Background information on the Dementia and Imagination research methods
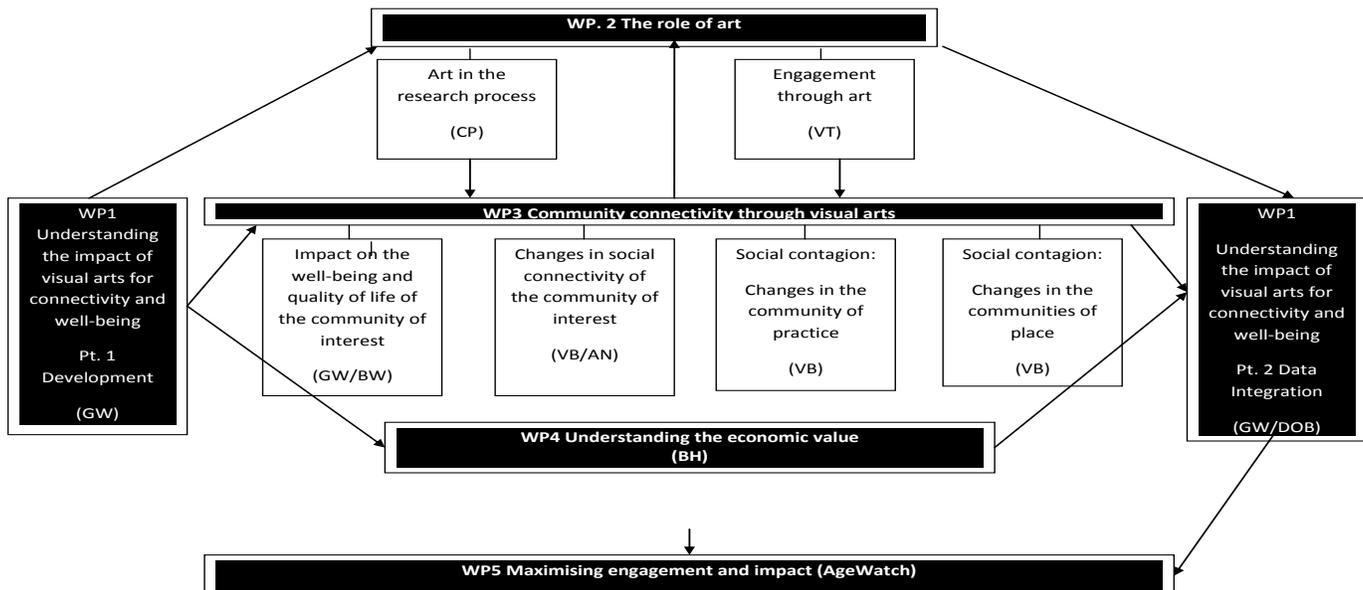
Research questions:
   How can visual arts interventions change, sustain and catalyse community cultures, beliefs, attitudes and behaviours to create dementia friendly communities?

We propose to elucidate this by addressing the following sub-questions:

1) What are the underlying processes of an effective, sustainable and socially engaged visual art programme that improves connectivity, promotes meaning and enhances well-being?

2) Can changes in community connectivity be demonstrated through participation in, or connections with a visual arts intervention?

3) Do different models of delivery, through different venues (cultural and community venues and outreach/satellite services) facilitate different forms of connectivity, potentially influencing well-being?

4) What sort of community links can be facilitated by visual arts interventions and is this influenced by the different research contexts?

5) Can engagement through this research with people with dementia, their carers and stakeholders/community organisations make a central contribution to the creation of dementia friendly communities?

6) How can the value and benefits (and disbenefits) from multi-disciplinary methodological approaches be synthesised and communicated?

7) To what extent can we maximise the impact of the study for policy, practice and research through engagement and dissemination?

8) What is the social return on investment for the visual arts intervention?

The research will be undertaken in distinct stages, with other activity programmed throughout the duration of the study. It consists of 5 inter-related thematic work-packages, each lead by a member of the research team.

