



## **Promoting Wellbeing and Combating Isolation: Arts and Dementia Pilot Project**

**Adele Irving**

**Centre for Public Policy, Northumbria University**

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**For Further Information, please contact:**

Adele Irving  
Research Associate

Centre for Public Policy  
Room 201 Lipman Building  
Northumbria University  
Newcastle-upon-Tyne  
NE1 8ST

0191 243 7757  
Adele2.irving@northumbria.ac.uk

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## Introduction

### **Report Overview**

The 'Promoting Wellbeing and Combating Isolation: Arts and Dementia' pilot project was commissioned by the National Dementia Strategy Lead, NHS South of Tyne and Wear, to explore whether participation in creative activity can help combat problems of isolation and loneliness amongst, and improve the wellbeing of, older people with dementia or depression. If successful, arts-based programmes could be used more widely by NHS South of Tyne and Wear to meet key priorities in relation to the National Dementia Strategy (2009-2014), the Gateshead Emotional Health and Wellbeing Action Plan and the Gateshead Joint Strategic Needs Assessment (2009). The aims of the project were:

- To provide a series of arts workshops to isolated older people showing early signs of dementia or depression.
- To build upon the current evidence-base regarding the impacts of arts-based workshops on the wellbeing of the client group.
- To evaluate the possibility of using arts-based workshops as an early intervention in dementia care.

The Centre for Public Policy (CPP), Northumbria University, was commissioned to support the third aim of the project. In order to do this, CPP was asked to:

- Assess the strengths and weaknesses of the management and delivery of the project.
- Evaluate the impact of participation in the workshops on the wellbeing of the participants.
- Assess the suitability of the Lodex Wellbeing Questionnaire as a tool for measuring the impact on interventions on the wellbeing of this client group.
- Identify key learning points to maximise the effective delivery and impact of any future projects of this nature.

Funding for the project was secured for the period October 2010 to March 2012. The evaluation period was January 2011 to November 2011. This report details the findings of the evaluation.

### **Methodology**

The evaluation involved the following components:

**Thematic Literature Review:** A literature review was undertaken to inform the methodological approach to the evaluation and to contextualise the project and evaluation findings. Literature was reviewed in relation to the following key themes:

- National and local policy context regarding the treatment and care of older people with dementia.
- Social prescribing.
- The evidence-base regarding the impact of the arts on the wellbeing of older people.
- Measuring the impact of the arts on wellbeing.
- Conducting research involving older people with dementia.

**Interviews with Key Stakeholders:** Semi-structured interviews were undertaken with the following stakeholders:

- Public Health Lead(s): Emotional Health and Wellbeing, NHS South of Tyne and Wear
- Director of Development, Equal Arts
- Lodex Ltd
- CIP Associate, Mental Health Concern
- Project Worker
- Project Support Worker
- Referral GP and Community Matron
- Workshop Artists
- Sheltered Accommodation Wardens

Interviews were undertaken in two phases. The first phase of interviews took place during March and April 2011. Follow-up interviews were undertaken during October and November 2011. Discussions focused on: the development of the project idea; the aims and objectives of the project; the design and delivery of the project; communication between stakeholders; measuring the impact of the workshops on the participants; the impact of the workshops on the participants; and, key learning points.

**Observation of Arts Workshops and ‘Sharing’ Events:** Approximately 10 workshops and 3 sharing events were observed. The aim of this was to gain an understanding of the delivery of the workshops; to gain the trust of the participants prior to conducting interviews and focus groups; and, to capture evidence of the impact of the workshops on the wellbeing of the participants. Notes were made documenting the structure and content of the sessions; changes in the nature of the participants and their level of engagement in the sessions over time; and, key learning points.

**Interviews and Focus Groups with Participants and Carers:** Approximately 5 focus groups and 15 interviews were undertaken with participants and carers throughout the evaluation period. The majority of formal interviews and focus groups were undertaken during the period March to April 2011. From April 2011 onwards, the main approach to data collection became informal interviews. At this point, several other evaluation tools were being used with participants and it was felt important not to overwhelm them with evaluation. Interviews and focus groups were generally conducted during the workshop sessions to ensure that the participants felt at ease when engaging in discussion. Discussions focused on issues such as: how and why they came to be involved in the workshop programme; their expectations of the programme; their thoughts on the delivery of the workshops; and, their perceptions of the impact of the programme on their sense of wellbeing.

**Analysis and Review of Additional Project Data:** Various forms of additional data contributed to the evaluation, including attendance records (attendance records yield important insights into the participants’ enjoyment and commitment to the programme) and artist diaries (reflecting on the delivery and outcomes of the workshops). Most importantly, however, impact data was collected via two measurement tools.

- **Lodex Wellbeing Questionnaire:** The Lodex wellbeing tool involves an anonymous questionnaire that can be completed online or on hard copy. It is completed at the start of an intervention by participants and repeated again at the end. Lodex Ltd matches questionnaires and maps the changes in wellbeing across four domains: general wellbeing, belonging, purpose and independence. The tool contains three separate sections: Lodex wellbeing questions; demographic data about the participant; and, optional ‘bolt-on’ questions. Lodex measures change as a result of participation in the intervention at the aggregate level.
- **Mental Health Concern (MHC) Outcomes Assessment Tools:** The MHC tools are based on a person-centred outcomes approach and comprise a semi-structured interview and completion

of a ratings scale. The ratings scale is used to quantify the opinions of participants and the interview is used to establish and record key narrative to support and explain the scores. A baseline is established by interviewing participants prior to attending the first session of the intervention. A follow-up interview is completed at the end of the intervention. The tools measure change as a result of participation in the intervention at the individual level.

It was hoped that the referral GP would be able to undertake an analysis of the impact of the workshops on, for example, the participants' levels of contact with health professionals and need for medication. It was later agreed, however, that such a dataset would not be meaningful in light of the number of caveats which would need to be applied (the relatively small sample size, the relatively short timeframe within which some of the participants had participated in the project and problems of attribution). Accordingly, it was not possible to undertake a cost-benefit analysis of the project.

## **Project Overview**

The project was managed strategically by the National Dementia Strategic Lead, NHS South of Tyne and Wear and at the operational level, by Equal Arts, with the support of Lodex Ltd. To support the design and delivery of the project, a core project management team, a project initiation document and a project board were established.

At the heart of the project was a series of arts workshops targeted at older people resident in Gateshead, who were at risk of social exclusion and showing early signs of dementia or depression. It was particularly aimed at people who were not accessing any other community activities. Furthermore, as the workshops were run by artists (not carers), the programme was only deemed suitable for those who had a reasonable level of independence, unless they could be supported by a carer during the sessions.

Referral criteria were developed to identify suitable participants for the programme and three referral routes were established (GP referral, community healthcare (community matron and occupation therapist) referral and sheltered accommodation referral). Potential participant contact details were passed on to Equal Arts, who would then contact them to discuss the workshop programme and confirm suitability.

Suitable participants referred to the programme during 2010 (approx. 30) were offered a place on a taster session; providing stakeholders with an opportunity to identify the most suitable participants to access the full workshop programme and participants with an opportunity to sample the various workshops on offer. Participants referred to the programme from January 2011 onwards were signposted to one of the workshops.

A significant level of resource was invested in supporting the participants throughout the workshop programme. Participants would receive a telephone call the day prior to the workshops reminding them about the sessions; for participants who live independently, free transport was provided to and from the sessions; and, a support worker was appointed to assist participants to attend, and during, the sessions.

The workshop programme consisted of five workshops, each comprising twelve sessions. The workshop themes were: animation, film, movement, music and photography / pop-up museum. Workshops took place at participating sheltered accommodation sites and in two community venues. A number of trips to local places of attraction were organised as part of the programme. In addition, various sharing events were held throughout the year, showcasing the achievements of the groups. Approximately 60 participants took part in the programme during the evaluation period.

## Summary of Research Findings

The findings of the evaluation suggest that following participation in the workshops, participants<sup>1</sup> experienced improvements in their overall sense of wellbeing and, for some, the improvements were significant. The quantitative and qualitative data collated indicates that the most significant impacts of the programme were increases in the participants' sense of belonging and the quality of their relationships with others. The project, therefore, was successful in meeting its primary aim to reduce social isolation amongst the client group. Additional impacts included: an increase in the participants' levels of confidence; their sense of enjoyment and happiness in life; their levels of energy and motivation; and the extent to which they feel valued and feel they have a sense of purpose of life. In some cases, the changes were so profound that participants began to think differently about their lifestyles and felt sufficiently empowered to begin to make positive changes.

The findings can be seen to add further weight to a growing evidence-base regarding the power of the arts to act as a catalyst for positive change. Indeed, there is a significant amount of evidence to suggest that participation in creative activity can stimulate change by: providing a safe environment for people to try new things; providing an opportunity to push personal boundaries and overcome fears; providing an opportunity to meet new people; nurturing a new means of self-expression; providing something for participants to focus on (thereby providing a distraction from negative thought patterns); and, providing an opportunity for participants to achieve something tangible.

A key factor impacting upon the level of change amongst participants was the length of their engagement in creative activity. The most significant changes to wellbeing were observed and measured amongst those who had participated in the programme since January 2011, while the smallest changes were observed and measured amongst participants who had joined the programme in September 2011.

Another important factor impacting upon the level of change amongst participants was the occurrence of other significant events in their lives. A number of participants experienced a period of illness or an accident or suffered a personal loss during the workshop period. This invariably tempered the impact of the intervention on their sense of wellbeing, particularly in relation to feelings of hope and optimism.

The impacts of the workshop programme are closely linked to the effectiveness of the project delivery model. The key strengths of the delivery model were: a person-centred, flexible approach to the project; effective project management; the level of resources invested in supporting the participants to attend, and during, the workshops; the skills, qualities and commitment of the workshop artists; and, the quality and flexibility of the workshop programme. Nonetheless, a number of difficulties were also experienced during the project process in relation to: the stakeholders' understanding of the 'strategic fit' of the project with wider NHS policy and practice; the workshop eligibility criteria and referral process; the level of care required by participants to participate in the workshop programme; partnership working with the sheltered accommodation sites; and, the measurement of impact. From this, a number of key learning points have been identified to help inform the planning and delivery of any future projects of this nature.

- Projects should adopt a person-centred focus and be responsive to the needs of individuals.
- Projects should have a detailed delivery plan and clearly articulated project roles; and project responsibilities should be delegated according to the skills and knowledge bases of individual team members.

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<sup>1</sup> When discussing the impact of the programme on participants, this applies to carers also.

- Project stakeholders should have a clear understanding of the strategic context within which the project operates. This will support the appropriate marketing of projects and ensure that project processes are standardised and integrated into any existing systems.
- Participants should be encouraged to support the delivery of projects.
- Careful consideration should be given to the range of conditions and participant needs which the project can support. This should be clearly outlined in the referral criteria.
- Artists recruited to such projects should possess both strong artistic skills and empathetic qualities.
- Supporting infrastructure (processes and support workers) is critical to the effective delivery of project workshops with this client group.
- For maximum impact, workshop programmes should be of high quality, flexible and responsive. The length and frequency of workshops should reflect the capacity of the participants. The target number of workshop attendees should reflect the nature of the participants and the levels of support which can be made available for each session.
- Expectations of all parties involved in the project should be established at the inception stage. Where possible, all parties involved should be encouraged to share a level of ownership of the project and should strive to work towards the achievement of common goals.
- The client group have problems of memory recall and an impaired capacity to make judgements and are likely to have impaired sensory, motor and communication skills. Evaluation methodologies must be sensitive and tailored to the needs of the group.



## Project Delivery Model Evaluation Findings

### Project Management

The management of the project was characterised by four core elements:

**Project Team:** At the outset of the project, a core project steering group (PSG) and wider project team were established. The table below outlines the key project roles and responsibilities.

Project Role	Main Responsibilities
Representative from Commissioning Body (PSG)	<ul style="list-style-type: none"> <li>• Monitor progress on behalf of the commissioning body.</li> <li>• Provide strategic input into the design and delivery of the project.</li> </ul>
Project Manager (PSG)	<ul style="list-style-type: none"> <li>• Develop the project delivery model.</li> <li>• Recruit the workshop artists, support worker etc.</li> <li>• Oversee the delivery of the workshop programme.</li> <li>• Monitor progress in relation to key deliverables.</li> </ul>
Project Worker (PSG)	<ul style="list-style-type: none"> <li>• Support the Project Manager.</li> <li>• Oversee the referral process/Assess the suitability of participants referred to the programme.</li> <li>• Support the workshop artists.</li> <li>• Deliver a series of workshops.</li> </ul>
Lodex Ltd (PSG)	<ul style="list-style-type: none"> <li>• Provide strategic support to the design and delivery of the project.</li> <li>• Collect and analyse impact data using the Lodex Wellbeing Questionnaire.</li> </ul>
Project Support Worker	<ul style="list-style-type: none"> <li>• Visit new referrals to discuss their participation in the project.</li> <li>• Arrange transport for participants to the workshops.</li> <li>• Support participants to attend the sessions.</li> <li>• Support participants during the sessions.</li> <li>• Other reasonable tasks as negotiated with the Project Manager.</li> </ul>
Project Referrers	<ul style="list-style-type: none"> <li>• Refer participants to the programme.</li> </ul>
Workshop Artists	<ul style="list-style-type: none"> <li>• Plan and deliver the workshop programme.</li> </ul>

**A Project Initiation Document (PID):** The PID was developed by Lodex Ltd, supported by Equal Arts. It outlined: the background to the project; project aims, scope, constraints, benefits, key deliverables and interfaces; the project delivery model; project management arrangements; a project timescale; project risks; and, quality controls. The PID formed the basis for the delivery of the project and the monitoring of progress.

**Project Board:** A project board was established to monitor and support the delivery of the project. Equal Arts were accountable to the South of Tyne and Wear Mental Health Model of Care Board, through the project board. The board was primarily made up of the PSG. In the initial months of the project, the board met monthly; this reduced to a 6-8 week basis once the project was fully established.

**Informal Communication Channels:** In addition to project board meeting, stakeholders communicated via ad hoc meetings, email and telephone.

Effective project management and communication channels were integral to the successful delivery of the project. Key strengths of the management of the project were the identification of necessary

project roles; the effective make-up of the project team; and the clear assignment of roles and responsibilities on the basis of the knowledge bases, skills and experience of the individual team members. There was considerable respect amongst stakeholders for individuals' respective knowledge bases and skill-sets, and roles/responsibilities had been allocated accordingly. Stakeholders particularly commended the contribution of the project worker to the project, who was seen to play an instrumental role in *'bridging the gap'* between those supporting the strategic aspects of the project and those involved in its ground-level delivery. The project manager explained that due to resource constraints, there was insufficient scope in the budget for regular meetings with the artists. As a result, it would have been difficult to gain an effective overview of the progress of the workshops without the project worker. The artists also praised the support of the project worker. They reported often calling the project worker with matters arising and feeling comforted by having this key point of contact. Artists specifically requested that the support received by the project manager and project worker be highlighted in the evaluation report.

Another key strength of the management of the project was the focus on the needs of the individual participants. Equal Arts invested a significant amount of time engaging in one-to one-discussions with participants outside of the workshops to check on their progress and the project manager and project worker reported meeting regularly to discuss the progress of individual participants. The project manager explained, *'we've had lots of discussion about where people are in their journey and where they would be happiest'*. The focus on individuals was most effectively demonstrated, however, by the appointment of an additional support worker mid-way through the workshop programme when it became clear that some participants required a higher level of support than was available initially.<sup>2</sup> The flexibility of the project management approach was further evidenced by the expanding membership of the project board as the project developed. In mid-2011, project board meetings came to be attended by a community matron and two service users, in addition to the PSG. The community matron initially attended a project board meeting to gain a sense of the project with a view to supporting the referral process; but as time went on, they continued to attend, providing valuable input to the project's strategic and operational development. Regarding service users, the project manager reported that there had always been an intention to invite service users to the project board, but that this had not been possible until several months into the project when suitable individuals could be identified. Stakeholders confirmed that the contribution of service users on the board added significant value to the project planning process. As one stakeholder explained, *'hearing key messages from service users is more powerful than hearing it from the project staff, even though we might be saying the same thing'*. Furthermore, stakeholders felt this had a positive impact on the participants themselves; giving them an opportunity to have their voices heard about the project and to *'give something back'*.

### **Aims and Objectives of the Project**

It was clear from discussions with stakeholders that all shared a common vision for the project. In the early stages, however, the project worker and artists reported that they lacked a clear understanding of the 'fit' of the project with wider NHS policy and strategy. They suggested that it would be helpful to have a greater understanding of the background and context to the project when pitching it to potential referrers and when designing the workshops. One stakeholder commented, *'I'm not clear what's motivating them to do community based work...I think it would have been helpful to have that sense so you know what is the overall purpose of the project and how it links with other projects'*. Once this was explained to them, the project worker stated, *'that was very useful....it certainly shaped my approach to engagement with medical staff when trying to recruit to the project'*; this was particularly in relation to the language which they used to describe

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<sup>2</sup> It should be noted that a charity had agreed to provide support to participants to attend and during the workshop programme from the outset but in the event, were unable to do so due to a lack of resources.

and contextualise the project. They did not feel it influenced their approach to the design of the workshops, however.

### Referral Criteria, Routes and Process

Clear referral criteria and a carefully considered referral process for the project were developed by the PSG. The project was aimed at people over the age of 60, living in Gateshead, who were identified as ‘at risk’ of social exclusion and were showing early signs of dementia or depression. It was particularly aimed at those who were not accessing any other community activities at the point of referral. As the workshops were delivered by artists rather than ‘carers’, the project was only deemed suitable for those who had a reasonable level of independence or had a carer who could accompany them to the sessions<sup>3</sup>. The referral ‘checklist’ for the project is outlined below.

