Strength in Networks

a comparative analysis of six creative interventions designed for people diagnosed with dementia across England and Wales

London
Arts in
Health
Forum

Arts & Humanities
Research Council

**Dementia
Connect**
Working together to build a
dementia innovation cluster

F A C T

Royal College of Art

NHS
Mersey Care
NHS Foundation Trust
Community and Mental Health Services

**UWE
Bristol** | **University
of the
West of
England**

<u>Contents</u>

Introduction

This report has been written as part of *Dementia Connect* funded by the Arts and Humanities Research Council (AHRC). *Dementia Connect* builds on the learning of the *Creative Economy Knowledge Exchange Hubs* (2012-2016) and aims to "grow a dementia innovation network" based in the North West of England. This report responds and builds on *Dementia Connect's* belief that: "in making sense of complex artistic interventions and their context-dependent effects, an understanding of different aesthetic, social, cultural, and economic impacts may be relevant."

It explores the different contexts which surrounding a very particular focus, beginning with a description of how one artist intervention working with people diagnosed with dementia came about in the North West (*Drawing on Strengths*). A wider scoping exercise then opens out with descriptions of five other examples of similar practice which also deploy creative interventions for people diagnosed with dementia, sited across the UK.

These six case studies were chosen with the aim of examining how different regional and national bodies - through different forms of partnership involving health and cultural organisations alike - are together attempting to meet the particular challenges posed for people in the crucial post-diagnostic period.

Evidence suggests that the post-diagnostic period is important as this is a time when mood can dip. When equipped with knowledge and support, people feel better able to manage, plan and sustain their lives. Such interventions build on research that shows that people diagnosed with dementia can experience poor quality of life due to reduced independence, activity and social contact. Stigma around the disease has been shown to reduce social contact too; people can be treated differently by others following a diagnosis. In this way, social attitudes compound the effect of the illness itself.

The case studies presented here all propose that opportunities for creative expression have a role to play in making the experience of illness feel less frightening and more manageable, allowing opportunities to express feelings, find out information, challenge stigma and meet others in safe, supportive contexts. Ultimately, it is hoped that opportunities for creative engagement might help people to live well for longer. The case studies presented here employ different evaluation methods by which to assess this proposition, (amongst others) while one used the creative arts as a method in its own right.

The report ends with a discussion around how these six differing models relate, synthesising some of the themes that emerge between them. It asks further questions around what kinds of support - including funding, partnerships and research - are required in order to sustain the role that creative interventions can play in this expanding and important, though still fragmented and specialist area of work.

2. How the report came about

Drawing on Strengths is one of three projects funded by the wider *Dementia Connect* programme. It came about as the result of conversations between participants attending a 'Development Lab', devised by Timothy Senior (Research Associate) and Tom Rowlands (Creative Producer) in September 2017.

This participant group discussed the challenges people face in the post-diagnosis period and how a 'social asset' approach might help mitigate feelings of grief and hopelessness commonly experienced by people at this time. Such an approach, it was suggested, might also help health professionals in better understanding the nature and extent of their patient's sufficiency and resource alongside their needs - information which is usually framed solely by way of a formal 'needs assessment'.

It could enable a focus on the exploration of people's strengths and resources. "By reframing our responses to the news of diagnosis, the arts can disrupt the medical model – which has to focus on what is lost – to one which explores assets." https://lahf.wordpress.com/2017/11/21/de-medicalising-dementia

Initial ideas were further developed and shaped into a proposal that was accepted as a 'voucher scheme' as part of *Dementia Connect*. *Drawing on Strengths* is a partnership between three organisations: Mersey Care NHS Foundation Trust (Sarah Butchard) The London Arts in Health Forum, (Damian Hebron) and Manchester Metropolitan University (Frances Williams). It was developed in line with Dementia Connect's methodology, to 'nudge' partners towards developing "rapid, small-scale and exploratory work". The project was conducted between November 2017 - March 2018.

It comprised a two-pronged approach: one involved commissioning an artist to explore an asset-based approach to mapping life post-diagnosis. This saw an artist (Kate Eggleston-Wirtz) develop a creative 'audit tool', working with people belonging to a long-standing group of people with dementia and their carers (drawn together by Mersey Care). The brief here was to "help people to map and to record, using visual means, the positive aspects of their lives," as one part of an existing seven week course. (A brief description of this artist intervention, along with a longer exploration of 'social assets', is given in the Appendix).

The other part of the project was to commission a researcher (Frances Williams) to explore current activities that similarly offer creative outlet for people in the post-diagnosis period. This report fulfils the latter commitment and aims to explore the factors that influence the scaling-up and further extension of the work. It is intended to be read primarily by commissioners, policy makers, heath care professionals and creative practitioners working in the field, but also be accessible for a more general readership.

3. Aim and scope of this study

The role of this research report is not to evaluate or demonstrate the effectiveness of a particular arts intervention but rather to look at the broader context of similar projects. An exploration of the concept of 'social assets', which underwrites the rationale for *Drawing on Strengths,* is explored by way of a short literature review in the Appendix. The main aim of this research has been to identify and describe current examples of creative opportunities for people post-diagnosis. The research questions were:

How unique is the Mersey Care model? In what other ways have creative interventions been deployed in the immediate post-diagnostic period? In what local contexts?

Decisions around the research were made for a number of reasons. Firstly, the intervention was too small to enable either quantitative or qualitative research in the timeframe and budget. Secondly, Mersey Care has already commissioned evaluative research into the effectiveness of their seven-week programme. It was not deemed necessary to add to this at this point in time.

It was also decided to limit the scope of this research to dementia only, despite research also being undertaken into the immediate impacts of other life-changing diagnosis, such as cancer. While studies in these other areas are undoubtedly relevant, they were considered to be beyond the scope of this timeframe and budget (which was modestly set to enable five days devoted to research and the writing of this report).

