

# Research spend in the UK

Comparing stroke, cancer, coronary  
heart disease and dementia

Rebuilding lives after stroke

**Stroke**  
Association



## Full report

A report produced by the Health Economics Research  
Centre, Nuffield Department of Population Health,  
University of Oxford for the Stroke Association.

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# Contents

Acknowledgements	2
Contents	3
Foreword by Juliet Bouverie	4
Foreword by Professor Tony Rudd CBE	5
Key Findings	6
Executive Summary	8
<b>Section 1</b>	<b>12</b>
Introduction	
Objectives	
<b>Section 2</b>	<b>14</b>
Methods: Research Funding	
Governmental Health Research Funding	
Charity Health Funding	
<b>Section 3</b>	<b>18</b>
Methods: Disease Burden	
Disease Prevalence	
Disability Adjusted Life Years (DALYs)	
Economic Burden	
<b>Section 4</b>	<b>20</b>
Results: Research Funding	
Sample	
Governmental Organisations	
Charities	
Levels Of Research Funding	
Research Funding And Burden of Disease	
<b>Section 5</b>	<b>24</b>
Discussion	
References	28
Appendix 1 Research Funding By Government:	30
Included Research Grant Programmes	
Appendix 2 Research Funding By Government:	32
Included Research Infrastructure Programmes	
Appendix 3 List Of Included Charities	34



# Foreword

**Stroke is the biggest cause of complex disability worldwide, with an estimated 1.2 million stroke survivors in the UK today. Living with the long term impact of the condition can be devastating, yet research funding dedicated to stroke remains disproportionately small.**

The Stroke Association commissioned this study to compare the burden of stroke, cancer, coronary heart disease (CHD), and dementia against levels of research funding.

An earlier study found that in 2007/08 only 3% of research funding spent on these four diseases was being allocated to stroke. The results from this latest study suggest that, although the UK spend on stroke research by government and the third sector has increased, stroke still lags behind other conditions.

Stroke prevalence in the UK places huge pressure on the NHS and social care services, which will only increase unless we further invest in stroke research to develop effective prevention, treatment and rehabilitation.

For too long, stroke was considered by many health professionals as a sad but untreatable condition. With fairly modest resource, the stroke research community has won major breakthroughs in the last 20 years, helping to transform the way stroke is treated.

If funding levels for stroke research remain the same, we will not be ready for the challenges that lie ahead. Current levels of research funding equate to £48 for every stroke patient, compared to £241 per person with cancer and £118 per person with dementia. We can, and must, do better for stroke patients.

As a research charity, the Stroke Association is proud to have funded pioneering research that has helped to save lives and improve stroke rehabilitation. It is vital that we bring together funders, researchers, stroke survivors and their families to help us increase investment into stroke research. Major advances in research are changing the world for patients affected by a range of different health conditions. With stroke now the second largest cause of death in the world, we cannot, and will not, let stroke research be left behind as a priority issue.



A handwritten signature in black ink, appearing to read 'Juliet Bouverie'.

**Juliet Bouverie**  
Chief Executive  
Stroke Association

# Foreword

**Stroke is the second largest cause of death in the world, and the leading cause of complex adult disability. When compared to its economic burden on society, stroke research has been, and remains, underfunded compared to other conditions.**

Over the last two decades, stroke research has been the driving force behind improvements that have transformed our acute and long-term stroke services. Twenty years ago there was only a handful of dedicated stroke units in the UK and many stroke patients did not even get a brain scan. Today, all stroke patients can expect to receive an urgent brain scan and clot-busting drugs if appropriate. Every major hospital has a stroke unit where patients are treated by a multidisciplinary team to address their needs. Patients receive rehabilitative care starting in hospital and then within the community.

Starting at a time when much of the medical community thought stroke was not worthy of investment, the Stroke Association has been pivotal in supporting and encouraging research which has increased our understanding of stroke and led to better treatments. The charity has consistently taken up early phase research studies, capturing the attention of larger research funding bodies, and leading to life changing outcomes for stroke survivors, those at risk of stroke and their families.

It is encouraging that in this report the total spend on stroke research in the UK has increased from £23m to £56m. At the same time, this report provides new evidence that stroke research continues to be significantly underfunded relative to other major diseases. We know that with a growing and ageing population, the burden of stroke is set to double worldwide by the year 2030, and we need a major shift in efforts and investment into this condition if we are to be in a position to respond.



A handwritten signature in dark ink, appearing to read 'Tony Rudd'.

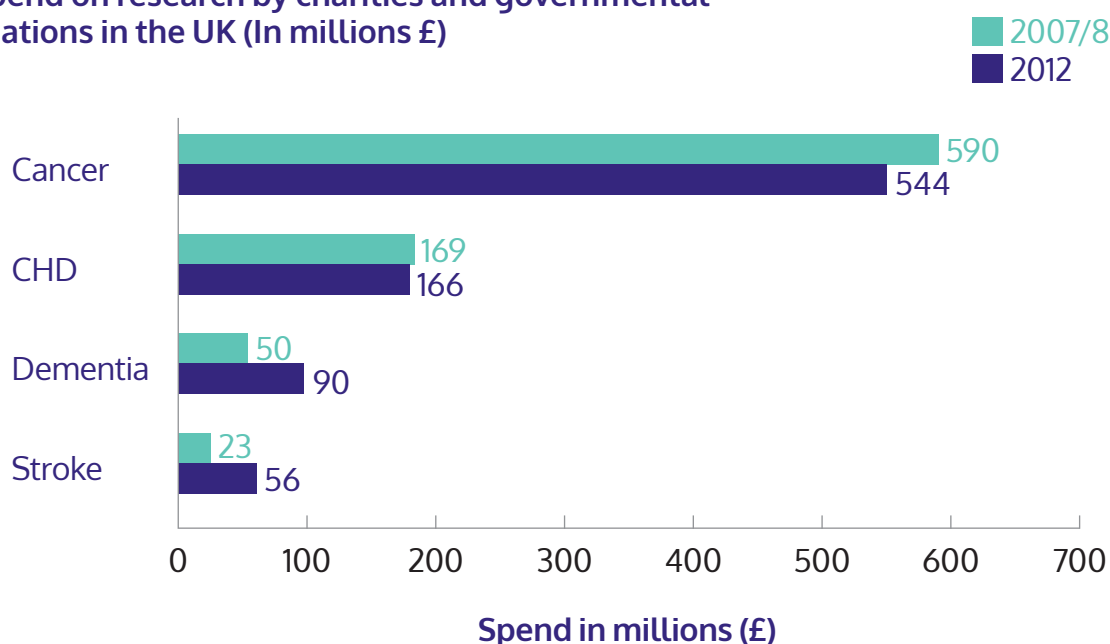
**Professor Tony Rudd CBE**  
**National Clinical Director**  
**for Stroke**  
**NHS England**

