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Carrying out research across the arts and humanities and social sciences: Developing the methodology for Dementia and Imagination

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Abstract This paper analyses how the methodological approach for a major Arts and Humanities Research Council and Economic and Social Research Council funded project entitled Dementia and Imagination was formulated. This multidisciplinary project brings together the arts and humanities with the social sciences with their different epistemological philosophies and subsequent understandings of research methods. The main objective was to determine how visual arts activities may change, sustain and catalyse community cultures, beliefs, attitudes and behaviours to create dementia friendly communities. This project involves six different UK Universities, fourteen researchers, ten formal partners, seven project artists, three research artists and a large number of civil society organisations. The analysis presents a series of themes that have been identified as influencing the approach taken to develop methods which aimed to speak to different audiences in the social sciences, arts and humanities, policy/practice and public domains. It is concluded that a research project of this type needs to embrace a wide variety of epistemological positions if it is to successfully achieve its objectives. This paper contributes to knowledge about how the methodology of large scale multidisciplinary projects may be constructed which will be of value to those building research consortia across different universities and between universities and community partners.

Introduction This paper explores the process of developing the methodology for a major UK research project entitled Dementia and Imagination. This national project, led by the Dementia Services Development Centre at Bangor University and funded by the UK Arts and Humanities Research Council and Economic and Social Research Council, explores how art might a) improve the quality of life and community connectedness of people living with dementia and b) challenge and change the public perception of dementia. These aims were explored through a series of visual arts activities for people in later life with dementia who were living in different settings. The activities were run by participatory artists

1 http://dementiaandimagination.org.uk/
and delivered in four waves of three months each in the Midlands (National Health Service assessment wards), North East England (residents in care homes) and North Wales (people in later life in domestic environments), with each wave consisting of 12 people with dementia and 12 carers/family members. The methodologies adopted included both social science and arts and humanities approaches. They were as follows.

- Quantitative scales which were used to measure social connectivity, quality of life, communication (at baseline and two time points), classification of dementia (at baseline) and systematic observation of participants (before the activity and twice during the activities).
- Qualitative semi-structured interviews (including open ended questions) were undertaken at baseline and two time points.
- Socio-demographic data was also recorded such as age, profession when working and education.
- At the suggestion of our main community partner (Age Watch) health economics was included. Data was collected to enable a Social Return on Investment (Cabinet Office 2009) analysis to be implemented. This approach calculated the value for money associated with the use of visual arts activities which is of interest to potential funders or commissioners of arts activities for people in later life with dementia, particularly those from Health and Social Care (please see Appendix 1 for the project’s aim and objectives and Appendix 2 for a description the different work packages that were undertaken).
- Visual art was used both as a methodology and as a public engagement tool. Art made by study participants was used to visually describe their experiences and identities, and the places in which the research took place. A series of exhibitions of artwork showcased work made by study participants and aimed to challenge and change attitudes towards dementia. Also three research artists were recruited whose practice was used to explore the process of the research itself.

The project brought together six different UK Universities (Bangor University, Newcastle University, Manchester Metropolitan University, Swansea University, Goldsmith's College, University of London and the University of Nottingham) and a wide range of civil society organisations that have an interest in improving the lives of older people with dementia, such as Age Watch (London), Alzheimer’s Society (London), BALTIC Centre for Contemporary Art (Gateshead), Equal Arts (Gateshead) and engage Cymru.

The project originated from an Arts and Humanities Research Council (AHRC) Research Development Workshop on Communities, Cultures, Health and Wellbeing that was held in Cardiff 19-21 September 2011 (AHRC, 2011). The development phase of the project lasted from September 2011 until June 2012 when

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2 http://www.agewatch.org.uk/
3 https://www.alzheimers.org.uk/site/index.php?gclid=COPU6u_Ylc4CFaoy0wod1thkFKA
4 http://www.balticmill.com/
5 https://equalarts.org.uk/
6 http://www.engage.org/engage-cymru
the final application was submitted. This phase was funded by a small grant from the AHRC and consisted of meetings between the research team and between the research team and various partners. The research group was then interviewed by a funding panel at the AHRC’s offices in Swindon and the grant awarded – the project commenced in August 2013 and is due to finish in February 2017.

In order to complete this paper members of the research team initially provided short written accounts of their contributions to the methodology and then met at Manchester Metropolitan University on the 10th June 2016. At this meeting the primary author of this paper gave a short account of different epistemologies together with their underlying assumptions and then a discussion ensued that identified the rationale for the various approaches adopted which, up to this point, were more implicit than explicit. This was the first time that the research team had collectively reflected on the project in this way, perhaps emphasising how embedded particular methods are within different traditions of research and the challenges of constructing large scale multidisciplinary projects. The resulting conversation was recorded and transcribed with themes identified through multiple readings. The themes were then checked with team members for consensus. This paper was written by the primary author (Newman) with detailed feedback and agreement from the other members of the team (an example of group single-author writing as defined by Lowey et al., 2004). The quotes originate from the written narratives provided by team members and from the meeting held on the 10th June 2016.

