

2018

# ALMO Final Evaluation Report



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## Executive Summary

### Key Objectives

- ✚ Over the three years of the programme, ALMO achieved 10,898 participations. This figure more than doubled its original target of 5,000 participations;
- ✚ The Dukes and the fifteen partner venues held 241 ALMO events over the course of the programme. Despite the 'loss' of three venues to the ALMO brand, it has been successful in achieving adoption and spread of its film screening programme across the Northwest of England and beyond.
- ✚ The ALMO programme set a target of recruiting sixty volunteers. Overall, the programme recruited 72 volunteers, involved 26 artists and was able to engage wider voluntary and community contributions to the programme.

### Target Audience

- ✚ Just under 60% audience members comprised people living with memory loss and their family members with just under a third made up of general filmgoers indicating that ALMO has been successful in reaching its target audience.
- ✚ The demographic profile of film screening participants across the ALMO venues is overwhelmingly one of white British females aged between 65-74.
- ✚ Lack of ethnic diversity has been an issue across all venues. As film screenings continue to roll out ALMO may want to consider focusing on areas of higher ethnic diversity and engaging with members of that ethnic community to identify films and activities appropriate to that cultural group.
- ✚ The term dementia still holds stigma for some minority ethnic groups, ALMO may want to consider using other terms when advertising events in these areas e.g. relaxed screenings or 'memory loss' events.

### Access and Environment

- ✚ The majority of ALMO participants travel to venues by private car. Those living in larger towns and cities are more likely to use public transport, reflecting the limited availability of public transport in rural localities. Whilst only a small number of participants relied on transport provided through partner organisations, these people can be amongst the most socially isolated. It is important to consider this in any future ALMO rollout.
- ✚ Whilst ALMO was set up primarily for people with dementia living in the community and their family members, a significant number of attendees came from residential care settings. ALMO activities were equally effective for these individuals who, in the main, tend to be frailer than those living at home.

- ✚ Most venues were able to adapt their environments to make them dementia friendly spaces with relative ease and at low cost. The programme demonstrated that with care and thought even spaces that were initially seen as challenging could be adapted to meet the needs of people living with dementia. Venues do need to allow time to implement these adaptations prior to each activity.
- ✚ Better wheelchair access, age-friendly seating and sufficient and appropriate room for wheelchairs and mobility aids were the most significant accessibility challenges faced by venues. These issues should be borne in mind for future refurbishments. Venues should work with wheelchair users and older people to improve accessibility.
- ✚ Frail older people are more susceptible to cold than general theatre-goers. Venues wishing to deliver dementia friendly events should monitor heating levels particularly in cold weather.
- ✚ The success of the film screenings depends on how venues are set up to support dementia-friendly screenings and the dementia-friendly ethos of these events. ALMO has demonstrated that well-trained staff and volunteers are critical to this success.

### *Why People Attend ALMO Events*

- ✚ Most people were initially attracted to ALMO as going to the theatre or cinema had been an important part of their everyday social activity in their earlier years. ALMO reawakened that interest.
- ✚ A diagnosis of dementia is not the overarching characteristic that defines an individual. Participants stressed the importance of social opportunities that allow them and their family members, to retain their roles as husband/wife/father/mother/friend. ALMO is a good example of how this can operate in practice.
- ✚ For many participants ALMO provided an opportunity to get out of the home and reengage with the outside world.

### *The Importance of Social Space*

- ✚ Social space was important to all participants, pop-up cafes, bistros, interval entertainment all provided important opportunities for social engagement during ALMO events. For some, the social opportunities were as important as the arts-based activities. Importantly, it was the arts-based activity that stimulated them to attend ALMO in the first place.
- ✚ Participants spoke of the need to overcome social isolation and loneliness and to the importance of the social opportunities provided by ALMO for sharing their experiences of living with dementia with others in similar situations.

- ✚ For those with dementia, the ALMO environment offered a space in which they could connect with others and feel comfortable knowing people understood their physical and cognitive limitations.

### *Workshops and 'Still Me' Activities*

- ✚ For some workshop and 'Still Me' participants, engaging with the activities provided inspiration and empowerment. Artists and staff noted how the activities encouraged some people with dementia to shift from being passive observers to active participants.
- ✚ There is a strong element of person-centeredness in the way in which workshops and the Still Me activities are designed. Artists involved in these activities recognized the importance of ensuring that the activities were suited to the needs and interests of individual participants.
- ✚ Person-centred and iterative approaches reflect a growing acknowledgement of the importance of working with 'in the moment' understandings of the experiences of people with short-term memory loss. This is particularly important where that short-term memory loss inhibits a person's ability to reflect back on recent events.
- ✚ The success of workshop and Still Me activities for people with dementia and their family members relies on activities being flexible and based on an iterative process of listening and responding to the group.
- ✚ The evidence from ALMO suggests that the workshop and Still Me activity had a number of impacts on health and wellbeing including: enhanced communication and social interaction; improved confidence; enhanced mood and positivity; a sense of happiness, play and creativity.
- ✚ The WEMWEBS analysis indicates that there may be a wellbeing benefit to be gained from taking part in Still Me activities. However, this analysis draws on data from a very small number of participants so no significant inferences can be drawn. More reliable results would require further work with a much larger group of participants.

### *Staff and Volunteers*

- ✚ Staff and volunteers emphasised the enhanced job satisfaction they gained from working with people with dementia and their family members on the ALMO programme. However, success was dependent on 'buy in' and an understanding of the requirements needed to run ALMO from senior management within venues.
- ✚ Friendly and approachable staff are key to developing dementia-friendly environments.

- ✚ For some staff and volunteers ALMO offered opportunities to develop an enhanced understanding of inclusive practices.
- ✚ An unanticipated benefit to staff and volunteers working on the ALMO programme was an enhanced understanding of how to engage with people with dementia – this understanding extended into their everyday lives.

### *Collaborative Working*

- ✚ Collaborative working with Age UK has been key to the success of the ALMO model, particularly in identifying and referring participants, arranging transport and providing a known face to 'meet and greet' when first attending events.
- ✚ Venues highlighted challenges to delivery where collaborative partnerships had not been developed with local dementia organisations.
- ✚ Many venues were able to engage wider community and voluntary contributions to ALMO including the provision of refreshments, lunches and interval entertainment.

### *Sustainability*

- ✚ Overall, dementia-friendly film screenings have been successful in most venues. With the introduction of an admission fee for carers/family members, film-screenings hold good potential for becoming self-sustaining in the future.
- ✚ Workshops and Still Me are highly valued by those participating but are resource intensive to run. ALMO needs to consider alternative and more sustainable models for running these activities. Attendance charges, reducing the number of artists facilitating activities and increasing the number of volunteers to support these activities may offer a potential way forward.

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## Context

### *Health, Wellbeing and the Arts*

In recent years, there has been increased recognition of the positive impact that participatory arts can have on the health and wellbeing of people who experience mental or physical health issues. A recent All-Party Parliamentary Group inquiry into Arts, Health and Wellbeing (2017) highlighted three key messages:

- i) The arts can help keep people well, aid recovery and support longer lives better lived;
- ii) The arts can help meet major challenges facing health and social care including ageing, long-term conditions, loneliness and mental health; and
- iii) The arts can help save money in health and social care.<sup>1</sup>

Whilst there are a number of different ways in which this body of evidence is referred to (for example, arts in health, arts for health, arts and health), essentially, they are all concerned with the effect that an active engagement with the arts can have on the health and wellbeing of individuals and communities.

Participatory arts programmes, with which this report is concerned, involve both the social and creative outlets that the arts can provide for people who experience either physical or cognitive health issues. Many care homes, GP surgeries and hospitals as well as community settings now provide opportunities for people to engage with the arts as a mechanism for improving wellbeing.

### *Why focus on dementia?*

There are currently over 850,000 people in the UK living with dementia and these figures are projected to increase rapidly. A recent survey undertaken by Alzheimer's UK revealed that 38% of the population now have a family member or close friend living with dementia.<sup>2</sup> Indeed, Public Health England has maintained that dementia is fast becoming the health issue of our time.

Across Lancashire and Cumbria, over 15,000 people aged over 65 years received a diagnosis of dementia between 2017-2018, a figure that is 5% higher than the national average<sup>3</sup>. With no treatment currently available to prevent dementia and no cure for the disease, there is increasing emphasis on the need to focus on ways in which we might enable people with a diagnosis of dementia to live as well as possible in their own communities.

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<sup>1</sup> Creative Health: The Arts for Health and Wellbeing, The Short Report (July 2017) All-Party Parliamentary Group on Arts, Health and Wellbeing Inquiry. Available at:

[http://www.artshealthandwellbeing.org.uk/appg-inquiry/Publications/Creative\\_Health\\_The\\_Short\\_Report.pdf](http://www.artshealthandwellbeing.org.uk/appg-inquiry/Publications/Creative_Health_The_Short_Report.pdf) [accessed 03/10/18]

<sup>2</sup> Dementia 2014: Opportunity for change, Alzheimer's Society, September 2014.

<sup>3</sup> Public Health England Dementia Profile 2018. <https://fingertips.phe.org.uk/profile-group/mental-health/profile/dementia/data#page/4/qid/1938133052/pat/15/par/E12000004/ati/120/are/E06000015/iid/92949/age/27/sex/4> [accessed 05/09/18].

The Prime Minister's Challenge on Dementia 2020 further highlighted a real need to: i) develop dementia friendly environments which both enhance the ability of those with dementia to live as well as possible within their communities; and ii) promote greater awareness and understanding of dementia within the wider community<sup>4</sup>.

### *Dementia Friendly Communities*

The focus on supporting people to remain at home in their own communities for as long as possible has underpinned the drive toward dementia friendly communities. This concept emerged from the 'age-friendly' movement that has been supported by the World Health Organisation for some time. This movement recognizes that for most older people, and those with chronic degenerative health conditions such as dementia, the desire to remain in one's own home for as long as possible is paramount - and preferable to an institutional setting such as a hospital or care/ nursing home. It also means that much of their everyday care and support falls to spouses, partners and other close family members.

