods and have been more or less inclusive of cost elements.

An epidemiological cost model was developed by McNamee et al (2001) to estimate costs for individuals aged 65 years or over with dementia (living in private households or in supported accommodation) and to provide future projections of formal care costs related to the current frequency and duration of service use. Mean costs were calculated by gender and five-year age bands. Costs for 1994 were £6.3 billion (£0.95 billion for men and £5.35 billion for women). Assuming lower prevalence rates and greater improvements in mental and physical functioning resulted, not surprisingly, in lower cost estimates.

Gray et al (1993) calculated direct and indirect costs of Alzheimer's disease using a 'top down' approach. Informal care time was not included in the estimates, but payments to carers were and these amounted to 6% of the total cost. Residential care was the most expensive service (66% of the total), followed by inpatient and outpatient care (18%). The total annual cost in 1990/91 prices was £1,039 million.

Kavanagh et al (1995) used data from an OPCS disability survey to estimate the proportions of people with cognitive impairment in different types of care. Cost of care packages were then calculated using a variety of cost sources and updated to 1992/93 prices. Care package costs were estimated for those living in private households, residential/nursing homes and hospitals. Informal care constituted 26% of the total costs, personal consumption 33.4% and accommodation costs 17.6%.

In a UK cross-sectional multi-centre study, Souetre et al (1999) examined costs associated with different severity levels of AD in non-institutionalised patients and matched controls. They took a societal perspective and found that informal care time accounted for 67% of the total, with the remainder consisting of hospital care, residential care, outpatient contacts, medication, social care and modifications to the patient's home.

Based on a review of published studies, Lowin et al (2001) produced updated cost estimates for AD in the UK. Total costs ranged between £7.06 billion and £14.93 billion, with the actual figure being largely dependent on the method used for calculating informal care costs.

Wolstenholme et al (2002) conducted a retrospective analysis of a longitudinal data set for a

cohort of 100 patients diagnosed with AD or vascular dementia and examined the relationship between disease progression and the cost of care. They reported the total cost per patient over the course of the study as £66,697, based on a mean follow-up over 40 months. Institutional care accounted for 69% of total cost. The authors also reported cost by disease severity categories defined using the MMSE and by Barthel index categories. Increases in severity were shown to result in higher costs.

Livingston et al (2004) report findings from a longitudinal epidemiological study of 224 AD patients. The objective of this study was to validate a functional classification model of AD patients, exploring the relationship between dependency and costs of care. Comprehensive service use was measured with information collected on formal and informal care received during a three-month retrospective period. Increased dependency was significantly associated with higher costs.

6.2 Methods

To estimate the cost of dementia it was necessary to attach service costs, plus informal care and lost employment costs, to the prevalence data described earlier. Studies that have either estimated dementia care costs or have evaluated specific interventions for dementia have previously been conducted by colleagues at the Institute of Psychiatry and the London School of Economics, and datasets containing resource use information relating to these studies were obtained.

The most comprehensive source of service use and costs data was a report for the Department of Health from Murray et al. One hundred and thirty-two people with dementia and their carers who were referred to psychiatric services between January 1997 and June 1999 were interviewed, with service use measured using a version of the Client Service Receipt Inventory (CSRI; Beecham and Knapp 2001). The CSRI asked for details of accommodation and services used during the previous three months. Services included medication, inpatient care, outpatient care, day hospitals, day centres, community health services, social care and respite care. The level of informal care (which, whilst unpaid, has previously been shown to have a substantial economic cost) was measured using the Caregiver Activity Survey (Davis et al 1997). Using that instrument the authors were able to measure the amount of time carers spent performing general tasks, specific tasks and supervisory activities. Costs of care were calculated by attaching unit costs (Netten et al 1998) to services received. Informal care was initially costed by applying: (i) the hourly cost of a home care worker to hours spent performing specific tasks, and by applying (ii) the minimum wage to time spent performing general tasks and supervisory activities. In sensitivity analyses we applied each of these unit costs in turn to all informal care hours.

We have inflated the costs reported by Murray et al in order to reflect 2005/6 price levels. However, we have also made an adjustment to reflect costs for the UK as a whole (the Murray et al sample was London-based). Costs were only used for definite cases of dementia (n=114) and were divided into two categories – those relating to people in residential care and those living in the community. The community sample was subdivided into mild, moderate and severe subgroups according to the Clinical Dementia Rating Scale (Hughes et al 1982). We did not subdivide those living in residential care into severity groups as the dominant cost is the accommodation itself. The cost of the latter was estimated by using a weighted average of unit costs for supported accommodation from Curtis and Netten (2006). Weighting was according to the numbers of people in different types of accommodation reported in the 2001 census.

Other studies that have calculated service costs or estimated levels of informal care for people with dementia were used in sensitivity analyses. There is very little information on care received by people with early onset dementia and therefore the costs here relate only to late onset dementia.

6.3 Results

The annual costs that were derived from the Murray et al data and subsequently attached to the prevalence estimates are shown in Figure 6.1. This clearly shows that for people living in the community, health care has the lowest annual cost and is unaffected by the severity of dementia. This might seem counterintuitive given that admissions and continuing care are more likely for those with more severe problems. However, such care may be offset by reduced access (or uptake) of more general healthcare services as dementia progresses. Non-accommodation care provided by social service departments rises with severity level as does unpaid informal care, which has the highest cost. Perhaps not surprisingly, the cost of care for people living in supported accommodation is dominated by the cost of the accommodation itself. Outside care from health or social service agencies is infrequently used and informal care also has a low cost. Elsewhere, an OECD report by Moise et al (2004) suggests that as severity of dementia increases so the role of health care decreases, but social care plays an increasingly important role. However, other studies have found a clear gradient between healthcare costs and severity (MacNamee et al, 2001; Kavanagh and Knapp, 1999). The latter study was based on data from the 1980s and since then there has been considerable reduction in use of hospital services and growth in the role of local authority-brokered social care services.

The total annual cost per person in the above categories is estimated to be as follows:

- people in the community with mild dementia – £16,689
- people in the community with moderate dementia – £25,877
- people in the community with severe dementia – £37,473
- people in supported accommodation – £31,296.

Murray et al compared people living in supported accommodation, those living with a co-resident and those living alone. For these three groups, primary care services accounted for 11%, 12% and 14% of NHS costs respectively. Inpatient costs differed substantially, accounting for 82%, 57% and 37% of NHS costs respectively. The other major NHS cost was community healthcare, accounting for 5%, 15% and 40% of costs respectively. Social services costs were dominated by day centre inputs for all three groups. Whilst these comparisons are different from those we report, the above figures do suggest that as severity increases (so the likelihood that people with dementia live alone decreases) that community healthcare costs are reduced relative to inpatient costs.

These annual costs, when aggregated and applied to the number of people living in the community with dementia, show a lower total cost impact for the severe group than for the moderate or mild groups (Figure 6.2), but this is entirely due to the fact that there are fewer people in the most severe group.

The distribution of service costs for all cases of late onset dementia shows that accommodation accounts for nearly half of all costs (Figure 6.3). Informal care accounts for

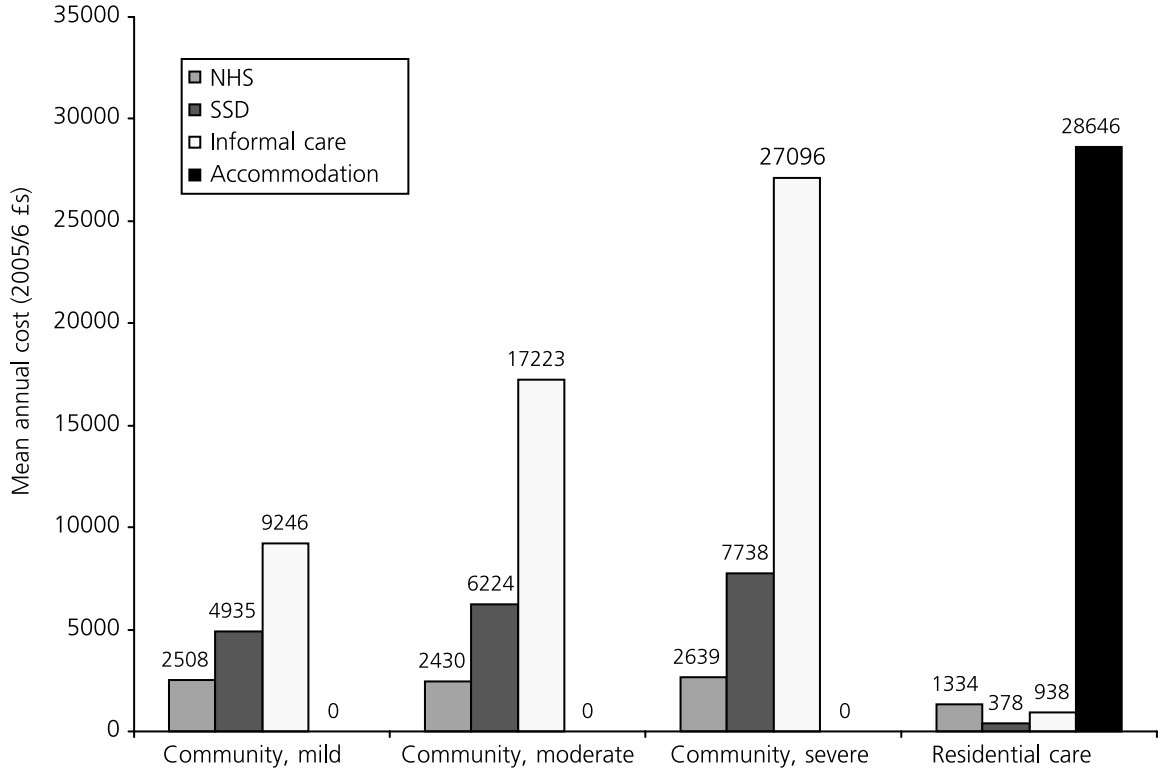


Figure 6.1 Annual cost of services used by people with late onset dementia

slightly more than one quarter of costs with one quarter accounted for by NHS and social care services.

The total cost of care for people with late onset dementia in 2005/6 prices estimated to be £17.03 billion (Figure 6.4). Supported accommodation and informal care costs account for by far the most of the total. The cost per person with dementia is £25,472.

Figure 6.5 shows the impact on total costs of using alternative costs for informal care. If all informal care is valued at the minimum wage then we can see that total costs are £1.42 billion lower. However, if all informal care is valued using the cost of a homecare worker then the costs are £7.36 billion higher.

The total number of carers according to hours of care provided and country was measured as part of the 2001 Census (Table 6.1). However, only 26% of carers were caring for someone with a mental health problem. Nevertheless, if we assume that the figures below represent the pattern of caring for people with dementia, and if we take the mid-point number of hours for each range and assume 60 hours per week for those receiving the most care then the weighted average is 24 hours of care per week. Valuing this (only for people in the community) at (i) the minimum wage, and (ii) the cost of a homecare worker, would result in total costs of £12.87 billion and £16.15 billion respectively.

Welfare benefits, lost production and lost tax revenue

People with dementia living in the community will usually be in receipt of Attendance Allowance (AA) or Disability Living Allowance (DLA). In May 2006, there were 164,040 people aged 65 or over entitled to AA because of mental health problems (most of whom would have dementia) and the total amount of this comes to £456 million. Total DLA costs

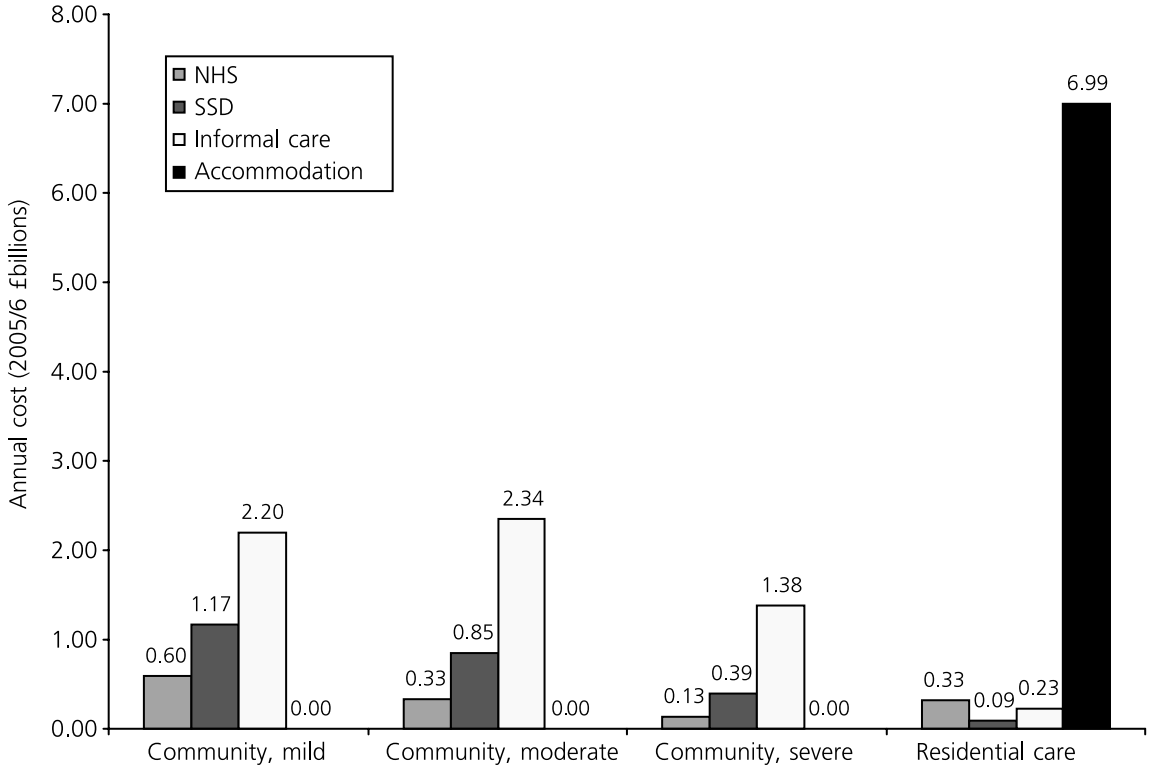


Figure 6.2 Annual cost of services used by people aged 65 and over with dementia in the UK

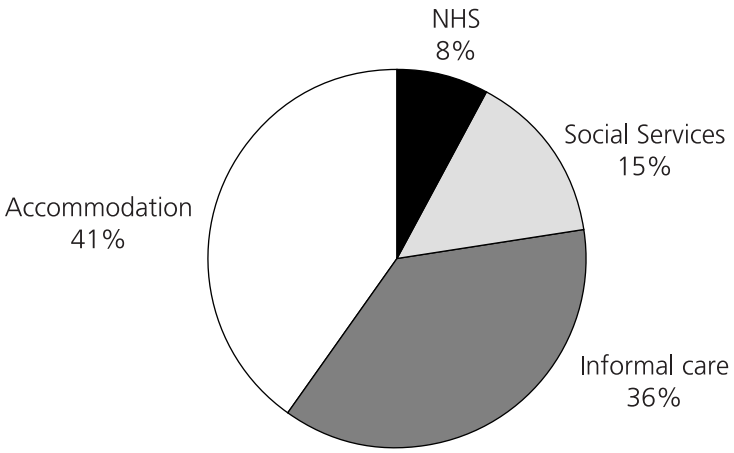


Figure 6.3 Distribution of dementia service costs

Table 6.1 Informal care hours provided according to 2001 Census

Zone	*All*	*1–19 hours/week*	*20–49 hours/week*	*50+ hours/week*
England	4,8770,60	3,347,531	530,797	998,732
Wales	340,745	208,291	42,850	89,604
Scotland	481,579	305,600	60,305	115,674
Northern Ireland	185,066	28,000	46,659	110,407
UK	**5,884,450**	**3,889,442**	**680,611**	**1,314,417**

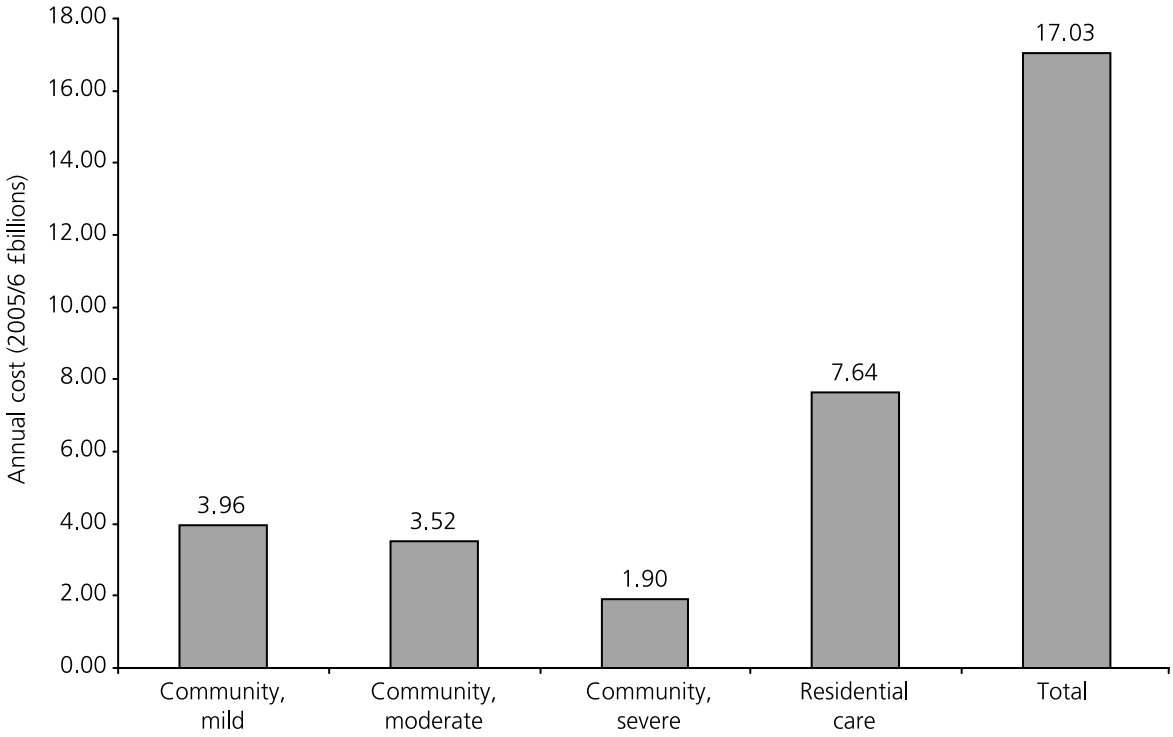


Figure 6.4 Total annual cost of care for people aged 65 and over with dementia in the UK

for people aged 65 or over with mental health problems are around £70 million. In the Murray et al study, 50% of people with dementia in the community received at least 35 hours of informal care per week. This qualifies carers to Carer's Allowance of £46.95 per week. Based on the prevalence estimates in this study, this implies a cost of £518 million. Therefore, the total cost of benefits is around £1 billion. Welfare benefits are not considered to be an *economic* cost as they are essentially a transfer of money from one group of people (taxpayers) to another (recipients) rather than a payment for a productive activity. They are of course a *financial* cost to the government though, but we need to be consistent with other economic studies and report the costs separately.

It is likely that some carers will have had to have given up work in order to care. In the Murray et al study, 30% of male carers were under the age of 65, whilst 52% of female carers were under the age of 60. However, only 16% of carers stated that they had actually given up work (7%) or cut down their working time (9%). The median weekly wage in the UK is currently £447 (National Statistics, 2006). If 7% of people with dementia in the community have carers who have given up work then the lost potential production based on the median wage is £690 million. Lost tax revenue (excluding national insurance), based on this foregone income and an average proportion of income that goes on tax of 17.8%, would be approximately £123 million. An assumption here is that people who give up work are under 65 and have average paid jobs. We would not want to add these costs though to the total because the benefits that carers receive will compensate them to some extent for lost work and leisure time due to their caring responsibilities.

6.4 Limitations

The estimates of service costs for people living in the community were limited to some extent by the small number of relevant datasets that we could draw on. The most com-

prehensive source of data (Murray et al) may not have been wholly representative of all people with dementia as it included only those people who had a carer, and patients were sampled from one part of London. However, we have adjusted the costs to remove the 'London effect'. Although everyone in the Murray et al sample had a carer at entry to the study, we can see that the amount of informal care for those in supported accommodation is very low. NICE has estimated that the ratio of persons with dementia to carers is 0.85 (following discussions with experts) and our data appear to be consistent with this other estimate. We should nevertheless be cautious in interpreting the results.

In addition, the costs used in the calculations are rather dated, even though we have inflated them to current price levels. This was unavoidable given the lack of available studies, but it should be recognised that care arrangements will have changed during the past 10 years particularly with the introduction of new medications. Finally, in this study we have not directly addressed the question of who pays for care. However, as Figure 6.3 shows, the NHS accounts for at least 8% of costs whilst families account for 36% in the form of informal care. Care homes and non-residential social care account for the remainder, and a certain amount of this will be paid for by services users themselves.

6.5 Discussion of findings

These analyses have shown an estimated service cost of late onset dementia of over £17 billion per year. Most of this is accounted for by supported accommodation costs and informal care. The cost per person has been estimated at nearly £25,472 per year, but we would urge some caution in using this figure. Elsewhere in this report we have provided tables showing the predicted number of cases of dementia for each English Local Authority with social services responsibilities (and equivalents in Wales, Scotland and Northern Ireland) and so there may be temptation to multiply the cost per person by these numbers. However, this cost is intended to be indicative of service provision. At a local level there will often be differences in the level of provision, prices and costs. In addition we would not wish to imply that the figure of £25,472 per year is optimal – appropriate care may cost more or indeed less than this figure.

6.6 Projected future costs

In the absence of major breakthroughs in prevention or treatment, the expected ageing of the population will mean much larger numbers of people with dementia. Although any future projection is by nature uncertain, and past projections for the UK have tended to underestimate what has actually happened, all estimates point to especially rapid growth in the number within the oldest age groups. For example, the Government Actuary's Department (GAD 2005) figures for England for the period between 2002 and 2041 suggest a 190% increase in the number of people aged 85 and over.

Making demographic projections is uncertain enough, but it is much more difficult to project individual needs, service responses and expenditure implications. However, a model has been built by the Personal Social Services Research Unit (PSSRU) at the London School of Economics and Political Science to make such projections. The model was first constructed 10 years ago, particularly to support the Royal Commission on Long Term Care (1999). It endeavours to project future demand for long-term care and associated

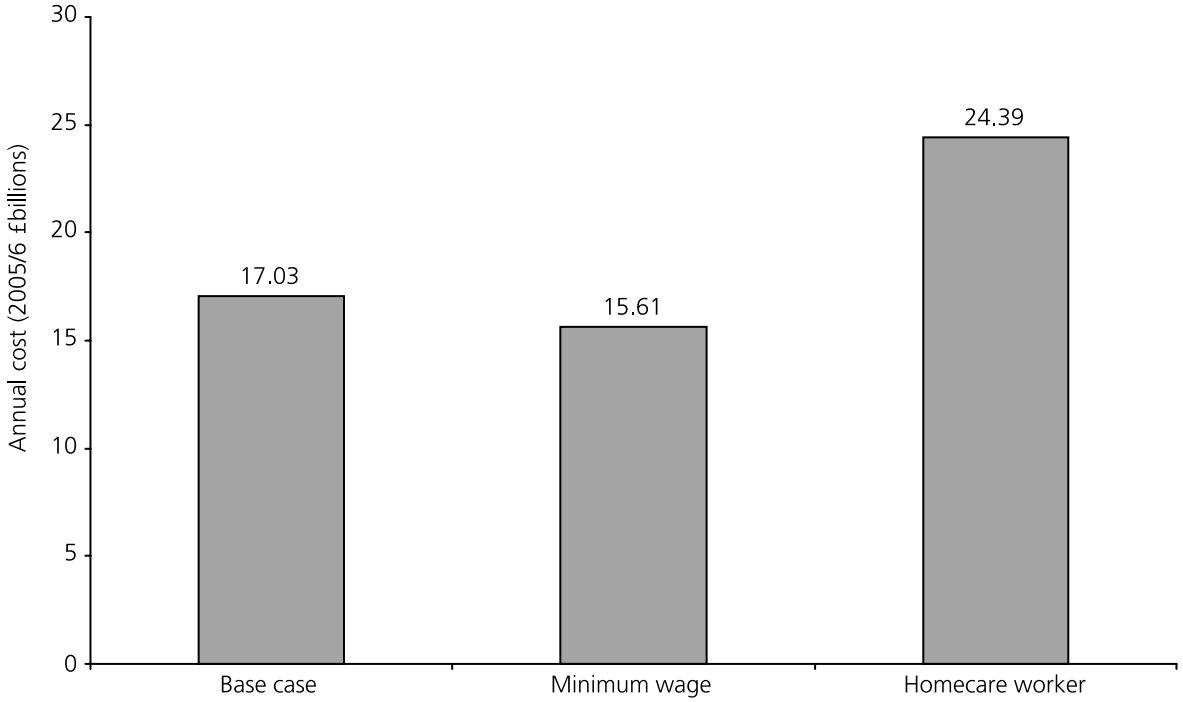


Figure 6.5 Impact on total costs of different values placed on informal care

expenditure under a range of scenarios (see Wittenberg et al 1998, 2001, 2006; and Comas-Herrera et al 2003 for more details). It is confined to England, although variants of the model have been constructed for some other countries.

The model has many elements, built up from expected demographic changes over future decades (taken from the Government Actuary's Department). It uses best available evidence to estimate the care needs of future generations of older people using current patterns of association and expected changes that could result from (for example) developments in public health, medical technology and treatment. It includes a module that estimates the availability of informal care, based in part on changing demographic patterns (which will have an impact on the potential numbers of both spouse carers and child carers) but also factoring in expected changes in labour force participation by women. It makes a range of assumptions about the ways in which governments will allocate resources to meet needs, taking into account such factors as the availability of informal care, the targeting of services on 'high-need' individuals, and the balance of provision between residential and home-based care. The model attaches costs to these various service arrangements under a range of assumptions about staff salaries, particularly in view of today's shortages of skilled staff and what are widely seen as low levels of pay. Finally, it includes projections of future levels of gross domestic product (GDP) in order to be able to estimate the proportion of total national economic wealth that would need to be allocated to supporting older people with long-term care needs. Finally the modelling process varies each of these assumptions about future trends, patterns and levels in order to explore the implications of a range of different scenarios. (For details see Wittenberg et al 2006.)

In work recently funded by the Alzheimer's Research Trust, the PSSRU long-term care model has been adapted in order to make projections specifically for dementia (Comas-Herrera et al 2007). Estimates have been made of the numbers of older people with dementia, their needs, the services required in response to those needs, and the costs of those services. The model as currently constructed does not make projections of the costs

falling to informal carers. The basis for these projections is not the most recent set of prevalence figures presented in Chapter 3, nor are costs calculated on quite the same basis as those presented in this chapter. However, these forward projections by Comas-Herrera and colleagues nevertheless offer some very interesting figures. The full details are awaiting publication and it is not possible to reproduce them here, but the modelling projects that expenditure on long-term care services for older people with dementia in England will rise from about £5.4 billion in 2002 (as estimated under the assumptions used in the model) to around £16.7 billion in 2031. These figures do not comprise the total costs of dementia to society, but alone they are equivalent to an increase from around 0.60% of GDP to 0.96% of GDP over the same period.

Projections of this kind make it essential that governments – and indeed the general public, since future responsibilities will be widely shared – give urgent attention to the question of how to finance the arrangements necessary to meet the future needs of an ageing population (Wittenberg et al 2002, Wanless 2006).

CHAPTER 7

Recommendations

1 **Make dementia a national priority**
2 **Increase funding for dementia research**
3 **Improve dementia care skills**
4 **Develop community support**
5 **Guarantee carer support packages**
6 **Hold a national debate on who pays for care**
7 **Develop comprehensive dementia care models**

Historically, a lack of attention from policy makers and service commissioners to the needs of people with dementia has led to dementia care being delivered piecemeal and in an inefficient fashion. More investment accompanied by careful planning will be needed in the years ahead in order to ensure that not only do we maximise quality of life for people with dementia and their families, but also that we do so in an efficient way with the resources available.

Despite areas of good practice, the UK's current health and social care system is characterised by a widespread failure to support people with dementia and their families. These findings have been demonstrated most recently in evidence from the Wanless report into social care (2006) and CSCI state of social care report (2007). This failure to develop services which meet the needs of people with dementia is perplexing given that dementia is a significant driver of demand for health and social care.

This *Dementia UK* report identifies:

1 People with dementia are substantial users of health and social care services.
2 The number of people with dementia and families affected by dementia is set to increase rapidly and we will therefore see increasing demand for support services.
3 Increased demand for support services will be driven both by the increases in the numbers affected and the shift in the age distribution towards a preponderance of the oldest people, who tend to be frailer and to have more limited informal support networks.

Dementia care is characterised by a significant lack of evidence on outcomes and the current state of service delivery. The recommendations that follow therefore contain both a series of proposals for policy development, and proposals on improving the evidence base.

Recommendation 1: Make dementia a national priority

Dementia must be made a publicly stated national health and social care priority. This must be reflected in plans for service development and public spending.

- A cross-government strategy for dementia must be developed to respond to the growing need for care from early diagnosis to end of life care.
- Dementia care and research must be prioritised in the 2007 Comprehensive Spending Review.
- Health and social care commissioners must develop local plans to support increasing numbers of people with dementia and their families.

Current government policies, including the National Service Framework for Older People, Carers Strategy, NICE care guideline and Everybody's Business provide a starting point. Although mental health is a national clinical priority along with cancer and heart disease, dementia has not received the attention it requires. A coordinated national dementia plan with political commitments is now a necessity. This will require planning between the public, private and independent sectors.

Recommendation 2: Increase funding for dementia research

As a matter of urgency there must be a review of UK medical research funding to establish a more ambitious funding programme into the causes, prevention, cure and care of dementia.

Increasing the amount of dementia research is an urgent priority if we are to improve the treatment of people with dementia in the future, and make evidence-based plans to provide high quality care to meet the evolving needs.

Recommendation 3: Improve dementia care skills

Dementia care training should be made a core and substantial part of the training curriculum for nurses and social care staff. National Minimum Standards must be developed to include dementia specific requirements on dementia care training.

Poor understanding of dementia and its consequences is currently leading to underdiagnosis, late diagnosis and an inadequate care response. This all creates an inefficient use of resources. For example, people who go in for similar procedures can stay twice as long in hospital if they also have dementia. Serious medical conditions are not being identified early and care packages in the community are put in place too late. Without significant focus on improving care across health and social care, outcomes will get worse and resources will be squandered.

The current National Minimum Standards were always meant to be a starting point for good practice. Now it is time to develop stronger requirements. We must go beyond the current dementia options in the Quality and Outcomes Framework for GPs to improve the early identification, diagnosis and management of dementia by GPs.

Recommendation 4: Develop community support

People with dementia need improved home care support packages, including low-level support to retain their independence and dignity.

Stated national policy focuses on early identification and intervention. However, local authorities across the country have been skewing access to home care support towards people with the highest levels of need. It is now very difficult for people not classed as having substantial or critical levels of need to access services. As the population ages and the number of people with dementia increases, this situation will worsen.

People with dementia can stay at home for longer with their families if the right support is put in place.

- The number and extent of home care packages must be increased.
- Home help services such as help with cleaning, shopping, DIY and gardening must be brought back.
- The opportunities for people with dementia and carers to access direct payment and individual budgets must be increased.

Recommendation 5: Guarantee carer support packages

Family carers must have guaranteed access to carer support. In particular:

- **psychological therapies including carer training and support groups**
- **quality respite care for people with dementia and carers.**

The *Dementia UK* report identified that people caring for people with dementia save the public purse over £6 billion a year. Although the total proportion of people who are able to care for relatives may decline in the future, there will remain a substantial proportion of people eager to continue providing informal care for people with dementia. The current policy response to carers is very weak and needs revision. Without formal commitments to an improved package of support for carers, an increasing number will be unable to continue caring and pressures on long-term care will increase.

Recommendation 6: Hold a national debate on who pays for care

We must have a national government-backed debate on who pays for care to establish a clear and fair balance between the contributions made by the state and the individual.

Dementia care is expensive and the divide between what the government defines as healthcare which should be free, and social care which should be means tested is becoming increasingly difficult to define.

The *Dementia UK* report demonstrates that the financial cost to society is on average £25,000 per person with dementia per year. Currently the majority of this cost is met by people with dementia and their families through informal care and care charges, whereas other long-term medical conditions receive far more support from the state. We need a national government-backed debate about who pays for care. The evidence is that people are willing to make a contribution towards their care if a number of conditions are satisfied. A new solution must be transparent, easy to understand and equitable. The care being paid for must also be of good quality.

Recommendation 7: Develop comprehensive dementia care models

Develop an integrated, comprehensive range of care models for people with dementia to bridge the gap between care at home and care in a care home.

The direction of health and social care policy in the last 20 years has been to increase the proportion of older people who can be supported in their own homes in the community. This has been partially successful. The impact on long-term care has been that the proportion of people in care homes with complex medical conditions has been increasing. The majority of people in care homes have a form of dementia. The real challenge now, aside from improving the quality of care in care homes, is to support people with dementia for longer in their own homes. More effort is required from the public, private and voluntary sector to find good quality, cost effective options to meet the needs of people with dementia and their families.

More information

For more information please contact the Alzheimer's Society by calling 0207 306 0883 or visit the website at www.alzheimers.org.uk.

