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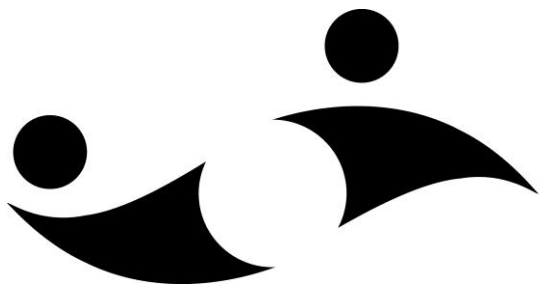
# **Memory-Friendly Neighbourhoods: International insights on developing dementia- friendly communities**

## **FINAL REPORT**

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December 2014

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## Project team

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Rowena Statt, Anderson Bell Christie architects

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Kate Fearnley, Alzheimer Scotland

Diarmaid Lawlor, Architecture and Design Scotland (A+DS)

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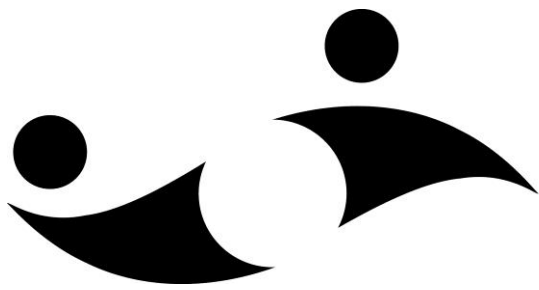
Website: <http://memoryfriendly.org.uk/>

**Acknowledgements:** The programme organisers would like to thank the SUII team for their support and assistance throughout this programme. Special thanks go to Ann and Nicola for their patience and support throughout. The help we received was invaluable in ensuring the smooth running of the events and the overall success of the programme.

Although not named as part of the project team, recognition and heartfelt thanks are due to Máire Cox (University of Edinburgh) who co-wrote, co-organised and co-led this programme of knowledge exchange, and whose ideas and creative problem-solving were instrumental to our achievements from the outset. Thanks are also due to Alastair Cox, whose technical wizardry ensured the capture and sharing of the proceedings from the events and the high quality design of the online networking resource.

Many thanks also to East Dunbartonshire Council for collaborating on our live site visit. We are especially grateful to the local residents who joined us for our participatory mapping activity and to Paula Brown and Julie Christie who helped to bring everything together so well within a very tight timescale.

Finally, we would like to say a big THANK YOU to the members of the Scottish Dementia Working Group (SDWG) who took part in the programme and made such an important contribution to it.



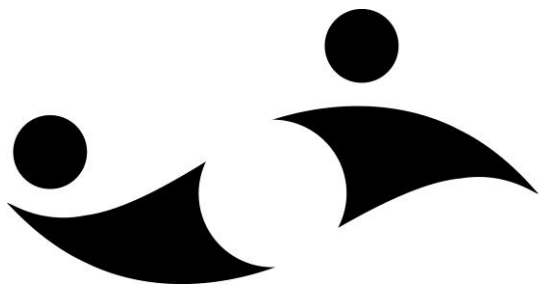
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**We would like to dedicate the Memory Friendly Neighbourhood Programme to the memory of Brian Malone – whose dream of a more dementia-friendly world we all share.**

## Executive Summary

- With a focus upon ‘memory-friendly neighbourhoods’ (MFN) this programme of knowledge exchange fostered debate, sharing and learning in regard to the notion of dementia-friendly communities that is currently of high policy concern.
- The programme consisted of a series of gatherings based initially at SUII HQ, each with a focus upon interactive exchange, alongside supporting online activity and the creation of an online networking resource.
- The themed events attracted a diverse international and UK mix of stakeholders from different sectors and disciplines. People with dementia and carers were involved throughout and gave presentations at two of the three gatherings.
- For one of our gatherings we included a ‘live site’ visit, where participants travelled to a nearby town, met with local residents living with dementia and collaborated in a participatory mapping activity.
- The main messages, highlights and insights to emerge from the programme include:
  - The importance of building upon existing resources and evidence from related fields, such as the WHO Guide to Age-Friendly Cities and the Inclusive Design for Getting Outdoors (I’DGO) research project
  - The identification of key areas where establishing connections between academia and community development could enhance future memory-friendly neighbourhood work
  - The benefits to knowledge exchange of using practical, task-based and experiential approaches, both in terms of the type of learning to be gained, and the potential for meaningful involvement of people with dementia; this was an outcome of the live site visit
  - The fact that, while there is a rich variety of definitions and understandings of memory-friendly neighbourhoods, there is consensus on the need to ensure the meaningful involvement of people affected by dementia in related research and community development.



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## **Context for the programme**

The projected rise in numbers of people affected by dementia poses a key political, social and economic challenge for Scotland in coming years. It has been estimated that dementia costs the UK £23 billion per year – more than heart disease, cancer and stroke put together. Despite this investment, services and provision for people with dementia and their support networks still varies from region to region and for different groups and communities. As a response, the Scottish National Dementia Strategy and the work of Alzheimer Scotland has given particular prominence to the role of local communities in supporting people with dementia to remain actively engaged and independent through collective and individual assets. This includes the environments in which people interact with each other and with nature (getting outdoors being crucial to wellbeing, social inclusion and quality of life for people at all life stages).

The recent commitment to post-diagnostic support across Scotland is aimed at further improving early intervention, prevention of problems and improved outcomes for people with dementia and their carers. This is underpinned by recognition of the need for the development of new approaches to dementia care practice, and the significance of more collaborative forms of service design and delivery in health and social care, including better integration of formal and informal support networks in the lives of people with dementia. Hence, the key questions around which this programme has been organised are:

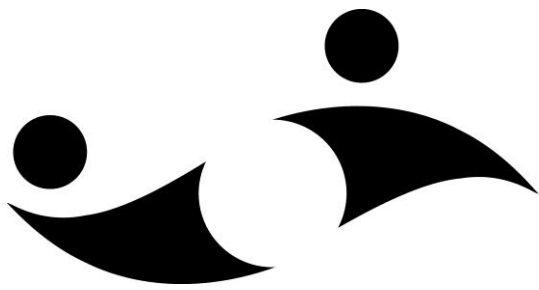
How can people with dementia be supported to remain socially and physically active in their local communities?

What role do the built and natural environments have to play?

What role do places play in supporting memory?

## **Main objectives**

Our theme of the ‘memory-friendly neighbourhood’ addresses a national and international priority in the field of dementia care across research, policy and practice. In part, this reflects a shift towards a citizenship model of dementia but also the pressing need to identify and enhance community-based sources of support beyond existing formal dementia services. However, the notion of a ‘dementia-friendly community’ is a contested one. It remains under-theorised and the emerging evidence base would benefit from integration and synthesis across the different disciplines currently contributing to our understanding. As such our programme objectives included:



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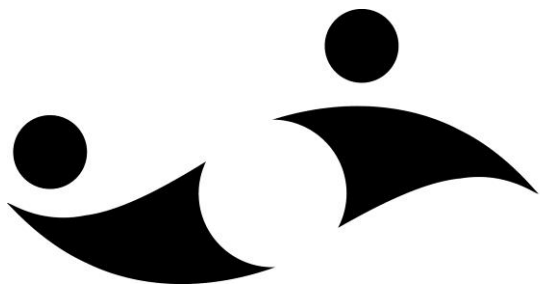
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- To share understandings of place and space and explore innovative methods for understanding the role and significance of neighbourhoods and their design in the lives of people affected by dementia
- To draw upon national and international expertise across disciplines and communities of practice in order to establish a shared understanding of the multi-faceted nature of neighbourhoods and the mechanisms involved in creating sustainable change
- To facilitate a debate on memory-friendly neighbourhoods across policy, research and practice, including the direct involvement and perspectives of people with dementia and carers, with the aim of planning future research collaborations that are relevant and accountable to non-academic stakeholders
- To produce a set of outputs to guide the development of memory-friendly neighbourhoods across Scotland and enlist the participation of councils, the NHS and community-based groups and organisations in taking this work forward.

