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## **Dementia UK: Update (Second edition)**

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# Dementia UK Update

**Document purpose** This report presents the findings of research commissioned by Alzheimer’s Society to update the Dementia UK (2007) report. It provides a synthesis of best available evidence for the current cost and prevalence of dementia. It aims to provide an accurate understanding of dementia prevalence and cost in the UK to assist in policy development, influencing, commissioning and service design.

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**Title** **Dementia UK: Update**  
Second edition

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**Publication date** November 2014

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**Target audiences** **Dementia UK: Update** is intended for a wide range of organisations and people who can improve quality of life for people with dementia. This includes partners from the public sector, the research community, local authorities, commissions of healthcare, civic organisations and government.

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# Foreword

A comprehensive and up-to-date review of dementia in the UK is essential for equipping policy-makers so that they can make the best decisions today about how to face the challenges of dementia tomorrow. This report provides a major review of the best available evidence on dementia and exposes the staggering financial and human impact of the condition. It provides hard facts that demand a response.

2015 is the year of a general election. But while the question of who will be in government remains to be decided, one of the greatest challenges that they will face is already apparent. This report, the most comprehensive review of dementia in the UK to date, shows that there will be 850,000 people with dementia living in the UK at the next election, more than ever before. The cost of this is currently £26 billion a year – enough to pay the energy bills of every household in the country. This price tag is set to rise as the number of people with dementia grows. Most strikingly, the report found that carers and families currently shoulder two-thirds of the cost themselves.

We are at a critical point in transforming how we care for people with dementia. While the last few years have seen unprecedented attention on dementia in the political sphere, a fragile health and social care service will have to face its greatest demographic challenge yet. It is plain to see that the deep-rooted failings of a divided health and social care system have left hundreds of thousands of unpaid carers bearing the brunt, and people with dementia are struggling without the support they need. As the first wave of baby-boomers reach their 70s in 2015, the generation that changed expectations throughout their lives will change expectations of health and social care services. The current service provision will not be enough – health and social care will have to change in order to cope with new demands.

It is essential that policy decision-making in 2015 is based on the best possible evidence. Alzheimer's Society commissioned this report from King's College London and the London School of Economics so this can happen. Since the first edition in 2007, the evidence has grown on the numbers of people with dementia and this report provides a review of the best available evidence on the prevalence and costs of dementia. It reveals the closest estimates available in the UK today of the true size and nature of the challenge we face.

Alzheimer's Society was formed in 1979 by 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 for people affected by dementia. Alzheimer's Society has an ambitious vision of a world without dementia. For over three decades the Society's staff, volunteers and supporters have worked hard towards a better future for everyone affected by dementia. It has achieved great things. Most importantly, Alzheimer's Society has made sure dementia cannot be ignored. Now, we need to make sure that people with dementia can expect to live well within a system that is ready to meet their needs.

A handwritten signature in black ink that reads "Jeremy Hughes". The signature is written in a cursive style with a horizontal line underneath the name.

**Jeremy Hughes**  
**Chief Executive**  
**Alzheimer's Society**

# Executive summary

## Overview

- This report provides an update to the Dementia UK 2007 report.
- A Delphi consensus approach was used to estimate dementia prevalence.
- The evidence base was reviewed and updated for the purposes of the report and was then evaluated by a panel of experts who provided estimations of the prevalence of dementia.
- The latest evidence and new prevalence estimates were used to calculate the numbers of people with dementia, and the societal and economic costs to the UK.
- Recommendations are made for future policy-making on the basis of the updated estimations and the future impact of dementia on society.

This report provides an update of the figures presented in the first edition of Dementia UK (Alzheimer's Society, 2007). It was researched and written by academics from King's College London and the London School of Economics in summer 2014.

The key findings from this report are:

- The total age-standardised 65+ population prevalence of dementia is 7.1% (based on 2013 population data).
- This equals one in every 79 (1.3%) of the entire UK population, and 1 in every 14 of the population aged 65 years and over.
- At the current estimated rate of prevalence, there will be 850,000 people with dementia in the UK in 2015.
- Compared to the 2007 estimates, the current prevalence consensus estimates are slightly higher for the youngest (65–69) and oldest (90+) age bands and slightly lower for the intermediate age groups (80–89).
- The total number of people with dementia in the UK is forecast to increase to over 1 million by 2025 and over 2 million by 2051 if age-specific prevalence remains stable, and increases are only driven by demographic ageing.

- This is a worst-case scenario. Improvements to education standards, cardiovascular health, activity levels and other known risk factors may all help reduce dementia incidence and prevalence in the future. However, available research in this area is not sufficient to allow this to be forecasted in current projections.
- There are over 40,000 people with early-onset dementia (under the age of 65 years) in the UK.
- The total cost of dementia to society in the UK is £26.3 billion, with an average cost of £32,250 per person.
  - £4.3 billion is spent on healthcare costs.
  - £10.3 billion is spent on social care (publicly and privately funded).
  - £11.6 billion is contributed by the work of unpaid carers of people with dementia.

## 1 The context of Dementia UK: Update

The Dementia UK report (Alzheimer’s Society, 2007) marked a step change in awareness of the gravity of the coming dementia epidemic and the worrying inadequacy of UK policy responses to this challenge at the time. The report contained the first comprehensive evidence-based estimates of the numbers of people with dementia in the UK, with future projections through to the year 2051. Services and treatments for people with dementia were reviewed, and the societal costs of dementia were estimated.

### Updating estimates on the prevalence and costs of dementia

An up-to-date and accurate understanding of dementia prevalence and cost in the UK is an important lever for policy development, influencing, commissioning and service design. Since the 2007 report, new evidence has been published that suggests there may have been changes in the prevalence of dementia. Most significantly for the UK have been the findings from the MRC Cognitive Function and Ageing Study II (Matthews et al, 2013), which suggest there has been a reduction in dementia prevalence in England during the last two decades. Similarly, data available on the costs of healthcare, social care and unpaid care for people with dementia have significantly improved since 2007.

In response to this, Dementia UK: Update presents a synthesis of best available evidence for the current prevalence (Chapter 3), numbers of people with dementia (Chapter 4) and cost of dementia to society and the economy in the UK (Chapter 5). However, estimates given in this report are by their nature provisional and subject to reappraisal when the coverage and quality of the evidence improves.

Decisions on priorities for research and for developing services for people with dementia should be informed by reliable estimates of the numbers of people with dementia and the costs – both to public funds and to society more widely – of providing treatment, care and support.

## 2 Methods used for estimating dementia prevalence

A methodology called the Expert Delphi Consensus was used to calculate dementia prevalence. This approach was used successfully for calculating prevalence of dementia for the 2009 World Alzheimer Report (Alzheimer's Disease International, 2009) and for the Dementia UK report (Alzheimer's Society, 2007).

The expert consensus group comprised 13 senior academics (see Chapter 2 for the full list), nine of whom were part of the panel for the previous 2007 Dementia UK Delphi consensus.

The Delphi consensus process involved a preliminary review of all the available evidence, which was then submitted to the expert panel along with a questionnaire. The panel reviewed the evidence and used their judgment to estimate prevalence. After a second round of reviews (during which the panel could re-adjust their estimations in light of the anonymised responses of their peers) an average was calculated from the individual responses of the panel, which formed the basis for the estimations of prevalence published in this report.

## 3 Results of the Delphi consensus process

### Context

Before the collected studies could be evaluated by the panel of experts, the contribution of age composition, study design, year of study and country to the heterogeneity of dementia prevalence between European studies was assessed. Study design and country made the largest independent contributions, and overall heterogeneity was greatly diminished when these factors were controlled. Dementia prevalence in Western Europe was also estimated using a quantitative meta-analysis.

### Results

The updated report shows that the current consensus estimates for the prevalence of dementia (for male and female combined) are slightly higher than the previous Delphi estimates for the youngest (65–69) and oldest (90+) age bands and slightly lower for the intermediate age groups (80–89).

### Prevalence of late-onset dementia

The number of people with late-onset dementia continues to rise for each five-year age band up to the age of 80–84.

The age-standardised population prevalence for those aged 65 years and over was similar in both the 2007 and 2014 Delphi consensus exercises (7.1%).

This age-standardised prevalence estimated in this report is intermediate between the two dominant population-based studies for the UK: the MRC Cognitive Function and Ageing Studies I (MRC CFAS, 1998) and II (Matthews et al, 2013). MRC CFAS I estimated 7.5% prevalence and MRC CFAS II estimated 6.4%. The results for this report were substantially lower than the 8.6% indicated by the West Europe region meta-analysis.

**Table A: The consensus estimates of the population prevalence (%) of late-onset dementia**

Age in years	Previous estimates (Dementia UK 2007)			Current estimates (Dementia UK 2014)		
	Female	Male	Total	Female	Male	Total
60–64	(0.1)*	(0.2)*	(0.2)*	0.9	0.9	0.9
65–69	1.0	1.5	1.3	1.8	1.5	1.7
70–74	2.4	3.1	2.9	3.0	3.1	3.0
75–79	6.5	5.1	5.9	6.6	5.3	6.0
80–84	13.3	10.2	12.2	11.7	10.3	11.1
85–89	22.2	16.7	20.3	20.2	15.1	18.3
90–94	29.6	27.5	28.6	33.0	22.6	29.9
95+	34.4	30.0	32.5	44.2	28.8	41.1

\* In the Dementia UK 2007 report, the prevalence of dementia among those aged 60–64 was estimated as part of the early-onset dementia consensus.

**Table B: Comparison of current consensus estimates for the prevalence (%) of late-onset dementia with estimate from previous literature reviews and key surveys**

Age in years	60–64	65–69	70–74	75–79	80–84	85–89	90–94	95+	Age- standardised 65+
<b>Dementia UK 2014 report</b>	0.9	1.7	3.0	6.0	11.1	18.3	29.9	41.1	7.1
<b>MRC CFAS I</b>	-	1.5	2.6	6.3	13	25.3	-	-	7.5
<b>MRC CFAS II</b>	-	1.5	2.7	5.7	10.0	16.1	30.1	-	6.4
<b>Updated World Alzheimer’s Report (Western Europe)</b>	1.6	2.5	4.2	7.2	12.4	20.7	40.7	-	8.6
<b>Dementia UK 2007 report</b>	-	1.3	2.9	5.9	12.2	20.3	28.6	32.5	7.1

### Prevalence of dementia in different care settings

The consensus group were asked, as in the Dementia UK 2007 report consensus, to estimate the age and gender-specific prevalence of dementia for residents of care homes in general (comprising residential care homes, nursing homes, and EMI care homes).

The prevalence of dementia among residents of care homes was considered, according to the consensus, to be slightly higher in women than men at all ages, and to increase in age up to age 90, falling slightly among the oldest old. The total prevalence of dementia in care homes was estimated by the consensus at 69.0% (62.7% for males and 71.2% for females).

**Table C: The mean consensus estimates of the prevalence (%) of dementia in different care settings**

Care setting	Female	Male	Total
Extra care housing	8.8	7.9	8.1**
Residential homes	62.1	52.7	57.9
Nursing homes	75.8	67.8	73.0
EMI care homes	90.6	86.7	90.1

\*\*Consensus not achieved – therefore this estimate should be treated with caution.

### Estimates that were not updated by the Delphi consensus

Due to limited new evidence, the following estimates from the 2007 report have not been updated: early-onset dementia (up to 60), prevalence of dementia among black, Asian and minority ethnic groups, dementia severity and subtypes of dementia.

#### Early-onset dementia

Prevalence of early-onset dementia, as with late-onset dementia, increases exponentially with increasing age, roughly doubling every five years. The 60–64 age group has been included in the late-onset dementia consensus, as there is more evidence available to estimate prevalence for this age band.

#### Prevalence of dementia among black, Asian and minority ethnic groups

Due to limitations in evidence on prevalence among black, Asian and minority ethnic groups, this is taken to be the same as for the UK population as a whole.

#### Dementia severity

Among people with late-onset dementia:

- 55.4% have mild dementia
- 32.1% have moderate dementia
- 12.5% have severe dementia

#### Dementia subtypes

- Alzheimer’s disease 62%
- Vascular dementia 17%
- Mixed dementia 10%
- Dementia with Lewy bodies 4%
- Frontotemporal dementia 2%
- Parkinson’s dementia 2%
- Other 3%

## 4 Numbers of people with dementia

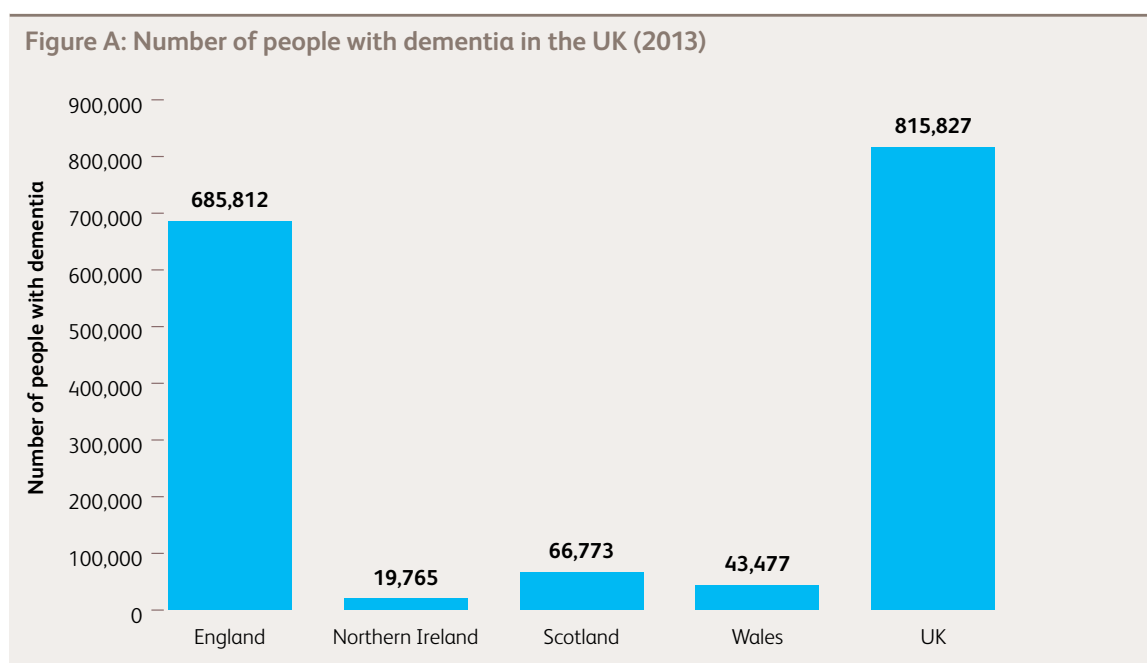
### Methods

The updated prevalence figures obtained by the Delphi consensus were used to estimate population numbers for the UK.

### Results

Applying estimated prevalence to 2013 population data, there were 815,827 people with dementia in the UK, of whom 773,502 were aged 65 years or over. This represents 1 in every 79 (1.3%) of the entire UK population, and 1 in every 14 of the population aged 65 years and over.

Of those living with dementia in the UK, 84% live in England, 8% in Scotland, 5% in Wales and 2% in Northern Ireland (Figure A).



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

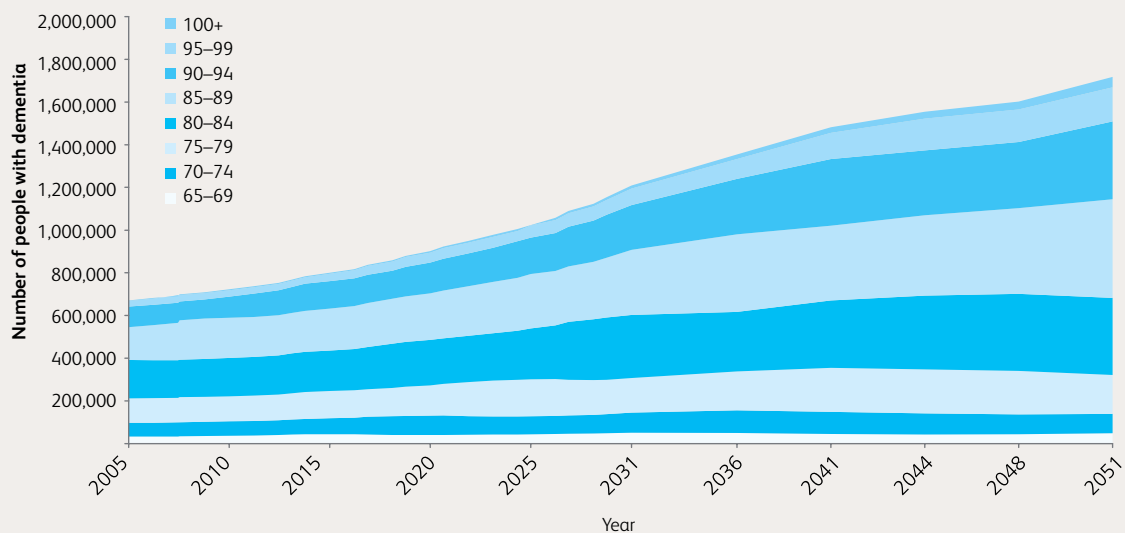
If the prevalence of dementia remains the same, The number of people with dementia in the UK is forecast to increase to 1,142,677 by 2025 and 2,092,945 by 2051, an increase of 40% over the next 12 years and of 156% over the next 38 years.

The increases in the number of people with dementia are not equal across the range of those affected (Figure B). Under the assumption that the age- and gender-specific prevalence of dementia will not vary over time, the projected increases presented are only driven by demographic ageing, with larger increases in the numbers of older people (more at risk for dementia). It is reasonable to argue that the projections presented in this report

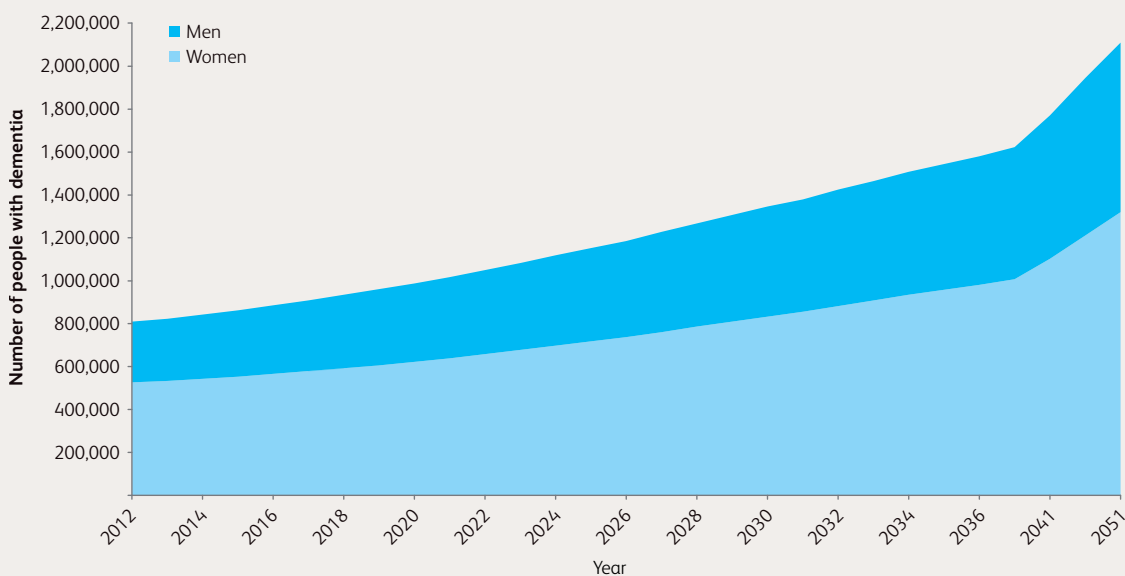


for the UK are uncertain and may only occur in absence of any improvement in public health (ie no improvement in the prevention of vascular factors or in healthier lifestyles). As such, these predictions should be treated with caution, and with increasing caution the further into the future that they are made. Numbers of men and women with dementia in the UK are projected to increase at a similar rate (Figure C).

**Figure B: Projected increases in the number of people with dementia in the UK, by age group (2012–2051)**



**Figure C: Projected increases in the number of people with dementia in the UK, by gender (2012–2051)**



## Population prevalence by region

The number of people with dementia for each local authority, clinical commissioning group (or equivalent) and parliamentary constituency in the UK was estimated. An online link to the detailed results is provided in Appendix A.

## Early-onset dementia

It was estimated that there are now 42,325 people with early-onset dementia (onset before the age of 65 years) in the UK. This number has significantly increased since the Dementia UK 2007 report, where it was thought to have been underestimated.

## 5 The costs of dementia

### Methods

Estimates were generated for the costs of healthcare, social care and unpaid care for people with dementia using the best currently available information.

The overarching framework used to pull these data together is a new version of a model of the costs and outcomes of dementia that builds on previous versions of the Personal Social Services Research Unit (PSSRU) aggregate long-term care model (Wittenberg et al, 1998, 2001) and of the PSSRU dementia care model (Comas-Herrera et al, 2007). The findings for England were grossed to the UK. All costs were inflated to 2012/13 prices.

### The cost of dementia in the UK

The overall economic impact of dementia in the UK is £26.3 billion, working out at an average annual cost of £32,250 per person.

- £4.3 billion is spent on healthcare costs, of which around £85 million is spent on diagnosis.
- £10.3 billion is spent on social care for people with dementia in the UK.
- Social care is either publicly funded (£4.5 billion; 17.2% of the overall total cost of dementia) or privately funded (£5.8 billion; 22.9% of the total).
- The cost of unpaid care for people with dementia in the UK is £11.6 billion, working out as 44% of the total cost of dementia.
- The total number of unpaid hours of care provided to people with dementia in the UK is worth £1.34 billion.

Figure D: Estimated breakdown of costs of dementia for the UK, 2013

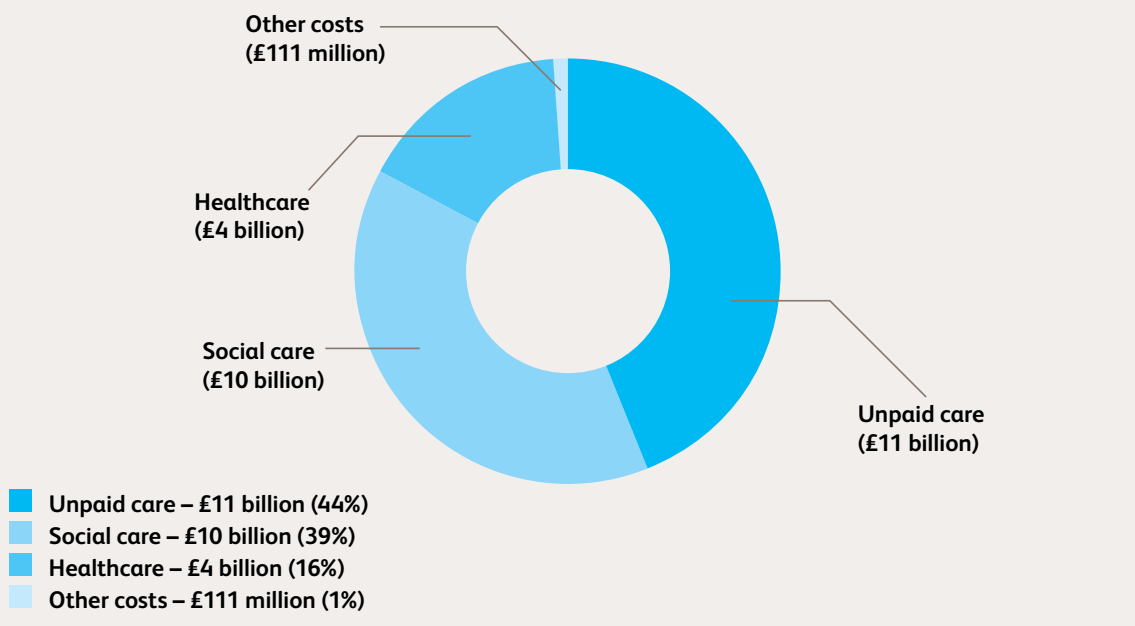


Table D: Average annual cost per person with dementia, by severity and setting (£, 2012/13 prices)

	Healthcare	Social care	Unpaid care	Other costs	Total costs
<b>People with dementia living in the community (average cost)</b>					
Mild dementia	2,751	3,121	19,714	137	25,723
Moderate dementia	2,695	7,772	32,237	137	42,841
Severe dementia	11,258	10,321	33,482	136	55,197
All severity levels	3,152	4,054	21,956	137	29,298
(Sector cost as % of total)	(10.8%)	(13.8%)	(74.9%)	(0.5%)	(100%)
<b>People with dementia living in residential care (average cost)</b>					
Mild dementia	4,504	24,737	1,067	136	30,444
Moderate dementia	9,438	25,715	2,901	136	38,190
Severe dementia	8,689	25,874	2,119	136	36,817
All severity levels	8,542	25,610	2,450	136	36,738
(Sector cost as % of total)	(23.3%)	(69.7%)	(6.7%)	(0.4%)	(100%)
<b>All settings (average cost)</b>					
Mild dementia	2,932	5,362	17,781	137	26,212
Moderate dementia	7,837	21,455	9,865	136	39,294
Severe dementia	9,300	22,176	9,575	136	41,187
All severity levels	5,285	12,584	14,237	136	32,242
(Sector cost as % of total)	(16.4%)	(39.0%)	(44.2%)	(0.4%)	(100%)

**Table E: Total annual cost, by severity and setting (£, in millions, 2012/13 prices)**

	<b>Healthcare</b>	<b>Social care</b>	<b>Unpaid care</b>	<b>Other costs</b>	<b>Total costs</b>
<b>People with dementia living in the community (total annual cost)</b>					
<b>Mild dementia</b>	1,120	1,271	8,029	56	10,476
<b>Moderate dementia</b>	168	484	2,007	9	2,667
<b>Severe dementia</b>	267	244	793	3	1,307
<b>All severity levels</b>	1,555	1,999	10,829	67	14,450
<b>(Sector cost as % of total)</b>	(10.8%)	(13.8%)	(74.9%)	(0.5%)	(100%)
<b>People with dementia living in residential care (total annual cost)</b>					
<b>Mild dementia</b>	212	1,165	50	6	1,434
<b>Moderate dementia</b>	1,887	5,142	580	27	7,636
<b>Severe dementia</b>	660	1,964	161	10	2,795
<b>All severity levels</b>	2,759	8,272	791	44	11,866
<b>(Sector cost as % of total)</b>	(23.3%)	(69.7%)	(6.7%)	(0.4%)	(100%)
<b>All settings (total annual cost)</b>					
<b>Mild dementia</b>	1,332	2,436	8,079	62	11,910
<b>Moderate dementia</b>	2,055	5,626	2,587	36	10,303
<b>Severe dementia</b>	926	2,209	954	14	4,102
<b>All severity levels</b>	4,314	10,271	11,620	111	26,316
<b>(Sector cost as % of total)</b>	(16.4%)	(39%)	(44.2%)	(0.4%)	(100%)

## 6 Recommendations

Since the first edition of the Dementia UK report in 2007, much progress has been made in tackling the dementia epidemic that is on the horizon, at both a policy and a community level. However, as this report makes evident, the means of surveying, estimating and reviewing the prevalence and numbers of people with dementia in the UK, and the costs of dementia to the economy and society, are far below the standard that is required for truly informed decision making. This is unacceptable, and steps should be taken to improve the quality of data available. This is especially relevant given the changing demographics of our ageing population and new pressures on the economy that supports this population.

More accurate estimations will ensure that decisions on priorities for developing services for people with dementia and on priorities for research are well-informed, resulting in the best treatment, care and support for those with dementia in our communities.

### **Recommendation 1 Push for improvements in the quality, coverage and regularity of surveys into the prevalence and numbers of people with dementia in the UK**

Good quality, generalisable population-based research for the estimation of numbers of people with dementia in the UK and other countries – their residential status, their needs for care, their access to and use of services, and attendant costs – is essential.

Nationally representative samples of adequate size are vital, along with specific locality studies that drill down into the demographics of those with dementia in our society and their needs. A combination of national and specific locality surveys are essential for informing policy-makers.

The surveys should be repeated, regularly, to monitor trends in prevalence over time. For comparisons to be meaningful, the same methodology should be applied on each occasion, particularly as regards the definition and ascertainment of dementia, and levels of severity.

There should be separate sampling of private homes, and over-sampling of all types of care home (providing different levels and types of care).

The data from high-quality surveys are vital for rational health planning, monitoring service delivery, and quality improvement in prevention and care. If the evidence-base were improved in this way, there would no longer be any need for Delphi consensus procedures.

### **Recommendation 2 Move towards a purely quantitative method for analysing and synthesising the data on the prevalence of dementia in the UK**

The current Delphi consensus was commissioned by the funders of this report as the preferred approach for incorporating the evidence into the bigger picture of dementia prevalence. However, the relative validity of this method of estimation will be a matter of judgment in the future.

It can be argued that, due to potential vulnerabilities in the Delphi consensus method, it would be highly desirable to move to a purely quantitative method for synthesising prevalence data. However, that will not be possible until the quality and coverage of prevalence estimates improves.

### **Recommendation 3 Enter into specific research on the number of individuals from black, Asian and minority ethnic groups with dementia, in order to reflect the changing demographic of the UK's ageing population**

This is an important yet under-studied area. Numbers of older people from black, Asian and minority ethnic groups are increasing rapidly in the UK, but as was the case in 2007, more epidemiological research is required to clarify dementia prevalence and risk among black, Asian and minority ethnic groups. It is essential that their needs are met by accessible and responsive services, and that any evidence for increased risk of dementia is addressed by focused attention on modifiable risk factors across life.

### **Recommendation 4 Continue to monitor the impact of factors that may reduce the prevalence of dementia in the UK**

There is some evidence from the UK, as well as other high-income countries that prevalence, or incidence of dementia, or both may be declining. This may be the result of improvements to education standards, cardiovascular health, activity levels and the reduction of other known risk factors. There is no reason to assume that age-specific prevalence will remain constant over time. Since the drift of government policy is towards earlier diagnosis, increased use of evidence-based healthcare services, increased integration and coordination of care, and reduced transition into residence in care homes, changes in age-specific prevalence can also be anticipated, and should be monitored.

Some studies have also noted a reduced age-specific incidence of dementia, and reduced survival after onset. This may be explained by incidence being deferred to older ages, closer to the natural limits of the life span, with survival time being determined by factors other than dementia. This is an important issue and as a result it would also be useful to estimate survival with dementia, by linking survey participants, prospectively, to mortality data from the NHS Central Registry.

### **Recommendation 5 Improve the evidence base for quantifying the impact of dementia on quality of life**

It remains difficult to accurately measure the impact of dementia on quality of life in economic terms. We still have relatively little information about the impact on unpaid carers in terms of health, forgone work opportunities and lost leisure time. There are also relatively few sources of information about how carer life quality relates to the care needs of the person they care for, and the formal care services they have access to. There are also important information gaps about the use of privately sourced home care and its impact. Further studies are needed in these areas.



# Introduction

### Overview

- The Dementia UK 2007 report was an instrumental force for change in influencing and shaping UK policy responses to the dementia epidemic.
- In the last seven years, much progress has been made to address the issues highlighted in the original report and dementia has become a much greater national priority.
- However, in the face of rising numbers of people with dementia and increased pressures on economic, health and social care resources, an updated report which reflects the latest data on the prevalence and costs of dementia in the UK is necessary.
- An updated report is necessary because of:
  - significant weaknesses and limitations in the prevalence data for the 2007 report
  - the need to assess whether the numbers of people with dementia has changed since the original report was published
  - the requirement for a full and up-to-date understanding of the changing costs of dementia, to both the economy and society, since 2007.