This paper makes a contribution to the literature on research methods by analysing how the methods adopted for a major research project were decided upon. It is also of value to those building research teams that aim to address topics that require researchers from a range of disciplinary backgrounds. Firstly, an account of the different possible epistemological positions is given which provides a theoretical framework to think through the range of methods that were adopted. Secondly, the identified themes influencing those methods are analysed and finally a discussion and conclusion are provided.

**Epistemologies** This section provides an account of the different epistemologies that were adopted for the project, namely positivist, non-positivist and those derived from the arts and humanities. As members of the research team had different disciplinary backgrounds they were more familiar with some approaches than others.

As Miller et al. (2008, p. 1) state epistemologies ‘shape how researchers answer questions regarding the validity of knowledge (qualitative vs quantitative etc.), the legitimacy of methods to produce knowledge and the assumptions inherent in particular conceptualisations of the object of study and certain methodologies’. As this study crosses the boundary between the arts and humanities and the social sciences, the approach taken has to satisfy the needs of different academic communities without compromising the extent to which they might not be taken seriously by those different communities. It is also important that the methods satisfy the needs of policy and practice community partners involved in the study who have their own sense of what research is and how it may support their strategic objectives.
Positivist approaches seek to ‘explain, predict, or describe the world in terms of generalizable laws, facts, or probabilistic relations between behavioural constructs and contextual variables’ (Suri, 2013, p. 895). The methods associated with such an approach are mainly quantitative (including validated scales\(^7\)), using statistical analysis of large datasets and possibly randomised control trials\(^8\). In this approach attempts are made to reduce researcher bias as far as possible. While the impact of one variable upon another can be proved or disproved, which is important for some sorts of research questions, as Suri (2013, p. 896) states ‘a drive for universal laws generalizable to all settings decontextualizes the findings to the extent that they can no longer be usefully applied to any setting’. The tools are selected in advance and therefore do not deal with uncertainty or unpredictable outcomes well. However, these methods are attractive to policy makers and practitioners who might wish to identify the efficacy of financial investment in a particular policy initiative as opposed to another.

Other non-positivist approaches are more normally associated with qualitative methods. These include ‘interpretive’, where an objective reality is contested and the ‘world is socially constructed in terms of the meanings we attribute to events’ (Suri, 2013, p. 897). Another method is ‘participatory research’ where ‘individuals and communities construct, understand and change themselves and their local world experientially’ (Suri, 2013, p. 897). Finally critically-orientated research explores and exposes how lives are ‘mediated by classism, racism and sexism’ (Lather, 1992, p. 87). These approaches are more about a ‘voyage of discovery rather than one of verification’ (Bryman, 1984, p. 84). While they allow for deep understanding of different phenomena they are less attractive to policy makers and practitioners as they are unable to provide generalizable conclusions about the relationships between specific variables.

Also of significance to the project are methods that are specifically related to the arts and humanities which are described by Bakhshi et al. (2008) as seeking to ‘understand human experience, agency, identity and expression, as constructed through language, literature, artefacts and performance’. This is aligned with the non-positivist approaches described above but not with positivist ones. Hope (2016) describes arts practiced-based research as involving the research questions and methods emerging through ‘making, doing and testing things out’ (p. 77) not necessarily being established at the start of the process. She presents three main ways of understanding this form of research which overlap. Firstly, research into practice, secondly research through practice and finally research for/as practice. She emphasises that within this classification there will be overlaps with researchers normally taking a combination of different positions in any particular project. Visual methodologies are used increasingly as a way in which to capture experiences and concepts that explore the complexity of the human condition (Reavey, 2012). In keeping with a social constructivist stance, visual data and its interpretation foreground subjective experience and acknowledge that in any study there are multiple realities. Artwork documents and communicates

\(^7\) A rating scale is valid if it measures what it is intended to measure in the specific study’. (Svensson, 2011).

\(^8\) RCTs have the following characteristics – ‘Random allocation to intervention groups. Patients and trialists should remain unaware of which treatment was given until the study is completed - although such double blind studies are not always feasible or appropriate. All intervention groups are treated identically except for the experimental treatment. Patients are normally analysed within the group to which they were allocated, irrespective of whether they experienced the intended intervention (intention to treat analysis). The analysis is focused on estimating the size of the difference in predefined outcomes between intervention groups’ Sibbald, B. and Roland, R., (1998, p.201).
psychological issues including emotions, memory and identity, all highly relevant to research on the condition of dementia.

**Factors influencing the methodology and its development** The following explores a number of themes which were identified at the *Dementia and Imagination* project methods analysis meeting held on the 10th June 2016 at Manchester Metropolitan University and during correspondence. They provide an insight into what determined the development of the methodology for the project and through this the reasons for working across disciplinary boundaries and how this might be achieved more generally.

