Scottish Universities Insight Institute

FOLLOW UP PROGRAMMES

FINAL REPORT FORM

1. Please give an account of the follow up activity carried out, and how this built on the previous project.

Memory-Friendly Neighbourhoods (MFN) is a knowledge exchange programme exploring how local communities can support people with dementia. It is led by the Universities of Stirling and Edinburgh.

The first phase of Memory-Friendly Neighbourhoods took place in 2014, with support from the Centre for Dementia Research at the University of Linkoping, Alzheimer Scotland, Anderson Bell Christie Architects and Architecture and Design Scotland. The focus of this phase was on understanding what makes a good, lifelong, inclusive neighbourhood for a person whose life is affected by dementia.

In the first phase, the MFN team held two events to exchange ideas with experts from around the world, share good practice from Scotland, hear from people living with dementia, and explore the challenges people face getting out and about in their local neighbourhood by walking with them. We produced podcasts, videos and written summaries of group discussions, as well as collating and publishing existing resources contributed by members of our Memory-Friendly Network.

Collectively, our early activities were devised on the premise that knowledge exchange events work most effectively if connections can be made in advance, are inclusive of people of all ages and abilities (including people living with dementia), and are enabled to continue afterwards. This is why our website - memoryfriendly.org.uk - was central to our collaboration. We wanted the site to be as dementia-friendly as possible and sought advice and guidance. We found very little, despite the fact that online access is becoming increasingly central to community participation for people living with dementia, as well as an important route to accessing information about their health, wellbeing and quality of life.

Focusing on the 'virtual neighbourhood', the second phase of Memory-Friendly Neighbourhoods was a means of directly addressing the knowledge gaps we had identified around digital exclusion and dementia in 2014. Beginning in early 2016, with the support of East Dunbartonshire Council, Age Scotland and the Life Changes Trust, we set about exploring how people living with dementia use and navigate online environments and what their needs and preferences might be for websites and applications.

In the first instance, we held an opening meeting of people involved in web design and content provision to find out what challenges they face in making their sites dementia-friendly. We also asked our delegates to tell us about any organisations, programmes and initiatives they were aware of in the area of widening digital participation for people with dementia.

Over the next six months, we set about talking to as many of the people who were involved in, or made use of, these services as possible. We surveyed 23 people online, engaged in a Twitter chat with 107 participants, met 19 groups across the Scottish central belt, and had in-depth follow up conversations with seven individuals to engage with internet users whose lives are affected by dementia.

We held our final event in January 2017, bringing around 30 delegates together to share and discuss what people had told us, critique a number of websites (including our own), share tips and techniques for making sites more user friendly for people with dementia, and prioritise potential future work streams. You can find out what we shared in our opening presentation and our reference sheet from this event.

Right: delegates at the final event working in groups to critique banking, shopping and travel websites

2. Describe the main outcomes and added impact of the follow up work. Please note any key recommendations for end user / policy communities.

The people we spoke to who are living with dementia and using internet-based technologies tend to do so to keep in contact with friends and family and for recording, reminding and reminiscing. But when it comes to technology that is less 'consequence free', like apps and websites that facilitate financial transactions (banking, buying groceries, booking travel etc.), many people do not use them to their full potential, often because they lack the confidence in their own skills to do so without "getting something wrong".

There are important implications here for technology developers and their clients, given that many key services are moving away from face-to-face transactions towards online service provision. In our presentation (slides 43-54), we have identified 11 positive things that service providers can do to help close the digital exclusion gap, as well as exploring the potential benefit of tools and techniques such as microinteractions (slides 55-60) and onboarding (slides 61-65) to people living with dementia.

We are also making five recommendations for future activity by stakeholders to tackle digital exclusion; at our final event, delegates prioritised these recommendations in the order they appear below…

1. Enable more people with dementia to get involved in design and usability testing for feeding back into existing accessibility guidelines.
2. Investigate training options, such as a community-led approach, to build people's confidence and skills.
3. Create a knowledge base of 'peer reviewed' resources, i.e. sites and apps recommended by other people with dementia, and practical guides for using them.
4. Widen the focus of activity to look at the dementia-friendly usability / application of new technology areas, such as smart-home devices and wearable/fitness devices.
5. Create a framework of practical web developer resources for those building websites and apps.