## **Structure of the programme**

### Stage 1: Preliminaries

Work began with the creation of a web space intended to support online activity in parallel with the planned events. The website was designed with the intention of facilitating networking and sharing beyond the life of programme. It includes individual profiles for all our participants and a section for memory-friendly neighbourhood resources such as published research, video presentations and reports as contributed by the participants.



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## Stage 2: Two-Day Evidence Briefing and Networking Event

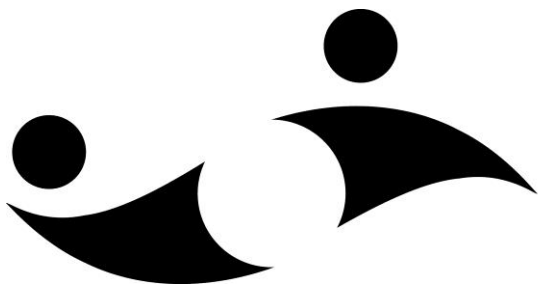


Our first event involved a series of six paired presentations from an international mix of experts, offering 'bite-sized' evidence briefings. Each presentation was recorded and subsequently uploaded to the project website. Themes addressed included: the wider context of evidence on ageing and the environment; dementia, design and outdoor spaces; and dementia, communities and the social environment. The day was opened by Brian Malone from the Scottish Dementia Working Group who offered a firsthand perspective on the need for memory-friendly neighbourhoods.

Our keynote speaker, Olivia Mastry from Act on Alzheimer's Minnesota, discussed one of the largest and most well-established projects on dementia-friendly communities in the US, sharing lessons and insights from the work so far.



The day was also punctuated with interactive workshops intended to foster debate around the definition and understanding of memory-friendly neighbourhoods.



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Following the event we hosted a less formal evening meal to facilitate further networking opportunities.

On day two, a smaller group of participants gathered for a less formal exchange of ideas and learning from different parts of the world. The emphasis here was upon networking and a number of proposed collaborations came out of this half-day meeting.

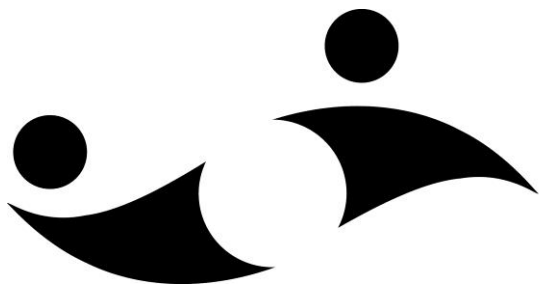
### Stage 3: Live Site Two-Day Workshop and Briefing and Networking Event

The second gathering also took place over two days. Our focus here shifted from hearing evidence on an international scale to finding out about the existing Scottish context and discussion of approaches to developing memory-friendly neighbourhood work in the future.



Day One involved a series of briefings from representatives of community development projects in Scotland and we heard from the Scottish Dementia Working Group about principles for doing research with people with dementia. Presentations were given on work taking place in different regions and at different scales, including a Highlands-based rural project, city-wide work in Stirling and the development of a project that began with a high street and has extended to include the wider town of Motherwell.

In the evening of the first day we held a separate Briefing and Networking event for people who were unable to attend the day-long event. We heard from two expert speakers about research on dementia and outdoor environments followed by Q&A and group discussion.



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Day Two took us to the town of Kirkintilloch in East Dunbartonshire. Participants joined forces with eight local residents living with dementia and a number of local practitioners and a council town planner. Splitting into groups, we used maps of the area as a focus for discussion of memory-friendly attributes as we visited different parts of town. We then reconvened to discuss our findings before returning to SUII HQ for debriefing.



An evaluation sheet was completed by 14 of the participants in the second, two-day event, the results of which have been collated and are attached as Appendix 1.

An internal report from East Dunbartonshire Council on their participation in the Memory-Friendly Neighbourhoods programme has been attached as Appendix 2.

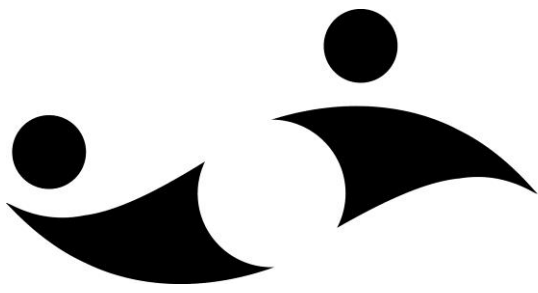
## Stage 4: Legacy

The planned-for legacy of the programme is an online networking resource which holds recordings of the presentations from each event plus an archive of resources contributed to the programme by participants. We have already amassed a good range of materials, including video presentations, project reports and research papers.

The network page includes profiles and contact details for all participants and this has already been used for networking and collaboration beyond the events held for the programme. Plans to upload a series of short briefings/factsheets based upon what was learned from the programme are in hand.

A key aim for this networking resource is to foster the development of research proposals and collaborations.





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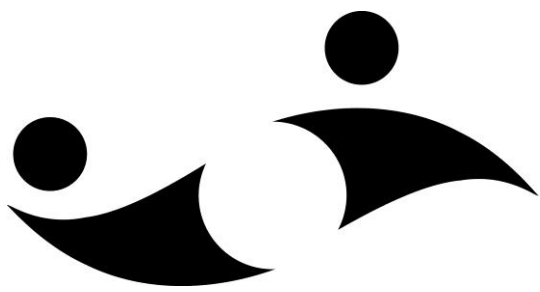
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## Innovation in Knowledge Exchange

While much of the programme relied upon more conventional approaches to knowledge exchange, in the form of oral presentations and follow-on discussion, we recognised from the outset that this emphasis on 'hyper-cognitive' styles of working may be less suitable for people living with dementia. As such, we introduced a 'live site' visit as an alternative route to knowledge exchange and one that we hoped would help to foster the meaningful involvement of people with dementia.



For this event, we worked closely with the design and architecture members of our network and adapted a mapping tool previously developed by Age Scotland (<http://www.ageuk.org.uk/scotland/get-involved/campaign-with-us/walk-in-our-shoes-act-on-our-issues/>). We also used a checklist developed previously by one of our presenters to guide designers of age-friendly outdoor environments, (available at: [http://www.housinglin.org.uk/library/Resources/Housing/Support materials/Other reports and guidance/Neighbourhoods for Life Findings Leaflet.pdf](http://www.housinglin.org.uk/library/Resources/Housing/Support%20materials/Other%20reports%20and%20guidance/Neighbourhoods%20for%20Life%20Findings%20Leaflet.pdf)). In collaboration with East Dunbartonshire Council, we transported our participants to a local town and met up with eight local residents living with dementia, and a number of local health and social care practitioners and a council town planner.



