



DEMENTIA 2010

The economic burden of dementia and associated research funding in
the United Kingdom

A report produced by the Health Economics Research Centre,
University of Oxford for the Alzheimer's Research Trust

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About the Alzheimer's Research Trust

The Alzheimer's Research Trust is the UK's leading research charity for dementia.

We are dedicated to funding scientific studies to find ways to treat, cure or prevent Alzheimer's disease, vascular dementia, dementia with Lewy Bodies and fronto-temporal dementia.

We do not receive any government funding and instead rely on donations from individuals, companies and charitable trusts, money raised by individuals and gifts left in people's Wills to fund our vital work.

Our registered charity number is 1077089.



**Alzheimer's
Research Trust**

Find out more at: www.alzheimers-research.org.uk

Acknowledgements

Our thanks go to Jane Wolstenholme for allowing us to access resource use information from a cohort of dementia patients. We would like to acknowledge all those charities and governmental organisations who very helpfully responded to our requests for information. Without their help this study would not have been possible. We are grateful to the England and Wales Charity Commission, especially Eleanor Tew, for providing us with a comprehensive list of all charities potentially funding health research. The help received from the Department of Health, Social Services and Public Safety of Northern Ireland, and Wales NHS who provided us with the data used in this analysis is also gratefully acknowledged. Finally our thanks go to Lydia Saroglou and Naoki Akahane for their assistance in collating data for this report.

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FOREWORD

Dementia costs UK plc £23 billion a year

How do you put a price on life? How do you demonstrate the cost of doing nothing? Thanks to the Alzheimer’s Research Trust who commissioned this study we have an answer: £23 billion in care costs and lost productivity.



Dementia poses many challenges. Challenges to scientists, challenges to policy-makers, challenges to society: left unanswered costs will continue to rise.

On present trends the UK’s approach to managing dementia is unsustainable. Leading scientists have already warned that the NHS will struggle to cope if the prevalence of dementia continues to rise.

The Government’s dementia strategy offers the prospect of a better model of care. But it offers no answer to the inexorable rise in the demand for care.

The answer must surely be human ingenuity and discovery. More funds are needed to enable scientists to research and understand dementia, to research and develop new treatments. Yet today for every pound spent on dementia care, less than a quarter of a penny is invested in research.

The Government held a summit on dementia research, but new money came there none. Instead, a Ministerial taskforce on research has been set up.

As Dementia 2010 shows dementia directly afflicts 820,000 people in the UK. Yet it touches the lives of so many more people. The economists may say dementia costs £23 billion; the true social impact is incalculable.

Dementia costs the UK twice as much as cancer, three times as much as heart disease and four times as much as stroke. Yet when it comes to research funding dementia is the poor relation. For every one pound spent on dementia research twenty six pounds are spent on cancer research and fifteen pounds on research into heart disease.

Dementia 2010 makes clear the scale of the challenge; it brings dementia into the spotlight. The case for investment in dementia research is powerful and clear.

A handwritten signature in black ink, appearing to read 'Paul Burstow'.

Paul Burstow MP

Liberal Democrat Member of Parliament for Sutton and Cheam

A wake-up call for us all

In 2009, the Alzheimer's Research Trust commissioned the Health Economics Research Centre at the University of Oxford to produce a report on the economic cost of dementia to the UK, and the country's



investment in research to find new treatments, preventions and cures. They were asked to calculate the care costs of dementia to health services, social services, unpaid carers and others, and compare this to the other great medical challenges of our age: cancer, heart disease and stroke. The outstanding work of Prof Alastair Gray, Dr Ramon Luengo-Fernandez and Dr Jose Leal on Dementia 2010 has produced important new evidence.

The Oxford team's findings are astonishing. Every one of the 821,884 people in the UK with dementia costs our economy £27,647 per year; that's more than the UK median salary. By contrast, patients with cancer cost £5,999, stroke £4,770 and heart disease £3,455 per year. Despite this, government and charitable spending on dementia research is 12 times lower than on cancer research. £590 million is spent on cancer research each year, while just £50 million is invested in dementia research.

This should be a wake-up call for all of us who can influence the priority given to dementia research: government, charities and the public as a whole. The Alzheimer's Research Trust is aiming to increase its annual investment in research and quickly; with extra support from the public, we could do so much more. All three main political parties accept that dementia research deserves more funding and – as the Prime Minister put it in a meeting with the Alzheimer's Research Trust – that “dementia has been neglected for too long”. We now need to translate this political sentiment into government action. We welcome the government's Ministerial Advisory Group on dementia research as a promising start.

If we spend a more proportionate sum on dementia research, we could unleash the full potential of our scientists in their race for a cure. Spending millions now really can save us crippling multi-billion pound care bills later.

Most importantly, we must not forget what these statistics really represent: hundreds of thousands of devastated lives, millions of families and friends, incalculable potential squandered.

With enough support, our scientists can defeat dementia and halt this tidal wave of suffering.

A handwritten signature in black ink, appearing to read 'Rebecca Wood'. The signature is fluid and cursive, with a large loop at the end.

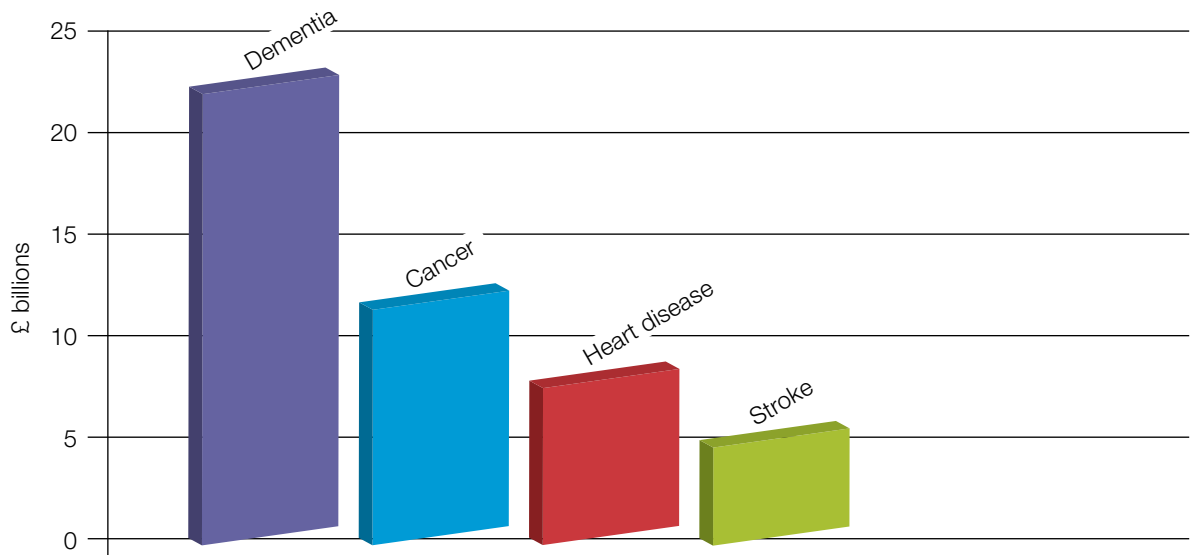
Rebecca Wood

Chief Executive, Alzheimer's Research Trust

KEY FINDINGS

821,884 people in the UK live with dementia

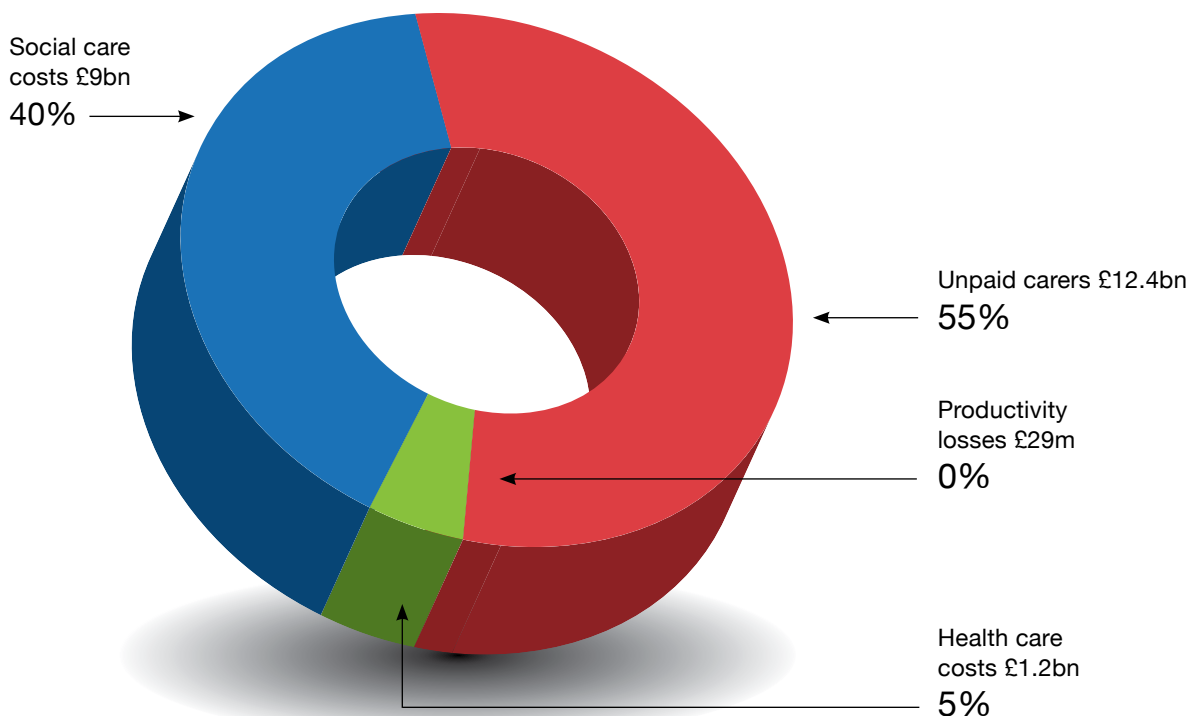
Dementia costs the UK economy £23 billion per year. This is more than cancer (£12 billion per year) and heart disease (£8 billion per year) combined.



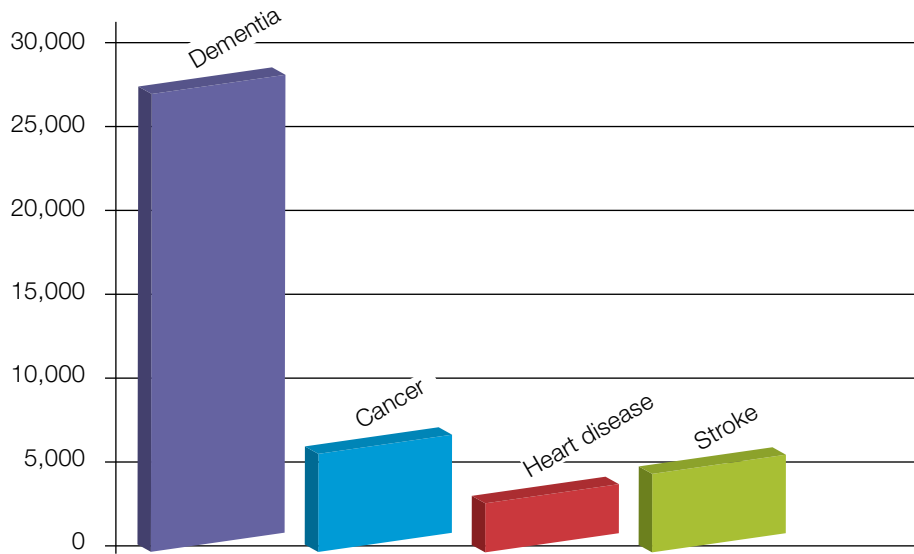
How the £23 billion cost of dementia is met

Long term institutional social care and informal care costs make up the majority of the £23 billion figure.

Most of the cost of dementia – £12.4 billion per year – is met by unpaid carers. Social care costs are £9 billion, health care £1.2 billion and productivity losses £29 million.