<u>Criteria</u>	<u>Criteria met?</u>
Do you live in the Gateshead area (particularly Teams & Bensham)?	
Are you over 60 years of age?	
Are you currently accessing other community activities? (Referral requirement: No)	
Can you answer yes to any of the following three questions?	
<ul style="list-style-type: none"> <li>• Do you have problems with your memory?</li> <li>• During the last month have you been bothered by having little interest or pleasure in doing things? (NICE depression question)</li> <li>• During the last month have you been bothered by feeling down, depressed or hopeless? (NICE depression question)</li> </ul>	

Referrals to the project were made via three main routes: GP referral (35% of referrals), community healthcare (community matron and occupational therapist) referral (15% of referrals) and sheltered accommodation referral (50% of referrals).

Efforts were made to make the referral process as simple as possible. The following documents were produced to support the referral process:

- A leaflet designed to provide an overview of the project to potential participants.
- A leaflet designed to provide an overview of the project to potential referrers.
- A referral template.

The project required no resource or management input from project referrers.

If an individual was felt to meet the referral criteria, the project was discussed with them. If the participant wished to take part in the programme, their details were passed on to Equal Arts via a referral slip or telephone call.

Upon receipt of the referral, the project worker would telephone or visit the potential participant to assess their suitability (verifying that they met the referral criteria, outlining the project process and identifying any specific needs which they may have). It was intended that unsuitable participants

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<sup>3</sup> It was hoped that the project would also be of benefit to the wellbeing of any carers who attended.

would be signposted to other services, where possible. This was not necessary, however. At the point of referral, all potential participants were deemed suitable for the workshop programme.

One GP provided referrals for the project. Equal Arts and the GP in question have had a good working relationship for several years and so, the GP was happy to support the pilot project. Efforts to widen the referral pool to other GP surgeries, however, were less fruitful. With the support of the PSG, the project manager and project worker identified a second local surgery that may have been willing to participate in the pilot. They presented the project to GPs at the surgery via a practice meeting and provided them with supporting documentation. Stakeholders explained, *'the GPs we met were really enthusiastic about the project...they said they could think of lots of people who could benefit from this'*. Despite this, however, no referrals were made by the surgery. Stakeholders suggested that this may have been due to the absence of a previous working relationship with the surgery and the absence of an evidence-base regarding the value of the project. However, a related research project, reviewing options for a new social prescribing referral model in South Tyneside, found that:

- During appointments, in addition to addressing patients' immediate needs, GPs do not have time to assess their overall wellbeing and quality of life, identify appropriate social prescribing activities for them and refer them to a project.
- A directory of alternative social prescribing activities is already available to GPs online.
- A standard patient pathway into such activities is already established via the Primary Care Mental Health Team (PCMHT) (Lodex, 2011).

The underlying reasons for the absence of referrals into the project, therefore, may be primarily linked to time constraints and the project's lack of integration into existing systems and processes.

Two community matrons and an occupational therapist were pro-active in providing referrals for the project. Building upon the findings outlined above, two key factors appear to account for the different referral responses from GPs and community-based health professionals: the longer period of time which community matrons have to spend with patients; and, the role of community matrons in looking holistically at patients' quality of life. One stakeholder commented, *'They are out in the community, witnessing people's home lives first hand...[Sarah] looks at whether [the patient's] house is tidy, if they are nicely dressed, if they are getting out of the house, significant life events...I think that's the difference'*. Indeed, one of the community matrons confirmed, *'The GP focuses on what the problem is there and then...they haven't got time to start looking at the wider picture...that's where other health professionals come in to play...and even with us, there are groups out there but if we don't use them all the time, we do forget what groups we can access'*.

Three sheltered accommodation sites were involved in the pilot project. Two sites were involved from the outset, having had a long history of partnership working with Equal Arts. One site was recommended to Equal Arts by a GP who felt the residents would benefit from this project. Wardens were asked to promote the project to any tenants who may benefit from the project. Wardens were particularly active in encouraging residents to attend the workshops.

### **The Suitability of Referrals**

Whilst all stakeholders agreed that the majority of participants referred into the project were appropriate, one key issue which may not have been fully considered at the planning stage was that of co-morbidities (the presence of one or more disorders (or diseases) in addition to a primary disease or disorder). Across the project as a whole, participants had a wide range of conditions and complex needs and there were a significant number of wheelchair users involved in the programme. In some cases, stakeholders commented, *'although they met the referral criteria, I think one or two*

would have really struggled if we hadn't allowed them to have their carers with them or if the workshops hadn't been based in their accommodation sites'. In the initial stages of the workshop programme, the participants' additional conditions placed a significant level of responsibility on the artists and in some cases, resulted in a degree of anxiety and struggle for the participants themselves. A number of participants found the sessions overwhelming at times. It should be noted that these participants joined through sheltered accommodation, where the formal referral process was not followed in all cases. Overall, however, stakeholders were very positive about how well the artists had met the support needs of the participants and managed to foster their inclusion and engagement in the project. With the assistance of a support worker, one stakeholder commented, *'I think we could do a lot of work with people right across the spectrum'*.

### **Recruitment of the Artists**

Equal Arts were responsible for the recruitment of the workshop artists. Initially, three artists were recruited to the project. Mid-way through the evaluation period, a fourth artist was recruited to cover the short-term absence of an artist and the project worker also delivered a set of workshops. In total, therefore, five artists contributed to the workshop programme.

The skills, qualities and experience of the artists were invaluable to the successful delivery of the workshop programme; with participants and carers alike praising the commitment and input of the artists to the programme. What was realised when the workshop programme began was that the skills, abilities and qualities required by the artists to make the programme a success were more wide-ranging than originally anticipated. Stakeholders commented, *'it's so much more than artistic skills'*. Indeed, in addition to artistic talent, creative vision and excellent facilitation, communication and organisational skills, the successful delivery of the workshops required the artists to provide the participants with a significant degree of care, empathy and friendship. One stakeholder commented, *'it's an important combination of artistic talent and people skills'*.

### **Taster Sessions**

It was originally anticipated that three taster sessions would be delivered in December 2010 to enable project stakeholders to assess the participants most suited to access the full workshop programme. In the event, just one taster session was held. It was felt that all participants and carers who had been referred into the programme at that point (approximately 30) could be accommodated in one session. During 2011, referrals flowed in slowly and therefore, new participants were referred immediately to one of the workshops.

Stakeholders, participants and carers described the taster session as *'incredibly useful'*. The session allowed participants and carers the opportunity to see what they could expect from the workshops before committing to the full programme and to select which workshop theme they would most like to participate in. One stakeholder stressed that the taster session supported the key principles of the project, *'choice'* and *'responsiveness'*. Meanwhile, the project worker and artists found the session invaluable; providing them with an opportunity to assess the physical space which they would be working, the appropriateness of the participants who had been referred to the programme and to gauge the participants' abilities. This information was used to inform the workshop planning process.

### **The Workshop Programme**

Equal Arts had responsibility for overseeing the design and delivery of the workshop programme. It was originally intended that the programme would be comprised of four sets of workshops, running in parallel; each lasting 20 weeks and involving approximately 15 participants. Over the lifespan of

the project, the programme developed to include five sets of workshops; each lasting 12 weeks and involving 8 – 15 participants. The workshop options were: animation, film, movement, music and photography / pop-up museum. Workshop themes were selected on the basis of research evidence of the types of art form which tend to have a positive social impact on older people and past experience of *'what works'*.

Central to the design of the workshop programme was for each set of workshops to have an overarching goal; to facilitate the participants' long-term enthusiasm for the programme and to enhance the sense of satisfaction from participation. Indeed, stakeholders agreed that one of the key things which makes art different from other activities is the sense of achievement gained from the development of a final product. Stakeholders commented, *'whilst participants enjoy the process, there's always a bigger sense of reward for them when they reach the end of the process if there is something tangible which they can show family and friends', 'making something for an audience has a real value. It gives people a sense of pride and achievement', 'it's exciting pushing people to a point where they have some adrenalin'* and *'it helps people to exceed their expectations of themselves'*. Also important, however, was for the workshops to have standalone sessional outcomes in order to give an immediacy of impact to the sessions and to accommodate participants' inevitable fluctuations in attendance and the possibility of new participants joining the sessions at different stages.

Whilst the focus and goals of the workshops was the responsibility of the artists, the specific content of the sessions emerged through a process of negotiation with the participants and carers. Artists spoke of the importance of striking the correct balance between product and process. One stakeholder commented, *'it's so driven by the people and where they are at...listening to what the participants want to do is essential to keeping people involved'*; while another said *'I would have liked to focus on product more but, for the first few weeks, they needed time to build trust, momentum and to start to feel comfortable before rushing into doing a play or anything'*. Another stakeholder commented, *'while product is important, the most important thing for me was to provide a social space and encourage people to interact...there can sometimes be a tension [there]'*. The importance of this was brought to the fore in relation to the photography workshops where the difficulty of using technical equipment and learning about the technical aspects of photography resulted in some of the group losing interest in the sessions. Here, the artist's workshop diary read, *'using the digital cameras was not as straightforward as I thought...old hands and small buttons did not mix and a screen instead of a viewfinder foxed some of our participants...the final nail in the coffin was a session when we looked at the more technical side of photography and people lost interest and energy...Rebellion followed...[but] a good rebellion, with participants saying they wanted to keep coming to sessions but do something different...they were the driving force to change the project to meet their needs'*.

Participants highlighted that a key strength of the programme was the range of workshop options available to them. One participant said, *well, there's something for everyone isn't there'*. When asked why they selected a particular workshop, participants gave different responses. Some were attracted to one of the workshop genres commenting *'It was the old films that attracted me at the beginning', 'we love singing and exercise keeps us fit...'* and *'I like photography and I've always wanted to learn more about it...and it's something that you can follow on in your life, you know'*, for example. Others opted for a particular workshop theme because it was something which they had never done before. In relation to the first cohort of film workshops, for example, a small group of participants explained that they had already participated in an exercise-based programme in the past and therefore opted for 'film' over 'music and movement' in order to *'try something different'*. Others found the thought of a particular workshop less daunting and more in keeping with their area of comfort than others,

with one male participant, for example, explaining, 'I liked the idea of film club...but oh, dancing is not for me'.

### **Photography / Pop Up Museum**

*'It was spring and working in Saltwell Park on a photography project seemed like a really good option. The first couple of weeks went well, with people enjoying being out and about in the park. People were full of stories about happy times in the park and clearly loved telling them; Robert catching fish in jam jars that died almost as soon as he got them home, Mary performing a version of Hiawatha in the park when she was only a girl. [Following technical difficulties]...we decided to develop our own museum about Gateshead, using the stories, objects and ideas that the group had in their homes and their heads. We started to meet at Gateshead Library with the group deciding what themes we would develop. We did 'radical card making', where images of war or childhood poverty replaced chocolate box kittens and roses. We talked about work, home life and social time, and wrote up our memories onto luggage tags that would sit next to the objects in a final exhibition. Over the weeks, we created our own memory boxes, reflecting the boxes that people had made for their grandchildren but never for themselves. In our final week, we set up the community room in the library as a pop-up museum, with all our objects and stories on display. People invited friends and family to see their work. What was so exciting was that the participants created the project for themselves...something that only 12 weeks before, they could never have imagined, as they sat quietly in a room as strangers, reluctant to speak. They went from a group of strangers to a collective of creative friends'.*

### **Film**

*'The workshop was a reminiscence project, which aimed to work with older people to explore themes of interest to the group. Each session focused on building and demonstrating positive group communication skills to engender a good foundation from which to explore shared memories. The games and exercises help to stimulate older people's minds, encouraging them to take an active role in group work and enabling them to feel comfortable in a safe environment, where people have similar shared memories to recall together. The group watched films about local history and went on a trip to Beamish Resource Centre to provoke discussion. Themes discussed included: families, homes, where we grew up, going to the cinema, life during the war and being evacuated. The group were encouraged to be partially responsible for the planning of activities and actively involved in providing stimulus for the sessions such as song sheets, written stories, photographs etc, as well as sharing their own reminiscences amongst the group. This has been a very positive experience for all participants and strong bonds and friendships have been created'.*

### **Music and Movement**

*'The idea for the workshop was to bring people together and develop a common bond through music and movement...a song that is planted in our brains at some point in our lives can remain with us forever. The workshops worked brilliantly. I played the guitar and sang, and week by week, the participants sang along more and more. We made up some basic actions to go with the songs too – some based on the song lyrics and some based on their hobbies and interests – they really enjoyed getting their bodies moving. We sang and acted out the same collection of songs each week so the participants would get to know them and we all got to know each other in the process, too. As the workshop developed, we decided to write a song. We discussed past memories from childhood and of notorious characters that we remembered in and around Gateshead. We came up with a song called 'Big Wheel', which we recorded with a sung chorus and a spoken verse. The group performed the song and acted out 'All that Jazz' from Chicago, at the final sharing event, with great energy and enthusiasm. It has been such a positive experience working with the participants...there is a much stronger sense of unity amongst them now'.*

## Animation

*'This workshop supported participants to make a film based on their stories from growing up in Gateshead. The workshop took place at Gateshead Library and utilised the library's maps and photograph collections, to prompt people's memories and provide visual material for the film. The group found lots of images of streets where they used to live, shop and work; some of which have since been knocked down. We also watched some short films about Gateshead. The room at the library was lovely and light, but was a big room...it took a few weeks to work out how to change the room around to create the intimacy needed to be able to share stories, bounce ideas around and to hear each other! The sessions all had a similar structure, but the activity shifted each week. On arrival, we would have a cup of tea and a natter, giving people the chance to catch up and build on their burgeoning friendships; play warm-up games, helping the group to focus and providing a supportive space for people to share good and bad moments from their week; and then we would do an activity to support the development of the film. Participants enjoyed the sessions and several asked for copies of the photographs that they had found to take home with them. As the sessions progressed, the group became more used to contributing to and more willing to share things about themselves; some who were initially really quiet and frail became more motivated and involved; the group increased in confidence and became more forthright in expressing their opinions; and, there was more laughing, joking, bantering and energy amongst the group. When the film made by the group was shown at the sharing event, the group were very proud of their achievements.'*

## Workshop Facilitation

The nature and quality of the workshop environment was reported to be of central importance to artists and participants alike. As one artist explained, *'many have never done anything like this before...this can be a very daunting process'*. As a result, the artists explained that they sought to create a space that was stimulating and challenging, yet open, accessible and friendly; a space where participants would feel safe to try new things and express themselves. They suggested that a unique quality of the arts is that it challenges people, but is an activity at which participants cannot 'fail'. One artist commented, *'The group environment is a really good environment to get things wrong or to not quite deliver what's expected of you...if you don't get it right, people laugh and it eases the atmosphere'*; while another explained, *'there are no judgements about the activity which they are doing...it's about displaying process through a final product, not the quality of the final product itself'*. The artists employed various approaches to ensure that the workshops provided a space where participants would feel safe to try new things and express themselves. Central to this was creating structure within the sessions. For example, at the start of each session, some of the artists would play 'warm-up' games, where the participants would learn each others' names, share something about their week with others or listen to each others likes and dislikes. The games were intended to develop the cohesiveness of the groups, to help stimulate the participants' memories, to give the participants a sense of familiarity and to support the participants to know what to expect each week.

Artists agreed that participant attendance, mood and occasional resistance could impact negatively upon the continuity of the sessions, particularly when allied with a lack of self-belief and relevant experience (these factors should be borne in mind when undertaking consultation). Therefore, facilitation methods needed to constantly adapt to suit individuals and changeable group dynamics.

Participants were overwhelmingly positive when talking about the workshop programme. They valued the overall approach of the artists and the quality of the atmosphere, culture and environment of the workshops themselves. Participants across the programme commented on the comfortable and informal relationships which had developed between them and the artists and suggested that they felt safe to express themselves openly within the workshop environment.



Participants liked the structured nature of the sessions; that each session had a focus and that everyone was encouraged to participate. When speaking to one of the artists about what they liked about the sessions, one participant said, *'I think we need someone like you to spur it on...you encourage us to say things...that's the main thing'*.

### **Workshop Venues and Trips**

A key strength of the programme was the variety of locations at which the workshops took place. Residents could choose to participate in a workshop taking place at their sheltered accommodation site; at one of the other participating sheltered accommodation sites; or, in a community setting (Saltwell Park or Gateshead Library). In all cases, there was a workshop location to suit the needs and wants of the participants. For some, that the workshops took place where they were resident was a major advantage of the programme. One sheltered accommodation warden commented, *'it's great that they do things here...it reaches people who you wouldn't normally reach as they are too uncomfortable to leave their own environment...for some people. Just getting out of the house is a really big thing'*. For others, having the opportunity to travel to an alternative venue was part of the attraction. Another sheltered accommodation warden commented, *'some were really desperate to get out of the accommodation...they don't get out much...so it's been great for them'*. For those who currently live independently, having the option to participate in a workshop based in the community was a key benefit of the programme, with participant comments including *'[The project] is not about your age...I feel like we are fitting in with the community'*, *'You are part of the community here...we'd rather try to live a normal life'*, *'I felt there was more on offer at this club...sitting in a chair, having cups of tea and making small talk isn't my thing'* and *'when we went to [the sheltered accommodation], I felt out of my depth as I'm only 65....when all the old people were sitting doing exercises, I thought 'ooh, that's not my thing''*.

As part of the workshop programme, trips were organised to Tyneside Cinema, Beamish Museum and the Sage. Wardens described this as giving a *'boost'* to participants and explained, *'the opportunity to go out and about has made a massive difference to them...to have new experiences that they wouldn't normally have the opportunity to do'*. When reflecting upon the trips, participants agreed, *'we love trips cos we wouldn't go there normally'*. A trip to the Sage left a particularly lasting impression on one participant, where several weeks later, they said, *'I still can't get over the Sage, it was just fabulous...I keep thinking about it'*.

Although it was not an issue in relation to this project, a key issue to bear in mind if project workshops are taking place in a community setting is accessibility. When talking about the photography workshop, the artist explained, *'the park staff were brilliant, bending the rules so that we could get taxis right into the park and up to the door of the old bowling clubhouse'* and when talking about Gateshead Library, another artist explained, *'the building was very accessible...there were plenty of lifts for the participants'*.

