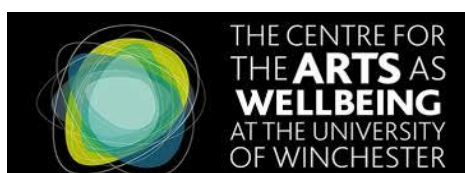


A report evaluating a training programme for use with People with Dementia, March 2017

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Forward

Joyful Jams CIC formed in 2012, we are now a group of 8 Hampshire based artists committed to bringing Joyful Arts Movement and Song to individuals living with and without dementia in care and in the community. We provide appropriate, meaningful, high quality, participatory arts experiences, to some of the most vulnerable people in our communities.

We believe that everyone has the right to be comfortable in their own skin and to form meaningful relationships. Through movement and dance, theatre and song JAMS artists make this a reality.

This paper will give an insight into the experiences of Joyful Jams artists, how we work, the joy and the challenges we face. I hope that you the reader will enjoy and learn from the approach we adopted. I am very proud of what we have achieved, the happiness we have created with others, the ideas and energy we have inspired, but perhaps most importantly the connections we have made along the way. Over the last year JAMS have trained and supported 8 artists to facilitate arts and dementia sessions, facilitated 120 care home and community sessions, creating joy with 1680 people living with dementia, shared enjoyment with relatives and friends and shared knowledge with care staff. We have developed and shared creative training with care home staff and provided 'props' to enhance care home life.

Today I had the privilege of visiting a successful community singing group to invite members to a Celebration which marks the end of the Peoples Project and a very successful year. It was through this group, and my dear friend and colleague Sandra Thibault that my passion for creating enjoyment and connection through the arts, for people living with dementia, was inspired and JAMS was formed. The additional support JAMS have received along the way, from our local Arts Centre, local and County Council and University has enabled JAMS to gather momentum and forge an exciting, challenging, interesting and successful path. Long may this continue.

A white rectangular box containing the handwritten signature "Louisa White" in a cursive script.

Executive Summary

The arts are recognised in academic literature as an effective way of addressing wellbeing amongst diverse populations. This document evaluates how such research was used in the implementation of a creative activities intervention for use by people with dementia resident in care homes and other supported settings, by an organisation known as Joyful Jams: CIC. In the current project, Joyful Jams: CIC commissioned expert practitioners from differing artistic backgrounds, to train artists, students and care home staff in dance and movement, theatre, music and dementia awareness. Evaluation of the training programme was undertaken by the Centre for Arts as Wellbeing, The University of Winchester.

Joyful Jams: Creative CIC

For four years, Joyful Jams: CIC has been undertaking an assortment of events designed to raise awareness of dementia and deliver a variety of activities with the intention of alleviating isolation and bringing pleasure to people with dementia. These activities utilise an array of artistic interventions delivered by experts at hospitals, day centres and care homes, reaching out to many.

Emerging changes in the delivery of health and social care necessitate a new approach to national health strategies that build on community-based solutions to wellbeing that maximise resources whilst minimising expense. The training programme designed by Creative Minds CIC emerged following a previous and generic Council run training event where they were able to access care home staff in a comfortable environment and where Joyful Jams: CIC showcased their framework for practice. This programme laid the foundation for the training programme featured in the current report. The programme initiated by Joyful Jams: CIC makes a meaningful contribution to supporting local incentives, at the same time as bringing joy to the lives of people with dementia.

The Centre for Arts as Wellbeing

The Centre for the Arts as Wellbeing is concerned with restoring a wider sense of value for the arts in the context of promoting wellbeing in individuals, communities, and the environment. It involves seeing the arts in a healing context, knowing how other cultures have used the arts as a rebalancing tool, looking at and valuing the work of arts therapists, seeing the arts in wider contexts than the concert hall or theatre and exploring new ideas for their relevance to the wider society. Their research focuses upon contextualised performing arts practices that are consciously related in a community context, particularly projects with hard to reach and marginalised people. As a research institution the Centre for Arts as Wellbeing is guided by the best available evidence and evaluates all work with rigour and transparency.

The evaluation

The creative activities intervention undertaken by Joyful Jams and named Creative Minds, was evaluated using a qualitative, formative methodology of the developmental processes involved in creating the training programme for use with people with dementia, with the findings used as a learning resource for conferences, presentations, workshops and online resources.

Findings

The findings suggested that the diverse experience of the expert artist trainers had both a beneficial and less helpful affect upon the training programme. For example the varied skills mix the artists brought meant that, no matter how dementia presented, people experiencing it at all levels could be reached. Conversely this same variance of skills inhibited the formation of a consistent model for a training programme for use in other settings. Nonetheless, the training programme brought greater awareness to trainers and care home staff that contributed to a change in perceptions of people with dementia. For some however, the artistic intervention exposed their vulnerabilities, a challenge that contributed to their disengagement. A finding of importance was that the creative sessions delivered to people with dementia impacted both their health and happiness. No matter how advanced their dementia, residents were able to respond with the tiniest gestures such as toe tapping or smiling. Most consistent throughout the data, was the need for good communication between artists and care homes to ensure both parties work in a transparent and cooperative way.

Future recommendations

- 1) Good communication, including a shared vision and goals is essential between care home and the external artist provider organisation.
- 2) Whilst this training programme has highlighted the benefits of arts based activities for residents, care home staff and artists, the aim of developing a standardised training model has been found wanting in favour of a more collaborative, person centred, flexible program for all involved.
- 3) The question of engagement/disengagement by care staff in the care homes needs to be sensitively managed with consideration given to the balance between on and off site training.

A report evaluating a training programme for use with People with Dementia

1.0 Programme outline

Following a successful bid for funding through the Big Lottery Fund, Joyful Jams: Creative Minds were able to undertake a community project with three principle aims:

- a) To develop an inclusive training programme, created by artists and care-home staff that improved understanding and insight into the lives of People with Dementia (PWD), whilst also providing care-home staff with a framework for future practice.
- b) To provide a resource for a regional arts centre for people with dementia to help reduce stigma, and train more artists and project leaders to sustain work with people with dementia into the future.
- c) To promote a dementia friendly arts centre to benefit people with dementia, their carers and family.

Joyful Jams: CIC is a community project within Hampshire providing the 20,000 people living with dementia in the county important time away from the disease. The values guiding their work are in supporting people living with dementia in care homes through music, performance and visual arts. Their intended outcomes are in increasing the provision of creative activities in care homes, community centres and hospitals, giving people with dementia opportunities for new social events to take part in, thereby reducing feelings of isolation, depression, boredom and confusion.

In the current project, Joyful Jams: Creative Minds commissioned expert practitioners from differing specialties to train artists, students and care home staff in dance and movement, theatre, music and dementia awareness. These art forms were selected on the basis that since research identifies them as effective in triggering memories, nurturing engagement, and combatting the boredom and isolation of people with dementia (Johnson & Sullivan-Marx, 2006; Sterrit & Pokorny, 1994). The intention was to develop a bespoke training programme that could be transferred to other settings, whilst also contributing to national research into effective arts practice for dementia. To this end, researchers at the University of Winchester were invited to evaluate the training programme developed by Joyful Jams: Creative Minds.