	WP1: Understanding the impact of visual arts on well-being and quality of life
Title:	*Part1 –Development of visual arts programme*
Objective:	Production of a theoretically informed visual arts intervention
Led by:	Gill Windle (with Clive Parkinson)
Methods:	A realist synthesis methodological review (Pawson et al., 2004) of published research on the visual arts will be undertaken. A realist synthesis enables an understanding of 'how' and 'why' something might be effective in what context. It is traditionally applied in the health arena of implementation science, and is used for theory development and to facilitate implementation into practice. Qualitative data will be obtained through a) a workshop with stakeholders/artists (up to 40) regarding existing practices and b) a survey of organisations delivering arts based projects for people with dementia, to enable practitioners to use their own experiences and expertise to share understanding of what they feel works best and why, and what was not good practice.
Title:	*Part 2 - Integration:*
Objective:	To integrate the newly produced evidence from each of the other WPs to generate theoretically informed holistic conclusions about visual arts interventions, and the implications for research, policy and practice on the value of arts research.
Led by:	Gill Windle and Dave O'Brien
Methods:	Synthesis of findings across WPs, e.g. link data on well-being to connectivity. Examine the epistemological basis for social policy, interrogating data from the work packages to reflect on this new, multi-disciplinary approach, addressing some of the debates in the arts and humanities such as the lack of robustness (O'Brien, 2010). Together with a full description of the intervention, it will contribute to the practitioner's handbook
	WP2: The role of art
Title:	Part 1: Art in the research process
Objective:	To generate output to ensure the research findings will be more widely understood.
Methods:	Three artists will be embedded across the three research sites. They will be briefed to use their medium to capture their perspectives on the unfolding research process, the impact of the intervention and their concept of a dementia supportive community.
Led by:	Clive Parkinson
Title:	Part 2: Engagement through art
Led by:	Victoria Tischler (with Teri Howson and Michael Baber)
Objectives:	To raise awareness of dementia and challenge attitudes. Sharing work in a range of non-traditional settings will provide greater opportunities for dissemination and public response from diverse communities.
Methods:	Exhibitions of work will be produced in each of the research areas and where possible people with dementia will be in attendance and involved in the organisation.The study plans to exhibit both the art produced and the documented processes in diverse settings including non-traditional spaces, like shopping centres and disused shops. Exhibited arts based research material will facilitate some responsive action research around public perceptions of people with dementia.
	WP3: Community connectivity through visual arts In order to establish whether the visual arts intervention improves community connectivity and well-being, this work package investigates several levels of community (see figure 1) structured in three parts, over specific periods of time. Baseline (T1), follow up (T2) and long term follow up (T3)
Title:	*The impact of the programme on the connectivity and well-being of people with dementia (the community of interest).*
Led by:	Gill Windle and Bob Woods, with Catrin Jones
Objective:	To respond to the identified need for further research to capture the subjective, unique aspects of the experience and meaning of the programme on the well-being of people with dementia (Mental Health Foundation, 2011); compare changes over time in well-being, communication, quality of life, memory, use of medications, receipt of services and self reported health; compare the intervention against a control condition.
Methods:	A within subject design is adopted. This is an experimental framework, with 'control' built into the design, with the participants themselves providing this control, by taking part in the intervention, but also providing data from a control condition. A systematic method of observation will be adopted which enables an examination of the unconscious responses, i.e. those that might not be verbalized during interviews. The participants will be observed in their groups during the intervention, and in the control condition for comparison (e.g. their usual activities, such as sitting in the day room if in a care facility, or an alternative non-participatory activity if in the community).The sessions will be videoed to enable further analysis and validation. Activity will be systematically coded using the Greater

