

Oxford Dementia Challenge Group

Evaluation of Dementia Friendly Communities Project

Report

August 2014

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Executive Summary

- This evaluation was prepared for the Oxfordshire Dementia Challenge Group by the Institute of Public Care at Oxford Brookes University.
- In the context of growing numbers of people with dementia in Oxfordshire and an increasing concern to meet the 'Dementia Challenge', the Dementia Friendly Communities Project was funded by the NHS South of England's Dementia Challenge Fund for a year from April 2013 to the end of March 2014.
- The project aimed to accelerate the pace of improvement in the pathway of care in Oxfordshire in order to raise the quality of life for people with dementia and their carers through:
 - Creating better awareness in the communities in Oxfordshire
 - Reducing stigma
 - Creating a social environment that encourages people with memory loss to present for assessment thereby increasing early diagnosis and in turn facilitating appropriate support at the right times and in the right places
 - A better informed voluntary workforce as measured by greater confidence in: recognising someone with dementia; prompting action resulting in a memory test or diagnosis; and supporting someone with dementia.
- Dementia awareness sessions were delivered to 58 community, voluntary and workplace groups, including a local theatre, housing association, and the fire service.
- More than 650 people took part in the sessions across the county which helped to raise their awareness, understanding and confidence in interacting and supporting people with dementia. By August 2014, the figure was 891 people.
- A total of 446 Dementia Champions were recruited, defined as those attendees who were willing to take further action around dementia either individually or as group.

- A greater number benefited through the sharing and application of the knowledge gained by participants in the Community Learning Groups.
- A limited number of action plans were developed, although three-quarters of those responding to the question, said they intended to continue in the group, and many of those participating in the sessions stated intentions to undertake specific activities more related to dementia either as individuals or in a group.
- In the longer-term, there may be concerns about how to maintain the momentum of the project in order to ensure its longer term sustainability.
- Data on the impact of the project on people living with dementia themselves in Oxfordshire were not collected, and it is also not known what the impact has been in terms of reduced social isolation and earlier presentation for diagnosis.
- In terms of the general intended outcomes: a more dementia-aware county and better skilled volunteers, the project has achieved considerable success, raising self-assessed levels of ability and understanding in those taking part. Feedback from those taking part in the Community Learning Groups was overwhelmingly positive.
- Overall, the project appears to have been successful in meeting its objectives and contributing to more dementia friendly communities in Oxfordshire, as defined by the interviewees, with greater awareness and understanding of dementia, and a more pro-active approach to supporting people with dementia and their carers.

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Report

1 Introduction

This evaluation has been prepared for the Oxfordshire Dementia Challenge Group by the Institute of Public Care at Oxford Brookes University. Work was carried out between April 2013 and the end of March 2014, involving a combination of quantitative and qualitative data collection, with analysis and drafting completed in June 2014.

2 Context

2.1 National

Since 2012, there has been some significant progress on dementia nationally, including: an increase in dementia diagnosis rates by 6% (from 46% to 48.7%); and over 50 communities across England have signed up to the national Dementia Friendly Communities recognition process. A Dementia Friendly Communities Champion Group with an increasing number of private, public and voluntary organisations now involved in its work has established six Task and Finish Groups aimed at significantly enhancing the work towards becoming dementia friendly in specific areas or sectors. For example, a retail task and finish group, another looking at power of attorney and data protection, as well as one focusing on dementia friendliness in rural communities.

In 2013, the Alzheimer's Society held the first ever national conference on dementia friendly communities, including publication of a report providing evidence about the factors and priorities that people with dementia say helps makes a dementia friendly community¹. The authors found that while there were some excellent examples of communities gearing up for dementia, many people with dementia did not feel supported and a part of

¹ Green, G & Lakey, L (2013) Building dementia-friendly communities: A priority for everyone, Alzheimer's Society, https://www.alzheimers.org.uk/site/scripts/download_info.php?downloadID=1236 [accessed June 2014].

their local area. Many people with dementia were not able to take part in activities that they enjoyed before they developed the condition. However, a poll of UK adults showed significant goodwill in the community to help people with dementia live well and a positive perception of the concept of dementia-friendly communities.

The report provides a definition of a dementia friendly community as:

A dementia-friendly community is one in which people with dementia are empowered to have high aspirations and feel confident, knowing they can contribute and participate in activities that are meaningful to them.

2.2 Local

Dementia is a significant issue in Oxfordshire. According to the Projecting Older People Population Information System (<http://www.poppi.org.uk/>) more than 8,000 older people in Oxfordshire are living with dementia in 2014. As the proportion of the county's population aged 85 and over increases, the number of people living with dementia is predicted to increase by more than 20% over the next six years.

The Dementia Challenge Group noted that despite the anticipated increase in the number of people living with dementia, awareness and understanding of dementia and dementia services within the county was limited. The consequences of this were perceived to be low rates of people coming forward for diagnosis, stigma, and lack of community support for people affected by dementia (including family carers), breakdown of family/community care leading to high levels of demand for intensive health and care services (including hospital beds). In February 2014, 46% of delayed transfers of care from hospitals in Oxfordshire were people awaiting a care home or nursing home placement or a home care package².

