BMJ Open UK research spend in 2008 and 2012: comparing stroke, cancer, coronary heart disease and dementia

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ABSTRACT

Objective: To assess UK governmental and charity research funding in 2012 for cancer, coronary heart disease (CHD), dementia and stroke, and to make comparisons with 2008 levels.

Design: Analysis of research expenditure.

Setting: United Kingdom.

Main outcome measures: We identified UK governmental agencies and charities providing health research funding to determine the 2012 levels of funding for cancer, CHD, dementia and stroke. Levels of research funding were compared to burden of disease measures, including prevalence, disability adjusted life years and economic burden.

Results: The combined research funding into cancer, CHD, dementia and stroke by governmental and charity organisations in 2012 was £856 million, of which £544 million (64%) was devoted to cancer, £166 million (19%) to CHD, £90 million (11%) to dementia and £56 million (7%) to stroke. For every £10 of health and social care costs attributable to each disease, cancer received £1.08 in research funding, CHD £0.65, stroke £0.19 and dementia £0.08. A considerable shift in the distribution of government research funding was observed between 2008 and 2012. In 2008, 66% of governmental research funding into the four conditions 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.

Conclusions: Although there has been much progress by government to increase levels of research funding for dementia and stroke, these areas remain underfunded when compared with the burden of disease.

INTRODUCTION

Cancer, coronary heart disease (CHD), dementia and stroke are leading causes of death and disability.¹ In the UK, these four diseases accounted for 55% of all deaths in 2012 and for 5.5 million disability adjusted life years (DALYs).^{2–4} Their impact on the health and social care services is also

Strengths and limitations of this study

- A UK government review recommended that the impact of diseases on the population and economy should be assessed to inform health research priorities.
- Since 2010, there have been significant changes in medical research allocation policies, particularly by the UK central government.
- There has been a considerable shift in the way government distributes research funding between 2008 and 2012. Out of the combined government research funding for cancer, coronary heart disease, dementia and stroke, 33% was devoted to dementia and stroke in 2012, compared with just 13% in 2008.
- As a result of the very large numbers of registered UK charities, we were unable to extract funding information from all of them.
- We omitted industry research and development on the grounds that it is not directly a subject of public policy.

considerable, with a combined cost of £20 billion in 2008. Owing to the burden placed on patients, carers and the healthcare system, there is an argument for investing in research so as to better understand how to prevent, diagnose, treat and manage these diseases.

In 2006, a UK governmental review recommended that the impact of diseases on the population should be assessed to help determine society's health priorities and in turn, inform research priorities.⁵ In contrast, research has highlighted that most of the UK medical research funding on chronic disease is allocated to cancer with other high burden conditions, such as dementia or stroke, receiving relatively low levels of research funding.^{6–9} However, over recent years, there have been significant policy changes affecting the way medical research is allocated, particularly by the UK central government. In 2010, the UK programme for government highlighted that it "...will prioritise dementia

research within the health research and development budget.”¹⁰ It is, therefore, important to assess whether research expenditure has moved more into line with the impact of different diseases on society. This is particularly relevant in the case of governmental-funded research, where limited funds have to be allocated over a large number of different diseases.

One approach is to quantify research expenditure and then compare it against measures of disease burden, the rationale being that research funding should be allocated towards diseases with the highest burden. The aim of this study is to estimate UK governmental and charity research funding in 2012 for cancer, CHD, dementia and stroke, to compare these quantum against different measures of disease burden and to assess whether there have been significant changes in the relative levels of research funding for these four conditions between 2008 and 2012.

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.⁵ In line with other studies evaluating the levels of UK health research funding, research funding provided by industry was excluded from this analysis.^{9 11}

For the purposes of this study, we focused on governmental and charitable funding from UK-based organisations, covering all types of human research into stroke, cancer, dementia and CHD. Although awards to overseas institutions from these funders were included, international funding sources to UK institutions were excluded (ie, these were under no obligation to file their accounts and annual reports in the UK). Research expenditure on basic science activities or generic health research, which are difficult to attribute to a specific disease, were excluded.

We included all governmental organisations in the UK Clinical Research Collaboration. For each governmental organisation, we searched for data on the total number and the value of research grants and fellowships awarded, as well as any other research infrastructure expenditure in the year 2012. If total research expenditure (grants/fellowships and infrastructure) were not reported by disease of interest, we used a two-step approach. First, we allocated research grants and fellowships to the four conditions under study after reviewing their titles, project key words and scientific abstracts. Second, we used the distribution of research grants and fellowships by disease in each organisation to allocate the respective research infrastructure expenditure.