### 1.1 The Dementia UK report

The Dementia UK report (Alzheimer's Society, 2007) marked a step change in awareness of the gravity of the coming dementia epidemic, and the inadequacy of UK policy responses at the time to this challenge. The report contained the first comprehensive evidence-based estimates of the numbers of people in the UK, with future projections through to the year 2051. Services and treatments for people with dementia were reviewed, and the societal costs of dementia were estimated.

In the light of the report findings, Alzheimer's Society called for urgent action to:

- 1 Make dementia a national health and social care priority
- 2 Increase funding for dementia research
- 3 Improve dementia care skills across health and social care
- 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



In the last seven years, progress has been made to address these issues. In particular, dementia has been accorded much greater national priority through the formulation of National Dementia Strategies for England (Department of Health, 2009), Scotland (The Scottish Government, 2010), Wales (Welsh Government, 2011), and Northern Ireland (Department of Health, Social Services and Public Safety, 2011), and the Prime Minister's challenge on dementia (Department of Health, 2012a).

## Key facts 1: Findings from the Dementia UK 2007 report

### Prevalence of dementia

- Prevalence of dementia doubled with every five-year increase in age from 30 to 95 and over.
- Fewer than 5% of cases were 'early-onset' before the age of 65 years.
- In older adults, prevalence increased from 1.3% among those aged 65–69 to 32.5% among those aged 95 years and over.
- Alzheimer's disease was the most common subtype, particularly at older ages, and among women.
- Frontotemporal dementia accounted for a substantial proportion of early-onset cases among younger men.
- The prevalence of dementia in care homes varied little by age or gender, increasing from 55.6% among those aged 65–69 to 64.8% in those aged 95 and over. Prevalence was higher in elderly mentally infirm (EMI) homes (79.9%) and nursing homes (66.9%) than in residential care homes (52.2%). 36.5% of people with dementia were living in care homes.
- It was estimated that there were 683,597 people with dementia in the UK. This represented 1 person in every 88 (1.1%) of the entire UK population.
- Numbers of people with dementia in the UK were forecast to increase to 940,110 by 2021 and to 1,735,087 by 2051, an increase of 38% over 15 years and 154% over the next 45 years.

### Service provision

- The state of dementia commissioning, care and policy that dealt with the coverage of memory assessment and care services was inadequate.
- There were significant variations in levels of provision, expenditure and (to a lesser extent) in unit costs across all services and in all UK countries.

### Costs

- Total costs amounted to £17 billion per annum, or an average of £25,472 per person with late-onset dementia.
- The cost of accommodation and care in care homes accounted for 41% of the total, with 36% coming from informal care inputs (family members and unpaid carers).

## Key facts 2: The impact of the Dementia UK 2007 report in England

The Dementia UK 2007 report was instrumental in raising awareness of the scale of dementia among public, government and other key stakeholders in England, as well as the costs of dementia. It has also been instrumental in guiding policy-makers and service providers in designing, planning and costing service innovations, and in monitoring the coverage of and access to a timely diagnosis, treatment and care.

The Dementia UK report provided the evidence base for a number of critical policy developments on dementia in England. Service development and improving quality of care for people with dementia was recognised as a priority by a range of government bodies (National Audit Office, 2007; Department of Health, 2008; House of Commons Committee of Public Accounts, 2008). This prioritisation led to the first National Dementia Strategy for England (Department of Health, 2009).

Early, effective diagnosis and intervention for people with dementia and their carers was at the core of the National Dementia Strategy for England (NDSE), and led to the establishment of a national network of memory clinics. Subsequently, early diagnosis and intervention was one of only two NHS areas given increased priority by the incoming coalition government.

Building on the progress of the NDSE, the Prime Minister's challenge on dementia (Department of Health, 2012a) was launched in March 2012. Three dementia challenge champion groups focus upon: driving improvements in health and care; creating dementia-friendly communities; and improving dementia research. The Prime Minister's challenge on dementia prioritised getting more people with dementia a formal diagnosis and the ambition was to achieve a national diagnosis rate of 66% by March 2015. This aim was underpinned by robust local strategic plans, commissioning and service improvement. This commitment was enshrined in the NHS Mandate (Department of Health, 2012b).

To support this ambition, the Department of Health commissioned the NHS Dementia Prevalence Calculator online tool (NHS England, 2014). This tool uses prevalence data from the Dementia UK report to generate estimates of numbers of people with dementia at a local level and compares these against numbers of diagnoses recorded in the Quality Outcomes Framework (HSCIC, 2014). The tool is now the backbone of the government's strategy to benchmark, and set trajectories for improvement in diagnosis rates – that, nationally, two thirds of the estimated number of people with dementia should have a diagnosis and access to post diagnostic support by 2015 (Department of Health, 2014).

## 1.2 Why update the Dementia UK report now?

In the face of rising numbers of people with dementia and increased pressures on economic, health and social care resources, an update to the Dementia UK report is timely. Several factors make an updated report especially necessary: significant weaknesses and limitations in the prevalence data for the 2007 report; the need to assess whether the numbers of people with dementia has changed since the original report was published; and the requirement for a full and up-to-date understanding of the changing costs of dementia, to both the economy and society, since 2007. An update is essential to provide an accurate knowledge base for critical policy going forward.

All such estimates are by their nature provisional, and subject to reappraisal when the coverage and quality of the evidence improves.

### Limitations of prevalence data in 2007

There were significant weaknesses in the evidence base for the Dementia UK 2007 report. The UK epidemiological studies that informed the Dementia UK estimates of population prevalence were carried out between 1986 and 1993 and no new studies were carried out in the UK in the 14 years between that period and the publication of the Dementia UK report in 2007.

Other weaknesses in the evidence base available at that time were that:

- a) Prevalence estimates were taken from surveys that sampled relatively small catchment-area sites that may not have been generalisable to the whole of the UK.
- b) Studies of early-onset dementia were limited to those individuals who were already diagnosed with the condition, and who were already in contact with local services. This was likely to have led to an underestimate of prevalence and numbers affected by early-onset dementia in the age range 30–64 years.
- c) There were very few studies of the prevalence of dementia in care homes, and none of them had been conducted recently. There was limited information on the prevalence of dementia in different levels of care. Changes in care provision and in criteria for banding may well have led to changes in prevalence over time.

Furthermore, in 2010, the Alzheimer's Research Trust (now Alzheimer's Research UK) published a report using a different methodology (a meta-analysis of European data, rather than a Delphi consensus of UK studies) with a slightly higher estimate of prevalence and numbers of people with dementia (Luengo-Fernandez, 2010). No UK studies were included in the meta-analysis.

### Evidence on changing dementia prevalence

The possibility of changes in prevalence over time needs to be considered. Projections of the numbers of people living with dementia in the future generally assume that age-specific prevalence remains constant, and that demographic ageing is the only changing influence on numbers. This assumption is unlikely to be true – prevalence may be affected by secular changes in incidence (the rate at which new cases occur in the population) or duration of dementia (effectively survival with dementia, since cure is currently not possible). Changes in incidence must be attributable to secular change in risk exposures. Observed changes can only be interpreted with confidence if study methodology is held relatively constant.

In England, the MRC Cognitive Function and Ageing Study (MRC CFAS) surveys (see Key facts 5) were repeated at two time points (1990–1993, CFAS I; 2008–2011, CFAS II) using identical random sampling (in catchment areas in Nottingham, Cambridgeshire, and Newcastle) and similar dementia ascertainment methodology (MRC CFAS, 1998; Matthews et al, 2013). A 30% reduction in prevalence was observed (or for CFAS II versus CFAS I = 0.7, 95% CI 0.6– 0.9), adjusted for age, sex, area, and deprivation status. If the fall in prevalence observed in the samples in these three areas were applicable to the whole of the UK, this would have been sufficient to have almost completely averted the increase in national numbers of people with dementia, anticipated from the ageing of the population.

The authors concluded that the scale of the reduction was substantial and ‘in line with major reductions in risk factors in higher income countries, which have been modified by societal changes such as improvements in education, and prevention and treatment strategies in recent decades’. The study further suggested that the impact of factors that may have led to an increased dementia prevalence (diabetes, survival after stroke, and vascular incidents) must have been outweighed by the greater effect of those likely to lead to a reduction (improved prevention of vascular morbidity and higher levels of education).

Although there was a comparable trend towards declining prevalence in a similar study from Zaragoza, Spain (Lobo et al, 2007), this has not been replicated in other studies (Mathillas et al, 2011; Rocca et al, 2011). There is tentative evidence consistent with a recent decline in incidence in Sweden and the Netherlands (Qiu et al, 2013; Schrijvers et al, 2012). Furthermore, evidence from China and other East Asian countries suggests a trend in the opposite direction (Wu et al, 2014; Chan et al, 2013). A modelling exercise in 2012 focused on recent increases in obesity among the middle-aged Chinese population and, assuming that the observed association between mid-life obesity and dementia in long-term cohort studies in high-income countries is causal, it suggested that future dementia prevalence in China may have been underestimated by up to 19% given the additional impact of epidemiologic transition (Loef and Walach, 2012).

In high-income countries, dementia prevalence studies have declined sharply this century, with investigators and research commissioners neglecting the urgent need to monitor the unfolding epidemic (Alzheimer’s Disease International, 2009). Future policy-making and planning require accurate up-to-date figures on prevalence and, ideally, incidence and mortality. Only then can current and future needs be met and anticipated.

Options for prevention have been relatively neglected, although more attention is now being paid to this (Lincoln et al, 2014). Improvements in education standards, cardiovascular health, and activity levels may all help to reduce dementia incidence, but trends need to be monitored to see if efforts in these directions have been successful. All national dementia strategies seek to encourage earlier help-seeking, timely diagnosis, better access to treatment and care, and avoid where possible transfer into care homes. Again, without up-to-date evidence from regular surveys it will be very difficult to monitor progress towards the achievement of these goals.

## Changing costs of dementia

An updated report must account for the changes in the costs of dementia in the UK to the economy and society since 2007. Changes in health and social care over this period may have impacted on support for people with dementia. In addition a change in the nature of the support for people with dementia – with increased care for people with severe dementia taking place in their own homes rather than in care homes – may have affected the costs of dementia to the UK. Changes in the cost of unpaid care are harder to value, but should also be recognised. Since 2007, new data for ascertaining the extent of the costs of dementia has become available through recent trials and studies, as well as the new prevalence figures generated by this report. This report utilises a new version of a model for ascertaining the costs and outcomes of dementia that builds on previous versions of the PSSRU aggregate long-term care model (Wittenberg et al, 1998, 2001) and of the PSSRU dementia care model (Comas-Herrera et al, 2007). This new version of the model, which was also used for recent work on the economic consequences of various dementia care scenarios (Knapp et al, 2014), produces estimates for England for 2013, at 2012/13 prices, on the basis of current care arrangements.

The Dementia UK 2007 report was lacking in specific data on costs for police, research or advocacy costs; costs for diagnosis or assessment; costs for people with early-onset dementia; or separate costings for the various severity levels in care homes, all of which require addressing in an updated report.

### 1.3 Structure of the Dementia UK 2014 report

- Chapter 2 describes the Delphi consensus approach used to estimate prevalence for the UK.
- Chapter 3 describes the evidence base and gives results of the Delphi consensus, along with results estimates that were not updated by the consensus process.
- Chapter 4 provides data on the estimated numbers of people with dementia, broken down by various subgroups.
- Chapter 5 sets out the costs of dementia to the UK.
- Chapter 6 outlines the recommendations made from the research findings.

# The prevalence of dementia: methods used for the Expert Delphi Consensus

## Overview

This report uses a methodology known as the Expert Delphi Consensus to produce estimates of the prevalence of dementia in the UK using currently available research data. This method was used for the Dementia UK 2007 report and the 2009 World Alzheimer Report.

The process used is outlined below:

- First an update of the systematic review carried out for the 2009 World Alzheimer Report was undertaken to identify new research conducted in Western Europe. Then a quantitative meta-analysis assessed the prevalence of dementia in this region.
- The prevalence estimates from the UK studies were compared with each other, and contextualised with the Dementia UK 2007 Delphi consensus, and with the Western European meta-analysis.
- Phase 1 of the Delphi consensus – an expert consensus panel reviewed the background documents and questionnaires and submitted their suggested for revisions to the questionnaire.
- Phase 2 – the panel used their judgment of the materials to provide individual estimates for prevalence of dementia as outlined by the questionnaire.
- Phase 3 – the experts then reviewed their estimates in the light of the anonymised estimates of all of the other experts and their comments, and were invited to make any changes to their answers that they thought necessary.
- A final consensus was calculated by taking a mean of the individual estimates submitted by the panel.

## 2.1 Background

An accurate understanding of dementia prevalence in the UK is an important lever for policy development, influencing, commissioning and service design.

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.

The size of sample used in a study is a crucial factor in achieving a precise estimate of prevalence – larger samples are preferable to smaller studies. Studies with low response rates may provide biased, inaccurate estimates, since those not responding may be more likely, or less likely than responders to have dementia; it is possible to model the effects of such bias.

The quality of the dementia diagnostic assessment is another important feature. The coverage of the survey, which may include one or more rural or urban districts in one or more regions of the country, determines the extent to which findings may be generalised to the country as a whole. Worldwide, there are, as yet, only two examples of surveys with truly nationally representative samples – one for the USA and one for Canada (Plassman et al, 2007; Canadian Study of Health and Ageing Working Group, 1994). Other factors, including the nature of the outcome studied and how recent the survey was, may impact on the relevance of the data.

A comprehensive approach requires a systematic review of all relevant studies. The evidence from such studies can be combined meta-analytically – essentially by taking a weighted average of the prevalence, accounting for the different sample sizes. This approach can work well when there are a relatively large number of studies, when study designs are similar, and when chance rather than systematic difference is the main source of variability in prevalence between studies.

However, meta-analysis is less applicable when fewer studies have been carried out, when the coverage in terms of the regions of the country surveyed is patchy, when study designs vary in ways that may have influenced prevalence estimates, and when the quality of those studies is variable. In the estimation of the global prevalence of dementia conducted by Alzheimer's Disease International (World Alzheimer Report, 2009) it was considered appropriate to apply meta-analysis in 11 of 21 world regions.

When meta-analysis is not suitable, a technique known as the Delphi Consensus can be used instead. This approach had been used successfully for the remaining world regions for the World Alzheimer Report, and, given the limitations of the available evidence base, for the Dementia UK report in 2007. The Delphi consensus process is described in more detail below. In summary, the process involves a panel of experts convening to weigh all of the available evidence, taking into account the quality of the studies, design factors that may have influenced prevalence, and its relevance to the UK context, before making their best judgment of probable prevalence.

The consensus comes from the second round, in which the experts then review their estimate in the light of the anonymised estimates of all of the other experts and their comments, and are invited to make any changes that they think necessary.

## 2.2 Expert Delphi Consensus procedure

### Systematic review of the available literature

For this update of the Dementia UK report the decision was made to revise the systematic review and meta-analysis of studies of the prevalence of dementia from Western Europe, carried out for the 2009 World Alzheimer Report. This was done to provide a broader context in which to interpret the UK-specific prevalence data and secular trends. The region of Western Europe includes the UK, and its countries share some demographic, political, socio-cultural and socio-economic characteristics.

First the researchers updated the systematic review carried out for the World Alzheimer Report for which the Pubmed search strategy was ('Dementia'[Mesh]) AND (('Prevalence'[Mesh]) OR ('Epidemiology'[Mesh])). They applied a cutpoint of 2009 for publications reviewed, since evidence published up to that date had previously been reviewed for the 2009 World Alzheimer Report. The database of studies included all the UK studies that were described in the Dementia UK 2007 report. Titles and abstracts were reviewed to identify research conducted in Western Europe, before applying other specific inclusion and exclusion criteria (see Key facts 3).

### Key facts 3: Inclusion and exclusion criteria

#### Inclusion criteria

Population-based studies of the prevalence of dementia (according to DSM-IV or ICD-10 criteria (American Psychiatric Association, 2003), or similar clinical criteria), for which the fieldwork started on or after 1 January 1980.

#### Exclusion criteria

Studies excluded on the basis of their sampling design:

- 1 Studies of prevalence from the follow-up phase of a population cohort.
- 2 Studies sampling from an out-of-date population register (prepared more than three years prior to the survey).
- 3 Studies of nursing home or residential care populations, primary care attendees or other unrepresentative service-user populations (included instead in the care home prevalence review).

Studies excluded on the basis of ascertainment/ outcome definition:

- 1 Studies in which the ascertainment of dementia depended upon help-seeking or receipt of dementia care services.
- 2 Studies in which 'dementia' was diagnosed purely on the basis of cognitive impairment.
- 3 Two-phase studies, in which screening procedures were clearly inadequate and two-phase methodology was not properly applied.
- 4 Studies of the prevalence of Alzheimer's disease or other single subtypes of dementia.



Final decisions on inclusion were made by a consensus of four of the report authors (DS, AMP, MG, MP) after reading the full, published version of the paper. Reference lists were also examined for potentially relevant studies. The data from UK-based studies were extracted and added to the existing dataset from the 2007 UK Dementia Report and those identified from Western Europe were used to update the 2009 World Alzheimer's Report database.

New UK and Western European studies were reviewed to see if significant new evidence was provided, such that the previous expert consensus on (a) the prevalence of early-onset dementia, and (b) the breakdown of dementia cases by subtype or severity, should be revisited. The default option in the event that significant new evidence was not identified, was for the estimates generated for the Dementia UK 2007 report to be used again.

It was decided a priori to extend the age range for the late-onset dementia estimates from 65 years and over to 60 years and over. In some European surveys, a 60-and-over cutpoint had been employed, and, as pointed out in the Dementia UK 2007 report, estimates for the 60–64 year age group were much higher when derived from direct ascertainment in such population-based surveys, than when estimated, as was the case for all early-onset dementia prevalence estimates, from all cases diagnosed by services within a defined population.

The limited information available for the previous consensus on the prevalence of dementia in care homes was also updated. The researchers searched for evidence by applying the search strategy ('Dementia' [Mesh]) AND ('Nursing Homes' [Mesh]) in PubMed, with a 2007 publication cutpoint. As before, the data presented was confined to studies carried out in the UK, given the difficulty in generalising data from other countries where types of care home and entry criteria may differ widely.

Given the paucity of relevant research, the researchers relaxed the inclusion criteria slightly to retain those studies that lacked all of the information necessary to make a robust clinical dementia diagnosis, but nevertheless attempted a classification of 'probable' or 'possible' dementia. Particular attention was given to any studies that had sought to compare the prevalence of dementia across different levels and types of care, ie extra care housing, residential care, nursing homes and Elderly Mentally Infirm (EMI) care homes (See Key facts 4 for details).

## Key facts 4: The care home context in the UK

Care homes in the UK are mainly sub-categorised into residential care homes and nursing homes.

- Residential care homes provide accommodation, food and help with personal care such as washing, dressing and eating.
- Nursing homes provide personal care but also have a qualified nurse on duty 24 hours a day, providing support for more complex health needs. Some homes that are registered for nursing care will accept people with personal care needs who may need nursing care in the future.
- Both residential care and nursing homes can be specially categorised as EMI (Elderly Mentally Infirm) homes, which provide a degree of specialised support and care for people with dementia (and/ or serious mental disorders) who have particularly complex needs for care.
- Changes in government policy and funding since the last Dementia UK report have led to the expansion of a new care sector, 'extra care housing', sometimes referred to as 'very sheltered housing' or 'housing with care'. This is social or private housing that has been modified to suit people with long-term conditions or disabilities that make living in their own home difficult, but who do not want or need to move into residential care.

### Synthesis of evidence

For the UK studies, details of excluded studies and the reason for exclusion were provided. For each of the included studies, the methodology used was summarised (including sampling technique, one- or two-phase design, sample size and response rates for each phase, screening instruments used and dementia diagnostic criteria). The researchers extracted data on prevalence, providing tables with age-specific, gender-specific and age-and-gender-specific prevalence with 95% confidence intervals where possible.

The updated Western European prevalence database (1980–2014) was subjected to quantitative meta-analysis using a random effect exponential (Poisson) model to assess the effects of age and sex on the prevalence of dementia. Random effects are assumed to have a gamma distribution – the alpha coefficient is an estimate of over-dispersion and an index of between-study heterogeneity. Age was coded as the estimated mean for each age group reported. For each region two models were run, one for the effect of age, and one for the main effects of age and sex, and an interaction between age and sex. The researchers then applied the relevant mean ages and sex codings to the coefficients estimated from the models, to estimate prevalence in five-year age bands from 60–89 years, and for those aged 90 and over, for both sexes combined (from the age-only model), and for men and women separately (from the age-and-sex model).

For the purposes of contextualisation the individual UK studies were compared with each other, and with the meta-analysed Western European prevalence, both graphically and as age-standardised prevalence (to the England and Wales population structure, 2012) for all those 65 years and over and 75 years and over. Estimations were also made from a meta-regression of the Western European data, controlling for age, gender and study design factors:

- a) The extent of any secular trends in prevalence across the region for the periods 1980–1989, 1990–1999; and 2000 and after.
- b) Any systematic effect of country, comparing prevalence recorded in other countries with that in studies conducted in the UK.

### **Phase 1 of the Delphi consensus**

In the first phase of the Delphi consensus, draft versions of the background evidence, and the questionnaires, were sent to the expert consensus panel, for review, comments and suggestions. The experts were asked to check the completeness and accuracy of the evidence as presented, its relevance to the proposed questions, and the clarity and appropriateness of the questions. Suggestions for modifications were then incorporated into final versions of the background material and questionnaires, which were then ready for circulation.

### **Phase 2 of the Delphi consensus**

Members of the expert consensus group were asked to review all of the materials provided, and provide their judgment on the following:

- a) The age- and gender-specific prevalence of dementia (in three age groups: 60–64 years, 90–94 years, and 95 years and over) in the UK population, including care home residents.
- b) As above, but only for care home residents.
- c) The total overall prevalence for those aged 60 years and over among residents of extra care housing, residential care homes, nursing homes, and elderly mentally infirm (EMI) care homes.

To ensure impartial answers were given, the experts were asked not to consult with each other before responding to these questions. They were encouraged to provide comments to explain or justify their choices, which would then be fed back in anonymised form to all experts in the next round.

### **Phase 3 of the Delphi consensus**

In the final phase of the Delphi consensus, individual estimates of the overall age- and gender- standardised prevalence (60 years and over) were calculated from the results of each expert. These estimates were then anonymised so they could not be identified by the rest of the consensus group.

From these results, the group mean of expert estimates for each age- and gender-specific prevalence column was then calculated and experts were asked to reconsider their earlier estimates in the light of group-wide choices, and any comments made. To improve the internal consistency of estimates, total prevalence within each age group was autocalculated from the gender-specific prevalences for that age group, by applying the population composition of England and Wales in 2012. The impact of any changes made, on group means for that parameter, and overall age- and gender-standardised prevalence were autocalculated and made apparent to the expert before they finalised their decisions.

### **Expert consensus group**

The expert consensus group comprised 13 senior academics (see Section 2.3 for full list), nine of whom were part of the panel for the previous 2007 Dementia UK Delphi consensus. They were asked to declare their interests before taking part in the consensus exercise. The panel comprised five epidemiologists or health researchers who had been involved in UK population-based research into dementia or cognitive ageing (Brayne, Matthews, Livingston, Stewart and Prince). Brayne and Matthews are senior investigators for the MRC CFAS studies. Four of the panel members were epidemiologists who have conducted similar research in other countries – Fratiglioni and Skoog (Sweden), Ritchie (France), and Langa (USA). Ferri and Albanese have been investigators for the 10/66 Dementia Research group studies in low- and middle-income countries ([www.alz.co.uk/1066/](http://www.alz.co.uk/1066/)), and have worked on similar global and national evidence-based syntheses. Burns and Banerjee are UK-based dementia clinical and health service researchers. Burns is the National Clinical Director for Dementia in England, and Banerjee was the Senior Professional Adviser for Older People's Mental Health at the Department of Health and co-lead for the development of the National Dementia Strategy for England (Department of Health, 2009).

### **Analysis of the Delphi results**

The mean prevalence estimate and its standard deviation were calculated for each age and gender group for Phases 2 and 3 of the Delphi Consensus process. Consensus would be demonstrated by a reduction in the spread of expert estimates around the group mean, as evidenced by a smaller range, and a reduced standard deviation. The agreement among the experts was also assessed for each parameter, and across all parameters, by calculating the intra-class correlation coefficient (ICC).

In the consensus process a value of zero indicates no agreement, and a value of one indicates a perfect agreement. If a consensus is being achieved, then the ICC will increase between phases, and move towards a value of one. A problem arises if the distribution of expert estimates in the final round is bimodal, with one sub-group selecting a much higher prevalence than the other (Green et al, 2014). Under such circumstances, the experts have effectively 'agreed to disagree', and it may not be appropriate simply to average the estimates across the two divergent groups. Otherwise, assuming that reasonable consensus has been achieved, the consensus estimate is the group mean from the final round.

## 2.3 Consensus group

Dr Emiliano Albanese, Assistant Professor in Public Mental Health, Psychiatry Department, Medical School (University of Geneva, Switzerland)

Professor Sube Banerjee, Professor of Dementia (Brighton and Sussex Medical School, UK)

Professor Carol Brayne, Professor of Public Health Medicine, Institute of Public Health (University of Cambridge, UK)

Professor Alistair Burns, Professor of Old Age Psychiatry, Institute of Brain, Behaviour and Mental Health (University of Manchester, UK)

Dr Cleusa Ferri, Senior Epidemiologist and Affiliated Professor (UNIFESP, Sao Paulo, Brazil)

Professor Laura Fratiglioni, Professor in Medical Epidemiology, Karolinska Institute (Stockholm, Sweden)

Professor Kenneth Langa, Professor Internal Medicine, Gerontology, and Health Management and Policy, Institute for Social Research and Institute of Gerontology (University of Michigan, USA)

Professor Gill Livingston, Professor of Psychiatry of Older People (University College London, UK)

Dr Fiona Matthews, Senior Research Scientist (University of Cambridge, UK)

Professor Martin Prince, Professor of Epidemiological Psychiatry, Centre for Global Mental Health, Institute of Psychiatry (King's College London, UK)

Dr Karen Ritchie, Neuropsychologist and Epidemiologist, Research Director (University of Montpellier/INSERM, France)

Professor Ingmar Skoog, Professor of Psychiatry, Institute of Neuroscience and Physiology (University of Gothenburg, Sweden)

Dr Robert Stewart, Professor of Psychiatric Epidemiology and Clinical Informatics, Department of Psychological Medicine, Institute of Psychiatry (King's College London, UK)

# The prevalence of dementia: results of the Expert Delphi Consensus

## Overview

The Dementia UK 2014 report estimates the following:

Prevalence of late-onset dementia

- The mean, age-standardised prevalence of dementia is 7.1% for the total age-standardised 65+ population (based on 2013 data).
- The current consensus estimates (male and female combined) are slightly higher than the 2007 Delphi estimates for the youngest (65–69) and oldest (90+) age bands, and slightly lower for the intermediate age groups (80–89).

Prevalence of dementia among those in care homes

- The prevalence of dementia among residents of care homes is considered, according to the consensus, to be slightly higher in women than men at all ages, and to increase in age up to age 90, falling slightly among the oldest old.
- The prevalence of dementia among care home residents is higher in the current consensus than in 2007, for all categories of care home combined, in every age group, and in each type of care setting.

Prevalence of early-onset dementia

- For early-onset dementia, as with late-onset dementia, the consensus is that prevalence increases exponentially with increasing age, roughly doubling every five years.

Prevalence among black, Asian and minority ethnic groups

- Estimations of prevalence among individual ethnics groups do not exist. With an increasingly diverse ethnic population in the UK, more epidemiological research is urgently required to clarify dementia prevalence and risk among black, Asian and minority ethnic groups.

Severity

- The proportions of dementia severity among people with late-onset dementia are as follows:
  - 55.4% have mild dementia
  - 32.1% have moderate dementia
  - 12.5% have severe dementia

Type

- The proportions of subtype of dementia are:

• Alzheimer's disease	62%
• Vascular dementia	17%
• Mixed dementia	10%
• Dementia with Lewy bodies	4%
• Frontotemporal dementia	2%
• Parkinson's dementia	2%
• Other	3%
- With the current poverty of data on the prevalence of dementia across Europe, the Delphi consensus process is the best option for estimating the prevalence of dementia in the UK, however the process is not without flaws. In the future, a quantitative survey of the prevalence of dementia would be preferable.
- The deficiencies in the evidence-base that are apparent in this process need to be addressed as they impose significant limitations on the interpretation of the results.

### 3.1 Context: the prevalence of dementia in Europe

Before the collected studies could be evaluated by the panel of experts, the heterogeneity of dementia prevalence between European studies was assessed. Factors such as age composition, study design, the year the study took place, and the country of origin were evaluated and controlled for. Study design and country made the largest independent contributions, and overall heterogeneity was greatly diminished when these factors were controlled for.

## A systematic review of the European studies

The search (see Chapter 2) identified 712 publications of work carried out in Europe. Following a review of abstracts, the full, published versions of 16 papers were reviewed. Two were excluded as ineligible – one because only estimates of Alzheimer’s disease prevalence were provided (Afgin et al, 2012), and one because prevalence estimates were derived from survivors from previous prevalence surveys (Virues-Ortega et al, 2011). Six of the 14 remaining eligible studies could not be included in the meta-analysis, since age-specific prevalence estimates were not provided, or only single-age groups were studied (Spada et al, 2009; Scafato et al, 2010; Dimitrov et al, 2012; De Deyn et al, 2011; Mathillas et al, 2011; Adelman et al, 2011). Thus, eight additional studies (four from Spain, two from Italy, and one each from Portugal and the UK) could be included in the updated meta-analysis (Table 3.1).

In these studies 15,447 older persons were surveyed, half of these (7,796) were recruited in the UK MRC Cognitive Function and Ageing Study (CFAS II) (Matthews et al, 2013). All but one of the studies (Nunes et al, 2010) explicitly included residents of care homes. The quality of the included studies was generally moderate to poor. Notably, none of the five two-phase studies were both implemented and analysed in an unbiased fashion.

**Table 3.1: New studies on the prevalence of dementia in Western Europe since the 2009 World Alzheimer Report.**

Author, publication year	Country	Setting	Survey year	Achieved Sample size	Design	Response rate (%)	Quality score (centile)
Gavrilá, 2009	Spain	Murcia	2004	1,074	2-phase	72	7 (40th)
Nunes, 2010	Portugal	Arouca (rural) and Sao João da Madeira (urban)	2003	1,146	2-phase	53	2 (5th)
Lucca, 2011	Italy	Monzino	2005	1,842	1-phase	75	9.5 (93rd)
Rodriguez-Sanchez, 2011	Spain	Salamanca	2009	327	1-phase	68	4.5 (17th)
Bernardi, 2012	Italy	Biv, Calabria	2004	509	2-phase	73	3 (8th)
Matthews, 2013	UK	Cambridgeshire, Newcastle and Nottingham	2009	7,796	1-phase	56	6 (23rd)
Tola- Arribas, 2013	Spain	Valladolid	2009	2,170	2-phase	79	7.5 (55th)
Bufill, 2009	Spain	Manlleu	1997	583	2-phase	77	4 (13th)



## Meta-analysis of the prevalence of dementia in Western Europe

With the 52 studies included in the earlier meta-analysis (Prince et al, 2013), the updated data set comprised 60 prevalence studies from 15 Western European countries. Of these studies, 13 were completed in the 1980s, 36 in the 1990s, and 11 from 2000 onwards. While the quality of prevalence studies has been improving globally (Prince et al, 2013), the same trend is not observable in Europe, with mean quality scores of 7.1 (SD 3.4) for studies completed in the 1980s, 7.5 (SD 1.7) for studies completed in the 1990s, and 6.4 (SD 2.4) for studies completed in the 2000s (weighted test for linear trend  $F=0.4$ ,  $p=0.53$ ).