2.0 Background

Historically, dementia research has focused primarily on 'cause and cure' efforts to locate etiology and to alleviate the caregiver burden (Beard, 2011, p.633). More recently, dementia specialists and researchers have been questioning how a more nuanced understanding of the lives of people with dementia could enable meaningful and responsive service provision as an alternative to pharmacological approaches (Daykin & Walters, 2015; Daykin, Walters & Ball et al., 2016; Hendry & McVittie, 2004; Lipe, 1991; Scholzel-Dorenbos et al, 2007; Thorgrimsen et al., 2003). Accordingly, art interventions are seen as a way of moving beyond a biomedical framework and to embrace a social context that provides a subjective understanding of the quality of life for people with dementia.

Rather than promoting behavioural or psychosocial change, Killick and Allan (1999) suggest that most arts in dementia fall into the category of a leisure activity, 'generating a sense of enjoyment and satisfaction' (p. 35). The use of the arts in dementia care are noted for promoting non-verbal communication, enriching lives by prompting memory recall, enrichment (Coaten, 2001) and offering hope and healing (Johnson & Sullivan-Marx, 2006; Sterrit & Pokorny, 1994). Additionally, Reynolds and Lim (2007) have found that through treating the whole person rather than the illness (Hirsch & Meckes, 2000) engagement with the arts helps maintain self-identity and worth, empowering people with dementia to retain some control over their lives. Lastly, Radley and Bell (2007) refer to the 'in-the-moment' benefits which afford temporary emancipation such that people with dementia can be given voice (Jonas-Simpson & Mitchell, 2005).

Arts interventions for people with dementia occupy many categories including music therapy, visual arts therapies, theatre and movement, and despite the benefits found from all such interventions, Beard (2011) highlights that few previous studies have focused upon process variables concerning satisfaction or quality of life. This omission he attributes in part to methodological effect, with quantitative clinical scales used to capture biomedical change following interventions and thereby offering a linear portrait (Moos & Bjorn, 2006). Although these studies generally report significant reductions in bio/psycho/social effects, such decreases are not sustained over time (Holmes et al., 2006; Jennings & Vance, 2002; Ledger & Baker, 2007). Conversely, Betts (2006) considers the most effective assessment to incorporate both objective and subjective accounts using participant interpretations (Daykin & Walters, 2015; Daykin, Walters & Ball, K., et al., 2016). Other innovative studies have used a systematic method for evaluation based on the perspectives of people with dementia (Brooker, 2005; Chung, 2004; Holmes et al., 2006) such variation serving to highlight that much consideration is needed as to the methods best suited to research.

3.0 Methodology

The intervention

The intervention designed by artists at Joyful Jams: Creative Minds involved four; two day training programmes delivered by expert trainers, to artists, students in the fields of dance, theatre, music and dementia awareness and care-home staff. Each expert trainer developed the content of their own sessions.

The trainers were experts in their field, providing training and mentoring to artists working on the project. The artists were individuals who facilitated sessions within the care homes having first undergone JAMS' training at the outset of the project and who were mentored by the trainers during this process.

The training days focused on four specific domains:

- Dementia Awareness
- Story telling
- Dance for Dementia
- Music

The original programme as described was as follows:

- a) 4 x two day training sessions delivered to trainee artists, students and care home staff by expert artists.
- b) 4 x development days (one per month), where the artists observe the care-home staff at work and get to know the residents so as to assess the continued development of the training model followed by two hour sessions for further discussion.
- c) Eight sessions where one artist trained by the experts during the initial training phase goes to a care home for one day to observe and support the care home staff and students in utilizing the knowledge accrued during the developmental and training days. This provides the care staff and students with the opportunity to facilitate group activities.
- d) Two, five hour symposiums, spaced over two weeks, where people with dementia, their carers and family are invited to exchange the learning accrued from the project, contribute their opinions and celebrate the contribution of the arts to wellbeing. These sessions also contribute to a public perception of The Point as a dementia friendly arts centre. In reality, steps b and c of the original protocol were not realised as planned, the reasons for this provided in the following report.

The research proposal

The research proposal formulated by the University of Winchester was designed to provide a qualitative, formative evaluation of the developmental processes involved in creating the training programme, with the findings used as a learning resource for use at conferences, presentations, workshops and online resources. Whilst Ballinger (2006, p.235) questions the reliability and validity of qualitative research, criticising it as a “merely subjective assertion supported by unscientific method”, in seeking to evaluate the subjective experiences and opinions of the participants in the current study, the more positivist criteria of reliability, validity and generalisability guiding quantitative research were generally less applicable. Accordingly, qualitative methods were selected to compliment the research questions (see appendix 1).

The research was guided by four main outcome aims:

- To celebrate difference and diversity
- To develop a bespoke training programme, created by artists and care-home staff that improved understanding and insight into the lives of people with dementia, whilst also providing care-home staff with a framework for practice.
- To provide a regional arts centre at The Point in Hampshire for people with dementia to help reduce stigma, and train more artists and project leaders.
- To promote The Point as a dementia friendly arts centre to benefit people with dementia, their carers and family

The principle research objectives were to:

1. Evaluate the developmental processes of a training programme for use with people with dementia, delivered by arts experts to artists, students and care-home staff.
2. Explore with the art experts, artists, students and care-home staff what went well and what did not.
3. Evaluate the processes and activities involved in developing the training model.
4. Formulate a concept of what a training model would look like.
5. Explore developmental changes in attitude and levels of awareness about people with dementia amongst artists, students and care-home staff.
6. Identify any distinctive features of the training model that might limit its transferability to other settings.

Data were gathered using focus groups pre and post the interviews, including participant artists, expert artists, students and care home staff. These explored the developmental processes involved in creating a training model for use with people with dementia and included enquiry as to what went well, the challenges, how these were addressed, and an exploration of the participants' views and experiences in order to inform the evaluation. The focus groups lasted between 60-90 minutes.

These data were supplemented by ten semi-structured interviews with individuals from the same participant group, four weeks after the training programme had concluded. They explored any developmental changes in attitude and levels of awareness of people with dementia amongst the artists, students and care-home staff as a response to the training model. As with the focus groups the interviews lasted between 60-90 minutes.

Ethical aspects of the research and data analysis

The proposal received favourable ethical opinion from the University of Winchester Ethics Committee. Before recruitment commenced, each participant was issued with a Participant Information Sheet (PIS) and consent form (see appendix 2&3). The PIS included the potential benefits and harm associated with the project. Confidentiality was maintained, with exceptions made clear in the PIS. Only once the researcher was sure that the participants had fully understood the study, and the PIS has been explained, did the researcher obtain informed consent. The expert training staff, artists, students and home-care staff were recruited to the study through the Creative Minds Department at the Point.

Qualitative data were audio recorded by a research fellow, transcribed, then manually analysed using thematic analysis, a recognised methodology for reducing and categorising qualitative data (Braun & Clarke 2006). Transcripts from the data were read through twice before initial themes were highlighted by the researcher. On a third reading, these initial themes were then amalgamated into sub-ordinate themes, thought to broadly represent the participant's narratives. Finally, following a fourth reading of the data, these subordinate themes were then refined into superordinate themes considered by the researcher as embodying the essence of the overarching topics.

