

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

Extended Summary

Sonja Marjanovic*, Enora Robin*, Catherine Lichten*, Emma Harte*, Calum MacLure*, Sarah Parks*, Veronika Horvath*, Grégoire Côté+, Guillaume Roberge+, Mohammed Rashid+

* RAND Europe + Science Metrix



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Extended Summary

Background and context

This report presents the insights 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 better understand 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 inform a blueprint for investing in research capacity-building in dementia.

Study design and methods

The study design and methods involved three key elements (all of which are elaborated on in the core report, together with associated caveats). The first was a bibliometric analysis of UK dementia research, which used publication data to assess research performance vis-à-vis global benchmarks, based on citation impact. Secondly, we conducted a pilot investigation, which traced the current position of people who completed their PhD in a dementia topic in the UK in order to attain 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 other countries to UK dementia research. Finally, we carried out a qualitative assessment of the strengths and gaps within UK dementia research and of the research workforce, in order to inform investment priorities for

capacity-building. We conducted 40 interviews with stakeholders from research, policy, health practitioner, private sector and funder communities, including representatives at varied stages in career pathways and from diverse fields. The interviews complement and provide more nuance, breadth and depth to the bibliometric analysis and PhD tracing exercise. Our findings have been interpreted within the context of wider knowledge about dementia research and science policy. The contents below present the key insights from each of the three investigations outlined above. The full report elaborates on each investigation, providing associated narrative detail, figures, graphs and quotes.

Highlights from the bibliometric analysis

Research production

- The UK is second in the world in terms of the amount of the dementia research knowledge it generated in the 1980-2013 period, as measured by the number of journal publications. This suggests that the UK punches above its weight in terms of publication outputs, which is in line with wider observations made for UK research.¹ 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 other classifications such as mild cognitive impairment, early-onset dementia and familial dementia.

¹ See for example Elsevier (2013).

- A total of 67% of all UK dementia papers are in the field of clinical medicine.² The 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: i.e. it has more specialisation in dementia.

Impact

- 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. In relation to the 30 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 of the full report).
- Most dementia disease research areas have pockets of excellence, indicated by a greater than expected percentage of highly cited papers.³ 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. There is, however, 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), with other pockets of research excellence in vascular dementia, small vessel disease, primary progressive aphasia and mild cognitive impairment. The entire portfolio of UK research on CADASIL (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 classified as familial and early-onset dementia, where the UK lags behind world averages for citation impact (this is further clarified in evidence from the interviews).
- The most influential UK dementia papers (citation-wise) are in the subfields of medicinal and biomolecular chemistry, and of pharmacology and pharmacy, while there are also particularly notable pockets of excellence in the subfields of general and internal medicine, nuclear medicine and medical imaging, and pathology (in terms of percentages of highly cited dementia papers). 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. possibly in the context of co-morbidities or links between viruses and dementia), pathology and biophysics.
- The vast majority of the UK’s most prolific dementia researchers (the top 200 in terms of the volume of research publications) publish in journals that belong to 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,

² 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 organising categories based on the topics of research and disciplinary lenses used.

³ We used 10% of an overall publication portfolio as the threshold for what would be expected to be highly cited, as this is a commonly used and accepted threshold in citation analysis. In the portfolio of all publications globally (not dementia specific) globally, 18.9% of UK dementia publications belong to the highly cited paper category (i.e. are in the top 10% of most cited papers globally, across all fields). By comparison, 16.3% of global dementia papers are in the top 10% of all highly cited papers worldwide.

psychology, speech and language, occupational health, physiotherapy and social work) tend to publish in a mix of more mainstream fields (such as 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. However, it may be that researchers in niche fields tend to disseminate

their work more frequently using means other than journal publications. 75% of the most prolific researchers perform above the world average in terms of the impact of their overall research portfolio, as well as in terms of percentages of highly cited papers. In addition, 75% of the most prolific researchers are concentrated in nine key institutions.

Table 1 provides definitions of key bibliometric indicators used in the analysis. Table 2 presents an overview of UK comparative performance in dementia research.

