

# A Review of the Dementia Research Landscape and Workforce Capacity in the United Kingdom

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\* RAND Europe    + Science Metrix



This research was funded by the Alzheimer's Society



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For more information on this publication, visit [www.rand.org/t/rr1186](http://www.rand.org/t/rr1186)

Published by the RAND Corporation, Santa Monica, Calif., and Cambridge, UK

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RR-1186-AlzSoc



## Preface

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The report presents an independent review of the United Kingdom's capacity in dementia research. The study had two core aims: (i) to improve understanding of the strengths and limitations of the UK dementia research landscape, and (ii) to examine the opportunities and challenges associated with dementia research careers in the United Kingdom, including key bottlenecks in the careers of researchers. The work was commissioned by the Alzheimer's Society to help develop a blueprint for investing in research capacity-building in dementia. The research was carried out by RAND Europe in collaboration with Science Metrix.

We used three key methods to inform our research: (i) a bibliometric analysis of UK dementia research using publication data to assess research performance vis-à-vis global benchmarks, based on citation impact; (ii) a pilot investigation tracing the current position of people who have completed their PhDs in a dementia-related topic in the UK in order to gain an estimate of retention and to provide proxies for the composition and profile of the current dementia research workforce; (iii) in-depth interviews with diverse stakeholders to investigate the strengths and gaps within UK dementia research and

the research workforce in more depth, in order to help inform investment priorities for capacity-building.

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## Acknowledgements

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The authors would like to thank the Alzheimer's Society for their supportive involvement in the project, especially James Pickett and Clare Walton.

We would also like to extend our thanks to the British Library for providing us with source data for our PhD-tracing exercise, and in particular to Heather Rosie for all her assistance.

We are grateful for the excellent design input from Jessica Plumridge and for the research support provided

by Dylan Marshall and Katherine Stewart from RAND Europe. We are also grateful to RAND Europe's David Kryl and Jirka Taylor for their constructive guidance through their quality-assurance roles.

Finally, and not least, the authors would like to acknowledge all the study participants who gave us their time and who provided valuable information for this project.



## Abbreviations

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<b>AHP</b>	Allied health professions
<b>ARC</b>	Average of Relative Citations
<b>BRU</b>	Biomedical Research Unit
<b>BSCT</b>	Basic Science Career Tracker
<b>CADASIL</b>	Cerebral Autosomal-Dominant Arteriopathy with Subcortical Infarcts and Leukoencephalopathy
<b>CCT</b>	Clinical Career Tracker
<b>CHD</b>	Coronary heart disease
<b>CLAHRC</b>	Collaborations for Leadership in Applied Health Research and Care
<b>CoEN</b>	Centres of Excellence Network in Neurodegeneration
<b>ESRC</b>	Economic and Social Research Council
<b>HCP</b>	Highly cited paper
<b>HESA</b>	Higher Education Statistics Agency
<b>INT</b>	Interview
<b>JPND</b>	Neurodegenerative Disease Research Joint Programme
<b>MRC</b>	Medical Research Council
<b>NHS</b>	National Health Service
<b>NIHR</b>	National Institute for Health Research
<b>R&amp;D</b>	Research & Development
<b>REF</b>	Research Excellence Framework
<b>WoS</b>	Web of Science



## Summary

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### Background and Context

This report presents the findings from an independent review of the United Kingdom's capacity in dementia research. The review was commissioned by the Alzheimer's Society and led by RAND Europe in collaboration with Science Metrix. The research had two core objectives: (i) to improve understanding of the strengths and limitations of the UK dementia research landscape; and (ii) to examine the opportunities and challenges associated with dementia research careers in the UK, including key bottlenecks in the careers of researchers. The work aims to help develop a blueprint for research capacity-building in dementia.

### Study design and methods

The study design and methods involved three key elements. The first was a bibliometric analysis of UK dementia research using publication data to assess research performance *vis-à-vis* global benchmarks, based on citation impact. Secondly, we traced the current position of people who have completed their PhDs in a dementia topic in the UK in order to gain an estimate of retention and to provide proxies for the composition and profile of the current dementia research workforce.<sup>1</sup> Finally, we carried out a qualitative assessment of the strengths of, and gaps within, UK dementia research and the research workforce in order to explore investment priorities for capacity-building. We conducted 40 interviews with stakeholders from research, policy, health practitioner, private sector and

funder communities, including representatives at different career stages and from diverse fields. Our findings have been interpreted within the context of wider knowledge about dementia research and science policy. Below, we present the key insights from each of the three elements of our study. An extended summary is also available.

### Highlights from the bibliometric analysis

The UK was second in the world in terms of the amount of dementia research it generated in the period 1980–2013, measured by the number of journal publications. This suggests that the UK punches above its weight in terms of publication outputs, given investment levels – a suggestion which is in line with observations about UK research more widely.<sup>2</sup> The majority of UK dementia publications (60.5%) are about Alzheimer's disease. Research on other types of dementia diseases individually accounts for between 0.1% and 6.1% of overall UK outputs and includes research on mixed dementia, Lewy body dementia, vascular cognitive impairment, frontotemporal dementia, and other classifications such as mild cognitive impairment, early-onset dementia and familial dementia.

A total of 67% of all UK dementia papers are in the field of clinical medicine, with the next two most prolific disciplines being<sup>3</sup> neurology and neurosurgery, and geriatrics.<sup>4</sup> There is comparatively very little research taking place in some subfields which are potentially

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<sup>1</sup> This was a scoping exercise, and we did not examine the attraction of researchers from other fields or other countries to UK dementia research.

<sup>2</sup> See for example Elsevier (2013).

<sup>3</sup> Over two thirds of UK dementia publications are in journals from the clinical medicine field. Dementia is a multidisciplinary research area and involves diverse fields and subfields of research. In journal databases, all papers are classified into specific fields and subfields according to categories based on the topics of research and disciplinary lenses used.

<sup>4</sup> 34.9% and 13.9% of all UK dementia papers respectively.

relevant, such as health policy and services, speech-language pathology and audiology, and nursing.<sup>5</sup>

UK dementia publications are influential: the vast majority of UK dementia research has higher scientific impact than the world average impact for a specific type of dementia disease. Compared to the 29 other most publishing countries, the UK ranks seventh for the citation performance of its entire portfolio (i.e. covering all types of dementia research) and ninth in terms of the percentage of particularly highly cited papers (i.e. those belonging to the top 10% of all papers globally in terms of citations). Most dementia disease research areas have pockets of excellence, indicated by a greater than expected percentage of highly cited papers. For the most prolific research area – Alzheimer’s disease – the citation performance of UK Alzheimer’s disease publications is only slightly above world average when the entire portfolio is considered. However, there is a subset of highly influential UK research outputs in Alzheimer’s disease, as indicated by a high percentage of highly cited papers. UK Lewy body dementia and frontotemporal dementia research also have a particularly high percentage of highly cited papers, with other pockets of research excellence in vascular dementia, small vessel disease, primary progressive aphasia and mild cognitive impairment research. The entire portfolio of UK research on CADASIL (Cerebral Autosomal-Dominant Arteriopathy with Subcortical Infarcts and Leukoencephalopathy, a rare inherited subtype of vascular cognitive impairment) stands out in terms of citation impact.

In contrast, there seems to be scope for improving the impact of UK research on familial and early-onset dementia, where the UK lags behind world averages for citation impact. Interviewees said that the key reasons for this include challenges to diagnosis, patient-recruitment challenges, the disjointed nature of service delivery for such patients, and competition between various clinical specialties for patient recruitment.

The most influential UK dementia papers (in terms of citations) are in the subfields of medicinal and biomolecular chemistry, and pharmacology and pharmacy. There are also notable pockets of excellence in

the subfields of general and internal medicine, nuclear medicine and medical imaging, and pathology. Some of the more prolific subfields in terms of publication volumes (e.g. neurology and neurosurgery) as well as some fields where publishing volumes are relatively low (e.g. genetics and heredity) also have a higher than expected percentage of highly cited papers, although not quite as high as the most influential subfields. The lowest-impact subfields associated with UK dementia research include epidemiology, speech-language pathology and audiology, virology (e.g. in the context of possible co-morbidities or links between viruses and dementia), pathology and biophysics.

### Highlights from the investigation of career pathways of UK dementia PhD graduates

At least a fifth (21%) of dementia PhD graduates remain in dementia research careers. A higher-end estimate would be 38%, while 43% of dementia PhD graduates remain in research careers (in dementia or other areas)<sup>6</sup> and just under half (48%) of those who remain in research continue to do research on dementia-related topics. A very small minority of dementia PhD graduates (0.6–1%) remain active in dementia-related activity but not research (e.g. careers in industry and care). A quarter (25%) of currently active dementia researchers who obtained a PhD in the UK are currently based in other countries including the USA, Canada, Germany and Australia. There are approximately twice as many junior and mid-level staff as senior staff in the UK dementia research workforce (2.3:1 ratio). This ratio broadly mirrors the mix of career stages observed in the biological sciences and subjects allied to medicine, but is somewhat higher than the ratio observed in the fields of medicine and dentistry.<sup>7</sup>

### Insights from interviews

We spoke to representatives at different stages in their careers and from diverse fields. Interviewee responses tended to reflect the areas of work with which they were more familiar, and their own professional

<sup>5</sup> Health policy and services (0.43% of the overall UK dementia research portfolio), speech-language pathology and audiology (0.27% of the portfolio), and nursing (1.2% of the overall portfolio).

<sup>6</sup> This is similar to the findings of the Royal Society investigation on researcher retention in science, which found that 47% of UK PhD science graduates remain in scientific careers.

<sup>7</sup> We analysed data requested from HESA (<https://www.hesa.ac.uk>) 2015. More detail is given in Chapter 4.

experiences. When reporting on research gaps in particular, respondents tended to comment primarily on limitations within their own research field. However, when commenting on research strengths, interviewees frequently highlighted strengths in areas other than their own. Overall, we are confident we obtained a rounded evidence base across the diversity of individuals interviewed.

### Strengths and limitations of the UK dementia research landscape

The UK dementia research portfolio is diverse, and the following strengths were most frequently highlighted: (i) dementia-related genetics research to advance knowledge of dementia disease-risk, for example in Alzheimer's and Parkinson's diseases; (ii) brain-imaging to provide evidence on disease progression; (iii) research on Lewy body dementia; (iv) research into the development of person-centred care; (v) epidemiological work with cohort studies; and (vi) research on the amyloid hypothesis and amyloid fibril formation.<sup>8,9</sup>

Interviewees also highlighted various gaps in knowledge about dementia and limitations in the UK research landscape. Some of these reflect global knowledge gaps (e.g. insights into cellular mechanisms in dementia, classification of dementia disease) or general challenges in biomedical research which may be accentuated in the dementia context (e.g. the challenges of engaging clinicians in research and translating research into practice), whilst others were highlighted as particularly notable in a UK context and in dementia research policy (e.g. a lack of critical mass in care-related dementia research, limited industry engagement, and insufficient focus on specific rarer dementias).

The most frequently identified gaps in the UK dementia research system were: (i) *a limited understanding of the cellular mechanisms that underlie dementia*; (ii) *insufficient clinician involvement in research*; (iii) *underinvestment in care-related research* (e.g. in nursing, allied health professions and social-care fields); (iv) *scope for*

*improvement in the conduct of clinical trials* (recruitment processes, incentives for clinicians to enrol patients, the accuracy of diagnosis, industry engagement); (v) *limited industry participation across diverse research and innovation challenges* (drug-discovery efforts, the development of medical apps and assistive-living technologies); and (vi) *insufficient focus on translational research*.<sup>10</sup> Most interviewees were in favour of balancing research investments across different types of dementia disease areas and across basic, applied and clinical research. Some, however, highlighted the potential benefits of more targeted strategies. Views on the balance of support related to prevention, treatment and care delivery were very mixed, reflecting individual professional experiences.

### Bottlenecks in the career pathway and barriers to dementia research careers

Many of the challenges to research careers in dementia and to building capacity in the research workforce apply to research careers in the UK more widely, but are accentuated in the dementia context. Dementia faces a comparative scarcity of funding vis-à-vis areas like cancer and is seen, in some disciplines, as a less attractive area of specialisation. There is a perceived need for more awareness-raising about dementia research opportunities, and for an attitude shift away from the view that little can be done about dementia towards a more positive outlook which celebrates milestones and prospects.

The lack of a secure career path is widely seen as the key challenge for those considering dementia research careers and for workforce capacity-building in the UK. This is linked to the prevalence of short-term research funding and a lack of permanent academic positions (e.g. lectureships) and fellowships for researchers who are ready to gain independence and establish their own projects, programmes and groups. Consistent with these concerns, interviewees widely saw the transition from a postdoctoral role to a lecturer role as the biggest career bottleneck, with the transition from a

<sup>8</sup> Epidemiological work with cohort studies and research on the amyloid hypothesis and amyloid fibril formation were both mentioned by five interviewees and hence share fifth place as most commonly mentioned strengths.

<sup>9</sup> Although mentioned less frequently, interviewees also noted examples of influential UK research across a broader array of dementia-related topics, including in: frontotemporal dementia; mixed dementia; work covering links between amyotrophic lateral sclerosis (ALS) and dementia, and Parkinson's disease and dementia; biomarkers; cognitive stimulation studies; research into interventions to improve the lives of those affected; work on early diagnosis; the development of clinical centres for dementia care; tau protein pathology studies; research into the clinical definition and classification of dementia; brain banks and neuropathology.

<sup>10</sup> Although mentioned less frequently or with mixed views, other research gaps identified by interviewees included large-scale cohort studies, improved animal models and combined human and animal work, and rare diseases.

PhD or clinical training to the first postdoctoral or clinical research position coming second. In the allied health professions and social care, a particular lack of junior-level studentships and fellowships (PhD and first postdoc) was identified. Barriers to clinical research careers in dementia are particularly high and relate to (i) a lack of time to combine research and clinical duties; (ii) a perception held by some clinicians that they are undervalued by universities due to challenges in meeting publishing and grant expectations in parallel with delivering clinical care; (iii) clinical career structures that make it difficult to engage with research and a prevailing – though gradually evolving – clinical culture where research is undervalued; (iv) the short-term nature of research contracts for clinical and allied health professions staff; and (v) insufficient attention to research training in medical education curricula. In addition, dementia as a field is not widely seen as the most attractive research area for clinicians.

Various examples of mechanisms that exist or are needed to support dementia research careers were identified by interviewees, who reinforced the need for a mix of interventions focused on individuals, teams and networks. The majority of such interventions relate to providing longer-term funding and improved job security, early- and mid-career research support and enhanced collaboration across fields, disciplines, sectors and institutions. Key examples are: (i) junior research fellowships, including ‘bridge-funding’ post PhD; (ii) mid-career research fellowships and lectureships; (iii) fellowships for clinicians, and more flexible employment arrangements to enable research activity for healthcare professionals; (iv) support focused specifically on developing mid-career researchers as future leaders (i.e. awards which combine professional skill development with research support and funding for the establishment of teams); and (v) institutions with long-term funding which can attract and bring together interdisciplinary talent from diverse fields and sectors (i.e. dedicated research centres and institutes or collaborations between organisations). Other existing enablers of dementia research where capacity could be enhanced

include professional skill development, generating interest in dementia and career flexibility.

The dementia research community welcomed enhanced national and global commitment to research in this area, but emphasised a need for (i) transparency in the strategy for allocating funding; (ii) some coordination between funders, but not at the expense of supporting diverse research; (iii) ensuring the long-term sustainability of the commitment to dementia research and redressing the still substantial imbalance between the burden of dementia disease and research investment, compared to some other disease areas.

## Conclusion

Our findings suggest that the UK has already displayed global leadership in diverse areas of dementia research. It is producing influential outputs, and is likely to be punching above its weight in many dementia research topics, given investment levels. However, there are also substantial challenges that need to be addressed to help nurture a sustainable and vibrant dementia research workforce, and international excellence in UK dementia research. Addressing research gaps and workforce capacity issues through an evidence-based strategy at national and organisational levels should help increase the impact of UK dementia research on the lives of all those affected. Renewing the leadership of the future will require attention to workforce and succession planning at present.

The findings discussed above, recommendations from interviewees, and our wider experience in science policy lead us to propose ten areas for action that could help support dementia research initiatives and dementia research careers going forward. These are summarised in Box 1 below. Our intention is not to be prescriptive. Rather, we present ten key policy considerations which aim to encourage further constructive dialogue and the exchange of ideas on the next steps for dementia research and research workforce capacity-building in the UK. Some of these insights are likely to also have international relevance.

**Box 1. Areas for policy action****Actions to support individuals**

1. **Consider scaling up existing schemes and introducing mechanisms to tackle bottlenecks in the transition from a postdoctoral position to independent investigator and lecturer posts:** Examples include (i) dementia-specific fellowships to support first PI roles; (ii) 'rising star' funding programmes for researchers with high potential that help towards establishing small research teams around a mid-career researcher as PI; (iii) training in leadership skills.
2. **Consider ways to increase the feed of future talent and to address bottlenecks in the transition from PhD to postdoc.** Examples include (i) dementia doctoral training centre schemes where investigators can apply for multiple dementia PhD studentships around a single bid; (ii) ring-fenced PhD studentships for dementia; and (iii) extensions to PhD studentships and bridge-funding to help new graduates develop ideas and find new posts.
3. **Reflect on the specific research career needs of distinct stakeholder groups.** In the context of clinician-researcher opportunities, this includes funders engaging in (i) advocacy activities to raise the profile of dementia research in the health service; (ii) dialogue with higher education institutions about selection criteria for clinician and allied health profession research fellowships and around research training in medical education criteria; and (iii) some allied health professions, nursing and social work where early career-stage fellowships may be particularly lacking.
4. **Support professional skill development:** (e.g. leadership, communication, dissemination, project management and writing effective grant applications). Current research leaders devote substantial effort to mentoring mid and early-career staff in leadership skills, but there are competing demands on their time. Coupling on-the-job learning with formal training programmes could enable more sustainable and consistent approaches to leadership development.

**Actions to support institutions and networks**

5. **Consider the long-term sustainability of existing dementia research centres, networks and partnerships, the legacy they wish to leave and succession planning.** Dementia research centres, partnerships and networks should think about and articulate a sustainability plan and legacy agenda early on in their existence. Given the importance of leadership in dementia research efforts, succession planning for key individuals and strategies for attracting and retaining long-term funding and the best talent from across diverse fields are important agendas to tackle.
6. **Establish mechanisms to attract researchers from diverse fields to collaborative and interdisciplinary dementia research efforts (i.e. to research teams and networks) to support interdisciplinary collaboration:** Examples include (i) joint grants for partnerships between dementia and non-dementia researchers; (ii) cross-disciplinary, problem-driven rather than discipline-driven studentships and fellowships; (iii) strong clinical leadership to help attract researchers from different fields; (iv) dementia-themed funding calls and prizes.

**Actions to inform prioritisation in research portfolios and wider research system issues**

7. **Consider the balance of diseases supported in a dementia research strategy:** More specifically, reflect on whether areas of current UK research strength but lower volume of research activity, as well as areas where the UK lags behind global averages impact-wise, merit more targeted and scaled-up support.
8. **Reflect on the balance of basic, applied and clinical, and health-services research in a dementia portfolio and the degree of emphasis on prevention, treatment and care-related research.**
9. **Reflect on coordination between different funding initiatives and funders,** to ensure that risks to duplication are minimised but that diversity and out-of-the-box thinking is supported.

**Other recommendations: learning from evaluation**

10. **Learn from evaluation of current and prior investments into dementia research capacity-building, and from the experiences of other fields, to improve the cost-efficiency, effectiveness and sustainability of dementia research capacity investments.** Key areas for learning are (i) evaluation of existing UK dementia-specific fellowship schemes and initiatives; (ii) comparative studies of international experiences with capacity-building schemes; (iii) learning from case-studies of effective Patient and Public Involvement (PPI) in dementia research; and (iv) tackling research ethics-related barriers; (v) Informing research workforce and succession planning: through transferrable learning from other areas.



## Chapter 1 Introduction

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### 1.1. Aims and objectives of the research

The report presents an independent review of the United Kingdom's capacity in dementia research, commissioned by the Alzheimer's Society. The research had two core aims:

1. To better understand the strengths and limitations of the UK dementia research landscape.
2. To examine the opportunities and challenges associated with dementia research careers in the UK, including key bottlenecks in the careers of researchers.

The work was commissioned by the Alzheimer's Society to help inform a blueprint for investing in research capacity-building in dementia. The work was carried out by RAND Europe, in collaboration with Science Metrix.

### 1.2. Background and context: the UK dementia research environment

The Global Observatory for Ageing and Dementia Care has predicted that the number of people with dementia worldwide will rise from 36 million in 2010 to 115 million in 2050.<sup>11</sup> Building on these estimates, governments at the 2013 G8 Dementia Summit reassessed and strengthened their commitment to invest in dementia research to improve the quality of care and prevention, find effective treatments, speed up the research translation process, and ultimately reduce the economic

and social burden associated with dementia. In the UK, approximately 800,000 people are estimated to be living with the condition, at a projected annual cost of £23 billion to the country's economy.<sup>12</sup> Actual figures are likely to be higher due to challenges to early diagnosis and a limited understanding of the diversity of disease subtypes that constitute dementia. It is expected that the number of people affected will double over the next 25 years, and that the costs of dementia to the UK economy and society will treble.<sup>13</sup>

The UK government has therefore identified dementia as a research and innovation priority, with Prime Minister David Cameron stating in 2012 that dementia amounts to a national crisis and should be treated as such.<sup>14</sup> At the heart of this increased commitment is the Prime Minister's Challenge on Dementia, which set a target of doubling UK spending on dementia research – from the public, private and charitable sectors together – by 2015. Below we outline the key research-related initiatives stemming from the Prime Minister's Challenge, along with those driven by other actors.

Both the government and dementia charities have acknowledged that improved research capacity and a sustainable research workforce must lie at the heart of UK's efforts to combat the disease.<sup>15,16</sup> This applies to diverse types of research and researchers in both the natural and social sciences and across sectors (academia, research institutes, clinical services and the allied health professions, and industry). UK-based dementia charities have long argued that the level of research funding

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<sup>11</sup> Alzheimer's Disease International (2013), p.2.

<sup>12</sup> Department of Health (2015a).

<sup>13</sup> Department of Health (2015a).

<sup>14</sup> Department of Health (2012).

<sup>15</sup> Department of Health (2015b).

<sup>16</sup> See for example Alzheimer's Society (2014a); Alzheimer's Research UK (2015a).

dedicated to dementia does not reflect the scale of the problem, and that it is neglected in comparison with disease areas such as cancer and heart disease.<sup>17</sup> Research by the Alzheimer's Society found that there were only 125 ongoing clinical trials in the dementia field in 2013, compared to 454 related to heart disease and 5,755 for cancer.<sup>18</sup> According to the Alzheimer's Society, total UK spending on cancer research for 2012/13 was £503 million – nearly seven times the amount invested in dementia research in the same period.<sup>19</sup> This spending gap is disproportionate to the comparative burden of these diseases on UK populations. Alzheimer's Research UK states that for every £1 million spent on dementia-related health and social care costs, the UK invests less than £20,000 in dementia research, while for cancer that figure is close to £140,000.<sup>20</sup> In a global context, the Alzheimer's Society estimates UK government and charitable spending on dementia research to be £73.8 million annually, compared to a US federal budget of £415 million<sup>21</sup> but the UK is likely to be 'punching above its weight' in terms of research outputs (discussed further in Chapter 3 of this report).<sup>22</sup>

With a view to redressing this imbalance, the government increased its spending on dementia research from £28.2 million in 2009/10 to £60.2 million in 2013/14.<sup>23</sup> The majority of this investment is being channelled through the National Institute for Health Research (NIHR) and the MRC, in collaboration with other partners. For example, the NIHR is providing £36 million for the Dementia Translational Research Collaboration.<sup>24</sup> NIHR funding has also supported the appointment of a National Director for Dementia

Research, and the NIHR has partnered with the Economic and Social Research Council (ESRC) on £20 million worth of joint research grants for research on the quality of life in dementia.<sup>25</sup> The government has also sought to partner with other funders, for example on the MRC-led Dementias Platform UK, a £53 million public-private partnership designed to facilitate collaborative research among its partner organisations.<sup>26</sup>

Charities continue to play a significant role, having contributed 28.3% of UK dementia research funding in 2012/13.<sup>27</sup> The Alzheimer's Society and Alzheimer's Research UK are the two largest UK charitable funders,<sup>28</sup> while other organisations also make contributions to dementia research and the training of dementia researchers. These include funders focusing specifically on dementia (e.g. Alzheimer Scotland and the Lewy Body Society) as well as those focusing on related conditions and fields of research (e.g. Age UK, the Brain Research Trust, the BUPA UK Foundation, the Motor Neurone Disease Association and Parkinson's UK).<sup>29</sup> Both the Alzheimer's Society and Alzheimer's Research UK are in the top five dementia research charities worldwide in terms of the number of studies conducted and papers published with their support.<sup>30</sup> The other three key not-for-profit players, all of which are based in the USA, are the Alzheimer's Association, the Michael J. Fox Foundation and the Mayo Foundation.<sup>31</sup>

Improving the UK's dementia research *workforce* is also a key element of the government's action on dementia. Specifically, the Prime Minister's Challenge on Dementia 2020, published in February 2015, included a commitment to fostering 'a motivated and inspired

<sup>17</sup> See for example Alzheimer's Society (2014b); Alzheimer's Research UK (2015d).

<sup>18</sup> Alzheimer's Society (2014b), p.47.

<sup>19</sup> Alzheimer's Society (2014b).

<sup>20</sup> Alzheimer's Research UK (2015f).

<sup>21</sup> \$640 million (US), exchange rates correct as of 27 February 2015. Source: personal Communication with Head of Research, Alzheimer's Society.

<sup>22</sup> UK dementia research papers account for 12% of global outputs, as discussed in Chapter 3 of this report. When compared, US spending is 5.6 times higher than UK spending and US research outputs (using publications as a proxy) are only 3.6 times higher, suggesting that the UK punches above its weight. (Source: personal communication with Head of Research, Alzheimer's Society.)

<sup>23</sup> Department of Health (2015b), p.18.

<sup>24</sup> National Institute for Health Research (2014).

<sup>25</sup> National Institute for Health Research (2015a).

<sup>26</sup> Dementias Platform UK (2015).

<sup>27</sup> Alzheimer's Society (2014b), p.50.

<sup>28</sup> Alzheimer's Research UK (2015e).

<sup>29</sup> Alzheimer's Research UK (2015e).

<sup>30</sup> Alzheimer's Research UK (2015e).

<sup>31</sup> Alzheimer's Research UK (2015e).

workforce supported by a clear career pathway'.<sup>32</sup> This includes research units funded by the Medical Research Council (MRC) which aim to attract, develop and retain dementia researchers.<sup>33</sup>

Initiatives targeting the dementia research workforce have so far been led by charities. Key charities in the dementia research field are also aiming to tackle workforce challenges, and specifically bottlenecks in career pathways. For example, the Alzheimer's Society and Alzheimer's Research UK both offer senior research fellowships, which are designed to support postdoctoral researchers in establishing themselves as principal investigators.<sup>34</sup> Both schemes provide funding to cover salaries for the fellow and their support staff, as well as running costs for their research. Schemes which aim to attract researchers to dementia at earlier stages of their careers have also recently been introduced. For example, since 2014 the Alzheimer's Society has provided funding for the establishment of eight dementia-focused doctoral training centres,<sup>35</sup> while both the Alzheimer's Society and Alzheimer's Research UK fund PhD studentships.<sup>36</sup> At the postdoctoral level, the Alzheimer's Society also offers junior fellowships to support research projects by recent doctoral graduates.<sup>37</sup>

A small number of additional initiatives provide pathways for clinicians looking to move into dementia research – an area in which interviewees identified a lack of opportunities.<sup>38</sup> The Alzheimer's Society Clinical and Healthcare Professionals Training Fellowships and Alzheimer's Research UK's Preparatory Clinical Research Fellowships provide clinical professionals with funding to complete a higher research degree (usually a PhD) while continuing their clinical practice.<sup>39</sup> In addition, the NIHR Collaborations for Leadership in Applied Health Research and Care (CLAHRCs) are leading the Research Capacity in Dementia Care Programme, which aims to train nurses, social care and allied health professionals to conduct dementia research.<sup>40</sup>

Despite growing interest and commitment from diverse stakeholders, significant challenges and unknowns persist in relation to mobilising additional and sustained funding for dementia research, and developing fit-for-purpose strategies for research capacity and workforce capacity development looking forward. It is equally vital that existing resources be allocated effectively, considering the scientific and social complexity of dementia, building on existing strengths and targeting research gaps.

It is against this background that the Alzheimer's Society commissioned RAND Europe, in collaboration with Science Metrix, to conduct an independent review of the UK's capacity in dementia research, to help inform a blueprint for investing in research and workforce capacity-building in this space. The insights obtained aim to be informative for the Alzheimer's Society, the wider stakeholder landscape and national policy.

### 1.3. Structure of the report

The current chapter (Chapter 1) presents the study aims and objectives and places these in a wider background and context. Chapter 2 describes the study design and methods, including associated caveats. Chapter 3 presents the findings of a bibliometric analysis of UK dementia research, which used publication data to assess research performance vis-à-vis global benchmarks, based on citation impact. Chapter 4 shares findings from a pilot investigation which traced the current position of people who completed their PhDs in a dementia field in the UK, to get an estimate of retention and to provide proxies for the composition and profile of the current dementia research workforce. Chapters 5 and 6 present the findings from a series of interviews with diverse stakeholders. The interviews were informed by the previous analyses and aimed to enrich knowledge about the UK dementia research landscape and workforce, including the strengths, gaps and capacity-building priorities for the future. Chapter

<sup>32</sup> Department of Health (2015b), p.37.

<sup>33</sup> Department of Health (2015b), p.19.

<sup>34</sup> Alzheimer's Society (2015a); Alzheimer's Research UK (2015b).

<sup>35</sup> Alzheimer's Society (2014c).

<sup>36</sup> Alzheimer's Society (2015b); Alzheimer's Research UK (2015c).

<sup>37</sup> Alzheimer's Society (2015c).

<sup>38</sup> See Chapter 5.

<sup>39</sup> Alzheimer's Society (2015d); Alzheimer's Research UK (2015g).

<sup>40</sup> National Institute for Health Research (2015a).

5 presents findings from interviews that relate specifically to the research landscape, while Chapter 6 discusses insights on workforce capacity issues. Chapter 7

reflects on the previous streams of evidence, and concludes with a focused set of capacity-building issues to consider in a future policy agenda.

## Chapter 2 Study design and methods

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### 2.1. Study design: an overview

As discussed in Chapter 1, this research aimed to address important gaps in dementia science policy by enriching the evidence base on the UK dementia research landscape and on research workforce capacity. To do so, the study drew on three key methodologies:

1. ***A bibliometric analysis of UK dementia research:*** to examine the landscape, including the fields and topics where UK researchers are active and the UK's academic impact in terms of citation performance, vis-à-vis global benchmarks. The analysis also provided an indication of how collaborative, specialised<sup>41</sup> and multidisciplinary UK dementia research is.
2. ***A pilot investigation which traced the current position of people who completed their PhDs in a dementia field, in the UK:*** to get an estimate of retention and to provide proxies for the composition and profile of the current dementia research workforce. It is important to highlight that this was a scoping exercise and that we did not examine the attraction of researchers from other fields or countries to UK dementia research.
3. ***A qualitative assessment of the strengths and gaps of UK dementia research and of the research workforce, to inform investment priorities for research workforce capacity-building.*** The qualitative research – namely interviews with multiple stakeholders – aimed to provide more nuance, breadth and depth to the bibliometric analysis and the PhD tracing exercise. It was informed by the previous analyses and aimed to enrich knowledge about the dementia research

landscape and workforce, including strengths, gaps and capacity-building priorities for the future. We conducted forty interviews with stakeholders from research, policy, health practitioner, the private sector and funder communities, including representatives at varying stages in career pathways and from diverse fields.

Together, these three complementary methods aimed to help inform a blueprint for investing in capacity-building for UK competitiveness in dementia research going forward. We discuss each methodology, along with associated caveats, in more detail in the following sections.

### 2.2. Bibliometric data and citation analysis

Bibliometrics is one of a number of tools that can be used to assess the impact of research. It is based on the use of statistical analysis to measure patterns of scientific publications and citation, and is typically focused on journal papers. It is effectively the 'epidemiology' of scientific publications: analysing the generation, transmission and scientific influence of research (which can be seen as a proxy for quality). Fundamentally, it is derived from bibliographic databases which record publications and the number of citations they receive.<sup>42</sup> Bibliometric analysis can help to assess the productivity and scientific impact of research (and consequently – to an extent – the productivity and impact of research funding), as well as help identify leading researchers, organisations and fields. From a practical point of view, it is a useful technique as it allows us to codify and quantify evidence on research performance in a

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<sup>41</sup> The term 'specialisation' refers to the intensity of the UK dementia research output in a given research area (e.g., Alzheimer's disease), relative to the intensity of the global dementia research output for the same research area.

<sup>42</sup> Science-Metrix maintains a version of Thomson Reuter's Web of Science (WoS) abstract and citation database of peerreviewed literature, which contains the majority of scientific publications (including health and biomedical research) for the period 1980 until 2014.

clear and comparable way, with some caveats (discussed below). Bibliometrics is particularly useful in combination with other evaluation methods such as qualitative analyses (e.g. through interviews, surveys and/or case studies, or peer review).<sup>43</sup>

### 2.2.1. Caveats of bibliometric analysis

There are a number of well-known limitations to bibliometric analyses,<sup>44</sup> and the results of our research need to be interpreted and used within that context. However, when used responsibly, bibliometrics also mitigates some of the limitations of more traditional research assessment approaches such as peer review. These include the potential for bias and the potential for supporting more ‘orthodox’ approaches at the expense of less common but innovative research, as well as cost and time implications.

The key caveats of bibliometric methods, relevant to this study, include:

- Although a number of studies have been carried out to try and explain why authors cite in the way that they do, citation behaviour is highly variable. Thus, assessments of quality based on publications and citations alone can be misleading because research may be cited for a variety of reasons, not all of which may reflect its quality. There is no accepted theory to explain citing motivations. Some studies suggest that there is a tendency for authors to favour citations to research from within their own country, research group or department,<sup>45</sup> or to self-cite.<sup>46, 47</sup> Attribution continues to be a challenging issue as it is not always easy to disentangle the contribution of different authors (or institutions and countries) to a particular research paper.<sup>48</sup>
- Certain research fields naturally have lower publication rates. For example, if medical informatics has a lower publication rate than molecular biology, then medical informaticians will automatically be discriminated against by using the volume of publications they have produced as an indicator

of research performance. This is why we also place emphasis on impact-related bibliometric indicators (described below) which are field-normalised (and in principle compare ‘like with like’). This mitigates differences between fields. A related issue stems from the variety of subjects that researchers publish in. Bibliometrics can be less reliable for those subjects that are not widely covered in journals contained within Web of Science (WoS), since their publications cannot be analysed.

- The bibliometric analysis looks at citations from academic literature (typically focusing on journal articles and reviews), and does not include citations from non-indexed literature (e.g. conference proceedings, policy papers) and other sources such as some clinical guidelines.
- Finally, bibliometric analysis is based on past outputs and cannot reliably measure the future potential of entities.

There are some additional caveats that apply specifically to this study:

- The classification of dementia is poorly understood – clarifying the nexus of conditions which fall within the scope of dementia requires further research by the community of scientists, practitioners and policymakers working in the dementia field.<sup>49</sup> To capture the diversity of dementia topics and subtopics with which UK researchers engage, and to facilitate analysis, we used a classification system suggested by and discussed with the Alzheimer’s Society and cross-checked with paper classifications in bibliometric databases. This served as an organising factor for the analysis. However, it is important to note that some dementia disease subtypes can belong to more than one key topic (type of dementia), and that not every dementia type has associated subtypes. Although the overall number of dementia publications in our analysis is unique (i.e. there is no double counting), some publications may be reported under more than one subtype and hence numbers provided at that level

<sup>43</sup> Moed (2005).

<sup>44</sup> See, for example: (i) Ismail et al (2009) (ii) Moed (2005).

<sup>45</sup> Evidence Ltd. (2007).

<sup>46</sup> Self-citations are removed in our analysis.

<sup>47</sup> Aksnes (2003).

<sup>48</sup> In this study, the number of publications was analysed using full-paper counting in which each paper was counted once for all the entities listed in the address fields of the publication.

<sup>49</sup> Taylor, Marjanovic et al. (2014); George et al. (2011).

**Table 1. Dementia disease classification used to guide the bibliometric analysis<sup>50</sup>**

Type	Subtype
Frontotemporal Dementia	Pick's Disease; Primary Progressive Aphasia; Primary Progressive Nonfluent Aphasia
Lewy Body Dementia	Parkinson Disease Dementia (Lewy Body Dementia is classified as a type but not a subtype in the Science Metrix Database)
Vascular Cognitive Impairment	Cadasil; Vascular Dementia; Small Vessel Disease; Post-Stroke Dementia; Binswanger's Disease; Subcortical Dementia; Subcortical Ischemic Vascular Dementia
Alzheimer's Disease	Alzheimer's Disease; Posterior Cortical Atrophy; Logopenic Primary Aphasia
Syndromes	Mild Cognitive Impairment; Familial Dementia; Early Onset Dementia; Late Onset Dementia
Mixed Dementia	Mixed Dementia

of analysis are not cumulative. Table 1 provides the classification that guided our research.

- In addition, citation impact indicators could not be calculated for some types and subtypes of dementia disease given low publication volumes (this is highlighted in Chapter 3).

### 2.2.2. Bibliometric indicators used in the analysis

Over the years, bibliometrics has incorporated a range of approaches and indicators. At a high level, these indicators are broadly related to publication volume measures, citation analysis as a measure of research impact, and journal-linked performance measures. Brief descriptions of the specific bibliometric indicators used in this study have been provided in Table 2, Chapter 3. The portfolio of dementia publications covered in our analysis spanned the period 1980 to 2013 for most indicators. For some indicators the time span used was somewhat different; this is further explained within the definitions of each indicator.