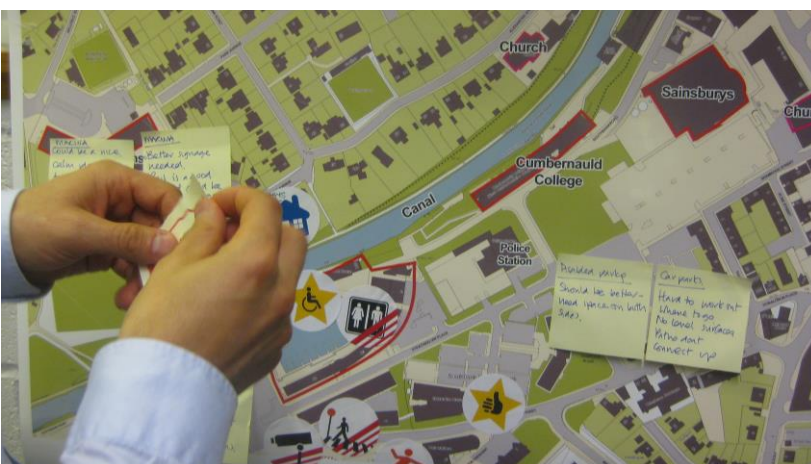
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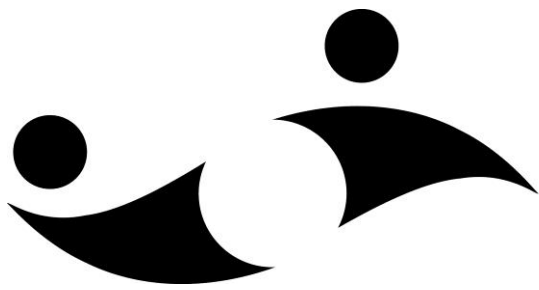
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The mapping method involved taking a walk, in groups of around five or six people, in different parts of the town, from the marina in the south, to the new community library and hub in the north. Depending on preference and mobility, some groups focused on one area only; others walked between the two along a canal towpath, then a busy shopping street. The sites and routes were chosen on the basis of having changed significantly over the course of the local residents' lifetime; in the case of the marina, for example, it had been regenerated and changed use after a period of industrial decline. Using our tools, which sparked lots of conversation with the local residents, we noted both facilitators and inhibitors to memory-friendliness in the local environment.

After our walk(s), we returned to council offices and, over lunch, participated in 'marking up' two large-format maps of the area based on our learning. This post-walk mapping was an opportunity both to create a map based upon the walking experiences and perspectives of people with dementia, but also for our participants to share their own knowledge and insights on what could be done to help bring about change.





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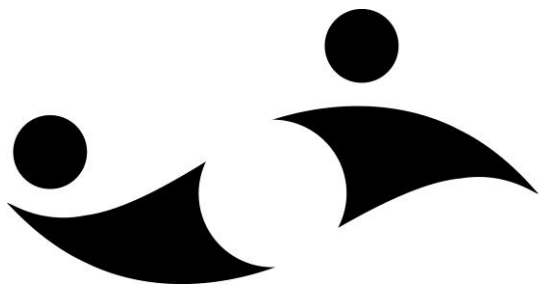
As an innovation to knowledge exchange, we identified a series of benefits to using this more activity-based approach.

- In the context of working with people with dementia, a focus on 'learning from doing' - rather than word-based forms of exchange - led to a far more equal level of participation and the potential to pace the activities according to the needs of those who took part. One lady with dementia who participated spoke about her "pride" in being able to get out of the house for the day, take people around her local area, and share her experiences; it seemed to give her a renewed sense of purpose.
- We were able to model a technique for data-gathering that was new to most of our participants. We showed that it was possible to gather different types of information, leading to broader insights into memory-friendly environments.
- We were able to feed our findings back to our partners in East Dunbartonshire in a very direct and inclusive way; the town planner who attended participated fully in all activities, took extensive notes and was keen to embed his learning in future plans.
- In the subsequent debriefing, we explored the pros and cons of our methods and supported people to begin to think more broadly and critically about the use of maps and mapping in the context of memory-friendly community development.
- Using a live site approach with a diverse range of stakeholders enabled the group to see one another's knowledge in action rather than relying upon the reporting of it. Participants and local residents were able to 'perform' their knowledge and expertise rather than (in some cases struggle to) articulate it.

## **Knowledge or understanding resulting from the programme and key recommendations for end user / policy communities**

A key feature of the programme is that it benefitted from the input of international experts in the field, alongside a diverse mix of UK and local stakeholders (many of whom had first-hand experience in the development of dementia-friendly communities), as well as the expertise of people living with dementia. We were able to combine knowledge and understanding derived from research, practice and lived experience in a way that helped inform the learning that came out of the programme. Key points of learning to take from the programme include:

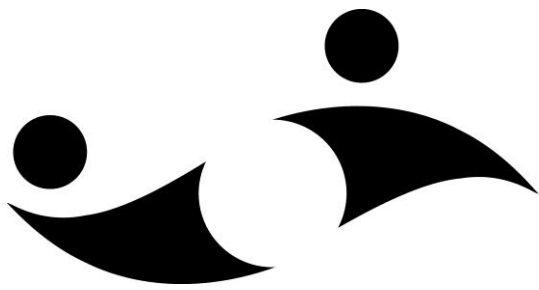
- No consensus was reached on a single definition or understanding of memory-friendly neighbourhoods, although agreement was reached on the need for more clearly articulated principles to guide community development.



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- The involvement of people with dementia and carers in memory-friendly research and community development was a point of consensus reached by the multi-disciplinary mix of participants. Greater emphasis on supporting people with dementia to set their own agenda for research was also highlighted.
- Much existing evidence in the field of dementia studies pertains either to design and the physical environment or to the social experience of living with dementia. The evidence briefings and accompanying discussion identified the need for future research to address the dynamic relationship between the social and physical dimensions of the environment in the lives of people with dementia.
- The live site visit and contributions from experts on ageing and the environment highlighted that many of the challenges that people with dementia face in getting out and about in their local area are shared with the wider population of older people. In looking ahead to future research, it would be useful to identify those challenges or enablers that are more specific to people living with dementia.
- The live site visit also underlined the value of activity-based approaches to knowledge exchange, both as a means to supporting the contributions of people with dementia and as a way to establish sharing and learning across disciplines and different working cultures and discourses. Future knowledge exchange activities could benefit from incorporating a more diverse mix of techniques, methods and media to this end.
- In the context of a growing commitment to dementia-friendly communities in Scotland, further facilitated through funding available from the Life Changes Trust, there is a clear role for academia to play in sharing and modelling different methods for evidence gathering and rigorous evaluation of community development initiatives. The programme demonstrated that the dementia-friendly agenda for Scotland provides a distinctive opportunity for strengthening connections between academia and the wider community.
- There is a need to recognise and incorporate the diversity of people living with dementia into the memory-friendly neighbourhood agenda. This includes approaches that concern communities of interest and identity, as well as those which are geographically defined.
- The programme identified the potential for a learning and sharing resource to facilitate connections between memory-friendly initiatives across Scotland and between Scotland and the wider global movement on dementia-friendly communities. This will ensure the sharing of good practice and potential for comparative perspectives on research and practice.
- A better understanding is needed of the potential that memory-friendly neighbourhoods might hold for people with dementia residing in rural communities.
- Approaches to demonstrating the business case for memory-friendly communities and their implications for local economies are an important consideration.