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TABLE A1.1

Regional variation in the prevalence of dementia by local authority across the UK

	Men						*Women*						*% of total population with dementia (men and women)*
Area	*30–64*	*65–74*	*75+*	*Total*	*% of over 65s with dementia*	*% of total pop with dementia*	*30–64*	*65–74*	*75+*	*Total*	*% of over 65s with dementia*	*% of total pop with dementia*	
Wales													
Anglesey	12	70	225	307	5.0	0.9	8	58	532	598	7.7	1.7	1.31
Blaenau Gwent	11	78	181	270	5.1	0.8	8	55	536	599	8.7	1.7	1.27
Bridgend	20	120	364	504	5.1	0.8	15	98	845	957	7.4	1.4	1.12
Caerphilly	26	149	407	583	4.8	0.7	18	114	954	1,086	7.0	1.2	0.98
Cardiff	39	236	808	1,082	5.6	0.7	28	194	1,783	2,005	7.7	1.2	0.97
Carmarthenshire	30	201	611	843	5.3	1.0	21	148	1,383	1,552	7.9	1.7	1.34
Ceredigion	13	79	262	354	5.0	0.9	9	59	579	647	7.7	1.6	1.28
Conwy	18	147	505	670	5.9	1.3	13	133	1,246	1,392	9.2	2.4	1.85
Denbighshire	16	126	391	533	6.3	1.2	11	101	991	1,103	9.7	2.2	1.70
Flintshire	24	138	401	563	5.1	0.8	17	106	915	1,038	7.7	1.4	1.07
Gwynedd	19	128	413	561	5.5	1.0	13	111	1,033	1,158	8.7	1.9	1.46
Merthyr Tydfil	8	49	147	204	4.9	0.8	6	41	327	373	7.1	1.3	1.05
Monmouthshire	15	87	274	377	5.0	0.9	11	67	558	636	6.8	1.4	1.16
Neath Port Talbot	21	127	413	562	5.1	0.9	15	104	990	1,110	7.7	1.6	1.23
Newport	20	114	373	507	5.1	0.7	14	92	944	1,051	8.0	1.5	1.12
Pembrokeshire	20	140	420	580	5.4	1.0	14	110	957	1,081	8.2	1.8	1.41
Powys	23	145	508	677	5.4	1.0	16	107	999	1,122	7.5	1.7	1.37
Rhondda, Cynon, Taff	35	208	626	870	5.1	0.8	25	167	1,462	1,654	7.4	1.4	1.09
Swansea	33	215	720	968	5.2	0.9	24	192	1,757	1,973	8.3	1.7	1.30

Torfaen	14	83	268	366	5.3	0.8	10	81	650	740	7.9	1.6	1.22
Vale of Glamorgan	19	111	389	520	5.6	0.9	14	93	975	1,082	8.9	1.7	1.30
Wrexham	21	119	392	532	5.7	0.8	14	106	1,023	1,143	9.3	1.7	1.28
England													
Barking and Dagenham	19	90	354	463	5.0	0.6	14	88	797	899	6.8	1.1	0.83
Barnet	40	240	903	1,182	6.0	0.7	31	236	2,258	2,525	9.4	1.5	1.12
Barnsley	35	207	587	828	5.2	0.8	24	172	1,539	1,735	8.3	1.5	1.15
Bath and North East Somerset	25	147	574	746	5.5	0.9	18	133	1,322	1,473	8.4	1.7	1.28
Bedfordshire	60	311	964	1,335	5.0	0.7	42	248	2,127	2,416	7.4	1.2	0.94
Bexley	30	162	555	747	4.7	0.7	23	134	1,164	1,321	6.4	1.2	0.94
Birmingham	116	789	2,415	3,320	5.4	0.7	85	622	5,351	6,058	7.5	1.2	0.94
Blackburn with Darwen	18	107	325	450	5.6	0.7	13	96	805	914	8.6	1.3	0.97
Blackpool	23	182	556	760	6.3	1.1	15	148	1,331	1,494	9.4	2.0	1.58
Bolton	40	213	624	876	4.9	0.7	27	175	1,620	1,822	7.9	1.3	1.02
Bournemouth	23	164	760	947	7.0	1.2	16	155	2,058	2,229	11.4	2.7	1.94
Bracknell Forest	15	66	209	290	5.1	0.5	11	56	465	532	7.1	1.0	0.74
Bradford	62	409	1,243	1,714	5.8	0.7	44	342	3,110	3,497	8.7	1.4	1.07
Brent	30	201	483	714	4.8	0.5	23	148	893	1,064	6.0	0.8	0.66
Brighton and Hove	31	217	785	1,034	6.3	0.8	22	173	1,967	2,162	9.6	1.7	1.25
Bristol	49	301	1,052	1,402	5.8	0.7	35	249	2,439	2,723	8.4	1.4	1.04
Bromley	42	233	893	1,169	5.3	0.8	32	204	2,166	2,402	8.1	1.5	1.18
Buckinghamshire	74	389	1,242	1,705	5.0	0.7	53	308	2,809	3,170	7.5	1.3	1.01
Bury	27	154	498	679	5.5	0.8	19	130	1,296	1,445	8.9	1.5	1.16
Calderdale	30	150	493	674	5.1	0.7	21	116	1,232	1,369	7.7	1.4	1.05
Cambridgeshire	87	475	1,543	2,106	5.2	0.7	61	383	3,402	3,847	7.7	1.3	1.01
Camden	23	165	396	584	6.2	0.5	18	112	688	818	6.8	0.7	0.62
Cheshire	111	661	2,133	2,905	5.4	0.9	77	541	5,041	5,658	8.3	1.6	1.26
City of London	2	5	24	31	5.8	0.6	1	2	26	29	5.6	0.7	0.65
Cornwall and Isles of Scilly	92	575	2,000	2,667	5.5	1.1	64	462	4,771	5,297	8.8	2.0	1.53
Coventry	39	267	858	1,164	5.7	0.8	27	191	1,853	2,072	7.8	1.4	1.06
Croydon	43	246	788	1,077	5.5	0.6	33	196	1,638	1,867	7.5	1.1	0.86
Cumbria	85	510	1,623	2,217	5.3	0.9	58	407	3,950	4,414	8.2	1.7	1.33
Darlington	15	107	321	443	6.1	0.9	11	117	867	995	9.8	1.9	1.45
Derby City	32	222	733	987	5.9	0.9	22	174	1,635	1,831	8.6	1.6	1.21
Derbyshire	125	699	2,295	3,119	5.4	0.8	85	566	5,414	6,065	8.3	1.6	1.23

Area	Men						Women						% of total population with dementia (men and women)
	30–64	65–74	75+	Total	% of over 65s with dementia	% of total pop with dementia	30–64	65–74	75+	Total	% of over 65s with dementia	% of total pop with dementia	
Devon	123	835	3,072	4,030	5.9	1.1	87	669	7,392	8,147	9.2	2.2	1.67
Doncaster	44	267	818	1,128	5.2	0.8	31	230	1,834	2,094	7.5	1.4	1.11
Dorset	68	438	1,827	2,333	5.4	1.2	49	351	3,940	4,341	8.0	2.1	1.66
Dudley	48	298	816	1,162	4.9	0.8	33	245	1,992	2,270	7.4	1.5	1.12
Durham	79	499	1,454	2,031	5.3	0.8	55	417	3,537	4,009	8.2	1.6	1.21
Ealing	35	215	599	849	5.3	0.6	26	155	1,192	1,373	7.0	0.9	0.74
East Riding of Yorkshire	57	353	1,139	1,549	5.4	1.0	40	301	2,869	3,210	8.9	1.9	1.45
East Sussex	80	579	2,418	3,077	6.3	1.3	58	559	6,199	6,816	10.2	2.6	1.99
Enfield	35	203	613	851	5.0	0.6	26	166	1,432	1,625	7.4	1.1	0.88
Essex	209	1,198	3,867	5,273	5.0	0.8	149	984	8,860	9,994	7.5	1.5	1.14
Gateshead	28	216	548	792	5.2	0.8	20	166	1,235	1,422	7.3	1.4	1.16
Gloucestershire	91	541	1,884	2,516	5.5	0.9	64	425	4,382	4,871	8.3	1.7	1.28
Greenwich	26	145	437	607	5.4	0.5	19	120	1,051	1,191	7.4	1.0	0.79
Hackney	19	110	318	447	5.0	0.4	16	83	594	693	6.7	0.7	0.55
Halton	18	96	282	396	5.3	0.7	13	80	647	740	7.8	1.2	0.96
Hammersmith and Fulham	18	99	252	368	4.6	0.4	14	76	518	608	5.9	0.7	0.54
Hampshire	197	1,113	3,911	5,221	5.4	0.8	140	901	9,244	10,285	8.4	1.6	1.23
Haringey	22	131	306	459	4.7	0.4	18	88	637	743	6.1	0.7	0.54
Harrow	27	157	517	701	5.2	0.7	21	143	1,156	1,320	7.5	1.2	0.95
Hartlepool	13	96	244	353	5.4	0.8	9	87	569	665	7.8	1.4	1.13
Havering	33	182	625	840	4.8	0.8	24	161	1,415	1,600	6.8	1.4	1.08
Herefordshire, County of	31	190	680	900	5.5	1.0	21	156	1,498	1,675	8.2	1.8	1.44
Hertfordshire	150	818	2,821	3,789	5.3	0.7	107	697	6,693	7,497	8.0	1.4	1.08
Hillingdon	32	172	521	725	4.8	0.6	23	153	1,170	1,346	6.7	1.0	0.82
Hounslow	25	133	354	512	4.5	0.5	19	113	795	927	6.8	0.9	0.68
Isle of Wight	24	167	611	802	5.9	1.2	17	151	1,607	1,775	9.9	2.5	1.84
Islington	18	104	270	392	5.0	0.4	14	68	464	546	5.5	0.6	0.51
Kensington and Chelsea	22	106	374	502	5.1	0.5	18	111	690	819	6.7	0.8	0.67
Kent	212	1,328	4,295	5,835	5.5	0.9	151	1,118	10,470	11,738	8.6	1.7	1.28

Kingston-upon-Hull	33	246	636	915	5.5	0.7	23	185	1,505	1,712	8.1	1.4	1.05
Kingston-upon-Thames	19	91	365	476	5.7	0.6	14	86	842	942	8.4	1.2	0.93
Kirklees	58	313	985	1,356	5.3	0.7	41	269	2,543	2,854	8.4	1.4	1.07
Knowsley	19	137	318	474	4.8	0.7	15	108	766	888	6.5	1.1	0.91
Lambeth	25	172	417	613	5.6	0.4	20	119	791	930	7.0	0.7	0.57
Lancashire	180	1,134	3,514	4,828	5.5	0.9	125	987	8,982	10,094	8.9	1.7	1.29
Leeds	94	571	1,914	2,579	5.4	0.7	68	481	4,388	4,938	7.7	1.3	1.04
Leicester City	33	203	686	922	5.7	0.7	24	175	1,486	1,684	7.9	1.1	0.90
Leicestershire	100	547	1,742	2,389	5.1	0.8	70	429	3,856	4,355	7.5	1.4	1.07
Lewisham	26	150	437	613	5.4	0.5	21	125	903	1,048	6.9	0.8	0.67
Lincolnshire	113	744	2,499	3,356	5.4	1.0	80	625	5,578	6,283	8.5	1.8	1.42
Liverpool	56	447	1120	1,623	5.6	0.7	42	377	2,566	2,984	7.8	1.3	1.03
Luton	23	134	348	506	4.4	0.5	16	105	712	833	6.6	0.9	0.72
Manchester	46	362	1,026	1,435	6.3	0.7	33	281	2,373	2,687	8.7	1.2	0.93
Medway	36	188	530	754	5.0	0.6	26	157	1,321	1,503	7.8	1.2	0.90
Merton	23	125	395	542	5.2	0.6	17	101	911	1,029	7.3	1.1	0.81
Middlesbrough	18	125	392	535	5.8	0.8	13	115	905	1,033	8.6	1.5	1.14
Milton Keynes	31	124	372	527	5.0	0.5	21	110	899	1,030	7.7	1.0	0.71
Newcastle-upon-Tyne	34	232	732	998	5.6	0.7	24	187	1,685	1,896	7.6	1.3	1.05
Newham	23	137	352	512	5.3	0.4	18	100	626	743	6.3	0.6	0.51
Norfolk	136	921	3,287	4,345	5.6	1.1	95	718	7,153	7,966	8.4	1.9	1.49
North East Lincolnshire	24	159	487	670	5.6	0.9	16	131	1,174	1,321	8.4	1.6	1.26
North Lincolnshire	26	165	513	703	5.6	0.9	18	134	1,187	1,338	8.6	1.7	1.30
North Somerset	33	224	858	1,114	6.5	1.2	23	190	2,183	2,396	10.8	2.4	1.80
North Tyneside	29	194	651	874	5.8	0.9	21	173	1,522	1,716	8.5	1.7	1.35
North Yorkshire	98	591	2,111	2,801	5.7	1.0	68	493	5,094	5,656	9.0	1.9	1.45
Northamptonshire	101	536	1,742	2,379	5.5	0.7	70	429	4,072	4,571	8.5	1.4	1.07
Northumberland	54	331	1,048	1,432	5.5	0.9	37	274	2,434	2,745	8.4	1.7	1.34
Nottingham City	31	213	659	903	5.6	0.6	21	160	1,389	1,570	7.4	1.1	0.89
Nottinghamshire	122	713	2,303	3,139	5.4	0.8	85	579	5,503	6,167	8.4	1.6	1.22
Oldham	31	184	516	731	5.2	0.7	22	167	1,374	1,564	8.4	1.4	1.05
Oxfordshire	88	482	1,588	2,158	5.1	0.7	63	365	3,597	4,024	7.6	1.3	0.99
Peterborough	22	115	392	529	5.1	0.7	16	91	794	900	7.0	1.1	0.89
Plymouth	35	228	744	1,006	5.9	0.8	25	194	1,937	2,156	9.3	1.7	1.28
Poole	21	131	559	711	5.7	1.1	15	114	1,327	1,457	8.8	2.0	1.58
Portsmouth	24	156	522	702	5.8	0.7	17	135	1,302	1,453	9.0	1.5	1.14
Reading	17	92	306	415	5.1	0.6	12	73	703	788	7.6	1.1	0.83

Area	Men						Women						% of total population with dementia (men and women)
	30–64	65–74	75+	Total	% of over 65s with dementia	% of total pop with dementia	30–64	65–74	75+	Total	% of over 65s with dementia	% of total pop with dementia	
Redbridge	32	176	550	757	5.2	0.6	24	138	1,343	1,504	7.9	1.2	0.90
Redcar and Cleveland	23	153	421	597	5.4	0.9	16	118	1,006	1,140	8.0	1.6	1.25
Richmond-upon-Thames	25	115	467	607	6.1	0.7	18	85	974	1,078	7.9	1.1	0.90
Rochdale	30	181	534	745	5.7	0.7	21	145	1,332	1,498	8.6	1.4	1.09
Rotherham	39	231	676	946	5.2	0.8	27	202	1,646	1,876	8.0	1.4	1.11
Rutland	6	37	100	143	4.7	0.7	4	28	275	307	8.2	1.7	1.20
Salford	30	204	538	771	5.2	0.7	21	166	1,308	1,494	7.5	1.4	1.05
Sandwell	39	264	766	1,068	5.3	0.8	27	223	1,760	2,010	7.4	1.4	1.08
Sefton	42	323	1,009	1,374	5.9	1.0	31	287	2,553	2,871	8.8	1.9	1.51
Sheffield	71	440	1,506	2,017	5.5	0.8	50	373	3,566	3,989	8.2	1.5	1.15
Shropshire	49	307	1,017	1,374	5.5	1.0	34	255	2,354	2,643	8.5	1.8	1.39
Slough	14	64	225	303	4.7	0.5	10	52	430	492	6.3	0.9	0.68
Solihull	32	168	569	768	4.9	0.8	23	134	1,315	1,472	7.2	1.4	1.11
Somerset	85	525	1,952	2,562	5.6	1.0	60	427	4,592	5,078	8.7	1.9	1.48
South Gloucestershire	38	217	672	928	5.2	0.8	27	172	1,503	1,701	7.9	1.4	1.06
South Tyneside	22	158	488	668	5.6	0.9	16	134	1,138	1,287	8.0	1.7	1.29
Southampton	28	152	553	733	5.4	0.7	18	119	1,244	1,381	7.7	1.3	0.95
Southend-on-sea	23	159	601	783	6.2	1.0	17	136	1,626	1,779	10.0	2.2	1.61
Southwark	25	141	428	594	5.1	0.5	20	105	844	969	6.5	0.8	0.61
St Helens	28	168	398	594	4.6	0.7	19	123	1,049	1,192	7.1	1.3	1.01
Staffordshire	136	776	2,294	3,206	5.2	0.8	94	639	5,599	6,331	8.1	1.5	1.17
Stockport	43	248	745	1,035	4.9	0.8	31	207	1,928	2,165	7.6	1.5	1.14
Stockton on Tees	28	179	458	664	5.3	0.7	19	143	1,136	1,299	8.1	1.4	1.05
Stoke on Trent	36	213	657	906	5.4	0.8	24	177	1,562	1,763	7.7	1.4	1.12
Suffolk	110	670	2,417	3,197	5.4	0.9	77	524	5,312	5,913	8.1	1.7	1.32
Sunderland	41	300	777	1,117	5.5	0.8	30	268	1,811	2,109	8.0	1.4	1.14
Surrey	163	933	3,312	4,409	5.6	0.8	116	773	7,929	8,818	8.6	1.6	1.23
Sutton	23	130	436	589	5.3	0.7	18	118	1,147	1,283	8.3	1.4	1.05
Swindon	25	146	441	612	5.1	0.7	18	110	947	1,075	7.3	1.2	0.92

Tameside	33	191	560	784	5.5	0.8	22	162	1,402	1,585	8.4	1.4	1.11
Telford and Wrekin	24	125	349	498	5.0	0.6	17	100	807	924	7.4	1.1	0.88
Thurrock	21	85	249	354	4.2	0.5	15	75	603	692	6.0	0.9	0.71
Torbay	22	169	666	857	6.6	1.3	16	146	1,756	1,918	11.0	2.8	2.09
Tower Hamlets	17	108	275	400	4.7	0.4	13	69	450	532	5.7	0.5	0.44
Trafford	30	178	575	783	5.1	0.8	22	150	1,342	1,515	7.5	1.4	1.08
Wakefield	50	280	824	1,153	5.1	0.7	34	231	1,945	2,210	7.5	1.3	1.05
Walsall	37	252	693	982	5.1	0.8	26	189	1,578	1,793	7.2	1.4	1.09
Waltham Forest	24	150	359	533	4.8	0.5	19	125	912	1,056	7.4	0.9	0.71
Wandsworth	26	166	501	693	5.8	0.5	21	145	1,137	1,303	8.1	0.9	0.71
Warrington	30	177	494	701	5.3	0.7	21	144	1,185	1,350	8.2	1.4	1.05
Warwickshire	86	468	1,450	2,004	5.0	0.8	59	368	3,399	3,826	7.7	1.4	1.09
West Berkshire	23	122	331	476	5.0	0.7	16	86	717	819	7.2	1.1	0.88
West Sussex	118	773	3,162	4,053	6.0	1.1	85	698	7,823	8,605	9.4	2.2	1.66
Westminster, City of	26	152	447	625	5.3	0.5	20	108	677	805	5.6	0.7	0.59
Wigan	49	269	634	952	4.6	0.6	34	223	1,677	1,934	7.3	1.2	0.94
Wiltshire	69	396	1,414	1,879	5.4	0.9	49	325	3,267	3,641	8.4	1.6	1.24
Windsor and Maidenhead	20	109	366	496	5.2	0.7	15	85	867	966	8.1	1.4	1.06
Wirral	48	310	990	1,348	5.5	0.9	35	278	2,633	2,946	8.6	1.8	1.37
Wokingham	23	108	342	474	5.1	0.6	17	93	772	881	7.8	1.1	0.88
Wolverhampton	32	244	722	998	5.5	0.8	23	192	1,589	1,803	7.8	1.5	1.17
Worcestershire	94	529	1,734	2,357	5.4	0.9	64	412	4,066	4,542	8.4	1.6	1.24
York	26	174	586	787	5.7	0.9	19	154	1,436	1,608	8.7	1.7	1.28
Northern Ireland													
Eastern	89	517	1,580	2,186	5.2	0.7	66	477	4,262	4,805	8.0	1.4	1.05
Northern	61	346	967	1,373	5.0	0.6	44	296	2,327	2,667	7.4	1.2	0.92
Southern	42	229	629	900	4.9	0.6	30	196	1,409	1,636	6.8	1.0	0.77
Western	37	220	562	820	5.3	0.6	26	177	1,180	1,383	7.0	1.0	0.76
Scotland													
Aberdeen City	29	188	574	791	6.3	0.8	20	164	1,441	1,625	9.7	1.6	1.19
Aberdeenshire	39	213	651	904	5.9	0.8	27	182	1,627	1,836	10.6	1.5	1.16
Angus	18	107	330	455	5.4	0.9	13	89	806	909	8.9	1.6	1.25
Argyll & Bute	16	93	289	398	5.4	0.9	11	94	733	838	9.4	1.8	1.36
Clackmannanshire	8	39	105	152	4.8	0.6	6	29	235	270	7.1	1.1	0.87
Dumfries & Galloway	26	160	499	686	5.4	1.0	18	131	1,147	1,297	8.6	1.7	1.34
Dundee City	20	124	361	504	5.0	0.7	14	113	866	994	7.4	1.3	1.05

Area	Men						Women						% of total population with dementia (men and women)
	30–64	*65–74*	*75+*	*Total*	*% of over 65s with dementia*	*% of total pop with dementia*	*30–64*	*65–74*	*75+*	*Total*	*% of over 65s with dementia*	*% of total pop with dementia*	
East Ayrshire	19	117	292	428	5.3	0.7	14	106	781	900	8.8	1.5	1.11
East Dumbartonshire	17	96	256	369	4.9	0.7	13	81	619	713	7.5	1.3	1.02
East Lothian	14	85	247	346	5.3	0.8	10	68	668	747	9.1	1.6	1.19
East Renfrewshire	13	72	202	287	4.9	0.7	10	68	593	671	8.6	1.4	1.07
Edinburgh, City of	59	334	1,138	1,531	5.9	0.7	44	308	3,029	3,381	9.6	1.4	1.07
Eilean Siar	5	25	70	99	4.6	0.8	3	23	192	218	8.2	1.6	1.20
Falkirk	22	134	346	502	5.2	0.7	16	134	871	1,021	8.4	1.3	1.02
Fife	55	299	896	1,250	5.2	0.7	40	272	2,375	2,687	8.9	1.5	1.10
Glasgow City	71	510	1,304	1,885	6.0	0.7	53	482	3,457	3,993	8.6	1.3	1.02
Highland	37	209	582	828	5.3	0.8	26	170	1,359	1,554	8.2	1.4	1.12
Inverclyde	12	95	210	317	5.9	0.8	9	84	622	716	9.6	1.7	1.26
Midlothian	13	76	212	301	5.8	0.8	9	70	539	618	9.7	1.5	1.16
Moray	14	78	240	332	5.2	0.8	10	67	551	628	8.2	1.4	1.09
North Ayrshire	21	127	344	492	5.2	0.8	16	118	915	1,049	8.7	1.5	1.13
North Lanarkshire	46	292	642	980	5.2	0.6	35	259	1,599	1,894	7.6	1.1	0.89
Orkney Islands	3	19	49	71	4.7	0.7	2	13	124	139	8.2	1.4	1.07
Perth & Kinross	23	139	425	587	5.4	0.9	16	111	986	1,114	8.4	1.6	1.23
Renfrewshire	25	180	477	683	6.3	0.8	19	154	1,065	1,238	8.7	1.4	1.13
Scottish Borders	19	110	345	473	5.4	0.9	13	93	791	897	8.6	1.6	1.25
Shetland Islands	4	15	45	64	4.5	0.6	2	10	123	135	8.3	1.2	0.90
South Ayrshire	18	114	342	474	5.3	0.9	13	99	893	1,005	8.9	1.7	1.32
South Lanarkshire	45	294	755	1,094	5.7	0.7	34	276	2,079	2,389	9.3	1.5	1.14
Stirling	13	89	234	336	5.9	0.8	10	78	601	688	9.5	1.5	1.18
West Dumbartonshire	13	71	205	290	5.2	0.7	10	73	593	676	8.6	1.4	1.06
West Lothian	24	121	297	441	5.1	0.6	18	111	728	857	8.2	1.0	0.79

Table A1.2

Number of prescriptions of dementia drugs per local authority, per person with dementia October 2005–September 2006

	Number 65+	*Number with dementia (65+ only)*	*Prescriptions per 1000 people 65+*	*Prescriptions per person with dementia*
Anglesey	13,600	884	93	1.4
Ashton Leigh & Wigan	45,800	2,803	230	3.8
Barking & Dagenham	21,900	1,329	291	4.8
Barnet	45,400	3,637	217	2.7
Barnsley	36,100	2,505	178	2.6
Bassetlaw	18,705	1,319	150	2.1
Bath & Somerset NE	30,400	2,176	152	2.1
Bedfordshire	57,500	3,650	147	2.3
Berkshire E Teaching	47,400	2,995	72	1.1
Berkshire W	58,200	3,745	24	0.4
Bexley Care Trust	35,300	2,016	96	1.7
Birmingham E & N	52,189	3,451	85	1.3
Birmingham S	51,356	3,395	104	1.6
Blackburn with Darwen Tch	18,200	1,333	211	2.9
Blackpool	27,500	2,217	235	2.9
Blaenau Gwent	11,900	850	149	2.1
Bolton	39,600	2,632	133	2.0
Bournemouth & Poole Tch	61,200	5,268	146	1.7
Bradford & Airedale Tch	68,300	5,104	74	1.0
Brent	31,500	1,725	142	2.6
Bridgend	22,200	1,426	313	4.9
Brighton & Hove City Tch	38,200	3,142	157	1.9
Bristol Teaching	55,600	4,041	220	3.0
Bromley	50,500	3,496	138	2.0
Buckinghamshire	73,800	4,748	371	5.8
Bury	27,800	2,077	147	2.0
Caerphilly	26,800	1,625	156	2.6
Calderdale	30,200	1,991	124	1.9
Cambridgeshire	88,300	5,805	165	2.5
Camden	20,900	1,361	126	1.9
Cardiff	44,300	3,021	62	0.9
Carmarthenshire	34,700	2,344	50	0.7
Ceredigion	15,100	979	70	1.1
Cheshire E	78,380	5,502	377	5.4
Cheshire W	40,872	2,869	157	2.2
City & Hackney Teaching	19,600	1,162	75	1.3
Conwy	26,000	2,031	125	1.6
Cornwall & Isls of Sclly	105,900	7,808	76	1.0
County Durham	85,000	5,906	186	2.7
Coventry Teaching	45,900	3,169	417	6.0

Table A1.2 Continued

	Number 65+	*Number with dementia (65+ only)*	*Prescriptions per 1000 people 65+*	*Prescriptions per person with dementia*
Croyden	43,000	2,868	138	2.1
Cumbria	93,800	6,489	158	2.3
Darlington	17,000	1,412	145	1.7
Denbighshire	19,500	1,609	286	3.5
Derby City	37,400	2,764	94	1.3
Derbyshire County	128,000	8,974	153	2.2
Devon	153,600	11,967	91	1.2
Doncaster	48,300	3,148	401	6.2
Dorset	95,400	6,556	70	1.0
Dudley	53,000	3,351	82	1.3
Ealing	34,500	2,161	71	1.1
East Riding of Yorkshire	63,200	4,662	139	1.9
Enfield	37,700	2,414	168	2.6
Essex NE	63,118	3,408	102	1.9
Essex SE	67,925	3,668	168	3.1
Essex SW Teaching	79,838	4,311	174	3.2
Essex W	56,221	3,036	283	5.2
Flintshire	23,800	1,560	153	2.3
Gateshead	33,700	2,165	303	4.7
Gloucestershire	102,100	7,232	150	2.1
Gloucestershire S	38,500	2,564	120	1.8
Greenwich Teaching	26,600	1,752	124	1.9
Gt Yarmth & Waveney Tch	38,970	2,790	140	2.0
Gwynedd	23,000	1,686	154	2.1
Halton & St Helens	45,200	2,845	701	11.1
Hammersmith & Fulham	17,700	944	84	1.6
Hampshire	214,000	15,169	182	2.6
Haringey Teaching	21,200	1,161	165	3.0
Harrow	30,300	1,973	151	2.3
Hartlepool	14,700	996	456	6.7
Hastings & Rother	38,999	3,346	149	1.7
Havering	39,900	2,383	158	2.6
Heart of Birmingham Tch	35,255	2,331	39	0.6
Herefordshire	36,000	2,523	225	3.2
Hertfordshire E & N	79,682	5,449	163	2.4
Hertfordshire W	81,618	5,581	84	1.2
Hillingdon	34,100	2,016	203	3.4
Hounslow	24,000	1,394	558	9.6
Hull Teaching	36,900	2,572	186	2.7
Isle of Wight Healthcare	30,900	2,536	158	1.9
Islington	17,200	906	153	2.9
Kensington & Chelsea	21,300	1,280	147	2.5
Kent Eastern & Coastl Tch	124,056	9,001	111	1.5
Kent W	113,144	8,210	84	1.2
Kingston	19,000	1,384	135	1.9
Kirklees	57,900	4,111	151	2.1
Knowsley	22,900	1,329	694	12.0
Lambeth	23,500	1,499	148	2.3
Lancashire Central	76,167	5,692	132	1.8
Lancashire E	64,802	4,843	197	2.6
Lancashire N	54,631	4,083	272	3.6
Leeds	109,900	7,355	209	3.1

Table A1.2 Continued

	Number 65+	*Number with dementia (65+ only)*	*Prescriptions per 1000 people 65+*	*Prescriptions per person with dementia*
Leicester City Teaching	36,500	2,549	59	0.8
Leicestersh Co & Rutland	108,900	7,013	45	0.7
Lewisham	25,700	1,615	479	7.6
Lincolnshire N	27,400	1,998	120	1.6
Lincolnshire NE	27,000	1,951	147	2.0
Lincolnshire Teaching	132,300	9,447	122	1.7
Liverpool	65,500	4,510	164	2.4
Luton Teaching	23,300	1,300	104	1.9
Manchester	52,600	4,042	227	3.0
Medway Teaching	33,200	2,195	213	3.2
Merthyr	9,200	563	282	4.6
Mid Essex	74,404	4,018	122	2.3
Middlesbrough	20,800	1,537	221	3.0
Milton Keynes	23,000	1,506	94	1.4
Monmouthshire	16,500	987	296	5.0
Neath & Port Talbot	24,700	1,635	31	0.5
Newcastle	41,900	2,836	84	1.2
Newham	20,900	1,216	95	1.6
Newport	22,600	1,524	180	2.7
Norfolk	129,730	9,290	141	2.0
Northamptonshire Teaching	94,500	6,779	136	1.9
Northumberland Care Trust	57,000	4,086	137	1.9
Nottingham City	36,400	2,421	134	2.0
Notts County Teaching	110,295	7,779	142	2.0
Oldham	31,700	2,241	227	3.2
Oxfordshire	92,800	6,031	157	2.4
Pembrokeshire	23,400	1,626	193	2.8
Peterborough	22,700	1,392	216	3.5
Plymouth Teaching	39,300	3,102	113	1.4
Portsmouth City Teaching	27,600	2,115	158	2.1
Powys	26,900	1,759	268	4.1
Redbridge	32,700	2,206	650	9.6
Radcar & Cleveland	24,700	1,698	118	1.7
Rhondda Cynon & Taff	38,300	2,463	239	3.7
Richmond & Twickenham	23,000	1,641	300	4.2
Rochdle Heywd & Middletn	29,600	2,192	176	2.4
Rotherham	40,700	2,756	589	8.7
Salford Teaching	33,900	2,215	122	1.9
Sandwell	46,300	3,012	93	1.4
Sefton	54,600	4,171	349	4.6
Sheffield	83,600	5,885	197	2.8
Shropshire County	55,000	3,934	178	2.5
Solihull	35,100	2,186	151	2.4
Somerset	101,600	7,496	204	2.8
Somerset N	38,500	3,454	126	1.4
Southampton City	30,800	2,067	186	2.8
Southwark	25,700	1,518	108	1.8
Staffordshire N	35,548	2,429	56	0.8
Staffordshire S	100,652	6,878	142	2.1
Stockport	48,200	3,127	184	2.8
Stockton-on-Tees Teach	27,800	1,916	255	3.7
Stoke on Trent Teaching	38,500	2,609	61	0.9

Table A1.2 Continued

	Number 65+	*Number with dementia (65+ only)*	*Prescriptions per 1000 people 65+*	*Prescriptions per person with dementia*
Suffolk	129,700	8,923	148	2.2
Sunderland Teaching	45,800	3,155	158	2.3
Surrey	176,900	12,948	289	4.0
Sussex E Downs & Weald	74,701	6,408	116	1.4
Sussex W Teaching	155,700	12,455	135	1.7
Sutton & Merton	49,700	3,362	122	1.8
Swansea	41,300	2,883	32	0.5
Swindon	25,900	1,644	242	3.8
Tameside & Glossop	32,400	2,314	141	2.0
Telford & Wrekin	21,700	1,381	171	2.7
Torbay Care Trust	30,000	2,737	145	1.6
Torfaen	15,800	1,082	296	4.3
Tower Hamlets	17,300	902	64	1.2
Trafford	34,500	2,246	168	2.6
Tyneside N	34,600	2,541	220	3.0
Tyneside S	27,500	1,918	126	1.8
Vale of Glamorgan	21,000	1,569	668	8.9
Wakefield	50,600	3,280	145	2.2
Waltham Forest	24,600	1,546	339	5.4
Wandsworth Teaching	27,500	1,949	101	1.4
Warrington	28,900	1,999	95	1.4
Warwickshire	86,900	5,685	115	1.8
Westminster	25,300	1,385	150	2.7
Wiltshire	76,000	5,402	143	2.0
Wirral	57,800	4,210	221	3.0
Wolverhampton City	40,300	2,747	749	11.0
Worcestershire	95,400	6,741	111	1.6
Wrexham	21,100	1,640	202	2.6
Yorkshire N & York	141,500	10,640	157	2.1

APPENDIX 1

England

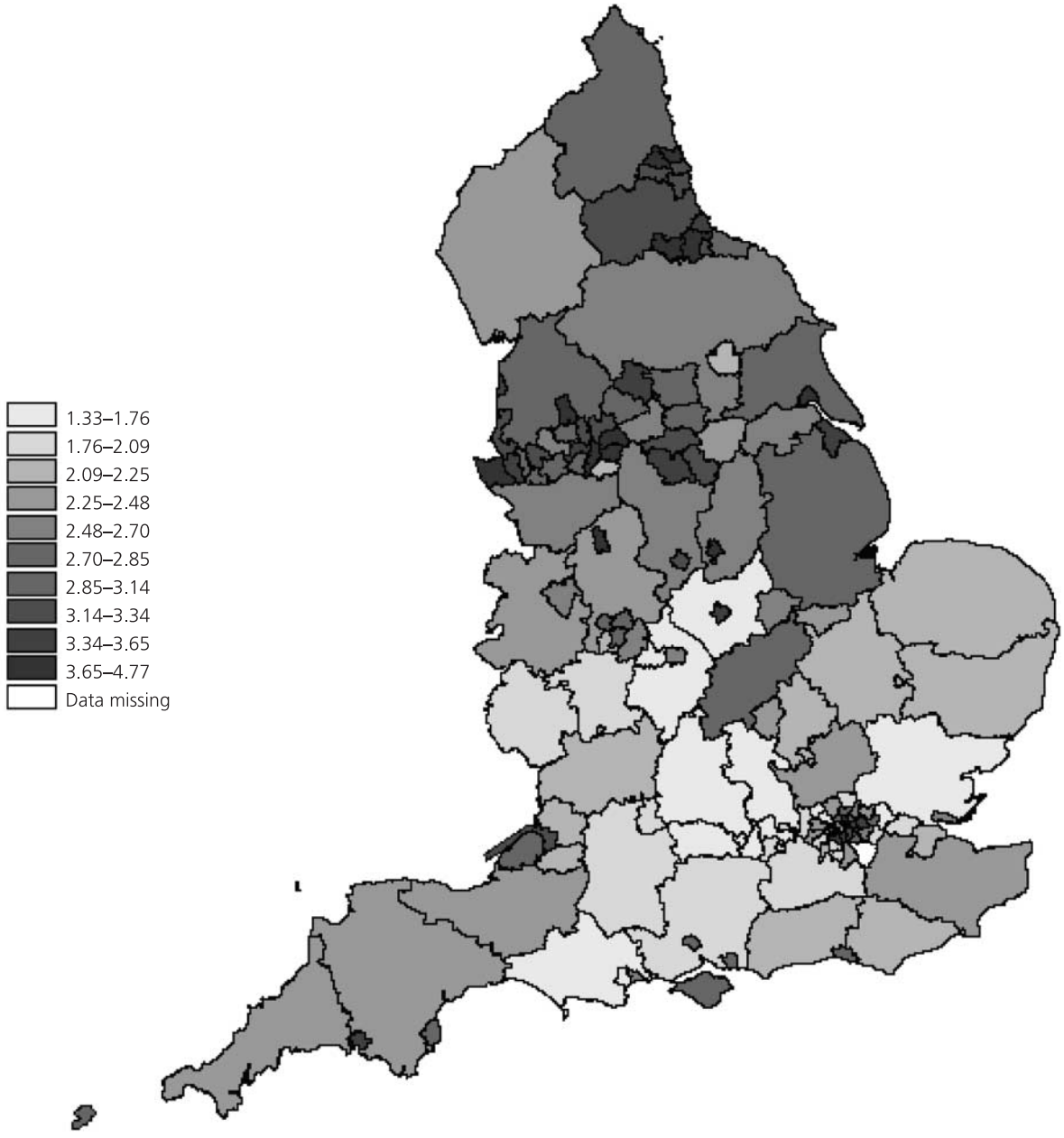

Figure E1 Spatial distribution (deciles) of the proportion of population over 65 living in CSSR and registered staffed care homes, England – 2005 (%)

