



Co-creating Meaningful Spaces: Stepping into Virtual Worlds Crafted by People Living with Dementia

Ethan Cheung*
eglc2@kent.ac.uk
University of Kent
Canterbury, United Kingdom

Sophia Ppali*
sp815@kent.ac.uk
University of Kent
Canterbury, United Kingdom

Boris Otkhmezuri
boris.otkhmezuri@manchester.ac.uk
University of Manchester
Manchester, United Kingdom

Clare Thomas
clare@brightshadow.org.uk
Bright Shadow
Herne Bay, United Kingdom

Alexandra Covaci
a.covaci@kent.ac.uk
University of Kent
Canterbury, United Kingdom



Figure 1: From physical to virtual model boxes

ABSTRACT

This paper presents a unique artistic endeavour that aims to foster an understanding of the profound impact of space, place, and human connection through the lens of individuals living with dementia. Our work involved a five-week co-creation process, comprising twenty sessions, where forty-four participants collaborated with artists to craft four physical boxes representing "Meaningful Places." These boxes were then transformed into immersive Virtual Reality (VR) environments, inviting the participants to engage with their creations in an entirely new way. The art installation during the

*Both artists contributed equally to this work.



This work is licensed under a Creative Commons Attribution International 4.0 License.

DIS Companion '23, July 10–14, 2023, Pittsburgh, PA, USA
© 2023 Copyright held by the owner/author(s).
ACM ISBN 978-1-4503-9898-5/23/07.
<https://doi.org/10.1145/3563703.3596645>

DIS 2023 Art exhibition features the VR experience alongside the physical boxes our workshop participants created. With this, we invite viewers to step into the worlds imagined and crafted by those living with dementia, but also explore them, in a celebration of the unique perspectives and experiences of those who made them.

Besides the main artists, this work would not have been possible without the contribution of:

Bright Shadow workshop participants
Morgan Hanna - Bright Shadow Project Coordinator
Caroline Millar - Facilitator (Writer - Lead Facilitator)
Chloe Chierico - Facilitator (Model Maker)
Jamie McCarthy - Facilitator (Musician and Sound Designer)
Chee Siang Ang - Research Project Supervisor

ACM Reference Format:

Ethan Cheung, Sophia Ppali, Boris Otkhmezuri, Clare Thomas, and Alexandra Covaci. 2023. Co-creating Meaningful Spaces: Stepping into Virtual Worlds Crafted by People Living with Dementia. In *Designing Interactive Systems Conference (DIS Companion '23)*, July 10–14, 2023, Pittsburgh, PA, USA. ACM, New York, NY, USA, 5 pages. <https://doi.org/10.1145/3563703.3596645>

1 BACKGROUND AND MOTIVATION

Worldwide, around 55 million people are living with dementia [6]; a term used to describe a decline in cognitive abilities severe enough to interfere with a person's daily functioning. This is an increasingly common phenomenon in the ageing population, with its incidence rising with age. Symptoms like memory loss, mood fluctuations, and sleep disturbances emerge gradually, persistently, and progressively [4]. These symptoms impact the quality of life of people who live with dementia [2], who become more dependent and vulnerable, both socially and in terms of physical and mental health [3].

Pharmacological treatments for dementia are limited and often accompanied by side effects. Thus, alternative non-pharmacological interventions (e.g., music therapy, art therapy, pet therapy, reminiscence therapy, cognitive stimulation therapy) have gained increasing attention in recent years as a means of alleviating symptoms and enhancing the quality of life for individuals living with dementia. Among them, reminiscence therapy is a popular intervention, which serves to rekindle memories, stimulate mental activity, and facilitate the re-experiencing of past emotions [10]. Although reminiscence can be a valuable activity for individuals living with dementia, it is important to recognise that it should not be the sole focus. As pointed out by Basting [1], present-focused activities are equally crucial for this population and should be emphasised to avoid overshadowing their current and future experiences. Exploring new experiences can offer hope and optimism and help develop resilience, which is important in dealing with the challenges faced by individuals living with dementia [1].