# Key findings

## There are 1.2 million stroke survivors in the UK today

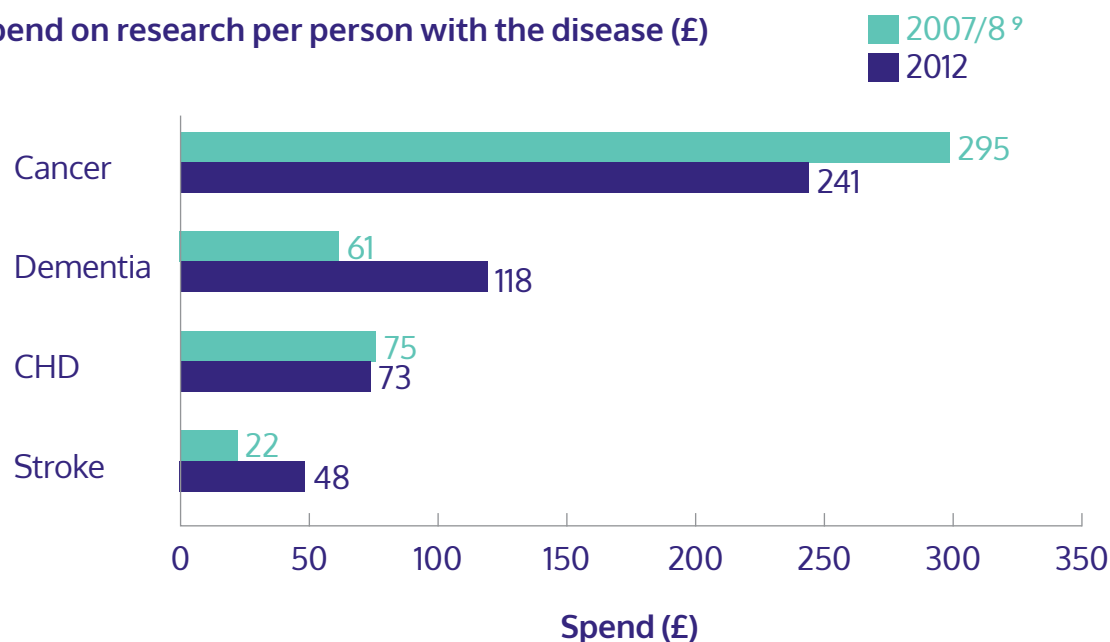
Although stroke research spend in the UK rose from £23 million in 2007/8 to £56 million in 2012, it remains dwarfed by the comparable spend on cancer research (£544 million), and still receives less funding than coronary heart disease (CHD) research (£166 million) and dementia research (£90 million).

### Total spend on research by charities and governmental organisations in the UK (In millions £)



In 2012, the total level of research funding per person with stroke was £48, which is about one fifth the comparable spend on cancer (£241) and less than half the comparable spend on dementia (£118).

### Total spend on research per person with the disease (£)

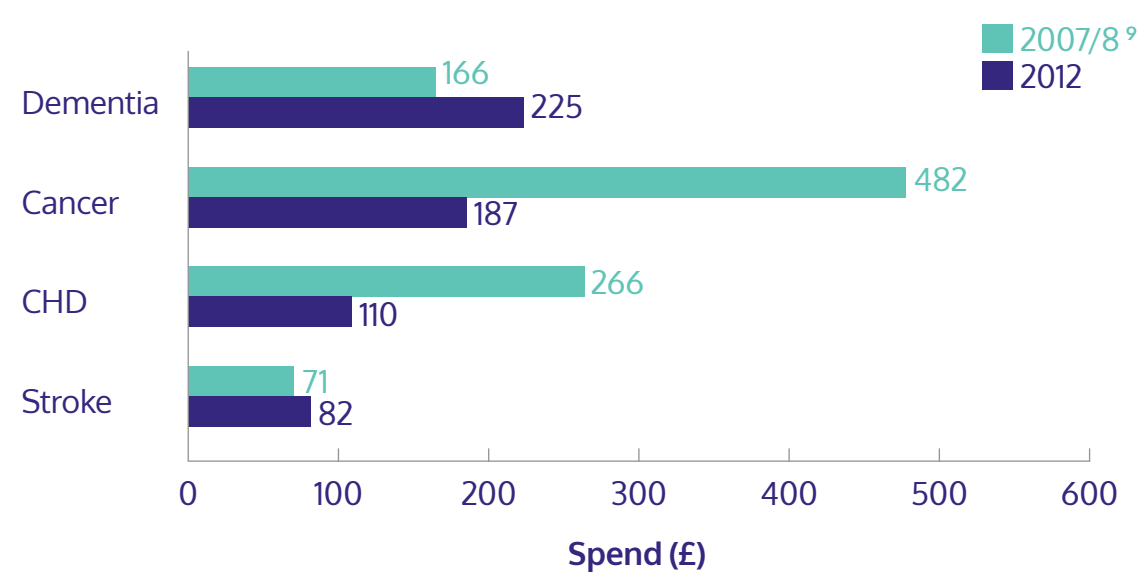


Stroke is the leading cause of complex adult disability. Over half of the 1.2 million stroke survivors in the UK are left with a disability, and over one third are left dependent on others for help with everyday tasks.

The disability-adjusted life year (DALY) is a measure of overall disease burden, expressed as the number of years lost due to ill-health, disability or early death.

In 2012, the total research spend per DALY lost due to stroke was less than half the comparable spend due to dementia or cancer.

Total spend on research per DALY lost (£)



# Executive Summary

## Rationale and objectives

Stroke is one of the leading causes of death, both globally and in high income countries. Stroke patients are at a high risk of death, and a large proportion of survivors face disability and having to rely on health and social care services, relatives and friends to provide care and assistance. This report is the outcome of a study commissioned by the Stroke Association to compare the burden and costs of stroke, coronary heart disease (CHD), dementia and cancer to the UK economy in 2012 with current levels of research funding. Cancer and CHD are also leading causes of death in Europe and, together with dementia, have a significant economic impact on health and social care services, on patients and relatives, and on the wider economy and society. The burden and costs of the four diseases were estimated using the same methodological approach. UK government and charity research funding was obtained for each of the diseases in the financial year 2011/12. The aim was to update previous estimates from a study comparing UK research funding with the economic burden of these four diseases in the year 2007/08. That study found that more than 70% of the research funding into these four diseases was targeted at cancer, with only 6% being allocated to dementia and 3% to stroke.