Charities funding health research were identified from two different sources. First, we obtained details of all the

member charities of the Association of Medical Research Charities (AMRC). Second, we obtained a list of all the charities potentially funding health research from the Charity Commission for England and Wales. Given that over 15 000 charities were identified, we only considered the first 214 charities ranked in terms of annual income, which represented 75% of the total income. We excluded educational/research organisations, such as universities or royal colleges which were registered as charities, as these receive a high proportion of their income from government and charitable grants. For each charity, we sought to determine if the charity funded health research and if so, the levels for the four conditions under study. Annual reports and accounts (derived either from the charity’s website or the Charity Commission) were 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 all health research-funded grants.

For both charities and government, a researcher used the available information available for each grant (eg, title, summary, background, etc) to categorise all research spending on the four diseases under question. Grants were subsequently reviewed by the lead author (RL-F), with final classification being made by him in all cases. In the cases where a research grant covered two or more diseases of interest, research expenditure was apportioned to each of the relevant diseases.

Standard χ^2 tests were used to assess whether the relative proportions of research funding into each of the conditions under study had significantly changed between 2008 and 2012. This analysis was repeated for government organisations and charities.

Disease burden

Levels of research funding from UK governmental organisations and charities for cancer, CHD, dementia and stroke were compared against different measures of disease burden.

Disease prevalence in 2012

Prevalence rates of diagnosed and undiagnosed dementia cases were obtained from the European Community Concerted Action on the Epidemiology and Prevention of Dementia (EURODEM) for individuals aged under 65 years,¹² and from the Cognitive Function and Ageing Study for those aged 65 years and above.¹³ Prevalence rates of dementia were applied to UK population estimates for 2012.¹⁴ The prevalence of cancer in the UK (with or having survived cancer) was updated from 2008 estimates, assuming an annual 3% annual increase.¹⁵ The prevalence of stroke and CHD in the UK was obtained from Quality and Outcomes Framework data.^{16 17}

DALYs in 2012

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, per 100 000 of population, of DALYs lost for cancer, dementia, stroke and CHD was obtained from Global Burden of Disease for the year 2010¹⁸ and applied to 2012 population estimates.¹⁴

Economic burden in 2012

The economic burden of cancer, CHD, dementia and stroke was obtained from a previously published study that evaluated their cost to the UK health and social care system in 2008 using the same methodology.⁹ This study adopted a prevalence approach whereby all costs within the most recent years for which data were available were measured regardless of the date of disease onset and adopting a 'top down' approach, that is, using aggregate data. We used the Hospital and Community Health Services (HCHS) pay and price inflation index to update costs from 2008 to 2012.¹⁹

All information for this study was collated and analysed in Microsoft Excel 2010.

RESULTS

Study 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 1439 research grants and fellowships, with a total combined value of £750 million (see online supplementary table S1), and £1138 million of research infrastructure expenditure were considered (see online supplementary table S2).

Charities

At the time of this research, the AMRC consisted of 121 charities. Of these charities, 51 (42%) were included in the analysis. AMRC listed charities were excluded if: (1) their health research funding was in diseases other than dementia, cancer, CHD or stroke ($n=65$, 93%); (2) it was not possible to elicit the nature of their research grants ($n=2$); (3) they were registered outside the UK ($n=1$); (4) they were a Royal College ($n=1$) and (5) they had provided no new grants during the year 2012 ($n=1$).

A total of 15 773 charities were identified through the Charity Commission as potentially funding medical research. Owing to the very high number of charities identified, we only included the first 214 representing 75% of the total combined income. Of these, only 15 (7%) were included in the analysis. Reasons for excluding the remaining 199 charities were: (1) they provided no health research funding ($n=138$); (2) they had already been identified through AMRC ($n=26$); (3) they provided no research funding in the diseases of interest ($n=21$); (4) they were a Royal College ($n=7$); (5) they were a university/educational establishment ($n=6$) and (6) it was not possible to elicit the nature of their research grants ($n=1$).

Through the AMRC and Charity Commission we identified a total of 66 charities providing research funding into dementia, cancer, CHD 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%) by both the AMRC and Charity Commission. A list of all the charities included in the analysis is reported in online supplementary table S3, including the financial year to which the accounts pertain.

Levels of research funding

A total of 1439 research grants and fellowships from governmental organisations were reviewed. Of these, 97 related to cancer, 51 to CHD, 41 to dementia and 27 to stroke (table 1). The total combined values of the 1439 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.

