

## **Hampshire County Council**

### **Evaluation of Hampshire Dementia Friendly Communities**

#### **Final Report**

**June 2015**

# Hampshire County Council

## Evaluation of Hampshire Dementia Friendly Communities

### Report

#### 1 Introduction

This report presents the results of an evaluation of the Hampshire-wide Dementia Friendly Communities (DFC) project. The evaluation was carried out by the Institute of Public Care at Oxford Brookes University for Hampshire County Council (HCC).

The DFC project began in March 2013, and the evaluation work has continued from the start date to the end of February 2015, involving a combination of quantitative and qualitative data collection, with analysis and drafting completed in spring 2015.

##### 1.1 Aims and Objectives of the Evaluation

The main objective of the evaluation was to explore whether the objectives and outcomes of the Hampshire-wide Dementia Friendly Communities project have been achieved. The aims of the proposed evaluation were to:

- Assess whether the project provider delivered the project as specified in the service specification.
- Assess whether the project provider achieved the expected project outcomes.
- Evaluate the project's impact on people with dementia and their carers in terms of enabling them to live well with dementia.
- Explore whether the project has delayed or reduced the need for more intensive support amongst people with dementia and their carers.

In addition, the evaluation aimed to address the following questions:

- What are the lessons for the further development of this approach in Hampshire and elsewhere?
- How can the concept of Dementia Friendly Communities be refined?
- How does the development of Dementia Friendly Communities impact on the use of other services, particularly health care?
- What is the business case for Dementia Friendly Communities?

## 2 Context

### 2.1 National

There are an estimated 850,000 people with dementia in the UK in 2015<sup>1</sup>. According to the National Dementia Strategy (2009) two-thirds of all people with dementia live in their own homes in the community, and some of these will “*just want access to services that should be available to everyone locally*” (p47).

Among a range of objectives, the Strategy aimed to: improve public awareness and reduce social exclusion; increase access to good quality information, advice, care and support for people following a dementia diagnosis; improve community support for people with dementia and their carers; and develop local peer support and learning networks. The Strategy emphasised the prevalence of the disease, and the impact both on individuals and society at large.

More recently, the Prime Minister’s Dementia Challenge in 2012 committed to: give a boost to dementia research; address the quality of dementia care; increase public understanding of dementia; and *make communities more dementia friendly*. The Four Cornerstones model of dementia-friendly communities focuses on: place, people, resources and networks<sup>2</sup>. It was developed through action research and collaborative work done for the Local Government Association and the Joseph Rowntree Foundation. The authors noted that: “*Communities can create barriers for people with dementia, and dementia friendly communities help people to take the barriers down*”.

According to the Alzheimer’s Society which has included a definition and development of Dementia Friendly Communities as a key ambition of its five year strategy:

*‘A dementia-friendly community is one in which people with dementia are empowered to have aspirations and feel confident, knowing they can contribute and participate in activities that are meaningful to them.’<sup>3</sup>*

Since 2012, there has been some significant progress on dementia nationally, including: an increase in dementia diagnosis rates; and over 50 communities across England have signed up to the national Dementia Friendly Communities recognition process.

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<sup>1</sup> Alzheimers Society (2015)  
[http://www.alzheimers.org.uk/site/scripts/documents\\_info.php?documentID=2761](http://www.alzheimers.org.uk/site/scripts/documents_info.php?documentID=2761)  
Accessed 25/2/15.

<sup>2</sup> Crampton, J, Dean J, & Eley R (2012) Creating a dementia-friendly York, JRF.

<sup>3</sup> [http://www.alzheimers.org.uk/site/scripts/documents\\_info.php?documentID=1843](http://www.alzheimers.org.uk/site/scripts/documents_info.php?documentID=1843)  
Accessed 25/2/15.

According to the Prime Minister's Challenge on Dementia 2020<sup>4</sup>, over one million people have been trained to be dementia friends to raise awareness in local communities, and over 400,000 NHS staff and over 100,000 social care staff have been trained in better supporting people with dementia.

The government's aspirations for 2020 include:

- Over half of people living in areas that have been recognised as Dementia Friendly Communities.
- Alzheimer's Society delivering an additional 3 million Dementia Friends in England.
- All businesses encouraged and supported to become dementia friendly, with all industry sectors developing Dementia Friendly Charters and working with business leaders to make individual commitments (especially but not exclusively FTSE 500 companies).
- All employers with formal induction programmes invited to include dementia awareness training within these programmes.
- All hospitals and care homes meeting agreed criteria to become a dementia friendly health and care setting.
- National and local government taking a leadership role with all government departments and public sector organisations becoming dementia friendly and all tiers of local government being part of a local Dementia Action Alliance.<sup>5</sup>

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 to make a dementia friendly community<sup>6</sup>. 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 their local area, and many people with dementia were not able to take part in activities that they enjoyed before they developed the condition.

For example: less than half of the respondents to the Dementia Friendly Communities survey thought their area was geared up to help them live well with dementia (42%); and less than half felt a part of the community (47%). Results became considerably lower the more advanced the person's dementia was.

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<sup>4</sup> Department of Health (2015) Prime Minister's challenge on dementia 2020, DH

<sup>5</sup> Department of Health (2015) Prime Minister's challenge on dementia 2020, DH.

<sup>6</sup> 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](https://www.alzheimers.org.uk/site/scripts/download_info.php?downloadID=1236)  
Accessed 25/2/2015.

Another report (2012) found that three in five (61 per cent) people diagnosed with dementia were left feeling lonely, and four in five (77 per cent) felt anxious or depressed<sup>7</sup>. 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.

## 2.2 Local

According to POPPI<sup>8</sup> projections, there are over 20,000 older people with dementia in Hampshire in 2015, and this number is likely to increase by 68% between 2015 and 2030. Given that two-thirds of this number are likely to be living in their own homes, there is a strong argument for ensuring that their communities are dementia friendly.

The Hampshire-wide Dementia Friendly Communities Project was developed following a short pilot project in Hart and Rushmoor districts. The pilot work was part of a small project commissioned by the Local Government Association (LGA) under the Ageing Well programme, which ran from 2010/2012 and was funded by the Department of Work and Pensions, to support councils to prepare for an ageing society. Innovations in Dementia, a Community Interest Company, was commissioned to undertake the work towards the end of 2011.

HCC wanted to understand more about what was meant by a '*dementia friendly community*' and what steps would need to be taken for Hampshire to become more dementia friendly. As part of this work, HCC also wanted some practical tools developed that could be used to take this work forwards at a local level.

The pilot delivered:

- A national report produced by the LGA outlining what the Hampshire project and a further project in Sheffield covered and achieved.
- Engagement tools that help put people with dementia and their carers at the heart of deciding what *dementia friendly communities* are and mean.
- A range of tools that can be used to support services and businesses to become more dementia friendly.
- A process to consider when developing *dementia friendly communities*.

An event was held in Hampshire at the end of April 2012 to share the learning from the pilot. This was attended by over 100 people. The practical tools covered:

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<sup>7</sup> Lakey, L, Chandaria, K, Quince, C, Kane, M, & Saunders, T (2012) Dementia 2012: A national challenge, Alzheimer's Society.

<sup>8</sup> <http://www.poppi.org.uk/>

- Finding out what a dementia friendly community means to people with dementia and carers: Toolkit for engaging people with dementia and carers.
- Why do we need to be dementia friendly?: Briefing note for businesses.
- Dementia awareness raising options for staff: Briefing note for businesses.
- Help-pack for customer-facing staff: Briefing note for businesses.
- A checklist for dementia friendly environments: Briefing note for organizations.
- Thinking about a 'Memory Aware' high street scheme: Briefing note for organizations.

The toolkit which has been shared nationally and internationally, including with the group working on the Prime Minister's Dementia Challenge, can be found at: <http://www3.hants.gov.uk/adult-services/adultservices-professionals/dementia/dementia-friendly-toolkit.htm>

### 2.3 Methodology

The evaluation adopted a pluralistic approach to evaluation, combining both quantitative and qualitative methods. The evaluation involved three stages:

- Preparation
- Ongoing monitoring, and
- End of project evaluation

In the preparation stage, an evaluation framework was developed to address the project objectives. This was followed by the development of survey questionnaires for individual attendees of peer groups for people with dementia and for carers groups of people with dementia in order to assess the project's impact in terms of living well. The questionnaire was based on one developed and tested by the Alzheimer's Society for people living with dementia. Hard copies were circulated by Andover MIND with Freepost envelopes provided (following the approach of the Alzheimer's Society). As the project evolved, an additional questionnaire for people who had attended dementia awareness sessions was developed. In addition, a semi-structured interview schedule for use with other stakeholders was developed, including dementia action group members, HCC staff, the Project provider, local voluntary and community sector groups working with people with dementia, and other relevant organisations, people with dementia and their carers. An information sheet was prepared for all interviewees and survey participants explaining the purpose of the evaluation, and a consent form.

Ongoing monitoring was conducted at six monthly intervals with meetings with the commissioner and project provider, and on one occasion a

teleconference. This provided an opportunity to understand how the project was evolving and progressing over time, discuss barriers and facilitating factors contributing to achievement of project objectives and outcomes. This provided insight into the process of implementation.