In recognition of this and in response to the publication of the first national dementia strategy for England³, NHS Oxfordshire and Oxfordshire County Council established a county-wide Dementia Development and Implementation Board (DDIB) in 2009. The DDIB produced a dementia plan for Oxfordshire, which it revised in 2011 following further national guidance prioritising early diagnosis, improvements in hospital and residential care, and reductions to antipsychotic medication⁴. The revised

² <http://www.england.nhs.uk/statistics/statistical-work-areas/delayed-transfers-of-care/delayed-transfers-of-care-data-2013-14/> [accessed June 2014].

³ Department of Health (2009) Living Well With Dementia: a national dementia strategy, DH, https://www.gov.uk/government/uploads/system/uploads/attachment_data/file/168220/dh_094051.pdf [accessed June 2014].

⁴ Department of Health (2010) Quality outcomes for people with dementia: Building on the work of the national dementia strategy, DH,

DDIB plan identified four main areas of work: community services (including quality of care in residential homes, use of antipsychotics and support for carers), care in general hospitals, early diagnosis, and community building (including awareness raising, provision of information and peer support).

In relation to both support for carers and community building, the county's volunteers play a vital role. Many however, have no dementia-specific training and sometimes feel out of their depth. Others who might volunteer to help are put off by the lack of information or support. Recognition of the lack of informed supportive communities is reflected in the Prime Minister's Dementia Challenge: creating dementia-friendly communities who know how to help⁵. It also informed the 2011-12 Oxfordshire project, 'Dementia care learning groups for rural communities' which successfully piloted an adult and community learning approach to dementia awareness and volunteer action in six rural communities.

A common outcome in the 2011-12 project was for the community learning group to establish itself as the point of contact within its local community for information on dementia and dementia care. The impact of the community learning groups was summarised as:

- Delivered up-to-date, specialist knowledge of dementia, dementia care strategies and local dementia care services in their local communities
- Provided an opportunity for speakers from a range of local services to disseminate information directly to local people active in their communities
- Brought together people minded to offer voluntary help and support in their local communities with people living with dementia and their family carers
- Identified local activists previously unknown to the project partners and other local service providers.

Other projects addressed these issues from different perspectives, for example, Hampshire's 'Dementia Friendly Communities' project and York's 'Dementia without Walls' project. Nationally, the concept of dementia friendly communities was a focus of Dementia 2012, the Alzheimer's Society's report⁶.

https://www.gov.uk/government/uploads/system/uploads/attachment_data/file/213811/dh_19828.pdf [accessed June 2014].

⁵ Department of Health (2012) Prime Minister's challenge on dementia: Delivering major improvements in dementia care and research by 2015, DH

https://www.gov.uk/government/uploads/system/uploads/attachment_data/file/215101/dh_133176.pdf [accessed June 2014].

⁶ Alzheimer's Society (2012) Dementia 2012: A national challenge, Alzheimer's Society, http://alzheimers.org.uk/site/scripts/download_info.php?fileID=1389 [accessed June 2014].

3 Project origins

On completion of the 'Dementia care learning groups for rural communities' project in Oxfordshire at the end of March 2012, a number of the organisations involved formed the Oxfordshire Dementia Community Learning Partnership (ODCLP) with a view to building on the project's work. In May 2012, the DDIB encouraged the ODCLP to seek funding for further work on the model of the 'Dementia care learning groups' project and the partnership developed a proposal.

In response to NHS South of England's Dementia Challenge Fund for work that would make immediate and sustainable improvements to the quality of life of people affected by dementia,⁷ members of the ODCLP developed a proposal to complement and significantly extend the work outlined in the proposal submitted to the DDIB. The DDIB accepted that initial, more limited proposal in June 2012, and the funding awarded was identified as matched funding in the proposal to the Dementia Challenge Fund. This proposal was approved by the DDIB and submitted by Oxfordshire Clinical Commissioning Group (OCCG) to the Fund in September. In October, a total of £127,000 NHS funding was awarded to the DFC project.

4 Aims and Objectives

4.1 Outcomes

For people with dementia and their carers, the project sought to deliver the following outcomes:

- People with dementia and their carers say,
 - 'I feel part of the community and I'm inspired to give something back.'
 - 'I lived at home/in the community for as long as possible.'⁸
- More people present for early diagnosis and enjoy the accompanying benefits for themselves and their carers e.g. opportunity to make advance plans for their future up to and including end of life.
- Reduced social isolation for people living with dementia and their families, leading to a reduction in unnecessary hospital admissions and delays in timely hospital and care home discharge.

⁷ Letter dated 7 June 2012 from NHS South of England Chief Executive to : Clinical Commissioning Group Leaders, PCT Chief Executives, NHS Provider Chief Executives, Local Authority Chief Executives, Directors of Adult Social Care, Attendees at 29 May conference.

⁸ Cf Dept of Health (2010) *Quality outcomes for people with dementia: Building on the work of the National Dementia Strategy*. Dept of Health, http://www.dh.gov.uk/en/Publicationsandstatistics/Publications/PublicationsPolicyAndGuidance/DH_119827 [accessed June 2014].