	Cincinatti Chapter Well-Being Tool. Up to 75 participants will be observed at 6 points to assess change over time. The quantitative data (below) will be collected. *Measures:* • Demographic data (e.g. age, gender, marital status,) T1 • Self reported health T1 & T2 • Dementia Quality of Life (DEMQOL: Smith et al., 2007). A 28 (31 for carers) item measure of QoL designed for people with dementia and their immediate carers T1, T2, T3 • Clinical Dementia Rating Scale (CDR; Hughes, Berg, Danziger, Cohen & Martin, 1982) T1 & T2 • Medication use; receipt of services T1 & T2 • Greater Cincinatti Chapter Well-Being Tool (Kinney & Rentz, 2005). Addresses 7 domains of well-being Interest, Sustained attention, Pleasure, Negative affect, Sadness, Self-esteem, and Normalcy)developed specifically to observe the effects of visual arts on the well-being of people with dementia (6 observations). To be completed by a) Care home staff–Newcastle (up to N=25), nurses and care workers –Derbyshire (up to N=25) and carers-North Wales (up to N=25) T1 & T2. • Holden Communication Scale (Holden & Woods, 1995): Assesses a range of social, behaviour and communication variables • Attitudes towards dementia – the Approaches to Dementia Questionnaire (Lintern and Woods, 1996). A 19 item scale that assesses a person's attitudes to dementia, including sub-scales of person-centred and hope.
Title:	*Changes in social connectivity of people with dementia (community of interest)*
Led by:	Ness Burholt and Andrew Newman
Objectives	To ascertain quantitative changes in social resources and loneliness. To understand qualitative changes in connectivity and communication at the micro-level between the participant and formal or informal carer(s) and other network members.
Methods:	Qualitative research (up to n=75 people with dementia and up to n=75 formal/informal carers,T1 & T2) will explore: a) participants' previous engagement with art, using cultural capital as a theoretical framework to guide the analysis. This provides a starting point upon which the complexity of the illness can be layered, enabling changes in arts engagement in relationship to the progression of the illness to be understood). The construct of social capital will be used to aid the analysis of connectivity, as it provides a systematic way of thinking about the qualities of communities (Elliott, et al. 2011). b) The boundary and nature of the community as experienced by the people with dementia themselves (following Murray & Crummett 2010) and how this changes over the time of the intervention. c) The extent to which changes, if any, have been sustained and/or lead to new aspects of connectivity (T3) Measures : People with dementia (up to N=75) • Lubben Social Network Scale (Lubben et al. 2006) 6 items • Emotional and social loneliness(de Jong Gierveld & Tilburg 2006) 6 item scale
Title:	*Social Contagion: Changes in the community of practice*
Led by:	Ness Burholt
Objectives	To investigate contagion dynamics over social networks in a real community of practice which will be of relevance to both practitioners and researchers (Van den Bulte & Lilien 2001; Watts & Peretti 2007). This analysis is based on the notion that (1) social contagion occurs through the community of practice, (2) some practitioners opinions have a disproportionate influence on others (3) the practitioners opinion of the intervention will influence social contagion. Thus, based on analysis, it is hypothesised that social contagion through the community of practice will be moderated by leadership qualities of the practitioner and their positive or negative opinions of the benefits of the intervention (Iyengar et al. 2010).
Methods:	• This WP will combine individual-level data from practitioners involved in the intervention (n=9) on the perceived benefits of the intervention (qualitative), together with demographic data, a measure of self-reported leadership (adapted from Childers 1986),and network data (adapted from Coleman et al. 1966 and Kahn & Antonucci 1980) on discussion within the community of practice. • Semi structured interviews within the practitioners' organisations will collect sociometric data (network centrality scores) on leadership and the processes involved. A "discussion" and a "collaboration" network matrix for each community of practice within each community of place will be identified to identify the unique members. • An email/online survey with all of the identified members of the community of practice (N=50/100) elicited through the network data above will assess the knowledge and/or