To the levels of research grant funding we added the respective research infrastructure expenditure by disease. In addition, we obtained data from the MRC on the combined grant and infrastructure research spend for the four conditions under study. For government, the 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 (ie, they only funded research into cancer). When combined, these charities spent £509 million on cancer, CHD, dementia and stroke research (table 1). Most of this research funding was devoted to cancer (£387 million—76%), followed by CHD (£91 million—18%), dementia (£17 million—3%) and stroke (£13 million—3%).

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 (11%) 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 the charities.

When compared with the levels of research funding in 2008, governmental organisations devoted considerably more research funding into dementia and stroke in 2012 ($p=0.005$). In 2008, governmental organisations devoted £36 million (9% of the total spent on the four diseases) to dementia, compared with £73 million (21%) in 2012 (table 2). Similar increases in stroke

Table 1 Total research grant expenditure by governmental organisations

	Total research grant expenditure, £	Number of research grants	Mean (SD) research grant expenditure, £	Median (IQR) research grant expenditure, £
Cancer	54 702 431	97	569 943 (640 027)	316 544 (217 911–539 780)
CHD	24 067 609	51	471 914 (520 496)	288 570 (179 496–526 114)
Dementia	21 946 131	41	535 271 (522 269)	367 226 (225 934–546 825)
Stroke	13 295 401	27	474 836 (619 431)	248 994 (218 327–403 634)

CHD, coronary heart disease.

research funding were observed, with levels of stroke research funding being £18 million (4%) in 2007/2008 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 2007/2008 and 2012 ($p=0.770$).

Research funding and burden of disease

In the UK, there were approximately 2.3 million cases of cancer, 2.3 million CHD cases, 0.8 million cases of dementia and 1.2 million stroke cases (table 3). 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 3). 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).

Dementia was found to have the lowest healthcare costs (figure 1) of £1.4 billion, compared with £4.4 billion for cancer, £2.4 billion for CHD and £1.8 billion for stroke. However, the costs placed by dementia on the social care system (£10.2 billion) outweigh 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 with £5.0 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 3).

Comparing measures of burden of disease with levels of research funding revealed a wide disparity between charity and governmental research spend (table 3). When examining levels of research spend by charities, regardless of the measure of disease burden under investigation, cancer received considerably more research funding than any of the other 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.

DISCUSSION

In 2006, an influential government review investigating how public bodies target medical research funding⁵ 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. Our results highlight that, in contrast to the estimated burden of disease, research funding into stroke is low compared with other diseases. Out of £856 million made available by charities and government for cancer, CHD, dementia and stroke research in 2012, 64% was devoted to cancer, 19% to CHD, 11% to dementia and 7% to 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 conditions under study, 46% was devoted to cancer, 21% to CHD, 21% to dementia and 12% to stroke. This is in

Table 2 Research funding by disease

	Research funding 2012 £ thousands (%)			Research funding 2008 £ thousands		
	Charity	Government	Total	Charity	Government	Total
Cancer	387 414 (76)	156 640 (45)	544 055 (64)	323 771 (76)	266 640 (66)	590 411 (71)
CHD	91 486 (18)	74 699 (21)	166 185 (19)	85 031 (20)	84 229 (21)	169 260 (20)
Dementia	16 637 (3)	73 481 (21)	90 118 (10)	13 913 (3)	36 331 (9)	50 244 (6)
Stroke	13 323 (3)	42 641 (12)	55 964 (7)	5833 (1)	17 522 (4)	23 355 (3)
Total	508 859 (100)	347 462 (100)	856 321 (100)	428 548 (100)	404 723 (100)	833 270 (100)

CHD, coronary heart disease.

Table 3 Research funding and disease burden

	Cancer	CHD	Dementia	Stroke
Total number of cases, thousands	2254	2286	761	1168
Funding per case				
Government	£69	£33	£97	£37
Charities	£172	£40	£22	£11
Total	£241	£73	£118	£48
Total number of DALYs, thousands	2914	1504	400	686
Funding per DALY				
Government	£54	£50	£184	£62
Charities	£133	£61	£42	£19
Total	£187	£110	£225	£82
Total health and social care, £ millions	£5020	£2544	£11 580	£2936
Funding per £10 in disease costs				
Government	£0.31	£0.29	£0.06	£0.15
Charities	£0.77	£0.36	£0.01	£0.05
Total	£1.08	£0.65	£0.08	£0.19

DALYs, disability adjusted life years.

stark contrast with the charity sector, where 76% of the total spend on the four conditions under study was devoted to cancer, 18% to CHD, 3% to dementia and 3% to stroke.