The updated meta-analysed estimates of prevalence are slightly lower than those for the 2009 World Alzheimer Report (Table 3.2). There is substantial heterogeneity of estimates among the 60 studies.

**Table 3.2: Meta-analysed estimates of prevalence in Western Europe: comparison between the 2009 World Alzheimer Report and updated meta-analysis, including studies published up to 2014**

Source	Gender	Age range						
		60–64	65–69	70–74	75–79	80–84	85–89	90+
<b>World Alzheimer Report, 2009</b>	Male	1.4	2.3	3.7	6.3	10.6	17.3	33.3
	Female	1.9	3.0	5.0	8.6	14.8	48.5	48.5
	All	1.5	2.5	4.2	7.3	12.7	21.5	42.7
<b>Updated to include 2009–2014 studies</b>	Male	1.4	2.3	3.7	6.2	10.4	17.0	32.4
	Female	1.8	2.9	4.8	8.4	14.4	24.1	47.4
	All	1.6	2.5	4.2	7.2	12.4	20.7	40.7

## The impact of age composition and study design on prevalence estimates

Age composition is an important driver of prevalence, but study design factors also seem to be important. Those studies that included a multidimensional cognitive test battery or that did not specify if care home residents were included in community sampling tended to record a higher prevalence. Those studies that included a structured disability assessment recorded a lower prevalence of dementia. There was no independent effect of inclusion of informant interviews on recorded prevalence. There was a complex effect of study design (one versus two phases, correctly or incorrectly applied) upon prevalence. In general, studies that used one-phase designs tended to record a lower prevalence, though it does not reach conventional statistical significance. There was no clear trend for change in prevalence over time (see Table 3.3).

**Table 3.3: Factors associated with prevalence in meta-regression of Western European studies (n=59)**

<b>Exposure</b>	<b>Prevalence</b>
<b>Stratum characteristic</b>	
Age (per year)	1.12 (1.11–1.12)
<b>Study characteristic</b>	
<b>Sampling</b>	
Care homes not specifically included in sampling	1.68 (1.31–2.14)
<b>Assessment</b>	
Multidimensional cognitive test battery	1.46 (1.17–1.82)
Structured assessment of disability	0.78 (0.61–0.99)
<b>Design</b>	
Two-phase with no screen negatives sampled	1 (REF)
Two-phase with screen negatives sampled but no weighting back	1.22 (0.90–1.65)
Two-phase correctly applied	0.97 (0.76–1.25)
One-phase	0.86 (0.71–1.05)
<b>Period of survey</b>	
1980–1989	1 (REF)
1990–1999	1.38 (1.11–1.72)
After 2000	0.99 (0.76–1.30)
<b>Year of survey as linear effect (as alternative to decennial periods above)</b>	
Per calendar year	0.986 (0.971–1.002)

### **Impact of the study’s country of origin on estimates of prevalence**

Having controlled for all of these factors (age, year of survey and design factors (cognitive battery, structured disability assessment, and one- or two-phase study)) the effect of the country in which the survey was conducted upon prevalence was evaluated by researchers, using the UK as the reference category (Table 3.4).

This analysis revealed that three European countries recorded a lower prevalence than the UK (Italy, Sweden and the Netherlands), while nine countries recorded a higher prevalence than the UK (Germany, Israel, San Marino, Spain, France, Denmark, Finland, Norway and Belgium). While it seems clear that UK prevalence is a little lower than that in most other European countries, there was no clear regional or cultural pattern in the prevalence of dementia across Europe.

**Table 3.4: The effect of country upon the prevalence of dementia in Western Europe (n=59)**

<b>Country</b>	<b>Adjusted prevalence ratio</b>
<b>Italy</b>	0.80 (0.59–1.10)
<b>Sweden</b>	0.87 (0.62–1.23)
<b>Netherlands</b>	0.95 (0.65–1.38)
<b>UK</b>	
<b>Germany</b>	1.17 (0.82–1.67)
<b>Israel</b>	1.28 (0.79–2.09)
<b>San Marino</b>	1.36 (0.68–2.72)
<b>Spain</b>	1.48 (1.07–2.05)
<b>France</b>	1.54 (0.85–2.76)
<b>Denmark</b>	1.57 (0.93–2.65)
<b>Finland</b>	1.95 (1.00–3.82)
<b>Norway</b>	2.19 (1.18–4.06)
<b>Belgium</b>	2.82 (1.53–5.12)

### **Other European evidence: the European Collaboration on Dementia and the Alzheimer Cooperative Valuation in Europe**

Two European collaborations have synthesised evidence on the prevalence of dementia across Europe: the European Collaboration on Dementia (EuroCoDe) and the Alzheimer Cooperative Valuation in Europe (ALCOVE) (EuroCoDe, 2009; Galeotti et al, 2013). EuroCoDe covered the period 1990–2008 and ALCOVE the period 2008–2011. ALCOVE then merged these studies with selected studies identified in EuroCoDe. Both studies used robust search strategies. Inclusion criteria were more restrictive than those used for the updated Western Europe meta-analysis for this report (see Chapter 2).

Included studies followed certain criteria: they were community-based; had at least 300 participants; used standardised diagnostic criteria; had a participation rate over 50%; and published or provided on request raw prevalence data for pre-specified age groups, suitable for a pooled analysis in which numerators and denominators were simply summed across all studies. These inclusion criteria meant that a much smaller number of studies were included; 17 in EuroCoDe, and 12 in ALCOVE versus the 60 included in this study’s meta-analysis. All of the UK studies identified in the updated review were excluded from EuroCoDe, either because they were conducted before 1990, or were not considered to have used standardised clinical criteria.

In EuroCoDe, the total population age-specific prevalence of dementia were estimated at: 0.6% for 60–64 years, 1.6% for 65–69 years, 3.5% for 70–74 years, 7.4 for 75–79 years, 15.7% for 80–84 years, 26.2% for 85–89 years, 41.0% for 90–94 years, and 46.3% for those aged 95 years and over (EuroCoDe, 2009). While in ALCOVE, the overall prevalence for people aged 60 and over was estimated at 6.5% (8.2% for 65 years and over). Then, a pooled analysis of studies included in EuroCoDe and ALCOVE that followed the DSM-IV criteria and obtained a high-quality score (>7) was performed. The last pooled analysis including only seven high-quality studies using the DSM-IV criteria (three from EuroCoDe and four from ALCOVE) estimated an overall prevalence of dementia at 7.2% for people aged 65 years and over (Galeotti et al, 2013).

In ALCOVE (Galeotti et al, 2013), this systematic review was updated to include new published studies covering the period between the 1 January 2008 and the 15 September 2011, which identified 14 further studies. This latest systematic review assessed the same quality criteria as that in the 2009 World Alzheimer Report with an additional inclusion criterion on the clinical criteria for dementia adopted, suggested in a paper from Erkinjuntti (1997), leaving 12 studies on late-onset dementia included in the analysis.

The restrictive inclusion criteria used in the EuroCoDe and ALCOVE reports persuaded the researchers to favour the meta-analysed figures for Western Europe when contextualising regional data for the Delphi consensus group.

### 3.2 Population prevalence of late-onset dementia in the UK

#### Evidence base

Since the previous (2007) Dementia UK report Delphi consensus on the prevalence of late-onset dementia, only two further population-based studies were identified: the CFAS II study conducted in Cambridgeshire, Newcastle and Nottingham between 2008 and 2011 (Matthews et al, 2013), and a small study comparing prevalence of dementia among white British people and those of African- Caribbean ancestry aged 60 years and over registered in five primary care practices in North London (Adelman et al, 2011). These were added to the six earlier eligible population-based studies (O'Connor et al, 1989; Brayne and Calloway, 1989; Livingston et al, 1991; Clarke et al, 1991; MRC CFAS, 1993; Saunders et al, 1993).

Four of the eligible studies were conducted in the 1980s, two in the early 1990s, and the MRC CFAS II study and the North London study in the late 2000s (see Table 3.5). There were no exclusions other than those reported for the previous systematic review for the Dementia UK 2007 report – two UK population-based prevalence 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, 2002). The researchers found no further relevant UK evidence on the prevalence of early-onset dementia, and no further studies reporting on the severity of dementia, or dementia subtype.

**Table 3.5: UK population-based studies of late-onset dementia**

Study	Setting (area)	Sampling	Design (screening instrument)	Number and proportion responding		Dementia diagnostic criteria
				Phase 1	Phase 2	
<b>O'Connor et al (1989)</b>	Cambridge City	All aged 75+. GP registers.	Two-phase (MMSE)	2,311 (90%)	481 (82%)	CAMDEX dementia
<b>Brayne and Calloway (1989)</b>	East Cambridgeshire	Women aged 70– 79. GP registers.	One-phase	365 (89%)		CAMDEX dementia
<b>Livingston et al (1990)</b>	Gospel Oak, London	All women 60+ and men 65+. Door knocked register.	Two-phase (SHORT- CARE)	813 (87%)	48 (80%)	Clinical dementia diagnosis guided by GMS
<b>Clarke et al (1991)</b>	Melton Mowbray	All aged 75+. GP registers.	Two-phase (MMSE)	1,579 (83%)	438 (84%)	CAMDEX
<b>Saunders et al (1993)</b>	Liverpool (linked to MRC CFAS I)	All aged 65+. GP registers. Oversampling of oldest old.	One-phase	5,222 (87%)		GMS/AGECAT 'organic' case
<b>MRC CFAS I (MRC CFAS, 1998)</b>	Cambridgeshire, Gwynedd, Newcastle, Nottingham and Oxford	All aged 65+. GP registers. Over- sampling of 75+	Two-phase (GMS/AGECAT organicity, MMSE and age)	13,009 (80%)	2,622 (83%)	GMS/AGECAT 'organic' case
<b>MRC CFAS II (Matthews et al, 2013)</b>	Cambridgeshire, Newcastle and Nottingham	Aged 65 and over. GP registers. Oversampling of 75+	One-phase	7796 (56%)		GMS/AGECAT 'organic' case

## **Key facts 5: The Medical Research Council Cognitive Function and Ageing Study (MRC CFAS) surveys**

In terms of sample size, scope and recency, the UK evidence base for dementia prevalence is dominated by the MRC Cognitive Function and Ageing Studies. These studies were set up specifically to provide generalisable estimates of dementia prevalence for policy-making and planning, with funding from the Medical Research Council and the UK Department of Health.

### **MRC CFAS I**

Field work was carried out in urban (Liverpool, Newcastle, Nottingham, Oxford) and rural (Cambridgeshire and Gwynedd) settings. The Liverpool MRC ALPHA study preceded the other CFAS I sites but used a broadly similar design for sampling and dementia ascertainment; however, a one-phase rather than a two-phase approach was used for dementia diagnosis, with all participants administered the full Geriatric Mental State (GMS).

### **MRC CFAS II**

The studies were conducted in Cambridgeshire, Newcastle and Nottingham (completed and published in Matthews et al, 2013), and Gwynedd and Neath, Port Talbot (still to report). The study design was almost identical to the CFAS I studies; however, as in the Liverpool MRC ALPHA study a one-phase diagnostic approach was used (ie all participants underwent an identical dementia ascertainment protocol, without pre-screening).

As well as the MRC CFAS studies (see Key facts 5), other eligible surveys were limited by their relatively small sample size (Brayne and Calloway, 1989; Livingston et al, 1990; Lindsay, 1990), or because only the oldest old (O'Connor et al, 1989; Brayne and Calloway, 1989; Clarke, 1991) or women were sampled (Brayne and Calloway, 1989). These studies sampled from much smaller single catchment areas in Cambridge, rural Cambridgeshire, London, and Melton Mowbray.

Other than the Liverpool MRC ALPHA study and the MRC CFAS II studies, all other studies used two-phase designs with an initial screening assessment, followed by a second-phase definitive diagnostic assessment usually based on clinical consensus. In contrast to the generally incorrect application of these study designs, in all but two of the UK two-phase studies (Livingston et al, 1990; Lindsay, 1990), screen negatives were also sampled and weighting back was carried out appropriately, to account for possible under-estimation. All of the population-based studies included older people living in care homes within the study catchment areas, and in their estimates of community prevalence. Only the MRC CFAS study further reported prevalence stratified according to residential status (care homes vs private residences) (Matthews et al, 2002).

The dementia diagnostic outcome for the earlier surveys 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 are made using an algorithm that maps quite closely to the clinical ICD-10 criteria (American Psychiatric Association, 2003).

MRC CFAS I (including Liverpool MRC ALPHA) and MRC CFAS II used the GMS (Geriatric Mental State) and its AGE-CAT computerised algorithm to generate diagnoses. GMS does not cover all of the standard criteria required for a clinical dementia diagnosis (lacking multidimensional cognitive test batteries and informant interview) but has nevertheless been validated against various DSM (Diagnostic and Statistical Manual of Mental Disorders) dementia criteria (Ames and Tuckwell, 1994; Copeland et al, 1990; Schaub et al, 2003). The full CFAS interview did include these features, but these data were not used to generate the majority of diagnoses.

The identical sampling and similar dementia ascertainment methodology between MRC CFAS I and II in Nottingham, Cambridgeshire, and Newcastle created an opportunity to compare prevalence between the early 1990s (1990–1993) and late 2000s (2008–2011). Standardised for UK age structure, prevalence was higher in both genders, particularly men, and overall in CFAS I than CFAS II – CFAS I 8.3% (95% CI 7.0–9.6%); CFAS II 6.5% (95% CI 5.9–7.0). Comparison of standardised prevalence across time showed a substantial decrease in prevalence of dementia (CFAS II vs. CFAS I 0.7, 95% CI 0.6–0.9,  $p=0.003$ , adjusted for age, sex, area, and deprivation status).

The age- and gender-specific prevalence of dementia from CFAS I and II, and the other UK studies is summarised in Figure 3.1 (men) and Figure 3.2 (women).

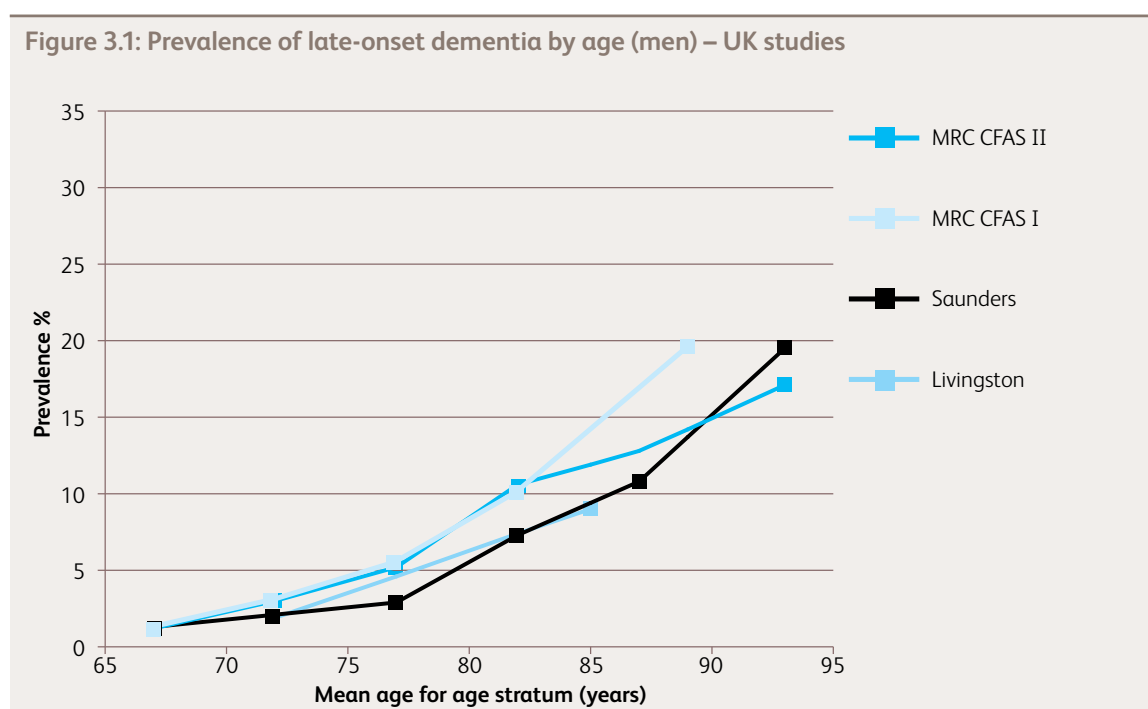
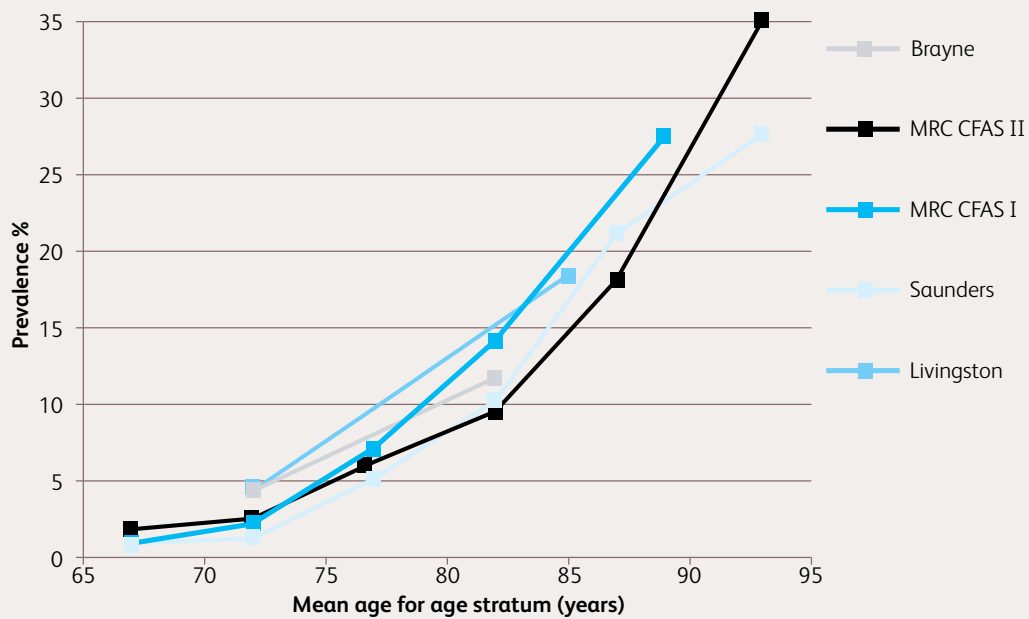


Figure 3.2: Prevalence of dementia by age (women) – UK studies



The prevalence estimates from the UK studies were compared with each other, and contextualised with the Dementia UK 2007 Delphi consensus, and with the Western European meta-analysis, using age-standardization to facilitate the comparison (Table 3.6).

Table 3.6: Age-standardised prevalence of late-onset dementia in UK population-based studies, 2007 Dementia UK Delphi consensus and updated Western Europe meta-analysis

Study/ source	Standardised prevalence (%) age 65 years and over	Standardised prevalence (%) age 75 years and over
O'Connor et al (1989)	-	12.0
Clarke et al (1991)	-	18.1
Liverpool MRC ALPHA (Saunders et al, 1997)	5.3	9.8
MRC CFAS I (1998)	7.5	13.8
MRC CFAS II (Matthews et al, 2013)	6.4	11.5
<b>Contextualiation</b>		
Dementia UK Delphi consensus (2007)	7.1	13.0
World Alzheimer Report (Western Europe region) updated to include studies published 2009–2014	8.6	14.8



## The Delphi consensus estimates for the prevalence of late-onset dementia

Both the range and the standard deviation of the estimates of the prevalence of late-onset dementia provided by the expert consensus group converged between the first and second rounds of the Delphi consensus.

Standard deviations ranged between 0.5% (age 60–64) and 7.3% (95+) in the first round, falling to 0.3% and 5.0% respectively in the second round. While the mean age-standardised prevalence (age 65 and over) remained the same between the two rounds (7.1%), the standard deviation of those estimates declined from 0.7% to 0.5%, and the range narrowed from 6.0–8.5% in the first round to 6.3–8.1% in the second round.

Although the overall level of agreement among respondents was already high in the first round (intra-class correlation coefficient = 0.93) this improved to 0.97 for the second round. Levels of agreement also improved for each age band (data not shown). As such, according to conventional criteria, the researchers considered that the Delphi approach had been successful in generating a consensus and that no further rounds were indicated.

The means of the age- and gender-specific prevalence rates for late-onset dementia from the expert consensus group are given in Table 3.7, and compared with those generated for the previous Dementia UK 2007 consensus exercise.

**Table 3.7: The consensus estimates of the population prevalence (%) of late-onset dementia**

Care setting	Previous estimates (Dementia UK 2007)			Current estimates (Dementia UK 2014)		
	Female	Male	Total	Female	Male	Total
<b>Age in years</b>						
<b>60–64</b>	(0.1)*	(0.2)*	(0.2)*	0.9	0.9	0.9
<b>65–69</b>	1.0	1.5	1.3	1.8	1.5	1.7
<b>70–74</b>	2.4	3.1	2.9	3.0	3.1	3.0
<b>75–79</b>	6.5	5.1	5.9	6.6	5.3	6.0
<b>80–84</b>	13.3	10.2	12.2	11.7	10.3	11.1
<b>85–89</b>	22.2	16.7	20.3	20.2	15.1	18.3
<b>90–94</b>	29.6	27.5	28.6	33.0	22.6	29.9
<b>95+</b>	34.4	30.0	32.5	44.2	28.8	41.1

\*In the Dementia UK 2007 report, the prevalence of dementia among those aged 60–64 was estimated as part of the early-onset dementia consensus. Since the prevalence of early-onset dementia is likely to be systematically underestimated (case ascertainment relies upon service contact), for the current exercise the prevalence in this age group was estimated as part of the late-onset dementia consensus. While no UK surveys provide estimates for this age group, some European studies do (see Section 3.4 on early-onset dementia).

The current consensus estimates (male and female combined) are slightly higher than the previous Delphi estimates for the youngest (65 to 69) and oldest (90+) age bands, and slightly lower for the intermediate age groups (80–89). The higher prevalence among women in older age groups is more marked in the current estimates.

In Table 3.8 the current Delphi consensus estimates are contextualised, after age-standardisation with the previous Dementia UK 2007 estimates, those from the two UK MRC CFAS studies and the updated Western Europe meta-analysis.

**Table 3.8: Comparison of current consensus estimates for the prevalence (%) of late-onset dementia with estimates from previous literature reviews and key surveys**

Age in years	60–64	65–69	70–74	75–79	80–84	85–89	90–94	95+	Age standardised 65+
<b>Current UK consensus</b>	0.9	1.7	3.0	6.0	11.1	18.3	29.9	41.1	7.1
<b>MRC CFAS I</b>	-	1.5	2.6	6.3	13	25.3	25.3	25.3	7.5
<b>MRC CFAS II</b>	-	1.5	2.7	5.7	10.0	16.1	30.1	30.1	6.4
<b>Updated World Alzheimer’s Report (Western Europe)</b>	1.6	2.5	4.2	7.2	12.4	20.7	40.7	40.7	8.6
<b>Dementia UK 2007 report</b>	-	1.3	2.9	5.9	12.2	20.3	28.6	32.5	7.1

It can be seen that, overall, the age-standardised population prevalence for those aged 65 years and over was similar in both Delphi consensus exercises (7.1%). This age-standardised prevalence is intermediate between that estimated in the MRC CFAS I (7.5%) and MRC CFAS II (6.4%) studies, but substantially lower than that indicated by the West Europe region meta-analysis (8.6%).

### 3.3 The prevalence of dementia among those living in care homes

#### Evidence base

Limited information was available for the previous consensus on the prevalence of dementia in care homes. As before, the data presented are confined to studies carried out in the UK, given the difficulty in generalising data from other countries where types of care home and entry criteria may differ widely.

The only age- and gender-specific estimates of the prevalence of dementia in UK care homes come from the MRC CFAS studies (Table 3.9), the data from CFAS I (Matthews et al, 2002) now supplemented by the more recent CFAS II study conducted in Cambridgeshire, Newcastle and Nottingham between 2008 and 2011 (Matthews et al, 2013). To facilitate

comparison, estimates from the original CFAS I study for all five centres (Cambridgeshire, Gwynedd, Newcastle, Nottingham and Oxford) were provided and also limited to the three CFAS II sites. The like-for-like comparisons between CFAS I and CFAS II indicate that while the proportion of all older people residing in care homes has decreased from the early 1990s to the late 2000s (from 5% to 3%), the prevalence of dementia among them seems to have increased, from 56% to 70%. In the three CFAS sites included in both CFAS I and CFAS II, the proportion of all people with dementia living in care homes decreased from 34% to 29%.

**Table 3.9: Studies on the prevalence of dementia in care homes**

<b>Study</b>	<b>Setting</b>	<b>Total population</b>	<b>Case ascertainment</b>
<b>MRC CFAS I (Matthews et al, 2002)</b>	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.
<b>MRC CFAS II (Matthews et al, 2013)</b>	All MRC CFAS II participants (aged 65 years and over) living in institutional care establishments in the three catchment area sites (Cambridgeshire, Newcastle and Nottingham).	197	One-phase survey; case ascertainment similar to that of MRC CFAS I.

The evidence base on the prevalence of dementia in different UK care home settings has expanded since the last consensus (Table 3.10). Such estimates are now available for non-EMI nursing homes (Macdonald et al, 2002); Council (ie local government-run) residential care homes, private residential care homes and nursing homes (CFAS I) (Matthews et al, 2002); residential care, nursing care and EMI care homes (Stewart et al, 2014); and extra care housing, residential care homes, and nursing homes (Darton et al 2012). None of these estimates are age- or gender-stratified. Given the improved evidence base, the BUPA homes survey data that was used to inform the earlier consensus have been excluded (Bowman et al, 2004) since in that survey dementia ascertainment was based upon ‘reason for admission’ only.

**Table 3.10: Studies on the total prevalence of dementia in different UK care settings**

Study characteristics				Prevalence estimates			
Study	Type of care setting	Total population	Case ascertainment	Extra care	Residential care	Nursing home	EMI care home
<b>Matthews et al (2002)</b>	Included those living in council residential care homes, private residential care homes and nursing homes.	571	Two-phase survey; screening using GMS/AGECAT organicity, MMSE and age to screen, and definitive diagnosis using GMS/AGECAT.	N/A	51.0% (council) 58.0% (private)	72.0%	N/A
<b>Macdonald et al (2002)</b>	Probability sample of residents in a probability sample of non-EMI nursing homes in south-east England.	445 (phase 1) 61 (phase 2)	Two-phase survey; screening using MMSE and definitive diagnosis using GMS/AGECAT.	N/A	N/A	74.0%	N/A
<b>Darton et al (2012)</b>	Residents of 19 extra care housing schemes opening between 2006–2007 and residents of care homes opening in 2005.	609 extra care and 409 care home residents	One-phase survey; cognitive impairment assessed using Minimum Data Set Cognitive Performance Scale; dementia case ascertainment based on moderately severe to very severe cognitive impairment.	3.1%	39.5%	54.0%	N/A
<b>Stewart et al (2014)</b>	All residents residing in a random sample of 15 care homes (of 25 approached) in four boroughs of south-east London.	301	Consensus clinical dementia diagnoses were made using DSM-IV criteria from a range of information collected by research workers.	N/A	55.8%	77.0%	91.0%

Given the evidence, the consensus group were asked, as before in the Dementia UK 2007 report consensus, to estimate the age- and gender-specific prevalence of dementia for residents of care homes in general (comprising residential care homes, nursing homes, and EMI care homes). For the estimates of prevalence of dementia in different categories of care home, the additional category of 'extra care housing' was included.

### **The Delphi consensus on the prevalence of dementia in care homes**

For each mean age- and gender-specific estimate of the prevalence of dementia in care homes in general, the standard deviation and range reduced between the two rounds of the Delphi consensus. The standard deviation for the overall prevalence reduced from 4.3% to 3.8%, and the range from 62.9–77.0% to 64.0–72.0%. The overall intra-correlation coefficient for those estimates increased from 0.29 to 0.60, showing an improved level of agreement between the experts at the end of the Delphi consensus process.

Similar patterns were observed when analysing the results of the Delphi process on the prevalence of dementia in each care setting: ranges and standard deviations (in brackets) reduced from 48.0–70.0% (7.2%) to 50.0–65.0% (5.6%) for residential care, from 65.0–80.0% (4.3%) to 65.0–77.0% (3.6%) for nursing home, and from 80.0%–91.0% (3.0%) to 89.0–91.0% (0.7%) for EMI care homes.

However, although convergence occurred for the estimates of the prevalence of dementia in extra care housing – ranges and standard deviations reducing from 2.5–55.0% (21.8%) to 2.5–25.0% (7.0%) – true consensus was not achieved. While the majority of experts considered the prevalence to be close to that observed in the one study conducted (3.0%), two selected a prevalence close to the eventual mean of 8.1% and two others a substantially higher prevalence (14.0% and 25.0%). Therefore, the mean consensus estimate should be treated with considerable caution.

The prevalence of dementia among residents of care homes was considered, according to the consensus, to be slightly higher in women than men at all ages, and to increase in age up to age 90, falling slightly among the oldest old (Table 3.11). The total prevalence of dementia in care homes was estimated by the consensus at 69.0% (62.7% for males and 71.2% for females).

**Table 3.11: The mean consensus estimates of the prevalence (%) of dementia among residents of care homes**

Age in years	Female	Male	Total
60–64	53.6	43.0	51.7
65–69	65.5	48.3	58.7
70–74	69.9	54.2	65.0
75–79	70.6	60.4	67.5
80–84	71.4	65.6	69.9
85–89	73.5	67.8	72.7
90–94	74.3	70.4	73.3
95+	71.8	68.2	70.4

The reduced proportion of older people and people with dementia living in care homes may relate to the effects of government policy (direct grants to local government) to promote the development of the additional category of ‘extra care housing’. Therefore, when looking at the effect of level of care upon prevalence of dementia, the panel were asked to estimate, using the evidence provided, the prevalence of dementia among those aged 60 and over residing in extra care housing – as well as those living in residential care homes, nursing homes and EMI homes (Table 3.12). Only one study estimated the prevalence of dementia in extra care housing, and did so at a figure of 3.1% (Darton et al, 2012).

**Table 3.12: The mean consensus estimates of the prevalence (%) of dementia in different care settings**

Care setting	Female	Male	Total
Extra care housing	8.8	7.9	8.1**
Residential homes	62.1	52.7	57.9
Nursing homes	75.8	67.8	73.0
EMI care homes	90.6	86.7	90.1
Average across all settings	71.2	62.7	69

\*\*Consensus not achieved – therefore this estimate should be treated with caution.

The prevalence of dementia among care home residents was higher in the current consensus than in 2007, for all categories of care home combined in every age group, and in each type of care setting (Table 3.13).

**Table 3.13: Comparison of the mean consensus estimates of the prevalence (%) of dementia in the different care settings**

Care setting	Previous estimates (Dementia UK 2007)	Current estimates (Dementia UK 2014)
<b>All categories of care home, by age</b>		
<b>60–64</b>	Not estimated	51.7
<b>65–69</b>	55.1	58.7
<b>70–74</b>	55.4	65.0
<b>75–79</b>	57.9	67.5
<b>80–84</b>	61.6	69.9
<b>85–89</b>	62.9	72.7
<b>90–94</b>	63.9	73.3
<b>95+</b>	66.4	70.4
<b>Specific categories of care home (all ages combined)</b>		
<b>Extra care housing</b>	Not estimated	8.1**
<b>Residential homes</b>	50.1	57.9
<b>Nursing homes</b>	66.2	73.0
<b>EMI homes</b>	79.9	90.1

\*\*Consensus not achieved – therefore this estimate should be treated with some caution.

