Understanding Dementia Friendly Communities through the testing of best practice models, in ‘Act on Dementia’ Joint Action

Final Report of Work Package 7 (WP7), Deliverable 7.2

October 2019
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Executive Summary

Work Package 7

The aim of the Act on Dementia Joint Action was: to promote collaborative actions among Member States to improve the lives of people living with dementia and their carers. The overarching objective of WP7 is to provide European Union (EU) Member States with clear, evidence-based and tested information and recommendations on how to effect change and improvement and support People with Dementia (PWD) to live at home through the development and promotion of Dementia Friendly Communities (DFC).

WP7 has two deliverables; 7.1 and 7.2. Deliverable 7.1 was the ‘Evidence Review of Dementia Friendly Communities’ (DFC) report, by Imogen Blood Associates; commissioned by the Department of Health and Social Care (DHSC), England. Deliverable 7.2 aimed to test, follow and refine the DFC model in two European pilot sites (Bulgaria, Greece) and collaborator sites (Italy and England), selected in line with recommendations made in 7.1; and using a toolkit and metrics informed by 7.1.

Partners

DHSC, England, was responsible for oversight of the pilots, ensuring consistency of methodology across test sites, and gathering evidence from sites to make recommendations as the ultimate output of deliverable 7.2. The two Joint Action pilot test sites were Bulgaria and Greece. A further two collaborator sites, Italy and England, also contributed evidence to the report to broaden the evidence base.

What is a Dementia Friendly Community?

The Evidence Review of Dementia Friendly Communities’ defines a DFC as follows: In a ‘Dementia Friendly Community’, people with dementia are included and respected. Citizens, organisations and businesses work together to remove the barriers which stop people with dementia and their supporters from participating in community life.

The ‘Evidence Review’ (deliverable 7.1) developed the ‘Four Cornerstones’ Model. The model identified four different aspects of DFCs: ‘People’, ‘Place’, ‘Networks’ and ‘Resources’, with the voices and experiences of people living with dementia running though the centre of each.
Activities

During the pilots, DFCs were established at the test sites. The establishment of a DFC at each site followed a similar pattern:

- Phase One: Forming alliances
- Phase Two: Implementation of activities
- Phase Three: Improving inclusion and community connections
- Phase Four: Raising awareness and tackling stigma

All sites engaged with PWD and their carers to inform the development and delivery of the DFC activities.

**Bulgaria** established memory cafes and elderly clubs. They gathered information from PWD and the community to understand the levels of stigma related to dementia. They also screened awareness raising films at the cinema and established caregivers’ support groups.

In **Greece**, caregivers’ school programmes were established, as well as intergenerational activities with schools and PWDs, including choir and art sessions. They also established Open Elderly Centres which have meaningful activities held in the centre in a social context, these events include Memory Enhancement Groups, Caregivers School and Memory Clinics by Health Professionals that involve PWD and carers.

In **England**, DFCs have been established for a number of years. Activities included making transport more accessible and dementia friendly, establishing activities for PWD and their families, and ensuring robust engagement with PWD in the design and delivery of the DFC activities.

In **Italy**, projects were also run in schools to reduce stigma, and a video was made of a local priest living with dementia talking about his experiences. A gym class for PWD and their carers was set up, and their local library was made dementia friendly. Police officers were also trained on how to communicate and engage with PWD.

Conclusions

The key findings of the pilot sites, for deliverable 7.2, building on the lessons learnt from the pilot sites are:

- A robust network of key organisations with good levels of engagement and buy-in and from local stakeholders, including local authorities and politicians is essential.
- Success of the DFC depends, to a large extent, on the development of the site itself, in terms of existing levels of stigma, resources available and existing networks. DFC sites go through a journey of development, and it is
essential to consider what stage the site is at before establishing a DFC initiative. Different stages will require different approaches.

- **A one-year pilot scheme is not enough time to demonstrate real change.** The most impact was demonstrated in Italy, which to some extent, is related to the longevity of the DFC site there, which has been established over a number of years.

- **A thriving network of volunteers grouped around a strong charitable sector** are essential. Volunteers not only provide a human resource but help to reduce monetary costs.

- **The nature of the site itself,** particularly the strength of existing community ties, affect the success of the DFC – tightly knit communities can offer more support but also increase the risk of stigma associated with disclosing a dementia diagnosis.

- **Involving people with dementia** is important, both at the development stage of what constitutes a DFC, and the delivery of DFC activities.

**Recommendations for communities wanting to become dementia friendly**

These are the new recommendations based on the ‘Four-Cornerstone’ model (7.1).

Based on the evidence reviewed for this report and drawn from the DFC model proposed in 7.1, this report has established a series of recommendations for EU countries who are planning to undertake a DFC project. They are grouped under the Four Cornerstones below. EU sites who establish a DFC based on these recommendations, and the lessons learnt set out earlier in the report, should be more likely to implement successful DFCs in their countries.

**Place**

- **Draw on local cultures and traditions** to help develop a truly context-specific approach, adapted to local need and want.

- **Use small scale, effective actions.** Focus on the local people that you have the most influence over; e.g. local branches of organisations rather than national chains.

- **Enable access to the wider community for PWD** by making public spaces like gyms and libraries accessible and help to normalise the presence of PWD in their communities.
People

- Put people with dementia and their families at the heart of the programme – using their input to shape and guide the activities. Establish levels of understanding, knowledge and stigma about dementia at the outset.
- Focus on a practical approach for training and use PWD as part of your activities.
- Children and young people are generally enthusiastic and engaged with the topic of dementia; use intergenerational activities to raise awareness.
- If not already in place, ensure that health and social care professionals receive high quality training to understand the importance of timely diagnosis, and post-diagnostic support.
- Educate key members of the community to increase respect and understanding of PWD and their carers and enable them to access the community.

Network

- Create a wider network through the use of social media and online sites which can be used to share information about dementia.
- Establish strong links with local administrations and political leaders. Buy in from the top is essential.
- Develop a robust network of volunteers based from a strong charity sector organisation.

Resources

- Use volunteers throughout all activities to minimise cost and maximise involvement.
- Train healthcare professionals and personnel in the initial stages, to maximise early intervention and increase sustainability of the DFC.
Conclusion: Would we recommend the Dementia Friendly Communities (DFC) model approach to other EU countries?

• The DFC model can work in a variety of contexts across the EU as demonstrated in the pilot sites.

• Takes into consideration local cultures; levels of resources and networks; and existing levels of stigma

• By taking these into account during the development and delivery of DFCs, sites will be more likely to establish a successful DFC.

• These were identified during the evidence review, deliverable 7.1, and reinforced by the findings from the pilots, including in new sites beyond North Europe.

• DFCs may not demonstrate measurable change in the short term, particularly in sites who have less robust networks, resources and higher levels of stigma.

• Important to view a DFC as a long-term commitment, which may not indicate change in the short term, particularly in sites which may require additional initial focus on understanding levels of dementia awareness and knowledge.

• Although the levels of improvement and impact vary dependent on the context, but DFCs have been demonstrated to be effective and make a positive impact across the pilot sites.
1. Introduction

1.1 What is the European Union’s Joint Action on Dementia (EUJA) and Work Package 7 (WP7)?

1.1.1 The ‘Act on Dementia’ has been a 3-year EU Joint Action which began in March 2016.

1.1.2 The aim of the Act on Dementia Joint Action was to promote collaborative actions among Member States to improve the lives of people living with dementia and their carers. It will provide practical guidance for policymakers developing and implementing their national dementia plans, policies and strategies. It also aims to provide cost-effective and practical examples of the core components of good dementia diagnosis, care and support.

1.1.3 The Joint Action is divided into 7 Work Packages, with each work package responsible for fulfilling specific objectives.

1.1.4 The overarching objective of WP7 is to provide European Union (EU) Members States with clear, evidence-based and tested information and recommendations on how to effect change and improvement and support People with Dementia (PWD) to live at home through the development and promotion of Dementia Friendly Communities (DFC).

1.1.5 The Scottish Government has overall responsibility for the Joint Action. The Department of Health and Social Care (DHSC), England, co-ordinated WP7. In its capacity as WP7 lead coordinator, the DHSC is responsible for overseeing and reporting the results of testing of DFCs in the European pilot sites (Bulgaria and Greece) and the collaborator sites (Italy and England). DHSC have also engaged with the collaborating partners: Alzheimer's Europe/European Working Group of People with Dementia; Imogen Blood & Associates Ltd; and Alzheimer’s Society, England.

1.1.6 WP7 has two deliverables; 7.1 and 7.2.
1.2 Aims and Objectives of WP7

The overall aims of WP7 was to test the validity and effectiveness of the DFC set out in the evidence report (deliverable 7.1). It seeks to answer the question: would we recommend the DFC approach to other EU countries?

1.3 What is deliverable 7.1?

1.3.1 Deliverable 7.1 was the ‘Evidence Review of Dementia Friendly Communities’ (DFC) report, by Imogen Blood Associates¹; commissioned by DHSC. It proposed a model (the ‘four cornerstones model’) summarising the structure, processes, values, and types of activities of an effective DFC. The model identified four different aspects, or ‘cornerstones’, of DFCs: ‘People’, ‘Place’, ‘Networks’ and ‘Resources’, with the voices and experiences of people living with dementia running as a common thread through each. These ‘cornerstones’ were used to evaluate several DFC initiatives in the UK.

1.3.2 Deliverable 7.1 aimed to:

- Identify best practice examples
- Provide a definition of DFCs
- Identify the components of a successful DFC, and propose a model which brings these together
- Develop a set of indicators to test the success of the pilots in the next phase of the Work Package

1.3.3 Deliverable 7.1 was based on the following primary and secondary evidence:

- 82 reports and articles identified through a systematic search for international published and ‘grey’ literature
- Three group discussions with people with dementia including the European Working Group of People with Dementia and two groups within the Dementia Engagement and Empowerment Project network in England
- 20 interviews with 25 participants with people involved in DFCs from a total of 10 countries across the EU, including two visits to DFC projects in the UK
- An online survey sent out to EU dementia leads and contacts to which 57 responses were received

¹ https://imogenblood.co.uk/dementiafriendlycommunitiesreport
1.4 **What is deliverable 7.2?**

1.4.1 Deliverable 7.2 aimed to test, follow and refine the DFC model in two European pilot sites (Bulgaria, Greece), a collaborator site (Italy) and England, selected in line with recommendations made in deliverable 7.1; and using a toolkit and metrics recommended by deliverable 7.1. This second phase of WP7 drew together data, evidence and lessons learnt from the pilot sites in combination with other evidence from deliverable 7.1.

1.4.2 The final deliverable of the WP7 is this report. It sets out the lessons learnt from the testing of the DFC model at the pilot sites and makes evidence-based recommendations that could be implemented across any EU member states which wanted to introduce a DFC.

1.4.3 The design and delivery of Deliverable 7.2 is based upon the evidence collated and presented in Deliverable 7.1. At the outset, it was agreed that the sites would follow the recommendations and conclusions set out in the earlier review, to ensure that the activities delivered were clearly evidence based. Best practice identified in the review was used to inform the selection of themes, locations, activities and models applied during the pilots.

1.4.4 **Selection of sites**

> "Pilot sites should cover both large and small populations, be set in a mix of urban and rural settings and be spread across a number of countries with different cultures, languages, economic circumstances and health and social care systems. The pilot sites should also constitute a mix of fledgling and more mature dementia friendly communities."

‘Evidence Review of Dementia Friendly Communities’

1.4.5 Based on the findings of the evidence review, the pilot sites were selected from a range of different EU countries, and the sites within the countries were also varied regarding population, levels of maturity of support for PWD and cultural differences.
1.4.6 Attributes of successful DFCs were identified in the evidence review. It was agreed that pilot sites would attempt to apply these attributes during the pilots, to ensure their activities were based on best practice. These included:

- Create a clear network of key stakeholders and organisations (a Dementia Action Alliance)
- Find out about the current experience and aspirations of people with dementia and carers
- Work with people with dementia and carers to agree intended outcomes
- Identify both community assets and obstacles to achieving the desired outcomes
- Maximise opportunities to learn and share experiences from other projects and nations
- Activities are mainstreamed into local plans, strategies and training initiatives
- Long term commitment to this agenda, including political commitment.

1.5 Evidence

1.5.1 This report forms the final output of deliverable 7.2. The report draws together evidence from:

- The ‘Evidence Review’ recommendations (Deliverable 7.1)
- The outcome of and feedback from quarterly programme board meetings, to monitor progress and update the EUJA Program Board led by the Scottish Government with findings from the pilot sites
- Findings from progress updates presented at Programme Board meetings and workshops
- Progress Test Reports received from pilot sites throughout the duration of the work package
- Final project reports provided by pilot sites
- Case studies and findings from the Alzheimer’s Society for content relating to England.

1.5.2 This evidence is drawn together to inform the recommendations and conclusions set out in this report.
### 1.6 WP7 Partners

<table>
<thead>
<tr>
<th>Logo</th>
<th>Organisation’s details</th>
<th>Role in WP7</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Bulgaria</strong></td>
<td></td>
<td></td>
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<tr>
<td><img src="image" alt="Bulgarian Society of Dementia logo" /></td>
<td><strong>Bulgarian Society of Dementia (BSD)</strong> is non-profit non-governmental national organisation of professionals which coordinates dementia diagnosis, treatment, care, and research at the national level. It works closely with universities, university hospitals, patient and professional organisations and other partners. BSD has the coordination role in the development of the National Dementia Strategy. The organisation has participated in several international projects on dementia research and care. It has a major role in educational programs for professionals involved in dementia care.</td>
<td>Leading organisation in organisation and implementation of DFC activities in Bulgaria.</td>
</tr>
<tr>
<td><img src="image" alt="Bulgarian Organization “Living with Dementia” logo" /></td>
<td><strong>Bulgarian Organization “Living with Dementia” (BOLD)</strong> is a patient organisation aiming at improving quality of life of PWD and their caregivers. It works closely in collaboration with BSD.</td>
<td>Partner organisation</td>
</tr>
</tbody>
</table>
| ![University Hospital “Alexandrovska” logo](image) | **University Hospital “Alexandrovska”**  
Alexandrovska Hospital is the first university and multispecialty hospital in Bulgaria and the largest hospital in the country. Ever since its establishment in 1879 it has been a leading national university and medical center providing round-the-clock medical care for diagnosis, treatment and rehabilitation of patients with acute or chronic diseases, injuries, conditions requiring surgery in hospital environment. | Partner organisation |
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<tr>
<th>Logo</th>
<th>Organisation’s details</th>
<th>Role in WP7</th>
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</thead>
<tbody>
<tr>
<td><img src="image" alt="Medical university of Sofia" /></td>
<td><strong>Medical university of Sofia,</strong> officially founded in 1917, is the first and largest Medical University in Bulgaria training Bulgarian and foreign graduate and postgraduate students.</td>
<td>Partner organisation</td>
</tr>
<tr>
<td><img src="image" alt="Greece" /></td>
<td><strong>A Hellenic Join Actions Core Alliances</strong> has been made with different associations including the Unit of E.U. of the Ministry of Health, the Directorate of Mental Health Ministry of Health and the National Observatory for Dementia and Alzheimer’s disease</td>
<td>Partner organisation</td>
</tr>
<tr>
<td><img src="image" alt="NESTOR Psychogeriatric Association" /></td>
<td><strong>The Psychogeriatric Association “Nestor”</strong> Nestor was founded in 2001 and is one of the largest providers of free services for the elderly in Greece. The operation of Nestor Psychogeriatric Association is threefold: an Alzheimer’s centre that houses a day centre and a clinic for short hospitalization, a day centre for Alzheimer patients, and two psychogeriatric care homes for elders with mental health issues. Nestor’s main area of activity is memory and its disorders. It operates two-day centres for Alzheimer’s disease offering many services for dementia patients and their caregivers, as well as the first short-term hospitalization clinic for patients with dementia in Greece. Every year Nestor undertakes many community awareness activities regarding issues related to dementia and old age, including seminars, public speeches, publications and awareness-raising events.</td>
<td>Responsible for the actions implemented in the municipalities of Vrilissia and Athens</td>
</tr>
<tr>
<td><img src="image" alt="NKUA National and Kapodistrian University of Athens" /></td>
<td><strong>The National and Kapodistrian University of Athens (NKUA),</strong> officially founded in April 14th, 1837,</td>
<td>Coordination of the actions implemented for Dementia Friendly</td>
</tr>
<tr>
<td>Logo</td>
<td>Organisation’s details</td>
<td>Role in WP7</td>
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<td></td>
<td>is the first University not only of Greece, but both the Balkan peninsula and the Eastern Mediterranean region. NKUA consists of academic, administrative, financial and technical units and offers a broad spectrum of services to the community that include educational, research and cultural activities. The 1st Department of Psychiatry based at Eginition Hospital works under the auspices of NKUA with a mission to serve the community and care for patients with mental health disorders through services including inpatient units, day-hospital places, and outpatient services in different specialty areas. Division of Geriatric Psychiatry (DGP) of 1st Department of Psychiatry is a specialized unit of NKUA that provides comprehensive evaluation and treatment for elderly people suffering from psychiatric and neurocognitive disorders. It consists of a network of specialized inpatient, outpatient, telemedicine and community-based services. Additionally, demonstrates a strong scientific and research interest on dementia, producing original research articles, evaluation reports, tools and other publications. The Centre for Health Services Research (CHSR) was established in 1998 comes under the authority of the Department of Hygiene, Epidemiology &amp; Medical Statistics, NKUA. The CHSR has been intensively involved in planning, organising and evaluating programs and services of health promotion and education for many years. The CHSR is the official organization that provides full scientific support to three National networks related to health promotion initiatives in Greece: The National Network of Health Promoting Hospitals, the National Network for Workplace Health Promotion and the National Network of Health Promoting Municipalities. The later aims at</td>
<td>Communities in Greece, providing methodological, scientific and expertise support.</td>
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<tr>
<td>Logo</td>
<td>Organisation’s details</td>
<td>Role in WP7</td>
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<tr>
<td></td>
<td>assisting each municipality to protect and improve the health of residents through the implementation of health promoting and educative activities.</td>
<td></td>
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**England**

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<tr>
<th>Logo</th>
<th>Organisation’s details</th>
<th>Role in WP7</th>
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<tbody>
<tr>
<td></td>
<td>Alzheimer’s Society is a UK charity that campaigns for change, funds research to find a cure and supports people living with dementia today.</td>
<td>Organisation which oversees the implementation of Dementia Friendly Communities in England (collaborating partner of WP7)</td>
</tr>
<tr>
<td></td>
<td>The Department of Health and Social Care supports ministers in leading the nation’s health and social care to help people live more independent, healthier lives for longer. DHSC is a ministerial department, supported by 15 arm’s length bodies and a number of other agencies and public bodies.</td>
<td>Responsible for oversight of pilot test site activities, as we didn’t have any day to day oversight of the pilots and gathering evidence from sites to make recommendations as part of deliverable 7.2</td>
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**Italy**

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<th>Logo</th>
<th>Organisation’s details</th>
<th>Role in WP7</th>
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<tbody>
<tr>
<td></td>
<td>Dementia Friendly Abbiategrasso: In 2016, this small town near Milan, Italy, started a journey which made it the first official Italian dementia friendly community.</td>
<td>Composed of a series of stakeholders, it is responsible for designing and implementing initiatives to make the community more inclusive, as well as measuring the results obtained</td>
</tr>
<tr>
<td></td>
<td>Federazione Alzheimer Italia is the biggest Italian non-profit organization that takes care of people living with dementia and their caregivers since 1993 with the mission of “improving the quality of life of both People with dementia and their families.”</td>
<td>Organisation which oversees the implementation of Dementia Friendly Communities in Italy, started the pilot project in Abbiategrasso and is collaborating partner of WP7.</td>
</tr>
</tbody>
</table>
2 What is a Dementia Friendly Community?

