

Institution: University of Westminster

Unit of Assessment: 4 Psychology, Psychiatry and Neuroscience

Title of case study: Connecting the public with the lived experience of pathological memory loss

Period when the underpinning research was undertaken: 2011 - 2020

Details of staff conducting the underpinning research from the submitting unit:

Name(s):

Role(s) (e.g. job title):

Period(s) employed by submitting HEI: 12/1994+

Catherine Loveday

Professor of Psychology Period when the claimed impact occurred: Aug 2013 – July 2020

Is this case study continued from a case study submitted in 2014? ¥/N

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

Prof Catherine Loveday's research has explored how engagement with new camera technologies and collaboration with multi-media artists can create understanding of pathological memory loss. This has resulted in impacts relating to:

- Enhancements to quality of life in sufferers of memory loss via the use of cameras.
- Changes to creative practice and the development of new therapeutic approaches through the advancement of art-science collaborations.

2. Underpinning research (indicative maximum 500 words)

The starting point for this body of work was an intensive research project with a severely amnesic patient, Claire [1]. In the course of this study, Loveday was invited by a team at Microsoft to investigate the efficacy of their SenseCam device within a health context. SenseCam is a wearable camera that automatically takes photos approximately every 20 seconds, or in response to changes in movement and light. Over the course of a month, Claire recorded events daily, both via the SenseCam and through written diary entries. Each weekend her memory was tested for every recorded event, with prompts from either the SenseCam pictures or her own diary entry. Prof Loveday, a neuropsychologist, and her colleague Prof Martin Conway (City, University of London), a cognitive psychologist, demonstrated that the visual data provided by SenseCam cues dramatically increased the number of details Claire could recall, and that this was significantly more helpful than the diary entries she had been keeping. In short, it led to a powerful improvement in her ability to lay down memories and she reports that this has subsequently given her and her family a significantly better quality of life. Loveday and Conway were the first to robustly demonstrate this effect in a patient with amnesia and proposed a novel and specific method for recording and reviewing the photos.

Following on from this study, the researchers entered into an extensive art-science collaboration with artist Shona Illingworth, taking a unique approach to exploring the lived experience of amnesia. Described further in Section 4, this Wellcome Trust funded collaboration provided a distinct and deep insight into the qualitative nature of daydreaming, the experience of continuity, and the role of the imagination in amnesia. An important feature of this collaboration is that Claire herself was actively involved and played an important role in the iterative development of the practical, theoretical and artistic outputs.

By integrating Claire's lived experience into previous experimental work undertaken by themselves and others, Loveday and Conway were able to propose a new conceptual framework, which they termed the modern view of human memory, consisting of two novel elements [2]. The first was that accuracy of memory can be conceptualised along two orthogonal dimensions: coherence, the extent to which a memory is consistent with our sense of self, and correspondence, the objective accuracy of a memory. The researchers argue that coherence is more important than correspondence in terms of an individual having an effective and healthy sense of self. The second concept proposed was that the construction of memories takes place within a Remembering-Imagining System, a window of highly accessible recent events and easily imagined near future events [2], which would be further elaborated in output [3].

The researchers describe this system as a bell-curve of consciousness that moves through time and which underpins our ability to make, act on, and monitor our goals. Crucially, Loveday and Conway demonstrate that this window is significantly reduced in people with amnesia, leading to significant effects on their ability to interact with the world and a profound effect on their sense of self. While these latter ideas were developed through the work with Claire and Illingworth, they were further demonstrated in output [3] via the study of a new participant. An additional feature of



the Remembering-Imagining System is that the memories constructed within it are driven by external and internal cues; a proposition that was shaped by detailed observations of Claire's interaction with the SenseCam.