Enabling community dwelling is important as the evidence demonstrates that remaining in a familiar environment becomes increasingly important as we age (Axia et al, 1991; Greenberg, 1982; Laws, 1994). This is particularly the case for people with dementia, where removing an individual from a familiar environment can compound their confusion and reduce their ability to cope (Burley and Pollock, 1992; Fogel, 1992; Goldsmith, 1996). Evidence suggests that people with dementia are more likely to injure themselves in unfamiliar environments, such as a respite settings, care homes or hospitals, due to increased anxiety and disorientation caused by having to cope with unfamiliar places, people, and objects (Baragwanath, 1997). Conversely, a *familiar* environment can present a predictable and reliable setting that is less likely to create stressful new situations that a person with dementia is unable to understand or contend with (Calkins, 1988; Golant, 1984).

The drive for dementia friendly communities has sought to find ways to translate this sense autonomy, independence and safety *beyond* the home and to a broader range of settings. Whilst there is no universally accepted definition of dementia friendly communities, these settings are widely acknowledged to be:

*'Places where people with dementia are understood, respected and supported, and confident they can contribute to community life'.<sup>5</sup>*

The aim of dementia friendly communities and environments is to be inclusive, welcoming and supportive to those affected by dementia, enabling them to contribute to, and participate in, mainstream society.

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<sup>4</sup> Department of Health (2015) Prime Ministers Challenge on Dementia 2020. Available at: <https://www.gov.uk/government/publications/prime-ministers-challenge-on-dementia-2020> [accessed 05/09/18].

<sup>5</sup> <https://www.alzheimers.org.uk/get-involved/dementia-friendly-communities/what-dementia-friendly-community> [accessed 22/11/18].

## A Life More Ordinary

*A Life More Ordinary* (ALMO) was designed to bring together thinking around the arts, memory loss and dementia friendly communities in a way that would give people living with dementia and their family members more choice, control and greater access to leisure and cultural opportunities at The Dukes Theatre in Lancaster and other art venues that would become part of the ALMO programme.

The programme built on evidence emerging from a three-year Age UK Lancashire (AUKL) Big Lottery Funded project, called *Linking Communities*. This project revealed that older people with dementia and their family members wanted to continue their everyday relationships beyond the home but found it highly challenging to participate in the sorts of activities enjoyed by the wider population; or to find existing services that allowed them to participate as couples or partners. Services are largely designed *either* to meet the needs of the person with dementia *or* their family carer – but not both, and not together. Yet as the findings of a survey conducted by the Alzheimer's Society in 2014 revealed, over 40% of those with dementia experience loneliness and 34% do not feel part of their local community, with a similar impact on their family carers<sup>6</sup>.

The evidence from the Linking Communities project provided the foundation for a joint bid developed by the Dukes Theatre and Age UK Lancashire. This bid was submitted to the Esmée Fairbairn Foundation, who subsequently funded a six-month pilot, called *Journeying Together*. In sum, the programme consisted of a series of dementia-friendly film screenings and taster arts workshops designed for people with dementia and their family members. The programme was offered at The Dukes Theatre in Lancaster. Over 250 people, comprising people with dementia and their family carers, as well as members of the general public, took part.

The pilot provided sufficient evidence to suggest the beneficial impact that such a programme might have on the lives of people with dementia and their family members. The Dukes and Age UK sought to further expand and progress the pilot work through a three-year project designed to:

- a) Develop a dementia-friendly film-screening model that could be rolled out to other venues across Northwest England and beyond;
- b) Continue and extend the programme of workshops offered at The Dukes; and
- c) Develop a new participatory theatre group at the Dukes for people with dementia and their family members.

### *ALMO Aims and Objectives*

The overall aim of ALMO was to enable The Dukes, in partnership with Age UK Lancashire, to make a significant transformational step from being a 'provider' of art-

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<sup>6</sup> Dementia 2014: Opportunity for change, Alzheimer's Society, September 2014.

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based opportunities for people with dementia and their family members to being a central 'stakeholder' in dementia-friendly access development.

Its three core objectives were to:

- Improve the quality of lives for people with memory loss and dementia and their families through the development and delivery of specialist arts-based services and activities;
- Give people living with dementia more choice, control and greater access to leisure and cultural opportunities at The Dukes and other arts venues across the county;
- Create a body of expertise, understanding and good practice to be disseminated to arts venues and providers of dementia services across Northwest England and beyond.

### **Goals:**

The ALMO programme set the following goals for the delivery of its core aims and objectives:

- i) Create a minimum of 5,000 participations throughout the life of the programme, to include people and their families living with dementia and integrated audiences;
- ii) Involve a minimum 60 strong volunteer group;
- iii) Roll out the programme to venues across Lancashire, the North West and beyond, to include localities chosen in consultation with Age UK Lancashire, which have limited dedicated venue spaces.

## **Evaluation Approach**

Funding constraints did not allow for a full independent evaluation, the Dukes Theatre and Age UK thus collaborated with Professor Christine Milligan from Lancaster University Centre for Ageing Research, who was commissioned to support the evaluation of A Life More Ordinary (ALMO) over the course of the three-year programme (from 1<sup>st</sup> November 2015 to 31<sup>st</sup> October 2018). Prof Milligan undertook a consultancy and training role linked to the evaluation that incorporated:

- 1) Support with the overall evaluation design and evaluation materials;
- 2) Training of staff in evaluation methods and how to apply these methods in evaluation research;
- 3) Oversight of ongoing data collection;
- 4) Oversight of the analysis of the data;
- 5) Support in writing the interim and final reports.

This level of input from Lancaster University was deemed to provide a sufficient level of independence to the final evaluation, whilst at the same time allowing for capacity

building amongst staff employed at the Dukes Theatre and other participating venues. An added advantage of this approach was that it enabled staff at participating venues to gain insight into some of the basic skills required to design and undertake internal evaluation for future programmes.

It is worth noting, that due to changes in the overall programme manager and a gap in the appointment of the current programme manager in the early years of the ALMO programme, some elements of staff involvement in training and evaluation did not occur. The bulk of the analysis and writing of the evaluation reports (both interim reports and the final report) was undertaken by Prof Milligan.

Rahena Mossabir, a doctoral student supervised by Prof Milligan, also contributed to the evaluation. Ms Mossabir undertook and transcribed some of the interviews with participants with dementia and their family members and also some focus groups with staff and volunteers. She also contributed to the analysis of interview data.

### *Evaluation Objectives*

The primary objective of the ALMO evaluation was to assess the impact of the programme on the lives of people living with dementia and their family members/carers, including their subjective sense of wellbeing.

Secondary objectives were to:

- a) Evaluate how the spaces offered by theatres or cinemas involved with the ALMO programme could be adapted/designed to be more inclusionary for people living with dementia; and
- b) Assess the impact of the ALMO programme on staff and volunteers involved in running and supporting ALMO within these venues.

### *Methods*

This was a service evaluation undertaken by the Dukes Theatre; hence, it did not require formal ethical review. Nevertheless, it was agreed with the Dukes ALMO programme manager that firstly, people would be apprised verbally of the purpose of the film screening survey and that completion of the survey was voluntary and did not affect their ability to attend the film. Secondly, that written informed consent would be gathered from all those taking part in the creative workshops, the Still Me theatre activity, as well as the interviews and focus groups. This included people with dementia and their family members/carers, staff and volunteers. Information sheets and consent forms were developed during the first three months of the programme. The process of gathering written informed consent from participants was overseen by the ALMO programme manager.

The evaluation adopted both a formative and summative approach and comprised:

- **A film screening survey** completed by those with dementia and their family members as well as members of the public attending the dementia-friendly screening across all participating venues;

- **Reflective Diaries** completed by staff, volunteers and co-ordinators involved in film screenings, workshops and the Still Me theatre group at the Dukes Theatre;
- **Observation/visual data/mini interviews** – undertaken with people with dementia and their family members at the Still Me theatre group during Still Me sessions;
- **Dyad Interviews** (with participants with dementia and their family member);
- **Focus groups** with staff and volunteers from participating venues;
- **A validated quality of life survey (WEMWEBS)** – completed before and after each set of Still Me sessions (run over 10 weeks each), by the small cohort of people with dementia and their family members participating in the Still Me theatre group.

Table 1 below summarises the data on which the evaluation draws:

Table 1: Evaluation Data

| Method                   | Number                 | Participants  |
|--------------------------|------------------------|---|
| Film screening surveys   | 1378                   | Film screening attendees across all participating venues - Years 1-3                          |
| Focus Groups             | 5 (N= 19 participants) | Staff and volunteers across participating venues - Year 3                                     |
| Reflective Diaries       | 128                    | Staff and co-ordinators across Years 1-3  |
| Interviews               | 24                     | Staff/artists (N=9) Years 1 & 3<br>People with dementia & their partners (N=15) Years 1 and 3 |
| Observational interviews | 12                     | Still Me participants – Years 2 & 3   |
| WEMWeBS QoL survey       | 24                     | Still Me participants – Years 2 & 3   |

It is important to note that whilst the film screenings were rolled out across fifteen partner venues as illustrated in Table 1 below, workshops and the Still Me programme were specific to the Dukes Theatre. So, whilst the evaluation of the ALMO film screenings relates to all participating venues, the evaluation of the other ALMO activities are specific to the Dukes Theatre. Furthermore, as venues have joined and left ALMO at different points in the programme, it is not possible to evaluate each venue independently. The evaluation of the film screenings presented below is thus a summary analysis of all venues across the three years of the programme.

### Achievement against targets

- Over the three years of the programme, ALMO achieved a total of 10,898 participations – a figure that more than doubled its original target;

- ii) The programme engaged seventy-two volunteers achieving beyond its original target of sixty volunteers. It also involved twenty-six artists and engaged a range of community and voluntary contributions to the programme.
  - iii) In terms of adoption and spread, the programme was rolled out to fifteen partner venues holding a total of 241 ALMO events over the course of the programme.
- Overall, the programme was successful in achieving its objectives.

## Partner venues

Table 2 below identifies all fifteen venues that became ALMO partners during the course of the programme. Whilst the three asterisked venues (Table 1) left the ALMO partnership after their initial commitment to six screenings, all have chosen to continue offering dementia friendly, or relaxed performances within their venues. FACT picture house also rolled these screenings out to all of their cinemas across the UK. Hence, despite some losses to the ALMO 'brand' the programme has thus been highly successful in rolling out its dementia friendly film-screening model across the UK.