2.1 Proposing a Europe-Wide Definition

2.1.1 The 7.1 evidence review attempted to identify common characteristics drawn from evidence of successful DFCs, that could be incorporated into a Europe-wide definition. The report also made it clear that there were important caveats to the definition proposed, primarily the importance of local definition, social model of disability with the onus on society to remove barriers and achieving alliance between citizens, organisations and businesses.

“In a ‘Dementia Friendly Community’, people with dementia are included and respected. Citizens, organisations and businesses work together to remove the barriers which stop people with dementia and their supporters from participating in community life.”

Definition of a Dementia Friendly Community, ‘Evidence Review of Dementia Friendly Communities’

2.1.2 The ‘Evidence Review’ developed the ‘Four Cornerstones’ Model, set out below:

![Four Cornerstones Model](http://www.repod.org.uk/downloads/dfc.pdf)

Figure 1: Four Cornerstones Model (adapted from Innovations in Dementia)

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2.1.3 The model identifies four different aspects of DFCs: ‘People’, ‘Place’, ‘Networks’ and ‘Resources’, with the voices and experiences of people living with dementia running though the centre of each. This model has been used successfully as an analytical tool and report structure in a number of evaluations of DFCs in the UK.

2.2 The Dementia Action Alliance

2.2.1 At the core of the DFC model is an alliance (a ‘Dementia Action Alliance’ or similar), a broad network of organisations, businesses, groups and individuals, including those with lived experience of dementia, which provides leadership and vision. The evidence review report (deliverable 7.1) defines this as:

“The ‘coalition of the willing’ brings together those in the community with a role to play in making it more accessible to PWD: the ‘citizens, organisations and businesses’ mentioned in the definition... The exact composition of the alliance may vary, but it should always include PWD and their carers.”

2.2.2 The alliance should establish and communicate the core values underlying the DFC which, according to the findings of 7.1. should include:

- Being asset-based: building on local resources and the strengths of individuals including PWD and their carers
- Removing barriers for PWD from mainstream services and provision;
- Taking a rights-based approach
- Placing co-creation with PWD and carers at its heart
2.3 DFC Model

Figure 2: DFC Model

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3 Specific outputs across DFCs are delivered within eight intersecting areas of community life (arts/leisure/recreation, shops/businesses, children/young people, emergency responders, health/social care, housing, transport. The activities (outputs) that take place within these areas will vary but fall broadly into five intersecting areas of activity (voices of people with dementia and carers, place, people, networks, resources).
2.4 Areas for Action

2.4.1 Although the ‘Evidence Review’ states that the exact focus for work in any DFC needs to be determined locally – not at a national or European level – a DFC demonstrates “principles which can and perhaps should be universal”\(^4\). The British Standards Institute (2015) in its Code of Practice for the recognition of DFCs in England sets out eight ‘Areas for Action’\(^5\). These can provide a useful framework for thinking about the breadth and different types of activities which might be undertaken in an area:

- arts, culture, leisure and recreation
- businesses and shops
- children, young people and students
- community, voluntary, faith groups and organizations
- fire and police
- health and social care
- housing
- transport

2.4.2 The implementation of activities in the above areas vary depending on local priorities and resources but should aim to generate meaningful changes within the four cornerstones of DFCs.

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\(^5\) [https://shop.bsigroup.com/upload/PASs/Free-Download/PAS-1365.pdf](https://shop.bsigroup.com/upload/PASs/Free-Download/PAS-1365.pdf)
2.5 Summary of indicators for each ‘Cornerstone’

2.5.1 As part of Deliverable 7.1, a set of indicators was developed to test the success of a DFC. These were based on evidence collected during 7.1. The table below sets out the summary of indicators.

<table>
<thead>
<tr>
<th>‘People’ and ‘Places’</th>
<th>‘Networks’</th>
<th>‘Resources’</th>
</tr>
</thead>
<tbody>
<tr>
<td>Higher accessibility of health and social services related to WP7 on DFC area’s interest.</td>
<td>Evidence of stronger collaboration between member states in relation to DFC</td>
<td>Toolkits and supported materials to enable replication of DFC approach for communities, businesses and services</td>
</tr>
<tr>
<td>Services and businesses report increased/ improved usage by PWD and their carers</td>
<td>Increase in the number of networks and partnerships, working for the benefit of DFC</td>
<td>Availability of publications and other printed material, websites and other information databases</td>
</tr>
<tr>
<td>PWD and their carers report improved accessibility of public spaces, buildings and/or information</td>
<td>Broad partnerships, including PWD</td>
<td>Policy developments</td>
</tr>
<tr>
<td></td>
<td></td>
<td>Local champions</td>
</tr>
</tbody>
</table>

Table 2: Summary of Indicators from The Four Corner Stone Model

2.6 The World Health Organisation (WHO) framework for effective Dementia Friendly Communities

2.6.1 The graphic below, by the WHO, presents a general framework which shows how certain resources and structures (the inputs) enable interventions in the form of policies, services and programs (the outputs) that help improve the age-friendliness of the physical and social environment (the outcomes). These, in turn, contribute to improving the health and wellbeing of older residents and of the population as a whole (the impact). It also places equity at the core, as a cross-cutting principle, to highlight the importance of ensuring equity in the distribution of inputs, outputs, outcomes and impact.

2.6.2 These indicators can be used to measure the baseline level of age-friendliness of the city and monitor how it changes over time as relevant

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6 [https://apps.who.int/iris/bitstream/handle/10665/203830/9789241509695_esp.pdf?sequence=1](https://apps.who.int/iris/bitstream/handle/10665/203830/9789241509695_esp.pdf?sequence=1)
interventions are implemented. They were developed as part of the WHO’s Age Friendly City Guide.

2.6.3 The indicators are a helpful tool in addition to the DFC indicators when considering how to measure the impact of DFCs.

Figure 3: WHO framework model for effective DFCs

2.7 Evaluation Methods

2.7.1 The approach taken for the pilots was for each pilot site to be managed locally by the WP7 partners under DHSC’s remote supervision. Partners had to be willing and able to participate for the duration of the pilot (and a little beyond) and have the capacity, resource and buy-in from the key local actors, with clear local leadership and participating partners. DHSC was able to apply, monitor and assess the DFC model remotely and realistically in order to test its universality, i.e. whether it works as a system-wide approach that could be adapted to other (European) contexts, in a way that is customised to local communities’ needs. This approach was considered to replicate how a DFC would be implemented outside of pilot conditions where third-party support could not be relied on.
2.7.2 Accordingly, it was agreed that the pilot sites would adopt, as evaluation criteria, the relevant indicators suggested in the deliverable 7.1 evidence review; and also develop their own, additional, measures, identifying criteria to measure success in accordance with local priorities. This enabled a collaborative approach to establish what a successful DFC would look like in their respective countries.

2.7.3 At the start of the funding period, the pilot sites were required to develop and agree an evaluation framework to test the indicators selected from those identified in Deliverable 7.1. This framework set out a Theory of Change for their initiative (i.e. which problems they planned to tackle and how) and selected relevant indicators from 7.1, and a plan for measuring these, in line with the premise that the DFC model must be adapted to suit local requirements.

2.7.4 A mix of evaluation methods was used to measure the success of Dementia Friendly Activities conducted at the sites, including:

- **Process evaluation**, to ensure that programme of action is carried out according to plan;
- **Impact assessment**, determining the changes in attitudes in the target audience;
- **Outcome evaluation**, allowing an estimate of improvements to the lives of PWD to be made.

2.7.5 The planned lifecycle of the pilots was 12 months (running from March 2018 until March 2019) however, this was extended during which time partners were required to monitor the progress of the pilots over time and evaluate final progress at end of year against the agreed indicators, with some support from the coordinating centre. See Joint Action Evaluation Framework in Appendix.

2.7.6 The Department of Health and Social Care (DHSC), England, was responsible for overseeing and testing the DFCs in the pilot sites, collating the findings and making recommendations. The pilot sites and collaborating partners were asked to submit final reports detailing their aims, activities, lessons learnt, and findings. These were reviewed and analysed by DHSC for the production of this report. Information such as surveys, numbers of activities, what worked well, and challenges identified were brought together by DHSC and key themes were identified. DHSC drafted recommendations and conclusions, which were developed in conjunction with the pilot sites and collaborating partners. These form the basis of this report.
2.7.7 The table below sets out how each site gathered evidence to evaluate the impact of their activities. The results of this evaluation are set out later in the report.

<table>
<thead>
<tr>
<th>Country</th>
<th>Source of evidence for evaluation</th>
</tr>
</thead>
</table>
| Italy    | • Features of the activities (planning, time, location, resources) and number of participants  
          • Satisfaction questionnaire  
          • Knowledge tests  
          • Attitude questionnaire  
          • Qualitative data come from focus groups or deeper interviews  
          • Interviews of PWD by psychologist |
| Bulgaria | • Knowledge questionnaire  
          • Attitude and stigma questionnaire  
          • Satisfaction questionnaire  
          • Features of the activities (attendees; numbers)  
          • Numbers of meetings and contract agreements |
| Greece   | • Stigma evaluation questionnaires  
          • Qualitative data collected through Focus Groups  
          • Number of activities as below:  
            • Number of Memoranda signed with Municipalities  
            • Number of specified activities in each Municipality planned for rendering the communities Dementia Friendly.  
            • Number of Dementia Municipality Friends  
            • Number of planned activities implemented (e.g. Memory Clinic, Caregiver School, Awareness-raising event, Alzheimer’s Café etc.)  
            • Number of participants and time line of the scheduled activities (Caregivers’ School, Memory Enhancement Groups, Intergenerational Activities, employee training)  
            • Number of Scientific Publications  
            • Amount of Media coverage |
3 Features of the Pilot Site Locations

3.1 Site selections

3.1.1 In the selection of the pilot sites, we looked to address some of the limitations of the 7.1 review, which drew evidence from more mature DFCs, namely in Northern European countries, meaning that the UK, the Netherlands, Germany and Norway were over-represented in the evidence base. However, the 7.1 evidence review sought to counter this with examples and feedback from participants from countries where the response to dementia was at a much earlier stage of development, including Bulgaria.

3.1.2 DHSC employed an inclusive approach engaging a range of partners across a reasonable EU geographical spread. This was in line with the 7.1. recommendation that, “for the tested toolkit to be most amenable to diffusion and successful adoption throughout EU28, the pilot sites should cover both large and small populations, be set in a mix of urban, suburban and rural settings and be spread across a number of countries with different cultures, languages, economic circumstances and health and social care systems. The pilot sites should also constitute a mix of fledgling and more mature dementia friendly communities.”

3.1.3 Accordingly, the sites for 7.2 were selected because they demonstrated a spread of appropriate characteristics whilst representing Southern and South-eastern European communities. This provided a strong social, cultural and economic counterpoint to the findings of 7.1.

3.1.4 Bulgaria was an example of a relatively inexperienced DFC; while key partners Italy and England represented more mature dementia communities. Two of the sites in Greece, meanwhile, provided a more rural focus and areas with different socioeconomical status.

3.1.5 Each country volunteered different background information, reflecting an important difference in starting points – and, by extension, the need for site-appropriate applications of the DFC model. Bulgaria contributed pre-pilot survey data that revealed prevalent baseline attitudes of stigma and a lack of general knowledge of or education and awareness surrounding dementia. These are issues which in Italy, as one of the more ‘mature’ partners (in terms of its approach to dementia and a country which exemplifies tight intergenerational ties, as well as having the oldest population in Europe), have
been overcome to a larger degree. Italy is also the most economically developed of the three, with an average income (based on monthly salary) of over 45% higher in Italy than in Greece and 80% than Bulgaria.

3.1.6 The decision to include sites in Italy and subsequently to draw on evidence from DFCs in England allowed the development of a more robust evidence base, by providing findings from a site that is different to the Bulgarian and Greek pilot sites. Italy and England, whose work on DFCs were more advanced in terms of development and evaluation (and much of whose work had been carried out ahead of and independently of the pilot programme), were added as collaborating partners.

<table>
<thead>
<tr>
<th>Country</th>
<th>Participating municipalities/town</th>
<th>Urban/rural</th>
<th>Dementia Prevalence by Country (%)</th>
<th>Population by Country &gt; 65 (%)</th>
<th>Socio-economic Status by Ranking in Europe (Country)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Bulgaria</td>
<td>Ravno Pole</td>
<td>Urban</td>
<td>1.49⁷</td>
<td>21⁸</td>
<td>26⁹</td>
</tr>
<tr>
<td></td>
<td>Elin Pelin</td>
<td>Rural</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td>Sofia</td>
<td>Urban</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>England</td>
<td>Amber Valley, Derbyshire</td>
<td>Urban</td>
<td>1.65⁷</td>
<td>18⁸</td>
<td>2⁹</td>
</tr>
<tr>
<td></td>
<td>Blackpool, Lancashire</td>
<td>Urban</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td>Bradford, West Yorkshire</td>
<td>Urban</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td>Alsager, Cheshire East</td>
<td>Urban</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td>Shropshire, Telford and Wrekin</td>
<td>Urban</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td>Luton, Bedfordshire</td>
<td>Urban</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td>Newport, Wales</td>
<td>Urban</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Greece</td>
<td>Vrilissia</td>
<td>Rural</td>
<td>1.77⁷</td>
<td>22⁸</td>
<td>21⁹</td>
</tr>
<tr>
<td></td>
<td>Byron</td>
<td>Rural</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td>Athens (Koukaki / Acropolis area)</td>
<td>Urban</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Italy</td>
<td>Abbiategrasso</td>
<td>Urban</td>
<td>2.09⁷</td>
<td>23⁸</td>
<td>4⁹</td>
</tr>
</tbody>
</table>

Table 3: Table comparing features of pilot sites

⁸ https://data.worldbank.org/indicator/SP.POP.65UP.TO.ZS

26
3.2 **Bulgaria**

Country profile

3.2.1 The prevalence of dementia in Bulgaria is 1.49%, with an estimated 110,000 people living with dementia. 21% of Bulgaria’s population is aged over 65. Bulgaria is fifth in the world for its growth in an aging population, with drastic changes in the demographic structures expected by 2050. The forecast is that by 2050 those age 60 and over will make up over 30% of the country’s population which could threaten social systems with degradation, according to demographic experts. ¹⁰

> “By contrast, the birth rate is low and young Bulgarians are now either emigrating or moving to larger towns. As a result, many older people in Bulgaria are now isolated, both in medical and in social terms”

3.2.2 The usual care for PWD in Bulgaria relies on the family at home, with 95% receiving care at home and 5% living in long-term institutions. There is a great impact on families, formal and informal caregivers, changing their lifestyle and reducing social contact and communication and activities in the community. Most family members and caregivers experience insufficient support and inclusion. Society (at national level, municipality level and individual level) is not prepared for the significant challenge of diagnosis and post-diagnostic care for PWD.

3.2.3 There have been few previous activities or campaigns for caregivers aimed at increasing their knowledge and awareness of dementia. These were mainly directed at early diagnosis of cognitive decline. Studies concerning attitudes toward dementia or dementia friendly community activities had not been introduced in Bulgaria previously.

Bulgaria established pilot sites in **three** participating municipalities:

<table>
<thead>
<tr>
<th>Pilot sites in Bulgaria</th>
<th>Urban/Rural</th>
</tr>
</thead>
<tbody>
<tr>
<td>Elin Pelin</td>
<td>Urban – Small town</td>
</tr>
<tr>
<td>Ravno Pole</td>
<td>Rural - Village</td>
</tr>
<tr>
<td>Sofia</td>
<td>Urban - Capital City</td>
</tr>
</tbody>
</table>

Table 4: Pilot sites in Bulgaria

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Characteristics of each site

Elin Pelin

3.2.4 A small town in Central Western Bulgaria with a population of 7,430, covering an area of 11.23 sq miles. It is the administrative centre of Elin Pelin Municipality, located in central Sofia Province. It lies in the Sofia Valley, with the slopes of the Balkan Mountains to the north and Sredna Gora to the south-southeast, 24 km southeast of the capital city of Sofia. Elin Pelin was renamed after the noted writer of the same name in 1950 and was proclaimed a town in 1960. The area of Elin Pelin is one of the best preserved centres of the traditional ethnocultural subgroup of the Bulgarian people, the Shopi. There are GP and Pharmacy offices, social care office, library, elderly club.

3.2.5 A Memorandum of Cooperation has been signed between Bulgarian Society of Dementia and the Municipality of Elin Pelin. The Municipal authorities agree to support the experts in organizing meetings, trainings with staff of libraries, healthcare and social services, police and post offices, schools, elderly clubs. Activities with regard to rising awareness, information and access to timely dementia diagnosis and treatment, campaigns concerning healthy and active ageing were also supported in Elin Pelin.

Ravno Pole

3.2.6 A village located 10km to the east of Sofia in the Obshtina Elin Pelin District of Western Bulgaria (Sofia province). The village, which covers 10 square miles and whose population is 1500, has a primary school, a kindergarten, a community center, GP office and a library, as well as a city hall and a post office and an elderly club. There are many mineral springs in the surrounding areas. It is the least socioeconomically developed of the three Bulgarian pilot sites. Activities with regard to rising awareness, information and access to timely dementia diagnosis and treatment, campaigns concerning healthy and active ageing were also supported in Ravno Pole.
**Sofia**

3.2.7 The capital and largest city of Bulgaria; the city is at the foot of Vitosha Mountain in the western part of the country. Being in the centre of the Balkan peninsula, it is midway between the Black Sea and the Adriatic Sea, and closest to the Aegean Sea. Sofia hosts some 1.23 million residents within a territory of 190 square miles, a concentration of 17.5% of the country population within the 200th percentile of the country’s territory.