Table 1. 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

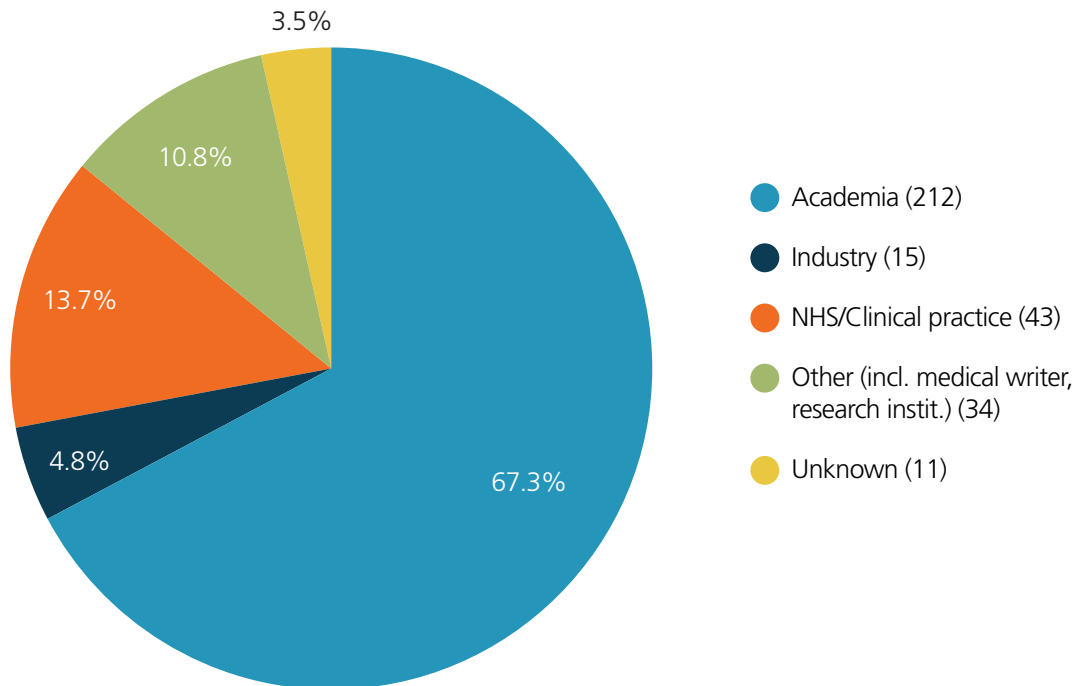
Table 2. Scientific output and impact of the 30 most publishing countries in dementia research (Global Dataset) (1980–2013)⁴

Rank	Volume of dementia papers (1980 - 2013)	Citation impact of dementia portfolio (ARC ⁴)	% 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

⁴ Note that countries sharing the same ranking for a particular indicator are marked with an *

Figure 1. Active dementia researchers by sector

(Please note that % are presented in the pie chart and the absolute number of individuals in the legend)



Source: researchers' own data from PhD tracking exercise⁵

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

- At a minimum, a fifth of dementia PhD graduates (21%) remain in dementia research careers. A higher-end estimate would be 38%.
- Of dementia PhD graduates, 43% remain in research careers (in dementia or other areas)⁶ 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. non-research 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. 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 industry (4.8%), clinical/NHS settings (13.7%) or other settings (10.8%).⁷ The employment sector of 3.5% of the dementia researchers surveyed could not be identified from the available data (Figure 1).
- 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.⁸ (Chapter 6 investigates bottlenecks in dementia research career pathways and transition points in more detail, based on interview data.)

⁵ In this context, the 'other setting' includes senior management; non-academic, non-industry, non-NHS researchers; and other.

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

⁷ In this context, the 'other setting' includes non-classified sectors, medical writing and those in research institutes.

⁸ We analysed data requested from HESA (<https://www.hesa.ac.uk>) 2015. More detail can be found in Chapter 4 of the main report.

Strengths and limitations of the UK dementia research landscape: insights from interviews

- Caveat: we spoke to representatives at different stages in their career pathways and from diverse fields. The current section focuses on findings relating to the dementia research landscape specifically. The next section presents findings pertaining to the dementia research workforce. 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 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.

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.^{9, 10}

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, insufficient focus on specific rarer dementias).

- The most frequently identified gaps in the UK dementia research system were:
 - *Limited understanding of the cellular mechanisms that underlie 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 allied health professions research career pathways. Several aspects of care research were seen as important to support, 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 into educating carers, and arts therapies for people with dementia.
 - *Scope for improvement in the conduct of clinical trials*, most notably in areas of: 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.

⁹ 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.

¹⁰ 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.

- *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 in the development of medical apps and assistive-living technologies.
- *Scope for greater emphasis on translational research* including research linking genetics, cellular-mechanisms studies and drug target discovery efforts, and also translational work which would help move advances from care-related research into improved service delivery.¹¹ 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 the low number of patients diagnosed with these conditions in the UK; patient recruitment challenges (which are accentuated by a lack of specialists able to diagnose these conditions accurately); the disjointed nature of service delivery for such patients (which impacts on recruitment); and competition between various clinical specialties for patient recruitment.
- 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 and largely reflected individual professional experiences and backgrounds. These issues are elaborated on in Chapters 5 and 6 of the full report.

Dementia research careers – stakeholder perspectives on challenges, bottlenecks and opportunities looking forward

- 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 such as 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 also for shifting attitudes away from the view that little can be done about dementia towards a more positive outlook which celebrates milestones and future prospects.

Bottlenecks in career pathways and barriers to dementia research careers

- The lack of a secure career path is widely seen as the key challenge for those considering a career in dementia research, and thus 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. A particular lack of junior-level studentships and fellowships (PhD and first postdoc) was identified in the allied health professions and social care.
- Barriers to clinical research careers in dementia are particularly high and relate to (i) a lack of time available 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 which 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

¹¹ 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.

than did not, and it may be more of a challenge for research-active clinicians or in 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 research 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 the fact that some countries offer more attractive core-funding packages for dementia research (e.g. US, 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 supporting dementia research careers

- Various examples of mechanisms that exist or that 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 these mechanisms relate to providing longer-term funding and improved job security; offering early- and mid-career research support; and enhancing collaboration across fields, disciplines, sectors and institutions.
- *Support for junior research fellowships, including 'bridge-funding' post PhD.* 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 that allow researchers to obtain international experience were highlighted as important. A need for more lectureships, and for fellowships to 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, Motor Neurone Disease 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 to attract their own funds, for example through (i) senior leadership that 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)¹² were seen as catalysts for research careers, and the Collaborations for

¹² Although not mentioned during interviews, the NIHR Dementia Translational Research collaboration is another example.

