

<p>Institution: University of Worcester</p>
<p>Unit of Assessment: 3 - Allied Health Professions, Dentistry, Nursing and Pharmacy</p>
<p>Title of case study: Advancing healthcare policies and practice in Europe for people living with dementia and their carers</p>
<p>1. Summary of the impact</p> <p>Dementia poses substantial public health and societal challenges for Europe as there is currently no cure, and it is estimated that 10 million Europeans will be living with the disease in 2040. Good quality information allows for decision-makers to establish appropriate health policies and target resources where they are needed and where they are effective. The ALCOVE project (2011-2013) established a European network where knowledge on dementia could be shared and developed a series of recommendations for improving dementia care and quality of life across Europe. A particular strand of research within the project on timely diagnosis of dementia led by Worcester's Association for Dementia Studies has already stimulated policy debate on this issue in the UK and elsewhere in Europe, while a 'toolbox' developed through the project for those living with dementia and their carers and for health and social care professionals has informed care practice.</p> <p>2. Underpinning research</p> <p>ALzheimer's COoperative Valuation in Europe (ALCOVE) was a Joint Action under the EU Health Programme which set out to produce evidence based recommendations for policy makers on dementia in four key areas: epidemiological data; timeliness of diagnosis; rights, autonomy and dignity; support systems for those living with behavioural and psychological disorders. The Association for Dementia Studies (ADS) led by Professor Dawn Brooker (2009-present) with Dr Simon Evans (2011-present) and Jenny LaFontaine (2009-13) successfully tendered in December 2011 to lead the work package focused on timeliness of diagnosis (Grant a).</p> <p>The research aimed to compare national recommendations for the diagnosis of dementia in order to develop a common definition with associated operational criteria; and to evaluate diagnostic systems in EU member states in order to formulate recommendations for improving diagnostic practice, both in ambulatory and in nursing home settings. A survey of health professionals across 27 EU member states was undertaken to identify who makes the diagnosis, how diagnosis is made, the provision of services following diagnosis, the availability of training and guidance on dementia diagnosis for health professionals, and the relationship between practice and official guidelines. Alongside this, the research team completed a review of scientific literature, policy documents and guidelines to establish in particular how diagnosis was classified across member states, the varying criteria for diagnosis, the timing of diagnosis and the care and support processes associated with diagnosis.</p> <p>The research found that recent advances in technical aspects of diagnosis have changed what is commonly understood by early diagnosis. The literature suggests it is desirable to have access to diagnosis <i>at a time</i> when people can use this information to make sense of what is happening to them, to support them in making lifestyle changes and planning for the future. The term timely diagnosis is used to reflect this approach. The survey suggested that it is also something that many European countries see as important and an area they would like to improve on. It was clear that timely diagnosis needs to be achieved within a context that decreases fear and stigma about dementia; respects the centrality of the rights and wishes of the person with suspected dementia; and recognises that the diagnosis of dementia is a key intervention and that the needs of the person and their family/significant others are central to assessment, diagnosis and post-diagnostic interventions (Ref. 1).</p> <p>Comprehensive evidence based recommendations were subsequently developed for timely detection, the diagnostic process, complex diagnoses, response to early cognitive changes and the work-force. These included the following:</p> <ul style="list-style-type: none"> • timely diagnosis of dementia should be person-centred, available to all citizens who require it and accessible to all sections of the community at a stage when people first notice changes in cognitive function • the diagnostic process should support positive adjustment, provide an evidence based

Impact case study (REF3b)

assessment and enable care planning to take place following diagnosis

- a consensus is required on how early cognitive changes (currently described as Mild Cognitive Impairment) should be responded to in clinical practice
- workforce development is required at all levels to facilitate timely detection, evidence based assessment and diagnosis and to facilitate good adjustment.

3. References to the research

1. Brooker, D., La Fontaine, J., Evans, S., Bray, J. & Saad, K. (2013). *Timely diagnosis of dementia. Recommendations to improve early diagnosis & care of Member States.* [http://www.alcove-project.eu/images/synthesis-report/ALCOVE_SYNTHESIS_REPORT_WP5.pdf]

Grants

- a) Brooker D, Evans, S and La Fontaine, J. Comparison and recommendations for best practice in improving early diagnosis for people with dementia across European Union member states. Department of Health/EU Health Programme. 2011-13. £148,715.

The University is confident the underpinning research meets the excellence threshold. Ref.1 is the final report of the funded project, funding for which was won through competitive tender. The University contends that this is indicative that it meets the 2* quality threshold.