The arts are becoming a popular means of promoting social inclusion among individuals living with dementia, not only because they offer opportunities for meaningful participation in activities that matter to both themselves and others but also because they provide new experiences. Through the arts, individuals living with dementia can engage in nonverbal communication and expression of affect, leading to a sense of empowerment, while simultaneously building connections with their communities [9]. Inspired by collaborative art making, our work aims to explore the process and the result of co-creating meaningful spaces with people living with dementia. We wanted to explore art not only as a communication medium – expressing thoughts, emotions, and intuitions – but also as an empowering, transformative force that leads to new experiences and viewpoints.

To accomplish this, we conducted a series of art co-creation sessions in partnership with a specialist arts organisation offering creative sessions for those living with dementia, aimed at enhancing their quality of life. We worked with them during a five-week period, running a series of twenty workshops (five workshops in four different locations) with a total of forty-four participants. During this time, each group of people living with dementia – supported by artists – actively participated and co-created together with artists and facilitators, a physical box (i.e., a *model box*) combining stylised elements describing places they perceived meaningful and reflecting their unique perspectives and experiences. This approach emphasised the need for distributed agency and enlivened accountability in the creation of new, resilient and meaningful collaborative spaces.

We then translated these co-created physical spaces accompanied with soundscapes to Virtual Reality (VR) and gave these virtual environments to the participants to explore during a sixth session with us. Through this, we wanted to leverage VR's ability to transport users to new worlds [7, 8], and explore how participants perceived the transition from art creation to art immersion, by being in a direct embodied relationship with it (immersed inside the art) and what was the impact of this shift on their emotional engagement [5]. Moreover, we also looked into how the experience of the VR content is influenced by the multilayered process of engaging participants in co-producing it.

Throughout our process – from creating the physical models to experiencing the digital replicas in VR – we engaged with our participants and discovered that VR for dementia does not only have to be about accurate representation of places and memories. Our participants experienced art as a transformative journey, from creating art from memories and preferences, to experiencing it in various ways – physical as a model box and virtual as a VR immersive experience. The process we involved our participants in allowed them to convey meanings, and provided them with a way for self-expression and communication.

A video of the work can be found at: <https://youtu.be/gpfdgXceSvQ>

2 CREATION PROCESS

2.1 *Model box* co-creation workshops

As part of the creation process, participants were supported in the twenty co-creation sessions by the organisers of the specialist arts organisation and by three artists who came in at different stages of the progress: *a writer*, *a model-box maker* and *a sound designer*. Each workshop included an icebreaker activity, a main creative activity and a half-an-hour tea & biscuit social time.

During the first workshop, we introduced the participants to our aims for the next five weeks and the use of VR to display their final outcome. The main activity for this session was done in collaboration with *the writer* and its goal was to help the participants identify and describe a place that held meaning for them but also to enable researchers and participants to learn about each other. For this, we asked each participant to create a 2D collage based on the brief "*What is a meaningful place to you*". Prior to the session, we prompted participants to bring with them some photos associated with their favourite places. These were scanned and re-printed to be used as collage materials together with wax pastels, promarkers, chalks, paints, textured paper/fabric and graphic-designed collage books. While the participants were working on their collages, the team of researchers went around and had conversations with them about their artwork and the photos they brought to the session. The final collages were presented during a final group discussion where each participant had the opportunity to show their art and talk about the place it represented.

During weeks two and three, participants started to design their *model boxes* as a group in collaboration with *the model-maker* artist. Participants worked on one box for each workshop location - 4 boxes in total. The boxes were designed based on the ideas emerging from the previous week's 2D collages, generalised with an overarching theme agreed upon between the group (e.g., woodlands, farmland, beach). Each *model box* was designed with a base and



Figure 2: Pictures from the workshops

three walls surrounding it as if it was a theatre stage, with the base and walls decorated with artwork made by the participants. They also had the opportunity to further add their personalised touch by adding props that aligned with their interests (e.g., pets, trees, gardening items). *The model-maker* and the workshop facilitators assisted the participants in the process while engaging with them in conversations about their creations.

During the final two weeks of the project, the participants worked on finalising their *model boxes*. Moreover, with *the sound designer's* help, participants created a soundscape piece for their boxes. This was done through a combination of activities, including identification of the location, different ambient sounds captured and the feelings they evoked, description of the type of sounds participants associated with their favourite locations, and group singing of songs that were meaningful to them. The final soundscapes were a combination of environmental sounds as well as recordings of participants singing and humming. At the end of the last session, the *model boxes* and associated soundscapes were presented to the group with participants discussing their thoughts on the outcome and the process. By the end of the five sessions, participants had taken part in a creative process that used a variety of stimuli including visual art making, conversations, making and constructing, music and play (see Fig. 2).

