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## Age Exchange and Manchester Camerata



*Image provided by Age Exchange*

### Supporting those with dementia through creative practice

There is increasing [interest](#) in methods and approaches to support those with dementia to “live well” with their condition as the numbers of those with dementia continues to rise. Alongside practical approaches to help people remain independent and cope with memory loss, there is a focus on helping people to keep their minds active and use their life experiences to improve their wellbeing. This increased interest comes from both [commissioners](#) and [researchers](#) who wish to understand how different creative practices and participatory approaches can affect the lived experiences of people with dementia.

Dementia is a term used for a series of symptoms including memory loss, difficulties with thinking, problem-solving or language<sup>1</sup>. As well as problems with cognition, dementia can affect people’s moods and perceptions of what they can see or are experiencing<sup>2</sup>. These changes can affect their mental and physical wellbeing. There are around [850,000 people](#) in the UK with dementia, and this is expected to increase to one million by 2025.

This case study focuses on two organisations that are using arts based approaches to work with those living with dementia and their carers. Both organisations focus on improving day to day quality of life and wellbeing for participants.

### About the projects

#### **Age Exchange**

[Age Exchange](#) is a theatre trust that has a commitment to supporting creativity and wellbeing in later life. It is based in South London and has developed a range of projects which offer reminiscence and arts activities for older people, intergenerational projects for young people and The Exchange, a community space offering a library, café and volunteering opportunities. It also offers a range of services for carers including activities at The Exchange as well as outreach work in homes. A recent Big Lottery award will also enable it to develop day care services for three years.

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<sup>1</sup> Alzheimer’s Society 2016, *About dementia*. Available at:

<https://www.alzheimers.org.uk/site/scripts/documents.php?categoryID=200120>

<sup>2</sup> Alzheimer’s Society 2016, *What is dementia?* Available at:

[https://www.alzheimers.org.uk/site/scripts/documents\\_info.php?documentID=106](https://www.alzheimers.org.uk/site/scripts/documents_info.php?documentID=106)

Age Exchange developed an initial project, Hearts and Minds, which received £250,000 from South London and Maudsley NHS Foundation Trust. Working across three care units, it trialed approaches to supporting people with dementia through reminiscence and arts. This initial project was evaluated qualitatively, enabling Age Exchange to develop a three-year programme of work in 12 residential or continuing care units in Southwark and Lambeth: "RADIQL". This £620,000 pilot was funded by Guys and St Thomas' Hospital Charity between 2012 and 2015. The aim of the work was to gather evidence on the impact of activities on wellbeing, by undertaking a robust mixed-methods approach through Dementia Care Mapping™ and arts based research on reminiscence arts as a narrative, sensory and embodied practice. Other partners include Alzheimer's Lambeth & Southwark, Guy's and St Thomas' NHS Foundation Trust, and South London and Maudsley NHS Foundation Trust.

Through weekly structured group sessions and one-to-one support, residents are supported by Reminiscence Arts Practitioners to participate in person-centred and themed activities which use specialised materials to produce a creative output. Age Exchange are now exploring the commissioning market to deliver the intervention and associated staff training.

### **Manchester Camerata**

[Manchester Camerata](#) is a chamber orchestra based in Manchester. As part of its work, it operates Camerata in the Community, delivering creative, music-based projects to enable people to make positive social change in their own lives and communities. This work is delivered across three strands of activity: Children and Young People in their Schools, Health and Wellbeing and a Youth Programme.

The Music in Mind project works with people with dementia and has a mix of funding including from public health teams across the Greater Manchester (GM) area. It has been running since 2012 and offers a programme of music therapy over 30 weeks for up to eight groups in each locality or GM borough. Each session is led by a music therapist and musicians from the orchestra who have received training in music therapy theory and practice, which includes dementia awareness training. This year Camerata in the Community plan to work with 350 people across Greater Manchester as part of their dementia programme.