Table 2: ALMO Partner Venues

| Partner Venue                       | Current Status  |
|-------------------------------------|---|
| Chorley Little Theatre*             | Left ALMO after their initial 6 screenings 10.11.16 (Year 2). Continuing with Inclusive screenings.                     |
| Fact Picture house, Liverpool*      | Left ALMO after initial 6 screenings. 20.7.16 (Year 1) Continuing dementia friendly screenings across their UK cinemas. |
| Hyde Park Picture House, Leeds      | Continuing with Memory Matinees   |
| Light Cinema Wisbech                | continuing as ALMO partner  |
| Light Cinema, Bolton                | continuing as ALMO partner  |
| Light Cinema, Cambridge             | continuing as ALMO partner  |
| Light Cinema, New Brighton          | continuing as an ALMO partner   |
| Light Cinema, Sheffield             | continuing as ALMO partner  |
| Light Cinema, Thetford              | continuing as ALMO partner  |
| Light Cinema, Walsall               | continuing as ALMO partner  |
| Ludlow Assembly Rooms,              | continuing as an ALMO partner   |
| Oldham Coliseum                     | continuing as ALMO partner  |
| Stephen Joseph Theatre, Scarborough | continuing as ALMO partner  |
| Theatre Colwyn,                     | continuing as an ALMO partner   |
| Wem Town Hall*                      | Left ALMO after their initial 6 screenings 5.12.16 (Year 2). Continuing with relaxed screenings.                        |

### Demographic Profile of Film Screening Participants

Based on analysis of the surveys over the three years of the programme, an average of 68% of those participating in the dementia friendly film screenings have been female and 24% have been male (the remaining 8% gave no response to this question). Audiences have thus been overwhelmingly female. There is no clear rationale for this although the choice of film screenings, which have been largely musicals, particularly in the first two years of the programme, may have influenced this pattern. It is also worth noting that whilst these events were initially targeted at people with dementia and their partner/family member living at home, film venues did experience a greater than anticipated take up from residential care homes. As the gender balance in care homes is overwhelmingly female (72% f v 28% m)<sup>7</sup>, and the percentage of residents in care homes who have dementia is higher than that of the proportion of those of the equivalent age group in the community, this is likely to have influenced the gender profile of attendees. Indeed these figures quite closely reflect the overall gender balance of film attendance.

Figures 1 and 2 below show attendance at film screenings by age cohort. Figure 1 illustrates the percentage of those attending by age for each individual year. Across all years, the overwhelming majority of those attending have been in the 65+ age cohorts. Interestingly there were significantly more in the 65-74 age group attending film screenings in year 1 than in the following two years. Figures for years 2 and 3 are very similar.

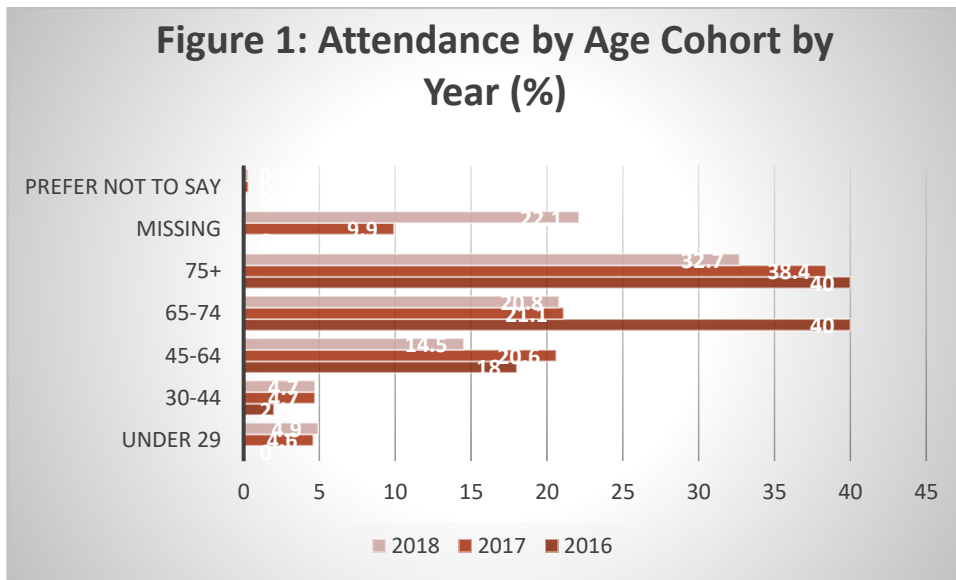
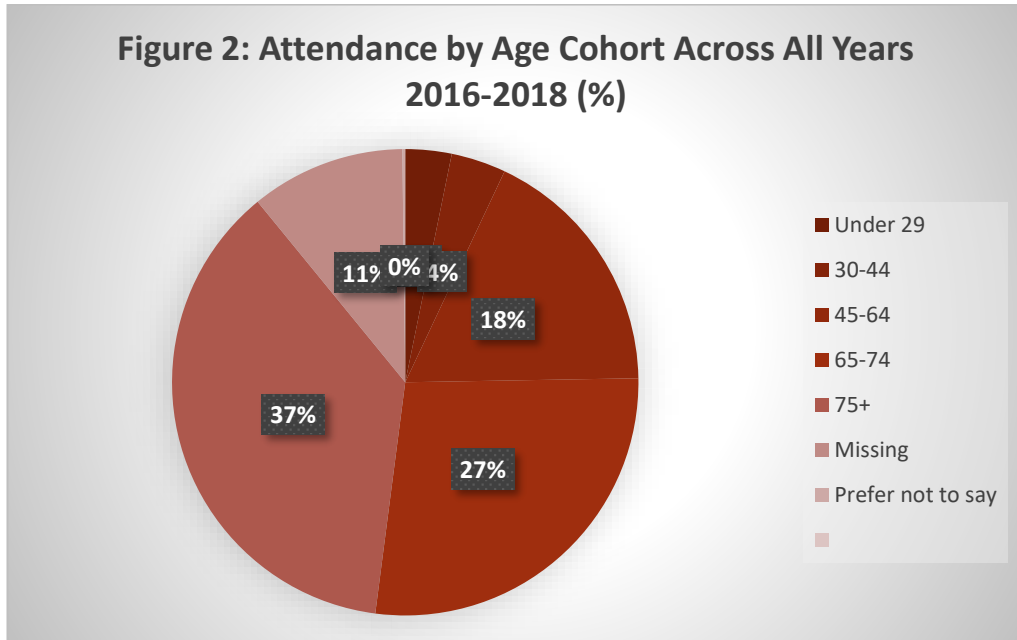


Figure 2 below shows the average (%) attendance across all three years of the programme. Overall, the majority of film screening attendees have been in the 75+ age group (37%) with just over 27% coming from the 65-74 years age group. Nearly

<sup>7</sup> Lievesley, N., Crossman, G. and Bowman, C. (2011) The Changing Role of Care Homes. BUPA and the Centre for Policy on Ageing. P.20 Available at: <http://www.cpa.org.uk/information/reviews/changingroleofcarehomes.pdf> [accessed 03/10/18]



2/3rds of the total film screening audience have thus been made up of those aged over 65 years.



In terms of ethnicity, the audience was almost entirely white British. The lack of ethnic diversity was raised in year 1 but has continued to be an issue throughout the programme. Less than 2% of those completing the film survey described their ethnicity as non-white. Venues are aware of this lack of diversity and have been considering how they might address it.

There are a number of reasons why ethnic diversity may have been limited. Firstly, it is possible that the film choices may not have appealed to specific ethnic groups. As film screenings continue to roll out, ALMO may want to consider: a) paying particular attention to encouraging venues in areas with a higher ethnic diversity to take part in the programme; and/or b) whether some screenings might be specifically designed for particular ethnic minority groups.

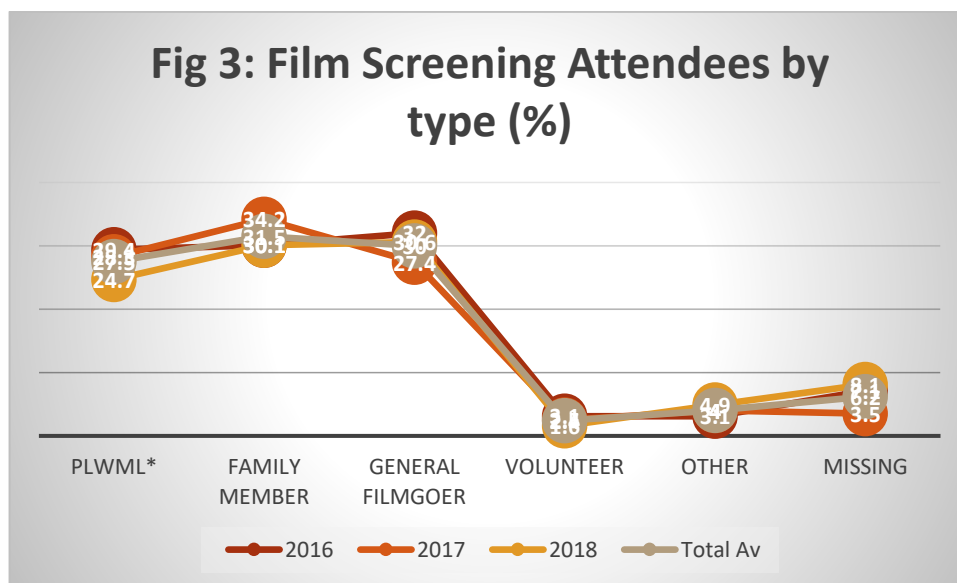
Secondly, there is still a sense of stigma attached to the term 'dementia' in some older ethnic minority groups and hence advertising these film screenings as 'dementia friendly' may create a barrier to people's willingness to attend. In areas where venues wish to attract a more diverse audience, they may wish to consider their advertising and look for an alternative to the term 'dementia friendly film screenings'. It would be worth discussing what terms would be most suitable with members of the local ethnic community that the venue wishes to target, but 'memory loss' or 'relaxed screenings' may be suitable alternatives.

As Table 3 and Figure 3 illustrate, the pattern of those attending across all venues was very similar across all three years of the programme. Just under 60% of the audience was made up of people living with memory loss and their family members, with just

under a third made up of general filmgoers. In sum, this demonstrates that the ALMO programme has been successful in reaching its target audience.