Research was largely desk-based, with interviews conducted over the phone, supplemented by the reading of relevant reports and academic literature. The research call for project was publicised on the London Arts Health Forum (LAHF) website, newsletter and blog, alongside Clive Parkinson's blog. http://artsforhealthmmu.blogspot.com

It was decided to limit the study to an examination of six case studies which could reflect a diversity of approaches. While most are based in the UK, one is part of a wider European initiative, giving an international perspective on this topic. This research report then, aims to extend and build on existing knowledge through examining other case studies which relate to the bespoke model established by Sarah Butchard at Mersey Care, comparing local and national working contexts.

5. NICE guidelines & Policy Frameworks

The National Institute of Health and Clinical Excellence (NICE) provides national guidance and advice to improve health and social care. It recommends cognitive stimulation groups as a psycho-social treatment for people living with mild to moderate dementia. A recent paper has noted that:

> cognitive stimulation may be a key aspect of art programmes as there is congruence between the 'guiding principles' of cognitive stimulation (Windle et al. 2017: 55)

Advocates of arts-based approaches in this sector have argued that if arts programmes reflect the foundations of excellent practice, commissioners might consider provision as a follow-on or even perhaps an alternative to a conventional cognitive stimulation groups. They have further urged Arts and health researchers and practitioners to register as stakeholders with NICE to remedy the current absence of the arts in NICE guidance.

Aside from NICE, other policy and commissioning frameworks relating to dementia and the arts vary across the UK. Some are taking a pro-active approach to this specific area of work. Arts Council of Wales (ACW), for example, has recently announced a focus on arts and dementia in a report mapping Arts and Health activity across Wales. It asserts that:

> Arts in Health work, so powerful in relation to dementia and the care home experience, is having beneficial impact across the full ranges of age, class and geography in Wales. And we need to do more (ACW, 2018: 7).

ACW has chosen to target investment in this area, building on current strengths in provision in the North of the country, as well as the scale of need in the nation overall. NHS Wales comprises seven health boards. This has allowed ACW to work with the NHS Federation to work collaboratively across the whole of the Welsh nation, setting-up consistently funded Arts in Health co-ordinators within each of these health boards. A three-year *Memorandum of Understanding* was jointly signed for the first time between these bodies in 2017. Mirroring England, The Welsh Assembly also has a Cross-Party Group on Arts and Health, led by Eluned Morgan AM, (now Jayne Bryant AM) which is helping facilitate developments here. A national dementia strategy, *Together for a Dementia Friendly Wales*, is expected to be published early in 2018.

In England, Arts in health is also high on the policy agenda following the publication of a major report published earlier in 2017, the result of a two-year long All-Party Parliamentary Inquiry. *Creative Health, The Arts, Health and Wellbeing*. Though primarily aimed at policy makers working in an English context, it includes examples of projects draw from across the UK (including Wales).

This comprehensive report dedicates a whole section to the efficacy of Arts in health projects in later life, providing a rich cluster of examples of Arts in health projects aimed at

people with dementia. Many of these build, it notes, on nationwide public health initiatives such as 'dementia friendly communities' in which the charity, The Alzheimer's Society, has played a key role. This organisation, for example, has looked at the role of arts centres within community contexts and published a guide to creating dementia-friendly arts venues, funded by the Prime Minister's *Dementia Friendly Communities* initiative in 2012. The Local Government Association has also published a report to give guidance to local councils on this topic (Dementia Friendly Communities, 2015).

In devolved city-wide contexts, Manchester's unique 'devo-deal' has allowed the Greater Manchester Combined Authority (GMCA) to take responsibility for shaping its own bespoke health and social care system through managing its own budgets for the first time. It is taking dementia as one of its priorities, including the creation of dementia friendly hospitals. Meanwhile, In Liverpool, a city-wide dementia strategy has similarly been drawn up by the city's council and Liverpool's Clinical Commissioning Groups, (LCCG) with major investment in the development of three new dementia 'hubs'.

One of the challenges of these strategic initiatives is that major investment tends to be targeted at people who have developed later stage dementia. NHS and local authorities are less able to address the well-being and health of people in the early stages of the disease as they do not have a significant level of need to reach the criteria for funding. This means that the onus for this area of work is often placed on existing community, voluntary bodies whose funding has been much reduced in recent years.
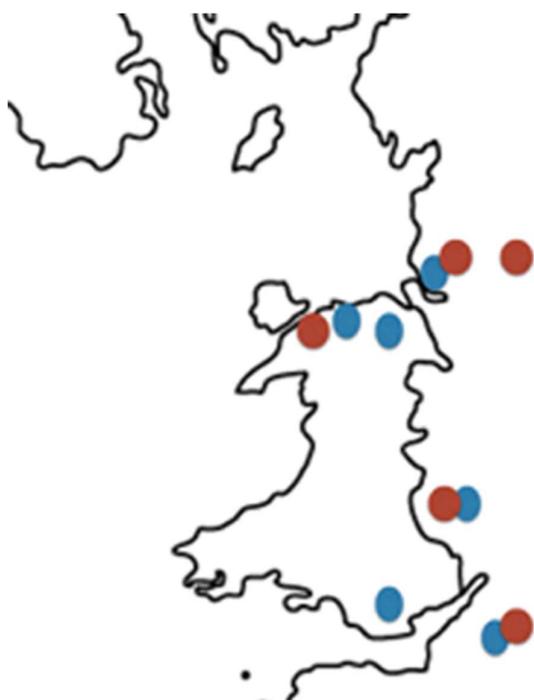
The Case Studies
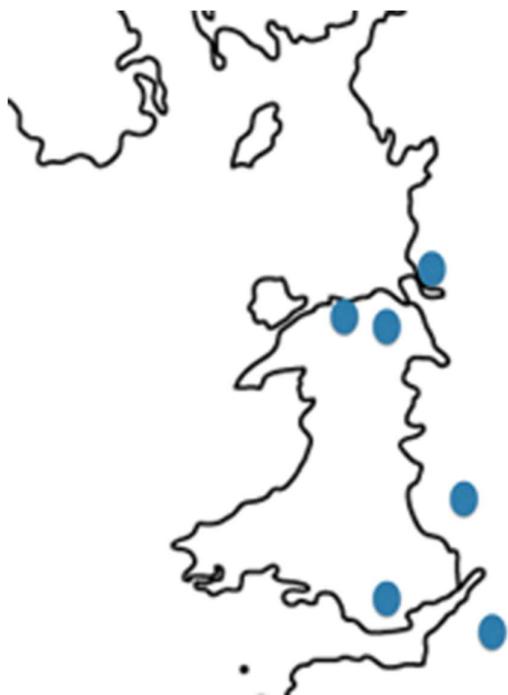
Projects (clockwise)

