

<b>Institution: King's College London</b>
<b>Unit of Assessment: UoA4</b>
<b>Title of case study:</b> 6: Improving quality of life for people with dementia through early diagnosis and intervention
<p><b>1. Summary of the impact</b></p> <p>King's College London (KCL) research and the engagement of KCL researchers in the process of national policy formation have led to the implementation of early diagnosis for people with dementia. Being diagnosed early and well is one of the most important interventions for people with dementia and their families, ensuring effective interventions can be provided early and throughout the course of the illness. This is the fundamental aim of the Croydon Memory Service Model, initially developed by KCL researchers. KCL research has also featured in patient-focused literature and in reports circulated globally by the World Health Organization and Alzheimer's Disease International.</p>
<p><b>2. Underpinning research</b></p> <p>Dementia, one of the most common and serious disorders in later life, has negative impacts on those with the condition and their carers, with an enormous societal cost. Researchers from Institute of Psychiatry, King's College London (KCL), led by Prof Subrata Banerjee (1992-2012, Professor of Mental Health and Ageing), Prof Martin Prince (1992-present, Professor of Epidemiological Psychiatry) and Prof Martin Knapp (1993-present, Professor of Health Economics), have investigated how to enable better outcomes for people with dementia by creating better services at an earlier stage in their illness for both them and their carers.</p> <p><b>KCL research highlights the dementia burden:</b> The 2007 'Dementia UK' report, produced by KCL researchers and the London School of Economics for the Alzheimer's Society, revealed that there were around 684,000 people with dementia in the UK and that it accounts for nearly 60,000 deaths annually. The prevalence of dementia doubles with every five-year increase – from 5.9% at 75-79 to 32.5% aged over 94 – and an estimated one million people by 2025 will have some form of dementia. Around 63.5% with dementia live in their homes and the total cost per annum for care is an estimated £17.03 billion. Recommendations of the report included making dementia a national priority and developing comprehensive dementia care models and community support (1).</p> <p><b>KCL research highlights the quality of life for carers:</b> Over the last two decades, KCL researchers have also sought to understand the needs for, barriers and facilitators to care for people with dementia. In a study of 100 people with dementia in south London, researchers found a 20-fold protective effect for remaining in the community when having a co-resident carer, most often a spouse. They also found that transition into residential care was associated with lower psychological quality of life (QoL) of the carer and higher ratings of behavioural problems in the person with dementia (2). Two aspects of carer QoL are burden of responsibility and psychological distress and another study, of 280 co-resident spouse carers of people with dementia from 14 EU countries, found both of these persistently high (3).</p> <p><b>KCL researchers set up a novel service for early detection:</b> Dementia care is at its best when people are diagnosed early and interventions set up accordingly. On finding that many people with dementia receive nothing in the way of specialist assessment and care, KCL researchers developed the Croydon Memory Service Model (CMSM). This is a medium cost, high-throughput, high-quality generic model to enable early identification, assessment and diagnosis of dementia alongside provision of medical, psychological and social interventions. This is carried out with a multiagency approach involving health and social services and the Alzheimer's Society. Following introduction of the model to the London Borough of Croydon, 290 consecutive referrals were assessed at 6-month follow-up. They found 95% acceptability, 94% appropriate referrals, 68% referrals with minimal-mild dementia severity, 63% increase in the number of new cases seen and successful engagement with minority ethnic groups. They also found that at 6-month follow-up those referred to the service had decreased behavioural disturbance and increased QoL (4). A further study of the CMSM showed that services should include: provision of broad-based care and assessment; clear communication about diagnosis and care; peer support groups and easy availability of professionally-behaved staff (5).</p> <p>To demonstrate the cost effectiveness of new interventions, KCL researchers developed a model</p>

to examine public and private savings associated with delayed admissions to care homes by commissioning memory services. They found that while new services in England would cost around £220 million extra per year, by Year 10, the estimated savings would be around £245 million if 10% of care home admissions were prevented. With a 20% reduction, the annual cost would, within around 6 years, be offset by the savings to public funds alone (6).