### **Number of Participants per Workshop**

It was originally planned that the four workshop options would each accommodate 15 participants. At the taster session, zero participants opted to take part in the proposed *'visual arts'* workshops. Only three workshop options ran initially, therefore, resulting in one workshop accommodating 17 participants. It quickly became apparent this number of participants per session was difficult for the artists to manage due to the level of care and support which they required throughout the sessions. Artists commented, *'you have to spend a lot of time with people individually...I think we underestimated that'*, *'It was a big group...it was difficult to manage'* and *'logistically, managing people was tough....setting the room up, making people listen, giving everyone a space to speak'*.

Drawing upon their experience throughout the year, artists agreed that 8 – 10 is an optimum number of participants per session.

### **Duration and Frequency of the Workshops**

Stakeholders, participants and carers agreed that the length and frequency of the sessions (one x 2-hour session per week) was appropriate for the project. The artist felt 2 hours was sufficient time to achieve a positive outcome within a session and that the attention of the participants was sustainable over this period. They agreed that if the sessions were longer, they may become tiring for some participants and some may start to lose interest. The artists also felt that they, personally, would have found it difficult to sustain the level of energy which they put into the sessions for longer than two hours. The same principles apply to the number of sessions in each workshop programme, with stakeholders agreeing that 12 weeks was a more optimal duration than 20 weeks.

### **Workshop Support**

A number of processes were put in place to support the effective delivery of the workshops.

- The day prior to each workshop, participants would receive a call from Equal Arts reminding them of the next workshop, confirming their attendance and checking whether transport to the session was required.
- On the day of the sessions, free transport to and from the sessions was provided for those who lived independently.
- A support worker was available to support participants in their journeys if necessary.
- At the sheltered accommodation sites, staff would remind participants about the sessions via telephone or door knocking and participants were supported down to the communal lounge.
- A support worker was appointed to support participants during the sessions.

Stakeholders stressed the importance of all of these factors to the successful functioning of the workshop programme, commenting *'those things might not cost a lot but they are generally the first things to be cut when you don't have a big budget...but they are the things which make the difference...these are the things which make people go'*. Stakeholders stressed that without this supportive infrastructure, the workshops would not have been able to take place. The participants who live independently were particularly grateful for transport to and from the sessions, commenting, *'you get up and the taxi is there and you just go'* and *'the taxi and the call...you've got no worry about it...you just come and enjoy it'*. When asked if they would consider attending other workshops in the future, one participant said they would like to, but only if transport was provided, *'I would...if I was taken there and brought back'*.

As mentioned previously, a key strength of Equal Arts' approach to the management of the project was the flexibility and responsiveness to participant needs. In September 2011, a support worker was appointed to the project, in recognition that some of the participants required a greater level of care than the artists could provide.<sup>4</sup> Stakeholders commended the positive impact which the assistance of the support worker had on the participants, reporting *'she's great with older people, incredibly hard working, very positive'*, and *'she's a great confidence builder...she has sometimes gone to people's houses who weren't confident about the process on the phone and they've come along'*. The artists also commented on the positive impact of the presence of the support worker on their capacity to deliver the workshops. One artist commented, *'having her there has really changed things...it means I can concentrate on delivering the workshop, rather than worrying about the*

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<sup>4</sup> It should be noted that a charity had agreed to provide support to participants to attend, and during, the workshop programme from the outset but in the event, were unable to do so due to a lack of resources.

*participants' needs'. Another commented, 'we didn't have anyone to start with and it was a bit of a panic...I didn't know who to run to first...and as an artist, you sometimes need five minutes down time to look over your notes and decide what to do next'. They also commented that not all artists would feel comfortable supporting participants in and out of wheelchairs and helping them from their flats to the communal lounge etc. The project manager conceded, 'I think we underestimated the amount of time and care involved in different tasks...and this is crucial to keeping people involved'. Another key benefit of the appointment of the support worker was that it reduced the resource input of the sheltered accommodation sites to the workshops. In the early stages of the workshop programme, one sheltered accommodation site made a carer temporarily available to support the workshops due to the size of the group and the level of care which the participants required. The warden commented, 'we could bring in additional staff at the time to support the sessions, but we wouldn't always be able to...we wouldn't be able to now due to staff shortages...the timing was lucky'. The other sheltered accommodation sites lacked sufficient resources to make a carer available for any period of time during the evaluation programme. The project manager reported that if they were to deliver such a project again, they would ensure that a support worker was appointed at the outset.*

### **Partnership Working with the Sheltered Accommodation Sites**

While the practical input of the sheltered accommodation staff was important to the effective delivery of the workshop programme, of equal importance was the level of ownership of the programme assumed by the sheltered accommodation. One warden reported trying to attend the sessions, where possible, to help the participants feel at ease; but more importantly, they commented, *'If I'm there, I think the ladies feel the group is part of [the accommodation site], rather than it just being something which Equal Arts come in and do...I think it's important to them that it's a team effort'. At another accommodation sites, one of the artists commented, 'I think [the participants] were suspicious of me at the beginning...I think some of them came because [the warden] was there...they trust him, they know him'. Yet, at another of the sites, where the warden is not generally present, one artist commented, 'they see it as us running a group rather than it being something which is to do with them...legacy-wise, it would have been nice for them to take more on'; whilst another commented, 'the priorities between the artist and sheltered accommodation are sometimes different...we all need to be working together for the same goals'.*

### **Sustainability**

Sustainability was a key theme within the project deliverables, which included: to collate information from other services provided by statutory and voluntary agencies and local communities; to signpost people into suitable community and/or mainstream activities; and, to improve the spread of information for people with dementia and their carers. These deliverables proved particularly problematic to achieve. Equal Arts took responsibility for identifying other activities which the participants may like to join but encountered difficulties due to the lack of appropriate activities which the participants could be signposted to. In particular, many of the activities which Equal Arts identified did not provide transport to the sessions and so many participants were reluctant to attend, nor did they match the participants' interests. As a result, it was only possible for Equal Arts to signpost people onto other projects which they deliver. In addition, Equal Arts arranged for volunteers from a local wellbeing network to attend a number of sessions and to pass relevant information on to the participants; but it appears that no information was shared. When asked if they would like to continue to engage in community activities once the programme ends, all participants stated that they would like to. Participants reported, *'we'll miss it when it finishes', 'when it ends, I don't know what we'll do', 'I think the communities could do with more things like this' and 'I'm pleased that I went...I would try another group in future'. One of the*

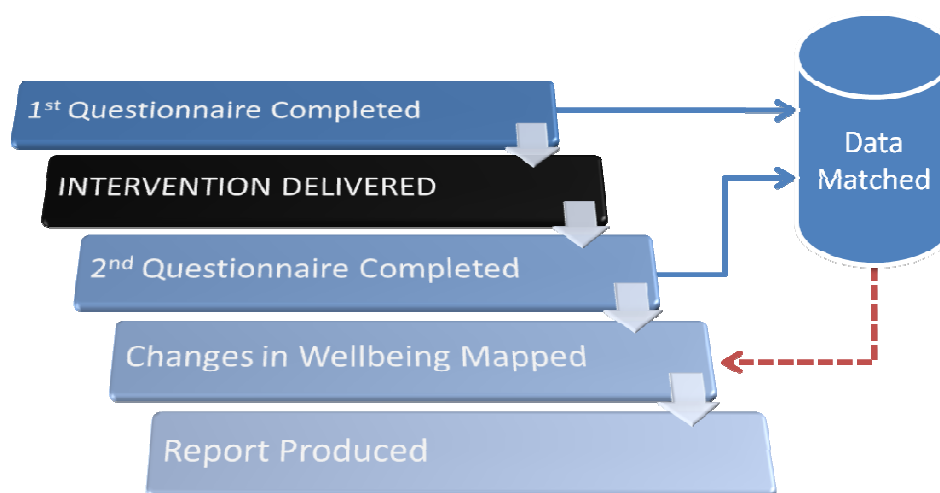
sheltered accommodation wardens confirmed, *'It's a big part of their lives now...it will be devastating if it ever stops as they really do look forward to it on'*.

## The Impact of the Workshop Programme on Participants and Carers

### Lodex Impact Findings

#### About the Lodex Tool

The Lodex wellbeing tool involves an anonymous questionnaire that can be completed online or on hard copy. It was developed in partnership with South Tyneside Primary Care Trust to provide a standard measurement of projects and interventions to help inform commissioning. It is completed at the start of an intervention by participants and repeated again at the end. Lodex Ltd matches questionnaires and maps the changes in wellbeing across four domains: general wellbeing, belonging, purpose and independence. Measures are taken to preserve participants' confidentiality throughout the process. The tool contains three separate sections: Lodex wellbeing questions; demographic data about the participant; and, optional bolt-on questions identified at the beginning of the evaluation by the project lead. The diagram below represents the Lodex process.










#### Lodex and the Pilot Project

The impact of the pilot project on the wellbeing of the participants was evaluated using the Lodex Wellbeing Questionnaire. Four participants completed the paper-based version of the questionnaire, both in February 2011 and November 2011<sup>5</sup>. Following completion of the questionnaires, the participants' answers were entered onto the Lodex database and changes in wellbeing within the four domains were mapped.

Lodex measures the impact of the intervention on the wellbeing of the participants at the aggregate level and reports the score as a percentage increase and in relation to a star system. Lodex calculates the star system differently depending on the length of the project as follows:

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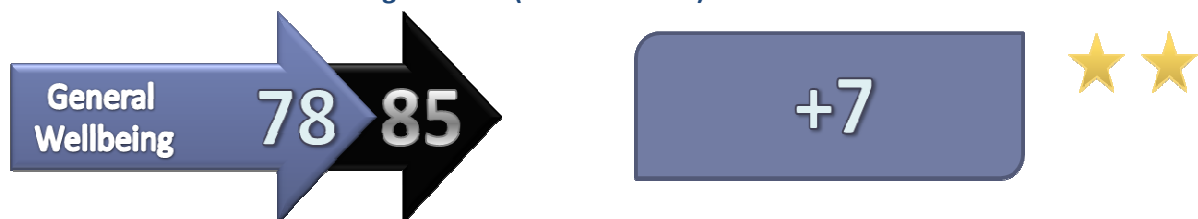
<sup>5</sup> More than four participants completed the questionnaire during the evaluation period but a number of those who completed the tool in February 2011 did not complete it for a second time in November 2011 and a further group of participants completed the tool in November 2011 but only for the first time.

Short Term Intervention (under 3 months)		Long Term Intervention (over 3 months)	
			Moderate (0- 4% increase)
	Good (0- 4% increase)		Good (5- 9% increase)
	Considerable (5- 9% increase)		Considerable (10- 14% increase)
	Exceptional (10% + increase)		Exceptional (15% + increase)

The participants who completed the questionnaires had been involved in the programme for 32 weeks. This is classified as a 'long-term' intervention. No 'bolt-on' questions were selected for the intervention.

### Lodex Wellbeing Questionnaire Results

#### Domain One: General Wellbeing – 2 Stars (Good Increase)



**This domain measures changes in Happiness and Vitality**

- A positive overall concept that includes a sense of happiness and vitality
- A general indication of the absence of psychological morbidity

Changes in happiness and vitality will have a long term positive effect on **all aspects of wellbeing**

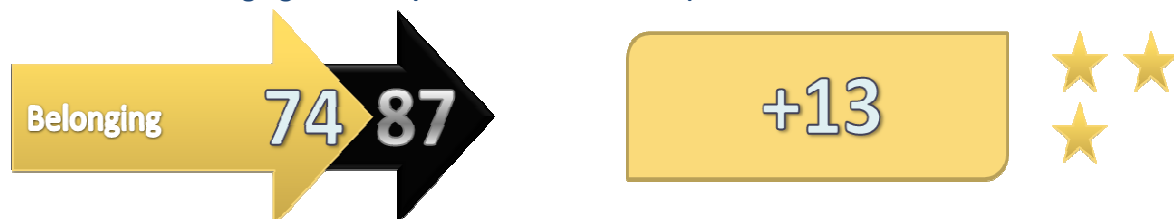
- Belonging
- Purpose
- Independence

#### Result Analysis



This is a self reported expression of how satisfied the participant is with their life overall, including their neighbourhood and surroundings. Before the intervention, the group scored 78% and after the intervention, the group scored 85%, giving an increase of 7% in the General Wellbeing domain. This reflects a good increase over the timescale of the measured intervention.

## Domain Two: Belonging – 3 Stars (Considerable Increase)



### This domain measures changes in Life Satisfaction

- An overall assessment of one's life
- A comparison reflecting perceived discrepancy between aspirations and achievements
- An optimistic outlook
- A perception of life as pleasurable

Changes in life satisfaction will have a long term positive effect on **social functioning**

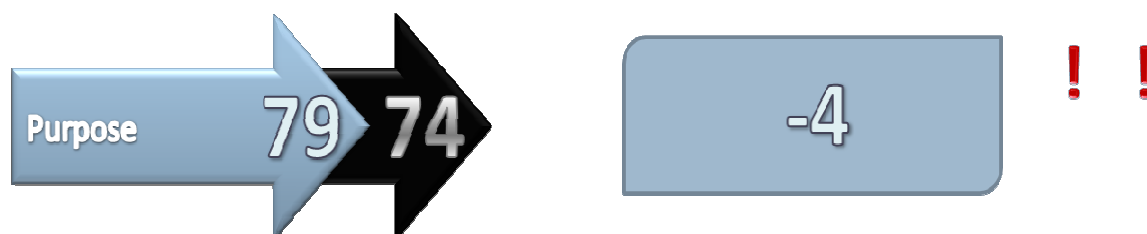
- Personal relationships (interpersonal trust, respect and sympathy)
- Overall assessment of the quality of personal relationships
- Social networks
- Function as community member
- Social participation
- Sense of belonging
- Valuing oneself and others

### Result Analysis



Before the intervention, the group scored 74% and after the intervention, the group scored 87%, giving an increase of 13% in the Belonging domain. This reflects a considerable increase over the timescale of the measured intervention.

## Domain Three: Purpose – 2 Cautions



### This domain measures changes in Optimism and Hope

- Positive expectations for the future
- A tendency to anticipate and plan for a relatively favourable outcome

Changes in optimism and hope will have a long term positive effect on **meaning and purpose**

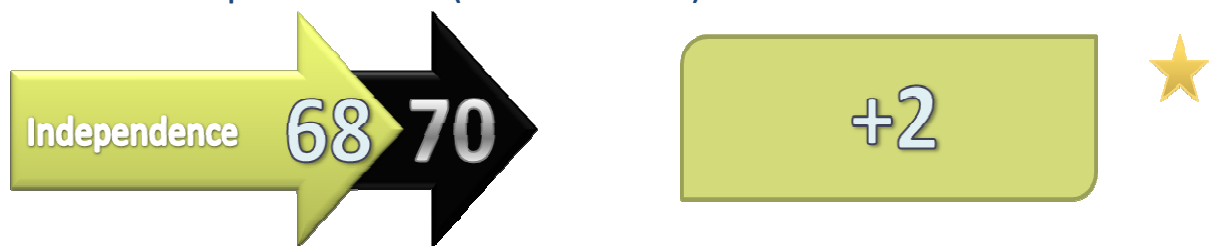
- A sense of purpose/meaning in life
- A sense that there is something beyond the material world
- Attempts to harmonise life with a deeper motivation

### Result Analysis



Before the intervention, the group scored 79% and after the intervention, the group scored 74%, giving a decrease of 5% in the Purpose domain. This reflects a decrease over the timescale of the measured intervention.

### Domain Four: Independence – 1 Star (Moderate Increase)



### This domain measures changes in Self Esteem

- A belief or evaluation that one is a person of value
- Accepting personal strengths and weaknesses
- A sense of worth
- How one feels about self (emotional safety/security)
- Confidence in personal relationships

Changes in self esteem will have a long term positive effect on **resilience and coping**

- Resistance to mental illness in the face of adversity
- Hardiness
- Learned resourcefulness
- A sense of coherence i.e. confidence that internal and external events are predictable and that things will work out as well as can reasonably be expected
- A cognitive evaluation of perceived resources to deal with perceived demands
- personal control

### Result Analysis



Before the intervention, the group scored 68% and after the intervention, the group scored 70%, giving an increase of 2% in the Independence domain. This reflects a moderate increase over the timescale of the measured intervention.

### Use of the Tool with the Client Group

The Lodex tool, (questionnaire) designed for use with a range of social groups (including older people) had not been used with older people with dementia prior to this project. Using the tool for



the purposes of this evaluation, therefore, was in part intended to trial its suitability with the client group.

Results indicate a considerable increase in participants' sense of belonging during the project period but also, contrasting levels of change across the four domains, suggesting the validity of the results. A similar level of change across all four domains would not be expected given the targeted nature of the intervention and the nature of the client group. Throughout the process, however, stakeholders and participants reported difficulties using the tool. Key concerns relate to:

**Protocols for Completion of the Questionnaire:** Participants are ideally required to complete the questionnaire on their own to ensure confidentiality (to avoid their responses being influenced by the presence of others). The majority of participants who were asked to complete the questionnaire were unable to do so, however, for various reasons, resulting in feelings of anxiety. In order for the questionnaires to be completed, two stakeholders were required to support the process. Stakeholders emphasised that the participants were less anxious when assisted to complete the questionnaire.

