

<b>Institution: University of the West of England, Bristol</b>		
<b>Unit of Assessment: 20</b>		
<b>Title of case study: Enabling people to live well with dementia through effective post-diagnosis support</b>		
<b>Period when the underpinning research was undertaken: 2012 – 2019</b>		
<b>Details of staff conducting the underpinning research from the submitting unit:</b>		
<b>Name(s):</b>	<b>Role(s) (e.g. job title):</b>	<b>Period(s) employed by submitting HEI:</b>
Richard Cheston	Prof of Dementia Research	2012 – present
Emily Dodd	Trial co-ordinator	2012 – present
Subitha Baghirathan	Research Associate	2016 – 2018
Richard Gray	Prof of Mental Health	2012 – 2015
<b>Period when the claimed impact occurred: 01.08.2013 – 2020</b>		
<b>Is this case study continued from a case study submitted in 2014? No</b>		
<b>1. Summary of the impact</b>		
<p>University of the West of England (UWE) research produced the only dementia support programme which focuses on adjustment to the condition, and which is now used in memory clinics throughout the UK. The '<i>Living well with Dementia</i>' course, based on UWE research, is unique in being aimed specifically at people living with dementia in the community, and promotes adjustment through greater professional understanding and more effective interventions which encourage users to talk about their illness with partners and others. The course is now used in one in ten UK memory clinics, as well as in Ireland and Italy, and has reached over 7000 people with dementia.</p> <p>Locally-focussed exemplar interventions in Bristol have demonstrated how dementia services can be made significantly more accessible. Responding to the research, new training and inter-agency partnerships have reduced stigma, transformed access and enhanced care, especially within Black Asian Minority Ethnic (BAME) communities.</p>		
<b>2. Underpinning research</b>		
<b>Adjustment to dementia</b>		
<p>Ten years ago, most services for people living with dementia focused exclusively on making a diagnosis, and, in the absence of effective treatment, failed to support people's subsequent adjustment to the condition. Health care staff, while aware of the need to provide social support, often lacked the necessary skills. UWE research produced the only structured dementia support programme that can be delivered by a wide range of professionals and which specifically focusses on adjustment to living with dementia. UWE's Professor Cheston led the first UK trial of a psychotherapeutic intervention for people living with dementia (<b>R1</b>), and adapted this into the <i>Living Well with Dementia</i> course or '<i>LivDem</i>' - a 10-week intervention to help people recently diagnosed with dementia to talk more openly about their illness (<b>R2</b>). Since the initial trial of <i>LivDem</i>, the team at UWE have continued to refine the intervention. Cheston led a review of the evidence (<b>G1, R3</b>) which identified how couples' relationships at diagnosis might impact on outcomes later in the illness. A series of qualitative studies have identified psychological processes affecting discussion of dementia amongst couples (<b>R4</b>). This research has been integrated into the <i>LivDem</i> manual.</p>		

**Access to services**

Support services for people living with dementia are typically provided in health care settings such as memory clinics. People from some communities struggle to access such specialist support and are consequently at risk of being marginalised or excluded. In 2012, UWE's Professor Gray was commissioned by health and social care managers (**G2**) to evaluate two separate pilot studies in which memory services were provided in GP surgeries; which are closer to the people who use them (**R5**). Using innovative participatory research approaches, this programme of work concluded that nurses based in the community played pivotal roles in both facilitating access to services within the community and ensuring that services were acceptable to stakeholders.

Following this study, Professor Cheston was commissioned by Bristol City Council in 2015 (**G3**) to identify gaps in community dementia services and establish the dementia needs of three Black Asian Minority Ethnic (BAME) communities in Bristol. Using innovative methodological approaches, the team was able to reach out to a wide range of potential study participants. For example, the team visited local barbershops to interview African-Caribbean men to ensure that they gathered reliable evidence from all sections of these communities. The research identified that there were three main causes of non-uptake of statutory services: lack of awareness, resources and training for health and social care staff when supporting people with dementia from ethnic minorities; lack of awareness of dementia specifically amongst BAME communities and a reluctance to engage with services when these were viewed as not being intended 'for us' (**R6**); and lack of research-informed guidance at the policy and planning level.

The report to Bristol City Council recommended improved training for GPs on the needs of people living with dementia from BAME communities, and dementia awareness training for staff working for BAME voluntary and community groups. It also highlighted the need for better awareness about dementia within communities and genuine partnership working across voluntary and statutory services. Further funding from the Avon Primary Care Research Collaborative (**G4**) has enabled continued monitoring of access to dementia services by people from BAME communities.

**3. References to the research**

**R1** Cheston, R., Jones, K. and Gilliard, J. (2003) Group Psychotherapy and People with Dementia, *Aging and Mental Health*, 7 (6), pp 452-461.