## Methods

### Disease burden and costs

For each of the four diseases, we obtained the number of prevalent disease cases, Disability Adjusted Life Years (DALYs) lost and their economic burden. Cancer was defined as International Statistical Classification of Diseases and Related Health Problems 10th Revision (ICD-10) codes C00-D48, CHD as ICD-10 I20-I25, dementia as ICD-10 F00-F03 and G30, and stroke as ICD-10 I60-I69. Prevalence estimates were obtained from sources such as the European Community Concerted Action on the Epidemiology and Prevention of Dementia (EURODEM) group, the Cognitive Function and Ageing Study (CFAS) and national disease registries. The number of DALYs lost for cancer, dementia, stroke and CHD was obtained from the Global Burden of Disease study. Finally, the economic burden of cancer, CHD, dementia and stroke was obtained from a separate study conducted by us, evaluating the annual prevalence costs of these four diseases to the UK health and social care system, using the same methodology and a “top down” approach,



## Research funding

We identified UK governmental organisations that provide health research funding and contacted them to determine the value of research grants and fellowships awarded for dementia, cancer, CHD and stroke in the financial year 2011/12. 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). To these levels of research grant funding, we added the research infrastructure expenditure from three governmental agencies: Chief Scientist Office (CSO), NIHR and the National Institute for Social Care & Health Research (NISCHR). Charity organisations that fund health research were 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 214 charities, in terms of their annual income, were considered in this study. These 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 diseases were obtained from annual reports. Research funding provided by the pharmaceutical and biotechnology industry was excluded from the analysis.

# Results

## Burden and costs of disease

In the UK, there were approximately 2.3 million people living with cancer, 2.3 million people living with CHD, 0.8 million people living with dementia, and 1.2 million people living with stroke in 2012. These corresponded to a total of 2.9 million DALYs lost due to cancer, 1.5 million due to CHD, 0.4 million due to dementia, and 0.7 million due to stroke. The combined health and social care costs of stroke were estimated at £2.9 billion in 2012, compared to £11.6 billion for dementia, £5 billion for cancer and £2.5 billion for CHD.

## Research funding

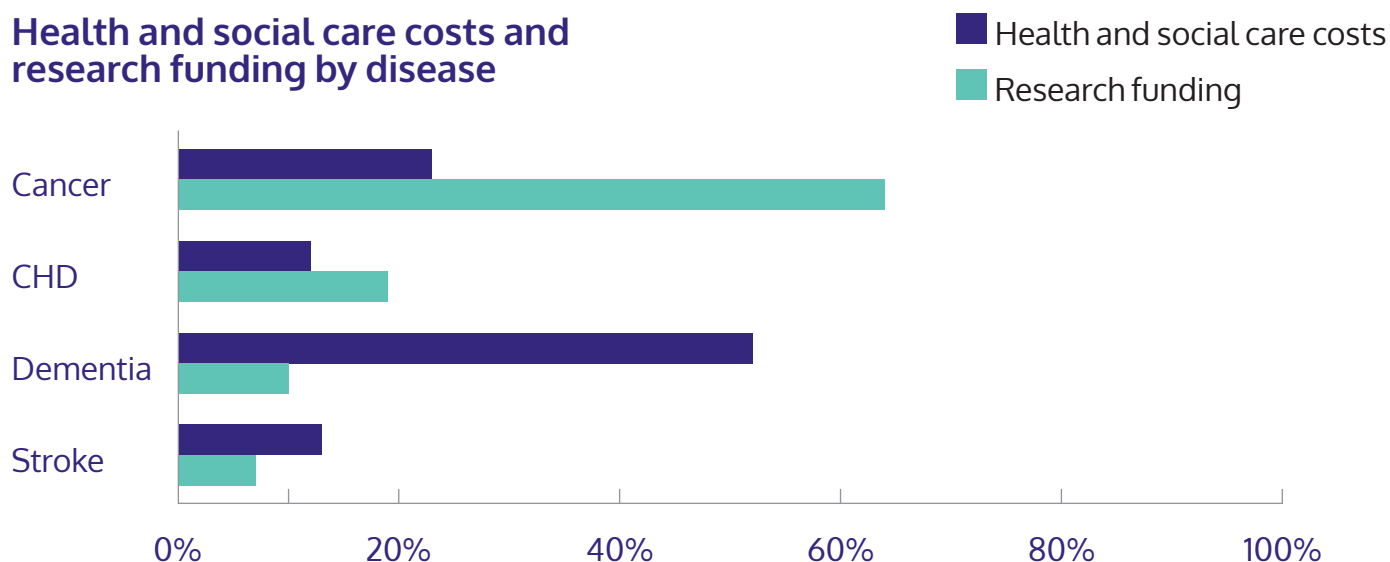
A total of 1,439 research grants and fellowships awarded were reviewed from seven out of eight governmental organisations, with a total combined value of £750 million. We added to these levels of research grant funding the respective research infrastructure expenditure by disease. The combined total research spend by government on cancer, CHD, dementia and stroke was £347 million, of which £157 million (45%) was devoted to cancer, £75 million (21%) to CHD, £73 million (21%) to dementia and £43 million (12%) to stroke. A total of 66 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 £509 million on cancer, CHD, dementia and stroke research. As with the governmental agencies, most of these funds were devoted to cancer (£387 million, 76%) followed by CHD (£91 million, 18%), dementia (£17 million, 3%) and stroke (£13 million, 3%). However, both in total and as a proportion of total research funding into the four diseases, governmental organisations devoted considerably more research funding into dementia and stroke than charities.

In total, the combined research funding into stroke, cancer, CHD and dementia by governmental and charity organisations in this study was £856 million. Of this total, £544 million (64%) was devoted to cancer, £166 million (19%) to CHD, £90 million (10%) to dementia and £56 million (7%) to stroke.

The total levels of research funding per person with the disease were evaluated at £241 per person with cancer, £73 per person with CHD, £118 per person with dementia and £48 per person with stroke. Dementia received the highest levels of total research per DALY lost, at £225 per DALY lost, followed by cancer (£187), CHD (£110) and stroke (£82). However, for every £10 of health and social care costs attributable to the disease, cancer received £1.08 in research funding, CHD received £0.65, stroke received £0.19 (or £0.11 depending on care costs of stroke used) and finally dementia received £0.08.

As shown opposite, although dementia accounts for over 50% of the combined health and social care costs of the four diseases under study, it receives 10% of combined research funding. Furthermore, stroke accounts for 13% of costs but only receives 7% of the research funding. In contrast, cancer, which accounts for approximately 20% of health and social care costs, receives nearly two thirds of the total medical research funding for these four diseases.

## Health and social care costs and research funding by disease



Proportion of research funding and health and social care costs by disease

When comparing how government distributed research expenditure by disease in 2007/08 and in 2012, there appears to have been a considerable shift in the way governmental organisations distribute research funding across different diseases. In 2007/08, 66% of total governmental research funding into the four diseases under study was devoted to cancer, 21% to CHD, 9% to dementia and 4% to stroke. In 2012, the proportions devoted to dementia and stroke had increased to 21% and 12%, respectively, with cancer accounting for 45% of total research spend. However, the relative proportions of charity research funding into cancer, CHD, dementia and stroke remained virtually unchanged between 2007/08 and 2012.

## Conclusions

There has been much progress by governmental research organisations to increase the levels of funding for dementia and stroke. However, the results of this report highlight that, in contrast to the estimated burden of disease, stroke remains underfunded compared to other diseases, such as cancer.