In video interviews, project partners Julie Christie (East Dunbartonshire Council, now HammondCare) and Richard Baker (Age Scotland) have told us why they chose to get involved in Memory-Friendly Neighbourhoods and what they perceive the project's benefits and achievements to be.

Sue Northrop (Dementia Friendly in East Lothian) has also told us that the digital work in particular "was great… really useful, not least because I am getting our website and Facebook etc. rejigged so perfect timing. I'm sharing the link with website workers here as I get the chance".

3. Were there any specific difficulties you encountered? How did you tackle these?

In our original project proposal, we envisaged holding three knowledge exchange events to enable people living with dementia, and those whose lives are affected by it, to share their experiences of accessing and navigating online environments and to critique specific websites, including our own.

However, even with the assistance of our partner, the Life Changes Trust (LCT), which funds a network of 14 Dementia Friendly Communities across Scotland, it proved difficult to draw even a small group of people with dementia together for our first meeting.

One factor was a relatively short lead-in time (of three weeks), but it was also clear that, although we had worked hard to ensure that the meeting would be in a comfortable, accessible and conveniently-located venue, and that our participants would not need to travel at busy times, people would prefer to meet at a place and time of their own choosing.

This prompted a change of approach from attempting to draw people to us to going out into established groups and environments (including online spaces) where people were already congregating; an important lesson for other projects who may want to work with people with dementia, as it is more time-intensive and, as is the case with some Twitter chats, meetings often take place outside office hours.

4. Are there any additional follow up activities planned at this stage?

The MFN programme has played a key role in the creation of a dementia-friendly community development programme funded by the Life Changes Trust. Beginning in September 2017, this three-year project will utilise the network and connections that have been forged over both phases of Memory-Friendly Neighbourhoods. Through a dedicated digital inclusion strand, it will build directly upon learning from the programme, including through a pilot intervention in the Stirling North area of Scotland. An integral part of the project will be the adaptation of the upgraded MFN website to facilitate communication and engagement, thus ensuring the sustainable reuse of this resource beyond the duration of our SUII funding.

In the time that has elapsed since we undertook the first phase of MFN, the landscape for dementia policy and practice has advanced significantly in Scotland, with the establishment of 14 dementia-friendly communities across the country and a further 14 newly funded projects about to commence later this year. We are keen to help maintain the momentum of MFN in facilitating developments and sharing good practice, and a subsequent application has been approved by SUII in order to support Scotland's

international profile as a leader in ground-breaking policy and practice on dementia. This latest proposal, aimed at 'shifting paradigms for dementia' will focus on direct involvement and leadership by people with dementia across different areas of support in their communities; it will further facilitate interaction between academics across Scotland with a shared interest in dementia; and will explore and model innovative approaches to knowledge exchange in a dementia context. The programme aims to expand the collaboration and co-working of different Scottish Universities in support of SUII's objective to strengthen links and interdisciplinary working across Scotland.

A key development identified in the early stages of the programme concerned the potential benefits of drawing together learning and expertise on age-friendly and dementia-friendly perspectives in order to work toward a more integrated picture of supportive and inclusive neighbourhoods. In the immediate future, our plan is to produce a summative account of the MFN programme for a suitable practitioner journal such as the *Journal of Dementia Care*. This will provide a further opportunity to share learning and disseminate findings as well as to direct people toward the newly-enhanced website, which serves as an exemplar of dementia-accessible digital design. In the longer term, our plan is to utilise the connections forged through the programme in order to develop research proposals based upon multi-disciplinary collaboration and close links with community groups, organisations and providers.

As well as research opportunities, MFN has also enabled the Universities of Edinburgh and Stirling to create linkages between different postgraduate teaching programmes, including the Master of Architecture (MArch) programme at Edinburgh College of Art and the Dementia Studies MSc programme at Stirling, thereby bringing together - across disciplines - the next generation of designers and practitioners.