Activity source: NHS Health and Social Care Information Centre *Council supported residents in CSSR and registered staffed care homes at 31 March 2005*
http://www.ic.nhs.uk/pubs/comcaresrae2005/SR12005RoundedClosed.xls/file
Population source: National Statistics Nomis website
http://www.nomisweb.co.uk
Data missing for Bromley

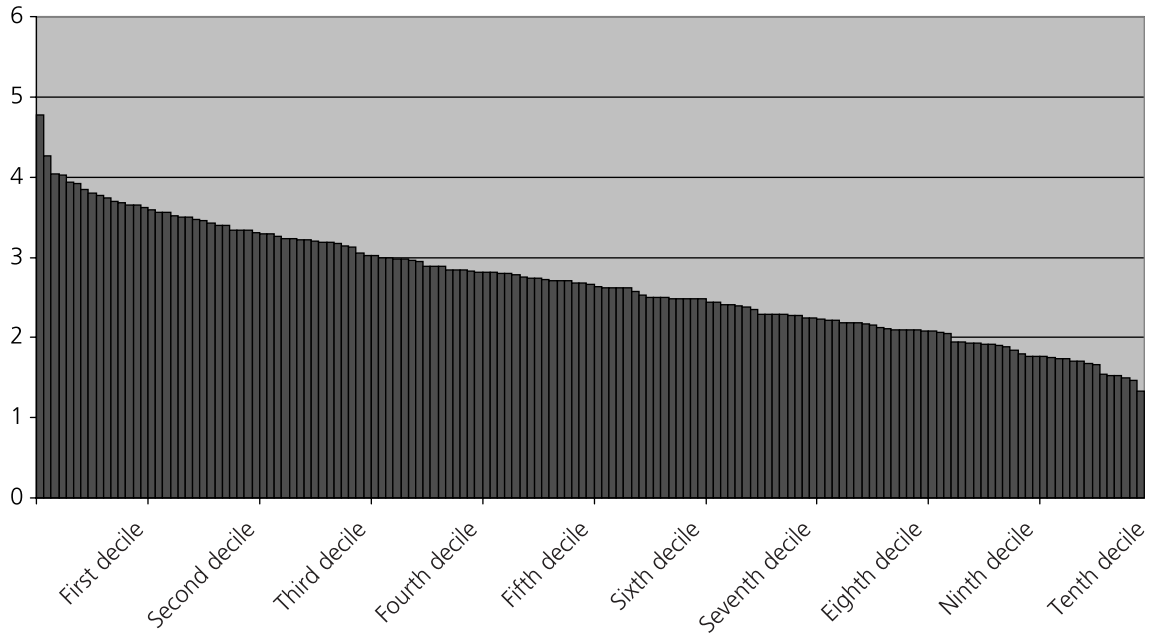

Figure E2 Distribution of the proportion of population over 65 living in CSSR and registered staffed care homes by local authority, England – 2005 (%)

Activity source: NHS Health and Social Care Information Centre *Council supported residents in CSSR and registered staffed care homes at 31 March 2005*
http://www.ic.nhs.uk/pubs/comcaresrae2005/SR12005RoundedClosed.xls/file
Population source: National Statistics Nomis website http://www.nomisweb.co.uk
Data missing for Bromley

Table E1 Distribution of the proportion of population over 65 living in CSSR and registered staffed care homes by local authority, England – 2005 (%)

First decile		*Third decile*		*Fifth decile*		*Seventh decile*		*Ninth decile*	
Kingston-upon-Hull	4.8	Sunderland	3.3	Hammersmith & Fulham	2.8	Hertfordshire	2.4	Wiltshire	2.1
Wirral	4.3	Bury	3.3	Hackney	2.8	Cumbria	2.4	Swindon	2.1
Blackburn with Darwen	4.0	Gateshead	3.3	Isle of Wight	2.8	Kent	2.4	Merton	2.0
Oldham	4.0	Derby	3.2	Trafford	2.8	Croydon	2.4	Herefordshire	1.9
Manchester	3.9	Southwark	3.2	Barking & Dagenham	2.8	Staffordshire	2.4	Enfield	1.9
Tameside	3.9	Middlesbrough	3.2	North Somerset	2.8	Shropshire	2.4	Richmond-upon-Thames	1.9
Nottingham	3.8	Bristol	3.2	Southampton	2.7	Barnet	2.4	Bracknell Forest	1.9
North Tyneside	3.8	Rochdale	3.2	Lewisham	2.7	Ealing	2.3	HIllingdon	1.9
Stockton-on-Tees	3.8	Rotherham	3.2	Leeds	2.7	Cornwall	2.3	Hampshire	1.9
Stoke-on-Trent	3.7	Durham	3.2	Portsmouth	2.7	Redbridge	2.3	Sutton	1.9
Islington	3.7	Sefton	3.2	Calderdale	2.7	Milton Keynes	2.3	Thurrock	1.9
Darlington	3.7	Brighton & Hove	3.1	Wigan	2.7	Devon	2.3	Surrey	1.8
Newcastle-upon-Tyne	3.7	Knowsley	3.1	Southend	2.7	Somerset	2.3	Bexley	1.8
Sheffield	3.6	Sandwell	3.1	North Lincolnshire	2.7	Luton	2.3	Leicestershire	1.8
Liverpool	3.6	Haringey	3.0	Greenwich	2.7	Medway Towns	2.2	Havering	1.8
Second decile		*Fourth decile*		*Sixth decile*		*Eighth decile*		*Tenth decile*	
North East Lincolnshire	3.6	Halton	3.0	Birmingham	2.6	South Gloucestershire	2.2	Reading	1.8
Leicester	3.6	Isles of Scilly	3.0	Nottinghamshire	2.6	Norfolk	2.2	Solihull	1.8
Plymouth	3.6	Walsall	3.0	Bournemouth	2.6	West Sussex	2.2	Essex	1.7
Bradford	3.5	Redcar & Cleveland	3.0	Derbyshire	2.6	Dudley	2.2	Brent	1.7
Salford	3.5	Camden	3.0	Kirklees	2.6	Kingston-upon-Thames	2.2	Warwickshire	1.7
Tower Hamlets	3.5	Northamptonshire	3.0	Rutland	2.6	East Sussex	2.2	Oxfordshire	1.7
Blackpool	3.5	Northumberland	2.9	Telford and Wrekin	2.5	Bath & North East Somerset	2.2	Harrow	1.7
Wandsworth	3.5	Warrington	2.9	Waltham Forest	2.5	Stockport	2.2	Dorset	1.7
Lambeth	3.4	Bolton	2.9	Coventry	2.5	Cambridgeshire	2.1	Buckinghamshire	1.5
Newham	3.4	Torbay	2.9	North Yorkshire	2.5	Suffolk	2.1	Kensington & Chelsea	1.5
Hartlepool	3.4	Wolverhampton	2.8	Cheshire	2.5	York	2.1	Windsor & Maidenhead	1.5
Barnsley	3.3	East Riding	2.8	Westminster	2.5	Bedfordshire	2.1	West Berkshire	1.5
South Tyneside	3.3	Lancashire	2.8	Doncaster	2.5	Gloucestershire	2.1	Poole	1.5
City of London	3.3	Wakefield	2.8	Hounslow	2.5	Worcestershire	2.1	Wokingham	1.3
St Helens	3.3	Lincolnshire	2.8	Peterborough	2.5	Slough	2.1		

Activity source: NHS Health and Social Care Information Centre *Council supported residents in CSSR and registered staffed care homes at 31 March 2005* http://www.ic.nhs.uk/pubs/comcaresrae2005/SR12005RoundedClosed.xls/file
Population source: National Statistics Nomis website http://www.nomisweb.co.uk
Data missing for Bromley

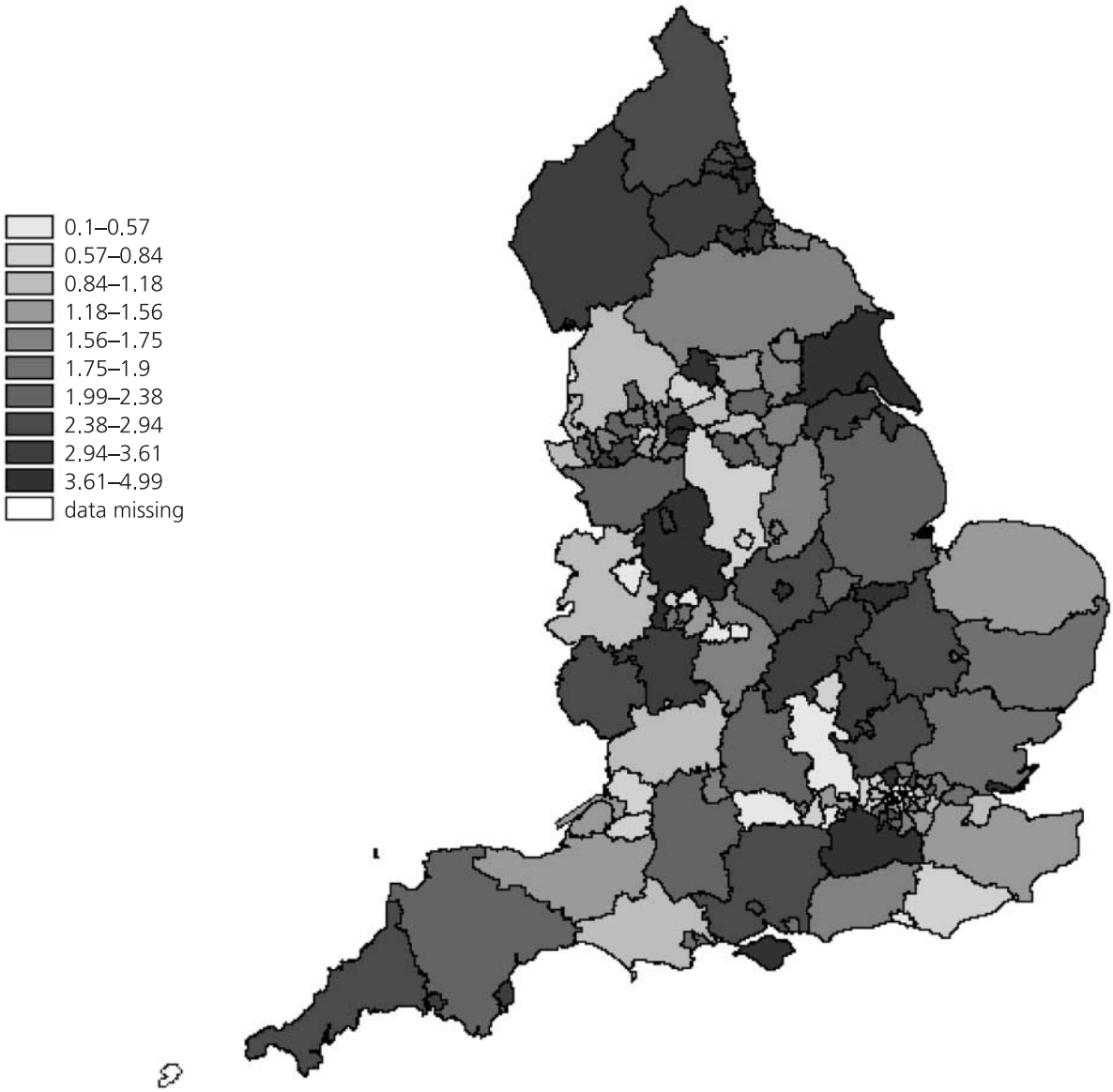

Figure E3 Spatial distribution (deciles) of the number of places in homes registered to take older people with dementia per 100 people aged over 65, England 2005–06

Source: Commission for Social Care Inspection (personal communication)

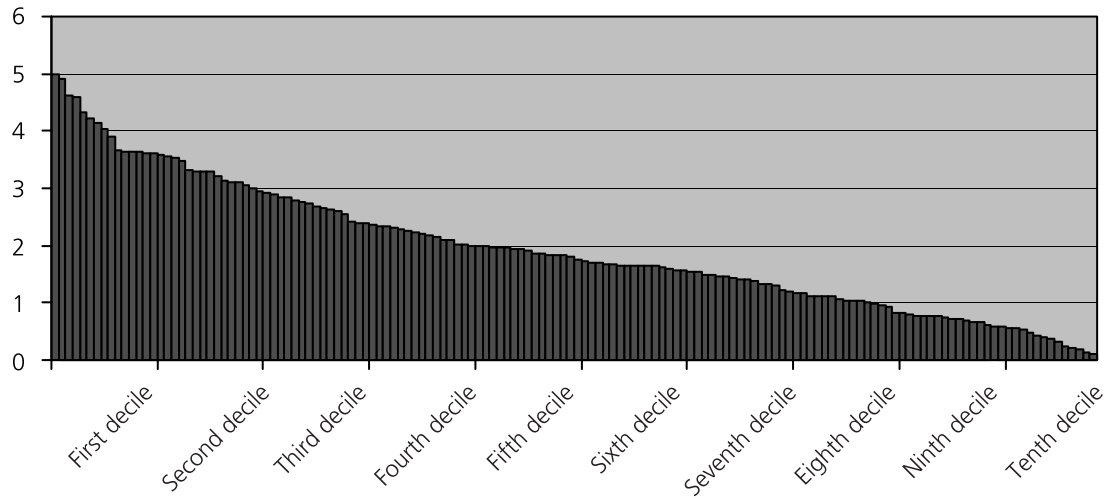

Figure E4 Distribution of the number of places in homes registered to take older people with dementia per 100 people aged over 65 by local authority, England 2005–06

Source: Commission for Social Care Inspection (personal communication)

Table E2 Distribution of the number of places in homes registered to take older people with dementia per 100 people aged over 65 by local authority, England 2005–06

First decile		*Third decile*		*Fifth decile*		*Seventh decile*		*Ninth decile*	
East Riding of Yorkshire	5.0	Northumberland	2.9	Essex	2.0	Wandsworth	1.5	Harrow	0.8
Oldham	4.9	Southampton	2.9	Liverpool	2.0	Birmingham	1.5	South Gloucestershire	0.8
Kingston-upon-Hull	4.6	Cambridgeshire	2.8	Rochdale	2.0	Haringey	1.5	Bath and North East Somerset	0.8
Isle of Wight	4.6	Hertfordshire	2.8	Bury	2.0	Bristol	1.5	Milton Keynes	0.8
Tameside	4.3	Luton	2.8	Suffolk	2.0	Kent	1.5	Wolverhampton	0.8
Leicester City	4.2	Kingston upon Thames	2.8	Portsmouth	1.9	Leeds	1.4	Salford	0.8
Southend on Sea	4.1	Hampshire	2.7	Poole	1.9	Trafford	1.4	Hackney	0.8
Bradford	4.0	Warrington	2.7	Thurrock	1.9	Somerset	1.4	Wokingham	0.7
Staffordshire	3.9	North Tyneside	2.7	Richmond upon Thames	1.9	Southwark	1.4	Hillingdon	0.7
South Tyneside	3.7	Waltham Forest	2.6	Sandwell	1.9	Greenwich	1.4	Derby City	0.7
Barnet	3.6	Herefordshire	2.6	Bolton	1.8	Windsor & Maidenhead	1.3	Hounslow	0.7
Peterborough	3.6	Cornwall	2.6	Dudley	1.8	Bromley	1.3	Islington	0.7
Sunderland	3.6	Leicestershire	2.4	Enfield	1.8	North Somerset	1.3	East Sussex	0.6
Surrey	3.6	Merton	2.4	Rotherham	1.8	Manchester	1.2	Derbyshire	0.6
Stoke-on-Trent	3.6	Blackburn with Darwen	2.4	St. Helens	1.8	Barnsley	1.2	Walsall	0.6
Second decile		*Fourth decile*		*Sixth decile*		*Eighth decile*		*Tenth decile*	
Worcestershire	3.6	Rutland	2.4	Doncaster	1.7	Kirklees	1.2	Buckinghamshire	0.6
Cumbria	3.6	Wakefield	2.3	Croydon	1.7	Bexley	1.2	Camden	0.6
Halton	3.5	Knowsley	2.3	North Yorkshire	1.7	Lancashire	1.1	Tower Hamlets	0.5
Northamptonshire	3.5	Sutton	2.3	Havering	1.7	Brent	1.1	Solihull	0.5
Torbay	3.3	Oxfordshire	2.3	Lewisham	1.7	Wirral	1.1	Brighton and Hove	0.4
Darlington	3.3	Wiltshire	2.3	Redcar and Cleveland	1.7	Sefton	1.1	Bracknell Forest	0.4
Hartlepool	3.3	Sheffield	2.2	Warwickshire	1.7	Dorset	1.1	Hammersmith and Fulham	0.4
Gateshead	3.3	Devon	2.2	Swindon	1.6	Lambeth	1.0	Westminster	0.3
Plymouth	3.2	Barking and Dagenham	2.2	York	1.6	Medway Towns	1.0	West Berkshire	0.2
Durham	3.1	Wigan	2.1	West Sussex	1.6	Shropshire	1.0	Kensington and Chelsea	0.2
Stockton-on-Tees	3.1	Lincolnshire	2.1	Nottingham	1.6	Gloucestershire	1.0	Blackpool	0.2
Bedfordshire	3.1	Stockport	2.1	Nottinghamshire	1.6	Ealing	1.0	Telford and Wrekin	0.1
North East Lincolnshire	3.0	Cheshire	2.0	Redbridge	1.6	Newham	1.0	Coventry	0.1
North Lincolnshire	3.0	Middlesborough	2.0	Reading	1.6	Slough	0.9		
Newcastle upon Tyne	2.9	Bournemouth	2.0	Norfolk	1.6	Calderdale	0.8		

Source: Commission for Social Care Inspection (personal communication)

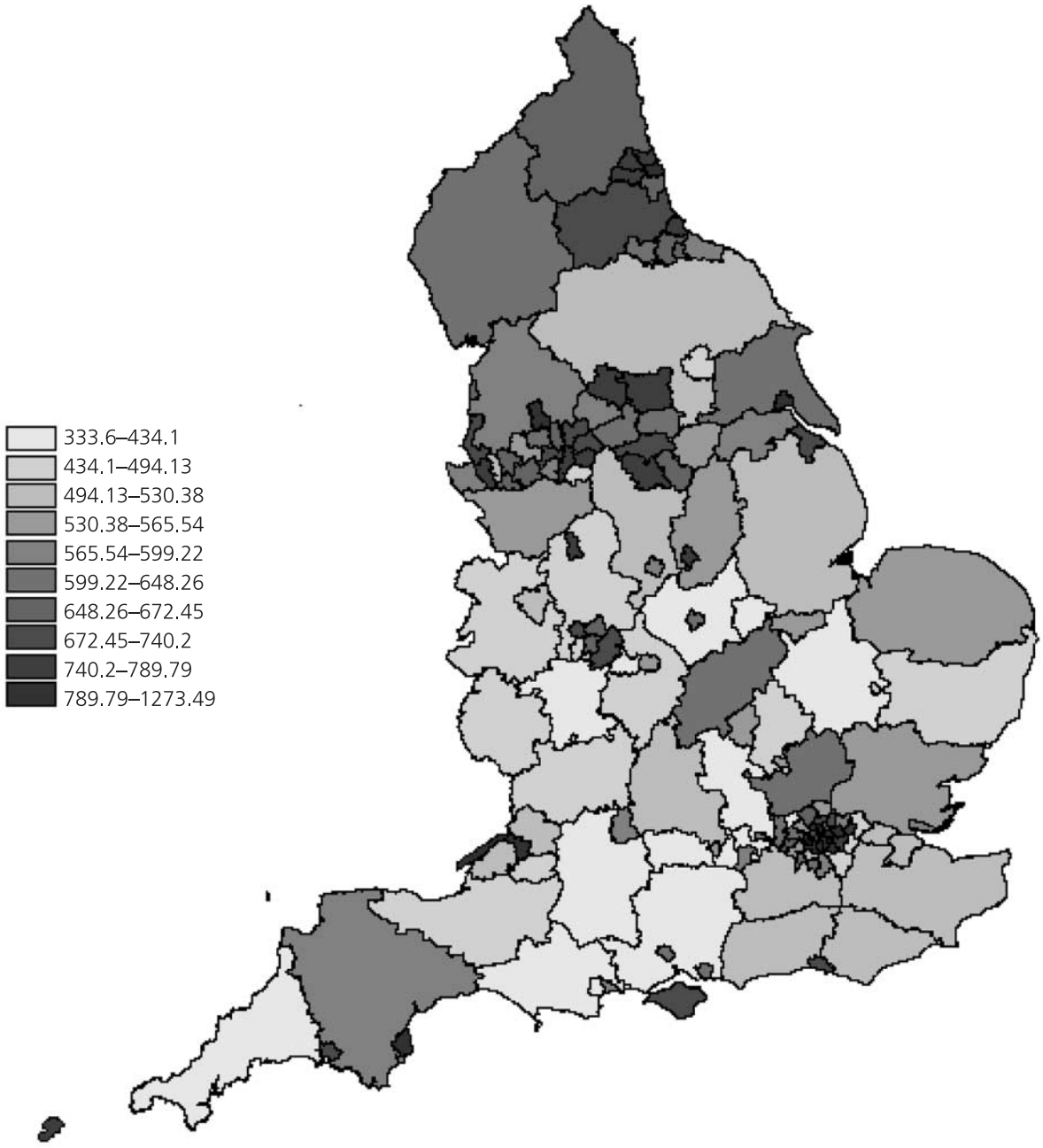

Figure E5 Spatial distribution (deciles) of the expenditure on residential and nursing care for older people per head of population over 65, England – 2004–05 (£)

Expenditure source: The Information Centre *Detailed unit costs by council, 2004–2005* http://www.ic.nhs.uk/pubs/persocservexp2005/Detailed_unit_costs_by_council_2004–05.xls/file

Population source: National Statistics Nomis website http://www.nomisweb.co.uk

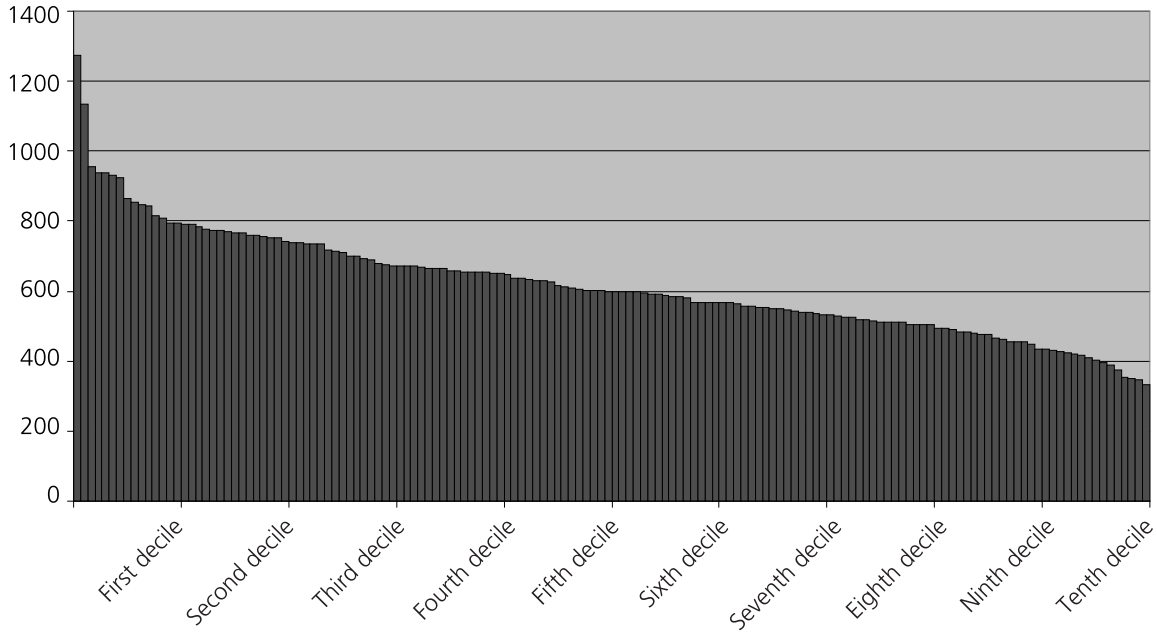

Figure E6 Distribution of the unit cost of residential and nursing care for older people by local authority, England – 2004–05 (£ per person per week)

Source: The Information Centre *Detailed unit costs by council, 2004–2005*
http://www.ic.nhs.uk/pubs/persocservexp2005/Detailed_unit_costs_by_council_2004–05.xls/file

Table E3 Distribution of the expenditure on residential and nursing care for older people per head of population over 65 by local authority, England – 2004–05 (£)

First decile		*Third decile*		*Fifth decile*		*Seventh decile*		*Ninth decile*	
Islington	1273.5	Brighton & Hove	740.2	Leicester	648.3	Brent	565.5	Suffolk	494.1
Camben	1132.3	Birmingham	740.0	Ealing	636.7	Luton	565.3	Bath & North East Somerset	492.8
City of London	955.4	Oldham	734.3	Wakefield	635.9	Peterborough	565.0	Stockport	489.6
Southwark	938.5	Haringey	733.6	Kirklees	633.5	Coventry	558.2	Staffordshire	483.8
Lewisham	938.1	Westminster	733.3	Kingston-upon-Thames	630.8	Kensing & Chelsea	556.2	Bedfordshire	482.3
Kingston-upon-Hull	931.9	Barnsley	716.6	Darlington	629.1	Doncaster	552.8	Bexley	479.5
Wandsworth	923.1	Salford	712.7	East Riding	627.2	Cheshire	551.7	York	477.0
Blackburn with Darwen	865.0	Waltham Forest	709.8	Portsmouth	616.2	Milton Keynes	550.2	Shropshire	475.6
Hammersmith & Fulham	854.9	Plymouth	700.6	Sutton	612.3	Richmond-upon-Thames	548.5	Havering	466.6
Lambeth	846.7	Sefton	699.6	Hertfordshire	608.0	Enfield	546.9	Dudley	463.7
Newham	842.9	Wolverhampton	692.6	Northamptonshire	605.1	Reading	542.9	Somerset	454.9
South Tyneside	815.7	North East Lincolnshire	688.9	Cumbria	601.3	Nottinghamshire	538.7	Bromley	454.4
Torbay	807.7	Isle of Wight	680.3	Bolton	600.8	Wigan	538.0	Warwickshire	454.3
Bristol	794.0	Durham	677.2	Hillingdon	600.6	Norfolk	536.8	Herefordshire	446.9
Tower Hamlets	793.3	Rochdale	672.8	Southampton	599.8	Essex	531.4	Gloucestershire	434.2
Second decile		*Fourth decile*		*Sixth decile*		*Eighth decile*		*Tenth decile*	
Leeds	789.8	Middlesborough	672.5	Wirral	599.2	Derbyshire	530.4	Windsor & Maidenhead	434.1
Tameside	789.5	Halton	670.7	Swindon	598.1	East Sussex	528.3	Buckinghamshire	430.6
Greenwich	785.0	Stockton-on-Tees	670.4	Devon	598.1	Thurrock	525.5	Hampshire	425.5
Sheffield	778.5	Hackney	669.6	Derby	597.7	Oxfordshire	525.2	Worcestershire	423.0
Newcastle-upon-Tyne	774.0	Walsall	666.4	Croydon	594.1	Kent	519.5	Cornwall	418.7
Gateshead	771.8	Bury	664.0	Slough	591.6	Medway Towns	518.1	Rutland	417.0
Manchester	769.3	Northumberland	663.5	Calderdale	591.5	Telford and Wrekin	513.2	Cambridgeshire	410.8
Liverpool	766.9	Sandwell	659.4	Trafford	588.3	Lincolnshire	512.1	West Berkshire	401.1
Hartlepool	765.5	St Helens	656.3	Bracknell Forest	585.7	Merton	510.5	Leicestershire	394.3
Stoke-on-Trent	761.0	Barnet	656.2	Southend	583.1	West Sussex	509.5	Poole	389.4
Isles of Scilly	758.0	Sunderland	656.1	Lancashire	582.1	North Yorkshire	509.3	Dorset	375.1
Barking & Dagenham	756.8	Blackpool	655.5	North Lincolnshire	568.4	North Somerset	504.1	Wiltshire	352.5
Nottingham	753.7	Warrington	652.9	Redcar & Cleveland	566.9	South Gloucestershire	503.7	Wokingham	348.6
North Tyneside	751.0	Hounslow	652.4	Bournemouth	566.5	Knowsley	503.5	Solihull	344.9
Bradford	742.4	Rotherham	652.4	Redbridge	566.1	Surrey	503.0	Harrow	333.6

Expenditure Source: The Information Centre *Detailed unit costs by council, 2004–2005*
http://www.ic.nhs.uk/pubs/persocservexp2005/Detailed_unit_costs_by_council_2004–05.xls/file
Population source: National Statistics Nomis website http://www.nomisweb.co.uk

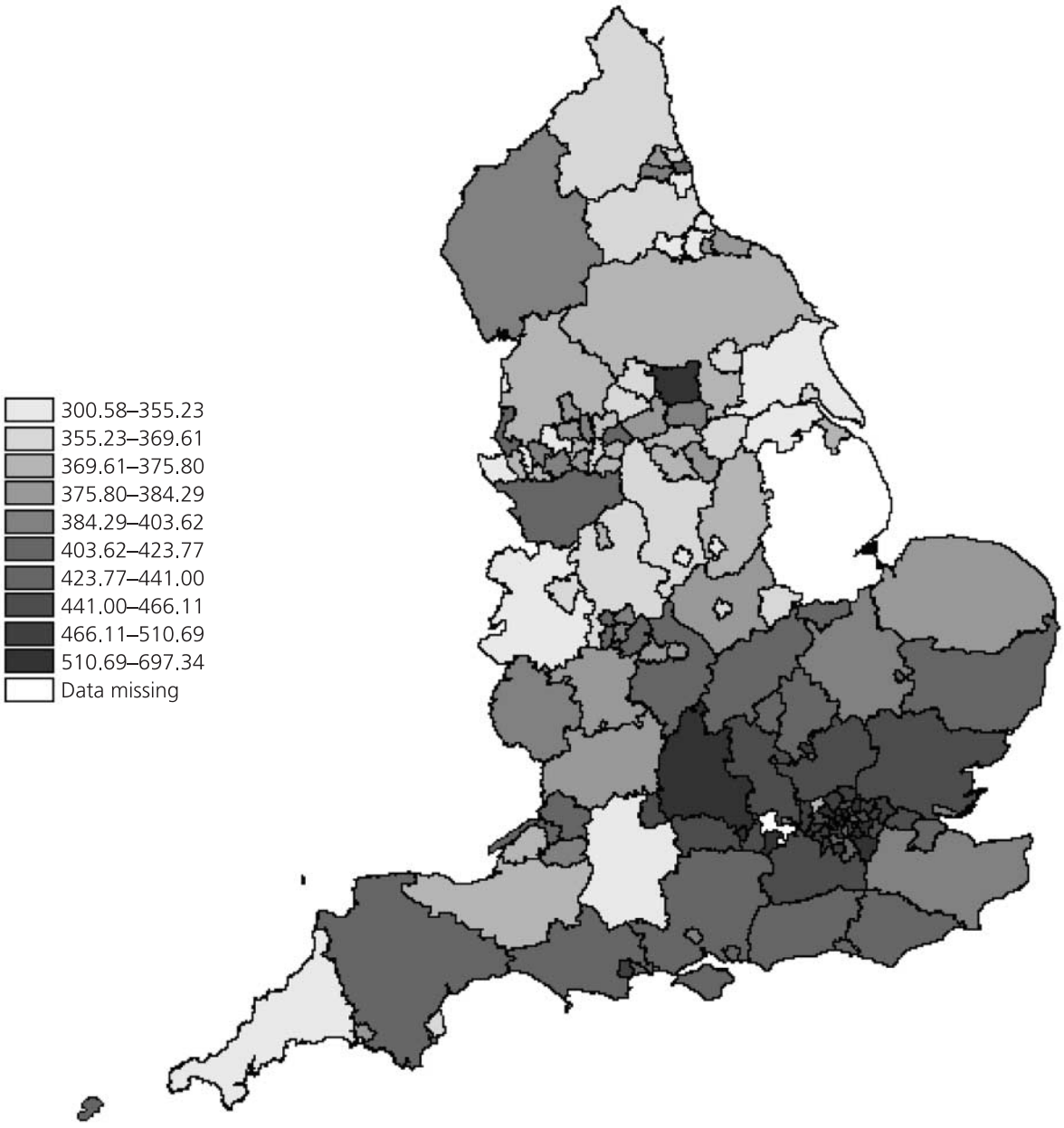

Figure E7 Spatial distribution (deciles) of the unit cost of residential and nursing care for older people, England – 2004–05 (£ per person per week)

Source: The Information Centre *Detailed unit costs by council, 2004–2005*
http://www.ic.nhs.uk/pubs/persocservexp2005/Detailed_unit_costs_by_council_2004-05.xls/file
Data missing for Rochdale, Lincolnshire, Windsor & Maidenhead

