# The Benefits of Community-Based Participatory Arts Activities for People Living with Dementia: A Thematic Scoping Review

Meghánn Catherine Ward<sup>1</sup>, Christine Milligan<sup>1, 2</sup>, Emma Rose<sup>3</sup>, Mary Elliott<sup>4</sup> and Bethany Rebecca Wainwright<sup>5</sup>

<sup>1</sup>Division of Health Research, Faculty of Health and Medicine, Lancaster University, Lancaster, UK.

<sup>2</sup>Centre for Ageing Research, Faculty of Health and Medicine, Lancaster University, Lancaster, UK.

<sup>3</sup>Institute of Contemporary Arts, Faculty of Arts and Social Sciences, Lancaster University, Lancaster, UK

<sup>4</sup>Theatre by the Lake, Keswick, UK.

<sup>5</sup>Department of Psychology, Faculty of Science and Technology, Lancaster University, Lancaster, UK.

Correspondence to: Meghánn Ward, e-mail Address: m.ward4@lancaster.ac.uk

*Postal Address:* Division of Health Research, Faculty of Health and Medicine, Furness Building, Lancaster University, Lancaster, LANCASHIRE, LA1 4YG.

### Abstract

*Background:* The drive towards living well with dementia has resulted in growing recognition of the value of community-based participatory arts. This review aimed to explore their overall impact and holistic benefits for people living with early to moderate stages of dementia. *Methods:* Using a scoping review methodology and thematic analysis, this review explores relevant literature published between 2008 and 2019. *Results:* 26 published papers were identified, comprising visual arts, literary arts, comedy, music and dance. The key themes included person-centred, in-the-moment approaches; participation and communication; attention and cognition; social cohesion and relationships; and the role of space, place and objects. *Conclusions:* There is strong evidence in support of using participatory arts for dementia, regardless of art form. In-the-moment and person-centred approaches were deemed impactful. Further research is needed to explore the important role of setting, material culture and the methodological or theoretical perspectives in participatory arts and dementia research.

*Keywords:* Dementia; participatory arts; creativity; health and wellbeing; person-centred; in the moment.

#### **Introduction and Objectives**

## The Worldwide Status of Dementia

There are over 850,000 people in the United Kingdom currently living with dementia, with diagnoses predicted to rise to over 1 million by the year 2025 (Alzheimer's Society, 2019). Worldwide, an estimated 50 million people are living with dementia, with 10 million additional diagnoses each year (World Health Organization [WHO], 2019). While research is dedicated to investigating possible treatments and preventions for dementia, there is currently no cure and only limited pharmaceutical interventions available to temporarily manage day-to-day symptoms (Alzheimer's Association, 2019). Given the limited biomedical options, recognition is growing for the potential importance of psychosocial interventions that can support people to 'live well' with dementia and a need for new worldwide dementia plans or national strategies to dedicate further research, resources and services to this area (e.g. Oyebode and Parveen, 2019).

# Dementia and the Arts

There has been a widespread 'flourishing' of cultural arts-based dementia services and programmes within the past 10 to 15 years in the drive towards 'living well with dementia' (Castora-Binkley *et al*, 2010; Zeilig *et al*, 2014). Commonly used activities – used in isolation or in combination - include visual art, music, dance, drama, storytelling and poetry (e.g. Beard, 2011), while more innovative programmes include participatory film-making (e.g. Capstick and Ludwin, 2015) and working with artefacts and objects (e.g. Lloyd, 2015). Overall, arts interventions and activities in all forms can feed into 'the creative, imaginative and emotional parts of a person' and may contribute to the quality of life and well-being of people living with dementia (Social Care Institute for Excellence [SCIE], 2015). While arts

activities can be approached and applied in different ways, this review focuses on participatory arts.

#### **Defining Participatory Arts Activities**

Participatory arts aim to promote health and wellbeing without being constituted as a therapy. They involve '...professional artists [or creative practitioners] that conduct creative or performing arts programs in community settings for the purpose of promoting health and wellness' (Zeilig et al, 2014, p.13). This is in contrast, firstly, to arts-based therapies which are usually associated with clinical settings and trained therapists (Castora-Binkley et al, 2010) and secondly, to recreational arts and crafts, which are commonly more ambiguous regarding setting and facilitation (Leitner and Leitner, 2012). Furthermore, the therapy approach traditionally remains centred on the health condition of a client and the end goal of 'psychological change' irrespective of art skill or completion, while arts and crafts primarily aim to complete an artwork (Schoenwald, 2012). Comparatively, participatory arts are more concerned with the process fostered by the intervention as opposed to creative or psychological outcomes (Dix and Gregory, 2010). Overall, they may encompass performing or auditory arts activities - such as drama, dance, singing and other music-based activities as well as the less performative but albeit participatory literary arts – comprising fictional literature, creative writing, storytelling and oral histories (e.g. Mar et al, 2011) - and visual arts – art-viewing and art-making using different mediums or forms such as painting, drawing, sculpture and textiles (e.g. Rose and Lonsdale, 2016).

## **Recent Literature on Dementia and Participatory Arts**

Two papers conducted in the past five years have specifically reviewed the application of participatory arts to dementia, with varying criteria and perspectives (Zeilig, *et al*, 2014; Young *et al*, 2016). Zeilig *et al*'s 'participative arts' review (2014) critically explores the

variety and accessibility of arts programmes for dementia - focusing primarily on a UK and Ireland context - while Young *et al*'s review (2016) explores participatory arts in international community settings with an emphasis on the cognitive benefits. Although encompassing a thorough and broad search criteria, the rapid growth of work around this area suggests that it is timely for an updated review including the newest work in this field, expanding beyond the UK/Ireland context and beyond the cognitive benefits of participatory arts.

Useful insights can be taken from a recent review conducted by Dowlen et al (2018) which focuses on active participation solely in musicking activities for people with dementia. Although inclusive of music therapy approaches, Dowlen *et al* specifically explore and thematically analyse qualitative studies to ascertain the psychological, social and emotional benefits of music activity for people with dementia - components of dementia health and wellbeing that can potentially be undervalued in favour of investigating cognitive benefits (e.g. Young *et al*, 2016). A thematic synthesis has not yet been applied to a broader overview of participatory arts for dementia literature, but could be beneficial in both highlighting the general benefits of participatory arts and recognising the important design features that are conducive to the creative experience, which have important implications for participatory arts implementation. While participatory arts programmes are well established both in practice and in the literature, there is often over-emphasis on the effectiveness of activity content and less acknowledgement of the most impactful 'design and evaluation' techniques which may contribute to the effectiveness of such programmes (Castora-Binkley et al, 2010). The present review will aim to address this knowledge gap by considering the underpinning design, facilitation and general process involved in participatory arts, where addressed in the literature.

## Aims and Objectives

Influenced by previous literature and knowledge gaps, this thematic scoping review aims to explore the in-depth effectiveness of participatory arts - inclusive of performing, visual and literary arts but exclusive of therapy approaches – on the health and wellbeing of people with dementia in community-based settings. The interpretation of health and wellbeing is influenced by the WHO definition, which involves 'complete physical, mental and emotional wellbeing' (WHO, 2019). Hence, this review will adopt a holistic perspective on what it means for participatory arts activities to be effective, considering physical, psychological or cognitive, emotional and social benefits. The review also aims to contribute to the gap in understanding the most effective design and approach when offering participatory arts interventions for dementia. Given the in-depth thematic nature of this review, the methodological and theoretical contributions of reviewed papers will not be explored in the reported findings. In accordance with the overall aims addressed, the review has the following objectives:

- To offer a descriptive overview of the different participatory arts implemented for people with dementia.
- To consider the overall holistic benefits of participatory arts activities for people with dementia by exploring:
  - the role of the 'individual' in the interventions.
  - the role of the 'group' in the interventions.
  - the role of space, place and objects.

# **Method and Criteria**

A scoping review approach was deemed most suitable for summarising and collating the overall range of literature included in this review, identifying knowledge gaps and doing so using "systematic, transparent and replicable" methods (Grant and Booth, 2009, p.101). This

review adopted an approach influenced by Arksey and O'Malley (2005), regarding the identification, selection and collation of the relevant literature.

# Inclusion and Exclusion Criteria

Based on results from preliminary literature searches, an Inclusion and Exclusion Criteria table was developed (see Table 1).

[Insert Table 1 here]

Literature focusing primarily on people living with more advanced dementia symptoms was excluded given that it is commonly conducted in nursing, residential or specialist care settings and frequently features therapy approaches (Wall and Duffy, 2010; Sampson *et al*, 2018). Furthermore, people living with advanced dementia may have different needs to those with early or moderate dementia symptoms, given that they are more prone to additional illness, hospitalization and more pronounced cognitive decline (Mitchell et al, 2009). For these reasons, the present thematic scoping review focuses specifically on people living with early to moderate stages of dementia in the community.