Table 3: Percentage of Film Screening Attendees by Type (%) 2016-2018

| Attendee   | PLwML* | Family Member | General Filmgoer | Volunteer | Other | Missing |
|------------|--------|---------------|------------------|-----------|-------|---------|
| 2016       | 29.4   | 30.1          | 32               | 3.1       | 3.1   | 7.1     |
| 2017       | 28.3   | 34.2          | 27.4             | 2.5       | 4     | 3.5     |
| 2018       | 24.7   | 30.1          | 30.6             | 1.6       | 4.9   | 8.1     |
| Av.2016-18 | 27.5   | 31.5          | 30               | 2.4       | 4     | 6.2     |



\*PLwML = Person living with memory loss

Interestingly across all three years of the programme, slightly more family members attended than people with memory loss (an average of 31.5% v 27.5%). This suggests that some people with memory loss have been accompanied to film screenings by more than one family member, or that family members have continued to attend after the loss of their loved one. This is not an unusual occurrence as ‘ex-carers’ look to maintain the friendships made through these types of activities. The percentage of those that defined themselves as ‘others’ in the survey are likely to be formal (paid carers) either from community care services or paid carers accompanying those with memory loss from residential care homes.

## The impact of ALMO on the Quality of Life of People with Memory Loss and their Family Members

### Inclusionary Access

Key to the success of a programme such as ALMO is ensuring the target audience is able to access suitable transport to the venue and that the venue itself is accessible to those with limited mobility and/or cognitive impairment. Within both the film

screening survey and the qualitative data, participants (including those with memory loss and their family members, staff, artists and volunteers) were asked about transport and access to the building, how the building needed to be adapted to meet the needs of people with dementia and the constraints the building itself imposed on their ability to make the necessary adaptations.

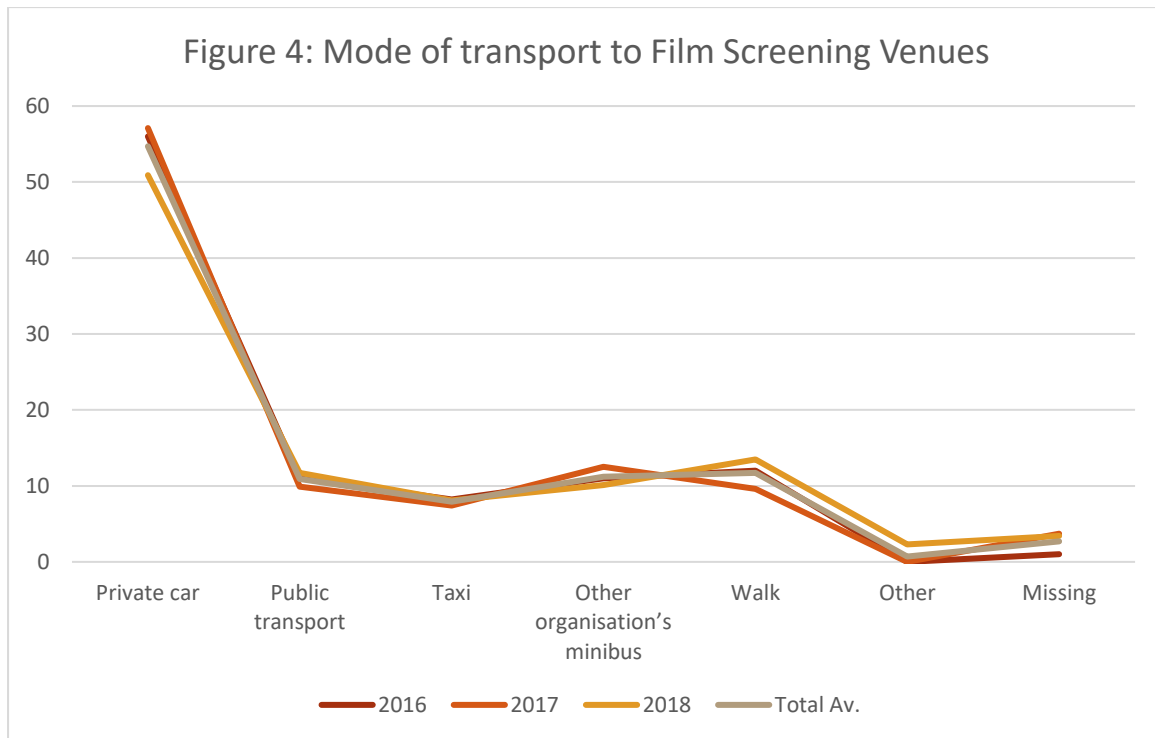
Table 4 and Figure 4 below illustrate the mode of transport used to get to the venue by film screening attendees (%) over the three years of the programme.

*Table 4: Mode of transport to Film Screenings 2016-2018*

| Mode of transport | Private car | Public transport | Taxi | Other organisation's minibus | Walk | Other | Missing |
|-------------------|-------------|------------------|------|------------------------------|------|-------|---------|
| 2016              | 56          | 11               | 8.2  | 11                           | 12   | 0     | 1       |
| 2017              | 57.1        | 9.9              | 7.4  | 12.5                         | 9.6  | 0     | 3.7     |
| 2018              | 50.9        | 11.7             | 8.1  | 10.1                         | 13.5 | 2.3   | 3.4     |
| Av. 2016-18       | 54.7        | 10.9             | 7.9  | 11.2                         | 11.7 | 0.7   | 2.7     |

The vast majority of those attending film screenings travelled to venues by private car (54%), although a significant number of people travelled by public transport or walked (22.6% in total). Those travelling by minibus included people coming from residential care homes, or those attending with a paid care-worker. The numbers of attendees who walked or who came by private car is also likely to be partially skewed by the number of general filmgoers attending. However, it is also important to bear in mind that where venues are located in more rural localities, or where attendees are drawn from more rural areas, public transport can be limited, so private transport is likely to be the main mode of travel. In Chorley, for example, a market town with a more rural population, nearly 2/3rds of all attendees came by private car compared to the FACT Cinema in Liverpool – a major city with good transport links – where around 46% came by public transport.

As the graph in Figure 4 (below) clearly illustrates, the mode of transport across all three years of the programme followed a remarkably similar pattern.



***Dementia-friendly film screenings: the physical environment***

In general, all those attending film screenings thought the quality and availability of information about the programme across all venues was excellent. The quality of facilities within the venues such as access to the building, toilet facilities, lighting, signage and the general atmosphere was also deemed good or excellent in most cases. Venues had gone to considerable effort to think about issues such as enhanced lighting, clear signage, easy access (or solutions to access where this was an issue e.g. separate screenings in smaller flat floor accessible rooms for those with particular mobility issues, or overspill as required). As one venue manager noted:

*We de-cluttered the foyer, including removal of all belt barriers, turned off front of house music and displayed clear signage. Lighting was slightly higher than normal, no ads or trailers and interval.*

*These events are always very well attended and it is wonderful to see how much people enjoy them. It is really difficult to squeeze in all the wheelchairs and it is time consuming seating everyone. Staff and volunteers went out of their way to help customers and engage with them. Everyone is committed to ensuring they have a positive experience.*

*We need a larger auditorium, but because we use ground floor screens – so we have two screens in use to accommodate all the customers (1 and 2). Versatile and adaptable seating would be really useful.*

(Theatre Manager diary)

Film screening attendees did comment that wheelchair access in some venues was poor and given the target population, the demand for wheelchair space, or space for walking frames, could outstrip availability. Some venues were able to address this through removable seating systems, taking out one or more rows of seating to provide additional space for wheelchairs and walking frames as required. For some older venues, however, this was a challenge. Some sought to deal with this issue by running parallel screenings. Although an innovative solution, this clearly influenced people's overall experience of attending an 'everyday event'.

The positioning of wheelchairs was also important. Some respondents commented on the need for better placing to enhance wheelchair users' viewing experiences. Others commented on the need for higher chairs with arms that would help older people with limited mobility to get in and out of their seating.

While venues are clearly limited by the configuration of the current space they have, these issues should be taken into account in future refurbishments. Venues should also consider working with wheelchair users to improve the location of spaces for wheelchairs.

Over the three years of the programme, a small number of respondents commented that they found venues to be cold. Whilst 2018 was a particularly cold winter, it is worth bearing in mind that frail older people are far more susceptible to cold than younger people, so venues offering dementia friendly screenings need to monitor heating levels, increasing the heating above the norm in colder weather for these events.

Over the course of the programme, a few respondents also noted that they had difficulties hearing the films. Conversely, one or two other respondents commented that they found the volume to be too loud. Heightened volume levels may have been a response by venues to earlier comments about difficulties hearing the films. Hearing loss does increase as people age, but this varies, so it may be worth considering the introduction of sub-titles to films as an alternative to adjusting volume levels.

#### *What stimulates people to attend ALMO activities?*

Of those interviewed, going to the cinema / theatre was something that they had done quite regularly when younger and had formed an important part of their social life. While some had stopped engaging in these activities as they grew older, either because they had become physically less mobile, had lost their partner or the friend who would normally have accompanied them, or had moved to an area where these facilities were less accessible, others had tried to continue to go occasionally with friends and family until they felt it had become too difficult because of their dementia.

The love of music and dance or having been a regular at their local theatre or cinema, made the ALMO programme particularly appealing:

*'As teenagers we went to the rep, but not in later years. So ALMO sort of gave us our interest back'*

(Still Me and film screenings participant 13- Carer)

*'The singing and dancing, it's wonderful... always loved to dance, yeah.'*

(Still Me participant 6- PWD)

*'Well I've come this afternoon because I like dance music and I like dancing as much as I can do'*

(Dance workshop participant 5-PWD)

Although some participants had not been involved in these types of activities since their younger years, the ALMO programme had reawakened that interest. As one participant noted:

*I used to do ballroom dancing, a long time ago, years ago. And then it stopped, I married, I didn't marry a dancer so... it's nice to get people together isn't it?*

(Dance Workshop participant 4-PWD)

As with decisions on film choices that focused on films and musicals that would have been popular in filmgoers' younger years, those facilitating workshop activities sought to draw on participant's past interests (dance and music genres from their younger years) to ensure activities held a wide appeal to the group:

*'I think singing songs from their memories and their past, songs that are very, still very well known to them. You know in a situation where things may not be very familiar, and they feel confused at times and it's lovely to have something so familiar that they can be part of in a group.'*

(Singing workshop facilitator, March 2016)

All those interviewed had attended dementia-friendly film screenings and had chosen to attend because the films shown were ones they knew and had enjoyed in the past. The experience of coming to the theatre or cinema and watching one of their favourite films brought back good memories and stimulated discussion between those attending with dementia and their family member. As one participant noted, the film stimulated conversation between her mother and herself about the *'outfits and the costumes, anything from the time she was young'*.