Drawing on Strengths
Lost in Art
Arts from the Armchair
The Meeting Room
I'll Sing This Song
The Art of Referral

University Partners (clockwise)

Bangor University
Liverpool John Moores University
Manchester Metropolitan University
Worcester University
Bristol University
Amsterdam University

Case studies were chosen on the basis that they all adopted an arts-informed approach to the psycho-social support of people given a diagnosis of dementia. They are equally numbered across England and Wales. The fact that different health services (NHS England, NHS Wales) operate across the border means that awareness of similar projects, even ones taking place very nearby, can be limited.

Of the six case studies, the primary example is based in the North West of the England, with two others based in the South West of England. The other three examples are all based in Wales. Most provide social support through face-to-face project work, undertaken across a period of weeks, in which artists play a direct role. One initiative is not based in any location as such: it saw the development of an app, building on an existing project involving community choirs.

1. Drawing on Strengths (North West)

The approach taken by Mersey Care to supporting people diagnosed with dementia through creative interventions is unusual in a couple of ways. Firstly, it was developed within the NHS by a team of clinicians whose commitment to creativity as a tool for engagement has always found support at senior management within Mersey Care.

Sarah Butchard set-up an initial group for people diagnosed with dementia here over ten years ago and the opportunity for consultation this group provides has been the driver for a range of services which utilise creative and arts-based approaches. In the past, these have included forging partnerships with local arts organisations.

For example, *Beyond Diagnosis* was a partnership with *The Open Eye* gallery based in the city which explored the post-diagnostic experience through the medium of photography. Mersey Care has also worked in partnership with *The Everyman Theatre* to produce a play based around experiences of people diagnosed with dementia. These cumulative arts partnership projects, taking many forms, have providing a depth of experience and learning out of which *Drawing on Strengths* could build.

Secondly, while Mersey Care is not the only service to offer a seven week course post diagnosis, they are the only one whose commitment is to make this offer available to everyone who receives a diagnosis. Furthermore, everyone is promised access to the course within an eight week waiting period. This is seen as essential, ensuring the course best meets people's immediate need - as it has been shown that this period is one where people's mood can dip post diagnosis.

The course is much in demand and people arrive from a diverse range of socio-economic and cultural backgrounds, including some who come from areas of significant social deprivation. On receiving an initial information pack, everyone who has a diagnosis of dementia (and their carer) is offered access to the course, which gives a broad range of information about the disease.

The course format comprises a mixture of presentations and open discussion across various themes and topics including: Facts and Myths about dementia, memory and the brain, social stigma, practical solutions to memory problems, wellness and wellbeing, future planning and resources are available in the community.

The course runs for 2 hours a week and includes a place for the carer of the person with dementia when appropriate. Once completed, participants are signposted onto a very wide range of on-going groups and projects also organised for people with dementia, organised not just by Mersey Care, but a range of other local organisations - including exercise groups, choirs, drop-in sessions, trips and social groups.

Equality of access was one of the main drivers behind establishing the service (although this consistency is not matched outside of the remit of The Trust). Having established the scale and quantity of the need, Mersey Care are now in the process of improving the quality of the course and see creativity as a key tool in achieving this.

From Sarah's point of view, previous arts pilots have remained very much as 'projects' rather than arts offers that could be integrated more sustainably into existing services. They were seen as "add-ons". Through *Drawing on Strengths*, she is seeking to address this by seeing how artists can enrich their current offer in a more holistic way. Sarah questions the long term involvement of artists, perhaps seeing their role more as 'catalysts' (she would not be able to afford to add artists to all of her courses.) Instead, she is hoping there may be opportunities for existing staff to learn from artists.

Mersey Care has also partnered with Chester University where research is being undertaken around the role of creativity in relation to the wider health service, led by Julia Boot and Nick Pontsillo. In this way, *Drawing on Strengths* is part of a longer and larger consolidation of North West health services in relation to forms of creative practice, one within which the *Dementia Connect* programme itself also sits.

2. The Art of Referral (South West)

Another project which focusses on the immediate period after a diagnosis of dementia using arts based interventions is The Art of Referral. This pilot project is the result of a partnership between North Bristol NHS Trust, The Brain Centre at Southmead and Willis Newson (an arts consultancy firm with long experience of working with the Trust on numerous Arts in Health programmes in the South West).

The programme is being overseen by Jane Willis, Director of Willis Newson. http://www.willisnewson.co.uk Jane brings a long background as an innovator in the field of Arts in Health and is interested in how Arts on Referral might work in acute settings as well as those based more usually in primary care. The Art of Referral is funded by a range

of bodies both public, private and charitable including: Arts Council England, Macmillan Cancer Support, and other charitable funds.

Like Drawing on Strengths, the Art of Referral project also aims to support people post a dementia diagnosis through a six week course, but in this case, it is entirely led by an artist. It takes place in a community arts room based within the hospital itself. The artist-led courses for people diagnosed with dementia is one of three partnerships within the hospital: the other two support chronic pain and cancer patients post-treatment. People in all these groups all present needs which the hospital alone is not fully ablate support going forward.