Annual cost (£) of one patient



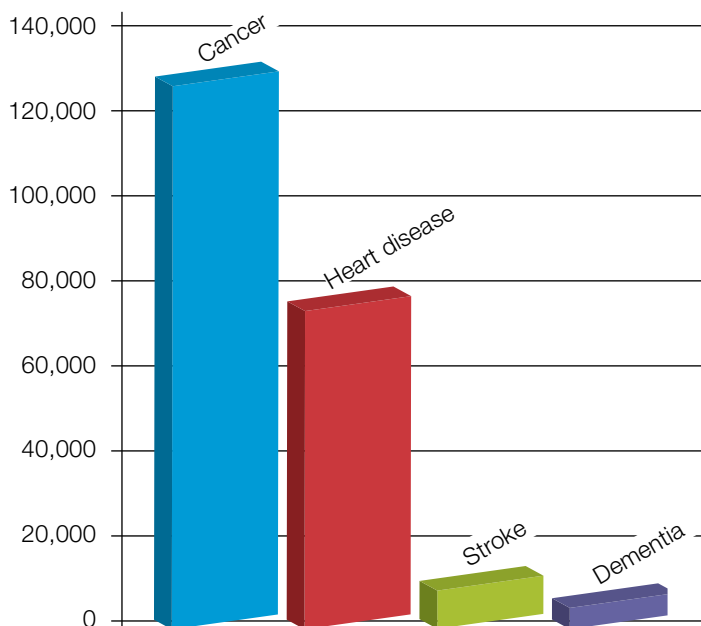
Every dementia patient costs the economy £27,647 per year: more than the UK median salary (£24,700). By contrast, patients with cancer cost £5,999, stroke £4,770 and heart disease £3,455 per year.

Annual government and charity investment in research

Government and charitable spending on dementia research is 12 times lower than on cancer research. £590 million is spent on cancer research each year, while just £50 million is invested in dementia research. Heart disease receives £169 million per year and stroke research £23 million.

For every person with cancer, £295 is spent each year on research. For dementia, that figure is just £61.

Investment (£) in research for every £1 million in social and health care costs



For every £1 million in care costs for the disease:
 £129,269 is spent on cancer research
 £73,153 on heart disease research
 £8,745 on stroke research
 just £4,882 on dementia research.

The Report

Executive summary

Rationale and objectives

This report is the outcome of a study commissioned by the Alzheimer's Research Trust to estimate the economic burden associated with dementia to the UK economy for the year 2008 in comparison with other major diseases, and then to compare the burden of these diseases with current levels of research funding. Dementia describes a group of symptoms associated with a progressive decline of brain functions, such as memory, understanding, judgement, language and thinking. People with dementia are at an increased risk of physical health problems and become increasingly dependent on health and social care services and other people. Hence, dementia has a significant economic impact on the health care system, on patients, on family and friends who provide unpaid care, and on the wider economy and society. The study reported here estimates the economic burden from a societal perspective that includes not only health care costs but also those costs falling outside the health care sector, such as the opportunity costs associated with unpaid care to patients, or productivity losses associated with premature death or absence from work due to dementia. The aim was to compare the economic burden of dementia with that of cancer, coronary heart disease (CHD) and stroke using the same methodological approach. Cancer, CHD and stroke are the three main causes of death in Europe and the USA. The UK government and charity research funding was also examined for each of the four conditions in the financial year 2007/08. The aim was to compare the levels of UK research funding with the respective economic burden of disease. It was expected that research into the causes, treatment and prevention of a particular disease should be broadly related to its economic burden.

Methods

Estimating the economic burden of illness

A prevalence approach was adopted whereby all costs within the most recent year for which data were available were measured regardless of the date of disease onset. A "top down" approach was used to estimate the total costs using aggregate data on morbidity, mortality, hospital admissions, disease related costs, and other health related indicators. Costs categories used included health care, social care, informal care, and productivity losses due to premature mortality and absence from work.

Dementia was defined as the International Statistical Classification of Diseases and Related Health Problems 10th Revision (ICD10) F00-F03 and G30, which include Alzheimer's disease, vascular and unspecified dementia, as well as dementia in other diseases such as Parkinson's. Cancer was defined as ICD-10 codes C00-D48, stroke as ICD-10 codes I60-I69, and coronary heart disease as ICD-10 codes I20-I25.

Research funding

We identified UK governmental agencies that provide health research funding and contacted them to determine the levels of funding for dementia, cancer, CHD and stroke in the financial year 2007/08. These agencies included research councils, such as the Medical Research Council (MRC), and research agencies from the Department of Health and its devolved administrations, such as the National Institute for Health Research (NIHR). Charity organisations that fund health research were also identified from the Association for Medical Research Charities (AMRC) and the Charity Commission for England and Wales. Due to the large number of charities in the Charity Commission register that potentially fund health research, only the top two hundred charities in terms of their annual income were considered in this study. These two hundred charities accounted for over 75% of the total income of all research funding charities. The levels of charity research funding for each of the four conditions were obtained from annual reports or direct contact with the charities.

Results

Economic burden of illness

The number of patients with dementia in the UK is estimated to be 821,884, representing 1.3% of the UK population. We estimate that 37% of all dementia patients in the UK are in long-term care institutions costing in excess of £9 billion per year in social care. Health care costs are estimated at about £1.2 billion of which hospital inpatient stay accounts for 44% of the total. Informal care is estimated to involve 1.5 billion hours of unpaid care provided to dementia patients living in the community, which we value at £12 billion. Finally, productivity losses due to dementia account for £29 million. Overall, dementia is found to cost £23 billion in terms of health and social care, informal care and productivity losses in 2008.

The combined health and social care costs of dementia are estimated at £10.3 billion in 2008, compared to £4.5 billion for cancer, £2.7 billion for stroke and £2.3 billion for CHD. Using UK prevalence data, the health and social care cost per person with disease was estimated at £12,521 for dementia, £2,559 for stroke, £2,283 for cancer, and £1,019 for CHD. In terms of societal cost, dementia also posed the greatest economic burden at £23 billion followed by cancer at £12 billion, CHD at £8 billion and stroke at £5 billion.

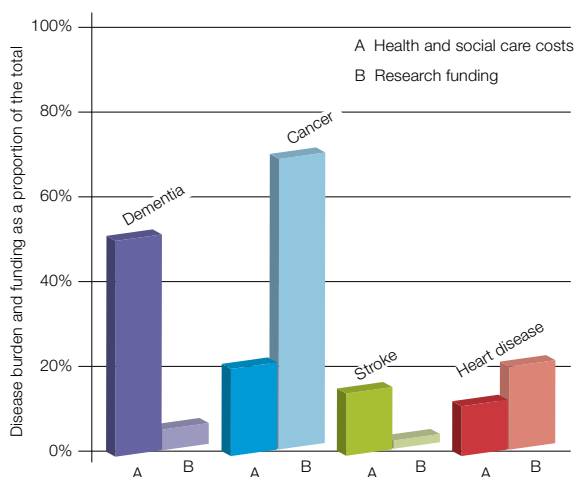
Research funding

Information on the levels of research funding for dementia, cancer, CHD and stroke in 2007/08 were obtained from seven of the eight identified governmental agencies. A total of £405 million of governmental funds was spent on these four diseases, of which 66% was spent on cancer research followed by CHD (21%), dementia (9%) and stroke (4%). A total of 65 charities that provided research funding for these four diseases were identified from the Charity Commission register and the AMRC. These charities had a combined spend of £429 million on cancer, CHD, dementia and stroke research. As with the governmental agencies, most of these funds were devoted to cancer (£324 million, 76%) followed by CHD (£85 million, 20%), dementia (£14 million, 3%) and stroke (£6 million, 1%).

In total, the combined research funding into dementia, cancer, CHD and stroke by governmental and charity organisations in this study was just under £833 million. Of this total, £590 million (71%) was devoted to cancer, £169 million (20%) to CHD, £50 million (6%) to dementia and £23 million (4%) to stroke. The total levels of research funding per person with the disease were evaluated at £295 per person with cancer, £75 per person with CHD, £61 per person with dementia and £22 per person with stroke. Put another way, for every £1 million of health and social care costs attributable to the disease, cancer received £129,269 in research funding, CHD received £73,153, stroke received £8,745 and finally dementia received £4,882.

As shown below, although dementia accounts for over 50% of the combined health and social care costs of the four diseases under study, it only receives 6% of combined research funding. In contrast, cancer accounts for just over 20% of health and social care costs but receives nearly three quarters of the total medical research funding for these four diseases.

Health and social care costs and research funding by disease



Conclusions and recommendations

The estimated economic burden of dementia is far greater than cancer, heart disease (CHD) and stroke. Despite this, most research funding in the UK is currently directed towards cancer. Our analysis suggests that research spending on dementia and stroke is severely underfunded in comparison with cancer and CHD.

SECTION 1

INTRODUCTION

Dementia describes a group of symptoms caused by the gradual death of brain cells, leading to the progressive decline of functions such as memory, orientation, understanding, judgement, calculation, learning, language and thinking [ICD 10 classification]. Dementia is a terminal disease where patients are expected to live three to nine years after diagnosis.¹⁻⁴ In the United Kingdom (UK), a previous study estimated that 683,597 people suffered from dementia in 2005, with the total forecasted to increase to 940,110 by 2021 and 1,735,087 by 2051.⁵ The disease occurs mainly in older people, referred to as late-onset dementia, but it may also occur in people under 65 years, referred to as young-onset dementia.

There are several diseases that cause dementia. In late-onset dementia, Alzheimer's disease is the most common disease, accounting for around 60% of all cases, followed by cerebrovascular disease (vascular dementia), and dementia with Lewy bodies which together account for 15-20% of cases. In young-onset dementia, fronto-temporal dementia is the most common disease, followed by Alzheimer's. Less common diseases that may also cause dementia include Parkinson's and Huntington's, HIV and AIDS, Korsakoff's syndrome, Creutzfeldt-Jakob disease, multiple sclerosis, and motor neurone disease, amongst others. Recently, mixed cases of dementia have also been identified such as Alzheimer's and dementia with Lewy bodies.⁶

Alzheimer's disease (AD) is a progressive condition for which no single cause has yet been identified, but several risk factors have been linked to it, of which age is the most relevant. AD progression can be divided approximately into three stages. In the early stage, a person with AD experiences very minor changes in their abilities or behaviour, e.g. short-term memory loss, which may be mistakenly attributed to stress or ageing. In the middle stage, changes in ability and behaviour such as increasing forgetfulness become more significant, and people with AD require more support to manage their daily activities, such as eating, washing, dressing or using the toilet. In the late stage, AD patients may become increasingly frail, have difficulty eating, lose memory and speech abilities, and so gradually become

completely dependent on others for care. People with vascular dementia, usually due to a series of small strokes, experience similar symptoms as in AD in addition to the symptoms of stroke. However, the symptoms may develop suddenly, remain stable for some time and then quickly deteriorate as the result of another stroke, or gradually decline.

Reasons for the appearance of Lewy bodies in the brain are still unknown and no risk factors have yet been identified. Dementia with Lewy bodies is progressive, although with some variation in the abilities of the sufferer over small periods of time, and is characterised by similar symptoms to Parkinson's disease. Several genetic mutations have been associated with fronto-temporal dementia but more than half of all cases have no previous family history. People with fronto-temporal dementia will experience progressive decline associated with extreme behavioural changes, such as apathy and euphoria, speech and language problems, movement disorders and, at a later stage, symptoms similar to those in AD which may require nursing care.^{6,7}

Few cases of dementia are diagnosed in early stages, as many of the associated symptoms, e.g. memory loss, could be attributed to other conditions such as depression, diabetes, thyroid abnormalities, delirium, alcoholism or simple ageing. This makes diagnosis particularly difficult, such that it may take up to one year or longer for a final diagnosis to be made. Formal testing for dementia requires mental ability tests, such as the Mini Mental State Examination (MMSE), a review of medical history and current medications, an examination of biological markers such as levels of abnormal proteins associated with AD, and sometimes imaging scans such as magnetic resonance imaging (MRI) scan to detect changes in the brain.