### 3.4 The population prevalence of early-onset dementia

The 2014 Dementia UK survey did not identify any further UK studies on the prevalence of early-onset dementia (defined as age less than 65 years), and therefore uses the estimates developed for the Dementia UK 2007 report (Table 3.14). These were derived from two studies (Ratnavalli et al, 2002; Harvey et al, 2003) in which the prevalence was 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 and are identified by services 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 early-onset dementia.

**Table 3.14: The Dementia UK 2007 consensus estimates of the population prevalence (per 100,000) of early-onset dementia**

Age in years	Female	Male	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)*

\* Not used in this report – see also Section 3.2 Population prevalence of late-onset dementia in the UK.

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, a discontinuity was noted in this smooth exponential increase, in that the prevalence for people aged 60–64 years was 156/100,000 (0.16%), whereas the prevalence for the next five-year age band (those aged 65–69) was nearly nine times higher. This was considered to be an artefact due to the underestimation of the prevalence in early-onset studies using service contact as the method of case ascertainment. For this reason, for the current report, the prevalence estimates for the 60–64 year age group were estimated as part of the late-onset dementia Delphi consensus.

### 3.5 The prevalence of dementia among black, Asian and minority ethnic groups

In the Dementia UK 2007 report, it was noted that there were very few estimates of the prevalence of dementia in minority ethnic groups in the UK, all of them based on small samples. In the absence of clear indications to the contrary, it was therefore assumed that prevalence would be the same as for the UK population as a whole.

A new study from North London does suggest a somewhat higher prevalence of dementia among people of African-Caribbean country of birth than among white UK-born people (Adelman et al, 2011). 218 people of African-Caribbean country of birth and 218 white UK-born people aged 60 years and over were recruited from five general practices. A two-phase design was applied, using different culture-specific screening assessments (standard Mini Mental State Examination for white British and modified MMSE for African-Caribbean group, and the same cutpoint of <26 for each group). Response rates were relatively poor – 76% of 666 approached could be contacted, of whom 66% completed screening, and 90% completed phase-2 assessment. Screen negatives were not assessed in phase 2. The prevalence of dementia (meeting either ICD-10 and/or DSM-IV dementia criteria) was 6.9% (95% CI 3.6–10.2) among white UK-born and 9.6% (95% CI 5.7–13.5) among African-Caribbean born participants. The crude prevalence difference



(African-Caribbean vs. white British) was not statistically significant (OR 1.44, 95% CI 0.72–2.88) but became so after adjusting for age and socio-economic status (OR 3.07, 95% CI 1.28–7.32). These findings are consistent with non-statistically significant trends reported in two other studies (Richards et al, 2000; McCracken et al, 1997).

More epidemiological research is required to clarify dementia prevalence and risk among black, Asian and minority ethnic groups. Risk factors for dementia, including hypertension, diabetes, stroke and heart disease, are consistently elevated in several black, Asian and minority ethnic groups (NHS Health and Social Care Information Centre, 2005). Given that the evidence is still sparse, the assumption has been that the prevalence of dementia is the same among all ethnic groups in the UK. This may not be correct, at least for some black ethnicities. The likely effect would have been to underestimate numbers of people with dementia.

In England, the proportion of those aged 65 and over who had a non-white British (black or other minority ethnic) origin increased from 6.7% in 2001 to 8.4% by 2009. Numbers of Asian or mixed ethnicity elders increased from 120,800 to 189,500 (2.3% of all those aged 65 and over), and numbers of those with black or mixed ethnicity increased from 74,600 to 111,200 (1.3% of all those aged 65 years and over). If the prevalence of dementia in the latter group was double that in white British and other ethnic groups, then the total numbers of people with dementia in the UK would have been around 7,900 higher.

### 3.6 Severity of dementia

The researchers did not identify any further UK evidence on the distribution of dementia by severity, and have therefore used the estimates developed for the Dementia UK 2007 report. In that report the consensus estimates were based upon findings from three population-based studies of late-onset dementia (O'Connor et al, 1989; Brayne et al, 1989; Clarke et al, 1991). These provided limited data on severity by age, but not by gender and used CAMDEX severity ratings (mild, moderate and severe – roughly equivalent to the same categories in CDR). None of the studies of early-onset dementia, or of dementia in institutions, include estimates of prevalence by severity. 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.

Among people with late-onset dementia:

- 55.4% have mild dementia
- 32.1% have moderate dementia
- 12.5% have severe dementia

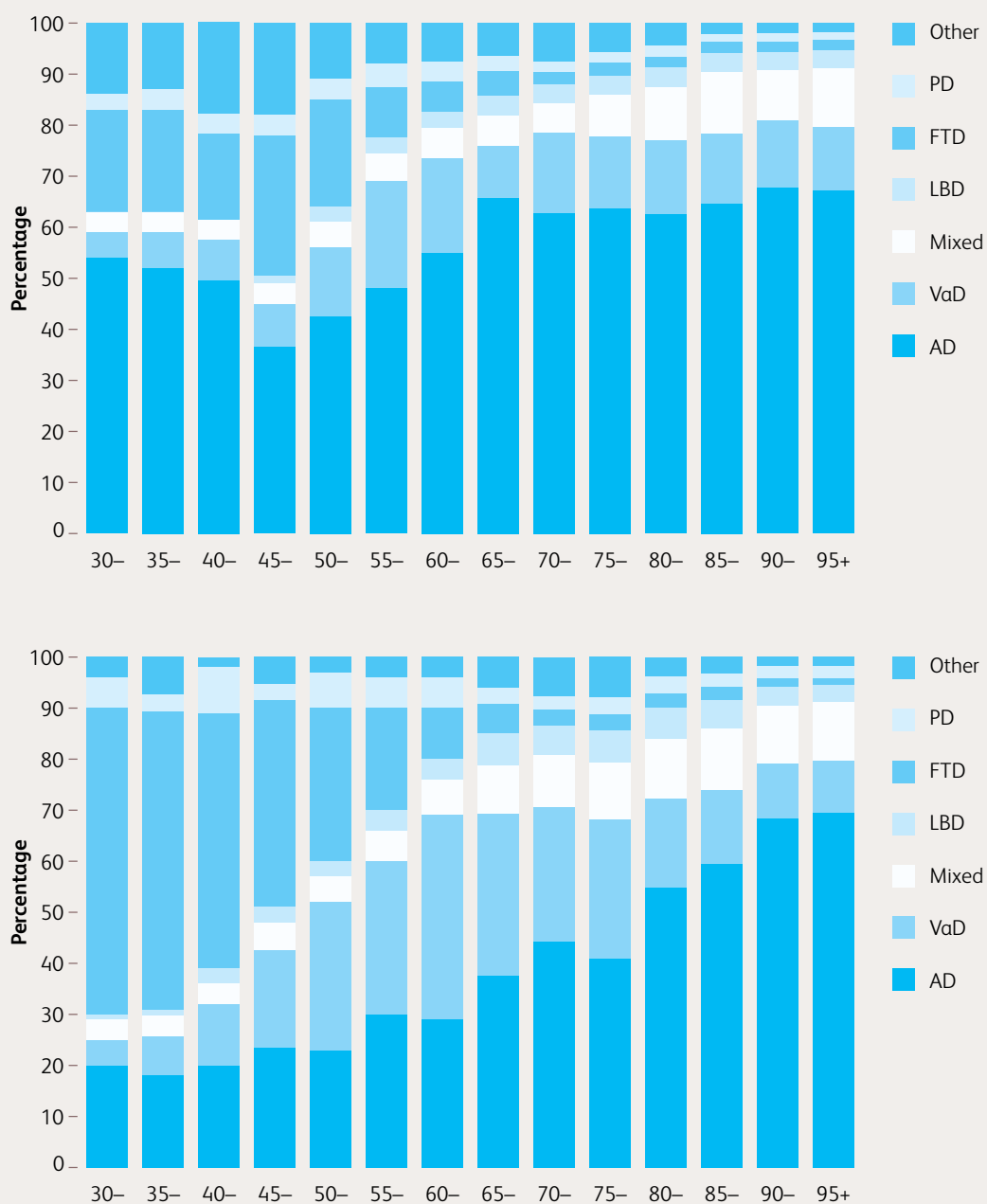
### 3.7 Dementia subtypes

The researchers did not identify any further UK evidence on the distribution of dementia subtype, and have therefore used the estimates developed for the Dementia UK 2007 report. These were based upon four UK population-based studies of late-onset dementia (O'Connor et al, 1989; Brayne et al, 1989; Clarke et al, 1991) and four of early-onset dementia (Ratnavalli et al, 2002; Harvey et al, 2003; McGonigal et al, 1993; Newens et al, 1993).

The proportions of subtype of dementia are:

- Alzheimer’s disease 62%
- Vascular dementia 17%
- Mixed dementia 10%
- Dementia with Lewy bodies 4%
- Frontotemporal dementia 2%
- Parkinson’s dementia 2%
- Other 3%

Figure 3.3 and 3.4: The consensus estimates of the proportion of all dementia cases accounted for by different dementia subtypes, by age and gender



\* Source: Alzheimer’s Society, 2007

### 3.8 Discussion

Many of the limitations identified in the 2007 Dementia UK 2007 report still apply now. While the evidence-base on the prevalence of dementia in care homes has been usefully extended, particularly with respect to different care settings, it remains limited. In 2007, no studies of the population prevalence of dementia had been carried out since 1993. Since then, there have been only two new studies from the UK, and one of these, MRC CFAS II (Matthews et al, 2013), is highly salient. No studies of the prevalence of dementia in care homes or the community are nationally representative. There is no new evidence on the prevalence of early-onset dementia, and there are no new estimates of the distribution of dementia by severity or subtype.

The paucity of research conducted in the UK seems to be part of a wider European pattern. The researchers for this report found only 13 new eligible studies carried out across Western Europe, only eight of which provided sufficiently detailed information to be included in the meta-analysis. With the exception of the MRC CFAS II study, other studies, mainly conducted in Italy (Bernardi et al, 2012), Spain (Rodriguez-Sanchez et al, 2011; Bufill et al, 2009; Gavrilu et al, 2009), and Portugal (Nunes et al, 2010) were based upon small samples from limited catchment areas, and were of poor methodological quality. In none of the recent studies using a two-phase design was this both implemented and analysed in an unbiased fashion.

It seems reasonable to conclude that neither policy-makers nor research-funding agencies have accorded adequate priority to the monitoring of the dementia epidemic through high-quality population-based research, and that European researchers have failed to convey the importance of design and analysis to the funders of studies in order to maximise the value of funded fieldwork, or to develop strategic collaborations to perform this task. Opportunities exist now, within Europe and the framework of the European Union Joint Programme on Neurodegenerative Disease Research (JPND), and it is hoped that the current gap will be addressed in a more sustainable manner across Europe, particularly in those countries and areas with no studies of any quality.

#### **Weaknesses of the Delphi consensus approach**

Until the quality and coverage of prevalence estimates improves, the Delphi consensus approach remains relevant. It would be highly desirable to move to a purely quantitative method for synthesising prevalence data, but this will not be possible until this shift occurs. While the Delphi consensus has many strengths, there are important weaknesses. The first and most obvious of these is that it, too, is dependent upon the validity and generalisability of the available evidence. To the extent that this is wanting, experts will need to apply educated and informed guesswork to estimate the impact of bias, and generalise beyond the bounds of the available evidence. Not all of the experts on the Delphi consensus panel for this report felt comfortable with doing this; one did not feel that the evidence was sufficient to provide gender-specific estimates, and two provided incomplete estimates regarding the prevalence of dementia in care homes.

Additionally, the Delphi consensus could be influenced in unknown ways by the manner and framing of the presentation of the existing evidence base. While the Delphi approach aims to generate a consensus without undue influence from any particular body of expert opinion, achievement of a consensus does not, in and of itself, guarantee the validity of the result.

### **Examining the Dementia UK 2014 report against the MRC CFAS surveys**

As seen earlier, the overall (age-standardised) prevalence of late-onset dementia generated by the consensus group remains very similar to the 2007 consensus, while, within this, there are some changes to the age and gender distribution. Also, the prevalence of dementia among care home residents is thought to have increased – this is in the context of a substantial fall in the number of older care home residents. This consensus needs to be examined critically in the light of the new data from the MRC CFAS II study.

The main strength and significance of the MRC Cognitive Function and Ageing Study (MRC CFAS) surveys is that these were repeated at two time points (1990–1993, CFAS I; 2008–2011, CFAS II) using identical random sampling (in catchment areas in Nottingham, Cambridgeshire, and Newcastle) and similar dementia ascertainment methodology. A 30% overall reduction in prevalence was observed over this 18-year period, having adjusted for age, sex, area, and deprivation status. The survey samples were relatively large, ensuring reasonable precision, and were of generally high methodological quality. The Delphi consensus prevalence estimates, when age-standardised, fall more or less halfway between the two extremes of the CFAS I and CFAS II studies. This raises two important questions, neither of which was asked explicitly, in the Delphi consensus:

#### **1 Has there been a fall in the prevalence of dementia in the catchment area districts surveyed in CFAS I and II?**

This is the most parsimonious conclusion from the detailed analyses conducted by the CFAS investigators. While the response rate in CFAS II was low, and much lower than in CFAS I, the analysis methodology adjusted for non-response missing at random (by deprivation, age, sex, area and care home setting) and sensitivity analyses to non-ignorable missing data patterns suggest that this is unlikely to account for the observed decline in prevalence. Chance (sampling error) is an alternative partial explanation, since the confidence intervals around the difference in prevalence (OR for CFAS II vs. CFAS I = 0.7, 95% CI 0.6–0.9) allow the possibility that the true relative decline in prevalence was much smaller (or larger) than the 30% central estimate. The use of a computerised algorithm (GMS-AGECAT) to identify those with probable dementia, rather than a clinical diagnosis, neutralises the problem of changing diagnostic concepts and thresholds over time.

There may, however, have been changes in the ability of older people with dementia to answer correctly orientation items that form an important part of the AGE-CAT algorithm. It should be noted that the design of CFAS II differed from that of CFAS I in that CFAS I used a two-phase design (with appropriate sampling of screen negatives and weighting back) while CFAS II used a one-phase design. The impact of this change should theoretically be negligible, and this was supported in practice by sensitivity analyses carried out with CFAS II data. While, in the European meta-analysis, there was a non-statistically significant trend for studies using a one-phase design to record lower prevalences than those using a two-phase design, this may have been because of confounding by other study characteristics. The

Liverpool MRC ALPHA study (Saunders et al, 1993), essentially part of CFAS I, but funded separately and carried out earlier, also used a one-phase design and recorded a lower prevalence than either CFAS I or II. However, there was no overall difference in prevalence between sites in CFAS I, including Liverpool, using comparable analytical methods, in CFAS I (MRC CFAS, 1998). Also, since the Liverpool site was not resurveyed in CFAS II, the possibility of a similar downward secular trend in prevalence in that site cannot be excluded.

## **2 Is the prevalence of dementia recorded in CFAS II (the most recent UK study, conducted between 2008–2011) generalisable to the UK as a whole?**

The Delphi consensus still represents a range of opinions. It is neither particularly meaningful, nor conventional to express this in terms of confidence intervals. However, it should be noted that the 12 individual estimates, when age-standardised, comprised three estimates that were very close to CFAS II (6.3%, 6.4%, 6.6%), six estimates that were close to the mean of the consensus (6.9%, 6.9%, 6.9%, 7.0%, 7.1%, 7.3%), and three estimates that were somewhat higher (7.6%, 7.6%, 8.1%). It is not possible to divine exactly what factors might have influenced the group, individually or collectively, in making this judgment.

Among the possibilities to be considered are:

- a) that the regions selected for CFAS might not have been considered representative of the UK as a whole. This may or may not be the case, but the direction and extent of any resulting bias is difficult to estimate, since only limited evidence is available from other areas in the UK with no nationally representative surveys. Social deprivation accounted for observed differences in prevalence between sites in CFAS II (Matthews, 2013), and comparing this and other potential compositional determinants of dementia prevalence between CFAS sites and national census data may be one way to address this question.
- b) that consideration was given to the European meta-analysis, suggesting a higher prevalence of dementia, with no clear trend towards a decline in prevalence over time, and with prevalence estimates from UK studies falling in the mid-range of prevalence by country.
- c) that the GMS assessment and its AGE-CAT algorithm may be systematically underestimating the prevalence of dementia as currently conceived. Different diagnostic criteria identify people in different ways, with no clear gold standard. AGE-CAT was initially calibrated against the concept of 'clinical significance' – a case meriting clinical attention, intervention and care (Copeland et al, 2002). It is possible that this threshold, imposed as all such thresholds are upon a continuum of cognitive decline, may fail to capture the full societal impact of dementia syndrome. Linked to this, boundary shifts towards the diagnosis of milder disorder in current clinical practice might have influenced the appraisal of the panel members. The potential impact of changes in conceptualisation and diagnostic criteria over time do need to be considered. However, none of these considerations would negate the clear inference from CFAS I and II studies of a decline in the prevalence of dementia between 1993 and 2011, since the same assessment tool and algorithm was used in both surveys.

The fact that the mean of the current consensus estimates was higher than that of CFAS II (but lower than CFAS I), and had not changed from the consensus of Dementia UK 2007, does not exclude the possibility that the prevalence of dementia has declined from the early 1990s to the late 2000s, as suggested by the CFAS surveys. This report has sought merely to provide the best estimate of the current prevalence of dementia in the UK, drawing on available evidence from the UK and other European countries. CFAS II is an estimate provided on the basis of observed populations in the UK, with confidence limits that quantify the possible effect of sampling error. The Delphi estimate is presented without confidence limits, but is actually freighted with uncertainty. This report has sought to clearly reflect this uncertainty through emphasis of the weakness of the available evidence-base, and by reporting the full range of estimates from individual expert consensus group members.

### 3.9 Conclusions

A balanced judgment suggests that the overall prevalence for all those aged 65 years and over is somewhere in the region of 7.1%. It seems unlikely that the true prevalence would lie outside of the bounds of the CFAS II survey estimates (6.4%) and the Western European meta-analysis (8.6%).

The deficiencies in the evidence-base that were apparent in this process need to be addressed. These have been acknowledged as significant limitations in the interpretation of the results. There is no substitute for contemporary, good-quality, generalisable population-based research for the estimation of numbers of people with dementia in the UK and other countries; their residential status, their needs for care, their access to and use of services, and attendant costs.

These data are vital for rational health planning, monitoring service delivery, and quality improvement in prevention and care. There is no reason to assume that age-specific prevalence will remain constant over time, and there is some evidence from the UK, as well as other high-income countries, that prevalence, or incidence, or both may be declining. Since the drift of government policy is towards earlier diagnosis, increased use of evidence-based healthcare services, increased integration and coordination of care, and reduced transition into residence in care homes, changes in these directions can also be anticipated, and should be monitored.

Trends in prevalence over time may show regional differences, because, for example, improvements in primary prevention and healthcare might be less effective in areas of relative social deprivation with health gains in mid-life translating to healthier later years taking longer to become apparent. Nationally representative samples of adequate size would ensure that findings can be generalised to the whole of the UK, and regional variations estimated directly.

There should be separate sampling of private homes, and over-sampling of all types of care home (providing different levels and types of care). While around 3% of those aged 65 years and over currently live in care homes, these settings include around one-third of all people with dementia among their residents. It is therefore important to estimate prevalence in those settings with adequate precision. Geographically defined catchment area studies cannot assess the impact of selective immigration and outmigration, other than by controlling for changes in the composition of the populations sampled. This may be a particular problem with regard to the location of care homes, and relocation to live closer to or with children, to the extent to which these patterns or propensities change over time. While there are some data available on these issues across the UK, only nationally representative studies conducted over time will capture and record the overall impact of such displacement effects.

While highlighting the potential of nationally representative surveys, it is important also to note the very real strengths of specific locality studies (MRC CFAS being one example), upon which, internationally, most estimations of national dementia burden have been based, to date. It is perhaps easier to maintain survey methodological quality when the interview effort is concentrated on a few geographic areas. Catchment areas can be selected to capture diversity (rural and urban areas, socioeconomic, regional and cultural differences). Sample sizes in each catchment area can be large enough to make meaningful comparisons, which may not always be the case in nationally representative surveys.

Such studies may be particularly useful for scrutinising the prevalence of dementia among black, Asian and minority ethnic groups, where catchment areas with a high proportion of such residents can be purposefully selected. Nationally representative surveys would require over-sampling of black, Asian and minority ethnic groups to generate precise estimates of prevalence, and settle the question of possible inter-ethnic variation. This is an important yet under-studied area. Numbers of older people from black, Asian and minority ethnic groups are increasing rapidly. Cross-generational effects will be even more marked than in the indigenous population. It is essential that their needs are met by accessible and responsive services, and that any evidence for increased risk of dementia is addressed by focused attention on modifiable risk factors across life.

The surveys should be repeated regularly to monitor trends in prevalence over time. For comparisons to be meaningful, the same methodology should be applied on each occasion, particularly as regards the definition and ascertainment of dementia, and levels of severity. While this would not reflect possible changes in standard diagnostic criteria or practice, a standard structured algorithm, as used in CFAS I and II, has obvious advantages over clinical consensus, which may vary over time independent of patterns of morbidity.

Changes in prevalence may reflect changes in incidence, or survival with dementia. Some recent evidence from high-income countries suggests a ‘compression of cognitive morbidity’ with both a reduced age-specific incidence of dementia, and reduced survival after onset (see Chapter 4 for a detailed discussion). This may be explained by incidence being deferred to older ages, closer to the natural limits of the life span, with survival time being determined by factors other than dementia. To examine this important issue, it would also be useful to estimate survival with dementia, by linking survey participants, prospectively, to mortality data from the NHS Central Registry.

If the evidence-base were improved in this way, there would no longer be any need for Delphi consensus procedures. The current Delphi consensus was commissioned by the funders of this report, after a stakeholder consultation convened by the Department of Health, as the preferred approach for incorporating the new evidence generated by the MRC CFAS II study into a broader evidence context. Therefore, in this report, these Delphi consensus estimates have been prioritised to estimate both current numbers of people with dementia (Chapter 4) and societal economic costs (Chapter 5). Nevertheless, as discussed in this chapter, the relative validity of the Delphi consensus estimates and the CFAS II estimates that have been empirically measured from direct assessment of three contemporary populations within the UK is open to debate, and prioritisation of one over the other for these and other purposes will be a matter of judgment.





# Numbers of people with dementia

## Overview

The Dementia UK 2014 report estimates the following:

- One in every 79 (1.3%) of the entire UK population, and 1 in every 14 of the population aged 65 years and over has dementia.
- At the current estimated rate of prevalence, there will be 850,000 people with dementia in the UK in 2015.
- The total number of people with dementia in the UK is forecast to increase to over 1 million by 2025 and over 2 million by 2051, if age-specific prevalence remains stable and increases are only driven by demographic ageing.
- There are now 42,325 people with early-onset dementia (onset before the age of 65 years) and 773,502 people with late-onset dementia (onset after the age of 65 years) in the UK.
- In total, 311,730 people with dementia in the UK are living in care homes, of whom 180,500 are living in residential care and 131,230 in nursing homes.
- As in 2007, nearly two-thirds (62%) of all people with dementia in the UK, 505,813 in total, have Alzheimer's Disease (AD), known to be the most common form of dementia.
- For those with dementia aged over 60 years, an estimated 55% have mild dementia, 32% have moderate dementia and 12% have severe dementia.
- Among people with late-onset dementia, 311,730 (38.7%) are living in care homes (either residential care or nursing homes) and 493,639 (61.3%) are living in the community.

## 4.1 Methods used to estimate the total numbers of people with dementia

The prevalence figures obtained by the Delphi consensus were applied to estimates of population numbers for the UK. Mid-year population estimates for 2013 were obtained from the National Statistics website for England and Wales ([www.statistics.gov.uk](http://www.statistics.gov.uk)), the Scottish census results website ([www.scrol.gov.uk](http://www.scrol.gov.uk)) and the Northern Ireland census website ([www.nisranew.nisra.gov.uk](http://www.nisranew.nisra.gov.uk)). Separate estimates were obtained for men and women, for the age bands specified in the consensus exercise. The total number of people with dementia was calculated by applying the first set of prevalence estimates (the total population prevalence) to the figures provided.

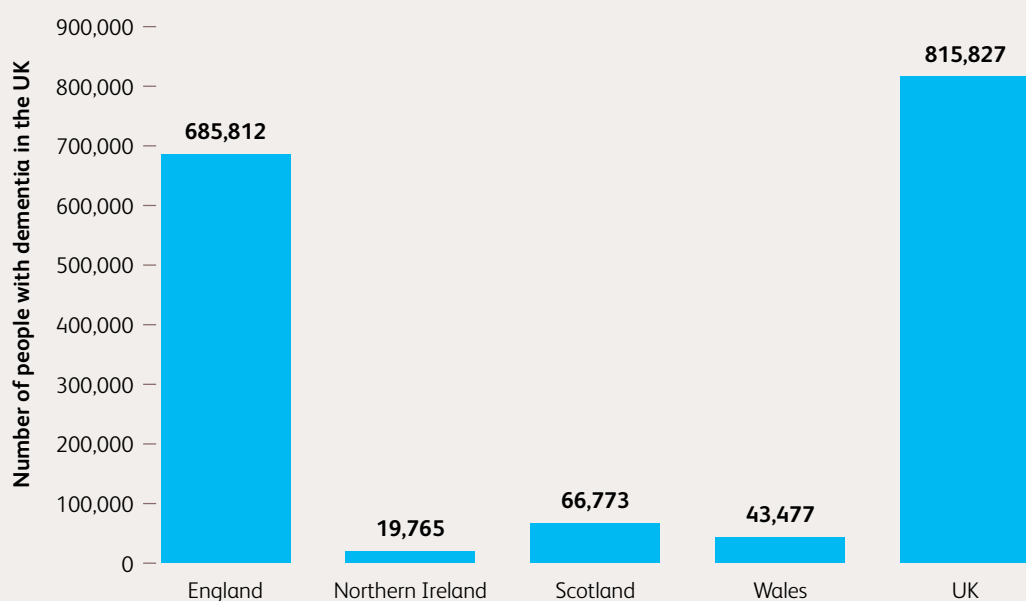
These prevalence estimates were applied to each local authority (or equivalent), parliamentary constituency and health area across the UK. The data presented in this report was applied to Westminster parliamentary constituencies for England and Wales, Scottish parliamentary constituencies for Scotland (as health and social care is devolved to the Scottish parliament), and Northern Ireland constituencies. Regarding health areas, data was used from Clinical Commissioning Groups in England for mid-2012, and from Health Trust Areas in Northern Ireland, and Health Boards in Wales and Scotland for mid-2013.

Projections of numbers of people with dementia were made by applying the population prevalences to projected population estimates for the years 2012 through to 2051, obtained from the Government Actuary Department ([www.gad.gov.uk](http://www.gad.gov.uk)).

## 4.2 Current number of people with dementia in the UK

This report estimates that in 2013 there were 815,827 people with dementia in the UK (Table 4.1), of whom 773,502 are aged 65 years or over. This represents one in every 79 (1.3%) of the entire UK population, and 1 in every 14 of the population aged 65 years and over. Eighty-four per cent of those with dementia live in England, 8% in Scotland, 5% in Wales and 2% in Northern Ireland (Figure 4.1).

Figure 4.1: Number of people with dementia in the UK, by country (2013)



**Table 4.1: Number of people with dementia in the UK, by age and sex, 2013**

Age in years	Male	Female	Total
30–34	191	207	398
35–39	124	185	310
40–44	180	446	626
45–49	735	649	1,383
50–54	1,348	1,209	2,557
55–59	3,330	1,854	5,184
60–64	15,611	16,256	31,867
65–69	25,467	32,286	57,753
70–74	37,250	40,126	77,376
75–79	50,580	75,093	125,674
80–84	67,040	105,187	172,226
85–89	51,818	118,932	170,750
90–94	28,236	96,517	124,754
95+	6,681	38,288	44,969
<b>Total</b>	<b>288,591</b>	<b>527,236</b>	<b>815,827</b>

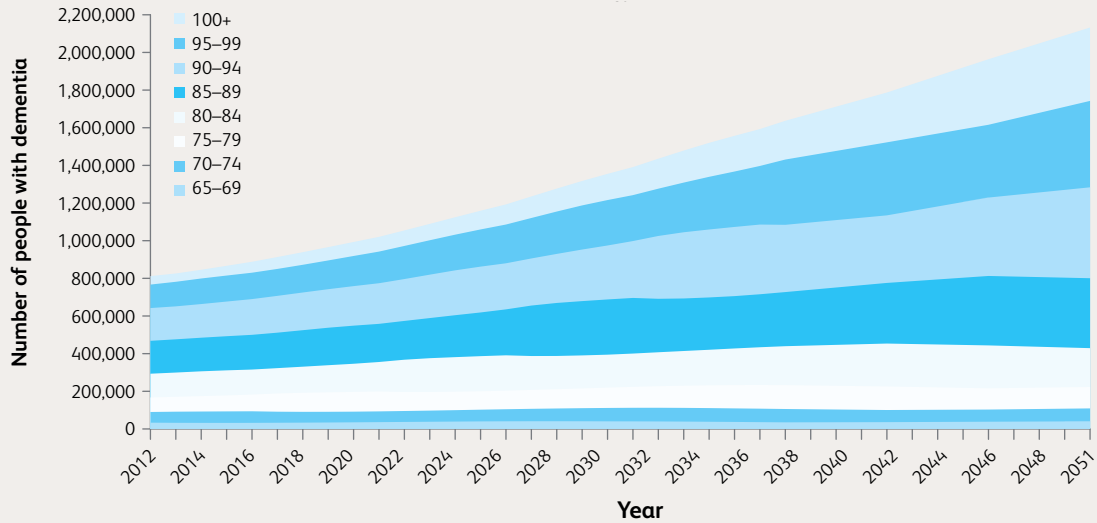
### 4.3 Projected increases in the number of people with dementia in the UK

If the prevalence of dementia remains the same, the number of people with dementia in the UK is forecast to increase to 1,142,677 by 2025 and 2,092,945 by 2051, an increase of 40% over the next 12 years and of 157% over the next 38 years.

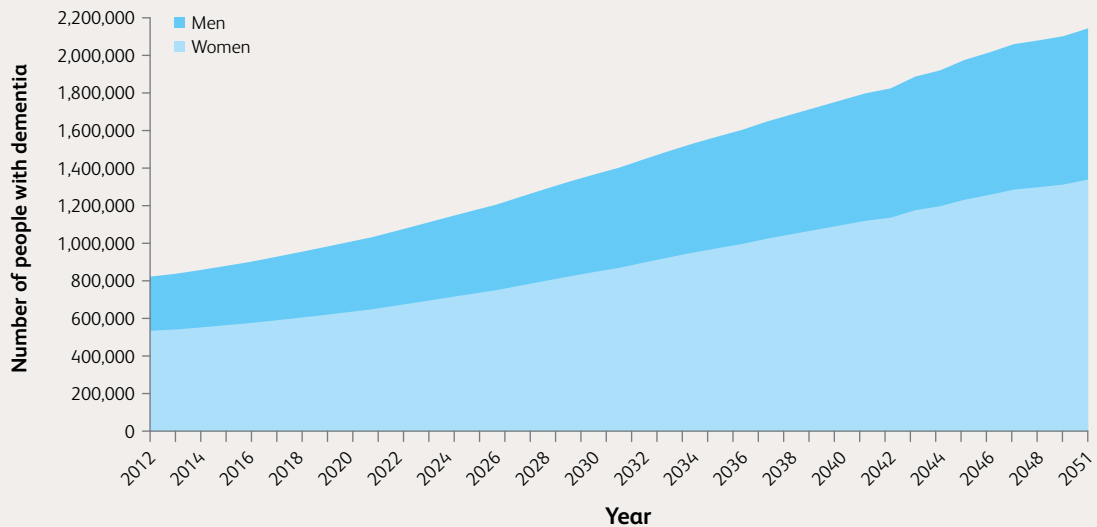
This growth would be driven by population ageing alone. Life expectancy for older people is increasing, as mortality declines, even for the oldest old. Older people are most at risk for dementia. Hence the largest increases in the number of people with dementia would occur in the oldest age groups (Figure 4.2). Numbers of men and women with dementia in the UK are projected to increase at a similar rate (Figure 4.3).