The data were manually entered into tables listing the subordinate theme, excerpts from the text highlighted, and in support of each theme, an interpretation of the content and the superordinate theme into which this narrative fell.

The subordinate and superordinate themes

As can be seen from table 1, the process of thematic analysis gave rise to six superordinate themes.

Subordinate themes	Superordinate themes
<ul style="list-style-type: none"> • Involvement with the training programme • The different training sessions offered • Fluidity and flexibility/working in the moment 	The developmental processes of the training programme
<ul style="list-style-type: none"> • Personal gain • Attitude in the care homes • Perception of the arts • Addressing generational change 	Attitude change
<ul style="list-style-type: none"> • Growing awareness for trainers and care home staff. • Resident autonomy • Evaluation of training programme 	What went well
<ul style="list-style-type: none"> • <i>Communication, coordination and</i> • <i>Negotiation, practical challenges,</i> • <i>Vulnerability and inhibition</i> • <i>A coherent model</i> • <i>Organisational culture</i> 	Main challenges
<ul style="list-style-type: none"> • Improving communication and building relationships • Content and duration of sessions • Organisational culture • The ideal space 	A future model
<ul style="list-style-type: none"> • Improving the health and happiness of residents • The health and happiness of the trainers and care home staff 	Wellbeing affects

4.0 Findings

The developmental processes of the training programme



“You want to end up with that group hug at the end but in the nicest British way, when nobody really touches each other”.

The first superordinate theme, *the developmental processes of the training programme*, gave rise to three subordinate themes, *Involvement with the training programme; the different training sessions offered and; fluidity and flexibility/working in the moment*, describing the various process and delivery techniques included in the different training programmes.

According to the data, the trainers were practitioners in diverse artistic approaches, bringing an array of skills to the training mix such as; clowning, singing, theatre, music, instrumentation and poetry. Each trainer had a wide range of experience which they had used in mixed settings, such as day centres, residential care homes and local hospital settings. Furthermore, attendance at the sessions delivered in the care homes was, at least 15 residents, and at most, 29. Such variables inevitably resulted in a mixed approach to session delivery, both during the training days and in the care homes, these latter also influenced by the severity level of the residents’ dementia and therefore, their cognitive abilities. These conditions necessitated that the trainers responded to the numerous requirements with extreme flexibility. For example to build a relationship with more distant residents, one trainer used familiar objects to stimulate discussion:

“I might take a collection of heart shaped stones, herbs from the garden, a poem, a piece of music and through using those things, get that person talking”

For those residents with advanced dementia or physical disabilities however, other tactics were used by the trainers to make a connection that did not entail movement, and often, no verbal response. For two of the trainers, this involved activities that connected with the senses:

“Poetry reading and hand massages and some multi-sensory things”

One of the artists commented as to how this had changed her perception of creative activities and their effect upon wellbeing:

“We did a lot of talking and people just really wanted to talk to me about things. I think, previous to this training, I would have thought I’m not doing enough”.

There was divergence of opinion amongst the trainers as to the necessity for a plan to guide their sessions. One trainer was of the view that those residents with early onset dementia benefitted from some uniformity, especially to contain escalating feelings:

“With early onset dementia...we have quite a strong structure to it. There’s always similar songs at the beginning, we always end with the same couple of songs...especially if things are emotional”.

Others of the trainers however thought it important to abandon their plan in response to their audience:

“Being brave enough not to have a plan...coming in with a few ideas about how the session will go and then just crumpling that piece of paper up, throwing it over your shoulder, and then picking it up and making it into a ball”.

In fact, there was general consensus as to the need for spontaneity and for malleable boundaries, suggesting the concept of a model which could be transferred to other settings, as unlikely. The trainers also considered less prescriptive approaches as favourable since this enabled more reticent residents and care home staff to challenge preconceptions as to their lack of creativity:

“If you’re too prescriptive it will turn people off because you’ll have the, ‘Well, I can’t sing. I can’t dance.’ So you have to ...say less...teasing things out of people.”

An additional incentive for flexibility was the need to respond according to the verbal and non-verbal feedback from the resident group, a sensitive process where the development of the resident’s identity was interwoven with the trainer’s response to their feedback.

“The other skill is listening to your group...and building a repertoire...because you’re helping people with their own identity...and that’s when people feel they can share things because it’s like family”.

For more physically and cognitively able residents however, the sessions in the care homes included greater activity such as passing a large elasticated ribbon between residents, often accompanied by singing. The trainers were agreed that, the residents' receptiveness was unpredictable, depending on the time of day, whether or not they had eaten or slept, suggesting that any plan was susceptible to such irregularities.

"I'd do one thing in one session and it would be completely different in the other sessions. It really depends on where the participants are...what time of day it is, what works and what doesn't".

As with the sessions in the care homes, the diverse skills mix and experience of the trainers brought assorted approaches to the training sessions. Broadly speaking, these combined a mixture of theory and practical work. For example, one trainer described a method which incorporated three areas:

"Dementia studies and practice... the values that underpin person-centredness... and the importance of relationships"

The motivation for this approach was founded on theory and practical experience that *"where cognition is failing...we can go by way of the body...through movement and dance and song"*.

The justification was, that whilst *"biomedical science tends to focus upon what doesn't work...let's find out what does remain"*. The trainer considered that a vital element of delivering creative sessions was a potential disconnect between oneself, as facilitator and the trainees in the group, such mismatch enabling resistance and ultimately compromising emotional, physical, psychological and spiritual engagement with the residents. To this end, the sessions were structured to include the breadth and depth of experience needed by trainees to work confidently in the area:

"The mornings were about the exploration of self in response to the arts activity. Strong theoretical foundations, value based foundations, exploration of different things...movement, music, dance and song. ...In the afternoon...giv[ing] a structure to running a session that's very potentially open-ended and [...] uniquely person-centred".

The trainer described their approach as offering *"only guidelines"*, adding that *"once you get into the session itself, you have to forget everything and just be there in the moment with the people"*, whereby suggesting that the delivery of creative activities cannot be moulded to plan either at the training stage or delivery.

Not all trainees were sympathetic to such theoretical concepts however, considering that notional approaches may overlook the practical requirements for residents with advanced dementia:

“I don’t think there was enough understanding of that stage of dementia and what’s actually practical for them to do movement-wise, understanding wise”

Attitude change



“The label very often comes before the person”

The second superordinate theme, **attitude change**, was formed of four subordinate themes, *personal gain; attitude in the care homes; perception of the arts and; addressing generational change.*

The findings indicated that the artist trainers and trainees involved in delivering the programme had a heightened awareness about the arduous circumstances in which care home staff worked and the negative effect this had upon their ability and motivation, inevitably prioritising a defensive agenda. However, based on feedback and evaluation forms posed to the participants by one trainer, as the programme progressed, the care home staff had experienced a change in attitude about their part in the training and the impact upon their work with people with dementia:

“I’ve been delighted by witnessing growth. Personal and professional growth of the people that I’ve mentored...as a result of taking part in the programme...they’re more intelligent, they’re more sensitive, they’re more aware, they’re more skilled...”.

According to one artist the change in attitude was partly attributable to the supportive structure of the programme:

“She [the programme organiser] has got a great resource”

Seemingly, this outlook chimed with values already existent within the care homes and it is possible that programmes such as that delivered revive existing values and incentives:

“For me, this is a vocation, I treat people here as if they’re my Nan or as if they’re my Mum”.

