Institution: University of St Andrews

Unit of Assessment: A4 – Psychology, Psychiatry and Neuroscience

Title of case study: CIRCA – a novel technology to support people with dementia

1. Summary of the impact (indicative maximum 100 words)

CIRCA, *Computer Interactive Reminiscence and Conversation Aid*, is a novel touchscreen computer system designed to support conversation between people with dementia and their caregivers. CIRCA was based on research into the memory and communicative problems of people with dementia. The beneficiaries of this research are: **i) practitioners and professionals in healthcare services**, who have improved training and caregiving relationships – a total of 46 NHS, third sector and private care organisations from across the UK have installed CIRCA since 2009; and **ii) people with dementia**, who have enhanced social interactions and quality of life.

2. Underpinning research (indicative maximum 500 words)

The research underpinning CIRCA was conducted by Prof. Arlene Astell (appointed to the School from 2001-13), Dr Barbara Dritschell (appointed from 2000 onwards) and an EPSRC-funded research assistant/PhD student, Maggie Ellis (2002-07, 2008-09), who continued this work in the School as a postdoctoral researcher, funded by the Alzheimer's Association and the Technology Strategy Board (2009-13), and is now employed as a fellow in the School.

Astell, Dritschel and Ellis conduct research on *autobiographical memory*, defined as the memory system that stores and retrieves specific episodes and events in an individual's life. Auto-biographical memories are based on a combination of biographical information and personal, episodic memories, alongside more general, semantic memories about the external world. Such memories are important in developing and maintaining social bonds, as sharing memories can promote personal relationships and reminiscing can promote positive social interactions.

The research has shown that performance on autobiographical memory tasks is impaired in a number of psychological disorders. For example, individuals with depression exhibit difficulties in retrieving specific autobiographical memories (Drummond et al., 2006), and individuals with Asperger Syndrome retrieve fewer specific memories, and take longer to retrieve these memories, than control subjects (Goddard et al., 2007). People with dementia also typically suffer from a loss of short-term autobiographical memory, while retaining long-term memories, and find it easier to talk about the past rather than recent events.

The researchers hypothesised that deficits in autobiographical memory play a significant role in others' perceptions of the loss of a sense of self in dementia. By countering these memory deficits, the researchers reasoned that perceptions of people with dementia would be enhanced, and social relationships with others would be improved. Ellis developed the 'Collaborative Personhood Model', which predicted that facilitating communication with social partners would have positive impacts on self-image and personhood in people with dementia.

To test this model, the researchers used photographs to prompt conversations between people with dementia and their interaction partners, and examined the impact on self-image and personhood. Astell and Ellis (2006) had shown that people with dementia maintain a strong desire to communicate with other people and that many aspects of social

interactions, such as turn-taking, remain intact. In addition, the researchers showed that both people with dementia and their social partners responded positively to the photographic material (Alm et al., 2004). As photographs were presented on a touch-screen computer, people with dementia were able to determine the pace of the conversation and decided which material to view.

People with dementia were found to initiate conversations about the material and were more equal partners in the conversations (Astell et al., 2010). Generic photographs promoted more positive social interactions than personal photographs, as people with dementia were not always able to identify people in personal photographs. Importantly, the research established that imitation between social partners and people with dementia, and supportive communication techniques, such as adapting to both verbal and nonverbal cues, enhanced awareness of self and personhood, even in individuals with severe dementia.

The researchers took their computer-based research tool and developed it into a system for presenting multimedia reminiscence material – photographs, videos and music – to people with dementia, in collaboration with computer scientists and design experts at the University of Dundee (Norman Alm and Garry Gowans). The resulting CIRCA system arose directly from their research on autobiographical memory and provided a tool that could enhance communication between people with dementia and their caregivers in healthcare settings. The system allows the person with dementia to choose from a range of subjects from the past, thereby facilitating their retained long-term memory and providing prompts for successful conversations.

The researchers worked with practitioners in a major care home provider, *Sanctuary Care*, during in the development of the CIRCA system, which was launched as a commercial product in 2009. The researchers and practitioners jointly devised protocols for successfully introducing and maintaining CIRCA into daily practices in care homes. In 2009, funding from Sanctuary Care allowed trials of CIRCA in care homes to examine issues relating to the introduction and adoption of CIRCA. This research contributed to the subsequent development of a training programme, *Dementia Gold*, launched by Astell and Ellis in 2012. The training programme provides practitioners with both hands-on experience of the CIRCA system and research-led training in how to promote rewarding social interactions and conversations with people at all stages of dementia.