These projections above should be seen as a ‘worst case scenario’ rather than an expected outcome – some current evidence suggests that the prevalence and incidence of dementia among older people is already beginning to fall in high-income countries such as the UK, associated with improvements in the level of education and in public health (healthier lifestyles and better prevention and control of cardiovascular risk factors). These trends, if they continue, have the potential to greatly attenuate or even eliminate the projected increases in numbers of people with dementia in the coming decades.

**Figure 4.2: Projected increases in the number of people with dementia in the UK (2012– 2051), assuming constant age-specific prevalence, by age group**



**Figure 4.3: Projected increases in the number of people with dementia in the UK (2012– 2051), assuming constant age-specific prevalence, by gender**



## 4.4 Population prevalence by region

This report estimates the number of people with dementia for each local authority, clinical commissioning group (or equivalent) and parliamentary constituency in the UK. An online link to the detailed results is provided in Appendix A.

For the local authorities, it had to be assumed that the proportion of over 90s who are 95+ is the same by area, which means that numbers of people with dementia in younger areas might have been overestimated while those in older areas might have been underestimated. However, any errors resulting from this assumption will be slight. The population estimates used for the clinical commissioning groups in England were from mid-2012, so it is likely that the numbers of people with dementia mentioned in Appendix A might be slightly lower than they would be now.

## 4.5 Early-onset dementia

### Number of people with early-onset dementia

This report estimates that there are now 42,325 people with early-onset dementia (onset before the age of 65 years) in the UK. This number has significantly increased since the Dementia UK 2007 report, where it was thought to have been underestimated.

Most of the increase in the estimated number of people with early-onset dementia, compared to the 2007 estimates, is accounted for by the 60–64 years age group (Figure 4.5). As highlighted in Chapter 3, changes in methodology for estimating the prevalence in this age group explain the increase. In the Dementia UK 2007 report researchers used studies of early-onset dementia to estimate prevalence for those aged 30–64 years old. However, these studies, which relied upon a diagnosis made and recorded by primary or secondary care services, were likely to have systematically underestimated the true prevalence.

This was striking for the older of the early-onset age groups, where some population-based surveys from European countries had recorded significantly higher prevalences. Therefore, for the 2014 Delphi consensus, it was decided, a priori, to estimate the prevalence for the 60–64 years age group as part of the late-onset dementia consensus (see Chapter 2). The prevalence for those aged 60–64 years that was estimated at 156 for every 100,000 people (0.16%) in 2007, has now risen to 0.9%, representing an increase of about 26,000 people across the UK. This is a more realistic estimate of prevalence in this age group. Prevalence and numbers in younger age groups (30–59 years) are still likely to be underestimated, but there is no alternative source of data.

It is now estimated that early-onset dementia accounts for 5.2% of all people with dementia in the UK (compared to 2.2% in 2007). As in 2007, 83% of people with early-onset dementia live in England, 9% in Scotland, 5% in Wales and 3% in Northern Ireland (Figure 4.4).

The number of people with early-onset dementia increases sharply with age, with the age group of 60–64 years showing the sharper increase (due to the different methods of estimation, as discussed earlier).

Figure 4.4: Number of people in the UK with early-onset dementia, by country (2013)

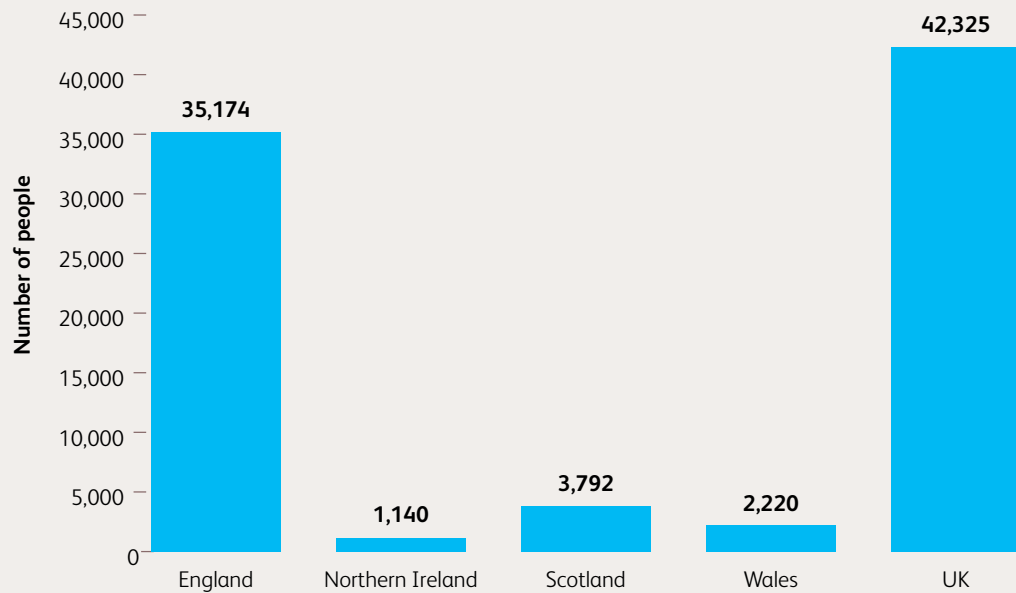
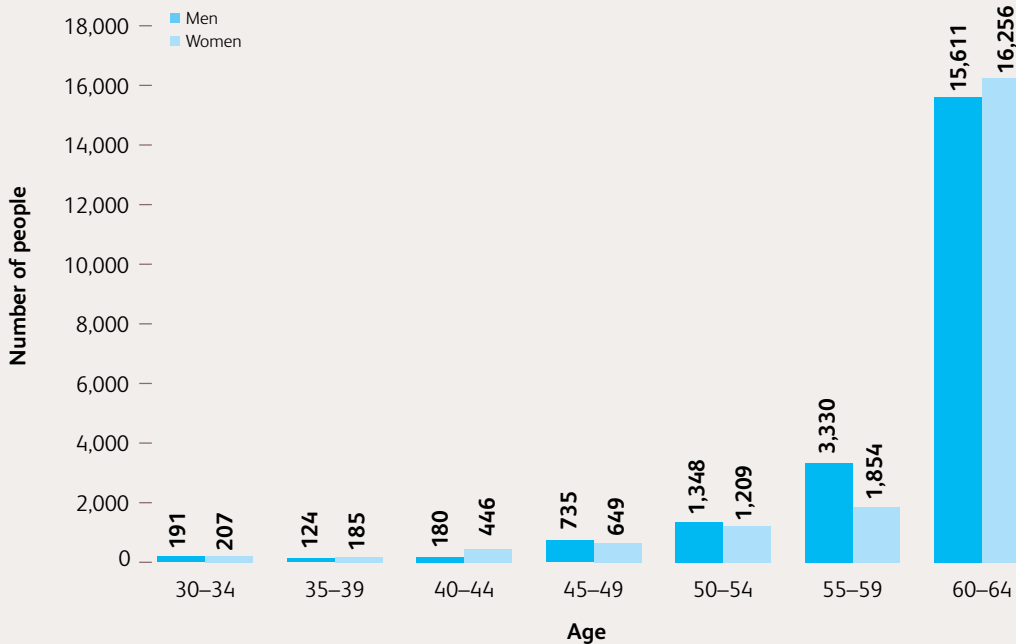


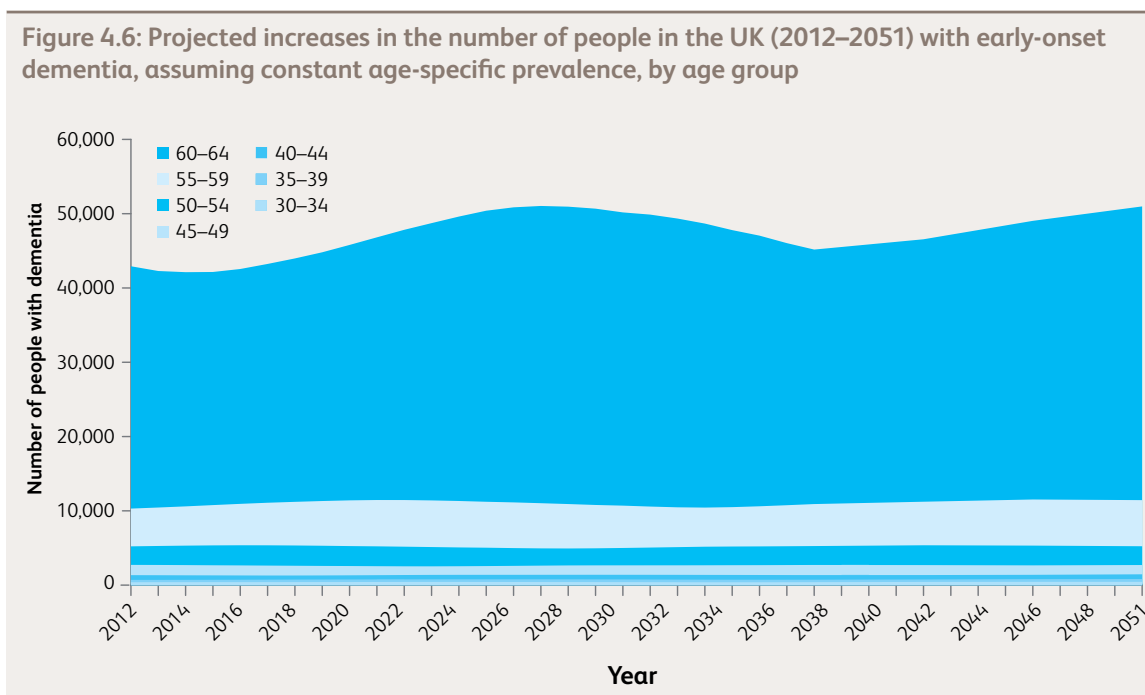
Figure 4.5: Number of people in the UK with early-onset dementia, by age and gender (2013)



Among all the people with early-onset dementia in the UK, this report estimates there is a slightly higher number of men than women (21,519 men and 20,806 women), a M:F gender ratio of 1.03 to 1.00.

## Projected increases

Assuming constant prevalence (see also Section 4.3 above) the number of people with early-onset dementia in the UK is projected to increase to 50,401 by 2025 and 50,979 by 2051, an increase of 20% over the next 38 years.



## 4.6 Late-onset dementia

### Number of people with late-onset dementia

This report estimates that there are now 773,502 people with late-onset dementia (onset after the age of 65 years) in the UK. Late-onset dementia accounts now for 95% of all dementia cases in the UK, slightly less than previously estimated in 2007. The distribution of all dementia cases in the UK nations is similar to the one presented in the Dementia UK 2007 report: 84% in England, 8% in Scotland, 5% in Wales and 2% in Northern Ireland (Figure 4.7).

The number of people with late-onset dementia continues to rise for each five-year age band up to the age of 80–84. However, the numbers start to decline after 80–84 years for men while they decline only after 85–89 for women. This distribution is explained by an increase in the age-specific prevalence according to the consensus group while the number of people in those age groups declines progressively because of increasing mortality. Two-thirds (66%) of all people with late-onset dementia are aged 80 and over, and over one-fifth (22%) aged 90 or over.

Overall, this report estimates that 267,072 men and 506,430 women have late-onset dementia, slightly less than two women for every man affected (Figure 4.8). The male to female gender ratio is 0.8 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 4.7: Number of people in the UK with late-onset dementia, by country (2013)

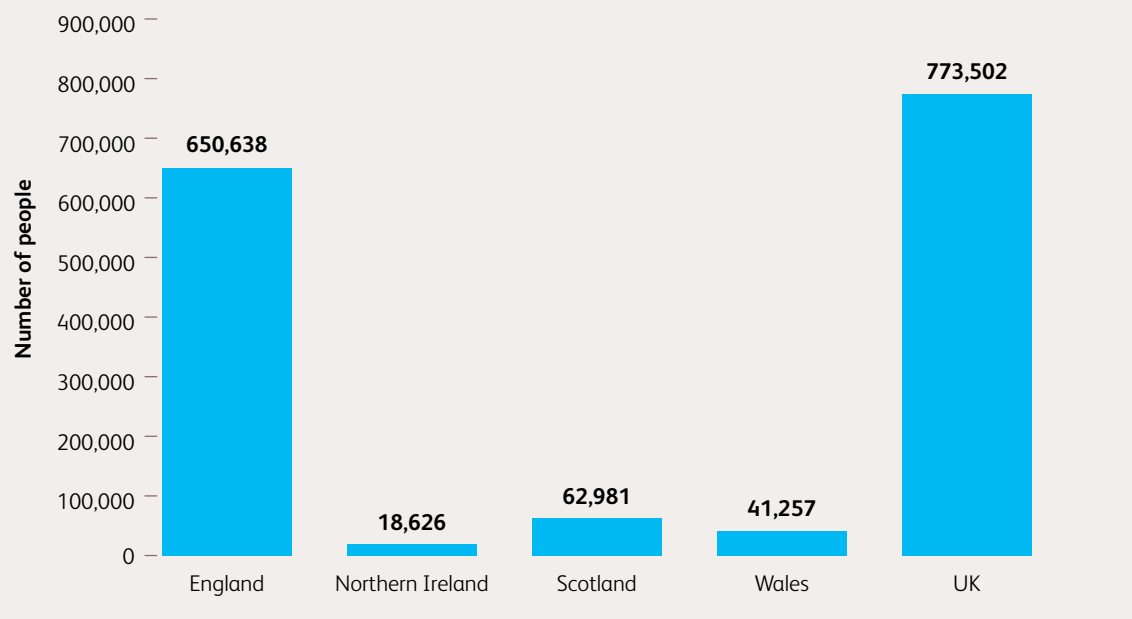
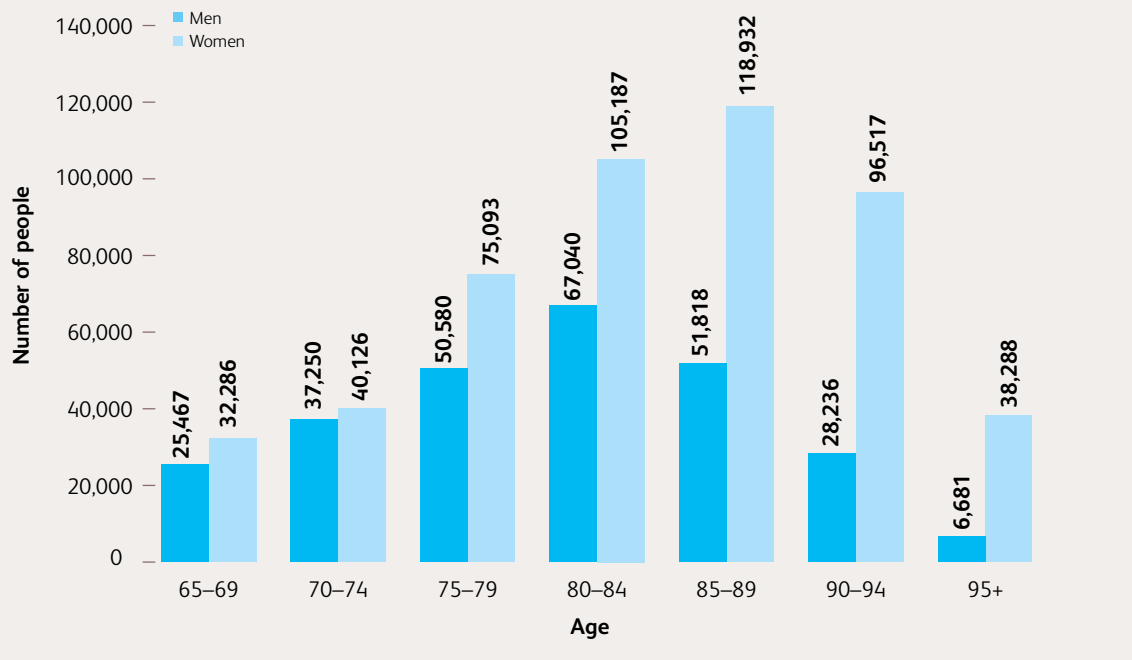


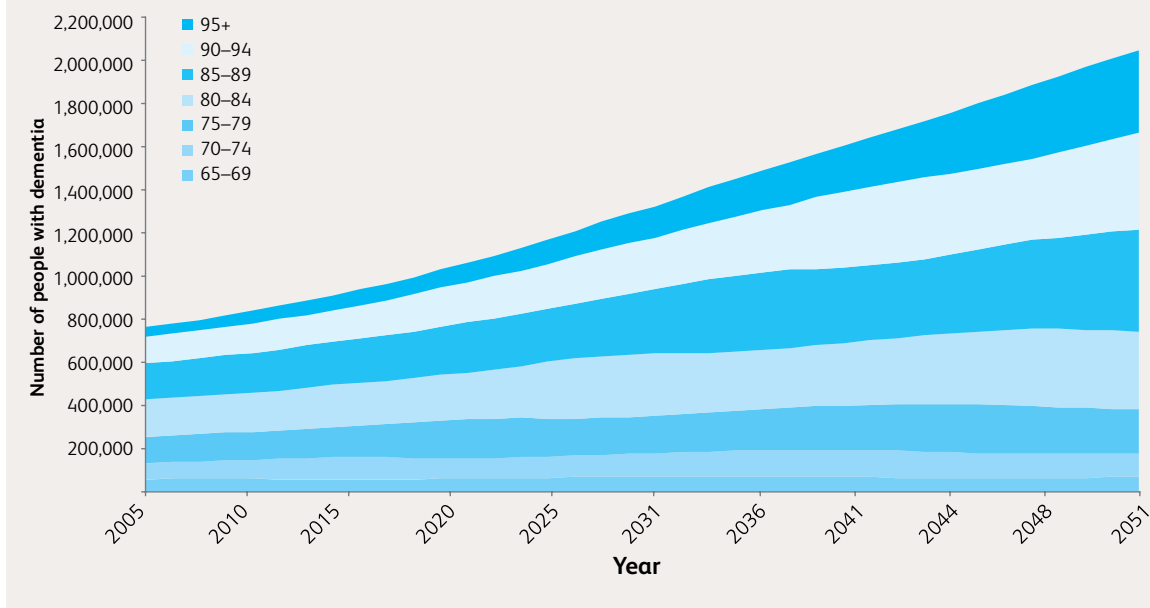
Figure 4.8: Number of people in the UK with late-onset dementia, by age and gender (2013)



## Projected increases

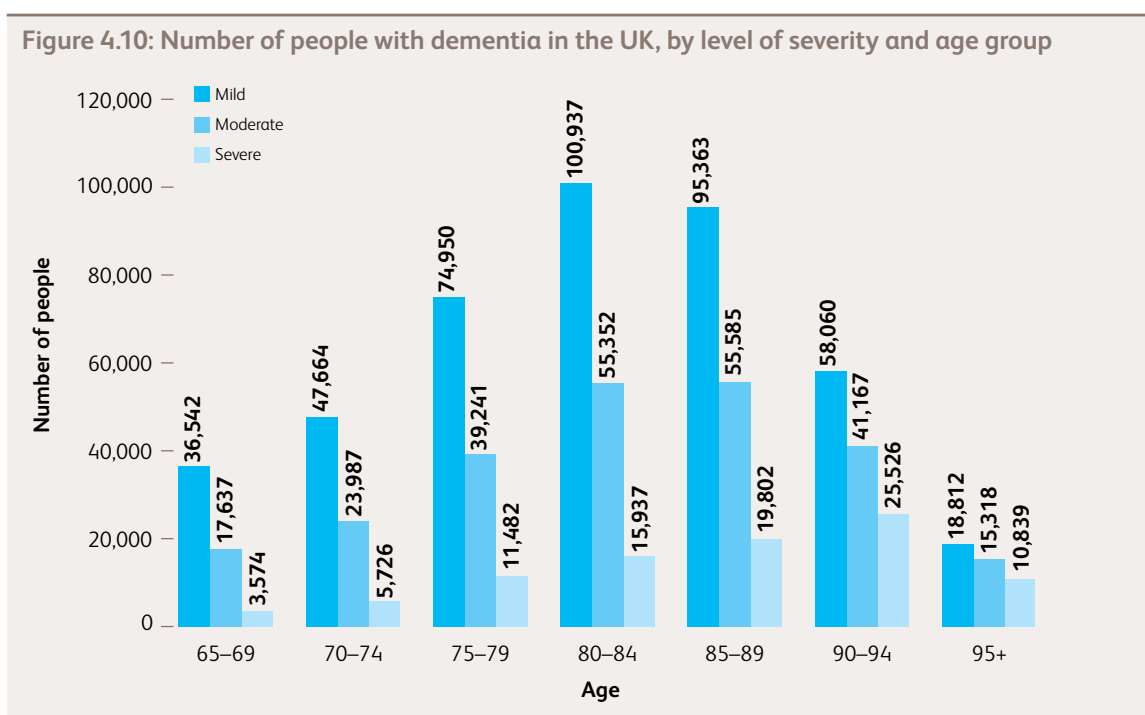
Assuming constant prevalence (see also Section 4.3 above), the number of people with late-onset dementia in the UK would increase to 1,092,276 by 2025 and to 2,041,966 by 2051, an increase of 164% over the next 38 years.

Figure 4.9: Projected increases in the number of people in the UK with late-onset dementia (2012–2051), assuming constant age-specific prevalence, by age group



## 4.7 Severity of dementia

For those with dementia aged over 60 years, this report estimates that 55% have mild dementia, 32% have moderate dementia and 12% have severe dementia (Figure 4.10). The proportion of people with severe dementia increases with age, from 4.8% for those aged 60–64 years to 23.3% for those aged over 95 years.

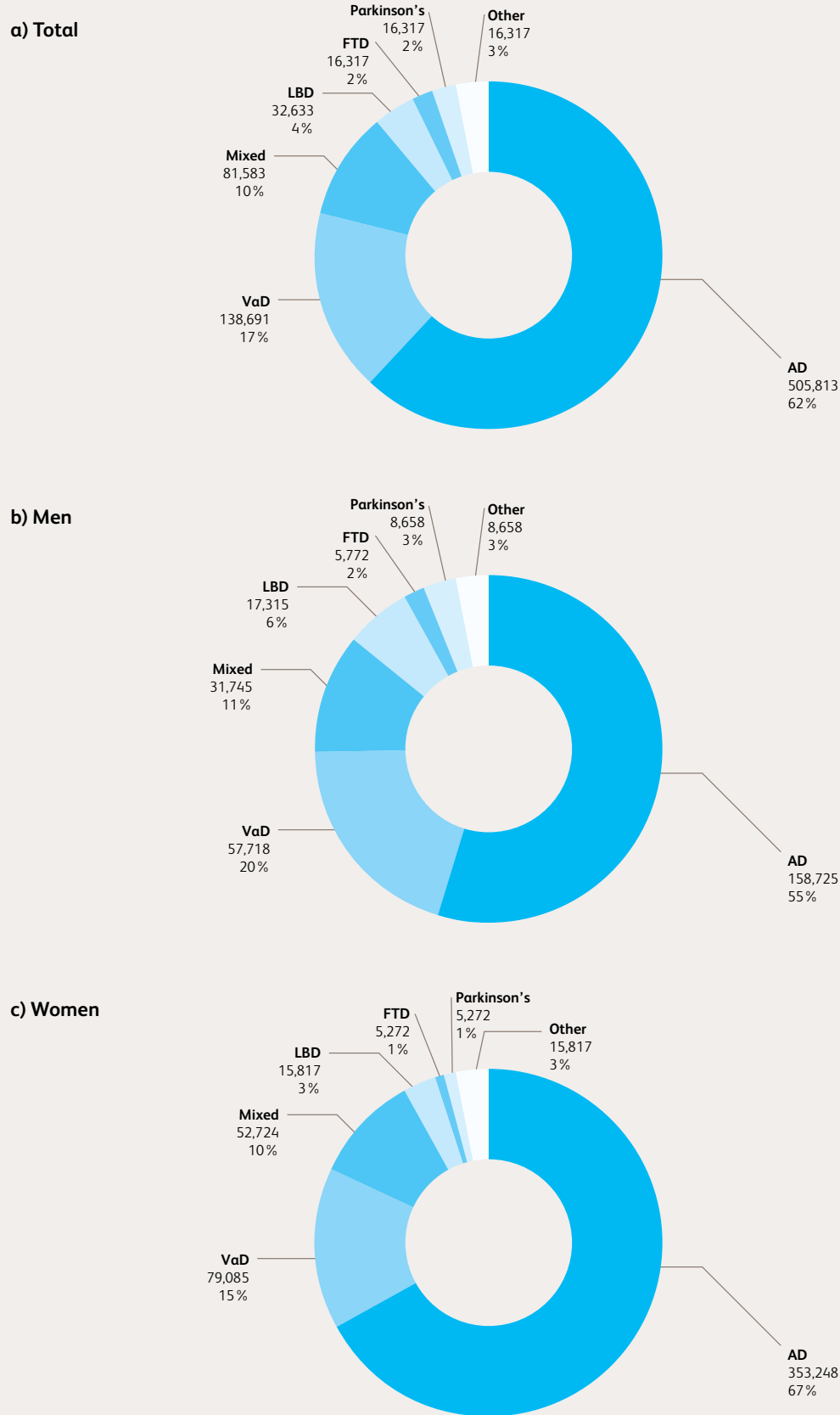


## 4.8 Dementia subtypes

As in 2007, this updated report estimates that nearly two-thirds (62%) of all people with dementia in the UK, 505,813 in total, have Alzheimer’s Disease (AD), known to be the most common form of dementia. The other most common subtypes are vascular dementia (VaD) and mixed (AD and VaD) dementia, respectively accounting for 17% and 10% of all cases (Figure 4.11a). Lewy body dementia (LBD), frontotemporal dementia (FTD) and Parkinson’s dementia have lower frequencies, accounting together for 8% of all cases.

The distribution of subtypes differs in men and women: AD is more common in women (67% in women compared to 55% in men), while VaD and mixed dementia are more frequent in men (31% of all cases in men, 25% in women) (Figures 4.11b and c).

Figures 4.11a, b and c: Number and percentage of people with dementia in the UK, by subtype and gender



## 4.9 Residential status

Among people with late-onset dementia, 311,730 (38.7%) are living in care homes (either residential care or nursing homes) and 493,639 (61.3%) are living in the community (Figure 4.12).

In total, this report estimates that 311,730 people with dementia in the UK are living in care homes, of whom 180,500 are living in residential care and 131,230 in nursing homes (Figure 4.13). Among all the people with dementia residing in care homes, 74% are women. In the UK, 38% of the people with dementia are now living in residential care or nursing homes.

Figure 4.12: Number of people aged 60 years and over in the UK with dementia living in residential care and in the community, by age group.

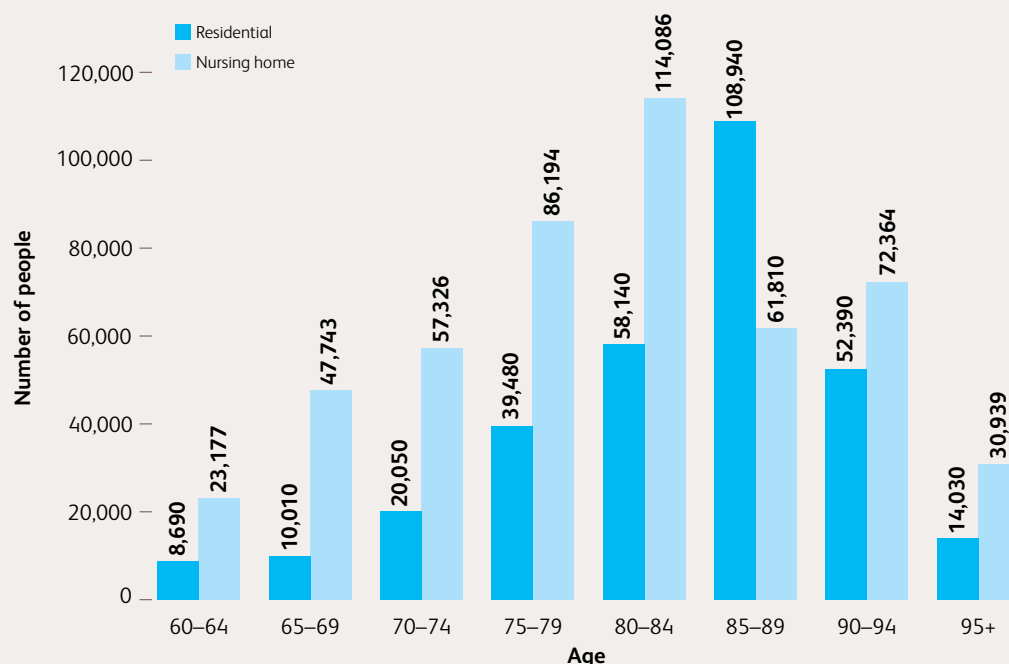
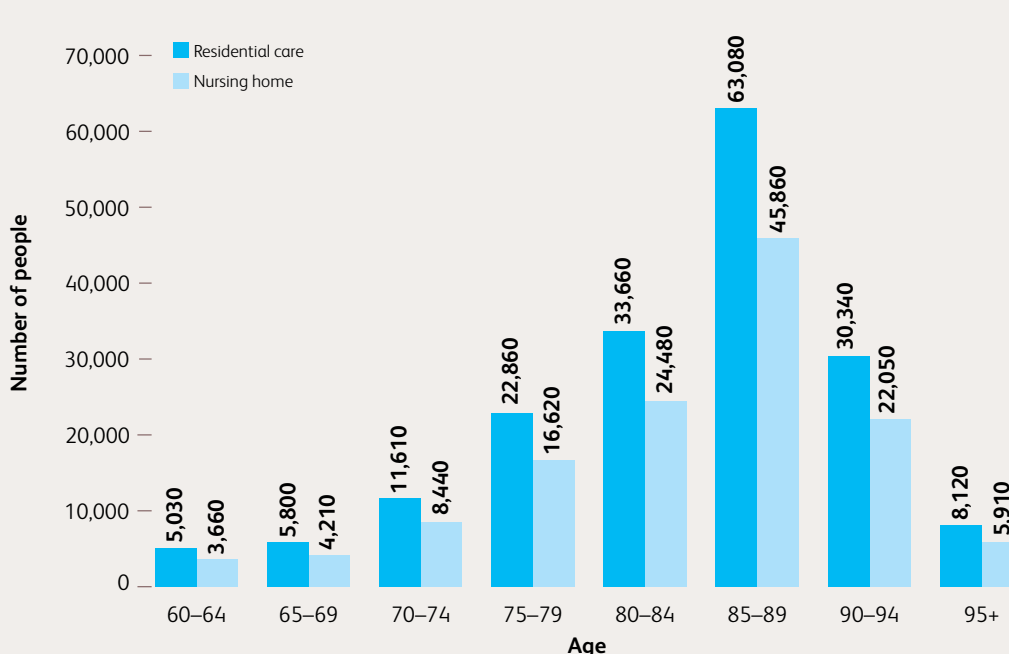


Figure 4.13: Number of people with dementia living in care homes in the UK (2013)



## 4.10 Discussion

While the number of people with late-onset dementia in 2013 according to the Dementia UK 2007 report was projected to be 668,563; this updated report estimates that the number of people with late-onset dementia in the UK is 773,502.