More general intended outcomes included:

- A more dementia-aware county (measured through the number of people enrolled for awareness sessions and their geographic spread across the county).
- Better skilled volunteers, measured through the number of volunteers trained, with pre- and post-test rating of improved knowledge and skills.

4.2 Aims and Objectives

The project aimed to accelerate the pace of improvement in the pathway of care in Oxfordshire in order to raise the quality of life for people with dementia and their carers through:

- Creating better awareness in the communities in Oxfordshire
- Reducing stigma
- Creating a social environment that encourages people with memory loss to present for assessment thereby increasing early diagnosis and in turn facilitating appropriate support at the right times and in the right places
- A better informed voluntary workforce as measured by greater confidence in: recognising someone with dementia; prompting action resulting in a memory test or diagnosis; and supporting someone with dementia

Specifically, the project aimed to establish:

- 60 Self-managing, volunteer-led, community and workplace groups
- 200 Lead volunteers with informal quality dementia training and
- 60 Community Dementia Champions⁹ in a range of Oxfordshire communities and workplaces
- 60 Local action plans to increase and sustain practical community led support e.g. local information points, memory cafes, carers support groups, befriending circles, good neighbourhood schemes, informal respite opportunities.

The project proposed to network individual groups to share and develop ideas and effective local approaches. Although the project was informed by the views of people with dementia and their carers, it was not aimed directly at people with dementia and did not plan to deliver advice or information to

⁹ The term 'Dementia Champion' was used to demonstrate those attendees that were willing to take further action around dementia, which was most of the people involved, either as individuals making a difference, or as part of their community, or as a volunteer. This is not the same as the definition used by the Alzheimers Society which involves a greater commitment.

people with dementia or any health and/or social care services to people with dementia.

5 Method

The evaluation of the DFC project involved the analysis of performance data, before and after surveys of participants, action plans, and six qualitative interviews with a sample of participants in the learning events from across the county.

6 Implementation

6.1 Launch

As mentioned earlier, the project followed an existing successful model of creating sustainable, self-managing, voluntary, rural community learning groups, led by local people, working in partnership with health, education and other service providers, to address community health and care needs. The groups in the earlier project maintained only informal infrastructure with minimal or no overheads, so required no funding per se; and the project partners supported community groups beyond the lifetime of the project according to their needs (e.g. older people, through Age UK).

Oxfordshire Rural Community Council (ORCC) launched The Oxfordshire Dementia Community Learning Partnership in March 2013, with the aim of using the Community Learning Group model to improve public awareness and understanding of dementia, and ultimately to bring people with dementia, and their families, back into the community from which they may have retreated. The Guideposts Trust, Oxfordshire County Council's Skills and Learning Service and Oxfordshire Skills Escalator Centre were also involved in the project and the county council.

6.2 Community Learning Groups

Between the project's launch and March 2014, 58 events were organised with the aim of setting up Community Learning Groups in geographic and workplace communities, such as community centres and working with service providers such as the fire service and housing associations, to share information, best practice and offer specialist dementia training. In most places, a number of sessions were delivered, however, there were also some one-off sessions. By March 2014, a total of 212 hours of training had been delivered. An additional 74 hours were subsequently delivered.

In each community learning group, participants generally undertook a short programme (three two-hour sessions) of free training and guidance to learn about dementia and how to best support and help people with dementia.

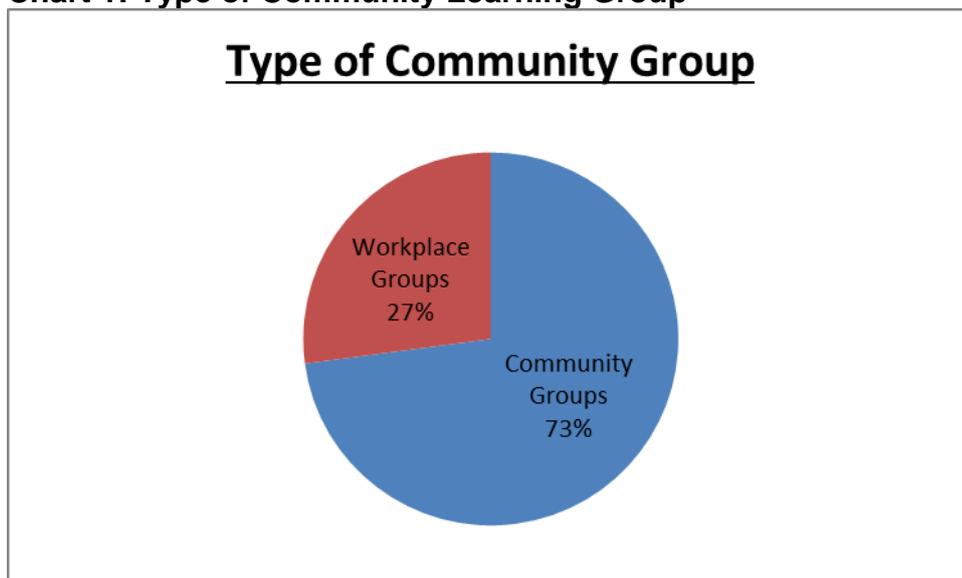
The first few groups received six two hour sessions, however the trainers found that most subsequent groups did not want to sign up for so many sessions, and reported that a three session programme seemed to meet the needs of the community learning groups.