3.2.8 Being Bulgaria's primary city, Sofia is a hometown of many of the major local universities, cultural institutions and commercial companies; and is one of the most visited tourist destinations in Bulgaria alongside coastal and mountain resorts.

3.2.9 The city's GDP (PPS) per capita stood at €29,600 ($33,760) in 2015, one of the lowest for a capital region in the EU, but well above other cities in the country. Services dominate the economy, accounting for 85.9% of gross value added.

3.2.10 There is great number of healthcare institutions – 67 public and private hospitals, 524 outpatient medical specialized centres for diagnosis and treatment, as well as for rehabilitation (data from 2019). Only some of the units at university hospitals are specialized for dementia diagnosis and treatment. The bigger expert centre is the Memory centre at University Alexandrovska Hospital, there are also specialized dementia units at University Hospital ‘St. Naum’ and at University Hospital ‘Queen Joanna’.

3.2.11 Social services for PWD at a more progressed stage are organized at municipality level (rehabilitation units, meals on wheels). Day-care centres for PWD are under development. Places for social interactions (elderly clubs, cafes, libraries) are not prepared to integrate PWD.
3.3 **England**  
**Country Profile**

3.3.1 In England the prevalence of dementia is 0.8%, with 18% of the country’s population aged over 65.

3.3.2 An estimated 850,000 people are living with Dementia in the UK, of those 676,000 in England.\(^{11}\)

3.3.3 An estimated 46.8 million people are living with dementia and the numbers affected are expected to double every 20 years, rising to around 115.4 million in 2050.

3.3.4 In 2015, the Challenge on Dementia 2020 was published by the Department of Health and Social Care. The Strategy’s aim was to make England the best country in the world for dementia care. It included commitments under the themes of research; health and care; awareness and risk reduction.

3.3.5 England is a country that is part of the United Kingdom. It shares borders with Wales and Scotland to the north. The Irish Sea lies west of England and the Celtic Sea to the southwest. England is separated from continental Europe by the North Sea to the east and the English Channel to the south. The country covers five-eighths of the island of Great Britain, which lies in the North Atlantic, and includes over 100 smaller islands, such as the Isle of Scilly and the Isle of Wight.

### Characteristics of each site

3.3.6 **Amber Valley** is a local government district and borough in Derbyshire, England. It takes its name from the River Amber and covers a semi-rural area with a number of small towns whose economy was formerly based on coal mining and engineering. The Local Authority population at the 2011 Census was 122,309.

3.3.7 **Blackpool** is a town and seaside resort on the Lancashire coast in North West England. In 2016, the population was 139,720. Tourism rates are high in the area.

\(^{11}\) [https://www.england.nhs.uk/mental-health/dementia/]
3.3.8 **Bradford** is a city in West Yorkshire, England, in the foothills of the Pennines, 8.6 miles west of Leeds, and 16 miles north-west of Wakefield. Bradford has a population of 529,870, which makes it the seventh-largest city in the United Kingdom.

3.3.9 **Alsager** is a town and civil parish in the unitary authority of Cheshire East and the ceremonial county of Cheshire, England, to the north-west of the city of Stoke-on-Trent, and east of the railway town of Crewe. The town has a population of 11,775.

3.3.10 **Shropshire, Telford and Wrekin** are an area in the West Midlands, made up of the boroughs of Shropshire, and Telford and Wrekin. The largest towns are Telford and Shrewsbury.

3.3.11 **Luton** is a large town, borough and unitary authority area of Bedfordshire, situated in the south east of England, but in the East of England region for administrative purposes. It has a population of 214,109.

3.3.12 **Newport** is a city and unitary authority area in south east Wales, 12 miles northeast of Cardiff. At the 2011 census, it was the third largest city in Wales, with a population of 145,700.

3.4 **Greece**

**Country profile**

3.4.1 Greece has an ageing population. By 2050, Greece’s population is expected to shrink by between 800,000 and 2.5 million, to between 8.3 and 10 million. One in three of its residents will be over the age of 65 (compared to 21% currently and 7% in 1951). In the past 65 years, the population has risen by 46% but the number of over-65s has quadrupled and the over-85s have doubled in the same period.\(^{12}\)

3.4.2 Greece has a historically strong tradition of intergenerational and extended family ties, but the emergence of urbanisation and industrialisation has meant that younger people seek economic solace in the big town and cities (with many leaving Greece altogether in the wake of the economic crisis), leaving rural areas almost exclusively to the aged.

3.4.3 The prevalence of dementia in Greece in over 65s is 5.0%, in the lower range of that reported in many other European countries and globally.\(^\text{13}\) In November 2014, a National Dementia Plan was approved and in December of 2014 a National Observatory for the implementation of National Dementia plan has been established. Greece was one of the first countries in Europe to introduce ‘memory screening’ on the 260 Municipalities open elderly care centers (KAPI) coordinated by different NGOs such as Hellenic Alzheimer’s Associations and/or by social services of municipalities.

3.4.4 This make municipalities the appropriate place for developing primary care dementia actions.

3.4.5 The Hellenic Join Action Group (1\textsuperscript{st} Department of Psychiatry, Nestor Psychogeriatric Association, Center for Health Services Research and the Directorate of Mental Health), established Core Alliances with different associations including the Hellenic Psychiatric Association, the Panhellenic Physiotherapists’ Association, the Hellenic Association of Gerontology and Geriatrics, the Athens Association of Alzheimer’s Disease and Related Disorders, the Hellenic Psychogeriatric Association, the National and Kapodistrian University of Athens (1\textsuperscript{st} Department of Psychiatry, Faculty of Nursing). The aim of the Group was to implement DFCs in Municipalities.

3.4.6 On 12 April 2018 a meeting with the Unit of E.U. of the Ministry of Health, the Directorate of Mental Health, Ministry of Health and the National Observatory for Dementia and Alzheimer’s disease took place in the Ministry of Health in order to provide all the necessary information regarding the Joint Action project on DFCs and get support for the actions scheduled in the Municipalities.

Greece established pilot sites in \textbf{three} participating municipalities:

<table>
<thead>
<tr>
<th>Pilot Sites in Greece</th>
<th>Urban/Rural</th>
</tr>
</thead>
<tbody>
<tr>
<td>Athens (Koukaki/Acropolis area)</td>
<td>Urban</td>
</tr>
<tr>
<td>Byron</td>
<td>Suburban</td>
</tr>
<tr>
<td>Vrilissia</td>
<td>Suburban</td>
</tr>
</tbody>
</table>

\textit{Table 5: Pilot sites in Greece}

\(^{13}\) Alzheimer Dis Assoc Disord _ Volume 32, Number 3, July–September 2018
Characteristics of each site

3.5  **Vrilissia**

3.5.1  Vrilissia is a suburban municipality, far inland, in the North Athens regional unit in the Attica region, an administrative region of Greece that also encompasses the capital. Located in the Athens basin, at the southwestern foot of Mount Penteli, Vrilissia covers a total area of 3.8km² and has a population of 30,700, the smallest of the three sites. An affluent (and green) suburb featuring substantial forest land, its per capita income is 36,624,87€ making it the wealthiest of the three sites.

3.5.2  Its healthcare services are: Sismanoglio General Hospital and two elderly centers (no dementia-specific services). The Organization of Social Protection and Solidarity of the Municipality of Vrilissia is one of the partners in the Hellenic Joint Action Core Alliance established by the partner.

3.5.3  A Memorandum of Cooperation has been signed with the Vrilissia Municipality with the aim of making it more dementia friendly.

3.6  **Byron**

3.6.1  Byron (or “Vyronas”) is an inner suburb of Athens, located about 3km southeast of Athens city center, and extending south-east to the forested Hymettus mountain. A continuation of Athens, and formerly officially part of the city, the built-up area, which covers approximately 9.2km, is both a suburban town and a municipality. The town is named after Lord Byron, the Romantic poet, who is a national hero of Greece. Byron has a population of 61,308, and an income of per capita of 24,477,18€.

3.6.2  Out of the three sites, Byron has the biggest offering of healthcare services: A national health center, a mental health center, and four open elderly centers. The Municipality of Byron was already known to be the first community that developed a memory clinic, in 2002, in the open elderly center providing services for patients with dementia and their caregivers. This was in collaboration with specialized care for the dementia unit of the 1st Department of Psychiatry and the Mental Health Center.
3.6.3 A Memorandum of Cooperation has been signed with the Byron Municipality with the aim of making it more dementia friendly.

3.7 **Municipality of Athens – Koukaki area**

3.7.1 Koukaki is a Southeast district of the Municipality of Athens, in the Acropolis area of the city. Covering an area of 6.8 km², with a population of 100,900 people, it is the most densely populated of the three sites, in keeping with its urban area status. A vibrant and creative residential neighbourhood bordering with the historical district of Plaka, Koukaki, whose popularity with tourists is growing, is located just south of the Acropolis and Mount Filopapou. Koukaki’s income per capita is 20.917€.

3.7.2 Koukaki has one friendship club for elderly residents, but no hospital, mental health or dementia-specific services of its own.

3.7.3 A Memorandum of Cooperation has been signed with the Athens Municipality, where several of the partners in the Greek alliance are based: The Athens Association of Alzheimer’s Disease and Related Disorders, the Ethniko Kai Kapodistriako Panepistimio Athinon, etc.

3.7.4 The partners estimated that the number of the total population of elders registered in the Open Care Centers for the Elderly (KAPI) in all the above areas are approximately 1,000 persons (2 KAPI Municipality of Vrillissia, 4 KAPI for Municipality of Byron, 1 KAPI in the KOUKAKI region of the Municipality of Athens (1st Municipal Sector).

3.8 **Italy**

**Country profile**

3.8.1 Italy has the oldest population in Europe, with the highest percentage of the population aged 80 or over, making it an ideal country in which to implement DFC.
In October 2014, a National Dementia Plan was approved in Italy. Italy was one of the first countries in Europe – or worldwide – to introduce ‘memory clinics’, centres that are specifically dedicated to diagnosis and management of Alzheimer’s disease and other dementias.

The response to the pre-pilot survey question “Who are caregivers?” conducted by the partner revealed that 60% of caregivers are children, reflecting the intergenerational ties and family-oriented makeup of Italy. (20% of carers are partners). This makes for fertile national conditions to empathise with and understand dementia. There is already an established need for Intergenerational Approach. However, the taboo surrounding dementia is still considered to be strong in many communities.

Italy had one participating pilot site:

3.8.4 Abbiategrasso (town)

Abbiategrasso represents the first DFC in Italy, but the pilot site was launched in July 2016, making it one of the mature dementia friendly community sites. As Italy’s DFC has been running for over 2 years, it had an opportunity to test and trial few different approaches that are useful to share with newly established sites, in Bulgaria and Greece, that are still in the development phase.

3.8.6 A core alliance or project group (Tavolo Promotore) was set up at the beginning of the project, with functions to promote and monitor initiatives with representatives of the municipality, ASST, Golgi Institute, Golgi Cenci Foundation, Italian Association of Psychogeriatric.

3.8.7 The site now has a large base of supporters from a range of stakeholders: the decision makers, businesses, people with lived experience, including PWD

In Italy, more than 1 million people are living with dementia, representing approximately 2.09% of the total population. The number of PWD as a percentage of the population is somewhat higher than the EU average of 1.55%. An estimated 40% of all PWD have not received a diagnosis.\(^1\) (CNR)
and their family/carers as well as local volunteers, including young people and other community groups. In that respect the Italian site has had the opportunity to trial various initiatives and is an invaluable resource of lessons learned, best practices as well as useful materials, including successful stakeholder engagement and management experience.

Characteristics of each site

3.9 Abbiategrasso

3.9.1 Abbiategrasso is a community and town in the Metropolitan City of Milan, Lombardy, northern Italy, situated in the Po valley approximately 22 kilometres from Milan and 38 kilometres from Pavia. It covers an area of 18.7 square miles and has a population of 32,000.

<table>
<thead>
<tr>
<th>Population by age</th>
<th></th>
</tr>
</thead>
<tbody>
<tr>
<td>Up to 25 years</td>
<td>7619</td>
</tr>
<tr>
<td>25-60 years</td>
<td>16,321</td>
</tr>
<tr>
<td>More than 60 years</td>
<td>8469</td>
</tr>
</tbody>
</table>

3.9.2 Abbiategrasso is a fairly cohesive local community, an urban area, gathered around a historical centre, not therefore a dormitory city of the Milan suburbs, but a territory with its own economic and social life. In addition, there is a historically important structure for the assistance and care of PWD, the Geriatric Institute C. Golgi, and a research centre, the Golgi Cenci Foundation, which carries out studies and research on brain aging and dementia. Furthermore, Federazione Alzheimer Italia has immediately found a wide availability to collaborate in the local institutions, the Municipality and the local sanitary district (ASST).

3.9.3 In Abbiategrasso, considered a “friendly” town, there is a good presence of associations of various kinds, many of them social volunteering. The community of Abbiategrasso was already the location of a longitudinal study on cognitive functions and dementia, which started in 2009 recruiting more than 1300 people born between 1935 and 1939. In the city there is also a Research Centre for studying brain aging and a geriatric multilevel facility with
memory clinic as well as special care unit for PWD in the moderate-severe stage of the disease, with behavior that challenges.

3.9.4 The first Dementia Friendly Community in Italy was promoted here by Federazione Alzheimer Italia in early 2016. The preference for this town was dictated by the number of inhabitants (32,000), and because it is located not far from Milan. Also, Abbiategrasso is already a friendly community with an embedded culture and tradition of solidarity, as demonstrated by the large number of voluntary associations. There was already an established base of volunteering and expertise. However, beyond the assistance services, there was not enough awareness about the relationship between PWD and the community itself.

3.9.5 On April 2016 the City Council passed a resolution for the Deputy Mayor, the councillor for Social Services and some other officials to be active participants in the dementia friendly initiative.

3.9.6 This is in line with the recommendation from the All-Party Parliamentary Group (APPG), that ‘A local authority representative should sit on the steering group of each dementia-friendly community’ which was referred to as good practice in the evidence review (deliverable 7.1).
4 Expected Outcomes

This Chapter sets out what outcomes each site expected their DFC activities to achieve. These expected outcomes are set out under the Four Cornerstones Model.

4.1 Places
The underpinnings of the Places cornerstone recognise how public spaces, housing, transport and written information affect people with dementia.

4.1.1 Bulgaria aimed to establish easily accessible places (e.g. library, movie screen places, elderly club, GPs office, memory centre) for meetings, discussions, workshops, leisure activities, consultations etc. with the aim to improve practical support for PWD and caregivers in three municipalities.

4.1.2 Greece intended to deliver training for professional groups working in key community services to help them communicate with PWD, resulting in improved access to local businesses and services for older persons and/or PWD.

4.1.3 Italy aimed to increase access to community spaces for PWD, including public spaces such as the library or municipal offices, and private sector places such as the shops and gym. Such Dementia Friendly spaces were intended to carry markers or signage to indicate that they were dementia friendly. Spaces such as meeting rooms and schools were also intended to be made available for DFC activity.

4.1.4 As the DFC programme has been running in England for a number of years, they have set out the recommended aspects of a successful DFC, as opposed to specific expected outcomes for each of the pilot sites. DFCs in England are recommended to raise the profile of their work to increase reach and awareness to different groups in your community and focus their plans on a number of key areas that have been identified locally.
4.2 **People**
The people cornerstone indicator is designed to improve the accessibility of health and social care services for PWD and identify whether services and businesses have reported increased and / or improved usage by people with dementia and their carers.

4.2.1 **Bulgaria** aimed to increase dementia awareness amongst the general public, and possibly change society’s attitudes and behaviours towards PWD; to reduce stigma and fear surrounding dementia; to improve understanding of how to practically support PWD, increase awareness, empathy, skills and confidence with regards to treatment of PWD and caregivers among the general public; health and social care professionals; administrative staff; private sector; and students.

4.2.2 They aimed to train them in how to respond positively and supportively to PWD and their caregivers; and to increase their knowledge and awareness of dementia; to allow exchange of knowledge and experience between caregivers; and to empower PWD to make a contribution to everyday life in the community.

4.2.3 DFCs in England are also recommended to develop a strong voice for people with dementia living in your communities.

4.2.4 **Greece** focused on the education and empowerment of PWD through effective programmes, seminars, groups and the development of Dementia friendly elderly centers with a variety of services such as Memory Clinics, Caregivers School, Intergenerational Activities; and the facilitation of their active participation in social life. Their aim was to raise public awareness on dementia, alleviate/eliminate stigma associated with dementia, and educate the public, on the prevention and management of dementia. **Dementia Friendly Municipalities team** aimed to inspire key stakeholders in the development of dementia-friendly action plans. Training of professional groups (e.g. bank, supermarket and local services employees) on how to communicate with PWD and alleviate caregivers’ burden.

4.2.5 In **Italy**, the DFC programme has developed along two themes: 1) promoting participation and giving voice to PWD and family members; 2) overcoming stigma and improving access to local resources and initiatives. They aimed to; a) empower PWD and their families through both the participation in and planning of the initiatives. They also aimed to reduce and overcome the
stigma associated with dementia. This included training of people who work in service industries and come into contact with PWD (e.g. policemen, clerks, shopkeepers and volunteers). An important goal was participation of the younger generation in DFCs, mainly students of high schools. Professionals such as geriatricians, neurologists, psychologists, nutritionists, social workers, and lawyers were to be involved for teaching and training. Journalists from the local press, radio and television participated from the beginning in disseminating news about dementia and DFC.

4.3 **Resources**
The resources cornerstone targets a community-based approach to encourage accessibility and the resources that are available for people with dementia and their carers involved.

4.3.1 **Bulgaria** anticipated the establishment of wide-reaching partnerships with key stakeholders and volunteers in the municipalities and the adoption of long-term prevention programs for elderly people and PWD in municipalities embedded into local municipal plans, e.g. information campaigns.

4.3.2 DFCs in **England** are recommended to identify the person to take responsibility for driving forward the work to support your DFC, and ensure that individuals, organisations and businesses are meeting their stated commitments. They are also recommended to have a plan to raise awareness about dementia in key organisations and businesses within the community that support people with dementia. They should also have in place a plan to update the progress of your community after six months or one year.

