Supplemental Information

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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This supplementary information file contains the following documentation:

1. Detailed description of interview methods
2. Description of categories used in career tracking
3. Interview invitation email
4. Interview protocol for dementia researchers
5. Interview protocol for individuals who left the dementia field
6. Interview protocol for individuals working outside of academic research

1. Detailed description of interview methods

Overview

The study team aimed to conduct 40 interviews, in line with resources available and based on expectations of saturation points. 60 individuals were initially invited (with the expectation that approximately two thirds would accept and be available within the study timeframe). Over time, two additional individuals were invited. Of the 62 individuals approached, 40 were interviewed, 1 email bounced (and another address could not be found), 8 did not respond and 13 declined the interview or were not available. The 40 telephone interviews were held between March and May, 2015. The profile of the 62 individuals invited is presented in Table S1.

Sampling

The study team aimed to interview individuals from diverse sectors and disciplines to investigate perspectives on the current state of the UK dementia research landscape, and research workforce issues from a variety of perspectives. Sectors covered were academic, clinical or social care, research funding and industry; disciplines were the allied health professions, clinical psychology, epidemiology, genetics, neurology, neuroscience, nursing, psychiatry and social care; and career stages were current PhD students, junior, mid-level, senior and individuals who left the field. Gender was not explicitly controlled for in sampling, but gender breakdowns are provided in Table S1.

Given the dominance of academic researchers in the field, it was expected that the majority of researchers active in the field would be based in academic organisations. However, the research team aimed to ensure that the views of researchers outside of academic settings were also reflected. The study aimed to include individuals at different career stages to see whether views on capacity-building priorities may differ. The team aimed for a broadly equal split between senior researchers and those in junior and mid-level positions given an interest in perspectives on capacity-building needs across the career pathway. In addition to approaching individuals who were active in dementia research or dementia research funding, the team also aimed to interview some individuals who had left the dementia field to understand reasons why they left.

In line with qualitative methods for conducting purposive sampling and interview-based studies in health (Bowling, 1997), a deliberately non-random approach, was applied aiming to ensure that a diversity of views and experiences was captured, but not strictly representative sample. We used grounded theory principles, whereby theoretical sampling is not statistical sampling, and considered expected saturation points (Glaser and Strauss, 1967).

Individuals to approach for interview were identified from a combination of data sources. Evidence from publication data was used to identify individuals who are currently active dementia researchers and are prolific in different fields. Differences in publication patterns were taken into account when assessing publication output (as different fields produce different volumes of publication output over a given time period).[1,2] To be considered 'currently active', a researcher had to be an author on

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[1] Wilsdon, J, et al. (2015). The Metric Tide: Report of the Independent Review of the Role of Metrics in Research Assessment and Management. DOI: 10.13140/RG.2.1.4929.1363

an article published in 2008 or later. The information came from a bibliometric analysis of data provided by Science Metrix (and reported in Marjanovic et al. 2015). To ensure that researchers at different levels of seniority were captured, the research team complemented the publication data with information from the career tracking exercise, as the latter helped identify individuals who may not yet have a high volume of publication outputs due to being in earlier phases of their research careers. These data also made it possible to identify individuals who had left the dementia field. JP and CW helped identify potential interviewees involved in research funding. Our sampling considered these criteria to ensure a diversity of views and experiences were reflected in the qualitative analyses.

Table S1 Profile of the pool of 62 individuals invited to participate in an interview.

Breakdown by field		Breakdown by sector	
N	Primary field of activity	N	Primary sector affiliation
9	Nursing, allied health professions and other care	43	Academia
		8	Academia with clinical appointment
11	Neuroscience	4	NHS clinical or care
6	Psychiatry	4	Research funding
10	Clinical neurology	3	Industry
5	Clinical psychology		
4	Genetics and genomics		
2	Epidemiology		
15	Other (research funding, industry, research in areas other than dementia)		
Breakdown by seniority		**Breakdown by gender**	
N	Career stage	N	Seniority level
29	Senior (Professors, readers, other senior)	33	Female (of which 26 were junior/mid-level and 7 were senior)
33	Junior/mid-level (Lecturers; senior lecturers; research fellows; research associates; postdoctoral fellows; PhD students)	29	Male (of which 7 were junior/mid-level and 22 were senior)
	*7 individuals were approached who had left dementia research, of which 2 were senior and 5 were junior/mid-level. (2 male and 5 female)		