This project unusually combines hospital and community-based referrals. Part of its aim is to explore how well the methods of referral operate from the point of a diagnosis in a hospital setting, as they extend out into the community, after the patient is discharged. In this way the project aims to connect GP, hospital as well as community contexts, running across "the entire patient pathway".

The six week course aims to act as a 'bridge' between clinical and community settings. In this way it represents a half way house, you could say, between models which are squarely set in the community against those which are developed in clinical settings and hospitals. The course(s) will all use mixed arts forms - utilising both visual and writing based approaches - and will be delivered by individual artists to groups of people comprising 10-14 individuals. The project is due to run from March 2018 - July 2018.

The Art of Referral will be evaluated by Jane and her team using a variety of evaluative methodologies, which draw on existing established benchmarks. The focus of this research will not be quantitative so much as qualitative, seeing to what extent continuity of care is established between existing services. The number of patients involved at this stage is a small proportion of those who are diagnosed with dementia overall in the area.

The initiative was prompted by current shortcomings in how patients were able to access support on leaving hospital. This was particularly evident in care post-treatment for cancer patients who, while receiving a great deal of care during treatment, were far more likely to face the consequences of the trauma of treatment after the event, without little support once discharged. In common with people diagnosed with dementia, "this is precisely the point where people need the most help it turns out", Willis confirms.

Referrals come direct from the Brain Clinic where diagnosis of dementia often coincides with her medical conditions (such as mental health). Sometimes this means that this method of delivering a diagnosis incurs a delay in being referred to a 'Dementia Navigator'. In Bristol, the role of 'Dementia Navigators' exists to support those who have been given a diagnosis, signposting other services in the community. They provide ongoing practical help and advice for people as the disease develops, including groups and activities in the community that can maintain independence and quality of life.

Jane explains that they do refer to 'community assets' but employ a different language to conceptualise the quality of life and the sense of empowerment that engagement in creative practice enables. She also utilises the concept and practice of 'health coaching'.

3. The Meeting Centres Support Programme, (South West & EU)

This model differs from the two previous ones in a couple significant ways. Firstly, it doesn't explicitly foreground creative practice as a focus in any way. 'Creative activities' are listed alongside physical, cognitive and social activities, as part of a broader context of evidence-based post-diagnostic psychosocial interventions it aims to investigate.

Secondly, it was instigated, not by clinicians or an arts organisation, but by way of an academic research project. It was part of a wider research initiative called, Meetinngdem, led by Professor Rose Marie Droes, based at the Medical Centre of Amsterdam University, supported through the EU Joint Programme - Neurodegenerative Disease Research (JPND). https://www.meetingdem.eu.

The UK partner was Professor Dawn Brooker, Director of the Association of Dementia Studies, based at Worcester University. The Association for Dementia Studies was established in 2009 as a designated research centre under her leadership. This brings not just European but many international links across the field. TAnDem (The Arts and Dementia) is a joint doctoral training centre between the University of Nottingham and the University of Worcester. https://www.worcester.ac.uk/discover/tandem-meet-our-supervisors.html

Funded from 2014-2017, the recent pan-european research project was designed around the possible extension of the 'Meeting Centre' model, first developed in Amsterdam in 1993, to see "whether it was possible to adapt the Dutch programme in three different European countries, Italy Poland and the UK" (Brooker et al, 2017).

Pilots of the Meeting Centre model were established in the UK, in Leominster and Droitwich Spa, with initial meetings comprising health, social care and community organisations, chaired by the university. In this way, the project took place within a community context and did not involve a formal partnership with an NHS Trust or specific CCG, although charity groups were involved in the project at the outset. The Alzheimer's Society provided support, advice and access to some funding as well as contributing to the final evaluation.

Beyond the initial two centres, other centres have since been established at two further local venues. Since the EU research project ended, the funding that went with it has also ended. Both the original centres now remain open and are run as Community Interest Companies. In the long-term, their sustainability will depend on fundraising from various sources (charitable or contributions by those who attend). The Leominster Centre, for example, is now managed by one of the CIO's trustees, who is also a professional carer.

The Meeting Centre model involves the setting-up of community-based clubs explicitly for people living with dementia and their carers, usually operating between 3 and 5 days per week. What happens there is driven by the needs of the members and their families. A key element here is that the venue offers a local resource which is integrated into the community - rather than day centres or more institutional health settings. These in turn rely heavily on local context.

To date, creative activities at these social settings have comprised a diverse range of formats, from creative writing to bell-ringing workshops. For example, these have included engaging with local arts in health groups, such as Beat It, a Community Interest Company (CIC) which works with groups of people to share music-making, experienced in working with people with dementia.

This meetingdem study has provided a wealth of relevant research findings drawn from both UK and European contexts, including one paper entitled 'Not re-inventing the wheel: the adaptive implementation of the Meeting Centres Support Programme in four European countries' (Brooker at al, 2016). This paper foregrounds the risk, that while knowledge of effective interventions already exist, the implementation of models in local contexts present more of a challenge.

This is a relevant consideration when setting the Meeting Centre model alongside the others here, raising questions that will be addressed, to some degree, in the summary of this report. Importantly, evidence from the European Union research project shows that having a strong connection to the local community is an important element in whether a Meeting Centre is successful or not.

4. Lost in Art (North Wales)

Denbighshire County Council, in Wales, has supported the delivery of a 10-week course for people with dementia, entitled, *Lost in Arts*, since 2010, co-ordinated by Sian Fitzgerald, Community Arts Development Officer. Each session comprises a 2 hour workshop delivered weekly (in the afternoon) over 10 weeks, led by a range of artists. Ruthin Crafts Centre hosts the sessions which take place in their education room.

This project has proved an influential one. It become part of a wider research programme when, in 2014, it was chosen as one of three UK models for the largest ever research project around dementia and the arts yet to take place in a UK, entitled: *Dementia and the Imagination*. http://dementiaandimagination.org.uk This visual arts research programme was undertaken with people experiencing dementia in three geographical areas: North Wales, Derbyshire and Newcastle.