### 3. References to the research

- 1) Knapp M, Prince M, Albanese E, Banerjee S, Dhanasiri S, Fernansez J-L, Ferri C, McCrone P, Snell T, Stewart R. Dementia UK. London, Alzheimer's Society. 2007. [http://www.alzheimers.org.uk/site/scripts/download\\_info.php?fileID=2](http://www.alzheimers.org.uk/site/scripts/download_info.php?fileID=2)
- 2) Banerjee S, Murray J, Foley B, Atkins L, Schneider J, Mann A. Predictors of institutionalisation in people with dementia. *J Neurol Neurosurg Psychiatry* 2003;74(9):1315-16. Doi: 10.1136/jnnp.74.9.1315 (55 Scopus citations)
- 3) Schneider J, Murray J, Banerjee S, Mann A. EURO CARE: a cross national study of co-resident spouse carers for people with Alzheimer's Disease I - factors associated with carer burden. *Int J Geriatr Psychiatry* 1999;14(8):651-61. Doi: 10.1002/(SICI)1099-1166(199908)14:8<651::AID-GPS992>3.0.CO;2-B (160 Scopus citations)
- 4) Banerjee S, Willis R, Matthews D, Contell F, Chan J, Murray J. Improving the quality of dementia care – an evaluation of the Croydon Memory Service Model. *Int J Geriatr Psychiatry* 2007;22(8):782-88. Doi: 10.1002/gps.1741 (33 Scopus citations)
- 5) Willis R, Chan J, Murray J, Matthews D, Banerjee S. People with dementia and their family carers' satisfaction with a memory service: a qualitative evaluation generating quality indicators for dementia care. *J Mental Health* 2009;18(1):26-37. Doi: 10.1080/09638230701529681 (8 Scopus citations)
- 6) Banerjee S, Wittenberg R. Clinical and cost effectiveness of services for early diagnosis and intervention in dementia. *Int J Geriatr Psychiatry* 2009;24(7):748-54. doi: 10.1002/gps.2191 (22 Scopus citations)

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### 4. Details of the impact

**KCL research impacts on the National Dementia Strategy:** The case for, and implementation of, early, effective diagnosis and intervention for people with dementia and their carers has been supported by KCL data. It is at the core of the 2009 National Dementia Strategy (NDS) for England. As a Senior Professional Advisor to the Department of Health (DH) (2006-10) Prof Banerjee was intimately involved in the production of this strategy. The NDS report sets out a number of ambitions and cites seven key documents that it aims to build on, including KCL's Dementia UK report, which it uses to highlight the number of people living with dementia and service costs. The NDS also cites Banerjee et al. 2007, 2009 when stating that "the evidence...points strongly to the value of early diagnosis and intervention to improve quality of life and to delay or prevent unnecessary admissions into care homes." It also refers to the Croydon Memory Service Model (CMSM) to show that "a 'spend to save' approach...can both increase the quality of care and save hundreds of millions of pounds...over a 10-year period" (1).

The development of the NDS was stimulated by a highly critical 2007 National Audit Office (NAO) report, which, in establishing that dementia represents a significant and urgent challenge to health and social care, took as its starting point the evidence from KCL's Dementia UK report (2a). Prof Banerjee was an expert witness to the 2008 Government Public Accounts Committee considering service development for dementia care in the context of the NAO report. Their development document details Prof Banerjee's oral evidence and utilises the Dementia UK report when providing background information on the unmet need for service improvement (2b). Subsequently, the DH published the 2008 report 'Transforming the quality of dementia care' that provides a summary of best evidence and priorities for change and says how the Dementia UK publication "has given us clear estimates of the number of people with dementia now, as well as projections of future growth." It also utilises the CMSM and cites several KCL papers when proposing specialist memory assessment for all new cases; commissioning of a single point of referral for diagnosis in each area; simple referral processes, rapid response and immediate and direct provision of

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treatment and support (2c).

**KCL research affects Government policy:** The Croydon Memory Service Model (CMSM) has been used by a number of DH follow-on documents to the NDS. The 2009 Impact Assessment of the NDS, which aimed to investigate possible consequences of a range of actions, stated that their estimation of the development of memory clinics nationally was based on CMSM evaluation (3a). Their '**Joint Commissioning Framework for Dementia**' report used the CMSM as an example of best practice and cites Banerjee et al. 2003 when discussing the role of the carer in people with dementia (3b). Subsequently, early diagnosis and intervention was one of only two NHS areas given increased priority by the incoming coalition government. As such, extra money was given to Primary Care Trusts for dementia services as part of their annual revenue allocation in 2009/10 and 2010/11. An NHS Information Centre report suggests widespread new investment in and **uptake of memory services in England with the establishment of at least 447 memory services** in this period (3c).

