

**Department of Health Policy Research**

**Programme Project**

**HEALTHBRIDGE**

**The National Evaluation of Peer Support**

**Networks and Dementia Advisers**

**in implementation of the**

**National Dementia Strategy for England**

**[Ref: 025/0058]**

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**Two alternative formats of this report are available: a brief report written primarily for service commissioners and providers, and a lay summary.**

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# HEALTHBRIDGE: The National Evaluation of Peer Support Networks and Dementia Advisers

## Executive summary

### Aims

1. To describe the range of Peer Support Networks and Dementia Adviser services, their evolution, establishment and delivery and governance characteristics.
2. To assess the models of Peer Support Networks and Dementia Advisers in relation to: influence on the well-being of people with dementia and carers; contribution to achieving the objectives of the National Dementia Strategy; integration, sustainability and transferability within the wider health and social care economy.
3. To identify ways in which Peer Support Networks and Dementia Advisers contribute to the well-being and resilience of people with dementia and carers, specifically in relation to: accessibility of services; involvement and information; support for making choices and independence.

### Background

The National Dementia Strategy for England (Department of Health, 2009a) recommended Dementia Adviser and Peer Support Network services and established 40 demonstration sites within a range of organisational settings. These services aimed to provide people with dementia and carers with information, guidance and advice, thus enabling access to a wide range of support including social groups that enabled peer learning. Many supported the immediate and community networks surrounding people living with dementia.

## **Evaluation methods**

The evaluation used a mixed methods approach to data collection, representing the breadth of activity across all of the 40 demonstration sites as well as exploring the depth of experience within eight case study sites. Data collection included:

- *Activity and outcome monitoring*: Data which represented the numbers and demographic information of people accessing all 40 demonstration sites; well-being measures (ASCOT).
- *Organisational surveys and collaborative discussions*: Survey data, completed by staff in the 40 sites at three points within the evaluation; collaborative discussions involving lead demonstration site staff and commissioners during five national workshops.
- *In-depth case studies*: In eight case study sites, qualitative interviews with people with dementia and carers (n = 101), including well-being and quality of life measures (ASCOT and DEMQoL), and interviews with staff, volunteers and other stakeholders (n = 82).

## **Patient and public involvement**

The involvement of people with dementia and carers was integral to the evaluation, with a priority placed upon ensuring that their views and experiences were privileged. This included in-depth interviews in the case study sites as well as well-being questionnaires in all demonstrator sites. Processes developed enabled the inclusion of those without capacity to provide informed consent and those for whom English was not a preferred language. Data collection tools and documentation for use by people with dementia and carers were developed in partnership with Voices North (older people, including those with dementia and carers, who are committed to supporting research).

## **Equality and diversity**

The evaluation sought to address equality and diversity by ensuring that information about service use by those with protected characteristics was identified through all forms of data sampling and collection, e.g. activity and monitoring data enquired about service usage by those with protected characteristics; sampling of case study sites ensured that those with a particular focus on, for example, black and minority ethnic (BME) communities were included; ASCOT was translated into Urdu, Punjabi and Gujarati; translation facilities were

available for the interviews; processes of consent to participate in the evaluation includes processes for those without the capacity consent.

## **Findings**

Key findings in relation to the needs of people with dementia and carers included:

- The timing and flexibility of support from Dementia Adviser and Peer Support Network services resulted in support that was tailored to individual needs and circumstances.
- Peer support by and for people with dementia and carers was rooted in identification with others in a similar position, enabling greater confidence and more independence.
- Dementia Adviser and Peer Support Network services had a significant role in enabling people with dementia and carers to re-narrate their lives, finding a new life which, though different from life prior to dementia, had meaning, value and purpose and in signposting people with dementia and carers to appropriate other services and support.
- New social networks alongside training and awareness raising enhanced social networks and community awareness and understanding, both of which enabled social inclusion.

Key findings in relation to organisational design and development included:

- Peer Support Network and Dementia Adviser services often filled a gap in support for people with dementia and carers. This had a positive impact upon well-being and quality of life and had resource-saving implications for the local health and social care economy.
- The relationship of the demonstrator services to pre-existing services and support for people with dementia and carers was a significant influence on their work, and in some areas service boundaries and remits were unclear, with consequent tensions.
- Peer Support Network and Dementia Adviser services had a key role in raising awareness of dementia and tackling stigma.

## **Results and recommendations**

The Peer Support Network and Dementia Adviser services were able to work successfully to meet the needs of people with dementia and carers (and indeed for the wider range of community and other services at times). These services do enable delivery of some aspects of the National Dementia Strategy (Department of Health, 2009a) and they can deliver on more recent policy statements such as the Prime Minister's Challenge (Department of Health, 2012) and the White Paper: Caring for our Future (HM Government, 2012).

*Recommendations for policy and policy implementation* – ensure recognition for, and further development of, the conditions under which services providing peer support and dementia advice and information flourish.

1. Peer support and advice and information are essential components of dementia care to meet the needs of individuals, families and communities. Services that provide these need to continue to be promoted in national policy.
2. A key mechanism for achieving this is through more explicit alignment of dementia care as a major public health concern.
3. The need of people to re-narrate their lives and of services to promote inclusion of people with dementia and carers within communities is an issue that transcends 'health' services. It is important, therefore, that policy continues to promote dementia care in a way that cuts across sector boundaries.
4. Mechanisms for supporting learning when implementing novel policy initiatives need to be built into Implementation Plans.
5. Greater attention should be given to securing commitment to sustainability before commencing so that unexpected changes in policy do not compromise service delivery.
6. The right balance between the following dynamics is essential to optimise the outcomes: nationally vs locally driven; specialist vs generic provision; consistency of a singular 'model' vs flexibility to adapt to varying and changing individual and community need.



*Recommendations for organisations* – ensure that the support and information needs of people with dementia, their families and communities are met and that the conditions are promoted under which services providing peer support and dementia advice and information flourish.

1. People with dementia, their families and communities need peer support, information and advice so assessment of local provision to meet these needs is essential.
2. Commissioning of services that enable peer support and information and advice are recommended to ensure that people with dementia are supported to remain independent and well for a longer period of time than may otherwise be achieved.
3. Innovative services need to have an organisational ‘space’ within and between health and social care organisations if they are to flourish.
4. Achieving equality of access to services requires a very proactive approach and a willingness to identify and work with some characteristics that otherwise result in people being marginalised from service provision.
5. Peer Support Networks and Dementia Adviser services played a role in supporting the learning about dementia of a wide range of staff and communities, and helped to ensure that services were aware of the needs of people with dementia.
6. There is no one definitive model on which to base future service development and attention is needed to local solutions to achieve sustainability within the local health and social care economy.

*Recommendations for practice* – ensure that practices with people with dementia and their families and communities are best able to meet their needs by promoting an environment and culture of inclusion.

1. Peer Support Networks and Dementia Adviser services have a role to play in understanding the needs of people with dementia and their families and communities, and are able to communicate these to services to ensure that services are best able to be attuned to meeting these needs. It is important that their community-based skills and knowledge is recognised as a key part of connecting services with meeting needs.

2. The part of staff and volunteers in supporting re-narration by people with dementia and families is a key part of meeting people's needs and helping people to 'live well with dementia'. Education needs to address person-centred and relationship-centred care.
3. Peer Support Networks and Dementia Advisers play a part in combating discriminatory attitudes towards ageing and dementia in their communities, and increasing the knowledge of other practitioners. It is essential that this function is enhanced to optimise the capacity of communities to be inclusive of those with dementia.
4. It is necessary to work with other staff and managers in all locally relevant services to ensure that there is good communication and clarity in role and purpose.

*Recommendations for future research* – ensure that research continues to inform, and be informed by, dementia policy and practice, specifically in relation to peer support and advice and information activities.

1. In relation to Healthbridge, there will be valuable information arising from the ongoing implementation of Peer Support Networks and Dementia Advisers. Specifically, a follow-up study should explore: How the demonstration sites evolve over the next 2–3 years and how this illuminates the processes of embedding or mainstreaming services; the views of people with dementia and carers who were part of the Healthbridge evaluation in Peer Support Network services and Dementia Advisers as their journey living with dementia progresses.
2. The outcome of the Healthbridge evaluation locates peer support and advice and information for people with dementia and their carers as a public health issue. Considerable research is required to ensure that all of the learning from the public health field is applied to dementia care, and that we continue to learn how best to ensure that needs are met through recognising dementia as a public health issue. Specifically, the data secured in this project is very rich and warrants re-analysis with an explicit public health frame of analysis. This would be enhanced by collecting further interview data from those people with dementia and carers in the case study sites to form a longitudinal aspect to understanding health literacy and the

contribution of advice, information and peer support to the experiences of re-narration and living well with dementia.

## **Conclusion**

The services established in the demonstrator sites show that they have been driven by a person and relationship centred focus, and with a strong orientation to public health approaches. The services have the potential to facilitate people and relationships with an important focus on building social networks and sharing information, supporting the re-narration of people's lives and enhancing people's control of their lives and their dementia. Achieving this potential requires them to be in an organisational space that allows them to work in partnership and collaboration with other services, and which values their distinct knowledge of their communities. In establishing the services, more attention was paid to the 'needs space' than to this 'organisational space' and as a result, for some, inter-organisational conflicts and tensions were present. Locating these initiatives more explicitly within a public health policy framework will be beneficial in meeting the needs of people with dementia and carers.

## **Dissemination plans**

In addition to dissemination in academic and professional publications, the evaluation team will work with national and local policy developers to ensure that there is effective communication of the key messages from this evaluation and influence on future policy and service developments.

## **Healthbridge: Background and literature review**

Section One aims to:

- Provide an overview of the policy context for the National Dementia Strategy (Department of Health, 2009a), with a focus on the background to the Implementation Plan, which included the setting up of the 40 demonstration sites being evaluated within this report.
- Provide an update on the development of dementia policy, and health and social care policy more generally (2010–2012).

Section Two aims to:

- Relate the policy outlined above to developing theoretical perspectives, with a focus on understandings of dementia and the shift away from a biomedical understanding towards an understanding of the social barriers to inclusion faced by people with dementia and their carers and the role of interpersonal interaction in well-being and quality of life for people with dementia and carers.
- Relate the themes that emerge from the above to the theoretical framework that underpinned the Healthbridge evaluation (social network theory, social learning theory and self-efficacy theory).
- Relate that theoretical framework to areas such as well-being, quality of life advice, peer support and information provision.
- Explore the tensions that arise from the role of people with dementia in the above.

The conclusion aims to:

- Clarify how the policy background, theoretical perspectives and theoretical framework have informed the design of and methods used in the evaluation.

## **Section One: Policy background and the National Dementia Strategy**

The beginning of the 21st century has seen an increase in the prevalence of dementia and it is now viewed as perhaps being the ‘most significant health crisis of the 21st century’ (Wellcome Trust, 2010). Dementia has become a growing global challenge, with the numbers of people living with dementia set to rise sharply in the future. From this global perspective, Alzheimer’s Disease International (2012) estimates the number of people living with dementia worldwide to be 35.6 million. The National Dementia Strategy (Department of Health, 2009a) stated that in the next 30 years, the number of people with dementia in England will double to 1.4 million. Parallel to this is an increase in health, economic and social care issues in society as a whole, at both national and community levels.

### **Healthbridge: Policy context**

This section of the report outlines the policy background to the Healthbridge evaluation. It seeks to demonstrate the current move away from a traditional model of care, where people accessing health and social care services and support were viewed as passive recipients of care, over which they often have no control, towards self-management and personalisation within services.

The background to policy on services for people with dementia and their carers begins by locating the National Dementia Strategy (Department of Health, 2009a) within developing policy on services and support for people with dementia and their carers. This is followed by an outline of the Implementation Plan (Department of Health, 2009b), from which the demonstration sites that were central to Healthbridge were established. The presentation of policy then moves on to outline policy that has developed alongside or as a result of the National Dementia Strategy (Department of Health, 2010a; Skills for Care and Skills for Health, 2011). The views of people with dementia and their carers are then focused up within a presentation of the Dementia Declaration (Dementia Action Alliance, 2010) and other related work, especially the creation of ‘dementia-friendly communities’.

We then move on to outline policy in relation to the future challenges, beginning with *The Prime Minister’s Challenge on Dementia* (Department of Health, 2012) and the role of

Champion Groups. In looking to the future of dementia care, we conclude this section on relevant policy with *Dementia 2012: a national challenge* (Alzheimer's Society 2012a); *Caring for our Future: reforming care and support* (Department of Health, 2012) and, considering an international perspective, the World Health Organization's work on dementia as a public health priority (World Health Organization, 2012). In summarising the themes which emerge from a review of relevant policy, and which are relevant to the Healthbridge evaluation, this section will then lead on to a discussion of the theoretical and ideological developments that have underpinned these policy developments.

### ***Background to the National Dementia Strategy***

*Living well with dementia* (Department of Health, 2009a) was the first national strategy for dementia in England. It was a response to the fact that:

The large majority of people with dementia and their family carers do not benefit from the positive intervention and support that can promote well-being and prevent crises for all involved.

Banerjee, 2010, p 917

The strategy was developed, through consultation, in response to the findings and recommendations of a number of reports which highlighted the need for a better understanding of dementia, and the need for improvements in services and support for people with dementia and their carers (Audit Commission, 2000; Department of Health, 2001a; Care Services Improvement Partnership, 2005; National Institute for Health and Clinical Excellence and Social Care Institute for Excellence, 2006; Knapp *et al.*, 2007; National Audit Office, 2007). In response to the issues outlined in these and other reports a senior committee of the House of Commons accepted the following recommendations (Banerjee, 2010, p 919):

### **Recommendations made by the House of Commons Committee**

- Dementia should be made a high priority for the NHS and social care.
- The need for explicit national ownership and leadership.
- Early diagnosis.
- Improving public attitudes and understanding.
- Coordinated care.
- All improvements to benefit carers too.
- Improvements in care in care homes.
- Improvements in care in general hospitals.

Banerjee 2010 p919

The National Dementia Strategy was developed as a response to this. Its development, which included a consultation process and involvement of a wide range of people and organisations, was structured around three main themes: improving public and professional attitudes and understanding of dementia; early diagnosis and intervention for all; and good quality care and support at all stages, from diagnosis through to the end of life. The strategy outlined the following 17 objectives (Department of Health, 2009a):

### **The 17 objectives of the National Dementia Strategy**

- Objective 1: Public information campaign
- Objective 2: Good quality early diagnosis and intervention
- Objective 3: Good quality information
- Objective 4: A dementia adviser
- Objective 5: Peer support and learning networks
- Objective 6: Improved community personal support services
- Objective 7: Implementing the Carers' Strategy
- Objective 8: Improving care in hospitals
- Objective 9: Improving intermediate care
- Objective 10: Housing and tele-care
- Objective 11: Improving care in care homes
- Objective 12: Improving end of life care
- Objective 13: Workforce competencies, development and training
- Objective 14: Joint local commissioning and world class commissioning
- Objective 15: Improved registration and inspection of care homes
- Objective 16: Dementia research
- Objective 17: National and local support for implementation

Department of Health 2009a

### ***Implementation of the National Dementia Strategy***

The implementation of the National Dementia Strategy (Department of Health, 2009b) sought to outline how the objectives of the Strategy would be realised by 2014 and how the 17 objectives would be achieved on a local, regional and national level. The purpose of the Implementation Plan was to “set out robust arrangements to support and assess progress with implementation of the Strategy” (Department of Health, 2010a). The action plan that was produced outlined how each of the 17 objectives would be met. This included, for example: an awareness-raising programme; an expert group being set up to address issues relating to good-quality early diagnosis; an information stakeholder group which was tasked with gathering evidence of usefulness and need for information and working with senior commissioners and clinicians in implementing objectives such as improved quality of care in general hospitals.

In implementing Objectives 4 and 5 of the strategy, 40 demonstration sites were established. There were two models upon which these sites based their activity: Peer Support Networks and Dementia Advisers. It was these 40 demonstration sites that the Healthbridge evaluation was tasked with evaluating.

Dementia Advisers were a direct response to Objective 4 of the National Dementia Strategy. The Dementia Adviser role was grounded in the following Case for Change (Department of Health, 2009a, p 40):

One of the most clear and consistent messages emerging from discussions with people with dementia and their carers has been the desire for there to be someone who they can approach for help and advice at any stage of the illness, or “someone to be with us on the journey”.

In the course of consultation it has become clear that this support needs to be provided without removing health and social care professionals from front-line care, and needs to be complementary to the other elements of the care pathway described here.

In order to stimulate debate, one possibility for testing would be a ‘dementia adviser’ who can provide a point of contact, advice, and signposting and enabling contact with other services if needed. These posts might best be commissioned from the third sector, but could be located within the early diagnosis and intervention



service described above to enable professional support and advice and seamlessness of service.

The role of a dementia adviser would not be that of intensive case management, as carried out by members of community mental health teams or outreach workers who go into people's homes, or Admiral Nurses. Rather they would provide a single identifiable point of contact with knowledge of and direct access to the whole range of local services available

Peer Support Networks were a direct response to Objective 5 of the National Dementia Strategy. Networks were grounded in the following Case for Change (Department of Health, 2009a, p 41):

One clear message we have received from people with dementia and their carers is that they draw significant benefit from being able to talk to other people living with dementia and their carers, to exchange practical advice and emotional support. People with dementia and their carers can obtain continuity of care and support not only from statutory services, but also in the form of peer support. If the strategy is successful in ensuring that early diagnosis of dementia becomes the norm, then this opens up the possibility for much greater levels of peer support and interaction. There is much good practice in this area already, but activity is often at a relatively low level. The challenge here is first to determine which models of peer working to adopt, and then how to make them available for all who want to access them locally. The value of such an approach is that this can empower people to make choices about what they want, and enable them to care for themselves. Providing people with dementia and their carers with peer support can assist enormously in helping them plan their own lives. On an aggregate level, this can generate advice for commissioners and providers on the local needs of people with dementia and their carers to inform the development of services.

It is important to note that, though Peer Support Networks and Dementia Advisers cover two specific objectives of the strategy, the site activity and experiences of people with dementia and carers that have been captured in the Healthbridge evaluation span the issues covered in other strategic objectives. These include: public information; good-quality early

diagnosis and intervention; good-quality information; improved community personal support services; and better support for carers.

Although the 40 sites that are central to the Healthbridge evaluation were established in response to the National Dementia Strategy of 2009, in order to explore and learn from the vast experience of people with dementia, their carers, staff and stakeholders and to ensure the relevancy and transferability of the outputs of the evaluation, it is important to consider policy from 2009 through to current developments. Policy developments between 2009 and 2012 have also had a direct impact on site activity, resources, staffing and continuation funding, with an ongoing fluidity in interpretation of policy as sites develop. It is therefore important to consider how policy developed during the demonstration period.

### **Development of policy 2010–2012**

When the coalition Government came into administration, strategic direction was revised with the publication of *Quality outcomes for people with dementia: building on the work of the National Dementia Strategy* (Department of Health, 2010a). This reflects the broader shift towards more outcome-focused policy and practice (Cook and Miller, 2012; Netten *et al.*, 2012a).

This update from the new administration linked Cameron's 'Big Society' ideal to the development of services and support for people with dementia and their carers, specifically in response to "the challenge in the context of a changed political and economic landscape, where the Department's role is more enabling and less directive" (Department of Health, 2010b, p 8):

...a huge culture change...where people, in their everyday lives, in their homes, in their neighbourhoods, in their workplace...don't always turn to officials, local authorities or central government for answers to the problems they face ...but instead feel both free and powerful enough to help themselves and their own communities. This means a whole new approach to Government and governing. We've got to get rid of the centralised bureaucracy that wastes money and undermines morale. And in its place we've got to give professionals much more

freedom. There are three strands... First, social action.... Second, public service reform. And third, community empowerment... there are three techniques we must use to galvanise them. First, decentralisation. Second, transparency. Third, providing finance....

David Cameron's Big Society speech, 19 July 2010

This update to the National Dementia Strategy (Department of Health, 2009a) placed an emphasis on an outcomes-focused approach which emphasised transparency and information provision for individuals (Department of Health, 2010a, p 9):

This enables people to have a good understanding of their local services, how these compare to other services and the level of quality that they can expect.

It also emphasised that (Department of Health, 2010a, p 10):

the improvement of community personal support services is integral to and underpins each of the four priorities as it supports early intervention; prevents premature admission to care homes and impacts on inappropriate admission to hospital and length of stay

This work coincided with the Government's White Paper *Liberating the NHS: Transparency in outcomes – a framework for the NHS* (Department of Health, 2010b) and developed a synthesis of outcomes, stating that, by 2014, all people with dementia in England should be able to say:

**Quality outcomes for people with dementia**

- I was diagnosed early.
- I understand, so I made good decisions and provide for future decision making.
- I get the treatment and support which are best for my dementia, and my life.
- Those around me and looking after me are well supported.
- I am treated with dignity and respect.
- I know what I can do to help myself and who else can help me.
- I can enjoy life.
- I feel part of a community and I'm inspired to give something back.
- I am confident my end of life wishes will be respected. I can expect a good death.

Department of Health 2010

Also published in 2010, the Dementia Declaration was “a major plan of action to change the experience of living with dementia in England for good” (Dementia Action Alliance, 2010, p 2). It brought together a wide range of statutory and voluntary sector health and social care organisations who were asked to commit to the outcomes listed below, and to state their intended actions in delivering a better quality of life for people with dementia and carers. It was a response to some defined needs relating to transforming quality of life for people living with dementia:

### **The need for the dementia declaration**

- Public awareness of dementia is high, but understanding about it is still very poor.
- NHS and social care systems have not historically developed to reflect the fact that people with dementia are now a key group using many services.
- Only one-third of people with dementia receive a specialist diagnosis and many are receiving that diagnosis late.
- Following diagnosis many people with dementia and carers report receiving no information about their condition or about what support might be available.
- Reports from regulator the Care Quality Commission (CQC) and its predecessor the Commission for Social Care Inspection (CSCI) show that although there are examples of excellent dementia care in care homes, many providers are struggling to deliver quality of life for people in the later stages of the condition.
- Equally, some people with dementia struggle for too long in their own homes without the help they need when better person-centred care or a good care home could provide a more stimulating and supportive environment.
- The All-Party Parliamentary Group on Dementia and Professor Banerjee have both produced reports revealing people with dementia are being inappropriately prescribed or over-prescribed antipsychotic drugs which increase risk of death and reduce quality of life.
- Health and social care staff routinely report that they have not received training in how to treat or care for people with dementia, despite the fact that they are now increasingly in contact with people with dementia.
- The National Audit Office and Parliamentary Public Accounts Committee have found that there is very ineffective use of current resources to deliver quality of life for people with dementia.
- UK spending from all sources on dementia research is low compared to other disease groups and by international standards.

Dementia Action Alliance 2010

People with dementia and their carers outlined seven outcomes they wanted to see in their lives and in the lives of people who are diagnosed with dementia in the future (Dementia Action Alliance, 2010):

**The dementia declaration: desired outcomes**

- I have personal choice and control or influence over decisions about me.
- I know that services are designed around me and my needs.
- I have support that helps me live my life.
- I have the knowledge and know-how to get what I need.
- I live in an enabling and supportive environment where I feel valued and understood.
- I have a sense of belonging and of being a valued part of family, community and civic life.
- I know there is research going on which delivers a better life for me now and hope for the future.

Dementia Action Alliance 2010

Within the Dementia Declaration, there was an emphasis on the ideal of creating ‘dementia-friendly communities’. In 2011, the *Common Core Principles for Supporting People with Dementia. A guide to training the social care and health workforce* (Department of Health, Skills for Care and Skills for Health) was published. This document set out eight core principles, which were developed using the National Dementia Strategy and the Dementia Declaration as guidance, for supporting people with dementia:

**Common core principles for supporting people with dementia**

- Principle one: Know the early signs of dementia.
- Principle two: Early diagnosis of dementia helps people receive information, support and treatment at the earliest possible stages.
- Principle three: Communicate sensitively to support meaningful interaction.
- Principle four: Promote independence and encourage activity.
- Principle five: Recognise the signs of distress resulting from confusion and respond by diffusing a person’s anxiety and supporting their understanding of the events they experience.
- Principle six: Family members and other carers are valued, respected and supported just like those they care for and are helped to gain access to dementia care advice.
- Principle seven: Managers need to take responsibility to ensure members of their team are trained and well supported to meet the needs of people with dementia.
- Principle eight: Work as part of a multi-agency team to support the person with dementia.

Department of Health and Skills for Health 2011

The report states that: “the common core principles will enable health and social care practitioners to respond in a timely and appropriate way to the needs of people with emerging signs of dementia as well as to those with a confirmed diagnosis of the condition” (Department of Health, 2010a, Skills for Care and Skills for Health, 2011, p 4).

Although these core principles were mostly aimed at professionals in the conventional sense of the role, the ideals within it are relevant to the Healthbridge evaluation as we seek to explore the role and impact of Peer Support Networks and Dementia Advisers.

### ***The challenge on dementia: 2012***

2012 has seen some more specific ‘challenges’ that seek to develop on a practical level the issues and ideals that had been outlined through previous policy developments. This included the development of ‘dementia-friendly communities’ as emphasised within the Dementia Declaration referred to above (Dementia Action Alliance, 2010). The Prime Minister’s Challenge on Dementia (Department of Health, 2012) set out targets for “delivering major improvements in dementia care and research by 2015”. Its aims were to:

- give a boost to dementia research
- address the quality of dementia care
- increase public understanding of dementia
- make communities more dementia friendly.

The key commitments outlined within the challenge relate to: driving improvements in health and care; creating dementia-friendly communities that understand how to help and better research. The following commitments are directly relevant to the Healthbridge evaluation:

- Promoting local information on dementia services (key commitment 5)
- Dementia-friendly communities across the country (key commitment 6)
- Awareness raising (key commitment 8)
- Participation in high-quality research (key commitment 14).

Areas of other commitments that are relevant to demonstration site activity, and therefore the Healthbridge evaluation include: increased diagnosis rates and the delivery of high-

quality relationship-based care and support for people with dementia, with involvement of and engagement with local communities.

The Prime Minister's Challenge also highlights the role of high-quality information in support for people with dementia, their carers, and wider networks (Department of Health, 2012, p 9):

people with dementia and their families and friends would like better information about health and care services. They want to know what they are entitled to, so that they can be sure they are getting all the support they need. Greater transparency in health and care services can also drive up quality and empower people with dementia and their carers. But currently, the quality of advice and information which people receive is variable. In all too many areas, it is extremely difficult for people with dementia to find out what support is available and to what they are entitled to.

Following the Prime Minister's Challenge on Dementia, three Champion Groups were set up in order to maintain progress. The Champion Groups focused on: driving improvements in health and care; creating dementia-friendly communities, and improving dementia research. The work of these groups has included online consultation around "How can we create dementia-friendly communities?" and "How could health and care for people with dementia and their carers be improved?"

### ***Dementia-friendly communities***

The idea of a 'dementia-friendly community' is rooted within the goal of empowering whole communities working together to enable people with dementia to 'live well with dementia' (Department of Health, 2012). It recognises ways in which lack of understanding and awareness of dementia can exacerbate and reinforce marginalisation and stigma, as well as the role that communities can play in maintaining independence, where there is an informed understanding of dementia and people with dementia are valued. Dementia-friendly communities also recognise and value roles for and contributions from people with dementia. The Alzheimer's Society launched their Dementia Friendly Communities Programme at the Dementia 2012 conference and it forms a core part of their 2012–17 strategy (Alzheimer's Society, 2012b).

### ***Local policy and dementia pathways***

In addition to national strategies, dementia policy has also been developed at a more local level, within local authorities, NHS Trusts and voluntary sector organisations. For example, within many areas a dementia pathway has been developed, guided by NICE guidelines (National Institute for Health and Clinical Excellence, 2011). Such pathways seek to practically implement a coherent pathway of support from point of diagnosis through to end of life care. Dementia pathways differ from locality to locality but include principles of care for people with dementia and processes relating to early identification, diagnosis and assessment situated alongside staff training and support for carers within an integrated and coordinated system of care that promotes independence and maintains function (National Institute for Health and Clinical Excellence, 2011). A range of interventions are included within a dementia pathway. It is within the context of these pathways, to a greater or lesser extent depending on the demonstrator site's organisational location, and local policy and practice, that the development of Peer Support Network and Dementia Adviser services was situated.

### ***General health and social care policy***

Policy on dementia cannot be separated from more general health and social care policy. As such, the National Dementia Strategy sought to maintain consistency with other policy affecting people living with dementia. Other relevant policies and White Papers have been referred to above and some longstanding concerns about the care of older people have been brought into sharp relief by reports exposing poor care (the most notable recent example being the Frances Report, HMSO, 2013). The recent White Paper: *Caring for our future: reforming care and support* (HM Government, 2012) outlines a vision of redefined care, which promotes well-being and independence at all stages, improving people's lives by reducing the risk of people reaching crisis point. It highlights problems in the current system, which include:

- Too often the system only reacts to a crisis.
- Society is not making the most of the skills and talents in communities.
- People do not have access to good information and advice.
- Access to care varies across the country and is confusing.



- Carers have no clear entitlements to support.
- Not all care is good. The quality of care is variable and inconsistent.
- People often feel ‘bounced around’ and have to fight the system to have the joined-up health, care and support they need.
- Our growing and ageing population is only going to increase the pressures on the current system.

As with previous policy, future statements from people who are using services are outlined, where a high-quality service would mean that, by 2015, people would say (HM Government, 2012):

**Caring for our future: vision for 2015**

- I am supported to become as independent as possible.
- I am treated with compassion, dignity and respect.
- I am involved in decisions about my care
- I am protected from avoidable harm, but also have my own freedom to take risks.
- I have a positive experience of care that meets my needs.
- I have a personalised service that lets me keep control over my own life.
- I feel that I am part of a community and participate actively in.
- The services I use represent excellent value for money.

HM Government 2012

In this White Paper, the transformation of care was envisioned within two broad areas:

1. The focus of care will be to promote people’s well-being and independence instead of waiting for people to reach a crisis point.
2. We will transform people’s experience of care and support, putting them in control and ensuring that services respond to what they want.

There are areas of this policy document which relate directly to the Healthbridge evaluation of Peer Support Network and Dementia Adviser services. These include people being supported to maintain independence for as long as possible, with an emphasis on the role of communities:

- strengthening support within communities
- supporting active and inclusive communities
- tackling social isolation
- making prevention and early intervention a core local authority role
- building community-based support into local commissioning plans
- supporting people to make connections
- community networks and venues
- encouraging supportive networks.

The importance of people understanding how care and support works, and what their entitlements and responsibilities are, is also highlighted, with an emphasis on:

- better information and advice
- better national care and support information
- improving outcome-focused information provided by local authorities.

Support for carers is also part of this most recent policy. Specifically:

- identifying and supporting carers
- ensuring people can maintain a life alongside caring
- clearer entitlements to carers' assessments and support.

The final area of the White Paper (Department of Health, 2012) which is relevant to the Healthbridge evaluation is that of people being in control of their care and support. This included:

- help for people to arrange their care and support
- empowering people to take control.

There has also been a growing recognition of the significance of peer support within national policy, including the English Mental Health Strategy (Department of Health, 2011).

Also published in 2012 was a report from the Alzheimer's Society describing how well people with dementia are living in England, Wales and Northern Ireland. This report shows

that (Alzheimer's Society, 2012a, p iv): "there is work being undertaken to improve quality of life for people with dementia and their carers, and much has been achieved.....at the current time people are still not living well with the condition".

This report made the following recommendations:

- improve awareness and understanding
- improve health and social care systems
- ensure that people living with dementia have appropriate information and support
- ensure that people with dementia are recognised as active citizens with the potential to live well in the community
- increase research.

Also published in 2012, a report from the World Health Organization (2012) highlighted dementia as a public health issue on a global scale. This report seeks to outline the involvement of researchers, practitioners, civil society, organisations, policy-makers, health planners and international development agencies (World Health Organization, 2012, p 92).

The framework for action promoted within this report highlighted the important role of:

- producing a dementia-friendly society globally
- making dementia a national public health and social care priority worldwide
- improving public and professional attitudes to, and understanding of, dementia
- investing in health and social care systems to improve care and services for people with dementia and their care-givers
- increasing the priority given to dementia in the public health research agenda.

(World Health Organization, 2012, p 94)

## **Summary**

The key drivers behind the policy development outlined above are:

- A recognition of the increasing prevalence of dementia, and the need to tackle this growing crisis.
- A recognition of the need to tackle stigma surrounding dementia, with all sections of communities and society being more informed about and aware of dementia.

- The move in health and social care provision in general away from a traditional care model towards self-management within services and support.
- A recognition of the need to tackle the social isolation faced by people with dementia and their immediate carers.
- A recognition of the need for and benefits of crisis prevention and early intervention.
- Evidence of poor diagnostic processes and a lack of access to support and positive intervention.
- A recognition of the need for advice and information that enables people to access appropriate support.

In response to these policy drivers, the focus is upon the development of services that provide:

- Information, advice and support which enables people living with dementia to access the services that are right for them, with a focus on independence, control and choice.
- Provision of support for those surrounding people with dementia as well as the person themselves.
- Services that are designed with (not for) people with dementia and their carers, meeting their needs and rooted in their knowledge and experiences.
- A whole community approach to supporting people with dementia, which enables people with dementia to remain part of that community, and which tackles stigma and raises awareness of dementia.
- Support which focuses on every aspect of people's lives, enhancing general well-being and quality of life.

## **Section Two: Theoretical perspectives**

When considering the policy developments outlined above, it is important to consider how practicable and applicable the ideals, set out by Westminster, are to people living with dementia across the diverse communities which represent the people to whom this policy is being applied. It is also important to remain aware of criticisms of policy on many different levels. In order to do this, an understanding of the theoretical and ideological developments in understanding dementia that have taken place alongside policy developments is useful, as well as a critique of some of the ‘buzzwords’ used in policy such as independence, choice and citizenship. We now draw upon the academic literature in order to do this.

### ***Dementia-friendly communities and the social model of disability***

As outlined above, the concept of ‘dementia-friendly communities’ is one which has been promoted within policy as well as within the Dementia Declaration. This concept represents a shift away from seeing dementia as an individual medical issue towards acknowledging the significance of communities, both in relation to the inclusion of people with dementia and in promoting independence, control and choice. There are parallels to be drawn between this shift in thinking and the social model of disability, although it is important to acknowledge that the person with dementia is living, often over a protracted period of time, with degenerative cognitive impairment. The social model of disability separates impairment (what is wrong with a person) from the barriers which exclude people who have an impairment from being included in society (Oliver, 1996). Within the context of the development of services that promote meaningful inclusion, Barnes and Mercer (2006, p 37) suggest that:

The social model focuses on the experience of disability, but not as something that exists solely at the level of individual psychology, or even interpersonal relations. Instead, it encompasses a wide range of social and material factors and conditions, such as family circumstances, income and financial support, education, employment, housing, transport and the built environment, and more besides. At the same time, the individual and collective conditions of disabled people are not fixed, and the experience of disability also demonstrates an ‘emergent’ and temporal character. This spans the individual’s meaning and experience of disability, in the context of

their overall biography, social relationships and life history, the wider circumstances of disabling barriers and attitudes in society, the impact of state policies and welfare support systems.

While acknowledging the challenges that arise from applying the social model of disability to dementia care in England, Gilliard *et al.* (2005, p 576) cite Marshall's (1994) summary of the benefits of applying a social model understanding to developing thinking around dementia:

- A focus on remaining abilities instead of losses.
- A recognition of the way in which people with dementia are discriminated against and marginalised.
- The importance of listening to the personal experience of dementia.
- The influence of the social and built environment in enabling or disabling people with dementia.

The theoretical ideals which underpin the social model of disability have also been central to the movement towards self-management and choice and control in services and support (French and Swain, 2012). This includes service user involvement/engagement, through which services are developed in partnership with, and based on the needs and views of, people who are accessing those services. Service user involvement or engagement represents a collective challenge to the barriers to inclusion which the social model of disability identifies (Barnes and Cotterell, 2012). While the service user involvement movement is more closely associated with mental health services and services for people with learning difficulties and other groups of disabled people, there is evidence that groups of people with dementia, such as the Scottish Dementia Working Group, are coming together to campaign and increase awareness (Weaks *et al.*, 2012).

A further theoretical perspective that has been influential in increasing involvement (of older people in general, of which many people with dementia are a sub-group) is that of critical gerontology. This perspective represents a shift away from seeing older people as a burden on society towards seeking to value and make use of the contributions they can make to society (Bernard and Scharf, 2007). This perspective has also highlighted the

relative lack of resources that are allocated to older people, as provision of, for example medical care, can be ageist (National Service Framework, Department of Health, 2001a). Bartlett and O'Connor (2007, p 123) further explore the area of citizenship and people with dementia further:

Understanding of dementia has evolved considerably over the past few decades, from considering serious cognitive impairment as an expectable part of the ageing process, to recognising dementia as a biomedical phenomenon, and then towards the importance of seeing beyond the bio-physiological issues to the person behind the label. It is time for the emergence of a fourth moment: centring dementia experiences, as shaped and constrained by broader socio-political systems, discourses and life events.

Similarly, writing in 1997, Downs (1997, p 604) referred to the language that was, at that time, being used within dementia research to describe people with dementia: *dementia sufferers*; or *dementia victims*, who place a *burden* of care on their families who are also *victims*. Social model thinking requires a complete U-turn away from these ideas towards valuing people with dementia as having a meaningful contribution to make to families, communities and societies as well as acknowledging the environmental, attitudinal and structural barriers to meaningful inclusion in society.

In considering citizenship and community approaches to understanding and supporting people with dementia, it is important to remain critical around ideals such as independence and interdependence. The view of independence as desirable and dependence as its (undesirable) opposite fails to acknowledge that most people do not function independently from others. On the contrary, a model of interdependence in society, where all people have valued roles within communities as well as receiving support from others in communities, is both more realistic and more desirable (Reed and Clarke, 1999). In order to consider this in more detail, we now move on to consider interpersonal relationships and people with dementia.

### ***Interpersonal relationships and people with dementia***

Within the competing constructions of dementia outlined above, a medical approach emphasises modifying the course of dementia through processes such as diagnosis, assessment and treatment. Conversely, if the experience of living with dementia is considered as being socially constructed with personal meanings and compensatory coping adjustments ascribed by the individual (and family) to make sense of a changing reality, then an interpersonal approach to supporting people with dementia emerges.

A medical model of disability would posit that dementia inevitably means a gradual loss of personhood, and therefore a loss of ability to socialise. Kitwood (1997) defined the construct of personhood as a “standing or status bestowed upon one human being, by others, in the context of a relationship and social being”. Recent work on the relationships of people with dementia has highlighted the importance of relationships in a number of care settings, including day centres (Sabat and Lee, 2012) and long-term care (Saunders *et al.*, 2012; Medeiros *et al.*, 2012). Similarly, research has been undertaken that has explored how to support the friendships of people with dementia (Ward *et al.*, 2012) and factors to consider in maintaining friendships in early stage dementia (Harris, 2012).

An increasing body of research has explored the experiences of living with dementia and studies have progressed from a focus on the burdens of caring to work focusing on the interrelationship underpinning care giving and receiving; for example, the phenomenological studies of Gates (2000) and Todres and Galvin (2006), and more recently by Nolan *et al.* (2008), where these interrelationships become the focal point for understanding the dynamics of living with dementia. This shift in focus to the ways in which people themselves live with dementia brings an interest in day-to-day experiences.

Studies relating to social interaction and dementia have reflected the expressed negative feelings of ‘belittlement’ and social exclusion experienced by some people with dementia (Gillies, 2000; Snyder, 2002; Sorensen *et al.*, 2008). This correlates with research undertaken by the Alzheimer’s Society (2007) which reports that 50 per cent of adults in the UK believe that there is a stigma attached to dementia. Other researchers, such as Sterin (2002), have asserted that participants can also be the recipients of condescending and paternalistic



attitudes displayed by others, arguing that this is propagated by the prevalent public and stereotypical assumptions about 'life with dementia', which all too often impairs the effort of the person with dementia to not 'bear the brand' of Alzheimer's disease. Also Katsuno (2005), in examining the quality of life (QoL) of people living with early stage experience dementia, highlighted that although the majority of participants stated that their QoL was quite good, also cited the impact of negative public attitudes towards dementia and their personal experiences of 'devaluation' and 'social exclusion'. Other studies have shown that people with dementia have expressed their anxieties in relation to a sense of being devalued if others were made aware of their diagnosis (Langdon *et al.*, 2007).

In contrast to the negative imagery of dementia, other studies have shown that a supportive and inclusive environment can further enhance the lives of people with dementia (Genoe *et al.*, 2010; Phinney *et al.*, 2007). For example with regard to their relationships and social interactions, Hazel (2011) found that the majority of people with dementia interviewed did not experience negativity in their contact with others. Participants reported that they received the essential support, cooperation and encouragement to enable them to not only create meaning within their life, but also to sustain their identity (Katsuno, 2005; Hazel, 2011). Researchers such as Snyder (2001) concur with this and suggest that in being denied the opportunity to remain socially involved, many people living with dementia, in avoidance of the experience of the negative responses of others, may adopt defence mechanisms culminating in withdrawal from future social interactions. In contrast, from their exploratory internet-based study, Clare *et al.* (2008) suggest that the social network process can not only benefit the person, but can further empower people living with mild to moderate stages of dementia in developing a 'voice' and thus rejecting the passive patient role. When people with dementia are empowered and are enabled to collectively band together, they perhaps not only achieve benefits to their individual psychological well-being, but also gain influential social attitudes through their mutual support and collaborative advocacy (Clare *et al.*, 2008).

Significant themes from the theoretical developments outlined above, and which were used to develop the theoretical framework that underpins the evaluation include:

- The importance of focusing not on ‘what is wrong’ with a person with dementia, but of focusing on environmental, attitudinal and social barriers to inclusion experienced by people living with dementia.
- By focusing on a social model of disability, the role of social networks and communities surrounding people with dementia, and the importance of awareness raising, is highlighted.
- It is important to remain critical and realistic about the extent to which policy which states that people with dementia should be included in shaping services translates into meaningful involvement of individuals within the services and support that they receive, as well as inclusion in wider society.
- While it is important to remain critical when considering the application of ideals such as independence, citizenship and people with dementia, there are examples of groups of people with dementia who have considered these ideals in relation to their own experiences, presenting a collective challenge to discrimination.
- Interpersonal relationships are crucial within this, and developing theory challenges notions around deficiency and people with dementia engaging in meaningful interaction with others.

### **Healthbridge: The theoretical framework**

The theoretical framework which underpinned the Healthbridge evaluation is rooted in the theoretical perspectives that have been outlined above. The framework sought to consider the impact of Peer Support Network and Dementia Adviser services in relation to social network theory, social learning theory and self-efficacy theory. In this process, the above points that emerged from the review of policy and theoretical perspectives above have been explored, with a specific emphasis on the role of interpersonal interaction within Peer Support Network and Dementia Adviser services.

### ***Social network theory***

The working definition of social network theory that was used within the evaluation was:

The set of relationships and connections between people that are influenced by sharing some social attributes and proximity.

Turner and Shepherd (1999) suggest that social network theory relates to the sets of relationships and connections between people that are influenced by factors such as geographical proximity and sharing some social attributes. As groups that so often encounter both physical and social isolation, the opportunities for social interaction and the development of social relationships are extremely important for people with dementia and their carers. Research has shown that social networks and social relationships are particularly important in the management of chronic conditions by providing resources, such as social support and information, boosting self-esteem and buffering responses to stress (Hawkey and Cacioppo, 2010; Thoits, 2011; Cornwell and Waite, 2012).

In exploring the impact of demonstration site services on the social networks of people with dementia and their carers, the Healthbridge evaluation sought to explore the impact of Peer Support Network and Dementia Adviser services on the social networks of people with dementia and carers, including the role of social networks developed as a result of Peer Support Network and Dementia Adviser services as well as ways in which support from the services enabled people living with dementia to be more socially included.

### ***Social learning theory***

The working definition of social learning theory that was used within the evaluation was:

The opportunity to 'model' behaviours will result in their adoption.

For many people with dementia and their carers, consideration must also be given to the management of negative experiences in relation to not only the social aspects of day-to-day living, but also their cognitive, behavioural and emotional capabilities. Social learning theory advocates the opportunity for people to seek positive stimuli to assist in the development of coping mechanisms to deal with negative experiences and also in the 'modelling' of behaviours which can result in their subsequent adoption. This is clearly stated in the

National Dementia Strategy (Department of Health, 2009a) in relation to the development of structured peer support and learning networks in offering direct local support to not only encourage, but also to enable people with dementia and their carers to actively participate fully in the “development and prioritisation of local services” (Department of Health, 2009a, p 5).

In evaluating the impact on and development of social learning within the experiences of people with dementia and their carers who were accessing Peer Support Network and Dementia Adviser services, Healthbridge sought to explore the role that learning from and through experiences of people in similar positions can play in maintaining independence and promoting choice and control.

### ***Self-efficacy theory***

The working definition of self-efficacy theory that was used within the evaluation was:

People’s confidence in their own ability to have a desired outcome.

Originating from social learning theory, self-efficacy theory places an emphasis on the importance of an individual having confidence in their ability to accomplish specific goals (Bandura, 1977). In addition to this, Bandura (1986) also suggests that, for an individual, perceived self-efficacy is a behaviour-specific psychological attribute which can be learnt or enhanced. However, researchers assert that self-efficacy is predicated by people’s psycho-social belief in their own abilities and the implementation of individualised coping strategies in dealing with the challenges of varying task-orientated demands and situational environments (Steffen *et al.*, 2002). For example, intervention studies relating to the perception of heightened self-efficacy amongst carers of people with dementia recorded enhancement to their mood and health (Gottlieb and Rooney, 2004), as well as having positive consequential effects on their abilities to cope and overall sense of well-being (Gignac and Gottlieb, 1996).

In evaluating the impact of Peer Support Network and Dementia Adviser services on self-efficacy of people with dementia and their carers, the Healthbridge evaluation has sought to explore ways in which these new ways of supporting people with dementia and carers can

impact on people's confidence and the positive consequences of this in many different aspects of living with dementia.

We now move on to consider the theoretical framework in relation to developments in public health, drawing parallels between Peer Support Networks and Dementia Advisers and some contemporary ideas within the area of public health.

The modelling of the 40 demonstration sites within the implementation of the National Dementia Strategy acknowledges the part that lay and peer support and advisers can play in supporting communities and families. It may be that parallels can be drawn with lay health advisers in public health. Such roles have three broad aims: access to individuals who are marginalised, access from marginalised communities into health and social care systems, and alternative delivery mechanisms to a professional provider. Broadly, these roles are theoretically underpinned by social network theory, social learning theory and self-efficacy theory. The mechanisms of intervention fall into three broad groups:

- Embellishment of standard care such as a 'bridge' between individuals and organisations.
- Providing social network support: affective support (caring, trust, love), informational support (advice, suggestions) and instrumental support (tangible aid and services).
- Information transmission such as individual one-to-one tailored message giving.

Key concepts within public health include well-being and quality of life; lay or peer advice; peer support and information.

### ***Well-being and quality of life***

In exploring *What makes us healthy?* Foot (2012, p 6) outlines an asset approach to health and well-being, which defines "focusing on the positive" as a public health intervention:

Asset thinking challenges the predominant framing of health as the prevention of illness and injury, instead looking at it as the promotion of wellness.

Foot suggests that a significant aspect of this approach is the role of whole communities in facilitating and supporting the well-being of people within them. Again, a parallel can be

drawn here with the work on social networks within Healthbridge, and in the development of dementia-friendly communities.

'Quality of life' is a term that has been used by many people in different ways. Some would argue that quality of life is quantifiable and that it is possible to objectively measure a person's quality of life; others view quality of life as only measurable from the subjective perspective of an individual (Beckie and Hayduck, 1997). Work done on quality of life and people with dementia includes work that has challenged assumptions as to the extent to which people with dementia can live a full and meaningful life (Biernacki, 2008) and work that has explored ways of improving quality of life for people with dementia (Chidgey, 2009; Davis Basting, 2009) including use of music and poetry (Gregory, 2011). Work has also been done to explore quality of life from the perspectives of people with dementia, prioritising their voices (Moyle *et al.*, 2007) and also in relating quality of life issues to dignity (Manthorpe *et al.*, 2010). Well-being sits alongside quality of life as a way of exploring and acknowledging positive aspects of a person's life. Both acknowledge that there are multiple and interacting factors that impact on well-being and quality of life (e.g. Cook, 2008). Caring for someone with dementia can put a serious strain on the carer's physical and mental health. How well carers cope with the stressors created through their role as carer is therefore critical not only for their health but also for the health of the person with dementia. The measurement of 'sense of coherence' (SOC) has been used to explain the extent to which an individual can cope with the challenges of daily living. Someone with a strong SOC is able to view life as coherent, comprehensible, manageable and meaningful, and has the confidence to identify and make use of resources in their internal and external environment (Antonovsky, 1987; Lindström and Eriksson, 2010). Carers with a strong SOC have been found to experience lower burden and better perceived health (Andrén and Elmståhl, 2008), while a low SOC seems to be associated with poor health-related quality of life and depression in individuals caring for someone with dementia (Välimäki *et al.*, 2009).

### **Advice**

A further concept that is central to the Peer Support Network and Dementia Adviser services that are being evaluated within this project is advice. Alongside other areas of these new ways of working with people with dementia and their carers, Peer Support Network and Dementia Adviser services represent a shift away from the conceptualisation of people with dementia and carers as passive recipients of advice administered by professionals towards a sharing of advice between 'lay people', with a further emphasis on advice being rooted in direct personal experience: peer–peer advice. Peer Support Network and Dementia Adviser services, at the same time as acknowledging the importance of medical advice about dementia as a health condition, broadened the impact of support for people with dementia and carers through the sharing of advice that would enable other principles that underpin the services, such as independence, choice, control and social inclusion. Within the evaluation, there has been an emphasis on the role of social networks in advice sharing. The application of social learning theory within Healthbridge also explored the positive impact of sharing advice which was based in direct experiences of people with dementia and carers.

### **Peer support**

Research undertaken during the last decade or so illustrates the benefits in relation to the formation of 'new friendships' within formal or informal support group environments (Snyder *et al.*, 1995). The origins of peer support can be traced back to developments within the disability and mental health movements. Rooted in a commonality of experience, in this instance living with, or caring for a person living with, a diagnosis of dementia, the focus with peer support is upon a sharing of experiential needs and perceived challenges in relation to their individual social and health care issues (Ward *et al.*, 2011). Mead (2003) defines peer support as "a system of giving and receiving help founded on key principles of respect, shared responsibility, and mutual agreement of what is helpful".

The benefits of peer support among people with mental health difficulties and people with learning difficulties are articulated further by Faulkner and Bassett (2010): "shared identity, increased self-confidence, developing and sharing skills, improved mental health and well-being, accompanied by less use of mental health".

Nevertheless, the significance and benefits of peer support amongst people with dementia has only recently been recognised, although Ward *et al.* (2011) highlight that groups such as the Scottish Dementia Working Group have existed in some areas for many years (Ward, the Scottish Dementia Working Group, and River, 2010, as quoted in Ward *et al.*, 2011).

The role of peer support in the theoretical framework of Healthbridge is significant. In relation to social network theory, support from peers can widen people's social networks, both through support from peers and through the impact of increased confidence from support with peers enabling people in developing and/or maintaining their social networks in a wider sense (Hazel, 2011). There is also a potential impact of peer support in relation to social learning theory: by interacting with and identifying with people who have similar experiences, new ways of thinking about difficulties as well as learning from practical solutions can emerge. This in turn can have an impact on self-efficacy, as confidence in the ability to overcome difficulties and live well can arise from interacting with others who are or have been in the same position (Collins, 1999).

### ***Information***

Whether it is through information from a Dementia Adviser or through information shared within a Peer Support Network group or peer-to-peer relationship, information is a key element of both Peer Support Network and Dementia Adviser services. This reflects the focus on information within support for people with dementia alongside many other long-term conditions.

Clarke *et al.* (2011) outline the role, alongside listening and acting on people's views, of information in autonomy for people with dementia. Clarke *et al.* (2011) also outline the important dynamic of giving *and* receiving information, and the need for information provision to be tailored so that each individual is provided with the information that is right and relevant to them at the point they are at in their dementia journey. In this way, information can be viewed as a means of either enabling or disabling people with dementia, and their carers.



Having set the policy and theoretical background for Healthbridge, we now set the scene for the methodology and methods used in Healthbridge by highlighting the significance of involving people with dementia in research.

### **Involving people with dementia in research**

Within the context of this evaluation, the involvement of people with dementia was significant. The work done within Healthbridge built upon a growing body of research, particularly qualitative research, which has sought to involve people with dementia in research, enabling their voices to be heard:

The voice of the person with dementia is becoming more visible in the literature, and these accounts must inform development of future methods of engagement in both research and clinical practice across a range of specialities.

McKeown *et al.*, 2010, p 1942

Previous work (in 2000) highlights the ethical responsibility of involving people with dementia, as well as their carers, in evaluating services, linking it with a recognition of the importance of valuing people with dementia and the contribution they can make to communities and societies (principles outlined in the section on policy and people with dementia):

If we fail to believe that the person with dementia is still a person in their own right, then we may easily fall into the habit of treating them as less than a person. Services for people with dementia need to place the person with dementia and the centre of their planning and service evaluation. We must hold on to the fact that the services we provide exist to serve the person with dementia – and that we cannot know that we are doing this unless we find some way of finding out from the person themselves.

Cheston *et al.*, 2000, p 478

Involvement of people with dementia and their carers in this evaluation, specifically within the in-depth case study sites, was significant because:

- It reflects the policy drive to involve service users in services. In order for this evaluation to reliably inform the future development of services for people with dementia and their carers it was essential that their views and experiences of the demonstration sites was captured within the evaluation.
- It also reflects the ideologies that underpin the theoretical perspectives, such as the social model of disability which has been outlined above.
- The many people with dementia and carers who were interviewed, from a wide range of geographical settings and personal backgrounds, provided invaluable insight into their experiences of living with dementia. This data is a significant source of qualitative data collected on a national scale from people living with dementia.

To summarise the literature relating to the theoretical framework underpinning Healthbridge:

- There were three interlinking theories which underpinned the evaluation: social network theory; social learning theory and self-efficacy theory.
- Parallels can be drawn between lay advisers in the field of public health and the roles that were established within the Peer Support Network and Dementia Adviser services.
- Within Peer Support Network and Dementia Adviser services, significant areas that are underpinned by the theoretical framework include well-being, quality of life, advice, peer support and information.
- The priority that was placed on meaningful involvement of people with dementia, and their carers, in Healthbridge mirrors a wider body of research that has responded to the importance and the challenges of involving people with dementia in research about their lives, informing policy and practice development.

## **Conclusion**

The policy, theoretical perspectives and specific framework outlined above provide a foundation for and inform the methodology and methods used in the evaluation. This includes:

- The importance of looking beyond dementia as a medical deficiency to consider how barriers to meaningful involvement in society can be broken down to include people with dementia as valued members of society.
- The acknowledgement that people with dementia can and do engage in meaningful interpersonal interaction.
- The role of social learning theory, social network theory and self-efficacy theory as a theoretical framework underpinning the evaluation.
- The significance of advice, information and peer support for people with dementia and their families.
- The growing body of research, including service evaluations, which have included qualitative data from people with dementia.

## Healthbridge: Evaluation design and methods

This section of the report aims to:

- Provide a background to the Healthbridge evaluation by setting the context for the demonstration sites and outlining the methodology and methods used, linking this with the policy and theoretical backgrounds that were outlined in the previous section of the report.
- Outline the aims and objectives of the evaluation, demonstrating how each of the aims were achieved through the research process.
- Describe and critique the methods that were used within each of the three main strands of the evaluation, including sampling, data collection and data analysis.
- Outline how ethical standards were maintained throughout the research process, including prioritising the views and experiences of people with dementia.
- Discuss and critique the application of a mixed methods approach to the evaluation, demonstrating how the methods used in each strand contributed to the evaluation design as a whole.

The methods section is presented as follows:

1. Background to demonstration period
2. Overview of evaluation
  - a. Mixed methods research
  - b. Evaluation strands
  - c. People involved
3. Ethics
4. Strand 1: Activity and outcome monitoring: methods; analysis; outputs
5. Strand 2: Organisational survey: methods; analysis; outputs
6. Strand 3: In-depth case studies: methods; analysis; outputs
7. Meta-analysis (drawing it all together)

## Background to evaluation

Altogether, 40 demonstration sites were set up. The 40 sites were chosen through a competitive application process in which applicant sites were required to describe their proposed activity and detail how this would fulfil the aims of the National Dementia Strategy. Twenty-two of these were set up around a Dementia Adviser model and 18 around a Peer Support Network model. Demonstration sites were located within a wide range of organisational structures, with a range of lead and partner organisations involved. Lead organisations included NHS Foundation Trusts, Older Adult Mental Health Teams, city councils, borough councils, Alzheimer’s Society, and other voluntary sector organisations including Age UK and Mind. Some sites were set up within pre-existing dementia services, such as memory clinics, Alzheimer’s Society groups or dementia café networks. Other sites were set up to run independently of pre-existing services and support for people with dementia and their carers. Table 1 summarises the organisational structure of the demonstration sites in relation to lead and partner organisations. The range of organisational structure meant that for some sites leadership was joint between more than one organisation. There was considerable variability between the demonstrator sites, but for illustrative purposes, four are described organisationally in Appendix A.

Organisations	Percentage of sites: lead	Percentage of sites: partner
NHS	31.25%	35%
Council	34.375%	32.5%
Voluntary sector	34.375%	32.5%

**Table 1.** Summary of lead and partnership organisations at demonstration sites.

## Overview of evaluation

### Evaluation aims

The aims of the evaluation were four-fold:

1. To describe the range of Peer Support Network and Dementia Adviser pilot services, their evolution, establishment and delivery and governance characteristics.
2. To support the effective implementation of the pilot services.

3. To assess the new service models of Peer Support Network and Dementia Advisers in relation to:
  - i. Influence on the well-being of people with dementia and carers.
  - ii. Contribution to achieving the objectives of the National Dementia Strategy (Department of Health, 2009a)
  - iii. Integration, sustainability and transferability within the wider health and social care economy.
4. To identify ways in which Peer Support Networks and Dementia Advisers, as new services models, contribute to the well-being and resilience of people with dementia and carers, specifically in relation to:
  - i. Accessibility of services
  - ii. Involvement and information
  - iii. Support for making choices and independence.

As such, it was important that evidence captured the wide range of activity that was taking place, at the same time as gathering in-depth evidence based on the views and experiences of people with dementia, their carers, staff, volunteers and other stakeholders. In order to achieve this, a mixed methods approach was adopted.

A mixed methods paradigm brings both strengths and limitations to a research project. Broadly, it can strengthen the quality of the research by combining the strengths of each approach and mitigating the internal limitations of each (Johnson and Onwuegbuzie, 2004). Not least, this is achieved by triangulating data sources in which different perspectives with the same message add weight to a finding. The most significant weakness arises from possible conflicts between the philosophical bases of different methods (classically the assumed positivism of quantitative research and the more constructivism of qualitative research). Mixed methods can, therefore, be used to add understanding that may be missed when only one method is used, providing stronger evidence through convergence and collaboration of findings (Johnson and Onwuegbuzie, 2004).

In order to manage this interrelationship of breadth and depth of data collection in a study of 40 demonstrator sites, some data were collected across all of the demonstrator sites, and

some (those more orientated to depth data) were collected from a sample of eight of the demonstrator sites that formed case study sites and were selected because they represented the diversity of all of the sites. Parahoo (2006) argues that qualitative research addresses each individual's experience and context while quantitative research seeks independence from context. It is this varied positioning of context within the research that further characterises mixed methods research. In this study, the more detailed and qualitative data collection within the case studies allowed the context in which the services were provided and received to be more visible (which is important for theory building) than could be achieved in the data that addressed breadth, while also allowing the study to accommodate data that could be more generalisable (which is important for theory testing).

