

# 2012

# Defeating Dementia

Building  
capacity to  
**capitalise**  
on the UK's  
research strengths



This report discusses the quality of dementia research in the UK and how capacity can be improved to maximise its impact. It is intended for anyone with an interest in dementia research, including policymakers, research funders and researchers, and people affected by dementia.

# Alzheimer's Research UK is the UK's leading dementia research charity

As research experts, we specialise in funding world-class, pioneering research at leading universities to find preventions, treatments and a cure for dementia. We believe science and innovation hold the key to defeating dementia and invest in the scientists learning more about the condition and its causes.

Our findings improve the lives of everyone affected by dementia now and in the future.

We forge partnerships with Government and other key organisations to make dementia research a national priority. We encourage everyone to join us in supporting research and achieving a world free from dementia.

Read more about our work and achievements at [www.alzheimersresearchuk.org](http://www.alzheimersresearchuk.org)

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## Note on terminology

Dementia research in this report refers primarily to biomedical research into the pathophysiological and clinical manifestations of dementia, which will enable more effective treatment, prevention and diagnostic strategies for which there is a clear and urgent need. Alzheimer's Research UK acknowledges that this does not represent the entire research effort and the bibliometric data used is not restricted to this definition.

However, it is integral to the bigger picture and has important implications for other areas such as care research and research with a non-physiological focus. Also, while we acknowledge and make reference to the investment made by industry in this field, a more detailed analysis is beyond the scope of this report.

# Foreword

Now that dementia research has taken its rightful place as a priority on the political agenda, it is crucial that it stays there. The Ministerial Advisory Group on Dementia Research, of which Alzheimer's Research UK is a member, has made a promising start. It has unpicked a lot of the important issues and begun to map out a way forward. We now need to build on this work and commit long-term to a cohesive national dementia research strategy. One-off initiatives and funding calls are a boost, but sustained interest and investment is critical if we are to get the results we so urgently need for the growing number of people affected by dementia.

One of the UK's greatest assets is its science base. And, as this report shows, despite being a relatively young and grossly underfunded field, UK dementia research is punching well above its weight on the global stage. As a major contributor to finding preventions, treatments or a cure, we not only have the ability but also a responsibility to capitalise on this. If we can do so well with a lot less money and far fewer researchers than other major disease areas, where a great deal has been achieved, imagine what we could do with more. New discoveries are made every day, which open up new possibilities for

potential treatments and medical interventions. We cannot afford to squander these opportunities.

Increasing investment and building capacity to the levels we need has to be a priority. This includes expanding the workforce so that existing expertise can be passed down and new skills brought in. This report suggests how we can do this. It also aims to ensure that the political engagement that has finally begun continues.

The number of people affected by dementia in the UK, excluding their family members and carers, is nearing 1 million. These numbers, as well as the economic burden, already estimated to be £23 billion, will continue to spiral. We already have a crisis, but we can prevent it from escalating if we commit wholeheartedly to defeating dementia through research.

Rebecca Wood



Chief Executive



We now  
need to  
commit  
long-term  
to a  
cohesive  
national  
dementia  
research  
strategy.

# Executive summary

## Overview

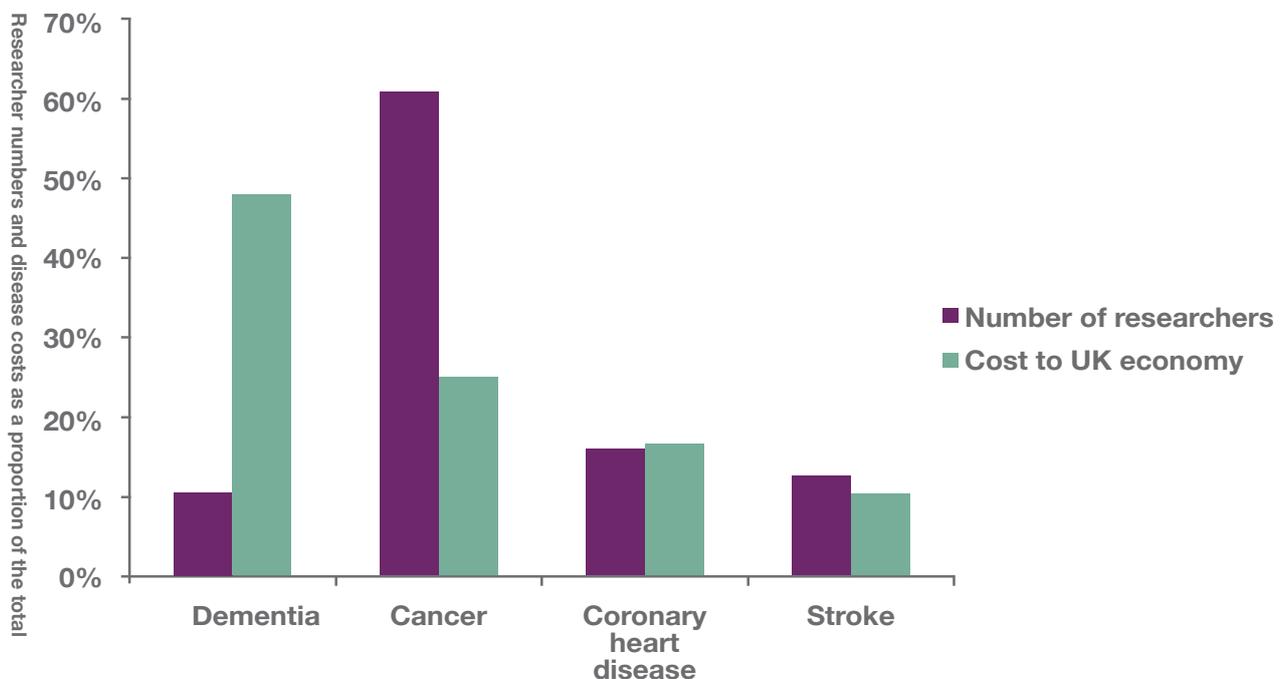
The aim of this report is to disentangle the knotty issue of UK research capacity in the dementia field. Capacity not only refers to the number of researchers working in the field, but also our ability to capitalise on our research strengths, take new discoveries forward and pursue new avenues of inquiry. Building our research capacity is essential if we are to effectively tackle the growing prevalence and spiralling social and economic costs of dementia. Our influential report, 'Dementia 2010',<sup>1</sup> showed that dementia affects over 820,000 people in the UK and costs the economy £23 billion a year. Yet investment in research, when compared to other major disease areas that cost the economy a lot less, is shockingly low.

Thankfully, dementia is now being recognised as a research priority. The Ministerial Advisory Group on Dementia Research (MAGDR), which published its Route Map in June 2011,<sup>2</sup> looked into ways of increasing the volume and impact of dementia research. Among the major themes it identified were 'Growing Capacity and Capability' and 'Harnessing

Existing Resources'. This is a positive start. However, to capitalise on the UK's research strengths and build capacity to levels more proportionate to our needs, discussions like this need to be ongoing. These can be usefully informed by the recommendations presented here, which are based on both quantitative and qualitative evidence:

- Bibliometric data on the output and quality of UK dementia research, provided in February and July 2011 by *Evidence*, a business of Thomson Reuters.
- The experiences and opinions of UK-based researchers working in the dementia field. These were gathered in July and August 2011 through a short questionnaire, to which 120 researchers responded. The respondents are engaged in clinical and non-clinical research, representing 30 institutions and a range of career stages, from PhD student to principal investigator (PI). Four further in-depth interviews were also carried out in July and September 2011.

## Number of researchers compared with cost to UK economy by disease



Data & analysis, *Evidence*, Thomson Reuters, and 'Dementia 2010'

1 'Dementia 2010: the prevalence, economic cost and research funding of dementia compared with other major diseases', Ramon Luengo-Fernandez, Jose Leal, Alistair Gray, Health Economics Research Centre, University of Oxford, 2010.

2 The Ministerial Advisory Group on Dementia Research – headline report, Department of Health, June 2011: [http://www.dh.gov.uk/en/Publicationsandstatistics/Publications/PublicationsPolicyAndGuidance/DH\\_127750](http://www.dh.gov.uk/en/Publicationsandstatistics/Publications/PublicationsPolicyAndGuidance/DH_127750)

# Key findings

## Bibliometric data

The research we commissioned from *Evidence* tells us that capacity in UK dementia research – in terms of the number of researchers – is low, particularly when compared to other major disease areas.

Estimating the number of researchers from the volume of research output, we find that the ratio of researchers working on dementia to those working, for example, on cancer is roughly 1:6. When these numbers are seen in relation to the economic costs of dementia, cancer, coronary heart disease and stroke, the vast disproportion in the dementia field is evident.

We also found that a large proportion of research output is distributed among a small base of researchers and institutions.

Nevertheless, the quality of UK dementia research, measured through its citation impact (how often UK papers are referred to by other research publications), is world-class and we are clearly punching above our weight. The high calibre of UK dementia research highlights how much more the field could achieve with more investment and greater capacity. Although we are a global leader in the field despite low investment and capacity, this is not a sustainable model. As new discoveries are made, new avenues of inquiry and potential treatment targets are increasing. We need sufficient capacity to be able to capitalise on this and make a real difference to the growing number of people whose lives are blighted by dementia.

## Questionnaire

The aim of our questionnaire was to draw on the experiences as well as the scientific expertise of people working at the ‘coal face’ of dementia research. These people have the keenest direct awareness of both barriers and possibilities in the field. We received a wealth of responses, which, overall, recognise the UK’s strengths in dementia research and emphasise the need for growth in the field. High levels of commitment, expertise, enthusiasm and frustration among researchers are evident. So are strong opinions and feelings about capacity and what needs to be done to increase it.

This report concentrates on the most widely-held concerns among our questionnaire respondents and interviewees. To increase capacity, the main issues that need to be addressed are:

- Insufficient research funding.
- Restricted career opportunities and inflexible pathways that impact on building and retaining a workforce.
- The need for more research into understanding the diseases that cause dementia.
- The increasing need for multidisciplinary research.
- Regulatory and bureaucratic barriers.

We look into these in detail, giving as much space as possible to the voices of researchers working in the field, who are at the forefront of defeating dementia.

The high  
calibre of UK  
dementia  
research  
highlights  
how much  
more  
could be  
achieved  
with more  
investment  
and greater  
capacity.

# Conclusion

Dementia is a research priority. Now that we have recognised this, we have to increase our capacity in the field. Given the scale of the problem, we have a responsibility to capitalise on our strengths and address the issues that are holding us back.

UK dementia scientists are doing excellent work and are global leaders in the field. With more proportionate financial backing and strategic support to maximise capacity and hence productivity, they could do even better. To capitalise on the expertise, ideas and high calibre of dementia research in the UK, we need to take a long-term view, with sustained investment and a cohesive national dementia research strategy.

At a time of economic hardship and severe restraints on spending, the obvious response is that there is no money. But if we don't find ways to invest more in dementia research now, there will be even less money later, due to spiralling care costs and the huge burden of care on family members, which impacts on their economic productivity. We also risk squandering the expertise and knowledge that we have built up if we don't harness it and ensure it is passed on to future generations of scientists. Continuity, momentum and collaboration are key, particularly when there is still so much more to know about dementia and the diseases that cause it.

The recommendations made in this report will, we hope, inform the capacity building process. Now it has begun it needs to continue. It is the only way to prevent what is already a medical, social and economic crisis from getting a great deal worse.

# Recommendations

1. UK dementia research needs a cohesive national strategy, with sustained, ring-fenced funding.

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2. We need to improve social awareness of the need for dementia research. Increased public funding would signal its importance and encourage greater voluntary giving.

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3. While we should continue to support the more established research base and areas of investigation in the dementia field, there needs to be a balance. Funders need to revise current structures and programmes so that they do not preclude novel approaches and 'riskier' projects that are founded on strong science.