**The Nature and Focus of the Questions:** Participants and stakeholders reported struggling to fully understand how the questionnaire would capture changes in wellbeing as a result of participation in the intervention. In particular, they perceived the tool to reflect a 'mental health' questionnaire and therefore, did not feel the questions provided participants with an opportunity to express the changes in wellbeing which they had experienced in a language which was meaningful to them. Furthermore, in supporting participants to complete the tool, it became evident to stakeholders that participants struggled to understand some of the concepts which they were being asked to reflect upon and became confused by the seemingly 'repetitive' nature of the questions. Many were eager to explain why they were responding to each question in such a way, seeking reassurance that they had correctly understood the focus of the questions. In some cases, stakeholders were required to think of examples to help participants to understand. Stakeholders expressed they were unclear about the intended focus of, and subtle differences between some of, the questions also and expressed concern that their involvement in the process may have influenced the results.<sup>6</sup>

**The Volume of Questions:** The questionnaire entails approximately 25 questions. Stakeholders reported that some participants seemed overwhelmed by the volume of questions and became tired during the exercise. In some cases, it took participants 45 minutes to complete the questionnaire.

**The Format of the Questionnaire:** Participants completed the paper-based version of the questionnaire. Several participants struggled to read the questionnaire due to the small font, the layout of the questionnaire and the grey-colour scheme used. In addition, a number of participants lacked sufficient motor skills to hold a pen to complete tool in this way.

The client group have problems of memory recall, impaired capacity to make judgements and impaired sensory, motor and communication skills. These difficulties clearly impacted upon their ability to complete the questionnaire on hard copy and unaided. While a number of participants were able to successfully complete the tool, the findings of the pilot exercise confirm the need to think creatively about the delivery of the tool with the client group. In order to address some of these issues, a 'board game' version of the tool was subsequently developed and trialled with one participant. This involved a stakeholder reading out the questions to the participant and supporting the individual to place a marker over their response to each question. Feedback suggested that the new version '*worked well*', '*the participant liked it*' and that '*their first reaction was that it would be*

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<sup>6</sup> A user guide has been produced by Lodex to accompany the tool and is available on the company website but it appears that this had not been accessed or passed on to and read by stakeholders.

*fun'*. The process took approximately 25 minutes to complete with the individual. Lodex Ltd is also currently working with academics at Northumbria University to develop an online version of the tool, where the questionnaire will be displayed in large font, using contrasting colours and where questions can be listened to in audio format. If the tool is to be used with the client group in the future, it is recommended that these developments continue to be pursued and protocols regarding completion of the questionnaire be flexible. In some cases, a creative and qualitative approach to the delivery of the tool with the client group will be required. Finally, all stakeholders who intend to use the tool should be advised to access the user-guide which accompanies the tool. Lodex Ltd may also want to consider developing, however, a standard narrative outlining the focus of each of the wellbeing questions and examples – reflecting everyday lived experiences – which would help the client group to engage with the questions correctly.

## **Mental Health Concern (MHC) Impact Findings**

### **About the MHC Tool**

The MHC Outcomes Assessment tools are based on a person-centred outcomes approach and comprise a semi-structured interview and rating scale. The rating scale is used to quantify the opinions of participants and the interview is used to establish and record key narrative to support and explain the scores.

### **Methodology**

Seven participants were interviewed in total (4 men and 3 women). These participants joined the project in September 2011. A baseline was established by interviewing participants before they were due to attend their first group session, with a follow up interview completed once the group ended 12 weeks later. In some cases, participants volunteered to be interviewed and in others, participants agreed when asked. The ability of each participant varied from having no communication or awareness issues to having significant speech difficulty and high levels of short term memory loss. Each interview began with general interview questions featured in the interview tools in order to generate an overview of the individual's life and what was important to them. Questions regarding the workshops which they were participating in were asked at the end of the interview if this had not already been mentioned during the generic questions. Key questions asked about the workshops were:

- During the baseline assessment: What do you hope to get out of attending the workshops?
- During the follow-up assessment: Did you enjoy going to the workshops? Can you think of any ways in which the workshop could be improved? Would you be interested in going to any other workshops or similar programmes in the future?

Often, the standard interview questions naturally trigger discussion about the workshops. For example, 'Do I enjoy chatting with or meeting people?' resulted in replies like 'Oh yes. It was nice to meet the new people at the club' or when 'what makes you happy?' resulted in 'Well going to that group was very good'. It was important to ask the participant about other aspects of their lives rather than just questioning them about the workshops as these can significantly impact upon how the workshops affect that individual. See Appendix B for an example of an anonymous completed interview and rating scale.

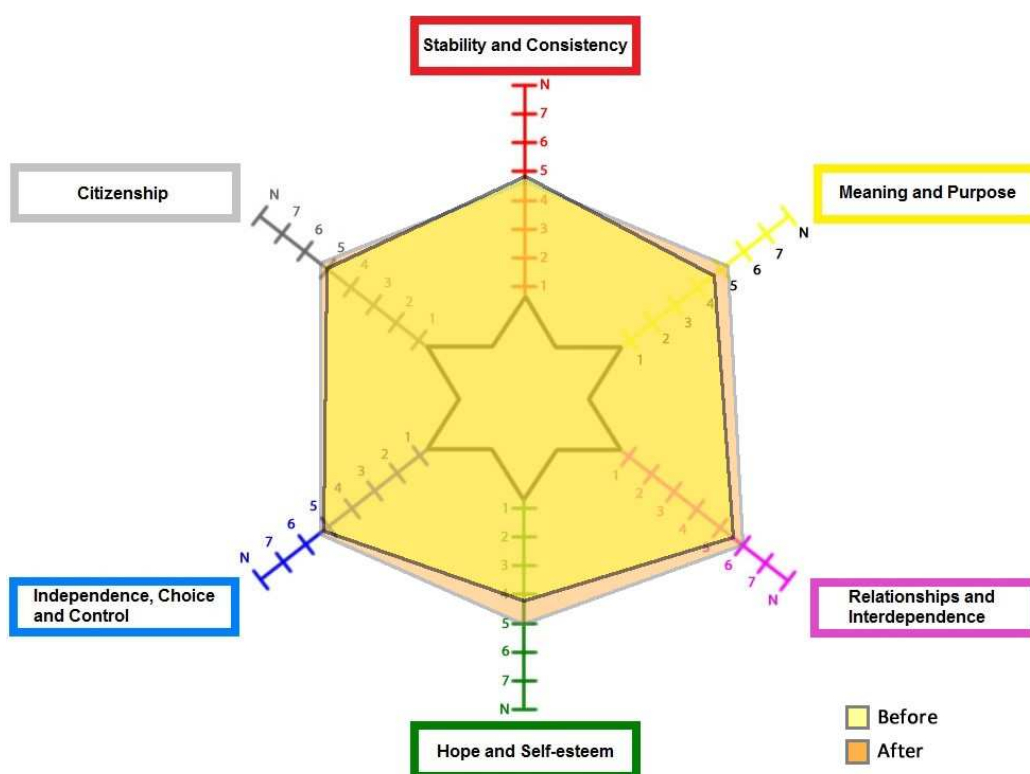
All participants were interviewed on a one-to-one basis. Participants who were able to independently read through and demonstrate understanding of the consent form were asked to read through the rating scale booklet after their interviews and provide one rating score per domain. Those who could not read through the booklet themselves were asked questions relating to the rating scale and were scored by the interviewer. For example, the interviewer would ask them if they had enough things to do during the day and would mark the closest corresponding rating scale score. Throughout all interviews, the interviewer would repeat key statements back to the individual to ensure that they were happy and confident with the responses they had given.

## Results of the Tool

*Participant rating scale scores before and after the workshops*

Participant	Total score before	Total score after	Difference in totals
1	33.75	36	+2.25
2	30	30	0
3	39	38	-1
4	24	26	+2
5	16	23.5	+7.5
6	34.5	32	-2.5
7	20	25	+5

As shown in Table 1, there was a significant level of variation between the scores before and after the intervention. In all cases, other variables unavoidably affected these scores. Participants with the negative scores were affected by a fall and the death of a pet. The largest positive score was explained in part by the arrival of a long-lost relative. It is clear that inspecting the scale scores alone is insufficient to accurately evaluate the impact of the intervention. The key narrative explanations behind these scores are shown in Appendix C, which also details individual results. Another noteworthy point is that not every participant attended every group session. 1, 3, 4 and 5 attended less than half of the sessions and 2, 6 and 7 missed just one session. This should be kept in mind when inspecting the scores. During the follow-up interviews, some participants had issues remembering details about the activities within the workshops. However, they remembered enjoying themselves and mentioned being around people, which they recalled clearly. Participants who remembered what they did at the workshops more clearly had the larger score differences, suggesting that the groups may have had a more positive impact on every participant, but due to memory problems, and with the workshops finishing a few weeks prior to their follow-up interview, they may have forgotten the full impact of the workshops.



**Figure 1:** Outcomes star displaying the average scores across all participants both before and after the groups. Two of the Hope & Self esteem scores were “N” (the future isn’t important to that person as they prefer to live in the now) so they have not been included in this average.

The narrative and rating score data suggests that the workshop can have a positive or maintaining impact on quality of life across the domains. Every participant said that they enjoyed attending and would be interested in going to further workshops. Suggested areas for improving the workshops varied from altering the demographic of other group attendees (e.g. more men, more able individuals) to changing one of the starter activities.

Consistent with previous research, every participant emphasised the importance of having regular social contact and this was the most popular reason for attending the workshops. Other positive aspects of the workshops included providing enjoyable activities, showing interesting films about the local area and having a reliable taxi service. The taxi service alone was well received as some individuals found it interesting to look out of the window at their local town and discussed how it had changed since the last time they saw it. For the outcomes identified by participants in order of domain, please see Appendix D.

### **Analysis of the Results**

When looking at the above results, it is clear that the participants reported positive outcomes following the workshops. Whilst we cannot disentangle the effect that the workshops had on individuals due to the complex interaction between other events in their lives, it would be fair to assume that the workshops can either improve or maintain the quality of life of the attendees. Despite variation in the strength of this positive impact between different people, it appears that the individuals would benefit further should additional workshops be available.

#### **Case Study: Arthur**

Arthur is 83 years old. He lives with his wife who is 84 and has a number of health conditions. Arthur has been her full-time carer since 2006. Arthur is also in poor health. He has an inoperable brain tumour which gives him frequent headaches and he has problems walking. Arthur describes life as physically *'tough'* on him, but prides himself on being independent and self-sufficient. Before joining the programme, Arthur reported feeling *'isolated'*, *'trapped'* and *'no longer part of the community'*. He rarely leaves the house, his wife is deaf so it is difficult for them to communicate and most of his friends have passed away. He said, *'I feel as though I'm locked in all the time in the flat'*. Arthur joined the programme in September 2011 to get some *'personal space'*, to have something to look forward to and to meet new people. Arthur said he really enjoyed attending the workshop, saying *'the film club was great'*. He was interested in the topics discussed during the sessions and enjoyed the liveliness and company of the group, *'going to that group was very good....the people there were more active than the group I go to at Hardman Hall on a Monday, which was nice'*. Arthur was particularly happy to have made friends with another of the gentlemen who attended the workshops. Arthur felt going to the group had *'made things better'* and he would like to attend other groups like this in the future. Following the intervention, Norman's overall outcomes assessment score was +5. His rating increased by 0.5 in relation to relationships and interdependence, by +2 in relation to independence, choice and control, and by +3 in relation to hope and self-esteem.

#### **Case Study: John**

John is in his 70s and lives with his wife. They have a large family but only see their grandson these days. John has dementia and his wife is classed as his carer, although he considers himself to be very independent as he does everything for himself and his wife. He said, *'I do all the jobs...we don't have any help'*. John used to enjoy photography and walking in the countryside, but is no longer able to do so due to his arthritis which makes it difficult for him to operate a camera and to walk long

distances. He said, *'the arthritis, it's really got a hold of me'*. John described life as 'sheer boredom', saying, *'where I am now, there is nothing to look forward to at all.... I get very black moods sometimes and just take a sleeping tablet and go to bed...eventually, this dementia will catch up with me too'*. John's pleasure in life comes from spending time with his wife and grandson. When talking about them, he said, *'they keep me going'*. Before attending the workshops, John thought he and his wife's lives would be improved by having support to get out of the house and having others to talk to. He said, *'I am a chatterer and will talk to anyone...I don't really have many chances to chat, so that would be nice'*. Indeed, when completing the MHC tool, John was incredibly talkative and seemed in great need of more stimulation. He was eager to talk about his time growing up in a large family, working in the hotel business and about his travels. Following the workshop programme, John's demeanour was 'happier'. He smiled and laughed more and his outlook was more positive. He reported enjoying the music club. He said, *'I chatted a lot when I was there and got on well with some people. If there was a photography group starting, I'd definitely give that a go'*. During the intervention period, John's son who he had not seen for 30 years visited him and they have plans to meet his family. John and his wife are now *'looking forward to Christmas'*. Following the intervention, John's overall outcomes assessment score was +7.5. His rating in relation to meaning and purpose increased by +2, in relation to relationships and interdependence by +2.5 and in relation to hope and self-esteem by +3.

### **Use of the Tool with the Client Group**

As the tool was designed specifically for use with this client group, it was not within the remit of the evaluation to assess its suitability. It may be worth noting, however, that stakeholders reported that participants who completed the outcomes assessment tool found it to be a pleasant experience. Stakeholders typically reported, *'People who did the interviews with her found it very easy and stress free...one lady said 'oh, it was lovely, we just had a nice cup of tea'...I think that's a really good sign of what's gone on there'*.

## Northumbria University Impact Findings

In order to contextualise the findings of the research in relation to the impact of the programme on the participants' sense of wellbeing, they were first asked why they joined the programme, what they hoped to gain from participation and how they felt during the initial sessions.

### **Participant Expectations of the Workshop Programme**

The participants interviewed joined the programme via two referral routes (GP and sheltered accommodation). Those who had been referred to the programme via their GP understood the intended aims of the project and why the programme had been suggested to them. For example, they explained that their doctor had recommended participation in the sessions as it may aid their recovery from illness, improve their memory and self-esteem and reduce their sense of isolation. One carer and participant recalled, *'[John] was advised by the doctor to take part...it was mainly for him, but she said I could come along too if I wanted to support him...[John] is recovering from illness...she said it might help him to recover more, meet different people and get out in the community'... 'I had a bad bout of depression after a stroke...basically, we weren't going out...we didn't really see anyone during the day'*.

Participants who were referred to the programme through sheltered accommodation were less aware of the intended impacts of the workshops on their wellbeing. One participant remarked, *'a carer just said 'there's something on downstairs, why don't you go and try it?''*. Stakeholders agreed that these participants largely saw the workshops as *'just an organised activity for them where they live'*. Indeed, when the music and movement participants were asked why they joined the sessions, their responses included *'to be entertained'*.

To some extent, these differences affected the ways in which participants articulated the impact of the programme on their sense of wellbeing. Across both groups, however, it was clear that the majority of participants joined the workshop primarily due to feelings of isolation and loneliness.

### **Initial Feelings about Attending the Workshops**

There was widespread agreement amongst stakeholders and participants that it required a great deal of courage for participants to join the programme. Stakeholders commented, ***'there's a lot at stake coming to a new session like this'*** and ***'it's a big leap for them'***. When asked how they felt about coming to the sessions initially, the majority of participants reported feeling nervous. Anxiety was principally related to the fact that they would not know anyone and did not know what to expect, commenting ***'It felt a bit strange, with all these people and I didn't know their names'***, *'at first, I thought...'god, what are you walking in to', but now I enjoy it'* and *'I felt a bit weird at first with not knowing anyone'*. Male participants reported feeling anxious that they would be the only male at the sessions. Others were worried about what the sessions would entail, given the workshop theme. For example, one photography workshop participant commented, *'I felt a bit nervous before...well the only time I've used a camera before was when someone on holiday said 'Ohm can you take my photograph?''*. Other participants, however, were happy to have been invited to the sessions and reported looking forward to them immediately, commenting ***'Glad...I thought 'ooh, it'll be good to have something to do''***.

Upon arrival at the sessions, participants reported feeling very welcome and quickly at ease. Comments included, ***'I think it was very friendly from the start'***, ***'as the morning went on, I felt comfortable'*** and ***'I was definitely made welcome'***.

When asked how the workshops make them feel and impacted upon their lives, the responses from participants can be understood in terms of eight key themes.

### Social Isolation

As supported by the results of the Lodex Wellbeing Questionnaire and the MHC Outcomes Assessment tools, the biggest impact of the programme on participants was a reduction in their sense of isolation and loneliness. When asked what they liked about the sessions, participants most commonly reported valuing the opportunity to be amongst other people. Responses included, *'[I like] just being among the company'*, ***'It's like seeing other people...[I'm makes me] happy because you're not sitting on your own'***, *'it's nice to just come here and meet everyone'* and ***'I love meeting all you lovely people...everyone is so nice to each other'***. Participants also valued the opportunity to share memories and their experiences with others. Here, participant comments included, *'I like to hear from other people, what they did in lives, what kind of jobs they had'*, *'it's interesting...you meet people that you would never normally meet'*, ***'I think it's the change... you meet other people from outside...you get other people's opinions'*** and *'I like to learn from other people'*. One of the sheltered accommodation wardens confirmed, ***'it's great that they have the chance to mix with others... they love the social stimulation they get from meeting new people'***.

### Positive Relationships

Linked to this, the data suggested that the workshops not only impacted positively upon the participants' sense of belonging, but also upon the *quality* of their relationships with others. Stakeholders reported being *'amazed'* by the strength of the bonds which developed amongst the participants over time. When talking about the initial film workshop, the artist commented, ***'I think the group really developed...you could tell every week that people felt more comfortable with each other...and if someone wasn't there, everyone would ask about them...everyone worried about each other'***. Similarly, when speaking about this particular group, the sheltered accommodation warden reported, ***'they very much see themselves as a group now...you see them all chatting about it and if anyone can't attend a session, the others will tell them what they've missed...it's definitely improved the quality of the time they spend together...they have a common bond now and wouldn't have had that without the group'***. Speaking about another group, one of the artists reported, *'they are a really strong group of women and they have really come to care about each other'*. Another artist recalled one session where the group shared some difficult memories from the past with each other. They reported, ***'it's great that they felt it was a safe enough space to share that with people and that they wanted to share that with the others...it really brought people together'***.