### ***The importance of 'being together'***

A second rationale for participating in ALMO activities related to the importance of being able to continue to do things together with close family and friends. Since receiving their diagnosis, people with dementia and their family members noted that they had given up certain activities due to the physical and cognitive changes arising from their dementia. As a result, both the person with dementia and their main family

carer found themselves increasingly restricted to the home, resulting in declining opportunities to meet and socialise with others in wider community settings. This reflects what the research evidence tells us about the restrictions on people's lives that arise as a consequence of dementia, not just for the person with dementia, but also for their family members.

Providing opportunities for people with dementia and their family members to take part in everyday and innovative activities within art venues was core to the ALMO programme. As one staff member described it:

*[the ALMO programme is] 'about inviting people with dementia to come along with their family member or carer, it's about the relationship and when that works it's beautiful... They are together; they hold hands and enjoy the experience together... There is a sense of coming to something to share with your family and carer.'*

This view was echoed by participants, as the wife of one participant with dementia noted:

*'I'm not here as his carer, I'm his wife... I was hoping this would be more of a day out for us... we've been offered groups for him about three times before and we've said 'no', I'm like 'no I'm here as well' so yeah.'*

**(Film Screening & Still Me participant 4-carer/wife)**

This emphasises the importance of providing opportunities that are not solely for the person with dementia or for the family carer. Rather, it reflects the need for opportunities that recognise that a diagnosis of dementia is not the overarching characteristic by which a person should be defined. Social opportunities should allow people with dementia and their family members, to retain their roles as husband/wife/father/mother/friend and so forth. This is particularly the case in spousal or partner relationships, where maintaining their identity as part of a couple is clearly important to both in retaining a sense of self and wellbeing.

*'It's stepping out of your role at home... being in a place to be yourself... just little things in the theatre - holding hands, be a couple, have fun.... It's important to know you can have a nice time doing what you're doing, but they're also having a nice time.'*

**(Still Me and Film Screening participant 11 carer/ volunteer)**

The importance of being able to continue to do everyday things together is poignantly summed up by the same participant in the following quote:

*'We want a life that is ordinary, to do things we've always done, perhaps slightly differently.'*

**(Still Me and film screenings participant 11- carer/ volunteer)**

### *Creating a dementia friendly atmosphere*

Whilst physical adaptations were clearly critical for ease of access and wayfinding, the success of the film screenings also depended on the dementia-friendly ethos that underpinned these events. As one artist commented:

*'the 'welcome is so important', to welcome them into the space. It becomes such a massive part of the session, to welcome the participants into the environment so that they are all around that table.'* (Jan 2018)

Participants commented on how helpful it was to have additional people to support them during the events:

*'... you get help and I mean there are people who meet us and greet us and they do help...I mean I use 2 sticks so it's not easy to carry a cup of coffee, and that's done for you. Yes, we get a lot of help. It's great.'*  
(film screening participant 15)

*'It's quite heavily manned, that makes a difference'*  
(Still me participant 3-PWD)

However, rather than talk about individual aspects of a venue, participants often referred to their appreciation of the overall atmosphere and the *feel* of the place. One participant in discussing the welcoming atmosphere of the venue during the film screenings described it as a *'kinder environment'* and considered dementia friendly spaces to be generally kinder and friendlier spaces for all.

*I think it's the very fact that you can get up and walk about if you needed to or you could chat whilst it's being screened, you know.'*  
(Film screening participant 10-Carer)

*'The whole atmosphere of the Dukes reminds me of what we used to do, it's not like these modern places...it's nice spirit, always friendly and staff couldn't be more helpful. It's got a very nice feel'*  
(participant 13-carer)

### *The importance of dementia-friendly social spaces*

For family members, one of the key benefits of attending dementia friendly cinema/theatre screenings was that it provided them, and their loved one with dementia, an opportunity to get out of the house and meet new people. The report has already alluded to how a diagnosis of dementia can result in a retraction of people's engagement in activities beyond the home; and whilst most of those attending film screenings as couples (whether spousal, sibling or other family member) lived at home, some resided in care homes. As one family member, whose mother lives within a specialist dementia residential unit noted:



*' [mother] complains she feels like a prisoner' (ALMO2).*

Coming to the film screening together thus:

*'gives them a bit of normality' (ALMO1).*

These brief quotes suggest that this type of activity can be effective not just for those living in their own homes, but also for those living in specialist dementia or residential environments. This was reinforced across the programme where most participating venues found that at least some of their audience (and in some cases, the majority of their audience) was made up of those living in residential care settings.

Where possible, venues also sought to set up social spaces (existing or 'pop-up' cafes) at film-screening events to maximise social opportunities and to have extra staff/volunteers available to provide support to participants alongside changes made to the physical environment. As one member of staff noted:

*'We are trying to be a dementia friendly café, so we have little pieces of paper on the table to help them [people with dementia and their family members] write down what they'd like for lunch, you know, just to make things a lot easier. Then we start the screening. We have ushers meeting them guiding them to their chairs. We have Care Homes come in minibuses that can drop off at the back and we help Care Homes get in and out easily. And then we have an interval half way through the film, we try and find a good point in the film to stop it. We have tea and biscuits and we normally have a quiz.'*

**(Marketing manager diary)**

There is a well-evidenced connection between social isolation, depression and poor physical health<sup>8</sup> and as noted in the previous section, following a diagnosis of dementia, both the person with dementia and their family carer can find themselves increasingly isolated within the home. As one spousal carer noted:

*'He [participant 12] got his diagnosis in 2015, then we were left in this state of flux. And I thought we really did something [referring to 'Still Me'].... I'm devastated it's coming to an end because it's been so important to us and others... I'm constantly looking for things to replace it, because I don't want us to become couch potatoes'*

**(Still Me and film screening participant: spousal carer)**

For many participants then, the ALMO programme was an opportunity to be able to get out of the home and do something that was enjoyable that enabled them to re-engage with the outside world. The social opportunities afforded by the ALMO

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<sup>8</sup> Milligan, C., Payne, S., Bingley, A., Cockshott, Z. (2014) 'Gender, place and health: shedding light on activity interventions for older men,' *Ageing and Society*. 35:1, pp. 124-149.

programme – through the pre-event cafes, intervals, workshops and ‘Still Me’ activity – enabled participants to meet with others who understood their circumstances and were able to share information and experiences. As one family carer noted:

*‘Benefit for us was, when we were at our worst time, feeling lonely and depressed, being able to go out to something that’s been properly organised and where people understood...we have a dementia community here that was so important at the beginning, people giving you snippets of information when you are able to receive and process it’*

**(Still Me and film screening participant 11: Carer/ volunteer)**

This suggests that whilst ALMO was set up to meet the needs of both the person with dementia and their family member, in fact some family members may have gained more from ALMO activities than those with dementia. This was echoed by one family carer who felt that the dementia friendly events were *‘really for the carers’* (ALMO7) since their caring responsibilities meant that their ability to take part in social activities outside of the home was limited. Though neither of these comments drew out the importance of activities specifically designed for people with dementia *and* their family members as couples, each indicated how the film screenings brought benefits for the two individually.

However, as the following quote from a participant with dementia illustrates, the ALMO programme was not just for family carers, but was seen as a positive and enjoyable activity for those with dementia too, one that has the potential to improve the wellbeing of those with a diagnosis of dementia.

*‘We’ve always come to the Dukes each time and we’ve come to some of the things. But I’ve got to the stage where I’ve got Alzheimer’s now and I was getting really depressed about it and got to the stage of crying sometimes and [Name] spoke to somebody and they recognised and thought this (film screenings) was a good thing to do. And I love it (laughs)... I’ve always liked coming to the theatre.’*

**(Film screening participant 8: person with dementia)**

Importantly, the ALMO environment offered a space in which they could connect with others and feel comfortable knowing people understood their physical and cognitive limitations.

### *Social engagement and friendships*

The social aspect of all of the differing elements of the ALMO programme was considered important by all participants, who spoke of the need to overcome social isolation and loneliness and to share their experiences of living with dementia with others in similar situations.

A number of participants referred to the importance of having something to look forward to over the course of the week. This is summed up by both a family member and workshop facilitator below:

*'...it's just nice to see the old films and talk with people.. The company...yeah... There's nothing much on a Monday. We like it on a Monday.'*

**(Film screening participant 14: family member)**

*'People look forward to the sessions, and base their week around these sessions - so we get that kind of feedback.'*

**(Workshop Facilitator January 2018)**

For some participants, the sociality of the activity was perhaps as of equal important as the creative activities they took part in. As one participant noted:

*'I come here instead of rattling around the home alone, I enjoy the company, it's a manageable group to be able to talk.... I hear other people talk, I talk, if you live in a big house like I do, you're in social isolation.... I wouldn't know about creativity if it hits me in the face... people benefit because they have no one to talk to except the telly at home.'*

**(Still Me participant 1).**

This echoes the findings of research on other social interventions<sup>9</sup> where for some, it was the enabling role that the creative activity played in bringing people together that was key to its success. This is not to downplay the importance of the activity itself, as people were attracted to participate because of the very nature of the activity and how they related to it.

Participants talked about forming friendships:

*'What makes the Dukes special, it's hard to put into words, it's the feeling of friendship... the most important elements are friendships, companionships, being among the company of people in a similar situation to yourself'*

**(Still Me and film screenings Participant 13: family carer).**

Friendships amongst participants and between participants and artists were based on mutual understanding and compassion. One participant described the friendships she had formed as a family carer with individuals at the ALMO programme as being:

*'all very genuine, you understand each other. I don't feel as vulnerable coming here'*.

<sup>9</sup> Milligan, C., Payne, S., Bingley, A., Cockshott, Z. (2014) 'Gender, place and health: shedding light on activity interventions for older men,' *Ageing and Society*. 35:1, pp. 124-149.

**(Participant 11: person with dementia)**

Continuing her involvement with the programme as a volunteer following the loss of her husband, she spoke of how she sought to honour and maintain those relationships, pointing to the importance of: *'being in it, not just helping, you have to leave your ego at the door'*. (Participant 11)

***Workshops and Still Me: Inspiration/empowerment***

For some workshop and 'Still Me' participants, engaging with the ALMO activities was about providing inspiration and empowerment. Artists and staff noted how some people with dementia went from being passive observers to active participants. Reflecting on one workshop experience a staff member recalls:

*'One chap from a care home, I'd never seen him get up, but he was inspired by a character, a magician, that he put on a hat and he was on his feet. I know I was surprised by that and I'm sure everyone else was too. The professional carer was surprised'*.