4.3.3 **Greece** aimed to promote the adoption of dementia friendly policies and the creation of long-term services, and the establishment of other Dementia Friendly Municipalities in rural and or underserved areas, through the education of local health professionals and local authority employees creating an interactive network of DFCs.

4.3.4 **Italy** identified their aim of ‘Empowerment of people with dementia’ was to work with PWD, families, municipality, health and care services and voluntary associations. For their aim of the ‘Reduction and overcoming of stigma against dementia’, they involved PWD, families, experts from Alzheimer’s Association, health services staff, socio-sanitary facilities, and drew in economic support from Alzheimer’s association and other local organisations.
4.4 **Networks**
The Networks cornerstone identifies how community sectors have worked well together in supporting people with dementia.

4.4.1 The establishment of a network for DFC in municipalities in **Bulgaria** featured the collaboration of 2-3 municipalities, the Bulgarian Society of Dementia, PWD through the patient organization ‘Living with Dementia’ and the memory centre of the Alexandrovska Hospital. Contract agreements with municipalities, patient organisations, and private/public sector partners were established.

4.4.2 DFCs in **England** are recommended to ensure they have the right local structure in place (a local Dementia Action Alliance is the recommended model). The establishment of local Action Alliances has been supported by establishment of a national Dementia Action Alliance to bring together a range of national organisations supporting implementation of the national dementia strategy.

4.4.3 In **Greece**, the adoption of a formal Memorandum of Cooperation was considered best practice. This led to the formal establishment of long-term commitments, policies, and services by both the municipal authorities and central government. It also enabled the collaboration and alliances among researchers and providers of dementia services.

4.4.4 **Italy** aimed for the involvement of local authorities to work together with health services, merchant associations, voluntary groups, and research centres. Ideas and activities of the DFC was disseminated through social media and by word-of-mouth.

4.5 **Metrics to Measure Success - How progress was measured:**

4.5.1 Each site established metrics to measure the outcomes of their DFC activities. These drew upon the best practice identified in the evidence review 7.1 and were tailored to suit the location and context. They are listed below, by site.

4.5.2 **Bulgaria**
- Proportion/number and characteristics of participants (age, education)
- Number of meetings/training sessions/workshops
• Number of contract agreements/memoranda/ supporting organisations/collaborators
• National Dementia Strategy Document
• Number of citations/publications of DFC online and in print
• Results of pre- and post-pilot questionnaires assessing
• Knowledge of dementia
• Self-reporting Dementia Attitude Scale questionnaire
• Expectations/attitudes, levels of stigma etc
• Quality of Life e.g. levels of distress of PWD
• Satisfaction levels
• Results of pre- and post-pilot questionnaires evaluating satisfaction levels
• Feedback on the usefulness of activities from health professionals
• Number of elderly people screened for cognitive impairment and dementia pre- and post-pilot

**England**

4.5.3 As the DFC programme has been running in England for a number of years, they have set out the recommended ways to measure the success of a DFC, as opposed to specific outcomes and metrics for each DFC in this report.

4.5.4 Progress is recommended to be measured by:
• Focus groups and interviews of those participating in the dementia friendly initiatives
• Focus groups and interviews with members of the community
• Research specifically with people with dementia and carers
• A ‘mystery shopper’ style exercise
• Working with another community to assess each other
• Seeking the opinions of staff in shops/businesses; one intends to do a baseline of where they are now and where they want to be when the Local Dementia Action Alliance is established
• Participating in the Alzheimer’s Society annual survey of people with dementia and those that care for them.

**Greece**

4.5.5 Measured through the following metrics:
• Attendance / participation in programs
• Feedback from awareness raising events
• Dementia Attitudes evaluation questionnaires results
• Feedback from focus group meetings
• Publication of articles / media coverage of activities

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4.5.6 An Implementation Pyramid Process (IPP) was designed to integrate the actions and the indicators needed in the implementation process (see appendix).

4.5.7 Italy selected the following:
- The achievement of the planned actions
- Attendance and number of participants from the target population and population in general
- Focus groups and interviews with members of the community
- Results of pre-post questionnaires assessing:
  - Knowledge of dementia
  - Dementia Attitude Scale (questionnaire about attitudes, levels of stigma etc)
- Results of pre-post questionnaires evaluating satisfaction levels about trainings
- Working with another community to assess each other
- Participating in the Federazione Alzheimer Italia annual survey for DFC which evaluate the project under the Four Cornerstones Model
5 What was being piloted at the sites?

5.1 Phase One: Forming alliances

5.1.1 The local contexts in Bulgaria, Greece and Italy are very different. In keeping with the core processes and structures underpinning the model outlined in 7.1, there were common approaches at the outset in terms of forming alliances.

“While the specific processes and inputs above are likely to be common to most successful DFCs, the outputs, i.e. activities will vary, depending on local priorities and resources” (IBA, 7.1)

5.1.2 Initially, and in preparation for implementing a range of dementia friendly activities, the focus of the pilot sites in Bulgaria and Greece was to form partnerships, build connections, secure resources and establish relationships with a range of stakeholders: PWD, their families and carers, local businesses, municipality authorities, healthcare organisations, public services and academics. During the first phase, both countries managed to secure official agreements with local authorities.

5.1.3 The alliances formed by the partners were fundamental to their work at the pilot sites, and as per the model outline, had a core function in planning the creation of a DFC. In order to set local priorities, the alliances consulted with PWD and their supporters to find out:

- How they currently use the community
- How they would like to use it
- What the barriers are
- How they could be reduced or removed and
- How PWD could be involved in making this happen

5.1.4 Following the identification of the indicators and a plan for measuring these, the next phase of the work was to design and implementation of activities using the DFC model and in response to country-specific needs.
5.2 **Phase Two: Implementation of activities**

5.2.1 Common themes to address that emerged in the pilot sites in **Bulgaria and Greece** were:

- Improving inclusion and community connections
- Raising awareness and tackling stigma

5.3 **Improving inclusion and community connections**

5.3.1 All sites **engaged with PWD, the most important aspect of DFC**, involving them in assessing and planning how to better support their needs in the community. Activities in both countries included:

- Setting up regular support groups for PWD and care givers
- Open memory assessment clinics
- Provision of cognitive enhancement services
- Launching a training programme for care givers
- Exploring how changes to the physical environment in local areas can benefit PWD and their carers.
- Video Interview with the local Pater to alleviate any myths and assumptions about dementia
- School projects to overcome stigma and educate students and teachers
- Gym classes to improve behaviour and mood of participants
- The design of easily accessible furniture in the library and comfort for PWD
- Training the local police to deal with people showing early signs of dementia

5.4 **Raising awareness and tackling stigma**

5.4.1 To influence the **public perception of dementia, address stigma and to raise the profile of the condition among wider audiences**, the following actions were implemented in a number of sites:

- Distribution of brochures and printed materials including publication of articles in local and scientific newspapers
- Awareness-raising sessions for the general public, local businesses and public services,
• Implementing reasonable adjustments, including basic staff training for providers of services most used by the PWD, such as various forms of transport, libraries, pharmacies, banks, post offices, police services and schools
• Screenings of themed documentaries and feature films in local cinemas
• Production of educational and promotional online videos
• Increased media coverage and publicity around activities
• Engagement with academics working in this area, similar services and dementia networks across the country to exchange ideas.

Activities in the pilot sites were a mix of regular activity and one-off events as appropriate, based on feedback received, attendance and the overall success rate of the activities.

5.5 Activities site by site

5.5.1 The type of activity undertaken, and the success of them, depended on the partner’s starting point in terms of development, attitudes, education, and stigma surrounding dementia.

5.5.2 Bulgaria’s starting point was further behind than its co-partners, who were more developed in economic terms and in terms of the running length of their dementia friendly programmes.

5.5.3 For this reason, the Bulgarian team adopted activities such as memory cafes and elderly clubs which Italy had already long moved on from. Because the country was still at an information-gathering stage in relation to the others, that is, investigating the contextual barriers in terms of national and local levels of knowledge, stigma etc, the questionnaires were a useful exercise in themselves – so not treated just as a preliminary stage but an integral activity in itself. The Bulgarian team then focused on delivering as much as possible information about dementia to different target groups of society.

5.5.4 The DFC implementation program in Italy has developed along two main lines: 1) promoting participation and giving voice to PWD and family members (a key ‘national driver’ in Italy, as shown by the number of carers who are children); and 2) overcoming the stigma and making it possible to take advantage of local resources and participate in local initiatives.

5.5.5 The next stage of the work within the pilot sites was to focus on evaluating and analysing the impact of their dementia friendly activities, while continuing
to run regular activities and one-off events to strengthen and expand the reach of their dementia friendly initiatives. The latter includes looking into the possibility of intergenerational work, further dissemination to academic peers working in the same area, exploring the possibility of making changes to the physical environment to provide better access for PWD.

5.5.6 In **Greece**, intergenerational activities were used to break down stigma and raise awareness, including creative activities like choir and art sessions for PWDs and children from a local school. Through the caregivers’ school, carers and families of PWDs were equipped with the skills and knowledge of how to care for PWD, based around a cycle of lessons, and sessions delivered by professionals including psychiatrists and doctors.

5.5.7 In **England**, DFCs have been established for a number of years. Activities included making transport more accessible and dementia friendly, establishing activities for PWD and their families, and ensuring robust engagement with PWD in the design and delivery of the DFC activities.

5.6 **Activities**

This chapter sets out the case studies of activities undertaken by each pilot sites.

5.6.1 **Bulgaria:**
**Alzheimer Disease’s Awareness Campaign – Cinema House**

*(Sofia, Capital of Bulgaria)*

5.6.2 In the capital city of Sofia, 12-20th September 2018, the cinema house screened 4 awareness-raising films in 3 days, in a cinema hall (with a capacity of 270 people) for the general public. There were also and meetings with the Memory Centre team before the movie presentations.

5.6.3 The movies presented at the cinema were as below and on these dates:
‘Et si on vivait tous ensemble ?’ *(France/Germany, 2011)*

– 12 September 2018


– 18 September 2018
‘Honig im Kopf’, (Germany, 2014)
– 20 September 2018

5.6.4 A qualitative study was conducted prior and post implementation regarding the level of satisfaction of participants.

5.6.5 On the 21 September 2018 the “Alzheimer Disease Campaign” was also launched in the Hall at Department of Neurology, University Hospital Alexandrovská with screening, discussions and audience surveys. This was to increase awareness and empathy of the general public and change the attitudes and behaviours towards PWD; reducing stigma and fear surrounding dementia.
Caregivers Support Groups
(Sofia, Capital of Bulgaria)

5.6.6 Caregiver and support groups were held twice per month in the Municipality of Sofia at the Memory Centre of University Hospital, called ‘Alexandrovska’ between September 2018 and May 2019. These included presentations, videos, case discussions, movie screens and models for managing challenging behaviour. It was intended to improve understanding of how to practically support PWD and increase skills and confidence of caregivers.

5.6.7 Group stimulation sessions for people with dementia were held at the same time, twice per month.
England:

Bradford – Face It Together (FIT)

5.6.8 Bradford Dementia Action Alliance launched in 2013; and is one of the first Dementia Friendly Communities in England.

5.6.9 Over the past 5 years they have worked to engage with a diverse number of communities such as Lesbian, Gay, Bisexual and Transgender (LBGT) communities and the Sikh community. They have also worked with various businesses and worked to involve people affected by dementia throughout. The diverse make up of supporters has led to 20 individual groups ranging in size and activity working to make Bradford dementia-friendly; from small groups holding awareness events, to communities fundraising on specific activities such as health, education and social care.

5.6.10 In most cases a council ward officer is responsible for developing a local plan. This meant that endorsement and support was received from local councillors who had an interest in their local success.

5.6.11 In Bradford the Dementia Action Alliance facilitates a monthly FIT (Face It Together) group. This is a user involvement group for people with a diagnosis of dementia. The members of the group all have dementia and contribute to dementia-friendly work by speaking at meetings, reviewing services, delivering Dementia Friends Information Sessions and taking part in mystery shopping.
Alsager – Dementia Friends and Memory Café

5.6.12 In October 2017 Alsager became the first town in Cheshire East to be recognised as ‘Working to Become Dementia Friendly’. They have a strong core group of 12 members who meet monthly, all with the same vision to achieve living well with dementia in Alsager.

5.6.13 A key part of Alsager's DFC is increasing awareness of people with dementia. They have run monthly Dementia Friends Information Sessions from January 2017, with a target of making 100 Dementia Friends by the end of the year. This target was reached and surpassed. Alsager DFC has also set up a network of safe places has been set up in the town with participating businesses. Identification (ID) cards have been introduced for people living with dementia and their carers so that a carer or other named individual could be contacted if the need arises.

5.6.14 In Alsager, a monthly Memory Café is run at the local library. At this café, extensive information is provided and is attended by various support providers and social visitors, including Cheshire Art for Health, young people’s groups (like the Beaver Scouts) and a local vet who brings along his trained dogs. The café is entirely free to customers thanks to the generosity of local businesses and services. Memory boxes, books and jigsaws are always available.
5.6.15 Dementia Friendly Community has also forged a close relationship with Alsager School, a co-educational secondary school and sixth form with academy status. The group asked the school if they could produce a piece of artwork related to dementia. Using Microsoft 365 Sway software, the school’s Digital Art and Technology lead produced a living memory box for couples to record their most valued memories. After a successful pilot the project has become part of the school curriculum. Year 9 students are paired with couples, one of whom is living with dementia, and help them to create their memory box.

They are now planning to present a Dementia Friend session to Alsager 6th form students.

Blackpool - Dementia Friendly Buses

5.6.16 Blackpool Dementia Action Alliance (DAA) launched in 2015.

5.6.17 One of Blackpool DAA’s key strategies was to improve the lived environment for those living with dementia. An essential part of this is the ability to be able to travel with confidence. People living with dementia in Blackpool struggled to use buses as they felt transport providers did not understand nor cater for the complexities facing people affected by dementia. This caused isolation and left people feeling unable to be an active part of their own communities. Blackpool DAA therefore looked at ways to improve the understanding of transport staff as one means to overcome the social isolation of people living with dementia.

5.6.18 Blackpool Transport, the leading provider of bus services in Blackpool, incorporated Alzheimer’s Society’s Dementia Friends programme into their
annual staff training programme (which all staff and new employees attend).

Blackpool Transport's training team then became Champions, so they could deliver Dementia Friends Information sessions themselves, creating over 600 Dementia Friends. They also implemented a yellow card scheme for passengers who might need more time to get on or off a bus or a tram. This card enables drivers to identify passengers who might be living with dementia.

**Telford & Wrekin Dementia Action Alliance (DAA) and Shropshire DAA**

5.6.19 The two DAAs merged to create one large DAA. The merger was driven by the belief that they would be ‘stronger together’.

5.6.20 Since the merge there are 42 DAA member organisations across Shropshire Telford & Wrekin. Members cover a wide range of sectors including:

- Local authorities and CCGs
- All NHS secondary care institutions
- Domiciliary care agencies and care homes
- Service and retail businesses and organisations

5.6.21 Successes of the DFC include the Safe Place Initiative was rolled out by West Mercia Police with Dementia Friends – so that locations sign up to be a Safe
Place and dementia-friendly. Shropshire Fire and Rescue service signed up as a member, and Fire and Rescue staff use their dementia awareness to provide more and appropriate support for people they rescue and work with. Lichfield Diocese Dementia Support Worker has developed dementia-friendly services and churches across Shropshire, including delivering Dementia Friends sessions to congregations. They also include reminiscence film screenings in several places.

**Amber Valley DFC – Dementia Friendly Places**

5.6.22 In 2016 Amber Valley Health Partnership identified dementia as a key health priority. With help from the Amber Valley Public Health Locality Fund and Alzheimer’s Society, the Amber Valley Dementia Action Alliance (DAA) was born. The Amber Valley Dementia Action Alliance is made up of a group of organisations and individuals who have come together with the aim of making the Amber Valley a better place to live for people with dementia and their carers.

5.6.23 Amber Valley developed several projects to enable the community to become more dementia-friendly. These include a dementia-friendly town centre which will include a dementia-friendly garden, large reminiscence boards in the local library, and training offered to shops in the centre. There is also a sporting reminiscence group, dementia friendly cinema screenings and a dementia friendly checkout at a Tesco supermarket.

5.6.24 The Alliance also ran training sessions for local people to become Dementia Friends, and nine GP (doctors) surgeries signed up to become Dementia Friendly.

**Newport, Dementia Action Alliance supporters**

5.6.25 In Newport a new dementia-friendly supporter process is being piloted. The supporter process allows small businesses and organisations to sign up to show that they ‘support’ the local DAA without becoming full members of the DAA. This process was created to be as simple as possible to overcome organisations’ concerns about additional workload. Supporter organisations commit to their staff and/or volunteers becoming Dementia Friends, and they learn how they can signpost people for support. In addition to this they also agree to one other small personal action.
5.6.26 Since starting this process in July 2017 62 organisations have become supporters in Newport.

Luton Town Football Club

5.6.27 In December 2015 Luton DAA approached Luton Town Football Club (LTFC) to join them. The Club has been part of the Luton community for 130 years and with average attendances of over 8,000 for home matches, it became clear that they could play a key role in raising awareness and understanding of dementia.

5.6.28 After a successful dementia-friendly football match organised by Exeter City, the Luton DAA contacted Luton Town Football Club to organise a similar event.

5.6.29 On Saturday 18th March 2017 the dementia-friendly match against Exeter City took place. Luton Town Football club invited Luton DAA and offered an executive box for people living with dementia, each accompanied by a friend, to attend the match.

5.6.30 Feedback was very positive. The dementia-friendly match was felt to be bringing the people in the community closer together and showing the impact of playing sports enjoyable for all.
5.6.31 Since then, Luton Football Club has continued to support Luton DAA and Alzheimer’s Society. Players including Johnny Mullins, defender for the men’s team, are encouraging their fans and the wider community to support the cause.
Greece:
Dementia Friendly municipality team
(Municipality of Athens, Vrilisia and Byron)

5.6.32 **Dementia Friendly municipality team**: consisted of key-position personnel from Social Policy and Health Directorate of the Municipalities with professional background covering important fields such as: social work, psychology, occupational therapy, nursing and physiotherapy so that through their different responsibilities in the municipality services could promote specific actions for the implementation of DFCs.

