

# BMJ Open How policy can help develop and sustain workforce capacity in UK dementia research: insights from a career tracking analysis and stakeholder interviews

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## ABSTRACT

**Objectives:** To identify research support strategies likely to be effective for strengthening the UK's dementia research landscape and ensuring a sustainable and competitive workforce.

**Design:** Interviews and qualitative analysis; systematic internet search to track the careers of 1500 holders of UK doctoral degrees in dementia, awarded during 1970–2013, to examine retention in this research field and provide a proxy profile of the research workforce.

**Setting and participants:** 40 interviewees based in the UK, whose primary role is or has been in dementia research (34 individuals), health or social care (3) or research funding (3). Interviewees represented diverse fields, career stages and sectors.

**Results:** While the UK has diverse strengths in dementia research, needs persist for multidisciplinary collaboration, investment in care-related research, supporting research-active clinicians and translation of research findings. There is also a need to better support junior and midlevel career opportunities to ensure a sustainable research pipeline and future leadership. From a sample of 1500 UK doctorate holders who completed a dementia-related thesis in 1970–2013, we identified current positions for 829 (55%). 651 (43% of 1500) could be traced and identified as still active in research (any field) and 315 (21%) as active in dementia research. Among recent doctoral graduates, nearly 70% left dementia research within 4–6 years of graduation.

**Conclusions:** A dementia research workforce blueprint should consider support for individuals, institutions and networks. A mix of policy interventions are needed, aiming to attract and retain researchers; tackle bottlenecks in career pathways, particularly at early and midcareer stages (eg, scaling-up fellowship opportunities, rising star programmes, bridge-funding, flexible clinical fellowships, leadership training); and encourage research networks (eg, doctoral training centres, succession and sustainability planning).

## Strengths and limitations of this study

- As efforts to tackle dementia increase, it is important that research funding investments are made on the basis of evidence about capacity-building needs.
- This study draws on the perspectives of diverse stakeholders engaged with dementia research, across disciplines, sectors and career stages, to provide insights on strengths, gaps and future workforce needs for dementia research in the UK.
- It is unique in combining qualitative insights with a complementary quantitative analysis of the retention of UK researchers in dementia research and a proxy profile of the research workforce; taken together, the data highlight areas in need of capacity-building and opportunities for policy consideration.
- Data limitation: the 40 interviews do not capture the views of all relevant individuals; and the career tracing approach was limited in its ability to trace some individuals, including very recent graduates who may not yet have a web-presence, those who changed surname and those who are active in UK dementia research but did not complete a PhD in this topic or did so outside the UK, hence the career tracing results should be interpreted as a proxy for the dementia research workforce.
- Despite these caveats, the data provide a well-rounded and multifaceted picture of capacity-related issues relevant for basic, clinical and health services research and for a sustainable and competitive dementia research workforce in the UK.

Interventions should also address the need for coordinated investment to improve multidisciplinary collaboration; balanced research portfolios across prevention, treatment and care; and learning from evaluation.

## INTRODUCTION

The prevalence of dementia is rising as are the associated costs, economic and social. This underscores the need for research to help improve disease prevention, care and treatment. Alzheimer's Disease International (ADI) estimates that 47 million people live with dementia globally with a cost of US\$818 billion, or 1.09% of global GDP in 2015, and that this figure will reach 132 million by 2050.<sup>1</sup> In the UK, an estimated 850 000 people currently live with dementia, resulting in an annual cost of £26 billion.<sup>2</sup> It is expected that one in three people born in the UK in 2015 will develop dementia over the course of their lives.<sup>3</sup>

In recent years, governments, charities, the research community and industry have increased their attention to tackling dementia and building research capacity. A G8 Dementia Summit was held for the first time in 2013, where governments announced commitments to support dementia research with the aim of finding an effective treatment by 2025.<sup>4</sup> In the UK, the government announced the 'Prime Minister's Challenge on Dementia' in 2012, which included a commitment to increase dementia research funding to £66 million by 2015.<sup>5</sup> In 2014, the UK Medical Research Council established Dementia Platform UK (DPUK), a 5-year, £53m public-private partnership for research on dementia prevention and treatment.<sup>6</sup> The Prime Minister's Challenge was updated in 2015 and includes aims to make the UK 'the best place for Dementia Research', increase research funding, support a dementia research institute in England and further increase public-private collaboration.<sup>7</sup> In addition to government support and industry collaboration, UK charities such as Alzheimer's Society (AS) and Alzheimer's Research UK (ARUK) also invest in building research capacity, for example, through fellowships and doctoral training centres. However, according to a recent assessment of government and charitable spending in 2008 and 2012, dementia research has been underfunded relative to its impact on patients and its costs, when compared with cancer and coronary heart disease.<sup>8</sup> There is also a scarcity of evidence on what the capacity-building priorities for a sustainable research workforce in this field are, and hence where to focus workforce capacity-building investments.