The sessions are designed as a way of working with those living with dementia using person centred improvisation, creating a piece or pieces in the moment responding to members of the group, their abilities and needs. The sessions do not require any previous knowledge of music and gradually support people to become more involved in the sessions. The Music in Mind project currently works within both care homes and community centres, and Manchester Camerata would like to extend this to work through professional carer training and working within hospitals



*Image provided by Manchester Camarata and Anderson Photography*

## Building the evidence base with research partners

Both organisations have built successful relationships with academic partners at the forefront of studies in dementia care and the impact of creative practices. They are developing research and evaluation approaches that are mutually beneficial for practical and theoretical work. Both organisations stated that there are challenges in gathering data from those with dementia. Therefore, approaches have been used which minimise the need for recall from participants, whilst gathering robust and comparable data.

Age Exchange has worked in partnership with researchers working on arts and social care at Royal Holloway University of London (RHUL) and Kingston University. The multi-disciplinary academic partnership includes specialists in the [significance of arts in community settings](#), [participant experience and reciprocity of activities](#), [medical statistics](#) and dementia care mapping. This partnership has allowed them to develop qualitative data collection tools using phenomenological and ethnographic methodologies such as observations, focus groups and practice-based methods to test ideas in practice. These enabled a deep understanding of what is happening within sessions.

In addition, they were able to collect observation data on participants during and after sessions using a Dementia Care Mapping™ tool. Dementia care mapping is an established approach to systematically gathering evidence from a patient perspective<sup>3</sup>. Staff are supported to critically reflect on the quality of care they offer from a patient's perspective, enabling an assessment of any changes to their Quality of Life. For example, one of the researchers supported a resident to walk to the session. The time taken to get down the corridor gave the researcher insight into the perceptions of the distance between rooms.

The data gathered allowed Age Exchange to understand the impact they were having on participants over the 24 weeks of the intervention. The quantitative data collected through the Dementia Care Mapping™ captured positive behaviour measures, such as whether people take part in activities, and Quality of Life measures, which combined scores on mood and engagement. It also allowed them to understand the limitations of the data they were collecting in terms of building the evidence base for commissioners. Age Exchange subsequently developed a partnership with [Simetrica](#) to build on the dementia care mapping work and to allow their staff to develop their skills and capacity to gather data. It was identified by Simetrica that this data lends itself to Cost Effectiveness Analysis (CEA), allowing an appraisal of the programme compared to other similar dementia programmes. Although the CEA was able to estimate the cost of creating a one-point change on the behaviour and mood scores, the authors were not able to find comparative studies to assess the cost effectiveness of this. Subsequently, Age Exchange has commissioned Simetrica to develop a Quality Adjusted Life Years (QALY) inventory tool which is currently being developed and tested. This will allow the gathering of data which can inform a more in-depth Value for Money analysis by comparing the outcomes they achieve with the cost of not intervening. It will be rolled out in 2016.

The evaluation of RADIQL found that there was a visible increase in positive mood and behaviour of the participants of the sessions. These positive outcomes were maintained for the duration of the programme and after three months they were found to have been maintained at the baseline or above. For example, a weekly one-hour intervention across twenty-four weeks was used to gather participants' levels of wellbeing. The evaluators found that improvements in mood and engagement were statistically significant, improving by 42%, and 'positive behaviour' also increased by 25%. In addition, relationships developed within the group. The researchers found that this relational approach, the process of engaging with others, had more impact than the type of reminiscence activities undertaken. They found that the most meaningful engagement for participants happened when there were opportunities for reciprocal learning: when they were able to share their experiences with others. This [video](#) offers insight into what this means for people involved.

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<sup>3</sup> For more information: <http://www.bradford.ac.uk/health/dementia/dementia-care-mapping/>



*Images provided by Age Exchange*

Manchester Camerata knew it needed to develop the evidence base from the start of this work. Whilst there is much evidence on the impact of music on health, Nick Ponsillo, Head of Camerata in the Community, wanted to be able to explain and evidence Camerata's role in a changing system of health provision.