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4. Funding application and reporting procedures need to be reviewed to ensure that time spent doing research, momentum and continuity are maximised to accelerate progress. Increased and longer-term funding would make a big difference, but simplifying procedures, especially for smaller grants, would be a productive first step.

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5. Scientific career paths have long been in need of revision. The bottlenecks and vicious cycles caused by existing career structures in a priority field like dementia can be eased by introducing:
  - a. A larger number of independent fellowships.
  - b. More permanent senior scientist/postdoc positions.
  - c. Ring-fenced funding for junior principal investigators.

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6. More dedicated funding calls as well as taster and Masters courses in dementia research are needed. This will pass down existing expertise and increase knowledge of recent discoveries and new avenues of research. Researchers need to be enthused and encouraged into the field at undergraduate and postgraduate levels.

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7. Funding for research and the training pathway for clinicians wishing to undertake research in the dementia field need to be more flexible, to accommodate both the time and income required to carry out clinical work and research.

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8. National Institute for Health Research Fellowships specifically for dementia research are welcome, but need to be continued and extended to senior clinicians. This will help ensure continuity of the clinical research workforce and the development of capacity at all levels.

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9. Increased investment needs to be funnelled into research that seeks to improve our understanding of the diseases that cause dementia. This will increase chances of success in trialling medical interventions.

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10. Stronger links between basic and clinical researchers need to be forged. Strengthening networks and increasing joint funding programmes can help achieve this.

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11. A multidisciplinary approach in dementia research is essential to take new findings forward and make meaningful progress. Targeted funding aimed at building this critical mass is needed.

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12. Research networks need to be strengthened and extended to promote more collaboration and support researchers and institutions beyond centres of excellence.

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13. New efforts by the Government to streamline the regulatory process are an ideal opportunity to address the difficulties in carrying out dementia research. Current delays in getting ethics approval, as well as the difficulties of accessing patient data and undertaking studies with dementia patients, restrict capacity.

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14. As the importance of tissue-based research grows, more consistent infrastructural support is needed to address the gaps in procedures for brain donation.

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# 1. Introduction

Scientific research has shown that dementia is not a normal part of ageing – it is the result of complex diseases of the brain for which, in most cases, risk increases with age. This knowledge has provided the basis and impetus for further research into causes, preventions and treatments that, step by step, will defeat dementia. As the prevalence, care costs and devastation wreaked by dementia continue to increase, so must our research response. This is why Alzheimer's Research UK, the UK's leading dementia research charity, specialises in investing in world-class, pioneering research and is raising more money each year to increase this investment.

Dementia science in the UK is world-class and many of our researchers are global leaders in the field. The UK is in a strong position to address the immense scientific and health challenge that dementia presents, but investment remains shockingly disproportionate to the scale of this challenge. Our previous report, 'Dementia 2010',<sup>3</sup> showed that dementia affects 820,000 people in the UK, as well as their families and carers, and costs the country £23 billion a year in care costs and lost productivity. This is twice as much the cost of cancer, three times as much as heart disease and four times as much as stroke. But Government and charitable spending on dementia research is 12 times lower than on cancer research. While the latter receives £590 million a year, just £50 million is invested in dementia research.

The recognition of this disparity by major research funders has grown in recent years:

- In 2008 the Wellcome Trust and Medical Research Council (MRC) launched the Neurodegenerative Diseases Initiative, a £30 million partnership to boost research into neurodegenerative diseases. In 2009, £18 million was awarded to three collaborative research programmes to advance understanding of the biological processes underpinning neurodegenerative diseases.

- The 2009 National Dementia Strategy and Implementation Plan,<sup>4</sup> though primarily focused on improving care for people with dementia, listed among its objectives 'a clear picture of research evidence and needs'.
- This was followed by the Dementia Research Summit and Ministerial Advisory Group on Dementia Research (MAGDR) which published its Route Map<sup>5</sup> in June 2011.
- In early 2011 the National Institute for Health Research (NIHR) issued a themed call for research in dementia, with funding decisions to be made by March 2012. It has also committed £18m funding over five years for four Biomedical Research Units to undertake translational clinical research in dementia, and is allocating a number of Academic Clinical Fellowships and Clinical Lectureships to trainee doctors undertaking dementia-relevant clinical research programmes.

We welcome these initiatives as positive first steps. They are long overdue and go some way towards tackling the dementia crisis we face. Prevalence is growing and there are no treatments that can alter the course of the diseases that cause dementia. To develop these, as well as better tools for early detection (such as tests using biomarkers), and better methodologies for clinical trials at the earliest stages of disease, a lot more work is required.

There is of course an urgency to develop medical interventions. The pharmaceutical industry has invested large sums of money in this and the Government's Life Sciences Strategy, particularly the £180 million Biomedical Catalyst Fund, may also succeed in driving discoveries forward into clinical interventions. However, a series of clinical trial failures suggests we still have a lot more work to do on understanding these diseases and how to combat them. Medical research is a painstaking and costly process, and the enormous complexity of the brain

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<sup>3</sup> 'Dementia 2010: the prevalence, economic cost and research funding of dementia compared with other major diseases', Ramon Luengo-Fernandez, Jose Leal, Alistair Gray, Health Economics Research Centre, University of Oxford, 2010.

<sup>4</sup> 'Living Well with Dementia: a national dementia strategy', Department of Health, Feb. 2009.

<sup>5</sup> The Ministerial Advisory Group on Dementia Research – headline report, Department of Health, June 2011: [http://www.dh.gov.uk/en/Publicationsandstatistics/Publications/PublicationsPolicyAndGuidance/DH\\_127750](http://www.dh.gov.uk/en/Publicationsandstatistics/Publications/PublicationsPolicyAndGuidance/DH_127750)

compounds this. If we are to develop the treatments we need, much more long-term investment in research is crucial.

Despite the significant progress made by dementia research in recent years, it is a relatively young field. It is generally accepted that dementia is roughly comparable to cancer 30 years ago, not only in terms of scientific understanding, but with respect to research funding, social attitudes and research capacity. The National Dementia Strategy observes that the stigma attached to dementia 'is similar in many ways to the stigma that cancer used to carry in the past', and some of the scientists who responded to the survey we carried out for this report refer to dementia research in the 1980s as a poorly understood and underfunded 'virgin' field: 'it was a major disease which at the time (1980s) was very underfunded (and still is) and poorly understood at a cell and molecular biology level' (senior/tenured researcher).

If we look at the advances that cancer research has made in the last 30 years, we have a model of success that demonstrates how much can be achieved with sustained and concerted investment. The 10th anniversary report of the National Cancer Research Institute (NCRI) shows that research spending by its members nearly doubled between 2002 and 2010, from £257m to over £500m.<sup>6</sup> Indeed, it is thanks to research that cancer survival rates have doubled in the past 40 years.

However, although investment in research must take a long-term view, this does not mean that it will necessarily take 30 years to reach a stage comparable to cancer today. As another of our survey respondents puts it:

In the UK we are very cost effective but a cash injection could have profound implications considering how far we have come over the last two years. 'Big' science costs large sums of money but we now have the technology at our disposal to answer many of the questions that need addressing (Prof Kevin Morgan, University of Nottingham).

## 1.1 Why capacity?

A major issue that has to be addressed regarding dementia research in the UK is capacity. This not only refers to the number of researchers working in the field, but also our ability to capitalise on our research strengths, take new discoveries forward and pursue new avenues of inquiry. Essentially, it is about building and sustaining a workforce of sufficient critical mass, and facilitating progress to achieve the best results possible for the growing number of people whose lives are blighted by dementia. With the number of people directly affected by dementia estimated to rise significantly in the future, the UK can no longer afford to neglect the potential it has to reach this goal.

The themes of 'Growing Capacity and Capability' and 'Harness Existing Resources' were highlighted by MAGDR sub-groups and the Route Map details the commitments made to do this. These include the NIHR-funded Biomedical Research Units and themed call for dementia research mentioned above, as well as the allocation of a number of Academic Clinical Fellowships and Clinical Lectureships to trainee doctors undertaking dementia-relevant clinical research programmes. The MRC also committed to a 10% increase in its funding for neurodegeneration research by March 2015, as well as to funding new collaborative research through its Centres of Excellence in Neurodegeneration (COEN) and EU Joint Programming (JPND) initiatives.

We hope these commitments will form the basis for increasing interest and investment. Rather than being wrapped up, we feel that serious discussion on this issue has only just begun. This report seeks to support and contribute to this discussion, as well as ensure that it continues. It highlights the main issues surrounding UK research capacity in the dementia field, and makes both short- and long-term recommendations on how to increase it to a level that is more proportionate to the scale of the challenge.

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<sup>6</sup> 'Celebrating a Decade of Progress through Partnership in Cancer Research', National Cancer Research Institute, June 2011.

## 1.2 Methodology

To obtain a multidimensional picture of the UK's capacity in dementia research, we collected both quantitative and qualitative evidence using:

- Bibliometric data looking into the research output and citation impact of UK dementia research.
- Questionnaire responses providing the experience-based opinions of researchers working in the field.

### 1.2.1 Bibliometric data

We commissioned *Evidence*, a business of Thomson Reuters, to provide the bibliometric data in February and July 2011. In order to assess the UK's dementia research output and citation impact over the last 50 years, we asked *Evidence* to look at these in comparison to three other major disease areas – cancer, coronary heart disease (CHD) and stroke – and four other leading research economies – the USA, Germany, France and Sweden.

Research evaluation is increasingly making use of bibliometric data and analyses. Publication of research outcomes in peer-reviewed journals is an integral part of the research process and is a universal activity. Consequently, bibliometric data have a currency across subjects, time and location found in few other sources of research-relevant data. While there are justifiable concerns about the way we measure 'quality' and how research impact is assessed in general, looking at output and citations in this way is at present one of the most quantitative methods we have. Here, it is used to illustrate the high calibre of UK dementia research and the potential it has therefore to achieve a great deal more.

The Thomson Reuters databases, based on ISI Web of Knowledge<sup>SM</sup>, are widely acknowledged to be the world's leading source of citation and bibliometric data. The authoritative, multidisciplinary content covers over 11,000 of the highest impact journals worldwide, including Open Access journals and over 110,000 conference proceedings. Coverage is both current and retrospective in the sciences, social sciences, arts and humanities, and can reach as far back as 1900. Within the research community these data are often still referred to by the acronym 'ISI'. *Evidence* has extensive experience with databases on research inputs, activity and outputs and has developed innovative analytical approaches for benchmarking and interpreting international, national and institutional research impact.

*Evidence*, a business of Thomson Reuters.

## 1.2.2 Questionnaire

The questionnaire we circulated to researchers working in the dementia field asked four simple, open-ended questions:

1. What attracted you into dementia research?
2. What, in your experience, are the barriers faced by researchers in this field?
3. What has been key in enabling you to reach this stage in your research, and what will be key in enabling you to progress further?
4. Finally, please add anything further you wish to say about dementia research capacity in the UK, including any opinions you may have on how to increase it.

These questions were designed to accommodate personal and wide-ranging opinions, insights and suggestions. Our aim was to draw on the experiences as well as scientific expertise of people working at the 'coal face' of dementia research, who have the keenest awareness of the barriers and possibilities in the field.

We received a wealth of responses from 120 non-clinical and clinical researchers, at different career stages, ranging from PhD student to principal investigator (PI), and representing 30 institutions across the UK. The respondents, some of whom are Alzheimer's Research UK grant-holders, were grouped into three broad categories representing important vantage points:

- Junior/intermediate (PhDs, postdocs and assistant staff).
- Senior/tenured (PIs, research fellows and tenured staff, i.e. lecturers and readers).
- Clinical researchers.

Where respondents were happy to be cited but not identified, the category they are grouped in is given.

Additional, more in-depth interviews were conducted with:

Prof John Hardy FRS, Professor of Neuroscience, Institute of Neurology and Chair of Molecular Biology of Neurological Disease, University College London.