2.2 Design of the VR experience

After the completion of the boxes, we proceeded by recreating the physical *model boxes* into virtual spaces, trying to keep true to the original work of the participants. For this, we used Maya 2023 together with Substance painter to develop the assets, Unity game engine to assemble the final environments and Meta Quest 2 as a VR device for delivering the final experiences. Image references were

used to get the exact proportions of the assets and environments, and drawings from participants were used as textures (see Fig. 1).

The replicated environments have an extra wall, which features picture frames with photos of the original *model box* and how this turned into the VR environment being experienced. The top side of each environment has been kept open, looking at a bright sky matching the theme of the location, mainly for two reasons, 1) to avoid feeling claustrophobic or trapped in a box and 2) to maintain the feeling that the user is in the box and that there is an environment outside it. Each of the four environments also includes the soundscape that the participants created during the workshop sessions.

Finally, to evolve the work of the four groups into a single art piece which can be seen by others beyond the scope of the original research, we brought together the four spaces as extensions of a single gallery space. When a user enters the experience they are placed in a lobby with four doors, each representing the locations that the workshops took place in, where they are able to select which environment they want to experience. The decoration of the lobby is inspired by the tea & biscuit time of the workshops, where everyone gathered around snacks and tea whilst catching up with each other.

3 DESCRIPTION OF ARTWORK

For the DIS 2023 Art Exhibition, our goal is to broaden the impact of our work, by inviting a wider audience to engage with and immerse themselves in the spaces co-created by people living with dementia. Our intention is to inspire a sense of fortitude and adaptability, celebrating the unique perspectives and experiences of those affected by dementia.



Figure 3: The lobby of the experience

Our art installation will showcase an intricate blend of physical and digital, offering visitors the opportunity to explore and appreciate the co-created spaces on multiple levels. The exhibit will feature the original *model boxes* crafted during our workshops, allowing visitors to witness first-hand the tangible representations of meaningful places as perceived by individuals living with dementia.

Complementing the physical *model boxes*, the installation will also incorporate the VR experience we developed. Visitors will have the ability to explore the spaces and soundscapes co-designed by people living with dementia. This multi-sensory experience will provide a deeper, more intimate understanding of the strength, determination, and creative spirit that fuelled the co-creation of the work.

By inviting a broader audience to interact with both the physical *model boxes* and their corresponding VR experiences, we aim to cultivate an atmosphere of open-mindedness, and creative exploration. This inclusive approach not only highlights the resilience and expressive capabilities of individuals living with dementia but also fosters a sense of shared humanity and interconnectedness among all participants. We believe that the presentation of our work at the DIS 2023 Art Exhibition has the potential to stimulate meaningful dialogues around art, resilience, and the transformative power of collaborative creation.

4 CONTRIBUTORS

Ethan Cheung is currently a Human Computer Interaction PhD researcher at the University of Kent. His research interests follow the impact of Virtual Reality and Artificial Intelligence in the field of Dementia care. He holds a Bachelor's degree in Biomedical Engineering from his current University and is particularly interested in game design, gamification and playful research.

Sophia Ppali is a transdisciplinary designer, researcher and digital artist. Her research interests include immersive experiences, interaction design, community-engaged participatory research and cultural sensitivity. She is currently a PhD student at the University of Kent doing research on exploring the design space of remote music performances. She holds a Bachelor's degree in Digital Arts from the University of Kent as well as an MSc from Imperial College London and an MA from Royal College of Art in Global Innovation Design. She has a special interest in designing for mental health and has worked on a number of projects aimed at reducing the stigma surrounding conversations around it. www.sppali.com

Boris Otkhmezuri is a technical specialist at the University of Manchester. His main interest lies in the area of Human Computer Interaction with an emphasis on digital health. Specific areas include: Games and virtual worlds; VR and AR (analysing user-computer interaction with various techniques such as usability testing, eye tracking, observation, etc); Use of technology for health care. He has worked extensively with collaborators in higher education institutions across different countries and industry. Moreover, he has a passion for digital art and software development and has been using the computer to generate traditional and interactive art for the past 5 years.