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

Researchers at the University of St Andrews are in **bold**; citations are from *Scopus*.

Alm, N., **Astell, A.**, **Ellis, M.**, Dye, R., Gowans, G., & Campbell, J. (2004). A cognitive prosthesis and communication support for people with dementia. *Neuropsychological Rehabilitation*, 14: 117-134. **Impact factor = 1.7; citations = 37**, doi: 10.1080/09602010343000147.

Astell, A. J. and **Ellis, M. P.** (2006). The social function of imitation in severe dementia. *Infant and Child Development,* 15: 311-319. **Impact factor = 1.2; citations = 9**, doi: 10.1002/icd.455.

Astell, A. J., **Ellis, M. P.**, Bernardi, L., Alm, N., Dye, R., Gowans, G., & Campbell, J. (2010). Using a touch screen computer to support relationships between people with dementia and caregivers. *Interacting with Computers*, 22: 267-275**. Impact factor = 1.2; citations = 24**, doi: 10.1016/j.intcom.2010.03.003.

Drummond, L. E., **Dritschel, B.**, **Astell, A.**, O'Carroll, R. E. and Dalgleish, T. (2006). Effects of age, dysphoria, and emotion-focusing on autobiographical memory specificity in children. *Cognition and Emotion*, 20: 488-505. **Impact factor = 2.4; citations = 24**, doi: 10.1080/02699930500341342.

Goddard, L., Howlin, P., **Dritschel, B.** and Patel, T. (2007). Autobiographical memory and social problem-solving in Asperger Syndrome. *Journal of Autism and Developmental Disorders,* 37:

291-300. **Impact factor = 3.7; citations = 24**, doi: 10.1007/s10803-006-0168-0.

Relevant grants since 2001

EPSRC (2001-2004; *Alzheimer's Scotland* as named partner) '*Multimedia reminiscence experience and conversation support*'; £115,210

EPSRC (2004-2007; *Alzheimer's Scotland* as named partner) 'Living in the moment: developing an interactive multimedia activity system for people with dementia'; £135,142

Alzheimer's Association (2009-2010) '*Prompting to support independence in dementia*'; £85,540

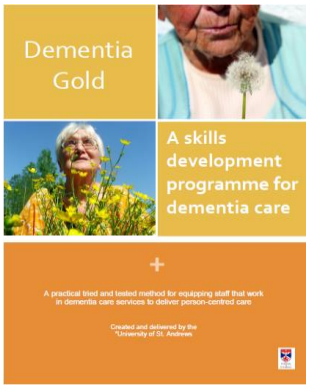
Technology Strategy Board (2011-2013) '*Tackling barriers to adoption of assisted living technology for older adults*'; £226,563

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

The research on collaborative communication between people with dementia and interaction partners, which led to the development of CIRCA, has impacted on: **i) practitioners and professionals in health care services**, who provide an enhanced quality of service as a result of CIRCA and specialist training courses designed by the researchers; and **ii) individuals with dementia**, who have enhanced quality of life and well-being, with concomitant benefits for families.

i) Impact on practitioners and professionals in health care services Astell and Ellis' research has had a positive impact on practitioners and professional practice through: **a) instillation of CIRCA into a broad range of care home settings**, **b) the development and delivery of staff training programmes**, **c) dissemination of the research to professionals and practitioners**, and **d) broader dissemination of the research to the general public**.

a) ***Instillation of CIRCA into care home settings*** CIRCA was initially commercialised in October 2009 through a non-exclusive licensing agreement between the Universities of St Andrews and Dundee with *Dementia Life*, a newly formed company that sold CIRCA to the care home market. The licensing agreement was terminated in December 2010 and the research team established a new company, *CIRCA Connect* (http://www.circaconnect.co.uk). In total, CIRCA units have been installed into **46 care home and dementia care organisations around the UK**; more specifically, the system has been adopted by **12 NHS/Council-run residential care homes or care centres** (e.g., Argyl and Bute Council, Camden Council, Gloustershire NHS Foundation Trust, South London and Maudsley NHS Foundation Trust), **25 private residential care homes** (e.g., Sanctuary Care) and **9 charity/not-for-profit day-care centres or residential homes** (e.g., Age Concern, Alzheimer's Scotland) (Supporting evidence, **S1**). In March 2013, the researchers signed a marketing agreement with *Paul James Contracts Ltd* to supply CIRCA direct to care homes.