# Strategy, Screening and Selection

Searches for relevant literature were conducted on the following databases between July 2018 and May 2019. The databases were chosen for their representation of arts, humanities, social and health sciences:

- PsycINFO
- Scopus
- SocINDEX with Full Text
- CINAHL Complete
- Medline Complete
- Web of Science

Hand searches were also conducted during the given time period using the complete volumes of the following journals. Both journals were considered relevant to the present review given their interdisciplinary contribution to research and practice in the field of arts and health:

- Journal of Arts and Health Volume 1 (2009) to Volume 11 (2019).
- Journal of Applied Arts and Health Volume 1 (2010) to Volume 10 (2019).

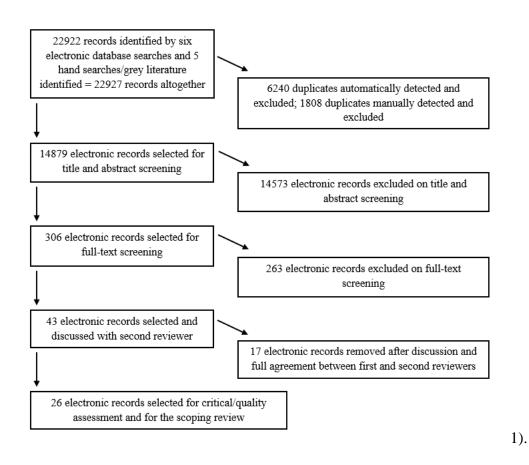
Grey literature searches were also conducted; however, none of the identified unpublished literature efficiently met the inclusion and exclusion criteria of this review due to missing information, presence of therapy approaches or noncommunity-based research locations, including residential and care homes.

After conducting a series of exploratory database searches, the review search terms were finalised (see Table 2). The listed terms aimed to represent the wide variety of participatory arts activities that exist and outcomes that may be measured. In addition to the search terms, filters were used on databases, where available, to manually exclude some subject areas, publication dates, formats and languages.

# [Insert Table 2 here]

Once all database search results were exported to an EndNote Library, duplicate papers were removed and simultaneous title and abstract screenings were conducted by MW on the remaining 14879 papers. 306 papers were identified as meeting the criteria for full text screening, including those with inconclusive titles and abstracts. Given the high volume of papers, an initial screening of methods sections was undertaken, since these sections held most of the relevant information for inclusion or exclusion criteria. After full text screenings, 43 papers – including inconclusive papers - underwent scrutiny with a second reviewer, BW, and an inter-rater reliability check measured using a Kappa coefficient of concordance. Following a meeting to discuss the papers and resolve differences, full agreement and a

perfect coefficient of 1.0 was achieved, with 26 papers finalised for the review (for details of full review process, see



[Insert Figure 1 here]

## Data Charting, Analysis and Quality Assessment

Data charting was guided by Arksey and O'Malley (2005) and included publication and author details, research aims/objectives, intervention type, methodology, sample, important results and review-specific features such as intervention location, facilitator type, inclusion of carers, demographics and dementia type (see Appendix 1 for simplified summary table).

Influenced by Dowlen *et al*'s recent thematic synthesis of musicking literature (2018), a thematic analysis was chosen to develop an in-depth understanding of participatory arts and the overall effectiveness, holistic benefits and design features of the research interventions in the final 26 papers (Braun and Clarke, 2006). The papers were each read thoroughly and

coded by hand, producing a thorough coding bank in which patterns were iteratively developed and refined to meet the aims and objectives of this review.

Quality assessments were conducted using an appraisal tool developed by Hawker *et al* (2002), designed to aid in the methodological assessment of disparate forms of data and exemplified in previous reviews (e.g. Milligan *et al*, 2016). The given quality scores in the current review ranged from 20 to 35 (M = 26.38) out of a total possible score of 36 (see Appendix 1). Whilst well-established and thorough, some papers may receive lower scores using this tool due to publication constraints and word limits as opposed to research quality; hence, scores were not considered final or decisive, but rather as an additional judgment process for the review.

# Findings

The 26 reviewed papers comprised different types of participatory arts based in seven countries (see Appendix 1). These are outlined in further detail below. Only five of the included papers defined or described their activities as 'participatory' arts (Hafford-Letchfield, 2013; Flatt *et al*, 2015; Swinnen, 2016; Richards *et al*, 2018; Tan, 2018). Nevertheless, all 26 papers recognised that increased participation – also referred to as engagement, involvement and interaction - was an integral part of the success of the interventions. The below discussion will remain centred on the concept of participation and contributing factors to the overall effectiveness of participatory arts for the promotion of health and wellbeing. The subsequent findings consider seven main themes according to three key areas: *The Individual; The Group;* and *Space, Place and Objects*. This will follow a descriptive overview of the participatory arts interventions from the 26 reviewed papers.

## 1. Participatory Arts: Descriptive Overview

Visual Arts: Art-viewing, art-making and object-handling

Thirteen of the 26 reviewed papers involved combinations of art-viewing, art-making and/or object-handling activities. Ten papers focused on balancing art-viewing and art-making activities (Ullán *et al*, 2013; Camic *et al*, 2014; Burnside *et al*, 2017; Flatt *et al*, 2015; Selberg, 2015; Belver *et al*, 2017; Chauhan, 2018; Schall *et al*, 2018; Windle *et al*, 2018) while the remainder involved viewing and object-handling (Johnson *et al*, 2017; Camic *et al*, 2019) or predominately art-making (Richards *et al*, 2018; Tan, 2018). While all 13 papers described similar features, five of the interventions were based on, or inspired by, the 'Meet Me at MoMA' [Museum of Modern Art, New York] model, which aims to make visual art accessible to people with early to mid-stage dementia through art-making workshops and interactive tours in small groups (Selberg, 2015: 476).

#### Music and Dance

Nine of the 26 papers involved singing, music and/or dance activities (Bannan and Montgomery-Smith, 2008; Camic *et al*, 2013; Harris and Caporella, 2014, 2018; McCabe *et al*, 2015; Osman *et al*, 2016; Unadkat *et al*, 2017; Evans *et al*, 2019; Zeilig *et al*, 2019). Seven of these papers involved choir and singing activities, while the remaining two papers also included improvisatory dance and instrument-playing (Zeilig *et al*, 2019) and a multiactivity musical production (McCabe *et al*, 2015). Similarly to the MoMA model for visual art, four of the choir-based papers were associated with the UK Alzheimer's Society's 'Singing for the Brain' model, which aims to improve social and cognitive stimulation through music (Bannan and Montgomery-Smith, 2008; Camic *et al*, 2013; Osman *et al*, 2016; Evans *et al*, 2019). Some of the interventions involved performances, thereby expanding the social sphere of the intervention to a more public setting (Harris and Caporella, 2014, 2018; McCabe *et al*, 2015; Unadkat *et al*, 2017).

## Theatrical Arts: Comedy and Drama

Two papers were based on unique comedy interventions, one specifically working towards a public comedy performance (Stevens, 2012) while the second created 'mockumentary'-style, video-recorded performances (Hafford-Letchfield, 2013). Both interventions were highly performative, drama-centric and improvisatory, making them accessible to people living with dementia without heavy reliance on memorising scripts or sketches.

## Literary Arts: Poetry and writing

The remaining two papers in this review involved contrasting poetry interventions. The first emphasised the spoken word alongside musical and movement activities (Swinnen, 2016), while the second was less performative, with emphasis on learning new poetry techniques (Petrescu *et al*, 2014).