It further involved multiple-partnerships drawn across the arts and health sectors right across the UK (involving six UK Universities in all). It was orchestrated and led by the *Dementia Services Development Centre Wales* (DSDC) at Bangor University, led by Professor Gill Windle. Involvement in this project enabled a rolling out of the Lost in Art programme to three neighbouring counties: Flintshire, Wrexham and Conwy.

As with the previous European Union funded research project, this UK-based research project was also dispersed over three different geographical sites. Unlike the EU project, in which the same model was rolled out in three different national contexts, these sites across the UK were all chosen to reflect *different* contexts in which *different kinds* of creative interventions took place (hospital, care home as well as community settings). In this way, this project explored the ways in which visual art interventions might lead to positive outcomes in people living with dementia at all stages of the condition.

Lost in Art was chosen because it offered insights into community settings: in this way, it worked with people at an earlier stage of their diagnosis, many recently-diagnosed. Lost in art had already been evaluated by Windle in 2013 prior to being chosen to join the wider *Dementia and The Imagination project* (Windle & Gregory, 2013), providing a basis on which further research could usefully build. Interestingly, Windle also draws on a wide range of European examples in her 2013 research paper.

Windle has since gone on to collaborate on joint research papers with Rose-Marie Droes, lead partner in the EU Meeting Room project, underlining the importance of international links for research in this field. *Dementia and the Imagination* has spawned a large body of research results which are in the process of being made public. http://dementiaandimagination.org.uk/dementia-care/presentations-and-publications/

5. Arts from the Armchair (North Wales)

North Wales is unusual in having two award-winning arts-based dementia projects. This is due in part to the strong leadership on Arts in health here by Liz Aylett, the strategic lead for their Arts, Health & Wellbeing Programme, based within the Betsi Cadwaladr University Health Board. BCUHB have acted as pioneers in many ways in the area of Arts in health in Wales. Liz Aylett, like Sarah Butchard, is an individual who has long been in post, facilitating and building a body of related projects and partnerships over many years.

Arts from the Armchair arose out of a partnership between Theatre Clwyd and the health board, winning a business in arts prize in 2017 http://www.aandbcymru.org.uk/arts-business-and-health-2017/. The project is aimed at people with a mild cognitive impairment and provides a "creative and participant led experience, with workshops and performances led by professional arts practitioners, within a theatre context."

The Theatre brings its own rich history of collaborative work in the community and is rare in being only one of handful still run directly out of Flintshire County Council. Programme

Co-ordinator, Andrea Davies, initially proposed the idea with the Theatre and together they plotted this project in its first stage, funded by ACW and evaluated by external researcher, Abigail Tweed.

The Theatre shows a strong commitment to arts in heath and this project is only one of many it acts as host to, including a range of choirs, some of which are targeted at specific health groups. Singing for Lung Health, for example, is funded by the Lung Association, as well as Singing for the Soul (for anxiety and depression), both groups hosted at the venue.

Led by pro-active director, Liam Ford-Evans, the theatre is actively engaged in how to develop this field of work. Theatre Clwyd has made initial steps in talking to Liverpool John Moores University around how this work might be best replicated or extended, possibly outside the venue in rural community settings near the theatre itself, (which is based in Mold). Liam is also leading on developing workshops to develop a North Wales Concordat for Arts Health and Well-Being, which is due to be developed in 2018.

6. I'll Sing this Song (Wales)

This project is included here as an example of new technology being brought to this area of work, something which is relatively rare, but which relates strongly to the aspiration of *Dementia Connect* that new technologies are part of the collaborative mix.

Evidence around the usefulness of new technology is mixed in this area of work: some strongly caution against social media in favour of face-to-face contact as psychological theories suggest that the need for direct human contact is critical (Pinker, 2015). Others seeing great potential for technology to help people with dementia (Gibson, 2016).

This particular app was devised by National Theatre Wales, a spin-off from their education and outreach work, which extended into community contexts in South Wales. It derives, in part, from their production *Before I Leave*, written by Patrick Jones, which invited community choirs to perform a particular song from the production. The National Theatre of Wales partnered with the Alzheimer's Society to produce the App, funded by the Baring Foundation.

The app invites users to 'watch', 'sing' or 'follow' the example of choirs from Wrexham, Barry and Brecon, all made up of people with a diagnosis of dementia. It invites groups across Wales to add themselves to a growing map of projects across the nation, spawning a 'do-it-yourself' approach.

It is advertised as: "a toolkit for individuals, community groups, choirs and schools to follow in the path of our choristers, to undertake the process and engage with the subject of dementia". The App is free to download and currently has drawn number of participating groups and projects to participate.

Summary

Themes arising out of comparisons of this sample of case studies relate closely to *Dementia Connects* initial aim to grow collaborative, innovative partnerships. While networks in UK regions are emerging that do just this, it remains the case that "support for families and for people affected by dementia is often fragmented and varies tremendously across the country" (Brooker, 2017). Some areas of the country, it should be noted, offer no provision of this type at all.

The case studies described here are mainly 'pilots' in that they test particular ways of working. Some have directly 'piggy-backed' on existing dementia services and programmes while others have sought to establish new programmes distinct from others already in existence, sometimes overlapping. A number of themes emerge and intersect here:

1. The Role of Research

Many of these projects have been driven, or extended, through research partnerships. These have forged links between across England and Wales (Demenitia & the Imagination) or extended links to European models (Meetingdem). More modestly, others projects have looked to their local universities nearby to support their work and help develop it in more regional contexts (Chester, Glyndwr and John Moores Universities).

While desirable, research partnerships bring their own challenges in terms of scale and funding. As has been noted, the large amounts of money spent on research can exceed that devoted to the project being studied, leading to some discomfort around the relative allocation of resource. While such complaints "misunderstand the nature of research funding" Gill Windle and her colleagues also acknowledges that "coming from a third sector organisation looking for alternative funding sources, particularly in a period of financial austerity, is an understandable comment" (Newman et al, 2017: 8).

