



# MAKING IN THE MOMENT: INSIGHT FROM PARTICIPATORY ARTS FOR CO-DESIGN PRACTICE IN DEMENTIA CARE SETTINGS

Henry Collingham, Abigail Durrant and John Vines

*Northumbria University, UK*

## **Abstract**

Design for dementia literature calls for greater degrees of personalisation and participation for people living with dementia, while acknowledging that 'alternatives are also needed to the one-on-one approaches, often used in the development of highly personalized outcomes' (Kenning 2018, 2).

We respond to these provocations by reporting on a qualitative study in a care home setting that informed Inclusive Design directions for dementia care. The professional practice of conducting participatory arts workshops in this setting was empirically observed and analysed, to deliver transferable insights that may advance co-design methodology for dementia care design contexts.

This paper presents an autoethnographic account taken from a year-long participant observation in a residential care home in Northern England, by a designer volunteering for a creative ageing charity that runs participatory arts workshops. In presenting the designer's account about his involvement in the development of a large-scale

participatory artwork with this charity, and his facilitation of 30 workshops, the paper captures empirical insight and learning from working alongside experienced creative professionals. We critically reflect on this insight, discussing its relevance to co-design practices in residential care contexts, and calling for designers to draw their strategic focus away from identifying notions of 'good; or 'bad' design outcomes, and towards celebrating the act of creative intent and voice-giving through co-design practice. We offer methodological insight for Design4Health that is grounded in a recognition of the importance of authorship and autonomy of people with dementia: the facilitation of creative expression should ensure that there is reciprocity within co-design methods, between those who are involved with creative practice in the form of one-to-many, or many-to-many.

Keywords: dementia, co-design, participatory arts, care home, creative ageing



## Introduction

We report on an autoethnographic account following a year-long participant observation by the first author in a residential care home specialising in advanced dementia care. This work was conducted alongside professional participatory artists from Equal Arts, a creative ageing charity who have been delivering arts workshops in care homes for over 30 years.

We critically reflect on how insights from this participatory arts practice may advance co-design methodology for dementia care contexts. Drawing on this case, we highlight three key challenges for design research, relating to the value of participatory arts practice in dementia care contexts. These challenges are to: (1) accommodate a greater focus on the moment of making and intentionality in co-creative practice; (2) recognise the key role of facilitators to creative expression, appreciating how this social practice has impact beyond each participatory activity; (3) understand the importance of increased personalisation in design practice while confronting the reality of the scale of deployment needed to benefit those living with dementia.

## Background

### Dementia and The Arts

With no cure for dementia, UK policy making focuses on finding ways for people to live well with the condition (NHS 2018) primarily following the framework of Person-Centred Care (Edvardsson, Winblad, and Sandman 2008). There is a substantive body of practice and research in the field of dementia and the arts which support such person-centric approaches (All-Party Parliamentary Group on Arts Health and Wellbeing 2017).

Arts practice has been empirically shown to aid communication, expression, confidence, social participation, and a sense of freedom (Zeilig, Killick, and Fox 2014). Benefits to

quality of life are observed through the act of participatory creative practice, with a broad range of arts therapies in dementia care reinforcing 'sense of control, life meaning, and personal satisfaction' (Cowl and Gaugler 2014, 308). Arguably, it is the job of the facilitating artist in a dementia care setting to enable each person 'to do what otherwise he or she would not be able to do, by providing those parts of the action - and only those - that are missing' (Kitwood et al. 2019, 109).

### Co-design practice for People with Dementia

Design literature has called for greater personalisation and participation to allow people living with dementia increased creative expression: 'Design [which] allows for individualisation is likely to be useful for people with dementia and acknowledges the multiplicity of experiences which people with dementia and their families may face in the course of the condition.' (Morrissey, McCarthy, and Pantidi 2017, 1328). Craig calls for designers to 'see individuals' creativity and resilience, have confidence in design ... to offer individuals structures and vehicles through which to be heard.' (Craig 2017, 62). Hendriks et al note the benefits of creative expression and acknowledge the need for designers to build embedded relationships in care settings (Hendriks et al. 2018, 59–60). Arguably, the need for embeddedness conflicts with the call for these design projects to be adopted at a scale with the potential to benefit the growing number of people living with dementia (Zeisel 2010; Wey 2006), especially those most vulnerable who are living in under-funded residential care homes (Thwaite 2017).

