National Institute for Health Research Policy Research Programme Project Dementia Friendly Communities: The DEMCOM evaluation (PR-R15-0116-21003)

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Glossary of terms and Abbreviations

Term		Definition
Age Friendly City's initiative	AFC	An initiative aimed at enhancing the ability of cities to better address the needs of an ageing population.
Age Friendly City Tool	AFC tool	Previous work by the World Health Organisation highlights 8 areas that cities can address to better adapt their structures and services to the needs of older people: the built environment, transport, housing, social participation, respect and social inclusion, civic participation and employment, communication, and community support and health services.
Black, Asian and Minority Ethnic	BAME	**BAME** is a term long used in the UK to refer to Black, Asian and minority ethnic people.
British Standards Institution	BSI	Service organisation that produces standards (codes of practice) across a wide variety of industry sectors.
Clinical Commissioning Groups	CCG	An organisation responsible for implementing the commissioning roles as set out in the Health and Social Care Act 2012.
Communities of interest	COI	We refer to communities of interest as dementia friendly communities that focus on a common interest or passion. In DEMCOM, communities of interest also include dementia friendly organisations. Communities of interest often do not have geographical boundaries.
Dementia Action Alliance	DAA	A national platform that aims to bring about a society-wide response to dementia. Organisations sign up to the DAA and make individual pledges for action to support people affected by dementia.
Dementia Café		Run across the country, these dementia-specific groups vary in the way that they are structured but usually are informal settings where people living with dementia (and sometimes their carers) can socialise and support one another.
Dementia Friendly Community	DFC	DEMCOM definition: A Dementia Friendly community can involve a wide range of people, organisations and geographical areas. A DFC recognises that a person with dementia is more than their diagnosis and that everyone has a role in supporting their independence and inclusion.

The Dementia Friendly Communities programme logo is trademarked by Alzheimer's Society but all other communities not on the recognition process are also referred to as dementia-friendly communities. |

Dementia Friendly Community co-ordinator		This term refers to somebody who takes on the role as co-ordinator for the individual DFC initiative. The level of responsibility varies across DFCs.
Dementia Friendly Community hub		A central place/building where people living with dementia can visit to find out information, receive a diagnosis, socialise and participate in activities.
Dementia Friendly Community recognition process		A national recognition programme run by Alzheimer's Society which encourages communities to work towards becoming dementia-friendly by following 7 foundation criteria. It enables communities to be publicly recognised for their work.
Dementia Friends		Founded by Alzheimer's Society, the Dementia Friends programme is an initiative to raise awareness and change perceptions of dementia through encouraging action, big or small, to make a difference for people affected by dementia.
Dementia Friends Champion		A volunteer who has attended further training to run Dementia Friends information sessions, encouraging others to learn more about dementia and make a positive difference to people living with dementia in their community.
Dementia Friends' Session		An informative session aimed to increase the public's understanding of dementia and encourage them to think about the things they can do in their community to make a difference. Sessions vary in size and attendees however follow structured guidelines in their presentation.
Director of Public Health	DPH	A role responsible for determining the overall vision and objectives for public health in a local area and delivering public health objectives.
Full-time equivalent	FTE	A unit that indicates the workload of an employed person.
Joint Strategic Needs Assessment	JSNA	A process by which local authorities and clinical commissioning groups assess the current and future health, care and wellbeing needs of the local community to inform local decision making.
Key informant(s)	KIs	Participants who are invested and engaged personally or on behalf of an organisation within a dementia friendly community.
Local Authority	LA	An administrative body in local government.
Patient and Public Involvement	PPI	INVOLVE defines public involvement in research as research being carried out 'with' or 'by' members of the public rather than 'to', 'about' or 'for' them.

Person affected by dementia	PAD	Refers to both people living with dementia and their carers, family and supporters who are affected by dementia.
Person living with dementia	PLWD	Refers to any person living with and identifying as having dementia.
Quality Outcomes Framework	QOF	Voluntary and annual reward and incentive programme for all GP surgeries in England, detailing practice achievement results.
Cognitive Function and Ageing Studies	CFAS	Large, multi-centred population based studies of individuals aged 65 and over in the UK.
Social return on investment	SRoI	Social return on investment is a principles-based method for measuring extra-financial value. It can be used by any entity to evaluate impact on stakeholders, identify ways to improve performance, and enhance the performance of investments.
Stakeholder(s)		People invested and engaged either professionally or personally to offer their knowledge and experience in the specified subject area.

Acknowledgements

Executive summary

As the number of people living with dementia is increasing globally, Dementia Friendly Communities (DFCs) offer one way of providing the infrastructure and support that can enable people affected by dementia to live well.

There is no universally agreed definition of a DFC, and DFCs need not be geographical entities. This study adopted a broad definition, recognising that becoming a DFC is an ongoing process only fully achieved when living with dementia is normalised into a community's culture, language, infrastructure and activities.

> *A DFC can involve a wide range of people, organisations and geographical areas. A DFC recognises that a person with dementia is more than their diagnosis and that everyone has a role in supporting their independence and inclusion.*

DFCs in England can apply for official recognition by Alzheimer's Society as working towards dementia friendly status. A growing number of national and international frameworks and guidance is available to communities seeking to become dementia friendly.

Evaluations of DFCs are largely descriptive. While work exists on identifying core outcomes of DFC initiatives, there are very few studies that have tested DFC effectiveness or compared current practice with known need. Evidence on cost effectiveness, cost benefit, social value and social return on investment (SRoI) of DFCs is also missing. This study is addressing key gaps in the evidence.

DEMCOM set out to answer the following questions:

1. What are the characteristics and foci of DFCs in England?
2. What factors and preconditions for these initiatives produce positive outcomes for people living with dementia and their carers/supporters?
3. What generalisable lessons can be drawn about the resources needed and economic benefits of creating and sustaining DFCs?

Using a mixed methods approach, the study was organised in three phases. Phase one involved mapping of DFC provision across England by dementia prevalence and known cases with a diagnosis and categorising a national sample of 100 DFCs by their scope, focus, location, and evidence of impact. In phase two, an evaluation tool that had originally been developed for Age-Friendly Cities (AFC) was pilot tested and adapted to assess dementia friendliness in two DFCs. Phase three entailed applying the evolving evaluation tool in six DFCs (the two pilot DFCs, and four further DFCs), assessing them while finalising the evaluation tool as an evaluation instrument for DFCs.

DEMCOM recognised the benefits of involving people with lived experience of dementia in the research. A total of 67 experts by experience (27 people living with dementia (PLWD), 31 carers, 8 former carers, 1 other) provided input into the study through 35 separate Public and Patient Involvement (PPI) activities. They were remunerated for their contributions, which included advice on strategic and operational aspects of the research, data collection, data analysis, and feedback on emerging findings. The study addressed equality and diversity issues in addition to the involvement of experts by experience. DFCs in England were mapped in relation to epidemiological need in order to gain insights into distribution, accessibility and reach. Purposive sampling ensured that the research sites for the case studies included DFCs with diverse populations. The research team reached out to diverse non-academic groups with an interest in dementia by running a Twitter feed and regular blogs

that invited comments. In the evaluation tool developed as part of DEMCOM, equality and inclusion are key areas for attention.

In Phase One, geographically defined DFCs that had been formally recognised by Alzheimer's Society (n=189) were plotted onto a map of Clinical Commissioning Groups (CCGs) in England. Epidemiological need by CCG was established in three ways: (1) dementia prevalence; (2) number of known dementia cases; (3) estimated number of known and unknown dementia cases. The analysis showed that at least one DFC is based in just over half (n=115) of all CCGs in England (n=209). DFCs are spread throughout the country in urban and rural areas. DFC presence is significantly associated with number of dementia cases (known and unknown), yet not with dementia prevalence. While it is unclear whether association of DFC presence with number of cases is a function of response to epidemiological need, adjustments in the analysis for population size suggest that DFCs have not solely emerged in areas of greater affluence. The findings indicate that DFC provision is consistent with epidemiological need, and that DFCs are located in areas where they can have the greatest impact. The extensive DFC coverage suggests that the very idea of DFCs has resonance.

A purposive sample of DFCs (n=100) was examined, based on online data and telephone conversations with stakeholders, to arrive at an overview of key DFC features. Data collection was guided by an existing evaluation tool that had its origins in an instrument for assessing age-friendliness in cities. Most DFCs - in the sample and in England overall - were geographically defined, while a minority were organised by shared cultural interests or experiences of dementia (Communities of Interest, or COIs), and the vast majority had been set up or started activities following policy endorsement of DFCs in 2012. Statutory agencies, including local government working through local collaborations, have played a central role in the setting up, managing, and resourcing of the DFCs reviewed. There was evidence of the ongoing involvement of PLWD in DFCs in advisory, operational, and strategic capacities. However, the centrality of citizen involvement was not as clearly articulated. In the provision of services and activities, the DFCs emphasised awareness raising, yet evidence of tangible outcomes was difficult to find. They also offered both dementia-inclusive (e.g. leisure activities) and dementia-specific (e.g. dementia cafés) provision. The majority of the DFCs did not report how they were resourced. Investment in the form of volunteers raising awareness was the favoured approach. There were instances where the involvement of local government, as well as health care organisations and charities, released funds for DFCs. However, the reported ad hoc and often short-term nature of funding raises questions about what resources are required to enable PAD to live well in their local communities. While DFCs have been promoted as a potentially cost-effective model, monitoring and evaluation were underdeveloped in the DFCs, and there is limited data available to test this. Access to services, and concern with the rights of PLWD, were not apparent starting points for most DFCs.

In Phase Two, two DFCs were selected as pilot sites where the existing evaluation tool was tested and refined. Data collection occurred through documentary analysis as well as interviews, focus group discussions and meetings with key informants and PAD. In addition, a national stakeholder event was held where an invited audience of PAD, professionals in policy & practice and researchers provided input into the evolving evaluation tool.

In both pilot sites, involvement in DEMCOM had the unintended effect of re-energising DFC activity. The emerging findings, combined with the discussions at the stakeholder event, led to modifications to the evaluation tool. These entailed a distinction between standalone and cross-cutting domains for the assessment of DFCs. Assessing the involvement of people affected by dementia (PAD) in all aspects of a DFC became central to the evaluation tool.

Phase Three was an in-depth case study of six DFCs (the two pilot DFCs, plus four additional DFCs). Data collection was organised to capture evidence for each of the tool's standalone domains: Basis of

the DFC, leadership and governance, Activities and environment, Resources Monitoring and evaluation and three cross cutting domains: Involvement of people affected by dementia, Equalities and inclusion and Evolution. This involved documentary analysis, interviews, focus group discussions and meetings with key informants and PAD. In addition, a survey with PLWD who were not directly involved with the running of the DFC sites was conducted.

The evidence from the three study phases is synthesised to develop a series of six "if then" statements to build a theory of change and logic model of how DFCs work. These were:

If there is a history of local organisations working together to promote social inclusion for people affected by dementia, with designated people with council/collaborator support to achieve this, **then** this creates a secure basis for planning, discussion and dissemination that normalises thinking about how to include people living with dementia as part of wider community work.

If DFC collaborators understand their role as challenging systems and services in the community that exclude people living with dementia, **then** this leads to activities focusing on raising awareness of the needs of people living with dementia that influence the responses of targeted services and amenities *And*

If DFC collaborators provide services for people affected by dementia that are linked to existing public amenities, **then** people living with dementia gain new networks of support and friendship and can be confident that their needs are understood.

If the resources of the DFC are used to deliver targeted community engagement and awareness raising activities (e.g. with businesses and planning local amenities and services), of which enables people living with dementia to participate in their community **then** the needs of people living with and affected by dementia are anticipated across the community, episodes of stigma are challenged, and people affected by dementia feel included and valued by their community.

If people living with dementia are supported to be active partners, influence decision making, provide feedback on their experiences and are recognised as central to the DFC work, **then** organisations and services learn to routinely consider the needs of people living with and affected by dementia and set priorities and activities that reflect that

If there is a link to statutory services (NHS and Local Authority) with access to routine data on people living with dementia in the community, **then** this enables the DFC to reach people living with dementia at different points of the disease trajectory, and to review its work against population need.

A logic model sets out the kind of evidence that would indicate the capacity and maturity of a DFC to have impact against each evaluation tool domain. A worked example is provided of how the social value and SRoI of a DFC might be assessed. Outcomes from the work of the DFCs at different stages in their trajectories are presented. Particular attention is paid to the SRoI of (different aspects of) the DFC initiatives.

Based on the findings, the following policy recommendations are made:

- Ensure that DFCs build on existing collaborations and have access to resources to support the ongoing review and evaluation of DFCs' work**.**
- Support and reinforce the basis of DFC work as challenging existing systems and services in the community to support PLWD to live well and maintain their involvement in their communities for as long as possible.

- Require statutory organisations (Local authorities, NHS and emergency services) to demonstrate how they are working with DFCs and supporting their monitoring and evaluation work.
- Develop a communication strategy for DFC work investing in local and national online platform(s) to promote DFC work within and across DFCs, share information, data sharing and inform future planning
- Support Dementia Friendly Communities to use population data to identify and include people affected by dementia through collaboration with statutory bodies and local organisations
- Support systematic approaches to the organisation and funding of leaders to coordinate and embody DFC work.
- Provide DFCs with additional support and expertise to meaningfully include PLWD in designing and shaping the work of DFCs
- Integrate DFC work with other dementia focused initiatives and local services that this population use.
- Clarify the role of the DAA and responsibilities of statutory services, particularly local government as partners and active collaborators in DFCs.
- Facilitate the development of DFCs through shared learning and tailor resources to address local needs identified by DFCs
- Invest in the implementation of an evaluation tool to enable DFCS to capture the impact of their work at different stages of development (early, developing, and embedding).

1 Study aims and background

1.1 Aim

To identify whether dementia friendly communities (DFCs) support people living with dementia and their carers to maintain their independence and feel valued members of their local community and, if so, which approaches have worked best and at what cost for which groups of people.

Research questions

1. What are the characteristics and foci of Dementia Friendly Communities in England?

2. What factors and preconditions for these initiatives produce positive outcomes for people living with dementia and their carers/supporters?

3. What generalisable lessons can be drawn about the resources needed and economic benefits of creating and sustaining Dementia Friendly Communities?

The DEMCOM evaluation used a mixed method approach organised in three phases. Phase One involved mapping of Dementia Friendly Community (DFC) provision across England by dementia prevalence and categorising DFCs by their scope, focus, location and evidence of impact. Phase Two took findings from phase one and earlier review work [1,2] to develop and adapt an evaluation tool that had been used to study English Age Friendly Cities [3]. It piloted the adapted evaluation tool with two DFCs and Phase Three extended the work recruiting four additional geographically disparate DFC study sites.

1.2 Structure of the report

Chapter 1 provides the background. Chapter 2 provides an overview of the methods used. Chapter 3 describes how the involvement of people affected by dementia (PAD) was threaded through the design, development, delivery and oversight of the study. Chapter 4 addresses issues of equality and diversity in the design, study delivery and presentation. Chapter 5 reports on the key findings from DEMCOM and Chapters 6, 7 and 8 present the methods and findings of three phases of the study in more detail. Chapter 9 synthesises the findings to develop a theory of how DFCs work and achieves impact that underpins the evaluation framework and tool. Chapter 10 discusses the project findings in relation to national and international policy on the development of dementia friendly initiatives and offers recommendations for policy and further research. Chapter 11 informs of the dissemination plan for the research.

1.3 Background

Globally there are increasing numbers of people living with dementia [4,5]. In the UK, 30% of the population will die with or from dementia [6-8]. There is a shared policy narrative that people living with dementia should not be defined by their diagnosis and that there are multiple assets and strengths that people can draw on to maintain their identity, key relationships and achieve personal growth [9-11]. Evidence however, shows that the experience leading up to and post diagnosis is often associated with anxiety, social isolation, stigma, social rejection, family stress, financial strain and crises [6,12,13]. Initiatives that support an individual's independence and ability to stay at home and delay transition to long term care need to achieve this without overwhelming family caregivers or statutory services [14,15]. DFCs are one way of ensuring the infrastructure, social and personal support that contributes to people living well with dementia.

1.3.1 Dementia Friendly Communities supporting inclusion and participation

DFCs recognise that people living with dementia should be valued and included members of their local communities [16-18]. Their goal is to increase the confidence of people living with dementia (PLWD) to participate in day to day life, as well as mitigating the effects of cognitive loss. This is achieved by

raising public awareness of what it is like to live with dementia, addressing barriers to participation and providing local support for people at all stages of the illness.

The thinking that has informed the identification of DFCs globally draws on learning from policy led initiatives that support access and inclusion such as Age Friendly Cities [19, 20] dementia specific service community-based provision [21, 22] as well as initiatives that favour asset-based community development [23, 24] and social justice/rights approaches [25, 26]. Dementia Friendly Communities are an example of where citizenship can be framed as occurring in ordinary places and relationships [8, 27-29]

Over 90% of OECD countries report having some community-based dementia interventions that can support ageing in place, maintain quality of life and delay the need for institutional care [30]. Japan is often credited as a pioneer in DFC initiatives [21]. Allan Kellehear [31] describes the example of the Japanese Compassionate Communities programme where financial support is provided to any community who can demonstrate being 'dementia-friendly'. He gives the example of how service provision for people living with dementia to meet and make a meal together was combined with awareness raising with local shopkeepers who encountered the members of the group when shopping for ingredients. This illustration of combining dementia specific service provision with dementia-awareness and training in the immediate neighbourhood illustrates how a DFC may combine funded support with wider programmes to promote community awareness.

In England, the starting point for the majority of DFCs has been the creation of Dementia Action Alliances (DAA), https://www.dementiaaction.org.uk/who_we_are, which are collaborations of local organisations and businesses with a remit to connect, campaign to raise awareness, share best practice and take action on dementia.

There is a heterogeneity of approach in how the boundaries of a DFC are set. For example, in addition to DFCs defined by geography, there are DFCs based on an experience of dementia (e.g. young onset) or as a DFC nested within a faith, ethnic or cultural community. All DFCs however, are working to promote dementia awareness and skills in supporting PLWD, adapting the environment; and ensuring that unpaid carers receive support [32-38]

'Dementia friendly' as a phrase can be problematic. It is intended to be positive, but risks not addressing how socially-imposed barriers, language and attitudes disable people living with dementia [39-41]. One of the key issues to consider and address in this study is how the underlying motivation and expressed aims and goals of a DFC affect how PAD are involved, and what are identified as priorities and measures of effectiveness.

1.3.2 England policy

In England, David Cameron's Prime Minister's Challenge on Dementia 2020 [9] called for an increase in the number of DFCs. In collaboration with Alzheimer's Society the British Standards Institute (BSI) developed a code of practice for the recognition of DFCs. Eight areas for action are set out in the guidance identifying specific groups/organisations that a DFC should work with (e.g. arts, transport and young people).

The following definition characterises the consequences and impact of an effective DFC:

> *"…In a dementia friendly community people are aware of and understand dementia, and people living with dementia feel included and involved, and have choice and control over their day-to-day lives".* British Standards Institution (2015).

The DEMCOM study adopted a similarly broad definition recognising that becoming a DFC is an ongoing process only fully achieved when living with dementia is normalised into a community's culture, language, infrastructure and activities.

A Dementia Friendly community can involve a wide range of people, organisations and geographical areas. A DFC recognises that a person with dementia is more than their diagnosis and that everyone has a role in supporting their independence and inclusion.

The Prime Ministers Challenge [9] and policy targets for improving dementia awareness and achieving dementia friendly communities were:

- Alzheimer's Society to deliver by 2020 an additional 3 million Dementia Friends in England

- Over half of people living in areas recognised as DFC, according to BSI guidance

- All businesses supported to become dementia friendly, with all industry sectors developing Dementia Friendly Charters. Formal induction programmes invited to include dementia awareness training within these programme

- National and local government taking a leadership role and all tiers of local government being part of a local Dementia Action Alliance.

England routinely collects data on people diagnosed with dementia and drawing on longitudinal data can model the proportion of people living with dementia within a geographical area [42, 43]. At the time of writing, there were 329 DFCs known to Alzheimer's Society as well as other DFCs who have not applied for recognition as a DFC.

1.3.3 Measuring impact: Models and evaluation frameworks

There are several models that characterise the cornerstones or building blocks of DFCs. Some describe specific settings (e.g. health care) and others address what is needed to set up a whole community-based DFC. These all recognise the importance of the contribution of key people, the significance of place, networks and resources to increase awareness, create networks of knowledgeable people and sustain activities and staff [17, 44]. Appendix I provides a summary of the guidance and frameworks that are currently available.

Evaluations of DFCs are largely descriptive, found mainly in the grey literature and detail how they were set up, barriers and facilitators, how many people have participated in awareness raising activities and numbers of initiatives [16, 18]. Attributing benefits to the individual from participation in or living within a DFC is challenging with some concluding that the diversity of approaches to DFC development means that no single model of DFCs can be imposed [45]

There are very few studies that have tested DFC effectiveness or compared current practice with known need. One example is in Wenham USA, where Coyle and colleagues [46] reported a systematic needs assessment of the assets and priorities of their community drawing on the WHO age friendly domains. The Dementia Friendly Community - Environmental Assessment Tool (DFC-EAT) is an Australian example that adapted an Environmental Assessment Tool (EAT) [47]. This tool involves people affected by dementia and once a building/environment is assessed provides a comparison with a sample of other buildings of the same type.

When assessing impact there is a growing consensus on the long term personal and social/organisational outcomes that the work of DFCs is meant to pursue, summarised in Box 1-1.

Box 1-1. Outcomes linked to Dementia Friendly Communities

a. Increased awareness and understanding of dementia

b. Increased social and cultural engagement for the person with dementia

c. Legal and other measures in place to empower people with dementia to protect their rights

d. Increased capability of health and care services to develop services that respond to the needs of people with dementia

e. Actions to improve the physical environment whether in the home, residential care, hospitals or public places

Source Dementia Friendly Communities key principles Alzheimer's Disease International https://www.alz.co.uk/adi/pdf/dfc-principles.pdf

Work on developing a core set of outcomes for non-pharmacological interventions for people living with dementia has identified what people living with dementia value [48] Of the four outcome domains, one was Friendly Neighbourhood & Home (Box 1-2).

This work is ongoing, it reiterates however, a focus on the experience as much as the long-term consequences, e.g. prolonging independence, function and delaying admission to long –term care.

Box 1-2. Outcomes relating to the domain Friendly Neighbourhood and Home identified as important to stakeholders, including people living with dementia.

Friendly Neighbourhood and Home

Communication	Having a safe and secure Neighbourhood
Access to social contact and company	Feeling safe and secure
Having a sense of social integration	Feeling valued and respected by others
Importance of relationships with family and friends	Reaction of family and friends to diagnosis

Source *: **What is important to people living with dementia?: the 'long-list' of outcome items in the development of a core outcome set for use in the evaluation of non-pharmacological community-based health and social care interventions** Harding et al 2019 BMC Geriatric s201919:94* https://doi.org/10.1186/s12877-019-1103-5

The investment by the public and private sector - and communities themselves - to develop DFCs makes it essential to understand what generalisable lessons can be drawn about the resources needed to sustain DFCs, to be effective and valued by affected members of the public. Little is currently known about the resources mobilised by these initiatives, and/or the short- and long-term benefits that accrue therefore [17]. That evidence gap reflects the lack of capacity to evaluate these complex interventions, challenges with measurement of resources and outcomes, and priority given in practice to economic evaluation.

Compared to traditional value for money approaches, assessing the social value of an intervention like a DFC (including policy, programme, and organisation) involves adopting a much broader concept of value. It seeks to reduce inequality and environmental challenges and improve well-being by

incorporating a wider range of social, environmental and economic costs and outcomes to capture the collective investment from and benefit to the local community [49, 50]. There is currently no evidence documenting the actual or potential cost-effectiveness, cost benefit, social value or social return on investment (SRoI) of DFCs.

This study maps the provision of DFCs in England. It develops an evaluation framework (tool) and accompanying logic model (based on a theory of change approach) to explore what the factors and characteristics are that DFCs need in order to achieve positive outcomes for PAD, and to provide the building blocks and key questions to guide the monitoring and evaluation of the processes and outcomes of DFCs. Combined, the outputs of the DEMCOM project are designed to support decision making at local and national levels with regards to investment in DFCs that will be the most beneficial for people affected by dementia and have the greatest social value for the whole community. Generalisable lessons are drawn about the resources needed and their economic benefits.

2 Methods overview

This chapter provides an overview of the methods of the DEMCOM study.

Data were collected in three distinct phases, using a multi-method approach. A review of the literature was ongoing throughout the study (see Figure 2-1).

Phase One (months 1-6) addressed the first research question:

What are the characteristics and foci of DFCs in England?

It was designed to provide a national overview of DFCs. DFCs were mapped according to i) prevalence; ii) number of known dementia cases; and iii) number of known and estimated number of unknown cases. Mapping drew on data from the Cognitive Function and Ageing Studies (CFAS I and II), Quality Outcome Framework (QOF) data accessed via Public Health England's Fingertips Toolkit, and Office of National Statistics (ONS) data [51-54]. Geographical boundaries were based on English Clinical Commissioning Groups (CCGs).

Phase One also involved a scoping study of 100 sample DFCs in England. This entailed analysis of online evidence and, where appropriate, supplementary information collected through phone calls to arrive at an understanding of the range of DFCs that existed in England and their key characteristics in terms of origins, resourcing and ways of working (see Chapter 7 for further detail).

Phases II and III adopted an in-depth perspective on selected DFCs, concentrating on the second and third (of the three) research questions:

What factors and preconditions for these initiatives produce positive outcomes for people living with dementia and their carers/supporters?

What generalisable lessons can be drawn about the resources needed and economic benefits of creating and sustaining Dementia Friendly Communities?

In addition to understanding individual DFCs, phases 2 and 3 focused on the development of an evaluation tool for DFCs.

Phase Two (months 3-14) concentrated on two DFCs. An existing evaluation tool that had originally been developed for Age-Friendly Cities [3] and applied to a DFC initiative in an earlier small study [55] was pilot tested. The research was guided by the evaluation tool, which specified thematic areas for data collection. Evidence in these areas was obtained through key documents in the DFCs, interviews with key informants from the DFC practice-based stakeholders and volunteers) including an interview with PLWD, focus group discussions with PAD, and field notes from meetings and observations. This allowed for an emerging assessment of the two DFCs.

At the end of Phase Two, a national stakeholder workshop brought together PAD, stakeholders in policy and practice, and researchers. The participants provided feedback on the evaluation tool. They suggested refinements and key features of a DFC that could be rated 'good'. The workshop contributions, together with the data collected in the two DFCs, and insights from the ongoing review of the literature, informed revisions to the evaluation tool (See Chapter 7 for further detail).

In Phase Three (months 12-30), the next iteration of the evaluation tool was used to structure data collection and analysis in six case study sites (sites A to F). There was an emphasis on obtaining the views of PLWD via surveys and interviews (see Chapter 8 for further detail). Drawing on the evidence from the three phases a theory of change and logic model were developed to capture what needs to be in place for DFCs to achieve impact. This includes a worked example of the potential benefits of DFCs using SRoI methods and the next iteration of the evaluation tool.
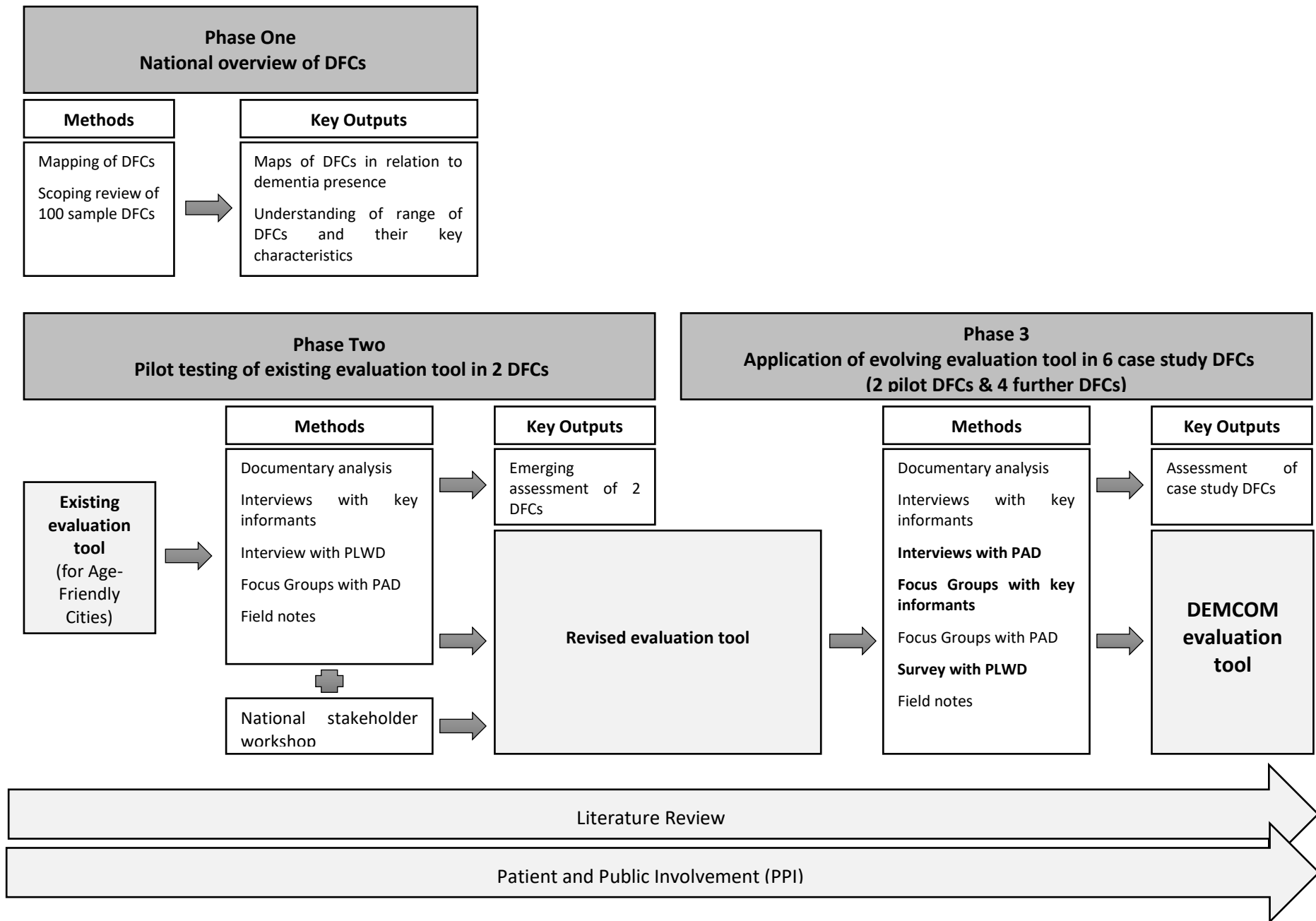
Figure 2-1. A visual overview of the three phases of DEMCOM.

3 Patient and Public Involvement

The benefits of having people with lived experience of dementia involved in shaping and designing research are recognised [56] . DEMCOM involved PLWD and their carers throughout the research cycle [57] from initial design to dissemination, which was separate and in addition to those involved as participants. PAD involved in shaping our study can be termed "experts by experience" or Patient and Public Involvement (PPI) contributors.

Within the DEMCOM research study there were 35 separate PPI activities with a total of 67 individuals (27 people living with dementia, 31 carers, eight former carers, one other). We involved a range of individuals, couples, people attached to groups (some existing PPI and some groups which were formed as part of the research study) to provide input to different research activities over the course of the study. The range of activities are summarised in *Box 3-1*. Involvement included advice on strategic and operational aspects of the research, data collection, data analysis, and feedback on emerging findings. PAD were involved as part of the research team and on the Steering Committee.

The following section uses the headings from the six UK National Standards for Public Involvement to report our Patient and Public Involvement [58].

Inclusion: We involved people living with dementia and family carers throughout the research, those who had previously been involved in research and those who were new to it. For example; meeting people within a dementia hub enabled individuals to be involved who might otherwise not travel to another location. Travel costs were also covered. For some attendees, this included a hotel stay in London. Experts by experience were paid for their time in accordance with the INVOLVE guidance of £20 per hour.

Working Together: We offered different opportunities and activities to enable a range of people to become involved in the study. Researchers worked with organisations but tried as much as possible to link into local networks, to provide local support.

Support and Learning: We offered and paid PPI contributors' money for their time and travel expenses. We aimed to make our meetings as dementia friendly as possible, for example, holding them in places where people met already and not expecting people to come to University premises.

At the beginning of the research a spreadsheet was set up for all researchers to record any PPI activities, number of people, time, outcomes and reflections. A reflections form was also made available to researchers who took part and were encouraged to log their views and identify issues. Twenty-two reflections were completed by researchers.

The stakeholder meeting was set up using guidance from DEEP, such as sending paper information beforehand with a photo of the venue, having a quiet room available (which was used for one discussion when the main room became too noisy), signage to rooms/toilets, and selecting a venue location within walking distance from a major train station. People affected by dementia were met at rail stations and accompanied to the venue and overnight hotel accommodation was also organised. Train tickets were bought in advance and sent to stakeholders to prevent out of pocket expenses.

Box 3-1 The range of roles and activities undertaken by people affected by dementia

Initial Proposal – Discussed with PLWD and Public Involvement in Research group (PIRg)

Research Team: A former carer joined our monthly teleconference, contributed to study design, study progress, commented on and co-authored papers and reports, and wrote a blog. This person's comments informed the design of the data extraction form and he participated in carrying out data extraction in phase one of the study. PPI was a standing agenda item at our meetings.

DEMCOM Steering Committee: The steering committee met every six months over the course of the study. Thirteen people were invited to the committee meetings including one PLWD and their partner who attended three of the four meetings. Their presence at the meetings confirmed project relevance, which affected how findings were reported and discussed.

Ethics Submission: Nine members from Alzheimer's Society Research Network commented on patient information sheets, consent forms and interview questions. All study documents were subsequently changed using their suggestions.

Advice on how to work with PLWD: We had individual conversations with a PLWD.

Working Group Meeting: In each of the six case study sites working groups were set up that included PAD who provided local knowledge of the sites. In some of the meetings, findings were presented by the research team and members were asked for their input as a "sense checking" exercise. Towards the end of the study a written report was presented to each of the case study sites. Each site provided verbal feedback.

Involvement of established PPI groups: The DEMCOM study proposal was discussed by the Public Involvement in Research group (PIRg) at UH. Two members provided detailed input. The Public Involvement in Research into Ageing and Dementia group (PIRAD) from the University of Cambridge, provided feedback on study design and progress and on the development of the survey questions. One researcher visited this group four times over the period of the study.

Stakeholder Event (February 2018). Thirty-nine people took part in the workshop, nine PLWD, six supporters/carers, 17 dementia researchers and seven representatives from dementia charities. At the workshop attendees discussed what a good DFC might look like, what to measure to evaluate DFCs, and what communities can do to become more dementia friendly. Those attending commented on the evaluation tool that was developed as part of the research.

Data Collection: One focus group in one of the case study sites was facilitated by a PLWD supported by a researcher.

Data Analysis (February 2019): We held a data analysis session in 4 different locations with a total of 10 PAD. These data analysis sessions ranged from individuals to a group of six PAD working with one or two researchers. A summary of the case study sites was provided in a photo format and a selection of quotes were discussed. Findings were verified, meanings expanded, and new interpretations were suggested. These discussions fed into our data analysis.

Dissemination: The PPI contributor who was a member of the research team is a co-author on publications.

In terms of dissemination, The Public Involvement in Research group (PIRg) based at University of Hertfordshire (15 members) are helping produce an easy read lay summary of the final report which will be used for dissemination.

Communication: We provided feedback to PPI contributors after our PPI activities. We produced a stakeholder report, wrote thank you emails, and sent letters letting people know what we changed as a result of their input. The PPI member who was part of the research group contributed to, and is a co-author, on DEMCOM outputs.

Impact: PPI activities impact on researchers, PPI contributors, the research study and wider society. Researchers recorded 'PPI impact' on the research project in a spreadsheet, keeping note of things we changed. Some participants noted a wider impact on being involved in the study itself and the importance of being involved to influence change. See Box 3-2 for feedback on the Stakeholder day from people living with dementia.

Box 3-2 Feedback on the Stakeholder day from people living with dementia

> *Delighted to have the opportunity to contribute and really enjoyed the day- very well organised and facilitated thank you*!
>
> *You were very aware of our possible needs and tried to cater for them and I appreciated this, thank you.*
>
> *Great day. So nice to contribute rather than just giving a presentation. You organised it very well, were so welcoming. I had a lovely time.*
>
> *Very interesting study and I look forward to seeing the final result. Thank you as well for recognising our contribution financially. Since stopping work last year I have no income for 6 years until I get my pension, so every little helps :) it does make a difference!*

Governance: We had PAD involved in our steering and our research group where decisions were made. PAD made suggestions and their discussions were recorded in the minutes which were circulated and provided feedback on the experience of involvement. For example, our research team member wrote a blog for the CLAHRC website https://www.clahrc-eoe.nihr.ac.uk/2017/10/reflections-involved-dementia-research-former-carer-blog-john-thurman/.

4 Equality and Diversity Issues

People living with dementia, in particular women, those living in areas of deprivation and /or from black and minority ethnic (BAME) communities appear to experience health and social inequalities when compared to those living without dementia [59-61]. In addition to the involvement of experts by experience or PPI contributors addressed in Chapter 3 the study addressed equality and diversity issues in three ways:

- The design of the study
- Discussion and dissemination of emerging issues and interim findings
- The development and testing of the evaluation tool

4.1 Design of the study

Phase one addressed issues of equality and access by mapping provision across the country and the number of known and estimated cases of dementia is associated with presence of a DFC. Phases two and three purposively sampled sites that offered the most opportunities for learning about the diversity of populations and communities served. This ensured the inclusion of DFCs that had reported involvement of BAME communities, people who live alone, rural and post-industrial sites and those that had focused on a group such as LGBT communities. Four of the selected study sites had significant multi-ethnic populations. Based on 2011 census data, the 14.8% BAME population in Site A is made up of 30 different nationalities. In site B, BAME communities constitute 19.2% of the population, in Site D 12%, and in Site F 49%.

This approach addressed contextual differences per site that can affect equality and inclusion, for example, deprivation, cultural differences and funding for specific sub-groups in specific communities.

All writing on DFCs emphasises that people living with and affected by dementia should be involved in the planning, delivery and review of the work. People affected by dementia were involved in the study management, data collection and analysis (see Chapter 3)

The study design, data collection and analysis specifically addressed the involvement of PAD to establish the frequency, quality and diversity of their involvement across the DFCs

4.2 Discussion and dissemination of emerging issues and interim findings

The thinking on what is meant by the term "dementia friendly" is changing rapidly as representative organisations and charities move towards a more explicit rights-based agenda. There is also an increasing online community of different groups of people living with dementia who are lobbying for change, recognition and increased awareness. To provide an opportunity for all groups to access and comment on findings and emergent issues/points of debate, the project ran an active twitter account @DEMCOMstudy and regular blogs with a range of contributions on the project's CLAHRC website. This provided another opportunity for participation and inclusion reaching non-academic but dementia active groups that invited comment and challenge to our thinking about how questions were framed and data analysed.

4.3 Development of the Dementia Friendly Evaluation tool

The evaluation tool from the outset had questions about inclusion and involvement of PAD in DFCs. The final iteration of the evaluation tool made Equality and Inclusion became a cross-cutting domain for evaluation of DFCs.

5 Key Findings

The following provides a brief summary of the DEMCOM findings.

5.1 Phase one

5.1.1 Mapping

In an analysis based on English CCG areas, 115 of 209 CCGs had at least one DFC. DFCs are spread throughout the country in urban and rural areas. DFC presence is significantly associated with number of dementia cases (known and unknown), yet not with dementia prevalence. It is unclear if there is an association between DFC presence and the number of PLWD. After adjustment in the analysis for CCG population size, we found no evidence that DFC presence was associated with areas of greater affluence.

This extensive coverage suggests that the very idea of DFCs has resonance, and that the (then) Prime Minister's Challenge that by 2020, over half of people will live in areas that have been recognised as DFCs will be met. The findings indicate that DFC provision is consistent with epidemiological need, and that DFCs are located in areas where they can have the greatest impact.

5.1.2 Scoping review

DFCs are characterised by variation in key features including type, resourcing, and activities. Of the 284 DFCs originally identified, 251 were defined by geographical location, while 33 were Communities of Interest (COIs) organised by shared cultural interests or experiences of dementia. Of the 100 sampled DFCs, 72 were geographically defined, and 28 were COIs.

Ninety-five per cent (269) of DFCs, were set up or started activities following policy endorsement of DFCs in 2012. This finding is similar to the experience of Japan and suggests that policy endorsement, coupled with a recognition system for DFCs, are important for initiation and growth.

Statutory agencies, and especially councils/local government, working in partnership with different bodies and through local collaborations such as DAAs, have played a central role in the setting up, managing, and resourcing of the DFCs reviewed.

The involvement of PLWD in DFCs in advisory, operational, and strategic capacities is strongly recommended. However, the centrality of citizen involvement was not clearly articulated in the DFCs reviewed. There is a difference between presence and participation and the lack of evidence of active and ongoing involvement of PLWD in DFCs could be an area for future policy attention.

The main emphasis in the provision of services and activities by the reviewed DFCs was on awareness raising. This focus arguably signalled that most DFCs were concentrating on building networks of interest and community responsiveness. Evidence of tangible outcomes from this work, however, was difficult to find. DFC organised activities fell into two groups. Those designed to be dementia-*inclusive* (e.g. improving access to public buildings, leisure and sports activities), and dementia-*specific* (e.g. dementia cafés, Singing for the Brain®). Dementia specific activities provided a safe place for PAD and were valued but risked separating PAD from the wider community. While policy support and a system for formal recognition of DFC status have provided an impetus for DFCs in England, they have not led to a consistent approach or local consensus about a social model of disability as the basis for DFC work.

The majority of the DFCs studied did not report how they were resourced. The combination of investment by people volunteering and raising awareness was the favoured approach. It may be that increasing acceptance is a key enabler for PAD to live well (see also survey findings, see section 8.4).

There were instances where the involvement of local government, as well as health care organisations and charities, released funds for DFC work. However, the reported ad hoc and often short-term nature of funding raises questions about what minimum resources are required. While DFCs have been promoted as a potentially cost-effective model for supporting PAD, monitoring and evaluation were underdeveloped in the DFCs reviewed and there is limited data available to test cost-effectiveness.

The findings suggest that access to formal support services (e.g. health and social care) and concern with the rights of PLWD, were not the starting points for most DFCs.

Evaluation guidance for DFCs is available [62] however , an agreed approach is needed that captures DFC at different stages of development could support DFCs in how they monitor their progress, involve PLWD, and agree on criteria for good practice for DFCs in different contexts and at different stages of development.

5.2 Phase two

5.2.1 Pilot sites

The findings from two pilot sites enabled us to build on phase one findings to understand how the different models of organisation and working were experienced by different stakeholders in two different DFCs.

DFC involvement in the study had the unintended effect of re-energising both groups' DAAs and increasing the number of times they met during the period of data collection. The DEMCOM study became a catalyst for representatives from different groups to re-engage with their DFC, share information and find out about each other's work. This demonstrates the value of external interest and input either through review or through sharing information about how DFCs are working in different locations.

5.2.2 The evaluation tool

An evaluation tool for DFCs was pilot tested in the two sites to refine/adapt the domains of the evaluation tool and identify likely sources of evidence. The evaluation framework was developed from an evaluation tool for WHO Age-Friendly Cities. This guided data collection and analysis in the Phase One scoping review.

Phase Two findings and the subsequent stakeholder event (see below) refined the evaluation tool to reflect the experience and priorities of PAD. It was feasible to capture DFCs' work using the evaluation tool and the range of involvement and activity while remaining user friendly. In particular, it was possible to document the impact of local context and how the different histories and ways of working led to different foci and potentially impact of the two DFCs.

5.2.3 Stakeholder event

Findings from the pilot phase were presented to participants from the two sites for comment and these combined with the feedback were taken to a national event that drew together 39 stakeholders of whom 15 were PAD. They reviewed the evaluation framework, highlighted areas that needed further clarification and extended the ambition of what DFCs should be doing; identifying different outcomes for impact at the individual and system level. Participants were concerned that a focus on process could lead to a DFC being positively evaluated, without affecting the experience of living with dementia for its local population.

5.3 Phase three

Findings from the six DFC study sites are organised by the key characteristics and features of the DFC and reflect the domains of the evaluation tool.

5.3.1.1 *Basis for the dementia friendly community:*

At a strategic and organisational level, DFCs recognised that there was a need to respond to the increased numbers of people living with and affected by dementia. The presence of a DAA or its equivalent and Alzheimer's Society recognition process were reference points for explaining the mission and purpose of the DFC. Two of the six sites used national guidance as the basis for their planning and organisation. At the individual level many participants and volunteers had a personal connection with dementia. Despite the recognition of the growing needs and a policy emphasis on the rights of PLWD to be included, it was personal experience and awareness of the need for support that was cited as a key motivation towards becoming dementia friendly. The basis of a DFC influenced what was prioritised and who was involved in its leadership and governance. The recognition of the DFC as a change agent in the local community, enabling PLWD to live well was often implicit and did not extend to articulating this work as an expression of social justice supporting the rights of PLWD.

5.3.1.2 *Leadership and governance:*

All sites had collaborative structures in place to lead the DFC work forward, and in five of the six sites this predated the DFC and built on the work of the DAA. All sites could identify an individual who was the contact for the DFC, but not necessarily in a leadership role. Interpretation of the leadership role ranged from being the focal point for partners and individuals working to deliver a DFC, to taking on the co-ordination, administration and in some cases delivery of services and events. In the bigger sites, or sites that had been established for many years the division between leadership and implementation was clearer. There is evidence from across the case study sites of how different leadership and governance arrangements enabled (or not) the DFC work to be strategic and sustained when key personnel left. The multi-agency governance structure such as a DAA helped the DFC to have a visible presence in the local community and links to NHS and LA services provided crossover links to local support services.

Different approaches to local government representation and linked funding were key and affected how the DFC leadership was linked with local policy and service delivery. If there was alignment between LA plans, engagement with their work and commissioning of services (e.g. to provide support to PLWD to navigate and access local health and social care services) this supported and expanded the impact of the DFC across the community. This type of local government engagement increased the opportunities for multi-agency working, integration and achieving infrastructure changes. In contrast, local government representation and funding that had limited engagement with the DFC work were less likely to enhance services that PAD could directly benefit from (e.g. transport and improving access to leisure and sport).

5.3.1.3 *Activities and environments and Equalities and Inclusion*

DFCs offered different kinds of provision (dementia-specific; dementia-inclusive; awareness raising/reaching wider community). In some sites, the awareness work was the precursor for connecting with target services or organisations that could improve the daily experience of living in the community (e.g. banking shopping). Alternatively, dementia specific services provided feedback to the DFC about the experience of living with dementia that then fed into further awareness work. We found limited evidence of DFCs engaging with dementia risk reduction as part of wider public health and intergenerational activities.

It was difficult to determine what activities were first organised or provided as part of a DFC especially when these were closely linked to activities for older people in general. Nor was it clear how frequent they were and how different members of the DFC knew what was happening. The main methods of increasing awareness of dementia in the wider community continue to be Dementia Friends' sessions and recruitment of organisations to the DAA. A consistent finding across all sites was the importance

and challenges of communicating within and between DFCs to establish what was being done, for whom and when.

For people whose dementia limited their ability to participate in groups or leave their home, community activities and places to visit were important. There were examples where this has met and even exceeded capacity, with waiting lists for some activities.

Achieving equitable access both in terms of geography/location, specific groups (e.g. PLWD from Black and Minority Ethnic groups (BAME)) and different stages of living with dementia was uneven and reflected the capacity of DFCs to run multiple groups and events. Benefits of dementia-specific and dementia-inclusive activities that improved individuals' sense of wellbeing were that they gave opportunities to socialise, carer respite, peer-to-peer learning, development of new social networks beyond dementia-specific activities, confidence about going out in their community - feeling welcome in these places and learning/ rediscovering skills.

5.3.1.4 *Resources*
Resources available dictated the choices and activities DFCs chose to engage with and across the sites there were examples of surges and slumps in activities. In one site, the DFC was closely aligned with a dementia hub funded by the LA. It also hosted an onsite memory clinic. This ensured access to services and groups for PLWD, but constrained ongoing outreach work to the wider community.

Funding of DFC specific posts or volunteers who treated the work as a job ensured that these DFCs were more likely to coordinate the work across the community and secure additional funding and or support. It was important to have identifiable people who "embodied" the work of the DFC.

The contribution of volunteers was foundational and essential to all DFCs and this affected how they worked and who from the community engaged with the DFC. For example, all DFCs lacked administrative support and in some DFCs the networks of involvement were a reflection of individuals' existing contacts. Where DFC work was aligned with other funded initiatives for older and or vulnerable people there was more potential to embed dementia enabling work into existing services. None of our study sites had access to secure and recurring sources of funding.

5.3.1.5 *Monitoring and evaluation*
All sites had annual action plans that detailed the ambition and focus of the DFC for the year ahead and measured what the DFC had achieved. A range of tools were being used to measure uptake and effectiveness of the DFC. Monitoring and evaluation invariably focused on activity and satisfaction (for example number of new Dementia Friends, numbers of participants at DFC activities and feedback on how the activity had been received) rather than outcomes. It was not always possible to demonstrate how these activities had changed or confirmed the DFC work although feedback from PLWD using dementia specific services was valued. None of the DFCs had the administrative capacity to be systematic in how they collected and analysed data and found it challenging to collect data beyond that relating to process and satisfaction.

5.3.1.6 *Involvement of people affected by dementia:*
All sites aspired to involve people living with and affected by dementia and there were a range of examples of how involvement was approached. Their involvement ranged from representatives at meetings to being involved in auditing work of local organisations and services. There was little evidence of how PLWD had shaped the organisation, direction, decisions, discussions, and activities of the DFC although there was evidence of episodic consultation events to generate involvement. In the sites where there was the most consistent input from PLWD this was facilitated via other groups and demonstrated the need for additional resources and expertise to achieve meaningful

engagement. There was limited evidence of the DFCs being able to connect with PLWD who were unable to attend meetings.

5.3.2 Survey

Survey data from 240 people living with dementia (PLWD) from the six sites found that awareness of their local DFC initiative was more prevalent among participants feeling that dementia is well understood and valued in their community.

Of the 148 participants who had stopped doing something because of dementia, nearly a third had stopped driving and improved access to public transport was a priority.

Over a third of participants reported that greater public understanding of what it is like to live with dementia would help them to live well in their community. This highlights the importance of DFCs and others in the community in addressing the negative and stigmatising attitudes towards dementia.

5.3.3 Theory of change and Evaluation tool

The synthesis of findings provided the basis for a theory of change and linked logic model that details key mechanisms and outcomes. This takes account of the different contexts of the DFCs to articulate what needs to be in place for DFCs to achieve their goals.

The economic benefits of DFCs were difficult to demonstrate because of the limited available data. Using Social Return on Investment (SRoI) methods we modelled how increasing numbers of Dementia Friends can improve individuals' confidence and benefit the local economy because of increased engagement from PAD.

The evidence-based evaluation tool for DFCs encapsulates this theory by setting out what needs to be measured to capture outcomes at different levels and stages of a DFC's development.

The evaluation tool provides a robust framework for detailed internal assessment and monitoring of progress. At the same time, it enables a DFC to review its work systematically, facilitate communication and address common gaps in the data. There is scope to enhance the evaluation tool's capacity to facilitate knowledge sharing, learning and to compare the impact of different approaches taken by DFCs.

6 Phase one

6.1 Mapping of DFCs across England

6.1.1 Methods

6.1.1.1 Identification of DFCs

Identification of DFCs for this component of the study took place between January and June 2017. Records of communities that had been formally recognised as 'working towards being a DFC' by Alzheimer's Society [63, 64] were obtained from the Society. Formal recognition entails a community successfully demonstrating its commitment to meeting the seven 'foundation criteria' for DFCs and monitoring and reporting on its progress towards them [65, 66].

6.1.1.2 Epidemiological based need

Geographical areas were based on the boundaries of English Clinical Commission Groups (CCGs). In England, health services are organised into CCGs who have responsibility for planning and commissioning service provision for a geographically defined local area. They are responsible for the health of the entire population in their area and serve populations ranged from approximately 68000 to 900000 with a mean population of 226995. In this study, the presence of dementia by locality was measured in three ways:

(1) Prevalence
(2) Number of known dementia cases based on primary care records, and
(3) Estimated number of dementia cases.

Dementia prevalence (the proportion of a specified population with dementia) and number of cases known to primary care services for those aged 65 years and over was based on English primary care records and accessed via the Fingertips Toolkit [54], a publicly available electronic source of key health indicators. Data are uploaded by every general practice and include presence of dementia diagnosis, age, and sex for each registered patient [53]. Each practice receives a financial incentive to report on the number and proportion of registered patients with known dementia diagnosis [67] Data for the estimated number of known and unknown dementia cases for each CCG area were accessed via NHS England (NHS England, 2017). These are calculated using 5-year age-sex group estimates from the CFAS II study and applied to the Office of National Statistics (ONS) population projections for people aged 65 years and over.[51]

6.1.1.3 Analysis

A map of CCGs in England was produced using [68]ArcGIS software 2016 version 10.4.1. Dementia prevalence data for each CCG were divided into quintiles and overlaid onto the map of CCGs in England. Dementia friendly communities were added to the maps with a marker representing the geographical centre of each DFC. Three independent *t* tests were performed comparing CCGs with a DFC with CCGs without a DFC in terms of three methods of epidemiological need: (1) dementia prevalence, (2) number of known dementia cases, and (3) estimated number of known and unknown dementia cases. To adjust for potential confounders and test whether the number of DFCs (rather than simply the presence of one or more) within a CCG area was associated with any of the three measures of dementia prevalence, three ordinal regression models were used. In these models, the outcome was number of DFCs within a CCG categorised into three levels (zero, one, two or more). Potential confounders were population size of CCG area and mean deprivation score as measured by the English indices of deprivation, a relative measure of deprivation [69]. Social deprivation was not included as a covariate in the model examining the estimated number of known and unknown cases of dementia. This model uses estimates produced from CFASII data, which already considers the social deprivation of a given area. We tested the proportional odds assumption using likelihood ratio tests. Where there was evidence the proportional odds assumption was violated, we reverted to binary outcomes using logistic regression models. All analysis was conducted using Stata12 version 14.2. [70]

6.1.2 Findings

A total of 196 DFCs that had been formally recognised by Alzheimer's Society were identified. Seven were communities of interest that were not linked to a geographical location compatible with the scale of mapping at CCG level. They were thus excluded from further analysis in this part of the study.

At the time of the study, there were 209 CCGs in England. Of those, 94 had no DFC, 77 had one DFC, and 38 had two or more DFCs. The maximum number of DFCs for one CCG was 11. Dementia prevalence based on primary care records ranged from 3.2% to 5.5%. Taking account of both known and unknown dementia cases, the mean estimated number of dementia cases for these 209 CCGs was 3057 (SD = 1986). Dementia friendly communities were located throughout England (Figure 6-1, Figure 6-2Figure 6-3) from the south-westernmost corner to the north-east coast.
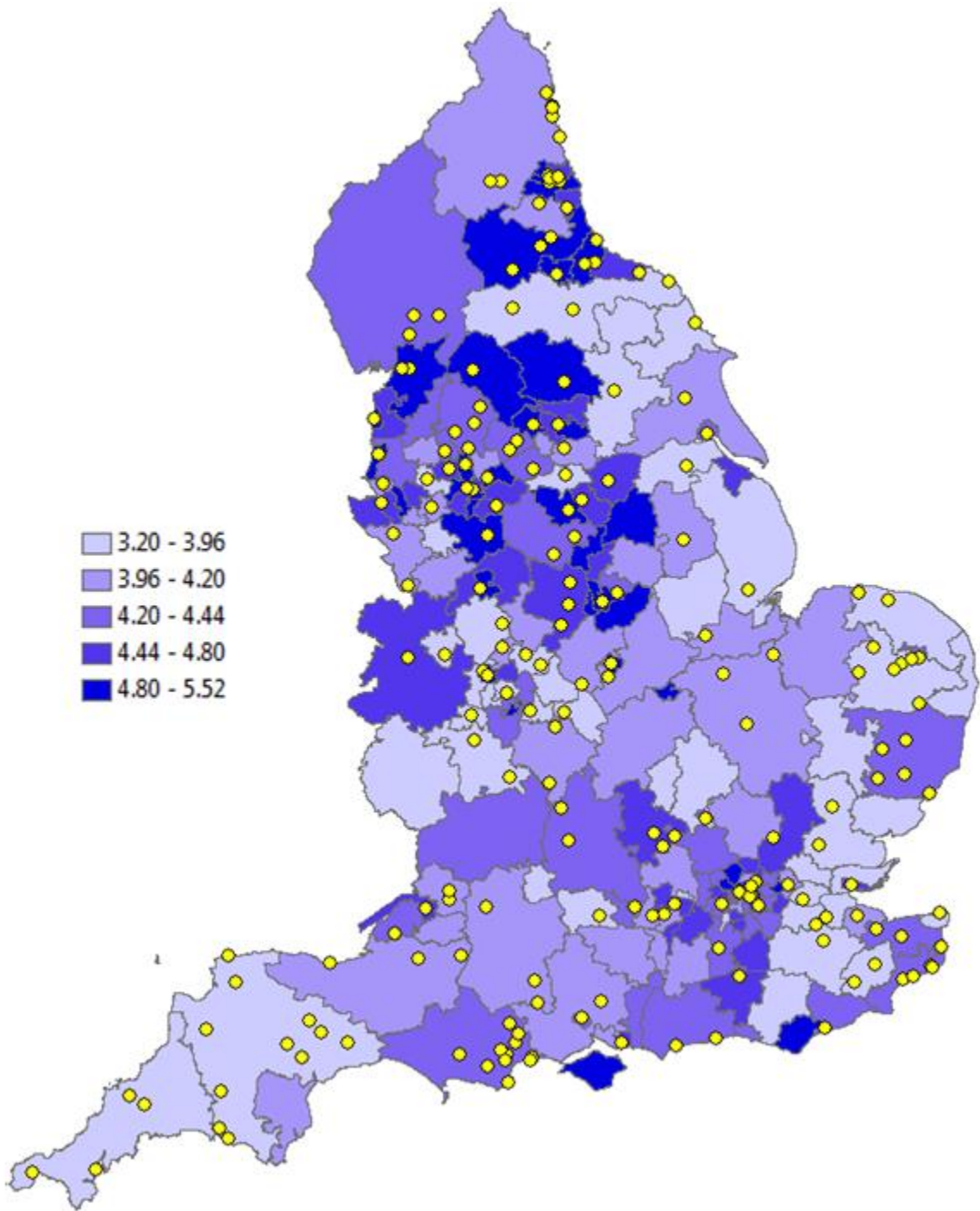
Figure 6-1 Prevalence of dementia (%) from QOF data by CCG area with DFC location (yellow dot)
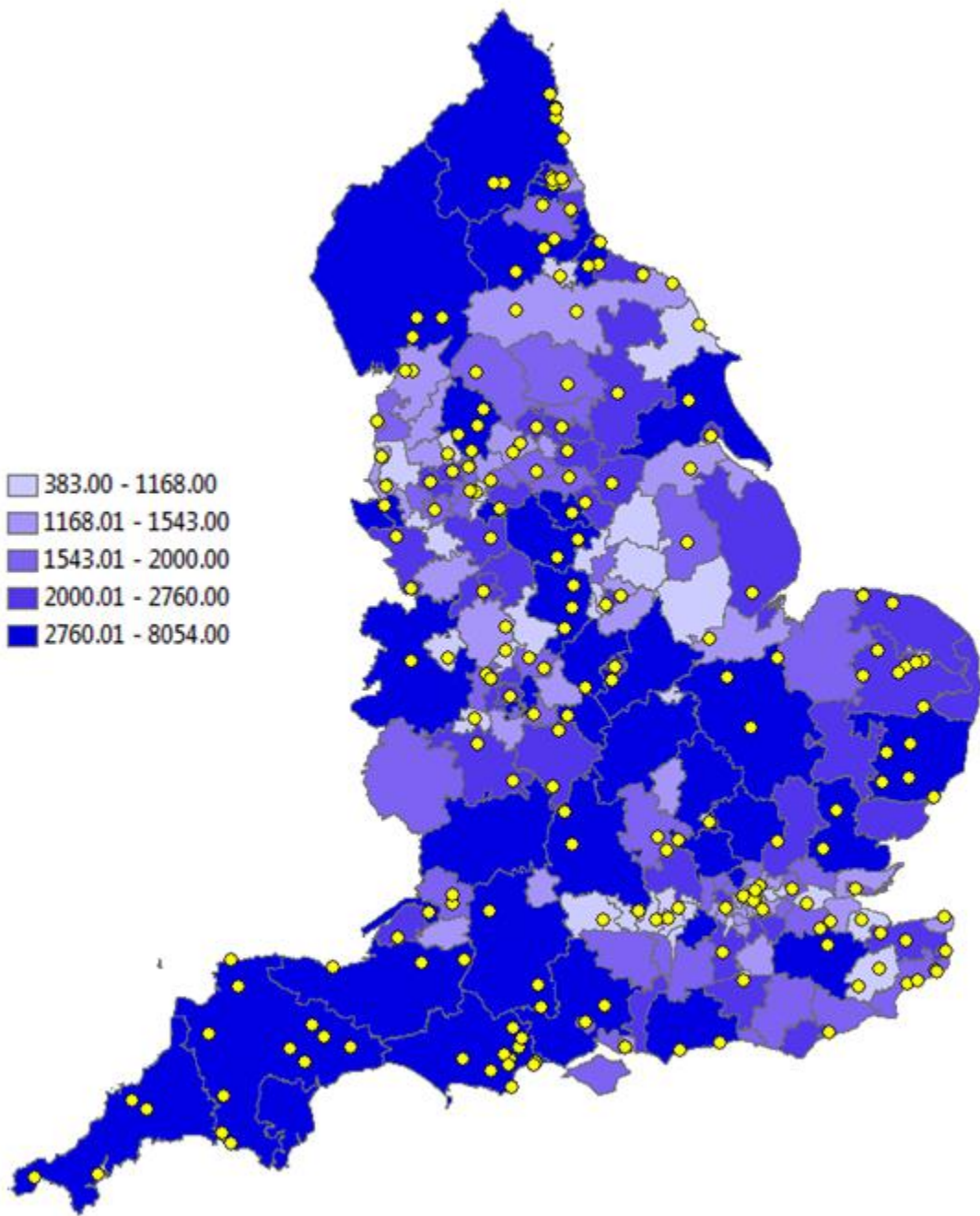
Figure 6-2 Number of people with a dementia diagnosis (QOF) per CCG area with DFC location (yellow dot)
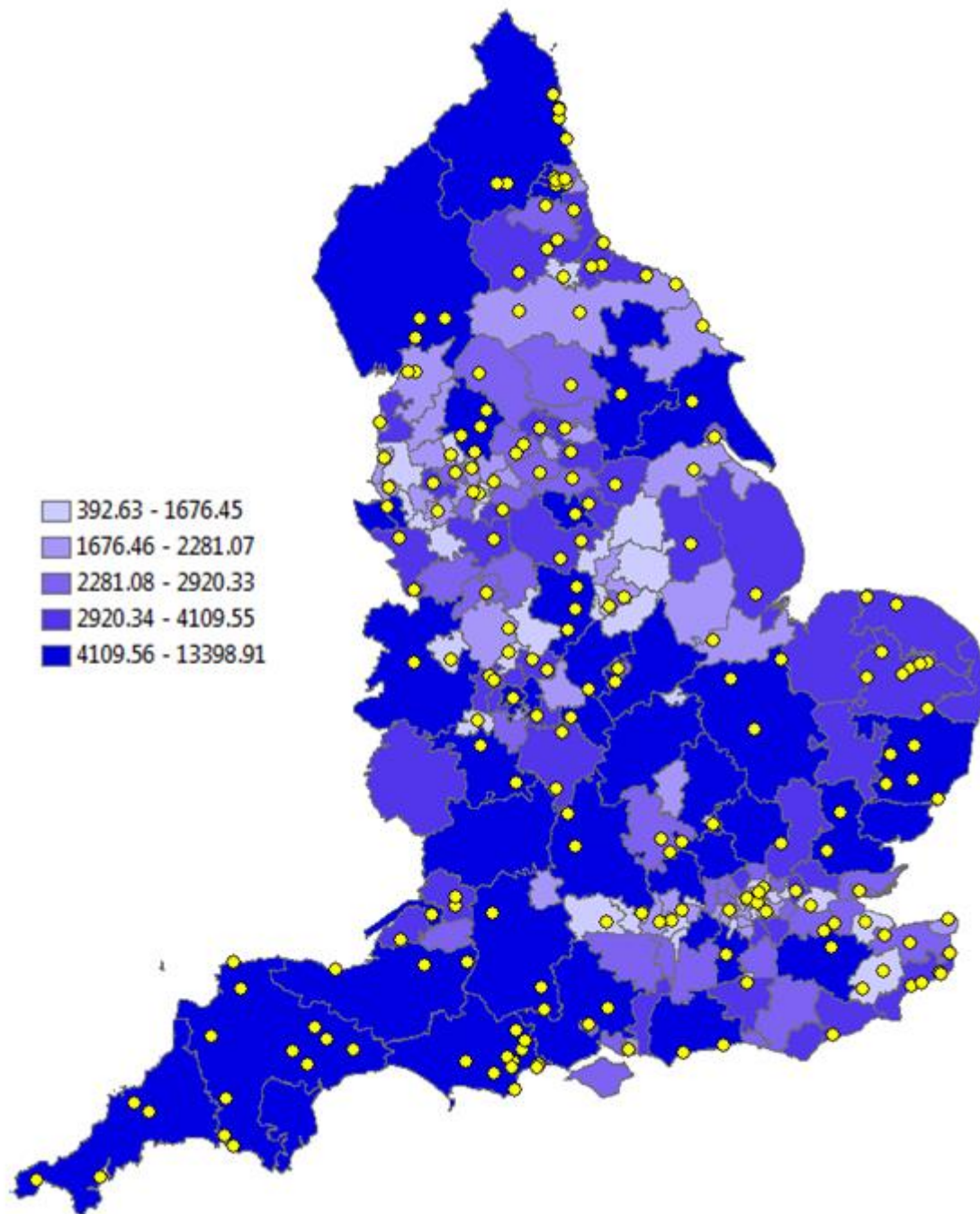
Figure 6-3 Predicted number of people with a dementia (CFAS II) per CCG area with DFC location (yellow dot)

Concentrations appear to be in London and the South East and from the Midlands up to the conurbations of the North West. When mapped against prevalence of dementia, CCG areas with higher prevalence appear to benefit from DFC initiatives. However, there was no statistical evidence of a difference in dementia prevalence between those CCG areas with (n = 115) and without (n = 94) a DFC (P = 0.61; see Table 1). This remained true after adjustment with the odds of a DFC being present in a CCG area 0.76 times that with an increase in 1% prevalence (95% CI, 0.40 to 1.47; P = 0.42). In contrast, when comparing CCG areas with and without a DFC in terms of unknown cases of dementia, there was evidence to suggest that areas with higher predicted cases of dementia had better provision of DFC initiatives (mean difference = 881; 95% CI, 349 to 1413; P = 0.001). This was still true when

analysis was restricted to known cases of dementia reported in primary care records (mean difference = 577; 95% CI, 249 to 905; P < 0.001) as shown in Table 6-1. In adjusted analysis, the increased odds of a DFC (zero to one, one to two or more) were 3.87 (95% CI, 2.13 to 7.02; P = <0.001) and 1.87 (95% CI, 1.36 to 2.58; P = 0.001) per 1000 people with a dementia diagnosis and per 1000 people estimated to have dementia, respectively.

The findings indicate that DFC provision is consistent with epidemiological need, and that DFCs are located in areas where they can have the greatest impact.

Table 6-1. Unadjusted and adjusted associations of DFCs and measures of epidemiological-based need.

	Unadjusted Analysis				Adjusted Analysis				
	DFC present in CCG Area n= 115 Mean (SD)	DFC not present in CCG Area n=94 Mean (SD)	Mean Difference (95% CI)	P Value[a]	0 vs 1 vs 2+ DFCs Present in CCG Area[b] OR (95% CI)	P Value[c] (Effect)	P Value[d] (Prop Odds)	Logistic Regression Model OR (95% CI)	P V
Dementia Prevalence (%) (QOF)	4.35 (0.45)	4.38 (0.47)	0.03 (-0.09 to 0.16)	0.61	0.76 (0.41 to 1.39)	0.36	0.044	0.76 (0.40 to 1.47)	0.
Number with a dementia diagnosis (n) (QOF)	2326 (1404)	1749 (877)	577 (249 to 905)	<0.001	3.87 (2.13 to 7.02)	<0.001	0.11		
Number estimated to have dementia (n) (CFAS II)[f]	3453 (2299)	2572 (1382)	881 (349 to 1413)	0.001	1.87 (1.36 to 2.58)[g]	<0.001	0.13		

Abbreviations: CFAS. Cognitive Function in Ageing Study, CCG, Clinical Commissioning Group; DFC, dementia friendly community; QOF, Quality Outcome Framework; SD, standard deviation

[a]Unpaired *t* test.
[b]Odds ratios from ordinal logistic regression model.
[c]*P* value from ordinal logistic regression model.
[d]Likelihood ratio test of proportionality of odds.
[e]*P* value from logistic regression model.
[f]Odds ratios are based on increased odds of higher number of DFCs per 1000 people living with dementia.
[g]Social deprivation not entered into the models due to being controlled for in the CFAS II estimates

6.2 Scoping Review of DFCs in England

6.2.1 Methods

6.2.1.1 *Identification and sampling of DFCs*

Identification of DFCs and data collection took place between January and June 2017. A multi-method approach to data collection was used. Alzheimer's Society records of formally recognised DFCs were complemented by online searches in Google, using the following search terms: "Dementia Friendly Communit*"; "Dementia Friendly *"; "Dementia Action Alliance"; "Dementia Friends". In addition, a 'Google Alert' was in place that generated notifications of the term 'dementia friendly' occurring in news articles.

Following initial mapping of all DFCs, a selection (n=100) were examined in depth. These were purposively sampled to reflect the diversity of DFCs by: i) type - DFCs defined by their location (e.g. cities, counties) called 'location-based DFCs', and DFCs that are organisations or entities with a specific focus (e.g. an airport, a national supermarket chain) summarised as 'communities of interest'; ii) geographical distribution across England; iii) geographical reach/size. Additionally, DFCs were included if the available data indicated characteristics that made them distinctive and offered opportunities for learning – for example, an explicit concern with the rights of people living with dementia, or attention to particular groups (e.g. Black and Minority Ethnic communities). Only 'active' DFCs were selected, defined as DFCs where online sources suggested activity in the previous six months, or whose active status was confirmed in a telephone call.

The different steps of the sampling process are outlined in Figure 6-4.

284 DFCs
(location-based DFCs: n=251; COIs: n=33)

203
(recognised by Alzheimer's Society)

81
(identified through online searches & alerts)

Sampling to ensure **diversity** in terms of:
- Type - location-based DFCs/COIs
- Geographical distribution in England
- Geographical reach

Inclusion of:
- DFCs that appeared to have distinctive characteristics and offered particular opportunities for learning
- 'Active' DFCs only

☐ All DFCs identified
☐ DFCs with Alzheimer's Society recognition
☐ DFCs without Alzheimer's Society recognition
☐ Location-based DFCs
☐ COIs
☐ Final sampled DFCs

47 selected

25 selected

39 location-based DFCs

8 COIs

5 location-based DFCs

20 COIs

44 location-based DFCs selected

28 COIs selected

Plotted 44 location-based DFCs onto map
➔ gaps in geographical distribution identified

28 (of original 251) **location-based DFCs** added, to ensure more even geographical distribution

72 location-based DFCs selected

100 DFCs

Figure 6-4. Selection process for 100 sampled DFCs in England.

6.2.1.2 Data collection and analysis

Online searches for data on the selected DFCs and related websites (e.g. local government; voluntary sector) were carried out to obtain key information. Guidance was provided by Stansfield et al.'s [71] three-stage framework for systematically identifying online information. Google was selected for the online searches using the selected 100 DFCs. The following search terms were applied consecutively: *"Dementia Friendly [name]"*; *"[name] Dementia Friendly Community"*; *"Dementia Action Alliance [name]"*; *"Dementia Friends [name]"*. This process was stopped once a minimum of four, and up to seven, online data sources for each identified DFC (including DFC website, reports in local media, etc.) had been selected from up to four pages of search results. The aim was to identify sufficient online

information to complete a data extraction form and gain a comprehensive picture of a DFC. Where gaps remained and contact details for a DFC were available, up to three attempts at a follow-up telephone call to a stakeholder (such as a DFC Co-ordinator) were made to obtain further information. Only information available in the public domain was sought.

The data extraction form identified different thematic areas for data collection. The latter had its roots in an evaluation tool developed for Age-Friendly Cities [3]. Thematic areas for data extraction included how a DFC was led and governed, what activities it involved, how people affected by dementia (people living with dementia, as well as their carers/supporters) were involved in a DFC, and whether and how a DFC's work was monitored and evaluated (Box 6-1).

Box 6-1. Data extraction form for sampled DFCs.

1) Type of DFC (location-based or COI)

2) Location in England (region)

3) Size and geographical reach

4) Key characteristics (e.g. focus on human rights of people living with dementia; focus on specific groups)

5) Origins (starting date; date DFC recognition gained; how set up)

6) Leadership and governance structure/organisation of DFC

7) Political support

8) Resources (financial; human; other)

9) Collaboration (within & beyond DFC)

10) Activities & specific priorities

11) Involvement of people affected by dementia

12) Monitoring and evaluation

13) Indicators of achievements

All team members were involved in data extraction. Double extraction was carried out for 17 DFCs to ensure a systematic and reliable approach. Ambiguities and disagreements were resolved through team discussion. Data analysis was carried out by four researchers. The findings were discussed and agreed by all team members.

6.2.2 Findings

6.2.2.1 *Number of DFCs*
A total of 284 DFCs were identified across England – the majority (n=203) from Alzheimer's Society records of communities formally recognised as 'working towards being a DFC', and 81 from additional sources. Table 6-2 presents an overview of the characteristics of the 284 DFCs identified, and how these are reflected in the 100 sampled DFCs.

Table 6-2. Overview of number of DFCs in England (n=284) and sampled DFCs (n=100).

Sampling criteria			n out of 284 DFCs in England	n out of 100 sampled DFCs
Type of DFC		Location-based	251	72
		Communities of interest (COIs)	33	28
Location in England		South West	49	14
		South East	47	11
		London	14	7
		East of England	40	13
		West Midlands	22	10
		East Midlands	14	4
		Yorkshire & Humber	28	10
		North West	34	15
		North East	25	7
		National or N/A	11	9
Geographical reach	DFCs that clearly define their geographical reach	County	15	8
		City	30	18
		Town	123	27
		Village	14	3
	DFCs that have less clear boundaries/align with local administration areas	Unitary Authority	5	5
		Borough	19	4
		District	24	3
		Parish	12	1
		Other (including COIs)	42	31
Additional features		Data indicate concern with human rights of people living with dementia	8	8
		Data indicate attention to particular groups (Black and Minority Ethnic; Lesbian Gay Bisexual Transgender)	7	7
		No additional features	269	85
Active status		Yes	204	100
		No	26	0
		Missing data	54	0

6.2.2.2 Online presence of DFCs

The online presence of the 100 sampled DFCs was variable, as were the quality and range of data that could be extracted for them. For some DFCs fewer than four online sources were available, with available sources ranging from one to ten. Insufficient online information to populate the data extraction sheet resulted in attempted telephone contact with 22 DFCs. This was successful in 13 DFCs, for which additional information was obtained.

6.2.2.3 Types of DFCs, geographical reach and size of population served

Of the 100 sampled DFCs, 72 were location-based, and 28 were communities of interest. The number of people living in the location-based DFCs ranged from 850 in a small parish to 5,300,000 in a county. The majority of the location-based DFCs covered comparatively large urban areas – more than a third (n=27) were towns, and a quarter (n=18) were cities. There were cases where DFCs overlapped, for example where a town with DFC status was located within a county DFC.

The 28 communities of interest included housing associations, churches, airports, banks, a supermarket chain, a police constabulary, a fire department, a university, support groups, a dental

surgery, and associations with a focus on cultural activities. Precise figures for the population they reached could not be identified. Many were located within location-based DFCs, but appeared to be self-regulating in their organisation.

6.2.2.4 *Origins, organisation and ways of working*

While DFCs have policy support, their characteristics – how they are organised, their priorities and the ways in which they work – reflect by whom they have been led, and how long they have been in place. The time when the sampled DFCs had been established, or when their work on dementia had started, ranged from almost two decades ago (1998, in one case) to 2017. The DFC whose activities date back to 1998 had developed from an organisation to support carers and people living with dementia among the African/Caribbean community. The vast majority of the DFCs (n=89) had been set up or started their activities since 2012, the year in which DFCs were endorsed by policy through the first UK Prime Minister's Challenge on Dementia[72][73] (Figure 6-5).
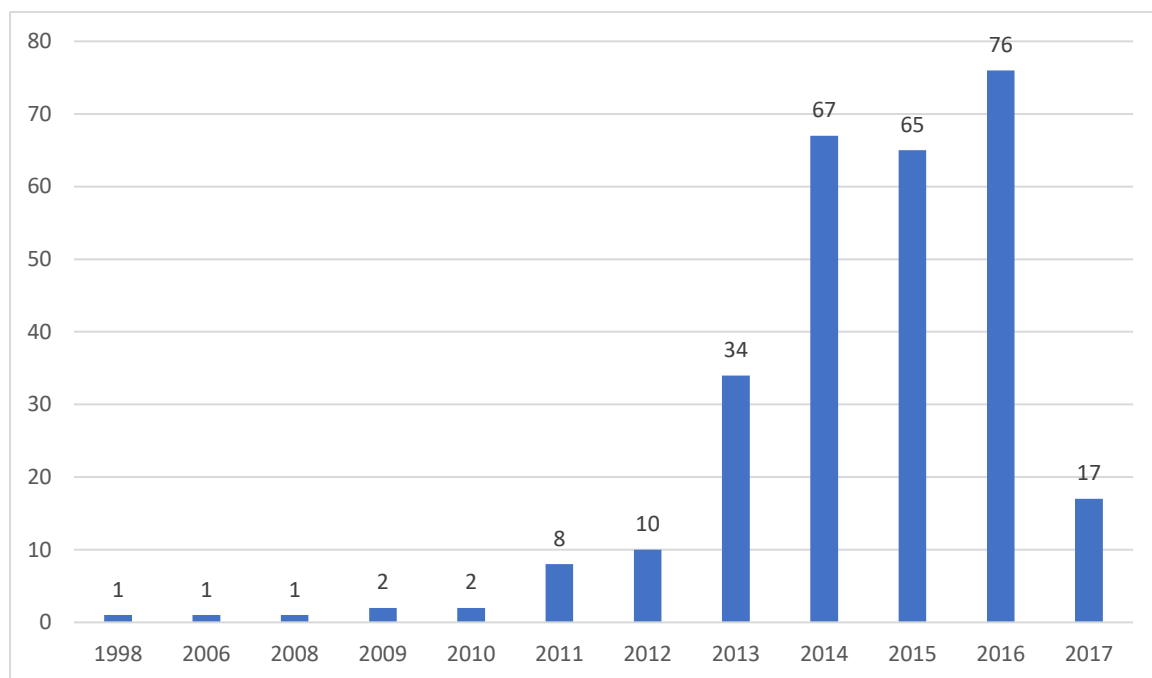
Figure 6-5. Number of DFCs set up by year (n(total) = 284).
Note: Data up to May 2017

In 45 of the 72 location-based DFCs and 18 of the 28 communities of interest, it was possible to identify key aspects of their history that had shaped their evolution. For 21 of the location-based DFCs, local needs assessments, dementia being a local government priority, and community initiatives for people living with dementia had formed the basis for becoming a DFC. In the case of the communities of interest, joining an already growing movement such as a local Dementia Action Alliance[74] and acting on Alzheimer's Society guidance on dementia friendliness played an important role. A further factor was a recognition by the communities of interest of the responsibility they had to people affected by dementia who used their services (e.g. church members, shoppers).

In over half of the sampled DFCs (n=53), collaborations between diverse agencies and individuals had shaped how the DFC had started and was being promoted. Regarding the 72 location-based DFCs, public sector organisations such as councils/local authorities, CCGs and emergency services were

involved in the creation of almost half (n=34) of them, often in partnership with each other and local charities. Volunteers were reported as having had a role in initiating just under a third of them (n=21).

Political support for DFC initiatives, and specifically the commitment of local politicians, has the potential to raise a DFC's profile, release funding and integrate dementia friendly projects with other local initiatives. There was some evidence of political endorsement of DFCs. Of the 72 location-based DFCs, 11 noted the backing and practical involvement of elected government representatives (Members of Parliament). The data also indicated political engagement, for example in the form of locally elected officials (mayors and councillors) participating in DFC related events and activities. In contrast, in a small number of settings (n=3) there was evidence of attempts to keep politics separate, emphasising locally grown leadership and involvement. In the case of the 28 communities of interest, the level of political support was not identified.

6.2.2.5 *Resources*

DFCs had varying - and often multiple - sources of income. For the majority of the DFCs studied (n=54) it was unclear how their activities were supported, or if there was long-term funding. Where it was reported, funds available to DFCs ranged from £200 from a fundraising event to £1 million of government funding for improvements to care homes badged as making the borough more dementia friendly. Almost a third of DFCs (n=29) had received grants, commonly from their local authority, but also from CCGs and voluntary sector organisations. Larger grants were funding improvements to infrastructure. One city council for example had allocated £250,000 to making customer facing council buildings dementia friendly. Fundraising and/or donations were further sources of income identified in a substantial number of cases (n=15).

Almost half of the sampled DFCs (n=48) reported access to salaried staff with support from local government, health care commissioners, charities and local partnerships. It was unclear whether these roles had an exclusive DFC focus, or whether staff were employed to deliver on specific projects (e.g. promoting dementia friendly businesses and transport). In 35 DFCs, more than one salaried position relevant to the DFC initiative was reported, but only eight DFCs differentiated between full time and part time employees. Volunteer input was referenced in just over a fifth of cases (n=22).

Three DFCs reported in-kind support for dementia-related activities, including free and subsidised use of facilities such as meeting rooms, and administrative support from a charity.

6.2.2.6 *DFC work on dementia - focus and activities*

There is a clear policy imperative for DFCs to address the stigma of living with dementia [75] [72]. Among the DFCs there was a strong sense of a commitment to promoting awareness of the needs of PLWD and finding ways of supporting participation in everyday activities. In the 72 location-based DFCs, a total of 269 activities were reported. The focus of half (n=132) of these was awareness raising in the wider community, with sessions to create Dementia Friends' (community members who have gained a better understanding of living with dementia [76]) (n=45) and Dementia Friends' Champions (volunteers helping others to learn about living with dementia and become Dementia Friends [77]) (n=11). Activities that created social media presence, information leaflets, and individual events were also widely reported. Awareness raising was also the most common activity among the 28 communities of interest, with 20 of them engaging in relevant activities, such as running Dementia Friends sessions for staff or the wider community.

Some DFCs offered a range of activities and services for PAD. Of the 269 activities in location-based DFCs, a quarter (n=69) were identified as attracting/'bringing in' users to venues that had been designated for a dementia-related purpose (e.g. memory cafés). Slightly fewer (n=59) offered activities that were dementia-inclusive, in which users had opportunities to be involved as part of the wider

community (e.g. in leisure and sports). There were initiatives and services that were designed exclusively for people living with dementia (e.g. reminiscence groups) or for their supporters (e.g. carer support groups). In some cases DFCs conflated the need to provide practical support and services for people affected by dementia with their role as promoters of community engagement and social inclusion.

Despite policy directives to promote the rights of people living with dementia as citizens and to challenge environments and attitudes that disable and stigmatise them[78, 79] , only two of the 100 DFCs made explicit reference to a rights-based approach informing their work.

6.2.2.7 *Involvement of people affected by dementia*
The involvement of people living with dementia and their supporters and carers in the setting up, running and monitoring of DFCs indicates their recognition as experts by experience, or active agents able to direct, contribute and participate[80, 81] . There was evidence of involvement of PAD for a fifth (n=20) of the sampled DFCs. This included people living with dementia acting as chairs of meetings, contributing to steering groups, and carrying out audits of how dementia friendly the local environment was. For a slightly larger group of DFCs (n=27), involvement could be inferred from references to consulting people living with dementia on DFC priorities, and a narrative on the importance of involvement. Statements emphasising the fact that people affected by dementia were contributing to a DFC were common. In over half of the DFCs (n=53), the extent and nature of involvement was not described. The ways in which the contributions of people affected by dementia shaped DFC strategy and activity also remained unclear.

6.2.2.8 *Monitoring and evaluation*
In a third of the DFCs studied (n=33) formal monitoring and evaluation were mentioned, defined as efforts to assess performance and/or progress within the DFCs. This included evaluations of specific projects (e.g. setting up a dementia friendly high street). More than half of DFCs (n=55) provided updates on what they had achieved. Commonly used indicators were: numbers of Dementia Friends and Dementia Friends Champions; number of dementia friendly businesses and dementia-related activities; achieving DFC recognition by Alzheimer's Society; and extent of membership of a Dementia Action Alliance or comparable group. In two of the DFCs, monitoring and evaluation had been planned but not progressed beyond an exploratory stage of what data could be collected. In three DFCs there were accounts of how findings had led to documented changes, for example activities being altered based on feedback from people affected by dementia. In one further DFC a self-assessment of progress made against recommended actions for becoming dementia friendly had been used for review and planning. measures such as number of people affected by dementia known to a DFC, evidence of barriers to participation being removed, and examples of changes in service provision (e.g. signage; transport; use of culture and leisure facilities by people living with dementia) were either not stated or implied.

6.3 Working with an existing evaluation tool
Data collection for the scoping review was guided by an evaluation tool that had its origins in an instrument for assessing age-friendliness in cities [3] . The evaluation tool had been applied to a DFC in a small study prior to DEMCOM[55] , where it had undergone minor modifications to ensure a dementia-specific focus. While age-friendliness and dementia friendliness are related, the two are not the same [82, 83]. DEMCOM's aim was to produce a dementia-specific evaluation instrument.

The evaluation tool at this stage was compatible with key elements emphasised by the British Standards Institution for the creation of DFCs [64] . It consisted of ten thematic 'evidence input areas' or 'domains'. These had been identified in previous studies [3, 55] as areas in which evidence is required for

an assessment of a DFC (Figure 6-6). The evaluation tool domains informed the data extraction form for the scoping review, together with additional areas of interest (Appendix IV).

	Evidence input areas/Domains	Definitions
1	**Political support**	Backing (verbal and/or practical) from key political players locally – e.g. mayor, councillors, parties
2	**Leadership & governance**	Structures & roles for strategic overview & management
3	**Financial & human resources**	Commitment of funding, material means, staff, volunteers, investment in staff & volunteers
4	**Involvement of people affected by dementia**	Instrumental roles and contributions from people affected by dementia (those living with the condition and their supporters and carers). Includes available structures, nature of structures, nature of contributions, impact of contributions
5	**Priorities based on needs assessment**	Initiatives have been prioritised on the basis of a JSNA and/or other ways of assessing needs
6	**Application of existing frameworks for assessing dementia-friendliness**	Use by the city of existing guidance, e.g. by Alzheimer's Society, to inform its work on dementia-friendliness
7	**Provision**	Availability of relevant services and facilities, including consistency (e.g. geographical coverage) and continuity (availability and personnel), and consideration of issues around uptake
8	**Interventions rooted in evidence**	Scientific evidence has been consulted and interventions have been based on the available evidence
9	**Co-ordination, collaboration & interlinkages**	Partnership working across sectors, co-ordination of relevant activities, and interlinkages between different areas of focus
10	**Monitoring & evaluation**	Monitoring and evaluation of ongoing and completed work, including plans for monitoring and evaluation and allocation of resources. Nature of monitoring and evaluation. Translation of findings into policy & practice

Figure 6-6. An emerging evaluation tool for DFCs – domains and definitions[55]

7 Chapter 7 Phase two

7.1 Methods

7.1.1 Pilot site recruitment

The findings from Phase One established the range and type of provision, populations served and the different histories and dominant approaches to how DFCs were organised. This informed the identification of two pilot sites, the questions and likely evidence sources for the different domains of the evaluation tool.

From a short list of three sites that were easily accessible for the team, two sites who had responded positively to an invitation to participate, were selected. Site A, a city with surrounding villages and an above average BAME population that worked closely with Alzheimer's Society, had a newly formed DAA and based its work from a dementia hub. Site B, a city DFC that had grown out of an established Dementia Action Alliance, had a history of cross city and cross organisational working (on ageing projects) and had weak links with Alzheimer's Society.

7.1.2 Data collection

Data collection in Phase Two consisted of: working group meetings; documentary evidence; interviews; and focus groups (see Chapter 2).

7.1.2.1 *Working group meetings*

To ensure we understood the local contexts and the relevance of the evaluation tool for the pilot sites, we recruited a range of local collaborators (e.g. representatives from local organisations) and informants (individuals working in with the DFC) in each site. These included people involved in policy and commissioning services for local populations, charities, and local services (e.g. NHS, police, leisure centre) and representatives from minority groups, volunteers, and people affected by dementia. In each site we worked closely with a link person, both of whom were volunteers. They organised and notified the team of upcoming DFC meetings, facilitated the involvement of PAD, and supported the collection of documentary evidence. In both sites the Dementia Action Alliance (DAA) was the link for all those involved in the DFC.

Initial meetings discussed 2-3 themes/tool categories for relevance, sources of evidence, who to interview and experiences of being involved in a DFC. Subsequent meetings included presentation of interim findings for comment and feedback.

Between July 2017 and April 2018, we organised five working group meetings in each pilot site. Attendance at these meetings varied, see Table 7-1 below.

Table 7-1. Working groups to support data collection and analysis in the pilot sites.

Working group meetings	Participants Site A (n)	Participants Site B (n)
1	16	6
2	13	7
3	12	8
4	10	2
5	13	9

7.1.2.2 *Documentary evidence*

Data collection in the pilot sites commenced with the collection of documentary evidence. This took place between approximately: May 2017 – March 2019. For Site A, a small number of documents were already available from phase one. Initial online scoping searches were carried out using the terms 'dementia friendly [Name of Site A/B]', 'dementia friendly community [Site A/B]', 'dementia friendly

city [Site A/B]'. Documentary evidence collection was an iterative process. Additional materials were obtained during site visits, and research participants forwarded relevant documents to the researchers. As further areas of work that were linked to the sites' DFC initiatives were identified during Phase Two, additional online searches located further relevant documentary evidence (e.g. minutes of council meetings; dementia-related strategy documents).

A total of 23 documents in Site A, and 106 documents in Site B were identified via online searches, during visits and from interviews with key informants. The discrepancy in numbers might be explained by how long each DFC had been in situ and the major developments regarding funding and activity levels in Site B and proactive information sharing by a key stakeholder. A breakdown of the documentary evidence linked to the domains of interest of the evaluation tool is provided in Figure 7-1.
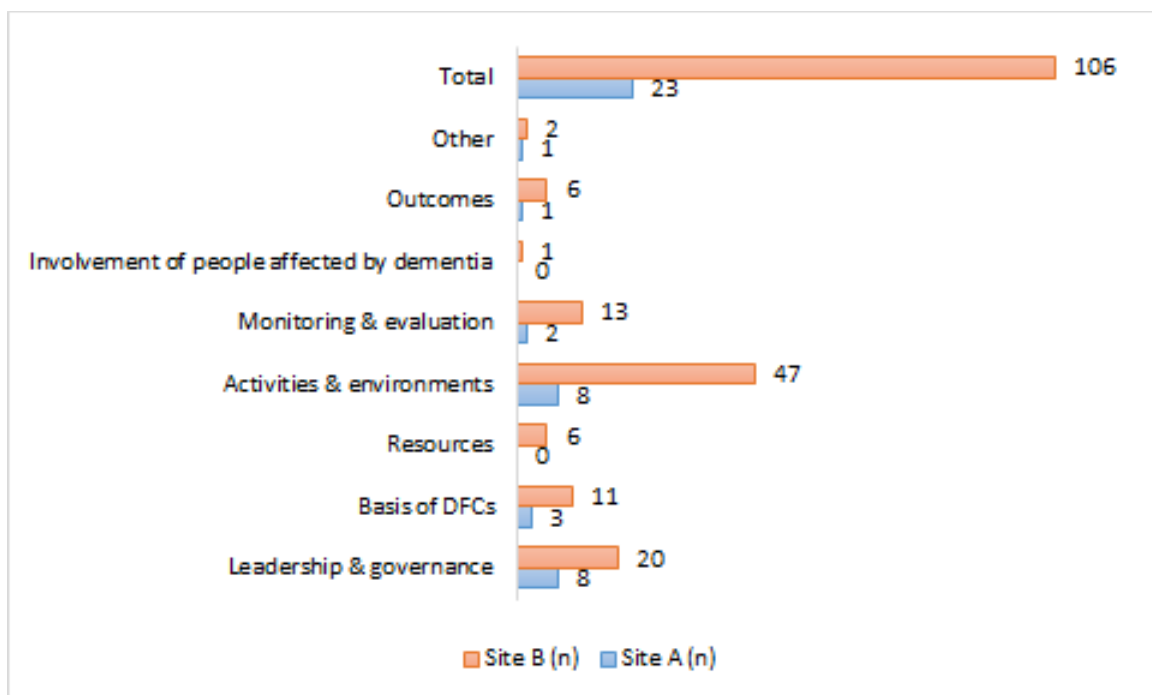
Figure 7-1. Documentary evidence collected for the pilot sites during Phases 2 and 3 combined.

Note: The different kinds of documents have been matched to the evaluation tool domains according to 'best fit'. This is useful for analytic purposes, although it must be acknowledged that there are areas of overlap.

7.1.2.3 *Interviews*

In Phase Two, interviews focused on how the DFC ran and followed up on issues raised in the DFC's group meetings and how the person's role or focus informed their involvement with the DFC. For example, the interview with a dementia outreach worker whose portfolio covered BAME communities emphasised questions on the DFC's connections with these groups. All participants had given prior consent for the discussions to be audio recorded and transcribed. In addition, the researchers sought ongoing consent from PLWD [84].

Between July 2017 and April 2018, 19 semi-structured individual interviews- 11 in Site A., eight in Site B- with key informants. The term 'key informants' referred to participants other than PLWD and their

supporters/carers[a]. The interviews were conducted on the telephone or face-to-face, and the majority lasted around one hour. With the exception of one interview in Site A, all of them were audio-recorded with the consent of the participants and transcribed. See Table 7-2 for a breakdown of the key informants by site and role.

Table 7-2 Key informants in sites A and B by organisation/role.

Key informant sectors, organisations & roles		Site A (n)	Site B (n)
Public Sector	Local Authority – Adult Health & Social Care	1	1
	NHS – primary care/GP	1	-
	NHS Trust/Memory Clinic	3	-
Voluntary sector	Organisation focusing on dementia	3	1
	Community organisation	-	1
Private sector	Care provider	-	1
	Legal	1	-
Other	Higher Education	-	2
	Self-employed	-	1
	Elected representatives	1	-
	Volunteers	1	1
Total		**11**	**8**

In Site A, one PLWD was interviewed. In Site B, an interview with a PLWD that had been arranged for did not take place as the participant withdrew for health reasons.

7.1.2.4 *Focus groups*

In both pilot sites there were focus group discussions with PAD. In Site A, a focus group was facilitated by a PLWD (see Chapter 3 for more detail on PPI), involving two further people living with dementia and one carer. Focus group participants in Site A were recruited through the local branch of a dementia organisation, and the discussions were hosted on the premises of this organisation in a local hub for dementia services. In Site B, one focus group with three people living with dementia was held. One carer sat in on the focus group in Site B to support their wife however they chose not to take part in the discussions. Recruitment occurred through the co-ordinator of an involvement group for people affected by dementia, and the discussion took place in the group's usual meeting space. The focus groups were no longer than an hour and a half and were audio-recorded.

7.1.2.5 *Stakeholder event*

Findings from phase two were presented to an invited audience of PAD, care home managers and staff, charity representatives and dementia care researchers. The event was held in London at an accessible venue. The day was designed to test the assumptions of the evaluation tool and how DFC effectiveness from the perspective of people affected by dementia should be assessed.

Delegates were recruited through the volunteer network of Alzheimer's Society, Independent Age, Innovations in Dementia, Dementia Engagement and Empowerment Project (DEEP) care home providers working with CLAHRCs in the West and East of England and researchers currently involved in projects focused on communities (e.g. the NIHR ESRC funded Neighbourhoods and Dementia programme).Targeted invitations were sent out to 36 delegates and a flyer provided to AS, DEEP and the Three Nations Working Group (part of AS) who recruited a further 11 people living with and affected by dementia. In total, 39 people attended the event.

[aa] 'Key informants' include policy- and practice-based stakeholders, elected members and volunteers as a group with distinct roles and experiences. The fact that people affected by dementia are not labelled 'key informants' is for analytical purposes only. It does not imply that their contributions to DEMCOM were not key to the study.

The event was organised café style with facilitated discussions about the evaluation tool and how to recognise and measure the reach and impact of a DFC. There was also a quiet room for participants if they wanted to take a break from group discussions

To prompt discussion and ensure everyone had the opportunity to contribute, people chose from an array of visual photo cards [85] a picture that represents "what 'dementia friendly community' means to you". They were then asked to use the picture to introduce themselves and explain to their table why they had chosen the picture.

The morning discussion groups focused on the original nine categories that had been based on the ageing friendly cities tool (Appendix II). In the morning session participants sat with their peer group and were asked: What categories work well? How could they be improved?

The afternoon groups were organised to discuss in depth one to two domains and what kind of evidence they would consider was relevant and how impact could be judged. These involved a mix of participants to encourage discussion and different perceptions.

Each table had a note-taker and summaries of the day's discussions were shared with delegates one month after the meeting. These summaries informed the next iteration of the evaluation tool's development.

Feedback forms were handed out at the end of the event.

One week after the event an email was sent to all those who attended the event thanking them for their time and contributions to the day. One month after the event the findings were compiled into a short report (Appendix III) and this was disseminated amongst the delegates. Care was taken to make this accessible. We used large font and pictures. Reports were reviewed by a PPI member of the research team prior to dissemination and contained researchers' contact details in case stakeholders had any questions about the study. Hard copies were sent to those who requested them.

7.2 Findings

The findings from the pilot sites enabled us to explore data collected via the scoping process to see how stakeholders in the two pilot sites experiences different models of organising a DFC. Both pilot sites continued in Phase Three, which collected data on four additional case study sites to further refine the evaluation tool. See Table 7-3 for an overview of data collection in the two sites during Phase Two.

Table 7-3. An overview of data collection in the two sites during Phase Two.

Method		Site A (n)	Site B (n)	Total
Documents reviewed		23	106	129
Interviews	Key informants	11	9	19
	person living with dementia	1	0	1
Focus groups with people affected by dementia (n participants)		1 (4)	1 (3)	2 (7)
Working group meetings with DFC members and representatives		5	5	10

The pilot sites' involvement in the study had the unintended effect of re-energising both groups' DAAs and increasing the number of times they met during the period of data collection. We observed the

meetings being a catalyst for representatives from different organisations that belonged to the DAA's to re-engage, share information and find out about each other's work. A summary of the findings from both pilot sites is below. These sites will be discussed in more detail in section 8.3 Findings.

7.2.1 Site A

Site A had been in operation as a DAA since 2014 and worked closely with Alzheimer's Society. Within a month of recruitment however, the salaried AS person working with the DFC had left their post.

All DFC meetings were held in a Dementia hub that hosted the memory clinic and offered support services and activities (the latter run by the local AS and funded on an annual basis by the city council). The chair was a local councillor and the deputy chair a member of a local charity.

Based on Public Health England reports the target of diagnosing 67% of people thought to have dementia had been reached. Within the city boundaries there are estimated to be 1700 people living with dementia.

There was some initial confusion in the first meetings about whether members of the DAA were recognised as a DFC, but they referenced national guidance on involvement of people affected by dementia and the need for an action plan. As a result, and despite already being on the AS DFC recognised list, they went through the official process for DFC recognition while we were visiting (submitting action plans etc.).

The close working with the Dementia hub provided a natural link for people who had received a dementia diagnosis at the Memory Clinic (also based in the Dementia hub) and with valued services and support groups.

The awareness focused work, to promote inclusion and participation from the wider community, was described as a series of Dementia Friends sessions with organisations (e.g. retail, care homes, local businesses) and was promoted opportunistically by the deputy chair.

There were numerous examples, in both sites, of individuals who were active in the DFC finding out new information from DEMCOM meetings, interviews and discussions of the interim report (See Box 7-1). As this quote demonstrates, for someone living with dementia, actively involved in the DFC and who was facilitating the focus group, he was unaware of a scheme that participants referenced as enabling them to be more confident going out and using local transport.

Box 7-1 Quote from site A focus group

> *Facilitator: …..now we already had a slight intro with your blue card.*
>
> *Brian*: Yeah. I think that was brilliant! That blue card, it's been very useful to me and every time I've shown it people have been helpful. I don't remember anybody ever telling me to buzz off or…you know, it has been very good and I think that was a very good idea, the way they thought of it in the first place.*
>
> *Facilitator: Where did you get the card from?*
>
> *Brian: From here [Dementia Hub].*
>
> *Facilitator: And you've got no problem with having that?*
>
> *Brian: Oh no. No, no. I know I can't remember things and I know I get lost and so to me it's just been one of the most helpful things I've had."*
>
> Extract from a focus group involving people affected by dementia in site A. The group was facilitated by a person with dementia. *Pseudonyms used to maintain anonymity.

7.2.2 Site B

Site B had a long history of working to support older people and people living with dementia in their city. The two leaders were at the time of the study working as volunteers though prior to that they had been employed by Alzheimer's Society.

Within the site an estimated 5000 people live with dementia. Based on Public Health England reports 80% of people thought to have dementia had received a diagnosis.

Although like Site A the co-ordination and "face" of the DFC was the responsibility of two people and there were pre-existing links to the city council, Site B's method of working was strategic rather than operational. The two volunteers worked to link and promote the work of the different organisations via their meetings and help secure funding to expand the DFCs work and address the needs of people living with dementia. They coordinated Dementia Friends across the city who targeted organisations (e.g. city council staff) and neighbourhoods.

Numbers of attendees were reported at DAA meetings and there was representation from the council, local charities, universities and the leisure and sports organisations. Meetings were held in the city centre sports complex. In contrast to site A, charity run dementia activities or services were one part of a city-wide network of activities and engagement.

The DFC had a history of success in securing additional funding to either integrate the need of people living with dementia existing activities to include people living with dementia or support access for people affected by dementia. For example, project funding to improve older people's access to sport was used to promote dementia friendly swimming lanes with additional support in the main pool. Also, a charity's welfare and financial advice clinic for all older people adjusted how it worked to accommodate the increased demand from people living with dementia and their supporters.

7.2.3 Findings under evaluation tool domains

Table 7-4 provides a brief outline of the DFC pilot sites' approach and work organised under the domains of the evaluation tool.

Table 7-4. DFC pilot sites' approach and work organised under the domains of the evaluation tool.

Domains	Site A	Site B
Basis of DFC	Synonymous with DAA Reference to BSI guidance but not evident in DFC documents or communications	Working group in place since 2015. Grew out of DAA, linked AFC work and a local consultation exercise led by the council focused on what services would support people living with dementia. No DFC specific documents. Dementia initiatives complement others to promote engagement of older people and people who are often excluded (e.g. because of mental health issues)
Leadership and Governance	Led by councillor and member of the local community (charity representative) with expertise from Alzheimer's Society.	Led by two volunteers with prior history in charity work. Local authority and the Clinical Commissioning Group, along with the Dementia Action Alliance and Alzheimer's Society are the main stakeholders.
Collaboration	Achieved through membership of the DAA and focal point Dementia Hub. Thirty-four local organisations involved, and approximately 14 actively engaged. Deputy chair liaises with organisations to promote Dementia Friends	Twenty-seven different organisations signed up to the local Dementia Action Alliance, although not all members meet regularly. Site B relies on a few key people from public health and Alzheimer's Society, who both provide time and support in managing the DFC. Not every member of the alliance met regularly. Examples of collaborative working include the police and fire service working on initiatives that have helped to benefit people affected by dementia. Unclear if the DAA started or promoted these initiatives and how different organisations learn about each other's work
Resources	Donations from fund raising events £350-£500 Resources in kind by using the dementia hub and having input from AS employed staff	The work done by a mix of paid staff as part of other roles, and volunteers. Funds are received from the Local Authority and the Clinical Commissioning Group for initiatives in line with *'People Keeping Well'*. Additional funding from the Big Lottery Fund and the Sport England Active Ageing Fund. Time limited supporting short term contracts. History of using general grants and funds (e.g. for older

		people) to benefit people living with dementia
Activities	Dementia Friends initiatives. (Number undocumented). Blurring of DFC work with the services and activities of the AS run Dementia hub and groups for people affected by dementia e.g. gardening groups, dementia cafés. Blue card system for people living with dementia to use if needing extra support when shopping or using public transport. No data held by DFC on how many using card or attending activities	Multiple activities available for people affected by dementia e.g tea dances, memory walks, and dementia friendly theatre Activities are spread out across Transport was valued by people affected by dementia as reducing anxieties about accessing the community. Also examples of Police service increasing awareness of possible fraud
Monitoring	Mystery shopping and hospital audit of environment by DFC member who lives with dementia. Unclear how information used	Informal feedback from the dementia involvement group
Equalities and Inclusion	Eighteen per cent of the population are from Black, Asian and Minority Ethnic groups. There is a dementia support worker but unclear if they link with the DFC	There is an awareness that the city has a diverse range of communities and languages, No evidence of work targeting these groups.
Involvement of people affected by dementia	Present in DFC as members of the Service User Review Panel (SURP), and/or who are involved in the Dementia Action Alliance. (See also monitoring). Unclear how many people are involved.	People affected by dementia are involved through the dementia involvement group and the *'Enrichment for the Elderly'* initiative. Information gathered through this group helps form reports that are shaping DFC. Unknown how many people affected by dementia are regularly involved in these groups.
Evolution	Evidence of multiple Dementia Friends sessions and awareness events, but difficult to establish what happens next.	Evidence of increasing breadth of activities over time especially in sport and leisure Unclear how the range of activities are co-ordinated, sustained (e.g. dementia friendly fire service) and built on.

Working with pilot sites in phase two of the study confirmed that the headings of the evaluation tool could meaningfully structure the data collection in Phase Three (involving six study sites) and begin to make links between the domains of the evaluation tool to understand how different histories and ways of working led to different foci and potentially impact.

Findings from the pilot phase (Phase Two) were presented to participants from the two sites for comment and these, combined with their feedback, were taken to the stakeholder event.

7.2.4 Stakeholder Event

The Stakeholder Event took place in February 2018. Thirty-nine delegates such as people living with dementia, carers/supporters, with different experience of and expertise of dementia attended. See Table 7-5.

Table 7-5. Number of delegates who attended the DEMCOM stakeholder event.

Delegate expertise	N attended
Expert by experience living with dementia	9
Family carer supporter	6
Representatives of dementia community interest groups/advocacy groups	7
Researchers working with people living with dementia	17

The event was widely disseminated and discussed in real time on Twitter via numerous twitter accounts. Subsequently, delegates created two written blogs and 1 video blog. (Box 7-2).

Box 7-2 Blogs written by stakeholder delegates

- Shibley's blog: http://shibleyrahman.com/dementia-2/dementia-friendly-communities-are-more-than-the-customer-experience/?utm_campaign=shareaholic&utm_medium=twitter&utm_source=socialnetwork

- Carol's blog has now been deleted by her but this was the link at the time https://t.co/s5H9RdD3jP

- Peter's video blog: https://dementiadiaries.org/entry/7004/peter-reports-about-the-DEMCOM-study-event-in-london-about-dementia-friendly-communities

Almost all the domains of the evaluation tool were confirmed as covering what participants recognised as important for a DFC and the centrality of having people living with dementia involved in all aspects of a DFC work. Feedback stressed:

- That there should be a wide range of activities that can promote community engagement and awareness and improving the local infrastructure (e.g. transport and environment such as signage and accessible buildings).
- That a DFC should be able to demonstrate how it is supporting the participation and engagement of people living with dementia. Attempts to have every domain discussed by a mixed group of participants had variable success and the hope of the research team to be able

to move towards discussing how to judge the quality and strength of the evidence was over ambitious and not achieved.

7.2.4.1 *Agreement, debate and challenge about the Evaluation Tool*

There were areas of debate within and across the groups during the Stakeholder event that echoed, and in part explained, the variation observed in the scoping review of DFCs (phase one findings). The provision of dementia specific venues (e.g. dementia cafés) and dementia specific activities (e.g. Singing for the Brain®) and infrastructure changes (e.g. slow shopping checkouts in supermarkets) were seen by some as core work of a DFC. This was described as providing a safe place, a shared space, and an environment where people knew they would be accepted. Similarly, what statutory services should be doing, for example continuity of care and post diagnosis support, were conflated with what needs to be in place to create a community that people can feel confident living in.

Others recognised that dementia specific activities and support could be helpful but argued that such provisions reinforced the perception that people living with dementia were different and did not have the support to participate in all aspects of their community. For these participants the work of the DFC was to complement and not augment funded services with additional provision. The focus should be outward looking, investing in activities to achieve a change in the local infrastructure (e.g. how organisations routinely accommodated the needs of PAD), and in the process changing culture of how people living with dementia were understood, talked about, encountered and maintained connections with people they met every day.

There was discussion at the Stakeholder event about whether some domains of the DFC evaluation tool could be subsumed into each other for example, was how a DFC monitored its activities and achievements a reflection of its basis and underlying values and assumptions?

The challenges to the evaluation tool and identified (possible) gaps focused on how the different domains were connected, and how people living with dementia who were at different stages of the disease trajectory were acknowledged and included. For example, how were people living in care homes involved and were there opportunities for intergenerational activities? Were the domains impersonal and in focusing on aspects of how to structure and organise a DFC had lost a sense of the person. A key challenge was whether it would be possible for a DFC to be evaluated well, although the experience of people living with dementia was still poor?

The importance of capturing how a DFC was developing over time and capturing the resilience of different types of DFC (for example by type of funding, who is involved or if this was the combined effect of doing well in all the domains) and if there is an over reliance on inputs rather than outputs and outcomes for individuals, organisations and those unaffected by dementia

There was recognition at the Stakeholder event of the difficulties of an evaluation tool that could be both easy to use and fully capture the range and reach of different types of DFC.

7.2.4.2 *Evidence of a "good" DFC*

Previous evaluations of dementia friendly communities have focused on what DFCs have done and on numbers of people involved (e.g. completion of Dementia Friends training sessions with different groups/businesses, Dementia Champions), events organised, resources available and which organisations are involved [1]. The facilitated discussions at our stakeholder event acknowledged that this was important to capture, but that the evaluation tool also needs to measure the reach and engagement of a DFC. We asked people to suggest evidence of what (within each domain) would be good, or reasonable to assume a functioning DFC could address.

Additional process measures suggested were those that could address the quality and variety of the collaboration. It was assumed that more active partners within the DFC including those with local political power would lead to more impact on the community. Therefore, the evaluation tool should address how different groups communicated with each other, the language used (was this inclusive?)

and how initiatives that affected the wider community as well as organisations supporting PLWD were known. Several people highlighted that some understanding of how many PLWD there were in the local community was important, especially those from groups who might not have a history of being involved in or invited to community initiatives.

The evaluation tool should also be able to identify and describe how the local community is adapting to/anticipating the needs of people living with dementia. Suggested areas that could be targeted as indicative of change were signage in retail, and hubs such as banking, health centres and transport making their staff more alert to the needs of PLWD.

Specific questions /measures to consider were:

Proxy measures of how dementia aware organisations (suggested by individual participants) were:

- Longer appointments at GP practices and other businesses for people known to be diagnosed with dementia and reminder systems that did not penalise missed attendance
- Routine provision for people to vote in local elections so that they could receive help in a voting booth
- Evidence of the needs of people living with dementia is referenced and accommodated in community initiatives and by shared standards in their approach and activities including (e.g. football clubs, homeless hostels, faith groups etc.)
- All public events provide quiet seating areas and opportunities for people to leave early if needed
- Number of completed Lasting Power of Attorneys in a district as an indirect measure of community awareness
- Evidence that care home residents had opportunities to go outside or leave the care home with a carer e.g. coats and shoes readily available
- Evidence in school curricula and other youth focused activities of children learning about dementia (e.g. scouts etc.)
- Raised knowledge of how to reduce risk of developing dementia through lifestyle choices and behaviours

A summary of the discussions, points of clarification and suggested changes to the evaluation tool are included and the summary report that was sent to participants is available at Appendix III.

7.3 Implications for development of the evaluation tool

Data collection in the pilot DFCs was guided by the existing evaluation tool. The learning from the pilot sites, together with the Phase One findings and insights from the literature, enabled an early draft of evidence-informed questions that an evaluation of a DFC might address in each of the tool domains (Jan 2018; see Appendix IV). It also led to revisions to the evaluation tool: While two of the original ten domains remained unaltered, five were merged into two new domains, and three were renamed without altering their content substantially (see Appendix V for further detail).

This resulted in a tool with seven 'thematic domains' (Figure 7-2). In addition, two new 'cross-cutting domains' were introduced. Emerging evidence from both pilot DFCs had highlighted the challenges regarding sustainability faced by DFCs. While funding was a major concern, sustainability had also emerged as a key issue in relation to other areas such as leadership and governance arrangements, or the involvement of PAD. Accordingly, 'Sustainability' was added as a domain that was relevant to, or cut across, the thematic domains. A further observation in the pilot sites had been inequalities across the thematic domains, exemplified by the limited reach of DFC activities of members of specific groups such as BAME, as well as the absence of members of such groups from leadership and governance structures. 'Inequalities' thus became a further cross-cutting domain.

Thematic domains	Cross-cutting domains	
Leadership & governance	Inequalities	Sustainability
Basis of DFC		
Resources		
Involvement of people affected by dementia		
Activities and environments		
Collaboration		
Monitoring & evaluation		

Figure 7-2. DEMCOM evaluation tool (version 2) based on the research in the pilot sites (prior to the Stakeholder event).

Where appropriate, existing domain definitions were reviewed on the basis of the modifications made and the available evidence (see Appendix VI).

In addition to the research in the piloting sites, in Phase Two a national stakeholder workshop was held. Feedback and advice for the development of the evaluation tool were collected from people with lived experience of dementia, professionals in policy and practice, and researchers. There was broad consensus among the participants on the following:

- Use positive language: 'Equalities' rather than 'Inequalities'
- 'Sustainability' appears to imply that DFCs are static. Rename this domain 'Evolution' to capture the diverse and dynamic nature of DFCs
- 'Involvement of people affected by dementia' needs to be a cross-cutting domain, as PAD need to be involved in all aspects of a DFC

These suggestions were compatible with the emerging findings, and they resonated with the researchers' experience and understanding of DFCs. They fed into the next and final iteration of the evaluation tool, which occurred in Phase Three (see Chapter 8).

The workshop participants also identified key criteria for a 'good' DFC that an evaluation tool should capture (Appendix VII). These guided the questions under the different evaluation tool domains against the available evidence.

8 Phase three case study of dementia friendly communities

8.1 Introduction

Phase three extended the work of phase two and addressed the question: "What generalizable lessons can be drawn about the resources needed and economic benefits of creating and sustaining Dementia Friendly Communities?" It involved an in-depth study of six DFC case study sites (the two pilot sites plus four additional DFCs). All the DFCs were defined by location as Phase One demonstrated this was the dominant approach.

8.2 Method

8.2.1 Identification and recruitment of case study sites.

The sampling frame was the 100 DFCs that had been the focus of the scoping exercise in Phase One. To generate a sample that would enable our research question to be addressed DFCs were purposively selected to be : geographically disparate and reflect a diversity of approach, underpinning values, demography, distinctive features (e.g. organisation and funding, serving a diverse community) and accessibility to researchers.

Exclusion criteria were: DFCs not defined by location, in the same regions as the pilot sites, London, as the Mayor's office is co-ordinating cross borough initiatives to set up the first dementia friendly capital, and those without an identifiable contact.

Thirty-three potential DFCs were identified (Figure 8-1) and invited to take part. Thirteen expressed an interest in participating. Twelve were considered and discussed in terms of the different opportunities for learning they offered against the domains of the evaluation tool. This produced a consensus amongst the research team on five DFCs as possible sites. Four DFCs replied and one was equivocal about participation. The two pilot sites (site A & B) were also confirmed as research sites.

8.2.2 Data collection

The domains of the draft evaluation tool provided the structure for data collection in the six sites. Sites were visited between three to five times over a period of nine months including overnight stays where necessary. This was supplemented by online and telephone contact, interviews, focus groups, documentary analysis and a survey.

8.2.2.1 *Interviews and observations*

A key informant in each site liaised with the team and supported the observation of DFC work and meetings and facilitated access to group and individual interviews. The research proposal suggested up to 30 participants per site including PAD. Numbers of participants reflected the size and frequency of meetings in the DFC. Interviews and focus groups were semi-structured, qualitative and iterative. In each site interim findings were presented as summary reports as a basis for discussion to highlight unanswered questions and points of clarification.

100 DFCs
- Exclusion of all non-location based DFCs (n=9)

91 DFCs
- Exclusion of all DFCs in the same regions as the Phase One pilot sites (East of England/n=13; Yorkshire & Humber/n=10)
- Exclusion of all London Based DFCs (n=7)

61 DFCs
- Exclusion of all COIs (n=11)

50 DFCs
- Exclusion of DFCs whose location could not be clearly identified (n=2)
- Exclusion of DFCs for which there were insufficient data (online & telephone) (n=2)
- Exclusion of DFCs already well researched (n=3)
- Exclusion of DFCs inaccessible by public transport (n=12)
- Retention of DFCs with exceptional characteristics (n=2)

33 DFCs
- Exclusion of DFCs that did not reply to invitation to expressions of interest in participation in DEMCOM (n=20)

13 DFCs
- Exclusion of DFC that subsequently declined being considered for participation (n=1)

12 DFCs
- Inclusion through consensus finding among research team based on selection criteria: sufficient evidence from the scoping survey against areas of evaluation tool; unusual/outstanding features; diversity of research sites; recommended by Alzheimer's Society; accessible to researchers (n=5)

5 DFCs
- Replies from 4 DFCs confirming wish to be included

4 DFCs
- Participation of the 4 DFCs confirmed and research in each site initiated

6 DFCs
- Addition of the 2 pilot sites

Figure 8-1: Phase Three case study site selection process

8.2.2.2 *Secondary analysis of documents*

In addition to online documents identified in phase one, additional sources of evidence not publicly available were reviewed e.g. funding bids, reports, DFC minutes and local consultations.

8.2.2.3 *Survey of people living with dementia*

To understand the reach and impact of the DFCs a cross-sectional postal survey of PLWD who were **not** actively involved in the running or planning of the DFC was completed in all sites. Data collection took place between March 2018 and March 2019. Survey questions reflected the DEMCOM evaluation tool domains combined with learning from previous surveys with people living with dementia (http://www.repod.org.uk/downloads/dfc.pdf and https://www.alzheimers.org.uk/about-us/policy-and-influencing/reports/turning-up-volume). A draft version of the survey was discussed, amended and piloted with PPI members who had direct experience of living with and being affected by dementia.

Questions covered participants' characteristics, eight closed questions including space for participants to expand on their answers, and the first part of their post code (see Appendix VIII).

8.2.2.4 *Survey recruitment*

To maximise opportunities to recruit PLWD not involved in a DFC organisation, a variety of distribution methods were used. Between January 2018 and August 2018 questionnaires were distributed in partnership with local clinical research networks (LCRN), via Join Dementia Research (JDR), research databases held at memory clinics, and via GPs. One site (B) distributed the survey via Alzheimer's Society to PLWD.

A survey was conducted over the phone or posted (with a pre-paid return envelope) to participants. Participants could either complete the questionnaire on their own or ask someone to support them. It was made clear that the responses were to reflect solely the experience and views of the person living with dementia.

8.2.3 Phase Three analysis

Qualitative data analysis of interview data, documentary data and field notes was guided by the domains of the DFC evaluation tool using NVivo 12 [86]. This process was supported by a two-day workshop to compare coding, interpretation of findings across sites and theoretical assumptions. The final NVivo coding tree is included as Appendix IX.

Documentary evidence was used to understand the history of events or experiences of each DFC [87]. It was then examined in conjunction with other data sources (interviews and focus groups) to triangulate key findings in relation to the evaluation tool.

Survey data were analysed using SPSS Version 25 (IBM Corp, 2017)[88]. Descriptive characteristics of the data were summarised. Chi-squared tests were used comparing categorical data between participants' awareness or lack of awareness of their local DFC initiative. Where the sample size for a category was less than five, Fisher's exact tests were used. For ordinal level data such as stage of dementia and age, Mann Whitney U tests were conducted. Thematic and content analysis was used for open ended, free text questions.

8.2.3.1 *Resources, social value and social return on investment*

For each site, data on resources collected through interviews, observations and secondary analysis of documents were analysed thematically as a separate domain to describe the sources, types, and quantities of resources available. Data were then tabulated to identify general patterns of how resources flow at different stages in the evolution of DFCs. Findings are presented narratively and summarised visually in a comparative table. These descriptions were then analysed in light of the data collected under each domain of the evaluation tool to derive lessons pertaining to the resources needed to develop and sustain DFCs.

8.3 Findings

The following provides a brief overview of the six participating case study sites and then examines in detail the evidence by domain of how the DFCs have interpreted and carried out their role and what can be learnt about what needs to be in place to achieve inclusion, participation and the opportunities for PLWD to contribute as valued citizens. The number of participants can be seen below.

Table 8-1. DEMCOM participant numbers and methods

Method		Site a	Site b	Site c	Site d	Site e	Site f	Total
Doc evidence (n)		24	101	47	31	70	27	300
Interviews	KI	10	8	8	8	9	9	52
	PAD	1	0	0	0	6	0	7
Focus groups (participants /groups)	KI	0	0	1:8	1:8	1:7	0	3:23
	PAD	14/2	3/1	8/2	16/2	12/1	6/1	59/9
Questionnaires with PLWD (method)		76 (NHS)	22 (Alzheimer's Society)	9 (GP/AS)	78 (NHS)	36 (NHS)	23 (GP)	244
Other (field notes from meetings/events)		5	9	2	1 (4 day site visit)	3	1	21

8.3.1.1 Site A

Site A is a DFC covering the population of a city in the East of England. The city's population is estimated at 196,640 in 2015. Site A has a relatively young population and the prevalence of dementia in site A for all ages is 0.6% (national average of 0.8 %.) However, recorded prevalence in people aged 65 and over is 4.9% (4.3% average for England).

Site A's Indices of Multiple Deprivation (IMD) Average Score at Local Authority District (LAD) level is 27.659, which gives it a Rank of Average Score of 58 (out of 326 LADs; where 1 = most deprived). Site A has a diverse population and 14.8% of its population are from Black, Asian, Minority Ethnic (BAME) groups identified at Census 2011 (*Figure 8-2*). Site A also has the second highest proportion of the UK population that cannot speak English or cannot speak English well.
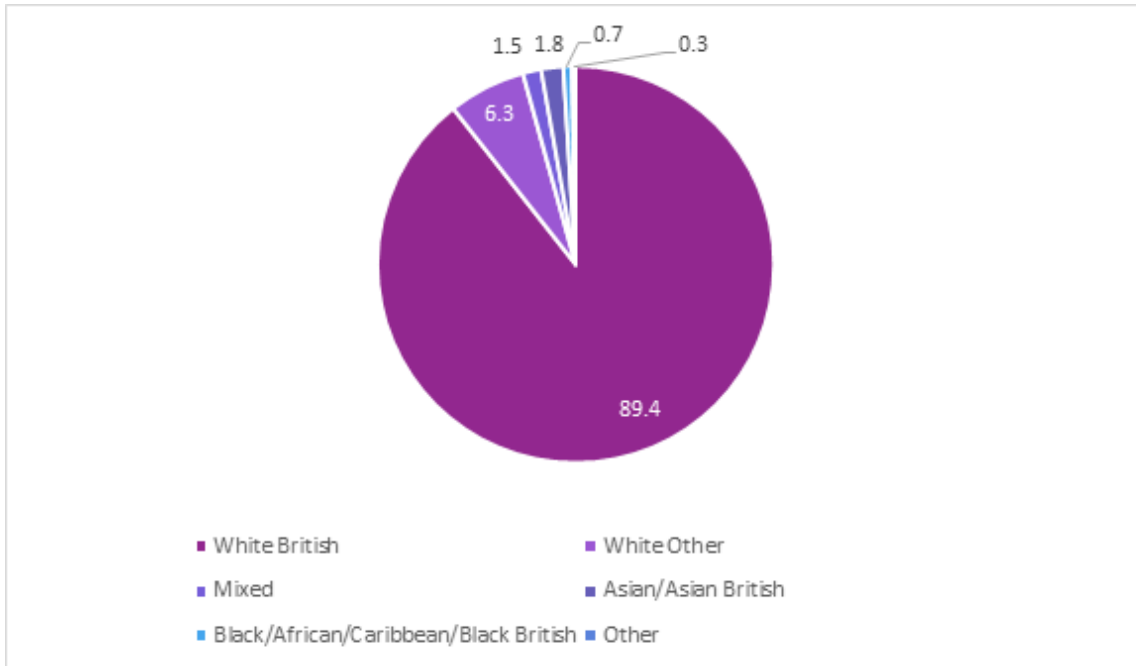
Figure 8-2. Population of site A by ethnic group, based on the Diverse Ethnic Communities Joint Strategic Needs Assessment for Site A, 2016.

The DFC started informally in 2012 when the city council set up a Dementia Steering Group whose aim was to develop a strategy for PLWD. This then formally merged into the local DAA in 2014 with support from the local council. The principle focus of the local DAA was to develop a dementia hub for the local community. This hub provides a wide range of support and services as well as being the base for the local memory clinic and Alzheimer's Society. See Figure 8-3 for a visual representation of the leadership structure of site A created by the research team.
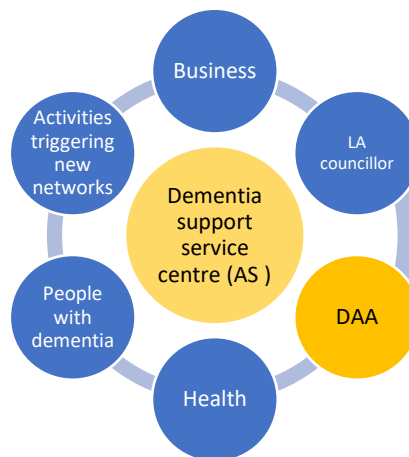
Figure 8-3. A visual representation of the leadership structure of site A.
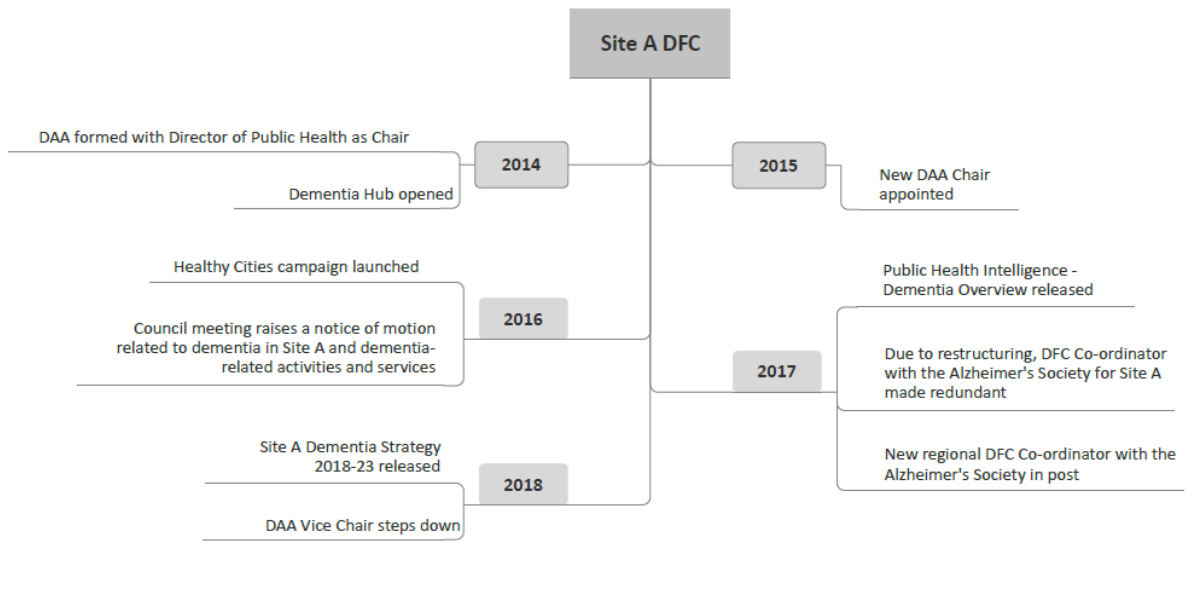
Figure 8-4. A timeline of site A's development

8.3.1.2 *Site B*

Site B is a city with over half a million population in the Yorkshire and Humber region. More than 7,000 of its residents are estimated to be living with dementia. The Joint Strategic Needs Assessment reports above average diagnosis rates compared to the national picture.

Site B's IMD Average Score at LAD level is 27.568, which gives it a Rank of Average Score of 60 (out of 326 LADs; where 1 = most deprived). The population of site B is ethnically diverse, (*Figure 8-5*).
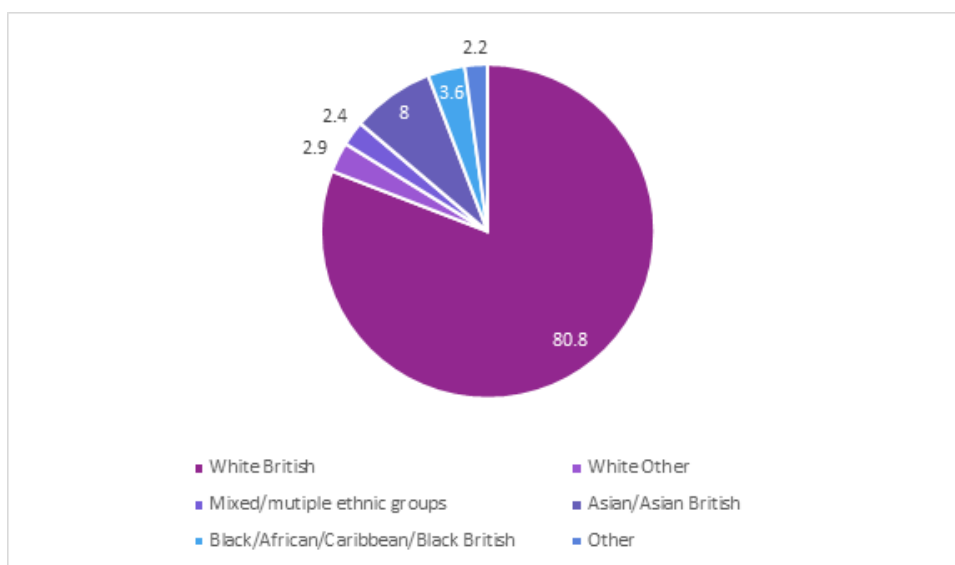
Figure 8-5. Population of site B by ethnic group, based on 2011 census data.

The site was one of the first cities in the country committed to becoming a DFC. Local work on dementia friendliness through a formalised approach dates to 2010 (Figure 8-7).

Following the Prime Minister's Challenge in 2012 Alzheimer's Society promoted a DFC agenda in the city. The DFC is closely aligned with its local DAA and chaired by a volunteer. These meetings are the forum for discussion, news exchange and debate. See Figure 8-6 for a visual representation of the leadership structure of site B.
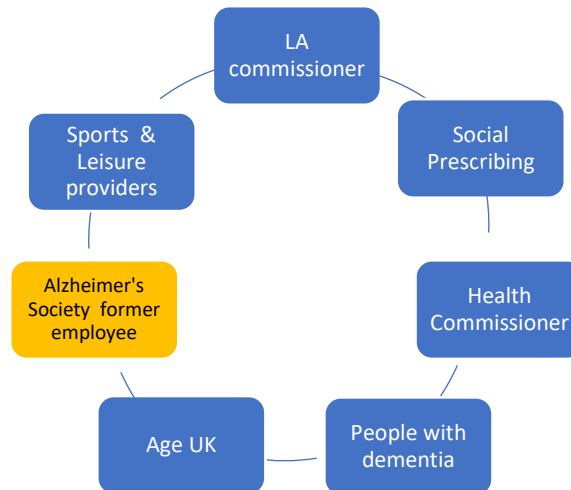
Figure 8-6. A visual representation of the leadership structure of site B

Funding from the City Council and other sources (e.g. charitable funds) are tied to specific projects and initiatives. Most recently a jointly funded initiative by the City Council and the CCG supported a social prescribing project delivered in 17 neighbourhoods and communities across the city through local partnerships. Integral to the project is the support of people affected by dementia. Each partnership is led by a voluntary sector organisation including residents' organisations, GPs, libraries, community groups and Neighbourhood Support Officers.
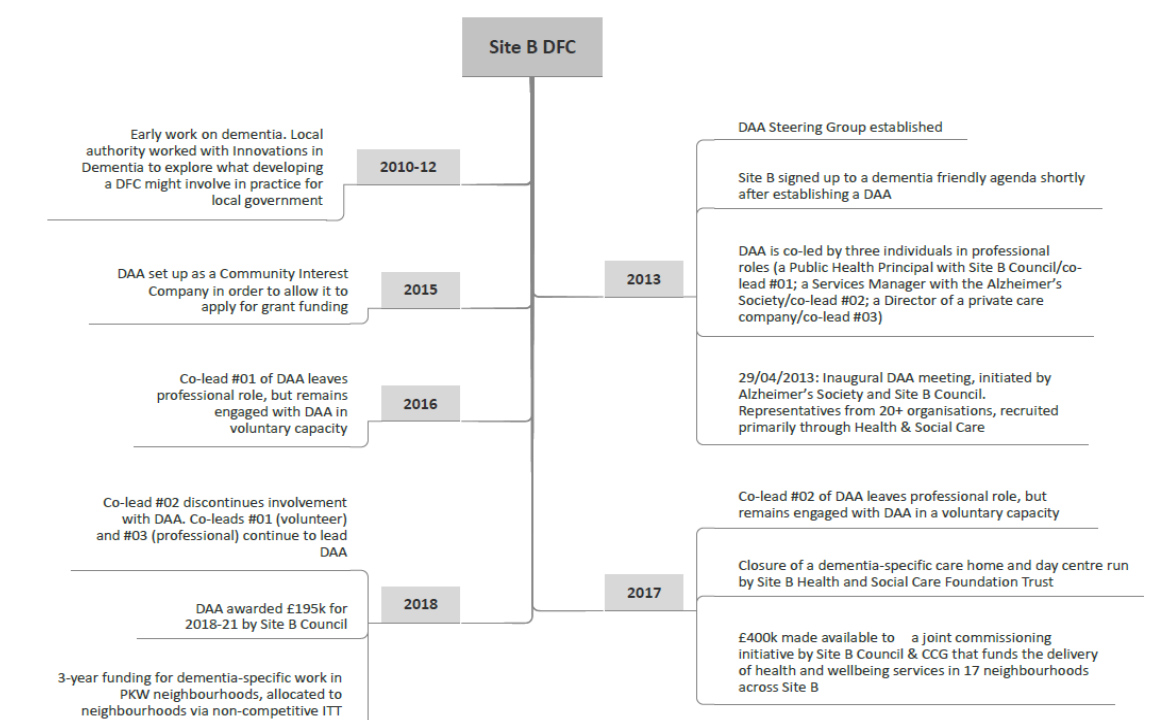
Figure 8-7. A timeline of site B's development

8.3.1.3 *Site C*

Site C covers the population of a small market town and parish in the West Midlands. According to the 2011 census, the town's population is estimated at 24,428. The population of site C is older than the national average. Due to the size of the DFC the estimated number of PLWD in the exact area is unavailable.

Site C's IMD Average Score at LAD level is 16.001, which gives it a Rank of Average Score of 194 (out of 326 LADs; where 1 = most deprived). Only 3.5% of the county population of site C have a BAME background.

Site C began working towards becoming dementia friendly in 2016 (Figure 8-9). Accounts vary about what was the trigger, whether it was because of an awareness of increasing demand from people living with dementia, or a recognition that local diagnosis rates were below the national average. Another account is that the DFC was developed to support the roll out of a project called 'Side by Side', which pairs a volunteer with a person with dementia with similar interests. Those involved had personal experience as a carer, were active in local charities or had become involved through Dementia Friends. See Figure 8-8 for a visual representation of the leadership structure of site C. The collaboration was reliant on key members (n=3) and links with other groups (symbolised as hexagons) were for information exchange.
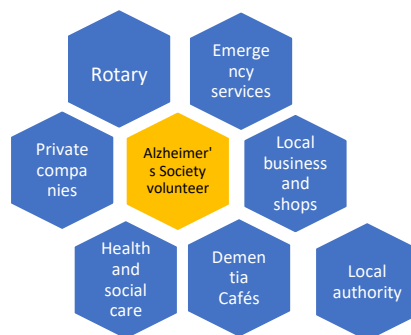
Figure 8-8. A visual representation of the leadership structure of site C
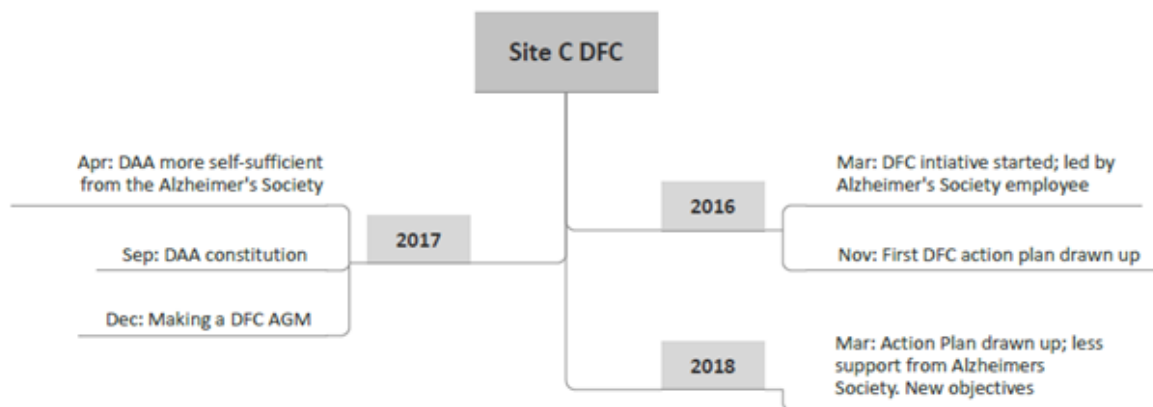
Figure 8-9. A timeline of site C's development

8.3.1.4 Site D

Site D covers the population of a large industrial town in north-east England. The town's population is estimated at 138,400. In 2015, there were 1,168 people recorded as having dementia on GP registers.

Site D's IMD Average Score at LAD level is 40.216, which gives it a Rank of Average Score of 6 (out of 326 LADs; where 1 = most deprived). Compared to other towns in the local area Site D is ethnically diverse (Figure 8-10). Twelve per cent identified at Census 2011 as coming from a BAME group. This is expected to grow further.
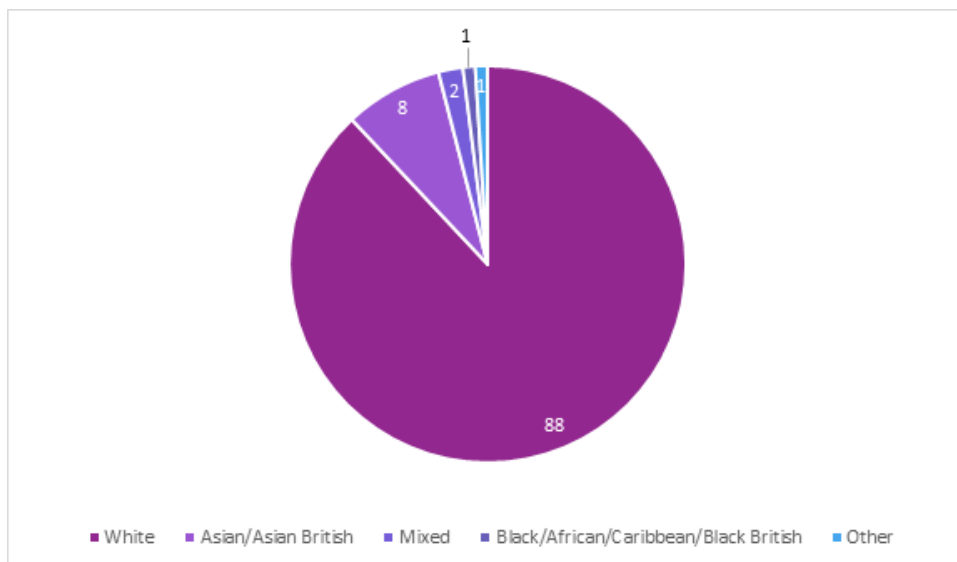
Figure 8-10. Population of site D by ethnic group, based on 2011 census data.

In 2015 the Director of Public Health's Annual Report had a specific focus on dementia and risk reduction, and supporting the development of a DFC was identified as part of that work.

In 2016 a working group was set up alongside a dedicated worker to engage local businesses and organisations. At the core of the project were the voices and opinions of 50 people affected by dementia who were consulted from the outset. Unlike the other sites there was no previous history of working as a DAA. See Figure 8-11 for a visual a representation of the leadership structure of site D.
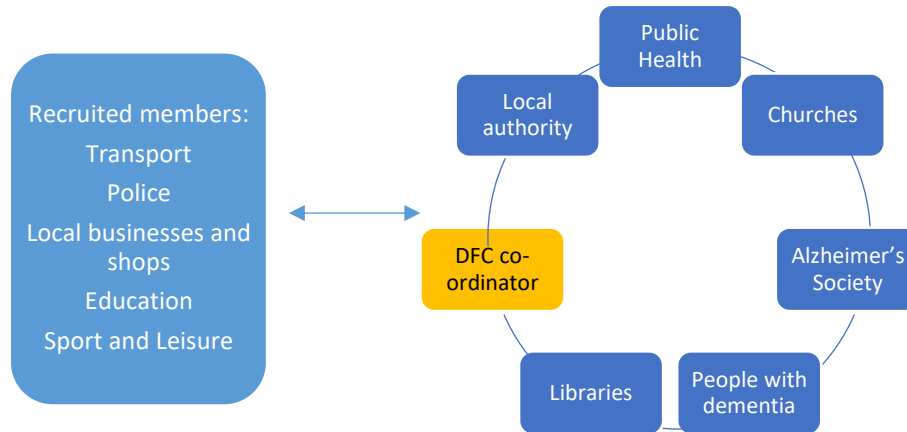
Figure 8-11. A visual representation of the leadership structure of site D

Figure 8-12 provides a timeline of the site's progress. From the outset there was endorsement from local politicians and in 2016 a part-time DFC co-ordinator was appointed and funded on an annual basis by the local public health team. In 2017 this DFC was nominated for a DFC award.
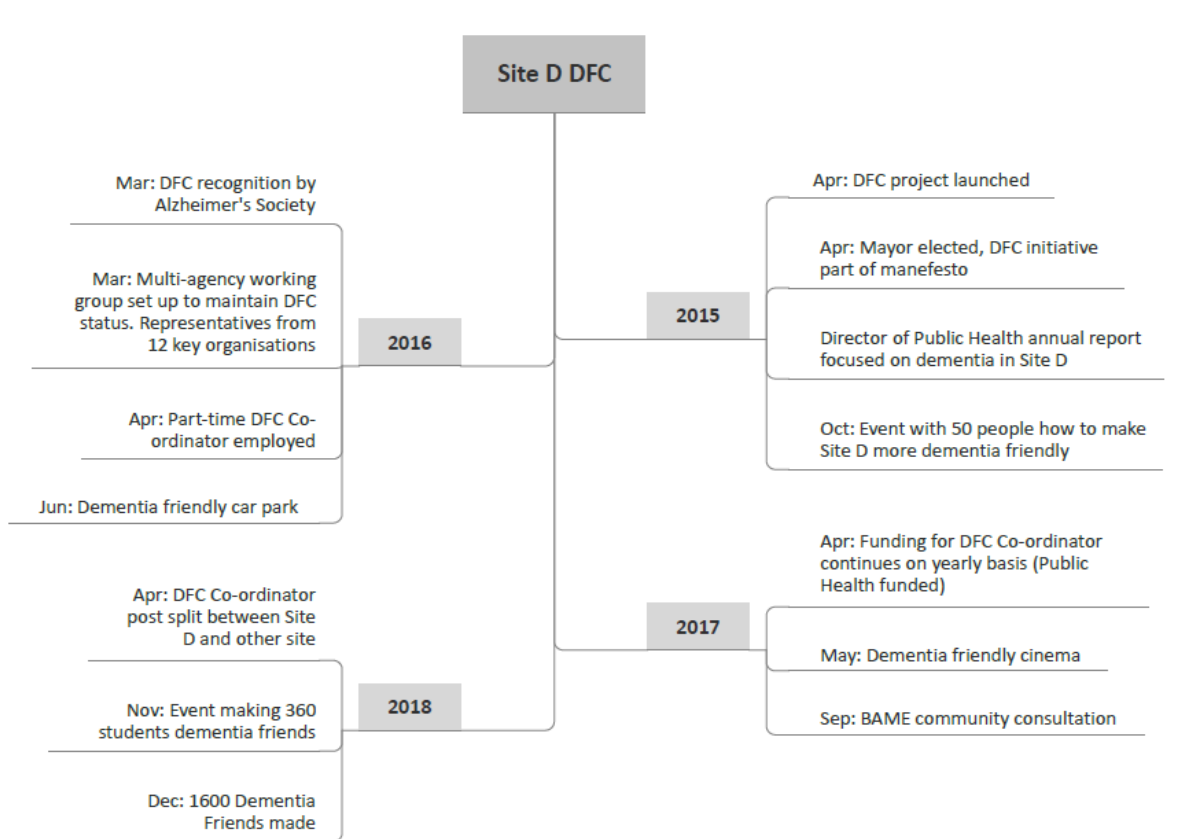
Figure 8-12. Timeline of site D's development

8.3.1.5 *Site E*

Site E covers a unitary authority in North West England with a mix of large towns and rural scattered populations. Of a population of 380,000 residents (in 2017), close to one fifth are over the age of 65, with those living with dementia in Site E estimated to be 6,300 in 2019 to almost 10,000 in 2035

Site E's IMD Average Score at LAD level is 14.132, which gives it a Rank of Average Score of 223 (out of 326 LADs; where 1 = most deprived). Site E's population is predominantly (93.6%) White British. There are, however, pockets of greater ethnic diversity, most notably one of the towns (Town X) that hosts a "nested" DFC (Figure 8-13).
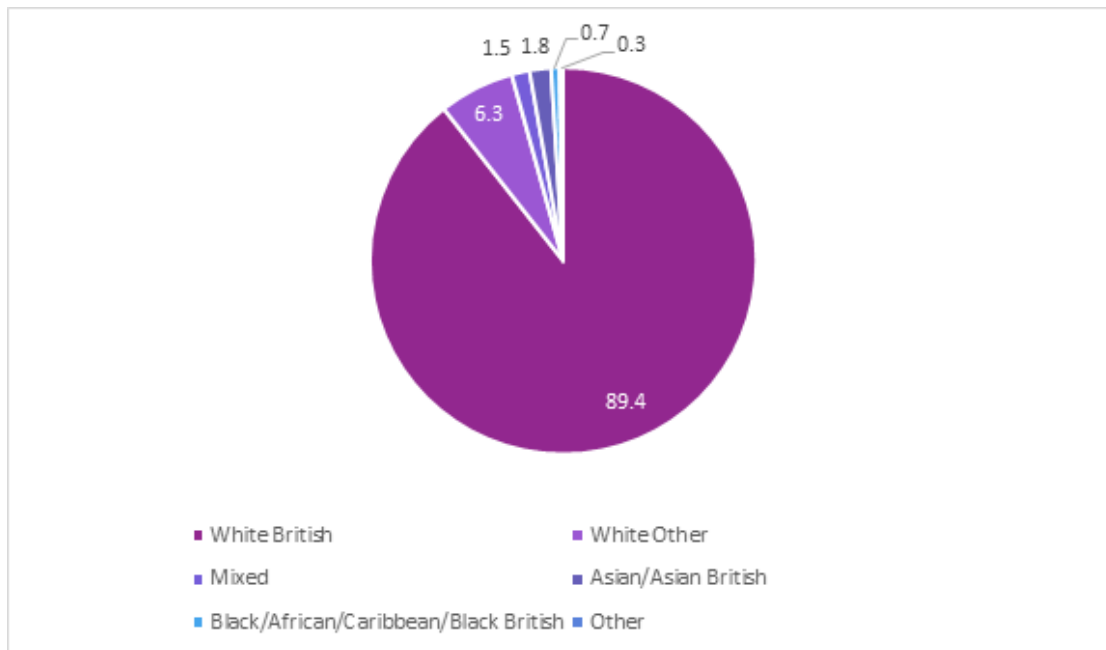
Figure 8-13. Population of Town X (nested in site E) by ethnic group, based on 2011 census data.

Site E was selected for inclusion because it incorporates several smaller DFCs in towns and villages (n=8 at the time of the data collection.), referred to as 'local DFCs' (Figure 8-15). In the last two years, the number of DFCs within Site E has increased, which means there are different histories and timelines of operation within the DFC. Site E DAA acts as an overarching structure. Its quarterly meetings provide a forum where representatives from the local DFCs as well as individuals from across Site E make strategic decisions, exchange information and share learning. The members of Site E DAA include volunteers as well as representatives from a wide variety of sectors such as local government, health, charities, leisure, culture and businesses. At the time of the fieldwork over 50 organisations were members. For almost two years, Site E DAA was supported by a DFC Co-ordinator. The loss of this post in September 2018, coincided with the end of the fieldwork. It triggered uncertainty about the future. See Figure 8-14 for a visual representation of the leadership structure of site E.
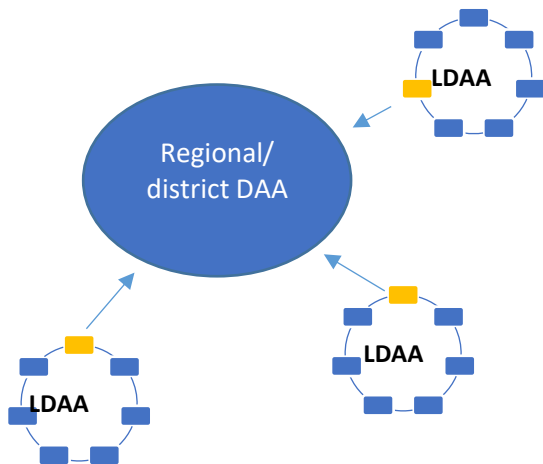
Figure 8-14. A visual representation of the leadership structure of site E

DFC activity in the local DFCs is driven by Dementia Steering Groups (DSGs) or similar bodies through which residents, businesses and organisations work together. The leadership of these local partnerships varies, with leads including a Town Council, a volunteer, a Police Community Support Officer, a representative of a large company
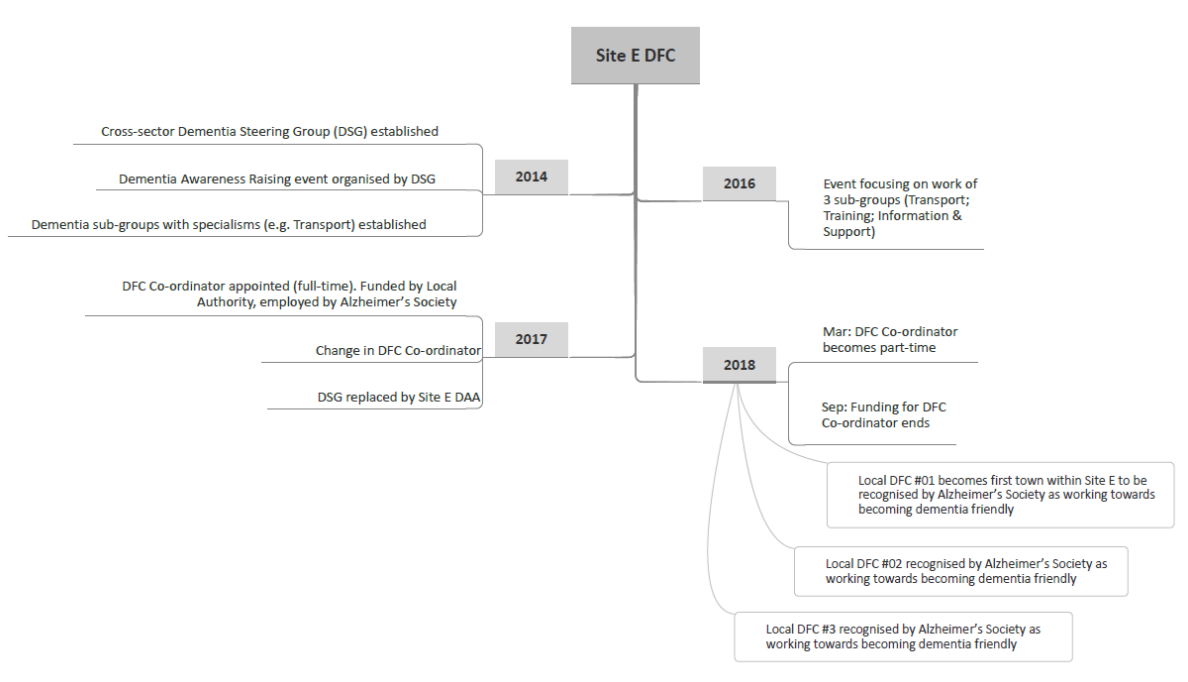
Figure 8-15. Timeline of site E's development

8.3.1.6 *Site F*

Site F is a city and unitary authority located in the East Midlands. The population is estimated at 348,300 in 2016. In site F there are 2,555 people living with dementia. According to Public Health England, Site F has a recorded prevalence of dementia for ages 65 and above as 5.5% as of September 2017. Site F has a higher recorded dementia prevalence in its 3 constituencies than the surrounding area.

Site F's IMD Average Score at LAD level is 33.065, which gives it a Rank of Average Score of 21 (out of 326 LADs; where 1 = most deprived). The DFC serves an ethnically diverse population. Based on 2011 census data, 51% of the population report as white, and 37% come from Asian or Asian British ethnicities. It is one of the most ethnically diverse local authorities in England (Figure 8-16).
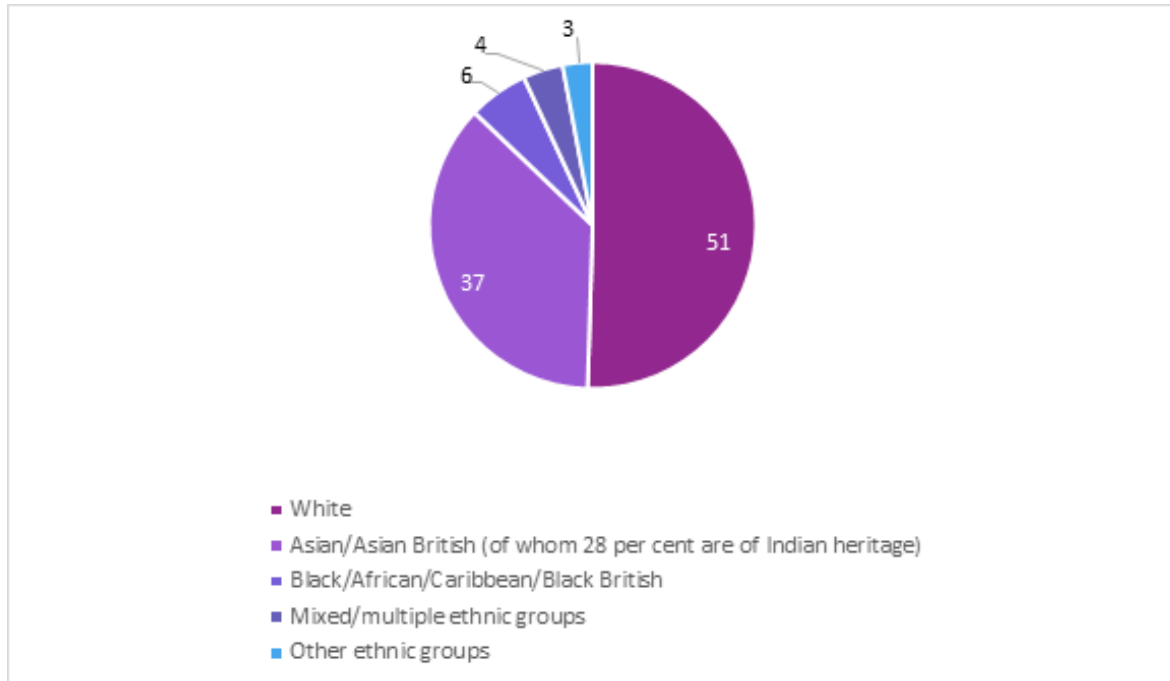
Figure 8-16. Population of site F by ethnic background, based on 2011 census data.

In addition to its diverse population, Site F was chosen as a research site because it appeared to have a high level of Council involvement in the DFC. The DFC initiative was first announced in 2015 and was part of the 2016 City Council Dementia Action Plan. The leadership and governance structure are interlinked with the local dementia action alliance (LDAA). Led by the City Council, an unspecified percentage of a commissioner's post is allocated to coordinate and support the DFC with meetings chaired by an elected official. Funding to improve the built environment for people living with dementia was an early initiative The DAA acts as the "hub" providing some leadership to the DFC, with each organisation involvement based on who the organisation is (e.g. police) or activities they represent. Each organisation (represented as hexagons) is semi-autonomous in the dementia friendly work it undertakes. Figure 8-17 shows a visual representation of the leadership structure for Site F.
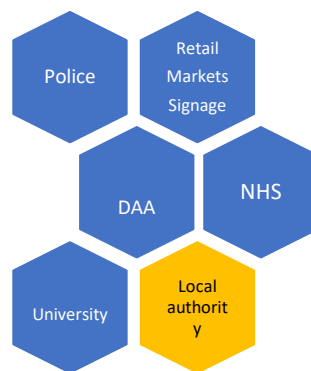
Figure 8-17. A visual representation of the leadership structure of site F

Figure 8-18 describes the timeline of site F.
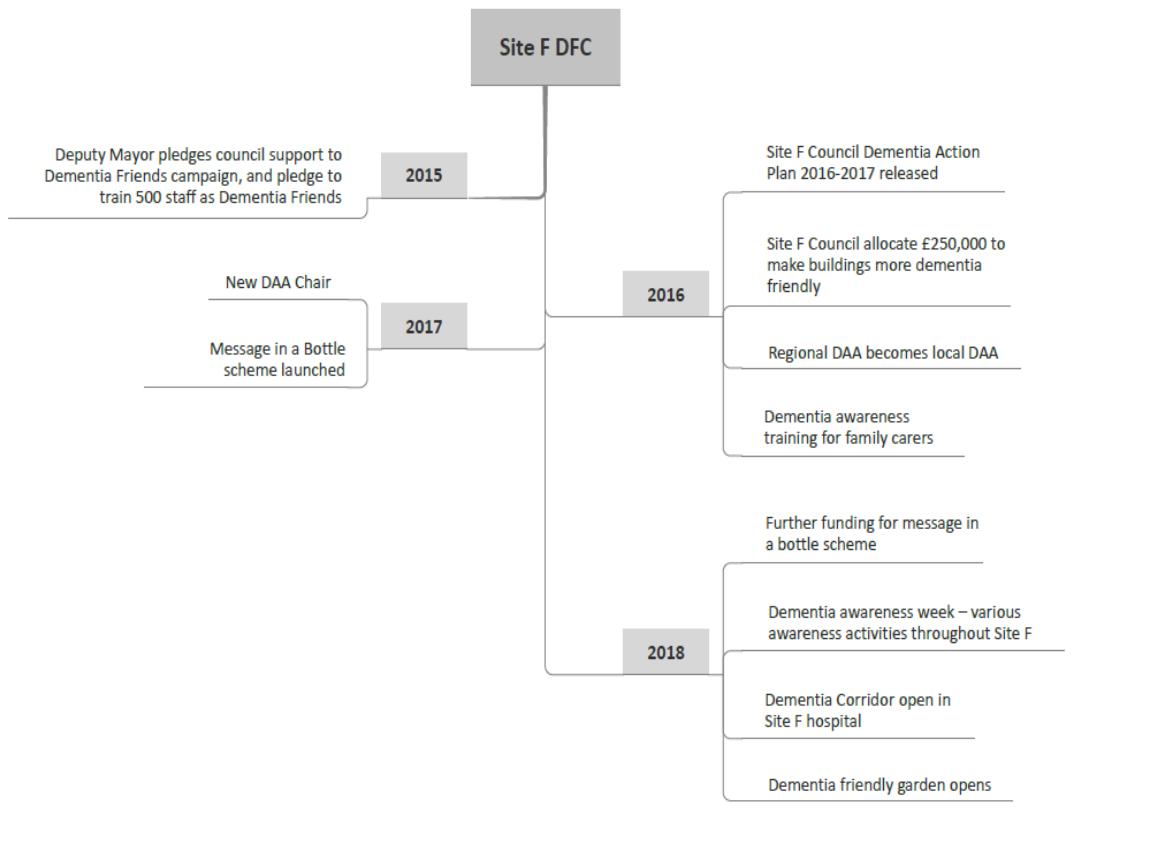
Figure 8-18. Timeline of site F's development

8.3.2 How DFCs work to enable people living with and affected by dementia to be active members of their communities

The following is an account of the findings from the six case studies. It is organised by the five standalone domains (Basis, Leadership and governance, Activities and environments, Resources, Monitoring and Evaluation), followed by three of the cross-cutting domains of the evaluation tool (Involvement of PAD, Evolution and Sustainability, Equalities and Inclusion).

Outcomes are integrated into the five standalone domains. The section for each standalone domain provides a descriptive account of what is in place in the case study DFCs in the respective domain; and ii) the linked outcomes. A distinction is made between, short-, medium- and longer-term outcomes. While this is useful for analytic purposes, it is often not clear-cut. Similarly, particular outcomes cannot necessarily be exclusively attributed to a specific standalone domain. The findings have informed the theory of how DFCs work and change over time and the linked logic model presented in chapter 9.

8.3.2.1 *Basis of the Dementia Friendly Community*
Overview

The foundations DFCs are built on and the resources they draw on, their motivations, underlying assumptions, and values all shape what DFCs do. This 'Basis' domain was defined as the *"extent to which espoused values and learning are known and have informed the development and approach of the DFC."* This included the DFC making use of existing guidance and evidence of what works.

Table 8-2 provides a summary of the key influences identified in the data on how each of the DFCs expressed the basis for their work.

Table 8-2. Key findings from Basis domain.

How DFC basis described	Site A	Site B	Site C	Site D	Site E	Site F
As part of local policy for PAD e.g. JSNA	+	+		++		
Linked with local LA and/or NHS commissioning		++		+	+	
Integral to DAA work and action plans	++	++	+		++	+
Referencing evidence on DFC		++		+	+	
Response to needs of PAD & anticipated demand	+	+	++	+	+	++
Response to local assessment/ consultation (specific organisation)		++		++	+	(+)
Part of risk reduction strategy	+			+	+	
Extension of service provision for PAD	++		+			+

+ indicates evidence of influence on the how basis and aims of DFC articulated and enacted
++ indicates key influence on the how basis and aims of DFC articulated and enacted
(+) indicates Evidence of one organisation (market) consulting on PAD expressed need

The research has identified a wide variety of influences that have shaped the work of the six DFCs. These included macro-level resources such as the scientific evidence on DFCs and how they can enable PAD to live well, and existing guidance and frameworks for DFCs such as those published by Alzheimer's Society. Sites B, D and E provided examples of how they were using guidance and evidence of what works as the basis for planning and discussions.

A major influence on the six DFCs have been an array of micro-level, locally specific community characteristics and resources, motivations, and personalities. Among these, population data and health data and needs and asset assessments (as captured for example in JSNAs, or dementia-specific JSNAs) played a key role. Further local influences included health and wellbeing priorities and guidance as reflected for example in local dementia strategies and NHS policies. Alignment of dementia with local priorities and associated funding opportunities through the LA and Health (e.g. site B, F) were important, as were insights from community consultations. Other influences included a long history and shared understanding of the value of partnership and community engagement (e.g. site B), and local champions with particular interests and service initiatives (e.g. site A, C). Finally, differing motivations shaped the DFCs.

Population data, diagnosis rates and projected numbers of PLWD were a reference point for all the case study sites that a strategic and organisational level response was needed. For three sites this data directly informed how local government and health (CCG and NHS organisations) engaged and worked with the DFC. This was articulated in terms of:

- What needed to be done (pragmatic response to growing demand and needs)
- Who needed to be supported (compassionate response to lack of support)
- The morally right response for people who were being stigmatised and excluded (social justice, human rights

Many participants had a personal connection with dementia that motivated them to work towards becoming dementia friendly. This quote from a manager of a market who had overseen it achieving dementia friendly status captures how a council imperative to improve access accorded with personal experience.

> *"We kept in touch over the years and then I went to see her (former work colleague) because she'd been poorly, she had dementia, I went to see her and I was just staggered at what it had done to her. By this time, she was bedridden. She's dead now, sadly. Not sadly, actually, I'm sure it was a release for her.*
> *But it really affected me, and I hadn't had that connection with someone with dementia before.*
> *So, I kind of think that probably underlines my reason behind it. If the council are asking me, because I'm spending their money, because I am, then I'll talk about making sure more sections of the community can use our market and feel comfortable in using our market, and that's how it should be anyway."* (Market manager, Site F).

Outcomes

In some of the sites, consultations with PAD informed the start-up of the DFC and strategic plans (sites B, D) as well as the provision of services (e.g. carers support, site E) and facilities (e.g. suggestions how a local organisation should improve access, site F).

The basis and intentions of some of the DFCs found concrete expression in implementation plans. Site B had a three-year DFC implementation plan outlining seven key areas for work, activities under each area, an individual leading each area and the skills required, and a target delivery date. In site D, the DFC's working group had written guidance and resources for new members to follow in six areas for action. Other case study sites had begun to consider this as part of their action plans for DFC recognition.

An ongoing review of a DFC's basis by all those provided an opportunity for community leaders to either shape the basis for their DFC or influence decisions It was also more likely to encourage engagement with activities that supported local infrastructure changes to promote wider inclusion. In contrast, where there were no opportunities or platform to review the basis of the DFC this was more likely to lead to standalone activities that did not reference each other or build a shared narrative of the DFC's purpose and goals.

A joint and strategic understanding of what was being done and why in a DFC, was more likely to reduce reliance on individuals. For example, at the end of data collection the site D coordinator reduced their involvement in the DFC, the work and the ethos and population focus however was maintained by the partner organisations. Three sites (A, E, F) that had looser associations between its members, reported losing focus when their co-ordinator either left or had to reduce their involvement.

Leadership and Governance

Overview

This domain addressed how a DFC was led, evidence of strategic overview, who was involved and how responsibilities were agreed. All sites had collaborative structures in place to lead the DFC work forward, in five of the six sites this predated the DFC. Table 8-3 summarises the key features.

Table 8-3. Key findings from Leadership and Governance domain

Leadership and Governance	Site A	Site B	Site C	Site D	Site E	Site F
Activist/Coordinator role leading DFC	(+)	++	++	++	(+)	(+)
Established collaboration across statutory business & voluntary sector	+	++	+	++	++	+
Targeting groups for community engagement	+	+		++		
Local Authority backing and funding	+	+		++		++
Core group meeting	2x year	2x year	4x year	monthly		

Key

+ Known individual(s) working to coordinate role

++ Individual identified as coordinating the DFC work (salaried or equivalent)

(+) Individual was involved but post lost or intermittent

All sites had a contact or liaison person for the DFC, but not necessarily in a leadership role. For example, in site F the person who co-ordinated the work of the DFC was a council employee who took on DFC work as a consequence of the council department she worked in, it was one of multiple competing priorities.

> "Well, [site F] DAA has always been chaired by an elected member…it's always fallen to someone in adult social care, and at the moment, my line manager, she is the lead commissioner within adult social care for dementia and older people, so it's fallen into her portfolio. That's not to say, when I say 'Fallen into' it's not that we don't appreciate the importance, but actually a lot of the work, in my view anyway, would be better sat in communities and neighbourhoods, rather than adult social care." (Commissioning manager, adult social care, Site F).

Structure and accountability

The five DFCs (A,B,C,E,F) that had grown out of the local DAA structures had a list of known members representing different sectors and local organisations. The number of members across the five local DAAs ranged from 7 (F) to 52 (E). DFC location and size of local population were not predictors of who would be involved. Those DFCs that had stronger representation from the LA were more likely to have engaged with local services (e.g. police, NHS) and have access to ongoing funding.

One DFC (D) had a working group of 13 members representing the different interests and organisations of the community who agreed on new members. Engagement and participation of the additional 136 members were limited to bi-annual celebration events to showcase the DFC's work. In other sites membership was based on interest and attendance.

Only one site (E) provided a structural diagram that explained how the DFC worked and was organised. In 4 DFCs it was either unclear from their documentation, or because of recent changes in personnel.

In the bigger sites (D, E F) and those that had been established for several years (B), the division between leadership and implementation of DFC work was clearer.

> *"So, it isn't about one person doing it all, it's about one person being a focal point, I think, and that's how I think it works well"* (Focus group participant, Site D).

In site C, operating in a market town most of the organisational work centred on one person, and coordination of volunteers to deliver services became an all-encompassing task.

> *"I have got my own life as well, and I'm doing this as a volunteer… But then the reality of what I'm doing in real life, managing this, trying to coordinate a big group of volunteers which is like herding cats. But that's fine, because I'm used to doing that in work life, but it is hard. I'm thinking, "I really haven't got the time to sit and do that,"* (DFC co-ordinator, Site C).

Funded posts were identified as very important for providing the resources and energy needed to start DFCs. If they were lost (as in site A), this led to a loss of momentum and focus. Site E had a nested structure with multiple smaller village DFCs linking together through a central DFC. The DFC co-ordinator was on a one-year fixed term contract. Members of site E were aware of the upcoming end of contract and its likely impact on how the DFC work would be coordinated. However, local "ownership" of ongoing DFC work was cited as a strength.

> *"I think there's a potential that it could have a major impact across [Site E]. I don't think necessarily it will affect those individual dementia-friendly communities that are up and running, because I think there's ownership with other people and they're being driven by other people now. But for any new towns, villages, wanting to set up dementia-friendly communities, I'm not quite certain how that information will be disseminated and who will support the initial set ups of those groups"* (Interview participant, Site E, discussing the ending of the DFC co-ordinators fixed term contract).

Across the research sites, the direct involvement of PAD in leadership and governance structures was limited.

All the sites catered for different size populations, with access to a range of resources. *Table 8-4* provides an overview of the wide range of involvement by focus and site of different groups and organisations. The DFCs' loose structures meant there was considerable discretion about what membership meant. In line with BSI guidance there was evidence of targeting specific groups (e.g. voluntary, faith based, businesses and shops; and emergency services), but this was not systematic or necessarily sustained.

Table 8-4. Summary of who was represented in case study sites (from documentary evidence and participant data). N= number of organisations involved.

Area for action	Site A N=39	B N=26	C N=31	D N=137	E N=52	F N=7
Arts, culture, leisure & recreation	3	2	3	20	6	0
Businesses and shops	11	5	5	38	7	2
Children, young people & students	1	0	1	7	0	0
Community, voluntary, faith groups & organisations	1	2	6	26	7	0
Emergency services	3	1	2	2	2	2
Health & social care	12	10	9	25	15	2
Housing	1	2	1	2	3	0
Transport	1	1	0	6	5	0
Other	6	3	3	11	7	1

Political support

All sites had political support, but it varied how influential this was to what the DFC could achieve. Three of the DFCs (A, D, F) were council led with an elected representative (counsellor) chairing the LDAA (A, F), or an elected mayor supporting the DFC as part of their manifesto (D). The remaining three DFCs had political representation from local commissioners (B), MPs and councillors being present at fundraising events (E, C), and the mayor choosing the DAA as their supporting charity (B). Four of the DFCs mentioned political support as an important factor (A, C, D, and E).

> *"If the mayor of that town isn't interested, then that sends out the wrong message. If the mayor of that town actually attends events and launches events connected with dementia frameworks and is prepared to present certificates to businesses who become dementia friendly, I think that puts out quite an image statement about the commitment of that town because a mayor is seen as quite a visual person of the town"* (DFC co-ordinator, Site D).

In the three DFCs with explicit political support (A, D, F) the ruling political party was unlikely to change. This was seen as providing organisational memory, and continuity of support. Although because dementia was such an important local issue, changing political allegiances were seen as irrelevant for the DFC by other sites.

Outcomes

Across the case study sites, leadership and governance structures supported the strategic direction and progression (or not) of the DFC work. Known and clearly defined leadership and governance structures were likely to have an enabling effect (e.g. sites B, D) in how the work was planned and discussed. In contrast, where these structures were loosely organised changes in key roles were disruptive and caused uncertainly and a slow-down in DFC work (site E, F)

The multi-agency governance structure such as a DAA or Dementia Working Group was key to ensuring the DFC was visible, and that awareness of it in the local community. Growing membership of representatives of organisations/local services either via new DAA members or through the DFC (e.g. Sites B and D) was indicative of wider buy-in, and recognition of the DFC. It could also lead to dementia becoming more visible at a strategic (e.g. Dementia being incorporated into an organisation's strategy)and operational (e.g. range of activities for PAD within existing services) levels.

Political support for a DFC was key but findings suggested that **how** a LA engaged was as important as who was present. If the LA saw the DFC as a partner addressing shared priorities for the local population then it led to allocation of sometimes substantial resources to the work of a DFC. In site A, resources gained through the practical support of a councillor were considered critical for the survival

of the DFC. In site B, political support enabled much additional city-wide and neighbourhood-based work. A participant from site F commented:

> *"If you don't have the political buy-in then nine times out of ten, you don't have the resource to be able to do what you need to do"* (Interview participant, Site F).

Participants from two different sites highlighted that political support can also increase visibility and support. If local government involvement was more passive, chairing or attending meetings but not engaging directly with the work then this limited the wider impact of the DFC. Often working in parallel to existing local services.

> *"So if you want your project in the paper you get the Mayor and the Council along and it'll get in their easier"* (Focus group participant, Site E).

The distinction between DAAs as enablers of the work and activities that led to the recognition of DFCs was blurred. This could affect how responsibilities were interpreted and lead to multiple activities but limited coordination of a DFC (e.g. Site F). Five of the sites were either closely associated with the local Dementia Action Alliance, with members in common or were one and the same virtual organisation. Site D was the exception but had a very similar structure to other DAAs with a core collaboration of representatives of local organisations and services.

8.3.2.3   *Activities and Environments*
Overview

This domain refers to the work of the DFC. Specifically, what was done for awareness raising, campaigning, risk reduction, and provision of services and medication of local environments (e.g. access to buildings, local amenities) for people affected by dementia?

We categorised activities as those that were:

- Community Engagement/awareness (e.g. Dementia Friends , School work , public events)
- Dementia specific (e.g. Singing for the Brain®, dementia walks Young onset groups),
- Dementia inclusive addressing the environment in which PLWD lived (e.g. improving access to sport and leisure and public buildings, transport)

Reflecting phase one findings, there was a wide range of single and ongoing activities that either brought people in by providing places and activities for people affected by dementia, and those that enabled people to go out. In some sites the awareness work was the precursor for connecting with target services or organisations that could improve the experience of living in the community (e.g. shopping). Alternatively, dementia specific services provided feedback to the DFC about the experience of living with dementia that then fed into awareness work.
Activities offered by all the sites included dementia cafés, carer support groups, and Dementia Friends' sessions. The Herbert Protocol had also been universally adopted, a police led scheme that encourages carers to compile useful information about a vulnerable person that can be used if they are reported missing.
Two of the DFC sites (A and C) favoured dementia specific service provision. There was awareness work with a programme of Dementia Friends sessions, but they prioritised reaching people who needed support. These were a physical and locally visible means of promoting the DFC. They provided a focus in the community.

The dementia café, I would say, is the hub. There are probably about - I'm guessing now - 40, 50 people a month go to the dementia café... once a month that, and then twice a month is Singing for the Brain® where there are probably a dozen to 20 people go to Singing for the Brain. That's a bit more niche, isn't it, I suppose. Then the local church, three churches together, have set up this afternoon tea service on a Friday afternoon, a dozen to 20 people going to that. (Interview participant, Site C).

In site E the person salaried to run the DFC wanted to shift the focus from dementia specific to dementia inclusive activities, but was having a mixed response.

"I am sort of encouraging communities to look at not having specific, just specific things for people with dementia, and I know that's sort of, sort of, that sort of opinion's sort of heard quite a lot throughout XXX, that they do, they tend to have different events, different things going on which are probably more accessible, rather than having something specific" (DFC co-ordinator, Site E).

Dementia inclusive activities either widened access to services for older people (e.g. fitness schemes, benefits and keeping safe advice), or introduced dementia specific initiatives in public spaces such as shops (e.g. slow shopping checkouts in supermarkets, stickers for participating shops) and leisure facilities (dementia friendly cinema and swimming).

For all the DFCs a focus on community engagement and awareness raising of dementia was foundational work. The main methods were Dementia Friends' sessions and recruitment of organisations to the DAA. The DFCs also participated in national initiatives such as Dementia awareness week.

To improve access and participation for PAD there were multiple examples of public facilities creating safe spaces, improving lighting and signage for people living with dementia to support people going out. Two sites (B and D) linked dementia awareness work with targeting services that could improve inclusion (e.g. retail, transport and leisure services). In other sites awareness raising activities were responsive to expressions of interest and not so strategic.

We found limited evidence of DFCs engaging with dementia risk reduction. It was discussed within site D as part of the public health agenda, yet no data from any of our DFCs suggested this was being actively addressed.

The stakeholder event raised questions about who with dementia would benefit from being in a DFC. Many of the activities and events assumed that people affected by dementia were mobile and able to communicate their preferences and interests (see also Chapter 4 on Equalities and inclusion). Accessibility was an issue for PAD. Site B was the only site that had targeted community transport although Site D had done work with local taxi firms. There was an example of a dementia café ceasing because people could not reach it on public transport.

For people whose dementia affected their ability to participate in groups or leave their home, we identified initiatives that improved the co-ordination of care or made it easier for people to be safe (police, use of GP services, hospitals), provided access to advice and support (befriending schemes, navigator services), and in two sites housing and assistive technology. These were either organised or publicised by the DFCs and invariably were linked to LA involvement. There was not, however, universal coverage, for example, engagement with one housing association or a fire station did not extend to the whole community. In site B there was an example of a LA supported city-wide initiative that funded different charities/community interest companies to work with people affected with dementia to access mainstream services and support. Initially developed for people with mental

health problems, it was a good example of how this DFC integrated the needs of people affected by dementia with wider city work.

The number of activities was not a useful measure of the reach of a DFC, as it was unclear how many were involved or if they described single or ongoing activities, and where they were located in the DFC. To demonstrate the range of provision, Appendix X provides a summary by site of the focus, organisations involved and PAD targeted.

Outcomes

Community Engagement/awareness: For a DFC to have an impact on a community's awareness of PAD, increasing numbers of Dementia Friends and Dementia Friends Champions were an important short-term outcome in different research sites (e.g. B, D, E), while greater awareness of dementia by staff of targeted organisations and services was identified as a medium-term outcome across or in specific parts of some of the sites (e.g. B, E, F). Another short-term outcome were additional dementia-related events triggered by the participation of the DFCs in national initiatives such as Dementia awareness week.

There was limited evidence of how awareness raising activities and recruitment of organisations to local DAAs affected organisations' ways of working. In site D retailers' participation in awareness raising and in conversations with PAD demonstrated to them the annual loss of income from shops not being dementia friendly.

It was unclear if awareness raising activities led to increasing involvement of individuals with the DFCs. The potential for this was demonstrated in site C, the volunteer providing administrative support to the DFC became involved after becoming a Dementia Friend but none of the DFCs saw this as a goal..

Dementia specific: A further short-term outcome of dementia-specific and dementia-inclusive activities is reach of/uptake by those PAD that activities are targeting (PLWD, carers, both). There are examples where this has met and even exceeded expectations (e.g. A, B, E), with waiting lists in place for some activities (e.g. site A). At the same time, challenges remain around equitable access both in terms of geography/location (e.g. site A, where a services hub means that access can be difficult for potential users), and for specific groups (e.g. BAME in sites A, E, F).

Medium- and longer term outcomes would be benefits resulting from the implementation of specific initiatives - e.g. use of the Herbert Protocol resulting in PLWD who have gone missing being found quicker than in the past and PAD feeling confident that it is safe for PLWD to go out in their community. While these are conceivable outcomes, relevant evidence from the DFCs was lacking.

Dementia inclusive: A number of further medium-term outcomes from dementia-specific and dementia-inclusive activities have been identified across the research sites: opportunities to socialise (sites A, C); carer respite (site D; as a gap to be addressed in site E); exchange of experiences (site D); social connectedness beyond dementia-specific activities (site A); sense of making a contribution (sites B, D); PAD feeling confident about going out in their community - feeling welcome and supported (site D); learning and rediscovery of skills (site E). Also, improved Quality of Life for PAD was mentioned as a longer-term outcome of a specific initiative (dementia-friendly parking in site D).

8.3.2.4   Resources
Overview

From our analysis across the 6 study sites, it was not possible to draw a full picture of resources mobilised for the DFC initiatives. Where provided, quantitative information was usually presented as

lump sums, e.g. for funding acquired from grants and fund-raising activities, with no details on how the money was allocated. Information for other sources of resources was generally absent from the data sources or presented in general terms, (e.g. one coordinator for a year; a constant flow of volunteers; access to the library on Saturdays; such and such printed the material for us…etc), which made it difficult to estimate an average or even the range of available resources within and across sites. Nevertheless, the information was granular enough to develop a summary table (*Table 8-5*) presenting the relative importance of different types/sources of funding per site.

Table 8-5. Summary table of the relative importance of resources WITHIN case study sites

	Site A	Site B	Site C	Site D	Site E	Site F
Source/Flow/Sufficiency - Sustainability						
✓ Charities	+	++	+	+++	+	++
✓ Public/Statutory funding	+++	++		++	++	
✓ Private sector	+					+++
✓ User charges & contributions	+	+				
✓ Fundraising	++	+++	-		++	
✓ Donations	+		++	+++		
✓ Grants		+	+	++	+	
Salaried staff	**+++**	**++**	**-**	**+**	**++**	**-**
Volunteers	**+++**	**+++**	**+++**	**++**	**++**	**+**
✓ Trained staff	+++	++	-	+	++	
✓ Members of community	++	+++	+++	+++	++	++
✓ PLWD	++	++	+	++	++	-
✓ Support from partner organisations	+	++	+++	+++	++	+++
Built infrastructure / technical support / Sundry						
✓ Information	+	++	+++	+		++
✓ Room/venues/offices	+++	++	+++	++	++	
✓ Printing & equipment	+		++			
✓ Design & tech support						
✓ Transport services	+		++			

Legend: +++ significant resources for regular and varied range of activities; ++ moderate resources for regular but limited range of activities; + minimal resources for some activities; - specific mention that resource is not available.

The patchy nature of the data is in part due to the difficulty, on the basis of the documentary evidence and interview data, to distinguish between resources associated with the DFC per se and those associated with the delivery of usual mode or care/services (e.g. where DFC is driven by statutory services, difficult to distinguish between DFC and mainstream dementia support/services), and the hesitation in some sites to label volunteers or in kind technical support or services (e.g. printing flyers, accessing the library community room) as resources to be monitored and quantified.

Little, if any, reference was made to incentives for participation in DFC activities.

Funding and sustainability were a recurrent theme, covering issues with available project funding as well as time and effort needed to develop grants and fundraising activities. Although presented as "challenges" and "fundraising fatigues in volunteers", these can be interpreted as barriers which can undermine the existence of the DFC, making it difficult to secure the long-term sustainability of these

initiatives. Withdrawal of funding can mean abrupt termination of activities, with undocumented impact on PAD and those involved in the operation of DFCs themselves.

There were substantial differences in the way the configuration of resources available in the case study sites for DFC activities had developed over time. The dominant experience for four of the six sites was one of limited financial resources and short-term funding. In the case of a DFC that was reliant on the council for funding (site A), this caused annual uncertainty.

One of the DFCs (site B) had set up a Community Interest Company in order to be able to engage in fundraising activities rather than waiting for CCG funding that was not forthcoming. One of the DFCs (site C) deliberately did not seek funding maintaining its minimal reliance on external funds. It kept its grant applications and fundraising activities limited to the (small) amounts required to cover the running costs of the local dementia Working Group. The rationale was to avoid the administrative burden financial accounting placed on volunteers.

Site B experienced a major shift in the local funding model. A transition occurred from an approach where local providers had been able to apply for repeated grants from the LA to the availability of limited seed funding for activities that was tied to expectations of sustainability beyond the funding period. At the same time, emphasis was placed on neighbourhood-based provision through a city-wide wellbeing programme that incorporated a focus on dementia. After increasing concerns about its financial situation, site B benefited from a major funding boost. This entailed a substantial amount (£195,000 over three years) to the local DAA from Public Health to allocate to dementia-related priorities (e.g. awareness raising) across the city, as well as dementia-specific funding made accessible to the neighbourhoods across the city for work on dementia friendliness. It was an example of how the work was recognised by the LA. This DFC, unlike smaller less well integrated DFCs had the capacity and infrastructure to use the funds. As this quote demonstrates, the coordinator funding was seen as key in achieving "joined up thinking" about how to improve the experience of PAD and the DFC to achieve cross sector working.

Interviewer: … *if you had to name the greatest challenge for dementia friendly work, what would that be?*

"I'm trying not to think money all the time but … it really is. Because I think if there's that kind of joined up thinking between the statutory authorities because as much as you, there's a lot of third sector, there's a lot of charity and voluntary sector organisations and things, but they do have to exist with support from the statutory authorities and at times they don't, they don't work together you know, so they should do, they really should and they don't, sometimes they pay lip service to wanting to make it change and be saying the right things even though their actions don't really demonstrate that they're following through on it." (DFC coordinator, Site B)

Closely interlinked with developments in the financial situation of the DFCs are the human resources on which they have been able to draw over time. The case study sites have reached different stages in a (not necessarily linear) process where posts dedicated to supporting the DFC have been created, reduced and lost. In site B, for example, recruitment of DFC co-ordinators for individual communities across the city that has been enabled by recent funding is underway. In site D, the FTE of the DFC Co-ordinator post has been reduced, while in sites A and E, regional DFC Co-ordinator posts have been lost. Across the sites, individuals who have supported the DFC as part of professional roles with or without a dementia portfolio have consistently played an important role. Similarly, the role of

volunteers has been crucial in all the DFCs – particularly in site C, which has been exclusively managed by volunteers, and in site B, where individuals have maintained central roles in supporting the DFC after transitioning from professional to voluntary positions.

Outcomes

Resource limitations affected the ability of DFCs to coordinate their work and their ambition and range activities. Where there was funding for posts (D.E) this directly affected communication, delivery and coordination of DFC work, operating at strategic and service level. Volunteers giving time equivalent to a job were effective (B,C) but this however, the example of Site C not seeking additional funding or support due to limited capacity to administer funds illustrates a limitation of not having people in salaried posts.

Funding allocation resulted in short-term outcomes. In site A it enabled continuation of the work of a services hub at the core of the DFC. Elsewhere (e.g. Sites B and E), additional funding has led to further DFC activity. In site E for example, this has included intergenerational work to raise community awareness and connectivity with PAD.

In several of the research sites (A, B, D, F) participants recognised that there was a policy interest in the cost-saving potential of DFCs in enabling PLWD to stay independent for longer and delaying use of social and long term care. While there is some speculation around this, none of them have clear evidence.

With regards to unpaid human resources, potential outcomes that have been identified in site E are benefits such as recognition and feeling included to people living with dementia who contribute to the DFC work as volunteers (example of PLWD volunteer for Fire Service events).

8.3.2.5 *Monitoring and Evaluation*
Overview

To be recognised as a DFC with Alzheimer's Society there need to be action plans in place. All sites had these in place and used them either to monitor individual projects or the DFC as a whole.

Table 8-6 summarises how the sites engaged in monitoring and evaluation activity.

As previously reported, to measure impact the majority focused on how many people had been involved (e.g. Dementia Friends, numbers of participants at DFC activities) and feedback on how the activity had been received. Two sites (B and E) looked for documented evidence of changes in service provision for PAD or improved outcomes for PAD (such as fewer emergency callouts).

All study sites monitored individual projects. For example, in Site A, organisations that are signed up to the DAA are expected to report their progress on their website. In all sites, the most constant reporting is that of Alzheimer's Society, which records numbers of Dementia Friends and Dementia Friends Champions. However, we did not find any reports of how any of these activities are impacting on the lives of people.

Some monitoring work was driven by funding and reporting requirements, with external evaluations of particular activities within the DFCs (often carried out by local universities) in four of the sites (A,B,D,F). These included external evaluations of the reading and exercise programmes (B) and a dementia enablement service (F).

People living with dementia contributed by providing feedback on specific activities and in some sites acting as "mystery shoppers" (only one or two individuals). In one site (D) feedback from PAD was

built into the recognition and monitoring of organisations in the DAA. This was organised to ensure that over 12 months every organisation had been visited and assessed by PAD for dementia friendliness. For other sites it was more ad hoc and was used to assess how well the message about dementia inclusion was known.

"They [the DFC] do a lot of good stuff but I don't see it out there. I, I do these sort of secret shopper things, you know, I go in the Town Hall, what have they got there, go in the hospital, what have they got there and so on, and it's very thin on the ground, sadly. I think it's sad because there's no acknowledgement out there that there's, let's call it a dementia problem, wrong words, there is an increasing diagnosis of dementia in people of my age and sadly even younger, and it's not reflected in the public face, although don't get me wrong, DFC do good work, yeah." (Person living with dementia, Site A).

Table 8-6. Summary table of monitoring and evaluation undertaken by the Phase Three case study sites

Monitoring and evaluation	Site A	Site B	Site C	Site D	Site E	Site F
Monitoring progress against action plan	*Every 6m reviewed at DAA meeting*	*Every 12m Services independently monitored = different service each month* *Quarterly review by DAA*	*Annual report DAA*	*Annual report DPH annual report includes DFC information. Single projects reporting*	*Individual projects reporting* *CCG diagnosis rates targets*	*National targets for staff training on dementia care*
Involvement of PAD	*Mystery shopping of services* *(e.g. NHS)*	*Mystery shopping* *Consultation with different groups e.g. care homes*	*Mystery shopping*	*Feedback on groups & services. "walk-throughs" of organisations checked against 6 point plan*	*Informal feedback*	*Unclear*
Evaluation tools used		*Making every evaluation count* *Instant feedback (thumbs up/down)*	*Survey of dementia awareness* *2 audits on provision* *Informal feedback*	*Consultation findings with 50 PAD reviewed against progress.*	*Case study of dementia cafés*	*Shopping centre survey included people affected by dementia*

How evidence used	Reported to DAA Reported online Feedback to services	Results uploaded DFC database & minutes. Maintaining funded programmes	Progress against action plan for planning & which activities continue	Update to LA Chief Executive. and press Feedback and keeping recognition	People linked to DFC on database Basis for review and discussion	Shared at DAA meeting
Impact	Participant numbers	Participant numbers crises avoided (e.g. missing people)Evidence services modified	Participant numbers Changes in existing provision	Participant numbers	Who has been contacted (e.g. safety awareness project)	Participant numbers Informal monitoring of local changes

Key
m=month

Monitoring systems and frequency of use were variable across the organisations involved in the DFC- e.g. some use a simple, immediate response to an activity done after each event- e.g. thumbs up, thumbs down (e.g. A,B,C), site A referenced using electronic voting systems but we could not find evidence of how this had been used. In site F an evaluation (of changes in the shopping centre of customers, using surveys and focus groups that included PAD) was fed back to the landlord. Health service targets for diagnosis rates, reducing falls, recruiting people into dementia schemes and training of staff in dementia awareness were referenced in two sites (E and F). However, this work whilst noted was not linked to planning work or DFC targets.

Involvement in monitoring had the potential to discourage volunteers from working with the DFC if it was an administrative task unrelated to the core work of the DFC. It was also challenging to collect data that was meaningful. This quote demonstrates the challenges:

> My commitment to outcomes but I feel that we're being pushed back towards outputs … I can set up a dementia café … whoopee I've got 50 people to attend, whereas I can set up something else tomorrow and get six people to attend and know that I've really impacted on their lives because I've targeted the right people but I can't prove anything. It's frustrating for me, it's frustrating for the voluntary sector … because they were used to being monitored on a widget counting basis and now obviously getting people's stories and tracking people's lives and impact is something they weren't set up to do. **They just want to provide stuff and have a positive impact on people's lives. They don't want to spend their time measuring things.** (Local authority commissioner, Site B).

For DFCs where the different activities of the partner organisations were loosely connected it was difficult to keep track of what is happening. The absence of administrative support was a recurring issue. Organisations did not always know how many Dementia Friends were working for them. The LA staff member working with the DFC needed this information but found it difficult to locate.

> *'Individual bits of evaluation happening'…That's one of the things that I'm finding difficult with the group is actually measuring our progress and what's happening….''you know it's quite bitty but there is ways where we are evaluating, it's not probably pulled together in one.* (Commissioning manager, Site F).

Others were more pragmatic, recognising that they could not reach everyone and that their informal networks and knowledge of their area would tell them if something was working or not.

> *'I think you'd know if something was successful'. 'I think we know enough to realise that with those numbers there is a significant chunk of people that we don't reach'*. (Interview participant, Site C).

While all sites engaged in monitoring and engagement activities, several factors limited their ability to demonstrate impact. These were resource limitations and not having the personnel to support the routine and regular collection of data, non-specific targets in their action plans, limited baseline information about the DFC, or difficulties in differentiating between their impact and wider changes arising from national targets and work to support older people in general.

Outcomes

None of the research sites had a comprehensive picture of what their DFC work had achieved and how this had changed over time. Although some DFCs collected information on who participated in events and activities this was not used to understand who was being reached and if the DFC was reaching more or new groups.

Some DFCs had benefited from collaborating with evaluations of individual projects and given the capacity of DFCs this offered a useful independent commentary on their work. It was the incentive for the six sites participation in DEMCOM.

When feedback from PAD was integral to a DFCs work (D) or informed particular services (E, F) this led to identification of future priorities. People affected by dementia have also informed standards for dementia friendliness (D), and shaped dementia-related provision of services and activities (A, B, D, F). Findings from site D had been published in a leading international medical journal as an example of good practice.

There was evidence of projects being adapted to the needs of PLWD as a result of evaluations (sites B, C, D). However, site D was the only site that informed participants of changes that had been made as a result, and it was also the only site that acted - by removing recognition - if an organisation was found to be "dementia-unfriendly". Others did not see monitoring as a punitive exercise:

> *..They're not smacked on the nose for not having done if. In terms of monitoring, that's not fantastically formal.* (Interview participant, Site B).

In site D, the idea of using the findings from monitoring and evaluation of services to create local league tables in an attempt to create 'competition' and encourage service providers to work towards greater dementia friendliness was mentioned.

8.3.3 Cross cutting domains

The findings from Phase Two – the pilot sites and the stakeholder workshop - identified three areas that should apply to all aspects of a DFC's work: Involvement of people affected by dementia, equalities and inclusion, and evolution and sustainability of the DFC. The following summarises the evidence on these as they relate to the five standalone domains reported on above.

8.3.3.1 *Involvement of People Affected by Dementia*
Overview

For most sites the involvement of PAD was evident but underdeveloped. Almost all the sites relied on PAD to be motivated to contribute opinions and engage. There was a continuum of involvement that ranged from trying to engage with the whole community at all stages of the dementia trajectory to working with those who self-identified as interested and able to attend meetings. The following considers how PAD were involved in the different aspects of the DFC.

If the basis of the DFC and its leadership favoured bringing people into activities and services organised by the DFC, engagement was often with the consumers and users of services.
In terms of numbers of PLWD involved, the 'groups who organised' and led the DFCs appeared to involve a small number of PAD (rather than a broad range of people). Two of the sites had PAD on their Working Group. In one case study site a commissioner (Field Notes CSF) was angry that representation often relies on one person. This person living with dementia reflected;

> *"That's all you're doing, you're just there to tick a box and that's it. Nobody takes people on board to see what they're going to do and see whether they can have an impact on what is available or what isn't available. They just want to tick boxes very often, I think. That's all the councils do, that's all they're there to do.* (Focus group participant, PLWD, Site F).

 Although PAD recognised that they were often invited to meetings to demonstrate the involvement of PAD there were positive accounts of how they worked together, being seen as colleagues and equal to other members of the DFC.

> *They're a group of people who are actually living with dementia, but who are actively involved in shaping agendas and participating. You would have no idea, actually - they're like colleagues - until you were told. So we did was on all of our site audits we included them so that they came around with us and told us. Obviously, we can't change everything, we've got listed buildings*. (Commissioner, Site F).

> *Everything we do at all is driven by the people who come to the group, so if they say actually this isn't what we want to do, we'd rather do this, then that's what the funding goes towards....we do follow through if people say yes, I'd like to do that*. (Volunteer, Site A).

In four sites there was consultation with people affected by dementia to inform their strategy however, this did not start with PAD. It relied on people providing feedback on existing plans. When we were told PAD had been involved from the outset we struggled to find evidence of how they had influenced the priorities and basis of the DFC. Though in some sites there was reference to using evidence on what it was like to live with dementia.

"we are currently drawing up a three-year plan which we have recently asked stakeholders, including patients and carers to feedback on". (Doc Evidence, Site E).

"…not as much as I would like, no [involvement]… what we do is take advice from the experts and then implement those changes based on they tell us" (Interview participant, Site F).

Site C identified the involvement of people affected by dementia as an early activity to provide practical feedback to new members and organisations in the DFC.

"So if an organisation like, say, the leisure centre joined, then this couple will go and do an audit, and go in and do an environmental audit to make sure that the signposting is clear, that they can navigate their way around the building, and make suggestions as to what signposting needs changing. So we try to keep them as involved as we can". (Interview participant, Site C).

It was difficult however, to know if those contacted were typical, reflected all stages of dementia or if needs were being missed. Repeating consultations and getting feedback as an iterative process was one way of capturing changes over time and new needs.

"I think with dementia being as it is on the journey, just revisiting that customer journey along the way as well, because that customer journey will change as the dementia progresses. So it's important to keep going back and keep asking. It's absolutely no good asking once or twice. You've got to keep going back and asking" (Volunteer, Site D).

For activities and environment and related monitoring and evaluation work PAD could set the standards for dementia friendliness and shaped dementia-related provision (sites A, B, D, F). This had the potential to become an important resource of what good practice and poor practice looked like from the perspective of PAD. Adapting the environment improved people's ability to retain independence. Feedback on specific issues such as seating, in shops and slow checkouts in supermarkets and public spaces were often acted on across the sites. However, this was not done systematically. In site D, planned activities or adjustments to environments (e.g. car parks, signage, cinemas, and cafés) were a direct response to an issue raised by PAD and taken up by the DFC coordinator. It also ensured that organisations received feedback.

The DEMCOM stakeholder event had highlighted the importance of places to go that were "safe". Proximity to home as a way of maintaining independence was also important and there were examples in the sites of where services such as dementia cafés had closed because they were not on a public transport route.

"is it was only round the corner from xxx, where we live, so we could actually walk there ourselves and it again gives both of you that feeling of independence, because when you've got dementia or when you're living with dementia, it is the loss of independence and the loss of, well, what you can actually do that becomes the frustrating part, doesn't it? And displays in not such nice behaviour and such things. Not by me, I hasten to add. Well, not often" (Person living with dementia, Site F).

Site C provided evidence of two initiatives that were appreciated and received consistent positive feedback: special services in churches and dementia cafés. These were valued, but these quotes hint at something more being wanted. Their needs could be accommodated if there is integration or bridging with mainstream provision within the community (e.g. quiet spaces or places to walk in the building, accessible menus, pre-ordered food and drink).

> *…..he gets spiritual comfort from that as well, going to church and reminding yourself without having it (dementia diagnosis) pushed on you**"** (Carer, Site C)*
>
> *he likes to come to the café, but unfortunately, he doesn't like to be reminded in his everyday life that he has dementia"* (Carer, Site C)

There were challenges in how to sustain input and engagement. During our research project people affected by dementia became unwell, died, could no longer attend meetings, and without support struggled to follow the meetings' progress and be actively involved in decision making.

> *"he used to come along [events committee] but he's not as good as he used to be and so he can't cope with that"* (Interview participant, Site C)

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In cases where there was a group of PLWD who were supported to participate in the DFC (B and D), the group provided continuity of input, peer to peer support and discussion of issues. If this was complemented by more opportunistic consultations, chances for feedback following events and proactive work to consult with PAD, this appeared more likely to result in leadership that was informed and accountable for its decision making. This type of input required funding to support involvement and it was unclear if or how PAD were remunerated for their time and input.

8.3.3.2 *Evolution and sustainability*
Overview

None of the DFCs studied had a linear development nor was length of time in operation a predictor of growth and development. The narratives were ones of surges (with the appointment of key people, local policy changes and or funding), fallow periods when people left or organisations became less active (e.g. the LA) and patchy growth as successful initiatives (e.g. neighbourhood focused support) were built on and others stopped. The evidence suggests that maturity of development relies on which individuals from the DAA are actively collaborating, how these relationships are negotiated over time, availability of resources and if the focus changes from dementia specific to mainstream. Finally, how information is managed and used by the DFC as it engages with more people and organisations to create a common understanding of what PAD need from local services and people.

Stable strategic leadership working closely with the LA supported continuity of effort and patterns of relational working in two of the case study DFCs (C, D). The other sites (A, B, E, F) had periods of stability interspersed with disruption, for example the loss of a DFC Co-ordinator due to loss of funding (site E), the loss of a volunteer in a leading role (site B), a withdrawal by a key volunteer (site A), a change in the local lead and the replacement having limited time to work on the DFC (site F). This led to uncertainty about the future (site E), and a slowing of local authority led DFC work (site F).

Where the membership and methods of working did not change and were centrally organised, and co-ordinated (Sites A, B, C, D) for an individual or organisation to join they either needed to know someone on the group or be approached by the DFC. This created a familiar and trusted working relationships (especially Sites B, C). There was however a risk of creating "cliques" discouraging new thinking or approaches. In contrast more loosely affiliated DFCs (Sites E and F) created opportunities for "entrepreneur led activities" that were responsive to smaller communities. Over time however, these sites were more susceptible to losing momentum and being unaware of what the DFC as a whole was doing.

Awareness raising activities are often a starting point for DFCs, and across the case study sites and can remain important as a DFC matures.

Most of the DFCs valued a focus on dementia-specific provision as a visible marker of what the DFC was doing. However, some were more strategic than others in using this provision to lead to integration with existing services. Sites B and D used these activities as a way of increasing access and normalising how people living with dementia were included. This quote provides an example of how a dementia café paved the way for greater involvement of the theatre in supporting people affected by dementia as well as additional dementia specific activities.

> *The XX Theatre and we set up some tea dances in 2015 that became very popular, so monthly we would get in excess of 70 people every month coming, and they are still going and what happened was always my idea was it would be nice to leave this and leave it with the organisation to carry it on. And so that's what we did with the theatre and they took it on board as part of their community engagement policy and they also do... a couple of dementia friendly performances a year.* (Volunteer, Site B).

Throughout the time of our data collection there were discussions in media and professional resources and Alzheimer's Society about whether "dementia friendly" was a helpful or patronising phrase and how DAAs and DFCs should and could work together. Establishing if thinking or priorities for action had changed or if there was a shift in emphasis and approach over time was difficult to establish across the sites. There was evidence of increasing numbers of people and activities in some sites (Sites A,C,D,E) and some DFCs focusing on particular organisations to improve services and awareness (D,F). One possible example of a change in approach by site B could be seen as a shift from an early commitment to age friendly provision and dementia specific service provision to investment in activities to support inclusion across the community.

Site B was also successful in attracting funding that was not necessarily for PAD (e.g. Sport England funds to increase access) alongside dementia specific funding. Similarly, a LA shift to neighbourhood-based commissioning meant greater opportunities for dementia specific provision that was dispersed across the city. This can be contrasted with the continuing provision of services in a central location in site A or responsive approaches based on interest and opportunity (site D,F) and the limited accessibility this brings with it.

The lack of coordination of activities and integration with other local services that PAD could use was noted in several sites. Only two sites actively worked with NHS partners, one of which was able to use the memory clinic to promote their work with people post diagnosis (A).

Monitoring whether people living with dementia used local services was only addressed by one site (F) when it surveyed shoppers and included questions on the needs of PAD. One DFC (B) linked with what was already available (e.g. healthy ageing initiatives) to expand access for people living with dementia to activities and services. Knowing if this inclusive approach was successful was more difficult. As this quote notes there were within site challenges to capturing what was happening.

> *What we do need is a better management information system. We struggle because obviously when you're working predominantly with the voluntary sector, some of those organisations have got no management information systems. They work with bits of paper … boxes of surveys locked in a cupboard. Right to the other extreme where we've got anchor organisations who I would say their management information system is better than the local authority's. So, when you're working with such a diverse range of experience, knowledge and resource, it's quite hard to get a city-wide picture. … [difficulties around sharing of GP patient data with community support workers]. So, we do lots of monitoring. We do wellbeing questionnaires … interviews, volunteers that the university have trained to go and have conversations with people. All different …of collecting impact, case studies, you name it but it's no coordinated and it doesn't give us a city-wide picture and it's something that we've raised as an issue.* (Local authority commissioner, Site B).

The need for an infrastructure that could sustain the work, coordinate and share the information about the DFC work was a key factor in enabling the DFC to develop and learn together.

8.3.3.3 *Equalities and Inclusion*
Overview

The extent to which the DFCs were able to demonstrate the inclusion of all groups was limited (e.g. by age, income, where people were on the dementia trajectory and ethnic background). Those that could demonstrate some diversity and inclusion had built on existing alliances with local groups, had been operational for over four years and their DAA reflected the local population.
The involvement of people who were not white and female and born in the UK was under represented in the DFCs. As one volunteer commented this was not specific to the DFC and reflected how services were accessed and provided more generally.

Equalities and Inclusion	Site A	Site B	Site C	Site D	Site E	Site F
Diverse DAA membership reflecting local community	+	++		+		
Working with existing partnerships	+	++		++	++	+
Targeting underrepresented groups	+	+		++	++	+

+ Some evidence of working with marginalised groups
++ Multiple sources of evidence of working with different marginalised groups

There was evidence of working through local partnerships (Site B), through Health and Wellbeing, community development teams and to reach men via football clubs (Site D), neighbourhood partnerships, resident-led initiatives, invitations via social media (Site E), AGE UK and Alzheimer's Society (Site F).

Equality and inclusion are a core component of DFCs' development and action plans. However, although BAME communities, for example, were represented at DAA meetings (Site A), this did not necessarily translate into awareness raising sessions or similar interventions being developed with

BAME communities. Cultural diversity, language barriers and varying cultural perceptions of mental health were given as reasons for not accessing communities.

Dementia related activities and awareness raising could be encompassed within a wider disability and health agenda (an overarching agenda for community development and inclusion (SiteA, E)), or as part of adult social care services (F). Site A had links with a dedicated support worker whose remit is to engage with ethnic communities. A volunteer from Site E commented on the fine line between *'including' but not 'targeting'* people from a range of ethnic backgrounds. In Site F one participant resisted the focus on services and commented that there was "...*too much local authority and health and not enough reality…*", suggesting that the DFC should actively seek out what PAD, from across the community, want and need to live their day to day lives.

Two sites were actively engaged with cultural groups to promote dementia awareness. Site B was working with a Pakistan Association "...*to establish a drop-in-centre to talk about dementia with health professionals who work in these communities*". Activities in Site D have included Dementia Friends sessions carried out in Mandarin and Cantonese, offering support to groups in a Chinese luncheon club, and a consultation at a football ground that was attended by more than 60 representatives from different backgrounds. They also gave examples of linking with asylum seekers and the Islamic community and ran a cultural awareness program called 'everyone matters', and a 'talking about dementia in BAME communities' project. In site E there were links with LGBT groups.

There was evidence that some initiatives actively discouraged inclusion, for example in site A the Dementia hub was underused by people from some of the BAME groups, because individuals were apprehensive about being seen by someone from their community where high levels of stigma appear to prevail. As one key interviewee remarked,

> "...p*eople from BAME communities won't engage with it… so instead of concentrating resources [in one place] we should try to focus [our efforts] in communities to avoid inequality*" (Interview participant, Site A).

DAAs also recognised that short-term funding is not the answer (Site B) and that longer-term planning is required. Site C has currently no BAME specific resource allocation due to small numbers of ethnic minorities in the county.

The provision of specific group Site E stated that "….*there is no specific resource allocation for dementia within ethnic communities…but then, not every minority group can have their own targeted workshops around their needs and fulfil their cultural difficulties…it does need to be more integrated"* (Site E). It is understood that it takes a long time to establish trust, and procedures, and "…*in terms of building relationships it helps if you are the same background and have the same faith…that really helps. We need to start with community development…and this takes an awfully long time*…." (Site E). Another study site received funding from a Cultural and Heritage Fund and uses 'community learning funding', "…*which is under the general umbrella of disadvantaged groups in the city*" (Site F). This highlights the need for creativity when looking to use budgets that would allow messages pertaining to health, mental health, and dementia to be conveyed outside of dementia specific settings.

Whilst there is funding earmarked for dementia related activities, funds have not been dedicated for use specifically in BAME communities. This reflects the broad approaches taken to resourcing dementia activities for all people affected by dementia, irrespective of which community they might belong to.

Overall, it appears that whilst DFCs made efforts to include those who are known to have limited engagement with services (e.g. men, BAME groups, PAD who have limited mobility), they were constrained by what they could achieve to support inclusion. Engagement and participation were low.

8.4 Survey findings

The survey of people living with dementia was completed towards the end of phase three data collection. It involved PLWD in the six sites who were not linked with the DFC. The survey explored the extent to which respondents were aware they were living in a DFC and what activities they took part in and their perceptions of impact.

Recruitment methods across sites and how many questionnaires were distributed were negotiated on the basis of the site's capacity to contact people (see Table 8-7 for survey recruitment methods and response rates). The survey recruitment process demonstrated the challenges echoing the experiences of locating and confirming DFCs in phase one of finding people living with dementia who were not self-selecting and the value of DFCs linking with services already working with PLWD such as NHS services.

Table 8-7. Survey recruitment methods and response rates.

Site	Access	Method of recruitment	Questionnaires disseminated	*n* received	Response rate (%)
A	Local NHS R&D team	Research database and memory clinic	189	76	40.2
B	Alzheimer's Society	Dementia cafés and groups	75	22	29.3
C	Dementia specialist nurse	Home visits and dementia cafés	24	9	37.5
D	Local NHS R&D team	Join Dementia Research (JDR)/Memory Clinic groups/dementia event	91	78	85.7
E	Local NHS R&D team	Dementia Cafés/Memory Clinic mail out	62	36	58
F	Local NHS R&D team collaborating with GP surgeries	Interested in research database/ 3x GP surgeries across site	124	23	18.5
TOTAL			565	244	43

A total of 244 questionnaires were returned, four were excluded due to missing or incomplete data (n=3) or not being filled out on behalf of somebody with dementia (n=1). Data were analysed from 240 participants which included 106 males (44.2%) and 126 females (52.5%). Most respondents were aged between 75 and 84 years (n=104, 43.3%) and identified as being in the 'early' stages of dementia (n=127, 52.9%). See Table 8-8 for sample characteristics.

Table 8-8. Description of sample (N=240).

		N (%)			N (%)
Location	A	73 (30.4)	**Race/Ethnicity**	White British/White Other	191 (79.6)
	B	22 (9.2)		Black, Asian and Minority Ethnic	10 (4.2)
	C	9 (3.8)		Not reported	39 (16.3)
	D	78 (32.5)	**Stage of**	Early	127 (52.9)
	E	35 (14.6)	**dementia**	Middle	72 (30.0)
	F	23 (9.6)		Advanced	24 (10.0)
Gender	Male	106 (44.2)		Not reported	17 (7.1)
	Female	126 (52.5)	**Residential**	Lives alone	59 (24.6)
	Not reported	8 (3.3)	**status**	Lives with another person	174 (72.5)
Age	<65	18 (7.5)		Not reported	7 (2.9)
	65-74	58 (24.2)	**Completed**	Yes	51 (21.3)
	75-84	104 (43.3)	**questionnaire**	No	181 (75.4)
	85+	51 (21.3)	**unaided**	Not reported	8 (3.3)
	Not reported	9 (3.8)			

We were interested to know if PLWD knew about their DFC, how they expressed their needs and if those who knew there was a DFC were more likely to express positive views about the experience of living with dementia in their local community. *Table 8-9* presents activities and perceptions of the survey responders grouped by the participant's awareness of their local DFC initiative.

Across the six sites there was almost an equal split between those who knew about the DFC and those who did not, 124 (52%) of participants were unaware that their community was working towards being dementia friendly. Awareness of the DFC presence was positively associated with activities that DFC's offered that were dementia specific. These included attendances at community centres, dementia activities e.g. Singing for the Brain® and dementia cafés and groups set up for PAD. Knowing there was a DFC was also positively associated with PLWD saying that they felt they were understood and valued for their contribution.

Table 8-9. Activities and perceptions of survey responders by awareness of DFCs (N=240).

			Participant awareness of local DFC initiative		Total column (*p* value)
			aware n(%)	unaware n(%)	
Activity**	Go to work	Yes	3 (42.9)	4 (57.1)	
		No	110 (47.8)	120 (52.2)	>0.55
	Meet with friends/family	Yes	83 (48.5)	88 (51.5)	
		No	30 (45.5)	36 (54.5)	0.67
	Leisure activities	Yes	40 (58.0)	29 (42.0)	
		No	73 (43.5)	95 (56.5)	0.042*
	Go out to pubs/cafés	Yes	67 (49.3)	69 (50.7)	
		No	46 (45.5)	55 (54.5)	0.57
	Shopping and errands	Yes	77 (50.3)	76 (49.7)	
		No	36 (42.9)	48 (57.1)	0.27
	Go to community centre	Yes	31 (64.6)	17 (35.4)	
		No	82 (43.4)	107 (56.6)	0.009*
	Use public transport	Yes	46 (50.0)	46 (50.0)	
		No	67 (46.2)	78 (53.8)	0.57
	Go for a walk	Yes	59 (48.4)	63 (51.6)	
		No	54 (47.0)	61 (53.0)	0.83
	Religious activities	Yes	24 (58.5)	17 (41.5)	
		No	89 (45.4)	107 (54.6)	0.13
	Other	Yes	38 (49.4)	39 (50.6)	
		No	75 (46.9)	85 (53.1)	0.72
Which dementia groups are you part of in your local DFC?**	None	Yes	41 (35.0)	76 (65.0)	
		No	68 (61.3)	43 (38.7)	<0.001*
	Dementia specific activities	Yes	47 (72.3)	18 (27.7)	
		No	62 (38.3)	100 (61.7)	<0.001*
		Yes	19 (63.3)	11 (36.7)	

Dementia support group	No	90 (45.7)	107 (54.3)	0.07
Dementia Action Alliance	Yes	1 (50.0)	1 (50.0)	
	No	108 (47.8)	118 (52.2)	>0.99
Service user group	Yes	13 (81.3)	3 (18.8)	
	No	96 (45.3)	116 (54.7)	0.008*
Research group	Yes	14 (70.0)	6 (30.0)	
	No	95 (45.7)	113 (54.3)	0.038*
Other	Yes	26 (56.5)	20 (43.5)	
	No	83 (45.6)	99 (54.4)	0.19
Stopped doing anything because of dementia	Yes	67 (45.6)	80 (54.4)	
	No/don't know	44 (52.4)	40 (47.6)	0.32
Safe in their community	Yes	50 (53.8)	43 (46.2)	
	No/don't know	60 (43.2)	79 (56.8)	0.11
I feel well understood	Yes	31 (64.6)	17 (35.4)	
	No/don't know	77 (43.0)	102 (57.0)	0.008*
Valued for their contributions	Yes	32 (66.7)	16 (33.3)	
	No/don't know	75 (41.9)	104 (58.1)	0.002*

DFC= Dementia Friendly Community, * p < 0.05, **Participants could pick more than one option for this question, [a] 4 missing values for this question.

In addition to suggested activities that could be ticked on the questionnaire, participants were asked if there were any other activities they did. Seventeen additional activities were reported (of which 15 required the PLWD to leave their home to do). Individuals reported being involved in: singing; hobbies; bingo and a film club. Fewer were involved in sports (cycling, walking, watching football) and only one relied on the involvement of others (dancing) or going out to local shops, and eateries. Two people took the opportunity to record that they did nothing, and others referenced nonspecific activities such as spending time with family.

One hundred and forty-eight (61%) of participants said that they had stopped doing something because of dementia. The most common activity stopped was driving (32%). Thirty-one participants (21%) said they no longer went out alone. The full list of activities revealed by the participants can be seen in *Table 8-10*.

Table 8-10. Summary of free text responses added to question: What sort of things have you stopped doing because of dementia?

Category	Activity	Total
Travel	Driving (47)Public Transport (4)Taxi (1)	**52**
Independence	Going out alone (31)Loss of independence (3)Going out less often (13)Banking and Finance (6) Work (16)Volunteering (1)Making choices/decisions (4)Using technology (2)Personal care (1)	**76**

Sport and exercise	Walking (15)Sport (10)Dancing (1)	**26**
Hobbies and Interests	Knitting/sewing (9)Gardening (5)	**27**
	Singing (2)Art (3)Family history research (1)Bingo (1)Crossword/ jigsaw (1)Concerts/theatre (2)Piano (1)Faith based activities(2)	
Activities inside the house	Maintenance/DIY/cleaning (9)	**25**
	Cooking (15)	
	Watching TV (1)	
Local amenities	Shopping (14)Library (1)Cafés (2)Pubs (2)Restaurants (1)	**20**
Socialising	Communication/conversation (2)All types of socialising (14) Going to noisy places (1)Local clubs (5)	**22**
Holidays and day trips	Holidays (9)Day trips (3)	**12**
Everything		**9**
Physical and Cognitive abilities	Mathematical abilities (1)Writing (1)	**17**
	Reading /Navigation (2) Personality change (1)Recognising family members (2)Mobility (8)	

Note. Participants could list more than one activity they had given up.

The need for more accessible and reliable transport was highlighted as an issue and these comments appeared to be linked to the impact of giving up driving.

Questions about what would help them live well in their local community had four response options. These reflected the National Dementia Declaration, seven expectations or statements of what life should be like for people with dementia [89]. They focused on public understanding of what it is like to live with dementia; extra support in public places; larger choice of activities available or better public transport. They were also given an 'other' option. To understand what was a priority for the PLWD participants were asked to tick one option only. Participants that ticked more than one option were excluded (n=32). Figure 8-19 presents data from 208 participants that completed this question. Some participants left this question blank (n=41, 20%). Over a third of participants described that more public understanding of what it is like to live with dementia would help them to live well in their community (77/208 participants, 37%).
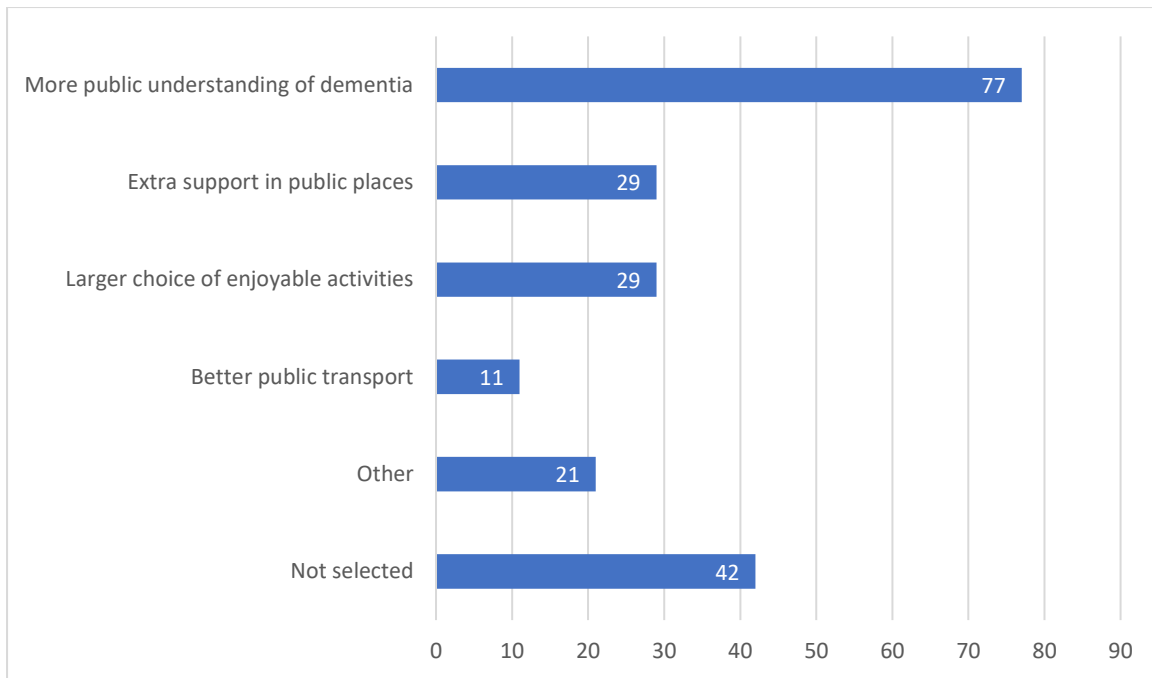
Figure 8-19. A bar chart to represent participant's answers to question 5: what would most help you to live well in your local community?

When results were split by awareness of DFC, more public understanding of dementia was sought by those who knew they were in a DFC (n=44, 44.4%) than those who were unaware of living in a DFC (n=32, 29.9%). This finding was significant (p 0.030) and could perhaps indicate higher expectations of what can and should be achieved.

Twenty per cent of participants (n=42) ticked 'other' and offered their own answer. Box 8-1 below provides the additional suggestions from people living with dementia on ways to make life better for them in their local DFC. Many of them were alternative expressions of the need to be free from stigma, to maintain their independence and still feel they had a purpose and could make a contribution. The need for additional support for friends and family was also highlighted. Answers are grouped into categories with the main theme highlighted in grey.

Box 8-1. Additional suggestions by people living with dementia on ways to make life better in their local DFC.

Q5. What would help you to live well in your local community? Free text suggestions
Addressing stigma
• Public diagnosis
• More understanding and patience by public reflected in radio and TV
Making a contribution
• To teach and lecture
Independence
• Shortly moving into care home
• Disabled blue badge
• Freedom by way of having my driving licence back

- To keep active as long as possible, continue all usual activities

Not wanting anything done

- None
- Nothing don't go into [local community]
- I don't want anyone to know I have dementia!
- All of above but not for me

Access to support and reduction of isolation

- Friends
- Coordinated services one stop shop where everything sorted
- Availability of self-help health facilities
- Longer time with carers
- Day centre geared to patients with dementia

Even with the limitations of how the sample was recruited and the very small numbers for some sites (e.g. C) findings from the survey demonstrated that the DFCs were known to some but not all PLWD The visibility and participation in dementia specific activities influenced that recognition. The free text responses expressed views and experiences that are well documented and are the focus for DFCs: promoting community engagement; the rights of PAD to live well and actively refuting negative stereotypes.

8.5 Implications for the evaluation tool

Data collection during Phase Three was informed by the evolving evaluation tool (see Chapter 7) which continued to be developed on the basis of the emerging findings from the case studies.

The evaluation tool was strong on capturing processes and structures, yet a gap remained with regards to outcomes. This had been observed by the researchers as they had been developing their interview and focus group schedules on the basis of the existing evaluation tool, and it had also been raised by commentators on the original AFC evaluation tool and at the stakeholder event. Many of the suggested outcomes identified at the stakeholder event had not been considered by the DFCs (e.g. quantifiable changes in how different services adjust to meet the needs of PLWD, such as GP appointment times, accessible shopping and access to legal and welfare services) or were not measurable.

It was also recognised that a DFC's work could have different kinds of outcomes in relation to the different thematic domains – short-term outcomes (e.g. greater number of Dementia Friends resulting from awareness raising activity in a DFC); intermediate outcomes (greater awareness of dementia in a DFC); and longer-term outcomes (e.g. better quality of life for PAD). See chapter 9 for development of a logic model of what needs to be in place for a DFC with different contexts/ resources to achieve different outcomes.

In order to ensure a systematic way of capturing outcomes, they were considered explicitly under each of the five thematic domains.

At a data analysis workshop after the fieldwork had been completed, consensus emerged that the domain 'Collaboration' was redundant. Relevant evidence tended to be double-coded in the data analysis software, most commonly under 'Leadership and governance' and 'Activities and

environments'. Accordingly, this domain was removed. These changes have resulted in the final iteration of the DEMCOM evaluation tool (Figure 8-20, for definitions see Appendix XI).

Thematic domains	Cross-cutting domains		
Leadership & governance	Involvement of people affected by dementia	Equalities & inclusion	Evolution
Basis of DFCs			
Resources			
Activities & environments			
Monitoring & evaluation			

Figure 8-20. Final DEMCOM evidence-based evaluation tool for DFCs.

Appendix XII provides an example of the possible sources of evidence and questions that can be used to evaluate the level of maturity and impact of a DFC. This is based on the findings of the three phases and reflects the different stages of development observed in the six study sites.

The following illustrates how the evaluation tool domains are linked (Figure 8-21).
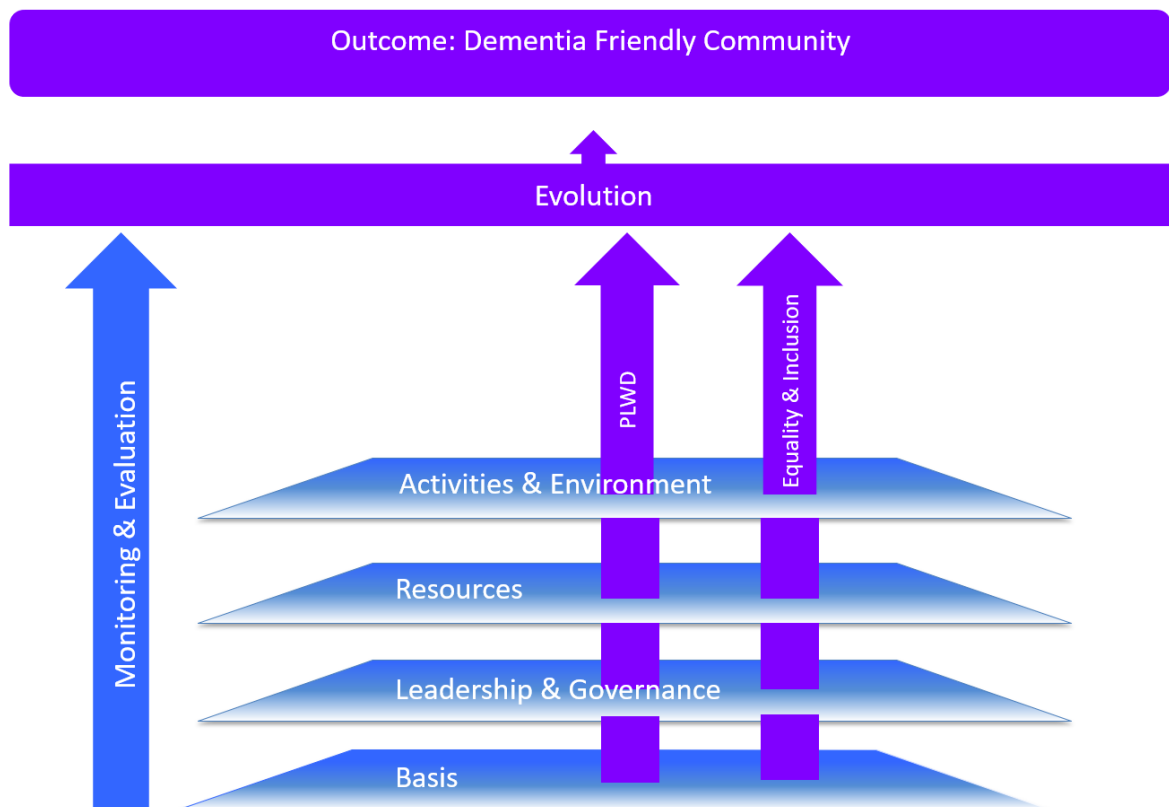
Figure 8-21. Illustration of DEMCOM evaluation tool

The next chapter and supporting appendices theorises what needs to be in place for DFCs to be effective and the kind of evidence that would demonstrate their maturity and impact.

9 Theory of change for dementia friendly communities

9.1 Overview

This chapter brings together the evidence from the three study phases to develop a theory of change, expressed as a logic model. This is then used to identify the kind of evidence that would indicate the capacity and maturity of a DFC to have impact against each evaluation tool domain. Finally, it provides a worked example of how the social value and social return of investment (SRoI) of a DFCs might be assessed. This addresses the study questions:

What factors and preconditions for these initiatives produce positive outcomes for people living with dementia and their carers/supporters?

What generalisable lessons can be drawn about the resources needed and economic benefits of creating and sustaining Dementia Friendly Communities?

All the DFCs' work is context driven. The theory of change, also referred to as a logic model in its visual form, takes this into account to provide a description and illustration of what, how and why a desired change is expected to happen. For a DFC it describes how it might be structured and function, the outcomes and benefits for PAD and the local community. It captures the enablers of community engagement and awareness, aspects of integrated working across organisations and individual, key components, outcomes and long-term benefits for PAD and the wider community (see Logic Model in section 9.3).

To theorise how certain contexts and activities can lead to certain outcomes, a series of six "if then" statements (section 9.2) set out what needs to be in place to achieve different outcomes. Building on this and drawing on the evidence, key activities by evaluation tool domains are then described (Section 9.4). This offers a worked example of the data that DFCs need to demonstrate benefit to individuals and the community and directly informed the logic model that provides a framework for DFCs to plan, review their work, make realistic plans and collect data that captures a DFC's process and desired impact. It also informs future thinking and refinement of the evaluation tool.

9.2 "If then" statements

The following six "if then" statements bring together the evidence from the three phases of the work to articulate how the observed components of the DFCs lead to certain outputs and outcomes. The statements draw on the evidence from the different domains of the evaluation tool.

1. **If** there is a history of local organisations <u>working together</u> to promote social inclusion for PAD, with designated people and council/collaborator support to achieve this, **then** this creates a secure basis for planning, discussion and dissemination that normalises thinking about how to include PLWD as part of wider community work.

Explanation: How long the sites had been in existence was not an automatic predictor of what had been achieved. For example, one site had been established as recently as 2016. What *was* important was: who the DFC was aligned with, and how the people working on behalf of the DFC were recognised by the collaborators and if DFC work "fitted" with local strategies and history of collaboration. The people working for the DFC (volunteer and salaried) were recognised by the collaboration as the

leaders. There was a need for a person(s) to represent or "embody" the DFC for all those involved and have the resources to communicate and disseminate what the DFC was doing and achieving.. Where there were volunteers or employees working to achieve collaborations across groups with no prior history of working together, reliant on an individuals' energy and personal networks or working on behalf of one organisation), this was vulnerable to stop/start initiatives, limited communication between collaborators, and initiatives that did not link up across the community.

2. If DFC collaborators understand their role as challenging systems and <u>services</u> in the community that exclude people living with dementia, **then** this leads to activities focusing on raising awareness of the needs of people living with dementia that influence the responses of targeted services and amenities

and

3. If DFC collaborators provide <u>services</u> for people affected by dementia that are linked to existing public amenities, **then** people living with dementia gain new networks of support and friendship and can be confident that their needs are understood.

Explanation: Statements 2 and 3 are linked and focus on the basis for DFC services and activities. The basis for the DFCs in our 6 study sites was implicit rather than explicit. Awareness raising through training of Dementia Champions and Dementia Friends was an important foundational activity in all sites. Depending on where and how it was implemented however, it had the potential to be the basis for changing local provision and services. All the sites had a mix of initiatives that were dementia inclusive (awareness raising, working to make public spaces accessible and usable), and dementia specific (cafés, support groups and sessions for PAD at sports and cultural activities). Where the expectation was that awareness raising initiatives would lead to changes within an organisation or service this could sustain dementia inclusive activities that were not reliant on single volunteers or salaried people. In contrast, where initiatives relied on DFC's members with the time and resources to be the organiser and driver of these services, the initiatives became an end in themselves.

4. If the <u>resources</u> of the DFC are used to deliver targeted community engagement and awareness raising activities (e.g. with businesses and planning local amenities and services) to enable people living with dementia to participate in their community **then** the needs of people living with and affected by dementia are anticipated across the community, episodes of stigma are challenged, and people affected by dementia feel included and valued by their community.

Explanation: Resources available to the DFCs were volunteers, salaried staff, use of local facilities and services in kind, donations and funds for schemes and events, and commissioned services. Where it was possible to give time and effort to supporting and linking the activities of the DFC this helped to raise awareness, maintain interest, attract new collaborators, share best practice and incrementally increase the reach of the DFC. When resources were limited, sites relied on individual organisations/groups working autonomously or mainly focused on service provision. This achieved increased awareness but did not create a shared understanding of what was being done (and why) across the community.

5. If people living with dementia are <u>supported</u> to be active partners, influence decision making, provide feedback on their experiences and are recognised as central to the DFC work, **then** organisations and services learn to consider routinely the needs of people living with and affected by dementia and set priorities and activities that reflect that.

Explanation: There are some straightforward questions that should be asked about how people affected by dementia are identified, recruited and supported to be involved over time. The contribution of people with mild to moderate dementia was evident in most of the sites.

How the involvement of carers and former carers is evaluated needs to consider who they represent and how current their experience is.

Where there was a commitment to service provision, this provided an arguably narrower focus on PAD as consumers. If there was a preoccupation with addressing the rights of people to participate in all aspects of the community, this was more likely to lead to proactive engagement with PAD as experts and core to the work.

The study found examples of where people affected by dementia were consulted where they lived and were not required to attend DFC meetings. This has potential for widening participation and inclusion, but also required additional resources and or people for whom this was part of their job or role. Similarly, the survey demonstrated that it was possible to canvass the opinions of people in the community living with dementia.

6. If there is a link to statutory services (NHS and Local Authority) with access to routine data on people living with dementia in the community, **then** this enables the DFC to reach people living with dementia at different points of the disease trajectory, and to <u>review</u> its work against population need.

Explanation: All our sites knew how many people were living with dementia in their community. This was an underused resource to inform systematically what they did and where. Two sites had recurring collaborative links with staff from memory clinics and post diagnostic community-based support services, and two had representatives from the NHS at their meeting. Where the NHS was aware of the DFC, this increased the likelihood of PAD being introduced to dementia specific services and schemes to support inclusion. Our survey demonstrated how difficult it is to find PLWD in the community, to involve them and to find out what is important to them. For example, the survey demonstrated that transport was a recurring issue for most participants. However, addressing this did not appear to feature in how activities were organised or even where they were located.

The six "If then" statements can be loosely summarised: working together, service focus, resources, supported involvement and review and can be used in conjunction with the next sections on the logic model and the DFC evaluation tool.

9.3 Logic model

Inputs

Basis of DFC
- Scientific evidence
- DFC guidance & frameworks
} Macro level

- Population data, needs & assets assessment
- Alignement with existing priorities, strategies, policies, funding
- History of collaboration & community engagement
- Individual personalities/ champions
- Motivations (collective & personal) - pragmatic, economic, compassionate, social justice
} Micro/ local level

Leadership & governance
- DFC leadership
- Multi-agency governance structure (DAA or comparable)
- Political support

Activities & environments
- Awareness raising
- Dementia specific
- Dementia inclusive
- Environmental improvements
- Dementia risk reduction
- Focus on specific groups
- Focus on all stages of dementia trajectory

Resources

Short-term Outcomes

Official DFC commitment/ recognition

- Awareness of DFC initiative
- Buy-in into DFC initiative
- Identification of DFC priorities
- Dementia strategies, policies, implementation plans
- Dementia standards & guidance
- Further resource commitments
- Further focus on activities & environments, incl. initiatives better targeted to needs
- Effective communication infrastructure that reaches diverse groups
- Increased reach of DFC (e.g. uptake of activities)
- Increasing numbers of Dementia Friends & Dementia Friends Champions

Medium-term outcomes

- Feeling confident & secure
- Sense of belonging
- Sense of choice & control
- Feeling respected
- Feeling supported
- Sense of making a contribution & being valued
} PAD

- Enhanced awareness & understanding of dementia
- Dementia normalised
- Social cohesion & interdependence, supportive community
- Social connectedness
- Businesses retain PAD as customers
} Community

- Enabling physical environment } Environment

Longer-term outcomes
- Improved health & wellbeing
- Improved quality of life
- PLWD live in own homes for longer
- Greater community sustainability
- Cost savings
- Social Return on Investment

Involvement of PAD

Evolution & sustainability

Inclusion & equality

Monitoring & evaluation

| External influences | Growing political & public awareness of dementia | Policy endorsement for DFCs | Recognition process For DFCs | Pressures on health & social care | Growing evidence base for DFCs | Human rights approach to dementia |

9.4 Evaluation Tool domains

The following outlines the key activities that characterise the main domains of DFCs at different stages of development or access to resources. It reflects the evidence that was used to develop the Logic Model and complements the BSI guidance [64] . This provides a framework for assessing systematically how different inputs or combinations of inputs lead to intermediate and long-term outcomes that includes how each domain addresses the involvement of PAD, how it addresses equalities and inclusion and evolution over time. Wherever possible we have tried to address what is essential regardless of the size and location of a DFC, and what will be reliant on the local context and resources available.

The tool enables those working in a DFC to document and review their work over time, to identify what is achievable within the available resources and to demonstrate its impact at different stages of development from the early stages of setting up to becoming embedded in its community.

Appendix XII provides a worked example of the evidence for each evaluation tool domains. It suggests the kind of evidence that would capture the reach and impact of a DFC at different stages of development (early, developing, embedding) for PAD.

9.4.1 Basis of the dementia friendly community

The four areas assessed for this domain reflect how DFCs drew on local knowledge, national guidance and research evidence to inform their work. They are:

- Whether knowledge of its local community and the priorities of PLWD informed: who was a collaborator, planning, activities and review and how the community engaged with risk reduction initiatives
- How the DFC articulated their priorities in relation to evidence of what is known people living with dementia want and what is known to be effective
- How the DFC understood the purpose of their relationship with different collaborators and organisations and those without dementia
- Whether success or effectiveness and how it was defined, reviewed and monitored over time has aligned with national and local policy and evidence, and reflects the experience and composition of its community

9.4.2 Leadership and governance

The foundational work of the DAAs or its equivalent shaped the leadership, organisation and collaborations of five of the six DFCs.

Relational based working built up over time, drew on local knowledge and insights and optimised the existing assets of those involved (e.g. knowledge of how to navigate local government, trust between organisations' representatives, local experience of being a carer, networks of influence). It favoured an organic development that harnessed interest, energy and passion to make a difference.

The absence of a strategic approach to recruiting leaders/collaborators meant engagement from key stakeholders (e.g. LA commissioners and NHS organisations) was more erratic. Presence at meetings was not synonymous with leadership or governance. DFCs with a loose or nested structure were at risk of not knowing what was happening within their boundaries.

The four areas to assess for this domain are:

- The level and type of engagement of local politicians and their representatives; if local government priorities align with and support the DFC

- If there is a designated person(s) who co-ordinates and liaises with collaborators across the DFC
- How collaborators are recruited, and how the relationship between those who lead and co-ordinate the DFC and those who engage with DFC work are agreed
- How information about the DFC is shared and how local policy and feedback from different initiatives informs future work

9.4.3 Activities and environments

Three areas of activity are driven by the basis of the DFC, leadership and governance, local need, and resource.

- Dementia specific (e.g. Singing for the Brain®, dementia walks, Young onset groups, carer support)
- Dementia inclusive (e.g. improving access to local infrastructure, amenities, sport and leisure and public buildings)
- Community Engagement/awareness that improves PLWD every day experiences and encounters (e.g. Dementia Friends, School work, public events, local businesses)

All are valued and engage with the needs of people affected by dementia. If the ability of an activity to support inclusion was considered from the outset, then this affected expectation of those involved about what PAD should and could be able to do.

Community engagement was foundational work in all the DFCs. A consistent finding was the difficulties of promoting the DFC to the local population, especially those from minority groups.

The four areas to assess for this domain are:

- Whether community engagement activities are strategic (rather than opportunistic), based on regular consultation and targeting groups and organisations who can make a difference to the experience of PAD. Is there evidence of linking with workers and services already in place for minority groups?
- Whether the activities and changes to the environment and infrastructure are visible, accessible and recognised as part of being a DFC
- Whether the dementia specific activities address the needs of PAD at different stages of the dementia trajectory
- In cases where there is evidence of progression from community engagement to inclusion with local services and organisations, whether the needs of PAD are routinely incorporated into their planning, organisation and review of their work

9.4.4 Monitoring and evaluation

The sites did not lack data from multiple sources. However, the monitoring work was not organised to reflect DFC's basis and goals and capture how the work developed over time (or not), what resources were used, and what outcomes were achieved. Feedback from PAD was a powerful incentive for people to engage and continue. This was not, however, done systematically or linked with the population being targeted.

Tracking the link between DFC activities, who they reach and, importantly, whether it makes a difference, was difficult due to DFC's lack of capacity. The involvement of statutory providers (e.g. NHS and LA) as partners in the process of data collection and analysis could integrate evaluation of DFC work with how mainstream services engagement with and inclusion of PAD are assessed. A theory of change expressed as a logic model (section 9.3 Logic Model), agreed by DFC collaborators could provide a robust underpinning that ensures as DFCs mature, there is a services and organisations

become inclusive of many perspectives, bringing these and other partnership issues to the surface to help achieve solutions [90].

The four areas to assess for this domain are:

- How information and feedback within the DFC is coordinated to achieve a sense of purpose and common direction
- How the activities of the DFC reflect the needs of different groups of PLWD (including those whose dementia has affected their ability to communicate and travel)
- How the theory of change is used to prioritise activities and outcomes that have social value for different groups of PLWD and PAD.
- How existing local data (or new data collection) that includes information on PAD is linked to the DFC and used to plan and conduct evaluations

9.4.5 Resources

The variability and patchy information about resources in all phases of the study were a limitation. Also, some resources used by the DFC were linked to, or integrated with, existing provision and funding.

The five areas to assess for this domain are:

- Whether DFC work is based on resourcing that is dedicated to dementia or part of mainstream commissioning of services
- Whether DFCs have their own resources to manage the initiative and how that might differ for the set-up phase, maintenance phase, and planning for sustained viability
- What types of resources are available to support the DFC initiative/DFC-specific activities, including: one off or sustained funding, salaried staff, volunteers, built infrastructure, technical and support services (room, venues, offices, phones, printing, transport services).
- Access to practical support from partner organisations including support with grant capture, data collection, management and interpretation; writing and dissemination.
- Whether the resources available allowed the DFC to pursue work identified as having social value and appropriate for local aspirations and needs (see also section below on Social Return on Investment)

9.5 Social Return on Investment

Drawing on the *principles* of cost consequence analysis [91] and social impact assessment (Scholten P et al. 2006), we developed evidence-informed scenarios (i.e. vignettes) that provide an initial account of the possible economic and social impacts for those involved in DFCs, i.e. people living with dementia, carers of people living with dementia, volunteers, and organisations (e.g. business, charity, public services, leisure organisations). Social value prompts us to ask the question: If £1 is spent on the delivery of activities or services, can that same £1 be used to also produce a wider benefit for the community?

A cost-consequence analysis is a form of economic evaluation in which direct and indirect costs and a catalogue of different outcomes of all intervention alternatives are listed separately. A social return on investment embraces a much broader concept of value to understanding, measuring and reporting the social, economic and environmental value created by an intervention, program, policy or organisation [50]. Although a full SRoI analysis was beyond the scope of this study, we drew on the approach and the resources and outcomes data we collected to develop hypothetical scenarios/vignettes. DFCs are framed as value generating approaches to help people living with dementia remain active, engaged and independent as long as possible; and the value chain is operationalised using the logic model/theory of change (section 9.3 Logic Model).

To develop a vignette, the first consideration was identifying a clearly defined activity or intervention that was common to most case study sites and could be generalisable beyond the context of the study. Creating Dementia Friends was identified as a core activity in all the sites to increase awareness, and in some sites seen as a precursor for connecting with or developing dementia inclusive services (e.g. dementia friendly shopping) or dementia specific activities (e.g. dementia cafés). The second consideration was making sure the interventions had benefits from the perspective of various key stakeholders (a core aspect of SRoI), e.g. people living with dementia and/or their carer, volunteers, and/or organisations. Thirdly, the information to cost the intervention AND assign a value to the benefits had to be available. The typical or indicative resources associated with delivering that activity were then listed, quantified drawing on the thematic analysis of study site data, and valued using cost estimates derived from data provided by Alzheimer's Society, national statistics and the scientific literature. The vignette draws as much as possible on quantitative data derived from each site , but some assumptions had to be made to develop a coherent narrative for illustrative purposes.

The case example focuses on Dementia Friends. This was selected because awareness raising is the foundational activity of most DFCs, and is often linked to Dementia Friends programmes and services (largely run by volunteers) and to activities that aim to adapt the environment (buildings, transport, retail, sport, arts and leisure) to improve access and inclusion.

9.5.1 The building blocks – Social value of Dementia Friends

9.5.1.1 *Intervention: Dementia Friends*

A Dementia Friend is somebody who learns about dementia so they can help their community. Dementia Friends help by raising awareness and understanding of the condition so that people living with dementia feel understood, valued and able to contribute to their community.

A Dementia Friends Champion is a volunteer who encourages others to make a positive difference to people living with dementia in their community. They do this by giving them information about the personal impact of dementia, and what they can do to help. Dementia Friends Champions attend an induction (delivered by Alzheimer's Society) and receive support when they need it. They deliver Dementia Friends' sessions, which in turn train new Dementia Friends – both are taking an active part in the development of DFCs.

9.5.1.2 *Resources*

Indicative resources needed to train Dementia Friends are tabulated below (Table 9-1) and assigned a financial value based on information received from Alzheimer's Society, scientific literature and national sources. Dementia Friends sessions are typically delivered by volunteers. Given that this study takes a societal perspective, the time of Dementia Champions and Dementia Friends is valued at the same rate as paid staff to more fully capture costs to communities.

Table 9-1. Resources needed to train Dementia Friends

Type of resources	Costs
Training a Dementia Champion	• Dementia champions receive a 1-day induction, estimated as taking 8 hours of their time; there is no registration fee[2].
	• Trainee's time is valued at the ONS hourly value of volunteering, based on Community Life Survey and ASHE dataset, updated to 2018 prices.[3]
	8 hours x £14.80 = £118.40
Training a Dementia Friend	• Accrued Alzheimer's Society cost:
	£3.75 per Dementia Friend[4]
	• Dementia Champion's time to prepare and deliver the session is estimated to take 4 hours at the ONS hourly value of volunteering, based on Community Life Survey and ASHE dataset, updated to 2018 prices[1,2]:
	4 hours x £14.80 = £59.20
	• Dementia Friend's time to be trained in a face to face session: 1 hour, at the ONS hourly value of volunteering, based on Community Life Survey and ASHE dataset, updated to 2018 prices[2]:
	1 hour x £14.80 = £14.80
Venue & printed material	• The venue is generally free of charge and is not costed here. A full costing would have estimated the average cost of renting a venue in the locality.
	• Printed materials and badges are provided by the AS and included in the accrued costs of training Dementia Friends.[3]
	• Additional volunteer time and/or in-kind resources may be deployed in individual communities, but our data didn't allow us to capture these.

9.5.1.3 Outcomes & Social values:

Several outcomes were identified as resulting from the activities of Dementia Friends in case study sites (*See 9.3 Logic model*). Here, we selected a few of these outcomes or proxies that have been shown to have a relationship to life satisfaction and/or well-being to demonstrate the potential social value of improving these outcomes for members of DFCs, i.e. patient, carers, volunteers, private sector stakeholders.

Conducting full well-being valuation was beyond the scope of DEMCOM, hence the choice of outcomes is based on the availability of UK-specific and age-relevant social values. Also, stated

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[2] Full costing would have included travel costs, but no such data were available from our study sites.
[3] National TOMs framework 2019 for social value measurement – Guidance 2018.
[4] Draft estimate provided by Alzheimer's Society (June 2019).

changes in these outcomes are hypothetical or inferred from interview statements as opposed to robust measures of change.

For selected outcomes, the yearly average of social values derived from the Social Value Bank are tabulated below. These can be used to estimate the value of a *change* in outcomes. To prevent over claiming for changes that would have happened anyway, regardless of any specific intervention, a "deadweight" i.e. chance that the event would have happened anyways, is considered and discounted (i.e. subtracted) using average deadweight figures (also derived from the Social Value Bank). For selected outcomes, the deadweight is 0.19.

Table 9-2. Social value for selected outcomes.

Outcome	Description of outcome	Average (for 50 years +)
Regular volunteering	Volunteers at least once per month over at least 2 months	£3,249
Regular attendance at voluntary or local organisation	Attends local and voluntary groups at least once per month for at least two months	£1,773
Good neighbourhood	Overall do you think your neighbourhood is a good or a bad place to live? 1. Good* 2. Bad 3. Mixed	£1,747
Feel belonging to neighbourhood	I feel like I belong to this neighbourhood 1. Strongly agree* 2. Agree* 3. Neither agree/disagree 4. Disagree 5. Strongly disagree	£3,753
Talk to neighbours regularly	I regularly stop and talk with people in my neighbourhood 1. Strongly agree* 2. Agree* 3. Neither agree/disagree 4. Disagree 5. Strongly disagree	£4,511

* The social value can be applied if someone has moved on the scale from a rating without a * to one with a *. (Social Value Bank Calculator version 4.0).

Net social impact: The net social impact of Dementia Friends can be derived using a robust evaluation with a control group to calculate the causal impact of the interventions on a range of outcomes for a representative sample of affected individuals. The second best approach would be to conduct a before and after survey. Here, we are using vignettes to tell a story about what that social impact could mean for individuals and communities.

9.5.2 Vignette – The social value of Dementia Friends for carers and people living with dementia

A carer and a person with dementia live in a market town where the estimated number of people living with dementia is 85, 80% of which have a known carer. The town prevailing approach is to encourage the community to engage in dementia friendly awareness and activities.

As a result, over the last year, 3 Dementia Champions were trained; they delivered 6 dementia friend sessions and 65 members of the community became Dementia Friends as a result. The cost of training Dementia Friends is £1916.15.

A survey revealed that many carers have routinely engaged in volunteering activities and attended voluntary organisations events with the person with dementia. Carer and PLWD alike have reported positive changes in the social cohesion of their neighbourhood.

For every dyad (PLWD and carer/partner/spouse/family member) who report a *positive change* on all our key outcomes, the social impact of Dementia Friends could be estimated as follows:

Table 9-3. Social impact of Dementia Friends

	Person with dementia (discounted)	Carer (discounted)	Reported change
Regular volunteering	-	£3,249 (£2,632)	From not volunteering to volunteering
Regular attendance at voluntary or local organisation	£1,773 (£1,436)	£1,773 (£1,436)	From not attending to attending voluntary or local organisation activities
Good neighbourhood	£1,747 (£1,415)	£1,747 (£1,415)	From having mixed feeling about the neighbourhood to feeling one lives in a good neighbourhood
Feel belonging to neighbourhood	£3,753 (3,040)	£3,753 (£3,040)	From not feeling one belongs to feeling one belongs to the neighbourhood
Talk to neighbours regularly	£4,511 (£3,654)	£4,511 (£3,654)	From not agreeing to the statement "I regularly stop and talk with people in my neighbourhood" to agreeing to the statement.
Sub-total	£11,784 (£9,545)	£15,033 (£12,177)	

TOTAL		Including discounting using a deadweight of 19%
	£26,817 * (1 - 0.19) = **£21,722**	

The **Net Social Impact** of Dementia Friends activities per dyad in that market town over the 1 year period covered by the survey is £21,722 (Total social impact) – £1,916 (Total costs) = **£19,806**.

The **Social Return on Investment** ratio (i.e. total social impact / total cost) *per dyad* would be £11.34. So, for each £1 invested in Dementia Friends, the community gets a return of £11.34 in social value…for that one dyad having reported changes in the selected outcomes.

Assuming the only outcome change observed for a particular dyad is that, say, a person with dementia feels he/she belongs to the neighbourhood as a result of feeling well understood (as our survey might indicate when people living with dementia say they feel understood; *Table 8-9*), the net social impact is also positive (£3,040 - £1,916 = £1,124) and so is the SRoI ratio (£3,040 / £1,916 = £1.59).

Finally, as indicated in our survey (*Table 8-9*), PLWD who are aware of DFCs are more likely to get involved in leisure activities and go to the community centre (i.e. regular attendance at voluntary or local organisation). The net social impact if only one dyad living in our market town reports this change is the net social impact is still important (£2872 - £1,916 = £956) and so is the SRoI (£2872/£1,916 = 1.50). The graph below demonstrates how this value could accrue as more dyads report attending events as a result of the place being more dementia friendly.
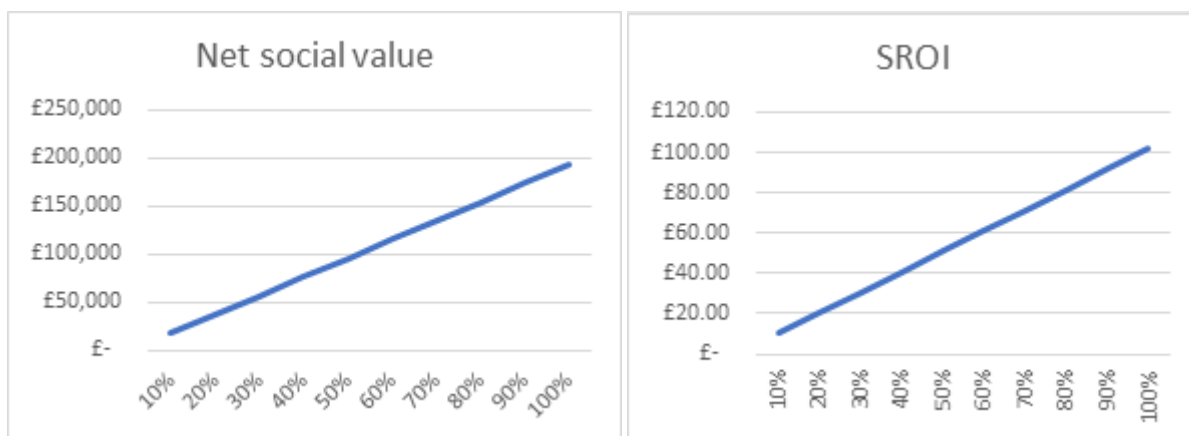
Figure 9-1. Hypothetical net social value and SRoI for outcome "regular attendance at voluntary or local organisation".

This vignette clearly demonstrates that if the social value of Dementia Friends was to be estimated for the whole community and based on robust local data collected as part of a monitoring and evaluation activity, a clear message would emerge regarding the added social value of Dementia Friends. This in turn could provide insights to further develop the dementia friendly agenda towards long term and sustainable outcomes, which we could not identify in this study due to lack of data.

This chapter has demonstrated how evidence has been used to create a theory of change and inform SRoI methods to inform an evaluation framework and evaluation tool that can be used for DFCs working with different populations, settings and stages of development.

This chapter has also set out how the evidence from the three phases has enabled us to answer the research question to build an evaluation framework and assess the value and benefits of DFCs to those involved. The final chapters focus on the implications of these findings for policy and research.

10 Discussion and policy implications

Chapter 9 answered the study questions about the factors and preconditions for DFC to produce positive outcomes for PLWD and their carers/supporters, modelled the resource requirements to achieve this and how to evaluate impact for PAD. This chapter discusses the findings in relation to current and future policy recommendations.

The Prime Minister's challenge [9] combined with the work of the DAAs and Alzheimer's Society funding, led to widespread uptake of the idea of DFCs and linked community engagement activities across England. The 2020 policy target of over 50% of the population living in an area with a DFC was being met. Almost all DFCs have only been in existence for five years or less. As emergent organisations their starting point was to raise awareness and the outcomes achieved reflect that. Key to their set up was the presence of DAAs or their equivalent, access to funded or volunteer workers who could embody the work of the DFC, statutory agencies and charities' involvement.

It is remarkable what had been achieved by some DFCs working with volunteers and loose associations between different local groups and organisations. These, however, were vulnerable to individuals leaving and reactive approaches, either working where there was an existing resource or focusing on well received activities (e.g. dementia cafés). The study also highlighted, that even in an active DFC there were PLWD who were unaware of its existence. The practical challenges of finding a local DFC and the difficulties of connecting with PLWD within a local community were significant.

A social model of disability informs current policy for DFCs. The evaluation considered how the basis of the DFC had informed work to ensure individuals and public services do not reinforce stigma or create barriers to participation. The imperative for most DFCs was to respond to known and observed need. This favoured activities that provided places for PLWD to go and meet but might not address social inclusion. Where activities were linked with targeting staff in key services (e.g. retail and transport) and integration with other community resources (e.g. placing dementia specific activities in public spaces and events) this could have lasting impact.

The All-Party Parliamentary Group (APPG) on dementia 2019 report [92] states that every DFC should have a LA representative sit on their Working Group. In the DFCs studied there was engagement from the LA and other public services. This did not guarantee integration of effort or local policy. Community impact was achieved only when the LA actively supported innovation and linked population-based initiatives for vulnerable groups to the DFC work.

The APPG also prioritised employment, transport and housing as areas for further development. Changing attitudes to adapting the environment and improving access to transport were areas that DFCs could engage with, and had discussed, but without LA or its equivalent involvement, these were piecemeal activities.

Related policies in the Prime Minister's challenge on dementia [9] on improving dementia diagnosis, access to service provision and risk reduction had some uptake by DFCs and was seen as relevant to their work . Co-ordinating this work with other services and agencies required access to relevant expertise in data collection, analysis and dissemination. For most DFCs they did not have the capacity to achieve this. Although, the examples of where DFCs were able to work with NHS services and LA departments of public health demonstrated the potential for joined up working that was community wide and intergenerational.

The following outlines implications for policy makers and those leading the work of DFCs that build on the six "if then" statements about a history of collaboration and communication, shared understanding of a DFC's purpose, links to existing provision targeting local populations, involvement of PAD and integration with local policy and the local economy.

Build on existing collaborations and have access to resources to support the ongoing review and evaluation of Dementia Friendly Communities' work.

The role of the DAA or its equivalent and the foundation criteria for the DFC recognition process and linked resources (Innovations in Dementia 2012, http://www.repod.org.uk/downloads/dfc.pdf see also Appendix I summary of DFC frameworks) were key in helping DFCs to set up. To develop however, further guidance and resources are needed to create and refine a shared narrative within a DFC of its priorities and purpose and how they will be realised.

This requires skills in working with and across organisations and a recognition of what is possible within the resources available. Teper and colleagues (2019) [93] observe that very few dementia plans articulate strategies for their diffusion or implementation. Our study endorses this and the need for pragmatic guidance that builds confidence and expertise between key organisations who may struggle with involvement over sustained periods.

The evaluation tool complements the BSI guidance, extends work on healthy ageing and provides a way for DFCs to review their progress systematically. It provides a way to identify where additional input and resources are required. To focus DFCs on key areas of need there is a need to standardise how effectiveness and expected impact are articulated and recognised within and across DFCs.

DFC work as challenging existing systems and services in the community

The policy goal of a DFC is normalisation where the needs of PLWD are seamlessly integrated with dementia specific activities, sitting alongside accessible mainstream services. This was implicit rather than explicit in how the work of DFCs were reported and observed. The role of people in creating a sense of community and specifically everyday social relationships directly contributes to wellbeing for PAD (Clark et al., 2016).

Most of the activities of the DFCs focused on PLWD in the earlier stages of the disease trajectory from white communities born in England. The focus on living well for this group arguably masked the need to consider what this meant for those who were further down the disease trajectory and/or from different cultural backgrounds.

The stakeholder event had suggested proxy outcomes to assess how accessible and aware a community has become (Lasting Power of Attorneys (LPAs)), organisational changes (signage, rest places, slow shopping lanes, longer GP appointment times and accessible voting booths). It also signalled the importance of how DFCs could facilitate how PAD report on the positive (or not) experience of everyday encounters. Outcome measures that demonstrate how a DFC is normalising the experience of living with dementia into a local community are needed. This was underdeveloped in the DFCs. Recent findings on how people affected by dementia living at home define outcomes that matter to them complement this work. It demonstrates the importance of basing future work on measures reflect the priorities and experiences of people living with dementia. [5, 6]

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[5] **Reilly S, Harding A, Morbey H**, Keady J, Elvish R, Leroi I et al. **A systematic review of the measurement properties of outcome measurement instruments for a core outcome set on non-pharmacological health and social care community-based interventions for people living with dementia at home in their neighbourhoods and communities**. 2019. 1 p.

[6] Harding AJ, Morbey H, Ahmed F, Opdebeeck C, Lasrado R, Williamson PR, Swarbrick C, Leroi I, Challis D, Hellstrom I, Burns A. What is important to people living with dementia?: the 'long-list' of outcome items in the development of a core outcome set for use in the evaluation of non-pharmacological community-based health and social care interventions. BMC geriatrics. 2019 Dec 1;19(1):94.

There is value in DFCs routinely using an evaluation framework to identify from the outset relative progress and impact indicators over time. Both internal monitoring and ultimately comparison of outcomes for PAD from DFCs with similar histories and resources using different approaches will demonstrate how DFCs are changing the environment and everyday experience of living with dementia.

Integrate DFC work with other dementia focused initiatives and invest in local and national platform for communication, information, data sharing and planning

Effective coordination of effort requires a dedicated person(s) who can embody the work of the DFC, with access to resources and support for cross DFC communication and information gathering, analysis and sharing. The study highlighted an unacceptable and unpredictable variation in all these areas.

There is potential to draw on the resources of local NHS services, councils, and universities all of whom are equally tied to the wellbeing of the populations they serve. From the perspective of DFCs, these "anchor institutions" [94] are influential in where and how resources can be spent for PAD. They have a role in providing continuity and consistency of input. It is unrealistic and wasteful of limited resources to expect DFCs to do monitoring and evaluation work.as a standalone activity. Future policy on dementia should require that statutory bodies support DFCs in data collection, for example to know how many in the local population are Dementia Friends and in which sectors. This could be linked to the PHE living well section of the Dementia Profile.

Research analysing cohort data of people living well with mild to moderate dementia found small effect sizes for the domains of social capital, assets and resources, and managing everyday life with dementia [95]. Whilst it is challenging to establish a causal link between the presence of a DFC and living well, future work could explore associations between living in a DFC and other measures such as social isolation of PAD.

Dementia Friendly Communities should consider from the outset their population and how different activities of their collaborators link to each other. Without this, the impact of specific initiatives is potentially limited, promotes silo working or fails to extend the conversation about how to address what matters to PLWD. This in turn has a negative knock on effect on the ability to monitor impact of DFC activities on agreed outcomes and the social and economic value of these initiatives – compromising their long term sustainability. For example, all the police services in the DFCs had a Herbert protocol for missing persons, but only one DFC had linked this to identifying known safe places in the community where people, if lost, could go to or be taken to. The latter addresses issues of safety, resource use and what helps PLWD to be confident that they can find their way and be helped if needed.

The evaluation tool domains, the theory of change (logic model), and suggested sources of evidence could be used to structure information exchange and how data is collected both within, and across DFCs and their members.

Dementia Friendly Communities are supported to identify and include people affected by dementia:

All the work of a DFC flows from how it articulates its purpose and priorities to those it is working with and the wider community. It is meant to be "a strong voice." and to achieve this requires the involvement of a range of people living with and affected by dementia whose experiences reflect local settings and context.

The findings demonstrate that it is unreasonable to expect this core work to rely on PAD's ability to attend and participate in meetings, or to assume that a DFC has the expertise and resources needed to sustain meaningful engagement. Where a DFC had access to a group of PAD that was externally facilitated, or to a local resource centre, it was possible to involve people on a regular basis. Bethell et

al 2018 [96] note that the development of infrastructure enables meaningful engagement. Our findings suggest that DFCs would benefit from structured approaches and dedicated resources to engage with and feedback to PAD. This should be threaded through their work with local collaborators as well as dementia specific activities. To extend this work, especially to include PLWD who cannot attend meetings, DFCs should be supported to develop expertise and work with staff who can enable the meaningful participation of PLWD.

Phase One and Phase three demonstrated the challenges of systematically locating PLWD (and not just their representatives), sharing information about DFC and related work and how it complemented the local NHS (Primary care and hospitals) and LA work for PAD. Policy makers should review the opportunities for sharing expertise and resources to foster a local culture open to change and innovation for PAD.

Organisation and resourcing of leaders of Dementia Friendly Communities and working with statutory services

The creation of a local structure and key individual(s) to lead the work are foundational criteria for working towards recognition as a DFC. The findings suggest that where a DAA or its equivalent supported the work of the DFC this provided the needed reference point, continuity and potential to integrate the DFC work with other organisations and services.

In some sites, there was an ongoing confusion about where a DAA ended and a DFC began. In smaller locations this might not be an issue but in larger towns and cities a lack of clarity affected who led and coordinated the work of the DFC.

The role and contribution of the local authority should be explicit within the DFC. When council officials as active collaborators linked their local priorities with those of the DFC (and vice versa) they provided a basis for dialogue, development and review and funding of DFC co-ordinator roles. It also made the work of the DFC visible and accountable.

Links with public health and those involved in commissioning of services reinforced a population-based approach with ongoing discussion of what should or could work. If local government involvement in the DFC was less strategic council officials and councillors were present, but involvement appeared discretionary and unpredictable.

The survey findings identified transport and being able to go out as a recurring cross DFC issue. This was also identified as a priority area by the APPG's research for their report on Dementia Care. There were examples of how this was being addressed (e.g. targeting Dementia Friends sessions for taxi and bus drivers and cards for people to show when using public transport). However, to achieve infrastructure change required a level of collaboration and leverage that only two of the DFCs studied potentially had through their links with their local council.

There is guidance on how councils can work with to promote dementia friendly communities https://www.local.gov.uk/sites/default/files/documents/dementia-friendly-communi-8f1.pdf). The findings indicate that policy makers should require local government partners to demonstrated how working with the DFC links to local policy and wider service provision.

The 2019 APPG report file:///C:/Users/rpcqcg/Downloads/SN07007.pdf identified promoting disability rights from diagnosis for people living with dementia in six areas: employment, social protection, social care, transport, housing and community life. Almost all of these areas were being addressed by some of the DFCs, and our findings support providing resources and ensuring LA and NHS representation on DFCs to support a systematic approach that integrates the work of care with the work of community engagement.

Future policy should address how DFCs can be supported to identify shared goals with other providers to promote integrated working and avoid duplication or gaps in provision. Related policy driven

initiatives to improve diagnosis rates, reduce risk factors for dementia, improve dementia training in the workforce and quality of care were sometimes, but not always, referenced by DFCs. There was an untapped potential for shared learning and using existing data and naturally occurring contacts with people affected by dementia to inform and link PAD with this work. Specifically, in raising expectations across the community about what PLWD should and increasing PAD's confidence that there is an integrated approach to community provision.

10.1 Limitations of the study

There are several limitations to the DEMCOM study. The approach to sampling and site recruitment is biased to DFCs who were active and engaged. We cannot comment on DFCs who have achieved recognition, but who did not have a local presence or person to contact and some of the findings may misrepresent the range of achievements and impact of DFCs across the country. The study favoured DFCs defined by geographical location. The data on resources and impact on PLWD are descriptive and limited however, the SRoI work offers a way forward for understanding the social benefit of DFCs. Despite many attempts to engage with different cultural and faith groups people from BAME backgrounds are largely underrepresented in this study. This has limited our ability to capture how cultural differences in attitudes towards PLWD can inform DFC work. However, it reinforces our recommendations that DFCs should work closely with existing local services who are supporting these groups and not work in parallel.

10.2 Conclusion

The Prime Ministers challenge on dementia [9] set out what needs to be in place for England to be the best country in the world for dementia care and support and for people living with dementia, their carers and families to live. The study has demonstrated there is not one model of DFC that is more or less likely to deliver the goals of inclusion and participation for people living with and affected by dementia. There are, however, key features and characteristics of DFCs that are more likely to achieve impact and reach for PAD than others. The evaluation framework/tool domains of assessment (Basis of DFC, Leadership and Governance, Activities and Environment, Monitoring and evaluation, Resources, Involvement of PAD, Equalities and inclusion and Evolution) and policy recommendations provides a way forward to determine systematically how local communities, organizations, and individuals view and understand their responsibilities towards dementia, and those living with and affected by dementia.

11 Dissemination plan

11.1 Introduction

Dissemination about the work and findings of the DEMCOM study has been threaded through the study. This has included online and national media (twitter @DEMCOMstudy , CLAHRC monthly blogs and national newspapers https://www.theguardian.com/social-care-network/2018/may/23/dementia-friendly-communities-isolation-stigma , peer reviewed papers (Appendix XIII and Appendix XIV), national and international conference symposia (Dementia Congress, Alzheimer's Society and International Association Geriatrics and Gerontology), and oral and poster presentations.

International work has included a plenary address in Catalonia at the first conference of Spain's first dementia friendly community team, and working with Alzheimer's Society briefings for the US AARP

(American Association of Retired Persons) and with the World Dementia Congress in collaboration on data collection tools.

For those working within DFCs and for practitioners we have also presented and discussed findings at regional events bringing together practitioners, academics and PAD. The study was also presented at an Alzheimer's Society event in the Isle of Man on recent research for NHS professionals and volunteers. Table 11-1 at the end of the chapter summarises the dissemination work to date and the audiences reached.

Study sites have all received interim reports and discussed them at site meetings. These both informed the final stages of data collection and provided feedback on emergent findings to participants.

11.2 Communication plan

The DEMCOM study has been supported and enabled by a network of academics, PLWD and their representatives. This will continue to be the audience and focus of how the findings are communicated. National and international presentations have provided networks of interested stakeholders in both the findings and the evaluation framework and tool.

The DEMCOM study was supported by the NIHR CLAHRC East of England and this has facilitated communication of the study both regionally and nationally and in particular the involvement of a range of PPI groups.

The study steering committee brought together leading researcher community engagement, researching in and with PLWD and policy researchers working in dementia care research and charity representatives. This has ensured the study has worked closely with those directly involved in supporting policy implementation and evidence creation.

These links will be maintained both as part of the communication and dissemination plan (see below) and to inform future policy and research work

The following sets out our dissemination plan following on from the completion of the study:

Table 11-1. DEMCOM dissemination activity.

Audience	Medium	Timing
Participants in the DEMCOM study and Study steering committee	Half day event to present final report and findings and recommendations	Oct/Nov 2019
Alzheimer's Society , Word Dementia Council and Potential users of the evaluation tool	Face to face meetings Briefings	Ongoing
Policy makers including APPG on dementia and academic audience	Briefing and summary report of DEMCOM	Nov 2019 _
	Peer reviewed papers on DEMCOM e.g. Milbank Policy , Health Policy, Dementia	Dec 2019-Jan 2020
Researchers working with people living with dementia	Paper on survey of PLWD	Dec 2019

	And involvement of PLWD in the study	
Local government organisations e.g. ADASS	Briefing and presentation at national meeting on the role of LA in DFCs	Ongoing
Consultations and development of Guide to using the DEMCOM evaluation tool with graphics and manual	Online resource and published booklet	Ongoing
Alzheimer's Society Community Engagement and evaluation teams	Briefing and meeting to discuss DEMCOM recommendations	28th August 2019

Table 11-2. Blogs, newsletters and articles

Title	Output Date	Link
A Q&A with the Chief Executive of Age UK Norwich as a Dementia Friendly Community	**Blog** 08 March 2017	Prof Tony Arthur Michael Woodward: http://www.clahrc-eoe.nihr.ac.uk/about-us/people/dementia-frailty-and-end-of-life-care/DEMCOM-national-evaluation-dementia-friendly-communities-2/
What is a Dementia Friendly Community?	**Blog** 13/04/2017	Nicole Darlington http://www.clahrc-eoe.nihr.ac.uk/about-us/people/dementia-frailty-and-end-of-life-care/DEMCOM-national-evaluation-dementia-friendly-communities-2/
When we say 'Dementia Friendly', what are we comparing it to?	**Blog** 09/05/2017	Dr Christopher Skedgel http://www.clahrc-eoe.nihr.ac.uk/about-us/people/dementia-frailty-and-end-of-life-care/DEMCOM-national-evaluation-dementia-friendly-communities-2/
Dementia Friendliness and Age Friendliness	**Blog** 01/06/2017	Dr Stefanie Buckner: http://www.clahrc-eoe.nihr.ac.uk/about-us/people/dementia-frailty-and-end-of-life-care/DEMCOM-national-evaluation-dementia-friendly-communities-2/
Mapping of DFCs with dementia prevalence "the thing with maps"	**Blog** 01/07/2017	Professor Tony Arthur http://www.clahrc-eoe.nihr.ac.uk/about-us/people/dementia-frailty-and-end-of-life-care/DEMCOM-national-evaluation-dementia-friendly-communities-2/
Community Engagement Approaches for	**Blog** 01/08/2017	Dr Marina Buswell :http://www.clahrc-eoe.nihr.ac.uk/about-us/people/dementia-frailty-and-

Dementia- what motivates us?		end-of-life-care/DEMCOM-national-evaluation-dementia-friendly-communities-2/
The "usual suspects" – patient and public involvement (PPI) in DEMCOM	**Blog** 01/09/2017	Dr Elspeth Mathie:http://www.clahrc-eoe.nihr.ac.uk/about-us/people/dementia-frailty-and-end-of-life-care/DEMCOM-national-evaluation-dementia-friendly-communities-2/
What do Dementia Friendly Communities offer people diagnosed with young onset dementia?	**Blog** 18/10/2017	Dr Andrea Mayrhofer :http://www.clahrc-eoe.nihr.ac.uk/about-us/people/dementia-frailty-and-end-of-life-care/DEMCOM-national-evaluation-dementia-friendly-communities-2/
Reflections on being involved in dementia research as a former carer.	**Blog** 30/11/17	John Thurman: http://www.clahrc-eoe.nihr.ac.uk/about-us/people/dementia-frailty-and-end-of-life-care/DEMCOM-national-evaluation-dementia-friendly-communities-2/
Measuring dementia friendliness- getting the balance right.	**Blog** 29/10/18	Stefanie Buckner:https://www.clahrc-eoe.nihr.ac.uk/2018/10/measuring-dementia-friendliness-getting-the-balance-right-blog/
Are dementia friendly communities the answer to isolation and stigma?	**Guardian newspaper** 23/05/18	Claire Goodman https://www.theguardian.com/social-care-network/2018/may/23/dementia-friendly-communities-isolation-stigma
IFA Newsletter Age Friendly Innovation Exchange Newsletter.	**Newsletter** October 2017	Stefanie Buckner:https://myemail.constantcontact.com/Age-friendly-Innovation-Exchange--AFIX--Newsletter.html?soid=1101901198311&aid=nYNDtz8SjI0
CLAHRC EOE	**Newsletter** March 2018	Louise Lafortune

Table 11-3. Table of conferences attended

Name of conference, location Date	Presenter Presenting (type/content)
CLAHRC event IPH- Cambridge15/03/2017	Stefanie Buckner**Poster presentation**.DEMCOM study outline.
Faculty of Public Health Conference-Telford 20/06/2017	Marina Buswell **Oral presentation**: Phase One overview and discussion

British Society of Gerontology (BSG) - Swansea 05/07/2017	Marina Buswell **Oral presentation**: Phase One overview and discussion
Service user and public involvement showcase- Univ of Hertfordshire, 13/09/2017	Elspeth Mathie **Oral presentation**: Patient and public involvement in DEMCOM
Dementia Congress- Doncaster08/11/2017	Nicole Darlington, Michael Woodward, Stefanie Buckner, **Symposium:** Phase One findings, Phase Two emerging findings
AgeNet- Univ of Hertfordshire28/03/2018	Claire Goodman **Oral presentation**: Phase One & Two findings
University of Nottingham 10/05/2018	Claire Goodman **Seminar :**Phase One & Two findings
Alzheimer's Society Conference- London 23/05/2018	Nicole Darlington,Elspeth Mathie **Oral presentation**: Phase One & Two findings
The Fundació Catalunya La Pedrera, Vilanova 18/06/2018	Claire Goodman **Plenary :** History of DFCs, DEMCOM evaluation tool
British Society of Gerontology (BSG)- Manchester 05/07/2018	Stef Buckner **Oral presentation**: Phase One & Two findings
International Federation of Ageing (IFA)- Canada 08/08/2018	Louise Lafortune **Oral presentation**: Phase One & Two findings
WHO international healthy cities conference- Belfast 03/10/2018	Stef Buckner **Oral presentation**: Phase Two & Three of DEMCOM
Age-Friendly housing and communities conference- Birmingham 18/10/2018	Claire Goodman **Plenary** Phase Two & Three of DEMCOM
IAGG-ER-2019 Sweden25/05/2019	Claire Goodman, Louise Lafortune, Elspeth Mathie, Stefanie Buckner, Nicole Darlington **Symposium :**DEMCOM findings
Isle of Man Dementia AS Conference 25/06/2019	Claire Goodman **Plenary** What makes good dementia friendly initiatives in health care?
British Society of Gerontology (BSG)- Liverpool 12/07/2019	Stefanie Buckner **Oral presentation**: DEMCOM findings
British Society of Gerontology (BSG)- Liverpool 12/07/2019	Elspeth Mathie :**Symposium**: PPI involving people living with dementia in DEMCOM

| HSRUK National conference Manchester 03/07/2019 | Claire Goodman **oral presentation** National evaluation of Dementia Friendly Communities: the DEMCOM project |

12 References

References

1. Buswell M, Goodman C, Russell B, Bunn F, Mayrhofer A, Goodman E. Community Engagement Evidence Synthesis: A final report for Alzheimer's Society. 2017.

2. Goodman C. Community Engagement Evidence Synthesis. 2016.

3. Buckner S, Pope D, Mattocks C, Lafortune L, Dherani M, Bruce N. Developing age-friendly cities: an evidence-based evaluation tool. Journal of Population Ageing. 2017:1-21.

4. Prince M. Progress on dementia—leaving no one behind. The Lancet. 2017;390(10113):e51-e3.

5. Prince MJ. World Alzheimer Report 2015: the global impact of dementia: an analysis of prevalence, incidence, cost and trends: Alzheimer's Disease International; 2015.

6. Livingston G, Sommerlad A, Orgeta V, Costafreda SG, Huntley J, Ames D, et al. Dementia prevention, intervention, and care. The Lancet. 2017;390(10113):2673-734.

7. Kingston A, Robinson L, Booth H, Knapp M, Jagger C, project M. Projections of multi-morbidity in the older population in England to 2035: estimates from the Population Ageing and Care Simulation (PACSim) model. Age and ageing. 2018;47(3):374-80.

8. Bartlett R, Gjernes T, Lotherington AT, Obstefelder A. Gender, citizenship and dementia care: a scoping review of studies to inform policy and future research. Health & social care in the community. 2018;26(1):14-26.

9. Health Do. Prime Minister's challenge on dementia 2020: Department of Health; 2015.

10. Wolverson E, Clarke C, Moniz-Cook E. Living positively with dementia: a systematic review and synthesis of the qualitative literature. Aging & Mental Health. 2016;20(7):676-99.

11. Wolverson EL, Clarke C, Moniz-Cook E. Remaining hopeful in early-stage dementia: A qualitative study. Aging & Mental Health. 2010;14(4):450-60.

12. Bunn F, Goodman C, Sworn K, Rait G, Brayne C, Robinson L, et al. Psychosocial factors that shape patient and carer experiences of dementia diagnosis and treatment: a systematic review of qualitative studies. PLoS medicine. 2012;9(10):e1001331.

13. Comas-Herrera A, Knapp M, Wittenberg R, Banerjee S, Bowling A, Grundy E, et al. MODEM: A comprehensive approach to modelling outcome and costs impacts of interventions for dementia. Protocol paper. BMC health services research. 2017;17(1):25.

14. Wübker A, Zwakhalen SM, Challis D, Suhonen R, Karlsson S, Zabalegui A, et al. Costs of care for people with dementia just before and after nursing home placement: primary data from eight European countries. The European Journal of Health Economics. 2015;16(7):689-707.

15. Cepoiu-Martin M, Tam-Tham H, Patten S, Maxwell CJ, Hogan DB. Predictors of long-term care placement in persons with dementia: a systematic review and meta-analysis. International journal of geriatric psychiatry. 2016;31(11):1151-71.

16. Hebert CA, Scales K. Dementia friendly initiatives: A state of the science review. Dementia. 2017:1471301217731433.

17. Lin S-Y. 'Dementia-friendly communities' and being dementia friendly in healthcare settings. Current opinion in psychiatry. 2017;30(2):145.

18. Shannon K, Bail K, Neville S. Dementia-friendly community initiatives: An integrative review. Journal of clinical nursing. 2019;28(11-12):2035-45.

19. Fitzgerald KG, Caro FG. An overview of age-friendly cities and communities around the world. Journal of Aging & Social Policy. 2014;26(1-2):1-18.

20. Turner N, Cannon S. Aligning age-friendly and dementia-friendly communities in the UK. Working with Older People. 2018;22(1):9-19.

21.   Nakanishi M, Nakashima T. Features of the Japanese national dementia strategy in comparison with international dementia policies: How should a national dementia policy interact with the public health-and social-care systems? Alzheimer's & Dementia. 2014;10(4):468-76. e3.

22.   Kretzmann JP, McKnight JL. Building communities from the inside out. Evanston, IL: Northwestern University. Center for Urban Affairs and Policy Research. 1993.

23.   Klee D, Mordey M, Phuare S, Russell C. Asset based community development–enriching the lives of older citizens. Working with Older People. 2014;18(3):111-9.

24.   O'Mara-Eves A, Brunton G, McDaid G, Oliver S, Kavanagh J, Jamal F, et al. Community engagement to reduce inequalities in health: a systematic review, meta-analysis and economic analysis. Public Health Research. 2013;1(4).

25.   Shakespeare T. The social model of disability. The disability studies reader. 2006;2:197-204.

26.   Cahill S. Dementia and human rights: Policy Press; 2018.

27.   Bartlett R. Scanning the conceptual horizons of citizenship. Dementia. 2016;15(3):453-61.

28.   Keyes SE, Clarke CL, Gibb CE. Living with dementia, interdependence and citizenship: narratives of everyday decision-making. Disability & Society. 2019;34(2):296-319.

29.   Hughes JC. Citizenship and authenticity in dementia: A scoping review. Maturitas. 2019.

30.   OECD. HEALTH AT A GLANCE: Europe 2018: ORGANIZATION FOR ECONOMIC; 2018.

31.   Kellehear A. Compassionate communities: end-of-life care as everyone's responsibility. QJM: An International Journal of Medicine. 2013;106(12):1071-5.

32.   Crampton J, Eley R. Dementia-friendly communities: what the project "creating a dementia-friendly York" can tell us. Working with Older People. 2013;17(2):49-57.

33.   Mitchell L. A Step Too Far? Designing Dementia-Friendly Neighborhoods. Wellbeing: A Complete Reference Guide. 2014:1-34.

34.   Morgan S, Williamson T. How Can 'Positive Risk-Taking'Help Build Dementia-Friendly Communities. Viewpoint, Joseph Rowntree Foundation, York, November. 2014.

35.   Lin S-Y, Lewis FM. Dementia Friendly, Dementia Capable, and Dementia Positive: Concepts to Prepare for the Future. The Gerontologist. 2015;55(2):237-44.

36.   Di Bona L, Kennedy S, Mountain G. Adopt a care home: An intergenerational initiative bringing children into care homes. Dementia. 2017:1471301217725420.

37.   Calkins MP. From research to application: Supportive and therapeutic environments for people living with dementia. The Gerontologist. 2018;58(suppl_1):S114-S28.

38.   Manthorpe J, Iliffe S, Clough R, Cornes M, Bright L, Moriarty J, et al. Elderly people's perspectives on health and well-being in rural communities in England: findings from the evaluation of the National Service Framework for Older People. Health & social care in the community. 2008;16(5):460-8.

39.   Hare PD, J. How can we make our cities dementia friendly? Sharing the learning from Bradford and York. York Joseph Rowntree Foundation; 2015.

40.   Shakespeare T, Zeilig H, Mittler P. Rights in mind: Thinking differently about dementia and disability. Dementia. 2017:1471301217701506.

41.   Rahman S, Swaffer K. Assets-based approaches and dementia-friendly communities. SAGE Publications Sage UK: London, England; 2018.

42.   Lincoln P, Fenton K, Alessi C, Prince M, Brayne C, Wortmann M, et al. The Blackfriars Consensus on brain health and dementia. The Lancet. 2014;383(9931):1805-6.

43.   Tampubolon G, Nazroo J, Keady J, Pendleton N. Dementia across local districts in England 2014 to 2015. International journal of geriatric psychiatry. 2018;33(8):1127-31.

44.   Dean J, Silversides K, Crampton J, Wrigley J. Evaluation of the York Dementia Friendly Communities Programme. JRF; 2015.

45.   Courtney-Pratt H, Mathison K, Doherty K. Distilling authentic community-led strategies to support people with dementia to live well. Community Development. 2018;49(4):432-49.

46.   Coyle C. Wenham Connects: An age and dementia friendly needs assessment. 2018.

47.   Fleming R, Bennett K, Preece T, Phillipson L. The development and testing of the dementia friendly communities environment assessment tool (DFC EAT). International psychogeriatrics. 2017;29(2):303-11.

48.   Harding AJ, Morbey H, Ahmed F, Opdebeeck C, Lasrado R, Williamson PR, et al. What is important to people living with dementia?: the 'long-list'of outcome items in the development of a core outcome set for use in the evaluation of non-pharmacological community-based health and social care interventions. BMC geriatrics. 2019;19(1):94.

49.   Nicholls J LE, Neitzert E, Goodspeed T. A Guide to Social Return on Investment. London The Cabinet Office; 2012.

50.   Scholten P. Social return on investment: a guide to SROI analysis: Lenthe Publ.; 2006.

51.   Matthews FE, Arthur A, Barnes LE, Bond J, Jagger C, Robinson L, et al. A two-decade comparison of prevalence of dementia in individuals aged 65 years and older from three geographical areas of England: results of the Cognitive Function and Ageing Study I and II. The Lancet. 2013;382(9902):1405-12.

52.   Matthews FE, Stephan BC, Robinson L, Jagger C, Barnes LE, Arthur A, et al. A two decade dementia incidence comparison from the Cognitive Function and Ageing Studies I and II. Nature communications. 2016;7:11398.

53.   England N. Dementia diagnosis rate workbook 2017 [Available from: https://www.england.nhs.uk/publication/dementia-diagnosis-rate-workbook/.

54.   England PH. Dementia Profile 2017 [Available from: https://fingertips.phe.org.uk/profile-group/mental-health/profile/dementia.

55.   Buckner S. An evaluation tool for Age-Friendly and Dementia Friendly Communities. Working with Older People. 2018;22(1):48-58.

56.   Morgan N, Grinbergs-Saull, A,Murray, M. 'We can make our research meaningful' The impact of the Alzheimer's Society Research Network;. Alzheimer's Society; 2018.

57.   INVOLVE. Briefing notes for researchers: involving the public in NHS, public health and social care research. INVOLVE, Eastleigh; 2012.

58.   NIHR. UK Standards for Public Involvement 2018 [Available from: https://sites.google.com/nihr.ac.uk/pi-standards/home.

59.   Moffat J, Sass B, Mckenzie K, Bhui K. Improving pathways into mental health care for black and ethnic minority groups: a systematic review of the grey literature. International Review of Psychiatry. 2009;21(5):439-49.

60.   Cooper C, Tandy AR, Balamurali TB, Livingston G. A systematic review and meta-analysis of ethnic differences in use of dementia treatment, care, and research. The American Journal of Geriatric Psychiatry. 2010;18(3):193-203.

61.   Wu YT, Clare L, Jones IR, Martyr A, Nelis SM, Quinn C, et al. Inequalities in living well with dementia—The impact of deprivation on well-being, quality of life and life satisfaction: Results from the improving the experience of dementia and enhancing active life study. International journal of geriatric psychiatry. 2018;33(12):1736-42.

62.   Life Changes Trust. Dementia Friendly Communities: evaluation guidance and resources. Glasgow 2015.

63.   Society As. How to become a recognised Dementia-Friendly Community [Available from: https://www.alzheimers.org.uk/get-involved/dementia-friendly-communities/organisations/how-to-become-dementia-friendly-community. .

64.   Institution BS. PAS 1365:2015 code of practice for the recognition of Dementia-Friendly Communities in England. London: British Standards Institution; 2015.

65.   Society As. Guidance for communities registering for the recognition process for De-mentia-Friendly Communities. London: Alzheimer's Society 2013.

66.   Society As. Foundation criteria for the Dementia-Friendly Communities recognition process.: Alzheimer's Society; 2014-15.

67.   2017 NDEG. Quality and outcomes framework (QOF). Prevalence, achievements and exceptions England: Government Statistical Service; 2017.

68.   Desktop EA. Release 10.4 [software]. Redlands, CA: Environmental Systems Research Institute. 2016.

69.   UK G. English indices of deprivation 2015. Accessed 04/06/2018) Available: https://www. gov. uk/government/s tatistics …; 2015.

70.   StataCorp L. Stata Statistical Software: Release 14.[computer program]. StataCorp LP. 2015.

71.   Stansfield CD, Kelly; Bangpan, Mukdarut. Exploring issues in the conduct of website searching and other online sources for systematic reviews: how can we be systematic? Systematic Reviews. 2016;5(1):191.

72.   Health Do. Prime Minister's Challenge on Dementia 2020: implementation plan. London 2016.

73.   Health Do. Prime Minister's Challenge on Dementia: Delivering Major Improvements in Dementia Care and Research by 2015. Department of Health London; 2012.

74.   Alliance DA. Local DAAs: Dementia Action Alliance2017 [Available from: https://www.dementiaaction.org.uk/local_alliances.

75.   Thomas C, Milligan C. How can and should UK society adjust to dementia? Joseph Rowntree Viewpoint. 2015.

76.   Society As. What is a Dementia Friend? [Available from: www.dementiafriends.org.uk/WEBArticle?page=what-is-a-friend#.W7sjEvYnY2w.

77.   Society As. What is a Dementia Friends Champion? [Available from: https://www.dementiafriends.org.uk/WEBArticle?page=what-is-a-champion#.W7sjw_YnY2w.

78.   Foundation MH. Dementia, Rights, and the Social Model of Disability: A New Direction for Policy and Practice? : Mental Health Foundation London; 2015.

79.   International DA. The human rights of people living with dementia: From rhetoric to reality. 2016.

80.   Bartlett R, O'Connor D. Broadening the dementia debate: Towards social citizenship: Policy press; 2010.

81.   Birt L, Poland F, Csipke E, Charlesworth G. Shifting dementia discourses from deficit to active citizenship. Sociology of Health & Illness. 2017;39(2):199-211.

82.   Buckner S. Collaboration for Leadership in Applied Health Research and Care East of England. 2017.

83.   Turner N, Morken L. Better together: A comparative analysis of age-friendly and dementia friendly communities. AARP International Affairs, Washington, DC, available at: www …; 2016.

84.   Dewing J. Participatory research: a method for process consent with persons who have dementia. Dementia. 2007;6(1):11-25.

85.   Life MH. Visual Inquiry Tool Scotland [Available from: http://myhomelife.uws.ac.uk/scotland/resources/visual-inquiry-tool/.

86.   NVivo Q. Qualitative data analysis software. Version 12.: QSR International Pty Ltd; 2018.

87.   Ritchie J, Lewis J, Nicholls CM, Ormston R. Qualitative research practice: A guide for social science students and researchers: sage; 2013.

88.   Corp I. IBM SPSS Statistics: Version 24. IBM Corporation Chicago, IL; 2017.

89.   Alliance DDA. Review of the Dementia Statements ; Companion paper 2017.

90.   Fielden SJ, Rusch ML, Masinda MT, Sands J, Frankish J, Evoy B. Key considerations for logic model development in research partnerships: A Canadian case study. Evaluation and program planning. 2007;30(2):115-24.

91.   Drummond MF, Sculpher MJ, Claxton K, Stoddart GL, Torrance GW. Methods for the economic evaluation of health care programmes: Oxford university press; 2015.

92.   dementia APPGAo. Hidden no more: Dementia and disability 2019.

93.   Teper M, Godard-Sebillotte C, Vedel I. Achieving the Goals of Dementia Plans: A Review of Evidence-Informed Implementation Strategies. Healthcare policy= Politiques de sante. 2019;14(4):10-20.
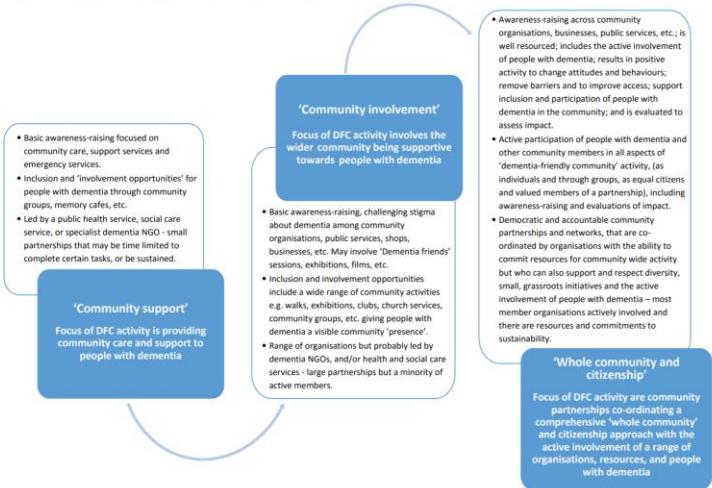
94.   Foundation TH. Building healthier communities: the role of the NHS as an anchor institution. London 2019.

95.   Clare L, Wu Y-T, Quinn C, Jones IR, Victor CR, Nelis SM, et al. A comprehensive model of factors associated with capability to "live well" for family caregivers of people living with mild-to-moderate dementia: findings from the IDEAL study. Alzheimer disease and associated disorders. 2019;33(1):29.

96.   Bethell J, Commisso E, Rostad HM, Puts M, Babineau J, Grinbergs-Saull A, et al. Patient engagement in research related to dementia: A scoping review. Dementia. 2018;17(8):944-75.

13 Appendices

Appendix I. Guidance and frameworks for the development of Dementia Friendly Communities

Framework/guidance	Author(s) & date Description
Four cornerstones model	Crampton et al., 2012 "...Communities need to consider four 'cornerstones' to test the extent of their dementia friendliness. • Place – how do the physical environment, housing, neighbourhood and transport support people living with dementia? • People – how do carers, families, friends, neighbours, health and social care professionals (especially GPs) and the wider community respond to and support people living with dementia? • Resources – are there sufficient services and facilities for people living with dementia and are these appropriate and supportive of their capabilities? How well can people use the ordinary resources of the community? • Networks – do those who support people living with dementia communicate, collaborate and plan together sufficiently well to provide the best support and to use people's own 'assets' well?" https://www.jrf.org.uk/sites/default/files/jrf/migrated/files/dementia-communities-york-full.pdf
Alzheimer's Society 7 foundation criteria for dementia friendly communities	• The right local structure in place to maintain a sustainable dementia friendly community • Identify a person or people to take responsibility for driving forward the work to support your community to become dementia friendly and ensure that individuals organisations and businesses are meeting their stated commitments • Have a plan to raise awareness about dementia in key organisations and businesses within the community that support people living with dementia • Develop a strong voice for people living with dementia living in your communities. This will give your plan credibility and will make sure it focuses on areas people living with dementia feel most important. • Raise the profile of your work to increase reach and awareness to different groups in the community • Focus your plans on a number of key areas that have been identified locally • Have in place a plan or system to update the progress of your community after six months and one year" https://www.alzheimers.org.uk/sites/default/files/2018-06/DFC%20Foundation%20criteria_Fs%20Albert_4.pdf
British Standards Institute PAS	2015 "Areas for action include but are not limited to: • Arts, culture, leisure and recreation; • Businesses and shops;

1365 code of practice.	• Children, young people and students; • Community voluntary, faith groups and organisations; • Emergency services; • Health and social care; • Housing; and • Transport." https://www.housinglin.org.uk/_assets/Resources/Housing/OtherOrganisation/BSI_Dementia_friendly.pdf
Alzheimer's Disease International: Dementia Friendly Communities new domains and global examples	2015 "In brief, the key outcomes which Alzheimer's Disease International believes should be pursued within dementia friendly communities include: • Increased awareness and understanding of dementia • Increased social and cultural engagement for the person with dementia • Legal and other measures in place to empower people living with dementia to protect their rights • Increased capability of health and care services to develop services that respond to the needs of people living with dementia • Actions to improve the physical environment whether in the home, residential care, hospitals or public places https://www.alz.co.uk/adi/pdf/dementia-friendly-communities.pdf
Evidence review of dementia friendly communities European Union Joint Action on Dementia	Blood et al., 2017 "**Voices of people living with dementia and carers** - how are people involved and heard? **Place** - how accessible are the buildings, public spaces and written information to people living with dementia? **People** - are there opportunities for raising awareness and sector specific training? **Networks** - how do organisations and services work together with others to support people living with dementia? **Resources -** how can resources be focused in a way that increase the accessibility of mainstream services for people living with dementia, builds resilience and provides a community-based response? https://www.actondementia.eu/sites/default/files/2018-02/Work%20package%207%20-%20Evidence%20review%20of%20Dementia%20Friendly%20%20%20%20%20Communities.pdf
An evaluation tool for age-friendly and dementia	Buckner, S., Mattocks, C., et al (2018) "The original AFC evaluation tool identified ten "evidence input areas" – thematic areas where evidence was required for an assessment of initiatives designed to be Age-Friendly (Buckner et al., 2017). Prior to data collection in Sheffield, these were modified slightly to adjust them to a focus on dementia friendliness

friendly communities	Evidence input areas: • Political support • Leadership and governance • Financial and human resources • Involvement of people affected by dementia • Priorities based on needs assessment • Application of existing frameworks for assessing dementia friendliness • Provision • Interventions rooted in evidence • Co-ordination, collaboration and interlinkages • Monitoring and evaluation" http://eprints.whiterose.ac.uk/125039/7/WWOP-11-2017-0032.pdf
European foundations initiative on dementia (EFID) (2016) mapping dementia friendly communities across Europe	Commonalities and essential factors: • Raising awareness, providing information, education and training • Inclusion of people living with dementia; involvement, participation, influencing • Building partnerships, networks, collaborations • Resources- financial, human, 'in kind'. Taxonomy for dementia friendly community activity (DEM-FACT) diagram below https://ec.europa.eu/eip/ageing/sites/eipaha/files/results_attachments/mapping_dfcs_across_europe_final.pdf
Dementia friendly communities: guidance for councils	Innovations in dementia "What can councils do? • Dementia-specific activities • One to one support • Peer group support and volunteering • Stimulating Support through mainstream services and activities https://www.local.gov.uk/sites/default/files/documents/dementia-friendly-communi-8f1.pdf
Dementia Action Alliance 10 characteristics of a dementia friendly community	2013 10 characteristics of a dementia friendly community: • Shaping communities around views of people living with dementia and their carers • Challenging stigma and building awareness • Ensuring that activities include people living with dementia

		- Empowering people living with dementia and recognising their contribution - Ensuring early diagnosis, personalised and integrated care is the norm - Befrienders helping people living with dementia engage in community life - Maintaining independence by delivering community-based solutions - Appropriate transport - Easy to navigate physical environments - Businesses and services that respond to customers with dementia

Appendix II Age Friendly Cities evaluation tool

The fieldwork in the two pilot sites started with a tool that had its origins in an instrument for assessing age-friendliness in cities (1), and which had undergone minor modifications for pilot testing in a DFC (2). While age-friendliness and dementia friendliness are related, the two are not the same (see 3,4) DEMCOM's aim was to produce a dementia-specific evaluation instrument.

The evaluation tool at the outset of DEMCOM identified ten thematic areas ('evidence input areas' or 'domains') in which evidence was required for an assessment of a DFC's performance (Fig.1a), and it provided a way of visually representing the findings (Fig.1b).

	Evidence input areas	Definitions
1	**Political support**	Backing (verbal and/or practical) from key political players locally – e.g. mayor, councillors, parties
2	**Leadership & governance**	Structures & roles for strategic overview & management
3	**Financial & human resources**	Commitment of funding, material means, staff, volunteers, investment in staff & volunteers
4	**Involvement of people affected by dementia**	Instrumental roles and contributions from people affected by dementia (those living with the condition and their supporters and carers). Includes available structures, nature of structures, nature of contributions, impact of contributions
5	**Priorities based on needs assessment**	Initiatives have been prioritised on the basis of a JSNA and/or other ways of assessing needs
6	**Application of existing frameworks for assessing dementia-friendliness**	Use by the city of existing guidance, e.g. by Alzheimer's Society, to inform its work on dementia-friendliness
7	**Provision**	Availability of relevant services and facilities, including consistency (e.g. geographical coverage) and continuity (availability and personnel), and consideration of issues around uptake
8	**Interventions rooted in evidence**	Scientific evidence has been consulted and interventions have been based on the available evidence
9	**Co-ordination, collaboration & interlinkages**	Partnership working across sectors, co-ordination of relevant activities, and interlinkages between different areas of focus
10	**Monitoring & evaluation**	Monitoring and evaluation of ongoing and completed work, including plans for monitoring and evaluation and allocation of resources. Nature of monitoring and evaluation. Translation of findings into policy & practice

Fig.1a: An emerging evaluation tool for DFCs – domains and definitions
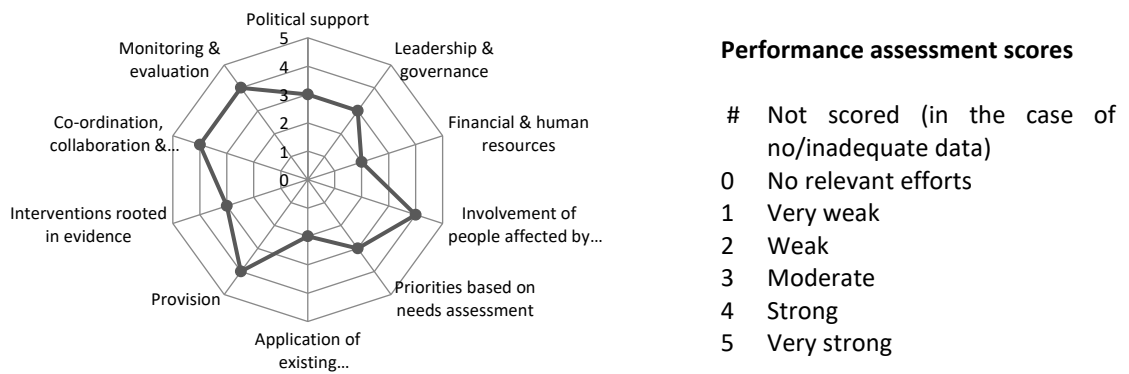
Fig.1b: Example – assessment of a community's efforts to become more dementia friendly

Performance assessment scores

#	Not scored (in the case of no/inadequate data)
0	No relevant efforts
1	Very weak
2	Weak
3	Moderate
4	Strong
5	Very strong

Integral to the pre-DEMCOM evaluation tool was a mechanism for quality appraisal of the available evidence. This has not been adopted for the DEMCOM tool which, unlike the original evaluation tool, is accompanied by detailed minimum data requirements.

References

1. Buckner S, Pop D, Mattocks C, Lafortune L, Dherani M, Bruce N. Developing Age- Friendly Cities: an evidence-based evaluation toll. J Popul Ageing. 2017.
2. Buckner S, Mattocks C, Rimmer M, Larfortune L. An evaluation tool for Age-Friendly and Dementia Friendly Communities. Working with Older People. 2018
3. Buckner S. Collaboration for Leadership in Applied Health Research and Care East of England 2017. 09/10/2017]. Available from: http://www.clahrc-eoe.nihr.ac.uk/2017/06/dementia-friendliness-age-friendliness/
4. Turner N, Morken L. Better Together: A comparative analysis of Age-Friendly and Dementia Friendly Communities. Washington DC; 2016.

Appendix III Stakeholder summary report sent to participants
(Double click for access)

National Evaluation of Dementia Friendly Communities

DEMCOM study

SUMMARY REPORT

Dementia Friendly Communities Workshop
Friends House, Euston, 2nd February 2018 11:00-15:45

Department of Health & Social Care | National Institute for Health Research (NHS) | Collaboration for Leadership in Applied Health Research and Care East of England | University of Hertfordshire UH | UEA University of East Anglia | UNIVERSITY OF CAMBRIDGE

Appendix IV. Evidence informed questions for the evaluation tool (early draft Jan 2018)

Domain	Evidence (emerging findings & literature)	Key questions
Political support	• Political endorsement/active engagement of councillors can facilitate access to resources	• Is the DFC endorsed by elected members and the local authority?
Leadership & governance	• If leadership is unclear, DFC can struggle • Involvement of PAD in leadership & governance structures (examples from Phase One survey of PLWD chairing DAA)	• Is there a clear leadership to drive the DFC forward? • Are PAD involved in leadership & governance structures?
Resources	• DFCs across England affected by austerity, short-term funding, uncertainty. Questions around sustainability of funding • Resource allocation within DFCs might involve competitive bidding and may not necessarily be equitable • In some DFCs reliance on one funding source, others drawing on different sources • Handling resource constraints: apply for non-dementia specific grants, use them to provide dementia-inclusive services	• Is the resourcing of a DFC appropriate for its purposes and sustainable? • Is allocation of resources within a DFC equitable? • Does a DFC draw on variety of resources, or rely on one source? • Does DFCs have mechanisms for handling resource constraints (e.g. pooling resources; enhanced creativity & innovation?)
Involvement of people affected by dementia	• There are opportunities for PAD to shape their DFC through involvement structures • PAD become involved in various ways (e.g. assessing their DFC; providing input into dementia strategy) • Involvement is meaningful, 'not just tokenism' (SITE A) • Feedback is given to PAD on their contributions and action taken as a result • PAD from seldom heard groups are involved	• Are there involvement structures for PAD? • Do PAD become involved in various ways? • Do PAD feel their involvement is meaningful and valued? • Are PAD given regular feedback about change affected by their contributions? • Are PAD from seldom heard groups involved?
Priorities based on needs assessment	• DFC activity is informed by local needs/assets assessment	• Is there evidence of DFC activity & priorities having been informed by a local needs-/assets assessment?
Application of existing frameworks for assessing dementia-friendliness	• Use of guidance such as BSI, Alzheimer's Society foundation criteria to inform DFC activity • Liaising with other DFCs and comparing activities and focus (SITE A & SITE B)	• Has DFC used existing frameworks to guide DFC work, including - guidance published by Alzheimer's Society (1 – 3) - BSI standards (4) - Other (5 – 8) • Does the DFC comparing activities/focus with other DFCs?
Provision	• Different models of service delivery (central hub/SITE A, neighbourhood-based/SITE B) can have implications for reach	• What is the DFC's model of service provision, and does it ensure appropriate reach?

	• Examples of DFCs that emphasise dementia-specific (SITE A) and dementia-inclusive provision (Site B). Either approach can be appropriate see (9, 10)
	• Reach different groups of people affected by dementia (PLWD, carers/supporters)
	• Reach of wider population – much emphasis on awareness raising, which the literature highlights as key (1,3,4,7 -13)
	• Some groups difficult to reach (e.g. BAME), and not much provision for some groups (e.g. LGBT in SITE B)
	• Provision that integrates different groups (e.g. intergenerational) (3-11)
	• Not all stages of dementia journey well covered – e.g. gap in between immediate post-diagnosis and later-stage dementia (SITE A?)
	• Potential gap around prevention/risk reduction. But some evidence that this is starting to get some attention (forthcoming SITE B Dementia Strategy)
	• Not necessarily a good match between provision and need
		• Does nature of provision match local priorities and preferences?
		• Do facilities & services reach different groups:
		  - PLWD
		  - supporters/carers
		  - wider population
		  - specific groups (e.g. BAME; LGBT)
		  - across boundaries (e.g. intergenerational activities (4); bringing together different groups)
		• Does provision cover different stages of people's dementia journeys?
		• Is there a focus on prevention/risk reduction?
		• Is there a match between provision & need?

Interventions rooted in evidence	• Activities based on existing scientific research or DFC-internal evaluation	• Is DFC activity based on scientific evidence? • Has DFC considered existing evaluations e.g. (9,10,14)?
Co-ordination, collaboration & interlinkages	• DAA with multi-sector membership • Collaboration among different sectors in the community • Collaboration beyond the DFC (e.g. liaising with other DFCs (SITE A&SITE B) • Strong interpersonal relationships between DFC leads (SITE B)	• *Is there a DAA/governance structure with multi-sector membership?* • Is there collaboration among different sectors within the DFC? • Is there collaboration and networking beyond the DFC (e.g. learning from others)? • Do DFC leads have strong and mutually supportive relationships?
Monitoring & evaluation	• DFCs are monitoring achievements/progress (e.g. monitoring number of dementia friends) • Formal evaluation of individual aspects of DFC • Findings from monitoring and evaluation as a basis for action • Involvement of PAD in monitoring & evaluation • Collaboration with local Universities on evaluation (SITE B)	• Does DFC routinely monitor its progress? • Has DFC been conducting formal evaluation of aspects of its work? • Re findings put into action? • Are PAD involved in monitoring and evaluation? • Does the DFC collaborate with local Universities on monitoring and evaluation?

Tab…: Preliminary evidence-informed questions for an evaluation of a DFC

References

1. Alzheimer's Society. Foundation criteria for the Dementia-Friendly Communities recognition process. London; 2014-15.
2. Alzheimer's Society. Guidance for communities registering for the recognition process for Dementia-Friendly Communities. London; 2013.
3. Green G, Lakey L. Building Dementia-Friendly Communities: a priority for everyone. London; 2013.
4. British Standards Institution. PAS 1365:2015 code of practice for the recognition of Dementia-Friendly Communities in England. London; 2015.
5. Life Changes Trust. Dementia Friendly Communities: evaluation guidance and resources. Glasgow 2015.
6. Alzheimer's Disease International. Dementia Friendly Communities (DFCs): new domains and global examples. London; 2015.
7. Hare P, Dean J. How can we make our cities dementia friendly? Sharing the learning from Bradford and York. York; 2015.
8. Local Government Association. Developing Dementia Friendly Communities: learning and guidance for local authorities. London; 2012.
9. Dean J, Silversides K, Crampton J, Wrigley J. Evaluation of the Bradford Dementia Friendly Communities Programme. York; 2015
10. Dean J, Silversides K, Crampton J, Wrigley J. Evaluation of the York Dementia Friendly Communities Programme. York; 2015
11. Imogen Blood & Associates Ltd and Innovations in Dementia. Evidence review of Dementia Friendly Communities. 2017.
12. Prior P. Knowing the foundations of Dementia Friendly Communities for the North East. 2012.
13. Buswell M, Goodman C, Russell B, Bunn F, Mayrhofer A, Goodman E. Community engagement evidence synthesis : A final report for Alzheimer's Society. Hatfield; 2017.
14. Institute of Public Care. Evaluation of Hampshire Dementia Friendly Communities. Oxford; 2015.

Appendix V. Revisions to the evaluation tool

	Original	Revised	Rationale for revisions
Renamed	Financial & human resources	**Resources**	To ensure domain names are concise and intuitive
	Provision	**Activities & environments**	
	Co-ordination, collaboration & interlinkages	**Collaboration**	
Merged	Leadership & governance	**Leadership & governance**	Emerging evidence from pilot sites had shown the relevance of political support (or, by implication, its absence) for the strategic direction and way forward for a DFC
	Political support		
	Priorities based on needs assessment	**Basis of DFC**	There were a wide range of resources available to inform the work of a DFC. While they differed on key aspects (e.g. a local needs assessment as a 'DFC-internal' document; official guidance by Alzheimer's Society on creating DFCs as an 'external' document; etc.), it seemed reasonable to consider these within one domain as sources of information and materials that provided a basis for a DFC's work.
	Interventions rooted in evidence		
	Application of existing frameworks for assessing dementia-friendliness		
Unaltered	**Involvement of people affected by dementia**		
	Monitoring & evaluation		

Fig.xx: Revisions to the evaluation tool based on the research in the pilot sites

Appendix VI. Evaluation tool- domain definitions

Definitions
Leadership and governance: Strategic overview and management. Role of stakeholders in consulting on, organising and reviewing the work of a Dementia Friendly Community. How key political players relate to the Dementia Friendly Community.
Basis of DFCs: Extent to which the following have informed a Dementia Friendly Community: • Assessments of local dementia-related need and assets • Existing guidance for Dementia Friendly Communities • Scientific evidence on Dementia Friendly Communities
Resources: Different kinds of resources available to support a Dementia Friendly Community, and ways of ensuring the sustainability of a Dementia Friendly Community.
Involvement of PAD: Involvement of people affected by dementia in shaping a Dementia Friendly Community through advisory, operational and strategic capacities. Effects of involvement on practice.
Activities and environments: Provision of services and facilities relevant to people affected by dementia, information about them, and their access and reach. The physical and social environments provided by a Dementia Friendly Community..
Collaboration: Nature and extent of collaboration among different stakeholders in a Dementia Friendly Community.
Monitoring & evaluation: Measuring the performance of a Dementia Friendly Community, or individual aspects of its work, at different points in time.
Inequalities: Imbalances in any aspects of a Dementia Friendly Community (e.g. geographical distribution of services not compatible with identified need; shortcomings in resource allocation to specific user groups; exclusion of specific stakeholder groups from leadership and governance arrangements; etc.)
Sustainability: Consistency and continuity in relation to the different elements of a Dementia Friendly Community (e.g. secure resourcing; continuity in leadership; etc.)

Fig.xx: Revised evaluation tool based on the research in the pilot sites – definitions

Appendix VII. Definitions of 'good' as proposed by the Stakeholder Event

Domain	Key criteria
Leadership & governance	o Passionate and proactive local leaders who drive the dementia agenda forward o Strong political support for dementia friendly agenda o Strong cross-sector collaboration, including between key agencies (e.g. health, social care, public health) o Individuals and organisations involved with a DFC need to network to increase the reach of the DFC o People involved with the DFC are linked to other services and organisations, and know about each other
Resources	o DFC is supported by people with excellent fundraising skills o Continuity of resources o Contributions from paid staff and volunteers
Activities & environments	o Range of activities for people affected by dementia that covers all stages of people's dementia journeys o Services and activities for carers/supporters o There's a choice between dementia-specific and dementia-inclusive services o Services and activities are well publicised, information is accessible o People affected by dementia have been involved in designing activities and environments o Choice & flexibility (e.g. 'slow check-out lanes' available at all times) o Local systems and services have anticipated what people living with dementia might need (e.g. shopping, voting, travelling, seeing GP, seeking financial advice)
Monitoring & evaluation	o Proxy measures of dementia awareness are in place (e.g. number of people who have taken up a Lasting Power of Attorney; dementia is mentioned in broader contexts)
Involvement of people affected by dementia	o People affected by dementia are involved in all aspects of DFC (strategic leadership; operational; evaluation) o Partnership working within DFC includes people affected by dementia
Equalities & inclusion	o Emphasis on the rights of people living with dementia o Language used in a DFC is respectful and inclusive o Day-to-day encounters and relationships with neighbours and people providing services are dementia friendly
Outcomes	o Dementia friendliness is a feature of communities of different scales (i.e. a small community such as a local club or church, and the wider local community within which the latter is situated)

Fig.x: Key criteria for a 'good' DFC identified by participants at the national stakeholder workshop (Feb 2018)
Note: These have been arranged here by (selected) domains of the post-workshop version of the tool

Appendix VIII DEMCOM survey for people living with dementia

National Evaluation of Dementia Friendly Communities

We want to ask you some questions about living with dementia in [site]
There are 8 questions on 3 pages. You do not need to answer all of them. Any information you give is very valuable to us.

We will keep your answers confidential. If you have any questions please call Nicole Darlington (DEMCOM researcher) on **01707 284457** or email **n.darlington@herts.ac.uk**.

Please return your completed questionnaire in the prepaid envelope.

Thank you for sharing your views.

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1. Which of the following best describes you?
☐ I am filling in this questionnaire on my own
☐ Someone else is helping me to fill in this questionnaire

2. Are you aware that [site] is trying to become a 'Dementia Friendly Community?'
☐ Yes   ☐ No

3. What sort of things do you do now in Site C? (Tick all that apply)

☐ Go to work
☐ Meet with friends/family in the home
☐ Leisure activities (e.g. cinema, clubs, sports)
☐ Go out to pubs/restaurants/cafés
☐ Shopping and errands (e.g. banking)
☐ Go to a community centre
☐ Use public transport
☐ Go for walk
☐ Attend religious services ☐ Other (Please say) _____

4. Have you stopped doing anything because of dementia?
☐ No
☐ Yes (please say) _____

_____

5. What would <u>most</u> help you to live well with dementia in [site]?
(Tick <u>one</u> only)
☐ Members of the public understanding what it is like to live with dementia
☐ Extra support in public places (e.g. shops, cinema, sports centres)
☐ Larger choice of enjoyable activities
☐ Better public transport
☐ Other (Please say) _____

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Please explain your answer



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6. How did you find out about services and activities around dementia in [site]? (Tick all that apply)

☐ Memory Clinic
☐ GP practice
☐ Alzheimer's Society
☐ Other (Please say)
☐ The Council

☐ Friends and family
☐ Internet _____

7. Which dementia groups in [site] are you part of?

☐ Activities for people living with dementia (e.g. Singing for the Brain, Dementia café)

☐ Dementia support group

☐ Dementia Action Alliance

☐ Service user group
☐ Dementia research group
☐ Other (please say) _____
☐ None

8. Do you agree with these statements? (Please tick)

a) People living with dementia can feel safe when they go out in [site]

☐ Yes   ☐ No   ☐ Don't know

b) What it means to live with dementia is well understood in [site]

☐ Yes   ☐ No   ☐ Don't know

c) People living with dementia are valued for their contributions in [site]

☐ Yes   ☐ No   ☐ Don't know

About yourself

I am
☐ Under 55   ☐ 55-64   ☐ 65-74   ☐ 75-84   ☐ 85+

I am
☐Male   ☐Female   ☐Prefer not to say

How would you describe your ethnic background (e.g. White British, White other, Asian, African, Chinese)
_____

I am in the
☐ Early stages of dementia
☐ Middle stages of dementia
☐ More advanced stages of dementia

I normally live

☐ On my own
☐ With someone who supports/cares for me
☐ With someone who is not my carer/person who supports me
☐ In a care home
☐ Other (please say)

What is the first part of your post code (e.g. WR11)

_____

Appendix IX DEMCOM final NVivo coding tree

01_Leadership and governance
- Motivation for involvement
- Players & roles
- Political support
- Structures and accountability
- Equalities and inclusion
- Evolution
- Involvement of people affected by dementia
- Outcomes

02_Basis of DFC activities
- Development of strategies & frameworks
- Experiencing dementia
- Frameworks & guidance used
- Motivation for DFC
- Needs & assets assessed
- Scientific evidence base considered
- What is a DFC & dementia friendliness
- Equalities and inclusion
- Evolution
- Involvement of people affected by dementia
- Outcomes

03_Activities and environments
- 1 dementia-specific provision
- 2 integration into mainstream
- 3 Community engagement and increasing awareness
- Access to information and awareness of dementia specific activities
- accessibility and uptake of services & facilities
- Communication
- Risk reduction & prevention of dementia
- Equalities and inclusion
- Evolution
- Involvement of people affected by dementia
- Outcomes

04_Resources
- Financial resources
- Funding sources for DFC
- Human resouces- paid
- Human resources- unpaid
- Other resources
- Equalities and inclusion
- Evolution
- Involvement of people affected by dementia
- Outcomes

06_Monitoring and evaluation
- Findings
- Impact of DEMCOM on research site
- Methods of monitoring
- Equalities and Inclusion
- Evolution
- Involvement of people affected by dementia

- Outcomes

Other
Quotes
Y Challenges and areas for further work in DFC
Y Strengths of DFC

Appendix X. List of activities by case study site and type of activity

List of activities by case study site and type of activity <mark>Focus group,</mark> <mark>Documentary evidence</mark>, Interview, **mentioned in more than one source of info such as interview and documentary**

	Dementia specific provision	Dementia inclusive/integrated provision	Community engagement
Site A	• Arts and crafts group • Carers Trust drop in service • Current affairs group • CRiSP (Carers Support and Information Programme • CROCUS café (Rotary Club) • DART (Review panel-PLWD who want to influence work of society) • Dementia Café Ferry Meadows • Dementia Eye Café • Dementia Café Longthorpe • Gardening Club (PLWD and carers) • Healthy Memories Men's Group • Healthy Memories Ladies Group • Knit and Knatter Group • Ladies Activity Group • Men's Activity Group • Oomph (Seated exercise-PLWD and carers) • Open Carers Group • Open Minds Group • Orton Wistow Activity Group • Singing for the brain • Sue Ryder Synergy Café (Monday) • Sue Ryder Synergy Café (Weds) • Whittlesey Carer's Group • Young On-Set Group • Vivacity (Exercise referral scheme) • Hairdressing Service • Chair Yoga • Dementia Walks (Run by PCC) • Café Church (Salvation Army)	• Inspire and Mobility Aids Centre Fitness Suite.	• Dementia friends • Dementia Champions • Tesco- dementia friendly training, community room available to be booked free to dementia champions to do DF training • Work with Schools (Nene Park Academy) • Dementia talk to insurance company (BGL Insurance) • Doctors surgery (Dementia support worker- ID hard to reach communities) • Information stand in John Lewis, plus dementia awareness for staff • Shopping Centre (Serpentine Green- signed up as PDAA member and representation of PLWD views for redevelopment to ensure inclusive as poss) • Police force wide Dementia Friend awareness, 3 dementia champions. Amended vulnerable adult referral forms and info leaflet and info on www. And Herbert Protocol (to speed up finding missing PLWD) • Inclusive Shopping events (December) for PLWD (Queensgate shopping C) (Reduced lighting, larger print, sensory room, dementia awareness for shop staff, and carer awareness, information stand • Working towards dementia friendly stickers • Hospital- 65 Dementia Champions and Dementia Specialist Nurse. Dementia strategy, Working Group, environmental dementia friendly charter. One-one, distraction therapy, ensuring patients eating and drinking enough, dementia champion study days, training on Abbey pain tool, screening all patients over 75 for cognitive

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	• Drop in Service		impairment, use of forget-me-not flower to ID patients. Various initiatives of wards- crockery, rummage boxes, disguising exit doors, sensory garden etc. • Mystery shopping
Site B	• Reminscence coffee afternoon 'Down Memory Lane' (Dementia Action Week 2/5/11 Meadowhall) • Monthly Dementia Café (Salvation Army) • Home Instead Friendship group (Devonshire Arms weds) • 'Love Sport' (Woodhouse Library) Monthly • Friendship lunch (monthly) Stag Inn Woodhouse • Age UK- evening respite care (for people outside normal working hrs) • Sporting memory groups (Libraries) weekly • Sporting memory groups (Crystal Peaks) • Heely City Farm (range of activity incl gardening group, Frontotemporal lobe dementia group, carer respite, animals to CHs/groups) • Dementia Information Advice and Support Service • Memory management Service • Dementia Rapid Response Team • Community Dementia Support Service • Darnall Dementia • 'Remember When' activities • Woodhouse dementia café • Valley Dementia café • Tea dance (Crucible Theatre) • Crucible theatre- dementia friendly performances • Orange pass- let people know you need extra help • Dementia Friend Training • Dementia Fire and Home Safety Project • Singing for the brain • SHINDIG • Cognitive Stimulation Therapy (5 weeks) Memory service • Time for change (5 weeks) Memory service • Walking group (PLWD and carer) • Dancing with Dementia (tea dances- 3 groups) • DF swimming	• Adopt a care home local school matched with Care Home • Carers centre (range of activity reaching 10,000 carers) • Operation Signature (ID victims of fraud) Fit a free True Call Secure telephone fitted for free. (police) • Reading friends (incl PLWD) • People Keeping Well Programme (activity supported by SDAA, provide info and advice to carers, Access to daycare +respite cross city) • SE People Keeping Well (PKW) Training GP receptionists, Partnership meeting focused on dementia, work with 11 GP practices (PKW involves around 24 organisations) • Midlife population- Health checks and health trainers • Move more Ambassadors network (encourage people to be more active, sportswear exchange in Manor and Castle) • Trading Standards ('Not born Yesterday' avoiding scams) •	Engagement with 21 organisations • Community transport • First direct buses • Supertram • Alz Soc • City council (dementia awareness for staff) • SDAA • Grenoside Grange Dementia Unit • CLARCH • Libraries • Home Instead • Age UK • Rotary Club • Museums Partnerships • High Green Trust

	• Dementia Friendly housing (Anchor Homes and 2 sheltered housing) • Young Dementia Group (same as below?) • Graves Health and Sports club Young Dementia UK (Not sure if same as above • 'Hold that thought' (Reminiscence groups Sth Wards, and resource pack) • Community Support workers (work with people for max 3 weeks, can take people to a group for first time) • Dementia Community Road Show (May 2018) • Manor Top and Hillsborough Craft centre (2 diff centres) • Herbert Protocol • Northern General Hospital Reminscence Ward Groups		
Site C	• 'Dementia information prescription' service • Dementia café young onset • 'Ed's Café' – 10:30-3pm. Drinks, singing, talks – more day care for PLWD, carers chat separately • Carers care line • **Dementia café** • Reading groups at the library • "Event where people who haven't necessarily been diagnosed or have just been diagnosed, they can go along for an hour or so and learn about dementia and then get signposted". • **Tea service** • Knees up teas up • 1960 reminiscence in churches • **Singing for the brain** • Irregular boat trips • Side by side • Trips to a rare dementia support group in Worcester • "that will be the day" 50s and 60s music event • Fire safety checks for PLWD • **Singing for the brain** • **Tea dances** • **Dementia café** • **Afternoon tea at church and church service** •	• Relaxed lane in supermarket • Trained till staff to increase awareness and not rush people • Local library has good ideas but not signed up to the website yet (presumably DAA?) • Community garden funded through Tesco grants (in planning stages) • Older peoples forum weekly exercise plan open to PLWD • Pensioners association exercise classes inclusive of PLWD • Afternoon screenings – in talks about making dementia friendly • Quiet hour and relaxed lane in supermarket	• **Working with schools being planned** • Getting companies to make a pledge • Bridging the generations – young design a menu and cook for PLWD • Awareness events run by a housing association for their residents to raise awareness • Events bringing college student together with PLWD • Dementia friends • Dementia champions • Go to cafés to publicise activities • **School classes to include dementia and planned future work** • Promoting side by side (not sure of specifics) • Dementia friends for school children • Awareness raising events and DAA stalls at events • **Dementia friendly stickers** • Recruitment to DAA • Event at college with lunch, activities, raising awareness and interaction intergenerationally. • **Dementia friends** • **Stickers in shops** • Posters e.g. in GP surgeries and library
Site D	• Dementia Friends • Dementia friendly pantomime • Dementia friendly cinema screenings • DF dances • Trip to Beamish	• Dementia friendly café • Dementia friendly faith groups • Housing group adapting houses to be dementia friendly • Dementia friendly screenings • Dementia friendly theatre	• Send out flyers promoting activities • Recruit to the DAA • Dementia Action Week poster (suggestions to make more DF)

	• DF sports village- Bowls, chair-based exercise, walk • DF Tour of football stadium • Dementia cafés • Creative Age- Museum and galleries (D awareness training for staff) Institute of modern art, and offering DF creative sessions. • Singing for the brain • The big sing • Dementia Advisory Service • DF Table Tennis sessions • Chair based exercise • Herbert Protocol	• Quiet space in bus station • Dementia friendly car park space • Dementia friendly sports centre • Nouveau wellbeing group – activities in care homes and community centres • Aim to make businesses dementia friendly environments (not specific how many/which ones)	• Dementia awareness is school children • Signing up businesses to be DF • Street performance • Information stalls •
Site E	• Dementia Friends • Bentley Motors Tea Party, BBQ/Xmas event – Brands Hatch • Dementia Friendship Group • Dementia Day support service • ST Georges Living Well Group • Friendship Café • Carers Dementia Support Services • In together Dementia support group • Poynton Golder memories group (Dementia) • Knutsford and District Good Neighbours • Dementia reablement Service (North and South) • Memory café (Barnies) • Dementia Support Service • Singing for the Brain (Sandbach) • Dementia café (adlington, Tytherington) • Dementia Support Service (AS) • Dementia Advisor Service (Age UK) • Monthly Dementia café (AS) • Golden Memories group • Dementia Connect (AS) • Dementia ID Cards • Dementia Friends events • Creative coffee afternoon • Arts and Dementia programme (Council's Arts, heritage and cultural services)- Dementia Friendly cultural venues. • Nantwich museum (dementia friendly activities) • Dementia Carer Wellbeing programme • Congelton Saw mill (afternoon Tea and activities) • Dementia friendly walks • Cricket club- Company Corner	• Assisted pension collection and shopping (Methodist Homes) • Teleprompt service (Methodist Homes) • Knutsford RVS Good Neighbours Befriending Service) • Disley Parish Council Befriending Service • Fire Services- Safe and Well visits- record PLWD • Inclusive swimming (mixed changing rooms- to carer can support PLWD) • Health and well event • Aqua relax (swimming for people with medical condition) • Assistive tech show flat- Macclesfield • Crewe station- designated room- safe haven for anyone, incl PLWD to await arrival or carer/police • Drop in centre for Veterans (to address social isolation) • Fall prevention classes (incl PLWD) •	• Constabulary (Herbert protocol) • Carer Wellbeing Programme • Film of project in supporting people living with dementia • Dementia Awareness with local schools and churches • Dementia awareness with 'Transport Solutions' • Awareness session with local retailers (M&S, Tesco etc) • Haylo Theatre- Theatre company-raising awareness of dementia • Working with churches to become DF • Library (Knutsford) section on info for carers of PLWD • CRiSP course (for carers of PLWD)
Site F	• Memory clinic referral to Alzheimer's Society dementia support workers (but not all the time)	• Support medical staff to increase awareness and improve services for PAD • Promote assistive technology	• **Recruit dementia friends mentioned numerous occasions over many sessions with targets of friends t recruit**

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- Dementia support groups - games
- Carers groups - support
- Privately funded support group (carers and PLWD)
- Card that says (I have got Alzheimer's)
- Continue to support the LPT Memory Assessment service and identify opportunities to work with partner agencies to identify people living with dementia through screening for example.
- To include an emphasis on ensuring that interventions meet the needs of local diverse and BAME communities and under-represented groups – including early onset dementia and people with a learning disability
- Monitor the current pathway and modify where appropriate with a view to achieving the most appropriate model and capacity
- Dementia Care Advisor service
- Ensure links to memory cafés, peer support groups, and other dementia services
- Ensure carers receive assessments
- Provide carers with day care services
- Carer support program running courses
- **Carers centre**
- Dementia Library service
- Singing for the brain
- **Memory café**
- Side by Side – out and about service designed to enable PLWD to do the things they enjoy
- **Hospital dementia support service – meaningful activities service**
- **Hospital dementia friendly 'café' mock café designed as a place to go for PLWD**
- *Validation* workshop – helping people to interact better with PLWD
- Cinema in patient bedrooms
- REMPODS
- Befriending services
- Dementia friendly faith services senior club
- **Herbert protocol**
- House of memories workshop – training for family and carers (also community engagement)
- **Meaningful Activity service and coordinators in the hospital**

- Shared Lives - carers work from their own homes to provide day care, short term respite or long term live-in arrangements for adults who have social care needs, including dementia
- Make buildings dementia friendly:
  - **11 x areas** reported in total to be made dementia friendly in the article
- **2**
- **3**
- **4**
- **5**
- 6 buildings referenced as becoming dementia friendly
- 7 counting each building separately
- **8**
- **9**
- **10**
- 11 buildings listed (not clear if all or even any are in the city though)
- **Major Environment adaption in shopping centre – seating, lighting, music, toilets, signage. Accessibility strategy includes dementia**
- Songs of praise at cathedral dementia inclusive
- **Hospital dementia friendly corridor**
- **Dementia friendly garden**
- **Message in a bottle**
- Message in a bottle
- **Dementia friendly garden**
- Crafts groups
- Social groups (called the well-seasoned group)
- Oral poetry group for all disabilities to be inclusive of dementia
- Markets undergoing major environment change – colour schemes, mats, lighting, toilets, signage, improve accessibility by rearranging stalls in market
- Made food hall or market more accessible – signage etc
- Environmental changes in the hospital – colour schemes, layout.
- Dementia friendly super market
- Museums adapting as much as possible to be dementia friendly (restricted by being listed buildings)
- Different museum site adapted lighting, mats.
- **Dementia friendly garden**

- **Recruit dementia champions**
- Train members of organisations about dementia including medical staff about carer needs
- Raise awareness with promotional events
- Identify key contacts in schools and higher education to raise awareness in students
- Review website information
- Audit information about dementia and address gaps
- Awareness event where members of organisations and support groups were on hand to offer information and advice
- Memory walk to raise awareness and funds
- Alliance launch event
- **House of memories awareness event**
- News articles promoting dementia friendly buildings and encouraging people to take part in the initiative
- Herbert protocol publicised via various forums including shopping centre and during awareness week
- **During awareness week: dementia friends mentioned lots, as well as linkages with different organisations, difficult to count…**
- GP holding afternoon tea events to promote mini mental tests
- 3 days of dementia roadshow event
- Recruit DAA members
- Arts centre at university offered dementia friendly activity days during awareness week
- Posters and leaflets being distributed as part of awareness week
- **Social media and twitter hashtags and communications**
- **Recruitment to DAA**
- **Recruitment to DAA**
- Publicise events at each group they attend – shopping events publicise their dementia friendly work
- **Dementia friends**
- **Dementia champions**
- Hospital dementia champions (same as dementia friends just in the hospital)
- **House of memories awareness event**

• Alzheimer's society hospital dementia support service • Free fire checks for PAD • **Herbert protocol** • Memory boxes and reminiscence resources • **Memory cafés** • **Carers centre** • Dementia support service (may be linked to other activities like advisors service, not clear) • Hospital dementia friendly mock café	• **Shopping centre changed environment – lights, toilets, signage, sounds etc** • Educational adult courses ore tailored to PAD • Hospital reminiscence ward	• Stands and posters I various locations such as in the restaurant • **Twitter** • Public meetings at the hospital and have stalls promoting the initiative • Hospital dementia meaningful activities service have distinct uniforms which helps promote awareness of dementia and where they operate such as A&E • Forget me knot scheme in hospital • Pop up shops during dementia awareness week • Awareness training for staff across different organisations (unsure if this is dementia friends, is in some cases, isn't in others) • Dementia ambassadors – shopping centre • 'training' offered at the university (unsure if it is dementia friends) • Community boards to promote activities • Word of mouth – specifically to promote the initiative • Dementia support service specifically targeted with raising awareness in hard to reach communities • Alzheimer society information workers

Appendix XI. DEMCOM final evaluation tool (definitions)

Definitions
Leadership & governance: How DFC is led, evidence of strategic overview, who is involved and how responsibilities are agreed. Role of local political leaders and wider infrastructure.
Basis of DFCs: Extent to which espoused values and learning are known and have informed the development and approach. Use of existing guidance and of evidence of what works.
Resources: Different kinds of resources available to support a DFC.
Activities & environments: Provision of services and facilities for people affected by dementia. Awareness raising, campaigning, risk reduction.
Monitoring & evaluation: Measuring the performance of a DFC, or aspects of its work, at different points in time.
Involvement of people affected by dementia: Involvement structures, and how people affected by dementia have shaped a DFC through advice and participation in strategies and decision making.
Equalities & inclusion: How inclusion and equitable distribution are achieved.
Evolution: How the work of the DFC has developed, maintained continuity, and responded to change over time.
Outcomes: Impact of DFC on the lives of people affected by dementia. Economic implications.

Fig.xx: DEMCOM evaluation tool for DFCs – definitions

Appendix XII. Example of sources of evidence and questions that can be used to evaluate the level of maturity and impact of a DFC

Evaluation framework for Basis domain

Basis of the DFC	Early	Developing	Embedding
Knows local community and priorities of people affected by dementia	Knows how many people living with dementia in the community and where Y/N	Knows how many people living with dementia in the community by cultural background	Evidence that the priorities and rights of people living with and affected by dementia discussed in local policy and action plans for transport, built environment and service provision based on local PAD feedback on priorities and preferences
Draws on best evidence of how to support PAD to live well	Evidence of linking work with local policies or community initiatives for people living with dementia and older populations. Y/N	Evidence of sharing information and resources with local organisations and services about the priorities and needs of people affected by dementia Y/N	
Basis informs its relationship with different collaborators	Evidence on the experience of living with dementia at different stages of the trajectory		Evidence of DFC working with others to promote awareness of risk reduction
Involvement person with dementia	Person(s) living with dementia involved in set up DFC and person identified to enable their involvement	People living with and affected by dementia actively supported to lead on DFC priorities and how effectiveness defined	People living with dementia and people affected by dementia who are unable to participate in meetings consulted on priorities
	Using evidence of what people living with		Evidence of people affected by dementia

	dementia identify as important Y/N	Opportunities for PAD to review and comment on DFC basis	active in collaborations organisations as experts by experience
Equalities and Inclusion	Knows the different groups affected by dementia in the DFC and has explored specific barriers and enablers for them to be included and participate (By functional ability, cultural background and ability to participate)	Evidence of having worked with different groups of people affected by dementia to identify their priorities and needs Public services address priorities of different groups of PAD e.g. transport, emergency services and adult social care	Addressing the access rights and needs of PAD is integral to local organisations and services planning and implementation plans
Evolution	Articulates what the DFC will be achieving and its principles e.g. how it will address a disability agenda and links this to action plans	Evidence of how the basis of the DFC is being shaped by monitoring and evaluation of the DFC Developing shared narrative of what a dementia enabling community does and prioritises with other DFCs	Shared narrative of what it means to be dementia enabling with challenges/sanctions to organisations and services where this is not evident
Outputs/ Outcomes	Website/DFC sets out aims and basis. Developed based on the local picture. Number of collaborators and populations they represent known PAD know there is a DFC in their community and what it is trying to achieve	Evidence of local system and environment changes linked to how priorities of PAD expressed Increasing numbers of people living with and affected by dementia influencing what is sustained as the basis of the DFC and who is involved	Local Policies, practice, recommendations reflect local priorities of PAD Rights of people living with dementia known and routinely considered across the community e.g. retail, leisure, education PAD know that it is their right be a part of their community without stigma or fear

Improvement in diagnostic rates and public awareness of risk factors

Evaluation framework for Leadership & Governance domain

Leadership and Governance	Early	Developing	Embedding
Political engagement with DFC	Local government representative with time allocated to DFC	DFC working closely with local government to link priorities and initiatives to enable PAD to access services and local facilities	DFC work embedded in Local government plans and evidence of DFC changing local policies
Designated leadership and agreed terms of reference	One or more people identified as the coordinator of the DFC	Leadership roles identified in key areas of the DFC e.g. awareness raising with target groups, securing funding	Leadership of DFC as a resource and reference point for when new services and initiatives planned evident in all aspects of local community life
Communication strategies in place	Collaborators involved in DFC have formal and informal methods of keeping in touch (e.g. meetings, email, social media) Plan in place for recruitment of collaborators and volunteers	Established online presence and opportunities for interaction	DFC priorities are known across the community
Involvement of people living with dementia	People living with dementia identified as part of the leadership of the DFC and evidence of what their contribution is.	People living with dementia supported to lead on key initiatives and inform how	Involvement in DFC is offered from diagnosis and opportunities to lead and comment on DFC organisation for PAD at all stages of dementia trajectory possible
Equalities and Inclusion	DFC has reviewed who should be invited to join the leadership group/collaboration and	DFC is targeting under-represented or seldom heard groups to be involved in the leadership of the DFC	DFC identifying where organisations and services are not addressing the needs

	this reflects the local community	e.g. faith groups, LGBTQ, cultural groups	of PAD and involved in resolving this.
Evolution	Core group identified and terms of reference agreed with plan for meetings over 12m	Evidence of strategy and terms of reference being changed and informed by work of DFC

Meetings and information exchange a regular feature of the DFC | Evidence of succession planning and leadership rotating to ensure representation from different groups |
| Outputs/Outcomes | PAD know who is leading and involved in the PAD

Local government are actively supporting the DFC

Local organisations and services (including the NHS) know about the DFC | Growing numbers of PLWD known to DFC and volunteers working with DFC.

Consistent engagement across the local community with the needs and priorities or PAD

DFC leadership reflects local population

DFC plans,activities and achievements widely known | Continuity of approach maintained, and DFC work linked with other public and local initiatives and services.

PAD priorities and interests systematically addressed and evident in work planned and implemented. |

Evaluation framework for Activities and Environments domain.

Activities and Environment	Early	Developing	Embedding
Community Engagement

Dementia Specific

Dementia Inclusive | Local government and NHS actively involved in supporting promoting DFC activities and changes to environment and linking DFC with statutory providers

One or more people identified as the coordinator of the DFC's | DFC working with local government transport, emergency services, business, culture and leisure enabling engagement enable PAD to access services and local facilities | Individual interactions with people living with and affected by dementia accommodate the person's dementia diagnosis and the importance of valuing the person |

	work on activities and environments	Contact for each activities known and how they promote dementia inclusion explicit.

Established online presence with news and updates

Community engagement and dementia specific work informs activities that promote inclusion | Majority of local businesses and services have DFC recognition and ongoing support to develop their dementia inclusive work

Activities and environment address all stages of dementia trajectory for PAD |
	Community engagement and awareness programme targeting specific groups and people		
	Collaborators in DFC have formal and informal methods of publicizing activities and initiatives		
Involvement of people living with dementia	People living with dementia identified as part of the planning, and co-ordination of activities and environment changes.	People living with dementia and affected by dementia supported to influence what is done and involved in audit and review	PAD in DFC systematically canvassed for opinions and priorities
Equalities and Inclusion	Activities and Environments mapped to reflect geography and characteristics of local community	DFC is targeting under-represented or seldom heard groups to be involved in its provision/work	DFC identifying where activities and local environment not meeting the needs of PAD and involved in resolving this.
Evolution	Core set of activities that include all three elements of DFC planned	Evidence of increasing number of collaborators taking a lead in promoting engagement and inclusion	Evidence of DFC work being routinely incorporated into work of LA and statutory services and local community groups
Outputs/Outcomes	PAD know what the DFC is doing

Local government are actively linking DFC with community services

Local organisations and services (including the | Growing numbers of PLWD actively involved in DFC Consistent engagement across the local community with the needs and priorities or PAD | PAD confident of being accepted and having purpose and being able to contribute either via new connections or sustaining current interests |

	NHS) know about the DFC work		
	People and organisations have opportunities to volunteer and join	DFC work taken up by local public initiatives and services to support inclusion	Carers report feeling supported.
			Records of crisis related events for PAD (e.g. missing persons, accidents) reduced.

Evaluation framework for monitoring and evaluation domain

Monitoring and evaluation	Early	Developing	Embedding
Standardised baseline measures of DFC work/activities	Establish what is currently available for PAD in DFC	DFC has support and (see also resources) to identify and systematically collect, interpret and share data across DFC	Organisations and services routinely linking, reporting, reviewing progress and sharing findings across the DFC on how they are working to be dementia friendly
Coordination of data collection, interpretation and sharing	Maintain record of who is involved and how across t DFC		
	Evidence of using local data to set the priorities and plan of the DFC	Prioritising and reviewing work to assess the social return on investment of planned activities and services	People living with dementia routinely identified and linked to DFC at annual GP review
Data to monitor reach and impact for PAD and those involved in DFC	DFC using evidence of what is important to PAD to inform Monitoring and Evaluation activities and planning		
Involvement of people living with dementia	People living with dementia supported to participate in audits and	Annual survey of people living with dementia via NHS and LA	PAD involved in local services and organisations to

	reviews of local services and organisations.		review their progress and development
Equalities and Inclusion	Mapping of different groups in DFC with PAD	Outreach and exploratory work with groups with limited involvement with DFC to identify priorities	DFC identifying where activities and local environment are and are not meeting the needs of PAD .
Evolution	Standardised methods of collecting information and plan with people identified to support programme of monitoring and evaluation	Evidence of findings from monitoring and evaluation being used to target activities and provide feedback and reach of DFC	Evidence of routine collection using common datasets of DFC relevant by LA and statutory services and local community groups and funding of posts
Outputs/Outcomes	DFC knows how PAD are linked to and known by the DFC against known population of people living with dementia	Feedback used to develop and modify new services and activities accessible to more PAD	PAD confident across DFC and know which services and facilities are highly rated
	DFC knows how many local services/ organisations/businesses have are dementia friends and dementia champions	Know who is involved in DFC	Evidence of Equitable uptake of services across DFC
	Local services and organisations visible as being DFC (provision of facilities, staff aware, stickers)	Known what DFC initiative has achieved so far (overall initiative, and individual projects)?	Good practice shared within DFC and across DFCs (building capacity)
	Feedback from PAD of what has been enabling in DFC (or not) recorded and shared	Social connections and networks known to support PAD mapped	Carers report feeling supported.
			Records of crisis related events for PAD (e.g. missing persons, accidents) reduced
			Effectiveness and appropriateness of different DFC services and initiatives for different groups known

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Evaluation framework for Resource domain

Resource use	Early	Developing	Embedding
Individual(s) supported or willing to work on behalf of DFc	Individual(s) funded or offering equivalent 0.25-0.5 FTE pw to lead the work of the DFC between	Identified officers in the LA and/or other public services with protected time to work with the DFC. Plus funding for additioanl DFC coordinators	Established funding to support dementia inclusive initiatives across the dementia trajectory
Access to practical support and in-kind provision	Evidence of having reviewed resources against the priorities and plan of the DFC		Majority of local businesses and services with DFC recognition providing financial and in kind support to promote dementia inclusion and support of PAD
Resources to deliver against plan and known priorities	Evidence of resources to support cross DFC communication and online presence	Access to data management and budgetary planning support	
		Prioritising and reviewing work on the basis of social return on investment	
Involvement of people living with dementia	People living with dementia enabled to participate in DFC (expenses paid, transport arranged).	DFC funds identifies a person(s) to enable and support living with dementia to participate in planning, delivery and review of	PAD in DFC
Equalities and Inclusion	Consider how resources (individuals' time, services etc) allocated across the DFC	DFC resources used to involve and promote inclusion of under-represented or seldom heard groups	DFC identifying where activities and local environment not meeting the needs of PAD and involved in resolving this.
Evolution	Investment in community engagement and activities that promote awareness	Evidence of increasing number of collaborators taking a lead in promoting	Evidence of DFC work being included in the budgets of of LA and statutory services and

		engagement that supports dementia inclusion	local community groups and funding of posts
	Investment in resources to maintain communication across the DFC		
Outputs/Outcomes	PAD know what the DFC is doing	Growing numbers of PLWD actively involved in DFC Consistent engagement across the local community with the needs and priorities or PAD	PAD confident of being accepted and having purpose and being able to contribute either via new connections or sustaining current interests
	Local government are actively linking DFC with community services		
	Local organisations and services (including the NHS) know about the DFC work		
	People and organisations have opportunities to volunteer and join	DFC work taken up by local public initiatives and services to support inclusion	Carers report feeling supported.
	Leveraging in additional funds when gaps in resources evident		Records of crisis related events for PAD (e.g. missing persons, accidents) reduced.

Appendix XIII. Phase One scoping paper (Buckner et al., 2019)
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RESEARCH ARTICLE

WILEY Geriatric Psychiatry

Dementia Friendly Communities in England: A scoping study

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Objectives: To describe the characteristics of Dementia Friendly Communities (DFCs) across England in order to inform a national evaluation of their impact on the lives of those affected by dementia.

Methods: DFCs in England were identified through online searches and Alzheimer's Society records. A subsample (n = 100) were purposively selected for in-depth study based on online searches and, where necessary, follow-up telephone calls. Data collection and analysis were guided by a pilot evaluation tool for DFCs that addressed how DFCs are organised and resourced and how their impact is assessed. The evidence was predominantly qualitative, in addition to some descriptive quantitative information.

Results: Of 284 DFCs identified, 251 were defined by geographical location, while 33 were communities of interest. Among 100 sampled DFCs, 89 had been set up or started activities following policy endorsement of DFCs in 2012. In the resourcing of DFCs, statutory agencies and charities played an important role. Among DFC activities, awareness raising was cited most commonly. There was some evidence of involvement of people living with dementia in organisational and operational aspects of DFCs. Approaches to evaluation varied, with little evidence of findings having effected change.

Conclusions: DFCs are characterised by variation in type, resourcing, and activities. England has policy endorsement and a recognition system for DFCs. These can be important catalysts for initiation and growth. A systematic approach to evaluation is lacking. This would enable DFCs to be consistent in how they demonstrate progress and how they enable people living with dementia to live well.

KEYWORDS
awareness raising, dementia, Dementia Friendly Communities, England, evaluation tool, inclusion, older adults, online data

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Appendix XIV. Phase One mapping paper (Woodword et al., 2019)

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RESEARCH ARTICLE

WILEY Geriatric Psychiatry

The place for dementia-friendly communities in England and its relationship with epidemiological need

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Objectives: The dementia-friendly community (DFC) initiative was set up to enable people living with dementia to remain active, engaged, and valued members of society. Dementia prevalence varies nationally and is strongly associated with the age and sex distribution of the population and level of social deprivation. As part of a wider project to evaluate DFCs, we examined whether there is a relationship between provision of DFCs and epidemiological need.

Methods: Dementia-friendly communities were identified through the formal recognition process of DFC status by the Alzheimer's Society and mapped against areas defined by English Clinical Commissioning Groups. We tested whether provision of a DFC was associated with: (1) dementia prevalence, (2) number of known cases, and (3) known plus estimated number of unknown cases.

Results: Of the 209 English Clinical Commissioning Group areas, 115 had at least one DFC. The presence of a DFC was significantly associated with number of known dementia cases (mean difference = 577; 95% CI, 249 to 905; $P = 0.001$) and unknown dementia cases (mean difference = 881; 95% CI, 349 to 1413; $P = 0.001$) but not prevalence (mean difference = 0.03; 95% CI, −0.09 to 0.16; $P = 0.61$). This remains true when controlling for potential confounding variables.

Conclusions: Our findings suggest that DFC provision is consistent with epidemiological-based need. Dementia-friendly communities are located in areas where they can have the greatest impact. A retrospective understanding of how DFCs have developed in England can inform how equivalent international initiatives might be designed and implemented.

KEYWORDS
dementia-friendly community, epidemiological need, mapping

1 | INTRODUCTION

Dementia-friendly communities (DFCs) are one way in which people living with dementia can remain active, engaged, and valued members of society. Typically, DFCs adopt a range of approaches to achieve their aims. These include working with people living with dementia to change policies, practice, and services; investing in staff and volunteers to promote dementia awareness and skills in supporting people

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