



Shifting Paradigms for Dementia: involving people living with dementia across research, policy and practice.

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For more information about the project, please visit our website.

<https://memoryfriendly.org.uk/programmes/shifting-paradigms-in-dementia/>

Executive Summary

- This programme of knowledge exchange sought to stimulate new ways of thinking about dementia within academia, policy and practice through the adoption of rights and asset based approaches towards dementia and the inclusion of people with dementia within their communities.
- The programme consisted of a series of five workshops, with each workshop focusing on how rights and asset based approaches to dementia can drive forward transformational change across a different area of dementia research, policy and practice; inclusion of people with dementia in dementia care policy; technology, dementia and social inclusion; dementia friendly communities and community empowerment, dementia and design and dementia, the arts and creative inclusion.
- Each of the events included local, national and international speakers, and attracted a wide range of attendees across both academic, policy and community based audiences. People with dementia attended all of the sessions, and provided several keynote sessions at four of the workshops, including an opening keynote session for the series.
- One of the workshops was located in Dementia Friendly East Lothian, a dementia friendly communities initiative and one of the project partners who provide a range of community outreach activities within the East Lothian area of Scotland. The session was highly attended, involved international keynote speeches, and led to a number of spinoff activities within the local community.

The main messages, highlights and insights to emerge from the programme include:

- Rights and asset based approaches to dementia and dementia care are gaining prominence and have the potential to lead to transformative change in both the provision of care and support, and in enabling people with dementia to continue to be fully participating members of their communities.
- Such approaches can pose a significant challenge to many current approaches to dementia policy and provision, however such challenges should be embraced, given their potential to lead to meaningful benefits for people living with dementia.
- Scotland has adopted a leadership role in terms of adopting and driving person centred, inclusive, rights and assets based approaches to dementia and dementia care practice. The gains associated from this leadership role should not be lost, and therefore need continued support at all levels of dementia policy and practice.
- The potential for innovative, rights and assets based approaches to dementia in Scotland, alongside the benefits they can bring are significant. A wide range of innovative projects working at a grassroots level are present in Scotland which cut across the five subject areas explored in this programme, and are leading to real gains. These gains should not be lost.
- While there are a range of projects promoting inclusion and participation of people with dementia, there is a need to continue supporting these organisations, in particular in helping them to learn from each other. Organisations such as Life Changes Trust, Alzheimer Scotland and the DEEP and TIDE networks are playing a key role in supporting the wider learning of such organisations.

Programme Context

The number of people affected by dementia is growing rapidly and is projected to more than double within the next 30 years. The projected rise in people affected by dementia poses a key political, social and economic challenge for Scotland. Dementia costs the UK £23 billion per year – more than heart disease, cancer and stroke combined. This challenge has also arisen against a backdrop of global economic and political uncertainty, which has led to questions about how far public health and social care services will be able to meet the needs of a growing population of people living with dementia. Unsurprisingly then, dementia is currently a politically hot topic, with attention focusing predominantly on how we might cure it and how we might treat it. Yet while the search for effective treatments goes on, the wider question of the role people with dementia will play in society, and what they will need to support their continuing involvement have been neglected. Yet, current research by the applicants and their networks has underlined a significant lag between person centred and rights-based policy regarding people with dementia and actual practice on the ground. People with dementia report facing social, political, cultural and physical barriers to their community participation, still have problems accessing mainstream services and have a limited say over how such services operates. As a result and despite the rhetoric, the interests of people with dementia are frequently overlooked the level of health and social care delivery, as well as at a broader community level.