5.6.33 Thus, one of the aims of the project was to train the key-personnel, following interactive scheduled group training activities with Academic experts on dementia (focus group aimed to explore feelings and experiences related to the existence of stigma in dementia, stereotypes and prejudices around dementia, consequences of behavioral disturbances in PWD, as well as family burden and psychosocial approaches for PWD and their caregivers). Participants proposed ways of developing actions aiming at eliminating stigma in dementia and enhancing Dementia Friendly Actions.
The Caregivers’ School’s Program
(Municipality of Athens, Vrilisia and Byron)

5.6.34 The program was designed to be helpful and cost-effective for Caregivers, providing comprehensive training and counselling from dementia experts on personalized care, recognition and management of neuropsychiatric symptoms, financial counselling and psychosocial approaches on reducing psychological burden, stigma as well as providing the opportunity to share experience of caring. Additionally, these meetings can help caregivers to take a break from their caring role.

5.6.35 Two cycles of the Caregivers’ School Program (CSP) have been organized (Spring – Autumn). The Caregivers’ School’s program took place in the Municipalities of Athens, Vrilissia and Byron. It consisted of educational cycles.

5.6.36 Each educational cycle consisted of 6 interactive meetings of 2-hour duration, every two weeks (which took place in Open Elderly Centers), by a multidisciplinary team of dementia health care experts (psychiatrists, social workers, psychologists and physiotherapists).

5.6.37 Targeting caregivers unable to access specialized community services or municipalities lacking specialized dementia services for PWD.
Intergenerational Activities
(Municipality of Byron, Greece)

5.6.38 The intergenerational activities were an effective way to reduce the stigma of dementia and educate the younger generation on becoming accepting and open minded towards older persons with and without dementia.

5.6.39 In the Municipality of Byron, the intergenerational activities were held with the children of the 3rd and 8th Kindergarten of the Municipality of Byron, their parents and their grandparents and took place in the K.A.P.I. and lasted 5 days from Monday 18th to Friday 22nd of March 2018 allowing older people including PWD and young pre-school children to interact and undertake activities together.

5.6.40 ‘Painting the most beautiful memories’ Children’s Painting exhibition of the Kindergarten followed by a discussion with the members of the Open Care Center. The exhibition was followed by the common choir by the elderly of K.A.P.I. and the children from the Kindergarten.

5.6.41 Different informative and interactive actions have been planned from the kindergarten teachers including choir, dances, art exhibitions and collaborative workshops. It brought the two generations closer and helped in reducing stigma.
Dementia Friendly Open Elderly Centers
(Athens, Byron and Vrilissia, Greece)

5.6.42 All three municipalities Open Elderly Centers, were referral points for patients and carers, featuring activities. The structure of activities included physiotherapy, activity therapy, artistic therapy, recreational therapies.

5.6.43 The objective was the development of Dementia Friendly Open Elderly Centers through several anti-stigma actions (awareness – raising leaflets on how to communicate with PWD in a non-stigmatizing way), informative interactive events by health professionals, involve PWD and carers in Open Elderly Centers meaningful activities, in a social context, establish Memory Enhancement Groups, Caregivers School, Memory clinics and providing a place for interaction and socialisation for PWD without discrimination.
5.6.44 Alzheimer Italia has published a video interview by Silvia Vitali, Medical Director of Geriatric Institute ‘Golgi Cenci’ of Abbiategrasso with Father Giancarlo Politi, who talks about his experience and living with dementia.
This supports a series of resources aiming to challenge common myths and assumptions in relation to dementia which have been created and disseminated as part of the DFC initiatives. This was the first time someone with dementia has spoken publicly in this way in Italy, where the taboo surrounding dementia is still strong in many communities. The Padre describes the challenges of his daily life since he developed dementia, but he also describes the huge support he receives from his family and community. He asserts the ongoing identity of PWD and their right to come forward and be heard.

The video is available here:

https://www.youtube.com/watch?v=XD1ddl6gGeI  (a shorter version with English subtitles)

School Project

(Abbiategasso, Italy)

In September 2017, a pilot project was developed for the training of teachers and students of two classes of a local high school (between 15 and 16 years old) in Abbiategasso. The overarching aim was to overcome stigma, educate teachers and students and to promote the relationship between the students and PWD. This facilitated in raising awareness and participation in younger people about dementia with active collaboration from the teachers. Students were responsible for delivering training to groups of parents. Initially a
questionnaire was administered and subsequently a training course was provided for both teachers and students.

5.6.47 Training carried out first was with three delegated teachers and then with the students.

5.6.48 During the school year, each teacher included the theme of dementia in their own subject (for example: In an English class, students translated into English a questionnaire on the knowledge of dementia. In Biology class, students learnt about what happens to the brain of a person with dementia). Students gave their parents a questionnaire on Abbiategrasso DFC. Students became a spokesperson intended for what they had learnt, measuring the degree of knowledge of dementia and at the same time involving themselves in DFC initiatives.
5.6.49 The final step was to involve the population with flash mob wearing gilets (waistcoats) with the symbol of DFC. This was organised by the students and the art teacher. It also involved an administration of a questionnaire post training and analysing and presenting the results to the students. The students also met with a Geriatrician and a Psychologist for two hours in order to ask any questions. Additionally, the trained students created a questionnaire dedicated to their families. The involvement of students who took part in the Dementia Friendly Initiatives (e.g. accompanying PWD to the market, reading in the library, etc.) which took place over the course of 2018-2019 school year.
5.6.50 The gym classes were organised for the empowerment and participation of PWD. This gave PWD and their carers an opportunity to get out of the house and meet others in a pleasant environment. Attending the gym class improved the behaviour and mood of the participants (both the PWD and their caregivers), which was demonstrated in the interviews.

5.6.51 Gym classes took place once a week and then twice a week from January until June and started again in September. Instructors were trained to equip them with the skills to interact with PWD. The support and participation of volunteers also helped PWD to take part.

5.6.52 Raising awareness of the activities locally through local, TV and newspapers has brought the project to the attention of a voluntary association for the elderly, which was already operating in the community. The association has opened its gyms for the activity with PWD and their family members.

5.6.53 An analysis of the effectiveness of the experience was carried out, through the assessment of a single person with dementia. The initial assessment was made by expert personnel (a physiotherapist and a psychologist) who also conducted a follow-up interview after the activity, to receive feedback from the
participant. The experience was welcomed in a positive way, so it was decided to continue and expand the project.

5.6.54 The needs assessment questionnaire administered to PWD at the outset of the pilot helped to identify the priority of increased physical activities, which led to the creation of a specific, low-impact gym class for PWD (Adapted Physical Exercise). Classes were for PWD and their caregiver.
Library
(Abbiategrasso, Italy)

5.6.55 The public library in Abiategrasso has been involved in the coordination of the ‘table of initiatives’ *(Tavolo Promotore)* since February 2016. An initial training course was held in November 2016. In 2017, it an exploratory intervention to make the library more Dementia Friendly was undertaken.

5.6.56 PWD who visited the library made suggestions as to how it could be made more dementia friendly. These included: replacing furnishings with armchairs and tables suitable for PWD; rearranging books and spaces to become more accessible; choosing appropriate books and dementia information; and establishing a room for small conferences or training courses. The indicative budget was approximately 8000 euros. An inauguration of the “Dementia Friendly” room in the Library was held September – October 2018. The project also created a relaxation area for elderly and / or PWD and their family members. This complemented a program of events to re-establish socialization of PWD and their families in to the community, involve library volunteers in initiatives to support PWD, and to increase overall awareness of dementia.
Police Training
Abbiategrasso, Italy

5.6.57 From July 2016, four training courses were held for local police officers and carried out periodically in Abbiategrasso. Participants were made aware of how to deal with PWD, and a post-training guide and a helpline were established. The first training cycle continued throughout 2017 and was resumed as soon as new officers were hired in 2018. The course was held in very small groups (due to the need of not disturbing the service), to teach local police how to deal with people who show early signs of dementia.

5.6.58 The course was structured over two sessions: the first on the nature, symptoms and progression of dementia and the second session on how to communicate and engage with the PWD. The sessions also included a visit to the special care unit of the Golgi Institute.
5.6.59 The goal of these sessions was to increase the participant's knowledge of dementia, to help reduce the isolation of people in the early stages of dementia who may experience disorientation and memory lapses, and who may find it difficult to move around the town alone.
6 Challenges to implementing DFCs

6.1 During the pilots, a number of challenges were identified to establishing a DFC. These were wide ranging but largely fell under the Four Cornerstones Model and are grouped accordingly below.

Places

6.2 In Bulgaria, limited time and human resources of stakeholders/business sector/administrative staff emerged as an obstacle to the success of certain activities. It was established that the best way to overcome this challenge was to explore the local traditions for communication, community spaces and activities, especially in rural areas.

6.3 In Greece, it was reported that PWD were unable to visit Memory Clinics at the Friendship Club of the Koukaki area due to the long distance across the Municipality, and the lack of transport. To overcome this challenge, the Municipalities of Byron and Vrilissia have put their local transport in service for citizens including patients with dementia and their caregivers.

6.4 The accessibility of places (shops, public spaces) remains a problem still to be faced in Italy as it is affected by public bureaucracy. This was managed by the library as it was a matter of changes to internal spaces not to accessibility, the library was already accessible for people with disabilities. The same was achieved for some of the shops, but the lack of adherence to the project by retailers (and the possible expenditure for adjustments) did not always allow it.

People

6.5 The local attitudes, habits of communication, and gender-specific differences emerged as cultural challenges in Bulgaria. These presented a barrier to; the population of rural areas to attend meetings. To address this, the topic of dementia was incorporated into pre-existing social activities and tradition, e.g. the library (“chitalishte”). This enabled a “traditional and individual approach for motivation and inclusion.”
6.6 Pilot activities targeted a broad range of social groups – the general public, elderly people, administrative staff, staff of public and private sector, GPs, students at 2 local schools, caregivers and PWD. Knowledge and attitudes of dementia were discussed in many cases for the first time.

6.7 In Greece, professional groups in larger organisations such as banks and large supermarkets were not able to participate in formal training seminars, as their Human Resources Departments had to approve and include such activities in their company’s annual plan of training activities. Therefore, it was easier to organise smaller training events at the local branches. In the Municipality of Byron, for example, employees at the local branch of the National Bank of Greece, as well as the employees of the Municipality of Byron took part in training.

6.8 Italy reported the cultural barrier of being embarrassed to be known to have a dementia diagnosis in a small town. They produced a video with a priest with dementia, born in the town, who agreed to be interviewed about his experience. The video was put on YouTube and projected during a large meeting with the inhabitants of the town.

Resources

Bulgaria

6.9 The issues identified in the analysis of the pre-pilot questionnaires revealed that the information-gathering itself was not simply a preliminary stage to other activities, but an important activity in itself, is by identifying the barriers to a DFC before they can be addressed. The main issue was the lack or insufficient information concerning general dementia knowledge, dementia diagnosis, possibilities for treatment and care, especially in the small municipalities.

6.10 In Italy, an unexpected, positive outcome was the number of young people who participated in the intergenerational activities, with students requesting more responsibility for the planned activities.
Networks

6.11 Discussion was difficult in the intergenerational activities in Bulgaria because of the large number of students involved. Case presentations were met with interest, but subsequent personal involvement was low in the medium term. In light of this finding, meetings with small groups of pupils (maximum 10) were organised instead, where direct involvement with PWD were discussed and music and art were introduced as a way of communicating with older people and PWD.

6.12 Another challenge was to introduce and develop a local network in small municipalities with the inclusion of GPs, social service and key figures from local administrative, and library staff in dementia friendly activities. Pilot activities with GPs to introduce dementia prevention knowledge was a good example to overcome this challenge.

6.13 In Greece, it is not standard for municipal authorities (especially located at different areas of Attica) to cooperate and develop joint actions. This project, and the Memoranda of Cooperation signed, created a unique opportunity for establishing cooperation among the three Municipalities, and to exchange good practices through common awareness raising events, focus groups and meetings. The publicity of the Memoranda of Cooperation signed, and the activities planned as part of the Act of Dementia initiatives have therefore raised interest from other Municipalities and Centres for the Elderly, who have requested a similar cooperation in their area.

6.14 A challenge that emerged in Italy was the difficulty of participant organizations to understand that establishing a DFC does not necessarily mean new services, but rather requires the change of mentality and the behaviour of a community. The increased activities and the educational meetings helped to overcome this challenge. Another challenge was to explain that PWD, particularly at an early stage of dementia, have a long period in which they can participate in many activities with pleasure. In addition to the video, the implementation of “normal” activities like gym groups and library attendance helped to overcome this assumption.
Challenges to implementing DFCs: Conclusion

6.15 There was some overlap in countries’ findings when it came to issues and challenges raised. These included difficulties in engaging, or maintaining contact with and participation from, the private sector (in terms of local businesses, e.g. banks, supermarkets, shops etc). Italy surmised that this could be due to a lack of practical messages and training; and that a more active involvement of PWD could have made a difference. This is re-enforced by the more general findings of the DFC, and Bulgaria’s findings on intergenerational activities. Greece found that the participation of larger private institutions was difficult to manage due to bureaucratic reasons, finding it easier to organise smaller training events at the local level through the participation of local branches (in the Municipality of Byron, for example).

6.16 These feed into another common observation, arrived at and under different contexts, but shared by all three pilot sites: that **scaling down activities is often more effective**, from both a logistical and impactful perspective. Bulgaria stated that:

> “Small group discussions with case examples were more successful - better feedback, knowledge and skills improvement.”

6.17 Bulgaria specifically found this in relation to the group size for intergenerational activities, which were initially too large to generate fruitful discussion; whilst Italy stated the importance of *following a different path for DFC, not only organising lectures or events for all the community*:

> “We also scheduled activities in small groups. Working in the community in small groups of caregivers, patients, and municipality personnel allows a personalized approach.”

6.18 Issues related to timings and organisation were identified. For example, Italy cited long lapses between meeting and training of local businesses, or delays
in implementation of initiatives (e.g. assessing how to improve access to the town centre); Bulgaria cited lack of time (and resources in general), and the difficulty in coordinating caregivers’ meetings, as an obstacle to coordinating activities.
7 Outcomes of DFC activities

7.1 All sites were required to report the outcomes of their DFC activities using either or both qualitative and quantitative methods, these are summarised below.

Bulgaria Evaluation Summary

7.2 Bulgaria used a number of activities for both the public and private sector to increase awareness for PWD and caregivers in the three municipalities. These were the involvement of workshops, training sessions, Dementia Café at elderly clubs and a wide range of both the public and private sector in the involvement of increasing awareness for PWD and caregivers in the three municipalities. This was measured by using pre- and post-questionnaires that essentially listed barriers and facilitators for the pilot activities; indicators for effectiveness of pilot activities from caregivers, administrative staff and services in municipalities, healthcare professionals (GP/nurses) before and after the pilot activities. Level of knowledge, needs, attitudes and stigma were obtained from general public and other target groups before pilot activities.

7.3 The effectiveness of these activities was assessed using different outcome measures; and analysed by using questionnaires, scales and other data using descriptive statistics as well as discussions from focus groups were collated to provide qualitative data. These are summarised below.

7.4 Targeting the general public was built on two questionnaires that were distributed and filled once before each screening the movies in cinema house:
Table 6: Knowledge/Information Questionnaire about Dementia (Cinema Attendees)

<table>
<thead>
<tr>
<th>Survey Questions</th>
<th>Pre-Pilot Questionnaire with Cinema Hall Attendees (n=275)</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Q1. How much information about diagnosis and treatment for dementia is available?</strong></td>
<td>Minimal or no information = 28%</td>
</tr>
<tr>
<td></td>
<td>Difficulty accessible information = 34%</td>
</tr>
<tr>
<td></td>
<td>Sufficient information = 1%</td>
</tr>
<tr>
<td><strong>Q2. Who can provide information about diagnosis and treatment?</strong></td>
<td>GP = 7%</td>
</tr>
<tr>
<td></td>
<td>Specialist = 36%</td>
</tr>
<tr>
<td></td>
<td>Internet = 17%</td>
</tr>
<tr>
<td><strong>Q3. How much information about care of people with dementia is available?</strong></td>
<td>Minimal or no information = 36%</td>
</tr>
<tr>
<td></td>
<td>Difficulty accessible information = 26%</td>
</tr>
<tr>
<td></td>
<td>Sufficient information = 0%</td>
</tr>
<tr>
<td><strong>Q4. Who can provide information about care for people with dementia?</strong></td>
<td>GP = 7%</td>
</tr>
<tr>
<td></td>
<td>Specialist = 34%</td>
</tr>
<tr>
<td></td>
<td>Social Services = 8%</td>
</tr>
<tr>
<td></td>
<td>Internet = 9%</td>
</tr>
</tbody>
</table>

7.5 The total population and participants that were involved/recruited from the general public were a total of 151, 125 and 137 for three consecutive days (12, 18 & 20 Sept 2018) for the screening of 4 movies in the Cinema House Alzheimer Disease Campaign activity in Sofia. The pre-pilot questionnaire that assessed the attendees’ (n=275) knowledge on needs and stigma indicated that it was more difficult to access information about dementia (34%), with minimal or no information had availed 28%. Only 1% of the attendees stated that there was sufficient information available.

7.6 This shows that it is essential to have more information available about dementia related topics especially around diagnosis, treatment, caregiver support, where and how to find specialists and the availability of services required for care and treatment.
Table 7: Expectations, attitudes and stigma related questions

<table>
<thead>
<tr>
<th>Survey Questions</th>
<th>Stigma Questionnaire on – “If you had Alzheimer’s Disease” – distributed at meetings and events (n=275)</th>
</tr>
</thead>
</table>
| Would you lose your self-esteem?                          | Yes = 33%  
No = 5%  
Maybe = 45%  
I don’t know = 17%                                           |
| Would you feel ashamed or embarrassed?                   | Yes = 35%  
No = 12%  
Maybe = 37%  
I don’t know = 16%                                           |
| Would you lose respect from your neighbours and colleagues? | Yes = 8%  
No = 14%  
Maybe = 57%  
I don’t know = 21%                                           |
| Do you think that others may ignore you?                  | Yes = 25%  
No = 12%  
Maybe = 53 %  
I don’t know = 10%                                           |
| Would your family be underestimated by your neighbours/colleagues? | Yes = 11%  
No = 34%  
Maybe = 43%  
I don’t know = 12%                                           |
| What is the attitude of people from your close circle to people with dementia? | Shame/fear = 25%  
Indifference = 8%  
Show interest = 14%  
Empathetic and ready for more information = 50%  
Empathetic volunteer = 3% |
Table 7 shows the results of a questionnaire designed to assess stigma associated with dementia. This shows a relatively high level of belief that having dementia would result in embarrassment and loss of self-esteem. High levels of shame and fear were reported relating to dementia. However, there was also high levels of ‘don’t know’ or ‘maybe’ responses to all questions. Encouragingly, 50% of people said that their close circle was ‘empathetic and ready for more information’ about dementia.