Loveday has since been able to further develop her work on memory in important new ways. In collaboration with Conway, Loveday has contributed to artist Jill Bennett and programmer Volker Kuchelmeister's development of *Amnesia Atlas* at University of New South Wales (UNSW), Sydney. *Amnesia Atlas* is a 3D immersive browser for viewing photographs taken by SenseCam and is intended to assist memory retrieval in cases of impaired memory. This also formed the basis for a large innovative experimental project supported by the Australia Council, which Bennett is now leading in Sydney, with Loveday as Co-I: *Mnemoscape: a study of digital lifelog images as memory cues*. This major study is the biggest to-date to test lifelog images/visual memory cues of memory retrieval in those aged 65+. Output [4] emerged from this project and involved the trialing of an innovative approach to the review of wearable camera photographs. Embedding such photographs within a virtual landscape that reinstates spatiotemporal context, the study of 46 healthy older adult participants found that wearable camera photographs are an effective support for event memory, regardless of whether they are presented in an experience-approximating format.

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

- [1] Loveday, C., & Conway, M.A. (2011). Using SenseCam with an amnesic patient: Accessing inaccessible everyday memories. *Memory*. 2011 Oct;19 (7):697-704. *Google Scholar [GS] citations:* 72 (31/12/20).
- [2] Conway, M.A. and Loveday, C. (2015) Remembering, imagining, false memories & personal meanings, *Consciousness and Cognition* (33) 574-581. *GS citations: 138 (31/12/20).*
- [3] Conway, Martin A., Loveday, C. & Cole, S.N. (2016) The remembering–imagining system. *Memory Studies* 9.3; 256-265. *GS citations:* 58 (31/12/20).
- [4] Selwood, Bennett, Loveday, Conway, Kuchelmeister (2020) Mnemoscape: Supporting older adults' event memory using wearable camera photographs on an immersive interface. *Gerontology* 66.4: 371–381

Funding

- Wellcome Trust Large Arts Award (Pre-CCGT) 102010/Z/13/Z £130,480 (P-I Ms Shona Illingworth, Co-I Catherine Loveday)
- Australian Research Council/Discovery Projects *Mnemoscape: a study of digital lifelog images as memory cues* DP160102907; 2016 2019, AUD\$149,192. (P-I Jill Bennett, Co-I Catherine Loveday)
- 4. Details of the impact (indicative maximum 750 words)

Impacts on those suffering Memory Loss via the SenseCam Methodology

Loveday's work adapting a SenseCam method with Claire – a patient whose brain damage led her to lose thirty years of memories – had **a direct impact on Claire's quality of life.** Claire now uses these techniques as part of her daily living and states that the SenseCam "gives me a sense of belonging. [...] So many people know so many things about my life, and I haven't any idea whatsoever. But I have these pictures now" [a-i]. In a separate video interview for *Time*, she explains how valuable this collaboration has been for her life: "I've got the memories but the SenseCam fits them back together so that I can relive them. I can't bring back my old memories just like that, but what I *can* do is try to preserve my new memories" [a-ii]. Claire's husband also notes how "she's used them [the SenseCam images] as part of her store of her friends and families, the people she knows, which she previously didn't have" [a-ii]. As indicated, Claire now feels she has a way to restore her quality of life: "I want to manage and go forwards and create my memories into ownership and a sense of belonging to a life that I'm living" [a-ii]. Claire concludes that "my life belongs to me again" [a-ii].

The beneficial impact of Loveday's work with Claire has also expanded its reach to other sufferers of severe and persistent memory loss, and their associated carers and family members. This is because the partnership has both enabled Claire to gain greater insight into her own condition and to widely share her lived experience of amnesia. Claire has spoken about how this technique has helped her at events for others with head injuries, and to broader audiences via radio and two books [a-iii]



Following this initial success, **implementation of the method was scaled up to larger groups of older people who suffer from various conditions affecting their memory**, specifically Alzheimer's Disease and early dementia. The project involved a pilot, undertaken between late 2019 and early 2020, in which an individual who has early Alzheimer's Disease used the alternative Autographer camera in accordance with Loveday's research-based methodology and guidance materials [a-iv]. The approach was to be finessed on the basis of this trial and use of the Autographer camera rolled out to a group of clients at Age UK, Barnet. This would have enabled the individuals to share in the quality of life impact on Clair. However, due to the emergence of COVID-19 and the targeted stakeholders being forced to "shield" during lockdown, the project only completed the pilot phase by the end of 2020.

