

<b>Institution:</b> University of Bradford		
<b>Unit of Assessment:</b> A3 Allied Health Professions, Dentistry, Nursing and Pharmacy		
<b>Title of case study:</b> Using research into the lived experience of dementia as a foundation for training the dementia workforce.		
<b>Period when the underpinning research was undertaken:</b> 2009 – 2020.		
<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>
Dr Andrea Clapstick	Senior Lecturer	26/09/1994 – Present
Prof Murna Downs	Professor of Dementia Care	01/04/2000-31/12/2020
Dr Sahdia Parveen	Senior Research Fellow	05/08/2013 - Present
Prof Jan Oyeboode	Professor of Dementia Research	01/01/2013 - Present
<b>Period when the claimed impact occurred:</b> 2015 - December 2020		
<b>Is this case study continued from a case study submitted in 2014?</b> N		
<b>1. Summary of the impact</b> (indicative maximum 100 words)		
<p>Feedback obtained from policy makers and implementers, service commissioners and dementia practitioners confirm the reach and benefits of our evidence-based training in dementia awareness and best practice, and the critical value of including stories from those affected by dementia. People with dementia who worked with us to create training content have described the benefits derived from being involved.</p> <p>As a result, our training is underpinned by innovative research into how to hear and authentically record the testimonies of people living with dementia, and research into how to respond to needs for training and education in dementia by the health and social care workforce.</p>		
<b>2. Underpinning research</b> (indicative maximum 500 words)		
<p>The Centre for Applied Dementia Studies at the University of Bradford is recognised for excellence in research, evidence-based practice and patient and public involvement. We pioneered the concept of person-centred care in dementia and raised policy and practice awareness of the importance of maintaining those affected by dementia at the heart of service development and delivery. In 2008 we created a panel of people with living with dementia (<a href="https://www.bradford.ac.uk/dementia/experts-by-experience/">https://www.bradford.ac.uk/dementia/experts-by-experience/</a>) to engage with our research, education, and training and they remain instrumental to our work.</p> <p>This impact case study is concerned with research involving people with dementia conducted by Capstick (Lecturer and then Senior Lecturer) 2009 - 2017, Parveen Post-Doctoral Researcher and then Senior Research Fellow) 2015 - 2019, and Oyeboode (Professor of Dementia Research) from 2015 - 2019 under the leadership of Downs.</p> <p>An early publication by Capstick <b>(1)</b> described how the involvement of people with dementia in dementia education and training must be conducted in an ethical and inclusive manner. A series of small grants obtained by Capstick from 2009 onwards investigated the previously unexplored question of how to hear and record the stories of people living with dementia including their experiences of services <b>(2)</b>. This corpus of work led to funding from the NIHR School for Social Care in 2011. The project identified creative methodologies that can be used to facilitate research with people whose voices are less heard <b>(3)</b>. Research by Oyeboode and Parveen funded by Bradford City Council and the UK Alzheimer's Society from 2015 focussed upon people with dementia who can be marginalised due to heritage and culture. This research</p>		

addressed the way that several minority communities understand dementia and highlighted the need to provide culturally sensitive services (4).

Knowledge from the previously described body of work was applied in research into the training needs of the dementia workforce. The 'What Works' study was funded by Department of Health Policy Research Programme (2015-2017). Surr (University of Bradford, 1998-2015) was the project PI and a member of staff at Bradford at the time of commissioning, with co-applicants Capstick, Parveen and Oyebode. As part of this project Parveen led a national survey of health and social care staff to establish the impact of training and Oyebode led case study research of existing provision, particularly that involving interactive training (5). Capstick facilitated the involvement of a group of people with dementia and their families in the creation of a series of vignettes based upon their lived experiences. This co-design process was carried out with the help of a professional artist who turned the lived experiences of people living with dementia into novel-style storyboards which were then used to evaluate dementia training. As described in (6) study findings defined what the workforce needs for training, and education, and underscored the centrality of personal testimonies from people lived experience of dementia for effective learning.

