

Impact case study (REF3b)

<p>Institution: Newcastle University</p>
<p>Unit of Assessment: UoA2</p>
<p>Title of case study: Shaping the UK's dementia care policy to reflect the importance of an early, sensitively-communicated diagnosis of dementia</p>
<p>1. Summary of the impact</p> <p>Newcastle research on dementia contributed two aspects that helped to shape high-level policy: first that prevalence of the condition was higher than previously suspected, with implications for care of the ageing UK population. Secondly, that patients often experienced long delays before a diagnosis of dementia was given, leading to distress both for patients and their families. This research informed policy documents such as the Prime Minister's 2012 Challenge on dementia and national guidance in the form of commissioning packs. Patients benefit from more timely diagnosis with a better understanding of their needs and wishes and the NHS benefits through potential reductions in long term care costs.</p> <p>2. Underpinning research</p> <p><u>Newcastle research staff</u> All staff were employees at the University during the research period unless otherwise stated.</p> <p>Professors John Bond, Ian McKeith and Louise Robinson were co-applicants and site leads of the Medical Research Council (MRC) Cognitive Function and Ageing Study (CFAS) study, with the data analysis performed by Dr Blossom Stephan (joined 2012). Professor Martin Eccles was Principal Investigator of the MRC Primary Care and Dementia study, with Ms Claire Bamford the Senior Research Associate and Dr Nicholas Steen the Senior Statistician. Professor Robinson was the co-applicant and site lead of the National Institute for Health Research (NIHR) Transitions study and Dr Clare Abley (joined January 2009) was the Senior Researcher of the NIHR Transitions study.</p> <p><u>Background: the challenge of dementia</u></p> <p>The 2009 World Alzheimer Report estimated that 35.6 million people worldwide were living with dementia, and ageing populations mean that this figure is likely to rise to 115 million by 2050. In terms of quality of life, dementia is the chronic illness that accounts for the greatest number of years lived with disability in those aged over 60 years. The estimated global financial burden is \$315 billion, with UK costs estimated at £17 billion (EV a).</p> <p>Dementia is characterised by impaired memory and communication, which inevitably lead to loss of independence and a need for long-term care. As people age, some loss of memory is natural; this is known as normal cognitive ageing. However, 1 in 14 people over 65 years, and 1 in 5 over 80 years will develop dementia. There is no long-term cure, but Newcastle research has contributed to a deeper understanding of the quality of clinical care that people experience along the diagnostic pathway.</p> <p><u>Understanding the prevalence and risk factors for dementia</u></p> <p>Prior to the 1990s, the majority of research into dementia was targeted towards finding a cure or understanding the cause of this devastating illness. However, the focus of research shifted towards understanding the natural history of dementia during the early 1990s with the MRC-funded CFAS study (R 1-2). Newcastle's contribution to this unique, primary care based cohort study was to recruit 20% of the 13,000 participants and perform data analysis. The two main findings of the study were first that prevalence was higher than previously thought, and second that age was a significant risk factor for dementia, implying that the prevalence would increase in the ageing UK population.</p> <p><u>Patient and family experiences of the diagnostic pathway</u></p> <p>Following this epidemiological research, Newcastle researchers, including Professor Robinson in her capacity as an academic GP, investigated the quality of care received by patients as they were assessed for dementia. An MRC-funded, Newcastle-based study (R3) analysed general practice</p>

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records of 300 people recently diagnosed with dementia, and found that average time to diagnosis was 18 months and the maximum was four years. In order to explore the reasons behind such delays, a qualitative study was conducted in 2009 to investigate the individual experiences of patients and their families during assessment in memory clinics. Results showed that despite national clinical guidance in this area (NICE CG42, 2006), people with memory problems continued to experience unnecessary delays and considerable distress during the diagnostic process (R4). In addition, Newcastle-led research examined the way in which a diagnosis of dementia was disclosed to patients and their families. The findings demonstrated that the majority of patients wished to be informed of a definitive diagnosis of dementia; however, the diagnosis was often withheld from the patients themselves, even though their families were told (R5).

Findings from a review of how diagnosis is carried out in primary care (R6) showed three aspects of relevance: first, that diagnosis involves good co-operation between primary and secondary care providers, secondly that patients with mild dementia wish to know their diagnosis, and thirdly that the benefits of a well-performed and early diagnosis include an end to uncertainty, allowing patients and their families to plan for the future and giving access to support.