Given limited resources and the scale of support needed, it is crucial that investments into research and research capacity strengthening are channelled in an evidence-based way. The UK has produced influential publications across diverse areas of dementia research.<sup>9 10</sup> For the period 1980–2013, the UK ranks second in the world for the production of journal publications on dementia and seventh for citation impact (table 1). In a wider analysis of the UK dementia research landscape, we have shown that UK-based researchers produce 12% of the world's dementia publications.<sup>10</sup> That report provides further detail on this analysis and additional study detail.<sup>10</sup> However, government and charitable funders have acknowledged that UK

**Table 1** The top 10 countries for scientific publication output, impact and citation performance in dementia research (1980–2013)

Rank	Volume of dementia publications	Citation impact of dementia publications portfolio (ARC)	Highly cited publications (%)
1	USA	Ireland	USA
2	<b>UK</b>	USA	Norway
3	Germany	Norway	Ireland
4	Japan	Finland	Portugal
5	Italy	The Netherlands	Switzerland
6	Canada	Canada	Finland
7	France	<b>UK</b>	Belgium
8	China	Belgium	Denmark
9	Sweden	Portugal	<b>UK</b>
10	Australia	Sweden	Canada

Bold text highlights UK entries.

Citation impact is calculated as the average of relative citations (ARC), which measures scientific impact based on paper citation counts normalised to account for different citation patterns across fields/subfields and the number of years since a paper was published. The percentage of highly cited publications refers to the percentage of publications in a country's portfolio that are in the top 10% most cited publications in their field. The table modified and reproduced with permission from Marjanovic *et al.*<sup>10</sup>

support for dementia research must entail improvements in the quality and sustainability of the research workforce.<sup>7 9 11</sup>

The aim of this study was to build an evidence base about the current status of UK dementia research, and explore opportunities and challenges associated with dementia research careers in the UK and associated policy implications. This is particularly important, given the limited evidence on capacity-building needs and opportunities for academic careers in dementia.

## METHODS

### Interviews

The study team aimed to conduct 40 interviews, in line with expectations of saturation points and resources available. A total of 62 individuals were invited for interview (see online supplementary information for profile and full details about interview methods) and 40 were interviewed (March–May 2015) (table 2). To obtain diverse perspectives from across the dementia research field, interviewees were sought from a range of sectors, disciplines and career stages, including individuals who left the field. Gender was not explicitly controlled for, but gender breakdowns are provided (tables 2 and online supplementary table S1). Adapted Higher Education Statistics Agency (HESA) contract-level classifications were used to categorise seniority levels (for details, see online supplementary information). In line with qualitative methods for conducting purposive sampling and interview-based studies in health,<sup>12</sup> a deliberately non-random approach was used, aiming to capture

**Table 2** Breakdown of interviewee group by field, sector, seniority and gender

Breakdown by field	
N	Primary field of activity
8	Nursing, allied health professions and other care
8	Neuroscience
5	Psychiatry
4	Clinical neurology
3	Clinical psychology
3	Genetics and genomics
2	Epidemiology
7	Other (research funding, industry, research in areas other than dementia)
Breakdown by seniority	
N	Career stage
22	Senior (professors, readers, other senior)
18	Junior/midlevel (lecturers, senior lecturers, research fellows, research associates, postdoctoral fellows, PhD students)
Breakdown by sector	
N	Primary sector affiliation
25	Academia
8	Academia with clinical appointment
3	NHS clinical or care
3	Research funding
1	Industry
Breakdown by gender	
N	Gender
21	Female (of which 15 were junior/midlevel and 6 were senior)
19	Male (of which 3 were junior/midlevel and 16 were senior)
There were 4 interviewees who had left dementia research (2 senior and 2 junior/midlevel).	

diverse views and experiences but not a strictly representative sample. We used grounded theory principles, whereby theoretical sampling is not statistical sampling, and considered expected saturation points.<sup>13</sup>

Prospective interviewees were identified on the basis of raw bibliometrics data (analysis presented in Marjanovic *et al*<sup>10</sup>) and the career tracking data. The bibliometrics data were used to identify researchers who were currently active (publications in 2008 or later) and prolific in each field; the career tracking data provided career-stage information to help identify active researchers across fields who may not yet have a high volume of publication outputs due to being in earlier career stages. Our sampling considered these criteria to ensure a diversity of views and experiences were reflected in the qualitative analyses. The selection of interviewees from the research funder community was informed by the professional network of CW and JP.