<https://doi.org/10.1080/136078603100015947>

**R2** Marshall, A., Spreadbury, J., Cheston, R., Coleman, P., Ballinger, C., Mullee, M., Pritchard, J., Russell, C. and Bartlett, E. (2015) A Pilot Randomised Control trial to compare changes in quality of life for participants with early diagnosis dementia who attend a "Living Well with Dementia" group compared to waiting list control, *Aging and Mental Health*, 19 (6), pp 526-535, <https://doi.org/10.1080/13607863.2014.954527>

**R3** Edwards, H., Whiting, P., Ijaz, S., Leach, V., Richards, A., Cullum, S., Cheston, R. and Savović, J. (2018) Quality of family relationships and outcomes of dementia: a systematic review, *BMJ Open*, 8:e015538. <http://dx.doi.org/10.1136/bmjopen-2016-015538>

**R4** Lishman, E., Cheston, R. and Smithson, J. (2016) The Paradox of Dementia: meaning making before and after receiving a diagnosis of dementia, *Dementia: the International Journal of Social Research and Policy*, 15 (2), pp 181-203.

<https://doi.org/10.1177%2F1471301214520781>

**R5** Dodd, E., Cheston, R., Fear, T., Brown, E., Fox, C., Morley, C., Jefferies, R. and Gray, R. (2014) An evaluation of Primary Care Led Dementia Diagnostic Services in Bristol, *BMC Health Services Research*, 14:592. <http://dx.doi.org/10.1186/s12913-014-0592-3>

**R6** Baghirathan, S., Cheston, R., Hui, R., Chacon, A., Shears, P. and Currie, K. (2018) A grounded theory analysis of the dementia experiences of people from three BME communities: balancing the need for support against fears of being diminished, *Dementia: the International Journal of Social Research and Policy*, 19(5), pp 1672-1691. <https://doi.org/10.1177%2F1471301218804714>

### Evidence of the quality of the supporting research

**G1** Cheston, R. *LIVDEM in primary care*, Avon and Wiltshire Mental Health Partnership Trust, 2013, £7,140.

**G2** Gray, R. *Bristol Dementia Care Pathway*, Bristol NHS Primary Care Trust, 2012 – 2013, £40,385.

**G3** Cheston, R. *Bristol Black and Ethnic Minorities and Dementia (Bristol Public Health)*, Bristol City Council, 2015 – 2016, £19,590.

**G4** Cheston, R. *Primary care led services for people with dementia: does it improve access and support without reducing diagnostic accuracy?* Avon Primary Care Research Collaborative, 2017 – 2018, £18,448.

## 4. Details of the impact

### Improving support after a diagnosis of dementia

In the UK, some 200,000 people are diagnosed with dementia each year. While there is a clear demand for support to help people adjust to their diagnosis, resources are limited. Many people living with dementia do not receive the support that they need and are at risk of being isolated and excluded from the wider community. *LivDem* was created by Professor Cheston to fill this gap in service provision. *LivDem* is directly underpinned by UWE research (**R1**) and is the only post-diagnostic course that is specifically designed for use in health and social care settings.

Since becoming available to use in 2015, *LivDem* has improved care for people with dementia. The manual was followed by a facilitator workbook in 2019 (**S1**), and a website in 2020 ([www.livdem.co.uk](http://www.livdem.co.uk)). Since 2015, over 100 *LivDem* course facilitators have been trained and the *LivDem* course has been used in 10% of UK memory clinics (22 sites), as well as in Ireland (**S2**, **S3**) and Italy (**S4**). Overall, by 2019 the course had helped over 7,000 people with dementia (**S5**, p137-8).

Two surveys of a total of 50 *LivDem* course facilitators have identified *LivDem* as having changed attitudes and working practices among providers of care, and indicated that the course enables people living with dementia to successfully adapt to their condition post-diagnosis (**S5**, pp134, 139-140). One facilitator commented:

*'...this course is invaluable. Being able to meet others in the same situation ... and start to consider how they can move forward is crucial. Carers ... have seen a huge difference in their loved one's responses to their diagnosis too.'* (**S5**, p139).

All of the survey participants agreed that *LivDem* was very important for their clients, with 93% also stating that it was very important for their clients' carers (**S5**, p139).

*LivDem* has had a significant positive impact on people living with dementia and their families. Service evaluations of *LivDem* with 143 people showed significant improvements in average levels of quality of life (37 up from 35 on the *Quality of Life in Alzheimer's Disease* scale) (S5, p4), well-being (17 up from 15 on the *WHO (Five) Well-being Index*) (S5, p4), self-esteem (20 up from 19 on the *Rosenberg Self-Esteem scale*) (S5, pp4, 25), and reductions in burden reported by caregivers (S5, pp26-28). Evaluations of *LivDem* courses in Cornwall, Leeds/Sheffield and Bath with 57 participants in total showed similar benefits for those attending the course (S5, pp42, 47, 69).

Feedback from people with dementia attending the *LivDem* course indicates that it has helped them to talk about their dementia more openly. One person attending a course in Sussex commented: *'I now feel that the best thing to do is to tell friends that you have dementia and not be afraid of it'*. (S5, p10) The course has helped people to develop a new way to approach their dementia and, as a carer of a *LivDem* attendee in Northampton commented:

*'Most importantly the group halted a decline into 'closing down' life, so life is opening up. We are looking at what is possible as opposed to what has been lost'* (S5, p12).