## 2. The Individual

## a) Person-centred and Personalised Activities

Fifteen of the reviewed papers recognised the prevalence of valuing and respecting the individual, their personhood and/or using a person-centred approach (Stevens, 2012; Hafford-Letchfield, 2013; Camic *et al*, 2013; 2014; Petrescu *et al*, 2014; McCabe *et al*, 2015; Selberg, 2015; Osman *et al*, 2016; Swinnen, 2016; Burnside *et al*, 2017; Unadkat *et al*, 2017; Harris and Caporella, 2018; Tan, 2018; Evans *et al*, 2019; Zeilig *et al*, 2019). A further three papers identified the importance of balancing the needs of the individual with the needs of the group to improve participation (Ullán *et al*, 2013; Belver *et al*, 2017; Chauhan, 2018). This personcentred approach regards the individual by offering them agency and opportunity to play an active role in the direction of a relevant service (Osman *et al*, 2016). Some actions taken to encourage person-centeredness in the papers include incorporating participants' hobbies and interests (Camic *et al*, 2013; McCabe *et al*, 2015; Swinnen, 2016; Belver *et al*, 2017; Chauhan, 2018; Schall *et al*, 2018; Evans *et al*, 2019) and ensuring the themes, topics and

materials were biographically relevant and relatable to them (Hafford-Letchfield, 2013; Osman et al, 2016; Belver et al, 2017; Schall et al, 2018). Notably, a few volunteers in Evans et al's study (2019) stated that it was a challenge attempting to cater for 'diverse musical experiences and preferences' within one group (2019, p.1188). This is therefore a potential weakness of group-based musical activities and suggests that one-to-one music therapy sessions may, in some cases, achieve more person-centred benefits. Nevertheless, participatory arts, regardless of the type of art form being used, have the capacity to reestablish an individual's dignity, reassert one's sense of identity independent of their dementia diagnosis and reaffirm a person with dementia as a "whole" person (Petrescu et al, 2014, p.213; Hafford-Letchfield, 2013, p.20; Burnside et al, 2017, p.36). In being personcentred, participatory arts activities subsequently promote a strength-based approach, in which participants can focus on their needs and what they are still capable of doing and learning, as opposed to the skills they are losing or struggling with as a consequence of dementia (Camic et al, 2013; Ullán et al, 2013; Harris and Caporella, 2014, 2018; Petrescu et al, 2014; McCabe et al, 2015; Swinnen, 2016; Chauhan, 2018; Richards et al, 2018; Tan, 2018).

Ullán *et al* (2013) demonstrated that person-centred participatory arts help to achieve Article 27 of the Universal Declaration of Human Rights, whereby people have a right "to participate in the cultural life of a community" and "enjoy the arts" (Ullán *et al*, 2013, p.443). This is a key reminder of the centrality of culture and arts to the human experience, and the importance of taking steps to apply these to the commonly over-medicalised dementia experience. Where biomedical methods towards health and wellbeing are limited, person-centred participatory arts and culture can help people to flourish (Chauhan, 2018).

b) Participation and Communication

The overall attendance of individual participants was typically high in the different interventions under study and demonstrated a desire to take part, as opposed to feeling obligated to attend:

'...we'd got out the door and she was in pain and she says, ''no, I want to go!''' (Carer; Evans et al, 2019, p.1187).

As demonstrated, some adults with dementia felt capable of attending the group, regardless of potential physical health barriers. In addition to enjoying the activities, the high attendance may be linked to the novel, creative, social occasion presented by the participatory arts activities, which contrasts to the habitual, socially isolated daily routines of the individuals involved (Hafford-Letchfield, 2013; Belver *et al*, 2017; Burnside *et al*, 2017). Hence, participatory arts may have an impact on the social motivation of individuals who are otherwise at risk of loneliness and isolation.

The participatory arts activities demonstrated a positive impact on engagement, in particular on the verbal communication of people with dementia (Stevens, 2012; Ullán *et al*, 2013; Harris and Caporella, 2014, 2018; Petrescu *et al*, 2014; Selberg, 2015; Swinnen, 2016; Belver *et al*, 2017; Burnside *et al*, 2017; Unadkat *et al*, 2017; Chauhan, 2018; Tan, 2018; Evans *et al*, 2019). Participants were respectful of others and displayed appropriate turn-taking in group conversations (Swinnen, 2016), in addition to instigating spontaneous conversations without any targeted stimulation from others (Ullán *et al*, 2013; Unadkat *et al*, 2017; Chauhan, 2018; Tan, 2018). These individual contributions demonstrate the willingness of participants to develop social exchanges and share personal life stories with other members of the group (Selberg, 2015; Osman *et al*, 2016; Chauhan, 2018; Harris and Caporella, 2018; Tan, 2018).

Some papers found no communication improvements or observed participants with verbal interaction difficulties (Selberg, 2015; Windle *et al*, 2018), thereby indicating the importance

of non-verbal means of communication. These were encouraged and noted throughout the interventions, commonly observed in the form of physical contact, body movement and the use of facial expressions (Bannan and Montgomery-Smith, 2008; Camic *et al*, 2013; Ullán *et al*, 2013; Harris and Caporella, 2014, 2018; McCabe *et al*, 2015; Unadkat *et al*, 2017; Chauhan, 2018; Swinnen, 2016; Tan, 2018; Evans *et al*, 2019; Zeilig *et al*, 2019).

Given the types of tasks usually involved in participatory arts – such as sculpting (Chauhan, 2018), dancing (Zeilig et al, 2019) and object-handling (Camic et al, 2019) – there is an inevitable use of the body, the senses and experiences of embodiment throughout the creative process. This is demonstrated by the reference to 'multi-sensory' experiences and stimulation in five recent papers (Johnson et al, 2017; Chauhan, 2018; Schall et al, 2018; Tan, 2018; Camic et al, 2019). Regarding embodiment and non-verbal communication, Zeilig et al (2019) demonstrated that participants were more expressive and playful in their improvisatory music and dance study, through non-verbal and 'non-traditional ways, such as a participant gently striking a tambourine against their head' (p.21). Even for participatory arts where verbal dialogue was central, one paper found that "motor gestures... reinforce the emphasis of the spoken words" and improved participants' abilities in call and response activities (Swinnen, 2016, p.1394). This demonstrates the value of considering how best to nurture the physical skills of participants. Though some participants did struggle with physical limitations (Petrescu et al, 2014), these were rarely considered obstacles, given that the arts were an outlet to manage one's condition and express their views in an adaptable manner. Therefore, benefits can be sought by embedding multi-sensory and non-verbal engagement within arts-based activities, alongside verbal means of communication.

Additionally, communicating emotional expressions and emotional responses was key to understanding the effectiveness of participatory arts. Across all papers, most participants experienced increased enjoyment, pleasure and improved mood after taking part in

participatory arts. This was described by some participants as "uplifting" (Camic *et al*, 2014, p.164), "a positive feeling" (Petrescu *et al*, 2014, p.210) and a way to "feel better...brighter... more like your old self" (Osman *et al*, 2016, p.1333). From reviewing the papers, it is clear that the health and wellbeing benefits that are derived from participatory arts are at their strongest when the participant truly enjoys what they are doing; this contrasts to most biomedical methods of improving health.

In statistical feedback, Johnson *et al* (2017) found that the greatest preference and enjoyment was for the more active art-making activities in comparison to art-viewing or socialising alone. Other papers emphasised that pleasure was experienced by being with other people and feeling part of a community (Selberg, 2015; Burnside *et al*, 2017; Harris and Caporella, 2018). Regardless of which element produces the greatest enjoyment for different participants, participatory arts can elicit enjoyment both through the act of being creative and through connecting with other people who are being creative together.

Positive emotions and improved mood were occasionally found to extend into the home environment after attending interventions (Belver *et al*, 2017; Chauhan, 2018; Richards *et al*, 2018). However, others found that positive affect was limited to the sessions: "...*as soon as you take them away, it's gone... it needs to be back in the group*" (Evans *et al*, 2019, p.1188). Therefore, the evidence for the longevity of participatory arts benefits remains mixed and inconclusive but the experiences during participation are positive, connecting to the increasing recognition of 'in the moment' experiences.

# c) 'In the Moment'

The main reason that participatory arts are ideally accessible for people with cognitive decline is that they rely on 'in the moment' interaction and immersion, a common theme across over half (n = 17) of reviewed papers, which connects to both social behaviour and

cognitive functioning (Bannon and Montgomery-Smith, 2008; Stevens, 2012; Hafford-Letchfield, 2013; Camic et al, 2014; Harris and Caporella, 2014; Petrescu et al, 2014; Flatt et al, 2015; Selberg, 2015; Swinnen, 2016; Belver et al, 2017; Burnside et al, 2017; Johnson et al, 2017; Unadkat et al, 2017; Chauhan, 2018; Windle et al, 2018; Evans et al, 2019; Zeilig et al, 2019). By focusing on 'in the moment', spontaneous conversations, activities and identities, participants were not reliant on their short-term memory (Burnside et al, 2017) but had the freedom to equally build upon their long-term memory and the situations that were unfolding before them (Hafford-Letchfield, 2013). Being 'in the moment' dissolved judgment and removed an emphasis on correctness or biographical accuracy, instead allowing participants to freely use their imaginations to reconnect 'past and present, making sense of the fragments that remain as aspects of a particular and unique person' (Petrescu et al, 2014: 212). This approach means that participants with dementia are not judged on their cognitive abilities, nor are the arts activities intended to overtly challenge or improve these abilities; rather, participatory arts remove pressure and focus on what happens 'in the moment', both socially and through the body and senses, and prioritising one's sense of present identity external to their dementia diagnosis (Petrescu et al, 2014; Unadkat et al, 2017; Chauhan, 2018). Placing emphasis on being 'in the moment' may give an explanation for the improved participation and communication levels of participants explored earlier.