By privileging qualitative methods within this mixed methods study, we are able to forefront the underpinning epistemology of social constructivism, which claims no objective reality and knowledge but understands these to be derivative of society and social dynamics. This is a reflexive process which Fosnot (1996) describes as knowledge that is in the first instance constructed as a social aspect, is then reconstructed as meaning, then owned by other individuals and internalised through interaction with others. In this study, the more quantitative methods, which individually claim objectivity, must be understood as being deployed within this underpinning epistemology of social constructivism. It is important, then, to acknowledge that research methods, and in particular interviews as a form of qualitative data collection, are inherently linked to context – research methods are not “neutral, context-free tools for data collection” (Mills *et al.*, 2006).

Consequent to adopting this position is to acknowledge and articulate the ways in which the context of the research is influenced too by the position of the researchers. This occurs in relation to the choices over design and methods of the research, but also in relation to the relationship between the researchers and the participants and the data itself since, in social constructivist research, the researcher brings themselves to the research event and it is, in part, shaped by this. In the first year of the evaluation, when the demonstrator sites were all active, the Department of Health National Implementation Team of the National Dementia Strategy organised a series of Project Lead Network meetings which were attended by representatives from all of the 40 sites, the National and Regional Implementation Leads

and some members of the evaluation team. Through these meetings we were able to establish a cooperative relationship with all of the demonstrator sites and the contribution of those attending to shaping the evaluation methods and our understanding of the context in which they were working was both very valuable and very valued. As a team of experienced researchers with, to varying degrees, experience of working with people with dementia and a grasp of the principles underpinning the Peer Support Networks and the Dementia Adviser roles, we nonetheless lacked context-specific information about the demonstrator sites and the ways in which they worked. These meetings, and our relationship with the sites, were invaluable in facilitating the development of methods, in shaping our understanding and in enabling data collection with the sites. They also contributed to the implementation support available to the sites. The importance of the position of the researcher in all aspects of the research (or what is referred to as reflexivity) also shapes the ways in which we engaged with data collection and data analysis, and the construction of ‘telling the story’ in the discussion – the ways in which this was managed is described at each relevant section of the report.

## **Evaluation strands**

Within this mixed methods approach, there were three main strands to the evaluation, represented in Figure 1:

1. Activity and outcome monitoring, including:
  - a. Quantitative data which represented numbers of people accessing the sites and demographic information.
  - b. Well-being and quality of life measures using established tools (ASCOT and DEMQoL), completed by people with dementia and their carers who had accessed the demonstration sites and a group from an area with no access to demonstrator site services.
2. Organisational surveys and collaborative discussions, including:
  - a. Postal survey data which represented organisational structure and development.
  - b. Structured discussions with demonstrator site leads and commissioners during national workshops.
3. In-depth case studies, including:

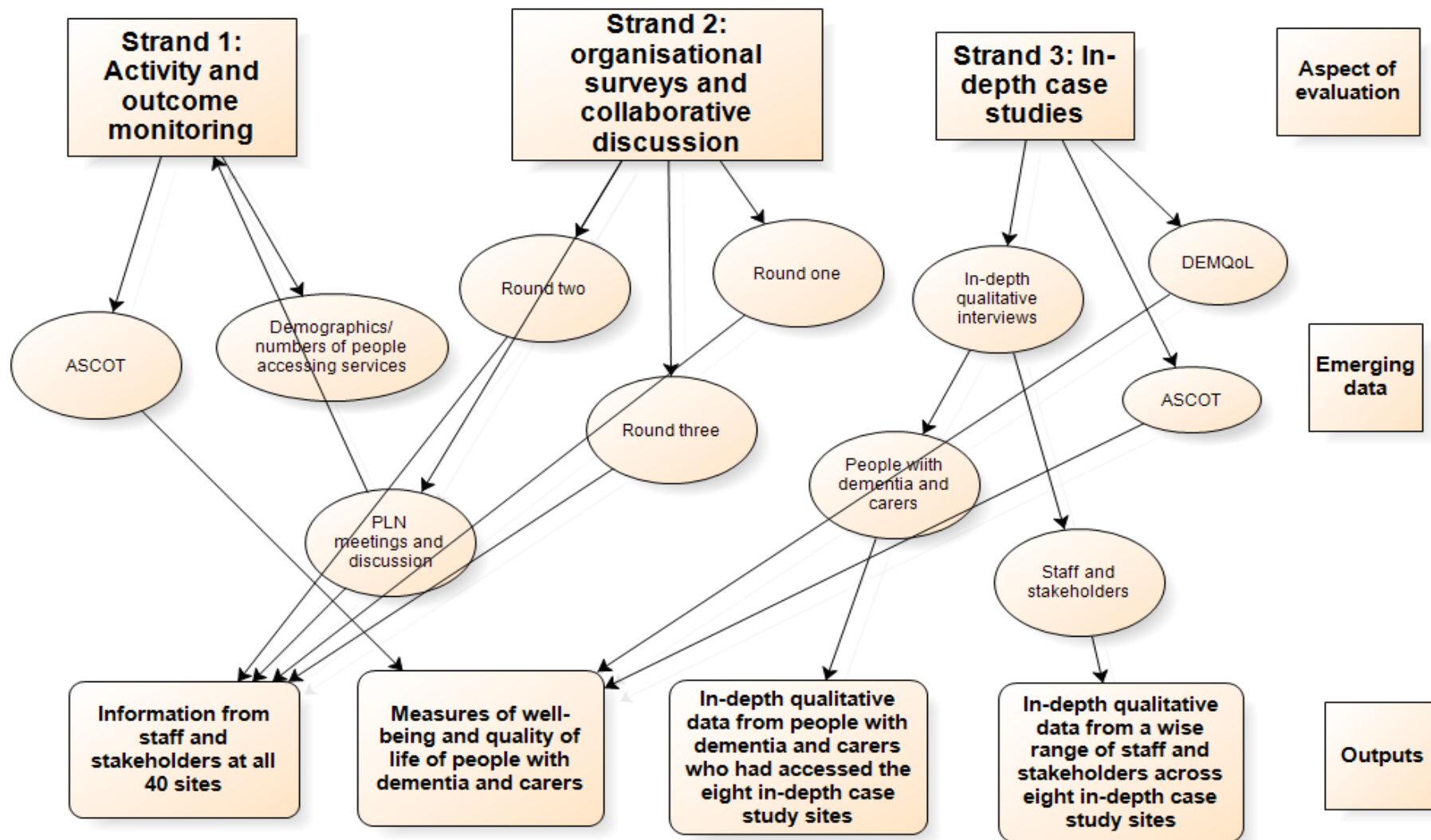


- a. In-depth qualitative interviews which allowed for a more in-depth exploration of the views and experiences of people with dementia, carers, staff, volunteers and other stakeholders involved in site activity.
- b. Well-being and quality of life measures.

Key decisions when using mixed methods concern how best to build the jigsaw of data to provide the strongest confidence in the findings and the conclusions that can be drawn from these. There are two aspects to this.

Firstly, deciding on the balance between the paradigms and whether one should be more dominant than the other. In this study, the dominant paradigm is qualitative, with narrative data collected from multiple sources, for example people with dementia, staff in the demonstrator sites and carers. Multiple forms of narrative data were also collected, for example interviews, open questionnaire questions. The dominant qualitative paradigm is augmented by some quantitative or more numerical data, again from multiple sources and in multiple forms, for example quality of life measures with people with dementia and carers, monitoring of service usage by demonstrator site staff.

Secondly, deciding on whether different methods should be used concurrently or sequentially. In this study, both concurrent and sequential approaches were used to both broaden the scope (for example, collecting DEMQoL and ASCOT data alongside interview data in the case study sites) and to deepen the scope so that one emerging issue could be checked out through alternative data (for example, the demonstrator site surveys enquired about organisational issues and in rounds two and three of these surveys we embedded ideas and sometimes data that had emerged in preceding interviews to provoke a response to these issues by different people in a different data collection format). This ability of sequential mixed methods research to be provocative creates the opportunity for emerging ideas to be 'tested' and as a result discounted, refined or confirmed.



**Figure 1.** Design of the mixed methods evaluation.

Data collection spanned a period of 26 months, with different strands of the evaluation interlocking with and contributing to the development of other strands. Table 2 outlines the timescale of the data collection and the timing of the strands within this.

	Apr '10	May	Jun	Jul	Aug	Sep	Oct	Nov	Dec	Jan '11	Feb	Mar	Apr	May	Jun	Jul	Aug	Sep	Oct	Nov	Dec	Jan '12	Feb	Mar	Apr	May	
Strand 1: Activity and outcome monitoring: well-being questionnaires							■	■	■	■	■	■															
Well-being questionnaires (non-demonstrator site group)																									■	■	■
Strand 1: Activity and outcome monitoring: numbers accessing services and demographics <sup>1</sup>							■	■	■	■	■	■								■				■			
Strand 2: Organisational surveys			■													■									■		
Strand 2: Project Lead Network meetings (collaborative discussion)	■		■			■		■			■																
Strand 3: In-depth case study, data collection: qualitative interviews and well-being/quality of life measures								■	■	■	■	■	■	■	■	■	■										

**Table 2.** Timescale of the data collection.

<sup>1</sup> Activity and outcome monitoring data collected for the first full week of each month indicated.

Table 3 outlines how the various strands met the aims of the evaluation.

	Strand 1a: Well-being questionnaires	Strand 1b: Demographics	Strand 2: Organisational surveys and PLN discussions	Strand 3a: Case study interviews: staff and stakeholders	Strand 3a: Case study interviews: People with dementia and carers	Strand 3b: Case study : well-being and quality of life measures
Description of range of Peer Support Network and Dementia Adviser services						
Description of evolution, establishment, delivery and governance						
Support the effective implementation of the pilot services						
Assessment of influence on well-being of people with dementia and carers						
Assessment of contribution of Peer Support Network and Dementia Adviser services to aims of National Dementia Strategy						
Assessment of integration, sustainability and transferability within wider health and social care economy						
Identification of contribution to well-being and resilience: accessibility of services						
Identification of contribution to well-being and resilience: information and involvement						
Identification of contribution to well-being and resilience: making choices and independence						

**Table 3.** Data collection mapped against evaluation aims.

### ***Involvement in evaluation: People***

In order to ensure that the aims of the evaluation were met through a rigorous research process, it was important that a wide range of people who had been involved in site activity were enabled to contribute their views and experiences to the evaluation. Table 4 outlines the people who were involved in each strand of the work (DA, Dementia Adviser; PSN, Peer Support Network; PLN, Project Lead Network).

Strand	Target group	How sampled	Number of participants/response rate
<b>1a: Activity and outcome monitoring: numbers accessing services and demographics</b>	Site staff from all 40 demonstration sites	Contacts made with most appropriate site representative	Oct 2010 to March 2011: 228 Nov 2011: 23 March 2012: 20
<b>1b: Activity and outcome monitoring: well-being questionnaires</b>	People with dementia and carers who were accessing all 40 demonstration sites plus the non-demonstrator site	Questionnaires distributed by site staff and returned by those completing directly to Healthbridge	Qs returned by DA sites: 282 Qs returned by PSN sites: 350 Qs returned by non-DS site: 37
<b>2: Organisational surveys</b>	Staff and stakeholders from all 40 demonstration sites	Surveys distributed to all 40 demonstration sites	Survey 1: 32 Survey 2: 37 Survey 3: 20
	Demonstration site leads and commissioners	Knowledge exchange activities in PLN meetings	Approx. 80 at each of five PLN meetings
<b>3a: In-depth case study sites: qualitative interviews</b>	People with dementia, carers, staff, volunteers, commissioners, other stakeholders and people with an interest from eight in-depth case study sites	Sampling matrix used (see below) to identify and recruit a range of service users and stakeholders within each site	People with dementia: 47 (interviewed 1, 2 or 3 times either alone or with carer) Carers: 54 (interviewed 1, 2 or 3 times, either alone or with carer) Staff and stakeholders: 82
<b>3b: In-depth case study sites: quality of life and well-being measures</b>	People with dementia and carers from eight case study sites who also took part in in-depth qualitative interviews	Completed (where appropriate) alongside in-depth qualitative interviews	DEMqoL people with dementia*: 79 ASCOT people with dementia*: 84 DEMqoL carers*: 66 ASCOT carers*: 82 *Denotes numbers of questionnaires completed

**Table 4.** Participants in each evaluation strand.

## Ethics

The Healthbridge evaluation sought to adhere to the highest ethical principles throughout the process of sampling, recruitment, data collection and analysis. The principles underpinning the evaluation – beneficence; non-maleficence; respect for autonomy; respect for persons and justice (Israel and Hay, 2006) – sought to ensure that the interests of participants were respected; that nobody came to any harm; that the rights of individuals were respected; and that participants were valued and treated fairly in every decision that was made.

Given the scale of the project, maintaining confidentiality and anonymity within and between sites was complex and required systems to be in place that would ensure that the principles outlined above were adhered to. The approach adopted within Healthbridge of prioritising the views and experiences of people with dementia also required carefully considered ethical procedures to be put in place from the outset.

Within Strands 1 and 2 of the evaluation, challenges relating to ethical integrity arose from the wide geographical spread of sites and ensuring that safe procedures were in place for collecting data. Procedures were established to:

- Ensure that people with dementia completing questionnaires knew who to contact if taking part caused distress in any way.
- Ensure that any situation in which there was reason for concern about the safety of a participant or those around them, or one of the evaluation team, was dealt with appropriately.
- Assure confidentiality and anonymity for people with dementia and carers who were returning ASCOT questionnaires.
- Assure confidentiality and anonymity to site staff who were returning information to the evaluation, including secure storage of data that had been returned by the sites.
- Maintain confidentiality and anonymity whenever presenting data that had been returned from the sites.

Within the in-depth case study sites the more complex face-to-face interaction required well-conceived and executed procedures. Challenges again arose from the distances involved, with members of the evaluation team collecting data across England. Significant ethical issues included:

- Maintaining anonymity, for example researchers were not given any personal details of people with dementia or carers prior to potential participants having received information (which was distributed by site staff).
- Maintaining and ensuring confidentiality. This was especially important in interactions between the researchers and the many people within each site with whom they had contact.
- Acknowledging the complexities of the process of consent to take part in research by people with dementia.
- Ensuring that any situation in which there was reason for concern about the safety of a participant or those around them, or one of the evaluation team, was dealt with appropriately. In order to ensure this, supervision processes were established within the evaluation team that would ensure that senior team members were alerted as soon as a concern arose. This led to advice, reassurance or action, depending on the situation.
- Secure storage of all data collection materials, including audio recordings, consent forms, names and addresses of participants and well-being and quality of life questionnaires.
- Anonymising all data as soon as possible after data collection. This was done by allocating a code to each participant, which was used to identify all materials relevant to that person.

Throughout the evaluation, including national meetings and contact with representatives from any of the sites, it was important that the evaluation team maintained integrity and were clear about their remit. For example, sites sometimes asked about progress in other sites but it was not appropriate for the evaluation team to pass on such information.

Maintaining clarity of role was also important for researchers conducting the in-depth case

study interviews and when, for example, participants sought information about their diagnosis or other aspects of care.

The evaluation team developed a protocol for managing situations in which participants sought information or team members had concerns about the welfare of an individual and those around them. This protocol reflected an escalation of intervention depending on an assessment of the seriousness of the situation and centred around the principles of safety and of enabling independence.

The physical safety and emotional well-being of researchers, who were away from home (often overnight) as lone workers when completing the interviews, was also important. In this regard, the team adopted systems of buddying so that there were ways of knowing that team members had reached their destinations and an alarm could be triggered if someone was not heard from with prescribed time limits. We explored the use of GPS-based security systems but decided against the use of these because they were vulnerable to blind spots in the country which reduced their effectiveness. On a one-to-one basis, and within team meetings, there were opportunities for debriefing and supervision so that all team members could access support for themselves and for decision making (sometimes by phone or e-mail when away in a case study demonstrator site).

The process of gaining ethical approval to conduct the evaluation involved approval from the Social Care Research Ethics Committee (Ref: 10/IEC08/13). NHS Research Governance approval was secured where necessary and also approval from the Association of Directors of Social Services (Ref: Rg 10-009). This reflected the organisational nature of the services as often spanning health and social care services. As the project evolved, amendments were sought and approved by the Social Care Research Ethics Committee. One substantial amendment was required in relation to the project's transfer to the University of Edinburgh as the lead organisation, dated December 2011. One example of a minor amendment was the development and distribution of organisational surveys 2 and 3, the final version of these being developed in response to preceding data collection. The project was also audited as part of the University of Northumbria research ethics management protocols in June 2011.



Having provided an overview of the aims of the evaluation and how these aims were met, the three main strands to the evaluation are now outlined in relation to their aims and methods used, including sampling, data collection, analysis and outcomes.

## **Strand 1: Activity and outcome monitoring**

The aim of this aspect of data collection and analysis was to gather evidence and information on the breadth of work undertaken across the demonstration sites, including numbers of people accessing services across all 40 demonstration sites. This aspect of the data relates specifically to the evaluation aim of describing the range of activity within the demonstration sites. People with dementia and their carers who were accessing the 40 sites were also involved in completing a well-being questionnaire (ASCOT). The completion of well-being questionnaires (ASCOT) by people with dementia and their carers is a direct response to aim 2.i of the evaluation: assessing the new service models of Peer Support Network and Dementia Adviser in relation to their impact on the well-being of people with dementia and their carers.

## **Strand 1: Methods**

### ***Strand 1a. Data and demographics on numbers of people accessing services***

Data collection took place during the first full week of the month. Forms (a copy of which can be found in Appendix B) were distributed to all 40 demonstration sites, asking staff, for each day in that week, to provide information on:

- numbers of people accessing services (broken down into people with dementia, carers, general members of the public, professional staff)
- whether this was the first contact that had been made or a repeat contact
- how many of the people accessing the services had a confirmed diagnosis of dementia
- numbers of people for whom diagnosis had not yet been confirmed and numbers where diagnosis was unknown
- information on whether people live alone or not
- gender and age, and numbers of people from specific groups:
  - BME communities
  - lesbian, gay, bisexual and transgender (LGBT) communities

- people with a learning disability
- people for whom English is not a first language.

Following an initial trial month in September 2010, during which the systems put in place for distribution were piloted, data were collected on the first full week of each month from October 2010 through to March 2011. In order to continue to monitor and evaluate services during the period of transition from the initial demonstration site period, further collection of data took place in November 2011 and March 2012. This means that data on people accessing the demonstration sites is available for eight different months, over an 18-month period of study. Over the initial six months of data collection there was a 95% response rate. Responses during the further two months of data collection decreased to 58% and 50%, respectively, reflecting the evolution of services, including that some services had ceased operation.

### ***Strand 1b. Well-being (ASCOT) questionnaires***

In addition to the above information collected from site staff, information on the well-being of individual people with dementia and carers was collected through completion of a well-being questionnaire (ASCOT), a copy of which can be found in Appendix C.

ASCOT (the Adult Social Care Outcomes Toolkit) was developed as part of a wide-scale project which sought to develop ways of measuring outcomes for people using public services (Office for National Statistics, 2010). It links the services and support that people are accessing with their quality of life, from their perspective. In measuring quality of life, ASCOT addresses eight areas of need. These begin with needs that would be considered basic, moving into more complex needs:

- Accommodation
- Personal cleanliness
- Nutrition (food and drink)
- Personal safety
- Social participation
- Occupation

- Control
- Dignity.

Each of the eight areas of need are addressed in turn by respondents, and the questions allow respondents to assess their needs in that particular area based on a four-point scale, which identifies high need; some need; no need; or being in an ideal state.

For example, respondents are offered the following responses in relation to social contact:

- I have as much social contact as I want with people I like (categorised as ideal state).
- I have adequate social contact with people (categorised as no needs).
- I have social contact with people, but not enough (categorised as some needs).
- I have little social contact with people and feel socially isolated (categorised as high needs).

Use of ASCOT (the version of which was used in Healthbridge can be found in Appendix C) results in a Social Care Related Quality of Life (SCRQoL) score. In doing this, the complexity of the relationship between people's quality of life and the range of services provided in a social care context is addressed (Malley *et al.*, 2012). In addition to this, a person's SCRQoL score is enabling in relation to people who are accessing services to have choice over *how* their needs are met. The way in which ASCOT measures an individual's SCRQoL is based on the 'capabilities and functioning' approach (Sen, 1985). This approach separates an individual's functioning (for example, how often they see other people) from their capability (for example, whether or not they are happy with how often they see other people).

ASCOT also reflects the move by people commissioning services towards an outcomes approach. ASCOT enables commissioners to work in partnership with people accessing services to shape services based on their perspective of many different areas which impact on quality of life. There is also a cost-effectiveness aspect to the outcomes measured within ASCOT which can be used to assess value for money. Consequently, ASCOT has also been used by commissioners in the process of deciding which services to commission (Office for National Statistics, 2010).

The process through which ASCOT was initially developed involved three different contexts: a voluntary sector context; an adult social care context; and an early years education context. This means that the toolkit is well suited to contributing to the evaluation of the range of organisational contexts of the demonstration sites of Healthbridge. An assessment of the construct validity of ASCOT is available in an article by Malley *et al.* (2012). The ASCOT toolkit has been applied previously within research and service evaluation in many different ways, including:

- To distinguish the difference between quality of life outcomes and quality of care home ratings (Netten *et al.*, 2012b). In this study, ASCOT was used to capture the SCRQoL for care home residents in relation to regulator quality ratings of care homes.
- To explore the impact and effectiveness of personalisation through individual budgets (Netten *et al.*, 2011b). Here, ASCOT was used alongside interviews about people's experiences within the process of personalisation through individual budgets. ASCOT enabled a comparison of the SCRQoL score of two groups of people; one group was receiving an individual budget, the other group was not.

The way in which ASCOT focuses on basic needs at the same time as more complex areas was significant in the decision to use ASCOT in the Healthbridge evaluation, as it provided an opportunity to capture many areas relating to the well-being and quality of life of people with dementia and carers across England. The focus on social participation is particularly relevant to our theoretical framework, especially social network theory. Similarly, the focus on occupation, control and dignity provided an opportunity for some of the ideals of the National Dementia Strategy to be considered, such as empowerment and the move towards services that are shaped and led by people with dementia and carers.

Using ASCOT in the Healthbridge evaluation also allowed for the well-being and quality of life of people with dementia and carers to be considered alongside the outcomes of accessing Peer Support Network or Dementia Adviser services. A further use of ASCOT within Healthbridge was in the in-depth case study site interviews and included use with people with dementia in mid to late stages who had difficulty in answering the more abstract questions about the Peer Support Network or Dementia Adviser services but were

able to answer the questions on ASCOT. This means that people in more advanced stages of dementia have been able to contribute their views about their experiences into the national evaluation.

A further significant aspect of ASCOT in relation to its application within Healthbridge is that, rather than focusing on whether or not the areas of need are met by the person themselves, ASCOT focuses upon:

how well people function in spite of their impairment, where care support and services can help people.....ASCOT asks not if people have problems with doing these things themselves but whether they are achieved or not (to a desired level), allowing for people to be helped in these activities.

Office for National Statistics, 2010

ASCOT data was collected across all participating sites on a monthly basis between November 2010 and March 2012. In addition to the standard format of ASCOT, the forms used in Healthbridge were adapted to capture the role of the person completing the form (carer, person with dementia or person with mild memory problems), and there was an additional section inviting general comments about the participant's well-being. The documents used in Healthbridge were translated into Urdu, Punjabi and Gujarati to ensure that ASCOT could be completed in a language of choice. The quality of these translations was checked by a process of back-translation into English to ensure that meaning was not lost. In practice, no questionnaires in these languages were returned. Questionnaires were distributed by site staff and returned to the evaluation team, either via site staff or by post directly to the evaluation team. The process ensured that the evaluation team were able to identify which site had been accessed by the person with dementia or carer who had completed each questionnaire. In discussion with the demonstrator site leads at the Project Lead Network meetings, it was evident that any system that would allow association of a single questionnaire with an individual respondent would be too complex to be practical in the sites or one in which we could assure confidentiality. As a result, the numbers of questionnaires returned does not necessarily correlate with the number of people completing them, because the procedure for returning these did not identify who had

completed each questionnaire and so potentially an individual may have completed multiple questionnaires.

Table 5 represents the number of questionnaires received by the evaluation team.

<b>Month</b>	<b>Number returned (Dementia Adviser sites)</b>	<b>Number returned (Peer Support Network sites)</b>	<b>Number returned (all sites)</b>
<b>Sept 2010</b>	39	42	81
<b>Oct 2010</b>	67	49	116
<b>Nov 2010</b>	38	85	123
<b>Dec 2010</b>	46	52	98
<b>Jan 2011</b>	25	51	76
<b>Feb 2011</b>	40	55	95
<b>March 2011</b>	27	16	43
<b>Total all months</b>	282	350	632

**Table 5.** Number of well-being questionnaires returned by post to evaluation team from all 40 demonstration sites as part of Strand 1 (activity and outcome monitoring).

In order to explore the ASCOT scores which were being returned or completed as part of Strand 1a and Strand 3, a sample was recruited who did not have access to either of the demonstrator site services. Participants from this group were asked to complete ASCOT only and did not take part in any of the other strands of data collection. The aim in recruiting this group was to collect ASCOT data from people with dementia and carers who were not accessing Peer Support Network and Dementia Adviser services. It is important to note, however, that recruiting a group who had access to no related services at all was impossible because the policy imperative around dementia advice and peer support networks meant that equivalent or similar services were available across England. Anyone not accessing such a service was likely to have chosen not to, and therefore, as an individual, be somewhat different from those accessing services within the demonstrator sites. However, by circulating questionnaires in this way, ASCOT scores from a further group of people with

dementia and carers can be considered alongside the scores from people who were accessing Peer Support Network and Dementia Adviser services and those who were interviewed as part of the in-depth case studies.

This additional group of participants, without access to demonstrator site services, were recruited from a geographical area in which there was a known low level of services available. Participants were recruited from a larger group who made use of a social services led forum about and for people with dementia and their carers. In order to establish what services and support were being accessed by this group, a further two questions were added to the questionnaire, one asking about opportunities to meet with others in a similar position, the other asking about sources of advice, if any. As with other versions of the tool used, an additional space was left for people completing the form to add further information about their well-being that they wanted to feed into the evaluation. Copies of this questionnaire can be found in Appendix D.

There were, therefore, three groups of people from whom ASCOT data was gathered as part of the Healthbridge evaluation. The methods used for distributing and returning the questionnaires were different for each of the groups:

- Questionnaires completed by people with dementia and carers who were accessing all 40 demonstration sites as part of Strand 1 of the evaluation (n = 632). These were distributed by site staff and returned to the evaluation team by post (either by people themselves or by site staff).
- Questionnaires completed by people with dementia and carers who took part in the in-depth case study interviews as part of Strand 3 of the evaluation and discussed in more detail below (n = 166). The questionnaires were completed with appropriate support from the researcher alongside the in-depth qualitative interviews.
- Questionnaires completed by people with dementia and carers who had not accessed any of the demonstration site services (n = 37). These were distributed at forum events by one of the evaluation team, who also explained the questionnaires and why people were being asked to complete them.

The different methods used in collecting ASCOT data present both weaknesses and strengths within each of the groups:

- The questionnaires distributed by site staff to people accessing all 40 demonstration sites were completed and returned anonymously, allowing for people's opinions to be expressed anonymously. However, the way in which they were completed provided very little context for people completing the forms, something which is so important especially for people with dementia. The evaluation team have no information as to what role site staff played in this strand of the completion of ASCOT.
- The questionnaires completed within the in-depth case study site interviews were completed within the context of the research relationship with the team member, potentially providing more context as to why the questions were being asked. Administration of the questionnaires by the team also made use of researcher skills in collecting the data. Many of the people with dementia and carers who completed the forms as part of this strand did so on more than one occasion, allowing for a longitudinal aspect to this strand of data collection. However, the fact that questions were not being answered anonymously made this strand of ASCOT data collection different to the other two.
- The questionnaires completed by people with dementia and carers who did not have access to a demonstrator site service were introduced to the group by one of the evaluation team during one of their monthly 'forum' meetings and then completed anonymously. The process of returning the forms via post to the team ensured anonymity, although the evaluation team had no influence over the process of the forms being completed.

## **Strand 1: Analysis**

### ***Strand 1a: Activity monitoring data analysis***

Activity and outcome monitoring data was entered on a monthly basis into IBM SPSS Statistics 19. Daily responses for each site were entered numerically, with information (such as specific BME groups identified as attending sessions or events) being coded when necessary. Where sites completed multiple responses for individual days, additional cases were created to capture this information. Monthly summaries and analysis were then



produced, and each monthly data set was merged to produce overall information on the sites. Data summaries were generated from each monthly data set within IBM SPSS Statistics 19.

### ***Strand 1b: Well-being questionnaires: analysis***

Participant responses to the questionnaires were input into the ASCOT data entry tool, which provides both a breakdown of group responses in each area, and an overall Social Care Related Quality of Life (SCRQoL) score for each respondent as well as the group as a whole. The percentage of people identifying themselves as having no needs or being in an ideal state in any one area was also produced as part of this analysis. In addition to presenting this data, which sheds light on the well-being of people with dementia and carers who responded as part of the data collection which spanned the 40 demonstration sites, in the findings section this data is compared with ASCOT data collected in Strand 3 of the evaluation and the group who did not have access to a demonstrator site service.

## **Strand 1: Outputs**

### ***Strand 1a: Outputs***

The outputs of this strand of data collection enabled a picture to emerge of the range of people who were accessing services. In addition to monitoring the activity of all 40 demonstration sites, the activity and outcome monitoring data collection process was designed to reflect the theoretical framework underpinning the evaluation (social network theory, social learning theory and self-efficacy theory) as well as economic dimensions (cost–benefit data, barriers and levers for change). The data collected also reflected outcome indicators for people with dementia and carers (social and community engagement, choices and autonomy) and client diversity (ethnicity, culture, gender, socio-economic status). The well-being questionnaires provided insight into the well-being of people with dementia and carers who were accessing the site, including in relation to the theoretical framework which underpinned the evaluation.

### ***Strand 1b: Outputs***

The ASCOT data collected as part of this strand of the evaluation has provided a quantitative analysis of aspects of the lives of people with dementia and their carers which the National Dementia Strategy set out to influence through the implementation of the demonstration sites. The data collected has been used as part of the process of assessing the influence of Peer Support Network and Dementia Adviser services on the well-being of people with dementia and their carers. The data has also fed into the assessment of Peer Support Network and Dementia Adviser services in achieving the objectives of the National Dementia Strategy, and ways in which approaches used within Peer Support Network and Dementia Adviser services might be transferred within the wider health and social care economy.

### **Strand 2: Organisational surveys and collaborative discussion**

The 40 demonstration sites were also involved in completing organisational surveys which have provided the evaluation with details around the purpose, scope and development of site activity as well as funding and commissioning activity. This aspect of the data provided evidence relating to the aim of describing the range of Peer Support Network and Dementia Adviser services in relation to their evolution, establishment, and delivery and governance characteristics. The information complemented the activity monitoring data information, providing more in-depth data about how the services were set up on strategic, governance and operational levels. In addition, the evaluation team participated in five Project Lead Network meetings with leads from each demonstrator site, commissioners of services and the Department of Health National Dementia Strategy Implementation Team (the national lead plus five regional managers). These meetings presented the opportunity, in part, for knowledge exchange, sharing information about the evaluation and its aims and methods, and also having an opportunity for facilitated discussion with those attending about their service developments.

## Strand 2: Methods

The use of structured surveys (Table 6) has provided an opportunity for patterns and trends across the 40 demonstration sites to be identified and explored in more detail. The surveys also provided data on what was and was not effective in implementing the National Dementia Strategy, and on integration, sustainability and transferability of the services within the wider health and social care economy, especially through figures from sites which provided a breakdown of budgets, resource allocation and use. The first of these surveys was also used in selecting the eight in-depth case study sites. Subsequent distribution of updated versions of the surveys has provided information on ways in which services have evolved and developed beyond the initial demonstration period, including information from those sites that have ceased operation.

Organisational survey	Surveys returned (and sites known to remain active)	Sites known to have ceased activity	Surveys not returned (site status not known)
Round one: July 2010 (case study site selection)	32	0	8
Round two: August 2011	30	5	5
Round three: March 2012	23	11	6

**Table 6.** Numbers of organisational surveys returned in Rounds one, two and three.

Organisational surveys were distributed to all 40 sites in three separate rounds, across a time span of 20 months. As an example of the organisational surveys, the third survey (returned by the sites in March 2012) can be found in Appendix E.

### ***Organisational surveys: Round one***

The initial organisational survey, distributed in July 2010, had two purposes. Firstly, to collect information from all 40 demonstration sites about the characteristics of their service. Secondly, this information was used to inform the selection of the eight sites to be involved in the in-depth case study aspect of the evaluation.

Sites were also asked for information relating to the organisational arrangements such as number of members of staff and involvement of volunteers; capital costs of running services and other infrastructure costs; variable costs such as transport, food and stationery; costs incurred by people accessing services; and frequency of contact with people with dementia and carers.

### ***Organisational surveys: Round two***

A further organisational survey was distributed by post and by e-mail to all 40 demonstration sites in August 2011. This enabled the collection of information about how site activity had evolved and developed in the course of the demonstration period. Records were also made of those sites that had ceased activity, with information up to and including the cessation of site activity collected from these sites wherever possible.

In addition to collecting updated information on ways in which the purpose and scope of services had evolved since their inception, and changes in partner organisations associated with sites, there was a specific focus on commissioning activity. The following quote, taken from an in-depth interview with a commissioner in one of the in-depth case study sites, was included in this second round of the survey, and each site was asked to comment on the extent to which they agreed or disagreed with the experiences and views expressed:

What started out as just a very small pot of money has mushroomed into all sorts of other benefits and spin offs.

This is a good example of how the mixed methods design of the evaluation enabled data collected from one source to be 'checked out' through another route.

### ***Organisational surveys: Round three***

In March 2012, organisational surveys were again distributed to all sites that had been active in any way between August 2011 and March 2012, enabling an up-to-date overview of development and purpose of site activity to emerge. There was a specific focus on the purpose of site activity, and ways in which this had evolved. This information was gathered by extracting, for each site, specific responses from surveys completed in August 2011

regarding the overall purpose of services, and asking each site to comment on if and how this had changed since the previous survey.

Questions around the extent to which social networks, social learning and personal effectiveness and mechanisms used within sites to achieve these remained the same as previous surveys, as did information on partnership working, specific groups benefiting from services, funding and commissioning activity.

## **Strand 2: Analysis**

The information provided by the sites in the organisational surveys was collated using Excel. This allowed for answers to each question to be considered in relation to each site as well as looking for patterns and differences between the sites. The information was also prepared and put into NVivo9 in order that the open-ended qualitative information could be searched to look for patterns emerging from the themes within the case study sites.

NVivo is a sophisticated software tool designed to help qualitative researchers to store, analyse and excavate simple or complex data that comes in different file formats; in the case of Healthbridge the transcripts from site surveys (Strand 2) and in-depth case study site interviews (Strand 3). NVivo assists the effective storage of complex data in ways that enable researchers to quickly and efficiently explore both general and specific elements of analysed data. NVivo potentially enables researchers to maximise the quality of the research and to provide an 'audit trail' of how the analysis has been conducted. The coding facility enables a researcher to highlight a piece of text, for example from an interview transcript, and assign it to a specific theme stored in a file which NVivo calls a node. In this way all of the data that has been coded at any one theme can be looked at altogether. There is no limit to the number of themes which any piece of text can be coded at, meaning that the relationship of themes to other themes within the data can be considered using NVivo. The storage facility in NVivo also allows nodes to be arranged according to their relationship with other nodes, so that a main theme (also referred to as a 'parent node') can be divided into sub-themes (also referred to as 'child nodes'). Alongside researcher manipulation of

nodes, this facility allows for themes to be condensed so that each theme in the data is represented only once within the coding framework.

Qualitative aspects of the site survey data were analysed using the tools of NVivo, with a focus on the questions that seemed to yield the data which provided most detail and insight. Initially, all surveys returned in Round one were coded question by question. That is, each section of the data was considered and assigned to the theme or themes within it. As many themes were repetitive but applicable across a range of the columns, these were condensed. To explore the themes in relation to the different sites, data at the sub-themes were gathered into the main themes. To generate nodes to represent the different sites, the survey was auto-coded, a process where all the data for each site can be stored at individual nodes representing each site. Further analysis enabled the researcher to locate nodes where pockets of data may be sitting. Nodes with the greater number of quotes became the focus used to understand what was happening at the individual sites in July 2010. This was informative for the emerging themes.

A similar process was begun for the Round three survey. It quickly became apparent that respondents sometimes recorded important information outside of the question columns. The analysis strategy was revised and the surveys were analysed site by site to ensure that all data relevant to the key themes were identified. As the key themes were developed, where there appeared to be gaps (surveys not returned or questions not completed), all three surveys for that site were reviewed to check for consistency of the findings.

### **Project Lead Network meetings and discussion**

Project Lead Network meetings took place on five occasions between March 2010 and March 2011. The meetings involved key staff and stakeholders from all 40 sites, as well as representatives from the Department of Health, regional leads, and the evaluation team. Initial Project Lead Network meetings took place over two consecutive days, involving representatives from Dementia Adviser sites (day one) and Peer Support Networks (day two). There were two ways in which these meetings informed the evaluation: inputting into the development of research tools; and structured round table discussions.

In relation to the development of the research methods used in the evaluation, particular attention was paid to the views of those at Project Lead Network meetings about the feasibility of methods. For example, the first iteration of the minimum data from each demonstration site that had been developed by the evaluation team was a multi-page document for each individual attending the services. Those at the Project Lead Network meeting felt that this would be completely beyond their capacity to administer. As a result, this was reworked by the team into a single-page document. This meant that the evaluation team lost some detail about individuals accessing the services, but was a practical way of achieving a good response rate from individual sites so that what data there was, was robust. In another example, there was a great deal of discussion about the use of ASCOT, with some feeling that it was inappropriate to ask some of the questions included in ASCOT (those concerning housing and cleanliness caused particular concern), that it would not measure what the services were designed to achieve, and that they were not confident in supporting people to complete it. Others, however, were very supportive of the use of this tool. Time was spent talking through the need to retain all items in a tool like ASCOT and that it was just one piece of the jigsaw of the evaluation, and rehearsing how to interpret some of the questions in case someone needed further explanation to support their completion of it.

In addition to the discussions with representatives from all 40 demonstration sites on the development of data collection tools, information was gathered from some small group discussions that were guided by the evaluation team. For example, those attending one Project Lead Network meeting were asked to discuss their experiences of setting up and running services and their advice to anyone undertaking a similar process in the future. Within groups of four to six, these led to discussion amongst staff and stakeholders from different sites who had been involved at both strategic and operational levels.

The discussion was guided by four questions:

1. If someone asked my advice about how to set up a similar service I would say ...
2. What they really need to focus on achieving for people with dementia and carers is ...
3. In order to achieve this they need to make sure that ...

4. They will know the service has been successful when ...

This information was recorded on notepaper and formed the basis for discussion in the whole group. Steps like this also allowed the evaluation team to have a 'reality check' with other data and to have a heightened sensitivity to issues emerging from data analysis.

These Project Lead Network meetings also allowed all those participating in the meetings to have some structured and facilitated space to articulate and share their experiences, and in this way supported the learning of the demonstrator site leads (Clarke and Wilson, 2007).

## **Strand 2: Outputs**

The outputs of the organisational surveys included comprehensive information from each of the 40 sites which, in the first instance, was used to inform the selection of case study sites, ensuring that the eight sites selected represented a range of settings, approaches to service delivery and target groups. By repeating the process of gathering information on two further occasions, a longitudinal representation of how service delivery was evolving, providing longitudinal data on site development and activity, was developed. This included monitoring which sites were successful in securing continuation funding and which sites had ceased operation due to lack of funding or had refocused their work.

## **Strand 3: In-depth case studies**

The third strand to the evaluation was eight in-depth case studies of demonstration sites. Considerable time and resources were invested in establishing and developing a research relationship with key staff at the eight sites. Four researchers worked on the sampling, recruitment and data collection, with continuity within each site being maintained through one researcher collecting all of the data within each site. Through the lead staff at each site, who in effect acted in the role of gatekeepers and facilitators to the service, research relationships were established with other staff, volunteers, stakeholders, commissioners and, arguably most importantly, people with dementia and their carers who had accessed the sites. The emphasis within this stage was on exploring in depth the views and experiences of a wide range of people who were involved in site activity. Altogether, 183



people were involved in interviews, with people with dementia and carers often taking part in a series of three interviews.

### **Strand 3: Methods**

#### ***Site sampling***

The organisational survey in July 2010 (Survey 1) provided data that allowed matrix sampling for eight case study sites, ensuring that these sites represented the range of service activity amongst the 40 sites, including:

- organisational position and structure (NHS, Social Services, voluntary sector, etc.)
- specific target groups
- situational demographics of sites and scope and purpose of services.

Sites were also asked to indicate their willingness to be selected as a case study for the evaluation.

This information allowed a matrix to be developed, mapping each demonstrator service against key criteria for identification as a potential case study site. The criteria selected represented the theoretical framework of the evaluation as well as seeking breadth of service model and ethnic and socio-demographic diversity of those accessing the services, as shown in Table 7.

Demonstrator site	Lead and project organisations in partnership	Q. 4 Please indicate how much your service develops			Q. 5 This is achieved by					Q.7 The service is designed to benefit
<b>Whether they would like to be a case study site:</b> - Yes* - Don't mind**	<b>Key:</b> - Lead (L) - Host (H) - Alzheimer's Society (AS) - Care Trust (CT) - Partnership Trust (PT) - Metro District - Council (MDC) - Community Mental Health Team (CMHT) - Foundation Trust (FT)	a.	b.	c.	a.	b.	c.	d.	e.	<b>Specific focus only :</b> People with dementia Carers Professional carers BME communities Younger PWD Learning disability LGBT communities Newly diagnosed Socio-economically deprived areas General public awareness

**Table 7.** Extract from organisational survey for case study site sampling.

The survey also enquired about the overall purpose of the service, and the extent to which each site prioritised the development of social networking, social learning and personal effectiveness. In order to establish the service mechanisms by which those purposes were being achieved, sites were asked about their focus in terms of:

- helping people access services
- helping provide information for other people
- helping people get emotional support from others
- helping people share information with others
- helping people access practical support
- other ways in which the aims and purposes of the pilot activities were achieved.

Four Dementia Adviser sites and four Peer Support Network sites were selected as in-depth case study sites. Within the four Dementia Adviser services, this included: one based within a local Mind Association and delivered as part of a multidisciplinary, early intervention Community Innovations Team; one based within a Community Mental Health Team for Older Adults and delivered in partnership with the local council; one based within a branch of the Alzheimer's Society and one based within a local NHS Foundation Trust.

Within the four Peer Support Network services, the settings included: a county-wide memory café network; a local council initiative; a Peer Support Network that was developed within two adjoining branches of the Alzheimer's Society and a partnership approach in which a Peer Support Network hosted by an Alzheimer's Society branch was supported by the local council, NHS and Age UK (formerly Age Concern).

The eight sites were also chosen as representative of services seeking to develop service provision that would benefit specific or 'harder to reach' communities, including BME communities (specifically South Asian) and a range of geographical locations (rural, borough, county, etc.)

***Participant sampling, selection and recruitment in the case studies***

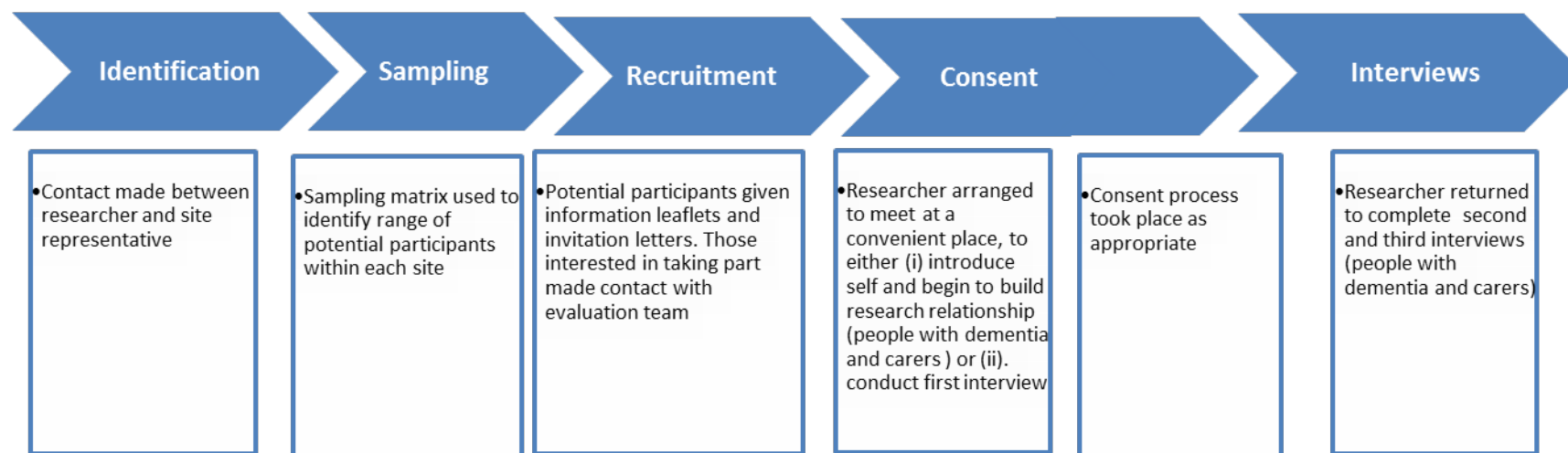
In order to secure a breadth of views and perspectives, the selection and recruitment process in the case studies ensured that a wide range of people were approached: people with dementia and their carers, as well as key staff, stakeholders, volunteers, commissioners, people who had an opinion of the service, people who had referred into the service, and people who are involved in supporting people with dementia in the localities.

Once the eight case study sites had been selected, contact was made with each site through the designated contact person or people. Table 8 outlines the sampling matrix that was produced, the purpose of which was to enable key staff to identify a range of people who were involved in their site.

Core staff and stakeholders	People with dementia and carers	Other stakeholders/people with interest or insight in services
Core staff and volunteers: <b>their role, including whether employed or a volunteer, employer details and length of time they had worked in dementia care</b>	Ten <b>people with dementia</b> : details about these people including whether or not they considered the person to have capacity to consent and if they had a carer living with them; how they had accessed the demonstrator site service; any reasons why it might be inappropriate to contact the person at that particular time and details of any communication challenges (including if an interpreter was needed in the interview process)	Five <b>professional/volunteer staff who had accessed the services</b> : the reason for accessing and the organisation they work in
	Five <b>carers of people with dementia</b> , and details about how they had accessed the service, and other personal information as above for people with dementia	Five <b>people who work in other dementia services locally</b> : their role and how their organisation(s) interact with the demonstrator site
		<b>People who commission services</b> for people with dementia or develop policy that influences services in the locality
		Any <b>local evaluators of the service</b> Three <b>people with an opinion about the service</b> (even if the key staff didn't agree with it)

**Table 8.** Sampling matrix within each case study site.

Methods used in making contact with potential participants were adapted to the circumstances within each case study site. In some instances, contact was made with potential participants through information leaflets and invitation letters, which were distributed by the key staff within the sites. In the case of staff and stakeholders, sometimes details were given to researchers who contacted potential interviewees directly. In the case of people with dementia and volunteers, contact details were not given to researchers prior to staff speaking to them to secure their permission to do so. A system for potential participants to return reply slips to the evaluation team was set up, although this was not used in the case of all sites due to approaches needing to be adapted according to the set-up within each site. Copies of information leaflets and invitation letters can be found in Appendix F. A service user led group of older people, including people with dementia and carers (Voices North) reviewed the materials in order to ensure accessibility and clarity from the perspective of people who might be receiving them. In light of their feedback, we added the contact details of the Alzheimer’s Society should anyone wish to follow up further information and support. Figure 2 illustrates the process of recruiting participants in the case studies.



**Figure 2.** Process of recruitment within sites.

### ***In-depth case studies data collection***

Table 9 details the interviews that took place within the eight in-depth case study sites.

Interviews were based on a semi-structured interview schedule (see Appendix G for schedules relating to staff/stakeholder interviews and interviews with people with dementia and carers). The schedules were used as a guide, and often interviewees had specific insight into the services that were focused on within each interview.

	Interviews with people with dementia on their own	Interviews with carers on their own	Joint interviews (people with dementia and carers)	Interviews with staff/volunteers/other stakeholders
Dementia Adviser sites	17	36	26	40
Peer Support Network sites	29	32	17	42
Total number of interviews	46	68	43	82

**Table 9.** People interviewed in in-depth case study site interviews.

In-depth interviews took place in a variety of settings, as preferred by those being interviewed, including people's homes, venues already used by the demonstration site services, or another public place.

#### ***Interviews with staff and stakeholders***

The majority of staff and stakeholders were interviewed once, although there were a few cases where a second interview was either necessary or desirable. The focus of the qualitative interviews, which were guided by a semi-structured topic guide and lasted between 45 minutes and 2 hours, varied according to the role of the interviewee in site activity. Copies of interview schedules can be found in Appendix H.

The consent process with staff and stakeholders ensured that they had received information on the purpose and scope of the evaluation, had an opportunity for any queries to be

addressed, and were willing to take part in an interview. Permission was also requested to audio record the interview, with assurances of anonymity, secure storage and appropriate disposal of data. Staff and stakeholders were also assured that taking part in the evaluation would not affect their work or volunteering in any way, and that they were free to withdraw at any stage.

Table 10 outlines the topics covered across the two different interview schedules (for people living with dementia and for other stakeholders).

<b>Topics covered in in-depth interviews</b>	<b>Interviews with people with dementia and carers</b>	<b>Interviews with staff and stakeholders</b>
General well-being and daily life/how services contribute to resilience		
Goals, roles and purposes of services		
How site activity fits in with wider health and social care system		
How Peer Support Network and Dementia Adviser services accessed		
Impact of services on policy and practice		
Impact of services on people with dementia and carers		
Support in relation to information and advice		
Conditions essential to the success of services		
Perceived strengths of models of intervention		
Setting up and running costs, resources, cost of accessing services, value placed on services		
Ranking of components of intervention		
Problematic/challenging areas and if/how overcome		
How services could be improved/ideas for future		
What would happen if services no longer existed		
Further general comments		

**Table 10.** Topics of interview schedules.

### ***Interviews with people with dementia and carers***

Interviewing people with dementia requires a well-considered and executed consent process, which must be revisited many times throughout the interview process. Informed consent in this study was regarded as being a process (Dewing, 2007) which required continual negotiation which supplemented the more conventional formal consenting process.

This process was guided by senior evaluation team members who have experience in the complex ethical issues surrounding consent processes and interviewing people with dementia. This included training on the Mental Capacity Act 2005 (HM Government, 2005) and people with dementia for researchers collecting data. A detailed consent protocol and a consent checklist was developed for the interviewers to follow so all aspects of the correct procedure have been followed in obtaining consent.

Initially, the staff member or stakeholder from the case study site who was involved in the selection process was asked to indicate whether or not, at the time of last contact, and in their opinion, the person with dementia had capacity to consent. The consent process was revisited as many times as was needed by each individual, and was repeated at each subsequent interview.

At each stage of involvement, the participant was asked to give consent appropriate to their level of understanding, ranging from written informed consent to verbal or non-verbal communication of assent. Where possible, verbal consent was captured using audio recordings. In accordance with the Mental Capacity Act 2005 (HM Government, 2005), careful consideration was given to ensure that nothing was done to the person to which he or she appeared to object, either verbally or via non-verbal means.

Process consent is one of continual renegotiations and is particularly appropriate in social research where there is reflexivity between data to be collected and data already collected, and where participants may wish to place limits on the information that is available as research data. In particular, people involved in the evaluation were reassured that declining to participate in the study would not affect the care that they receive or impede the services



they were accessing. They were also reassured that data collection would be of no harm to them and that all data would be kept in a secure place, and transcripts made anonymous.

The design of the evaluation sought to be inclusive of people who were unable to consent to taking part. For these circumstances, a separate consent process involving a consultee was set up. If no family carer could be identified for this, a consultee could be nominated by the study team but they must have no other connection with the project. In reality, only two people were nominated and recruited who did not have capacity to consent. In these instances, one consultee was a family member; the other was a volunteer who knew the person well.

Allowance was also made for loss of mental capacity in a participant during the study. The consent form included a statement to the effect that should the person with dementia lose mental capacity during the study:

1. They grant permission for the study team to contact a 'named consultee' (next of kin and not a paid carer) to revisit the consent process.
2. They are happy for any anonymised data collected prior to loss of capacity to be used in data analysis.

In practice, it was not necessary for this provision to be operationalised.

Within two of the sites, where there was a focus on specific BME communities, interpreters were used within the consent and interview process. People who acted as interpreters included family members, demonstration site staff and professional interpreters. There were three interviews with carers and one interview with a person with dementia where professional interpreters were used.

Copies of all consent forms used can be found in Appendix I.

While staff at the sites had been asked to identify people with dementia and their carers separately, it was often the case that couples were expecting and/or preferred to be interviewed together. Where possible, the researchers sought, in the second or third visit to a couple, to speak to the person with dementia and carer separately in order to establish

personal views. However this was not always appropriate and, in this instance, researchers did not press for individual interviews. As a general guide, the interview schedule was divided into three sections, with more complex questions being left until the third interview, although different circumstances meant that the pace and format of interviews varied considerably.

Given the importance of listening to the voice and experience of people with dementia in policy and service development as previously outlined, it was essential that the evaluation provided multiple and meaningful opportunities for contributions from people with dementia themselves. Our approach was rooted in the belief that:

People with dementia are persons first with views, likes and requirements that co-exist with their illness. It is for services to devise ways of actively listening to people with dementia on an individual basis and respond imaginatively to what they hear. It has been shown that methodologies can be developed and modified in order to allow this to occur.

Reid *et al.*, 2001, p 390

Meaningful involvement of people with dementia and their carers in the data collection process was significant, both in relation to listening to their views and in meeting the aims of the evaluation. By considering these views alongside policy developments, outputs from the evaluation have been developed in a way that contributes to the shift in approach to service development, away from service users as passive recipients of care with no control over the services and support they receive.

In approaching the inevitable challenges of involving people with dementia in interviews and well-being/quality of life surveys, the research team took the following four challenges of doing research with people with cognitive disabilities (Booth and Booth, 1996) into consideration:

1. Inarticulateness in which language use is influenced by lack of self-esteem, social isolation, anxiety as well as language skills.
2. Unresponsiveness in which open questions results in limited responses.

3. A concrete frame of reference, with difficulty generalising from experience and thinking in abstract terms (the very things required of someone being interviewed as a rule).
4. Problems with time such that it may be difficult for people to 'tell their story'.

Booth and Booth, 1996

The referential function of the standard research interview asks for information from interviewees that is both reflective and prospective. This dependence on memory and anticipation renders this form of data collection challenging with people with dementia at times. Booth and Booth (1996) also suggest that an appropriate interviewing style is direct in its questioning, validating of the individual, reduces anxiety, and avoids asking about frequencies or time sequences.

Similarly, Clarke and Keady (2002) identify the following criteria as crucial in data collection with people with dementia, so that they are able to articulate and express their perspective in such a way that researchers can have confidence in the data. Each of the criteria were addressed in developing the methods of this study.

- Sufficient engagement to allow confirmation of issues raised – through repeated interviews.
- A mutually trusting relationship – through a sustained period of engagement.

Within the above two points, the area of clearly defining the remits of the research relationship at the same time as valuing people's contributions was important. For example, 'endings' were marked as appropriate, in some cases with a card or small bunch of flowers to show appreciation for input. Once all of the in-depth case study interviews were completed, the Principal Investigator wrote a letter of thanks to the people with dementia and carers who had taken part.

- A collaborative approach with the person with dementia, allowing a mutual process of agenda setting.
- Minimising anxiety and tiredness – considering the duration, pacing and location of data collection.

- Augmentation of data collection – through visual prompts, for example in use of service promotion material with a picture of the Dementia Adviser, which prompted a person with dementia to remember the adviser and speak about the support they had received. Involvement of family carers was a further way in which data collection was augmented. For example in one interview a carer was able to remind the person with dementia about the Peer Support Network group by using the nickname that the facilitator used, enabling the person with dementia to recall the meeting that she had been at the previous day. Similarly, many of the interviews with people with dementia took place within their own home, meaning that researchers were able to engage in conversation with people with dementia through contextual information, such as family photographs or cards from a recent wedding anniversary.
- Emotional engagement by the researcher so that the person is clearly valued, and know that they are valued, for their knowledge.
- Detailed attention must be paid to reliable data recording, using observational recordings as well as tape recordings. This was done through researchers collecting further information about the environments in which data was collected and noting key non-verbal communications, for example.

Boxes 1 to 3 provide three examples of the process of engagement with people with dementia.

**Box 1. The process of engagement with a younger carer**

Molly is a carer for both her parents, who continue to live as a couple at home with support from Molly. Her mother has dementia. Molly had received an invitation letter and information sheet about the evaluation from her Dementia Adviser. She returned the reply slip to the team. When the team member contacted her, she said that she would prefer to be interviewed at the NHS base where the Dementia Adviser's offices were. The interview lasted an hour, during which all of the questions on the schedule were answered with little deviation from the schedule (which, in the case of some people with dementia and carers was an essential part of the research relationship). She completed a DEMQoL-proxy for her mother and an ASCOT questionnaire from her point of view as a carer. Molly completed a consent form at the beginning of this interview.

**Box 2. The process of engagement with a person with dementia and a carer**

Mike and Maria were a couple who had accessed support from a Dementia Adviser. Maria had completed two reply slips, one for herself and one for Mike. She stated on Mike's slip that he would need support from her in taking part in the interview. The researcher visited them in their home on two occasions. On the first occasion, Mike and Maria were interviewed together, with the discussion focusing on the support they had received from the Dementia Adviser. On this occasion, Mike completed a DEMQoL questionnaire and an ASCOT questionnaire with the researcher. Time was spent before and after this interview ensuring that both Mike and Maria had given informed consent to take part, with formal consent forms being completed prior to the interview.

The researcher returned six weeks later, and on this occasion suggested that as Mike knew her a little, she might be able to speak to Mike and Maria separately. The researcher spent half an hour with Mike whilst Maria was upstairs doing housework – they completed an ASCOT questionnaire and a DEMQoL questionnaire at the same time as chatting about Mike's well-being and general daily life. The researcher returned to the consent process during this half hour, and he completed a consent form. Following this, Mike left the room to check his e-mails on the computer upstairs and Maria and the researcher completed an ASCOT questionnaire from Maria's perspective as a carer and also completed the in-depth interview schedule. Maria became tearful whilst talking about other people's attitudes to them as a result of dementia and the researcher switched off the recording for ten minutes, after which Maria said that she would like to continue with the interview. Again, the consent process was returned to and Maria completed a consent form.

### **Box 3. The process of engagement with a person with dementia**

Monique was a person with dementia who had accessed a Peer Support Network group. The researcher first met her when she (the researcher) had attended the group as part of the relationship-building-process with the Peer Support Network facilitator. Further into the evaluation, Monique gave permission for the Peer Support Network facilitator to give the researcher her telephone number and the researcher visited her in her home. On this occasion, Monique seemed quite agitated and the focus of the visit was on the researcher building a rapport with her. The researcher started to work through the DEMQoL questionnaire but realised that this was making Monique more unsettled so stopped after four questions and did not ask Monique to complete an ASCOT questionnaire. On the second occasion, Monique was more relaxed, commenting herself halfway through that she felt it was going better than last time. Monique completed a DEMQoL and ASCOT questionnaire with the researcher and also chatted about her experiences of attending the Peer Support Network group, including some ideas about how the group might be improved. Time was spent at the beginning and end of each interview ensuring that Monique had given informed consent to take part in the evaluation. Formal consent forms were completed at the beginning of the first interview and the end of the second interview.

### ***DEMQoL and ASCOT***

The same ASCOT tool that was used in Strand 1 of the evaluation was used in some of the interviews with carers and people with dementia. Interviewers used their discretion as to how appropriate this was. This was administered by the interviewer at the same time (and usually immediately following) the qualitative interview questions.