There is still no cost-effective method of identifying people with dementia through population screening.⁶ Early diagnosis of dementia is important, allowing those with dementia and their carers to plan better for their future and to start treatments that may slow disease symptoms. There is, however, a significant gap between the expected number of people with dementia and the number of diagnoses made in the UK: only 60 of the expected 122 people with dementia per 1,000 people over 80 years of age have been formally diagnosed.⁸ Several barriers have

been identified which may explain this gap, such as fear of the disease in the patient or family, inability to separate dementia symptoms from normal ageing process, GPs' lack of training and confidence in diagnosing dementia, unclear roles or inconsistent approaches of specialist services such as Memory Services, and variation and inconsistency in the available diagnostic tools.⁸

No interventions have yet been developed that prevent, change or reverse the progressive decline of brain functions. There are, however, a number of potential pharmacological (e.g. cholinesterase inhibitors), and non-pharmacological (e.g. cognitive behavioural therapy) interventions that focus on treating the symptoms of dementia.⁶ Nevertheless, people with dementia are at an increased risk of physical health problems and become increasingly dependent on health and social care services and other people. The progressive nature of the disease associated with significant changes on daily living activities, behaviour, appetite and eating habits, may make people more susceptible to other diseases. This will be translated into multiple contacts with the National Health Service and social care services together with increased reliance on family and friends for support. Amongst all carers, the carers of people with dementia are one of the most vulnerable, suffering from high levels of burden and mental distress, depression, guilt and psychological problems.^{6,9} The behavioural and psychological symptoms of dementia patients, such as aggression, agitation and anxiety, are particularly difficult for carers and are a common cause for institutionalisation of dementia patients in care homes.⁵ It is therefore well recognised that dementia has a significant economic impact on the health care system, on patients, on family and friends who provide unpaid care, and on the wide economy and society.

Despite the high burden of dementia, there are concerns that its diagnosis and treatment in the UK is generally low. An international comparison published in 2007 suggested that the proportion of patients receiving pharmacological treatment in the UK was less than half the level in countries such as Sweden, Ireland, France and Spain.¹⁰ Furthermore, a report from the National Audit Office

in 2007 identified several problems in the services and support for people with dementia and set up a list of recommendations to address these.⁸ In 2009, the Department of Health released the first National Dementia Strategy for England setting out a work programme over five years to improve dementia services across three areas: improved awareness, earlier diagnosis and intervention, and higher quality of care.¹¹ This will involve an investment over the first two years of £150 million to fund the implementation of the Strategy.

This report aims to estimate the economic burden of dementia in the UK in 2008 from a societal perspective that includes not only health care costs but also those costs falling outside the health care sector, such as social care costs, the opportunity costs associated with unpaid care to patients, and productivity losses associated with premature death or absence from work due to dementia. Cost of illness (COI) studies, such as this, can help to inform research priorities by providing estimates of the economic burden of particular public health problems. If COI studies can be performed consistently across several diseases it will be possible to identify main cost components and rank diseases according to their economic burden. This can then be used to help plan the allocation of future research funds towards those diseases with the greatest burden.

However, decision and policy makers are often faced with several COI estimates that vary considerably within and across diseases. These variations are likely to be due in part to the use of different perspectives, scope and methods to estimate costs, raising concerns about the comparability and usefulness of COI studies to inform research decisions.¹² Using a common approach across all diseases of interest can help overcome these difficulties. Hence, another aim of the report was to compare the costs of dementia with cancer, coronary heart disease (CHD) and stroke using the same methodological approach. These three diseases are the main causes of death in the Western world. The methodological framework of our costing analysis was previously used to estimate the economic burden of cardiovascular disease, CHD and stroke in the UK.¹³⁻¹⁶ In this report, we provide

new estimates for costs of dementia and cancer and update the previous CHD and stroke studies to 2008 prices.

In the UK, a governmental review published in 2006 investigated how public bodies should target medical research funding.¹⁷ A recommendation coming from the review was that the impact of diseases on the UK population and economy should be assessed to determine the UK health priorities which will in turn inform UK health research priorities. To evaluate the current funding situation in the UK, governmental and charity research funding was quantified for dementia, cancer, CHD and stroke in the financial year 2007/08. The aim was to compare the levels of UK research funding with the respective estimated economic burden of disease and evaluate whether health research priorities are linked with the respective economic burden.

Structure of the report

The remainder of the report is divided into six sections as follows:

Section 2 describes the methodology used to estimate the economic burden of dementia and cancer;

Section 3 describes the methodology used to estimate the governmental and charity health research funding for dementia, cancer, CHD and stroke;

Section 4 estimates the costs of dementia and cancer which are compared against CHD and stroke;

Section 5 sets out the levels of government and charity research funding for the four conditions and compares research funding with disease prevalence and economic burden; and

Section 6 discusses the results and the key limitations of our approach.

SECTION 2

METHODS: COST OF ILLNESS STUDY

2.1 INTRODUCTION

A costing study consists of the identification, measurement and valuation of all resources related to an illness, in which all resources consumed by patients are measured and ascribed using a monetary value.¹² The perspective of the analysis is fundamental in determining which resources should be included, and how they should be measured and valued.¹³ A health service perspective, for instance, would only consider costs imposed on hospitals and other health care providers. A societal perspective enables a wider analysis, in which all costs are considered, irrespective of who bears them or where they are incurred. Such a perspective not only includes health care costs but also those costs falling outside the health care sector, such as social care costs, the opportunity costs associated with unpaid (i.e. informal) care to patients, or productivity losses associated with premature death or absence from work due to illness.

Using a societal perspective this study evaluates the combined costs of dementia and Alzheimer's disease (AD), defined here as International Statistical Classification of Diseases and Related Health Problems 10th Revision (ICD-10)18 F00-F03 and G30, and collectively referred to as "dementia" in this report. These costs will then be compared to those of cancer (ICD-10: C00-D48), stroke (ICD-10: I60-I69), and coronary heart disease (CHD, ICD-10: I20-I25).

The framework used to estimate health care and non-health care costs is similar to the approach by Leal et al (2006),¹³ Luengo-Fernandez et al (2006),¹⁴ Leal et al (2008),¹⁵ and Leal et al (2009)¹⁶ to estimate the economic burden of cardiovascular disease (CVD), CHD and stroke in the European Union and the United Kingdom (UK). In addition, the results of these studies were updated to 2007/08 prices using recent unit costs,^{19;20} and appropriate inflation indices for health and social care costs²⁰ and wage inflation indices,^{21;22} in order to compare these costs with those of dementia and cancer.

In order to evaluate the costs of dementia and cancer an annual time frame was adopted for our analysis, in which all costs due to the diseases under investigation within the most recent year for which data were available were measured, regardless of the time of disease onset. All health care and non-health care costs were expressed in 2008 prices. A “top down” approach was employed to calculate the total expenditure due to these conditions across the UK. This approach used aggregate data on morbidity, mortality, hospital admissions, disease related costs, and other health related indicators.

A variety of national sources of epidemiological and health care utilisation data were used. Among the sources consulted were the Office of National Statistics (ONS), the Information Services Division Scotland (ISD), the Department of Health (DoH), the Health and Social Care Information Centre, the Department for Work and Pensions (DWP), Hospital Episode Statistics (HES), the Labour Force Survey (LFS), the Annual Survey of Hours and Earnings (ASHE), the HM Revenue and Customs Statistical Office, and the DoH Quality and Outcomes Framework.

2.2 COSTS OF DEMENTIA

2.2.1 Number of dementia cases in the UK

The number of cases of dementia was obtained from the European Community Concerted Action on the Epidemiology and Prevention of Dementia (EURODEM) study.^{23;24} As part of EURODEM, data on the prevalence of diagnosed and undiagnosed moderate to severe dementia in population-based studies and surveys conducted in several European countries, including the UK, were pooled to obtain a set of prevalence rates for men and women in 9 different age groups (30-59, 60-64, 65-69, 70-74, 75-79, 80-84, 85-89, 90-94 and 95-99) for the UK and 30 other European countries (Table 1).

Table 1 EURODEM prevalence rates of diagnosed and undiagnosed dementia in the UK

| Age group, years | Male | Female |
|------------------|--------|--------|
| 30-59 | 0.16% | 0.09% |
| 60-64 | 1.58% | 0.47% |
| 65-69 | 2.17% | 1.10% |
| 70-74 | 4.61% | 3.86% |
| 75-79 | 5.04% | 6.67% |
| 80-84 | 12.12% | 13.50% |
| 85-89 | 18.45% | 22.76% |
| 90-94 | 32.10% | 32.25% |
| 95-99 | 31.58% | 36.00% |

Prevalence rates were then applied to the latest detailed UK population estimates derived from the Government Actuary Department for 2006.²⁵ In addition, prevalence rates were also obtained from an Expert Delphi Consensus exercise of ten UK and European experts and applied to the UK 2006 population.⁵ Although this information was not used in the main analysis, it was used in a separate sensitivity analysis to show the impact of prevalence on the costs of dementia.

2.2.2 Social care

LONG TERM CARE: NURSING AND RESIDENTIAL CARE HOMES

Nursing and residential care was measured as the number of dementia-related weeks spent in care homes. There are two types of care homes, nursing homes and residential homes. A residential home provides care for people who are not able to manage everyday tasks or maintain an independent home of their own while a nursing home provides 24-hour nursing care.

Using information on the UK population aged 65 years or more²⁵ and the proportion of this population living in long-term care institutions,²⁶ we determined the number of people aged 65+ living in long-term care institutions in the UK. (Due to lack of data, we conservatively assumed that no patient with dementia under the age of 65 years would be institutionalised.) Finally, the number of people living in these institutions with dementia was estimated

using prevalence data from a UK population-based study of 13,004 elderly people (i.e. the Medical Research Council Cognitive Function and Ageing Study – MRC CFAS).²⁷ This study assessed the prevalence of dementia in those living in residential and nursing care homes on the basis of a clinically oriented assessment interview.

The weekly costs of residential and of nursing home care were derived from the UK Unit Costs of Health and Social Care as reported in the year 2008 compendium.²⁰ These two costs were then combined into a weekly cost of long-term institutionalised care, weighted to reflect the proportion of patients living in each type of institutional care, which was derived from the MRC CFAS study.²⁷ These costs were then converted into annual costs, and multiplied by the number of dementia cases living in long-term institutionalised accommodation.

2.2.3 Health care

PRIMARY CARE

Primary care activities consisted of dementia-related visits to general practitioners (GPs), GP home and telephone visits, nurse visits at clinic, and nurse home visits.

The consultation rates of patients with dementia were obtained from published evidence from a study estimating the relationship between the costs of dementia care and disease progression.²⁸ Although all patients in that study were derived from a single geographical location in the UK, i.e. Oxfordshire, the patient sample was shown to be representative of the general population with regard to the distribution of social class.²⁹ That study provided information on the number of primary care visits over a period of up to 11 years from diagnosis made by 100 patients diagnosed with either AD or vascular dementia, with separate consultation rates for those patients living in the community and those living in institutionalised care settings. These consultation rates were then applied to the number of dementia patients living in institutionalised settings and those living in the community. The number of dementia patients living in the community was estimated by subtracting the total number of patients living in institutionalised long-term care from the total number of estimated

dementia cases in the UK. The total number of primary care consultations due to dementia was then multiplied by their unit costs. Unit costs were obtained from the UK Unit Costs of Health and Social Care for the year 2008 compendium.²⁰

HOSPITAL OUTPATIENT VISITS

Hospital outpatient care comprised all dementia-related consultant visits taking place in outpatient departments in acute care institutions.

The outpatient visit rates of patients with dementia were obtained from the same study as that used to determine primary care consultations.²⁸ As with primary care, visit rates were obtained separately for those patients living in long-term care institutions and those living in the community and were multiplied by the estimated number of dementia patients living in these two settings. The total number of outpatient visits due to dementia was then multiplied by their unit cost. Unit costs were obtained from the NHS Reference Cost Schedules for the year 2007/08.¹⁹

ACCIDENT & EMERGENCY VISITS

Accident and emergency (A&E) care consisted of all dementia-related hospital emergency visits.

Use of A&E services was derived from a study of 132 people diagnosed with dementia in South London, of which 101 lived in the community and 31 in institutionalised settings.³⁰ This study provided information on the proportion of patients accessing A&E services over the last three months, which was then multiplied by four to obtain an annual estimate. As the study showed no differences in A&E use between patients living in the community or in institutions ($p=0.742$), A&E visit rates were multiplied by the total number of dementia cases in the UK, without further stratification by living arrangements.

The total number of A&E visits due to dementia was then multiplied by their unit cost. A&E unit costs were obtained from the NHS Reference Cost Schedules for the year 2007/08.¹⁹

HOSPITAL INPATIENT CARE

Hospital inpatient care was estimated from the number of days in hospital due to dementia, which included rehabilitation sessions, community hospital

respite care and hospital day cases. Hospital day case admissions were obtained separately from hospital inpatient care. In England, hospital inpatient stay and day cases were obtained from the Hospital Episode Statistics (HES) by primary diagnosis of dementia and Alzheimer's disease. In Wales, Scotland and Northern Ireland, equivalent information was obtained from their respective statistical bodies.³¹⁻³³ Unit costs for a hospital bed day and day case were then obtained from NHS Reference Cost Schedules for the year 2007/08,¹⁹ using the Health Resource Group (HRG) for Alzheimer's disease.