In presenting this study that engages with professional participatory artists' practice, we contextualise calls for design research to push further towards forming empathetic, creative collaborations with residents (Swaffer 2016). Our insight builds on work that discusses the heightened emotional

experience of living with dementia through creative practice (Killick and Craig 2012; Kitwood et al. 2019) and that acknowledges its potential to influence social dynamics within the care home (Bratteteig and Wagner 2012). We also wish to highlight challenges for designers delivering greater personalisation to people living with dementia in light of the shortage of resources in the care sector.

## The Study

Each workshop involved 5 to 20 residents, one or two professional arts practitioners, activities coordinators, and the first author in a dual role as Design Researcher and Volunteer Facilitator. Thirty workshops were documented over a year-long period in which a large-scale collaborative textiles artwork was produced with residents.

Our key research questions follow.

1. How can we design to deliver greater degrees of personalisation and participation for people living with dementia at a scale commensurate with the context?
2. How can techniques from professional participatory arts practice translate into co-design practice in a dementia care setting?

## Methodology

Our approach was informed by Sensory Ethnography (Pink 2015), which allows verbal and non-verbal communication to be considered equally. Pink's methodological focus on the relationship between the material and emotional experience of selfhood guided particular a focus on sensorial qualities and interactions when documenting field notes. This was valuable in the arts workshops, which were rich in multi-sensory stimuli, including music, aroma, textural exploration, food and drink, embodied movement and dance alongside visual activities.

Participant Observation enabled embedded research practice, for building relationships over time within a community of residents.

Interpersonal dynamics were focused on in workshops alongside the needs and expressions of individuals.

Field notes were interpretatively coded following completion of the field work. Notes and codes were then re-coded using Ethnographic Analysis (Ghodsee 2015) to form an autoethnographic account, extracts from which are presented here.

## Ethics

This research received ethical approval from Northumbria University and was conducted within the Ethical Working Guidelines of our partner Equal Arts. All names, places, and identifying details within the account presented have been pseudonymized.

## Autoethnographic Account

The following vignettes have been chosen from the first author's autoethnographic account to elucidate key methodological insights. Note that the authorial voice shifts to the first author in this section. Key moments have been selected to demonstrate the artists' methods put into practice.

### Extract 1

Emily and Pip had initially been asked to decorate a fabric starfish that lay untouched beside them, but they had instead taken control of the direction of their work.

Pip leaned in to watch as Emily moved two pieces of fabric from position to position on the table in front of them like a chess game. They used a fabric maple-leaf Pip had previously made, with deep autumn colours chaotically scribbled onto its spiky form and a plain offcut of peach-coloured felt.

Emily used deliberate gestures to describe the relationship between the two pieces, moving her hands in unison to carve a neat circle in space around them to make her meaning clear, something that would often elude her in strictly verbal communication.

'Similar? Balanced? Opposing? Unified? Playful?' I suggested.

'They're nice, the way they play together.' She nodded.

They continued experimenting throughout the workshop, discussing the layout intensely; adding, and amending, elements they found. Eventually settling on a composition both were satisfied with, showing it off carefully.

Seeing their pride, I asked what they thought should happen next.

'Ooh, you could see it properly then, if it was up on the wall! You know, ironed and pressed and in a frame...'

Facilitators had the ability in the space to encourage, prolong, and celebrate these moments of creation.

I helped carefully pin the design onto a piece of blank calico, with Emily correcting me as I made mistakes. Working as the facilitating artist I was guided by Emily to help realise the piece as she saw it.

Emily is usually quite shy, though when we held the final piece up for everyone to see she admitted;

'I'm not that bad, am I?' with her shoulders raised.

## Extract 2

Artists were able to personalise the pursuit for creative expression while enabling collective participation and contributions, afforded by the careful choices of material and spatial interactions.

Residents each chose a fallen autumn leaf and traced around it onto fabric, then coloured their artworks in using marker pens.

The spatial arrangement of the activity was very clear to interpret; the leaf and resulting drawing ended up exactly equal in size as a result of tracing, and all of the residents chose to use colours closely matching their leaves at first, resulting in highly figurative artworks.

If people drifted in and out of engagement with the activity, they could get back on track easily as the materials in front of them were physically suggestive of the activity in hand without having to vocally question what was going on, or what to do next. This resulted in a particularly high uptake which, in turn, encouraged yet more residents, often less keen to take part, to engage with the activity.