Prospective interviewees were initially contacted by JP, who explained the purpose of the study and reasons

for an interview. Individuals were then invited by email from ER, SP, EH or CML. The invitation (see online supplementary information) included information about the study and how the data would be used, covering informed consent and confidentiality. Interviewees were informed that no quotes would be attributed to them without their explicit consent and were asked whether they would be happy to be named in the list of participants in the study.<sup>1</sup> This information was reiterated at the start of the interview and interviewees' informed consent was recorded. The research ethics process followed was in line with RAND Europe's institutional ethics framework guidelines and process, and with other evaluative studies. If needed, the research team followed invitations up by email or phone.

Each interview was conducted by a single researcher (CAL, EH, SP, CM, ER, SM or VH) following a semistructured format, and lasted 30–60 min (for protocols, see online supplementary information). Interviewees were asked to share their perspectives on the current state of the UK dementia research landscape, and on career progression and capacity-building needs and opportunities. The interviews combined questions exploring particular themes (but not driven by any positivist hypotheses on the themes) and allowing emerging issues to be captured, coded and grouped into analytical constructs.

The analysis (detailed in online supplementary information) followed principles rooted in grounded theory.<sup>13 14</sup> In brief, each interview was transcribed and initially coded into an excel template that followed the protocol questions and included space to record emerging themes. Next, responses to each question/issue were analysed, with responses categorised and tallied with information on interviewee profile (eg, discipline, sector, seniority). Themes were further assessed at a higher level during a research team workshop, which allowed the team to discuss broader themes and capture issues that emerged from the interviews but were not directly enquired about. This level of coding enabled the research team to move from the first level of granular analysis to higher-level, more generalised categories with properties and relations important for explaining the nature of the data under observation. In line with grounded theory principles, the protocol and analyses were designed to let the categories emerge rather than coming into the study with preset granular categories based on existing theories.<sup>13</sup>

### Online career tracking

Interviews were complemented with a career tracking exercise of 1500 individuals who completed a PhD on a dementia-related topic, using data from the British Library's E-thesis online service (EThOS) portal for doctoral theses.<sup>15</sup> The initial keyword search of titles,

<sup>1</sup>All but one agreed to be named.

abstracts and subject headings<sup>ii</sup> yielded 1923 records. Removal of duplicates, false positives and those published outside the eligible timespan (1970–2013) left 1862 eligible these records. From these and given study resources available, 1500 authors were randomly selected for career tracing.

For each record, the tracer (CM or EH) first searched in Google, reviewing the first 20 results.<sup>iii</sup> Based on the available evidence (with additional Google, PubMed or LinkedIn searches as needed), individuals were classed as traced or not, active in research or not and active in dementia or not (see online supplementary information for definitions). In uncertain cases and when tracing failed, the tracers consulted each other and/or with others (SM, CAL) to assign categories. CW and JP also reviewed 98 uncertain cases. Ethos data were also used to benchmark the supply of dementia doctoral graduates against the cancer field.<sup>iv</sup>

## RESULTS

### Interviewees' views on the current status of the dementia research landscape: strengths and challenges

Interviewees identified a range of strengths in UK dementia research, spanning disease-related and functional areas. The two most frequently highlighted strengths were genetics research (eg, to identify genes linked to Alzheimer's and Parkinson's disease-related dementia) (n=17) and advances in brain-imaging to understand disease progression (n=13). Other highlighted strengths were Lewy body dementia research (n=6), research into the development of person-centred care (n=6), epidemiological work with cohort studies (n=5) and research on the amyloid hypothesis and amyloid fibril formation (n=5). Some interviewees expressed optimism about the research environment, noting that momentum is building around dementia research in the UK and that there are more opportunities for collaborative work:

It used to be that there were lots of people in different pockets of the UK just doing their own thing, and now... people are sharing a lot more.—Junior/midlevel neurologist.

Dementia has rocketed up people's consciousness.—Senior researcher, allied health professions/nursing/other care.