## d) Attention and Cognitive Stimulation

Firstly, it was evident from the reviewed papers that any cognitive decline associated with dementia in the early to moderate stages of dementia was not an obstacle and did not noticeably interfere or negatively affect a participant's engagement with participatory arts (Bannon and Montgomery-Smith, 2008; Ullán *et al*, 2013; Harris and Caporella, 2014, 2018; Swinnen, 2016). Given the emphasis on 'in the moment' events, 11 papers acknowledged an improvement in attention, concentration and focus, particularly in cases where participants

had previously been more socially disengaged or absent (Stevens, 2012; Camic *et al*, 2013, 2014; Hafford-Letchfield, 2013; Ullán *et al*, 2013; Belver *et al*, 2017; Burnside *et al*, 2017; Johnson *et al*, 2017; Chauhan, 2018; Tan, 2018; Evans *et al*, 2019). Improved attention was often attributed to the multisensory stimulation that creative activities offer, through tactile stimulation and the handling of materials or artefacts (Chauhan, 2018; Schall *et al*, 2018; Tan, 2018; Camic *et al*, 2019); through visual cues and stimulation (Johnson *et al*, 2017; Evans *et al*, 2019); and through auditory sounds, rhythms and music (Swinnen, 2016; Unadkat *et al*, 2017; Zeilig *et al*, 2019). Therefore, better attention and focus can, in part, be attributed to the consideration and integration of multiple senses.

While Camic et al (2013) measured deterioration over the intervention period of study, other papers found improvements in participants' memory, particularly of recent events in the participatory arts groups, such as conversations (McCabe et al, 2015), other people at the sessions (Hafford-Letchfield, 2013; Swinnen, 2016), activities with visual cues (Chauhan, 2018) and lines from scripts and songs which did not need to be memorised (Stevens, 2012). Furthermore, 18 of the 26 papers discussed evidence relating to the learning of new skills, including new song material (Bannon and Montgomery-Smith, 2008; Camic et al, 2013; McCabe et al, 2015; Unadkat et al, 2017), new art-making and sculpting techniques (Ullán et al, 2013; Camic et al, 2014; Flatt et al, 2015; Selberg, 2015; Belver et al, 2017; Johnson et al, 2017; Chauhan, 2018; Richards et al, 2018; Schall et al, 2018; Tan, 2018), drama and comedy skills (Stevens, 2012; Hafford-Letchfield, 2013), creative writing (Petrescu et al, 2014) or simply learning from each other (McCabe et al, 2015; Burnside et al, 2017). This demonstrates that new learning was not solely attributed to one art form using one particular technique, but that all types of interventions were capable of encouraging new learning through different mediums and senses. Furthermore, it was identified that it was less about the sophistication of a skill and more about one's willingness to try something new, such as

in the case of not being required to be a good singer to partake in singing activities (Unadkat *et al*, 2017). Overall, the experience of new learning led to improved confidence and often surprise at their potential to learn (Bannan and Montgomery-Smith, 2008; Camic *et al*, 2013, 2014; Ullán *et al*, 2013; Belver *et al*, 2017; Tan, 2018), given that dementia is typically associated with loss, rather than the acquisition of new knowledge. Therefore, participatory arts are effective because participants are not being restricted by dementia assumptions and stigma but can freely explore their abilities and boundaries through cognitive stimulation.

# 3. The Group

#### a) Social Cohesion and Togetherness

All 26 reviewed papers made a varying level of reference to the underlying social benefits of participatory arts, which were viewed as an effective way to reduce social isolation, both for people with dementia and their carers (Camic et al, 2013; Harris and Caporella, 2014; Flatt et al, 2015; Osman et al, 2016; Swinnen, 2016; Tan, 2018). They were found to improve social interactions by creating a social "safe space" (Zeilig et al, 2019, p.22) and the sense of a "circle of friends" (Burnside et al, 2017, p.35) in a "party atmosphere" (Hafford-Letchfield, 2013, p.19). The dementia diagnosis was removed from the agenda and all involved parties were considered as equals (Bannan and Montgomery, 2008; Camic et al, 2014; McCabe et al, 2015; Unadkat et al, 2017; Harris and Caporella, 2018). The participatory art replaced dementia as the focal, shared experience, which was appreciated and created by all members (Camic et al, 2013; Harris and Caporella, 2014; Osman et al, 2016; Johnson et al, 2017: Unadkat et al, 2017; Zeilig et al, 2019). The activities were valued and deemed as a type of "mediator", "channel" or "catalyst" for social relations and benefits, demonstrating that different types of arts can elicit the same social benefits in group settings (Bannan and Montgomery-Smith, 2008; Hafford-Letchfield, 2013; Belver et al, 2017; Harris and Caporella, 2018).

Another group-centric feature studied in over half of the papers (N = 15) was humour and laughter (Stevens, 2012; Hafford-Letchfield, 2013; Ullán *et al*, 2013; Harris and Caporella, 2014, 2018; McCabe *et al*, 2015; Selberg, 2015; Belver *et al*, 2017; Swinnen, 2016; Unadkat *et al*, 2017; Schall *et al*, 2018; Chauhan, 2018; Tan, 2018; Camic *et al*, 2019; Zeilig *et al*, 2019). The use of humour, which is entangled in social occasions, helped to increase participation and led to lively and relaxed environments where friendships could blossom (Hafford-Letchfield, 2013; Belver *et al*, 2017; Tan, 2018). Laughter was also capable of dissolving dementia-related tensions and moments of cognitive difficulty, giving an impression of a non-judgemental shared attitude (Selberg, 2015). Notably, both comedycentric papers by Hafford-Letchfield (2013) and Stevens (2012) found that performing to create laughter was more beneficial than "passively induced laughter" (Stevens, 2012, p.61). The role of humour is therefore especially beneficial when introduced into performative settings.

#### b) New and Existing Relationships

Fifteen of the reviewed papers explored the role of participatory arts in the dyadic relationship between the person with dementia and their carer (Bannan and Montgomery-Smith, 2008; Camic *et al*, 2013, 2014; Hafford-Letchfield, 2013; Ullán *et al*, 2013; Harris and Caporella, 2014, 2018; McCabe *et al*, 2015; Osman *et al*, 2016; Burnside *et al*, 2017; Unadkat *et al*, 2017; Chauhan, 2018; Schall *et al*, 2018; Evans *et al*, 2019; Zeilig *et al*, 2019). This common theme demonstrates the emphasis that participatory arts place on familial relationships and inclusivity. The interventions were considered by some researchers as a non-clinical opportunity to support and reinforce dyads (Camic *et al*, 2014), which was benefited by their shared attention and experience when the interventions were targeted to both of them (Johnson *et al*, 2017). In particular, the novelty of participatory arts activities helped to introduce refreshed relationship perspectives (McCabe *et al*, 2015; Osman *et al*, 2015; O

2016) and partners learned new things about each other and from each other, regardless of who had dementia:

"Yes, I have to teach you! I didn't half laugh at your efforts, it's very funny, you are getting better though" (Person with dementia; Unadkat *et al*, 2017, p.476).

Participating in creative activities can therefore help strengthen relationships through dementia, contrasting to the assumption that relationships will be exposed to deterioration. Additionally, the enjoyment from both sides of the dyadic relationship highlights the potential of unified, joint respite (Flatt *et al*, 2015; McCabe *et al*, 2015; Burnside *et al*, 2017). Reviewed papers also acknowledged the importance of building new friendships in participatory arts groups (Hafford-Letchfield, 2013; Ullán *et al*, 2013; Harris and Caporella, 2014, 2018; Flatt *et al*, 2015; McCabe *et al*, 2015; Osman *et al*, 2016; Swinnen, 2016; Belver *et al*, 2017; Burnside *et al*, 2017; Evans *et al*, 2019; Zeilig *et al*, 2019). People with dementia were consistently observed making strong connections with others, with some participants labelling others as their friends (Harris and Caporella, 2014; Zeilig *et al*, 2019). In one particular paper (Swinnen, 2016), a participant was observed to have made a strong bond with another, in which they remembered each other and expressed their connectedness through warm greetings and extended physical affection. Overall, whether friendship was demonstrated physically, emotionally or verbally, it remains a central element of

participatory arts and to human experience in general, contributing to a sense of community and belonging.