In addition, information was obtained from HES, and its counterparts in Wales, Scotland and Northern Ireland, on inpatient stay and day cases where dementia and Alzheimer's disease were underlying causes for the hospitalisation, rather than the primary diagnosis. Although this information was not used in the main analysis, it was used in a separate sensitivity analysis showing the costs of all dementia-related hospitalisations.

MEDICATIONS

The costs related to consumption of anti-dementia, antipsychotic, anxiolytic, hypnotic and antidepressant medications by dementia patients were included in the analysis.

Costs of anti-dementia medications (i.e. donepezil, galantamine, rivastigmine and memantine) were derived from the Prescription Cost Analysis (PCA) for each of the four countries in the UK³⁴⁻³⁷. The PCA provides details of the number of items and the net ingredient cost of all prescriptions dispensed in the community.

The use of antipsychotic, anxiolytic, hypnotic and antidepressant medications amongst dementia patients was obtained from a study of 445 people in South East England living in nursing homes, of which 74% had probable clinical dementia.³⁸ The proportion of residents regularly taking these medications was multiplied by the total number of dementia cases in the UK. The most prescribed drugs in each medication group were then identified from the PCA and its annual cost per person was multiplied by the number of dementia users.

As the PCA data does not include any dispensing costs or fees, the drug dispensing fee per

prescription was added to the total medication costs of dementia patients.³⁹

PRIVATE HEALTHCARE

Currently 12.7% of all health care in the UK is being provided privately,²¹ but information on the breakdown of this by disease type is limited. We assume here that patterns of private health care use parallel public services, and account for this by inflating public health care expenditure on primary, outpatient, A&E, and hospital inpatient care by 12.7%.

2.2.4 Informal care

Informal care costs are equivalent to the opportunity cost of unpaid care. This opportunity cost can be considered a measure of the amount of money that carers forgo to provide unpaid care for their spouses, friends or relatives suffering from dementia. For this analysis we assumed that only those patients living in the community would receive informal care.

The average hours per week spent by relatives and friends providing unpaid care for dementia sufferers was obtained from Schneider et al. (2002).³⁰ This study of 101 patients living in the community, asked carers how much time was spent over one week providing care in three principal forms:

- 1:** general tasks (i.e. shopping, paperwork, cooking, eating meals and other household chores);
- 2:** specific tasks (i.e. bathing, dressing, grooming and providing transport); and
- 3:** supervision. The average hours per week providing informal care were then multiplied by the number of dementia cases living in the community, and annualised by multiplying by 52 weeks.

To value the amount of informal care provided, care provided by employed carers was valued using the gender-specific average wage in the UK,²² whereas care provided by unemployed, inactive or retired carers was valued using the minimum wage.⁴⁰

To determine the employment status of the carer we used information from the study by Schneider et al. (2002)³⁰ on the carer's relationship with the patient (spouse, son/daughter, son/daughter in law,

sibling, other relative or friend) and the gender of the carer. Due to the advanced age of the patient group in this study (mean age was 80 years), we assumed that spouses, siblings and friends providing the care would typically be aged 65 years of age or more, and therefore be retired. If care was being provided by either the patients' children or their children's spouses, then it was assumed that these informal carers would be under 65 years of age. Using gender-specific economic activity and unemployment rates,⁴¹ we then determined the proportion of these carers who were employed or unemployed/economically inactive.

2.2.5 Productivity losses

MORTALITY LOSSES

The costs associated with lost productivity due to mortality comprised the foregone earnings from premature death due to dementia. Age and gender specific deaths, where the main cause was either dementia or Alzheimer's disease, were obtained from UK mortality databases.⁴²⁻⁴⁴ Deaths where dementia or Alzheimer's disease was the underlying cause of death were also obtained and included in our analysis.

UK labour statistics report economically active individuals from age group 16-17 to 65+ years of age.⁴¹ We used an initial working age for both men and women of 16 years and assumed that above 70 years of age the proportion of people working would be negligible. The number of working years lost due to premature mortality was estimated both for males and females, using expected working years left by age group together with the number of deaths broken down by age and gender. However, not everyone of working age will be economically active (i.e. either working or actively searching for work) or employed. Therefore, the estimated working years lost due to premature mortality were adjusted using age and gender specific unemployment and activity rates for the UK.⁴¹ The average annual earnings of male and female workers were taken from the Annual Survey of Hours and Earnings.²² The product of these earnings and potential working years lost provided the mortality costs due to dementia.

As these productivity costs would be incurred in future years, all future foregone earnings were discounted using a 3.5% rate per annum following

current UK HM Treasury recommendations.⁴⁵

A separate sensitivity analysis was undertaken showing by how much costs would increase if deaths where dementia was the underlying cause were included in the analysis.

MORBIDITY LOSSES

The morbidity costs due to dementia included the number of days lost covered by incapacity claims, and other working days lost.

The number of incapacity benefit working days due to dementia was obtained from the Department of Works and Pension Information Centre,⁴⁶ which provided the days of certified incapacity in the period between April 2001 and March 2002 by gender and diagnosis (as coded in ICD-10).

The number of working days lost not covered by incapacity claims was obtained from a report by the Chartered Institute of Personnel and Development,⁴⁷ which provided the working days lost due to all-cause illness per worker for the UK. The average number of working days lost was then multiplied by the total number of employed people in the UK.⁴¹ To determine the number of working days lost due to dementia, the total days lost was multiplied by the proportion of incapacity days claimed for dementia in the UK.⁴⁶

The product of working days lost and average daily earnings provided the productivity losses associated with dementia morbidity. However, absent workers after a certain period are likely to be replaced at work by other workers, and so the total morbidity loss as computed above is likely to be an upper limit of the "real" loss from dementia. Hence, we estimated the "friction period", i.e. the period of employee's absence from work due to illness before he or she is replaced by another worker, which is estimated to be 90 days in Europe. The friction period adjusted morbidity loss was then estimated by multiplying the unadjusted productivity loss estimates by the friction period, and dividing this product by the average duration of each spell of work incapacity; this was estimated in this study to be 232 days on average, following the estimates used by Leal et al (2006)¹³ and Luengo-Fernandez et al (2006)¹⁴ when estimating the burden of cardiovascular diseases.

2.3 COSTS OF CANCER

2.3.1 Social care

HOSPICE PALLIATIVE CARE

Hospice care consisted of all cancer-related stays in hospices providing end of life and palliative care across the UK. We only considered stays in independent hospices, i.e. those funded by charities and other not-for-profit organisations, as palliative care funded by the NHS was already included under inpatient hospital care.

A report from the National Audit Office (NAO) provided the annual expenditure of all independent hospice care providers in England as well as the proportion of total deaths due to cancer.⁴⁸ The product of the annual expenditure and the proportion of deaths due to cancer provided the total annual hospice expenditure on cancer. By using ONS data on the number of deaths due to cancer in hospices⁴⁴ and the proportion of hospice care that was provided independently⁴⁸ it was possible to estimate the number of cancer-related deaths occurring in independent hospices. The care cost per person dying of cancer in an independent hospice in England was estimated by dividing the annual hospice expenditure on cancer by the number of cancer deaths in hospices.

Assuming that the proportion of cancer-related deaths occurring in independent hospices was the same across England and Wales, Northern Ireland and Scotland, the proportion of all cancer-related deaths in independent hospices was applied to the total number of cancer deaths in each country.⁴²⁻⁴⁴ Finally, it was assumed that the cost per cancer death in an independent hospice for England would be the same in Wales, Northern Ireland and Scotland.

2.3.2 Health care

PRIMARY CARE

Primary care activities consisted of cancer-related GP visits at clinic, GP home and telephone visits, nurse visits at clinic, and nurse home visits.

In order to obtain the number of cancer-related primary care consultations, the proportion of primary care visits due to cancer⁴⁹ was applied to

the total number of consultations in primary care for all diseases and conditions.⁵⁰⁻⁵³ The total number of primary care consultations due to cancer was then multiplied by their unit costs. Unit costs were obtained from the UK Unit Costs of Health and Social Care for the year 2008 compendium.²⁰

HOSPITAL OUTPATIENT VISITS

Hospital outpatient care comprised all cancer-related consultant visits taking place in outpatient wards in acute care institutions.

In order to evaluate the number of cancer-related consultant visits, the proportion of outpatient visits due to cancer was applied to the total number of hospital outpatient visits. The proportion of outpatient visits in each medical speciality due to cancer was obtained from a Scottish report,⁵⁴ in which consultants working within each medical speciality were asked to provide, based on their expert opinion, the proportion of all visits attributable to cancer. These proportions were then applied to the total number of outpatient visits in each medical speciality, which was obtained from routinely collected UK data.⁵⁵⁻⁵⁸ The total number of cancer-related outpatient visits in each speciality was then multiplied by their unit cost. Unit costs were obtained from the NHS Reference Cost Schedules for the year 2007/08.¹⁹

ACCIDENT & EMERGENCY VISITS

A&E care consisted of all cancer-related hospital emergency visits. As with outpatient visits, the proportion of total A&E visits due to cancer was obtained from a report evaluating the costs of cancer in Scotland.⁵⁴ The proportion of total A&E visits due to cancer was then applied to total A&E visits in the UK, again derived from routinely collected statistics.⁵⁵⁻⁵⁸ The total number of A&E visits due to cancer was then multiplied by their unit cost. A&E unit costs were obtained from the NHS Reference Cost Schedules for the year 2007/08.¹⁹

HOSPITAL INPATIENT CARE

Hospital inpatient care was estimated from the number of days in hospital due to cancer, which included hospital-based palliative care and hospital day cases. Hospital day case admissions were obtained separately from hospital inpatient care.

Hospital inpatient stay and day cases by primary diagnosis of cancer were obtained from HES in England,⁵⁵ and from its counterparts in Wales,³² Scotland,³³ and Northern Ireland.⁵⁹ Unit costs for a hospital bed day and day case were then obtained from the NHS Reference Cost Schedule for the year 2007/08.¹⁹ The unit costs obtained were the cost per bed day and day case for patients grouped in the Health Resource Groups (HRG) for cancer.

MEDICATIONS

Costs related to consumption of medications by cancer patients were included in the analysis. The costs of cancer medications included all expenditure on British National Formulary (BNF) Chapter 8 medications, i.e. "Malignant Diseases and Immunosuppression", with expenditure on immunosuppression medications being excluded. Expenditure on medications was obtained from the Prescription Cost Analysis (PCA) for each of the four countries in the UK,³⁴⁻³⁷ to which dispensing costs were added.³⁹

PRIVATE HEALTHCARE

As currently 12.7% of all health care in the UK is being provided privately,²¹ to account for this private spending all NHS healthcare costs (i.e. primary, outpatient, A&E, and hospital inpatient care) were inflated using this proportion.

2.3.3 Informal care

Informal care costs were equivalent to the opportunity cost of unpaid care. This opportunity cost is a measure of the amount of money that carers forgo to provide unpaid care for their spouses, friends or relatives suffering from cancer. For this analysis we assumed that those patients diagnosed with non-malignant cancers (ICD 10: D00 to D48) would not require informal care. The total number of hours of informal care provided to patients with cancer was obtained by multiplying the probability of receiving informal care, the number of hours of care provided and the total number of patients in need of care.

The probability of receiving informal care was evaluated for four different cancer patient groups:

- 1:** newly diagnosed patients receiving treatment and surviving past the first year of diagnosis;
- 2:** newly diagnosed patients receiving treatment and dying within the first year of diagnosis;
- 3:** newly diagnosed patients receiving palliative terminal care; and
- 4:** patients whose cancer was diagnosed in the past and who were receiving palliative terminal care.

Using cancer registration statistics for each of the four countries in the UK,⁶⁰⁻⁶³ we obtained the total number of malignant cancer cases in the UK. Using UK cancer survival rates,⁶⁴ we then estimated the proportion of cases dying:

- 1:** in the same year as that of diagnosis, and
- 2:** one year after diagnosis. With this information we were then able to determine from the total number of cancer-related deaths in the UK⁴²⁻⁴⁴ that occurred within the same year as diagnosis and those in which cancer was diagnosed in previous years.