A note on classification by seniority: To categorise individuals by seniority (senior, mid-level and junior), adapted Higher Education Statistics Agency (HESA) contract-level classifications were used. The classification was adapted to ensure classification was done consistently for interviewees and for the career tracking exercise. For example, in the career-tracking exercise, it was often not possible to distinguish between junior and mid-level roles from the data that could be collected because individuals with positions as postdoctoral or research associates or fellows can have different levels of seniority. In the classification used in this study (as applied both in the career tracking and in the interviews), senior staff categories include: senior management, head of

[2] Gunashekar S, S Parks, C Calero-Medina, M Visser, J van Honk & S Wooding. 2015. Bibliometric analysis of highly cited publications of biomedical and health research in England, 2004-2013. Santa Monica and Cambridge: RAND Corporation.

schools/senior function head, professor, function head, non-academic section manager, senior/principal lecturer, reader, and principal research fellow. Mid-level and junior staff include: team leader (professional, technical, administrative), lecturer, senior lecturer, senior research fellow, senior professional (technical), lecturer, research fellow, researcher (senior research assistant) and teaching fellow.

Invitation process

Prospective interviewees were initially contacted by JP, who explained the purpose of the study and the reasons for an interview. The interviewers then followed up this introduction with an invitation email (included in this supplementary information document), which included information about the study, the interview purpose and scope, who commissioned the study, and how the data would be used, including issues of informed consent and confidentiality. This information was reiterated at the beginning of the interview, and interviewees' informed consent was recorded. Interviewees were informed that no quotes would be attributed directly to them without their explicit consent and were asked whether they would be happy to be named in a list of participants in the study (and all but one agreed to be named as participants). The research ethics process followed was in line with RAND Europe's institutional ethics framework guidelines and process, and was in line with other evaluative studies. The research team followed up the invitations, if needed, with two emails and, if possible, a telephone call.

Interview conduct

Each interview was conducted by a single researcher (CL, EH, SP, CML, ER, SM, VH) following a semi-structured format, and lasted 30-60 minutes. Protocols are included in this supplementary information document. With informed consent recorded, interviews were audio-recorded and transcribed, and permission to list interviewees' names and affiliations was requested.

Interviewees were asked to share their perspectives on the current state of the dementia research landscape in the UK, and their insights and experiences regarding career progression opportunities and capacity-building needs and opportunities. The research team aimed to allow interviewees to express their views regardless of whether they related to specific types of dementia disease or specific disciplines of research. This was to ensure that they answered based on their own expertise and experience of the field, and in line with an interest in the overall system. The interviews combined questions exploring particular themes (but not driven by any positivist hypotheses on the themes) and also allowing for emerging issues to be captured, coded and grouped into analytical constructs – thus the analysis followed principles rooted in grounded theory (Gubrium 2012, Glaser and Strauss, 1967).

To ensure interviews were carried out in a consistent fashion across all interviewers, a consistent semi-structured protocol approach was used. The study leader (SM) met with the research team to talk through the protocol in advance, and to ensure consistency in approach. For early interviews, as another measure to ensure consistency, two interviewers were present – one to conduct the interview and one to take notes and listen to help ensure consistency in approach. (Interviewees were informed when there was an additional researcher present.) Interview transcripts were produced for all interviews and a common template used for coding and analysis. After each

interview, the interviewer reported key issues to SM for wider dissemination to the team, again with a view to shared learning and consistency and effectiveness in approach.

Analysis of interview data

Each interview was transcribed and each interviewer initially coded information from the transcript into an Excel workbook that consisted of a template following the questions in the protocol (as first level coding themes) and included space for recording additional emerging themes and issues (in line with a grounded theory approach). The coding of all interview data was checked by a second researcher (CL), guided by initial interview themes. The coding of a random sample of the interviews was checked by a third researcher (SM).

Additional second-level coding and analysis was done in another excel workbook (led by CL with support from SP and ER, and review by SM) with one spreadsheet created per question topic, where responses to each question were categorised and tallied alongside information about the interviewees making each type of response (seniority, sector, field and associated unique identifier) and a list of relevant quotes. This ensured that insights could be triangulated against particular disciplinary and career profiles of interviewees.

Themes were further assessed – at a less granular level – during a team workshop where the team moved from granular analysis to focus on higher-level, more generalised categories with properties and relations important for explaining the nature of the data under observation. This also allowed the research team to capture and reflect on issues that emerged from the interviews but were not directly enquired about in the protocols. In line with grounded theory principles, the protocol and analyses were designed to let the categories emerge rather than coming into the study with pre-set granular categories based on existing theories (Glaser and Strauss, 1967) were followed.