This problem of relative scale and funding necessary for research is reflective of the fact that it is common for those delivering Arts in Health projects to feel unable to conduct evaluation on their own behalf. "Despite a general understanding of the importance of evaluation, less than two thirds were able to undertake this task as well as deliver on their projects" (ACW, 2017: 75). Pressures around self advocacy are also strongly felt.

The degree to which projects are able to sustain themselves financially is not only due to the 'evidence' that research and evaluation can provide. Differing policy and funding frameworks across regional contexts also play their part. In this way, longer-term sustainability does not always depend on what is "known to work", but on other, more random factors (such as the commitment to this area of work by any given commissioner or the particular emphasis of a regional health board). The challenge appears to be less one of robust evidence - which has now gathered much momentum in this field - so much as the challenges of implementation, funding and sustainabilty. Further scrutiny could be given to the

commissioning process itself in the precise use it makes of research as it is often uncertain as to what criteria is being used to judge proposals.

For example, the NHS's own innovation agency - The Academic Heath Science Network, aims to present "opportunity to align education, clinical research, informatics, innovation, training and education and healthcare delivery." This body leans towards technological innovation and there is uncertainty whether pyscho-social approaches and interventions 'count' in this context. Acknowledging the focus on medical technologies, Jennifer Dodd, the AHSN lead for the North West notes that "We don't reach into that space as well as we might…" This focus mitigates against the innovative pyschosocial interventions which have been found to be effective - and cost effective too - in relation to early-stage dementia.

2. The role of policy contexts

The two recent reports act as catalysts and present opportunities to explore shared research initiatives in the future. *Creative Health, The Arts, Health and Wellbeing*, (APPG, 2017) though aimed primarily at English decision-makers, also includes Welsh case studies and discusses devolved contexts for Arts in health around the UK as a whole.

Meanwhile, the more recently published *Arts and Health in Wales, A Mapping study of current activity* (ACW, 2018) recommends the exploration of a National Research Network. within Wales. Significantly this also notes how any new body would also need to collaborate with universities beyond Wales. It notes how:

> We should look outwards to learn from international research in the Arts and Health field and connect, if possible, with the new Strategic Centre proposed for England through the Creative Health report (ACW, 2018: 91).

Perhaps this is an area of work where the Welsh and English bodies could actively support joint research initiatives going forward, especially as dementia has been identified as key focus in relation into research in both reports. *Creative Health, The Arts, Health and Wellbeing*, identifies particular gaps for research namely:

> prevention, management of long-term conditions and delaying dementia onset and admission into residential care. We need more evidence of sustained benefits in larger population groups over time which invite further comparison in order to find shared aims (APPG, 2017:156).

The distinctions made here around the stages of dementia appear key to understanding which interventions are also most effective. This is something that the Art of Referral has begun to explore: how community contexts work alongside hospitals and care homes to better support people's independence.

3. Organic versus strategic growth

Growth in this field to date has been organic not strategic (although this is now perhaps beginning to change in Wales, which is adopting a more consistent offer across its seven health boards through a unique new partnership between ACW and the NHS Federation.) One interviewee underlined the necessity of identifying where need is, not just where the possibilities (for funding) lie. This is perhaps a key distinction when thinking about what constitutes the 'creative economy' in this particular field. It relates to the wider economy and its uneven - and unequal - distribution of resource across different regions.

Creative Health underlines 'the social determinants of health' as a key concept that under-pins current health policy. Taking the World Health Organisation definition, it understands social determinants to be the conditions in which people are born, grow, work, live, and age, and the wider set of forces and systems shaping the conditions of daily life. It further notes that:

> Many would agree that unequal distribution of power, income, goods and services within and between countries creates large differentials in health and wellbeing (APPG, 2017: 10)

While acknowledging that the arts cannot address these structural inequalities, it does propose that they can mitigate the negative effects of adverse environments. In this way, the *Creative Health* report aims to "bridge the gap" between an embrace of strategies tackling the social determinants of health and an acknowledgement of the role the arts can play. Report author, Rebecca Gordon-Nesbitt has spoken specifically around this in relation to dementia, pointing to studies which show that those people at the early stage of diagnosis go on "die younger than those that live in affluent areas".

This presents an ethical dilemma for those seeking to take more entrepreneurial approaches, or at least invites more discussion of the relationship between the state and private-finance interests and how they can combine around the public good. Any impetus for 'growth', driven by innovation or not, must be carefully thought through as a result.

4. The Role of Networks

Networks remain a key, if often unacknowledged factor, in how successful projects are sustained. Recently, the director of The Baring Foundation, David Cutler, praised Wales's approach to innovation in relation to dementia care in the arts, calling it "Welsh Magic". https://baringfoundation.org.uk/blog-post/welsh-magic-whats-behind-the-magnificent-work-taking-place-in-arts-with-older-people-in-wales/

He claims that Wales is "better networked" than England, also citing collaborative approaches and leadership here as key to success. His account of the deeper reasons for the success of this approach are worth quoting at length perhaps:

Wales has some structural advantages, not only in scale but in innovations such as the creation of the officer of [Older People's Commissioner](#), combined with her clear appreciation that culture is a right for older people. New legislation, the Social Services and Wellbeing (Wales) Act 2014, is also offering new opportunities and these are being taken in a practical ways such as the [Age-Friendly Communities Resource Hub](#) (Cutler, 2017).

Such observations around how centralised strategic policy can work alongside more adaptive local practices invite further attention. Dementia Connect brings a wealth of more general resource around the importance of networks, showing how "universities can help build R&D-driven regional networks across sectors in order to identify, connect, and nurture creative talent" as well as "identify key issues in these sectors" (Senior, 2016: 9).