*LivDem* has been cited as an example of good practice in guidance documents of the British Psychological Society, such as the 2014 *Clinical psychology in the early stage dementia care pathway* (S6) and the 2016 evidence briefing *Psychological therapies for people with dementia* (S6). *LivDem* is also cited as an example of good practice by the Irish National Dementia Office in *The Next Steps: Dementia post-diagnostic support guidance* (S2). The Director of Dementia Services Information and Dementia Centre at St James' Hospital, Dublin, who contributed to *The Next Steps*, commented *'the LivDem programme stood out as an exemplar of a properly researched intervention'* (S3).

### **Improving access to dementia services in Bristol**

In 2017, the Bristol BME People and Dementia Research Group reported to the Bristol Health Partners (BHP) on access to dementia services, basing their report on research published in R6 (S7). BHP is a strategic collaboration between the NHS in Bristol, the city council and local universities. In response to the report, the BHP prioritised two distinct areas of change to dementia services (S8): 1) Changes within communities and local services, and increased awareness in Primary Care; 2) BAME-led voluntary community organisations and faith communities.

Drawing on R6, the report stressed the need for better awareness of dementia within BAME communities, highlighting *'a need for clearer messages to be communicated [about dementia] in a range of ways'* (S7, p60) and to develop the role of Community Development Co-ordinators (CDCs) (S7, p63). In response to BHP, Bristol Dementia Well-being Service (BDWS, a partnership organisation between the NHS and the Alzheimer's Society) expanded the reach of CDCs to link local community groups with statutory dementia services (S9), and commissioned a series of films in six different languages to raise awareness of dementia. These films have been included in the [Alzheimer's Europe database of initiatives for inter-cultural support](#).

The report made a series of recommendations about the need to raise awareness about the needs of BAME people with dementia among GPs and NHS interpreters (S7, pp61-62) and among BAME-led voluntary community organisations and faith communities (S7, p66). Funded by the Alzheimer's Society, the BHP working group provided training based on UWE research (R6) to 46 primary health care staff (including 20 GPs) and interpreters working in the six key GP practices with the highest numbers of registered patients from BAME

communities (**S10**). A number of participants indicated that the training would lead to changes in their practice. For example, one GP said she would '*change the questions I ask ... [focussing on] their behaviour rather than their memory*' (**S10**, p13). Other participants highlighted changes in attitude and awareness. For example, another GP referred to '*increased understanding*' of the need to screen BAME patients for dementia (**S10**, p13). The BHP working group also delivered dementia awareness and training sessions based on UWE research (**R6**) to 150 staff and volunteers from BAME-led voluntary organisations, gurdwaras, mosques, temples and churches (**S10**, pp14-15).

The implementation of the report's recommendations (based on **R6**) led to dramatically increased levels of engagement between the Bristol Dementia Well-being Service and people living with dementia from BAME communities. In February 2016, before the report's publication, just 18 people living with dementia from South Asian communities, four people from the Chinese community and 46 people of Caribbean origin were registered with BDWS (**S7**, p15). By November 2019 these figures had increased to 29, seven and 115 respectively (**S11**) – a total increase of over 120%. A recent study comparing BAME referrals to BDWS in 2018/19 with a matched sample of referrals of white people, showed that both groups now receive roughly equivalent levels of assessment and post-diagnostic support (**S9**).

### 5. Sources to corroborate the impact

**S1** Cheston, R. and Marshall, A. (2019) *The Living Well with Dementia course - a workbook for facilitators*. Taylor-Francis: London.

**S2** The Irish National Dementia Office – *The next steps: dementia post-support guidance*.

**S3** Testimonial from the Director of the Dementia Services Information and Development Centre in Dublin.

**S4** Testimonial from a Psychologist at the Primary Care (Clinical Neuropsychology Unit) and the Centre for Cognitive Disorders and Dementias, Vicenza, Italy.

**S5** Collated feedback from NHS trusts implementing *LivDem*, *LivDem* training events and surveys.

**S6** British Psychological Society documents - *Clinical Psychology in the Early-stage Dementia Care Pathway* and *Psychological therapies for people with dementia: evidence briefing*.

**S7** The Bristol BME People Dementia Research Group – *The dementia experiences of people from Caribbean, Chinese and South Asian Communities in Bristol*.

**S8** BME Dementia Research Project Action Plan Working Group – *Progress Report June 2019*.

**S9** Dodd, E., Pracownik, R., Popel, S., Collings, S., Emmens, T. and Cheston, R. (2020) Dementia services for people from Black, Asian and Minority ethnic and white-British communities: does a primary care service provide equity of access? *Health and Social Care in the Community*. <https://doi.org/10.1111/hsc.13167>

**S10** Bristol and South Gloucestershire BAME people and dementia working group *Dementia and the experiences of people from Black and Minority Ethnic communities in Bristol – dissemination of study findings*.

**S11** Bristol Dementia Well-being service *Demographic data (2017-2019) Ethnicity*.