**(Staff member interview excerpt)**

Participants spoke of the sense of positivity, which the project instilled, with one 'Still Me' participant remarking in relation to her husband with dementia:

*[he] 'used to hide his dementia... worrying about what he can't do anymore... here we were learning how to play and be with friends again'. She also recalls that she 'hoped we'd blossom as the sessions went along'*.

**(Spousal carer 11)**

Another commented that:

*'people would get up and help you with the chair and then get right back into the conversation, as though it is normal. Well it is normal, just a new normal'*

**(Participant 11: person with dementia)**

This sense of empowerment is linked to the perception expressed by a number of participants that ALMO enabled them to 'let themselves go' and 'let their hair down'. As one participant pointed out:

*'Nobody will question what they (PWD) are doing... there's no right or wrong... whatever we've done we've joined in to the best of our abilities. We've realised we can still learn and discover things, life doesn't have to close.'*

**(Participant 11: person with dementia)**

This was reinforced by artist facilitators who noted that the sessions enabled people to do things they probably would not do at home. As one noted:

*'We get people with dementia to do things they probably wouldn't do at home, although they probably would like to- one participant likes jiving and we'd do it at the end of a session and it will just happen because the whole session has sort of built up to that'*

**(Artist facilitator: Jan, 2018)**

### *Person centered and 'in the moment' activities*

There is a strong element of person-centeredness and inclusivity in the way in which the ALMO programme is designed. As one carer noted:

*'For people who can't or don't want to join in but want to go to something, the film screenings are particularly important. There's a little bit more in the workshops and Still Me, there's the idea of being creative, but again there's no right or wrong.'*

**(Spousal carer 11)**

The Still Me sessions and workshops took a similarly person-centred approach in the way in which the creative sessions were delivered. As one facilitator noted, the dance workshops were designed:

*'to include everyone that wants to be here, everyone that wants to find a way into dancing... we're inclusive in terms of we don't mind if you've got a dodgy hip or a dodgy knee or you'd like to enjoy the session from sitting down in a comfy chair, not a problem'*

**(Artist facilitator, Feb 2016)**

Participants who took part in the workshops and Still Me sessions recognized the efforts artists made to ensure that that the activities they engaged with were suited to their needs and interest:

*'The whole thing about Still Me is the idea of somebody thinking "I found this and they're going to really love it", you know that's what they [artist facilitators] were thinking and we'd be getting ready to absorb it all. And we'll be asked how did that go down? How did you find that?'*

**(Spousal carer 11)**

Being able to spend time on the project allowed Still Me artists to develop a more personalised focus on in the moment activities. Artists were able to pick-up on ideas from previous sessions, enabling them to tailor the sessions to participants.

As one Still Me artist noted:

*'... for each person with dementia you have to find out what their area of interest is, like the lady who was really good at writing and loves doing it. So having a wide range of things at the beginning is really helpful, because some people go towards music, some people go towards making or movement or whatever it is.'*

**(Still Me artist facilitator, 2018)**

For artists, the creativity within workshops and Still Me sessions was based on an iterative process of listening, reflecting and evaluating on what worked best in response to the group. As one artist commented:

*'So in our planning, we didn't like to be too detailed, it was sort of like make sure we know a structure that we can work from, have a really strong opening and then be able to play with what comes out of that'*

**(Artist facilitator, Nov 2016)**

This person-centred and iterative approach reflects the growing acknowledgement of the importance of acknowledging and working with 'in the moment' understandings of the experiences of people with short-term memory loss, especially as it relates to the arts and wellbeing.<sup>10</sup> Being in the moment is particularly important for some people with dementia where short-term memory loss inhibits their ability to reflect back on events that happened a short while ago. As participant 13 (family carer) stated:

*'Once we got home [name] would forget... so anything he does now is "in the moment", the Still Me project is very much about that.'*

**(participant 13: family member)**

Asked about the benefits to her mother, of attending the dementia-friendly film screenings, one family carer also commented:

*'I think she is very much in the moment, it is very difficult to evaluate the impact because this evening she might not remember she's been, but in the moment she is very, very happy.'*

**(ALMO2)**

Being in the moment for some allows people with dementia and their family members to:

*'an escape from their daily life, and the artists can help people to connect with others as they used to or wish to- perhaps because we don't know them in the way we know our family members we can do that, because I can't connect in the same way with my grandmother who has dementia. I can connect with people I work with and do it more intuitively than I can with my grandmother at home.'*

**(Artist facilitator, Jan 2018)**

Allowing themselves and the participants to 'be in the moment' requires artists to ensure that sessions are not designed in a rigid way but are flexible and open to

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<sup>10</sup> S MacPherson, M Bird, K Anderson, T Davis (2009) An Art Gallery Access Programme for people with dementia: 'You do it for the moment', *Aging & Mental Health*, 13: 5, 744–752.

Robyn Dowlen, John Keady, Christine Milligan, Caroline Swarbrick, Nick Ponsillo, Lucy Geddes & Bob Riley (2018) The personal benefits of musicking for people living with dementia: a thematic synthesis of the qualitative literature, *Arts & Health*, 10:3, 197-212, DOI: [10.1080/17533015.2017.1370718](https://doi.org/10.1080/17533015.2017.1370718);

ongoing improvisation and adaptation. The following diary excerpts from workshop facilitators give illustrations of how this worked in practice:

*'We used more of an improvisation technique of being in the moment and making up stories from a given image and some questions about that image... .. there's some strong evidence that reminiscence isn't the ideal way to go when you work with people who are living with dementia because sometimes they find it difficult to reminisce, they find it difficult to remember, this sort of improvisation technique sort of changes that a little bit.'*

**(Artist facilitator, May 2016)**

*'Reminiscence definitely has its place as does any working with memory, but we wanted this session to be as you say about the here and now and in our bodies and from my point of view that comes from a somatic point of view. Here we are in our bodies today let's work with our hands, let's work with our feet.'*

**(Artist facilitator, Nov 2016)**

*'It is purely in the moment play time, being in a certain time and it just flowing...creating something that works in that moment, that's what drives me as an artist..'*

**(Artist facilitator, Jan 2018)**

For workshop facilitators this meant not reflecting on what has happened over the past week unless something comes up and somebody wants to talk about it.

## **'Still Me'**

Whilst all of the roll out theatres were involved in the dementia friendly film screenings, the Still Me activity was unique to the Dukes. Hence, though this is referred to elsewhere in the report, this section focuses specifically on this new development.

'Still Me' was a process led; participatory multi arts programme developed and run by the Dukes as part of the ALMO programme. It consisted of a total of 30 sessions, commencing with an initial 10 week block in May 2017; a second block of 10 weeks commencing in October 2017 – this was split into two 5 week sessions due to the Christmas break, with half of the sessions running in early 2018. There then followed a series of 10 sessions focused around devising and rehearsals for the final performance of The Jamboree.

Activities undertaken as part of 'Still Me' ranged from the re-creation and collapse of a clap-board house using stop animation (as viewed by participants in a Laurel and Hardy video); creation of a musical band, a sound track to a silent film and a 'Still Me'

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version of the Sergeant Pepper's Lonely Hearts Club Band album cover; creation of a model of a local park; shadow play; developing models and the creation of one of those models into a life-sized interactive installation.

In sum the 'Still Me' programme sought to incorporate four broad areas of 'in the moment' performative activity:

- Sound and music;
- Movement and dance;
- Film-making;
- Visual art.

A key artistic outcome of the programme involved all participants engaging in a final interactive 'in the moment' performance of a 'Jamboree' incorporating a 'cake bake' that ran over the two days of the ALMO Conference in May 2018 (see Plates 1 and 2).



*Plate 1: The 'Jamboree'*



*Plate 2: 'The Jamboree 'cake bake''*

As illustrated in Plate 3 below, 'Still Me' worked collaboratively over each 10-week session with a small group of people living with early-stage dementia and their spouses or carers in an adapted and safe environment. Most participants comprised spousal dyads but in one case, it involved a person with memory problems and their paid care-worker. Participants were encouraged to participate in all ten of these sessions where possible. Artist facilitators comprised a Musician, Dancer, Film Maker/Theatre Facilitator, and Visual Artist, with sessions focusing on improvisation and using responsive practice.



Plate 3: 'Still Me' Multi Arts Session



(Photograph by Darren Andrews)

### **Constructing Space for 'Still Me'**

Diary entries from facilitators and staff working on the 'Still Me' programme highlighted the importance of setting up the space in ways that accommodated the needs of people with dementia, ensuring the space appeared friendly, attractive and non-intimidating. Importantly, both staff and volunteers highlighted the need to allow sufficient time to do this. As one staff member noted:

*It's evident that the set-up is very important to the session, making the space as welcoming and appropriate as possible. .... The space was dressed for the first session in order to make the space as homely and less intimidating as possible. The participants expressed an interest in the space and were impressed with the decoration.*

*Effort will have to be made on a weekly basis to ensure the space doesn't feel intimidating. If there is some consistency in relation to how the space is dressed on a weekly basis with aspects reflective of the content of each session I think this will be helpful.*

**(Staff Member Diary)**

Artists highlighted the initial challenges that the space available for the 'Still Me' activities presented, the importance of natural light and contrasting colours to help people with dementia to navigate that space. In particular, concern was raised about the 'black box' theatre space available for the Still Me activity, which had no access to natural light. As the artist commented:

*'I have very strong feelings about environments that work for people with dementia. I was so worried about working in a black space [theatre stage], so what we had to do was try and make something that was really comfortable for people. What I absolutely wanted to do was have a big round table that we all sat around, so we can all see each other and communicate properly... In the end what happened, within a few weeks people were saying they really like the space because they feel completely safe being in a black space.'*

**(Still Me artist, Jan 2018)**

and

*Working in a black theatre space is not ideal for this type of session – no daylight, theatre lights in your eyes and black spaces between things. The grey dance floor [staff member] put down made a big difference but it meant that there was now a big black abyss between the entrance doors and the grey floor. ....Next session it would make a difference to have a wide bit of light coloured flooring taped down as a 'bridge' to help people navigate it.*

**(Still Me artist diary excerpt)**

As a consequence, facilitators felt it was important to change the space by transforming parts of it, for example, by breaking up the darkness of the space with furniture, plants and other colourful props to ensure the space was fit for purpose (see Plate 4). Facilitators highlighted the importance of having a large round table that could serve as a central focus for activities, enabling all participants, whether artist, volunteer, family member or person with dementia, to connect equally with each other (Plate 5).