This paper updates previous estimates of research expenditure for 2008.⁹ Since then, overall research expenditure by government bodies has increased by around 20%. Despite this, our analysis of total government expenditure on the four diseases under study in 2012 produces a slightly lower figure than in 2008 (£347 million vs £405 million), with the biggest difference being on cancer research expenditure (£157 million in 2012 vs £267 million in 2008). Data supplied from the MRC showed that in 2008 total research funding on cancer was £89 million.⁹ MRC Annual Reports show a reduction in research programme expenditure on cancer from 8.9% of the total—or £67 m—in 2009/2010 to 6.2% of the total—or £48 m—in 2012/2013.^{20 21} Equally, for the National Institute for Health Research (NIHR), 2008 research funding on cancer was £159 million, compared with £88 million in 2012. However, the methodology used

to obtain NIHR research funding for this study was different to that used in 2008. Unlike in 2008, we did not receive a response to our request for information and instead, extracted detailed information for over 350 research grants starting in 2012, with a combined value of £217 million. In total, £650 million of research infrastructure spending was then attributed to each of the four conditions assuming 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. Therefore, some caution should be placed when making comparisons on the absolute levels of research expenditure by disease between 2008 and 2012.

Over the 4-year interval, governmental research expenditure seems to have increased considerably in relative terms for stroke and dementia. In 2008, 66% of total governmental funding into the four conditions 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. Although a number of reasons could be put forward for this diversification of governmental research funding, the increases in research funding into dementia and stroke could be explained partly by the strong commitment by the UK government, since 2010, to increase the levels of research funding into dementia¹⁰ and within a context when overall expenditure on research also increased. Stroke, as a recognised major risk factor for developing dementia,²² may also have benefited from this commitment.

In contrast to government research funding, the relative proportions of charity research funding into cancer, CHD, dementia and stroke remained virtually unchanged between 2008 and 2012. The high levels of charity research funding into cancer relative to other conditions, such as dementia or stroke, could be explained in part by

Figure 1 Economic burden of disease (CHD, coronary heart disease).

public preferences towards cancer charities. This might reflect heightened fear or dread of particular diseases, perceptions of life-time risk or a form of ageism, with the view that dementia and stroke are inevitable conditions associated with the ageing process.⁶ Additionally, cancer is a very heterogeneous condition, with over 200 types of cancer affecting all major organs, which could explain in part why cancer as a whole receives such a high proportion of research funds.

Our study only quantified the research expenditure into stroke, cancer, CHD and dementia in the UK. However, these four diseases are major conditions in all areas of the world, with other countries also devoting resources to research. Therefore, it is possible that other countries could devote substantial resources to those areas that are relatively underfunded in the UK. However, evidence from Europe showed that the UK accounted for 40% of all European research expenditure on diseases of the brain, which included both stroke and dementia.²³ Systematic analysis of research expenditure by condition could enable stronger research collaborations across countries, particularly in those diseases that are underfunded in relative terms and reduce research duplication.

Additional limitations to our study are acknowledged. First, as a result of the very large numbers of registered UK charities, we were unable to extract funding information from all of them. Second, although we took great care to avoid double counting of research funding (eg, charities making grants to each other), this could not always be identified. We omitted industry R&D on the grounds that it is not directly a subject of public policy and due to the difficulty in obtaining detailed information on research spend by the pharmaceutical industry. Fourth, 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 2008,⁹ with costs updated to 2012 using healthcare inflation indices. We, therefore, assumed that the only change between 2008 and 2012 was the price of health and social care. Finally, some caution should be placed when comparing the figures on the absolute levels of research expenditure between governmental organisations and charities. In the UK, many governmental funding streams cover indirect research expenditure, such as building maintenance, university administration and library services.²⁴ However charities, in general, do not cover such indirect research activities in their grants and only cover direct research expenditure, for example, research staff salaries.

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 with its burden, and disproportionately low when compared with cancer.

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Contributors RL-F and JL were responsible for data collection and management, did the analyses and wrote the manuscript. AG supervised the analysis, provided direct input into the interpretation of results and revised, edited and decided on the final content of the manuscript. All authors had full access to all of the data in the study and can take responsibility for the integrity of the data and the accuracy of the data analysis.

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Competing interests None.

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Data sharing statement Data on all of the organisation's funding health research into cancer, dementia, coronary heart disease and stroke are included in the manuscript and online only material.

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