The prevalence estimates from the new Delphi consensus lie inside the bounds of the (lower) CFAS II survey estimates and the (higher) estimates from the Western European meta-analysis (see Chapter 3). As a sensitivity analysis, the researchers for this report re-estimated the number of people with dementia in the UK (and its constituent countries) using those estimates (Table 4.2). These numbers could be considered as the lower and upper bounds of the likely true number of people living with dementia in the UK.

The number of people with dementia estimated for 2013 is consequently between the number of people estimated according to the CFAS II and the Western-Europe meta-analysed prevalence, although closer to the CFAS II numbers.

The increase of the prevalence of dementia among people aged 60–64 years (an age group which was included in the figures for late-onset dementia in the Delphi consensus) had a significant impact on the total number of people with dementia. While in 2007, the Dementia UK report estimated that 5,513 people aged 60–64 had dementia in the UK, this number increased to 31,867 for 2013. The estimates developed for the Dementia UK 2007 report were derived from two studies (Harvey et al, 2003; Ratnavalli et al, 2002) in which the prevalence was calculated as the number of cases known to local service providers divided by the total local population as enumerated in the census. However, as all of those with early-onset dementia don't seek help early in the disease course, there is probably a general tendency for such studies to underestimate the true prevalence of dementia. Even if it is not possible to update the age-specific prevalence for people aged 30 to 59 years in absence of further evidence, it is reasonable to think that the latest estimates are more reliable and closer to the real number of people with early-onset dementia.

**Table 4.2: Number of people with dementia in the UK according to the CFAS II and Western Europe meta-analysis prevalence estimates**

	<b>CFAS II*</b>	<b>Western Europe meta-analysis (up to 2014)**</b>
	Total (late-onset dementia)	Total (late-onset dementia)
<b>UK</b>	720,958 (705,225)	1,046,550 (979,544)
<b>England</b>	606,322 (593,226)	879,656 (823,784)
<b>Scotland</b>	58,788 (57,379)	85,889 (79,861)
<b>Wales</b>	38,440 (37,648)	55,829 (52,278)
<b>Northern Ireland</b>	17,408 (16,972)	25,423 (23,626)

\* 2007 Delphi estimates used to generate the number of people with early-onset dementia and CFAS II estimates applied to people aged 65 years and over.

\*\* 2007 Delphi estimates used to generate numbers from 30 to 59 years old and Western Europe meta-analysed estimates applied to people from 60 years and over.

This chapter presents several projections of possible increases in the number of people with dementia in the UK, from 2012 to 2051. All of these projections were generated by applying the same age- and gender-specific prevalences obtained from the current Delphi consensus to projections of the UK population over the next decades. Therefore, the assumption is that the age- and gender-specific prevalence of dementia will not vary over time, and that population ageing alone (increasing the number of older people at risk) drives the projected increases.

The basis for this assumption was uncertain in 2007, since, as acknowledged in the report at the time, prevalence is a product of incidence and survival with dementia, and a fall in either or both of these indicators would lead to a fall in age-specific prevalence. A decline in age-specific incidence, at least in high-income countries, was theoretically possible, driven by changes in exposure to suspected developmental, lifestyle and cardiovascular risk factors for dementia. Thus, each generation is better educated than the one before. Although trends differ between countries, genders, age groups and time periods, there has been a general trend towards less smoking, falling total cholesterol and blood-pressure levels, and increasing physical activity. On the other hand, the prevalence of obesity and diabetes has been increasing in most developed countries.

These changes can be attributed to a variety of factors, including increased prosperity, public health campaigns, legislation, and improvements in healthcare. After a lag period, to the extent that these factors are genuinely causally associated with dementia, one would expect to see changes in the incidence of the condition. The net effect of these changes on survival with dementia is harder to estimate, and other factors – for example, standards of health and social care for people with dementia, and provision of life-prolonging critical interventions – might also be expected to have an influence.

In 2007, what very few data were available from certain high-income countries did not suggest any clear pattern of a decline or increase over time in either the incidence or prevalence of dementia. Just a few years later, and linked to a greatly increased interest in the potential for prevention of dementia by targeting modifiable risk factors (Barnes et al, 2011; Lincoln et al, 2014) the quality and extent of the evidence has expanded greatly.

As highlighted in Chapter 1, in England, the MRC Cognitive Function and Ageing Study (MRC CFAS) surveys were repeated at two time points (1990–1993, CFAS I; 2008–2011, CFAS II) using identical random sampling in catchment areas in Nottingham, Cambridgeshire, and Newcastle (Matthews et al, 2013). A near one-third (30%) reduction in prevalence was observed over this period, adjusting for any differences in age, sex and deprivation status. If a similar fall in prevalence had occurred across the whole of the UK, this would have been sufficient to have almost completely averted the increase in national numbers of people with dementia, anticipated from the ageing of the population.

Although a similar trend towards declining prevalence was observed in a similar study from Zaragoza, Spain (Lobo et al, 2007), this has not been replicated in all other studies (Mathillas et al, 2011; Qiu et al, 2013; Rocca et al, 2011). More compelling evidence comes from the long-term USA Health and Retirement Survey (Langa et al, 2008), in which there was a substantial decline in the prevalence of cognitive impairment between survey waves conducted in 1993 and 2004, accompanied by a higher relative mortality risk for those who had developed cognitive impairment. There is some evidence consistent with a recent decline in incidence in Sweden and the Netherlands (Qiu et al, 2013; Schrijvers et al, 2012).

Preliminary findings from two important studies were presented at the Alzheimer's Association International Conference in July 2014. In the US Framingham Study (Satizabal et al, 2014), dementia incidence was tracked over thirty years in four five-year periods. Compared to the first five-year period, incidence had fallen by 17%, 32% and 42% respectively. Reductions were largest in the younger age groups, suggesting that dementia incidence was being delayed or deferred to older ages. The second study (Doblhammer et al, 2014) used claims data of the largest public health insurance company in Germany to track the incidence and mortality of dementia in 2007–2010, compared with 2004–2007. Incidence had fallen by around 20%, while mortality among those with dementia had increased for women but remained stable in men.

Evidence from these studies collectively presents a more consistent pattern of declining incidence, with onset of dementia when it occurs happening at an increasingly older age. This probably explains the higher mortality – if you develop dementia at the end of life, your period of living with dementia will be shorter. This phenomenon, which Langa described as 'the compression of cognitive morbidity' (Langa et al, 2008), would be a desirable outcome, both for public health and individual quality of life – longer, healthier lives, with fewer years spent with reduced independence and higher care needs.

The MRC CFAS study suggested that factors that may have led to an increased dementia prevalence (diabetes, survival after stroke, and vascular incidents), may have been outweighed by those likely to lead to a reduction (improved prevention of vascular morbidity and higher levels of education). This was echoed in the findings of the Framingham study, which proposes that declines in the incidence of dementia over a 30-year period were accompanied by improvements in educational status, more use of antihypertensive and statin medication, lower blood pressure and cholesterol levels, and reductions in prevalence of smoking, heart disease and stroke, whereas prevalence of obesity and diabetes increased.

However, evidence from China and other East Asian countries suggests a worrying trend towards an increase in the prevalence of dementia over the last 20 years (Chan et al, 2013; Wu et al, 2014; Loef and Walach, 2012). While cardiovascular health is improving in many high-income countries, it is deteriorating elsewhere. Many low- and particularly middle-income countries show a pattern of increasing incidence of stroke and ischaemic heart disease mortality, linked to an epidemic of obesity, and increasing blood pressure levels.



In conclusion, it is no longer reasonable to assume that the age-specific prevalence (and incidence) of dementia in the UK will remain stable over the next 40 years. This is, in many ways, the least likely of a range of possible scenarios, from an overall reduction in total numbers affected (assuming a very substantial decline in age-specific incidence and prevalence, more than offsetting any increases expected because of population ageing), to no growth at all (assuming, as observed between CFAS I and II (Matthews et al, 2013), that the expected growth in numbers is completely offset by declining prevalence), to a more modest increase than that outlined in the projections (assuming that the growth in numbers from population ageing is partly offset by declining age-specific prevalence).

Which of these scenarios plays out will depend upon the success of continuing efforts to improve public health. Those who will be old in 2050, were born around the 1970s, and have already received their basic education. They are now in their third and fourth decades of life, a crucial 'sensitive period' where, evidence suggests, efforts to prevent, detect and control obesity, hypertension, diabetes and dyslipidaemia (high cholesterol) are likely to have maximum positive impact upon brain health and dementia risk in late-life (Lincoln et al, 2014). Further details on the evidence base to support this argument are contained in Alzheimer's Disease International's World Alzheimer Report 2014, focusing upon modifiable risk factors for dementia (Alzheimer's Disease International, 2014).

## 4.11 Conclusions

This chapter presents an estimation of the numbers of people affected by dementia in the UK today. To maximise the utility of these estimates, the numbers are broken down by age and gender, and region, and, among people with dementia, by severity and residential status (community or care home).

However, as outlined in Chapter 3, the prevalence estimates are somewhat uncertain. Given these limitations, the true numbers of people with dementia may be somewhat lower (as suggested by the recent MRC CFAS II study conducted in three English communities), or somewhat higher (as suggested by a meta-analysis combining results of all recent western European surveys).

The accuracy of the numbers presented will diminish as they are applied to smaller population sub-groups and geographic regions, since these may have special characteristics (other than age and gender distribution that are accounted for) that may mean that the prevalence of dementia will differ from the 'national average'.

The future projections presented in this report are a 'worst case scenario'. They represent what can be expected if there are no further improvements in public health of successive generations of older people. Therefore they can be used to benchmark progress with healthy brain promotion and dementia prevention initiatives. A sign of progress made will be if the prevalence and numbers in 2025, or 2050, are significantly lower than the unrealistically pessimistic projections in this report.

To monitor progress, as outlined in Chapter 3, cognitive health and dementia prevalence needs to be assessed and reassessed in repeated surveys of nationally representative samples of the general older population, using robust methods that can be held constant over time. Such surveys would not only track changes in prevalence over time, but would also have a vital role to play in monitoring earlier diagnosis, access to evidence-based treatment, changes in care arrangements, and quality of life of people with dementia and their carers.



# The cost of dementia

### Overview

- The total cost of dementia to society in the UK is £26.3 billion, with an average cost of £32,250 per person.
  - £4.3 billion is spent on healthcare costs.
  - £10.3 billion is spent on social care (publicly and privately funded).
  - £11.6 billion is contributed by the work of unpaid carers of people with dementia.
- Police costs of missing person enquiries attributable to dementia probably range between £22.1 and £40.3 million per year.
- Overall, it has been estimated that research expenditure in the dementia area in the UK in 2013 was around £75 million (compared to £45 million in 2009) (Alzheimer's Society, 2014).
- Unpaid care accounts for three-quarters (74.9%) of the total cost for all people with dementia living in the community.

### 5.1 Introduction

Dementia can have considerable impact on the quality of life of people with the condition, as well as on their families and other carers. People living with dementia experience declining cognitive function that, over time, affects their ability to live independently and can shorten life expectancy. Their unpaid carers, usually spouses or adult children, experience often quite heavy demands on their time and energy, which can affect their own health, employment and well-being. Each of these consequences of dementia will be likely to generate costs.

As the population ages, the number of people affected by dementia increases markedly. Chapter 3 shows that the prevalence of dementia rises sharply with age. As successive generations survive longer due to reduced mortality rates associated with other conditions, they may face a rising lifetime risk of dementia onset. A major challenge in this context is how to provide high-quality treatment and support to these individuals in ways that are therapeutic to and valued by them and their family carers, but at a cost considered by society to be affordable.

This chapter provides an estimate of the overall economic impact of dementia in the UK in 2013. Impact is estimated from a societal perspective: including the costs of health and social care services; providing unpaid care; other services such as police expenditure on missing person enquiries; expenditure on dementia research; and the value of

quality-adjusted life years (QALYs) lost due to dementia-related premature mortality. It also tackles other types of costs attributable to dementia that it is not possible to quantify due to lack of suitable information. These new estimates are compared with figures previously published for the UK.

The estimates in this report build on previous work by members of the team – including a number of trials (detailed below), the researchers' long-term care model and recent economic analyses of dementia care scenarios – as well as on the Delphi consensus prevalence figures provided earlier in this report.

## 5.2 Methods

### Modelling the costs of dementia

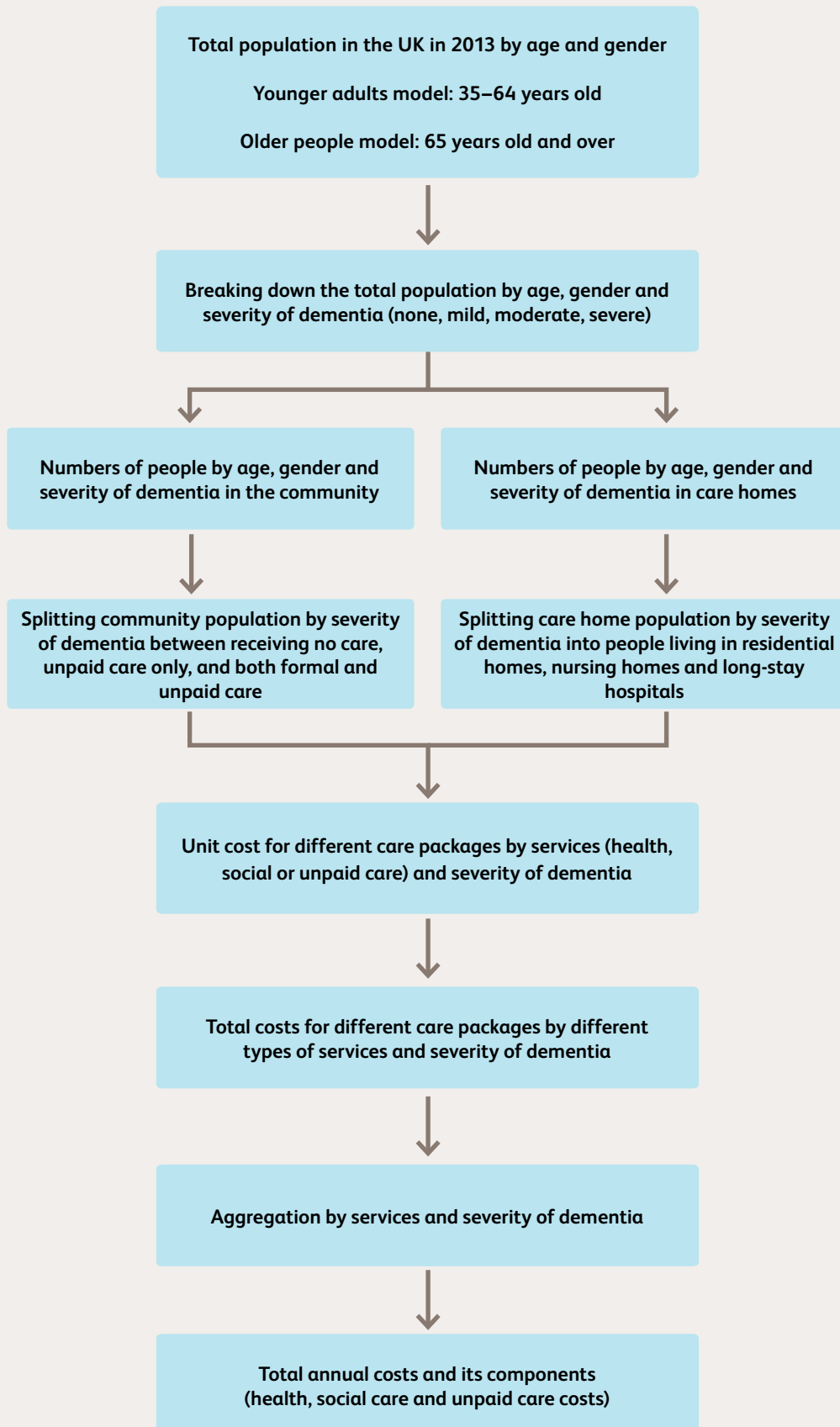
This report estimates the costs of healthcare, social care and unpaid care for people with dementia using the best currently available information, including data from various sources and from baseline data collected in a number of clinical trials. The costs estimated are annual figures for the UK for 2013, based on estimated numbers of people with dementia and numbers of service users in that year. They relate to a cross-section, or snapshot, and are not lifetime costs of a longitudinal cohort.

The overarching framework used to pull these data together is a new version of a model of the costs and outcomes of dementia that builds on previous versions of the PSSRU aggregate long-term care model (Wittenberg et al, 1998, 2001) and of the PSSRU dementia care model (Comas-Herrera et al, 2007). This new version of the model, which was also used for recent work on the economic consequences of various dementia care scenarios (Knapp et al, 2014), produces estimates for England for 2013, at 2012/13 prices, on the basis of current care arrangements. Findings for England were grossed to UK-wide prices, taking into account the population size in question, as the researchers did not have separate data on service use by people with dementia for England, Scotland, Wales and Northern Ireland.

The model makes estimates of four key variables: the number of older people with dementia; their receipt of unpaid and formal health and social care; the costs of this care (including opportunity costs of unpaid care); and the outcomes in terms of quality of life (measured using EQ-5D), although this last element is only used in a limited way for the purposes of the current study. The structure of the model is summarised in Figure 5.1; there are four main parts:

- the first divides the projected older population into subgroups by age, gender and severity of dementia
- the second assigns people to different care settings: care in the community (including care in special housing) or in care homes (or in a few cases in hospital)
- the third part estimates expenditure on care by attaching an average weekly cost to each type of care and each severity category
- the fourth estimates quality of life in a similar manner (but is not reported here, since this study concentrates on costs).

Figure 5.1: Structure of aggregate dementia models for younger adults and older people



A parallel model has also been developed for younger people with early-onset dementia. As discussed below, however, available data for this group are much more limited. In previous calculations of dementia costs for 2005/06, figures for people with early-onset dementia were not included (Alzheimer's Society, 2007). As this chapter will go on to explain, the coverage of economic impacts in this report differs from these earlier calculations.

## Population data

The models use figures for the 2013 mid-year population by age and gender as estimated by the Office for National Statistics (2014).

## Prevalence of dementia by age, gender and severity

Costs are calculating using the new Delphi consensus prevalence rates of dementia by age band and gender for people aged 65 years and over, as reported in Chapter 3. The Delphi consensus prevalence rates for people aged 60 to 64 years are also used. Since the Delphi consensus did not cover people aged under 60, however, prevalence rates from the Dementia UK 2007 report were used for age bands younger than 60 (Alzheimer's Society, 2007). The current Delphi prevalence rate for people aged 60 to 64 is much higher than the 2007 Dementia UK rate for this age group. This means that the estimate of the number of people with early-onset dementia is more than double previous estimates.

To ensure optimum accuracy when calculating costs, the overall numbers of people with dementia were divided into three categories (mild, moderate and severe dementia, using a breakdown that maps to the conventional MMSE ranges of 21–26 for mild, 10–20 for moderate and <10 for severe). This distinction is important, as the cost implications can be very different between severity groups. For this purpose, the researchers used the severity of dementia breakdown by age and gender from the Dementia UK 2007 report (Alzheimer's Society, 2007). If, for example, 15% of a specific age and gender group in the 2007 report have severe dementia, it was assumed that 15% of the numbers estimated for the same group using the new Delphi consensus prevalence rate have severe dementia.

In the absence of suitable data for younger age groups, it was assumed that the breakdown by severity of dementia for people aged under 65 is the same as for those aged 65–69.

## Patterns of care and support

The overall numbers of older people with dementia are divided between institutional and household populations using information from a number of sources and a number of steps of analysis:

- The estimated overall numbers of older people in care homes and hospitals by age band and gender are derived from the Personal Social Services Research Unit (PSSRU) long-term care model (based on official data on supported care home residents, Laing & Buisson data (Health and Social Care Information, 2013) on NHS-funded and privately funded care home residents, and Census data on hospital residents).
- The proportions of people in care homes who have dementia have been obtained from the Delphi study and applied to the overall numbers (and similar proportions have been applied for people in long-stay hospital care) to obtain estimated numbers with dementia.
- An assumption that 5% of people with dementia living in the community have severe dementia – drawn from studies in other countries in the absence of relevant UK data – is

used to determine the breakdown of people with severe dementia between institutional and household populations. The studies concerned comprise the ADAMS study (Rhee et al, 2011), the CSHA study (Hux et al, 1998) and the German community study (Schwarzkopf et al, 2013).

- The remaining institutional numbers are divided between mild and moderate dementia on the basis of evidence in the CANE trials; for more information on the CANE study see Orrell et al, (2007).
- The numbers in care homes are then subtracted from the overall numbers to produce estimates of the numbers of older people with dementia living in the community.

In the absence of suitable data on the patterns of care of younger people with dementia, it was assumed that the proportion of people aged under 65 in care homes or hospital is the same as for those aged 65–69.

Data from a number of UK trials and other studies that the researchers had previously participated in are used to identify the detailed patterns of care and support for each group of people with dementia in the community.

These studies were:

- SADD (Banerjee et al, 2011; Romeo et al, 2013)
- Component studies within the SHIELD programme (Orrell et al, 2014; D’Amico et al, 2014; unpublished CSP data)
- DADE (Lacey et al, 2012; Trigg et al, 2014)
- DOMINO (Howard et al, 2012 – for quality of life data only)
- EVIDEM (Lowery et al, 2013; and unpublished cost data), CST (Spector et al, 2003; Knapp et al, 2006)
- CANE (Orrell et al, 2007)
- START (Livingston et al, 2013; Knapp et al, 2013).

The researchers were also given access to data from the LASER-D trial (Livingston et al, 2008), which was added to the pooled comparison. Use of services for individual people with dementia was recorded in those trials, in all but one case using adapted versions of the Client Service Receipt Inventory (CSRI) completed by people with dementia, family members or professional carers (Beecham and Knapp, 2001).

Coverage in those studies was comprehensive across all services, including (but not confined to): inpatient stays, outpatient attendances, day hospital treatment, visits to social clubs, meals at lunch clubs, day care visits, hours spent in contact with community-based professionals such as community teams for older people, community psychologists, community psychiatrists, general practitioners, nurses (either practice, district or community psychiatric), social workers, occupational therapists, paid home help or care workers, and physiotherapists. In most of these studies, information was also collected on unpaid support provided by family and friends.

Overall, the dataset from these sources includes detailed information on about 1,400 people with dementia and on more than 200 carers. A lot of the information used in the cost calculations therefore comes directly from people with dementia or from carers. From the



trials only data collected (retrospectively) at baseline was used, and for both intervention and control groups, and not data collected in any of the post-randomisation follow-up assessments. In this way the researchers were able to focus on 'usual' care and support rather than what was delivered in the experimental stages of those studies. First everyone from the trials was categorised by severity of dementia and then all people in severity/setting combinations that were in conflict with the exclusion/inclusion criteria for the trials were excluded. (For example, some people in a trial of a carer intervention were recorded as 'formal care only', yet these people must have an unpaid carer in order to be included in the study. In another study of cognitive stimulation therapy for people with mild or moderate cognitive impairment a few people were found with severe dementia.)

It is notoriously difficult to estimate the number of hours spent by carers in the support of a relative or friend with dementia. Some of the time devoted by carers is taken up with hands-on care, and some of it with 'supervision' to ensure that nothing untoward occurs. Estimates are based upon time reported by carers in the various trials and other studies, using what was a fairly consistent wording in the interview schedules. Data on hours of unpaid care provided by carers are available for co-resident and non-co-resident carers. These are summed to provide an estimate of overall hours of unpaid care. In some studies, co-resident carers had been asked to estimate the percentage of time they could spend away from the person with dementia (eg 0–25%, 25%–50%), and so these 'away' hours were subtracted from the assumed normal waking day to estimate the number of hours taken up with providing care. Mid-points of these ranges were taken and converted into hours (assuming a waking day of 16 hours).

The trials recruited participants on the basis of a variety of inclusion and exclusion criteria, and therefore cannot be assumed to be representative of the entire population of people with dementia. In particular, all participants in the trials used had been diagnosed with dementia, whereas currently it is estimated that only about 50% of the total prevalent population in England has been formally diagnosed (Department of Health, 2013a). While no reliable information from any source could be found on differences in service use between people who have and have not been diagnosed with dementia, it was assumed that those without a diagnosis are likely to use fewer (formal) services than those with a diagnosis. Specifically, it was assumed that all people who have not been diagnosed are in the mild or moderate severity group and that they have not used services such as memory clinics, visits to a psychiatrist or psycho-geriatrician or community psychiatric nursing.

It was also assumed that receipt of unpaid care and formal health and social care for those aged under 65 is the same as for those aged 65 to 69, and that everyone with early-onset dementia has received a diagnosis. This may be an over-statement, but there is no guiding evidence, and in fact if it is assumed that if (say) only 75% received a diagnosis it would make only a tiny difference to the overall cost estimates.

## Costs of health and social care

The service use data collected in the individual studies noted above were converted to cost estimates. The studies from which data were drawn used unit costs that are widely employed in UK studies, and which reflect long-run marginal opportunity costs reasonably well. They generally come from sources in the public domain – mainly from the annual PSSRU volumes on unit costs (Curtis, 2013) and the National Health Service Schedule of Reference Costs (for inpatient and outpatient costs) – or, in a few cases, were calculated for the specific trial. All costs were inflated to 2012/13 prices using rates reported in Curtis (2013).

Some of the trials did not include people in care homes. The care home fees reported in those trials, which did include people in care homes, cannot be regarded as representative of care home fees nationally. The researchers therefore used local authority data on care home fees from the official Health and Social Care Information Centre report (2014) on expenditure and unit costs in 2012/13.

The costs are those of the total care and support used, not just those that might be attributed to dementia. It is not possible with currently available data to separate costs associated with treatment and care of dementia from those associated with treatment and care linked to other health or social care needs. Indeed, in a clinical context it would anyway often be difficult to separate the reasons for particular treatments and care arrangements, or for the duration of treatment.

People newly diagnosed with dementia should receive an assessment. This report estimates the number of new cases using findings on incidence from analysis of CFASI data by Matthews et al, (2005), giving an estimate of around 225,000 older people in a year. It should be recognised that reliable incidence estimates in this area are hard to establish. This report uses costs from the trials for younger people with dementia as well as for older people.

Data on the costs of services used by carers that might be associated with the responsibility of providing unpaid care was not included even though it is well known that there can be adverse health consequences. The two primary reasons for that exclusion are the paucity of data on carers' service use patterns (ie this information is collected in very few studies), and the difficulty of disentangling which health, social care or other services used by carers stem exclusively or predominantly from their roles as carers and which stem from their own needs, or indeed how those two might be distinguished conceptually.

## Expenditure breakdown by source

It is assumed that healthcare costs are met entirely by the NHS. Social care costs are met partly by local authorities (councils) and partly by people with dementia themselves, either through self-funding their care or through user charges. Therefore this report uses estimates of the numbers of self-funders of residential and home care and data on the proportion of the gross costs of local authority supported care met by user charges to divide social care costs between local authorities and care recipients. There are also direct cash costs to families of care recipients where they make up the cost of care home fees for an individual whose fee exceeds the amount the local authority usually meets; but there is no good data on this. The costs of unpaid care fall to the carers, although they may receive social security benefits (especially Carer's Allowance) and/or social care support in recognition of their caring role. The measurement of the costs of unpaid care is discussed further below.

## Other healthcare-related costs

Government policy in this area is shaped by the 2009 National Dementia Strategy and the Prime Minister's challenge on dementia published three years later, and is committed to improving care and support, raising awareness and stimulating more research of dementia (Department of Health 2009, 2012). Some of the additional funding committed to this area has been used to provide support and incentives to general medical practitioners (GPs) and hospitals to increase rates of diagnosis.

Incentives for GPs are in the form of a one-off payment of £0.37 per registered patient when they join an Enhanced Service Specification programme 'facilitating timely diagnosis and support for people with dementia'. General practices that join can obtain a performance payment based on the number of completed assessments carried out by the practice during the financial year.

There is also a financial incentive scheme for hospitals: the Dementia Commissioning for Quality and Innovation (CQUIN) is targeted at finding out whether people over the age of 75 admitted to hospital for more than three days have dementia, assessing their risk and referring them for further investigations. As part of CQUIN, all hospitals have to confirm whether they have a lead clinician for dementia and an appropriate staff training programme. They must also undertake a monthly audit of carers of people with dementia (Department of Health, 2013a).

## Housing costs

People with dementia may incur additional housing costs. Changes in housing costs are likely to be low for people who continue to live in their own home, but are likely to arise for those who move to a care home, sheltered housing, extra-care housing or to live with relatives.

For care homes and hospitals, total costs are included as represented by the care home fee or hospital cost. This is appropriate where the person has not given up their home in the community, for example because their spouse/ partner still lives there. It is however an over-statement of costs where the person has sold or terminated the lease of their former home. No adequate data has been found to produce an estimate of the extra costs of sheltered or extra care housing in comparison with ordinary housing, or of net changes in housing costs where a person moves to live with relatives.

## Costing unpaid care

While dementia cost-of-illness studies differ in their methods and coverage, they consistently show that the largest single cost element is borne by unpaid carers. Caring for a person with dementia usually involves very long hours, some of which are clearly identifiable as active caring, such as assisting with activities of daily living. Some caring involves less 'hands-on' care, such as time spent performing household tasks (eg cooking) or supervising and ensuring that the person with dementia is safe and comfortable.

There is no clear consensus on the best approach to measure carer costs, but learning can be taken from previous studies. Given the large number of hours of unpaid care provided, relatively small variations in methods used to cost them can produce wide differences in total costs. The researchers for this report have provided a range of estimates to illustrate the consequences of adopting different approaches.

The two most widely used methods to cost unpaid carers are the replacement cost and opportunity cost methods. The replacement cost method assigns a cost to an hour of unpaid care equal to the cost of employing a professional carer such as a home care worker. The opportunity cost method attempts to reflect the value to carers of the activities that they are no longer able to carry out because of their caring commitments (such as paid employment, leisure, housework and caring for other people such as their children). More sophisticated methods take into account the circumstances of individual carers, as well as the types of activities that are carried out. (See Appendix C for further discussion.)

The approach adopted to produce the 'core' estimate of unpaid care costs draws on both replacement and opportunity cost methods, distinguishing between type of care activities provided, and using all available information about carer characteristics and circumstances.

Estimates from Wimo et al, (2002) on the proportion of caring time spent by unpaid carers of people with dementia in Sweden on different caring tasks were used to calculate costs. (This is on the assumption that carers in the UK do not differ greatly from those in Sweden with regards to how they divide their caring time between different tasks.) Wimo and colleagues found that unpaid carers spent 14% of their caring time on assisting with activities of daily living (ADLs), 35% assisting with instrumental activities of daily living (IADLs) and 51% on supervision/surveillance. These percentages were applied to the hours spent caring reported in the datasets.

To account for the intensive, taxing nature of assisting with ADLs, a replacement cost (£19 per hour, the cost of an hour of formal home-based care; from Curtis, 2013) to 14% of reported care hours. Compared to assisting with ADLs, assistance with IADLs and supervision/surveillance (amounting to 86% of care hours) are typically less time-bound and provide more opportunities for joint production (Hassink et al, 2011). The opportunity cost value is therefore considered to be more appropriate for these activities, taking into account carer age and employment status.