Resources were focussed on evaluation at the end of the project to assess whether objectives and outcomes had been met, and the perceived impact of the project on people with dementia and their carers. The end of project evaluation involved interviews with a wide range of stakeholders; participation in the Dementia Friendly Hampshire conference in February 2015; a survey of carers of people living with dementia; and a survey of people who had attended one of the many dementia awareness sessions. Interviewees included people living with dementia and carers, members of local dementia action groups, retailers, educators, care providers, carers and others involved in Dementia Friendly High Streets, staff of local voluntary and community sector organisations, project staff, and HCC staff. It is not possible to give response rates for the surveys, as it is not known exactly how many people received questionnaires; however the carers survey elicited responses from 15 carers – 7 from Winchester and the rest from five other districts; and the survey of people attending a dementia awareness session obtained 53 responses.

In addition, the evaluator reviewed documentary material including stakeholder group minutes, newsletters, the service specification and other relevant materials.

HCC also carried out a service user survey in 2013 with questions related to dementia friendly communities and will be repeating the survey in 2015 to review against 2013 findings. The results are due in May 2015.

Research governance approval was obtained from Hampshire County Council.

## **3 Inputs**

### **3.1 Project origins**

Building on the pilot work described earlier, the project aimed to establish sustainable Dementia Friendly Communities across Hampshire, reaching as full a range of different communities as possible. The project covered the five new Clinical Commissioning Groups in Hampshire and the 11 districts.

### **3.2 Funding**

The overall cost of the two year project across the whole of Hampshire was £402,000. The project was initially planned to run for only 12 months and was funded using a one off payment from the Department of Health badged

to support 'Memory services': Hampshire's funding allocation was £212,000 and it was agreed between NHS Hampshire (the Primary Care Trust at the time) and Hampshire Adult Services that as part of the implementation of The Joint Hampshire Commissioning Strategy for Older People's Mental Health, 2008-2013, the funding would support the roll out of learning from the Dementia Friendly Communities pilot and enable a county-wide Dementia Friendly Community Project. It was recognised that a 12 month project was an exceedingly challenging timescale for a project of this nature, but it was felt that progress could be made within this timeframe, and every effort would be made to secure additional funding to extend the delivery time.

The additional £190,000 was secured following a successful bid by Hampshire Adult Services, supported by the five Hampshire Clinical Commissioning Groups, to the South of England Dementia Challenge Fund in 2012. This enabled a 12 month extension to the project. £22,000 of the initial funding was allocated to the independent evaluation of the project carried out by Oxford Brooks University.

Significant efforts were also made to secure further funding by partnering with Devon County Council and others, including Plymouth University, in a bid for European Union Funding. Devon County Council led the bid, but it was unsuccessful.

### **3.3 Project outcomes**

The key project outcomes were:

- A shared understanding amongst participants in the project of what constitutes a Dementia Friendly Community across Hampshire.
- People with dementia and their carers will have been at the heart of deciding what this means in their communities.
- Hampshire will have:
  - Groups of empowered people with dementia and their carers who will have a voice and role in developing services and support that enable them to "live well" with dementia.
  - An engaged community enthusiastic about and supportive of people with dementia that promotes inclusivity in its universal services such as leisure centres, opticians, shops, restaurants, hairdressers etc.
- Sustainable mechanisms for continuing developments once the project has ended, for example developing a Dementia Action Alliance for Hampshire, identifying community dementia champions and cascading approaches.

- External evaluation of the project will demonstrate a positive impact for people with dementia and their carers in terms of “living well” with dementia.<sup>9</sup>

Expected benefits included:

- Increase in the number of people receiving an early diagnosis rates.
- Increase in the number of peer support groups for people with dementia and their carers.
- Positive impact on the ability of people to live well with dementia.
- Change in the use of resources and services e.g. increased access to and take-up of very locally based services, activities and supports, less reliance/use of statutory services over time.
- Increase in the knowledge and understanding of dementia for those members of communities who participate in the project.
- Memory Aware High Street Schemes in place which improve access.
- Network of community champions in place and self-sustaining, promoting the development of a more dementia friendly Hampshire across a range of interests, sectors and geography.
- A Dementia Action Alliance in place in Hampshire, promoting the development of a more dementia friendly Hampshire across a range of interests, sectors and geography<sup>10</sup>.

### 3.4 Tendering

The level of funding meant that a full tender exercise was required to identify the project provider. Andover Mind was successful in winning the contract for delivering the project which was finally awarded in January 2013. The tender process ensured that should further funding become available, the project could extend for a second year.

The project began on March 1st 2013, some months after new Dementia Advisor Services started in Hampshire (October 2012). It was envisaged that the DFC project would work in tandem with these services to meet outcomes associated with prevention, early intervention, maintaining independence, addressing stigma and access difficulties, and delaying the need for more intensive support.

### 3.5 Project specification

The original specification set out the aims and objectives as follows:

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<sup>9</sup> HCC Evaluation Brief 28/8/12

<sup>10</sup> HCC Evaluation Brief 28/8/12

- Develop a shared understanding amongst those participating in the project of what makes a community dementia friendly and actively promote the concept and the work of the project.
- Ground the project in the experiences and views of people with dementia by making connections with them across Hampshire, and ensuring that they identify the focus for future local work.
  - Developing a rolling programme of consultations.
  - Promoting the development of peer support for people with dementia by:
    - Identifying and mapping current peer support groups.
    - Identifying where there are gaps in provision.
    - Supporting and promoting the development of new groups in areas where these are not currently available.
- Support people with dementia and their carers to continue to live as “normal” a life as possible and to stay connected to their communities for as long as they would like to by:
  - Focussing on well-being and empowerment of people with dementia and their carers, in order to build resilience and independence.
  - Raising awareness of dementia and supporting local groups and services across Hampshire to understand more about dementia and how they can better support people with dementia and their carers.
  - Identifying and working with traditionally excluded groups and particularly focussing on communities where there is a low level of awareness and recognition of dementia. Equality and Inclusion Community Development Officers are available to support in the identification of such groups and to advise as to best methods of engagement.
  - Identifying what is working well for people with dementia in their local communities and identifying how this can be built upon and replicated elsewhere.
  - Identifying difficulties that people with dementia and their carers face in continuing to connect with their communities and work with key stakeholders to address these difficulties, where possible.
  - Using the processes, models and tools identified in the Hart and Rushmoor pilot and other national research and experience, further testing out their effectiveness and honing as appropriate.
  - Building on the pilot tools to develop a “Dementia friendly”/Memory aware scheme for shops/organisations/groups/services. (See

Background Information) and pilot in 3 areas in Hants, including a Memory Aware Card scheme<sup>11</sup>.

- Identify and apply strategic levers to bring about change:
  - Working with local partnerships and bodies, such as Chambers of Commerce and other business communities, Local Health and Well-Being Boards, district councils, libraries, police, fire service and the leisure industry.
  - Developing a Dementia Action Alliance in Hampshire (see <http://www.dementiaaction.org.uk> ).
  - Identifying local “Dementia Champions” to promote the viewpoint of people with dementia across a range of communities, including in minority communities.
  - Creating a network of champions and ensuring this will be sustainable at the end of the project period.
- Work collaboratively with other community partners to:
  - Maximise opportunities for progressing the development of dementia friendly communities and synergy achieved from working together.
  - Minimise duplication of effort.
- Promote the principle of early diagnosis

At the end of the first year, this was revised reflecting the evolution of the project and the emergence of new activities. Dementia Champions were rebranded as Dementia Ambassadors to avoid confusion with the Alzheimer’s Society Dementia Friends Champions. Two new outcomes were added:

- There will be a defined and agreed course of promotion and publicity of the scheme to promote awareness of dementia and Dementia Friendly Communities that will be agreed with the commissioners.
- There will be an increased awareness of dementia within traditionally excluded communities on how to seek help and live well with dementia.

### 3.6 Staffing

A full-time project manager and six part-time local area coordinators were appointed and three pilot sites were selected for the Dementia Friendly High Streets work. The original project manager stepped down in September 2013, and after initially being replaced by two managers from the team as an interim holding measure, from March 2014 this was taken on by a single project manager.

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<sup>11</sup> As the Alzheimer’s Society already had a Memory Aware Card scheme, it was decided that it would cause confusion to introduce yet another scheme. Instead, interested parties were signposted to the Alzheimer’s Society card.

The main role of the local coordinators has been to engage with people with dementia and their carers, raise awareness, provide more tailored Dementia Friends Plus sessions, develop Dementia Friendly High Streets, recruit Dementia Ambassadors, and support and create peer support groups where needed.

### **3.7 Steering group**

HCC and Andover MIND established a steering group for the project. Membership included: the HCC Commissioning Manager, health (CCG member), police, a person with dementia, a carer of someone with dementia, a minority group representative and others from local health and third sector organisations.