The Independent Supported Living Facilitator that undertook the pilot attested to how her client, whose early Alzheimer's is such that "her memory for events is usually very impaired – often she will forget she's been anywhere within an hour of getting home", exhibited significant improvements in her memory recall on the basis of the trial: "we found that looking at the Autographer pictures really helped her to recall where she'd been, who she'd chatted to and even some of the thoughts and feelings she'd had" [a-v]. This included recall "even [of] things that weren't visible in the pictures but which I remembered myself to be true" [a-v]. Further, the Facilitator indicates an enhancement of her client's social life through the "really positive experience" of the trial, describing how "she went through the photos with a neighbour" which "led to a lovely connection between them" [a-v].

The Volunteer Manager at Age UK, Barnet, confirms that plans for a further roll out, which would expand this impact on the quality of life of those suffering memory loss, were put on hold by the COVID pandemic: "Given the positive findings from your earlier work we were enthusiastic about trying the cameras out, and our clients were keen to have an opportunity to exercise their day-to-day memory. [...] We are hoping that the Autographer project will not only help to support memory in some of our clients, but will also encourage them to have new and different conversations. I look forward to continuing to work with you on this" [a-vi].

Impacts created through the Lesions in the Landscape Art-Science Collaboration

As a result of her collaborations with Loveday, Claire, and Conway, multi-media artist Shona Illingworth produced a series of highly acclaimed works, collectively titled "Lesions in the Landscape" (2012-16). Illingworth confirms: "Working with Catherine had a **significant impact on my [...] practice as an artist**" as "Catherine's research, neurological insight and expertise transformed my understanding of the consequences of amnesia and the central role of memory in our ability to imagine the future" [b-i].

This synthesis of art and science was fluid, reciprocal and iterative: while the scientific work has informed the art, the artistic methods and outputs have also fed the science, demonstrating the benefits of such art-science collaborations. Samina Zahir of Hybrid Consulting, who conducted an independent evaluation of the project, attests to this: "Clearly, creative collaboration between Illingworth, Conway, Loveday & Claire was core to the programme", with knowledge exchange taking place "in an equal and profound way [by which] particular attention was given to being non-hierarchical, so that **knowledge systems and processes could flow and thereby mobilise new thinking**" [b-ii, p.3-4]. For instance, Illingworth's major three screen video and immersive multichannel sound installation, *Lesions in the Landscape* (2015) – the title piece of the broader series of works – featured artworks created on the basis of Loveday's research (e.g. a 3D model of the lesion of Claire's brain which came from Loveday's data, in this case a brain scan), while the 5 days Claire and the team spent on St Kilda – a remote uninhabited island off the coast of Scotland – as part of the project provided Loveday with extraordinary insight into Claire's experience of amnesia and how she uses SenseCam, which fed into outputs [2], [3], and [4].

Importantly, Illingworth writes that: "Catherine's knowledge and expertise **directly shaped and developed the ethical research methods used in the project** and ensured creative collaboration with Claire maintained her agency throughout" [b-i]. This methodology was also highlighted by Zahir, who writes of the importance of medical professionals being present "to oversee and manage Illingworth's collaboration with Claire", stating that "on St Kilda, Loveday took care of Claire's needs and was sensitive, alongside others, to her personality and limitations" [b-ii, p.7]. Illingworth believes these "new ethical research methods in creative production [...] made a substantial contribution to the success of this interdisciplinary research project" and adds that:



"These research methods and the expertise I gained from working with Catherine continue to inform my research practice and my teaching across artist film and documentary filmmaking" [b-i].