The sheltered accommodation wardens reported that the workshops had also improved the participants' relationships with residents who do not participate in the workshops, as they have something new to talk to them about. Wardens explained, *'they have been telling the other tenants about the club...it's really brought them out of themselves and made them more sociable'*, *'it gives them something else to talk about...what they've done, what they are going to do...its difficult if you see the same people every day to bring something new into the conversation'* and ***'if they have been out on a trip, they would come back and tell the others about it, so it's definitely helped build friendships'***.

The workshops also had a positive effect on the quality of relationships between the participants and the sheltered accommodation staff. One warden commented, ***'it's been beneficial to staff as we saw what their lives used to be like and its changed the way staff relate to them as they have got to know them more'***.



Of particular significance, however, is the impact of the sessions on the relationships between participants and carers. Stakeholders commented, ***'I think it's had an enormous impact on the quality of their lives...especially between the participants and their carers'***. A number of participants and carers spoke of how the workshops had improved the quality of the time they spend together. One carer (the daughter of a participant) reported enjoying the sessions as, ***'they are something special that me and my mam can do together'***. They explained that while they spend a lot of time with their mother, much of this time is spent together at home or doing basic errands. The sessions, therefore, gave them something different to look forward to and the opportunity to experience something which is unique to them. For carers and participants who are married, the workshops provided them with a space where the dynamics of their relationships are not 'carer' and 'cared for'; the workshops gave them something to look forward to together, something enjoyable to do together and something new to talk about.

### **Confidence**

Another positive impact of the programme was an increase in the participants' levels of confidence. As one stakeholder put it, ***'creativity stimulates a person and brings them out of themselves'***. Stakeholders were particularly passionate when talking about the increased levels of confidence amongst the groups over time. When talking about their first group, one artist explained, *'for me, this group is a real success story...they came the first week, they were virtually silent, didn't speak, barely looked at each other...everyone was anxious...embarrassed...now, the amount of laughter and chatter amongst the group, the level of eye contact, the way that they look out for one another, it's amazing'*.

Artists also spoke passionately about the changes noticed amongst individual participants. One artist explained, *'[Michael]...was really reluctant to speak, very shy...he used to rely on his wife a lot for answering questions and remembering things from the past...and over time, showing films, giving him props to look at...I've noticed a real change in him, he come out of his shell and he became so much more willing to answer his questions'*. This same participant later commented, ***'I'm not a really good mixer...I always get a bit timid...but since I've come and met everyone, I feel fine...there's no way I would normally sit and talk like this'***. In relation to another participant, one of the wardens explained, *'one of my ladies would find a reason not to go to the sessions...I think she felt she didn't have anything to say and she was worried about that...but after some encouragement, she now really looks forward to it...she often goes'*. Indeed, the majority of the participants interviewed reported that as a result of coming to the sessions, they felt *'more confident'* and *'more sociable'*.

For some participants, simply leaving their flat or home was a daunting prospect. Yet, following participation in one set of workshops, a number of participants opted to take part in a workshop taking place in a community setting. Furthermore, when the participants who attend the sessions with carers were asked if they would now come to the sessions alone, opinions were mixed, but almost half of those spoken to said *'oh yes...I think I would'*. Stakeholders and participants considered these to be *'big step[s] forwards'* and *'the first step[s] towards bigger changes'*.

### **Enjoyment and Happiness**

Without exception, the participants interviewed reported experiencing greater feelings of enjoyment and happiness in their lives, as a result of participation. When asked how the workshops made them feel, happiness was central to their responses. Comments included, *'we have a laugh, we enjoy it'*, *'you get a laugh'*, ***'when I came initially, it was for my mam but the more I come, the more I enjoy it'***, ***'there is so much laughter...I think that makes you feel so much happier'***, *'you just feel better in yourself'* and *'we're happier'*. Participants particularly enjoyed the workshops which

involved an element of reminiscence and the sharing of memories and experiences. They explained, *'I think when you've put the films on, it makes you think 'eeh I remember that and I remember that'', 'I can remember a long time ago more than I can yesterday, so watching the films is good...'*, *'I think it's nice, taking your mind back and thinking 'oh I remember this and I remember going there', 'the workshops take you back and you remember things that you had more or less forgotten' and 'its good to have something which gets your mind ticking, rather than just sitting in front of the television'.*

Changes in levels of happiness as the workshop programme went on were evident from observation; noticeable were the greater levels of engagement, smiling, laughter and eye contact amongst the participants over time. This was also evidenced by the attendance data. Participants reported that if they did not enjoy the sessions, they simply wouldn't attend, stating *'Well if we didn't like it, we wouldn't come', 'If I thought this wasn't not for me, I would have just told them and not come back'*. A number of participants attended 85 – 100% of the sessions. Where participants did not consistently attend the sessions, this was typically linked to illness or personal loss. This was particularly true amongst participants who joined the workshop programme late in 2011.

### **Feeling Valued**

A key issue raised by stakeholders, participants and carers was the value attached by the participants to having an opportunity to express themselves and the impact of this on their feelings of self-worth. As noted earlier, participants reported liking the structure of the sessions and the fact that everyone was encouraged to actively participate, with one participant saying, *'I think we need someone like you to spur it on...you encourage us to say things...that's the main thing'*. When asked what they liked about the sessions, others said, *'it gives everyone some interest...and everyone can voice their opinion, rather than just sitting in the flat'*.

A number of participants also valued the fact that the artists recognised and accommodated their needs and included them in activities and conversations despite sensory impairment. One participant, in particular, used to be very active but since the loss of much of his sight and hearing, he explained that he no longer participates in community activities. When reflecting upon the sessions, however, he explained, *'It's opened my eyes and my mind...I'm deaf and I'm short of sight but Richard showed me things right in front of my eyes so I could understand and follow what was happening...it's been wonderful'*. When asked how the workshops made them feel, another participant replied, *'I felt wanted'*.

The sense of value attached to the sessions was evidenced by changes in the way the participants presented themselves over time. For example, regarding a trip to the Sage, stakeholders commented on how *'well dressed', 'well turned out'* and *'smart'* the participants looked. Similarly, when presenting the 'pop-up' museum developed by the photography workshop participants to family and friends, stakeholders commented on the effort made by participants to look smart and the professional demeanour adopted when engaging with the library staff. Another stakeholder recalled the day that one of the participants forgot his hearing aids for the session. They explained, *'he was really upset with himself... he felt bad and a bit rude coming along and not being able to hear ...we had a chat about it and I told him not to worry...the support worker later said when she went to his home, there were post-it notes saying 'don't forget aids for the session' in every room of the house...I was really touched that he had really taken it to heart and really wanted to get things right for the session'*.

## Sense of Purpose

A renewed sense of purpose was also suggested by some of the participants to be a key impact of the sessions. Participants valued having something to look forward to, reporting, **'It breaks the monotony of everyday life'**, *'when you are just stuck in here, you are glad of anything', 'it's a morning of your week that you look forward to'* and **'I look forward to it every week'**. The sheltered accommodation wardens and carers also reported how much the participants looked forward to the sessions, saying *'We bring the subject up during the week...he looks forward to it...he'll say 'ooh we're going there tomorrow, aren't we, and we'll talk about what we have been doing''*. Some participants talked about the sessions as **'a new challenge'** and when reflecting on their experience of the sessions, one participant and carer agreed, **'it's a new life for us'**.

The participants' renewed sense of purpose was strongly linked to the sense of achievement which they derived from participation in the workshop. This was both solidified and evidenced by the various 'sharing' events held throughout the year. At the sharing events, project participants would gather at one of the sheltered accommodation sites and each group would present what they had been working on to the other groups. Feedback from the participants at the sharing event included, *'people enjoyed talking about the old days and when you see it all come together, it makes you see how far you have come', 'It's really good if you think where we started....when you see where have come to, it's brilliant', 'you couldn't have dreamed they could have done that...the whole point of the project is to inspire people and it really has'*. One sheltered accommodation warden stated, *'the sharing events have been really important...it makes them realise that they aren't isolated and that there are other people out there who also get involved in these types of activities'; while another commented, 'the ladies were very pleased at how professional it all looked. I think it's given them a huge sense of achievement'*.

## Energy and Motivation

Particularly noticeable as the workshop programme progressed was the impact of the sessions on the participants' levels of energy and motivation. A number of participants commented on how motivated they felt after completing a session, saying **'well I didn't feel well one day and it got me motivated', 'I feel smashing [after doing the sessions]'** and **'if you are depressed, you come here and it lifts you up'**. It was clear, however, that the sessions also had a lasting impact on participants, with comments including, *'since I've come here, I feel like I still have force in me, I feel like it's made such a difference to me', 'it uplifts you....when you do something like this, it gives you the strength to do something else'* and *'I feel like my old self again'*. In many cases, participants found the workshops to be a welcome distraction from negative thought patterns or problems of illness and continued engagement brought an increased motivation to think about other things.

For those who engaged with the workshops for a longer duration, there was a desire to move on to new challenges or to extend skills and continue to develop through more advanced work. In support of this, the sheltered accommodation wardens commented, **'they are much more motivated to do other things...it boosts them...it's definitely improved their well being, without a doubt'**. Similar observations were reported by the artists. When talking about one of their groups, the artist recalled, *'[there were] more laughs, joking, bantering as time went on...the energy of people, the energy of the group increased as time went on'*.

## Autonomy

In some cases, the workshop programme had a profound effect on participants and represented an important step towards achieving a greater independence of spirit, a shift in attitude towards being more able to question those aspects of life that they had not previously questioned and to think

about making changes to their lives. One participant was reported to be on oxygen for 16 hours each day and therefore does not leave their flat; yet, one of the artists reported, *'when she comes to the sessions, she sings along and joins in with all the movements, she's brilliant'*. In relation to another participant, an artist recalled, *'there was one man, he is old and frail...he walked with two sticks....he was keen on amateur photography...with some persuasion, he cast aside his sticks, stood up and took the photos...that was really lovely....and you could tell that he really enjoyed it'*.

Taking this one step further, a number of participants and carers reported feeling much more able to cope with life situations as a result of participation in the workshops, which had in turn, had a significantly positive impact on the quality of their lives. Following a stroke, one participant lost their confidence to leave their home. At the same time, however, the carer did not want to leave the participant in the house alone and therefore, stopped going out themselves. Following participation, the couple reported feeling more confident to go out together in public and that they now have the freedom to make choices about their lifestyle. They explained, *'we often go to the metro now and we just sit and people watch...we enjoy it'*. Furthermore, the carer explained, *'Well I've been to the doctors and I've started doing some exercise sessions and lost some weight...and it's great because he will come with me and he just sits in the cafe and chats to people'*. They agreed that they could not envisage regaining this sense of control over their lives prior to participation in the workshops.

#### **Case Study: Robert and Mary**

Robert and Mary joined the programme in June 2011. They attended the photography workshops at Saltwell Park and the pop-up museum and animation workshops at Gateshead Library. Robert and Mary are in their 80s. Robert has a number of health conditions. He is also deaf and has very poor eyesight. Robert and Mary are a cheerful couple and used to enjoy doing courses at their local college to help keep their minds active. As Robert's health and eyesight have deteriorated, however, they are no longer able to do so and now rarely leave their home. Their health visitor has informed them of alternative community activities which may likely to do in the past, but they feared some of the activities would be 'too much' for them and others did not appeal to their interests. When they received a call from the project worker asking them if they would like to join the photography group, they were delighted. Robert commented, ***'photography...is something which would never have entered my mind...but I'm amazed by it all. I was a bit nervous [before coming]...the only time I've ever held a camera was when someone's said 'I've set it all up, just press that'...but it's magic coming here and seeing what can be done'***. Robert and Mary thoroughly enjoyed the sessions. Robert said, ***'I've really enjoyed it...it's been fascinating. It's opened my eyes and my mind...I'm deaf and I'm short of sight but Richard showed me things right in front of my eyes so I could understand and follow what was happening...and trying to hear other people talking, that's been very interesting for me. This has been a new challenge'***, while Mary said ***'Yes, we enjoy them, very much so...it's a new life for us...it's been a means of getting us out because we can't get out...we've enjoyed the company and the surroundings...and the taxi and Ann ringing, that all helps. You've got no worries about it. You just come'***. The couple particularly liked that the workshops took part in community settings, saying *'[We] thought there was more on offer with this one...it's not about your age. [We] couldn't visualise sitting in a room, having cups of tea and making small talk....here, [we] feel as though we are fitting in with the community...[we] aren't being pushed away'*.

#### **Case Study: David and Jean**

David and Jean joined the programme in December 2010. They took part in the film, photography/pop-up museum and animation workshops. David is in his early 60's. He was a semi-professional boxer in his youth and following retirement, worked as a coach for many years. In 2009, David had a serious stroke and for the last two years, has been on a long road to recovery. He continues to experience mobility, motor and communication problems today and before joining the

programme was suffering from depression and a loss of confidence. He and his wife Jean commented, 'we didn't really go out anymore...David can't walk very far...and where we live, a lot of people are still out of work all day so we don't really see anybody throughout the day'. In January 2011, David's GP suggested that he join the programme. Jean is David's full-time carer and so went along to support him. David and Jean reported really enjoying the sessions. Jean explained, '**It was really nice coming here because you get to meet different people, you get to know what they have done in their life and you find it interesting. Some of the films that we've watched, you think 'I remember that and I remember that' and it's started a conversation off. Watching the films about the Hoppings, it takes you back...the rides, the lads, the music, a bag of chips and candy floss. We sort of knew a few people because everyone is local, so that was quite good...if we saw them outside, we'd stop and have a bit chat now. [The artist] is really good. She would put the spring in anyone's step. She's warm and welcoming. And that it's free is great....because you don't have to worry about anything. We bring the subject up during the week...he looks forward to it...he'll say 'oooh we're going there tomorrow, aren't we' and we'll talk about what we have been doing. It keeps us away from the TV...if we weren't here, we would be sitting watching the TV and saying to the dog 'get down off there'! It gets your mind ticking over. We are pleased that we have stuck to this and I hope that whoever deserves it, [has the opportunity to take part]'. I think there should be more of this for elderly people'**. David and Jean feel that participation in the workshops have reduced their sense of isolation and improved the quality of their relationship and they feel confident to go out in public once again, commenting, 'we often go to the metro now and we just sit and people watch...we enjoy it'. Furthermore, Jean has started to make a number of positive changes to her lifestyle. She explained, 'Well I've been to the doctors and I've started doing some exercise sessions and lost some weight...and it's great because he will come with me and he just sits in the cafe and chats to people while I exercise'. David and Jean agreed that they did not envisage being able to regain such a sense of control over their lives prior to participation in the workshops.

## Conclusion

### **The Findings of the Evaluation**

Central to the 'Promoting Wellbeing and Combating Isolation: Arts and Dementia' pilot project was the delivery of a series of arts workshops to isolated older people showing early signs of dementia or depression. The project was commissioned to explore the extent to which a programme of creative activity (based upon the principles of 'social prescribing') can help combat problems of isolation and loneliness and improve the wellbeing of older people with dementia or depression (and their carers). If successful, programmes of this nature could be used more widely by NHS South of Tyne and Wear to meet key priorities in relation to the Dementia Strategy (2009-2014), the Gateshead Emotional Health and Wellbeing Action Plan and the Gateshead Joint Strategic Needs Assessment (2009), for example.

Many of the participants referred into the project were suffering from a range of conditions, primarily linked to cognitive and sensory deterioration and mobility. For some, this was profound and when combined with their social circumstances, had led to a decreased ability and desire to socialise, a reduction in perceived quality of life and low expectations of experiencing improvements in their health and wellbeing in the future.

The findings of the evaluation suggest that following participation in the workshops, participants (and carers) experienced improvements in their overall sense of wellbeing and, for some, the improvements were significant. The quantitative and qualitative data collated indicates that the most significant impacts of the programme were increases in the participants' sense of belonging and the quality of their relationships with others. The project, therefore, was successful in meeting its primary aim of reducing social isolation amongst the client group. Additional impacts included increases in: the participants' levels of confidence; their sense of enjoyment and happiness in life; their levels of energy and motivation; and the extent to which they feel valued and feel they have a sense of purpose of life. In some cases, the changes were so profound that participants began to think differently about their lives and felt sufficiently empowered to begin to make positive changes to their lifestyles. This can be seen to add further weight to a growing evidence-base regarding the power of the arts to act as a catalyst for positive change. In this case, the workshops helped stimulate change by: providing a safe environment for people to try new things; providing an opportunity to push personal boundaries and overcome fears; providing an opportunity to meet new people; nurturing a new means of self-expression; providing something for participants to focus on (thereby providing a distraction from negative thought patterns); and, providing an opportunity for participants to achieve something tangible. In addition, the 'sharing' events helped inspire the participants to see things differently and reinforced positive messages of change by celebrating their personal achievements and showcasing the achievements of others. It can also be seen to add further support to arguments that art is an effective way of engaging people in community activities and that any *'anxiety around participation can be quickly offset by the excitement, the social contact and sense of achievement derived from participation'* (Matarasso, 1997); that artistic interventions have the added advantage of being largely immune to the effect of 'adaptation' (Marks and Thompson, 2006); and, most importantly, what makes art different from other types of intervention is the quality of the experience (Matarasso, 1997).

The findings of the evaluation also indicate that levels of impact are proportionate to levels of exposure to creative activity. The most significant changes in various domains of wellbeing were observed and measured amongst those who had participated in the programme since its inception in January 2011, while the smallest changes were observed and measured amongst participants who

had joined in September 2011. This emphasises the importance of having the opportunity for prolonged and repeated cycles of engagement with the arts. It also highlights that that art is '*not a quick fix*', as one stakeholder put it. At the start of the workshop process, participants are particularly vulnerable and a reasonable period of time must be invested in the building of relationships between artist and participant and amongst the participants themselves and in developing momentum in relation to the creative process.