Prof Julie Williams, Professor of Neuropsychological Genetics, University of Cardiff.

Prof Simon Lovestone, Professor of Old Age Psychiatry, King's College London.

Dr Selina Wray, ARUK Research Fellow, University College London.

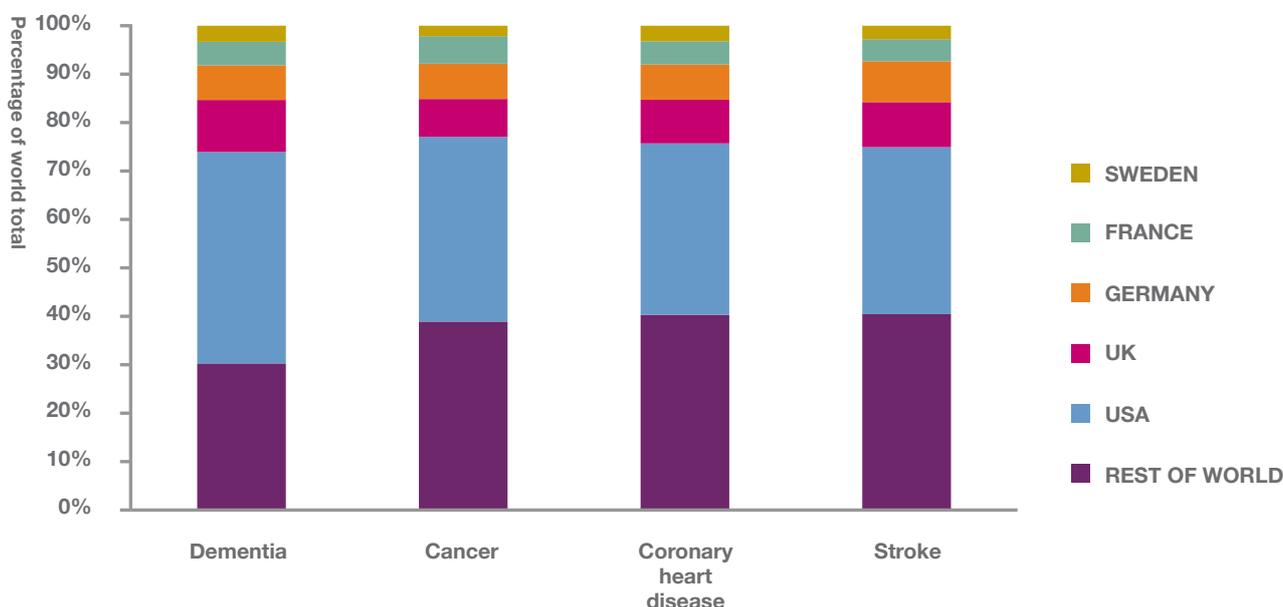
**Our aim**  
was to draw on  
the experiences  
as well as  
scientific expertise  
of people  
working at the  
'coal face' of  
dementia research.

## 2. Punching above our weight

The research commissioned from *Evidence* makes clear that in comparison to other major disease areas, research output in the dementia field is low. This can be related to the vastly lower number of researchers working in the field. Nevertheless, when we look at the impact of UK dementia research in terms of citation, as well as how our output compares to that of other countries, we are a global leader in the field.

Looking at the number of articles and reviews published by each country, the *Evidence* data show that the same relative positions are held by each country irrespective of disease area – the UK is always second to the USA and ahead of its European peers. This broadly follows the balance of research volume both overall and in biomedical research that might be expected from general international comparisons.<sup>7</sup>

**Figure 1**  
**Share of research output of each country as a percentage of the world total for each disease area, 1961-2011**



*It should be noted that these may be collaborative papers between two or more of the selected countries.*

Data & analysis, *Evidence*, Thomson Reuters

In the last five decades, the UK has published 10.7% of world research in dementia compared to 3.3% published by Sweden, 4.9% by France, 7.1% by Germany and 43.7% published by the USA.

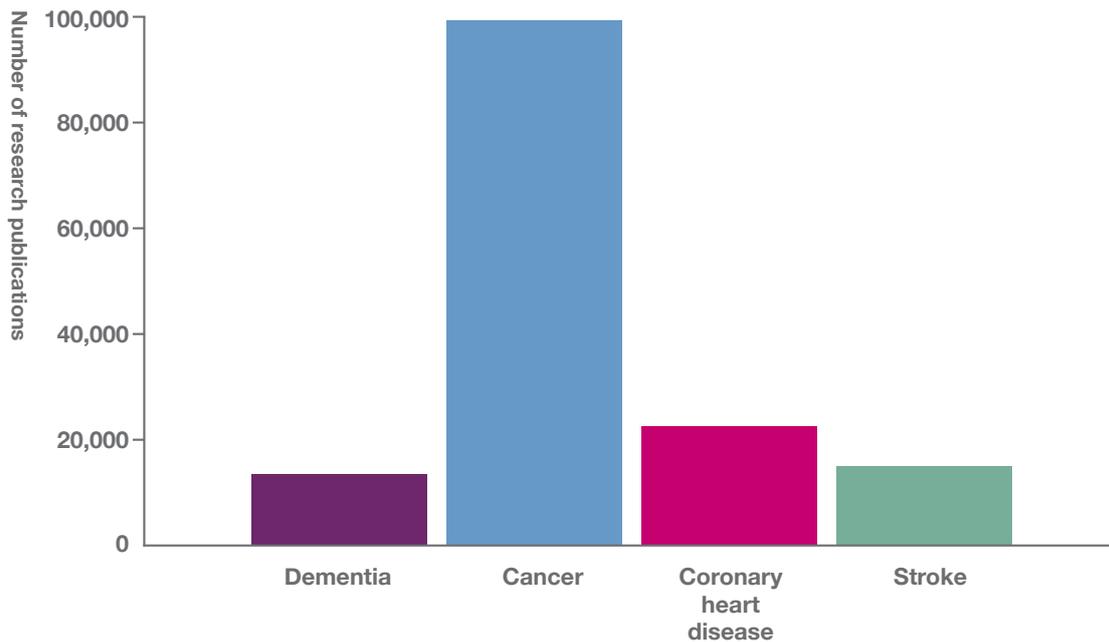
Honing in on publication output from 2008-09, we find the balance is the same, with the UK publishing 9% of world research in dementia compared to 2.8% published by Sweden, 4.7% by France, 7% by Germany and 37.6% published by the USA .

While this confirms that in terms of its share of global output, UK dementia research is on a par with other major disease areas, it is important to look at this in absolute figures. The Thomson Reuters citation databases extracted 125,404 papers published in dementia research from 1961-2011, of which 13,463 were published by the UK. Meanwhile, the global total for cancer in this period is 1,270,373, with the UK publishing 99,358.

<sup>7</sup> 'International Comparative Performance of the UK Research Base', *Evidence*, 2009.

Figure 2

UK research output in major disease areas, 1961-2011



Data & analysis, *Evidence*, Thomson Reuters

This vast difference in output can be related to the number of researchers working in each field. In their analyses, *Evidence* used the output from 2008-09 in the selected disease areas in the UK, France, Germany, Sweden and USA to estimate the capacity of the researcher population. They did this using the

author-address data, refining the process at different stages to remove duplication. To allow for margins of error, they provided a lower and upper estimate where the actual value may be expected to be nearer the lower estimate.

Table 1

Estimates of numbers of researchers in each country in selected disease areas

	Number of researchers in dementia	Number of researchers in cancer	Number of researchers in coronary heart disease	Number of researchers in stroke
UK	3,209 – 4,061	18,497 – 28,062	4,858 – 6,433	3,841 – 4,784
France	2,195 – 3,872	18,132 – 33,825	3,451 – 6,025	2,897 – 4,540
Germany	3,225 – 3,994	21,790 – 34,443	5,706 – 7,896	4,677 – 6,194
Sweden	958 – 1,234	4,695 – 6,772	1,717 – 2,486	1,221 – 1,621
USA	14,771 – 21,186	82,761 – 146,123	22,607 – 32,702	16,380 – 22,754

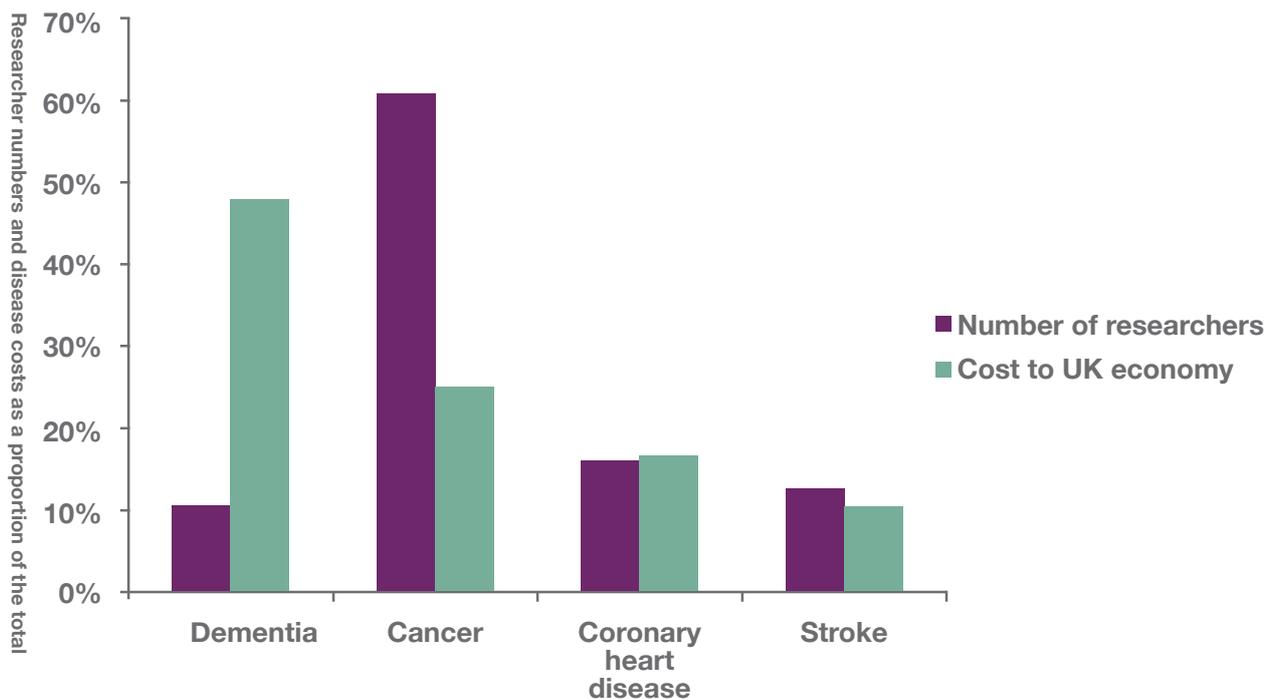
Data & analysis, *Evidence*, Thomson Reuters

If we take the lower estimate for each of these disease areas in the UK, we see that the ratio of dementia researchers to those working on cancer is around 1:6. For heart disease it is 1:1.5 and for stroke 1:1.2. Although there would appear to be more of a balance with heart disease and stroke, the disproportion is

made clear when we look at these figures in relation to the economic burden of each disease (as shown in 'Dementia 2010'), where dementia costs twice as much as cancer, three times that of heart disease and four times that of stroke.