Illingworth further highlights that the collaboration has "opened up new avenues for neuroscientific discourse about amnesia" [b-i], while Zahir writes that the project: "Developed practice-based research methods for working with people with debilitating memory impairment, to gain deeper insight into the experience of memory loss" [b-ii, p.27]. The scientific basis for the artworks, developed through Loveday's research, became the subject of an academic investigation into how such collaborative art-science research can also have a therapeutic effect on those who suffer a range of conditions that affect memory [b-iv]. The collaborative team invited two groups of people with dementia to visit the "Lesions in the Landscape" exhibition when it showed in both Liverpool, UK, and Sydney, Australia. This independent evaluation of how the exhibition might "support shared and distributed memory" found that the artworks created powerful metaphors for the experience of amnesia which opened up new, deeply engaged, dialogue between audiences living with memory impairment and their carers [b-iv]. Describing the participants' response to the exhibition, one of the researchers undertaking this evaluation observed: "they were astonishingly and moving[ly] engaged in Shona's piece [...] They were very aware of the sound and imagery and the emotional qualities of loss and mourning and the sense of desolation in the landscape – the piece was central to this. We realised that we'd found the way for people with moderate dementia to express that response" [b-iii, p.20]. Combining this stimuli of the artwork with the application of the evaluators' own group dialogue method ("Visual Matrix Protocol"), it was found that such combinations "can be used in group care to promote selfexpression, reflection and communication" [b-iv]. This evaluating research team consider this an important clinical impact as "[a]II too often, access to stimuli that elicit the full gamut of human emotions, including negativity, is limited by professionals with welfare concerns who inadvertently restrict potentially transformative experiences" [b-iv].

The art works were reviewed positively in 20+ mainstream media outlets, including science publications such as *The Lancet* [b-v], and the impact of **elevating Illingworth's professional profile as an artist via her engagement with Loveday's concepts** is also confirmed by the extensive reach of the works. Gallery visitors to solo exhibitions of the "Lesions in the Landscape" series (on show in the UK for 32 weeks; 12 weeks internationally) amounted to approx. 23,800 visitors, while individual works from the broader series achieved the following: *Time Present* featured in the "States of Mind: Tracing the Edges of Consciousness" exhibition at the Wellcome Collection, which had 66,374 visitors and online viewers in excess of 100,000; *The Amnesia Museum* had 193,070 attendees; *Searching*, a short film, was seen by 19,766 visitors at Whitechapel Gallery and 86,000 viewers via a Channel 4 broadcast [b-iii, p.65-6].

Impacts created through the Memory of Clothes Art-Science Collaboration

As Zahir notes, institutions such as the Wellcome Trust recognise the increasing importance of the "close integration of arts practice with emerging scientific research [in] providing an interesting methodology of engagement through interdisciplinary forums. In responding to these aims, stakeholders considered Lesions in the Landscape to have had a significant impact" [b-ii, p.17]. This impact on **the furthering of art-science collaborations in an effective way** has been aided by what Illingworth describes as "Catherine's considerable expertise in the public communication of science", which was, for instance, "invaluable in convening international symposia and interdisciplinary forums on the project" [b-i].

"Invisible Architectures", a two-day international interdisciplinary symposium held at the Whitechapel Gallery, brought together leading experts in sociology, mental health, cultural history, archaeology and social psychology, artists, performers, composers, filmmakers and musicians. Attendee feedback included: "We form our ideas collecting and linking different kinds of stimuli - loved the approach"; "It stretched me but also exonerated some thinking I've been exploring"; "in terms of impact on my practice, its (sic) been huge" [b-ii, p.45-6]. An instance of this symposium facilitating further art-science collaboration is demonstrated by its directly leading to Loveday's own engagement with artist <u>Helen Barff</u> and writer <u>Suzy Joinson</u>.

This art-science collaboration resulted in the "Memory of Clothes" exhibition at Worthing Museum in 2019 [c-i]. The art works for this exhibition were developed on the basis of workshops held at care homes with a group of elderly women recalling WW2 memories from their late teens



/ early twenties, as elicited by clothing held at Worthing Museum; this being the research component of the collaboration as led by Loveday.