# 4. Space, Place and Objects

The role of setting and use of materials are important factors which can affect how well the participatory arts activities are received. With regards to setting, all 26 reviewed papers were based in settings such as museums, day care centres or theatres and were conducted in small

groups. These community-based locations were praised by participants, who enjoyed the creative space (Camic *et al*, 2013; Belver *et al*, 2017; Burnside *et al*, 2017; Tan, 2018) and appreciated the quiet atmosphere (Camic *et al*, 2014; Selberg, 2015; Schall *et al*, 2018) but also felt connected to the wider community and society in the 'semi-public setting' (Selberg, 2015; Belver *et al*, 2017). Therefore, it is beneficial to conduct arts activities in semi-public spaces, where there are less distractions but an increased sense of societal contribution. However, settings must be practical, ensuring that they are easily located and have all the necessary, accessible amenities to meet the needs of participants (McCabe *et al*, 2015). Beyond these practical suggestions, there is a lack of exploring the impact of space and place in the conduct of participatory arts.

Regarding props and objects, five papers demonstrated that extended enthusiasm and creative engagement were connected to the accessibility of the materials outside of the intervention environment (Camic *et al*, 2013, 2019; Belver *et al*, 2017; Unadkat *et al*, 2017; Schall *et al*, 2018). Specifically considering the art-viewing and art-making activities, some participants continued visiting museums and art galleries independently (Belver *et al*, 2017). Furthermore, a greater number of participants said that they would like to maintain painting or drawing as hobbies, as opposed to sculpting or clay modelling (Schall *et al*, 2018), which may indicate a preference for activities that involve less complex or messy materials. However, the most accessible of the activities for this purpose were music-based, in which few or no props were required: "…*because we can just pick it up again instantly, without needing any props or equipment or things*" (Person with dementia; Unadkat *et al*, 2017, p.474). Other music-based interventions demonstrated that participants continued to sing or listen to music at home (Camic *et al*, 2013). Therefore, while object-handling special artefacts may offer benefits (Johnson et al, 2017; Camic *et al*, 2019), other more accessible activities may be more useful in encouraging extended creativity after interventions end.

Additionally, objects and created artworks were often a point of conversation and connection for participants, in which participants showed interest in the artwork of others, including praising, encouraging and conversing with others while participating (Ullán *et al*, 2013; Flatt *et al*, 2015; Burnside *et al*, 2017; Chauhan, 2018; Tan, 2018). Objects therefore have social agency in participatory arts contexts, given that many of the documented interactions would have been lost had the physical object or artwork been removed from the setting or social network. Hence, having available objects to see or feel demonstrates the significant, inanimate role they play in the social group, creating a point of contact for people with dementia.

## Discussion

# Key Findings

Given the recent growth of recognition in arts for people living with dementia, this thematic scoping review offers an up-to-date analysis of community-based participatory arts literature and identifies that they can have a positive impact on the overall health and wellbeing of people living with dementia, including psychological, cognitive, emotional, social and physical components. While visual art and music activities remain the most common art types analysed in the literature, other literary, drama, dance and comedy-based activities have also shown to benefit people with dementia. This indicates that different participatory arts, regardless of the specific art form, have potential to offer comparable benefits for people with dementia, so long as the approach and facilitation method is appropriate and encouraging. This is a useful finding, given that researchers often aim to explore which type of art form is most effective and previous reviews have studied art forms separately or comparatively (e.g. Zeilig *et al*, 2014; Young *et al*, 2016). This suggests that rather than seeking to compare different arts, the focus should be on identifying the *underlying* processes and mechanisms

employed by facilitators of participatory arts activities, to promote wellbeing for people with dementia.

The data suggests that process and the facilitation approaches involved in running arts activities play an important role in the effectiveness of participatory arts. Common themes in over half of the reviewed papers involved 'person-centred' and 'in the moment' approaches, both of which support participants to take part without an over-reliance on memory or prior knowledge, focusing instead on needs and preferences. The value of this for dementia is that activities can match the capabilities of participants and emphasise the sharing of experiences in the present moment. Hence, the impaired cognitive abilities of participants did not inhibit their engagement in arts activities, instead highlighting strengths and focusing on what people with dementia can do, including learning new skills. Participatory arts offer a positive contribution to dementia-friendly communities and have potential to act as a platform for improving societal attitudes – both on a local and global scale.

The multisensory features and novel forms of stimulation that participatory arts offer through 'in the moment' experiences can lead to improved verbal and non-verbal communication. Through the use of props (Tan, 2018), different art mediums (Chauhan, 2018) and communication through movement (Swinnen, 2016), participatory arts create a focal point and shared attention that can encourage interaction amongst people, as well as improving participants' engagement with activities. The commonality of this theme across the reviewed papers highlights the value of non-traditional forms of communication and expression in the lives of those experiencing progressive verbal communication difficulties. However, none of the papers undertook an in-depth look at why certain props, objects or multisensory engagements aided participation and communication for people with dementia. Moving forward, research could usefully add to our understanding of the value of participatory arts for dementia, by examining the relationality and materiality of space and place, in particular,

the relationship between objects, the senses and engagement within the participatory arts environment.

Another key finding was that the experience of being part of a group – socialising with each other and building relationships - was a positive element of the interventions, with some suggestions that group-based arts activities can offer benefits that conversational social activities alone are unable to (Johnson et al, 2017). Hence, there may be unique benefits connected to using an art form in a social group which requires more research to further understand. Although some papers suggested that carers felt it was at times difficult to please all the musical preferences of individuals in one group (Evans et al, 2019), the general effectiveness of group-based activities for people with dementia indicates the potential of participatory arts interventions over individualised, client-based therapies to maintain healthy social skills through creative engagement. Importantly, people with dementia demonstrated increased social motivation, whereby their attendance took priority over other barriers, including poor health and physical pain (Evans et al, 2019). This highlights the potential role of participatory arts in combating isolation for people living with dementia and is a reminder that the creative and social sphere offered by participatory arts can and should have a strong position in the health care plan of people living with a dementia (Baker and Irving, 2016). Furthermore, participatory arts can benefit how people perceive the intimate, lived experience of dementia, demonstrating that new potentials are possible for personal relationships after a dementia diagnosis (Belver et al, 2017; Burnside et al, 2017) and furthermore debunking the assumption that new learning is not possible when living with dementia.

Unlike biomedical interventions, creative and cultural interventions are most effective when they are truly enjoyed and lead to improved mood, as indicated in the reviewed papers. Considering this, having a diverse range of arts interventions available for dementia may be a strength as opposed to a hindrance. Given that individual participants at times showed varied preferences– for different types of activities, songs or creative styles – and given that the benefits deriving from the different art forms are relatively consistent, a wider range of available activities gives the opportunity of choice to participants, to best suit their interests and enjoyment. Hence, while well-established and transferrable intervention models, such as MoMA or Singing for the Brain, can be applied and adapted across organisations on an international level, these models may be more beneficial from organisational, financial and facilitative perspectives, rather than from the participants' perspectives, who can thrive off of variability and diversity.

The review findings demonstrate that community-based participatory arts activities are typically conducted in museums, theatres and community day centres, which offer participants a quiet and protected location with connections to the wider community. Therefore, both the social setting and physical setting play important roles in combating the isolation that people with dementia are at risk of experiencing. While some practicalities of setting and location were considered (McCabe *et al*, 2015), there is limited discussion centred on the overall accessibility of settings, including proximity and travel required by participants; the number of places available in participatory arts programmes; and the selection process involved for potential participants, such as whether anyone can be turned away from joining based on their dementia symptoms or challenging behaviours. From both research and practice perspectives, it is therefore useful to consider how easily available a location and service is for people living with dementia, reflecting on the practical 'before' and 'after' experiences of participants outside of the intervention, alongside attending to the creative 'in the moment' encounters during them.

## Limitations and Future Research

While this paper aims to provide a thorough, in-depth review of the literature on the effectiveness of participatory arts for people with dementia, there are some limitations that should be considered in future publications.

Firstly, the review focuses predominantly on the practical side of papers – reporting on the arts activities, approaches, materials and outcomes - but gives less consideration to the methodological and theoretical research-oriented choices of the authors. Although the summary table (see Appendix 1) demonstrates that the included papers are predominantly qualitative and mixed methods-based, further exploration of the impact of methods on results was not accounted for. In particular, no investigation was undertaken into how inclusive the research methods were of people with dementia, which has been highlighted in previous review papers as an area of concern (Dowlen *et al*, 2018). Additionally, the 'in the moment' approach that is central to participatory arts recognises that researching the underlying process of activities is more useful than evaluating the participatory art according to its long-term benefits. Following this lead, research methods would have greater validity if they measured 'in the moment', processual features of participatory arts, and future reviews could further explore how this is being addressed within the relevant literature.