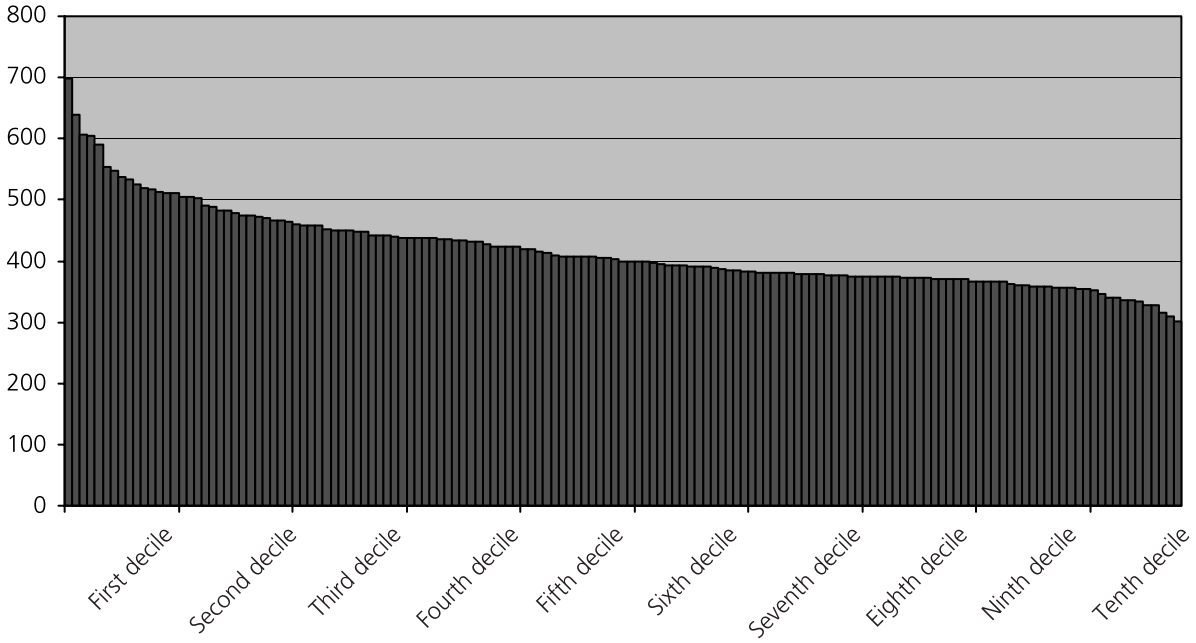

Figure E8 Distribution of the unit cost of residential and nursing care for older people by local authority, England – 2004–05 (£ per person per week)

Source: The Information Centre *Detailed unit costs by council, 2004–2005*
http://www.ic.nhs.uk/pubs/persocservexp2005/Detailed_unit_costs_by_council_2004-05.xls
Data missing for Rochdale, Lincolnshire, Windsor & Maidenhead

Table E4 Distribution of the proportion of older people receiving home care by local authority, England – 2004–05 (%)

First decile		*Third decile*		*Fifth decile*		*Seventh decile*		*Ninth decile*	
Lewisham	697.3	Hertfordshire	459.7	Northamptonshire	419.2	Redcar & Cleveland	382.2	Telford & Wrekin	367.3
Kensington & Chelsea	638.6	Buckinghamshire	458.3	South Tyneside	419.2	Bolton	381.1	Bradford	366.7
Camden	607.4	West Berkshire	457.7	Hampshire	414.8	Newcastle-upon-Tyne	380.4	Rutland	366.3
Islington	605.5	Newham	457.6	Sefton	414.2	Coventry	380.2	Durham	365.6
Westminster	590.6	Swindon	452.2	Bournemouth	409.9	Norfolk	379.7	Torbay	362.7
Bracknell Forest	554.6	Haringey	450.7	Cheshire	408.1	Worcestershire	379.7	Staffordshire	360.6
Hammersmith & Fulham	548.0	Ealing	450.5	Dorset	407.6	Blackburn with Darwen	379.3	Doncasster	360.0
Reading	536.9	Essex	449.6	South Gloucestershire	407.4	Middlesbrough	378.8	Kingston-upon-Hull	358.7
Waltham Forest	534.1	Thurrock	448.6	Wolverhampton	407.1	Plymouth	378.2	Leicester	358.4
Oxfordshire	525.2	Bexley	447.1	Warwickshire	406.5	Rotherham	378.1	North Tyneside	358.0
Brent	518.7	Hackney	442.4	Dudley	405.2	Leicestershire	377.4	Northumberland	356.7
Greenwich	516.5	Wokingham	441.2	Oldham	404.2	Solihull	376.4	Derbyshire	356.4
Leeds	513.7	Bedfordshire	441.0	Walsall	403.6	North Somerset	375.8	Derby	355.2
Bromley	511.8	Suffolk	440.5	Southampton	400.0	Sheffield	375.4	Shropshire	354.2
Southwark	510.7	Birmingham	438.5	Gateshead	399.5	Stoke-on-Trent	375.4	North Lincolnshire	353.5
Second decile		*Fourth decile*		*Sixth decile*		*Eighth decile*		*Tenth decile*	
Hillingdon	505.7	Peterborough	438.2	Kent	398.3	Nottinghamshire	375.0	Hartlepool	352.2
Sutton	505.3	East Sussex	438.2	Slough	398.0	Lancashire	375.0	Sunderland	346.5
Luton	503.8	Tower Hamlets	437.8	Warrington	397.5	Salford	374.9	Cornwall	340.9
Kingston-upon-Thames	491.1	Devon	436.8	Wakefield	394.8	Tameside	374.2	East Riding	339.2
Enfield	488.1	Isles of Scilly	436.1	St Helens	392.6	Stockport	373.7	Wiltshire	336.6
Havering	483.5	Isle of Wight	435.8	Bath & North East Somerset	392.4	Halton	373.4	Darlington	336.4
Poole	482.6	Brighton & Hove	432.9	Cumbria	392.0	Liverpool	372.5	Balckpool	334.6
Redbridge	478.3	Lambeth	432.6	Herefordshire	390.8	North East Lincolnshire	372.2	Nottingham	327.9
Barking & Dagenham	475.2	Merton	432.2	Bury	390.4	Barnsley	371.9	Stockton-on-Tees	327.2
Barnet	475.0	West Sussex	431.0	Cambridgeshire	390.4	North Yorkshire	371.2	Wirral	316.5
Wandsworth	472.7	Bristol	427.7	Southend	388.8	Somerset	370.8	Wigan	309.2
Richmond-upon-Thames	469.5	Milton Keynes	424.1	Sandwell	387.5	Harrow	370.1	Knowsley	300.6
Hounslow	466.8	Portsmouth	423.8	Kirklees	384.3	York	369.6		
Surrey	466.1	Croydon	423.7	Trafford	383.8	Calderdale	369.6		
City of London	464.3	Medway Towns	422.4	Gloucestershire	382.9	Manchester	367.4		

Source: The Information Centre *Detailed unit costs by council, 2004–2005*
http://www.ic.nhs.uk/pubs/persocservexp2005/Detailed_unit_costs_by_council_2004-05.xls/file
Data missing for Rochdale, Lincolnshire, Windsor & Maidenhead

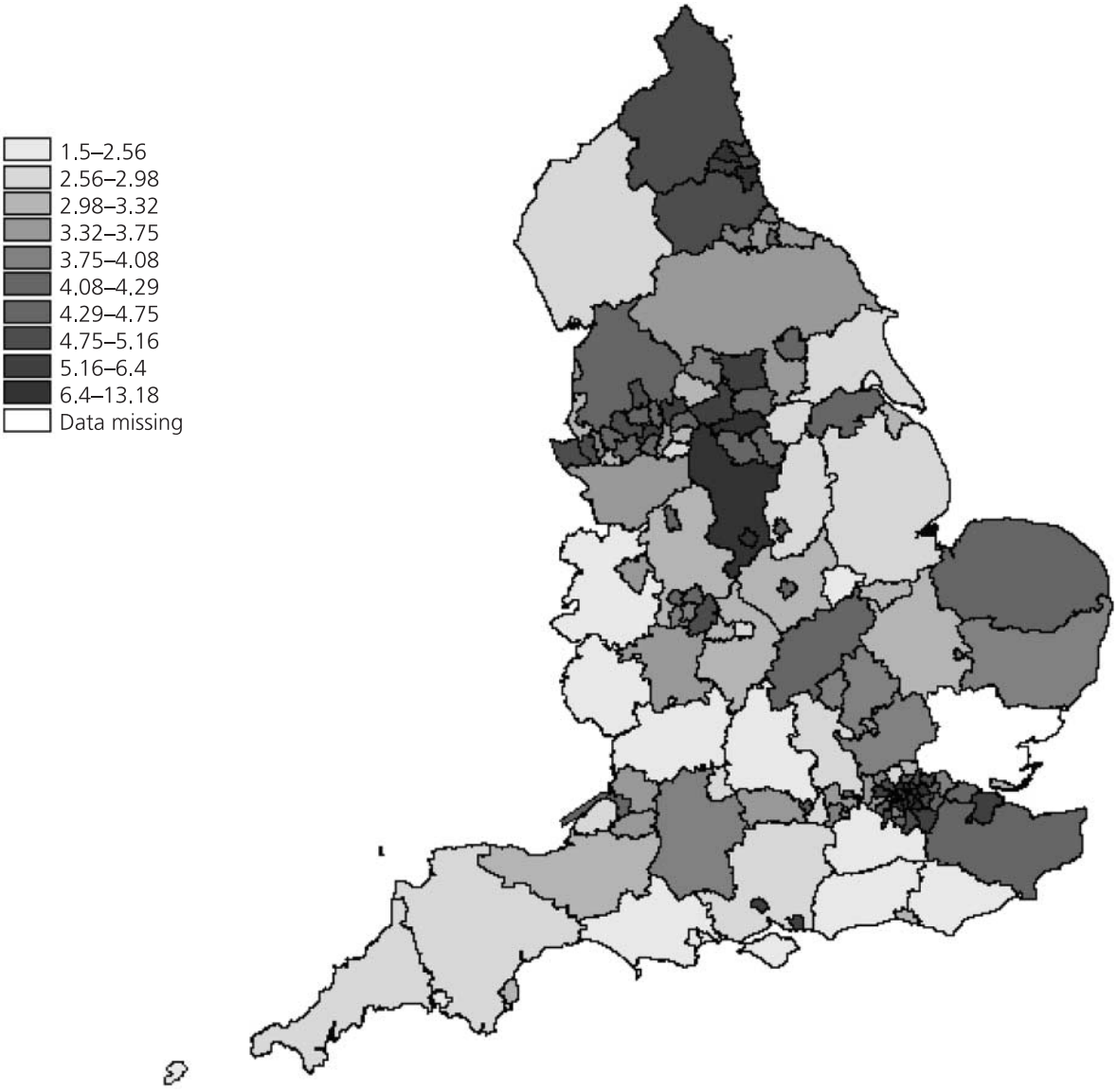

Figure E9 Spatial distribution (deciles) of the proportion of older people receiving home care, England – 2004–05 (£)

Activity source: The Information Centre *Community care statistics 2004–05: Referrals, assessments and packages of care for adults, England: National report and CSSR tables*
http://www.ic.nhs.uk/pubs/commcare05adultengrepcssr/P2s.1a%20to%20P2s.1d.xls/file
Population source: National Statistics Nomis website http://www.nomisweb.co.uk
Data missing for Essex

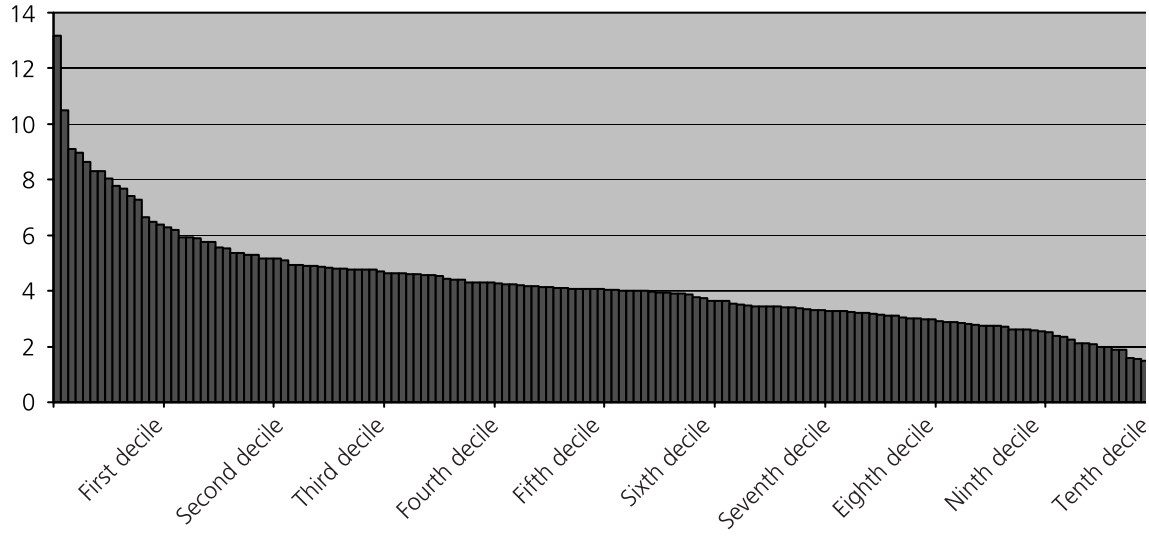

Figure E10 Distribution of the proportion of older people receiving home care by local authority, England – 2005 (%)

Activity source: The Information Centre *Community care statistics 2004–05: Referrals, assessments and packages of care for adults, England: National report and CSSR tables*
http://www.ic.nhs.uk/pubs/commcare05adultengrepcssr/P2s.1a%20to%20P2s.1d.xls/file
Population source: National Statistics Nomis website http://www.nomisweb.co.uk
Data missing for Essex

Table E5 Distribution of the proportion of the older people receiving home care by local authority, England – 2005 (%)

First decile		*Third decile*		*Fifth decile*		*Seventh decile*		*Ninth decile*	
Tower Hamlets	13.2	Kingston-upon-Thames	5.2	Wakefield	4.3	Blackpool	3.6	Barnet	2.9
Barnsley	10.5	Greenwich	5.1	Sheffield	4.3	Telford and Wrekin	3.6	Cumbria	2.9
Sunderland	9.1	Liverpool	4.9	Stoke-on-Trent	4.2	Cheshire	3.5	Doncaster	2.9
Lambeth	9.0	Blackburn with Darwen	4.9	Warrington	4.2	Luton	3.5	Devon	2.9
Hammersmith & Fulham	8.6	North Tyneside	4.9	York	4.2	Manchester	3.5	Buckinghamshire	2.8
Derby	8.3	Croydon	4.9	Slough	4.2	Hounslow	3.5	Nottinghamshire	2.8
Wandsworth	8.3	Northumberland	4.9	Richmond-upon-Thames	4.1	Hillingdon	3.5	Hampshire	2.8
Camden	8.0	Durham	4.8	Lancashire	4.1	North Yorkshire	3.4	Stockport	2.8
City of London	7.8	Wigan	4.8	Bury	4.1	Windsor & Maidenhead	3.4	Swindon	2.7
Islington	7.7	Birmingham	4.8	Sutton	4.1	Bath & North East Somerset	3.4	Lincolnshire	2.7
Derbyshire	7.4	South Tyneside	4.8	Trafford	4.1	Worcestershire	3.4	Wokingham	2.6
Newcaste-upon-Tyne	7.3	Wirral	4.8	Norfolk	4.1	South Gloucestershire	3.4	East Riding	2.6
Newham	6.7	Redbridge	4.8	Middlesbrough	4.1	West Berkshire	3.3	North Somerset	2.6
Lewisham	6.5	Leicester	4.8	Suffolk	4.1	Leicestershire	3.3	Coventry	2.6
Ealing	6.4	Barking & Dagenham	4.7	Knowsley	4.1	Peterborough	3.3	Isle of Wight	2.6
Second decile		*Fourth decile*		*Sixth decile*		*Eighth decile*		*Tenth decile*	
Kirklees	6.3	Bristol	4.6	Merton	4.1	Halton	3.3	Plymouth	2.5
Westminster	6.2	Northamptonshire	4.6	Dudley	4.0	Calderdale	3.3	Oxfordshire	2.4
Kensington & Chelsea	5.9	Rotherham	4.6	Bracknell Forest	4.0	Warwickshire	3.3	Gloucestershire	2.4
Southampton	5.9	Bexley	4.6	Hertfordshire	4.0	Staffordshire	3.2	Kingston-upon-Hull	2.2
Southwark	5.9	Oldham	4.6	Havering	4.0	Tameside	3.2	Dorset	2.1
Leeds	5.8	Reading	4.6	Harrow	4.0	Somerset	3.2	Rutland	2.1
Gateshead	5.8	St Helens	4.6	Wiltshire	4.0	North East Lincolnshire	3.2	Bournemouth	2.1
Portsmouth	5.6	Bolton	4.5	Darlington	3.9	Torbay	3.1	Isles of Scilly	2.0
Hackney	5.5	Walsall	4.4	Bradford	3.9	Southend	3.1	East Sussex	2.0
Bromley	5.4	North Lincolnshire	4.4	Sandwell	3.9	Brighton & Hove	3.1	West Sussex	1.9
Medway Town	5.4	Wolverhampton	4.4	Milton Keynes	3.9	Sefton	3.0	Shropshire	1.9
Rochdale	5.3	Nottingham	4.3	Bedfordshire	3.9	Cambridgeshire	3.0	Surrey	1.6
Salford	5.3	Thurrock	4.3	Hartlepool	3.8	Solihull	3.0	Poole	1.6
Waltham Forest	5.2	Harringey	4.3	Redcar & Cleveland	3.8	Enfield	3.0	Herefordshire	1.5
Brent	5.2	Kent	4.3	Stockton-on-Tees	3.7	Cornwall	3.0		

Activity source: The Information Centre *Community care statistics 2004–05: Referrals, assessments and packages of care for adults, England: National report and CSSR tables* http://www.ic.nhs.uk/pubs/commcare05adultengrepcssr/P2s.1a%20to%P2s.1d.xls/file.xls/file
Population source: National Statistics Nomis website http://www.nomisweb.co.uk
Data missing for Essex

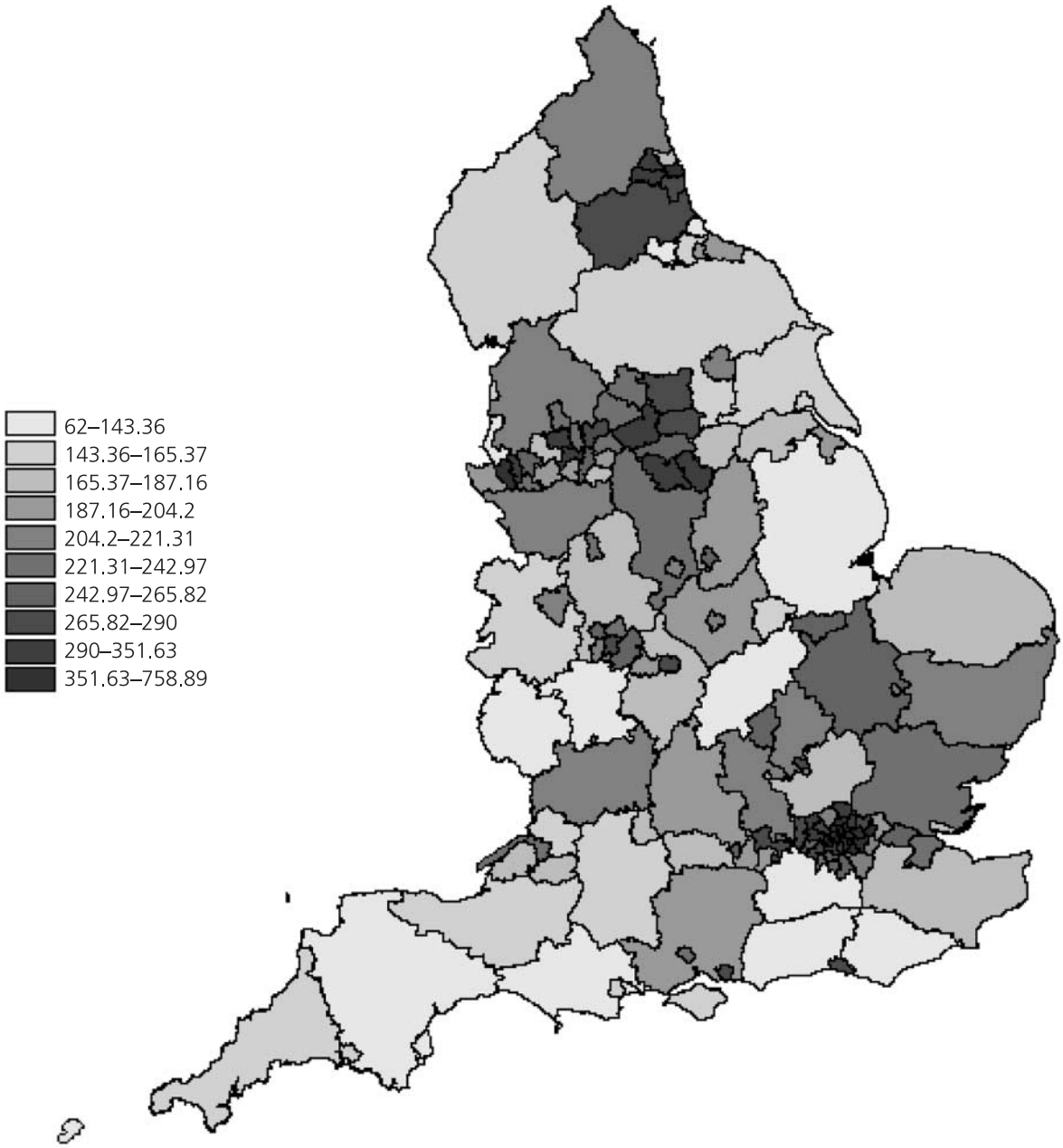

Figure E11 Spatial distribution (deciles) of the expenditure on home care for older people per head of population over 65, England – 2004–05 (£)

Expenditure Source: The Information Centre *Detailed unit costs by council, 2004–2005*
http://www.ic.nhs.uk/pubs/persocservexp2005/Detailed_unit_costs_by_council_2004–05.xls/file
Population source: National Statistics Nomis website http://www.nomisweb.co.uk

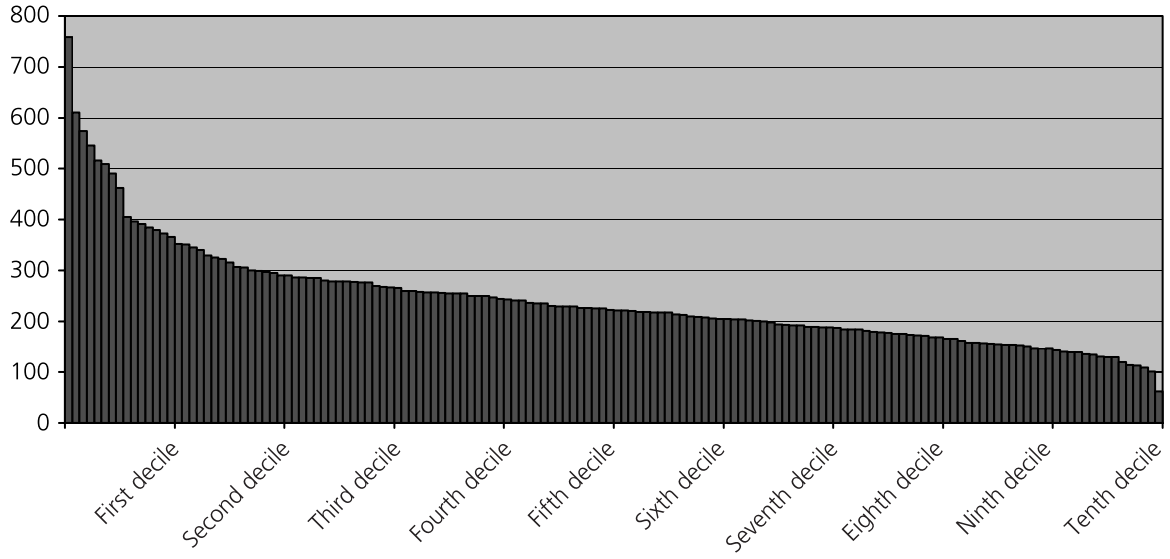

Figure E12 Distribution of the expenditure on home care for older people per head of population over 65 by local authority, England – 2004–05 (£)

Expenditure Source: The Information Centre *Detailed unit costs by council, 2004–2005*
http://www.ic.nhs.uk/pubs/persocservexp2005/Detailed_unit_costs_by_council_2004–05.xls/file
Population source: National Statistics Nomis website http://www.nomisweb.co.uk

Table E6 Distribution of the unit cost of home care for all recipients by local authority, England – 2004–05 (£ per hour)

First decile		*Third decile*		*Fifth decile*		*Seventh decile*		*Ninth decile*	
City of London	25.9	Cheshire	16.3	Portsmouth	14.3	Medway Towns	13.2	Suffolk	12.1
Windsor & Maidenhead	22.1	Brighton & Hove	16.3	Luton	14.3	Cambridgeshire	13.2	Blackpool	12.0
Wokingham	20.2	Barnet	16.3	Shropshire	14.2	Newham	13.2	Rutland	12.0
North Somerset	19.8	Rochdale	16.1	Stockport	14.2	Kingston-upon-Thames	13.1	Kensington & Chelsea	12.0
Islington	19.7	Devon	16.1	Walsall	14.2	Manchester	13.0	Merton	11.9
Isles of Scilly	19.2	Hampshire	15.9	Essex	14.1	Oxfordshire	13.0	Bromley	11.8
Gloucestershire	18.6	North Yorkshire	15.9	Calderdale	14.1	Hartlepool	13.0	Leeds	11.8
Dorset	18.5	Surrey	15.8	Leicestershire	14.1	Hammersmith & Fulham	12.9	St Helens	11.7
Ealing	18.3	Bournemouth	15.6	Norfolk	14.1	Wigan	12.9	Salford	11.6
Barking & Dagenham	18.2	Wolverhampton	15.5	North Lincolnshire	14.1	North East Lincolnshire	12.8	Doncaster	11.6
Plymouth	18.2	Worcestershire	15.5	Kirklees	14.0	Southend	12.8	Dudley	11.6
South Tyneside	18.1	Hertfordshire	15.5	Southampton	14.0	Gateshead	12.7	Brent	11.5
Sutton	18.0	Bristol	15.4	Wiltshire	13.9	Bexley	12.7	Middlesbrough	11.4
Lewisham	17.7	York	15.3	HIllingdon	13.9	Durham	12.7	Somerset	11.1
Harrow	17.7	Bracknell Forest	15.2	Bradford	13.8	Redbridge	12.6	Halton	11.1
Second decile		*Fourth decile*		*Sixth decile*		*Eighth decile*		*Tenth decile*	
South Gloucestershire	17.6	Herefordshire	15.2	Havering	13.8	Redcar & Cleveland	12.6	Waltham Forest	11.1
Nottinghamshire	17.6	Milton Keynes	15.2	Lambeth	13.8	Thurrock	12.5	Darlington	10.9
Westminster	17.6	East Sussex	15.1	Cumbria	13.8	North Tyneside	12.5	Bolton	10.7
Torbay	17.5	Telford and Wrekin	14.9	Camden	13.7	Tameside	12.5	Peterborough	10.7
Bedfordshire	17.0	Bath & North East Somerset	14.9	Nottingham	13.7	Birmingham	12.5	Derby	10.4
Reading	17.0	Hackney	14.8	Southwark	13.7	Coventry	12.5	Warrington	10.2
Trafford	16.9	Richmond-upon-Thames	14.7	Sheffield	13.6	Croydon	12.5	Blackburn with Darwen	10.0
Slough	16.9	Wakefield	14.7	Staffordshire	13.6	Isle of Wight	12.4	Lancashire	9.9
Enfield	16.7	Northamptonshire	14.6	Solihull	13.6	Stockton-on-Tees	12.4	Wirral	9.8
Buckinghamshire	16.7	Hounslow	14.6	Liverpool	13.6	Newcastle-upon-Tyne	12.4	Knowsley	9.8
Poole	16.6	Greenwich	14.5	Sunderland	13.6	East Riding	12.4	Oldham	9.7
Kent	16.6	Tower Hamlets	14.5	Warwickshire	13.6	Barnsley	12.4	Wandsworth	9.5
Haringey	16.5	Rotherham	14.5	Cornwall	13.5	Leicester	12.3	Lincolnshire	9.4
West Berkshire	16.4	Kingston-upon-Hull	14.5	Stoke-on-Trent	13.5	Derbyshire	12.3	Bury	9.4
West Sussex	16.3	Sandwell	14.4	Swindon	13.5	Northumberland	12.2	Sefton	9.2

Source: The Information Centre *Detailed unit costs by council, 2004–2005*
http://www.ic.nhs.uk/pubs/persocservexp2005/Detailed_unit_costs_by_council_2004–05.xls/file

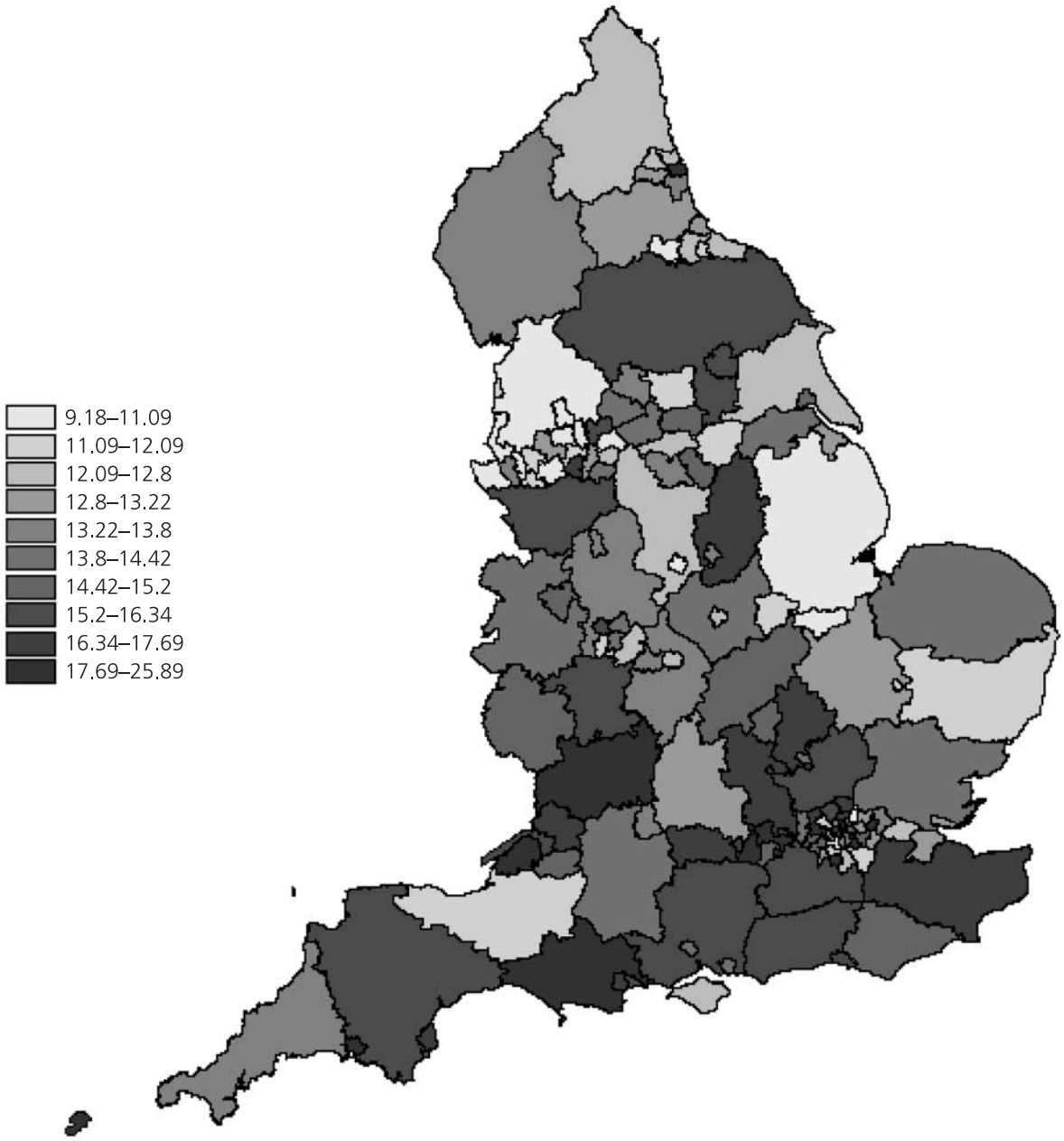

Figure E13 Spatial distribution (deciles) of the unit cost of home care for all recipients, England – 2004–05 (£ per hour)

Source: The Information Centre *Detailed unit costs by council, 2004–2005*
http://www.ic.nhs.uk/pubs/persocservexp2005/Detailed_unit_costs_by_council_2004–05.xls/file

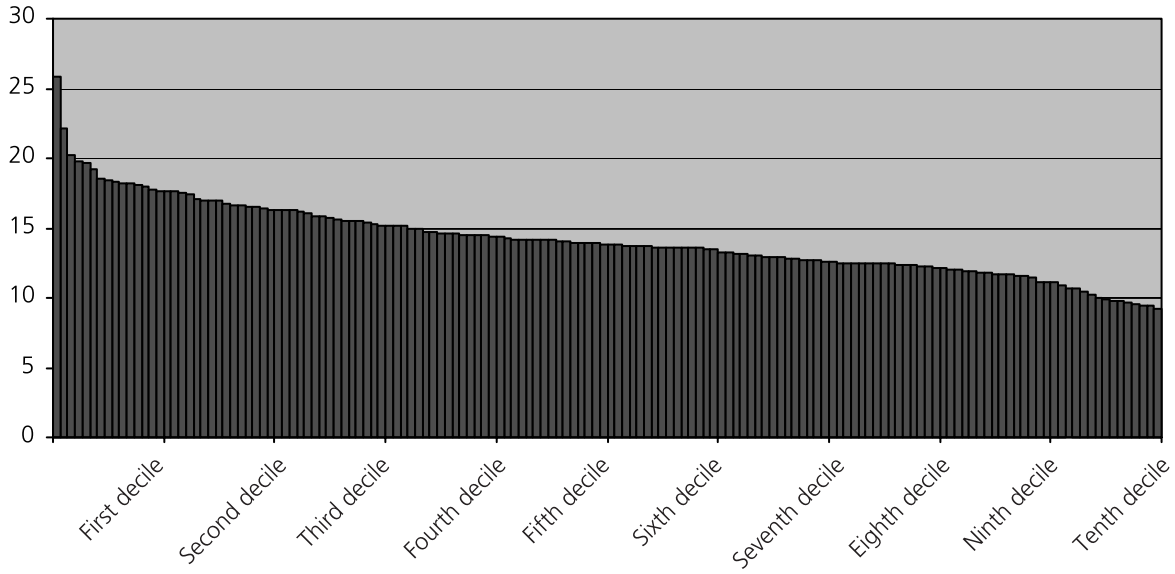

Figure E14 Distribution of the unit cost of home care for all recipients by local authority, England – 2004–05 (£ per hour)

Source: The Information Centre *Detailed unit costs by council, 2004–2005*
http://www.ic.nhs.uk/pubs/persocservexp2005/Detailed_unit_costs_by_council_2004–05.xls/file