Scotland has proven to be a world leader in driving a recognition of people with dementia not as passive recipients of care, but as active agents, able to, demanding of and having the right to participate fully within society. In Scotland, the response to the challenge of dementia has been to pioneer a rights-based approach to dementia, driven in large part by people with dementia themselves, and spurred on by extensive campaigning and awareness-raising by organisations such as the Scottish Dementia Working Group and DEEP Network (Dementia Empowerment and Engagement Project). Driven by the growth of community organisations and activists, people with dementia themselves are increasingly demanding that they be included as active participants within society, fully accorded their rights as citizens. Examples of Scotland's place in advocating for what have been termed rights and asset-based approaches to dementia include the Scottish 5 and 8 pillars models, as laid down within the 1st, 2nd and 3rd Scottish Dementia Strategies. The growth of these approaches within Scotland also reinforces the potential benefits that more collaborative, inclusive approaches to dementia, which engage with the perspectives, experiences and priorities of people living with dementia can bring. Scotland has been an exemplar of the adoption of a rights-based approach to dementia, and has been recognised internationally with a variety of organisations, with other countries developing advocacy groups which represent the rights of people with dementia based on the Scottish model. However, despite such a forward thinking and inclusive approach to Dementia being adopted in Scotland, in practice how services are provided to people with dementia, or people's ability to participate in society can still be significantly limited.

This programme sought to build on Scotland's existing expertise in driving new perspectives around dementia by putting forward new ways of conceptualising dementia within research, policy and practice. In doing so, the programme demonstrated how the adoption of rights and asset-based approaches to dementia continues to challenge current perspectives regarding dementia, which can lead to transformative change. Focusing on three domains (Technology, Dementia Friendly Communities and the Arts) which have seen increasing attention as a means to improve the lives of people with dementia, our goal was to explore how new ways of thinking about dementia, which support the use of community assets and connections. Rooted in people with dementia and their

experience, the programme promoted a re-conceptualisation of dementia based on assets and rights-based approaches to community engagement. Consequently, this programme offered up a catalyst for change, by demonstrating the potential for rights-based approaches, exploring the challenge of translating rights-based policy into everyday practice, and by providing examples of media and activities through which such translation could be achieved. The programme fits closely with SUII objectives for promoting interdisciplinary exchange between groups that may not otherwise have had the opportunity to connect. We are also addressing a key policy focus for Scotland by exploring mechanisms for empowering local communities.

Main Objectives

Adopting a rights-based approach to dementia, the over-arching aim of the programme was to explore methods through which people living with dementia could influence change within their communities, and how such changes could challenge existing orthodoxies in relation to dementia care policy and practice. With support from an interdisciplinary network of national and international academics, researchers, practitioners and activists the programme explored how knowledge exchange can take place, across five key domains in relation to dementia; around overall dementia policy, in relation to technology, dementia friendly communities, the arts and architecture and design. These domains were chosen as areas which demonstrate how adopting rights based and inclusive approaches to dementia can change policy and practice.

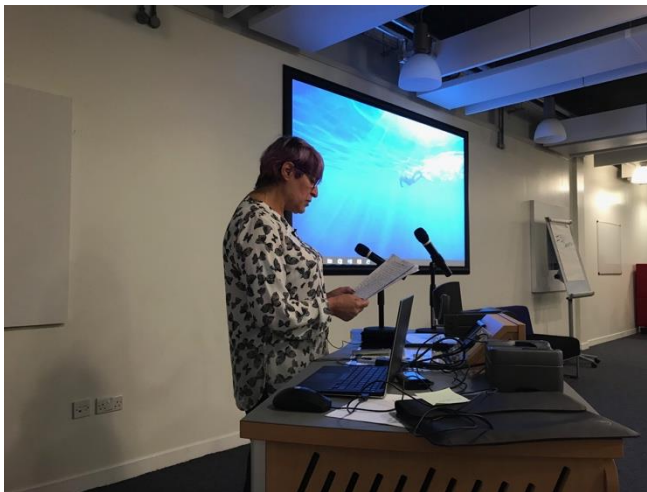
Our objectives, explored over the course of a series of five innovative knowledge exchange workshops include:

- To provide a critique of current conceptualisations of dementia and build approaches to dementia based on rights, assets and community involvement.
- To promote knowledge exchange within three four domains – dementia and technology, dementia friendly environments and communities, and dementia, the arts and architecture and design.
- To encourage debate across disciplines and across policy, research and practice which is inclusive of people living with dementia, and to inform new forms of dementia practice.