Additional data collected about unpaid carers participating in one of the trials was used for this report: individual-level data from the SHIELD-CSP trial gave a more refined estimate of opportunity cost for each carer. Carers identifying themselves as employed were assigned the average wage for their gender and age band (18–21, 22–29, 30–39, 40–49, 50–59, 60+), as reported (provisionally) by the ONS for 2013. Those providing a job description were assigned the average wage for the relevant job category, also by gender and age band. Those reporting that they were not employed were assigned a wage rate equal to National Minimum Wage if at retirement age (65) or older, and to national average wage for their gender and age band if 64 years old or younger. This cost is indicative of the potential wage these carers may have been earning had they been in employment.

To test the sensitivity of the estimates, three variants were also examined:

- All reported hours of unpaid care costed using the replacement cost approach (£19 per hour, based on the average cost of formal home care).
- All hours costed following a basic opportunity cost approach. The researchers ran two versions of this, one using National Minimum Wage of £6.00 per hour and the other using national average wage of £15.15 per hour.
- Finally, the costs of unpaid care were estimated by using replacement costs for time estimated to be spent carrying out personal care (ADL) tasks and then costing the remaining hours using (separately) the National Minimum Wage and the national average wage, as above.

### **Value of quality-adjusted life years lost**

While many people with dementia die from other causes, dementia does generally reduce life expectancy. For example, an 85-year old man with dementia has 1.7 years lower remaining life expectancy than a man of the same age without dementia; for a woman the difference is 1.9 years (Jagger et al, 2007; Jagger personal communication).

Cost-of-illness studies in other clinical areas have tended to value life years lost due to illness in terms of lost output (the so-called ‘human capital approach’), but this does not seem appropriate for dementia given that most people with the condition are aged well above state pension age and unlikely to be in paid employment. Therefore this report estimates quality-adjusted life years (QALYs) lost in 2013 due to premature mortality of people with dementia, and then values those QALYs using the NICE threshold for recommendation of a health technology in the NHS of £20,000 per QALY.

For this report, two approaches were adopted for examining the QALYs lost due to premature mortality relating to dementia. First, years of life lost (YLL) attributable to dementia were considered. These were estimated for all world regions for 2010 in the Global Burden of Disease study (Horton, 2010). The researchers took the 2010 per capita YLL for the Western European region, in five-year bands from 30–34 to 75–79, and 80 and over, and applied them to the total population for these five-year bands from UK census data, to generate the total YLL for each age group.

Second, they looked at the annual number of deaths of people with dementia. Studies by Brayne et al, (2006) in the UK and Hebert et al, (2013) in the USA suggest that around one-third of older people will experience onset of dementia in their remaining lifetime. This implies that around one-third of deaths are of people with dementia (but not necessarily caused by dementia). On the basis of the difference in life expectancy at age 85 noted above, it can be assumed that 1.8 life-years are lost per person with dementia. Average EQ-5D-based utility for a person aged 75 and over is 0.73 (Woods et al, 2012), which suggests that 1.3 QALYs are lost per person with dementia due to dementia.

QALYs are lost not just through premature mortality but also through years lived with poorer quality of life due to dementia. However, no sufficient reliable data could be found to produce an estimate of QALYs lost through poorer quality of life.

## **Police costs**

Data from Sussex suggest that one in fifteen missing person enquiries are for people with dementia (Masters, 2013). The authors of this report estimated a cost to the police force arising from these enquiries using data on the numbers of missing persons with dementia and the associated cost per person.

## **Fire service costs**

As a direct consequence of the Prime Minister's challenge on dementia, fire services across the UK were given the opportunity to pledge to become more dementia-friendly, and a number of services encourage their staff to train as Dementia Friends (Dementia Friends, 2014). This stimulated the Chief Fire Officers Association to coordinate fire services across the UK into having and maintaining capacity for dementia care within the existing framework of fire services. Currently 27 fire services have acknowledged their support for building community capacity for dementia (Chief Fire Officers Association, 2014). The appointment of a Lead Officer for dementia within the Association is a small indication of some costs incurred as a result of the pledge.

A conference in September 2012, Fire Services and Dementia, highlighted fire safety concerns which prompted outreach programmes in some fire services, including provision of tailored support and advice, more frequent fire safety checks or provision of specialist equipment as necessary. Training is also provided for carers and support workers in the early identification of fire safety risks (Alzheimer's Society, 2013a). Although a relevant development, it was not possible to cost these activities for the purposes of this report.

## **Advocacy and support service costs**

Some third sector (voluntary) organisations provide a range of advocacy and support services to people with dementia and their carers. The researchers of this report gathered expenditure information from the two main charities in the UK whose activities can be clearly identified as working for people affected by dementia (the Alzheimer's Society and Dementia UK). They did not collect data from charities with a wider remit, such as Carer's UK or Age UK; even though both would be providing substantial advocacy and support in the dementia area, it would be hard to separate the dementia-specific activities.

## **Research costs**

Both the National Dementia Strategy and the Prime Minister's challenge on dementia emphasised the need for more and better research in the dementia field. The authors sought evidence on research spending by government (directly through the National Institute for Health Research or indirectly through the Research Councils) and by the main dementia charities.

## 5.3 Results

### Prevalence

The Delphi exercise concluded that in 2013 there were 815,827 people with dementia in the UK (Chapter 4). Of those, 42,325 are aged under 65 years. These are substantial increases from the numbers of people estimated to have dementia in the previous Delphi exercise and reported in the Dementia UK 2007 report. There are around 323,000 people with dementia in care homes in the UK and an assumed 8,500 whose primary residence is a hospital (However, the studies on which the prevalence rates are based did not survey hospital wards. This means that the prevalence rates may be marginally under-estimated. Healthcare costs for people whose primary residence is a hospital ward are however included.) The total estimated number of people in care homes with dementia includes a rather uncertain estimate of 11,750 people aged under 65 with dementia in care homes. The figures used as a platform for the cost calculations are summarised in Table 5.1.

**Table 5.1: Estimates of the prevalence of dementia in the UK from the 2014 Delphi study, compared to estimates from 2007**

	2007 Delphi consensus	2014 Delphi consensus
<b>Number of people with dementia in the UK</b>	683,597	815,827
<b>Estimated prevalence rate</b>	1.1% (1 in every 88)	1.3% (1 in every 79)
<b>Older people with dementia (65 years and over)</b>	668,563	773,502
<b>Younger people with dementia (&lt;65 years)</b>	15,034	42,325
<b>Number of people with dementia in England</b>	574,717	685,812

### Healthcare costs

Average healthcare cost per person with dementia was calculated for each of the three severity levels and two settings by drawing on data from a number of trials and other studies. The first column of numbers in Table 5.2 shows these average annual costs at 2012/13 price levels.

These healthcare costs cover all primary, community and secondary care services used. For people living in the community these average healthcare costs are: £2,751 per annum for those with mild dementia, £2,695 for those with moderate dementia, and considerably higher at £11,258 for those with severe dementia. The pattern of healthcare costs is different for people in residential care: £4,504 (mild), £9,438 (moderate) and £8,689 (severe). The reason for the different pattern is that the NHS pays the full costs for those in long-stay hospital care and some of the costs for those in nursing home care, under the continuing healthcare arrangements. Over the full prevalent population of people with dementia, healthcare costs average £5,285 per person per year.

**Table 5.2: Average annual cost per person with dementia, by severity and setting (£, 2012/13 prices)**

	Healthcare	Social care	Unpaid care	Other costs	Total costs
<b>People with dementia living in the community (average cost)</b>					
<b>Mild dementia</b>	2,751	3,121	19,714	137	25,723
<b>Moderate dementia</b>	2,695	7,772	32,237	137	42,841
<b>Severe dementia</b>	11,258	10,321	33,482	136	55,197
<b>All severity levels</b>	3,152	4,054	21,956	137	29,298
<b>(Sector cost as % of total)</b>	(10.8%)	(13.8%)	(74.9%)	(0.5%)	(100%)
<b>People with dementia living in residential care (average cost)</b>					
<b>Mild dementia</b>	4,504	24,737	1,067	136	30,444
<b>Moderate dementia</b>	9,438	25,715	2,901	136	38,190
<b>Severe dementia</b>	8,689	25,874	2,119	136	36,817
<b>All severity levels</b>	8,542	25,610	2,450	136	36,738
<b>(Sector cost as % of total)</b>	(23.3%)	(69.7%)	(6.7%)	(0.4%)	(100%)
<b>All settings (average cost)</b>					
<b>Mild dementia</b>	2,932	5,362	17,781	137	26,212
<b>Moderate dementia</b>	7,837	21,455	9,865	136	39,294
<b>Severe dementia</b>	9,300	22,176	9,575	136	41,187
<b>All severity levels</b>	5,285	12,584	14,237	136	32,242
<b>(Sector cost as % of total)</b>	(16.4%)	(39.0%)	(44.2%)	(0.4%)	(100%)

Figures may not add up due to rounding.

Applying these per-person averages to the corresponding prevalent populations generated estimated total healthcare costs for each of the severity-setting categories and overall (Table 5.3). In making these calculations an adjustment was made to exclude the costs of dementia-specific services, such as memory clinic attendances, for the proportion of people whose dementia it can be assumed is undiagnosed. For those people who do have their dementia diagnosed the overall cost of diagnosis is estimated on the basis of £650 per diagnosis. An estimate was also included of additional investment in dementia care in the form of incentives to GPs to increase diagnostic rates (estimated at £25.6 million; communication from the Department of Health). The overall total is £4.31 billion, of which around £85 million is spent on diagnoses.



**Table 5.3: Total annual cost, by severity and setting (£, in millions, 2012/13 prices)**

	Healthcare	Social care	Unpaid care	Other costs	Total costs
<b>People with dementia living in the community (total annual cost)</b>					
<b>Mild dementia</b>	1,120	1,271	8,029	56	10,476
<b>Moderate dementia</b>	168	484	2,007	9	2,667
<b>Severe dementia</b>	267	244	793	3	1,307
<b>All severity levels</b>	1,555	1,999	10,829	67	14,450
<b>(Sector cost as % of total)</b>	(10.8%)	(13.8%)	(74.9%)	(0.5%)	(100%)
<b>People with dementia living in residential care (total annual cost)</b>					
<b>Mild dementia</b>	212	1,165	50	6	1,434
<b>Moderate dementia</b>	1,887	5,142	580	27	7,636
<b>Severe dementia</b>	660	1,964	161	10	2,795
<b>All severity levels</b>	2,759	8,272	791	44	11,866
<b>(Sector cost as % of total)</b>	(23.3%)	(69.7%)	(6.7%)	(0.4%)	(100%)
<b>All settings (total annual cost)</b>					
<b>Mild dementia</b>	1,332	2,436	8,079	62	11,910
<b>Moderate dementia</b>	2,055	5,626	2,587	36	10,303
<b>Severe dementia</b>	926	2,209	954	14	4,102
<b>All severity levels</b>	4,314	10,271	11,620	111	26,316
<b>(Sector cost as % of total)</b>	(16.4%)	(39.0%)	(44.2%)	(0.4%)	(100.0%)

Figures may not add up due to rounding.

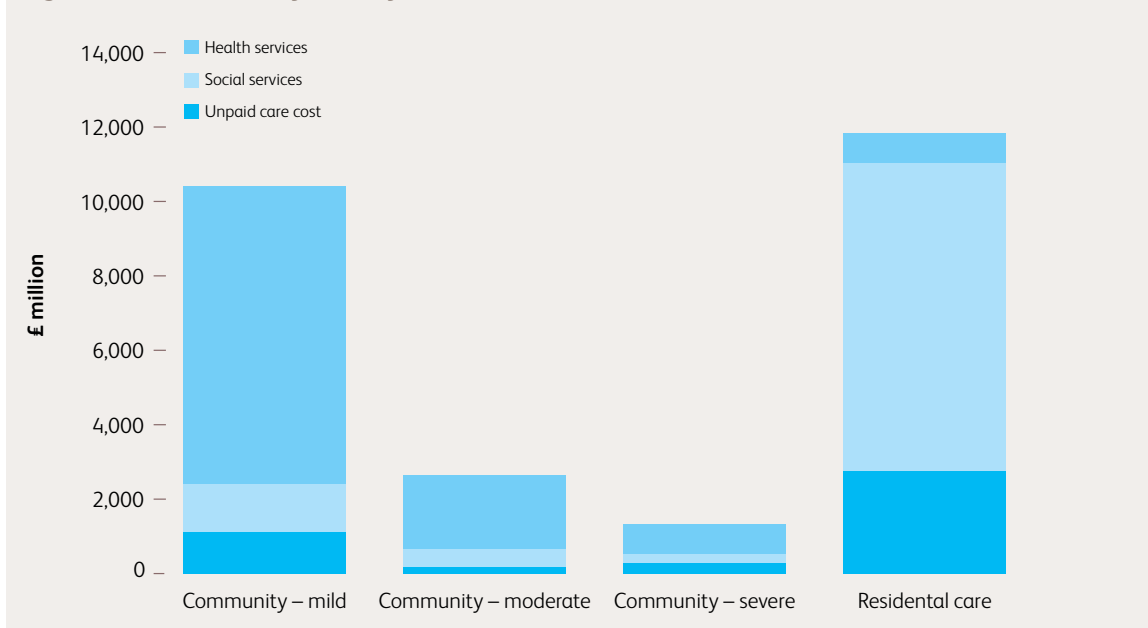
Healthcare accounts for 10.8% of total cost for people with dementia living in the community, 23.3% for people in residential care, and 16.4% overall.

### Social care costs

Average annual social care costs per person with dementia, by severity level and setting, are given in the second column of figures in Table 5.2. These figures cover the public and private costs of assessment and care management, residential care and home-based community care. For people living in the community these average annual social care costs are: £3,121 (mild dementia), £7,772 (moderate) and £10,321 (severe). For people living in residential care settings there is much less variability, partly because of the difficulty of identifying per-person differences within care homes: £24,737 (mild), £25,715 (moderate) and £25,874 (severe). Over the full prevalent population of people with dementia (and all severity levels), social care costs average £12,584 per person per year.

Applying these per-person averages to the corresponding prevalent populations gives the total social care costs in Table 5.3. The overall social care figure for the UK in 2013 is £10,271 million. This total includes costs for assessment and care management of around £450 million. Residential care costs excluding assessment and care management total around £8,100 million, of which about one-third is paid by local authorities and two-thirds by care home residents themselves. The costs of community care excluding assessment and care management are around £1,075 million to local authorities and around £650 million to service users themselves.

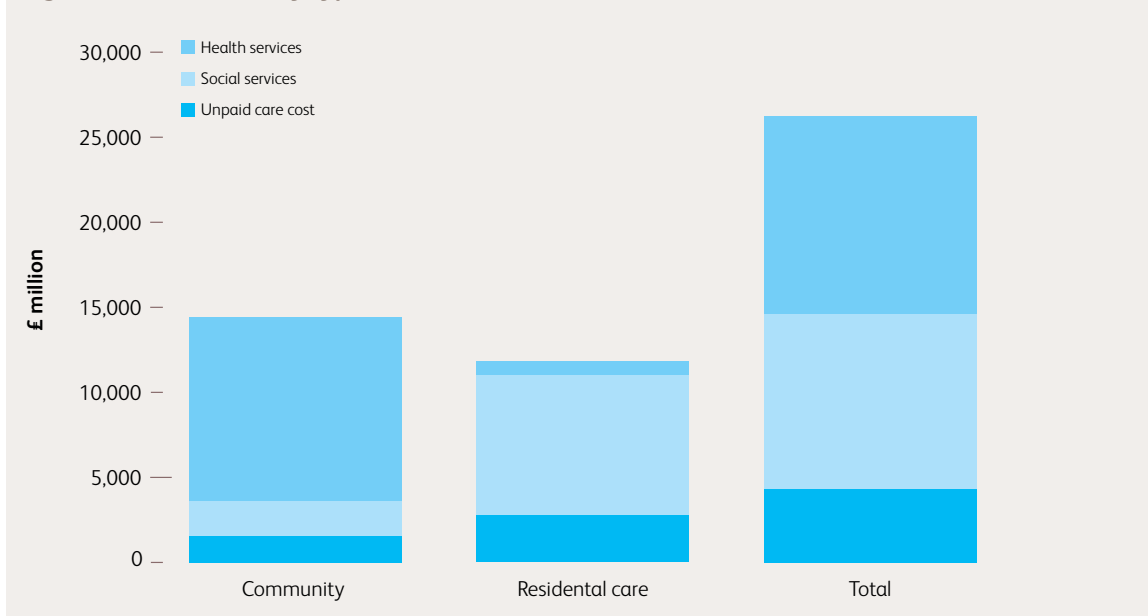
**Figure 5.2: Total costs by severity of dementia**



Social care accounts for 13.8% of total cost for people with dementia living in the community, 69.7% for people in residential care, and 39.0% across both settings.

For people with dementia aged 65 and over, official local authority data for England, together with estimates of self-funders, suggest that around 65% of residential social care costs and around 40% of community-based social care costs are met by the users themselves (although there is much uncertainty about the 40% figure). For people with early-onset dementia, official local authority data suggest that only around 10% of residential social care costs and only around 5% of community-based social care costs are met by the care recipients themselves. Social care is either publicly funded (£4.5 billion; 17.2% of the overall total cost of dementia) or privately funded (£5.8 billion; 22.9% of the total).

**Figure 5.3: Total costs by type of care**



## Distribution of costs between services

The nature of the data available makes it impossible to provide an overall breakdown of health and social care costs into each of its service components, but in Table 5.4 illustrations are provided of the disaggregation of costs from three previous studies. It is clear that there are quite marked variations between studies, in part an illustration of the inherent heterogeneity of needs and responses to them within the population of people with dementia.

**Table 5.4: Distribution of costs of care between services (%), excluding unpaid care**

	<b>CST<sup>a</sup></b>	<b>MCST<sup>b</sup></b>	<b>MCST<sup>c</sup></b>	<b>SADD<sup>d</sup></b>	<b>SADD<sup>e</sup></b>
	<b>Community &amp; care homes</b>	<b>Community</b>	<b>Community &amp; care homes</b>	<b>Community</b>	<b>Community &amp; care homes</b>
<b>Short-stay accommodation</b>	0.7	2.4	1.9	n/a	n/a
<b>Hospital services</b>	43.1	13.1	13.6	44.1	47.2
<b>Community healthcare</b>	15.9	6.3	8.8	10.9	18.8
<b>Community social care</b>	15.9	28.5	24.3	25.2	16.0
<b>Adaptations and equipment</b>	n/a	0.4	0.4	n/a	n/a
<b>Day services</b>	28.5	37.0	32.1	19.8	18.0
<b>Medication</b>	11.8	12.4	19.0	n/a	n/a
<b>(Total)</b>	(100.0)	(100.0)	(100.0)	(100.0)	(100.0)

a People recruited for the CST study; data refer to baseline (pre-randomisation) service use; community and care home samples combined. Source: Knapp et al, 2006.

b People recruited for the MCST study; data refer to baseline (pre-randomisation) service use; community sample only. Source: D'Amico et al, 2014.

c People recruited for the MCST study; data refer to baseline (pre-randomisation) service use; community and care home samples combined. Source: D'Amico et al, 2014.

d People recruited for the SADD study; data refer to baseline (pre-randomisation) service use; community sample only. Source: Romeo et al, 2013.

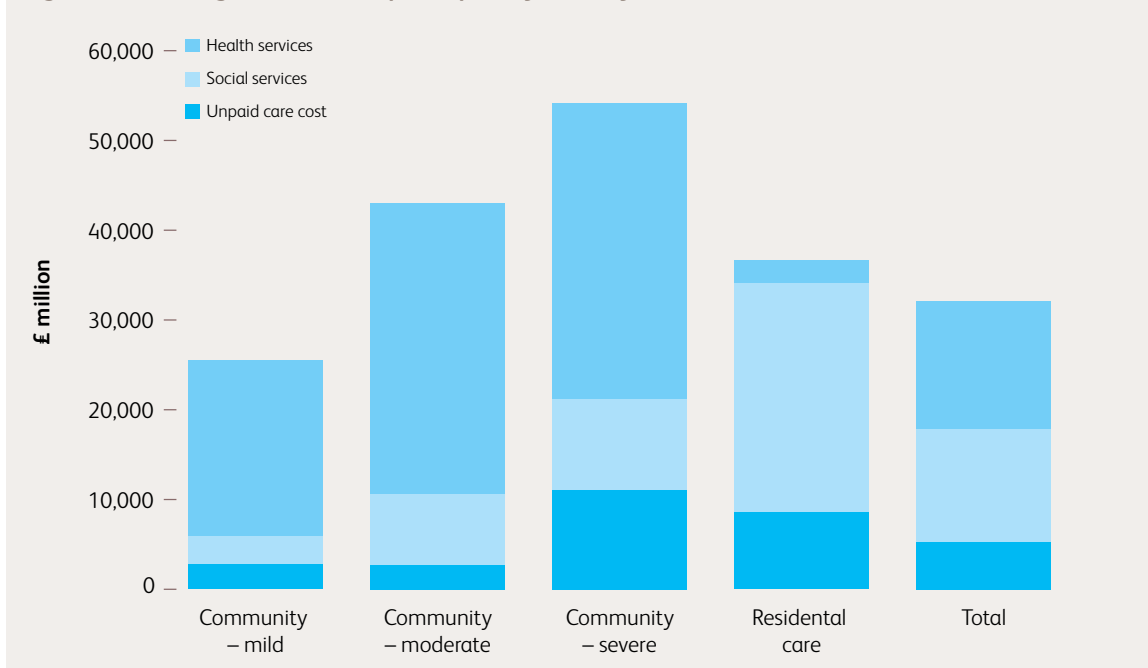
e People recruited for the SADD study; data refer to baseline (pre-randomisation) service use; community and care home samples combined. Source: Romeo et al, 2013.

## Unpaid care costs

The imputed total cost of unpaid care for people with dementia in the UK is £11.6 billion using 'core' assumptions, which distinguish between the estimated time spent providing different types of care by valuing the more 'hands-on' ADL-type care at replacement cost and valuing other hours at opportunity cost, and taking into account carer age and employment status. The per-person costs are summarised in Table 5.2, and the aggregate costs in Table 5.3.

For people living in the community, the average annual cost of unpaid care is £19,714 for people with mild dementia, £32,237 for those with moderate dementia, and £33,482 for those with severe dementia. Unpaid care accounts for three-quarters (74.9%) of total cost for all people with dementia living in the community.

Figure 5.4: Average annual cost per capita by severity of dementia



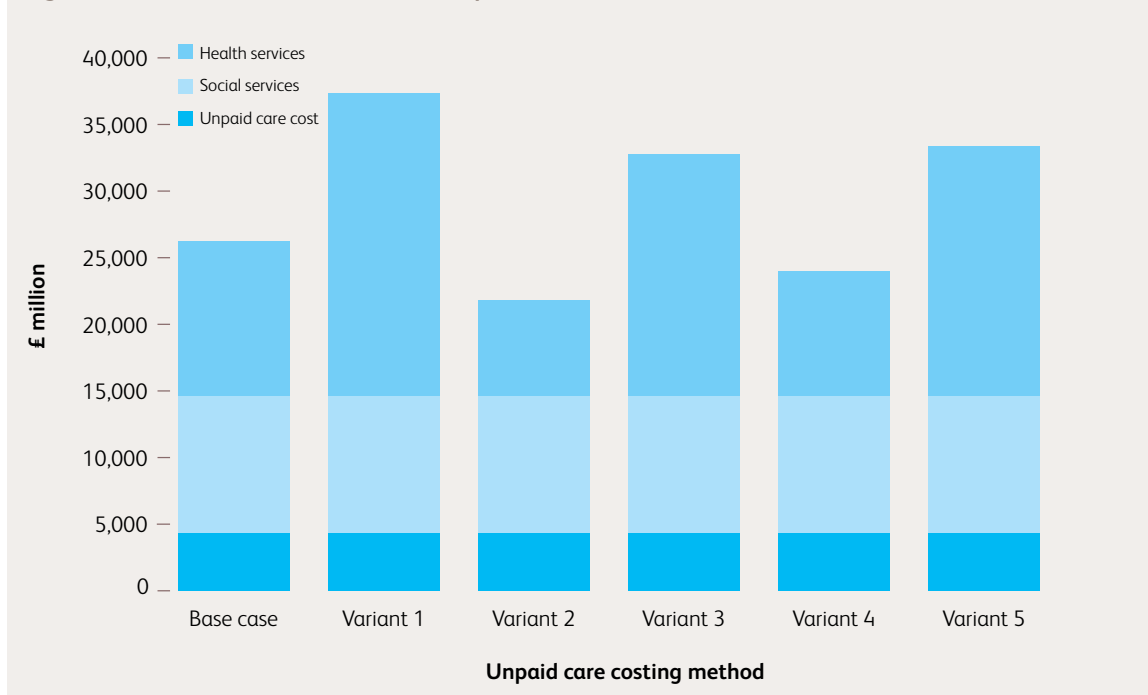
For people with dementia in residential care, the inputs from unpaid carers are considerably smaller, with costs averaging £1,067 (mild), £2,901 (moderate) and £2,119 (severe). Over all severity levels, 6.7% of the total cost of residential care is accounted for by unpaid care. For the full prevalent population of people with dementia (and all severity levels), unpaid care costs average £14,237 per person per year (44.2% of total cost).

The researchers of this report explored some variant approaches to the costing of unpaid care:

- Variant 1: Replacement costs approach, using as an hourly rate the cost of using formal home care (£19 per hour).
- Variant 2: Opportunity cost approach, using the National Minimum Wage (£6 per hour).
- Variant 3: Opportunity cost approach, using the national average wage (£15.15 per hour).
- Variant 4: Distinguishing by type of care provided, using replacement costs for ADL activities (£19 per hour) and the National Minimum Wage for the estimated time providing help with IADLs and supervision (£6 per hour).
- Variant 5: Same as Variant 4, but using the national average wage for the time spent on IADLs and supervision (£15.15 per hour).

Total costs under variant assumptions range very widely: from £7.1 billion to £22.5 billion. Figure 5.5 illustrates that the overall estimate of the cost of dementia is very sensitive to the method used to cost unpaid care.

Figure 5.5: Variants in total costs for unpaid care



## Police costs

Police costs of missing person enquiries attributable to dementia probably range between £22.1 and £40.3 million per year. This report takes the mid-point (£31.2 million) as the 'core' estimate for the purposes of aggregation.

Data from Sussex suggest that one in fifteen missing person enquiries are for people with dementia (Masters, 2013). Nationally, the number of missing person reports in the UK is in the region of 250,000 people annually (Houghton-Brown and Newiss, 2010), which suggests that every year the police deal with around 16,700 missing person enquiries related to dementia. Shalev Greene and Pakes (2014) estimate that the police cost for each missing person case is '£1,325.44 as a realistic minimum and £2,415.80 as a realistic estimate of cost of medium-risk medium-term cases'. Taking their 'realistic minimum' cost per case estimate, the yearly police costs would be of £22.1 million; the total would be £40.3 million if their realistic estimate of a medium-risk case is used.

## Advocacy and support costs

Figures provided to the authors on advocacy and support activities by Alzheimer's Society and Dementia UK amount to nearly £5.2 million a year. Since there are other charities providing such support, this figure is certainly an underestimate.

## Research costs

Alzheimer's Society spent £5.8 million on research in 2013 and Alzheimer's Research UK funding was £6.8 million. Overall, it has been estimated that research expenditure in the dementia area in the UK in 2013 was around £75 million (compared to £45 million in 2009) (Alzheimer's Society, 2014). This figure excludes research by pharmaceutical companies and other private-sector companies. Research expenditure is likely to grow rapidly, as a result of increased government and voluntary sector commitment to research on dementia.

## Costs of premature mortality

Two different approaches were used to estimate QALYs lost due to premature mortality relating to dementia. The first approach considers YLLs and uses data from the 2010 Global Burden of Disease study (Horton, 2010). The total YLLs for all those aged 30 and over is estimated at around 161,200, which amounts to some 118,000 QALYs lost. If each QALY is valued at £20,000, this implies a value of lost QALYs from premature death due to dementia of around £2.4 billion.

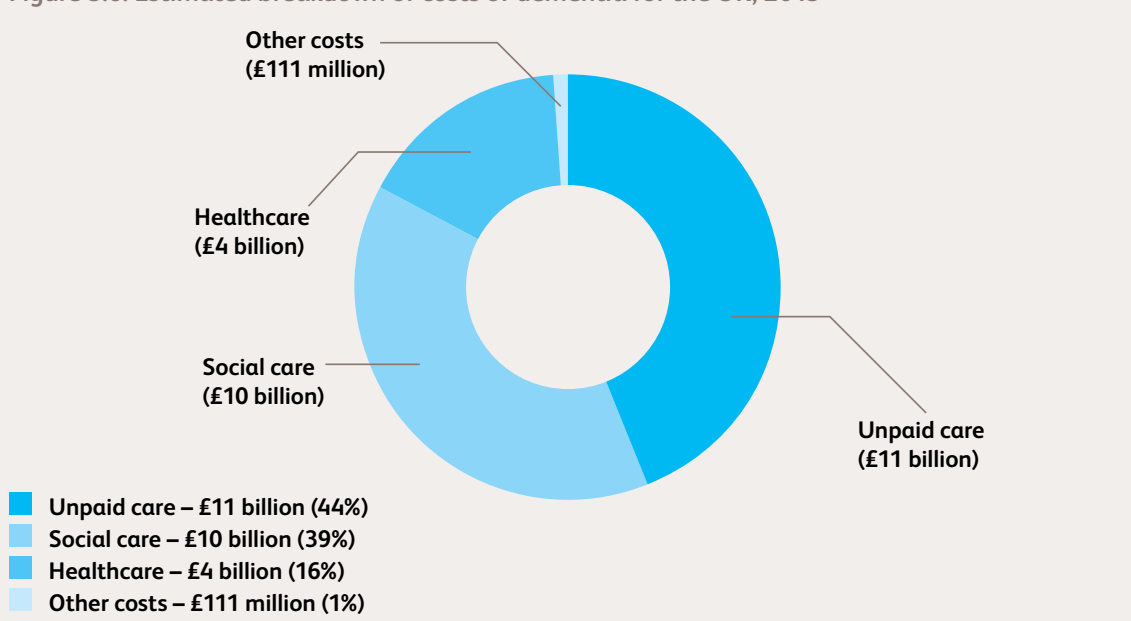
The second approach considers numbers of deaths of people with dementia. In 2013, there were around 490,000 deaths in the UK of people aged 65 and over. On the basis that 30% of these people had dementia, there were about 150,000 deaths of people with dementia. Assuming that each death with dementia involves on average a loss of 1.3 QALYs, and valuing each QALY at £20,000, implies a value of lost QALYs from premature death due to dementia of £3.8 billion.

This latter estimate should be treated with considerable caution as it does not include any deaths below age 65 of people with early-onset dementia. More importantly, it assumes that lost QALYs for a person dying at age 85 can be treated as the average case. The loss is clearly greater for those dying before 85 and lower for death at higher ages.

## Total costs and their distribution

The analyses suggest that the direct cost of health and social care associated with dementia in the UK is £14.6 billion (at 2012/13 prices), 70% of this direct cost falling to the social care sector. Unpaid care costs add another £11.6 billion, and other costs (police time, research, advocacy and support by the voluntary sector) amount to approximately £0.1 billion. Aggregating these components gives an overall cost of £26.3 billion, of which the unpaid care element accounts for 44.2%. These estimates are illustrated in Figure 5.2. There are, in addition, costs associated with premature mortality of between £2.4 billion and £3.8 billion, but the authors hesitated to include these in the overall total as the figure is very tentative (on both conceptual and empirical grounds).