Table E7 Distribution of the average weekly home care package for older people by local authority, England – 2004–05 (hours)

First decile		*Third decile*		*Fifth decile*		*Seventh decile*		*Ninth decile*	
City of London	25.9	Cheshire	16.3	Portsmouth	14.3	Medway Towns	13.2	Suffolk	12.1
Windsor & Maidenhead	22.1	Brighton & Hove	16.3	Luton	14.3	Cambridgeshire	13.2	Blackpool	12.0
Wokingham	20.2	Barnet	16.3	Shropshire	14.2	Newham	13.2	Rutland	12.0
North Somerset	19.8	Rochdale	16.1	Stockport	14.2	Kingston-upon-Thames	13.1	Kensington & Chelsea	12.0
Islington	19.7	Devon	16.1	Walsall	14.2	Manchester	13.0	Merton	11.9
Isles of Scilly	19.2	Hampshire	15.9	Essex	14.1	Oxfordshire	13.0	Bromley	11.8
Gloucestershire	18.6	North Yorkshire	15.9	Calderdale	14.1	Hartlepool	13.0	Leeds	11.8
Dorset	18.5	Surrey	15.8	Leicestershire	14.1	Hammersmith & Fulham	12.9	St Helens	11.7
Ealing	18.3	Bournemouth	15.6	Norfolk	14.1	Wigan	12.9	Salford	11.6
Barking & Dagenham	18.2	Wolverhampton	15.5	North Lincolnshire	14.1	North East Lincolnshire	12.8	Doncaster	11.6
Plymouth	18.2	Worcestershire	15.5	Kirklees	14.0	Southend	12.8	Dudley	11.6
South Tyneside	18.1	Hertfordshire	15.5	Southampton	14.0	Gateshead	12.7	Brent	11.5
Sutton	18.0	Bristol	15.4	Wiltshire	13.9	Bexley	12.7	Middlesbrough	11.4
Lewisham	17.7	York	15.3	Hillingdon	13.9	Durham	12.7	Somerset	11.1
Harrow	17.7	Bracknell Forest	15.2	Bradford	13.8	Redbridge	12.6	Halton	11.1
Second decile		*Fourth decile*		*Sixth decile*		*Eighth decile*		*Tenth decile*	
South Gloucestershire	17.6	Herefordshire	15.2	Havering	13.8	Redcar & Cleveland	12.6	Waltham Forest	11.1
Nottinghamshire	17.6	Milton Keynes	15.2	Lambeth	13.8	Thurrock	12.5	Darlington	10.9
Westminster	17.6	East Sussex	15.1	Cumbria	13.8	North Tyneside	12.5	Bolton	10.7
Torbay	17.5	Telford and Wrekin	14.9	Camden	13.7	Tameside	12.5	Peterborough	10.7
Bedfordshire	17.0	Bath & North East Somerset	14.9	Nottingham	13.7	Birmingham	12.5	Derby	10.4
Reading	17.0	Hackney	14.8	Southwark	13.7	Coventry	12.5	Warrington	10.2
Trafford	16.9	Richmond-upon-Thames	14.7	Sheffield	13.6	Croydon	12.5	Blackburn with Darwen	10.0
Slough	16.9	Wakefield	14.7	Staffordshire	13.6	Isle of Wight	12.4	Lancashire	9.9
Enfield	16.7	Northamptonshire	14.6	Solihull	13.6	Stockton-on-Tees	12.4	Wirral	9.8
Buckinghamshire	16.7	Hounslow	14.6	Liverpool	13.6	Newcastle-upon-Tyne	12.4	Knowsley	9.8
Poole	16.6	Greenwich	14.5	Sunderland	13.6	East Riding	12.4	Oldham	9.7
Kent	16.6	Tower Hamlets	14.5	Warwickshire	13.6	Barnsley	12.4	Wandsworth	9.5
Haringey	16.5	Rotherham	14.5	Cornwall	13.5	Leicester	12.3	Lincolnshire	9.4
West Berkshire	16.4	Kingston-upon-Hull	14.5	Stoke-on-Trent	13.5	Derbyshire	12.3	Bury	9.4
West Sussex	16.3	Sandwell	14.4	Swindon	13.5	Northumberland	12.2	Sefton	9.2

Source: The Information Centre *Detailed unit costs by council, 2004–2005*
http://www.ic.nhs.uk/pubs/persocservexp2005/Detailed_unit_costs_by_council_2004–05.xls/file

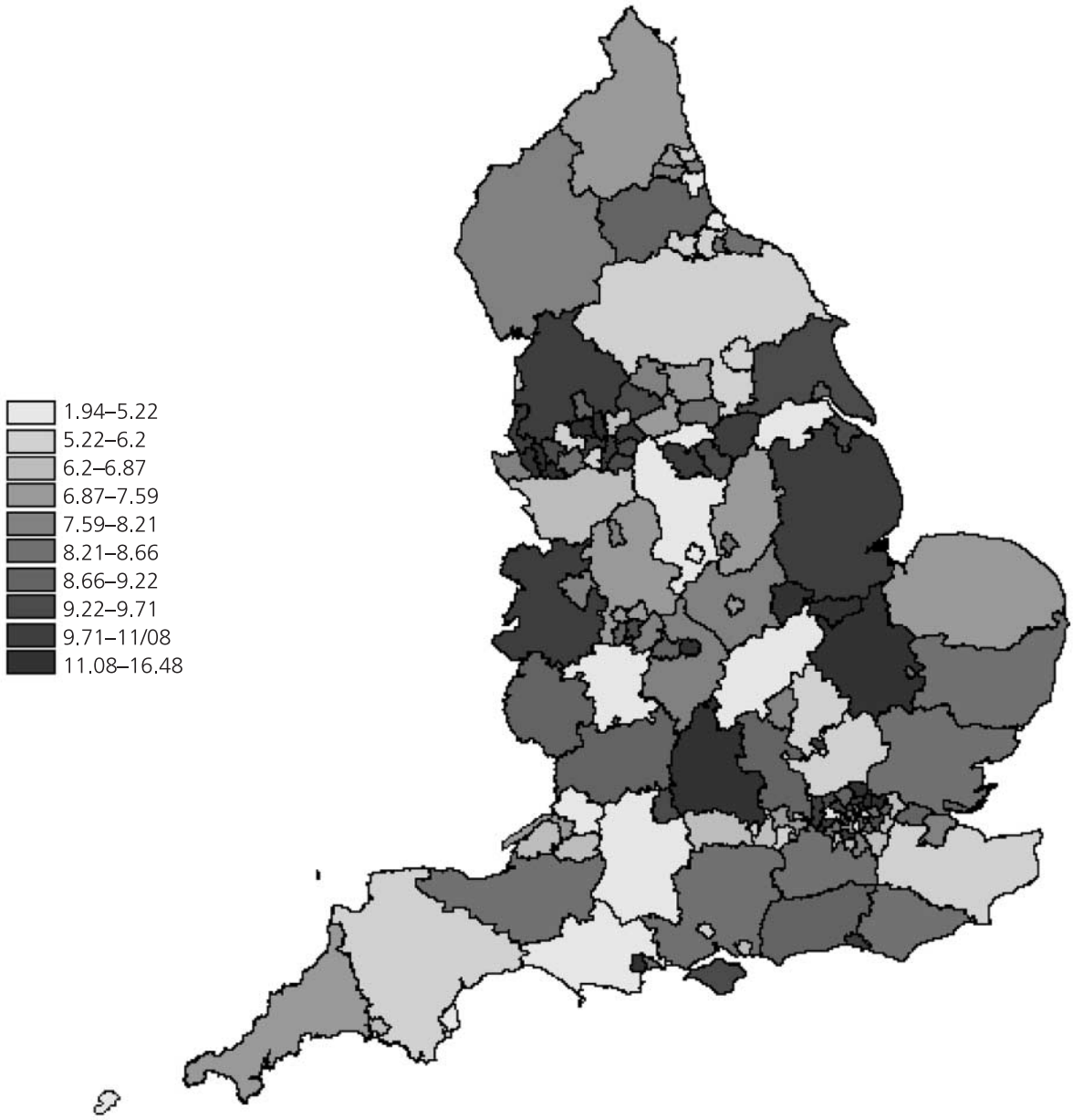

Figure E15 Spatial distribution (deciles) of the average weekly home care package for older people, England – 2004–05 (hrs)

Source: The Information Centre *Detailed unit costs by council, 20004–05*
http://www.ic.nhs.uk/pubs/persocservexp2005/Detailed_unit_costs_by_council_2004-05.xls/file

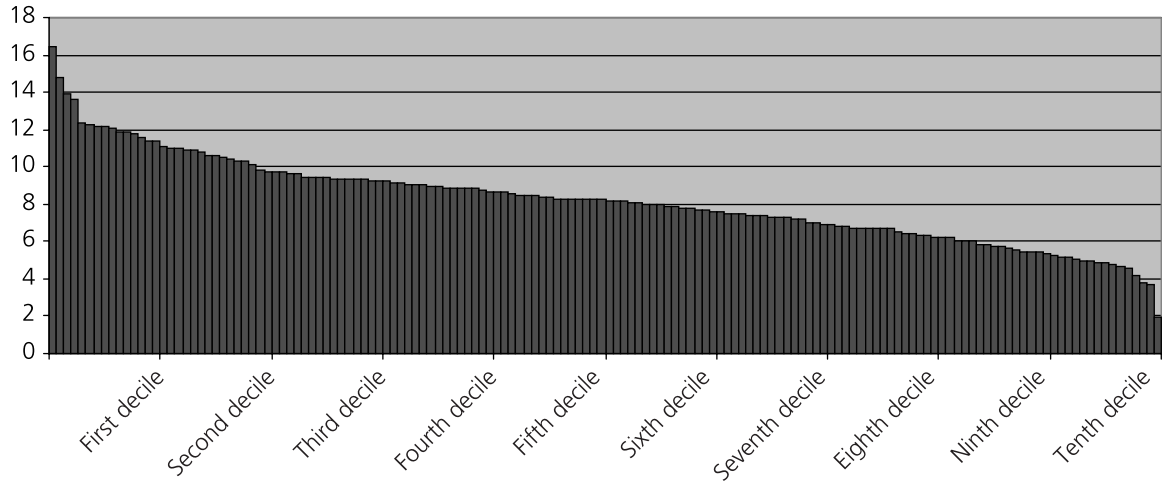

Figure E16 Distribution of the average weekly home care package for older people by local authority, England – 2004–05 (hours)

Source: The Information Centre *Detailed unit costs by council, 2004–2005*
http://www.ic.nhs.uk/pubs/persocservexp2005/Detailed_unit_costs_by_council_2004-05.xls/file

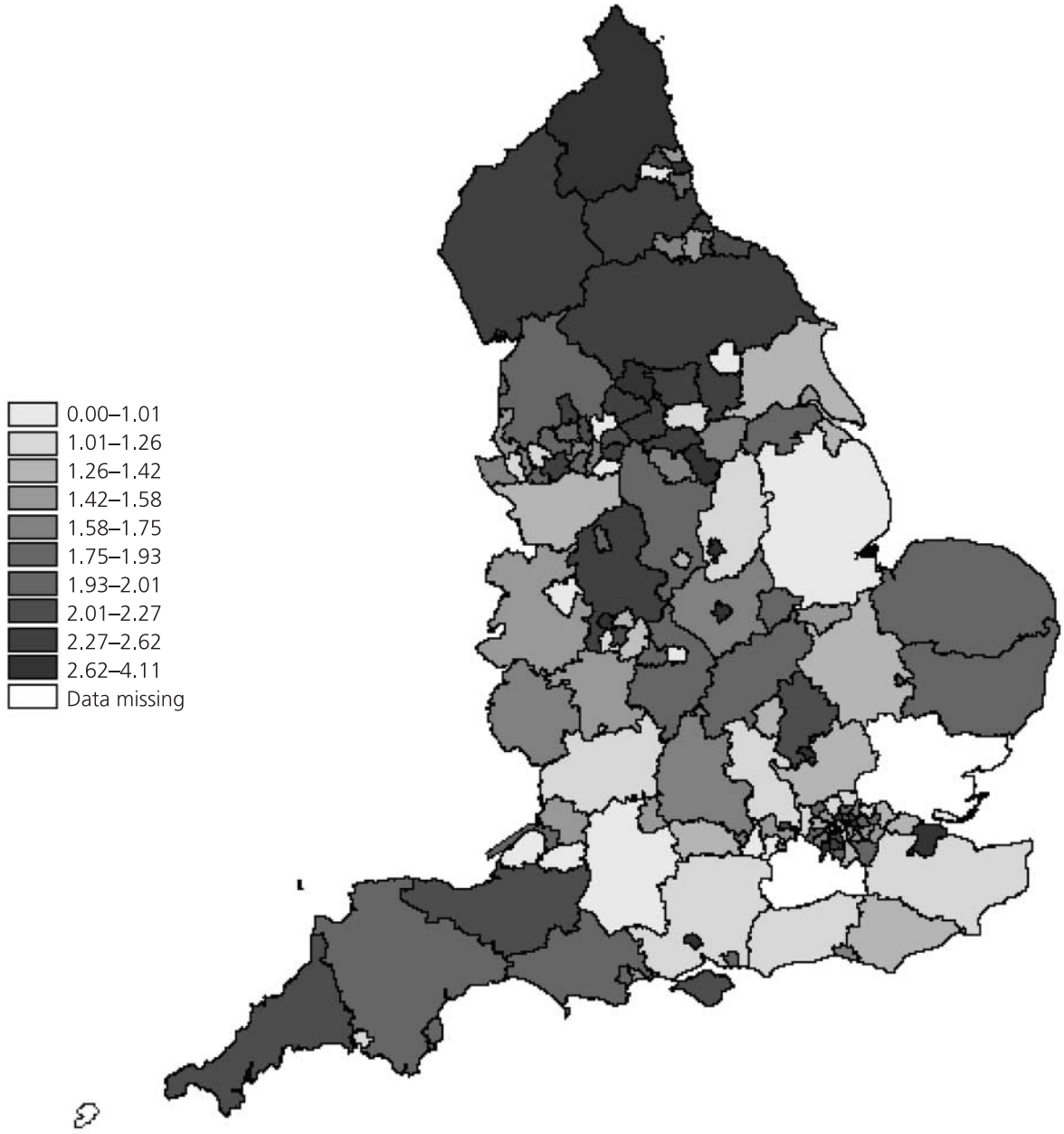

Figure E17 Spatial distribution (deciles) of the proportion of older people receiving day care by local authority, England – 2004–05 (%)

Activity source: The Information Centre *Community care statistics 2004–05: Referrals, assessments and packages of care for adults, England: National report and CSSR tables*
http://www.ic.nhs.uk/pubs/commcare05adultengrepcssr/P2f.1a%20%20to%20P2f.1c.xls/file
Population source: National Statistics Nomis website http://www.nomisweb.co.uk
Data missing for Birmingham, Essex, Surrey, City of London and Isles of Scilly

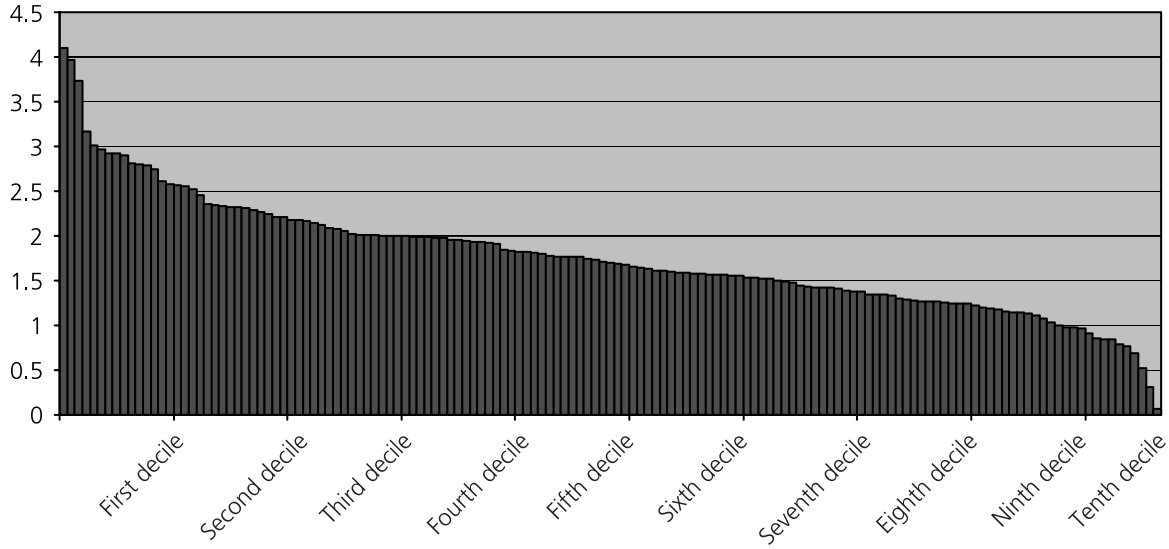

Figure E18 Distribution of the proportion of older people receiving day care by local authority, England – 2004–05 (%)

Activity source: The Information Centre *Community care statistics 2004–05: Referrals, assessments and packages of care for adults, England: National report and CSSR tables*
http://www.ic.nhs.uk/pubs/commcare05adultengrepcssr/P2f.1a%20%20to%20P2f.1c.xls/file
Population source: National Statistics Nomis website http://www.nomisweb.co.uk
Data missing for Birmingham, Essex, Surrey, City of London and Isles of Scilly

Table E8 Distribution of the proportion of older people receiving day care by local authority, England – 2004–05 (%)

First decile		*Third decile*		*Fifth decile*		*Seventh decile*		*Ninth decile*	
Kingston-upon-Thames	4.1	Wandsworth	2.2	Bolton	1.8	Southwark	1.5	St Helens	1.2
Leicester	4.0	Cornwall	2.2	Rutland	1.8	Sefton	1.5	Nottinghamshire	1.2
Wolverhampton	3.7	Isle of Wight	2.2	Dorset	1.8	Bexley	1.5	Gloucestershire	1.2
Bradford	3.2	Sandwell	2.1	Bristol	1.8	Brent	1.5	West Sussex	1.2
Tower Hamlets	3.0	Slough	2.1	Barking & Dagenham	1.8	Peterborough	1.5	Kent	1.2
Nottingham	3.0	Bury	2.1	Solihull	1.8	Shropshire	1.5	Lambeth	1.1
Rotherham	2.9	Bedfordshire	2.1	Sunderland	1.8	Worcestershire	1.5	Plymouth	1.1
Southampton	2.9	Redcar & Cleveland	2.1	Halton	1.8	North Tyneside	1.4	Liverpool	1.1
Luton	2.9	Newcastle-upon-Tyne	2.0	Trafford	1.8	Windsor & Maidenhead	1.4	Enfield	1.1
South Tyneside	2.8	Devon	2.0	Waltham Forest	1.7	East Riding	1.4	Kensington & Chelsea	1.1
Medway Towns	2.8	Newham	2.0	Reading	1.7	Cheshire	1.4	Dudley	1.0
Northumberland	2.8	North Lincolnshire	2.0	Darlington	1.7	Walsall	1.4	Wokingham	1.0
Camden	2.7	Hounslow	2.0	Wirral	1.7	North East Lincolnshire	1.4	Telford and Wrekin	1.0
North Yorkshire	2.6	Portsmouth	2.0	Doncaster	1.7	Westminster	1.4	Gateshead	1.0
Cumbria	2.6	Warwickshire	2.0	Salford	1.7	West Berkshire	1.4	Hammersmith & Fulham	1.0
Second decile		*Fourth decile*		*Sixth decile*		*Eighth decile*		*Tenth decile*	
Kirklees	2.6	Bromley	2.0	Richmond-upon-Thames	1.7	Havering	1.4	Southend	0.9
Hartlepool	2.6	Norfolk	2.0	Leicestershire	1.6	Hertfordshire	1.3	Lincolnshire	0.9
Calderdale	2.5	Northamptonshire	2.0	Sheffield	1.6	Milton Keynes	1.3	Stockport	0.8
Barnsley	2.5	Wigan	2.0	Knowsley	1.6	Cambridgeshire	1.3	Rochdale	0.8
Tameside	2.4	Suffolk	2.0	Oxfordshire	1.6	Croydon	1.3	Bracknell Forest	0.8
Durham	2.3	Islington	2.0	Brighton & Hove	1.6	Thurrock	1.3	York	0.8
Staffordshire	2.3	Stoke-on-Trent	2.0	Manchester	1.6	Derby	1.3	Wiltshire	0.7
Merton	2.3	Poole	2.0	Herefordshire	1.6	Ealing	1.3	Coventry	0.5
Blackburn with Darwen	2.3	Lancashire	1.9	Swindon	1.6	East Sussex	1.3	North Somerset	0.3
Leeds	2.3	Sutton	1.9	Stockton-on-Tees	1.6	Wakefield	1.3	Bath & North East	
Warrington	2.3	Blackpool	1.9	Kingston-upon-Hull	1.6	Hampshire	1.3	Somerset	0.1
Hackney	2.3	Derbyshire	1.9	Greenwich	1.6	Barnet	1.3		
Somerset	2.2	Harrow	1.9	South Gloucestershire	1.6	Redbridge	1.3		
Oldham	2.2	Haringey	1.8	Bournemouth	1.6	Buckinghamshire	1.2		
Middlesbrough	2.2	Torbay	1.8	Lewisham	1.6	HIllingdon	1.2		

Activity source: The Information Centre *Community care statistics 2004–05: Referrals, assessments and packages of care for adults, England: National report and CSSR tables*
http://www.ic.nhs.uk/pubs/commcare05adultengrepcssr/P2f.1a%20%20to%20P2f.1c.xls/file
Population source: National Statistics Nomis website http://www.nomisweb.co.uk
Data missing for Birmingham, Essex, Surrey, City of London and Isles of Scilly

APPENDIX 2

Northern Ireland

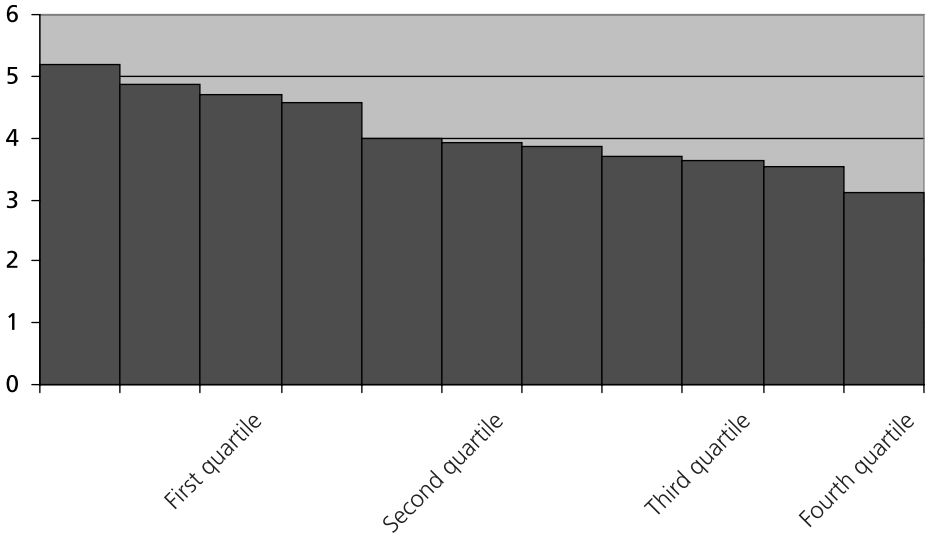

Figure N1 Distribution of the proportion of population over 65 living in care homes, by Health and Social Services Trust, Northern Ireland – 2004–05 (%)

Table N1 Distribution of the proportion of population over 65 living in care homes, by Health and Social Services Trust, Northern Ireland – 2004–05 (%)

First quartile		*Second quartile*		*Third quartile*		*Fourth quartile*	
North & West Belfast	5.2	Craigavon & Banbridge	4.6	Down Lisburn	3.9	Foyle	3.5
Armagh & Dungannon	4.9	Causeway	4.0	Sperrin Lakeland	3.7	South & East Belfast	3.1
Ulster Community & Hosp	4.7	Newry & Mourne	3.9	Homefirst	3.6		

Activity source: DHSSPS Northern Ireland *Community Care Statistics 2004–05*
http://www.dhsspsni.gov.uk/master_community_statistics_(2004–05).pdf
Population source: DHSSPS Northern Ireland (personal communication)

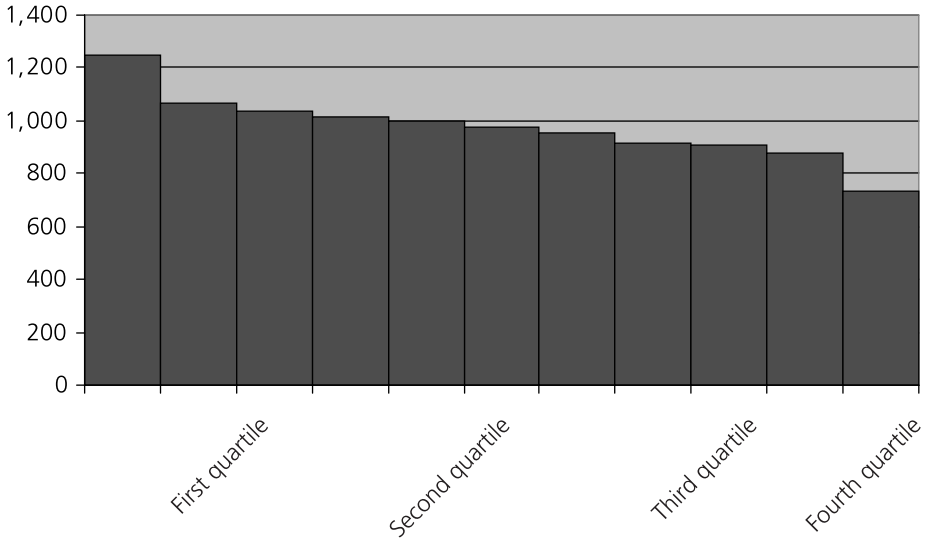

Figure N2 Distribution of the expenditure on residential and nursing care for older people per head of population over 65, by Health and Social Services Trust, Northern Ireland – 2004–05 (£)

Table N2 Distribution of the expenditure on residential and nursing care for older people per head of population over 65, by Health and Social Services Trust, Northern Ireland – 2004–05 (£)

First quartile		*Second quartile*		*Third quartile*		*Fourth quartile*	
North & West Belfast	1,252.0	Sperrin Lakeland	1,013.2	Newry & Mourne	954.9	Down Lisburn	877.1
Armagh & Dungannon	1,065.2	Causeway	998.1	Foyle	919.2	South & East Belfast	735.6
Ulster Community & Hosp	1,034.4	Craigavon & Banbridge	975.0	Homefirst	904.3		

Source: DHSSPS Northern Ireland (personal communication)

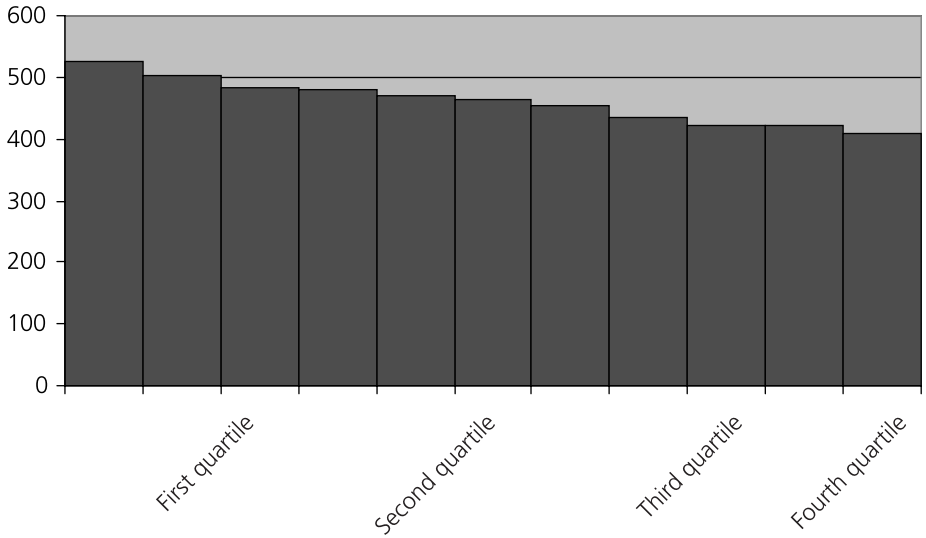

Figure N3 Distribution of the unit cost of residential and nursing care for older people, by Health and Social Services Trust, Northern Ireland – 2004–05(£ per person per week)

Table N3 Distribution of the unit cost of residential and nursing care for older people, by Health and Social Services Trust, Northern Ireland – 2004–05(£ per person per week)

First quartile		*Second quartile*		*Third quartile*		*Fourth quartile*	
Sperrin Lakeland	526.5	Homefirst	479.2	South & East Belfast	455.0	Armagh & Dungannon	422.0
Foyle	502.3	Newry & Mourne	469.4	Down Lisburn	436.2	Craigavon & Banbridge	408.8
Causeway	481.9	North & West Belfast	464.6	Ulster Community & Hosp	422.3		

Activity source: DHSSPS Northern Ireland *Community Care Statistics 2004–05*
http://www.dhsspsni.gov.uk/master_community_statistics_(2004–05).pdf
Population and expenditure source: DHSSPS Northern Ireland (personal communication)

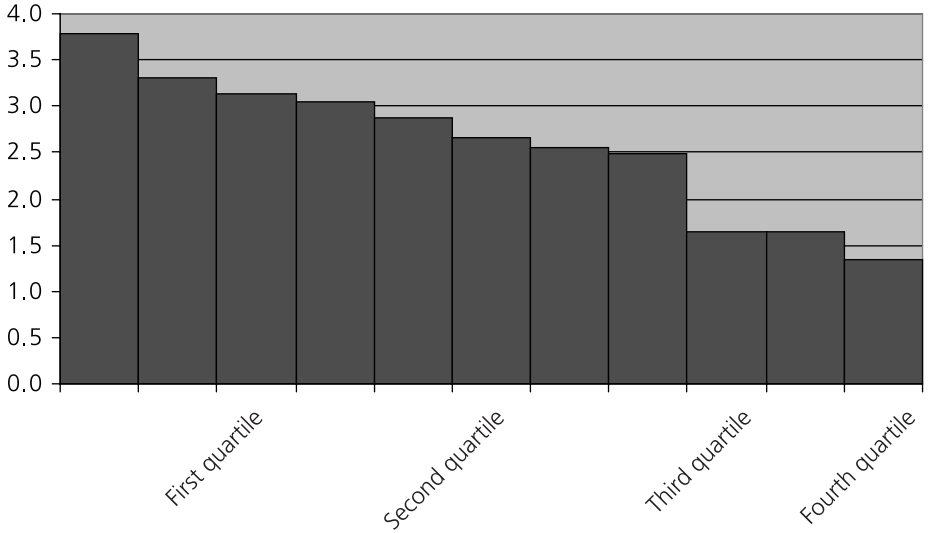

Figure N4 Distribution of the proportion of older people receiving domiciliary care, by Health and Social Services Trust, Northern Ireland – 2005 (%)

Table N4 Distribution of the proportion of older people receiving domiciliary care, by Health and Social Services Trust, Northern Ireland – 2005 (%)

First quartile		*Second quartile*		*Third quartile*		*Fourth quartile*	
Causeway	3.8	Foyle	3.1	Down Lisburn	2.5	Craigavon & Banbridge	1.6
North & West Belfast	3.3	Armagh & Dungannon	2.9	Sperrin Lakeland	2.5	South & East Belfast	1.3
Newry & Mourne	3.1	Ulster Community & Hosp	2.7	Homefirst	1.6		

Activity source: DHSSPS Northern Ireland *Community Care Statistics 2004–05*
http://www.dhsspsni.gov.uk/master_community_statistics_(2004–05).pdf
Population source: DHSSPS Northern Ireland (personal communication)

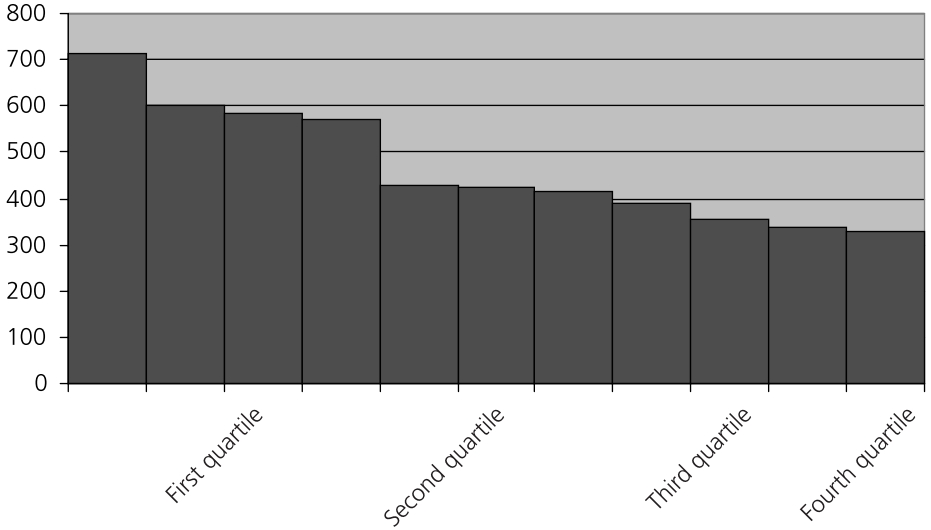

Figure N5 Distribution of the expenditure on domiciliary care for older people per head of population over 65, by Health and Social Services Trust, Northern Ireland – 2004–05 (£)

Table N5 Distribution of the expenditure on domiciliary care for older people per head of population over 65, by Health and Social Services Trust, Northern Ireland – 2004–05 (£)

First quartile		*Second quartile*		*Third quartile*		*Fourth quartile*	
Newry & Mourne	715.2	Sperrin Lakeland	568.7	Ulster Community & Hosp	413.4	Homefirst	338.5
North & West Belfast	600.9	South & East Belfast	428.1	Craigavon & Banbridge	391.1	Causeway	328.9
Armagh & Dungannon	583.4	Down Lisburn	424.0	Foyle	355.8		

Source: DHSSPS Northern Ireland (personal communication)