Based on information about the time cancer patients were absent from work (more information on how this was evaluated is provided in section 2.3.4 below), we assumed that newly diagnosed cancer patients surviving past one year would potentially require 44 weeks of informal care whilst they were receiving treatment for the disease.⁶⁵⁻⁷¹ For newly diagnosed cancer patients dying within the first year, we assumed that the average life expectancy would be 6 months, with the first 3 months being treated for the disease and the remaining 3 receiving palliative care. Finally, for patients whose cancer was diagnosed in previous years, we assumed they would potentially require 3 months of informal care whilst receiving palliative care.

The probability of receiving informal care whilst patients were being treated for cancer and during the palliative care phase was derived from a UK study of 262 patients with lymphoma, breast, colorectal or lung cancer.⁷² As the study did not provide the total hours of informal care provided, we used data from the 2001 National Censuses,⁷³⁻⁷⁵ assuming that the hours of informal care received by cancer patients was the same as that provided

for all causes. Informal care provided by employed carers was valued using the gender-specific average wage in the UK²², whereas care provided by unemployed, inactive or retired carers was valued using the minimum wage.⁴⁰

2.3.4 Productivity losses

MORTALITY LOSSES

The costs associated with lost productivity due to mortality were calculated as the foregone earnings from premature death due to cancer. Age and gender specific deaths, where the main cause of death was cancer, were obtained from UK mortality databases.⁴²⁻⁴⁴ The same sources and methods used to estimate dementia-related mortality costs were used to estimate mortality associated with cancer.

MORBIDITY LOSSES

The morbidity costs due to cancer included the number of days lost due to incapacity and the working days lost. The same sources and methods used to estimate dementia-related morbidity costs were used to estimate those associated with cancer, the only difference being the friction period used: for cancer the friction period used was 307 days, based on results from seven studies which evaluated work absence after cancer diagnosis.⁶⁵⁻⁷¹

SECTION 3

METHODS: RESEARCH FUNDING

3.1 INTRODUCTION

In the UK, research into health and medical sciences is funded by a number of different organisations including the Department of Health, and its counterparts in the devolved administrations; the UK research councils; charities; and research and development (R&D) investments from the pharmaceutical and biotechnology industries.¹⁷

The aim of this analysis was to examine the levels of research funding for dementia, cancer, CHD and stroke for the year 2007/08. In line with other studies evaluating the levels of UK health research funding, research funding provided by the pharmaceutical and biotechnology industry was excluded from the analysis.⁷⁶⁻⁷⁹

3.2 GOVERNMENTAL HEALTH RESEARCH FUNDING

Governmental agencies responsible for funding health research were identified from a report by the UK Clinical Research Collaboration,⁷⁶ which evaluated UK levels of research funding during the 2004/05 financial year. Governmental agencies funding health research included: the Biotechnology and Biological Research Council (BBRC); the Engineering and Physical Sciences Research Council (EPSRC); the Economic and Social Research Council (ESRC); the Medical Research Council (MRC); the Department of Health through the National Institute for Health Research (NIHR); the Research and Development Office for the Northern Ireland Health and Personal Social Services; the Scottish Executive Health Department Chief Scientist Office; and the Wales Office of Research and Development for Health and Social Care.

For each governmental agency, we sought to determine the levels of research funding for stroke, CHD, cancer and dementia. The first step was to browse through each of the agencies' websites in order to obtain information on the research grants funded by these organisations (i.e. title, disease area and amount of funding received), by searching through their annual reports and/or databases of grants. If no annual report/database of grants was identified, or the information was not detailed

enough, agencies were contacted by electronic mail, based on the contact details provided in their websites, and asked to provide information on the levels of research funding in the financial year 2007/08 for the four diseases under investigation.

3.3 CHARITY HEALTH FUNDING

In order to determine the levels of research funding on stroke, CHD, cancer and by UK charities, we identified charities potentially funding health using two approaches.

First, a list of all the charities that potentially funded health research was obtained from the Charity Commission for England and Wales. The Charity Commission contains a register of all registered charities holding detailed information, including annual accounts and reports, for every registered charity in England and Wales.⁸⁰ The list of potentially relevant charities was obtained by identifying all the charities classified, in the Charity Commission register, as “Medical/Health/ Sickness” and providing monetary funds either by “making grants to organisations” or “sponsoring or undertaking research”. Due to the very high number of charities identified using this search criteria (n=6,751), charities were ranked in terms of their annual income and only the first two hundred charities, which had a combined income of over 75% of the total, were considered.

Second, a list of all the charities that were part of the Association of Medical Research Charities (AMRC) was obtained. The AMRC, an established charity since 1987, is a membership organisation of the leading UK charities that fund medical and health research. In order to join the AMRC, charities must demonstrate that they have a clear research strategy, have a peer review process for allocating funding, and support AMRC position statements on issues such as payment of indirect costs in universities and use of animals in medical research.⁸¹ At the time of this research, the AMRC consisted of 116 charities with a joint spend of over £800 million on medical and health research in the UK.⁸¹

Charities identified either through the Charity Commission or AMRC as potentially funding health research were only excluded from the analysis if they:

- 1: were registered in another country, regardless of the levels of health research funding in the UK, and were therefore under no obligation to file their accounts and annual reports in the UK; or
- 2: were educational/research organisations, such as universities, or royal colleges that were registered as charities. Royal colleges and educational/research organisations were excluded as a great proportion of their income is received through externally funded grants rather than charitable donations, endowments or legacies. Therefore, to minimise the potential of double counting the same research funding, these organisations were excluded.

For each charity, we sought to determine if the charity funded health research and, if so, the levels of funding for stroke, CHD, cancer and dementia. We excluded research expenditure on support costs such as administration and infrastructure (e.g. research buildings), but included funded research taking place outside of the UK. Information on whether each charity was involved in health research, and if so, the levels of research funding on the four diseases under investigation was obtained in three steps with all the data extracted using a structured proforma (Appendix 1). Firstly, the charity’s annual report and accounts were obtained. For charities registered in England and Wales, a copy of the annual report and accounts was available through the Charity Commission. Annual reports were then reviewed to obtain information on the research grants funded. Secondly, if the information contained within the annual report was not detailed enough, the charity’s website was browsed in order to identify if a database of all the grants for health research was available. If no relevant information was obtained from the charity’s website, in the final third step, charities were contacted by electronic mail and asked if they funded health research and if so the levels of research funding in the financial year 2007/08 for the four diseases under investigation.

As charities included in the study could potentially make grants to each other, the annual reports and accounts were checked in order to identify whether any of their research funding came from grants from other charities already included in the analysis. This was undertaken in a bid not to double count the same research funding.

SECTION 4

RESULTS: COSTING STUDIES

4.1 COSTS OF DEMENTIA

4.1.1 Prevalence of dementia in the UK

The estimated number of patients with diagnosed and undiagnosed dementia in the UK was 821,884 (Table 2), representing 1.3% of the UK population. Of total cases, 318,010 (39%) were men and 503,874 (61%) were women. 61% (n=499,166) of dementia cases occurred in individuals aged 80 years or more, and 64,037 (8%) cases were identified for those younger than 65 years of age, with dementia being more prevalent in males in this age group.

Table 2 Number of diagnosed and undiagnosed dementia cases in the UK in 2006

| Age group, years | Male | Female | Total |
|------------------|---------|---------|---------|
| 30-59 | 19,840 | 11,381 | 31,221 |
| 60-64 | 25,034 | 7,782 | 32,816 |
| 65-69 | 28,056 | 15,378 | 43,434 |
| 70-74 | 50,085 | 48,319 | 98,404 |
| 75-79 | 42,805 | 74,037 | 116,842 |
| 80-84 | 68,343 | 120,482 | 188,825 |
| 85-89 | 50,439 | 124,465 | 174,903 |
| 90-94 | 28,399 | 78,606 | 107,006 |
| 95-99 | 5,008 | 23,424 | 28,432 |
| Total | 318,010 | 503,874 | 821,884 |

4.1.2 Social care costs

We estimated that 304,850 patients aged 65 years or more with dementia would be living in institutionalised long term care, representing approximately 37% of all dementia patients in the UK (Table 3). With accommodation in long-term nursing and residential care settings generating an annual cost of approximately £30,000 per patient, the annual cost of long-term care accommodation due to dementia was in excess of £9 billion.

4.1.3 Health care costs

There were over 7 million primary care consultations in the UK due to dementia, with nearly 50%, 3.6 million, consisting of GP home visits. This resulted in an annual cost to the healthcare system of over £317 million, two thirds of which was attributable to home GP visits. For the same year there were 298,867 A&E visits and 489,766 outpatient consultations due to dementia. This represented an annual cost of over £26 million in A&E care and £55 million in outpatient consultations (Table 3).

Tables 3 and 4 show there were a total of nearly 1.5 million inpatient bed days and day cases due to a primary diagnosis of dementia. Inpatient care resulted in an annual cost of over £463 million, with the great majority of these costs related to overnight stays in hospital. However, when hospitalisations due to dementia as an underlying cause were also included in the analysis, the number of hospital bed days increased to nearly 4.3 million and the number of day cases was nearly 7,000. Assuming that there was no difference in the cost of a hospital bed day or day case whether dementia was the primary diagnosis or an underlying cause, the dementia-related inpatient costs increased nearly three-fold to £1,344 million when hospitalisations due to dementia as an underlying cause were included in the analysis (Table 4).

Table 3 Costs of dementia in the UK

| Type of resource used | Unit of measurement | Units of resources consumed | Average unit cost, £ | Total cost, thousands, £ |
|--|--|-----------------------------|----------------------|--------------------------|
| HEALTH CARE | | | | |
| Primary care | Nurse home visits | 2,492,220 | 26 | 64,798 |
| | Nurse surgery visits | 186,753 | 9 | 1,681 |
| | GP home visits | 3,567,046 | 58 | 206,889 |
| | GP surgery visits | 1,161,197 | 36 | 41,803 |
| | GP telephone visits | 83,939 | 22 | 1,847 |
| | Total | | | 317,017 |
| A&E | Attendances | 298,867 | 89 | 26,737 |
| Outpatient care | Attendances | 489,766 | 112 | 55,044 |
| Inpatient care | Hospital bed-days | 1,485,471 | 311 | 462,590 |
| | Hospital day cases | 209 | 2,755 | 576 |
| Medications | | | | 228,399 |
| Private care | Private part of total health expenditure | 12.70% | | 109,469 |
| Health care cost subtotal | | | | £1,199,832 |
| SOCIAL CARE | | | | |
| Long-term care | Years in long-term care accommodation | 304,850 | 29,822 | 9,091,177 |
| Social care cost subtotal | | | | £9,091,177 |
| NON-HEALTH/SOCIAL CARE | | | | |
| Informal care | Hours of care provided by economically active carers | 512,457,980 | 13 | 6,671,816 |
| | Hours of care provided by economically inactive carers | 996,638,065 | 6 | 5,710,736 |
| Mortality | Working years lost (men) | 2,025 | 32,838* | 22,515 |
| | Working years lost (women) | 1,933 | 18,958* | 5,994 |
| Morbidity (friction adjusted) | Certified incapacity days | 160,603 | 104 | 16,743 |
| | Work days lost | 38,380 | 104 | 4,001 |
| Non-health/social care subtotal (friction adjusted) | | | | £12,431,804 |
| Total economic burden (friction adjusted) | | | | £22,722,813 |

*Future earnings discounted using an annual rate of 3.5%.

Table 4 Sensitivity analysis: hospitalisations by dementia diagnosis

| | Primary diagnosis | Any diagnosis |
|----------------------------|---------------------|-----------------------|
| Number of bed-days | 1,485,471 | 4,254,061 |
| Unit cost, £ | £311 | £311 |
| Total cost of bed-days, £ | £462,589,784 | £1,324,754,919 |
| Number of day cases | 209 | 6,924 |
| Unit cost, £ | £2,775 | £2,775 |
| Total cost of day cases, £ | £575,898 | £19,078,805 |
| Total cost, £ | £463,165,682 | £1,343,833,725 |

Total annual expenditure on dementia-related medications, including dispensing fees, was £228 million. Nearly half of this expenditure, £100 million, was on anti-dementia drugs (i.e. donepezil, galantamine, rivastigmine and memantine), with the

remaining expenditure, £128 million, being due to prescriptions for antipsychotic, anxiolytic, hypnotic and antidepressant medications (Table 3).

Combining all healthcare costs due to dementia, the total cost to the NHS was £1,090 million if only the costs of hospitalisations for dementia as a primary diagnosis were included. Including private healthcare expenditure on dementia, the total cost to the healthcare system would increase to £1,200 million. If however, all dementia-related hospitalisations were included in the analysis the costs to the NHS would increase to £1,971 million, and those to the healthcare system to £2,192 million.