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## Main outputs and impact

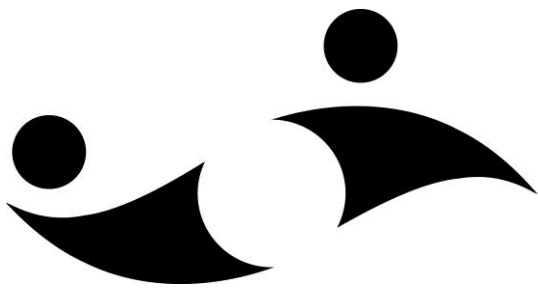
A number of outputs from the programme are still in the planning and preparation stage and opportunities for measuring impact remain at an early stage.

- So far, the main concrete output from the programme is the online networking resource. This was developed during the course of the programme and now includes over 100 members from the UK and internationally, who share an interest in memory-friendly neighbourhoods. The website was intended to sustain memory-friendly work beyond the period of funding and has been designed to grow and expand over time as interest in this emergent area of policy and practice develops.
- This networking resource has already facilitated contact and connections between members that would not otherwise have occurred. We have seen sharing of materials, ideas and strategies for work in this area and the building of channels of communication across disciplines and sectors and different regions.
- Members of the network have been invited to participate in a large-scale bid for research funding submitted to the European Horizon 2020 funding stream
- A series of short 'factsheets' summarising the insights and messages from the programme are currently in preparation and will be uploaded to the website on completion
- Plans for future research tied to learning from the programme are also being developed. We have identified the need for research into techniques and methods for memory-friendly work that involves people with dementia.

## Follow up activities

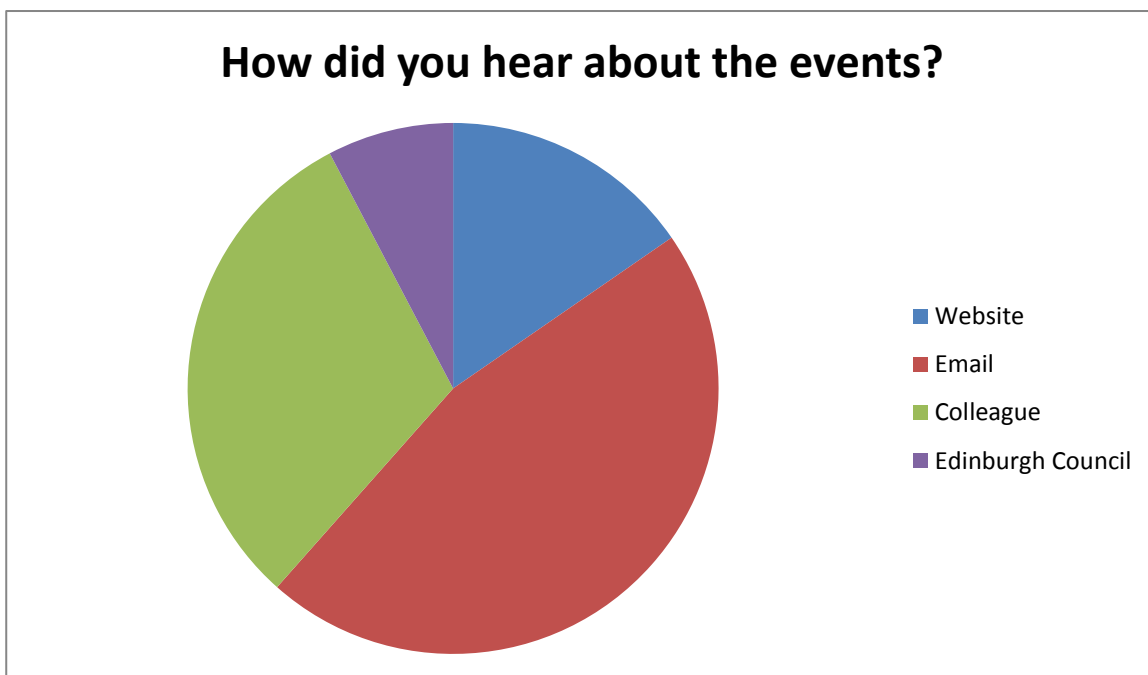
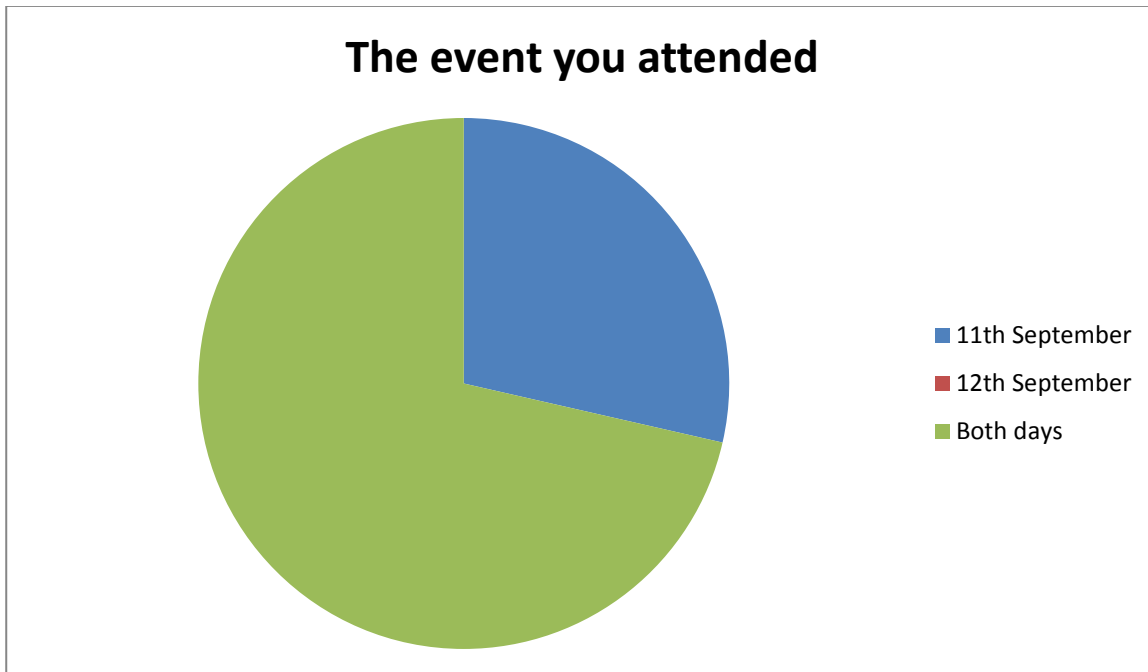
A series of follow-on and dissemination activities are now underway for the programme.

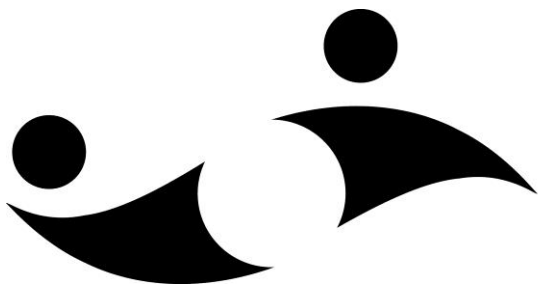
- Richard Ward reported on the Memory Friendly Neighbourhood programme at the Alzheimer Europe Annual Conference held in Glasgow in October 2014.
- We have been invited to submit a proposal to develop the website into a learning and sharing hub for memory-friendly initiatives across Scotland. If successful, this will enable the website to be developed over a number of years and to promote joint working and communication between academia and community development.
- A paper reporting on the process and insights from the Memory Friendly Neighbourhood programme is planned for the *Journal of Dementia Care* – the main publication read by dementia practitioners in the UK.