Interviewees also highlighted challenges to overcome. Some reflect global knowledge gaps, such as limited insights into cellular mechanisms in dementia (n=8). Others are issues affecting biomedical research in the UK in general, such as time constraints that make it difficult for clinicians to get involved in research (n=7). Challenges that are more specific to the UK dementia research policy context include a lack of research in nursing, allied-health professions and social care<sup>v</sup> (n=6); a need to attract and facilitate industry engagement with dementia research (n=3) and insufficient focus on rarer dementias (n=4), which was linked to a combination of (1) low numbers of patients diagnosed with these conditions in the UK and (2) difficulties with patient recruitment related to competition between clinicians from different specialties for patients, inaccurate diagnoses and the fact that patients with mild cognitive impairment are often cared for in general practice, where they are less often recruited for familial studies.<sup>vi</sup>

Interviewees who discussed the need for more dementia care research highlighted ethics approvals as a significant research barrier (n=6), and one interviewee who had left dementia research cited this issue as a factor that would impact whether they return to the field. Interviewees explained that existing ethical approval procedures are often inappropriate in the dementia context because dementia patients are often unable to give informed consent:

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 the reality of human subject work with someone who cannot give consent.—Junior/midlevel researcher, allied health professions/nursing/other care.

### Interviewees' views on issues affecting those pursuing careers in dementia research in the UK

The lack of a secure career path is a key workforce challenge for dementia research (n=16), and was perceived to be accentuated in the dementia context compared with some other areas of science. Interviewees identified a key bottleneck at the transition from a postdoctoral position to a permanent post as a lecturer or independent investigator post (n=16), with a secondary bottleneck occurring at the transition from a PhD or clinical

<sup>ii</sup>Keywords used: Alzheimer's; dementia; cognitive impairment; mixed dementia; early onset dementia; vascular dementia; 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>iii</sup>Search terms commonly used: name; name+graduating institution; name and thesis title; name and thesis title keyword; name+graduating institution+dementia; name+dementia; name+Alzheimer's.

<sup>iv</sup>This was a proxy comparison based on the identification of all these containing the word 'cancer' in the ethos database.

<sup>v</sup>Several aspects of care were seen as important areas for research, including care homes research, end-of-life care and care for patients with different types of dementia (including mixed dementias and advanced stages of dementia) and comorbidities care for marginalised and hard-to-reach groups, research into the carer-patient relationship and the impact of dementia on a patient's family and acquaintances.

<sup>vi</sup>Three interviewees commented that in the UK, dementia patients are usually seen by psychiatrists rather than neurologists, with the result that UK neurologists are less active in dementia than their peers in other countries (eg, the USA, France and the Netherlands). They explained that this situation can adversely affect the recruitment of young patients, who tend to see neurologists, to dementia studies.

training to the first postdoctoral or clinical research post (n=8):

In the stage I am in now, postdoc, early career, it's a very difficult time. That's a time where many people drop out. ... The insecurity involved with not having a permanent position... is very difficult for young scientists and that is also the case in the dementia field.—Junior/midlevel neuroscientist.

Some said the issue had escalated over time:

[I]n 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...—Senior neuroscientist.

Some individuals highlighted that the allied health professions and social care have a particular capacity-building need at the early-career stage (ie, PhD and first-postdoc studentships and fellowships) (n=3). Barriers to clinical research careers were seen to be particularly pronounced in the dementia context, in part driven by more universal challenges to clinical research careers (related to eg, time, incentives, skills) and in part by a low profile of dementia research in the NHS:

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.—Junior/midlevel psychologist in academia.

Although not explicitly enquired about by the research team, gender-related challenges to career progression were raised by six interviewees (four women and two men from diverse disciplines in academia). The interviewees highlighted that women are more likely to leave research than men due to career prospect uncertainty and risk, and due to career breaks. Interviewees discussed that this generally occurs at the transitions from postdoctorate to lecturer and reader to professor stages. However, this issue was not seen as dementia-specific.

### Interviewees' perspectives on mechanisms to support research capacity building

Interviewees were consulted on the mechanisms they have encountered and found important for supporting dementia research capacity, as well as on interventions that are needed going forward. They identified various examples of existing mechanisms (table 3), though many would need scaling up to support dementia research careers.