3. References to the research

(Newcastle authors in bold type, citation counts from Scopus, July 2013.)

- R1.** MRC CFAS Medical Research Council Cognitive Function & Ageing Study, including **McKeith I, Hrisos S** and **Bond J**. Cognitive function and dementia in six areas of England and Wales: The distribution of MMSE and prevalence of GMS organicity level in the MRC CFA Study. *Psychological Medicine* 1998, **28**(2), 319-35. DOI: 10.1017/S0033291797006272. **Cited by 162**
- R2.** The Neuropathology Group of the Medical Research Council Cognitive Function and Ageing Study, including **Ince P** and **McKeith I**. Pathological correlates of late-onset dementia in a multicentre, community-based population in England and Wales. Neuropathology Group of the Medical Research Council Cognitive Function and Ageing Study (MRC CFAS). *Lancet* 2001, 357 (9251):169-75. DOI: 10.1016/S0140-6736(00)03589-3. **Cited by 673**
- R3.** **Bamford C, Eccles M, Steen N, Robinson L**. Can primary care record review facilitate earlier diagnosis of dementia? *Family Practice*, 2007; 24(2): 108-116. DOI: 10.1093/fampra/cml068. **Cited by 13**
- R4.** Manthorpe J, Samsi K, Campbell S, **Abley C**, Keady J, **Bond J**, Watts S, **Robinson L, Gemski A**, Warner J, Goodman C, Drennan, V, Iliffe S. The transition from CI to dementia: older people's experiences. 2011. NIHR Service Delivery and Organisation programme. Southampton. HMSO Queens Printer and Controller. Available at <http://www.kcl.ac.uk/sspp/kpi/scwru/pubs/2011/manthorpeetal2011transitionfinalreport.pdf>
Citation data unavailable in Scopus.
- R5.** **Bamford C, Lamont S, Eccles M, Robinson L, May C, Bond J**. Disclosing a diagnosis of dementia: a systematic review. *International Journal of Geriatric Psychiatry*. 2004; 19(2): 151-169. DOI: 10.1002/gps.1050. **Cited by 101**
- R6.** Iliffe S, **Robinson L**, Brayne C, Goodman C, Rait G, Manthorpe J, Ashley P. Primary care and dementia: 1. diagnosis, screening and disclosure. *International Journal of Geriatric Psychiatry*. 2009; 24(9): 895-901. DOI: 10.1002/gps.2204. **Cited by 40.**

Relevant funding awards, by funder:

- The Economic and Social Research Council (ESRC). An award of £155,286.
- The Medical Research Council (MRC). Three awards totalling £3,736,655
- The National Institute for Health Research (NIHR). Three awards totalling £1,429,563

4. Details of the impact

Impact of Newcastle research on informing prevalence rates

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A fundamental difficulty in tackling the challenges posed by dementia was the lack of knowledge of the scale of the problem, including prevalence rates and progression pathway. This was addressed by two reports that would prove influential in informing subsequent policy. The first, a report to the Alzheimer's Society entitled '*Dementia UK*' (EV a), contains prevalence and incidence data that were largely contributed by the CFAS (R 1-2): "*In terms both of sample size and scope the evidence base is dominated by the Medical Research Council Cognitive Function and Ageing Study*" (EV a, pg. 10). Consequently, Dementia UK acted as the major source of information for the second report, a 2007 National Audit Office document (EV b). These two reports formed the basis for the National Dementia Strategy (EV c), a high-level policy document published in 2009.

Impact of Newcastle research on an improved care pathway

Newcastle research has informed healthcare improvement programmes that highlight the importance of early diagnosis, a well-performed disclosure and a well-planned care pathway. When preparing the National Dementia Strategy, the Early Diagnosis and Intervention working group became aware of the lack of evidence to support opinions regarding earlier diagnosis and its more sensitive disclosure (EV d). This prompted research that resulted in the publication of R6, which went on to inform the 2011 Health Foundation Improvement report. This cites R6 twice (EV e, pg 74), stating:

- "*patients are most likely to benefit from an early diagnosis if there is a coordinated team with representatives of different types of health and social care to plan the care of the patient*"
- "*Patients and carers prefer to be told the diagnosis early, as this ends their uncertainty about the problem, allows them to learn more about the condition and how to cope with it. It also gives them an opportunity to access support and allows them to achieve unfulfilled ambitions in the short term.*"