# Section 1

## Introduction

Stroke is the second leading cause of death after ischaemic heart disease both globally and in high income countries.<sup>1</sup> In the UK, a population-based cohort study found that one month after stroke onset, 14% of patients had died, and approximately 50% were dead within five years of the event.<sup>2</sup> For survivors, stroke in many cases exerts a significant negative effect on patients' lives by affecting speech, swallowing, ambulation, mood, and therefore the ability to perform and carry out activities of daily living,<sup>3</sup> with approximately one third of stroke survivors becoming newly disabled after the event.<sup>2</sup> As a result, many will have to rely on health and social services, and relatives and friends to provide care and assistance.

Minor strokes and transient ischaemic attacks (TIA – referred to colloquially as “mini-stroke”) leave, in general, little or no permanent damage to the brain. However, the overall effect of medication, anxiety about experiencing subsequent events and, for those in employment, the impact on their working life, will have a negative impact on a patient's quality of life.<sup>4</sup> For example, a UK study found that minor stroke and TIA patients had significantly lower quality of life levels than age-and-gender matched controls with similar co-morbidities.<sup>5</sup> In addition, regardless of severity, both stroke and TIA have been found to be important risk factors for subsequent major stroke and vascular dementia.<sup>6</sup>

In 2005, the National Audit Office (NAO) published a report evaluating the care received by UK stroke patients in the UK.<sup>7</sup> The report concluded that stroke was accorded low priority by the National Health Service (NHS), with low implementation rates of medical and technological developments, and was widely perceived as an inevitable risk of growing old. Although stroke services have improved considerably since then, especially in acute care, a follow-up report by the NAO found continuing deficiencies in how stroke care services were configured and delivered, especially after discharge from hospital.<sup>8</sup>

The NAO report also described a lack of research-based evidence on the cost-effectiveness of clinical and other support for long-term care of stroke survivors.<sup>8</sup> This hampered the provision of long-term therapy in the NHS, as commissioners were unwilling to fund interventions with no good evidence of value for money. This finding is also in line with those from previously published studies, which suggest that stroke is considerably underfunded, both in the UK and in Europe, when compared to its prevalence and, especially, its associated health and social care costs.<sup>9-12</sup>

A hand holding a pen is pointing at a bar chart on a document. The chart has several bars of different colors (yellow, blue, green, red, purple) and is partially obscured by a dark blue overlay containing text. The background is a blurred image of a person's arm and hand.

## Objectives

A study,<sup>9</sup> commissioned by Alzheimer's Research UK, evaluated UK research funding by government and charities into cancer, heart disease, dementia and stroke in the year 2007/08. The study found that more than 70% of the research funding into these four diseases was targeted at cancer, with only 6% being allocated to dementia and 3% to stroke.

Therefore, the aim of this study is to assess the levels of research funding by UK governmental organisations and charities to cancer, coronary heart disease (CHD), dementia and stroke in 2012. As with Luengo-Fernandez et al. (2012),<sup>9</sup> we will also assess whether levels of research funding are associated with different measures of burden of disease. For the purposes of this study, cancer was defined as International Statistical Classification of Diseases and Related Health Problems 10th Revision (ICD-10) C00-D48, CHD as ICD-10 I20-I25, dementia as ICD-10 F00-F03 and G30, and stroke as ICD-10 I60-I69.



# Section 2

## Methods: Research Funding

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.<sup>13</sup>

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.<sup>9,14</sup>

## Governmental Health Research Funding

Governmental organisations responsible for funding health research were identified from a report by the UK Clinical Research Collaboration,<sup>14</sup> which evaluated UK levels of research funding during the 2009/10 financial year. Governmental organisations funding health research included:

### Research Councils:

- Biotechnology & Biological Sciences Research Council (BBSRC);
- Economic & Social Research Council (ESRC);
- Engineering & Physical Sciences Research Council (EPSRC); and
- Medical Research Council (MRC).

### Health Departments:

- Chief Scientist Office, Scottish Government Health and Social Care Directorates;
- Health and Social Care (HSC) R&D Division of the Public Health Agency;
- National Institute for Health Research (NIHR); and
- National Institute for Social Care and Health Research.

For each governmental organisation, we sought to determine the levels of research funding for cancer, coronary heart disease (CHD), dementia and stroke. We aimed to obtain information on the research grants funded by these organisations (i.e. title, abstract and amount of funding received) by searching through databases of grants. If no database of grants was identified, organisations were contacted by electronic mail, based on the contact details provided on their websites. Through freedom of information requests, they were asked to provide information on research grants starting in 2012 for the four diseases under investigation.

**Appendix 1** provides a list of the research programmes evaluated.

For some organisations, considerable expenditure is devoted to supporting research through research infrastructure. For example, in the financial year 2012/13 the NIHR devoted over £600 million of its £959 million budget to research infrastructure, including Clinical Research Networks, Biomedical Research Centres and Units, Clinical Research Facilities, and Information Systems.<sup>15</sup> Given the difficulties in directly attributing such research infrastructure to a particular disease,<sup>14</sup> we assumed that the proportion of research infrastructure spending attributable to a specific condition would be the same as the proportion of research grant funding for that same condition. **Appendix 2** lists the governmental organisations providing research infrastructure expenditure not included under research grants.







## Charity Health Funding

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

First, 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.<sup>16</sup> At the time of this research, the AMRC consisted of 121 charities with a joint spend of over £1 billion on health research in the UK.

Secondly, 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, which provides detailed information, including annual accounts and reports, for every registered charity in England and Wales. The list of potentially relevant charities was obtained by identifying all the charities classified in the Charity Commission register as having as one of their aims: "The advancement of health and savings lives" and providing monetary funds either by "making grants to individuals", "making grants to organisations" or "sponsoring or undertaking research." Due to the very high number of charities identified using these search criteria ( $n=15,773$ ), charities were ranked in terms of their annual income and only the first 214 charities, which had a combined income of 75% of the total, were considered.

Charities identified as potentially funding health research, either through the Charity Commission or AMRC, were only excluded from the analysis if they: were either 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 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, heart disease, cancer and dementia. We excluded research expenditure on support costs, such as administration and management, 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 from the charity's annual report and accounts. 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. If the information contained within the annual report was not detailed enough, the charity's website was browsed to identify whether a database of all the grants for health research was available.

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





# Section 3

## Methods: Disease Burden

For each condition, levels of research funding from UK governmental organisations and charities were then compared to the number of prevalent disease cases, Disability Adjusted Life Years (DALYs) lost and their economic burden.