**Figure 3**

**Number of researchers compared with cost to UK economy by disease**



Data & analysis, *Evidence*, Thomson Reuters, and 'Dementia 2010'

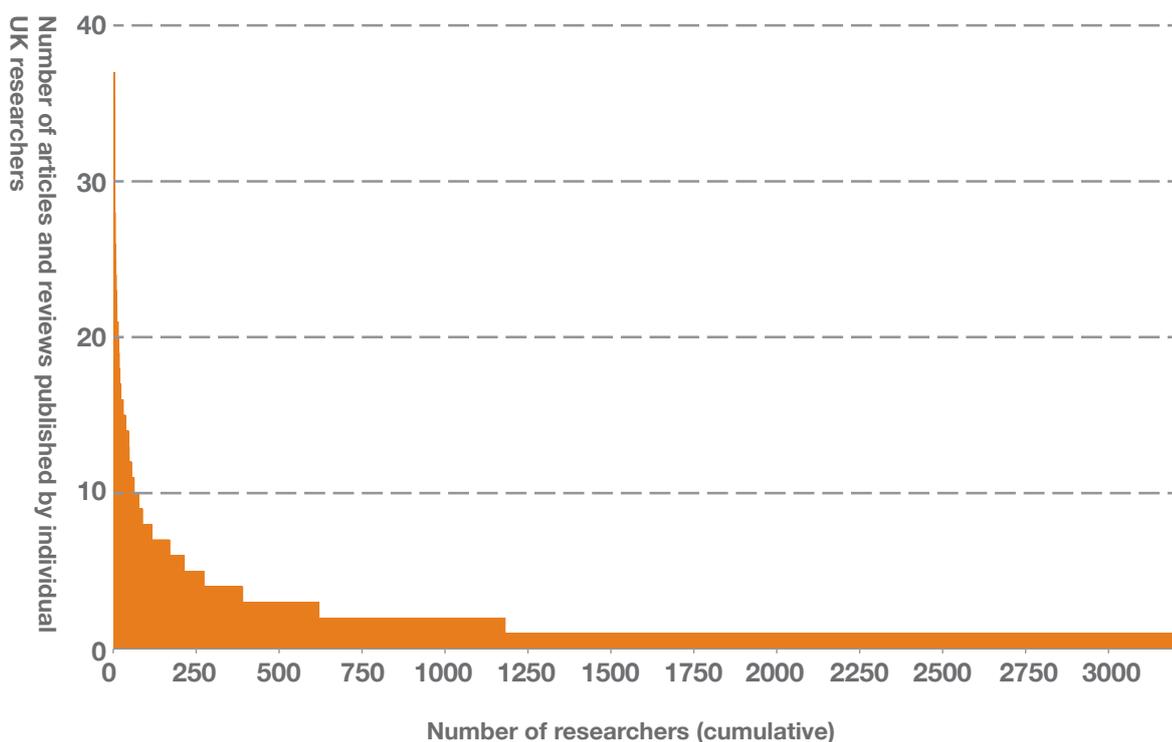
What also comes out of the data provided by *Evidence* is that the distribution of research output in relation to the number of researchers working in the dementia field is highly skewed. Out of the estimated number of researchers, only 17 published over 15 papers in 2008-09, with almost two-thirds publishing once.

While this is not atypical for research activity, it does emphasise the reliance of UK dementia research strength on a small base. Furthermore, over 60% of the UK's output in dementia research for 2008-09 was produced by just six of the top 20 UK institutions in the field.

In the UK, the ratio of dementia researchers to those working on cancer is around 1:6.

Figure 4

Number of publications per researcher, 2008-09



Data & analysis, *Evidence*, Thomson Reuters

Table 2

Leading UK institutions in dementia research, ranked by output (2008-09)

Rank	Institution	Number of papers	Percentage of UK Output
1	University College London	245	15.2%
2	Kings College London	232	14.40%
3	University of Cambridge	172	10.70%
4	University of Manchester	119	7.40%
5	University of Oxford	112	6.90%
6	Imperial College London	93	5.80%

Data & analysis, *Evidence*, Thomson Reuters

The relatively small size of the dementia research community was noted by MAGDR, together with the fact that the volume of new entrants is insufficient to balance those retiring from the profession. In spite of this, UK scientists are having a significant impact and influencing the field at a global level. Of the top 100 investigators in Alzheimer’s disease reported for

2009,<sup>8</sup> 12 were based in the UK. All of these were identified by the methodology used by *Evidence*.

Therefore, although dementia research is clearly a far less mature field than other major disease areas such as cancer and CHD, its contribution to global research in the field, both in terms of volume and quality, is just as strong.

8 ‘Alzheimer’s Disease Research: scientific productivity and impact of the top 100 investigators in the field’, *Journal of Alzheimer’s Disease* (16), A.A. Sorenson, 2009.

## 2.1 'Research in the UK is excellent'

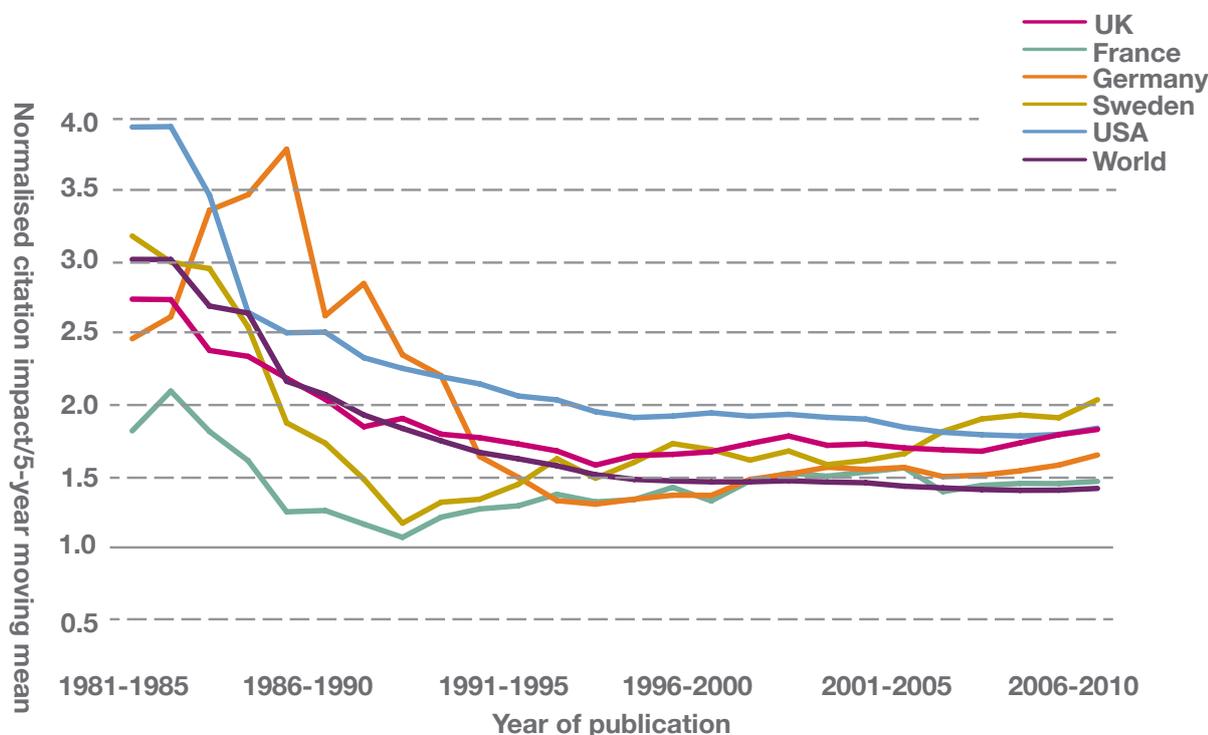
To assess the quality of UK dementia research, *Evidence* looked into the citation impact of research publications from the early 1980s to the end of 2010. Research publications accumulate citation counts when they are referred to by more recent publications. Citations to prior work are a normal part of publication, and a reflection of the value placed on earlier work by current researchers. Some papers

are cited frequently, whereas many remain uncited. Highly-cited work is recognised as having a greater impact and *Evidence* has shown that high citation rates correlate with more qualitative evaluations of research performance, such as peer review.<sup>9</sup> This relationship holds across most science and technology areas and, to a limited extent, in social sciences and humanities subjects.

*Evidence* found that dementia research published by UK-based researchers is very well cited compared to similar research published by other countries.

Figure 5

Trends in citation impact of dementia research by selected country



1.0 represents the world average citation impact of papers in all research fields.

Data & analysis, *Evidence*, Thomson Reuters

Figure 5 clearly illustrates how well cited dementia research published by UK researchers is in comparison to similar research published by other countries. The citation impact is also well above the world average of 1.0.

Unusually, the USA has not maintained a leading role in the last decade and UK-based research has

a citation impact second only to Sweden, which has improved over a similar period. Although some German papers in the 1980s were particularly well cited, since the early 1990s UK dementia research has had a higher citation impact than similar German research. Many of our survey respondents refer to the excellence of UK dementia research, but there is clearly frustration over its unfulfilled potential:

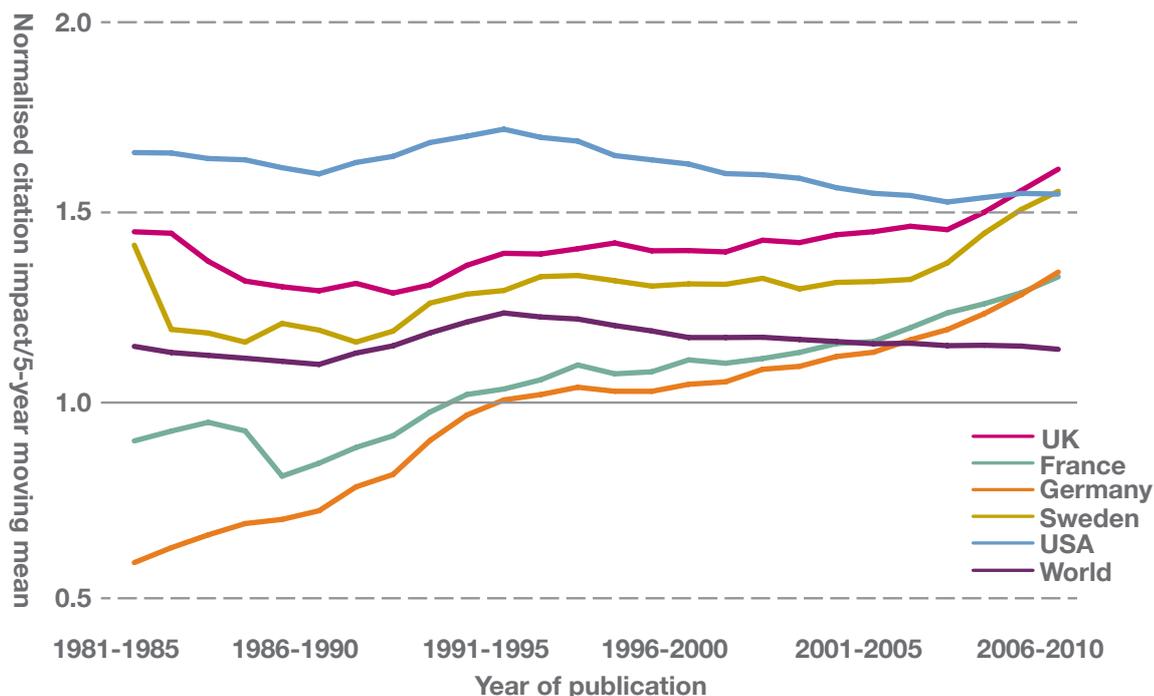
<sup>9</sup> 'Maintaining Research Excellence and Volume: a report by *Evidence* Ltd to the Higher Education Funding Councils for England, Scotland and Wales and to Universities UK', J. Adams et al., 2002.

There is immense potential for dementia research in the UK. It has continually proved its resourcefulness despite the limited budgets etc. available to it – certainly if compared to the US etc. Think of how much more could be achieved with more funding (senior/tenured researcher).

In the other disease areas analysed by *Evidence*, for example in cancer below, the citation impact of UK research is similarly high.

Figure 6

Trends in citation impact of cancer research by selected country



Data & analysis, *Evidence*, Thomson Reuters

The greater relative stability in the citation impact of cancer and CHD worldwide during this time period indicates a more mature and well-established research field, while the pattern of citation behaviour in dementia is typical of developing research fields, which are still very dependent on earlier findings that were made a number of years ago. But UK dementia research is as well regarded and influential as research in other major disease areas. Where it lags behind is in investment.

