

<b>Institution:</b> Newcastle University		
<b>Unit of Assessment:</b> 34 Communication, Cultural and Media Studies, Library and Information Management		
<b>Title of case study:</b> Improving the Quality of Life of Older People Living with Dementia Through the Arts		
<b>Period when the underpinning research was undertaken:</b> August 2013 and August 2017		
<b>Details of staff conducting the underpinning research from the submitting unit:</b>		
<b>Name(s):</b>  Andrew Newman Bruce Davenport	<b>Role(s) (e.g. job title):</b>  Professor Research Associate	<b>Period(s) employed by submitting HEI:</b> 1993 onwards 2007 onwards
<b>Period when the claimed impact occurred:</b> August 2013 to December 2020		
<b>Is this case study continued from a case study submitted in 2014?</b> N		
<b>1. Summary of the impact</b>  <p>Research in this case study led to important changes in the ways that the visual arts are used with older people living with dementia, impacting upon individual carers, care staff, artists and organisations (Arts Council England, care homes and charities supporting older people living with the condition). The work led to positive changes in attitudes, regarding the social and creative capacities of older people living with dementia, amongst those who participated in the research or who encountered the project through dissemination activities. This will result in improvements in the lives of people living with dementia who engage in future arts projects.</p>		
<b>2. Underpinning research</b>  <p>Research into the potential of arts activities to improve the quality of life (QoL) for older people living with dementia was prompted by evidence that it can be poor, which is a particular problem in care homes. While arts activities for older people living with dementia are well established there were no systematic studies that explored the effectiveness of such work that could, for example, support policy initiatives and funding requests.</p> <p>These issues were addressed by Andrew Newman's research which has focussed, since 2013, on how visual arts practice enrichment activities can improve the wellbeing and QoL for older people living with dementia and their carers. This research was supported by a major GBP1,219,353 grant from the AHRC/ESRC entitled <i>Dementia and Imagination</i> (2013-17: <a href="http://dementiaandimagination.org.uk/">http://dementiaandimagination.org.uk/</a>). This work involved nine lead researchers, five universities and four community partners. Overall, the project worked with 149 people with dementia and 130 carers across 3 sites in the UK (North Wales, Midlands &amp; Tyneside). Participants at each site lived in distinct settings (respectively: living independently, in hospital settings &amp; in care homes). Project artists worked with participants and carers to deliver participatory arts activities in those settings. Newcastle University researchers took responsibility for the work that recruited participants from four care homes in the Tyneside region. 3 research artists were also invited to reflect on the research process and produce work that would contribute to public understanding of the topic. Following a systematic review of the literature (<b>PUB 6</b>) a mixed methods research protocol was developed (<b>PUB 5</b>).</p> <p>The main outputs paper (<b>PUB 4</b>) incorporated qualitative and quantitative approaches and was the first systematic exploration of the topic. The results demonstrated participants' wellbeing was improved during the arts activities and that QoL was improved by the end of the programme, compared to baseline. It was concluded (<b>PUB 3</b>) that the success of this project was dependent</p>		

on embracing a wide range of different epistemological positions providing guidance for researchers building research project teams.

Newcastle researcher Bruce Davenport joined Andrew Newman to undertake detailed analysis of the qualitative data. This demonstrated, for the first time, how those with advanced dementia could demonstrate resilience through adapting to the daily difficulties they face (**PUB 2**) and how a complex narrative can be expressed in an embodied fashion by older people living with dementia who have lost verbal language (**PUB 1**). Newman and Davenport brought a distinctive 'arts and humanities' approach to the interdisciplinary research team and embodied that in their analysis of the research data.

### 3. References to the research

#### Publications

All publications are published in peer-reviewed journals and are being cited as reference points for further research beyond the D&I research team. We therefore judge the papers to be at least 2\*.