## Disease prevalence

Prevalence rates of diagnosed and undiagnosed dementia cases were obtained from the European Community Concerted Action on the Epidemiology and Prevention of Dementia group (EURODEM) for individuals aged under 65 years,<sup>17</sup> and from the Cognitive Function and Ageing Study for those aged 65 years and older.<sup>18</sup> Prevalence rates were then applied to UK population estimates for 2012.<sup>19</sup>



The number of people with cancer, or having survived cancer, in the UK was obtained from a published study evaluating cancer prevalence in 2008.<sup>20</sup> These estimates were updated to 2012 by assuming a 3% annual increase as estimated by Maddams et al. (2009).<sup>20</sup> The number of people living with stroke and CHD was obtained from Quality and Outcomes Framework data for 2012.<sup>21;22</sup>

## Disability Adjusted Life Years (DALYs)

DALYs are a measure combining years of life lost due to premature mortality, and years of life lost due to time lived in states of less than full health. The rate of DALYs lost, per 100,000 in the population, for cancer, CHD, dementia and stroke was obtained from Global Burden of Disease for the year 2010,<sup>23</sup> and applied to 2012 population estimates.<sup>19</sup>

## Economic burden

The economic burden of cancer, CHD, dementia and stroke was obtained from a previously published study that evaluated the cost of these four diseases to the UK health and social care system in 2008, using the same methodology.<sup>9</sup> This study adopted a prevalence approach whereby all costs within the most recent year for which data were available were measured, regardless of the date of disease onset and adopting a “top down” approach, i.e. using aggregate data. Given that various estimates of costs exist for stroke, we also used the estimates provided by Saka et al. (2009).<sup>24</sup>

Our cost figures are based on a top-down analysis, using aggregate national data on resource use, such as Hospital Episode Statistics, and evidence from cohort studies (e.g. Oxford Vascular Study in the case of stroke). By contrast, Saka et al. (2009) made their calculations based on a bottom up analysis of a cohort of patients from the South London Stroke Register (SLSR). We used the Hospital and community health services (HCHS) pay and price inflation index to update costs to 2012.<sup>25</sup>





# Section 4

## Results: Research Funding Sample

### Governmental organisations

We obtained information on the total number of research grants and fellowships awarded in the year 2012 for all eight of the governmental organisations identified. A total of 1,439 research grants and fellowships, with a total combined value of £750 million (**Appendix 1**), and £1,138 million of research infrastructure expenditure were considered (**Appendix 2**).

### Charities

#### Charities identified through the Association for Medical Research Charities

At the time of this research, the AMRC consisted of 121 charities. Of these charities, 51 (42%) were included in the analysis, with the remaining 70 being excluded. The majority of charities (n=65, 93%) were excluded as health research funding was in diseases other than cancer, CHD, dementia or stroke. Six further charities were excluded because:

- We could not elicit the nature of their research grants (n=2);
- Was registered outside the UK (n=1);
- Was a Royal College (n=1); and
- Had provided no new grants during the year 2012 (n=1).

#### Charities identified through the England & Wales Charity Commission

Through the Charity Commission, a total of 15,773 charities were identified as potentially funding medical research. Due to the very high number of charities identified, charities were ranked in terms of their annual income and only the first 214 charities, which had a combined income of 75% of the total, were considered.

Of the 214 charities, only 15 (7%) were included in the analysis. Reasons for excluding the remaining 199 charities are reported in **Table 1**.

**Table 1. Reasons for exclusion of charities identified through the Charity Commission**

Reason for exclusion	Number (%)
No health research funding	138 (69%)
Already identified through AMRC	26 (13%)
No research funding in diseases of interest*	21 (11%)
Royal Colleges	7 (4%)
University/educational establishment	6 (3%)
Could not elicit the nature of their research grants	1 (<1%)
Total exclusions	199

\* Or 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).

Through the AMRC and Charity Commission, we identified a total of 66 charities providing research funding into cancer, CHD, dementia, and/or stroke. Of these 66 charities, 34 (52%) were identified solely by the AMRC, 15 (23%) solely by the Charity Commission, and 17 (26%) from both the AMRC and Charity Commission. A list of all the charities included in the analysis is reported in **Appendix 3**, including the financial year to which the accounts pertain.





## Levels of research funding

A total of 1,439 research grants and fellowships from governmental organisations were reviewed. Of these, 97 were on cancer, 51 on CHD, 41 on dementia and 27 on stroke. The total combined values of the 1,439 research grants reviewed was £750 million, of which £55 million (7%) was on cancer, £24 million (3%) on CHD, £22 million (3%) on dementia and £13 million (2%) on stroke. We added to these levels of research grant funding the respective research infrastructure expenditure by disease (**Appendix 2**). In addition, we obtained data from the MRC on the combined grant and infrastructure research spend for the four diseases under study. Therefore, combined total research spend on cancer, CHD, dementia and stroke was £347 million, of which £157 million (45%) was devoted to cancer, £75 million

(21%) to CHD, £73 million (21%) to dementia and £43 million (12%) to stroke (**Table 2**).

Of the 66 charities included in the analysis, 52 (79%) funded research into cancer, 17 (26%) funded CHD research, 12 (18%) funded stroke research and 11 (17%) funded research into dementia. Of these charities, 27 (41%) were cancer-specific charities (i.e. they only funded research into cancer). Combined, these charities spent £509 million on cancer, CHD, dementia and stroke research (**Table 2**). Most of this research funding, £387 million (76%), was devoted to cancer, followed by CHD (£91 million - 18%), dementia (£17 million - 3%) and stroke (£13 million - 3%).

**Table 2. Research funding by disease in 2012**

	Cancer	CHD	Dementia	Stroke	TOTAL
<b>Charity, £ thousands</b>	387,414	91,486	16,637	13,323	508,859
<b>(% of total)</b>	(76)	(18)	(3)	(3)	(100)
<b>Government, £ thousands</b>	156,640	74,699	73,481	42,641	347,462
<b>(% of total)</b>	(45)	(21)	(21)	(12)	(100)
<b>Charity &amp; government, £ thousands</b>	544,055	166,185	90,118	55,964	856,321
<b>(% of total)</b>	(64)	(19)	(10)	(7)	(100)

In total, combined research funding into cancer, CHD, dementia and stroke by the charities and governmental organisations under study was £856 million. Of this total funding, £544 million (64%) was devoted to cancer, £166 million (19%) was devoted to CHD, £90 million (10%) to dementia and £56 million (7%) to stroke (**Table 2**). Both in total and as a proportion of total research funding into the four diseases, governmental organisations devoted considerably more research funding into dementia and stroke than did charities.

When compared to the levels of research funding in 2007/08, governmental organisations devoted considerably more research funding into dementia and stroke in 2012. In 2007/08, governmental organisations devoted £36 million (9% of the total into the four diseases) to dementia, compared with £73 million (21%) in 2012 (**Tables 2 and 3**). Similar increases in stroke research funding were observed, with levels of stroke research funding being £18 million (4%) in 2007/08 compared with £43 million (12%) in 2012. However, in contrast to government research funding, the relative proportions of charity research funding into cancer, CHD, dementia and stroke remained virtually unchanged between 2007/08 and 2012.