Secondly, the theoretical perspectives of papers were not included as a key element of this review, though some indications of researcher perspectives are drawn from the exploration of person-centred and in-the-moment approaches. Nevertheless, it would be beneficial for any future review to focus on the research practice and conduct used to study participatory arts, to better understand the most effective ways of investigating this area of research, in addition to adding to knowledge about the best ways to design or facilitate the activities on a practical level.

Furthermore, this thematic scoping review excluded publications which focused primarily on participants with more advanced forms of dementia, with such studies often investigating therapy-based interventions in residential or assisted living settings (Wall and Duffy, 2010; Sampson *et al*, 2018), all of which were part of the review's exclusion criteria. It is possible that excluding these studies may have omitted some relevant and insightful literature from the review. Hence, there is an opening for future research to explore the in-depth benefits and differences between participatory arts approaches and arts-based therapy routes for advanced dementia symptoms. Additionally, further research could investigate the effectiveness of conducting arts-based interventions in mixed groups – including people with varying types and stages of dementia – and considering the impact that this may have on one's individual, creative and social participation, in addition to whether there are ways of achieving all health and wellbeing needs in one supportive, creative setting.

## Conclusion

This thematic scoping review has summarised, reviewed and evaluated the published literature considering the benefits and implications of community-based participatory arts activities for people living with dementia. The review has demonstrated that all papers, spanning a variety of art forms, observed some form of social, relational, psychological/cognitive or emotional health-based benefit/s of participatory arts activities for participants. Additionally, the 'in the moment', person-centred and strength-based approaches taken when facilitating participatory arts interventions were deemed more impactful than the type of art form used, suggesting that the underlying processes and additional features are also important and should be considered for their effectiveness alongside the different art forms and activities. Hence, when contemplating future research, it may be more meaningful to further investigate the impact and effectiveness of different approaches and facilitation methods to using participatory arts, as opposed to making comparisons between different art

forms such as music, drama and art-making. Furthermore, the role of additional features such as space, setting and objects can be usefully explored to better understand their agency and accessibility in the context of participatory arts for dementia, while methodological and theoretical standpoints require further investigation to understand how they are being applied to researching arts for dementia.

# **Disclosure Statement**

The authors report no conflict of interest.

## Funding

This research was funded and supported by the Economic and Social Research Council and Theatre by the Lake, Keswick, Cumbria.

# References

## Thematic Scoping Review Literature References:

- 1. Bannan, N. and Montgomery-Smith, C., 2008. Singing for the Brain': reflections on the human capacity for music arising from a pilot study of group singing with Alzheimer's patients. *Journal of the Royal Society for the Promotion of Health*, *128*(2), pp.73-78.
- 2. Belver, M.H., Ullán, A.M., Avila, N., Moreno, C. and Hernández, C., 2017. Art museums as a source of well-being for people with dementia: an experience in the Prado Museum, *Arts & Health*, pp.1-14.
- 3. Burnside L.D., Knecht, M.J., Hopley, E.K. and Logsdon, R.G., 2017. *Here:now* Conceptual model of the impact of an experiential arts program on person with dementia and their care partners. *Dementia*, 16(1), pp.29-45.
- 4. Camic, P.M., Williams, C.M. and Meeten, F., 2013. Does a 'Singing Together Group' improve the quality of life of people with a dementia and their carers? A pilot evaluation study. *Dementia*, 12(2), pp.157-176.
- 5. Camic, P.M., Tischler, V. and Pearman, C.H., 2014. Viewing and making art together: a multi-session art-gallery-based intervention for people with dementia and their carers. *Aging & Mental Health*, 18(2), pp.161-168.
- 6. Camic, P.M., Hulbert, S. and Kimmel, J., 2019. Museum object-handling: A healthpromoting community-based activity for dementia care. *Journal of Health Psychology*, 24(6), pp.787-798.
- 7. Chauhan, S., 2018. Dementia and sculpture-making: Exploring artistic responses of people with dementia. *Dementia*, 19(2), pp.1-17.

- 8. Evans, S.C., Garabedian, C. & Bray, J. 2019. 'Now He Sings'. The My Musical Memories Reminiscence Programme: Personalised interactive reminiscence sessions for people living with dementia. *Dementia*, *18* (3), 1181-1198.
- Flatt, J.D., Liptak, A., Oakley, M.A., Gogan, J., Varner, T. and Lingler, J.H., 2015. Subjective experiences of an art museum engagement activity for persons with earlystage Alzheimer's disease and their family caregivers. *American Journal of Alzheimer's Disease & Other Dementias*, 30(4), pp.380-389.
- 10. Hafford-Letchfield, T., 2013. Funny things happen at the Grange: Introducing comedy activities in day services to older people with dementia innovative practice. *Dementia*, 12(6), pp.840-852.
- 11. Harris, P.B. and Caporella, C.A., 2014. An intergenerational choir formed to lessen Alzheimer's Disease stigma in college students and decrease the social isolation of people with Alzheimer's disease and their family members: A pilot study. *American Journal of Alzheimer's Disease & Other Dementias*, 29(3), pp.270-281.
- 12. Harris, P.B. and Caporella, C.A., 2018. Making a university community more dementia friendly through participation in an intergenerational choir. *Dementia*, *18*(7-8), pp.2556-2575.
- 13. Johnson, J., Culverwell, A., Hulbert, S., Robertson, M. and Camic, P.M., 2017. Museum activities in dementia care: Using visual analog scales to measure subjective wellbeing. *Dementia*, 16(5), pp.591-610.
- McCabe, L., Greasley-Adams, C. and Goodson, K., 2015. What I want to do is get half a dozen of them and go and see Simon Cowell': Reflecting on participation and outcomes for people with dementia taking part in a creative musical project. *Dementia*, 14(6), pp.734-750.
- 15. Osman, S.E., Tischler, V. and Schneider, J., 2016. 'Singing for the Brain': A qualitative study exploring the health and well-being benefits of singing for people with dementia and their carers. *Dementia*, 15(6), PP.1326-1339.
- Petrescu, I., MacFarlane, K. and Ranzijn, R., 2014. Psychological effects of poetry workshops with people with early stage dementia: An exploratory study. *Dementia*, 13(2), pp.207-215.
- Richards, A.G., Tietyen, A.C., Jicha, G.A., Bardach, S.H., Schmitt, F.A., Fardo, D.W., Kryscio, R.J. and Abner, E.L., 2018. Visual Arts Education improves self-esteem for persons with dementia and reduces caregiver burden: A randomized controlled trial. *Dementia*, 18(7), pp.3130-3142.

- Schall, A., Tesky, V.A., Adams, A. and Pantel, J., 2018. Art museum-based intervention to promote emotional well-being and improve quality of life in people with dementia: The ARTEMIS project. *Dementia*, 17(6), pp.728-743.
- 19. Selberg, S., 2015. Modern art as public care: Alzheimer's and the aesthetics of universal personhood. *Medical Anthropology Quarterly*, 29(4), pp.473-491.
- Stevens, J., 2012. Stand up for dementia: Performance, improvisation and stand-up comedy as therapy for people with dementia: a qualitative study. *Dementia*, 11(1), pp.61-73.
- 21. Swinnen, A.M.C., 2016. Healing words: A study of poetry interventions in dementia care. *Dementia*, 15(6), pp.1377-1404.
- 22. Tan, M. K. B. (2018). Connecting reminiscence, art making and cultural heritage: A pilot art-for-dementia care programme. *Journal of Applied Arts & Health*, 9 (1), pp.25-36.
- 23. Ullán, A. M., Belver, M. H., Badia, M., Moreno, C., Garrido, E., Gomez-Isla, J., Gonzalez-Ingelmo, E., Delgado, J., Serrano, I., Herrero, C. & Manzanera, P. (2013). Contributions of an artistic educational program for older people with early dementia: An exploratory qualitative study. *Dementia*, *12* (4), pp.425-446.
- 24. Unadkat, S., Camic, P.M. and Vella-Burrows, T. (2017). Understanding the experience of group singing for couples where one partner has a diagnosis of dementia. *The Gerontologist*, 57(3), pp.469-478.
- 25. Windle, G., Josling, K. L., Howson-Griffiths, T., Woods, B., Jones, C. H., van de Ven, P. M., Newman, A. and Parkinson, C. (2018). The impact of a visual arts program on quality of life, communication, and well-being of people living with dementia: a mixed-methods longitudinal investigation. *International Psychogeriatrics*, 30 (3), pp.409-423.
- 26. Zeilig, H., Tischler, V., van der Byl Williams, M., West, J. & Strohmaier, S. (2019). Cocreativity, well-being and agency: A case study analysis of a co-creative arts groups for people with dementia. *Journal of Aging Studies, 49*, pp.16-24.