The themes were:

- The AHRC Research Development Workshop and the formation of the research team;
- The reasons for the use of art activities to improve the lives of people with dementia;
- Policy/practice engagement and co-production;
- Development of methods as the project progressed.

**The AHRC Research Development Workshop and the formation of the research team** An important factor in the choice of methodologies, for this and other Research Councils UK funded projects, is the requirements of the funding call. In this case it was framed by a published document (AHRC, 2011) and the specialisms and interests of those invited to the Research Development Workshop held in Cardiff. This determined how the needs of the funding call (please see Appendix 3) were interpreted and so the application constructed. The call aimed to bring academic researchers and community partners together to interrogate how community cultures and community-based cultural activities might improve the health and wellbeing of communities, with a particular emphasis on how the results of the research might inform initiatives and services that meet the health and caring needs of particular populations. It was also stated that community organisations needed to be engaged at all stages of the research and that cross-disciplinary consortia needed to be developed that combined arts and humanities expertise together with other disciplines and community policy and practice partners. This emphasised the need for arts and humanities approaches and also methods that were able to provide evidence in a way that will be of value to policy makers and practitioners (this is explored below).

The requirements of the call determined the range of people who were invited to the workshop. Those present included researchers who worked in the arts and humanities and social sciences as well as a wide range of people from voluntary organisations and charities. Because of the ways that subjects are studied and funded in universities there are few opportunities to have discussions and to build multidisciplinary projects across subjects and with external partners even though this is encouraged. Very few of those present at the workshop had worked together before and none of the core (excluding those who joined at a later date) Dementia *and Imagination* group had come across each other, even though there were commonalities in their work.
It was clear that in order to address the topic and to fulfil the needs of the call the team would need to go beyond their traditional disciplinary boundaries and embrace research methods that they were unfamiliar with. This can be difficult as researchers are ‘loath to acknowledge the value judgements in their work (Lele, 2005). The differences between team members were both of ideology and interest (Druckman and Zechmeister, 1973) and so disagreements had the potential to become intense. However, the development of the project methodology did not require individuals to abandon their disciplinary modes of working but to accept that there were other equally valid approaches that could be adopted (see discussion below). As Klein (2008, p. S116) states ‘tensions among different approaches must be carefully managed in balancing acts that require negotiation and compromise’, a process that was undertaken successfully.

Because of the way that the core of the team was brought together at the workshop, with members not knowing each other previously, it was important that they were trusted to deliver what they claimed they could. This trust was inevitably built upon on the team member’s track records of work in previously funded research projects and publications aimed at academic or public audiences.

The reasons for the use of art activities to improve the lives of people with dementia The original decision to build a collaborative project that would examine the role of arts activities in improving the lives of people with dementia came from an initial discussion between Windle and Newman at the Cardiff Research Development Workshop. This was based upon knowledge that while practice in this area was well established research that demonstrated the success or failure of these activities was limited with few systematically designed studies and little attention given to the role of the art activities themselves (Beard, 2011 and Mental Health Foundation, 2011). Although it was acknowledged that there was research using non-positivist social science methods that showed positive impacts of the arts with healthy older people (Newman et al., 2013).

This prompted the design of the study mixing positivist, non-positivist and arts based approaches (please see Appendix 2 for a detailed description of the range of methods) to respond to the limitations of the research in this area and to the needs of policy makers and practitioners. In order to do this a consortia needed to be built that had the expertise to work across the arts and humanities and social sciences. Members originated from the development workshop with others joining later to provide expertise where needed. While individual consortia members worked in research traditions that covered all of these areas, none were able to claim expertise across all of them. It is noted that members with an arts practice background started with the assumption that arts activities were capable of transforming people, a view that is widely embedded in society (Belfiore and Bennett, 2007) and that older people with dementia would benefit from arts activities. While those with a social science background were more reticent in expressing

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9 See for example the following organisations and websites Arts4 Dementia (http://www.arts4dementia.org.uk/), Creative Dementia Arts Network (http://www.creativedementia.org/), Equal Arts (https://equalarts.org.uk/) and Timeslips (https://www.timeslips.org/)

10 The need for this work is illustrated by the fact that in 20 years nearly a million people in the UK will be living with dementia and by 2051 this number is projected to increase to 1.7 million (Alzheimer’s Society, 2007). As there is no cure for the condition this situation is of major concern to policy makers internationally (Alzheimer’s Society, 2012).
such views. Questions over the relationship between the effectiveness of the art activities and aesthetic quality also needed to be explored\textsuperscript{11}.