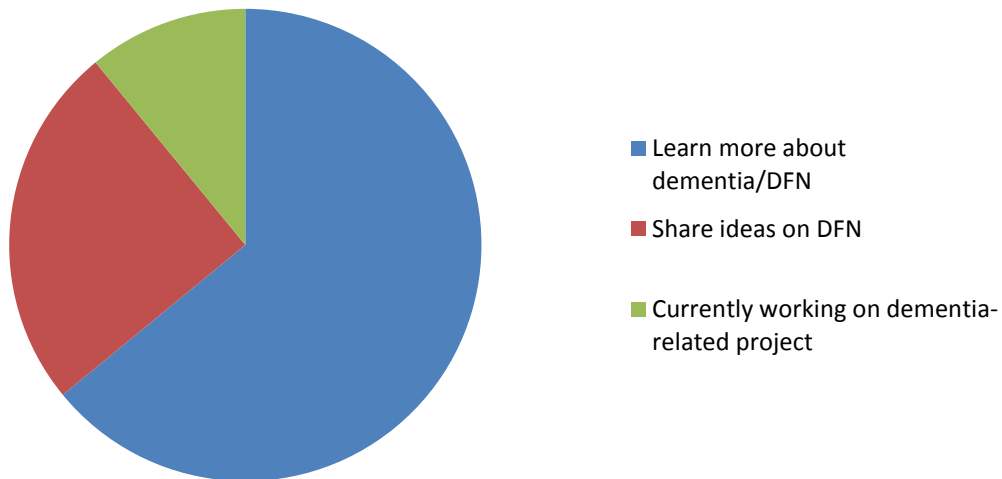
## Appendix 1.

### Feedback Questionnaire – Memory Friendly Neighbourhoods – 11<sup>th</sup> & 12<sup>th</sup> September 2014

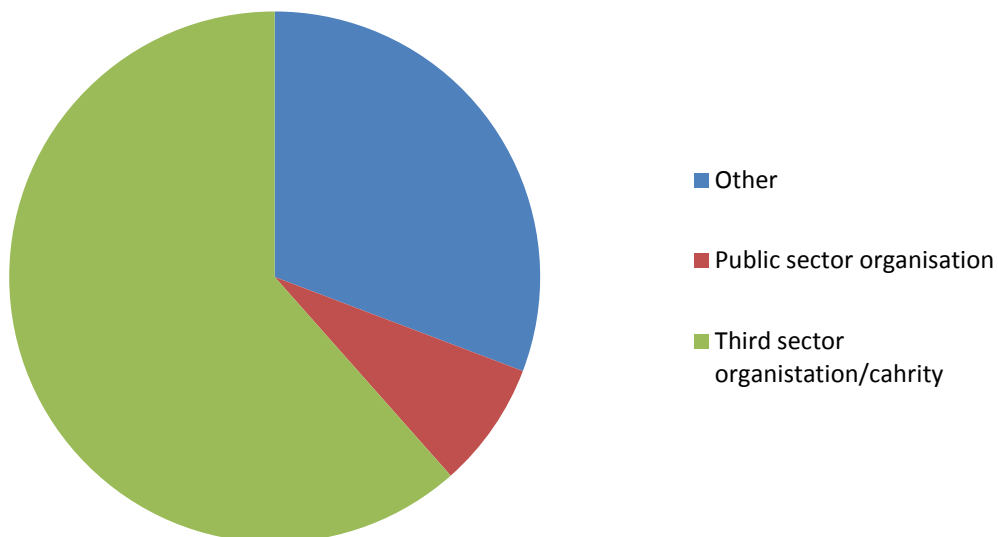


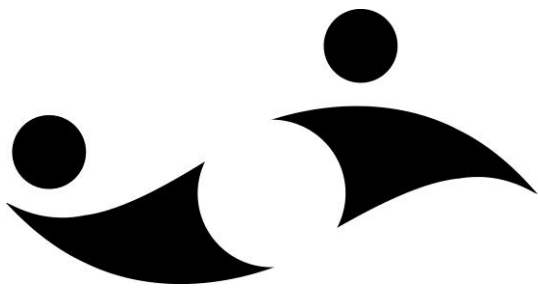


## What were your primary reasons/objectives for attending this event?

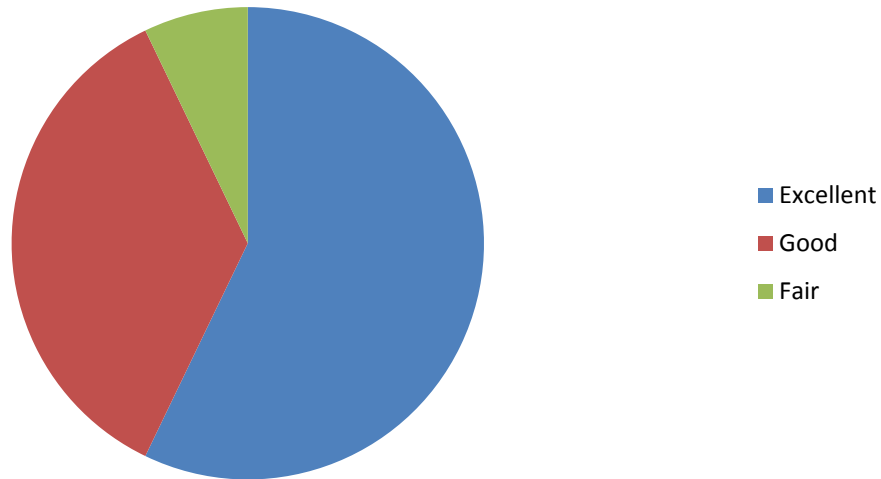


## Are you attending the event as:

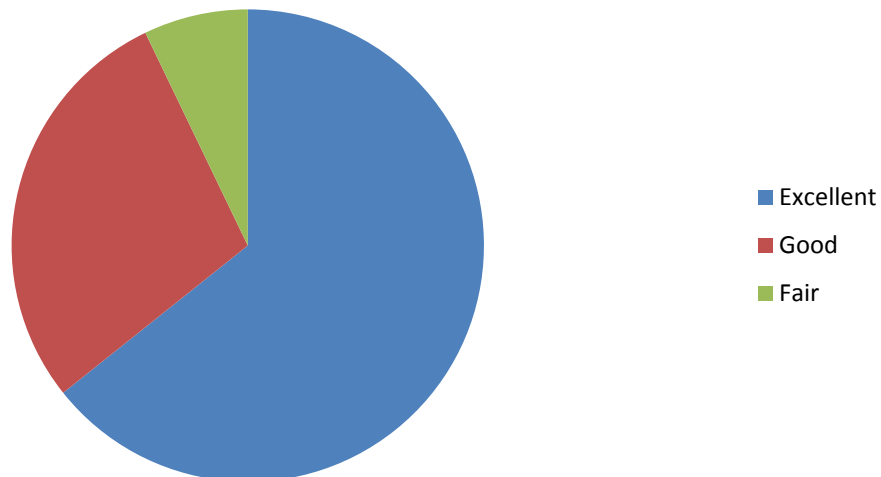




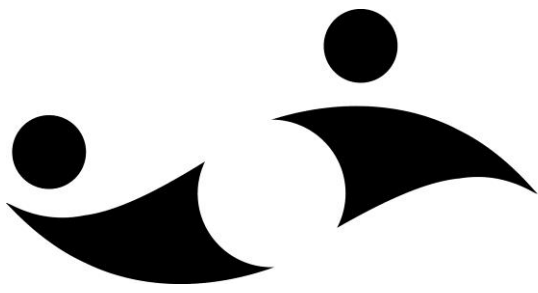
## General quality of the event: Breadth and depth of the topics covered