To investigate whether suggested NDS changes were being implemented, a 2012 All-Party Parliamentary Group on Dementia report discussed both the personal and societal need for early intervention, using written evidence and oral reports from KCL experts. Report recommendations include that "public health directors ... should make early dementia diagnosis a priority;" that "commissioners should invest in appropriate memory service resources" and that "adequate information and one-to-one support should be provided to patients and their families immediately following diagnosis." KCL research was used to provide background information regarding the financial benefits of early diagnosis in delaying admission to hospital and to care homes (3d).

**KCL experts provide guidance on setting up memory services:** In 2011 Prof Banerjee chaired the DH group to deliver detailed commissioning guidance on the contracting of memory services. Here, the CMSM was endorsed, enabling this network of services to be further maintained and model fidelity improved. This Dementia Commissioning Pack aims to "bring together... a range of tools, templates and guidance in order to make the process of commissioning easier" (4a). A key document in the pack cites KCL's Dementia UK report when discussing current and predicted numbers of people with dementia and cost of services. It references Banerjee et al, 2009 when discussing that "the benefits of commissioning a memory service for the early identification and care of people with dementia include...reducing total care expenditure by delaying the time to nursing home admissions and other costly outcomes" (4b).

A central feature of the 2012 Prime Minister's challenge on dementia is a requirement for a quantified ambition for improving diagnosis rates across the country, underpinned by robust local strategic plans, commissioning and service improvement. In 2012, the DH commissioned NHS South of England to produce a new model for understanding prevalence with Prof Prince as technical consultant for the project. The resulting NHS Dementia Prevalence Calculator online tool uses prevalence data from KCL's Dementia UK report applied at the small area level, accounting for local factors, to generate estimates of numbers of people with dementia at general practice level, then aggregated to Clinical Commissioning group, Local Authority and Local Area teams. These are then compared against numbers of cases recorded on the Quality Outcomes Framework data. The national dementia diagnosis rate (currently 46% diagnosed, hence a diagnosis gap of 54% lacking a formal diagnosis) is published annually through the NHS Information Centre. **The tool, informed by KCL research, is now a central plank of the Government's strategy** to benchmark, and set trajectories for improvement in diagnosis rates (4c).

**Wider reach of KCL research:** KCL work has also been used to educate people beyond those in government and health services. The Alzheimer's Society, a UK organisation with 20,000 members, highlights the CMSM calling it 'a model service' (5a). Both the **2011 World Alzheimer Report on 'The benefits of early diagnosis and intervention'** (5b) and the **2012 World Health Organization (WHO) dementia report** (5c) make use of KCL research and are co-authored by Prof Prince. They discuss the CMSM and utilise Banerjee et al. 2007, when highlighting the need for "effective coordination between primary and secondary specialist care services...to ensure

accurate early diagnosis and access to appropriate early and continuing care.” They also quote from Banerjee et al. 2009 when discussing “the value of early diagnosis and intervention in delaying or preventing transitions into care homes” and utilise these papers to highlight the potential costs and savings of care using the CMSM. The World Alzheimer Report cites the Dementia UK paper when discussing concerns about the growing incidence of dementia and the WHO report calls this paper “the most sophisticated analysis of dementia subtype”, using it to illustrate the rising prevalence of dementia and gender differences in incidence. They also refer to Schneider et al. 1999 when discussing spousal carers and Banerjee et al. 2009 when illustrating an “invest to save” approach to dementia care.

**5. Sources to corroborate the impact**

**1. Living well with dementia: a national dementia strategy** 2009 (pgs 16, 34-36, 77, 94):

[https://www.gov.uk/government/uploads/system/uploads/attachment\\_data/file/168220/dh\\_094051.pdf](https://www.gov.uk/government/uploads/system/uploads/attachment_data/file/168220/dh_094051.pdf)

**2. Development of the National Dementia Strategy**

a) NAO. Improving Services and Support for People with Dementia. 4 July 2007:

<http://www.nao.org.uk/wp-content/uploads/2007/07/0607604.pdf>

b) House of Commons Public Accounts Committee. Improving services and support for people with dementia. 2008. (pgs 7,8 and Ev1 from p 21).