Attendees joined the first session and were encouraged to sign up for two more, taking part in group discussions and role-play to widen their understanding of the issues. Learning included input from specialist dementia trainers and also from providers of local dementia-related services. The intention was that participants would take the information back to their communities, sharing it with other residents and organisations, and identifying people they could help.

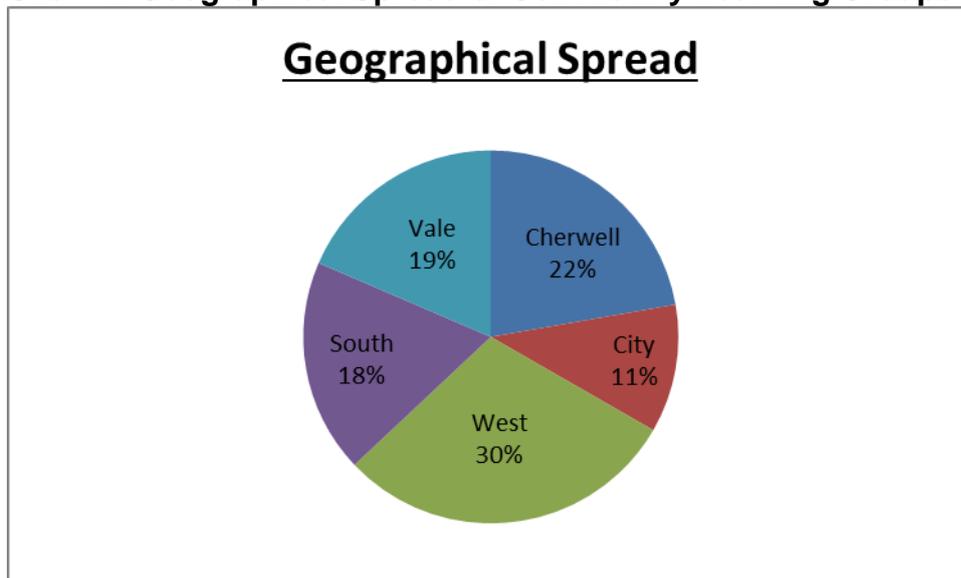
The final group session included guidance on producing a basic action plan to make their community or workplace more dementia-friendly, and ensure a long-term impact. Planning focused on practical ways for each community to support local people affected by dementia.

Nearly three-quarters (74%) of groups were community groups and 26% were workplace groups.

Chart 1: Type of Community Learning Group

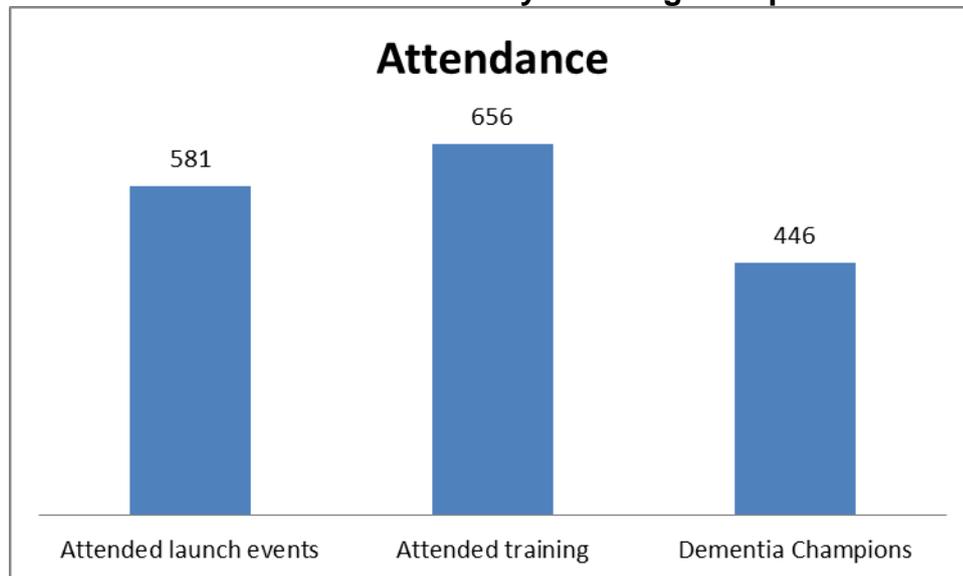


The Community Learning events were organised throughout the county (see Chart 2).

Chart 2: Geographical Spread of Community Learning Groups

In terms of the geography of participants, those completing pre or post-training questionnaires came from all over the county, with the greatest number of participants from the OX29 (Eynsham and Cassington) and OX14 (Abingdon) postcodes. No participants were identified from only a couple of areas (Appleton and Kingston Bagpuize OX13 and Woodstock OX20), demonstrating the wide coverage of the county by the project.