Interviewees commented that getting engagement from health on the steering group was not always easy at the beginning. More recently, there has been good engagement from a local GP who has taken on a specific project to promote dementia friendly practices in conjunction with Wessex Academic Health Science Network.

### **3.8 Initial consultation and engagement**

An initial consultation and engagement exercise was undertaken between March and May 2013. Across the two years, 141 consultation and engagement events were held and 1,025 people consulted. This included 9 consultative events with traditionally excluded groups. Local area coordinators used questionnaires as a basis for talking with people, exploring what activities people engaged in, and what helped or prevented them from doing those things. The majority of these completed questionnaires reflected the views of carers (66%).

Going out for refreshments and shopping locally emerged as the main pastimes of respondents (It is not clear to what extent this reflected the views of carers or people with dementia). Carers and helpers were the most important factors which enabled people to undertake these activities, along with helpful and understanding people, and physical provision for people with disabilities. Factors which made it more difficult for people to take part in activities included environmental factors such as: lack of seating; poor signage; no transport; poor personal health; and lack of confidence. Respondents thought that having someone to help or befriend them would help them restart previous activities and start new activities.

When asked about what would help make communities more dementia friendly, raised awareness in shops, transport, GPs, hospitals, schools, and the community generally were widely mentioned, along with practical steps to improve access to services. The difficulty of finding out about activities and the lack of activities was also a hindrance. In terms of personal

support, respondents mentioned the need for more carers, befrienders, and volunteers. The survey results are presented in Table 1 below:

**Table 1: Survey of people with dementia and their carers, Summer, 2013**

	Agree or Strongly Agree	Neither/ Nor	Disagree or Strongly Disagree	N=
In my local area people with dementia are respected	31%	59%	9%	1,025
In my local area the signage and layout of buildings and towns makes it easy for people with dementia to find their way around	18%	66%	16%	1,022
In my local area people with dementia are enabled to do the same things other people do	19%	67%	14%	1,015
In my local area people with dementia have the opportunity to fully take part in family social and civic life	23%	66%	11%	1,1014

Source: Andover Mind

Five of the 15 carers responding to the IPC questionnaire said that they had been asked for their views by the DFC Team.

### 3.9 Evolution of the project

In the first year of the project, links were developed with local Alzheimer's Society and Age Concern staff, and the Council's own PACT team which provides training to Hampshire Adult Services Department, independent and third sector organisations. These collaborative relationships contributed to the greater effectiveness of the project, by maximising the use of the available resources.

The activity in the first year was wide-ranging and project staff adopted a flexible approach, undertaking a variety of activities which were felt to be testing possible activities to prioritise. Project staff commented during the project's development on the difficulty of deciding where to focus and prioritise effort. The original focus was around developing the Hampshire Dementia Action Alliance through the dementia friendly high streets work, and the recruitment of Dementia Ambassadors.

In the second year, the project found itself responding to a high volume of interest in dementia awareness sessions and the emergence of dementia action groups, in addition to the activities conducted in the first year, having built up a '*head of steam*'. The project staff also sought to increase the involvement of people from traditionally excluded communities.

The project originally aimed to create a number of Dementia Champions, however, a decision was taken to relabel this group as Dementia Ambassadors to avoid confusion with the Alzheimer's Society's National Dementia Friends and Dementia Friends Champions campaign.

## **4 Activities and outputs**

There was widespread recognition that the DFC project team and volunteers had demonstrated high levels of commitment and enthusiasm for the project, contributing many hours of time and effort. The range of activities was considerable over the two years of the project's lifespan.

### **4.1 Dementia awareness sessions**

There was an unexpectedly high volume of demand for the dementia awareness sessions offered by the local area coordinators and volunteers involved in the DFC project. The start of the DFC project coincided with the Alzheimer's Society Dementia Friends campaign, as one interviewee observed: '*an ideal marriage*'. The Dementia Friends sessions are simple and can be delivered in an hour. Andover MIND staff and volunteers underwent Dementia Friends Champion training to equip them to deliver dementia awareness sessions (under the Dementia Friends umbrella) across the county. Open sessions were advertised in the local press and on the Dementia Friends website.

The specification in Year One set a minimum target of 15 sessions including 4 for traditionally excluded groups, and in Year Two, a minimum target of 60 sessions including 8 for traditionally excluded groups. By the end of the DFC project's first year, 130 sessions had been delivered to 1,305 people across Hampshire. By the end of the second year, the staff team had delivered 348 sessions to 3,404 dementia friends. Of the estimated 9,000 Dementia Friends in Hampshire, one in three became Dementia Friends through sessions provided by Andover MIND staff.

These figures underestimate those reached through the DFC project, as they do not capture those delivered by volunteers, in-house by businesses or via on-line sessions. At the end of January 2015 there were approximately 69 Dementia Friends Champions attached to the Dementia Action Groups. These Champions will have been running Friends sessions in tandem with Local Area Coordinators. The number of sessions delivered was well beyond the minimum required in the specifications.

Most sessions were delivered to a specific organisation or group. Session participants have included: library staff and volunteers, council staff, district and county councillors, customer-facing retail and bank staff, opticians, hairdressers, theatre ushers, faith groups, housing association staff, police, judges, firefighters, GP surgery staff, meals on wheels delivery drivers, care home staff, domiciliary care staff, town rangers, teachers, students, school children, voluntary groups, carers groups, and the general public.

Awareness sessions were most numerous in those areas where Dementia Friendly High Streets activities were carried out. This is probably mainly because some organisations included an aim to achieve a target proportion of staff as Dementia Friends as part of their Dementia Action Alliance Action Plan. For example, the Fire Service aim to get 75% of all firefighters to attend a Dementia Friends session, and it is planned to incorporate it as part of induction training for new firefighters. In one GP surgery, four Dementia Friends sessions were delivered over two days for all staff (40 people), and the surgery is now looking to recruit a Dementia Friends Champion from its patient support group. Primary care services are a potentially useful focus for Dementia Friends activities as they are a key service for people with dementia and their carers.

Targets for the numbers of people attending awareness raising sessions were exceeded fourfold. The demand from businesses and other organisations meant that by September 2014, open public sessions had stopped. Staff decided to focus on sessions tailored to businesses and organisations to maximise impact. Five Dementia Lead Training sessions to '*train the trainer*' were provided for 29 people and 16 other sessions for 174 people.

Interviewees who had been to Dementia Awareness sessions were very positive about it. One interview from a local retailer commented that they had quite a few customers with dementia and were now looking at how they could support them, both practically and in terms of the shop design. Retail staff wear Dementia Friends badges once they have been to a session. The interviewee commented about the project: '*They've done an amazing job to get as many people engaged as they have*'. Another retailer had done the Dementia Friends Champion training which involved a day of training to enable her to deliver Dementia Friends training. This had been cascaded to other staff. She commented on the value of the project as '*a great relationship building thing*'.

Questionnaire responses from participants in dementia awareness sessions were overwhelmingly positive (Table 2). The great majority felt they knew more about dementia and were more comfortable about the illness. More than three-quarters of respondents said that they felt more confident about helping people with dementia and had applied the knowledge gained at the session in their daily life. Three of those responding had become Dementia

Champions, one had become a Dementia Ambassador, two had become involved in running a memory group at their local library, and others had shared the information with family, friends, neighbours and colleagues.

More than 80% of respondents were female and all described their ethnic origin as White. Half of the respondents came from East Hampshire and the rest from five other districts. Half had attended a workplace session.

**Table 2: Participants views of dementia awareness sessions**

	Agree or agree strongly
By attending this awareness session I have gained knowledge about dementia that I would not have gained in any other way during this period	92%
	More comfortable about dementia
Participating in the awareness session has made me feel...more or less comfortable about dementia	88%
	More confident
Has the awareness session given you more or less confidence in helping people with dementia?	77%
	Agree or agree strongly
I have applied the knowledge I have gained at the session in my daily life	77%

N=53

The sessions appear to have provided a useful mechanism for getting people involved in other aspects of the DFC project. One interviewee with dementia thought the awareness sessions were invaluable as a way of raising awareness about dementia among those working with the public.

In addition to the Dementia Friends sessions, a course on Supporting Customers who have Dementia was developed for Hampshire by Jackie Pool, one of the Dementia Ambassadors (details are available at: <http://www.dementiaaction.org.uk/resources/awareness>). This course, delivered to a range of organisations, was piloted by Fareham Shopping Centre Security staff. Boots UK were also one of the early participants on the course, with their 8 Hampshire leads being trained to deliver the two hour sessions. This led to 130 of their pharmacists/dispensing staff and 70 store managers becoming dementia aware. It is now being rolled out to other staff.

## 4.2 Dementia Action Groups

The Dementia Action Groups (DAGs) were recommended for investigation in the project Implementation Plan for Year One, and have grown organically over the life of the project out of the work on Dementia Friendly High Streets, reflecting the flexible approach of the project team. The DAGs are now planned to be key, largely self-sustaining, groups in the future of Dementia Friendly Communities work.

The DAGs emerged from the pool of volunteers supporting Dementia Friendly High Streets and are composed of volunteers, professionals, carers and some people with dementia. For example, the Action Group being developed in Fareham includes a former carer, staff from Andover MIND and Age Concern, another carer, and staff from care organisations.