**Table 3. Research funding by disease in 2007/08**

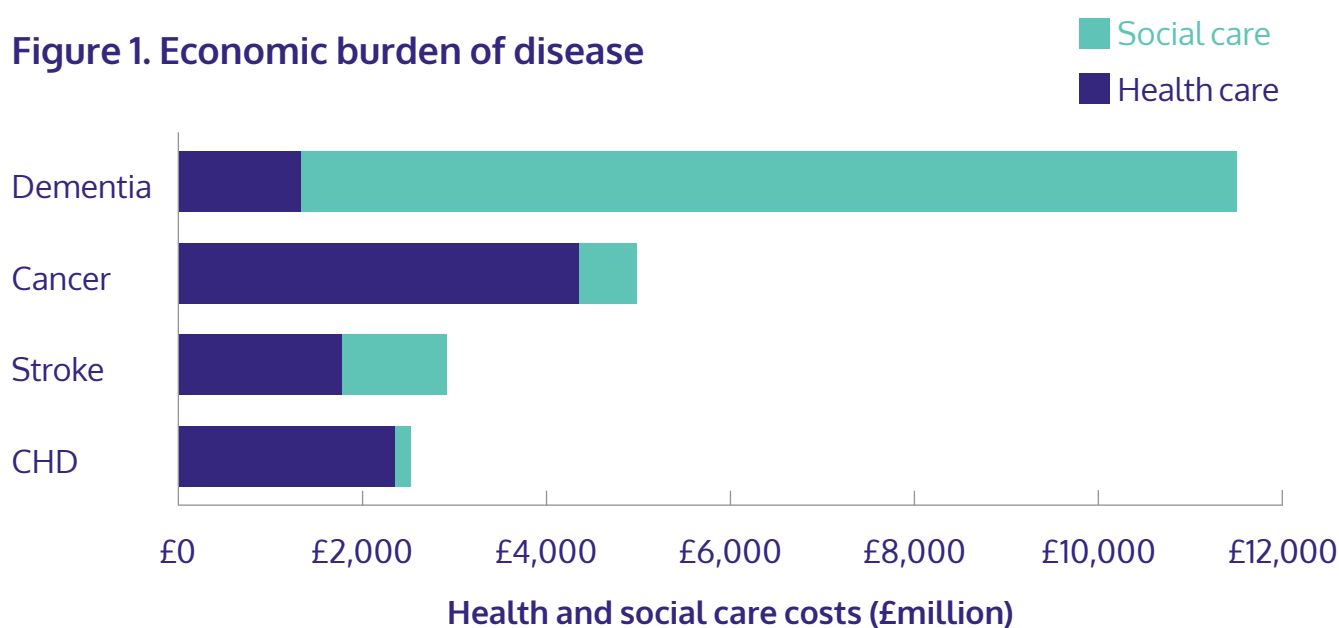
	Cancer	CHD	Dementia	Stroke	TOTAL
<b>Charity, £ thousands</b>	323,771	85,031	13,913	5,833	428,548
<b>(% of total)</b>	(76)	(20)	(3)	(1)	(100)
<b>Government, £ thousands</b>	266,640	84,229	36,331	17,522	404,723
<b>(% of total)</b>	(66)	(21)	(9)	(4)	(100)
<b>Charity &amp; government, £ thousands</b>	590,411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

## Research funding and burden of disease

In the UK, there were approximately 2.3 million people living with cancer, 2.3 million people living with CHD, 0.8 million people living with dementia, and 1.2 million people living with stroke in 2012. (**Table 4**). Per person with disease, the total levels of research funding equated to £241 per person with cancer, £73 per person with CHD, £118 per person with dementia and £48 per person with stroke.

A total of 2.9 million DALYs were lost due to cancer, 1.5 million due to CHD, 0.4 million due to dementia, and 0.7 million due to stroke (**Table 4**). Per DALY lost, dementia received the highest levels of total research funding, at £225 per DALY lost, followed by cancer (£187), CHD (£110) and stroke (£82).

**Figure 1. Economic burden of disease**



Dementia was found to have the lowest healthcare costs of £1.4 billion, compared to £4.4 billion for cancer, £2.4 billion for CHD, and £1.8 billion for stroke (**Figure 1**). However, the costs placed by dementia on the social care system (£10.2 billion), outweighed the social care costs of cancer, CHD and stroke combined. Combining the costs to the UK health and social services, dementia was estimated to cost £11.6 billion in 2012, compared to £5 billion for cancer, £2.9

billion for stroke and £2.5 billion for CHD. Hence, for every £10 in health and social care costs of each disease, cancer received £1.08 in research funding, CHD received £0.65, followed by stroke with £0.19 and finally dementia with £0.08 (**Table 4**). However, if the health and social care costs estimated by Saka et al. (2009) for stroke were used, i.e. £4.9 billion in 2012, for every £10 in care costs, stroke received £0.11 (£0.09 from government and £0.03 from charities).

**Table 4. Research funding and disease burden**

	Cancer	CHD	Dementia	Stroke
<b>Total number of cases, £ thousands</b>	<b>2,254</b>	<b>2,286</b>	<b>761</b>	<b>1,168</b>
<b>Funding per case:</b>				
Government	£69	£33	£97	£37
Charities	£172	£40	£22	£11
<b>Total</b>	<b>£241</b>	<b>£73</b>	<b>£118</b>	<b>£48</b>
<b>Total number of DALYs, £ thousands</b>	<b>2,914</b>	<b>1,504</b>	<b>400</b>	<b>686</b>
<b>Funding per DALY</b>				
Government	£54	£50	£184	£62
Charities	£133	£61	£42	£19
<b>Total</b>	<b>£187</b>	<b>£110</b>	<b>£225</b>	<b>£82</b>
<b>Total health and social care, £ millions</b>	<b>£5,020</b>	<b>£2,544</b>	<b>£11,580</b>	<b>£2,936</b>
<b>Funding per £10 in disease costs</b>				
Government	£0.31	£0.29	£0.06	£0.15
Charities	£0.77	£0.36	£0.01	£0.05
<b>Total</b>	<b>£1.08</b>	<b>£0.65</b>	<b>£0.08</b>	<b>£0.19</b>

When comparing measures of burden of disease with levels of research funding, there was a wide disparity between charity and governmental research spend (**Table 4**). When examining only levels of research spend by charities, regardless of the measure of burden under investigation, cancer received considerably more research funding than any other of the three diseases. For example, per disease case, total charity funding was £172 for cancer, compared with £22 for dementia and £11 for stroke.

Per DALY lost, charity research funding was £133 for cancer, £61 for CHD, £42 for dementia, and £19 for stroke.



# Section 4

## Discussion

In 2006, an influential government review investigated how public bodies target medical research funding.<sup>13</sup> It recommended that the impact of diseases on the UK population and economy should be assessed to determine the UK health priorities which would, in turn, inform the nation's health research priorities. The results of this report highlight that, in contrast to the estimated burden of disease, research funding into stroke is low compared to other diseases, in particular when compared to cancer. Out of £856 million made available by charities and governmental organisations for cancer, CHD, dementia and stroke research in 2012, 64% was devoted to cancer, 19% to CHD, 10% to dementia and 7% 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 £10 in health and social care costs attributable to each disease, cancer received £1.08 in research funding, CHD received £0.65, followed by stroke with £0.19 (or £0.11,

depending on the estimates of costs used) and finally dementia with £0.08. The only exception was when the levels of research funding were compared to DALYs lost, where dementia received the most research funding (£225 per DALY lost), compared with £187 for cancer, £110 for CHD and £82 for stroke.