Data collected by the session facilitators, indicate that a total of 656 people attended the Community Learning Groups, of whom 446 became Dementia Champions (see Chart 3). By August 2014, a total of 891 people had been trained. The term 'Dementia Champion' was used to demonstrate those attendees that were willing to take further action around dementia, which was most of the people involved, either as individuals making a difference, or as part of their community, or as a volunteer. They all either filled an action out on their evaluation or were part of the community planning activity in the final sessions.

Chart 3: Attendance at Community Learning Groups

7 Findings

Participants in the Community Learning Groups were asked to complete questionnaires before and after the dementia awareness sessions. Although it is not possible to match before and after responses with specific individuals, the completed 490 questionnaires provide useful data on the profile of participants, and the impact of the sessions on individuals. It should be noted that completion of the questionnaires varied considerably across the groups, which means that it is not possible to assign any confidence level to the reliability of the data. However, the size of the response provides a good indication of the profile of respondents and the effect of the sessions on those taking part.

7.1 Participants' profile

The great majority of those taking part in the groups were female (79% of those completing the pre-session questionnaires, and 82% of those completing the post-session questionnaires). Two-thirds of those taking part were aged 50-74, with equal but smaller proportions in the 25 to 49 and 75 and over age groups (see Table 1).

Table 1: Age profile of participants

Age group	Pre-sessions	Post-sessions
Under 19	0%	0%
19-24	1%	2%
25-49	16%	14%
50-74	66%	69%
75+	16%	15%
Total	225	195

Note: figures subject to rounding.

Participants were asked about the age they left education, over 40% left aged 21 or above, while between 40 and 50% had left at age 18 or below.

In terms of ethnicity, 95% of those participants providing a response to the question were White British with a small proportion of White Other (4%) and an even smaller percentage of Asian/Chinese (1%). None of those responding identified themselves to be of Afro-Caribbean ethnicity. However, the questionnaire responses do not reflect that sessions were held with a Chinese community group in Oxford, and sessions with an Oxford based black and minority ethnic group were planned.

7.2 How people found out about the Community Learning Groups

Interviewees found out about the Community Learning Group events through a range of local networks: fliers, adverts in the local paper or parish magazine, emails, and workplace publicity.

7.3 Motivation

All the community interviewees had some personal experience of dementia through family members, friends and/or neighbours; while interviewees who had attended a workplace group had had experience of people living with dementia in a work context, for example, in a theatre and in social housing.

My mother had dementia. She had Alzheimer's, so we were interested in it from that point of view. Interview 1

None of the interviewees were currently caring for someone with dementia, unlike some of those completing the pre- and post-training questionnaires.

Respondents to the pre-session questionnaires were asked what they would really like to know about dementia. Many also indicated a personal

interest due to a family member, friend or neighbour with a diagnosis. Others stated a desire to know how to help and support someone with dementia or their carers through communication, practical help or other means:

A little more information about the condition and how to help the carer.

Better skills for interacting and supporting dementia sufferers. What we can do locally.

Some wanted general information about dementia, symptoms, progress, treatment and prevention, while other wanted specific information about local services and groups:

Gain a better understanding of symptoms and how to help people who have it.

How housing officers can support, be signposted to services, adjustments.

A small number of respondents emphasised the community aspect:

Ways the community can help victims and their carers.

How a community can work together to support people with dementia.

7.4 The sessions

On the whole, the sessions were well received by those who were interviewed:

I really enjoyed the training, I thought it was really really good. Loved the fact that you could do it for free. Loved the fact that there was no obligation, you could just turn up for one or the other session and you still got really good information. The trainer did a really good job. She made it very interactive and understandable. And actually I was surprised about some of the information that she gave. A lot of it wasn't necessarily common practice at the moment, and not necessarily what you'd automatically think and she wasn't afraid to contradict us, and she wasn't afraid to say "you shouldn't really do that", which was really refreshing to hear, because lots of the time in training these days, you hear "oh well whatever works for you" and all of that stuff. Interview 2

Post-training questionnaire responses and evaluation forms were also generally positive about the running and content of the sessions:

Very informative, useful and practical. Allows me to communicate with people with dementia and their carers

Interviewees from one of the workplace based sessions felt that although the event had been about 'dementia awareness', it had not met their needs:

It's our fault probably for not explaining what we were looking for, or maybe it was pitched a little bit too low for us, because, in fairness, the course was 'dementia awareness', but I think probably, one of the first things, we all have some awareness of dementia, but what we were looking for, maybe, was something that could lead us to draw up action plans, and perhaps a little policy and procedure around it. Interview 3

This indicates the importance of being clear about the purpose and content of these sessions, and where possible, exploring the possibility of tailoring sessions to the needs of particular groups – particularly in the work context.