Core thematic coding categories reflected views on strengths in the research landscape (spanning disciplinary, disease related, cross-cutting elements and properties) with a focus on understanding diversity of views over quantification; limitations in the research landscape as seen to be priority challenges by interviewees; insights on issues affecting career opportunities in dementia research and workforce capacity in this field); and insights on mechanisms to support capacity-building. Emerging themes related to research ethics needs, gender, patient recruitment challenges (which related to competition between specialities and the differing roles of neurologists and geriatric specialists in the UK versus other countries).

2. Description of categories used in career tracking

Active researchers: Consistent with the approach used when selecting interviewees, individuals were considered 'active researchers' if they had authored an article (in any field) that was published in 2008 or later.

Active dementia researchers: These were active researchers whose publications (published in 2008 or later) related to dementia, with the range of topics matching the keywords used to initially select dementia theses from the Ethos database.[3]

Active in dementia (non-research): Individuals whose current position is relate to dementia (e.g. dementia patient care), but who are not currently active researchers.

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[3] Alzheimer's; dementia; cognitive impairment; mixed dementia; early onset dementia; vascular dementia; Lewy bodies; frontotemporal dementia; posterior cortical atrophy; familial dementia; Creutzfeld-Jakob; Korsakoff's syndrome; cognitive impairment; supranuclear palsy; Biswanger's; Multiple Sclerosis; motor neurone disease; Parkinson's; Huntington's.

3. Interview invitation email

Dear [NAME],

You will have recently received an email from James Pickett at the Alzheimer's Society. As James mentioned in his email, RAND Europe is currently conducting a study for the Alzheimer's Society, looking at current strengths and gaps within the UK dementia research landscape and within the dementia research workforce. This research should help inform future strategies aiming to support the dementia research community in the UK.

A vital part of this study is a series of interviews with stakeholders from both within and outside the dementia field that will take place in the next [TIMEFRAME]. We are eager to capture the expertise and individual experiences of people at different stages of their careers and working in diverse disciplines. We are keen to reflect the insights of researchers and practitioners active in dementia, policy makers, industry representatives, as well as dementia research graduates who may have left the field and/or are working in other related disciplines.

You have been identified as someone we would greatly appreciate the opportunity to talk to. This should take between 30 minutes and 1 hour of your time. Would you be available for a telephone interview on [DATE]?

Please do not hesitate to get back to me with an alternative suggested time and date, or if you need any further information.

All information collected during the interview will be kept strictly confidential. Interview transcripts might be quoted in publications with no reference to your name, or organization. You will also have the option of not being quoted at all.

With best wishes,

[NAME]

4. Protocol for Group 1 (dementia researchers)

Please note that not each interviewee can speak to the same level of detail on each issue. The interviews are semi-structured which allows for adaptability and responsiveness to the interviewee's skills and experience.

PART 1: SCIENCE AND SKILLS

1) Can you just briefly tell us a little bit about your job and role, and any key related activities in the dementia space?
2) Based on your knowledge of the dementia research landscape, what are some of the areas where you think the UK research community has done particularly well (e.g. produced particularly important and influential findings)? We are interested in your views on both 'strong' disease areas and fields/disciplines.
3) And are there any disease areas and fields/disciplines where we have not done so well and where you think we could do better?
4) The bibliometric data from our study suggests that the UK generally does well in terms of the citation impact of dementia research, but that it lags behind global averages in a few areas – for example in familial dementia and early onset dementia. Do you know why that might be? Do you think these are areas we should focus on, vis a vis other priorities or not?
5) Do you think the UK should pursue a broad research portfolio across various types and subtypes of dementia, or focus investments in on specific diseases (i.e. specific types of dementia)?
6) Do you think funders should prioritise research on prevention, or treatment/cure, or care and service delivery? Why?
7) Similarly, do you think funders should prioritise basic or applied and clinical research? Why?

PART 2: THE CAREER PATHWAY AND PIPELINE

We would like to discuss your insights and experiences regarding career progression in dementia research.

8) (i) What do you think the key barriers to progression in dementia research careers in the UK are? Have you experienced any of these? (ii) At what stages of the career pathway are there the biggest 'bottlenecks'?
9) Based on your experience and knowledge of the UK landscape, are there any *stages of the research career pathway and transition points* where UK dementia research has a particular lack of capacity at present? What could be done to tackle this?
10) What about enablers of dementia research careers in the UK? Have you experienced and do you know of any supportive mechanisms for pursuing a research career in this field
11) Do you think these barriers and enablers are specific to dementia research or apply more generally to other research areas?
12) Has your work contributed to capacity-building in terms of the training and empowerment of future dementia researchers? If so, how?
13) Are there any areas of dementia research – either disease areas or important fields/disciplines - that you think the dementia investment community has *particularly* neglected and where research workforce capacity is *particularly* low?

a. Future work in the dementia space will possibly be linked to substantial growth in big data and informatics resources. Do you think the UK has a sufficient pool of people and skills to support this? How could the UK go about building or accessing these skills?