Table 8: Knowledge Questionnaire about Dementia (Community Staff and Caregivers)

<table>
<thead>
<tr>
<th>Survey assessed Dementia knowledge of community staff and caregivers (Survey Questions)</th>
<th>Dementia Knowledge Questionnaire Pre-pilot</th>
<th>Dementia Knowledge Questionnaire Post-pilot</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Knowledge about Dementia (Staff responses)</strong></td>
<td>Detection Process = 3.54 Scales = 1.77 Timely diagnosis = 3.46 Prevention methods = 3.23 Post-diagnosis support = 2.23 Overall = 2.85</td>
<td>Detection Process = 5.30 Scales = 2.69 Timely diagnosis = 5.85 Prevention methods = 6.15 Post-diagnosis support = 4.31 Overall = 4.86</td>
</tr>
<tr>
<td><strong>General Knowledge (Caregiver responses)</strong></td>
<td>Pre-pilot = 23.58</td>
<td>Post-pilot = 29.08</td>
</tr>
<tr>
<td><strong>Knowledge of Psychological Symptoms (Caregiver responses)</strong></td>
<td>Pre-pilot = 31.77</td>
<td>Post-pilot = 36.50</td>
</tr>
<tr>
<td><strong>Knowledge about management (Caregiver responses)</strong></td>
<td>Pre-pilot = 14.35</td>
<td>Post pilot = 18.12</td>
</tr>
<tr>
<td><strong>Attitudes (Community Staff responses)</strong></td>
<td>Pre-pilot Comfort = 28.15 Knowledge = 29.00</td>
<td>Post-pilot Comfort = 32.15 Knowledge = 34.46</td>
</tr>
</tbody>
</table>
### Table 1: Attitudes (Total – Community Staff responses)

<table>
<thead>
<tr>
<th></th>
<th>Pre-pilot</th>
<th>Post-pilot</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>57.15</td>
<td>66.61</td>
</tr>
</tbody>
</table>

#### 7.8 The knowledge questionnaire (table 8) about dementia distributed to community staff and caregivers assessed different levels of knowledge. The pre and post pilot responses revealed that there was a significant improvement in the three sub-scales to include; general knowledge, psychological symptoms and management after the activities had taken place.

#### 7.9 There was a total of two questionnaires, the first was a Dementia Knowledge for Caregivers questionnaire with a total of n=30 who participated. The graphs below indicate the score pre-and post from the general knowledge, psychological symptoms and information about management scores before and after the activities.

**Graph 1: Questionnaire results testing General Dementia Knowledge from Caregivers (n=30)**

![Bar Graph](image)

#### 7.10 This graph shows that less people knew about dementia overall before the activities. Post activities more people were able to understand the questions that explored characterisations of dementia, types, as an illness and BPSD.
Graph 2: Questionnaire results from Caregivers (n=30) – Knowledge of Psychological symptoms in Dementia

Graph 3: Questionnaire results from Caregivers (n=30) – Knowledge about the Management in Dementia

7.11 The above graphs 1 and 2 show the results from the questionnaires that were distributed to Caregivers (n=30) to test their knowledge about psychological symptoms and management of dementia.
The Dementia Attitude Scale survey was distributed and completed before and after training sessions, and workshops by participants from the municipalities (staff of municipality administration, library, pharmacy, post office, police, GPs, nurses).

The scale includes 20 statements about dementia and the person had to choose on 7 step rating scale from "0 = strongly agree" to "6 = strongly disagree".

The scale asks the respondent to answer on two themes: Social comfort (max score = 60) and Dementia knowledge (max score = 60).

The pre-pilot assessment of Dementia attitude level revealed low levels on both themes. - Comfort level had an average response rate of 28.2, and Knowledge level had an average response rate of 29.0. This resulted in average total of 57.2 out of a maximum 120.

Post-pilot questionnaire demonstrated that the Community staff had more positive attitudes towards PWD after the training program; the changes were relatively small but significant. The level of knowledge showed slightly greater increase than level of comfort, and the overall level of acceptance, positive emotions and behaviour as well as knowledge concerning PWD remained at an average level. Therefore, signs of stigmatisation were not found to have been overcome.

Levels of satisfaction were recorded and considered an important factor for the staff and caregivers. The survey about the satisfaction level of staff in the community concerning workshops and training sessions revealed satisfaction (m=mean) indicators with 6 satisfactory levels. The average results indicated that there was a very good level of satisfaction overall. With the results of training being the highest at m=3.62 and low levels for organisation at m=2.62. Every question had scored a rating scale from 1 (poor) to 4 (very good). These results indicated that training was a core tool and essential to use to support staff and caregivers in understanding PWD.
Knowledge levels

7.18 The pre-pilot assessment revealed low levels of knowledge with an overall rating of 2.8 out of 10; where 0 is affirmed as (no knowledge at all) to 10 (extremely knowledgeable). Post-pilot assessment of Dementia knowledge of Community actors/staff revealed significant improvement although the overall score could be estimated as still being at a moderate level. There were five questions for administrative staff in two small towns around neurocognitive disorders around detection processes, assessment scales, benefits of a timely diagnosis, prevention methods and post-diagnosis support and services that are available. The results are indicated below:
Graph 5: Questionnaire results from administration staff for Neurocognitive Disorders (NCD) (n=13) pre- and post- interventions/dementia friendly activities data

7.19 The results demonstrate that staff were unaware of processes, prevention methods and the post diagnosis support. However, once they participated in the activities and from the knowledge acquired the results have risen significantly. With preventative measures scoring the highest, the staff are more aware of including physical activity, cognitive training and diet when dealing with patients who suffer from dementia.

7.20 A dementia attitude questionnaire that tested the knowledge of the administration staff’s level of knowledge and comfort revealed the services had improved the knowledge and acceptance of PWD, although these positive changes were relatively small and insufficient. There is a great need for regular, updated and practical information for all services involved in dementia medical and social care. The following results (graph 6) is from the questionnaire filled out by the administration staff to test dementia attitudes.
Graph 6: Questionnaire results for Dementia Attitudes amongst administration staff (n=13)

7.21 The questionnaire tested how comfortable staff were at understanding dementia and Alzheimer’s Disease and related Dementia (ADRD). This involved a series of 10 statements with two subscales with the level of knowledge and comfort. Understanding needs, interactions, communication and care involved when dealing with those who suffer with dementia.

7.22 The metrics set out at the start of the DFC, and their results, are listed below.

Table 9: Bulgaria metrics

<table>
<thead>
<tr>
<th>Metric</th>
<th>Result</th>
</tr>
</thead>
<tbody>
<tr>
<td>Recorded number of participants who attended</td>
<td>670</td>
</tr>
<tr>
<td>Number of meetings</td>
<td>21</td>
</tr>
<tr>
<td>Number of contract meetings</td>
<td>4</td>
</tr>
<tr>
<td>Number of contract agreements, Memorandum =</td>
<td>1 - National Dementia Strategy Document was approved by the Minister of Health in Bulgaria for 2020-2025 with</td>
</tr>
</tbody>
</table>
7.23 The National Working Group for developing National Dementia Strategy Concept was approved by the Ministry of Health on 5 June 2019. Representatives from the following stakeholders were included: Ministry of Health, Ministry of Labour and Social Policy, Bulgarian Society of Dementia, National Social Agency, National Association of General Practitioners, National Nurse Association, Bulgarian Alzheimer Association, Foundation Compassion Alzheimer’s Bulgaria, Bulgarian Organization "Living with Dementia", Medical University of Sofia, Medical University of Varna, Medical University of Plovdiv, Ombudsman of Bulgaria, Bulgarian Non-profit Organization of Low. The Working Group has already 2 meetings (22 May and 14 June 2019). First version of the National Dementia Strategy (2020-2025) proposal will be delivered to the Ministry of Health in December 2019 with embedded results from DFC activities – need to rising public awareness and developing DFCs.

7.24 There was a total of 13 representative stakeholders that have been involved in implementing results from the DFC activities.

7.25 The data collated revealed that responses received after activities were subsequently higher than those of pre-pilot questionnaires. This demonstrates building on strong communities and sharing knowledge amongst PWD and carers was effective. Attitudes, knowledge and perceptions around dementia were also improved; as well as factoring in successful implementation and maintenance of the targeted activities for that group of population that have either been affected or dealing with PWD.
7.26 Overall, the most effective activity was training sessions for staff of municipalities and services such as libraries and pharmacies. The survey showed good increases in knowledge levels after the training. Rates of satisfaction reported by caregivers after Knowledge levels also increased on the Dementia Attitudes Scale, but there was little improvement on levels of stigma reported after the activities, and they remained low or average after the intervention. Satisfaction rates for training amongst caregivers and community workers were high, with the highest rating going to impact of training, and the lowest to the organisation of the session.
England Evaluation Summary

7.27 The DFC programme in England has been running for a number of years, and as it is not an official EUJA site, there are not quantitative results available to measure the outcomes, which the pilot sites do have. Therefore, this summary sets out some of the qualitative achievements of the DFCs in England, and how they are encouraged to self-assess.

7.28 DFCs complete an annual self-assessment (14 questions) which is used to assist Alzheimer's Society Dementia Friendly Officers evaluate actions taken by communities and if they are considered ‘active’. The data helps each officer decide whether they should re-award recognition to that community.

7.29 Dementia Friendly Communities in England have undertaken a variety of actions, including:

- Making GP (doctor) surgeries more dementia-friendly
- Encouraging housing providers to consider how they support their residents with dementia
- Focussing on an area or neighbourhood to make all the shops and businesses in that are aware of dementia
- Dementia-friendly performances and exhibitions at museums and galleries
- Dementia-friendly screenings at local cinemas
- Delivering Dementia Friends sessions to school groups
- Factoring dementia-friendly design into refurbishments of buildings
- Slow checkouts and quiet hours in supermarkets
- Leisure centres running dementia-friendly and wellbeing activities
- Encouraged councils to make it easier for people with dementia to claim council tax relief and other benefits
- Set up ‘use our loo’ schemes so that more toilets are available and accessible for people with dementia whilst out shopping
- Made taxi drivers ‘Dementia Friends’ and encouraged councils to only give licenses to firms who have done this
- Dementia friendly church services

7.30 Beyond community-level activities, the English office of the Alzheimer's Society has also worked with different business sectors to develop sector guides and charters to encourage a more dementia-friendly approach. These include retail, housing, arts and sports.
7.31 The Dementia Friendly Communities programme in England is complemented by the Dementia Friends Programme. The initiative aims is to transform the way the nation thinks, acts and talks about dementia.

7.32 Dementia Friends tackles the stigma and discrimination people with dementia can face through increasing awareness, driving attitude change and action. It centres around five positive key messages to change how people view the condition. Dementia Friends is about learning more about the condition in an easy and engaging way as well as the small ways everyone can take action to support those living with the condition.

7.33 Dementia Friends are those who have watched an online video or attended a session where they learn more about dementia and the ways in which they can help. With 3 million Dementia Friends across England, Wales and Northern Ireland Alzheimer’s Society’s Dementia Friends programme is the UK’s biggest ever initiative to change people’s perceptions of dementia.

7.34 In Amber Valley, a local retailer has made all their staff Dementia Friends. A weekly Walking for Health and Dementia Friendly Swimming session was launched, involving PWD in the development and design of the sessions. Overall, in Amber Valley, there was a 30% increase in Dementia Friends (1234 new Friends created); 168 organisations were given advice on becoming dementia friendly, and 10 community awareness events were held, where 370 people attended.

7.35 In Blackpool’s Dementia Friendly Community, staff from the bus provider attended Dementia Friends training sessions and implemented a yellow card scheme for passengers who might need more time to get on or off a bus or a tram. This card enables drivers to identify passengers who might be living with dementia.

7.36 In Bradford, the Dementia Action Alliance established a monthly FIT (Face It Together) group. This is a user involvement group for people with a diagnosis of dementia. The members of the group all have dementia and contribute to dementia-friendly work by speaking at meetings, reviewing services, delivering Dementia Friends Information Sessions and taking part in mystery shopping.

7.37 In Alsager, Dementia Friends information sessions were run and exceeded making 100 new dementia friends. ID cards were being introduced for people living with dementia and their carers so that a carer or other named individual could be contacted if the need arises and A network of safe places has been set up in the town with participating businesses. A monthly memory café is run
at the local library. Intergenerational projects with local school children have also been a success and they are planning to engage with older children, too.

7.38 In Shropshire, Telford and Wrekin DAA, Dementia Friends Information Sessions delivered to local schools and faith groups, and the Shropshire Fire and Rescue service signed up to become dementia friendly, as well as local churches.

7.39 In Luton, over 45 organisations are now members of the DAA. These include the police, fire and rescue services, high street businesses, local authority, charities, care providers and health trusts, faith groups and schools. It is the largest Action Alliance within the Eastern Region of England. The DAA has worked with a local hospice to improve end of life care; a ‘Luton Dementia Guide’ has been published and activities such as dementia cafes, swimming sessions and carers groups have been set up. A partnership with the local football club has been particularly effective.

7.40 Overall, England DFCs have been successful due to a strong leadership usually formed around a DAA. They have placed PWD at the core, seeking their input to identify the needs of the community and to make it truly context specific. Often, PWD have been key in the establishment and success of the DFCs. They have engaged key organisations and leaders, such as businesses and local authorities (councils).
Greece Evaluation Summary

7.41 The most impactful activities reported in Greece are summarised under the Four Cornerstones:

- **Networks:** The adoption of formal Memoranda of Cooperation is a best practice which led to long-term commitments, policies and services by both the Municipal authorities and the central government. Establishing effective collaboration amongst researchers and providers of dementia services is key.

- **People:** Educate and empower people with dementia through effective programs such as the Caregivers’ Schools and enable them to actively participate in the social life. Eliminate the stigma of dementia. Inspire key stakeholders in developing dementia friendly action plans.

- **Places:** Improved access of older persons and/or people with dementia to local services.

- **Resources:** Adoption of policies and creation of long-term services and processes for the creation of dementia-friendly communities.

7.42 Greece used various metrics to collect data to analyse the activities that were piloted in the three municipalities. These were attendance numbers at activities; results of the dementia attitudes evaluation questionnaire; evaluation questionnaires; and outputs of focus groups and meetings.

7.43 Attitudes and perception evaluation questionnaires were distributed before and after the events. In addition, the numbers of attendees at focus group meetings and events were recorded to measure the number of participants. Questionnaires were analysed using SPSS by Psychology Researchers. This revealed a statistically significant difference (p=0.020) indicating slight improvement on the Subscale 2 suggesting a greater recognition of personality.

7.44 This data was used to publish research articles about DFC and the creation of a booklet called: *Creating Dementia Friendly Communities: Municipality Toolkit*.

7.45 Media articles were published and there were good levels of media coverage of the activities, which helped to raise awareness. The significant publicity surrounding the Memorandum of Cooperation being signed and activities undertaken as part of the Act of Dementia initiatives raised interest from other Municipalities and Centres for the Elderly. This resulted in a similar Memorandum being signed in another area.
The most successful activities reported were the caregivers school program, which empowered and educated caregivers in their role as carers for PWD. This was evident by the high uptake of attendance shown amongst caregivers who had participated in the program. Other key successes of the DFC were awareness raising activities which facilitated dialogue during the activities. The intergenerational activities which were planned in the Municipality of Byron aimed to bring together the older and younger generation. This was enthusiastically received by all the participants involved. Positive feedback was received in from all the participants from the professional group. Training was perceived as an essential in helping to increase the social inclusion of PWD in their communities.

Table 10: The results of the Greece metrics to measure impact are reported below:

<table>
<thead>
<tr>
<th>Metric</th>
<th>Result</th>
</tr>
</thead>
<tbody>
<tr>
<td>Number of Memorandum signed with Municipalities</td>
<td>3</td>
</tr>
<tr>
<td>Number of specifying activities in each Municipality planned for rendering the communities Dementia Friendly.</td>
<td>7 (Caregiver School, memory clinics, informative workshops, Intergenerational activities, Memories cafe, Memory enhancement group, anti-stigma actions)</td>
</tr>
<tr>
<td>Number of Dementia Municipality Friends</td>
<td>30-40 (including social workers, psychologists, physiotherapists, nurses, administrative personnel)</td>
</tr>
<tr>
<td>Number of planned activities implemented (e.g. Memory Clinic, Caregiver School,</td>
<td>All 7 activities have been implemented in all municipalities.</td>
</tr>
</tbody>
</table>
| Awareness-raising event, Alzheimer's Café etc.) | Number of Caregivers school participants  
190 caregivers  
Number of Caregiver school multidisciplinary training team  
12-15 experts  
Number of memory enhancement courses  
2 courses of 7 groups a total 70 participants  
Number of municipalities personnel participated in the pilots  
30-40 (including social workers, psychologists, physiotherapists, nurses, administrative personnel) |
| --- | --- |
| Number of participants and time line of the scheduled activities (Caregivers' School, Memory Enhancement Groups, Intergenerational Activities, employee training) | Number of Scientific Publications in Greek  
1 publication. “Psychiatriki” official journal of Hellenic Psychiatric Association (academic journal) |
| Scientific Publication regarding the actions undertaken | Number of Media coverage  
All municipalities sites disseminate info regarding DFCs actions  
This is a pool of on-line info regarding the DFCs actions  
https://www.dimosbyrona.gr/article.php?id=8013  
https://www.dimosbyrona.gr/article.php?id=8257  
https://www.dimosbyrona.gr/article.php?id=8666  
https://www.militaire.gr/filikes-pros-tin-anoia-koinotites/  
https://www.nooz.gr/health/1533778/anagki-gia-pio-filikes-koinotites-se-atoma-me-diataraches-mnimis  
https://www.newsbeast.gr/greece/arthrto/4673889/anagki-gia-pio-filikes-koinotites-kai-geitonies-se-atoma-me-diataraches-mnimis  
https://enypografa.gr/?p=253150  
7.47 Data analysis of pre and post surveys are still ongoing. There were some conclusions that were implemented directly.

7.48 Each municipality had established a Dementia Friendly team that was recognised by the municipality authorities. These had incorporated of memory centres network that were linked with other community health services in the open elderly centres. Surveys had been distributed before and after the activities to understand the knowledge improvement on dementia as a disease for people from the municipality personnel. There were high levels of acceptance and interest shown by participants from the Caregivers School. This indicates that a significant number of caregivers need to get support and help from within their community either from open elderly centres and / or homebased.