<http://www.publications.parliament.uk/pa/cm200708/cmselect/cmpublicacc/228/228.pdf>

c) DoH. Transforming the quality of dementia care: consultation on a national dementia strategy. 2008. (pgs 9, 18, 19, 34-36, 67, 73, 74, 78-83).

[http://webarchive.nationalarchives.gov.uk/20130107105354/http://www.dh.gov.uk/prod\\_consum\\_dh/groups/dh\\_digitalassets/documents/digitalasset/dh\\_085567.pdf](http://webarchive.nationalarchives.gov.uk/20130107105354/http://www.dh.gov.uk/prod_consum_dh/groups/dh_digitalassets/documents/digitalasset/dh_085567.pdf)

**3. Outcomes of the National Dementia Strategy**

a) DoH. Living Well With Dementia: impact assessment. 2009. (pg 12).

[https://www.gov.uk/government/uploads/system/uploads/attachment\\_data/file/168223/dh\\_094055.pdf](https://www.gov.uk/government/uploads/system/uploads/attachment_data/file/168223/dh_094055.pdf)

b) DoH. Joint commissioning framework for dementia 2009. (pgs 24, 32).

<http://www.rcpa.org.uk/MyFiles/Files/Jun%2009%20-%20DoH%20Joint%20Commissioning%20Framework,%20National%20Dementia%20Strategy.pdf>

c) NHS Information Centre for Health and Social Care. Establishment of Memory Services - Results of a survey of Primary Care Trusts, final figures, 2011.

<https://catalogue.ic.nhs.uk/publications/mental-health/surveys/est-mem-serv-res-surv-pct-fin-2011/est-mem-serv-res-surv-pct-fin-2011-rep.pdf>

d) All-Party Parliamentary Group. Unlocking Diagnosis: The key to improving the lives of people with dementia. 2012. (pg 15). (n.b: Banerjee et al. 2009 is quoted as DoH 2009a publication).

[http://www.alzheimers.org.uk/site/scripts/download\\_info.php?fileID=1457](http://www.alzheimers.org.uk/site/scripts/download_info.php?fileID=1457)

**4. KCL experts provide guidance on setting up memory services**

a) DoH. Dementia Commissioning Pack. 2011. (pgs 7, 27).

[http://webarchive.nationalarchives.gov.uk/20130107105354/http://www.dh.gov.uk/en/Publicationandstatistics/Publications/PublicationsPolicyAndGuidance/Browsable/DH\\_127388](http://webarchive.nationalarchives.gov.uk/20130107105354/http://www.dh.gov.uk/en/Publicationandstatistics/Publications/PublicationsPolicyAndGuidance/Browsable/DH_127388)

b) Case for change – memory service for people with dementia. Evidence. (pgs 6, 7, 10).

[http://webarchive.nationalarchives.gov.uk/20130107105354/http://www.dh.gov.uk/prod\\_consum\\_dh/groups/dh\\_digitalassets/documents/digitalasset/dh\\_128580.pdf](http://webarchive.nationalarchives.gov.uk/20130107105354/http://www.dh.gov.uk/prod_consum_dh/groups/dh_digitalassets/documents/digitalasset/dh_128580.pdf)

c) NHS England. Dementia Prevalence Calculator; Introduction to the online tool for improving dementia diagnosis and diagnosis pathways. 3<sup>rd</sup> Edition, April 2013:

<http://www.dementiapartnerships.org.uk/archive/wp-content/uploads/DPC-introduction-v3.pdf>

**5. Wider reach of KCL research**

a) Alzheimer’s Society. Living with Dementia. A model service. February 2009:

[http://www.alzheimers.org.uk/site/scripts/documents\\_info.php?documentID=853](http://www.alzheimers.org.uk/site/scripts/documents_info.php?documentID=853)

b) Prince M, et al. Alzheimer’s Disease International. World Alzheimer Report. The benefits of early diagnosis and intervention. 2011. (pgs 10, 16, 18, 29, 60, 62)

<http://www.alz.co.uk/research/WorldAlzheimerReport2011.pdf>

c) World Health Organization Dementia report. Dementia. A public priority. 2012. (pgs 20, 24, 28, 69, 91). [http://apps.who.int/iris/bitstream/10665/75263/1/9789241564458\\_eng.pdf](http://apps.who.int/iris/bitstream/10665/75263/1/9789241564458_eng.pdf)