14) Are there any areas (dementia diseases, fields, disciplines) where you think there is a notable lack of _next generation_ researchers? (e.g. a lack of new feeds into the workforce at more junior levels - phds, postdoc, lecturers levels etc.)

15) We would like to explore the problem of retention of researchers in dementia in a bit more depth.
   a. Firstly, how big of a problem do you think retention of dementia researchers in the field is?
   b. What about retention in the UK? Is that a challenge in your experience? Is it important in a 'brain circulation world'?

16) We hear a lot about the need to attract researchers from other fields or currently training in other fields, and to redirect researchers from other fields to dementia research
   a. Which fields/disciplines do you think are particularly suited as targets for attraction to dementia research, and why?
   b. How could we encourage this, what mechanisms might work? Based on your knowledge, are there examples of contexts where this has worked?
      i. Do you think people could work in other areas and contribute to dementia in parallel (e.g. sabbaticals, staff exchanges, informal thematic interest networks etc.) or do you have to have 'complete commitment'?

17) With recent UK policy focus on dementia, we have seen an increase in funding committed to dementia research. Do you think the scale of increased commitments can make a difference and contribute to a critical mass of dementia researchers?

18) In addition to core scientific and technical skills, are there any professional skills which need to be built in the dementia research workforce?

19) Are there particular areas and types of research where you think (i) clinicians/allied health professional -driven research and (ii) industry research is particularly important for advancement of the dementia field?

20) It is particularly difficult to engage clinicians and allied health professionals in research careers, and we recognise that this is not specific to dementia only. Do you know of any support mechanisms/enablers for clinical academic/clinician researcher careers in dementia? What are the key barriers?

PART 3: ON REFLECTION

21) On reflection, what do you consider the biggest challenges to progress in dementia research to be?

22) What do you consider to be the three key priority issues for workforce capacity investment in the UK? Why? What would happen if that sort of capacity isn't supported?

23)

5. Protocol for Group 2 - people who left dementia research (from PhD tracing)

Please note that not each interviewee can speak to the same level of detail on each issue. The interviews are semi-structured which allows for adaptability and responsiveness to the interviewee's skills and experience.

PART 1: CAREER HISTORY RELATED QUESTIONS

1) What is your current job/position and can you tell us a bit about your work?
2) What had attracted you to do a PhD in dementia? What was your research on?
3) Why did you leave dementia research?
4) Is there anything that would have helped retain you in dementia research?
5) Would you ever consider returning to dementia-related research?
   a. If so, under which conditions and what do you think you could contribute? What areas of dementia would you work in?
   b. If not, why not?
6) IF THEY WORK IN ANOTHER RESEARCH FIELD: How does you current research field compare with the dementia research field in terms of:
   a. Research capacity
   b. Career progression opportunities?
7) Do you still broadly follow developments in the dementia field?

PART 2A: ONLY FOR PEOPLE WHO ANSWER NO TO Q7

8) IF THEY ANSWER NO to Q 7:
   a. What do you perceive the dementia research landscape in the UK to be like, in terms of your general knowledge? Do you think there are any strengths or weaknesses?
   b. More generally, what do you see as the key strengths and weaknesses of the UK research environment to be (e.g. in your field and more generally).
9) Do you have any thoughts on priority areas for capacity-building of the dementia research workforce in the UK?
10) Do you have any thoughts on key current barriers to progress for UK dementia research?
11) Do you have any thoughts on key enablers barriers to progress for UK dementia research?

PART 2B: THE CAREER PATHWAY AND PIPELINE

THIS SECTION IS FOR PEOPLE WHO SAY YES OR TO AN EXTENT OR AT LEAST A LITTLE BIT TO Q7

We would like to discuss your insights and experiences regarding career progression in dementia research.

12) What do you consider the key strengths and weaknesses in the field of dementia research in the UK to be?
13) What do you see as the biggest bottlenecks to dementia research careers in the UK?