A decision had to be made as to whether to view the arts activity as a way of improving health (within the arts and health tradition see for example the journal *Arts & Health: An International Journal for Research, Policy and Practice*\textsuperscript{12}) with the associated need to demonstrate specific measurable health outcomes, or as ‘enrichment’, where the aim was to improve quality of life in a wider/holistic sense. It was decided to follow an arts as enrichment rather than arts as therapy route (as supported by Beard, 2011) as this allowed us to place more emphasis on the role of art (which appears to be downplayed in the arts and health tradition) and to use the sociological/gerontological literature (which again the arts and health tradition tends not to consider) to support the analysis. It was also unclear whether it was possible to demonstrate direct health outcomes for people with dementia (such as reductions in medication or GP visits) through arts activities. The focus shifted to consider how older people might live well or even thrive with dementia rather than improving specific health outcomes. The approach taken was more associated with gerontology than medicine, with its growing arts/culture component (see papers given at the British Society of Gerontology conference 2016\textsuperscript{13} for the general approach). While the call came from the UK cross-Council Connected Communities programme\textsuperscript{14} it was managed by the AHRC and this also influenced the decision to emphasise quality of life rather than health (even though the connection between these constructs are acknowledged) as it was viewed as being more appropriate for this particular funder.

**Policy/practice engagement and co-production** In common with many research projects *Dementia and imagination* was to be co-produced with a wide range of community partners and this inevitably had an impact upon the choice of methods\textsuperscript{15}. It was important that the research provided results that were of practical and strategic value to them. Providing evidence of the role of arts activities in improving the lives of older people with dementia, in a way that would satisfy potential funders of this work, was seen as important. Given that funding for arts and dementia activities often comes from the voluntary sector or local government the research methods adopted needed to be able to provide results in a form that would support funding requests. Guidance for this is provided by *The Green Book* and *The Magenta Book* which are published by the HM Treasury in order to provide guidance on the evaluation of policy initiatives. The methods recommended included positivist and non-positivist approaches although it is stated in *The Magenta Book* (p. 27) that ‘the method offering the strongest measure of policy impact is randomisation, often in a form known as a randomised controlled trial’. However, the authors go on to say that such an approach is not always appropriate or possible for a variety of reasons. The wider use of randomised

\textsuperscript{11} This was considered by O’Brien and Parkinson through analysis of the artist’s notes.

\textsuperscript{12} http://www.tandfonline.com/toc/rahe20/current

\textsuperscript{13} http://www.stir.ac.uk/bsg16/

\textsuperscript{14} http://www.ahrc.ac.uk/research/fundedthemesandprogrammes/crosscouncilprogrammes/connectedcommunities/, at present there are seven UK research councils http://www.rcuk.ac.uk/.

\textsuperscript{15} Research team members worked with those in their respective areas (North Wales, Midlands and North East) and two national meetings were held. The first took place at the Lowry Centre in Manchester on 24th May 2012 and enabled participants to identify issues that the project could respond to and comment on the aims, delivery and outcomes of the proposal. The second, ‘Creative Voices’ was held at Nottingham Contemporary on 30th May 2012 with funding from NIHR-CLAHRC (National Institute for Health Research-Collaboration for Leadership in Applied Health Research – Nottinghamshire, Derbyshire, Lincolnshire). Those involved included Royal Society of Arts, Creative Scotland, Arts Council Wales and the Baring Foundation.
controlled trials (RCTs) has been advocated by the Behavioural Insights Team\(^\text{16}\) (Haynes, et al., 2012). Criticism of this approach is provided by Cartwright and Hardie (2012) who state that RCTs can only demonstrate that something works in a particular place and at a particular time and so that the evidence provided may not be transferable to other contexts. Guidance on this from the AHRC was not to go down this route but to concentrate on the Connected Communities aspect of the project. RCTs are also more suited to research where factors/variables are more easily isolated and replicable and it is not possible to replicate the arts activities exactly across the project (please see below). However, this has meant that the conclusions from some of the quantitative data is more limited than it might have been otherwise.

None of the guidance provided by government on evaluation addresses the possible value of evidence provided by arts and humanities research methods as a way of influencing policy and practice. Such research is often caricatured as lacking robustness, particularly within discussion of evidence-based policy making (O’Brien, 2010). However, it was decided to produce a number of exhibitions documenting the work of the arts activities as a way of communicating the results to practitioners/policy makers either on their own or as contributing to seminars/workshops. It is interesting to note that a care home group\(^\text{17}\) in NE England wished to implement the techniques used by the participatory artists after observation of the arts sessions, rather than waiting for evidence that would be provided by the analysis. In certain circumstances policy and practice can be influenced by case studies or direct observation rather than traditional research results. This is particularly the case when a belief in the effectiveness of the work already partially exists as it does with many policy makers and practitioners in this area. It was seen as important that community partners and respondents (as far as possible) played a role in interpreting the results and events were held as part of the AHRC Connected Communities festivals\(^\text{18}\) in 2015 and 2016 to provide a focus for this activity.

A consequence of the belief in the effectiveness of arts activities in improving the lives of people in later life with dementia was the suggestion, by one person at one of the community engagement meetings, that spending large amounts of money on research was not necessary and it should be spent on initiatives in this area instead. This misunderstands the nature of research funding and the importance of addressing research questions, but coming from a third sector organisation looking for alternative funding sources, particularly in a period of financial austerity, is an understandable comment.