### 2.2.3. Levels of analysis to which bibliometric methods were applied

In this study, we used bibliometric analysis to investigate publication output and impacts at the levels of:

- Comparing the UK dementia research portfolio to other countries.
- Understanding UK publication outputs and citation performance for specific types of dementia.
- Examining the publication outputs and citation

performance of research fields where UK dementia researchers are active (e.g. biochemistry, genomics, neurology, psychology, nursing and others).

- Analysing individual researcher performance (see 2.2.4 below). The aim of this component was not to identify specific individuals but to assess the profile of the most prolific researchers in terms of career stages, fields of activity and other factors.

### 2.2.4. Analysis of the 200 most prolific researchers with attention to 'special interest' fields

The most prolific 200 UK researchers in dementia research (based on publications) were identified from the overall pool of publications covered in the bibliometric analysis, using a recent time window (2008–2014). This time window helped us avoid selecting highly publishing UK researchers who may no longer be active. However, for the selected active researchers, we traced all their publications dating back to 1980 and up to 2013 (i.e. covering the same period as the overall bibliometric analysis). 2008 is the first year for which the Web of Science bibliometric database includes most of the links between authors and their addresses. This allowed for the identification of researchers located in the UK, as opposed to identifying the most active researchers on papers with at least one address from the UK (to avoid including foreign authors collaborating frequently with the UK in our analysis).

In discussion with the Alzheimer's Society, we reserved places in the most prolific researcher list (top 200) for

<sup>50</sup> This classification is based on the Alzheimer's Society's initial suggestion, but also stemmed from existing classification within the Web of Science bibliometric database.

researchers from special interest research areas identified by the Alzheimer's Society. These represent disciplines where there is a perceived potential under-investment. The special interest categories are nursing, psychology, speech and language, doctors' professions, occupational health, physiotherapy and social work. It is important to note that different doctors' professions can be strung through multiple areas of dementia research, and the top 200 list includes some research-active clinical professions. However, there is no specific bibliometric field purely for doctors' professions, explaining why this does not appear as a special interest category in the overall results. In the results, however, we do highlight individuals with clinical affiliations.

The main reason for using volume as a primary criterion was that our initial analyses and consultation revealed that special interest category individuals often publish in more mainstream journals (rather than journals specific to their own field of activity), where they may be seen as niche contributors. In such instances, they could be disadvantaged if their performance was assessed based on citation impact alone. It is rare for researchers to publish the majority of their research in journals that are specific to a distinct special interest category. However, it is important to bear in mind that different fields can have different levels of publishing activity. Researchers having at least a certain number of publications in a special interest category were flagged as a 'special interest researcher' for that category. That threshold was 15 papers, or having 25% of the total publication in that category.<sup>51</sup> To identify special interest researchers, we complemented the results from the overall search of individuals in the pool of publications identified for bibliometric analysis based on dementia disease classifications with an additional keyword-based query approach drawing on the special interest areas. This helped ensure that we did not miss any individuals who may be substantially active (publishing-wise) in special interest areas of dementia research, but possibly not in the

areas covered by our disease classification. We did not find any individuals who were not already in our list of most prolific researchers, given the thresholds we used. Within the overall list of top 200 researchers, we ended up with 64 individuals who could be identified as particularly active in special interest fields, and 136 other researchers in more traditional areas (more detail on the breakdown is provided in the results of Chapter 3).

### 2.3. PhD tracing: a scoping analysis of the retention of UK dementia research graduates in the dementia field

To better understand the career pathways of UK-based dementia researchers, we gathered data on the current positions of a sample of researchers who completed a doctoral degree in the UK in a topic related to dementia, from 1970 onwards.

As the basis for this approach, we obtained records held in the British Library's E-thesis online service (EThOS) database for doctoral theses completed on topics related to dementia. According to information provided by EThOS, the database contains records for over 380,000 theses, covering most of the doctoral degrees awarded by its 131 participating institutions (EThOS 2015<sup>52</sup>). We obtained an initial set of 1,923 'dementia thesis' records from EThOS on the basis of keyword searches in titles, abstract and subject heading fields.<sup>53</sup> Duplicates,<sup>54</sup> theses unrelated to dementia research (i.e. false positives) and theses published outside the timespan under consideration (pre-1970 or post-2013) were removed from the database. This cleaning process resulted in a set of 1,862 thesis records. From this list, 1,500 authors were randomly selected for online tracing.

The online tools and resources used for tracing included Google, LinkedIn, bibliographic databases and research networking sites (e.g. PubMed Central, Web of Science,

<sup>51</sup> This threshold was decided on in consultation with Science Metrix, who are leading global experts in bibliometric data.

<sup>52</sup> EThOS (2015).

<sup>53</sup> The keywords used were: Alzheimer's; dementia; cognitive impairment; mixed dementia; early onset dementia; vascular dementia; Lewy bodies (dementia with Lewy bodies); frontotemporal dementia; posterior cortical atrophy; familial dementia; Creutzfeldt-Jakob; Korsakoff's syndrome; cognitive impairment; supranuclear palsy; Biswanger's; Multiple Sclerosis; motor neurone disease; Parkinson's; Huntington's.

<sup>54</sup> Duplicate thesis records were removed and, in a case where one author had published two theses, only the first record was kept for that individual.

ResearchGate and PubFacts), and institution websites.<sup>55</sup> Individuals with certain characteristics proved more challenging than others to trace. These included individuals with common names, individuals for whom only the first initials of forenames were provided, and individuals who had received their PhD shortly before the search was conducted.<sup>56</sup> The search process was also complicated by variation in individuals' levels of online presence. For example, individuals working in academia appeared more likely than those in industry to have an institutional profile online.

The key objective of the tracing process was to determine the current position and research activity of each thesis author, in order to assess whether they were still active in dementia research. Hence, for each individual successfully traced, we recorded the readily available information on their current job title and position, employer, country, institutional affiliation, and sector of activity (e.g. academia, industry, NHS/clinical, other). In addition, individuals were considered 'active researchers' if they had authored a publication from 2008 onwards (consistent with the bibliometric analysis approach). They were considered 'active in dementia' (even if not research) if there was evidence that their current role relates directly to dementia. An 'active dementia researcher' was defined as an individual for whom at least one publication was found which (i) dated from 2008 onwards, and (ii) related to dementia.<sup>57, 58</sup>

It is worth bearing in mind the following caveats associated with this method:

- First, and related to the scoping nature of this work, we did not identify individuals who may be active in dementia research but who may not have done a PhD in a dementia-related topic or who may have

joined the UK dementia research community but who did their PhD in another country. Hence, the findings resulting from the analysis need to be interpreted as a proxy for the workforce but not as an absolute representation of the current status of the dementia workforce.

- Second, we could not within the scope of the work devote more than half an hour to an individual and it may be that a minority of individuals in our sample could have been traced with additional time and resources. However, we believe this would only apply to a minority of research-active individuals, if any, as they would tend to have web-pages or publications which would have helped us assess their positions, unless they were at very junior levels.
- Third, not all theses are indexed in the EThOS database. The database includes around 95 per cent of theses awarded between 2000 and 2013, but coverage is lower for older theses, particularly those awarded before 1980.<sup>59</sup>

## 2.4. A qualitative, multi-stakeholder lens on research system and workforce capacity strengths, gaps and opportunities looking forward

We conducted 40 interviews with diverse stakeholders in order to enrich the insights emerging from the bibliometric analysis and PhD tracing aspects of this study. More specifically, the aim of the interviews was to help deepen our understanding of the dementia research landscape and workforce in both a historical and a forward-looking strategic context, to further assess workforce pipeline issues (strengths and opportunities, weaknesses or gaps) and to examine drivers of future workforce investment needs. Semi-structured interviews were conducted over the telephone and lasted

<sup>55</sup> Search terms used mainly consisted of combinations of author names and 'dementia', 'research' and more specific thesis title keywords to allow for distinct research topics to be included in the trace. We also used a snow-balling approach to facilitate a trace and to help cross-check individuals' links to dementia and dementia research or to confirm institutional affiliations. We spent a minimum of five minutes and a maximum of 30 minutes per individual trace attempt. In some cases, the trace was unsuccessful (discussed further in the results section).

<sup>56</sup> Individuals who might have changed to their spouse's surname after their PhD could also sometimes be missed, although the bibliometric search algorithms did aim to mitigate this risk.

<sup>57</sup> Both conditions (i) and (ii) needed to be met.

<sup>58</sup> Authors who had completed their thesis within the time window for classification as an 'active researcher' (i.e. in 2008 or later) were classed as active researchers only if further evidence of post-PhD research activity could be found. If there was no evidence found, these authors were considered neither active nor inactive in research but were instead classed as 'recent graduate – no evidence'.

<sup>59</sup> Personal communication with H. Rosie, British Library, May 2015.

between 30 minutes and 1 hour. Informed consent was obtained from each interviewee.<sup>60</sup>

We included different sectors and levels of seniority in the interviewee pool, to ensure a rounded evidence base reflecting diverse perspectives and experiences. We drew on individuals identified from our bibliometric analysis (top 200 researchers), the PhD tracing exercise and other actors relevant to dementia research policy (e.g. funders and industry representatives). The profile of interviewees is presented in Chapter 5.

The in-depth interviews included dementia researchers at different stages of the career pathway (ranging from PhD students through to postdoctoral researchers, lecturers, readers and professors) and from diverse fields, research-active clinicians, nurses and allied health professionals, funder and policymaker representatives, an industry representative as well as people who have left dementia research (to understand challenges to retention in the field). Selection was largely random within specific categories of stakeholders. In a minority of cases, either the client or RAND Europe team suggested specific individuals to approach. These were either individuals in categories that were particularly challenging to access (e.g. PhD students, industry) or individuals who were felt to be particularly suitable to comment on the issues under investigation due to deep and broad experience in the dementia field.

We acknowledge that there are other individuals and organisations who would have been relevant to this study but who were not included within the scope

and boundaries of the current work. Examples might include additional funders or representatives of patient groups, or additional representation of specific professions (e.g. public health, although some representation was included). Expanding the pool of informants could be an element of a future research agenda or future dementia policy consultations.

Figures 18–21 in Chapter 5 provide a more detailed breakdown of the interviewees. Although the core topics covered applied across diverse interviewees, we tailored the interview protocols to specific target groups to ensure relevance and to ensure the language we used in the interviews would be understandable to all interviewees. Appendix 1 presents the protocols we used. The aim of the interviews was to explore a diverse range of issues, and not all interviewees could comment on each issue, nor were diverse responses on specific questions mutually exclusive – as such we did not aim to quantify the strength of different responses but rather to capture a multiplicity of perspectives, priorities and experiences. All interviewees bar one agreed to be named in Appendix 2.

Finally, it is worth bearing in mind that different interviewees may have brought their own interests to bear on questions related to areas for prioritising future investments in dementia research. However, overall, we believe we established an honest relationship with the interviewees and that triangulation across different fields, sectors and levels of seniority helped mitigate this challenge.

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<sup>60</sup> Before beginning the interview, interviewees were asked verbally if they consented to their interview being recorded for the purpose of analysis and to being named in a list of interview participants. This was recorded as proof of verbal consent. Prior to giving consent, interviewees were informed that their comments would be kept confidential through anonymisation, and that no quotes would be directly attributed to them directly, without their permission. Interviewees had been provided with information on the purpose and content of the interview (by email in advance of the interview, and verbally before beginning the interview).

## Chapter 3 The UK dementia research landscape: insights from the bibliometric analysis

### 3.1. Chapter summary: highlights from the bibliometric analysis

#### Research production

- The UK is second in the world in terms of the amount of dementia research knowledge it generated between 1980 and 2013, as captured through journal publications. In light of investment levels into dementia research and insights from other studies on UK research performance,<sup>61</sup> it is likely that UK dementia research punches above its weight in terms of publication outputs.
- The majority of UK dementia publications (60.5%) are in Alzheimer's disease. Research on other types of dementia diseases individually accounts for between 0.1% and 6.1% of overall UK outputs and includes research on mixed dementia, Lewy body dementia, vascular cognitive impairment, frontotemporal dementia, and classifications such as mild cognitive impairment, early-onset dementia and familial dementia.
- Dementia is a multidisciplinary research area and involves diverse fields and subfields of research. In journal databases, all papers are classified into specific fields and subfields, as organising categories based on topics of research and disciplinary lenses. 67% of all UK dementia papers are in the field of Clinical Medicine. The next most prolific subfields in terms of publication volume are neurology and neurosurgery (34.9% of UK dementia) papers, geriatrics (13.9%),

psychiatry (6.2%), biochemistry and molecular biology (4.9%), and experimental psychology (4.3%). There is comparatively very little research taking place in some subfields which are potentially relevant, such as health policy and services (0.43% of the overall UK dementia research portfolio), speech-language pathology and audiology (0.27%) and nursing (1.2%).

- UK dementia researchers frequently collaborate with colleagues in other countries: 40.3% of all UK dementia papers involve at least one international collaborator. UK dementia research draws on knowledge from diverse disciplines, similar to global trends. The UK does more research in dementia specifically as a proportion of all UK research (including in other disease areas) than most other countries, and thus is more specialised in dementia.

#### Impact

- UK dementia publications are influential: the vast majority of UK dementia research has a higher scientific impact than the world average impact for a specific type of dementia disease. In relation to the 29 other most active countries, the UK ranks seventh for the citation performance of its entire portfolio (i.e. covering all types of dementia research) and ninth in terms of the percentage of particularly highly cited papers (i.e. those belonging to the top 10% of all papers globally in terms of citations, as defined in Chapter 2).
- Most dementia disease research areas have pockets of excellence, indicated by a greater than

<sup>61</sup> See for example Elsevier (2013).

expected percentage of highly cited papers.<sup>62</sup> For the most prolific research area – namely Alzheimer’s disease – the citation performance of UK Alzheimer’s disease publications is only slightly above world average when the entire portfolio is considered, but there is a subset of highly influential UK research outputs in Alzheimer’s disease, as indicated by the high percentage of highly cited papers. UK Lewy body dementia and frontotemporal dementia research also have a particularly high percentage of highly cited papers (i.e. more than would be expected), but there are also pockets of research excellence in vascular dementia, small vessel disease, primary progressive aphasia and mild cognitive impairment research. The entire portfolio of UK research on CADASIL stands out in terms of citation impact.

- In contrast, there seems to be scope for improving the impact of UK research classified as familial and early-onset dementia, where the UK lags behind world averages for citation impact. (This is further discussed in Chapter 5, drawing on interview evidence.)
- The most influential UK dementia papers (citation-wise) are in the subfields of medicinal and biomolecular chemistry, and pharmacology and pharmacy, but there are also particularly notable pockets of excellence (in terms of percentages of highly cited dementia papers) in general and internal medicine, nuclear medicine and medical imaging, and pathology. Some of the more prolific subfields in terms of publication volumes (e.g. neurology and neurosurgery) as well as some fields where publishing volumes are relatively low (e.g. genetics and heredity) also have a higher than expected percentage of highly cited papers, although not quite as high as the most influential subfields.

- The lowest-impact subfields associated with UK dementia research include epidemiology, speech-language pathology and audiology, virology (e.g. in the context of possible co-morbidities or links between viruses and dementia), pathology and biophysics.

#### Profiles of the most prolific researchers

- The vast majority of the UK’s most prolific researchers (top 200 in terms of the volume of research publications) publish in journals in the field of clinical medicine (87.5%) and to the subfields of neurology and neurosurgery (66.5%) and geriatrics (18.5%). Individuals working on dementia from more niche perspectives (i.e. less frequently funded disciplines such as nursing, psychology, speech and language, occupational health, physiotherapy and social work) tend to publish in a mix of more mainstream fields (such as in geriatrics and neurology and neurosurgery journals, where their inputs may be seen as more niche contributions) and in some journals more specific to their primary field of focus, amongst which contributions to nursing journals and psychology journals are most common. Although tentative, it may be that researchers in niche fields tend to disseminate their work more frequently by means other than journal publications.
- Of the most prolific researchers, 75% perform above the world average for the impact of their overall research portfolio and in terms of percentages of highly cited papers.
- As expected, the most prolific researchers publication-wise tend to be more senior (57%; 114 individuals), while 19.5% (39 individuals) are in junior- to mid-level roles. They are employed across 37 research institutes, but 75% (150 individuals) of the most prolific researchers are based at 9 key institutions, indicating significant concentration of research workforce capacity.

### 3.2. Context

The contents below present the core insights obtained from the bibliometric analysis of UK dementia research publications, covering the 1980-2013 period. The analysis was conducted in collaboration between RAND

Europe and Science Metrix. As described in Chapter 2, we used bibliometric methods in which publications and citations are used as a proxy for research productivity, quality and impact, in order to examine the UK dementia research landscape. This included looking at research on different types of dementia disease and research from

<sup>62</sup> 10% of an overall portfolio of publications is what would be expected to be highly cited. In the portfolio of all publications globally (not dementia specific), 18.9% of UK dementia publications belong to the highly cited paper category (i.e. are in the top 10% of the most cited papers globally, across all fields), slightly higher than the 16.3% average of global dementia papers in the top 10% of all highly cited papers worldwide.

Table 2. Bibliometric indicators: summary

Bibliometric indicator	Explanation	
Number of papers	This is the number of publications at each level of analysis (e.g. field, topic).	Measure of scientific production
Growth Ratio (GR)	The growth ratio (GR) is an indicator of growth in output over time (in this case 2004-2008 and 2009-2013).	
Average of Relative Citations (ARCs)	This is a direct measure of the scientific impact of an entire publication portfolio based on paper citation counts, normalised to account for different citation patterns across fields/subfields of science and for differences in age of papers. When the ARC is above 1, it means that an entity scores better than the world average; when it is below 1, it means that on average, an entity publishes papers that are not cited as often as the world level. This is a key 'quality' indicator (using citations as a proxy) along with HCP (see next entry).	Measures of scientific impact (proxies for 'quality')
Highly Cited Publications (HCPs) – absolute number and percentages	This is the second key indicator: it measures research excellence based on the identification of 'top-performing' papers in a particular field, citation-wise. These are papers that belong to the top 10% of highly cited papers in a specific area, based on the citations they receive.	
Average of Relative Impact Factors (ARIFs) - journals	This provides an indication of the visibility of research and can be used as a proxy for the 'aspiration' or 'ambition' of an entity. When the ARIF is above 1, it means that an entity scores better than the world average in terms of the types of journals it targets its publications in; when it is below 1, it is below the world average. The ARIF score is normalised to account for different citation patterns across fields and sub-fields of science.	Measure of journal impact (proxy for 'ambition')
Specialisation Index (SI)	The SI is an indicator of research intensity in a given entity (e.g. country) for a given research area, relative to the intensity in a reference entity (e.g., the world, or the entire output as measured by the database) for the same research area. In the context of this analysis, it would indicate whether UK researchers publish more or less work in a specific dementia topic or field, relative to the amount of research other comparators (e.g. a global benchmark) do in the same field or topic compared to other fields or topics.	Measure of specialisation in a given field of science
Transdisciplinarity	This indicator measures the variety of disciplines (i.e. scientific subfields based on Science-Matrix's Ontology) cited in a given paper.	Measure of the variety of disciplines cited in a given paper
International collaboration	This refers to the number and proportion of publications involving at least one researcher affiliated with UK-based dementia research and at least one researcher from another country.	Measure of the level of collaboration activities

different fields. The analysis also provided an indication of how collaborative, specialised and multidisciplinary UK dementia research is.<sup>63</sup>

To make this chapter accessible to a diverse readership, we do not use the terminology of specific bibliometric indicators (defined in Table 2 in Chapter 3) in the narrative. Instead, Table 2 above summarises what specific bibliometric indicators show.

### 3.3. UK dementia research: a global perspective

The UK is second in the world in terms of the amount of dementia research it generated in the 1980-2013 period, as proxied by the number of journal publications (Table 3). UK researchers published 13,166 papers, which accounts for 12% of global dementia research outputs over the period under analysis. In terms of the volume

<sup>63</sup> The term 'specialised' refers to UK research intensity in dementia compared to the world average.

of publishing, the UK was surpassed only by the US. A recent report from the Alzheimer's Society estimates UK government and charitable spending on dementia research to be £73.8 million annually, compared to a US federal budget of £415 million.<sup>64</sup> US federal spending is 5.6 times higher than UK government and charitable spending, while US dementia publication outputs are 3.6 times higher. This might suggest that the UK punches above its weight in terms of the volume of research outputs, which is in line with the findings of the Elsevier report on UK research performance more widely.<sup>65</sup> The growth rate for UK dementia research outputs has been modest over the last three decades, compared to other countries (Table 3).

The UK is in the top 10 countries in terms of the impact of its dementia research portfolio, as measured by citations. It ranks seventh for the citation performance of its entire portfolio (i.e. covering all types of dementia research) and ninth in terms of the percentage of particularly highly cited papers (i.e. those that belong to the top 10% of all dementia papers worldwide, in terms of the number of citations they receive). Aside from the USA and Canada, countries that are higher than the UK based on the overall impact of their portfolio tend to have smaller portfolios in terms of publication volumes.<sup>66</sup> Their high impact may in part be attributable to excellence in a narrower set of research areas, although this assumption is tentative and merits further investigation (Table 3).

Dementia publications from the UK are substantially more collaborative than the global average, with 40.3% of all UK dementia papers involving at least one international collaborator. In comparison, only 19.8% of all dementia publications globally involve international collaborations. However, compared to the top 30 countries, the UK is in 21st place in terms of the percentage of papers involving international collaboration, meaning that 20 other countries have a greater percentage of all their dementia papers involving at least one international collaborator. Although tentative, this may partially relate to the fact that the UK has a comparatively larger dementia research portfolio and tends to collaborate more across institutions at the national level. UK dementia research

builds on a similar variety of disciplines as is the trend globally, meaning that UK dementia publications cite research from a similar variety of disciplines.

The UK ranks sixth in terms of the degree of specialisation in dementia vis-à-vis all areas of research, compared to other countries, meaning that the UK does more research in dementia as a proportion of all UK research than most other countries (Table 3).

### 3.4. Analysis by type of dementia

Dementia is an umbrella term for a set of symptoms that can be caused by a number of different diseases and conditions. There are over 100 different types of dementia, but the most common cause is Alzheimer's disease which accounts for about 62% of all dementia cases.<sup>67</sup> We analysed UK research performance for the core types of dementia disease, as discussed in Chapter 2.

When interpreting the findings, it is important to bear in mind that the classification of dementia disease types is poorly understood and requires further research, as discussed in Chapter 2. To capture the diversity of research topics covered within the dementia research community, we used a dementia classification system discussed with the Alzheimer's Society and cross-checked with paper classifications in bibliometric databases. This served as an organising factor for the analysis. It is, however, important to note that some dementia disease subtypes (as described in Table 1, Chapter 2) belong to more than one overall type. In addition, not every dementia type has associated subtypes (e.g. mixed dementia).

The majority of UK dementia publications (60.5%) are in Alzheimer's disease. Other types of dementia individually account for between 0.1% and 6.1% of overall UK outputs and include mixed dementia, Lewy body dementia, vascular cognitive impairment, frontotemporal dementia, and syndromes such as mild cognitive impairment, familial dementia, early-onset dementia and some conditions classified as late-onset dementia (Table 4).<sup>68</sup> Publication volumes for most dementia

<sup>64</sup> \$640 million, XE.com rates as of 27 February 2015. Personal communication with head of research, Alzheimer's Society.

<sup>65</sup> Elsevier, for the Department of Business, Innovation and Skills (2013).

<sup>66</sup> Countries with higher citation impact than the UK are Ireland, the USA, Norway, Finland, the Netherlands and Canada. Countries with higher share of highly cited papers are the USA, Norway, Ireland, Portugal, Switzerland, Finland, Belgium and Denmark.

<sup>67</sup> Alzheimer's Society (2012).

<sup>68</sup> From lowest to highest share of UK output.

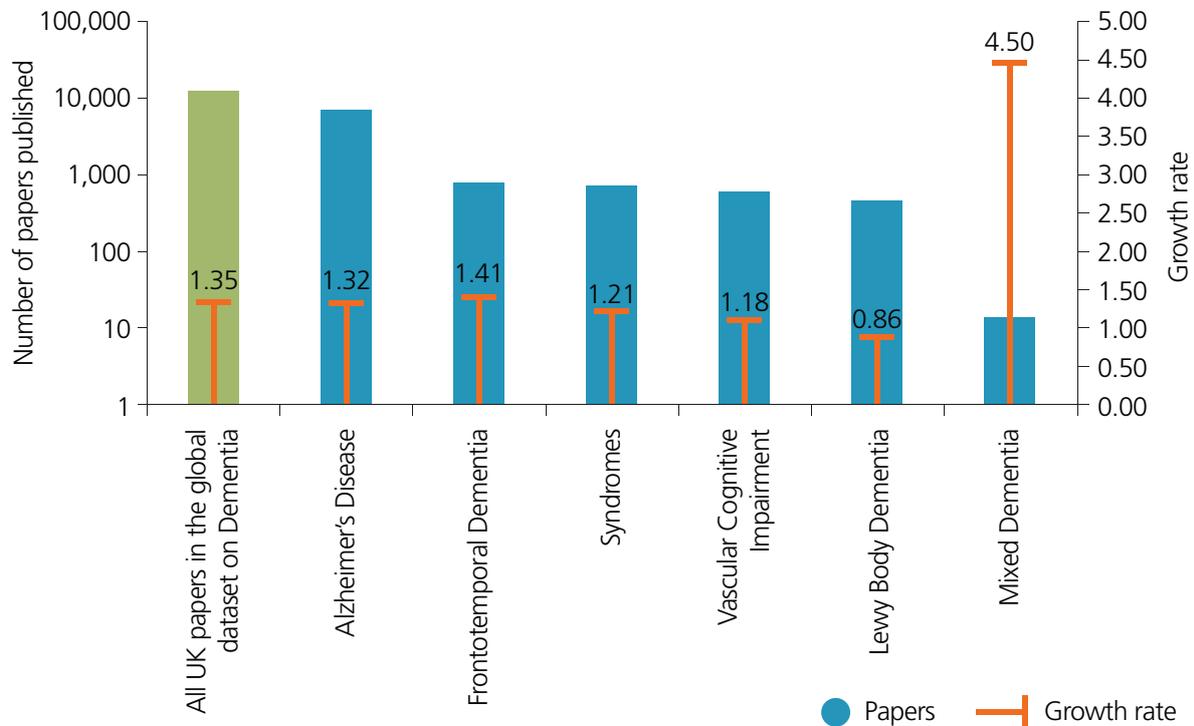
Table 3. Scientific output and impact of the 30 countries publishing the most in dementia research (Global Dataset) (1980–2013)<sup>69</sup>

Rank	Volume of dementia papers (1980 - 2013)	Citation impact of dementia portfolio (ARC <sup>4</sup> )	% Highly cited papers (%HCP)	Journal citation impact (ARIF)	Growth ratio (increase in publication volume over time)	Intern. Collaborations (% collaborative papers)	Specialisation Index
1	World	Ireland	US	Belgium*	China	Switzerland	Sweden
2	US	US	Norway*	Netherlands*	India	Ireland	Finland
3	UK	Norway	Ireland*	US	Brazil	Belgium	Italy
4	Germany	Finland	Portugal*	Finland	Portugal	Norway	Ireland
5	Japan	Netherlands*	Switzerland*	Canada	Ireland	Denmark	Austria*
6	Italy	Canada*	Finland	UK	Rep. of Korea*	Greece	Netherlands*
7	Canada	UK	Belgium	Switzerland*	Turkey*	Austria	UK
8	France	Belgium*	Denmark	Portugal*	Australia	Portugal	Belgium
9	China	Portugal*	UK	Ireland*	Norway	Hungary	Chile
10	Sweden	Sweden*	Canada	Sweden	Chile	Sweden	US
11	Australia	Australia	Netherlands	Norway*	Denmark	Finland	Switzerland
12	Spain	Switzerland	Sweden	Australia*	Finland	Russia	Australia*
13	Netherlands	World	Australia	Denmark	Poland	Germany	Spain*
14	Switzerland	Denmark	Chile	Italy	Spain*	Canada	Canada
15	Rep. of Korea	Germany	World	Israel	Greece*	Chile	Portugal
16	Belgium	Austria	Germany	World	Netherlands*	Netherlands	Israel
17	Finland	France	Austria	Germany	Sweden*	Poland	Japan*
18	Austria	Italy	France	France*	Russia	Australia	Germany*
19	Israel	Chile	Italy	Chile*	France	Israel	World
20	Brazil	Israel	Japan	Greece*	Belgium	France	Hungary
21	Poland	Japan	Brazil	Hungary*	World	UK	France
22	India	Greece	Israel	Austria	Italy*	Italy	Rep. of Korea
23	Denmark	Turkey	Greece	Japan	Germany*	Spain	Norway
24	Ireland	China*	Spain*	Spain	UK	China	Denmark
25	Portugal	Spain*	China*	China	Switzerland*	Rep. of Korea	Greece
26	Norway	Brazil	Turkey	Rep. of Korea	Canada	Brazil	China
27	Hungary	Hungary	Hungary	India*	Austria	India	Brazil
28	Russia	Rep. of Korea	India	Poland*	US	Turkey	Poland
29	Turkey	Poland*	Poland	Brazil	Hungary*	US	Turkey
30	Greece	India*	Rep. of Korea	Turkey	Japan	Japan	India
31	Chile	Russia	Russia	Russia	Israel	World	Russia

<sup>69</sup> Note that countries sharing the same ranking for a particular indicator are marked with an \*.

**Figure 1. Key indicators on the scientific output of the UK in dementia research by type (1980–2013)<sup>70</sup>**

(This table shows the volume of publications on different types of dementia disease and growth or decline in publishing outputs over time – please refer to Table 2 for definition of growth rate)



Note: The green and blue columns show the number of papers published per type of dementia between 1980 and 2013. The red arrows indicate the growth rate for each of type over the period of analysis.

types have had gradual and modest growth ratios over the timeframe analysed. Lewy body dementia is an exception – scientific production has declined despite this being one of UK's leading dementia research topics in terms of impact (Figure 1, Table 4).

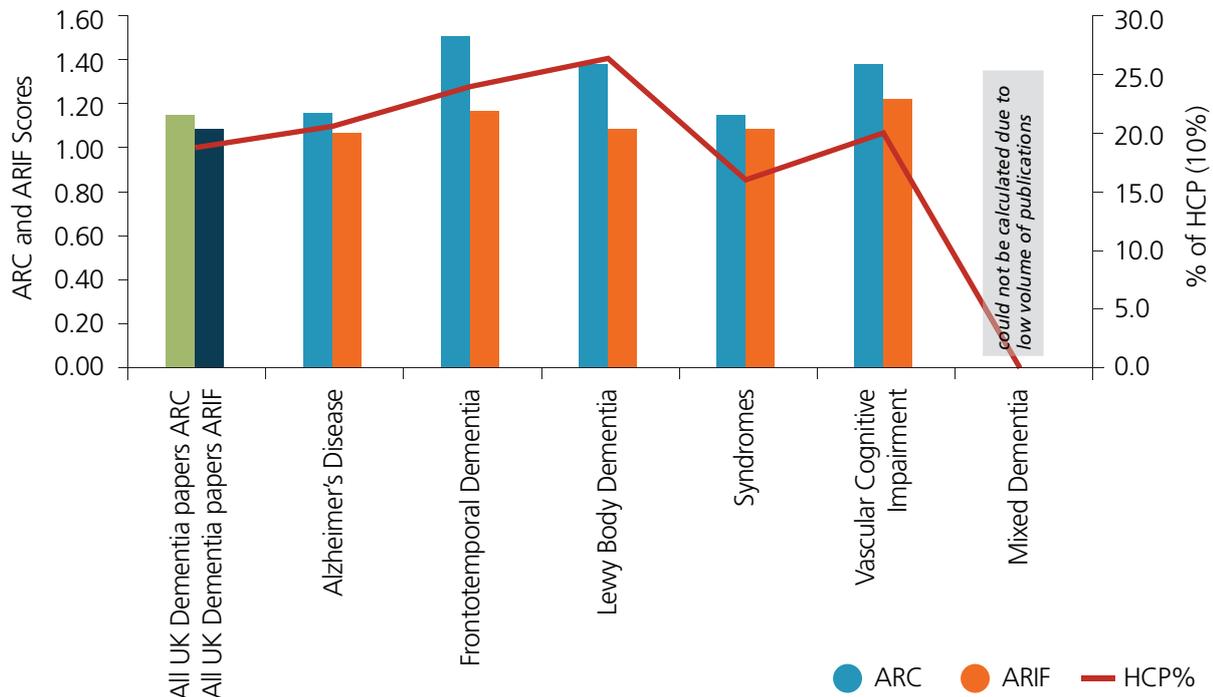
UK research has higher scientific impact than the world average across all key dementia types and most subtypes (Figure 3). However, there is not one specific type of dementia with particularly high impact when comparing within the UK research portfolio.<sup>71</sup> This is perhaps not surprising, especially for larger-volume disease research portfolios, given that research outputs include highly influential publications as well as those of newer researchers who are contributing to capacity-building in the field, but may not produce the most highly cited publications. For example, for Alzheimer's disease (which has the largest volume of UK publications) the impact of the UK research portfolio is not substantially

higher than the world average, but the percentage of highly cited papers is, suggesting a subset of highly competitive and academically influential UK research outputs in Alzheimer's disease (Table 4).

Most dementia disease types have pockets of excellence, indicated by a greater than expected percentage of highly cited papers. Lewy body dementia research and frontotemporal dementia research have a particularly high percentage of highly cited papers. Across the portfolio, the UK generally publishes in journals with an average impact factor, with vascular cognitive impairment and frontotemporal dementia showing slightly more ambitious journal targeting on average (Figure 2). In terms of dementia disease subtypes, UK research on CADASIL has a particularly high citation impact in comparison to other UK research dementia subtypes (Table 4). Based on the percentages of highly cited papers, there are also notable pockets of excellence within vascular dementia, small vessel disease, primary progressive aphasia and mild

<sup>70</sup> Note that the growth rate is an indicator of output between two periods (2004–2008 and 2009–2013) in that case.

<sup>71</sup> All ARC values are below 2.

Figure 2. Citation impact across different types of dementia disease (1980–2013)<sup>72</sup>

cognitive impairment research in the UK. UK research impacts in familial, early-onset and late-onset dementia lag behind the world average, although this might be a byproduct of the classification system that was used. For example, the UK research community does not refer to late onset dementia as a classification very often (Table 4).

Please note when reading Table 4 that papers can belong to more than one subtype or type, and numbers should not be read as cumulative. There is no duplication at the disease type level.<sup>73</sup>

### 3.5. Analysis by research field

Dementia is a multidisciplinary research area that involves many diverse fields of research (e.g. clinical medicine, biomedical research, social sciences, psychology and cognitive science, and others). All papers (and journals) are classified into specific fields and subfields in the Web of Science bibliometric database, as organising categories based on the topics of research and disciplinary lenses. For example, the field of clinical medicine includes dementia research in the subfields

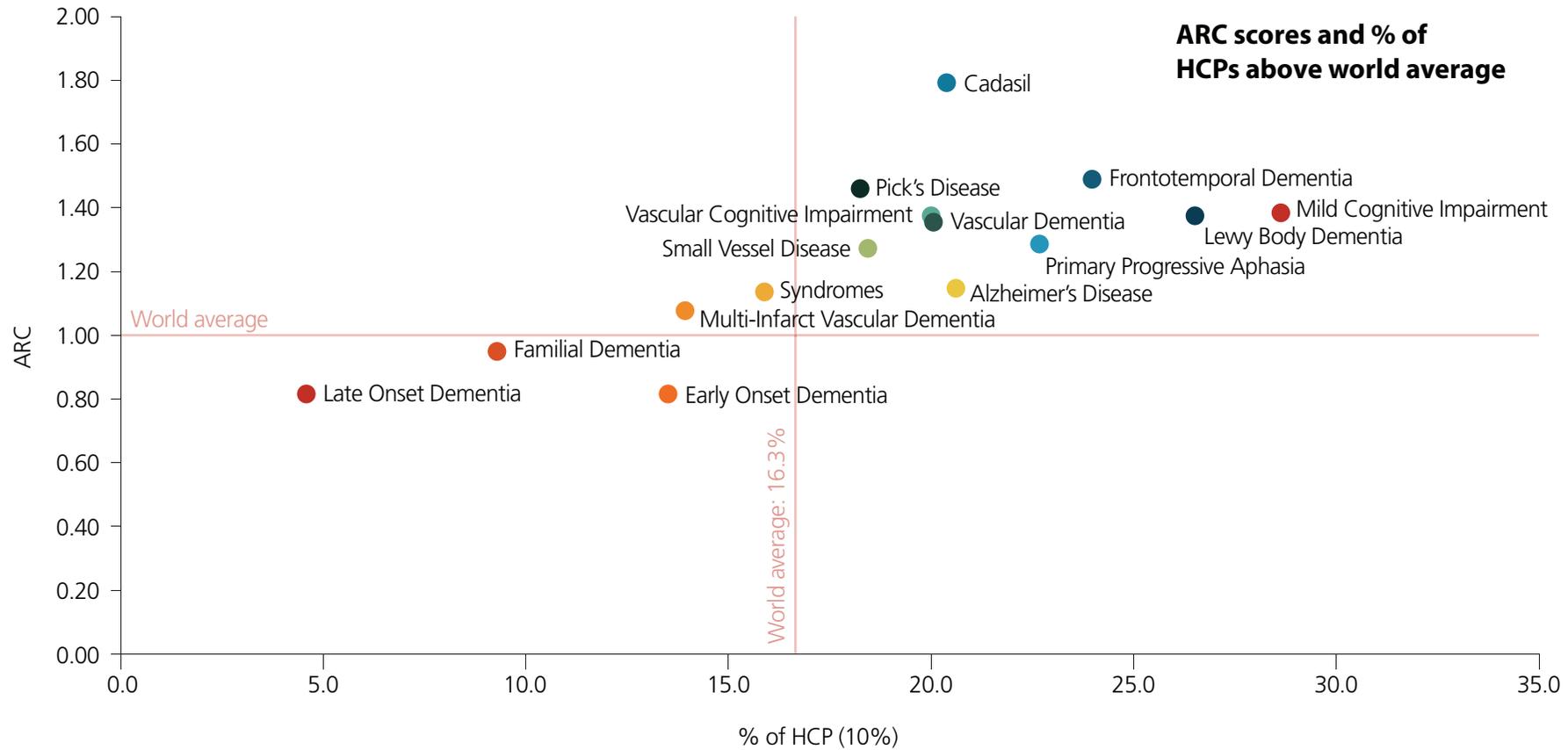
of neurology and neurosurgery, geriatrics, psychiatry, general and internal medicine and others. The field of public health and health services includes subfields of gerontology, nursing, rehabilitation, public health, epidemiology, health policy and services, and speech-language pathology and audiology.