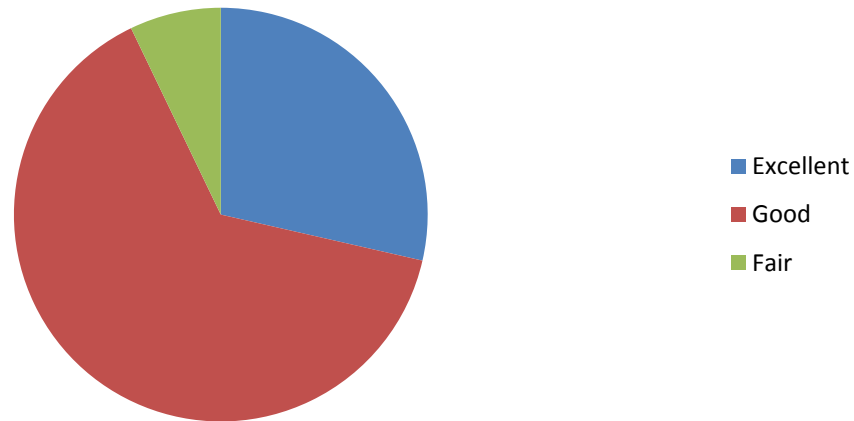
## General Quality of the event: Relevance to you of the topics covered