**Development of methods as the project progressed** An example of the compromises that are essential when using different epistemological approaches are those that were involved in the decisions about the nature of the arts activity that was to be undertaken by the participatory artists across the three data collection areas. A realist synthesis methodological review (Pawson et al., 2004) of published research on visual arts activities for people in later life with dementia was undertaken (please see Appendix 2, Work Package 1) (Windle et al., 2014) to help identify which approaches might be most effective. However, this

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\(^\text{16}\) The Behavioural Insights Team is a social purpose company jointly owned by the UK Government, Nesta and its employees, its aims are: making public services more cost-effective and easier for citizens to use; improving outcomes by introducing a more realistic model of human behaviour to policy; and wherever possible, enabling people to make ‘better choices for themselves’

\(^\text{17}\) The Executive Care group \url{http://www.execcaregroup.co.uk/}

\(^\text{18}\) \url{http://www.ahrc.ac.uk/newsevents/events/calendar/connected-communities-festival-2016/}
exercise did not identify a consensus that one approach would be better than another and ultimately the experience of the participatory artists themselves was relied upon, most of whom had worked in this field for some time and had built up expertise\(^{19}\) (one having worked with Newman and Goulding\(^{20}\) and another with Windle \(^{21}\) on projects with people in later life who had dementia engaging in arts activities). A positivist approach would describe the work of the participatory artists as an intervention which would need to be highly structured and directly replicable across the project, so, for example, timings and topics addressed would be identical in all settings. However, this would be contrary to the ways that participatory artists work as they are directly responsive to the needs of the participants (using a person centred approach\(^{22}\)) in terms of topic and pace and would place unrealistic restrictions on their artistic practice. Practically, strict standardisation would have been unachievable and have risked both the social scientists and arts and humanities team members being unsatisfied with how the arts activities were being undertaken and so data collected. In response to this situation best practice guidance was produced but they provided a relatively loose structure, ensuring quality of provision and some replicability, while allowing the participatory artists to pursue their own practice. The result of this was that team members ceased to use the term *intervention* and instead used *activity*, as a more accurate descriptor of what was being delivered.

Over the period of the research (data collection was completed by January 2016), views on the ways that art might help achieve the aims and objectives of the project changed. Initially, as can be seen from the wording of the objectives of Work Package 2, entitled ‘The Role of Art’ (see Appendix 2) the work of the three research artists\(^{23}\) was ‘to generate output to ensure the research findings will be more widely understood’. However, while this objective has not been lost, the research artists are also using their medium to respond to the research process itself\(^{24}\). This research through practice (Hope, 2016), was a useful way of reflecting on the research methods used. The researchers found the research artists’ responses challenging, particularly their questioning of the positivist aspects of the data collection. Even though it was not part of the original project two of the participatory artists (Kate Sweeney\(^{25}\) and Lisa Carter\(^{26}\)) have used the experience of working in care homes with older people with dementia to reflect on what research participants can offer creative practice itself (Hope, 2016) through their immediate and often unencumbered responses. Parkinson who recruited the research artists stated that he saw his role as ‘supporting the freedom of the artists, whilst respecting the constraints of the research objectives, mixed methodological approaches and (potentially) competing agendas which is a complex process’. Baber, from the point of view of a community partner, stated that he found the approaches that the research artists took ‘not only challenging but also enlightening’ representing a positive evolution in the methodology of the project.

\(^{19}\) For example, one of the participatory artists working in the NE had obtained a Churchill Fellowship travelling to observe work with arts and older people with dementia in North America see [http://we-engage.blogspot.co.uk/](http://we-engage.blogspot.co.uk/).

\(^{20}\) [https://blogs.ncl.ac.uk/annagoulding/author/nag47/](https://blogs.ncl.ac.uk/annagoulding/author/nag47/)

\(^{21}\) [https://denbarts.wordpress.com/tag/lost-in-art/](https://denbarts.wordpress.com/tag/lost-in-art/)

\(^{22}\) Focusing on the needs and interests of the individual at that moment.

\(^{23}\) Please see [http://communityartsinternational.com/2016/06/16/dementia-and-imagination-project/](http://communityartsinternational.com/2016/06/16/dementia-and-imagination-project/)

\(^{24}\) Bartlett (2015) recognises that using the arts to communicate research findings is potentially problematic as creative practice will inevitably create new perspectives and should really be part of the research process itself.

\(^{25}\) Please see [https://vimeo.com/124503277](https://vimeo.com/124503277) for work she created from the *Dementia and Imagination* project.