There was wide variation between charities and governmental organisations in the distribution of research spending across disease areas. Of the £347 million of governmental research spend on the four diseases under study, 45% was devoted to cancer, 21% to CHD, 21% to dementia, and 12% to stroke. This is in stark contrast with the charity sector, where 76% of the total devoted to the four diseases under study was to cancer, 18% to CHD, and 3% each to dementia and stroke. When considering levels of government funding only, we found that when comparing different measures of disease, levels of research funding were more equally distributed across the four diseases. For example, for every person with the disease, £69 was devoted by government to cancer research compared with £37 for stroke.



This compares with the levels of charity funding, whereby for every person with the condition, cancer received £172 compared with only £11 for stroke.

For 2007/08, we evaluated the levels of research expenditure by both government and charities into cancer, CHD, dementia and stroke.<sup>9</sup> Since 2007/08, overall research expenditure by government bodies has increased by around 20%. Despite this, our 2012 analysis of total government expenditure on the four diseases under study produces a slightly lower figure than in 2007/08 (£347 million vs. £405 million), with the biggest difference being in cancer research expenditure (£157 million in 2012 vs. £267 million in 2007/08). Data supplied by the MRC showed that in 2007/08 total research funding on cancer was £89 million. MRC Annual Reports for 2009/10 to 2012/13 do show a reduction in research programme expenditure on cancer from 8.9% of the total – or £67 million – to 6.2% of the total – or £48 million, respectively.<sup>26;27</sup> Equally, for NIHR, 2007/08 research funding for this study was different to that used in 2012. Unlike

in 2007/08, we did not receive a response to our request for information, and instead extracted detailed information on over 350 research grants starting in 2012, with a combined value of £217 million. £650 million of research infrastructure was then distributed across the four diseases, assuming that the proportion of research infrastructure spending attributable to a specific disease would be the same as the proportion of research grant funding for that same disease. Therefore, some caution should be placed when making comparisons on the absolute levels of research expenditure by disease between 2007/08 and 2012.

When compared to 2007/08,<sup>28</sup> there appears to have been a considerable shift in the way governmental organisations distribute research funding across different diseases. In 2007/08, 66% of total research funding into the four diseases under study was devoted to cancer, 21% to CHD, 9% to dementia and just 4% to stroke. In 2012, the proportions devoted to dementia and stroke had increased to 21% and 12%, respectively, with cancer accounting for 46%





of total research spend. A number of reasons could be put forward for this diversification of governmental research funding. However, the increases in research funding into dementia and stroke could be explained, in part, by the strong commitment by the UK government, since 2010, to increase the levels of research funding into dementia,<sup>29</sup> and in a context when overall expenditure on research also increased. Stroke, as a recognised major risk factor for developing dementia,<sup>6</sup> may also have benefited from this commitment.

In contrast to governmental research funding, the relative proportions of charity research funding into cancer, CHD, dementia and stroke remained virtually unchanged between 2007/08 and 2012.<sup>27</sup> The high levels of charity research funding into cancer, relative to other diseases such as dementia or stroke, could be explained in part by public preferences towards cancer charities. This might reflect heightened fear or dread of particular diseases, perceptions of lifetime risk, or a form of ageism, with a view that dementia and stroke are inevitable diseases associated with the ageing process.<sup>12</sup> Additionally, cancer is a highly heterogeneous disease, with over 200 types of cancer affecting all major organs. This could explain, in part, why cancer as a whole receives such a high proportion of research funds.

The limitations of our study should be also acknowledged. First, as a result of the very large numbers of registered UK charities, we were unable to extract funding information from them all. Secondly, although we took great care to avoid double counting research funding (e.g. charities could potentially make grants to each other), this could not always be identified. Third, we omitted industry research and development, on the grounds that it is not directly a subject of public policy. Fourthly, the economic burden of the four diseases under study was obtained from a previously published study evaluating the cost to the UK health and social care system in 2008,<sup>9</sup> with costs updated to 2012 using health care inflation indices. We, therefore, assumed that the only change between 2008 and 2012 was the price of health and social care. In addition, given the number of data, and assumptions, required to estimate the economic burden of a particular disease,



it is not uncommon for the results of different cost-of-illness studies to diverge. For example, in this study we have estimated the cost of stroke to the UK in terms of health and social care to be £3 billion in 2012. However, a previous study found that the cost of stroke to the UK health and social care system was £4.4 billion in 2005.<sup>29</sup>

In conclusion, our study shows that there has been much progress by governmental research organisations to increase the levels of funding for dementia and stroke. However, the total overall research funding by charities and government into stroke is small when compared to its burden, and disproportionately low when compared to cancer.



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# Appendix 1

## Research funding by government: included Research Grant Programmes

Funding Body	Research Programmes	Number of grants starting in 2012	Total value of awards starting in 2012
<b>Research Councils</b>			
Biotechnology & Biological Sciences Research Council (BBSRC)	Research Grants and Awards (on human health): Ageing Diet & Health (humans) Immunology Microbiology Neuroscience & Behaviour Pharmaceuticals Regenerative Medicine	379	£158,298,307
Economic and Social Research Council (ESRC)	Research Grants on Health and Wellbeing	99	£49,720,643
Engineering and Physical Sciences Research Council (EPSRC)	Research Grants on Health	82	£45,534,291
Medical Research Council (MRC)	Grants & Fellowships	405	£250,960,374

Funding Body	Research Programmes	Number of grants starting in 2012	Total value of awards starting in 2012
<b>Health Departments</b>			
Chief Scientist Office, Scottish Government Health and Social Care Directorates	Fellowships Project grants in Health Services & Population Health or Experimental & Translational Medicine	64	£9,907,113
Health and Social Care (HSC) R&D Division of the Public Health Agency	Bamford Implementation Fellowships Knowledge Transfer Awards Opportunity-led research	22	£12,000,000 <sup>1</sup>
National Institute for Health Research (NIHR)	Efficacy and Mechanism Evaluation (EME) Faculty Trainees Health Technology Assessment (HTA) Health Services and Delivery Research (HS&DR) Invention for Innovation (i4i) Programme Development Grant (PDG) Programme Grants for Applied Research (PGfAR) Public Health Research for Patient Benefit (RfPB)	362	£217,207,231
National Institute for Social Care & Health Research	Health & Social Care Studentships & Fellowships Social Care Small Grants Translational Health Research Platforms Health & Social Care Research Awards	26	£6,567,195