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 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; raising dementia’s profile more generally and improving the field’s prestige; 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 to be 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 prove 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. Uptake of 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 attracting individuals with strong quantitative skills, particularly those related to big data. Integrating these skills into dementia research efforts will require addressing associated challenges connected with 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 a diversity of research aims; (iii) ensuring the long-term sustainability of the commitment and the still substantial imbalance between the burden of dementia disease and research investment, compared to some other disease areas.



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..."



"...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..."

"...[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..."



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..."



"...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..."



"...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..."



"...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..."

"...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..."



"...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..."

Conclusion

Our findings suggest that the UK has already displayed global leadership in diverse areas of dementia research. It is producing influential research outputs and, as discussed earlier, most likely 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.

Our insights suggest that renewing the leadership of the future will require attention to workforce and succession planning at present. There may be transferable learning related to workforce planning that could be gained from the experiences of other healthcare 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.

In general, we did not find contradictions in the findings resulting from the three methods used. For example, interviewee views on areas of key research strength complemented the findings from the bibliometric analysis well (Chapter 7 discusses this in more detail).¹³ However, we do note some interesting observations. For example, interview evidence suggests that UK research into the genetics of dementia is perceived to be highly influential. Although the volume of UK genetics papers on dementia is low (3% of all UK dementia research outputs), and although the citation performance of UK genetics-based dementia research publications is only

slightly above world average when the entire portfolio is considered, there is a subset of highly influential UK research outputs in the genetics of dementia, as indicated by the high percentage of highly cited papers. In addition, interviewees highlighted strengths in research related to person-centred care, although both bibliometric and interview evidence suggest low volumes of UK research activity in fields which would feed into these areas (e.g. health policy and services, and nursing fields), and modest citation impact. 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 do both are issues for policy debate, and these observations may be helpful in future dialogue on dementia capacity-building.

Evidence from the interviews also enriched and complemented key messages from the investigation of career pathways of UK dementia PhD graduates, highlighting similar research-workforce challenges. For example, the PhD career-tracing element of this work suggests that approximately a fifth of individuals who complete PhDs in a dementia-related topic remain in dementia research careers.¹⁴ Given the challenges of building a dementia research community and the comparative scarcity of funding vis-à-vis areas like cancer,¹⁵ policymakers may wish to consider ways of encouraging retention in dementia careers, along with ring-fenced posts and funding in this space.

The analysis of the current dementia research workforce (based on profiles of dementia PhD graduates currently active in dementia research as a proxy) shows that the ratio of junior and mid-level staff to senior staff in UK dementia research broadly mirrors the patterns observed in the biological sciences and in some

¹³ 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 and its role in advancing knowledge of disease-risk in Alzheimer's and Parkinson's diseases; brain imaging to provide evidence of disease progression; 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 citation-wise have contributed to research across these topics. Research gaps in conditions classified as familial and early-onset dementia, where the UK lags behind world averages citation-wise, were identified by both the bibliometric analysis and interview data.

¹⁴ We do not have evidence on how this compares to other disease areas and we could not examine the attraction to dementia from other fields or other countries within the scope of this work.

¹⁵ Alzheimer's Research UK (2012). 'Defeating dementia: building capacity to capitalise on the UK's research strengths'. Alzheimer's Research UK policy reports. http://www.alzheimersresearchuk.org/wp-content/uploads/2015/01/ARUK_Defeating_Dementia_-_Building_capacity_to_capitalise_on_the_UKs_research_strengths.pdf (Accessed 29 May)

subjects allied to medicine.¹⁶ However, it is somewhat higher than the ratio observed in the medical sciences and dentistry fields.¹⁷ Our interviews complemented these insights by highlighting key bottlenecks within the junior and mid-level category of the dementia research workforce – i.e. the transition from a post-doctoral role to an independent PI or lecturer role, and from a PhD or clinical training to a first postdoctoral or clinical research position. Interviewees also identified profession-specific workforce issues (e.g. a particular lack of more junior-level fellowships in the allied health professions and social care, and barriers to clinical research careers in dementia).

Some of the issues identified are not necessarily dementia-specific, but are heightened in the dementia context. The contents below reflect on key themes from the analysis and put forward issues and actions to consider in a future policy agenda.

Actions for a policy agenda: informing a dementia research capacity blueprint

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. Our intention is not to be prescriptive. Rather, we present ten key policy considerations with the aim of encouraging 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.

¹⁶ We analysed data requested from HESA (<https://www.hesa.ac.uk>) 2015. More detail can be found in Chapter 4.

¹⁷ Again, data was taken from HESA (<https://www.hesa.ac.uk>) 2015. More detail can be found in Chapter 4.

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.