The UK dementia research portfolio spans 21 research fields and 118 subfields. There is a high concentration of dementia publications in the field of clinical medicine (Figure 4). The top five fields based on volume of dementia outputs are clinical medicine (67% of all UK dementia papers), biomedical research (14%), public health and health services (5.5%), psychology and cognitive sciences (5.4%), and general science and technology (2.9%). However, more detailed analysis is more nuanced and informative at the level of subfields. The top five subfields of dementia research in terms of publication volume are neurology and neurosurgery (34.9% of UK dementia papers), geriatrics (13.7%), psychiatry (6.2%), biochemistry and molecular biology (4.9%), and experimental psychology (4.3%) (Table 5). Subfields with the lowest volume of publications are

<sup>72</sup> Impact indicators could not be calculated for mixed dementia due to low number of publications.

<sup>73</sup> Note also that Parkinson's Disease Dementia papers were not picked up under Lewy Body dementia. This may be because UK Parkinson's Disease dementia research is classified under Parkinson's Disease and not as Parkinson Disease dementia in the bibliometric database.

**Figure 3. Scientific Impact of the UK by dementia disease types and subtypes expressed by ARC scores and percentage of highly cited papers (1980–2013)<sup>74</sup>**  
 (See Table 2 for indicator definitions)<sup>75</sup>



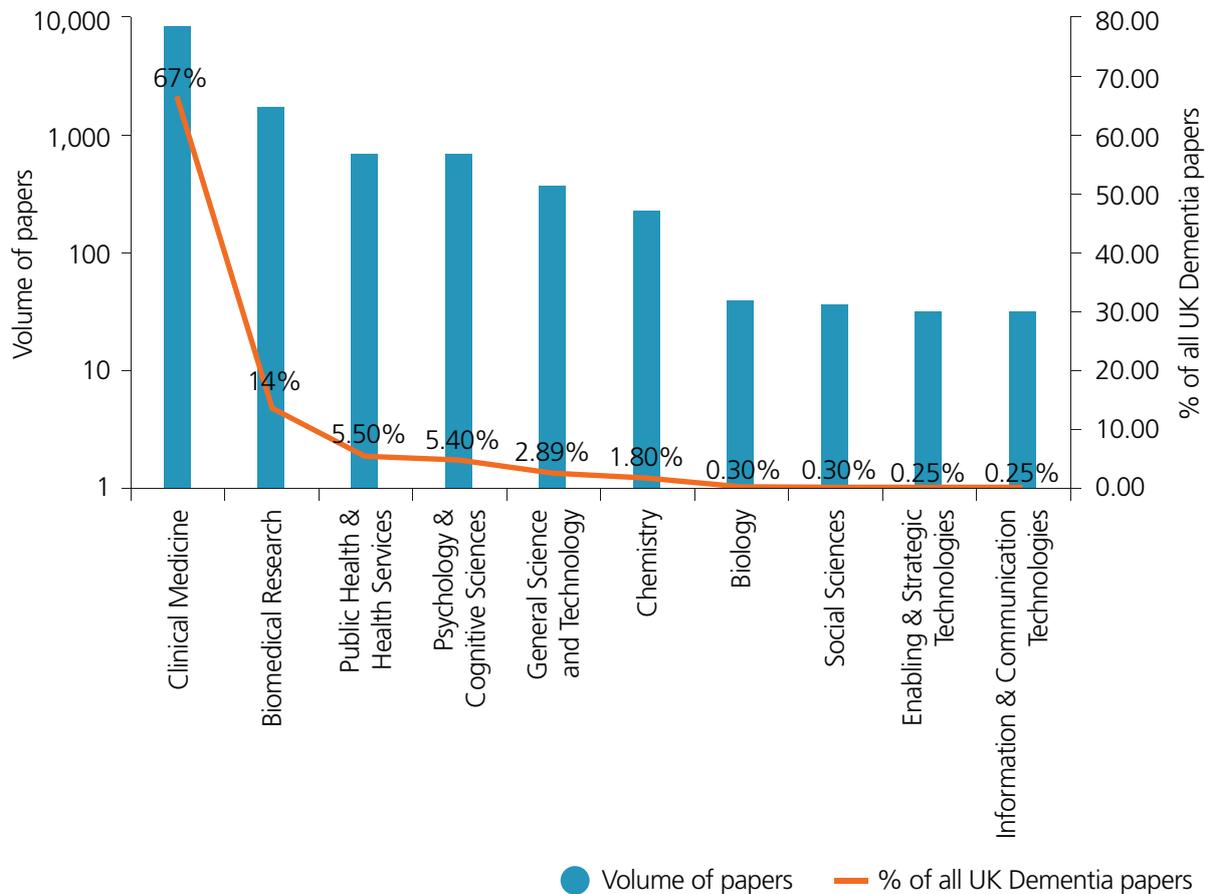
<sup>74</sup> Impact indicators could not be calculated for the following subtopics due to low publication volumes: primary progressive nonfluent aphasia (Syndromes); Poststroke Dementia, Binswanger's Disease, Subcortical Dementia, Subcortical Ischemic Vascular Dementia (Vascular Cognitive Impairment), Mixed Dementia.

<sup>75</sup> The world dementia reference value for highly cited papers is 16.3%.

Table 4. Scientific output and impact of the UK in dementia research by topic and subtopic (1980–2013) – sorted by volume of papers<sup>76</sup>

Type/Subtype	Papers	% Dementia	ARC	HCP Papers	HCP (%)	ARIF	SI	GR	Transdisciplin.	International collaboration %
<b>All UK papers</b>	<b>13,166</b>	<b>100.00%</b>	<b>1.15</b>	<b>2,135</b>	<b>18.90%</b>	<b>1.09</b>	<b>1.41</b>	<b>1.35</b>	<b>0.51</b>	<b>40.30%</b>
<b>Alzheimer's Disease</b>	<b>7,959</b>	<b>60.50%</b>	<b>1.15</b>	<b>1,431</b>	<b>20.70%</b>	<b>1.07</b>	<b>1.22</b>	<b>1.32</b>	<b>0.52</b>	<b>44.30%</b>
<i>Alzheimer's Disease</i>	7,954	60.40%	1.15	1,431	20.70%	1.07	1.22	1.32	0.52	44.40%
<i>Posterior Cortical Atrophy</i>	33	0.30%	N/C	5	N/C	1.46	2.26	5.25	0.4	39.40%
<i>Logopenic Primary Aphasia</i>	14	0.10%	N/C	1	N/C	N/C	2.42	13	N/C	28.60%
<b>Other classifications (Syndromes)</b>	<b>1,477</b>	<b>11.22%</b>	<b>1.2</b>	<b>257</b>	<b>21.76%</b>	<b>1.11</b>	<b>1.57</b>	<b>1.87</b>	<b>0.48</b>	<b>51.05%</b>
<i>Mild Cognitive Impairment</i>	779	5.92%	1.39	159	28.68%	1.13	1.17	2.36	0.51	62.77%
<i>Familial Dementia</i>	239	1.80%	0.96	21	9.40%	1.04	1.94	0.86	0.51	49.40%
<i>Early Onset Dementia</i>	112	0.90%	0.83	13	13.50%	1.03	2.17	1.24	0.5	39.30%
<i>Late Onset Dementia</i>	47	0.40%	0.81	2	4.70%	1.06	1.36	1.5	0.55	44.70%
<b>Frontotemporal Dementia</b>	<b>798</b>	<b>6.10%</b>	<b>1.5</b>	<b>165</b>	<b>24.00%</b>	<b>1.17</b>	<b>2.32</b>	<b>1.41</b>	<b>0.41</b>	<b>48.00%</b>
<i>Pick's Disease</i>	134	1.02%	1.47	23	18.26%	1.17	1.55	1.32	0.45	49.25%
<i>Primary Progressive Aphasia</i>	363	2.80%	1.29	72	22.70%	1.13	3.77	1.34	0.37	30.90%
<i>Primary Progressive Nonfluent Aphasia</i>	38	0.30%	N/C	2	N/C	0.98	3.82	3.38	0.39	26.30%
<b>Lewy Body Dementia</b>	<b>504</b>	<b>3.80%</b>	<b>1.38</b>	<b>119</b>	<b>26.40%</b>	<b>1.08</b>	<b>2.56</b>	<b>0.86</b>	<b>0.43</b>	<b>36.70%</b>
<b>Vascular Cognitive Impairment</b>	<b>590</b>	<b>4.50%</b>	<b>1.37</b>	<b>104</b>	<b>20.00%</b>	<b>1.22</b>	<b>1.39</b>	<b>1.18</b>	<b>0.48</b>	<b>31.40%</b>
<i>Cadasil</i>	58	0.40%	1.8	10	20.40%	1.23	1.15	0.83	0.47	37.90%
<i>Vascular Dementia</i>	489	3.70%	1.36	88	20.10%	1.21	1.37	1.02	0.49	33.70%
<i>Small Vessel Disease</i>	157	1.20%	1.28	24	18.50%	1.27	1.6	2.04	0.43	24.80%
<i>Post-Stroke Dementia</i>	19	0.10 %	N/C	2	N/C	N/C	2.13	2.75	0.39	5.30%
<i>Binswanger's Disease</i>	16	0.10%	N/C	2	N/C	N/C	0.69	0.67	0.4	31.30%
<i>Subcortical Dementia</i>	13	0.10%	N/C	2	N/C	N/C	1.25	N/A	0.4	15.40%
<i>Subcortical Ischemic Vascular Dementia</i>	10	0.10%	N/C	1	N/C	N/C	1.32	3.5	0.43	80.00%
<b>Mixed Dementia</b>	<b>15</b>	<b>0.10%</b>	<b>N/C</b>	<b>4</b>	<b>N/C</b>	<b>N/C</b>	<b>1.68</b>	<b>4.5</b>	<b>0.5</b>	<b>53.30%</b>

<sup>76</sup> Note when reading Table 4 that papers can belong to more than one subtype or type and numbers should not be read as cumulative. There is no duplication at the disease type level. Note also that Parkinson's Disease Dementia papers were not picked up under Lewy Body dementia. This may be because UK Parkinson's Disease dementia research is classified under Parkinson's Disease and not as Parkinson Disease dementia in the bibliometric database. The remainder of UK Dementia papers that were not classified under any type or subtype do not appear in this table but are reflected in the total of 13,166 papers (these 'other' papers would account for the difference between the total number of UK dementia papers and the sum of the papers under each core type).

Figure 4. Top 10 fields in which dementia research is published – based on volume<sup>77</sup>

dementia papers in subfields of speech-language pathology and audiology, pediatrics<sup>78</sup> (although counterintuitive, this includes research into childhood diseases that present as dementia, for example), organic chemistry, endocrinology and metabolism, biophysics, health policy and services, and oncology and carcinogenesis (although tentative, this includes dementia research in the context of co-morbidities).

Due to a low number of publications in some specific dementia subfields in the UK, impact indicators could only be calculated for 32 out of the 118 research subfields. Over half (56.2%) the research subfields in which UK dementia research publications appear have a higher

overall citation impact than the world average within the dementia portfolio. The subfields with the highest impact for dementia-related publications are medicinal and biomolecular chemistry, pharmacology and pharmacy, pediatrics,<sup>79</sup> organic chemistry, developmental biology, and general and internal medicine. There are particularly notable pockets of excellence for UK dementia research in the subfields of general and internal medicine, nuclear medicine and medical imaging, and pathology (Table 5). The lowest-impact subfields associated with UK dementia research include epidemiology, speech-language pathology and audiology, virology,<sup>80</sup> pathology and biophysics (Table 5).

<sup>77</sup> Volume of papers presented as log scale.

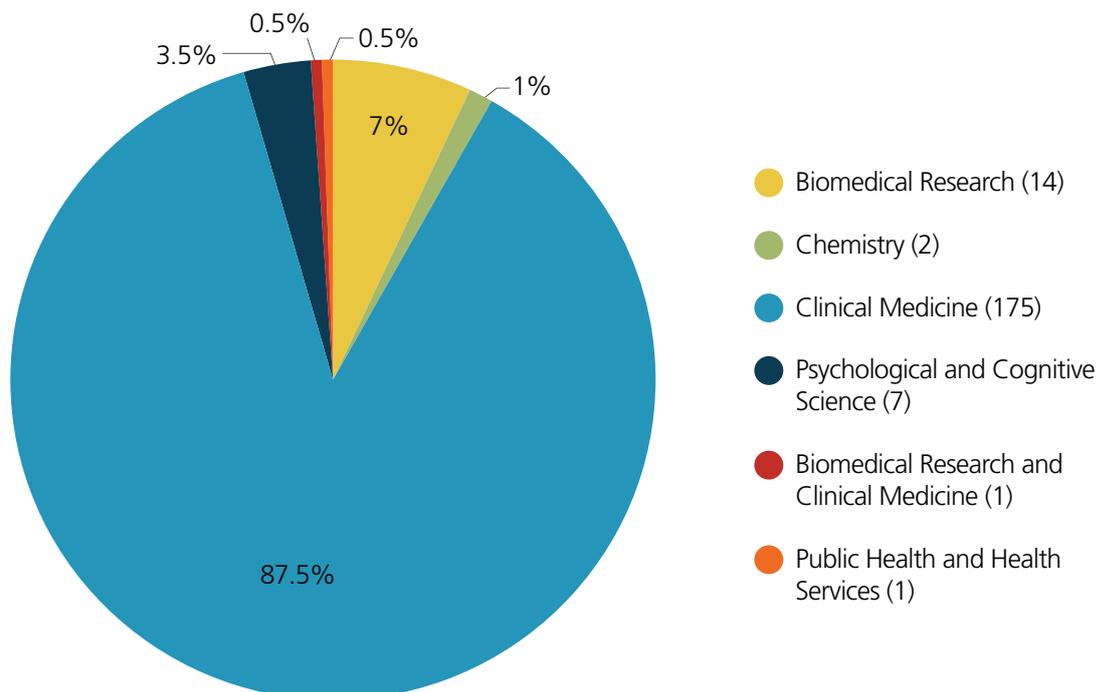
<sup>78</sup> Some fields like pediatrics appear high on the list, which is surprising. The volume of dementia-related papers in pediatrics is low (in fact the lowest of all identified dementia-related subfields of publication). However, the impact of papers was high. Some of these papers are indirectly related to dementia – for example, concerning childhood diseases which present as dementia. Although tentative and outside of scope for further analysis, the remainder of the papers may relate to the impact on children in families affected with dementia.

<sup>79</sup> See footnote 12.

<sup>80</sup> Some of these papers may relate to co-morbidities or be interdisciplinary in focus. In addition, some viruses such as Lyme disease and herpes simplex (Piacentini et al. 2014) have been linked to dementia.

**Table 5. Impact and output of UK research subfields (1980–2013) – sorted by volume**

Subfield	Volume of dementia papers (1980-2013)	% of UK dementia papers	Citation impact of dementia portfolio (ARC)	Number Highly Cited Papers (10%)	% Highly Cited Papers (%HCP)	ARIF (Journal Citation Impact)
<b>World</b>	<b>109,858</b>		<b>1</b>	<b>15,218</b>	<b>16.30%</b>	<b>1</b>
<b>All UK papers</b>	<b>13,166</b>	<b>100%</b>	<b>1.15</b>	<b>2,135</b>	<b>18.90%</b>	<b>1.09</b>
Neurology & Neurosurgery	4,595	34.9	1.22	893	22.50%	1.12
Geriatrics	1,800	13.67	1.09	186	11.70%	0.93
Psychiatry	821	6.24	1.3	115	15.30%	1.22
Biochemistry& Molecular Biology	640	4.86	1.03	135	23.20%	0.99
Experimental Psychology	564	4.28	1.08	71	14.40%	1.02
General & Internal Medicine	540	4.1	1.4	150	30.60%	1.44
Genetics & Heredity	431	3.27	1.15	90	23.20%	1.04
General Science & Technology	381	2.89	1.12	38	13.50%	1.06
Microbiology	354	2.69	1.34	54	15.90%	1.04
Developmental Biology	191	1.45	1.43	40	25.00%	1.24
Pharmacology & Pharmacy	178	1.35	1.51	45	27.60%	1.47
Gerontology	174	1.32	0.94	22	16.40%	1.04
Nuclear Medicine & Medical Imaging	166	1.26	1.16	42	30.20%	1.07
Nursing	154	1.16	0.97	15	12%	1.1
Cardiovascular System & Hematology	125	0.95	0.96	13	11.80%	0.96
Rehabilitation	123	0.93	0.95	7	6.80%	1.05
Medicinal & Biomolecular Chemistry	109	0.83	1.53	31	34.80%	1.02
Public Health	97	0.74	0.92	6	7.40%	0.97
Pathology	95	0.72	0.85	27	29.30%	0.95
Clinical Psychology	94	0.71	1.12	5	5.70%	1.32
Immunology	89	0.68	0.88	13	16.90%	1
Epidemiology	83	0.63	0.67	5	7.30%	0.92
General Clinical Medicine	77	0.58	1.05	13	17.40%	0.86
Nutrition & Dietetics	71	0.54	0.9	11	18.00%	1.03
Virology	68	0.52	0.85	6	9.40%	1.13
Oncology & Carcinogenesis	60	0.45	0.98	2	4%	1.1
Health Policy & Services	57	0.43	0.94	3	7.90%	1.05
Biophysics	50	0.38	0.86	6	15.00%	1.05
Endocrinology & Metabolism	47	0.36	1.08	7	18.90%	1.04
Organic Chemistry	42	0.32	1.43	7	20.60%	1.05

Figure 5. Distribution of the top 200 most prolific dementia researchers by field<sup>81</sup>

### 3.6. Analysis of UK top-publishing dementia researchers

The top 200 most prolific researchers analysis is based on bibliometric data and the methods have been discussed in detail in Chapter 2 (Study design and methods). The analysis was conducted to enable us to analyse the profile of prolific researchers by field, subfield, career stage and institutional affiliation. This is complemented by a wider analysis of the profile of the dementia workforce which draws on other methods and is described in Chapter 4.

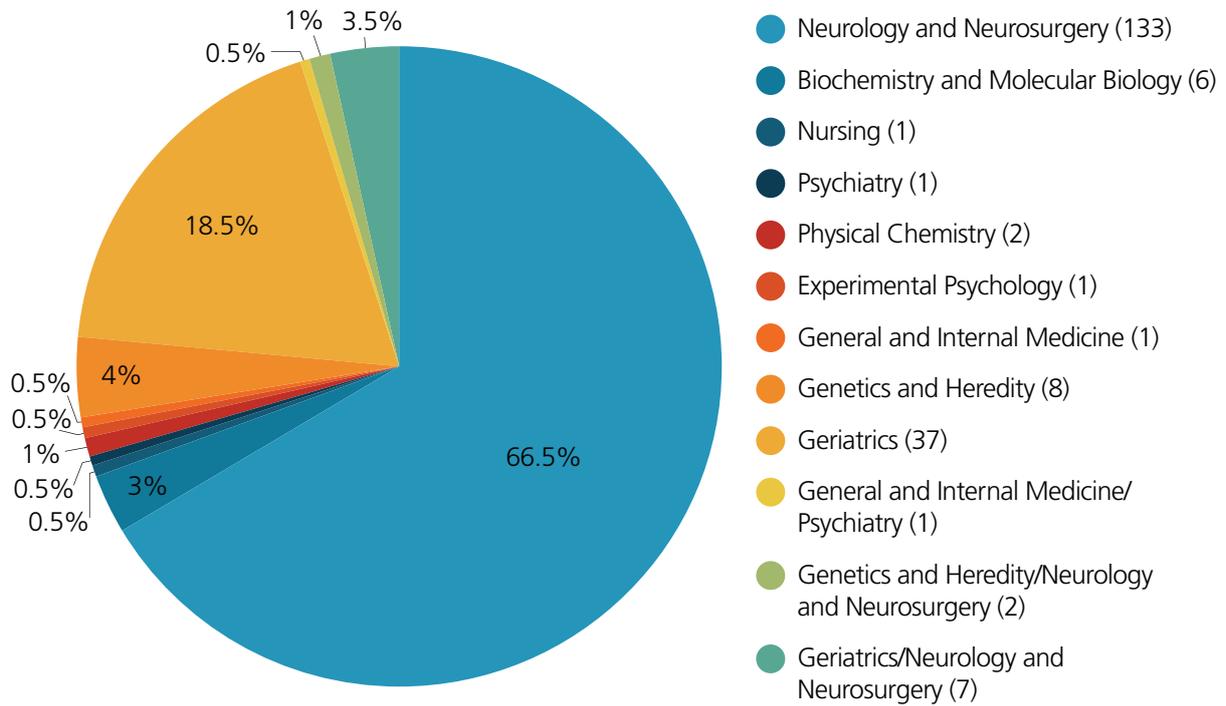
We first identified *active* researchers, defined as those publishing from 2008 onwards (see Chapter 2 for more detail). The bibliometric performance of the selected 200 most prolific active researchers – based on volume of publications – was then analysed over the 1980–2013 period in line with the timeframe of the overall study. We also focused on researchers from the top 200 list publishing in special interest research areas identified by the Alzheimer’s Society. These are disciplines where there is a perceived potential underinvestment.

As discussed in Chapter 2 (Study design and methods), the special interest categories are nursing, psychology, speech and language therapy, doctors’ professions, occupational health, physiotherapy and social work. It is important to note that doctors’ professions can be strung through multiple areas of dementia research, and the top 200 most prolific researchers includes some research-active clinical professionals. However, there is no specific bibliometric field purely for doctors’ professions, explaining why this does not appear as a special-interest category in the overall results.<sup>82</sup> Within this top 200 list, 64 researchers were identified as special interest researchers based on the criterion of publishing more than a quarter of their papers within a special interest field or subfield of research (e.g. nursing, psychology, speech and language therapy, etc.). However, these researchers rarely publish *only* in journals dedicated to special interest fields but instead tend to publish in both traditional fields and subfields of research and less traditional fields and subfields of dementia research. The 136 other researchers were active mainly in more traditional research fields and subfields.

<sup>81</sup> Note that one researcher has published equally in the fields of biomedical research and clinical medicine, and so is indicated as belonging to both fields.

<sup>82</sup> The list considered both volume and an impact check, but was primarily selected based on volume. This was important in light of the need to include special-interest researchers who, when they publish in more orthodox journals, may receive fewer citations in the field given that their work may be seen as a niche contribution – a frequent occurrence.

**Figure 6. Distribution of the top 200 most prolific dementia researchers by subfield**



**Table 6. Publishing profiles for special interest category researchers**

Special interest area of research	% of special interest category researcher's publications that are in specialised journals
Psychology	57
Nursing	52
Public health and health services	10
Speech and language therapy	9
Social work and social care	2
Occupational therapy	0
Physiotherapy	0

The vast majority of the UK's most prolific researchers (top 200 in terms of the volume of research publications) publish in journals in the field of clinical medicine (87.5%), and in the subfields of neurology and neurosurgery (66.5%) and geriatrics (18.5%) (Figures 5 and 6). This broadly mirrors the field and subfield patterns observed for all UK researchers in dementia research.

Researchers in the special interest categories generally publish in a mix of journals belonging to traditional (mainstream) and special interest subfields. Amongst the researchers who had at least a quarter of their publications in a special-interest category, the most common subfields are psychology (where nearly 57% of special interest researchers have over a quarter of their publications) and Nursing (where 52% of special

interest researchers have over a quarter of their publications). Amongst special interest researchers, 10% have over a quarter of their portfolio in public health and health services subfields, while 9% have over a quarter of their portfolio in the speech and language therapy subfields (and associated journals), and less than 2% in social work and social care (Table 6). There were no UK researchers in the top 200 list who publish more than a quarter of their publications in journals specifically devoted to physiotherapy or occupational therapy.

More than half the top 200 researchers are currently in senior roles (57%; 114 individuals), while 19.5% (39 individuals) are in junior- to mid-level roles; the level of seniority could not be ascertained from the available

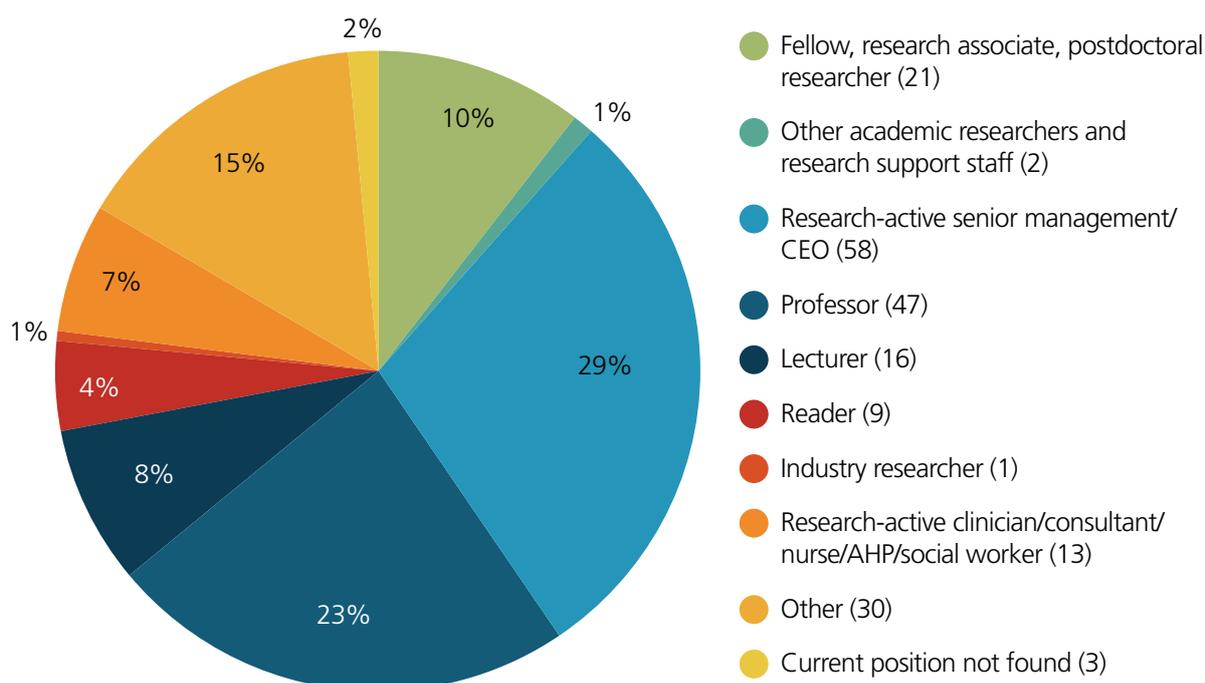
**Table 7. Top 200 researchers: seniority levels**

Top200 Seniority Level	Absolute number	%
Junior-Mid Level	39	19.5%
Senior	114	57%
Seniority not known	47	23.5%
<b>Total</b>	<b>200</b>	

**Table 8. Special interest category researchers: seniority levels**

Special Interest researchers Seniority Level	Number of Researchers	%
Junior-Mid Level	9	14%
Senior	39	61%
Seniority not known	16	25%
<b>Total</b>	<b>64</b>	<b>100%</b>

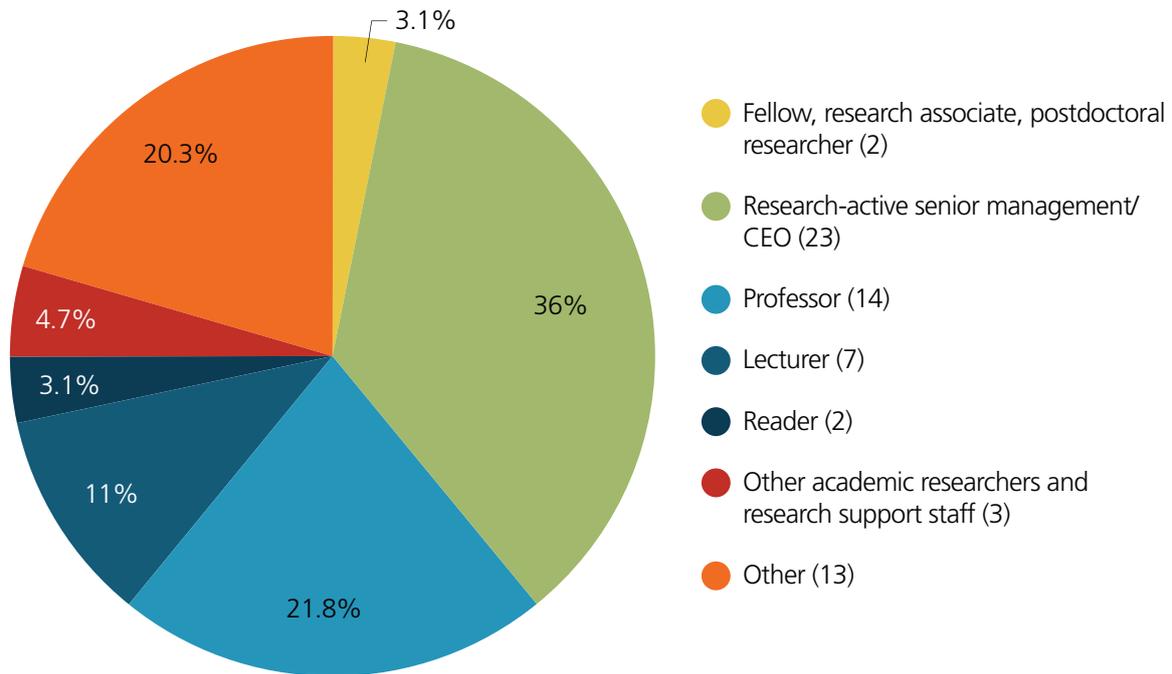
**Figure 7. Top 200 researchers: current position**



data for 23.5% (47 individuals) (Table 7).<sup>83</sup> Senior roles in our classification include: research-active reader, research-active professor and research-active senior manager/CEO. Mid-level to junior level roles include:

fellow, research associate, postdoctoral researcher, research-active lecturer, other academic researchers and support staff (Figures 7 and 8). For special interest category individuals, the staff category breakdown broadly

<sup>83</sup> It should be noted that the 'other' category included nine retired researchers, four consultants, and 13 others including research-active clinicians, a consultant, a nurse, an allied health professional and a social worker.

**Figure 8. Special interest category researchers: current position**

mirrors the overall top 200 list, with a slightly higher percentage of senior staff (61%; 39 individuals) and 14% junior to mid-level (9 individuals), with 25% (16 individuals) whose seniority was not known (Table 8). It is not surprising that the most prolific researchers, in terms of publications, tend to be more senior. We discuss the composition of the wider dementia research workforce in Chapter 4.

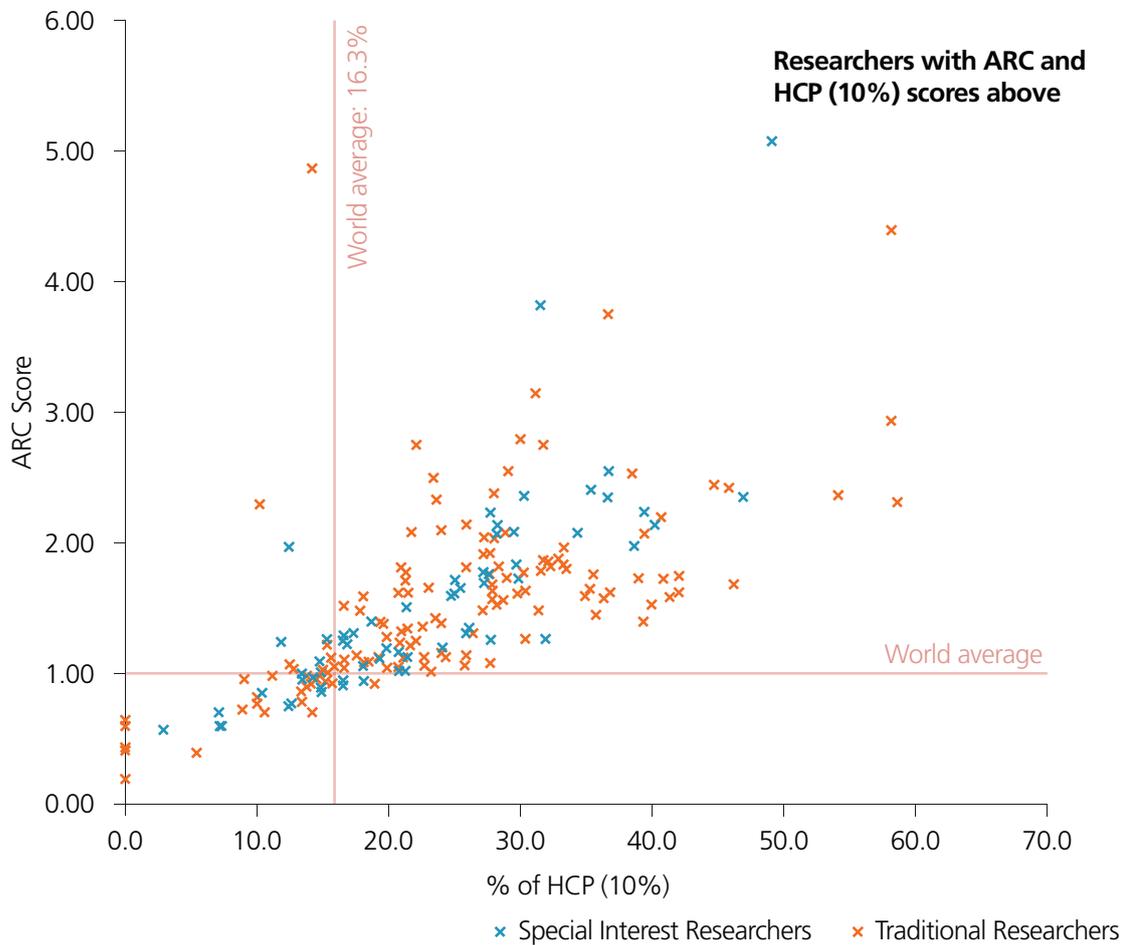
Three quarters of the top 200 UK dementia researchers perform above the world average in terms of the impact of their overall research portfolio and in terms of percentages of highly cited papers. This is similar to the impact profile of researchers in the special interest categories (i.e. 46 individuals; 71.8%). Approximately one

fifth of individuals in the top 200 list perform below the world average for the impact of their overall portfolio and in terms of percentages of highly cited papers. Proportionally fewer special interest researchers (16 individuals; 8%) perform below the world average for citation indicators (Figure 9).

The top 200 most prolific researchers are spread across 37 research institutes, but 75% (150 individuals) of the most prolific researchers are concentrated in 9 institutions. Out of the total number of individuals working at all 37 research institutes, 166 are located in England (83%), 15 in Wales (7.5%), 12 in Scotland (6%) and 2 in Northern Ireland (2.5%). The remaining 5 are industry/NHS research institutes).

**Figure 9. Impact of the 200 most prolific researchers<sup>84</sup>**

(Blue highlights indicate researchers publishing in more mainstream dementia research areas; orange highlights indicate researchers in the special interest category. The impact profile is similar across the two groups, as discussed in the narrative above.)



<sup>84</sup> Please refer to Table 2 for indicator definitions: ARC is the average of relative citations and shows the average citation impact of all publications on a particular topic; % HCP is the percentage of particularly highly cited papers

## Chapter 4 Tracking the careers of doctoral graduates in dementia research

### 4.1. Summary

- **At a minimum, a fifth (21%) of dementia PhD graduates remain in dementia research careers. A higher-end estimate would be 38%.** Of the 1,500 dementia PhD graduates in our sample pool, we could trace the positions of 829, of whom 315 were identified as active in dementia research. This represents 21% of the overall sample pool, and 38% of successfully traced individuals. It is likely that the majority of individuals that we could not trace are not active in dementia research in any substantial way, since if they were they would be likely to have some minimal web-presence in the form of academic publications. Of all PhD graduates who remain active in research, just under half (48%) remain active in dementia research specifically. A very small minority of dementia PhD graduates (0.6–1%) remain active in dementia-related activity but not research (e.g. careers in industry and care).
- **A total of 43% of dementia PhD graduates remain in research careers – dementia or other.** From our sample of 1500 dementia PhD graduates, we traced 651 to research careers, including both dementia and other research careers (43% of the overall sample pool). This is similar to the findings of the Royal Society investigation on researcher retention in science,<sup>85</sup> which found that 47% of UK PhD science graduates remain in scientific careers.
- **A quarter (25%) of currently active dementia researchers who obtained a PhD in the UK are currently located in other countries including the USA, Canada, Germany and**

**Australia.** Within the scope of this study, we do not have data on researchers coming to the UK from other countries or entering dementia from other research fields.

- **Most active dementia researchers work in academic settings (67.3%), while the remainder work in clinical/NHS settings (13.7%), industry (4.8%) or other settings (10.8%).<sup>86</sup>** For 3.5% of researchers, the sector could not be identified.
- **There are approximately twice as many junior and mid-level staff as senior staff in the dementia research workforce (2.3:1 ratio). This ratio broadly mirrors the mix of career stages observed in the biological sciences, and subjects allied to medicine, but is somewhat higher than for medicine and dentistry.<sup>87</sup>** (Chapter 6 investigates bottlenecks in career pathways and transition points in more detail, based on interview data.)
- **The rise in the number of dementia doctoral theses published from the 1980s onwards (which can indicate early-stage research capacity-building) is broadly similar to the patterns observed for both coronary heart disease (CHD) and stroke, but the number of theses on cancer has risen much more sharply.** The proportion of theses that are related to dementia (in relation to all PhD theses across any area of science) has also increased, nearly doubling from 0.45% in 2001–2005 to 0.83% in 2011–2013, but is still substantially lower than the proportion of all theses that are in the cancer field (1.8% for 2001–2005 and 4.2% for 2011–2013).

<sup>85</sup> Royal Society (2010).

<sup>86</sup> In this context, 'other settings' includes non-classified sectors, medical writing and those in research institutes.

<sup>87</sup> We analysed data requested from Higher Education Statistics Agency (<https://www.hesa.ac.uk>) 2015. More detail is in the Chapter 4.