As another of our survey respondents summarises:

The UK produces excellent research in the field of Alzheimer’s. However, with the limits on funds available we may lose our top ranking position to other countries and may also lose some brilliant scientists who work in the field (Dr Eric Hill, Aston University).

The fact that UK dementia research is doing well on a global scale with relatively low investment should be celebrated. However, this is not a sustainable model. As new discoveries are made, new avenues of inquiry and potential treatment targets are increasing. We need sufficient capacity to be able to capitalise on this. The high calibre of UK research, as indicated by its citation impact, demonstrates its potential to make a real difference to people affected by dementia. A cure is the ultimate goal of research, but small advances that are made along the way can have a big impact. For example, The US Alzheimer’s Association’s Trajectory Report 2010<sup>10</sup> argues that a hypothetical intervention that delayed the onset of Alzheimer’s disease by five years would result in a 57% reduction in the number of patients. So, with more investment and support, UK dementia research could prevent a terrible situation from getting a lot worse.

10 ‘Changing the Trajectory of Alzheimer’s Disease: a national imperative’, Alzheimer’s Association, May 2010.

### 3. What the dementia experts say

The responses to our questionnaire recognise the UK's strengths in dementia research and emphasise the pressing need for growth in the field. They also express strong opinions and feelings about capacity and what needs to be done to increase it. We focus here on the most widely-held concerns expressed by respondents and their suggestions for overcoming these; our conclusions and recommendations are drawn from this evidence. As much space as possible has been given to individual voices as they clearly express the high levels of commitment, expertise, enthusiasm and frustration of those who are at the forefront of understanding and defeating dementia.

### 3.1 'Lack of funding, lack of funding, lack of funding'

Unsurprisingly, the most common answer among all respondents to the questions about barriers, past and future progress and how to increase capacity, is 'funding'. Most respondents see limited research funding as a major barrier faced by researchers in this field. Some acknowledge it to be a common problem for scientific research in general, but many point out the 'inappropriate' level of investment in relation to the growing prevalence and impact of dementia:

If you think about it in terms of numbers of people involved multiplied by impact on quality of life, this is one of the biggest issues of the 21st century, yet we are expending insignificant amounts of money trying to prevent the problem (Dr Guy Brown, University of Cambridge).

Some attribute such underfunding to perceptions of dementia as an 'old person's disease' and because of this 'money isn't spent in the same way as for instance on cancer':

The elderly and those suffering from dementia are stigmatised in diverse ways, some subtle, some less so. The stigma may account for the relatively small amount of funding relative to the social and economic burden (Prof Hugh Perry, University of Southampton).

There are frequent comparisons with investment in other disease areas, usually cancer and often heart disease. A number of respondents point out the vast difference in charity funds available, which emphasises the reliance of researchers on charity funding and also points to the relationship between public awareness, stigma and levels of giving. To put things in perspective, Alzheimer's Research UK is the largest charitable funder of dementia research in the UK. In 2010-11 it invested £5.1 million. This is its highest investment to date, but if we compare it to the £332 million invested by Cancer Research UK, or the £120.7 million by the British Heart Foundation, the scale of disparity becomes clear.

A recent report by the Office of Health Economics for Cancer Research UK concluded that 'government funding for research acts as a "quality signal" for public institutions or charities, therefore "crowding-in" private contributions'.<sup>11</sup> More public funding would not only boost research but would also stimulate charitable donations by helping to raise awareness and signalling the importance of dementia research.

Many  
point out  
the  
'inappropriate'  
level of  
investment  
in relation  
to the growing  
prevalence  
and impact  
of dementia.

11 'Exploring the Interdependency between Public and Charitable Medical Research' Martina Garau, Arik Mordoh, Jon Sussex, April 2011.

Charities are also recognised as playing a pivotal role in raising awareness of the need for research investment. Professor Chris Peers from the University of Leeds says the barrier faced by researchers in the field is ‘the lack of significant funding, despite the efforts of Alzheimer’s Research UK and Alzheimer’s Society. The Government needs to face the longer-term future issues. Research now will save lives and money later.’

Another common argument related to the limited funds available is that these are becoming increasingly concentrated among ‘a few key players’, making it difficult for new researchers to enter the field and for new, more ‘risky’ ideas to gain support. This is seen as perpetuating the dominance of certain theories and groups:

There is not enough funding and everyone is fighting for a diminishing pot. This means anything with a level of risk is not funded, which reduces the likelihood of novel treatments. The large amounts of funding seem to be going to the same groups, which is polarising research into smaller and smaller areas (senior/tenured researcher).

**'The  
Government  
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the longer-term  
future issues.  
Research now  
will save  
lives and  
money  
later.'**

Another senior researcher outlines this problem in more detail:

The number one priority is money. I sit on various committees and it is very noticeable that excellent research is not getting funded; this is for various reasons:

- a. A reluctance within the scientific community to think outside the box. There has been a creeping movement of having to do the work before you get the money. This was the ‘American way’, but it is interesting that the US is no longer pursuing that approach. Previously there was an air of risk-taking, which was acceptable; funding and research in general has become rather like stamp collecting, and so much preliminary data are required that the project is usually done before the grant is awarded.
- b. Funding consortia is good. However, there can be a reluctance to do this as groups of universities. This is mainly geared by Government’s obsession with assessing research, e.g. REF issues are counter-productive if you really want to try and tackle diseases. Who is first and last on papers are the only criteria that count. Pooling initiatives has been very successful in some parts of the country. But there is a difficult balancing act here, as large consortia can miss small independent researchers who are not part of one these ‘clubs’.

This and a number of other responses point to the necessity for a 'balancing act' between concentrating funding around centres of excellence, established research groups and consortia on the one hand, and providing project grants for smaller, riskier projects, which can often open up new possibilities. Professor John Hardy at University College London likens the concentration of research at the 'big five' (Oxford, Cambridge, UCL, Imperial, King's) to the Beeching rail cuts in the 1960s:

Research is being concentrated at the big five: Oxford, Cambridge, UCL, Imperial, King's and, to a lesser extent, Manchester and Newcastle. And it is being cut at other universities, which is often where PhD students, postdocs and young faculty members get their chances. It's like the Beeching rail cuts, when they cut all the branch lines and were then surprised that traffic on the main lines went down. It seems like not much comes from the other universities, but they are having a very, very tough time. It is difficult to build a big research operation just using the big five. Money is being pushed at the big groups and older guys with established careers, and young faculty people are having a terrible time, e.g. being a senior postdoc or junior lecturer. The stupid thing is that these are the people who make new discoveries. I am most famous for the research I did three years after I got my lectureship – 20 years ago. People who are at that stage now are finding it really tough. We see really good postdocs trying to get fellowships and there are really few places for them to go. Young lecturers getting their grants triaged. Being on Alzheimer's Research UK's Scientific Advisory Board I have seen that the quality of applications from PhDs has gone up and up and up – in part that is because they have nowhere else to go. MRC funding is going down. Wellcome has changed its granting programme so that it favours the big five and the big names. It is the people in their late 20s-30s who are really suffering.

The Wellcome Trust's decision to phase out the majority of its existing biomedical science grants and replace them with 'Investigator Awards' is a concern also voiced by other respondents. One tells us that in order to progress in future they will need to generate increased project grant funding to make up for the loss of Wellcome Trust project grants. A number of respondents place the responsibility for increased funding in the hands of the Wellcome Trust and the MRC. Many also observe the need for a more coherent government strategy in this field:

Clearly, what is required is a novel research focus and policy of the Government on how to guide and support research in neurodegenerative diseases. So far, there only have been individual calls for specific funding projects. There appears to be a lack of cohesion and planning in this very important research field. The BBSRC recently announced that they want to shift away from neuroscience projects. The MRC has made attempts to support vital research in Alzheimer's disease and other ageing-related diseases, but it seems to be only a side issue. There should be funding committed to focused research in this field, and a focused policy to support and guide research in this area (senior/tenured researcher).

**'It's like the  
Beeching rail  
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In a disease area as complex as dementia, where the need for a broad investigative range is so great, dedicated funding not only needs to increase, it also needs to be as flexible as possible: ‘the complexity and uncertainty about dementia require keeping a very open mind’ (Dr Vincent O’Connor, University of Southampton).

This is not to say that it should be taken away from more established areas and groups. Rather, a fine balance must be sought and dementia research funders must address the funding structures and programmes that perpetuate dominant trends and crowd out new approaches:

We need a more collegiate supportive environment that is open to new concepts. Extended (ring-fenced) funding opportunities from major funders, including the Government, will help bring new people into the field and support those that are not necessarily in the big groups (major initiatives that pour more money into the already successful will not necessarily expand capacity) (senior/tenured researcher).

ARUK’s Pilot grants go some way towards helping this situation and have often led to larger projects, supported by public funding. We have invested over £2.5million in Pilot projects, but this area needs greater investment from all dementia research funders.

## Recommendations

1. UK dementia research needs a cohesive national strategy, with sustained, ring-fenced funding.

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2. We need to improve social awareness of the need for dementia research. Increased public funding would signal its importance and encourage greater voluntary giving.

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3. While we should continue to support the more established research base and areas of investigation in the dementia field, there needs to be a balance. Funders need to revise current structures and programmes so that they do not preclude novel approaches and ‘riskier’ projects that are founded on strong science.

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### 3.1.1 'More time spent on the quest for funding is less time doing research'

The lack of funding for dementia research also impacts on capacity by increasing the amount of time researchers have to spend in their efforts to acquire it. Many of our respondents point out that the process of applying for funds, waiting for results, writing reports and fulfilling, as one senior researcher puts it, 'over-complicated contractual agreements with some funding organisations' reduces research time and harms productivity:

The capacity for research into dementia is phenomenal in the UK, as we have superb skills, ambition and knowledge at levels of excellence. The lack and anxiety surrounding funding dampens the enthusiasm and the quest for securing funds takes time away from the laboratory (Dr Roxana O Carare, University of Southampton).

Fierce competition necessitates a thorough approach towards allocating funds, but this is often seen to impede progress in a field where the need for meaningful results is so pressing and capacity is already so restricted. Given how painstaking medical research can be, time is at a premium. One respondent suggests that 'funding agencies should have application and reporting procedures commensurate with the levels of funding and type of research being undertaken'. Processes could also be simplified without compromising their integrity. For instance:

Two-stage grant applications are a waste of time because the first stage applications usually require relatively accurate costings that need to be thought through in detail – so we might as well just go the whole hog, get a decision sooner and if unsuccessful then move on – it will reduce the overall amount of time that researchers are waiting (senior/tenured researcher).

Another frequently-made point is that continuity and momentum are crucial to maximising progress. A major concern among respondents is maintaining funding and the continuity of expertise they have built up in the laboratory:

Continuity is especially important since momentum and lab expertise are essential for rapid progress. Loss of funding or spending much time writing grant applications in a fiercely competitive environment is counterproductive for progress and also very short-sighted in terms of the next generation of researchers. Many are turning to alternative careers due to the lack of prospects for a research career (Prof Anne Stephenson, School of Pharmacy).

### Recommendation

4. Funding application and reporting procedures need to be reviewed to ensure that time spent doing research, momentum and continuity are maximised to accelerate progress. Increased and longer-term funding would make a big difference, but simplifying procedures, especially for smaller grants, would be a productive first step.