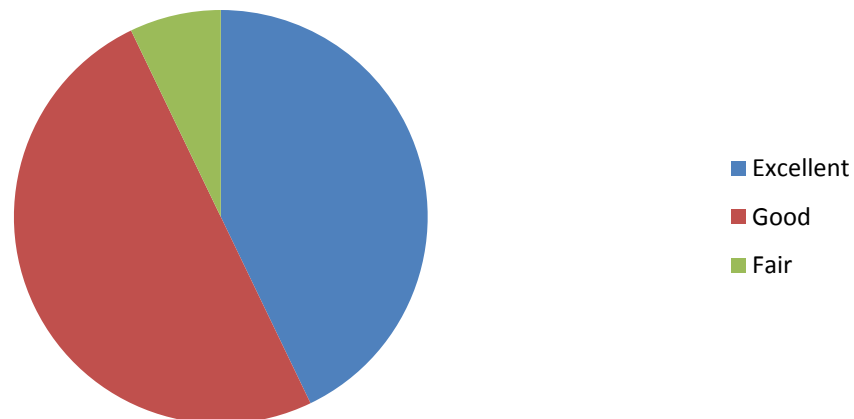


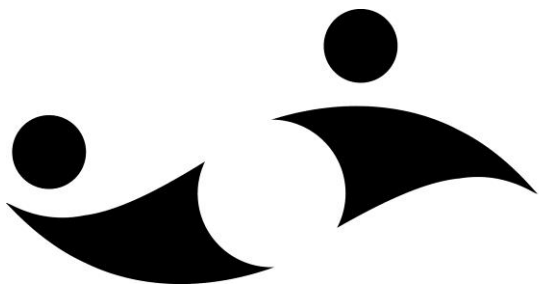


## General quality of the event: Balance between speaker presentation and discussion time

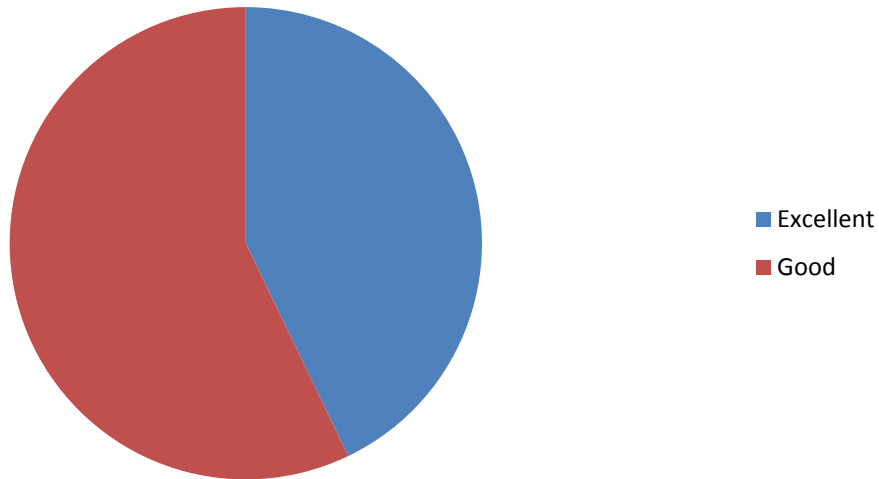


## General quality of the event: Opportunities to contribute to discussion and content

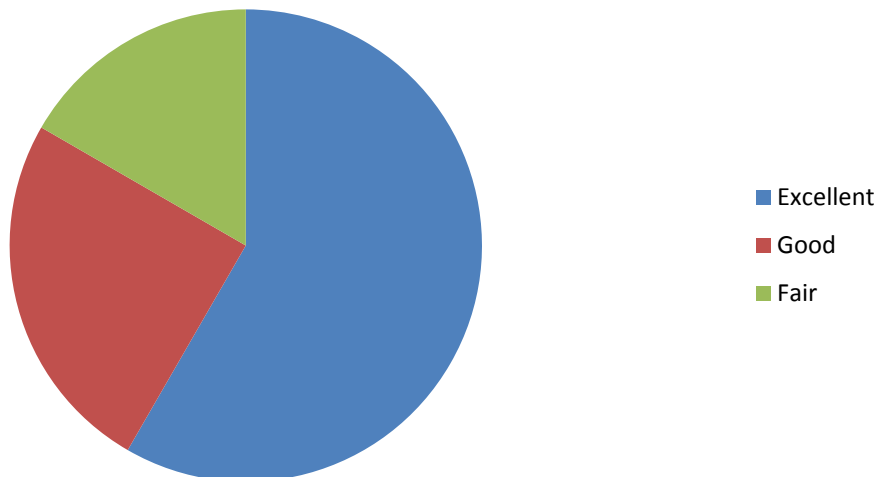


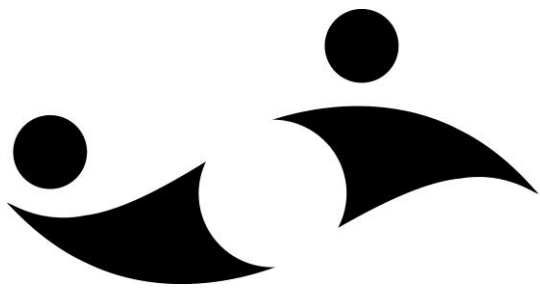


## General quality of the event: Overall value of the event

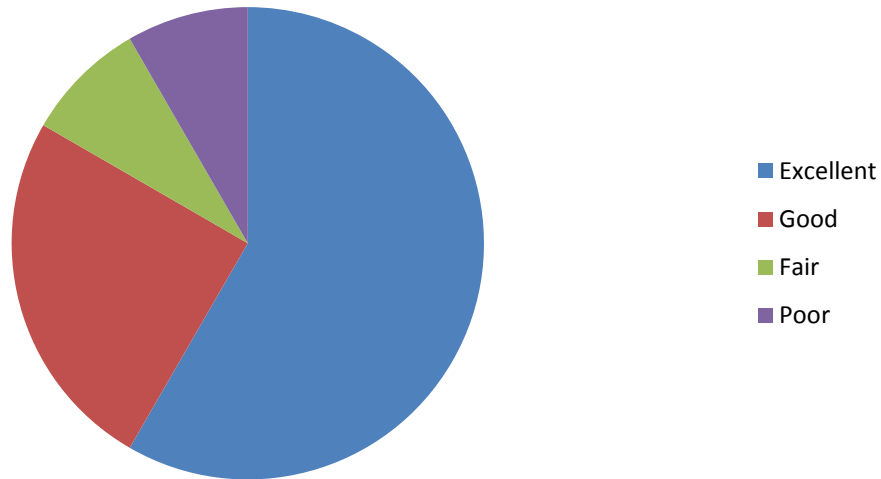


## Facilities and Services: Suitability of space

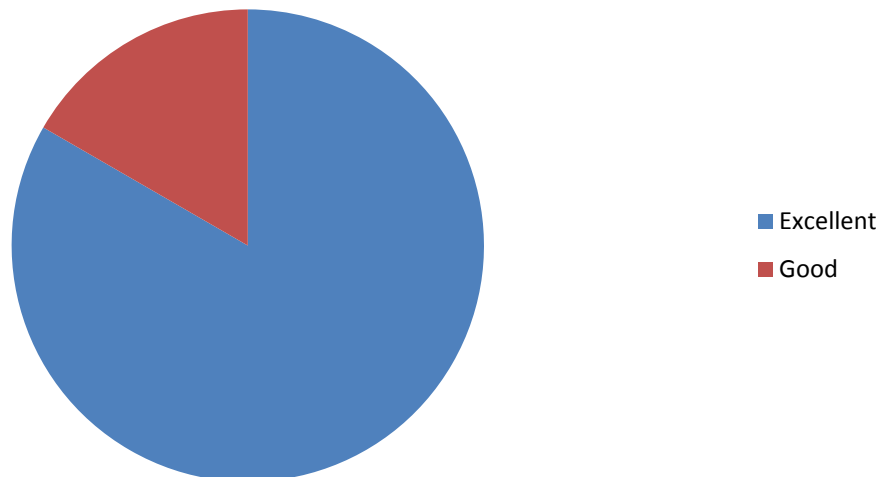


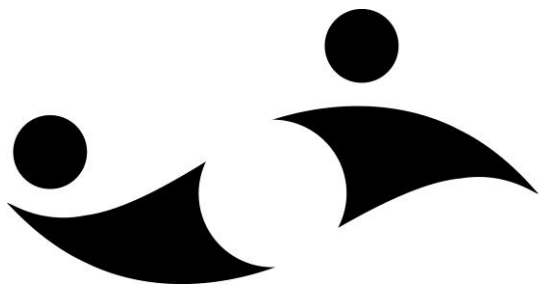


## Facilities and services: Level of comfort for users of the space

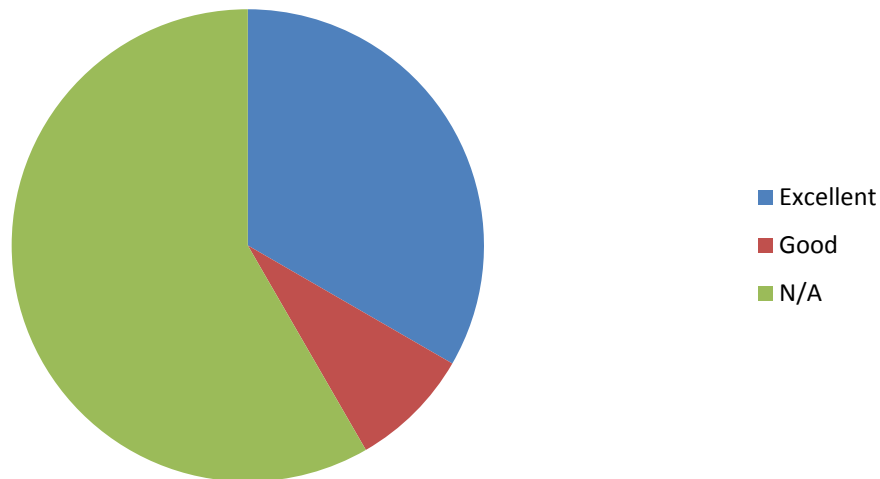


## Facilities and services: Catering





## Facilities and services: Administrative support



- **All delegates** anticipated sharing many of the event's findings or outputs with colleagues.
- **All delegates** anticipated finding a way of using the experience/knowledge/ideas from the event in their role.
- **All delegates** anticipated getting in touch with others they met through the event.

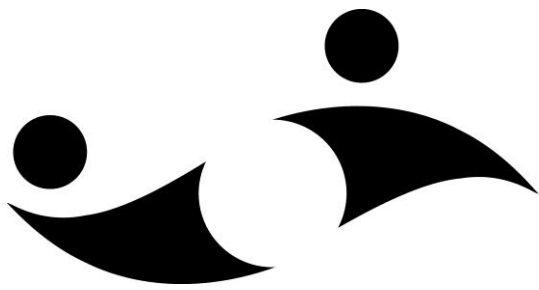
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**All delegates** found the site visit to Kirkintilloch worthwhile. The aspects they found particularly beneficial were:

- Talking to people with dementia and getting a first-hand account of living with dementia
- Gaining practical experience of collaborating with people with dementia
- Mapping
- Observing the environment and learning of the specific difficulties for people with dementia
- Walking

Recommendations from the delegates included:

- More time allocated for the walks
- More discussion time
- Better sound system
- Changing the name of the event to 'Dementia-friendly Communities' instead of 'Memory-friendly communities' as the latter caused confusion and was not in line with dementia strategy and initiatives
- Better grouping of delegates



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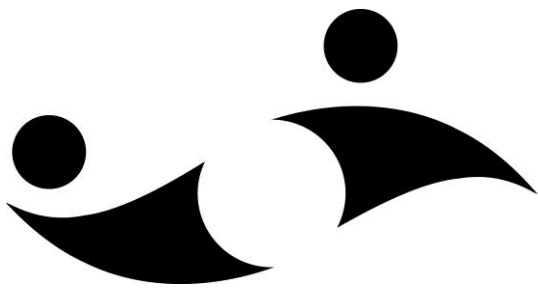
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Delegates were generally happy with the services and facilities, but it was suggested that the room temperature could have been warmer and the sound could be improved upon as there was noise disruption on one of the days.

**All delegates** would encourage a colleague to participate in the programme as it is an excellent opportunity to hear about different initiatives and a good way of networking.