*Plate 4: Breaking up the 'Still Me' space*



Plate 5: A large round table served as the focus of activities



As one artist noted:

*.....the big table worked, with blue tablecloth, fresh flowers and paper napkins folded into water lilies and swans. In the centre a Dutch windmill with internal light and music box, so a special moment when the music box played and we dimmed/changed the lighting state – fine to do as everyone was sitting down at the time. The space looked welcoming and attractive, the size was fine and the focus was on each other across the table so the black space around disappeared, except when we wanted people to get up and look at it.*

**(Artist Diary Excerpt)**

### *Impact of 'Still Me' on participants*

Artists and volunteers running the programme reported that the 'Still Me' model produced some extremely creative work with positive social and artistic outcomes including:

- Engendering a sense of 'play' in participants;
- Developing creativity and improvisation skills;
- Enhancing social interaction;
- Improving communication including conversations between people living with dementia;
- Enhancing mood;
- Engendering a sense of fun; and
- Improved confidence.

The following interview quote and diary excerpt summarise the outcomes identified above:

*“..we have been lucky enough to join a small group in the Dukes latest creative dementia project. Working with a handful of highly talented creative professionals, we have explored music, mime, movement, art and design and we feel that we have all been given the gift of play. Dementia sufferers and their carers/companions have been encouraged to participate and contribute to the most wonderful creative sessions in which we use all of our senses to stimulate discussion, memory, positivity and happy feelings. Within the group we have found companionship, shown and accepted the support of other group members, worked in pairs, smaller groups and teams in a cooperative way and have all been encouraged to contribute and feedback on sessions and to make any suggestions for the content of future sessions. We all feel as if we are helpful, creative and valued and staff have been friendly, enthusiastic, and encouraging. ...We join in everything and leave tired and very, very happy every week .... There is no space or time for outside or negative thoughts: the whole time is for positive learning and play. How brilliant is that?”*

**‘Still Me’ Participant**

*‘Everyone fully engaged, offering suggestions, having a go with everything – including all being prepared to wear a silly moustache and talk gibberish! I was surprised that people were more than happy to just cut out letters with scissors. I think it is because we are all working to the same end point and everyone enjoys doing their bit towards the whole - the wonderful thing about collaborative working and theatre – there is always a role for everyone whatever your ability and it’s great to all be able to contribute to the end product.’*

**(‘Still Me’ Artist facilitator)**

### *Measuring impact on wellbeing*

To further assess the impact of the ‘Still Me’ programme on individuals, each participant was asked to complete a validated well-being survey (WEMWEBS) over the duration of the programme. As the ‘Still Me’ model was not designed for large numbers of people, this phase of the evaluation did not aim to produce data that would be of statistical significance. Rather, it sought to assess whether there had been any within-person change in mental wellbeing over the course of the programme.

WEMWBS is a validated tool that was developed to enable the monitoring of mental wellbeing in the general population and for the evaluation of projects, programmes and policies which aim to improve mental wellbeing. Importantly, it has been assessed as being suitable for use with people with dementia and carers.

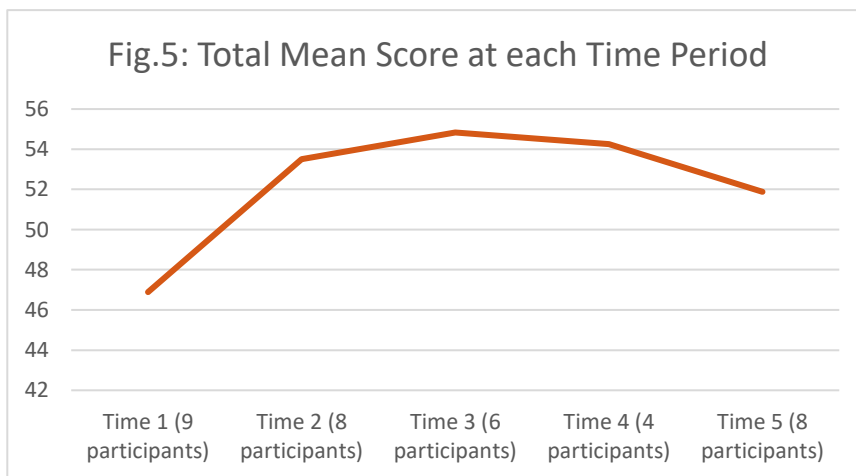
WEMWEBS comprises a 14 item scale with five response categories that are summed up to provide a single score ranging from 14-70. The score is representative of mental wellbeing and the higher the total score, the better an individual’s mental wellbeing. Items on the tool are all worded positively and cover both feeling and functioning aspects of mental wellbeing.

**Analysis of WEMWEBS Data**

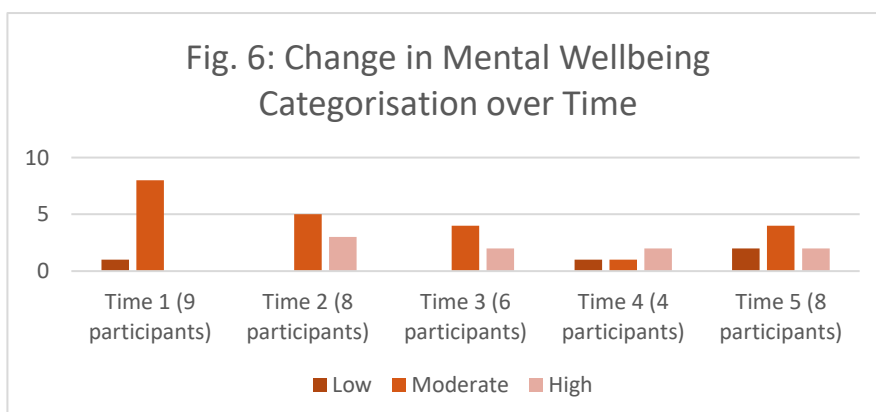
For ease of understanding, the scores have been categorised into ‘low’, ‘moderate’, and ‘high’ mental wellbeing.

A total of 11 individuals took part in the ‘Still Me’ programme with data being collected at five time periods including both start and end point.

Although data was collected at five time points, participants did not complete an assessment at each time period. Therefore numbers for each analysis will fluctuate between time periods. Figure 5 below shows a graph displaying the change in the average mental wellbeing score over time. This graph displays a general increase as time progresses, with the exception of a small dip towards the end. This suggests that there was a general improvement in individuals’ mental wellbeing over the duration of the programme.

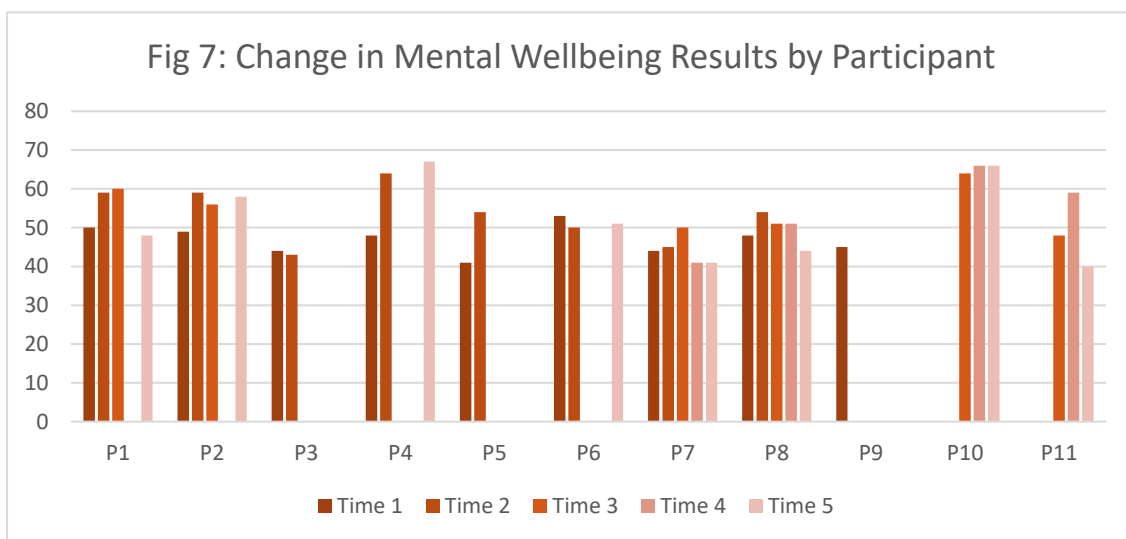


Another way in which this can be illustrated is through the change in the number of participants categorised as having ‘low’, ‘medium’, or ‘high’ mental wellbeing as illustrated in Figure 6 below.



As the figure above illustrates, prior to participating in the programme, no participants were classed as having ‘high’ mental wellbeing; at the end of the programme this had increased to 2. However, it is also important to note that there was an increase from 1 to 2 participants classified as having ‘low’ low mental wellbeing by the end of the programme compared to the beginning. This suggests that some individuals may have benefitted from taking part in the programme more than others. However, it is also important to point out that these data do not account for changes in overall health condition during the one year time period during which the survey data was gathered. For those with dementia and their family members a one-year time frame can see considerable change in health status. Indeed one member of the group died between 10 week sessions and this had a notable influence on participants at the start of the following session.

How people reacted to the programme at the level of the individual, a graph is set out in Figure 7 below.



In the majority of cases, participants who did not show any change in mental wellbeing over the course of the programme, reverted to their ‘pre-intervention’ mental wellbeing levels. This means that individuals who may not have measurably benefitted from the programme were no worse off by the end of it, i.e. there was no benefit or cost to their taking part.

There is one exception to this, where ‘P11’ did show a big decrease between Time 4 to Time 5. However, it is important to note that there were some missing scores in this participant’s data, which explain this sudden drop.

The findings of this small WEMWEBS dataset indicate that there is benefit to be gained from taking part in the programme. However, it needs to be borne in mind that with such a small number of participants it is not possible to make any meaningful

inferences from these data. Rather the findings offer an indication of the potential benefits to mental wellbeing from taking part in the 'Still Me' programme. To gain more meaningful results a much larger group of participants would be required.

### **ALMO: staff, artists and volunteers**

Staff, artists and volunteers involved in the delivery of the film screenings, workshops and Still Me programme were asked to keep brief reflective diaries of their experiences of participating in these events. This was supplemented by focus groups and individual interviews. Those taking part were asked to not only record their observations and experiences of the ALMO programme and activities, but also to reflect on how ALMO impacted on their own practice. These data were supplemented by interview data from participants on the importance of staff/volunteers to the programme.