As with her contribution to Illingworth's work, Barff highlights how Loveday's ability to work empathetically with the subjects of this research has enhanced the artist's own engagement practice: "Her [Loveday's] sharing of this knowledge is never just theoretical, but always striving to find a way that it might have a beneficial social impact, and the ways to do this most effectively. This collaboration has enabled me to build this [approach] more effectively into my practice [...] particularly when working with people with early stage dementia" during the workshops, and subsequently also, having "inspired new inclusive working methods that build connections, e.g. running cross generational workshops. It has opened up new, exciting possibilities for future developments" [c-ii].

This research component of the collaboration "helped secure funding for the project" from the Arts Council for its creative component, i.e. the exhibition of art works created by Barff on the basis of the stories told by the participants, Loveday's analysis of the findings from the workshops and the latter's communication of broader concepts around memory: "Catherine has greatly deepened my knowledge and understanding in this area, particularly in the formation, necessity and function of autobiographical memory as a structure or 'scaffolding' for identity" [...] This, together with all of the other insights I had gained from Catherine, fed into my Memory of Clothes" work. [c-ii] Barff further states that the **impact of this communication of the science of memory on her creative practice is ongoing**: "I now place more emphasis on this in my sculptural work - the memory, or 'narrative' associated with each piece of work is now pivotal to its formation, as if I am reinterpreting each memory in material form" [c-ii].

That the work on "**Memory of Clothes**" has further advanced recognition of the value of art-science collaborations amongst other researchers and creatives is demonstrated by the University of Brighton's Centre for Design History funding a June 2019 study day around the exhibition, enabling its participants – "fashion bloggers and curators, artists and writers, students and academics" – "to reflect on the way that clothes have been used as a means to remember and to forget, to memorialise and to mythologise, to reconstruct histories and to create new imaginative forms" [c-iii].

As intended through its design as a reciprocal and iterative process, this approach to artscience collaboration also had **therapeutic benefits**, as evidenced via feedback obtained several months after the workshops. The Guildcare carers who facilitated the workshops at the nursing homes observed the following positive effects in well-being among the participants as a result of the workshops: improvements in memory, sense of identity, socialising/connecting with others, and dexterity (via the practical workshops in which the participants created clay figures) [c-iv]. The carers found that the handling of items from the museum had aided in participants being better able to remember things (belongings, people or places) they might have forgotten or did not previously prioritise. These improvements in memory were also attested to by participants themselves, with one stating they are now able to access "memories of my childhood in Scotland during the war", that the approach of hearing other people's memories had helped them to recall their own, and confirming that being able to recall memories has had a positive effect on how they feel [c-iv].

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

- [a] (i) Harrell, E. <u>2010</u>. Recovering Memory: Can a New Device Help Amnesia Patients? *Time*, Monday, Oct. 11 (ii) Fleishman, L. <u>2010</u>. Amnesia and a Camera: Photos as Memories. *Time*. Video interview (iii) Document listing Claire's dissemination work (iv) Loveday, C. *Autographer Instructions* (v) Testimony: Independent Supported Living Facilitator (Mental Health) (vi) Testimony: Volunteer Manager, Age UK, Barnet
- [b] (i) Testimony: Shona Illingworth. (ii) Zahir, S. at Hybrid Consulting. EVALUATION LEGIONS IN THE LANDSCAPE. June 2018 (iii) Illingworth, S. Lesions in the Landscape End of Project report 102010/Z/13/Z; June 2018 (iv) Bennett, J., et al. <u>2019</u>. Memory Loss and Scenic Experience: An Arts Based Investigation. Forum Qualitative Sozialforschung 20:1 (v) Document of 'Lesions' media coverage
- [c] (i) Memory of Clothes Worthing Museum: 23rd February 8th June 2019 (ii) Testimony from Helen Barff and Suzy Joinson (iii) Centre for Design History, "Memory of Clothes Study Day at Worthing Museum and Art Gallery" [link] (iv) Memory of Clothes - Workshop feedback