## 3.2 Creating 'an attractive, sustainable area in which to build a research career'

Science research careers in the UK are beset by insecurity and the debate around this is longstanding. The campaign group Science is Vital recently reported that 'the scientific career structure in the UK is not fit for purpose. If the situation is not improved, we risk seriously undermining our research base and, in turn, imperilling the economy.'<sup>12</sup>

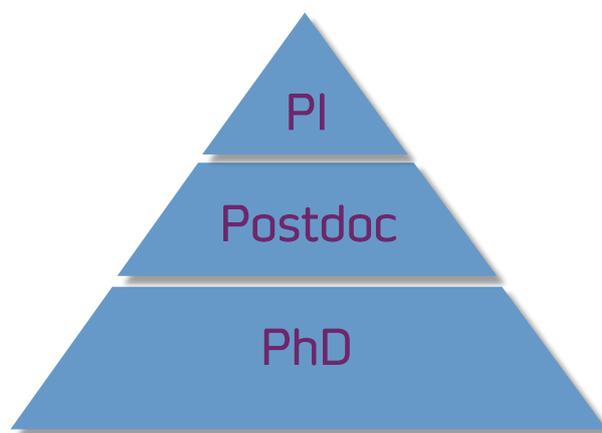
This holds true for dementia research where there is a clear need, voiced by many of our respondents, not only to attract bright young researchers into the dementia field, but also retain those who have built up skills and expertise in the area. Many senior researchers who responded to our survey cited research personnel as being essential to past and future progress. Again, continuity is key and the struggle to maintain funding not only 'risks work being stop-start in nature and promising avenues generated from work not being followed up', but also 'losing key research staff as they are beginning to develop expertise' (Dr Stephen Wharton, University of Sheffield). This has a big impact on capacity.

This can also act as a disincentive for new researchers to enter the field. PhD student, Matthew Burke tells us, 'it is very disheartening when you see numerous scientists leaving the field due to lack of funding and job security'. Professor Andrew Doig observes that 'talented students and postdocs who want to work in this field get disillusioned and leave science' and Professor David Allsop remarks 'many high profile UK researchers in the field have relocated, particularly to the USA. We need to improve the research funding environment in the UK to prevent this from happening in the future.'

As well as longer-term funding that allows group leaders to recruit good people, retain them and help them build a career, there is also a need to address the bottlenecks that are common to science careers in general, by revising traditional pathways and creating new ones. This would allow postdocs

greater career progression and development within dementia research. Many respondents highlight the importance of early- and intermediate-stage career development, particularly at postdoc level. As one postdoctoral fellow points out, 'funding bodies support a large number of PhD studentships but when it comes to the next stages of their career there are very few options available and a large bottleneck occurs'.

Dr Selina Wray, an Alzheimer's Research UK Research Fellow at University College London, elucidates the problem in detail. She refers to the pyramid structure of science careers in terms of the number of people at each stage:



This can be likened to most career structures, but the difference is that if you do not progress to the next level, you may have to leave science altogether as it will be too difficult to find funding:

Inevitably, at each stage, a certain number of people will leave science to go and do other things. Also, each group leader will train dozens of people during their career, but when s/he retires, only one replacement is needed. This leaves a huge pool of dedicated scientific talent with no long-term career prospects in research. It is not possible to be a postdoc forever because you eventually become too expensive to employ.

<sup>12</sup> 'Careering out of Control: a crisis in the UK science profession', Science is Vital, Oct. 2011.

Dr Wray proposes two possible solutions to this:

- Fellowship schemes: this does not solve the problem of insufficient PI positions, but it does mean that postdocs are writing grants and obtaining funding (and therefore being more independent) from an early stage in their career.
- Senior scientist/permanent postdoc positions, so that it is possible to make a career in science research without progressing to PI level.

Dr Wray also comments on postdocs and fellowships usually being fixed-term, for three years. This means candidates have to move on to another laboratory or institute, which is often beneficial, but this, together with job insecurity becomes more difficult and less feasible once people start to settle down and have families. Dr Wray suggests that more security could be provided by 3+2 schemes, where a further two years' funding could be offered subject to satisfactory progress. Also, more long-term funding for specific projects would make them more productive as, when a grant expires and the project is going well, a PI will not have money to replace staff and keep the project going.

On PI positions, she suggests 'having grant competitions where funds are ring-fenced for junior PIs':

The lucky few that do reach the PI stage don't get there until age 35+ on average. Even at this stage, the position is not secure. Universities can terminate employment if, after a certain period, the person is not attracting significant external funding. However, unlike at the fellowship stage when one is competing against peers/people of the same level, at the PI stage people will be competing in the same grant rounds as established group leaders who have been in the field for many years. This can lead to a vicious cycle of not getting funding → not being able to generate data for papers → not having data to put into grant applications and so on.

Dr Wray's observations and suggestions chime with some of the recommendations by the Science is Vital report:

- The creation of more permanent research staff positions that are not principal investigators/lab heads.
- More funding earmarked to help bridge the transition from postdoc to independent position.
- More independent fellowships, and the abolition of eligibility criteria that effectively discriminate against older postdocs or those who have followed a non-traditional career path.
- Increased opportunities for postdocs to apply for project grants as the named investigator in their own right.

Applied to the dementia field, such measures would have a significant impact on increasing capacity and building the workforce continuum that is essential to tackling dementia effectively:

Young researchers need to be convinced that it will be an attractive, sustainable area in which to build a research career with enough funding and the potential to make a real difference to people's wellbeing (senior/tenured researcher).

We need to  
**attract**  
researchers  
into the  
**dementia field,**  
and also  
**retain**  
those who have  
**built up**  
**expertise**  
in the area.

The question of enthusing people into the dementia field is an important one. Dementia research is a field where scientific progress will have a powerful impact, and the need for more people to pursue a career in it has to be driven home so that capacity continues to increase:

Increased capacity entails not only greater funds and resources but also the research staff eager to make the most of the resulting opportunities. I think we need to ensure that the next generation of scientists and researchers view dementia and neurodegenerative disease as a vibrant and central topic, which, with current prevalence, an ageing population and the current lack of disease-modifying treatments, represents THE scientific, medical and socioeconomic challenge of this century (Dr Sebastian Crutch, University College London).

Much of the responsibility for this lies in science education:

At the 'grass-roots' level we need to enthuse undergraduates both in science and medicine about dementia and dementia research. Funding for tasters in dementia research (e.g. electives, Masters etc.) in centres of excellence with international leaders in the field who can act as role models would be very helpful (Dr John-Paul Taylor, Newcastle University).

Enthusing prospective researchers is not only about educating them on the social importance of carrying out research in this field. It is also about communicating the discoveries that are being made every day and how exciting and challenging the science is – instilling both the 'personal horror and abstract fascination' that Dr Sebastian Crutch describes as drawing him into dementia research. Many of our respondents cite the importance of mentorship, or the influence of 'passionate lecturers' and 'excellent supervisors' as both attracting them into the field and being key to their progress. We need to ensure that this chain of influence continues and spreads so that we establish and maintain 'a cohort of scientifically trained people who will go on to lead developments in the field as they mature' (Prof Michael Duchon, University College London). If we don't expand this workforce now, this chain will be broken and capacity depleted.

## Recommendations

5. Scientific career paths have long been in need of revision. The bottlenecks and vicious cycles caused by existing career structures in a priority field like dementia can be eased by introducing:
  - a. A larger number of independent fellowships.
  - b. More permanent senior scientist/postdoc positions.
  - c. Ring-fenced funding for junior principal investigators.

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6. More dedicated funding calls as well as taster and Masters courses in dementia research are needed. This will pass down existing expertise and increase knowledge of recent discoveries and new avenues of research. Researchers need to be enthused and encouraged into the field at undergraduate and postgraduate levels.

### 3.2.1 'For clinicians the training conveyor belt is inflexible'

Our questionnaire responses also highlight the difficulties in clinical research careers. Among this group of respondents, the attraction to and indeed recognition of the need for dementia research is most often a result of clinical experience:

As a junior doctor working on a geriatric ward I was struck by how many people had dementia and how different the more severe end of the scale was from the happy go lucky image of 'forgetful but happy granny'. The loss of mind and individual is so profound in the later stages of the condition; I remember one relative of a patient telling me that their mother was 'one of the living dead' and 'only a fraction of her soul remains'. This with the lack of meaningful treatments, the lack of clinical and research interest (I have always been attracted to Cinderella areas!) and my own inherent enthusiasm to try and make things better drew me into dementia research (Dr John-Paul Taylor, Newcastle University).

Limited knowledge among clinicians, both about working with dementia and about research taking place in this field is also an issue. Respondents also point out that within the wider medical profession, dementia is not always viewed as a priority ‘that deserves the same level of diagnostic and therapeutic attention as cardiac failure or cancer’ (Prof Karl Herholz, University of Manchester). It does appear that dementia is still regarded as more of an issue for social rather than health care, which has negative implications for the promotion of dementia research in the health system. This is a further example of the stigma surrounding dementia and mental health in general, a category that many people still restrict it to. It could also be attributed to the lack of effective treatments available and the need to respond to the demands on social care posed by dementia. In any case, while we can try to manage the situation, without more research it will get worse.

Regarding clinical research careers, Professor Nick Fox and others tell us that ‘for clinicians the training conveyor belt is inflexible’ and time is a critical issue. One respondent outlines the ‘difficulties associated with clinical academic pathways’ in more detail:

What is needed are funding opportunities that provide opportunities to do dementia research within these pathways. There are PhD studentships available. However, I am not surprised that there has been poor take up of the one-year preparatory fellowships to get experience of dementia research. No clinician would generally be released from their training pathway to take time out to do research unless it contributed to a PhD or an MD (clinical researcher).

This respondent also points out the ‘paucity of clinical academic leaders in dementia research’ and the ‘difficulties of finding out about what opportunities there are as a clinician and where these are based. Lack of representation of research in more clinical arenas also leads to difficulty encouraging other clinicians into the research area’:

There is a lack of funding opportunities for researchers and in my particular case senior fellowship opportunities suitable for senior clinicians. On completion of clinical training, those who wish to continue an academic career need to secure funding for clinical time and also research time. There are now few senior lecturer posts funded by universities or the NHS available to take

up straight after completion of specialty training. Hence opportunities are limited to clinician scientist fellowships from Wellcome, NIHR or MRC where researchers in the dementia field are up against those in other research areas. In cardiology, for example, there would also be charities such as the BHF with substantial funds available. The key to these fellowships is to provide funding for both clinical as well as academic work, and also funding pools large enough to provide a consultant level salary. The only current equivalent from ARUK is a senior fellowship, but the amount provided would be unlikely even to cover a senior clinician salary let alone the research, and would hence rely on securing additional funding for a salary through the NHS. Therefore senior clinicians wanting to pursue an academic career are at a disadvantage as compared for example to academic clinicians in cardiology (clinical researcher).

One of the actions listed in the MAGDR Route Map was NIHR funding for Clinical Lectureships and Academic Clinical Fellowships to trainee doctors undertaking dementia-relevant clinical research training programmes. One respondent tells us that a similar fellowship has been key to their progress so far:

The Academic Clinical Fellowship programme (an NIHR initiative) for junior doctors allows protected time to put together research ideas, pilot work and PhD funding applications – without this I would have a very limited opportunity for research (Dr Ellen Tullo, Newcastle University).

Fellowships specifically for dementia should therefore help bring more clinical trainees into the field. However, this needs to be more than a one-off initiative to help build capacity for the long term and create more widespread engagement with dementia research in the clinical arena. Flexibility is crucial:

The key to my progress so far has been flexibility of funding (especially Alzheimer’s Research UK’s willingness to permit me to complete my post-doctorate and Senior Research Fellowships on a part-time basis to enable the completion of clinical training) (Dr Sebastian Crutch, University College London).

Several respondents also bring to our attention the limited research culture in old age psychiatry or geriatric medicine. This makes it difficult for candidates to compete in the MRC/NIHR market

and is partly attributed to ‘misperceptions’ that this is not a very rewarding field. John Starr, Honorary Professor of Health and Ageing and a Consultant Psychiatrist in General & Geriatric Medicine tells us he was attracted to dementia research because it ‘breaks down the mind-body paradigm that splits physicians from psychiatrists’. Being a disease of the brain, which affects the mind, dementia requires investigation from both perspectives. In this respect, Professor Karl Herholz comments that ‘the complete separation of neurology and psychiatry training in UK does not help’.