b) ***Staff training programme*** In May 2012, Astell and Ellis launched a skills-based staff training programme, *Dementia GOLD*, which they designed for professional caregivers of people with dementia. The training programme is based on their research findings and extensive hands-on experience of communicating with dementia sufferers. The training programme has already been adopted both in the UK (six trainees, Partridge House Care Home, Anchor Trust, Brighton, 2012; **S6**) and in mainland Europe (nineteen trainees, Compassion Alzheimer, Bulgaria, a non-governmental support organisation, 2012; **S2**). The CEO of the organisation in Bulgaria has stated that:

> *'The training has helped the most in creating relationships based on caregivers' tolerance which has … influenced the wellbeing of people with dementia',* and the training '*has also helped the relationships among caregivers to become stronger, caregivers became more sensitive not only towards their clients but towards each other.'* (**S2**)

c) ***Caregiver education*** Since 2008, Astell and Ellis have given numerous invited talks on their

research at practitioner conferences and have spoken at events for family carers and medics, e.g., *Intensive Interaction Annual Conference*, Leeds (2010); *Scottish Caring and Dementia Congress*, Edinburgh (2011); *Dementia Services Information and Development Centre*, St James's Hospital, Dublin (2011) (**S7**). Since 2012, CIRCA has been on display in the *Design and Technology Suite* at the *Dementia Services Development Centre* in Stirling, as an example of technology that can improve the lives of people with dementia, and this Centre receives an average of 200 visitors per month (**S3**). Astell and Ellis have also written articles for publications aimed at practitioners (e.g., **S8**).

d) *Broader dissemination* Further evidence of impact can be seen in the media coverage that the research has attracted both at home and abroad as an aid for families and dementia care providers. The research has been disseminated by news and technology broadcasters (e.g., BBC, **S9**), and the researchers have given public talks and engaged in public debates, e.g., *Alzheimer's Public Debate*, Ninewells Hospital, Dundee, 2011 (**S4**).

ii) Impact on quality of life and well-being of people with dementia The impact of CIRCA on the quality of life and well-being of people with dementia and their families is summed up in the following quote from the Unit Manager of a residential care home, which states that CIRCA has:

> '*helped to restore a sense of dignity and respect to some of our frailest people. They are able to interact more confidently with their loved ones and staff as past experiences and memories are un-locked. It is heartening to observe what appears to be an improvement in self-confidence after sessions with the system*' (**S5**),
>
> and '*the ability to converse with other residents and their families is improved after using CIRCA*', and that CIRCA is a '*useful tool which can help open up conversations and enable [people with dementia] to interact with their loved ones much more freely. This contributes to making visits a much more positive and fulfilling experience for all*.' (**S5**)

For both people with dementia and their caregivers, the benefits of enhanced training are nicely summed up as follows: '*To see residents using it suddenly come alive, and find their own words to express themselves and share memories, is such a reward, for both the carers who want to make conversation and help [people with dementia] to have a better life, and of course their relatives – as they can see them come back to being more like their old selves.*' (**S10**)

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

S1 Written confirmation from Director, CIRCA Connect, of instillation of CIRCA into 46 residential or day-care settings, including the specific examples listed.

S2 Written confirmation from CEO of Compassion Alzheimer, Bulgaria, of the impact of the Dementia Gold training on practioner skills and practices.

S3 Written confirmation from the Library & Information Service Manager, Dementia Services Development Centre, Stirling, that CIRCA is housed at the centre and visitor numbers.

S4 Written confirmation of Astell's participation in public debate from ARUK East Central Scotland Network Centre coordinator of participation in Alzheimer's Public Debate.

S5 Written confirmation of quotes from Unit Manager, Eadar Glinn residential care home, Oban.

S6 Documented evidence of *Dementia Gold* training event at Partridge House Care Home, Brighton.

S7 Event programmes corroborate Astell and Ellis' outreach to professional caregivers.

S8 Example of outreach in a journal aimed at professionals working with people with dementia: Astell, A. J., Alm, N., Gowans, G., Ellis, M., Dye, R., Campbell, J., & Vaughan, P. (2009). Developing technology to meet psychosocial needs. *Journal of Dementia Care*, 17, 36-38.

S9 Evidence of research dissemination in the media, http://news.bbc.co.uk/1/hi/8598208.stm.

S10 Corroboration of quote: http://www.carehome.co.uk/news/article.cfm/id/1558824/residents-with-dementia-come-alive-and-unlock-memories-through-innovative-touch-screen-system