# **Other references:**

- 27. Alzheimer's Association. (2019) *Treatment Horizon*. Retrieved from: http://www.alz.org/research/science/alzheimers\_disease\_treatments.asp
- 28. Alzheimer's Society. (2019) *Facts for the Media*. Retrieved from: <u>https://www.alzheimers.org.uk/site/scripts/documents\_info.php?documentID=535&page</u> <u>Number=2</u>
- 29. Arksey, H. & O'Malley, L. (2005). Scoping Studies: Towards a methodological framework. *International Journal of Social Research Methodology*, 8 (1), pp.19-32.

- 30. Baker, K., & Irving, A. (2016). Co-producing approaches to the management of dementia through social prescribing. *Social Policy & Administration*, *50*(3), pp.379-397.
- 31. Beard, R. (2011) Art therapies and dementia care: A systematic review. *Dementia*, 11(5), pp.1-24.
- 32. Braun, V. & Clarke, V. (2006). Using thematic analysis in psychology. *Qualitative Research in Psychology*, *3* (2), pp.77-101.
- 33. Capstick, A. & Ludwin, K. (2015) Place memory and dementia: Findings from participatory film-making in long-term social care. *Health & Place*, 34, pp.157-163.
- 34. Castora- Binkley, M., Noelker, L., Prohaska, T. & Satariano, W. (2010) Impact of arts participation on health outcomes for older adults. *Journal of Aging, Humanities and the Arts*, 4 (4), pp.352-367.
- 35. Dix, A. & Gregory, T. (2010). *Adult Participatory Arts: Thinking It Through*. London, England: Arts Council England.
- 36. Dowlen, R., Keady, J., Milligan, C., Swarbrick, C., Ponsillo, N., Geddes, L. & Riley, B. (2018). The personal benefits of musicking for people living with dementia: A thematic synthesis of the qualitative literature. *Arts & Health, 10* (3), pp.196-212.
- 37. Grant, M. J. & Booth, A. (2009) A typology of reviews: an analysis of 14 review types and associated methodologies. *Health Information and Libraries Journal*, 26 (2), 91-108.
- Hawker, S., Payne, S., Kerr, C., Hardey, M. & Powell, J. (2002). Appraising the evidence: reviewing disparate data systematically. *Qualitative Health Research*, 12 (9), pp.1284-1299.
- 39. Leitner, M. J. & Leitner, S. F. (2012) *Leisure in Later Life* (4th ed.) Urbana, IL: Sagamore Publishing LLC.
- 40. Lloyd, J. (2015) The role of objects in supporting older adults with dementia to tell stories about their lives. *Journal of Applied Arts and Health*, 6 (2), pp.171-186.
- 41. Mar, R. A., Peskin, J. & Fong, K. (2011). Literary arts and the development of the life story. *New Directions for Child and Adolescent Development*, 131, pp.73-84.
- 42. Milligan, C., Neary, D., Payne, S., Hanratty, B., Irwin, P. & Dowrick, C (2016). Older men and social activity: a scoping review of Men's Sheds and other gendered interventions. *Ageing & Society, 36* (5), pp.895-923.

- 43. Mitchell, S. L., Teno, J. M., Kiely, D. K., Shaffer, M. L., Jones, R. N., Prigerson, H. G., Volicer, L., Givens, J. L. & Hamel, M. B. (2009) The clinical course of advanced dementia. *The New England Journal of Medicine*, 361 (16), pp.1529-1538.
- Oyebode, J. R., & Parveen, S. (2019). Psychosocial interventions for people with dementia: An overview and commentary on recent developments. *Dementia*, 18(1), pp.8-35.
- 45. Rose, E. & Lonsdale, S. (2016). Painting place: Re-imagining landscapes for older people's subjective wellbeing. *Health and Place*, 40, pp.58-65.
- 46. Sampson, E. L., Candy, B., Davis, S., Gola, A. B., Harrington, J., King, M., Kupeli, N., Leavey, G., Moore, K., Nazareth, I., Omar, R. Z., Vickerstaff, V. & Jones, L. (2018) Living and dying with advanced dementia: A prospective cohort study of symptoms, service use and care at the end of life. *Palliative Medicine*, 32 (3), pp.668-681.
- 47. Schoenwald, C. (2012) Is It Art Therapy? Distinguishing Art Therapy from Arts and Crafts. *Chicago Bridge*. Retrieved from: <u>http://www.thechicagobridge.org/is-it-art-therapy-distinguishing-art-therapy-from-arts-crafts/</u>
- 48. Social Care Institute for Excellence [SCIE] (2015). *Creative arts for people with dementia*. Retrieved from: <u>https://www.scie.org.uk/dementia/living-with-dementia/keeping-active/creative-arts.asp</u>
- 49. Wall, M. & Duffy, A. (2010) The effects of music therapy for older people with dementia. *British Journal of Nursing*, 19 (2), pp.108-114.
- 50. World Health Organisation (WHO). (2019) *Towards a dementia plan: a WHO guide*. Retrieved from: <u>https://www.who.int/mental\_health/neurology/dementia/policy\_guidance/en/</u>
- 51. Young, R., Camic, P. M., & Tischler, V. (2016). The impact of community-based arts and health interventions on cognition in people with dementia: A systematic literature review. *Aging & Mental Health*, 20(4), 337-351.
- 52. Zeilig, H., Killick, J. & Fox, C. (2014) The participative arts for people living with a dementia: a critical review. *International Journal of Ageing and Later Life*, 9 (1), pp.7-34.

First Author, Year and Country of Publication	Study Aims, Objectives or Research Questions	Participant Sample	Arts-based Intervention	Study Design and Data Collection	QA Score
1. Bannan (2008); Australia.	To assess whether people with dementia and their carers would be able to participate, progress and benefit from group singing activities.	21-25 participants per session (including people with dementia and carers; insufficient detail).	Alzheimer's Society 'Singing for the Brain' musical reminiscence sessions.	Mixed methods pilot study. Video and audio recordings. Carer-completed questionnaires.	26/36
2. Belver (2017); Spain.	To design and evaluate the effectiveness of an arts activity programme for people with dementia.	<ul><li>12 people with dementia.</li><li>4 family carers.</li><li>2 professional carers.</li></ul>	'We Have a Date with Art' – visual art MoMA-inspired model in Prado Museum.	Qualitative, ethnographic study. Participant observation. Field journals. Photographs. Video recordings.	31/36
3. Burnside (2017); USA.	To explore the impact of an experiential museum-based arts program on people with dementia and carers	<ul><li>21 people with dementia.</li><li>21 family and professional carers.</li></ul>	<i>here:now</i> visual art MoMA- inspired model in Frye Museum.	Qualitative, grounded theory analysis study. Semi-structured telephone interviews with people with dementia and their carers.	31/36
4. Camic (2013); UK.	To determine whether participating in a community singing group can have a positive impact on well-being and daily functioning of people with dementia and their carers.	10 people with dementia. 10 carers.	'Singing Together Group'.	Mixed methods pilot evaluation study. Semi-structured interviews. Standardised measures. Observational scales. Carer diaries.	28/36
5. Camic (2014); UK.	To understand the experience of an art gallery intervention and its impact on social inclusion, carer burden, quality of life and daily living for those with dementia.	<ul><li>12 people with dementia</li><li>12 carers.</li></ul>	Visual art programme in traditional and contemporary art galleries.	Mixed-methods pre-post study design. Standardised questionnaires. Interviews. Fieldnotes.	29/36
6. Camic (2019); UK.	To determine whether interacting with objects from museum collections would increase subjective wellbeing for people in early to mid- stages of dementia and with different dementia diagnoses.	80 people with dementia.	Object-handling activity and discussion programme, conducted in an Alzheimer's Society day centre and a museum.	Quasi-experimental study design. Pre- and post-intervention questionnaires.	31/36