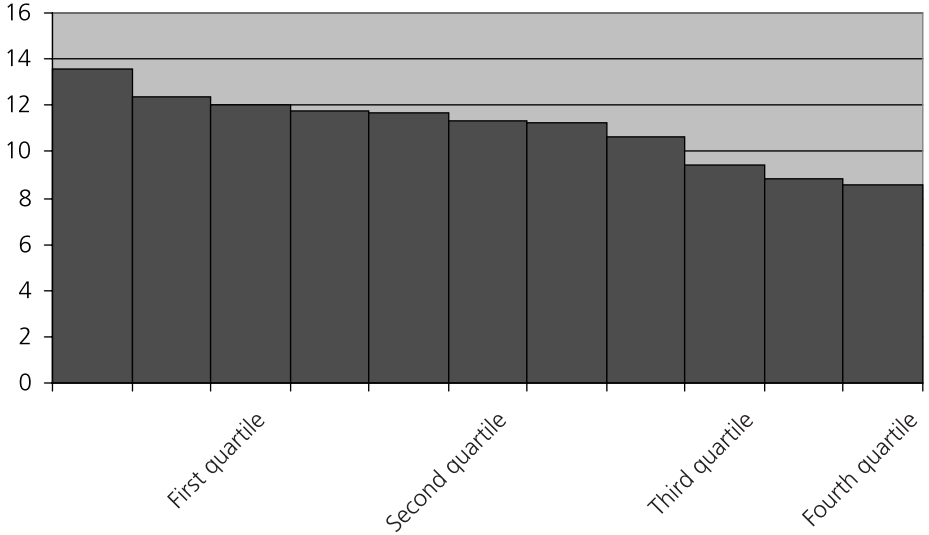

Figure N6 Distribution of the unit cost of domiciliary care for all recipients, by Health and Social Services Trust, Northern Ireland – 2004–05 (£ per hour)

Table N6 Distribution of the unit cost of domiciliary care for all recipients, by Health and Social Services Trust, Northern Ireland – 2004–05 (£ per hour)

First quartile		*Second quartile*		*Third quartile*		*Fourth quartile*	
Newry & Mourne	13.6	Craigavon & Banbridge	11.7	Causeway	11.3	Armagh & Dungannon	8.8
Homefirst	12.4	Ulster Community & Hosp	11.7	Down Lisburn	10.7	Sperrin Lakeland	8.6
South & East Belfast	12.0	North & West Belfast	11.3	Foyle	9.4		

Source: DHSSPS Northern Ireland (personal communication)

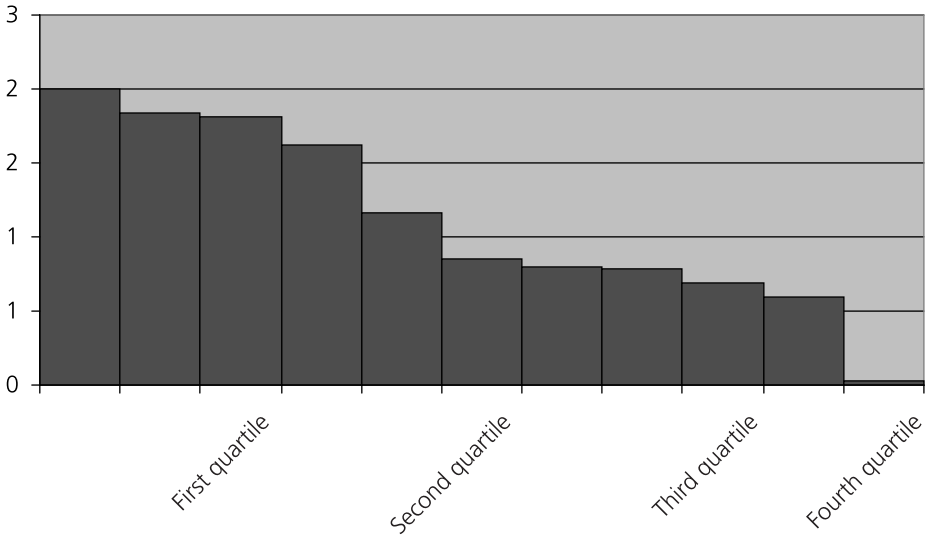

Figure N7 Distribution of the proportion of older people receiving day care, by Health and Social Services Trust, Northern Ireland – 2005 (%)

Table N7 Distribution of the proportion of older people receiving day care, by Health and Social Services Trust, Northern Ireland – 2005 (%)

First quartile		*Second quartile*		*Third quartile*		*Fourth quartile*	
North & West Belfast	2.0	Sperrin Lakeland	1.6	Newry & Mourne	0.8	Causeway	0.6
Armagh & Dungannon	1.8	Foyle	1.2	Homefirst	0.8	Down Lisburn	0.0
South & East Belfast	1.8	Ulster Community & Hosp	0.8	Craigavon & Banbridge	0.7		

Activity source: DHSSPS Northern Ireland *Community Care Statistics 2004–05*
http://www.dhsspsni.gov.uk/master_community_statistics_(2004–05).pdf
Population source: DHSSPS Northern Ireland (personal communication)

APPENDIX 3

Scotland

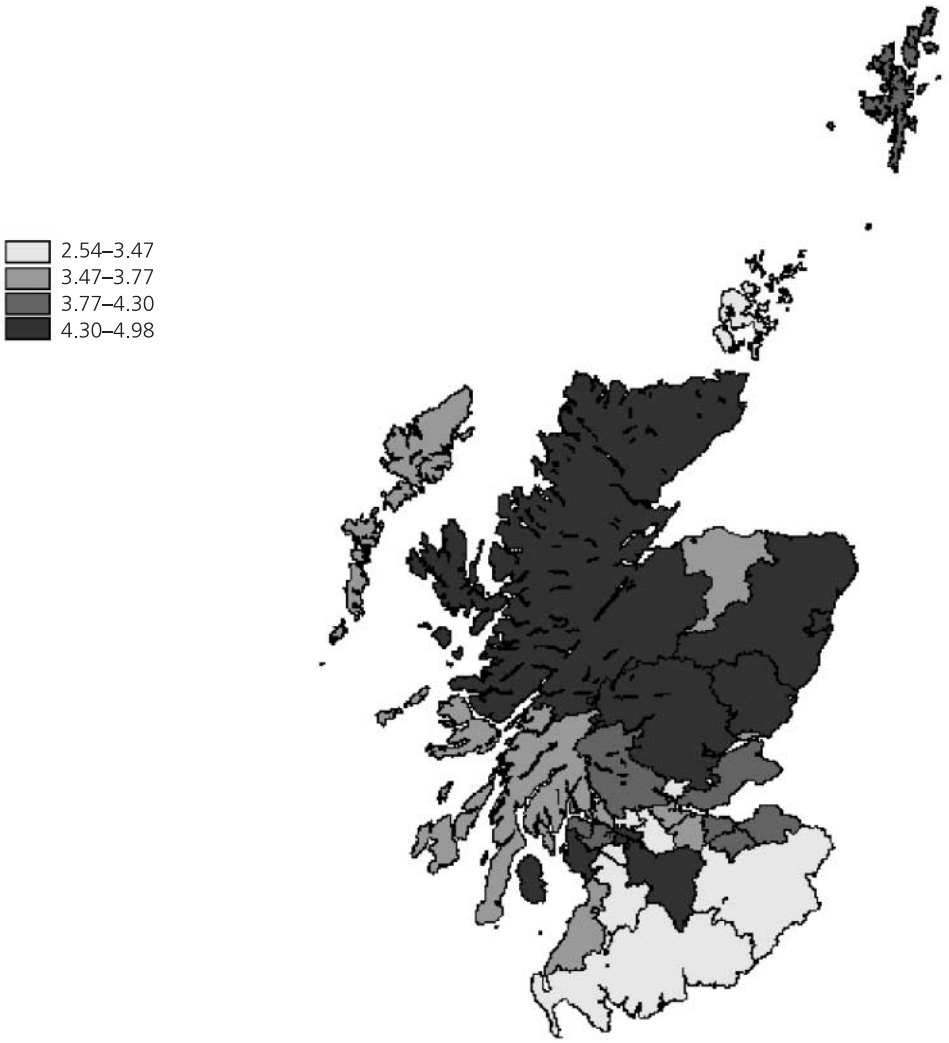

Figure S1 Spatial distribution (quartiles) of the proportion of population over 65 living in care homes, Scotland – 2005 (%)

Activity source: SEHD Community Care Statistics *Care Homes for Older People; Beds, Homes and Residents; by sector and Local Authority, March 2005*
http://www.scottishexecutive.gov.uk/Topics/Statistics/Browse/Health/Data
Population source: National Statistics Nomis website
http://www.nomisweb.co.uk

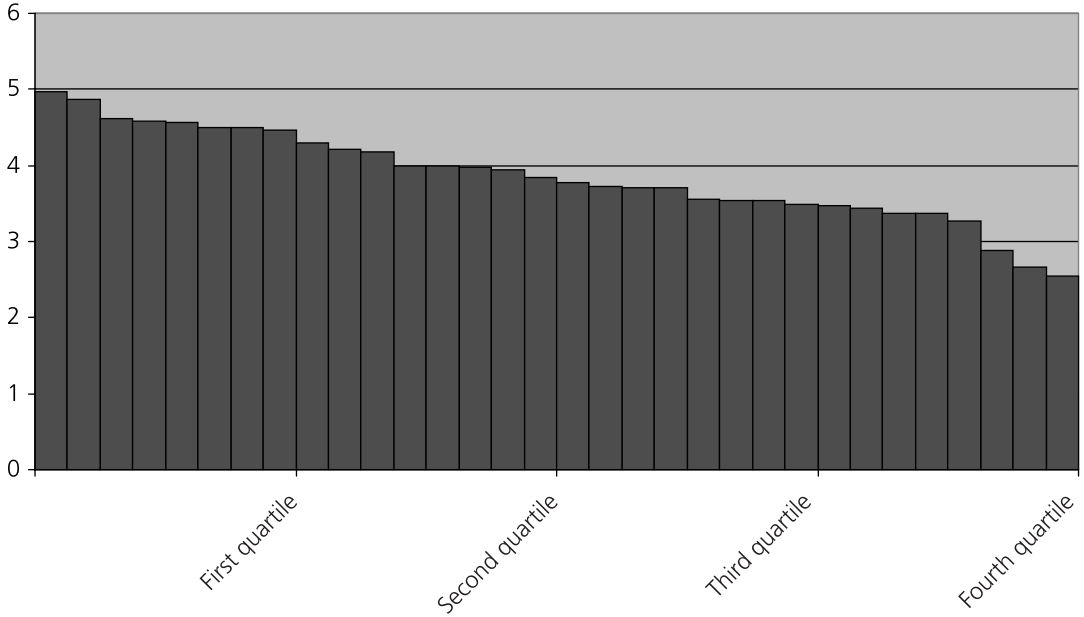

Figure S2 Distribution of the proportion of population over 65 living in care homes by local authority, Scotland – 2005 (%)

Table S1 Distribution of the proportion of population over 65 living in care homes by local authority, Scotland – 2005 (%)

First quartile		*Second quartile*		*Third quartile*		*Fourth quartile*	
South Lanarkshire	5.0	Renfrewshire	4.3	Eilean Siar	3.8	East Ayrshire	3.5
Aberdeenshire	4.9	Midlothian	4.2	South Ayrshire	3.7	North Lanarkshire	3.4
Highland	4.6	Stirling	4.2	West Lothian	3.7	Dumfries & Galloway	3.4
Aberdeen City	4.6	East Lothian	4.0	West Dunbartonshire	3.7	Scottish Borders	3.4
Perth & Kinross	4.6	Shetland Islands	4.0	Dundee City	3.6	East Renfrewshire	3.3
Glasgow City	4.5	Inverclyde	4.0	Argyll & Bute	3.5	Clackmannanshire	2.9
Angus	4.5	Edinburgh, City of	3.9	Falkirk	3.5	East Dunbartonshire	2.7
North Ayrshire	4.5	Fife	3.8	Moray	3.5	Orkney Islands	2.5

Activity source: SEHD Community Care Statistics *Care Homes for Older People; Beds, Homes and Residents; by sector and Local Authority, March 2005*
http://www.scottishexecutive.gov.uk/Topics/Statistics/Browse/Health/Data
Population source: National Statistics Nomis website (http://www.nomisweb.co.uk)

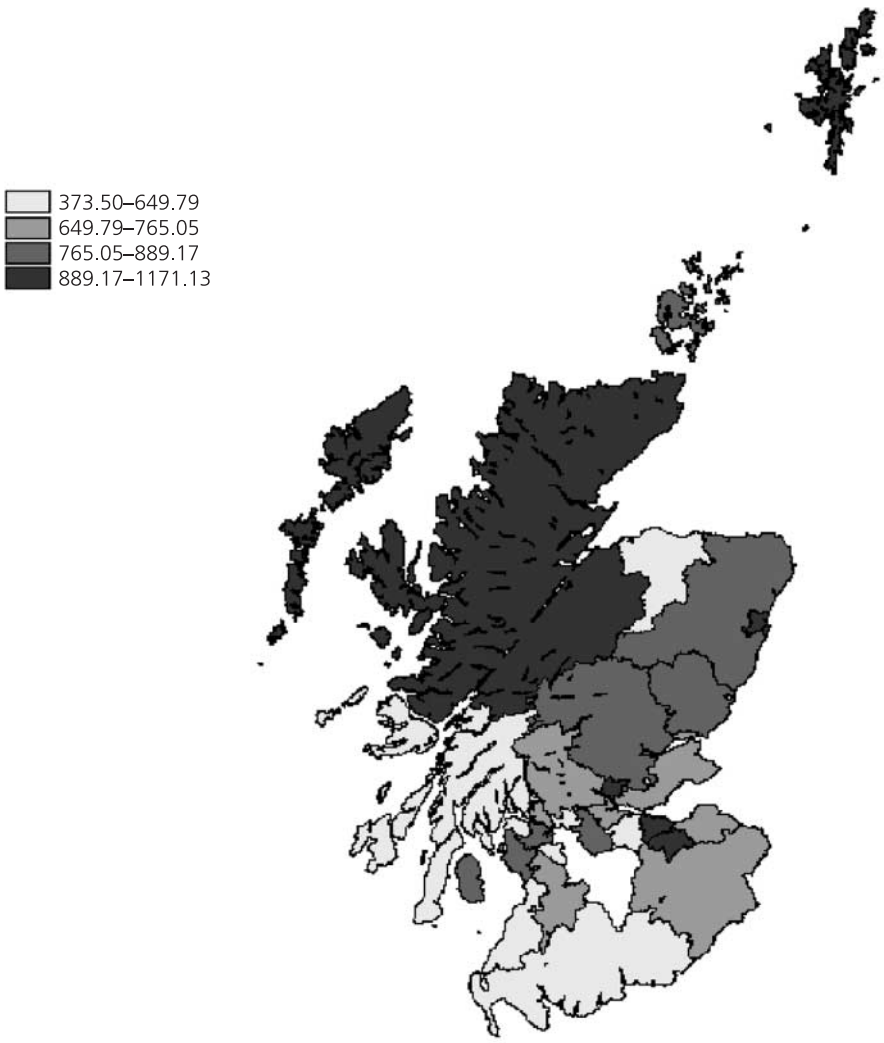

Figure S3 Spatial distribution (quartiles) of the expenditure on residential and nursing care for older people per head of population over 65, Scotland – 2004–05 (£)

Expenditure source: Scottish Executive, Health Department (personal communication)
Population source: National Statistics Nomis website
http://www.nomisweb.co.uk
Excludes data for Glasgow City and South Lanarkshire

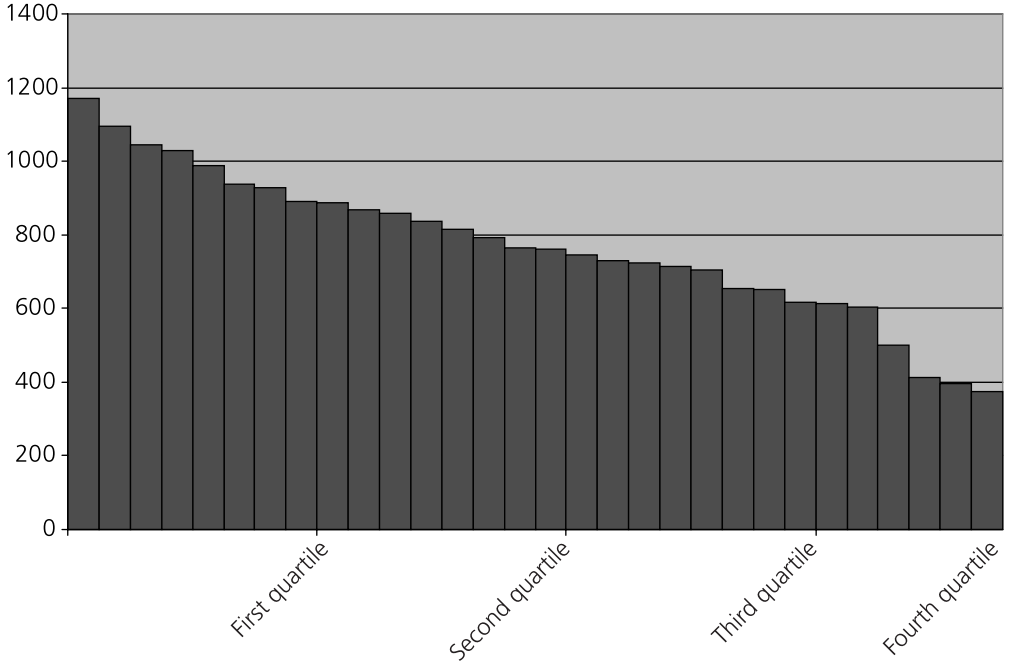

Figure S4 Distribution of the expenditure on residential and nursing care for older people per head of population over 65 by local authority, Scotland – 2004–05 (£)

Table S2 Distribution of the expenditure on residential and nursing care for older people per head of population over 65 by local authority, Scotland – 2004–05 (£)

First quartile		*Second quartile*		*Third quartile*		*Fourth quartile*	
Eilean Siar	1,171.1	Renfrewshire	887.8	Dundee City	762.4	West Lothian	615.7
Clackmannanshire	1,094.7	Orkney Islands	869.4	Fife	744.4	Argyll & Bute	612.8
Aberdeen City	1,044.1	Aberdeenshire	859.6	West Dunbartonshire	731.2	Dumfries & Galloway	604.2
Shetland Islands	1,028.8	Angus	835.7	Scottish Borders	723.0	Moray	500.5
Highland	988.7	North Ayrshire	816.0	Stirling	715.3	East Renfrewshire	412.6
Midlothian	936.7	Perth & Kinross	792.6	Falkirk	703.9	East Dunbartonshire	396.8
Edinburgh, City of	928.5	East Ayrshire	765.1	East Lothian	654.9	South Ayrshire	373.5
North Lanarkshire	889.2			Inverclyde	649.8		

Expenditure source: Scottish Executive, Health Department (personal communication)
Population source: National Statistics Nomis website
http://www.nomisweb.co.uk
Excludes data for Glasgow City and South Lanarkshire

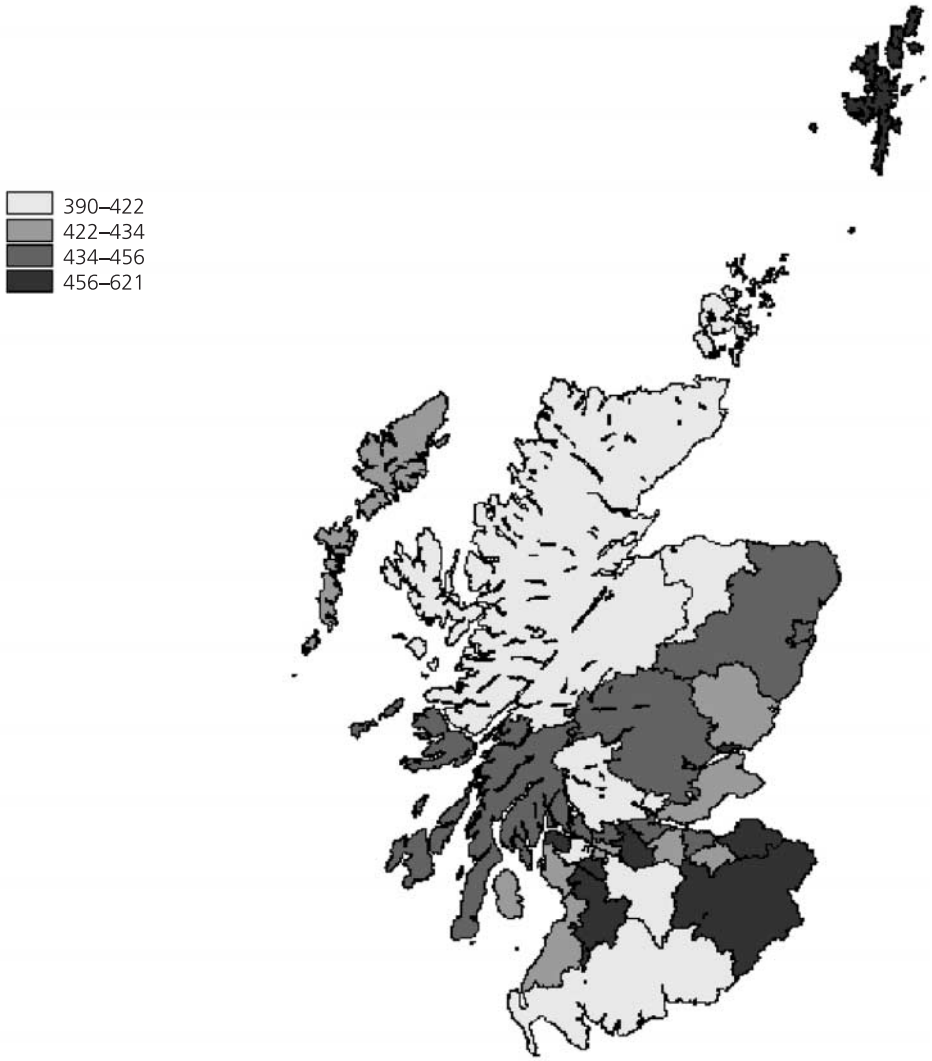

Figure S5 Spatial distribution (quartiles) of average weekly charge in care homes for older people, Scotland – 2004–05 (£)

Source: SEHD Community Care Statistics *Average gross weekly charge in Care Homes for Older People, by local authority, 2003 – latest*
http://www.scotland.gov.uk/Topics/Statistics/Browse/Health/Data/DataCHCharge

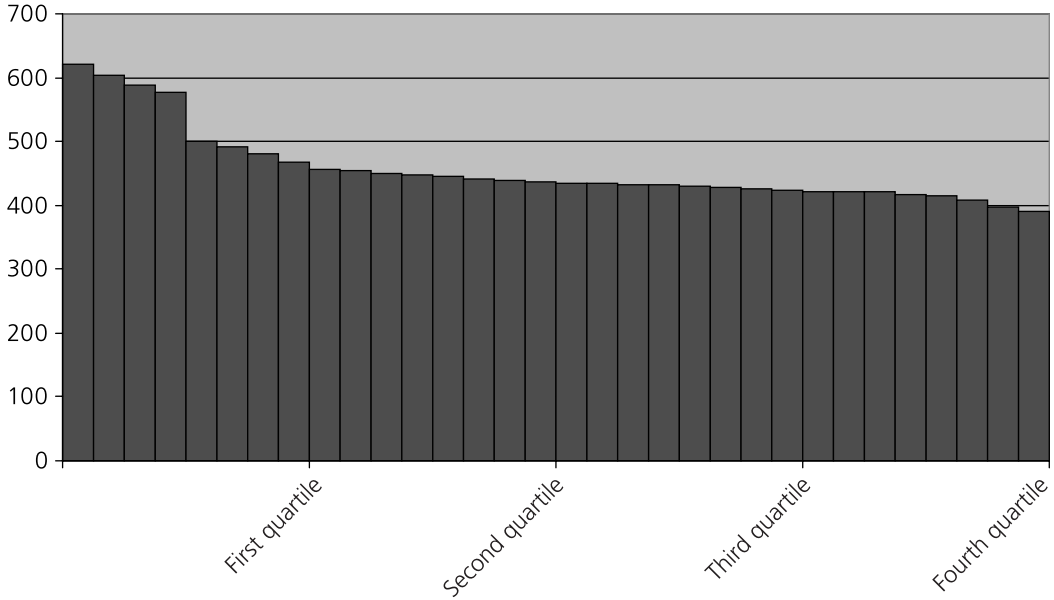

Figure S6 Distribution of the average weekly charge in care homes for older people by local authority, per person per week, Scotland – 2004–05(£)

Table S3 Distribution of the average weekly charge in care homes for older people by local authority, per person per week, Scotland – 2004–05(£)

First quartile		*Second quartile*		*Third quartile*		*Fourth quartile*	
Orkney Islands	621.0	Fife	456.0	Highland	434.0	Perth & Kinross	422.0
Shetland Islands	604.0	Aberdeen City	455.0	West Dunbartonshire	434.0	Inverclyde	421.0
Eilean Siar	588.0	East Renfrewshire	450.0	South Ayrshire	432.0	Stirling	421.0
Edinburgh, City of	578.0	Dundee City	447.0	West Lothian	432.0	North Ayrshire	417.0
East Lothian	500.0	Falkirk	446.0	North Lanarkshire	430.0	Scottish Borders	415.0
Clackmannanshire	492.0	Renfrewshire	441.0	Angus	428.0	South Lanarkshire	409.0
East Dunbartonshire	481.0	Aberdeenshire	439.0	Glasgow City	426.0	East Ayrshire	397.0
Midlothian	467.0	Argyll & Bute	437.0	Moray	423.0	Dumfries & Galloway	390.0

Source: SEHD Community Care Statistics *Average gross weekly charge in Care Homes for Older People, by local authority, 2003 – latest*
http://www.scotland.gov.uk/Topics/Statistics/Browse/Health/Data/DataCHCharge

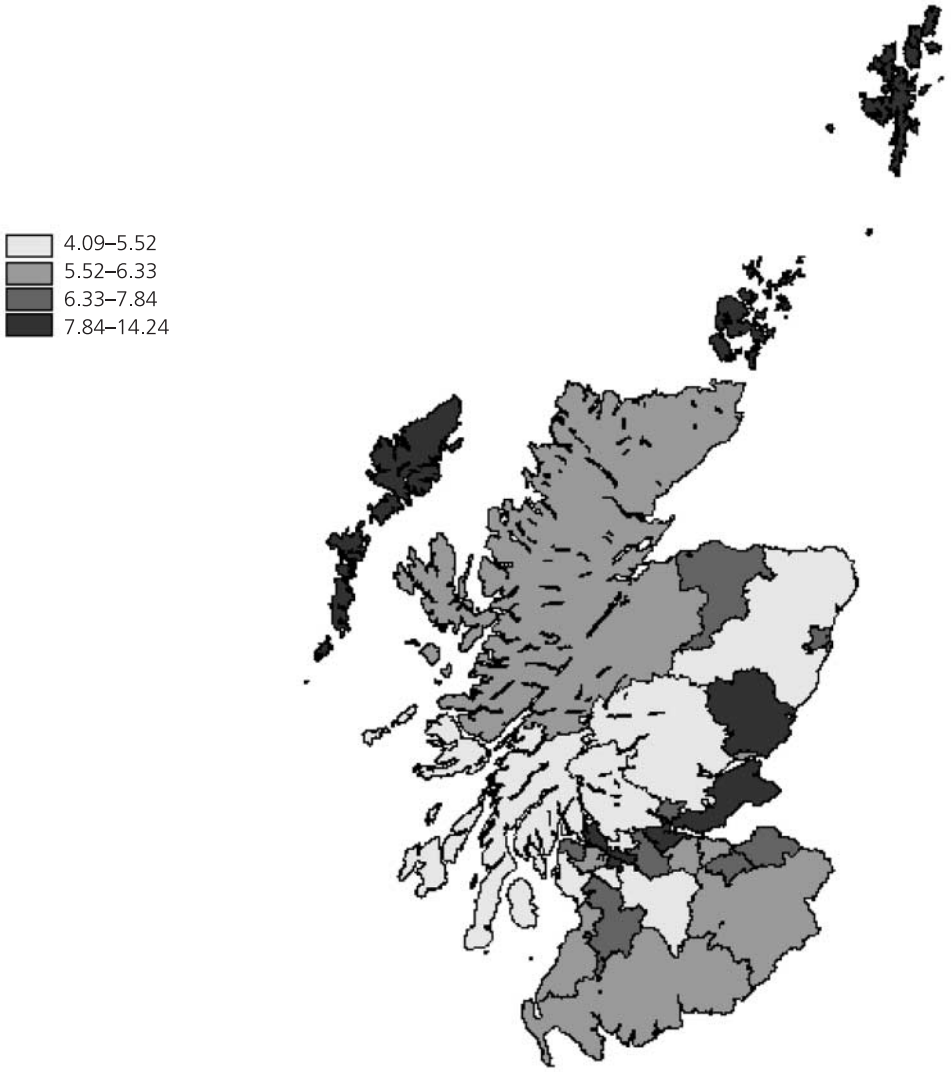

Figure S7 Spatial distribution (quartiles) of the proportion of older people receiving home care, Scotland – 2006 (%)

Activity source: SEHD Community Care Statistics *Number of People aged 65+ Receiving Home Care, by Local Authority, 1999–Latest* [2006 data]
http://www.scottishexecutive.gov.uk/Topics/Statistics/Browse/Health/Data
Population source: National Statistics Nomis website
http://www.nomisweb.co.uk

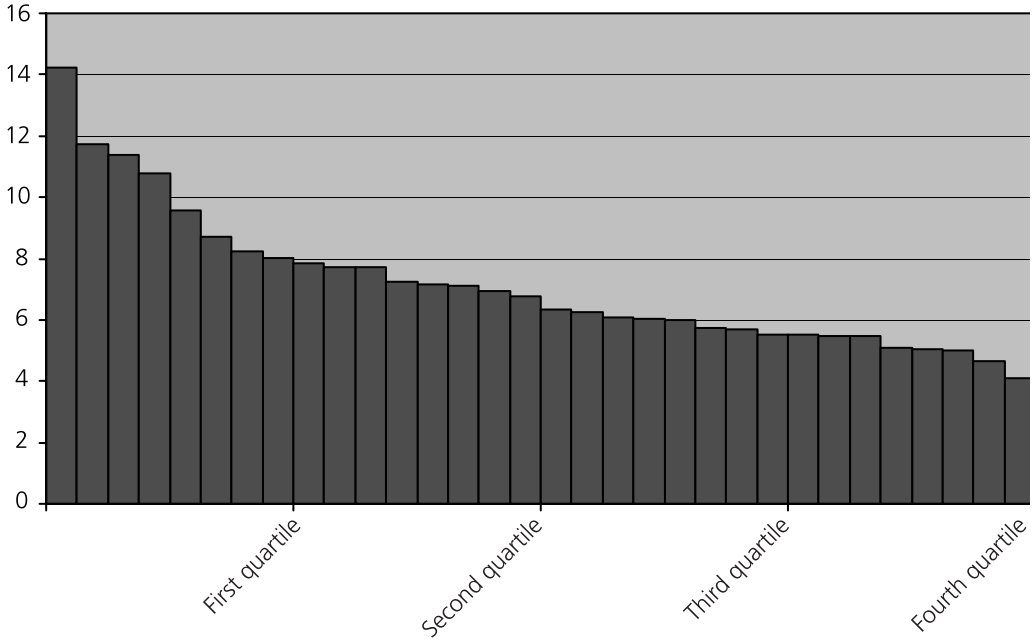

Figure S8 Distribution of the proportion of older people receiving home care by local authority, Scotland – 2006 (%)

Table S4 Distribution of the proportion of older people receiving home care by local authority, Scotland – 2006 (%)

First quartile		*Second quartile*		*Third quartile*		*Fourth quartile*	
Shetland Islands	14.2	Clackmannanshire	7.8	Edinburgh, City of	6.3	East Renfrewshire	5.5
Orkney Islands	11.7	Aberdeen City	7.7	Dundee City	6.3	East Dunbartonshire	5.5
West Dunbartonshire	11.4	Midlothian	7.7	South Ayrshire	6.1	South Lanarkshire	5.5
Eilean Siar	10.8	North Lanarkshire	7.2	Scottish Borders	6.0	Aberdeenshire	5.1
Fife	9.6	Moray	7.1	Highland	6.0	Stirling	5.0
Glasgow City	8.7	East Ayrshire	7.1	Dumfries & Galloway	5.7	North Ayrshire	5.0
Angus	8.3	Inverclyde	7.0	West Lothian	5.7	Argyll & Bute	4.6
Falkirk	8.0	East Lothian	6.8	Renfrewshire	5.5	Perth & Kinross	4.1

Activity source: SEHD Community Care Statistics *Number of People aged 65+ Receiving Home Care, by Local Authority, 1999–Latest* [2006 data]
http://www.scottishexecutive.gov.uk/Topics/Statistics/Browse/Health/Data
Population source: National Statistics Nomis website
http://www.nomisweb.co.uk

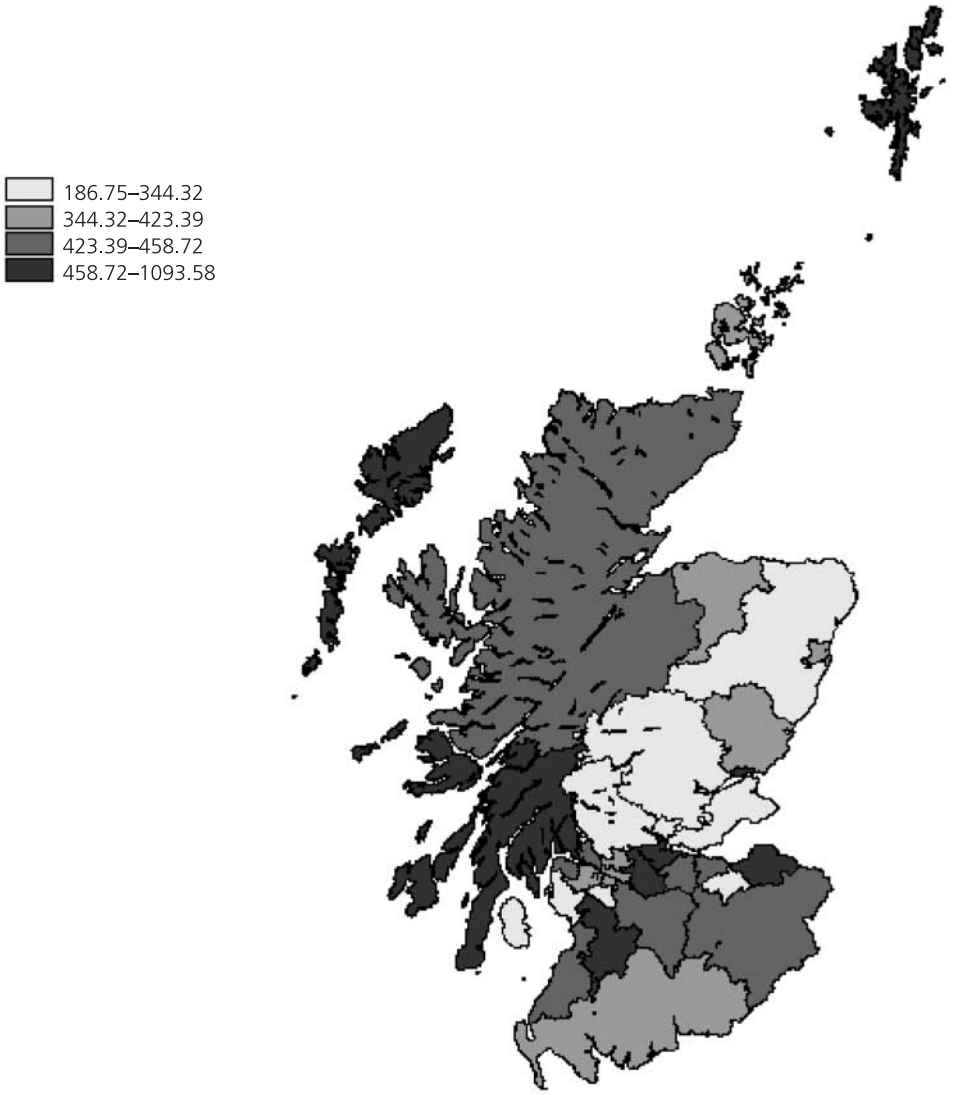

Figure S9 Spatial distribution (quartiles) of the expenditure on home care for older people per head of population over 65, Scotland – 2005–06 (£)
Expenditure source: Scottish Executive, Health Department (personal communication)
Population source: National Statistics Nomis website
http://www.nomisweb.co.uk