All delegates felt that they would take something away from the event. These included:

- New contacts
- Ideas to help promote the concept
- Information on the different approaches surrounding dementia-friendly communities
- Initiatives to help make their local area more dementia friendly
- Mapping exercises



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## Appendix 2. Report from East Dunbartonshire Council

### Co-production Stories

#### 1. Tell us how it all started.....

##### Our work-

##### **Transforming private and public spaces into highly visible and accessible dementia friendly places.**

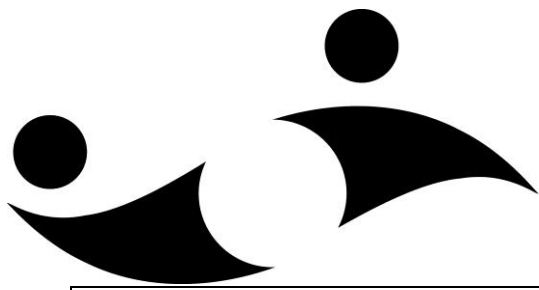
East Dunbartonshire Council is participating in a Scottish Universities Insight Institute-funded programme to share knowledge and expertise on how local communities can support people with dementia. Led by the Universities of Stirling and Edinburgh, this programme is called Memory-Friendly Neighbourhoods (MFN). Memory-Friendly Neighbourhoods involves a range of knowledge exchange activities, including the establishment of a Network of stakeholders, currently comprising around 100 people. The Network is international, with many people participating in activities online, as well as in person.

As part of an MFN event focusing on dementia-friendly initiatives in Scotland, people living with dementia in East Dunbartonshire were invited to 'walk their neighbourhood'. This involved auditing places and spaces in their local community, providing their 'expert by experience' views on what aspects of the environment worked for people living with dementia; and what needed to be improved. We used two toolkits; Walk in Our Shoes - Act on our Issues (Age Scotland, 2012) and Checklist of Characteristics of Dementia-friendly Neighbourhoods (Oxford Brookes University, 2004). The toolkits were developed independently of one another (one by a charity; one by academics), but their end goal is the same; to help guide the people who shape our built environment towards a more age-friendly approach to planning and design.

Liaising with members of the MFN Network, people living with dementia, their carers, family and friends, members of the dementia network, and town planners, a date was set to host this event. This included inviting people with dementia from outside East Dunbartonshire to join us.

#### 2. Who was involved in the co-production story? E.g. you, managers, practitioners, partners, service users, community groups etc?

Delegates from Memory-Friendly Neighbourhoods Network including architects, researchers, and community groups, people living with dementia, housing associations, members of the Dementia Network, our co-production facilitator and town planners.



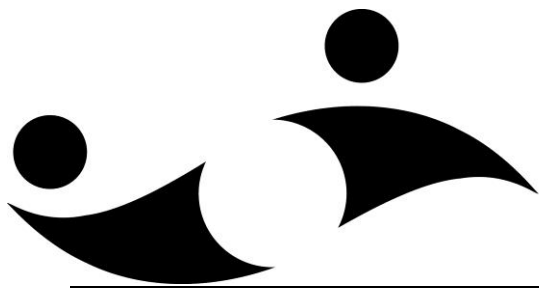
### 3. What were each of your roles and your motivation to get involved?

East Dunbartonshire Council have an established Dementia Network which has a long history of co-creation and co-production. As a result we have a co-production facilitator. We had already established that people living with dementia wanted to be as independent as possible. A local priority had been to improve community connectivity and make local assets more visible. People living with dementia told us what they could do to inform this agenda and in turn what they wanted and expected from the other members of the Dementia Network. We joined the Memory Friendly Neighbourhoods Network in 2014 to share our experiences and learn from others.

We met with the MFN Network to plan the event. This included ensuring that as many people could participate as possible and that the event would cover the agenda set by people living with dementia. This included trial walk through the town to agree how long audits would take, what assistance people needed to be part of the audit and formats to record people's views. We then prepared a local over- sized map for people to record their real life experiences on as part of the event. This map was then taken by town planners for inclusion in the planning process.

From the perspective of the researchers, they were interested in the changes our town centre in Kirkintilloch has experienced. These changes included a history of industrial revolution and a thriving textile industry to a period of decline in the latter half of the twentieth century. Recent regeneration work made it an ideal location for this examination. How did changes to the physical environment impact on people and how do participatory activities, like mapping, inform co-design possibilities, future planning and development processes?

On the day 40 delegates split into small groups using the two toolkits and walked the specified areas. Participants prepared a map of the areas in Kirkintilloch that were being assessed. This included walking around key sites in the town where there has been regeneration work completed in the last few years, from the marina in the south, to the new library and community hub in the north. Important spaces and places within these areas were agreed upon by the delegates who then marked their locations on the map. One example was the post office. Delegates then walked around the locations in smaller groups and made observations on issues such as way-finding, pedestrian access, noise, encouragement to use outdoor space, disabled access and travel routes.



#### **4. Were there any hurdles in the way?**

No not with good planning to ensure the right people were available, that people had assistance to reach the town centre, that pre-event information was provided, catering and rest facilities were arranged and that people felt able to air their views in the spirit of confidentiality and action.

#### **5. Tell us about why you think this story is an example of co-production?**

This work was initiated by people living with dementia and would have not been possible without them. Using the resources of the Dementia Network and the Memory Friendly Neighbourhoods Network people set the agenda. Working together we pooled resources to contribute practical assistance, knowledge and recording mechanisms to turn the events of the day into a journal record, part of the town planning process, feedback on toolkits that might be used to audit town centres for older people in other areas.

#### **6. What were the highs and lows of your co-production experience?**

The event was full of humour and stories of life in Kirkintilloch through the decades. It did take a lot of co-ordination but was a good test of our existing networks in making the event a success.

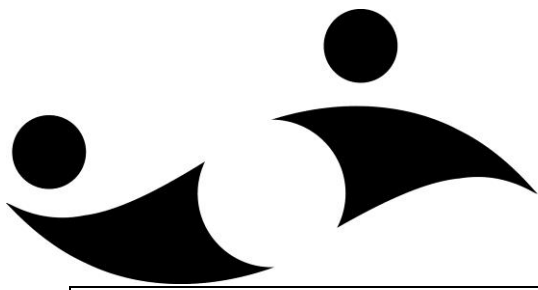
#### **7. What one key message would you give someone else who is trying to begin working in this way?**

Communities are the people who live in them and the physical environment. Co-production provided us with the means to look at culture change from both perspectives. Co-ordination is essential and people need practical information and support to be able to take part or lead the experience.

#### **8. What were the outcomes you set out to achieve? How were these identified?**

Facilitate 'walk your neighbourhood' events.  
Record experiences and views, from the perspective of people living with dementia.  
Find out what people living with dementia can do to lead or participate in changing culture.  
Researchers wanted to work with people living with dementia to audit available toolkits and make recommendations in this area  
Share our learning.  
Contribute to our local town planning  
Record local assets from the perspectives of people living with dementia.





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9. **Can you provide existing material about this story that we can link to, e.g. case studies, online information**

The benefits and learning from the day will be shared via the online community of [www.memoryfriendly.org.uk](http://www.memoryfriendly.org.uk) throughout Scotland and internationally.

Press release –

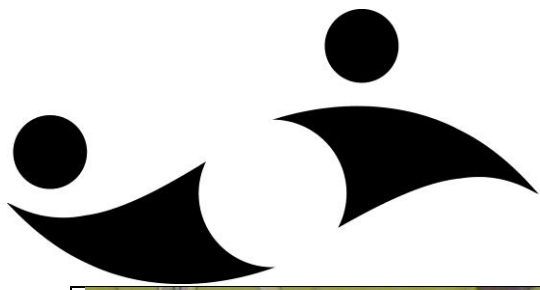
<http://www.eastdunbarton.gov.uk/default.aspx?Page=23832>

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10. **Do you have any pictures or video content we can also share?**





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