Across interviewees, there was a clear message on the importance of supporting individuals, institutions and networks. The mechanisms individuals saw as particularly important relate to providing longer term support to improve job security and address career bottlenecks, and interventions which could enhance opportunities for collaboration across disciplines and sectors. Interviewees highlighted the importance of dementia-specific mid-career fellowships (n=3) and 'bridging' fellowships to support individuals who have just completed PhDs and

**Table 3** Types of dementia career enablers, with specific UK examples. Adapted from Marjanovic *et al.*<sup>10</sup>

Dementia career enablers	Examples of existing support mechanisms cited by interviewees
Doctoral training support	<ul style="list-style-type: none"> <li>▶ Alzheimer's Society Doctoral Training Centres</li> <li>▶ Alzheimer's Society PhD studentships</li> </ul>
Midcareer support	<ul style="list-style-type: none"> <li>▶ Alzheimer's Research UK PhD studentships</li> <li>▶ British Society of Gerontology Emerging Researchers in Ageing Scheme</li> <li>▶ Dementia-specific fellowships, eg, Alzheimer's Research UK fellowships, Alzheimer's Society Future Leaders' Programme</li> <li>▶ Fellowships that enable the fellow to gain international experience</li> <li>▶ Parkinson's Disease UK fellowships</li> </ul>
Support for clinicians to engage in research	<ul style="list-style-type: none"> <li>▶ Alzheimer's Society clinical fellowships</li> <li>▶ Motor Neurone Disease Association/Medical Research Council clinical fellowships</li> <li>▶ Guarantors of Brain charity support for clinicians to begin research</li> </ul>
Support for multidisciplinary, collaborative research	<ul style="list-style-type: none"> <li>▶ Academic-NHS collaborations (eg, National Institute for Health Research (NIHR) Biomedical Research Units and Centres with dementia as a priority area, NIHR CLAHRCs* Research Capacity in Dementia Care training programme)</li> <li>▶ Dedicated institutes, and centres for research and drug discovery (eg, existing centres at Bradford, Cardiff, Newcastle and Oxford Universities and University College London)</li> <li>▶ Funding for collaborative research between dementia and non-dementia researchers (eg, ARUK Interdisciplinary Research Grants)</li> <li>▶ NIHR Dementia Translational Research Collaboration</li> <li>▶ Public-private partnerships (eg, DPUK)</li> </ul>

\*Collaboration for Leadership in Applied Health Research.

facilitate their transition into postdoctoral positions (n=4). A need for support in developing leadership skills was mentioned by interviewees across disciplines (n=7), with two highlighting a need for leadership in nursing research in particular. Interviewees also highlighted the need to train research leaders to manage research groups more effectively (n=1), and to improve mentorship opportunities (n=3):

One of the solutions would be to emphasise project management a bit more. Training leaders to manage young researchers effectively... would be very welcome and have a positive impact on research outputs.—Senior academic, allied health professions/nursing/other care.

Three individuals noted the potential for capacity-building that is offered by doctoral training centres, while one emphasised the importance of fellowships which enable researchers to gain international experience. ‘Rising star’ programmes for researchers with high potential were cited (n=3) as a way to support early- and midstage dementia research careers.

For clinical research, interviewees highlighted career-development constraints to engaging with dementia research (n=7) and the importance of addressing this with dementia-specific fellowships and flexible employment arrangements to allow movement between research and clinical work (n=4). Addressing these issues would require supportive NHS environments and a change in attitudes to dementia research in the NHS and allied health professions, as well as more attention to research training in medical education curricula:

Bureaucracy, I think, in the NHS and [higher education] sectors just seems to limit clinical academic careers. ... An attitudinal shift is needed in the NHS and other institutions to learn to understand clinical academic careers —there is still a lot to do on this.—PhD candidate who had worked in the NHS.

Interviewees also valued long-term funding to support dedicated research centres or institutes, or collaborations between organisations, which can bring together talent from different fields and sectors (n=5):

Regional research centres ... would help increase collaboration between basic scientists but also clinicians, nursing and care and people with dementia, and we are far from that.—Senior academic.

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

Sustained support for collaborative approaches was seen to be important for overcoming challenges to cross-sector, cross-disciplinary collaboration that could help tackle dementia research gaps, such as those related to the lack of insights on cellular mechanisms underlying

dementia, classification issues or translational work challenges (ie, research that would link genetics, cellular mechanism studies and drug discovery, as well as work to translate care-related research into improved service delivery).

### Insights from the career tracing of individuals who completed doctorates in a dementia-related topic

Out of the sample of 1500 individuals who completed a PhD on a dementia-related topic in the period 1971–2013 in the UK and who we attempted to trace, tracing was successful for 829 (55%).<sup>vii</sup> Overall, ~1 in 5 (315 of 1500) are still active in dementia research. Of these 315, 25% (79 of 315) are now active in dementia research outside the UK. Also among the 315 active dementia researchers, 67% (212 of 315) have a primary affiliation that is academic, 14% (43 of 315) have a clinical affiliation, 5% (15 of 315) work in industry and the remainder work in other areas, including medical writing and non-academic research institutes (11% or 35 of 315), or their affiliation was not traced (4% or 11 of 315). Overall, the ratio of junior and midlevel staff to senior staff is 2.3:1.