One activities coordinator was of the opinion that it was not solely her influence, as a trainee that would instigate attitudinal change in the care homes, but that modelling her skills would cascade these new approaches to caring:

“Get[ting down to eye level....hold[ing] hands, it affects the person really, really well, because it’s making them less isolated, but the other carers see that as well and that has a knock-on effect in attitudes to their caring”.

All participants expressed awareness as to the competing demands upon care homes such that the position of activities coordinator may not be rooted as a creative priority.

“(The position of activities coordinator) is not sitting on a really firm foundation of creativity”.

This was a dilemma understood but regretted by the trainers who were keen to make a willing contribution towards providing creative activities in care homes but torn as to the effect a voluntary involvement may have upon the value of the arts:

“If these homes haven’t got any money to pay me, I’ll go in as a volunteer but it feels that that will diminish the project’s value”.

However, the participants acknowledged that the training programme offered an opportunity to promote the value of the arts in a receptive environment that also afforded the chance to elevate perceptions of dementia above the normative:

“It’s [the creative activities] a really good opportunity to celebrate the beauty of dementia...it’s often represented in a very ugly way”.

Changing perceptions of dementia through their creative intervention, not only of care home staff but also family members, was an earnest desire for the trainers and trainees, a repeated theme within the data that was a key motivation for their work. These participants were keen that seeing people with dementia taking part in activities moved from something abnormal to customary:

“Because that’s [doing creative activities] a normal activity”

The participants were nonetheless mindful that introducing a programme of creative activities did not come without its trials since recipients who are moved beyond their comfort zone may respond defensively:

“It’s (creativity) all about challenging. It will challenge people all the time because it’s the essence of what we’re about it’s the whole point of why we’re here...which is why people will be unhappy. They’ll be cross, they’ll be uncooperative”.

In addition, the artists expressed that they already battled the existing misunderstanding of creative activities as *“wafting scarves”*, implying an ineffectual contribution, ultimately meaning that whilst, *“the arts in some ways are celebrated...in terms of engagement for everybody, it’s still a massive barrier”.*

An unexpected finding to emerge was the trainers’ perception of the creative activities they delivered as enabling generational change for some of the female residents:

“Generationally, you’re giving voice to a group of women who just didn’t really have a voice...their husband spoke for them and did everything, made all the decisions...being creative takes them back to that moment – it’s almost that they’re picking up where they left off”

What went well



“It’s making people realise there are no wrong notes”

The superordinate theme ***what went well*** was characterised by three subordinate themes; Growing awareness for trainers and care home staff; resident autonomy and; evaluation of training

programme. Whilst these themes in no way represent all that was celebrated of the programme's successes (these detailed in other superordinate categories) it focusses on less expected benefits. Although previous data have indicated the positive effect of the training programme upon the residents, a less predictable outcome appears from the findings to be how the dynamic between artist and activity coordinator affected delivery and reception of the creative activities.

“When it went right...there was an exchange of energy between the artist and the activity coordinators...when that happens [it] has a wonderful affect in that the artist then feels supported...what they're doing is valued and understood. The residents, the participants, they're given so much more permission then to join in and enjoy and to be free to express themselves... It's about permission giving”.

The data hints at a symbiosis between artist and activity coordinator, which communicates to recipients in a way that facilitates their self-expression. However, one trainer expressed how, during a session which no care home staff were able to attend, the residents' tenure appeared to nurture autonomy.

“I felt there was a real sense of ownership in that session [without any care staff present]. It was something that just the residents were doing”.

This same sense of empowerment was iterated by those trainees interviewed during the evaluative process for whom, *“growth of ability”* improved their skills at *“knowing what to look for [regarding resident wellbeing]”*.

The value of training sessions were also extolled since, through using group activities, they had enabled team bonding, but also learning as to entering and leaving personal space, an attribute according to the trainers since creative activities often involved shedding inhibitions.

an important attribute for artists who commonly practice alone.

“There was a lot of group interaction and one-to-one interaction, and bringing down your guard...getting people to move into each other's spaces as well and learning when to move away...It was very good for team bonding”.

Gleaning such information from the trainees had been achieved using an evaluation questionnaire designed by one of the trainers, used both as an informative aid but also as a point of learning for future sessions.

“Questionnaire laid out what went well...what’s not going so well? What might the learning be...what are the actions or goals that you would like to move towards?”

The main challenges



**“There’s a real world
out there but we only
have access to our
version of it.”**

The fourth superordinate theme, **main challenges**, was formed of five subordinate themes; *communication, coordination and negotiation; practical challenges; vulnerability and inhibition; a coherent model and; organisational culture.*

Whilst the intention outlined in the original proposal for the training programme had been for eight sessions to be delivered to the care homes by one trained expert, including support for care home staff to utilise their knowledge accrued during training, this could not, in reality, be implemented.

This shortfall was commonly attributed by the participants in the study to difficulties communicating with care homes. With the majority of correspondence undertaken by email, combined with the hectic schedules of staff both on the training side and the care homes, the original proposal was therefore moderated *in situ* allowing those care home staff who could attend, to observe the sessions delivered by the trainers:

“The only thing I foresee with care staff is the restrictions of their workload...[they’re] very, very busy....suffer with being short staffed” .

Based on her experiences of coordinating visits in other care homes, one trainer suggested that building a relationship with one activity coordinator from each location provided a representative who could then champion the work of the trainers.

“...dealing...directly with the activity coordinators have had a better success rate.”

In interview, this idea was condoned by an activity coordinator who had found that advancing managerial investment was enhanced through good communication with senior staff, placing activity coordinators in an important position as envoys for creative activities in care homes.

“I was trusted by the team here to actually go to the managers and the staff team and say, ‘Well this is what’s happening’...I keep them informed and it’s really important that our managers are informed about what we do”.

An alternative suggestion for overcoming the communication dilemma was for the trainers to write a formal proposal outlining the intended content of their sessions on the premise that this may enhance engagement by providing senior staff with an outline of what delivery of the sessions would entail:

“I think, really being focussed and you know, having a real – this is what we’re going to achieve, this is how much it’s going to cost”.

Almost without exception, the artist participants interviewed referred to the practical challenges of undertaking their sessions in the care homes, a difficulty enhanced by the need for mobility aids and other assistive devices such as profile chairs for the residents with dementia. Such bulky accessories created a need for space, often limited in care homes already filled with domestic equipment and raising concerns about health and safety. The trainers also expressed awareness as to the additional responsibility this placed upon care staff:

“Getting staff to bring them [people with dementia] across can be quite difficult [for those] in wheelchairs. The manoeuvring in and out can take quite a bit of time”.

Whilst ideally, the trainers and activity coordinators acknowledged that a space specifically designed for creative activities would be best, they also recognised that many care homes faced budget cuts necessitating re-evaluation of priorities:

“The reality of an artist coming in weekly, a lot of places can’t afford”

Moreover, the trainers recognised that a challenge for the care home staff, and sometimes the residents as well, was that taking part in creative activities often meant that people stepped beyond their comfort zone, since dance and movement in particular necessitated exposing the inner self:

“Movement and dance is something that people feel perhaps a little self-conscious about”.