4.1.4 Informal care costs

A total of 1,509 million hours of informal care was provided by friends and relatives of the 517,033 dementia patients living in the community. Approximately 34% (512 million hours) of this care was provided by economically active and employed relatives/friends, with the majority of care (997 million hours) being provided by retired, inactive or unemployed informal carers. Combined, the total annual costs of informal care-giving were estimated at £12,383 million (Table 3).

4.1.5 Productivity costs

There were a total of 23,418 deaths with dementia registered as the main cause of death, of which 610 (3%) occurred in patients under the age of 70 years. This resulted in an estimated loss of 3,958 working years lost, resulting in annual cost of £34 million when future foregone earnings were not discounted, and £29 million after discounting future earnings (Tables 3 and 5).

When deaths with dementia registered as an underlying cause were accounted for, there were a total of 53,676 dementia-related deaths, of which 1,371 (3%) occurred in patients under the age of 70 years, resulting in a loss of 9,243 working years (Table 5). This generated productivity losses of £82 million when future foregone earnings were not discounted, and £68 million when these were discounted.

Table 5 Sensitivity analysis: dementia deaths by cause

| | Main cause | Main & underlying causes |
|--------------------------------------|--------------------|--------------------------|
| Number of deaths | 23,418 | 53,676 |
| Number of deaths, < 70 years | 610 | 1,371 |
| Potential working years lost | 3,958 | 9,243 |
| Mortality costs £, undiscounted | £33,956,727 | £82,359,860 |
| Mortality costs £, discounted | £28,508,341 | £68,300,834 |

An estimated 512,936 days of work were lost due to sickness absence or incapacity related with dementia. This represented a cost of £53 million, which when adjusted by the friction period resulted in a cost of just under £21 million.

Overall, dementia was found to cost £22.7 billion in terms of health and social care, informal care and productivity losses in 2008. Of these costs, 5% were due to healthcare, 40% to social care and 55% to informal care, with productivity losses accounting for less than 1% of total costs.

4.1.6 Sensitivity analysis: Prevalence rates

Using prevalence rates from the Expert Delphi Consensus group,⁵ the estimated number of patients with dementia in the UK was 701,143. The proportion of dementia cases occurring in individuals aged 80 years or more was 67%, whereas only 2% of total cases were predicted in those younger than 65 years of age. If prevalence rates from this study were used to re-calculate the costs relating to primary, emergency, outpatient and pharmaceuticals, the costs to the NHS would be £1,011 million, and those to the health care system would be £1,113 million. These prevalence rates would also alter our estimates of informal care, resulting in a total of 1,157 million hours of care provided to 396,293 dementia patients in the community, and slightly decreasing the total costs of informal care to £9,941 million.

Therefore, using the prevalence rates from the Expert Delphi Consensus group, the cost of dementia to the UK economy decreased from £22.7 billion when using EURODEM rates to £19.7 billion,

of which 6% was due to healthcare, 46% due to social care and 48% due to informal care.

4.2 COSTS OF CANCER

4.2.1 Social care

Of the 159,520 registered deaths with cancer as the main cause, 20,233 occurred in independent (i.e. non-NHS) hospices, with an estimated annual cost of £572 million (Table 6).

4.2.2 Health care costs

There were over 4 million primary care consultations in the UK due to cancer, with over half, 2.2 million, consisting of GP surgery visits. This resulted in an annual cost to the healthcare system of over £127 million. For the same year there were 314,000 A&E visits and nearly 7.5 million outpatient consultations due to cancer. This represented an annual cost of £28 million in A&E care and £793 million in

outpatient consultations (Table 6).

Table 6 shows a total of over 5 million inpatient bed days and in excess of 1 million hospital day cases due to a primary diagnosis of cancer. This resulted in an annual cost of over £2.3 billion, of which £1.8 billion was accounted by overnight stays in hospital and the remaining £500 million by hospital day cases.

For cancer patients, the two most commonly prescribed medications were tamoxifen citrate and anastrozole, accounting for 753,183 (20%) and 671,987 (18%), respectively, of the 3,753,525 prescriptions dispensed for cancer. The total annual expenditure on these two medications was £62 million, representing 19% of the £326 million total annual expenditure on cancer-related medications, including dispensing fees (Table 6).

Table 6 Costs of cancer in the UK

| Type of resource used | Unit of measurement | Units of resources consumed | Average unit cost, £ | Total cost, thousands, £ |
|--|--|-----------------------------|----------------------|--------------------------|
| HEALTH CARE | | | | |
| Primary care | Nurse home visits | 296,398 | 26 | 7,706 |
| | Nurse surgery visits | 599,857 | 9 | 5,399 |
| | GP home visits | 293,855 | 58 | 17,044 |
| | GP surgery visits | 2,203,111 | 36 | 79,312 |
| | GP telephone visits | 806,857 | 22 | 17,751 |
| | Total | | | |
| A&E | Attendances | 313,974 | 89 | 28,088 |
| Outpatient care | Attendances | 7,482,712 | 106 | 792,857 |
| Inpatient care | Hospital bed-days | 5,310,423 | 340 | 1,807,504 |
| | Hospital day cases | 1,135,127 | 441 | 500,336 |
| Medications | | | | 326,117 |
| Private care | Private part of total health expenditure | 12.70% | | 413,512 |
| Health care cost subtotal | | | £3,995,625 | |
| SOCIAL CARE | | | | |
| Hospice care | Cancer cases in hospice care | 20,233 | 28,255 | 571,687 |
| Social care cost subtotal | | | £571,687 | |
| NON-HEALTH/SOCIAL CARE | | | | |
| Informal care | Hours of care provided by economically active carers | 58,527,648 | 14 | 791,308 |
| | Hours of care provided by economically inactive carers | 83,086,320 | 6 | 476,085 |
| Mortality | Working years lost (men) | 329,863 | 32,838* | 4,165,990 |
| | Working years lost (women) | 316,239 | 18,958* | 1,573,951 |
| Morbidity | Certified incapacity days | 11,183,000 | 104 | 1,165,828 |
| | Work days lost | 2,672,476 | 104 | 278,606 |
| Non-health/social care subtotal (friction adjusted) | | | | £7,431,153 |
| Total economic burden (friction adjusted) | | | | £11,998,465 |

*Future earnings discounted using an annual rate of 3.5%.

Combining all the healthcare costs due to cancer, the total cost to the NHS was £3,582 million. Including private healthcare expenditure on cancer, the total cost to the healthcare system would increase to £3,996 million.

4.2.3 Informal care costs

A total of 142 million hours of informal care was provided by friends and relatives of the cancer patients whilst they were receiving treatment or palliative care. Approximately 41% (59 million hours) of this care was provided by economically active and employed relatives/friends, with the majority of care (83 million hours) being provided by retired, inactive or unemployed informal carers. Combined, the total annual costs of informal care-giving were estimated at £1,267 million (Table 6).

4.2.4 Productivity costs

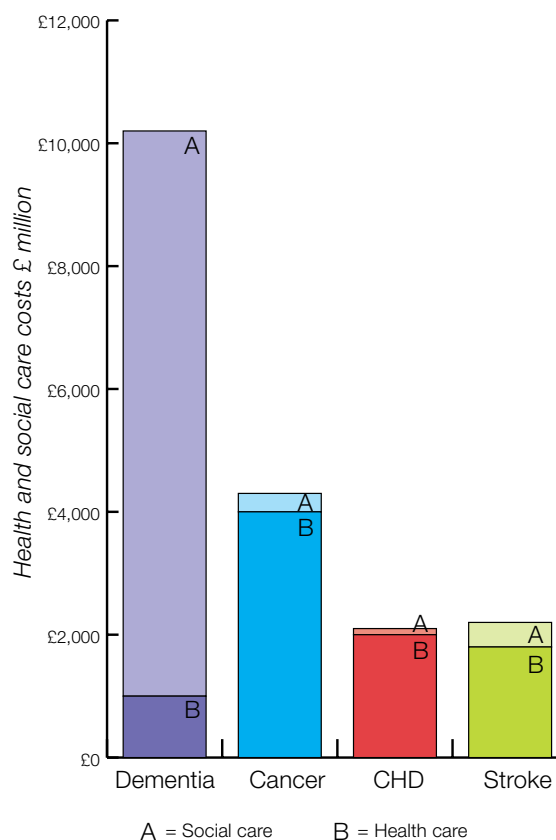
A total of 159,520 deaths were registered with cancer as the main cause of death, of which 55,494 (35%) occurred in patients under the age of 70 years. This resulted in an estimated loss of 646,102 working years lost, resulting in an annual cost of £7,769 million when future foregone earnings were not discounted, and £5,740 million after discounting future earnings (Table 6). In addition, an estimated 14 million days of work were lost due to sickness absence or incapacity related with cancer. This represented a cost of £1,445 million that when adjusted by the friction period resulted in a cost of just under £424 million.

Overall, cancer was found to cost £12 billion in terms of health and social care, informal care and productivity losses in 2008. Of these costs, 33% were due to healthcare, 5% to social care and 11% to informal care, with 51% of total costs being accounted for by productivity losses.

4.3 COST COMPARISONS ACROSS DISEASES

The societal costs of dementia and cancer were compared to each other and also to the costs of CHD and stroke. The costs of the latter two diseases were derived from previous studies,¹³⁻¹⁶ which used similar methods and sources of information, and whose cost results were updated to 2008 prices.

Figure 1 Health and social care costs



Although dementia had the lowest healthcare costs (Figure 1), £1.2 billion, compared to £4.0 billion for cancer, £2.2 billion for CHD, and £1.6 billion for stroke, the costs placed on the social care system (£9.1 billion), far outweighed the social care costs of cancer, CHD and stroke. Combining the costs to the UK health and social services, dementia cost £10.3 billion in 2008, compared to £4.5 billion for cancer, £2.7 billion for stroke and £2.3 billion for CHD, representing a direct cost to each citizen of £168 for dementia, £74 for cancer, £44 for stroke and £38 for CHD. Using UK prevalence estimates for these four diseases, the health and social care costs per person with the disease were evaluated at £12,521 for dementia, £2,559 for stroke, £2,283 for cancer, and £1,019 for CHD.

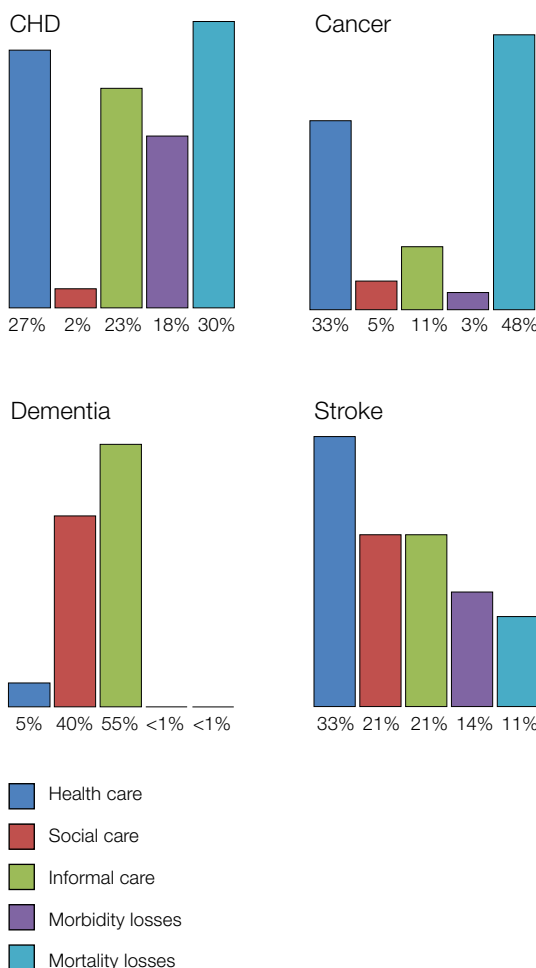
Table 7 Total costs by disease

| Disease | Health and social care costs, £ million | Total cost, £ million |
|----------|---|-----------------------|
| Dementia | 10,291 | 22,723 |
| Cancer | 4,567 | 11,998 |
| CHD | 2,314 | 7,848 |
| Stroke | 2,671 | 4,997 |

In terms of health and social care, informal care and productivity losses, dementia had the highest cost at nearly £23 billion (Table 7), followed by cancer (£12 billion), CHD (£8 billion) and stroke (£5 billion). Figure 2 shows how these costs were distributed amongst health, social and informal care, and productivity losses.