## 4.2. Context

As part of this study, we attempted to investigate the composition of the current dementia research workforce and to explore retention of dementia PhD graduates in the field. To do so, we conducted a scoping exercise where we traced the current position of a sample of 1500 graduates who completed a PhD in dementia-related research in the period 1980–2013 (with some exceptions for the 1970s). As discussed in more detail in Chapter 2, we obtained information on PhD theses from the British Library EThOS database,<sup>88</sup> and identified the current position of individuals through systematic internet searches.

It is important to highlight that this was a pilot exercise, and that we did not examine the attraction of researchers from other fields or other countries to dementia research in the UK, within the scope of the work. Hence, the findings presented in this chapter should be interpreted as proxies for the profile of the current workforce and retention trends, rather than absolute figures. The findings, together with qualitative insights from interviews (discussed in Chapter 5), seek to enrich current insights on career pathways for dementia researchers in the UK.

It is also worth noting that, while data on the career progression of PhDs can be difficult to collect and are not widely available, interest in these data has grown in recent years.<sup>89</sup> For example, in the UK, the Wellcome Trust has begun to track the careers of the researchers it funds through its Basic Science Career Tracker (BSCT)<sup>90</sup> and Clinical Career Tracker (CCT)<sup>90</sup> (BSCT and CCT) surveys, and their data now cover cohorts of researchers who completed PhDs in 2009 (for the BSCT) and 2011 (for the CCT) onwards. In the USA, the UMETRICS initiative, which builds on the STAR Metrics data platform,<sup>92</sup> aims to assess the impacts of research funding and interplay between funding, careers and research outputs.<sup>93</sup> These approaches, and the data emerging from them, may be useful resources for organisations to consult if they are considering establishing career-tracking management information systems.

## 4.3. Retention of dementia PhD graduates in dementia research

Our findings suggest that between a fifth and a third of dementia PhD graduates remain in dementia research careers. Amongst the 829 dementia PhD graduates whose current position we could trace (from a sample pool of 1500), nearly 80% were still active in research (651 out of 829, or 79%) and 38% were active in dementia research specifically (315 of 829) at the time of this analysis (Figure 10). However, if we consider all dementia PhD graduates in our sample pool (1500) - i.e. not only the 829 successfully traced individuals, but also those we could not trace and who are unlikely to be active in dementia research - then the figure for retention in dementia research careers drops to 21% (i.e. 315 current dementia researchers from a sample pool of 1500 theses). The highest-end estimate - if researchers who are classified as 'uncertain' (due to publishing in brain research and neurodegeneration) were to be included and only traced individuals considered - would be 48% of all dementia PhD graduates remaining in dementia research (394 individuals out of 829) (Figure 10).

As mentioned previously, of the successfully traced dementia PhD authors, 79% (651 of 829) remain in research careers, dementia or other. A lower-end estimate for retention in research, assuming that most untraced individuals would have been traced had they continued with research careers is 43%. This latter estimate is closer to the findings reported in a recent report by the Royal Society,<sup>94</sup> which showed that approximately 47% of all PhD graduates, across different areas of science, remain in research careers, while 53% pursue careers outside science.

Based on the number of current active dementia researchers, retention in the field has fluctuated over time (see Figure 11 and Table 9). The number of dementia-related PhD graduates currently active in dementia research varies from 18.5% (1991–1995) to 27.1% (2006–2010) of all graduates. This number is lower for

<sup>88</sup> British Library (2015).

<sup>89</sup> Sinche (2014).

<sup>90</sup> Wellcome Trust (2013a).

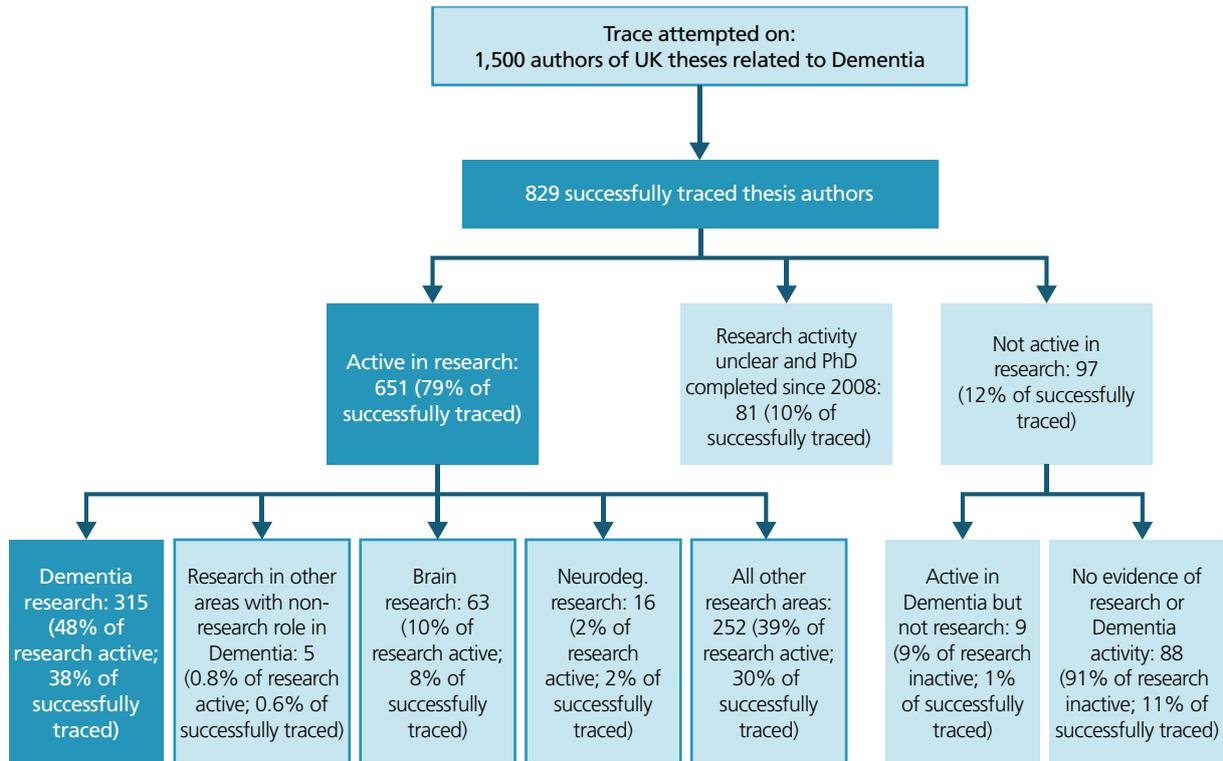
<sup>91</sup> Wellcome Trust (2013b).

<sup>92</sup> STAR Metrics (2015).

<sup>93</sup> Lane et al. (2015).

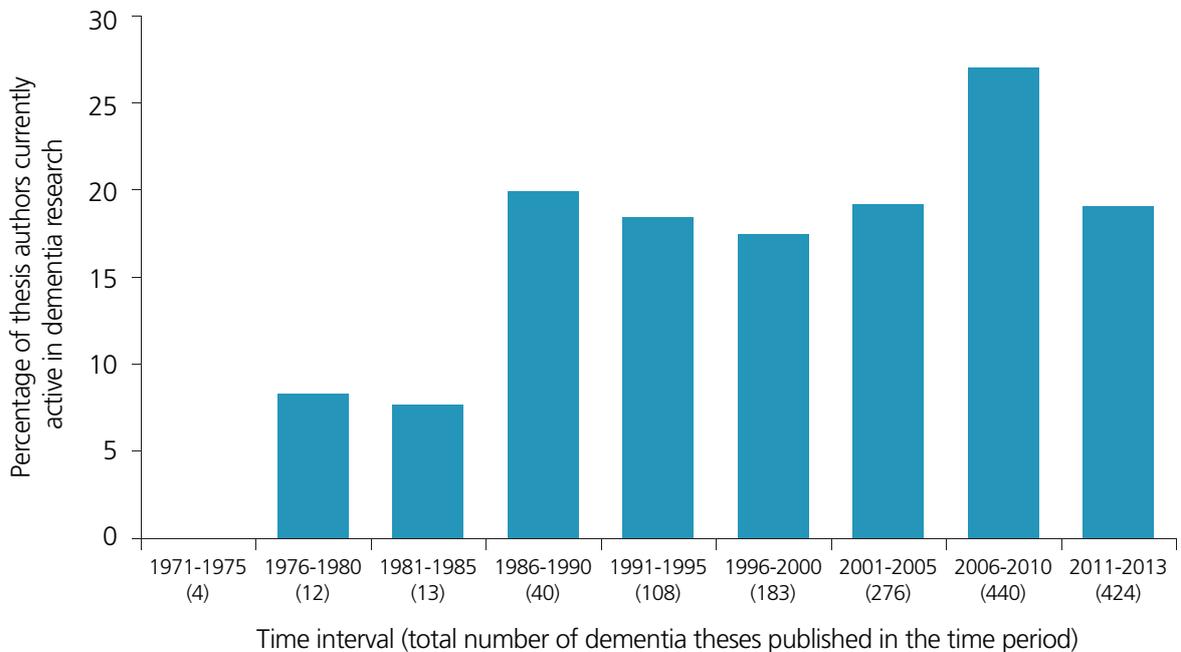
<sup>94</sup> Royal Society (2010).

**Figure 10. Summary of results for successfully traced dementia-related PhD graduates: activity in research, dementia and related areas**



Source: researchers' own data from PhD tracing exercise

**Figure 11. Retention: percentage of dementia thesis authors who are now active dementia researchers per time interval.**



Source: researchers' own data from PhD-tracking exercise

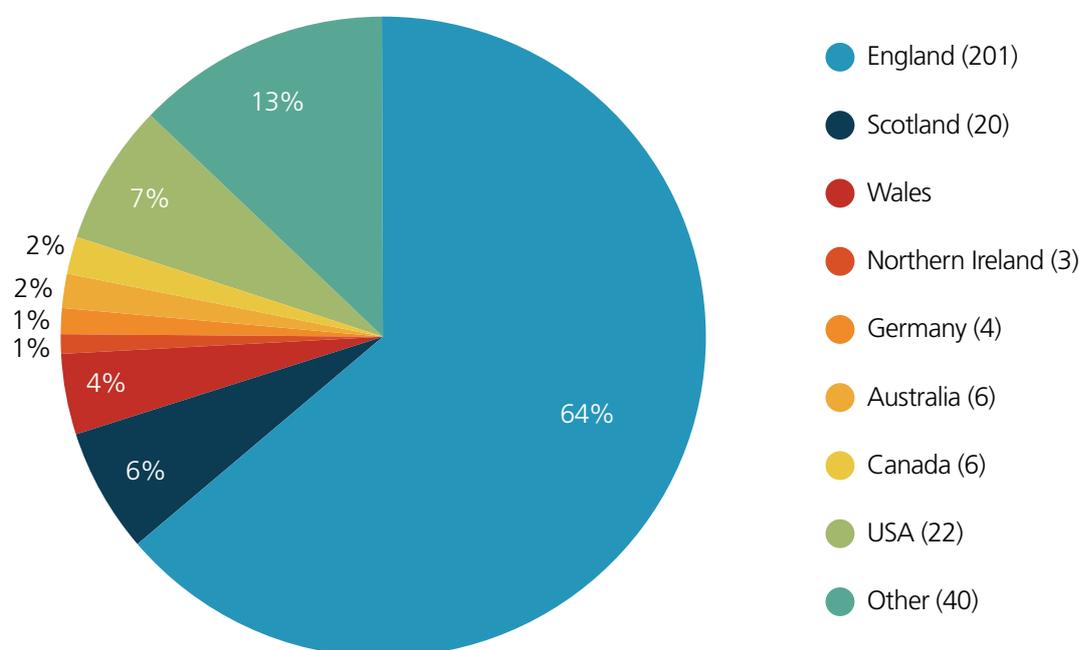
individuals who completed PhDs in the 1980s, where retention ranges from 7.7–20% although absolute

numbers of dementia-related PhD graduates from the 1980s are much lower compared with 1991 onwards.

**Table 9. Retention: number of dementia thesis authors who are now active dementia researchers per time interval (in absolute numbers and as a percentage of the total number of dementia-related theses)**

	1971-1975	1976-1980	1981-1985	1986-1990	1991-1995	1996-2000	2001-2005	2006-2010	2011-2013
Number of dementia-related theses	4	12	13	40	108	183	276	440	424
Number (and percentage) of traced authors active in dementia research	0	1	1	8	20	32	53	119	81
	0%	8.3%	7.7%	20.0%	18.5%	17.5%	19.2%	27.0%	19.1%

Source: researchers' own data from PhD tracing exercise

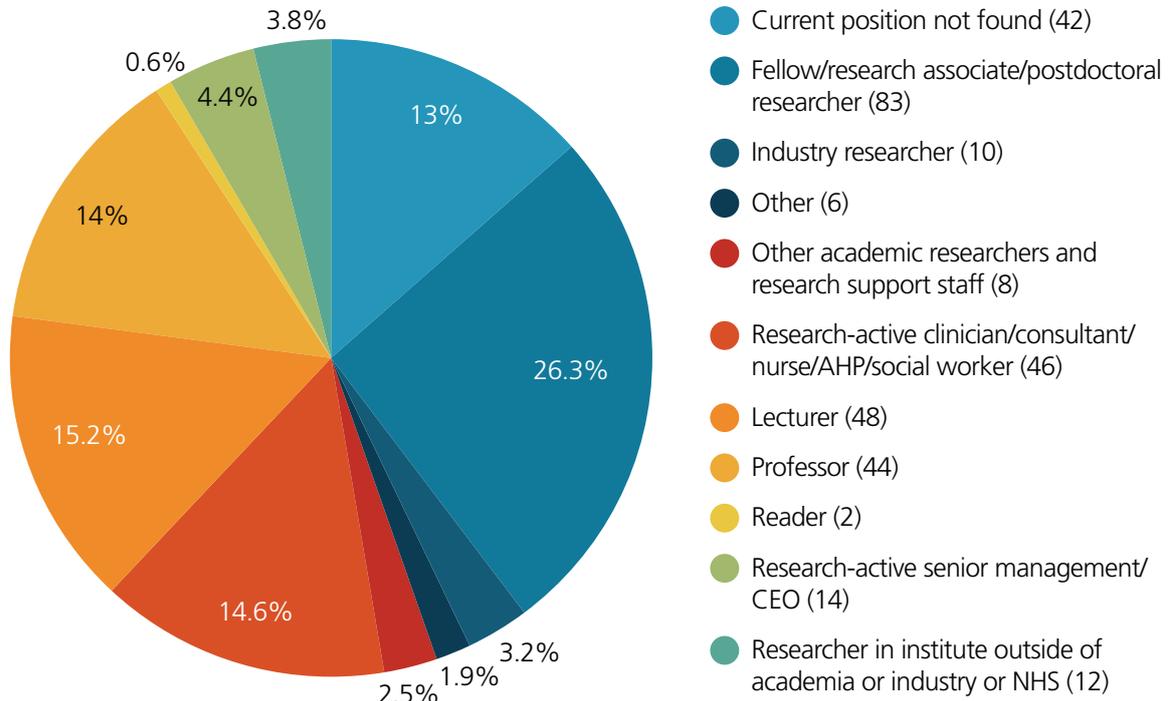
**Figure 12. Geographic distribution of the 315 active dementia researchers**

Source: researchers' own data from PhD tracing exercise

In terms of 'brain drain', of the 829 traced individuals who obtained a PhD in the UK in dementia, 31% are currently located in other countries, including the USA, Canada, Germany and Australia. Among the 315 individuals active in dementia research, this figure is 25% (Figure 12). Within the scope of this study, we do not have data on researchers coming to the UK from other countries or entering dementia from other research fields.

#### 4.4. Profile of UK dementia researchers based on research-active dementia PhD graduates as a proxy

Of the 315 individuals who were identified as active in dementia research, the research team was able to identify job titles for 273 (87%). Each individual was then categorised under a harmonised professional position to facilitate analysis of the workforce composition (Figure 13). In total, 26.3% of all active dementia researchers

**Figure 13. Active dementia researchers by profession**

Source: researchers' own data from PhD tracing exercise

are either fellows, research associates or postdoctoral researchers<sup>95</sup>; 15.2% are research-active lecturers; 14.6% belong to clinical and allied staff (e.g. research-active clinicians, consultants, nurses and allied health professionals); and 13.9% are research-active professors (see Figure 13 for the breakdown). The remainder include dementia researchers representing research-active senior management and executives (4%); researchers in dementia outside academic, clinical or industry settings such as in research institutes (4%); industry researchers (3%), research support staff such as research assistants and research tutors (2%), readers (1%) and other staff (2%) (Figures 13 and 14). In the 'other' category, individuals included an engineer, an instructor in radiology, medical writers, a trials manager and a visiting academic. For 13.3% the exact position could not be identified.

Overall at the sector level, among the 315 active dementia researchers we traced, 67% (212 people) are working in an academic setting, while 14% (43) are in

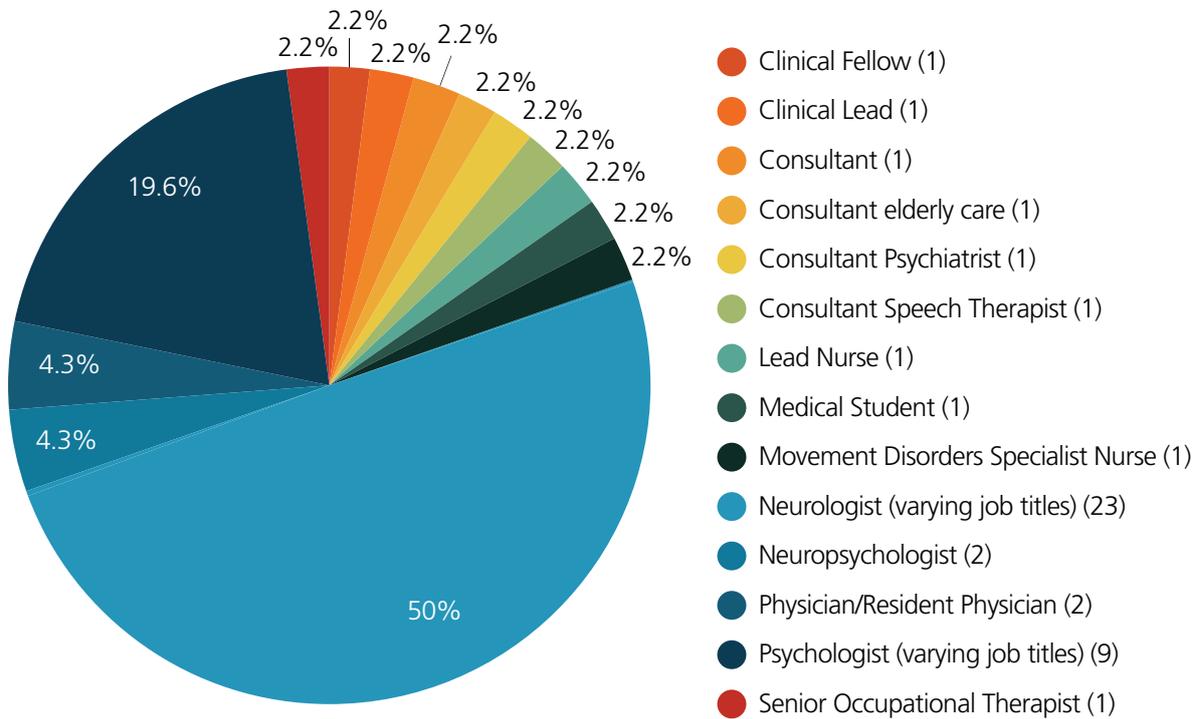
a clinical setting in the NHS (Figure 15). A further 5% (15 people) are working in industry. Of the remaining individuals, 11% (34) are working in another area while 3% (11) could not be categorised by sector.

We also divided PhD graduates who are still active in dementia research into categories reflecting the stages of the career pathway and current levels of seniority. We used an approach consistent with that used in Chapter 3 for the categorisation of the most prolific researchers identified through the bibliometric analysis. We harmonised available information on researcher positions into categories that drew on but adapted Higher Education Statistics Agency (HESA) contract-level classifications (see Table 10 for categorisation).<sup>96</sup> We could not distinguish between junior and mid-level roles from the data we had (e.g. postdoctoral and research associates or fellows can have different levels of seniority). However, we investigate issues related to specific stages of dementia research career pathways in more detail in

<sup>95</sup> This group was merged to facilitate subsequent career-stage analysis. Absolute numbers for each group are: 83 fellows, research associates and postdoctoral researchers; ten industry researchers; eight other academic researchers and research support staff; 46 research-active clinicians/consultants/nurses/allied health professionals/social workers; 48 lecturers; 44 professors; two readers; 14 people active in research from senior management/CEO; 12 researchers in institutes outside academia or industry or the NHS. Six individuals were placed in the 'other' category and the current position for 42 individuals was not identified as a result of the PhD tracing exercise.

<sup>96</sup> Data obtained from HESA (<https://www.hesa.ac.uk>) 2015 and analysed by RAND Europe.

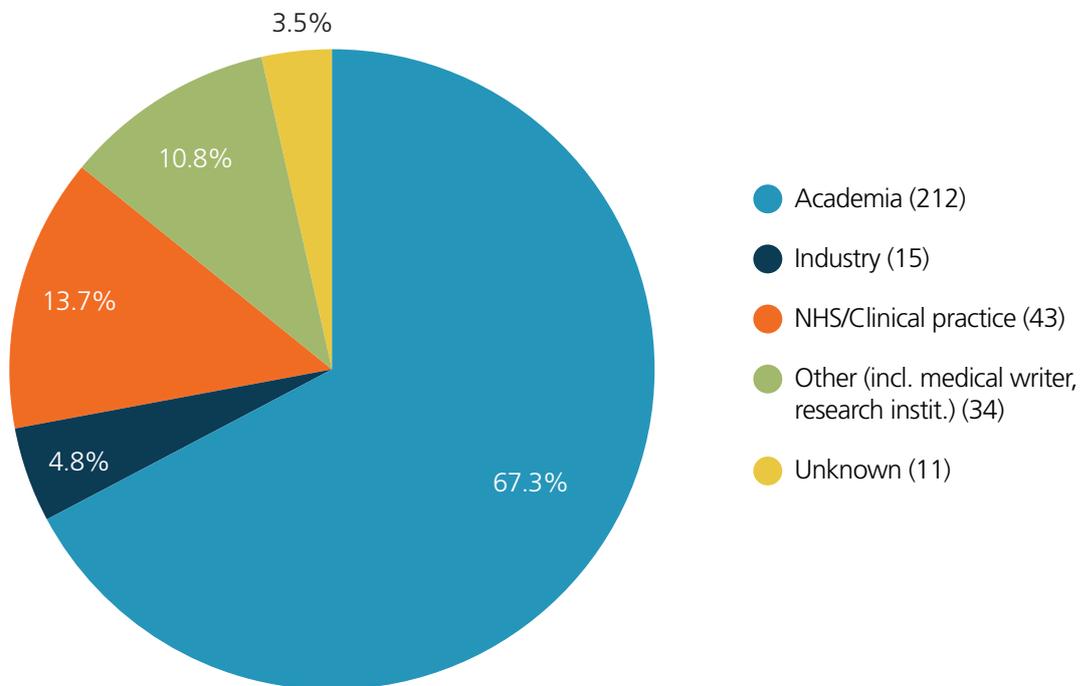
**Figure 14. Breakdown of dementia researchers with clinical and related roles (e.g. allied health)**



Source: researchers' own data from PhD tracing exercise

**Figure 15. Active dementia researchers by sector**

(Note that percentages are presented in the pie chart and the absolute number of individuals in the legend.)



Source: researchers' own data from PhD tracing exercise<sup>97</sup>

<sup>97</sup> In this context, the 'other setting' includes senior management; non-academic, non-industry, non-NHS researchers; and other.

**Table 10. Breakdown of seniority levels by harmonised professional position**

Junior or mid-level	Fellow, research associate, postdoctoral researcher (83)
	Lecturer (48)
	Other academic researchers and research support staff (8)
Senior	Reader (2)
	Professor (44)
	Research-active senior management/CEO (14)
Seniority not known	Research-active clinician/consultant/nurse/AHP/ social worker (46)
	Industry researcher (10)
	Researcher in institute outside of academia or industry (12)
	Other (6)
	Current position not found (42)

**Table 11. Seniority level of successfully traced PhDs who are still active in dementia research**

Seniority Level	Absolute number	% of traced active dementia researchers
Junior or mid-level	139	44.1%
Senior	60	19%
Seniority not known	116	36.8%
<b>Total</b>	<b>315</b>	

Chapter 5. In total, 139 active dementia researchers from the PhD trace fall into the junior or mid-level range of seniority (44.1%), 60 individuals are at a senior level (19%), and 116 individuals' level of seniority could not be determined (36.8%) (Table 11).<sup>98</sup>

Drawing from the above, and based on the findings of our PhD tracing exercise as a proxy, the ratio of junior and mid-level to senior staff in UK dementia research is 2.3:1. We tried to explore how this compares to the patterns observed in other areas of science. To do so, we obtained HESA data on contract levels for all higher education staff and also specifically for staff working in biological and medical-related fields. More specifically, we analysed workforce profiles for HESA field categories of: (i) all higher education; (ii) biological sciences; (iii) subjects allied to medicine; and (iv) medicine and dentistry. As we were specifically interested in research-active

staff, we restricted our analyses to staff with a research only, or a research and teaching contract.<sup>99</sup>

Table 12 shows the percentage of staff at different grades, based on HESA contract levels, slightly adapted in order to be comparable to classifications used in our career-stage analysis in the PhD tracing exercise and in the bibliometrics chapter. Senior staff include: senior management, head of schools/senior function head, professor, function head, non-academic section manager, senior/principal lecturer, reader, and principal research fellow. Mid-level and junior staff include: team leader (professional, technical, administrative), lecturer, senior lecturer, senior research fellow, senior professional (technical), lecturer, research fellow, researcher (senior research assistant) and teaching fellow. Support staff were included in the 'seniority not known' category to ensure compatible comparisons across the

<sup>98</sup> Each traced active dementia researcher was categorised, based on their job title, if it was known, into a harmonised professional position, e.g. a 'research tutor' (job title) was categorised as 'Other academic researchers and research support staff' and a 'head engineer' (job title) was categorised under 'Other', to name but two examples. The level of seniority could not be determined for a number of individuals (e.g. those in the category 'Research active clinician/consultant/nurse/allied health professional/social worker') on the basis of job title alone. In these cases, the study team declined to make a judgement on individuals' seniority level and classed them as 'seniority not known'.

<sup>99</sup> However, we know from previous studies that some universities give research and teaching contracts to most staff, so it is possible that this data includes staff with varying levels of research activity.

work-packages. Based on HESA data, this category includes support staff at various levels of seniority. Table 12 below shows the breakdown of staff and how this relates to our findings for career stages in the dementia research workforce. Broadly, the ratio of junior and mid-level to senior staff in the dementia research workforce mirrors that found in biological sciences and subjects allied to medicine. The ratio is somewhat higher than for all areas of science considered together. We explore major career bottlenecks and challenges in more detail in Chapter 6.

#### 4.5. Knowledge production: changes in the numbers of UK dementia PhD graduates over time

Finally, we also investigated changes in the number of dementia theses produced over time. To do this we compared the numbers of dementia theses indexed in the EThOS database with the numbers of all theses

indexed, as well as the number of theses on cancer, CHD and stroke.<sup>100</sup> As shown in Figure 16, the number of dementia theses published increased nearly 60% from 276 in the period 2001–2005 to 440 in the period 2006–2010. The rise in the number of dementia theses published from the 1980s onwards is broadly similar to the patterns observed for both CHD and stroke, but the number of theses on cancer has risen more sharply. Consistent with this pattern, overall UK research spending on cancer is much higher than for the other conditions; the combined spend from government and charity sources in 2008 was £590 million for cancer, compared with £170m for CHD, £50m for dementia and £23m for stroke.<sup>101</sup> Figure 17 shows that the proportion of theses on dementia has also increased, nearly doubling from 0.45% in 2001–2005 to 0.83% in 2011–2013, but is still substantially lower than the proportion of all theses in the cancer field (1.8% for 2001–2005 and 4.2% for 2011–2013).<sup>102</sup>

**Table 12. Levels of seniority for active dementia researchers (from the PhD tracing exercise) and for staff employed at UK higher education institutions with a contract to do research only, or research and teaching, for specific fields and overall**

Seniority level	Dementia (as proxied by dementia PhD graduates still active in dementia research)	Biological sciences	Subjects allied to medicine	Medicine and dentistry	All higher education
Junior or mid-level	44.1%	56%	63%	51%	54%
Senior	19%	28%	29%	33%	36%
Seniority not known	36.8%	16%	8%	16%	10%
Ratio of junior or mid-level to senior	2.3: 1	2:1	2.2:1	1.5:1	1.5:1

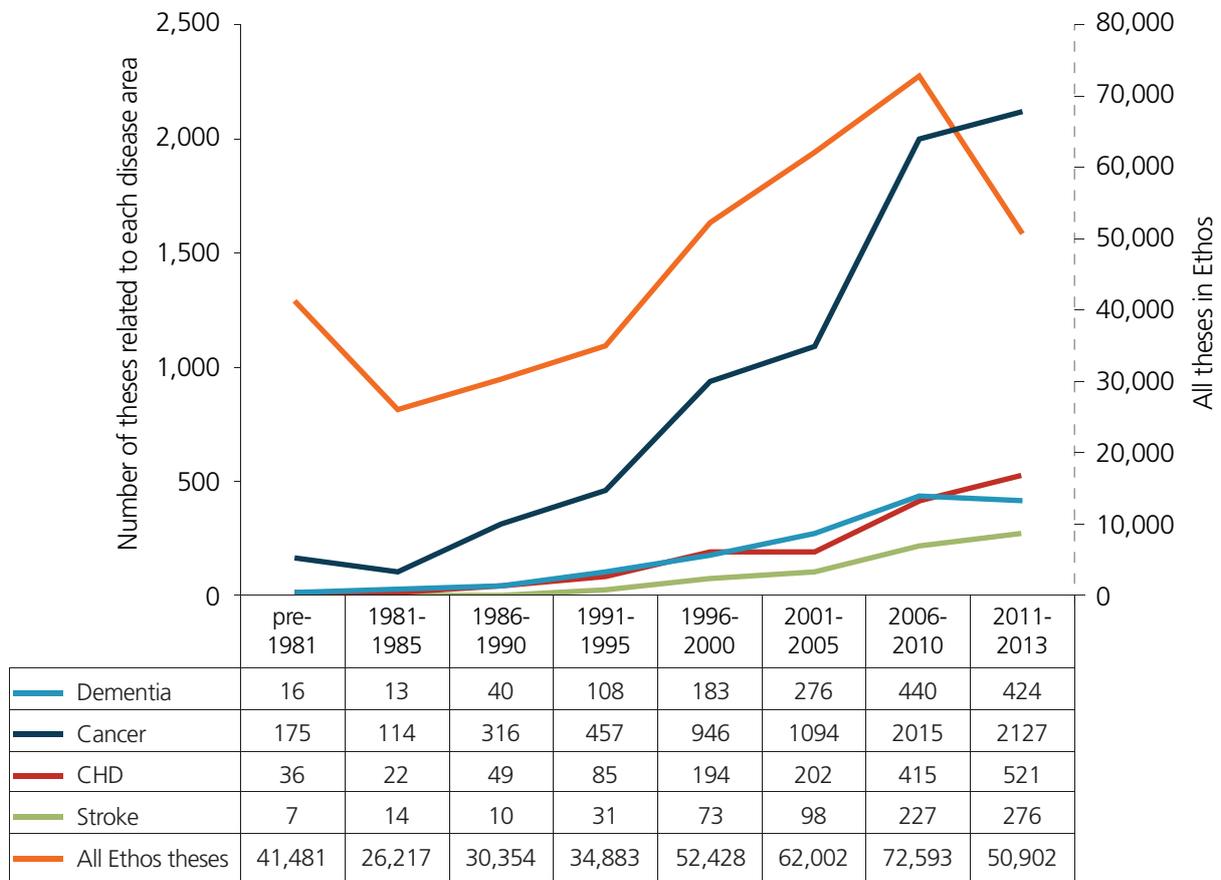
Source: HESA 2015; data analysed by RAND Europe

<sup>100</sup>As noted in the chapter on methodology, the EThOS database does not hold all theses published in the UK. Moreover, the figures on numbers of theses in each disease area are not mutually exclusive (e.g. a thesis covering both stroke and dementia would be counted in figures for both).

<sup>101</sup>Luengo-Fernandez et. al (2015) report that total UK government and charity research spending on cancer and CHD declined slightly from 2008 to 2012, while spending nearly doubled for dementia and more than doubled for stroke.

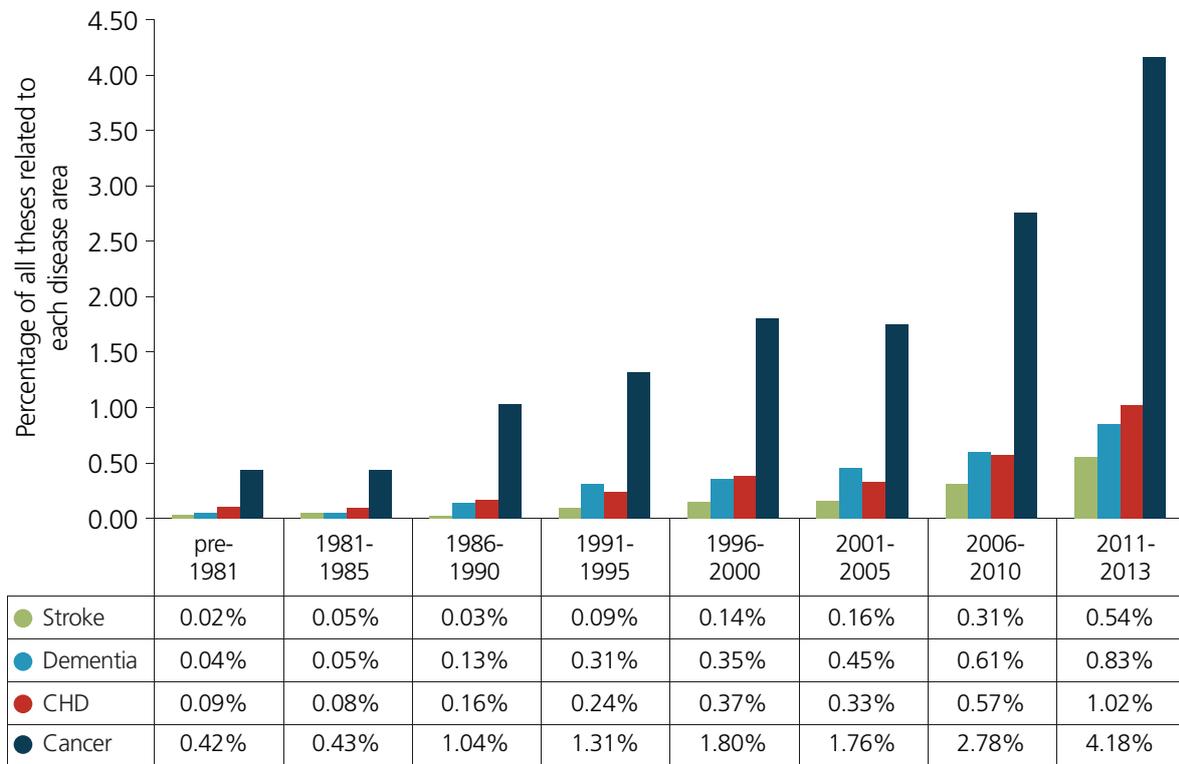
<sup>102</sup>It should be noted that an increase in the proportion of theses about cancer, CHD and stroke also increased over time, although we cannot rule out the possibility that changes in the use of keywords over time could be partly responsible for the increase observed.

**Figure 16. Number of theses published over time (and indexed in the ETHOS database) overall, and in dementia, cancer, CHD and stroke.**



Source: ETHOS at the British Library.

**Figure 17. Percentage of all UK theses (as indexed in the EThOS database) that relate to dementia, cancer, CHD and stroke.**



Source: EThOS at the British Library

## Chapter 5 The UK dementia research landscape from the perspectives of multiple stakeholders

### 5.1. Chapter summary: strengths and limitations of the UK dementia research landscape – insights from interviews

- This chapter presents insights from interviews with diverse stakeholders in research, policy, funder, service provider and industry communities. The interviews aimed to achieve a better understanding of the strengths, gaps and capacity-building priorities for the UK dementia research system and dementia research workforce. We spoke to representatives at varied stages in their careers and from diverse fields. The current chapter (5) focuses on findings relating to the dementia research landscape specifically. The next chapter (6) presents findings pertaining to the dementia research workforce.
- Caveats: interviewee responses tended to reflect their professional experiences and areas of work with which they were more familiar. When reporting on research gaps in particular, respondents tended to comment on limitations within their own research field. However, when commenting on research strengths, interviewees frequently highlighted strengths in areas (disease-foci, fields and disciplines) other than their own. Overall, we are confident we obtained a rounded evidence base across the diversity of individuals interviewed.

#### Key strengths

- The UK dementia research portfolio is diverse, and the following strengths were most frequently highlighted: (i) dementia-related genetics research to advance knowledge of dementia disease-risk, for example in Alzheimer's and Parkinson's diseases; (ii) brain-imaging to provide evidence on disease progression; (iii) research on Lewy body dementia; (iv) research into the development of person-centred care; (v) epidemiological work with cohort studies; and (vi) research on the amyloid hypothesis and amyloid fibril formation.<sup>103, 104</sup>

#### Gaps and limitations to inform research capacity-building

- Interviewees also highlighted various gaps in knowledge about dementia and limitations in the UK research landscape. Some of these reflect global knowledge gaps (e.g. insights into cellular mechanisms in dementia, classification of dementia disease) or general challenges in biomedical research which may be accentuated in the dementia context (e.g. the challenges of engaging clinicians in research and translating research into practice), whilst others were highlighted as particularly notable in a UK context and in dementia research policy (e.g. a lack of critical mass in care-related dementia research, limited industry engagement,

<sup>103</sup>Epidemiological work with cohort studies and research on the amyloid hypothesis and amyloid fibril formation were both mentioned by five interviewees and hence share fifth place as most commonly mentioned strengths.