#### *Approachability*

All participants commented on the importance of friendly and helpful staff and volunteers at ALMO events. As one venue manager commented:

*'Staff and volunteers were as good as they always are, they are there ready to help people with the stairs or into a seat, you don't see them standing around they are helping or talking to people, they make the experience special for people.'*

**(Staff diary, 2017)**

Family members commented that knowing that help was there if needed was a key contributory factor to making the environment dementia friendly. Knowing that staff knew what to expect and how to help gave family members peace of mind.

Friendly and approachable staff and volunteers was also important to the person with dementia. As one family member commented: *'even though mum doesn't know who they are, their smiles make a difference'*.

*'The Dukes has allowed us to have new, but trusting relationships, we are our best assets and the Dukes has allowed us to be that for each other... volunteering now is about keeping connections with people who have become friends'*

**(Still Me and film screening volunteer)**

Within workshops and Still Me, an important part of this trusting relationship has been a way of working that seeks to break down the barriers between 'them and us'. As one Still Me participant put it:

*'We are all a group of friends, we don't think of them as artists'*

**(Still Me group, participant 13)**

For staff and volunteers, this meant being trained and supervised to work differently, placing greater emphasis on listening carefully to what people with dementia are telling them and responding accordingly. As one staff member noted:

*'I want all our volunteers to be enablers. I have witnessed that some people can really inhibit - that can be a family member, carer, facilitator or volunteer. So training them about the bigger picture... to enable people with dementia to have the experience is important.'*

**(staff member: interview 2018)**

### *Developing Inclusive and Collaborative Practices*

At the heart of this enabling practice has been a commitment to participatory collaborative working. As one artist noted, while her background had made her aware of inclusive practices, the ALMO programme enabled her to sharpen up her understanding of what inclusive practices should be for people with dementia. This heightened awareness has resulted in staff (particularly artist facilitators) being attentive to instances where participants with dementia may not be given opportunities to fully participate and to reflect on how this practice might be adapted. As one artist facilitator noted:

*'In the poetry workshops we felt people with dementia were being talked at, perhaps there is a value in listening to poetry, but when people are not joining in, I have to question'.*

For those with dementia and their family members the inclusive practices adopted by artist facilitators in workshops and the Still Me activity resulted in a sense of equality and collaboration:

*'It's (Still Me) for everyone and there's no division'*

**(participant 9: Person with dementia)**

*'With Still Me, we connected very quickly to a wonderful team of artists, dance and performance professionals, they were so lovely, they grew with us in our understanding of dementia, they were "with us". It wasn't just waving and watching passively, it was collaboration, there was no us and them.'*

**(participant 11- carer/ volunteer)**

*'There was no them and us, we all became even and that was the secret of it (Still Me). They were not teaching us, in the end we were all helping each other'*

**(participant 13 – family carer)**

One artist facilitator also alluded to a sense of reciprocity and collaborative learning gained from participating in the ALMO programme, noting:



*'I learn more and more each time we run a session and it's something really important for me. I think at the beginning of the session today was the first time I talked about my Grandma who passed away some years back now but had dementia - and certainly in some deep recesses somewhere, it's part of the reasons for me wanting to give back and do these workshops'.*

**(Artist facilitator May, 2016)**

### *Enhanced dementia awareness*

An important outcome of ALMO that was not set out in the original programme aims and objectives has been an enhanced understanding of dementia and how to engage with people with dementia for both staff and volunteers. Whilst some staff and volunteers had friends or relatives that had had dementia, many spoke of having little knowledge or understanding of what dementia was, and the range of dementias that exist, prior to their engagement with the programme.

*'I didn't know anything about dementia to be honest with you, I thought it was a mental illness and it's absolutely not'*

**(staff focus group, March 2018)**

and

*'I had no direct experience of dementia – the real eye-opening experience of what we're doing was the huge RANGE [of types and stages of dementia] – and we have quite a few groups from care home and I think they're at the extreme end ...'*

**(volunteer focus group, March 2018)**

Dementia friends training prior to their involvement with the programme was seen as an important part of their induction into the programme. Engagement with ALMO has also increased their knowledge and understanding of working with people with dementia in arts-based venues and how practice needs to be adapted to ensure a dementia friendly environment. As one staff member noted:

*'You're more aware, you're more tolerant and you take more time, because you've got a little bit more knowledge about it [dementia]. It makes you more tolerant of people.'*

**(staff focus group, March 2018)**

As staff and volunteers noted, this knowledge has also spilled over into an enhanced understanding of dementia in the wider community. As one volunteer commented:

*Volunteer: 'for me it has really opened up my eyes and my awareness. It made me more understanding. If you see somebody outside [of the arts venue] .. you might be queuing behind somebody for a train ticket or the*

*supermarket or whatever and you just think YES, yeah – so I think TOLERANCE'*

*Interviewer: So you think the understanding of dementia you've gained from your engagement with the programme has spilled over ..*

*Volunteer: YES absolutely. No question it has ..*

**(Volunteer Focus Group March 2018)**

### **Increased job satisfaction**

Many staff and volunteers spoke of the enhanced job satisfaction they gained as a result of their involvement in the delivery of ALMO. For some, it was knowing that the extra effort they put into their engagement and interaction with people with dementia was recognized and valued, for others it was about the pleasure they gained from being part of something that enhanced the lives of those living with dementia.

*'.. and a woman came up to me and said "I just want to say how much I appreciate that one of your staff took the time to listen to him [person with dementia] – and I fed that back to him [staff member] and he was really chuffed, you know?'*

and

*'it's seeing the enjoyment people get from something very simple'.*

**(Staff focus group March 2018)**

and

*'our staff and [venue] volunteers were on top form .. everyone was interacting with the audience'*

**(Staff diary excerpt, April 2016)**

## **Partnership working**

Key to the success of the ALMO model has been the development of partnerships with other organisations involved in the delivery of services to older people, family carers and people with dementia. In particular, Age UK Lancashire has played a crucial role in supporting the programme – from the development and implementation of the Journeying Together pilot programme through to the development of the ALMO bid with the Dukes Theatre and its subsequent implementation. For venues that have become part of the ALMO partnership during the adoption and spread phase of the programme, partnership working with other organisations has been equally important.

Venues have pointed to their ability to provide dementia friends training, their knowledge and expertise in working with people with dementia and their families, as points of referral to the ALMO programme and in providing transport to ALMO events for those with no alternative transport options.

*'Our partnerships with Age UK works very well, it's having that relationship with people who are the experts, who are working with these people... They signpost the families.'*

**(Staff member)**

*'Well, I've come along to several film screenings and... and.. it's been organised with Age UK 'cos I go to a lunch club every week, with Age UK at The Scarthwaite, so that's great, and through that I knew about these screenings and quite enjoy it.'*

**(Film screening participant 16: person with dementia)**

A number of venues operated their activities with the support of staff and volunteers from their partner organisation, Age UK, who often arranged transport or initially met and greeted attendees when they first arrived and saw to their needs. Attendees were often familiar with these people through other services and these partner organisations were often the source of referral to the film screenings and other activities.

This emphasises the benefit of a joined up approach in which cinemas and theatres work closely with other organisations providing support to older people and those with dementia.

Where there has been a failure to develop working relationships with local dementia groups and organisations for various reasons, recruiting people with dementia to the programme has been more difficult. As one member of staff in a venue where this had proved challenging noted:

*'One of our actors at the theatre here works with the Alzheimer's Society. He does plays so I think that might be a group we work with, he already has contacts there... it's difficult there seems to be a few in Chorley but they don't seem to talk to one another and that seems to be the problem. I think, maybe there is a problem we have in that by choosing one charity the others have been annoyed that that charity has been the exclusive one so they've left it to them cos it's not their thing, it's probably better to open it to all.'*

**(Staff member)**

This emphasises the value of a joined up approach in which cinemas and theatres work closely with other organisations providing support to older people and those with dementia.

## Challenges

Whilst participants attending ALMO activities clearly gained much from participation, recruitment has been a the key challenge for the programme overall. A number of venues have commented that in part, this is because attending a 'dementia friendly' event still holds an element of stigma, or that general film-goers do not necessarily want to attend an event that they see as targeted at those with dementia. For others, it is linked to an unwillingness to define themselves as someone with a diagnosis of dementia.

*'Challenge has been attracting the individuals as well as the Care Homes to try and come and bring relatives and also get past the stigmatism of being at a screening with people with dementia, getting the word across that it is open to everyone, it is all inclusive it's not just for people with dementia...'*

**(Staff member)**

*'I suppose the main challenge actually has been to get dementia people in. Because its...erm we've been contacting groups, societies and care homes and stuff like that but still the majority are all still just of the regular view that they just want to see an old film, they're not really dementia sufferers or they're not knowing dementia sufferers not carers or anything like that...'*

**(Staff member)**

Even where venues have been more successful in attracting a wider audience to their ALMO activities, there is still an acknowledgement of the lack of cultural diversity amongst the audience as noted earlier in this report. As one staff member noted, a particular challenge is:

*'Building a broader audience, most are currently 75 years plus, white British and we live in a multi-cultural society.'*

**(Staff member)**

## Sustainability of the programme

Overall, attendance at dementia-friendly film screenings has been successful, drawing in almost equal numbers of general theatre-going public and those with dementia and their family members. To date, entry to film screenings has been free for carers/family members accompanying the person with dementia, the introduction of an admission fee for all, including carers/family members should help to ensure these events become self-sustaining and are thus able to continue beyond the life of the funded ALMO programme.

Though much valued by participants and highly successful, workshops and the Still Me programme are both resource intensive and costly requiring appropriate space,

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lunches/refreshments and the employment of specialist artist facilitators to run the activities. The Still Me activities in particular, were run for a total of six couples by four artists, the programme director and a volunteer. Though there is some preliminary evidence that participating in Still Me could have a positive impact on wellbeing, the dataset is small and at best can provide an indication of its potential that would require larger numbers before any definitive conclusions could be drawn. It is unlikely, therefore that at this stage, commissioners with hard-pressed budgets would be willing to fund these activities.

If workshop and Still Me activities are to continue within the ALMO model, ALMO needs to look at alternative and more sustainable models of running these activities. This may include introducing viable charges for attendance and running Still Me programmes with a significantly reduced number of artists. A focus on attracting and training more volunteers to support the programmes could alleviate some of the financial pressures.