A key issue to bear in mind when considering the impact of participation in creative activity on the wellbeing of participants is the occurrence of other significant life events which may impact upon the participants' perceived sense of wellbeing. As evidenced by the findings of MHC, in particular, a number of participants experienced a period of illness or an accident or suffered a personal loss during the workshop period. This will inevitably have tempered the impact of the intervention of their sense of wellbeing, particularly in relation to feelings of hope and optimism.

The success of the programme is, in large part, attributable to the effectiveness of the project delivery model. Through the evaluation process, a number of strengths and weaknesses of the delivery model were identified and, from this, it was possible to identify a number of key learning points for any future programme of this nature. The key strengths of the project were:

**The Person-Centred Approach to the Project:** From the outset, the needs of individuals were at the heart of programme.

**Effective Project Management:** The project had a clear delivery plan; key project roles had been accurately identified; and, there was a clear delegation of responsibilities based upon the skills and knowledge of the individual team members. The project management process was also assisted by the involvement of service users on the project board.

**Workshop Support:** Critical to the effective functioning of the workshop programme was the level of support invested in supporting the process (transport; the role of the project worker and support worker; and, the support of sheltered accommodation staff). This element of any programme is generally most vulnerable when resources are limited, but the evaluation findings suggest that this is a key contributing factor to the success of such programmes.

**Workshop Artists:** The skills, qualities and commitment of the artists were integral to the successful delivery of the workshops. The artists demonstrated not only a high level of skill in their art form, creative vision and excellent facilitation, communication and organisational skills; they also had strong people skills, were empathetic to the participants' needs and were comfortable fulfilling a caring role.

**Taster Session:** The taster session played an important role in supporting the workshop planning process; providing stakeholders with an opportunity to assess the physical space which they would be working in, to assess the appropriateness of the participants who had been referred to the programme and to gauge the participants' abilities.

**Workshop Programme:** A number of factors contributed to the effectiveness and impact of the workshop programme, including:

- The quality and flexibility of the workshop programme (the range of workshop options and variety of workshop locations).
- The effective balance achieved between process and product.

- The choice afforded to participants over the specific content of the workshops, resulting in the participants developing a sense of ownership of the programme.
- The matching of the workshops to the participants' interests and abilities.
- The length and frequency of the workshops.
- The structured nature of the workshops.

The key difficulties encountered during the project were:

**Aims and Objectives of the Project:** Whilst all stakeholders shared a common vision for the project, operational stakeholders reported lacking a clear understanding of how the project fitted into wider NHS policy and strategy. This issue was quickly addressed by a member of the commissioning body. Once explained, this knowledge was reported to have helped inform one stakeholder's approach to their project responsibilities.

**Referral Criteria:** The issue of co-morbidities was not fully considered when designing the referral criteria for the project. Whilst all of the participants met the referral criteria, many had additional needs which resulted in them requiring a significant level of additional care during the workshop programme, which had not been fully anticipated. Prior to the appointment of a support worker, this placed a considerable level of responsibility on the artists.

**Referral Process:** The referral process was the key element of the project which proved particularly problematic to develop. In particular, efforts to widen the referral pool to additional GP surgeries were not successful. A related research project reviewing options for a new social prescribing referral model, in light of recent changes in commissioning and the introduction of the personalisation agenda, found that:

- During appointments, in addition to addressing patients' immediate needs, GPs do not have sufficient time to assess their overall wellbeing and quality of life, identify appropriate social prescribing activities for them, brief them about the range of options available to them and then refer them to a project.
- A directory of social prescribing activities is already available to GPs online.
- A standard patient pathway into such activities is already established via the Primary Care Mental Health Team (PCMHT) (Lodex, 2011).

The underlying reasons for the absence of additional referrals into the project, therefore, may be primarily linked to time constraints and the project's lack of integration into existing systems and processes. It should be noted, however, that community matrons and occupational therapists were pro-active and effective in referring 'suitable' and deserving participants to the programme.

**Workshop Numbers:** It was originally anticipated that 15 participants could be accommodated per workshop. It quickly became clear, however, that this number was difficult for the artists to manage given the support needs of the participants. It may also have reduced the impact of the workshops by reducing the opportunity for all participants to play an active role in the sessions.

**Partnership Working with the Sheltered Accommodation Sites:** Of equal importance to the practical input of the sheltered accommodation staff in supporting the workshop programme, was the level of ownership of the programme assumed by the sites. Stakeholders were disappointed at the lack of ownership assumed by the sites and the practical difficulties which arose from the sometimes different and competing priorities of the artists and wardens.



**Sustainability:** Sustainability was another key element of the project which proved difficult to achieve. Equal Arts experienced difficulties identifying additional activities which would satisfy the interests and meet the support needs of the participants. This highlights the uniqueness of this particular project and the importance of continued funding for projects of this nature.

**Measuring Impact:** The Lodex wellbeing tool had not been used with older people with dementia prior to this project. The use of the questionnaire in this evaluation, therefore, was, in part, intended to trial its suitability with the client group. Results indicated a considerable increase in participants' sense of belonging during the project period but also, contrasting levels of change across the four domains, suggesting the validity of the results. A similar level of change across all four domains would not be expected given the targeted nature of the intervention and the nature of the client group. During the pilot exercise, however, participants experienced difficulties completing the questionnaire due to: difficulties understanding the nature and focus of the questions; the volume of questions; and, the layout of the tool. In some cases, this resulted in a level of anxiety when participants were asked to complete the questionnaire unaided. In the event, the questionnaire was completed as a group exercise, with the support of stakeholders. The findings of the pilot exercise highlighted the need to think creatively about the delivery of the tool with the client group. It should be stressed, however, that Lodex are working to develop additional versions of the tool, which will overcome some of the difficulties encountered.

### **Key Learning Points**

A number of key learning points have been identified to help inform the planning and delivery of any future projects of this nature. These are:

- Projects should adopt a person-centred focus and be responsive to the needs of individuals.
- Projects should have a detailed delivery plan and clearly articulated project roles; and project responsibilities should be delegated according to the skills and knowledge bases of individual team members.
- Project stakeholders should have a clear understanding of the strategic context within which the project operates. This will support the appropriate marketing of projects and ensure that project processes are standardised and integrated into any existing systems.
- Participants should be encouraged to support the delivery of projects.
- Careful consideration should be given to the range of conditions and participant needs which the project can support. This should be clearly outlined in the referral criteria.
- Artists recruited to such projects should possess both strong artistic skills and empathetic qualities.
- Supporting infrastructure (processes and support workers) is critical to the effective delivery of project workshops with this client group.
- For maximum impact, workshop programmes should be of high quality, flexible and responsive. The length and frequency of workshops should reflect the capacity of the participants. The target number of workshop attendees should reflect the nature of the participants and the levels of support which can be made available for each session.
- Expectations of all parties involved in the project should be established at the inception stage. Where possible, all parties involved should be encouraged to share a level of ownership of the project and should strive to work towards the achievement of common goals.
- The client group have problems of memory recall and an impaired capacity to make judgements and are likely to have impaired sensory, motor and communication skills. Evaluation methodologies must be sensitive and tailored to the needs of the group.

## **Appendix A: Literature Review**

### **The Treatment and Care of Older People with Dementia**

The UK has a rapidly ageing population. Older people (aged 50+) now account for nearly 20% of the UK population and this figure is set to increase (Champion and Shepherd, 2006). By 2034, 23% of the population is projected to be aged 65 and over, compared to 18% under the age of 16. However, while life expectancy has increased by 2.2 years in the last decade, 'healthy' life expectancy has increased by just 0.6 years. The number of older people living with debilitating conditions, therefore, is rising. For example, there are approximately 750,000 people in England suffering from dementia, representing 1.2% of the population and this is predicted to increase by 15% over the next 45 years (Alzheimer's Society, 2007). Furthermore, older people face a number of particular life challenges that threaten their health and wellbeing. As individuals age, families change structure and disperse and experiences of bereavement become more common, leading to increasing social isolation and loneliness.

In recent years, therefore, there has been an increasing emphasis on how to ensure the highest quality of life for older people with debilitating conditions, in addition to providing high quality treatment and care (for example, Department of Health, 2009; Kitwood & Bredin, 1992; Banerjee et al. 2009). At the heart of this is the National Dementia Strategy (NDS) (Department of Health, 2009) which aims to help people with dementia and their significant others *'to live well with dementia, no matter what the stage of their illness or where they are in the health and social care system'* (NDS, 2009; p.21). It states, *'dementia is not an immediate death sentence; there is life to be lived with dementia and it can be of good quality'* (Department of Health, 2009; p.29). More recently, the Coalition government began developing the cross-government 'Big Society' policy programme (HM Government, 2010), which states that the government aims to make public services more 'transparent' by making them more diverse and giving people power and control. This is being taken forward, in part, by the implementation of Personalisation, whereby self-directed support allows service users to tailor their own care and support package to meet their specific needs.

### **Social Prescribing**

'Social prescribing' has the potential to play a key role in improving the quality of life of older people with dementia and their carers. Social prescribing is a mechanism for linking people with non-medical activities or sources of support within the community (Friedli 2009), thereby offering alternatives to clinical provision or medication. Social prescribing activities may involve opportunities for arts and creativity, physical activity and learning new skills, or support with employment, benefits and housing, for example. Social prescribing has been used for people with mild to moderate mental health problems and as a route to reducing social exclusion for disadvantaged, isolated and vulnerable populations (Bates 2002; Gask et al. 2000). It has been shown to provide a range of positive cognitive, emotional and social benefits (increased mood, self-esteem, optimism and confidence; improved cognitive function; and, increased social networks, contact and sense of belonging) and is part of a wider recognition of the influence of social and cultural factors on mental health outcomes (Brown et al 2004).

### **The Impact of Participation in Creative Activity on the Wellbeing of Older People**

A growing body of medical evidence which advocates the positive impacts of the 'arts' (in all its diversity) on the health and wellbeing of older adults, including those with dementia and their carers. Staricoff's (2004) comprehensive review of medical literature highlighted the contribution of the arts to positive physiological and psychological changes in clinical outcomes; reducing drug

consumption; shortening length of stay in hospital; promoting better doctor-patient relationships; and, improving mental healthcare. Basting (2006) provided examples of the power of creative expression in the lives of people with dementia and their families and research by Hannemann (2006) found that creative and art therapy may be effective in sharpening the capacity of the senses of older people, thereby influencing wellbeing. Different art forms have also been shown to have different effects on patient health. For example, the use of literature, creative writing and poetry in mental health services is argued to produce significant benefits for both the patient and the care provider. Theatre, drama and visual arts all provide patients with powerful ways of expressing themselves and understanding their own world. This promotes empathy between patients and staff. Music, singing and dancing all help mental health patients to recall events from their lives. These art forms help them to express themselves and, on a physical level, to increase their range of movement. Indeed, 'arts therapies' are increasingly being employed by NHS Trusts as part of mental health services. It should be noted, however, that provision remains patchy (Mind, 2011).

Social science research also suggests that creative activity can have a positive impact on wellbeing. A groundbreaking study by Matarasso (1997) demonstrated improvements in wellbeing as indicated by: enhanced motivation, greater connectedness to others, a more positive outlook and a reduced sense of fear, isolation or anxiety. These benefits were brought about by the opportunities that engagement in art afforded for: self-expression, an enhanced sense of value and attainment and pride in achievement. Friedli's review of the literature (2007) found that arts activities improved wellbeing by: improved self-esteem; enhanced motivation; more positive outlook; greater sense of meaning; improved quality of life; reduced sense of fear, isolation or anxiety; and, greater social contact and participation. A recent review of the evidence-base regarding the impact of the arts on older people (2010), by Mental Health Foundation concluded that for older adults with dementia, participatory art can help improve cognitive functioning, communication, self-esteem, musical skills, pleasure, enjoyment of life, memory and creative thinking, by providing opportunities for meaningful social contact, friendship and support within the art groups themselves, as well as improving relationships between those living in care homes. It concluded that there is significant potential for participatory art to improve the quality of life of older people in general as well as those older people who are most excluded including those with dementia, those who are socially and economically disadvantaged.

Various 'arts on prescription' schemes are in operation. Evaluation of the Stockport Arts on Prescription scheme showed a moderate impact on self-esteem and social functioning. However, the increase in involvement in social activities, particularly participative activities, was found to be statistically significant, with some evidence that the use of GPs, social workers and other services was reduced (Huxley, 1997; Health Education Authority 1998; Tyldesley and Rigby, 2003). A further case study on people referred to arts activities by health and social services found that participants used in-patient and other hospital services less often and that the risk of relapse was reduced (Department for Culture, Media and Sport, 1999).

Participatory arts activities can be extraordinarily effective at drawing in people with no previous intention of becoming involved. Matarasso (1997) suggests that *'it is one of the qualities of the arts that the idea does not seem a frightening prospect to take on. It is an approachable way of getting people involved in community activities and the difficult elements are easily offset by the excitement, the social contact and the sense of achievement derived from participation'*. (p. 69) Studies have also found that, unlike simply focusing upon material and environmental circumstances in the quest for personal development, artistic interventions have the added advantage of *'being largely immune to the effect of adaptation (the 'novelty' wearing off)'* (Marks & Thompson, 2006). Most importantly, however, theorists argue that art is different from other activities because of the quality of the experience. Art is suggested to be a unique form of communicative experience which takes as its

subject the whole of human experience and that engages an individual with that experience at the emotional, intellectual and aesthetic level. Dewey argues that the greatest social impact of participation in the arts arises from its ability to help people think critically about and question their experiences and those of others, with all the excitement, danger, magic, colour, symbolism, feeling, metaphor and creativity that the arts offers. It is in the act of creativity that empowerment lies and through sharing creativity, that understanding and social inclusiveness are promoted. It is the opportunity to get involved in and indeed, to define, what matters that motivates people, transforming them from passive consumers of culture and social policy into engaged participants in arts projects and, by extension, in society (cited in Matarasso, 1997: p. 89-90).

The growing evidence-base regarding the positive impacts on the arts on wellbeing are beginning to have an impact at the policy level. Various policy documents, in recent years, have recognised the need for a broader range of services to support older people. For example, under New Labour, in *The Case for Change* (2008), the Department of Health described the social care system as, '*the activities, services and relationships that help people to be independent, active and healthy – as well as able to participate in and contribute to society – throughout their lives*' (DoH, 2008:13). This description went beyond 'care' and 'services'; implying the need to deliver support and care that older and disabled people need to live fulfilling lives (Yeandle, 2009). In 2005, in *Opportunity Age*, New Labour presented a new vision for social care in England, with 'independence' and 'choice' as key messages (HMG, 2005). In England '*Building a society for all ages*' (2009) recognises the positive role of culture and leisure in the lives of older people, but does not commit to increasing access to creative activities in its programme of work. Similar documents have been produced in Scotland, Wales and Northern Ireland. Furthermore, Arts Councils across the UK have begun to advocate the value of the arts in promoting the wellbeing of older people, with Northern Ireland, for example, launching a £700,000 'Arts and Older People' Programme (Arts Council for Northern Ireland, 2011).

Across the UK, the 'unmet needs' of older people have been recognised by community groups and voluntary organisations. These projects form part of the complex mix of support services, often identified as 'low level services' that fill the gaps between specialist and universal public services (Manthorpe et al, 2004). These small-scale local services appear to be particularly innovative, especially in responding creatively to the importance older people attach to support to care for themselves, rather than being recipients of care (Clark et al., 1998). Indeed, many older people perceive the services as 'help' rather than 'care' (ibid.). Research warns us not to underestimate the older consumer – older people, particularly those in the younger age brackets, are sophisticated consumers who do not want to be 'targeted' as old (Scottish Arts Council, 2010). Levels of funding are generally low. Few projects tend to secure a significant amount of funding and participant costs are typically very low or free. Although most projects are small-scale, they appear to work (Scottish Arts Council, 2010).

### **The Measurement of Impact**

Although there is currently a wealth of anecdotal evidence to support the case for the arts, the processes of capturing value are not yet able to fully reflect the complexity and interplay of impacts arising from engagement (Holden, 2006). Within clinical settings, the preferred focus may be on assessing effectiveness in terms of reduced symptoms or improved mental health scores. Increasingly, however, there is a case for complementing this focus with broader measures such as quality of life and social inclusion. Such measures are inherently difficult to define, however. For example: The concept of 'quality of life' has been described as '*confusing, elusive, controversial and lacking clarity*' (Ettema, 2005) and as yet, there is no agreed definition. The concept is based around the individual and their circumstances and includes factors such as their expectations (Selai, 2001), values (Liu, 1976), psychosocial well-being (e.g. coping styles, social comparison and stigma), impact of stigma and the changes in function as a direct result of the dementia itself (Williamson, 2010).

There are 3 ways of approaching the assessment of an individuals' quality of life (Williamson, 2010): Objective measures by others, such as carers, through methods including observations and questionnaires (e.g. Kitwood & Bredin, 1992); Subjective measures by the individual with dementia, such as self-reporting through interview (e.g. Trigg et al. 2007) or within psychotherapeutic approaches towards dementia, such as Validation Therapy (Feil, 1989) and Reminiscence Therapy (Gibson, 1994); and, a mixture of the two measures, establishing conclusions based on self-reports, observations and any other relevant evidence (e.g. Smith et al. 2005a) or approaches such as 'the partnership approach' (Adams, 1999). There has been much debate over which approach is most reliable and valid when assessing quality of life, particularly when the individual is affected by a progressive condition such as dementia. It has been assumed in the past that people with dementia are inherently unreliable, too confused or too out of touch with reality to be considered as valid respondents (Cotrell & Schultz, 1993; Goldsmith, 1996). Indeed, there are issues to consider when trying to gain a subjective account from people with dementia. Smith et al. (2005b: p8) summarised the issues as follows:

- Memory problems in generating accurate self-assessment.
- Problems with maintaining attention/focusing on the assessment approach.
- Lack of insight. Some people are unaware of their impairments or may deny/minimise them.
- Language disorders (often a symptom associated with dementia) can limit full discussion.
- Impaired capacity to make judgements can make the person unable to produce valid judgements on quality of life.
- Accurate self-assessment may be compromised by challenging behaviour, such as agitation or anxiety.
- The progressive nature of dementia suggests that the nature of quality of life, and therefore the means to assess it, is likely to vary over time.