	adoption of the visual art intervention with people with dementia.
Title:	*Social contagion: Changes within the community of place*
Led by:	Ness Burholt
Objectives	To investigate contagion dynamics in the wider communities of place, which are the geographic locations in which the interventions are delivered (e.g. residential care homes, art galleries, NHS assessment unit, villages). This analysis is based the same three underlying principles outlined above in the work with practitioners.
Methods:	Interviewees are located in the community of place and selected on the basis of a high level of engagement with the project (compared to others in the community of place). • It will combine individual level data from people (N=9) who are in some way engaged with the project team who are delivering the intervention of the perceived benefits (qualitative), with demographic data, self-reported leadership, and network data on discussion within the community of place. • Telephone interviews within each interviewees organisations (N=30 in each data collection area) will collect sociometric data (network centrality scores) on leadership, and the processes involved. A "discussion" and a "collaboration" network matrix for each community of practice within each community of place (here including the wider community of place beyond the organsiation e.g. the local community) will identify the unique members. • An email/online survey with all of the identified members of the community of place (elicited through the network data above) will assess their attitudes, beliefs and knowledge about people with dementia (using the attitudes measure, N estimated 50/100), again to consider contagion dynamics. These data will be compared to that of the staff. To be completed by all staff who have been exposed to the intervention (up to N=125) T1 & T2. • Attitudes towards dementia – the Approaches to Dementia Questionnaire (Lintern and Woods, 1996). A 19 item scale that assesses a person's attitudes to dementia, including sub-scales of person-centred and hope.
Title:	**WP4: Understanding the economic value**
Objectives:	To develop an economic case for socially engaged visual arts interventions, adopting a variation of cost benefit analysis, social return on investment (SROI), to measure the social environmental and economic costs and benefits.
Led by:	Rhiannon Tudor-Edwards with Carys Jones
Methods:	The evaluative SROI will be conducted in accordance with the principles and methodology set out in the Cabinet Office (2009) guide. The six stages of SROI are summarized as: 1. Establishing the scope and identifying key stakeholders. This will be accomplished through links to the stakeholders identified in WP 3 and 5. A search and review of the literature will also be undertaken to identify similar studies that could provide inputs to stages 2 to 5 below. 2. Mapping outcomes. This principally involves construction of an Impact Map informed by the engagement with stakeholders (as above). The range of costs and benefits to be measured will be identified. 3. Evidencing outcomes and giving them a value. This will be accomplished through links to WP3 (data collected such as: self-reported health and social care service use for people with dementia and their carers; medication use; quality of life), semi-structured interviews with participants), and WP1 (engagement with the art practitioners). These data will provide evidence of outcomes. 4. Establishing impact. This involves calculating the impact through considering: deadweight and displacement (what would have happened without the intervention); attribution (how much of the outcome should be assigned to the activities of other organisations); drop-off (how long the outcomes lasted). 5. Calculating the SROI. Using the data assimilated in the earlier stages to calculate the SROI and conduct appropriate sensitivity analysis. **6.** Reporting, using and embedding. The SROI has the potential to inform public sector commissioning decisions and is compatible with guidance from HM Treasury (2003).
Title:	**WP5 Maximizing engagement and research impact**
Objectives:	To facilitate the impact of the research, knowledge exchange with stakeholders, partners, policy and interested organisations, and engagement with our research communities.
Led by:	Michael Baber, with Teri Howson
Methods:	A programme of engagement and dissemination activities has been planned (see appendix timetable and pathways to impact, WP2 part 2 also feeds into this WP). Age Watch has developed a comprehensive knowledge transfer and communication strategy, on which they will lead the implementation. Building on the development activities we will continue the engagement cycle, working with the community of interest, and more widely, working with our existing community

	partners/stakeholders – our wider community of practice. The engagement events were attended by at least 60 key stakeholders (regional and national) who will continue into this research. Age Watch will establish and manage an interactive website.

Data collection site: lead investigators

Denbighshire	Gill Windle
Derbyshire	Clive Parkinson
Newcastle	Andrew Newman