Clare Thomas is the CEO of Bright Shadow, an award winning arts and dementia charity based in Kent. Clare has always had a passion for the arts, particularly theatre, graduating from Goldsmiths College, University of London with First Class Honours in 1999. From there she was drawn into the exciting and enriching world of Disability Arts, working as Administrator for renowned organisations Oily Cart Theatre Company and Heart n Soul. Clare spent ten years in total with Heart n Soul in a range of roles, becoming Deputy Chief Executive in 2009. She has acted as a Consultant to Southbank Centre and Jasmin Vardimon Dance Company and is delighted to now be leading Bright Shadow at this exciting time in its development.

Bright Shadow is a specialist arts organisation with the mission to enable people living with dementia, and those affected by it, to live well and to thrive. Established in 2009, they are experts in creative activities that are fun, meaningful, accessible and challenging. All that they do promotes wellbeing for people living with dementia. Bright Shadow is passionate about a brighter quality of care, which is invigorating, mood boosting and enhances relationships. www.brightshadow.org.uk

Alexandra Covaci is a researcher in the field of virtual reality and currently a Lecturer in the Digital Design course at the University of Kent. Her research activities lie at the confluence of VR, multisensory media, human computer interaction and psychology. She is particularly interested in creating a systematic understanding of multisensory experiences for interactive technologies. Her approach is driven by a mix of human factor studies and creativity.

ACKNOWLEDGMENTS

We would like to thank Clare and Morgan for allowing us to take part in their *Zest* sessions and their continuous support during this project. Also to Mayank Loonker for the ideas around running the workshop and to all those who helped with organising the activity sessions during the workshop period, especially Caroline, Chloe,

Jamie and Nina. Final thanks to all the participants and family members involved in the creation of the model boxes. We hope you had enjoyed the sessions and seeing the final product in the end.

REFERENCES

- [1] Anne Davis Basting. 2009. *Forget memory: Creating better lives for people with dementia*. JHU Press.
- [2] Helen B Burks, Jude KA des Bordes, Riya Chadha, Holly M Holmes, and Nahid J Rianon. 2021. Quality of life assessment in older adults with dementia: A systematic review. *Dementia and geriatric cognitive disorders* 50, 2 (2021), 103–110.
- [3] EL Cunningham, B McGuinness, B Herron, and AP Passmore. 2015. Dementia. *The Ulster Medical Journal* 84, 2 (May 2015), 79–87.
- [4] Silvia Duong, Tejal Patel, and Feng Chang. 2017. Dementia: What pharmacists need to know. *Canadian Pharmacists Journal / Revue des Pharmaciens du Canada* 150, 2 (2017), 118–129. <https://doi.org/10.1177/1715163517690745>
- [5] Cathy A. Malchiodi (Ed.). 2018. *The handbook of art therapy and digital technology*. Jessica Kingsley Publishers, London ; Philadelphia.
- [6] World Health Organisation. 2022. Dementia. <https://www.who.int/news-room/fact-sheets/detail/dementia> Accessed on September 06, 2022.
- [7] Sophia Ppali, Vali Lalioti, Boyd Branch, Chee Siang Ang, Andrew J. Thomas, Bea S. Wohl, and Alexandra Covaci. 2022. Keep the VRhythm going: A musician-centred study investigating how Virtual Reality can support creative musical practice. In *Proceedings of the 2022 CHI Conference on Human Factors in Computing Systems (CHI '22)*. Association for Computing Machinery, New York, NY, USA, 1–19. <https://doi.org/10.1145/3491102.3501922>
- [8] Mel Slater and Maria V Sanchez-Vives. 2016. Enhancing our lives with immersive virtual reality. *Frontiers in Robotics and AI* 3 (2016), 74.
- [9] Aagje Swinnen and Kate de Medeiros. 2018. “Play” and people living with dementia: A humanities-based inquiry of TimeSlips and the Alzheimer’s Poetry Project. *The Gerontologist* 58, 2 (2018), 261–269.
- [10] Bob Woods, Laura O’Philbin, Emma M. Farrell, Aimee E. Spector, and Martin Orrell. 2018. Reminiscence therapy for dementia. *Cochrane Database of Systematic Reviews* 2018, 3 (2018). <https://doi.org/10.1002/14651858.CD001120.pub3>