The experience of working on a multidisciplinary project meant that a number of the team have used methods that they had not used before and while this was challenging they felt that the learning involved was beneficial. Newman, for example, has decided to use social network analysis (Crossley and Edwards, 2016) in future work, a method he might have rejected before. Also Parkinson states that he ‘continues to learn about the complexities of large-scale mixed methodological research projects’, and Jones mentioned ‘I have used new approaches collecting a range of quantitative and qualitative data. And as an ‘early career researcher’ this has been particularly beneficial’. This was also important for the main community partner (Age Watch – Baber) who states ‘as someone not normally involved in research I’ve been on a steep learning curve, partly due to the challenge of understanding and getting to grips with the concepts and language of a multidisciplinary team’.

**Discussion** The choice of methods for this and other similar projects that cross disciplinary boundaries are partially influenced by how established those methods are and the narrative that surrounds them. In the case of *Dementia and Imagination* social science methods initially dominated thinking, making up the majority of the methods suggested. Such methods are more established than some arts and humanities approaches (for example creative practice PhDs have only been available in UK universities relatively recently) and have a successful track record of being used to explore the lives of older people with dementia. This also reflects the predominance of biomedical models of service delivery and evaluation when working with this group. It was also evident that the narrative associated with positivist methods within the social sciences of rigour, the minimisation of bias, and the use of systematic approaches, meant that those who espoused arts based research were perhaps less confident in arguing their case. Although a balance between the various approaches was achieved, Parkinson states that he saw himself as providing a ‘critical eye to the emerging cult of ‘scientism’’. It was also of significance that some of the team (for example Howson), because of their backgrounds, were able to translate between the social sciences and the arts and humanities having some knowledge of both.

It is useful for researchers building projects to reflect upon the consequences of decisions that have been taken. In hindsight *Dementia and Imagination* can be described as largely multidisciplinary where ‘multiple researchers investigate a single problem, but do so as if each were working within their own disciplinary setting’ (Miller, 2008, p. 47). This describes the approach taken in terms of the decisions about the choice of methods but not in terms of their implementation. Not blurring the boundaries between disciplines too much made it easier for researchers to accept the range of methods finally adopted. Other approaches such as interdisciplinary (with methods being shared) and transdisciplinary (Aboelela et al., 2007, p. 340) (an epistemology that might be unique to the project) were not attempted because of their challenging nature and the possible difficulty of getting results published in high ranking disciplinary journals (important if researchers are to score highly within the UK Research Excellence Framework). Despite this, efforts will

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27 Catrin Hedd Jones
28 [http://www.ref.ac.uk/](http://www.ref.ac.uk/)
be made to integrate the positivist and non-positivist social science findings together with those from the arts and humanities in a way that goes beyond the ‘stapling together’ of results as described by Miller (2008, p. 47). While it is common in multidisciplinary, interdisciplinary and transdisciplinary work that one epistemology dominates and is supported by the others, this was not the case with this project. While social science methods may have initially dominated, the arts and humanities methods were seen as producing results in their own right and were considered as having more than a supporting role. The stance taken is an example of epistemological pluralism (Healy, 2003) which counters the tendency of one epistemology to overly dominate research projects. The use of multidisciplinarity rather than interdisciplinary or transdisciplinary approaches was unwittingly encouraged through the organisation of the project into work packages. Individual researchers reported that it was straightforward to focus on those aspects that were their responsibility and related to their disciplinary background and to take less notice of the others. This pragmatic stance was understandable given the large scale of the project. While the aims and objectives were agreed by all those who took part, the goals of the individual research team members varied somewhat. Predictably, those with a social science background emphasised those aspects of the study, while those with an arts background were more interested in what the arts-based research might show. As Klein (2008) observed this sort of project is often not driven by a single focused goal and that sensitivity to context and individual interests is important.

The methods finally adopted were reviewed for their effectiveness as the context being worked in was sometimes challenging. For example, while it is widely accepted that it is possible to undertake qualitative research with people with dementia (McKeown et al., 2010) it is easy to attempt this without understanding the complexities involved. Initial reflection on this aspect of the data collection shows that for those who are severely disabled by the condition (which was only a proportion of those recruited to the study), following a predetermined interview schedule was not possible. While interviews were carried out (except for those who were non-verbal or who became so over the data collection period) it required the researchers to take a very flexible open approach, listening and letting the respondent largely take control of the interaction. This has resulted in a number of interviews that will be challenging to interpret but ones that have the potential to reveal fascinating insights into the nature of the condition of dementia and the impact of the arts activities that were undertaken. By enabling the respondents to talk about things that were important to them, rather than predetermined topic areas, the researcher is required to put aside the inevitable assumptions that are made and be open to new ways of thinking about the issue under consideration. It does, however, involve the potential risk of not being able to address the aims and objectives that had been set.