There are currently 10 established DAGs in Hampshire: BasDag (Basingstoke); Fleet DAG; Four Marks, Ropley and Medstead DAG; Lymington DAG; Overton and Oakley DAG; Dementia Friendly Alton; Dementia Friendly Liss; Milford-on-Sea DAG; Hartley Wintney DAG; Dementia Friendly Hythe and Waterside. There are seven more that are more than half-way to setting up, and another nine potentially in formation.

The Action Groups were seen by project staff as a key ingredient in maintaining sustainability with a role in getting people to sign up to the Hampshire Dementia Action Alliance, and organising dementia awareness work. Depending largely on volunteers, they are vulnerable, and finding a lead person is seen as critical to their ongoing success and survival.

District and parish council support has helped in some areas, for example, providing funding in Lymington. The Alton Action Group has also been able to raise funds and produce a bi-monthly newsletter which goes to the local CAB, cafés, barbers and hairdressers, supermarkets, doctors, community hospital and local day centre.

Lymington Action Group is composed of local business representatives, Andover MIND, Alzheimer's Society, other related professional staff, a person with dementia, and care providers. It has provided awareness/information sessions for 43 businesses, and 26-27 have done Action Plans. The group also provides public awareness sessions once a month, and is planning to put up 20 information points around the town to hold information leaflets. Other activities include: developing relationships with local GP surgeries to make them more dementia friendly; actively fund-raising and planning to start a sports reminiscence group; using the redevelopment of local community centre, to make it a more dementia friendly environment.

### 4.3 Dementia Friendly High Streets

The concept of Dementia Friendly High Streets emerged from a workshop about developing 'dementia advisor' services and community support for people with dementia in 2011, where people living with dementia and their carers said that the most helpful thing for them was to have a sticker in a shop window indicating that a shop was dementia friendly. This theme was picked up and developed by Innovations in Dementia, as part of the pilot project work, through development of the 'Memory Aware High Street' tool in the Hampshire toolkit.

Eleven Dementia Friendly High Streets have been successfully launched: six of which were led by members of the DFH team, but all involving local people volunteering their help in many ways. The scheme began with three pilots reflecting different types of location: Fareham, Lyndhurst and Fleet, and the pilot areas had support from the local district councils. Since then, Romsey, Alton, Eastleigh, Andover, Lymington, Milford-on Sea and Winchester have signed up. Basingstoke and Hythe are also due to launch in 2015.

To become a Dementia Friendly High Street a minimum of 20 businesses/services in a close geographical location must sign up to the Hampshire Dementia Action Alliance (HDAA), committing to ensure their customer-facing staff are dementia aware. A launch date for the Dementia Friendly High Street is set to encourage businesses to participate.

The first high street to launch was Fareham Shopping Centre which also provided a vacant shop for the project staff and volunteers to promote dementia awareness in the local community. The initiative was strongly supported by the local shopping centre manager and 26 retailers signed up to the HDAA. All shopping centre staff attended an awareness session, and the shopping centre developed an Action Plan in addition to those developed by individual retailers. A vacant shop was made available for drop-in sessions and meetings.

In a number of areas, work on Dementia Friendly High Streets has led on to other activities. For example, in Alton, the Dementia Friendly High Streets work has led on to the formation of a Dementia Action Group and publication of a regular newsletter, and some retailers are building dementia awareness into their induction training.

One interviewee commented that:

*'The Dementia Friendly High Streets has caught the imagination most. Brought communities together and huge numbers of stakeholders, not just a public sector thing – embraced by businesses too'.*

Interviewees from retail and other organisations were positive about the value of the awareness sessions provided. Staff felt that it helped increase their awareness and understanding of how they could support customers with dementia and their carers:

*'We all loved the training. It was unique, interesting, fun...We needed the practical side and that's what we got'.*

It was also felt that having a launch date helped to focus activity by providing a deadline, and also to raise awareness among the general public. Most of the launches were attended by local mayors (and in some cases, the local MP) and attracted positive media coverage.

However, the high street work was seen as very labour intensive, involving 'a lot of leg work', talking to retailers and persuading them to take part. Staff thought that it took on average three visits to a shop to talk to the manager, and further time was then needed for each business to develop an Action Plan. The value of the face-to-face contact was important: one business manager commented that they were glad that someone approached them about the scheme, as they might not have signed up without the face-to-face contact. Local coordinators said they targeted organisations likely to have the most contact with people with dementia, as a way of maximising their effectiveness.

Two particular challenges were identified: some shops could not free staff up to attend sessions and some could not put stickers up. Sole traders in particular had little time to attend an awareness session or meetings. In some cases, one-to-one sessions were provided over the counter during a quiet morning or afternoon. Chain stores sometimes had policies from headquarters which presented obstacles to making changes to window displays or staff induction arrangements.

Two main benefits were identified in the Dementia Friendly High Streets work. Staff reported feeling more confident in dealing with incidents involving customers with dementia, in terms of how to talk to the customer and carers; and there were a number of examples where someone with dementia had wandered away from their carer and dementia aware staff had been able to help (Lymington, Fareham).

The success of the existing schemes appears to have encouraged some areas (eg, Eastleigh) to set up their own Dementia Friendly High Street with little input from Andover MIND. It has been described as a DIY Dementia Friendly High Street.

One interviewee suggested that it would be good to provide some form of recognition to those organisations which were dementia aware but unable to meet fully the requirements of the HDAA.

The High Streets work has attracted considerable interest from other parts of the country (eg, Buckinghamshire, Dorset). A DIY guide has been developed.

#### **4.4 Dementia Action Alliance**

A national Dementia Action Alliance was set up in 2012 and there are now a number of regional and local alliances. The alliances are made up of organisations and individuals committed to making a positive difference to the quality of life for people with dementia and their carers. Alliance members sign up to the National Dementia Declaration. The declaration was created in partnership with people with dementia and carers: it explains the huge challenges presented to our society by dementia and some of the outcomes sought for people with dementia.

Signatories to the Dementia Action Alliances publish their own action plans, setting out what their organisation will do to help to secure these outcomes and improve the lives of people with dementia and carers. Actions may include such things as:

- Dementia awareness training for staff.
- Building dementia training into customer service or induction training.
- A review of environmental factors, such as signage and seating and making appropriate changes.
- Appointment of a Dementia Ambassador.
- A review of published materials to ensure they are accessible to people with dementia.

The Hampshire Dementia Action Alliance (HDAA) was launched in September 2013, with 112 organisations signed up by the end of Year One, and 440 organisations and businesses signed up in total across Hampshire by the end of Year Two. The DFC project significantly exceeded its target of 140 HDAA members by the end of the project. However, it has not been able to meet the target of 7 traditionally excluded groups, with 4 members from these groups at the end of Year 2.

Membership covers all sectors and areas of the county, ranging from one-person businesses to the regional signings of national organisations, such as Boots, Nat West, Waitrose, Argos and Costa. Examples of the diverse range of local groups and organisations include: Hampshire Library Service, Test Valley Borough Council, Hampshire Cricket in the Community, Alton Community Centre, The Blue Star Bus Company and Parker Meadows Care Home.

Every member of the Hampshire Dementia Action Alliance (HDAA) was required to:

- Have an action plan setting out what the role of their organisation is in delivering the outcomes described in the National Declaration.
- Publish their action plan on the Dementia Friendly Hampshire website, which will host the HDAA information.
- Report to the secretariat on progress in delivering their action plans.

Andover Mind put the action plans and information on signatories on the national DAA website, and will add to the HDAA website when it is updated. Information is also shared through DFC newsletters.

Most HDAA signatories came from the Dementia Friendly High Streets areas; consequently most members of the HDAA have come from the retail sector, but other types of organisation include care providers, voluntary organisations, leisure and banking. The DFC staff worked with HDAA organisations, if required, to help to draw up their action plans.

A lot of the organisations signed up nationally to the DAA were not doing anything at the local level (eg, Argos). The DFC project was useful in reaching these local branches of a range of organisations.

A couple of concerns for the future were expressed by interviewees. There was a perceived risk that momentum and commitment could be lost where key staff moved on. There was also a question raised as to whether the requirement for a minimum number of 20 organisations to sign up to the HDAA before a high street could be launched as Dementia Friendly was necessary. It may be more appropriate to set a percentage of organisations as a minimum requirement.

#### 4.5 Dementia Ambassadors

The concept of the Dementia Ambassador was defined by the DFC project as:

*'a person who has the ability and opportunity to influence others and is willing to use that influence to promote the interests of people with dementia and dementia friendly communities'.*

The Ambassador role was seen as something which could be done as part of a person's work, public or private life, rather than as an extra piece of work.

By the end of the two years, there are 26 active Dementia Ambassadors (out of 30 in total) across Hampshire representing a wide variety of people, including:

- Retail and other businesses
- Third sector organisations

- Public sector organisations, including the Fire Service
- Care providers
- Education

Two of the Dementia Ambassadors are people living with dementia. One of them, reflecting the amount of time he was contributing to the project, commented that 2014 had been the '*busiest year of my life*'. Two of the 15 carers responding to the IPC questionnaire had become Dementia Ambassadors.