<sup>104</sup>Although mentioned less frequently, interviewees also noted examples of influential UK research across a broader array of dementia-related topics, including: frontotemporal dementia; mixed dementia; work covering links between Amyotrophic Lateral Sclerosis (ALS) and dementia, and Parkinson's disease and dementia; biomarkers; cognitive stimulation studies; research into interventions to improve the lives of those affected; work on early diagnosis; the development of clinical centres for dementia care; tau protein pathology studies; research into the clinical definition and classification of dementia; brain banks and neuropathology.

- insufficient focus on specific rarer dementias).
- The most frequently identified gaps in the UK dementia research system were:
    - *Limited understanding of the cellular mechanisms underlying dementia* and the need for more collaboration between different fields towards that end (e.g. cell biologists, electrophysiologists, geneticists, neurophysiologists, pathologists and others).
    - *Insufficient clinician involvement in research*, given the crucial role clinicians play in defining research questions to reflect clinical and patient needs, the knowledge they have from observing patients, and their ability to contribute to research translation.
    - *Underinvestment in care-related research* (e.g. in nursing, allied health professions and social care fields), given the costs of dementia care to the UK economy, and an associated need to explore new ways of overcoming difficulties in research careers in the allied health professions. Several aspects of care research were seen as important to support, including end-of-life care, care for patients with advanced-stage dementia, care for marginalised and hard-to-reach groups, research into patient–carer relationships, research on educating carers, and arts therapies for people with dementia.
    - *Scope for improvement in the conduct of clinical trials*, most notably in recruitment processes and incentives for clinicians to enrol patients in trials, the accuracy of diagnosis (which can affect recruitment as well as trial outcomes and interpretation), and mechanisms to attract and facilitate industry engagement in dementia research.
  - *Retaining and enhancing industry engagement with the dementia challenge* in areas including (but not confined to) collaboration in applied R&D drug-discovery efforts, and the development of medical apps and assistive living technologies.
  - *Scope for greater emphasis on translational research*: both research which would link genetics, cellular mechanism studies and drug target discovery efforts; and translational work which would help move advances from care-related research into improved service delivery.<sup>105</sup>
  - Our bibliometric analysis highlighted that UK research in familial dementia and early-onset dementia lags behind that of other countries in citation impact. Interviewees said that the key reasons for this include a low number of patients diagnosed with these conditions in the UK, patient recruitment challenges (which are accentuated by a lack of specialists able to accurately diagnose these conditions), the disjointed nature of service delivery for such patients (which impacts on recruitment), and competition between specialties for patient recruitment.
  - Most interviewees were in favour of balancing research investments across different dementia disease areas and across basic, applied and clinical research. Some, however, highlighted potential merits in more targeted strategies. Views on the balance of support related to prevention, treatment and care delivery were very mixed, and largely reflected individual professional experiences and backgrounds.

<sup>105</sup>Although mentioned less frequently or with mixed views, other research gaps identified by interviewees included large-scale cohort studies, improved animal models and combined human and animal work, and rare diseases.



## The UK dementia research landscape...views from the ground

### On opportunities...



"...There is a definite momentum building which is fantastic but we need to learn from the past so we don't get railroaded on one route suggested by big guns and charismatic individuals..."



"...The best way to organise a lab is to have young PhDs and young MDs in the lab. MDs bring knowledge of the disease, PhDs bring scientific rigour – a good lab has a mixture of both..."



"...I think in ten years we'll have a medicine that slows the disease down... The general perception that things have failed is wrong and is a major hurdle. Actually I think dementia and Alzheimer's disease in particular is one of the more tractable mental health disorders..."



"...The UK generally, across the research landscape, punches above its weight with publications and often science done on a shoestring, so we have got a lot of return for our buck and there is a degree of efficiency and intellectual rigour which has always been great..."

### Key strengths of the UK dementia research landscape highlighted by interviewees

- Genetics
- Brain imaging
- Lewy body dementia
- Psychosocial interventions & person-centred care
- Cohort studies and epidemiology
- Amyloid hypothesis, amyloid fibril formation

### On challenges...



"...Basic scientists on their own will work on drosophila from now until their retirement days... Clinicians will see patients and do clinical trials without ever thinking about underlying science... Bringing everybody together so that they all understand what the other is trying to do is really a challenge and it requires sustained funding..."



"...[Allied health and nursing research] should be high up the research agenda as they are the mainstay of social and community care... [However,] within these health professions, working with people with dementia is still not seen as a career pathway of choice..."



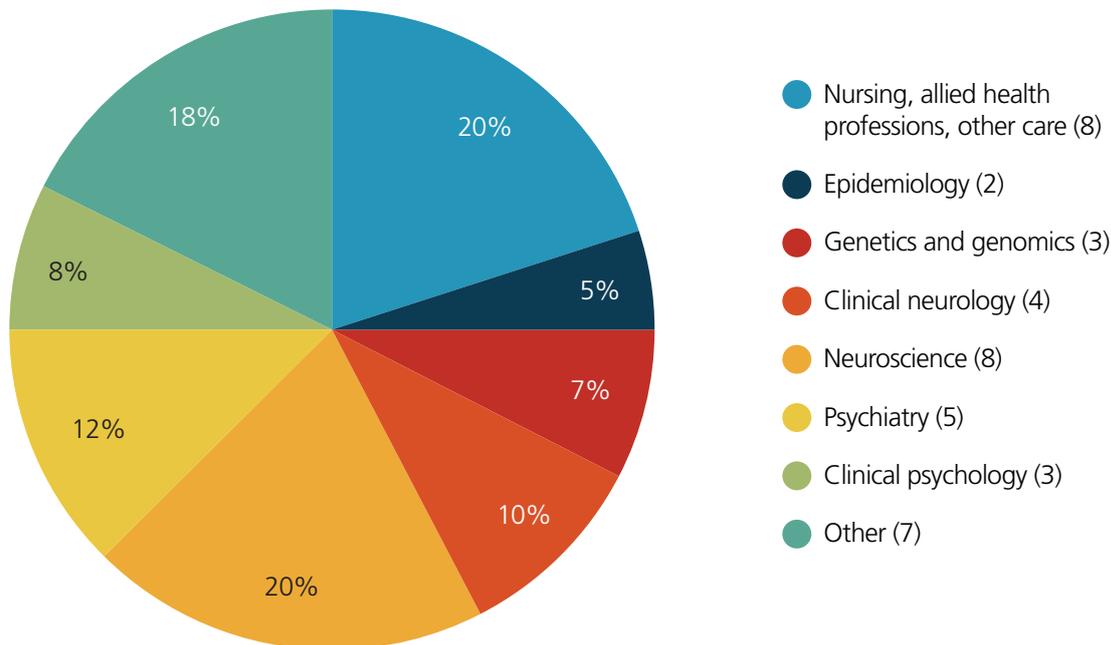
"...Both [care and treatment research] are important. We won't find a cure for dementia overnight; we'll see small inroads like with cancer and HIV, and hopefully bigger inroads with time. The prevalence of the disease will increase and put more pressure on the care side of things. You might say your vision of the world is a world free of Alzheimer's disease, but before you get there, you'll have a world full of it..."



"...It is extremely difficult to recruit patients and researchers interested in trials might be discouraged..."



"...For every one person who has a diagnosis of dementia there are conservatively 10 around them impacted... A lot of people in that circle are still lacking a lot of information. We need to research how to educate and train people in that circle to better communicate with a person who has dementia, and about the course of the type of dementia they might have..."

**Figure 18. Breakdown of interviewees by field**

## 5.2. Context

We conducted interviews with diverse stakeholders in research, policy, funder, service provider and industry communities, to obtain a better understanding of the strengths, gaps and capacity-building priorities for the UK dementia research system and dementia research workforce. We also aimed to gather insights about ways to better support research and researchers. The interviews helped add more nuance, breadth and depth to the insights gained through our bibliometric analyses and the PhD tracing exercise. We spoke to representatives at diverse stages in their career pathways and from varied fields.

A total of 40 individuals were interviewed by telephone; the interview methodology and selection process are discussed in Chapter 2 (for interview protocols, see Appendix 1). Most of the interviewees are currently involved in some aspect of dementia research. The majority are active researchers (some

with joint clinical appointments), while others have clinical or therapeutic roles, or work in research funding and policy, or in industry (or have had prior experience working in industry). We also consulted a small number of dementia PhD graduates who are no longer in the field, in order to understand reasons for leaving this area of research. Together, the interviewees represented a range of disciplines, sectors, and levels of seniority (see Figures 18–21).

To aid the interpretation of our findings, interviewees were grouped by disciplinary background (see Figure 18) and stages of career pathways (see Figures 20 and 21). The disciplinary categories were determined from information on current areas of activity, provided by the interviewees. The nine broad categories of interviewee include: nursing, allied health professions and other care;<sup>106</sup> epidemiology; genetics and genomics; clinical neurology; neuroscience; psychiatry; clinical psychology; and ‘other’ (which includes representatives of research funding bodies<sup>107</sup> and industry,<sup>108</sup> an individual who

<sup>106</sup>The ‘Nursing, allied health professions and other care’ category includes occupational health, social work, nursing, healthcare research, arts therapy and evaluation of arts therapy, and physiotherapy.

<sup>107</sup>Three people.

<sup>108</sup>One person.

Figure 19. Breakdown of interviewees by sector

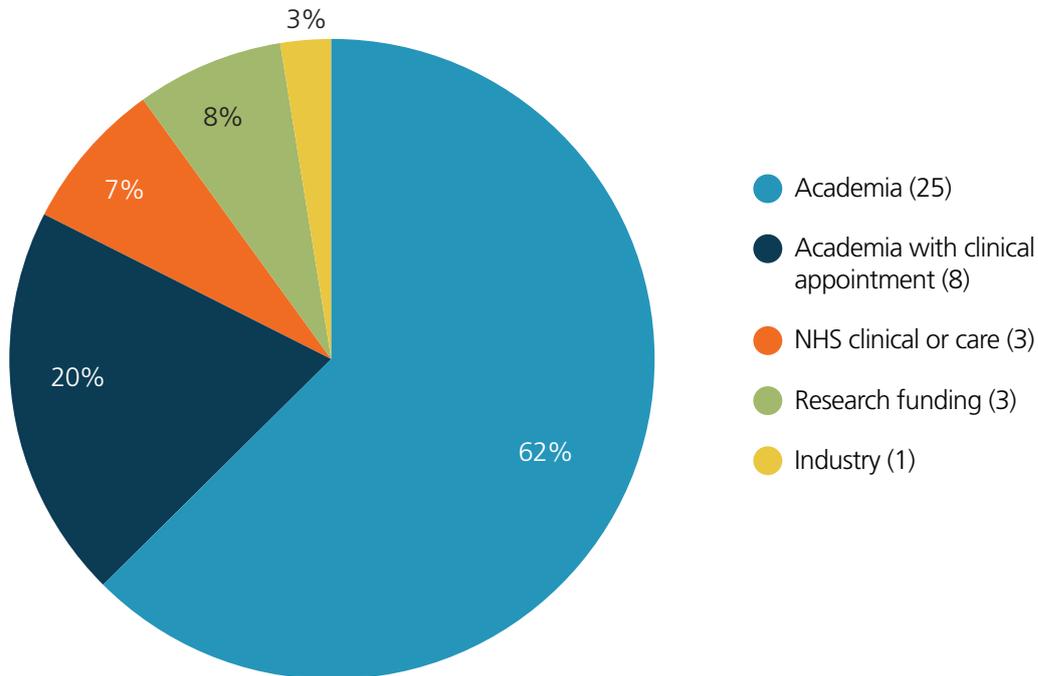
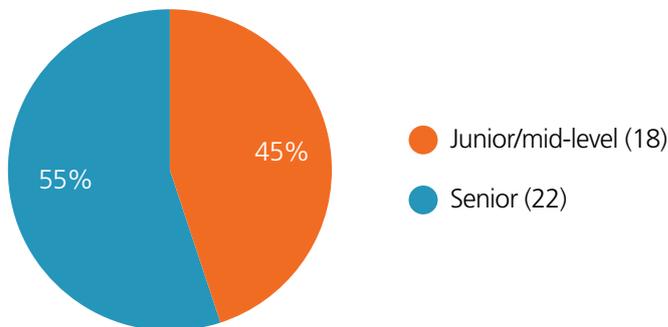


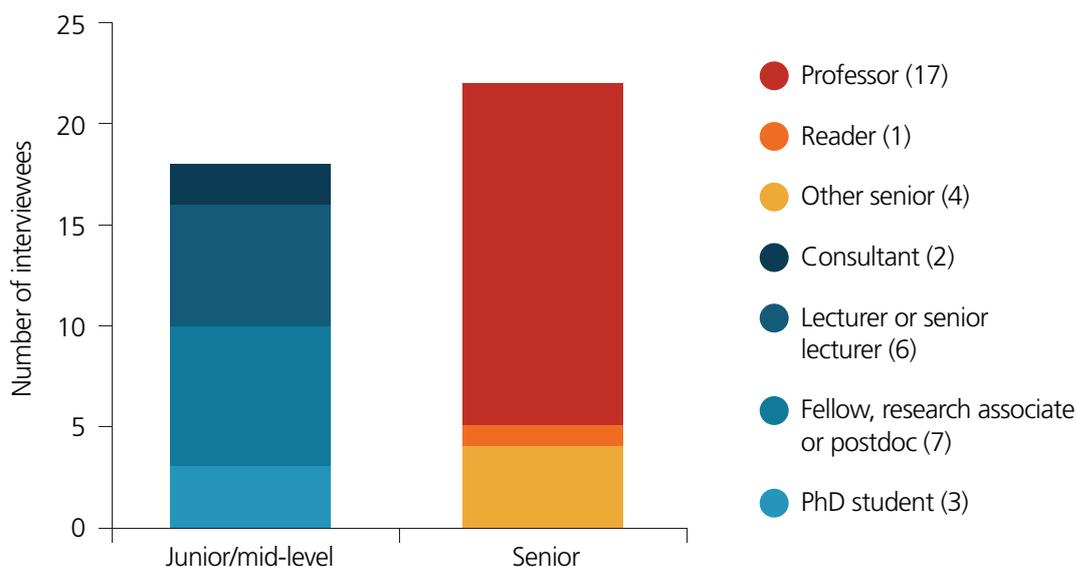
Figure 20. Breakdown of interviewees by seniority (junior/mid-level vs senior)



completed a PhD related to dementia and now does research that does not fall under our main categories, and a radiologist). Although classifications were made based on the interviewee's primary professional activities, it should be noted that some individuals do work that falls into more than one of these categories. In addition, there are instances throughout the report where we refrain from providing detailed information about the field of the interviewee(s) who made specific comments, in order to preserve the requisite degree of anonymity. However, we do discuss general patterns that may emerge as differences across interviewees' fields. A list of all interviewees (bar one who requested to remain unlisted) is provided in Appendix 2. Figure 18 presents a breakdown of individuals interviewed by their primary field of activity, indicating a multidisciplinary spread of individuals.

The majority of the interviewees we spoke to were from the academic sector (83%; 33 people), while others worked in clinical or care positions in the NHS (3 people), research funding (3 people) or industry (one person). Among the 33 who work in academia, 8 (nearly a quarter) have joint clinical appointments and the remaining 25 only have an academic affiliation. Figure 19 shows the breakdown of sectors across interviewees.

We also grouped individuals into two categories of seniority in order to indicate stages in career pathways: whether junior or mid-level (including PhD students, postdoctoral fellows, research fellows, research associates, lecturers, senior lecturers and clinical consultants), or senior (including readers, professors, and others who did not have a standard academic or clinical rank but

**Figure 21. Breakdown of interviewees by seniority (detailed)**

were considered to be senior based on their degree of experience and responsibility). This classification is consistent with that used elsewhere in this study. Figures 20 and 21 present a breakdown of interviewees by career stage, indicating a 55:45 mix of senior to mid-level and junior staff.<sup>109</sup>

While broad agreement across several interviewees indicates that a view is shared by multiple people, minimal emphasis should be placed on quantifying responses. Rather, responses should be understood and interpreted in context. Interviewees tended to focus on issues that were within or near their own area of expertise, or which were otherwise of particular interest to them. In addition, in some interviews, specific questions and issues were discussed in more depth than others. Finally, in some instances there was variation in how questions were interpreted. For example, we deliberately left questions about areas of strength or weakness relatively open-ended to ensure that respondents discussed what they found most important. This meant that some interviewees discussed specific disease areas, others highlighted strengths or weaknesses related to research fields, while some individuals focused on issues of basic versus applied and clinical research, or biomedical versus services research. We

aimed to ensure a representative sample of interviewees across fields, but recognise that there are individuals, professions and organisations that could add additional perspectives in future follow-up work.

The contents discussed in this chapter focus specifically on findings related to insights on the dementia research landscape. We asked interviewees about their views on areas of strength and weakness in UK dementia research, and we solicited insights on issues interviewees saw as being important to future investment strategies (e.g. breadth of portfolio; comparative emphasis on prevention, treatment or care research; and the balance between supporting basic, applied and clinical research). Findings related to the research workforce are presented in Chapter 6.

### 5.3. Science and skills: strengths of the UK dementia research landscape

Interviewees most frequently highlighted strengths in dementia-related genetics research, brain-imaging, Lewy body dementia, and psychosocial interventions and person-centred care (Box 2). Five interviewees also stressed that UK research generally performs very well considering the resources available.<sup>110</sup>

<sup>109</sup> Aside from wanting to ensure a consistent approach across the work-packages, we felt that it would have been challenging to distinguish consistently and accurately whether some interviewees were junior or mid-level. This issue could be investigated further in related future studies.

<sup>110</sup> INT11, INT14, INT25, INT27, INT31.

<sup>111</sup> INT01, INT02, INT05, INT08, INT09, INT11, INT12, INT15, INT16, INT22, INT23, INT25, INT26, INT27, INT31, INT32, INT40.

**Box 2. Key strengths of the UK dementia research landscape highlighted by interviewees**

- Genetics
- Brain imaging
- Lewy body dementia
- Psychosocial interventions and person-centred care
- Cohort studies and epidemiology
- Amyloid hypothesis, amyloid fibril formation

**5.3.1. Excellence in genetics research, particularly as applied to understanding Alzheimer’s and Parkinson’s disease-related dementia**

A total of 17 interviewees from a range of fields – including basic, clinical and care research areas – highlighted work in genetics.<sup>111</sup> Some of them referred specifically to genome-wide studies identifying genes linked to the risk of developing Alzheimer’s disease and Parkinson’s disease, carried out by research groups in Cardiff and London.<sup>112</sup> Focusing on developments specific to Alzheimer’s disease, a neuroscientist emphasised that “*Genetics is a strong point in Alzheimer’s disease research in the UK, as well as basic research studying the aggregation of the Alzheimer’s disease protein using modelling and in vitro techniques.*”<sup>113</sup>

**5.3.2. Strengths in brain-imaging to understand dementia disease progression**

Brain-imaging was highlighted as a strength of UK dementia research by 13 interviewees in the categories of genetics, clinical neurology, neuroscience, psychiatry and other.<sup>114</sup> One interviewee stated that imaging had ‘taken off’ in the past 15-20 years, and that it is now possible to look at living brains in great detail (INT02), while another emphasised that brain-imaging techniques are particularly important for improving the capacities of researchers and practitioners to monitor

disease progression.<sup>115</sup> Five interviewees highlighted the quantitative MRI work being developed and carried out at UCL.<sup>116</sup> However, one geneticist and one neuroscientist expressed some concern that the UK’s strengths in imaging research could be capitalised on more.<sup>117</sup> One of them observed that novel imaging methods take off more slowly in the UK than the US (and said that the reasons for this are unclear but could be related to funding challenges or slow ethics approval processes).<sup>118</sup> Another interviewee noted that existing positron emission tomography imaging tools are useful for research but too expensive for use in the general population.<sup>119</sup>

**5.3.3. Pockets of excellence in research on different types of dementia disease**

In addition to research on genes linked to the risk of developing Alzheimer’s disease and Parkinson’s disease,<sup>120</sup> research on Lewy Body dementia was mentioned as a key strength by six interviewees from nursing/allied health professions (AHP)/care, epidemiology, and clinical neurology and neuroscience (some of whom highlighted work being carried out in Newcastle in particular).<sup>121</sup> Interviewees also mentioned fronto-temporal dementia (four interviewees,<sup>122</sup> with one<sup>123</sup> specifically mentioning work on genetics related to ALS and FTD), mixed dementia (although the interviewee highlighting this area said it had been largely neglected,

<sup>112</sup>INT08, INT11, INT25.

<sup>113</sup>INT05.

<sup>114</sup>INT02, INT03, INT06, INT12, INT16, INT18, INT22, INT23, INT24, INT25, INT26, INT31, INT40.

<sup>115</sup>INT22.

<sup>116</sup>Work at UCL was highlighted both by interviewees from that institution and other institutions.

<sup>117</sup>INT26, INT03.

<sup>118</sup>INT03.

<sup>119</sup>INT40.

<sup>120</sup>INT08, INT11, INT22, INT25.

<sup>121</sup>INT04, INT10, INT14, INT18, INT23, INT25.

<sup>122</sup>INT06, INT14, INT23.

<sup>123</sup>INT22.

which supports insights obtained in the bibliometric analyses),<sup>124</sup> and Parkinson's disease and dementia (stated twice).<sup>125</sup>

#### 5.3.4. Leadership in psychosocial interventions and person-centred care

Six interviewees (from the nursing/AHP/care, clinical psychology and other fields) said that the UK had also made important contributions in psychosocial interventions and person-centred care, with the work of the late Tom Kitwood often cited.<sup>126, 127</sup> A clinical psychologist stressed that *“in psychosocial research that's been talked about at the current initiative of the World Dementia Research Council, the UK has been very much in the lead”*.<sup>128</sup> Interviewees from clinical psychology, and nursing, allied health professions and other care-related professions also referred to work in cognitive stimulation, the development of interventions to help people live with dementia (either at home or in long-term care settings),<sup>129</sup> the development of clinical centres for dementia care<sup>130</sup> and work on early diagnosis.<sup>131</sup>

#### 5.3.5. Other areas of UK research excellence

Other developments in clinical work and basic research were also highlighted. Work related to (i) cohort studies and epidemiology<sup>132</sup> and (ii) the amyloid hypothesis and amyloid processing<sup>133</sup> were both mentioned by five interviewees from various fields, along with work on biomarkers (mentioned by four interviewees),<sup>134</sup> and tau pathology (mentioned by two interviewees).<sup>135</sup> One interviewee stressed that biomarkers were “the holy grail of neurodegeneration”

and that more samples should be collected during clinical trials for use in research into biomarkers.<sup>136</sup> Three interviewees (from neuroscience and clinical neurology) said that UK researchers had made significant contributions to the clinical definition and characterisation of dementia.<sup>137</sup> UK brain banks and work in neuropathology were also seen as valuable and mentioned as a key strength by two psychiatrists.<sup>138</sup>

### 5.4. Gaps and limitations in the UK dementia research landscape

Interviewees also highlighted a number of gaps in the UK's dementia research landscape, many of which are also global bottlenecks in dementia research efforts, and some which are perceived as being particular limitations in the UK research portfolio.

The most common responses on limitations in UK dementia research related to: (i) limited progress in cell biology research and understanding the mechanisms underlying dementia (a limitation which mirrors global gaps in the knowledge base); (ii) limited focus on care research in the UK dementia research portfolio; (iii) an insufficient number of large cohort studies (with existing ones being highlighted as a strength – see Section 5.3); and (iv) a paucity of research on rarer forms of dementia.

It is important to highlight that, in general, interviewees' responses on research limitations focused on the areas with which they were more familiar. For example, basic researchers and clinical neurologists discussed research into our basic understanding of dementia and drug discovery, while interviewees who work in roles related to patient therapy and care focused on those areas.

<sup>124</sup>INT14.

<sup>125</sup>INT20, INT42.

<sup>126</sup>INT07, INT17, INT19, INT38, INT41, INT43.

<sup>127</sup>Kitwood was a psychogerontologist known for championing person-centred care (Mead 1999).

<sup>128</sup>INT07.

<sup>129</sup>INT21, INT41.

<sup>130</sup>INT21.

<sup>131</sup>INT17.

<sup>132</sup>INT04, INT16, INT21, INT24, INT40.

<sup>133</sup>INT05, INT20, INT27, INT40, INT41.

<sup>134</sup>INT08, INT25, INT26, INT40.

<sup>135</sup>INT20, INT22.

<sup>136</sup>INT37.

<sup>137</sup>INT01, INT03, INT09.

<sup>138</sup>INT18, INT24.

### 5.4.1. Poor understanding of the cellular mechanisms of dementia

Eight interviewees (from neuroscience, clinical neurology, genetics and research funding communities) highlighted gaps in knowledge and limited research activity in the UK on the cellular mechanisms in dementia, while also recognising that there is scope for more work in this area globally. More specifically, they identified limited research progress that would link basic knowledge about the genetics of dementia to drug discovery (i.e. translational research).<sup>139</sup> “Once you have the genetics, what next?” said one interviewee, adding that “a lot of genes are not going to be drug targets.”<sup>140</sup> Understanding the mechanisms responsible for the toxicity of protein aggregates associated with Alzheimer’s disease (amyloid plaques and tau tangles), and how they drive neurodegeneration, was seen as an important research question by individuals who have had experience in industry.<sup>141</sup> As one of these individuals observed: “The whole field is moving from a primarily molecular understanding to understanding how some of these aggregates spread in the brain and how this can lead to brain dysfunction,” adding that the UK has begun doing research on these issues already.<sup>142</sup>

Individuals from neuroscience and genetics communities highlighted a need for more work in cell biology,<sup>143</sup> electrophysiology,<sup>144</sup> genetics<sup>145</sup> and the development of chemical probes for brain-imaging to contribute to better understanding of cellular mechanisms.<sup>146</sup> One person<sup>147</sup> emphasised that this requires more interaction between neurophysiologists on the one hand

and pathologists and geneticists, (who have traditionally driven much of the research into Alzheimer’s disease) on the other. This interviewee stated that “The Alzheimer’s disease community are often looking for structural biomarkers...not looking to measure EEG signals,” and explained that other biomarkers could enable earlier detection and possibly intervention.<sup>148</sup>

### 5.4.2. Potential for improvement in the conduct of clinical trials in dementia

Interviewees also linked some dementia research bottlenecks more explicitly to the UK research context and landscape. Four interviewees said that the UK had been weak in running clinical trials, though it was noted that this situation could change as a result of recent investments in this area.<sup>149, 150</sup> However, a psychiatrist pointed out incentive-related challenges, saying: “It is extremely difficult to recruit patients and researchers interested in trials might be discouraged,” and adding that clinicians are often reluctant to help recruit patients because they do not want to “lose” their patients.<sup>151</sup>

Some interviewees discussed the challenges of recent clinical trials for two candidate drugs that target the accumulation of the protein beta-amyloid, which is linked to Alzheimer’s disease (Alzheimer’s Society 2013). Views on the trials’ progress and outcomes were mixed, as illustrated by one neuroscientist:<sup>152</sup> “If there is one thing that the failure of the clinical trials has showed us, it’s that we don’t yet know enough about the disease. We have learned a lot from the fact the clinical trials have failed and it’s a shame so much money was spent...but that shouldn’t prevent us from trying to look for ways to translate the basic

<sup>139</sup>INT01, INT09, INT11, INT15, INT23, INT26, INT37, INT40.

<sup>140</sup>INT11.

<sup>141</sup>INT40, INT42.

<sup>142</sup>INT42.

<sup>143</sup>INT01.

<sup>144</sup>INT22, INT40.

<sup>145</sup>INT02, INT15.

<sup>146</sup>INT11.

<sup>147</sup>INT40.

<sup>148</sup>INT40

<sup>149</sup>These investments include the UK Dementias Research Platform and drug-discovery institutes at University College London, Oxford University and Cambridge University (INT42).

<sup>150</sup>INT01, INT04, INT12, INT25.

<sup>151</sup>INT39.

<sup>152</sup>INT03.

*science into research that will help in finding a cure that will benefit the patient. That should happen in parallel.”*

Other interviewees discussing the trials’ results suggested that: (i) inaccurate diagnosis of patients could have adversely affected the outcome of the trials;<sup>153</sup> (ii) there is a need to improve basic understanding of dementia to enable effective drugs to be developed;<sup>154</sup> and (iii) either more focus should be placed on prevention<sup>155</sup> or patients should be identified and treated earlier.<sup>156</sup> In contrast, an interviewee who had experience in industry emphasised that some widely held perceptions of trial failure were “a common misconception” reflecting lack of awareness about developments occurring within industry.<sup>157</sup> This interviewee was more optimistic about the outlook for other drugs in the pipeline, saying: “*I think in ten years we’ll have a medicine that slows the disease down,*” adding, “*The general perception things have failed is wrong and is a major hurdle. Actually I think dementia and Alzheimer’s disease in particular is one of the more tractable mental health disorders.*”

In addition, two interviewees noted that the long timescale required for carrying out clinical trials in dementia poses a challenge to attracting clinicians into research activity.<sup>158</sup>

#### **5.4.3. A need to enhance industry participation in the dementia challenge – including in drug-discovery, medical apps and assistive living technologies**

Views on the role industry has played in the advancement of dementia research in the UK were mixed. Three interviewees highlighted the importance of interaction and coordination of efforts between industry and

academia along with the need to consider mechanisms that can enable more such interaction (e.g. organised meetings or small conferences, or joint funding opportunities).<sup>159</sup> However, consistent with comments made about the poor outcomes of clinical trials for dementia drugs, a few interviewees were pessimistic about progress with efforts to engage industry in dementia innovation, saying that the current industry-involvement model is not working due to the high costs of drug development<sup>160</sup> and that large companies are “largely giving up” on the UK and moving to Asia.<sup>161</sup> These are challenges that are not specific to the dementia field alone, but may be accentuated given the lack of understanding of dementia disease mechanisms and drug targets which could attract industry involvement.

Interviewees also saw potential roles for industry in developing tools other than pharmaceuticals, such as medical apps or assisted living technology.<sup>162</sup> “*If industry has the money, machinery, technical know-how to create some helpful technology and work with really creative people, then that would be fantastic,*” said one interviewee working in nursing/AHP/care.<sup>163</sup> Another interviewee suggested that there may be potential for devices like smartphones to be used to monitor patients in the home and “*run clinical trials in a more natural way...as opposed to bringing people in every three months for assessment.*”<sup>164</sup>

#### **5.4.4. A need to increase the involvement of clinicians in dementia research in order to ensure the relevance of research to patients and to facilitate translation**

Interviewees widely supported the need to involve clinicians and other care professions (e.g. allied health professions, nursing, social work) in dementia research

<sup>153</sup> INT12.

<sup>154</sup> INT22.

<sup>155</sup> INT04.

<sup>156</sup> INT03.

<sup>157</sup> This interviewee explained that the reasons for failure had been identified, at least for one of the drugs, and implied that there was a problem with a specific aspect of how the drug worked. The interviewee added that there are now companies “funding very expensive clinical trials for their molecules, and they wouldn’t do this unless they believed the data because it’s incredibly expensive” (INT40).

<sup>158</sup> INT11, INT40.

<sup>159</sup> INT40. View on need for more interaction also supported by INT03, INT37.

<sup>160</sup> INT02, INT14.

<sup>161</sup> INT01.

<sup>162</sup> INT06, INT10, INT14, INT21, INT36, INT38, INT40, INT41.

<sup>163</sup> INT36.

<sup>164</sup> INT40.

efforts. Nine interviewees highlighted that clinicians play an important role in dementia research because they help define relevant questions that reflect clinical and patient needs, and because they have knowledge that comes from observing patients.<sup>165</sup> As one neurologist put it: “Research should be about patients and not about cells and mice. Clinicians – neurologists, and also psychiatrists and psychologists – working with dementia sufferers are fundamental to this.”<sup>166</sup> An epidemiologist emphasised that all applied research (including care, prevention and diagnostics) should require clinical collaborators.<sup>167</sup> A neuroscientist stressed the importance of the interaction between clinicians and basic scientists: “The best way to organise a lab is to have young PhDs and young MDs in the lab. MDs bring knowledge of the disease, PhDs bring scientific rigour - a good lab has a mixture of both.”<sup>168</sup>

Five interviewees saw a particular problem in the UK’s ability to translate knowledge into practice in both care and drug innovation,<sup>169</sup> while four people pointed out that increased collaboration with both clinicians and carers would enable translation and application of research results.<sup>170</sup> Examples included GPs potentially learning from research and becoming better at identifying symptoms,<sup>171</sup> and the use of dementia mapping to improve care in care homes.<sup>172</sup> Other roles suggested for clinicians included obtaining samples;<sup>173</sup> developing biomarkers, diagnostics and other tools;<sup>174</sup> and improving methods for running clinical trials.<sup>175</sup> Finally, one interviewee said that more non-traditional, practice-based therapies could benefit from

engaging more with clinicians, noting: “[My colleagues and I] work a bit with music practitioners and therapists but I’d like to work more with neurologists. To get credibility, it would be good if those in arts connected more with GPs, nurses, neurologists.”<sup>176</sup>

#### 5.4.5. A need to further enhance the UK’s care-related research portfolio in dementia

Although UK dementia care-related research was seen as an area of strength by many interviewees (as discussed previously in Section 5.3.4), it was also identified as a key area for improvement and highlighted to some extent by 15 interviewees from all fields.<sup>177</sup> The view that improvement is needed in this area is consistent with our bibliometric analysis, which indicated that the volume of work in this area is low and of variable quality. Interviewees referred to the need for investing more in dementia care in general, and also in several aspects of care research. Interviewees from nursing/AHP/care and psychology emphasised the need for a cultural change and for more nursing and allied health research.<sup>178</sup> One nursing/AHP/care interviewee pointed out that allied health and nursing research “should be high up the research agenda as they are the mainstay of social and community care.”<sup>179</sup> However, this interviewee also emphasised an associated challenge, saying that “within these health professions, working with people with dementia is still not seen as a career pathway of choice”. A psychiatrist observed that, apart from clinical psychology, it is difficult to develop research careers in the allied health professions. However, a clinical psychologist said there are

<sup>165</sup> INT01, INT03, INT04, INT06, INT07, INT19, INT37, INT42, INT43.

<sup>166</sup> INT06.

<sup>167</sup> INT14.

<sup>168</sup> INT01.

<sup>169</sup> INT11, INT19, INT39, INT43, INT17.

<sup>170</sup> INT03, INT38, INT41, INT43.

<sup>171</sup> INT03.

<sup>172</sup> INT38.

<sup>173</sup> INT05.

<sup>174</sup> INT03, INT07, INT14, INT23.

<sup>175</sup> INT23.

<sup>176</sup> INT36.

<sup>177</sup> INT08, INT10, INT12, INT16, INT17, INT19, INT21, INT26, INT31, INT32, INT34, INT36, INT38, INT39, INT41.

<sup>178</sup> A total of six interviewees from allied health professions, psychiatry, neurology, epidemiology and genetics mentioned one or more aspects of nursing and allied health research (INT02, INT07, INT10, INT12, INT14, INT18).

<sup>179</sup> The annual cost of dementia, for care and lost productivity, has been estimated to be £23 billion per year (Luengo-Fernandez et al. 2010).

not enough PhD studentships and research fellowships available for clinically qualified psychologists.<sup>180</sup>

Several aspects of care were seen as important areas for research, including care homes,<sup>181</sup> end-of-life care and care for patients with different types of dementia (including mixed dementias and advanced stages of dementia)<sup>182</sup> and co-morbidities,<sup>183</sup> and care for marginalised and hard-to-reach groups.<sup>184</sup> A few interviewees focused on the importance of the carer–patient relationship and the impact of dementia on a patient’s family and acquaintances.<sup>185</sup> One interviewee said that there is a role for social sciences and nursing research in looking at aspects of carer–patient relationships, explaining: “People with dementia know what they want and it may be different from what their carers want. Lumping people together and getting carers as surrogates is not appropriate.” Another interviewee stressed the importance of including and educating carers: “For every one person who has a diagnosis of dementia there are conservatively 10 around them impacted... A lot of people in that circle are still lacking a lot of information. We need to research how to educate and train people in that circle to better communicate with a person who has dementia, and about the course of the type of dementia they might have.”<sup>186</sup>

Interviewees also suggested focusing more research on various aspects of care delivery, including the organisation of services, nursing,<sup>187</sup> care homes,<sup>188</sup> occupational and speech therapy (and other allied health professions),<sup>189</sup> community support<sup>190</sup> and arts therapy.<sup>191</sup> Interviewees with relevant expertise noted the great

potential for creative arts therapy to enable dementia patients to live a better life day to day, saying that the area of arts and health is growing and noting the excellent work being done, but also stressing that more research is needed.<sup>192</sup> The role of music and other arts therapy in dementia treatment was emphasised by two interviewees, who felt that these perspectives on dementia had historically been neglected.<sup>193</sup> Another interviewee suggested a “shake-up” of research panels to include people with experience in diverse aspects of care for dementia patients, observing: “Academic research can be an elitist club. The dementia research world is focused on cure and my focus is on care.” This individual added: “We need to see a lot more money going towards alternatives to pharmaceutical medication... towards the arts – music, movement, dance, visual arts, animation, film... The arts, as an intervention for enabling the care and treatment of people with dementia, are very underdeveloped.”<sup>194</sup>

Although many interviewees highlighted UK care-related research as a strength, one psychiatrist emphasised a need for better-quality research in care: “We need more research to define what constitutes a good care environment, but we need more quality. If you look at research literature, time and time again you find very sound studies on pharmaceuticals and poor-quality studies on everything else: care interactions, music. Where pharma money is, we have high-quality data for badly designed interventions, and in non-pharma fields we don’t have enough quality research.”<sup>195</sup>

<sup>180</sup>INT07.

<sup>181</sup>INT16, INT21.

<sup>182</sup>INT17, INT39.

<sup>183</sup>INT10.

<sup>184</sup>INT19.

<sup>185</sup>INT31, INT36, INT38.

<sup>186</sup>INT36.

<sup>187</sup>INT16, INT17.

<sup>188</sup>INT16, INT21, INT32.

<sup>189</sup>INT10, INT17, INT38.

<sup>190</sup>INT38.

<sup>191</sup>INT32, INT36.

<sup>192</sup>INT32, INT36.

<sup>193</sup>INT32, INT36.

<sup>194</sup>INT32.

<sup>195</sup>INT39.