<sup>1</sup> Includes expenditure on Northern Ireland Clinical Research Network, Northern Ireland Cancer Trials Unit and Northern Ireland Biobank. Total research expenditure obtained from: HSC Research and Development. <http://www.publichealth.hscni.net/sites/default/files/HSC%20R&D%20detailed%20overview.pdf> Accessed 18 February 2014

# Appendix 2

## Research funding by government: included Research Infrastructure Programmes

Funding Body	Research Infrastructure	Total value of research infrastructure expenditure
<b>Research Councils</b>		
Biotechnology & Biological Sciences Research Council (BBSRC)	Capital grants *Total value of capital grants was £107 million. The proportion attributed to human health was attributed using the proportion of total research grants on human health topics (see Appendix 1)	£55,000,000 <sup>2</sup>
Engineering and Physical Sciences Research Council (EPSRC)	Institutes & Research Facilities Postgraduate awards International Subscriptions *Total expenditure on these programmes was £217 million. The proportion attributed to health was attributed using the proportion of total research grants on health topics (see Appendix 1)	£16,596,000 <sup>3</sup>
Medical Research Council (MRC)	Research Programmes in MRC centres and units International Subscriptions	£360,900,000 <sup>4</sup>

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Funding Body	Research Infrastructure	Total value of research infrastructure expenditure
<b>Health Departments</b>		
Chief Scientist Office, Scottish Government Health and Social vCare Directorates	Research support structures through NHS Research Scotland	£42,000,000 <sup>5</sup>
National Institute for Health Research (NIHR)	Biomedical Research Centres/Units Bioresources/Biobank Clinical Research Networks/Facilities Collaborations for Leadership in Applied Health Research and Care Experimental Medicine Centres Information systems Patient Safety & Service Quality Centres Research Design Service Research Ethics Committees	£649,800,000 <sup>6</sup>
National Institute for Social Care & Health Research	NHS Research & Development Funding Allocations	£13,465,000 <sup>7</sup>

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# Appendix 3

## List of included charities

	Charity number	Charity income	Member of AMRC	Charity Commission – largest charities <sub>8</sub>
Cancer Research UK	1089464	£536,600,000	Yes	Yes
British Heart Foundation	225971	£263,607,000	Yes	Yes
The Wellcome Trust	210183	£242,435,287	Yes	Yes
Age UK	1128267	£167,655,000	Yes	Yes
Macmillan Cancer Support	261017	£155,688,000	No	Yes
Marie Curie Cancer Care	207994	£148,952,000	Yes	Yes
Alzheimer's Society	296645	£70,771,000	Yes	Yes
Great Ormond Street Hospital Children's Charity	235825	£66,335,000	Yes	Yes
The Monument Trust	242575	£41,919,000	No	Yes
Anthony Nolan	803716	£31,910,436	No	Yes
Stroke Association	211015	£31,051,000	Yes	Yes
Prostate Cancer UK	1005541	£29,377,000	Yes	Yes
Movember Europe	1137948	£27,104,901	No	Yes
The Hospital Saturday Fund	1123381	£24,187,030	No	Yes
Clic Sargent Cancer Care for Children	1107328	£22,261,000	No	Yes
The Wolfson Foundation	206495	£21,320,000	No	Yes
Leukaemia & Lymphoma Research	216032	£20,353,000	Yes	Yes
Breakthrough Breast Cancer	1062636	£18,077,000	Yes	Yes
Association for International Cancer Research	SC022918	£16,745,954	Yes	No
The Grand Charity	281942	£15,834,800	No	Yes
The Christie Charitable Fund	1049751	£13,705,000	No	Yes
Teenage Cancer Trust	1062559	£12,998,788	No	Yes
The Peter Sowerby Charitable Foundation	1139854	£12,826,575	No	Yes
Barts and the London Charity and Related Charities	212563	£12,613,000	No	Yes
Guy's and St Thomas' Charity	251983	£12,119,000	Yes	Yes
Children with Cancer UK	298405	£11,920,467	Yes	Yes
Breast Cancer Campaign	299758	£10,584,883	Yes	Yes
The Royal Marsden Cancer Charity	1095197	£10,544,452	No	Yes
St Gemma's Hospice	1015941	£9,273,132	No	Yes
Alzheimer's Research UK	1077089	£9,123,121	Yes	Yes
World Cancer Research Fund	1000739	£8,962,031	Yes	Yes
Tenovus	1054015	£8,539,853	Yes	Yes

	Charity number	Charity income	Member of AMRC	Charity Commission – largest charities <sup>8</sup>
The Dr Mortimer and Theresa Sackler Foundation	1128926	£8,433,375	No	Yes
Chest Heart & Stroke Scotland	SC018761	£7,761,777	Yes	No
Kidney Research UK	252892	£7,468,151	Yes	No
Action Medical Research	208701	£6,946,837	Yes	No
British Lung Foundation	326730	£6,375,679	Yes	No
Yorkshire Cancer Research	516898	£6,212,124	Yes	No
The Roy Castle Lung Cancer Foundation	1046854	£4,953,840	Yes	No
SPARKS - The Children's Medical Research Charity	1003825	£4,608,166	Yes	No
Dunhill Medical Trust	1140372	£3,852,102	Yes	No
Myeloma UK	SC026116	£3,238,744	Yes	No
BUPA Foundation	277598	£3,121,879	Yes	No
Northern Ireland Chest, Heart & Stroke Association	XN47338	£2,350,077	Yes	No
Ovarian Cancer Action	1109743	£2,334,827	Yes	No
Wellbeing of Women	239281	£2,130,200	Yes	No
The Brain Tumour Charity	1128354	£2,105,065	Yes	No
Heart Research UK	1044821	£1,820,614	Yes	No
Brain Research Trust	1137560	£1,748,000	Yes	No
Medical Research Scotland	SC014959	£1,740,550	Yes	No
Cancer Focus Northern Ireland*	XN48265	£1,621,841	Yes	No
Pancreatic Cancer UK	1112708	£1,525,424	Yes	No
British Skin Foundation	313865	£1,098,767	Yes	No
Target Ovarian Cancer	1125038	£1,029,906	Yes	No
North West Cancer Research	223598	£1,011,306	Yes	No
British Liver Trust	298858	£939,672	Yes	No
William Harvey Research Foundation	803012	£783,393	Yes	No
The Urology Foundation	1128683	£758,376	Yes	No
The Blond McIndoe Research Foundation	1106240	£593,270	Yes	No
Circulation Foundation	1102769	£590,167	Yes	No
The Pelican Cancer Foundation	1019311	£509,049	Yes	No
Sarcoma UK	1139869	£408,221	Yes	No
Northern Ireland Leukaemia Research Fund	XN48014	£206,064	Yes	No
Wessex Medical Research	274839	£165,613	Yes	No
Remedi	1063359	£100,849	Yes	No
Bardhan Research & Education Trust of Rotherham	328452	£48,189	Yes	No

<sup>8</sup> Representing 75% of total combined income of charities potentially funding health research

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