7.5 Knowledge and understanding

Most of the interviewees were very positive about the sessions they had attended, and felt that they had increased their knowledge and understanding of dementia:

In the sessions, which made us realise in ourselves, what we were really thinking about things. It was quite interesting. You know, how we were actually feeling. It was very enlightening, really. And just the fact that everybody was able to speak about it. So many people can't talk about it. They don't admit that they've got relatives, or that they're worrying about themselves. Interview 1

Well I didn't really have any knowledge prior, only sort of stereotypical views of it. And I really enjoyed all of the sessions because I found it so interesting and it totally wasn't what I thought it would be, and I didn't think there would be so many different forms [types of dementia], and how it works in the brain, and the different parts of the brain that it affects, so I just loved it. Interview 4

A couple of those interviewed were already familiar with the SPECAL approach promoted by the Contented Dementia Trust which is based in West Oxfordshire. However, even these relatively well informed participants found the sessions added to their knowledge:

I think that you can always always learn more, can't you? And I can't be specific about anything new that I learnt, but I know I found it very interesting. Interview 5

Participants were asked to rate themselves in relation to two questions concerned with their knowledge of dementia before and after the sessions. The responses indicate a clear shift with a much higher proportion feeling able to: identify the signs and symptoms of dementia in a person; and understanding the needs of a person with dementia both verbally and non-verbally. Post-training, the proportion of participants rating themselves 1 or 2 in their ability dropped markedly – particularly in relation to understanding the needs of a person with dementia. The shift is also indicated by the higher mean scores for each of the two questions after training, with the greatest change in the mean for understanding the needs of person with dementia.

Table 2: Able to identify the signs and symptoms of dementia in a person

Feel able to identify the signs and symptoms of dementia in a person (n=467)	Pre-training	Post-training
1 - Not able	10%	1%
2	14%	2%
3	57%	45%
4	12%	43%
5 - Very able	7%	8%
Mean	2.93	3.57

Table 3: Able to understand the needs of a person with dementia both verbally and non-verbally

Feel able to understand the needs of a person with dementia both verbally and non-verbally (n=465)	Pre-training	Post-training
1 - Not able	22%	0
2	27%	6%
3	39%	46%
4	8%	43%
5 - Very able	4%	6%
Mean	2.44	3.48

Participants in the sessions were also asked whether they had gained knowledge about dementia that they would not have gained in other ways during the period. Nearly every respondent (98%) agreed that this was the

case; and 71% agreed that they had applied the knowledge they had gained in their daily life.

Those attending the sessions were also asked who they had shared the knowledge gained in the group with. Of those responding, 59% said they had shared the knowledge with family, 50% had shared it with friends, 20% with neighbours and 25% with work or study colleagues. Less than 7% said they had shared it with no-one, and in some instances this was due to lack of time since the training to take any further action.

7.6 Confidence when interacting with people with dementia

Nearly all those interviewed felt that the sessions they had attended had increased their confidence when interacting with people with dementia:

Interviewer: How has the project affected your own confidence when interacting with people with dementia?

Respondent: Personally quite a lot. I think that was the best part of the training. I really like the way that she [the trainer] spoke about how people who have dementia were still aware of what was going on in their circumstances and although on a particular day they might not know who you are, if you talk to them long enough, if you are patient enough, then you will get a response from them. And you will get some recognition from them.

And the interesting part was about quality of life, as well. She was talking a lot about quality of life, and how people with dementia still have that, whereas prior to the meeting, I almost thought that they were sat there in a cabbage like state, so that was very good. That was very illuminating and quite reassuring in a way. Interview 4

A couple commented similarly:

And it's stopped the sort of fear of it, and there used to be a sort of smiling at someone, thinking oh she can't really do something, trying to be kind, yes we really understand she's past it. Whereas it's made you realise that they're not past it, it's the short term memory that's really suffering badly, and the rest not so bad. Interview 1

Participants were asked to rate themselves in relation to three questions concerned with confidence before and after the sessions. The responses indicate an important shift with a much higher proportion feeling able to: interact with a person with dementia both verbally and non-verbally; manage situations when a person with dementia becomes confused or agitated; and feeling confident being around people with a diagnosis of dementia. Post-training, the proportion of participants rating themselves 1

or 2 in their ability and confidence dropped markedly, and the shift is also indicated by the higher mean scores for each of the three questions.

Table 4: Able to interact with a person with dementia

Feel able to interact with a person with dementia both verbally and non verbally (n=460)	Pre-training	Post-training
1 - Not able	11%	1%
2	29%	6%
3	43%	42%
4	12%	43%
5 - Very able	4%	8%
Mean	2.68	3.53

Table 5: Able to manage situations when a person with dementia becomes confused or agitated

Feel able to manage situations when a person with dementia becomes confused or agitated (n=458)	Pre-training	Post-training
1 - Not able	21%	3%
2	31%	9%
3	37%	50%
4	9%	32%
5 - Very able	3%	6%
Mean	2.42	3.29

Table 6: Feel confident around people with a diagnosis of dementia

Feel confident around people with a diagnosis of dementia (n=460)	Pre-training	Post-training
1 - Not able	13%	1%
2	25%	9%
3	32%	32%
4	22%	42%
5 - Very able	7%	16%
Mean	2.85	3.62

One respondent commented that they feel: *a lot more confident and know I will use tools and implement what I've learned*, following the training sessions.

7.7 Impact and outcomes

All the interviewees (with one exception) felt the sessions had made a difference in a variety of ways. These included practical changes, such as setting up new monthly groups for people living with dementia, activities around Dementia Awareness Week, changes to signage and design of public buildings, to softer outcomes such as increased awareness and reduced fear of dementia, and enabling a woman with dementia to continue to be involved in church activities.