An initial evaluation was undertaken by a [music therapist and music lecturer at Coventry University](#). This evaluation focused on the impact of group music therapy sessions on the participants, carers and the experiences of the participating musicians. The evaluation found that the participants in the sessions enjoyed their time, and subsequently some reported feeling happier and more relaxed. In addition, families and carers reported an immediate positive impact on their relationships. The findings from this study were published in the editorial of a peer reviewed journal, *Dementia*<sup>4</sup>. For the musicians, the specialist training helped them to develop new skills, and they reported positive experiences of working together in a group to make music and how this impacted positively on their playing within the orchestra.

In developing their evidence base, Camerata also worked with [New Economy](#) to undertake an evaluation of its work in 2013-14 and 2014-15 in order to gain an understanding of whether the duration of projects could affect the outcomes. This evaluation similarly gathered qualitative feedback to indicate that there had been improvements in mood and communication levels. This research found that longer engagement was important for development of relationships and sustaining wellbeing outcomes. In particular, it found that extending the duration of the programme over the core ten weeks had a positive impact on communication, social skills and relationships with other residents and carers. It also helped to develop the relationships and trust between participants and musicians. Throughout and alongside this evaluation, Manchester Camerata has collected observation data from carers and has published a number of videos which showcase the [stories](#) of those participating. These stories enable those who have participated to explain the experience of taking part, and how it made them feel.

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<sup>4</sup> John Habron, 'A conversation without words' – reflections on music therapy and dementia, *Dementia*, Volume 12, Issue 1, January 2013

Building on the evidence it has gathered to date, Manchester Camerata has developed a strong working relationship with specialists at [Manchester University](#) and [Lancaster University](#). This partnership has brought together specialists in dementia and ageing research and has been awarded funding for three years from the Economic and Social Research Council (ESRC) to fund a PhD studentship to develop an ‘in the moment multi-sensory music assessment tool. This tool will be used to gain a deeper understanding of the experience people are having “in the moment”, thereby overcoming some of the aforementioned challenges of gathering data from those with limited recall. As Nick Ponsillo stated “this is a way to test and retry our work, which will be backed up with evidence”.

The current work, with Manchester and Lancaster Universities, to develop a multi-sensory assessment tool is essential for Manchester Camerata to gather the quantitative evidence they need to share with clinicians who may seek to fund such work. This bespoke work will add to the emerging evidence base on the impact of music therapy of those with dementia.



*Image provided by Manchester Camerata and Anderson Photography*

### **Working in partnership with commissioners**

A significant proportion of Age Exchange’s work was funded by Guys and St Thomas’ Charity, as part of a programme to develop new approaches to tackling social issues. This partnership gave Age Exchange the flexibility to develop its work and test how it can create the most impact. As part of this programme, Guys and St Thomas’ Charity brought together all of their funded projects to discuss the challenges and opportunities of commissioning. The discussions amongst funded projects included ways in which to meet the needs of commissioners, many of which struggle to balance immediate with longer term needs. The funded projects have identified the need to develop the evidence base in order to show how they can create short term impact which can be articulated to commissioners.

Manchester Camerata initially approached public health commissioners to describe and promote their work. Since 2010, their relationships have gradually developed with a number of public health commissioners across Greater Manchester, including Tameside. They have found that they have developed an excellent working relationship with Tameside, which Nick describes as a “partnership” where they co-develop solutions to local problems through collaborative design. Nick feels that some of Manchester Camerata’s success is due to partners who have some background knowledge of the kind of interventions they offer, and a commitment to piloting new approaches which may help resolve public health challenges, such as the volume of prescribed medicine. Using a pilot approach, informed by a robust evidence base and alongside the development of further evidence has allowed them to become trusted partners, and now other councils are also interested in their work.

## Summary

These projects offer insight into the ways in which organisations offering creative practice and research organisations can work together to implement new, effective approaches. Both projects use staff who have a combination of creative ability with knowledge and understanding of dementia care. They have worked in partnership with funders and research agencies to co-design and deliver projects and ensure their work is underpinned by the latest theoretical and methodological knowledge. The breadth of their evidence base can be useful to commissioners and other providers: it provides quantitative evidence of the scale of the impact, with qualitative reflections about why their approach works. This can allow other organisations to use the learning within their own context to support local needs.

For more information and resources on Cultural Commissioning visit <http://www.ncvo.org/CCProg>

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