Figure 5.6: Estimated breakdown of costs of dementia for the UK, 2013



## 5.4 Discussion

### Context and aims

Decisions on priorities for developing services for people with dementia and on priorities for research should be informed by reliable estimates of the numbers of people with dementia and the costs – both to public funds and to society more widely – of providing treatment, care and support. The Alzheimer’s Society commissioned two linked studies in this context: a new study of the prevalence of dementia in the UK and a new study of the costs of dementia. The aim was for these studies to revisit and update findings reported in Dementia UK 2007 report (Alzheimer’s Society, 2007). (Appendix B summarises some of the details of this and other previous studies of the cost of dementia.)

### Strengths and limitations

The cost estimates use newly available data drawn from a range of sources. They build in part on the framework in the PSSRU long-term care model, on recent work by members of the team on dementia scenarios, on data collected in a number of recent UK trials and other studies of people with dementia, and of course in part on the new prevalence figures reported earlier in this report. This has allowed the cost estimates in this report to be grounded in today’s health and social care system context, and to include a wider range of costs than has been previously been possible (as discussed further below). The estimates in this report also benefit from developments in the international literature on the costs of dementia, in particular recent literature on methods to cost unpaid care. In many ways, therefore, these new estimates represent a considerable improvement – in terms of method, data sources and coverage – on previous studies.

Nevertheless, this study has a number of limitations. The researchers were not able to attach costs to all of the likely impacts of dementia in the UK. Notable among the omissions are: costs associated with the use of healthcare and other services by carers attributable to being a dementia carer; the full costs to non-health sectors such as police and fire services; and the impact on hospital admissions and other healthcare use not related to but complicated by co-morbid dementia (longer periods of inpatient stay, for example).

They were also not able to capture adequately the impact of dementia on quality of life for people living with dementia or their carers. Some estimates of costs have been included that are linked to reduced length of life, as a way to capture the economic impact of premature mortality. Loss of quality of life while living with dementia is not included in the estimates: it may in aggregate cost terms be somewhat lower than the loss of QALYs due to premature mortality related to dementia.

It was not possible to estimate costs separately for the individual countries of the UK since the requisite disaggregated data were not available for each country. The breakdown by country may be broadly in line with the breakdown of the older population, but it should be noted that public expenditure on healthcare per person is lower in England than in the other three countries (Bevan et al, 2014).

The authors of this report used data from trials that recruited people who cannot be assumed to be representative of the entire population of people with dementia. In particular, all participants in the trials used had been diagnosed with dementia, and it can be expected that those without a dementia diagnosis are likely to use fewer care services than those who have a diagnosis. Assumptions were made to address this consideration. The estimate of diagnosis and assessment costs is based on an uncertain estimate of incidence.

There has been very little research on the use of care by people with early-onset dementia, and the researchers had to assume that they use similar amounts of care as those in the youngest-old age group (65 to 69 years) for which there is no available service use data.

Generally, estimates inevitably require many assumptions, especially as they have to draw on different sources and bridge gaps in available data. This report has explored the sensitivity of its estimates with respect to some of the assumptions, particularly the costing of unpaid care.



## Implications of these cost estimates

### Overall costs

The overall economic impact of dementia in the UK is enormous: £14.6 billion in direct costs, £11.6 billion in indirect costs associated with inputs from unpaid carers, somewhere between £2.4 billion to £3.8 billion as the imputed cost of premature mortality, and some other, much smaller, measurable costs (police, research and advocacy).

A word of caution should be entered here immediately. For some purposes it does not make sense to aggregate the direct and indirect costs, as argued by Chisholm et al (2010), among others. Nor can total dementia cost be compared with national gross domestic product (GDP) since GDP only measures the value of the 'formal' economy and does not contain any of the unpaid contributions to the economy (such as unpaid care).

### Healthcare costs

The healthcare costs of dementia are considerable, totalling £4.3 billion. This is equivalent to approximately 3.4% of total NHS spending in the UK in 2013. Healthcare costs are particularly high for people with severe dementia living in the community, and those with moderate or severe dementia living in care homes. It was not possible to obtain estimates for all relevant activities: the efforts made by the NHS to improve dementia awareness, to increase diagnosis rates and to provide enhanced training to key staff would all represent additional health-related costs.

### Social care costs

Although healthcare costs are high, social care costs are 2.5 times higher. For the UK as a whole, these social care costs amounted to £10.3 billion in 2013. This total comprises around £4.5 billion to local authority social services for publicly funded care and around £5.8 billion to services users themselves in terms of privately purchased care and user charges for publicly subsidised care. This breakdown should be treated with caution because of uncertainty about the numbers of service users self-funding their care. It nevertheless illustrates the extent to which the current means-tested arrangements, prior to implementation of the government's funding reforms from 2016 (introduced by the 2014 Care Act), require service users to meet or contribute to the costs of their social care. It is not possible to calculate the proportion of total adult social care expenditure which is accounted for by dementia because, although there are good data on what local authorities (and their equivalents across the UK) spend on social care, there are not good estimates of total private social care spending. Consequently there is no reliable denominator (total social care expenditure) against which to compare the estimated dementia costs reported here.

For people living in the community, social care costs have quite a steep 'severity gradient', with annual average cost being around £3,100 for mild dementia, £7,800 for moderate dementia, and £10,300 for severe dementia. For those people in care homes, there is little observable difference between severity levels, with social care costs averaging around £25,600 across the full group of residents with dementia. This small gradient may be a result of limitations in the data, since available sources of care home expenditure do not report costs by dementia severity.

When the researchers grouped together people living in the community with those in care homes, they found that average direct cost by dementia severity rose from around £8,300 for mild, to £29,300 for moderate and £31,500 for severe. The contribution of social care to these totals was 65%, 73% and 71%, respectively.

A proportion of the social care cost is privately funded, given that social care is means-tested in the UK. The proportion that is privately funded is higher for people with moderate or severe dementia than for people with mild dementia. This is because care home provision is concentrated on people with moderate and severe dementia and people in care homes are more likely to be required by the means-test rules to fund their own care privately than users of home-based care.

### **Unpaid care and support**

Even though the direct health and social care costs of dementia are high, they are dwarfed by the indirect costs associated with unpaid care and support provided by family members and other carers. As noted previously, it is neither straightforward nor uncontroversial to attach a cost to unpaid care, and a range of approaches is explored here. However, the method used for the 'core' estimate in this report, seems appropriate for the circumstances, conservative and broadly consistent with what has been done in previous dementia costing studies (including in the Dementia UK 2007 report calculations).

Consequently, comparisons can be made between the two studies: the cost of unpaid care is now 54% higher than in 2005/06 (after adjusting for inflation, and removing costs for people with early-onset dementia, who were not included in the earlier study). Although there are some differences between the two studies in the methods of calculation of these costs, it is clear that the contribution that society places on unpaid dementia carers is not only huge but also growing faster than expenditure on 'formal' health and social care services (see below). Carers need to be supported and nurtured: their own needs should be assessed and responded to, not just because 'they are citizens too', but also because poor carer wellbeing is likely to be associated with poorer outcomes for the person with dementia, and with higher costs.

### **Variations**

The estimated costs reported here are the averages for people with different severities of dementia living in different settings. Applying those averages to the prevalent population is the correct way to arrive at overall national figures for direct and indirect costs. Nevertheless, such estimates hide considerable variation from one individual to another in patterns of care and support – and therefore also in patterns and levels of cost – to be found in the UK today. It is beyond the scope of this study to examine those variations, but commissioners and providers will obviously want to be able respond to individual characteristics and circumstances in making their decisions.

## Comparisons with 2005/06

The new costs for dementia in the UK proposed in this report can be compared with the estimates for 2005/06 published seven years ago (reported in Alzheimer's Society, 2007), although with caution. The earlier study did not include: costs for police, research or advocacy costs; costs for diagnosis or assessment; costs for people with early-onset dementia; or separate costings for the various severity levels in care homes.

After removing the 'other', diagnosis and assessment, and early-onset elements, it was estimated that the total cost of dementia in 2013 was £24.4 billion. After adjusting the 2005/06 figures to the same price base (which requires uplifts of between 12% and 20%, depending on cost category), the researchers found that the total figure is 24% higher today than seven years previously. Over that same period, there was a 16% increase in the estimated prevalent number of people aged 65 or over with dementia, which suggests that perhaps two-thirds of the increase in total cost could be attributed to growth in the numbers of people with the condition, and about one-third to an increase in cost per individual.

Some of that per-person cost difference over time will be due to differences in method between the two studies, but it is difficult to say precisely how much, since both service and unpaid care costs are calculated in similar but not identical ways across the two studies. This is one reason why any comparisons between the two years should be made cautiously. Another reason is that the earlier figures were based on just one study (in South London), whereas the new estimates reported here draw on data from a dozen studies conducted across England (and with some individuals recruited from other parts of the UK).

At 2012/13 price levels, average annual service cost (healthcare and social care) for someone with mild dementia living in the community was £8,634 in 2005/06, compared with £5,872 in 2013. For someone with moderate dementia the figures were £10,039 and £10,467, respectively, and for someone with severe dementia they were £12,037 and £21,579.

It is difficult to say with confidence whether there have been changes in the intensity of formal care support in the community over the period, but from these comparisons it might be concluded that there has been a reduction in the level of formal care support for people with mild dementia, which may reflect the tightening of health and social care budgets over this period, and a sizeable increase in support for people with severe dementia, consistent with efforts to support people in their own homes rather than admit them to care homes. (The authors estimate that the number of older people with dementia in care homes increased by 10% between the two years, whereas the number of older people with dementia increased by 16%.) Inflation-adjusted costs of residential care are fairly similar: £35,215 in 2005/06 and £34,152 in 2013.

For unpaid care, this report has already noted growth of approximately 54% in the inflation-adjusted cost of unpaid care over the period. Because of differences in costing method between the two studies, it is not possible to say how much of this is due to any change in the availability or intensity of unpaid care.

## **Altering the level and pattern of costs**

It should be emphasised that the costs of dementia have been calculated in this report, but treatment, care or support arrangements have not been evaluated. Consequently, the figures here cannot be used as a basis for guiding detailed decisions by commissioners or providers, although it is hoped that the sheer scale of the overall economic impact will help to concentrate their minds on the scale of the dementia challenge facing the UK today and, in all likelihood, in the decades ahead.

Actions taken to meet more effectively the needs of people with dementia and their carers would be likely to change the pattern of care and support, and in turn to influence overall costs. For example, better recognition of dementia and a higher rate of diagnosis would push up some costs (such as those associated with assessment, diagnosis and immediate post-diagnostic support), but could subsequently reduce other costs, such as those associated with care home admissions (Dixon et al, 2014; Knapp et al, 2014). Wider access to good post-diagnostic treatment and care or better support for family carers could also change the pattern of costs and probably also total costs, as demonstrated in some recent simulation modelling (Knapp et al, 2014). A major contribution to cost containment might come from better preventive strategies, such as those outlined by Norton et al (2014).

## **‘Good’ and ‘bad’ costs**

Finally, it must be recognised that costs are not necessarily ‘bad’, even though it might often appear to be the objective of a policy-maker or commissioner to reduce them. What those decision-makers are generally trying to do is to contain costs within the constraints of available budgets, and to allocate resources in ways that are efficient and equitable. Although the distinction between ‘good costs’ and ‘bad costs’ is not one that would be found in a standard economics textbook, there is a difference that needs to be recognised. The ‘good costs’ are associated with care and support delivered in response to assessed needs and in cognisance of expressed preferences, while the ‘bad costs’ are those economic impacts associated with failure to do just that, ie failure to identify or respond appropriately to needs and preferences (such as crisis admissions to hospital, unnecessarily long periods of inpatient stay, unnecessarily early admissions to care homes). The figures presented here for the cost of dementia do not differentiate the ‘good’ and the ‘bad’.

## 5.5 Conclusions

This chapter has provided an updated estimate of the economic impacts of dementia in the UK using a robust methodology. As emphasised throughout, cost findings but not cost-effectiveness findings are offered here, since this report contains no evaluation of any treatment, care or support interventions.

The new estimates of the costs of dementia are considerably greater than those previously suggested for the UK. In particular, the overall total of just over £26 billion is 24% higher than the figure reported in the Dementia UK 2007 report. About two-thirds of the growth over time can be attributed to the increase in the number of people with dementia.

# Recommendations

### Overview

This report recommends the following five actions:

- Push for improvements in the quality, coverage and regularity of surveys into the prevalence and numbers of people with dementia in the UK.
- Move towards a purely quantitative method for analysing and synthesising data on the prevalence of dementia in the UK.
- Enter into specific research on the number of individuals from black, Asian and minority ethnic groups with dementia, in order to reflect the changing demographic of the UK's ageing population.
- Continue to monitor the impact of factors that may reduce the prevalence of dementia in the UK.
- Improve the evidence base for quantifying the impact of dementia on quality of life.

Since the first edition of the Dementia UK report in 2007, much progress has been made in tackling the dementia epidemic that is on the horizon, at both a policy and a community level. However, as this report makes evident, the means of surveying, estimating and reviewing the prevalence and numbers of people with dementia in the UK, and the costs of dementia to the economy and society, are far below the standard that is required for truly informed decision making. This is unacceptable, and steps should be taken to improve the quality of data available. This is especially relevant given the changing demographics of our ageing population and new pressures on the economy that supports this population.

More accurate estimations will ensure that decisions on priorities for developing services for people with dementia and on priorities for research are well-informed, resulting in the best treatment, care and support for those with dementia in our communities.

## **Recommendation 1 Push for improvements in the quality, coverage and regularity of surveys into the prevalence and numbers of people with dementia in the UK**

Good quality, generalisable population-based research for the estimation of numbers of people with dementia in the UK and other countries – their residential status, their needs for care, their access to and use of services, and attendant costs – is essential.

Nationally representative samples of adequate size are vital, along with specific locality studies that drill down into the demographics of those with dementia in our society and their needs. A combination of national and specific locality surveys are essential for informing policy-makers.

The surveys should be repeated, regularly, to monitor trends in prevalence over time. For comparisons to be meaningful, the same methodology should be applied on each occasion, particularly as regards the definition and ascertainment of dementia, and levels of severity.

There should be separate sampling of private homes, and over-sampling of all types of care home (providing different levels and types of care).

The data from high-quality surveys are vital for rational health planning, monitoring service delivery, and quality improvement in prevention and care. If the evidence-base were improved in this way, there would no longer be any need for Delphi consensus procedures.

## **Recommendation 2 Move towards a purely quantitative method for analysing and synthesising the data on the prevalence of dementia in the UK**

The current Delphi consensus was commissioned by the funders of this report as the preferred approach for incorporating the evidence into the bigger picture of dementia prevalence. However, the relative validity of this method of estimation will be a matter of judgment in the future.

It can be argued that, due to potential vulnerabilities in the Delphi consensus method, it would be highly desirable to move to a purely quantitative method for synthesising prevalence data. However, that will not be possible until the quality and coverage of prevalence estimates improves.

## **Recommendation 3 Enter into specific research on the number of individuals from black, Asian and minority ethnic groups with dementia, in order to reflect the changing demographic of the UK's ageing population**

This is an important yet under-studied area. Numbers of older people from black, Asian and minority ethnic groups are increasing rapidly in the UK, but as was the case in 2007, more epidemiological research is required to clarify dementia prevalence and risk among black,

Asian and minority ethnic groups. It is essential that their needs are met by accessible and responsive services, and that any evidence for increased risk of dementia is addressed by focused attention on modifiable risk factors across life.

#### **Recommendation 4 Continue to monitor the impact of factors that may reduce the prevalence of dementia in the UK**

There is some evidence from the UK, as well as other high-income countries that prevalence, or incidence of dementia, or both may be declining. This may be the result of improvements to education standards, cardiovascular health, activity levels and the reduction of other known risk factors. There is no reason to assume that age-specific prevalence will remain constant over time. Since the drift of government policy is towards earlier diagnosis, increased use of evidence-based healthcare services, increased integration and coordination of care, and reduced transition into residence in care homes, changes in age-specific prevalence can also be anticipated, and should be monitored.

Some studies have also noted a reduced age-specific incidence of dementia, and reduced survival after onset. This may be explained by incidence being deferred to older ages, closer to the natural limits of the life span, with survival time being determined by factors other than dementia. This is an important issue and as a result it would also be useful to estimate survival with dementia, by linking survey participants, prospectively, to mortality data from the NHS Central Registry.

#### **Recommendation 5 Improve the evidence base for quantifying the impact of dementia on quality of life**

It remains difficult to accurately measure the impact of dementia on quality of life in economic terms. For example, we still have relatively little information about the impact on unpaid carers in terms of health, forgone work opportunities and lost leisure time. There are also relatively few sources of information about how carer life quality relates to the care needs of the person they care for, and the formal care services they have access to. There are also important information gaps about the use of privately sourced home care and its impact. Further studies are needed in these areas.

#### **More information**

For more information please contact Alzheimer's Society by calling 020 7423 3500 or visit [alzheimers.org.uk](http://alzheimers.org.uk)





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Appendix A

# Number of people with dementia according to local authorities across the UK in 2013

To view the number of people with dementia according to local authorities across the UK in 2013, please see [alzheimers.org.uk/dementiauk](http://alzheimers.org.uk/dementiauk)

## Appendix B

# Recent studies of the cost of dementia

Appendix B: Cost of dementia studies summarised below were found to be interesting and useful in conducting this own study. They were not retrieved via systematic review.

Author and publication date	Country/region	Cost components (society)	Cost components (public sector)
Connolly et al (2012) <sup>a</sup>	Ireland	Unpaid care – care by person in full-time employment per hour; care by person not in full-time employment per hour. Assumption of 8.33 caring hours per day – opportunity cost approach. Costs premature mortality – ‘forgone earnings from premature death due to dementia’ (discounted at % per annum).	Primary and community resource use – GP visit; physiotherapist visit; occupational therapist visit; social worker visit; other (specialist) visit; respite day care; home help visit; meals on wheels; registered nurse visit; out-patient care – including Accident & Emergency; psychiatric inpatient care; residential care; mortality costs; medication costs.
Delavande et al (2013) <sup>b</sup>	USA	Out-of-pocket spending – looks at dental care and prescription medication (Consumer Expenditure Survey, average spending in 2009).	-
Ersek et al (2010) <sup>c</sup>	Hungary	Unpaid care – productivity loss related costs of the working-age caregivers; indirect costs; unpaid care costs of retired caregivers.	Drugs; GP visits; outpatient visits; inpatient care; emergency care; transportation; diagnostic; non-dementia-related health; direct medical; social care; other people’s (paid) help; healthcare cost of the caregiver; direct non-medical; direct.
Gustavsson et al (2011) <sup>d</sup>	Multiple	Unpaid care; time spent on supervision was assumed to have a zero value cost. Lost production for those under 65; Lost leisure time for those over 65.	Accommodation; hospitalisation; community care services.

Total cost [price base]	Total healthcare costs [price base]	Total social care costs [price base]	Total unpaid care costs [price base] (unpaid care as % of total)
EUR 1.7 billion [2010] (annual cost to Ireland – premature mortality costed at EUR 4.3 million)	Costs not split into equivalent categories.	Costs not split into equivalent categories.	EUR 807 million [2010] (47% of total cost)
\$5,646.42 [2009] (annual cost per person)	Spending on prescription drugs \$649.7 [2009]	Spending on nursing home care \$4,649.01 [2009]	
Severe: EUR 884.72; moderate: EUR 623.60; mild: EUR 355.23. Total EUR 535.71 [2007] (monthly cost per person)	-	-	EUR 49.96 [productivity loss related costs of the working-age caregivers] [2007] (9% of total average cost)
£9,308 in mild (ADAS-cog range 0–25), £13,980 (V16,408; \$20,055) in moderate (ADAS-cog range 26–40), and £19,957 in severe dementia (ADAS-cog range 41–70) [2006] (Annual cost of care per person in each severity is presented)	-	-	-



<b>Author and publication date</b>	<b>Country/region</b>	<b>Cost components (society)</b>	<b>Cost components (public sector)</b>
<b>Hurd et al (2013)<sup>e</sup></b>	USA	Unpaid home care. Caregiving time valued according to replacement cost and cost of forgone wages separately. Costs valued both ways according to split between ADL and IADL. Replacement cost approach and opportunity cost approach utilised.	Care purchased in marketplace (out-of-pocket spending; Medicare spending; formal home care; nursing home care). The following services were included: nursing home and hospital stays; medical visits; outpatients; home healthcare; special services (eg outpatient rehabilitation); prescription medication and dental services. Spending by Medicare was also recorded.
<b>Kang et al (2007)<sup>f</sup></b>	Korea	Out-of-pocket spending, person with dementia and carers loss of productivity.	Hospitalisation; institutionalisation; doctor visits; alternative medical visits.
<b>Knapp, Prince et al (2007)<sup>g</sup></b>	UK	Unpaid care, with three different unit costs applied as sensitivity analyses. Minimum wage for all unpaid carers, replacement cost for all unpaid care and replacement cost for specific unpaid care presented. Welfare benefits, lost production and tax revenues were calculated, but not included in the total as they are transfer payments.	Services include medication; inpatient and outpatient care, day hospitals; day centres; community health services; social care and respite care.
<b>Luengo-Fernandez (2010)<sup>h</sup></b>	UK	Unpaid care, differentiating carers who are economically active and inactive. National average wage applied as a unit cost for those economically active, and National Minimum Wage for those economically inactive. Productivity losses calculated (mortality and friction-adjusted morbidity losses).	Social care costs including only residential and nursing care home stays. Healthcare included primary care (dementia specific GP and telephone visits/telephone calls); hospital inpatients and outpatients Accident & Emergency; medication and private healthcare.

Total cost [price base]	Total healthcare costs [price base]	Total social care costs [price base]	Total unpaid care costs [price base] (unpaid care as % of total)
<p>\$215 [2010] (Unpaid care costed using replacement cost approach, plus care purchased in the marketplace), \$159 [2010] (Unpaid care costed using opportunity cost approach, plus care purchased in the marketplace)</p>	<p>Costs not split into equivalent categories.</p>	<p>Costs not split into equivalent categories.</p>	<p>\$106 [2010] (replacement cost), \$50 [2010] (opportunity cost). (49% of total if using replacement costs, 31% if using opportunity costs)</p>
<p>\$4,045,668 [2004] (The costs were converted to US dollars pre-publication)</p>	<p>\$982,338 [2004] – direct medical costs [costs paid by the insurer]</p>	<p>\$312,199 – nursing home costs</p>	<p>Productivity loss patient \$52,834, carers [\$456,252] [2004] (11% of total costs)</p>
<p>Minimum wage: £15.61bn; specific: £17.03bn; all: £24.39bn [2005/06]</p>	<p>£1.36bn [2005/6]</p>	<p>£9.54bn [2005/6]</p>	<p>Replacement cost for specific care: £6.13bn [2005/6], replacement cost for all care: £13.49bn [2005/6], minimum wage for all care: 4.71bn [2005/6] (as percentage of total costs: 36%, 55% and 30% respectively.)</p>
<p>£22.7bn [2008]</p>	<p>£1.2bn [2008]</p>	<p>£9.1bn [2008]</p>	<p>£12.1bn [2008] (53% of total costs)</p>

Author and publication date	Country/region	Cost components (society)	Cost components (public sector)
<b>Schwarzkopf et al (2011)<sup>i</sup></b>	Germany	Unpaid care – ‘Unpaid care was valued via replacement costs with the average wage rate of a home-help as proxy.’ ‘We assumed a minimum of 6 hours sleep and limited unpaid care giving time to a maximum of 18 hours per day.’ Travel expenses were included per day for caregivers who did not live with the person with dementia.	Long-term care; physician visits; drug prescriptions; in-hospital stays; non-physician services; medical aids; home healthcare; rehabilitation. Based on community living persons with dementia. Stage dependent cost of dementia; assumption that most with severe dementia were in residential care.
<b>Wimo &amp; Prince (2010)<sup>j</sup></b>	Western Europe	Unpaid care costed using average wage rate for all unpaid care. Sensitivity analyses conducted applying 50% and 25% of average wage to spouse caregiving, as well as applying a replacement cost approach (applying cost of a ‘social care professional’). Also investigated costing assistance with ADLs & IADLs, only basic ADL assistance, and combined ADL & supervision.	Direct social care costs (provided by community care professionals and in residential care settings) and direct medical care costs (costs of treating dementia and other conditions in primary and secondary care) were calculated. Direct medical care includes costs for hospital care, medication and visits to clinics. Direct social care costs include community services such as home care, meals on wheels and transport, and nursing and residential home care.

a A combination of top-down and bottom-up approaches were utilised in this study to address the lack of available data in certain key areas of interest. A societal perspective was adopted in this cost-of-illness study that determined the size of dementia in relation to the Irish economy.

b Out-of-pocket (OOP) spending determines the range, quality and quantity of services that are afforded to the person living with dementia and their carer. Using the Health and Retirement Study data, Delavande et al show that high dementia-related OOP does not affect spending as needed on other healthcare needs, although it may affect spending on other areas of life such as food spending.

c The cost to society is the primary focus here, with costs associated with service use being determined, not by the unit cost, but by the reimbursement rate. Resource Utilization in Dementia (RUD), Mini Mental State Examination (MMSE) and quality of life (EQ-5D) are brought into relationship with each other in this study. Costs are disaggregated according to severity as determined by the MMSE.

d This paper utilises the Resource in Dementia Lite (RUD) measurement to determine service use on cost of care. The focus on cost of care means the study omits discussions of quality of life and out-of-pocket spending, but not informal care. ADAS-cog severities are used to determine distinctions. Like the Wimo et al study (2002), carers indicated the amount of time per day spent on ADLs, IADLs and supervision tasks.

e Based on data from the Health and Retirement Study (HRS), this study used a subsample of 856 persons with a diagnosis of dementia to impute cognitive status to the full HRS sample (10,903 people). The study estimated the costs attributable to dementia by conducting multivariate regression models relating a cost component to imputed probability of dementia, coexisting conditions (eg hypertension) and demographic characteristics.

Total cost [price base]	Total healthcare costs [price base]	Total social care costs [price base]	Total unpaid care costs [price base] (unpaid care as % of total)
EUR 47,561 [2008] (annual cost per person)	EUR 9,396 [2008]	EUR 38,165 [2008]	-
\$210.12bn [2010]	\$30.19bn [2010]	\$92.88bn [2010]	\$87.05bn [2010] (100% average wage applied to spouse carers), \$67.56bn (50% average wage applied to spouse carers), \$57.82bn (25% average wage applied to spouse carers), \$95.1bn (replacement cost applied to spouse carers). (As percentages of total costs: 41%, 35%, 32% and 44%, respectively)

f 'The patients were stratified into three limitation groups according to their ADL score. The cost according to the three limitation groups was analysed.' This stratification is the more interesting aspect of this study as it sets the basis for determining levels of care and costs according to the amount of help needed rather than the MMSE score which, though useful, does not address informal care as helpfully as basing the discussion on the ADL–IADL balance. Out-of-pocket spending makes up \$1,644,368 of the costs, eg prescription medication. \$1,106,763 is made up of direct non-medical costs – 'includes out-of-pocket purchase for alternative medicine, subsidiary supplies, home helper, transportation, food, and accommodation'.

g Expert Delphi Consensus prevalence data is used. The dementia split reported is based on the Clinical Dementia Rating, not MMSE. Results here are based on a study conducted using a CSRI to collect service receipt data.

h Prevalence data taken from the European Community Concerted Action on the Epidemiology and Prevention of Dementia (EURODEM) study. The study compares cost of dementia to cost of other illnesses (eg cancer).

i Unpaid care time was determined according to carer responses given in interviews. In these interviews the researchers found there was some difficulty for the carers in differentiating between the time spent on ADLs, IADLs and supervision as separate from the two former caring categories. For this reason supervision was not included as a separate category in these costs. To gain the formal care costs, insurance claims data was used.

j This study, by including costs of unpaid care as well as costs of formal services, presents a comprehensive account of the costs associated with dementia. Like other studies included here, it takes account of the difference between help with IADLs and help with ADLs. It also takes account of differences in pay by gender in estimating the opportunity cost of unpaid care. Prevalence figures are obtained from a systematic review as part of the World Alzheimer Report 2009.



## Appendix C

# Methods for costing unpaid care

While most dementia cost-of-illness studies differ in their methods and coverage, they consistently show that, when included, one of the most important costs of dementia is that borne by unpaid carers. Caring for a person with dementia usually involves very long hours. Typically, carers of people with dementia provide help with a combination of personal-care tasks and household tasks such as cooking, but also spend considerable time ensuring that the person with dementia is safe and comfortable.

There is no clear consensus on the best methods to accurately reflect the costs of providing unpaid care. Given the large amount of hours of unpaid care provided to people with dementia, even relatively small variations in the methods used to cost unpaid care can result in large differences in the estimated total costs of dementia. The table in Appendix B shows that, mostly as a result of different estimation methods, estimations for the costs of unpaid care can represent from 9% to up to 66% of the total costs of dementia. An increasing number of studies are reporting their results using more than one method to show how sensitive the results are (for example, see Knapp et al, 2007; Hurd et al, 2013; Peña-Longobardo and Oliva-Moreno, 2014).

The two most widely used methods to calculate the cost of the hours of care provided by unpaid carers are the opportunity cost and replacement costs methods (see van den Berg et al, 2004, for a useful overview). The opportunity cost method (sometimes also referred to as the 'proxy goods method') costs unpaid care in terms of the value of the activities that carers are no longer able to carry out because of their caring commitments (work, leisure, housework, caring for other members of the family such as children, etc.). Most studies use wage rates as an approximation to the opportunity costs of caring, using information on the carers' own wages if they are working, or on the previous occupation if they are not currently working. A large proportion of carers are above the age of retirement and not in the labour market. Where individual wage information is not known, this is often inferred from the occupation if known, or from their age, gender and other characteristics. In studies where there is not enough information to make these assumptions, the minimum or the average wage figures are often used. It is important to consider that the wage rate may not be the best way to measure the cost of lost leisure time. Also, the other costs to unpaid carers, particularly the impact of caring on their own health would not be captured with this approach (Netten, 1993).

The replacement costs method attempts to value the care produced. This is typically done by assigning a cost to the hours of unpaid of care equal to how much it would cost to

replace those hours with professional carers, such as home care workers, or household help. This method tends to produce higher cost estimates than most versions of the opportunity costs method. An important issue is that, if all hours of unpaid care were to become paid care, it is unlikely that the same hours of care would be used. Particularly for care that involves supervision or carrying out household tasks, there are opportunities for joint production, meaning that tasks that are needed by the rest of the household can be carried out at the same time as providing care. For example Hassink et al (2011) estimated that about 20% of time caring for people with dementia was simultaneously used for household activities. This approach typically involves attempting to estimate the numbers of hours of care that are spent in different types of caring activities and the more sophisticated studies attempt to estimate the hours where there has been co-production.

In this report we have used a combination of the two methods. We have made a distinction between time spent providing help with personal care activities (such as providing help with 'activities of daily living', ADLs), to which we have applied a replacement costs approach; and time spent providing help with household tasks (such as 'instrumental activities of daily living', IADLs) and supervision, to which we have applied an opportunity costs approach. The rationale for making this distinction is that providing personal care is a more taxing form of caring, as it is usually 'time-bound' (it often needs to be provided at a time that is not of the carers' choosing) and unlike household help or supervision, it is not often possible to combine it with other activities, or to have joint production (Hassink and van den Berg, 2011).

## References for Appendix C

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**Alzheimer's Society is the UK's leading support and research charity for people with dementia, their families and carers. We provide information and support to people with any form of dementia and their carers through our publications, National Dementia Helpline, website, and more than 2,000 local services. We campaign for better quality of life for people with dementia and greater understanding of dementia. We also fund an innovative programme of medical and social research into the cause, cure and prevention of dementia and the care people receive.**

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