#### 5.4.6. Other gaps in UK dementia research

Interviewees also identified some other areas where the UK could strengthen its dementia research portfolio in the future.<sup>196</sup> These relate to an insufficient number of large-scale cohort studies,<sup>197</sup> insufficient research into rare diseases such as progressive supranuclear palsy; Pick's, Lewy body and posterior cortical atrophy;<sup>198</sup> and a need for more animal research, such as developing mouse models for studying dementia.<sup>199</sup> Two interviewees were concerned that there may be a gap in support for animal studies, noting that research carried out through the NIHR Biomedical Research Units needs to be done only in humans,<sup>200</sup> and the UK's research councils tend only to fund either very basic research (in the case of the Biotechnology and Biological Sciences Research Council) or human studies (in the case of the Medical Research Council).<sup>201</sup> However, views on research using animal models were mixed. For instance, one neuroscientist suggested there was a need for more animal modelling work,<sup>202</sup> while another interviewee felt that a combination of human models and other models, studied in parallel, is more important.<sup>203</sup> Another neurologist stressed that more work should be done in humans because animal models are not very useful for studying and treating human dementia: *"It is necessary to start looking at humans. Rather than inducing Alzheimer's in rats, testing their memory through artificial means and giving them drugs that would cure the artificial disease in their brain, it would be much more useful to study how the human memory changes with dementia. This approach might help to identify the disease as early as possible in the*

*human subject and give the patient novel treatments."*<sup>204</sup>

#### 5.4.7. Understanding why the UK lags behind global averages in terms of impact of early-onset dementia and familial dementia research

Our bibliometric analysis highlighted that the UK lags behind other countries in terms of impact in research on familial dementia and early-onset dementia. The most commonly cited reason for this, amongst those we spoke to, was the low number of patients diagnosed with these conditions in the UK who could participate in studies.<sup>205</sup> Challenges in recruiting these types of patients were also highlighted by four interviewees.<sup>206</sup> These challenges were thought to be accentuated by a lack of dementia specialists, and related underdiagnoses or misdiagnoses due to difficulties in understanding the unique symptoms of different types of dementia.<sup>207</sup>

One psychiatrist stressed that the UK's performance in early-onset and familial dementia *"reflects a major problem we are facing with the way our clinical services are set up,"* and explained that there is a *"disconnect between academic and NHS structures, and a situation where clinics for people with mild cognitive impairment are discharging patients back to general practice so we're not collecting them for familial studies."*<sup>208, 209</sup> A psychologist explained that in the UK, most dementia patients see psychiatrists, whereas younger dementia patients, who may have early-onset dementia, tend to visit neurologists.<sup>210</sup> In contrast, interviewees said that in other countries (e.g. the

<sup>196</sup>At least two people discussed each area.

<sup>197</sup>INT07, INT18, INT24; note existing ones were highlighted as a strength.

<sup>198</sup>INT02, INT22, INT26, INT39.

<sup>199</sup>INT01, INT05.

<sup>200</sup>INT22.

<sup>201</sup>INT27.

<sup>202</sup>INT01.

<sup>203</sup>INT40.

<sup>204</sup>INT06.

<sup>205</sup>This reason was given by eight interviewees from across genetics, neuroscience, clinical neurology and nursing/AHP/care: INT02, INT03, INT06, INT07, INT11, INT13, INT15, INT25.

<sup>206</sup>INT16, INT17, INT18, INT26.

<sup>207</sup>INT16, INT17.

<sup>208</sup>INT27.

<sup>209</sup>Part of the issue, according to this interviewee, is a lack of resources: "NHS structures are so stretched that while there is lip service to research they don't have resource" (INT27).

<sup>210</sup>INT07.

USA, France and the Netherlands), all dementia patients tend to be seen by neurologists or geriatricians.<sup>211</sup> This situation brings multiple challenges, according to the interviewees. First, UK neurologists may have less interest in dementia compared to psychiatrists in the UK and neurologists elsewhere, which could lead to less recruitment of younger dementia patients. One interviewee described a “turf war” between clinical psychiatry, neurology and geriatric medicine that makes collaboration very difficult.<sup>212</sup> Another pointed out that this situation adversely affects continuity of care.<sup>213</sup>

Other possible reasons for the UK’s weaker performance in these area included: challenges in exploiting technology to study the genetics of these conditions (in the past)<sup>214</sup>; restrictions on using animals in research;<sup>215</sup> a lack of data sharing among researchers who study these conditions;<sup>216</sup> and a lack of UK funding for international research studies on these conditions (resulting in much of this work taking place in the US).<sup>217</sup> A few interviewees (from neuroscience and neurology) said they were surprised by the results because they thought UK researchers had performed well in work on genetics related to dementia.<sup>218</sup>

However, a neuroscientist highlighted that there has been an overall positive shift in the past five years towards looking at earlier stages of disease progression and at early-onset variants of dementia disease.<sup>219</sup> The interviewee thought this was facilitated by (i) an understanding that the disease begins to develop up to 15 years before symptoms become apparent (developed in part on the basis of evidence from longitudinal studies); and (ii) the idea that a reason for the failure of recent dementia drug trials could have been that the drugs were given too late.

## 5.5. Breadth versus focus in the UK dementia research portfolio: a forward lens on priorities

In reflection of discussions about perceived strengths and weaknesses of UK dementia research, we asked interviewees about investment priorities looking forward. We investigated views on (i) breadth versus focus in the disease portfolio; (ii) basic versus applied and clinical research; and (iii) the balance between research into prevention, treatment and care.

Most interviewees agreed with the need to balance research investment across different types of dementia disease areas and across basic, applied and clinical research; however, some highlighted potential merits in more focused and targeted strategic approaches. Views on the balance of investment in research related to prevention, treatment and care-delivery were very mixed, and to a large extent reflected individual professional experiences and backgrounds.

The most notable differences emerged in views on the balance of research investment in prevention, treatment and care. Interviewees working in nursing, the allied health professions and other aspects of care expressed strong views about the importance of care and care research. They emphasised the need to improve care for people living with dementia today while also generally recognising the importance of research that could lead towards treatments or cures in the longer-term. On the other hand, some (but not all) of the interviewees from more basic research areas, such as neuroscience and genetics, expressed the view that it is more important to focus on long-term solutions. While they saw the need for care, they had limited familiarity with care research and tended to prioritise it less.

<sup>211</sup> INT07, INT23, INT27.

<sup>212</sup> INT43.

<sup>213</sup> INT27.

<sup>214</sup> INT02.

<sup>215</sup> INT01.

<sup>216</sup> INT06.

<sup>217</sup> INT01.

<sup>218</sup> INT22, INT23, INT25.

<sup>219</sup> INT03.

### 5.5.1. Disease-related research investment portfolios

For those supporting a broad portfolio of research (17 interviewees),<sup>220</sup> the key argument was that the knowledge gained through research into one type of dementia disease could help efforts to understand others, and that there may be commonalities across different diseases which could inform a dementia breakthrough. The following quotes illustrate this group's wider views:

- *“There are commonalities across different diseases. A wider approach is a good approach.”*<sup>221</sup>
- *“Not pursuing a broad research portfolio would be counterproductive and limit our efforts.”*<sup>222</sup>
- *“Obviously there is a lot of heterogeneity so looking at a broader subsets of diseases when testing drugs can be useful.”*<sup>223</sup>

The key arguments other interviewees communicated in support of more targeted portfolios included: (i) linking the level of funding support to disease prevalence (highlighted by three interviewees)<sup>224</sup>, but also offering some support for rare dementia diseases (supported by two interviewees)<sup>225</sup>; and (ii) focusing on areas of established research strength where the UK has a comparative advantage to avoid “being all things to all people”<sup>226</sup> (highlighted by three interviewees).<sup>227</sup> The following quotes illustrate this view:

- *“Research strategies should focus on areas of strength and where the UK has leading people. Comparative advantage lies in non-Alzheimer dementias (Lewy body, frontotemporal, vascular and progressive supranuclear palsy). The Alzheimer’s research landscape is dominated by the US.”*<sup>228</sup>

- *“If there is good research elsewhere in the globe and it is transferable to the UK wouldn’t it be better for the UK to develop its own expertise rather than try to be all things to all people?”*<sup>229</sup>
- *Funding should reflect what is experienced in general population not sexy topics or areas where we can be excellent.”*<sup>230</sup>

### 5.5.2. Balance of focus on prevention, treatment and care-delivery research:

For those supporting a balanced research portfolio (seven interviewees),<sup>231</sup> the key argument was a need to balance the concerns of those affected today for high-quality care with research into the longer-term objective of finding a preventative medicine and cure. This was highlighted by two interviewees:

- *“There is an argument that we need to look after people with dementia much better than we currently do. It’s quite pitiful how some people are treated and looked after. They’ve contributed their whole life to the system, so to speak, and when they need it most, the system just lets them down. But on the other side, unless we get in there and find preventive medicines and things that can slow the progression of the disease, that situation is only going to get worse.”*<sup>232</sup>
- *“Both [care and treatment] are important. We won’t find cure for dementia overnight; we’ll see small inroads like with cancer and HIV, and hopefully bigger inroads with time. The prevalence of the disease will increase and put more pressure on the care side of things. You might say your vision of the world is a world free of Alzheimer’s disease, but before you get there, you’ll have a world full of it.”*<sup>233</sup>

<sup>220</sup>INT03, INT05, INT06, INT10, INT11, INT14, INT15, INT16, INT19, INT20, INT22, INT23, INT25, INT27, INT37, INT41, INT42.

<sup>221</sup>INT05.

<sup>222</sup>INT06.

<sup>223</sup>INT42.

<sup>224</sup>INT02, INT09, INT12.

<sup>225</sup>INT02, INT12.

<sup>226</sup>INT38.

<sup>227</sup>INT24, INT26, INT38.

<sup>228</sup>INT24.

<sup>229</sup>INT38.

<sup>230</sup>INT14.

<sup>231</sup>INT02, INT07, INT08, INT11, INT13, INT37, INT40.

<sup>232</sup>INT02.

<sup>233</sup>INT37.

Other individuals supported more emphasis on one of these areas. Four interviewees highlighted that more work in the prevention space should be done to leverage progress on risk factors that has been made to date.<sup>234</sup> This view was challenged by others (also four interviewees) who highlighted that a lot is already known about risk factors and there are other priority unknowns for research to tackle.<sup>235</sup>

Individuals advocating for the prioritisation of care research (also four interviewees) highlighted the ability of research advances in that field to make a difference to those affected today, and hence to have a more immediate impact<sup>236</sup> (although it is worth emphasising that the majority of these individuals also recognised the importance of searching for a cure). The following quotes illustrate these views:

- *“If it is care-related, you can actually do something to help people in the near future and the short term.”*<sup>237</sup>
- *“Care and service delivery, I’m tempted to say, has the most impact on people’s day to day lives and quality of life in terms of the here and now.”*<sup>238</sup>
- *“We need to be more open minded and broader but also link funding to the scale of the problem... Care is a massive issue and if you allocated money proportional to the needs, you would allocate more money to the care side of things... Even if it sounds harsh, research must reflect what is experienced in the general population instead of focusing on sexy topics or picking areas where we think we can be excellent.”*<sup>239</sup>

These views were challenged by three interviewees who felt that, although care was important, investment should be targeted towards delivering more care, rather into research on care.<sup>240</sup> They argued:

- *“A lot of that comes down to common sense. What we need in dementia is for people to have time and facilities for people to work with patients one on one. It’s hard to imagine people doing a lot of research on that. I think there are sometimes new approaches, but a lot comes down to getting more people involved to work with people with dementia and their carers.”*<sup>241</sup>
- Another interviewee thought various types of therapy (speech, arts and music, etc) were important and had clear benefits, suggesting that *“maybe instead of studying these things and whether they are beneficial, we should just do them more.”*<sup>242</sup>

Finally, interviewees who advocated prioritising treatment and cure research stressed that this is the biggest of all dementia challenges, and the one where we are most lacking in knowledge. As one explained: *“Speaking as someone with a close family member who needs care, no matter how much care patients get, their quality of life deteriorates, the disease progresses and families are affected. It would be more useful to have something that stops the disease or cures it.”*<sup>243</sup>

### 5.5.3. The balance of basic versus applied and clinical research

The idea that there is a need for a balance or combination of different types of research emerged strongly again in regards to basic and applied/clinical research priorities. Many interviewees (13) said there is a need for both basic and applied research, and several also stressed the importance of linking the two.<sup>244</sup>

- Six interviewees said that basic and applied research priorities should be balanced, since both are valuable.<sup>245</sup> As highlighted by a neurologist: *“Basic*

<sup>234</sup>INT04, INT10, INT39, INT42.

<sup>235</sup>INT03, INT19, INT36, INT38.

<sup>236</sup>INT18, INT21, INT36, INT38.

<sup>237</sup>INT41.

<sup>238</sup>INT38.

<sup>239</sup>INT14.

<sup>240</sup>INT02, INT11, INT22.

<sup>241</sup>INT11.

<sup>242</sup>INT02.

<sup>243</sup>INT22.

<sup>244</sup>INT01, INT02, INT03, INT04, INT05, INT07, INT08, INT09, INT11, INT22, INT23, INT37, INT40.

<sup>245</sup>INT04, INT07, INT08, INT09, INT37, INT40. Note that 16 interviewees did not respond (either because they were not asked this question or they chose not to answer).

*and applied research are equally important. The best research is when they are done in collaboration.*<sup>246</sup>

- Six interviewees said basic and applied research investment should be mostly balanced, but that basic research should be somewhat prioritised because (i) there is a need for more fundamental work to be done in dementia research before applied work can be done; and/or (ii) basic research reveals fundamental information that can be widely applicable.<sup>247</sup>
- Seven interviewees pointed out the need for a combination of basic and applied and clinical research activity, and interaction among the researchers involved, in order to enable translation of research.<sup>248</sup> These two quotes illustrate this view:
  - *“You need to understand the disease before you can come up with the therapy. You want to do that in humans but you need to do it hand in hand with models that allow you to look at fundamental processes in much higher detail. You can’t do one without the other. Both sides of the coin – clinical and preclinical – need to be done right. If you try to test new therapies in humans based on very poor justification, you’re wasting a lot of time and money.”*<sup>249</sup>
  - *“Basic scientists on their own will work on drosophila from now until their retirement days without it ever doing any good. Clinicians will see patients and do clinical trials without ever thinking about underlying science from now until the cows come home. Bringing everybody together so that they all understand what the other is trying to do is really a challenge and it requires sustained funding.”*<sup>250</sup>

With regards to the current situation in the UK, a psychologist raised the issue that while there is a need for balanced support, there is a lack of transparency in how UK research funding for dementia is allocated that makes it difficult to tell what the balance is at present.<sup>251</sup>

## 5.6. Reflections on points of agreement and divergence among interviewees from different professions

Interviewees’ views on the current landscape for UK dementia research were similar in many ways, with

broad agreement about areas of strength and concerning challenges in research translation and clinicians’ involvement in research.

Looking ahead, many interviewees felt that it would be important to balance investment in basic, applied, clinical and care-related research, and investment in different disease areas. Interviewees largely agreed that the UK has performed well in areas such as genetics, neuro-imaging and Lewy body dementia research. However, whereas we observed that researchers from clinical and care professions were generally aware of UK advances in basic and applied research in more traditional fields, the neuroscientists and geneticists were less cognisant of UK developments in care research, such as person-centred care.

Some differences also emerged with regard to future research priorities, and particularly about whether to prioritise research on care, treatments and cures, or prevention. In general, interviewees working in more basic science areas of research tended to prioritise research geared at developing treatments and cures over that on prevention and care, reasoning that in the longer-term, the impact of a cure would be more significant. Other interviewees said that there is an obligation to support research that seeks to improve care for people living with dementia today, across health and social care domains. They expressed concern about a perceived disproportionate focus on research which would ultimately inform drug development, at the expense of care-related research. Although recognising the need for a balance across different types of research, these interviewees argued that care-related research could deliver impact in the short and medium term as well as in the long term, contribute to improvements in the quality of life for those affected with dementia and their families, and help mitigate the social and economic costs of dementia for the UK.

<sup>246</sup>INT09.

<sup>247</sup>INT02, INT03, INT05, INT11, INT22, INT23.

<sup>248</sup>INT01, INT03, INT04, INT08, INT09, INT37, INT40.

<sup>249</sup>INT40.

<sup>250</sup>INT01.

<sup>251</sup>INT07.



## Chapter 6 The UK dementia research workforce: career opportunities, enablers and challenges from the perspectives of multiple stakeholders

### 6.1. Chapter summary: dementia research careers – challenges, bottlenecks and opportunities looking forward

- This section focuses on interview findings relating to the dementia research workforce specifically.
- Many of the challenges to research careers in dementia, and to building capacity in the research workforce apply to research careers in the UK more widely, but are accentuated in the dementia context. Dementia faces a comparative scarcity of funding vis-à-vis areas like cancer and is seen, in some disciplines, as a less attractive area of specialisation. There is a perceived need for more awareness-raising about dementia research opportunities, and for an attitude shift from a view that little can be done about dementia to one which celebrates milestones and prospects.

#### Bottlenecks in the career pathway and barriers to dementia research careers

- The lack of a secure career path is widely seen as the key challenge for those considering dementia research careers and for workforce capacity-building in the UK. This is linked to the prevalence of short-term research funding and a lack of permanent academic positions (e.g. lectureships) and fellowships for researchers who are ready to gain independence and establish their own projects, programmes and groups.
- Consistent with these concerns, interviewees widely saw the transition from a postdoctoral role to a lecturer role as the biggest career bottleneck, with the transition from a PhD or clinical training to the first postdoctoral or clinical research position coming second. In the allied health professions and social care, a particular lack of more junior-level studentships and fellowships (PhD and first postdoc

was identified. These gaps represent workforce planning challenges which need to be addressed to ensure a sustainable pool of future research leaders.

- Barriers to clinical research careers in dementia are particularly high. These barriers relate to factors including: (i) a lack of time to combine research and clinical duties; (ii) a perception held by some clinicians that they are undervalued by universities due to challenges in meeting publishing and grant expectations in parallel with delivering clinical care; (iii) clinical career structures that make it difficult to engage with research and a prevailing – though gradually evolving – clinical culture where research is undervalued; (iv) the short-term nature of research contracts for clinical and allied health professions staff; and (v) insufficient attention to research training in medical education curricula. In addition, dementia as a field is not widely seen as the most attractive research area for clinicians.
- Views on the extent to which researcher retention in dementia presents a policy challenge were mixed. More respondents considered the retention of researchers in the dementia field to be a challenge than did not, and it may be more of a challenge for research-active clinicians or areas of research specific to the UK context (e.g. some aspects of dementia care delivery). Some interviewees stressed that the growing commitment to dementia at the national level raises optimism about future research opportunities. Retention of dementia researchers in the UK was seen to be less of an issue, and the benefits of global knowledge circulation were recognised. However, interviewees highlighted that some countries offer more attractive core funding packages for dementia research (e.g. the USA, Germany and Australia) or more competitive opportunities for clinicians with an interest in dementia research (e.g. Belgium, France and the Netherlands) than the UK.

### Mechanisms for enabling dementia research careers

- Various examples of mechanisms that exist or are needed to support dementia research careers were identified by interviewees, who stressed the need for a mix of interventions focused on individuals, teams and networks. The majority relate to providing longer-term funding and improved job security, early- and mid-career stage research support, and enhanced collaboration across fields, disciplines, sectors and institutions.
  - *Support for junior research fellowships, including post PhD 'bridge-funding'.* Examples cited by interviewees included the Alzheimer's Society's Doctoral Training Centres, where PhD studentships focus on diverse areas of dementia research (including biomedical and social sciences, and arts therapy). The need for additional support in the form of extensions to PhD fellowships or bridge-funding for dementia PhD graduates to develop ideas and find new posts was also identified.
  - *Support for mid-career research fellowships and lectureships.* Dementia-specific fellowships and fellowships which allow researchers to obtain international experience were highlighted as important. The need for more lectureships and for fellowships that help postdoctoral researchers establish themselves as principal investigators was also emphasised. Cited examples (not all dementia-specific) included fellowships from the Alzheimer's Society, Alzheimer's Research UK, Parkinson's UK and the British Society of Gerontology's Emerging Researchers in Ageing scheme.
  - *Fellowships and more flexible employment arrangements to enable sustainable and longer-term clinician engagement in research.* Examples of successful enablers cited were clinical fellowships from the Alzheimer's Society, MND Association and support provided by the Guarantors of Brain charity for young clinicians to start research. Interviewees highlighted the need for flexible fellowships that allow movement between research and clinical work at different points in a career. Establishing criteria other than the number of publications to assess research potential and select applicants for clinical researcher posts was seen as a policy priority,

whereas current means of assessment were highlighted as a significant barrier to clinician engagement in research.

- *Supporting mid-career researchers as future leaders, in addition to focusing on projects and large teams,* for instance through 'rising star' programmes for researchers with high potential. Mid-career dementia researchers working within large research programmes need to be offered the opportunity to demonstrate leadership or attract their own funds, for example through: (i) senior leadership which encourages senior postdocs to act as the principal investigator on some funding applications; (ii) fellowship schemes that are receptive to (and supportive of) such applicants; and (iii) training and mentoring in research leadership skills. Current senior research leaders in dementia play substantial roles in mentoring and developing leadership skills within the mid and early-career researcher pool, but the time they can devote to such activity is limited. Coupling on-the-job training with formal programmes could enable more sustainable and consistent approaches to leadership development.
- *Institutions that bring together talent from diverse fields and sectors, with long-term funding – i.e. dedicated research centres and institutes or collaborations between organisations.* Examples of dedicated institutes and research centres highlighted by interviewees include those at University College London and Cardiff University. Academic-NHS collaborations such as the NIHR Biomedical Research Units (BRUs with dementia as a priority area are linked to the University of Cambridge, King's College London, Newcastle University and University College London) were seen as catalysts for research careers, and Collaborations for Leadership in Applied Health Research and Care (CLAHRCs) are leading the Research Capacity in Dementia Care Programme, which trains nurses and allied health professionals in dementia research. The MRC-led Dementias Platform UK, a public-private partnership, was seen as important for increasing collaboration with industry. Interviewees stressed the need for ongoing, stable funding for such

initiatives, both to attract people to dementia careers and to improve retention.

- *Other existing enablers of dementia research where capacity could be enhanced include professional skill development, generating interest in dementia and career flexibility.*

Interviewees highlighted: (i) the need for training research leaders in group management skills, enhancing mentorship for earlier-stage researchers, and training dementia researchers to communicate and publicise their work; (ii) raising dementia's profile more generally and improving the field's prestige; and (iii) supporting courses in dementia at the undergraduate level to help create interest at an early stage, and providing more career flexibility, particularly for researchers with family responsibilities. Finally, challenges related to research ethics were seen as being particularly acute in the dementia context and have discouraged people from dementia research in the past. Learning from successful management of research ethics in studies with dementia patients could be important for future research efforts.

- *Attracting researchers from other fields.* The majority of interviewees saw value in efforts to create an interdisciplinary research community bringing together diverse disciplines across the natural, health and social sciences, and industry, academic and clinical sectors. Diverse enabling mechanisms were highlighted, spanning (i) funding that supports partnerships between a dementia and non-dementia researcher,

such as that offered by Alzheimer's Research UK; (ii) cross-disciplinary, problem-driven rather than discipline-driven studentships; (iii) strong clinical leadership to help attract researchers from different fields; (iv) dementia-themed funding calls and prizes; and (v) dementia research centres, networks and hubs such as the NIHR and MRC initiatives, the EU's Neurodegenerative Disease Research Joint Programme (JPND), the Centres of Excellence Network in Neurodegeneration (CoEN), and the European network Interdem. Encouraging uptake for some interventions (e.g. cross-disciplinary fellowships or dementia research prizes) might benefit from strong awareness-raising campaigns. There is also a growing recognition of the importance of quantitative skills, particularly those related to big data. Integrating these skills in dementia research efforts will require addressing associated challenges relating to effective data governance, bureaucracy, privacy and security concerns, and public support.

- The dementia research community welcomed enhanced national and global commitment to research in this area, but emphasised a need for: (i) transparency in the strategy for allocating funding; (ii) some coordination between funders, but not at the expense of supporting diverse research aims; (iii) ensuring the long-term sustainability of the commitment and addressing the still substantial imbalance between the burden of dementia disease and research investment, compared to some other disease areas.



## Dementia research careers in the UK...views from the ground

### On opportunities...



"...There is a clear need to come up with a clearer strategic vision for research and for building capacity by maintaining and developing younger researchers. It is [also] very important to open up communication across centres on the type of research that is going on..."



"...If you get the right people together, they can set up a problem and say: we need a physicist to help with that, a chemist with that, a biologist with that..."



"...I don't know if there's ever been a time when there's been such an opportunity for people to do a PhD in dementia research..."



"...If I hadn't had funding to do half clinical training and half research at the end of my PhD, I wouldn't be doing research now..."

### On challenges...



"...People's attitudes also act as a barrier to dementia research careers... People may think there isn't much to be done for people with dementia. Accepting the idea that people can be helped might enable more research. This is about an attitude shift..."



"...Funding infrastructure is pretty patchy in the UK in terms of grant support, building and equipment infrastructure, and the ability to recruit and retain the best staff because of [limited] 'start-up' support... They'll get in the US, for example, a start-up package of \$2 million... In the UK it's nowhere near that amount... it's less than 10% of the start-up for equivalent junior faculty in the US..."



"...A lack of funding continuity leads to wasted resources because a shortage of mid-level researchers results in principal investigators needing to spend a lot of time training very inexperienced researchers..."



"...Clinicians are 'stretched to the limit doing their daily job, so to find time for research means spare time – hard to come by unless they get a training fellowship that buys them out and allows them to do research..."



"...It's really hard to combine NHS work and research as I could [in the past]... I'm not sure if it's the incentives or increased demands of clinical work, or health boards and trusts not allowing people space to do research. Universities probably have some role to play; they tend to look down on clinicians a bit. CVs are evaluated on numbers of papers or grants – things that are quite difficult to do if you're also doing a clinical service..."



"...In my department, working on Alzheimer's disease, I can think of five people in their 30s who, when I was younger, would easily have gotten lectureships. There are simply no lectureships to apply for..."

## 6.2. Context

As discussed in Chapter 5, our interviews also investigated workforce issues, to help inform a blueprint for research workforce capacity-building in dementia. We sought to identify the career pathway-related challenges faced by UK dementia researchers, and key issues to inform future workforce capacity-building. We explored supportive mechanisms that are already in place or that could be implemented to address career bottlenecks. We also aimed to understand the extent to which career pathway challenges apply specifically to the dementia context, as opposed to research careers more widely.

The profile of interviewees and the interview methodology has been described in Section 5.2. Here, we present the findings from the interviews that are specific to research workforce capacity issues.

## 6.3. Key barriers and challenges for progression in dementia research careers

### 6.3.1. Academic career insecurity and bottlenecks to transition from junior to mid-level posts

The most frequently raised workforce issue was the lack of a secure career path, which was linked to a prevalence of short-term research funding and a lack of both permanent academic positions (i.e. university lectureships) and fellowships for researchers who are ready to gain independence and start their own lab. This was frequently reported to be a key driver of brain-drain from dementia research.<sup>252</sup> Consistent with these concerns, the transition from a postdoctoral researcher to principal investigator was seen as

the biggest bottleneck, with the transition to the first clinical researcher or postdoctoral position (discussed further below) coming second.<sup>253</sup>

Many early-career researchers – particularly postdoctoral fellows – rely on fixed-term employment contracts for extended periods of time and face uncertainty about whether they will eventually be able to secure a permanent academic position. One junior interviewee,<sup>254</sup> who was planning to leave academic research, explained this decision: *“In the stage I am in now, early career, it’s a very difficult time where many people drop out. It’s the pressure of having to secure funding and a more permanent position... If you want to buy a house or flat you have to tell the bank you don’t have a permanent position... In my department there aren’t any lecturer positions offered to apply for, so I’d have to move to another department, university or city. I really love the research but the pressure of having to constantly apply for money put me off, so I want to get outside the academic bubble and see what else is out there.”*<sup>255</sup> One neuroscientist highlighted that *“due to university assessments and the Research Excellence Framework (REF), people want to hire professorial staff but are not prepared to grow their own faculty. This is a real problem.”*<sup>256</sup> The REF was also seen as contributing to career instability by some due to a perception that it encourages universities to adopt strategies where they *“swell the numbers for the assessment and then cut jobs again”*.<sup>257</sup>

This interviewee’s comments were echoed by others, such as a senior neuroscientist, who said: *“In my department, working on Alzheimer’s disease, I can think of five people in their 30s who, when I was younger, would easily have gotten lectureships. There are simply no lectureships to apply for.”*<sup>258</sup> A research funder agreed: *“It’s not a pleasant process so people end up leaving science... Going from one three-year contract to another and you*

<sup>252</sup>A total of 16 researchers (from all fields) referred to retention issues related to funding and job insecurity, while five said it could result in researchers moving to other fields such as cancer or other genetic disorders (INT02, INT04, INT12, INT14, INT18).

<sup>253</sup>The lack of funding stability and permanent positions was raised by 16 interviewees from all categories in response to the question about barriers to career progression (INT01, INT02, INT03, INT04, INT06, INT08, INT12, INT14, INT17, INT18, INT19, INT22, INT23, INT24, INT25, INT37) and by 18 interviewees in response to the question about which career stages have bottlenecks (INT01, INT02, INT03, INT04, INT05, INT06, INT08, INT14, INT15, INT16, INT19, INT20, INT22, INT24, INT25, INT31, INT33, INT37) (some interviewees are counted in both sets of respondents). Respondents were from all fields.

<sup>254</sup>INT03.

<sup>255</sup>INT03.

<sup>256</sup>INT01.

<sup>257</sup>INT11.

<sup>258</sup>INT01.

*can't get a mortgage or settle down because you might move to the other side of the world in a year's time – it is obviously a big problem.*<sup>259</sup>

After the transition from being a postdoctoral fellow to becoming an independent investigator, the most frequently cited career bottleneck was the transition from a PhD or completing a medical degree into the first postdoctoral fellowship or clinical research post. Eight interviewees (three junior and five senior) raised this issue.<sup>260</sup> One neurologist explained that the career bottleneck situation for basic scientists might be slightly different than it is for clinical researchers; the challenge in basic science is to keep postdocs involved in research while in other areas, the bottleneck occurs earlier.<sup>261</sup> This view was consistent with comments from a psychologist who believed the bottleneck occurred at the entrance to the PhD, and that most people stayed in research once they had completed their PhD.<sup>262</sup> But an interviewee from nursing/AHP/care commented that much of their time was also spent applying for short-term grants to maintain funding for junior researchers and that their graduating PhD students “do not seem to have any place to go”.<sup>263</sup> An epidemiologist also observed that PhD students struggle to find another research post or fellowship before their PhD ends, and leave research as a result.<sup>264</sup>

There was also a general recognition that many of these challenges apply to research careers in the UK more widely, and not only to the dementia context, but that they are accentuated in the dementia context given issues such as a comparative lack of funding vis-à-vis areas like cancer.<sup>265</sup>

### 6.3.2. Barriers to progression in clinical careers and challenges to combining clinical work and research

Some workforce challenges are specific to clinical research careers, and clinicians and allied health professionals wishing to pursue dementia-related research.

Eighteen interviewees (juniors and seniors from a range of fields, including individuals who have clinical experience and those who collaborate with clinicians) highlighted the challenges to combining clinical duties and research.<sup>266</sup> These related mainly to: (i) a lack of time to do research;<sup>267</sup> (ii) clinical researchers' perception that they can be undervalued by universities due to challenges in meeting publishing and grant expectations in parallel with delivering clinical duties<sup>268</sup>; and (iii) clinical career structures that make it difficult to engage with research (discussed in more detail below)<sup>269</sup> and a prevailing – though evolving – clinical culture where research is undervalued.<sup>270</sup> As described by a clinical psychologist: “*It's really hard to combine NHS work and research as I could [in the past]... I'm not sure if it's the incentives or increased demands of clinical work, or health boards and trusts not allowing people space to do research. Universities probably have some role to play; they tend to look down on clinicians a bit. CVs are evaluated on numbers of papers or grants – things that are quite difficult to do if you're also doing a clinical service.*”<sup>271</sup>

Four interviewees worried that universities tend to place a lot of importance on researchers' publication and citation records, but clinicians do not always find it possible to produce many publications.<sup>272</sup> As a result,

<sup>259</sup>INT37.

<sup>260</sup>INT12, INT14, INT15, INT17, INT21, INT23, INT24, INT44.

<sup>261</sup>INT23.

<sup>262</sup>INT41.

<sup>263</sup>INT17.

<sup>264</sup>INT04.

<sup>265</sup>This point was raised by seven interviewees (INT08, INT12, INT14, INT16, INT17, INT20, INT27).

<sup>266</sup>INT01, INT02, INT06, INT07, INT08, INT09, INT12, INT16, INT18, INT19, INT21, INT22, INT23, INT28, INT36, INT37, INT38, INT39.

<sup>267</sup>INT01, INT02, INT07, INT09, INT36, INT37.

<sup>268</sup>INT07, INT19, INT23.

<sup>269</sup>INT06, INT16, INT22, INT23, INT28.

<sup>270</sup>INT38, INT39.

<sup>271</sup>INT07.

<sup>272</sup>INT17, INT18, INT19, INT39.

one senior interviewee observed: *“Academic employers often prefer to hire a young academic rather than an experienced clinician.”*<sup>273</sup> Another interviewee stressed that these challenges are not only faced by medics but also by psychologists and others in the allied health professions, while others added that medics generally face fewer barriers to doing research than other health professionals because there are more positions and fellowships available for medics.<sup>274</sup> Difficulties in recruiting patients for research were also identified as a barrier that could discourage clinicians from getting more involved in research,<sup>275</sup> and another interviewee noted that research translation work can be slow and risky.<sup>276</sup> Finally, an epidemiologist explained that researchers doing observational studies do not receive the same support, in terms of research funding and investment from universities, as those doing basic science.<sup>277</sup>

Five interviewees (including four clinicians) described a lack of clear career pathways for clinical academic work.<sup>278</sup> One respondent described clinical training as a “conveyor belt” which results in students becoming consultants but makes it difficult to take time out for research.<sup>279</sup> Two other senior interviewees explained that it can be difficult to become a full-time clinical academic because one must compete for fellowships and academic posts after consultant-level training, which requires specialising at an early stage in clinical training.<sup>280</sup> The problem with this structure, they said, is that many people become interested in research later in their training, when it is more difficult to obtain fellowships due to the lack of prior research experience and publication outputs. Some interviewees reported the need for a culture change on the clinical side which would place more value on research.<sup>281</sup> Perhaps related to the

challenges in career structure, two interviewees (a senior clinical academic and a funder) said it can be difficult to attract strong candidates to apply for those clinical research fellowships that are available. One reported: *“We recently had a clinical fellowship. It was 100 to one [ratio of applicants to places] for basic science applicants and five to one on clinical.”*<sup>282</sup> The other also reported difficulties in attracting high-quality candidates for clinical fellowships, suggesting that *“this is partly because clinicians progress within a particular specialty, but academic clinical fellowships tend to cut across specialties.”*<sup>283</sup>

However, as highlighted by one interviewee, the clinical academic career path still seems to be evolving and there is a growing recognition by some government bodies and charities that clinicians have an essential role to play in research: *“Clinical academic careers in general are very new and we’re still working out how to make them work although I think everyone is in agreement that... they are really valuable.”*<sup>284</sup> This interviewee added that it is not common, for instance, to find researchers working both in care homes and in universities, and also discussed administrative obstacles which make it very difficult for one person to work in both the NHS and a university, or to do close collaborations. The interviewee stressed that *“There needs to be clearer pathways between institutions... You end up with two institutions and neither seems to have a pathway for supporting your career track or offering job security. The contracts are short-term. The NHS salaries are different to the universities.”*

Others noted that many researchers, particularly clinicians, simply lack the time to reflect on their research, with one senior interviewee saying: *“You don’t have unscheduled time. You cannot just come up with an idea and go and chat, especially to a clinician.”*<sup>285</sup> Another

<sup>273</sup>INT19.

<sup>274</sup>INT16, INT17.

<sup>275</sup>INT39.

<sup>276</sup>INT11.

<sup>277</sup>INT18.

<sup>278</sup>INT06, INT16, INT22, INT23, INT38.

<sup>279</sup>INT23.

<sup>280</sup>INT18, INT39.

<sup>281</sup>INT38, INT39.

<sup>282</sup>INT23.

<sup>283</sup>INT43.

<sup>284</sup>INT38.

<sup>285</sup>INT01.

senior interviewee agreed that most clinicians are “stretched to the limit doing their daily job, so to find time for research means spare time – hard to come by unless they get a training fellowship that buys them out and allows them to do research.”<sup>286</sup>

A lack of early-career research opportunities was highlighted as a particular barrier to allied health and social work professions. A nursing/AHP/care interviewee said that a lack of post-PhD funding causes PhD students to lose interest in research and suggested that it would help if a greater number of longer-term grants (lasting five to ten years) and postdoctoral fellowships were available.<sup>287</sup> Another interviewee commented that there are not enough PhD positions available in social care and almost no postdoctoral fellowships,<sup>288</sup> while a junior/mid-level researcher said that there are particularly few positions available for people who complete dementia-related studies.<sup>289</sup>

### 6.3.3. Researcher retention in dementia

Views on the extent to which researcher retention in dementia presents a policy challenge were mixed. More respondents considered the retention of researchers in the dementia field to be a challenge than did not. Retention of dementia researchers in the UK was seen to be less of an issue, with the benefits of brain circulation more widely recognised, (aside from in some areas of research which are very specific to the UK care system).

Fifteen interviewees from diverse fields and stages of career pathways highlighted researcher retention in dementia to be a substantial challenge.<sup>290</sup> One epidemiologist called it “an enormous problem, affecting all

*the research groups I know,”* and explained that “a lack of funding continuity leads to wasted resources because a shortage of mid-level researchers results in principal investigators needing to spend a lot of time training very inexperienced researchers.”<sup>291</sup> This issue was not generally seen as being specific to dementia, but some interviewees did mention that dementia researchers in particular tended to more frequently drift towards other fields for funding. Meanwhile, a research funder felt that there is “a lack of role models for dementia researchers, particularly in biomedical science and clinical research.”<sup>292</sup>

Four of the interviewees had stopped working in dementia research, and their reasons for leaving included personal and professional factors.<sup>293</sup> Among these were challenges associated with finding time to publish papers while handling a full teaching load and then parental leave,<sup>294</sup> being put off by funders’ apparent lack of interest in care research,<sup>295</sup> and believing that their technical skills were better suited to other research opportunities that arose.<sup>296</sup>

Four clinicians felt that retention was an issue because clinicians who might have an interest in pursuing some research activity often end up moving into posts where they do clinical work full time<sup>297</sup> (although one neurologist disagreed).<sup>298</sup> A psychiatrist observed: “In clinical research there is a need for more security in the job. We need... to make university jobs as attractive and secure as NHS jobs. People go to the NHS when they leave [research].”<sup>299</sup>

Another four interviewees (from neuroscience and nursing/AHP/care, and both junior/mid-level and senior positions) said that growth in national-level commitment to – and a rise in the profile of – dementia

<sup>286</sup>INT02.