I mean, P still comes to bible study and still contributes to that. Now that's changed a lot of people's minds because they realise she can think. You know, and she can argue, and she can put her point of view and ask sensible questions. Interview 1

It's Dementia Awareness Week, [18th – 24th May 2014] so throughout the week we've got different things going on, the WI, I'm doing something with the toddler group, all the different community groups are doing something. Interview 2

It has prompted us to think more about what we actually do need, which is always a good thing. After the meeting, [DFC facilitated session] I did check the policies and procedures that we have in Housing. We've got nothing on the tenancy policy about competency. Interview 3

They've already had somebody in to look at the bar, and when we have 'relaxed screenings', how we can make it more dementia friendly, in the sense of, we were learning about 3D things are quite hard and if it's the same colour it's harder to find the edges, and they really assessed the foyer and said this is what you'd need to do and they've already started putting some things in place that they can put up every time they have a screening, [e.g. large signs] to make it a bit more easy access. Interview 4

We got stuck in straight away, learning about it and taking notes and what we could compile that would relate to the theatre directly that we could give out to other members of staff who couldn't be there. So we created a little booklet by the end of the course, that we can hand out to staff. Interview 4

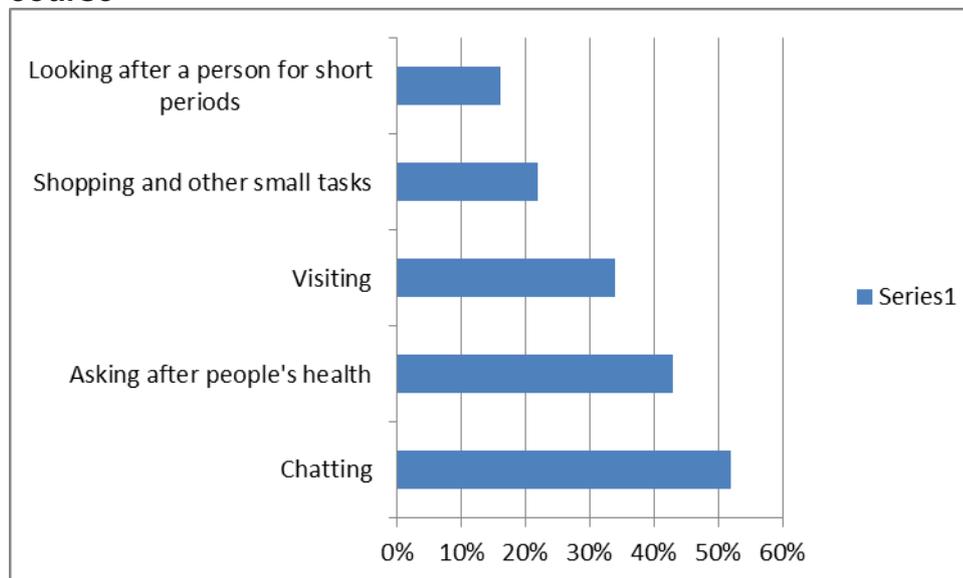
However, a couple of interviewees felt it was too early to identify any major changes in terms of the wider community:

Well it hasn't really got going. The project hasn't really got going, has it? We've just had the three preliminary training sessions, and there's another meeting with some other professionals coming along, so we haven't actually started. The memory café hasn't got off the ground, for instance. It's rather difficult to answer that question.

Interview 1

The post-session questionnaires also asked participants about what they were doing, or intending to do more for people with memory loss in their area following the course. The chart below indicates that the most frequently mentioned action was chatting with people, followed by asking after a person's health. More time-consuming activities were less frequently mentioned, although more than 15% said they were or intending to look after a person with dementia for short periods.

Chart 4: Actions to become more dementia friendly following the course



Of those responding to the question, three quarters (75%) said they intended to continue in the group. For some of those who did not respond or said that they did not intend continuing, this may reflect the nature of the group they were in: some groups were work-based (Sanctuary Housing, Fire Service, Chipping Norton Theatre) or pre-existing groups or clubs, such as Connexions or the Dig 'n' Grow group. For these sessions, setting up an ongoing self-sustaining group as a result of the course may not have been particularly appropriate.

Many of those completing the post-training questionnaires mentioned other activities they were doing or intending to do as a result of the sessions. These included:

- *Being a support to neighbours and friends at church who are living with dementia*
- *Interact with my mother better who has early stages of dementia*
- *Involving local businesses in helping people who are lost due to dementia*
- *Hopefully help new groups/activities for those with memory problems*
- *Rolling out scheme for carers*
- *Raise visibility in village through established neighbourhood action group*
- *Initiate art/memory groups for villagers to join*
- *Run lunch club, want champion for dementia in my church*
- *Help people and their families attend relaxed performances with confidence*
- *Possibly set up a music evening with others*

Other positive outcomes were identified in the post-training questionnaires related to more general benefits for individuals and communities. About three-quarters (74%) of those completing the post-training questionnaires said that they felt less stressed about dementia as a result of participating in the group, with 24% reporting no change, and a small proportion (2%) saying that they felt more stressed. In addition, 61% said they had met people in their community that they didn't know before; 53% reported that they had learned things about their community that they did not know before; and 21% said that they had got to know their neighbours better.