For dementia, 55% of total costs were attributable to informal care, 40% to social care and 5% to health care (Figure 2). Productivity losses for this disease were almost negligible. In contrast, for cancer half of all total costs of the disease were due to productivity losses (mainly mortality losses), with informal and social care only accounting for 16% of total costs. For both stroke and CHD, total costs were more evenly distributed across the different categories of cost. Stroke was the only disease for which health and social care costs accounted for over 50% of total costs.

Figure 2 Distribution of costs by disease



SECTION 5

RESULTS: RESEARCH FUNDING

5.1 SAMPLE

5.1.1 Governmental agencies

A total of 8 governmental agencies funding health research were identified. These included 4 research councils and 4 research agencies from the Department of Health and its devolved administrations:

- the Medical Research Council (MRC);
- the Biotechnology & Biological Sciences Research Council (BBSRC);
- the Economic & Social Research Council (ESRC);
- the Engineering & Physical Sciences Research Council (EPSRC);
- the National Institute for Health Research (NIHR);
- the Research and Development Office for the Northern Ireland Health and Personal Social Services;
- the Scottish Executive Health Department Chief Scientist Office; and
- the Wales Office of Research and Development for Health and Social Care.

Information on the levels of research funding for the fiscal year 2007/2008 for dementia, cancer, CHD and stroke were obtained for 7 of the 8 governmental agencies identified, with only the Wales Office of Research and Development failing to respond to our request for information.

5.1.2 Charities

Charities identified through the England & Wales Charity Commission

A total of 6,751 charities were registered by the Charity Commission as being active in the “Medical / Health / Sickness” area and providing monetary funds either by “making grants to organisations” or “sponsoring or undertaking research”. Due to the very high number of charities identified using this search criteria (n=6,751), charities were ranked in terms of their annual income and only the first two hundred charities, which had a combined income of over 75% of the total, were considered. Of the 200 charities, 36 (18%) were included in the analysis. Reasons for excluding the remaining 164 charities are reported in Table 8.

Table 8 Reasons for exclusion of charities identified through the Charity Commission

| Reason for exclusion | Number (%) |
|---|------------|
| No health research funding | 74* (45%) |
| No research funding in diseases of interest | 51 (31%) |
| Funded generic health research | 22 (13%) |
| Royal Colleges | 8 (5%) |
| Part of another bigger charity | 3 (2%) |
| Contacted for information, but failed to reply | 2 (1%) |
| Only funded research infrastructure | 2 (1%) |
| University | 1 (<1%) |
| Refused to provide relevant health research expenditure | 1 (<1%) |
| Total exclusions | 164 |

* One charity included in this category was found to provide relatively small donations for research to cancer and CHD research charities. As these charities were already included in the analysis, it was decided to exclude this charity.

A total of 73 (45%) charities were excluded because there was no evidence in their annual records and accounts of any expenditure on health research. 31% of charities were excluded because, although funding health research, this funding was targeted at diseases other than dementia, cancer, CHD or stroke. A further 22 (13%) charities were excluded because its research funding was aimed at generic research (e.g. genetics or lifestyle interventions that could have an impact on a wide range of diseases rather than one in particular). Only 3 charities were excluded because they either failed to respond to our contacts for information or refused to provide the relevant information, which was not held in their annual reports.

Charities identified through the Association for Medical Research Charities

At the time of this research, the AMRC consisted of 116 charities. Of these charities, 44 (38%) were included in the analysis, with the remaining 72 being excluded. The majority of charities (n=69, 96%) were excluded as health research funding was in diseases other than dementia, cancer, CHD or stroke. One charity was excluded because it was registered in Switzerland and therefore was under no obligation to file accounts in the UK, and a further two because they either failed to reply to our contacts for information or refused to provide the relevant information.

Through the AMRC and Charity Commission we identified a total of 65 charities providing research funding into dementia, cancer, CHD and/or stroke. Of these 65 charities, 29 (45%) were identified solely by the AMRC, 21 (32%) solely by the Charity Commission, and 15 (23%) from both the AMRC and Charity Commission. A list of all the charities included in the analysis is reported in Appendix 2. However, the amounts of research funding into the four diseases under investigation by individual charities is not provided as some of this information was provided in confidence.

5.2 LEVELS OF RESEARCH FUNDING

Of the 65 charities included in the analysis, 47 (72%) funded research into cancer, 20 (31%) funded CHD research, 17 (26%) funded stroke research and 15 (23%) funded research into dementia. Of these charities, 28 (43%) were cancer-specific charities (i.e. they only funded research into cancer). Combined, these charities spent £429 million into cancer, CHD, dementia and stroke research (Table 9). Most of this research funding, £324 million, was devoted to cancer, followed by CHD (£85 million), dementia (£14 million) and stroke (£6 million).

Table 9 Research funding by disease in 2007/08

| | Cancer | CHD | Dementia | Stroke | TOTAL |
|-----------------------------------|---------|---------|----------|--------|---------|
| Charity, £ thousands | 323,771 | 85,031 | 13,913 | 5,833 | 428,548 |
| (% of total) | (76) | (20) | (3) | (1) | (100) |
| Government, £ thousands | 266,640 | 84,229 | 36,331 | 17,522 | 404,723 |
| (% of total) | (66) | (21) | (9) | (4) | (100) |
| Charity & government, £ thousands | 590,411 | 169,260 | 50,244 | 23,355 | 833,270 |
| (% of total) | (71) | (20) | (6) | (3) | (100) |

Research funding into cancer, CHD, dementia and stroke from the 7 governmental agencies included in the analysis amounted to £405 million, slightly less than the total funding made available by charities. Again, cancer was the disease area receiving most funding (Table 9), £267 million, followed by CHD (£84 million), dementia (£36 million) and stroke (£18 million). Although, as a proportion of total research funding into the four diseases, governmental agencies devoted more research funding into dementia and stroke than charities (Figure 3), cancer still accounted for 66% of all government research funding.

Figure 3 Proportion of research funding by disease area

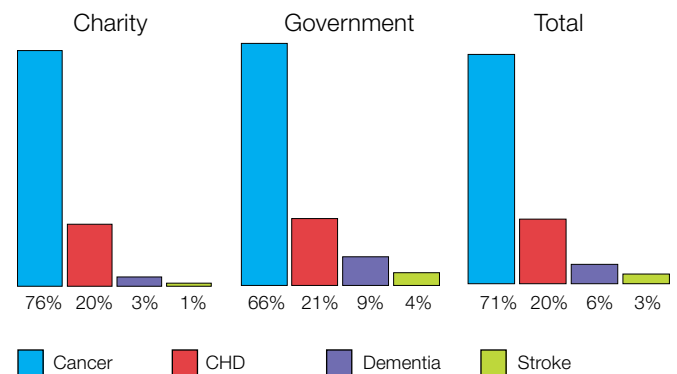


Table 10 Research funding, number of cases and total costs of disease

| | Cancer | CHD | Dementia | Stroke |
|--|----------|----------|----------|---------|
| Total research funding, £ thousands | £590,411 | £169,260 | £50,244 | £23,355 |
| Total number of cases, thousands | 2,000 | 2,271 | 822 | 1,044 |
| Funding per case | £295 | £75 | £61 | £22 |
| Total health and social care, £ millions | £4,567 | £2,314 | £10,291 | £2,671 |
| Funding per £1 million in disease costs | £129,269 | £73,153 | £4,882 | £8,745 |

Prevalence of cancer was obtained from Cancer Research UK statistics.⁸⁵ Prevalence of stroke and CHD

SECTION 6

DISCUSSION

Results from this report showed that the health care, social care, informal care and productivity costs of dementia were nearly £23 billion a year. Over 55% (£12 billion) of these total costs was due to informal care, representing 1.5 billion hours of unpaid care provided by relatives and friends of dementia patients. Long term institutionalisation costs represented 40% (£9 billion) of the total annual costs with an estimated 304,850 patients in care homes. Conversely, the costs to the NHS were comparably low accounting for just over £1 billion, most of which was due to overnight stays in hospital (42%). Due to the late onset of dementia in most cases, the productivity losses due to morbidity or mortality were very low (less than 1%).

The report also confirms the diagnosis gap between the expected number of dementia cases and the number of patients with dementia in GP registers.

For example, in England only an estimated 31% of people with dementia are registered in GP lists.¹¹ A number of reasons have been proposed for the low rates of diagnosis in primary care settings, including GPs' lack of training and confidence in diagnosing dementia as discussed in a recent National Audit Office report.⁸ In early 2009, the National Dementia Strategy for England was published in order to help address these concerns and raise awareness about the needs of people with dementia and their carers.¹¹

A number of previously published studies have also evaluated the costs of dementia for the UK.^{5,82} In 2006, the total cost of dementia was estimated at approximately £17 billion per year.⁵ These costs were derived from a London-based study of 132 people with dementia followed between 1997 and 1999,³⁰ which were then updated to 2005/06 price levels and extrapolated to the whole of the UK using dementia prevalence estimates derived from expert opinion. In our study we found the cost of dementia

to be approximately £5 billion more at £23 billion for the year 2008. These differences in cost were largely explained by the different prevalence rates and methodological approaches used to estimate the costs. So, for example, when prevalence rates obtained from the expert panel in Knapp and Prince (2007)⁵ were used in the sensitivity analysis of this study the total costs of dementia decreased from £23 billion to £20 billion. Nevertheless, regardless of the methodological approach used, the total cost of dementia in the UK far outweighed the costs of cancer, CHD and stroke.

In order to compare the economic burden of different diseases, the costs associated with each disease must be estimated using the same methods and analytic framework. The methods used to evaluate the costs of dementia in this report were similar to previous approaches used to estimate the economic burden of cardiovascular disease (CVD), coronary heart disease (CHD) and stroke in the European Union and the UK.¹³⁻¹⁶ After updating the results from these studies to 2008 prices, a direct comparison was made between the costs of dementia with those of CHD and stroke without concerns that the estimated variation in costs was attributable to the use of different methodologies. In addition, using the same methodology, we estimated the economic burden of cancer as no other comparable estimates were available for the UK. Stroke and dementia were associated with relatively low costs to the health care system (£1.6 billion and £1.2 billion, respectively) when compared to cancer (£4 billion) and CHD (£2.2 billion). However, with high rates of long-term institutionalisation, dementia generated costs to the social care system of £9 billion per year, compared to £1 billion for stroke, £0.5 billion for cancer and £0.1 billion for CHD. When costs other than health and social care were considered, such as informal care costs and productivity losses, dementia was again estimated to have the highest cost of all four diseases (approximately £23 billion), which was almost twice the cost of cancer, three times that of CHD and over 4 times that of stroke.

However, the aim of a cost-of-illness study is not to suggest how much the UK should spend on a particular disease. Our aim was not to estimate the

burden of disease on UK Gross Domestic Product (GDP): for example, we did not include all the costs and transfer payments associated with each of the diseases such as home care, social services such as meals on wheels and day care centres, pensions and other social benefits. One of the main aims of a cost-of-illness study is to help monitor policy initiatives and to inform decisions on the distribution of research effort. This is consistent with a recent governmental review into how public bodies should target medical research funding. The review recommended that an assessment of the impact of diseases on the UK population and economy was necessary to inform the UK health research priorities.¹⁷ Therefore, after estimating the costs of cancer, CHD, dementia and stroke we also evaluated the link between the impact of these four diseases and the allocation of research funds by charities and governmental organisations.

The results of this report highlight that, contrary to the estimates of the economic burden of disease, research funding is highly dominated by cancer followed a long way behind by CHD. Our results, in line with those from previously published studies, suggest that both dementia and stroke are grossly underfunded when compared to their prevalence and, especially, their health and social care costs.^{77;78;82} Out of £833 million research funds made available by charities and governmental organisations for cancer, CHD, stroke and dementia research, 71% was devoted to cancer research, 20% was devoted to CHD, 6% was devoted to dementia and 4% to stroke. Comparing the economic burden of these four diseases with the amount of research funding received, results of our study show that for every £1 million in health and social care costs, cancer receives £129,269 in research funding, CHD receives £73,153, followed by stroke with £8,745 and finally dementia with £4,882.