<sup>287</sup>INT17.

<sup>288</sup>INT13.

<sup>289</sup>INT36.

<sup>290</sup>INT02, INT04, INT05, INT06, INT07, INT11, INT12, INT14, INT15, INT18, INT19, INT20, INT21, INT23, INT24.

<sup>291</sup>INT14.

<sup>292</sup>INT43.

<sup>293</sup>INT31, INT32, INT33, INT34.

<sup>294</sup>INT33.

<sup>295</sup>INT32, INT34 (fields: psychology and nursing/AHP/care).

<sup>296</sup>INT31.

<sup>297</sup>INT06, INT15, INT18, INT38.

<sup>298</sup>INT09.

<sup>299</sup>INT39.

research could help reduce challenges to retention, if sustained. They highlighted that many current dementia researchers are very passionate about the field and do not wish to leave, if they have opportunities to follow.<sup>300</sup>

We also asked whether interviewees felt that it was a challenge to encourage dementia researchers to stay in the UK; most said that retention of researchers in the UK was not a major issue. Three commented that it used to be more of an issue in the past than it is now,<sup>301</sup> while others pointed out that the issue is no more serious in the UK than in other countries.<sup>302</sup> While three interviewees (from nursing/AHP/care, neurology and neuroscience) said they thought that the UK is an attractive place for research,<sup>303</sup> one nursing/AHP/care interviewee stressed that keeping foreign students in the UK after their studies can be challenging.<sup>304</sup> Four other interviewees cited reasons why other countries could be seen as more attractive places for research. Two thought that the USA, Germany and Australia provide better core funding.<sup>305</sup> Two identified other EU countries such as Belgium, France and the Netherlands as providing better support for clinicians doing research.<sup>306</sup> One interviewee pointed out: *“Funding infrastructure is pretty patchy in the UK in terms of grant support, building and equipment infrastructure, and ability to recruit and retain the best staff because of [limited] ‘start-up’ support. The best neuroscience people will be recruited by top neuroscience departments in the US, for example Harvard, Stanford, Hopkins, or elsewhere such as the Max Planck Institutes. They’ll get in the US, for example, a start-up package of \$2 million. In the UK it’s nowhere near that amount... it’s less than 10% of the start-up for [an] equivalent junior faculty*

*in the US. So you just can’t start research because you have to write grants... that’s a big problem.”*<sup>307</sup>

Five interviewees did not agree that retention in dementia research or in the UK should be a major concern because circulation among fields and countries helps with the exchange of ideas and skills.<sup>308</sup> One neuroscientist said that researchers should be encouraged to move around to different fields because circulation of researchers “is crucial to doing excellent science.”<sup>309</sup> Other interviewees stressed that it is helpful to have programmes that enable researchers to spend time doing research abroad and then to return again.<sup>310</sup> One said: *“I don’t think keeping people in the country should be the goal – it’s good to send people abroad to learn new skills as long as there is a system in place to bring them back.”*<sup>311</sup> Others noted that it is quite common for researchers to move abroad and while this could be considered a loss for the UK, it is not necessarily a loss for the field.<sup>312</sup>

#### 6.3.4. Other cross-cutting challenges

##### Ethics approvals and bureaucracy

An issue raised by six interviewees (three from nursing/AHP/care, and one each from psychology, psychiatry and neuroscience) was that existing ethical approval processes are not generally appropriate for dementia research because many dementia sufferers are unable to give informed consent.<sup>313</sup> *“A huge barrier for research in dementia is ethics,”* said one nursing/AHP/care interviewee.<sup>314</sup> *“It’s good to have the ethics processes be as stringent as they are, but it’s a big difficulty that they are so biomedically oriented, so they don’t accommodate*

<sup>300</sup>INT08, INT13, INT25, INT36.

<sup>301</sup>INT11, INT24, INT37.

<sup>302</sup>INT05, INT12, INT15.

<sup>303</sup>INT13, INT22, INT23.

<sup>304</sup>INT26.

<sup>305</sup>INT14, INT40.

<sup>306</sup>INT16, INT18.

<sup>307</sup>INT40.

<sup>308</sup>INT03, INT06, INT10, INT25, INT38.

<sup>309</sup>INT25.

<sup>310</sup>INT03, INT10, INT25.

<sup>311</sup>INT03.

<sup>312</sup>INT06, INT38.

<sup>313</sup>INT03, INT27, INT33, INT34, INT36, INT41.

<sup>314</sup>INT36.

*the reality of human subject work with someone who cannot give consent.*<sup>315</sup> This interviewee had found that working with social science research ethics committees, comprised largely of sociologists, had been “*a much more productive experience*” and the committee “*was much more supportive of the work*”. Another interviewee explained that reading a long interview preamble to a participant with dementia could cause the participant to become confused or upset. This person had left dementia research, but said they would be more likely to return if difficulties around informed consent were reduced.<sup>316</sup> Bureaucracy and administrative burdens (including but not limited to those related to ethics) were also discussed more generally as a barrier to research progress by two interviewees.<sup>317</sup>

Issues related to gender and diversity in the dementia research workforce

We did not ask interviewees specifically about workforce issues related to gender and diversity, but six interviewees did discuss these issues in relation to various questions about careers and workforce capacity.<sup>318</sup> These interviewees said that they have observed more women leaving dementia research than men, and that this tends to happen around mid-career levels, specifically after the postdoc stage,<sup>319</sup> and then after the reader level in academia.<sup>320</sup> Interviewees recognised a variety of reasons for women leaving research careers, including career instability,<sup>321</sup> family commitments and career breaks.<sup>322</sup> Four interviewees said that retaining women in science should be a priority,<sup>323</sup> in part

because many of the people leaving research are women and represent a large reduction in the workforce.<sup>324</sup> This problem, however, is not dementia-specific. It was suggested that increasing flexibility in careers, for example by enabling more part-time work, could help,<sup>325</sup> and two interviewees thought the Athena SWAN Charter<sup>326</sup> may help improve retention of women.<sup>327</sup> Another suggestion was that retaining researchers at the post-doc stage could be facilitated by making research units more collaborative. “*At present, researchers who go on parental leave may lose their contracts and relationships, but in a collaborative model these would belong to the team,*” said one interviewee.<sup>328</sup>

### 6.3.5. Are these issues specific to dementia research?

Overall, the majority (31) of interviewees said that either some or all of the challenges of supporting the dementia research workforce were common to research in general, though perhaps accentuated in dementia research given lower levels of investment compared to some other disease areas. The issue of an insecure career path in research, for instance, was not seen as being specific to dementia research. However, some interviewees suggested that the issue may be more acute in dementia research than in areas such as cancer or cardiovascular disease research, where they believe there to be more funding and more flexibility in the funding schemes.<sup>329</sup> To tackle this problem, three people suggested that it would be helpful to provide more dementia-specific support, particularly for early career researchers

<sup>315</sup> INT36.

<sup>316</sup> INT34.

<sup>317</sup> INT01, INT27.

<sup>318</sup> INT05, INT11, INT22, INT25, INT26, INT34 (including four neuroscientists, four females, four seniors).

<sup>319</sup> INT05, INT11, INT34.

<sup>320</sup> INT11.

<sup>321</sup> INT05, INT34.

<sup>322</sup> INT26, INT34.

<sup>323</sup> INT11, INT25, INT26, INT34.

<sup>324</sup> INT11.

<sup>325</sup> INT26.

<sup>326</sup> This charter, established in 2005, promotes efforts to advance women’s careers in science and medicine, among other areas, and to support their employment in these areas in research and higher education in the UK (Equality Challenge Unit 2015).

<sup>327</sup> INT11, INT22.

<sup>328</sup> INT34.

<sup>329</sup> INT14, INT16, INT27.

and those looking to make a transition to mid-level post.<sup>330</sup> A clinical psychologist observed that dementia is still just emerging as an area of study and so there are few courses offered in dementia<sup>331</sup> and few departments doing high-profile dementia research. Other issues – such as research-ethics related challenges – were thought to be particularly acute in the dementia context.

Many interviewees highlighted the challenge posed by dementia historically not receiving enough policy attention or enough research funding, which is a point that has been recognised in government policy (as discussed in Chapter 1).<sup>332</sup> Some interviewees felt that dementia research (and dementia care research in particular) is underfunded because it's not seen to be a 'sexy' area of research,<sup>333</sup> because there has not been enough awareness of and willingness to discuss dementia;<sup>334</sup> or because of the view that nothing can be done about the condition.<sup>335</sup> Multiple interviewees reported a challenge to be a lack of interest in dementia among medics and others working in nursing, allied health professions and other areas of care.<sup>336</sup> "People's attitudes also act as a barrier to dementia research careers," said one psychologist. "People may think there isn't much to be done for people with dementia. Accepting the idea that people can be helped might enable more research. This is about an attitude shift."<sup>337</sup> A nursing/AHP/other care interviewee said that dementia "needs people to become activists",<sup>338</sup> while an epidemiologist called for better public engagement with and communication about dementia research.<sup>339</sup>

However, other interviewees recognised that dementia is now much more in the public eye than it has been in recent years, and that the public now has more of an interest in dementia research.<sup>340</sup> As one junior/mid-level interviewee said: "In the UK things are probably as good as ever." Referring to doctoral training centres for dementia research, this interviewee also noted: "I don't know if there's ever been a time when there's been such an opportunity for people to do a PhD in dementia research."<sup>341</sup>

#### 6.4. Enablers of dementia research careers

We consulted interviewees about examples of effective mechanisms they have encountered or believe could be implemented to address the barriers to dementia research careers. The majority of suggestions focused on providing longer-term funding mechanisms and more secure positions,<sup>342</sup> and more collaboration across disciplines and sectors.<sup>343</sup> As illustrated by one interviewee: "There is a clear need to come up with a clearer strategic vision for research and for building capacity by maintaining and developing younger researchers. It is [also] very important to open up communication across centres on the type of research that is going on."<sup>344</sup> Specific suggestions for addressing challenges to dementia research careers and for workforce capacity-building are discussed below. Evidence from the interviews suggests the need for a mix of interventions focused on individuals, teams and networks.

<sup>330</sup>INT08, INT12, INT19.

<sup>331</sup>One undergraduate course in dementia studies is offered by the University of Bradford. Established in 1992, this part-time distance learning course claims to be the only one of its kind in the world. It targets individuals who would like to work on improving care in their organisation or become dementia care specialists (University of Bradford 2015).

<sup>332</sup>INT01, INT07, INT10, INT12, INT15, INT16, INT19, INT24.

<sup>333</sup>INT11, INT20.

<sup>334</sup>INT12, INT36.

<sup>335</sup>INT12, INT18, INT21.

<sup>336</sup>INT07, INT14, INT17, INT18, INT41.

<sup>337</sup>INT41.

<sup>338</sup>INT17.

<sup>339</sup>INT14.

<sup>340</sup>INT03, INT05, INT21.

<sup>341</sup>INT36.

<sup>342</sup>E.g. INT11, INT12, INT22, INT40.

<sup>343</sup>E.g. INT12, INT40.

<sup>344</sup>INT12.

### 6.4.1. Support for junior and mid-level career posts, including 'bridge-funding'

Support for junior researchers, including at PhD level, was seen as important for nurturing fresh talent. Three interviewees with clinical and/or care experience referred to the Alzheimer's Society's Doctoral Training Centres as one example of effective early-career support.<sup>345</sup> One interviewee explained that these centres are particularly beneficial because they focus not just on traditional biomedical research but also cover areas like the creative arts.<sup>346</sup>

Given the bottleneck between PhD and postdoctoral research posts, it is also important to consider transitional support that could complement research fellowships. For example, 'bridging' fellowships to help retain researchers as they complete their PhDs were suggested by four interviewees,<sup>347</sup> giving graduates more time to find another position or funding source.<sup>348</sup> A neurologist stressed the importance of providing funds to enable successful PhD students to extend their time in their PhD lab for one or two years, saying: *"If I hadn't had funding to do half clinical training and half research at the end of my PhD, I wouldn't be doing research now."*<sup>349</sup>

Many (16) interviewees discussed the need for more lectureships and other career options for mid-level researchers, such as "intermediate-level" research fellowships.<sup>350</sup> Dementia-specific fellowships and programmes<sup>351</sup> and fellowships that allow researchers to obtain international experience were highlighted. *"If you are given a fellowship in dementia, chances are that you'll establish a lab in dementia that will employ more people, and more PhD students will be drawn into the work that*

*you're doing,"* reasoned one geneticist.<sup>352</sup> Specific examples of effective existing fellowships for which dementia researchers are eligible (not all dementia-specific) cited include the British Society of Gerontology's Emerging Researchers in Ageing scheme<sup>353</sup> and Parkinson's UK fellowships. The Alzheimer's Society and Alzheimer's Research UK both offer "senior fellowships" designed to support postdoctoral researchers in establishing themselves as principal investigators.<sup>354</sup> Both schemes provide funding to cover salaries for the fellow and their support staff, as well as running costs for their research. One interviewee felt that these senior fellowships should be renamed "intermediate fellowships" because there is a need for fellowships for more senior researchers as well, saying: *"It doesn't matter how long ago you finished your PhD; what matters is whether you have a permanent position."*<sup>355</sup> A funder suggested that it can be helpful to encourage researchers to be included as principal investigators on grants so that they can demonstrate they are able to attract funding.<sup>356</sup>

### 6.4.2. Fellowships and more flexible employment arrangements to enable sustainable and longer-term clinician engagement in research

More generally, interviewees referred to fellowships that enable clinicians to build research careers as being helpful,<sup>357</sup> with three interviewees specifically highlighting clinical fellowships provided by the Alzheimer's Society.<sup>358</sup> Other examples of existing schemes included clinical fellowships from the Motor Neurone Disease (MND) Association and support provided by the Guarantors of Brain charity for young clinicians to start

<sup>345</sup>INT19, INT36, INT38.

<sup>346</sup>INT36.

<sup>347</sup>INT04, INT05, INT10, INT17.

<sup>348</sup>INT04.

<sup>349</sup>INT23.

<sup>350</sup>INT01, INT02, INT03, INT05, INT08, INT12, INT14, INT15, INT16, INT19, INT20, INT22, INT24, INT25, INT39, INT40.

<sup>351</sup>INT08, INT12, INT19.

<sup>352</sup>INT02.

<sup>353</sup>INT19.

<sup>354</sup>Alzheimer's Society (2015b), Alzheimer's Research UK (2015b).

<sup>355</sup>INT14.

<sup>356</sup>INT37.

<sup>357</sup>INT07, INT16, INT18, INT19, INT39.

<sup>358</sup>INT18, INT19, INT39.

research.<sup>359</sup> Some interviewees highlighted the need for flexibility in clinical researcher careers to accommodate people who may move in and out of research at different points during their career.<sup>360</sup> One psychiatrist specified that more research opportunities should be provided, particularly for clinicians at the consultant level.<sup>361</sup> Finally, as discussed earlier, a few interviewees noted the need to find criteria other than an individual's number of publications to assess research potential when making fellowship decisions, given that clinicians may be well placed to do or contribute to research even if they have not produced many publications.<sup>362</sup>

Although not mentioned by interviewees, a small number of additional initiatives are in place to provide pathways for clinicians looking to move into dementia research. The Alzheimer's Society Clinical and Healthcare Professionals Training Fellowships and Alzheimer's Research UK's Preparatory Clinical Research Fellowships provide clinical professionals with funding to complete a higher research degree (usually a PhD) while continuing their clinical practice.<sup>363</sup> In addition, the NIHR Collaborations for Leadership in Applied Health Research and Care (CLAHRCs) are leading the Research Capacity in Dementia Care Programme, which aims to train nurses, social care and allied health professionals to conduct dementia research.<sup>364</sup>

#### 6.4.3. Supporting individuals and not only projects and programmes

Related to the issue of supporting development of early- and mid-career researchers, a few researchers suggested it could be helpful to focus funding more on individuals as opposed to projects, for instance through "rising star"-type programmes for researchers with high potential.<sup>365</sup> Related to this suggestion, an

interviewee from the nursing/AHP/other-care category identified challenges facing people working within large research programmes or labs to demonstrate leadership and attract their own funds. This person explained that a relatively small number of research teams dominate dementia research opportunities: *"This leaves PhDs with two opportunities: either carry on doing work in dementia that you don't own [by joining a research group] or end up taking your skills to a different area of work."*<sup>366</sup>

#### 6.4.4. Establishing dedicated research centres with core funding and promoting collaboration between disciplines and organisations

The need to encourage collaboration across diverse professions and fields was widely supported, whether through co-location of interdisciplinary talent within a centre or through collaborations and networks between teams and institutions. Examples of dedicated research centres highlighted by interviewees include those at University College London and Cardiff University. Five interviewees suggested that research centres also act as a means of providing longer-term core funding.<sup>367</sup> Academic–NHS collaborations such as the NIHR Biomedical Research Units (BRUs; those with dementia as a priority area are linked to the University of Cambridge, King's College London, Newcastle University and University College London) were seen as catalysts for research careers,<sup>368</sup> and the Collaborations for Leadership in Applied Health Research and Care (CLAHRCs) are leading the Research Capacity in Dementia Care Programme, an initiative to train nurses and allied health professionals in dementia research.<sup>369</sup>

Strategies for promoting collaboration, cross-disciplinary work and networking were also seen as

<sup>359</sup>INT06.

<sup>360</sup>INT16, INT17, INT18, INT23.

<sup>361</sup>INT18.

<sup>362</sup>INT07, INT19, INT23.

<sup>363</sup>Medical Research Council (2015).

<sup>364</sup>National Institute for Health Research

<sup>365</sup>INT21, INT27, INT34.

<sup>366</sup>INT21.

<sup>367</sup>INT02, INT06, INT07, INT14, INT42.

<sup>368</sup>INT24.

<sup>369</sup>INT43.

promising ways to bring both researchers and patient populations together.<sup>370</sup> In the UK, examples cited include the NIHR Dementia Translational Research Collaboration<sup>371</sup> and the MRC-led public–private partnership, Dementias Platform UK.<sup>372</sup> In the EU, examples included the EU’s Neurodegenerative Disease Research Joint Programme (JPND 2015) and Centres of Excellence Network in Neurodegeneration (CoEN 2015), the European Interdem (Dementia Services Development Centre Wales 2015) network, and the umbrella organisation Alzheimer Europe.<sup>373</sup>

#### 6.4.5. Attraction of researchers from other fields

Interviewees (mainly but not exclusively those active in basic science research) suggested that a wide range of basic scientists would have valuable skills to apply to problems in dementia research. The most popular response (supported by 12 interviewees from genetics, epidemiology, neuroscience, neurology, psychiatry and other fields) was that in dementia research, there is a need for more researchers with mathematics and computer science expertise, with suggestions of useful skill-sets including bioinformatics, mathematical modelling and statistics. Views on the need for ‘big data’ skills are discussed further below.

Other frequent suggestions focused on cell biology, molecular biology, inflammation and immunology expertise (seven interviewees, of which six were senior). Some interviewees suggested that cancer and heart disease researchers may have useful cell biology skills, for instance in understanding cellular signalling mechanisms (four interviewees). Physics and engineering, genetics, and chemistry and pharmacology were also suggested by multiple interviewees as potentially fruitful disciplines from which to try to attract researchers to study dementia.

Interviewees with clinical expertise focused more on clinical fields, suggesting that it could be beneficial to attract geriatricians and primary care clinicians to dementia research because they see many dementia patients on a daily basis. It was also suggested that people with expertise in running clinical trials would be a valuable addition to the workforce, as would psychologists, other allied health professionals and neuropathologists.<sup>374</sup>

Other suggestions included people with experience in public engagement, humanities and the arts, and other areas.<sup>375</sup> An epidemiologist said that some of their most interesting projects have involved people from diverse backgrounds, including a mathematician with little prior knowledge of dementia.<sup>376</sup> This person added that there are also roles for social researchers, people with management experience who could work on patient and care management, and people with drama experience who could assist with public engagement and effective communication about dementia. Another interviewee said dementia could involve people with experience in a wide range of areas, including end-of-life care, gerontology, learning disabilities and general disability, mental illness and autism, adding that “*even philosophy and ethics should be looking at dementia*”.<sup>377</sup>

In terms of attracting researchers from other fields to dementia, the most common suggestion was collaborative funding mechanisms (11 interviewees from a range of fields). One neuroscientist explained that this sort of funding could be open to teams made up of a current dementia researchers working with someone from outside the field, and said that Alzheimer’s Research UK has run a programme of this type. Another option highlighted by the same interviewee would be to offer cross-disciplinary studentships where, unlike doctoral training centres that focus on specific disciplines, a programme could highlight a specific problem but be open to a range of disciplines: “*If you get the right people*

<sup>370</sup>INT05, INT10, INT11, INT12, INT26, INT38.

<sup>371</sup>INT43; National Institute for Health Research (2014).

<sup>372</sup>INT37, INT40, INT42, INT44; Medical Research Council (2014).

<sup>373</sup>Alzheimer Europe (2015).

<sup>374</sup>Each of these suggestions was supported by two interviewees.

<sup>375</sup>A similar set of responses, covering aspects of basic and clinical science as well as other areas, was obtained in response to a related question about which areas of dementia research lack next-generation researchers.

<sup>376</sup>INT14.

<sup>377</sup>INT36.

together, they can set up problem and say: 'we need a physicist to help with that, a chemist with that, a biologist with that.'<sup>378</sup> However, the prospective take-up of such opportunities is uncertain.

While many interviewees focused on funding needs, a neurologist stressed that strong clinical leadership is needed to attract neuroscientists, engineers, chemists and others to clinical research groups.<sup>379</sup> Another four interviewees from different fields said it is important to make researchers and the wider public aware of what is happening in dementia – particularly the successes already achieved and the field's potential. As one neurologist said: "People who are working in and who fund dementia need to be more positive about the success achieved and opportunities for the future... We need to get across the message that things in dementia can change. This would attract good people from other areas."<sup>380</sup>

Other suggestions included dementia-themed calls and prizes, and establishing dementia research centres, networks and hubs. Interviewees said that dementia-themed calls can be useful in generating interest outside the field and noted that the NIHR, the ESRC and the MRC have already run calls of this type. Centres, hubs and networks at both national and EU level were noted as possible initiatives to learn from in informing future capacity-building interventions. Interviewees from nursing/AHP/care, clinical psychology and neurology said that networks, centres and other platforms for interaction can help bring together data from different patient populations, enabling cross-fertilisation and exposure to new ideas, providing support and information for early-career researchers, and providing a platform for discussing issues such as ethics in dementia care. Specific initiatives mentioned were the EU's Neurodegenerative Disease Research Joint Programme (JPND) and Centres of Excellence Network in Neurodegeneration (CoEN), the European network Interdem, the Alzheimer's Europe annual working group, and, in the UK, primary care research networks and networks coordinated by the Alzheimer's Society.

Short sabbaticals and staff exchanges were also discussed, although views on these were mixed, with two interviewees saying that they could be useful and two questioning what could be achieved without making a complete commitment to the field. An epidemiologist said that having the chance to work with a computer scientist or statistician, even for just six months, would be useful, while a statistician added that the important thing in data analysis is to have "a fresh pair of eyes".<sup>381</sup> On the other hand, a neurologist stressed: "I think you need to immerse yourself rather than just have a superficial experience," but did add that "maybe those kind of things would give people a taster and make a decision to dive deeper."<sup>382</sup> Many interviewees also stressed the importance of demonstrating the availability of funding as a way to attract interest, and several individuals reiterated the need for long-term, flexible funding, permanent positions, and pay that is competitive vis-à-vis remuneration packages for other fields and areas of research.

### Big data

There has been growing interest in the potential of big data approaches to advance biomedical research. Big data spans a wide range of data including genetic, biochemical and administrative information, and approaches include emerging methods of integrating and analysing new and existing data.<sup>383</sup> As noted above, several of our interviewees said they thought quantitative and data-analysis skills could be useful in dementia research. We also asked interviewees whether they thought that the pool of people with big data skills in relation to dementia was sufficient. The majority of interviewees who answered this question (9 out of 12) said there is a need for more individuals with big data skills, although views varied on exactly which skills are required. One interviewee noted that a lot of progress had been made recently in bringing together data that were available around the world, and referred to the EU-wide AdNeuroMed project and the European Medicine Implement Framework (funded by the Innovative Medicines Initiative) as examples of useful initiatives.<sup>384</sup>

<sup>378</sup>INT11.

<sup>379</sup>INT23.

<sup>380</sup>INT12.

<sup>381</sup>INT44.

<sup>382</sup>INT06.

<sup>383</sup>Deetjen et al, 2015.

<sup>384</sup>INT44.

Mathematical modelling, computer science, and bio-informatics and statistics were all mentioned as being potentially useful skills related to big-data analysis. A senior geneticist pointed out that many life sciences researchers who do quantitative data analysis are self-taught, although courses for teaching data analysis skills are now coming in. Another pointed out that it can be difficult for people within the dementia field who are self-taught to really understand complex data, and that people with stronger informatics skills are needed.<sup>385</sup> Two interviewees mentioned that it can be difficult to bring people with these skills into dementia, with one epidemiologist reporting that they “*had difficulty finding a group interested in dementia research as they said they mainly did genetic research.*”<sup>386</sup> Similarly, a neurologist highlighted: “*There are many people but they often get attracted into the financial sector.*”<sup>387</sup> As emphasised by a neuroscientist, people with numerical skills are particularly difficult to find at postdoc level, which may reflect the low uptake of physics and maths within schools.<sup>388</sup>

The most common suggestion for supporting the development of skills for handling big data in dementia was to invest specifically in it, for example through themed training fellowships in informatics (such as those that the MRC supports), funding for collaborative projects, and other interdisciplinary grants and posts. As well as supporting staff, three interviewees said it is also important to encourage researchers to share data, analysis tools and analysis results, and to convince scientists that it is worthwhile to share and re-use data and tools.<sup>389</sup>

However, a neurologist cautioned that combining data from diverse patients was “lumping rather than splitting” disease types and could cause important

information unique to specific types of dementia to be overlooked, highlighting the importance of careful data analysis, management and interpretation by dementia specialists. While one interviewee said that the UK is likely to be a good place for big data research due to the joined up health service,<sup>390</sup> barriers to the use of big data were also raised by two interviewees.<sup>391</sup> These barriers include a lack of clarity about information governance, bureaucratic and other obstacles to gaining access to data, and the risk of losing public support for the use of personal administrative data and health records.

#### 6.4.6. Other notable enablers and areas for intervention

Interviewees also highlighted the need to train research leaders to manage research groups more effectively,<sup>392</sup> enhancing mentorship for earlier-stage researchers in dementia,<sup>393</sup> supporting courses in dementia at the undergraduate level to help create interest at an early stage,<sup>394</sup> and, more generally, raising dementia’s profile and improving the field’s prestige.<sup>395</sup> Other suggestions included providing greater career flexibility, particularly for women and others with family responsibilities.<sup>396</sup> Funding partnerships (e.g. joint funding from charities and other funders) were also suggested as an area for attention.<sup>397</sup> Finally, the consensus of interviewees with whom professional skills were discussed was that skills for publicising dementia research and communicating it with the public were lacking. One geneticist cautioned: “*We need to get away from this notion of academics in their ivory towers, beavering away, creating monsters in the labs. We should be better at presenting what we’re doing so everyone can understand it and hopefully see its value.*”<sup>398</sup>

<sup>385</sup>INT18. This view was also supported by an interviewee working in statistics in dementia (INT44).

<sup>386</sup>INT04.

<sup>387</sup>INT23.

<sup>388</sup>INT25.

<sup>389</sup>INT03, INT07, INT11.

<sup>390</sup>INT09.

<sup>391</sup>INT16, INT07.

<sup>392</sup>INT13.

<sup>393</sup>INT04, INT05, INT14.

<sup>394</sup>INT19.

<sup>395</sup>INT24, INT25.

<sup>396</sup>INT26, INT33, INT34.

<sup>397</sup>INT31.

<sup>398</sup>INT02.

A neuroscientist said that as well as skills for communicating with the public, researchers needed to be taught how to communicate with those with dementia.

### 6.5. Reflection on points of agreement and divergence among interviewees from different professions and career stages

Interviewees from diverse fields and career stages broadly agreed on the key challenges facing researchers pursuing careers in dementia. They shared views on the lack of sustainable funding and job security, and obstacles that make it difficult for clinicians and other healthcare professionals to engage in research. Specific groups also emphasised individual issues as primary obstacles. For academic researchers, short-term funding combined with a lack of permanent positions has created a career progression bottleneck at the transition from postdoc to principal investigator. For clinicians, the training pathway steers many individuals towards full-time clinical work, offering little time to train in or do research. Individuals in the allied health professions reported support for early-career researchers as the key obstacle. Two cultural challenges were also identified for health care professionals: clinician researchers being undervalued by universities, and research being undervalued in the clinical setting.

To a large extent, the challenges identified are not all dementia specific, but appear to be accentuated in the dementia context, given a scarcity of support compared to some other disease areas like cancer. Some barriers (such as difficulties with meeting research ethics requirements and negative attitudes about prospects for success with dementia research efforts) were seen as particularly relevant in the dementia context.

Researchers from care research – including allied health professionals, psychologists and psychiatrists – cautioned of a prevailing view that there is little opportunity for impact in the dementia field, and warned that dementia research was not seen as a particularly attractive area of specialisation. Much more optimistic sentiments were expressed by academic researchers, who highlighted growing public awareness of dementia and

heightened interest in dementia research.

The range of solutions proposed for tackling these career challenges corresponded to the range of issues raised. Interviewees from all fields cited a need for more fellowships and lectureships, while clinicians saw a need for more flexible career pathways. Interviewees from diverse fields believed that dedicated dementia research centres, networking initiatives and funding mechanisms that promote collaboration could help bring researchers together and improve the sustainability of funding. To respond to the wide range of challenges encountered, there is a need for a mix of interventions to support dementia research careers and build capacity in the dementia research workforce.

### 6.6. Reactions to growing national commitment to dementia research and to recent policy initiatives

As populations age and the number of people affected by dementia continues to rise, dementia has increasingly become a focus of attention from policymakers and the public around the world. In the UK, developments include Prime Minister David Cameron's launch of a dementia challenge in 2012, followed by a five-year strategy to tackle dementia through research, care and awareness. The strategy, published in February 2015, included a pledge to establish an international dementia institute in England and make the UK 'the best place in the world to undertake research into dementia and other neurodegenerative diseases' by 2020.<sup>399</sup> In December 2013, the UK hosted a G8 summit on dementia – a meeting of health ministers from the G8 countries focused on improving global coordination of dementia research and policy. On the occasion of the summit, Cameron pledged to double commercial, public and charitable R&D spending on dementia by 2025.<sup>400</sup> Among other developments, in June 2014, the UK's Medical Research Council launched the UK Dementias Research Platform (UKDP), a £16m public-private partnership for dementia research aiming to enable earlier detection, better treatment and potentially prevention of dementia.<sup>401</sup> This initiative includes analysis of data from two million volunteer participants

<sup>399</sup>Department of Health (2015b).

<sup>400</sup>Department of Health (2013).

<sup>401</sup>Of the £16m, £12m is from the UK Medical Research Council. (Source: Department of Health, 2014).

and involves six industrial and eight academic partners. The NIHR is also providing £36 million for the Dementia Translational Research Collaboration.<sup>402</sup> NIHR funding has also supported the appointment of a National Director for Dementia Research, and the NIHR has partnered with the ESRC on £20 million worth of joint research grants for research on the quality of life in dementia.

We asked interviewees for their reactions to the increased interest in dementia research in national policy and the research funding commitments announced (which we described in Chapter 1). We also asked interviewees about their views on the coordination of dementia research funding by charities and other funders. The most common response (given by eight interviewees)<sup>403</sup> was that the enhanced focus and funding commitment at national level and from charities is welcome, but is still relatively low compared to what is allocated to cancer research and considering the social cost of dementia. Interviewees added that it will be important to sustain the commitment in the long term (ten to twenty years), and two interviewees said that the commitment to double funding will have little impact because the initial level of support was very low.<sup>404</sup>

Interviewees from across fields said that the increased interest has been positive in that it raises awareness, generates research interest and momentum, and helps to reduce the stigma associated with dementia. *“Dementia has rocketed up people’s consciousness”* said one interviewee. Another positive aspect, according to one neurologist, was that industry is becoming more involved alongside academics and funders.<sup>405</sup>

Another neurologist observed that the research effort has become more coordinated: *“It used to be that there*

*were people in different pockets of the UK just doing their own thing. Now it is much better that research is [more] joined up and transparent, and people are sharing more. This is as important as the amount of money.”*<sup>406</sup>

Overall, however, interviewees’ views on coordination and transparency were mixed. Six interviewees said that coordination was generally desirable and that it is happening to a degree.<sup>407</sup> As examples of coordination, they cited joint calls between the ESRC and NIHR,<sup>408</sup> and the MRC and Alzheimer’s Society (a clinical fellowship,<sup>409</sup> along with the varied remits of the research councils and charities. However, one interviewee advised that more coordinated and strategic thinking, particularly among the charities, is needed. Others said that there should be more interaction and coordination between industry and academia. They cited work on amyloid and tau as an area currently being covered by industry, and suggested that the whole community should consider a shift to new priorities together.<sup>410</sup>

However, three neuroscientists warned that too much coordination can be risky,<sup>411</sup> and one explained that over-coordinating can lead to “one world view taking hold” and stifle exploration of new or different ideas.<sup>412</sup> A psychiatrist cautioned that *“there is a definite momentum building which is fantastic, but we need to learn from the past so we don’t get railroaded on one route suggested by big guns and charismatic individuals.”*<sup>413</sup>

While interviewees did generally respond positively to the increased political and public awareness of dementia and dementia research, some questioned whether funds would be spent effectively and whether they represented a real political commitment backed by new public money, as opposed to a reallocation of funds that had already been earmarked for research. One interviewee said:

<sup>402</sup>National Institute for Health Research (2014).

<sup>403</sup>INT01, INT07, INT10, INT12, INT15, INT16, INT19, INT24.

<sup>404</sup>INT14, INT26.

<sup>405</sup>INT12.

<sup>406</sup>INT09.

<sup>407</sup>INT02, INT04, INT07, INT09, INT10, INT23.

<sup>408</sup>Economic and Social Research Council (2013)

<sup>409</sup>Medical Research Council (2015).

<sup>410</sup>INT23, INT40.

<sup>411</sup>INT01, INT05, INT22.

<sup>412</sup>INT01.

<sup>413</sup>INT27.

*“The concern is that it diverts from other areas of research and it’s been put into areas where the impact is not so big.”* This interviewee added that *“shifting priorities to new areas is really important and the whole community needs to get together and decide that, ideally,”* echoing concerns

expressed by other interviewees about a lack of transparency about how some funds had been and would be allocated. Two interviewees raised concerns were also raised about funding becoming too concentrated in certain areas, such as London, Oxford and Cambridge.<sup>414</sup>

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<sup>414</sup>INT11, INT27.



## Chapter 7 In reflection: informing a future capacity-building agenda

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### 7.1 In reflection

This report provides a novel evidence base on the strengths and limitations of dementia research and the research workforce in the UK and identifies capacity-building priorities going forward. Given the growing burden of dementia on populations in the UK and globally, and limited progress with research and innovation efforts, the report provides timely insights which could help inform future science policy and the research capacity-building strategies of public, private and third-sector funders.

The research drew on an innovative combination of qualitative and quantitative methods, spanning bibliometric analysis, the tracing of career pathways of dementia PhD graduates, and 40 in-depth interviews with individuals spanning diverse stakeholder groups, sectors, stages of career pathways, and disciplinary backgrounds (as overviewed in Figures 18–21, Chapter 5). In general, the views expressed by interviewees supported the evidence from the bibliometric analysis and from the investigation of dementia PhD graduate career pathways.

Our findings suggest that the UK is leading in diverse areas of dementia research. It is producing influential outputs and punching above its weight in many research topics, especially given investment levels. However, there are also substantial challenges that need to be addressed to help nurture a sustainable and vibrant dementia research workforce and international excellence in UK dementia research. Addressing research gaps, and workforce capacity issues through an evidence-based strategy at national and organisational levels should help increase the impact of UK dementia research on the lives of all those affected.

Below, we reflect on key themes from the analysis and put forward issues and actions to consider in a future policy agenda.

#### 7.1.1. In reflection of UK dementia research landscape strengths

The bibliometric analysis identified pockets of excellence and influential research within the Alzheimer's disease research portfolio: Lewy body dementia, frontotemporal dementia, vascular dementia, small vessel disease, primary progressive aphasia, mild cognitive impairment and CADASIL research. Interviewees most frequently highlighted strengths in dementia-related genetics research to advance knowledge of disease-risk in Alzheimer's and Parkinson's diseases; brain-imaging to provide evidence on disease progression (the bibliometric analysis also highlights high-impact papers in the field of medical imaging); Lewy body dementia; research into the development of person-centred care; epidemiological work with cohort studies; and research on the amyloid hypothesis and amyloid fibril formation. Some of the fields which were identified as particularly influential in terms of citation have contributed to research across these topics.<sup>415</sup>

It is interesting to observe that the bibliometric analysis points to a low volume of UK dementia papers in the genetics field (3% of all UK dementia research outputs), despite this being perceived as a key strength by the dementia research community. Interview evidence suggests that UK genetics dementia research is perceived to be highly influential. Although the citation performance of UK genetics research publications is only slightly above world average when the entire portfolio is considered, there is a subset of highly influential

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<sup>415</sup> These fields include medicinal and biomolecular chemistry, general and internal medicine, nuclear medicine and medical imaging and pathology).