Awareness was voiced that creativity may often be flamboyant and require a largesse that can encroach upon the reserve of some care home staff.

“A major reason why activities Coordinators don’t engage [is] because it is so vulnerable...they [need to] feel safe in their own bodies”.

A bi-product of such potential anxiety was acknowledged by the trainers as placing additional strain on care home staff who already face constant exposure to emotionally charged relationships with the residents.

“(Exposing the care staff’s vulnerability) can increase the emotional load that they’ve already got...”

However, it was agreed, that a key way of overcoming such apprehension would be through immersion in the training the artists provided as it was through this medium that care home staff could overcome their inhibitions and move towards a greater understanding of creative activities in relation to their work:

“Inculcate in people a sense that strangeness, the otherness and the difference that they might see, is the norm, not the exception”.

In addition, the more that care home staff joined in the training, the greater the inter-departmental support they could afford each other:

“You’re more likely to turn them around once others have said – who have been involved – ‘Oh, this was great’”.

The data suggested a divergence of opinion amongst the artist participants as to the varied programmes utilised in the training programme by the artists because of their wide-ranging skills

and experiences. One trainer expressed concern that a lack of uniformity may have undermined coherence:

“Although a basic overview went out to each of the trainers, perhaps there wasn’t enough communication between the trainers in knowing where they were coming from.”

Whilst this notion was rejected by the other participants who were of the opinion that creativity transcends uniformity, the original trainer expressed further concern that progressing the training programme to a sustainable future may require a more collaborative approach.

An important theoretical consideration as far as the participants were concerned was that, no matter the content of the training programme or the sessions provided to the residents, facilitating delivery is challenging without a nurturing organisational culture.

“You could go on the most inspiring course, but you still work within a team and a culture which expects you to deliver your work, your service, in a particular way, within a particular, defined timeframe...”

The relationship between a successful model of training and the culture of the organisation was viewed as inseparable.

“I don’t think there’s any one model of training that can work independently of the organisation in which you want to see change”.

When applied to context, the participants agreed that cultivating organisational change could best be achieved through a team approach to training such that, for care home staff, a supportive network was engendered.

“Encourage more than one person from a team to do the same training so you can support each other in delivering something a bit different...because that’s how change happens isn’t it?”

A future model



“...a bit of human contact, not by somebody with an apron and gloves on”

The superordinate theme *future model* was representative of the participant’s views and concerns as to a sustainable training model for use in other care homes as a result of their experiences during the evaluative phase. It included three subordinate themes; *improving communication and building relationships; content and duration of sessions and; the ideal space.*

A repeating theme throughout the data was the importance of communication in advancing collaboration between trainer and care home, a process according to the findings, often interrupted by the demanding duties of both parties. Participants suggested that the teamwork process was founded upon relationship building, a processes undermined by challenging communication situations. Additionally, they considered that the care homes may have been more receptive had they information in advance as to precise details of what delivery of the sessions would entail:

“The manager, activity coordinators, artists, need to get together to get dates, make sure that ...everybody knows what’s going on, the aims, objectives, what’s going to be expected of them”.

The data highlighted recurrent concerns that creative activities could exacerbate staff vulnerabilities and voiced that a good way of overcoming this hurdle was to alternate training sessions between neighbouring care homes such that all staff at some point underwent training within the safety of their familiar environment:

“I would work with cluster care homes and invite people to come to one care home each time and do...a training session there...It’s really important for activity coordinators to be in their own environment in order to feel safe...more convenient, less travel”.

The participants were agreed that any creative model would be guided by the principles of person-centredness¹ and empathy since these were the key values informing their work and that it was through such ideals that people with dementia were able to express themselves:

“If people are enabled to stand in the shoes of somebody with a range of cognitive impairments, that will help them to communicate well”.

In order to do this, the participants expressed the need for *“an understanding of all the different kinds of impairments that can arise”*, as well as enough time to speak with the residents so as to understand how they had experienced the sessions delivered by the artists. In this respect, the trainers were united in the view that more sessions would have facilitated on-going and sustainable progress for the residents.

“There needed to be more sessions than there were. I feel like it was very bittersweet the last sessions...I felt like it was too soon to be doing that. I’d just got them to a point where they were really comfortable and really happy to come and join in”.

For the trainers, *“becoming familiar with the residents was... an important part of the project”*. Hence, an important element of a future model was for more sessions that enabled the work of the trainers to be realised.

“I (trainer) would come back once every four weeks for a period of six months and then come again for another period of 8 weeks...”

Moreover, how the sessions were concluded was of significance for people with dementia whose cognitive abilities made it difficult for them to cope with an abrupt finish since longer was needed to embed ‘ending’ in their memory:

“For some people, I would imagine it [the ending] felt quite abrupt because even though I reminded them the week before, potentially, people might not remember that”.

The participants reflected that in an ideal world, *“people should be given paid time out to reflect on what they’re doing and why it can be done differently”*, an additional reference to organisational culture. Once again, a possible solution was considered to be through a team approach:

¹ Person-centred care is about considering people’s desires, values, family situations, social circumstances and lifestyles; seeing the person as an individual, and working together to develop appropriate solutions

“...encourage more than one person from a team to do the same training so you can support each other in delivering something a bit different...because that’s how change happens isn’t it?”.

There was consensus amongst the participants that ensuring sustainability also depended upon offering support to the care home staff once the trainers had withdrawn and there were several suggestions as to how to provide this:

“If they could have some back-up resource so that once we’ve gone there was a visual thing that they could go back to support...a toolbox”.

“Find homes that are very strong...the activity coordinators could take the ideas back...to their training days that they do and filter them out as well”.

Overall, it was agreed that mentoring played an important part in offering regular and maintainable support and was considered by the participants a worthy addition to a future model:

“Mentoring – it’s an important part of the development of a [care home worker] to be mentored by somebody more experienced”

Nonetheless, one trainee was of the opinion that the mentoring system used in the current programme had inhibited relationship building since the mentor allocated them during the training phase was not the same person as during the delivery of sessions:

“Better to have your mentor who then you would meet for meetings and have email contact with as the person that you’re working with”.

Resonant throughout the data was the issue of space within the care homes both from a practical viewpoint but also from that of health and safety, thereby representing an important learning point. For example, the participants spoke about sessions where numerous residents (29 at one session) had crammed into the allocated space, many in wheelchairs, inhibiting direct access to exit routes. The perfect space was described by the trainers as:

“Ideally...a space where you can see everything in the room...furniture that enables a circle...good lighting, no obstructions”.

They were nonetheless under no delusions as to the multipurpose demands upon rooms in the care homes. However, a room dedicated to purpose was also expressed as an important consideration for people with dementia for whom sudden or unanticipated change can be unsettling:

“It would have been so wonderful to be able to just have a very brief conversation with people and say, this is what we’re here to do, this is what’s going to happen...just join in and be yourself”.

Wellbeing affects



**“You’ve made me remember I
have memories to
remember.”**

The final superordinate theme, **wellbeing affects** included the categories; *improving the health and happiness of residents* and; *the health and happiness of the trainers and care home staff*.