Gender analysis showed that, of the 315 active dementia researchers, 55% (172 of 315) are women and 43% (137 of 315) are men (analysis was uncertain<sup>viii</sup> for 2%), but this balance differed by seniority level. Sixty-six per cent of research fellows/associates/postdocs (55 of 83) are women; among professors, 43% (19 of 44) are women.

To examine recent graduate retention, we also assessed retention in dementia research for graduates who completed their doctorate during the last 10 years covered by our data set (2004–2013). In that period, the highest retention occurred for 2009 graduates and was 31% (30 of 96).<sup>ix,\*</sup> For 2010 graduates (the next highest year), retention was 29% (38 of 130). Thus, ~70% (and potentially more) of recent dementia doctorate holders leave dementia research within 4–6 years of thesis publication. Over a longer timeframe, retention stayed roughly constant with the exception of the 2006–2010 publication period, where retention was slightly higher (table 4). Meanwhile, the fraction of doctoral theses related to dementia has risen steadily over time, increasing almost 17 times from the period 1981–1990 to the period 2011–2013. Cancer-related doctoral theses increased just under 10 times in the same period (based on a comparison of data from Ethos).

<sup>vii</sup>Those who were not traced are unlikely to be highly active in research (particularly in academia) as they would otherwise be expected to have publications or other forms of web presence.

<sup>viii</sup>Owing to ambiguity in the name and a lack of additional information.

<sup>ix</sup>Retention was defined here as the percentage of all dementia thesis authors from a given year who were found to be active in dementia research.

\*Retention was lowest for 2013 authors (14%), but may be attributable to thesis authors having not yet completed the process of finding a new research position and establishing a web presence.

**Table 4** Number and percentage of theses on dementia and cancer in Ethos database over time, and retention of dementia thesis authors in dementia research over time

	1981– 1985	1986– 1990	1991– 1995	1996– 2000	2001– 2005	2006– 2010	2011– 2013
Total dementia theses indexed in Ethos (and as per cent of all theses in Ethos)	13 (0.050%)	40 (0.13%)	108 (0.31%)	183 (0.35%)	276 (0.45%)	440 (0.61%)	424 (0.83%)
Total cancer theses indexed in Ethos (and as per cent of all theses in Ethos)	114 (0.43%)	316 (1.0%)	457 (1.3%)	946 (1.8%)	1094 (1.8%)	2015 (2.8%)	2127 (4.2%)
Total number of theses indexed in Ethos	26 217	30 354	34 883	52 428	62 002	72 593	50 902
Authors of dementia theses who are still active in dementia research (absolute number and % total dementia theses in ETHos)	1 7.7%	8 20.0%	20 18.5%	32 17.5%	53 19.2%	119 27.0%	81 19.1%

## DISCUSSION

### Our paper in context

This study is unique in bringing together career tracking methodology with expert interviews to explore research workforce capacity in a disease field. There is a shortage of such data, particularly in Europe, despite its importance for informing research training and career development programmes.<sup>16</sup> In the UK, the Wellcome Trust<sup>17 18</sup> and research career development organisation Vitae<sup>19</sup> run surveys to track researchers' career paths, but challenges with response rates persist, particularly for longer term tracking. The approach taken in this study enabled the gathering of data for graduates going back over three decades. The study also addresses the scarcity of work on research-capacity issues and draws on views of researchers across career stages, providing a rounded lens on the opportunities and challenges ahead.

Evidence from the interviews and the proxy profile of the research workforce from the PhD tracing exercise support each other well, as do the perspectives of individuals across different career stages. Together, they highlight important capacity-building issues within dementia career pathways across sectors (eg, relatively low proportion of research-active clinicians, bottlenecks to progression to senior posts and retention challenges).

There was broad agreement across interviewees on strengths and gaps in the research landscape and on research workforce issues. Researchers from clinical and care professions were generally aware of research taking place in molecular biology, neuroscience and genetics-related dementia research, but neuroscientists and geneticists were less cognisant of UK developments in care-related research.

Some differences in views across interviewees related to balancing research priorities across prevention, care, and treatment/cure spaces, although there was a general recognition that all types of research are important and require a coordinated funding portfolio:

Both [care and treatment] are important. ... 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.