The questionnaire responses demonstrate that the initiative generated a lot of enthusiasm and interest among participants, with a wide range of planned individual and community activity. However, there were few examples of action plans emerging from the sessions. Three workplace based action plans were developed which set out plans to review policies and practices. It is not known how far these have progressed.

7.8 Sustainability

Some of those interviewed discussed future plans for activities and developments in their community as a result of the sessions.

I think that largely it's going to be finding a few more people within the community who we can help specifically, that would be really helpful and keeping up the awareness activities, and certainly there's talk of doing a buddy system and a memory café, at the institute once a month, and probably getting closer to some of the care homes, because that's where a lot of them are. Interview 2

Plans for a dementia friendly performance of the local panto were in the pipeline in one area. However, not all interviewees had clear longer-term

future plans, and one interviewee was very negative, largely due to a previous history of ill-feeling between them and other participants in the DFC sessions.

As mentioned earlier, the limited number of action plans raises some concerns about the longer-term impact of the sessions. While a majority of those completing the post-session questionnaires said that they intended continuing with their local group, and many respondents had intentions to carry forward a range of activities and initiatives, it is not known how far these have been implemented.

7.9 Obstacles

A number of obstacles to promoting the concept of dementia friendly communities were mentioned by interviewees. These included data protection legislation making it difficult to identify who was living with dementia in the local community, along with the stigma of the illness, and in one instance a concern that involvement would mean having to visit local residents with dementia. One interviewee also felt that the project was not linked into the work of other relevant organisations locally. This could have limited its effectiveness.

7.10 Definition of a Dementia Friendly Community

Interviewees were asked to provide their own definition of what a dementia friendly community. Their responses share some common features, emphasising greater awareness and understanding of dementia, wider knowledge of how to help and support people with dementia, and a more pro-active approach. Responses have been quoted at some length here:

It would be that everyone in the village or in the community, has an awareness of dementia and that they treat people as sensitively as they can, and not write them off. They're there to keep an eye. It's like M's neighbours, who kept an eye when she was wandering about. So I would think it would be people who care for their neighbours, and who keep an eye open, and it applies to the shops, and staff in the shops. Interview 1

I supposed where everybody who interacts has got an awareness of what's involved with dementia. And it's the understanding that there are different types of dementia as well. The training was very good at that. For us, personally, I wouldn't say that we had any dementia friendly communities, because we don't put our people with dementia into one area together, but I like to think that every Housing Officer would contribute to a dementia friendly community, in that they are aware of it and will treat anyone with sympathy, patience, and refer as far as they can, if necessary. Interview 3

I guess it's that people are aware, and have better and more knowledge of it, so that, for example, the lady that I helped, I think her name is D, so that people know her and are aware of her and know how to help her if the situation comes to it. And that shops and businesses in town are aware of it. I think it's so important if businesses are aware of it. I don't know how they can spread the word more, but I think it's so nice if they can. It also makes the community nice. You get to meet people as well, and that's good.
Interview 4

Oh well, one where if they see somebody with dementia walking down the road, will walk along with them, and will stop what they're doing, will walk along with them, and then will distract them and get them home again. That would be an immediate example. Somebody who carries on including, if they're friends of theirs in the first place, somebody who carries on including them in daily activities. Interview 5

8 Conclusion

In conclusion, the Dementia Friendly Communities project has been successful in reaching a wide number of people across the county and raising their awareness, understanding and confidence in interacting and supporting people with dementia. More than 650 people took part in the sessions across the county and a greater number have benefited through the sharing and application of the knowledge gained by participants in the Community Learning Groups.

In terms of the general intended outcomes: a more dementia-aware county and better skilled volunteers, the project has achieved considerable success, raising self-assessed levels of ability and understanding in those taking part. Feedback from those taking part in the Community Learning Groups was overwhelmingly positive.

In terms of the specific goals:

- Dementia awareness sessions were delivered to 60 community, voluntary and workplace groups, including a local theatre, housing association, and the fire service.
- According to facilitators a total of 446 Dementia Champions were recruited, defined as those attendees who were willing to take further action around dementia either individually or as group.
- A limited number of action plans were developed, although three-quarters of those responding to the question, said they intended to continue in the group, and many of those participating in the sessions stated intentions to undertake specific activities more related to dementia either as individuals or in a group.

In the longer-term, there may be concerns about how to maintain the momentum of the project in order to ensure its longer term sustainability. This is a question for the project providers and the commissioners to consider.

This evaluation did not obtain data on the impact of the project on people living with dementia themselves in Oxfordshire and it is also not known what the impact has been in terms of reduced social isolation and earlier presentation for diagnosis. The impact on these aspects of dementia friendly communities is one that is likely to take longer to be felt, but may also be difficult to attribute causality given the range of other factors that may affect social isolation and presentation for early diagnosis.

Overall, the project appears to have been successful in meeting its objectives and contributing to more dementia friendly communities as defined by the interviewees – with greater awareness and understanding of dementia, and a more pro-active approach to supporting people with dementia and their carers.