The findings revealed what the participants spoke of as the most important element of their work, in fact, their guiding motivation, that being the welfare of the residents. Plentiful examples were given of how such benefit had been realised through delivery of the sessions at the care homes, predominantly through triggering memories although notably, the participants diverged as to this latter point as a primary route to improved wellbeing for people with dementia:

“So, any sort of creative activities, you’re getting the participants to connect to themselves... perhaps, when we felt good or we knew ourselves, when we don’t feel like we know ourselves now”.

The outcome of these benefits was often manifest non-verbally, meaning that even those with end-stage dementia registered their enjoyment:

“...toes might start tapping, it might be laughter, some people will start moving their arms and legs even if they don’t normally, it might just be the corner of their eyes go, it can just be a bit of extra blinking and a tiny little smile”.

One activities coordinator spoke of the changes sustained throughout the days and sometimes the nights following a creative activities session:

“Positive change in health and wellbeing...less bored...slept less after the session. Sometimes they would feel very joyful about things and sometimes they would feel a little bit upset”.

As the excerpt above reveals, whilst the residents frequently responded positively to engaging with the trainers, there were equally occasions when heightened emotions were triggered, however, this was evaluated by one trainer as a healthy response since it was generated by memories:

“They might have cried and we’ll talk about that...but that was good to cry wasn’t it? Why was that good to cry? It was good to remember”.

For the trainers, progress was realised through the resident’s increased energy and endurance, a rewarding experience for the trainers since this also enabled recognition and engagement with the activities:

“The stamina in terms of them being able to maintain interaction, increases. On the last week I walked into the room...some people had an association already...[they] were ready to bring something of themselves to the session...movement range increased. They seemed braver”.

This reference to increased bravery was not peculiar to the residents but also referred to by an activities coordinator during interview. For her, the training sessions had not just brought personal aid but exposure to ongoing improvements that would affect the care home:

“I’ve learned a lot from this...ideas for interactions and building confidence... how to move with people....it’s made us a bit braver. Continuous professional development is just so important to keep things fresh, to give you new ideas, to think creatively in different ways”.

The findings suggested that such benefits were not confined to the activities coordinators but that others of the care home staff had also been enthused:

“Our staff really enjoyed it too. I had one of assistant practitioners say ‘Have you got the marvellous dancing and singing thing today?’”

According to one trainer, cohesion and cooperation were vital elements of session delivery in the care home as a heightened awareness of the care home staff's needs, and putting them in the picture facilitated inclusivity which was essential for the project to work.

"You respect everybody in that space as an equal...the staff, the volunteers enter that space with their own anxieties and fears and interests and likes and dislikes and skills and abilities...I have to be quite sensitive to the staff and them feeling they still have a place in the room...I make a point of letting the staff know the agenda...and the aim of the project...I want also your knowledge...[and] passing our knowledge to the staff"

The trainer described this respect for and exchange of knowledge as a "gentle, honest dialogue".

The overall benefit of the training and session delivery in the care homes was summarised by one trainee whose quote infers both professional and personal gain:

"It was very empowering. I feel I've grown so much more as a human...in terms of...what it might be like to lose my memory, lose my motor skills...my own cognitive skills. My own personal life has been one of struggling with depression, mental health...this project has helped me...the joy I've received from it"

5.0 Discussion

The number of people with dementia in the UK is forecast to increase to 1,142,677 by 2025 (Alzheimer's Society, 2015), placing an ever greater emphasis on how best to care for their wellbeing in the future. In this respect, care homes assume a significant provisional role, with over 30 per cent of those with dementia living in residential homes (Bisla et al., 2010). Previous research into dementia has focused primarily upon pathological and pharmacological treatments, and whilst this situation is slowly changing, more subjective approaches to care such as person-centredness remain under-explored (Beard, 2012), particularly the impact of dementia upon care homes (Bisla et al., 2010). Willemse et al (2011) conclude that for those care home staff looking after residents with dementia, job satisfaction, intention to leave and burnout are significant issues. Such concerns places emphasis upon the timeliness of the current evaluation.

The consistency and sustainability of training programmes and creative activities

Dementia specialists have begun asking how more nuanced understandings of life with dementia can be obtained, including the design of more meaningful, responsive services (Gray, et al., 2001). In this respect, the diversity of experience and various artistic disciplines that contribute to a training programme designed for use with residents with dementia appears to have both helpful and less helpful outcomes. On the one hand, an array of expertise inhibits the formation of a model that can

be consistently applied across settings. On the other, an assortment of creative style offers approaches appropriate to the vast range of impairments experienced by people with differing levels and manifestations of dementia. Whether or not to be guided by a plan introduces similar conflicts for artists for whom responding in the moment to the fluctuating needs of residents, whilst also fitting in with the unpredictable timetable of care homes, requires a flexible response. Training models are subject to analogous uncertainty due to the skills mix of expert trainers, a difficulty which results in a combination of theoretical and practical approaches, the latter not always reflecting the realities of staff working with residents with end-stage dementia. Moreover, such varied approaches limit the design of transferable training models. Nonetheless, the team approach afforded through group working in training sessions offers considerable support and learning, of particular relevance since artists often practice alone. Of value to trainers is an evaluation system that records the feedback of trainees such that future programmes can be moderated to include suggestions for change, be they positive or negative.

Attitude change and its affect upon trainers, staff and care homes

A significant outcome of both the training sessions and delivery of creative activities in care homes is the change of attitude these activities produce in trainers, artists and care home staff. Whilst care home staff may first attend training depleted by their responsibilities, once more engaging with the core values consistent with their vocation reignites original incentives and reasons for caring and revives flagging motivation; of importance given the prevalence of burnout and exhaustion amongst this group (Willemse et al.,2011). An additional bonus is that skills renewed or learnt whilst training are modelled in care homes, these then cascading throughout the workforce. This likewise re-values the work of activity coordinators who play a pivotal role as creative ambassadors. Affirmation of the arts through training and interventions not only elevates the profile of creative activities from 'scarf waving' to significance but also changes perceptions of dementia, since participating becomes the norm, rather than something confined to others. The potential of creative activities to change perceptions of dementia are recognised in the work of Reynolds et al (2016), where musicians with dementia performed to family and friends in an orchestra. Whilst preceding the performance, family described their relative as "manag[ing] a horrid disease", post-performance these same people with dementia were re-evaluated as "no different to anyone else". Contemporary social science research, has clearly demonstrated diagnosed individuals' enduring ability to meaningfully interact with artistic stimuli, despite the stigma resulting from a perceived inability to navigate their social worlds according to normative expectations (Beard, 2012). Such findings place emphasis upon the power of training and creative activities to alter existing attitudes. Furthermore, artistic interventions have the ability to change the person with dementias profile of self, such as empowering femininity through generational change. This, in many ways, reveals the impact of dementia upon identity, as Daykin

says, “notions of choice and enrichment in the context of lives that felt denuded by [...] diagnosis and treatment” (p.364). Hence experiences of empowerment and autonomy in any training model or creative intervention need stronger focus. However, they also suggest that the various skills brought to programmes by an array of artists may enable individualised responses that help establish identity (Fraser, 1981; Johannessen, 1996; McClean, 2006).