7.49 The Greek National Plan of Dementia will use results to develop similar services in the municipalities to overcome the lack of dementia services. The Neuropsychiatric Inventory (NPI) training module in the community setting will be implemented given that there were an exceptional number of participants that found it beneficial. Using the NPI module in educating and raising awareness on Behavioural and Psychological Symptoms on Dementia (BPSD) by caregivers enabled positive results and outcomes. All caregivers understood dementia as a memory problem but if they received severe burden as a consequence of their dementia from their beloved one, they would not be able to understand the behaviours.

7.50 NPI was used for the first time in a community setting and not in a specialised dementia centre with training sessions and an expert was also involved on BPSD. For homework, the caregivers were asked to translate the behaviour of their beloved one based on the NPI module they had taken. The results were
highly satisfying, and the knowledge gained on BPSD led to change in their attitudes, behaviours such as empathy, psychosis, anxiety and depression.

7.51 Overall, pre- and post-activity measures showed the largest acceptance of the DFCs actions in the municipalities that were involved in the project. All the initiatives have been adopted as regular actions in the municipalities. Two suburban municipalities and one rural were willing to participate in the development of DFCs adopting the implementation procedure used in the project. Regarding satisfaction rates, these were the highest among participants in the actions regarding Dementia Municipality Friends and caregivers’ school.
7.52 **The overarching impact of the DFC in Italy is summarised under the Four Cornerstones:**

- **People:** people with dementia felt valued by being interviewed, a number of groups of people learnt about dementia and PWD for the first time.
- **Place:** social and physical environment were assessed, and input from PWD gathered, to identify how places could become more dementia friendly, and increase levels of access by PWD.
- **Networks:** the promoting committee guaranteed a constant link between different institution, authorities and private organizations.
- **Resources:** all participants, including people with dementia were considered a resource. Staff members of Federazione Alzheimer, psychologists, geriatricians, sociologists as well as volunteers were integral resources.

7.53 There was a total of five activities held in the site in Italy (Abbiategrasso). These were: a video interview with the local community leader, an intergenerational school project, gym class (adapted physical activity), a dementia friendly library, education meetings and training sessions for the local police.

7.54 Two different kind of measures were adopted. The first was the number of activities undertaken, and the number of the participants from the target population. The second records the responses of the participants, and any reported impact of the activity. At the beginning and the end of all activities, participants were asked to fill a questionnaire or take part in an interview. This varied according to the type of the meeting; satisfaction, knowledge or attitude surveys were used, depending on context. PWD participating in some of the activities were also interviewed by psychologists.

7.55 Most of the qualitative data was collected through focus groups and deeper interviews. Around 22 people with dementia participated in a semi-structured interview which revealed their needs and provided invaluable insights into the initiatives that the DFC must undertake. People with dementia wanted to do something more active. Like taking a walk with a friend or a caregiver, going to a gym class, going shopping, buying some food in the weekly market of Abbiategrasso.
7.56 PWD did not find specific obstacles for their daily routine activities, however, some of them did highlight the burden of needing to be accompanied. 15 people with dementia out of 22 abandoned activities that they would have done in the past. The activities that the PWDs would like to do are: participate in gymnastic groups (7), meeting relatives and friends (15), shopping / going to the market (14). 20 out of 22 find Abbiategrasso a "frendly" town. Some People with dementia have expressed the need to be accompanied as a burden (6) and do not know who to ask for help in case of need (2); a personal loss of motivation ("I lost the will"; 5) but also and the presence of urban obstacles: lack of rest points (1) and public transports (1), distance (1) and fear of scams (2).

7.57 From 2018 the Abbiategrasso experience was presented at 25 national conferences as well as the rich and continuous testimony that was given during the ordinary work and institutional presentations. More than 100 local newspapers, online magazines and local newspapers have highlighted it in addition to the article published in January 2019 in National Geographic. In support of this 7 radio interviews and participation on the main national television channels during in-depth programs and newscasts.

7.58 9 stakeholders involved in the "Promoter Table" of the DFC: Municipality, local police representative, ASSt Golgi, Golgi Foundation Research, Psychogeriatric Association, Elderly association, School, library and merchant association.

7.59 59 Family caregivers actively participated in the early survey of their needs within the community.

7.60 In terms of the needs for caregivers, these emerged as a need to preserve or regain the normality of everyday life in the activities. Caregivers wanted to continue in supporting the person with dementia. These are mainly related to simple everyday activities like meeting friends or relatives. Some of the obstacles to the maintenance of daily habits, were around two trends.

7.61 On the one hand there were some difficulties in being able to move in the city (lack of public transportation, the need for more places to rest, some of the physical barriers), on the other hand some people are worried about not knowing how to manage behaviours of people with dementia (fear that there is no one that will be able to understand and help), and about the safety (fear of scams..). There was a total of:

- 66% of caregivers is a family caregiver
- 90% are women
• 28% would like to share their experiences with other caregivers
• 37% of Caregivers finds Abbiategrasso sufficiently "friendly" (inclusive), 26% insufficiently and 29% do not have an opinion.
• 1 spokesperson with dementia (Father Giancarlo)
• 88 caregivers received a training course divided into 3 editions (each one consists in 4 lessons)
• 66 trained caregivers have completed a pre and post questionnaire about knowledge, stigma and how to approach to a person with dementia.

**Results of the questionnaire are being submitted for a publication.**

Initial results related to a partial sample: at the end of the course participants showed a significant improvement in perceptions concerning the knowledge of the dementia as a disease, the ability of verbal and non-verbal interaction, to identify the needs of the person with dementia, to manage difficult situations, and to lend help to others in dealing with difficult situations with the PWD.

• 24 officers of the local police received a training course and we collected a satisfaction questionnaire

7.62 The police stated that: "For us it was important to understand what the best way is to behave and communicate with a person with Alzheimer's in our work. These are training opportunities that should be extended as much as possible, because it could happen to anyone to have to deal with the family with this disease". The training was appreciated and how the lessons are structured in an interactive and more theoretical way. They suggested that the course will be enriched by a third meeting with examples of some possible situations such as: missing person, accidents and collaboration with social services.

• 19 people of the local elderly association attended a training course about clinical and psychological aspects of dementia. They were positively impressed by what they learned about dementia and how to interact with people with dementia

• 300 questionnaires were collected from the general population about accessibility of the city and their usual route to reach the market. Results are in process.

• 7 people with dementia and their caregiver attended twice a week for two years for a gym class. At the end of the first group a semi-structured interview was conducted with the participants to explore: 1. Perception of their physical activity in a short term; 2. Overall assessment of the course; 3. Perception doing gym in a group. All participants expressed satisfaction
participating in the group of gentle gymnastics and doing physical exercise, they recognized the context adequately, they appreciated the gym instructor and they enjoyed being in the company of other people. Everyone recommended this experience to other people. 5 coaches have been trained to better manage the activity. They were very happy with the training that gives the possibility to increase the participation of people with dementia and their families in new gym class but also improve their general approach to elderly people.

7.63 All the staff of the library were trained, and this gave the possibility to adapt and create an Alzheimer’s space into the library. In particular, the head of the library after attending the training course said “It was very interesting to have these first information about the disease and how to behave, for us it would be important to be followed regularly in the future, as we plan to revise the books reference and the indications inside the library, to make it easier to access our service and have a simpler consultation even for those with a cognitive impairment problem”. 10 merchants participated in a training course and they became ambassadors to other merchants.

7.64 Quantitative data was analysed using descriptive and inferential statistics and recorded on a spreadsheet. It was found that interviews by trained professionals were more effective than using long questionnaires to collect data from participants. This yielded better outcomes for PWD and was demonstrated by having participation of people with dementia and their families.

7.65 Italy set out two goals for their DFC. For the first goal “empowerment and participation of the people with dementia”, the most effective activities were reported to be: PWD participating in the planning of the DFCs, the high number of families attending the education meetings, the small but persistent group of APA (Adapted Physical Activity), and interview by Father Giancarlo who spoke talks about his experience living with dementia.

7.66 For the second goal “overcoming stigma”, the most successful activity reported was been the involvement of the high school student and their teachers. The promotion of the project by the teachers was seen to be integral, and the teachers had undertaken training prior to the project about DFC and dementia. Satisfaction questionnaires were used to analyse and record those that attended the activities. A knowledge test (table 12) was also administered, as well as an attitude and perceptions questionnaire. 44 students are involved in
the project with 4 teachers. 35 of these students have completed two pre and post questionnaire about motivation and knowledge. Students after participation in training, gave their parents survey about knowledge on dementia.

Table 11 - Knowledge Questionnaire for high school students and teachers

<table>
<thead>
<tr>
<th>Questions</th>
<th>Pre-answers (%)</th>
<th>Post-answers (%)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Knowledge of costs in caring for people with dementia</td>
<td>2</td>
<td>9</td>
</tr>
<tr>
<td>Knowledge of the symptoms that may suggest dementia</td>
<td>23</td>
<td>55</td>
</tr>
<tr>
<td>Knowledge of the relationship between good lifestyles and dementia</td>
<td>32</td>
<td>72</td>
</tr>
<tr>
<td>Knowledge of the age of people diagnosed with dementia</td>
<td>36</td>
<td>42</td>
</tr>
<tr>
<td>Knowledge of the causes of dementia</td>
<td>36</td>
<td>81</td>
</tr>
<tr>
<td>What percentage approximately of people with dementia receive a diagnosis?</td>
<td>48</td>
<td>49</td>
</tr>
<tr>
<td>Dementia is another term for Alzheimer’s</td>
<td>52</td>
<td>63</td>
</tr>
<tr>
<td>Knowledge of the problems of the people with dementia</td>
<td>73</td>
<td>93</td>
</tr>
<tr>
<td>Dementia is part of the normal aging process</td>
<td>73</td>
<td>95</td>
</tr>
</tbody>
</table>
If a person becomes confused, it means that he/she has dementia

<table>
<thead>
<tr>
<th></th>
<th>93</th>
<th>98</th>
</tr>
</thead>
<tbody>
<tr>
<td>Dementia is a brain disease</td>
<td>100</td>
<td>100</td>
</tr>
</tbody>
</table>

7.67 The results from the knowledge questionnaire revealed low levels of knowledge before the activities and a significant improvement in knowledge post activities. The highest was knowing that dementia is a brain disease, with the lowest figures that indicated poor knowledge around the knowledge of costs, causes of dementia, age of when dementia is diagnosed and the symptoms that are suggestive of having dementia.

7.68 Participation in education meetings was very high and the results from the pre and post questionnaire demonstrate a good level of learning and high satisfaction rate of the participants. However, there was little increase in the reported rate of visiting local facilities such as shops or coffee shops by PWD.

7.69 Data that was collated after the first meeting which gave validation for the continuation of the activity, but also included helpful criticisms, that were useful to address in subsequent activities to further improve the sessions.

7.70 The qualitative interviews revealed that many people with dementia who engaged in planning with the activities of DFC contributed interesting proposals and felt valued at the same time. This was evident in the gym class, as it improved the behaviour and the mood of the participants both with PWD and their caregivers.

7.71 The act of distributing questionnaires to students for the school project activity before and after educational meetings also helped improve the knowledge and attitudes regarding PWD. "I am proud to be part of the DFC project where I see volunteers who put their heart and soul into helping people who are in difficulty and teach me that in life doesn't count the steps you take but the footprints you leave." Anna – student.

7.72 Over 300 elderly people who filled out the questionnaire provided suggestions on how to improve walking routes in the city. The results of the survey will be shared with the municipality to plan necessary interventions to improve pedestrian routes. This is an excellent example of using PWD to directly inform DFCs.
7.73 The public library established a dementia friendly area, with a comfortable place designed for PWD to access and use the library facilities.

7.74 Interviews about life in the community and responses to the gym classes were conducted and analysed. "When I've been asked what I was missing in my life after the diagnosis - I immediately said gymnastics. Before I did it and then I didn't go any more and I told my husband 'but look, we don't want to do that kind of gymnastics' so I thought 'we do things at home on our own', but it is not the same thing. Now - as part of the DFC's initiatives - I am followed by an instructor and I feel more relaxed. I'm happy! The movement is needed and doing it together is even better! My husband is with me but there are also people I didn't know before. Even if the town is small you don't know everyone, you know!" Emanuela (Gym class).

7.75 The promotor of the committee held regular meetings to facilitate and create a constant relationship between the public and private bodies taking part in the DFC. "We have enthusiastically joined the invitation to participate in these trainings. We believe it is important to know dementia and to network so that people feel welcomed and at ease when they enter a store, and they can always be in front of someone able to help them in times of difficulty." Tiziana - President Merchant association.

7.76 Training for policemen, shopkeepers, library staff, front line clerks all incorporated a good level of satisfaction and helped reduce the notion of stigma. "The fact of living dementia alone or communicating with others, having the support of a network of social relations, even changes the fate of the disease, not just the mood of the person." (Alberto - family caregiver).

7.77 After undertaking the training, the policemen felt “We realized that our approach to the person with dementia, until now, was not adequate. Thanks to training we have understood how to support the person and help them in case of need. More than once we have put to use what we have learned.” (Simone - Local police agent).

7.78 Overall, it was reported that engaging PWD in the planning of the DFC; the gym class; and education meetings for families were the most successful at increasing the Participation of people with dementia and their families. Training for policemen and other community members; intergenerational school activities; and the flash mob in the centre of the town were the most successful for Reducing Stigma.
8 Lessons learned from the three pilot sites

8.1 This Chapter sets out the lessons learned from the sites, grouped under the Four Cornerstones.

Places

The importance of tightly-knit communities

8.2 This is a cultural issue that was identified in both Greece and Italy. Greece, on the importance of its Dementia Municipality Friends initiative stated:

“Most of the DMC know patients and carers as members of neighborhood, know their family relationships, they have almost daily contact and they know the network of the services in and out of the municipality. Thus, they could provide guidance, support and allow them to build close relationships of trust.”

8.3 In close-knit communities, locals know and support each other, establishing an informal network which could be optimized for the development of local neighbourhood initiatives, for example, sharing joint responsibility for returning lost PWD back to their home etc.

8.4 However, this benefit of small communities also has a downside: Italy cited the issue of stigma at a local level, i.e. community members not wanting to be known by everyone as someone with dementia. Italy addressed this issue by making and disseminating an interview with a well-respected local figure and figurehead of the community – a priest – who was open about his dementia.

8.5 Local community activities for introduction and inclusion of Dementia issues were successful when embedded in existing social activities and tradition. Unique Bulgarian local social place “chitalishte” is a national specific appropriate place for meetings, different relaxing activities for young and elderly people. Pilot activities at these local places were good examples how to facilitate inclusion and communication with PWD and their family members. This is a best-practice example of awareness-raising which could be a source of learning for other DFCs, e.g. Bulgaria, who recognises that “Increasing
awareness and reducing stigma has a key role in improvement of dementia care in society” and stated that DFC I could help this. However, findings suggest that DFC might not make a significant impact at local or national level until certain education and attitudinal barriers have been addressed.

People
The importance of involving PWD and their carers

8.6 All activities reported good outcomes by involving PWD, which is the key principle underpinning the Four Cornerstones DFC Model.

8.7 Bulgaria stated that they were over-reliant on “theoretical” training, as opposed to the practical involvement of PWD, which they cited as a possible reason for their relatively low level of engagement. This reiterated a conclusion that Bulgaria, who went on to involve PWD and caregivers in its caregiver support groups, also arrived at:

“People and the staff were more satisfied when more practical information is introduced and shared. Case discussions are of key importance.”

Greece states:

“(We recommend) involvement of the PWD and their families with focus groups and interviews. This is crucial for developing programs and establishing priority that can meet the needs of the PWD.”

8.8 Beyond the planning phase, direct involvement of PWD in shaping and guiding activities had significant benefits, as Italy found with regards to its successful library initiative, which relied on consultation of PWD. The first-hand involvement of PWD in DFC guarantees a practical, hands-on approach.
Italy found:

“The involvement of PWD and families in the planning phase is crucial.”

8.9 Italy stated of a shopkeeper training initiative, which had low long-term uptake:

“In the case of the shopkeepers we may speculate that a direct relationship and a programmed experience with person with dementia might have been more effective.”

8.10 In England, the Bradford DFC said;

“Have people affected by dementia at the forefront. The FiT Group shows the huge impact of having people with dementia leading projects in their communities.”

Resources

The importance of volunteers

“Time, energy and leadership are the key non-monetary resources... Some people believe much can be done locally with little money if there are strong networks and volunteers.” (7.1 Evidence Review).

8.11 The centrality of People to the success of DFC is summarised by Italy, who treated its participants (and, by extension, its Networks) as the most important Resource of all:

“All participants, including PWD were considered a resource. Staff members of Federazione Alzheimer, psychologists, geriatricians, sociologists as well as volunteers were a formidable resource. They all gave a personal contribution to the DFC activities.”
8.12 The importance of volunteers, specifically, was a theme that emerged from all the pilots. Italy states that:

“The involvement of municipality and socio sanitary service may give professionals for the activities. On the other hand, the participation of volunteer organization is of paramount importance not only for social reasons but also for saving costs.”

8.13 Greece also understood the importance of volunteers (and People as a whole) as a resource:

“The Dementia Friendly Initiatives are the result of municipality personnel volunteering and their will to change. Funding provided from Municipalities and Joint Action.”

8.14 In England, the creation of a strong Dementia Action Alliance, or similar group, was essential for the success of the DFCs. These were often built upon a core base of volunteers and key organisations.

Identify a group of people to drive forward a Dementia Friendly Community from the start. Involve local people and organisations of influence to help lead an imbedded approach where organisations and the local community can take ownership. – Alsager

8.15 Therefore, the establishment of networks (including strong leadership) is a necessary precursor to securing resources, both monetary and human. Bulgaria, who listed a future objective as “searching possibilities for volunteer inclusion”, secured less in the way of network support than the other two sites; and cited a lack of resources as a barrier in the implementation of its DFC. Bulgaria (particularly its rural municipalities) is considerably less economically developed than Italy and Greece, which may mean lower availability of resources.

8.16 Although other evidence indicates that DFCs work best in smaller communities, the most successful activities in Bulgaria actually took place in Sofia, the
Capital, where resources – and stakeholder support – are more readily available (and where education and attitudes are potentially more progressive).

Networks

The importance of Alliances

8.17 The importance of building strong and broad alliances to the success of DFC was consistently confirmed throughout the pilot programme, in line with the recommendations outlined in 7.1.

8.18 Italy stated that the:

“Involvement of local administration, like Municipality and health services, was crucial in our experience. Scheduled meetings of the Promoter Committee in order to establish relationships between the stakeholders has been of great importance.”