Programme Structure

The programme was structured around five knowledge exchange workshops, each dealing with a specific theme. Themes were identified as subjects in which new conceptualisations of dementia, demonstrated within examples from the academic and policy literature are being developed, which could lead to potential transformations in dementia policy and care if they were to be adopted more widely. In each workshop, current paradigms in relation to dementia were subject to critique, before new conceptualisations for dementia within the three domains, alongside examples from practice were offered. In order to ensure that each workshop was as participatory and inclusive of people living with dementia as possible, interactive activities were placed at the core of each workshop. Such activities demonstrated the potential for new conceptualisations of dementia being offered within real world practice.

Workshop 1. October 2017. *Shifting paradigms: The politics of dementia in an era of uncertainty.*



The first workshop sought to set the scene for the wider programme by providing an overview of our key goals, and more importantly detailing how, despite significant progress, people with dementia currently face significant challenges if they are to participate in society. Further goals of the workshop included a discussion of how these challenges enable or indeed undermine the inclusion of people within policy frameworks, and what needs to happen if a truly rights-based approach to

dementia is to be felt on the ground. It was essential that the voices of people living with dementia are at the centre of the discussion. Therefore, our first two speakers were Joy Watson and Agnes Houston MBE; two people living with dementia who have become powerful advocates in England and Scotland for the need to hear and include people with dementia in policy making and service delivery. We first heard about Joy and Agnes's experiences of dealing with two important elements of state service delivery, namely around the provision of post diagnostic support services, and experiences of the dementia assessment. Both presentations challenged the inclusive rhetoric emerging from much current policy making in dementia by arguing that while policies such as self-directed support or the provision of 1 year's post diagnostic support for people with dementia in Scotland are laudable, they are still a long way from being effectively delivered on the ground.

The afternoon session moved from the perspectives of individuals living with dementia to next capture perspectives from the growing number of dementia advocacy groups, which are providing powerful collective voices for people living with dementia. Philly Hare, from Innovations in Dementia spoke about the rights-based philosophy underpinning the DEEP (Dementia Engagement and Empowerment Project) network, a national network of people with dementia. Finally, Paul Thomas, also representing DEEP, provide a detailed and powerful critique of the 3rd and current Scottish Dementia Strategy. Specifically, Paul's critique revealed that, although Scotland has proved extremely innovative in promoting rights based and participatory approaches in its policy making in relation to dementia, the 3rd Scottish dementia strategy was a step backwards compared to its previous strategies.

More details, including video recordings of the workshop can be found at

<https://memoryfriendly.org.uk/programmes/shifting-paradigms-in-dementia/the-politics-of-dementia-in-an-uncertain-era/>

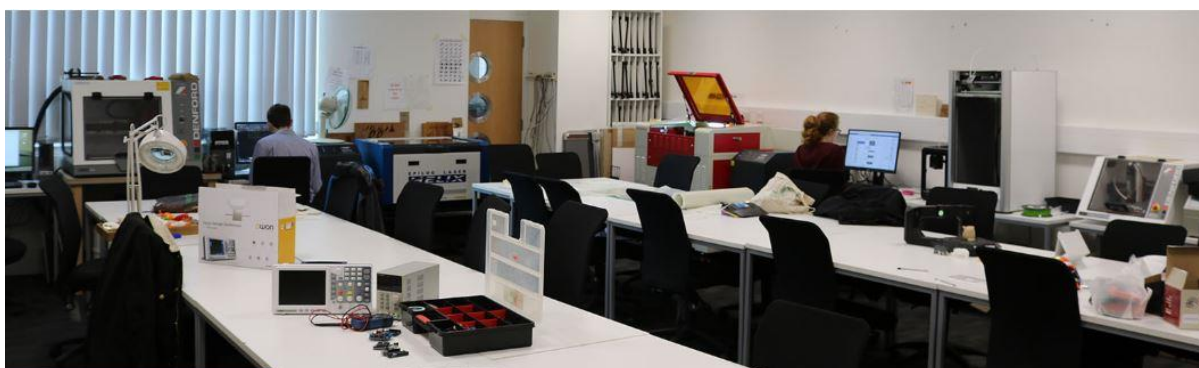
Workshop 2. November 2017. *Dementia, technologies and digital inclusion*

In our second workshop, we discussed the increasing role of technology within dementia care, some of the policy rhetoric's regarding technology enabled dementia care and how alternative ways of thinking about technology can produce care in ways which are both inclusive for people with dementia, which provide individualized and personalized solutions according to their needs and which



actually work for them in practice. In the morning we heard about an innovative technology programme being led by Alzheimer Scotland called 'Dementia Circle' which crowd sources information about everyday technologies and provides advice and guidance to people with dementia about how they can make use of these technologies in their everyday lives. Dementia Circle is significant in posing a shift away from 'one size fits all' approaches to most care technologies, to instead consider how the potentially vast range of everyday technologies can help people develop their own, individual care arrangements using technology, based on their individual needs. Dementia Circle is therefore an example of focusing on what people with dementia want from technology, rather than what services think they need. After this we heard from Matthew Lariviere, a PhD student from the University of East Anglia, who spoke about how people with dementia make use of technologies in their everyday lives, and what they need if technologies are to work for them. This question of what is needed to make technologies 'work' was continued by Andrew Eccles from the University of Strathclyde, who spoke about how current policies around the provision of technology in dementia currently do not reflect how people with dementia actually make use of technology, as well as suggesting what changes to policy may be required.

In the afternoon we gave attendees the opportunity to gain some hands-on experience of developing prototype technologies for people with dementia. Dr Diane Pennington led a session which explored the potential to personalize assistive technology solutions in order to meet individual's needs. Held in the 'fab lab' at Strathclyde University, over a two-hour session attendees were given the opportunity to develop their own ideas for technological solutions for people with dementia. Using the example of wayfinding which emerged during discussions between attendees, a number of simple prototype keyrings were produced, which could include the names and addresses of a person with dementia.



Such an object provides a simple, unobtrusive technological solution for a person, could be easily 'upgraded' to include a GPS chip. The fab lab session illustrated the potential for individualizing technologies according to individual need, as well as the benefits that emerge when people living with dementia are included as equal participants within the design process. Due to size of the fab lab, not all people at the workshop could attend, so a second parallel session, led by Dr Grant Gibson explored what needs to happen if personalized approaches to assistive technologies can be delivered as a routine part of dementia care, and how people with dementia can be included in this process. A range of both assistive and everyday technologies which can help people with dementia were on display throughout the day, and gave people attending the event to have a look at just some of the devices currently available to help people living with dementia.

More details, including videos of the workshop presentations can be found at <https://memoryfriendly.org.uk/programmes/shifting-paradigms-in-dementia/dementia-technologies-and-social-inclusion/>

Workshop 3. January 2018. *People and Place: Dementia Friendly East Lothian (DFEL)*



In our third workshop, we wanted to explore what makes up a living and breathing dementia friendly community, in order to explore what makes these organisations work, and what they need in order to become successful. In order to do so, we located the workshop within Dementia Friendly East Lothian, a Community Interest Company with the focus of promoting dementia friendliness and inclusiveness across the communities of East Lothian. In addition, locating the workshop within a dementia friendly community gave us the opportunity to connect national and international research to practices within our local communities.

First, a number of people with dementia within involved with DFEL spoke about their priorities and experiences of being involved in creating a dementia friendly community. Following this session, we heard from a number of national and international academics about the importance of community-based initiatives in driving dementia friendly communities. Professor Myrra Vernooij Dassen from Radboud University introduced us to the concept of social health, which prioritises social and community connections as a means of supporting people with dementia to live independently as valued citizens within their communities. Social Health poses a challenge to biomedical definitions of health by focusing on the role that social interconnectedness plays in driving good health, as well as enabling those people with dementia to continue to live well. Professor Dawn Brooker then spoke about an evaluation of the Dutch model of meeting centres to support people with dementia in their communities. Such centres are run in and by the community, provide a rich social and cognitive environment for people with dementia and are an example of an effective, community based programme which can boost the health, well-being and quality of life of people living with dementia.

In the final session of the day, Cormac Russell from Nurture Development and Northwestern University, introduced the workshop to asset-based community development, a premise that argues that communities themselves are best placed to act as drivers for change by using a wide range of local, existing but often unrecognized community assets. This presentation formed the basis for a group workshop, which focused on how local communities can provide real support to people with dementia, and what needs to happen in order to support communities to do so. Workshop 3 provided a real highlight for the programme, and demonstrates what can emerge when academic experts, policy and service providers and people living with dementia are brought together to promote real change.

A pre workshop event was also organized between DFEL and the DEEP which focused on providing a forum for discussion between people with dementia and their carers. This meeting focused on what mattered in terms of dementia friendly communities at grassroots level, and fed into the topics under discussion during the workshop on the following day. Several of the people with dementia and carers who attended this pre workshop event also stayed to attend the workshop.



More details, including videos of the workshop presentations can be found at <https://memoryfriendly.org.uk/programmes/shifting-paradigms-in-dementia/community-empowerment-and-dementia/>

Workshop 4. May 2018. *The Arts, Dementia and Cultural Inclusion*



The two final workshop took place at the University of Stirling. The first workshop, exploring the arts and dementia was held at the MacRobert Arts Centre and explored the transformative role of the arts in dementia, and the potential for arts-based approaches to creatively engage with people with dementia. During the day a number of examples of the use of the Arts in dementia were demonstrated through several interactive activities. First, artwork from the Artist Edward McLaughlin was displayed, while Edward also discussed his work and its role in challenging common assumptions about dementia. All delegates were given a copy of a book cataloguing Edward's work. Magdalena Schamberger then discussed the use of humour as a tool to connect with people with dementia.

Alongside more traditional presentations, a range of interactive and arts-based activities also took place. An interactive activity from With All explored co-creativity with people with dementia, demonstrating a ten-week co-creative arts project using non-verbal arts such as music and dance. The presentation illustrated some of the ways in which co-creative arts can be effective for people with dementia, as well as some of the challenges involved in using such methods.



Dr Claire Garabedian from the University of Worcester introduced those attending the workshop to the value of music as a shared activity. During her presentation Claire gave a performance of her use of music as a therapeutic activity with people with dementia. Paul Hudson then discussed the use of Dance in a creative project at the Festival Theatre, Edinburgh

Andrew Clarke from Salford University also discussed the use of Arts based and wider creative approaches as a research tool within the 'Neighbourhoods: our people, our places' project. Such methods have proved useful in terms of developing and communicating stories emerging from research and demonstrated how such stories can be told using visual media such as comics.

More details, including videos of the workshop presentations and activities can be found at <https://memoryfriendly.org.uk/programmes/shifting-paradigms-in-dementia/arts-and-dementia/>

Workshop 5. May 2018 *Architecture, Design and Dementia*

In the second workshop we focused on the role of design and the environment in supporting and enabling people living with dementia. This is an area where the University of Stirling has a worldwide reputation for excellence and the dissemination of good practice. Our aim for the day was to challenge current thinking and practices in the design community and not least the overall exclusion of people with dementia in the design process.

The day began with a co-design workshop led by students at the School of Architecture and Landscape Architecture at the University of Edinburgh. Continuing our theme of offering people 'hands-on'



practical experience of new and innovative approaches the architecture students worked alongside delegates including people with dementia and carers to highlight and explore design challenges from the perspectives of people with dementia. We used a range of materials to visually represent and model design ideas and showed how collaborative working on design can be used as a route to ensuring that design of the built environment attends more closely to the perspectives and

needs of people with dementia. As a part of the morning workshop we also heard from Lesley Palmer, the Chief Architect at the Dementia Services Development Centre at the University of Stirling who outlined the work of the Centre and highlighted some of the key considerations for dementia-friendly design.

In the afternoon we heard from firstly from Dr Chrissy Buse from the Buildings in the Making project at the University of York who discussed current architectural approaches to the design of dementia care settings such as care homes and senior 'villages'. We were also delighted to welcome Dr Jos Boys whose work on disability and architecture has been widely influential in helping to transform design practices in the architecture industry. Jos looked at the parallels between issues for disability and design and dementia-related design.