**PUB 1, Newman A., Davenport B.,** Howson-Griffiths T. Narrative identity and resilience through visual arts activities for people in later life with dementia. In: Goulding, A., Davenport, B. and Newman, A. ed. *Resilience and Ageing: Creativity, Culture and Community*. Policy Press, 2018, available on request.

**PUB 2, Newman A.,** Goulding A., **Davenport B.,** Windle G. The role of the visual arts in the resilience of people living with dementia in care homes. *Ageing and Society* 2018, 45(11), 5609-5616, <https://doi.org/10.1017/S0144686X18000594>

**PUB 3, Newman A.,** Baber M., O'Brien D., Goulding A., Jones CH., Howson T., Jones C., Parkinson C., Taylor K., Tischler V., Windle G. Carrying out research across the arts and humanities and social sciences: Developing the methodology for Dementia and Imagination. *Cultural Trends* 2016, 25(4), 218-232, <https://doi.org/10.1080/09548963.2016.1241338>

**PUB 4, Windle G., Joling K., Howson T., Woods B., Jones Catrin, Newman A.,** Parkinson C. The impact of a visual arts program on quality of life, communication, and well-being of people living with dementia: a mixed-methods longitudinal investigation. *International Psychogeriatrics* 2018, 30(3), 409-423, <https://doi.org/10.1017/S1041610217002162>

**PUB 5, Windle G., Newman A.,** Woods B., O'Brien D., Baber M., Hounsborne H., Parkinson C., Tischler V. Dementia and Imagination: a mixed-methods protocol for arts and science research. *BMJ Open* 2016, 6(11):e011634, available on request.

**PUB 6, Windle G., Newman A.,** Goulding A., O'Brien D., Parkinson C. Understanding the impact of visual arts interventions for people living with dementia: A realist review protocol. *Systematic Reviews* 2014, 3(1), 91, <https://doi.org/10.1186/2046-4053-3-91>

#### Research Grant

2013-17, AHRC/ESRC, Dementia and Imagination, AH/K00333X/1, GBP1,219,353 (Newman as Co-Investigator)

### 4. Details of the impact

Dementia & Imagination (D&I) had impacts on a wide range of individuals (participants with dementia, carers, artists & the public who have encountered the project) and organisations (care homes, Arts Council England, Equal Arts and Age Watch). This societal impact can be divided into several categories:

**Impact of D&I on participants with dementia and their carers/family members**

Analysis of the impact of D&I on the participants and their carers/family members is based on data gathered during the project: semi-structured interviews with 33 participants with dementia (79 interviews across all sites) and 31 family members or carers (76 interviews across all sites) as well as open text survey responses from 128 family members or carers. Analysis of the interviews showed that the impacts of the activities were wide ranging. For example, increased enjoyment, improved relationships and pride in achievements, which contributed to QoL and general wellbeing. **(IMP 1)**

For example, one participant who was lonely stated: 'I thought it was good and I thought how good love, care and attention they paid us. You see, I'm on my own, I feel as if I don't belong anywhere; you made me feel I belonged. And the people were nice; you were very nice. Well, for a certain part of the day, when I went there, I wasn't.'

The director of a participating care home in Sunderland, noted that people living with dementia were able to effectively communicate in the arts enrichment sessions even if they had lost verbal language. She stated: 'It really did feel quite different to me all of the activities were bringing everybody together, I had a greater interaction with <a participating resident> that I'd ever had before. She was dancing with me and singing, [...]. She was really connecting with other people as well in the group as well. Her body language seemed to be different.' **(IMP 2)**

**Impact of D&I on the practices of carers involved in the project**

In semi-structured interviews, 15 care staff and 6 family members indicated that the activities had prompted changes to practices of care that either incorporated more creative work or were more person-centred (a marker of the quality of care) providing a better understanding of resident's lives. **(IMP 1)**

41 of the 52 open text survey responses from family members indicated that the project had prompted changes to their caring practices. 51 of the 76 open text survey responses from care staff indicated that the project had positively impacted them whilst 9 responses indicated that their experience had changed (or would change) their practices. **(IMP 3)**