There are 2 routes to becoming a Hampshire Dementia Ambassador:

- An organisation which joined the HDAA could commit to fielding an appropriate manager as an Ambassador as part of their action plan. The action plan would state what the Ambassador would do to contribute to the relevant outcomes in the National Dementia Declaration.
- An individual could put themselves forward as an Ambassador. There was a short form to complete to describe the contribution a person could make to the DFC project. Although it was not compulsory, individuals who wished to become Dementia Ambassadors were encouraged to join the HDAA and create their own action plan.

Some Dementia Ambassadors had initially become involved through attending an awareness session and becoming a Dementia Friend.

One hour Dementia Friends information sessions, e-learning and training workshops were available for Dementia Ambassadors.

The role of the Dementia Ambassadors is relatively undefined and their level of involvement varies, reflecting the voluntary nature of the role. Some of the Dementia Ambassadors have contributed significantly to raising overall awareness about dementia in Hampshire; for example, one has a regular slot on local radio, as well as giving a large number of talks around the county both promotional and awareness raising.

It was originally hoped that the Dementia Ambassadors would form a network across Hampshire, however, this has not happened. In the future, there was a view among some interviewees that they had a role to play in keeping the local Dementia Action Groups going.

#### **4.6 Peer support groups**

The project mapped 238 existing local groups that provide peer support to people living with dementia and their carers. A number of care homes and the domiciliary care agencies (eg, Home Instead), have played a part in supporting peer support groups, for example, by offering a meeting place.

The difficulty of getting people with dementia involved is partly due to the stigma. As one interviewee with dementia explained: *'Because I don't tell my friends – it's hard to tell people...I would appreciate the opportunity to talk to others but not ready for that yet...I don't want people to know – afraid of people's reactions. It's like when people said they had cancer in the past'*.

The DFC project has helped other organisations to establish 23 new peer support groups over the two years of the project. It was widely perceived that this aspect of project work involved a lot of time and effort. This was the area which project staff thought had been least successful, although the number was more than double the target of ten new peer support groups over the lifetime of the project.

Some positive examples of peer support groups include:

- Dementia cafés which were seen as a positive by carers, reflecting a widening range of support available for people with dementia and their carers.
- A carers' organisation which ran a regular drop-in café where all the staff had received Dementia Friends training. Although not exclusively for people with dementia and their carers, the training had extended the range of support that staff could provide to the group.
- A local library runs a monthly memory group which is open to the public, but is mainly attended by residents of a local care home. Another library based group is due to start in 2015.

Four of the 15 carers responding to the IPC questionnaire had attended a new support group meeting. One commented: *'I attend an excellent support group meeting. It is good to talk to fellow carers. It is comforting to know that others are experiencing similar problems'*, illustrating the benefits these groups can provide if people can attend them.

The difficulty of supporting people with dementia and their carers was also identified in the evaluation of the Oxfordshire Dementia Friendly Communities project. To some extent, it reflects the isolation of people living with dementia in the community and the difficulty of providing information to them about the support that is available.

The challenges experienced in relation to establishing peer support groups in Hampshire (time required, stigma and reluctance of some people with dementia and their carers to engage, isolation of people with dementia and their carers, and the difficulty of providing information to them) highlight the need to find more effective ways to target people with dementia and their carers.

#### **4.7 Traditionally excluded groups**

Local area coordinators have worked hard to reach excluded groups, providing dementia awareness sessions to 95 people from traditionally excluded groups and engaging four minority organisations in the HDAA, as well as attracting a number of representatives of traditionally excluded groups to the end of project conference in February 2015.

Project staff have worked with a local Nepalese welfare organisation, as well as other excluded groups such as Travellers, people with disabilities and transgender groups. However, one interviewee said that it had been challenging for a variety of reasons. For example, among the Nepalese community, there is no word for dementia, and memory loss is perceived as a normal part of the ageing process. The stigma around dementia can also be even greater among some groups, than the wider community.

#### **4.8 Promotion and PR**

The Dementia Friendly Hampshire website is currently hosted by HCC. It provides information on the project and links to other organisations, along with individual pages on the HDAA, Dementia Ambassadors, Dementia Friendly High Streets, Awareness raising initiatives, and Peer Support Groups.

There have been 249 promotional events attended by the DFC team over the two years of the project, which together with media articles in press, and on radio and TV, have publicised the project to the public at large.

In February 2015, the lead commissioner and Andover MIND project staff organised a large conference to celebrate the successes of the project. More than 200 people from across the county attended representing a wide range of organisations and groups, including retailers, people living with dementia, and carers, fire service, health staff, care providers.

#### **4.9 Sustainability plan**

A sustainability plan has been developed to keep the HDAA going as an information and administrative hub – monitoring action plans and sending out reminders. The HDAA will have a role in ensuring information between and about different organisations and activities is disseminated via newsletters, meetings etc. It will also offer advice and guidance to DAG's, though, due to funding constraints, this will primarily be by phone/email. The HDAA would be a 'stand-alone' entity.

Staffing will be reduced initially to 2 part-time staff (1 East and 1 West) for the first 2-3 years post project (with some bank hours to provide support), in order to ensure a smooth transition from the current format to the new format. While in the longer term, an independent charity is planned to apply

for its own funding. Staffing levels could be reviewed / reduced, though not below 2 people to ensure sufficient cover for absences and continuity should someone leave

The sustainability plan identified a number of areas for further development:

- A system for gathering feedback from people with dementia and carers post project.
- An agreed role for the secretariat work of the HDAA.
- A format for continuing the inclusion of local volunteers in keeping their community engaged.

The plan proposed to continue gathering information from people with dementia and carers by asking service providers, such as the Alzheimer's Society, and Age Concern Hampshire and Healthwatch Hampshire, to gather feedback for and disseminate information to/from the HDAA as one of their Action Points.

Longer term, there was felt to be a need for a secretariat function for the HDAA as a means to support the local Dementia Action Groups (DAGs). DAGs are to be the vehicle for ensuring the ongoing engagement of communities and volunteers, eg delivering awareness sessions; signing up new organisations to the HDAA; fundraising in their own right (Lymington and Hythe have already secured £1,200 and £1,000 respectively, from different sources); and as autonomous organisations able to engage and develop as relevant to their local context.

Networking of DAG representatives could provide support and exchange of ideas/best practice, and possibly supply members for a steering group for the HDAA.

## **5 Outcomes**

This section reviews the outcomes achieved by the DFC project in terms of the original proposed project outcomes (section 3.3). As noted earlier, the project evolved and responded to where the opportunities arose and therefore some of the original outcomes may seem less relevant in the current context.

### **5.1 Shared understanding of the concept of Dementia Friendly Communities**

The DFC project aimed to achieve a shared understanding of what constitutes a dementia friendly community. Interviewees representing a range of different stakeholders, both professional and volunteers, were asked about their understanding of the concept of a dementia friendly community.

While there were some differences in emphasis, it was clear that there was a common understanding of increased awareness and understanding in communities which would enable people with dementia and their carers to feel safe and comfortable in their community. A sample of definitions provided by interviewees is set out below.

A dementia friendly community is:

*'Where everyone has some consideration and knowledge to help people with dementia feel comfortable and not afraid to go out. Just getting that community spirit back'.*

*'People with dementia can go out into the community and know they feel safe and their carers would have somewhere to go if they needed'.*

*'A community where people in customer facing roles in shops and banks understand what dementia is instead of being phased by it, and react with empathy for them and their carer'.*

*'A community that's making an effort to be conscious about dementia and make people aware. It will always be an ongoing project'.*

## **5.2 An engaged community enthusiastic about and supportive of people with dementia that promotes inclusivity**

The number of people attending dementia awareness sessions voluntarily (3,404), and the success of the Dementia Friendly High Streets work (11 launched and 6 in development), along with the large number of signatories to the HDAA (440) and the establishment of 10 Dementia Action Groups (with another 16 in development or discussion) indicates that the project was able to contribute to the development of an engaged community keen to promote inclusivity.

Many interviewees were striking in their passion and commitment to the DFC concept and their wish to create more inclusive communities. This generated a high level of engagement among these members of the local community.

## **5.3 People with dementia and their carers will have been at the heart of deciding what this means in their communities**

There was widespread consultation and engagement, especially in the first year of the project, with people with dementia and their carers to obtain their views about what would help or hinder the development of Dementia Friendly Communities.

The results of that work and the ongoing involvement of a number of people with dementia and carers in the project steering group and local groups, indicates that people with dementia and their carers have played a role in deciding how the project has developed and what has been prioritised. However, some interviewees felt that there is scope for greater involvement of people with dementia and their carers in the future.

#### **5.4 Groups of empowered people with dementia and their carers who will have a voice and role in developing services and support that enable them to “live well” with dementia**

This outcome has some overlap with the preceding one. Those interviewed who were living with dementia did not feel that the project had particularly empowered them, although this may be because they felt they already had a voice. Those who were involved in the project were doing so as individuals rather than as members of a particular group. This reflects the difficulties encountered in trying to develop peer support groups, and the general isolation of many people with dementia living in the community.