Innovation in Knowledge Exchange



The programme used a mix of traditional academic presentations alongside interactive activities and performances as means of knowledge exchange. It was important for the programme to discuss often weighty policy issues, but also ensuring these discussions were engaging for attendees, including the many people living with dementia who attended our events. As a result, we attempted to make sure that each workshop included a mix of presentation and activities, as well as frequent rests. The DEEP groups provided invaluable advice regarding how the workshops could be run in ways which ensured they were run in a dementia friendly manner, such as in the use of cards to indicate if a person had a question. This advice was invaluable, and certainly informed the development of future workshops in the programme after the first.

The programme also gave us the option to use a range of innovative forms of knowledge exchange. Three are highlighted here. In the first, the 'hackathon' session in workshop 2 was a great success, not least in terms of encouraging attendees to co-create with people living with dementia. This activity has provided the impetus for us to further develop this activity into a fully-fledged Hackathon, and we will be looking for further support to hold this event via follow up funding from SU11 or from other sources.

In the second form of knowledge exchange, we held workshop three within a dementia friendly community project. This was a great success and was by far our best attended event, both in terms of numbers and in the range of delegates and breadth of organisations they represented. Holding this workshop enabled us take our programme from an academic, university setting right into a dementia friendly community, ensuring that a range of different attendees from various local community and political organisations attended. The shared learning that occurred from this setting created a real momentum for change – not least due to the attendance of local politicians who were involved in Scottish transport policy, who were visibly moved by discussions, and who would feed back the discussions during this workshop into future transport policy in relation to older people. Situating the workshop with a dementia friendly community also gave attendees to see what makes such communities work in practice and the various challenges they faced in implementing them.



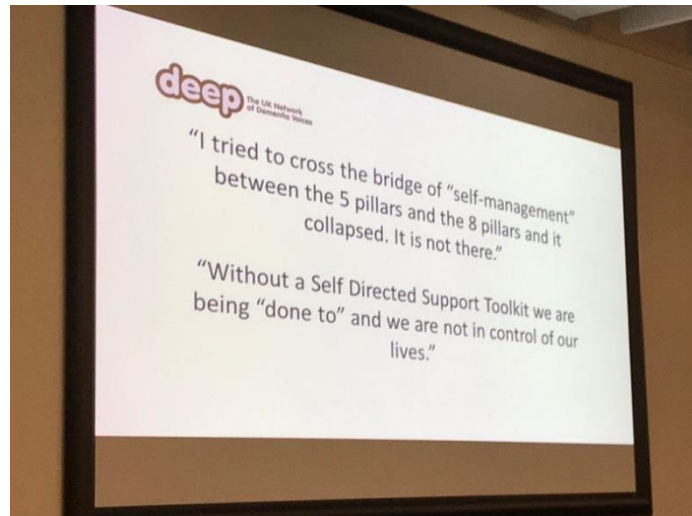
The third form of knowledge exchange highlighted here are the inclusion of a series of poster visual records for each workshop. The posters, funded through SUII and provided by a graphic design service, provided visual form of minute taking of the workshops, and highlighted each of the key points discussed during the workshops in a visually stimulating way. The visual records were extremely well received, provided a locus for a number of discussions among delegates, and have also enabled us to present the workshops at a number of other venues, including the Scottish Dementia Research Consortium annual conference, as well as at a number of events held within the Dementia and Ageing Research Group at the University of Stirling.

Knowledge or understanding emerging from the programme and key recommendations for end user / policy communities

A key feature of the programme, and reflecting the increasingly multi-disciplinary nature of dementia care practice, was that it brought together experts within dementia care policy and practice from a range of different perspectives. Events brought together national and international experts, as well as expertise from people with lived experience of dementia, and stakeholders involved in the provision of local dementia care services. The workshop held in Dementia Friendly East Lothian exemplified this approach, and indeed its taking place within the community itself meant that national and international experts were brought into contact with local organisations.