DEMQoL was also used within the process of evaluating the demonstration sites. It was used alongside ASCOT in the in-depth case study site interviews with people with dementia and carers. DEMQoL (completed with people with dementia) and DEMQoL-proxy (completed by carers on behalf of people with dementia) are tools used to measure health-related quality of life (HRQoL). They were developed through a rigorous process which involved: the use of a literature to develop a conceptual framework; qualitative interviews with people with dementia and carers; discussion with experts and the piloting and development of the tools using psychometric testing techniques (Smith *et al.*, 2005). Within the process, HRQoL was

defined as “a multidimensional concept that reflects the individual’s subjective perception of the impact of a health condition on everyday living” (Bullinger *et al.*, 1993).

Thus, DEMQoL acknowledges quality of life as a complex phenomenon that can be influenced by many factors (Banerjee *et al.*, 2006).

Unlike ASCOT, DEMQoL and DEMQoL-proxy have been developed specifically for use with people with dementia and their carers. DEMQoL uses a 28-item interviewer-administered questionnaire. DEMQoL-proxy uses a 31-item interviewer-administered questionnaire answered by care-givers on the person for whom they care. Copies of both forms can be found in Appendix J.

All questions focus on how three main areas have been for the person in the last week:

- the person’s thoughts and feelings
- their memory in general
- everyday life.

For example, the questionnaire asks: “In the last week, have you felt worried or anxious?”

Respondents are given the choice of four options:

- a lot
- quite a bit
- a little
- not at all.

The overall quality of life score is calculated as a total of the average response to each question in each population group. The final result produces an overall quality of life score ranging from 28 (lowest) to 112 (highest) for DEMQoL and 31 (lowest) to 124 (highest) for DEMQoL-proxy. DEMQoL has been previously applied within the context of an evaluation to studies such as Edwards *et al.* (2013) in an evaluation of the impact of a therapeutic garden which involved 12 people with dementia, and Banerjee *et al.* (2007) in evaluating a memory service.

Within the in-depth case study interviews, wherever possible, the questionnaire was completed at each interview, meaning that some people with dementia or carers completed the questionnaire on more than one occasion, providing longitudinal information on quality of life. Questionnaires were always administered by a researcher from Healthbridge and therefore within the context of the research relationship. Researchers made use of large-print flash cards, which enabled people to choose their response.

As with the use of ASCOT during Strand 3 of the evaluation, the questionnaires were usually completed at the same time as the in-depth interviews, meaning that the DEMQoL scores can be looked at alongside qualitative information about people's experiences, particularly experiences of accessing Peer Support Network or Dementia Adviser services. In several instances, audio recording continued whilst the questionnaires were being completed, meaning that discussion relating to the issues covered in these questionnaires has also been collected as qualitative data. An illustration is provided in Box 4.

These questionnaires were also invaluable tools in exploring experiences of people with dementia themselves, particularly those interviewed who were in the later stages. There were people with dementia for whom more abstract questions about the services were hard to engage with (especially if the interview was not taking place at a demonstration site venue and therefore providing environmental cues), but who, prompted by the focus and structure of the questionnaires, were able to talk about their well-being and quality of life.



**Box 4. Completing DEMQoL: an excerpt from an interview with Stan (a person with dementia from a PSN site)**

*Interviewer:* In the last week, have you felt that you are enjoying life? A lot, quite a bit, a little or not at all?

*Stan:* A lot.

*Interviewer:* A lot – that's good. In the last week, have you felt frustrated?

*Stan:* No.

*Interviewer:* No, not at all.

*Stan:* No, not at all. No.

*Interviewer:* Have you felt confident?

*Stan:* Yes, I have, actually.

*Interviewer:* Right, right. So would that be a lot or quite a bit?

*Stan:* Quite a bit, yeah.

*Interviewer:* Quite a bit. In the last week, have you felt full of energy?

*Stan:* My energy levels are quite good.

*Interviewer:* Good. So is that quite a bit...? What, sort of...?

*Stan:* Yeah, quite a bit.

*Interviewer:* I think you would have to have a lot of energy to take the dog out. She's... She bounces around, doesn't she?

*Stan:* We're alright going – it's when you come back.

*Interviewer:* Oh, right, does she not like to come back?

*Stan:* I bought one of those... You know, the... They're on a plastic thing and you just sort of throw them.

*Interviewer:* Oh, right, a ball, like, sort of thing.

*Stan:* So what I've done is I've had to buy the... Because my shoelaces – I've gone through all... What she does is she bites the back of my foot. She plays in them. As we go out, she's all over the place.

Right? But when we're coming back, now then – it's her turn to play. Right? And she's always...

Bangs the back of my foot when she's... Gets hold of this, and she's got hold of that, you know. And my laces have all gone. You know, so I bought this... This thing on a stick. She ran after it twice, and then she's just left it. So...

*Interviewer:* Right. In the last week have you felt sad? A lot, quite a bit, a little or not at all?

*Stan:* Not at all.

*Interviewer:* In the last week have you felt lonely? A lot, quite a bit, a little or not at all?

*Stan:* Not at all.

*Interviewer:* In the last week have you felt distressed? A lot, quite a bit, a little or not at all?

*Stan:* No...

*Interviewer:* In the last week, have you felt lively?

*Stan:* Yes. To be quite honest it's... Dementia is really weird because it's how you wake up in the morning. You know? I mean, sometimes you wake up and other times... I... To be quite honest, I put a lot down to the pills. My stomach feels a little bit off. You've got a headache – sickly headache and stuff, you know. But those. By dinnertime or something like that – 10 o'clock or anything – it's gone. You don't... Don't take any notice of it, sort of thing, you know. So... What category would that be? What was the question again?

*Interviewer:* The question was in the last week have you felt lively? A lot, quite a bit, a little or not at all?

*Stan:* Quite a bit.

*Interviewer:* Quite a bit.

*Stan:* Unfortunately I don't get that zing anymore that I used to have when I went to work, you know. It's... It's nice. I've got back into it now, because I mean... It's nearly two years now I've been diagnosed. And I was still going to work. I was running about and doing all sorts, sort of thing, like,

you know. And now it's got down the... Down the scale sort of thing, like, you know. And I haven't got time for it, like, you know. Did we answer that question?

*Interviewer:* We did. We did. With regard... In the last week, have you felt irritable? A lot, quite a bit, a little or not at all?

*Stan:* That's really hard to... You get little bits of it. It's like... It's nothing of... Nothing to worry about or anything. It's just... I'll give you an instance – just... [Name] will give me a shout for dinner, like, sort of thing. You'll go in and I'll pick it up and I might leave the fork there. And she'll go, "You've left a fork here." And just that little bit of irritation. It's nothing though, whatsoever. But it's... It's nothing, really, anything at all. Like, sort of thing, you know. But it is a little bit. And I'll go... "Oh God, I've forgotten it again" you know. But it's... I mean, it's nothing. So the question was what?

*Interviewer:* In the last week, have you felt irritable? A lot, quite a bit, a little or not at all?

*Stan:* A little. [Coughs] Excuse me.

*Interviewer:* Are you alright to continue?

*Stan:* Yeah.

### **Strand 3: Data analysis**

#### ***Qualitative interviews***

The audio recordings of the in-depth case study site interviews were transcribed verbatim.

The data analysis of the qualitative interview data was driven from a 'bottom-up' (inductive) approach in terms of developing the coding framework using data from individual interviews, at the same time as working 'down' from the theoretical framework that was central to the evaluation. Within this, it was important that the views of people with dementia were represented. It was also important that the range of views expressed by a range of stakeholders across a range of sites was considered within the coding framework and emerging thematic framework. In order to assist data management, the computer-assisted qualitative data analysis software (CAQDAS) NVivo 9 was used.

The process of data analysis for the in-depth case study interviews began with the creation of the initial coding framework. This was done through a descriptive content analysis of 25 transcripts. These 25 transcripts were randomly selected to represent people with dementia, carers, staff and stakeholders across all eight case study sites. This initial content analysis generated themes which were translated into codes in NVivo9. The topic guides which were used in interviews were also used in developing some of the more general overarching codes. From here, the coding framework was refined in order that each theme was only represented once throughout the framework, ensuring coherence within the framework as a whole and limiting duplication within the coding process. An outline of this initial coding framework can be found in Appendix K.

Once the initial coding framework based on these 25 transcripts had been established, a team meeting took place at which a wider group of the evaluation team assessed and further developed the coding framework. From here, a further 70 transcripts were inputted into NVivo9 and coded using the framework. Only minor changes and additions to the coding framework were made at this stage, as the process was nearing saturation, meaning that the majority of the data could be coded within the framework. Again, a descriptive content analysis approach was taken to establishing what had been said by the range of people interviewed for the evaluation.

Following this, transcripts were circulated to a further wider group of the evaluation team. A total of 18 transcripts between four people (who had not previously been involved in detailed analysis) were looked at and coded or commented on. These comments and the coding were then incorporated into NVivo, informing the developing analysis. By this stage, a picture of the data as a whole was beginning to emerge, and codes were grouped into wider overarching themes. The overall direction of the model which was beginning to emerge at this stage suggested a process of enabling in which Peer Support Network and Dementia Adviser services had a role to play, leading to an optimal state of 'living well with dementia'. The codes were grouped into:

- codes relating to service delivery
- codes that represented factors which affected service provision
- codes relating to awareness raising
- codes which shed light on the process of enabling
- codes which shed light on personal experiences of people with dementia and carers
- mediating factors which influenced the process of enabling
- codes which would verify the developing framework.

An outline of this overall model, and ways in which the aspects of the data outlined above relate to one another within that model, can be found on page 95.

Following this, a process of modelling was undertaken – data at each of the codes was mapped out using the modelling tools of NVivo. Modelling in NVivo provides a visual representation of themes and how they relate to each other, at the same time as linking the researcher back to the data represented within the models. It is these models which have been used in the presentation of the qualitative findings in this report.

Once the data had been modelled in this way, a process of verification took place, using a selection of NVivo tools based on some of the key themes that had been identified within the analysis and modelling process. Slightly different approaches were taken to verifying data, but the focus was upon verifying the data being presented in the findings section of this report alongside the developing discussion. Our aim at this stage was to ensure rigour within the findings reported, and the conclusions which we have drawn from this. By this stage, all of the interviews had been transcribed and inputted into NVivo, meaning that all qualitative data that was collected in the project was used in the process.

The steps taken within the process of verifying themes and developing arguments within this report enabled all of the data to be incorporated in the search to be grouped together in order to ensure that the search included all relevant data. The (then developing) findings section of this report, alongside the models in NVivo, was used to identify themes to be explored. The quotes in the report were then reviewed to gather information about the language used by the respondents, especially people with dementia and carers, and a word search was created using this information. Following this, the range of interview transcripts that were identified holding the search terms selected was reviewed. Throughout the process, checks were made to ensure that a representative range of interview transcripts had been incorporated into the search.

Based on word search, a word tree was produced by NVivo, an example of which can be found in Appendix L. Reviewing the text in the word tree enables the researcher to get a 'feel' for the data and whether the search terms used were useful. Following this, a range of the data across the sites was reviewed, checking that the data retrieved in this way refers to the theme being sought. Data that contradicts the theme chosen was noted.

### ***Well-being questionnaires***

The well-being questionnaires that were completed during in-depth interviews were analysed using the same methods as for the questionnaires completed in Strand 1.

Following this, individual responses to each question from the questionnaires completed as part of the in-depth case studies were inputted into SPSS. This allowed for a statistical representation of the frequency of responses to each question, including the modal (most commonly selected) response. Further statistical analysis provided evidence for areas where there was a statistically significant difference between responses from people with dementia and carers.

### ***DEMqoL***

Responses to DEMqoL were entered into Microsoft Office Excel, and categorised using the code given to the interview data: site name, respondent role (carer/person with dementia) and interview stage. Overall quality of life scores were produced for the group as a whole, and subsets were produced based on the following themes:

- Respondent role (carer or person with dementia)
- Interview stage when questionnaire was completed (interview 1, 2 or 3)
- Site type (Peer Support Network or Dementia Adviser site).

Aside from overall quality of life scores, average scores were also calculated for each questionnaire item in Excel and compared across each subset.

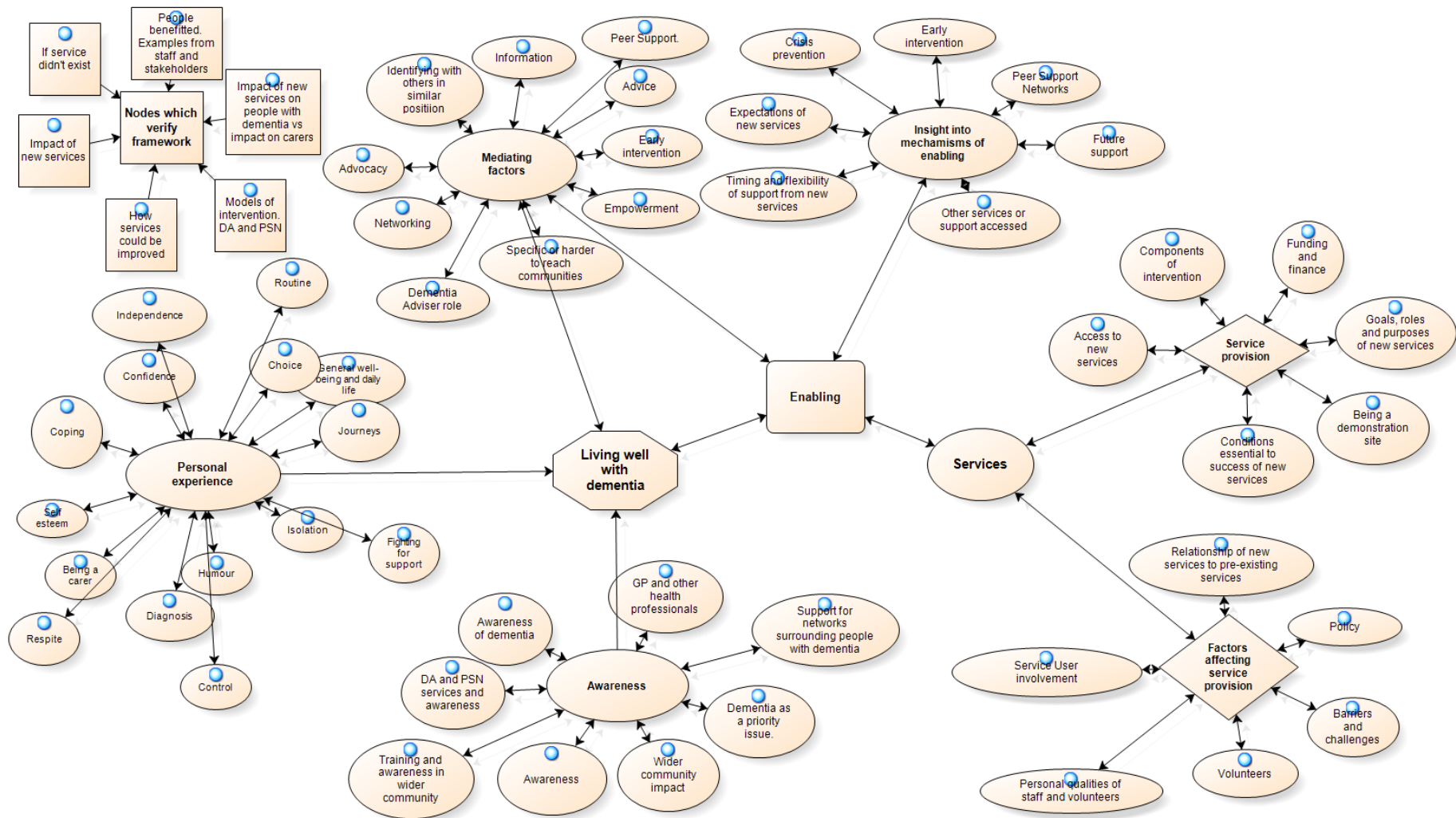
## **Strand 3: Outputs**

The in-depth case study strand of the evaluation added a depth of insight from people who were involved with the sites across eight sites that were representative of the 40 sites as a whole. The range of staff and stakeholders interviewed ensured that opinions about the services were gathered. This included commissioners, staff involved in day-to-day running, people who had a critical opinion of service and 'key people' within each site who perhaps did not have a pivotal role such as commissioning but whose support was integral to the development and success of sites.

The qualitative interviews with people with dementia and carers represent a wide range of experience and views from people who came from a range of nationalities, socio-economic background and geographical areas as well as a range of lived experience of dementia, experiences of diagnosis and other support accessed, types of dementia and gender. The data includes insight into day-to-day life for people living with dementia as well as experiences of accessing Peer Support Network and Dementia Adviser services. The ASCOT and DEMQoL data provides insight into well-being and quality of life of people with dementia and carers. The fact that these were completed at the same time as the in-depth interviews means that, unlike the questionnaires that were distributed as part of Strand 1, the scores for these questionnaires could be considered alongside other aspects of the experiences of people with dementia and carers who were accessing services as expressed in in-depth interviews with researchers from the evaluation team.

Model one below outlines the themes that emerged from the analysis of qualitative data in NVivo and the framework created in order to explore how the different aspects of the interview data from the range of people who were interviewed fitted together.

**Model One.** Theme framework for interview data.



## **Drawing it all together – meta-analysis**

The data which has been collected and analysed from the three strands outlined above has enabled the evaluation to evidence:

- Information and views from staff and stakeholders at all 40 demonstration sites, including: number of people accessing services and demographics; organisational position and structure; specific target groups; purpose and focus of service; funding and finance; and evolution and development of services over time.
- Measures of well-being of people with dementia and carers who were accessing all 40 demonstration sites (distributed by site representatives and returned to the evaluation team by post).
- Measures of well-being and quality of life of people who were accessing the eight case study sites (completed with researchers from evaluation team at the same time as in-depth qualitative interviews).
- In-depth qualitative data from people with dementia and carers who had accessed the eight in-depth case study sites, including: general well-being and daily life; other support accessed; aspects of services and ranking; accessibility of services; involvement and information; choice and independence; cost of access and willingness to pay for services.
- In-depth qualitative information from a wide range of staff, volunteers and other stakeholders across the eight in-depth case study sites, including: goals, roles and purposes of services; organisational position and structure; impact on policy and practice; impact on people with dementia and carers; conditions essential to the success of services; strengths and weaknesses of Peer Support Networks and Dementia Advisers as models of intervention; information and views on funding and finance; components of the intervention and barriers and challenges encountered.

In addition to the ethical approach to data collection and analysis, which maintained integrity within the research process, it is important to consider how best to judge the quality of research in a mixed method design. Each methods piece of the data jigsaw must of course be robust according to the specific nature of that data, but in a mixed method design the whole seeks to add up to more than the sum of the parts, and so there is another



level at which quality of the research must be judged. One obvious way is through the completeness of the jigsaw – are there in fact gaps between the pieces; are there an unnecessary number of data sources that address the same issue? Figure 3 provides an overall ‘map’ of the data collected in relation to each strand of the evaluation design, participants and outputs.

In critiquing this evaluation, there needs to be consideration of whether it should be judged by the quantitative criteria of reliability and validity, or in accordance with its privileging of qualitative research. If the latter, there are differing views of what criteria are most appropriate, but many now adopt three core standards of qualitative rigour: credibility, auditability and fittingness. Chiovitti and Piran (2003) add some detail to these three standards which provide a useful guide:

1. Credibility

- a. *Let participants guide the inquiry process.* For example, in this study this took place in three ways: public and patient involvement in developing research tools such as the interview schedules; within interviews with the interviewer frequently ‘taking a lead’ from participants within a single interview or over a series of interviews (with people with dementia and carers); through linking data sources such as embedding interview quotes within subsequent organisational surveys.
- b. *Check theoretical constructions generated against participants’ meanings.* For example, the study design was explicit about the theoretical framework used, and this was explored in data analysis in relation to the data.
- c. *Use participants’ actual words,* making extensive use of quotations, for example.
- d. *Articulate the researchers’ personal views and insights into the phenomenon explored.* Achieving this in a large project with many team members is complex, yet arguably all the more important. Whilst we have not been very explicit about our personal views and insights in this report, it was something we discussed extensively in team meetings. This was to ensure that our value base was not so divergent that it would compromise the integrity of the study (that we had a shared understanding of person-centred care and personhood, for example), but also to ensure that we draw on the varying skills and experiences of all the team

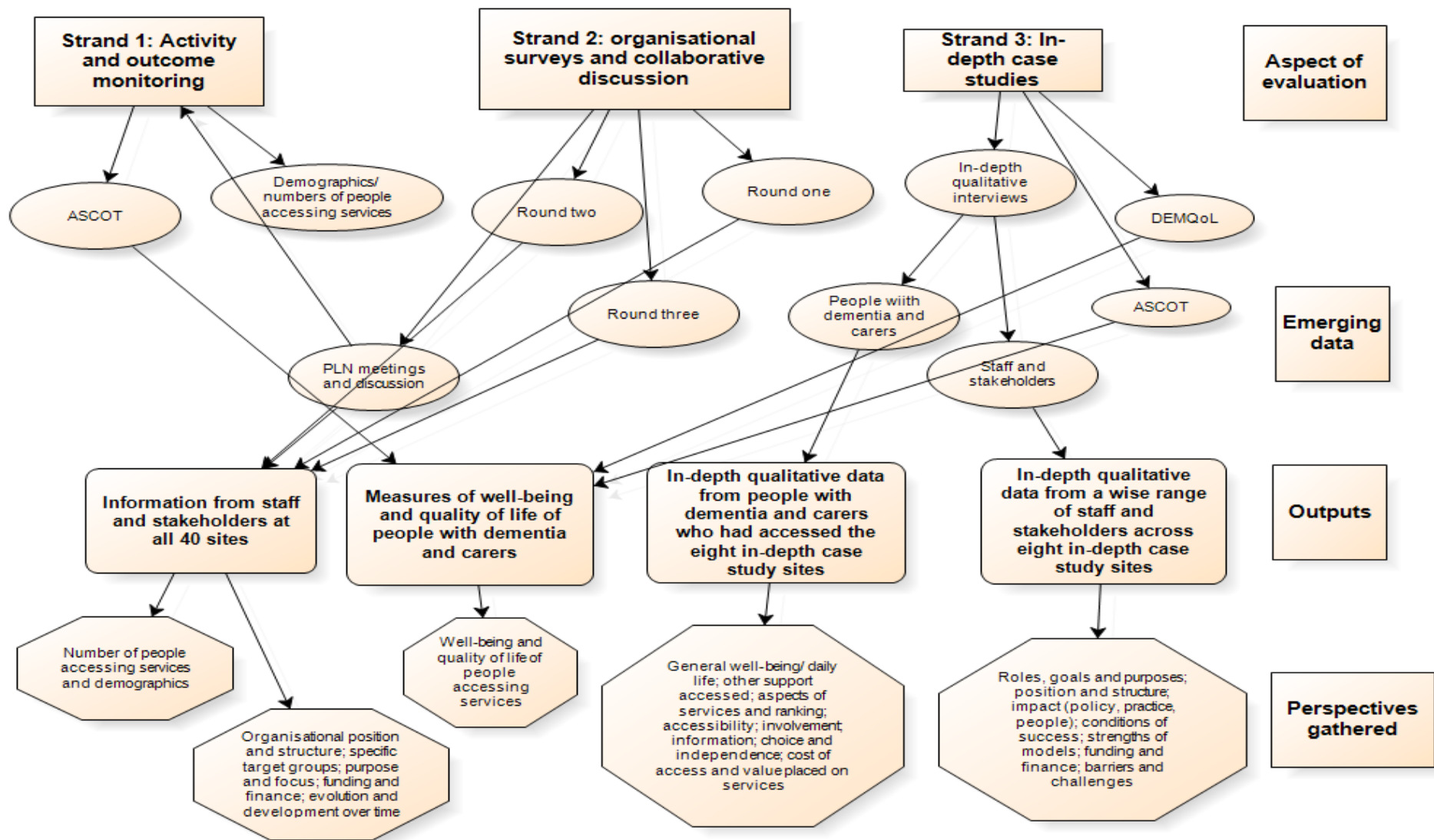
members to enrich the research (for example, in multiple people informing the development of the coding framework).

2. Auditability

- a. *Specify the criteria built into the researchers' thinking.* In this study, this relates to the explicit theoretical framework.
- b. *Specify how and why participants were selected,* for example we have described the nature of participants and the process of selection and recruitment.

3. Fittingness

- a. *Delineate the scope of the research in terms of the sample, setting, and the level of the theory generated.* Whilst in reporting this study we have provided a description of the context of the research and the methodology and methods used, we do not claim to have generated theory. What we have done is use an extensive range of modelling to describe the experiences of services and people living with dementia and to provide an account of how the former may influence the latter.
- b. *Describe how the literature relates to each category which emerged in the theory,* for example through discussing the findings in relation to policy and literature as in the Discussion section.



**Figure 3.** The way in which the data from the various strands has interlocked with the others.

## Conclusion

This section of the report has outlined a research process in which we have sought to ensure rigour by enabling many different aspects of demonstration site activity to be considered from many different angles. The strengths of the data which has been collected and analysed through the process outlined above are:

- The use of mixed methods in order to consider site activity in breadth and depth on both a quantitative and qualitative level.
- The triangulation of the data which emerged from the use of those methods, enabling a robust representation of site activity, and the views and experiences of people involved.
- The involvement of a wide range of people with different perspectives on site activity.
- Meaningful involvement of people with dementia and carers, in particular in the in-depth interviews, resulting in a wide range of views and experiences informing the evaluation.
- The rigorous process of analysing that data, with use of tools that enabled rigour within the analysis of each aspect of the data as well as in the meta-analysis which brought all of the datasets together.
- A team approach to collecting and analysing the data, resulting in perspectives from researchers with a range of interests and methodological viewpoints.

We return to these criteria and the extent to which they were met within the research process in the Discussion section on page 292.

## Healthbridge: Findings

This section is a presentation of the findings from the evaluation. In presenting the various aspects of the data that was collected, each section of the findings relates to one of the main aims of the evaluation, thus providing evidence for the discussion which follows. The findings are in six main sections:

- Section One: description of the range of Peer Support Network and Dementia Adviser services.
- Section Two: description of the evolution, establishment, delivery and governance of Peer Support Network and Dementia Adviser services.
- Section Three: assessment of the integration, sustainability and transferability within the wider health and social care landscape and economy.
- Section Four: identification of the contribution of Peer Support Network and Dementia Adviser services on well-being and resilience: accessibility of services; information and involvement; making choices and independence.
- Section Five: assessment of influence on well-being of people with dementia and carers.
- Section Six: sustaining the implementation of Peer Support Network and Dementia Adviser sites and their contribution to the aims of the National Dementia Strategy.

In presenting the findings from the evaluation, each subsection begins with a summary of the key themes that emerged from that aspect of the data. Sections of quantitative data have been presented using tables and charts. When presenting qualitative data, a visual representation of the data is provided using the models that were created in the process of data analysis in NVivo9 (see page 90). Each model represents a theme (or idea) relating to Peer Support Network and Dementia Adviser services, with each 'branch' of the model breaking down the idea further and representing different things that were said about that idea. The themes represented in the models are then outlined further, using quotations from people with dementia, carers, staff and stakeholders within the case study site interviews. Space has not allowed for every aspect of every model to be included in the discussion: the models provide an overview of the breadth of themes, while the discussion which follows provides further detail on the more significant or noteworthy themes. The

aim of the presentation of qualitative data is to paint a picture of the themes that emerged from the rigorous analysis of qualitative data. It is not a comprehensive presentation of everything that was covered in the in-depth interviews. Similarly, the range of aspects of experience of a wide range of people within a vast range of settings is complex, with each aspect interacting with other aspects on many different levels. While the individual models are an effective way of demonstrating some of these complexities, it is hard to represent the multidimensional nature of views and experiences. We refer readers seeking to understand the data as a whole and how the aspects of the data relate to one another to Model 1 (framework for interview data) on page 95.

The findings section as a whole begins with more descriptive data around what took place within the sites and moves on to a more in-depth critique of the main aspects of the data that was collected for the evaluation. All names given to participants are pseudonyms. Each participant has been allocated a different pseudonym, therefore the range of names used in this presentation of findings directly represents the range of people we are quoting. Our intention is not to identify individual sites, but to provide the reader with context by signifying the type of site (Dementia Adviser, DA, or Peer Support Network, PSN) and the role of the person being quoted within that site.

### **Section One: The range of Peer Support Network and Dementia Adviser services**

The aim of this section is to describe the range, both the breadth and depth, of site activity. In doing this, we draw upon qualitative data from in-depth case study interviews as well as the relevant data from the activity and outcome monitoring that involved all 40 demonstration sites.

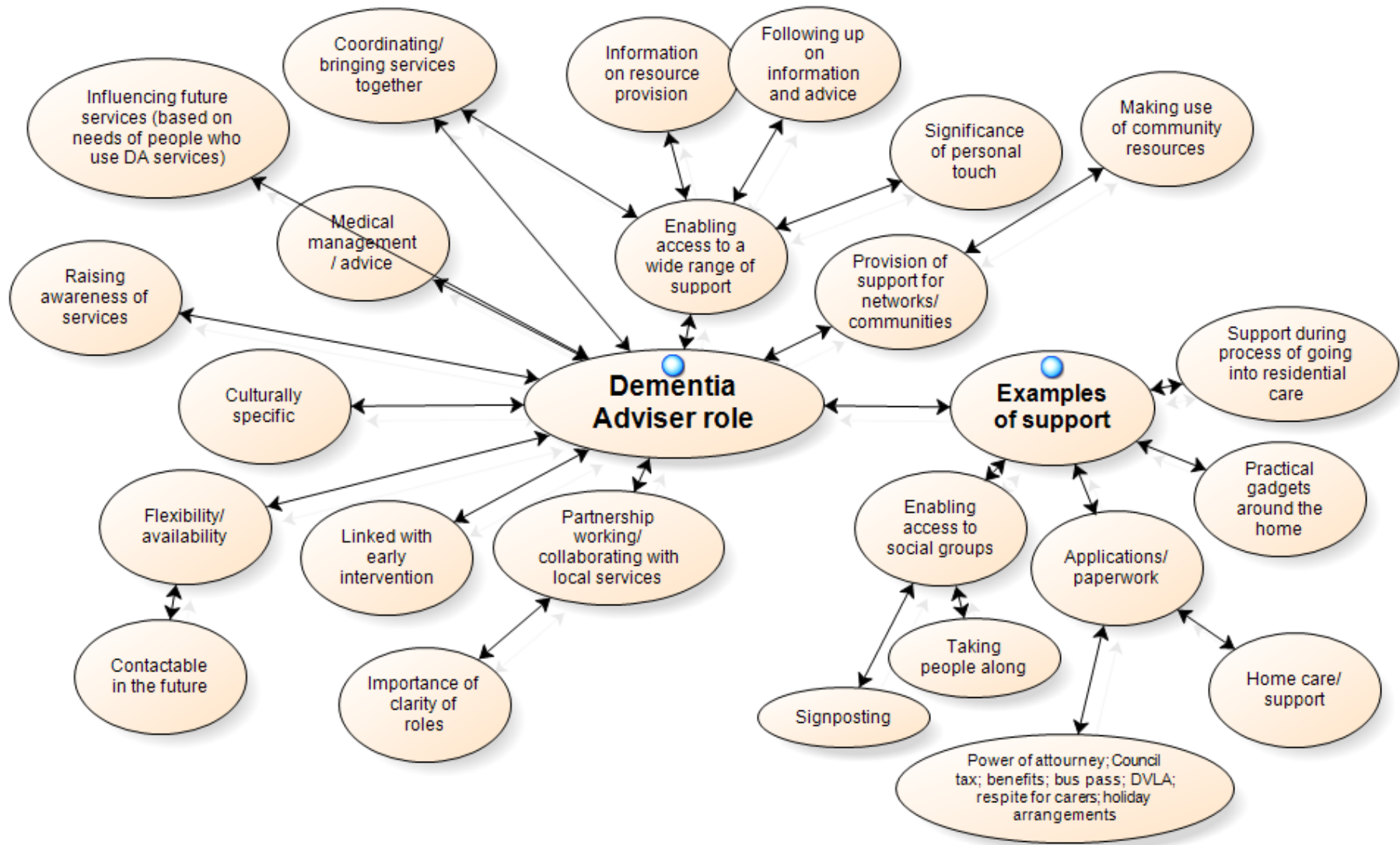
In this section:

- A description of activity within the in-depth case study sites from the perspective of staff, stakeholders, people with dementia and carers:
  - The role of the Dementia Adviser, including examples of support within Dementia Adviser sites.

- Peer Support Networks: positive aspects; the facilitator’s role; and some of the specific activities which took place within Peer Support Network sites.
- Numbers of people accessing the 40 demonstration sites.
- Goals, roles and purposes of the Peer Support Network and Dementia Adviser services:
  - Data from the organisational surveys that were completed by all of the demonstration sites.
  - Qualitative data from the in-depth case study site interviews.
- An outline of the ‘ingredients’ of Peer Support Network and Dementia Adviser services (what went into the design delivery and development of services, and what made them successful), mostly using qualitative data from in-depth case studies, mainly from staff and stakeholders.

### **The role of Dementia Advisers**

- **The role of Dementia Advisers included enabling access to a wide range of support, including social groups, financial and legal support and support that enabled people to remain independent for longer.**
- **Within their role of coordinating information about services and signposting, Dementia Advisers also had a role in working in partnership and collaboration with other local organisations, ensuring that their role in signposting to other services was followed up by those services.**
- **Dementia Advisers also had a role in supporting immediate networks and communities surrounding people with dementia and carers, making use of community resources and pre-existing social networks.**





Overall, people with dementia, carers, staff and stakeholders in the in-depth case study interviews spoke about the range of roles as represented within the evaluation of Dementia Adviser services as a whole. People with dementia and carers were also asked for specific examples of support.

A range of examples were given:

Barry, carer who had accessed DA services: *Right, well, in the beginning she gave me information, I have got a file upstairs, information about what I should be doing in respect of, was I getting a carer's allowance, disability living allowance for [person with dementia]. So I did that, and then [Dementia Adviser] got forms and things for me for power of attorney..... that was no problem, but [Dementia Adviser] did get me all the sort of the information that I needed..... Then she registered us with the carers.....So that if I do need a carer, I can sort of maybe call on somebody if the need was there, which could well happen in the year, distant, who knows, future.....as [Dementia Adviser] explained the situation that they would prioritise any caring that I might need, or the carer like if I needed to go to the hospital for an appointment, that sort of gets me top priority. If I just wanted maybe for going somewhere else.*

Support included help with finances and paperwork, including support in accessing benefits:

Sue, carer who had accessed DA services: *Well, obviously [Dementia Adviser]'s helped us with, like benefits. She's helped us with that. Because we'd got no idea we were entitled to anything. And also [Dementia Adviser] got a lady to come out and fill in the form for us, because the form... I think the lady that came out – it took 2 hours for her to fill in the form. So we would never have been able to do it.*

Data provided evidence of support from Dementia Advisers in enabling access to social groups and a wider range of activities:

Beth, daughter of couple who had accessed DA site: *I think it's actually made my parents realise that there is help out there. Because they're now getting mum onto some... I mean, we've only been recent. But we're now getting mum on to doing some different things. We're going to go up to [day centre], she's going to get to do*

*things. We've got a pamper day, I think, in... .....It's things also to keep mum occupied. [Dementia Adviser] is going to get me some literature and some leaflets that we can keep her occupied. I mean, keep her doing things. Get her to meet people.*

There was an emphasis on the Dementia Adviser as a single point of access who enabled access to a wide range of support, with a role of bringing a wide range of services together:

*Suzanne, carer who had accessed DA service: I think she's been an absolute key because she's been the person there that we've been able to phone up and say, "Hang on, we've got a slight problem. How do we do...? What do we do? Where can we go?" And she's been like... I don't think there was anything really before. The services, before, I think, were very fractured.*

*Julie, mental health nurse who had referred people to DA services: They're the link between everything that's available and the family, basically. Anything that they can possibly get for this person and to help them – then they're the link that can facilitate it, really. They're like a facilitator, I think, of... Of advice and support and guidance and day care and respite and... And the link between the mental health teams as well. It sort of links us all together, doesn't it? The Acute Trust and the mental health teams and the Dementia Advisers and the voluntary services as well. Because they signpost to voluntary services as well. Yeah, they're sort of like a facilitator.*

The personal aspect of support from Dementia Advisers was also key within support that enabled people to negotiate complex and difficult situations. As this extract shows, for many people with dementia it was that personal aspect that had most impact for them. It is taken from an in-depth interview with a person with dementia (John) and two family carers (Rob and Sally):

*Interviewer: What's been the most important aspect of the help and the support that you've had from [Dementia Adviser]?*

*Rob: Pointing us in the right direction of the places to get the possible help.*

*Sally: And just know that she's there.*

Rob: *Just to help us see something simple that we hadn't seen before. Something that was right in front of our eyes that could have helped us, that we didn't see. But we get too stressed out, we don't see something that's so easy in front of us, and there's she to...*

Sally: *She can see the whole picture.*

Interviewer (turns to John (person with dementia)): *John – what's the most important aspect of the support that you've had from [Dementia Adviser]?*

John: *[Dementia Adviser] knows me. And she has an understanding of the... My behavioural problems, if you want to put it that way. But the most important help I've had is definitely the fact that I trust [Dementia Adviser] and that [Dementia Adviser] is able to get me to do things in the past and in the future if it comes up, that nobody else would get me to do. So I think it's trust.*

In addition to providing advice and information on a wide range of aspects of living with dementia, Dementia Advisers were able to build up a range of resources based on strategies discovered within their work. These resources were subsequently available to other people with dementia and carers:

Louise, manager of NHS services where Dementia Adviser was located: *I'm an individual and I want to be treated as an individual and I think the Dementia Adviser role allows that to happen. Enables that to happen; not 'allows' it to happen.....Promotes that independence. And the way it's worked is that [Dementia Adviser] the sort of portfolio of information that she's built, is directly related to what people want to know.....so she's building that up, so that's right, and she'll see somebody and give them whatever information she thinks they'll need at that time. And then she'll ask if there's anything that they would like to know more about..... And if she doesn't know it, she can go away and research it and come back with it, and then the next person that she goes to, that's on offer there as well, and that just gets bigger and bigger and bigger.*

Dementia Advisers provided support for whole communities, including in training GPs, both in issues around dementia and in promoting Dementia Adviser services:

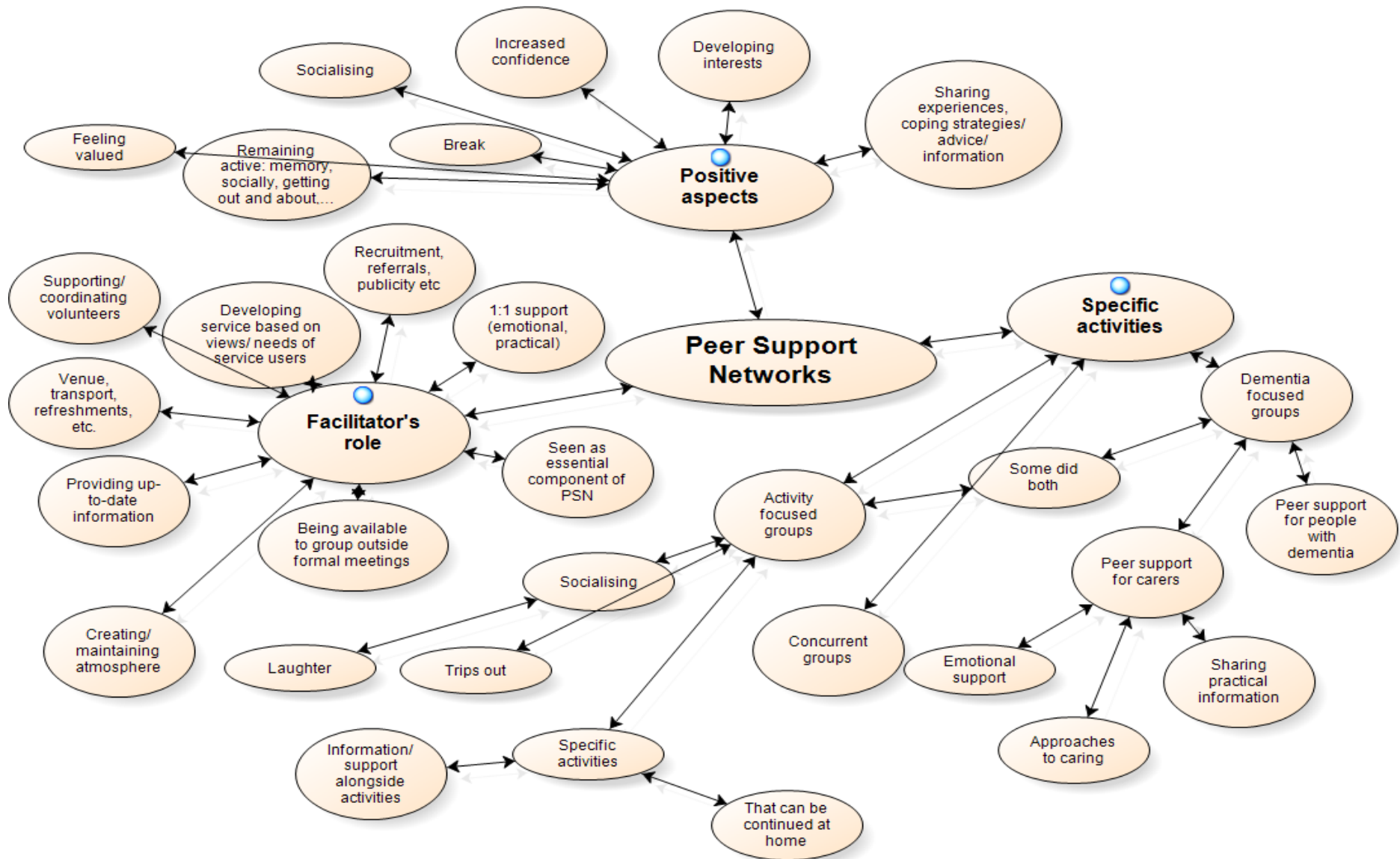
Carmen, commissioner, DA site: *And, in fact, I think we've covered all the surgeries in [site] and [Dementia Adviser] has attended every one of those. So that's been a really, sort of, fantastic outcome for us – that [Dementia Adviser] has been able to go in, talk to the staff at all levels.*

There was also a role for Dementia Advisers in raising awareness around dementia at the same time as promoting their services. Within this, engagement with whole communities was important:

Riyaz, commissioner from DA site: *One of the things that they did for them to get a rural area... Rural area involvement, was quite... Quite interesting, actually. They decided that they would go on the mobile libraries. Both [Dementia Adviser] and [Dementia Adviser] which... And so they went on the mobile libraries, and they got to lots of different areas that they would never have got to before. And they found out who, like, the village leaders were. So they were able to actually connect with different parishes by doing that. Which .. I thought was quite innovative of them, actually.*

### **Peer Support Networks**

- **Some groups within Peer Support Networks were activity-based, others had more of a focus on dementia and discussion. There were some groups where both took place. Some people kept in touch with one another outside of formal meetings, others chose not to or were not able to.**
- **Peer Support Network groups included socialising, and developing interests, within the context of interpersonal interaction with people who had common experiences of living with dementia. The groups enabled people to remain active, whether that be through maintaining memory, or getting out and about and socialising.**
- **The facilitator's role within Peer Support Networks included recruitment, processing referrals and publicity; ensuring the smooth running of groups and, at times, providing information, advice and one-to-one support.**



Some of the groups within Peer Support Networks were set up with a focus on specific activities, such as gardening, art, craft, t'ai chi, dancing and singing. Other groups focused more upon a discussion around issues that group members had faced, and the way in which other group members had overcome similar issues. Some groups focused on both:

*Katrina, staff from PSN site: We've also used activities as a way of bringing people together in the hope that peer support would occur naturally. Which it had. So some people are coming in to the activity, rather than coming into a group to meet people with dementia.....But, similarly, we've also started doing peer support groups just for that purpose – so that people would come together with the purpose of, you know, talking about their own experience.*

The supportive atmosphere, and opportunity to have a laugh at the same time as supporting one another, was important for some. The quote below from a person with dementia who had attended a Peer Support Network group illustrates the importance of building up trust in order to be able to speak about experiences relating to dementia:

*Ron, person with dementia who had attended PSN group: I have started this one at the cafe, where we... There's... What? 2, 4 – there's 6. 6 of us. That's... [Peer Support Coordinator] takes that one. And we sit there and most of the time we just have a really good giggle, you know. Now I've been there early this morning and it was the first time it's came up about dementia. One of the lads fetched it up, you know. And it was nice to... Nice to actually see. Or rather listen to. You know, because everybody has their own say and everything, you know. And it's very good. You know. It's just that... It's just you can go down there for a couple of hours and just forget about everything. Which is really nice, you know. And that's done a... Everybody agrees it's done everybody the world of good, you know.*

The positive impact of attending groups included support in maintaining or improving memory:

*Denise, person with dementia speaking about attending a PSN group: It gives you ideas for trying to keep... You know, improve your memory. And keep your mind ticking over and, like, doing things like crosswords and quizzes and things like that. It helps... It advises you on things that you can do now for when your memory gets*

worse. So that if you do them now... It's like where you put... Where you're going to put your keys and things like that. Advises you about things like that. We do crafts. We have people come in to talk to us about different things. And we do quizzes there. And we also get a lady who comes to do exercises with us, which is very good. Yeah, there's a variety of things...

Others emphasised the social aspect of the groups:

Evelyn, person with dementia who had attended PSN groups: *Now what I got out of it I honestly don't know. Now I don't know if it's helping my memory or not, I haven't got a clue as to that, but I like the company.....And what [PSN facilitator] does is fantastic, she is a golden...and the other carers are lovely as well....And there is a good, its, its company, it's interesting.*

Peer Support Networks also provided people with information:

Anthony, carer who had accessed PSN site: *So it's helped a lot, the information they've given and then... There's always somebody here if you've got an issue or if you've got a problem. They can point you in the right direction of where to go if they can't help you themselves. You know, then it's... For me, I wouldn't know where to look for any of that information. And I probably wouldn't know that I needed to do it until it was too late.*

There was also reference to the positive effect on people's confidence in social situations, rooted in the group experience of socialising with others who had similar difficulties:

Frank, person with dementia who had accessed peer support group: *We can all talk and you're not scared of being.....Saying something wrong, because we're all the same. We're all in the same boat.*

Peer support groups that were specifically for carers tended to focus on sharing strategies for coping, for example practical information such as accessing financial support or care packages, or just an opportunity to 'offload' about difficulties and challenges:

Dawn, PSN staff: *Full-time care of people with dementia is an extremely stressful role. And I think they do need to speak to other people about how it feels and... And,*

*sometimes, they do get the mutual benefit by sharing experiences. I'm particularly thinking now about the education group that we had last year and how beneficial that was for carers to... To have that opportunity to share their experiences and... And pick up hints and tips, if you like, from other carers. "Oh yes, I've dealt with that and this is how I... This is how I coped with it." And, yet, it sort of... And it gives them the opportunity to... If you like, it gives them the... The right to say, "I'm struggling" or, you know, "This is how I feel and sometimes I feel like this." And somebody else can say, "Well yes, I felt like that."*

Positive aspects of Peer Support Network groups spoken about by people with dementia and carers included: increased confidence, an opportunity to socialise, feeling valued within the group and an opportunity to share with people who had a commonality of experience. Family members spoke about the positive impact on many different aspects of life, not just specific to the Peer Support Network group:

*Denise, person with Dementia who had attended PSN group: Yes. And I've found, since I've been to the [PSN group] and got more confidence, I tend to chat to people more. You know, people on the bus or people you see in town. Whereas I wouldn't do that before. So I think it's helped me a lot. Yeah.....Definitely. And even my daughter has noticed that.*

*Interviewer: Really? Oh, what has she said to that?*

*Denise: Well, just different things. "Oh, you wouldn't have done that before" or... You know.*

People also spoke about the opportunity to remain active (getting out and about with groups and sometimes maintaining memory through group activity), an opportunity to rediscover previous interests, or take up new ones, and groups providing a break from day-to-day routine:

*Frank, person with dementia who had accessed PSN group: Well it does because I look forward to going now on a... We look forward to Friday coming, so we all can meet up. Because a lot of the time I'm here on my own. I mean, I do like jigsaws to keep my memory going, and crosswords, but on a Friday we all meet up and we can have a talk and a laugh and... It's just like as though we've been friends forever.*



The role of the facilitator within Peer Support Network groups was significant. This included providing overall direction and day-to-day support for the networks, as well as providing emotional support for people with dementia and carers. Specific roles included promoting the service and managing enquiries, referrals, etc.; developing and maintaining partnerships with other local organisations; ensuring safe, smooth and successful running of groups; developing the service based on the views and needs of service users:

*Bev, PSN facilitator: So my role would be to take the referral, either do home visits or ask somebody to come and we could meet and I could talk to them, or I could do a telephone call or send information in the post. I would... Let me think... After we've done the home visit and given lots of information – we've been encouraging people to come to the groups. I also facilitate, or co-facilitate, most of the groups that we have here in [site] as well. And my role there, again, is to bring that structure so that bringing people together in a structured way... And shaping, sometimes, how the group might go. But mainly the people who are attending do that themselves, anyway. I do all the ringing round to make sure people are reminded to come to some of the groups.*

The activities within Peer Support Network groups did not appeal to all people with dementia. Previous interests, personal preferences and life experiences were factors in determining whether the groups were a positive experience for people.

### **Frequency of accessing services**

In describing the range of Peer Support Network and Dementia Adviser services, we now present the statistical data representing the frequency that the services were accessed. All 40 demonstration sites were asked to provide figures over an 18-month period (October 2010 to March 2011; November 2011 and March 2012). There was a 95% return rate for these forms from October 2010 to March 2011, dropping to 50% in March 2012.

Figures reported by staff indicate the number of times each service was accessed in that week, which is not necessarily the same as the number of people accessing the sites as some people will have accessed a site more than once during any one week.

Site staff from the sites that returned data reported that:

- The number of occasions on which a record was made of somebody accessing one of the 40 demonstration sites in one week within any one month ranged from 669 (December 2010 reported by 36 sites – an average of 19 per site for the sample weeks) to 386 (March 2012 reported by 20 sites – an average of 14 per site for the sample week).
- Of these, 85.7% were people who had a confirmed diagnosis of dementia, and:
  - 9.1% did not have a confirmed diagnosis and
  - 5.2% were people for whom site staff were unsure about their diagnosis.
- 23% were people living alone.
- 50.6% were male; 49.4% female.
- 56% of points of contact with services were with Dementia Adviser services. Of these:
  - 37% were with people with dementia
  - 63% were with carers of people with dementia.
- 44% of points of contact with services were with Peer Support Network services. Of these:
  - 56% were with people with dementia
  - 44% were with carers.

The activity and outcome monitoring forms were designed to gather information on numbers of people from specific or 'harder to reach' groups who were accessing services. This included people with early-onset dementia (aged under 65) and 'oldest old' people with dementia (aged over 85):

- The majority (78.5%) of people accessing services were aged between 65 and 85.
- 12.4% of those accessing services were identified as having early-onset dementia.
- 9.1% of people accessing services were aged over 85.

On 11.9% of occasions sites were accessed by someone from a BME community. This compares with 8% of people over 60 years in the UK being from BME communities (Age UK, 2012), suggesting that in the demonstration sites there were effective strategies for reaching BME communities (although see below for more detail about the variability of

engaging BME communities between individual services ). On 8.3% of occasions services were accessed by people who were identified as not having English as their first language.

There was one person identified as LGBT across all 40 sites for the demonstration period. It is important to recognise that personal information available to the demonstration site staff who were returning the figures may have been limited by the hidden and sensitive nature of sexual orientation, and the sensitive issues relating to collecting such data. However, the lack of access to Peer Support Network and Dementia Adviser services by people within this significant minority group must be noted.

There were four instances recorded of people accessing sites who were identified as having a learning disability. Amongst people who have Down's syndrome, 1 in 3 people aged 50–59 and over half of people over 60 also have dementia. Amongst people with other learning disabilities, 1 in 10 people aged 50–65 and 1 in 7 of those aged 65–75 also have dementia (Alzheimer's Society, 2011). When compared with overall UK statistics for people with learning disabilities and dementia, people with learning disabilities and dementia are a significant group who were not accessing the demonstration sites (or were not recorded as doing so).

#### **Activity and outcome monitoring data figures: Case study sites**

The activity and outcome monitoring data collected from the eight case study sites, on the whole, reflected national responses.

The case study site data, however, sheds light on patterns relating to access to services by people from specific or 'harder to reach' groups. For example, services that had a specific remit in providing support for people from BME communities had a higher number of people from those communities accessing services than services that did not specify reaching BME communities as central to their service. For example, one of the Peer Support Network case study sites which set out to focus on providing support for a specific BME community identified 47 people from BME communities accessing their services, whereas there were other case study sites that reported nobody from BME communities accessing their services.

Further patterns that are of note within the data collected at the case study sites:

- There were significantly more people accessing Peer Support Network sites than Dementia Adviser sites:
  - Site staff recorded 281 occasions when people with dementia had accessed the four Dementia Adviser case study sites during the 8 months when data was collected.
  - Site staff recorded 635 occasions when people with dementia had accessed the four Peer Support Network case study sites across the 8 months when data was collected.
- As with the data across all 40 sites where there were very few people from LGBT communities, zero people were identified in the data that was returned from the case study sites.
- Similarly, few people with a learning disability and dementia were represented in the people accessing the case study sites. Across all of the figures collected throughout the evaluation, there was a record of one person with a learning disability accessing any of the in-depth case study sites.

#### **Goals, roles and purposes of Peer Support Network and Dementia Adviser services**

- **The range of goals, roles and purposes for Peer Support Network and Dementia Adviser services outlined in the organisational surveys on the whole reflected those that were spoken about within the in-depth interviews.**
- **There were some specific goals and purposes such as information, advice and signposting, enabling access to support and services and crisis prevention/early intervention.**
- **There were further roles and purposes of the services which emerged as a result of site activity. These included maintaining independence, well-being and quality of life and enabling participation and engagement. A further specific goal within specific services was that of reaching specific communities, for example BME communities.**

### ***From organisational surveys***

Data collected from all of the demonstration sites includes insight into the range of goals across all of the sites which were part of the National Dementia Strategy pilot. A range of purposes were outlined, including:

- awareness raising
- advice and information giving
- signposting to other services in the community, voluntary and statutory services
- providing peer support
- improving the well-being of people with dementia and their family was paramount.

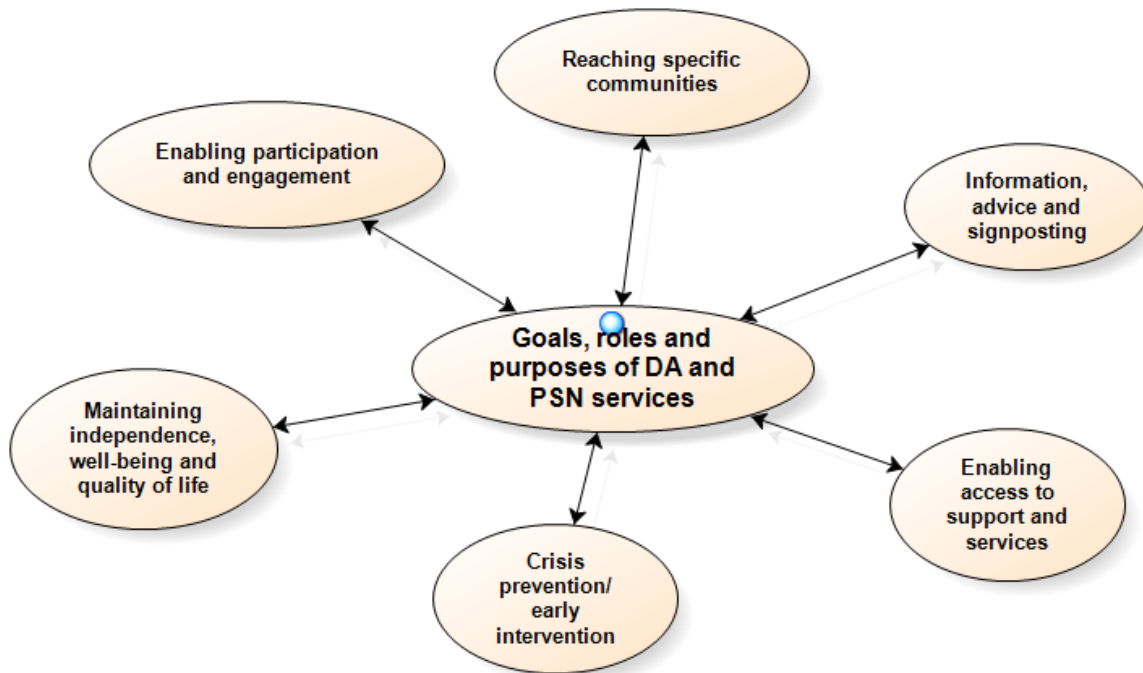
Services were intended to be responsive to need, in some cases user-led, providing people with choice and control in the information and service they obtained, which would enable independent living and delay the need for more intensive support.

Staff and stakeholders who returned information stated that the target audience was also key within the purposes of sites. In general the different sites sought to reach people affected by dementia living in the community. Some sites, exclusively or in addition to the general public, sought to reach one or more of the following:

- younger people with dementia
- those who were pre- or newly diagnosed
- people from specific or 'harder to reach' communities
- people with learning difficulties.

Some services included professional staff among their recipients of resources and information. Services targeting people affected by dementia who also lived in specific or 'harder to reach' communities had some difficulties integrating services in the community and with other professional services.

*From in-depth case study site interviews*



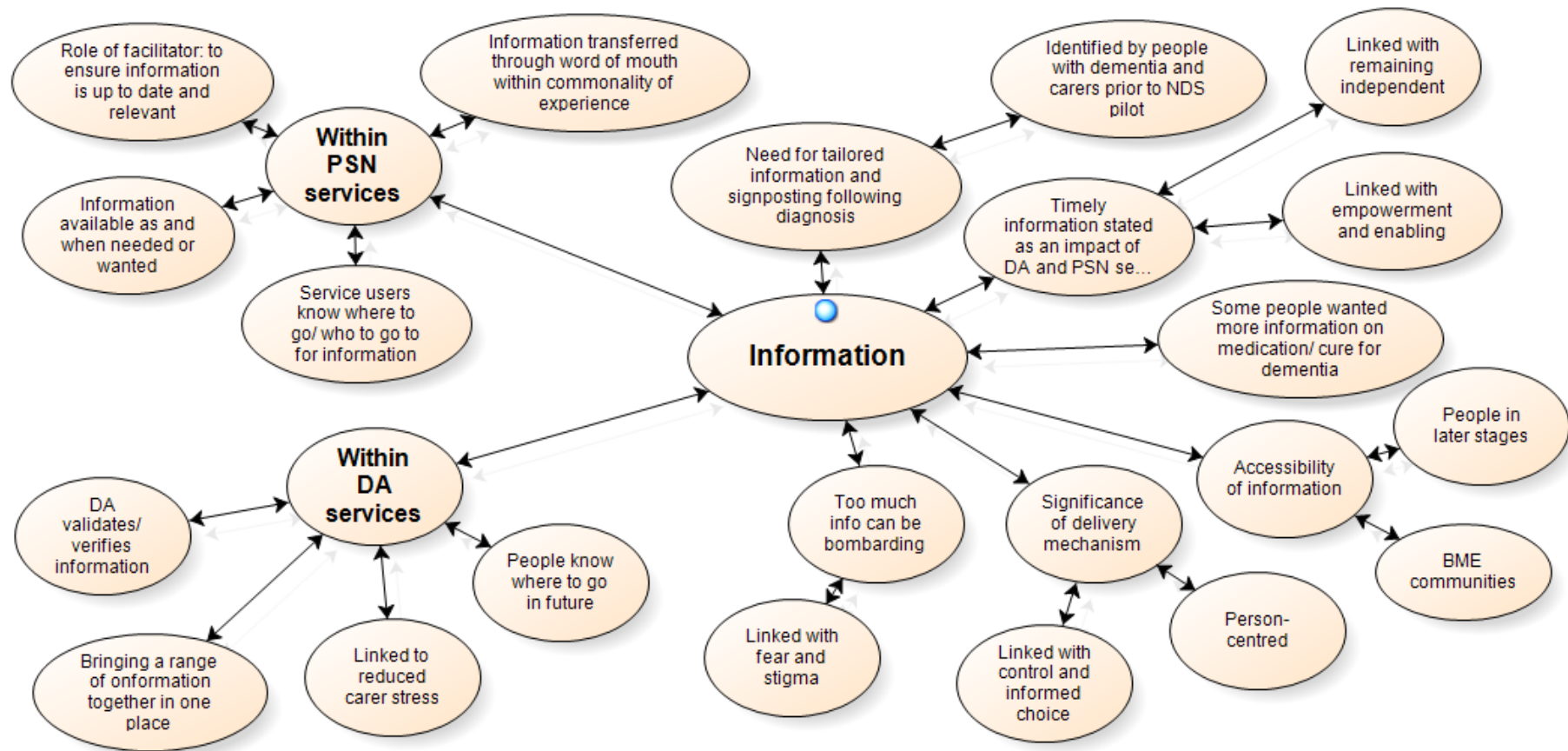
Qualitative data from the in-depth case study interviews which explained the goals, roles and purposes of Peer Support Network and Dementia Adviser services from the perspective of those who had been involved have been grouped into six main areas:

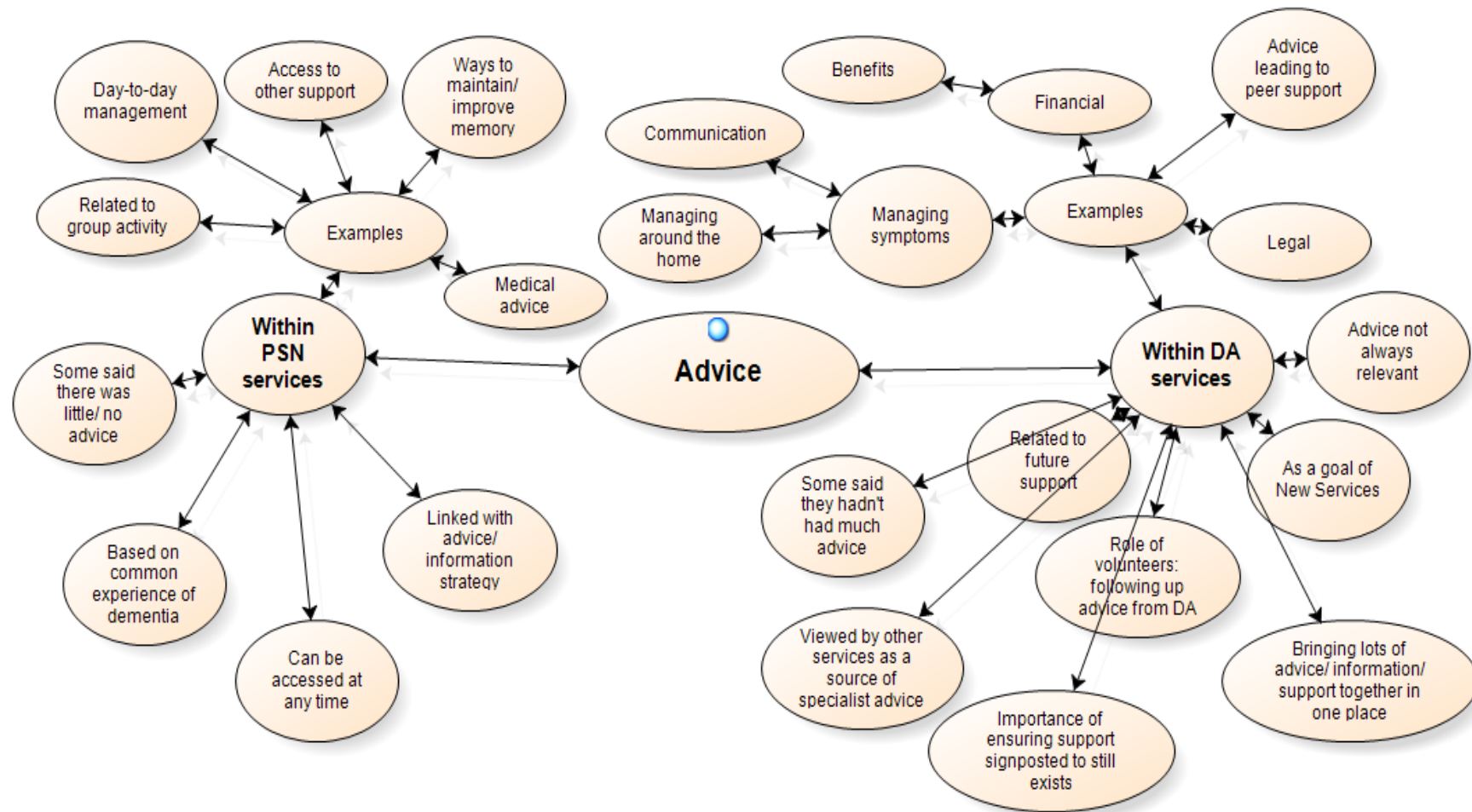
- information, advice and signposting
- enabling access to support and services
- crisis prevention and early intervention
- maintaining independence, well-being and quality of life
- enabling participation and engagement
- reaching specific communities, such as BME communities.

The goals, roles and purposes outlined in this section include data from staff and stakeholders in which they stated what they viewed the goals, roles and purposes to be. This data is backed up with evidence from people with dementia and carers about their experiences relating to the goals, roles and purposes.

### **Information, advice and signposting**

Information, advice and signposting were referred to within the goals, roles and purposes of both Peer Support Network and Dementia Adviser services. The models below outline the aspects of advice and information spoken about, demonstrating the commonalities and differences between ways in which they were delivered and developed within Peer Support Network and Dementia Adviser services.







Provision of information, about services and support available as well as medical information and understanding of the condition, was seen as a role and purpose of both Peer Support Network and Dementia Adviser services. Advice was also a significant aspect.

Within Dementia Adviser services, the emphasis was on bringing information and advice together in one place, facilitated by the Dementia Adviser:

Nighat, carer who had accessed DA services: *She came and she gave us lots of advice and different services which are available and what we can do and...*

Within Peer Support Network services, on the other hand, the emphasis was on a pooling of information and advice based on direct experience of people with dementia and carers:

Gill, carer who had accessed PSN group: *I think it's good because you can air your opinion, you know, and you might be able to tell somebody something or... You know, they'll give you a piece of information.*

Although the way in which advice was given and received differed, the goals related to advice within Peer Support Network and Dementia Adviser services were similar: increasing knowledge about a wider range of support, and enabling access/signposting to local support services/organisations.

Within Dementia Adviser services, the timing and content of advice was significant, as Dementia Advisers sought to provide information tailored to people's needs and delivered as and when appropriate to individuals:

Anita, Services Manager from DA site: *And not to bombard people with information at that stage.....Just as soon as they get a diagnosis about the whole ..... what they're going to need, say, in two years' time. It's actually about doing it as a stepping stone, really. Because people in other areas where they've had information, and they've received diagnosis, it's been too much information and actually it's quite scary and quite frightening for people.....I think that creates that stigma around dementia.*

Within Peer Support Network services, the emphasis was on advice within the context of supportive groups or one-to-one relationships in which there was a commonality of

experience. The following example is from a person with dementia who had attended a Peer Support Network group:

Denise, person with dementia who had accessed PSN group: *I know people have asked about claiming benefits and somebody else asked about... Do they call it...? When you're not competent to do something and you want to.... There's a form you can fill in or something for somebody else to do things... You know, sign for you and... I can't remember what it's called.*

Timing and flexibility of support from Peer Support Network and Dementia Adviser services was a key issue that will be returned to later in this presentation of findings. Within Peer Support Network services, the emphasis was on providing a forum to share information, experiences and difficulties with people in a similar position, with an emphasis on the role of interpersonal interaction. There was also an emphasis on ending isolation:

Marion, PSN coordinator: *So a large part of the project has been building the network into something that, you know, breaks their isolation. The isolation of memory cafés mirrors the isolation of carers and people with memory loss. So we all need people to feel like they weren't on their own when they were in a memory café – they were tapped into something bigger. They were supported. That they could share experiences with others who knew how it was. And that had, perhaps overcome similar problems.*

### **Enabling access to support and services**

Both Peer Support Network and Dementia Adviser sites sought to enable access to support and services. Whether it be through the direct provision of groups (Peer Support Network services) or through signposting people to local groups (Dementia Adviser services), access to support groups was a common theme.

Services and support accessed as a result of support from Peer Support Network and Dementia Adviser services will be returned to in Section Two of this presentation of findings on page 180.

### ***Filling a gap in service provision***

Both Peer Support Network and Dementia Adviser sites saw a specific role for Peer Support Network and Dementia Adviser services in filling the gap in service provision that so often occurs after diagnosis but before there is a need for more intensive support.

In relation to goals of service provision, creating a link between services and support available and families living with dementia was significant within Dementia Adviser services, with the provision of a one-stop shop where services and information are together in one place, liaising with services to ensure signposting/information is realised. Both Peer Support Network and Dementia Adviser sites saw a role for Peer Support Network and Dementia Adviser services in complementing pre-existing services; identifying gaps and optimising service delivery, within a specialist service for GPs to refer into.

The significant area of the relationship of Peer Support Network and Dementia Adviser services to pre-existing services will be returned to in Section Three of this presentation of the findings on page 175.

### ***Reaching specific or 'harder to reach' communities***

Seeking to support people with dementia and carers within specific (what might be considered 'harder to reach') communities was a specific goal for three of the in-depth case study sites. In these instances, the sites were located within geographical areas where there were specific BME communities. For some sites, the whole remit of the service was to support these specific communities. Other sites set up support groups or services that were designed to support specific groups alongside other aspects of the support they were providing. Where sites had a specific goal of reaching specific communities, the set-up of the service reflected that goal, for example in employing staff who were able to speak their language, and who would be culturally aware and sensitive to differing understandings of dementia and mental health.

### ***Crisis prevention/early intervention***

Crisis prevention and early intervention were significant aspects of Peer Support Network and Dementia Adviser services and were common goals across both Peer Support Network

and Dementia Adviser sites. This included getting future support in place and supporting people all the way through the dementia journey. Within Dementia Adviser sites, there was an emphasis on the significance of the relationship that was built up with people with dementia and carers during the earlier stages of dementia, which would provide a firm basis for and source of future support, as and when it was needed.

Goals, roles and purposes: Maintaining independence, well-being and quality of life, for example enabling people to remain in their own home for longer was a further role for Peer Support Network and Dementia Adviser services. This was situated within overall purposes of building resilience and enhancing well-being and quality of life. Within Peer Support Network sites, the provision of focused activities was also referred to, as was the goal of establishing self-sustaining networks of support.

The area of independence, well-being and quality of life is explored in detail in Section Four of this presentation of the findings, on page 246.

Goals, roles and purposes: Enabling engagement and participation, both individual and collective, in developing services was referred to within Peer Support Network services:

*Gerry, commissioner from PSN site: We are very supportive of the whole idea of peer support. The concept, you know, from user-led, the whole participation-engagement agenda. And I think peer support is a key element with that. When you're moving beyond consulting about services to working in partnership in delivering them to people controlling them themselves.....I think we recognise there's particular challenges in some areas. Dementia being one of them. But that doesn't stop you from attempting to do it, and finding ways to do it.*

As Gerry continues to explain, there was an emphasis, primarily within Peer Support Network sites, on providing meaningful and accessible support for people with dementia and not just their carers:

*Gerry, commissioner from PSN site: Well I suppose there's a few layers to that.....I mean, the first thing was one of the things we were very interested in was work that directly targeted people with dementia, rather than carers. Not that we're not very*

*supportive of carers, but one of the things we'd found is that....quite often in terms of low level support, there was more directed at carers than actual people with dementia themselves.*

A goal that was more prevalent within Peer Support Network services was that of nurturing emotional support and/or friendship, with an emphasis on social interaction with people who have a commonality of experience:

*Kathryn, staff from PSN site: So that, perhaps particularly in cases where people are fairly early in diagnosis, they might be able to meet socially with people who have had direct experience of that process. Direct experience. Personal experience, so they can share it.....*

### **What went into sites and what made them successful?**

Having outlined the goals, roles and purposes of services, we now move on to present what was said about the conditions that were essential to their success and the components of the intervention. We begin with data from the organisational surveys which were circulated to all 40 demonstration sites, and then move on to consider the in-depth case study site data.

#### ***From site survey data: what made services flourish?***

This section relates to the analysis of site survey data, from which the following themes emerged:

- Infrastructure was clearly an important element of a successful service.
- Staff and stakeholders commented on the existence and quality of the partnership and collaborative working that took place.

#### ***Infrastructure***

Staff talked about a range of factors within their environment that impacted on service development. A supportive infrastructure could be described as the bones of the skeleton on which the new service could 'flesh out'. If some of the bones were missing or weak, the service could collapse. The factors were closely intertwined, and therefore hard to separate from one another.

A supportive infrastructure had other services to which it could be *referred by* and to which it could *refer to*. Services must exist in the first place:

DA site, site survey round 3: *The main focus of the service has remained with delivering advice, information and signposting although with pressures on economy and some service cuts both in the statutory and voluntary sector signposting to appropriate services has at times been restrictive due to demand and limits on service delivery.*

The position of the Peer Support Network or Dementia Adviser service within the health and social care system and within voluntary sector organisations within localities was important, as without this the service could be overlooked and falter simply by not being visible enough:

PSN service, site survey round 3: *There is not a ready source of referrals to the project, as it is not embedded within current mental health provision.*

Visibility and clarity in the purpose of the services was also key:

PSN site, round 3: *A display stand was on show in each surgery for one week at a time and members of each team participating attended the surgeries during one week.....(and) Visiting local GP surgeries and attending clinician meetings.*

Lack of visibility and clarity could inhibit key professionals from recognising what it could offer to others, and how the services and support offered was unique to other services:

DA site, round two (responding to a question about what hindered 'mushrooming'):  
*Other services already providing much work of the DA service. Too many commissioners involved and unable to agree on development. Lack of cooperation from the staff at the memory clinic. Poor interest from GPs.*

Commitment and a reasonable amount of certainty in the present and in the near future was essential as it affected the planning and functioning of the new service. Funding was an essential part of that as it didn't just affect the service as it currently was:

DA service, site survey round 3: *Service is no longer provided due to further funding not being available.*

Funding also affected what the service could become:

DA service, site survey round 2: *The potential is there, but has been constrained by funding opportunities. There have been developments in offering a wider range of family carer support.*

Commitment to the service was not just evident through money but was clearly influenced by personal commitment: goodwill of those delivering and receiving the service was significant:

PSN site, survey round 2: *The money has not mushroomed into either more money or other benefits but the concept of memory cafés has. There is a lot of goodwill and support to the memory cafés but this has not translated into financial support.*

However, both types of commitment are necessary, as the same respondent goes on to say:

*Also the huge number of memory cafés, and budget cuts within health service sector has also meant that initial promised regular support (from CPNs) has not been sustained. Therefore, although this county now has 23 memory cafés it will be interesting to see whether they still exist in 5 years' time, and are still independent and community led.*

### *Partnership*

Partnership was a key theme that recurred throughout both site survey data and in-depth interview data. Whilst partnership is essential within any organisation seeking to support people with dementia and carers, the role of partnership in demonstration site activity was often specifically focused on the way in which the demonstration sites were established. Partnership was also key in developing and maintaining demonstration site activity in the context of the tensions between the National Dementia Strategy as national policy and strategy and governance within each site. (See findings on 'Being a demonstration site' on page 149 for further insight into this.)

Partnership varied from minimal to quite extensive, particularly as a service might flourish and develop. This section unpacks some of the influences of and impact upon partnership within the site surveys that were distributed to all 40 demonstration sites.

- Partnership enabled new and developing services to become known to the relevant organisations, services and professional staff and to people affected by dementia, and increase referrals to the new service.
- Partnerships could be dynamic not just in developing service quality but also in raising awareness of their respective services and the two-way flow of referrals between the different agencies and the Peer Support Network or Dementia Adviser. This two-way process was beneficial to all parties:

*DA site survey round 1: The service has also enabled great partnership working across all agencies in the statutory, voluntary and private sector in ensuring that dementia care is at the forefront of service provision.*

In contrast, some Peer Support Networks and Dementia Advisers commented on difficult relationships with some services and how this impeded the development of the service and the ability to ‘mushroom’ (we explain the idea of mushrooming in more detail in Section Three of this presentation of findings), as staff appeared hostile or disinterested in the concept or contact with Peer Support Networks and Dementia Advisers. On occasion, a service might fail to see the relevance, or indeed be threatened by, a new service and be resistant to it, delaying or impeding the ability of the service to embed. Over time, as the service developed, one service commented that previously resistant staff:

*DA, site survey round 2: Can now identify that the service is an addition and a benefit to people with dementia and their carers and families and not as a replacement for their services.*

Establishing Peer Support Network and Dementia Adviser services where statutory or voluntary services may be ‘closed’ to them was one difficulty and those endeavouring to work with specific or ‘harder to reach’ communities had the added difficulty of accessing communities that could be regarded as having a ‘closed’ community infrastructure. Cultural differences could markedly influence service creation and development:



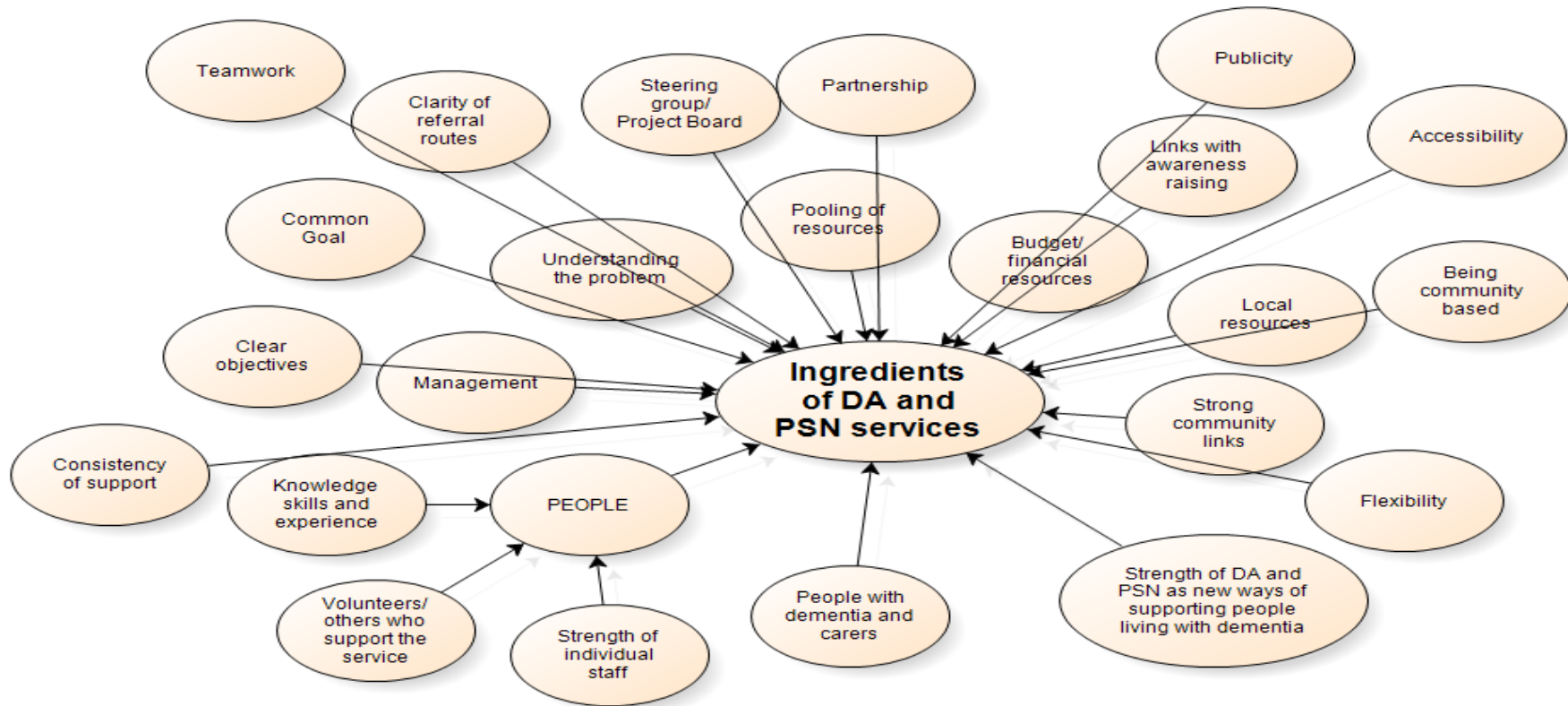
*PSN, site survey round 3: Low levels of awareness about dementia and the existence of stigma in the community may explain why people from this community are currently under-represented in local dementia services.*

Staff and stakeholders from sites which were specifically targeting those specific or 'harder to reach' communities spoke of having to focus on relationship building and awareness raising within these communities before a service could be offered. Inevitably, this delayed the development of services or even shifted their focus from service building to relationship building:

*PSN, site survey round 2: Key learning about the local [BME] population is helping to 'shape' the tactics used to engage with this community and raise awareness of dementia. For example, the launch of carers' support groups did not 'take off' for this particular community, so the project is now concentrating on building relationships and trust within the community, alongside existing local BME groups to raise awareness.*

**What went into the design, delivery and success of Peer Support Network and Dementia Adviser services: In-depth case study site interview data**

This section combines data emerging from two specific questions asked to staff and stakeholders: 1. What were the components of the intervention. 2. What were the conditions essential to the success of Peer Support Network and Dementia Adviser services? The themes which emerged from the two were very similar and have therefore been combined into one section: the ingredients of Peer Support Network and Dementia Adviser services.



## *People*

Specific staff were referred to within the conditions essential to service delivery. For Dementia Advisers, this included the Dementia Adviser as a named point of contact, and their knowledge and skills. Within Peer Support Networks, the commitment, knowledge and skills of facilitators were also referred to. Volunteers and others who support the service were also referred to as essential to the success of delivering Peer Support Network and Dementia Adviser services. The significance of being part of a team and importance of good supervision was also referred to.

Staff and stakeholders stated that, whilst in the long-term they would hope that groups would become self-sustaining, there was at first a need for a skilled member of staff:

*Gerry, commissioner from PSN site: We always knew that, for peer support to work effectively, you would probably still need a bit of a focus. A focused person, a role, to sometimes do some of the practical things. Sometimes to keep it on track before it diverts into a stamp collecting club or whatever. But, bizarrely, within that, it's trying to take as back a seat as possible so maybe they become self-sustaining. Particularly if you were to start developing a number of different groups. Because we don't have the resources to staff all of those. So I think that was... That was a key end – to make it as self-sustaining, or as where it could be sustained with as little input as possible.*

Feedback from and involvement of people with dementia was also referred to:

*Norman, PSN facilitator: Things that are essential – one is finding out what people want. So first of all is discussing people with dementia and carers – what they want regarding support. Throughout the journey. So that's the key. There's no point providing something that they don't want. So it's discussing things with those people.*

## *Strategy*

Given the complex, multi-agency set-up of the Peer Support Network and Dementia Adviser sites, alongside the number of people involved and the complexities related to liaising with other local organisations, management was key, as was partnership with local services and organisations, and support from commissioners who drive the process and have passion.

Links with statutory organisations, including relationships with GPs, were also referred to as essential.

The importance of a common goal or strategy was also referred to:

*Maria, commissioner from DA site: I think in order to get the thing off the ground, you need strategic direction and partnership and an ability to work together, and after that, it's about what's really strong in delivery. It's being clear about what objectives are and getting the right people to do the right work and having the right local managers in place to unblock problems. So I think there's a sort of strategic success criteria and then there's actually getting on and being successful.*

Funding and finance was also a key resource referred to, as was the pooling of resources to ensure use of the budget in focused ways.

Other key components of Peer Support Network and Dementia Adviser services included: venue, in particular the need to be creative and flexible around where and how people met; and being community-based and accessible.

The strengths associated with new ways of supporting people with dementia and carers were viewed by some as key elements. Within Dementia Adviser services, the nature of services as a single point of access was referred to, as was flexibility within the approach:

*Julie, RMHN who had accessed DA service: Yeah, that they fit in with the patient and carer's needs, rather than Monday to Friday, 9 to 5. And the location is very flexible. Some people don't like to have people in their house. They don't like the neighbours to know that there's a problem. So they do meet people all over the place.*

Within Peer Support Network services, the strength of peer support as a model of support by and for people with dementia and carers was referred to:

*Emma, PSN facilitator: I think that part of the success as well is the concept of peer support itself. I think that makes the difference in terms of the range of services that are being provided and how different and better this one is because it puts people in the centre of the, of their own process of, well, help or support; they are supporting*

*each other. So, I think that is also, that is one of the reasons why it's a success, people feel valued, almost automatically because they are given the opportunity to be heard.*

Strong community links and other local resources were also referred to, often alongside recognition of the importance of raising awareness of dementia alongside promoting Peer Support Network and Dementia Adviser services.

Publicity (including visibility and profile of services) was also significant, as was the importance of continuing to clarify the remit of Peer Support Network and Dementia Adviser services, especially in relation to other local services and sources of support.

For some, developing a culturally specific service (BME communities/harder to reach communities) was an aspect that was regarded as essential to ongoing service development:

*Stephanie, Dementia Adviser: It's essential, I would say – we need to have more activities for the people with dementia from [BME] origin. With the cultural specific... Their own familiar environment. And... So that they can feel integrated, communicate...*

## **Section Two: The evolution, establishment, delivery and governance of Peer Support Network and Dementia Adviser services**

This section of data describes the evolution, establishment, delivery and governance of Peer Support Network and Dementia Adviser services. It includes in-depth interview data on:

- funding and finance
- the process of and experiences within being a demonstration site
- access to Peer Support Network and Dementia Adviser services
- barriers and challenges within the design, delivery and development of Peer Support Network and Dementia Adviser services
- timing and flexibility of support from Peer Support Network and Dementia Adviser services.

The section on funding and finance also includes data from the organisational surveys which were distributed to all 40 demonstration sites.

### **Funding and finance**

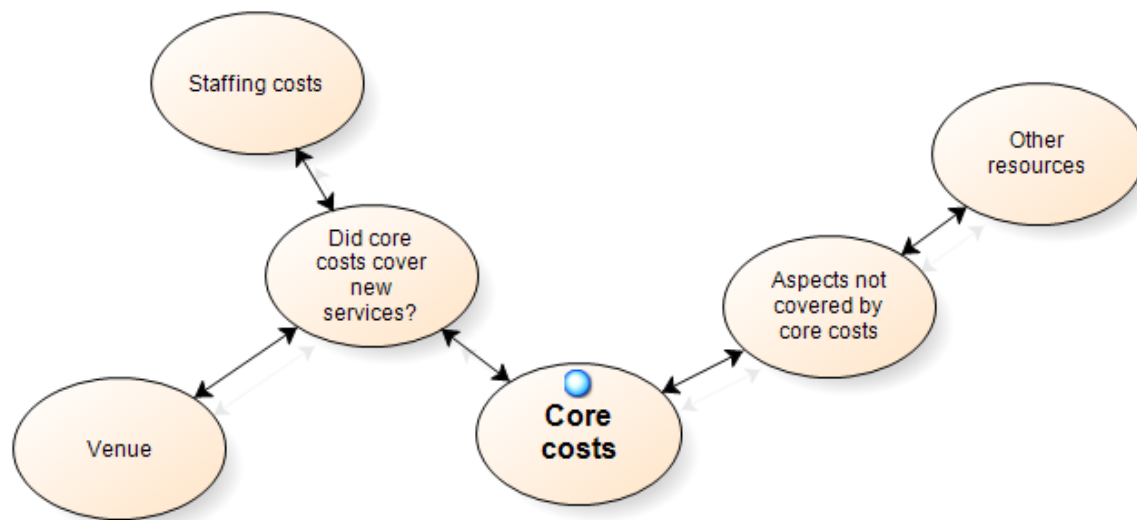
There is no doubt that this is an essential component of all Peer Support Network and Dementia Adviser services, and this was reflected in the in-depth interviews, in particular interviews with staff and stakeholders. Topics covered within this section of the data include:

- Staff and stakeholder responses to questions about their core budget, whether the core budget covered all of the setting up and running costs of the demonstration sites.
- The resources invested in the sites that were outwith the initial Department of Health budget, including:
  - Resources from other organisations.
  - Volunteers as a resource.
  - Resources associated with venues and transport.
  - Service users' resources, including personal cost, e.g. in time and travel costs invested in accessing services. This section of the data also outlines views expressed by people with dementia and their carers as to whether they would be willing to pay for services.
- Evidence from site survey data in response to the idea of 'mushrooming'.
- Uncertainty associated with funding and finance.
- Evidence from site survey data about future and continuation funding for Peer Support Network and Dementia Adviser services.

### **Core costs**

- **Sites reported a range of experiences with regard to the initial budget covering the core costs of service delivery, although there were few reports of the money not being stretchable to cover planned service activity.**
- **There were other resources invested in the pilot services that were not covered by the core budget. This included support from host organisations, use of venues and volunteer time.**

- The majority of the core budget was invested in staff, either Peer Support Network facilitators or Dementia Advisers.



### ***Did core costs cover Peer Support Network and Dementia Adviser services?***

There was a range of responses to the question of whether the costs of the Peer Support Network and Dementia Adviser services were covered by the core budget, although nobody said that the costs were substantially more than the budget provided. There were examples of people using budgets in new and resourceful ways. People were by far the greatest source of expenditure within sites.

Some said that they did not use the entire budget during the initial period and so, in negotiation with the Department of Health, were able to carry forward a proportion of the funding. There was a general feeling amongst the sites that the budget invested had a relatively wide impact. For some, this included the momentum provided by the budget being part of the implementation of the National Dementia Strategy:

*Oliver, commissioner from PSN site: The \_\_\_ money does... Does go a long way. We are quite expert at sharing our \_\_\_ and finding a way that... Very small amounts of money. But it's good to have that opportunity where they're not anxious about what's happening beyond the next 6 months that we've been able to find to pay for a room. You know, for something to happen, so... And, you know, that... That profile. That profile that allows you to open the doors. We had that when we did the \_\_\_ programme, and it continued with this. Because we were able to walk into a room*

*and say, "Oh, actually, this is part of the DH demonstrator site, national pilot." And usually other people listen differently.*

### **Aspects not covered by core costs**

Staff and stakeholders reported that some of the running costs of services, for example venues, refreshments and transport, were not covered by the core budget, and were sometimes gifted to the service by local organisations:

*Elsa, volunteer from PSN site: Not everyone is fortunate enough to have a free venue and free cake.*

Some services had secured extra funding by bidding for small project grants in order to cover specific aspects of the services, for example specific sessions which required someone with specific skills to facilitate, or specific activities that entailed extra costs.

Many referred to the main cost within the budget being the key staff – either Peer Support Network facilitators or Dementia Advisers:

*Maria, commissioner from DA site: And there's an expected capacity within local authorities, within the health service, to be able to manage new developments at the same time. So we've tried to put most of the money into the Dementia Adviser post itself, and that was a deliberate and concerted effort.*

The 'expected capacity' referred to above is an example of organisational contributions to development within sites, referred to by many as a component of the success of the service that used resources outwith the initial budget:

*Chris, Chair of Project Board, PSN site: Our time, you know, that's not, we never got paid for that and we're not going to get any funding for that, but I think the good thing about here is that people kind of think, well this sort of thing is part..... its part of the job to get actively and enthusiastically involved in it without kind of thinking about the implications on, kind of, time and capacity.*

The area of other resources that were invested in the demonstration site activity is explored further below.



### **Site survey data**

Data from the organisational surveys which were circulated to all 40 demonstration sites sheds further light on the use of core budgets. The questioning within round two of the survey was based on a response within an in-depth qualitative interview with a commissioner at one of the Dementia Adviser case study sites: “What started out as just a very small pot of money has mushroomed into all sorts of other benefits and spin offs.”

This section of data relates to responses across all 40 sites when asked whether they agreed or disagreed with the statement above. In particular, the focus is on what enabled (or not) the process of mushrooming.

### ***The evidence of mushrooming***

When asked whether the service had ‘mushroomed’:

- eleven of the sites agreed
- nine sites agreed ‘partially’ with the statement
- five sites disagreed with the statement
- information was missing for the remaining sites.

Examples of how a service had mushroomed included:

- increased referrals
- an increase in the number or variety of activities offered
- the development of additional Peer Support Network or Dementia Adviser activities.
- 

Evidence of the service flourishing is described here:

Peer Support Network site: *We have developed this service and have many support groups. We are receiving more referrals and this continues. There are so many different opportunities developing as a result of the work we are doing.*

Good infrastructure support and partnership could contribute to further successes. For example:

PSN site: *Due to the nature of the partnership, other successful ventures have been*

*established for people with dementia – the funding and joint working have enabled innovation.*

Conversely, unsatisfactory partnerships and collaboration could impede service 'mushrooming':

PSN site: *lack of good will towards partnership working.*

There was also data referring to absent infrastructure leading to services not succeeding:

Dementia Adviser site: *I think the fact that the service could not be delivered as planned until 2 months before it was due to end – the MATS clinics weren't full online until 01/2011 – meant that we couldn't spend the money as intended.*

On occasions the limited access to other statutory services with limited resources was considered inhibiting to the development of the service. There were an additional two factors that influenced a service's ability to mushroom and these were:

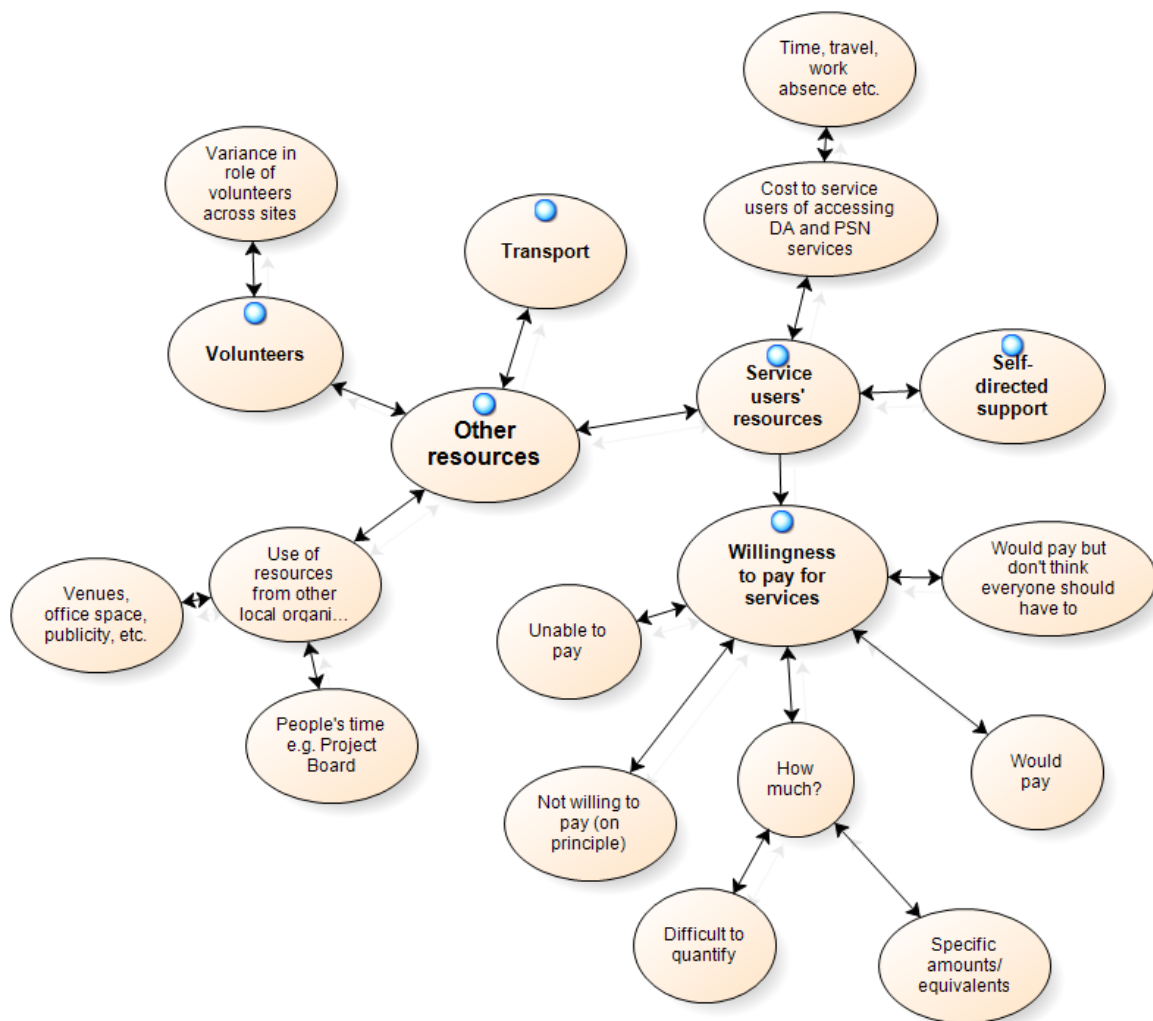
- the ability to gather evidence of success that would encourage funding
- the uncertain economic climate that fostered uncertainty and lack of commitment.

In continuing to explore the area of funding and finance, we now return to the in-depth interview data which is relevant to the area of other resources outwith the core budget that were part of the Peer Support Network and Dementia Adviser services.

### **Other resources**

- **Staff and stakeholders listed a range of other resources outwith the core budget that had enabled the success of Peer Support Network and Dementia Adviser services. These included practical aspects, such as venue and office space, and also aspects of resources that came from within pre-existing organisations and structures.**
- **Volunteer time and resources were referred to across many of the sites.**
- **Service users and carers also reported some costs to them of accessing services. As a measure of the value placed on services, the extent to which they would be willing to pay for services varied amongst service users: some would be willing to pay,**

others would be unable to, whereas others on principle would not be willing to pay for services.



Staff and stakeholders reported the use of resources from within other local organisations. This included use of office space and office resources, venues and existing channels for publicity in addition to people’s time and expertise in developing services, beginning with the initial bids and proposals to be a demonstration site.

**Service users’ resources**

People with dementia and carers were asked whether they would be willing to pay for services. There was a range of responses. This question was phrased in such a way as to assure interviewees that the evaluation team were interested in knowing the value that service users placed on the services they were accessing, and not that there were any plans to charge participants.

Some people said they would be willing to pay, quantifying the amount that they would be willing to pay:

Annie, carer who had accessed DA services: *Erm, probably yes on a sort of hourly basis, erm, now what sort of money, now that's a tricky one. Erm, I would say it's a more valuable service than a care worker for example, but then you wouldn't need it so often.....P: I don't know, I would say; if I am assuming that the person doing that role has been selected for their skills in dealing with people.....That's why I am talking about, what we're describing, then I would say it is probably the same sort of value as a nurse.*

Liz, carer who had accessed PSN group: *I'm sure if we each paid, what? A couple of quid? Alright, so, what? 20... that's £40. Once a... Well, twice a month. But if that happens to other memory cafés – because [Name] doesn't just do our one down there, obviously. They must... I mean, £2 isn't an awful lot, I don't think. And I think... That's a bit reasonable. You know, I mean, when you get those adverts on telly saying, oh, "£2 a month for this. And £2 a month for that." And you think, "Yeah, if you did that you would have nothing at the end of the day." And you wouldn't see... Well if it goes to Africa or what have you, that's different. But if you want it for something of your own benefit, then I don't think that's a big deal to be quite honest.*

Frank, person with dementia who had accessed PSN group: *Oh yeah. I don't know... Well... £2 or £3, because I go swimming once a week and that's £3 so... For an hour or so, yeah. I'd say about £3.*

Other people said that they would not be financially able to pay for services. Other people said that, although they could afford to, they would not pay for services on principle, or did not think that people should be made to pay for services because not everyone would be able to afford it. Others said that the service they had received was so invaluable that it would be impossible to put a price on it:

Judy, carer who had accessed PSN group: *I think it's priceless, really. I don't know what money could cover the pleasure and value that we get out of it. Because we come out feeling "well that was a good couple of hours, wasn't it?"*

Service users were also asked about the cost to them of accessing services. The majority of those people who listed costs said that the benefits far outweighed the cost. Some people said that it did not cost them anything, others listed costs such as time, absence from work, or transport:

Andrea, carer who had accessed PSN site: *The t'ai chi set off, that was £4.50. And they said that your partner could join in as well, so that would have been £9. Well, to some people £9 might not seem a lot – but now they've reduced it. And it's £4.50, and it's 50p if your partner wants to join. 50p if your partner wants to join in. Which makes it more... It makes it, you know, less expensive. I mean, when he goes out with [Support Worker], obviously, I mean, I've got to give him some money if he goes out and has lunch. So you've got... You know, if you don't... If you're doing that every week – luckily the t'ai chi is only once every two weeks. So financially I'm managing, you know, with all these things. If he needs to go anywhere transport-wise I do drive, so I have a car. So I don't really look at it as a... That as an expense, you know.*

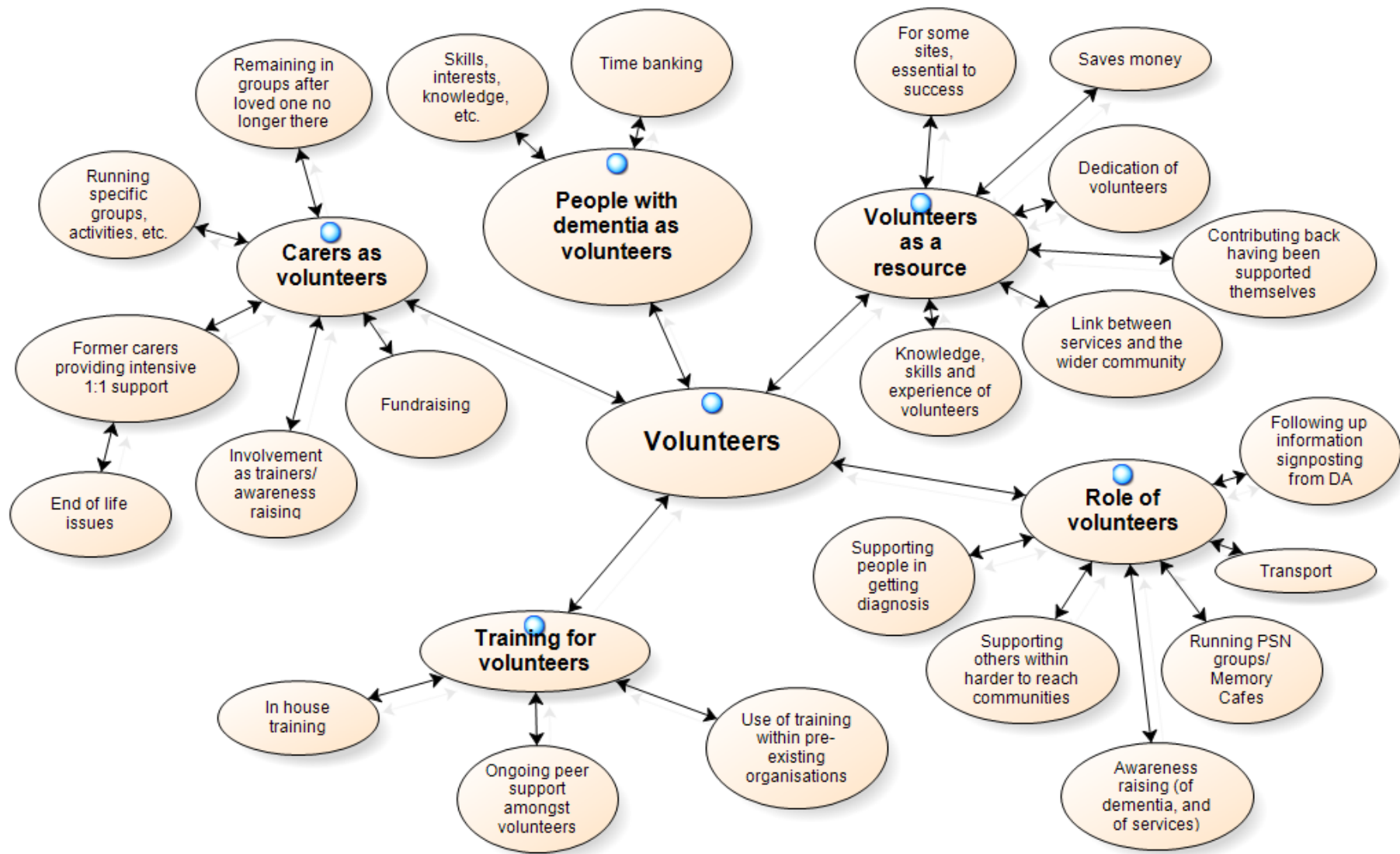
Liz, carer who had accessed PSN group: *Not really, no. The only thing it costs us is the petrol money to get down there, you know, in the car. But, I mean, because we said to [Name] before now about we're quite happy to give a donation.*

Transport was listed by staff and stakeholders as well as people with dementia and carers as an essential cost within running services. This has also been covered in the section on 'Access to Peer Support Network and Dementia Adviser services' on page 154.

Some services relied upon 'lifts in kind', from staff, volunteers and sometimes other service users in order for people to attend groups.

## **Volunteers**

- **Volunteers were viewed as a resource within Peer Support Network and Dementia Adviser services. Within some services their input was essential to the day-to-day running of services and support.**
- **Roles of volunteers included running/facilitating peer support groups, raising awareness, transporting people to group meetings and 1:1 support for carers and people with dementia.**
- **Some volunteers had previously been supported themselves, and viewed their roles as volunteers as a way to contribute back to communities and society.**



Volunteers were a further resource within Peer Support Network and Dementia Adviser services. Some services reported minimal use of volunteers, while other services were reliant on volunteers in order to function at all.

Many referred to volunteers as an invaluable resource:

*Leslie, PSN facilitator: Yes we get support from volunteers, especially towards the end of life care because those volunteers have to go and provide one-to-one support so they have to .....dedicate a lot of time toward that. So I think their support is, it's quite vital and I think it's equally valued as is the financial resource that we have at our disposal through the Department of Health.*

Within some sites, the role of volunteers was considered essential to the running of the site. They were viewed as a resource that saved money. They were also seen as a resource in relation to the contribution they made within services (for some, this was about contributing back having been supported themselves previously):

*Nancy, carer who had accessed PSN: As part of that I've.....I'm contributing back – so I don't know whether you're aware of this but I run a reiki and relaxation group for them as well.*

They were also seen as a link between services and the wider community, especially within specific groups where volunteers were from the same minority group as people that the services were supporting.

There were several roles for volunteers outlined by those interviewed, including following up on information and signposting provided by Dementia Advisers, transport, running support groups or memory cafés and supporting people through the process of getting a diagnosis. Training for volunteers was also mentioned. Some sites made use of pre-existing training within their wider organisation, others provided in-house training. Within the intensive support undertaken in end-of-life issues, carer-volunteers were provided with 3 days of training, with ongoing peer support amongst volunteers being encouraged.



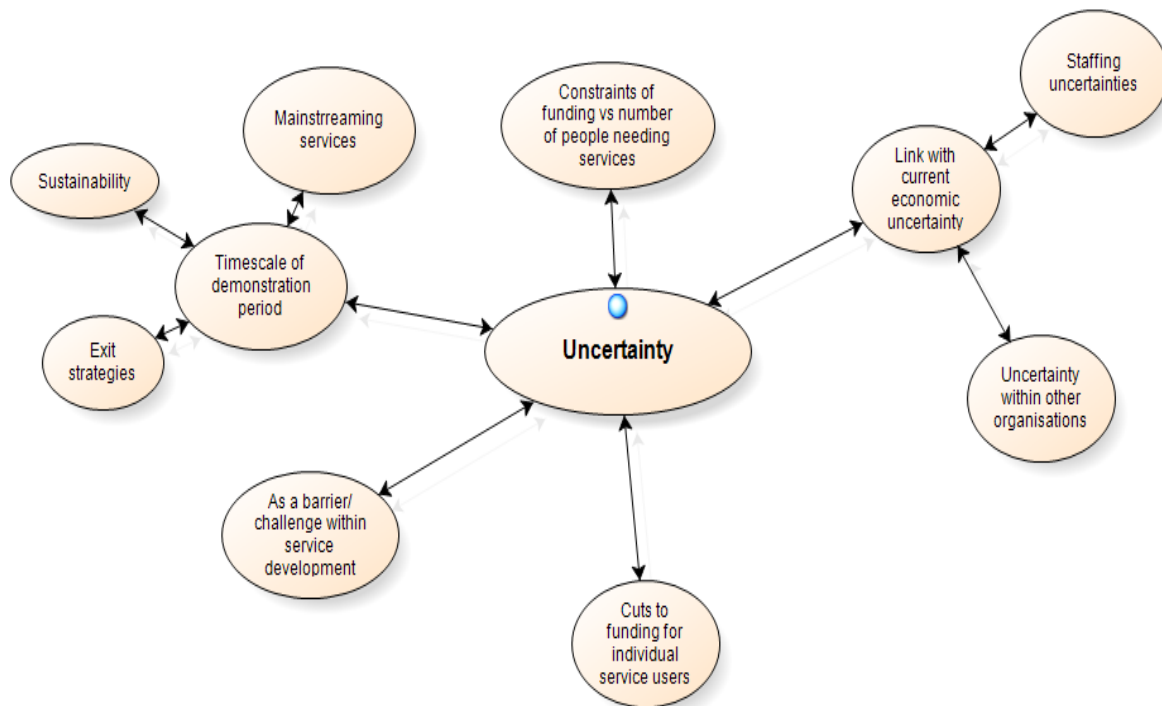
There were instances where carers, or people who had previously cared for someone with dementia, were volunteers. In addition to the intensive one-to-one support provided in end-of-life issues within one site, carers were also involved in running specific groups, fundraising and training, and awareness raising. There were instances where carers who had been part of support groups had continued attending those groups once their loved one was no longer there, providing continued support within the social network:

Laurie, person with dementia who had accessed PSN group: *And one of the ladies – the carers – her husband is now in [care home] ..... But she's still coming as a helper.*

There were fewer examples of people with dementia themselves as volunteers, although the importance of valuing contributions based on previous occupation and/or interests of people with dementia was acknowledged.

### **Funding and uncertainty**

- **Uncertainty around funding was a common experience within the sites. Staff and stakeholders often linked this with current economic uncertainty and service or budget cuts.**
- **Uncertainty was also linked with the time-limited period of the demonstration site initiative, with staff and stakeholders referring to challenges around sustainability and mainstreaming of services after the end of the initial pilot.**
- **Staff and stakeholders referred to ways in which the above led to uncertainty and lack of continuity amongst staff, including those who had direct contact with service users.**



The current economic uncertainty, as well as the change of administration within the UK during the pilot period, was referred to by staff and stakeholders as a barrier and/or challenge in the development of services. Uncertainty within other local pre-existing organisations (health, social care and voluntary sector) also affected Peer Support Network and Dementia Adviser services:

Gill, carer from PSN site: *People are stretched already. Everything's doubling. Services are being cut, waiting lists are getting longer, and people with dementia haven't got the time to wait on waiting lists, have they, really?*

The inevitable turnover of staff within sites also impacted upon people with dementia and their carers:

Seamus, carer who had accessed PSN carer support group: *And I felt quite outraged, really, because this was... Was going to spoil the... Well, I use the word momentum – you know, it was certainly going to stop that. It's a sort of stop and start again with somebody else. Then you've always got, in the back of your mind, no matter... I mean, logically you would say, well, somebody else could do it just as well, but then you have to adjust. And most... I would point out, although it's pretty obvious, that the vast majority of carers that I've come across so far with Alzheimer's disease is*

*that they themselves are all elderly people. Probably retired people themselves. Who... As you get older, you find it harder... Not impossible, but harder to make changes – to adapt to changes.*

People also spoke about the impact of cuts to funding for individual service users:

*Jean, Dementia Adviser: I think a lot of it is going to.....possibly be a struggle for people to access, just financially.*

The timescale of the demonstration period was also linked with financial uncertainty. The uncertainty around funding led people to consider the long-term sustainability of the Peer Support Network and Dementia Adviser services:

*Chris, Lead of Project Board, PSN site: The money isn't going to last forever, so....I would presume we're not always going to be in that luxurious position of having that member of staff who can organise all this kind of stuff so people need to be supported to take responsibility for it in a gentle way, but in a real way around kind of seeing the point of this and wanting to carry it on.....one of our goals is to put that across to people and to enable them to carry on with things.*

Staff referred to the need to establish exit strategies on a regular basis, and as far as possible to ensure sustainability from the inception of services:

*Bev, PSN facilitator: When we first set out, it was looking at things that were self-sustainable. Because the project was coming to an end on 31 March 2011. So we were looking at, you know, life beyond the project. Making everything as, you know, cost effective as we possibly could.*

People with dementia and carers also referred to uncertainty around the long-term sustainability of services:

*Nancy, carer from PSN site: It more than met our expectations. And it would be devastating if it could not – for any reason – continue. Because that's always a worry – that when you start something how long is it able to continue.*

Mainstreaming services was achieved by some of the sites:

Val, commissioner from DA services: *At the moment, the funding ends – as you know – when the pilot ends. So at the moment we are jointly working with the Dementia Commissioner from [site] Council and [site] NHS, which are... What was the PCT – the commissioners. We're working up a joint business case to actually get the Dementia Adviser service mainstreamed into what we call our block health contract. Embedded within the memory assessment service.*

### **Future funding: Evidence from site survey data**

The following are themes that emerged around future funding from the site surveys which were distributed to all 40 demonstration sites:

- Funding issues in very difficult economic times had a profound effect on services developing and flourishing.
- Services found access to staff or their budgets removed, reduced or not renewed for the future.
- The unstable economic climate was often referred to and considerable uncertainty and a lack of commitment resulted.
- In one example, changing government policies were regarded detrimental for growth. Lack of financial commitment could have a 'knock-on' effect on attitude and service commitment. This was clearly demonstrated by the 'mixed messages' received by one site:

*PSN site, site survey round 2: We are being asked to develop more groups and plan exit strategies in case funding ceases and we are only 6 months into contract – annual contract restricts development.*

Funding appeared to be a crucial but not exclusive factor in the success of the services. Other sites did refer to Peer Support Networks that managed to be self-sustaining, or where innovative action facilitated service development even within budget constraints (Dementia Adviser site). Infrastructure appeared vital but sustaining services was also affected by providing timely evidence for potential funders. The intertwining of the different factors influencing the development and sustainability of Peer Support Network and Dementia

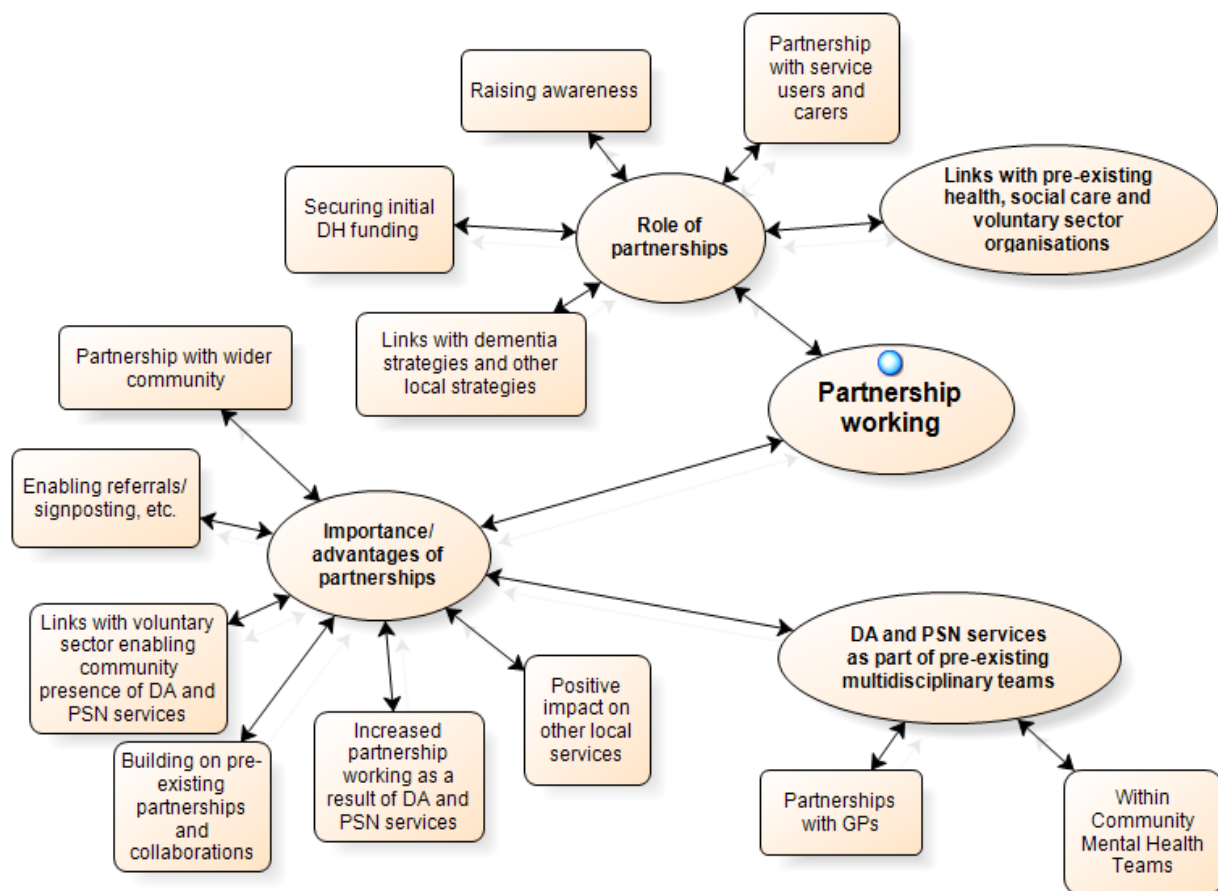
Adviser services was clearly evidenced in the data collected from all 40 demonstration sites in the site surveys.

### **Being a demonstration site**

This section of data relates to the views and experiences expressed by staff, volunteers and stakeholders around the design, delivery and development of Peer Support Network and Dementia Adviser services in relation to the National Dementia Strategy demonstration site initiative:

- The role and importance of partnership working was a key theme within this aspect of the data.
- The important role of Steering Groups/Project Boards within the process of setting up, maintaining and developing site activity.
- Insight into the impact of timescales involved in the work.

### **Partnership working**



Some people referred to the process of being part of the National Dementia Strategy Implementation Plan as an enriched experience from the point of view of service providers:

Emma, PSN facilitator: *I think this being part of the National Dementia Strategy gave it a very big, well, made it strong I think or.....Because I think we all feel that there are services and there is support that, that carers and people with dementia benefit, would benefit from and that are still not in place. So if this is part of that, if this is part of starting to put in place the right services for something that we know that it needs, then I think, naturally makes it strong from the beginning.*

The role of partnerships within the demonstration site activity included creating and/or maintaining links with pre-existing health, social care and voluntary sector organisations, thus optimising impact:

Margaret, local voluntary sector worker who had accessed DA site: *Yeah. And I think having that single focal point, as a Dementia Adviser, you know, being that focal point, um, and you know, maybe the world can be expanded. Um, I don't know in what way, but there's always opportunities hopefully, um, but maybe one's not enough. Erm, maybe it needs two and the joint working between health and social care.*

Katrina, PSN staff: *Before we'd even started the role we were having meetings with professionals and memory services, saying "look, this is what we're going to be doing.... How can we work together?" and we've tried to do things in partnership, rather than set things up that can't, that are just solely dependent on [Peer Support Coordinator] so that things can be embedded.*

Partnerships also had a role in securing initial Department of Health funding, and in raising awareness:

Carmen, DA site commissioner: *The important linking with the dementia awareness raising programme. I think look for more and more opportunities for...health and social care to work together to promote, you know, the awareness raising of dementia.....from our point of view it's been absolutely key to work together on that project.*

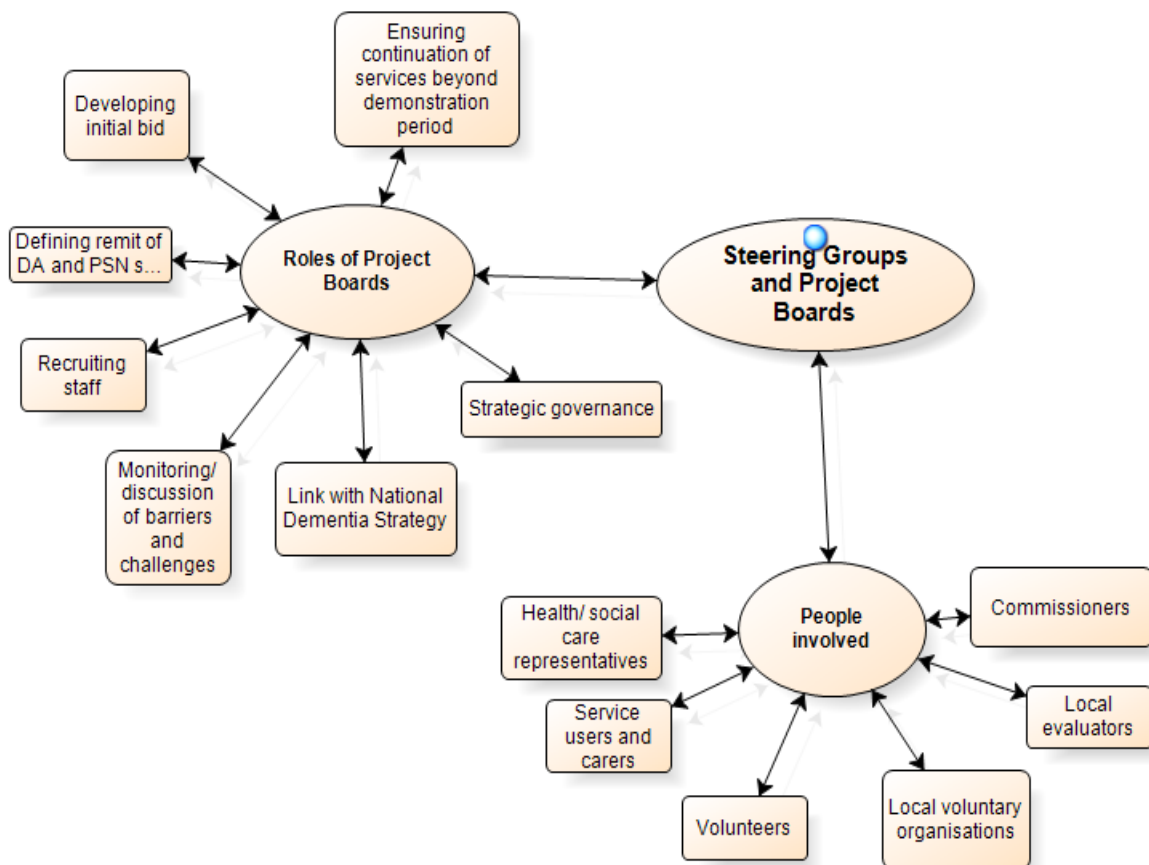
Partnership with service users and carers was also significant to some staff and stakeholders:

Irene, local evaluator from DA site who had been on Steering Group: *I think we just have quite an open forum, really, you know, we've got people from, um, the [local Alzheimer's Society] and we have a carer representative. I think that was another really good thing, was that we had a carer on the interview panel that employed [Dementia Adviser].*

The significance of partnership working was also emphasised in people's views on how Peer Support Network and Dementia Adviser services could be improved for the future:

*I think also, they need to find ways of working with partners to help to reach more into communities that they're not actually reaching into at the moment.*

### **Steering Groups and Project Boards**



Steering Groups (also referred to as Project Boards) were key to formalising and maintaining partnership working, and people referred to their effectiveness across many aspects of the processes involved in 'being a demonstration site'.

The role of Steering Groups included monitoring and discussing barriers and challenges as well as strategic governance. This included work specific to involvement in the Department of Health/National Dementia Strategy pilot, including developing initial bids to become a demonstration site, as well as ensuring the transition of Peer Support Network and Dementia Adviser services beyond the demonstration period:

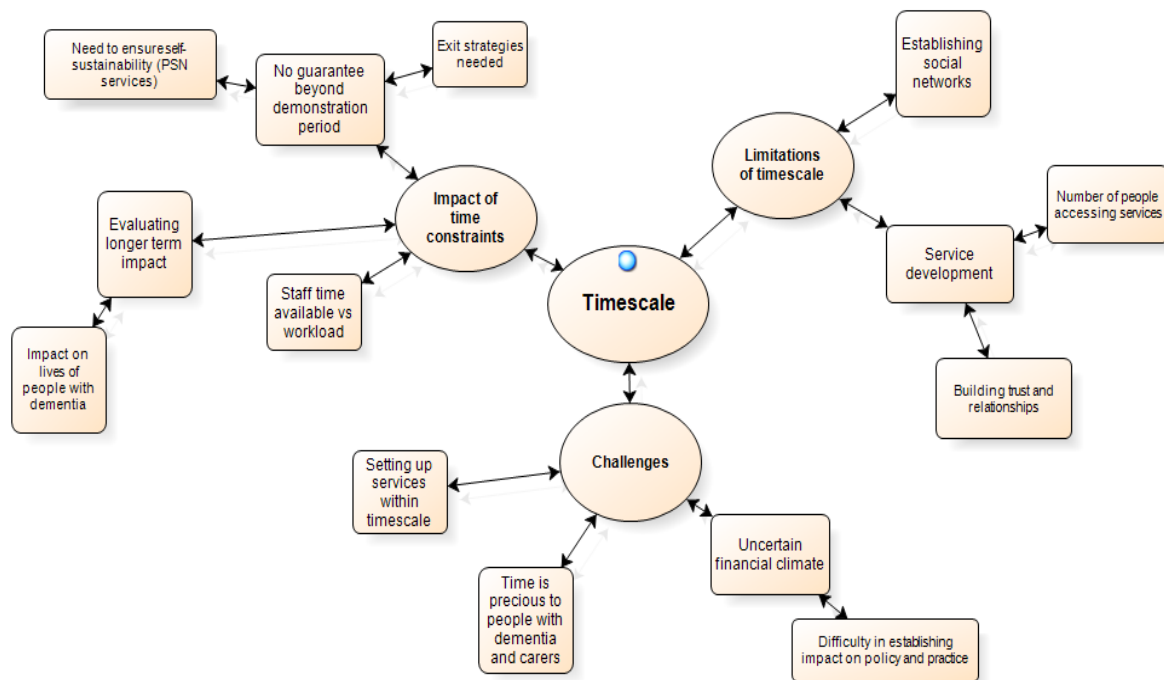
*Chris, commissioner from PSN site: We spent quite a lot of time. It was [site] PCT, [site] PCT [local group] and the Alzheimer's Society that developed it and so we met quite a few times....over a two or three week period we dedicated quite a lot of time to that.....So that was good, actually, that, it was from then we had a strong sense of partnership I think of kind of working together around this. Which wasn't difficult because I think we do, maybe one of the things that's been successful, that's kind of underpinned the success, is there is quite a strong sense of partnership across the agencies already. It wasn't a new thing.*

Other roles fulfilled by Project Boards included recruiting staff. Project Boards also sought to define the remit of Peer Support Network and Dementia Adviser services:

*Katrina, staff from PSN site: Absolutely. You need to know where it sits in the infrastructure and what you want it to achieve. You need to work in partnership – that has been the key thing.*



## Timescale



Limitations in the timescales involved in being part of the Department of Health pilot were identified by participants. Specifically, people spoke about the tensions between the time-limited nature of the pilot and the time necessary to build relationships and develop a new service:

Seamus, carer who had accessed PSN support group: *I was hesitant at first, but I said yes, okay – we’ll give it a go. Now, to get something like that going from a standing start, it takes some time, because you go. You don’t know any of the other people, they don’t know you. And in its, sort of, human experience, you approach things cautiously and deferentially. And so it’s taken time, but as... And a few more people have come along and so on. But it’s now just got to a point where I think most of the carers, like me, look forward to this once a month.*

In relation to the establishment and development of demonstration sites, timescale was referred to in relation to the number of people accessing services and building trust and relationships:

Norman, PSN facilitator site staff: *One of the things with this project is that, yeah, it’s a 12 to 18 months project. Quite a lot of that is building trust initially, over a few months, before they actually attend groups. And that’s the biggest thing that I’ve*

*learnt from this. So it's building up the trust, it's building up relationships with people with dementia and their carers.*

Further challenges spoken about by staff and stakeholders included setting up services within timescale. The uncertain financial climate was also referred to, specifically difficulties in establishing impact on policy and practice as a result of cuts to services:

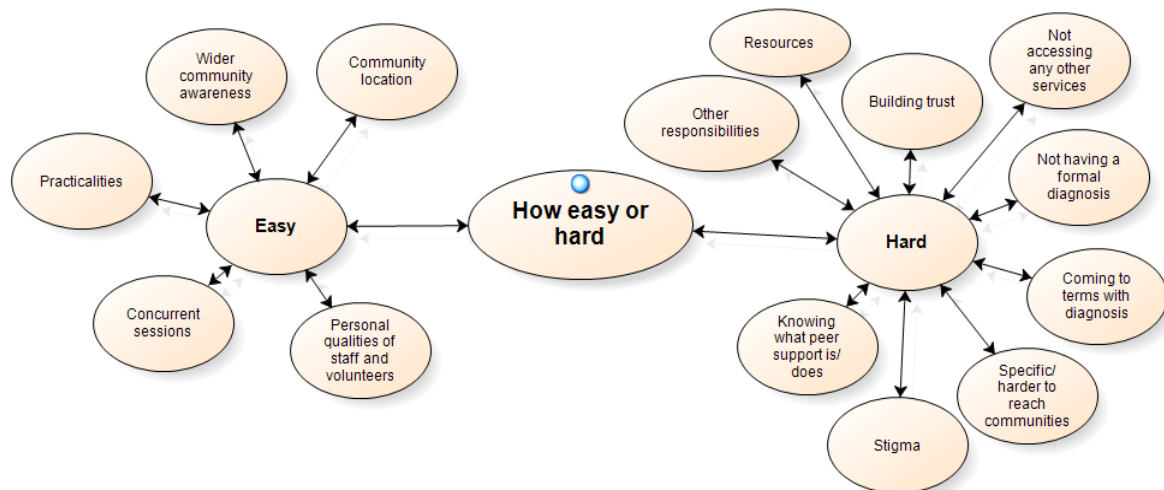
*Moazzam, PSN services manager: This is not a very good time for new projects to have an impact on policies, because people, at the moment, the departments are thinking of cutting services, cutting money....So yes, there seems to be potential, they welcome the service, but at the moment would they resource it or be able to fund or commission those services? If that is a way of setting whether it has an impact on their policy I think it is not a good time to judge that.*

The impact of time constraints included tensions between staff time available and the workload.

The fact that there was no guarantee of service continuation beyond the demonstration period also meant that exit strategies were needed and there was a need to ensure self-sustainability beyond the demonstration period.

#### **Access to Peer Support Network and Dementia Adviser services**

- **The community presence of Peer Support Network and Dementia Adviser services was a significant factor in people accessing them (or not).**
- **Relationships with other local services – organisations and individual professionals – was also significant in relation to access to Peer Support Network and Dementia Adviser services.**
- **There was also a key role for social networks in people accessing Peer Support Network and Dementia Adviser services.**



Factors that made accessing services easier included the positive effects of Peer Support Network and Dementia Adviser services being ‘in the community’ and ways in which this makes access easier for people with dementia and their carers:

Val, DA commissioner: *They are very, very approachable. To the point where people approach them on the street if they’ve seen their literature and what have you.*

Eve, carer from PSN site: *And um, so I was trying to look around for somewhere to go where you didn’t have to be referred to by a social services...*

The community presence of the Dementia Adviser (not being physically constrained by an office or organisationally as constrained as in statutory services) was also referred to.

Within Peer Support Network services, sessions for people with dementia and carers running concurrently made accessing services easier:

Eve, carer from PSN site: *And doing it while we’re at the café, it’s really because you know, you know, that the other half is fine downstairs, yeah..... Because if it was... If it was another day, then I wouldn’t be able to go all the time because I would have to have someone in here to, you know, stay with mum, sort of thing, you know. And, I mean, that’s fine on a casual basis, but, I mean, I know I’ve got my sister, but... And she would do it, but asking them to do it, sort of, every 3 weeks or every month, you know, is a... Is a bit different, you know. Because mum... Well, she just totally forgets.*

*She would totally forget where I've gone, you know. So, I mean, I couldn't leave her here on her own, no.*

A further factor that influenced people's access to services included wider community awareness – both awareness of dementia and awareness of the Peer Support Network and Dementia Adviser services. The area of awareness and Dementia Adviser and Peer Support Network services is explored further in the section on awareness, see page 243.

Factors that made it harder to access Peer Support Network or Dementia Adviser services included not having a formal diagnosis, or perhaps people's stage in the process of coming to terms with a diagnosis of dementia:

*Ginny, carer from couple who had accessed PSN group: But on the last occasion that I did make it to it, he [person with dementia] was extremely resentful of my going up to the care group meeting. And before that he was even more resentful that I would go off and leave him there, you know. He didn't like that at all, you know. And he would... You know, really berate the place when he would come... You know, when it would come to the next... "No, I'm not going." You know. You know, "I don't need that sort of place. I'm not like them." So that has been hard. I'm at a great loss as to know what other sort of help I can get. Because at the moment he wants to do everything with me.*

A further factor which made accessing services harder for people in the early stages of dementia was being faced with the reality of people in later stage experiences:

*Anna, sister of person with dementia from PSN site: The problem is with [person with dementia], she's very sensitive to what she's got. To having Alzheimer's. And sometimes... She won't go to places because. I don't know how to... I think I mean institutionalised. I think she feels as if she's being pushed into going places where everybody's got Alzheimer's and she doesn't... I don't... She'll go to the art group and feel comfortable, and yet to take her somewhere like that, she's not...*

The fact that accessing Peer Support Network and Dementia Adviser services was harder for people who were not already accessing any services at all was also identified within interviews.

The location of the services (in relation to the physical location of meetings) also influenced how easy or hard it was to access services:

*Gabby, Services Manager from PSN site: And something that we planned as well, we already knew that we could have learned more from this project, is that there are people that could live, for us it would be a ten, fifteen minute bus ride, but they don't want to cross to another ward or another part of the borough or over to a different borough, even though it could be a fantastic service for them.*

A further aspect relating to how hard it was to access Peer Support Network services was that of needing to build up trust in order for people to attend groups, and people's knowledge and/or assumptions around the scope and purpose of peer support itself:

*Eve, carer who had accessed PSN site: But it's actually getting people through the door. Because there's a lot of people who wouldn't want to attend something like that. Maybe they don't understand what a peer support group is. Maybe they don't really want to talk about how things are for themselves. Because there are lots of people out there who have struggled for years and years in a caring situation. And it's not until after the person has died or whatever that they suddenly come out of their shell and say, "Well, I didn't realise I could have this" or "I didn't realise, you know, when I was doing it before".*

Other responsibilities/lifestyle also affected people's access to services, in particular for carers who worked or who were unable to leave the person they were caring for in order to attend meetings.

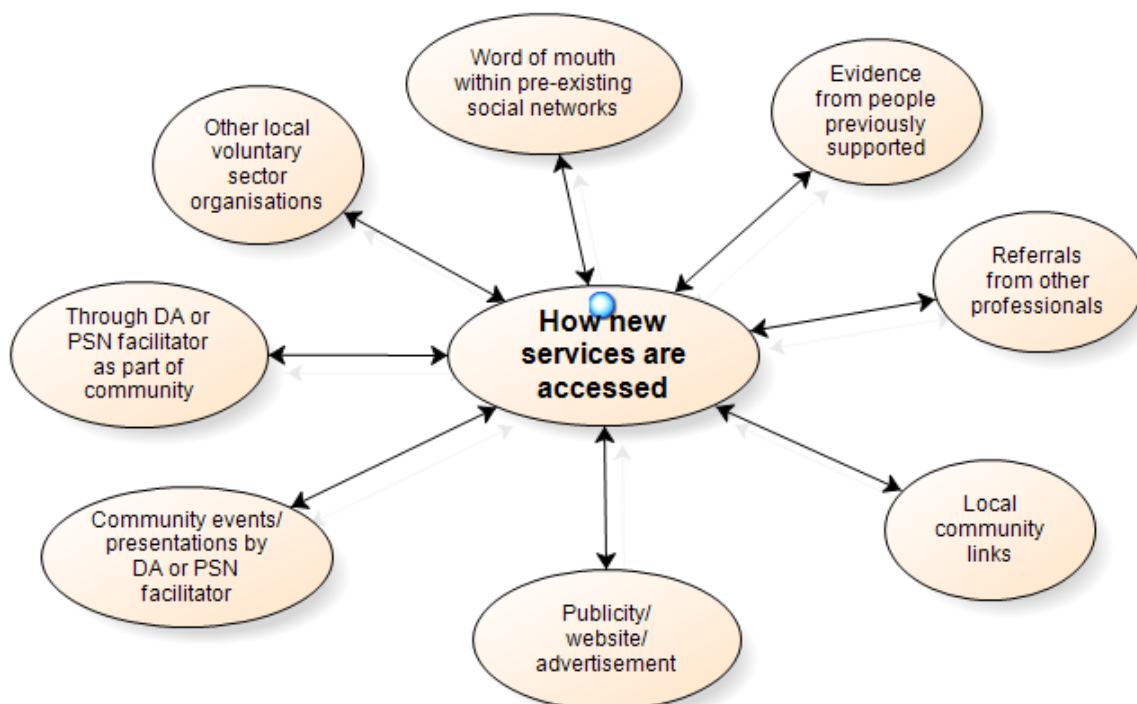
There was also reference to the stigma associated with accessing services that were specifically for people with dementia.

There were some factors affecting how easy or hard it was to access services that were specific to 'harder to reach' communities, such as BME communities.

Availability of resources was also a factor in accessing services.

There is some data relating to the practicalities of accessing support from Peer Support Network and Dementia Adviser services. At one of the sites, there were some difficulties (referred to by more than one service user) around getting hold of the Dementia Adviser, as one carer explained:

*Nina, carer from DA site: "Any problems, just phone me and..." Mind you, trying to get through to her. That was... That was a nightmare sometimes because if she wasn't there, the girls – they pick up. And you leave messages. But whether she never got the message or... She didn't get back to me and I'm thinking I know... I know it's a busy role, but I really think an answer phone would have been a bit beneficial, and then she would have got back to people, you know, when it suited her, really. But... Because she was always in and out and doing... You know, going to various bits and bobs.*



There was a role for social networks in accessing Peer Support Network and Dementia Adviser services, for example the way in which people hear about services from people they know being a much more powerful way of advertising groups:

*Norman, PSN facilitator: And the main thing is that you've got [to] build trust within relationships before people attend groups. I can advertise a group and put posters up and nobody will come. People will only come if, for example, they know I'm going – or somebody else that they're familiar... Got a familiar face, are going as well. And it's a trust thing. So people will not just attend groups if you just set groups up on their own. And that takes time.*

The power of 'word of mouth' information about services, especially when recommendations came from people who had previously benefitted from services, was highlighted by some:

*Judy, carer who had accessed PSN group: But... Our next door neighbours come. They've not been diagnosed with anything, but one day I said we were going over there and he said, "Oh, my wife seems to be a bit forgetful. Can you get me details?" Well I brought home a couple [of leaflets] saying when it was held and what it was, sort of thing. "Oh," he said. "We'd love to try that." And they've been going... In fact, they're our taxi there now, you know. And they enjoy it very, very much as well.*

The reference in the following quote to someone 'in the coffee shop' as a referrer sums up the role of community links in accessing services:

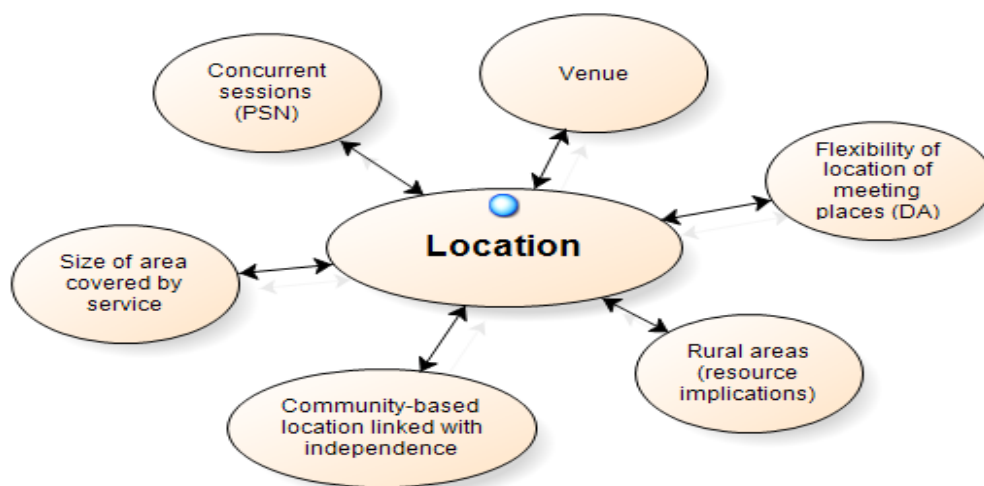
*Sheila, staff from DA site: I think it has had an impact. It certainly has. We have referrals from all sources. So statutory services, health and local authority, other care agencies, hairdressers, chiropodist, [name] in the coffee shop...*

There were also examples of people accessing Peer Support Network and Dementia Adviser services through local support groups (not directly related to demonstration site activity); community events/presentations on dementia by Dementia Advisers or Peer Support Network facilitators; publicity and website advertisement. People also spoke about Peer Support Network facilitators and Dementia Advisers having a high profile in communities. This was another factor in how people accessed Peer Support Network and Dementia

Adviser services. People were also referred into Peer Support Network and Dementia Adviser services by other professionals or through other local services.

People referred to specific challenges relating to how people from specific or 'harder to reach' communities accessed services.

## Location



The geographical location of Peer Support Network and Dementia Adviser services was varied, with a wide range of locations across England. As well as being spread across the country, the sites were located in a range of settings: rural, small towns, large cities. The area covered by each of the sites also varied greatly, with some sites serving a small and compact borough and others a vast rural county. Location (including size of area covered by Peer Support Network and Dementia Adviser services and resource implications linked with rural areas) was referred to in relation to access to Peer Support Network and Dementia Adviser services. Flexibility of location of meeting places was also referred to.

Services being based in the community also contributed to people maintaining independence and remaining in the community for longer:

*Sheila, staff from DA site: I think mostly because [Dementia Adviser] doesn't see herself as being constrained by an office. So a lot of the stuff that she does, she meets people in their community. So while she's with somebody, someone will walk past and say hello to the person – that's an immediate contact. And if someone stops, she*



*can tell them who she is and what she does. So it... It is that because it's community-based and because she sees people in their homes. She talks to them about it's not just about dementia. This is about life.*

The venue for services was also significant in relation to people accessing them. The sessions for carers running concurrently with sessions for people with dementia included the venue for meetings.

### **Publicity**

A further factor in access to Peer Support Network and Dementia Adviser services was publicity. The role of interpersonal interaction within this was perceived to be more powerful than things like advertisements and leaflets. There were instances of specific/open events in raising awareness/publicity of services. The profile of Peer Support Network and Dementia Adviser services in the community was also significant in people finding out about and accessing them.

There was also a role for pre-existing social networks in publicity about Peer Support Network and Dementia Adviser services. People also spoke about publicising Peer Support Network and Dementia Adviser services with GPs, again referring to the power of evidence from people who had previously benefited from services.

There were also references to the significance of involving people with dementia and carers in training and publicity.

Publicity was also related to the importance of reaching people with dementia and carers who were not accessing any other services or who did not have a formal diagnosis of dementia.

### **Referrals**

The systems and dynamics involved in referrals to and from Peer Support Network and Dementia Adviser services is directly linked to their relationship to pre-existing services, a complex area that is addressed in more detail on page 175.

The means by which people with dementia and carers had been referred to Peer Support Network and Dementia Adviser services included GPs or other health professionals, memory clinics, hairdressers, chiropodists, self-referral, social services and local voluntary sector organisations.

There was a range across the services, and sometimes within the same service, of different levels of formality in the referral process.

### ***Transport***

The role of transport in people accessing services also emerged from the data. This was a particularly emotive subject for people with dementia who had been drivers themselves but no longer held a licence due to their diagnosis. Funding for transport was also referred to, with potentially serious implications for the continuity of site activity.

Transport to and from meetings was also linked with safety. Sometimes transport was provided through the service that was being accessed but in most of these cases this was a role for volunteers:

Tony, staff from PSN site: *We provided the transport and the staff. Mostly volunteers.*

There were references to the role of social networks in transport to and from meetings:

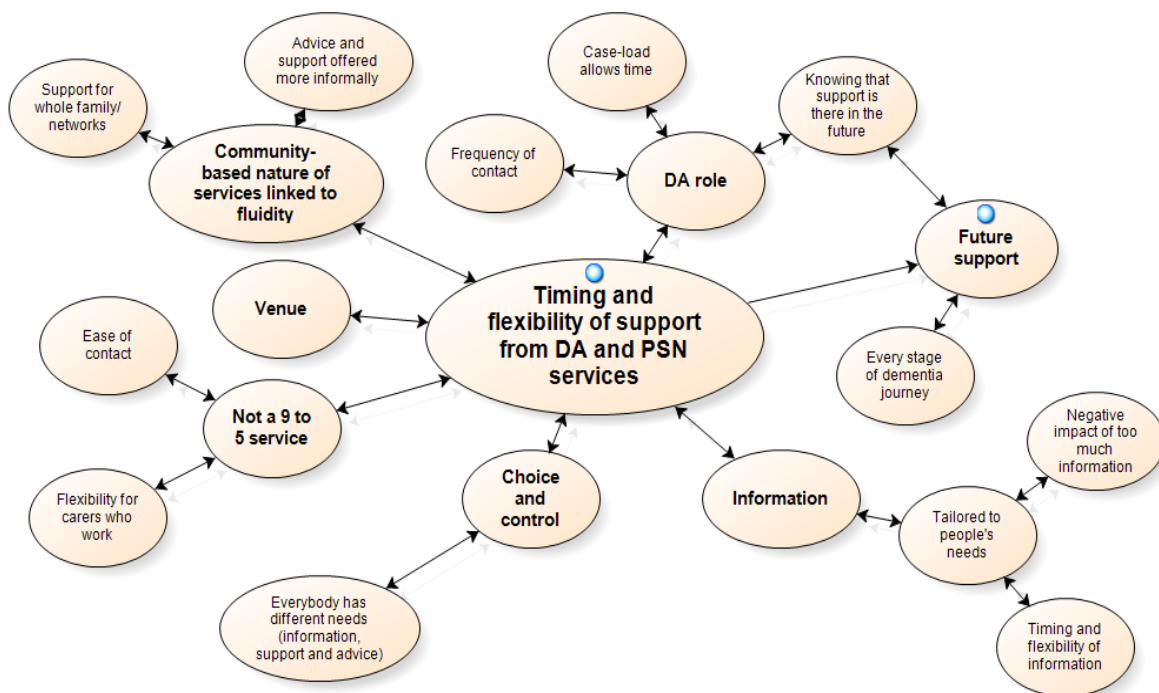
Judy, carer from PSN site: *So we just booked it – a taxi – and it came and picked us up. And the next fortnight we booked one again, and he came and picked us up. And [neighbour] from [location] said, “You had a taxi twice?” And I said, “Yeah.” “Oh, no need to do that,” she said. “I’ll pick you up and bring you back. Take you back, you know.*

### **Timing and flexibility of support from Peer Support Network and Dementia Adviser services and future support**

- **Flexibility within Peer Support Network and Dementia Adviser services was viewed by many as a strength, in particular in relation to information being tailored to**

people's needs, both in timing and content, with a recognition that different people need/want different information at different points along their dementia journey.

- Flexibility as to where and when support was received from Peer Support Network and Dementia Adviser services was also seen as a strength, with a link being made between the community-based nature of services and their fluidity.
- Knowing that support from Peer Support Network and Dementia Adviser services would be available in the future was a common thread throughout interviews with people with dementia and carers, as well as peace of mind that support could be accessed flexibly in the future.



This section relates to ways in which timing and flexibility of support from Peer Support Network and Dementia Adviser services contributed to their effectiveness. This includes ways in which these services are flexible in relation to their situation within organisational structures, as well as where and when services were delivered. The community-based nature of services was also linked to flexibility, resulting in support for family units and wider networks and advice, information and support being offered more informally than within statutory services. Information was also tailored to people's needs and delivered at the time that was appropriate for each individual. This flexibility in timing and content of support acknowledges people's differing needs, and the negative impact that can result from advice and information being delivered at the wrong time for an individual:

Jennifer, local professional who had accessed DA services: *I think the [Dementia Adviser] provides a valuable point when people are diagnosed in particular, um, in that, obviously, when you go to a hospital, you see someone... yes, you're supposed to be given lots of information, but it may not be the right time for you to have a lot of information, whereas [Dementia Adviser] can go into someone's home; can actually meet with them and their carers, or their families at a time when people are ready to find out a bit more. Perhaps have recovered from the initial shock of the diagnosis and then think "Okay, well, what is the future going to be like?" And that's, I think a very valuable time for them to come in.*

Timing and flexibility in provision of information within Peer Support Network and Dementia Adviser services acknowledged that different information is needed by different people at different stages in their dementia journey:

Anita, Services Manager, DA site: *Because people in other areas where they've had information, and they've received diagnosis, it's been too much information and it's actually quite scary and quite frightening for people.....I think that creates stigma around dementia. As soon as, you know, you hear that you've got dementia, you think that's it. Curtains.....But actually it's about saying to live well, to live as you are but to live well. And to encourage those people around you to....help you live well.*

Flexibility was also reflected in ways in which Peer Support Network and Dementia Adviser services were able to respond to fluctuating needs:

Eleanor, volunteer from PSN site: *The couple of times that I've been asked to go in and do a little bit of extra one-to-one it's because they are picking up that actually someone is experiencing huge burden. Carer burden.*

Timing and flexibility in provision of support from Dementia Adviser services was also referred to by other local professionals, in this case in contrast to constraints within their own services:

Julie, mental health nurse who had referred people to DA service: *It's the fact they're so flexible. They meet people wherever is suitable for them, and they can do things in places that people feel comfortable doing it in. In a hospital environment, it's...*

*People are a bit on edge, really, aren't they? As well. And they can meet people in cafés or whatever really – just find what's suitable for them. Whereas I have to have a lot of my conversations on people – on their mobile phones at work. So I have to phone the family, and I work 8 until 4, really, so... I often have these... Quite difficult conversations with people when they're on their mobile phone at work. And that sort of thing. Because if they work all day and can't get in, and... But, yeah, the Dementia Advisers are a lot more flexible with what they do.*

The fact that people would know where to go for support as and when was needed in the future was also referred to:

*Debbie, carer who had accessed DA site: Yeah, my mum is still in early stages, so I'm hoping that as, later on, as things progress worse, that [Dementia Adviser] will be a lot... The service will be a lot more of use to us than it is now. Because, as I say, mum is still quite independent, and still able to go out on her own and things. So she doesn't need an awful lot of help at the moment, so... But just hoping that we know the contact's there, as and when we need it.*

Brian, a carer who had accessed Dementia Adviser services, spoke of this future peace of mind as one of the central benefits of having received support from a Dementia Adviser:

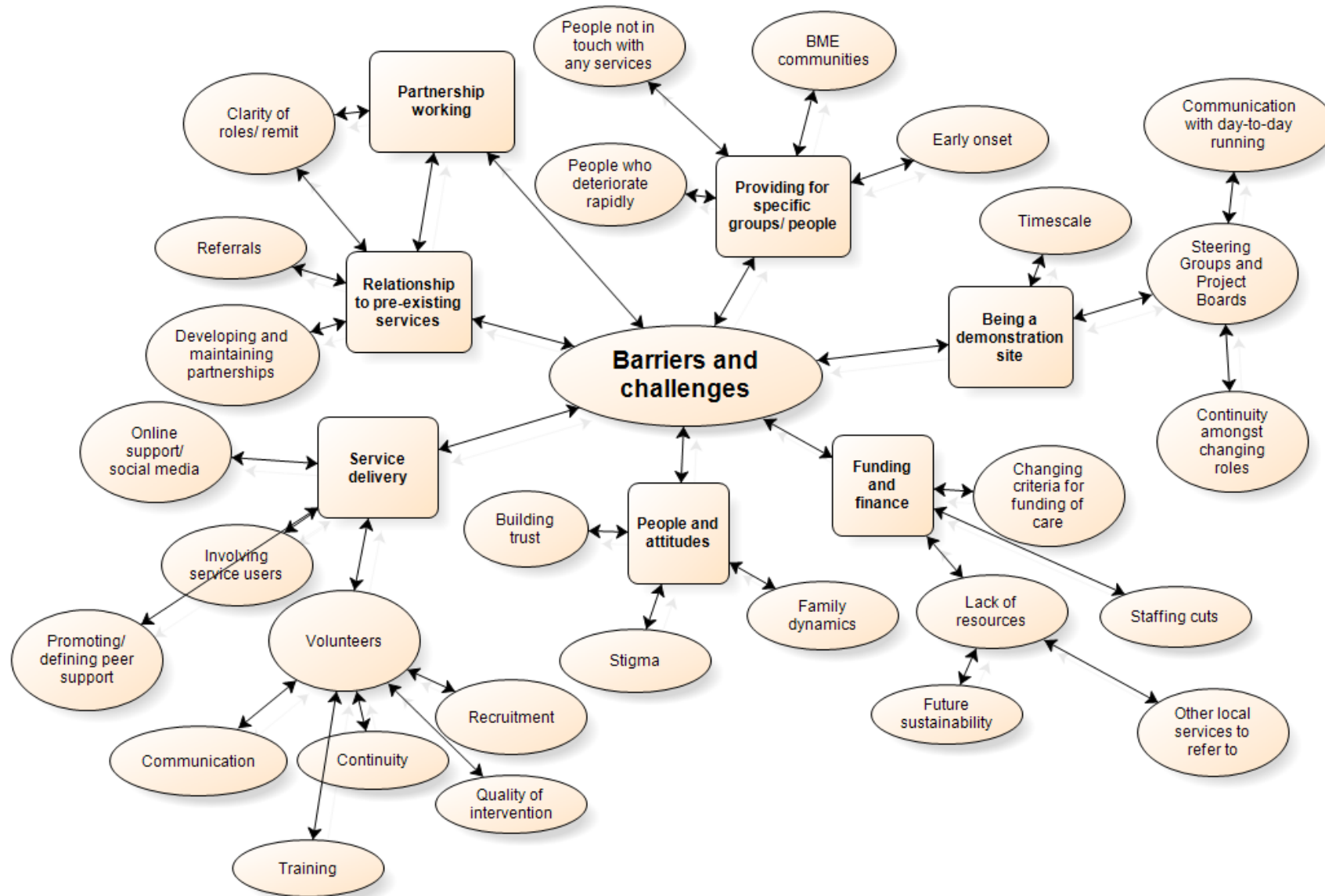
*Interviewer: Perhaps we could think of three things that having help from [Dementia Adviser] has meant – so the difference that it has made to yourselves.*

*Brian, carer of person with dementia: Well for me it has given me a bit more self-confidence to do this sort of thing, that's one of them. Peace of mind, because, I know that there is somebody at the other end of phone if I needed it. And the third one, three things, well, I think they are all wrapped up in the first two aren't they?*

### **Barriers and challenges**

- **Barriers and challenges that related to service delivery included: lack of resources; providing for specific groups; involving service users and setting up specific aspects of projects, such as online support, stigma and family dynamics.**

- **Barriers and challenges that related to governance and strategy included barriers related to being a demonstration site; the relationship of Peer Support Network and Dementia Adviser services to pre-existing services and supporting volunteers.**
- **People spoke about ways in which they had resolved barriers and challenges. Resolutions included: a multidisciplinary review of care packages; partnership working; promoting services; communication and training/awareness raising.**



This section of qualitative data from the in-depth case study site interviews presents what was said by staff and stakeholders about the barriers and challenges they had encountered within Peer Support Network and Dementia Adviser sites, as well as some of the resolutions to these barriers spoken about. As with other aspects of the qualitative data, our aim is to provide insight into the themes spoken about within the interviews. This is therefore not a comprehensive list of all of the barriers and challenges spoken about within the interviews.

When asked about the barriers and challenges faced within Peer Support Network and Dementia Adviser services, funding and finance was referred to, specifically in relation to changing criteria for funding of care and staffing cuts, both of which had an impact on future sustainability of services. People also referred to a lack of resources, specifically in relation to transport and a decrease in other local services and support to signpost or refer people with dementia and carers on to.

Some of the barriers and challenges spoken about relate to 'being a demonstration site', with specific reference to communication with Project Boards and the tight timescale that Peer Support Network and Dementia Adviser services were working to, specifically in relation to the time that it takes for social networks to evolve and have demonstrable impact:

*Leslie, PSN facilitator: Because I think some of the impacts are long term, which you cannot evaluate on a short-term basis. If you see the carer or person with dementia doing well, happy, feeling ok in a couple of years' time or in one year or two years down the line, then you can say that because of that network that exists around that person has helped them, helped him or her, they keep going and doing well. So, I would like, I think I would not comment on that.*

Involving service users in a meaningful way that was also within the resources available was a challenge, especially people with dementia in mid- to late stages of their illness. Here, a carer articulates some of the barriers to being more involved in services:

*Eve, carer who had accessed PSN support group: Because you've got to send our papers, you've got to organise the meetings you've got to do and whatever. And we don't really have time as carers, you know, to take that on board and do. Quite a*



*while ago [PSN group facilitator] did approach me and ask me if I was interested in being a facilitator. Because they would do the providing me with training and it wouldn't cost me anything. And I said it's something I would, perhaps, consider at a later date. I said but I didn't feel I could take it on at the moment, because I can't... With everything else going on, I can't do that and look after mum, you know. She said, "Well that's okay. The offer is still there even in 6 months' time." I said, "Well, you know, I..." Don't get me wrong, they're all very nice – the people – but sometimes, only on the odd occasion, I often wonder to myself, "Do they really understand what it's really like? That you don't have 5 minutes in the day to take on board, you know, doing something like that, you know?" Because she said, "Oh, we think you'd be an ideal candidate" and everything else. I said, "Well I am flattered and honoured." I said, "But I really can't... If I want to put myself under more pressure, I could say yes." But you have to reach a point, don't you? And think, "Well, no, I can't take on board doing this and I can't do whatever because I physically can't do it anymore." You know, unless I'm going to run myself into the ground at the end of the day.*

Barriers to service user involvement were also referred to by staff and stakeholders:

*Gabby, Service Manager from PSN site: ...there's opportunity within the peer support services to be able to influence directly local policy and form a kind of hub of consultants that can...talk about different policies and review policies and feed into that.....at the moment there's not the numbers.....it's not established enough to be able to do that, as a service.*

Challenges faced by Project Boards included maintaining continuity amidst changing roles:

*Anita, Services Manager, DA site: Unfortunately people moved out of roles in that Steering Group and changed around. So very often I was left to lead quite a lot of different things really. But that was good for me, because that actually helped me think in how we could develop, even after the demonstration site was finished.*

A further challenge was that of understanding the day-to-day running of sites and influencing site activity:

*Maria, commissioner, DA site: Cos you can have all the bright ideas you want as a director, but if you haven't got staff who can take it and lead on some of those things....so that's been important, and I think that was reflected in the bid process itself, with the key players involved.....*

The relationship of Peer Support Network and Dementia Adviser services to pre-existing services was also a specific challenge highlighted by the people spoken to, including clarity of roles and referral routes and developing and maintaining effective partnerships. This data will be addressed further when we consider the relationship of Peer Support Network and Dementia Adviser services to pre-existing services.

Some of the challenges referred to relate to the role of volunteers within Peer Support Network and Dementia Adviser services. Challenges included ensuring that people were suitable for roles, maintaining the continuity of support that is essential for people with dementia, recruiting people and communication. One Peer Support Network facilitator referred to tensions over the quality of the intervention delivered by volunteers, and the skills needed to pitch support at the right level, also echoed by this person with dementia who had accessed a memory café:

*Laurie, person with dementia who had attended PSN group: A couple of the volunteers that come don't seem to realise that. They think everyone is the same level, I think. You know, some of us aren't as bad as others, you see.*

The process of recruiting and training volunteers was also referred to by some as a challenge. This included challenges in recruiting people willing to volunteer, with specific reference to the need for people with dementia to receive reasonable continuity in people supporting them.

There were some issues referred to in relation to the training of volunteers, volunteer roles and consistency of support from volunteers. Some challenges relating to instances where the attitudes and ethos of volunteers were not the same as the Peer Support Network or Dementia Adviser services arose:

Ross, person with dementia who had attended PSN group: *I think with the volunteers – I don't know whether they have any basic, sort of, training or they're from the community? Like the one at [location] is an ex-school teacher. They are the world's worst. Because if they have been dealing with young adults, that's not so bad. But if they've been a primary school teacher, they're talking to you, automatically, like a child.*

Further barriers and challenges included building trust and the stigma related to promoting and developing dementia-related services. People who had been involved in working with people with dementia and carers referred to the challenge of family dynamics, in particular financial and legal issues and the impact of struggles within families to understand dementia.

Some staff referred to challenges relating to setting up specific aspects of projects, including time banking (a scheme where reciprocal support within a community is encouraged through people offering their skills and time in exchange for support from someone else in the community who has different skills) and the use of online support and social media.

Provision of support for specific groups of people was also an area of service development which had posed challenges. This included people with early-onset dementia, people who deteriorate rapidly and BME communities:

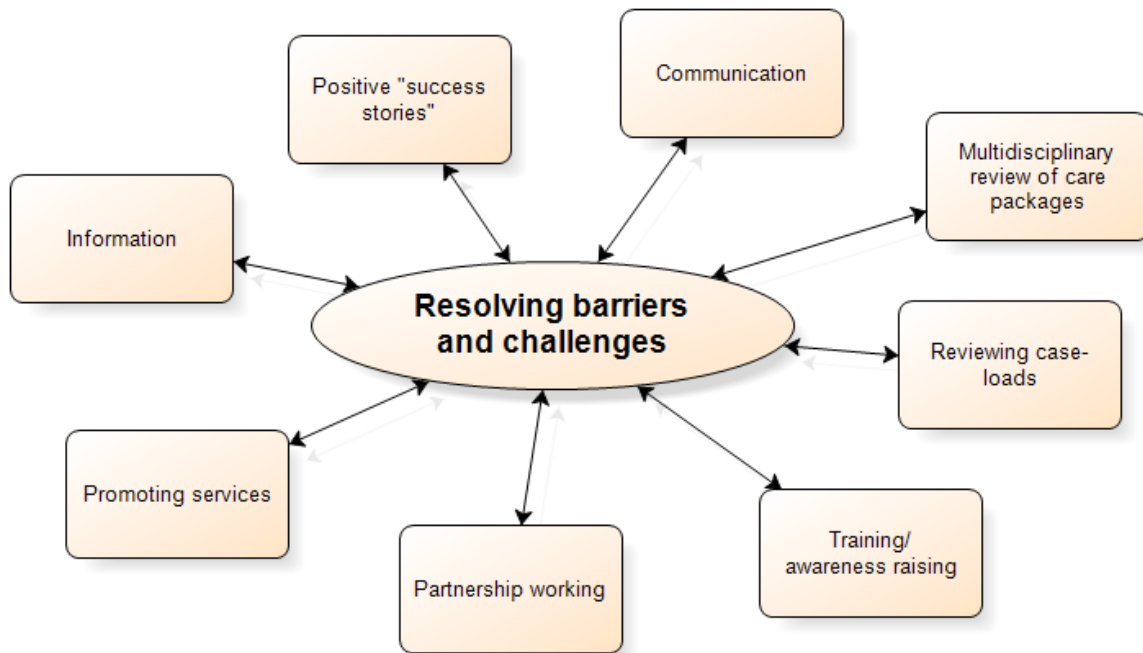
Glen, Dementia Adviser: *The biggest problem has been to de-stigmatise dementia. Erm, and I don't think that was as successful as it could have been because the materials available in alternative languages haven't been as readily available as I think everyone concerned with the project would have liked.*

The importance of ensuring that support is available to everyone who might benefit from it, especially people who are not currently in touch with any services, was also referred to:

Chris, Lead of Project Board, PSN site: *Our biggest challenge I think has been how we reach people who are not in touch with our services. So, I don't use the term any more, but, the term I have used in the past – 'the hard to reach people' – some say there is a need to reach people. We think about it, we're quite good, I think we can be*

pretty good at linking people who we already know have got an interest, but it's how we reach the people who are on their own or who don't understand the language or who just don't believe in dementia for whatever reason.

### Resolving barriers and challenges



Ideas relating to greater use of the skills, knowledge and experience of people with dementia within Dementia Adviser sites included use of people's previous life and work experience in supporting other people with dementia.

Here, a commissioner from a Dementia Adviser site speaks about how the service had sought to overcome the barriers and challenges relating to reaching a specific BME community:

Leigh, commissioner from DA site: *How we have overcome them? We have tried to maintain an awareness campaign, both in, both the Dementia Advisers had both gone and done presentations within local community settings. We carried articles in local appropriate, newspaper articles. The use of the [BME] communities' network, articles in [newspaper name]; which is the BME [location], newspaper. [Newspaper name], which is specifically for the [BME] community. We have done radio interviews, again, that wouldn't have been possible if it had not been for the fact that*

*both (person's name) and (person's name) were bilingual and were able to freely take phone calls to and from, in the, in the appropriate language to the person who's required the support and assistance. But I don't think we have matched that as a society. I don't think we have matched the, the positives of the individuals appointed with delivering appropriate printed material. I think that has been a weakness and that has only just been overcome. We are only at the point of overcoming that.*

In relation to the overlap or blurring of boundaries or remits, clarity and communication was spoken about:

*Val, commissioner from DA site: So, you know... But I think you have to respect that any pilot that comes in and is doing bits of other people's work, or what they may have been doing at that time, will immediately be seen as a threat. So it's very important in how that is handled.*

The role of Peer Support Networks and Dementia Advisers in raising awareness about dementia was viewed as a potential resolution to the barriers and challenges relating to stigma and isolation:

*Amit, Dementia Adviser: I've still found within a lot of the villages, there's a stigma attached. It's erm, it's not a real stigma, but it's the thought that's a stigma, so like, if there's a couple and one of them's got dementia, they tend to start withdrawing from village life a bit, because they think people will talk about them and stuff, but actually, if I go and talk to the WI group, or a local group and explain about dementia and how you can communicate, people are actually very supportive and it starts breaking down those barriers within the communities and then, you know, families do get a lot more support, and it's not so vital if they get to the dementia café if they've got the local support anyway, 'cos they've got the networks in place.*

The positive impact of individual 'success stories' was viewed as a vehicle for promoting the usefulness of services within the wider professional context and amongst people living with dementia:

*Bev, PSN facilitator: [He] came to some of our groups, built his confidence. Now attends lots of our groups. He's on our Project Board. He's coming to our memory*

*drop-in sessions to give talks to other people with dementia, to tell them about his journey. And to use that as an example to inspire other people to come to structured peer support.*

Partnership working, although seen by some as a barrier and challenge, also had a potential positive impact in overcoming barriers and challenges that were identified:

*Val, commissioner, DA site: And we spent a lot of time trying to maintain and build that relationship and it works really well now. So, you know... But I think you have to respect that any pilot that comes in and is doing bits of other people's work, or what they may have been doing at that time, will immediately be seen as a threat. So it's very important in how that is handled.*

### **Section Three: Integration, sustainability and transferability within wider health and social care landscape**

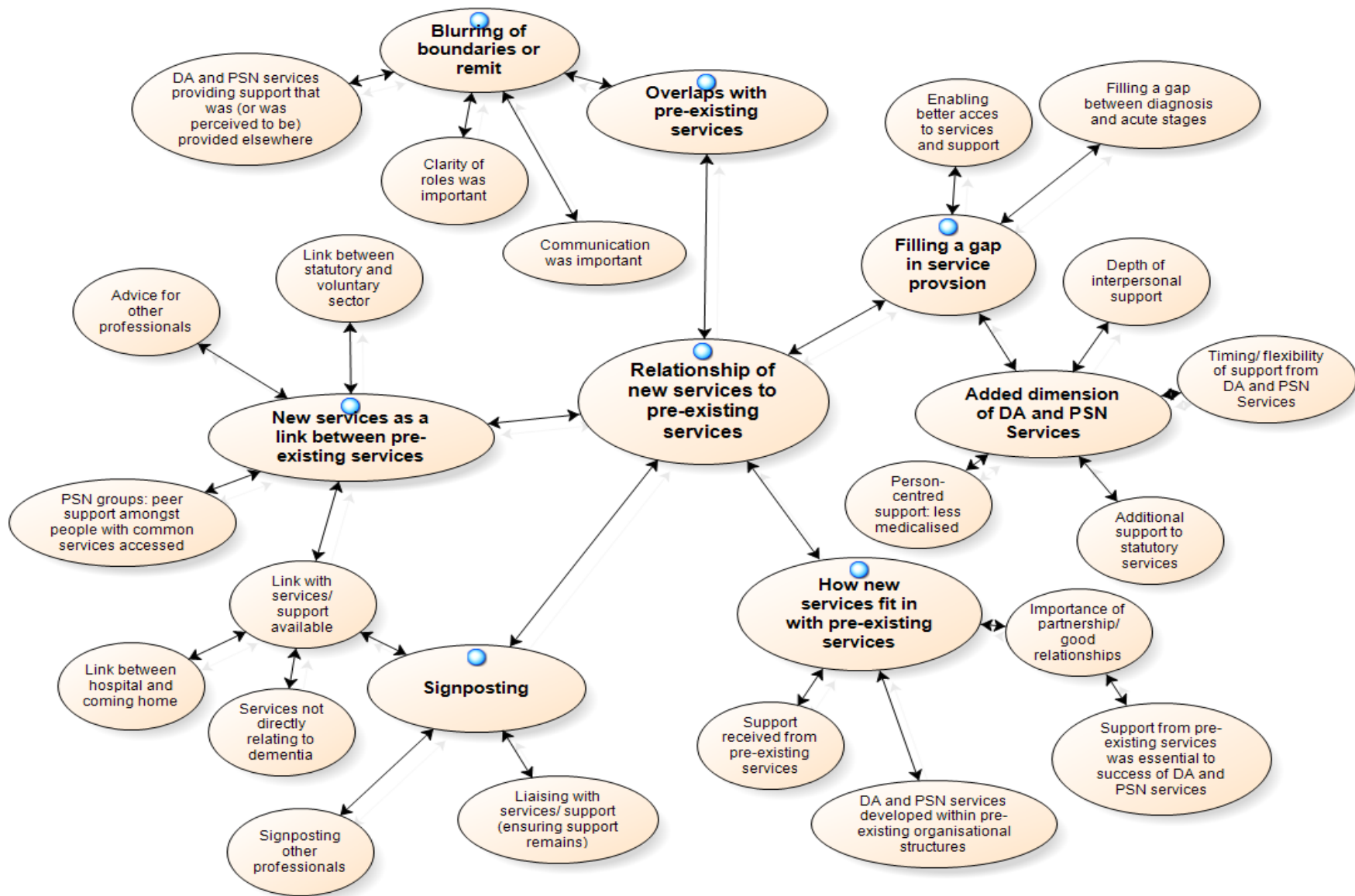
This section of data relates to the interaction of Peer Support Network and Dementia Adviser services with wider health and social care services. We assess the integration, sustainability and transferability of Peer Support Network and Dementia Adviser services, considering economic and organisational factors within both policy and practice. This is a significant area, as the nature of the relationship between pre-existing services and Peer Support Network and Dementia Adviser services was (uniquely) defined by the nature of the National Dementia Strategy Implementation Plan. In order to be integrated within the wider health and social care landscape at the same time as developing the remits of the National Dementia Strategy demonstration sites, there were a number of complex tensions to be negotiated.

- Data relating to this includes: the relationship of Peer Support Network and Dementia Adviser services to pre-existing services (i.e. services and support that was available to people with dementia and carers prior to the demonstration period).
- Within this section, we also outline data which explores other services and support that people accessed, either prior to, alongside, or as a result of support from Peer Support Network or Dementia Adviser services. Data relating to the resources saved

by Peer Support Network and Dementia Adviser services is then followed by data on crisis prevention and early intervention, which was referred to across many of the qualitative interviews.

**Relationship of Peer Support Network and Dementia Adviser services to pre-existing services**

- **The relationship of Peer Support Network and Dementia Adviser services to pre-existing services and support for people with dementia and carers was significant, both to staff and stakeholders directly involved in these services and to those interviewed from pre-existing support agencies and organisations.**
- **Both core staff and wider stakeholders referred to the need for clarity of roles, and the role of partnership and communication in defining boundaries and remits.**
- **When relationships between Peer Support Network and Dementia Adviser services and pre-existing services were working well, Peer Support Network and Dementia Adviser services acted as a link between service users and services and support as well as filling gaps in services and support that was available.**





The relationship of Peer Support Network and Dementia Adviser services to pre-existing services was significant, both to staff and stakeholders who were central to site activity, and to people interviewed from other local statutory and voluntary organisations.

When considering the relationship of Peer Support Network and Dementia Adviser services to pre-existing services, the importance of partnerships and good relationships were emphasised. Within this, there was a recognition that support from pre-existing services was essential to establishing and maintaining the work done by Peer Support Network and Dementia Adviser services.

Within each of the eight case study sites, Peer Support Network or Dementia Adviser services were organisationally situated very differently. Staff and stakeholders referred to ways in which Peer Support Network and Dementia Adviser services filled a gap in service provision. In addition to filling this gap in service provision between diagnosis and the need for more intensive support, Peer Support Networks and Dementia Advisers were seen as a mechanism through which better access to services and support was established. Additionally, there was a perceived added dimension to Peer Support Network and Dementia Adviser services: allowing flexibility around timing and content of support and providing a person-centred, less medicalised approach to support for people with dementia and their carers, and being more responsive to the needs and views of people accessing services.

The way in which Peer Support Network and Dementia Adviser services filled a gap in service provision is backed up by what was said by professionals when asked what would happen if the services no longer existed. Some people spoke about a return to a situation with more crisis and residential care needed, a negative impact on knowledge and awareness raising that had been central to work done by many Peer Support Network and Dementia Adviser services, and an increased pressure on statutory services with an expectation that they would fill the gap in support left by Peer Support Network and Dementia Adviser services if they were to cease:

Interviewer: *What would you do if (Dementia Adviser)'s service didn't exist?*

Annie, carer who had accessed DA service: *Well I guess that we would be slightly lucky and that being part way down the path.....I've kind of got some of that information, but erm, she is kind of the link to what is available and what might be changing, what's not changing. So what would have happened is that I would have probably had to put a lot more effort into, erm, I don't know, I would have probably have had to try and connect up to some group to... I don't know, it's difficult, I can't, from where I am, I can't see a single point of contact anywhere, they're all in kind of different departments, like to get the council tax thing, I had to talk to someone in the housing thing and from the outside looking in, the council services all seem very non-joined up.*

There was also reference to Peer Support Network and Dementia Adviser services as a source of specialist support:

Heidi, professional who had accessed DA site: *And I think one of the things that has happened, by having that specialist service, Care Managers and Social Workers, don't necessarily have to be experts in that field because there is one. And I think that's... That has been, as a resource, as a source of information and advice, just picking up the phone to... To be able to pick up the phone and say, you know, "I'm just about to go and work with somebody who has dementia, you may know them, what is the best way approaching this subject with them?"*

Peer Support Network and Dementia Adviser services were also seen as a link between pre-existing services. This included: providing a link between the statutory and voluntary sector, specialist dementia advice for other professionals, and linking people with dementia and carers with the support and services available to them:

Nancy, carer who had accessed PSN support group services: *It's an outlet, I think, sometimes. You know, if things have... Are getting on top of you, you know, there's somebody who'll listen or there's somebody who can point you in the right direction or... We've never... Previously, you know... Experience of anything like this. And it just... Just that knowledge that to go the GP is not... You don't get the information that you need – you can come here and you can get some information on how the condition is going to progress. You can get information on any benefits or anything*

*that you might be entitled to. Any activities that we've got. That information – I wouldn't know where to find it and it's not one place anywhere else. There's just so much here but... And then we've come to the meeting and you might have some of the nurses from the memory clinic who my dad sees for his 6-monthly reviews up there. So, you know, it ties everything in together, really.*

Themes which emerged as an illustration of Peer Support Network and Dementia Adviser services as a link included supporting people who had in common services that they had accessed prior to accessing demonstration site services.

Also in relation to Peer Support Network and Dementia Adviser services as a link between pre-existing services was the role of these services in signposting to local services and support. Within the role of Dementia Advisers, this included liaising with local support and services in order to ensure that signposting was followed up (and that the organisations they were signposting people with dementia and carers to were continuing to deliver support and services):

*Anita, Services Manager from DA site: I see the role of the Dementia Adviser as actually to liaise with all different agencies and services to ensure that all the signposting and advice and information we are giving out is out there for people. And the services are out there, and there is that link.*

### **Overlaps with pre-existing services**

The overlap of Peer Support Network and Dementia Adviser services with pre-existing services was referred to, both by core staff and stakeholders within Peer Support Network and Dementia Adviser services and stakeholders from organisations with which those overlaps may occur, for example voluntary sector organisations which were already providing services that they felt were similar to the demonstrator sites, in particular Dementia Adviser sites:

*Amit, area manager from voluntary sector: It's confused local policy and practice in a very big way. There was clarity previously, now there isn't clarity – there is confusion, there's a reduction in referrals to all the services. And for the reason [other respondent in joint interview] has just explained a minute ago, I think people now*

*don't know what to do. I think they're more confused now than they were before the service existed. Because they have introduced ambiguity and blurred the role boundaries.*

Within this, it was important that good communication between services was maintained, as was a need for clarity of roles between Peer Support Network and Dementia Adviser services and other local services and organisations providing support for people with dementia and carers:

*Leigh, commissioner from DA site: There will always be issues, I think, about potential duplication around that kind of a role. And if you've got an Alzheimer's café that provides information and you've got a memory service that provides information and you've got... That can enable... One of the things that... I have just been down to [site] to meet with a number of people there, and the element of keeping up the communication seems to be a critical factor. So that bit about collaborative working, keeping communicating, making sure that people are clear about care pathways and their roles within that seems to be a very important part of making it work.*

#### **Other services or support accessed**

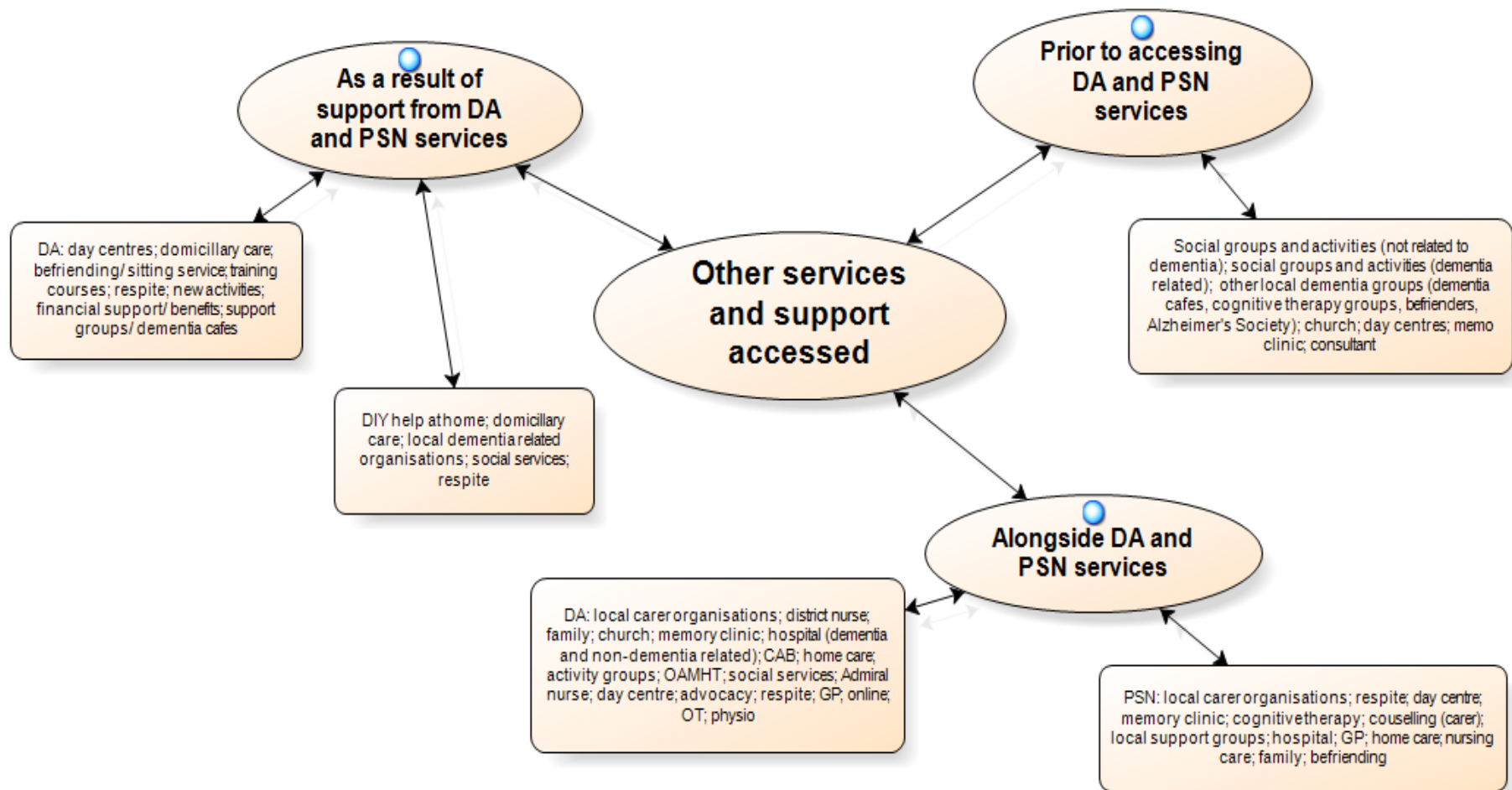
- **It is important to acknowledge that people with dementia and carers were not accessing Peer Support Network and Dementia Adviser services in isolation.**
- **People spoke about a range of other services and sources that they had accessed: prior to accessing Peer Support Network and Dementia Adviser services and alongside these services, as well as a result of support from these services.**
- **The overall spread of other services and support accessed by people with dementia and carers in Peer Support Network and Dementia Adviser services were similar, and included support from voluntary sector and statutory sector organisations providing a range of services and support.**

In evaluating the impact of Peer Support Network and Dementia Adviser services, it is important to consider other services and support that people were accessing, both prior to and alongside accessing support from Peer Support Network and Dementia Adviser services. The goal of both Peer Support Network and Dementia Adviser services in enabling access to

a wider range of support is significant within this aspect of the data; in particular services and support accessed as a result of support from Peer Support Network and Dementia Adviser services.

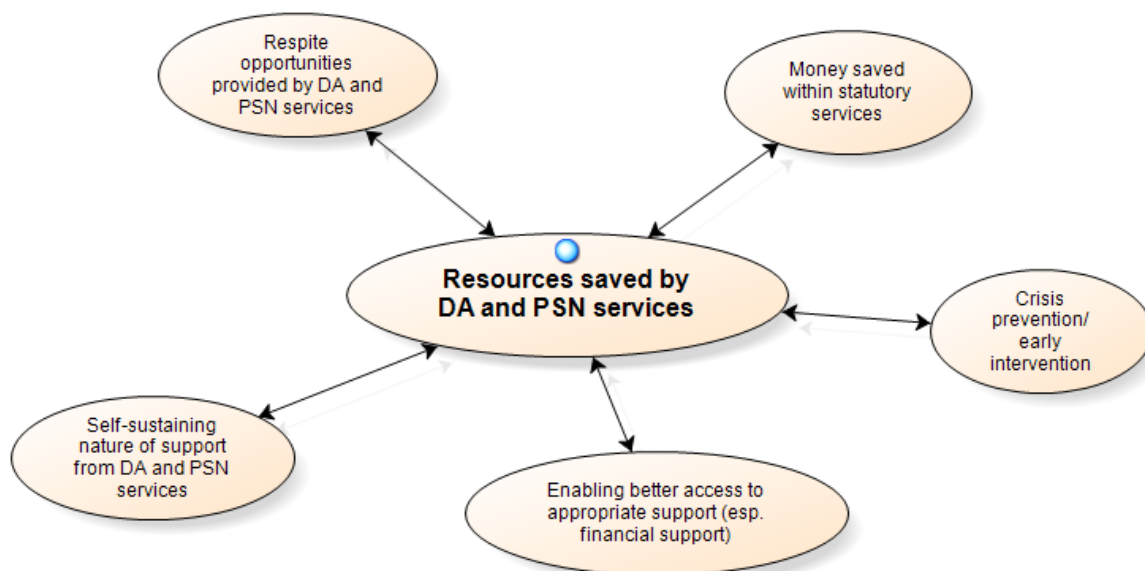
Examples of support accessed as a result of support from Dementia Adviser services included: day centres; domiciliary care; befriending or sitting services; training courses; respite; new activities; financial support and benefits; and dementia-related support groups such as dementia cafés.

Examples of support accessed as a result of support from Peer Support Network services included: DIY help at home; domiciliary care; local dementia-related organisations; social services and respite.



### Resources saved by Peer Support Network and Dementia Adviser services

- The focus within Peer Support Network and Dementia Adviser services on crisis prevention and early intervention has the potential to save resources within statutory services.
- Peer Support Network and Dementia Adviser services also saved resources within wider systems of support for people with dementia and their carers through enabling people to access the support that was most appropriate within their situation.
- Respite opportunities within Peer Support Network and Dementia Adviser services were referred to as support which saved resources within other local services.



Also significant in the integration, sustainability and transferability of Peer Support Network and Dementia Adviser services in the wider health and social care economy is the resources that were saved by these services. The nature and scope of the Healthbridge evaluation and the complex organisational settings did not allow for financial figures on the impact of Peer Support Networks and Dementia Advisers on other organisations to be gathered. Such figures would need to account for the increase in use of some pre-existing services as a result of signposting, information and advice from the demonstration sites at the same time as the decrease in use of pre-existing services as a result of support from Peer Support Networks and Dementia Advisers.

However, there was considerable reference by core staff, management staff, commissioners and people from other local organisations, within the in-depth interviews, to resources being saved within pre-existing services as a result of Peer Support Network and Dementia Adviser services.

For example, the knock-on effect of supporting carers, enabling them to cope with their role, included a positive effect for people with dementia, as well as for services in general:

*Carmen, commissioner from DA site: You know, there's so much stress and anxiety and I think, you know, those levels could sort of increase again and spiral. And I think particularly, you know, [site] was a 101% increase. We're going to have so much more. And it's the effect on the health of the carer as well as the person with dementia, isn't it, that you need to look at. And so there is a huge cost-saving implication there in making sure that the carers are well supported. Because I think that's something that, you know, has been a focus for one of the carers we... It was a theme – about looking after yourself and how important that is. So there's a lot of publicity about that, but actually the reality is that carers don't always really take care of their own health very well.*

Interviews with staff and stakeholders, including commissioners, provided information on resources saved locally within pre-existing statutory services. This idea of people with dementia and carers needing to access statutory services less is backed up by Keith, a person with dementia who had accessed support from a Dementia Adviser:

*Because [Dementia Adviser] has been so helpful and such a good source of information, we're possibly, over the period of time we've had to call on social services themselves, less than we might do otherwise. You know, whereas we might have had to ring social services and say, you know, can you, sort of, tell us what sort of networking or what sort of, you know, meetings there are. We haven't had to do that because [Dementia Adviser] has provided all that information. So, yeah, possibly we use social services less than we would have done.*

When asked what would happen if Peer Support Network and Dementia Adviser services no longer existed, commissioners and other stakeholders referred to the financial implications:



Heidi, professional who had accessed DA site: *All I can say is that the cost to statutory services – if it wasn't there – would rocket....People have sort of been led to expect more. ....they know now that dementia can be .....helped through a range of interventions....And they would expect them to be provided by the statutory organisations.*

However, as Louise, the manager of NHS services where one of the Dementia Adviser services was located, points out, the relatively short timescale involved means that a specific assessment of resources saved is not realistic:

*We're trying to look at what the benefits of having the Dementia Adviser are and how many people it's kept out of mainstream services or out of hospital. I don't believe you can do that in two years and practically, we've had much less than two years – or will have much less than two years. I think this needs to be done in five years and I don't think you can get a true picture until then.*

### **Enabling better access to support**

There was also a view expressed that resources were saved by Peer Support Network and Dementia Adviser services because support from them enabled people with dementia and carers to access the support they were entitled to, and in accessing that support more efficiently:

*Sheila, DA site staff: .....people weren't sure of their right with some of the financial... And their benefits. And actually people did write back to us and said, "We didn't know that was out there for us. And that's actually made our lives a lot more easier." So pulling away from activities, some of the benefits that we've managed to get back for people.*

Resources saved by the fact that Peer Support Network and Dementia Adviser services enabled independence, control and choice were also referred to:

*Heidi, local professional from DA site: Not only that, there are so many people in the local community being supported – and once people are confident their level of access to the service actually drops off, making space for new people to come in.*

A further resource saved by Peer Support Network and Dementia Adviser services occurred through the opportunities for respite provided by, for example, a carer having a regular break while the person with dementia attended a Peer Support Network group. This had a direct impact on the well-being and resilience of carers:

Ethel, carer (speaking about how she spends time when her partner is at a PSN group): *No, I.....I just have that bit of free time to be able to.....I usually spend it running up to town like a mad woman, quickly shopping and coming back.*

Brian, carer who had accessed DA services: *I didn't know anything about was this grant that I can have as the carer for respite. And [Dementia Adviser] has got me that this year. And the middle of March, when the weather turns better, my daughter, and I, we're going down to \_\_\_ for three days. Into a hotel. But my daughter will look after [person with dementia] completely. So I'm going to have three days of luxury.*

It is important to note, however, that many site staff and commissioners said that the development of Peer Support Network and Dementia Adviser services was not just focused on saving resources for the sake of saving money, they also emphasised the importance of improving quality of care for people living with dementia.

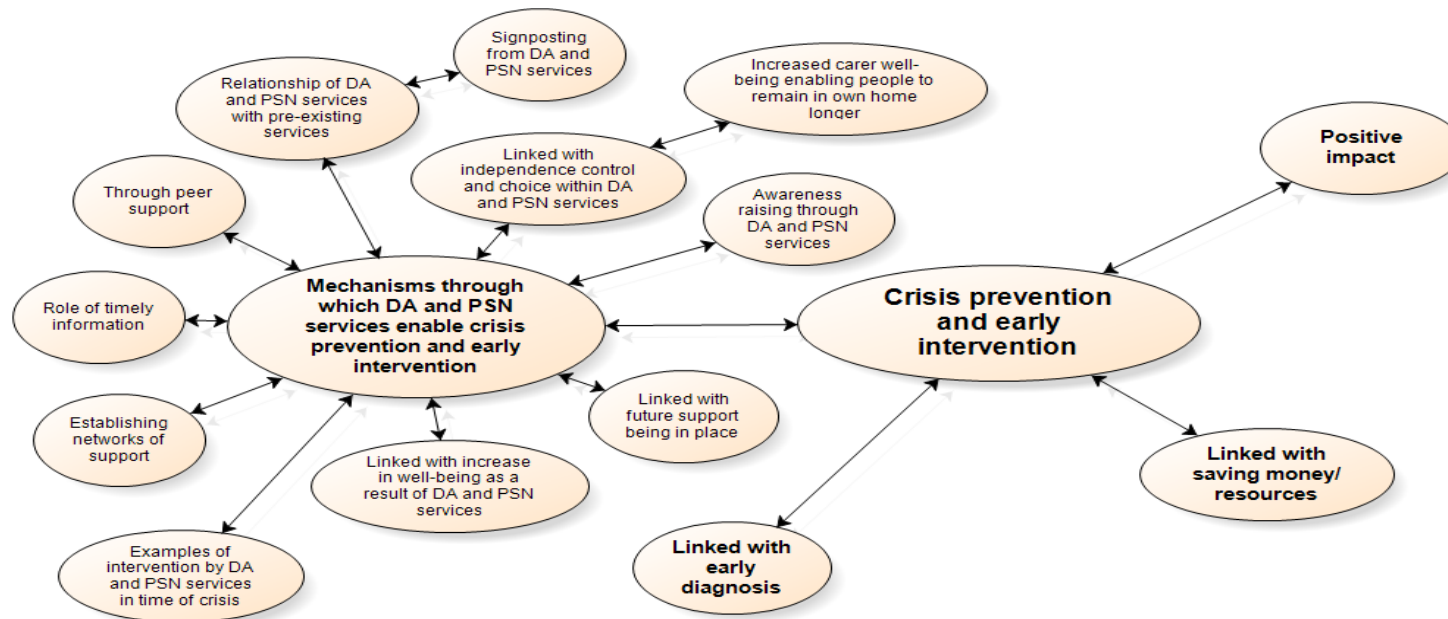
In considering the integration, sustainability and transferability of Peer Support Network and Dementia Adviser services within the wider practice and policy arena, the resources saved by these services due to crisis prevention and/or early intervention were also referred to, in relation to support for people with dementia and in relation to carer stress:

Carmen, commissioner from DA site: *If you're looking at cost, I'm not a financial person, but I've had to be, but if you're looking at cost then the cost of looking after carers starts increasing. So they're on antidepressants. They're on, sort of, the edge almost.....They don't know how to care....Early intervention, support is a huge cost-saving benefit to our population.*

Arshad, local voluntary sector worker who had accessed DA site: *It's preventative work, in that if somebody is supported and has the information they need earlier on, it could stop them from reaching a crisis.*

**Crisis prevention and early intervention**

- **Crisis prevention and early intervention, referred to as a positive impact of Peer Support Network and Dementia Adviser services, was linked with resources saved by these services. There were also links made between earlier diagnosis as a result of Peer Support Network and Dementia Adviser services and crisis prevention/early intervention.**
- **Mechanisms of Peer Support Network and Dementia Adviser services through which crisis prevention and early intervention were achieved included timing and flexibility of support from these services, with future support being in place, and increased well-being, including an increase in coping amongst carers.**
- **Awareness raising, peer support and an increase in signposting to local support were also mechanisms through which Peer Support Network and Dementia Adviser services achieved increased crisis prevention and early intervention.**



Crisis prevention and early intervention were referred to as both a goal and an impact of Peer Support Network and Dementia Adviser services, sometimes in relation to the resources saved by crisis prevention and early intervention. Crisis prevention and early intervention were also linked with saving of resources and early diagnosis. The relationship of Peer Support Network and Dementia Adviser services with pre-existing services was also significant within crisis prevention and early intervention. The role of independence, control and choice within Peer Support Network and Dementia Adviser services was also referred to, in particular in relation to increased carer well-being resulting in people with dementia remaining in their own homes for longer. Similarly, crisis prevention and early intervention were also linked with timing and flexibility of support from Peer Support Network and Dementia Adviser services, including the impact of people knowing where to go to for support in the future:

*Lisa, staff from DA site: And, I mean, from the cases that I have directly been involved – and obviously reading through cases and that – I mean, I would say that there’s evidence that people have been able to remain in their own homes for a lot longer than previously may have been. And now whether that’s because the right information was given at the right time, and also knowing that there is somebody to contact when carers stress.*

*Lindsay, PSN facilitator: The opportunity to build relationships up with professional services... traditionally, especially in areas like this, it’s... Family services \_\_\_\_, it’s “They’re going to take your children from you.” It’s always very negative connotations or you only go to them if you’re poorly or something. So it’s building up the relationships. So if people feel comfortable to come to people in those organisations before they hit crisis point. So it’s all the prevention. So it’s... Building... Yeah, building... Building confidence in our services, so they can say, “Could you just tell me, what would I do if...?” Rather than waiting for, “I can’t manage any more. I can’t cope any more. You know, that’s it – I can’t care. That’s it, I’m done.” So it’s like... And we know that that’s... That’s what happens usually, it’s... And we can’t effect... We’re not effective in crisis. We’re more effective on the preventative stuff. So I’m hoping that’s building up the relationships so people have those... The confidence in asking before it happens.*

## **Section Four: Influence on well-being of people with dementia and carers**

Here, we present the ASCOT data which was collected as part of the Healthbridge evaluation:

1. **ASCOT DATA FOR CASE STUDY SITES:** data for all people who completed ASCOT as part of the in-depth case study interviews; data for people with dementia; data for carers.
2. **ASCOT DATA FOR ALL DEMONSTRATION SITES:** data for people with dementia; data for carers; data for Dementia Adviser sites; data for Peer Support Network sites.
3. **ASCOT DATA: NON-DEMONSTRATION SITE GROUP:** data for group as a whole; data for people with dementia; data for carers.

### **ASCOT data for case study sites**

- **For the group as a whole, the areas identified as having most unmet need were accommodation, occupation and control.**
- **People with dementia identified as having more need than carers in the areas of dignity and social participation.**
- **People with dementia from Dementia Adviser case study sites identified as having more need than people with dementia from the Peer Support Network sites in the areas of accommodation, personal cleanliness, social participation, occupation, control and dignity.**
- **Carers from Dementia Adviser case study sites identified as having more need than carers from Peer Support Network sites in the areas of personal cleanliness, food and drink, and dignity.**

Figures 4 and 5 show the ASCOT data that was collected as part of the in-depth case study interviews. It includes data collected from both people with dementia and carers.

Altogether, there were 166 instances where ASCOT was completed with people with dementia or carers within the in-depth case studies.

This data shows the following scores (presented as number of people identifying as no needs or being in an ideal state) for each of the domains:

**Accommodation:** There were 104 instances (63% of responses) where people with dementia and carers who had accessed the eight case study sites identified themselves as having no needs or being in an ideal state.

**Personal cleanliness and comfort:** There were 150 instances (90% of responses) where people with dementia and carers who had accessed the eight case study sites identified themselves as having no needs or being in an ideal state.

**Food and drink:** There were 153 instances (92% of responses) where people with dementia and carers who had accessed the eight case study sites identified themselves as having no needs or being in an ideal state.

**Safety:** There were 147 instances (89% of responses) where people with dementia and carers who had accessed the eight case study sites identified themselves as having no needs or being in an ideal state.

**Social participation and involvement:** There were 146 instances (88% of responses) where people with dementia and carers who had accessed the eight case study sites identified themselves as having no needs or being in an ideal state.

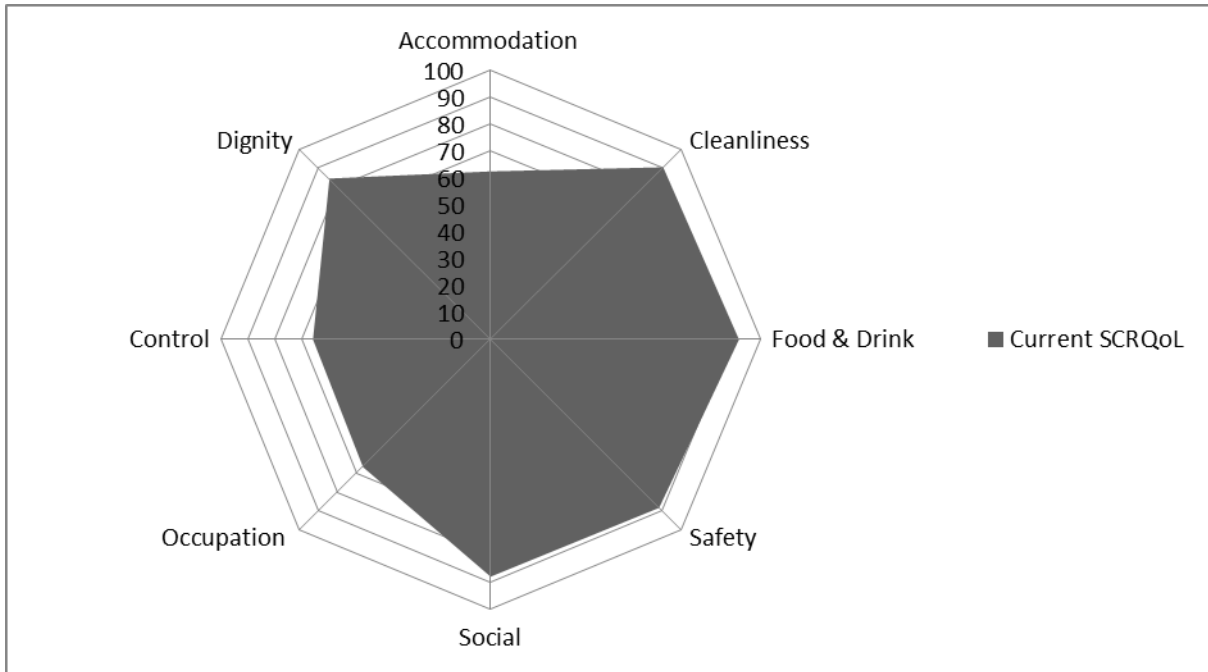
**Occupation:** There were 111 instances (67% of responses) where people with dementia and carers who had accessed the eight case study sites identified themselves as having no needs or being in an ideal state.

**Control:** There were 109 instances (66% of responses) where people with dementia and carers who had accessed the eight case study sites identified themselves as having no needs or being in an ideal state.

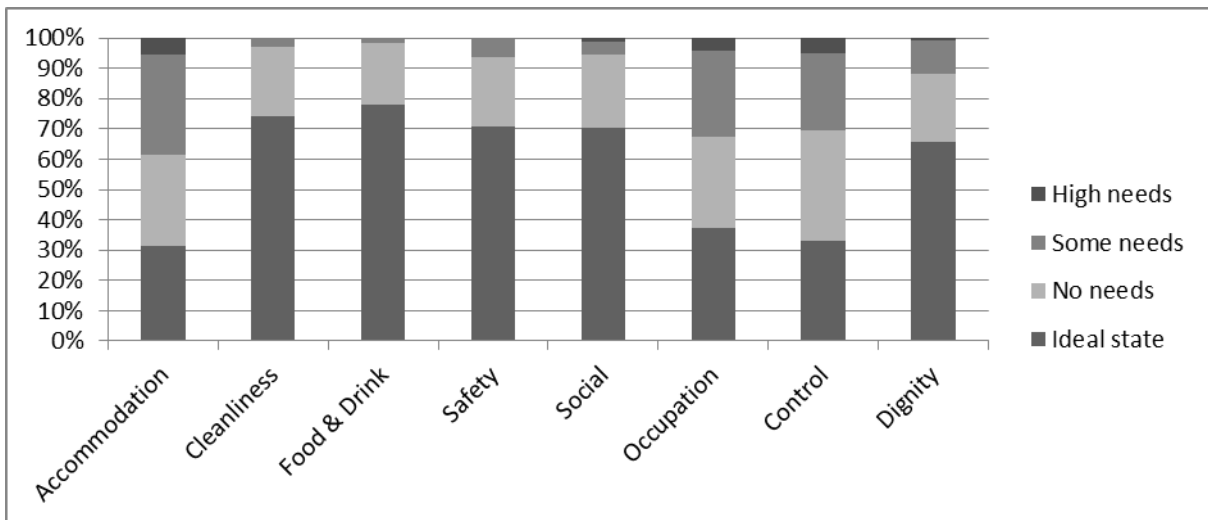
**Dignity:** There were 140 instances (84% of responses) where people with dementia and carers who had accessed the eight case study sites identified themselves as having no needs or being in an ideal state.

These figures show that the areas where there were **most unmet needs for people with dementia and carers** (as a whole group) who were accessing **the eight case study sites** were:

- Accommodation (62 instances, 37% of responses, indicated unmet need)
- Occupation (55 instances, 33% of responses, indicated unmet need)
- Control (57 instances, 34% of responses, indicated unmet need)



**Figure 4.** SCRQoL scores for people with dementia and carers (in-depth case study sites).



**Figure 5.** SCRQoL scores for people with dementia and carers (in-depth case study sites).

**ASCOT data case study sites: People with dementia**

This section of data outlines the scores for people with dementia who were interviewed as part of the case study sites. The scores are represented in Figures 6 and 7. Altogether, there were 84 instances of people with dementia completing the ASCOT questionnaire as part of the in-depth case studies.

**Accommodation:** There were 59 instances (70% of responses) where people with dementia who had accessed the eight case study sites identified themselves as having no needs or being in an ideal state.

**Personal cleanliness and comfort:** There were 77 instances (92% of responses) where people with dementia who had accessed the eight case study sites identified themselves as having no needs or being in an ideal state.

**Food and drink:** There were 77 instances (92% of responses) where people with dementia who had accessed the eight case study sites identified themselves as having no needs or being in an ideal state.

**Personal safety:** There were 79 instances (94% of responses) where people with dementia who had accessed the eight case study sites identified themselves as having no needs or being in an ideal state.

**Social participation:** There were 72 instances (86% of responses) where people with dementia who had accessed the eight case study sites identified themselves as having no needs or being in an ideal state.

**Occupation:** There were 61 instances (73% of responses) where people with dementia who had accessed the eight case study sites identified themselves as having no needs or being in an ideal state.

**Control:** There were 60 instances (71% of responses) where people with dementia who had accessed the eight case study sites identified themselves as having no needs or being in an ideal state.

**Dignity:** There were 67 instances (80% of responses) where people with dementia who had accessed the eight case study sites identified themselves as having no needs or being in an ideal state.

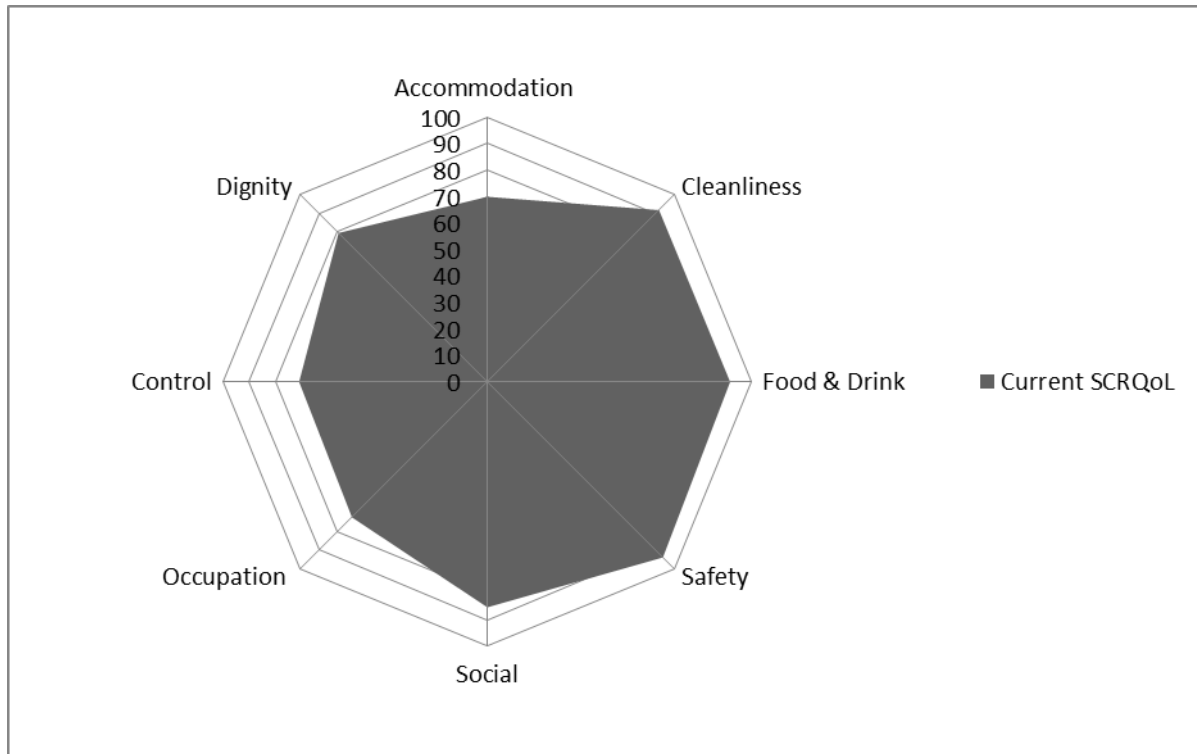
This means that for **people with dementia** who completed ASCOT as part of the **eight in-depth case study sites**, areas identified having some or high needs were:

- Accommodation (25 instances, 30% of responses, indicated unmet need)
- Control (24 instances, 29% of responses, indicated unmet need)
- Occupation (23 instances, 27% of responses, indicated unmet need)

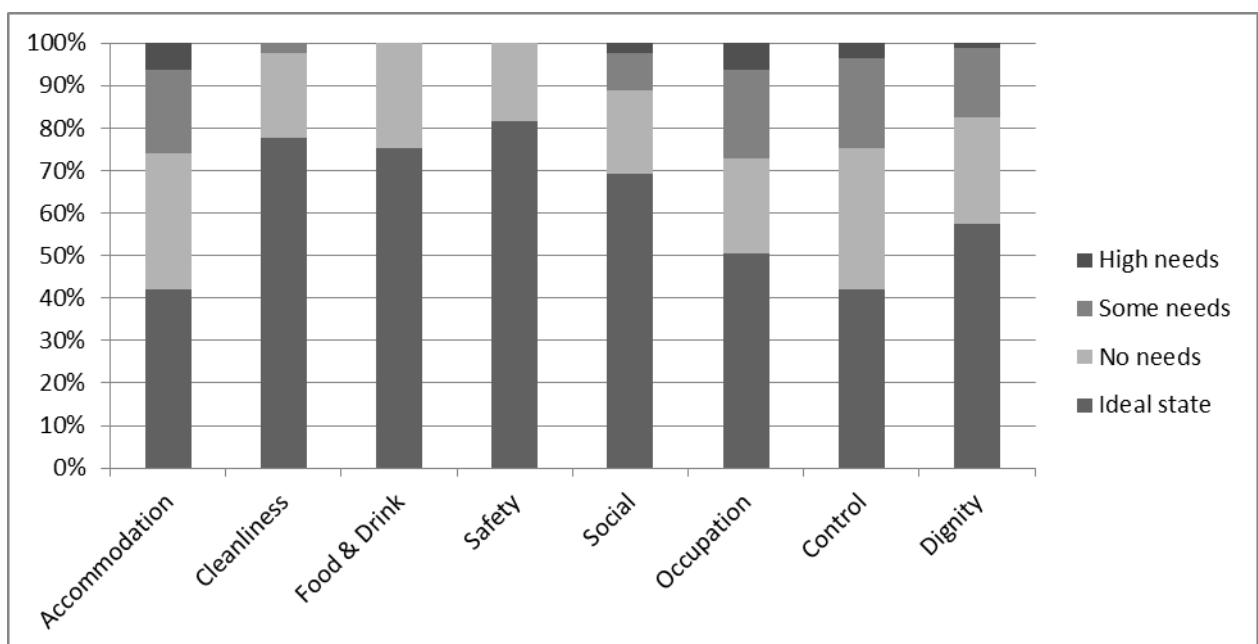


There were other areas where people with dementia identified more need than the figures from the group (people with dementia and carers completing ASCOT as part of case study site interviews) as a whole:

- Dignity (24 instances, 29% of responses, indicated unmet need)
- Social participation (12 instances, 14% of responses, indicated unmet need)



**Figure 6.** SCRQoL scores for people with dementia who completed ASCOT as part of the case study interviews.



**Figure 7.** SCRQoL scores for people with dementia accessing case study sites.

**Box 5. Completing ASCOT: an example from Jim (person with dementia who accessed Dementia Adviser site)**

Jim did not complete a well-being questionnaire at the first interview. At the second interview, he gave the following responses:

- I have as much control over my daily life as I want.
- I feel clean and able to present myself the way I like.
- I get all the food and drink I like when I want.
- My home is as clean and comfortable as I want.
- I feel as safe as I want.
- I have as much social contact as I want with people I like.
- I'm able to spend my time as I want, doing things I value or enjoy.
- Having help sometimes undermines the way I think and feel about myself.
- The way I'm helped and treated makes me think and feel better about myself.

Jim added the following comment: *"A year ago, my answers would have been very different. It's about coming to peace with self"*.

Jim completed the questionnaire again at the third interview (two months after he had previously completed it). He answered:

- I have as much control over my daily life as I want.
- I feel adequately clean and presentable.
- I get all the food and drink I like when I want.
- My home is as clean and comfortable as I want.
- I feel as safe as I want.
- I have as much social contact as I want with people I like.
- I'm able to spend my time as I want, doing things I value or enjoy.
- Having help completely undermines the way I feel about myself.
- The way I'm helped and treated makes me feel better about myself.

***Ascot data case study sites: Carers***

The following outlines the responses from carers who completed the ASCOT questionnaire as part of the in-depth case study site interviews. The SCRQoL scores for this group are

represented in Figures 8 and 9. Altogether, there were 82 instances of carers completing ASCOT as part of the in-depth case study site interviews.

**Accommodation:** There were 45 instances (55% of responses) where carers who had accessed the eight case study sites identified themselves as having no needs or being in an ideal state.

**Personal cleanliness and comfort:** There were 73 instances (89% of responses) where carers who had accessed the eight case study sites identified themselves as having no needs or being in an ideal state.

**Food and drink:** There were 76 instances (93% of responses) where carers who had accessed the eight case study sites identified themselves as having no needs or being in an ideal state.

**Safety:** There were 68 instances (83% of responses) where carers who had accessed the eight case study sites identified themselves as having no needs or being in an ideal state.

**Social participation:** There were 74 instances (90% of responses) where carers who had accessed the eight case study sites identified themselves as having no needs or being in an ideal state.

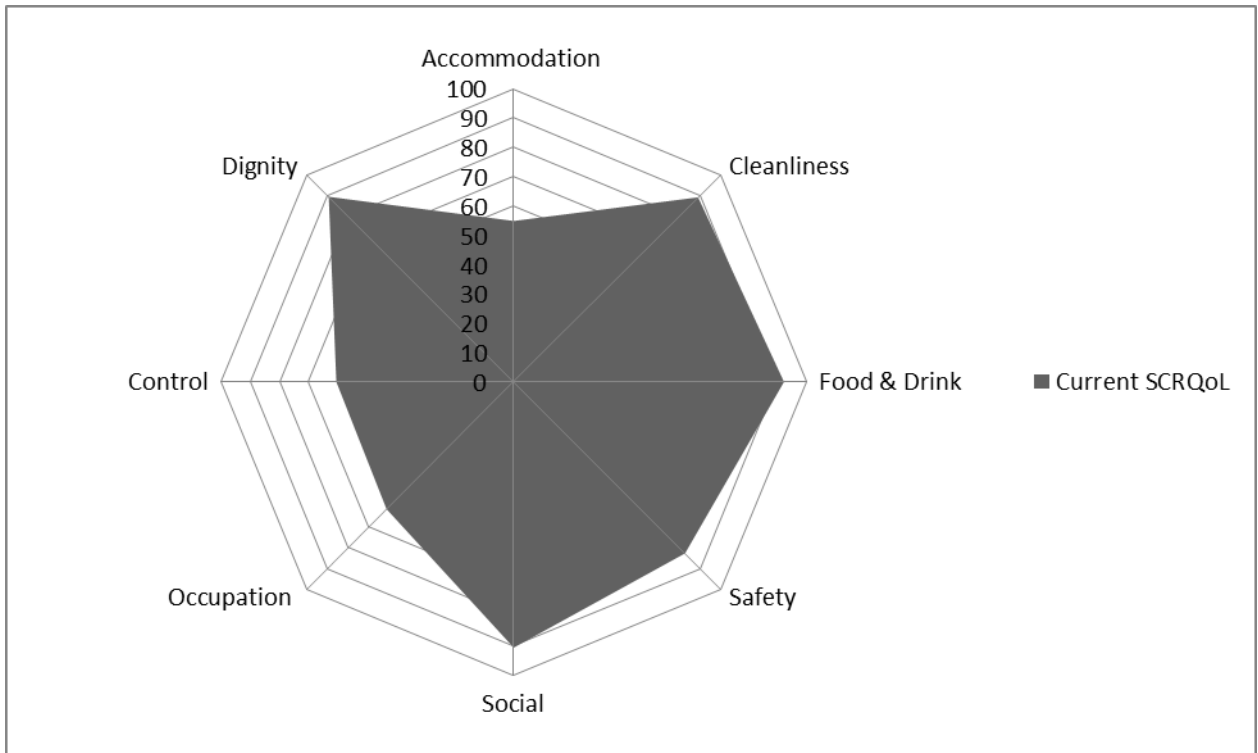
**Occupation:** There were 50 instances (61% of responses) where carers who had accessed the eight case study sites identified themselves as having no needs or being in an ideal state.

**Control:** There were 50 instances (61% of responses) where carers who had accessed the eight case study sites identified themselves as having no needs or being in an ideal state.

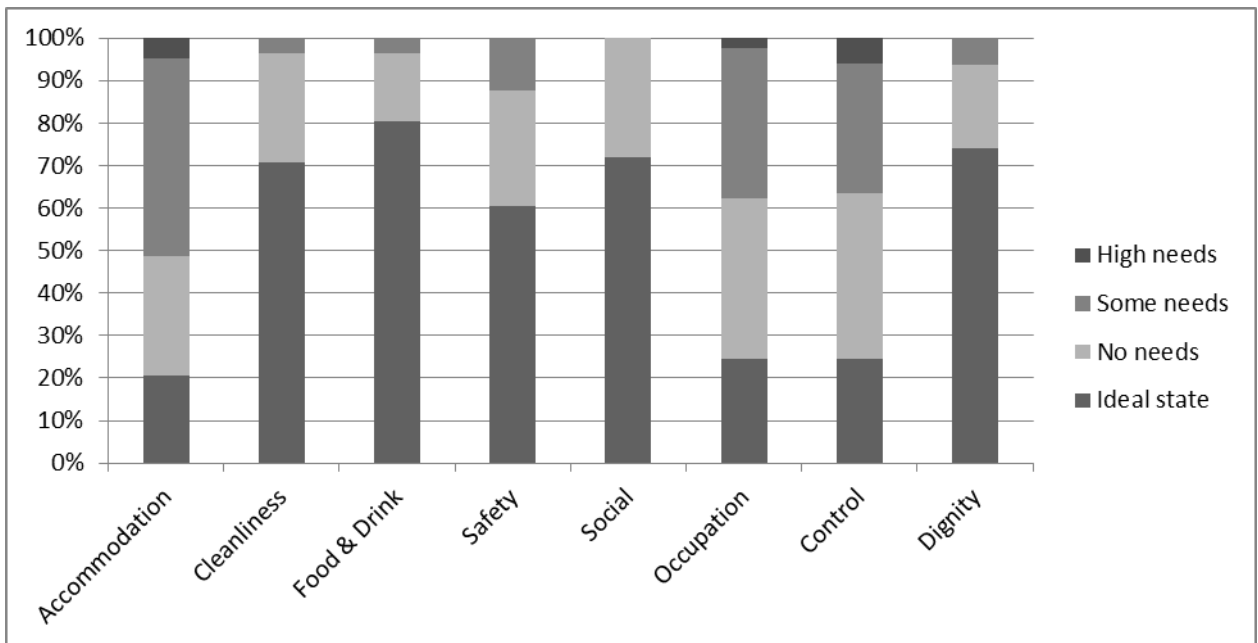
**Dignity:** There were 73 instances (89% of responses) where carers who had accessed the eight case study sites identified themselves as having no needs or being in an ideal state.

This data shows that, for **carers who completed ASCOT as part of the eight in-depth case study sites**, areas identified as having **most unmet needs** were:

- Accommodation (which was particularly low for this group) (37 instances, 45% of responses)
- Occupation (again, considerably lower than for the group as a whole) (32 instances, 39% of responses)
- Control (which was again particularly low in relation to the scores for people with dementia) (32 instances, 39% of responses, indicated unmet need).



**Figure 8.** SCRQoL data for carers who completed ASCOT as part of in-depth case study interviews.



**Figure 9.** SCRQoL score for carers accessing case study sites.

Table 11 summarises the ASCOT data which was collected as part of the eight in-depth case study site interviews.

	People with dementia (n = 84)	Carers (n = 82)	People with dementia and carers (n = 166)
Accommodation	70%	55%	62%
Personal cleanliness	92%	89%	90%
Food and drink	92%	92%	92%
Personal safety	94%	83%	88%
Social participation	86%	91%	88%
Occupation	72%	61%	67%
Control	71%	61%	66%
Dignity	80%	89%	84%

**Table 11.** Summary of ASCOT data collected from in-depth case study sites, showing the percentages of responses where people were identified as having no need in each area or being in an ideal state. Figures show the percentages of people who were identified as having no need in each area or being in an ideal state.

**Box 6. Completing ASCOT: an example from Suzanne (carer for Jim)**

During the first interview Stephanie completed the questionnaire with the researcher after Jim had left for an evening socialising with friends. She gave the following responses:

- I have as much control over my daily life as I want.
- I feel clean and able to present myself the way I like.
- I get all the food and drink I like when I want.
- My home is not quite clean and comfortable enough.
- Generally I feel adequately safe but not as safe as I would like.
- I have adequate social contact with people.
- I do some of the things I value or enjoy with my time.
- Having help makes me feel better about myself.
- The way I'm helped and treated makes me feel better about myself.

Suzanne added the following comment to her questionnaire: *“My well-being is vital to my husband as without it he could be faced with life away from his home. I have to work full time, stress caused by these factors has impacted on my otherwise good health.”*

Suzanne completed the questionnaire again at the third interview (which took place four months after the first). Her answers were:

- I have adequate control over my daily life.
- I feel adequately clean and presentable.

- I get all the food and drink I like when I want.
- My home is not quite clean and comfortable enough.
- Generally I feel adequately safe but not as safe as I would like.
- I have adequate social contact with people.
- I do some of the things I value or enjoy with my time.
- Having help makes me feel better about myself.
- The way I am helped and treated does not affect the way I think and feel about myself.

By looking at frequencies of answers from people with dementia and carers (using the descriptive statistics functions in SPSS), it is possible to consider the modal answer for each question (that is, the answer which was chosen the most by people completing the well-being questionnaire). The following trends emerge.

For people with dementia and carers as a group, the most common answers given were:

- I have as much control over my daily life as I want.
- I feel clean and able to present myself in the way I like.
- I get all the food and drink I like when I want.
- My home is adequately clean and comfortable.
- I feel as safe as I want.
- I have as much social contact as I want with people I like.
- I'm able to spend my time as I want, doing things I value or enjoy.
- Having help makes me think and feel better about myself.
- The way I'm helped and treated makes me think and feel better than myself.

By breaking down the data further and looking at the most common answers for people with dementia and the data for carers separately, it is possible to see some differences between the two groups.

For people with dementia, the modal answers were:

- I have as much control over my daily life as I want.
- I feel clean and able to present myself in the way I like.
- I get all the food and drink I like when I want.

- My home is as clean and comfortable as I want.
- I feel as safe as I want.
- I have as much social contact as I want with people I like.
- I'm able to spend my time as I want, doing things I value or enjoy.
- Having help makes me think and feel better about myself.
- The way I'm helped and treated makes me think and feel better than myself.

The modal answers for carers were:

- I have adequate control over my daily life.
- I feel clean and able to present myself in the way I like.
- I get all the food and drink I like when I want.
- My home is not quite clean or comfortable enough.
- I feel as safe as I want.
- I have as much social contact as I want with people I like.
- I do enough of the things I value or enjoy with my time.
- Having help makes me think and feel better about myself.
- The way I'm helped and treated makes me think and feel better than myself.

Further statistical analysis (Mann–Whitney *U*-test) shows areas where the differences between the two groups (people with dementia and carers) are significant, i.e.  $p < 0.05$ .

In the following areas, carers identified more unmet need than people with dementia:

- Control
- Safety
- Occupation
- Accommodation
- Food and drink
- How having help makes people feel

We now go on to compare the data collected within the Dementia Adviser sites with the data collected in the Peer Support Network sites (see Table 12). The data is for the eight in-depth case study sites.

People with dementia from Dementia Adviser case study sites identified more unmet needs than people from Peer Support Network sites in the areas of:

- Accommodation
- Personal cleanliness
- Social participation
- Occupation
- Control
- Dignity

There were two areas where people with dementia from Dementia Adviser case study sites identified the same needs as people with dementia from Peer Support Network sites:

- Food and drink
- Personal safety

There were no areas where people with dementia from Peer Support Network sites identified more need than people with dementia from Dementia Adviser sites.

Carers from Dementia Adviser case study sites identified more unmet needs than carers from Peer Support Network sites in the areas of:

- Personal cleanliness
- Food and drink
- Dignity

Carers from Dementia Adviser case study sites identified the same needs as carers from Peer Support Network sites in the area of:

- Social participation

Carers from Peer Support Network case study sites identified more unmet needs than carers from Dementia Adviser sites in the areas of:

- Accommodation
- Personal safety
- Occupation



- Control

	People with dementia – case study sites		Carers – case study sites	
	Dementia Adviser (n = 15)	Peer Support Network (n = 22)	Dementia Adviser (n = 25)	Peer Support Network (n = 15)
<b>Accommodation</b>	63%	82%	52%	44%
<b>Personal cleanliness</b>	94%	100%	94%	100%
<b>Food and drink</b>	100%	100%	94%	100%
<b>Personal safety</b>	100%	100%	91%	83%
<b>Social participation</b>	81%	94%	100%	100%
<b>Occupation</b>	50%	88%	65%	58%
<b>Control</b>	60%	86%	67%	58%
<b>Dignity</b>	68%	92%	91%	97%

**Table 12.** Comparison of ASCOT data between people with dementia and carers, across Peer Support Network and Dementia Adviser sites, showing the percentages of responses where people were identified as having no need in each area or being in an ideal state. Having considered the ASCOT data collected within the case study site interviews, we now move on to ASCOT data collected from all 40 demonstration sites (Strand 1b of the evaluation).

### **ASCOT data for all 40 demonstration sites**

- **The areas identified as having the most unmet needs by people with dementia and carers accessing all 40 demonstration sites were accommodation, occupation and control.**
- **People with dementia from the Peer Support Network sites were identified as having more need than people with dementia from the Dementia Adviser sites in the areas of accommodation, personal cleanliness, food and drink, personal safety, occupation, control and dignity.**
- **Carers from Peer Support Network sites identified more need than carers from Dementia Adviser sites in the areas of personal cleanliness, food and drink, personal safety, social participation, control and dignity.**

**ASCOT data: All respondents**

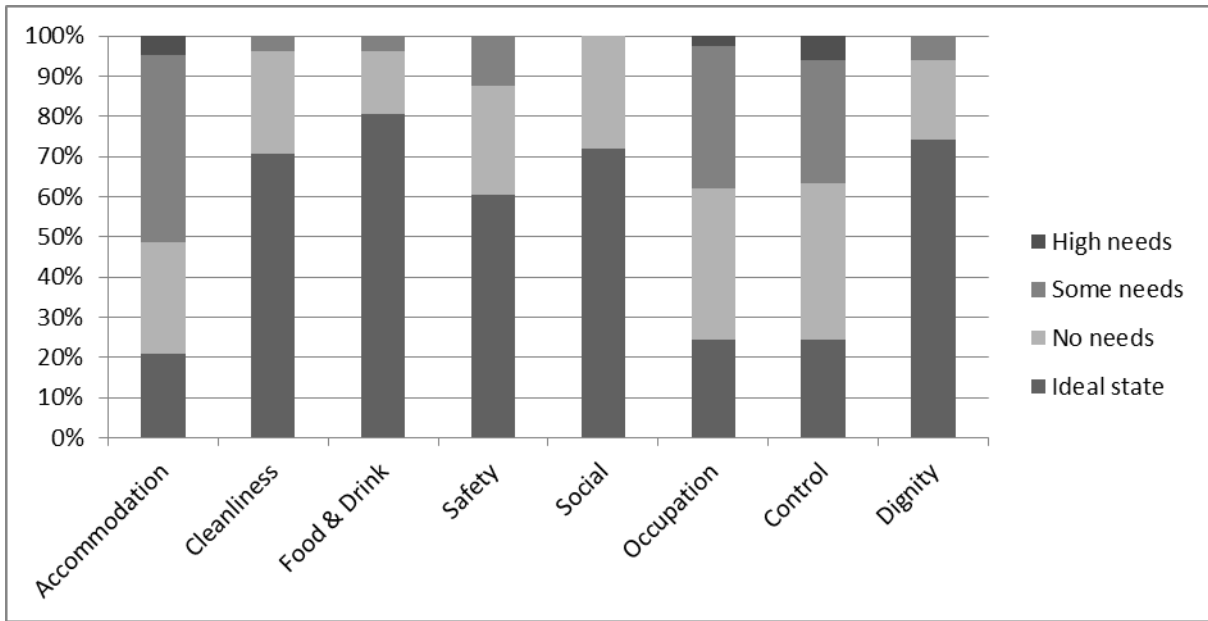
Altogether, there were 602 questionnaires returned over the 7-month period. A total of 282 of these were from Dementia Adviser sites, 320 were from Peer Support Network sites. The evaluation does not have information for this aspect of the data as to whether any of the people with dementia or carers completing the questionnaires did so more than once, or what support people had in completing them.

Table 13 represents the scores from people with dementia and carers who had accessed the 40 demonstration sites (shown as percentage of responses where people were identified as having no needs or being in an ideal state) and is also illustrated in Figures 10 and 11.

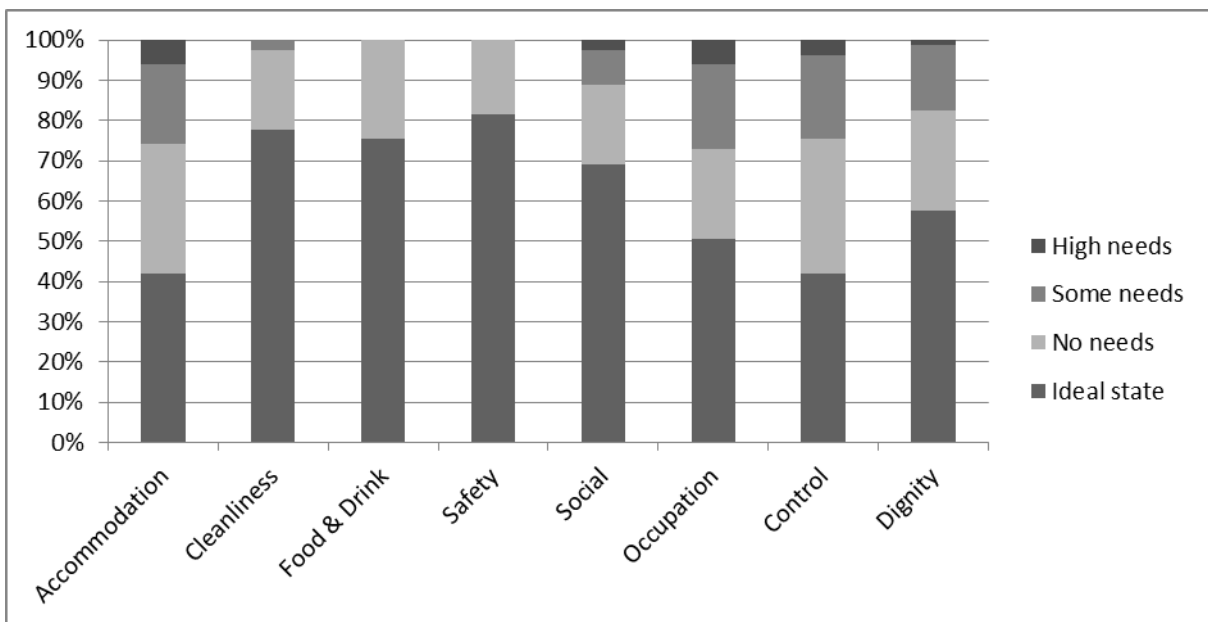
	People with dementia (all demonstration sites)	Carers (all demonstration sites)
<b>Accommodation</b>	66%	52%
<b>Personal cleanliness</b>	85%	87%
<b>Food and drink</b>	88%	90%
<b>Personal safety</b>	88%	84%
<b>Social participation</b>	83%	85%
<b>Occupation</b>	69%	64%
<b>Control</b>	69%	62%
<b>Dignity</b>	76%	82%

**Table 13.** ASCOT scores for people with dementia and carers across all demonstration sites.

**ASCOT data: By respondent**



**Figure 10.** SCRQoL scores for carers accessing all 40 demonstration sites.



**Figure 11.** SCRQoL scores for people with dementia accessing all 40 demonstration sites.

In the area of accommodation, there were 177 instances (66% of responses) where people with dementia identified themselves as having no need or being in an ideal state and 112 instances (52% of responses) where carers identified themselves as having no need or being in an ideal state.

In the area of personal cleanliness, there were 228 instances (85% of responses) where people with dementia and 188 instances (87% of responses) where carers identified themselves as having no need or being in an ideal state.

In the area of nutrition, there were 236 instances (88% of responses) where people with dementia and 195 instances (90% of responses) where carers identified themselves as having no need or being in an ideal state.

In the area of personal safety, there were 235 (87% of responses) where people with dementia and 181 instances (84% of responses) where carers identified themselves as having no need or being in an ideal state.

In the area of social participation, there were 224 instances (83% of responses) where people with dementia and 184 instances (85% of responses) where carers identified themselves as having no needs or being in an ideal state.

In the area of occupation, there were 186 instances (69% of responses) where people with dementia and 138 instances (64% of responses) where carers identified themselves as having no need or being in an ideal state.

In the area of control, there were 183 instances (68% of responses) where people with dementia and 134 instances (62% of responses) where carers identified themselves as having no need or being in an ideal state.

In the area of dignity, there were 206 instances (76% of responses) where people with dementia and 178 instances (82% of responses) where carers identified themselves as having no need or being in an ideal state.

Therefore, the areas that people with dementia accessing all 40 demonstration sites identified as having the most need were:

- Accommodation
- Control

- Occupation

The areas that carers accessing all 40 demonstration sites identified as having the most need were also:

- Accommodation (carers identified more need than people with dementia on this)
- Control (again, carers identified more need than people with dementia)
- Occupation (again, carers identified more need than people with dementia on this)

People with dementia accessing the 40 demonstration sites identified more need in the area of dignity.

**ASCOT data: By Peer Support Network/Dementia Adviser site (all 40 sites)**

Continuing with data that was collected from all 40 demonstration sites we now compare data that was collected from Dementia Adviser sites with data that was collected from Peer Support Network sites. Table 14 shows the percentage of responses where people identified themselves as having no needs or being in an ideal state.

	People with dementia – all demonstration sites		Carers – all demonstration sites	
	Dementia Adviser	Peer Support Network	Dementia Adviser	Peer Support Network
<b>Accommodation</b>	73%	64%	46%	47%
<b>Personal cleanliness</b>	97%	94%	97%	91%
<b>Food and drink</b>	97%	96%	96%	95%
<b>Personal safety</b>	75%	94%	95%	89%
<b>Social participation</b>	90%	92%	93%	92%
<b>Occupation</b>	76%	71%	57%	67%
<b>Control</b>	83%	72%	72%	65%
<b>Dignity</b>	86%	74%	92%	84%

**Table 14.** ASCOT data from people with dementia and carers across Peer Support Network and Dementia Adviser sites (all demonstration sites) (shown as percentage of responses where people were identified as having no needs or being in an ideal state).

People with dementia in Dementia Adviser sites identified more need than people with dementia in Peer Support Network sites in the area of social participation, although this difference was not very big.

People with dementia in Peer Support Network sites, therefore, identified more need in the areas of:

- Accommodation
- Personal cleanliness
- Food and drink
- Personal safety
- Occupation
- Control
- Dignity

Carers from Dementia Adviser sites identified more need than carers from Peer Support Network sites in the areas of:

- Accommodation
- Occupation

Carers from Peer Support Network sites identified more need than carers from Dementia Adviser sites in the areas of:

- Personal cleanliness
- Food and drink
- Personal safety
- Social participation (although the difference was very small)
- Control
- Dignity

Having outlined the ASCOT data which was collected within Strands 1 and 3 of the evaluation, we now move on to consider data that was collected from the non-demonstration site group of people with dementia and carers.

### ASCOT data: Non-demonstration site group

- The non-demonstration site group as a whole (both people with dementia and carers) identified more unmet needs than people with dementia and carers from the demonstration sites in the areas of accommodation, cleanliness, safety, occupation, control and dignity.
- People with dementia from the non-demonstration site group identified more unmet needs than people with dementia from the in-depth case study sites as well as people with dementia from the 40 demonstration sites in the areas of accommodation, personal cleanliness, occupation, control and dignity.
- Carers from the non-demonstration site group identified more unmet needs from carers from the in-depth case study sites and the 40 demonstration sites on all areas except social participation.

	Non-demonstration site group (people with dementia and carers)	Non-demonstration site group (carers)	Non-demonstration site group (people with dementia)
Accommodation	50%	43%	56%
Cleanliness	84%	82%	83%
Food and drink	93%	90%	96%
Safety	84%	73%	96%
Social	89%	90%	85%
Occupation	61%	53%	69%
Control	58%	53%	58%
Dignity	70%	67%	73%

**Table 15.** Non-demonstration site group ASCOT data (shown as percentage of responses where people were identified as having no needs or being in an ideal state).

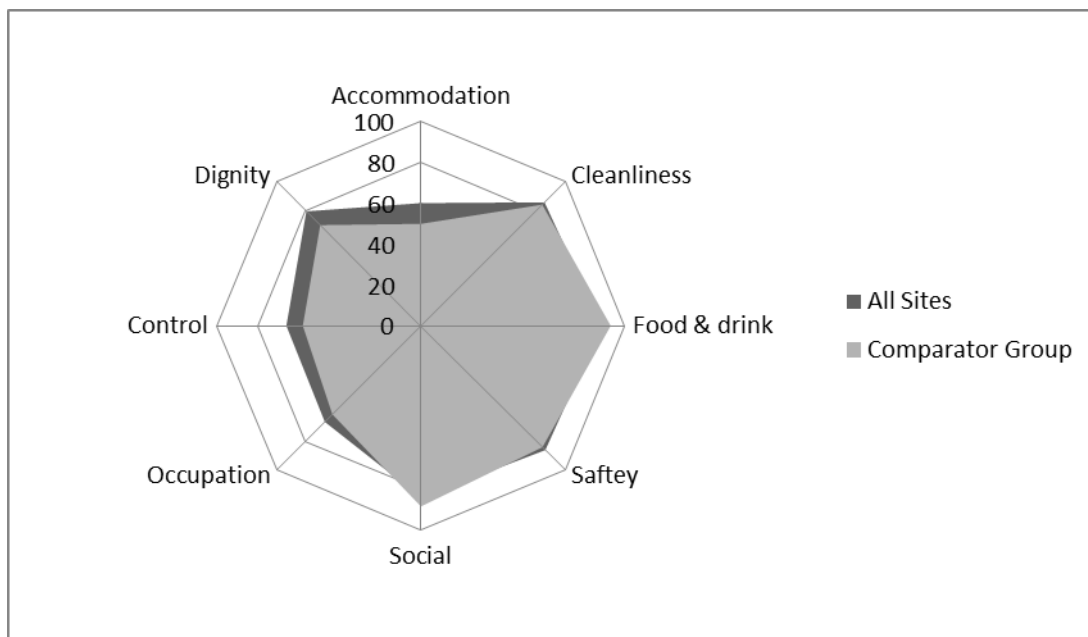
Table 15 identifies levels of no need in the non-demonstration site, while Figure 12 maps out responses from the non-demonstration site group against respondents from all demonstration sites. Thirty-seven questionnaires were returned in total.

The non-demonstration site group as a whole identified less need than the demonstration site group in the areas of

- Food and drink
- Social participation

The non-demonstration site group identified more need than the demonstration site group in the areas of:

- Accommodation
- Cleanliness
- Safety
- Occupation
- Control
- Dignity



**Figure 12.** Comparison of non-demonstration site group SCRQoL scores against SCRQoL scores for demonstration sites.

We now draw together ASCOT data from the three different groups.



	People with dementia – case study sites	Carers – case study sites	People with dementia – all demonstration sites	Carers – all demonstration sites	People with dementia – non-demonstration site group	Carers – non-demonstration site group
<b>Accommodation</b>	70%	55%	66%	52%	56%	43%
<b>Personal cleanliness</b>	92%	89%	85%	87%	83%	82%
<b>Food and drink</b>	92%	92%	88%	90%	96%	90%
<b>Personal safety</b>	94%	83%	88%	86%	96%	73%
<b>Social participation</b>	85%	91%	83%	85%	85%	90%
<b>Occupation</b>	72%	61%	70%	63%	69%	53%
<b>Control</b>	71%	61%	68%	62%	58%	53%
<b>Dignity</b>	80%	89%	76%	82%	73%	67%

**Table 16.** ASCOT data from all three groups (in-depth case studies; all demonstration sites and non-demonstration site), showing the percentages of responses where people were identified as having no need in each area or being in an ideal state.

As discussed in the previous sections, Table 16 highlights that, of the three sample groups, most unmet need was expressed by the carers in the non-demonstration site; in particular this related to accommodation, personal safety, occupation, control and dignity. For people with dementia, most unmet need was expressed by those also in the non-demonstration site; in particular this related to accommodation and control.

In considering the complexities of attributing outcomes to service use, it must be acknowledged that there are many different factors that must be considered in addition to support from any one service. This includes other services or support that people might be accessing in addition to the services being evaluated as well as informal support from family, friends and wider social networks. It must also be noted that quality of life does not necessarily directly correlate with quality of care. Some studies have used other sources of data such as external evaluations or routine inspections of services in evaluating services, whilst other studies have done a ‘before and after’ comparison of SCRQoL scores or used ASCOT personal outcomes measures. The latter was not within the scope of Healthbridge,

however the ASCOT data that was collected within Healthbridge can be used in the meta-analysis alongside other data collected for the evaluation.

### **DEMqoL results**

- **DEMqoL and DEMqoL-proxy (quality of life questionnaires) were completed as appropriate within the in-depth case study site interviews.**
- **In general, people with dementia scored themselves as having a lower quality of life than carers completing questionnaires on behalf of people with dementia.**
- **People expressed fewer concerns (and therefore better quality of life) in the area of everyday life.**
- **More concern (and therefore poorer quality of life) were expressed in areas relating to thoughts and feelings.**

There were 79 DEMqoL questionnaires completed with people with dementia and 66 DEMqoL-proxy questionnaires completed with carers for the Healthbridge evaluation (see Figures 13 and 14).

The average DEMqoL score for people with dementia across all of the in-depth interviews was 90.9. The average DEMqoL-proxy score (questionnaires completed on behalf of people who were unable to answer themselves) across all of the in-depth interviews was 93.1.

The average DEMqoL score from people with dementia from Dementia Adviser sites was 88. The average DEMqoL-proxy score for the Dementia Adviser sites was 89.7.

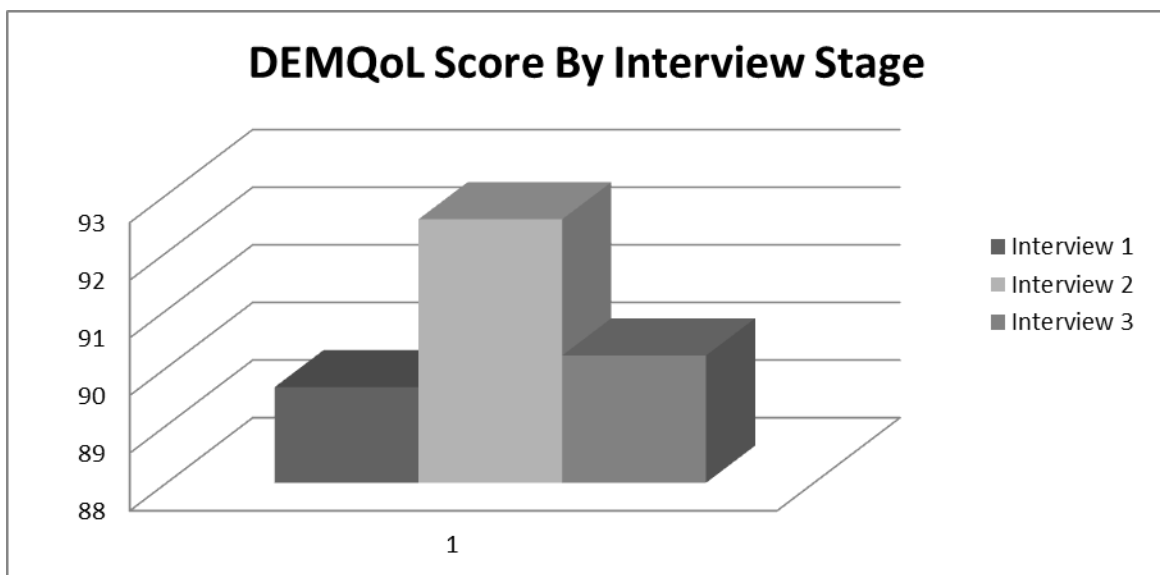
The average DEMqoL score for people with dementia from Peer Support Network sites was 92.8. The average DEMqoL-proxy score from Peer Support Network sites was 96.6.

DEMqoL and DEMqoL-proxy scores reflected recurring concerns amongst responses. Most notably, thoughts and feelings offered lower responses (particularly feeling cheerful, lively and full of energy) than the other categories. Concerns about everyday life (such as getting

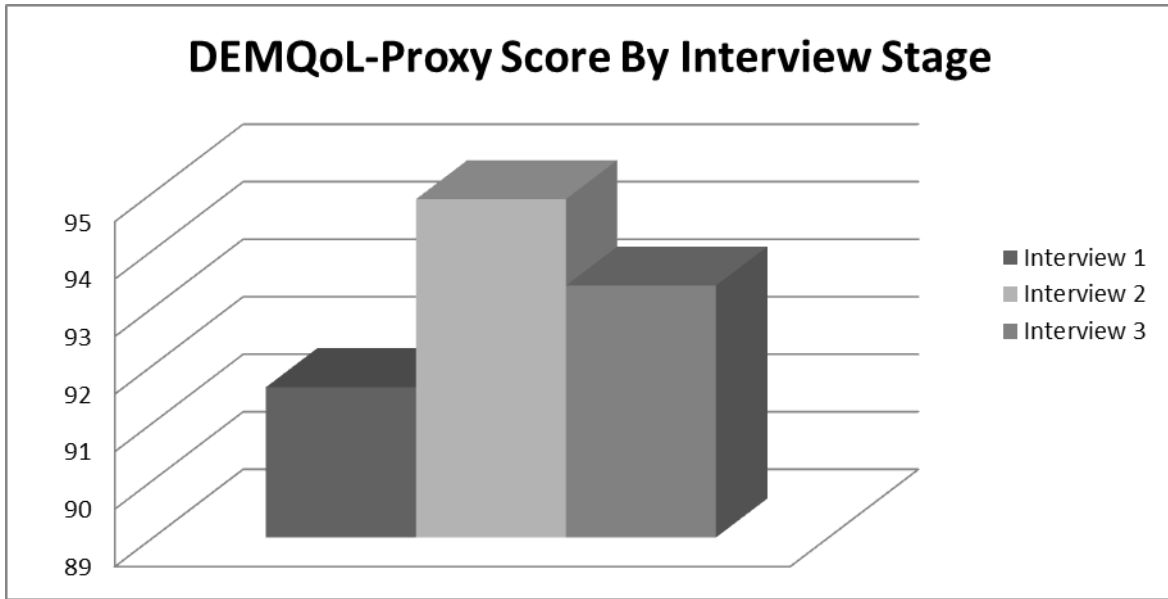
help or getting to the toilet on time) were of less concern. Below are the average DEMQoL scores for all people with dementia.

Boxes 7 and 8 outline the individual responses given by Jim and Anayat, both people with dementia who had accessed a Dementia Adviser site. These examples provide the individual responses from a person with dementia whose DEMQoL scores were higher than average (Jim, whose DEMQoL score on both occasions was 94), and from a person with dementia whose DEMQoL scores were lower than average (Anayat, whose DEMQoL scores were 44 and 50), providing a picture of the range of DEMQoL scores and how people with those scores responded to each question.

It is also interesting to consider how the scores differed across the three interviews. The DEMQoL and DEMQoL-proxy data remain consistent throughout. Both DEMQoL and DEMQoL-proxy data reflect that the overall scores are similar across three interviews, although reached their peak in interview two. The DEMQoL-proxy scores were, on average, slightly higher than the DEMQoL scores.



**Figure 13.** DEMQoL scores across three interviews.



**Figure 14.** DEMqoL-proxy scores across three interviews.

### Box 7. Completing DEMQoL: an example from Jim

Feelings. In the last week, have you felt:

	First interview (Jan 2011)	Third interview (June 2011)
Cheerful	Quite a bit	A lot/quite a bit
Worried/anxious	Not at all	Not at all
Enjoying life	A lot	A lot
Frustrated	A little	Quite a bit
Confident	A lot	Quite a bit
Full of energy	Quite a bit	Quite a bit
Sad	Quite a bit	A lot
Lonely	Quite a bit	A little
Distressed	A little	A lot
Lively	A lot	Quite a bit
Irritable	A little	A little
Fed up	A little	A little
That there were things you wanted to do but couldn't	A lot	Quite a bit

Memory. In the last week, how worried have you been about.....

	First interview (Jan 2011)	Third interview (June 2011)
Forgetting things that happened recently	A little	Not at all
Forgetting who people are	Not at all	Not at all
Forgetting what day it is	A little	Not at all
Your thoughts being muddled	A little	A little
Difficulty making decisions	Not at all	Not at all
Poor concentration	Not at all	Not at all

Everyday life. In the last week, how worried have you been about.....

	First interview (Jan 2011)	Third interview (June 2011)
Not having enough company	A little	Not at all
How you get on with people close to you	Not at all	Not at all
Getting the affection that you want	Not at all	Not at all
People not listening to you	Not at all	Not at all
Making yourself understood	Not at all	Not at all
Getting help when you need it	Not at all	Not at all
Getting to the toilet in time	Not at all	Not at all
How you feel in yourself	A little	Not at all
Your health overall	Not at all	Not at all

Overall quality of life: on both occasions, Jim rated his overall quality of life as very good.

On both occasions, Jim's DEMQoL score was 94.0. This compares with an average of 90.9 for all people with dementia who completed DEMQoL; an average of 88 for people with dementia in Dementia Adviser sites and an average of 92.8 for people with dementia from Peer Support Network sites who completed DEMQoL.

**Box 8. Completing DEMQoL: an example from Anayat, a person with dementia who had accessed a Dementia Adviser site**

Feelings. In the last week, have you felt:

	First interview (April 2011)	Third interview (June 2011)
Cheerful	A little	Not at all
Worried/anxious	Quite a bit	A lot
Enjoying life	Not at all	Not at all
Frustrated	A lot	Quite a bit
Confident	Not at all	Not at all
Full of energy	A little	A lot
Sad	A lot	A lot
Lonely	Quite a bit	A lot
Distressed	Quite a bit	A lot
Lively	A lot	Not at all
Irritable	A lot	Not at all
Fed up	A lot	A lot
That there were things you wanted to do but couldn't	A lot	Not at all

Memory. In the last week, how worried have you been about.....

	First interview (Apr 2011)	Third interview (June 2011)
Forgetting things that happened recently	Quite a bit	A lot
Forgetting who people are	A lot	A lot
Forgetting what day it is	A lot	Quite a bit
Your thoughts being muddled	A lot	Not at all
Difficulty making decisions	A lot	A lot
Poor concentration	A lot	A lot

Everyday life. In the last week, how worried have you been about.....

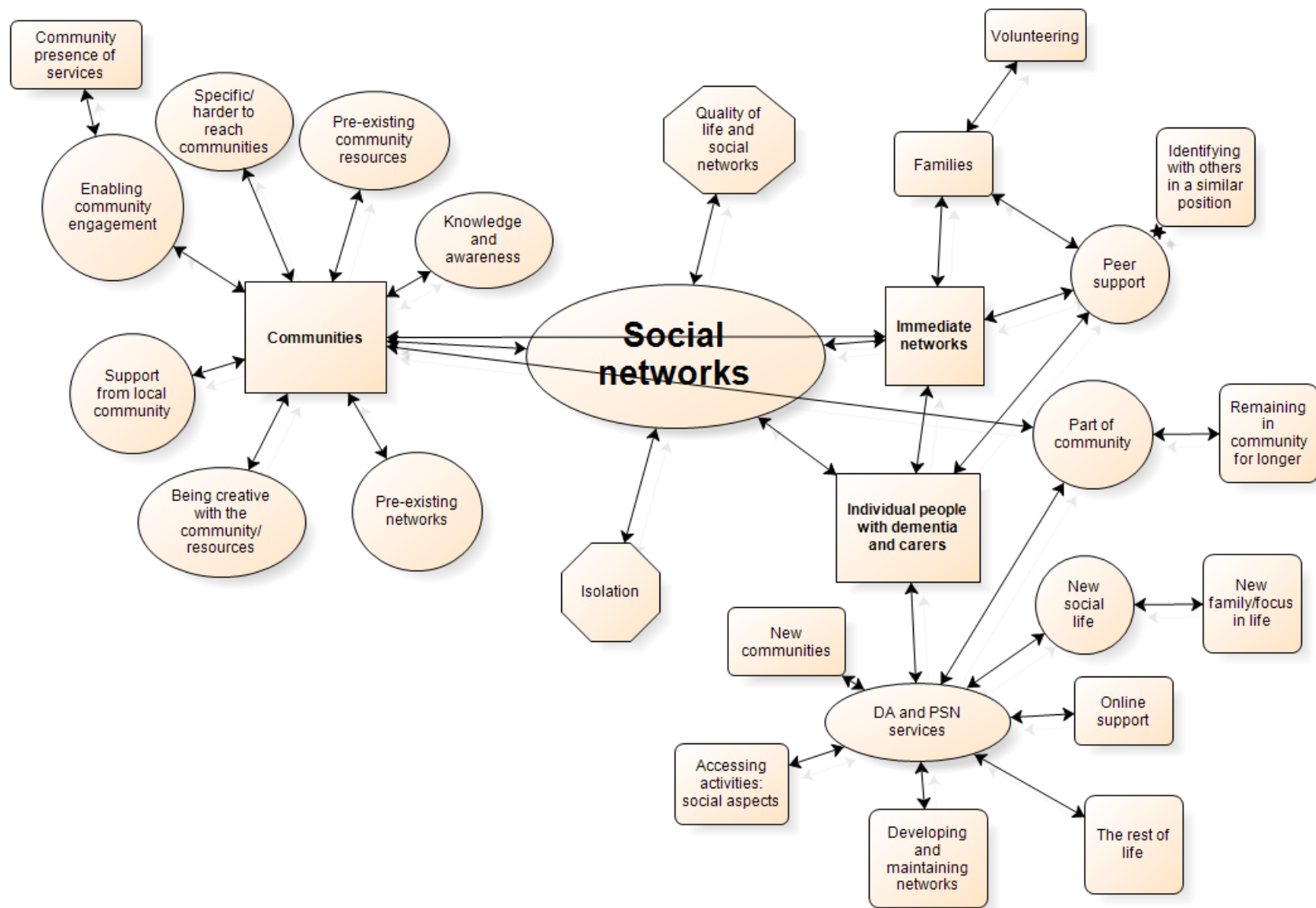
	First interview (Apr 2011)	Third interview (June 2011)
Not having enough company	Quite a bit	Quite a bit
How you get on with people close to you	A lot	A lot
Getting the affection that you want	A lot	Not at all
People not listening to you	A lot	A lot
Making yourself understood	Quite a bit	Quite a bit
Getting help when you need it	A lot	A lot
Getting to the toilet in time	Not at all	Quite a bit
How you feel in yourself	Quite a bit	Quite a bit
Your health overall	A lot	A lot

Overall quality of life: on both occasions, Anayat rated his overall quality of life as poor. On the first occasion DEMQoL score was 44, on the second, 50. This compares with an average of 90.9 for all people with dementia who completed DEMQoL; an average of 88 for people with dementia in Dementia Adviser sites and an average of 92.8 for people with dementia from Peer Support Network sites who completed DEMQoL.

### **Impact on social networks**

Returning to the theme of this section of the findings (the impact of Peer Support Network and Dementia Adviser services on well-being of people with dementia and carers), the Healthbridge evaluation set out to consider the impact of the services on people's social networks. Here we present qualitative data relating to Peer Support Network and Dementia Adviser services and social network theory.

- **Living with dementia is an isolating experience which can impact negatively on people's pre-existing social networks.**
- **Peer Support Network and Dementia Adviser services had a role to play in enabling new social networks and connections. This included support from others in a similar position as well as enabling people to rebuild connections with their immediate and wider community.**
- **Peer Support Network and Dementia Adviser services also had an impact on communities, enabling community engagement for people with dementia and carers as well as raising awareness of dementia.**





This section of data relates to social network theory. The data demonstrates the impact of Peer Support Network and Dementia Adviser services in relation to their impact on social networks. This includes the impact on the social networks of individual people with dementia, their immediate networks and communities. This data also relates to isolation and quality of life of people with dementia and the impact of Peer Support Network and Dementia Adviser services in reducing isolation and improving quality of life.

### ***Individual people with dementia and carers and their immediate networks***

Living with dementia is an isolating experience, and one which can impact negatively on people's pre-existing social networks:

Jim, person with dementia who had accessed DA services: *Sometimes I feel a bit... You know, sometimes I'm on my own in the house and I feel very lonely. You know, and... I can't... I don't go anywhere – I don't drive anywhere or anything like that.*

The significance of interpersonal support is backed up by one carer's idea for future development of Dementia Adviser services:

Suzanne, carer who had accessed DA service: *That's the one thing I would like....a circle of support. A circle of maybe half a dozen people within your area that they are going to give you instant support at the end of the phone if you have a crisis.....It doesn't matter if you're not having a crisis, but if emotionally and mentally you feel you're having a crisis, to pick up the phone...*

There were examples of ways in which both Peer Support Network and Dementia Adviser services have enabled people to access a new social life. This was perhaps most obvious within Peer Support Network services, but people from Dementia Adviser sites also spoke about accessing support groups as a result of support from Dementia Adviser services, and the positive aspect of this:

Elsa, volunteer from PSN site: *You know, when you get... When a person gets diagnosed, sometimes they want to hide away. And this actually gets them out somewhere where everybody that... You know, we all look upon each other as equal. And... I think that encourages them to take more part in the community.*

Sue, carer who had accessed DA service: *[Dementia Adviser]'s arranged these afternoons, or evening things. And she said something to me on the phone the other day. Little trips out might be occurring, providing they've got the money, the funds. Like going to \_\_\_ Abbey or something like that. So it looks as though she's carrying on looking into different things..... We wouldn't have known them otherwise... And you know that they're in a similar situation and you can chat to someone like that more, rather than if it's someone... I know you've got your own friends and things, but it's a different kind of thing, isn't it? Talking about a certain illness or something like that. Yeah. So I think if she does... Which she said she probably will be able to, arrange something, yeah.*

People spoke about ways in which Peer Support Network and Dementia Adviser services enabled people to find a new focus in life – this section of data outlines social aspects of this new focus in life – referred to by some as their 'new family':

Elsa, volunteer from PSN site: *Yeah. You see, we're like a... I don't know whether you would call it family, but they have [name]'s telephone number and they have mine. And they ring up.....they ring up and chat and say, "We're not coming this week because..." or "Can we bring along so and so, because they're down on holiday?" And all that sort of thing.*

People spoke about new communities being created as a result of Peer Support Network and Dementia Adviser services. This aspect of the data was relevant to both Peer Support Network and Dementia Adviser services. As well as the obvious communities created by Peer Support Network services, people from Dementia Adviser services talk about the creation of a community of people who had accessed support from the Dementia Adviser:

Heidi, professional who had accessed DA site: *So, you know, [Dementia Adviser] goes there – the people there have all been in touch with her at some time or another. And it's a really nice way of getting whole families together. To come together.*

Within Peer Support Network services, there was variance between an impact on social networks through focused activities that led on to peer support, and groups were formed for the sole purpose of peer support relating to issues specific to dementia. Some groups

focused on reaching people who had previously been unable to access group work:

Tim, local professional from memory clinic who had worked alongside PSN site: *And then, certainly, some of the other groups that we set have been about trying to bring in isolated groups for some of the older people that don't have family or other supports and they might not be able to access some of our groups within the memory service, because you need a carer to come along with you. How can we offer them a service? Where actually they would feel able to engage. And it's much more activity-based, rather than actually thinking about some of the... Our other groups are very, sort of, theory led about implementing coping strategies. Which, for them, they would need one-to-one support from a member of staff to go home and to be able to implement it. It needed to be a different set of goals, if you like, for those individuals.*

For some, accessing activities had a social impact:

Nancy, carer who had accessed PSN group: *Very positive. It's good because it's not just all singing. It gives them an opportunity to talk a little bit about themselves. To meet other people who are in a similar situation. And to do an enjoyable and participatory event. .... Certainly in terms of your well-being. And as I've seen, it boosts confidence. It really does. And for people who... Because there are people in the group who sometimes don't really have any other contact – or not very much contact – in the week, it's a real opportunity for them to be able to socialise, to be able to express any problems or difficulties.*

Peer Support Network and Dementia Adviser services also had a role in developing and maintaining social networks:

Lindsay, volunteer from PSN site: *And to see couples actually playing together, and laughing and joking together, was one of the those moments where you think that you don't get emotionally involved any more, but actually it was a very... It's a privilege to be able to be involved in something where you're giving people back that fun and happiness together again, and give them a glimpse of their old... How things used to be. So that was really good, so... Although they're only small things, those small things make masses of difference.*

When considering the impact of Peer Support Network groups on the social networks of those attending, the extent to which people with dementia and carers supported one another outside of formal group activities was significant. There was a range of experience identified in relation to this. Some people had social contact within a different context, such as other local dementia-related groups or pre-existing social networks. Others spoke about the difficulties of finding time and respite in order to do so.

Others spoke about building up relationships that went beyond the formal group activity:

Laurie, person with dementia who had attended PSN group: *And that's because I hadn't seen her and we had an outing to the gardens and she wasn't there. I was a bit concerned, so I rang, and she told me that her husband was in [hospital] and he was very poorly.*

People also spoke about how support from Peer Support Network or Dementia Adviser services supported them with the rest of their lives, in particular socialising:

Marianne, PSN volunteer (who had previously cared for her own husband): *I think being able to offload onto somebody like me and [name] and [name] and so on means that they are, therefore, going to be easier with other people, rather than tidily wrapped up. And the fact that they are therefore probably going to enjoy... Be able... Allow... They are going to be able to enjoy whatever is around them rather more than if they were hoarding all these feelings and stress inside them. I'm not saying it releases them totally, because it can't. But I think it makes things easier for them – reaching out. And also when we meet, often, we will meet in a café or we will meet in a restaurant or we will meet in the park. And we sometimes engage with other people.*

There were some references to online support, although this did not appear to be as effective as direct person-to-person interaction. Some staff and stakeholders referred to online support as a potential aspect of future service development.

Data also included ways in which support from Peer Support Network and Dementia Adviser services enabled people to be more part of their local community. This included people

remaining in their own homes for longer as a result of support from Peer Support Network and Dementia Adviser services.

It would not be possible to cover social network theory in relation to Peer Support Network and Dementia Adviser services without considering peer support in relation to social networks. There were examples of Peer Support Network and Dementia Adviser services establishing networks that were built around people socialising with others who are in a similar position:

*Lindsay, volunteer from PSN site: The most important things, for me, are... It's provided the platform for people to be able to meet each other with likeminded... With like... In effect similar problems or different stages, so they can support each other.....It's... just providing people with the opportunity to get together but onto something that they enjoy doing themselves. That they enjoy doing – to give them the opportunity to build up relationships. So that... They feel comfortable doing other things and going other places.*

Families are an inevitable aspect of social networks, as illustrated in the following quote:

*Ange, Dementia Adviser: A lot of the work is really with families. ...This family that I'm involved with – I mean, the police have been involved. It's been quite... You know, an emotional sort of thing with the family... And the stepfather. And he's... You know... Absolutely idolises his wife and is really, really trying his best. And you know, sometimes \_\_\_ and you have to... If the house isn't as tidy as it's always been, it doesn't really – it's not the end of the world. But it's... Going out and doing things with the person with dementia than sitting in an immaculate house and doing nothing... But the family have said, you know, because the house is untidy... Where really it's a matter of focusing on what is important, isn't it? At the time? And he's very... I think because the family have criticised him so much, he's very reluctant to let anybody visit or – which I can understand, you know, if he feels like – he's worried that people are checking up on him or whatever... And, again, I've been taking this person to go to the Day Centre, because he sees it as quite negative, where I'm trying to make him see how positive it can be. You know, she's stimulated, she's mixing with other ladies... It gives them both a time away from each other. You know, you try and*

*establish a bit of a routine. So that he's sort of like... He'll say "Well, you don't want to go today, do you?" Rather than say, you know... Be encouraging or "Let's get up and see..."*

### ***Dementia as a community issue***

As stated in the literature review, there has been a drive within policy as well as within the theoretical perspectives that underpin this evaluation towards the development of inclusive communities which support people with dementia and their carers. The emphasis on dementia as a family/community issue was echoed in what was said in relation to support for carers, families and communities having a positive impact on people with dementia themselves.

Both Peer Support Network and Dementia Adviser services made use of people's pre-existing networks. Sometimes there was use of pre-existing community groups:

*Marion, PSN coordinator: The first [goal] was to not only set up about 20 memory cafés across [site], but to set them up so that they were, sort of, community grown, really. Community led. Very much using local people and a real emphasis on the building of a socially cohesive network.*

Some said that the support from their pre-existing networks was sufficient and that they did not need any further social support from Peer Support Network or Dementia Adviser services:

*Hannah, carer who had accessed DA site: That's true, but I've never been one for being with groups, etc. My husband is really, really good and I've got a good friend network who I can sound off and... So it's... You know, I don't really feel that is a problem.*

Staff from both Peer Support Network and Dementia Adviser sites spoke about use of pre-existing community resources:

*Lisa, staff from DA site: And I know that a lot of people I've been involved with as well, it's about being creative within the community. Because it is very much based on community resources, because it's not an agency that can say: "Well, actually,*

*yeah, we can fund you to go so many days a week here, there and everywhere.” It is being very, very creative. So I think it’s opened up in a lot of people of actually what is out there, you know, in the community. Where they hadn’t previously known, because they haven’t needed to know.*

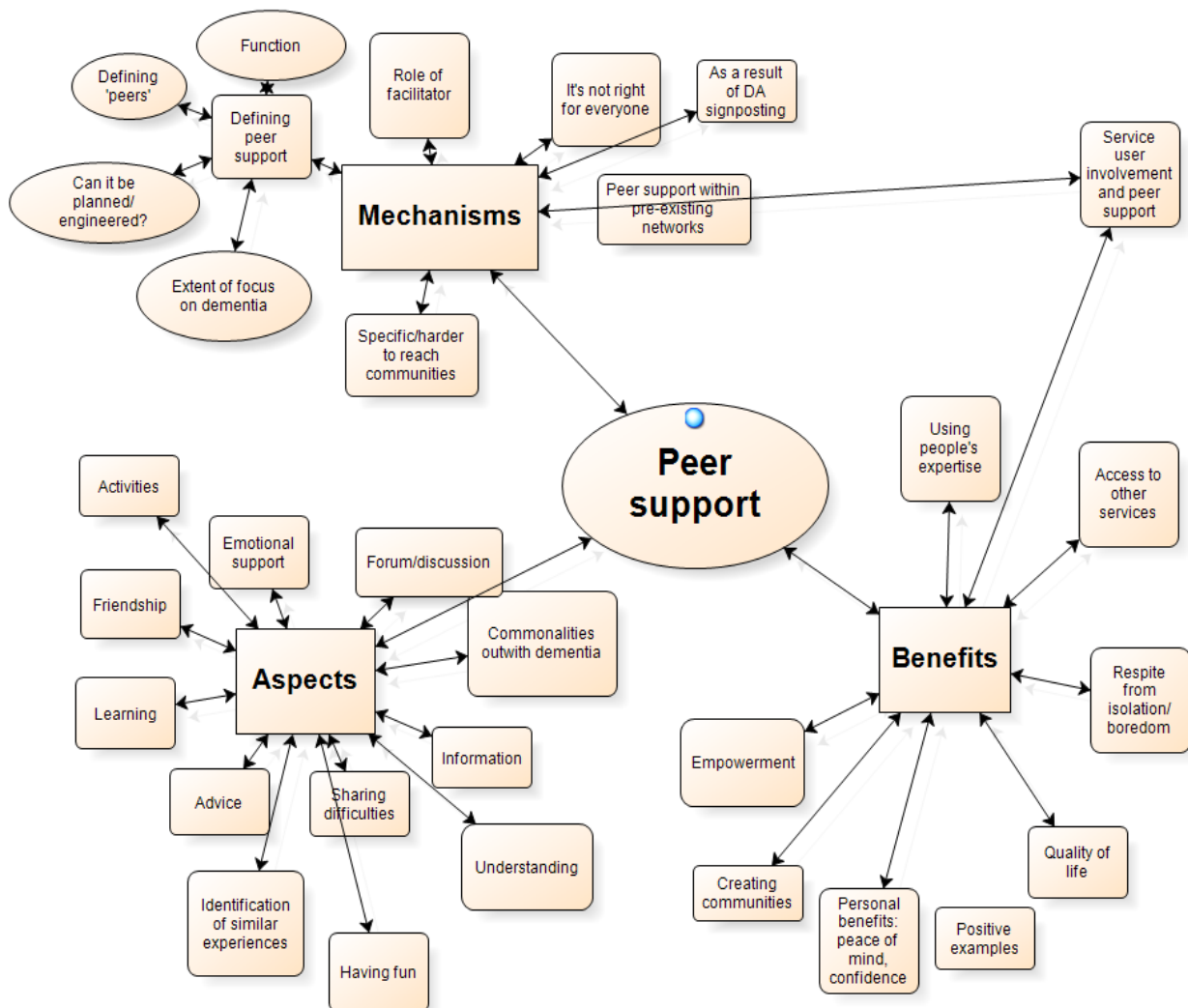
Support for people with dementia and carers from their local community is important, and relevant to the development of ideas around social networks. This is associated of course with the findings on awareness:

*Jim, person with dementia who had accessed DA services: We always have a chat, you know. Right the way down... Right the way down to the garage, you know. Right the way down – the people down there. If I’m walking down the street they’ll all say, “Well good morning Jim” you know, and we have a chat for five minutes or something like that. And, you know, people over the road and a couple of people up the road. But I get around all that way.*

The community presence of services was significant. Support from Peer Support Network and Dementia Adviser services also enabled community engagement:

*Mike, professional who had referred people to DA services: She meets people in their community. So while she’s with somebody, someone will walk past and say hello to the person – that’s an immediate contact. And if someone stops, she can tell them who she is and what she does. So it... It is that because it’s community-based and because she sees people in their homes. She talks to them about it’s not just about dementia. This is about life. And I think that’s what’s been most... That of the people that I know who are using the service, I think that has been, for me, the most... The most important thing that I see is the fact that it’s not just about that single person. You don’t... There is no individual in dementia. This is something that affects whole communities.*

## Social networks and peer support



A significant aspect of the social networks of people who were accessing Peer Support Network and Dementia Adviser services was the role of peer support. Whilst peer support was more immediately obvious within Peer Support Network sites, it was also spoken about by people with dementia and carers who had accessed Dementia Adviser sites. The model above outlines some of the aspects of peer support spoken about as well as the mechanisms through which peer support took place and the benefits of peer support.

### *Aspects of peer support*

There were many aspects to peer support spoken about within the data, including friendship; specific activities; emotional support; practical support; learning together and from each other; advice; sharing difficulties and having fun. People also spoke about sharing information and discussing dementia-related issues within a more formal discussion forum.



There was an identification with people who had similar experiences as well as identification of commonalities outwith dementia.

### *Benefits of peer support*

Benefits of peer support included the way in which people's expertise and life experiences act as enablers for other people; empowerment and the creation of new communities. Peer support also enabled access to other services.

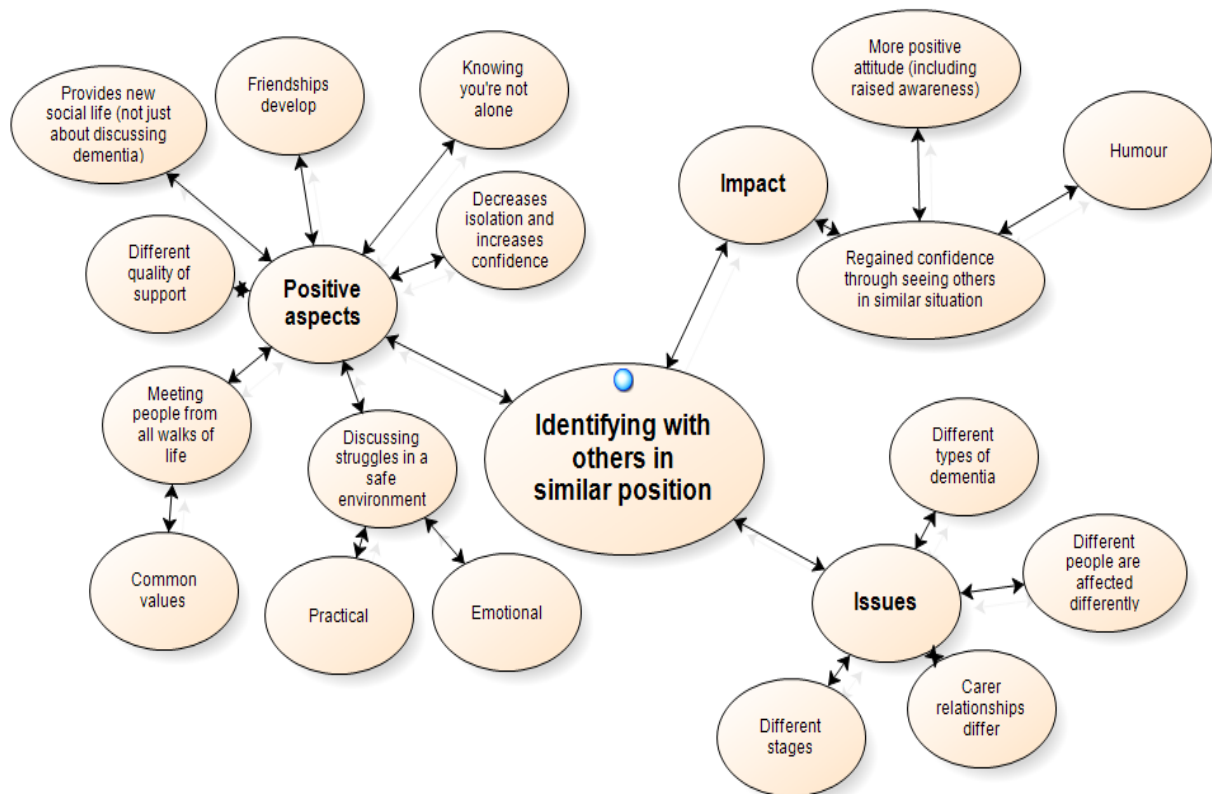
### *Mechanisms through which peer support was enabled*

Data also provided insight into the mechanisms through which peer support was enabled. These included the importance of defining peer support in relation to how it is distinctive from other forms of interpersonal support. The role of the facilitator within Peer Support Networks was significant within this. Data also shed light on the significance of peer support within specific (BME) communities. It was also recognised that peer support must be considered alongside other services and support, and not everyone found peer support useful.

### **Identifying with others in a similar position**

- **Positive aspects of peer support related to giving and receiving support from people in a similar position and included decreased isolation and increased confidence. People also spoke about a different quality of support emerging from being able to discuss struggles (and triumphs) in a safe environment with people who had similar experiences.**
- **The impact of support from others in a similar position included regained confidence, and a more positive attitude emerging from seeing how others overcame similar difficulties.**
- **Some people highlighted difficulties in identifying with other people with dementia and carers, based on assumptions that they are a homogenous group: different types of dementia affect different people in different ways at different stages. Relationships between people with dementia and carers also differed within any one group.**

Within Peer Support Network and Dementia Adviser services, there was evidence of the positive impact on people’s well-being and reliance as a result of giving and receiving support from others who have been or are in a similar position. This includes evidence from within both Peer Support Network and Dementia Adviser sites around the impact of sharing, whether that be on a practical or emotional level, with people who had a common experience of dementia.



The following conversation is between a person with dementia and their carer from a Dementia Adviser site, speaking about a support group they had attended:

Suzanne (carer): *A huge group of people and, you know, we're both friendly with people that are suffering and obviously their carers as well. So it's quite nice.*

Jim (person with dementia): *Oh, it is.*

Suzanne: *And they understand, don't they? Because, you know, it has no...*

Jim: *Nobody argues with anybody or anything like that. Everything is the same – they're just one happy bunch.*

Suzanne: *You know, there's people with Alzheimer's from all walks of life, you know.*

*We're all thrown in on the same boat and, you know, you sink or swim.*

Jim: *That's it.*

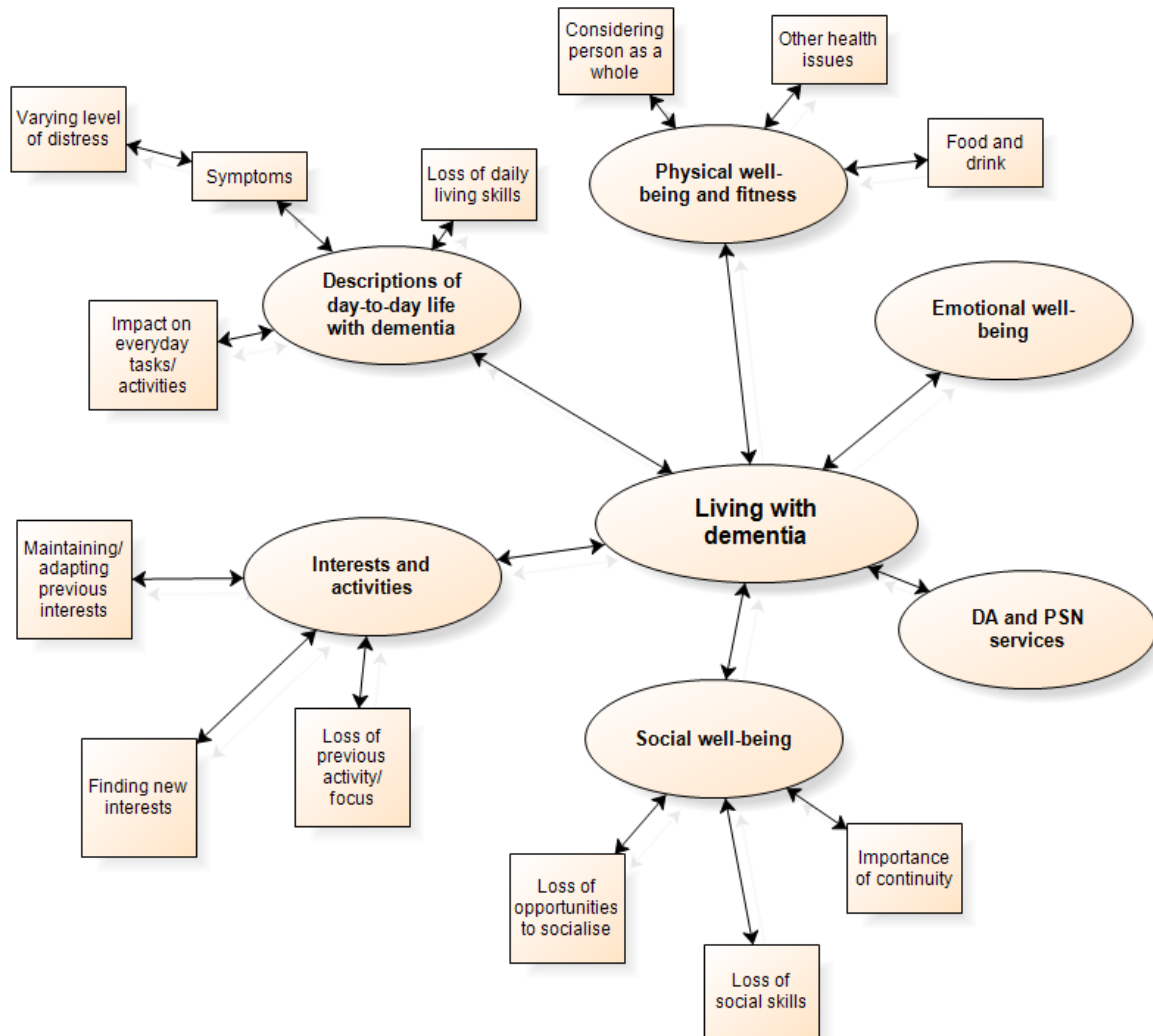
Positive aspects related to identifying with other people in a similar position included: knowing you're not alone; an increased confidence through socialising in a safe environment; decreased isolation; an opportunity to discuss both practical and emotional struggles and meeting people who, although from all walks of life, had common values. People also spoke about a different quality of support emerging from people who were in a similar position:

Eve, carer who had accessed PSN group: *Yes, I think there are differences [between support from a carers' peer support group and other support]. Because when you're at the support... The carers' group, you're talking to someone who's in the same position as you. You know. I mean, talking to [nurse] – I mean, she's lovely and she comes up with all the... The right ideas and everything. But she's not actually in the same position as you. Although she's got everything at her fingertips, you know, and she can direct you this way or that way or get whatever you need, you know, I think it's... She's still, sort of like, you know, a nurse, isn't she? You know, and not a person who's in the same position as you, no.*

People with dementia spoke about the positive effect of interacting with people who had similar difficulties with their memory, although some struggled with seeing people who were at a later stage in dementia than they were. Other issues referred to within this aspect of the data include the differences in different types of dementia, and in people's situation, including relationships between people with dementia and their carers.

### **Living with dementia**

- **Dementia impacts on people's physical, emotional and social well-being.**
- **Those interviewed spoke about the impact of dementia on their day-to-day lives, which were at times altered significantly.**
- **People spoke about the importance of maintaining social contact and interests/activity, sometimes adapting previous interests to regain a sense of 'normality' in everyday life.**



In continuing to explore the influence of Peer Support Network and Dementia Adviser services on the well-being of people with dementia, this section of the data relates to what people with dementia said about the impact of dementia on their general well-being and daily life. When asked about general well-being and daily life, people with dementia (and/or their carers answering on their behalf) spoke about physical well-being and fitness, social well-being and emotional well-being.

In relation to physical well-being, people referred to the importance of remaining fit, with some people speaking about generally feeling less fit, or referring to specific health conditions:

Ron, person with dementia who had accessed PSN group: *Unfortunately I don't get that zing any more that I used to have when I went to work, you know. It's... It's nice. I've got back into it now, because I mean... It's nearly two years now I've been*

*diagnosed. And I was still going to work. I was running about and doing all sorts, sort of thing, like, you know. And now it's got down the... Down the scale sort of thing, like, you know. And I haven't got time for it, like, you know.*

People were open about the impact of dementia on their social well-being, with a loss of social opportunities and social skills impacting on social aspects of people's lives.

People also spoke about the positive impact of Peer Support Network and Dementia Adviser services on general well-being and daily life:

Lillian, person with dementia who had accessed PSN site: *Well this last month, or just over a month, it's been the best thing that's happened to me for a few years now. I've been going to, like, an art class for Alzheimer's and meeting people. It's fantastic because we can all talk to each other. And I know in my old friends' circle, or what I thought was my friends' circle, it just gradually went.*

People spoke about their interests and activities, both before diagnosis and post-diagnosis. Some spoke about a loss of previous interests and focus in life, whilst others spoke about the process of finding new ways to pursue interests within their limitations:

Interviewer: *Does it feel like quite a big difference between how you spend your time now, compared to what it was like before your diagnosis? Is it quite different now?*

Jessica, person with dementia who had accessed DA services: *I suppose it is, really, because I would have... You know, probably have gone on and done something in a shop or something. Or do something, definitely.*

Interviewer: *But in terms of other hobbies – like the dogs and things – that's not stopped has it?*

Jessica: *Oh, gosh, no. That's never going to stop.*

There was a sense in which establishing a 'new normal' enabled a better sense of well-being and quality of life:

Suzanne, carer who had accessed DA services: *Yeah, we've, sort of, got back to some sense of normality now. He's got quite a nice week of things happening most days.*

*There's something happening. He's just re-joined the bowling club as a bowling member then, yesterday, didn't you? So he's quite happy about that.*

When asked about their well-being and daily life, people also described the impact of dementia on everyday tasks, and a loss of daily living skills, such as sequencing in order to complete basic tasks. There was a wide range of responses to symptoms – some people expressed distress whilst other people did not.

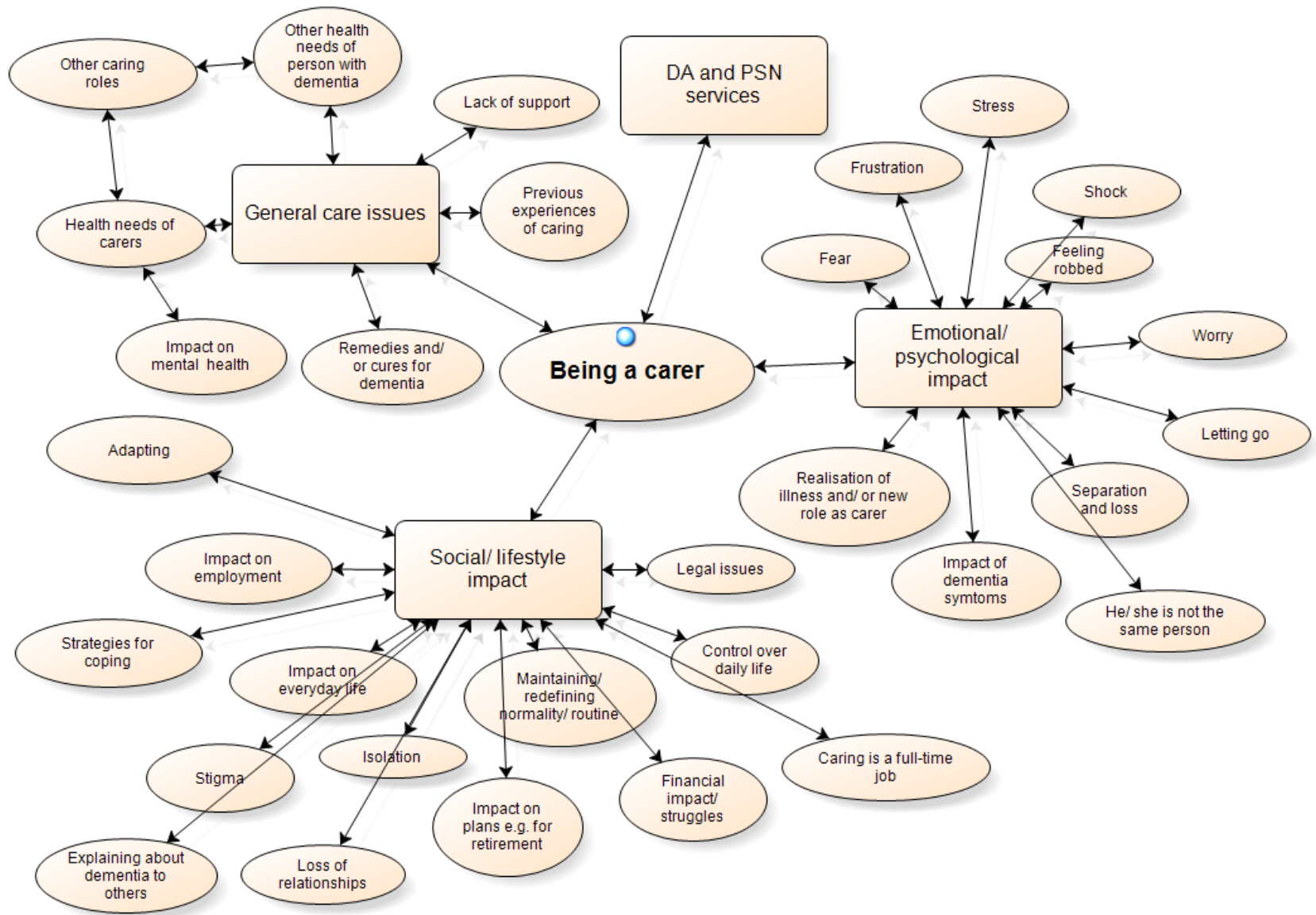
Staff and stakeholders also referred to the impact of Peer Support Network and Dementia Adviser services on general well-being and daily life:

*Norman, PSN facilitator: Yeah, they... Yeah, like I say... People that... Actually some comments that were made was that these projects have actually changed their lives. They went, maybe, out once a week. And now they probably attend the singing group and one of the cafés as well, playing \_\_\_\_, so now they've got two things else that they can go out on a weekly basis for. So it's changed their outlook on life – they're more positive about life. A reason to go out, if you like, mix with other people, socialise with other people. So they've got that back, which they didn't have. Which they lost for a time.*

### **Being a carer**

This section of the data includes insight from carers into their lives as a carer of someone with dementia. It provides accounts of experiences as well as issues that are significant to people who are caring for people with dementia.

- **Being a carer of someone with dementia, referred to by some as a full-time job, has an emotional/psychological impact and an impact on lifestyle.**
- **Caring for someone with dementia is not exclusive to other caring roles: carers often had their own health needs and other people to care for. People with dementia can also have other health needs in addition to dementia.**
- **Carers spoke about the impact of dementia on finance, employment and everyday life. There were examples of ways in which carers had sought to maintain or redefine normality for themselves and those they were caring for.**



Accounts from carers who were interviewed included their experiences of being a carer, and the impact of dementia on their lives and on their relationship with the person they were caring for. The data has been grouped into three main areas: emotional/psychological impact; social/lifestyle impact and general care issues.

Carers also spoke about the role and impact of Peer Support Network and Dementia Adviser services within their experiences but this aspect of the data has been outlined elsewhere: the purpose of this section of the presentation of data is to outline what carers said about their lives as carers for people with dementia.

Carers expressed a range of emotions in relation to their experiences of living as a carer for someone with dementia. These included: fear, worry, frustration, shock, and feeling robbed. A common theme was that of the effect of dementia on the person they were caring for and the range of emotions associated with adjusting:

*Liza, peer support volunteer who had previously cared for her father: We talk more about it now, but at the time, to say to somebody, "Yeah, I adored my father, but I didn't like him very much..." You know, people would go, "That's shocker. That's dreadful." But when you've been through, you know, looking after someone with dementia, I think people understand what you mean. And also the fact that you... You love the person they were, you're allowed not to love the person they... They are. And almost to be, sort of, disgusted by them and... You know, I mean Dad he... He'd, you know... And I don't think you understand – truly understand that – until you've been through it. To be able to talk about those... You know, those issues. I think that makes a big... A big difference.*

Carers also spoke about the impact of the symptoms of dementia on their lives, and the realisation of the illness alongside their realisation of their new role as a carer.

Caring for someone with dementia has been referred to as a 'full-time job'. A volunteer from within a Peer Support Network site who had herself been a carer for someone with dementia reflects:



Marianne, volunteer supporter from PSN site: *A lot of people look on it as a very practical task. It's not practical. It's practical, it's emotional, it's draining. It's.....it is full of love, and yet it is also full of.....Not necessarily sadness.....Yes, sadness. It's a mix of so many things, and I think the people caring for those with dementia have such wonderful strengths that I don't think they are aware of, and won't be aware of until their journey is over. And I don't even know it is ever completely over, even though you might close the door, because the experience is like no other. I know my door will never close.*

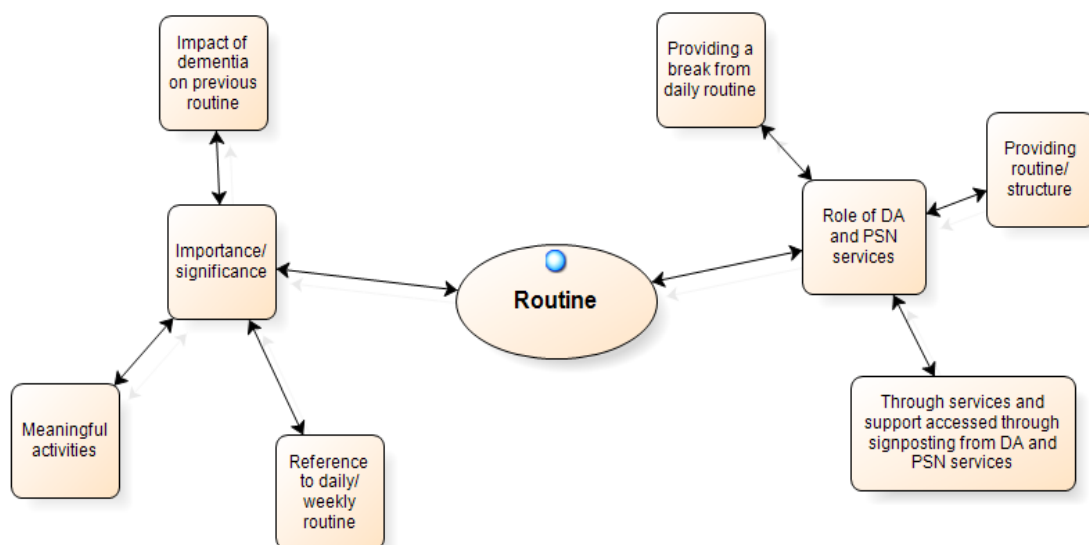
Carers spoke about the effect of dementia on every area of their lives: employment, finance and future plans (for example retirement plans). They also spoke about the social stigma and isolation, which will be referred to in more detail in the section of the presentation of data on awareness and social networks on page 243.

Experiences of dementia do not take place in isolation from the rest of people's lives: people with dementia can experience other health issues, and some carers interviewed referred to other family members they were caring for in addition to the person with dementia, and carers themselves have health needs:

Seamus, carer who had accessed PSN site: *My lease on life is running out, and so my energy is not what it was, you know. And I joke about it sometimes and I say, you know....They say "Is there anything we can do for you?" And I say "Well, yes, if you've got a couple of gallons of energy in a bottle, I will buy some, you know".*

Some carers spoke about their desire to find a cure for dementia, or about remedies that they had used.

## Routine



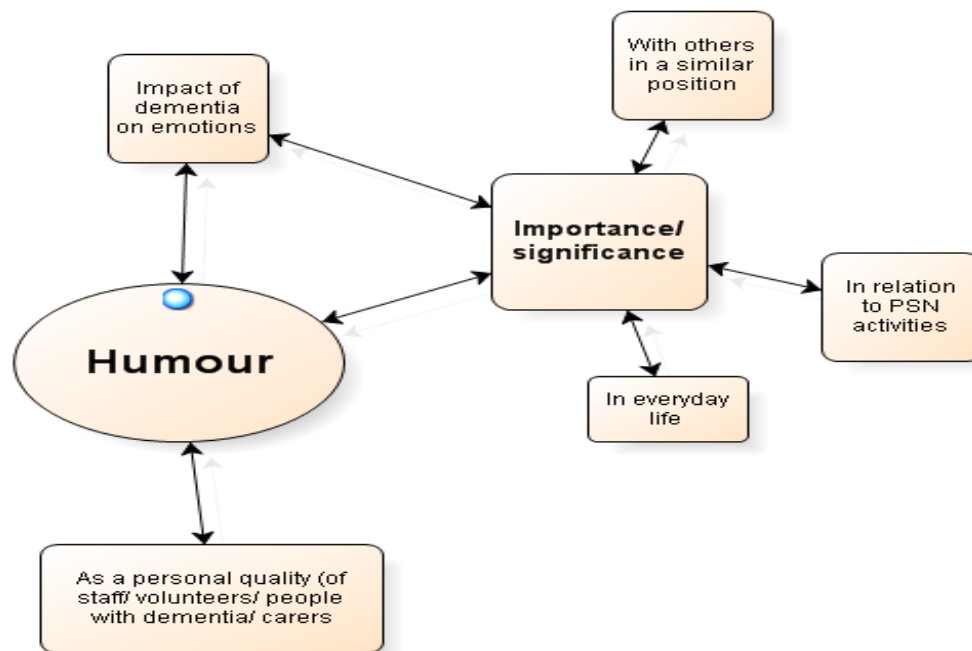
People's accounts of their experiences often referred to their daily routine. They spoke about the interruption to their previous routines and the importance of maintaining routine:

*Nina, carer who had accessed DA site: I mean [person with dementia] keeps saying "you don't have to go to work". And I say "[person with dementia] I do," Because I do, I do need that normality in my life, really.*

Some referred to the role of Peer Support Network and Dementia Adviser services, especially groups and activities within Peer Support Networks, in providing a break from their usual routine; others referred to the role of such meetings in providing a new focus and structure in life, providing meaningful activity and something to look forward to:

*Andi, carer who had accessed PSN: We just love going. We look forward to it. I tell you, she'll ask me what day because she gets mixed up with the day. And she'll ask me what days we're going.*

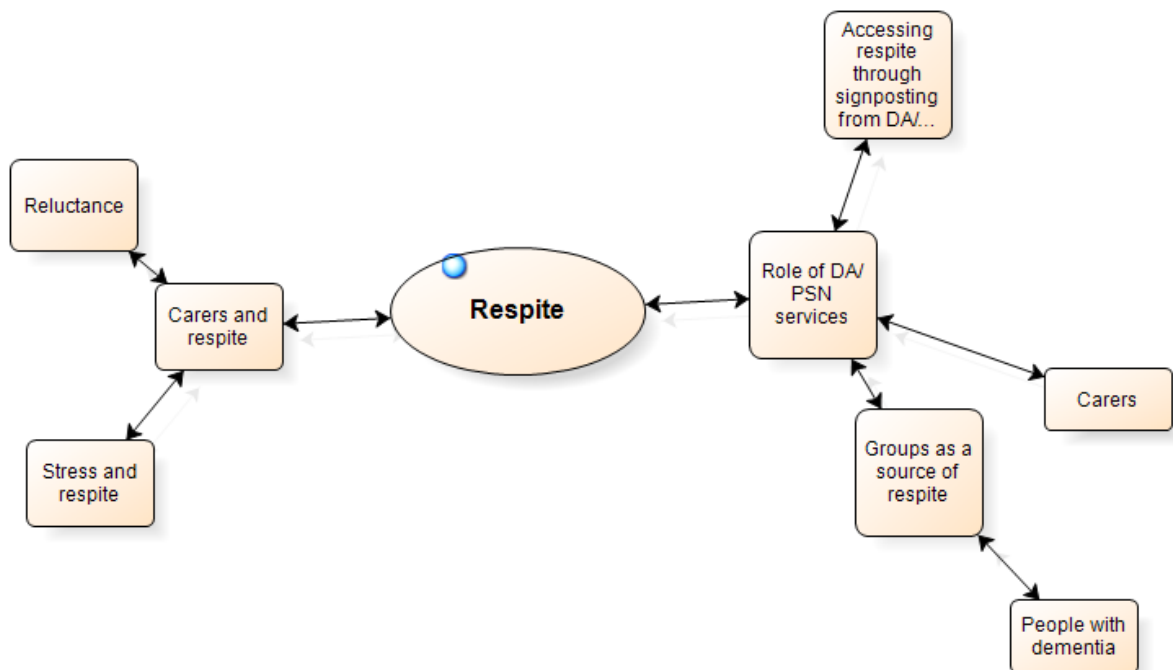
## Humour



People spoke about the importance and significance of humour, especially with others in the same position, and therefore in the context of support groups within Peer Support Network and Dementia Adviser services as well as in everyday life. Humour was referred to as an important personal quality of staff and volunteers as well as people with dementia and carers:

Denise, person with dementia who had accessed PSN services: *I think it's mostly because they're other people in the same situation as yourself. And, as I say, you can talk about the things that you've done or situations that you've been in where you can't remember things, and you can laugh about it and realise that other people are exactly the same. And I think that's really important.*

## Respite



A common theme that arose from carers' accounts of their experiences was that of respite. People spoke about the tensions between their need for a break and their reluctance to allow somebody else to take their place. Carer stress was often the driver behind people accessing respite care. This carer, who had accessed support within one of the Dementia Adviser sites, describes her situation:

Janice, carer who had accessed DA site: *I've been banging on to quite a lot of people, really, about respite for me. Because I'm feeling I'll get to the stage now that, you know, I'm pulling my hair out. And I said, "I need to have something to look forward to on a regular basis".*

As this carer continues to explain, Peer Support Network and Dementia Adviser services had a role to play in signposting people to respite services, through advice from a Dementia Adviser or through recommendations within peer support groups.