The study findings also complement insights from related studies. Draper *et al*<sup>20</sup> identified barriers in the translation of dementia research into practice that resonate with interviewees' views on the need for research capacity building in the allied health professions and social work, and the low profile of dementia research in the NHS. This review reported that care of the elderly was a poorly regarded career option by undergraduates, and that dementia was not covered consistently across training programmes for nursing, occupational therapy and social work.<sup>20</sup>

In line with this study's findings, ARUK<sup>9</sup> identified an increasing need for multidisciplinary research to build capacity in UK dementia research and emphasised that career instability is a longstanding issue across scientific research fields in the UK, perhaps accentuated in dementia, given the scale of burden. In dementia, ARUK's study also identified an inflexible training pathway that makes it difficult for clinicians to take time out for research.<sup>9</sup> Other data also support this study's finding that gender imbalances in research tend to be more pronounced at senior levels.<sup>21</sup> In our study, interviewees' perceptions about gender-related challenges were consistent with the reduced proportion of women at more senior levels that was observed in the career tracking data.

Luengo-Fernandez *et al*<sup>8</sup> showed that UK funding for dementia research (from public and charitable sources) increased significantly from £50m (in 2008) to £90m (in 2012), while cancer funding decreased slightly (from £590m in 2008 to £544m in 2012). The present study findings would suggest that these changes do not appear to have yet had an effect on early career opportunities in dementia or the PhD graduate pipeline.

The importance of cross-sector and cross-discipline collaboration for facilitating breakthroughs in challenging medical research areas has also been demonstrated in other disease areas, such as HIV.<sup>22</sup>

### Study limitations

It is worth bearing in mind the following caveats for this study. For the PhD-holder tracing exercise, the approach consisted of searching for individuals who were awarded

a doctorate in a dementia research by a UK university and whose thesis is indexed in the EThOS database.<sup>15</sup> Because researchers who completed their PhD in another country or topic were excluded, and because the EThOS database covers 95% of theses awarded in the period 2000–2013 (and a somewhat lower percentage prior to 2000; Rosie H. (British Library). Personal communication. May. 2015), the findings from the career tracing exercise represent a proxy for the workforce but not an absolute representation of the current status. In addition, the criteria applied to judge whether someone is a ‘current dementia researcher’ may have resulted in false negatives or false positives in a minority of instances (eg, name changes, recent graduates who had not yet established a web presence for a post-PhD position).<sup>xi</sup> Finally, while the study aimed to cover all types of dementia, it is possible that the keyword search process did not capture all relevant theses, given wider challenges in dementia disease classification.

The study did not consider the lateral movement of researchers across disciplines and disease areas. For instance, recent recognition that inflammation may have an important role in the aetiology of Alzheimer’s disease has provided more opportunity for immunologists to work in dementia research. The finding that 70% of dementia research graduates are not working in the field of dementia research may therefore paint a starker picture than the reality, where graduates from other disciplines may enter the dementia research field at post-graduate level. However, the scale of such movement would need to be researched to make credible assertions on horizontal flows.

Interviewees’ responses naturally reflected their professional experience. For instance, respondents tended to comment on limitations within their own research field when asked about research gaps. However, when commenting on research strengths, interviewees frequently highlighted strengths in areas other than their own. Overall, the authors are confident that a rounded evidence base was obtained by speaking to a diverse set of interviewees, but recognise that not all potentially relevant individuals in the UK participated in the research. Insights in the study are also interpreted in the light of the wider evidence base. Finally, while the study reports the number of interviewees who made comments on specific issues, and while some issues raised may be particularly relevant for particular stakeholders, the aim was to capture the diversity and multidimensional nature of the dementia research challenge rather

than to quantify perspectives. Overall, we did not observe notable contradictions in views.

## CONCLUSION

This paper provides a comprehensive analysis of issues that are relevant for stakeholders to consider as part of an effort to build dementia research capacity in the UK. The UK has many strengths across biomedical, clinical and care-related dementia research, but notable disease-specific and research workforce challenges need to be addressed to ensure future sustainability and competitiveness. Based on the findings presented above, and the study team’s wider experience with capacity-building and leadership in health research and dementia,<sup>22 23</sup> four areas of action for policy consideration are suggested: empowering individuals; supporting institutions and networks; informing research priorities and addressing wider system issues; and learning from evaluation (table 5). They do not represent definitive recommendations. Rather, they constitute areas for policy engagement, presented with the aim of encouraging further constructive dialogue and the exchange of ideas on ways forward in the dementia challenge.