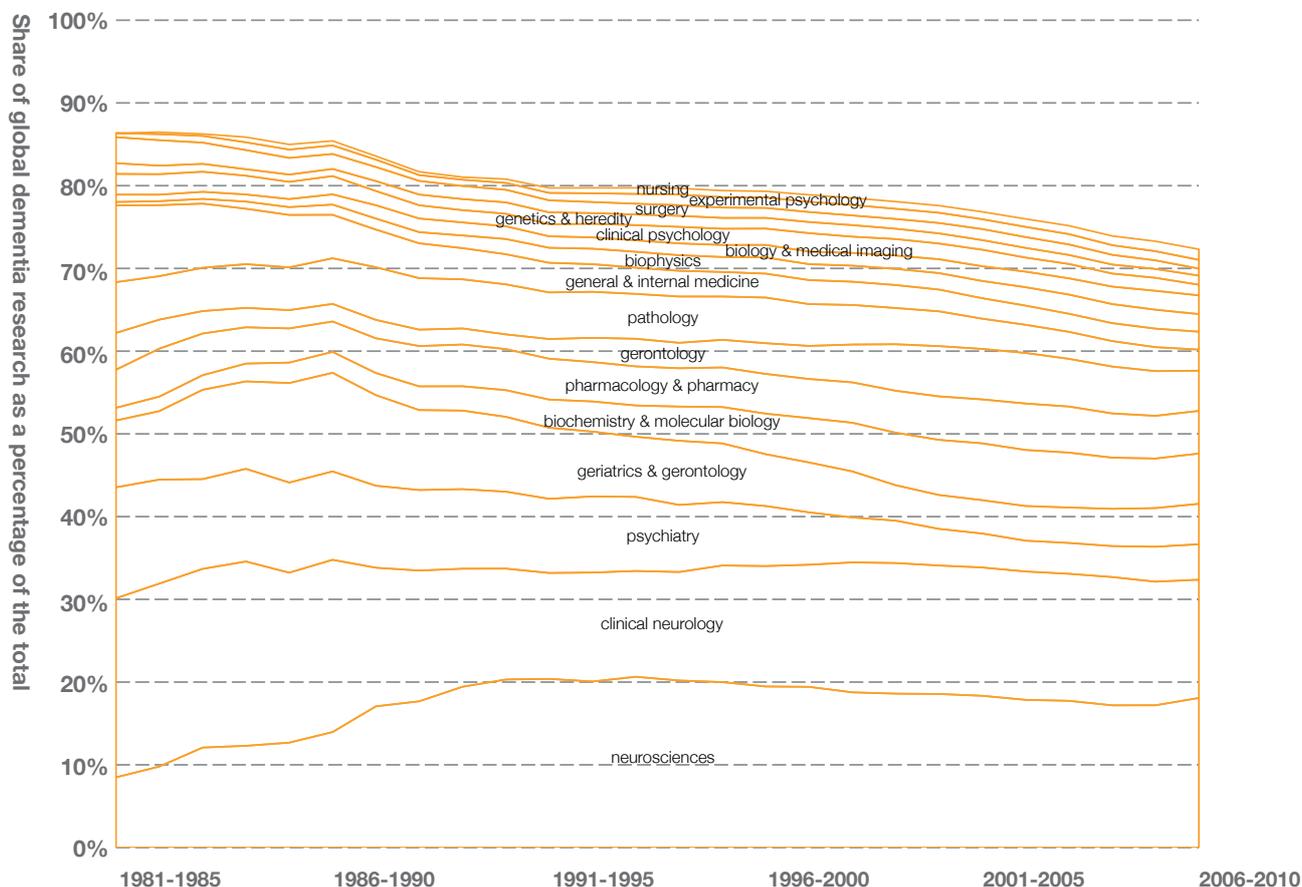
In light of these responses, it is interesting to note *Evidence*’s findings on the publication of dementia papers in different journal categories, which shows that, globally, psychiatry has not seen as strong a growth in paper numbers as would be expected with the increasing volume of dementia research. This could, as observed by *Evidence*, also be attributed to this area becoming less important in dementia research worldwide.

## Recommendations

7. Funding for research and the training pathway for clinicians wishing to undertake research in the dementia field need to be more flexible, to accommodate both the time and income required to carry out clinical work and research.
8. National Institute for Health Research Fellowships specifically for dementia research are welcome, but need to be continued and extended to senior clinicians. This will help ensure continuity of the clinical research workforce and the development of capacity at all levels.

Figure 7

### Share of global dementia research by journal category



Data & analysis, *Evidence*, Thomson Reuters

### 3.3 'So much about the origin and progression of dementia is still unknown'

Recent Government initiatives to boost dementia research – the NIHR's themed call and funding of four Biomedical Research Units, as well as the Government's Strategy for Life Sciences – are geared towards accelerating translational research and the trialling of medical interventions. While these initiatives are welcome, many respondents argue that they should be augmented by direct efforts towards an understanding of the diseases that cause dementia. This is not about some abstract, academic interest, but rather about resolving the fundamental questions about exactly why and how dementia develops.

While there is always room for serendipity in research, the complex spectrum of diseases which develop in the brain over many years needs to be understood more fully if we are to have a sound basis for preventions, treatments, and diagnoses. This should encompass both 'basic' research, which uses model systems (molecular, cellular, animal) and observational clinical research, which depends on human volunteers. These approaches can usefully inform each other and promote the transition from bench to bedside, being equally essential for the development of disease- and symptom-modifying treatments, as well as accurate methods of diagnosis and prevention. Yet, there are significant bottlenecks in both.

Furthermore, the success of clinical trials depends on the findings that come from studies involving pre-clinical and clinical models. The fact that dementia has a protracted pre-clinical pathology, where changes in the brain are taking place long before symptoms occur, would support this:

The main difficulty has been in translating advances in our understanding of the pathobiology of dementia into improved treatments for patients. Clinical trials in this area of research are notoriously difficult and very expensive to run. Part of the reason for this is the often chronic nature of disease progression, so trials must run for prolonged periods of time. Another big issue is heavy reliance on clinical (dementia) rating scales for drug trials. The availability of good biomarkers for disease progression would help enormously. Also, the recent failure of some high profile drugs in phase III clinical trials will continue to make this a difficult area (Prof David Allsop, Lancaster University).

The lack of success in drug discovery programmes for brain disorders has led some prominent companies – GlaxoSmithKline, Astra Zeneca, MSD (Merck) and Novartis – to reduce or pull out of neurosciences research in the UK and elsewhere. While their interest in neurodegeneration (and Alzheimer's disease in particular) continues for the moment, drug development in this field is seen as a very high-risk activity at a challenging and uncertain time for the sector. Some see this as a need to go back to the drawing board at the basic science level, and others as a need for non-basic research in better trial methodologies, biomarkers and early detection. The Life Sciences Strategy announced by the Government in December 2011 may help drive discoveries forward into treatments, but it is widely acknowledged that so much is still unknown about the biology of the brain and its disorders.

Furthermore, greater investment in basic and observational clinical research would increase the potential for future industry investment, which as well as benefitting patients is good for the economy. Life sciences have been identified by the Government as a vital growth area and treatments for dementia have a potentially huge global market. But short-termism that seeks quick wins can lead to misguided investment that does not take the bigger picture into account. Professor Julie Williams at the University of Cardiff argues that there is currently a mismatch between what is needed and what is available:

Within the field of dementia one of the main bottlenecks is understanding the causes. It's really at the applied basic level. That is where our bottleneck is. And will be for the next ten years.

Gaining a better understanding of dementia is enhanced by efforts to bridge the perceived lab/ clinic gap. Several respondents recommend more cross talk, collaborations and the sharing of expertise and data:

I have been fortunate as a basic scientist to work closely with clinical colleagues who have taught me a lot about the dementias. I am frequently reminded as to how complex these conditions are in elderly patients, each with a whole lifespan of influences that may impact on how their nervous system ages, and whether they reach some critical burden of disease that will then express itself as dementia (Prof Hugh Perry, University of Southampton).

This works both ways, and an increase in such mutually beneficial partnerships would make research as productive as possible and enable all researchers to focus on the bigger picture. Networks are one way of achieving this, as are more joint funding programmes.

## Recommendations

9. Increased investment needs to be funnelled into research that seeks to improve our understanding of the diseases that cause dementia. This will increase chances of success in trialling medical interventions.
10. Stronger links between basic and clinical researchers need to be forged. Strengthening networks and increasing joint funding programmes can help achieve this.

The  
complex  
spectrum of  
diseases  
which develop in  
the brain  
over many years  
needs to be  
understood  
more fully.

## 3.4 'Ageing/ dementia research is by definition multidisciplinary'

Dementia is caused by a complicated set of diseases of the brain. The complexity of the brain and the long pre-clinical pathology of these diseases necessitate both longitudinal and multidisciplinary approaches to research. A large number of respondents stress the importance of this, while also recognising that it is a far from straightforward process:

The brain is arguably the most complex organ in our body; this complexity means that many different approaches are needed to study the brain at different levels of complexity. Therefore dementia research requires a high degree of interdisciplinarity. Coordinating such an orchestrated effort is a mammoth, but essential task (Dr Alessio Vagnoni, King's College London).

Specialists from different fields have to join forces if substantial advances are to be achieved. This process of 'joining forces' is very laborious and difficult, and from my point of view represents the most important barrier towards a more profound understanding of neurodegeneration (Dr Johannes Attems, Newcastle University).

It is becoming evident that as new discoveries are made, dementia research needs to draw on a broader pool of expertise that crosses disciplinary boundaries. The expertise required ranges from cell biologists to physicists and those with advanced computing skills. Dementia is not just a biological challenge, it is a cause that calls for 'big' science. Increasing capacity is not just about increasing numbers and bringing new people into research, but harnessing existing resources to pursue a common aim:

The dementia research field must become more interdisciplinary in its approach and the contributions of the various perspectives, from animal models to human population studies, must be better integrated. Funding bodies have the potential to achieve this by modulating the way they distribute funds and by positively encouraging information exchange and cooperation between research groups from different perspectives (Sally Hunter, University of Cambridge).

Centres of excellence certainly have a central role to play in this, but as Professor Julie Williams at the University of Cardiff points out, this can also be done virtually if people are encouraged to work more collaboratively across areas of expertise.

In Professor Williams' field of neuropsychological genetics the identification of ten genes that increase the risk of common Alzheimer's disease has paved the way for further work, to develop our understanding of what these genes do and the role they play in the disease:

We need to attract new people into the field, with skills in the areas highlighted by some of these research findings. These people are not necessarily working on Alzheimer's disease at the moment and to bring them into the field a structured approach is needed.

She emphasises the need to partner people who are currently not working on the disease with those who have experience of Alzheimer's disease research 'so they can marry their knowledge together and produce more efficient and tractable ideas'.

But, as Professor Williams points out, there are no funding mechanisms in place to target these sorts of scenarios:

To get a fellowship or grant you have to have a track record in that area. By definition these people won't have a track record in Alzheimer's research. We need to find mechanisms that bring these groups of people or individuals together.

Targeted senior fellowships is one possible solution suggested by Professor Williams, as well as a structured funding call to specifically attract scientists from outside the dementia research field:

We have to do this at all sorts of levels. We have to exploit the expertise we have. Collaborations need to involve those who understand the Alzheimer's field, so that you don't reinvent the wheel and get to ask the important questions first off. In time these people can become more independent once they are aware of what's going on. It's building structures. Specific calls that take account of the fact that people have not worked on Alzheimer's before and would not otherwise get a grant. We need to take these limitations into account and build capacity in a strategic way.