However, delivering creative activities to care home staff does not come without complications, since the confidence necessary both to engage with trainers, then deliver to residents can challenge the boundaries for some and trigger vulnerabilities. Whilst artists have the right to challenge as creativity is inherently challenging, it is only legitimate if it moves the recipient from resistance and is sensitively done. From this viewpoint, training for care home staff offers a potentially supportive environment in which to explore their fears.

Negotiating the delivery of creative interventions in a healthcare setting

Of utmost significance when delivering creative activities to care homes is the need for good communication from the outset as this engenders trust and relationship building (Corazini et al., 2013). Setting out plans clearly in proposals, defining aims and outcomes and impact for both artists and care homes, enables inclusivity and equality. This is true also for care home staff, whose existing knowledge of residents may be undermined by exclusion. However, it is equally dependent upon care staff to engage. Accordingly, training programmes and arts interventions need to “create a social context in which all people will be better supported” (Gray, Sinding, & Fitch, 2001p. 246).

Also of import is the space allocated for creative activities to be delivered. Compromises to this essential not only inhibit delivery of sessions in the way most advantageous to artists and residents, but also threaten health and safety regulations. This in part is due to the multi-purpose needs for each space available in care homes, but also a contemporary fixation with bio-medical and political models that prioritise clinical imperatives and quality assurance in a way that predetermines the allocation of space (Bisla et al., 2010). Related studies advocate moving beyond biomedical frameworks that privilege some illness narratives over others (Gray, Sinding, & Fitch, 2001). However such lofty aspirations may not be possible for artists delivering creative interventions who can only respond to issues of space with extreme flexibility and patience, an example perhaps of how creativity transcends uniformity.

Such challenges are rooted in the conflicting priorities for the provision of healthcare versus that of arts as wellbeing where, even though underlying values may be shared, an understanding of the delivery of care for artists may understandably diverge from that of care homes. Justifiably, the organisational culture for care homes is founded around the beliefs and behavioural norms that

most benefit their staff and residents (Yafang, 2011). However, difficulties arise when the motivation for sustainable change is driven by an external organisation whose underlying values may not appear to directly chime with those of their host's (Bertels et al., 2010). Overcoming these potential boundaries may require paradigm breaking attitudes achieved through the sharing of values, through discussion, observation, modelling and experience that align organisations on the same pathway to change. In this respect, leadership plays an important role in nurturing supportive networks and team approaches.

Considering the framework of a future model

Such requirements also resonate for care homes once trainers withdraw, a future model that facilitates sustainability for care home staff should ideally include a toolbox of the creative activities used by trainers including the structure of the programme and visual aids, as well as access to on-going mentoring that provides one-to-one support. Further care could be afforded to trainees, especially those who are particularly cautious of exposing their vulnerabilities, through the provision of training on familiar territory and symposiums held at host care homes. Such an approach may also facilitate an environment where knowledge gained could then transfer between different care homes and synthesise managerial views as to how the delivery of creative activities can most effectively be delivered alongside existing quality of care priorities.

The impact of creative activities upon wellbeing

In keeping with existing literature, the current report testifies to the wellbeing effects of creative activities, not just for residents but also for care home staff who are seemingly uplifted and inspired by training that raises their awareness but also provides continued professional development. Research (Hanson, Gfeller, Woodworth, Swanson, & Garand, 1996) suggests that as far as specific artistic approaches for people with dementia are concerned, there is no one size fits all. This introduces some conflict as, whilst the varied disciplines of artists inhibit the development of a sustainable model, they also provide an array of interventions that complement the multiple needs and medical presentations of people with dementia. From this viewpoint, even those residents unable to contribute verbally, can affect a non-verbal response (Odell-Miller, Hughes, & Westacott, 2006), testifying to the potential for creative activities to empower people with dementia by treating the whole person, not the illness (Hirsch & Meckes, 2000). Moreover, whilst the pleasure derived for residents with dementia may be fleeting, it in no ways negates its value (Allan & Killick, 2000; Gibson, 1994, p. 53). This sense of the uniqueness of each person with dementia is described by Kitwood and Bredin (1992) as their 'Personhood' and informs the focus of their work. Similarly, Coaten and Newman-Bluestein (2013) work with what is left of the body, a concept known as embodiment, relating to the phenomenological experiences held within the body of those with

dementia, where human awareness is grounded in a subjective arena of lived experience. Seemingly then, dementia has complex presentations that require expertise to treat and understand. Whilst creative activities may arouse feelings of joy through memory, they are also capable of evoking expressions of loss and sadness (Waller, 1999). Although sorrowful recall may be enriching (Norberg, Melin, & Asplund, 2003) how residents were left once trainers withdrew was not elaborated on in the current evaluation, and it is possible that residents remained in a heightened emotional state. Any future training model needs consideration as to how this situation can be sensitively addressed.

6.0 Conclusion

The creative intervention programme evaluated through the current report highlights the benefits of person-centred and subjective approaches to care for residents with dementia in care homes, rather than normative, outcomes-based approaches. In this way they aspire to reframe perceptions of dementia through holistic engagement with the whole person that facilitates a narrative of empowerment. Whilst creative activities can inspire care home staff they may also arouse discomfort that can prevent full engagement. Overcoming these and other challenges requires a whole team approach, led by invested managers but also facilitated through discussion and good communication.

7.0 Recommendations for future practice

- 4) Good communication, including a shared vision and goals is essential between care home and the external artist provider organization and would form the basis of future research.
- 5) Whilst this training programme has highlighted the benefits of arts based activities for residents, care home staff and artists, the aim of developing a standardised training model has been found wanting in favour of a more collaborative, person centred, flexible program for all involved.
- 6) The question of engagement/disengagement by care staff in the care homes needs to be sensitively managed with consideration given to the balance between on and off site training.



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9.0 Appendices

Appendix 1

Research questions

1. What are the collaborative and developmental processes involved in creating a training model for use with PWD? What would be the elements of a training model?
2. What is the impact upon those who deliver the training and those who receive it? How do artists, students and care-home staff respond to the developmental processes and the activities involved?
3. What effect does the development of a training model for use with PWD have upon the attitudes and levels of awareness amongst artists, students and care-home staff?
4. What are the distinctive features of the training that might limit its transferability to other settings?

Appendix 2

Participant Information Sheets (artists and care home staff)



Project Information Sheet (artists)

An evaluation of a training programme for use with people with dementia

Version 1, 03/05/2016

You are being asked to take part in a research study evaluating a training programme for use with people with dementia. The research is being undertaken by the Centre for Arts as Wellbeing, at the faculty of Research Knowledge and Exchange. It is being undertaken to appraise the strengths and weaknesses, values and structures of the training programme with the aim of developing a training framework for future use.

Please take time to read the following information carefully. If anything is not clear, or you would like more information, please get in touch with the research team (contact details at the end of this information sheet).

Researchers: David Walters, Head of the Centre for Arts as Wellbeing, University of Winchester. Dr Kit Tapson, Research Officer, University of Winchester.

Why have I been chosen?

You are being asked whether you would like to participate in this study because you are an artist involved in the training programme for use with people with dementia. Your views will be highly valued.

Do I have to take part?

It is up to you to decide whether or not you would like to take part. Should you decide to participate, you will be given this information sheet to keep and be asked to sign a consent form. If you decide to take part, you are free to withdraw at any time, without giving a reason and without consequence.