First, there is a need to support individuals and consider how scaling up existing schemes and establishing new initiatives can help attract future talent and support transitions from early to midcareer posts, and from mid-career to senior roles (which this study identified as key bottlenecks to dementia research career pathways). Dementia-specific interventions (eg, fellowships, studentships, rising star programmes, doctoral training centres) need to consider ways of integrating more general professional skills training to ensure sustainable approaches to leadership development. As suggested by evidence from this study, some professions (eg, allied health professions, nursing) may be in particular need of junior level opportunities, and hence the distinct needs of specific stakeholder groups need to be considered as part of a capacity-building agenda. Similarly, clinicians may only be able to make use of funded posts if the creation of such posts is accompanied by advocacy efforts to raise the profile of dementia research in the NHS, which the study identified as a particular challenge to attracting clinical research talent.

Second, the investments which have been made in recent years into initiatives such as the NIHR Dementia Translational Research Collaboration, DPUK, and dementia centres at University College London and Cardiff University will need to translate into research, policy, clinical and social care impacts. This requires sustainable support for the long term, and central to this is also timely legacy and succession planning.

Third, supporting institutions and centres which facilitate collaboration across disciplines and sectors will be important for tackling key bottlenecks to the development of new treatments and care interventions. As dementia is an interdisciplinary challenge, there is also

<sup>xi</sup>Individuals were also categorised as ‘not traced’ in cases where some evidence suggested they were the appropriate individual but was insufficient to link them to their PhD, or where there was no evidence of an individual’s online presence. Although we erred on the side of caution and thus expect relatively few false-positive traces occurred, we are unable to estimate the number of false positives, given the scope of the study and the fact that individuals were not contacted directly.



**Table 5** Summary of issues and potential approaches for building up UK dementia research capacity

Key issues	Options for addressing them
1. Tackling bottlenecks in the transition from PhD to postdoctoral positions and from postdoctoral to independent investigator positions	<ul style="list-style-type: none"> <li>▶ Dementia-specific funding for fellowships and lectureships</li> <li>▶ 'Rising star' fellowships for researchers with high potential to establishing small research groups</li> <li>▶ Support professional skills-development programmes such as leadership training and project management</li> <li>▶ Enhance scale of PhD studentships for some professions with a notable lack of early-stage opportunities (eg, allied health professions, nursing)</li> </ul>
2. Long-term sustainability of existing dementia research centres, networks and partnerships	<ul style="list-style-type: none"> <li>▶ Address succession planning for key individuals</li> <li>▶ Develop a legacy plan together with host universities</li> </ul>
3. Attract researchers from diverse fields to collaborative dementia research efforts (ie, to research teams and networks) to support interdisciplinary collaboration	<ul style="list-style-type: none"> <li>▶ Problem-driven grants</li> <li>▶ Grants with specification for partnership between researchers from different disciplines</li> </ul>
4. Coordinate of investments across initiatives and funders and improve the cost-efficiency, effectiveness and sustainability of dementia research capacity investments	<ul style="list-style-type: none"> <li>▶ At a national level, consider balance of diseases supported; basic, applied, clinical and health services research on dementia; and prevention, treatment and care-focused research within the dementia research funding portfolio</li> <li>▶ Learn from evaluation of current and prior investments into dementia research capacity-building, and from the experiences of other fields and countries</li> </ul>

a need to explore how researchers from diverse fields can be attracted to collaborative and interdisciplinary dementia initiatives. Some ways of doing this may include joint grants for partnerships between dementia and non-dementia researchers, and problem-driven rather than discipline-driven fellowships involving clinical leadership.

Finally, stakeholders need to consider actions that can inform prioritisation of research portfolios and the balance of research investments across prevention, treatment and care-related research and basic, applied, and clinical and health services research. Coordinating investments to minimise risks from duplication, while supporting diversity and out of the box thinking which underpins innovation will be central to this effort. Effective investment decisions need to learn from the past as well as from ongoing initiatives as they unfold, and evaluation is central to evidence-based research capacity-building in dementia. This includes evaluation of UK schemes and comparative studies of international experiences with capacity building. Some interviewees perceived that specific countries outside the UK offer attractive core-funding packages for dementia research (eg, USA, Germany, Australia) and may attract a greater proportion clinicians to research careers (eg, Belgium, France, the Netherlands). Experiences from these contexts may offer useful transferrable or adaptable learning to the UK context.

There has been an intense spotlight put on the global issue of dementia, which has resulted in many countries publishing research strategies and an increase in funding for dementia. The results put pressures on a workforce due to the time to train and develop

researchers with specialist expertise. The increased prioritisation of dementia research requires a cohesive workforce development strategy, elements of which could be informed by the issues and areas for policy consideration raised here. This should help enable initiatives to deliver the research progress that many government actors and people affected by dementia urgently wish to see.

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