### 3. References to the research (indicative maximum of six references)

1. Hope K, Pulsford D, Thompson R, **Capstick A** and Heyward T (2007) Hearing the voice of people with dementia in professional education. *Nurse Education Today*, 27 (8): 821-824. <https://doi.org/10.1016/j.nedt.2007.06.005>
2. **Capstick** (2011) Travels with a flipcam; bringing the community to people with dementia through visual technology. *Visual Studies*, 26(2), 142-147. <https://doi.org/10.1080/1472586X.2011.571890>
3. **Capstick A** and Ludwin K (2015) Place memory and dementia: findings from participatory film-making in long-term care. *Health and Place*, 34: 157-163. <https://doi.org/10.1016/j.healthplace.2015.05.012>
4. **Parveen S**, Peltier C. & **Oyebode JR** (2016) Perceptions of dementia and use of services in minority ethnic communities: a scoping exercise. *Health and Social Care in the Community*. <https://doi.org/10.1111/hsc.12363>
5. **Parveen S**, Smith SJ, Sass C, **Capstick A**, Dennison A, **Oyebode J** & Surr, C.A. (2020) The impact of dementia education and training on health and social care staff knowledge, attitudes and confidence: A cross-sectional study. *BMJ Open*. <https://doi.org/10.1136/bmjopen-2020-039939>
6. Surr CA, Sass C, Drury M, Burnley N, Dennison A, Burden S, **Oyebode J**. (2019) [A collective case study of the features of impactful dementia training for care home staff](https://doi.org/10.1186/s12877-019-1186-z). *BMC Geriatrics*. 19(1):175. <https://doi.org/10.1186/s12877-019-1186-z>

### Grant Income

2009 - 2011 **Capstick, A**. Developing the educational use of participatory video with people with dementia. Yorkshire and the Humber Strategic Health Authority. GBP15,000.

2011 - 2012 **Capstick, A**. Arts based approaches to service user involvement with people with dementia. Higher Education Funding Council for England GBP12,500

2011 - 2014 **Capstick, A**. & Chatwin, J. Can participatory video enhance social participation and well-being for people with dementia in long-term care?' NIHR School for Social Care Research. GBP101,000

2014 – 2015 **Capstick, A.** & Ludwin, K. Can participatory video enhance social participation and well-being for people with dementia in long-term care?’ added value funding NIHR School for Social Care Research. GBP4,176

2015 - 2019 **Parveen, S.** Familism, willingness to care and preparedness of current and prospective carers to support a person with dementia. UK Alzheimer’s Society Fellowship GBP225,000.

2015 - 2017 Surr, C., Smith, S., **Parveen, S., Oyebode, J., Capstick, A.,** Dennison, A., Meads, D. & Irving, D. Understanding Effective Dementia Workforce Education and Training: A Formative Evaluation (DeWET Evaluation). Department of Health. GBP450,000.

#### Awards

In November 2015, the University of Bradford received the [Queen’s Anniversary Prize](#) for “for its leadership in developing person-centred dementia care, and for influencing policy and practice in the UK and internationally.”

#### 4. Details of the impact (indicative maximum 750 words)

In 2015 NHS England and Skills for Health published the ‘Dementia Core Skills and Knowledge Framework’ to support development and delivery of dementia education and training to the health and social care workforce. The Framework formed part of national policy: namely the first Dementia Strategy (2009), the Prime Minister’s Challenge on Dementia 2020 (launched 2015) and a mandate from Health Education England to develop dementia practitioners with the right skills and values (2015). Downs was a member of the expert working group that developed the Core Skills Framework.