Professor Williams says there are many lessons to be learned from cancer research, which has succeeded in building effective collaborations, something which dementia and neurodegenerative disease research needs to work towards. She also points out that one crucial difference is the money that has been invested in cancer research through focused funding. Building bridges and channels of communication can have a huge impact on maximising capacity. As another respondent points out, the field will not only benefit from other disciplines, but also basic research in other disease areas:

When studying the basic biochemistry (of molecules etc.) there is a very large area of overlap between fields and disease areas. For example, the human and other genome projects have been (and are) very useful; many of the tools and reagents developed by cancer researchers are invaluable to neuroscientists. Therefore, other basic research often does benefit dementia research. So, as well as (obviously) increasing the funding, I'd like to see good and imaginative projects that are not necessarily very closely related to dementia (senior/tenured researcher, retired).

Respondents recognise the importance of research networks for sparking collaborations and suggest that these could be used more to facilitate

interdisciplinary research, for example by organising networking and brainstorming sessions. Networks are also particularly valuable for people working in smaller institutions where it can be challenging to achieve the full complement of expertise required.

The field is held back by lack of collaboration and lack of appropriate networks. The REF assessment in 2013 encourages selfish behaviour in both scientists and institutions. The complexity of the problem is daunting and will not be solved without interdisciplinary teams tackling complex problems, and the individuals with those skills are not necessarily all in the same institution (Prof Hugh Perry, University of Southampton).

The NCRI is also a good example of successfully uniting Government, industry and charity research funders, funding joint initiatives and holding conferences and meetings on particular research focuses. Such a model would serve dementia research well as long as it did not neglect those on the periphery who would benefit from more opportunities for collaboration as well as making a valuable contribution.

## Recommendations

**11.** A multidisciplinary approach in dementia research is essential to take new findings forward and make meaningful progress. Targeted funding aimed at building this critical mass is needed.

**12.** Research networks need to be strengthened and extended to promote more collaboration and support researchers and institutions beyond centres of excellence.

## 3.5 'Excessive ethics and bureaucracy'

Access to research tools and resources is also an issue that our respondents singled out as affecting capacity. A significant level of frustration is evident regarding the regulations and ethics around animal and tissue research and studies involving dementia patients. While nobody opposes the need for robust regulation, the level of bureaucracy involved is seen as causing significant delay and becoming a disincentive for researchers to enter into or continue such work in the UK.

Bureaucracy is a minefield in the UK if you want to undertake studies or trials in patients. It has taken us up to 9-12 months to get permission to go ahead, and on one occasion we lost the contract (clinical researcher).

Another clinical researcher outlines the problem in more detail:

NHS Ethics is such an enormous hurdle to actually starting research as it takes many months of dedicated research time to get an application approved – and this is for non-invasive behavioural tests that pose no risk to anyone. Also the hoops that have to be jumped through to get ethics agreement massively delay research and reduce participation rates, such as: (a) difficulties in procedures for selecting and actually contacting patients with dementia, which reduce recruitment rates and bias samples towards the most able and articulate; (b) requirements for massive information/consent sheets that are so long-winded and scary that they put potential participants off; (c) making it as difficult as possible to access medical notes which are essential for publication in respectable journals; (d) making it almost impossible to recruit patients who do not have capacity to consent, thus making that group difficult to research – yet their needs are so important (Prof Louise Phillips, University of Aberdeen).

Professor Phillips also expresses doubts about continuing dementia research because of the difficulties of getting funding and ethical approval as well as running the practicalities of dementia studies.

Questions of mental capacity understandably complicate dementia research, but some respondents, while recognising the need to protect patients, do see this as causing 'net harm' as these patients are also the beneficiaries of this research. This has been addressed by the Nuffield Council for Bioethics, who concluded that the ability of people with dementia to give or withhold consent to research should not be underestimated, although information may need to be presented in different forms depending on people's levels of cognitive impairment:

Both researchers and ethics committees should adapt the informing process in a way to enable, rather than to exclude, people with dementia in making a valid decision as to whether or not to participate in research.<sup>13</sup>

The establishment in December 2012 of the single regulator, the Health Research Authority (HRA), aimed at streamlining the regulatory process, should help to resolve some of these issues. It is hoped that the complications peculiar to dementia research will be taken into account, particularly as the HRA implements its 'comprehensive plan for effective patient and public involvement'.<sup>14</sup>

The growing importance of tissue-based research is also emphasised by many respondents:

After 20 years or so of trying (generally unsuccessfully) to get answers from animal studies and *in vitro* systems there is better understanding that the tissues from humans suffering from these diseases (and controls) will provide the key, but it will only be realised if there is increased funding for tissue-based research. Cancer research has benefited from 20-30 years of tissue-based research which has led to the understanding needed to produce effective therapies. There will only be effective therapies for neurodegeneration when there has been an opportunity for similar in-depth tissue-based research, to be carried out, building on the progress that has been made in understanding the genetics (Prof Margaret Esiri, University of Oxford).

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13 Dementia: ethical issues, Nuffield Council on Bioethics, Oct. 2009.

14 'Summary Plan of Activity, Dec. 2011-March 2012', Health Research Authority, Dec. 2011.

One barrier is that of accessing post-mortem brain tissue due to infrastructural gaps in the system:

As a neuropathologist, a key issue is access to tissue for research for the broader research community. There are already initiatives in this area, but there can be difficulty with funding for ad hoc research autopsies of individuals wishing to donate locally. We also need to encourage donation from individuals without dementia for control brain (and spinal cord) tissue (Dr Stephen Wharton, University of Sheffield).

Brain banks are a crucial area of research support, but at present they are funded on an ad hoc basis by charities and the MRC. NHS infrastructure support is inconsistent and there is a gap in infrastructural support for recruiting donors, obtaining consent, body transport, autopsy and the primary diagnostic evaluation of the brain. This was raised at a meeting of MAGDR and passed for consideration to DeNDroN, but has yet to be resolved. The expansion of research could lead to demands on brain banks that cannot be met, such as increases in donations that might have to be refused – causing a great deal of distress to families – and the unfulfilled needs of researchers. This too has important implications for capacity and needs to be addressed.

## Recommendations

13. New efforts by the Government to streamline the regulatory process are an ideal opportunity to address the difficulties in carrying out dementia research, which is a research priority. Current delays in getting ethics approval, as well as the difficulties of accessing patient data and undertaking studies with dementia patients, restrict capacity.
14. As the importance of tissue-based research grows, more consistent infrastructural support is needed to address the gaps in procedures for brain donation.

'Bureaucracy  
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in patients.'

# 4. Conclusion

Dementia is a research priority. Now that we have recognised this, we have to increase our capacity in the field. We accept that this cannot be done overnight but, given the scale of the problem, we have a responsibility to capitalise on our strengths and address the issues that are holding us back.

The evidence presented in this report demonstrates that UK dementia research is in a strong position to effectively address the crisis we face. The bibliometric data provided by *Evidence* show that in terms of our share of global research output and its citation impact, we are punching well above our weight. Still, capacity in terms of numbers of researchers in the field is low. In terms of our ability to take forward new discoveries and fulfil our outstanding potential, a number of barriers stand in our way.

Commitment, ideas and research quality are not the issue. Underinvestment and the lack of a cohesive national research strategy to defeat dementia are. It is not surprising that most of the concerns highlighted by the researchers we surveyed relate to the need for much more funding. Some, however, point to the need for strategic planning and reorganisation. When diseases reach a crisis point like dementia, and threaten to get worse, the barriers and gaps in the existing structures we have to tackle them are thrown into relief. Changes then need to be made. Focused funding to build, retain and perpetuate a workforce of sufficient critical mass is a case in point. So is the need to adapt regulatory procedures. Continuity, momentum and collaboration are key, particularly when there is still so much more to know.

At a time of economic hardship and severe restraints on spending, the obvious response is that there is no money. But if we don't find ways to invest in this now, there will be even less money later because of the increasingly huge amounts that will be needed for care. We also risk squandering the expertise and knowledge that we have built up if we don't harness it and ensure it is passed on to future generations of scientists.

While research uncovers new avenues of hope every day, we have to take a structured, concerted and long-term approach. Rather than being a one-off, dedicated funding initiatives need to continue and grow. The history of cancer research is evidence of this. It is also evidence that research can, step by step, tackle seemingly undefeatable chronic disease. UK dementia scientists are doing excellent work. With financial backing more proportionate to the scale of the problem, and strategic support to maximise productivity, they could do even better. This is not an aspiration, it is a necessity – and the only real hope for people affected by this devastating disease, now and in the future.

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# Glossary of terms and acronyms

**BBSRC:** The Biotechnology and Biological Sciences Research Council is funded by the Government's Department for Business, Innovation and Skills (BIS). BBSRC's budget for 2011-12 is around £445M. It supports a total of around 1600 scientists and 2000 research students in universities and institutes in the UK.

**CHD:** Coronary heart disease.

**DeNDroN:** The Dementias and Neurodegenerative Diseases Research Network is one of six topic-specific Clinical Research Networks funded by the National Institute for Health Research in England. It was created to support the development and delivery of randomised prospective trials and other clinical studies in the dementias, Parkinson's disease, motor neurone disease, Huntington's disease and other neurodegenerative diseases.

**MAGDR:** The Ministerial Advisory Group for Dementia Research was established in February 2010 to consider ways to increase the volume and impact of high quality dementia research. The aim was to build on the momentum begun at the earlier Ministerial Summit on Dementia Research in 2009. Comprising scientists, representatives of funding bodies, charities (including ARUK) and industry, as well as people with experience of dementia, MAGDR published its Headline Report and Route Map for Dementia Research in June 2011.

**MD:** Doctor of Medicine.

**MRC:** The Medical Research Council is a publicly funded organisation that receives annual 'grant-in-aid' funding from Parliament through the Department for Business, Innovation and Skills (BIS). To achieve its mission of improving human health through world-class medical research it supports research across the biomedical spectrum, from fundamental laboratory-based science to clinical trials, in all major disease areas.

**NCRI:** The National Cancer Research Institute is a UK-wide partnership between the Government, charity and industry which promotes co-operation in cancer research

among the 22 member organisations for the benefit of patients, the public and the scientific community.

**NIHR:** The National Institute for Health Research provides the framework through which the Department of Health can position, maintain and manage the research, research staff and research infrastructure of the NHS in England as a national research facility.

**Normalised Citation Impact:** To account for variations in citation rate between research field and year, absolute citation count is normalised to the average number of citations for that field along with the average number of citations in that year worldwide. This information can be presented in relation to a five-year moving mean to smooth out fluctuations in citation rate across a five-year period.

**PI:** The principal investigator in biomedical research is the person who directs a research project or program. The PI usually writes and submits the grant application, oversees the scientific and technical aspects of the grant, and has responsibility for the management of the research.

**Postdoc:** A postdoctoral researcher is usually a researcher who has completed their PhD and has not yet secured either a faculty position or their own independent source of funding. Postdocs form the bedrock of experimental science but the limitations of short-term contracts and an uncertain career path for the majority is a real cause for concern.

**REF:** The Research Excellence Framework is the new system for assessing the quality of research in UK highereducation institutions. It will replace the Research Assessment Exercise (RAE) and will be completed in 2014.

**Senior Research Fellowship:** This can be a standalone, fixed-term grant (very often from charities or Government funding agencies) to individual postdoctoral researchers who have already demonstrated some independent research success. It can also be used to describe certain faculty or college-funded positions for academics who may already be firmly established in their careers.

## Acknowledgements

This report was written and the research coordinated by Munizha Ahmad-Cooke, with input from Dr Simon Ridley and Dr Laura Phipps. It was informed by research carried out by *Evidence*, a business of Thomson Reuters, questionnaire responses and interviews from researchers working in the dementia field. Alzheimer's Research UK would like to thank Dr Karen Gurney at *Evidence*, the 120 researchers who took time to respond to the questionnaire, and those who contributed in person: Professors John Hardy, Julie Williams and Simon Lovestone, and Dr Selina Wray.

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# Alzheimer's Research UK

Defeating Dementia

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