5. The field of Arts in Health: a national reconfiguration

Finally, it is worth noting how the field of Arts in health is itself set to become less centralised and more regionally dispersed in the very near future. At the time of writing this report, the National Alliance for Arts Health and Wellbeing (which for four years has been supported by the London Arts in Health Forum, or LAHF) was being amalgamated with the National Alliance for Museums, Health and Wellbeing to create The Culture, Health and Wellbeing Alliance. This a new membership organisation will seek to represent all those who believe in the value of cultural engagement and participation for our health and wellbeing.

The new Alliance will provide monthly updates on policy and developments in the field, as well as training, conferences and events. It will advocate for the work at a regional and national level and work with cultural organisations and their partners so that more people can benefit from the impact of high quality cultural experiences.

The Culture, Health and Wellbeing Alliance will be an Arts Council England Sector Support Organisation delivered by Arts & Health South West. It has a clear aspiration and remit to unify and advocate for this work and it is likely that it will generate significant traction for this work in England and perhaps can generate support further afield.

Conclusion

The context for this specific field of inter-sectoral work diverges across devolved nations and cities - not just across the Welsh and English border, but between devolved English cities too (in Manchester and Liverpool). How can boundaries be constructively breached, as well as respected? Research partnerships and Arts in Health networks can join together better to play a role in providing more effective and equitable services.

The wider context of European work is most especially at stake with the UK's imminent withdrawal from the EU set for 2019. This single event might be the catalyst alone for UK researchers and partners to share their knowledge and thoughts for how to best progress the work within a UK context, post-Brexit.

How can existing networks be better supported and make themselves understood to one another and decision-makers alike? These case studies show distinct strengths, but also serve to highlight weaknesses, contradictions and dangers around current thinking and understandings around 'growth' and 'innovation'. *Dementia Connect* would be wise to acknowledge these going forward as it develops its own innovation pathway model.

Questions inevitably arise as to which models might be best extended where, up to what scale and within what regulatory and policy framework. The answers to these question lie well beyond the scope of this study. But it is our hope that the comparison across case studies made available through this report have clarified some of the emerging issues, highlighting the challenges of how existing programmes work alongside each other and where future potentials might lie.

Appendix

An Artist's Approach

Kate Eggleston-Wirtz brings a strong background of working with people diagnosed with dementia, along with experience of working in illustration and design (http://eggwirtz.com). She admits that the brief for *Drawing on Strengths* was a "learning process". Though the concept of social assets was not new to her, the task of interpreting this through her own practice was more novel in this instance and context.

Her main concern and focus for this project was with language, both verbal and visual, as well as the different types of language used by medical professionals in relation to their patients. She was very aware, she says, of needing to interpret the brief in a way that people with dementia would understand, work with, even enjoy - through taking a creative approach to thinking about the positive aspects of their own lives at a time of anxiety and fear.

Kate consulted with two groups twice, one at Mossley Hill Hospital and SURF (Service User Reference Forum) engaging them primarily through creative conversation with opportunities to draw. Through these sessions a better understanding of the project was achieved. The groups were then able to articulate how "life does not end with a diagnosis of dementia" focusing on community engagement post diagnosis. They suggested the images of a tree as a metaphor for life providing a framework on which activities that gave meaning to them could be placed. Kate took up this image, creatively responded and created graphic motifs for different areas of life.

The motif of the tree subsequently mutated into a 'field' of colour as it was made clear through the process that the wall mounted paper resource needed to be simplified for better understanding and higher visibility. However, the tree became a powerful metaphor out of which conversations around 'social assets' might be meaningfully generated and useful within a session setting. Thus Kate developed a three-dimensional resource to be used in the post diagnostic sessions and tested using ideas created through the consultation. These initial designs and ideas with the on-going support of Mersey Care are aimed to enhance the current post dementia diagnostic delivery programme. This plan includes an evaluation of how useful such an approach might become an integral part of their course and wider offer.

What is a 'social assets' approach?

The term 'social assets' has gained common use across many disciplines over recent decades. A useful briefing paper, by the Glasgow Centre for Population Health on the concept and its usage, shows the variety of its application in diverse contexts over time:

> Early psychiatry literature refers to the importance of 'assets' as a foundation for managing change (Beiser, 1971), and the health assets concept was introduced to nursing practice in the 1980s (Barkauskas, 1983). The term 'health asset' is also used in psychology (Petersen and Seligman, 2004), social sciences (Kolm, 2002) and more extensively in public health (Murray and Chen, 1993; Halfon and Hochstein, 2002; Friedl et al., 2005).

Some researchers have noted how the term has, on occasion, evolved directly as a rejection of the (negative) effect of being given a medical diagnosis. Lynne Friedli, points out how:

> Asset-based approaches draw on the language of recovery, which traditionally adopted a strengths-based lexicon as a form of resistance to the imposition of psychiatric labels and diagnostic categories (Freidli, 2012).

However, the term is most commonly used in relation to preventative health measures, as much as those of recovery, cited as a way of highlighting the positive resources at people's disposal which allow them to stay well (as opposed to concentrating exclusively on the negative impact of illness). Social assets are now widely recognised as the "protective and promoting factors to buffer against life's stresses" (NICE, 2009).

In this regard, a social asset approach sits amongst other related concepts such as 'social capital' (Putman, 1998), the 'social determinants of health' (Wilkinson & Marmot, 1998), and 'salutogenesis' (Aronovsky, 1996). Health sociologist, Aaron Aronovsky, developed the term 'salutogenesis' to denote the creation of health through an ongoing process of healing and recovery. He rejected a binary notion of illness / wellness, coupling them into a more nuanced continuum over the life span, including later life. Some have seen specific value in applying a social asset approach when working with older people where many negative assumptions can come into play:

> A salutogenic orientation on health in later life helps to counteract stereotyping "the elderly" as diseased and reconceptualise questions about health in later life towards why and how aged persons stay healthy and cope well with chronic illness (Sidell, 2009).