UK research outputs in the genetics of dementia, as indicated by the high percentage of highly cited papers. Similarly, interviewees highlighted strengths in research related to person-centred care, although both the bibliometrics and interview evidence suggest low volumes of UK research activity in fields which would contribute to these areas (e.g. health policy and services, and nursing fields) and only modest citation-impact (bar some pockets of excellence). We recognise that individuals working in these fields may also disseminate their work through channels other than academic journals. Decisions about whether to support areas of strength, target areas of weakness or both are issues for policy debate; these observations may be helpful for future discussions on dementia capacity-building.

### 7.1.2. In reflection of UK dementia research landscape gaps and limitations

Research gaps in conditions classified as familial and early-onset dementia, where the UK lags behind world averages citation-wise, were identified through both the bibliometric analysis and interview data. According to key informants, these gaps relate to low numbers of patients diagnosed with these conditions in the UK (though increasing over the last decade),<sup>416</sup> but also to patient recruitment challenges which are accentuated by a lack of specialists able to provide an accurate diagnosis. In addition, the disjointed nature of service delivery for such patients impacts on recruitment and the competition between specialties for recruitment also acts as a barrier to research projects involving these patients. Supporting research on the classification of different dementia diseases could potentially contribute to better diagnosis for specific types of dementia. Collaborative research grants bringing together disciplines which may not otherwise overlap much (e.g. neurologists and psychiatrists) could help overcome some of the challenges to patient recruitment for research in these rarer forms of dementia.

Insufficient clinician involvement in dementia research more generally (and not only in research related to a specific condition such as familial or early-onset dementia) was highlighted as a key policy challenge by some interview participants and one which was particularly

acute in the dementia context. Learning from examples of successful clinician recruitment to research – including perhaps through evaluations of dementia-related schemes such as the clinical fellowships offered by the Alzheimer’s Society, MND Association and support provided by the Guarantors of Brain charity, and wider schemes such as NIHR Clinical Academic Fellowships – could help inform how incentives can be created to secure and sustain clinician participation in dementia research. A wider challenge to clinician involvement has to do with assessment processes which favour publication and grant track-records – both of which interviewees from clinical and allied health research professions saw as inappropriate criteria for reflecting their potential to make contributions to research.

Related to the above, interview evidence suggests a particular underinvestment in care-related research (e.g. in nursing, allied health professions and social care fields) given the costs of dementia care to the UK economy, and an associated need to explore new ways of overcoming difficulties related to research careers in allied health professions. This argument is also supported by the bibliometric data which shows low publishing volumes in these areas and low numbers of researchers who specialise in care and care-related dementia research, and modest citation impact. (We recognise that individuals working in these fields may also disseminate their work through channels other than academic journals).

According to a recent report by Prince et al.,<sup>417</sup> the cost of dementia care to UK society is £26.3 billion, of which £4.3 billion is costs spent on healthcare, £10.3 billion on social care costs, and the remaining £11.6 billion being the cost of unpaid work by the carers of dementia sufferers. The importance of supporting various aspects of care-research was noted, including end-of-life care, care for patients with advanced stages of dementia, care for marginalised and hard-to-reach groups, research into patient–carer relationships, research on educating carers, and arts therapies for people with dementia.

Other key limitations of the research landscape include limited understanding of the cellular mechanisms underlying dementia and the need for more collaboration between different fields and sectors towards that end. Related to this are challenges to and scope

<sup>416</sup> Prince et al (2014).

<sup>417</sup> Prince et al (2014).

for improvement in the conduct of clinical trials, most notably in areas of recruitment processes<sup>418</sup> and incentives for clinicians to enrol patients in trials, the accuracy of diagnosis (which can affect recruitment as well as trial outcomes and interpretation), and mechanisms to attract and facilitate industry engagement in dementia research. Industry engagement was seen to be needed in areas including (but not confined to) collaboration in applied R&D drug-discovery efforts, for example in the development of medical apps and assistive living technologies.

Evidence from this study, as well as from other studies and contexts, has highlighted the importance of advancing basic science understanding of dementia (including disease causes, classification, cellular mechanisms and pathophysiology to help identify biomarkers) in order to enhance industry engagement with drug-development efforts. However, in dementia, as in other areas, basic and clinical research (as well as health services research) may be undertaken in parallel, and there is scope for further public–private collaboration and industry engagement both in experimentation with novel compounds and drug-repurposing efforts, as well as in areas such as medical applications and assistive living technologies.<sup>419</sup> Interviewees highlighted a need for greater emphasis on translational research, including research which would link genetics, cellular mechanisms studies and drug target discovery efforts; and translational work which would help move advances from care-related research into improved service delivery.

To enable industry engagement, it will also be important to address regulatory incentives in a timely manner, to pave the way for further industry involvement once tractable drug-targets are in sight. This includes considering issues such as regulation associated with drug-repurposing efforts and patent pools, as well as prospects for accelerated review and drug approval processes.<sup>420</sup>

### 7.1.3. In reflection of research workforce issues

Our study also examined issues which are crucial for capacity-building in the dementia research workforce. Insights from the pilot investigation into the career pathways of dementia PhD graduates suggest that approximately a fifth of individuals who complete PhDs in a dementia-related topic remain in dementia research careers. We do not have evidence on how this compares to other disease areas and we could not examine attraction to dementia from other fields or other countries within the scope of this work. However, given the challenges of building a dementia research community and the comparative scarcity of funding compared to areas like cancer,<sup>421</sup> policymakers need to consider ways of encouraging retention in dementia careers and ring-fenced posts and funding in this space, particularly for areas of dementia research where there may be particularly notable underinvestment. Based on our evidence, approximately one quarter of dementia PhD graduates who are active in dementia research leave the UK, although this was seen as less of a concern to most experts we interviewed than retention in field (while the benefits of brain circulation were also recognised). An exception would be research into UK-specific care issues, where workforce capacity is already low.

The ratio of junior and mid-level research staff to senior researchers in dementia broadly mirrors that observed for many other areas of the life-sciences (e.g. biological sciences, subjects allied to medicine)<sup>422</sup> but is higher than the ratio observed for medicine and dentistry.<sup>423</sup> However, our interviews highlight that particular career bottlenecks exist within the junior and mid-level dementia research workforce. Most notably, the transition from a postdoctoral role to a lecturer role was identified as the biggest career bottleneck, with the transition from a PhD or clinical training to the first postdoctoral or clinical research position coming second. A particular lack of junior level studentships and fellowships (PhD and first postdoc) was identified in the allied health professions

<sup>418</sup> See for example Join Dementia Research (National Institute for Health Research, 2015b), an initiative (introduced by the NIHR in partnership with Alzheimer Scotland, Alzheimer's Research UK and Alzheimer's Society) which "allows people to register their interest in participating in dementia research".

<sup>419</sup> Taylor, Marjanovic et al. (2014).

<sup>420</sup> Taylor, Marjanovic et al. (2014).

<sup>421</sup> Alzheimer's Research UK (2012).

<sup>422</sup> HESA classification considers these to be anatomy, physiology and pathology, pharmacology, toxicology and pharmacy, complementary medicines, therapy and well-being, nutrition, ophthalmics, aural and oral sciences, nursing, medical technology, and others in subjects allied to medicine.

<sup>423</sup> We analysed data requested from HESA (<https://www.hesa.ac.uk>) 2015. More detail is given in the Chapter 4.

and social care. Some of these workforce challenges apply to science careers in the UK more widely but are accentuated in the dementia context. Barriers to clinical research careers in dementia were seen as particularly high, as mentioned above. Interviewees pointed out that these barriers are related to time constraints; a perception that clinicians are undervalued in academic environments and that research is undervalued in clinical settings; inappropriate assessment mechanisms for clinical research posts that are based on publication and grant histories; the short-term nature of research contracts for clinical and allied health professions staff; and insufficient attention to research training in medical education curricula.

These insights suggest that renewing the leadership of the future will require attention to workforce and succession planning at the present time. Funders, policy-makers and higher education institutions may wish to engage in discussion around these issues. There may be transferable learning related to workforce planning that could be gained from the experiences of other health-care sector organisations (e.g. the General Medical Council) or from capacity-building and workforce planning efforts in areas such as science, technology, engineering and maths (STEM) skills.

## 7.2. Actions for a policy agenda: informing a blueprint for dementia research capacity-building

The findings discussed above and in previous chapters of this report, recommendations from interviewees, and our wider knowledge of science policy issues (including from previous research in the dementia context),<sup>424</sup> lead us to propose a number of areas for action which could help support dementia research initiatives and dementia research careers going forward. We recognise that these actions require collaboration and commitment from all the actors involved in dementia research (public, private and not-for-profit) – no single institution will have the resources to support all the actions identified on its own. We also highlight areas in need of further investigation and evaluation. Our intention is not to be prescriptive. Rather, we present policy considerations, which aim to encourage further constructive dialogue and the exchange of ideas on the next steps

for dementia research and research workforce capacity-building in the UK. Some of these insights are likely to also have international relevance.

Key areas to consider in a policy-mix are elaborated on below. Table 13 at the end of the chapter provides an overview of some existing policy levers mentioned throughout the report, and areas identified as being in need of further scale-up or new investment.

### Actions to support individuals

**1. Introduce mechanisms to tackle bottlenecks in the transition from postdoc to independent investigator and lecturer posts.** Some examples of such interventions exist and have been discussed (see Chapter 6), but scale-up is needed. This includes:

- Enhancing the scale and scope of **dementia-specific fellowships to support individuals in their first role as principal investigator and to help build research teams**, particularly fellowships which go beyond simply covering salary costs to providing some infrastructure and research team recruitment support.
- Considering **‘rising star’ programmes** for researchers with high potential – e.g. **fellowship schemes** which are receptive to and supportive of mid-career applicants being named principal investigators on applications, coupled with **training and mentoring in research leadership skills**. These types of mechanisms would require supportive senior institutional leadership.
- **Learning from the experiences of countries that support longer-term positions for researchers across different stages of a career pathway** (e.g. the Canada Research Chair programme),<sup>425</sup> which could potentially help towards lectureship posts for longer periods of time (although not tenure) in a similar way to professorial chairs;

**2. Consider ways to increase the feed of future talent and to address bottlenecks in the transition from PhD to postdoc.** Examples of mechanisms to support this include:

- **Dementia doctoral training centre schemes** (such as that offered by the Alzheimer’s Society)

<sup>424</sup>Taylor, Marjanovic et al, (2014)

<sup>425</sup>Canada Research Chairs (2015).

where investigators can apply for multiple dementia PhD studentships across diverse disciplines in a single bid.

- **Ring-fenced PhD studentships** in dementia.
- **Extensions to PhD studentships** and ‘**bridge-funding**’ to help new graduates develop ideas and find new posts.

**3. Reflect on the specific research career needs of distinct stakeholder groups, including clinicians more widely as well as some allied health professions, nurses and social workers.** Examples of associated interventions to consider include:

- **PhD and first postdoctoral fellowships for early-stage clinical and care staff to engage with research** in order to help attract talented individuals early in their careers and to help nurture research skills in the clinical community.
- **Advocacy efforts with NHS Trusts.** The experiences of initiatives such as the NIHR CLAHRCs and the R&D Managers stream of the NIHR Leadership programme may provide examples of how to lobby successfully for clinician engagement in research.<sup>426</sup> As highlighted by Brown et al.,<sup>427</sup> in the context of cancer but applying to research more widely, there is significant variation in the support for research within different NHS trusts and a need for a health research strategy developed in partnership between NHS England, the NIHR, Department of Health and other key stakeholders. The dementia health research context could be considered within that wider strategy, and in the context of the Health and Social Care Act
- **Dialogue between funders and higher-education institutions about selection criteria for clinician and allied health profession research fellowships:** Consider new metrics for assessing the research potential of clinicians, which do not rest on publication and fundraising track-records. This could possibly be done in consultation between evaluation specialists, and different charities and government bodies awarding clinician researcher fellowships.

- **Engage in dialogue with medical schools and allied health professional training programmes regarding the role, nature and extent of research training in educational curricula.** It could also be helpful to discuss what type of training at pre-registration and postgraduate stages would best enable clinicians to engage with research and assume joint NHS-academic appointments, including at early career stages. (We recognise that this type of discussion needs to be held with an understanding and awareness of staffing shortages for clinical service requirements. With this in mind, the potential benefits of dementia research for improved health and social care service delivery would need to be clearly articulated).

**4. Support professional skill development.** Leadership, mentorship, communications and dissemination skills, project management and grantsmanship are all important elements of research workforce capacity-building across all areas of science.<sup>428</sup> Current senior research leaders in dementia play substantial roles in mentoring and developing leadership skills within the mid- and early-career researcher pool. But the time such leaders can devote to this type of activity is limited. Coupling on-the-job training with formal programmes might enable more sustainable and consistent approaches to leadership development.

Actions to support institutions and networks

**5. Consider the long-term sustainability of existing dementia research centres, networks and partnerships, the legacy they wish to leave and succession planning.** Dementia research centres, partnerships and networks should think about and articulate a sustainability plan and legacy agenda early on in their existence. Given the importance of leadership in dementia research efforts,<sup>429</sup> it is important to tackle succession planning for key individuals and strategies for attracting and retaining long-term funding and the best talent from across diverse fields. As pointed out by Taylor, Marjanovic et al. (2014), public-private partnerships are important for advancing research and innovation

<sup>426</sup>Marjanovic et al. (2015) *Forthcoming*.

<sup>427</sup>Brown et al. (2015).

<sup>428</sup>Marjanovic et al. (2015) *Forthcoming*.

<sup>429</sup>Taylor, Marjanovic et al. (2014).

efforts but also need to reconcile the incentives of different stakeholders and the long-term nurturing of partnership relationships.

- 6. Establish mechanisms to attract researchers from diverse fields to collaborative dementia research efforts (i.e. to research teams and networks) to support interdisciplinary collaboration.** This may require redirecting the attention of existing researchers in some functional areas to dementia. This study supported the findings of previous work which made a case for an interdisciplinary community of scientists and health and social care professionals, as well as other stakeholders (patient and public-involvement groups, industry, regulators) which would be committed to understanding the science of dementia, advancing clinical and care research and contributing to innovation.<sup>430</sup> Although tentative given lack of evaluation and uptake-related evidence, examples of interventions that could help in this regard include:
- **Funding grants or contracts which support partnerships between a dementia and non-dementia researcher.**<sup>431</sup>
  - **Cross-disciplinary, problem-driven rather than discipline-driven studentships.**
  - **Strong clinical leadership within existing partnerships to help attract clinical and allied health care researchers** from different disciplines.
  - **Dementia-themed funding calls and prizes.**
  - **National advocacy for research campaigns** to help attract interdisciplinary researchers to dementia research initiatives. This involves identifying individuals who could act as the most credible advocates for dementia research across different professional communities (e.g. research, care, policy, funder, patient-representatives) and the general public (e.g. well known individuals).<sup>432</sup>

Actions to inform prioritisation in research portfolios and wider research system issues

Decisions on how broad or focused a research portfolio should be are likely to be made within a wider science, health and social policy context and in consideration of the research landscape of specific national funders and

international activities. We therefore do not aim to be prescriptive, but to identify this as an important point for reflection and discussion.

- 7. Consider the balance of diseases supported in dementia research strategy. More specifically, reflect on whether areas in which current UK research is strong but has a lower volume of activity (as well as areas where the UK lags behind global averages in terms of impact) merit more targeted and scaled-up support.** Our analysis highlighted diverse areas of research strength and some areas of weakness. There are areas where UK dementia research was identified as having high influence, but where volumes of publishing and scales of research activity appear to be low (e.g. genetics research on dementia, person-centred care and inputs of fields like health policy and services research and nursing). Similarly, there are areas where the UK seems to be lagging behind global averages in terms of impact and where the scale of research activity is also relatively low, but where disease burden is on the rise (e.g. conditions classified as early-onset and familial dementia).<sup>433</sup>
- 8. Consider the balance of basic, applied and clinical, and health services research in a dementia portfolio and the degree of emphasis on prevention, treatment and care-related research.** In our interviews, most respondents were in favour of balancing research investments across different dementia disease areas (not least given potential relationships and interdependencies of risk factors and pathology) and across basic, applied and clinical research; some, however, highlighted potential merits in more targeted strategies. Views on the balance of support relating to prevention, treatment and care delivery were very mixed, and largely reflected individual professional experiences and backgrounds.
- 9. Consider coordination between different funding initiatives and funders to ensure that risks of duplication are minimised but that diversity and out-of-the-box thinking is supported.** Annual funder meetings may be one means of supporting coordination, while national and international funder networks could also

<sup>430</sup>Taylor, Marjanovic et al. (2014).

<sup>431</sup>Such as that offered by Alzheimer's Research UK.

<sup>432</sup>Taylor, Marjanovic et al. (2014).

<sup>433</sup>Prince et al. (2014).

be important (e.g. the International Alzheimer's Disease Research Portfolio and the Dementia Research Funders Forum in the UK). Overcoming the dementia challenge will depend heavily on successful cross-sectoral and cross-organisational collaboration, and on a well-coordinated national and global effort.

Other recommendations: learning from evaluation

**10. Learn from evaluation of current and prior investments into dementia research capacity-building, and from the experiences of other fields.** Evaluating the diversity of dementia-specific interventions that we have discussed, as well as interventions which have been used to address research and research workforce capacity issues in other fields, could provide meaningful formative learning for a future blueprint for dementia research capacity-building, and feed into continual adaptation and improvement. We therefore recommend that policymakers and funders in the dementia space consider learning through evaluation in a number of areas:

- **Learning from the experiences of UK dementia-specific fellowship schemes and initiatives.** This would apply to programmes such as the Alzheimer's Society and Alzheimer's Research UK fellowship for mid-career researchers and clinical fellowship schemes, but also to the evaluation of networks such as the MRC-led Dementia Platform UK and the NIHR Dementia Translational Research Collaboration.
- **Comparative studies.** The design, implementation and scaling of diverse interventions which have been identified as important for research capacity-building could benefit from comparative research and analysis of similar schemes in different countries, or in other fields and sectors. Similarly, international learning could be relevant in understanding why and how some other countries are seen to offer more attractive clinical research opportunities in dementia (for example, Belgium, France and the Netherlands were identified as offering more attractive opportunities for clinicians with an interest in dementia research).
- **Effective patient and public involvement (PPI) in dementia research.** There was very little mention of patient and public involvement in dementia research by the people interviewed in this study. Clinical researchers emphasised the role of clinicians as the representatives of patient and public needs and research priorities. However, the importance of patient and public involvement in health research is increasingly recognised, with various national networks and initiatives responding to this need (e.g. INVOLVE,<sup>434</sup> PPI platforms convened by charities). There are unanswered questions about how patients (or carers of dementia patients) can best be involved in dementia research initiatives, and there may be useful learning to be gained from a deeper understanding of successful approaches which may have been adopted in other disease areas (e.g. in the mental health sphere) and from advocacy efforts. In general, there is a need to highlight distinctions between patient recruitment into clinical trials and active and engaged PPI, as these are not the same.
- **Tackling research ethics-related barriers.** Finally, challenges related to research ethics were seen to be particularly acute in the dementia context and have discouraged people from dementia research in the past. Learning from examples of successful management of research ethics in studies with dementia patients could be important for future research efforts.
- **Informing research workforce and succession planning** by drawing on insights from sectors where this has been done successfully. This could help mitigate risks to the sustainability of leadership roles in UK dementia research. There may be transferable learning to be gained from the experiences of organisations such as the General Medical Council and from workforce planning strategies in areas such as STEM skills.

<sup>434</sup>INVOLVE (2015).

Table 13. Mechanisms for enabling dementia research careers

Enablers of dementia research careers	Some examples of existing UK initiatives that may be scaleable	Examples of other needed support mechanisms and associated activities
Support for junior researchers interested in dementia, through research fellowships	<ul style="list-style-type: none"> <li>Alzheimer's Society Doctoral Training Centres</li> <li>Alzheimer's Society PhD studentships</li> <li>Alzheimer's Research UK PhD studentships</li> </ul>	<ul style="list-style-type: none"> <li>Bridge-funding and extensions to PhD studentships, to support the formulation of proposals for future dementia research and to help search for and secure new posts</li> <li>Support for dementia-related training at undergraduate level, to help generate interest in dementia research at an early stage</li> </ul>
Support for mid-career research fellowships and lectureships	<ul style="list-style-type: none"> <li>Dementia-specific fellowships and fellowships that allow researchers to obtain international experience, such as:               <ul style="list-style-type: none"> <li>Alzheimer's Society fellowships</li> <li>Alzheimer's Research UK fellowships</li> <li>Parkinson's disease UK fellowships</li> <li>British Society of Gerontology Emerging Researchers in Ageing scheme</li> </ul> </li> </ul>	<ul style="list-style-type: none"> <li>'Rising star' funding programmes to establish mid-career researchers as PIs</li> <li>Senior leadership that encourages senior postdocs to act as PI on funding applications</li> <li>Fellowship schemes that are receptive to and supportive of mid-career applicants as PIs</li> <li>Training and mentoring in research leadership skills (e.g. NIHR Leadership programme) and other professional skills (e.g. project management, communication, dissemination)</li> <li>Learning from international initiatives (e.g. Canada Research Chair programme) which provide 'chair-like' support across different stages of the career pathway and different fields (akin to professorial chairs)</li> </ul>
Fellowships and more flexible employment arrangements to enable sustainable clinician engagement in research	<ul style="list-style-type: none"> <li>Alzheimer's Society clinical fellowships</li> <li>Motor Neurone Disease Association clinical fellowships</li> <li>Support provided by the Guarantors of Brain charity for early-stage clinicians to start research</li> </ul>	<ul style="list-style-type: none"> <li>Advocacy efforts to help raise the profile of research in NHS Trusts</li> <li>Discussion and debate around the selection criteria that are currently used to award research fellowships to clinicians and allied health professionals</li> <li>Dialogue related to research training in medical education curricula</li> </ul>
Attracting multidisciplinary talent and building collaborations	<ul style="list-style-type: none"> <li>Dedicated institutes and research centres (e.g. at University College London and Cardiff University)</li> <li>Academic-NHS collaborations (e.g. NIHR Biomedical Research Unit, CLAHRCs Research Capacity in Dementia Care Programme)</li> <li>Public-private partnerships (e.g. Dementias Platform UK)</li> <li>NIHR Dementia Translational Research Collaboration</li> <li>Funding for partnerships between dementia and non-dementia researchers (e.g. Alzheimer's Research UK Interdisciplinary Research Grants)</li> </ul>	<ul style="list-style-type: none"> <li>Cross-disciplinary, problem-driven rather than discipline-driven studentships and fellowships</li> <li>Strong clinical leadership to help attract researchers from different fields</li> <li>Dementia-themed funding calls and prizes</li> </ul>

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## Appendix 1: Interview protocols

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### Protocol for Group 1 (dementia researchers)

*RAND Europe has been commissioned by the Alzheimer's Society to conduct an analysis of UK's dementia research landscape and to explore the strengths and gaps in the dementia research workforce, across diverse fields and disciplines. We hope that the evidence will help the Alzheimer's Society and others to build a strong and vibrant research community to enable dementia research. As part of this study, we conducted a bibliometric analysis of UK publications in different disease areas and a tracing exercise looking at what people who did their PhD in dementia are doing now. At this point, we are building on those findings to through interviews with people like yourself get a better understanding of the strengths and gaps in UK dementia research, and we are particularly interested in insights on dementia research careers and workforce capacity issues, challenges and opportunities. In this context, the interview has three main parts:*

1. *A section on the UK dementia research landscape – including strengths and gaps in terms of science and skills- which we hope to spend about 10 minutes on this part with you*
2. *A section on research careers and capacity which we hope to spend 20-30 minutes on*
3. *A section on broader horizon-scanning and reflections on the future of dementia research in the UK, which we hope to spend 5-10 minutes on at the end*

*We recognise that the people we are speaking to have diverse backgrounds and we are deliberately soliciting diverse views from both those still involved with dementia in some way and those who may have left the field. But if there are any questions you do not feel you can comment on please let us know, and that is not a problem.*

*Also, all responses will be kept confidential and we will not link any quotes to you directly, without your permission. Is that ok?*

### PART 1: SCIENCE AND SKILLS

1. Can you just briefly tell us a little bit about your job and role, and any key related activities in the dementia space?
2. Based on your knowledge of the dementia research landscape, what are some of the areas where you think the UK research community has done particularly well (e.g. produced particularly important and influential findings)? We are interested in your views on both 'strong' disease areas and fields/disciplines.
3. And are there any disease areas and fields/disciplines where we have not done so well and where you think we could do better?
4. The bibliometric data from our study suggests that the UK generally does well in terms of the citation impact of dementia research, but that it lags behind global averages in a few areas – for example in familial dementia and early onset dementia. Do you know why that might be? Do you think these are areas we should focus on, vis a vis other priorities or not?
5. Do you think the UK should pursue a broad research portfolio across various types and subtypes of dementia, or focus investments in on specific diseases (i.e. specific types of dementia)?
6. Do you think funders should prioritise research on prevention, or treatment/cure, or care and service delivery? Why?
7. Similarly, do you think funders should prioritise basic or applied and clinical research? Why?

### PART 2: THE CAREER PATHWAY AND PIPELINE

We would like to discuss your insights and experiences regarding career progression in dementia research.

8. (i) What do you think the key barriers to progression in dementia research careers in the UK are? Have you experienced any of these? (ii) At what stages of the career pathway are there the biggest 'bottlenecks'?
9. Based on your experience and knowledge of the UK

landscape, are there any *stages of the research career pathway and transition points* where UK dementia research has a particular lack of capacity at present? What could be done to tackle this?

10. What about enablers of dementia research careers in the UK? Have you experienced and do you know of any supportive mechanisms for pursuing a research career in this field
11. Do you think these barriers and enablers are specific to dementia research or apply more generally to other research areas?
12. Has your work contributed to capacity-building in terms of the training and empowerment of future dementia researchers? If so, how?
13. Are there any areas of dementia research – either disease areas or important fields/disciplines - that you think the dementia investment community has *particularly* neglected and where research workforce capacity is *particularly* low?
  - a. Future work in the dementia space will possibly be linked to substantial growth in big data and informatics resources. Do you think the UK has a sufficient pool of people and skills to support this? How could the UK go about building or accessing these skills?
14. Are there any areas (dementia diseases, fields, disciplines) where you think there is a notable lack of *next generation* researchers? (e.g. a lack of new feeds into the workforce at more junior levels - phds, postoc lecturers levels etc.)
15. We would like to explore the problem of retention of researchers in dementia in a bit more depth.
  - a. Firstly, how big of a problem do you think retention of dementia researchers in the field is?
  - b. What about retention in the UK? Is that a challenge in your experience? Is it important in a 'brain circulation world'?
16. We hear a lot about the need to attract researchers from other fields or currently training in other fields, and to redirect researchers from other fields to dementia research
  - a. Which fields/disciplines do you think are particularly suited as targets for attraction to dementia research, and why?
  - b. How could we encourage this, what mechanisms might work? Based on your knowledge, are there examples of contexts where this has worked?
    - i) Do you think people could work in other areas and contribute to dementia in parallel (e.g. sabbaticals, staff exchanges, informal thematic interest networks etc.) or do you have to have 'complete commitment'?

17. With recent UK policy focus on dementia, we have seen an increase in funding committed to dementia research. Do you think the scale of increased commitments can make a difference and contribute to a critical mass of dementia researchers?
18. In addition to core scientific and technical skills, are there any professional skills which need to be built in the dementia research workforce?
19. Are there particular areas and types of research where you think (i) clinicians/allied health professional -driven research and (ii) industry research is particularly important for advancement of the dementia field?
20. It is particularly difficult to engage clinicians and allied health professionals in research careers, and we recognise that this is not specific to dementia only. Do you know of any support mechanisms/enablers for clinical academic/clinician researcher careers in dementia? What are the key barriers?

### PART 3: ON REFLECTION

21. On reflection, what do you consider the biggest challenges to progress in dementia research to be?
22. What do you consider to be the three key priority issues for workforce capacity investment in the UK? Why? What would happen if that sort of capacity isn't supported?

### Protocol for Group 2 - people who left dementia research (from PhD tracing)

*RAND Europe has been commissioned by the Alzheimer's Society to conduct an analysis of UK's dementia research landscape and to explore the strengths and gaps in the dementia research workforce, across diverse fields and disciplines. We hope that the evidence will help the Alzheimer's Society and others to build a strong and vibrant research community to enable dementia research. As part of this study, we conducted a bibliometric analysis of UK publications in different disease areas and a tracing exercise looking at what people who did their PhD in dementia are doing now. We are equally interested in talking to people who are currently active in dementia research, and with those – like yourself- who work in other areas.*

*In this context, the interview has two main parts:*

4. A section on your career history and experiences where we would like to understand why you left dementia research and what might have kept you in the field, as well as what you work on now
5. A section on your general views on the dementia

*research landscape and workforce capacity – to the extent that you can comment on those issues*

*If there are any questions you do not feel you can comment on please let us know, and that is not a problem.*

*Also, all responses will be kept confidential and we will not link any quotes to you directly, without your permission. Is that ok?*

## **PART 1: CAREER HISTORY RELATED QUESTIONS**

23. What is your current job/position and can you tell us a bit about your work?
24. What had attracted you to do a PhD in dementia? What was your research on?
25. Why did you leave dementia research?
26. Is there anything that would have helped retain you in dementia research?
27. Would you ever consider returning to dementia-related research?
  - a. If so, under which conditions and what do you think you could contribute? What areas of dementia would you work in?
  - b. If not, why not?
28. IF THEY WORK IN ANOTHER RESEARCH FIELD: How does your current research field compare with the dementia research field in terms of:
  - a. Research capacity
  - b. Career progression opportunities?
29. Do you still broadly follow developments in the dementia field?

## **PART 2A: ONLY FOR PEOPLE WHO ANSWER NO TO Q7**

30. IF THEY ANSWER NO to Q 7:
  - a. What do you perceive the dementia research landscape in the UK to be like, in terms of your general knowledge? Do you think there are any strengths or weaknesses?
  - b. More generally, what do you see as the key strengths and weaknesses of the UK research environment to be (e.g. in your field and more generally).
31. Do you have any thoughts on priority areas for capacity-building of the dementia research workforce in the UK?
32. Do you have any thoughts on key current barriers to progress for UK dementia research?
33. Do you have any thoughts on key enablers/barriers to progress for UK dementia research?

## **PART 2B: THE CAREER PATHWAY AND PIPELINE**

THIS SECTION IS FOR PEOPLE WHO SAY YES OR TO AN EXTENT OR AT LEAST A LITTLE BIT TO Q7

We would like to discuss your insights and experiences regarding career progression in dementia research.

34. What do you consider the key strengths and weaknesses in the field of dementia research in the UK to be?
35. What do you see as the biggest bottlenecks to dementia research careers in the UK?
36. We hear a lot about the need to attract researchers from other fields or currently training in other fields, and to redirect researchers from other fields to dementia research:
  - a. Are there any fields/disciplines do you think are particularly suited as targets for attraction to dementia research, and why?
  - b. How could we encourage this, what mechanisms might work? Based on your knowledge, are there examples of contexts where this has worked?
  - c. Do you think people could work in other areas and contribute to dementia in parallel (e.g. sabbaticals, staff exchanges, informal thematic interest networks etc.) or do you have to have 'complete commitment'?
37. We would like to explore the problem of retention of researchers in dementia in a bit more depth.
  - a. Firstly, how big of a problem do you think retention of researchers in the dementia field is?
  - b. What about retention of dementia researchers in the UK? Do you think that is a challenge? Is it important in a 'brain circulation world'?
  - c. Do you have any thoughts about ways of addressing retention challenges?

## **PART 3: ON REFLECTION**

38. On reflection, what do you consider the biggest challenges to progress in UK dementia research to be?
39. What do you consider to be the three key priority issues for dementia workforce capacity investment in the UK? Why? What would happen if that sort of capacity isn't supported?

## **Protocol for Group 3 - non-researchers<sup>435</sup>**

*RAND Europe has been commissioned by the Alzheimer's Society to conduct an analysis of UK's dementia research*

landscape and to explore the strengths and gaps in the dementia research workforce, across diverse fields and disciplines. We hope that the evidence will help the Alzheimer's Society and others to build a strong and vibrant research community to enable dementia research. As part of this study, we conducted a bibliometric analysis of UK publications in different disease areas and a tracing exercise looking at what people who did their PhD in dementia are doing now. At this point, we are building on those findings to through interviews with people like yourself get a better understanding of the strengths and gaps in UK dementia research, and we are particularly interested in insights on dementia research careers and workforce capacity issues, challenges and opportunities. In this context, the interview has three main parts:

6. A section on the UK dementia research landscape – including strengths and gaps in terms of science and skills- which we hope to spend about 10 minutes on this part with you
7. A section on research careers and capacity which we hope to spend 20-30 minutes on
8. A section on broader horizon-scanning and reflections on the future of dementia research in the UK, which we hope to spend 5-10 minutes on at the end

We recognize that the people we are speaking to have diverse backgrounds and we are deliberately soliciting diverse views from both those still involved with dementia in some way - either as researchers, or policy makers, or practitioners or funders - and those who may have left the field. But if there are any questions you do not feel you can comment on please let us know, and that is not a problem.

Also, all responses will be kept confidential and we will not link any quotes to you directly, without your permission. Is that ok?

## Questions:

### PART 1: SCIENCE AND SKILLS

40. Can you just briefly tell us a little bit about your job and role, and any key related activities in the dementia space?
41. Based on your knowledge of the dementia research landscape, what are some of the areas where you think the UK research community has done particularly well (e.g. produced particularly important and influential findings)? We are interested in your views on both 'strong' disease areas and fields/disciplines.
42. And are there any disease areas and fields/disciplines where we have not done so well and where you think we could do better?
43. The bibliometric data from our study suggests that the UK generally does well in terms of the citation impact of dementia research, but that it lags behind global averages in a few areas – for example in familial dementia and early onset dementia. Do you know why that might be? Do you think these are areas we should focus on, vis a vis other priorities or not?
44. Do you think the UK should pursue a broad research portfolio across various types and subtypes of dementia, or focus investments in on specific diseases (i.e. specific types of dementia)? (If they think there are specific focal areas ask why and which)
45. Do you think funders should prioritise research on prevention, or treatment/cure, or care and service delivery? Why?
46. Similarly, do you think funders should prioritise basic or applied and clinical research? Why?

### PART 2: THE CAREER PATHWAY AND PIPELINE

47. (i) What do you see as the biggest barriers to dementia research careers in the UK? And at what stages of the career pathway are there the biggest bottlenecks? (i.e. at specific transition points? getting senior, mid, jr posts?)
48. What about enablers of dementia research careers in the UK?
49. Do you think these barriers and enablers are specific to dementia research or apply more generally to other research areas?
50. We hear a lot about the need to attract researchers from other fields or currently training in other fields, and to redirect researchers from other fields to dementia research:
  - a. Are there any fields/disciplines do you think are particularly suited as targets for attraction to dementia research, and why?
  - b. How could we encourage this, what mechanisms might work? Based on your knowledge, are there examples of contexts where this has worked?
    - i) Do you think people could work in other areas and contribute to dementia in parallel (e.g. sabbaticals, staff exchanges, informal

<sup>435</sup> People outside the top 200 and PhD tracing lists (e.g. policymakers, funders, industry representatives).

thematic interest networks etc..) or do you have to have 'complete commitment'?

51. We would like to explore the problem of retention of researchers in dementia in a bit more depth.
  - a. Firstly, how big of a problem do you think retention of researchers in the dementia field is?
  - b. What about retention of dementia researchers in the UK? Do you think that is a challenge? Is it important in a 'brain circulation world'?
  - c. Do you have any thoughts about ways of addressing retention challenges?
52. With recent UK policy focus on dementia, we have seen an increase in funding committed to dementia research. Do you think the scale of increased commitments can make a difference and contribute to a critical mass of dementia researchers?
53. Are there particular areas and types of research where you think (i) clinicians/allied health professional -driven research and (ii) industry research is particularly important for advancement of the dementia field?
54. It is particularly difficult to engage clinicians and allied health professionals in research careers, and we recognise that this is not specific to dementia only. Do you know of any support mechanisms/enablers for clinical academic/clinician researcher careers in dementia? What are the key barriers?

### **PART 3: ON REFLECTION**

55. On reflection, what do you consider the biggest challenges to progress in dementia research to be?
56. What do you consider to be the three key priority issues for capacity investment? Why? What would happen if that sort of capacity isn't supported?



## Appendix 2: List of interviewees

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Table 14 below lists the people who were interviewed as part of this study. One interviewee is not listed as they wished to remain anonymous.

**Table 14 List of interviewees**

Name	Institution
Rosemary Bradley	University of Bradford
Dr Lucie Byrne-Davis	University of Manchester
Dr Richard Coaten	South West Yorkshire Partnership NHS Foundation Trust
Dr Brian Dickie	Motor Neuron Disease Association
Professor Nick Fox	University College London
Claire Garabedian	University of Worcester
Professor Claire Goodman	University of Hertfordshire
Professor Frank Gunn-Moore	University of St Andrews
Dr Diane Hanger	King's College, London
Professor John Hardy	University College London
Industry representative	Anonymous
Professor James Ironside	University of Edinburgh
Dr John Isaac	Wellcome Trust
Professor John Keady	University of Manchester
Dr Larissa Kempenaar	Glasgow Caledonian University
Dr Manja Lehmann	University College London
Dr Mariah Lelos	Cardiff University
Emily Lewis	University of Bradford
Dr David Llewellyn	University of Exeter
Professor Simon Lovestone	King's College, London

Name	Institution
Professor Jill Manthorpe	King's College, London
Dr Anne McIntyre	Brunel University
Professor Kevin Morgan	University of Nottingham
Professor John O'Brien	Newcastle University
Professor Jan Oyebode	University of Bradford
Dr George Pengas	University Hospital Southampton NHS Foundation Trust
Dr Petroula Proitsi	King's College, London
Dr Anna Richardson	Salford Royal NHS Foundation Trust
Dr Liz Sampson	University College London
Dr Claire Sarell	University College London
Dr Rebecca Sims	Cardiff University
Dr Blossom Stephan	Newcastle University
Professor David Stephens	University of Bristol
Professor Robert Stewart	King's College, London
Dr John-Paul Taylor	Newcastle University
Nicola Voyle	King's College, London
Dr James Warner	Imperial College London
Dr John Wilkinson	NIHR
Professor Julie Williams	Cardiff University
Professor Bob Woods	Bangor University