Possible reasons for the underfunding of both stroke and dementia could be that both stroke and dementia are still largely perceived as untreatable diseases, which are difficult to research and occur mainly in the elderly population.^{77;78} Contrary to cancer and CHD, stroke is mostly treated by generalist doctors while there is still no international

consensus about which medical specialty should diagnose and treat dementia.⁷⁷ This attitude towards care of dementia and stroke patients may hamper the research initiative of health professionals applying for funds.⁷⁸ As shown in our results, cancer research funding by charities received an even greater proportion of total funds than stroke, CHD and dementia when compared to governmental funding. This possibly reflects a public preference towards CHD and cancer charities. It is unclear why this happens, but ageism, with a perception that dementia and stroke are confined to the very elderly, has been forwarded as a possible explanation.^{77;78}

Reflecting the historically low investment in dementia research, there are worryingly few data on epidemiological characteristics and use of health and social services by people with dementia. This lack of high quality data makes studies such as this more difficult to conduct. The last population based study to estimate the prevalence of dementia in the UK was performed over 17 years ago.^{83;84} The EURODEM prevalence rates were obtained from 1980-1990 prevalence studies across Europe.²³ More recent estimates on the prevalence of dementia, such as that by Knapp and Prince (2007),⁵ were based solely on expert opinion. In this report, we used the EURODEM meta-analysis prevalence rates as the baseline of our cost estimation and compared it with the results of using the recent expert opinion rates estimated in Knapp and Prince (2007).⁵

In addition, there are no currently published large UK based studies following cohorts of patients with dementia and their carers to inform on their health and social care usage. The studies that are available have generally small sample sizes and represent levels of care over 10 years ago.^{28;30} Naturally, this is likely to affect the precision of our estimates of the costs of primary care, outpatient, and accident and emergency use in our analysis, and estimates in previous studies such as by Knapp and Prince (2007).⁵ Furthermore, as the studies used to evaluate primary, outpatient and emergency care usage were based on patients diagnosed with dementia, in our study we made the assumption that undiagnosed patients would have similar patterns of resource usage: this may not be the case in practice.

Another limitation of our study is that we did not include all the costs associated with the four diseases under question. First, the impact of disease on informal carers was solely evaluated as the opportunity of unpaid care. We did not account for any health and social services usage related to the additional demands of caring for someone. Second, due to the paucity of data and in order to compare the cost estimates with those due to CHD, stroke and cancer, some social care costs, such as home and day care and meals on wheels, were not included in the analysis. Nevertheless, the main cost drivers of health and social care in dementia patients were included in the analysis, with the omitted costs being a relatively small proportion of total costs.^{28;30}

The limitations of our review on the levels of research funding allocated by charities and governmental organisations to cancer, stroke, CHD and dementia should also be acknowledged. As with other studies evaluating levels of research funding for different diseases,⁷⁶⁻⁷⁹ our study should be viewed as giving an estimate of the proportion of research funding allocated to each disease, but not necessarily reflecting the total amount of funding.

First, we did not include funding from all the charities registered in the UK, with our analysis being restricted to charities in the Association for Medical Research Charities (AMRC), and to the top 200 health-related charities, in terms of income, registered with the England and Wales Charity Commission.

Second, charities registered solely in Scotland or Northern Ireland were identified only through the AMRC, as the charity registers for Scotland and Northern Ireland did not contain sufficient detail to identify relevant charities. However, out of the 116 charities in the AMRC, only 4 (3%) and 2 (2%) were registered solely in Scotland or Northern Ireland, respectively, reflecting the fact that most of the charities funding medical research are registered in England and Wales.

Third, although we did our utmost to avoid double-counting research funding, charities included in the study could potentially make grants to each other and this could not always be identified in annual reports and accounts.

Fourthly, some relevant research funding bodies were not included in the analysis. We were unable to obtain any information on the levels of research funding allocated by the Wales Office of Research & Development, and five charities either refused to participate or did not respond to our requests for information. However, it is unlikely that the inclusion of the research funds made available by these organisations would change the relative levels of research funding across the four diseases.

Finally, as in the study by Pendlebury et al. (2004)⁷⁸ we did not include basic science research funding, as much basic science research is potentially relevant to many disease areas rather than a single disease. However, these limitations are unlikely to bias any disease area in particular, and as a result will not alter the wide disparities of funding observed.

In conclusion, dementia creates a significant burden mainly through the costs placed on unpaid carers and long-term institutionalised care. The costs associated with dementia are considerably higher than those of cancer, CHD or stroke. Previous studies evaluating levels of research funding have suggested that research into both dementia and stroke is severely underfunded. This report strongly confirms that finding using up-to-date data, and shows that research on dementia and stroke remains grossly underfunded when compared to cancer and CHD.

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APPENDIX 1 CHARITY RESEARCH FUNDING PROFORMA

1: Name of charity:

2: Type of charity: Non-disease specific Disease specific

3: Charity number:

4: Registered in (circle): England & Wales Scotland Northern Ireland

5: Part of Association of Medical Research Charities?: Yes No

6: Annual report and accounts obtained for year 20___/___ Yes No
(for charities in England & Wales available from Charity Commission)

7: Annual income: £ Annual spending: £

8: a. If disease non-specific charity information on annual report on specific grants: Yes No
b. If no, reports/documents detailing funding for different grants/diseases: Yes No
If no in a. or b. contacted charity on: ___/___/2009 E-mail Telephone Post
Responded: Yes on ___/___/2009 No

9: Diseases/conditions for which funding given:

Cancer Stroke
 Coronary heart disease Other diseases
 Dementia/Alzheimer's disease No research funding

If "Other diseases" only or no research funding DO NOT PROCEED

10: Research expenditure for year 20___/___

| | |
|-------------------------------------|------------------------|
| Expenditure on Medical Research | £ <input type="text"/> |
| Expenditure on Cancer research | £ <input type="text"/> |
| Expenditure on CHD | £ <input type="text"/> |
| Expenditure on Dementia/Alzheimer's | £ <input type="text"/> |
| Expenditure on Stroke | £ <input type="text"/> |

11: Research grants received for charity to conduct research for year 20___/___

| | |
|---|------------------------|
| Overall Medical Research funding obtained | £ <input type="text"/> |
| Funding for Cancer research | £ <input type="text"/> |
| Funding for CHD | £ <input type="text"/> |
| Funding for Dementia/Alzheimer's | £ <input type="text"/> |
| Funding for Stroke | £ <input type="text"/> |

12: Net research expenditure (research expenditure – research grants) for year 20___/___

| | |
|--------------------------|------------------------|
| Overall Medical Research | £ <input type="text"/> |
| Cancer | £ <input type="text"/> |
| CHD | £ <input type="text"/> |
| Dementia/Alzheimer's | £ <input type="text"/> |
| Stroke | £ <input type="text"/> |

APPENDIX 2 LIST OF INCLUDED CHARITIES

| Charity name | Charity number | Charity income | Member of AMRC | Charity Commission – largest 200 charities |
|---|----------------|----------------|----------------|--|
| Cancer Research UK | 1089464 | £476,559,000 | Yes | Yes |
| Wellcome Trust | 210183 | £304,987,360 | Yes | Yes |
| British Heart Foundation | 225971 | £185,089,000 | Yes | Yes |
| Marie Curie Cancer Care | 207994 | £119,868,000 | Yes | Yes |
| McMillan Cancer Support | 261017 | £92,081,000 | No | Yes |
| Help the Aged - Research into Ageing | 272786 | £71,907,000 | Yes | Yes |
| The Maurice Wohl Charitable Foundation | 244519 | £56,258,182 | No | Yes |
| Great Ormond Street Hospital Charity | 235825 | £52,549,000 | No | Yes |
| Alzheimer's Society | 296645 | £45,482,000 | Yes | Yes |
| Anthony Nolan | 803716 | £22,250,172 | No | Yes |
| Henry Smith Charity | 230102 | £21,309,000 | No | Yes |
| The Royal Marsden Hospital Charity | 1050537 | £21,023,000 | No | Yes |
| Breakthrough Breast Cancer | 1062636 | £20,759,000 | Yes | Yes |
| CLIC Sargent Cancer Care | 1107328 | £20,550,000 | No | Yes |
| Stroke Association | 211015 | £20,173,812 | Yes | Yes |
| Leukaemia Research | 216032 | £19,325,000 | No | Yes |
| Guy's & St Thomas' Charity | 251983 | £18,442,000 | Yes | Yes |
| Association of International Cancer Research (AICR) | SC022918 | £17,985,495 | Yes | N/A |
| Freemason's Grand Charity | 281942 | £15,838,100 | No | Yes |
| Barts and the London Charity | 212563 | £15,245,000 | No | Yes |
| Christie's Hospital Charitable Fund | 1049751 | £14,947,000 | No | Yes |
| Breast Cancer Care | 1017658 | £12,215,000 | No | Yes |
| Children with Cancer | 298405 | £12,196,989 | Yes | Yes |
| Breast Cancer Campaign | 299758 | £10,030,146 | Yes | Yes |
| Universtiy College London Hospital's Charity | 229771 | £9,625,359 | No | Yes |
| World Cancer Research Fund | 1000739 | £9,260,951 | Yes | Yes |
| Royal Marsden Cancer Campaign | 1095197 | £8,801,786 | No | Yes |
| Teenage Cancer Trust | 1062559 | £8,609,836 | No | Yes |
| Leeds Teaching Hospitals Charitable Foundation | 1075308 | £8,383,466 | No | Yes |
| Addenbrooke's Charitable Trust | 1048868 | £8,040,000 | No | Yes |
| St. Luke's Hospice | 254402 | £7,625,899 | No | Yes |
| BUPA Foundation | 277598 | £7,516,080 | Yes | Yes |
| Chest, Heart & Stroke Scotland | SC018761 | £7,150,000 | Yes | No |
| Central Manchester & Manchester Children's University | 1049274 | £6,887,000 | No | Yes |
| Oxford Radcliffe Hospitals Charitable Funds | 1057295 | £6,636,000 | No | Yes |

| Charity name | Charity number | Charity income | Member of AMRC | Charity Commission – largest 200 charities |
|---|-----------------------|-----------------------|-----------------------|---|
| Action Medical Research | 208701 | £6,567,405 | Yes | Yes |
| Tenovus | 1054015 | £6,561,240 | Yes | Yes |
| Royal Brompton & Harefield | 1053584 | £6,458,339 | No | Yes |
| Prostate Cancer Charity | 1005541 | £6,053,000 | Yes | No |
| Yorkshire Cancer Research | 516898 | £5,675,150 | Yes | No |
| SPARKS | 1003825 | £4,888,937 | Yes | No |
| British Lung Foundation | 326730 | £4,753,929 | Yes | No |
| Alzheimer's Research Trust | 1077089 | £4,570,173 | Yes | No |
| Wellbeing of Women | 239281 | £4,090,529 | Yes | No |
| Roy Castle Lung Cancer Foundation | 1046854 | £3,924,274 | Yes | No |
| Ulster Cancer Foundation | XN48265 | £3,506,588 | Yes | N/A |
| Dunhill Medical Trust | 294286 | £3,312,183 | Yes | No |
| Northern Ireland Chest Heart & Stroke | XN 47338 | £3,190,391 | Yes | No |
| Wellchild Trust | 289600 | £3,061,559 | Yes | No |
| Heart Research UK | 1044821 | £2,554,154 | Yes | No |
| Brain Research Trust | 263064 | £2,419,000 | Yes | No |
| Foundation for Liver Research | 268211 | £1,472,526 | Yes | No |
| Medical Research Scotland | SC014959 | £1,344,146 | Yes | N/A |
| Samantha Dickson Brain Tumour Trust | 1060627 | £1,255,969 | Yes | No |
| Prostate Cancer Research Foundation | 1117399 | £1,205,137 | Yes | No |
| William Harvey Research Foundation | 803012 | £1,118,223 | Yes | No |
| North West Cancer Research | 223598 | £1,092,379 | Yes | No |
| British Skin Foundation | 313865 | £1,071,889 | Yes | No |
| Ovarian Cancer Action | 1109743 | £973,825 | Yes | No |
| The Restoration of Appearance and Function Trust (RAFT) | 299811 | £917,585 | Yes | No |
| Pelican Cancer Foundation | 1019311 | £533,174 | Yes | No |
| Vascular Society | 1102769 | £441,926 | Yes | No |
| Remedi | 1063359 | £325,665 | Yes | No |
| Wessex Medical Research | 274839 | £304,873 | Yes | No |
| The Hypertension Trust | 289139 | £10,283 | Yes | No |



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