Along with raised awareness of dementia in shops and elsewhere, the early consultation events highlighted a need for more volunteers and befrienders to support carers and people living with dementia as part of making a community dementia friendly. This was not an area which the project addressed, as the Dementia Advisor Service was tasked with finding volunteers to support people with dementia to participate in community life/leisure activities etc and live well with dementia.

#### **5.5 Sustainable mechanisms for continuing developments once the project has ended, for example developing a Dementia Action Alliance for Hampshire, identifying community dementia champions and cascading approaches**

The project sustainability plan aims to ensure the continuing development of the project with a reduced number of staff.

Sustainability was widely seen as a big challenge by interviewees. Having achieved success with the awareness training work, there was a perceived need to encourage others to develop and continue this work. At the time of the fieldwork, it was not confirmed that funding would be secured to provide a secretariat for the HDAA, providing space for the establishment of a self-sustaining charity to continue the work over the longer term. Although the team would shrink, it was hoped that some core staff would remain enabling promotional work and monitoring of action plans to continue, in order to get the work of the project embedded, and to build in ongoing renewal. A grant has been provided for the transitional period to provide time to establish a charity to develop the project in the longer-term.

Sustainability will require a continuing input from volunteers through the DAGs. However, the risk of volunteer fatigue was acknowledged. There was a concern that when funding finished, the enthusiasm would die because the lead came from the centre. While interviewees expressed some concerns about whether or not the project would be able to maintain its momentum after the reduction in funding, members of the local DAGs were optimistic that they would be able to continue their activities without losing impetus.

Different DAGs had different interests, for example, the focus in Liss is on schools, while others have a broader range of activities planned. It seems likely that this variability will help to sustain the DAGs as it enables them to focus on the local issues that most engage their local volunteers.

## 6 Evaluation questions

This section considers the extent to which the DFC project has achieved the results identified as the aims of the evaluation.

### 6.1 Delivery of the service specification

The project exceeded most of the performance targets. Both local authority and Andover MIND staff felt that the project had more than exceeded the targets set for it in the service specification, particularly in terms of the number of dementia awareness sessions and the numbers of organisations signing up to the HDAA. As one interviewee put it: '*The team have spent the whole two years on the run*'. Appendix I presents the extent to which performance indicators have been achieved. The key targets and what was actually achieved are presented in Table 3 below.

**Table 3: Key performance targets and achieved performance**

	Target	Actual
Dementia awareness sessions	75	348
Dementia Friendly High Streets	6	11
HDAA Members	140	440
Peer support groups	10	23
Dementia Ambassadors	16	30

Source: Andover Mind

Reaching traditionally excluded groups and more diverse communities has been more of a challenge. However, local area coordinators have worked hard to reach excluded groups, providing dementia awareness sessions to 95 people from traditionally excluded groups and engaging four minority organisations in the HDAA, as well as attracting a number of

representatives of traditionally excluded groups to the end of project conference in February 2015.

Although the involvement of people with dementia has been difficult to achieve, some strong spokespeople who are living with dementia have become Dementia Ambassadors and got involved in the steering group. Carers have become involved in the steering group and local Dementia Action Groups, as well as one Dementia Ambassador.

## 6.2 Achievement of project outcomes

As discussed earlier, the project has delivered excellent outcomes in terms of the work with local communities. Most interviewees felt that the project had got communities engaged and talking about dementia and this was helping to reduce the stigma. The work on awareness raising was seen as particularly successful, generating enthusiasm and support, and galvanising people into action.

*'In the last four to six months, everyone seems to be talking about it – gaining momentum. It gives an avenue for people to get involved if they want to'.*

An important outcome mentioned by interviewees was turning dementia into something that can be talked about – normalising it. Comparisons were made by a number of interviewees with public attitudes to cancer in the past, when it was seen as carrying a stigma.

Interviewees thought that levels of awareness about dementia across Hampshire had increased significantly, with a shared understanding of what a dementia friendly community means. Performance data and the questionnaire results also provide evidence of increased levels of awareness across the county. Wider community engagement was felt to be highest where Dementia Friendly High Streets have been established. The number of shops and other organisations signed up to the HDAA was felt to be a great success.

Some interviewees gave examples of how dementia awareness had been mainstreamed within their organisation as part of induction and training programmes. Others, including local libraries, had made changes to make the physical environment more dementia friendly.

One stakeholder observed that the project had raised the profile of dementia, which helped the work of other groups providing services to people with dementia and their carers. She commented *'It makes our job easier'* and had also helped networking among organisations working with people with dementia and their carers.

The project has also reached a very diverse range of organisations across private, public and voluntary sectors; and equally from retail to leisure to local groups and clubs, to care providers and GPs surgeries, to firefighters, police and education.

However, there is still a long way to go: 9,000 Dementia Friends out of a total population of more than 1.3 million throws some light on the scale of the task. And staff turnover within organisations means that there will be a continuing need for sessions to raise dementia awareness.

People with dementia and carers are encouraged to participate in promotional events and the project has helped establish new support groups, working with other organisations such as Alzheimer's Society and care homes to do so.

### **6.3 Impact on people living with dementia**

Project staff commented on the difficulty of finding people with dementia who were willing to participate in the project. There were no pre-existing groups of empowered people with dementia. Instead, some people with dementia and their carers were referred to the project by local Dementia Advisers and Alzheimer's Society staff. One interviewee commented that *'getting information to people with dementia and their carers is the most difficult bit'*. Low participation does not appear to be uncommon.

Two people living with dementia are on the steering group (membership has fluctuated between 10 and 15 people) and have contributed actively to the project. One felt empowered, but there was a feeling that more people were needed. Another person who had been involved had become too poorly to continue. The involvement of people living with dementia was not as strong as project staff would have liked.

One interviewee did not feel that the project had empowered him, but that it had provided him with an opportunity to talk to people and so improve their understanding of dementia and the needs of people with dementia.

A Dementia Ambassador felt that involving people with dementia and their carers needed to be done incrementally. There were so many things to be done, it was important not to try to do everything at once.

However there were perceived to be indirect positive benefits for people living with dementia. Potential improvements in the quality of care, as a result of awareness sessions for care home and home care staff were mentioned by interviewees. However, robust evidence of this was not available, and it might be expected that other training on dementia is provided to social care staff by their employers.

Twenty-three new peer support groups were established over the lifetime of the project, and it is reasonable to assume that these have had a positive impact on people living with dementia. There was limited agreement among carers in their responses to the IPC questionnaire that since 2013, there has been a change in the contribution that people with dementia are able to make to their community, for example, volunteering or sharing skills (3 out of 15 respondents agreed). However 9 out of 15 said that there had been a change in the range of things that people with dementia are able to do in the area since 2013. Activities mentioned included:

- Lots of activities, groups and social groups such as coffee mornings, afternoon tea groups, lunch groups.
- There is a special club for dementia people, ranging from Stage 1 through to advanced stage. There are lots of activities for all to participate.
- More groups to go to: Meon Valley Carers, Kitbags & berets.
- Memory café lunches once a month, pop up cafes in Fareham, pop in café in Rotary Clubhouse, Dementia Friendly week at local library.
- New memory cafes have opened up.
- More opportunity to take part in everyday activities (shopping) knowing that help is at hand.
- Only a small amount.
- I understand that there are more activities, but information is often by word of mouth, rather than given on diagnosis or updated afterwards.

#### **6.4 Impact on carers of people living with dementia**

There was limited evidence of the direct impact of the project on the carers of people living with dementia. Carers have been involved in consultation activities. Some carers who have attended dementia awareness sessions have found them helpful. Two Dementia Friendly High Streets were able to provide examples of how they had helped a carer locate a person that had wandered.

The great majority of carers responding to the IPC questionnaire (14 out of 15) thought that people in their area were more understanding towards people with dementia since 2013. This was illustrated with a range of comments:

- People are more aware, not necessarily more understanding.
- Live in fairly close-knit community where majority of people near my person with dementia are kind, caring and patient. Some are also trained dementia friends.
- To a certain degree.
- Only at times - if I mention dementia have had people offer to keep a lookout for Mum while I use the loo for example.

- Yes, it is more widespread now, on TV more and in newspapers.
- The DAG works with businesses which means their staff are more understanding of dementia.
- I think there is greater awareness about what dementia is and how it affects people.
- Neighbours are very supportive when my spouse is being very difficult.

Seven of the respondents to the IPC carers' questionnaire said that the DFC project had affected their well-being, although 5 said that it had not. Explanations of how it had affected them are presented below:

- It is helpful to know that most shops are dementia friendly and that staff have been trained in this respect.
- Helped me deal with my wife having to go into care because of her dementia.
- More people now have an understanding of dementia and it makes it easier shopping etc with my husband who often says strange things.
- It has given us the opportunity to meet in a friendly environment with other carers and their sufferers.
- My mother attends 'Sing for your life' which she loves and it gives me a break.

One carer involved in his local DAG felt that the project had increased his self-confidence and improved his quality of life. For him as a carer – he commented that there is not enough support for carers – so much he had found out about had been by accident:

*'It isn't one thing, it's a whole situation. It's made it better in some ways for people to feel more comfortable – to go on for longer... If you support the carer, you support the person'.*

A care provider commented that he would like to think the project had improved the life of carers by making them feel not alone and that there are places they can go for help.

## **6.5 Delayed or reduced need for more intensive support amongst people living with dementia and their carers**

The evaluation aimed to explore whether or not the DFC project had delayed or reduce the need for more intensive support amongst people with dementia and their carers. The limited evidence from the available service data provides no clear evidence of whether or not this has been achieved (Table 4) which is unsurprising given the relatively limited timespan of the project. It would be very unlikely to be able to observe this kind of change taking place within a couple of years. In addition, the number of confounding variables and other factors which affect service use mean that

it is not realistic to try to draw conclusions about a direct causal link between the DFC project and changes in the need for care and support amongst people with dementia and their carers. There are too many other factors which influence whether or not somebody moves into a care home or receives a higher level of care and support at home, such as the progression of the dementia, other health factors, the availability of informal care, policy and practice etc.

**Table 4: Service data 2012/13 – 2013/14**

	2012/13	2013/14
Number of residents aged 65 and over supported by Hampshire in residential care, nursing care and adult placements as at 31 March.	3,925	3,915
Number of clients aged 65 and over, achieving independence through rehabilitation during 1 July to 31 December, by age group and gender. (NI125; Achieving independence for older people through rehabilitation/intermediate care).	1,135	860
Number of clients receiving services during the period, provided or commissioned by the CSSR, aged 65+.	19,365	18,585
Number of clients receiving community-based services during the period, provided or commissioned by the CSSR, aged 65+.	15,015	15,040
Number of planned hours and visits per week for those clients on the books to receive homecare as of 31st March.	6,305	6,420

Source: NASCIS Tables S2, I1, P1, P2F, H1

Interviews with carers and others revealed some scepticism as to whether the DFC project would be able to achieve this in the short term. Respondents commented that the pathway into residential care was usually more complex than a simple causal relationship between community attitudes and the need for care, and often associated with the progress of the dementia:

*'People stay at home for a multiplicity of reasons. You could improve quality of life but still not prevent someone going into care. The project is more about increasing understanding and quality of life'.*

*'It's a comforting thing that someone would realise that dementia was the problem, but the road to a care home is more to do with how the dementia is increasing'.*

However, some observed that by providing support to carers and reducing their sense of isolation and the stigma of dementia, this could potentially enable them to continue caring for someone in the community for longer. Another commented that, by providing information about sources of support and advice, the DFC project could potentially help carers to carry on for longer. Five of the 15 carers responding to the IPC questionnaire thought that the project had helped the person they care for to continue living at home, although seven said no or were not sure.

## 6.6 Enabling factors

Interviewees frequently mentioned the timeliness of the project and its fit with national policy initiatives and media interest: *'we hit the wave'*.

*'The timing has worked really well. There's been a lot of comment nationally and locally. No one single organisation can take the credit. In terms of local authority stakeholders and local media, the profile definitely raised'.*

*'Stars have aligned – a particular set of circumstances – the Prime Minister's Challenge and the wider context have supported us, with a national campaign [on Dementia Friends] that has supported awareness'.*

The fortunate coincidence with the Alzheimer's Society Dementia Friends campaign provided a useful arena for volunteers to get involved in – and this was something the Andover MIND team encouraged – freeing up their own time to deliver more tailored dementia awareness sessions when needed. The simplicity and consistency of the message were also seen as important ingredients in the success of the awareness sessions.

The contribution of the work done during the pilot stage and prior to the project commencement also played an important role in enabling the project team to *'hit the ground running'*. The pre-project work helped to define and clarify project expectations. In addition, the pilot, toolkit and other work prior to the start of the project helped to develop materials and thinking which contributed both to local and national work on dementia friendly communities.

Staff and volunteers demonstrated high levels of commitment and enthusiasm for the project which helped to generate the momentum and resulted in time contributions over and above their contracted hours. One Ambassador commented on the amount of additional time contributed by staff.

*'Andover MIND have been brilliant – really helpful. They've supported us every step of the way'.*

Andover MIND's flexible approach to the development and roll-out of the project, for example, adapting to the high demand for awareness sessions, helped the project to seize and respond to opportunities.

Political support at district and county level as well as buy-in from senior management in Adult Services was significant. Staff commented on the key role district councils have played in the helping to enable the success of the DFC project, and also county councillors: *'County councillors have been really interested – recognising how it affects communities. It's something they can connect with'*.

Project staff commented on the great degree of good will in the general public towards people living with dementia, but the lack of knowledge about how to help and support people out in the community. The DFC project provided a channel for this good will.

Allowing time for the local area coordinators to meet people face to face was seen as useful in building trust and commitment to the project.

*'You need someone on the ground constantly. Coordinators can show retailers that actions need not be too difficult and will help customer relations'*.

However, this placed a heavy demand on staff in terms of time. The personal qualities of the project staff and their skills in collaborative working and partnership were seen as important contributors to the success of the project.

There were some good examples of collaborative working between members of the project team and local Alzheimer's Society staff and dementia advisers, and equally there was strong support from the HCC project commissioner.

Some of those involved in the steering group or other aspects of the programme are able to contribute considerable relevant skills and experience. For example, one Dementia Ambassador has been involved in PR and publicity for over 25 years. This enabled him to play an active role in promoting the project in the local media – both print and radio. This led to 27 stories about dementia in 2014 in local media.

## **6.7 Obstacles to implementation**

A key obstacle was the delay in receiving confirmation of the second year's funding which affected planning the activities for the second year. The short-term nature of the original funding limited the ability of the project team to take a more strategic approach to project planning, as they were under pressure to hit the ground running. A number of stakeholders

thought that even two years was too little time to get the DFC project properly established to build up enough momentum to sustain itself.

Reflecting on the early days of the project, staff thought it would have been useful to have had more time to settle the team of local area coordinators. However, because the original project was for 12 months, this was not possible as the pressure was on to deliver from the outset.

Some interviewees commented that the various elements of the DFC project presented a complex message to promote. The complexity of the message reflects the many different aspects of living with dementia and what could contribute to a dementia friendly community.

*'We're very good at making things very complicated. I see all these things coming together: the Action Alliance, Dementia Friendly High Streets, Dementia Friends. I am not sure which goes with which'.*

*'There are so many people involved and different initiatives that it can get confusing. Not very joined up the dementia world. That can be off-putting to many people'.*

For retailers, there was a perceived overlap with the Safe Place campaign, while stakeholders sometimes appeared to confuse the roles of Ambassadors and Champions in interviews.

## **6.8 Other comments**

### **6.8.1 Role of health**

Over the life of the project, the local health context has changed considerably with the move from a single PCT to 5 CCGs. Partly as a result of these changes, the role of health has been variable in the project. For example, contact was lost with the link person from public health, and in September 2014, staff were hoping to identify a replacement to attend steering group meetings.

Engaging health practitioners has been a challenging element of the project. However, there has been considerable progress with the involvement of a local GP who has worked to promote dementia friendly practices. CCGs are also now engaged in promoting this work.

One respondent commented that there had been limited involvement on the health side – that *'GPs were just waking up'* and an increasing number of GPs are joining the Dementia Action Alliance. A good example of health involvement was one GP surgery, where four Dementia Friends sessions were delivered over two days for all staff (40 people). The surgery was now looking to recruit a Dementia Friends Champion from the patient support group, had put up new signage in the waiting room, submitted an Action Plan, joined the HDAA, and checked that it has information in records on

carers of people with dementia. Surgery staff now felt they had a better understanding of dementia pathways and sources of help in the community – which could help to support carers and people with dementia.

#### 6.8.2 Other initiatives

The DFC project has been carried out in parallel with other initiatives. For example, the appointment of dementia advisers has already been mentioned. In addition, local trading standards staff have done work on raising dementia awareness.

#### 6.8.3 Spin-offs

Work in some areas has resulted in spin-offs from the original project. For example, in Eastleigh, the council's Community Safety Team is now looking to establish a voluntary registration scheme so that if a person with dementia is in an incident, they can be identified quickly and the carer contacted. Funding from Public Health has also been obtained to fund a one year post for a Dementia Friends Champion coordinator.

In Basingstoke, the local writers' circle wrote some poetry for a dementia roadshow in the town. This group have requested an awareness session and a wish to read to people in a care home.

#### 6.8.4 Strategic approach

The pressure on the staff team to deliver within a limited time frame may have restricted the development of a stronger strategic approach. The flexibility and adaptability of the project team was a strength, but the consequence of this may have been less focus on strategic issues.

### 6.9 Lessons learned and recommendations for other DFC projects

Stakeholders were asked about the lessons and recommendations from the DFC project for other projects. There were a range of responses which are presented below:

- Several interviewees mentioned the importance of having a key person locally who was passionate about dementia in order to provide the drive and enthusiasm to get activity going.
- Focus activity and think carefully about how to target the development time available. Given a fixed amount of resources, it was important not to try to do too much.
- Keep the message simple and consistent. This would help to avoid confusing people who want to get involved.
- Be clear what awareness sessions are for and who they are aimed at, so that people attending have appropriate expectations.
- Success brings its own challenges. Where people are having to work flat out, there is an increased risk of burn-out.

- To maximise impact, engage as many local charities as possible as they will have their own contacts, and work with local GP surgeries.
- A DFC project needs a consistent level of communications support.
- Establish clear roles and protocols from the start between the organisations involved so that there is clarity about expectations.

## 7 Refinements

Although the project covered a very broad range of organisations, there was a view among some stakeholders that education and health were two sectors where more work was needed. Several interviewees thought more could be done in education with secondary school and college students, especially as young people had been very receptive to awareness sessions.

One carer commented that there was a need for greater dementia awareness in hospitals. Another interviewee observed that the project had been very business oriented.

The project has punched above its weight in terms of publicity and media coverage. However there is scope to look at greater use of social media, and the internet, including an update of the website to act as a resource for local Dementia Action Groups and Dementia Friendly High Streets, and to ensure people know where to go to get information.

Volunteers delivering dementia awareness sessions could benefit from opportunities to meet and share experiences, as well as receiving refresher or top-up sessions.

Some interviewees commented on the variety of organisations and groups working with people with dementia, including the DFC project, and wondered whether there was scope to simplify the range of activities. The potential for confusion between Dementia Ambassadors and Dementia Friends Champions remains, and some felt that support for people with dementia and their carers was fragmented and remained difficult to find out about.

Carers were asked what they thought would make their community more dementia friendly. Responses included:

- More groups: eg, GP surgeries holding carer clinics with support workers seeing people.
- Continued expansion of the DFC project to more businesses and satellite communities.
- Increased awareness of what happens to people with dementia.
- Ask non-involved people to attend some of the meetings to see what is being done to help sufferers.

- Continue with champions talks. Have a dementia day in a community centre or village hall with displays, activities and professionals for advice and signposting.

## 8 Conclusion

The Dementia Friendly Communities project in Hampshire provides a good model of a dementia awareness raising initiative. In the two years of its operation, more than 3,400 people have attended awareness sessions delivered by project staff, and many more have attended sessions provided by volunteers. Eleven Dementia Friendly High Streets have been launched and 10 Dementia Action Groups established with 440 organisations signed up to the Hampshire Dementia Action Alliance. Thirty Dementia Ambassadors have been recruited and the project has helped to support the establishment of 23 new peer support groups.

Given the time needed to establish a new project covering an area the size of Hampshire, the project has done well in the range and scale of its activities. Many sections of the community, particularly the service and retail sectors, have a better awareness of dementia and how to support people with dementia and their carers.

The project team responded energetically and flexibly to demand, seizing new opportunities where they emerged and working collaboratively with a range of other organisations and individuals. This enabled the project to maximise its effectiveness in reaching as many people and groups as possible.

The timing of the project contributed to its success, coinciding as it did with growing policy interest and national campaigns around dementia. The support of leaders in local politics and social care also contributed to the impact and success of the project.

There were areas where the project was less successful – specifically around developing peer support, engaging traditionally excluded groups, and empowering people with dementia and their carers. These are areas which other dementia friendly communities projects have also found challenging. As one interviewee commented, '*they are not called hard to reach for nothing*'. It is possible that with more time at the start to develop and plan, more could have been achieved in this area, however it is not certain that the results would have been significantly different.

There is no evidence that dementia friendly communities directly affect the need for more intensive support and care of people living with dementia. However, over the longer-term, by improving the quality of life of carers and people with dementia and reducing the stigma of dementia, it may be possible that it enables people with dementia to live longer and better in their communities.

The evidence for a business case is weak as there is no evidence of a direct link between dementia friendly communities activity and delayed moves into residential care. However, the project levered in large amounts of volunteer time which added value to the project, and individual cases illustrated the ways in which it contributed to the quality of life of people with dementia and their carers.

In the future, the sustainability of the project is not guaranteed until a more secure funding arrangement is established. Staff were optimistic that this would be possible. The other risk is the dependence on volunteer efforts and the risk of volunteer fatigue. The current levels of commitment and enthusiasm are very high and given this, there is also reason to be optimistic, but not complacent about the project's long-term future.

### Appendix 1 - Project Performance Indicators

Indicator	Year 1 Target	Year 1 Actual	Indicator	Year 2 Target	Year 2 Actual	Total Target	Total Actual
Number of organisations signed up to Hampshire Dementia Action Alliance	At least 40 to include a number from traditionally excluded groups, such as Learning Disability, Black and Minority Ethnic, Lesbian, Gay, Bi-sexual, Transgender (LGBT)	112		100 at the end of year 2 not including those organisations signed up in year 1. This must include a minimum of 7 organisations from traditionally excluded groups such as Learning Disability, Black and Minority Ethnic, Lesbian, Gay, Bi-sexual, Transgender (LGBT) Travellers etc	288	140	440
						Traditionally excluded gps 7	Traditionally excluded gps 4
			Number of Action Plans submitted to HDAA in Year One of the project reviewed for progress	Headline report to Stakeholder Group mid-way through year two and to be included in Final Project Report to the Stakeholder Group.			
Number of pilot sites for "Dementia Friendly"/ Memory Aware	At least 3  At least 20			At least a further 3 that will give coverage to those areas not included in year 1 of the project and agreed		6	11 + 6 in development

Indicator	Year 1 Target	Year 1 Actual	Indicator	Year 2 Target	Year 2 Actual	Total Target	Total Actual
High Street scheme Plus number of establishments signed up in each				by the Council. There are to be at least 20 establishments signed up in each new area.			
Numbers of newly developed peer support groups where there are currently gaps	At least 5	9		At least 5 that are placed in areas that have been identified from the mapping undertaken in year 1 of the project	14	10	23
Number of structured awareness raising sessions e.g. one for libraries, for leisure staff, for transport, for councillors, for emergency services, for Chambers of Commerce plus different locality focussed ones	At least 15 Including at least 4 traditionally excluded groups	130		At least 60 – including at least 8 to traditionally excluded groups	218	75	348
						Traditionally excluded gps 12	Traditionally excluded gps 5
			Number of	4 – with one at project			

Indicator	Year 1 Target	Year 1 Actual	Indicator	Year 2 Target	Year 2 Actual	Total Target	Total Actual
			Stakeholder Newsletters produced in Year Two of the project	end highlighting achievements and sustainability plans			
Number of community champions identified	At least 8 Including at least 2 champions from traditionally excluded groups	11	Number of Community Ambassadors identified, trained and active	At least 8 including 2 from traditionally excluded groups	19	16	30
						Traditionally excluded gps 4	Traditionally excluded gps 3
			Role of Ambassadors defined by Andover Mind and agreed by Stakeholder Group	Reported to Stakeholder Group by the end of the first quarter of year two of the project			
			Written reports to the Council on all the Performance Measures and Indicators on a quarterly basis	4 reports including the Final Project report			
			Project Sustainability delivered and	Reports on a 6 monthly basis to the Council and			

Indicator	Year 1 Target	Year 1 Actual	Indicator	Year 2 Target	Year 2 Actual	Total Target	Total Actual
			agreed	Stakeholder Group			
			Numbers of staff/volunteers in place	Quarterly written report submitted to commissioners a minimum of one week before the agreed stakeholder meeting dates and verbal report to stakeholder meeting			
			Records of training and supervision of staff and volunteers undertaken and planned Must include training around diversity particularly focussing on characteristics protected by the Equalities Act 2010	As above			
			Record of all engagement activity	As above			

Indicator	Year 1 Target	Year 1 Actual	Indicator	Year 2 Target	Year 2 Actual	Total Target	Total Actual
			undertaken				
			Record of all consultations undertaken and summary of collated findings	As above			
			Record of all engagements with service providers to address issues identified and outcomes of any interventions	As above			
			Numbers of organisations signed up to a Hampshire Dementia Action Alliance and record of what they committed to do. Progress on these (self-assessed by organisations) at the end of the project.	As above			

Indicator	Year 1 Target	Year 1 Actual	Indicator	Year 2 Target	Year 2 Actual	Total Target	Total Actual
			Plans for sustainability of the Action Alliance at the end of the project	As above			
			Map of peer support groups with identified gaps in provision and steps taken to address gaps	As above			
			Record of all work conducted with traditionally excluded groups and outcomes of engagement	As above			
			Reports on “memory aware” scheme, numbers signed up and views of people with dementia on progress, including experiences of using memory	As above			

Indicator	Year 1 Target	Year 1 Actual	Indicator	Year 2 Target	Year 2 Actual	Total Target	Total Actual
			aware card				
			Identified list of Dementia Ambassadors and evidence of network developed and in sustainable shape	As above			
			Delivery of the final project report outlining plans set in place to ensure sustained work on Dementia Friendly Community development.	End of project			