Working with human subjects requires ethical approval and the approval process itself embodies certain epistemological assumptions about the nature of research. Because some of the respondents lacked the capacity to consent to their involvement National Health Service (NHS) ethical approval was required. As the project could not be undertaken without this it influenced the choice of methods and introduced a rigidity into the data collection process. Achieving ethical approval required a data collection protocol to be
developed and the data collected could only be used in strictly proscribed ways. This made the work of one
the research artists difficult because she wished to use some of the data in her practice and this was not
specified in the original ethics application. While alterations to the ethical approval could be requested (this
was done on two occasions) the process of achieving this was time consuming and difficult. Once research
ethics approval of this type is achieved the methods are largely fixed and this restricts creative practitioners
who might not work out in advance exactly what they wish to achieve (please see section above on
epistemologies). NHS ethical approval is tailored towards positivist methods and so can be problematic for
creative practice-based research.

A clear protocol and training was also necessary to ensure that the data collection was being undertaken
correctly (for example, to ensure consistency in the structured observations of the arts activity – see
Appendix 2, WP3, objective 1) was essential. Initially, there were differences across the team as to the
importance of this as Windle states:

> I was aware of the need for clear protocols for the various stages of the research. I learnt that there
appears to be some differences in the understanding of this need, depending on disciplinary
background. I suspect that some of the arts and humanities team members found it frustrating to
have to specify their plans in advance in such detail.

While there were differences in views these were overcome with the understanding that such a protocol
was required both for the ethical approval and as to provide a guide for the data collection aspects of which
were unfamiliar for some.

An important aspect of the development of the methodology for this and other research projects is the
leadership role of the principal investigator (Windle). The amount of work required in coordinating a group
such as this, with a wide range of specialisms and approaches to research is considerable. It requires an
appreciation and understanding of different epistemologies (together with their underlying assumptions)
and a willingness to make decisions about which ones to adopt. It also required the ability to make
judgements about the range of skills that were present in the team and to bring in others when needed
resulting in the involvement of six different universities. This impacted on the financial management of the
project particularly when organising subcontracts between Bangor University and the others involved. The
initial set up and any subsequent changes required the agreement of all parties and was very time
consuming to achieve. Inevitably, over the period of the project team members changed universities and
roles requiring the agreements to be redrafted and agreed a number of times.

The results generated through non-positivist methods will be used to address questions that might be
categorised as interpretive and critical, considering themes such as identity expression and formulation and
communication through arts activities for people in later life with dementia who may have become or were
becoming non-verbal. The artistic outputs are used as visual data to capture public imagination, to
communicate findings, and to connect individuals and the wider community with the condition of dementia. The methods also included participatory elements, particularly participation in the arts activities that enabled people with dementia, their carers and the wider community to potentially change their views about the nature of the condition and the extent to which this might facilitate wider dementia friendly communities.

**Conclusion** In order to address the aims and objectives of the project it was necessary to draw on a range of research methods representing different epistemological positions. This is described as epistemological pluralism, (Healy, 2003, Miller et al., 2008) or post-positivism (Wildemuth, 1993) and is increasingly required when working on solutions to complex contemporary societal challenges such as how dementia friendly communities may be created. It is clear that projects such as this are not achievable by individuals and team working is essential to their success. Researchers are required to be flexible to undertake research (from whatever epistemological starting point) that answers the aims objectives that have been set and that satisfies the needs of various stakeholders, such as community partners who have their own understanding of research and how it might help them achieve their objectives. *Dementia and Imagination* provides an example of a project team successfully working across the arts and humanities and social sciences and overcoming the inherent challenges and benefitting from shared approaches.

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**Appendix 1, *Dementia and Imagination* Aims and Objectives**

1. How can visual arts interventions change, sustain and catalyse community cultures, beliefs, attitudes and behaviours to create dementia friendly communities?
2. What are the underlying processes of an effective, sustainable and socially engaged visual art programme that improves connectivity, promotes meaning and enhances wellbeing?
3. Can changes in community connectivity be demonstrated through participation in, or connections with a visual arts intervention?
4. Do different models of delivery, through different venues (cultural and community venues and outreach/satellite services) facilitate different forms of connectivity, potentially influencing wellbeing?
5. What sort of community links can be facilitated by visual arts interventions and is this influenced by the different research contexts?
6. 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?
7. How can the value and benefits (and disbenefits) from multi-disciplinary methodological approaches be synthesised and communicated?
8. To what extent can we maximise the impact of the study for policy, practice and research through engagement and dissemination?
9. What is the social return on investment for the visual arts intervention?
10. These research questions are underpinned by the objectives (see objectives) and multi-disciplinary activity.
Appendix 2, methods and work packages

WP1: Understanding the impact of visual arts on wellbeing and quality of life
   Objective 1: Development of a theoretically informed visual arts intervention.
   Methods: A realist synthesis review (Pawson et al., 2004) of published research on visual arts programmes for those with dementia and two workshops with artists and a survey of stakeholders, including people living with dementia, were undertaken.
   Objective 2: To integrate the newly produced evidence from each of the work packages (WPs) to generate theoretically informed holistic conclusions about visual arts interventions and the implications for research, policy and practice.
   Methods: Synthesis of findings across work packages was undertaken linking data on wellbeing to connectivity.