14) We hear a lot about the need to attract researchers from other fields or currently training in other fields, and to redirect researchers from other fields to dementia research:

    a.   Are there any fields/disciplines do you think are particularly suited as targets for attraction to dementia research, and why?

    b.   How could we encourage this, what mechanisms might work? Based on your knowledge, are there examples of contexts where this has worked?

           i.   Do you think people could work in other areas and contribute to dementia in parallel (e.g. sabbaticals, staff exchanges, informal thematic interest networks etc.) or do you have to have 'complete commitment'?

15) We would like to explore the problem of retention of researchers in dementia in a bit more depth.

    a.   Firstly, how big of a problem do you think retention of researchers in the dementia field is?

    b.   What about retention of dementia researchers <u>in the UK?</u> Do you think that is a challenge? Is it important in a 'brain circulation world'?

    c.   Do you have any thoughts about ways of addressing retention challenges?

<u>PART 3: ON REFLECTION</u>

16) On reflection, what do you consider the biggest challenges to progress in UK dementia research to be?

17) What do you consider to be the three key priority issues for dementia <u>workforce capacity</u> investment in the UK? Why? What would happen if that sort of capacity isn't supported?

6. Protocol for Group 3 - non-researchers[4]

Please note that not each interviewee can speak to the same level of detail on each issue. The interviews are semi-structured which allows for adaptability and responsiveness to the interviewee's skills and experience.

PART 1: SCIENCE AND SKILLS

1) Can you just briefly tell us a little bit about your job and role, and any key related activities in the dementia space?
2) Based on your knowledge of the dementia research landscape, what are some of the areas where you think the UK research community has done particularly well (e.g. produced particularly important and influential findings)? We are interested in your views on both 'strong' disease areas and fields/disciplines.
3) And are there any disease areas and fields/disciplines where we have not done so well and where you think we could do better?
4) The bibliometric data from our study suggests that the UK generally does well in terms of the citation impact of dementia research, but that it lags behind global averages in a few areas – for example in familial dementia and early onset dementia. Do you know why that might be? Do you think these are areas we should focus on, vis a vis other priorities or not?
5) Do you think the UK should pursue a broad research portfolio across various types and subtypes of dementia, or focus investments in on specific diseases (i.e. specific types of dementia)? (If they think there are specific focal areas ask why and which)
6) Do you think funders should prioritise research on prevention, or treatment/cure, or care and service delivery? Why?
7) Similarly, do you think funders should prioritise basic or applied and clinical research? Why?

PART 2: THE CAREER PATHWAY AND PIPELINE

8) (i) What do you see as the biggest barriers to dementia research <u>careers</u> in the UK? And at what stages of the career pathway are there the biggest bottlenecks? (i.e. at specific transition points? getting senior, mid, jr posts?)
9) What about enablers of dementia research careers in the UK?
10) Do you think these barriers and enablers are specific to dementia research or apply more generally to other research areas?
11) We hear a lot about the need to attract researchers from other fields or currently training in other fields, and to redirect researchers from other fields to dementia research:
    a. Are there any fields/disciplines do you think are particularly suited as targets for attraction to dementia research, and why?
    b. How could we encourage this, what mechanisms might work? Based on your knowledge, are there examples of contexts where this has worked?
    c. Do you think people could work in other areas and contribute to dementia in parallel (e.g. sabbaticals, staff exchanges, informal thematic interest networks etc..) or do you have to have 'complete commitment'?

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[4] These interviewees were policymakers, funders and industry representatives.

12) We would like to explore the problem of retention of researchers in dementia in a bit more depth.
    a. Firstly, how big of a problem do you think retention of researchers in the dementia field is?
    b. What about retention of dementia researchers <u>in the UK?</u> Do you think that is a challenge? Is it important in a 'brain circulation world'?
    c. Do you have any thoughts about ways of addressing retention challenges?

13) With recent UK policy focus on dementia, we have seen an increase in funding committed to dementia research. Do you think the scale of increased commitments can make a difference and contribute to a critical mass of dementia researchers?

14) Are there particular areas and types of research where you think (i) clinicians/allied health professional -driven research and (ii) industry research is particularly important for advancement of the dementia field?

15) It is particularly difficult to engage clinicians and allied health professionals in research careers, and we recognise that this is not specific to dementia only. Do you know of any support mechanisms/enablers for clinical academic/clinician researcher careers in dementia? What are the key barriers?

<u>PART 3: ON REFLECTION</u>

16) On reflection, what do you consider the biggest challenges to progress in dementia research to be?

17) What do you consider to be the three key priority issues for capacity investment? Why? What would happen if that sort of capacity isn't supported?