However, while the above issues are important, steps can be taken to compensate for or overcome them and indeed, the exclusion of people with dementia in research ignores variability in their communicative abilities and fails to recognise their ability to provide accurate reports of their current situation (Cotrell and Schulz 1993; Feinberg & Whitlatch, 2001). Various research studies have successfully ascertained quality of life information from people at all stages of dementia (e.g. Grut et al., 1993; Kiyak, Teri, & Borson, 1994; Teri & Wagner, 1991; Logsdon et al., 1999; Hoe et al., 2005; Trigg et al., 2007; Vigurs, 2009). In addition, there has been a recent increase in the involvement of people with dementia in healthcare policies and recommendations, including the NDS (2009). This suggests that the previous stigma of people with dementia being unreliable or too confused to provide their own views is becoming a fading issue.

When comparing observational reports from professionals such as carers to self-reports from the person with dementia, some studies have found that the perception of quality of life between the two differs. These differences of opinion raise concerns over whose responses are most accurate. It could be argued that differences between carer and service user opinion occur due to the person with dementia having a lack of insight into their own quality of life (Naglie et al., 2006). This could explain why the gap in agreement widens as the dementia becomes more severe. However, according to different 'Stages of Dementia' scales, lack of insight does not usually occur until the individual is at a moderate stage of the condition (Alzheimer's Association, 2010; Wallace, 2010), therefore enabling them to participate in reasonably accurate assessment regarding their views at the earlier stages of the condition. Indeed, Thorgrimsen et al. (2003) conducted a study involving focus groups for service users and relatives and concluded that there may be an increased loss of insightfulness as the condition progresses, but some insightfulness was still found to be intact during

focus group sessions and Byrne-Davis et al. (2006) found that people with moderate to severe dementia were able to talk about quality of life in meaningful ways.

Finally, another key issue is whether the same quality of life measures apply to dementia sufferers and the general population. Whilst debate is ongoing, Banergee et al. (2009), Ready & Ott (2003) and Ettema et al. (2005) recommend dementia-specific measures over generic ones on the grounds that generic measures assess physical illness not related to dementia and may miss key aspects.<sup>7</sup>

### **Research involving Older People with Dementia**

When working with someone with memory and/or communication difficulties (such as those faced in dementia) to assess quality of life, a number of issues need to be considered. Smith et al. (2005) provided a useful summary of some of the key issues (outlined above) which may impact upon the style and quality of interviews. Below are their thoughts on how these issues can be minimised.

**Memory problems:** Questions should be clear and concise, phrased in simple terms and asked one at a time to make them easier for participants to remember. Interviewees can be helped to remember their past through the use of visual images or items that may be important to them.

**Problems with Maintaining Attention:** If an interviewee becomes tired or restless, the interview should be paused and resumed at another time (providing the interviewee would prefer this). The interview will only focus on aspects that are important to the individual. This should help to maintain their interest.

**Lack of insight:** As stated previously, visual aids can be used to aid recall but a lack of insight into their own condition could mean that the interviewee responses are inaccurate. Therefore, carer opinions can also be requested.

**Language Disorders:** Approaches, such as Talking Mats (Murphy et al. 2005), can be used in order to replace the need for the interviewee to be able to speak. The responses gained may not be as detailed as someone with full speech abilities, but the key information can still be gained.

**Impaired Capacity to Make Judgements:** As the carer will also be interviewed where possible, this information can help to clarify any confusion. If the interviewee does not understand the question, it will be repeated or rephrased in a calm and patient manner. The interviewer should listen to their story and avoid correcting, interrupting or speaking on behalf of the person. If a participant's answer is unclear, the interviewer can ask for clarification or repeat what they have understood for confirmation.

**Variation in Quality of Life over Time:** In the long term, the interview tools can be used again and again in order to assess any improvement, which will also highlight any anomalies and reduce the possibility of conducting the interview on an 'unusual' day.

**Word-finding Difficulties:** The interviewer should be patient and encouraging throughout the interview, and should not correct any mistakes. General conduct during the interview should also include showing an interest in what the person has to say, encouraging them in a friendly manner so that they feel comfortable, and generally speaking slowly and clearly.<sup>8</sup>

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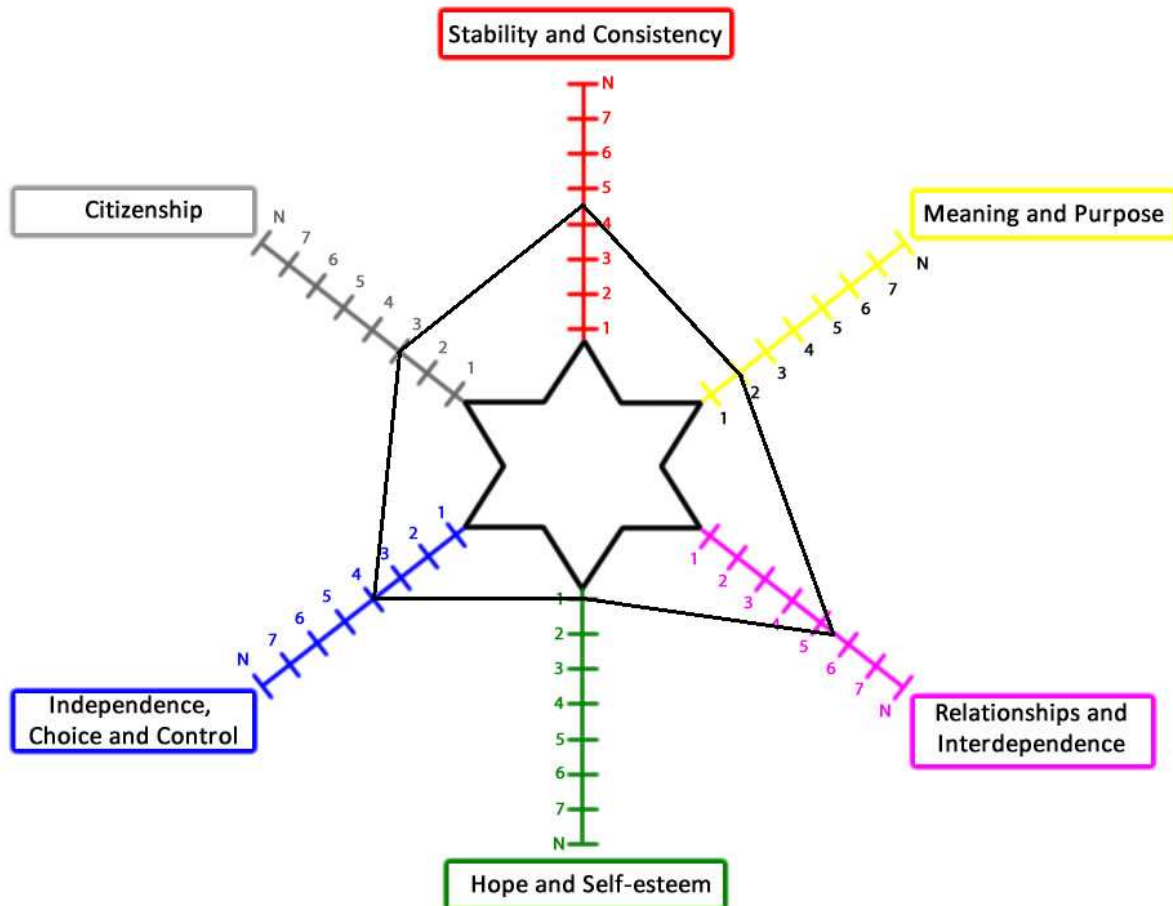
<sup>7</sup> This section was drawn from Johnson, V. (2011) 'Person Centred Outcomes: Assessing and measuring outcomes in quality of life for people with dementia', Mental Health Concern, Newcastle University and Gateshead PCT.

<sup>8</sup> As above.

In addition to problems linked to dementia, it is likely that older people will be suffering from a range of physical and motor conditions which may impact upon their ability to participate in assessment approaches. This may include: poor eyesight, poor hearing, eye-hand co-ordination and the ability to hold objects. Any tools used with this group must reflect the capabilities of interviewees and be sensitive to needs. It is also likely that older people, particularly if suffering from dementia or if they are socially excluded, may lack confidence. It is important, therefore, that assessment takes place at a venue which is familiar to the interviewees and effort is made to make the interviewee feel at ease.

# My Outcomes Assessment

Name: William  
Date of Assessment: 08/09/11  
My signature: \_\_\_\_\_



## Key points from my assessment

N lives with his wife and has been her full time carer since 2006. He has two daughters who help him with things such as housework and emotional support and they visit often.

N feels quite trapped at the moment – he would like to get out more and appreciates peace and quiet as he has what sounds like a growth on his brain that gives him frequent headaches.

N hopes to get some personal space through attending the group as well as meeting more people and making friends.



**Things that are important to me**

My wife. She's 84 this month and she has an aneurism, osteoporosis, cataracts, deafness, asthma and COPD. I help as much as I can – I'm her carer and have been since 2006 when she had the aneurism. About 2years ago she fell down and broke her leg. I looked after her for 7 weeks. Our daughters help out with things like changing the beds. Then she had sciatica for 20 weeks. But now she's finally out of the woods and seems ok which is really nice.

A couple of weeks ago I was given the all-clear from getting MRSA as well so it's been quite tough lately.

**The support I get at the moment includes...** (e.g. getting out and about, emotional support, support with household tasks, help with finances etc.)

My two daughters come. One nearly every day and the other comes as much as she can because she works. It's a bit of emotional support and they help around the house.

I do the shopping and take my wife on a Saturday.

Everybody helps – it's a team effort.

**My support could be improved by...**

Well it couldn't really. I'm happy with the help from my daughters.

**If someone gave me money to spend on improving my life, I would spend it on... (e.g. activities, support, equipment, improving my house)**

A new house – a nice little bungalow. I've got a flat at the moment with 4 of us in it and we've had a bit of trouble with one of the couples that lived there. A young girl lives there now with her 7 year old son which is fine at the moment because she keeps to herself and we have no trouble from the kiddy. But I feel as though I'm locked in all the time in the flat and would have more space in my own bungalow.

**What do I hope to get out of attending the group?**

A little bit of space. I go out once a week on a Monday with my wife to the pub and that's it then for the week. I'd like to meet more people too.

## Meaning and Purpose

“A reason to get up in the morning” – things that motivate me, satisfaction with activities, ways of improving these and why these things are important:

**Activities/places to go:** things enjoyed, things missed (and barriers – why stopped?), any new things I would like to try, where I like going, whether I would like to go out more

**Good feelings:** things I do that make me happy, things that give me a sense of achievement/pride

**Changes:** what has changed with these things as I have got older? Is there anything I used to do that I'd like to do again? Do I need any help with that?

### How are things now?

I used to like walking when we used to go away. We used to go to Portugal for 6 weeks and several weeks in Benidorm. I used to love swimming as well but with the wife I just don't have the time. We haven't been away for 9 years.

I'm 83 now so there's not much more that I can do \*laughs\*. But if I was asked if I wanted to do something I would give it a go.

I love peace and quiet – it makes me happy. I have something in my head that the doctors say I've had for about 20 years and it can't be operated on. But the noise bothers me.

### How do I want them to be?

I'd like to be able to go on holiday and get some space.

I want to keep in with the peace and quiet as noise really bothers me.

### Other comments

## Relationships and Interdependence

**People around me:** relationships with people in my life (family, friends, neighbours, professionals) and how satisfied I am with them. Ways of improving or keeping these relationships going.

**Important people:** The most important person/people to me (and why), whether I see them enough, how I rely on them, how they rely on me

**Social contact:** do I see people enough? Do I enjoy chatting with or meeting people? How important this is, how I like to be around people (at home, in a cafe, one-on-one, group, new people), any times of loneliness, any communication difficulties or other barriers.

**Pets:** whether I have any/want any, their importance and why. Do I see them enough?

**Changes:** what has changed with these things as I have got older? Is there anything I used to do that I'd like to do again? Do I need any help with that?

### How are things now?

I see the one daughter every day. They have coordinated themselves to go away one at a time so that they can help with the wife.

Nearly all of my friends have died. I have one friend up at the club who I see once a week. I'd like to make new friends.

The wife is deaf so she doesn't really hear what I say.

I'm not really bothered about seeing my neighbours but I'd like to make more friends.

### How do I want them to be?

I would like to make more friends – possibly though coming to this group.

Otherwise I'm happy with my family – they are very supportive.

### Other comments

## Hope and Self-esteem

**Hope:** my feelings about the future, could I be more hopeful?, what I would like to avoid happening, things I'm looking forward to, do I have wishes or plans?

**Self-esteem:** things that are good in my life. Do I feel relied upon or important to someone else? Do I feel confident? How could my confidence be improved? What things do I do that make me feel good? (going for a walk, having a cup of tea, having a bath)

**Changes:** what has changed with these things as I have got older? Is there anything I used to do that I'd like to do again? Do I need any help with that?

## Independence, Choice and Control

**My home:** Do I do any housework? (cleaning, washing up, washing clothes, cooking, shopping, gardening, DIY). How is my medication managed?

**Myself:** would I call myself an independent person? In what ways am I independent?

**Changes:** what has changed with these things as I have got older? Is there anything I used to do that I'd like to do again? Do I need any help with that?

### How are things now?

My wife said that she fancied going on a cruise so my daughter went to Age Concern to ask about the insurance and they said that I'm uninsurable so she didn't even ask about my wife. They said it's because I'm on 6 different kinds of tablets. So even though I can take care of myself and my wife they won't let us go away. We just wanted to stop on the boat. I think I am independent. I look after myself and my wife most of the time. We help each other with the cooking and I make the bed. The house is well designed for her. We've got lots of equipment to help her.

### How do I want them to be?

I'd like more freedom and space.

### Other comments

A very crucial domain for N. Throughout the interview he kept mentioning feelings of being trapped and wanting more space and more freedom.

## Citizenship

**My community:** do I feel a part of the community? In what way? (neighbours, local group, cafe, pub, church, community services)

**Changes:** what has changed with these things as I have got older? Is there anything I used to do that I'd like to do again? Do I need any help with that?

### How are things now?

I don't really feel a part of the community. I'd like to be more involved which I think the group will help with that. I'd like to be more involved.

I think I've spoken to my neighbours about 10 times in 20 years. They just keep to themselves. One of them is just a waste of time.

### How do I want them to be?

I'd like to move house to a bungalow with good neighbours and more space – where we don't have to share a flat with people that I don't really talk to.

### Other comments

## Stability and Consistency

**Lifestyle:** How would I describe my typical day? (routines and habits)

**Home:** What makes me feel comfortable or "at home" wherever I go?

**Changes:** what has changed with these things as I have got older? Is there anything I used to do that I'd like to do again? Do I need any help with that?

### How are things now?

When I was away I've always felt at home. But at the moment I'm just frightened of someone making a noise. I've got this headache all the time.

When we lived in our other place I used to feel at home but then they played football outside and it was too noisy so we moved. So I said I wanted to come here.

We've been where we're living for 21 years and before that we lived in our other place for 27 years. So we get very settled.

### How do I want them to be?

I would like to move house to a nice quiet bungalow but the wife refuses to move.

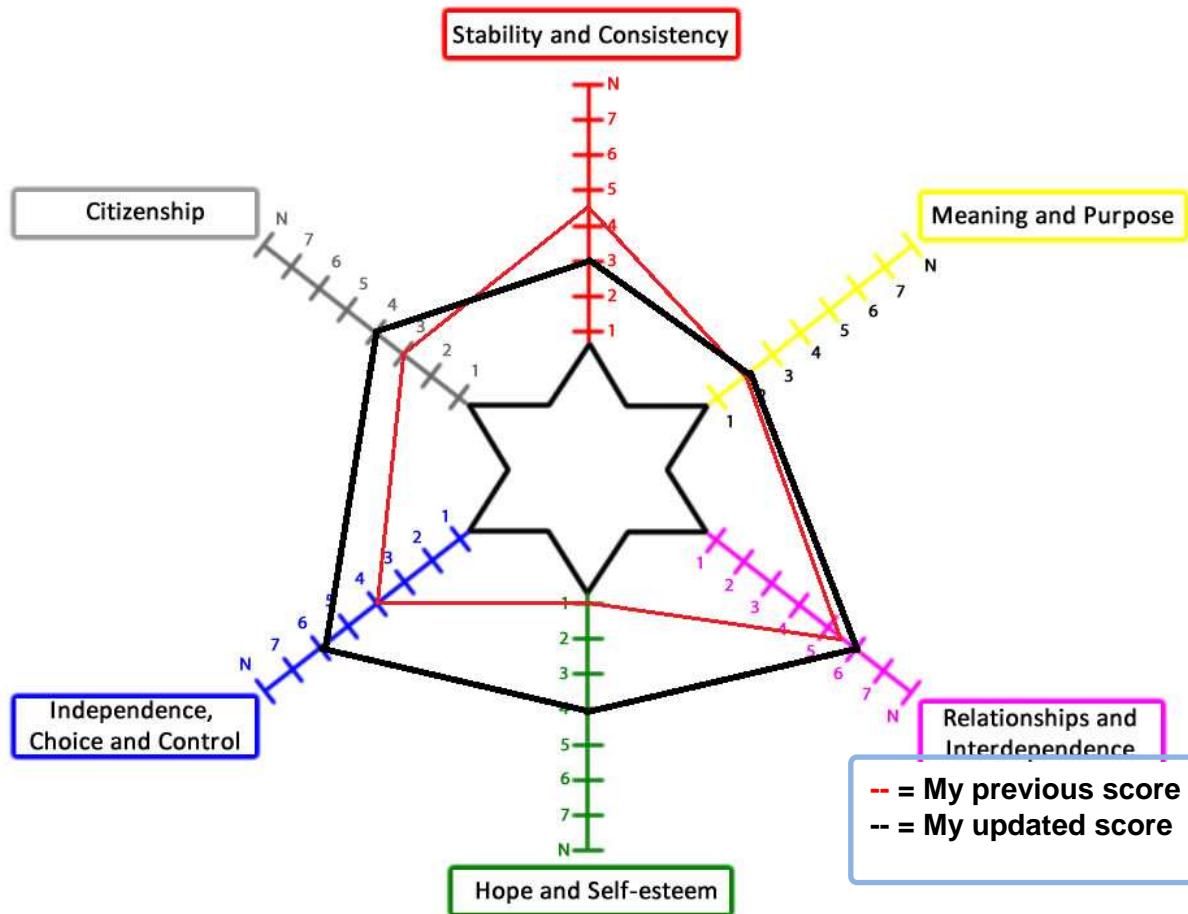
### Other comments

# My Outcomes Review

## What has happened over the past 4 months?

Name: William Date of assessment: 25.11.11

My signature: \_\_\_\_\_



### Key points from my assessment

The only aspect of N's life that has really changed is attending the film club. He really enjoyed going to the club and got on well with the one other gentleman who attended. Attending this group has had a positive effect on N's rating scores.