What will taking part involve?

If you decide to take part:

1. You will be asked by a researcher to sign a consent form.
2. You will be asked to take part in a focus group run by a researcher from the University of Winchester at the mid-point and end-point of the training programme developmental period, to explore the processes of the training programme, including what went well and what did not. The focus group will last approximately 60 minutes and will be audio recorded and transcribed.
3. You will also be asked to participate in an interview lasting approximately 60-90 minutes which will be audio recorded and transcribed.

For both the focus group and interview, you will be allocated a code so that you cannot be

identified.

The interview questions will ask your opinion of the training programme and the processes involved.

There are no foreseen risks attached to taking part in the study and your lifestyle will not be affected.

Would my taking part in the study be kept confidential?

All research collected about you in the course of the study will be kept confidential in accordance with the Data Protection Act 1998. Should the work be published you will not be identifiable because of the use of anonymous codes.

Who has approved the study?

The study has been approved by the Research and Knowledge Exchange Ethics Committee.

Contact for Further Information:

David Walters Tel: 01962 827333 Email: David.Walters@winchester.ac.uk

What if something goes wrong?

Should you consider there is something wrong about the study, you can contact either:

The Chief Investigator: David Walters (as above) or,

The Chair of the University RKE Ethics Committee: Tel: 01962 827589 ext 7589 Dr Maru Mormina
Email: Maru.Mormina@winchester.ac.uk

Thank you for your time



Project Information Sheet (care-home staff)

An evaluation of a training programme for use with people with dementia

Version 1, 03/05/2016

You are being asked to take part in a research study evaluating a training programme for use with people with dementia. The research is being undertaken by the Centre for Arts as Wellbeing, at the faculty of Research Knowledge and Exchange. It is being undertaken to appraise the strengths and weaknesses, values and structures of the training programme with the aim of developing a training framework for future use.

Please take time to read the following information carefully. If anything is not clear, or you would like more information, please get in touch with the research team (contact details at the end of this information sheet).

Researchers: David Walters, Head of the Centre for Arts as Wellbeing, University of Winchester. Dr Kit Tapson, Research Officer, University of Winchester.

Why have I been chosen?

You are being asked whether you would like to participate in this study because you are a care-home employee involved in the training programme for use with people with dementia. Your views will be highly valued.

Do I have to take part?

It is up to you to decide whether or not you would like to take part. Should you decide to participate, you will be given this information sheet to keep and be asked to sign a consent form. If you decide to take part, you are free to withdraw at any time, without giving a reason and without consequence.

What will taking part involve?

If you decide to take part:

1. You will be asked by a researcher to sign a consent form.
2. You will be asked to take part in a focus group run by a researcher from the University of Winchester at the mid-point and end-point of the training programme developmental period, to explore the processes of the training programme, including what went well and what did not. The focus group will last approximately 60 minutes and will be audio recorded and transcribed.
3. You will also be asked to participate in an interview lasting approximately 60-90 minutes which will be audio recorded and transcribed.
For both the focus group and interview, you will be allocated a code so that you cannot be identified.

The interview questions will ask your opinion of the training programme and the processes involved.

There are no foreseen risks attached to taking part in the study and your lifestyle will not be affected.

Would my taking part in the study be kept confidential?

All research collected about you in the course of the study will be kept confidential in accordance with the Data Protection Act 1998. Should the work be published you will not be identifiable because of the use of anonymous codes.

Who has approved the study?

The study has been approved by the Research and Knowledge Exchange Ethics Committee.

Contact for Further Information:

David Walters Tel: 01962 827333 Email: David.Walters@winchester.ac.uk

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The Chief Investigator: David Walters (as above) or,

The Chair of the University RKE Ethics Committee: Tel: 01962 827589 ext 7589 Dr Maru Mormina
Email: Maru.Mormina@winchester.ac.uk

Thank you for your time

Appendix 3

Consent form



An evaluation of a training programme for use with People with Dementia

Version 1, 03/05/2016

Consent Form

I have read and understood the information about the project. I understand that my participation in this project is completely voluntary, and that I may withdraw at any time during the project, without penalty.

I understand the arrangements that have been made to ensure my anonymity and privacy. I am aware that I have the right to see what has been written about me.

The researcher has made clear to me any risks which may be involved in my participation in the project.

The arrangements for secure storage of data, and for its eventual disposal, have been explained to me.

On this basis, I consent to take part in the project.

Signed. Date.....

JAMS!

Joyful Arts Movement and Song

The West Wing Studios
The Point, Leigh Road
Eastleigh
SO50 9DE

Office Mobile 07530 895404
Email louisa@joyfuljams.co.uk

Name
Address Artist

Dear Artist,

Honorary (Temporary) Contract for facilitating 'JAMS' sessions to residents at 'Care home name'

I am pleased to confirm our agreement that you will facilitate a series of sessions for residents as detailed below and would be grateful if you would confirm acceptance of the terms and conditions of this contract by signing and returning a copy.

1. It has been agreed that you will facilitate the following sessions:

Date and Time

And session type

2. In facilitating the sessions you will be supervised and supported by both JAMS and Care home staff and you agree to consult with staff to enable the workshops to have maximum impact for residents. Please ask and follow care staff's guidance when a situation occurs in which it is not immediately clear how best to work with one or more of the residents.
3. The total fee for this work is:

Development days 1 x £
Sessions 7 x £
4. The fee will be paid monthly on completion of your sessions, and on receipt of your invoice.
5. We require you to complete an evaluation form, including any feedback given from residents and/or staff during or after your sessions. And to take part in a larger evaluation if you have been notified of this.

JAMS! is the operating name of Joyful Jams C.I.C Company Registered in England 8002780
Registered office: West Wing Studios, The Point, Leigh Road, Eastleigh, SO50 8NA

JAMS!

Joyful Arts Movement and Song

The West Wing Studios
The Point, Leigh Road
Eastleigh
SO50 9DE

Office Mobile 07530 895404
Email louisa@joyfuljams.co.uk

Name
Address Care Home

Dear Care Home manager and activity co-ordinator.

Honorary (Temporary) Contract for facilitating 'JAMS' sessions to residents at 'Care home name'

I am pleased to confirm our agreement that JAMS artists NAME and NAME will facilitate a series of sessions for residents as detailed below and would be grateful if you would confirm acceptance of the terms and conditions of this contract by signing and returning a copy.

1. It has been agreed that you will host the following sessions:

Date and Time

And session type

2. In hosting the sessions you will provide a suitable space for the sessions and support the artists practice and provide suitable care home staff in the session. Equally the artist will follow care staff's guidance when a situation occurs in which it is not immediately clear how best to work with one or more of the residents. The care home will be supported by both JAMS managerial and artists and you agree to consult with staff to enable the workshops to have maximum impact for patients.
3. Due to funding from The National Lottery, The Peoples Project and with support from The Point, Eastleigh and the University of Winchester we are able to offer these sessions for free.
4. We require you to complete an evaluation form, including any feedback given from residents and/or staff during or after your sessions. And to take part in a larger evaluation if you have been notified of this.
5. You are responsible to ensure appropriate permissions are in place before any film or photography documenting the joy of the project takes place.

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