The manager from one of the participating care homes recognised the benefit of the project activities for the participants and, during the interview at the end of the project, indicated that they were already changing their practices with care-home residents: "Because of [D&I], now we started to carry it on. So, our next project, [...] is gonna be along the river. [...] And we're gonna take every aspect of the river and bring it in, if we can, bring it into the home." **(IMP 2)**

One of the directors of this home introduced more arts-practice-based activities as a result of the project. The techniques adopted by the artists were rolled out across the homes run by care home group Executive Care (now Mariposa Care), who also participated in the project (personal communication with A. Newman, April 2017). Mariposa Care now run 9 care homes across the country with 3 in the north of England. This indicates on-going impact of the project on the wellbeing of people who did not participate in the project.

Impact on care staff who did not participate in the project has also been achieved through training sessions. A practitioner information day was undertaken at the Wellcome Trust, London (January 2017). Over 100 people attended the event, including people working in the care and creative sectors alongside researchers. 31 feedback responses were gathered, and a content analysis indicated the following responses: developing practice through the day (5 responses), ideas for future practice (3); increased confidence as a practitioner (2); inspiration (3); learning (8). For example: '[it was] interesting to learn more about making processes and methodology of working with people with dementia which I will apply'. **(IMP 4)**

**Impact upon D&I project artists' practice**

Two groups of artists were actively involved in the project: those that delivered the arts activities (project artists) and those that reflected on the research project (research artists). Involvement in

the project changed the practices of both sets of artists and made them much more aware of the needs of older people living with dementia. The research project introduced a broad structure including 12 weekly sessions, a pair of collaborating project artists at each site and a broad set of principles for good practice (derived from **PUB 5**).

The collaboration and the long-term nature of the engagements had an impact on the project artists. **(IMP 5)** The process also allowed them to reflect on and develop their practices: 'The relationship between the activity and the art will also grow I think as we continue to experiment. The whole project is really exciting [...] it's making me think A LOT about my practice and I am really wanting to push and grow ideas.' (North East Project Artist 1, Project Diary). It also shifted their sense of the value of the work: 'And I think for me, it was the first time I had been involved closely with the university, so it felt like [...] people are interested in this, so it must be important. Which gave me the confidence to take it forward.' (North East Project Artist 2). **(IMP 5)** The project has had an enduring impact on their work leading to new projects (e.g., their 'Moving In' artists residency in a Gateshead care home in August 2017) and being recognised as embodying good practice in arts and dementia work both in the UK and Australia. The North East project artists have also publicly shared their reflections on the impact of their involvement in D&I via a film on YouTube. **(IMP 6)** For example, they discuss the importance of the performative aspects of making artworks with care home residents.

The Nottingham Project Artist stated 'I think for me the one of the key outcomes was the fact that it was losing a fear of worrying about how you're going to do it. It was really stimulating and exciting thing to do. We did a lot of interesting things and developed some great relationships with patients and staff, and it helps you feel more confident that you can take the practice into any setting and somehow make it work in some way'. **(IMP 5)**

#### **Impact upon practice of community partners – Equal Arts and Age Watch**

The main community partner in NE England was Equal Arts (<https://www.equalarts.org.uk/> a creative ageing charity). Despite having extensive experience of working with older people with dementia, their involvement in D&I further enhanced their existing approaches. The Creative Age Programme Manager for Equal Arts stated that as a result of taking part in D&I, Equal Arts is 'now in a position to share best practice and support the professional development of the sector whilst critically improving the lives of older people living with dementia in an inclusive way'. **(IMP 7)** This indicates the longevity of the impact of the project.