Impact of Newcastle research on policy implementation

The Department of Health appointed an expert group to develop "commissioning packs" which enable the implementation of recommendations, via enabling health and local authority commissioners to design cost-effective services that are suited to local needs. Professor Robinson was recruited to this expert group on the basis of her relevant research expertise. She was able to bring to the group's deliberations both the results of her research on the beneficial effects of early diagnosis for patients and their families, and the findings from Newcastle-led research on best practice in disclosing a diagnosis of dementia. The National Clinical Director for Dementia stated: "*I ... confirm that the evidence and advice [Professor Robinson] provided in [her] role as a key member of the Department of Health [DH] Expert Group responsible for the development of the DH Commissioning Guidance packs for Dementia care, was crucial to determining key commissioning targets and outcomes of good quality care*" (EV f). These packs were also informed directly by Newcastle research (R5) and indirectly via the 2009 National Dementia Strategy (EV c, itself including Newcastle research).

The two Dementia Commissioning Packs (EV g, h), published in 2011, include the statement: "*Identifying people earlier in the disease pathway enables more people suffering from the disease to make choices rather than at a point when it is too late*" (EV g, pg. 15). Newcastle research (R5) is included in EV h (pg. 9) as evidence that a rapidly and sensitively communicated diagnosis of dementia has several advantages to the patient over traditional diagnosis pathways, including "*a better understanding of the situation*" and "*an end to uncertainty*". These packs also went on to form the basis of the Prime Minister's 2012 Challenge on Dementia.

The Prime Minister's Dementia Challenge

In the latest step in policy development, the Prime Minister established a "Dementia Challenge" in 2012 (EV i) to increase implementation of recommendations. Professor Robinson was appointed to a senior role, as confirmed by the National Clinical Director for Dementia (EV d): "*[Professor Robinson's] expertise as a national researcher in dementia care contributed to [her] selection as Primary care advisor to the Secretary of State for the Prime Minister's National Dementia Challenge*". The National Dementia Challenge identifies major improvement targets for dementia

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care by 2015. Its first interim report notes that those responsible for implementation believe they are on track for working with professionals to improve early diagnosis (EV j, pg. 38).

Summary

Newcastle contributed to a large, multi-centre cohort study that broke with the prevailing focus of research. The study showed that dementia was more common than previously thought, and that age was a significant risk factor, with implications for the ageing population. Subsequent Newcastle research that identified poor quality of the diagnosis and care pathway informed several high-level policy documents, including the 2012 Prime Minister's Dementia Challenge, and guidance in the form of the Department of Health's 2011 commissioning packs.

5. Sources to corroborate the impact

- EV a.** Dementia UK 2007, produced for the Alzheimer's Society
http://www.alzheimers.org.uk/site/scripts/download_info.php?fileID=2
- EV b.** National Audit Office report "Improving services and support for people with dementia" 2007
<http://www.nao.org.uk/wp-content/uploads/2007/07/0607604.pdf>
- EV c.** Living Well With Dementia; A National Dementia Strategy. Produced by the Department of Health 2009.
https://www.gov.uk/government/uploads/system/uploads/attachment_data/file/168220/dh_094051.pdf
- EV d.** Letter from the Professor of Primary Care for Older people, University College London, available on request
- EV e.** Health Foundation improvement report: Spotlight on dementia care, 2011:
http://www.health.org.uk/public/cms/75/76/4181/2703/Spotlight_Dementia%20Care.pdf?realName=1pWJno.pdf
- EV f.** Letter from the National Clinical Director for Dementia, available on request
- EV g.** Service specification for dementia: memory service for early diagnosis and intervention. July 2011.
http://webarchive.nationalarchives.gov.uk/20110907180004/http://www.dh.gov.uk/prod_consum_dh/groups/dh_digitalassets/documents/digitalasset/dh_128877.pdf
- EV h.** Case for change – memory service for people with dementia. July 2011
http://webarchive.nationalarchives.gov.uk/20130107105354/http://www.dh.gov.uk/prod_consum_dh/groups/dh_digitalassets/documents/digitalasset/dh_128580.pdf
- EV i.** The Prime Minister's Challenge on Dementia. March 2012.
https://www.gov.uk/government/uploads/system/uploads/attachment_data/file/215101/dh_133176.pdf
- EV j.** The first annual report on progress on the Prime Minister's Dementia Challenge. May 2013.
https://www.gov.uk/government/uploads/system/uploads/attachment_data/file/200030/9535-TSO-2900951-PM_Challenge_Dementia_ACCESSIBLE.PDF