4. Details of the impact

ALCOVE aimed to enhance the wellbeing of persons with dementia, by increasing knowledge and understanding of dementia and developing preventive and care recommendations for health care policy and practice across Europe. The ADS recommendations can be used by policy makers and influencers across the EU to improve timely diagnosis and to benchmark progress at a local, national and European level in the key areas of timely detection, the diagnostic process, complex diagnoses, response to early cognitive changes and work-force. Although it is too early to state how far these recommendations will change policy across EU member states, the outcomes of the project have already begun to stimulate policy debate. Further, the associated development of a 'toolbox' aimed at limiting the use of antipsychotics in dementia care has begun to inform care practice.

A comprehensive communication strategy for the project was established from the outset. ALCOVE circulated a periodic newsletter directly to 4,000 key decision makers across member states. ADS presented its work in progress in a number of contexts: for example, at Alzheimer Europe's Annual Conference in Vienna, Austria (4-6 October 2012) which included representatives from a number of Europe's national Alzheimer associations; and at two lunch debates in the European Parliament. A final symposium was held in Paris in March 2013 to report the results of the project to an audience consisting of government ministers (or their representatives) from 23 EU Member States, as well as senior figures from organisations such as WHO and OECD. In total, ALCOVE research findings were disseminated in 51 separate instances through a variety of different means.

Further, ADS sought to engage both policy/decision makers and direct beneficiaries in the research process. For example, the project steering group consisted of: Professor Alistair Burns, National Clinical Director for Dementia; Jerry Bird, project manager at the Department of Health for the implementation of the National Dementia Strategy; and Dr Karim Saad, Regional Clinical Lead for Dementia, NHS West Midlands; whilst a reference group, consisting of people with dementia, family carers, health and social care professionals, were involved in the iterative process of reflection, clarification and verification throughout the research.

ADS's research has fed directly into UK policy debate on dementia. Professor Brooker is a member of the NHS England-BMA Timely Diagnosis of Dementia Consensus Group. At its meeting in July 2013 it recognised the importance of the ALCOVE evidence in creating a consensus on timely diagnosis (**Source A**). It also highlighted the importance of the terminology of "timely" as opposed to "early" diagnosis, as timely emphasised that benefit would accrue from the diagnosis. This significant distinction has elsewhere been identified by the project manager for the Dementia

Impact case study (REF3b)

Policy Team as a key contribution to this debate (**Source B**).

ADS's research has also had impact on policy in a European setting, in particular through work with Alzheimer Europe, the European umbrella organisation of national Alzheimer associations. ADS worked closely with Alzheimer Europe during the ALCOVE project as it was simultaneously carrying out a project to review national dementia strategies and policies with a particular focus on recommendations in the field of diagnosis and treatment of Alzheimer's disease and other forms of dementia. This collaboration is reflected in the resulting *Dementia in Europe 2012 Yearbook* on national policies, an important resource for policy makers across Europe (**Source C**). The ALCOVE project is also referenced in the evaluation of France's Alzheimer Strategy 2008-12, wherein the importance of the project's outcomes going forward are highlighted (**Source D**).

Another key product of the project was a 'toolbox' designed to limit the use of antipsychotics in the treatment of dementia (**Source E**). The toolbox is an information-exchange platform which includes tools & feedback to facilitate benchmarking and the implementation of public health actions relating to the use of antipsychotics. A specific toolbox was developed around timely diagnosis which, in particular, emphasises the central importance of timely diagnosis in limiting the later use of antipsychotics. An evaluation undertaken at the final symposium highlighted the immediate value of the toolbox, not only to those living with dementia and their carers but also to health and social care professionals and policy makers.

5. Sources to corroborate the impact

- A. Burns, A. & Buckman, L. (2013) *Timely diagnosis of dementia: Integrating Perspectives, Achieving Consensus. Report of the Timely Diagnosis of Dementia Consensus Group Meeting July 2013.*
(http://www.dementiaaction.org.uk/assets/0000/3808/NHS_England_BMA_Diagnosis_Consensus.pdf).
- B. Email from Jerry Bird, Project Manager, Dementia Policy Team, Department of Health, dated 12/7/2013.
- C. Letter from Jean Georges, Executive Director of Alzheimer Europe, dated 20/8/2013.
- D. Ankri, J. & Van Broeckhoven, C. (2013) *Evaluation du Plan Alzheimer 2008-2012.*
(<http://www.alzheimer-europe.org/content/download/45040/292604/file/Evaluation%20of%20the%20French%20Alzheimer%20Plan%20-%20June%202013.pdf>).
- E. ALCOVE Toolbox for limiting the use of antipsychotics in the treatment of dementia
(http://www.alcove-project.eu/index.php?option=com_content&view=article&id=47&Itemid=258).