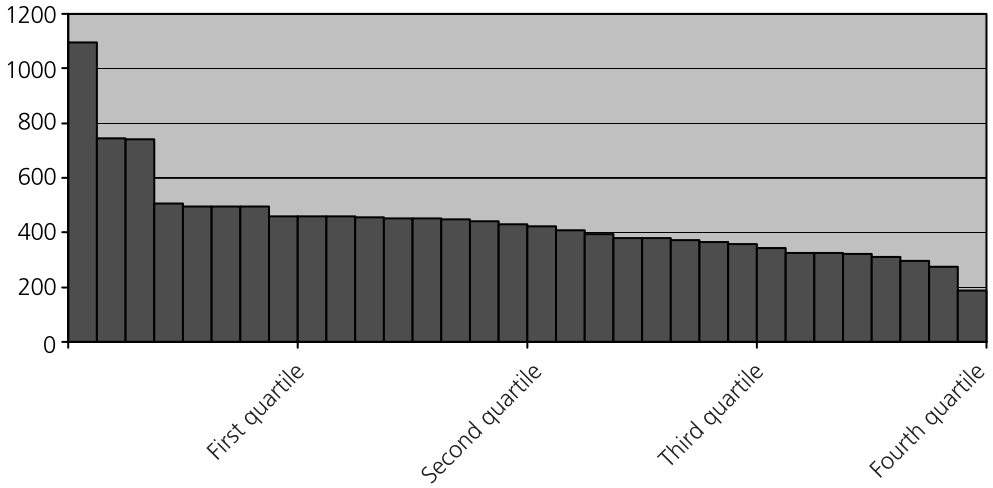

Figure S10 Distribution of the expenditure on home care for older people per head of population over 65 by local authority, Scotland – 2005–06 (£)

Table S5 Distribution of the expenditure on home care for older people per head of population over 65 by local authority, Scotland – 2005–06 (£)

First quartile		*Second quartile*		*Third quartile*		*Fourth quartile*	
Eilean Siar	1093.6	Inverclyde	458.7	Aberdeen City	423.4	North Ayrshire	344.3
North Lanarkshire	746.3	South Lanarkshire	458.0	East Dunbartonshire	410.0	Aberdeenshire	325.5
Shetland Islands	742.1	Highland	457.1	Orkney Islands	394.6	Perth & Kinross	325.5
Argyll & Bute	504.5	West Dunbartonshire	451.6	Moray	380.8	Fife	322.7
Falkirk	494.3	Edinburgh, City of	451.5	Dumfries & Galloway	378.3	Midlothian	310.2
East Lothian	494.0	South Ayrshire	448.6	Angus	373.1	Clackmannanshire	297.8
Dundee City	493.8	Scottish Borders	440.1	Glasgow City	366.1	Stirling	273.0
East Ayrshire	459.6	West Lothian	429.0	Renfrewshire	357.5	East Renfrewshire	186.8

Expenditure source: Scottish Executive, Health Department (personal communication)
Population source: National Statistics Nomis website
http://www.nomisweb.co.uk

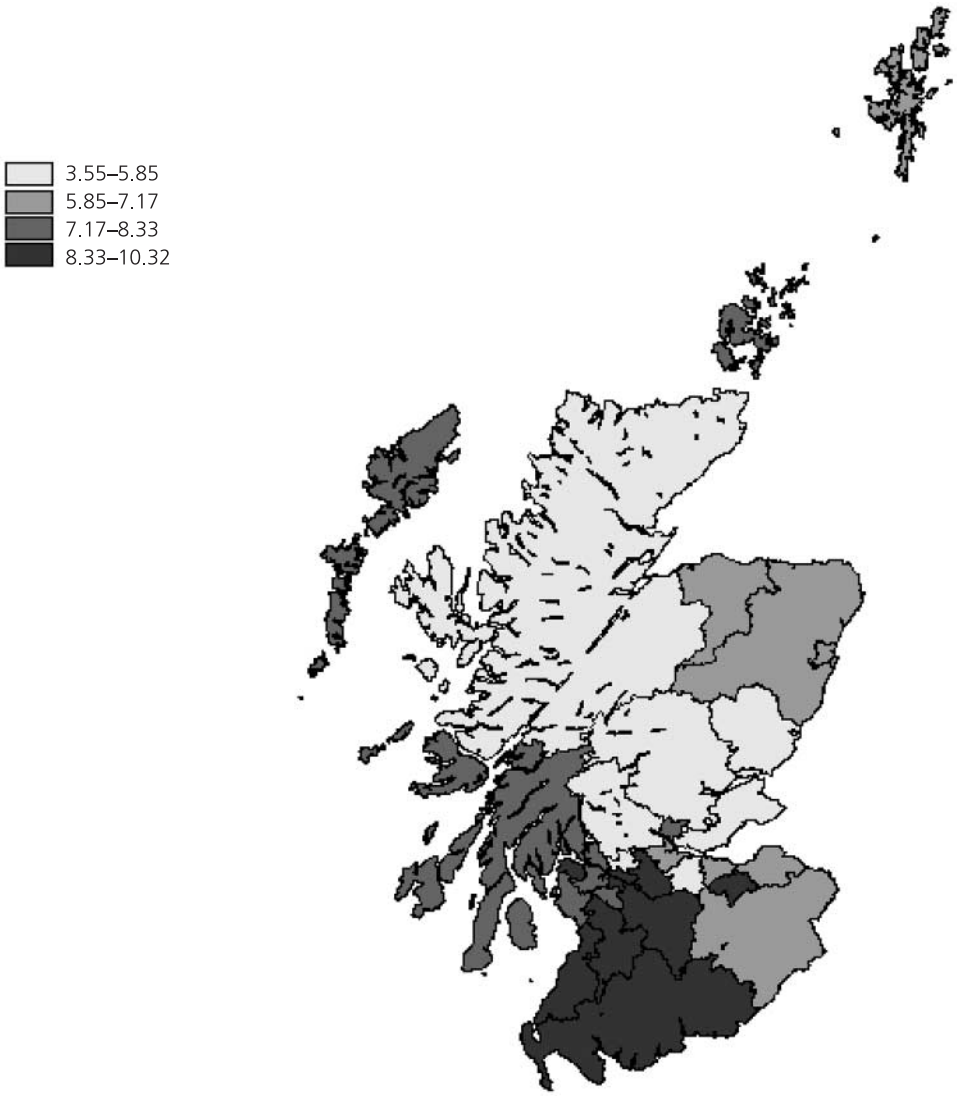

Figure S11 Spatial distribution (quartiles) of the average weekly home care package for older people, Scotland – 2005 (hours)

Sources: Activity: SEHD Community Care Statistics *Number of People aged 65+ Receiving Home Care, by Local Authority, 1999–Latest* [2005 data]
http://www.scottishexecutive.gov.uk/Topics/Statistics/Browse/Health/Data
Hours: Scottish Executive, Health Department (personal communication)

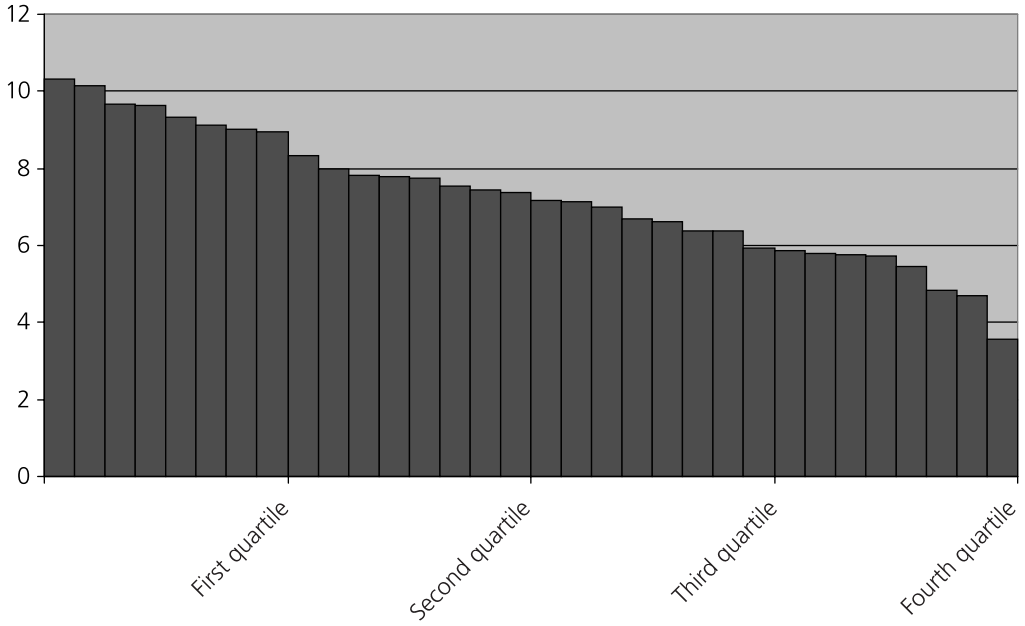

Figure S12 Distribution of the average weekly home care package for older people by local authority, Scotland – 2005 (hours)

Table S6 Distribution of the average weekly home care package for older people by local authority, Scotland – 2005 (hours)

First quartile		*Second quartile*		*Third quartile*		*Fourth quartile*	
Midlothian	10.3	Eilean Siar	8.3	East Lothian	7.2	Perth & Kinross	5.9
South Ayrshire	10.1	Renfrewshire	8.0	Falkirk	7.1	Stirling	5.8
South Lanarkshire	9.7	Argyll & Bute	7.8	Scottish Borders	7.0	Highland	5.8
Glasgow City	9.6	North Ayrshire	7.8	Moray	6.7	West Lothian	5.7
Dumfries & Galloway	9.3	Clackmannanshire	7.8	Aberdeen City	6.6	East Dunbartonshire	5.5
North Lanarkshire	9.1	West Dunbartonshire	7.5	Edinburgh, City of	6.4	Fife	4.8
Inverclyde	9.0	East Renfrewshire	7.4	Aberdeenshire	6.4	Dundee City	4.7
East Ayrshire	9.0	Orkney Islands	7.4	Shetland Islands	5.9	Angus	3.6

Sources: Activity: SEHD Community Care Statistics *Number of People aged 65+ Receiving Home Care, by Local Authority, 1999–Latest* [2005 data]
http://www.scottishexecutive.gov.uk/Topics/Statistics/Browse/Health/Data
Hours: Scottish Executive, Health Department (personal communication)

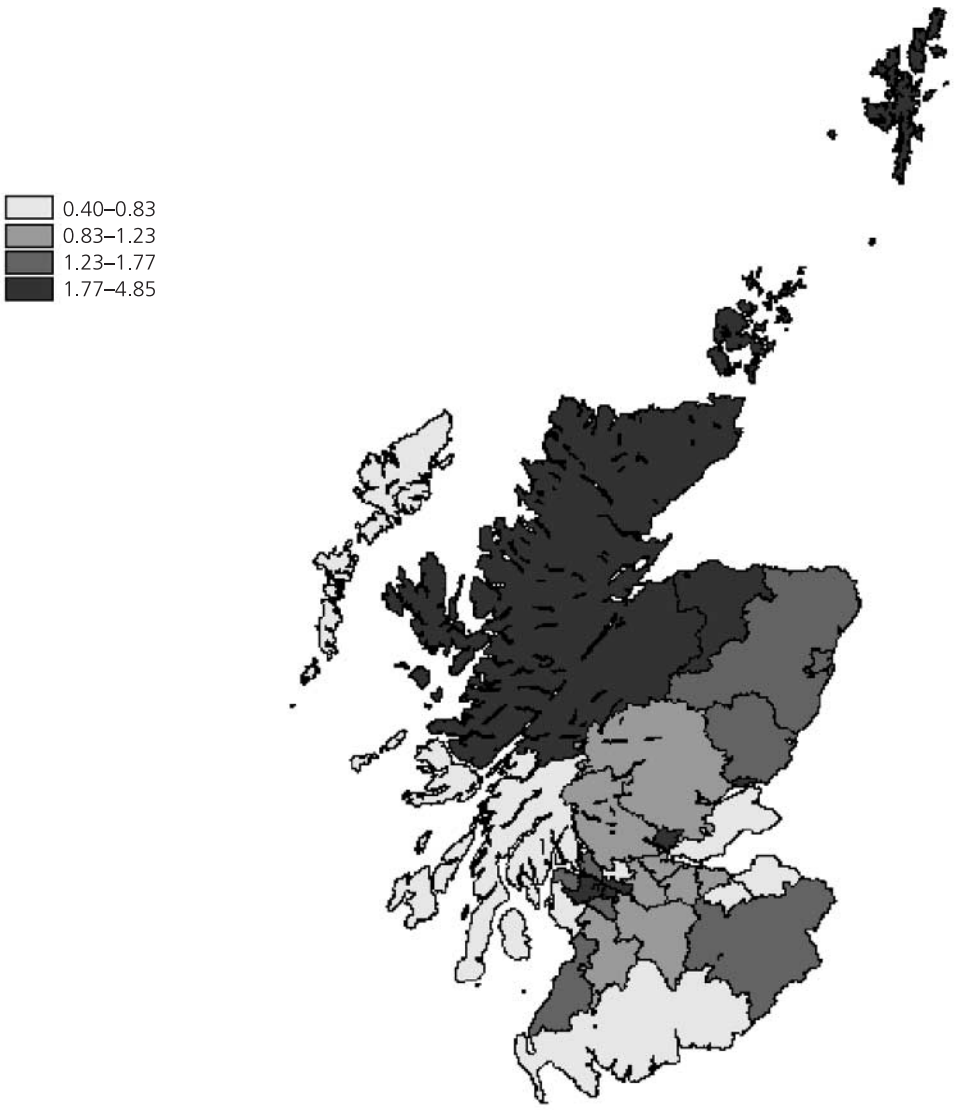

Figure S13 Spatial distribution (quartiles) of the proportion of older people receiving day care, Scotland – 2005 (%)

Activity source: SEHD Community Care Statistics *Number of Day Centres for Older People, Places and People Attending, by Local Authority and sector, 2005*
http://www.scottishexecutive.gov.uk/Topics/Statistics/Browse/Health/Data
Population source: National Statistics Nomis website
http://www.nomisweb.co.uk

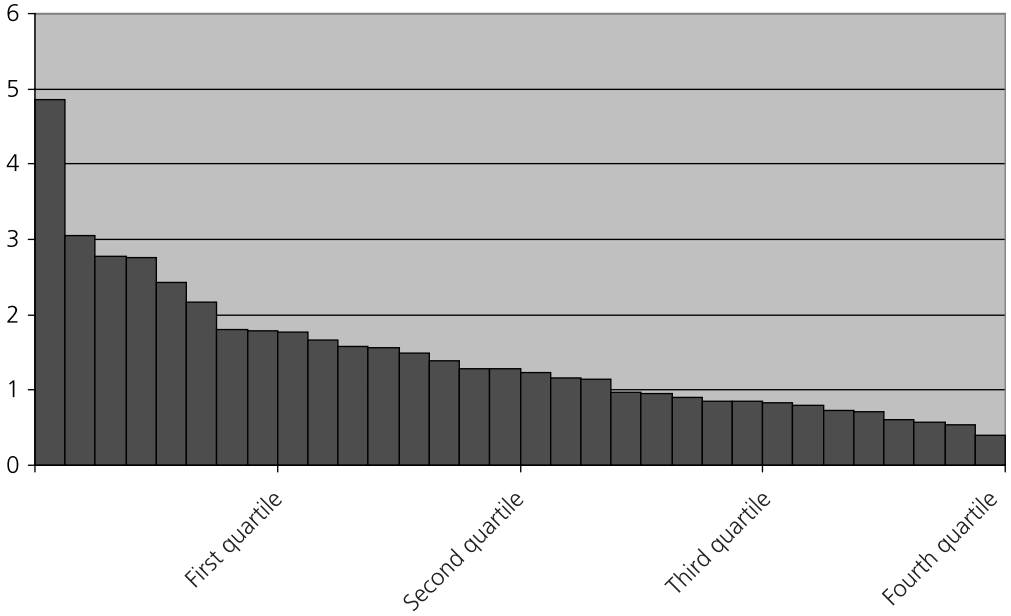

Figure S14 Distribution of the proportion of older people receiving day care by local authority, Scotland – 2005 (%)

Table S7 Distribution of the proportion of older people receiving day care by local authority, Scotland – 2005 (%)

First quartile		*Second quartile*		*Third quartile*		*Fourth quartile*	
Shetland Islands	4.8	West Dunbartonshire	1.8	South Lanarkshire	1.2	Fife	0.8
Orkney Islands	3.1	South Ayrshire	1.7	Perth & Kinross	1.2	North Ayrshire	0.8
Renfrewshire	2.8	East Renfrewshire	1.6	North Lanarkshire	1.1	East Dunbartonshire	0.7
Highland	2.8	Scottish Borders	1.6	West Lothian	1.0	Dumfries & Galloway	0.7
Clackmannanshire	2.4	Angus	1.5	East Ayrshire	1.0	Eilean Siar	0.6
Dundee City	2.2	Inverclyde	1.4	Stirling	0.9	Argyll & Bute	0.6
Glasgow City	1.8	Aberdeenshire	1.3	Edinburgh, City of	0.9	East Lothian	0.5
Moray	1.8	Aberdeen City	1.3	Falkirk	0.9	Midlothian	0.4

Activity source: SEHD Community Care Statistics *Number of Day Centres for Older People, Places and People Attending, by Local Authority and sector, 2005*
http://www.scottishexecutive.gov.uk/Topics/Statistics/Browse/Health/Data
Population source: National Statistics Nomis website
http://www.nomisweb.co.uk

APPENDIX 4

Wales

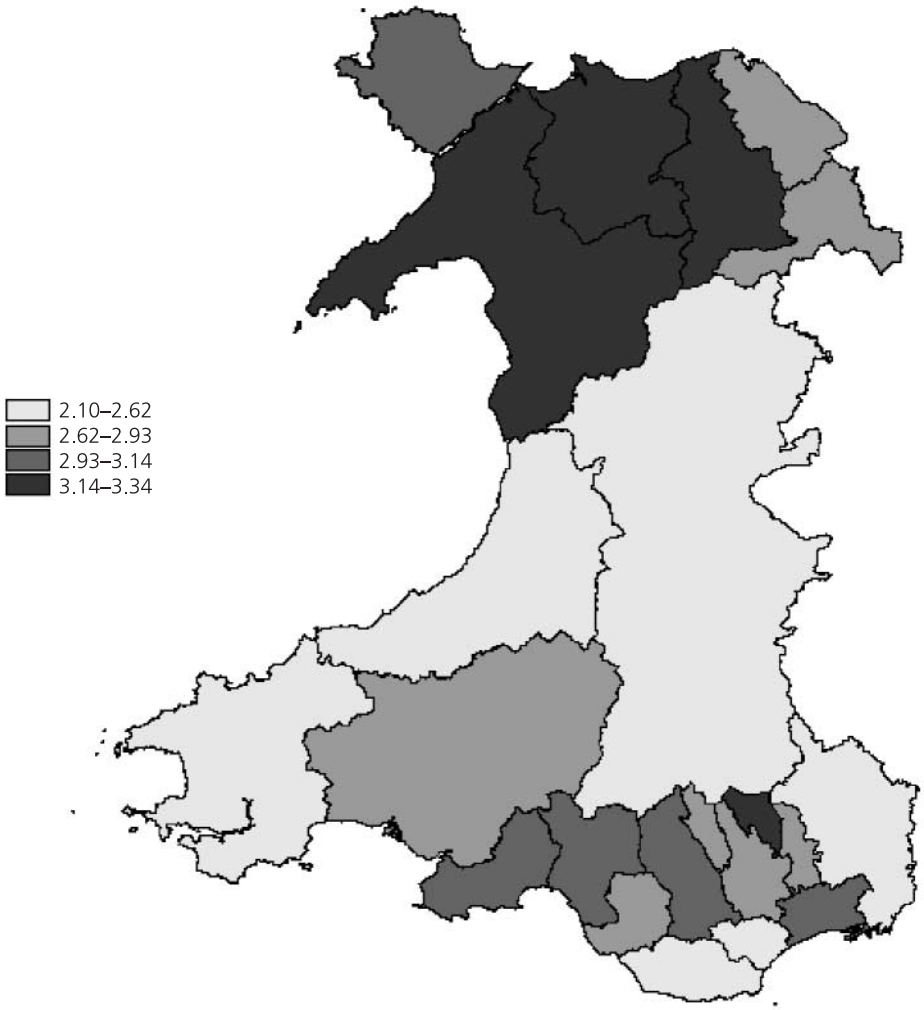

Figure W1 Spatial distribution (quartiles) of the proportion of population over 65 supported in residential care homes or nursing homes, Wales – 2004–05 (%)

Source: Local Government Data Unit – Wales *PM 2.15: Adult Personal Social Services Indicators 2004–05* http://www.lgdu-wales.gov.uk/Documents/Data_Set/PSS/2004_2005/lgd01115_pm2_2004_05_table_2_15_adult_pis_v2_bi.xls

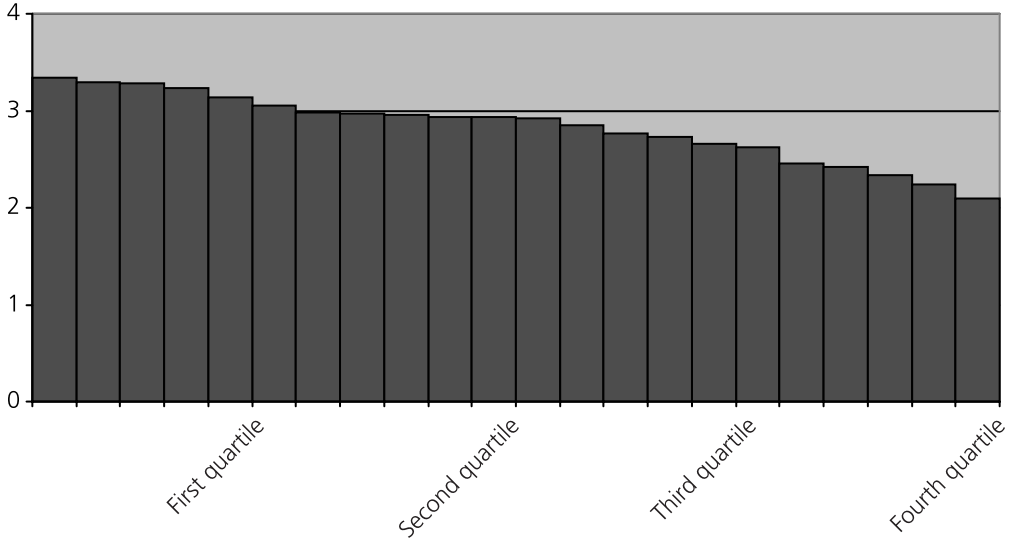

Figure W2 Distribution of the proportion of population over 65 supported in residential care homes or nursing homes by local authority, Wales – 2004–05 (%)

Table W1 Distribution of the proportion of population over 65 supported in residential care homes or nursing homes by local authority, Wales – 2004–05 (%)

First quartile		*Second quartile*		*Third quartile*		*Fourth quartile*	
Gwynedd	3.3	Newport	3.1	Wrexham	2.9	Cardiff	2.6
Blaenau Gwent	3.3	Neath Port Talbot	3.0	Carmarthenshire	2.9	The Vale of Glamorgan	2.5
Denbighshire	3.3	Swansea	3.0	Flintshire	2.8	Pembrokeshire	2.4
Conwy	3.2	Isle of Anglesey	3.0	Torfaen	2.7	Ceredigion	2.3
Rhondda Cynon Taf	3.1	Merthyr Tydfil	2.9	Caerphilly	2.7	Powys	2.2
		Bridgend	2.9			Monmouthshire	2.1

Source: Local Government Data Unit – Wales *PM 2.15: Adult Personal Social Services Indicators 2004–05*
http://www.lgdu-wales.gov.uk/Documents/Data_Set/PSS/2004_2005/lgd01115_pm2_2004_05_table_2_15_adult_pis_v2_bi.xls

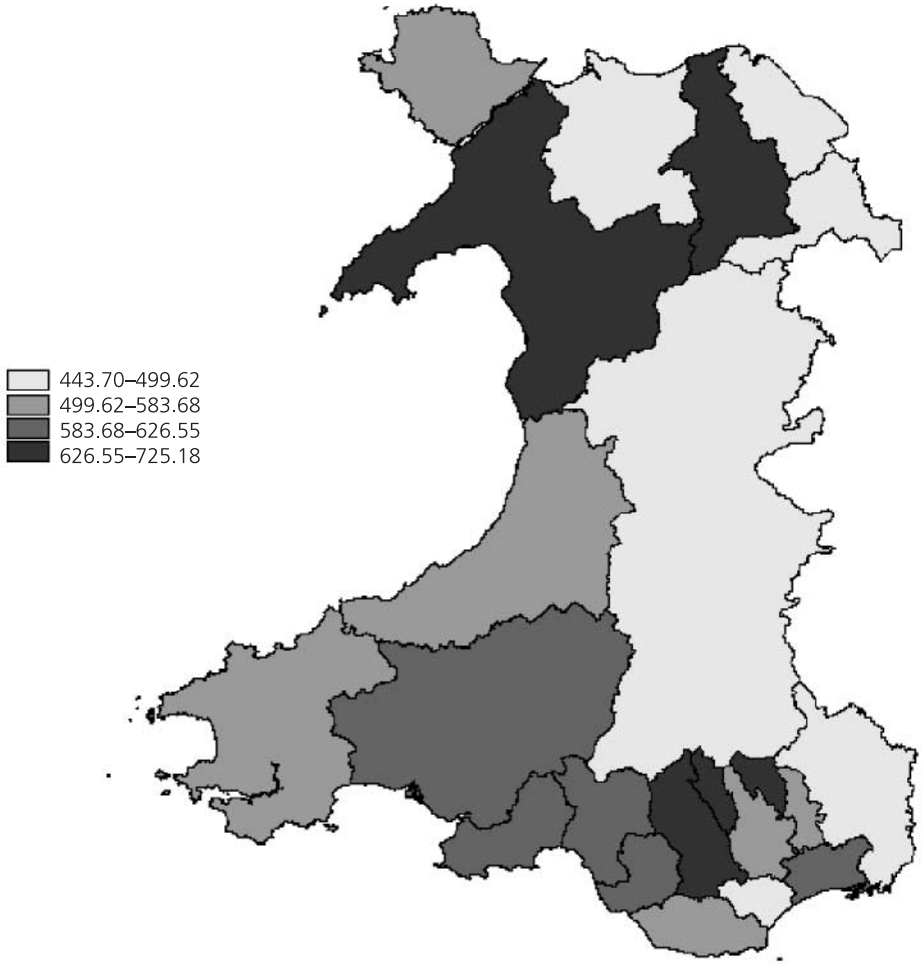

Figure W3 Spatial distribution (quartiles) of the expenditure on residential and nursing care for older people per head of population over 65, Wales – 2004–05 (£)

Expenditure source: Local Government Data Unit – Wales *PM 2.2: Table B Gross service costs in £1,000s for adult personal social services 2004–05*
http://www.lgdu-wales.gov.uk/Documents/Data_Set/PSS/2004_2005/lgd01115_pm2_2004_05_table_2_2_b_v-2_bi.xls
Population source: National Statistics Nomis website
http://www.nomisweb.co.uk

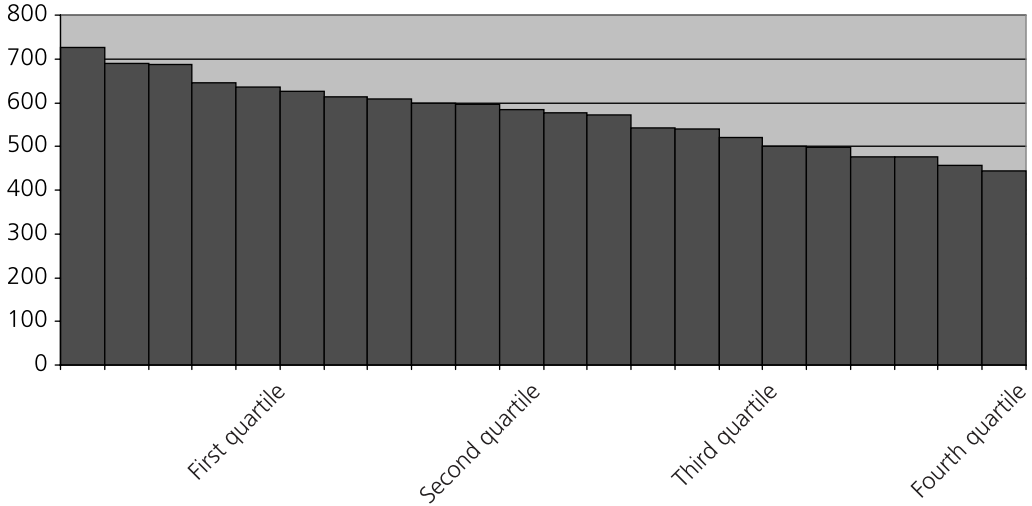

Figure W4 Distribution of the expenditure on residential and nursing care for older people per head of population over 65 by local authority, Wales – 2004–05 (£)

Table W2 Distribution of the expenditure on residential and nursing care for older people per head of population over 65 by local authority, Wales – 2004–05 (£)

First quartile		*Second quartile*		*Third quartile*		*Fourth quartile*	
Rhondda Cynon Taf	725.2	Neath Port Talbot	626.5	Caerphilly	576.6	Flintshire	499.6
Gwynedd	690.6	Newport	613.9	Pembrokeshire	570.8	Conwy	499.0
Blaenau Gwent	688.2	Carmarthenshire	607.9	Torfaen	541.5	Powys	476.8
Merthyr Tydfil	645.1	Bridgend	598.7	Ceredigion	540.1	Wrexham	476.5
Denbighshire	634.4	Swansea	596.5	The Vale of Glamorgan	520.5	Cardiff	456.2
		Isle of Anglesey	583.7			Monmouthshire	443.7

Expenditure source: Local Government Data Unit – Wales *PM 2.2: Table B Gross service costs in £1,000s for adult personal social services 2004–05*
http://www.lgdu-wales.gov.uk/Documents/Data_Set/PSS/2004_2005/lgd01115_pm2_2004_05_table_2_2_b_v2_bi.xls
Population source: National Statistics Nomis website
http://www.nomisweb.co.uk

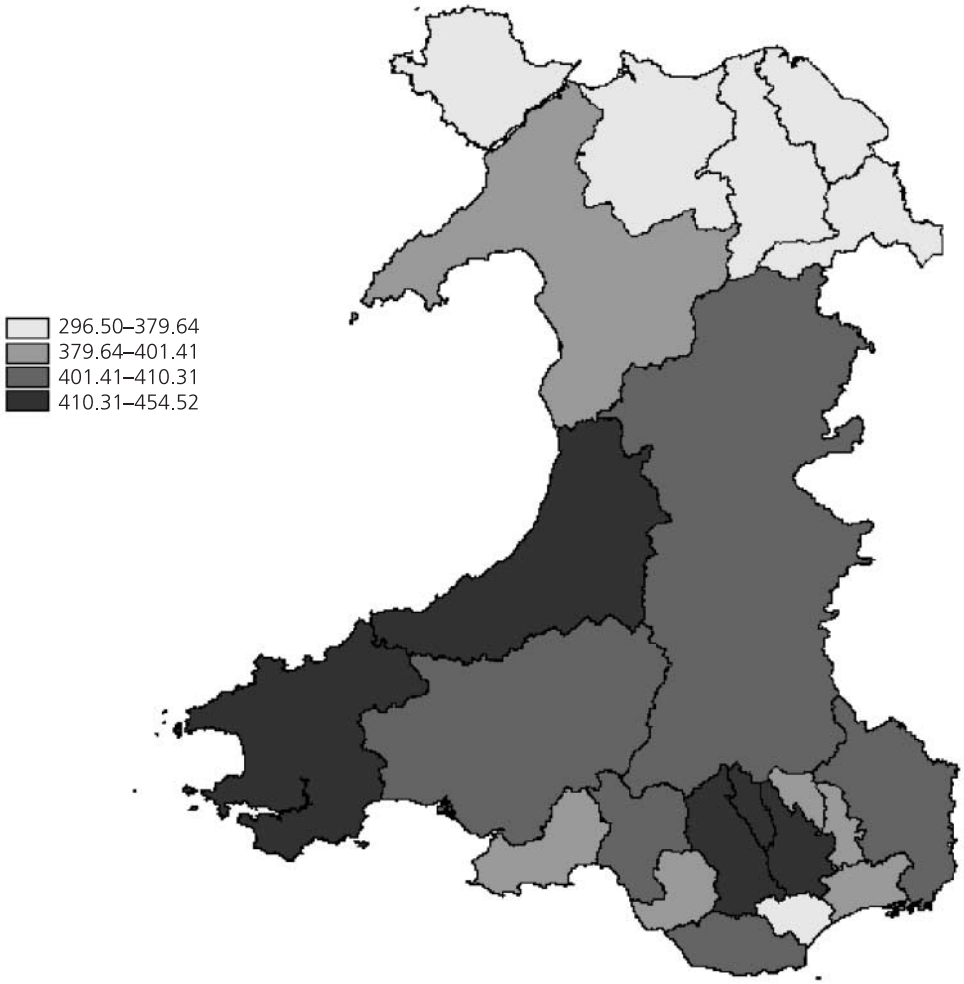

Figure W5 Spatial distribution (quartiles) of the unit cost of residential and nursing care for older people, per person per week, Wales – 2004–05 (£)

Expenditure source: Local Government Data Unit – *Wales PM 2.15: Adult Personal Social Services Indicators 2004–05*
http://www.lgdu-wales.gov.uk/Documents/Data_Set/PSS/2004_2005/
lgd01115_pm2_2004_05_table_2_15_adult_pis_v2_bi.xls
Population source: National Statistics Nomis website
http://www.nomisweb.co.uk