Appendix 1: Summary table of key information from reviewed papers

7. Chauhan (2018); UK.	To examine how the creative potential of people with dementia	7 people with dementia.	Dynamic sculpture-making intervention using multiple	Creative, practice-based investigative study.	26/36
	can be explored through		channels (e.g. clay, papier	Observations.	
	meaningful artistic engagement in		mâché and virtual means).	'In-the-moment' interviews.	
	sculpture-making.			Questionnaires.	
				Video recordings.	
				Audio-recorded interviews.	
8. Evans (2019); UK.	To explore whether a music-based programme can enhance quality	20 people with dementia.	'My Musical Memories' Reminiscence programme	Mixed methods pre-post intervention design.	25/36
	of life for people with dementia		designed by Alzheimer's	Creative Expressive Activities observation	
	and their carers.		Society England.	tool.	
				Focus groups.	
				Feedback from volunteer observations.	
9. Flatt (2015); USA.	To gather the subjective experiences of older adults with	10 people with dementia.	Visual art engagement activity session based on the MoMA	Cross-sectional qualitative study.	27/36
	early stage Alzheimer's/ dementia	10 carers.	model, conducted at The Andy	Focus groups.	
	and their family carers during an art museum activity.		Warhol Museum.	Satisfaction surveys.	
10. Hafford- Letchfield	To use a community-based comedy/drama project as an	12 people with dementia.	The Grange comedy project of unscripted, improvised acting	Mixed methods study.	20/36
(2013); UK.	unconventional means to	4 family carers.	with humour and parody,	Interviews.	
(2010), 010	communicate with people with	Fining curcis.	based in community day	Video recordings.	
	dementia, and to share outcomes and evaluations of using comedy in this context.	8 staff members.	centre.		
11 + 12. Harris (2014,	To evaluate the use of an intergenerational choir [for	22 people with dementia.	Intergenerational choir music programme based at a	Mixed methods study.	30/36
2018); USA.	combating dementia stigma] and lessening social isolation for	21 family carers.	university.	Qualitative questionnaires for students. Focus groups for people with dementia and	
	people with dementia.	62 undergraduate students.		carers. Observations.	
13. Johnson (2017); UK.	To compare the impact of two museum-based activities and social activity on the subjective	36 people with dementia. 30 carers.	A visual art programme of museum object-handling and art viewing with refreshment	Quasi-experimental study with mixed 2 x 4 repeated-measures crossover design.	33/36
	wellbeing of people with dementia and their carers.	so cureis.	break in-between activities.	Four-stage visual analogue scales. Open-ended evaluative questionnaires at end of intervention.	

14. McCabe (2015); UK.	To evaluate outcomes of a creative musical project for	44 people with dementia and carers.	A creative musical project, led by Scottish Opera company,	Qualitative participatory study.	26/36
( /)	people with dementia and their carers.		involving development and performance of a musical production.	Interviews.	
15. Osman (2016); UK.	To explore the impact of Singing for the Brain for people with	10 people with dementia.	Alzheimer's Society 'Singing for the Brain' musical	Qualitative study.	28/36
	dementia and their carers by considering their in-depth experiences.	10 family carers.	reminiscence sessions in community setting.	Semi-structured interviews.	
16. Petrescu (2014);	To test the effectiveness of poetry-writing for psychological	4 people with dementia.	Poetry writing workshop.	Qualitative study.	20/36
Australia.	functioning in people with early stages of dementia.			Structured interviews.	
17. Richards (2018); USA.	To investigate whether participants with dementia would	27 people with dementia.	Visual Arts Education programme.	Randomised controlled single-blind trial design.	31/36
	improve on measures of quality of life, self-esteem and activities of daily living after attending a visual arts program.	26 carers.		Quantitative outcome measures.	
18. Schall (2017); Germany.	To assess the impact of an arts- based intervention on outcomes including cognitive status, self-	<ul><li>44 people with dementia.</li><li>44 carers.</li></ul>	ART Encounters: Museum Intervention Study (ARTEMIS) visual art	Randomised wait-list controlled study with mixed-methods design	32/36
Germany.	reported quality of life and emotional well-being.	44 Calcis.	programme. Control group included.	Standardised measures (self-reported). Subjective evaluations by informal carers.	
19. Selberg (2015); USA.	To investigate how a museum- based arts program can reveal the	People with dementia and carers (insufficient detail)	'Meet Me at MoMA' New York Museum of Modern Art	Qualitative, ethnographic study.	21/36
	connection between dementia, art and personhood.		Alzheimer's programme.	Participant observation. Interviews.	
20. Stevens (2012);	To investigate the benefits of a stand-up comedy improvisation	6 people with dementia.	Stand-up comedy and improvisation workshop	Qualitative study.	24/36
Australia.	workshop programme for people with mild dementia living in the community.	6 carers.	intervention.	Fieldnotes. Semi-structured interviews.	
21. Swinnen (2016); The	To examine how live poetry can encourage the inclusion of people	15-35 people attending each session (insufficient	Alzheimer's Poetry project including slam poetry, call and	Ethnographic case study.	24/36
Netherlands.	with dementia in dialogue; and identify key strategies for	information).	response, rhythm and rhyme and memorised song activities.	Participant observation. Fieldnotes.	

	enabling people with dementia to participate in collaborative poetry performances and improvisations.			Audio and video recordings. Photographs. Semi-structured conversations. Corpus of poems.	
22. Tan (2018) Singapore.	To examine the impact of a pilot participatory visual art, multi- sensory dementia care programme.	8 people with dementia.	'Let's Have Tea at the Museum' visual art programme using visual art, art-making and storytelling. Conducted in Peranakan Museum.	Mixed methods study. Observations. Fieldnotes and journal writing. Video recordings. Photography.	26/36
23. Ullán (2013); Spain.	To determine whether people with dementia could participate in a contemporary artistic educational program and gain better understanding of their viewpoints and the benefits experienced.	21 people with dementia.	Visual art educational programme using contemporary photographic cyanotype methods.	Mixed methods study. Participant observation. Focus groups. Observational assessments by educators.	25/36
24. Unadkat (2017); USA.	To better understand the benefits of group singing for people with dementia and their partners across different singing interventions and settings.	<ul><li>17 people with dementia.</li><li>17 spousal carers.</li></ul>	Five varied community singing/music groups from which participating couples were attending prior to/during the research project.	Qualitative study based on grounded theory. Interviews.	33/36
25. Windle (2018); UK.	To strengthen the evidence base for visual art programs and investigate whether visual art can improve the well-being, quality of life and communication of people with dementia in different settings.	54 people with dementia in community settings (site 3).	Visual art programme disseminated across three different sites (library, arts centre with gallery, and international music and arts venue.) Control group also included.	Longitudinal mixed methods design with repeated measures. Questionnaires. Qualitative open-ended interviews. Self-evaluation forms. Behavioural observations.	35/36
26. Zeilig (2019); UK.	To investigate how co-creativity – in the context of music and dance - can impact well-being from the subjective perspectives of people living with dementia and their carers.	<ul><li>5 people with dementia.</li><li>3 spousal carers.</li></ul>	'With All' multi-activity, co- creative art programme of improvisatory music and dance.	Intrinsic case study methodology and mixed methods approach. Dialogic interviews. Video recordings. Well-being questionnaire.	24/36

Table 1:	Inclusion	and Exclusion	Criteria	Table
----------	-----------	---------------	----------	-------

	Inclusion Criteria	Exclusion Criteria
Population	Adults of any age with a diagnosis of any form of dementia in early or mid-stages.	Advanced dementia stages.
		Research where dementia is
	Carers or partners of people living with	not the primary focus or
	early or mid-stage dementia.	where specific results for dementia are not reported.
Intervention/ Mediation	Participatory arts-based interventions which could include one or more of the following activities: singing, playing and	Therapy or clinical-based interventions.
	making music, dancing and movement, drama and theatre, storytelling, creative writing or visual arts.	One-to-one interventions that are not conducted in a group setting.
Outcomes	Outcome measures broadly related to effectiveness, participation, or health and wellbeing.	Invasive/biological testing or measurements using blood sample, x-rays or scans.
Setting	Community or semi-public settings e.g. theatres or community centres, which are multi-purposeful and have dedicated safe spaces for the art activities.	Healthcare settings like residential homes, hospitals and hospices, given their association with therapy, recreation and more advanced symptoms.
Study Design	Any empirical research design including quantitative, qualitative or mixed methods.	-
Additional features of	Papers published in English language only.	Publication languages other than English.
papers	Publication date between 2008 and 2019. This search period is based on previous publication start dates up to the current period.	Formats including book reviews, commentaries, literature reviews and meta- analyses, dissertations or theses.

Table 2: List of Database Search Terms

# **Search Terms:**

dementia OR Alzheimer\* OR "memory loss"

# AND

participatory\* OR performing\* OR "community-based\*" OR art OR arts OR "community art\*" OR "dramatic art\*" OR drama OR music\* OR singing OR dance OR dancing OR movement OR storytelling OR acting OR arts-based OR reminiscence OR art-making OR "literary art" OR "visual art" OR creativ\*

AND

"quality of life" OR wellbeing OR "well-being" OR "well being" OR health OR happiness OR behaviour OR expression OR social\* OR communicat\* OR engage OR engaging OR cognit\* OR therapeutic OR interact\* OR carer OR caregiver OR spouse\* OR partner\*

# Figure 1: Flow Diagram of Literature Search Process, July 2018 - May 2019