The relaxed atmosphere of joining-in encouraged greater creative exploration, with some residents moving away from the representative into more abstract and self-expressive imagery within subsequent artworks.

## Extract 3

Convivial group activities were sometimes at odds with individualized interactions, where artists sought and identified discrete authorship among collective work.

During a drawing activity Claire was searching restlessly through the papers at her table. I saw she was strumming her thumbnail along the corner of each sheet of paper in turn to see if any individual pieces were actually two stuck together. After some time, we were able to work out she was looking for the artwork she'd started in the previous week's workshop.

She tried in vain to describe to me what it was she was looking for; it took a long time checking each piece of paper in the room with her until finding the drawing she was looking for. Once recovered, Claire recognized it instantly and started working again as soon as she had it back. What was particular about the artwork was how small and gentle it was, yet still completely recognisable to her. The artwork was just four tiny circles, lightly drawn in pencil towards one corner of an A4 page, no bigger than a coin.

The beauty of created artworks was foregrounded in interaction by residents and artists; built over time through empathy. Artists sought to simultaneously

hear the quietest voices while bringing group activities to as many residents as possible.

## Discussion

We present three transferable insights for co-creative practice, framed as challenges for the community and highlighting structural tensions in the context of co-design methods in dementia care.

### 1. Making in The Moment

During our workshops artists' key focus was on the making; resultant perceived aesthetic beauty in the objects was derived from collective celebration and careful curation. This was, at times, in tension with the perceived agenda of external agencies in the project, whose focus was typically more on the material manifestation of artworks, rather than the moments of creation.

A conscious focus on celebrating the moments of creativity during a making process can define the collective experience of participants and foster a sense of designers being open to and sensitized to ideation by those moments. We echo extant reviews of arts practice reporting benefits to 'personal sense of control, life meaning, and personal satisfaction'(Cowl and Gaugler 2014, 308) regardless of the material arts process employed.

Inputs from participants may be critical during creative processes to define the design response, rather than that being led by the designer on a problem-solving trajectory. We encourage designers to step back and give more control on the direction of design work, creation and decision making to participants in co-creative practice.

### 2. Curating Social Spaces

Significant expertise is needed to orchestrate social activities which are collective, while also bringing individual meaning for many participants. The degree

to which interactions are carefully tailored reinforces the necessity for skilled creative practitioners to 'be there', to share in and observe moments of making. Co-creative work in dementia care has the potential to ensure reciprocity between actors.

Key moments of the workshops were those where individuals felt comfortable enough to; break rules, question, and disrupt established expectations. Playful and joyful creativity came about through mutual encouragement, facilitation, and openness. Artists were attuned to the emotional and therapeutic potential of making and creating together (Killick and Craig 2012). We suggest that design researchers can also deliver in this regard, given the right approach, by learning from other creative disciplines and practices.

Dynamic flexibility is needed to invite people living with dementia to meaningfully disrupt and personally explore the bounds of creative practice. The artists in our study keenly encouraged social dynamics in which people were supported to develop and express individual creativity, often challenging the discourse of the space at the same time as working within it. Recognition of the importance of authorship and autonomy superseded preconceived expectations.

Listening to the choice of each person living with dementia was transformative for the first author. Co-design has the potential to position individuals as experts, navigators, and inventors. Surrendering ideas of good or bad design, and rather advocating for designing itself, we have an opportunity to disrupt power imbalances. Handing over the reins and letting people in can lead to aesthetically pleasing processes and unexpected happy results. Significantly, the act of making is democratized and can be celebrated aside from any material outcomes.

### 3. Personalisation at Scale

Designers are well placed to approach the daunting problem of delivering individualized participatory practice at scale, appropriate to the numbers of people living with dementia in residential care.

This undertaking involves confronting key tensions within the existing discourse, and real-world context of care homes. With limited resources available, we invite designers to embrace personalisation and participation, at a scale commensurate with the context of care. We call for future work that creates opportunities for more people with dementia to benefit from these moments of creation which 'should work to enrich this co-presence rather than provide a facsimile of it' (Morrissey, McCarthy, and Pantidi 2017, 1328).

### Acknowledgments

We gratefully thank all of the residents, families, friends, staff and artists involved in workshops, as well as Equal Arts for their continued support as valued research partners.