N has not been well recently and was sorry to miss the last session because of this. It is starting to effect his ability to walk for longer distances.

N would still like to move house as he would prefer a home without a garden due to the upkeep. He would also like to move somewhere with neighbours of a similar age.

**What has happened over the past few months?**

Well it's been a bit better. I'm still not happy living here like, but the wife is so we can't move.

<What has made things better?> Well going to that group was very good. There was only one other man there and me and lots of women. My wife was there. It was good. Last week we went to Beamish. The wife went but I couldn't go as I wasn't well. I had palpitations and it took 4 hours to go away. The wife isn't well at the moment either. She was up at 4am today coughing. She's still suffering with her COPD, aneurism, asthma, cataracts and she's deaf.

**How has this affected me and my life?**

Me being ill mean that I couldn't go to the group, which I'm sad I missed. The people there were more active than the group I go to at Hardman Hall on a Monday, which was nice.

My wife being ill impacts on me. I do most of the things around the house. She does as much as she can and won't sit still though. But when she's doing it she's always out of breath. She's getting there anyway.

**How would I like things to be?**

I'd like to go to another club again.

I'd still like to move but it looks like we're staying here as the wife likes it here.

When I go to the Hardman Hall group, it would be nice to have a bit more activity. The film club was great.



## Summary of my previous and new scores

### Meaning and Purpose

Score before:	Score after:	Reasons for any changes
2	2	I enjoyed going to the group – especially the film about Gateshead. I'd like to do that again. We go to Hardman Hall every Monday. We get picked up and dropped off. It's alright but it's not my cup of tea as people there aren't active at all. They just sit there.

### Relationships and Interdependence

Score before:	Score after:	Reasons for any changes
5.5	6	I got on really well with the other gentleman (Ken) who went to the film club. The wife enjoyed it as well. It would have been nicer to have more men there as I felt a bit lonely when Ken didn't come.

### Hope and Self-esteem

Score before:	Score after:	Reasons for any changes
1	4	I would look forward to having another group to go to as I enjoyed the one that's just finished. We're going to a party with Hardman Hall at Christmas so we're looking forward to that.

### Independence, Choice and Control

Score before:	Score after:	Reasons for any changes
4	6	I've had a bad stomach for over 40 years and it's getting worse now. I walked down the street the other day and had to come straight back. I do most things around the house because of the wife's health but she still helps and doesn't sit still.

### Citizenship

Score before:	Score after:	Reasons for any changes
3	4	Our neighbour above us has a young son but they're still no bother, Much better than the last couple who were there.

### Stability and Consistency

Score before:	Score after:	Reasons for any changes
4.5	3	It would be nice to move house – that's an issue for me. I want to go somewhere with people similar to us but the wife likes it here and doesn't want to move so we're staying put.

**Additional Notes**

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## Appendix C: MHC Breakdown of Participant Scores and Key Narrative Explaining Scores

### Participant 1

Domain	Score before	Score after	Difference
Meaning and Purpose	6	6.5	+0.5
Relationships and Interdependence	6.25	6.5	+0.25
Hope and self-esteem	5	5	0
Independence, Choice and Control	4.5	5	+0.5
Citizenship	6	6.5	+0.5
Stability and consistency	6	6.5	+0.5
<b>Total</b>	<b>33.75</b>	<b>36</b>	<b>+2.25</b>

#### **Before the group**

I'm happy with my life but am interested to see what's around the corner. I need something to do to replace what I can't get on with anymore (arts etc.). Both of my hands are painful now which makes it harder.

<What do I hope to get out of attending the group?> It's curiosity really. I understand that it's creative films which sounds interesting. I don't get many visitors – I see my granddaughter once a year. I'd like to see some of my friends more often. I have one friend who can't travel to see me and would like to go and see her more. I do rely on people if I want to go out because I have fallen all over the place. I would like to be able to do the things that I used to do, such as the arts and going to church.

#### **After the group**

I have been going to the film club for quite a few weeks. The group has come to an end. I missed one I think. With the group, we didn't seem to have done the things that we were intending to do in this place but they seem to have got themselves really organised now. I met different people and they do things that get you to remember the person's name. Of course we would all forget but doing that was nice. It was a nice little group. One lady was very nice but there was a film that we were watching about Newcastle and the art gallery and she talked over it so I missed it! I enjoyed learning about what's happened with Newcastle and Gateshead. The first film we watched was an American one and it was awful! \*laughs\*. The acting was poor.

They asked us about our lives and some people's were very interesting. Some people struggled with their memories but when they talked about their past they never faltered. It's quite amazing really. In a sense, it's given me a day out. I'm pleased that I went.

Being on a Thursday, it splits the week up, which is great. I enjoyed meeting people. I don't like being alone. It would have been better if there were people there who were interested in the same things as me. I've been quite happy going to this film club once a week. It has cheered me up. I would try another group in future. Going in the taxi was interesting: seeing all of the places that I hadn't seen before or for a long time.

### Participant 2

Domain	Score before	Score after	Difference
Meaning and Purpose	7	7	0
Relationships and Interdependence	6	6	0
Hope and self-esteem	N	N	0
Independence, Choice and Control	6	6	0
Citizenship	7	7	0
Stability and consistency	4	4	0
<b>Total</b>	<b>30</b>	<b>30</b>	<b>0</b>

### **Before the group**

I like to meet people. I like to be out. I like joining in things. I play indoor boules once a week. I'm a widow so I've got to get out. I've got no close family – my cousin is the closest and I go to her. I have one close friend who I've been close to since 1946 but she hasn't been well lately. I don't really make plans and go with the flow. I do get frustrated at times. I think most women do as you don't always have someone to talk to. I'm generally happy with the way things are.

<What do I hope to get out of attending the group?> It's just nice mixing in with people and talking about old times.

### **After the group**

Nothing much has happened really. I've just been getting on with things as I've been doing for a while. I went to the film club and enjoyed it. They were very nice people. I'm quite busy anyway so me going to the film club was enjoyable but didn't change much as I've got other things to fill my time.

If there were more new things to try I would give it a go, but it would depend on the time and day as I'm quite busy. I especially enjoyed the film shows they put on. It filled time and was something different. I wasn't keen on the exercise where we threw the rubber balls but other than that it was good. I liked spending time with the people at the group as they were nice.

I'm still going and visiting my relatives and friend. I'm a mixing person so I like to have the company. I just want to carry on as I am – keeping busy and seeing people. Friends usually invite me out so I just paddle along and go if that happens.

### **Participant 3**

<b>Domain</b>	<b>Score before</b>	<b>Score after</b>	<b>Difference</b>
Meaning and Purpose	6	6	0
Relationships and Interdependence	6.5	6.5	0
Hope and self-esteem	7	6	-1
Independence, Choice and Control	7	7	0
Citizenship	6	6	0
Stability and consistency	6.5	6.5	0
<b>Total</b>	<b>39</b>	<b>38</b>	<b>-1</b>

### **Before the group**

I'm fortunate to still be able to get out and about more than other people can. It's important to me to be able to get out and about and get outside and get out walking. My family and that have all got their own jobs and things. I do see them. I have friends – one in particular called D who lives in my building and is going to come to the film club.

<What do I hope to get out of attending the group?> Just to enjoy coming and get opinions on things and seeing what everyone's up to. What I'm doing makes me happy – getting out and about and the fact that I can still do that because I'm lucky to be able to do that. I don't feel very confident in myself. It could be improved although I haven't a clue how. If I knew that I would have done something about it by now \*laughs\*. I think I'm a fairly independent person. I just get on with my own thing regardless. I go to meetings in this building. I wasn't going to at first but then I wanted to find out what's going on. I get there eventually on some bits of it.

### **After the group**

My dog died but other than that not much has happened. I have been joining in with odd things at home. I went to the film club a few times to see what was happening and meet the people. I enjoyed

going to the club. I don't remember much of it but what I do remember I liked. I missed the last couple of times I think as I was busy.

I miss having a dog but I still make sure I got out walking as long as the weather is good. It's definitely more incentive to go out walking when you have a dog though. I would be happy to join in on other clubs in future, depending on what they were and when they were on. There's always new people about here (where I live), so it's nice to meet them. If I could get a dog, I would really look forward to that. Otherwise, I just take each day as it comes and enjoy what I'm doing at the moment: getting out and about and meeting people.

#### **Participant 4**

<b>Domain</b>	<b>Score before</b>	<b>Score after</b>	<b>Difference</b>
Meaning and Purpose	5	6	+1
Relationships and Interdependence	7	7	0
Hope and self-esteem	N	N	0
Independence, Choice and Control	4	4	0
Citizenship	4	5	+1
Stability and consistency	4	4	0
<b>Total</b>	<b>24</b>	<b>26</b>	<b>+2</b>

#### **Before the group**

*IG's narrative:* I get support from my son. I live with him. He keeps me company. My son and daughter take me out shopping. I have 3 children – 2 daughters and a son, as well as 2 grandchildren. They're trouble! I have too much family. I can't afford them \*smiles\*.

*IG's son's narrative:* More stimulation would benefit my mum. <What do I hope to get out of attending the group?>Getting out of the house and having more stimulation, which my mum would benefit from. We seem to sit and watch television together a lot. It's just me and her in the house. We go out for family meals. Mum is very reliant on me so the group will be a learning curve for her, which is why I'm going with her for the first visit and maybe more. Mum gets visits from local friends and her daughter. She doesn't go to any other clubs.

#### **After the group**

*IG's son's narrative:* Mum went to two film club sessions. I went with her to both of these because when she is on her own, she always tries to leave. Mum has been ill over the past couple of months and so only went to a couple of sessions. Even though mum missed a lot of the sessions through being ill, I think that she benefitted from getting out of the house. It's good that she has had that extra bit of stimulation. Mum wasn't very talkative – I think I did more of the talking – but it's good for her to see other people.

#### **Participant 5**

<b>Domain</b>	<b>Score before</b>	<b>Score after</b>	<b>Difference</b>
Meaning and Purpose	1	3	+2
Relationships and Interdependence	1.5	4	+2.5
Hope and self-esteem	2	5	+3
Independence, Choice and Control	5	5	0
Citizenship	3	3	0
Stability and consistency	3.5	3.5	0
<b>Total</b>	<b>16</b>	<b>23.5</b>	<b>+7.5</b>

### **Before the group**

<What do I hope to get out of attending the group?> Just to get out of the house. That's all. Living here is sheer boredom. We're very bad at walking and can't really get out. We go to Victoria House every Friday. We (my wife and I) don't have any friends. It's just the two of us. We've been together over 50 years. My grandson visits now and again. I am a chatterer and will talk to anyone and I don't really have many chances to chat so that would be nice. Where I am now, there is nothing to look forward to at all. It's sheer boredom. It would be better if I didn't have painful legs. They do slow me down.

### **After the group**

I've still not been sleeping well lately but I sometimes get these black moods where I just sleep now. We go down to Stockton on a Wednesday which we enjoy. We've got plans for Christmas – we're going to Farley to see the baby. I'm looking forward to Christmas now. My son who I've not seen for 30 years came round the other week.

I went to the music club a couple of times and it was alright. If there was a photography group starting I'd definitely give that a go. At the music group I would have liked more people like me to be there but it doesn't really matter.

They asked us to go to the group but I don't fancy singing at 10.30 in the morning \*laughs\*. It's nice to visit but there were a couple of people in wheelchairs who were really bad and it got to me...you couldn't have a conversation with them. I met some new people at the group. I chatted a lot when I was there and got on well with some people but I felt that it was a bit false at times.

We've applied for a council flat to get out of here as we can't handle the garden. We're waiting for the paperwork now. It's dead here. We want to be in the middle again where the shops and other people our age are.

### **Participant 6**

<b>Domain</b>	<b>Score before</b>	<b>Score after</b>	<b>Difference</b>
Meaning and Purpose	5	5	0
Relationships and Interdependence	6	6	0
Hope and self-esteem	5.5	5	-0.5
Independence, Choice and Control	6	5	-1
Citizenship	6	6	0
Stability and consistency	6	5	-1
<b>Total</b>	<b>34.5</b>	<b>32</b>	<b>-2.5</b>

### **Before the group**

I see my family quite often – my son visits 3 times a week, I see my daughter at least once a week, and my granddaughter lives a couple of streets away so I see her quite often too. We go out shopping and for dinner. I love my sports – I watch them all of the time on the tele. Normally, I would love to do the garden but for the first time ever I have had to pay someone to do it for me because my arms and wrists just don't have the strength. It would be nice to be busier but I'm not moaning that I'm really bored.

<What do I hope to get out of attending the group?> Just general friendship and being introduced to other people. To share stories and possibly enlarge upon them \*laughs\*.

A large part of my life was going to the pub after work. I miss that.

### **After the group**

Well I've had a fall recently and hurt my left side and back so I now have nurses coming in 3 times a week to check me over. My fall has stopped me from getting about as much but I get more visitors in the nurses which is nice. I also enjoy the people visiting to give me my memory pill. They're like

friends now and I enjoy them coming for the company. My family still visit – each one once a week. They're marvellous.

The film club I enjoyed. It was a pity that I missed the last 2 through illness. It got me out of the house. The taxi was brilliant! It took me there and back and we had a light lunch to boot. The company – old fogies like me – talked about things like how we used to do our washing 60 years ago \*laughs\*. It was all quite enjoyable. There's nothing I would suggest to improve it. If the club started up again I'd like to go. I'm not ready to go out and about yet though.

### **Participant 7**

<b>Domain</b>	<b>Score before</b>	<b>Score after</b>	<b>Difference</b>
Meaning and Purpose	2	2	0
Relationships and Interdependence	5.5	6	+0.5
Hope and self-esteem	1	4	+3
Independence, Choice and Control	4	6	+2
Citizenship	3	4	+1
Stability and consistency	4.5	3	-1.5
<b>Total</b>	<b>20</b>	<b>25</b>	<b>+5</b>

#### **Before the group**

My wife (is important to me). My two daughters come: one nearly every day and the other comes as much as she can because she works. It's a bit of emotional support and they help around the house. Just getting out of my house is something I look forward to. I looked into moving and the wife refused to move so I'm stuck here now. I don't really feel a part of the community. I'd like to be more involved which I think the group will help with that. I'd like to be more involved.

<What do I hope to get out of attending the group?> A little bit of space. I go out once a week on a Monday with my wife to the pub and that's it then for the week. I'd like to meet more people too. Nearly all of my friends have died. I have one friend up at the club who I see once a week. I'd like to make new friends. The wife is deaf so she doesn't really hear what I say.

#### **After the group**

Well it's been a bit better. <What has made things better?> Well going to that group was very good. My wife was there. The film club was great. The wife enjoyed it as well. I'd like to go to another club again. I enjoyed going to the group – especially the film about Gateshead. I got on really well with the other gentleman (Ken) who went to the film club. It would have been nicer to have more men there as I felt a bit lonely when Ken didn't come. I would look forward to having another group to go to.

Me being ill mean that I couldn't go to the group (for the last session), which I'm sad I missed. The people there were more active than the group I go to at Hardman Hall on a Monday, which was nice. The wife isn't well at the moment either. She was up at 4am today coughing. She's still suffering with her COPD, aneurism, asthma, cataracts and she's deaf.

I'm still not happy living here like, but the wife is so we can't move. It would be nice to move house – that's an issue for me. I want to go somewhere with people similar to us but the wife likes it here and doesn't want to move so we're staying put.

## **Appendix D: User Reported Outcomes relating to the Programme**

### **Participant 1**

- I met different people
- I enjoyed learning about what's happened with Newcastle and Gateshead
- It's given me a day out
- I'm pleased that I went
- It splits the week up, which is great
- It has cheered me up
- I would try another group in future
- Going in the taxi was interesting: seeing all of the places that I hadn't seen before or for a long time

### **Participant 2**

- I enjoyed it
- I liked spending time with the people at the group as they were nice
- It filled time and was something different
- If there were more new things to try I would give it a go

### **Participant 3**

- I enjoyed going to the club.
- I would be happy to join in on other clubs in future

### **Participant 4**

- Has benefitted from getting out of the house
- Has had that extra bit of stimulation
- Has seen other people

### **Participant 5**

- I would be interested in going to more groups
- I met some new people at the group
- I chatted a lot when I was there and got on well with some people

### **Participant 6**

- The film club I enjoyed
- It got me out of the house
- The taxi was brilliant! It took me there and back and we had a light lunch to boot
- I had more company
- It was all quite enjoyable
- I would be interested in going to more groups



### **Participant 7**

- Going to the group has made things better
- The wife enjoyed it as well
- Would be interested in going to more groups
- I enjoyed going
- I got on really well with another gentleman
- It gave me something to look forward to

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