The main national community partner was Age Watch (<https://www.agewatch.net/> whose aim is to enable older people to live longer in better health). Being involved in D&I has had 'a lasting impact' on the work of Age Watch. As a result of their experiences: they have become more involved in research and carried out their own research work; they have become more proactive in policy engagement, including providing written evidence to the House of Lords Select Committee on Intergenerational Fairness and Provision; they have also made greater use of visual arts in their communication strategy. **(IMP 8)**

#### **Impact upon wider cultural sector**

In 2015 Arts Council England (ACE) were unsure if their arts and older peoples work should continue as an area of work or be absorbed into a broader policy around arts and health. The then Arts Council England's Director of Engagement attended a seminar we were running sharing the work of D&I and afterwards stated 'You had been working with a group of older people as an advisory panel and they were there as delegates. I remember one woman getting quite emotional and saying, 'I don't want it to be about health – I want to live', I have quoted this numerous times. The session helped me to move away from a medical outcomes driven approach – at least when it comes to prioritising ACE funding. Interestingly we are now speaking to Public Health England and again this standpoint is helping us negotiate those conversations'. He also states that it helped shape their policy work in this area and the shape their future.

As part of the D&I impact strategy an arts practitioner handbook was produced. It is a set of useful ideas and recommendations setting out some foundations for developing visual arts

projects with and for, people affected by dementia. 9000 copies have been downloaded since June 2018 and it has been translated into Dutch. Newman presented the findings from D&I at a regional event organised by Arts 4 Dementia (24 July 2020), aimed at driving forward social prescribing as a pre-diagnostic practice. At the event, the Founder and Director of Research of Arts 4 Dementia advocated the value of the handbook and, in a subsequent letter of support, stated that 'The information in the *Cultural Trends* paper and the protocol papers also helped to inform and move forward [the Social Prescribing] programme, which we have rolled out across the country'. (IMP 10)

Other outputs from the project have had an impact on organisations working in the arts & wellbeing sector. The CEO of Creative Dementia Arts Network commented that one of the project publications (not listed in Section 3) helped 'to shape up [their] Mentorship scheme for arts and dementia projects'. (IMP 11)

An AHRC-funded Follow-on project, The Imagination Café (value GBP99,000), trained approximately 100 artists in the techniques developed by the project. 53 participants completed the project evaluations from training events in London and Edinburgh. Of these, 41 responses indicated that they had learnt something from the training. These responses were coded hierarchically as indicating: consolidation of existing knowledge (1); general learning of something new (18); learning new practices (11); learning new practices with an explicit intention to implement them in future work (11). As an example of the latter, a participant at the Edinburgh event wrote, 'I am about to begin a project with later stage dementia groups; I have learned ways to introduce an activity and stimulate responses will be very useful as my previous experience is with earlier stage dementia'. (IMP 12)

The Dementia and Imagination project has enriched the lives of older people living dementia, both those directly involved and those who have encountered the partner organisations and artists involved. In doing so the work has helped to address a major current societal challenge.

## 5. Sources to corroborate the impact

**IMP 1** Codebooks from analysis of semi-structured interviews - across Sites 1, 2 & 3 (available on request)

**IMP 2** Collated excerpts from transcripts of interviews with participants with dementia and carers/family members indicating impact on participants and/or on carers

**IMP 3** Open-text survey responses from carers and family members indicating an impact on them and/or their practices of care

**IMP 4** Codebook of content analysis of feedback from participants at D&I national practitioner day at the Wellcome Trust, London

**IMP 5** Interviews with artists on project from the North East, Midland and N Wales

**IMP 6** <https://www.youtube.com/watch?v=IQOE1lopvwY&sns=em> Video showing the impact of the project on artists' practice

**IMP 7** Letter of support from Equal Arts

**IMP 8** Letter of support from Age Watch

**IMP 9** Email from Arts Council England's (then) Director of Engagement

**IMP 10** Letter of support from the founder of Arts 4 Dementia

**IMP 11** Email from the CEO, Creative Dementia Arts Network

**IMP 12** Collated feedback from Imagination Café training for artists (available on request)