WP2: The role of art
   Objective 1: To ensure that the research findings will be more widely understood.
   Methods: Three artists were embedded across the three research sites – to use their medium to capture their perspectives on the unfolding research process.
   Objective 2: To raise awareness of dementia and challenge negative attitudes towards it. Sharing work in a range of non-traditional settings provided greater opportunities for dissemination and public response from diverse communities.
   Methods: Exhibitions of work were produced in each of the research areas and where possible people with dementia and staff/carers were in attendance and involved in the organisation.

WP3: Community connectivity through the visual arts
   Objective 1: To capture the subjective aspects of the experience and meaning of the programme on the well-being of people with dementia, communication, quality of life, memory, use of medications, receipt of services and self-reported health. To compare changes over time and to compare the intervention against a control condition.
   Methods: Data was collected three time points. Systematic observation at baseline and twice within the arts activity using the Greater Cincinnati Chapter Well-being Tool (Kinney and Rentz, 2005).
   Measures: Demographic data (age, gender, marital status, prior arts engagement) was recorded at baseline. Self-reported health was recorded at T1 and T2. Dementia Quality of Life (Smith et al., 2007) was recorded at T1, T2 and T3. The Clinical Dementia Rating Scale (Hughes et al., 1982) was completed as well as medication use and receipt of services recorded at T1 and T2.
   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) at T1 and T2 completed the Holden Communication Scale (Holden and Woods, 1995) and Approaches to Dementia Questionnaire (Lintern and Woods, 1996).
**Objective 2:** To ascertain changes in social resources and loneliness. To understand qualitative and quantitative 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 and T2) explored participant’s previous engagement with art (using cultural capital as a theoretical framework), the boundary and nature of community (as experienced by people with dementia), the extent to which changes, if any, have been sustained and/or lead to new aspects of connectivity.

Measures: The Lubben Social Network Scale (Lubben et al., 2006) and Emotional and Social Loneliness (de Jong Gierveld and Tilburg, 2006) scales were used.

**Objective 3:** To investigate contagion dynamics over social networks in a community of practice which will be of relevance to both practitioners and researchers (Van den Bulte and Lilien, 2001, Watts and Peretti, 2007).

Methods: This combined 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 and Antonucci, 1980) on discussion within the community of practice. Semi-structured interviews within the practitioner’s organisations collected data on leadership and the processes involved. An email/online survey with all of the identified members of the community of practice (n=50/100) elicited through the network data above was used to assess the knowledge and/or adoption of the visual art intervention with people with dementia.

**Objective 4:** To investigate contagion dynamics in the wider communities of place.

Methods: Interviewees were located in the community of place and selected on the basis of a high level of engagement with the project. This combined individual level data from people (n=9), who are in some way engaged with the project team, 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 of the interviewees organisations (n=30 in each data collection area) collected data on leadership, and the processes involved. An email/online survey with all of the identified members of the community of place (about n=50/100). The Approaches to Dementia Questionnaire (Lintern and Woods, 1996) were completed by all staff who have been exposed to the intervention (up to n=125) at times T1 and T2.

**WP4: Understanding the economic value**

**Objective:** To develop an economic case for socially engaged visual arts interventions using social return on investment (SROI).

Methods: The evaluative SROI was conducted in accordance with the principles and methodology set out in the Cabinet Office (2009) guide.

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WP5: Maximizing engagement and research impact

Objective: To facilitate the impact of the research, knowledge exchange with stakeholders, partners, policy and interested organisations, and engagement with our research communities.

Methods: A programme of engagement and dissemination activities are planned to facilitate the impact of the research. The engagement events during the development phase were attended by more than 60 stakeholders (regional and national) who continued this relationship during the research. Academic papers have also been presented at appropriate conferences (for example, the British Society of Gerontology conference 2015 and 2016).

Appendix 3, The questions presented by the Arts and Humanities Research Council for the funding call to address were as follows:

- What role does participation in community-based cultural and creative activities and ‘cultural connectivity’ play in promoting purpose and meaning in life and in enhancing mental health and wellbeing? How can we better capture the value and benefits (and dis-benefits) of such activities for wellbeing in communities?
- How can an understanding of community histories, cultures and values inform more targeted and better designed community-based initiatives and services that meet the health and caring needs of specific local or cultural communities (e.g. youth, ageing, disability, ethnic, faith, diasporic communities)?
- How can cultural and creative activities help to engage communities with the challenges of promoting healthier behaviours and lifestyles (e.g. mental or physical exercise, better diets etc.), in the co-design, co-production and co-delivery of services and in tackling addictive behaviours (e.g. drug and alcohol misuse)?
- How might it be possible to enhance the role that creative and cultural institutions, community organisations and/or cultural heritage play in supporting the health and wellbeing of communities and to better understand any associated value and benefits for communities.