All of these related ideas and terms emphasise underlying societal factors and conditions which together combine to inform the state of our health. Our awareness of these factors, however, either as individuals or as communities, can be limited:

> Assets can be described as the collective resources which individuals and communities have at their disposal, which protect against negative health outcomes and promote health status. Although health assets are a part of every person, they are not necessarily used purposefully or mindfully. An asset based approach *makes visible* and values the skills, knowledge, connections and potential in a community. It promotes capacity, connectedness and social capital (GSPH, 2011).

This 'visibility' of assets can be seen in terms of people's own awareness of what will best enable them to keep well, encouraging people to take an active role in their own care.

However, while many policy literatures claim they adopt a 'social asset' approach, there are far fewer examples of how this notion is applied in clinical or community settings. Some attempts have been made towards this, both individually (Foot & Hopkins, 2010)

and more collectively, through group work (Janjua, A. & Goss, S. 2012). (The latter report give guidance for how to run an asset-mapping workshop, for example.)

Some commentators, by contrast, have questioned the usefulness of the concept of 'social assets' in real life contexts. These cite a poor evidence base, pointing out that many exemplar projects only claim to use this approach in retrospect. One Arts in Health advocate also qualifies the term, emphasises creative participation over any economic interpretation of the term:

> a process of emotional transaction through creative participation… makes for genuine empowerment rather than a balance sheet deduction of how much social or cultural capital a community may possess (White, 2009: 60)

Lynne Friedli also gives a nuanced critique of the term in which she warns against psychological resources being privileged over those of material wealth, serving to obscure or downplay the effects of socio-economic inequality and poverty (Freidli, 2012).

As these examples of academic literature on the topic demonstrate, whilst the language of 'social assets' draws on the terminology of economics - and can indeed include measurements of economic wealth - it seeks to recognise broader psycho-social resources. These are often harder to quantify, measure or even name (and can include such things as: self-esteem, confidence, purposefulness, knowledge and skills, resourcefulness and resilience). Creative interventions may offer a way of making visible these more elusive factors, providing alternative methodologies to more traditional forms and formats.

<u>References</u>

Antonovsky, A. (1996). The salutogenic model as a theory to guide health promotion. *Health Promotion International, 11*, 11–18.

Foot, J. & Hopkins, T. (2010) A glass half-full: how an asset approach can improve community health and well-being. The Improvement and Development Agency.

Friedli, L. (2012): 'What we've tried, hasn't worked': the politics of assets based public health , Critical Public Health, DOI:10.1080/09581596.2012.748882.

GCPH (2007) Asset-based Approaches for Health Improvement: Redressing The Balance. p 5.

Janjua, A. & Goss, S. (2012) Ageing Well, An Asset Based approach. Local Government Association.

Putman, R. (2000). Bowling Alone: The Collapse and Revival of American Community. simon & Schuster.

Sidell, M. (2009). Older people's health: Applying Antonovsky's salutogenic paradigm. In C. Lloyd, L. C. Jones, & J. Douglas (Eds.), *A reader in promoting public health. Challenge and controversy* (pp. 27–32). London: Sage.

White, M. (2013) Arts Development in Community Health: A Social Tonic. p 60.

Wilkinson, R. & Marmot, M. (2006) Social Determinants of Health. Oxford University Press.

9. References and links in the main report

Alzheimer's Society (2013). Guidance for Communities Registering for the Recognition Process for Dementia-friendly Communities. London: Alzheimer's Society, p. 2. https://www.alzheimers.org.uk/downloads/download/911/guidance_and_criteria_for_the_recognition_process_for_dementia-friendly_communities

APPG (2017) Creative Health: The Arts for Health and Wellbeing, All Party Parliamentary Group. http://www.artshealthandwellbeing.org.uk/appg-inquiry/

Arts Council Wales (2018) 'Arts and Health in Wales, A Mapping study of current activity Volume 1: Analysis, findings and proposals'. http://www.arts.wales/arts-health/

Brooker, D. (2016) Not re-inventing the wheel: the adaptive implementation of the meeting centres support programme in four European countries. https://doi.org/10.1080/13607863.2016.1258540/

Creative Economy Knowledge Exchange Hubs, AHRC http://www.ahrc.ac.uk/documents/project-reports-and-reviews/creative-exchanges-ke-hubs/

Cuter, D. (2017) Welsh magic: what's behind the magnificent work taking place in arts with older people in Wales? The Baring Foundation. https://baringfoundation.org.uk/blog-post/welsh-magic-whats-behind-the-magnificent-work-taking-place-in-arts-with-older-people-in-wales/

Dementia Connect https://dementiaconnect.dcrc.org.uk

Local Government Association (2015) Dementia Friendly Communities: Guidance for councils. London: Local Government Association. https://www.local.gov.uk/sites/default/files/documents/dementia-friendly-communi-b7f.pdf

Newman et al (2016) 'Carrying out research across the arts and humanities and social sciences: Developing the methodology for Dementia and Imagination'. Taylor and Francis. https://www.tandfonline.com/doi/full/10.1080/09548963.2016.1241338

Meeting Centres Support Programme: Overview Evidence and Getting Started https://www.worcester.ac.uk/documents

Senior, T. et al (2017) Connecting to Innovate A Preliminary Report on the Achievements of the AHRC Knowledge Exchange Hubs for the Creative Economy. UWE Bristol
http://www.creativeworkslondon.org.uk/wp-content/uploads/2016/07/Connecting-to-Innovate-Final.pdf/

The Academic Heath Science Network
https://www.england.nhs.uk/ourwork/part-rel/ahsn/

Windle, G. et al (2017) Exploring the theoretical foundations of visual art programmes for people living with dementia. Sage. p 1-26.
http://journals.sagepub.com/doi/abs/10.1177/1471301217726613

10. Thanks

Kate Eggleston Wirth's initial design for a post-diagnostic resource for Mersey Care, co-developed with SURF.