Health Education England (HEE) work with a community interest programme of IT providers (eIntegrity) to produce polished on-line training products. In 2015 HEE commissioned the Centre for Applied Dementia Studies to work alongside eIntegrity to produce evidence-based dementia training to meet the requirements of the 2015 Framework. Based on our research, we proposed to HEE that content would be greatly enhanced by testimonials from people with dementia, which was accepted.

The Framework was soon revised in recognition of the 2017 NHS England Well Pathway for Dementia, and in 2017 HEE again commissioned the Centre to further develop on-line sessions with a focus upon enabling people with dementia to live well. As before, a body of work was conducted with people with dementia and their family carers to hear, record and integrate their testimonials <https://www.eintegrity.org/e-learning-healthcare-course/dementia.html>. Commissioner views of the value of our work is given in **(A)**.

The refreshed training was launched in 2019 with a call to action to service commissioners and providers **(B)** and are now free to anyone living in the UK. HEE website metrics up to November 2020 and detailed in **(C)** show that more than 22,000 individuals launched sessions and 106,460 modules were completed. Analysis of reach by professional group demonstrates the real need for this training **(C)**. Learner scores **(C)** for modules were between 4.46 and 4.53 (out of 5) demonstrating that needs are being met. Free text learner feedback included **(C)**; when referring to the module on dementia awareness a learner said, “an excellent course, made me think about dementia in a new light”. Regarding the module on communication, interaction and behaviour in dementia care, another wrote “Has really improved my understanding, not only in relation to people with dementia but more generally”. The authenticity of this data is confirmed in **(D)**.

A recent brief survey of English NHS Trust training units confirmed that some are encouraging use of the modules; e.g. “Yes we do use some of your eLearning modules in our trust and are part of everyone’s online learning”. For others we raised awareness of the training; “The

*organisation doesn't use the E-modules at present- I've just looked through them and I think they are excellent".*

People living with dementia who provided testimonies for training content described receiving significant benefits from their involvement e.g.

*"It's so important for NHS staff to hear our voices to bring reality to their teaching. They may learn facts from textbooks, but to hear the lived experience is far more powerful.....Why do I get involved? Because I know Bradford will do all in its power to do things right. Simple as that. Their passion for inclusion is plain for all to see in all aspects of dementia..... What do I get out of it? Well the feeling of being allowed to be heard, of being valued".* Further narratives are provided in (E).

Through eIntegrity the modules have global reach e.g.by Jersey Hospice Care in 2020. eIntegrity are keen to continue working with the Centre to enable module reach across Asia (F).

Research informed face to face training including testimonials from people with dementia has been delivered to significant UK care providers e.g.to Methodist Homes (the largest UK charitable care provider) in 2018/19. Evaluation of this training identified a large positive shift in staff knowledge regarding residents' feelings. The manager of one of the participating homes, interviewed in March 2021 reported that staff had received "*immense benefits*" and that "*care plans had been changed to be person-centred*" (G,H).

Another example was with Home Instead, a large UK home care franchise. The Centre was commissioned to redesign their dementia training in 2017 with a focus upon the lived experiences of people with the condition. Refreshed quality standards state that 50% of all carers should receive this training going forwards.

#### **5. Sources to corroborate the impact** (indicative maximum of 10 references)

A. Testimonial letter from National Programme Lead – Advancing Practice, Allied Health Professions, Dementia and End of Life Care Health Education England.

B. Letter to NHS providers giving information about HEE on-line dementia training and encouraging use.

C. Website metrics provided by HEE to the Centre for Applied Dementia Studies.

D. Letter from HEE England confirming the authenticity of website metrics

E. Documented accounts of verbal testimonials received from people with dementia (Experts by Experience), who participated in creating videos for HEE training materials.

F. Corroborator: Consultant for e-Integrity who if contacted, has agreed to explain how the HEE training modules are being marketed globally

G. Summary of evaluation of training delivered to Methodist homes, including views of participating care home staff.

H. Corroborator: Dementia Lead, Methodist Homes, who, if contacted will provide further details of the impact of training upon care home staff.