### Funding

The project was funded by the AHRC Northumbria-Sunderland CDT.

### References

All-Party Parliamentary Group on Arts Health and Wellbeing. 2017. *Creative Health: The Arts for Health and Wellbeing* (2nd Ed.). [http://www.artshealthandwellbeing.org.uk/appg-inquiry/Publications/Creative\\_Health\\_Inquiry\\_Report\\_2017\\_-\\_Second\\_Edition.pdf](http://www.artshealthandwellbeing.org.uk/appg-inquiry/Publications/Creative_Health_Inquiry_Report_2017_-_Second_Edition.pdf).

Bratteteig, Tone, and Ina Wagner. 2012. "Disentangling Power and Decision-Making in Participatory Design." *ACM International Conference Proceeding Series* 1: 41–50. doi:10.1145/2347635.2347642.

Cowl, Andrielle L., and Joseph E. Gaugler. 2014. "Efficacy of Creative Arts Therapy in Treatment of Alzheimer's Disease and Dementia: A Systematic Literature Review." *Activities, Adaptation & Aging* 38 (4): 281–330. doi:10.1080/01924788.2014.966547.

Craig, Claire. 2017. "Giving People Living with Dementia a Strong Voice: Reflecting on the Role of Design to Create Enabling Activities," no. December: 60–63. <http://shura.shu.ac.uk/17601/>.

Edvardsson, David, Bengt Winblad, and PO Sandman. 2008. "Person-Centred Care of People with Severe Alzheimer's Disease: Current Status and Ways Forward." *The Lancet Neurology* 7 (4): 362–367. doi:10.1016/S1474-4422(08)70063-2.

Ghodsee, Kristen. 2015. "From Notes to Narrative." *From Notes to Narrative*. doi:10.7208/chicago/9780226257693.001.0001.

Hendriks, Niels, Liesbeth Huybrechts, Karin Slegers, and Andrea Wilkinson. 2018. "Valuing Implicit Decision-Making in Participatory Design: A Relational Approach in Design with People with Dementia." *Design Studies* 59. Elsevier Ltd: 58–76. doi:10.1016/j.destud.2018.06.001.

Kenning, Gail. 2018. "Reciprocal Design: Inclusive Design Approaches for People with Late Stage Dementia." *Design for Health* 2 (1). Taylor & Francis: 142–162. doi:10.1080/24735132.2018.1453638.

Killick, John, and Claire Craig. 2012. *Creativity and Communication in Persons with Dementia*. 1st ed. London: Jessica Kingsley Publishers.

Kitwood, Tom, Dawn Brooker, Christine Bryden, Richard Cheston, Jan Dewing, Ruth Elvish, Reinhard Guss, et al. 2019. *Dementia Reconsidered, Revisited*. Edited by Dawn Brooker. London: Open University Press.

Morrissey, Kellie, John McCarthy, and Nadia Pantidi. 2017. "The Value of Experience-Centred Design Approaches in Dementia Research Contexts." *Proceedings of the 2017 CHI Conference on Human Factors in Computing Systems - CHI '17*, 1326–1338. doi:10.1145/3025453.3025527.

NHS. 2018. "Living Well with Dementia." <https://www.nhs.uk/conditions/dementia/living-well-with-dementia/>.

Pink, Sarah. 2015. *Doing Sensory Ethnography*. 2nd ed. London: SAGE.

Swaffer, Kate. 2016. "Co-Production and Engagement of People with Dementia: The Issue of Ethics and Creative or Intellectual Copyright." *Dementia* 15 (6): 1319–1325. doi:10.1177/1471301216659213.

Thwaite, Alice. 2017. *Growing the Creative Ageing Movement : International Lessons for the UK*.

Wey, Stephen. 2006. "One Size Does Not Fit All: Person-Centred Approaches to the Use of Assistive Technology." In *Perspectives on Rehabilitation and Dementia*, edited by Mary Marshall, 348–367. London: Jessica Kingsley Publishers.

Zeilig, Hannah, John Killick, and Chris Fox. 2014. "The Participative Arts for People Living with a Dementia: A Critical Review." *International Journal of Ageing and Later Life* 9 (1): 7–34.

Zeisel, John. 2010. *I'm Still Here: Creating a Better Life for a Loved One Living with Alzheimer's*. Hachette UK.