Key points for learning which emerged from the programme included;

- Scotland remains a world leader in promoting rights-based approaches in dementia, however there is a danger that this momentum may be lost if such approaches do not remain at the forefront of current research, policy making and practice.
- The domains of technology, the arts and dementia friendly communities each provide opportunities to challenge current thinking about dementia, by reconceptualising those accessing activities or services within each domain as individuals able to be fully involved in decision making and service design. However making such changes requires significant buy in across the dementia care sector, which may be difficult to achieve
- Better cases however need to be made to support the use of such approaches when communicating with services or organisations involving in dementia service or care delivery if such changes are to become a mainstream part of care.
- While the rhetoric around promoting rights-based approaches for people with dementia in Scotland is laudable, it is important first that the momentum achieved from previous policy interventions such as the Scottish Dementia Strategies is not lost, and second, that services are fully supported to deliver on their aims. Self-Directed Support and Post Diagnostic Support were highlighted by people with dementia as examples where the reality did not currently meet the rhetoric.
- Evidence for many interventions which are designed to improve quality of life for people with dementia focus on outcomes in terms of service delivery. Further focus needs to be given to different forms of evidence within evaluations of interventions for people with dementia. In particular, questions should be asked about what supports the provision of successful interventions (e.g. technology) in terms of how people with dementia actually make use of interventions themselves, and how such goals are enabled or constrained by current policy and/or practice.
- Across Scotland there is a wide range of innovative projects, working at a grassroots level to improve the lives of people with dementia. Much of this work is emerging independently of existing networks such as the Universities or Health and Social Care Partnerships. More learning is therefore required about what is happening at such grass roots levels, and out the benefits emerging from such projects can be captured and disseminated across the dementia care economy. The upcoming National Policy Forum and School of Leadership, to be funded by the Life Changes Trust, should provide an important opportunity for such knowledge capture and exchange to occur.



Main outputs and impact

A number of outputs have emerged from the programme. In addition, further outputs are currently in the planning stage. There has also been evidence of impact resulting from people's attendance at the workshop events, with a many attendees mentioning changes they would like to introduce to their professional practice as a result of attending.

- The main concrete output from the programme is the online resource containing videos and other information regarding the workshop programme, which are available for review. An existing website providing a summary of the 'Memory Friendly neighbourhoods' programme held in 2014-2015 has been expanded, with this website now providing a repository for the online content produced as part of this programme. The website includes information regarding each of the four workshops, and video of the presentations and activities which took place during each of the workshops.
- A further output emerging from the programme were four posters, which provided a visual record of the first three workshops. These posters have been displayed at a number of recent events in relation to dementia, including the Scottish Dementia Research Consortium annual conference, and Dementia and Ageing Research Group conference at the University of Stirling. The posters repeatedly receive a great deal of interest and attention when displayed and provide a means of entry into the issues emerging during the workshops.
- Members of the programme team have recently submitted a large-scale bid for research funding to the National Institute for Health Research in relation to the development of personalised solutions for the delivery of assisted living technologies for people living with dementia. The submitted bid is for £1.25m.
- Members of the programme team have also submitted an application for the Life Changes Trust National Policy Forum and School for Leadership in Dementia. This application draws heavily of the topics and networks developed through the Shifting Paradigms programme and involves all of the partners responsible for the delivery of this project. The submitted application is for £2m.
- As a result of the workshop, Dementia Friendly East Lothian have joined the Meeting Centres Support Programme (UKMCSP) project, funded by the Big Lottery fund to establish Meeting Centres for people and families affected by Dementia. This project is being led by Professor Dawn Brooker, University of Worcester, who gave one of the academic keynote's during the third workshop on dementia and community inclusion.
- As a result of attendance from local councillors and politicians at the third event, further consultations have taken place between Dementia Friendly East Lothian and East Lothian Council regarding the promotion of East Lothian as a dementia friendly community.

Follow up activities

- A bid for follow on funding to the Scottish Universities Insight Institute is currently being developed, which will expand the hack activity held during workshop 2 into a full hackathon session. The proposed hackathon event will invite people with dementia, informal carers, and technology designers to take part in a short term, intensive workshop session, with the goal of identifying and producing technological solutions in order to meet the needs of people living with dementia. This event will challenge technology designers to work with people living with dementia and will draw upon co-production methodologies. A submission for follow on funding will be made in the Autumn of 2018.
- The project has provided key networking opportunities for participants within the network. Several projects are currently being developed alongside those mentioned above, which have already been submitted. For example, a project application to ESRC call for Innovations in Social Care, involving project partners is currently in development.
- A video report summarising the study and acting as a companion to this report is currently in development and will be uploaded to the website on completion.