8.19 Italy established broad agreements with national and local authorities which proved buy-in from key local actors (e.g. government and other officials) and guaranteed clear local leadership.

8.20 Having strong local and national sign-up is also important in terms of dissemination activities. Journalists of the local press, radio and television participated from the beginning in disseminating stories about Dementia and DFC in Italy.

8.21 **Bulgaria** reported:

“DFC activities have to be included and embedded in National Dementia Plans”.

8.22 Support from local authorities had to be galvanised so that, for example, staff are motivated to attend meetings, etc:
Support from local authorities has to be ensured so that, for example, the staff are motivated to attend meetings. For Bulgaria, signing the Memorandum was an important pre-requisite for the pilot activities’ success. Another key issue was to involve GPs in the local network as a leading figure in dementia detection, diagnosis and treatment, as well as promotion of healthy ageing.

In Bradford (England) DFC, they gained support from across the political spectrum in their local councils. In most cases a council ward officer is responsible for developing a local plan. This meant that endorsement and support was received from local councillors who had an interest in their local success. This created a positive non-political rivalry and good political support from Bradford council.

The partner is currently working on a National Strategy Development with the inclusion of DFC and “reducing stigma” as key topics.

National Working Group for developing National Dementia Strategy Concept has been approved by the Ministry of Health. Representatives from the following stakeholders were included: Ministry of Health, Ministry of Labour and Social Policy, Bulgarian Society of Dementia, National Social Agency, National Association of General Practitioners, National Nurse Association, Bulgarian Alzheimer Association, Compassion Alzheimer Bulgaria, Bulgarian Organization "Living with Dementia", Medical University of Sofia, Medical University of Varna, Medical University of Plovdiv, Ombudsman of Bulgaria, Bulgarian Non-profit Organization of Low. The Working Group has already 2 meetings in May and June 2019. First version of the National Strategy proposal will be delivered in December 2019 with embedded results from DFC activities.

The results of pilot activities were of key importance for starting the development a National Dementia Strategy. Inclusion the “DFC”, rising awareness, information and education at different levels is the focus issue of the document in preparation.

Bulgaria did not reach the same level of buy-in or strong stakeholder network, which impacted the success of its DFC projects. It secured a ‘Memorandum of

“Very important to explore and find key actors that could help to establish and support the place for meetings especially in rural areas.”
Cooperation with the Municipality of Elin Pelin’, but not at the other sites; and cited administrative support at national and local level as crucial to – and its lack thereof as a barrier – to success.

**Greece**

8.29 The site identified the involvement of creating local community networks and engaging with different municipality services is a key factor to success. They secured a Memorandum of Cooperation (duration of two years) with Dementia Friendly Municipalities (DFM).

8.30 Creating alliances and ratifying formal agreements with local authorities and the government proved the commitment to the project’s specific goals.

**The Importance of local definition**

8.31 Another, related issue raised in Bulgaria was the unforeseen challenge of cultural barriers in small, rural communities: namely “local attitudes and habits of communication, gender specific differences in motivation for meetings in rural areas.” The site stated the importance of “Exploring local established traditions” as a way to overcome this barrier.

8.32 The importance of adapting the DFC model to local needs and “both national and regional drivers” cannot be underestimated. Local contexts are so diverse, that a system-wide model must be very flexible.

8.33 Italy recognised the context-specific nature of DFC: “The “Dementia friendly community” project comes from a foreign model. For this reason, it has been necessary to bring some changes in order to adapt it and make it understandable in Italy. This is a good way to share good practice: evaluate, analyse, work with other countries and adapt a model to their own characteristics.”

8.34 Intergenerational activities, which all the pilots carried out, were highly influenced by local definition, and demonstrated that outcomes are to a large extent culture-specific. Italy stated that “Intergenerational relationships and the support by the young are an important step of the DFC progress”.

8.35 Intergenerational programmes worked well in Greece and Italy - Mediterranean countries with ageing populations and traditionally tight intergenerational ties
that are loosening. 60% of caregivers are children (20% are partners), according to Italian pre-pilot data, suggesting an enduring sense of intergenerational duty of care, at least in smaller communities. The biggest differences in care givers are found between urban and rural setting.

8.36 The intergenerational programmes were less successful in Bulgaria (where 95% of PWD are cared for at home). Some of this may be attributed to the way the activity is implemented – Bulgaria stated that the group size of students was too big to have a meaningful impact. In addition, Bulgaria faces similar issues to Greece), where young people are moving to big cities or abroad for economic reasons, leaving the elderly feeling isolated in rural provinces.

8.37 Caregivers schools worked well in both Greece and Bulgaria. In Greece, caregivers were educated on behavioural disturbances with the use of Neuropsychiatric Inventory (NPI) (a way of measuring the development of dementia behavioural disturbances) which had an excellent outcome. The caregivers were able to define, describe and manage the Behavioural and Psychological Symptoms of Dementia (BPSD).

Lessons Learned: Conclusion
Successes

8.38 The involvement of young people in intergenerational activities were proven to be a success. Using smaller groups to facilitate training or educational activities, the involvement of community activities i.e. those of the library, gym for PWD and intergenerational activities and caregivers' schools were demonstrated to be more constructive. Positive feedback and results were demonstrated in Greece by both the health professionals that had joined in the Neuropsychiatric Inventory (NPI) programs and the participants. The recognition of patients’ neuropsychiatric symptoms through the use of NPI (Cummings et al.,1994) assesses dementia related behavioural symptoms with 10 sub-domains of behavioural effectiveness. The NPI supports multiple types of dementia and not just Alzheimer’s Disease. Several iterations of the NPI are available in over 75 different countries which can be found at: http://npitest.net/npi/translations.html.

8.39 The use of visual learning was proven to be a positive feature, for example in Bulgaria, where the screening of 4 awareness-raising films at the cinema for the general public in the capital city Sofia helped towards reducing stigma associated around dementia. The video interview of Father Giancarlo Politi in Italy who is living with dementia was publicised to challenge myths and assumptions as part of the DFC initiative. The success of the Caregivers’ School’s Program held in Greece through exchanging experiences and opinions with other carers demonstrated a reduction in the burden of family care and giving the carers a break from the caring role.

Challenges

8.40 Cultural barriers and stigma remained in some sites. One of the challenges identified in Italy was the understanding that the DFC does not necessarily require new services, but instead aims to change the mentality and the behaviour of a community. Training carers and PWD with health literacy skills to understand challenges around the fact that people with dementia, particularly in early stages of the condition, have a long period in which they can participate in many activities with. Making community activities e.g. the gym and library more dementia friendly, and educational training for PWD and Caregiver School Programs is a way to address this assumption.
9 Conclusion

9.1 This report has synthesized findings from implementation of the DFC model in the European pilot sites; drawn on and incorporated the learning from evidence review 7.1; and tested if the DFC model can be flexible to and driven by local needs and circumstances.

9.2 The key conclusions of the findings of the pilot sites, deliverable 7.2, building on the lessons learnt from the pilot sites are:

- A robust network of key organisations with good levels of engagement and buy-in and from local stakeholders, including local authorities and politicians is essential.
- Success of the DFC depends, to a large extent, on the development of the site itself, in terms of levels of stigma, resources available and existing networks. DFC sites go through a journey of development, and it is essential to consider what stage the site is at before establishing a DFC initiative. Different stages will require different approaches.
- A one-year pilot scheme is not enough time to demonstrate real change. The most impact was demonstrated in Italy, which to some extent, is related to the longevity of the DFC site there, which has been established over a number of years.
- A thriving network of volunteers grouped around a strong charitable sector are essential. Volunteers not only provide a human resource, but help to
- The nature of the site itself, particularly the strength of existing community ties, affect the success of the DFC – tightly knit communities can offer more support but also increase the risk of stigma associated with disclosing a dementia diagnosis.
- Involving people with dementia is a key, both at the development stage of what constitutes a DFC, and the delivery of DFC activities.

9.3 Sites were asked to identify the most successful activities in their DFCs, which they would recommend to other countries establishing a DFC. There were a number of overlaps in their recommendations, and the most successful activities were identified as follows. Therefore, it is recommended that countries consider undertaking the following activities:
9.4 **People**
- Caregivers schools or support groups
- Involvement of PWD and their caregivers
- Education of service and community staff
- Improve health and social care staff’s knowledge of dementia

9.5 **Places**
- Improve accessibility to community spaces
- Adapt physical layout of town, for example roads and pavements, to improve accessibility
- Establish centres for PWD to attend and socialise

9.6 **Networks**
- Signing of local agreements and memoranda
- Establishing an online network and social media presence

9.7 **Resources**
- Use of volunteers in all activities
- Include DFCs in national dementia plans

Expanding the evidence base for DFCs

9.8 This pilot helped to expand the evidence base for DFCs and to re-enforce the findings of the evidence review, deliverable 7.1.

9.9 The ‘Evidence Review 7.1’ stated that DFCs are most sustainable when:
- They are based on a broad and strong alliances, which includes PWD and in which responsibility and leadership is shared;
- Activities are mainstreamed into local plans, strategies and training initiatives;
- There is a long-term commitment to this agenda, including political commitment; not a belief that a DFC is something which can be quickly achieved;
- Evidence is gathered to build a ‘business case’ for activities;
- Opportunities to learn and share experiences from other projects and nations are maximised; and
- The focus is on bringing the Dementia Friendliness agenda in line with the disability rights agenda.
9.10 The pilots provided further evidence the importance of these attributes. In particular, the importance of involving PWD and their carers in the development of the DFC, identified in all the sites. Also, the pilots indicated that DFCs must be a long-term commitment, and that change cannot be guaranteed in a short space of time (in this case, just over a year). This was particularly true in Bulgaria, where dementia awareness levels were comparatively low before the DFC programme was established. Therefore, it will take longer than a year to see a real change. The pilots also re-enforced the importance of alliances, and strong networks of influential stakeholders to help ensure the success of the DFCs, which the evidence review highlighted. In Greece, this included formal alliances through the signing of a memorandum, and in Italy included good engagement with the local media to raise awareness.

9.11 The pilots have also contributed new, emerging themes to the evidence base. In the evidence review, it was noted that most of the existing evidence came from more mature DFCs, typically from Northern European Countries. By including a more diverse range of countries in the pilots, the programme has demonstrated how DFCs can be applied in a different context. This has also reiterated the importance of local definition, incorporating local needs and culture, such as in Bulgaria, where existing community networks and cultural events were used to raise awareness. As well as adapting to suit the site’s culture, the pilots evidenced the importance of considering the stages of development of the site, and the need to build in a longer development stage in these cases. The pilots also indicated the importance of building on intergenerational ties, particularly in countries where these are already strong, e.g. Italy. Engaging young people in the DFCs in these contexts were demonstrated to be successful.

Summary

9.12 The conclusion of this report is that the DFC model can work in a variety of contexts across the EU, as demonstrated in the pilot sites. However, the DFC model must take into consideration local culture; levels of resources and networks; and existing levels of stigma. By taking these into account during the development and delivery of DFCs, sites will be more likely to establish a successful DFC. These were identified during the evidence review, deliverable 7.1, and re-enforced by the findings from the pilots, including in new sites beyond North Europe.
9.13 Furthermore, DFCs may not demonstrate measurable change in the short term, particularly in sites who have less robust networks, resources and higher levels of stigma. It is important to view a DFC as a long-term commitment, which may not indicate change in the short term, particularly in sites which may require additional initial focus on understanding levels of dementia awareness and knowledge.

9.14 Although the levels of improvement and impact vary dependent on the context, but DFCs have been demonstrated to be effective and make a positive impact across the pilot sites.
10 Recommendations for other EU sites who wish to establish DFCs

10.1 Based on the evidence reviewed for this report and drawn from the DFC model proposed in 7.1, this report has established a series of recommendations for EU countries who are planning to undertake a DFC project. They are grouped under the Four Cornerstones below. EU sites who establish a DFC based on these recommendations, and the lessons learnt set out earlier in the report, should be more likely to implement successful DFCs in their countries.

10.2 Place
- Draw on local cultures and traditions to help develop a truly context-specific approach, adapted to local need and want.
- Use small scale, effective actions. Focus on the local people that you have the most influence over; e.g. local branches of organisations rather than national chains.
- Enable access to the wider community for PWD by making public spaces like gyms and libraries accessible and help to normalise the presence of PWD in their communities.

10.3 People
- Put people with dementia and their families at the heart of the programme – using their input to shape and guide the activities. Establish levels of understanding, knowledge and stigma about dementia at the outset.
- Focus on a practical approach for training and use PWD as part of your activities.
- Children and young people are generally enthusiastic and engaged with the topic of dementia; use intergenerational activities to raise awareness.
- If not already in place, ensure that health and social care professionals receive high quality training to understand the importance of timely diagnosis, and post-diagnostic support.
- Educate key members of the community to increase respect and understanding of PWD and their carers and enable them to access the community.
10.4 Network
- Create a wider network through the use of social media and online sites which can be used to share information about dementia.
- Establish strong links with local administrations and political leaders. Buy in from the top is essential.
- Develop a robust network of volunteers based from a strong charity sector organisation.

10.5 Resources
- Use volunteers throughout all activities to minimise cost and maximise involvement
- Train healthcare professionals and personnel in the initial stages, to maximise early intervention and increase sustainability of the DFC.

10.6 Conclusion: Would we recommend the Dementia Friendly Communities (DFC) model approach to other EU countries?
- The DFC model can work in a variety of contexts across the EU as demonstrated in the pilot sites.
- Takes into consideration local cultures; levels of resources and networks; and existing levels of stigma
- By taking these into account during the development and delivery of DFCs, sites will be more likely to establish a successful DFC.
- These were identified during the evidence review, deliverable 7.1, and re-enforced by the findings from the pilots, including in new sites beyond North Europe.
- DFCs may not demonstrate measurable change in the short term, particularly in sites who have less robust networks, resources and higher levels of stigma.
- Important to view a DFC as a long-term commitment, which may not indicate change in the short term, particularly in sites which may require additional initial focus on understanding levels of dementia awareness and knowledge.
- Although the levels of improvement and impact vary dependent on the context, but DFCs have been demonstrated to be effective and make a positive impact across the pilot sites.
Appendix 1: Acronyms used in this report

APPG  –  All-Party Parliamentary Group on Dementia
DHSC  –  Department of Health and Social Care
DFC  –  Dementia Friendly Communities
EU  –  European Union
EUJA  –  European Union Joint Action
GPs  –  General Practitioners
IBA  –  Imogen Blood & Associates
IPP  –  Implementation Pyramid Process
JA  –  Joint Action
NPI  –  Neuropsychiatric Inventory
PWD  –  People with Dementia
WHO  –  World Health Organisation
WP7  –  Work Package 7
UK  –  United Kingdom
Appendix 2: List of Tables, Graphs and Figures

Table 1 - List of countries and organisations
Table 2 - Summary of Indicators from The Four Corner Stone Model
Table 3 – Comparing features of pilot sites
Table 4 – Pilot Sites in Bulgaria
Table 5 – Pilot Sites in Greece
Table 6 - Knowledge Questionnaire about Dementia (Cinema Attendees)
Table 7 - Expectations, attitudes and stigma related questions
Table 8 - Knowledge Questionnaire about Dementia (Community Staff and Caregivers)
Table 9 – Bulgaria Metrics
Table 10 - The results of the Greece metrics to measure impact are reported
Table 11 - Knowledge Questionnaire for high school students and teachers
Graph 1 – Questionnaire results testing dementia knowledge from Caregivers (n=30)
Graph 2 – Questionnaire results from Caregivers (n=30) – knowledge of psychological symptoms in dementia
Graph 3 – Questionnaire results from Caregivers (n=30) – Managing dementia knowledge
Graph 4 – Satisfaction levels for Staff and Caregivers (m=mean)
Graph 5 – Questionnaire results from administration staff for Neurocognitive Disorders (NCD) (n=13) pre- and post-data
Graph 6: Questionnaire results for Dementia Attitudes amongst administration staff (n=13)
Figure 1 - Four Cornerstones Model
Figure 2 – DFC Model
Figure 3 – WHO framework model for effective DFCs
Figure 4 – The Socio-ecological Model and Corresponding C4D Approach
## Appendix 3: Joint Action Evaluation Framework p.21

Indicators for each of the four ‘cornerstones’ of People, Place, Networks and Resources, based on the evidence reviewed and appraisal of the methods used in existing DFC evaluations

<table>
<thead>
<tr>
<th>Inputs</th>
<th>Outputs</th>
<th>Outcomes</th>
<th>Impact</th>
</tr>
</thead>
<tbody>
<tr>
<td>Description</td>
<td>Structures and resources which enable DFC, e.g.: involvement of people with dementia multiple stakeholder alliance financial and human resources high level political commitment</td>
<td>The activities undertaken to create a DFC, including interventions in: the physical environment the social environment and within any of the 8 output areas outlined in the DFC model (transport, housing, Health and Social Care, Emergency responders, Faith and Community groups, children and young people, shops and businesses, Arts Leisure recreation)</td>
<td>Improved accessibility of public spaces and buildings improved accessibility of information improved participation in or access to people with dementia across the 8 output areas. increased positive social attitudes towards people with dementia</td>
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<table>
<thead>
<tr>
<th>Types of Measures</th>
<th>Inputs</th>
<th>Outputs</th>
<th>Outcomes</th>
<th>Impact</th>
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<tbody>
<tr>
<td>Process evaluation</td>
<td>Will vary from project to project but may include: evaluation of processes monitoring of activities changes in policy</td>
<td>Measures should include: Data from formal sources, e.g. government/ service provider datasets, and Self-reports from people with dementia/ carers.</td>
<td>Challenges here include demonstrating causality in relation to the benefits of DFC on health and wellbeing or people with dementia and caregivers. However, developing impact measures for DFCs can support cross sector working to achieve</td>
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| Indicators can be binary (yes/no) or measure the level of availability | |

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| Focus on measuring inputs most clearly linked to a broad range of outcomes. | media coverage | number of events or meetings | attendance levels | common goals. In this sense perceived benefits by end-users can be collected in qualitative terms as proxies together with quantitative testing measures. |
Appendix 4: Implementation Pyramid Process (IPP) p.39

The Implementation Plan Pyramid (IPP) has been evolved from the Division of Geriatric Psychiatry intend to integrate the actions needed in the process of Friendly Communities for Dementia (DFC). The IPP follows the evidence review report by Imogen Blood & Associates, structured around the four different aspects of Dementia Friendly Communities – ‘People’, ‘Place’, ‘Networks’ and ‘Resources’ include 4 levels: