



**EUROPEAN FOUNDATIONS'  
INITIATIVE ON DEMENTIA**

# Mapping dementia-friendly communities across Europe

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A STUDY COMMISSIONED BY THE EUROPEAN FOUNDATIONS'  
INITIATIVE ON DEMENTIA (EFID)

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## Foreword

Europe is facing the challenge of a rapidly ageing population. There are more than 8 million people in Europe living with dementia, and this number is expected to grow. In the absence of a cure, communities should support people with dementia to enable them to live well. The community approach is beneficial to change the attitudes and the perception towards people living with dementia and to see in them an opportunity for society rather than a burden. With this in mind, the Foundations involved in EFID, the European Foundations' Initiative on Dementia, decided to support the development of sustainable and inclusive environments for people living with dementia and their carers.

What are the trends? How do communities in Europe react to the challenges linked to dementia? What are the factors that enable the development of inclusive and sustainable communities for people living with dementia? Numerous practitioners across Europe have been asked with the purpose of 'mapping' existing initiatives and drawing up a set of underlying 'principles' with regard to 'dementia-friendly communities' (DFCs). There is no agreed definition of what a 'dementia-friendly community' is, and this report does not claim to provide one. Instead, the report outlines evidence-based outcomes from the research carried out over the years 2014 and 2015 in several European countries.

Through this report, we wish to invite readers to explore the variety of initiatives existing in Europe to support people living with dementia, not only to enable them to live well in the community but also to be active citizens. This 'mapping survey' sheds some light on what is good practice in 'dementia-friendly communities', although these are just a few examples of many more activities which have been initiated throughout Europe. The variety of grass-root and community-based initiatives on dementia demonstrates that a social 'movement' towards changing perception with regard to dementia is gaining ground progressively. However, there is still a lot to do. As people live longer, foundations should strengthen and support civil society organisations in their endeavours in making communities more inclusive for people with dementia.

One of the respondents of the survey stated that *"our society has managed to give time to life but now we need to give life to time"*. EFID wants to be a solid vehicle enabling community-based organisations to give people living with dementia a stronger voice, to empower them to be present in their community, and to encourage all the actors of our society to take responsibility for their fellow citizens.

I hope the work that EFID has started in Europe on promoting better lives for people with dementia and their carers will encourage other donors, public authorities and citizens to take the initiative and to contribute in shaping communities we really want to live in – with or without dementia.

Dr. Bernadette Klapper

EFID Chair

## Summary

The aim of this study was to gather information about the so called 'dementia-friendly communities' across Europe to increase understanding, knowledge and awareness. It was commissioned by the European Foundations' Initiative on Dementia (EFID) and carried out by a UK non-governmental organisation (NGO), the Mental Health Foundation in 2014 and 2015.

It is estimated there are 8.7 million people in Europe with dementia. 'Dementia-friendly communities' is a term given to describe a wide range of activities, projects and initiatives aimed at improving the quality of life for people with dementia. The main methods of information gathering were:

- An online survey (n=194 respondents)
- Telephone interviews (n=17 interviewees)
- A literature review

Online survey respondents and interviewees included: people working for dementia organisations; local and national NGOs; health and social care services; local, regional and national governments; and academics. The detailed findings from the online survey, telephone interviews and literature review are contained in appendices A-C. The report includes a number of examples of 'dementia-friendly community' work from across Europe; however these are not intended to be a comprehensive list of all the activity taking place. Concepts, approaches, and practices of 'dementia-friendly communities' in Europe are analysed in order to describe commonalities, differences, strengths and weaknesses, and to draw up a set of underlying principles and recommendations with regard to 'dementia-friendly communities'.

Some key findings, related to 'dementia-friendly community' concepts and principles, are as follows:

- 'Community' was defined mainly in terms of geographical localities, with few references to communities of identity (i.e. LGBT, ethnic minorities) or interest.
- Confusion could arise between making an organisation or service 'dementia-friendly' and developing 'dementia-friendly communities'; the former is an important building block of the latter but on its own does not create a 'dementia-friendly community'.
- The study focused on people with dementia as citizens and 'whole communities', not on people defined by their dementia as 'patients' or 'service users'. It therefore did not focus on the role of health and social care services or dementia specialist organisations; however it was clear from the online survey responses that these services and organisations often played a vital role in developing and supporting 'dementia-friendly communities'. Due to the fact that many people with dementia use these services and organisations, it is important to include them in activities around 'dementia-friendly communities', while retaining a focus on people as citizens, not solely defined by their dementia.
- Some 'dementia-friendly community' initiatives were led by national organisations, regional or municipal governments and were quite centralised and 'top down' in their approach. Other initiatives were local, community, grassroots and very much 'bottom up'. Some combined these two approaches well, others perceived or experienced tensions. However, activity of either type appeared to be beneficial by generating more dementia-friendly awareness and activities in the community or communities where it took place.

- Communities are diverse and community development needs to work with diversity in relation to many contextual factors including demographics, culture, geography, and public policy. For the reasons described above the development of ‘dementia-friendly communities’ therefore must work with and reflect this diversity.
- In the current study, there were very few links identified between ‘age-friendly initiatives’ and ‘dementia-friendly communities’. However, there is potential and opportunity for learning and collaborating between the two ‘movements’.
- Addressing issues of resources and sustainability were considered to be vital; it is unrealistic to expect most ‘dementia-friendly communities’ to be initiated or sustained by communities themselves without some government commitment or support. Finding ways of evaluating and demonstrating the impact of ‘dementia-friendly communities’ is a crucial part of this but there were limited examples of evaluation tools and measurements of impact.

The study also collected information on policies and strategies relating to ‘dementia-friendly communities’. In particular, the research found out that:

- There are some European-wide initiatives that include support for ‘dementia-friendly communities’ but no single agreed model for what a ‘dementia-friendly community’ is, nor is there a comprehensive European programme supporting the development of ‘dementia-friendly communities’.
- Six countries had government-led national dementia strategies that supported the development of ‘dementia-friendly communities’.
- There were several national programmes led by NGOs (usually Alzheimer’s associations) that supported the development of ‘dementia-friendly communities’.
- Most ‘dementia-friendly community’ activity was taking place at regional, municipal or local levels.

Four essential factors were identified as key elements in developing ‘dementia-friendly communities’. These were:

1. Providing training, education and awareness-raising about dementia
2. Active inclusion and involvement of people living with dementia (together with the involvement of the communities in which they live)
3. Encouraging and supporting partnerships, networks and collaborations focused on developing ‘dementia-friendly communities’
4. Securing and sharing resources for developing ‘dementia-friendly communities’.

In addition to the concepts and principles described above, several strengths and challenges were identified relating to the development of ‘dementia-friendly communities’. Strengths identified in the study included numerous European countries applying these four essential factors in practice, in turn, improving the quality of life and well-being of people with dementia. Furthermore, the diversity of people, organisations, and countries involved in developing ‘dementia-friendly communities’ creates space for innovation, creativity, new partnerships and resources – and new conceptualisations of dementia itself, and the way society responds to it.

At the same time, the study indicated that the level of diversity and different approaches utilised may be off-putting for organisations wanting to develop ‘dementia-friendly communities’, and who may

be unsure where to start or what to do. Differences in culture, language, and systems mean that concepts such as 'community' or 'inclusion' may be understood and interpreted differently. It is crucial that initiatives developing 'dementia-friendly communities' do not lose sight of people with dementia being at the centre of these activities, and maintaining a view of them as people, citizens, and equal members of society, not just service users or patients.

Drawing upon the findings from the report it is possible to identify three general "descriptors" or groupings that we hope may be helpful for organisations wishing to be involved in developing 'dementia-friendly communities'. Diagram 1, 'Taxonomy for 'dementia-friendly community' activity' describes these steps (page 44).

Finally, the report concludes by outlining a number of possible areas of action or 'ways forward' to support further development of 'dementia-friendly communities' across Europe.

# 1. Introduction

This report describes the findings from a study of what is commonly referred to as ‘dementia-friendly communities’ in Europe. As the numbers of people with dementia has steadily increased in most European nations: national, regional and local governments; health and social care services; non-governmental organisations (NGOs); and businesses have been developing a number of approaches to support people with dementia to live, as well as possible, in the community. These approaches are commonly (but not always) described as developing ‘dementia-friendly communities’. To date however, there has been no European-wide study of ‘dementia-friendly communities’.

The European Foundations’ Initiative on Dementia (EFID) is a programme undertaken by a group of European foundations comprised of The Atlantic Philanthropies, the Fondation M d ric Alzheimer, the King Baudouin Foundation, the Robert Bosch Stiftung, the Joseph Rowntree Foundation, the Genio Trust and the Life Changes Trust. EFID, through the Network of European Foundations (NEF), works towards changing societal perceptions of dementia through the support of local projects. EFID’s mission is to improve the lives of people with dementia by enabling a dementia-friendly and inclusive environment in communities across Europe. EFID also works towards dissemination of good practice and strengthening the network of practitioners engaged in ‘dementia-friendly communities’. To support this EFID has made 20 “EFID awards” to organisations in 11 different countries that focused on creating inclusive, sustainable environments and promoting active citizenship for people with dementia (these projects are listed on the website of EFID)<sup>1</sup>.

In 2014 EFID commissioned the Mental Health Foundation - a social research, development and public affairs NGO in the UK - to undertake this study into ‘dementia-friendly communities’ across Europe. This report describes the findings from that study.

## ***Structure of the report***

The report starts by giving a brief background to dementia and the emergence of ‘dementia-friendly communities’. It then goes on to describe how the survey was undertaken and the concepts and parameters that were used, as agreed between the Mental Health Foundation and the EFID Steering Committee. As the report is a synthesis of an online survey, telephone interviews and a literature review (all of which are contained as Appendices), the “Findings” section is structured in a particular way that best reflects this. As such, the “Findings” section starts with observations about how the findings challenged the initial concepts and parameters for the survey, together with some other important conceptual aspects that emerged. It then goes on to present results separately at European, national and municipal levels, before considering commonalities, essential factors, differences, strengths and challenges. In conclusion it suggests some principles for developing ‘dementia-friendly communities’ and makes recommendations for European and national bodies.

The report includes a number of examples of ‘dementia-friendly community’ work, from across Europe, however these are not intended to be a comprehensive list of all the activity taking place

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<sup>1</sup> <http://www.efid.info/>



across Europe. This includes some projects that received an EFID awards (identified throughout the report). Examples of dementia-friendly activities and quotes from the survey respondents and interviewees are presented in boxes, numbered from 1 to 32, throughout the report. These are used to illustrate general themes described in the sections of the report where they are located, not specific points or findings. EFID will be producing an online collection of case studies with the title “Dementia-friendly community case studies across Europe: a mapping commissioned by the European Foundations’ Initiative on Dementia”<sup>2</sup>, using information gathered in the survey, to inform ‘dementia-friendly community’ work in Europe.

The detailed findings from the online survey, telephone interviews and literature review are contained in appendices A-C. The literature review and online survey are broken down by country and numerous examples; quotes and references are included to illustrate the range and diversity of ‘dementia-friendly community’ practice across Europe. The main report draws upon these appendices but does so quite selectively in order to remain concise and focused. The reader is therefore recommended to browse the appendices if s/he wants to consider, in more detail, the data that informed the findings presented in the main report.

## 2. Background

### 2.1. Dementia

Dementia is a term used to describe a range of organic and progressive brain diseases, all of which cause a decline in cognitive abilities including memory, thinking, communication, concentration and perception. In the later stages of dementia physical functions are also affected. The most common form of dementia is Alzheimer’s disease which affects around two thirds of people with dementia. Age is the greatest risk factor for dementia but it is also linked with diabetes, hypertension, smoking and learning disabilities (e.g. Down’s syndrome). There are no cures or universally effective treatments for any form of dementia.

In 2013, Alzheimer Europe (a Europe-wide NGO which represents national Alzheimer associations) estimates there are 8.7 million people with dementia living in the 28 member states of the European Union and an additional 500,000 people in Switzerland, Norway, Iceland, Jersey and Turkey (Alzheimer Europe, *Dementia in Europe Yearbook*, 2013). This figure is set to rise because most of the western European nations have ageing populations.

Most people with dementia live in their own homes in the community. For example, in the UK two thirds of people with dementia (around 600,000 people) live in the community. Residential or institutional care (care homes and hospitals) are mainly provided for people in the later stages of dementia as their condition deteriorates and more professional care is required. Historically dementia has been under-diagnosed or only diagnosed late in the illness. Consequently, until recently, the main focus of health and social care services, as well as dementia organisations such as NGOs, has been on

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<sup>2</sup> The mapping paper “Dementia-friendly community case studies across Europe” is available on the website [www.efid.info](http://www.efid.info)

the care and support of people with more severe dementia. Family members have been the main source of care and support for people with dementia living in the community although NGOs have also played an important role.

However, diagnosis rates have increased and the numbers of people known to be living with dementia has grown, especially people in the early stages of the condition. As a result, there has been growing recognition that organisations and businesses in the community, as well as communities in general, need to ensure that they can also provide appropriate support to ensure that people with dementia are able to live as well as possible. Public amenities such as: libraries; parks; leisure centres; shops and businesses; transport services; faith communities; civil society organisations; employers; and many other organisations that have contact with the public may all be used by people with dementia. However, until recently they have not considered how they make themselves accessible for people with dementia. The stigma associated with dementia, ignorance of the condition, and practical difficulties that people with dementia experience as a result of associated impairments, all create barriers and obstacles for living their lives as normally as possible in the community.

At a time when public services, such as health and social care, in most countries have been under enormous financial pressures, usually without a strong focus of working with communities (in the broadest sense), and with the numbers of people with dementia steadily increasing, both government and society has begun to recognise that a new approach is needed. This is the origin of the move towards developing ‘dementia-friendly communities’.

## 2.2. ‘Dementia-friendly communities’

Japan is widely credited for being the nation where ‘dementia-friendly communities’ began. With an ageing population (25% of Japanese people are over the age of 65) and a system of care that was struggling to cope with the numbers of people with dementia, the Japanese government, in 2005, developed a community-focused policy of supporting people with dementia. Many elements of this policy involved improving care services in the community but it also involved 1) awareness-raising; 2) challenging the stigma associated with dementia (the term used for “dementia” was outlawed because of its negative connotations and replaced with another term<sup>3</sup>); and 3) training volunteer supporters for people with dementia (4 million people had been trained by 2012). With the Japanese model in mind, governments and NGOs in a number of European countries have developed a range of ‘dementia-friendly community’ initiatives. Germany and Belgium were among the first countries where these developments took place but several other countries were not far behind.

There is no single model or template for a ‘dementia-friendly community’, or how to develop one. Definitions of “community” and “dementia-friendly” vary significantly, as does the relationship between the *processes* for developing a ‘dementia-friendly community’ and the *outcome* of what a ‘dementia-friendly community’ looks like or feels like. Alzheimer’s disease International (ADI) published a booklet in March 2015 containing information on ‘dementia-friendly community’ projects

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<sup>3</sup> Before 2004, the term for dementia in Japan was “*chihō*.” *Chihō* is a compound word, with *chi* means foolish and stupid, and *hō* means foolish and absent-minded. When paired, both characters have connotations that can be interpreted as insulting and stigmatising. In 2004 the term was officially changed as part of a public campaign to raise public awareness about dementia. The new name for dementia, “*ninchishō*,” was selected. “*Ninchishō*” means “recognition disease”.

from countries and regions across the world (*Dementia-friendly Communities (DFCs) – New domains and global examples*). The booklet highlights six areas of community planning which it suggests should be the focus of ‘dementia-friendly communities’:

- Public awareness and information access
- Planning processes
- The physical environment
- Access and consideration for dementia among local businesses and public services
- Community-based innovation services through local action
- Access to transportation

This survey came about partly because of the diversity in practice and approach, attempting to identify commonalities in definitions and practical activity in the development of ‘dementia-friendly communities’ across Europe.

### 3. Aims and objectives of this study

The aim of this study was to gather information about ‘dementia-friendly communities’ across Europe, in order to increase understanding, knowledge and awareness. This information would be used to analyse concepts, approaches, and practices of ‘dementia-friendly communities’ in Europe, with the intention of describing commonalities, differences, strengths and weaknesses, and to draw up a set of underlying principles and recommendations with regard to ‘dementia-friendly communities’.

### 4. Methodology

Planning, collecting and analysing data took place over a twelve month period between May 2014 and May 2015. There were three main data collection activities:

- An online survey (see Appendix A)
- Telephone interviews (see Appendix B)
- A literature review (see Appendix C)

Interim findings from the study were presented and discussed at an EFID workshop in Dublin, in March 2015, for representatives of local projects that had been selected for an EFID award as well as delegates from the EFID funding organisations. This provided useful feedback and additional information that have informed this report.

#### 4.1. Online survey

The online survey was carried out between October 2014 and January 2015. It was disseminated via the Mental Health Foundation’s networks (including a mailout to all 800+ delegates who attended the Alzheimer Europe conference in Glasgow in October 2014) and through networks of members of the

EFID Steering Committee. An email, inviting people to complete the survey was used; it was available in English and seven other European languages. The survey itself was also available in English and seven other European languages (see Appendix A – Report of findings from the online survey, for more details). Respondents were self-selecting; it was not possible to know whether they were a representative sample according to location, role, activity or views expressed. The breakdown of responses can be seen in Table 1.

*Table 1. Breakdown of online responses*

Country	Number of respondents
England	65 (33%)
Belgium	22 (11%)
Scotland	21 (11%)
Germany	19 (10%)
Republic of Ireland	15 (8%)
France	8 (4%)
Italy	6 (3%)
Netherlands	6 (3%)
Austria	4 (2%)
Norway	4 (2%)
Wales	4 (2%)
Northern Ireland	2 (1%)
Bulgaria, Czech Republic, Estonia, Finland, Slovenia, Spain, Switzerland	1 each
Unknown	11 (6%)
<b>19 countries</b>	<b>194</b>

Note: The four UK nations have been shown separately – in total there were 92 responses from the UK.

#### *4.2. Telephone interviews*

Seventeen telephone interviews were undertaken, representing eight different countries. Potential interviewees were selected via the online survey but also as advised by the EFID Steering Committee, partly in order to ensure a mix of strategic and local perspectives (see Appendix B – Thematic analysis of the telephone interviews, for more details).

Different methodologies and analytical approaches were used for these activities which are described in each of the appendices. However, there were four key focus areas that were used in the analysis for all three data collection activities:

- Identifying the kinds of activities taking place to develop ‘dementia-friendly communities’ in as many different countries as possible across Europe
- Identifying the key concepts, factors and building blocks for developing ‘dementia-friendly communities’
- Identifying possible strengths and challenges in the different approaches and activities

- Identifying conceptual and practical differences and similarities in the development of ‘dementia-friendly communities’ across Europe

Note: Unless otherwise stated in the text, all quotes are taken from responses to the online survey.

### 4.3. Literature review

The literature review was carried out between May 2014 and October 2014. It was a rapid literature review mainly involving an online search using the term ‘dementia-friendly community/ communities’ translated into a number of different European languages (see Appendix C - Literature Review, for more details). Advice was taken from members of the EFID Steering Committee about variations to this term in different countries (e.g. in France it was advised that “bien vivre avec la maladie d’Alzheimer dans la communauté locale” - “living well with dementia in the community” was a more commonly used term). Finally, staff working on the project at the Mental Health Foundation were familiar with much of the critical literature from the UK but asked members of the EFID Steering Committee to identify other European publications, which they considered important for informing the survey. Where literature or websites were in languages other than English, staff at the Mental Health Foundation and translation services were used to translate them. The breakdown of documents reviewed is in Table 1.

Table 2. Breakdown of documents reviewed

Country	Publications/literature	Webpages
Belgium	3	7
Cyprus	-	1
Denmark	1	3
England	22	13
Finland	1	1
France	1	1
Germany	5	9
Italy	-	1
Luxembourg	1	-
Netherlands	2	7
Northern Ireland	2	3
Norway	2	-
Portugal	-	2
Republic of Ireland	5	7
Scotland	3	1
Spain	3	3
Sweden	1	1
Turkey	-	1
Wales	3	3
Europe-wide	5	4
Memory-friendly communities (see section on <i>Language, culture, systems</i> below)	-	3 (England–2; Scotland-1)
<b>Total</b>	<b>59</b>	<b>71</b>

Note: The four UK nations have been shown separately – in total there were 28 publications and 23 webpages from the UK included in the review.

#### *4.4. Clarifying concepts and parameters*

It was important at the start of the study to have some clear parameters about its focus. This was important in relation to the theoretical concepts and definitions that the study was using and investigating. There were four areas in particular that EFID and the Mental Health Foundation agreed needed acknowledgement or clarification at the start:

- Defining ‘community’ - although open to other definitions it was agreed that this was generally taken to be geographically defined.
- Clarifying the difference between ‘dementia-friendly’ and ‘dementia-friendly communities’ – it was agreed that dementia-friendly activities within a service, organisation, etc. were not seen to be the same as a ‘dementia-friendly community’ unless they were explicitly linked with wider ‘dementia-friendly community’ initiatives.
- The role of health and social care services and specialist dementia organisations – the EFID Steering Committee made it clear that the provision of health and social care services for people with dementia, (regardless of who delivers these services) was not the primary focus of the study, since how people use those services was defined by their dementia, not by being a member of a community. The aim of the study was to collect information about initiatives and activities that went beyond these services and were community and citizen-focused.
- Language, culture, systems – these contextual differences between countries, and the enormous diversity of populations and communities across Europe, was acknowledged as posing particular challenges for this study.

However, as the next chapter describes, the findings from the study posed challenges to these concepts and parameters.

## **5. Findings**

### *5.1. Concepts and parameters*

Although the study had agreed parameters in order to give it sufficient focus, these were challenged by the findings from all three elements of the study.

#### ***Defining ‘community’***

‘Community’ in this study was broadly defined and understood as being geographical: countries, regions, municipalities, cities, towns, villages. At one level this was common sense since people with dementia lived in these communities and activities to develop ‘dementia-friendly communities’ generally took place in these settings. However, it is important to acknowledge that ‘community’ can

also be defined in other ways and this emerged particularly in the telephone interviews, as this interviewee describes:

*“I live in the neighbourhood and I have loads of communities which are around the different things that I do and that I am interested in, you know. Friendship, particular places that I go and do things with other people, I am a musician so I have a whole musician community around gigs and things, I don’t think of communities being a single entity.”*

Community could be used to describe a community ‘of interest’ such as a faith community, an arts community, a sporting community, or in some cases, a retail business community (e.g. shops and supermarkets). ‘Community’ could also be used to describe groups of people from different countries that share a common identity and culture, even though they may be geographically dispersed. For example, all European countries have some degree of diversity within the population, most notably in terms of having significant Black, Asian and other minority ethnic groups. However other types of groups also exist, which span ethnicity but remain a minority, such as Lesbian, Gay, Bisexual and Transgender groups (LGBT). Many countries recognise that these are communities in their own right, even though they spread across a number of geographical areas. For example, one interviewee noted that,

*“In France ‘community’ has always the sense of, for instance, ethnic minority and so on. So sometimes it’s not clear...”*

Dementia affects these population groups just as much as the rest of the population. People with learning disabilities are disproportionately affected by dementia and experience very high prevalence rates at earlier ages than the rest of the population; it could be said that they also represent a community of shared identity. The study found little evidence of ‘dementia-friendly communities’ or activities that were defined by communities of interest or identity, although there was not a specific brief to investigate this issue<sup>4</sup>.

A further possible complication (identified in some of the interviews) was ‘community’ being understood in terms of formal structures such as municipalities governed by public authorities, as compared to definitions involving informal social networks of individuals and organisations in a less well defined geographical space.

This meant that the focus of ‘dementia-friendly community’ activities could vary significantly, from activities driven by public services to the activities conducted by civil society organisations, informal groups, and individuals.

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<sup>4</sup> In September 2015 the Joseph Rowntree Foundation published its reports on work being done to develop York and Bradford in England as dementia-friendly cities. Time did not permit these to be included in the literature review or main body of the report but it is noted that ‘communities of identity’ were included in this work. The reports can be found at: <https://www.jrf.org.uk/report/evaluation-york-dementia-friendly-communities-programme>.

### ***Clarifying the difference between ‘dementia-friendly’ and ‘dementia-friendly communities’***

A large number of organisations that have contact with people with dementia, especially those providing care and support services, claim to have increasingly developed their services to be ‘dementia-friendly’. In many countries a number of non-dementia specialist hospitals and community health services have, for example, undertaken activities to try and ensure that they are more ‘dementia-friendly’ for those accessing their general services but whom also happen to have dementia (e.g. through staff training and adaptations to the physical environment). Similarly, providers of household technology and equipment have developed their products so they are easier and safer to use for people with dementia, such as kitchen equipment, electrical items, and household security. Adapting services, technology and products in this way, as well as developing specialised products (such as GPS tracking and alarm systems) for people with dementia and their families is often referred to as being ‘dementia-friendly’. The literature review in particular, generated an enormous amount of articles, documents and other literature that focused on dementia-friendly activities, products, organisations, and services without necessarily linking these to ‘dementia-friendly communities’; although these are often important components of how organisations and services have developed in order to contribute to ‘dementia-friendly communities’. However, these developments were either beyond the scope of the study because they often were not linked with ‘dementia-friendly community’ activity, or were only one element of a larger set of activities to develop ‘dementia-friendly communities’, or alternatively because their focus was on health and social care (see next section).

### ***The role of health and social care services and specialist dementia organisations***

Across Europe the main source of support for people with dementia (apart from families and friends) has historically been provided by health and social care services (public and private, including generic services) and specialist dementia organisations such as NGOs (e.g. Alzheimer associations). Perhaps unsurprisingly organisations (usually dementia-specialist ones) from these sectors have been heavily involved in initiatives to develop ‘dementia-friendly communities’ in many countries. Hospitals, clinics, care homes, day centres, social services, and other forms of care and support are all located within geographical communities and are important components of communities. A significant number of those services, and practitioners who work within them, have recognised the value of ‘dementia-friendly communities’ and the role that they themselves can play in supporting their development. It could be argued therefore that they should be included in any study of ‘dementia-friendly communities’. Furthermore, many people with dementia may choose to define those services as part of their community. However, as previously stated, it was agreed that the focus of this study should be on people with dementia as ordinary citizens and members of communities rather than defining them in terms of their use of health and social care services as a result of their dementia. As the study reports, this conceptualisation of people with dementia as ordinary citizens and members of communities, rather than just users (or “patients”) of health and social care services has been the focus of many of the ‘dementia-friendly community’ initiatives.

However, in a number of areas, the study found that it was difficult in practice to disentangle the roles of health and social care organisations. The online survey clearly demonstrates this, with responses



grouped in accordance with the role the organisation played in relation to ‘dementia-friendly communities’ – as described by the respondent (see Table 3).

*Table 3. Role of the online respondents*

Type of organisation	Number of respondents
NGOs (both national and local/regional)	66 (34%)
Health and/or social services	50 (26%)
Academic, research,	23 (12%)
Local/regional/municipal government	20 (10%)
Local community projects/initiatives	19 (10%)
Emergency services	5 (3%)
Other	11 (6%)

As Table 3 shows, the online survey found that 26% of respondents to the online survey reported their role as providing health or social care services.

There were some variations to note between countries. Of the countries that had eight or more respondents, France and Belgium had the greatest proportion of health and social care organisations. Germany and England had a low proportion of respondents from this sector but the greatest proportion of NGOs responding, although some of these NGOs were also providing community care and support (see Appendix A for more details). The proportion of respondents from local/regional/municipal government was fairly even across countries.

The relatively high response rate from health and/or social services (as well as NGOs providing community care and support) emphasises the difficulty of separating these organisations from activities related to the development of ‘dementia-friendly communities’. This may partly reflect the simple fact that it is often these organisations that have most contact with people with dementia and therefore may recognise the importance of developing ‘dementia-friendly communities’. A significant number of respondents described community-based care and support being provided to people with dementia as being an important factor in creating ‘dementia-friendly communities’; this directly challenges one of the predefined parameters of this study – community support and participation should go beyond what is provided to individuals based primarily on their diagnosis.

**Box 1: The Birches Alzheimer’s Day Centre - Louth, Republic of Ireland**

This is an NGO that receives some government funding. It has six day services for people with dementia, and a weekly outreach day service in a rural coastal community. It provides a family support group, training to family carers, and is organising an advocacy programme for family members. It describes itself as “a mixed model of care and encompasses all the current models medical/social/and rights model of care”. It is involved with a local age-friendly forum which is part of the WHO age-friendly city programme to include dementia-friendly aspects to the area plan. It plans to organise monthly dementia-friendly events to raise dementia awareness, interact with the older people’s forums to engage with local businesses and government agencies about becoming dementia-friendly, reminding everyone that the person with dementia is part of the community and together with their family should have their rights respected.

The survey therefore clearly indicated the important role that health and/or social services played together with specialist-dementia organisations, in developing ‘dementia-friendly communities’. This appeared to be particularly the case in smaller countries where services and policies for people with dementia were less developed; in these countries it seemed that it was often the specialist dementia organisations that were trying to develop ‘dementia-friendly communities’.

**Box 2: Foundation Mental Health Care Centre – Tartu, Estonia**

The Foundation provides help for people with dementia at their home, at a day care centre and at Nõlvaku Care Centre (24 hour care). They work closely with relatives of clients and also with people involved in dementia care. They are developing respite care at person's home to enable relatives to continue living their own life and continue working. They are trying to be very flexible in the way they provide their services.

However, the view was also expressed in the interviews that health and social care services for people with dementia should be more closely connected with ‘dementia-friendly communities’. The study raised important questions about the link between health and social care services and the emerging of DFCs. A pharmacy shop or general clinics were often seen to be part of a community. Community-based care and support provided by specialist dementia organisation was also frequently cited as an example of a ‘dementia-friendly community’ but the parameters of the study have attempted to separate these out from other ‘dementia-friendly community’ activities.

**Box 3: Foundation Compassion Alzheimer - Bulgaria**

The Foundation aims to improve the quality of life for people with Alzheimer’s and dementia by changing attitudes and practices towards them and providing access to treatments and social support. Activities include: provision of innovative social services (legal, psychological consultations for people with dementia and families), art-therapy, non-pharmacological methods of prevention, Alzheimer café, and information campaigns for prevention of the disease, awareness-raising and lobbying for improved services, accessible treatment and other services and policies. Training for the staff in residential homes for people with dementia is also provided.

*Foundation Compassion Alzheimer Bulgaria was an EFID award winner in 2012.*

***Language, culture, systems***

Any European-wide study is likely to encounter challenges around language and culture and this study was no exception. A concept such as ‘dementia-friendly communities’ is both complex and broad, in terms of what it can mean to people. Inevitably there is the risk that a study like this may not fully reflect what people understand the concept to mean in different countries and cultures. As the literature review identified, in English alone there are other terms apart from ‘dementia-friendly community’ that may never-the-less indicate similar activities, such as ‘dementia capable communities’ or ‘memory-friendly communities’. In other languages there were not always precise translations of ‘dementia-friendly community’ or different terms were used, such as ‘living well with

dementia in the community'. EFID foundations often use the term 'sustainable environments for people living with dementia' to indicate the concept of inclusive and 'dementia-friendly communities'.

Furthermore, the culture and structures of communities, organisations, and systems (especially public services) vary significantly from country to country but it was beyond the scope of the study to investigate and describe these in any detail. As a result, there may be inaccuracies in some of the information presented which could affect the findings and conclusions. These limitations are present despite the extensive use of translation and interpretation services in the study, and advice was obtained from members of the EFID Steering Committee and elsewhere.

### *5.1.2. Conceptualising 'dementia-friendly communities' – challenges*

Although the online survey did not specifically ask respondents to define the term 'dementia-friendly community' (DFC), both the literature review and the interviews generated a variety of definitions. These included both definitions of process – how to develop a 'dementia-friendly community'; and definitions of outcome – what a 'dementia-friendly community' looked like, although there could be a considerable overlap between the two. These are explored in more detail in the literature review and the interviews. The definitions range from simple statements that focus on ensuring communities are dementia-aware, inclusive, supportive (and other such terms), to much more detailed lists of criteria. These criteria relate to numerous aspects of community life, activity, services and organisations that are deemed necessary before a community can call itself dementia-friendly. This range is illustrated by the following quotes taken from the literature review and one of the telephone interviewees:

*“An integrated society where people with dementia live in ‘normal’ home-like situations throughout their lives with support to engage in everyday community activities.”*

*“One where people with dementia are empowered to have high expectations, feel confident, know they can contribute, participate in activities that are meaningful to them. It is also one of our objectives to have the people with dementia in the centre of the society, not on the margin.” (Translated)*

There were some dissenting voices among those interviewed who believed that the use of the word 'dementia' could undermine an approach to community developments that was truly inclusive:

*“I think I have re-interpreted it as an inclusive neighbourhoods and communities but I think the term dementia friendliness is unhelpful for a number of reasons, 1) it separates off dementia as a disease and focuses on the disease, the illness, all the awareness in everything around friendliness is trying to, is basically focussed on that one aspect of somebody, of people rather than any other traits that they might have that also exclude them or might help include them.”*

This report will go on to consider these definitions in more detail when presenting the findings from the online survey. However it is clear from the issues emerging from the literature review and

interviews that challenges exist when attempting to come up with a single, agreed definition. Three of these key challenges will be discussed in more detail below:

➤ **Challenge 1: Centralised, top down or grassroots, bottom up?**

*“Creating a change in mentality, working to break through taboos has to grow organically and has to be carried by the people it’s about and by policy makers: local and above local.” (Translated)*

Should the process and outcomes for developing and defining a ‘dementia-friendly community’ be prescribed centrally, according to a single set of criteria or standards, or by a national organisation with responsibility for overseeing the development of ‘dementia-friendly communities’? Alternatively, should process and outcome grow organically from within local communities who chose their own definitions of what is a ‘dementia-friendly community’? We have characterised this as ‘top down vs bottom up’, or ‘centralised vs grassroots’ approaches. From the literature review one might draw the conclusion that those countries with national strategies or programmes on ‘dementia-friendly communities’ might be more centralised in their approach and those without would have a more grassroots focus. However, the survey indicated that this wasn’t really the case. All the countries where ‘dementia-friendly community’ activity featured in national policies, strategies or programmes (see Box 4) also had plenty of community-based, grassroots examples (which often operated quite independently of national programmes or policies). Some countries without national approaches still had extensive ‘dementia-friendly community’ activities covering large municipalities involving co-ordination and partnerships between many large organisations. The message seemed to be that the more ‘dementia-friendly community’ activity there was, the more energy and activity was generated, even though this might be different in focus or scale. This is perhaps a more general reflection of the reach and role of the state and national bodies in public policy development and implementation, together with the history and culture around community development, in different countries.

**Box 4: British Standards Institute (BSI) - UK**

BSI is a national and international standards organisation. It has produced a national standard to support the recognition process for dementia-friendly communities. Publicly Available Specification (PAS 1365) will support the continuous development of communities in accordance with the behaviours and characteristics defined by the Alzheimer’s Society. The PAS covers who should be involved, how to engage stakeholders, and areas of or action to develop a ‘dementia-friendly community’. It is aimed at local government, business, health and social care organisations, and NGOs.

Compromise was not always possible where there were differences of opinion between local and national organisations. Perhaps the clearest example can be seen in the use of different symbols to denote a ‘dementia-friendly community’; the ‘Forget-me-not’ flower, the Purple Angel (both used in the UK), and the Red Scarf (used in Belgium). The survey indicated that most countries veered towards more bottom up/grassroots approaches, however the literature review indicated that England stands

out as the example of a much more centralised approach involving national government, a national NGO, and a national partnership. One of the interviewees expresses this tension well:

*“Developing dementia-friendly communities should be a joint effort undertaken by what is called civil society. The identified measures (“setting-standards”; “disseminating knowledge”) suggest that building dementia-friendly communities is something which can be achieved top down and by applying technical and rather abstract (“scientific”) procedures. In our understanding, building DFCs should be considered as a bottom-up, discursive and participatory process, one of exchange and negotiation, a process in which the social resources of the live world are being appreciated and handled with great care.”*

#### **Box 5: A reminiscence promenade - Aalbeke, Belgium**

This project was developed by a residential care home in a village in West Flanders. It consists of four walks with reminiscence information points on them. The walks are for people with dementia living in the care home but are open to anyone in order to encourage intergenerational dialogue and to enable people with dementia to become part of local daily life. An educational programme is being organised so that people will understand the symptoms of dementia and the promenade. The reminiscence points were made by local unemployed people wanting to develop more skills and contribute to the community. The points have information about local history to encourage conversation. The walks are also designed to improve mobility and are wheelchair and baby buggy friendly to encourage families, but there are plenty of places to sit down and have a rest!

*The reminiscence promenade was an EFID award winner in 2014.*

#### ➤ **Challenge 2: dementia-friendly or age-friendly?**

*“The aim is to promote cultural participation, social cohesion, social resilience, empowerment of older persons and promotion of intergenerational collaboration.” (Translated)*

Is focusing community development on a group that is defined by their diagnosis the most effective way of creating communities that work well for people with that diagnosis? The scope for exploring this issue was more limited, nonetheless the risks of ‘ghettoising’ dementia (separating it off) and thereby potentially adding to stigma and exclusion were raised in the survey. ‘Age-friendly’ communities were sometimes seen as not being sufficiently dementia “sensitive” but had advantages in other respects. Age-friendly communities had the appeal of being inclusive and potentially good for everyone, including people with dementia, but also had the risk of lacking sufficient focus on people with dementia. On the other hand – a ‘dementia-friendly community’ could be friendly for everyone.

### **Box 6: Entr'ages - Anderlecht, Belgium**

This project involved older people who experienced some form of disorientation (but not necessarily due to dementia) living in a local care home, doing creative art workshops with young art students once a week for nine months. Artworks were then exhibited in public spaces.

Underlying this debate was the sense that communities needed to be friendlier and more inclusive, *per se*, as this interviewee described;

*“In the Netherlands it’s difficult because they don’t want to ... focus on one ... specific group of people.”*

However, Europe-wide initiatives such as the European Innovation Partnership on Active Ageing and Healthy Ageing, despite supporting a European collaborative forum for dementia supportive communities, have tended still to treat dementia as a specific issue, separate from other ageing issues. A UK-based NGO, Age UK, has undertaken a piece of work to make its mainstream services for older people more dementia-friendly, with the aim of making 50 of its local, community-based organisations more dementia-friendly.

### **Box 7: Dublin City University – Republic of Ireland**

The university has been launched as an ‘Age friendly’ university. It has scrutinised its campus to make the environment more dementia-friendly and commenced a communication strategy to see how staff and the student body are affected by dementia and what can be done to make life easier. It runs a public facing clinic called ‘memory works’ designed to help people make sense of their memory problems and cope better with the impact of these on their lives. It also coordinates a national education and training programme to up-skill communities and workplaces in dementia. It works closely with dementia-friendly counties to develop and disseminate training to where it is most required. *“Fear and stigma are the biggest barriers.”*

### ➤ **Challenge 3: a question of resources?**

*“I think it is vital that the mayor and local council are...prepared to create the financial framework necessary to establish the right infrastructure (e.g. by supporting volunteer agencies or similar).” (Translated)*

Whose role was it, and perhaps more importantly, whose resources should be used to create ‘dementia-friendly communities’? Although there was widespread recognition of the value of self-organised, grassroots activism and citizen participation, using local community resources, there was also the concern expressed that the existence of such resources could be used to justify withdrawing or withholding support from the state and other large organisations. This created a paradox; the very activity that state bodies and national organisations want to encourage, to enable the development of ‘dementia-friendly communities’, could be inhibited or come to a halt because those national bodies were not contributing sufficient resources; withholding resources was either for ideological

reasons or because resources were too limited (or both). However, innovative solutions were to be found with regard to resources (see ‘Resources’ section below).

### *5.1.3. European-wide and national strategies involving ‘dementia-friendly communities’*

Through the literature review the study looked at European-wide initiatives and national strategies, examining supporting evidence for DFCs while also seeking to understand the wider context that influenced the development of DFCs. Therefore, before examining in more detail the factors that were considered to be essential in the development of ‘dementia-friendly communities’ (as identified in the online survey), the report will describe the wider geographical and political context for the development of these communities, as identified through the literature review.

#### ***Europe-wide initiatives***

As already indicated there is no single model or template for what a ‘dementia-friendly community’ is, or how to develop one. Although the European Union has carried out work on dementia, this has primarily focused on 1) risk reduction and increasing research into dementia or 2) dementia being part of wider healthy ageing strategies (see Appendix C – literature review). Alzheimer Europe, which represents Alzheimer associations across Europe, has not yet published any report or guide to ‘dementia-friendly communities’, although the issue has been presented and discussed at several of its events<sup>5</sup>. However, to mark World Alzheimer’s Day in September 2012 the ‘European Innovation Partnership on Active and Healthy Ageing’, ‘AGE platform Europe’ and ‘Alzheimer Europe’ issued a press release calling for a European Covenant of local and regional authorities on demographic change; the Covenant, launched in December 2015, aims to promote age-friendly environments across the EU. They identified four projects aimed at supporting independent living for people with dementia through the use of new information and communication technologies (ICT). These projects were not included in this study because their focus was on addressing the cognitive impairments experienced by individuals with dementia rather than the development of community-based solutions<sup>6</sup>. The ALCOVE project (Alzheimer Cooperative Valuation in Europe) was another pan-European project, involving 19 European member states and 30 European partners, with wide ranging recommendations on dementia for policy makers, although nothing specific on ‘dementia-friendly communities’.

In this respect, the work of EFID is the most significant pan-European initiative supporting ‘dementia-friendly communities’. EFID has made 20 awards to organisations in 11 different countries. The focus of these awards has been on creating inclusive, sustainable environments and promoting active citizenship for people with dementia<sup>7</sup>.

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<sup>5</sup> Alzheimer Europe published a Dementia in Europe Yearbook on dementia-friendly communities in December 2015. The title of the yearbook is “Is Europe becoming more dementia friendly?”. Time did not allow the author to include the publication in this report.

<sup>6</sup> <http://www.alzheimer-europe.org/News/Alzheimer-Europe/Friday-21-September-2012-Alzheimer-Europe-and-AGE-Platform-Europe-issue-joint-press-release-for-World-Alzheimer-s-Day>

<sup>7</sup> <http://www.efid.info>

### ***'Dementia-friendly communities' in national dementia strategies***

A number of governments across Europe have developed national dementia strategies aimed at ensuring a more comprehensive response to the challenges posed by dementia and the needs of people living with dementia. Common themes in these strategies include raising awareness, improving services that provide care and support to people with dementia, and increasing research on dementia.

However, primarily through the literature review, the study found only six strategies which included an explicit reference to developing 'dementia-friendly communities'; Belgium (Walloon and Flemish), the Republic of Ireland, and the UK (England, Scotland and Wales). For example, in England developing 'dementia-friendly communities' was one of three commitments that formed part of the Prime Minister's 'dementia challenge', published in 2012<sup>8</sup>. In this respect 'top down' approaches led by national governments were in the minority across Europe. It is worth noting that these strategies have usually been led by government departments or ministries responsible for health; in England the government's Department for Communities and Local Government has played no significant role in the development of 'dementia-friendly communities'. Other countries had government-led dementia strategies which made no mention of 'dementia-friendly communities', were in the process of developing strategies, or had no plans to do so.

### ***Other 'dementia-friendly community' national programmes***

In a number of countries, NGOs, usually national Alzheimer associations, had taken a lead in promoting and developing programmes focused on 'dementia-friendly communities', as in Ireland for example, which is supporting seven projects aimed at making local communities more dementia-friendly. In countries where governments had included 'dementia-friendly communities' in their national dementia strategies, the programmes were usually done in partnership with NGOs, who led the process, because of their reach into local communities and contact with people with dementia and their families.

The status and role of these programmes varied. In some countries (e.g. England, Finland, Scotland, Wales) national Alzheimer's associations took on some responsibilities for delivering the governments' commitment to developing 'dementia-friendly communities' (in Finland, a "memory friendly" nation, and in Wales, a "dementia-friendly nation"). For example, this involved identifying ten key components that were seen to be essential to creating a 'dementia-friendly community' and a defined process that communities were expected to follow in order to be recognised as being dementia-friendly. This included developing local 'Dementia Action Alliances' (DAA), made up of any organisation, business or service in a community that was supporting the development of a 'dementia-friendly community' and by providing 'dementia friends' awareness training for staff and volunteers of DAA member organisations (for more information see the literature review).

In most other countries (e.g. Germany, Portugal, Spain, Northern Ireland, and Belgium) national NGOs played more of a co-ordinating role without being as directive as those in England. While the evidence indicated that these countries were supportive of national organisations (including government) playing an important role in creating policies and providing resources to support 'dementia-friendly communities' developing, it was felt that there should be limitations to this and that community,

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<sup>8</sup> *Prime Minister's Challenge on Dementia* (2012). London: Department of Health.



grassroots/‘bottom up’ activity was equally as important. This seemed to reflect a number of factors that varied between countries but included: strong semi-autonomous regional, local or municipal government; recognition of the enormous diversity within and between communities; limited resources and influence of national organisations (including governments); and a belief in the importance of independent community initiatives and activity. It may be the case that these looser arrangements might go some way to addressing the tensions identified around ‘top down’ vs ‘bottom up’, discussed on pages 18-19, but exploring this was beyond the scope of this survey and would therefore require further research.

#### *5.1.4. Local, regional and municipal public services and NGOs*

The relatively low response rate from local, regional and municipal governments in the online survey (10% of respondents) does not altogether reflect the findings from the literature review, nor does it reflect some of the comments from the interviews, which emphasised the important role that these organisations play. The low response rate from these organisations may partly reflect the types of networks that the Mental Health Foundation and the EFID Steering Committee members had, which were more linked with NGOs than government bodies.

The role of local, regional and municipal public services and NGOs varied significantly from country to country. However, in most countries, these services were involved at some level due to the geographical focus of most ‘dementia-friendly community’ activities. The enormous variations between countries, in terms of delegated responsibilities, structures and power, made the analysis particularly challenging.

#### **Box 8: Arnsberg, Germany**

Arnsberg addresses the challenges of demographic change with its concept “Living a Long and Good life in Arnsberg” led by the Special Department for Future and Old Age. This includes bringing professional and civil society services supporting people with dementia together in the “Arnsberger Learning Workshop Dementia” to create a tight-knit support network for people with dementia and their environment – the main focus is on projects to connect generations, generate ideas, raise awareness, network, develop support and promote projects.

*Arnsberg was an EFID award winner in 2014.*

In the interviews, for example, the view was expressed that difficulties existed for these services and organisations, contributing to ‘dementia-friendly communities’, because they tended to be delivered from a traditional public service or diagnosis perspective, rather than a person or citizen perspective. This included many activities and support provided by local NGOs that focused on the person’s dementia – a number of responses in the online survey described these kinds of activities. However, in some countries, especially where national dementia policies and services were less developed, it was only these local NGOs that appeared to be active in creating ‘dementia-friendly communities’. This did not appear to be problematic from the perspective of many individuals and organisations; any activity (including care and support provided to individuals, or to groups of people with dementia) that enabled people to live independently and as well as possible in the community was considered to be

creating a 'dementia-friendly community'. Furthermore, these activities often attracted resources, either because they were part of public services, or because they were seen to be of direct benefit to individuals with dementia. An example of combining these roles was given by one national Alzheimer's association in their online survey response, describing a dementia-friendly municipality:

*"promotes the dissemination of [information and awareness on] dementia on a large scale; refers [to] people with dementia as pro-active individuals; promotes the integration and cooperation; creates an environment for a better quality of life for those affected and relatives; ensures a high quality and quantity supply of care along the whole course of the disease (from diagnosis)."*

**Box 9: Genio Living Well with Dementia, Stillorgan - Blackrock, Dublin, Republic of Ireland**

This is a community based project supported by the Health Services Executive. The project's vision *"is of a community that respects, supports and empowers people with dementia, a community in which people with dementia are culturally & socially valued, a community where people with dementia actively participate in a safe environment"*. As well as activities such as community support, advice and information, training for carers the project includes public awareness information events, education in schools and the retail sector, people with dementia participating and re-connected with social activities in their community e.g. choirs, physical activities, golf, bridge (playing cards), creative writing etc.

Apart from the differences between countries, these conflicting perspectives (traditional public service or diagnosis vs person or citizen perspective) raise important questions. Doing things 'for' (or even 'to') people with dementia is not the same as doing things 'with' people, but there was clearly a view that the former was acceptable if the outcome was a 'dementia-friendly community'. Where people with dementia were capable of participating and contributing to activities aimed at developing 'dementia-friendly communities' but were not being supported (where support was required) to do so, meant those activities were being done 'for' them or 'to' them, not 'with' them. This poses the question as to how far these activities were really contributing to a 'dementia-friendly community'. People with dementia are still citizens of a community even if they are being assisted by a doctor or being supported in a care home as much as if they are going to the shops, catching a bus, or volunteering. Separating them implies that people with dementia have different identities in these settings i.e. 'patient', 'care home resident', etc. which may be detrimental to also seeing them as equal members of a community. In other words, public services, both specialist dementia services, and generic services had their part to play in the development of 'dementia-friendly communities'. As one interviewee put it:

*"There's also the issue of what local authorities do with their own services – not just the dementia specific services, but the whole range of other local authority services that impact on all of us. Because if there are local authority services [that] impact on citizens within their area, then they're important to people with dementia as well."*

A good example of this is the role of emergency services (e.g. missing persons' units). As citizens, people with dementia should have exactly the same access to emergency services as anyone else in

the community. But emergency services saw the person primarily from the perspective of their dementia diagnosis. Emergency services recognised that they were not always very effective when dealing with people with dementia, especially if a person was very distressed, agitated or lost. In order to provide a dementia-friendly service some of these services developed protocols (Box 10), provided training to staff, and responded in special, more appropriate ways when dealing with people with dementia.

#### **Box 10: Emergency services – Belgium**

The federal police in Belgium has a Missing Persons Unit that has set up a protocol with institutions, police forces and the Public Prosecutor's department in order to improve responses from each when someone with dementia goes missing. An example of a protocol was in the Hekla police zone which led this work, where police collaborated with the broad care sector to find wandering people within about 2 hours. The protocol gave care providers information and a guided response on what to do should a person with dementia go missing.

*Hekla was an EFID award winner in 2012.*

It would seem therefore that activities that focus only on providing care and support in the community can contribute to the development of 'dementia-friendly communities'. However, at most, they can only be one element in a range of activities required for a community to call itself dementia-friendly. One interviewee summed it up as:

*"Dementia-friendly community should be on two levels. The first is the public and professional services, that means the healthcare services, the doctors, the care service...counselling...day care and so on...the other level is that of civil society for these [banks, sports or music clubs, associations] supermarkets, police and so on should have a certain knowledge about people with dementia and...know how to communicate...and treat them with respect."*

## *5.2. Commonalities, essential factors and differences in the development and practice of 'dementia-friendly communities'*

A key aim of the project was to try and identify commonalities in the approaches used to develop 'dementia-friendly communities' across Europe. An analysis of the findings from the literature review, online survey and interviews indicated several commonalities and essential factors across Europe, as well as indicators of strengths and weaknesses.

### ***Commonalities and essential factors***

As a starting point, for identifying commonalities and essential factors, it is helpful to consider the findings from the online survey which asked respondents to describe what they believed these to be. These were then grouped under common themes which are shown in Table 4.

Table 4. Breakdown of responses per key factor

Factors	Number of responses (n > 194 because some respondents gave more than one factor)
1. Raising awareness, providing information, education and training	126 (48%)
2. Inclusion of people with dementia; involvement, participation, influencing	67 (26%)
3. Building partnerships, networks, collaborations	49 (19%)
4. Resources – financial, human, ‘in kind’	18 (7%)
Other factors included: adapting the physical environment; monitoring and evaluation; and service provision.	

#### *Variations between countries*

There were some differences in emphasis between countries. Germany and Belgium had the greatest proportion of responses focusing on raising awareness and building partnerships. A large number of respondents from the Republic of Ireland also focused on raising awareness but, together with Germany, emphasised inclusion of people with dementia less. Belgium and England had the greatest proportion of respondents referring to the inclusion of people with dementia (see Appendix B for more details).

The four factors, presented in table 4, will now be presented in more detail, taking into account additional findings from the literature review (see Section entitled ‘Components of dementia-friendly communities’) and interviews.

### **1. Raising awareness, providing information, education and training**

#### **Box 11: Urbach – Germany**

Urbach is a municipality in Germany. A collection of dementia relevant literature was distributed to 28 libraries, including books and DVDs which offered introductory information about dementia. A range of books and resources have also been made available online and includes short stories, first-person accounts of living with dementia, novels and books for children.

**Box 12: Some quotes from the online survey**

*“We therefore need to set a good example by organising events linked to the illness in order to raise awareness among the public (conference, monthly Alzheimer Café, training for different audiences, practical guide, raising awareness among businesses, etc.).” (Translated)*

*“We must communicate to important institutions and stakeholders (mayor, town council, GPs, clubs, churches, media, etc.) that dementia is an important issue for the inhabitants of any town.” (Translated)*

*“Challenging citizens to talk about dementia, get rid of taboos and embrace people with dementia as ‘normal’ citizens with some particular needs for support.”*

*“Create awareness and provide basic training to local community services... Awareness/training incentives should be rolled out in schools for students from 14 years up.”*

*“Above all, educate people in the wider community.”*

*“Public awareness at a national level...People in public services and sales should be trained to deal with disoriented people (bank, bus, supermarket, police, etc.).” (Translated)*

The importance of raising awareness about dementia in communities, challenging stigma associated with it, and providing information, education and training to achieve these goals was a consistently important theme from the literature review, the online survey, and the interviews (Boxes 11 & 12). This could include the stigma felt by people with dementia themselves, as some online survey responses indicated and illustrated by this interviewee talking about involving people with dementia:

*“y’know it can be a slow process first to get people [with dementia]...because when they’re being diagnosed sometimes they don’t want to come near an organisation, d’you know, or be involved.”*

Levels of knowledge and understanding about dementia were generally seen to be low, partly due to fear, shame and stigma. Essential steps for a community to become more dementia-friendly were 1) to ensure as many people as possible understood what dementia was, and 2) that all people living with dementia were integrated into the community. Belgium, England and the Netherlands all strongly emphasised these points while most European countries referred to the importance of them, as these two interviewees indicated:

*“You know there is stigma ... out there in relation to dementia. People have an idea of what dementia is and there may be a fear of dementia...some of the barriers really are ... a lack of understanding of dementia.”*

*“Ultimately dementia-friendly communities have got most chance of happening where we can develop a new narrative about dementia, which is not just about*

*decay and decline and despair, but ... which actually contains a very real message,  
and a very real hope and aspiration to live well."*

**Box 13: Bruges - Belgium**

'The customer is always right' is a short film showing how having people trained in dementia awareness who work in local businesses such as shops, pharmacists and hairdressers, can make a big difference to the lives of people living with dementia. The traders show kindness and patience in prompting someone as to what day of the week it is, and recognise the things that the customer with dementia may not know, such as the word for newspaper or how to get home again – recognising the need for some guidance and gentle prompting.

*Foton Bruges was an EFID award winner in 2012.*

The literature review and online survey identified a wide range of activities aimed at awareness-raising, challenging stigma, and providing information about dementia, including:

- Awareness-raising sessions and training for a range of different audiences, often reflecting where 'dementia-friendly community' activity was focused. This could include family members and other carers, health and social care staff working in the community (as well as hospitals and care homes), school students, volunteers in local NGOs and churches, people working in shops, businesses, and public services (including emergency services and public transport), and the general public;
- exhibitions, displays, performances, talks, cultural events, etc. about dementia, involving people with dementia, or by people with dementia;
- community events or discussion groups supporting people with dementia to have a visible, ongoing community presence, and participation in community life;
- 'virtual' and actual dementia information centres which are open to the community, can provide support to people with dementia and their carers, but also host events, exhibitions etc. about dementia;
- the use of symbols, leaflets, films, local and national media, etc. to communicate positive messages about dementia.

**Box 14: Dementia Friends - UK**

'Dementia Friends' is an awareness-raising initiative developed by the Alzheimer's Society and Alzheimer's Scotland. It involves a 45-minute awareness-raising and information session given to any group of individuals who may have contact with people with dementia in the community (e.g. shop staff, public transport workers, volunteers in civil society organisations and faith communities, etc.). It provides basic information about dementia and suggests helpful responses that people can give when encountering with people with dementia. People who have participated in a Dementia Friends session (including people with dementia) can become Dementia Friends Champions and deliver the session themselves.

However, definitions of awareness-raising and the types of information it might include varied significantly, usually depending upon the audience it was aimed at. As the literature review and online survey indicated it could include:

- Basic information about dementia for staff, in organisations, who may occasionally come into contact with people living with dementia (e.g. shops, public transport, churches, etc.);
- information about post-diagnostic support for people with dementia, carers and practitioners on how to live well with dementia in the community;
- educational resources for schools and colleges;
- creative ways of presenting dementia to the public to challenge stigma (e.g. through art, poetry, film and theatre);
- more sophisticated information and guidance (see ‘resources’ section below) about developing ‘dementia-friendly communities’.

#### **Box 15: Churches – Denmark, England and Germany**

The Evangelical Centre for Development in the Community in Denmark has offered dementia awareness training for people working in its parish (church district) services. The Diocese of Oxford (Church of England) also does awareness-raising training and has introduced a dementia-friendly church award. In Pilsum in Lower Saxony, Germany, a church service was developed that took into account the needs of people with dementia through the use of visual presentation and music.

Awareness-raising activities are probably the most tangible in relation to developing ‘dementia-friendly communities’ because they potentially engage a wide range of community members, while providing practical information, guidance and advice to enable people to respond in more supportive and inclusive ways, towards people living with dementia. These activities are essential. Yet the type of information that people receive and how they act upon it is much harder to measure. If the information focuses too much on negative aspects of dementia (what the person with dementia cannot do) there is the danger that it adds to stigma and can make it harder for people with dementia to be seen as active participants and equal citizens of a community. It is also difficult to know what differences these activities make over the longer term – whether individuals, organisations, services and businesses actually change significantly in the way that they respond to people living with dementia. Sustainability of impact is essential.

#### **Box 16: Accompagnement, Soins et Santé (‘Coaching, Care and Health’) – France**

This project aims to maintain people with cognitive problems in, or bring them back to, public life, create social links, involve them and their carers in their care decisions, combat isolation and reclusion within the family. It has developed leisure and support activities for carers: individual or group outings, day trips, holidays, intergenerational gardening project, and a partnership with a technical college. It aims to change society’s stereotypes and campaign for greater adaptation of social practices and spaces to integrate people with dementia (cinemas, swimming pools, theatres, administrative services, etc.). It looks at people not through their dementia but through their remaining capabilities and skills. It doesn’t consider dementia as a “burden” to society, but rather as an opportunity to get rid of stereotypes and change society’s practices. Society has managed to give “time to life”, but now it needs to give “life to time”.

## 2. Inclusion and involvement

### **Box 17: Some quotes from the online survey**

*“I would highlight the involvement of people with dementia in community development activities; recognition of the diversity of people living with dementia.”*

*“Working with groups in a positive way to look at how we can make things more dementia-friendly, what is working, having the person with dementia central to the conversation.”*

*“Experts are not the only stakeholders because they often develop blind spots. Without citizen involvement there can’t be the ‘right’ kind of thinking ...Real opportunities for participation and sharing.” (Translated)*

*“Utilise those living with dementia on every steering group, every focus group and wherever you can.”*

The second essential factor in developing ‘dementia-friendly communities’ was the inclusion and involvement of people with dementia. In some ways this seems obvious; how can a community be dementia-friendly if people with dementia are not included and involved? The importance of supporting people to remain autonomous, independent and self-determined citizens, for as long as possible, was a particular theme in the literature from England, Germany and Belgium (as identified in the literature review). Promoting social inclusion and community involvement of people living with dementia was a theme in the literature from the Republic of Ireland, while literature from Spain, France, and the Netherlands emphasised the importance of participation by people with dementia. Although variation exist between countries, it is not overly important – the key message is that people living with dementia should not be treated in a ‘dementia-friendly community’ as passive objects or recipients of things ‘done to them’. Given the often negative ways in which dementia is described in the media and other public forums, this is clearly a welcome and positive finding. The online survey did indicate that the involvement of people “living with dementia” was understood by some to include family and friends (‘informal carers’) – this may pose challenges, since the wishes and needs of carers may not always be the same as their family member or friend living with dementia. Furthermore, carers will often find it easier to express their views and have their voice heard. On the other hand, carers are often valuable advocates for people with dementia if they are having difficulty expressing themselves or being heard.



### **Box 18: Dementia Support Stuttgart gGmbH – Germany**

Dementia Support does practical research, project development, events, publications, symposia with the guiding principles of inclusion, self-determination and quality of life for people with dementia. It is committed to the genuine involvement and participation of people with dementia in its work to make communities more dementia-friendly, inclusive of people with dementia, and *“overcome the purely medical idea of dementia as a deficit”*.

There was also a significant overlap with awareness-raising. People living with dementia were frequently seen to be central to awareness-raising activities; evidence from the interviews certainly emphasised the effectiveness of challenging stigma and fear among the general public, by having direct contact with people living with conditions such as dementia as this interviewee indicated;

*“You learn more when you have ... people with dementia, for example, who are delivering ‘dementia friends’ sessions. That’s an incredibly powerful way of ... breaking down stigma at a local level... it also gives ... hope potentially to people who might be about to get a diagnosis or have recently had a diagnosis. You’re seeing people with dementia being active citizens. It’s a really, really powerful way ...of ... giving energy to and sustaining that kind of resilience that people with dementia need to stay connected.”*

However, it was clear from the analysis of the survey responses and interviews that inclusion and involvement could be defined in many different ways. These included ensuring people living with dementia were:

- Not excluded from receiving care and support provided to groups with other disabilities or health conditions in the community;
- able to access ordinary community activities so that people living with dementia could continue with their day to day lives (shops, theatres, cinemas, galleries, museums, libraries, parks, restaurants, cafes, public transport, leisure services, churches and faith groups, community groups, etc.);
- actively involved in ordinary community activities (e.g. volunteering, choirs, outdoor activities, etc.);
- actively involved in activities specifically aimed at developing ‘dementia-friendly communities’ (e.g. giving talks, planning activities, speaking to the media, evaluating how dementia-friendly a community was, etc.);
- provided opportunities to be active citizens and campaigners (through empowerment groups actively involving or led by people living with dementia).

All these activities were seen to be important in developing ‘dementia-friendly communities’, although only Alzheimer Europe (European Working Group of People with Dementia – EWGPWD (Box 19)), England (the Dementia Engagement & Empowerment Project network - DEEP (Box 20)) and Scotland (Scottish Dementia Working Group – SDWG) appeared to have well established empowerment groups involving people living with dementia. It is interesting to note, that while groups connected with DEEP were often involved with the more centrally driven ‘dementia-friendly community’ programme, the DEEP network had developed largely in parallel with the centralised

programme; furthermore DEEP was primarily focused on empowerment and participation more widely, rather than specifically supporting the development of ‘dementia-friendly communities’.

**Box 19: The European Working Group of People with Dementia (EWGPWD) – Europe-wide**

The EWGPWD is comprised of people with *dementia*. They work to ensure that the activities, projects and meetings of Alzheimer Europe duly reflect the priorities and views of people with dementia. The group operates independently, with its own Board and agenda of activities. The Chairperson of the EWGPWD also sits on the Board of Alzheimer Europe.

There were some difficulties identified in this study relating to the issues of involvement and inclusion. One example was the reluctance of people living with dementia to get involved or even publicly state they were diagnosed with dementia was seen to be one barrier.

*“Many people are still in the frame of just understanding what their dementia is, let alone thinking about what that means in the context of their own kind of day to day lives.”*

**Box 20: Dementia Engagement & Empowerment Project (DEEP) – United Kingdom**

DEEP is a UK-wide network of independent groups led by or actively involving people with dementia that are involved in activities aimed at influencing services and policies affecting the lives of people with dementia, and the communities where they live. There are over 60 groups that are part of the network ranging from small local groups up to national groups. Examples of activities include consultations on national policies, training staff, speaking at conferences and through the media. Some groups employ people with dementia to help raise awareness and provide support to others.

Active involvement is difficult for people who are isolated and becomes harder for people more generally as dementia becomes more severe. What a ‘dementia-friendly community’ looks like for a person living in a remote rural area, or who is about to go into a residential care home, may be very different from that of a person who has had a recent, early diagnosis. However, this raises the question again of how ‘dementia-friendly communities’ apply to people with more severe dementia in care homes. There were several examples of communities reaching out to more isolated people (through mobile advice services, etc.) and the community being taken into care homes (e.g. school students regularly visiting, or a mother and babies group in a care home).

### Box 21: Rifugio Re Carlo Alberto – Italy

The Refuge provides services for older people, including people with dementia. Services include residential, day centres and home helps for people with dementia and an Alzheimer's cafe.

Members of the public not directly affected by dementia are invited into a cinema on the premises to integrate the local community and people with dementia. People with dementia are involved in activities at summer camps for children, a second-hand clothes shop for the local area, everyday activities offered in the neighbourhood (markets, local festivals, restaurants, cafe's), awareness-raising activities (conferences, seminars, films) and meetings between residents and the city council so that citizens and politicians can get together and have discussions. *“Dementia structures and services [are presented] in a new way, as normal part of daily life in the area, [promoting] activities not necessarily linked to conditions related to the disease – to create contexts where the illness can be discussed and to spread a concept of sharing amongst all citizens without excluding people.”*

*Rifugio Re Carlo Alberto was an EFID award winner in 2014.*

Another difficulty arose where responses appeared to define 'inclusion' as involving the whole community. This raises interesting questions about effective community development and the importance of mobilising whole communities. This may not always result in the community being more dementia-friendly, but may be more effective in efforts to build more inclusive, 'age-friendly' communities.

Finally, although 'rights' were occasionally mentioned there was little reference to a more political understanding of inclusion and involvement. This is interesting because other disability groups have been much more politically active in what they do and many national and international laws (e.g. the United Nations Convention on the Rights of Persons with Disabilities – CRPD) use a social model of disability which emphasises the importance of changing attitudes and adapting social practices and physical environments to make them more disability-accessible. In this respect, developing 'dementia-friendly communities' appears to be a softer, less demanding activity than ensuring communities are truly dementia-accessible in terms of applying the social model of disability to dementia. In some countries people living with dementia may decide to make legal challenges that call into question the softer option.

### 3. Partnerships and collaboration

#### **Box 22: Some quotes from the online survey**

*“A belief in, and strong commitment to, learning about team work between the various institutions.” (Translated)*

*“The community must go for it together, shopkeepers, the police and the fire department, the citizens, the associations, together.” (Translated)*

*“Non-medical decision-makers at the local level (local authorities, etc.) need to be persuaded that there is no danger in integrating initiatives for people with dementia in public life.” (Translated)*

*“The willingness to create networks (as closely knit as possible) involving a large variety of stakeholders.” (Translated)*

*“Joint working across all sectors—health, social work, voluntary and private sector.”*

The third essential factor in developing ‘dementia-friendly communities’ involved building partnerships, networks and collaborations. Communities are made up of many different groups, organisations and services, since clearly no one organisation can initiate the development process of a ‘dementia-friendly community’ on its own. Collaboration, both through formal and informal processes, is essential, as this interviewee indicated;

*“It is in the community where citizens, politicians, and other local actors can identify networks of contacts and support as well as create new ones.”*

#### **Box 23: The PG-raad [Programme Council Care Renewal in Psychogeriatrics] – the Netherlands**

The PG-raad started in 2012 through inter-regional collaboration, together with Flanders, Limburg and Germany, creating and supporting four local networks in Brabant, in the lead municipalities, to create dementia-friendly municipalities. A lead municipality starts by forming a local network, consisting of a group of stakeholders that is as diverse as possible. With the lead municipalities of Brabant, the PG-raad has signed a declaration of intent which describes the municipalities role and the tasks in the project. These lead municipality networks receive support and project guidance from the PG-raad over four years consisting of:

- Support in setting up the local network Dementia-friendly municipality (DVG network);
  - Project guidance and advice in developing plans;
  - Offering substantive expertise in the development of trailblazer actions;
  - Input of expertise from other provincial networks.

In most countries where there was significant activity developing ‘dementia-friendly communities’ (but particularly Germany, Belgium, the Republic of Ireland, the Netherlands, and throughout the UK)

partnerships, networks and collaborations existed at regional, municipal or local levels. These partnerships involved public services and officials (e.g. mayors), NGOs, businesses, public authorities, community groups, faith organisations, people living with dementia and their families. In some countries they also existed at a national level, most notably England, with its National Dementia Action Alliance (although English respondents to the online survey did not mention partnerships as much as other countries). These partnerships had many functions including: sharing information; learning and resources; monitoring progress and impact; supporting members and promoting 'dementia-friendly communities'; and enabling community development and cohesion.

#### **Box 24: Duren - Germany**

The 'With Us' campaign to make Duren a dementia-friendly city involved politicians, health and social care services and local businesses. An open civil forum was created to ensure that people living with dementia and their families had a public voice. 'With Us' created an information booth, a theatre event, poster campaigns in local transport services, and workshops for the general public. Specific efforts were made to ensure that the voices of seldom-heard groups of people who have dementia were included, such as people living with dementia who are from Black, Asian and minority ethnic (BAME) backgrounds or from LGBT communities.

Examples of partnerships and networks included:

- Informal support networks of organisations;
- networks co-ordinated by a dedicated team or individual;
- formal stakeholder steering groups or governing bodies.

Apart from the possible tension that could arise through the involvement of health and social care services (and sometimes public services more generally) and dementia-specialist NGOs, there was little evidence from the online survey of other tensions in these partnerships. This was a positive finding, while also interesting - given the diverse range of organisations that were often represented in these partnerships and the different reasons why organisations might participate (public duty, desire to help, religious or moral reasons, good for business and/or business image, etc.). However the literature review, while also emphasising the importance of partnerships, identified some contrasting views. Some countries, such as Belgium, Germany and parts of the UK, had developed large national, regional or municipal partnerships with many organisations often involved (including local government), whereas other countries, such as Ireland, emphasised the importance of local, community-based, grassroots partnerships as being important. While the former may be more effective in ensuring widespread awareness-raising, the latter may be more successful in community and social engagement (including people with dementia).

#### **Box 25: West Dunbartonshire (WD) – Scotland**

WD is a partnership of statutory, NGO third and independent sector agencies of the WD Community Health and Care Partnership, WD Community and Volunteering Services and Scottish Care. The Partnership has developed a local Dementia Strategy; with commitments for the creation of Dementia-friendly West Dunbartonshire as well as supporting the development of neighbourhood services to meet the needs of all citizens locally, including those with a diagnosis of dementia. This has begun with specific work within its 22 identifiable neighbourhoods. WD is working with local schools and nurseries to create unique identifiers and branding for each area. We are using “Promoting Excellence” as their preferred education approach to create and deliver cultural and behavioural change within each community to the benefit of those with dementia. We are evaluating progress using the “Individual, Social and Material” tool (ISM) and taking pledges from each participant which lays out their commitment to make professional and personal change to their practice.

Sustainability of these partnerships was an issue that was identified by some interviewees, which links with the following section on resources, but also the political priority that dementia was given – the more informal the partnership the easier it was for organisations to withdraw or not fulfil their commitments, as this interviewee indicated;

*“The continuing [of DFCs] depends on having money and personnel and that is very often the problem; you can do this for one or two years and then different priorities come...the economic crisis and other things.”*

#### **4. Resources**

#### **Box 26: Neighbourhood support and Zeitvorsorge (NUZ) e.V. – Germany**

This project involved neighbourhood support based on “time credits” – this is a way of promoting the life experience, knowledge and skills of people with dementia because they are still wanted and needed and can be a resource for a community. The project is involved in raising awareness and providing information about dementia, and educating different parts of society: administrative organisations, church communities, banks, retail, police, doctors and clubs.

*“Infrastructure, as the community centre couldn’t have happened if it hadn’t been for subsidies we received. Financial resources, such as the “Alzheimer” grant, enable us to improve the quality of the activities and offer diversity.” (Translated)*

Although resources were mentioned less frequently in the survey (18 responses – 9%) a number of interviewees talked about their importance and they also featured significantly in the literature review. Resources could include financial resources, people, and ‘in kind’ (providing services for free e.g. meeting spaces, printing leaflets, etc.). Several interviewees emphasised the importance of creative and low cost ways of getting resources, for example, getting volunteers from existing community groups or schools, or supporting people living with dementia themselves to be volunteers, as this interviewee indicated;

*"[It's] not particularly to do with monetary resources ... but human resources ... yes. Because there's such a lot of pressure on people's time now, this ... you know the most successful of the dementia-friendly communities that we've been involved with here in [a region] have been the ones where it has been, if you like, volunteer-driven. I mean people have actually come forward and wanted to do this, and knock on doors in their own community, go visiting the shops in their High Street ..."*

#### **Box 27: Beauraing Centre for Social Action – Belgium**

This is a centre for people aged 60 or over during the day in order to combat isolation. Activities are adapted to the needs of people with dementia (e.g. musical workshops, massages, gentle exercises, craft, games). Participants enjoy being with others who are less dependent and thrive during these precious moments in groups. They organise joined-up activities with a care home or with services such as libraries and cultural centres, in order to engage participants through different events, for example, a project around remembrance of the First World War. *"It all depends on resources. It is crucial to engage a minimum number of participants in order to organise meetings, coordinate activities and supervise people. Infrastructure such as the Community Centre « La parenthèse » couldn't have happened if it hadn't been for subsidies we received. Financial resources such as the "Alzheimer" grant enable us to improve the quality of the activities and offer diversity."*

*"It has to focus on a welfare community by involving every resource citizens have to offer, whether as individuals or associations." (Translated)*

Some suggested that 'dementia-friendly communities' worked best where they built upon existing community assets and capacity – working with resources already available rather than duplicating or going through complex processes of securing new resources. However, it did appear that the development of 'dementia-friendly communities' was most active in countries where significant resources had been made available; furthermore in many smaller countries, where resources were limited even for specialist dementia services, it was much more difficult. Having the right resources in place at the right time (i.e. people with the authority to make changes, volunteers with the right skills, etc.) could also be challenging.

Resilience and sustainability were issues related to resources. The nature and complexity of the work, and the resistance that could be experienced, required energy and perseverance, as this interviewee described:

*"I think you have to ... act stubborn [laughs] and keep going on... with developing dementia-friendly communities."*

There was concern that 'dementia-friendly communities' could be vulnerable if organisations withdrew support or if their community capacity was limited. There was also concern that government and funding organisations might see successful mobilisation of existing resources as an excuse to withdraw support, or that they may not fully appreciate the value of 'dementia-friendly communities'. Two interviewees expressed this:

*“The State withdraws more and more from providing these essential services and leaves the volunteers doing the job and kind of expect too much from them...the State should really take more of the burden and make sure that the volunteers actually like doing the job”.*

*“If people think that a dementia-friendly community is just something fluffy and nice and will make things a bit better for people, we don’t need to do anything else, then I think that is a real danger, a drawback. But if it’s seen as one part of a jigsaw, one important part, so a part of a bigger jigsaw, then I think that’s how it should be viewed really.”*

**Box 28: Bishopbriggs Academy community action project – Scotland**

This project enables school pupils to undertake dementia informed training and encourages them to participate in intergenerational initiatives within Bishopbriggs, supported by a local dementia action team. Once trained, the pupils will devise opportunities within the town that can support older people e.g. dementia cafes and "Youth on Bikes" (a scheme involving young people visiting older people in the community to provide practical and emotional support, but receiving advice and expertise in return, with input from a cycle co-op).

The importance of “tools” and specific guides for supporting the development of ‘dementia-friendly communities’ was remarked on. In particular, tools to evaluate and monitor progress and the impact of ‘dementia-friendly communities’, beyond a simple measurement of how many communities had been declared as becoming dementia-friendly, was felt to be important (England, the Republic of Ireland and the Netherlands all referred to this in the online survey).

*“Developing locally sensitive toolkits that can be used by organisations to self-audit premises, services, programmes, training and other relevant activities.”*

Evidence of such evaluative tools was quite limited, although there were some good examples including:

1. Two guides from Belgium: Baert, V (2013) *Handleiding – Dementie Vriendelijke Gemeenten*. Brussel: Uitgeverij Politeia nv. De Rynck, P. and Teller, M. (2011) *Communes Alzheimer Admis - Un guide pour vous inspirer*. Bruxelles: Fondation Roi Baudouin
2. E-learning tools, resources and guidance produced by the Alzheimer’s Societies in England and Scotland.
3. The PG-raad/DVG network of dementia-friendly municipalities in the Netherlands (see case study above in box 23) is developing evaluation and measuring instruments, with which the living environment, opportunities for participation and various (service-providing) sectors can be screened for their level of dementia-friendliness (e.g. check lists). In the development phase, the checklists were tested to ensure ‘user friendliness’ by a range of stakeholders, including policy makers and organisations/business owners. The aim is to evaluate and report on progress annually. A final evaluation report is due in 2017.



4. A recently published book in Germany on ‘dementia-friendly communities’ includes a consideration of evaluation (but was published too late to be included in the literature review): Rothe, V, Kreuzner, G & Gronemeyer R (2015): *Im Leben Bleiben. Unterwegs zu Demenzfreundlichen Kommunen*. Bielefeld.
5. A toolkit to monitor and evaluate changes within communities and dementia-friendly initiatives (Easton, A. (2014) *Overview of the dementia-friendly communities initiative*. Co Dublin: The Alzheimer Society of Ireland). More information is available in the literature review under ‘Monitoring and evaluation’.
6. EFID published the brochure “I am still the same person”, an invitation to communicate differently about Alzheimer’s disease and related illnesses (2012)<sup>9</sup>

The literature review found some examples of evaluations using mixed methodologies, for example: measuring achievements against objectives; numbers of people participating in awareness sessions; numbers of organisations that were committing to become dementia-friendly; individual and group interviews with key stakeholders including people with dementia; surveys; audits; visits and observations. However it was not possible to identify a simple yet comprehensive methodology for evaluating impact, or to definitively say that certain communities had become a ‘dementia-friendly community’. This is clearly an area that needs further exploration and development. It could also potentially benefit from more established literature, derived from methods used to evaluate ‘age friendly communities’ and community developments more widely.

**Box 29: Evaluating dementia-friendly communities in Bradford and York - England**

In September 2015 the Joseph Rowntree Foundation (JRF) published its evaluations of activity to develop York and Bradford as dementia-friendly cities. The evaluation used a framework based upon the JRF’s ‘Four Cornerstones’ model (place; people; resources; networks) for developing dementia-friendly communities; it involved online surveys and interviews with key local stakeholders (including people with dementia).

## 5. Other factors

Several other factors were identified from the literature review although they were mentioned less frequently in the online survey and the interviews.

Ensuring that technology and the physical environment of buildings and activities in the community were dementia-friendly was a factor mentioned by several respondents (e.g. clear signs, reducing noise distraction, making ATM machines ‘dementia-friendly’).

*“Specifically better signage, better pavements, dementia aware staff within shops and services.”*

The importance of assistive or adapted technology was raised in a numbers of countries, such as equipment to enable people to 1) live safely in their own homes, 2) stay in communication with others, and 3) more controversially, GPS systems and mobile phone technologies to enable carers to monitor

<sup>9</sup> <http://www.nef-europe.org/wp-content/uploads/2013/03/EFID-Leaflet-I-am-still-the-same-person.pdf>

the geographical location of the person with dementia. As previously discussed any physical environment or piece of equipment may present challenges to people with dementia and therefore may need to be adapted to make them more dementia-friendly. Furthermore, the range and diversity of environments and technology that people with dementia may encounter, in any community setting, is so vast that it was beyond the scope of this survey to list or categorise them. Some of the tools identified above, together with 'dementia-friendly' architects and designers providing guidance, and 'dementia-friendly' audits of public environments and technology (carried out by people with dementia) can also help organisations and communities to develop in these areas (Box 30).

**Box 30: Dementia-friendly environments and design – Scotland, the Netherlands and England**

The Dementia Services Development Centre at Stirling University is world-renowned for its work on dementia-friendly design, environments and housing (see also Mitchell L 2012 in the literature review for dementia-friendly housing). Eindhoven University of Technology in the Netherlands brings in its knowledge on intelligent lighting systems which can improve the physical and mental well-being of people with dementia and their (informal) care providers and knowledge on how dementia lighting innovations can create sustainable business. A guide on how to do dementia-friendly 'access audits' of buildings has been produced by an NGO in England, Innovations in Dementia.

As already stated the importance of care and support services for people living with dementia was frequently mentioned in the online survey and literature review. While it was clear that these services were essential in supporting people with dementia to live in the community, this was not analysed in detail due to the scope of the study, as agreed originally.

*"It is also very important to work in partnership with different types of professionals (medical, social, etc.). Individual support must go hand-in-hand with coordination between care and support."* (Translated)

### **Strengths and challenges**

**Box 31: Some quotes from the online survey**

*"Having people with dementia occupying ordinary public spaces also promotes a positive image of the illness."* (Translated)

*"Our hard work on the local level and our consistent approach to inclusion are recognised and rewarded."* (Translated)

The survey was primarily exploratory, mapping the current landscape of 'dementia-friendly communities', and was not intended as an evaluation of DFC activities. Although commonalities, key factors and differences could be observed through the exploratory survey, caution is required when assessing strengths and weaknesses of activities and approaches, given limited information and knowledge of different cultures, structures and systems, and language issues. It would be unfair and potentially misleading to identify specific projects, activities or organisations (about which information

was gathered in the survey) as having particular strengths or weaknesses, as there is insufficient evidence to make assessments or judgements of that nature, nor was it indicated to participants that assessments of that kind were going to be carried out. However, it is possible to make some more general observations and discuss strengths and weaknesses of the range of approaches and activities identified, particularly in light of the key factors described in the previous section.

### ***Strengths***

Clearly, approaches which include all the key factors identified above are likely to have the greatest success in terms of embedding organisational, attitudinal, behavioural and environmental change within communities that are trying to become more dementia-friendly. One might expect that this could also have benefits for the quality of life and well-being of people with dementia (and their families), potential cost savings (by enabling people with dementia to live in the community for longer and delaying entry into institutional care) and potential wider community development – making communities more ‘friendly’ in general (although it must be noted that this was an exploratory study and did not investigate these as outcomes of ‘dementia-friendly communities’).

Even where activities focus only on one of the factors there are still strengths and benefits to this such as: reduction of stigma and negative attitudes towards people as a result of awareness-raising; people with dementia having their voice heard or feeling more empowered as a result of greater involvement; or sharing resources and expertise through better partnerships.

The enormous diversity of approaches and activities is also a potential strength as it creates space for innovative and creative projects to be developed, drawing upon a wide range of experiences and expertise. This means that DFC activity can potentially start anywhere – a church, an arts organisation, a dementia NGO, a care provider, a group of shops or businesses, or a municipal government. It also means that it can take different forms – a local alliance of organisations, an arts exhibition involving people with dementia, a group of people with dementia walking through a neighbourhood to identify how it could become more dementia-friendly, or a local Alzheimer’s association providing information and awareness-raising sessions to public transport workers.

‘Dementia-friendly communities’ have also given significant impetus to different conceptualisations of dementia, particularly where they emphasise inclusion, access and participation for people with dementia. In some countries, Scotland being a notable example, this has linked well with a human rights based approach to national dementia policy and service development. Using the social model of disability, as expressed through national laws and international treaties such as the United Nations Convention on the Rights of Persons with Disabilities (CRPD), potentially enables ‘dementia-friendly community’ activity to achieve greater sustainability in policy and practice. This social model also has potential for people with dementia to secure legal protections, in addition to support and social acceptance.

## ***Challenges***

The diversity of approaches and activities, make it difficult to come up with a detailed or specific definition of a 'dementia-friendly community'. For organisations starting off, it may be difficult to know what to do first or where to focus resources. At the time of writing this report there was no European-wide dementia strategy, template or incentives for developing 'dementia-friendly communities' – with the sole exception of EFID. Responsibility for community development and health policy still resides with national or regional governments and variations therefore are inevitable.

Definitions of terms such as 'community' and 'inclusion' could also be problematic because they tended to vary, often used in very different ways. For example, 'dementia-friendly community' activity often did not focus on people with more severe dementia, living in institutional care. Yet these institutions were still located in communities and it is difficult to see a justification for them being excluded from a 'dementia-friendly community' activity. Institutions usually have significant resources such as communal areas and gardens. 'dementia-friendly community' work, that tried to make positive use of these spaces and be inclusive by bringing the community into the care homes (or enable people living there to get out into the community), should be encouraged. 'Inclusion' (or 'involvement') was also used in a variety of ways. Sometimes to simply indicate that 'dementia-friendly community' activity was aimed at involving communities, in general, to help people with dementia, or by providing more communal facilities for people with dementia to use, in order to meet others. But in some cases it indicated activity that aimed to give people with dementia more opportunities to participate in public and civil life as citizens, in addition to providing opportunities for them to have a real voice and community presence. All of these are important, but it is important that 'inclusion' does not become so sophisticated that it excludes other forms of involvement, however it does show the challenges of achieving a shared understanding.

It is unclear what truly works in developing 'dementia-friendly communities' – there is a lack of robust evidence on what is genuinely a well-established and well recognised 'dementia-friendly community'. Through the literature review, this report has identified a focus on more theoretical or policy descriptions of what a 'dementia-friendly community' is (including, to some extent, the factors identified in this report), and inputs or 'building blocks' that make up the process of developing a DFC. At the same time many municipalities and regions such as Arnsberg, Bruges, Brabant, Motherwell (in Scotland), York, and the initiatives funded by EFID, have clearly been very active in a number of different ways, (incorporating some or all of the key factors identified in this study), towards becoming more dementia-friendly. Yet, there do not appear to be any comprehensive evaluations of impact, such as changes in quality of life for people with dementia, or reductions in institutional costs or usage were reported. As the literature review identified, there have been toolkits developed to guide dementia-friendly activity (e.g. Easton, 2014, *Overview of the dementia-friendly communities initiative* - The Alzheimer Society of Ireland) and a number of more qualitative evaluations of 'dementia-friendly communities' (e.g. Joseph Rowntree reports on York and Bradford), but the challenges of proving the success of 'dementia-friendly communities' are methodologically complex and resource intensive. To sustain commitment, and resources being directed towards 'dementia-friendly communities', it will be important nevertheless to provide robust evidence that DFCs make a positive difference. Evaluation tools used in other forms of community development may be useful and have the potential to be adapted for use with 'dementia-friendly communities'. Whatever tools might be used, it is

essential that the lived experience of people with dementia remains central to evaluation of ‘dementia-friendly communities’.

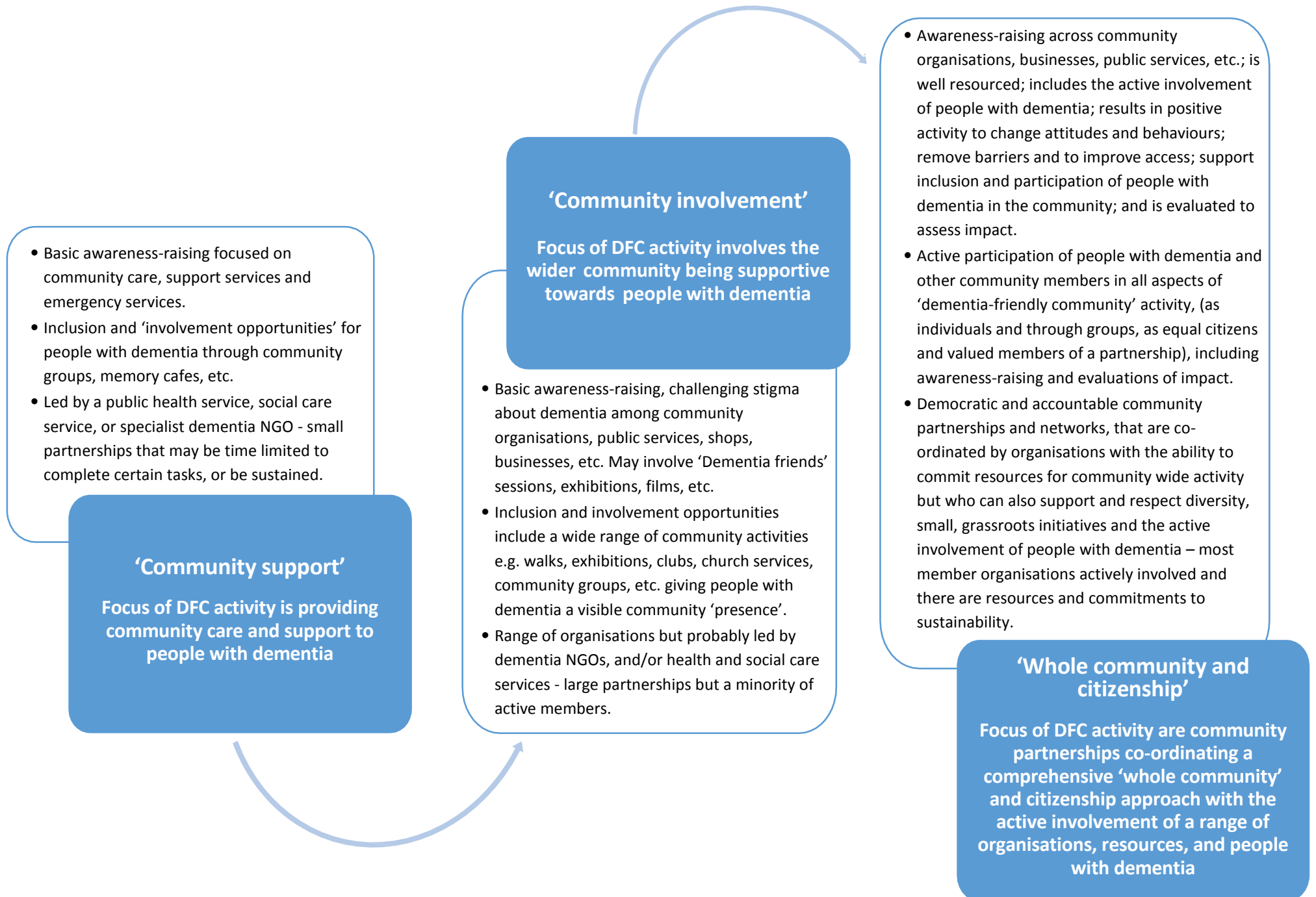
As identified in the interviews, there is the risk that DFCS will not be sustained where resources, energy, or commitment needed to develop ‘dementia-friendly communities’ is no longer available. This is a real concern because the “safety net” of public services is much more limited in many countries, or not particularly well developed in others.

The fact that a significant number of more traditional health and social care providers identified themselves, and their work, as contributing to the development of ‘dementia-friendly communities’, raises the question of whether people with dementia are seen as citizens of those communities, as opposed to “patients” or “service users”. Of course, it is possible within these traditional services to see people with dementia as both, but the dominance of the biomedical model of dementia may make this more challenging. In countries where health and social care services for people with dementia were dominated by institutional care, activity to develop ‘dementia-friendly communities’ sometimes appeared to be more focused on providing basic support and care for people with dementia in the community (such as day centres, dementia cafes, home helps, support for carers, etc.) rather than more inclusive, ‘citizen-focused work’ (enabling people to participate in public and ordinary community life).

### *5.2.1. A taxonomy for ‘dementia-friendly community’ activity*

Drawing upon the key factors and commonalities described earlier in the report, as well as taking into account the range of dementia-friendly activities that have been identified as occurring in different countries, it is possible to categorise these into three general “descriptors” or groupings. We are choosing to call this a ‘taxonomy for ‘dementia-friendly community’ activity’, or DEM-FACT, as seen in Diagram 1 below. This may represent a development process but it is important to note, however, that the survey showed that this is not necessarily a linear process. As such, some of the activities in one descriptor may also be occurring in another descriptor, and not all the activities in a descriptor may occur at the same time; all are important components for developing ‘dementia-friendly communities’ and will contribute to improvements in the quality of life for people with dementia. They may also reflect the levels of public, political and organisational capacity and the commitment and resources that are available, in any given area, for the development of dementia-friendly-communities. Activists may be keen to adopt a ‘whole community and citizenship’ approach but the resources, commitment and capacity available may mean that a ‘community support’ approach is more appropriate or realistic.

Diagram 1 - A taxonomy for 'dementia-friendly community' activity (DEM-FACT)



## 6. Key principles for developing ‘dementia-friendly communities’

Drawing upon the findings from the study it is possible to identify some important principles for developing ‘dementia-friendly communities’ but it is important to stress that these should not be applied in an overly-prescriptive (strict) way.

- The **essential factors in developing ‘dementia-friendly communities’** appear to be:
  - Training, education and awareness-raising
  - Active inclusion and involvement of people living with dementia (together with the involvement of the communities they live in)
  - Encouraging and supporting partnerships, networks and collaborations
  - Securing and sharing resources
- **Communities are diverse** and therefore ‘dementia-friendly communities’ will be diverse. Ways in which ‘dementia-friendly communities’ are developed differ, depending upon political, social, economic and cultural factors. A top down, national approach may work for one country but local, community initiatives may be more appropriate for other countries.
- The **role of health and social care organisations, and dementia-specialist organisations** in the development of ‘dementia-friendly communities’ can be complicated, but should broadly be welcomed. These services and organisations may be the place where ‘dementia-friendly community’ work begins. They are part of communities and provide essential services to people living with dementia and their families. Separating them from ‘dementia-friendly community’ development suggests that when people living with dementia use them that they are no longer members of the community – this is unhelpful, especially for people with more severe dementia, residing in care homes and hospitals. The challenge is to create synergies between civil society organisations and health and social care services.
- Where there are **‘age-friendly’ initiatives** taking place, ‘dementia-friendly communities’ could consider seeking to build alliances and influence those initiatives. A focus on dementia always runs the risk of community developments adding to stigma, separation and exclusion – age-friendly initiatives may need to be better informed about dementia (including the need to be inclusive of younger people with dementia e.g. below the age of 65). In the long term, however, age-friendly initiatives offer wider opportunities for more inclusive community development that is not defined primarily in terms of diagnosis.
- Community development is complex and usually takes place over a long period of time. **Embedding and sustaining** ‘dementia-friendly’ community development is therefore key, but requires commitment and resources to support organisational processes and to achieve outcomes. Investing resources for long term development is essential. Evaluating impact and outcome (which actively involves people with dementia), and sharing the lessons learned from these evaluations, is also a vital part of this process.

## 7. Conclusion

This survey was a limited ‘snapshot’ view of ‘dementia-friendly community’ activity across Europe at a particular moment in time. While it was clear that an enormous amount of activity was taking place, the survey cannot claim to present a comprehensive picture of everything that has been occurring in this field across Europe. Because of the challenges of doing a pan-European project like this, especially regarding language and understanding different cultures and systems, together with the fact that respondents to the online survey were self-selecting, the findings should be treated with some caution. However, even with these limitations the survey clearly showed how much enthusiasm, commitment, diversity, creativity, learning, collaboration, sharing of resources, and positive energy ‘dementia-friendly community’ activity has generated.

An online survey respondent from Wales described the aim of their work as creating “*a social movement that mobilises all sections of the community*”. The survey clearly showed that the ‘dementia-friendly community’ ‘movement’ is occurring across Europe in many different ways. It is perhaps no coincidence that it has occurred at a time when public policy is faced with the double challenge of ageing populations and increasing numbers of people with dementia, coupled with static or reduced spending on health and social care services in most European countries. Different solutions, therefore, have had to be developed to support the millions of people living with dementia, and their families, in the community. Mobilising community capacity and the resources that a whole range of organisations possess has been the solution. But to achieve this, the survey identified key common activities involving awareness-raising and sharing information, the active inclusion of people living with dementia, building partnerships and collaborations, and securing resources. These activities have clearly energised and engaged massive numbers of individuals and organisations.

But the activities have also generated lots of questions. How to define community or the focus of those activities? What is the role of health and social care services? Is an approach used in one country or region suitable for another? What is the balance of responsibility in community development between large organisations and governments, small local organisations and citizens, and of course, people living with dementia themselves? What does a ‘dementia-friendly community’ look like and how is it possible to know? How can ‘dementia-friendly communities’ become the norm, and how might age friendly communities help with this? Can the energy, engagement and activity be sustained when faced by the scale and long term nature of the challenge?

Although the survey doesn’t provide definitive answers to these questions it provides important indicators about what are the essential building blocks for ‘dementia-friendly communities’. The report also identifies some weaknesses and possible risks to sustaining the DFC ‘movement’. But in the absence of a cure, or universally effective treatments, for Alzheimer’s (and other forms of dementia) for the foreseeable future, there is both the opportunity and necessity for creative, positive community-based solutions to support people with dementia, not only to live well but also be active participants in their communities. Although institutional care for dementia will not disappear and different European countries have different health and social care systems for people with dementia, communities will remain the place where the majority of people with dementia live their lives. Communities must therefore be the place where solutions are found and created. Communities come in all shapes and sizes, so it is perhaps inevitable that community-based solutions to enable people



with dementia to live well will also be highly diverse – one size doesn't fit all. The examples and evidence provided in this report clearly demonstrate this.

### *7.1. Ways forward*

For the reasons described above, particularly the diversity and amount of 'dementia-friendly community' activity occurring, but also the limitations of a mapping survey of this kind, this report does not contain specific recommendations. However, based upon the findings from the survey a number of possible areas of action or 'ways forward' to support the further development of 'dementia-friendly communities' across Europe have been identified. These are as follows:

- Pan-European organisations with an interest in dementia should consider collaborating on a joint statement/work programme to support the further development and evaluation of 'dementia-friendly communities' across Europe, including building links with European-wide dementia and age-friendly initiatives and other international organisations with an interest in supporting this work e.g. Alzheimer's Disease International, World Health Organisation, etc.;
- Pan-European organisations with an interest in dementia should consider collaborating on developing a DFC communication strategy to raise awareness of DFC activity and good practice, through the use of: social media; promotional materials that can be used in different settings (e.g. schools, education, businesses, public services, etc. ); and an online 'dementia-friendly European community' website to contain resources, information, and other ways to communicate and connect with individuals and groups involved in this work, etc.;
- Pan-European organisations with an interest in dementia could develop a work programme focusing on non-geographical 'dementia-friendly community' development e.g. communities of shared identity, communities of interest etc.;
- Pan-European organisations with an interest in dementia could enter into dialogue to discuss ways of continuing the development of an evidence base for 'dementia-friendly community' activity, drawing upon the DEM-FACT taxonomy in this report and other approaches to evaluate impact/outcomes (but ensuring that any approach remains person and community-centred).
- National, regional and municipal governments that have made commitments to developing 'dementia-friendly communities' should consider this report and ensure, wherever possible, that the key factors identified for developing 'dementia-friendly communities' are incorporated into their plans, strategies and activities.
- National governments, NGOs and other organisations that have or are developing dementia policies or strategies, and which do not currently contain commitments to 'dementia-friendly communities', should consider the findings of this report and how they can incorporate 'dementia-friendly community' initiatives into those policies and strategies.

- National governments, NGOs and other organisations should consider providing “seed” funding to enable new DFC activities and initiatives to get off the ground and reduce the time and energy spent on pursuing piecemeal funding;
- National, regional and municipal organisations involved in DFC work must prioritise investing in people to sustain the work: ensuring people with dementia are at the centre of DFC activity; creating a pool of people skilled in the promotion of DFCs, to reduce the reliance on volunteers; facilitating peer mentoring and networking to enable people to learn from one another about how best to create DFCs and solve problems, as they arise.

**The European Foundations’ Initiative on Dementia invites the stakeholders identified above to explore ways to collaborate, in order to take forward one or more of these areas for action.**

**Box 32: Concluding quotes**

*“Some communities seem to worry that they will be hit by a cost explosion if they tackle this issue. We believe the opposite is the case: There will be a cost explosion if communities are **not** prepared.” (Translated)*

*“We don’t consider dementia as a ‘burden’ to society but rather as an opportunity to get rid of stereotypes and change society’s practices. Our society has managed to give “time to life” but now it needs to give “life to time”.” (Translated)*

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## Cyprus

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## **Appendix A**

### **Report of findings from the online survey**

#### **1. Summary of findings**

##### **Role of organisations in developing ‘dementia-friendly communities’**

The majority of respondents across Europe were working within non-government organisations (NGOs) (n=66 – 34%), closely followed by those working within health and/or social care services (n=50 – 26%). This would suggest that the majority of current developments in ‘dementia-friendly communities’ (DFCs) across Europe are led or delivered by NGOs and via health and social care services.

Twenty respondents were working within local authorities or municipalities; ten respondents were working to develop community projects and initiatives within their communities and were not apparently associated or connected with an organisation. Ten respondents were college students and three respondents were working within emergency services (e.g. Fire and rescue, police services).

##### **Role of respondents in developing DFCs**

Respondents described their roles in developing DFCs, with 86 responses (44%) indicating that the work was focused on raising awareness, providing information, education and training. Similar numbers were involved with coordinating services and developing partnership networks (n=43 – 22%) and providing health and/or social care services and activities in the community (n=41 – 21%).

Nineteen respondents described their role as research-based and nine respondents described their role as supportive, including allocation of funding for community-based projects and initiatives to develop DFCs. Three respondents were working to develop dementia-friendly emergency services, namely the fire and rescue service and police services.

##### **Factors in the development of DFCs**

Across 16 European countries, the most prominent factors were consistently related to raising awareness of dementia and DFCs, in order to improve attitudes, knowledge and understanding towards people who are living with dementia (n=126 responses – 65%). It was evident that the majority of responses, from most European countries, held awareness of dementia as a crucial factor in the successful development of DFCs, which may indicate that DFCs are perceived primarily as communities that have a good understanding and empathic attitudes towards members of the community who are living with dementia.

Aspects of inclusion and involvement were identified in responses from across Europe as key factors in the development of DFCs and generally related to ensuring opportunities for people living with dementia to be, or feel social included (n=67 – 35%). In some responses, inclusion appeared to extend to of all members of the community. Inclusion related to participation by people living with dementia in community activities and day-to-day living, as well as in relation to participation in influencing, planning and developing DFCs.

Partnerships and building networks were important factors in the development of DFCs which frequently reoccurred in responses across Europe (n=49 – 25%). The theme of partnerships indicated an emphasis on coordinating activities and services, sharing resources and embedding monitoring processes in the development of DFCs.

Resources (financial, human, 'in kind', etc.) occurred less frequently (n=18 – 9%) and related to the other themes, having been cited as a factor in relation to the resources required to raise awareness, develop working partnerships and to ensure full inclusion of communities (particularly supporting the involvement of people living with dementia).

## 2. Survey – Report of Findings

### 2.1. Methods

#### *Survey development and promotion*

The survey was carried out between October 2014 and January 2015 as an online questionnaire, using an online survey provider, Survey Monkey. Survey questions were developed in consultation with the EFID Steering Committee members (survey questions are at the end of this document). The survey was kept intentionally short for several reasons:

- the areas of investigation required free text answers;
- to encourage a high response rate;
- it was expected that a number of respondents would respond in languages other than English;
- more in-depth data collection could be achieved through the telephone interviews;
- to manage the process of analysis within the time and resources available.

The survey was made available to complete in seven different languages:

- English
- Dutch
- Flemish
- French
- German
- Italian
- Spanish

A link to the survey was disseminated via the Mental Health Foundation's networks (including the Alzheimer Europe newsletter) and through members of the EFID Steering Committee. The survey was promoted at events and conferences, including all delegates (800+) at the Alzheimer Europe conference in Glasgow in October 2015, who were emailed a link to the survey.

Members of the Steering Committee were asked to encourage active dissemination of the survey through their networks. A pro forma email that could be used to promote the survey was provided by the Mental Health Foundation in the different languages listed above.

Active promotion of the survey was carried out in January 2015 to encourage individuals and organisations known to be active in 'dementia-friendly communities' to complete the survey.

Respondents were self-selecting: it was not possible to know whether they were a representative sample according to location, role, activity or views expressed. In the write up of the survey the terms ‘respondent’ and ‘response’ are used interchangeably.

The survey in English is available at the end of this report.

### *Analysis*

The organisations, in which respondents were working, were categorised by the area of work each organisation placed greatest focus on. Categories included health and social care service providers, academic institutions, emergency services (e.g. fire and rescue, police service) and local authorities or municipalities.

Respondents also described what their roles involve, in working to develop DFCs. The types of work carried out by respondents were described, and frequencies indicated, in order to build a picture of what current initiatives are being used to develop DFCs.

Two researchers analysed the literature review and online survey responses. Common or recurring key words and phrases were identified relating to DFC inputs and activity (e.g. training, resources, staff, participation, etc.), outputs (e.g. information, events, partnerships, etc.) and outcomes (e.g. inclusion, awareness, empowerment, etc.). These were categorised into themes indicating key factors or requirements for the development of DFCs.

## **2.2. Overall findings**

A total of 194 responses were received, from 19 European countries.

### ***Findings from the online survey***

#### *Role of organisations respondents in developing ‘dementia-friendly communities’*

Responses to the online survey were grouped in accordance with the organisational role, as described by the respondent, in developing ‘dementia-friendly communities’. Obviously there is the risk of some inaccuracy when categorising organisations that are based in countries less familiar to the researchers. The information is shown in Table 1.

**Table 3**

<b>Type of organisation</b>	<b>Number of responses</b>
NGOs (both national and local/regional)	66 (34%)
Health and/or social services	50 (26%)
Academic, research,	23 (12%)
Local/regional/municipal government	20 (10%)
Local community projects/initiatives	19 (10%)
Emergency services	5 (3%)
Other	11 (6%)

### *Variations between countries*

Of the countries that had eight or more responses, Germany reported the greatest proportion of NGOs (9/19 – 47%), followed by Scotland (8/21 – 38%) and England (19/65 – 29%), though some of these NGOs were also providing community care and support.

France had the greatest proportion of health and social care organisations (6/8) followed by Belgium (11/22 – 50%) and the Republic of Ireland (7/15 – 47%). Germany (6/19 – 32%) and England (6/65 – 9%) reported a relatively low proportion of such organisation.

The proportion of local/regional/municipal government was fairly even (15-20%) across countries.

### *Discussion*

Table 3 (above) provides clear evidence of the significant role that NGOs and community-based projects play in developing ‘dementia-friendly communities’. The relatively low response rate from local, regional and municipal governments does not altogether reflect the findings from the literature review, nor does it reflect some of the comments from the interviews, which emphasised the important role these organisations play. The low response rate from these organisations may partly reflect the types of networks that the Mental Health Foundation and the EFID Steering Committee members had, which were more linked with NGOs than government bodies. This may also explain the lack of responses from national governments.

The relatively high response rate from health and/or social services emphasises the difficulty of separating these organisations from activities developing ‘dementia-friendly communities’. This may partly reflect the simple fact that it is these organisations that have most contact with people with dementia and therefore may recognise the importance of developing ‘dementia-friendly communities’. A significant number of responses described community-based care and support being provided to people with dementia as an important factor in creating ‘dementia-friendly communities’; this directly challenges one of the predefined parameters of this study – community support and participation should go beyond what is provided to individuals based primarily on their diagnosis.

Of course, the role of the organisation may not be a clear indicator of the role of the respondents, with 43% of respondents describing their role, in developing ‘dementia-friendly communities’, in terms of raising awareness, providing information, education and training. The next section explores this in more detail, indicating that some respondents working in health and social care services may have had roles that were not conventional ‘health or social care roles’ in terms of providing care and treatment to individuals. Twenty percent of respondents indicated that their role did involve providing community health and/or social care services, or similar activities.

## **2.3. Factors in the development of DFCs—Thematic analysis**

Thematic analysis of the factors emphasised by respondents, led to the emergence of three primary themes as factors in the development of DFCs:

1. Raised awareness — knowledge and education, attitudes and understanding, influencing communities
2. Partnerships — collaboration, building networks and involving whole communities

3. Inclusion — active participation and involvement of people living with dementia in community activities, planning, discussions and decision-making

A fourth overarching theme was identified, which underpinned the other three themes, having only been cited as a factor in relation to aspects of the three primary themes:

4. Resources—human, financial, ‘in kind’.

## **Raised awareness**

One hundred and twenty-six (126) responses (65%) from 17 countries cited the need to raise awareness as a crucial factor in the development of DFCs and several responses indicated that fear and stigma continue to pose difficulties for people living with dementia in their communities. Raising awareness encompassed a need for communities to have greater knowledge of dementia and the need to influence community members’ attitudes towards people who are living with dementia.

A number of target groups were identified as particularly important to raise awareness among, including: police services; health and social care services; political groups and government agencies; policy-makers and commissioners; community volunteers; families of people living with dementia; activity groups and sports clubs; the retail and service industries (e.g. shops, restaurants, etc.); people living with dementia; the general public.

As regards information and awareness levels of people living with dementia, responses indicated that providing supportive post-diagnostic information is crucial. It was evident that supportive attitudes within health and social care services entailed providing a capacity-building, personalised and holistic service. Such services can contribute to supporting people with dementia to remain well and actively involved in their communities for longer.

Influencing the educational sector was cited in several responses and often related to calls for more intergenerational initiatives in the development of DFCs. Dedicated spaces and venues for intergenerational interactions were described as useful in facilitating a cultural shift towards positive attitudes with regards to dementia, and ageing in general. Similarly, a number of responses suggested the delivery of dementia-specific groups and activities within public spaces, as this facilitates opportunities for positive interactions between community members who may not otherwise have opportunities to interact.

A range of methods or approaches were suggested for raising awareness across communities, such as delivering lectures, informational events and workshops and conferences to widely disseminate accurate information about dementia, and specifically about how to support people living with dementia in their communities.

Responses described the need for awareness-raising methods to include messages about what it feels like to live with dementia in the community. It was suggested that this approach facilitates a deeper understanding towards people living with dementia and promotes positive, empathic attitudes towards people with dementia. Other responses indicated that age-friendly attitudes and ‘friendly communities’, more generally, should be promoted.

It was suggested that awareness-raising initiatives should also aim to offer practical guidance for how DFCs can be developed and how community individuals or groups can become involved and actively contribute. Employing local culture and the arts in awareness-raising messages was suggested in several responses, as was the development of links with local and national media to maximise the impact of campaigns. In addition, it was suggested that having public recognition of projects, events and initiatives from external partners or national organisations can contribute to community awareness.

## **Inclusion**

Aspects of inclusion were highlighted in 67 responses (35%) from 13 countries, which included a focus on the active participation and involvement of people living with dementia in community activities, planning, discussions and decision-making in their communities. 'Living with dementia' was primarily defined as people with a dementia diagnosis, although it also often included family and friends. It was suggested that developing DFCs requires the involvement of people who are living with dementia in their communities. Responses indicated that initiatives to develop DFCs are most effective where they ensure that people with dementia have a public voice and are involved in planning and DFC developments.

Many responses referred to social inclusion as denoting the continued participation of people with dementia in their usual day-to-day activities. These responses placed greater focus on activity groups for people with dementia, and several suggested the development of dementia-friendly activities within public spaces to facilitate opportunities for interactions with the wider community.

Suggestions to facilitate social inclusion for people with dementia included developing activity hubs within public areas of communities and adopting a personalised, holistic approach to community care, support and activities. Co-production processes were described in which people with dementia are acknowledged as equal partners alongside professionals, commissioners and other community groups involved in the development of DFCs.

Responses from several countries referred to 'genuine' involvement of people with dementia, an intentional word which often seemed to imply previous experience of non-genuine or tokenistic involvement of people with dementia in initiatives to develop DFCs. Several responses also referred to 'citizen' involvement, a word which appeared to suggest adoption of a rights-based approach to developing DFCs, in which people with dementia are supported to access their rights to citizen involvement in their communities.

Several requirements for enabling full social inclusion were highlighted in responses, including the need for support in the community for people with dementia, enabling them to remain active in their communities for longer. Asset-based approaches were described as useful for enabling social inclusion, which requires bespoke approaches to the involvement of individuals who are living with dementia. Truly inclusive communities can be developed through recognition of barriers to the inclusion of people living with dementia, from which solutions can be jointly identified.

An aspect of social inclusion that was raised in several responses, across several countries, highlighted the importance of ensuring that public spaces, in the community, have been suitably adapted for the

needs of people living with dementia. Physical adaptations to community spaces were described as an important aspect of enabling safe, independent lives for people who are living with dementia.

## **Partnerships**

A third theme that was identified in 49 responses (25%) from 14 countries indicated the development of partnerships and collaborative networks as a crucial factor in the development of DFCs. These partnerships were often described as informed, supportive networks which promote cooperation between individuals and groups, ensuring efforts are coordinated and resources are shared. Several responses suggested the creation of a dedicated team or individual within each community, who is responsible for co-ordinating networks and promoting local developments.

Partnerships can enable more effective monitoring processes to be implemented, in the development of DFCs, measuring impact and progress more consistently. Partnership networks can broaden the impact of project and initiatives and enables more widespread sharing of good practice information and guidance. Several responses suggested the implementation of multi-stakeholder bodies and reviews, in developing DFCs, to strategically document progress and share learning. Suggestions for adopting these processes included developing steering groups or governing bodies which include representatives of small-scale, grassroots community initiatives to develop DFCs.

Various agencies or groups within communities were suggested as key partners to involve in developing DFCs. These included local government agencies to enable legal reform, local businesses and services, housing and social care services and emergency services. It was suggested that these organisations can be persuaded to collaborate by identifying clear objectives and the cost effectiveness of developing DFCs. By involving a range of community groups or agencies in developing DFCs, a greater sense of community cohesion can be developed, which itself facilitates the development of DFCs.

## **Resources**

The need for sustainable resources in developing DFCs was emphasised in 18 responses (9%) as a barrier to developments in the above three factors. Responses referred to both human and financial resources as a crucial factor in developing DFCs and the sustainability of resources was a common concern among respondents. Responses suggested greater creativity and innovation to identify solutions to resource constraints.

## 2.4. Findings by country

### **AUSTRIA (n=4 – 2%)**

#### Organisation's role in developing DFCs

Four respondents described their work in Austria as developing DFCs. Two respondents worked within NGOs and two respondents worked within an academic research setting.

#### Respondents' role in developing DFCs

A respondent working with an NGO was focused on delivering social support and activity programmes for people with dementia, as well as working to improve dementia care services. Another respondent working within an NGO focused on promoting awareness among the general public, as well as providing support services for people living with dementia and their families. One of the respondents worked within an academic institution to develop ethical palliative care practices.

#### Factors

One respondent from Austria, working within an NGO, indicated a number of factors and requirements in the development of DFCs. Social support was cited as necessary to enable inclusion and involvement of people who are living with dementia. The need for raising awareness was also suggested, through lectures, free consultations and using a range of media to disseminate information.

*“Public awareness at a national level...People in public services and sales should be trained to deal with disoriented people (bank, bus, supermarket, police, etc).”*

(Translated)

Intergenerational projects were described as useful for involving communities beyond those who are directly affected by dementia. This respondent highlighted the value in working in partnership and collaborations to disseminate information and widen the impact of campaigns and projects. It was reported that DFCs require a team embedded within each community, who is committed to local DFC developments. Resources were also cited as a requirement to enable DFCs to develop, as were developing strong links with local media.

*“Creation of model communities that offer financial assistance for national training, lectures and free consultations.”* (Translated)

Three responses from Austria did not cite any factors or requirements in the development of DFCs.

### **BELGIUM (n=22 – 11%)**

#### Organisation's role in developing DFCs

Twenty-two responses were received from Belgium. Eleven respondents were working within health and/or social care services (including social services). Six respondents were working within NGOs and



three respondents worked within local authority or municipality administration. Two respondents were working within the police service.

#### Respondents' role in developing DFCs

Fourteen respondents were involved in delivering training and good practice guidance for health and social care staff and other statutory service providers, as well as dissemination of information to raise awareness. This work often involved delivering conferences, community events and using media to share information.

Six respondents described their role of coordinating networks to develop working partnerships across sectors, including working with retailers, service providers and policy makers. For one respondent, the role entailed allocating resources and monitoring community initiatives. Another respondent described their role as supporting the involvement of people with dementia in non-medicated interventions for people who have dementia.

Two respondents' indicated their role was to provide policing services in the community, one of whom worked specifically within the Missing Person's Unit. These two respondents were developing and implementing appropriate, dementia-friendly police services and protocols.

#### Factors

The need to raise awareness among communities, professionals and policy-makers was highlighted in the majority of responses from Belgium (n=18 – 9%). Raising awareness of dementia included the need to provide training, information and education for community members (service providers, police services, volunteers, general public) in responding to dementia and how to best support people in the community who are living with dementia. Responses suggested that raised awareness and improved knowledge can positively impact on how dementia is understood by individual community members. The widespread dissemination of factual information about dementia is valuable to the promotion of positive, capability-enhancing attitudes towards people living with dementia.

*“We therefore need to set a good example by organising events linked to the illness in order to raise awareness among the public (conference, monthly Alzheimer Café, training for different audiences, practical guide, raising awareness among businesses, etc).” (Translated)*

The training of various members in any community was also highly valued by respondents, with suggestions that this can enable people who have dementia to remain living in their own home for longer. Well-trained health and social care staff can reportedly contribute to prolonged independent living for people who have dementia; professionals who received appropriate training can contribute to developing supportive, empowering relationships with the people they work with who are living with dementia. In addition, it was also suggested that by training staff in local businesses and services, people with dementia can be enabled to remain autonomously active in their community for longer.

*“By demystifying dementia, people can react more sympathetically and are no longer scared by the disease...Training and raising awareness among community*

*care workers allows people with dementia to stay at home for as long as possible.” (Translated)*

Two responses also stressed the importance of garnering political interest in developing DFCs, as well as aligning the interest of political groups to community objectives. One response suggested the recruitment of dedicated supporters or ambassadors, who can champion local causes and ensure focus on key issues for people living with dementia, based upon personal lived experience of dementia. People who have dementia, volunteers of various ages, as well as family and friends of people living with dementia can contribute in a significant, meaningful way to developing DFCs.

*“Finding supporters for your project is very important. Partners, children who have experienced it, are often ambassadors for your actions!” (Translated)*

The importance of recognising inclusion was an important factor, which highlighted the need for hubs of activity to facilitate the involvement of people living with dementia in community activities and opportunities (n=9 – 5%). Centres or activity hubs were perceived as an excellent starting point that can bring together a range of individuals in the community, including those who are living with dementia. Seven responses referred to the need for personalised services which ‘see the person, not the illness’ as a crucial aspect of enabling inclusion.

*“The aim is to promote cultural participation, social cohesion, social resilience, empowerment of older persons and promotion of intergenerational collaboration.” (Translated)*

It was emphasised that inclusion requires recognition of the strengths and assets that people living with dementia can contribute to their communities, and to developing DFCs. Truly personalised services enabled individuals to feel empowered, thereby facilitating active participation of people with dementia. For one respondent, personalised services are those which place value on holistic approaches, such as nutritional therapy and therapeutic art programmes.

*“I think that you should start from a common interest (such as walking, sports, culture) in order to bring together different target groups and cultures and thus work on integration.” (Translated)*

*“If we can’t add days to life, we can add life to days.” (Translated)*

Inclusion extended to the inclusion of communities at the heart of projects and initiatives to develop DFCs. Grassroots initiatives were praised as particularly suited to representing the needs and interests of local communities and individuals; small-scale, local initiatives which have developed organically have the additional benefit of being able to influence upwards, towards improving policy and practice, while setting priorities for the development of DFCs. This response asserted that DFCs require the inclusion of such initiatives to enable DFCs to develop successfully:

*“Working to break through taboos has to grow organically and has to be carried by the people it’s about and by policy makers—local and above local.” (Translated)*

Eight responses asserted the importance of supportive networks and coordinated efforts within and across communities. Two responses suggested that oversight of projects and initiatives by a supervisory body, steering group or leading agency can contribute to coordinated networks. Another response suggested that a well-developed infrastructure is essential to ensuring oversight and coordination of projects. A third response indicated that developing networks requires a commitment from local government, services and retailers to contribute. It was suggested that, typically, it has not been difficult to garner support from local businesses and services in developing DFCs.

*“It is also very important to work in partnership with different types of professionals (medical, social, etc.). Individual support must go hand-in-hand with coordination between care and support.” (Translated)*

Three responses also raised the issue of resources, both human and financial, which must be sufficient to allow for DFC developments to become a priority. One response indicated that local governments require financial incentive as motivation to become active contributors in developing DFCs.

*“Infrastructure, as the community centre couldn’t have happened if it hadn’t been for subsidies we received. Financial resources, such as the “Alzheimer” grant, enable us to improve the quality of the activities and offer diversity.” (Translated)*

## **BULGARIA (n=1)**

### Organisation’s role in developing DFCs

The respondent based in Bulgaria worked within an NGO to provide a range of services to change attitudes and practices towards people living with dementia.

### Respondent’s role in developing DFCs

The respondent working to develop DFCs described their role as focused primarily on improving access to appropriate treatment and social support for people living with dementia. This worked involved developing networks and influencing service providers, as well as creating community-based initiatives and projects to promote the development of DFCs.

### Factors

Factors highlighted in Bulgaria included the need to improve awareness and knowledge about dementia throughout communities, as well as influencing policy at a local and national level, to ensure resources are allocated to the development of DFCs. Campaigning and delivering information events were described as effective methods of raising awareness. The value of providing quality training and education for health and social care staff was highlighted, in order to better support people who are living with dementia to maintain a good quality of life.

## **CZECH REPUBLIC (n=1)**

### Organisation's role in developing DFCs

The respondent from the Czech Republic described their organisation's role as a consultation service for people with dementia, their families and others who have impaired memory function.

### Respondent's role in developing DFCs

This respondent did not indicate their role in relation to developing DFCs.

### Describing DFCs

DFCs were described as a municipality which is accepting and supportive towards people living with dementia. DFCs are communities wherein members of the community support individuals who have dementia to defend their rights, interests and needs.

### Factors in developing DFCs

A key factor in developing DFCs was the development of good teamwork processes, which take a humane and educated approach when responding to dementia. Other factors that were described included the physical environment, which should be peaceful and accessible, using creativity to develop communities.

## **ENGLAND (n=65 – 34%)**

### Organisation's role in developing DFCs

The majority of respondents based in England were working within NGOs (n=19 – 10%) to develop DFCs. Nine respondents were working with local authorities and ten respondents were college students in the field of dementia care. Six respondents were working within local projects and community initiatives to develop DFCs, without an affiliation to particular NGOs, service providers or government agencies. These included local influencing groups made up of people who are living with dementia. Six respondents also described their organisation as providers of health and/or social care services.

Eight respondents were working in various other types of organisations or groups, which included two independent consultants and three individuals working within a church to develop DFCs. Two additional respondents were working within fire and rescue services in England.

### Respondent's role in developing DFCs

Sixty-five (34%) responses were from individuals based in England, or who were working for organisations which are based in England. Some organisations, such as Innovations in Dementia and the Joseph Rowntree Foundation, work across the UK. These organisations were included in this section where the organisation's main office was based in England.

Ten respondents were students and were not involved in developing DFCs.

Just over a majority of respondents in England described their role in developing DFCs as focused on raising awareness through education, disseminating information and influencing community groups

to promote positive attitudes towards people living with dementia (n=33 – 17%). Twenty-three of these respondents focused specifically on influencing retail sectors and statutory service providers, in order to promote their involvement in developing DFCs. Methods of raising awareness included holding community events, utilising the media and campaigning to promote positive attitudes among the general public. Of the 33 respondents who were working to raise awareness, 14 were delivering workshops, talks or training and education for people who are living with dementia, professionals and service providers.

Twenty-one respondents (11%) from England were involved with providing services and community-based support programmes, including peer support groups, health and social care programmes and at-home care and support.

Sixteen respondents (8%) described their role in developing DFCs as building and facilitating networks, both within and across communities, in order to develop DFCs. This included individuals who worked as part of their local dementia action alliance to build partnerships between agencies and communities. Four of these respondents were involved with the development of standardised processes and accreditation for DFCs, while two respondents described their role in the development of DFCs as research-based.

Ten respondents were facilitating the inclusion and involvement of communities, specifically to include people who have dementia in community initiatives and activities. These individuals indicated their role as amplifying the voices of people with dementia, facilitating their involvement in DFC initiatives and ensuring their involvement in consultations and policy developments. One respondent was focused on adapting public spaces to ensure that communities were physically adapted to enable the inclusion of people who are living with dementia in the community.

Twenty-six respondents indicated their affiliation with local or national dementia action alliances, with the Dementia Friends/Champions programme, the Purple Angel scheme, or similar standardised recognition processes for DFCs.

### Factors

Responses most frequently highlighted the level of awareness within communities as a crucial factor in the successful development of DFCs (n=35 – 18%). Seventeen of these responses (9%) indicated that awareness, of what it means to live with dementia, can be improved by providing education and information for people who are living with dementia, for carers/family members of people with dementia, as well as for professionals and members of the general public. One response emphasised the value of enabling communities to develop personal experience of communicating with people who are living with dementia. Several responses suggested that awareness-raising methods should focus on intergenerational projects to inform and involve young people in developing DFCs.

*“Engaging young people and helping them to improve their knowledge of dementia. They are our future communities after all.”*

As part of raising awareness, a number of responses suggested that information and education should offer practical ways for individuals and communities to become involved in dementia-supportive activities and initiatives to develop DFCs. These responses proposed that many sectors of society are willing to become dementia-friendly, but that they lack the knowledge and confidence to get involved in effective ways. Making connections with local and national media, to disseminate awareness-raising information was also recommended.

Fifteen responses (8%) highlighted the need for a cultural shift, throughout society, in order to foster a more tolerant, accepting attitude towards all members of society who are living with a frailty or illness. One response suggested that attitudes towards all older members of society will require a positive shift if DFCs are to be more widely developed.

*“The penny has to drop in enough minds to tip a balance. But it doesn’t take many minds - I don’t encounter much resistance.”*

Twenty-seven responses (14%) described various aspects of inclusion as crucial to the development of DFCs, primarily in relation to the inclusion of people living with dementia, as well as including community groups. The involvement of people who are living with dementia in developing DFCs was cited as an important factor in 11 responses. It was suggested that local individuals who are living with dementia should be supported to be involved in all aspects of planning and developing; this was seen as an integral aspect of developing truly ‘dementia-friendly communities’. One response referred to this practice as “considerate planning”, as it affords consideration of the needs and preferences of individuals who are living with dementia in the community.

It was suggested that individuals who are living with dementia should be supported to have a public voice, to feel actively involved and included in their communities and to feel that their views and experiences are of value to their community. This can be achieved by holding the views and experiences of people living with dementia at the centre of initiatives to develop DFCs. The need to adapt public spaces to become dementia-friendly was also cited as an important aspect of enabling the full inclusion of people living with dementia in community planning and activities.

*“Utilise those living with dementia on every steering group, every focus group and wherever you can.”*

*“Living with dementia is a complicated issue—being welcome and happy in your local community is just one part of the puzzle.”*

Several responses highlighted the value of delivering community programmes and activities, which are specifically dementia-inclusive, in community venues; this can ensure that people with dementia remain as visible members of the public. This will also support communities to be more inclusive towards people with dementia, reducing the social isolation that is often associated with living with dementia. It was also suggested that fully engaging communities to participate in developing DFCs is crucial to the success of DF initiatives.

*“Each DAA [Dementia Action Alliance] is different and decide on their own priorities with regard to becoming more dementia-friendly.”*

Sixteen responses (8%) cited the importance of ensuring that grassroots, small scale community initiatives are included in larger-scale programmes to develop DFCs. It was suggested that organically developed DFCs can more accurately reflect the abilities, needs and priorities of each local community. Communities all have unique challenges and strengths — initiatives to develop DFCs are best implemented by adopting an asset-based approach to communities, and utilising the passion and drive of individuals within each community. The development of DFCs inherently requires bespoke

adaptations, tailored to communities' / individuals' interests and skills, in order to fully reflect principles of inclusion.

*“Communities need to make sure that anything they do really reflects the wishes of people with dementia in the community.”*

Several responses described the need for a cultural shift with regard to how communities cooperate internally, referring to the necessity for wider social cohesion within communities. These responses suggested that DFCs can arise naturally out of cohesive communities — those which recognise and enable the inclusion of a range of individuals and sectors within any given community.

*“The whole community must take a far more tolerant attitude towards the elderly and take time to accommodate them, then dealing with dementia is simple.”*

Ten responses (5%) cited working partnerships as a crucial factor to developing DFC, as this enables cross-sector coordination of services and enables supportive networks to emerge within and across communities. Ten responses also indicated the importance of making adaptations to health and/or social care services, housing agencies and emergency services as a core part of developing DFCs. It was suggested that it can be helpful to explicitly outline the potential cost effectiveness of collaborating to develop DFCs, particularly for encouraging the involvement of services and local businesses in developing DFCs.

*“Typically, dementia-friendly community organisations include everything from existing Neighbourhood Watch schemes to bowling clubs, allotment associations to charitable groups. Faith group inevitably play a major role...”*

Two responses emphasised the value of measuring the effectiveness and impact of initiatives to develop DFCs. This can promote the widespread sharing of learning and good practice which can benefit other communities who face challenges with implementing and developing DFCs.

Two responses also suggested that resources, both financial and of personal support, are needed to enable DFCs to emerge.

## **ESTONIA (n=1)**

### Organisation's role in developing DFCs

The respondent was working within a day centre in Estonia and described the organisation's role as primarily providing respite care and support for families of people living with dementia.

### Respondent's role in developing DFCs

The respondent described their work in Estonia as providing social care and support services to people living with dementia in their own homes. This respondent was also working to develop wider networks, build partnerships between services and communities, and to share knowledge and good practice.

## Factors

A lack of resources to enable adequate service provision was cited as the biggest factor impacting the feasibility of developing DFCs in Estonia. The need for sufficient information about dementia was also highlighted, as it was suggested that many people still do not even consider what it means to live in the community with dementia, until they are personally affected.

*“Usually people don’t think about dementia before they themselves need help.  
That’s why the information is the most important.”*

This respondent highlighted the importance of amplifying awareness about dementia among the general public, to promote improved attitudes and understanding towards people living with dementia.

## **FINLAND (n=1)**

### Organisation’s role in developing DFCs

The respondent from Finland described the organisation they work in as an NGO which works towards improving the quality of life of people with dementia and their families. This includes working to develop support services, disseminating information and training professionals, as well as raising awareness to influence attitudes towards people who have dementia.

### Respondent’s role in developing DFCs

This respondent worked to deliver the Finnish National Memory Programme 2012-2020 which aims to create a memory friendly Finland. Work to develop DFCs included coordinating networks to implement improvements and facilitating a working group of people with dementia and carers to ensure their voices inform policy and implementation.

### Factors in developing DFCs

The respondent described the sharing of information and good practice guidance across organisations and sectors as an important factor in developing DFCs. Legal reform was described an important aspect to ensure DFCs are given priority in policy and decision making, at a national level.

## **FRANCE (n=8 – 4%)**

### Organisation’s role in developing DFCs

Eight respondents from France described their work to develop DFCs, six of whom were working within health and/or social care services. Two respondents were working in NGOs to deliver social care and support services.



### Respondent's role in developing DFCs

Three respondents were involved with delivering social support activities in the community for people with dementia. Activities included memory cafés, carer support groups and intergenerational activity groups.

Two respondents were also working to raise awareness of what it means to live with dementia by disseminating information at conferences and community events. One respondent was involved in delivering training for health and social care professionals, while another was working to develop assistive technologies for people who are living with dementia.

### Factors

The most commonly cited factor for developing DFCs in France related to improving levels of understanding and empathy towards people living with dementia, among the general public as well as among professionals (n=4 – 2%). One response suggested that levels of understanding about dementia can be improved by employing local culture and artistic media to promote positive messages. Another response indicated that understanding what it means to live with dementia is a crucial pre-requisite to recognising solutions to common challenges or difficulties experienced by people who are living with dementia.

*“Having people with dementia occupying ordinary public spaces also promotes a positive image of the illness, as opposed to secure units.” (Translated)*

Four responses referred to aspects of inclusion as crucial to the development of DFCs. The importance of supporting people who have dementia to maintain social connections and active participation in their usual activities was highlighted. Two responses suggested that understanding and awareness can be increased within communities by ensuring community inclusion for people living with dementia. This can entail delivering social activity groups for people who have dementia within public spaces, such as providing dementia-specific walks, information sessions and activities in public environments.

*“We want to foster social links and are also working with the area's culture centre. It's very important for us to maintain this link...It is important for us to participate in the local public life.” (Translated)*

*“We shouldn't 'confine' them to a specific space but instead we should maintain open doors without putting them at risk. Walks, restaurants and cinema are all activities that need to be available in order to maintain social connections.” (Translated)*

Such community-wide activities can reduce the stigma associated with dementia, as well as normalise interactions between people who have dementia and other community members or groups. One response indicated that adapting the local environment and public spaces to be dementia-friendly is a crucial component of ensuring that people living with dementia are able to maintain connectedness with their community.

*“We don’t consider dementia as a ‘burden’ to society but rather as an opportunity to get rid of stereotypes and change society’s practices. Our society has managed to give “time to life” but now it needs to give “life to time”.” (Translated)*

One response suggested that DFCs require the participation of local businesses in development work; another participant asserted the importance of persuading local authorities and statutory service providers (e.g. housing, social care agencies) to contribute to developing DFCs. Both responses stated that it had not been difficult to get interest from local political groups and statutory services, but that their involvement in working partnerships is central to the success of developing DFCs.

*“Non-medical decision-makers at the local level (local authorities, etc.) need to be persuaded that there is no danger in integrating initiatives for people with dementia in public life.” (Translated)*

## **GERMANY (n=19 – 10%)**

### Organisation’s role in developing DFCs

Nine respondents in Germany were working within NGOs to develop DFCs. Six respondents were working with health and/or social care services, including outpatient service and psychiatric service providers. Four respondents were working within their local authorities or municipalities to develop local DFC initiatives.

### Respondent’s role in developing DFCs

Ten respondents (5%) described their role as raising awareness, by providing education and training, offering guidance and disseminating information to enable the development of DFCs. Work to disseminate information and raise awareness included delivering conferences and symposia; workshops and learning events; films and educational materials; and individual consultations about services for people living with dementia, carers and professionals.

Three respondents (2%) were providing social activity groups in the community for people living with dementia and the general public; these roles focused on enabling opportunities for intergenerational interactions in order to promote greater awareness and positive attitudes towards people living with dementia. Three respondents described their role as delivering training within various sectors of the community, such as police services and retailers. Two respondents were working to influence political groups and commissioners, to improve care and support for people living with dementia.

Six respondents (3%) described their role as developing networks and facilitating collaborative partnerships between a range of organisations and community groups. These roles were often focused on project development and employed co-production models, with people living with dementia supporting the development of local DFC initiatives.

Six respondents were providing health and/or social care services. Two respondents were also delivering an advocacy or representation service which aimed to amplify and garner recognition of issues commonly faced by people living with dementia. Lastly, two respondents were involved in supporting research developments to improve the care and support available for people with dementia and their families.

## Factors

Sixteen responses (8%) highlighted the need to raise awareness as a crucial factor in the development of informed, understanding DFCs. Several respondents explained that bringing about an attitudinal change towards dementia will contribute to creating supportive, inclusive communities. Raised awareness within communities can be brought about through widespread dissemination of information, as well as influencing and providing training for a range of community groups and organisations in order to improve attitudes towards people living with dementia.

*“Information events about dementia, advice on dealing with dementia, training.”*  
(Translated)

Responses highlighted the necessity to disseminate information about dementia more widely in order to garner full support for initiatives to develop DFCs. The development of practical guidance was suggested to support individuals with accessing relevant information about dementia care and services, as well as how to become involved with community initiatives to develop DFCs. One response suggested the development of dementia-specific information centres, which can provide advice and information for people living with dementia, family carers and professionals in the community. Another response suggested that training should be implemented for employees and staff in all community sectors, retailers and the service industry (e.g. cafés, restaurants), as well as health and social care service providers.

The development of partnerships and networks to facilitate collaborations was frequently highlighted in responses (n=9 – 5%). One response explained that widespread networks and effective working partnerships can also encourage wider sharing of good practice, in addition to guidance and learning from successfully developed DFCs. Another response suggested that partnerships can also enable distinct groups or organisations to share resources, as well as maximise impact.

*“The willingness to create networks (as closely knit as possible) involving a large variety of stakeholders.”* (Translated)

Several responses asserted that networks and partnerships should include a wide range of community groups and individuals, including people living with dementia, family and carers, as well as professional service providers and NGOs. One response also explained that developing expanded partnerships can contribute to the development of an informed, supportive infrastructure which facilitates the development of DFCs.

*“We must communicate to important institutions and stakeholders (mayor, town council, GPs, clubs, churches, media, etc.) that dementia is an important issue for the inhabitants of any town.”* (Translated)

*“Creating strong networks with all concerned—relatives, surgeries, stakeholders from science and politics.”* (Translated)

Responses highlighted the value in establishing clear aims and objectives at the start of initiatives to develop DFCs. This can provide a clear focus and enables external groups (e.g. commissioners, policy makers) to more easily recognise progress and how they have contributed to developing DFCs. Two

responses also suggested the creation of an “approachable” individual responsible for drawing attention to, and considering, dementia in relation to community initiatives and local policy.

The need to influence political groups, policy makers and commissioners was highlighted, in order to encourage their active involvement in the development of DFCs. It was suggested in one response that this can be more easily achieved by making robust economic arguments for the long-term cost effectiveness of creating DFCs. Another response asserted that all groups within a community should become involved in developing DFCs, including administration, retail and banks, faith groups, police services, health and social care service providers, medics and social/sports clubs. They indicated that working with local media, and gaining recognition from external agencies or partners, can contribute towards influencing the various groups within a community.

*“Our hard work on the local level and our consistent approach to inclusion are recognised and rewarded.” (Translated)*

Four responses (2%) cited inclusion as a key factor in developing DFCs, particularly in relation to developing co-production processes and providing personalised support to facilitate inclusion. Personalised community-based support enables people living with dementia and their families to be more able to participate in community-influencing and activities, which was described as essential to the development of DFCs.

*“Offering differing forms of living for people with dementia in each district helps people with dementia to lead a good life in their own individual way.”  
(Translated)*

Ensuring genuine citizen involvement in community initiatives to develop DFCs was also emphasised as a crucial factor. It was asserted that people living with dementia should be involved and at the centre of plans and actions to develop DFCs. A co-production process was called for, which places equal value on the lived experience of people with dementia and the knowledge and expertise of professionals who work with people living with dementia. One response specifically highlighted that DFCs are most effective where they include people living with dementia at the forefront of hosting workshops, political lobbying, developing projects and generating ideas and solutions.

*“Experts are not the only stakeholders because they often develop blind spots. Without citizen involvement there can’t be the ‘right’ kind of thinking ...Real opportunities for participation and sharing.” (Translated)*

One response suggested that the physical environment of communities must enable safe, autonomous movement for people living with dementia. The development of intergenerational projects was also suggested, as these create numerous opportunities for encounters between younger members of a community and those who are living with dementia. Spaces should be made available to facilitate such encounters within communities.

Three responses (2%) highlighted resources as a factor in enabling the development of DFCs. These respondents suggested that increased financial resources are necessary to develop sustainable DFC models. One response suggested greater involvement of volunteers as a way to reduce the financial impact of developing DFCs, within communities with limited resources. One response called for

greater innovation in developing DFCs — by supporting new ideas and concept developments, it was suggested that resource constraints might be mediated.

*“Some communities seem to worry that they will be hit by a cost explosion if they tackle this issue. We believe the opposite is the case: There will be a cost explosion if communities are **not** prepared.” (Translated)*

*“I think it is vital that the mayor and local council are...prepared to create the financial framework necessary to establish the right infrastructure (e.g. by supporting volunteer agencies or similar).” (Translated)*

### **ITALY (n=6 – 3%)**

#### Organisation’s role in developing DFCs

The six survey respondents were equally divided between organisations which provide health and social care services (n=3) and academic or research-focused organisations (n=3).

#### Respondent’s role in developing DFCs

Three respondents (2%) were working primarily to provide health and/or social care services for people who have dementia and their families. One of these respondents was also supporting dementia research, as well as delivering social care and support services in the community. In addition, three respondents described their work as research-based and focused on improving treatment and support for people who have a diagnosis of dementia.

#### Factors

Three responses (2%) suggested a need to raise awareness, as a key factor in the successful implementation of DFCs, and highlighted the need to engage the general public, as well as commissioners and political groups. One response indicated that awareness-raising should aim to communicate positive, inclusive attitudes about people living with dementia and another respondent recognised the value of intergenerational programmes as a means of raising awareness about what it means to live with dementia. Another response indicated that advice and guidance should be available for communities, and people living with dementia, to support their involvement in developing DFCs.

*“Advice for the public about the illness and on diversity in general. Experts of the illness and its characteristics and on how to adapt the environment.” (Translated)*

*“To create contexts where the illness can be discussed and to spread a concept of sharing amongst all citizens without excluding people.” (Translated)*

Three responses (2%) emphasised the importance of ensuring the full inclusion of people living with dementia in community activities and initiatives. It was suggested that the genuine involvement of people living with dementia in community initiatives requires recognition of the barriers to genuine involvement, as well as offering solutions to support people living with dementia to maintain active involvement. Community events (e.g. local festivals, markets, cafes) can be a starting point for bringing people together to identify common aims and preferences.

*“This cannot work without involving the culture and good practice of a community.” (Translated)*

*“The promotion of activities not necessarily linked to conditions related to the disease.” (Translated)*

A key aspect of inclusion was the appropriate employment of the skills and experiences of individuals and groups within communities in developing DFCs. The unique abilities and experiences of people with dementia, and other community members and groups, must be fully recognised and utilised in order to maximise on local strengths and assets in developing DFCs.

*“It has to focus on a welfare community by involving every resource citizens have to offer, whether as individuals or associations.” (Translated)*

Two responses also emphasised the need for a commitment from key individuals and groups to work in partnership, sharing good practice and resources where possible. One response indicated that a commitment to working partnerships is a requirement of any successful DFC and should include commissioners, NGOs, as well as individual community members.

*“A belief in, and strong commitment to, learning about team work between the various institutions.” (Translated)*

## **NETHERLANDS (n=6 – 3%)**

### Organisation’s role in developing DFCs

Of the six respondents from the Netherlands, two were working within health and/or social care services. Two respondents worked within NGOs or NGO networks; one respondent worked within an academic institution and another worked within the police service’s missing persons unit.

### Role of respondent in developing DFCs

Two respondents were working to provide health and/or social care services. Two respondents were involved with disseminating information and good practice in relation to developing DFCs, which entailed facilitating inter-organisational networks. One respondent was working in academic research to improve dementia care services; another was working with a missing persons unit to identify supportive ways to identify risks and locate missing people who are living with dementia.

### Factors

A wide range of factors were highlighted by respondents from the Netherlands and one response went into considerable detail, listing 10 factors which can contribute to developing DFCs. The importance of supporting people with dementia to maintain social inclusion was important to respondents (n=3 - 2%), as was the need to improve attitudes towards people who are living with dementia (n=3 – 2%).

*“Creating a change in mentality, working to break through taboos has to grow organically and has to be carried by the people it’s about and by policy makers: local and above local.” (Translated)*

Responses indicated that respectful, inclusive and understanding attitudes towards people with dementia are important to developing inclusive communities which are conducive to DFCs. It was suggested in one response that societal attitudes should be generally 'friendly' and does not necessarily need to focus on people living with dementia. Other responses emphasised the importance of widely disseminating information across community groups. Suggestions to disseminate knowledge and improve attitudes included delivering informational events (e.g. conferences, workshops) and developing guidance materials (e.g. websites, newsletters).

*"Providing information, giving advice and specific referrals; training and mentoring of professionals; creating awareness in society about dementia."*  
(Translated)

Three responses (2%) asserted that DFCs should be led from the start by people living with dementia and their families. Personal accounts and testimonials, provided directly by people who have dementia, can be the most effective and informative methods of ensuring inclusion, whilst garnering support to develop DFCs from others in the community. Another response highlighted the importance of adapting the physical environment to facilitate safe, autonomous movement within community spaces for people who are living with dementia.

*"Finding 'supporters' for your project is very important. Partners, children who have experienced it, are often ambassadors for your actions!"* (Translated)

It was also suggested that initiatives to develop DFCs must move beyond the care sector as a skewed emphasis on care sector involvement in developing DFCs can contribute to the maintenance of an illness-based understanding of dementia. By moving beyond the care sector, a more nuanced approach to dementia will be more widely accepted.

*"When forming network inviting non-care organisations to participate (associations...education, cultural and welfare organisations). This can already change the image of dementia."* (Translated)

The importance of working partnerships was also raised in three responses (2%), while two responses suggested that networks to develop DFCs should include intergenerational projects, with the educational sector, to influence younger people's attitudes towards dementia. It was also suggested that by developing wider networks which can work in partnership towards mutual aims, information and good practice guidance can be more easily disseminated and built upon. One response described the importance of getting support from political groups and government agencies, highlighting the need to provide motivation for policy makers to become involved in DFCs.

*"The community must go for it together, shopkeepers, the police and the fire department, the citizens, the associations, together."* (Translated)

*"It is important that the core group is open to new participants, parties and anyone who creates space to contribute within his/her own possibilities."*  
(Translated)

In addition, one response suggested incorporating consistent evaluation methods to determine outcomes and highlight good practice in working partnerships. Initiatives to develop DFCs can have robust monitoring and evaluation methods built in to the project, which can substantially contribute to developing a wealth of learning and guidance, to inform a range of sectors on to successfully become involved in developing DFCs.

Responses emphasised the need for small, locally-driven initiatives as a crucial aspect of partnerships working together to develop DFCs. It was suggested that, in this way, the genuine involvement of people who have dementia in developing DFCs can be more easily maintained. In addition, priorities of local community groups are more likely to be accurately represented with smaller scale initiatives to develop DFCs. One response suggested that as initiatives to develop DFCs expand to cover a larger geographical region, top-down approaches can often crowd out the involvement of local individuals.

*“Not imposed from above, but thinking together about how every town or every village can do something with it for themselves. It can start off small, adjusting and improving is possible.” (Translated)*

Two responses also highlighted the availability of resources as a factor in developing DFCs as they described a need for financial and human resources to maintain support for, and the involvement of, people who have dementia. A component of this factor was the need to support carers as their role in supporting people with dementia and developing DFCs is crucial to the success of initiatives to develop DFCs.

#### **NORWAY (n=4 – 2%)**

##### Organisation’s role in developing DFCs

Four responses were from individuals in Norway, all of whom worked within the research and service development sector.

##### Respondent’s role in developing DFCs

All four respondents described their roles as focused on research and service development in relation to diagnosis, treatment and support for people who have dementia and their families. One respondent was also involved with delivering projects to support people who have dementia to continue living at home by enabling home modifications and carer support.

##### Factors

Responses highlighted the need to raise awareness of dementia, particularly among the general public, by providing education and accessible information. One response suggested including the retail sector in disseminating information about adaptations and suggestions for good practice. Several methods of raising awareness were suggested, including TV campaigns, news stories about people with dementia, and de-stigmatising articles and poster advertisements.

*“Challenging citizens to talk about dementia, get rid of taboos and embrace people with dementia as ‘normal’ citizens with some particular needs for support.”*



*“It is a question of awareness-raising, respect and understanding, as well as physical adaptations and planning easy to understand information.”*

One response also emphasised the importance of including people who have dementia in local adaptations and DF initiatives.

*“I hope this work will involve people with dementia...it will be carried out in collaboration [co-production] with the local Alzheimer’s Society as well as health and social workers.”*

## **NORTHERN IRELAND (n=2 – 1%)**

### Organisation’s role in developing DFCs

Two responses were from Northern Ireland; one respondent worked within a large NGO delivering a range of services and activities across Northern Ireland. The other respondent was working within local government to improve service provision for people living with dementia.

### Respondent’s role in developing DFCs

The respondent working within the NGO described their role as primarily focused on raising awareness, through providing information and education and by supporting the inclusion of people who are living with dementia. The other respondent who was working within a local government agency was primarily involved with providing staff training, with the aim of improving health and social care service provision for people who are living with dementia.

### Factors

Both responses emphasised the need to raise awareness, particularly in how individuals and organisations can make adaptations to become dementia-friendly.

*“Awareness-raising of how the person with dementia experiences the world at different stages, understanding how confusing situations can be addressed.”*

*“Having the knowledge to understand the issues that those who live with dementia and carers face on a daily basis and simple ways that they can make a difference.”*

One response also highlighted the value of working partnerships, which provide opportunities for those leading initiatives to offer partnered organisations guidance and support with becoming dementia-friendly. It was suggested that organisations and businesses are often keen to be involved in initiatives to develop DFCs but that a lack of knowledge and awareness about simple adaptations and practical measures that can be implemented.

*“Developing locally sensitive toolkits that can be used by organisations to self-audit premises, services, programmes, training and other relevant activities.”*

*“Support work with enabling other organisations and businesses to also join up with the scheme.”*

## REPUBLIC OF IRELAND (n=15 – 7%)

### Organisation's role in developing DFCs

15 responses were received from individuals based in the Republic of Ireland; seven of these respondents (4%) were working in organisations which provide health and social care services, including both statutory and NGOs. Two respondents were individuals working in academic institutions and four respondents (2%) were working within community projects, contributing to the development of DFCs. One respondent worked for a local authority and an additional respondent delivered a range of projects within NGOs.

### Respondent's role in developing DFCs

Seven respondents (4%) were providing health and/or social care services, with a particular focus on inclusion and dementia-friendly adaptations within service provision. Four respondents (2%) were delivering community-based development projects to raise awareness of dementia, to promote service improvements and develop support services within communities. One respondent described their work as developing national dementia-specific services and information by supporting local, grassroots initiatives to develop DFCs.

A respondent working with a local authority was developing partnership networks to disseminate good practice and awareness-raising information across sectors. Two respondents were involved in academic research with the aim of sharing good practice information and delivering educational sessions for a range of community groups.

### Factors

Eleven responses (6%) suggested that community awareness is crucial to the success of DFCs, as fear and stigmatising attitudes towards people with dementia are reportedly significant barriers to the success of community initiatives. Six of these responses (3%) indicated a need for training and education for health and social care staff, retailer employees and the general public. Suggestions for raising awareness and educating communities included developing a guide which offers tips and strategies for becoming dementia-friendly.

*“Create awareness and provide basic training to local community services...  
Awareness/training incentives should be rolled out in schools for students from 14  
years up.”*

*“Fear and stigma are the biggest barriers.”*

The need to involve people with dementia as central to conversations about DFCs was also highlighted (n=5 – 3%). Responses emphasised the importance of supporting people with dementia to feel empowered in effecting positive changes in their communities. It was suggested that physical spaces should be adapted to be dementia-friendly, ensuring that people living with dementia are included in community planning and activities.

*“Enabling/empowering the person living with dementia to live full active lives within their local communities, with the necessary supports in place to assist this process.”*

*“Promote the inclusion and participation of the person with dementia and their families in the project.”*

Five responses (3%) also highlighted the need for working partnerships to develop networks which can affect positive change at a broader level. Four responses (2%) also highlighted the value of working positively in partnership with existing community groups to facilitate a community-wide response. Continuous multi-stakeholder reviews were suggested to enable partnerships to document learning and good practice. Continuous reviews can also enable monitoring of progress and offer greater motivation for community groups to become involved in developing DFCs. Responses suggested that working partnerships require supportive infrastructures and indicated a need for clearly defined outcomes and recognition processes for developing DFCs. One response also suggested the appointment of a Dementia Lead within each community, to maintain focus on key issues and progress community initiatives to develop DFCs.

*“Multi-stakeholder local government review of all aspects of community planning.”*

*“Working with groups in a positive way to look at how we can make things more dementia-friendly, what is working, having the person with dementia central to the conversation.”*

Two responses suggested that resources can be the biggest barrier to developing DFCs. Sufficient resources are required to support the genuine inclusion of people with dementia in community developments, such as by providing transport to enable people to attend events in the community. The appropriate allocation of resources can also contribute to building capacity and sustainable initiatives within communities.

*“Ensure evaluation, sustainability and dissemination of learning.”*

## **SCOTLAND (n=21 – 11%)**

### Organisation’s role in developing DFCs

There were 21 responses from individuals in Scotland, most of whom were either working within NGOs (n=8 – 4%) or health and social care services (n=8 – 4%). Two of the respondents working in NGOs described the primary role of the organisation as facilitating and building collaborative partnerships between groups, sectors and organisations. Two of the respondents who described their organisational role as related primarily to health and/or social care provision have described their organisation as offering community support and activity for people living with dementia and their families.

One respondent described their work within an academic institution and four respondents were working within local authorities to develop DFCs in their local areas.

### Respondent's role in developing DFCs

Eight respondents (4%) were working to raise awareness among communities, influencing policy and practice, and delivering community engagement programmes. Eight respondents were delivering health and/or social care services, and several of these were also engaged in awareness-raising or educational programmes to reduce stigma associated with dementia among professionals and members of the general public.

One respondent, based in a university, described their work as research involving the development of community-based initiatives to promote the continued involvement of people with dementia in their communities.

Six respondents (3%) described their role as related to developing networks to promote working partnerships across sectors and communities. This was often related to delivering informational events and ensuring widespread dissemination of knowledge and good practice in relation to developing DFCs. Several of these respondents indicated that coordinating the involvement of various community groups was a key aspect of their work to develop DFCs. Two respondents described their role in facilitating working groups which involve people living with dementia and which are focused on influencing national and local policy, attitudes and community decisions.

### Factors

Scottish responses most commonly cited the need to raise awareness about dementia as an important factor in successfully developing DFCs (n=8 – 4%). Raising awareness included highlighting the abilities of people with dementia to reduce stigma, informing people about how to communicate with people who have dementia, as well as how to adapt environments to become dementia-friendly. A number of methods to raise awareness of what it means to live with dementia were suggested, including education, campaigns and providing information to communities.

*“Attitudes and preconceived ideas of how people with dementia behave.”*

*“How we develop awareness must be created from ground up with the active participation of communities from a range of fields and interests.”*

More in-depth education was suggested for professionals, higher education students, primary and nursery school children and the general public, in order to raise awareness and improve understanding about how to communicate with people who are living with dementia. It was proposed that by thoroughly raising awareness, improved understanding and a cultural shift can be achieved across communities.

*“Encouraging a culture where we are not afraid to ask someone if they need a little help.”*

*“...Improving understanding of how people with dementia and carers use the local spaces they inhabit and what types of environments they value and why.”*

The need to involve people living with dementia in locally-led initiatives to develop DFCs was also cited as an important factor in responses (n=5 – 3%). Five responses (3%) described the importance of using local, bottom-up approaches to community initiatives, which reflect the views and experiences of local individuals living with dementia.

*“Every community is different and the most successful initiatives are led by local people.”*

*“With citizens being active decision makers in meeting the specific needs of their communities.”*

This point also linked to adopting a person-centred approach, in order to effectively involve and engage individuals who are living with dementia in their communities. Several responses suggested a relationship between raising awareness and understanding among professionals (including service providers, policy maker and commissioners), and the extent to which community initiatives are person-centred and locally-driven.

*“...close involvement of carers and people with dementia.”*

*“An understanding of inclusion and person-centred practice.”*

*“I would highlight the involvement of people with dementia in community development activities; recognition of the diversity of people living with dementia.”*

The importance of working partnerships in the development of DFCs was also emphasised in several Scottish responses (n=5 – 3%), which carried over into effective signposting - providing information and sharing good practice among communities. Several responses indicated the need to develop dementia-friendly local spaces and community environments. This included influencing the retail sector and community services, as well as implementing signage and adaptations to promote accessibility (n=4 – 2%).

*“Joint working across all sectors—health, social work, voluntary and private sector.”*

*“Specifically better signage, better pavements, dementia aware staff within shops and services.”*

*“There is a need for strategic buy-in from all partners council/area-wide as well as to provide context and commitment.”*

Two responses also highlighted the need to improve resources, which enable the provision of support services for people who are living with dementia in their communities.

## **SLOVENIA (n=1)**

### Organisation’s role in developing DFCs

The respondent based in Slovenia described the organisation they worked in as an NGO which was focused primarily on providing education for professionals, businesses and organisations to improve responses to people who are living with dementia.

### Respondent's role in developing DFCs

This respondent indicated their role involved developing support services with the aim of influencing attitudes towards dementia within communities and organisations. This respondent was also working to develop a recognition process and logo to indicate that individuals or organisations within communities had received dementia training and were actively contributing to developing DFCs.

### Factors

Education was highlighted as a crucial factor to effecting positive change in the attitudes of community members towards people living with dementia. The need to engage with educational institutions to influence students' attitudes towards dementia was also emphasised.

*"Above all, educate people in the wider community."*

## **SPAIN (n=1)**

### Organisation's role in developing DFCs

The respondent based in Spain described their organisation as a social care and support service provider, which offered services and information for community members who were affected by dementia.

### Respondent's role in developing DFCs

This respondent described their role as providing supportive social activities for community members and people with dementia to share experiences and enjoy activities.

### Factors

The respondent from Spain emphasised a need for attitudinal changes to facilitate the development of safe, supportive communities as crucial to enabling DFCs, and to maintaining the active involvement of people with dementia in community groups and activities. The need for campaigns to increase knowledge and raise awareness was highlighted as crucial to promoting more tolerant attitudes towards people who are living with dementia.

*"Reducing stigma through campaigns to publicise the problem. Knowledge helps people to be more tolerant of the problem." (Translated)*

## **SWITZERLAND (n=1)**

### Organisation's role in developing DFCs

There was one respondent based in Switzerland who worked within a national NGO which offers advice and advocacy services for people living with dementia and their families.

### Respondent's role in developing DFCs

The respondent in Switzerland described their role in developing DFCs as focused on disseminating information and advice, with the aim of developing concepts and improving levels of information and awareness within target groups. Their role also involved influencing changes at a political level.

### Factors

This respondent indicated that the stigma which continues to affect people living with dementia was a significant barrier to developing DFCs. More knowledge about dementia is needed to improve public understanding of what it means to live with dementia. Increased awareness can also contribute to positive changes in health and social policy.

*“Social factors and stigma; more knowledge about dementia and thus a better understanding.”*

The need for political influence was also highlighted; this can be achieved through widespread dissemination of information via national and local media to promote cooperation at an individual and community-wide level.

*“Cooperation and coordination, public media.”*

### **WALES (n=4 – 2%)**

### Organisation's role in developing DFCs

Four respondents were based in Wales, three (2%) of whom were working within NGOs to provide support to individuals and communities. One respondent described their organisational aim as creating *“a social movement that mobilises all sections of the community”*. A fourth respondent worked with a local government agency to develop initiatives and projects to promote the development of DFCs.

### Respondent's role in developing DFCs

One respondent working with a local government agency described their role in developing DFCs as primarily focused on working as a Dementia Champion, which entailed developing partnerships, offering training and raising awareness of key issues and providing guidance for becoming dementia-friendly. Three respondents who were working within NGOs described their role in developing DFCs as focused primarily on providing community-based support services and projects which offer opportunities for involvement and inclusion for people who are living with dementia.

### Factors

Awareness was cited most frequently as a crucial factor in successfully developing DFCs (n=3 -2%). This was particularly related to awareness of the needs of people living with dementia, and their families, in relation to the community adaptations that contribute to DFCs.

*“Increase awareness and understanding, support and promote social inclusion.”*

*“Greater understanding/knowledge of dementia and what it takes to become a dementia-friendly community.”*

One response also highlighted the importance of working partnerships, which was focused on the coordination of existing services to enable joint implementation of initiatives. Another response emphasised the need to ensure that people living with dementia are empowered and supported to have a public voice, which can also provide opportunities for meaningful social inclusion.

*“Most importantly give a voice to people with dementia and their carers so their needs can be fully recognised and the appropriate support offered.”*

## **OTHERS (n=11 - 6%)**

### Organisation’s role in developing DFCs

Eleven respondents, all of whom completed the English-language survey, did not indicate the name of their organisation or geographical location. For this reason, it was not possible to identify the role of their organisations in developing DFCs.

In many responses, it seemed likely that the respondents were living/working within the UK, although it was not possible to verify where in the UK they were working towards the development of DFCs.

### Respondent’s role in developing DFCs

Six respondents (3%) were providing health and/or social care services and activities for people living with dementia and their families. Activities focused on engaging with various groups in the communities, including one intergenerational activity groups. Three of these respondents were also delivering internal training programmes for health and social care staff.

*“We have become part of a health and well-being initiative in the community and have a dedicated room in a hub for people of nursery age up to currently one person aged 102!”*

One respondent was not working towards developing DFCs but described their personal experience of a friend who had dementia. Another respondent described their main work in developing DFCs as influencing organisations to develop dementia-friendly webpages to promote and stimulate interaction and communication with people who are living with dementia and their families.

### Factors

The importance of raising awareness of what it means to live with dementia was highlighted in four responses, suggesting the use of campaigns to foster understanding and a supportive culture towards people who are living with dementia.

*“A better understanding of what dementia is...Strategies to help the everyday individual to be able to notice if someone may have dementia and how best to support them.”*



Three responses (2%) indicated the importance of ensuring genuine community involvement in DFC initiatives. It was suggested that communities can become intrinsically involved through intergenerational projects, as these facilitate opportunities for interactions between various community groups, while also improving attitudes and understanding about dementia from an earlier age.

*“Getting the community on board is really important I think, from an early age, so that people can show kindness and give practical support where needed.”*

Four responses (3%) also described the importance of providing sufficient resources to deliver effective care and support within communities. Responses suggested that support services, including those for family carers, can enable people with dementia to live longer in their own homes and to stay active in their communities. One response particularly emphasised the need for early diagnoses, and prompt post-diagnostic support, as a crucial factor in enabling the involvement of people with dementia in developing DFCs.

*“Availability of funding and resources, availability of appropriate services and support.”*

Improvements in care and support for people living with dementia can be brought about with the provision of practical guidance for groups within communities (e.g. care sector), particularly around how to effectively and supportively communicate with people who are living with dementia.

**Living well with dementia in the community**  
**Mapping ‘dementia-friendly communities’ in Europe**  
**Online questionnaire**

**If you require this survey in another language, please request a translation from [kjenkins@mentalhealth.org.uk](mailto:kjenkins@mentalhealth.org.uk)**

EFID, the European Foundations Initiative on Dementia, is undertaking an analysis of concepts and practices of ‘**dementia-friendly communities**’ and similar initiatives in Europe. The work will be undertaken by Mental Health Foundation, the leading UK charity working in mental health, dementia and learning disabilities. For more information please go to our website: [www.mentalhealth.org.uk](http://www.mentalhealth.org.uk)

We are seeking the views and experiences of individuals and organisations across Europe regarding ‘dementia-friendly communities’ and similar initiatives. The views collected in this brief survey will inform the development of practical information, guidance and examples to support good practice and to encourage the development of ‘dementia-friendly communities’ and similar initiatives across Europe.

**A note on terminology:** The term ‘dementia-friendly community’ may include projects and programmes which use other terms such as ‘memory friendly communities’, ‘dementia supportive’ or ‘dementia capable communities’ and those which ‘enable people with dementia to live well in

their community'. We are mainly interested in initiatives which go beyond health and social care and which help to integrate and involve people with dementia in their natural community.

The information given in this survey will be stored confidentially and will be anonymised. You are free to withdraw from participating in this survey at any time. Please contact Katrina Jenkins by email: [kjenkins@mentalhealth.org.uk](mailto:kjenkins@mentalhealth.org.uk) or telephone: + 44 (0)207 803 1130 for more information or for any queries about this survey.

If you are happy to take part in this brief survey, please click 'next'.

1. What is the name of your organisation (if applicable)?
2. Please briefly describe the work of your organisation
3. Please could you give a brief definition of a 'dementia-friendly community' or a community that enables people with dementia to live well? (max. 250 words)
4. Please briefly describe the type of work you are doing to help communities become more dementia-friendly or similar initiatives (max. 250 words).
5. From your experience, are there specific requirements or factors which influence how communities can become dementia-friendly or that enable people to live well with dementia (max. 250 words)?
6. Would you be willing to take part in a telephone interview about 'dementia-friendly communities' or similar initiatives?  
 Yes  
 No

If yes:

7. If you are willing to take part in an interview, will an interpreter be required?  
 Yes  
 No

If yes:

8. If you are happy to take part in a telephone interview, please provide your name and contact details (Email/phone).

**If you have literature or webpages about the work you do with 'dementia-friendly communities' or similar initiatives, we would be grateful if you could send the information to [kjenkins@mentalhealth.org.uk](mailto:kjenkins@mentalhealth.org.uk)**

Thank you for taking the time to complete this survey. Please pass the survey on to others you think may be interested in responding with their views.

## **Appendix B**

### **Thematic analysis of the telephone interviews**

#### **1. Participants**

Seventeen telephone interviews were conducted. Interviewees were selected via the online survey and as advised by the EFID Steering Committee. The aim was to interview a cross-section of individuals from different European countries who were involved in developing 'dementia-friendly communities'. A long list of over 40 possible potential interviewees from key organisations or who had indicated they were willing to be interviewed was discussed by the Steering Committee who then advised the Mental Health Foundation on who to prioritise. Interviewees were selected also to ensure a geographical spread across Europe and who represented different levels of involvement with 'dementia-friendly communities'; from individuals with national policy and strategic overviews through to people actively involved at a local level. The breakdown of nationalities of interviewees is as follows:

England - 3  
Germany - 3  
Belgium - 2  
Netherlands - 2  
Ireland – 2  
UK-wide - 2  
France - 1  
Italy - 1  
Scotland – 1

#### **2. Methodology**

Interviews were semi-structured with a topic guide (see Section 9 – Interview Schedule). All interviews were carried out in English except for one where a translator was used for a German-speaking interviewee. Interviews were transcribed and analysed thematically according to the following themes:

- Common themes emerging in relation to both conceptual understandings and practice in the development of DFCs;
- Any significant outliers to these themes;
- Significant supporting or conflicting evidence in relation to the following themes (identified through the online survey as important factors in the development of DFCs):
  - Raising awareness about dementia, providing information, education and training
  - Inclusion of people with dementia; involvement, participation, influencing
  - Building partnerships, networks, collaborations (locally and nationally)
  - Resources – financial, human, 'in kind'
  - Other factors e.g. adapting the physical environment, service provision

Some of the themes were broken down into sub-themes. Data was validated by reviewing the primary and secondary categorisations and any differences were resolved. Through this process some of the broad themes such as 'human resources' were broken down to highlight the prominence given to the role of volunteers, for example.

### 3. Definitions

In order to understand the cultural nuances involved in exploring this aspect of Pan-European social policy, and to understand the national contexts in which they operate, we asked our respondents to explain their own understanding of the key concepts of community, dementia and 'dementia-friendly communities'.

#### **“Community”**

Respondents discussed how the concept of community is defined within their culture. For some the term refers primarily to a geographical community within a nation state, although this ranged from a street, a block of flats, a council ward or a village. Others focused on communities of interest that unite around faith, the arts or sports, while a couple of respondents noted the increasing importance of online social networking or virtual communities. Community could also mean a community of identity, such as an ethnic minority. In this respect it is important to note the caveat that within this discussion, for some respondents, the term 'community' held some confusion due to its translation into the native language of their nation state. For example, one respondent noted that,

*“In France “community” has always the sense of, for instance, ethnic minority and so on. So sometimes it’s not clear...”*

Nevertheless there was a consensus that, whether geographic, interest or virtual, that the smaller a community, the more effective it is likely to be; therefore towns or cities, by this reckoning, cannot be considered communities. This simple typology of generic communities framed subsequent responses about what is meant by 'dementia-friendly communities'.

*“I live in the neighbourhood and I have loads of communities which are around the different things that I do and that I am interested in, you know. Friendship, particular places that I go and do things with other people, I am a musician so I have a whole musician community around gigs and things, I don’t think of communities being a single entity.”*

#### **“Dementia”**

Some respondents suggested that their discussion of 'dementia-friendly communities' (DFCs) could only be understood within the context of the cultural construction of dementia. These respondents talked about local discourses where competing claims were played out; on one hand, the medical domain – with attendant professional priorities of research, diagnostics and treatments – and on the other hand, the social care domain - where the day-to-day support needs of people with dementia and their carers take precedence. One respondent described how this discourse played out in his/her own country;

*“People want to know about the illness and, you know, like they do about any impairment or any medical condition, you see it as a medical condition rather than their disability, I think that really gets in the way of being able to look beyond that and almost humanising dementia.”*

This debate presented some respondents with a strategic and tactical dilemma with regard to DFCs: are DFCs to be regarded as the logical outcome of a broader ‘humanising’ process, or do DFCs in themselves serve to humanise dementia to the general public?

### **“Dementia-friendly community”**

Like the term community, ‘dementia-friendly community’ (DFC) meant different things to different respondents and it was defined in different ways. Many felt that DFCs were based within a geographical location, such as a street or village where all the shops, services and local population worked together to make things accessible. Some respondents felt that successful DFCs were based upon people, those with dementia and those without the condition, working together on the back of a shared interest, such as golf or music, while a few respondents mentioned that DFCs are arising online, as more and more people with dementia use forums to communicate with each other.

As with community, DFCs were seen as small scale: respondents agreed that ideas of DFCs being a whole town or city as proposed by some politicians and leaders was not possible and would not work. Respondents were also clear that whether geographic, interest or virtual, DFCs tend to have unique characteristics meaning that they will differ from location to location. In policy terms, it is not possible to have a ‘one size fits all’ approach.

There was a great deal of discussion as to what the term DFC actually meant in each nation state and whether it is a useful term. Respondents’ views on meaning differed depending on nation and their role within the dementia field, although it was possible to discern a common set of aspirations for an ‘ideal’ DFC, which was summed up in two contributions:

*“One where people with dementia are empowered to have high expectations, feel confident know they can contribute, participate in activities that are meaningful to them.”*

*“It is also one of our objectives to have the people with dementia in the centre of the society, not on the margin.”(Translated)*

A number of respondents felt the term DFC was useful because it’s shared understood is sufficiently wide for everyone to be working towards the same goal. This respondent bemoaned the confusion caused by attempts to avoid the term dementia:

*“I don’t understand why they use different names ‘cos it just is confusing [stressed] for people, ordinary people, affected by the dementia. They say, “why do we have all these funny names?” And I sometimes think the names are given to be politically correct. I may be wrong on that but ... I mean a memory friendly neighbourhood [laughs] ... and I do work for these people, y’know, I’m actually on their panel and all sort of things. But to me dementia-friendly, everyone has now known what dementia-friendly is, so let’s stick to it.”*

However, this point of view was countered by another respondent who felt that linking the terms dementia and community ran contrary to a more general principle of inclusiveness:

*“I think I have re-interpreted it as an inclusive neighbourhoods and communities but I think the term dementia friendliness is unhelpful for a number of reasons, 1) it separates off dementia as a disease and focuses on the disease, the illness, all the awareness in everything around friendliness is trying to, is basically focussed on that one aspect of somebody, of people rather than any other traits that they might have that also exclude them or might help include them.”*

The use of symbols to identify DFCs was regarded as useful by many respondents. However, one respondent felt that these were unhelpful, because there are too many in different parts of the country; furthermore they hoped that DFCs becoming normalised in society would make symbols redundant.

Some respondents felt that ‘dementia-friendly community’ was not helpful in achieving the goal implied by the term. These individuals suggested other terms such as inclusive community and age-friendly community, amongst others, reflecting more of a rights-based or equality perspective.

*“But the dementia-friendly community is, you know, takes that a whole step further, where ... y’know it’s a place where **dementia** itself is understood, perhaps and ... where people with the condition are treated with respect and are supported, to enable them to continue to live amongst their friends and their family, and ... the things and the facilities that they know well, for as long as it’s possible for them to do so.”*

#### **4. Barriers and challenges to creating DFCs**

Respondents gave their views about the principal barriers to creating DFCs that exist within their respective nations.

##### **Stigma**

The most widely cited barrier facing DFCs, and the one rated as the biggest single barrier, was the stigma and an associated lack of awareness amongst the public towards dementia and the reality of living with dementia. Several spoke about how fear of dementia, and ignorance about the daily lives of people living with the condition, made it difficult to foster a culture of inclusiveness in communities.

*“You know there is stigma ... out there in relation to dementia. People have an idea of what dementia is and there may be a fear of dementia ... and I suppose, you know, we’ve heard that said many, many times. So I suppose ... some of the barriers really are, y’know, a lack of understanding of dementia.”*

##### **Resources**

The lack of resources available to set up and sustain DFCs was a widely cited barrier, in particular the funding and the human resources available to provide services. In addition, respondents spoke about the demands placed upon those leading DFC initiatives, to be constantly applying or fighting for

funding, which diverted them from their core business of improving lives. Others spoke of an inability to secure community resources for the benefit people with dementia reflecting, perhaps, a low political profile for this group. Allied to this was the problem of identifying key people – local champions, social entrepreneurs and so on – with an interest in this aspect of social care who could lead the development of DFCs. Several mentioned that a reliance on volunteers, and while volunteers were very welcome, it invariably meant that DFCs were only as good as the skills sets available.

*“While we have the **expertise**, we don’t have the funding and we don’t have the ... the authority to make change.”*

*“It’s mostly ... a problem of availability of people willing to go to speak, to meet, and ... than to have money. You know.”*

## **Governance and policy**

The attitude of national governments towards DFCs was seen either as a barrier or as a potential barrier, especially where a political consensus had not been reached about the desirability of DFCs; indeed, the future of some DFCs was tied to the outcome of the next election.

*“So at the moment dementia is very high on the political spectrum, but come you know next election, a different government, you know, that might not be the case.”*

Contradictory and competing national policies, and a lack of national government guidance about DFCs, were also cited as constraining factors.

*“In the Netherlands it’s difficult because they don’t want to ... focus on one ... specific group of people.”*

*“In Italy we don’t have a government dementia agenda. The association of family association are very weak, you know. In Italy we don’t ... have all these structures.”*

## **Health and social care services**

The health and social care services available within an area, how they are commissioned and the focus of those running those services, was seen as a challenge to establishing successful DFCs. Of particular concern was a tendency in some countries for health and social care services to operate in parallel to DFCs. Some interviewees resisted separating out health and social care activities from ‘dementia-friendly community’ activities:

*Dementia-friendly community should be on two levels. The first is the public and professional services, that means the healthcare services, the doctors, the care service...counselling...day care and so on...the other level is that of civil society for these [banks, sports or music clubs, associations] supermarkets, police and so on should have a certain knowledge about people with dementia and...know how to communicate...and treat them with respect.*

## Physical Environment

The physical environment in which a DFC was based was seen as a barrier to its success, with the inaccessibility of buildings and transport being a common concern. Some respondents went on to describe how they are tackling these issues:

*“We’ve asked people with dementia to go into businesses ... everything from a local garden centre that wanted to know how it could improve what it was, you know, doing to help people with dementia, and encourage them to come to shop with them, and to use their café and so on. But we arranged for not just one but a number of couples to go visit and report back. We’ve done the same in ... we’ve done mystery shopping exercises in banks and building societies.”*

*“So, physical and social environments are crucial factors in that: how elderly [people] can stay healthy for a long period and stay independent and live ... in any independent way.”*

## People with dementia, their families and other carers

Some respondents mentioned how people with dementia, their families and carers were also a barrier to successful DFCs being created. While this related to some extent to the fear that people with dementia and their families might have to face stigmatising attitudes and discrimination by being involved in DFC initiatives, respondents also suggested that families in particular were often reluctant to take on the role of activist or leader because of the time and energy that it might entail. Moreover, getting people involved in the early stages post-diagnosis was seen as particularly difficult.

*“I think there are quite a few challenges. I think one of fundamental ones is actually ... ascertaining from people with dementia what they would like. I think ... because it’s still a massive stigma ... I think people are still, many people are still in the frame of just understanding what their dementia is, let alone thinking about what that means in the context of their own kind of day to day lives.”*

*“So we’ve found that, even with the working group, is that ... y’know it can be a slow process first to get people ... because when they’re being diagnosed sometimes they don’t want to come near an organisation, d’you know, or be involved.”*

## 5. Tackling the barriers and challenges

As well as highlighting the barriers/challenges, all respondents talked about how work was being done in each of their nation states to overcome them.

### Training, education and awareness-raising

Educating those within the wider community about dementia was discussed by many respondents. This work is being done in schools, providing training to those working within services, and by going into businesses, services or community buildings to look at how it can be made more accessible. In many cases people with dementia are involved in conducting this training. There was a very strong



consensus that this direct, personal approach is the most effective way of challenging stigma and raising awareness about the condition amongst the general population:

*“So every time a person with dementia gets up on their hind legs and says, I think X, Y and Z, then a little bit of that stigma gets knocked away. People start to think differently. And again **ultimately** dementia-friendly communities have got most chance of happening where we can develop a new narrative about dementia, which is not just about decay and decline and despair, but ... which actually contains a very real message and a very real hope and aspiration to live well... You learn more when you have, y’know ... people with dementia, for example, who are delivering dementia friends sessions. That’s an **incredibly** powerful way of ... breaking down stigma at a local level..., it also gives ... hope potentially to people who might be about to get a diagnosis or have recently had a diagnosis. You’re seeing people with dementia being active citizens. It’s a really, really powerful way of again ... of ... giving energy to and sustaining that kind of resilience that people with dementia need to stay connected.”*

### **Collaborative working, joint working, and networks**

Collaboration, working jointly and networking were regarded by respondents as vital components to any strategy for tackling stigma and building the capacity of local communities to welcome and support people with dementia. In practice, this means not simply working with community services, local businesses, official agencies such as the police, GPs and council employees, but recruiting them as positive actors in the process:

*“It is in the community where citizens, politicians, and other local actors can identify networks of contacts and support as well as create new ones. They have to partially re-invent their communities to effect actual positive change for people with dementia. Both shared reflection and direct local action are prerequisites for building a dementia-friendly community.”*

*“It is important that it is not just some isolated project in a sense of community, but networks, roundtables....where people get together to take different initiatives in the community.”*

### **Human resources**

Many respondents spoke of the need to optimise existing resources within local populations, as a way of addressing the financial constraints common to many DFC programmes. Some argued that the real challenge is less in finding people from a geographical area to work with, and more in engaging those people in the right way; for example and perhaps especially, by appealing to a persons’ shared interests with someone with dementia. Others spoke about tapping into volunteers attached to existing services or groups, or utilising established community spaces such as schools and cafes.

*“You don’t have, or you don’t need resources in from financial and from money, but you need a lot of people who are willing to work.”*

*“There are some lovely volunteer programmes around where rather than you match people up as volunteers because they want to look after people with dementia, you match people up because of a love of sport, or they have a love of music or theatre whatever, or reading, they can connect with people with dementia because they represent something, a connection or an interest and there is an organisation called Sporting Memories Network.”*

*“[Its] not particularly to do with monetary resources ... but human resources ... yes. Because there’s such a lot of pressure on people’s time now, this ... you know the most successful of the dementia-friendly communities that we’ve been involved with here in [a region] have been the ones where it has been, if you like, volunteer-driven. I mean people have actually come forward and wanted to do this, and knock on doors in their own community, go visiting the shops in their high [main] street...”*

The involvement of people with dementia and their families and carers was cited as the most effective way of tackling stigma and poor awareness about dementia.

*“These are people that are living, and their families, are on this journey: they’re the experts.”*

One respondent noted that people with dementia can sometimes utilise skills from a past trade or profession, for specific tasks, such as training professionals.

## **Resilience**

Another facet of the human resources to be deployed, in order to meet the challenges and to overcome the barriers to DFCs, was the resilience of those involved. This was described in a number of ways; making sure the voice of people with dementia is heard (“shouting loudly”), not ‘taking their eye off the ball’, and not being deterred by set-backs.

*“I think you have to ... act stubborn [laughs] and keep going on ... with developing dementia-friendly communities.”*

*“We have to drive [stressed] forward relentlessly and not take the knock-backs in, you know, in a negative way. We’ve just simply got to have a ... our eye on the prize.”*

*“So you know we know what we want, but getting it is so hard...”*

## 6. The governance of DFCs

Respondents discussed what the role of government and statutory organisations should be within DFCs.

### National Government

Respondents felt that national governments, within nation states, were responsible for setting national standards, writing legislation and guidance for the DFCs to follow. All agreed that governments, as well as national dementia organisations, should provide support to DFCs by providing information, knowledge and inspiration.

*“I personally think the role of national organisations and government agencies should be about ... inspiring, sharing good practice, or inspiration practice. Yes, definitely about disseminating knowledge.”*

*“So there are strong responsibilities for the state side...but the state can’t do everything, I think this is the idea of civil society, everybody should do something.”*

The nuance to this discussion was in finding the right balance between governmental direction and support for local variation. Some respondents reported that their national government had not issued legislation or guidance, which made it difficult to legitimise the creation of DFCs, yet others found too much guidance was equally unhelpful. All respondents, except one, felt that ‘top-down’ efforts needed to be matched with ‘bottom-up’ approaches, led by communities themselves and that people with dementia be involved at both ends of the spectrum.

### Local authorities and statutory services

Local authorities sit naturally between national government and local communities. All respondents felt that the role of local authorities was to administer national legislation, policy and guidance within their area of responsibility, although this was more important to some respondents than others. The degree to which local authorities were deemed able to identify and address the local needs of people with dementia through statutory services varied, as was their ability to influence local infrastructure and resources to promote DFCs.

The role of health and social care services were seen by many respondents as conflicting with the needs of people with dementia and DFCs. They are run from a service perspective, not from a person perspective. However, many respondents suggested that the path for many people with dementia will lead to them needing such services, at some point, and therefore working with them was important. Personal choice of services was also important to people.

*“Local authorities in particular should be operating in order to support DFC at a local level. One of them is as ... commissioners of services, in terms of setting service specifications. So you know when the local authority are commissioning services ... what level of accessibility they’re asking for, from the people from whom they ... from the service providers. There’s also the issue of what local authorities do with their **own** services – not just the dementia specific services,*

*but the whole range of other local authority services that impact on all of us. Because if there are local authority services [that] impact on citizens within their area, then they're important to people with dementia as well."*

## **7. What makes a good DFC?**

All of our respondents were able to describe what a good DFC looks like, even where the ideal had not been achieved within their country. All placed a premium on having people with dementia involved from the outset and throughout the lifespan of anything that is done to develop and sustain a DFC. While most respondents were careful not to be prescriptive in their observations, reminding us that DFCs are unique to their particular set of circumstances, their testimony reflected a preference for leadership and governance, grounded in a philosophy of inclusiveness and participation.

*"Developing dementia-friendly communities should be a joint effort undertaken by what is called civil society. The identified measures ("setting-standards"; "disseminating knowledge") suggest that building dementia-friendly communities is something which can be achieved top down and by applying technical and rather abstract ("scientific") procedures. In our understanding, building DFCs should be considered as a bottom-up, discursive and participatory process, one of exchange and negotiation, a process in which the social resources of the live world are being appreciated and handled with great care."*

In conjunction with good local governance it was suggested that DFCs work best where they build on, and contribute to, existing community capacity. Interestingly, there were few references to financial resources at this point in respondents' narratives, which instead focused on the importance of 'working with the grain' of the resources already available (financial, human, services or 'in kind'), thus avoiding duplication and waste. There was a sense that the ideal DFC is one where community rather than dementia is the defining feature.

*"Reflecting on the two years of our project, since we became involved, we have found the community so embracing, so interested, so committed. And that's from our schools tour, supermarkets tour, shopping centres tour, clubs ... any place that we've had communication with. We haven't found any of them that just did not want to participate, in 99.9% of the way."*

## **8. The future of DFC's**

In the final part of the interview, the respondent was invited to reflect upon the value of DFCs, the threats to their further development, and to suggest requirements to sustain DFCs in the future.

Unsurprisingly respondents were overwhelmingly positive about the value of promoting DFCs. This stemmed not just from a rights and equalities perspective, but also recognition that the process of building the capacity of communities to be inclusive is a social good in itself. The economic benefits of DFCs were not explored but were implied by several respondents.

Nevertheless, some respondents expressed concern at the vulnerability of DFCs, especially in those countries where the underpinnings of capacity building had not yet been achieved. They articulated a

paradox; that the very measure of success – the mobilisation of existing community resources to support people with dementia – might be used by governments and statutory bodies to withdraw dedicated funding to develop and sustain further DFCs. For some there was a more fundamental fear that the real and enduring value of DFCs had not been recognised by decision-makers.

*“If people think that a dementia-friendly community is just something fluffy and nice and will make things a bit better for people, we don’t need to do anything else, then I think that is a real danger, a drawback. But if it’s seen as one part of a jigsaw, one important part, so a part of a bigger jigsaw, then I think that’s how it should be viewed really.”*

## 8.1. A manifesto for sustainable DFCs

We have summarised our respondents’ thoughts on the priorities for establishing sustainable DFCs in Europe.

Invest in development. Provide seed funding to reduce the time and energy spent on pursuing piecemeal funding, and create a pool of people skilled in the promotion of DFCs to reduce the reliance on volunteers.

Training, education and awareness-raising. Sponsor training and education, beginning in schools, to raise awareness about how people live with dementia, reduce stigma and encourage individuals and groups to make connections with people with dementia.

Involve people with dementia, families and carers. The experiences and expertise of people with dementia, their families and carers should be at the heart of all future developments around DFCs, including legislation and policy.

Disseminate resources. Share knowledge about what works and resources to support good practice, making better use of social media to achieve this.

Encourage collaboration and networking. Help local actors, including statutory services, to work collaboratively within their communities to avoid duplication and waste of effort. Facilitate peer mentoring and networking, so that the people can learn from one another about how best to create DFCs and how to solve problems as they arise.

*“Networking is key. I mean that ... absolutely it’s networking, you know learning who your stakeholders are, learning who your people with dementia, carers, people affected by dementia, and moving that ripple, you know, the pond, the stone in the pond, moving that networking ripple out more and more to get into government, into ... obviously you know ... to get to know all the people. So ... it can start very small.”*

## 9. Interview schedule

**Interview schedule: An analysis of concepts and practices in ‘dementia-friendly communities’ across Europe.**

- *Permission to record (yes/no)*
- *Anonymity (Would you be happy for the service/project to be listed in the report?)*

**1. What are your views about the term ‘dementia-friendly community’?**

- i. How would you define a DFC?

**2. What are the main barriers to developing ‘dementia-friendly communities’?**

- i. Have you had difficulties with defining ‘community’?
- ii. With resources?
- iii. How have you responded to these challenges? Solutions?

**3. What is the role of government agencies or national organisations in developing ‘dementia-friendly communities’? (e.g. setting standards; disseminating knowledge; funding?)**

**4. What is the role of local, community-led initiatives in developing DFCs and similar initiatives?**

**5. What is the role of people who are living with dementia in developing DFCs?**

**6. What are your views on having national standards for ‘dementia-friendly communities’ (e.g. adopting a ‘kite mark’ symbol)?**

- i. How could DFC standards and progress be measured effectively? What are the hallmarks of a successful ‘dementia-friendly community’?

**7. Do you feel there are any drawbacks to developing DFCs?**

- i. Do you think DFCs may begin to act as a substitute for state-provided services?

**8. What advice would you give to individuals/organisations who are working towards developing a ‘dementia-friendly community’?**

**9. Is there anything else you’d like to add?**

# Appendix C

## Literature review

### Introduction

This review identified a number of processes and practices in ‘dementia-friendly communities’ (DFCs) across Europe. A wide range of local, regional and national initiatives, projects and programmes were highlighted, which contributed to DFCs, in a number of different countries. These offered insights into the variety of features inherent within DFCs. It was evident that there are a number of benefits that can be derived from the development of DFCs, and not solely for community members who are living with dementia. All members of a community stand to benefit from a cultural, social and political environment which supports and values the involvement of each member of the community, including those who are living with dementia.

The literature relating to ‘memory-friendly’ and ‘age-friendly’ communities often focused on aspects of daily living that can be made difficult with the onset of cognitive problems. For this reason, a brief section to describe and illustrate memory friendly communities was also included in this review.

The review was carried out in 2014 but all the URL links were checked in December 2015.

### Methods

This review of the literature firstly identified the European nations that have a national dementia strategy or programme, with the aim of highlighting those that referred to ‘dementia-friendly communities’ within the strategy. National dementia strategies were also of interest where they focused on key pre-requisites, which enable the development of DFCs, such as recognising the importance of involving people who are living with dementia at the centre of discussions and decisions. This part of the review provided a cultural and political backdrop within which existing DFCs have emerged.

National programmes to promote DFCs were also identified, indicating the extent to which existing ‘dementia-friendly communities’ employed a top-down approach to development. National programmes also offered insight into the extensive networks that can facilitate the development of ‘dementia-friendly communities’. Literature related to national DFC programmes also highlighted a range of local ‘dementia-friendly communities’ across Europe. There was considerable variation in the areas of focus and methods employed in developing these communities, which were influenced by a number of local factors.

Stakeholders in this project were invited to suggest key publications from outside of the UK, with the aim of obtaining an accurate account of ‘dementia-friendly community’ initiatives across Europe. These formed the base of the literature review and informed the various search terms that were used.

Online literature searches to identify evidence of ‘dementia-friendly communities’ were carried out in a number of languages. Because of limitations of time and resources, and the need to do the search in different European languages this was limited to Google and Google Translate. Academic search engines were not used because of the large number of countries that the review covered and the

limitations on time. For this reason, search terms were limited to no more than three for each language. The search terms used included:

Czech

- Demence přátelské komunity

Danish

- Demens venlige samfund

Dutch:

- Dementievriendelijke gemeenschappen/omgevingen/gemeenten

English:

- Dementia friendly communities/community
- Memory-friendly communities/community
- Age-friendly cities/communities

Finnish

- Dementia ystävällinen yhteisöt

French:

- La démence collectivités amicales
- Communautés amicale de démence
- Bien vivre avec la démence en communauté

German:

- Demenzfreundlichen Gemeinden/Gemeinschaften

Italian:

- Comunità amichevoli demenza
- Demenza comunità

Norwegian

- Demensvennligelokalsamfunn

Portuguese

- Comunidades amigas a demência

Spanish:

- Comunidades amigas de demencia
- Demencia comunidades amigables



## Swedish

- Demensvänliga samhällen

### **Some general definitions**

'dementia-friendly communities' (DFCs) emerged out of developments that emphasise the rights of individuals who are living with dementia, with the aim of ensuring that they are supported to maintain active and fulfilling lives within their communities. Kirche (2010) observed that any society requires some adaptations and negotiations between individuals and groups—in DFCs, these same principles are applied equally to members of the community who are living with dementia, both as individuals like people without dementia, but also as a group with particular characteristics.

An individual living with dementia defined DFCs as:

*“An integrated society where people with dementia live in ‘normal’ home-like situations throughout their lives with support to engage in everyday community activities.” (Mitchell, 2012)*

A core aim of DFCs is that people living with dementia should be able to enjoy full social inclusion and that this should be a cultural norm, rather than as an exception. To achieve this aim, DFCs inspire individuals and organisations to develop their own creative ideas and tailor-made solutions to promote a better quality of life for citizens in the community who are living with dementia ([http://www.zukunft-pflegen.info/pflegezukunft/uploads/media/Abstract\\_Rothe.pdf](http://www.zukunft-pflegen.info/pflegezukunft/uploads/media/Abstract_Rothe.pdf)).

DFCs often differ in their specific areas of focus, design and implementation but are generally underpinned by an ethos of social inclusion and community involvement. These aims can be achieved in a variety of ways, for example, through changes to the physical environment, raising awareness and implementing local schemes (e.g. Crampton and Eley, 2013). A consistent aspect of DFCs is that people living with dementia are at the heart of all community developments and changes (Innovations in Dementia, 2012; Alzheimer's Society, 2013a; Dementia Services Development Centre, 2013; <http://theprotocity.com/bruges-dementia-friendly-city/>).

By promoting the values inherent within DFCs, people living with dementia reported feeling empowered, confident and emboldened with a sense that they can contribute and participate (Alzheimer's Society, 2013a). In addition, by ensuring community involvement, stigma and the associated taboos that have long shrouded the experience of living with dementia can be more rapidly dispelled; instead, promoting habits of friendship and interaction throughout the community (Alzheimer Nederland, 2013; <http://www.alzheimer-nederland.nl/media/19428/Herkennen%20en%20omgaan%20met%20dementie%20-%20Dementie%20vriendelijk%20oktober%202013.pdf>).

Several organisations have identified specific criteria for DFCs. These include the Joseph Rowntree Foundation (JRF) and the Alzheimer's Society in England. These are described in more detail below, in the section dealing with national 'dementia-friendly community' programmes.

Providing support with activities of day-to-day living can strengthen the development of DFCs, for example, by offering support with shopping or using public transport; enabling social opportunities to share skills and enjoy meaningful social engagement; or by working with community members to raise awareness of dementia and of the benefits of DFCs (Alzheimer's Society, 2013a). Through raising awareness and promoting dialogue about dementia, communities can become more accessible and connected ([Alzheimer's Society, 2013a; http://theprotocity.com/bruges-dementia-friendly-city/](http://theprotocity.com/bruges-dementia-friendly-city/)).

By making changes in the way that dementia is understood, and how people with dementia are supported and included in society, communities can develop a culture and environment which is conducive to a flourishing DFC. These changes also promote respect and consideration for the needs of people in the community who are living with dementia (Alzheimer's Society, 2013a; Innovations in Dementia & the Alzheimer Society of Ireland, 2012). Initiatives to promote DFCs provide an important cultural service and have a significant humanitarian value, both for people living with dementia and for community members who are not directly affected by dementia, since DFCs can alleviate much of the social and financial costs of living with dementia (Gronemeyer and Rothe, 2012).

The economic argument for DFCs appears robust with the Alzheimer's Society (2013a) estimating that savings of £11,296 per year per person diagnosed with dementia can be made in health and social care costs, by supporting people with dementia to remain living in their own home for longer. By delaying a move to residential services for 5% of people living with dementia in the UK, an annual saving of £55 million, in health, social care and housing costs, could be achieved across England, Wales and Northern Ireland.

## **Terminology**

### Dementia-friendly

The term 'dementia-friendly' was primarily used in this review because it is the term most commonly used in the English-language literature to describe initiatives and programmes that support people who are living with dementia to maintain a good quality of life. However, a range of other terms were also identified throughout the literature, such as 'dementia supportive' and 'dementia capable'.

'Age-friendly' and 'memory-friendly' were also commonly used terms. The term 'age-friendly' refers to a movement to develop communities that promote a good quality of life for all older people. 'Memory friendly communities' was also a commonly used term and was often used to refer to communities that enable a good quality of life for people who have cognitive problems, including people who are living with dementia.

Depending on the locality of the DFCs identified in this review, terminology varied and it was not always appropriate to use a direct translation of the term 'dementia-friendly' when carrying out searches for DFCs in some European countries.

For instance, initiatives and projects which support the development of DFCs in France were generally referred to as projects that promote "living well with dementia in the community" or "bien vivre avec la démence en communauté". Similarly, Dutch-language literature differed slightly in terminology, depending on whether the literature was developed in the Netherlands or Belgium. Flemish literature related to DFCs tended to use the term "dementievriendelijke omgevingen", while literature from the

Netherlands leaned more towards use of the term “dementievriendelijke gemeenten”. These linguistic differences were accounted for in the search terms used for this review.

### Community

The term ‘community’ can be used to describe a variety of population groups, such as ethnic minority groups or LGBT communities. However, for the purposes of this review, the term ‘community’ was considered to denote geographically defined areas, such as villages, town or a local government area. Some DFCs focused on ensuring the inclusion of community groups that were not defined by geographical locality but by common experience, such as supporting the inclusion of individuals from ethnic minority groups who are living with dementia. However these DFC initiatives were inherently located within specific geographical areas and were therefore included in the review.

### ‘Dementia-friendly communities’ (DFCs)

This review identified a wide range of projects, initiatives and programmes described as ‘dementia-friendly’. However, some of the literature related primarily to dementia-friendly adaptations for use, for example, in health and social care service provision or in private residences. Others described projects or community activities, which were designed specifically for people living with dementia, that were separate from the rest of the community, such as a dementia-specific bingo group.

The benefits derived from these projects was evident, however there was a need to limit the scope of this review to initiatives and projects, within mainstream community settings, that contribute to creating ‘dementia-friendly communities’. Descriptions of dementia-friendly projects and initiatives were considered relevant to this review only where they related to, or promoted, the rights and full participation of people living with dementia, in any aspect of ‘normal’ community life, such as social involvement, political influence and day-to-day autonomy.

### Assistive technology

There has been extensive development in new technologies and product design to support people living with dementia to maintain independent lives. These technologies are often referred to in the UK as ‘assistive technology’; some of these technologies were described as ‘dementia-friendly technologies’. This review recognised a role for assistive technologies in enabling DFCs, but it was beyond the scope of this review to undertake an extensive exploration of developments in ‘assistive technology’. Literature was of interest for this review where it provided evidence for the promotion of ‘community’ aspects within ‘dementia-friendly communities’, so literature was excluded where there was no reference or clear emphasis to how the activity or product linked with the aim of developing a DFC. For instance, several articles that cited evidence of assistive technology were included in this review where they supported the continued social engagement and community participation of people who are living with dementia.

## **Europe-wide evidence of ‘dementia-friendly communities’**

Although there have been European Union initiatives on dementia, these have focused mainly on research, improving diagnosis rates and care and support, however this review identified no references to DFCs. In July 2009, the European Commission adopted the ‘Communication from the Commission to the European Parliament and the Council on a European initiative on Alzheimer’s

disease and other dementias' (COM (2009) 380/4). This communication highlights the support from the EU to member states in national efforts in areas of prevention, including: measures to promote mental well-being; support early diagnosis; coordinating research across Europe; promoting best practice for treatment and care; and developing a common approach to ethical issues such as rights, autonomy and dignity of individuals with dementia.

In February of 2009, The European Parliament adopted the 'Written Declaration 80/2008' on the priorities in the fight against Alzheimer's disease, in which members of the European Parliament called on the European Commission and the Member States to recognise Alzheimer's disease as a European public health priority and to develop a European Action Plan. However, to date, no such plan has been produced.

In 2011, the European Parliament adopted a motion for a resolution on a European initiative to combat Alzheimer's disease and other neurodegenerative diseases. This called member states to: make dementia a priority; raise awareness about dementia across the EU; increase cooperation between countries in relation to research, care and prevention of Alzheimer's disease and other dementias; setup specialists centres and improve the skills of healthcare professionals; and develop action plans aimed at improving the well-being and quality of life of people with dementia and their families.

In March of 2013, the results of the Alzheimer Cooperative Valuation in Europe (ALCOVE) project were presented. This network was comprised of 19 European Member States and 30 European partners. Recommendations for policy makers included the need to: better understand prevalence and other demographic data about dementia; improve the quality and timeliness of dementia diagnosis; improve the care of people experiencing challenging behaviour; explore ethical and legal issues related to advanced directives; and develop competency assessment in the context of dementia.

Other ongoing EU initiatives that have an impact on dementia issues include: the European Innovation Partnership on Active and Healthy Ageing (as part of its EU Horizon 2020 and Innovation Union strategies); AFE-INNOVNET, a European consortium of older people's organisations working towards developing age-friendly environments across Europe<sup>10</sup>; the "Covenant on demographic change" (it builds on the outcomes of AFE-INNOVNET); and the European Joint Action on Mental Health (aims at building a framework for action in mental health policy at the European level).

However, the Dublin Declaration on Age-Friendly Cities and Communities in Europe (2013), that forms part of the WHO initiative on 'age-friendly cities', makes no mention of dementia (or Alzheimer's). In December 2015 Alzheimer Europe (which represents the Alzheimer NGO associations) published its annual yearbook which was themed on 'dementia-friendly communities' but it was published too late for consideration in this review (Alzheimer Europe 2015).

The European Foundation's Initiative on Dementia (EFID) was initiated in 2011 and aims to support local developments in the way people living with dementia are integrated and supported by their

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<sup>10</sup> In October 2014 AFE-INNOVNET held a workshop on dementia-friendly cities. More information about this is available at: <http://afeinnovnet.eu/news/afe-innovnet-workshop-dementia-friendly-cities>.

community. The network is made up of seven European foundations and the Network of European Foundations that manages the programme. These include:

- The Atlantic Philanthropies
- King Baudouin Foundation
- Robert Bosch Stiftung
- Fondation Mederic Alzheimer
- Joseph Rowntree Foundation
- Genio Trust
- Life Changes Trust

A ministerial conference of the 'UN Commission for Europe on Ageing' took place in Vienna in 2012, with the theme "Ensure a society fit for all ages: promoting quality of life and active ageing". Topics that were highlighted at the conference included:

- Measures to be adopted in order to promote a longer, more active life
- Participation, non-discrimination and social inclusion of older people
- Creating an environment adapted to promote independence, dignity and health in ageing
- Promoting intergenerational dialogues and solidarity (Fondation Mederic Alzheimer, 2013).

In an effort to achieve these aims, EFID has supported a variety of local initiatives to create DFCs. EFID has also presented a number of awards to European organisations that are working to support local-level developments in the way people living with dementia are integrated into, and supported by, their community (go to [www.efid.info](http://www.efid.info) for further information and follow links to lists of organisations receiving awards in 2012 and 2014).

## **National government dementia strategies**

A number of national governments have country-wide dementia strategies that contain references to 'dementia-friendly communities'. This section gives consideration to these.

According to Alzheimer Disease International and Alzheimer Europe, governments in 22 European countries have developed, or are developing a national dementia plan<sup>11</sup>. Fourteen of these have a national dementia strategy in place.

Some EU countries have developed national dementia plans or strategies in response to the growing number of people living with dementia; several countries are currently working towards the development of a national plan for dementia care. The main focus in national dementia strategies was the quality and availability of health and social care for people living with dementia, relating to diagnostic processes, post-diagnostic support and end-of-life care. Most strategies also considered the impact of dementia on the lives of carers, reflected in their commitments to provide carer support and information.

While this review has not focused on the dementia strategies in place across Europe, those which contributed to, or recognised the importance of, 'dementia-friendly communities' were included in

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<sup>11</sup> <http://www.alz.co.uk/alzheimer-plans> and <http://www.alzheimer-europe.org/Policy-in-Practice2/National-Dementia-Plans> [accessed 14 September 2015]

this review. National dementia strategies or programmes which are currently under development were also included, where they indicated the intention to develop DFCs.

### Belgium

Belgium has two separate dementia plans in place, which reflects the geographical division in the country between the Flanders and Walloon. The Flemish government's strategy aimed to involve people living with dementia in the discussions and decisions about dementia care and quality of life in the community. The Walloon government has adopted a regional 'dementia-friendly community' programme and has launched a call for funding proposals in partnership with the King Baudouin Foundation (2013).

The Flemish government has made consistently positive moves towards creating a dementia-friendly Flanders. Revised Flemish care policies have recognised a number of pre-requisites to implementing DFCs across Flanders, such as ensuring maximum autonomy and a good quality of life, through community participation, for all people living with a dementia. A key aspect of this was the recognition that carers are valuable partners for professional care-providers and to enable community involvement (<http://www.zorg-en-gezondheid.be/Zorgaanbod/> [accessed 02/12/2015]).

### Republic of Ireland

Ireland published their national dementia strategy in 2014. This includes an explicit commitment to develop 'dementia-friendly communities', as part of the priority to improve awareness and understanding of dementia. This commitment is also placed within a wider context of the Irish government's 'Age Friendly Cities and Counties Programme' and the 'Healthy Communities/Cities Programme'. The commitment aims to enable people with dementia to live well and as valued citizens, for example, through the representation of people with dementia on Older People Councils (the establishment of which is a commitment in the Programme for Government 2011-2016).

The strategy emphasises that a "whole community" approach is required to support people with dementia, involving formal and informal supports. Examples of community supports currently available for people with dementia include Alzheimer Cafés, social clubs, arts-based activities, family carer training and peer-led support groups. The strategy indicated that there are seven 'communities of interest' across the country that are being supported to deliver a range of DFC activity including: community education; developing volunteering opportunities; supporting local businesses to become dementia-friendly; and improving the social and physical environment.

### United Kingdom

Dementia is part of government health policy in the UK but responsibility for health is devolved to the four UK nations (England, Scotland, Wales and Northern Ireland). Each country therefore has its own approach to dementia, so all four are considered separately below.

## England

England's national dementia strategy does not refer to 'dementia-friendly communities' or similar initiatives (Department of Health, 2009). However, the Prime Minister's Challenge on Dementia (Department of Health, 2012) superseded the strategy (which officially came to an end in 2015). Both documents placed emphasis on the importance of developing DFCs (Mitchell, 2012).

The Prime Minister's Challenge on Dementia made a commitment to create DFCs. The Challenge had two other commitments: improving health and social care services for people with dementia; and increasing dementia research. This work is led in close collaboration with, the largest dementia NGO in England, the Alzheimer's Society (see section below: *National programmes to develop 'dementia-friendly communities'*). A 'Dementia-friendly communities' 'Champion's Group' was established to promote and support the implementation of the Prime Minister's Challenge and included large commercial, retail and banking organisations as well as NGOs, and individuals who are living with a dementia.

The Challenge made commitments to develop 20 dementia-friendly towns, cities and villages by the year 2015. This would be achieved by supporting local businesses and organisations to raise awareness of dementia within society, as well as contributing to an environment which is conducive to developing DFCs.

An annual progress report on the Prime Minister's Challenge indicated the extent to which DFCs have been developed across England since the challenge was put forward in 2012. It was reported that 50 cities, towns and villages had taken steps towards becoming dementia-friendly by 2015, which surpasses the initial aims as stated in the Prime Minister's challenge (Department of Health, 2013). In addition to this, 140 national health service trusts (state funded providers of health care) have been working towards becoming dementia-friendly, in partnership with local Dementia Action Alliances, as part of the National Dementia Action Alliance (see section below, *National programmes to develop DFCs*) ([http://www.dementiaaction.org.uk/who\\_we\\_are](http://www.dementiaaction.org.uk/who_we_are)).

## Scotland

Scotland's current national dementia strategy (Scottish Government 2013) makes a commitment to work with Scottish dementia NGOs to build dementia-aware local communities. A key outcome of the strategy is to develop 'dementia-enabled' and dementia-friendly local communities that will contribute to greater awareness of dementia and reduce stigma.

It should be noted that Scotland adopted a Human Rights-Based Approach (HRBA) to the development and delivery of its national dementia strategy. This involved ensuring that policies affecting people with dementia meet the 'PANEL' principles. PANEL stands for:

- Participation – everyone has the right to participate in decisions which affect their lives
- Accountability - effective monitoring of human rights standards and remedies for breaches
- Non-discrimination and equality - all forms of discrimination in the realisation of rights is prohibited, prevented and eliminated with priority given to the most vulnerable
- Empowerment - individuals and communities should understand their rights and be supported to participate in the development of policy and practices which affect their lives

- Legality - recognition of rights as legally enforceable entitlements (linked to national and international law)<sup>12</sup>

### Wales

The Welsh national dementia plan placed the creation of ‘dementia supportive’ communities as a key priority for Wales (Welsh Assembly Government, 2011). It indicated recognition that DFCs enable people living with dementia to receive treatment and community support in a way which enhances their dignity and respect (<http://www.alzheimer-europe.org/Policy-in-Practice2/National-Dementia-Plans/United-Kingdom-Wales>).

A key factor in developing ‘dementia-friendly communities’ was a need to build capacity within communities to better enable them to respond to the needs of community members who are living with dementia. The Welsh vision had the objective of facilitating a network of DFCs to develop through encouraging local partnerships, each of which can be tailored to the particular community. In support of this national plan, the Welsh Government pledged to establish high-level influencing groups so that people living with dementia can influence change within communities and services.

It was evident that the National Dementia Vision for Wales placed importance on ensuring the voices of people living with dementia are central to decisions that affect their community (Welsh Assembly Government, 2011). The Wales Mental Health Strategy (2012) incorporates previous dementia strategies but does not supersede existing dementia policy.

### Other EU countries

The following EU countries have a national dementia strategy or plan which did not refer to, or contribute explicitly to progress in, developing DFCs:

- Denmark
- Finland
- France
- Italy
- Luxembourg
- Malta
- Netherlands
- Northern Ireland
- Norway
- Portugal
- Sweden
- Switzerland

However several of these countries have ‘dementia-friendly community’ components within their plans. France has a priority to ensure the “quality of life of patients and their caregivers” which includes priority being given to maintaining employment and vocational rehabilitation for younger

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<sup>12</sup> From the Alzheimer Society of Ireland (2013) and the Scottish Human Rights Commission <http://www.scottishhumanrights.com/eqhria/eqhriaaddvalpolicy>



patients. Similarly, Italy has also identified this as an issue in its strategy. Norway is very committed to involving people with dementia in the development of its new national dementia plan and Luxembourg highlights the importance of social inclusion for people with dementia. Malta identifies the importance of ensuring health and social care services are 'dementia-friendly'.

The governments of the following countries are committed to developing a dementia strategy:

- Austria
- Bulgaria
- Cyprus
- Czech Republic
- Portugal
- Slovenia

### **Other national 'dementia-friendly community' programmes**

NGOs in a number of European countries have developed national dementia-friendly programmes. Some of these develop links with government-led programmes at national, regional or local levels.

#### Belgium

Local authorities in Belgium have increasingly engaged in collaborative efforts with local partners, centres of expertise and dementia associations to promote DFCs across Belgium (King Baudouin Foundation, 2013). DFCs in Belgium, which were identified in this review, seemed to have taken on local-level implementation while receiving support, funding and guidance from larger national organisations (primarily the King Baudouin Foundation). For this reason, the majority of evidence for DFCs in Belgium was included in the section below on *Local initiatives to develop DFC*.

#### France

Dementia-friendly projects in France are typically referred to as projects that promote the concept of 'living well with dementia in the community' (Bien vivre avec la démence en communauté). A range of community based drop-in centres in various regions across France were described by the Berlin Institute (2011). The centres offer support with age-related needs, including dementia-specific information and support. Each Local Information and Coordination Centre is located within the centre of communities across France and a wide range of activities are offered, dependent upon the local need and interests of community members. Centres typically offer self-help groups, health-promoting activities, discussion groups, and seminars or conferences for professionals. Despite considerable variation between centres, all reportedly offer opportunities for social inclusion and to discuss relevant issues with peers and experts (Berlin Institute, 2011).

#### Germany

Although Germany does not have a national dementia plan, there is a German Dementia Alliance, 'Allianz für Menschen mit Demenz' (Alliance for People with Dementia), which was started by the German government in partnership with the German Alzheimer Association, Deutsche Alzheimer Gesellschaft (DALZG). In September 2014 the Alliance launched an agenda to implement the foundation of a national dementia strategy.

A hub of dementia-friendly activity appeared to be taking place in Germany as several third sector (voluntary and community) organisations have lobbied for change in how society responds to dementia. Stuttgart Impuls has made a series of requests for change within society, services for people living with dementia and within the political agenda. A proposal for change received over 200 signatories, of those attending the 'Vielstimmig (Many Voices)' event, to present to the Minister for Social Welfare (Stuttgart Impulse, 2012).

The Robert Bosch Foundation, a major German philanthropic foundation, has delivered a national programme, Aktion Demenz, which has supported the development of 50 dementia-friendly initiatives across Germany. The Aktion Demenz programme resulted in the development of a web-based platform for sharing views and ideas, offering a connection point for existing networks and acting as a resource for emerging DFCs to benefit from shared learning and guidance around good practice ([www.demenzfreundliche-kommunen.de](http://www.demenzfreundliche-kommunen.de)).

A similar programme, 'Working together for a better life with dementia' (also delivered by Aktion Demenz), focused on reducing the stigma attached to dementia. The programme is based upon the idea that citizens themselves should contribute to the well-being of people living with dementia by offering opportunities for social inclusion ([www.zukunft-pflegen.info/pflegezukunft/uploads/media/Abstract\\_Rothe.pdf](http://www.zukunft-pflegen.info/pflegezukunft/uploads/media/Abstract_Rothe.pdf)). The Robert Bosch Foundation, also has a national programme, 'People in the Community Living with Dementia', and through this programme has supported 50 local projects across Germany. These include projects that: support encounters between people with and without dementia; provide practical support and assistance; enable people with dementia to continue to participate in community life; give people with dementia a stronger influencing "voice" and strengthen their civil rights. The programme is organised through Aktion Demenz's programme, mentioned above.

### Netherlands

The evidence related to DFCs in the Netherlands indicated a wide variety of projects and initiatives to implement DFCs, which were developed through small, grassroots efforts and activities. These local-level initiatives and projects, which promoted the development of DFCs, received substantial support from national organisations and further benefits arose from being connected with a wider, national network. Alzheimer Nederland seemed to have taken on a coordinating role for the wide range of projects to implement DFCs, since the bulk of evidence for DFCs in the Netherlands was reported by Alzheimer Nederland. Due to the regional nature of dementia-friendly work in the Netherlands, these initiatives will be described in a further section on Local and Regional initiatives (<http://www.alzheimer-nederland.nl/media/19428/Herkennen%20en%20omgaan%20met%20dementie%20-%20Dementie%20vriendelijk%20oktober%202013.pdf>).

### Portugal

The NGO Alzheimer Portugal developed the programme 'Promoting the participation of people living with dementia', which promoted access to social and cultural integration for people living with dementia. A set of community-based interventions was devised to maximise the cognitive functioning of people living with dementia and to help them adapt to the experience of living with dementia, by

promoting the person's well-being and quality of life. Therapeutic activities, including recreational, sporting, creative and outdoor activities, formed part of the intervention programme and were delivered across trustworthy sites in Portugal. These contributed to the personal support and community involvement of people who are living with dementia in the community ([http://alzheimerportugal.org/pt/news\\_text-77-1-290-projetos-da-alzheimer-portugal-apoiados-pelo-inr](http://alzheimerportugal.org/pt/news_text-77-1-290-projetos-da-alzheimer-portugal-apoiados-pelo-inr)).

### Spain

The NGO, Confederacion Espanola de Asociaciones de Familiares de Personas con Alzheimer y Otras Demencias (CEAFA), is reportedly the only national organisation in Spain that works with families and people living with dementia. It represents their views about how to promote a good quality of life in ways that are important to people living with dementia. CEAFA have formed collaborative partnerships with 300 associations that represent over 200,000 families affected by dementia, as well as a partnership with the Ministry of Health. The CEAFA campaigned for the development of a national plan and are continuing to work towards that aim. The Association recognised, in equal measure: the importance of enabling social inclusion for people living with dementia; the importance of ensuring access to appropriate care and treatment; and the impact of garnering political, as well as community, support in achieving their aims (<http://www.ceafa.es/>).

Recent changes to legislation in Spain has also brought about a national emphasis on facilitating autonomous living in the community, whilst receiving adequate medical treatment and support for dementia (Oliva et al, 2011; <http://envejecimiento.csic.es/documentos/documentos/gacetasanitaria2011-oliva-desafios-01.pdf>).

Hermida-Porto (2012) highlighted the unique factors at play within each region of Spain, which are affected heavily by local resource constraints and historical tensions between local regions and national government. This has created specific challenges for Spain to improve the quality of life for people living with dementia, on a national level. There will be an inherent necessity to adapt the suitability of processes and practices in developing DFCs across the various regions of Spain.

### Switzerland

This review did not identify any clear evidence of DFCs in Switzerland. However, it was suggested that discussions are now emerging that recognise the need for appropriate services and long-term care for people who are living with dementia. An increasing shortage of resources will necessitate the development of alternative, community-based, means to support people who are living with dementia to maintain a good quality of life in their communities. There is, as yet, little political motivation for developing DFCs in Switzerland, but initiatives will begin to emerge as the demand on traditional service provision increases (Kazis, 2013).

### United Kingdom

Similar to the governments devolved approach to dementia, most NGOs in the UK work within each of the four UK nations, although some (e.g. Joseph Rowntree Foundation) support the development of 'dementia-friendly communities' across the UK.

## England

The Alzheimer's Society in England has taken the lead on a three-year programme to support the implementation of DFCs under the Prime Minister's Challenge on Dementia (2012).

Through the DFC 'Champion's group', the Alzheimer's Society has been working directly with a number of leading businesses and organisations to develop practices which support the creation of DFCs. This champion group has also established six national "Task and Finish groups", which are engaging key members of local communities to further develop DFCs. The Task and Finish groups are currently developing guidance to specifically address various aspects of community life and involvement (Department of Health, 2013). They include:

1. Retail group — (including national retail organisations such as supermarkets and banks) developing guidance on how to make the retail sector more dementia-friendly.
2. Employers group — developing guidance on what steps businesses can take to become dementia-friendly employers.
3. Legal and data protection group — developing consumer-directed leaflets that contain: dementia-friendly messaging; sign-posting; and provide advice to support people living with dementia when dealing with companies and organisations, focusing on the issues of Power of Attorney and Data Protection.
4. Civil society and the voluntary sector group — developing a framework of key characteristics to assess and promote innovative practices and projects within mainstream communities to enable the participation of people living with dementia.
5. Rural communities group — identifying key issues and outcomes that people living with dementia in rural areas rely on in order to live well in their communities.
6. Technology group — developing a dementia-friendly technology charter that will help people living with dementia, and their carers, gain access to and navigate assistive technology options.

An additional three Task and Finish Groups, focussing on transport, leisure and personal services, was due to have commenced work by September 2014 (Department of Health, 2013).

The Alzheimer's Society in England identified ten key aspects to the development of DFCs (Alzheimer's Society, 2013a). These are:

1. Ensuring the meaningful involvement of people living with dementia in decision-making and planning services
2. Ensuring early diagnosis, personalised and integrated care is the norm
3. Ensuring that community-based solutions to health and social care are utilised to support people living with dementia to continue living in their own home
4. Providing appropriate, consistent and reliable travel options
5. Actively challenging stigma and increasing community awareness of living with dementia
6. Developing befriending services and practical support
7. Providing easily navigable physical environments
8. Ensuring that community activities are accessible for people living with dementia
9. Encouraging local businesses to be respectful and responsive

10. Acknowledging the potential of people with dementia and including the voices, of people living with dementia, from seldom-heard groups and geographically remote individuals (Alzheimer's Society, 2013a)

In addition to these, the Alzheimer's Society highlighted the value of the National Dementia Action Alliance (DAA) in working to improve the quality of life of people living with dementia in England, while also supporting the development of DFCs. Hosted by the Alzheimer's Society, the DAA brings together partnerships between a wide range of agencies, businesses and organisations to ensure that people living with dementia are included and valued in family, community and civic life (Alzheimer's Society, 2013a).

Individuals and organisations, from the private, statutory and voluntary sectors, are invited to join as members of the Dementia Action Alliance. Ongoing partnerships have been developed between schools, football and sports clubs, emergency services and the British Transport Police, individuals living with dementia, among many others (Department of Health, 2013). Membership of the DAA can be taken on at local or national levels, depending on the particular focus or aim of each partnering organisation (Alzheimer's Society, 2012; Alzheimer's Society, 2013a; <http://www.dementiaaction.org.uk>; [http://www.alzheimers.org.uk/site/scripts/documents\\_info.php?documentID=2432](http://www.alzheimers.org.uk/site/scripts/documents_info.php?documentID=2432)).

Local Dementia Action Alliances are smaller units, working in partnership, and are described as the local vehicle to DFCs (Department of Health, 2013). One hundred and fifty-one (151) local Dementia Action Alliances have been developed, with local alliances encouraged to collaborate and share good practice for achieving DFCs ([www.dementiaaction.org.uk](http://www.dementiaaction.org.uk)).

The Alzheimer's Society, in partnership with Dementia Action Alliance, has been working towards the creation of a national standard for 'dementia-friendly communities'. They have proposed the adoption of an official symbol (a five-petal, blue forget-me-not flower:

<http://www.digitalflaneur.co.uk/pn145-Dementia-Awareness-Volunteers>), which would indicate where recognised standards for DFCs have been met. Accreditation would be required, involving a formal recognition process, whereby specified criteria would have to be met in order to be considered 'dementia-friendly' (Alzheimer's Society, 2013b). Components of this recognition process may include:

1. The support of specific values by working towards agreed standards.
2. The use of a recognisable symbol, indicating that the community has been registered with the Alzheimer's Society as 'dementia-friendly'.
3. Ensuring mechanisms for feedback, particularly from people living with dementia and carers, to form part of an annual assessment process.
4. Provision of local information about progress via the Alzheimer's Society website.

This proposal assigns oversight of any recognition process to the Alzheimer's Society, although initial consultations indicated that an official symbol (also referred to as a kite mark) and formal recognition process was not appropriate at that stage of national developments. As the Alzheimer's Society concluded from their consultation process:

"Overly bureaucratic processes that require expensive assessment by external reviewers could actually dis-incentivise engagement. There is also not yet enough detailed evidence on what is dementia-friendly for formal accreditation." (Alzheimer's Society, 2013b, pg. 6).

To date, over 69 communities have signed up to the Alzheimer's Society's DFC recognition process ([http://www.alzheimers.org.uk/site/scripts/documents\\_info.php?documentID=2136](http://www.alzheimers.org.uk/site/scripts/documents_info.php?documentID=2136)). A national approach may facilitate consistency between geographical areas, but it may also serve to limit the recognition of DFCs to only those who adhere to the Society's proposed model.

The Alzheimer's Society worked with the British Standards Institution (BSI) to develop a 'code of practice', for communities working towards becoming dementia-friendly, which includes the recognition process. The BSI is a multi-national business services provider whose principal activities are the production of standards and the supply of standards-related services. The code is available (but not free) at: <http://shop.bsigroup.com/ProductDetail/?pid=000000000030300514>

Several additional criteria were developed by the Alzheimer's Society (2014b) for businesses, organisations and communities to adhere to, in order to be considered for the kite mark DFC recognition process. The criteria included:

1. An appropriate local structure (e.g. Dementia Action Alliance) that can include a range of community members.
2. An individual who is responsible for ensuring dementia-friendly progress in the community.
3. A plan of how to raise community awareness of dementia in key organisations.
4. The facilitation of opportunities for people living with dementia to have a public voice. Seldom-heard groups of people living with dementia must also be considered to ensure equal representation from all sectors of society.
5. An assurance that initiatives are applicable across various community groups and that messages to the public are also designed to be dementia-friendly.
6. A focus on key areas which are important locally, such as transport system improvements or access to shop facilities.
7. The production of an annual progress report and action plan, enabling learning and sharing of information.

The Alzheimer's Society (2014a) also developed criteria for the 2014 Dementia-friendly Awards, which were granted to communities or businesses that had met the Alzheimer's Society's criteria for recognition as a DFC. The criteria included:

1. Providing evidence, and a proven track record, of having made a difference towards improving the lives of people living with dementia.
2. Supporting individuals and/or groups who are driving the dementia-friendly movement, following their established priorities and delivering plans in a cohesive way.
3. Showing evidence of: working in partnerships; networking; and integration with other services, organisations, businesses and/or individuals.
4. Involving people living with dementia and their carers in planning and promoting DFCs.

In support of a national recognition process, the Alzheimer's Society produced a number of guidance materials and criteria for developing dementia-friendly initiatives. For instance, a charter was produced, in cooperation with Lloyds Banking Group, which aimed to improve the experience of people living with dementia when using financial services (Alzheimer's Society, 2013d). Additionally, a guide for developing dementia-friendly technology offered a number of examples for good practice

in the use of assistive technologies to enhance the capacity and inclusion of people living with dementia, as well as family carers (Alzheimer's Society, 2013e).

The Alzheimer's Society indicated that dementia-friendly promotional work should seek to engage local shops, schools and colleges, banks, professional bodies, community groups, hospitals, care homes and housing associations. Effective methods of influencing communities were identified and included:

- Distributing information leaflets
- Enabling e-learning opportunities
- Providing local education and training for service staff
- Working with voluntary organisations who specialise in dementia
- Employing the Dementia Friends' Champions scheme.
- Utilising focus groups, reference groups, interviews and 'Mystery-shopper' programmes to effectively maintain progress reports and mutual assessments between partnering organisations.

The 'Dementia Friends' initiative is delivered, at a national level, by the Alzheimer's Society and Public Health England. Dementia Friends aim to raise awareness and understanding of dementia in order to create DFCs. Any individual can become a 'Dementia Friend' by watching a short online video about what it feels like to live with dementia, by attending one face-to-face dementia awareness session, or by engaging with e-learning tools which address common challenges faced by people living with dementia when dealing with financial and retail sectors. 'Dementia Friends' receive a booklet, entitled 'The Little Book of Friendship', that suggests small ways in which individuals can be dementia-friendly. A 'Dementia Friends' badge is also issued to individuals who sign up to the scheme, which depicts the Alzheimer's Society's dementia-friendly kite mark symbol (<https://www.dementiafriends.org.uk/>). Upon becoming a 'Dementia Friend', a person is not required to take any specific action but individuals and organisations are encouraged to participate further in the scheme by becoming 'Dementia Champions'. A 'Dementia Champion' offers information sessions about dementia for other individuals or organisations, whether in their own workplace, personal networks or local communities. 'Dementia Champions' undertake approximately 1-2 days of training from the Alzheimer's Society.

As previously noted, other NGOs in England have also undertaken national programmes of work to support the development of 'dementia-friendly communities'. Most notable is the Joseph Rowntree Foundation (JRF). The JRF developed the 'Dementia without Walls' programme supporting 'dementia-friendly community' initiatives across the UK. Based upon initial learning from this programme, the JRF identified certain pre-requisites to developing DFCs which formed the Four Cornerstones Model (Crampton and Eley, 2013). The Four Cornerstones are:

1. People — how community members respond to and support people who are living with dementia.
2. Places — how the physical environments (e.g. housing, transport) can support people who are living with dementia.
3. Resources — the allocation of appropriate resources to enable the development of sustainable DFCs.

4. Networks — that can enable more widespread communication, dissemination of learning and good practice, as well as maximising on the individual strengths of community members (Crampton and Eley, 2013).

The Four Cornerstones Model highlighted the various areas or aspects of a community that require adaptation, in order to truly enable people living with dementia to maintain full social inclusion. It is often small changes that can enable people who are living with dementia to move freely within their communities, to feel safe doing so, and to maintain access to their local facilities and social networks (Crampton & Eley, 2013; Innovations in Dementia & the Alzheimer Society of Ireland, 2012).

A UK-based older people's NGO, Age UK, has undertaken a piece of work to make its mainstream services for older people more dementia-friendly, with the aim of making 50 of its local, community-based organisations more dementia-friendly: <http://www.ageuk.org.uk/health-wellbeing/fit-as-a-fiddle/dementia-friendly-programme/>

Two other programmes of work are also worth mentioning. A number of 'good practice' guidance documents were produced by Innovations in Dementia, in partnership with the Local Government Association (LGA) and Hampshire County Council (a geographically-based local government). These guidance documents offer a range of dementia-friendly adaptations which can contribute to creating DFCs. Key elements were:

- Engaging with people with dementia and their carers
- Dementia awareness raising for businesses and other organisations
- Advice for customer-facing staff
- A checklist for dementia-friendly (physical) environments
- 'Memory aware' streets (Innovations in Dementia, 2012b; Innovations in Dementia, 2012c; Innovations in Dementia, 2012d; Innovations in Dementia, 2012e; Innovations in Dementia 2012f)

The LGA report is also noteworthy because it came out of a programme of work that focussed on the general ageing population, rather than specifically on people living with dementia. In this respect, it links DFCs with the age-friendly initiatives referred to at the end of this review.

The Dementia Engagement and Empowerment Project (DEEP) has also contributed to significant national and local developments in creating DFCs. DEEP is a national network of independent groups led by or actively involving people with dementia, that are influencing policies, services and the communities that they live in. DEEP is supported by Innovations in Dementia (a Community Interest Company) in partnership with the Mental Health Foundation, a UK leading social research and development charity. The project has brought together groups and individuals who are living with dementia to support each other in their dementia-friendly promotional work. Local groups determine their focus, offering a truly grassroots perspective to development work, while being supported by a network of larger, national organisations. Several groups in the national DEEP network have focused their efforts on developing DFCs and indicated that this requires effective networking to share good practice and learning, as well as to raise awareness within communities, services and the general public ([www.dementivoices.org.uk](http://www.dementivoices.org.uk); <http://www.innovationsindementia.org.uk>).



## Northern Ireland

The Alzheimer's Society described the launch of the DFC initiative in Northern Ireland, attended by celebrity chef Paul Rankin

([http://www.alzheimers.org.uk/site/scripts/news\\_article.php?newsID=1966](http://www.alzheimers.org.uk/site/scripts/news_article.php?newsID=1966)).

The Alzheimer's Society — North and East Northern Ireland — also delivered workshops, awareness raising events and community activities to facilitate the creation of DFCs.

The Joseph Rowntree Foundation has called for more dementia champions and committed up to £80,000 for quality proposals for contributing to developing DFCs across Northern Ireland. The Dementia Services Development Centre Northern Ireland was awarded funding for a three-year project to implement DFCs (<http://dementia.stir.ac.uk/communities/dementia-friendly-northern-ireland>). The Development Centre, in partnership with the University of Stirling, has produced a range of guidance materials, research reports, publications and other practical guidelines in relation to supporting people who are living with dementia (<http://dementiacentreni.org/>)

## Scotland

Since the development of Scotland's first national dementia strategy, substantial changes have taken place with regards to the involvement of people living with dementia in wider society. Three hundred (300) Dementia Champions were in place in 2013 (Scottish Government, 2013) and a national campaigning group, the Scottish Dementia Working Group, have made considerable headway in influencing national policy and societal awareness ([www.sdwg.org.uk](http://www.sdwg.org.uk)). The Scottish Dementia Working Group (SDWG) is made up of individuals who are living with dementia and is supported through partnerships with third sector (voluntary and community) organisations and government agencies. Among the groups key aims was the intention to develop DFCs across Scotland, with a number of guidance documents having been produced to support this aim (e.g. travelling with Dementia,

<http://www.sdwg.org.uk/wp-content/uploads/2008/05/Travelling-with-Dementia.pdf>).

The SDWG also played a major role in the development of the 'Charter of Rights for People with Dementia and their Carers in Scotland' that was published in 2009 and aims to empower people with dementia, those who support them and the community as a whole, to ensure their rights are recognised and respected.

## Wales

The aim to create dementia-supportive communities across Wales was announced at the National Assembly for Wales (2012). The Alzheimer's Society in Wales has committed to supporting the movements to create DFCs by promoting inclusive attitudes towards people who are living with dementia. The National Assembly for Wales emphasised 1) the role of support with daily living for people who are living with dementia, and 2) the role of local businesses in contributing to DFCs (<http://www.crossroads-wales.org.uk/2013/04/new-programme-announced-to-create-dementia-supportive-communities-in-wales/>).

## Other EU countries

The following EU countries have a national dementia programme but these did not refer to, or contribute explicitly to, progress in developing DFCs:

- Turkey
- Greece

## **Local and regional dementia-friendly initiatives**

### Austria

“Dementia-friendly community pharmacy”, a project of the Institute for Palliative Care and Organisational Ethics, formed a partnership between Alzheimer Austria, various support groups, and pharmacists within the community. The partnership contributed to developing DFCs by ensuring that pharmacies are welcoming and inclusive of people living with dementia, with adaptations made if necessary. By mobilising resources and furthering the knowledge and skills of individual pharmacists, as well as by delivering a number of educational initiatives across lower Austria, the project also aims to fight stigma associated with Alzheimer’s disease (EFID special nominee, 2014).

### Belgium

The King Baudouin Foundation and the Minister of State commissioned 30 projects to develop dementia-friendly projects across Belgium. Commissioned projects included those that aimed to improve public perceptions of dementia and to increase local involvement with creating DFCs. As part of this wider initiative, a ‘dementia platform’ was developed in Brussels to ensure that people living with dementia are able to influence initiatives to create DFCs (King Baudouin Foundation, 2013).

Supported by the King Baudouin Foundation, Bruges undertook a long-standing initiative (‘For a Dementia-friendly Bruges’) to become a DFC. Across Bruges high streets, small business owners have adopted dementia-friendly symbols in their stores, as part of this initiative. It also resulted in changes to the local police, changes that have been important in influencing public attitudes towards dementia, in addition to databases being set up to track lost individuals with dementia. Furthermore, community activities are offered, such as a choir, designed to elicit nostalgic memories, which cater for, but are not exclusive to, people living with dementia (<https://webgate.ec.europa.eu/eipaha/news/index/show/id/344>). The ‘Expertisecentrum Dementie Foton’ was nominated by the EFID Awards for the work implemented in Bruges aiming at raising awareness of dementia among the general public. Activities included: planned outings for older people; art exhibitions; the development of a dementia-specific website ([www.dementievriendelijkbrugge.be](http://www.dementievriendelijkbrugge.be)); the production of a newsletter; and a support slogan, “For a Dementia-friendly Bruges” (Hahn, 2010). The project, ‘For a dementia-friendly Bruges’, pledged to ensure changes in a number of areas of community life, including:

1. Images of dementia — to present a more nuanced image, through better and more widespread information, emphasising the possibilities of living with dementia rather than the limitations.

2. Stigma — to break taboos by involving, and listening to, people living with dementia, to encourage debate, acceptance, understanding, tolerance, visibility, recognition and contact.
3. Respect — to normalise the use of humane and respectful language about dementia
4. Social — to facilitate the integration of people living with dementia and to increase solidarity across generations and community groups.

The King Baudouin Foundation (2013) described a number of projects across Belgium which contributed to the creation of DFCs:

- ‘The Pleasure of Walking’ promoted social inclusion by facilitating walking activities, using reminiscence and sensorial experiences to find quietude in nature, and to engage in social participation.
- The Charleroi Improv group highlighted the abilities of each member whilst being suitable for people living with memory difficulties. The Improv theatre offered an outlet for self-expression, promoted social engagement and offered opportunities for meaningful activity.
- The Antwerp police services supported communities with finding lost individuals more quickly and in a more supportive manner. Standardised forms were introduced to potentially vulnerable individuals, including, but not exclusive to, people who are living with dementia. Police officers worked with social services and voluntary sector organisations to distribute leaflets, training and information sessions.

Facilitating walks and holidays for people living with dementia was another initiative undertaken in Belgium. A ‘Reminiscence Promenade’ for all ages and abilities was developed in Aalbeke (Flanders) to promote intergenerational work, and to improve accessibility, mobility and social integration for people living with dementia. These involved group-based reminiscence walks and each walk was designed to elicit memories of past events and encourage people living with dementia to talk about their past experiences. The Promenade improved community participation and raised awareness of dementia, enabling the provision of community support and de-stigmatising information within a sustainable community activity (<http://www.afeinnovnet.eu/news/%E2%80%9Cgo-back-time%E2%80%9D-reminiscence-promenade-belgium>).

The police department ‘Hekla’ produced a guide to support the development of DFCs. The project focused on ensuring that missing persons who have dementia are found quickly and easily by distributing circulars in mailboxes across the community. The distributed leaflets described protocols for responding to lost or confused people living with dementia and were designed to ensure that all community members could be involved with the scheme (Hahn, 2010).

‘Project Nature’, in the Walloon municipality, connected teenagers in the community with people who have dementia by involving both community groups in nature-restoring projects. A Brussels-based project facilitated weekly meetings between university students and older people (who may or may not have dementia). Meeting attendees worked together on creating plastic art which formed part of a larger art exhibition to promote awareness and the value of contributions from people who are living with dementia (Hahn, 2010).

De Rynck and Teller (2011) described a collaboration between a care home and an art school which contributed to developing DFCs by facilitating intergenerational participation in arts activities.

Younger art students were encouraged to support older students and resulting artworks were displayed in a number of public spaces, including train stations, parks and tramways. Reports indicated that people living with dementia were able to discover new interests and meaningful hobbies which impacted positively on their quality of life, and reduced the occurrence of frustrating and confusing experiences.

In the municipality of Namur, the NGO “Age Well”, provided training for staff from the local council, social services and the Accident and Emergency Department of the regional hospital. The training catered for individuals who have not otherwise interacted with people who have dementia. Training offered practical advice for supporting people living with dementia who are experiencing a moment of crisis, such as communicating calmly and respectfully, thereby reducing the stress experienced by the person who is living with dementia. An outcome of the training course was the production of course materials which can be adopted for use in other organisations (De Rynck & Teller, 2011).

### Cyprus

The EFID award winner “Act and React 4 Dementia” aimed to improve awareness and understanding of Alzheimer’s disease and associated cognitive impairments. To do this, the project supported people living with dementia to maintain active, participatory lives in their communities, in addition to raising public awareness around the need for ‘friendly societies’ to improve attitudes and practices towards people living with dementia (EFID, 2014).

### Denmark

A DFC parish (a church territorial region and the lowest tier of local government) was described as an example of how small parishes can influence other community groups to contribute to developing DFCs. The Evangelical Centre for Development in the Community offered dementia awareness training for people working in the parish services, as well as support for people living with dementia and their families. The Evangelical Centre also provided information, opportunities for community and social involvement, workshops, needs assessments as well as psychological support (Jensen & Sichlau, 2014).

A Danish blog was identified in this review, entitled ‘Dementia — but not incapacitated’, which discussed progress in relation to the full participation of people who are living with dementia in the democratic process. A large proportion of older people in Denmark have reportedly shown a keen interest in participating. However, a predominant cultural attitude maintains that people living with dementia would be “too confused” to make an informed decision, particularly in regards to the electoral process. The blog suggested that a change in attitude and specific processes are needed to ensure that people living with dementia are supported to vote in elections. This may be achieved through the assertion and raised awareness of the constitutional rights of every Danish adult to participate in elections (<http://blogs.bt.dk/leder/2014/05/28/dement-men-ikke-umyndiggjort/>).

### England

The Joseph Rowntree Foundation’s (JRF) programme, ‘Dementia Without Walls’, focused on enabling DFCs to emerge within various localities across England (JRF, 2014; Alzheimer’s Society, 2014b). The programme has supported initiatives that offer support to people living with dementia in continuing their daily activities (such as shopping, managing finances, using transport and keeping active), with the aim of preventing the social exclusion of people who are living with dementia (Crampton & Eley,

2013). The Joseph Rowntree Foundation's 2014 Progress Report indicated that DFCs are not based solely upon partnerships with health and social care service providers, although these can be important. However, it was evident that partnerships with community agencies and individuals within communities are crucial to the success of initiatives to create DFCs (Joseph Rowntree Foundation, 2014).

The city of York was highlighted as a prime example of a successful DFC. As such, the Joseph Rowntree Foundation facilitated developments with regards to housing, shopping, leisure and transport, which removed challenges and barriers to the full inclusion of people living with dementia. Crucially, community development work has been informed extensively through consultations with people who are living with dementia, their family and carers, professional services, local business, as well as the wider community (Department of Health, 2012; Crampton & Eley, 2013). The Joseph Rowntree Foundation's 'Dementia Without Walls' programme developed key outcomes for 'dementia-friendly communities' which included supporting local businesses, statutory services, third sector (voluntary and community) organisations and individuals living with dementia and their relatives, to share ideas and implement change. The programme has been linked to a 'Resource Hub' which offers information and guidance for becoming a 'dementia-friendly community' (Joseph Rowntree Foundation, 2014).

Hampshire County, a local government area, has also committed to becoming a DFC through the adoption of dementia-friendly 'kite marks' for a number of collaborating high street stores. Supported by 'Innovations in Dementia' and the Local Government Association, Hampshire implemented 'dementia-friendly zones', with 400 local businesses signing up to the initiative. A help card scheme has also been introduced, which enables people living with dementia to inform members of their local community of their dementia and any related support requirements. The card also includes a checklist that indicates how the person who is living with dementia would like to be supported (Innovations in Dementia, 2012a).

Several other local developments in creating DFCs were identified in this literature review. For instance, the South Lincolnshire Dementia Action Alliance, developed in 2012, has involved the voluntary sector, community sector organisations, private businesses and community-based activities. The alliance aims to develop sustainable activities and services to promote the development of DFCs. The partnership also aims to involve people who are living with dementia in the decision-making process and to maintain their connections to the local community. Five parishes (a church territorial region and, in England, the lowest tier of local government) in South Devon have also committed to ensure that people who are living with dementia have a public voice and are supported to maintain social interaction in their local community (Alzheimer's Society, 2014a).

In Kent, the Northfleet School for Girls initiated dementia awareness education as part of PHSE (Personal, Social and Health Education) lessons. This included meeting up with people in the community who have dementia, writing thoughts or fears about dementia to share with classmates and compiling photo books to record the life stories of people living with dementia (Alzheimer's Society, 2014a).

In another example, Wigan town council developed dementia-friendly initiatives in the community by organising a focus group and a community vote regarding the key areas of focus in developing DFCs. In the county of Surrey, a range of initiatives have altered local services, in turn contributing towards the creation of a DFC. For instance, dementia-friendly parking was introduced at the local supermarket

and dementia-friendly champions have toured the high streets to generate interest in the project and to connect with cafes, hairdressers, supermarkets and other retailers (Alzheimer's Society, 2014a).

Some initiatives to create DFCs have focused on improving particular aspects of community life for people who are living with dementia. For instance, the Yorkshire and Humber Dementia Action Alliance displayed awareness literature in police stations and offered training for police staff in understanding dementia. This initiative enabled an internal police staff network of Dementia Champions, who worked towards ensuring that the police force is committed to delivering a dementia-friendly service. In another Northumberland county, bus drivers were offered awareness training to achieve a Certificate of Professional Competency. An initial project was followed up by an enhanced training package which offered practical measures for responding to the needs of customers who are living with dementia (Alzheimer's Society, 2014a).

### France

A series of workshops called 'Puzzles', took place in Aveyron, which created sketches and improvisations taken from the daily lives of people living with dementia and their close relatives. The theatre workshops involved younger people who were affected by dementia and emphasised the value of contributions from individuals who are living with dementia. The series of workshops led to the publication of a booklet entitled 'Listen to us differently', which raises awareness of the experiences of young people affected by dementia, as well as advocating for a greater exchange of views and experiences of living with dementia (Fondation Mederic Alzheimer, 2013).

### Germany

In a three-year initiative to implement DFCs, the town of Arnsberg focused on ensuring that people living with dementia can maintain a network of support and services in the community. The programme offered a counselling service, practical advice, educational programmes and courses. An outcome of the programme was a dementia awareness-raising exhibition, showcasing films, literature and open discussions about dementia. A poster campaign was reportedly under development, which aimed to highlight the benefits for all citizens arising from the development of DFCs. A local information centre, run by volunteers, offered practical support for people living with dementia, such as attending medical appointments, shopping and taking walks in the town centre ([http://www.weser-kurier.de/region/wesermarsch\\_artikel,-Demenzfreundliche-Gemeinde-ist-das-Ziel-arid,807777.html](http://www.weser-kurier.de/region/wesermarsch_artikel,-Demenzfreundliche-Gemeinde-ist-das-Ziel-arid,807777.html)). Inspired by the success of the initiative in Arnsberg, the Hilfe-Netzwerk Schwanewed (Help-Network Schwanewede) also aimed to adapt the municipality of Schwanewede to become dementia-friendly.

A programme to make the town of Duren a DFC involved politicians, health and social care services and local businesses in the development of the 'With Us' campaign. The campaign enabled an open civil forum, ensuring that people living with dementia and their families have a public voice. 'With Us' created an information booth, a theatre event, poster campaigns in local transport services, and workshops for the general public. A 'multi-generational house' offered further information about how to contribute to the development of a 'dementia-friendly community'. Specific efforts were made by the 'With Us' campaign team to ensure that the voices of seldom-heard groups of people who have dementia were included, such as people living with dementia who are from BAME (Black, Asian and minority ethnic) backgrounds or from LGBT (Lesbian, Gay, Bisexual, Transgender) communities

<http://www.demenzfreundliche-kommunen.de/projekte/mit-uns-%E2%80%93-demenzfreundlicher-kreis-d%C3%BCren>).

Another German project, based in Dresden, captured the views of people who have dementia, their carers and members of their communities, to exchange ideas about local history, changes, experiences and relationships that have occurred throughout the neighbourhood. These were used to exhibit a collection of work which emphasised the diversity within each community, highlighted the views of people living with dementia, and was used in training sessions and conferences, particularly in relation to a training programme designed for public transport staff (<http://www.demenzfreundliche-kommunen.de/projekte/nicht-ohne-meine-nachbarn-%E2%80%93-menschen-mit-demenz-unserer-mitte>).

An example of a smaller initiative to create a DFC entitled ‘People with dementia—our neighbours’, was centred on the church-going community and indicated a need to involve churches in facilitating the emergence of DFCs (Kirche, 2010). A unique church service was subsequently created for the community which accounted for the experience of living with dementia. For instance, stories or talks were accompanied by visual presentations, illustrations and often used music to enhance understanding. The church services offered a valuable contribution to the creation of a DFC as it offered a hub of intergenerational support, exchange of ideas and human connections. Kirche (2010) suggested that places of worship can be an ideal place for some communities to explore ways of implementing DFCs.

In another community initiative, in the municipality of Urbach, a collection of dementia relevant literature was distributed to 28 libraries, including books and DVDs which offered introductory information about dementia. A range of books and resources have also been made available online and include short stories, first-person accounts of living with dementia, novels and books for kids ([http://www.urbach.de/servlet/PB/menu/1347765\\_l1/index.html](http://www.urbach.de/servlet/PB/menu/1347765_l1/index.html)).

Another example was an event in Stuttgart, which supported the artistic contributions of people living with dementia for widespread publication, with the aim of raising awareness of the abilities and individuality of people who have dementia. An outcome of this event was the production of a film (‘Die Andere Sprache’ or ‘Another Language’) which showcased many of the communicative forms of expression that can be used by people who have dementia ([http://www.demenz-support.de/vielstimmig/Sich\\_artikulieren](http://www.demenz-support.de/vielstimmig/Sich_artikulieren)). Demenz Support suggested that activities which promote health and well-being, art and creativity, and music can enable people living with dementia to have full participation in meaningful community activities. These projects also serve to promote a new cultural understanding of, and response to, dementia.

Another event in Berlin offered an open-air exhibition of photos, quotes and information about dementia. Activities included a demonstration by a seniors’ martial arts group; a dance for people with dementia and their carers; sessions to share testimonies; and debates. The event aimed to raise awareness that people living with dementia are just like any other community members and to break down the fear of interacting with people who have dementia. Portrayals of dementia showed that people living with dementia can live in dignity and enjoy life, whilst stimulating debate about housing and care options for people living with dementia. These events can foster collaboration between healthcare providers, the voluntary sectors, business and other organisations, to promote good information provision and effective signposting (De Rynck & Teller, 2011).



In another project, Essen city council developed partnerships with local statutory services, social services, advisory groups, schools and other community groups to provide activities within a sheltered accommodation site. De Bijster, known in the region as an expert in dementia, has provided a number of dementia supports and activities through the sheltered accommodation service. The partnership produced a leaflet which offered accessible information and advice, testimonies about daily life with dementia and signposting to support services. Crucially, people living with dementia have been involved at the centre of the project. As part of the project, financial support has also been offered to community groups to promote contact between groups and to support retail involvement in creating DFCs (De Rynck & Teller, 2011).

### Italy

Two projects supported by EFID were developed in Italy. Alzal House in Lamezia Terme offers a wide range of activities encouraging the participation of people from all age groups. The project fosters effective intergenerational communication and narrows the generation gap, whilst ensuring stronger integration of people with dementia in the community. Rifugio Re Carlo Alberto, in northern Italy work towards capacity-building with individuals in the community who are living with dementia. The project aims to provide education about dementia, as well as offering advocacy services. Through this project people living with dementia can become ambassadors who campaign on behalf of others who are living with dementia. Training, support and information workshops are also provided as part of the project, as are social engagement and community outreach opportunities within community settings, such as local coffee shops (EFID, 2012 and 2014).

### Netherlands

Bladel, Peel and Walwijk are municipalities and geographical localities in the North Brabant area of the Netherlands and are cited as leading national examples of how communities can become dementia-friendly (e.g. <http://www.waalwijk.nl/Pub/Home/Wonen/Wonen-Waalwijk-dementievriendelijke-gemeente.html>). These partly arose from a dementia symposium that highlighted the work of Joan Veldhuizen in implementing dementia-friendly initiatives. Veldhuizen has taken a lead in highlighting the importance of implementing greater proficiency and recognition of the needs of people living with dementia to remain in their communities ([http://www.alzheimercentrumlimburg.nl/tinimce\\_files/20130314\\_Peel\\_en\\_Maas\\_dementievriendelijk\\_-\\_verslag\\_conclusies\\_en\\_vervolg\\_cve.pdf](http://www.alzheimercentrumlimburg.nl/tinimce_files/20130314_Peel_en_Maas_dementievriendelijk_-_verslag_conclusies_en_vervolg_cve.pdf)). She made a number of recommendations for creating DFC which were presented to the Psychogeriatric Care Review Board to inform policy and to encourage the involvement of local associations and voluntary organisations in Bladel. Veldhuizen called on local agencies to sign the declaration of intent, 'A dementia-friendly community' and to actively contribute towards creating DFCs (<http://www.bladel.nl/dementie-om-niet-te-vergeten>).

Alzheimer's Netherland ([www.alzheimer-nederland.nl](http://www.alzheimer-nederland.nl)) offered a number of sample initiatives to promote the creation of DFCs. However, although these initiatives included projects such as a film cafe, walking groups and weekly bridge games, they were usually dementia specific services and did not involve the wider community. To illustrate, a carer and member of the weekly bridge group indicated that it would be better if community bridge groups formed part of a larger DFC so that specialist dementia bridge groups would not be necessary (<http://www.alzheimer-nederland.nl/media/20521/Vijf%20inspirerende%20dementievriendelijke%20voorbeelden.pdf>).



A bookshop in Weesp was highlighted by Alzheimer's Netherland, as contributing to the development of DFCs by offering training for staff in recognising dementia and responding appropriately to the needs of customers with dementia. The book shop owner, Fons Plukker, explained that this initiative felt insufficient, and as a result he began to engage with other community businesses and departments to provide information about how to contribute to developing a DFC. Plukker expressed the hope that Weesp will be a DFC within a few years whilst feeling incredulous that these initiatives are not more widespread (<http://www.alzheimer-nederland.nl/media/20521/Vijf%20inspirerende%20dementievriendelijke%20voorbeelden.pdf>).

The Woensdrecht community, a village in a southern district of the Netherlands, have delivered workshops focused on providing information and education about dementia for community volunteers and directors of local institutions and associations (Broad Welfare Institution, (<http://www.bwiwoensdrecht.nl/nieuws/37-workshop-for-dementia-friendly-verenigingen#.U70NYWxwa70>)).

#### Northern Ireland

Coleraine town has committed to becoming a DFC, with over 30 local businesses signed up to a local initiative. Partnerships between the Northern Health and Social Care Trust, the Alzheimer's Society and the mayor of Coleraine proved effective as the town aims to be the first DFC in Northern Ireland. The partnership also aims to demonstrate good practice as a means to inspire other communities to follow suit (<http://www.colerainetimes.co.uk/news/your-community/a-dementia-friendly-coleraine-1-6121283>).

#### Republic of Ireland

The Galway City Dementia-friendly Communities Initiative brings together local agencies to implement aspects of DFCs. These include the Dementia Friends initiative, developing dementia-friendly businesses and promoting awareness of dementia by providing training for staff in community services (<http://www.alzheimer.ie/Get-Involved/Dementia-Friendly-Communities/Dementia-Friendly-Projects/Galway-City-Dementia-Friendly-Communities-Initiati.aspx>).

The local community of Ballina/Killaloe is adapting their community to become dementia-friendly, focusing primarily on improving the external environment, such as removing barriers to autonomous mobility in public spaces, improving signage, walkways and public seating. An initiative to create a DFC in Donegal County focused on raising awareness of dementia within the community. The 'Dementia Aware Donegal' campaign included a creative writing competition, titled 'Dear Grandma' which focused on involving primary school children, particularly those aged 10-11 years (<http://www.alzheimer.ie/Get-Involved/Dementia-Friendly-Communities/Dementia-Friendly-Projects/Dementia-Aware-Donegal.aspx>).

County Wicklow was working to become a DFC by removing barriers often faced by people living with dementia due to a lack of knowledge among community members of what it means to live with dementia. Targeted awareness and educational workshops were delivered throughout the county and included GPs, pharmacists, dentists, retailers, leisure, sports and social clubs (<http://www.alzheimer.ie/Get-Involved/Dementia-Friendly-Communities/Dementia-Friendly-Projects/Dementia-Friendly-Co-Wicklow.aspx>).

A project in Callan, County Kilkenny, implemented a county programme by providing information sessions about dementia for service providers in the community; intergenerational school programmes to raise awareness; social and creative activities, such as the Inclusive Arts Festival; advocacy and befriending services; and building a dementia-friendly environment, by changing signage, seating, and working with the town planner (<http://www.alzheimer.ie/Get-Involved/Dementia-Friendly-Communities/Dementia-Friendly-Projects/Memory-Matters---Callan,-Co-Kilkenny.aspx>). Guidance resources were developed as an outcome of the initiative, which also aimed to ensure appropriate monitoring and evaluation as DFCs are developed. In addition, a guide to creating DFCs was produced which highlighted key success factors and key lessons learned from the development of dementia-friendly projects (The Alzheimer Society of Ireland, 2014).

The Alzheimer Society of Ireland also delivered drama workshops in social clubs and Alzheimer's Cafés in various sites across the country, including Wexford, Dublin, Cork, Limerick, Galway, Sligo and Mayo. The workshops used drama to explore issues related to living with dementia. Workshops were concluded by facilitated discussions with audience members, who were invited to explore their own understanding of the drama scene (<http://www.alzheimer.ie/Get-Involved/Dementia-Friendly-Communities/Dementia-Friendly-Projects/The-Abbey-Theatre.aspx>).

### Scotland

Supported by Alzheimer Scotland, Motherwell has been working to become a 'dementia-friendly community' and a steering group identified key areas for development work. Awareness-raising activities involved the production of flyers and information packs which were disseminated by Alzheimer Scotland. The initiative recruited 20 local shops, businesses and organisations to sign up to become dementia-friendly, which involved providing staff with practical advice and information about dementia. The initiative resulted in the implementation of schemes within transport systems, police services, pubs and churches, as well as stores and local businesses to promote the development of DFCs (Shafii & Crockett, 2013).

The Motherwell initiative also distributed a leaflet containing tips for shops and businesses; displaying information and promotional materials about dementia, such as Help Line cards; partnering with key organisations to develop joint aims; and encouraging the local community to respond with understanding, dignity and respect to people who are living with dementia. A local opinion poll that asked about the scheme indicated that the public were supportive of developments to create DFCs (Shafii & Crockett, 2013).

### Sweden

A Swedish article explored dementia-related work in Scotland, Greenland, Norway and Sweden, particularly in the use of digital solutions to support independent living and the provision of quality care. Sweden is beginning to explore ideas for creating DFCs and similar initiatives will likely develop in Sweden as the result of an emphasis on sharing good practice information and support for community-borne initiatives

(<http://www.bd.komforb.se/download/18.121e30a14373481e1f444f/1393854697392/Nyhetsbrevet+fr%C3%A5n+Kommunf%C3%B6rbundet+Nottbotten+februari+2014.pdf>).

## Wales

Crossroads Care in the Vale (EMI) ([www.crossroads-vale.org.uk](http://www.crossroads-vale.org.uk)), a charity organisation that provides care and support for older people, offered examples of how shops can contribute to the development of DFCs, using a local Tesco store as an example of how services can contribute to creating DFCs. Contributions to DFCs included the ability of customer-facing staff to show awareness of the customer's needs in relation to their dementia, such as reminding a customer if they had already done their shopping earlier that day. Of greatest importance was ensuring that the customer had a respectful, kind interaction with staff, who were ready to offer support if the customer appeared to have been confused or anxious (<http://www.crossroads-vale.org.uk/2013/04/new-programme-announced-to-create-dementia-supportive-communities-in-wales/>).

In Wrexham, the symbol of a purple angel ([www.purpleangel.org.uk](http://www.purpleangel.org.uk)) has been adopted as a kite mark standard to indicate commitment to creating DFCs, since the town pledged to become the first DFC in Wales. Training manuals on how to contribute to DFCs were distributed to local shops and businesses to promote community involvement. Pendine Park care organisation launched the initiative and highlighted the value of building partnerships between a wide range of sectors and organisations, particularly with regards to their intergenerational work with Glyndr University and Coleg Cambria, one of the Wales' largest colleges (Bagnall, 2014).

### **Components of 'dementia-friendly communities'**

This review highlighted a number of important features in 'dementia-friendly communities' across Europe. These key features were highlighted in research reports and policy documents. It should be noted, while some reported these key factors in piloted projects or project outcomes, they did not necessarily refer to the implementation or development of particular projects. These documents offered guidance around good-practice and often highlighted important areas of focus from the perspective of people who are living with dementia.

- ***Autonomy, independence and empowerment***

The Department of Health (2013b) in England suggested that the promotion of individual autonomy and independence is required to create DFCs. The Alzheimer's Society (2009) indicated that enabling autonomy will require the use of assistive technologies and innovative housing solutions, which are well-integrated into mainstream communities. Maintaining autonomy in respect to decision making, planning care and being involved in research and policy developments was also of considerable importance to people living with dementia (Alzheimer's Society, 2009).

The Berlin Institute (2011) also asserted that DFCs should involve people in dementia research, care planning and design; DFCs should also enable people to contribute politically, by providing appropriate support for people living with dementia to maintain independence and autonomy. The King Baudouin Foundation highlighted the importance of respecting individual autonomy in the creation of DFCs, and that people living with dementia should not be referred to as 'patients' but as people (or in some cases, citizens) who are living with dementia. A core component of DFCs is enabling the provision of practical support to mediate, rather than emphasise, potential vulnerabilities or challenges (see for example, 'Social Innovation for Active and Healthy Ageing' (<https://www.kbs-frb.be/en/Activities/Publications/2014/312599>)).

The Northern Ireland Dementia Strategy was informed by the views of people living with dementia, who indicated that being supported to remain in their own homes and communities for as long as possible is crucial to their continued autonomy (Department of Health, Social Sciences and Public Safety, 2011). As such, initiatives to support people living with dementia to maintain autonomy and independence form a key component of DFCs. Communities can benefit from the provision of guidance for implementing schemes to promote and contribute to developing DFCs (Mitchell, 2012).

DFCs also show recognition for, and place value in, the personal experience of people who are living with dementia; a core aim is to include the voices and views of people living with dementia in all decisions that affect their lives. This can be best achieved through adopting an asset-based approach which builds on existing talents and experiences to enable a person's full involvement in their community (The Alzheimer Society of Ireland, 2012).

A German article raised important issues about the values and priorities embedded within many European cultures. The practice of judging people on the basis of their autonomy, performance and intellect are highly prized in Western culture but are incompatible with the experience of living with dementia. Further, such a culture ignores the value of emotional fulfilment within the human experience. A person with dementia may be unable to work (related to performance); they may depend on support (autonomy); and they may experience cognitive decline (intellect). It was suggested that DFCs have been successful due to their focus on promoting revised cultural values, such as using art and culture, to emphasise the value of understanding the experience of living with dementia (Kazis, 2013; [www.zukunft-pflegen.info/pflegezukunft/uploads/media/Abstract\\_Rothe.pdf](http://www.zukunft-pflegen.info/pflegezukunft/uploads/media/Abstract_Rothe.pdf); Gronemeyer & Rothe, 2012).

- ***Awareness and challenging stigma***

The Alzheimer's Society (UK) suggested that change can be achieved on a wider level through raising awareness and promoting conversations about dementia with members of the community, for example, by becoming a Dementia Friend as part of the Dementia-friendly Communities programme ([www.alzheimers.org.uk/site/scripts/documents\\_info.php?documentID=2070](http://www.alzheimers.org.uk/site/scripts/documents_info.php?documentID=2070); [www.alzheimers.org.uk/site/scripts/documents.php?categoryID=200436](http://www.alzheimers.org.uk/site/scripts/documents.php?categoryID=200436)). They called for individuals and organisations to become involved in their national Dementia Friends campaign to raise awareness of dementia and "push it to the top of the political agenda" ([www.alzheimers.org.uk/site/scripts/documents\\_info.php?documentID=790](http://www.alzheimers.org.uk/site/scripts/documents_info.php?documentID=790)). People who are living with dementia also highlighted the need to raise awareness of dementia within communities as a key aspect of developing DFCs. Evaluation studies have shown that media portrayals and awareness-raising campaigns are an effective method of 'normalising' the experiences of people who have dementia (Innovations in Dementia, 2011).

A convention in Northern Ireland, the 'Change Event', indicated that people living with dementia face difficulties in their communities due to a poor general understanding by the public and professionals, hampered by a lack of information. The Dementia Services Development Centre in Northern Ireland suggested that the importance of DFCs should be more widely publicised and best practice should be more widely communicated (Dementia Services Development Centre, 2012).

Stuttgart Impuls in Germany (2012) indicated that 'dementia-friendly communities' can be brought about by creating opportunities for an exchange of ideas, and meetings between people in the

community who have dementia and those who do not. Communities should take proactive responsibility for raising awareness of dementia, highlighting the need to learn about and accommodate the needs of people living with dementia. An attitude within communities can therefore develop, which is supportive of community-based support and activities (Demenz Support Stuttgart, 2012).

DFCs place great value on the lived experience of individuals who may no longer be active citizens, participants or consumers in their community. The recognition of these cultural challenges is a considerable factor in enabling DFCs to develop. Cultural changes require more than simply implementing a few 'measures' — a new cultural understanding of dementia is needed (Gronemeyer & Rothe, 2012). A number of projects to promote the development of DFCs highlighted the value of arts-based exhibitions and events to effect cultural change to promote the positive involvement of people living with dementia in creating DFCs (e.g. Hahn, 2010; De Rynck & Teller, 2011).

A lack of awareness and understanding contributes to maintaining stigma associated with dementia. Stigma was described as a disabling factor for DFCs, since dementia is often understood and responded to within the context of existing social constructs or narratives. Research indicated that the perception of dementia remains excessively negative, with members of the general public tending to focus on the final stages of the illness. As a result, people living with dementia often experienced increasingly limited interactions with their local environment, leading to isolation and subsequently a reduced quality of life (King Baudouin Foundation, 2013; [www.bladel.nl/dementie-om-niet-te-vergeten](http://www.bladel.nl/dementie-om-niet-te-vergeten)).

The King Baudouin Foundation indicated that awareness and understanding of dementia can be promoted by facilitating discussions about all aspects of dementia. Feelings of powerlessness, shame, anger, confusion and other difficult emotions should be openly talked about and can help to share the burden — these discussions can promote a deeper understanding of what it means to live with dementia. Discussions of this nature should reflect a nuanced image of dementia, which evolves over time ([www.kbs-frb.be/en/Search/MiscSearchOverview?title=discussions%20about%20dementia&type=docs](http://www.kbs-frb.be/en/Search/MiscSearchOverview?title=discussions%20about%20dementia&type=docs) then click on link, 'Working together for a better society').

Issues around stigma may be resolved by creating concrete opportunities for people living with dementia to continue meeting and interacting in public life. Facilitating spontaneous interaction between people living with dementia and people who have not otherwise had contact with dementia reduces social isolation and promotes public support in creating DFCs (<http://www.vumc.nl/afdelingen/Amsterdam-Center-on-Aging/nieuws/7824812/>). The involvement of celebrities or 'familiar faces' was important to raising awareness, as it fosters trust and acceptance in the general public. Mistrust between professional agencies and the general public can impact on the efficacy of awareness-raising efforts, but this can be mediated by showing recognition for the value of community members' work (De Rynck & Teller, 2011).

A project in the Netherlands found that open discussions about stigma can highlight the issue and create opportunities to change perceptions. Media portrayals, which perpetuate stigma towards people living with dementia, need to be openly acknowledged in order to break down taboos and ensure that communities understand how to contribute to a culture that is conducive to DFCs ([http://www.alzheimercentrumlimburg.nl/tinimce\\_files/20130314\\_Peel\\_en\\_Maas\\_dementievriende](http://www.alzheimercentrumlimburg.nl/tinimce_files/20130314_Peel_en_Maas_dementievriende)

[lijk - verslag conclusies en vervolg cve.pdf](#)). Media portrayals should focus on the abilities and contributions of people living with dementia, rather than the condition's frightening "symptoms" or deficit-based features (Gronemeyer & Rothe, 2012; King Baudouin Foundation, 2013).

- ***Physical environments, practical support and assistive technologies***

It has been suggested that as health and social care provision improves for people living with dementia, many more individuals will be enabled to stay living in their own home for longer. For this reason, alterations to public spaces within communities will become increasingly necessary. Designs to promote DFCs can be considered in the early stages of city-wide planning and local developments ([www.theprotocity.com](http://www.theprotocity.com)).

Developing a good business argument for creating DFCs can impact on the success of community initiatives (Innovations in Dementia, 2011). People living with dementia indicated the importance of having physical environments which enable DFCs to emerge, by removing physical barriers to full community participation (Innovations in Dementia & the Alzheimer Society of Ireland, 2012; Veiga et al, 2012). Practical support with accessing services and improving public systems, such as transport, are crucial aspects of enabling DFCs to flourish (Innovations in Dementia, 2011).

A brief guidance document was produced by the Alzheimer's Society which offered practical suggestions to improve the quality of life-experiences for people who have dementia. Areas of cognition which are typically affected by dementias were outlined, such as problems with memory, time and place orientation, sight and vision and emotional responses. Members of communities can consider how they might offer reassurance and understanding to put a person with dementia at ease. How to communicate clearly, using short sentences, was also explained ([https://www.alzheimers.org.uk/site/scripts/documents\\_info.php?documentID=130](https://www.alzheimers.org.uk/site/scripts/documents_info.php?documentID=130)).

Noisy and busy environments were highlighted as particularly confusing for many people living with dementia and guidance suggested offering practical support and alternative options, such as the use of a signature to purchase items if a person with dementia is unable to remember their PIN. Staff in community shops and facilities should be able to recognise key issues and use creative solutions to enable people living with dementia to live well within their communities (The Alzheimer Society of Ireland, 2012).

A partnership between Innovate Dementia and a number of technological development agencies in Belgium has led to technological developments which can support the involvement of people living with dementia in creating DFCs (<http://www.innovatedementia.eu/en/partners>). A Finnish research project also found that assistive technologies can support people living with dementia to remain in their communities for longer (Fondation Mederic Alzheimer, 2013). Participants in this research project indicated preferences for GPS systems and mobile technologies which assisted with localisation and access to public areas in the community. This research project also indicated that autonomy-assistive technologies were less suitable for people living with the later stages of dementia. In addition, a number of ethical questions arose from the trial of these technologies, such as identifying what is the purpose or benefit of using GPS tracking for people living with dementia, or ensuring that informed consent has been adequately granted prior to trialling any device (Fondation Mederic Alzheimer, 2013).

- ***Providing information***

Information should be provided in a way that enables a person living with dementia to make informed choices about day-to-day decisions and activities.

Nine regional dementia expertise centres across Flanders contributed to the application of evidence-based research, for example, in education and architecture. These centres can act as information hubs for more in-depth information about dementia and dementia-friendly initiatives (<http://www.vumc.nl/afdelingen/Amsterdam-Center-on-Aging/nieuws/7824812/>). Cultural events, information sessions, mainstream media, as well as campaign posters and leaflets, can also contribute to creating a culture that is conducive to DFCs. The success of initiatives should be promoted widely, with particular emphasis on disseminating examples of good practice and other key outcomes (King Baudouin Foundation, 2013; <http://www.alz.co.uk/sites/default/files/pdfs/global-dementia-charter-enablers-spanish.pdf>).

A number of documents in this review offered guidance and information about responding positively to people who have dementia. Advice, specifically related to communicating with distressed or anxious individuals who have dementia, was provided in several documents (e.g. Veiga et al, 2011; <http://www.psykoweb.dk/research/senildemens.htm>). These documents described common difficulties faced by people living with dementia, followed by tips for responding appropriately to promote positive interactions between people who have dementia and other community members. These guidance documents were mostly tailored for carers or professionals but could also be useful informational tools for members of the general public.

- ***Promoting social inclusion and community involvement***

People living with dementia indicated the importance of having adequate local support groups and other social opportunities. In addition, mainstream services can often be adapted, in relatively simple ways, to make them more accessible and inclusive for people who are living with dementia. Adequate funding and resources were key to removing barriers to social inclusion, as was the joint efforts of partnered organisations and community groups (Innovations in Dementia, 2011).

Active efforts should be made to consult communities in decision making, as this will enable the continued participation in community activities by people who have dementia, as well as family carers. These community-wide efforts can contribute to developing a culture that is inherently supportive of DFCs (Welsh Assembly Government, 2011).

Following a series of consultations with people who have dementia, and family carers, Innovations in Dementia and The Alzheimer Society of Ireland (2012) suggested several factors that impact on the extent of social integration achieved within dementia-friendly initiatives. Challenges faced by people living with dementia can be mediated by ‘normalising’ dementia. The concept of ‘being seen’ — to be perceived by community members as active and engaged — was paramount to people living with dementia, particularly with regards to attending church services, local activities and groups.

A number of actions were suggested which can be implemented to promote the social inclusion of people living with dementia. These actions also serve to involve a wide range of community members in dementia-friendly initiatives. Suggested actions include:



1. Instigating a designated 'dementia friend' in supermarkets.
2. Facilitating community-based activities which are dementia-friendly.
3. Ensuring an individual within each local organisation is responsible for maintaining facilities that contribute to DFCs (Innovations in Dementia & the Alzheimer Society of Ireland, 2012).

Overall, initiatives to create DFCs should seek to raise the visibility of people who have dementia within their communities, while also facilitating the creation of important social networks (Innovations in Dementia & the Alzheimer Society of Ireland, 2012). The King Baudouin Foundation (2013) emphasised the importance of taking into account the person behind the illness, as a person who holds a lifetime of experiences, with a unique life journey, identity and personality. Community members should seek to recognise the resources and talents of the people living with dementia in their communities, viewing people living with dementia as experts of their own lives. Above all, DFCs place value on inclusion, on the basis that a society should not exclude any of its members.

Among the more persistent negative stereotypes about dementia was the idea that people living with dementia are no longer able to make decisions. Belgian DFC projects have also placed focus on creating a culture of autonomous decision making, supported through a renewed emphasis on early care planning. Respecting people's wishes and preferences, according to their capacity, is crucial to maintaining a good quality of life (King Baudouin Foundation, 2013). Respectful, supportive attitudes can be fostered by ensuring that people living with dementia have a public voice (<http://www.alz.co.uk/sites/default/files/pdfs/global-dementia-charter-enablers-spanish.pdf>).

It should be noted that some countries have introduced legislation concerning the decision-making rights of people, including people living with dementia. In the UK, this is referred to as 'mental capacity' and specific mental capacity legislation exists in England, Wales and Scotland.

Veiga and colleagues (2012) made suggestions for supporting people living with dementia to engage fully in social activities. Encouraging quality interactions between family members is crucial as it can support their understanding of a person's interests, wishes and life history. In respect of facilitating social activity, Veiga and colleagues advised programmes to utilise the past, through identifying existing interests, hobbies and abilities, combined with the introduction of new possibilities for future physical and social activities.

The Fondation Mederic Alzheimer (2013) highlighted the importance of accounting for individual cultural identities in the creation of DFCs. They question how memory programmes can be developed if the personal identity of those who benefit from the programme is ignored. The Foundation emphasised the cultural variation that must be accounted for in creating DFCs, in order to ensure their relevance and inclusion of smaller community groups, such as minority ethnic groups or people from LGBT communities.

Social activities with other people who have dementia were also important for people living with dementia (Innovations in Dementia, 2011; Innovations in Dementia & the Alzheimer Society of Ireland, 2012). A qualitative Norwegian research project (Wogn-Henriksen, 2012) found that certain aspects of support groups were of particular importance to people living with dementia. All participants were involved with projects that aimed to maintain dignity and self-respect, which was of great value in mediating difficulties arising from stigma within society. Support groups with other people who have dementia can present opportunities to share coping strategies, human interactions and discuss specific aspects of dementia.



Alzheimer's Netherland suggested that information events and community activities should be delivered in mainstream settings, in order to involve as many community members as possible. They indicated a need to involve community members who were referred to as the 'social middle ground'— individuals and organisations who are not involved in providing specific care or support for people living with dementia. Involving the police and fire services, art and cultural institutions, schools, sports clubs, libraries, businesses and retailers can develop a more nuanced and positive image with regards to people living with dementia ([www.alzheimer-nederland.nl/media/19428/Herkennen%20en%20omgaan%20met%20dementie%20-%20Dementie%20vriendelijk%20oktober%202013.pdf](http://www.alzheimer-nederland.nl/media/19428/Herkennen%20en%20omgaan%20met%20dementie%20-%20Dementie%20vriendelijk%20oktober%202013.pdf)).

The Broad Welfare Institution ([www.bwiwoensrecht.nl](http://www.bwiwoensrecht.nl)) in the Netherlands found that 70% of older people in the Netherlands were members of at least one club or association, indicating the high importance of continued social inclusion for people who are living with dementia in the Netherlands. It was suggested that 'dementia-friendly community' initiatives can naturally arise from these community group settings. The need to provide support for family carers, participating in the continued social involvement of people living with dementia, was also emphasised since the Broad Welfare Institution found that 80% of carers felt stressed or overloaded. Support for, and from, carers is crucial to enabling the continued community involvement of people who are living with dementia in their lifelong hobbies and interests (<http://www.bwiwoensrecht.nl/nieuws/37-workshop-for-dementia-friendly-verenigingen#.U70NYWxwa70>).

- ***Monitoring and evaluation***

A toolkit was developed to monitor changes within communities and dementia-friendly initiatives in Ireland (Easton, 2014). The toolkit aimed to identify the impact that dementia-friendly initiatives have had on the lives of community members living with dementia. Four priorities were highlighted in the toolkit;

1. The need to promote the inclusion and participation of people with dementia, which should be evident in the design, development and implementation of any dementia-friendly project.
2. Key activities and outcomes should be monitored which can help to build the capacity of communities in responding to dementia.
3. The sustainability of projects, dissemination of any findings, outcomes and resources, should be recorded to promote learning in the successes and challenges of creating 'dementia-friendly communities'.
4. Crucially, desired outcomes of monitoring and evaluation methods should prioritise the views of people with dementia, in order to ensure that projects maintained relevance for community members who have dementia (Easton, 2014).

Innovations in Dementia and The Alzheimer Society of Ireland (2012) produced a range of recommendations, based on a series of consultations with people who have dementia, to ensure that 'dementia-friendly communities' achieve maximum benefit. Key actions to monitor in the development of 'dementia-friendly communities' included:

1. Keeping the voices of people with dementia at the heart of community developments.
2. Initiatives should also be suited to people who may not know that they have dementia, in addition to members of the community who may not wish to disclose their diagnosis.

3. Local solutions must be implemented — what worked well somewhere else may not be locally applicable.
4. Ensuring that individuals who are living with dementia are part of the influencing and lobbying processes, at local and national levels.
5. Promoting supportive attitudes towards dementia is crucial to developing ‘dementia-friendly communities’.

These key actions can enable the sharing of guidance around good-practice and strategies for implementing dementia-friendly initiatives within other localities. The development of good-practice guidance documents can prompt the creation of guidelines and toolkits for creating ‘dementia-friendly communities’ (Innovations in Dementia & the Alzheimer Society of Ireland, 2012).

A component of the Alzheimer’s Society’s DFC recognition process is an evaluation procedure, which ensures regular feedback, as part of annual assessments. In addition, one of the seven criteria for recognition as a DFC, by the Alzheimer’s Society, is the production of a progress report and an action plan to enable the sharing of lessons learned and other relevant information at a national level (Alzheimer’s Society, 2014b). Formal assessment processes may be difficult for smaller DFC initiatives that developed naturally, such as the DFC parish in Denmark, described earlier (Jensen & Sichlau, 2014). However, it was evident that maintaining evaluative feedback on outcomes and progress of local initiatives can offer valuable guidance for communities in effecting sustainable change.

Because of the importance of involving and including people with dementia in the development of ‘dementia-friendly communities’, it is also important that they can be involved in evaluating the impact of DFC initiatives and activities. In reality, there were few examples of this taking place, although Innovations in Dementia undertook a consultation with people with dementia. As part of this consultation, they were asked about their views of what ‘dementia capable communities’ meant to them and what factors made them good for people with dementia (innovations in Dementia 2011). This identified a range of important factors such as: improving public awareness of dementia; support for people with dementia to continue to participate; the involvement of people with dementia; making communities and mainstream services more accessible; dedicated resources; and working collaboratively.

- ***Organisational and community partnerships***

A key feature of ‘dementia-friendly communities’ is extensive joined-up working and partnerships between health and social care agencies, government bodies, local businesses, NGOs and civil society organisations. A community-wide partnership should focus on building the achievements of existing organisations and should involve a range of stakeholders. This requires a balanced approach which recognises that agencies will vary in their resource availability and organisational structures. For this reason, DFCs require recognition of the unique needs and challenges within each community (The Alzheimer Society of Ireland, 2012; Easton, 2014).

Organisations should give priority to innovative services and schemes which provide support for people living with dementia and their carers. Partnered organisations can build on existing empowerment work and should seek to develop communication resources and dissemination messages to promote a more accurate image of dementia (The Alzheimer Society of Ireland, 2012). By supporting local DFC initiatives, and gathering them into a network, entire towns and neighbourhoods

can be transformed to enable people living with dementia to maintain a sense of well-being and a good quality of life. Dementia action alliances, in England, were considered an essential (if not required) role in the development of DFCs (Department of Health 2013).

The need to build and maintain networks across regions and organisations was reiterated, as this can promote consistently good practice and cultural change. However, city-wide projects can be time consuming and require a large support base to enable the expansion of community networks and collaborations between community sectors. The city of Arnsberg illustrated this perspective, as the local authority adopted a unified approach within a city of 80,000 inhabitants. The success of these city-wide initiatives depended heavily on the collaboration of various partners, as well as the full support and involvement of people living with dementia in planning and delivering projects (King Baudouin Foundation, 2013).

The King Baudouin Foundation (De Rynck & Teller, 2011), indicated that a top-down approach can be particularly useful in making progress in community initiatives. In Belgium, local authorities have propelled local initiatives; furthermore these agencies were responsible for specific actions, such as network development. However, these top-down approaches acknowledged and valued the contributions of particular individuals and organisations within the community, which offered benefits through championing and publicising local initiatives. The Foundation asserted that a key challenge to creating 'dementia-friendly communities' relates to the need to raise awareness of the issues among the general population, which requires a cohesive communication strategy and sustained networking efforts (De Rynck & Teller, 2011).

However, a number of reports (e.g. Innovations in Dementia and The Alzheimer Society of Ireland, 2012; The Alzheimer Society of Ireland, 2012) indicated that dementia-friendly initiatives should develop from a grassroots perspective, to ensure that developments accurately represent the priorities and views of people in the community who are living with dementia. The Alzheimer Society of Ireland (2012) described 'dementia-friendly communities' as inherently community-led, rather than influenced by external agencies. By adopting a community-led approach, initiatives will more likely account for the diversity within communities, work flexibly and learn to adopt a variety of approaches (The Alzheimer Society of Ireland, 2012).

Community-led initiatives also offer a route to social engagement and peer support, as well as a channel for meaningful community involvement and influence (Innovations in Dementia and The Alzheimer Society of Ireland, 2012). It is crucial that community developments reflect the influence of people who have dementia in order to enable active citizenship and self- advocacy (The Alzheimer Society of Ireland, 2012).

### **Memory-friendly communities and similar initiatives**

The terms 'memory-friendly communities' or 'memory-friendly neighbourhoods' have sometimes been used to describe projects and initiatives which are similar to DFCs. 'Memory-friendly communities' is also used to describe projects and initiatives which more broadly support 'ageing in place' (term used to describe a person living in the residence of their choice, for as long as they are able, as they age, with the support they need) and maintain social inclusion (<http://www.scottishinsight.ac.uk/Programmes/Programmes201314/MemoryFriendlyNeighbourhoods.aspx>).

Finland's national dementia strategy is called "*Creating a "memory-friendly Finland"*" but it does not refer to 'dementia-friendly communities', apart from a general call to ensure that community support is available for people with dementia.

#### Examples of memory-friendly communities

A new collaboration was announced between the Universities of Stirling and Edinburgh in Scotland, to promote the development of insight and guidance for creating 'dementia-friendly communities'. This collaborative project, entitled 'Memory Friendly Neighbourhoods', works cooperatively with not-for-profit partners and relevant experts to deliver seminars and events, and to disseminate best practice in developing DFCs (<http://memoryfriendly.org.uk/events/>).

Buckinghamshire, in England, also described their local memory-friendly initiative. The Dementia Partnerships aim to help people living with dementia, and others with memory problems, live well in their communities. A five-year plan was devised which highlighted the need for extensive alliances between community agencies in order to create a memory-friendly society. The partnership initiative has adopted a similar approach to that used by the Dementia Action Alliance and anticipates the achievement of similar outcomes to those of DFCs, such as ensuring that people are able to remain in their own home within communities and to reduce isolation for people living with dementia and their carers (<http://dementiapartnerships.com/project/towards-a-memory-friendly-buckinghamshire>).

#### **Age-friendly initiatives**

The 'healthy ageing initiative' was born out of demographic changes and increasing life expectancy over the last 50 years. These changes have seen reductions in the threat of communicable diseases while longer term, non-communicable, conditions are increasingly common. This indicated a need for policy change, brought about through the World Health Organisation's initiative, Active Ageing (Green, 2012). Four aspects of healthy ageing were assessed in relation to member cities of the WHO Healthy Cities Network, which included 77 cities across Europe. Aspects included the extent to which older people have a public presence at strategic levels and across sectors; older people are empowered to influence personal concerns and decisions that affect them; older people are supported through age-friendly environments; and increased access for older people to a full range of services. In short, these are the prerequisites which facilitate the development of dementia-friendly cities (Green, 2012).

Europe-wide assessments of healthy ageing approaches indicated positive outcomes for policy and programme development. A key factor in developing age-friendly cities was enabling older people's access to social and physical activities which promote mental health and physical well-being. These were prioritised by older people, above access to health and care services, which in some countries are determined primarily by income and other financial resources. Enabling extensive physical mobility within and beyond the neighbourhood was key to removing physical barriers to social inclusion. Green (2012) found that the voice of older people has increasingly influenced policy development and implemented age-friendly initiatives at a city-wide level. Age-friendly environments in Europe (AFEE) brought about local and regional assessments of progress in meeting commitments towards creating age-friendly communities (<http://www.euro.who.int/en/health-topics/Life-stages/healthy-ageing/activities/age-friendly-environments-in-europe-afee>; Fondation Mederic Alzheimer, 2013).

The Centre for Strategic Analysis in France (Fondation Mederic Alzheimer, 2013) analysed good practice in developing age-friendly cities and initiatives within France and elsewhere. They suggested that cities that are suitable for adaptations, in response to an ageing population, are more densely populated. As a result, micro-adaptations can facilitate the free movement of individuals and encourage older people to be active and healthy, as well as encouraging participation in transformative projects.

Manchester has committed to becoming an age friendly city as part of the World Health Organisations' Age-Friendly Cities programme. The city's 'Valuing Older People' team (VOP) forms part of 'Public Health Manchester' and aims to implement a range of age-friendly projects, partnerships and policies. Such initiatives have paved the way for the emergence of projects and initiatives that are specifically dementia-friendly (Alzheimer's Society, 2012a; Dementia 2012).

#### An example of an age-friendly initiative in practice

Magic Me is a London-based organisation which connects intergenerational communities, using a range of performing, visual, literary and media arts to maintain connections between older people and younger members of the community. Magic Me has developed a range of projects that seek to offer meaningful connections between generations, in order to foster social progress, artistic expression and connectivity between members of the community. Anti-ageism campaigns are included in the scope of work carried out by Magic Me, as are several projects focused specifically on promoting achievements for women and girls through intergenerational connections. Magic Me do not focus particularly on dementia or enabling 'dementia-friendly communities'. However, projects tend to promote age-friendly environments which are also highly conducive to the development of 'dementia-friendly communities'. It would appear that such programmes could be ideal for adaptation to enable 'dementia-friendly communities' in a more direct way, through artistic connectivity and expression within communities (<http://www.magicme.co.uk>).

#### Factors of age-friendly environments

The World Health Organisations offered guidance related to dementia care and palliative care for long-term conditions - such as providing further training and enabling the transfer of learning through international collaboration - to improve the quality of available care, particularly within low-resourced localities (WHO, 2012). The European Innovation Partnership on Active and Healthy Ageing has facilitated multi-stakeholder partnerships, which include NGOs, technology and research providers, as well as regional and local authorities. These partnerships work jointly to raise awareness and promote better environments for older people living within communities. The Action Group D4, as part of the European Innovation Partnership on Active and Healthy Ageing, have developed 'smart' environments through the use of assistive technologies. These adapt urban environments to become more suitable for the needs of older people (European Innovation Partnership on Active and Healthy Ageing, Action Group D4, 2013).

WHO also produced a guide to developing age-friendly cities, which followed from an initiative involving 33 cities across 22 countries worldwide. Eight aspects of community environments were found to be of relevance to developing 'dementia-friendly communities':

1. The design of outdoor spaces and buildings

2. The design of housing
3. Transportation
4. Social participation
5. Respect and inclusion
6. Civic participation and employment
7. Ability to communicate and receive information
8. Access to community support and health services

([http://www.who.int/ageing/publications/Global\\_age\\_friendly\\_cities\\_Guide\\_English.pdf](http://www.who.int/ageing/publications/Global_age_friendly_cities_Guide_English.pdf)).

An international research project was announced, which seeks to explore and evaluate the role of the neighbourhood in the ability of people living with dementia to maintain a good quality of life. The research project is a collaborative effort, spanning several UK Universities (e.g. Stirling, Manchester) and one Swedish university (Linköping) (<http://www.stir.ac.uk/news/2013/12/stirlingtotakepartinneighbourhoodsanddementiastudy/>).

## Conclusions

This literature review revealed a wealth of dementia-friendly initiatives, work and progress that has taken place across Europe. National dementia strategies offered insight into the socio-political context of emerging and existing DFCs and it was evident that DFCs in some countries are rapidly expanding into regional and national networks. Where they were implemented, national programmes seemed to offer a structured method of funding, evaluating and sustaining initiatives to develop DFCs. Europe-wide projects, such as the EFID partnership, which brings together organisations from across European nations, offers such a network on a larger scale.

It seemed that local initiatives to develop DFCs can derive learning and support from the impetus of larger organisations who are implementing national programmes to promote DFCs. However, it was also evident that local community organisations were essential in the effort to ensure that community developments remain relevant and important to individuals living with dementia in the local community.

Regional and cultural differences appeared to have an impact on the nature and focus of programmes that support the development of DFCs. For instance, some parts of the UK placed considerable focus on ensuring that businesses and retailers are involved in developing DFCs, indicating a strong business-oriented focus. In contrast, the Republic of Ireland focused more on effecting cultural change, through implementing intergenerational programmes and producing guidance for other communities to become dementia-friendly.

Initiatives in Germany and the Netherlands placed considerable focus on raising awareness and increasing understanding among professionals and the general public, while providing information about dementia. This was evidenced by the range of awareness-raising events and community based activities that were developed with the aim of removing the stigma attached to living with dementia and promoting a cultural understanding. A socio-cultural change was emphasised in initiatives to promote DFCs in the Netherlands and Germany, and they often employed creative and social engagement methods to achieve DFCs. Community-based social activities and art exhibitions aimed

to inform the public and provide opportunities for interactions between community groups, including people living with dementia.

It seemed that cultural differences impacted on the emphasis within each region, highlighting the importance of context in developing DFCs. For instance, historically in Spain, community-based social care and support has been provided primarily by family members, as they often take on the main caring responsibilities for relatives who have dementia. It was suggested that smaller, localised initiatives to promote DFCs would be more appropriate within this socio-political context (Oliva et al, 2011). DFCs in the Republic of Ireland have also promoted a local, grassroots approach in the development of DFCs. They suggested that a localised perspective can ensure that the priorities and views of people living with dementia in the community are at the heart of community developments, as well as enabling a flexible approach to adopting changes.

In contrast, England has taken a more top-down approach to developing DFCs, as evidenced by the Prime Minister's Challenge on Dementia, which called for the development of DFCs. In addition, the Alzheimer's Society has implemented a national standardised process for communities to become officially recognised as a DFC. As part of the Alzheimer's Society's recognition process, membership with the Local Dementia Action Alliance is a pre-requisite, which ensures that DFCs are linked into a wider network. However, partly due to cultural differences, the recognition system may not be appropriate for some communities.

The Walloon government in Belgium implemented a region-wide programme to support the development of DFCs, in partnership with the largest national charity in Belgium, the King Baudouin Foundation. However, it seemed initiatives and programmes which promote DFCs in Belgium have taken on a grassroots perspective, whilst engaging with support, information and guidance through the larger national network. It was suggested that a top-down approach can be useful in progressing community initiatives by providing a larger network, provided they are also able to place central value on the contributions, and drive of, particular individuals and organisations within communities.

A number of aspects of DFCs were identified in this review. A lack of awareness was highlighted as a significant barrier to the progress of initiatives to create DFCs and stigma can prevent individuals living with dementia from feeling like an included member of the community. Stigma was commonly reported as a barrier to community involvement and the continuation of day-to-day activities. The promotion of autonomy and independence for people living with dementia was a central aspect of DFCs. This was facilitated by ensuring that the voices of people living with dementia are valued in discussions and decisions that affect their lives and the community.

Another crucial aspect of DFCs was the provision of practical support and adaptations to public areas in the community. This was highlighted by the Joseph Rowntree Foundation's Four Cornerstones model, as it recognised that social inclusion, influence and having a voice is often prevented due to barriers to physical mobility and difficulty navigating the physical environment. Practical support with carrying out day-to-day tasks, attending groups and events and using public transport can have substantial benefits for the community involvement of people living with dementia.

An important aspect of DFCs was the active provision of education and dissemination of information about dementia. This can promote public involvement, reduce stigma and can provide a channel for people living with dementia to have a voice in their community. The development of monitoring

systems and the evaluation of DFCs was also important, since these can contribute to the development of guidance around good-practice and the dissemination of learning.

In some countries, such as England, standardised recognition processes were adopted to ensure continuous monitoring and evaluation of ongoing DFC projects. A component of this recognition process sometimes involved the use of symbols or 'kite marks' to indicate where communities, or groups within communities, have contributed to the development of DFCs. This can enable the development of wider networks made up of communities or groups, which are all contributing to the creation of DFCs. Monitoring and evaluation of processes and outcomes can also facilitate the sharing of information and key lessons learned, as well as enabling more sustainable initiatives to promote DFCs. Some regions have taken a different approach to gathering lessons learned and examples of good practice through the production of toolkits and guidance documents for creating DFCs. These can be widely disseminated and adapted to the particular needs and priorities of local communities.





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