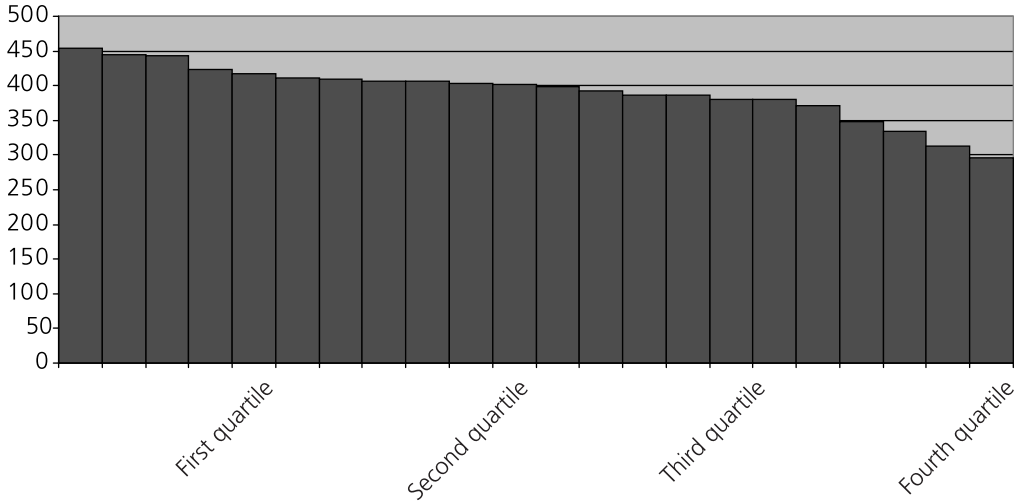

Figure W6 Distribution of the unit cost of residential and nursing care for older people by local authority, Wales – 2004–05 (£ per person per week)

Table W3 Distribution of the unit cost of residential and nursing care for older people by local authority, Wales – 2004–05 (£ per person per week)

First quartile		*Second quartile*		*Third quartile*		*Fourth quartile*	
Pembrokeshire	454.5	Powys	410.3	Gwynedd	398.1	Isle of Anglesey	379.6
Rhondda Cynon Taf	444.0	Carmarthenshire	409.4	Bridgend	393.0	Denbighshire	371.7
Ceredigion	443.7	The Vale of Glamorgan	406.9	Newport	386.8	Flintshire	347.8
Merthyr Tydfil	422.9	Monmouthshire	406.0	Swansea	385.7	Cardiff	334.8
Caerphilly	417.3	Neath Port Talbot	404.1	Torfaen	380.8	Wrexham	313.0
		Blaenau Gwent	401.4			Conwy	296.5

Expenditure source: Local Government Data Unit – *Wales PM 2.15: Adult Personal Social Services Indicators 2004–05*
http://www.lgdu-wales.gov.uk/Documents/Data_Set/PSS/2004_2005/lgd01115_pm2_2004_05_table_2_15_adult_pis_v2_bi.xls
Population source: National Statistics Nomis website
http://www.nomisweb.co.uk

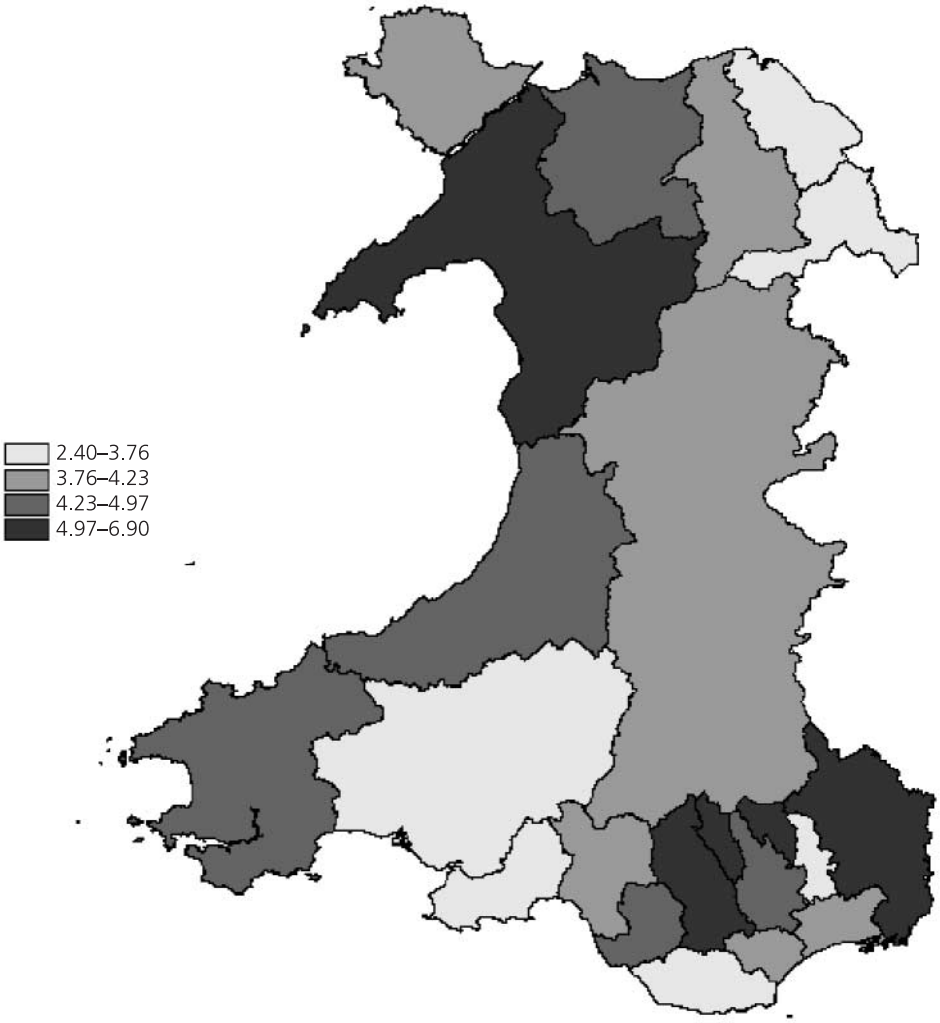

Figure W7 Spatial distribution (quartiles) of the proportion of older people receiving home care, Wales – 2004–05 (%)

Source: Local Government Data Unit – Wales *PM2.16: The rate of older people (aged 65 or over) helped to live at home by service, per 1,000 population aged 65 or over, 2005–05*
http://www.lgdu-wales.gov.uk/Documents/Data_Set/PSS/2004_2005/lgd01115_pm2_2004_05_table_2_16_pa_10a_supplement_v1_bi.xls

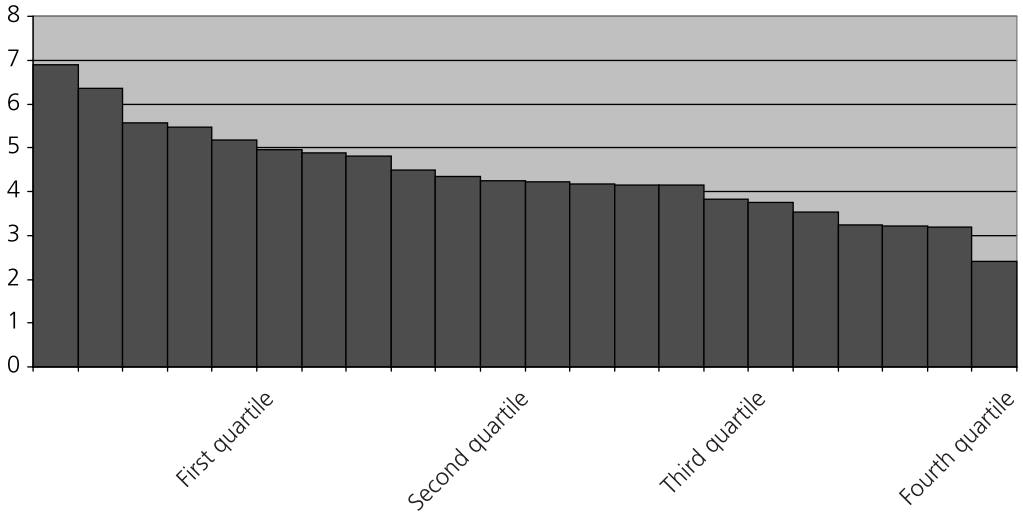

Figure W8 Distribution of the proportion of older people receiving home care by local authority, Wales – 2004–05 (%)

Table W4 Distribution of the proportion of older people receiving home care by local authority, Wales – 2004–05 (%)

First quartile		*Second quartile*		*Third quartile*		*Fourth quartile*	
Monmouthshire	6.9	Caerphilly	5.0	Powys	4.2	Flintshire	3.8
Gwynedd	6.3	Conwy	4.9	Denbighshire	4.1	The Vale of Glamorgan	3.5
Rhondda Cynon Taf	5.6	Pembrokeshire	4.8	Neath Port Talbot	4.1	Swansea	3.2
Merthyr Tydfil	5.5	Bridgend	4.5	Cardiff	3.8	Wrexham	3.2
Blaenau Gwent	5.2	Ceredigion	4.4	Newport		Carmarthenshire	3.2
		Isle of Anglesey	4.2			Torfaen	2.4

Source: Local Government Data Unit – Wales *PM2.16: The rate of older people (aged 65 or over) helped to live at home by service, per 1,000 population aged 65 or over, 2005–05*
http://www.lgdu-wales.gov.uk/Documents/Data_Set/PSS/2004_2005/lgd01115_pm2_2004_05_table_2_16_pa_10a_supplement_v1_bi.xls

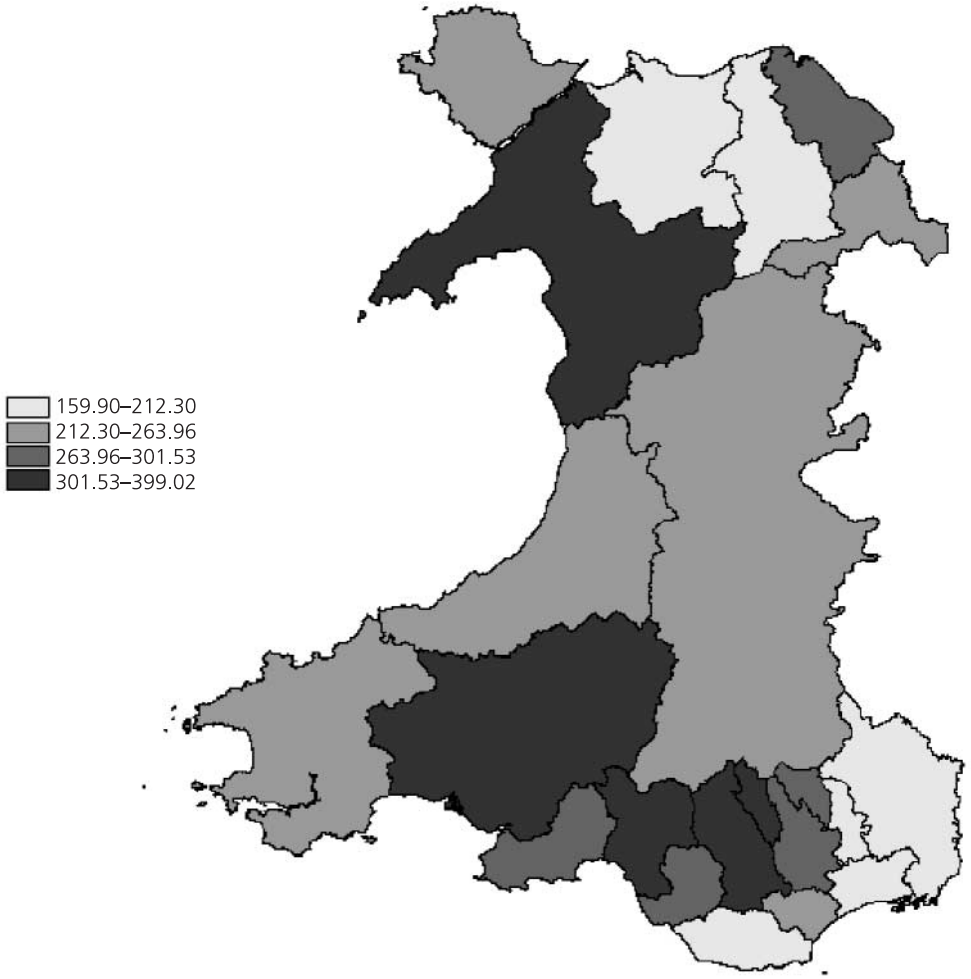

Figure W9 Spatial distribution (quartiles) of the expenditure on home care for older people per head of population over 65, Wales – 2004–05 (£)

Expenditure source: Local Government Data Unit – Wales *PM 2.2: Table B Gross service costs in £1,000s for adult personal social services 2004–05*
http://www.lgdu-wales.gov.uk/Documents/Data_Set/PSS/2004_2005/lgd01115_pm2_2004_05_table_2_2_b_v-2_bi.xls
Population source: National Statistics Nomis website
http://www.nomisweb.co.uk

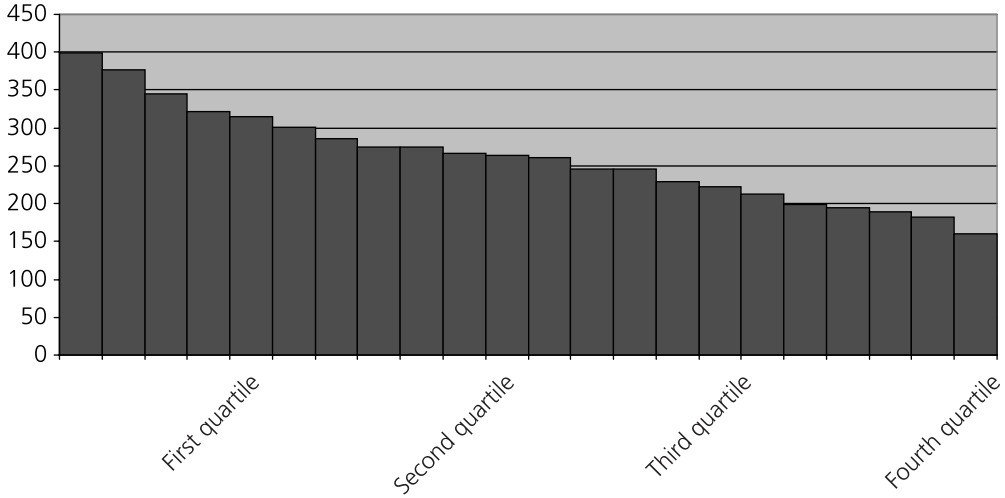

Figure W10 Distribution of the expenditure on home care for older people per head of population over 65 by local authority, Wales – 2004–05 (£)

Table W5 Distribution of the expenditure on home care for older people per head of population over 65 by local authority, Wales – 2004–05 (£)

First quartile		*Second quartile*		*Third quartile*		*Fourth quartile*	
Merthyr Tydfil	399.0	Caerphilly	301.5	Ceredigion	261.3	Monmouthshire	212.3
Neath Port Talbot	377.3	Swansea	285.5	Pembrokeshire	245.2	Torfaen	199.1
Rhondda Cynon Taf	344.7	Blaenau Gwent	274.7	Cardiff	245.1	The Vale of Glamorgan	195.0
Carmarthenshire	322.0	Bridgend	274.6	Wrexham	228.5	Newport	189.2
Gwynedd	314.8	Flintshire	266.7	Isle of Anglesey	222.6	Conwy	182.1
		Powys	264.0			Denbighshire	159.9

Expenditure source: Local Government Data Unit – Wales *PM 2.2: Table B Gross service costs in £1,000s for adult personal social services 2004–05*
http://www.lgdu-wales.gov.uk/Documents/Data_Set/PSS/2004_2005/lgd01115_pm2_2004_05_table_2_2_b_v2_bi.xls
Population source: National Statistics Nomis website
http://www.nomisweb.co.uk

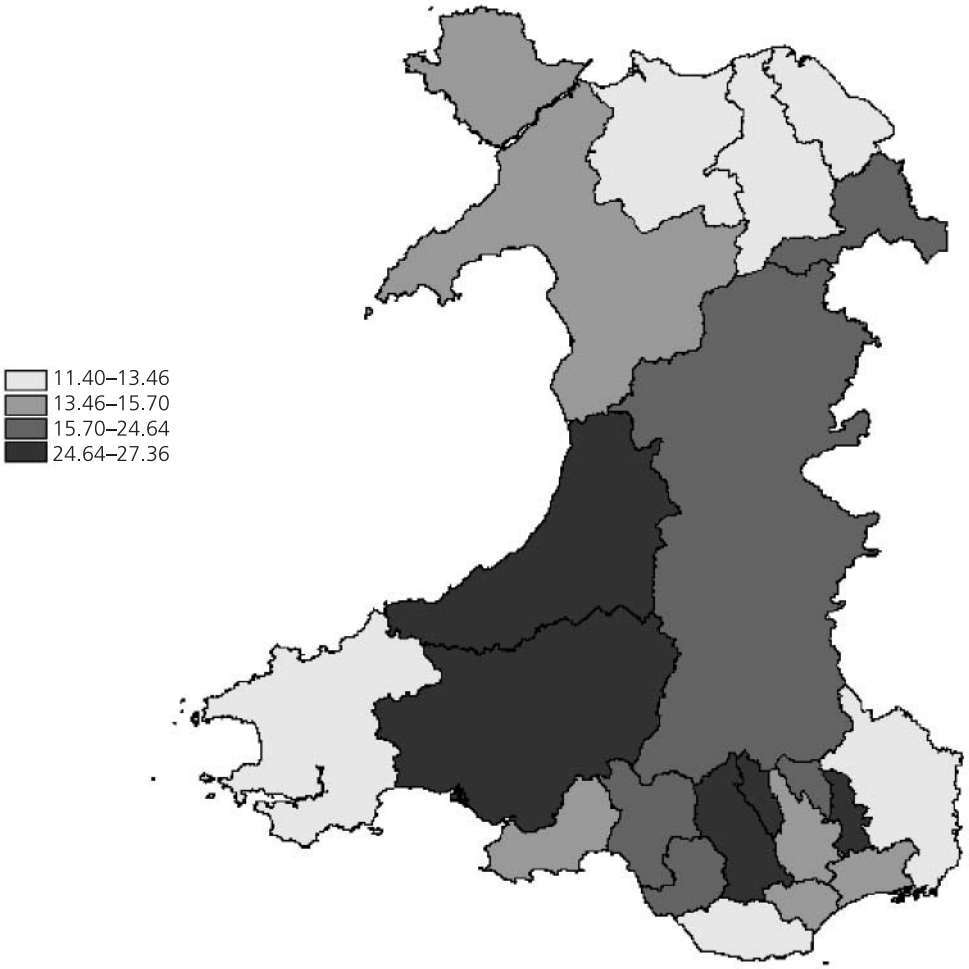

Figure W11 Spatial distribution (quartiles) of the unit cost of home care for older people,* Wales – 2004–05 (£ per hour)

* Data from survey week, conducted during last full week in September 2004

Expenditure source: Local Government Data Unit – Wales *PM 2.2: Table B Gross service costs in £1,000s for adult personal social services 2004–05*
http://www.lgdu-wales.gov.uk/Documents/Data_Set/PSS/2004_2005/lgd01115_pm2_2004_05_table_2_2_b_v2_bi.xls

Activity source: Local Government Data Unit – Wales *PM2.13: Table M Adult homecare service intensity analysis in sample week 2004–05*
http://www.lgdu-wales.gov.uk/Documents/Data_Set/PSS/2004_2005/lgd01115_pm2_2004_05_table_2_13_m_v2_bi.xls

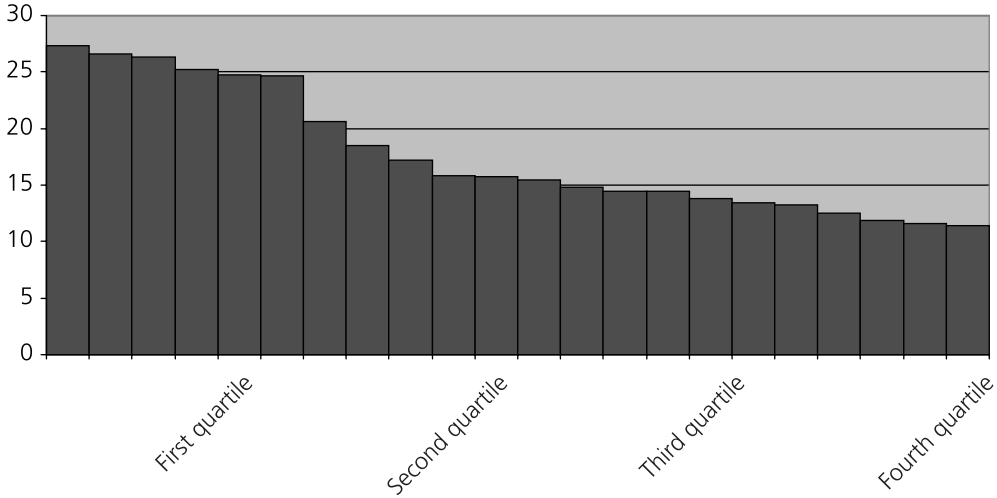

Figure W12 Distribution of the unit cost of home care for older people by local authority,* Wales – 2004–05 (£ per hour)

Table W6 Distribution of the unit cost of home care for older people by local authority,* Wales – 2004–05 (£ per hour)

First quartile		*Second quartile*		*Third quartile*		*Fourth quartile*	
Carmarthenshire	27.4	Wrexham	24.6	Newport	15.4	Conwy	13.5
Torfaen	26.6	Neath Port Talbot	20.7	Caerphilly	14.8	Monmouthshire	13.3
Ceredigion	26.3	Bridgend	18.5	Cardiff	14.5	The Vale of Glamorgan	12.5
Merthyr Tydfil	25.2	Blaenau Gwent	17.2	Swansea	14.4	Pembrokeshire	11.8
Rhondda Cynon Taf	24.8	Powys	15.8	Isle of Anglesey	13.8	Denbighshire	11.6
		Gwynedd	15.7			Flintshire	11.4

* Data from survey week, conducted during last full week in September 2004
Expenditure source: Local Government Data Unit – Wales *PM 2.2: Table B Gross service costs in £1,000s for adult personal social services 2004–05*
http://www.lgdu-wales.gov.uk/Documents/Data_Set/PSS/2004_2005/lgd01115_pm2_2004_05_table_2_2_b_v2_bi.xls
Activity source: Local Government Data Unit – Wales *PM2.13: Table M Adult homecare service intensity analysis in sample week 2004–05*
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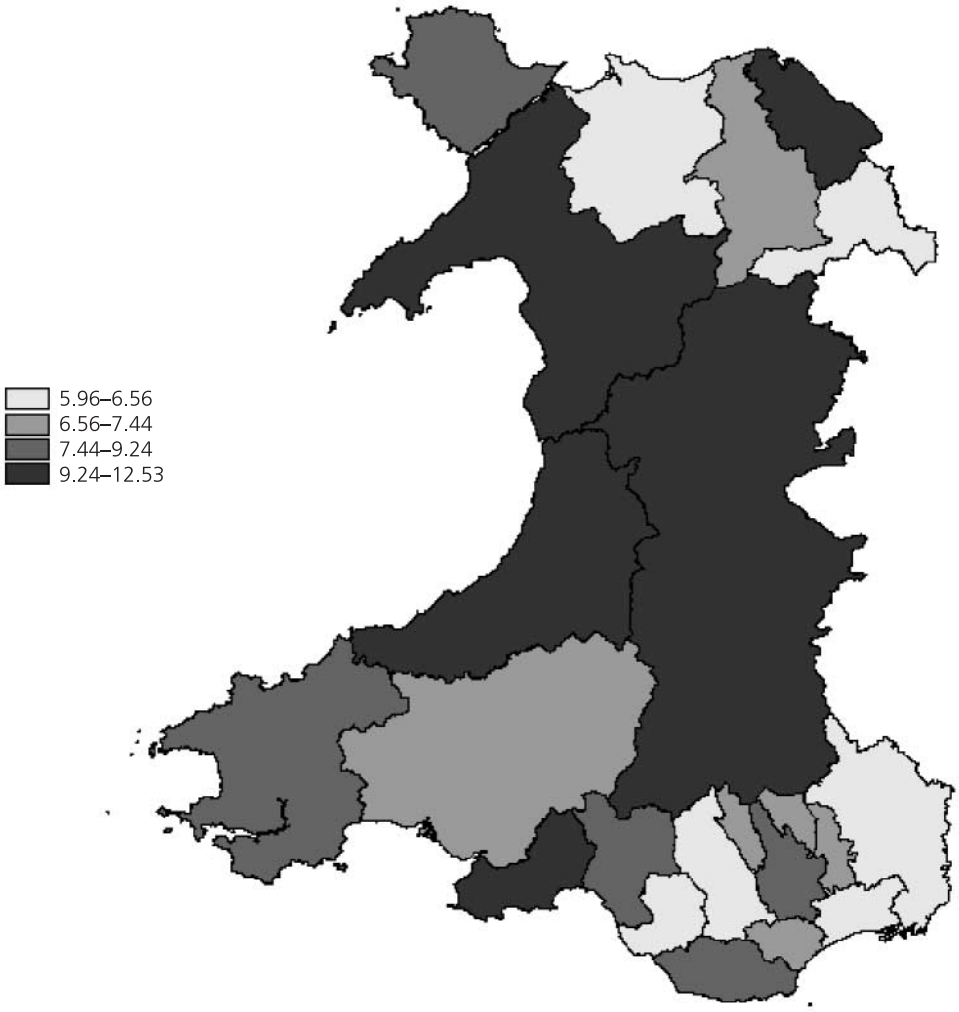

Figure W13 Spatial distribution (quartiles) of the average weekly home care package for older people,* Wales – 2004 (hours)

* Data from survey week, conducted during last full week in September 2004

Source: Local Government Data Unit – Wales *PM2.13: Table M Adult homecare service intensity analysis in sample week 2004–05*
http://www.lgdu-wales.gov.uk/Documents/Data_Set/PSS/2004_2005/lgd01115_pm2_2004_05_table_2_13_m_v2_bi.xls

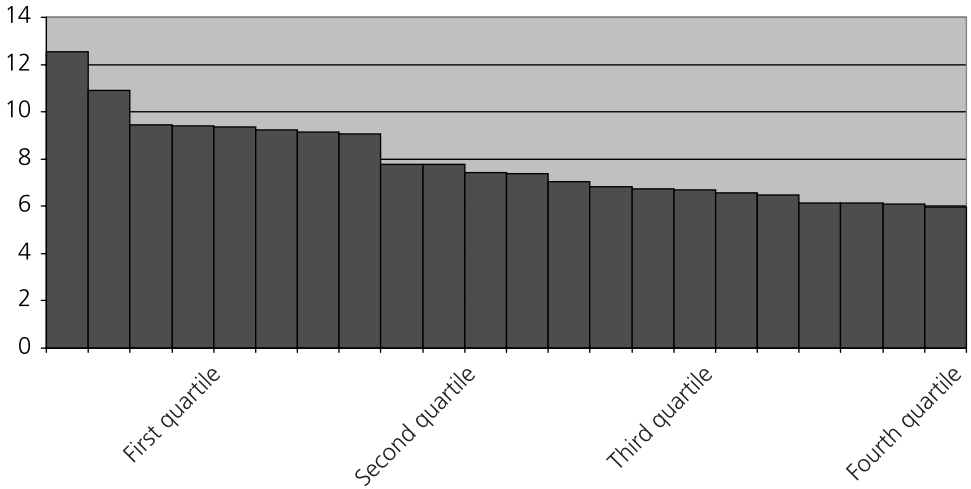

Figure W14 Distribution of the average weekly home care package for older people by local authority, Wales – 2004 (hours)

Table W7 Distribution of the average weekly home care package for older people by local authority, Wales – 2004 (hours)

First quartile		*Second quartile*		*Third quartile*		*Fourth quartile*	
Flintshire	12.5	Neath Port Talbot	9.2	Merthyr Tydfil	7.4	Conwy	6.6
Swansea	10.9	The Vale of Glamorgan	9.1	Carmarthenshire	7.0	Bridgend	6.5
Powys	9.5	Pembrokeshire	9.1	Blaenau Gwent	6.8	Rhondda Cynon Taf	6.1
Gwynedd	9.4	Isle of Anglesey	7.8	Denbighshire	6.7	Newport	6.1
Ceredigion	9.4	Caerphilly	7.8	Torfaen	6.7	Wrexham	6.1
		Cardiff	7.4			Monmouthshire	6.0

* Data from survey week, conducted during last full week in September 2004
Source: Local Government Data Unit – Wales *PM2.13: Table M Adult homecare service intensity analysis in sample week 2004–05*
http://www.lgdu-wales.gov.uk/Documents/Data_Set/PSS/2004_2005/lgd01115_pm2_2004_05_table_2_13_m_v2_bi.xls

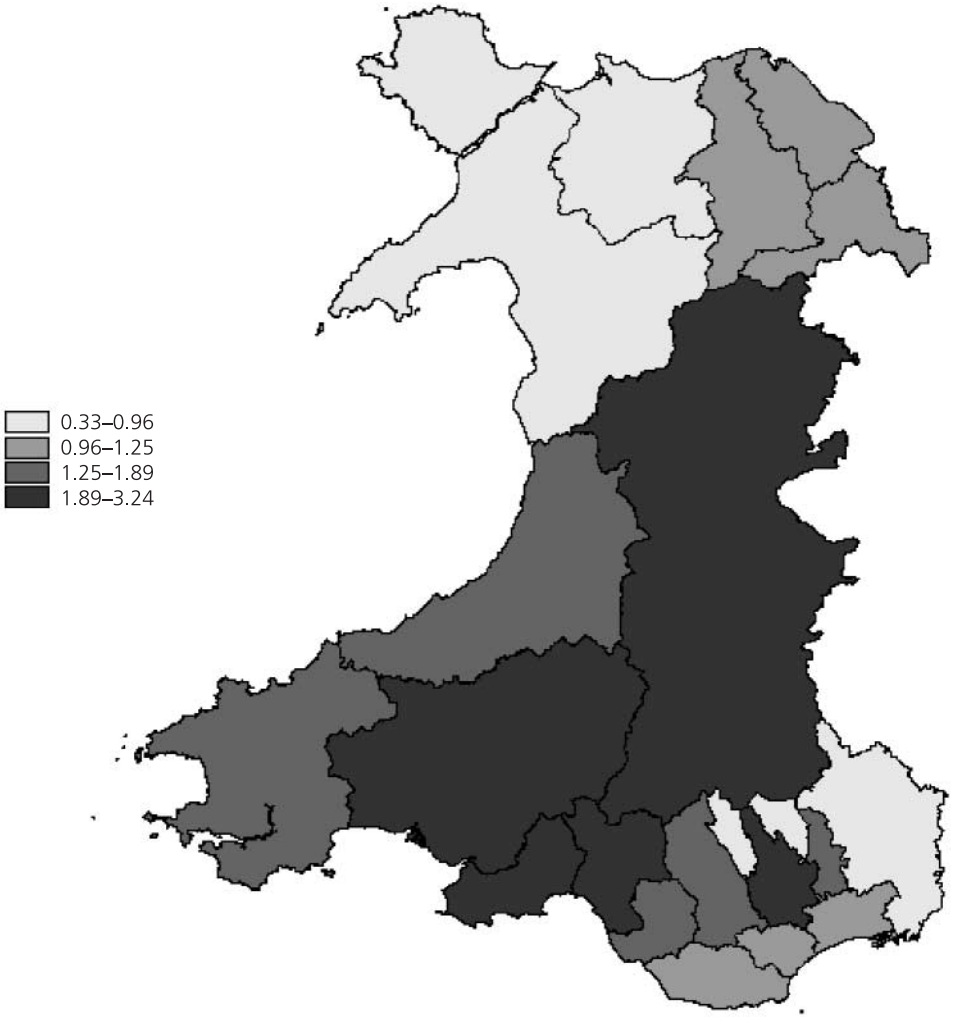

Figure W15 Spatial distribution (quartiles) of the proportion of older people receiving day care, Wales – 2004–05 (%)

Source: Local Government Data Unit – Wales *PM2.16: The rate of older people (aged 65 or over) helped to live at home by service, per 1,000 population aged 65 or over*
http://www.lgdu-wales.gov.uk/Documents/Data_Set/PSS/2004_2005/lgd01115_pm2_2004_05_table_2_16_pa_10a_supplement_v1_bi.xls

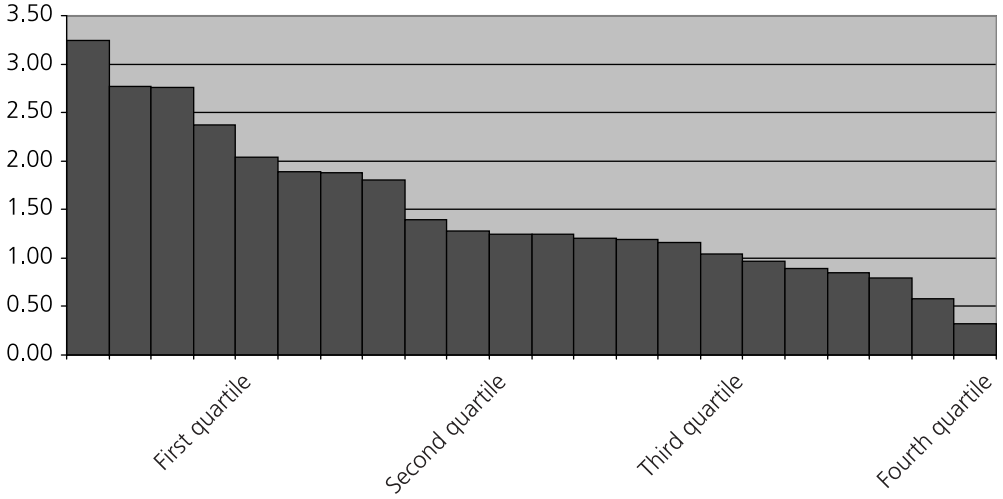

Figure W16 Distribution of the proportion of older people receiving day care by local authority, Wales – 2004–05 (%)

Table W8 Distribution of the proportion of older people receiving day care by local authority, Wales – 2004–05 (%)

First quartile		*Second quartile*		*Third quartile*		*Fourth quartile*	
Carmarthenshire	3.2	Torfaen	1.9	Denbighshire	1.2	Conwy	1.0
Caerphilly	2.8	Ceredigion	1.9	Flintshire	1.2	Monmouthshire	0.9
Swansea	2.8	Bridgend	1.8	Newport	1.2	Isle of Anglesey	0.9
Neath Port Talbot	2.4	Pembrokeshire	1.4	Cardiff	1.2	Merthyr Tydfil	0.8
Powys	2.0	Rhondda Cynon Taf	1.3	The Vale of Glamorgan	1.0	Blaenau Gwent	0.6
		Wrexham	1.2			Gwynedd	0.3

Source: Local Government Data Unit – Wales *PM2.16: The rate of older people (aged 65 or over) helped to live at home by service, per 1,000 population aged 65 or over*
http://www.lgdu-wales.gov.uk/Documents/Data_Set/PSS/2004_2005/lgd01115_pm2_2004_05_table_2_16_pa_10a_supplement_v1_bi.xls