Where Peer Support Network and Dementia Adviser services were providing meetings and/or activities for people with dementia, they also acted as providers of respite for carers:

Frederick, volunteer from memory café (PSN): *Well, now and again, we have a time where the carers go off in the room on their own and talk about their issues – and*

*leave the volunteers with the people with dementia. And we do... We do the games with them and, you know, the reminiscence stuff. Whilst the carers then have a chance to chat and share their issues.*

Similarly, attendance at a peer support group for carers provided respite from their life as a carer. Sessions for people with dementia running alongside sessions for carers were also a source of respite for both people with dementia and carers:

*Seamus, carer who had accessed carer peer support group: It provides two hours a week where you're talking to people with whom you can have what I call a normal conversation.....the nearest thing I come to having a day off.*

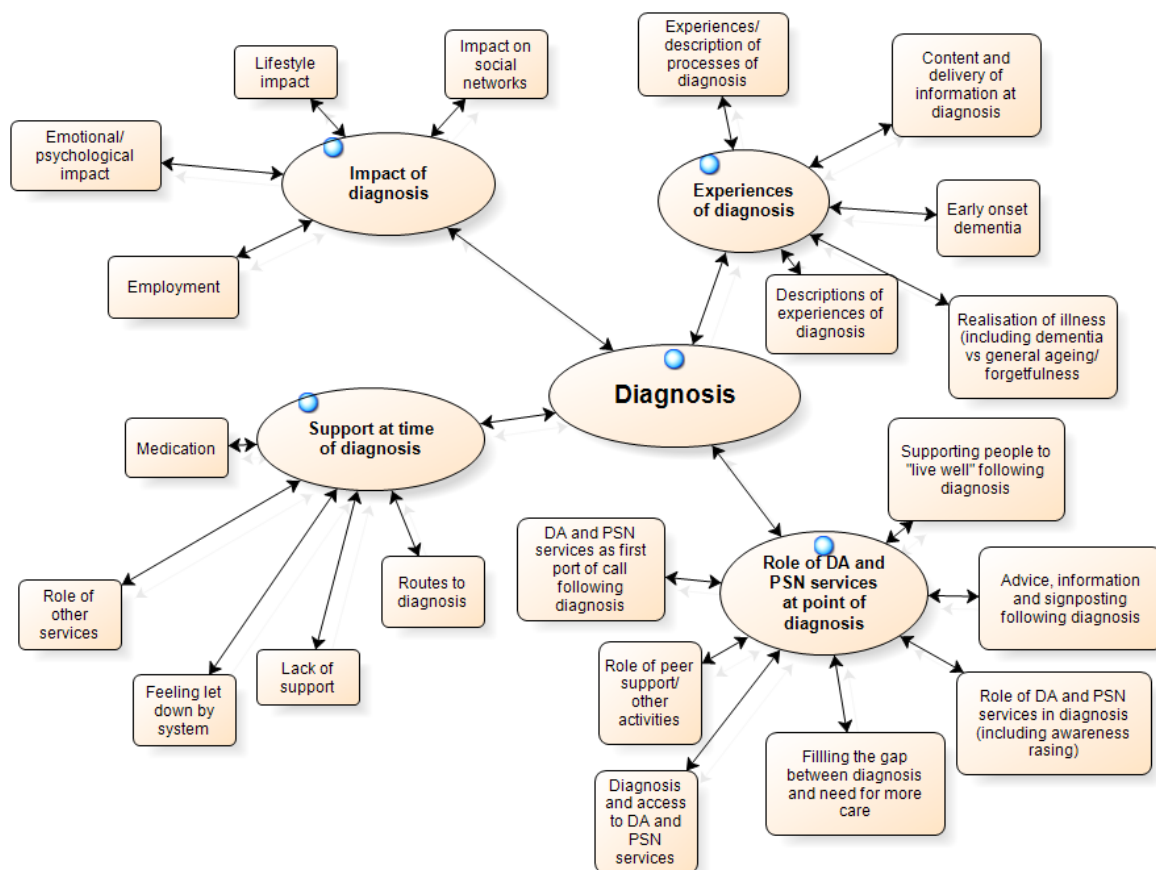
### **Section Five: Contribution of Peer Support Network and Dementia Adviser services to well-being and resilience: Accessibility of services; information and involvement; making choices and independence**

The next section of data considers the contribution of Peer Support Network and Dementia Adviser services to the well-being and resilience of people with dementia and carers. This section focuses on accessibility of services, in particular ways in which Peer Support Network and Dementia Adviser services enabled access to a wide range of support and also access to communities and society in the wider sense. In this section we consider:

- diagnosis, and in particular people's experiences of diagnosis and the role of Peer Support Network and Dementia Adviser services in diagnosis
- specific or 'harder to reach' communities
- raising awareness about dementia
- independence, control and choice
- empowerment
- confidence and self-esteem
- coping.

## Diagnosis

- **Timing of diagnosis, content and delivery of information at the point of diagnosis are significant: they can influence the impact of diagnosis of dementia on lifestyle, social networks and the emotional/psychological impact of a diagnosis.**
- **Peer Support Network and Dementia Adviser services had roles to play in people receiving a diagnosis, and in tackling the stigma that can prevent diagnosis. At times, Peer Support Network and Dementia Adviser services were the first support/service that people accessed post-diagnosis.**
- **Peer Support Network and Dementia Adviser services also ‘filled a gap’ that often exists between diagnosis and the need for more intensive services/support.**



Experiences surrounding diagnosis were significant to many of those interviewed across both Peer Support Network and Dementia Adviser sites, with staff, volunteers and stakeholders as well as people with dementia speaking about the role of these services at the point of diagnosis. People with dementia and carers also spoke about their experiences of diagnosis, the support they received (or did not receive) within the process of diagnosis, as well as the impact and implications of receiving a diagnosis of dementia.

### ***Experiences of diagnosis***

Both people with dementia and carers spoke about their realisation, sometimes sudden, other times gradual, that they or the person they were caring for had dementia. For some, accounts of this realisation included an emphasis on the differences between forgetfulness as an aspect of the general ageing process and dementia:

*Natalie, carer who had accessed DA service: Because, I mean, it started off, it was just....you know, the forgetfulness, the, you know, spent my life looking for keys, glasses. And I mean we can all do that.....But then it's sort of got to a point which I think, you know, this is a bit.....a bit more than normal now.....and I suppose that was at least 6 months down the line before he went to the GP.*

Experiences of diagnosis were unique to each person with dementia/carers interviewed. Some people talked at length about their experiences, others referred to this aspect of their dementia journey in passing. Common themes in relation to people's experiences included timing of diagnosis and the content and delivery of information within the process of diagnosis.

In relation to timing of diagnosis, some people with dementia and carers spoke about a delay in getting a diagnosis:

*Rosalind, carer who had accessed DA site: Actually, she's.....Got the problem the last 3 or 4 years and we didn't know what it is. So she's been diagnosed only, I think a year ago.....now we understand why she is like this.*

Staff and stakeholders spoke about the importance of earlier diagnosis, acknowledging a role for Peer Support Network and Dementia Adviser services within this.

A further aspect relating to people's experiences of diagnosis was the content and delivery of information and advice at the point of diagnosis. Some people felt they had been given too much information, others too little. This relates directly to the timing and flexibility of support from Peer Support Network and Dementia Adviser services, which was addressed earlier in this presentation of findings.

Some people were given very little or no information or advice following diagnosis:

*Lillian, person with dementia who had accessed PSN site: For like 18 months, 2 years, maybe 2½ years, I was just sat in the house every day, doing nothing, really. I mean, my family came to see me and that, but other than that I take my dog for a walk. I... I didn't really know it was there. I knew there would be something out there, but I didn't think I would qualify for being part of it.*

There were instances where lack of support at diagnosis had a negative impact on people with dementia and carers.

### ***Impact of diagnosis***

People with dementia and carers also spoke about the impact of having a diagnosis. Within the analysis of qualitative data, these impacts were grouped into four key areas: lifestyle impact; impact on social networks; emotional impact; and psychological impact.

People spoke about the adjustment in their lifestyles following a diagnosis of dementia, including impact on employment and impact on retirement plans:

*Shilpa, carer from PSN site: Before of that we'd heard of Alzheimer's, things like that, but because it didn't affect us personally, you've got no.....But once it affected us personally, and really changes our life quite a bit from what it was. Because we've always been active and all the rest of it. And suddenly, things have gone a bit pear-shaped.*

As outlined in the previous section on social networks, people also spoke about the impact on their social networks as a result of the stigma so often associated with a diagnosis of dementia.

There were accounts of a range of emotional and psychological impacts of diagnosis, from both people with dementia and carers, including shock, denial, fear and shame, impacting on the support that people did or did not access:



Laurie, person with dementia who had accessed PSN service: *And she told me there were.....That I had started with dementia..... We've had quite a lot of experience with one person and another person – and it frightened me to death.....Maybe I would have been better not knowing, but I don't want to drift off like other people have and....Are not aware of what's going on around me.....It is going to happen. And when you wake at half past 3, half past 4 in the morning, and you can't go back to sleep because your stomach is knotted up and you're wondering what the hell is going to happen to you...*

### ***Support at time of diagnosis***

There was a range of routes that people had taken to the point of being diagnosed with dementia. Within people's accounts of this process, they spoke about the support they had received. This aspect of the data includes: experiences of accessing services other than those that are central to this evaluation; medication; feeling let down by the system and lack of support:

Ron, person with dementia who had accessed PSN site: *When I was found with the....what I've got sort of thing. The dementia, you know. We didn't know what to do, like, sort of thing, and we just.....we just sat at home....And it was the same with any benefits or anything like that. We didn't know about anything....*

### ***Supporting people to live well: The role of Peer Support Network and Dementia Adviser services in and after diagnosis***

Participants discussed the role of Peer Support Network and Dementia Adviser services in the process of diagnosis. Again, the timing of contact with these services was significant, as was the difference that support from Peer Support Network and Dementia Adviser services made in people's dementia journeys.

Some of the people interviewed referred to a role for Peer Support Network and Dementia Adviser services in diagnosis itself, or in supporting people to get a diagnosis. The following quote from a commissioner involved with a Dementia Adviser site highlights the role of volunteers within this:

Leigh, commissioner from DA site: *Alongside supporting people who had already had a diagnosis, that the service would look to support people to achieve a diagnosis as well. That wouldn't necessarily be the Dementia Adviser, but alongside having a Dementia Adviser there's a service where there are volunteers who would support someone to seek a diagnosis....We know that sometimes that can be quite a .... an onerous journey for people and that some people want some support in doing that. We set up both to do that and to provide advice on diagnosis.*

The role of Peer Support Network and Dementia Adviser services in tackling stigma and raising awareness of dementia, presented in a subsequent section of this presentation of findings on page 243, has also impacted on the process of diagnosis.

As stated in the section on 'Access to Peer Support Network and Dementia Adviser services' on page 154, there were instances where people who did not (yet) have a formal diagnosis found their lack of formal diagnosis to be a barrier to accessing services.

Peer Support Network and Dementia Adviser services have a role to play in filling a gap that so often occurs between being diagnosed and the point at which the need for more intensive health and social care support is needed. This was done through advice and information, through supporting people with dementia and carers to engage with new interests and social groups and through empowerment through peer support:

*Katrina, PSN staff: We absolutely needed to capture people in the earlier stages. Ideally from as close to the point of diagnosis as we could.....what we wanted was people to go through memory services and then immediately, where appropriate be referred to the peer support service.*

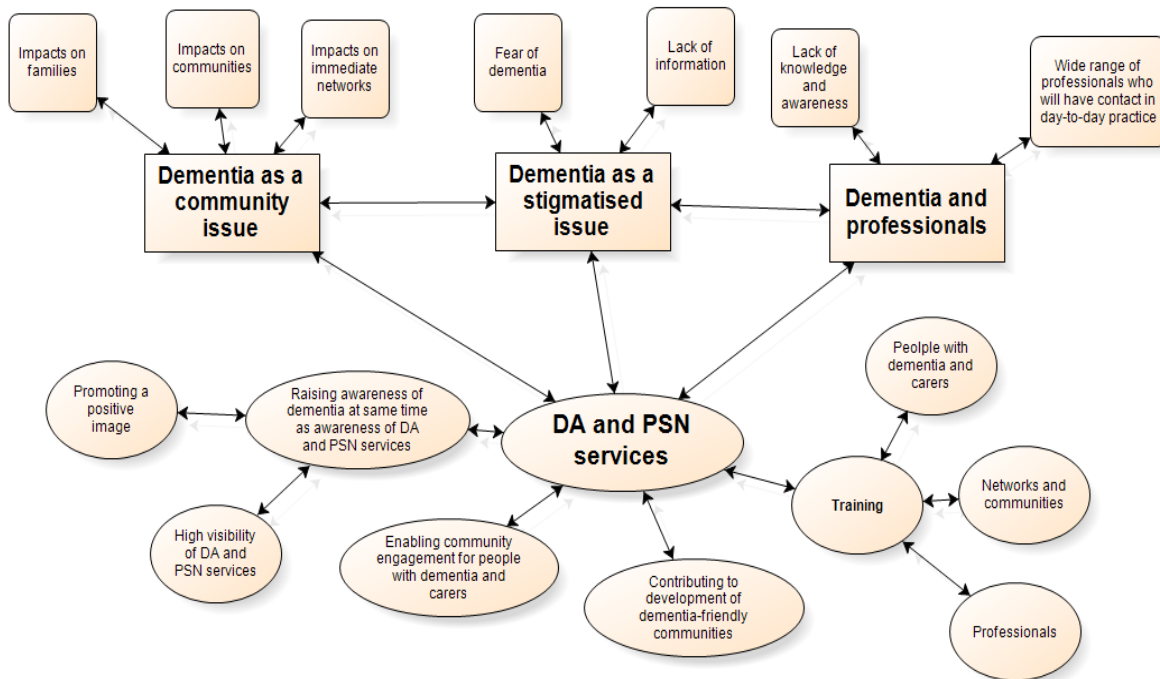
Professionals from other local services supporting people with dementia and their carers commented on the impact of Peer Support Network and Dementia Adviser services in relation to filling a previous gap in support available to people with dementia and carers:

*Bev, PSN facilitator: So we are looking at people who are newly diagnosed, who are going through the Trust – so [local NHS Trust] – who are then organising memory groups for people. So that will run for a short space of time. Following the memory*

group that newly diagnosed people will be attending, we are then looking at cognitive stimulation therapy, who... This group – I would co-facilitate with a member of staff from [local NHS Trust]. I will then do the maintenance sessions for that. And then people will be referred into peer support. So I think we fit in in the bigger picture – as in people are unsure where they would go from diagnosis.

## Awareness

Increased awareness and recognition of dementia can also be linked to better well-being and resilience of people with dementia and their carers. Qualitative data relating to the role of Peer Support Network and Dementia Adviser services in raising awareness about dementia will now be presented.



### *Awareness of dementia as a stigmatised issue*

People referred to the stigma that surrounds dementia, often relating this to people’s fear, with a lack of informed knowledge leading to it remaining, for many, a ‘taboo’ subject.

Within this, people highlighted the need for more training and awareness raising:

Beth, daughter of couple who had accessed DA service: *Because we didn’t know anything about it. I was saying to [Dementia Adviser], it’s not like a fluffy thing, is it? You know, people are more into it now. They don’t talk about dementia. It’s*

*something that's whispered.....I think people need a lot more training on it, because it's something that is not to be frightened of.*

People also spoke about the role of Peer Support Network and Dementia Adviser services in raising awareness and providing training, including reaching people who had no access to services or support:

*Stephanie, Dementia Adviser: Alongside, we will do like a workshop, information, drop-in.....Just drop-in in the sense that we offer drop-ins if given community venues.*

The relatively high visibility of Peer Support Network and Dementia Adviser services was referred to as having a positive impact on training and awareness raising.

Promotion of Peer Support Network and Dementia Adviser services was often linked with raising awareness and a better understanding of dementia, with Peer Support Network and Dementia Adviser services providing evidence for the fact that people can 'live well with dementia'. This was done through providing activities which support and enable awareness raising at the same time as enabling people with dementia to 'live well' through the support that Peer Support Network and Dementia Adviser services made available to people:

*Naureen, local professional who had interacted with PSN site services: So, for instance, with the... The thinking art group at the gallery, that's a place that people wouldn't necessarily have thought about attending otherwise. Without the group there. And the library as well. And that's something that people have continued with beyond the life of the group. So now they're using... They've been introduced to the facilities and the... And what's available at the library that they had... They didn't have any knowledge of before. And now they're making use of that in a way that they wouldn't have otherwise. So there's certainly something around broadening people's awareness and raising people's awareness and understanding of what's out there.*

There was also a role for Peer Support Network and Dementia Adviser services in relation to awareness and support for the immediate networks surrounding people with dementia.

### *Awareness of dementia as a community issue*

Dementia as an issue which impacts on the whole community, with implications of this for Peer Support Network and Dementia Adviser services:

*Jim, commissioner DA services: It was a way of you know, making the resources to go further which we needed to do because we knew it would get more people with dementia, both because of the, you know, just because of the prevalence data and the demographics, but also because there was so much effort to increase awareness.*

Some referred to dementia as a public health issue, highlighting the current and future cost implications of dementia, and the importance of Peer Support Network and Dementia Adviser services in raising awareness of this:

*Carmen, commissioner from DA site: And I think GPs will become very much more aware of what the cost implications are for not putting in a service like this. So I think when it starts to hit home, that the benefits of providing that service.....You know, when they are footing the bill they'll become more aware of the cost-saving implications of, you know, having a Dementia Adviser.*

People also referred to a role for Peer Support Network and Dementia Adviser services in framing dementia as a community issue, enabling positive attitudes towards people with dementia in the community, providing training for the whole community and making use of community resources:

*Heidi, professional who had accessed DA site: It's about education of people around the edges, to make sure that they understand that people can still take active, and valuable control of their lives.....the more knowledgeable a community is, or a family is, the better the outcomes for the individual. Because people know how to deal with it. They're not afraid of it.*

There was a role for site staff and volunteers in contributing to dementia-friendly communities:

*Anita, staff from DA site: Well, actually, one of our volunteers in the early... She's not with us now because she's moved area – but in the early days, one of our volunteers of the Dementia Advice service was also a member of staff at the leisure centre. So*

*that was quite good because she went back and she was often there on reception. But she also talked to her colleagues. And I think that has actually developed... In a roundabout way, that developed an awareness – that she did for us, really. Yeah.*

### *Awareness of dementia and professionals*

People also referred to the need for better understanding of dementia among professionals, with understanding from and links with GPs not always being easy to build and maintain. There was a role for Peer Support Network facilitators or Dementia Advisers in educating other professionals about dementia at the same time as promoting Peer Support Network or Dementia Adviser services:

*Stephanie, Dementia Adviser: We're trying to influence, like GPs, other organisations to take a ..... To help and support the client to receive follow-on support.*

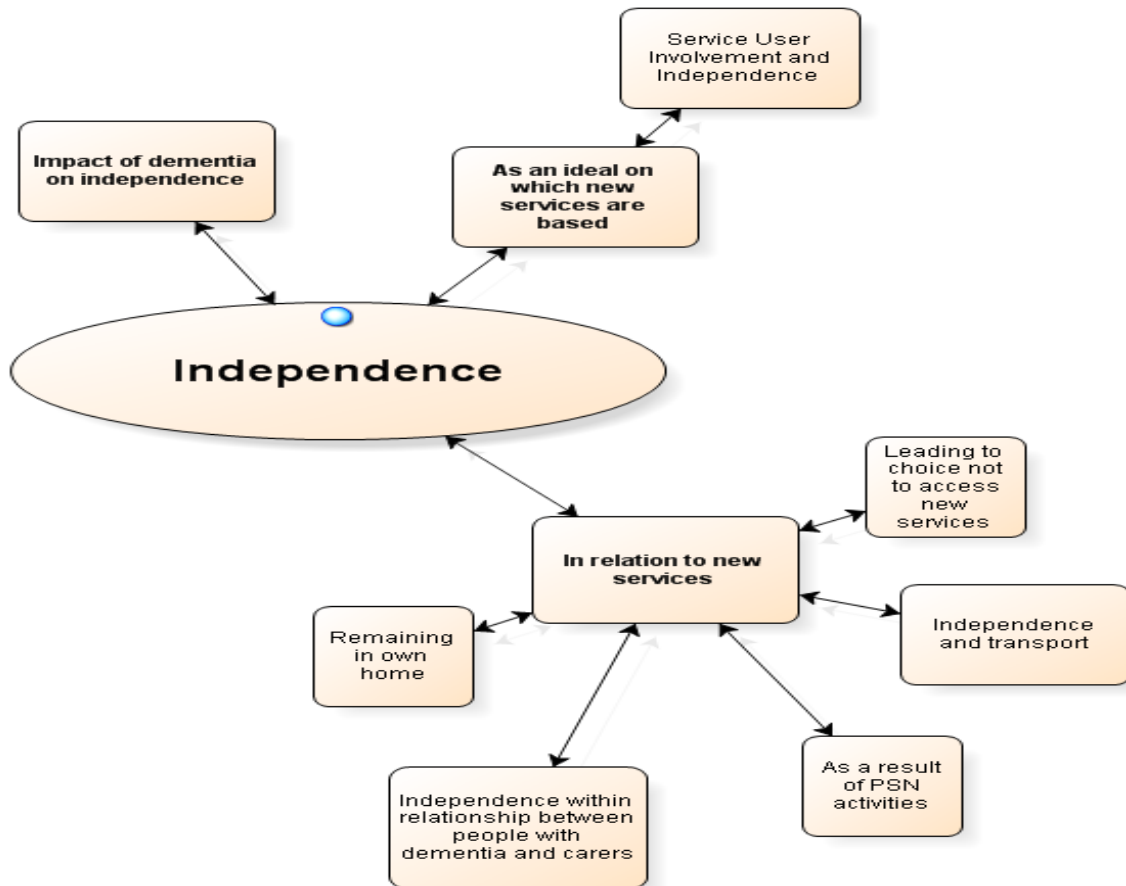
There was also acknowledgement of the wide range of people who come into contact with dementia within their day-to-day practice. Some sites were beginning to develop roles for people with dementia in educating other people about their experiences, including professionals.

In continuing to consider the contribution of Peer Support Network and Dementia Adviser services to well-being and resilience, data relating to information and involvement is now presented. This begins with data relating to information within both Peer Support Network and Dementia Adviser sites. Data relating to the significant area of the role of support by and for people who are in a similar position is then followed by a section on advice, again across both Peer Support Network and Dementia Adviser sites.

### **Independence, control and choice**

- **Independence, control and choice were central within the design and implementation of both Peer Support Network and Dementia Adviser services.**
- **People referred to ways in which they had been empowered by advice, information and signposting from Peer Support Network and Dementia Adviser services, and ways in which this had enabled them to make informed choices.**

- There were examples given by people with dementia and carers of ways in which both Peer Support Network and Dementia Adviser services had enabled them to remain independent and have more control over their lives.



The presentation of data now moves on to consider the impact of Peer Support Network and Dementia Adviser services in relation to positive impact on people with dementia and carers, specifically in the areas of independence, control and choice. These areas are key not only because they are ideals on which Peer Support Network and Dementia Adviser services were built but also because they are areas of the lives of people with dementia and carers that are very often impacted by dementia. Thus, looking at these areas in relation to Peer Support Network and Dementia Adviser services contributes to the discussion around the contribution of the services to well-being and resilience of people who were accessing them.

Acknowledging the impact of dementia on people’s independence, staff and stakeholders spoke about Peer Support Network and Dementia Adviser services being grounded in the

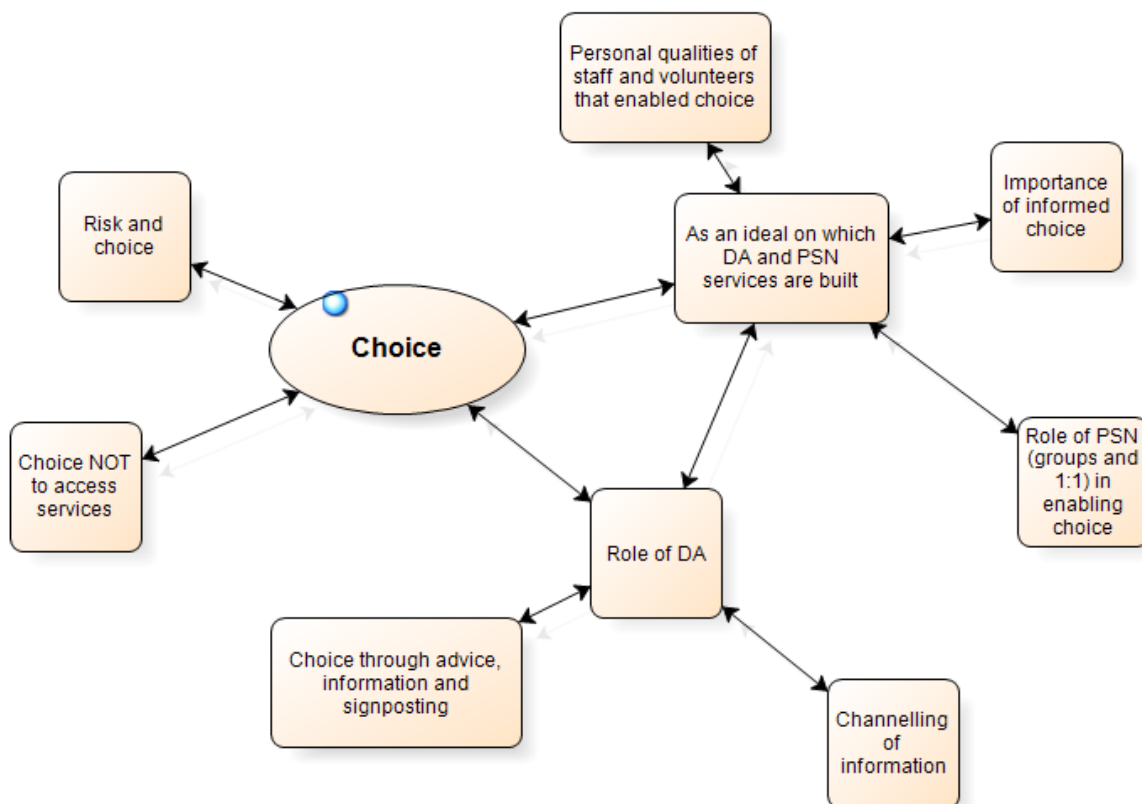
principle of enabling independence for people with dementia and carers, in particular enabling people to remain in their own homes for longer:

Tom, staff from PSN site: *My understanding of the pilot is to support people with dementia and their carers in helping them lead as normal a life as possible, and to maintain independence.*

The Peer Support Network services in particular sought to maintain independence between people with dementia and their carers:

Nancy, carer from PSN site: *It's something that we can do ....we can both participate in, but independently as well as together.....It removes some of the responsibility while you're there because ....yes, you're obviously with your partner, but he's.....able to function independently. And ....As am. So that you become as an individual again, if you like.....And it allows him to feel independent, and it allows me to be myself. Or more myself.*

### Choice



A further ideal upon which both Peer Support Network and Dementia Adviser services were built was that of choice.



In relation to empowerment and choice through advice, information and signposting, there was specific reference to the role of Peer Support Network and Dementia Adviser services in channelling appropriate information:

Rob, carer who had accessed DA services: *It's like a menu. So you need to know what's available and..... [Dementia Adviser] has all that information. And she knows the situation you're in.....And that's the sort of things where she'll, sort of, point you in the right direction. Which is crucial because you don't always know what's happening.*

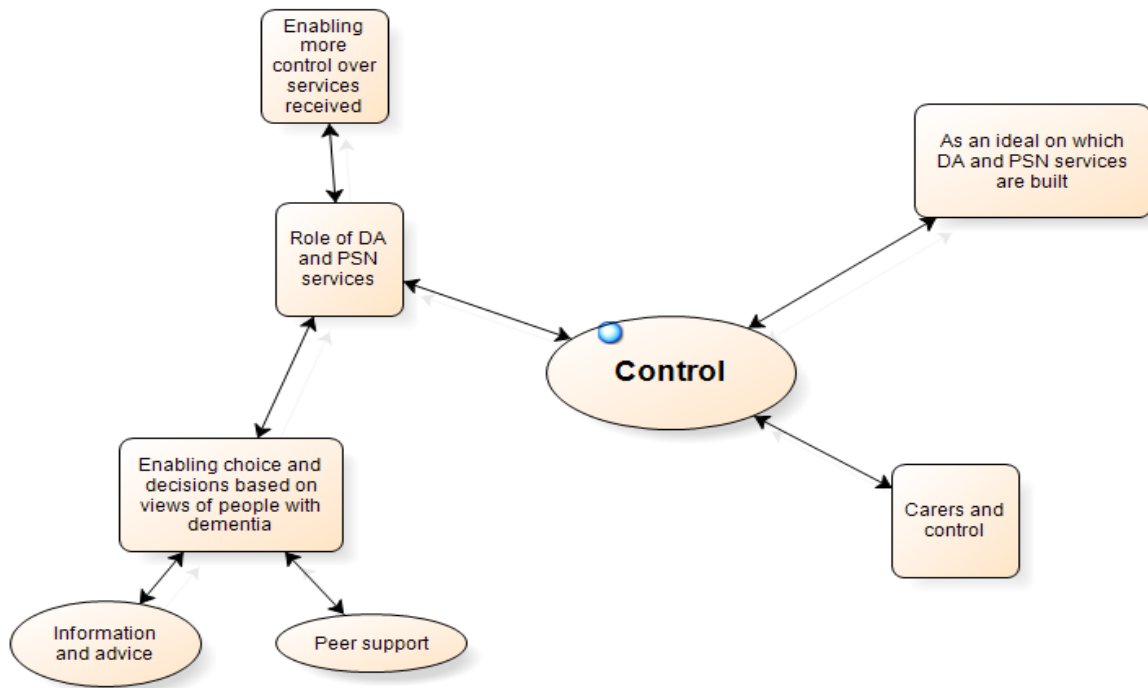
There was also reference to the role of support from peers in enabling people to make decisions and choices:

Marianne, peer supporter from PSN site (who had previously cared for her own husband): *I think possibly it helps them feel stronger and more able to make decisions.*

This is backed up with the following response to the question of the strengths and weaknesses of Dementia Advisers as a new way of supporting people with dementia and carers:

Anita, staff from DA site: *I guess the biggest strength is actually working with people to empower people and offering the informed choices, really. And rather than focus on the negativity of diagnosis – which perhaps a lot of supporting care may do – is actually working with people to normalise their lives and create a whole well-being model, really.*

## Control



Control, a further principle on which Peer Support Network and Dementia Adviser services were built, was a further aspect of the experiences spoken about by people with dementia and carers:

John, person with dementia who had accessed DA site: *I hate when decisions are made for me that I don't know about or agree to. And I'm not always sure about.....I understand the implications of that, but I know it's done for reasons that are to help me. But I do get a wee bit annoyed about that.*

People also spoke about the impact of Peer Support Network and Dementia Adviser services in regaining control over aspects of their lives.

Peer Support Network and Dementia Adviser services had helped people with dementia and carers to gain and/or retain control in their lives, specifically in the ways in which they were helped to make decisions and choices:

Rhoda, neighbour of person with dementia speaking alongside the person with dementia about support from a DA: *But then, when she spoke to you, really I was even more impressed, because she wanted to know how you felt....Not what, in her mind, what would be best for you, but what in your mind would be best for*

*you.....Then I started to relax about you a bit, because I felt that somebody was really keeping an eye on you and had your best interests at heart.*

In addition to being more in control in specific aspects of life, the impact of Peer Support Networks enabled people to feel less overwhelmed and therefore more in control:

*Rosemary, carer who had accessed PSN: And then I spoke to other women in our section who could all relate to things that happen. And that helped me. And they're always there for me. And then [person with dementia] goes to the garden on Friday morning, which gives me time to clean up and have a bit of time to myself. And then another thing that I went to was a reiki, holistic thingee, where I met up with all the other ladies from the group that we'd met with. And we have, sort of, stayed as friends. And I feel more well-being because of it. And before I didn't really do much with myself and I've not... I've dyed my hair and started taking more interest in myself. And, I mean, before I just used to feel I'd given up.*

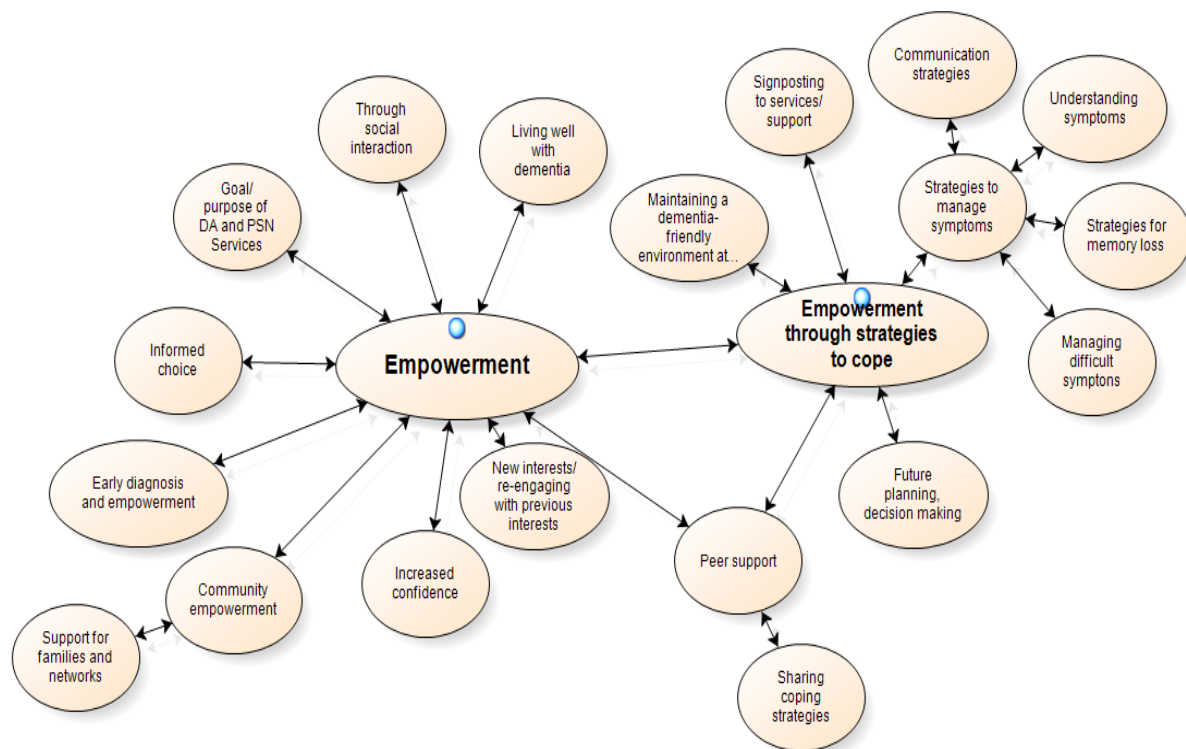
Support from Peer Support Network and Dementia Adviser services had also enabled people to retain control at each step along the dementia journey:

*Heidi, professional who had referred people to DA services: The wife eventually went off into.....she was just....could not be cared for at home safely any more. But the husband was left with a whole need to feel that he'd done something and his memory, then, was starting to fail. So [Dementia Adviser] has supported him through that. Not only through the initial stages of caring for his wife and the acceptance of her need for the care elsewhere, and the maintaining of the relationship between husband and wife while they're separate.....Because he still feels the need to actually make sure that he's in control of the care of his wife.*

### **Empowerment**

- **Empowerment, defined by some as a goal/purpose of Peer Support Network and Dementia Adviser services was promoted within those services through early diagnosis, increased choice and confidence and community empowerment (support for immediate and wider networks surrounding people with dementia and carers).**

- **Mechanisms through which people were empowered included new interests and activities, social interaction and the processes of enabling that led to people ‘living well with dementia’.**
- **People were empowered to ‘live well with dementia’ through strategies to cope, for example managing symptoms, future planning and decision making and maintaining a dementia-friendly environment at home.**



This section of data relates to ways in which Peer Support Network and Dementia Adviser services empowered people to ‘live well with dementia’. It includes examples from people with dementia and carers around advice and information from Peer Support Network and Dementia Adviser services that enabled them to maintain a dementia-friendly environment at home. Data has been presented elsewhere in the findings relating to empowerment, such as early diagnosis and empowerment; empowerment through social interaction; empowerment as a goal of Peer Support Network and Dementia Adviser services; empowerment of social networks surrounding people with dementia and their carers; and empowerment through peer support.

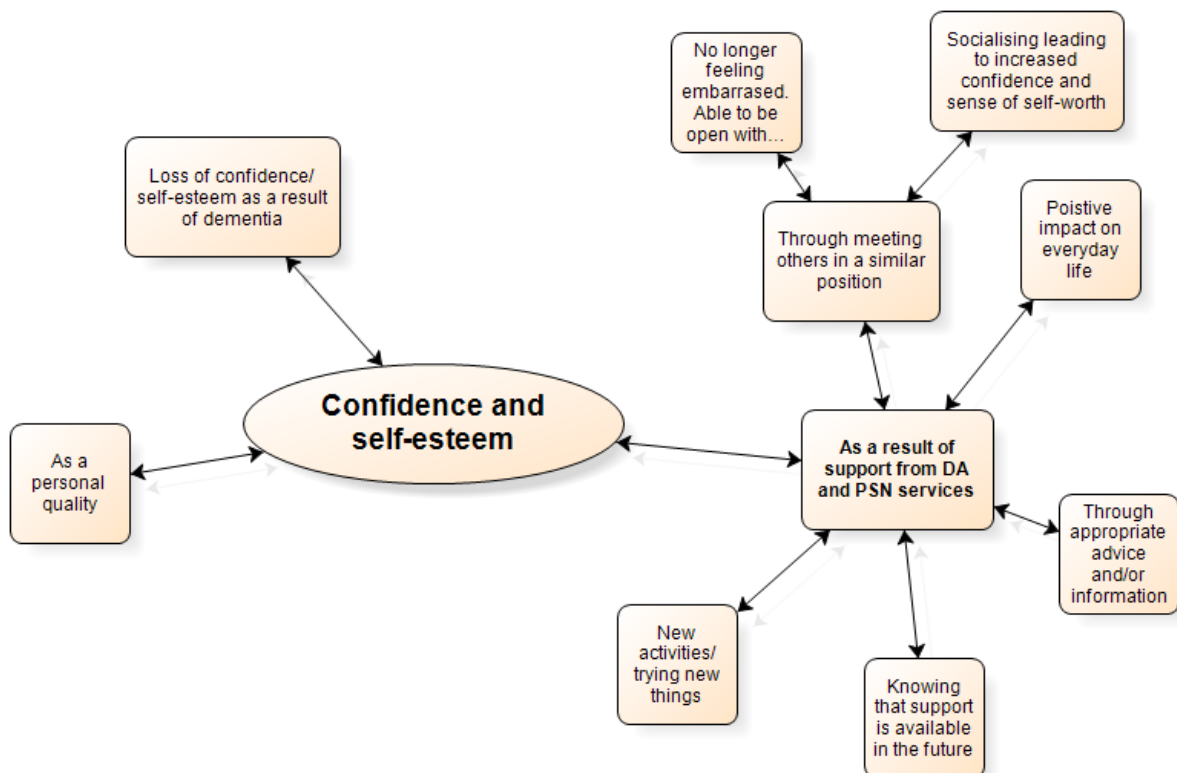
People spoke too about discovering ways to manage symptoms, and a regained confidence. People also referred to empowerment for carers through information and support, again

impacting on people with dementia. This quote refers to empowerment through strategies to cope at a family level:

Glen, Dementia Adviser: *That is because we are providing them information. We are empowering the family how to deal with the situation. The majority of clients, they are at the later stages of dementia – they have got care needs. Personal care needs. And in that way I will network with the organisations so it could improve and give the respite services for carers – alongside improving the care of the person with dementia.*

People also spoke about empowerment through future planning and decision making, and the role of peer support in empowerment through strategies to cope.

**Confidence and self-esteem**



People were open about the impact of dementia on their self-esteem, often reinforced by stigma and isolation. Peer Support Network and Dementia Adviser services impacted on people’s self-esteem through opportunities of new experiences, and an increased sense of self-worth though socialising with others with dementia that then impacted on their social

interactions in other areas of their lives. This included a positive effect of no longer feeling the need to hide dementia, and an ability to be more open with people as a result of interacting with others who have dementia.

Group activities also provided opportunities for people to regain confidence:

Bev, PSN facilitator: *He has then built his confidence enough over a year... I've known this gentleman for a year now, and he's built his confidence enough now to go to some mainstream services... Sorry, not services... Mainstream computer sessions at a local college. So further education, which he wouldn't have done a year ago. Still needs that... To be in that environment with people who are in a similar situation, because he needs that support. But just to be able to be signposted to somewhere else, and to go and attend, in a further education college, is just... Yeah, wonderful.*

Tim, local professional from memory clinic who had interacted with PSN services: *And I think, you know, that there's one gentleman, in particular, who has just completely flourished, you know. And a lot of that is to do with this contact with the Peer Support Network. You know, prior to that it was really quite isolated and lacking in confidence and those sorts of things – and... And now is... Is signed up to do an evening class.*

As did support from a Dementia Adviser:

Jilly, carer who had accessed DA service: *It gave us the confidence to move in the directions we wanted to move in and really push these applications.*

## **Section Six: Sustaining the implementation of Peer Support Network and Dementia Adviser sites and their contribution to the aims of the National Dementia Strategy**

This final section of the presentation of findings from the Healthbridge evaluation presents data relating to the contribution of Peer Support Network and Dementia Adviser services to the aims of the National Dementia Strategy. Here, we outline data relating to the long-term sustainability of Peer Support Network and Dementia Adviser services as well as their

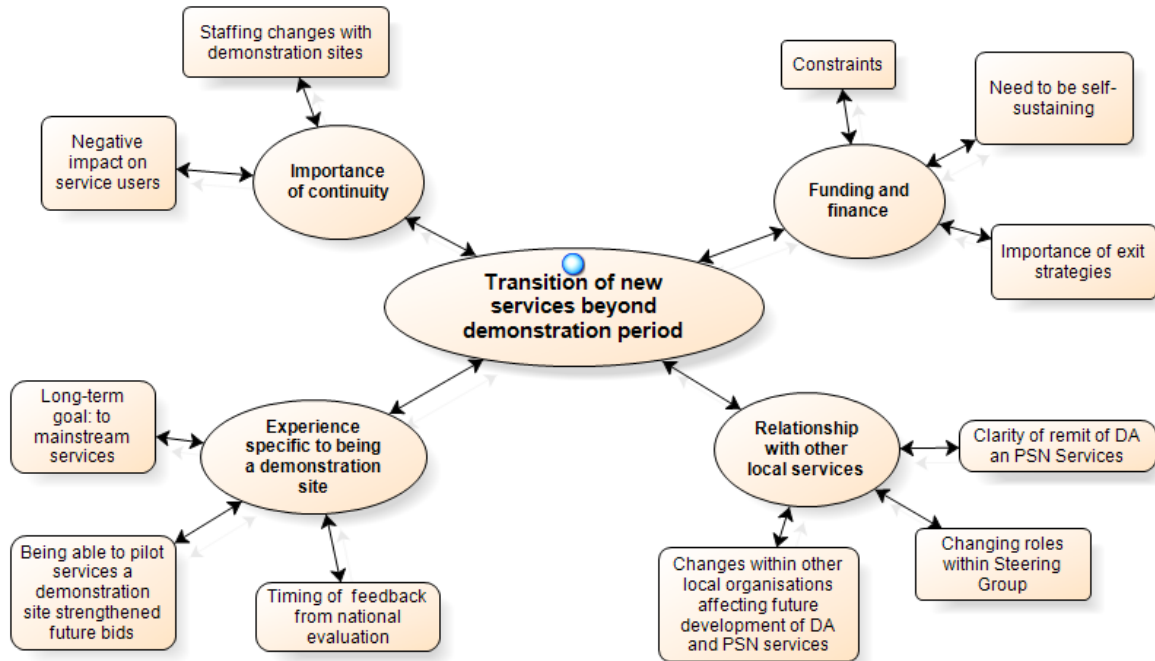
contribution to the aims of the National Dementia Strategy as highlighted in the background section of this report on page 14-15.

In this section:

- Data from in-depth case study interviews relating to the transition of Peer Support Network and Dementia Adviser services beyond the demonstration period.
- Data from site surveys which provides an overview of the extent to which Peer Support Network and Dementia Adviser sites were able to sustain their activity in the longer term.
- We conclude this section by returning to the 'case for change' for Peer Support Network and Dementia Adviser services, as outlined in the National Dementia Strategy.

### **Transition of Peer Support Network and Dementia Adviser services beyond demonstration period**

In considering the contribution that Peer Support Network and Dementia Adviser services have made to the aims of the National Dementia Strategy, it is first important to explore whether or not Peer Support Network and Dementia Adviser services continued beyond the initial demonstration period. The following themes emerged from the data which was collected in the in-depth case study interviews:



Staff and stakeholders who took part in in-depth case study interviews reflected on the transition beyond the demonstration period. The areas covered within this aspect of the data included: funding and finance; relationship with other local services and the importance of continuity.

Funding was the key issue in relation to the transition of Peer Support Network and Dementia Adviser services beyond the demonstration period. Within this, staff and stakeholders referred to the need to be self-sustaining. This seemed to be particularly key within Peer Support Network sites:

Leslie, PSN facilitator: *Yes, resource. I think although the expectation is that these groups to become sustainable on their own, gradually with very little help, I think that is not possible straight away. We would still be needing more resources to continue on this kind of development support available to these groups. If we want to make it a good example.*

The importance of exit strategies was also referred to.



The relationship with other services was again significant in the transition of Peer Support Network and Dementia Adviser services. Within this, the clarity of remit of Peer Support Network and Dementia Adviser services was significant:

*Lisa, Dementia Adviser (who had taken on role after initial pilot phase): No, I mean, my personal experience, from, sort of, observing – when it was to be in the pilot phase, still. And then sort of moving over, transitioning, now, to having the year contract... I mean, I think there's some... Some areas that became highlighted as I was kind of taking over the transitional period. And I think it wasn't necessarily directly within this service, it was the actual health and social care services that were involved. And it had become quite apparent that the remit of this service had become quite blurred.*

Changing roles within Steering Groups and changes within other local organisations affecting future development of Peer Support Network and Dementia Adviser services were also factors that affected the transition of services for some sites, often causing confusion and lack of continuity of support for people with dementia and carers.

Also in relation to the transition of Peer Support Network and Dementia Adviser services, there were some aspects of experience specific to being a demonstration site. For example, this commissioner from a Dementia Adviser site spoke about the timing of feedback from the national evaluation:

*Leigh, commissioner from DA site: Because in terms of the future, that was vital information for us in determining what we were going to do in terms of moving post-demonstrator site. The contract of the demonstrator site obviously finished at the end of March, so that was very valuable in helping us think about, okay, well what should we be doing post-the end of March. So we've extended the contract for another year, but we're looking at how we will be taking the Dementia Adviser role forward during that time. We were very aware that the national evaluation... We won't get the information in time for when we need it – if we're going to do any tendering for rolling out the service. Which is a big issue, I think, nationally, isn't it? For everybody? So [local Mind CEO]'s information is really helpful in that context in terms of how well received the service has been I mean, obviously, there's... I suspect*

*that there will be things we'll need to look at in the context of that. I don't... I will be interested to hear, when your evaluation is done, what comes out in terms of the nuances of people's views.*

However, there was also reference to the positive impact of being able to pilot services as demonstration, including strengthening future bids. For some services (although by no means all), this led to the mainstreaming of services or an extension of funding:

*Maria, commissioner, DA site: I think sometimes if you've got those arrangements in place, erm, they do tend to work quite well, and of course, it's never free money, but d'you know what I mean? We didn't have to go through a bidding war in three or four separate organisations to try and find the money, so the fact that we were able to tease it out, test it out, erm, has been a strength and also is, you know, the basis on which we're trying to secure further funding.*

People referred to the importance of continuity in relation to the transition of Peer Support Network and Dementia Adviser services beyond the demonstration period:

*Glen, Dementia Adviser: The approach hasn't been identical to, erm, the way that the mainstream Alzheimer's Society activities are run, nor the expectations in term of, we've had to put in place the realism that because of a pilot we've got to ensure that there's continuity after the project has ended.*

People with dementia and carers, when asked about their future ideas for Peer Support Network and Dementia Adviser services, often stated that their hope for the future of services is that they would continue and expand to support others in the future:

*Interviewer: Are there any negative aspects of the group? Things that aren't going so well or anything that could be improved?*

*Gill, carer from PSN site: I don't think so. Not from my point of view. Just hopefully that it will be able to carry on.....*

Across both Peer Support Network and Dementia Adviser sites, people also spoke about training for nursing staff in hospitals, and rolling out/mainstreaming services:

Marianne, volunteer peer supporter: *I would like to see, in 5–10 years’ time, it being part and parcel, automatically, of when somebody is diagnosed with dementia, that people are aware that that carer is going to need some support.....*

**Site survey data: Site activity in the Peer Support Network and Dementia Adviser services in March 2012**

Also significant to the transition of services, and subsequently the extent to which Peer Support Network and Dementia Adviser services contributed to the aims of the National Dementia Strategy, is the number of demonstration sites which secured continuation funding. This is represented in Table 17.

	<b>Sites secured permanent funding</b>	<b>Sites secured funding beyond March 2011 (but not permanent)</b>	<b>Sites ceased activity</b>	<b>Sites lost contact with evaluation</b>
<b>Dementia Adviser sites</b>	3	11	5	2
<b>Peer Support Network sites</b>	3	10	6	0

Table 17. Future funding arrangements for sites.

**The extent to which Peer Support Network and Dementia Adviser services have contributed to the aims of the National Dementia Strategy**

We return at this point to the case for change for Peer Support Networks and Dementia Advisers, as outlined in the background to this report on page 16-17. Firstly, Dementia Advisers were developed because:

*One of the most clear and consistent messages from discussions with people with dementia and their carers has been the desire for there to be someone who they can approach for help and advice at any stage of the illness – ‘someone to be with us on the journey’.*

Peer Support Networks were developed because:

*One clear message we have received from people with dementia and their carers is that they draw significant benefit from being able to talk to other people living with dementia and their carers, to exchange practical advice and emotional support.*

In considering the contribution of Peer Support Network and Dementia Adviser services to the National Dementia Strategy (Department of Health, 2009a), the following key commitments from the Prime Minister's Challenge on Dementia are also significant:

- Promoting local information on dementia services
- Dementia-friendly communities across the country
- Awareness raising
- Participation in high-quality research.

There are six main areas to be considered within this discussion: good quality information; supporting people with dementia and carers in decision making; public awareness raising; improved personal support services; good quality early diagnosis and better support for carers. We will return to these areas in the discussion section which follows.

## **Conclusion**

This findings section has brought together the range of qualitative and quantitative data that was collected through the various strands of the Healthbridge evaluation. In presenting the findings, we have described the range of services and support provided by the Peer Support Network and Dementia Adviser demonstration sites as well as their evolution, establishment, delivery and governance. The findings section has also provided an assessment of the integration, sustainability and transferability within the wider health and social care landscape. This has included the important area of the relationship of Peer Support Network and Dementia Adviser services to pre-existing services. Through the presentation of well-being and quality of life measures alongside in-depth interview data on the well-being and daily life of people living with dementia who were accessing Peer Support Network and Dementia Adviser services, the data has identified the contribution of these services to their well-being and quality of life. Significant areas of experience for

people accessing services, such as independence, control, choice and access to services has also been considered. Finally, the findings section has identified areas that relate to the long-term sustainability of Peer Support Network and Dementia Adviser services, and consequently their contribution to the implementation of the National Dementia Strategy. The discussion will return to these areas identified: good quality information; supporting people with dementia and carers in decision making; public awareness raising; improved personal support services; good quality early diagnosis and better support for carers.

## **Healthbridge: Discussion**

In this section we explore what we can learn from the findings of the evaluation and how Peer Support Networks and Dementia Advisers influence people living with dementia, other practitioners and services. The purpose of this section is to:

- From the viewpoint of people living with dementia, consider their needs, and how the Peer Support Network and Dementia Adviser services are addressing these needs.
- Discuss the Peer Support Network and Dementia Adviser services as organisations that are new and trying to become sustainable among a range of other services in their areas.
- Reflect on the contribution of Peer Support Networks and Dementia Advisers to delivery of the National Dementia Strategy and subsequent policy imperatives.
- Reflect on the strengths and weaknesses of the research design and methods.
- Propose a set of recommendations for practice, for services and for policy, and for future research.

### **Working with people living with dementia, working with services**

The Peer Support Network and Dementia Adviser services are located in the middle – on the one hand, they work with people with dementia and their carers; on the other hand, they work with communities and a wide range of other services. They play a connecting role, communicating with, raising awareness and bringing together communities and services. In this process, people with dementia and their carers know about services that are available to them and communities understand better the needs of people living with dementia. Yet, Peer Support Network and Dementia Adviser services are far more than brokers, because for many people with dementia and carers these new services are a destination in themselves, which offer opportunities to enhance their well-being and provide support on the often bewildering journey of living with dementia.

## **Re-narrating everyday life**

- **A diagnosis of dementia impacts on previously familiar ways of living. This places people living with dementia in a position of needing to re-narrate and establish new patterns of living. We described this as the ‘re-narration of everyday life’.**
- **Within this re-narration, there is a new or different interaction with services, support and practitioners, as well as a need for different or adapted social networks. Peer Support Network and Dementia Adviser services had roles to play in re-narration for people living with dementia who took part in this evaluation. This happened through provision of new structures or routines; maintaining or developing new social networks and opportunities for people to ‘benchmark’ their experiences.**
- **Peer Support Network and Dementia Adviser services enabled a balancing of the presence of dementia in people’s lives; a reclamation of aspects of people’s lives and an engagement with future events.**

In order to understand the way in which Peer Support Networks and Dementia Advisers influence and impact on those living with dementia, we need to revisit the experiences and needs that people have. The carers and people with dementia interviewed in this evaluation spoke about their personal experiences, often echoing things that have been found in other studies (e.g. Gates, 2000):

- the isolation they feel
- the mixed emotions felt on diagnosis
- the challenges of getting appropriate service support
- the ways in which they cope with their situation.

Some of these experiences were spoken of with warmth and humour; some experiences had left (sometimes deep) traces of distress and anxiety.

What people living with dementia also spoke of concerned a time of change in their lives; a transition from one (familiar) way of living into another that was unfamiliar and had an uncertain future. In seeking some adjustment to the changes that result from living with the

presence of dementia on a day-to-day basis, carers and people with dementia find themselves seeking to redefine what 'normal' is to them now. Mitchell and Glendinning (2007) also highlight the importance for older people of seeking a 'normal' life, even if this normality was redefined as people's circumstances changed. What was once experienced as 'normal' transitions through to a new normal, and it is in this re-narration of everyday life that there is the opportunity for Peer Support Networks and Dementia Advisers to influence and support this most challenging of life's transitions.

Not only is the fabric of a familiar life undergoing enormous internal change, including a redefining of close personal relationships (Botsford *et al.*, 2012), but this re-narration of everyday life must also contemplate and engage with an array of services and practitioners. Mediating the private experiences of someone with dementia and the public nature of health and social care systems is a role that Galvin *et al.* (2005) ascribes to the family carer. This mediating (or bridge-making) role often takes place in the context of "differing assumption of family carers and practitioners" (Clarke and Heyman, 1998; Mitchell and Glendinning, 2007) and creates another point at which Peer Support Networks and Dementia Advisers bring a different relationship to the situation, one which perhaps closes the gap on these differing assumptions, as we shall discuss later.

Elsewhere, in a study of risk construction and risk management in dementia, we have argued that this process of re-narration of day-to-day life, including the tensions within this process, is very purposeful for people living with dementia (Clarke *et al.*, 2010). It is a process we referred to in that study as the contested territories of everyday life. There are four purposes:

- Sense making, providing an explanation for events and rationalising engagement with some activities.
- Maintaining self, undertaking activities which reinforce their identity and akin to Crisp's (1999) description of people with dementia as engaged in the process of "defending, negotiating and reconstructing an identity for themselves" as they make sense of their diagnosis and their changing relationships with the people around them.
- Claiming and relinquishing decision making, reflecting the changing social and family positioning of the person with dementia in which their decision-making role is



gradually adjusted. This recognises too that people with dementia are vulnerable to disempowerment, through decisions being made for them, and may no longer be regarded as autonomous individuals, capable of making decisions for themselves (Parker and Penhale, 1998).

- Creating purpose(lessness), framing purpose (and purposelessness) in the life of the person with dementia.

Morgan (1999) also emphasises how, in the everyday nature of life, there is interplay between multiple perspectives and interpretations, and a dynamic nature despite there being a regularity and biographical dimension. So too is there conceptualisation of individuals adopting a shared sense of what is normal and expected – this is particularly apparent in the few studies of caring among minority ethnic groups, with Adamson and Donovan (2005) arguing that this collective norm arose from reinforcements to collective self-identify. This makes it particularly hard to provide services for some who may seek to make different distinctions between what is normal and abnormal in a caring relationship because it is so culturally located (Botsford *et al.*, 2012).

A key question for this current research then is in what ways Peer Support Networks and Dementia Advisers support these largely unseen processes of the re-narration of everyday life, including sustaining engagement with established day-to-day patterns of life. A further point for consideration is ways in which Peer Support Network and Dementia Adviser services achieve a closing of the gap between lay and health/social care professional assumptions of care need and service need.

We see evidence of this in the data from this evaluation:

- Peer Support Networks and Dementia Advisers provided new focus and structure in people's routines of their lives, and both people living with dementia and the practitioners in the demonstrator services spoke of the importance and significance of these.
- People living with dementia highlighted the importance of maintaining social networks and connection in regaining a sense of normality, and the role of Peer Support Networks and Dementia Advisers in achieving this.

- The services provided people living with dementia the opportunity to make social comparisons, to ‘check’ how they were doing and in this way benchmark their experiences. This took place in multiple directions (e.g. ‘we are better than/worse than’, ‘she said we were doing OK/could be doing better’).

Let us take just one family as an exemplar of the impact on their lives of working with a Dementia Adviser to identify a new range of activities for the person living with dementia. Let us call them Jim and Suzanne:

*Suzanne: We’ve sort of got back some normality now. He’s got quite a week of things happening most days... we have had a whole complete reshuffle of our lives really over the last 18 months... (our emphasis).*

*Suzanne: Not long after you retired you had your diagnosis didn’t you? And that was quite a blow as well. And we’ve sort of been trying to get back some sense of normality since really.*

*Jim: Yeah, I just want to get on with my life as such, I don’t want to be sitting down and they’re “oh yeah, you’re not going to be able to do this, that and the other”. I don’t want that you know. I just want to get on with my life. (our emphasis)*

It is this ‘getting on with life’ that the staff in the demonstrator sites also evidenced awareness of. There are three key dimensions to this, illustrated here through the words of one person (who we will call Karen), who worked in a Peer Support Network demonstrator site:

- Balancing the presence of dementia in people’s lives

*Karen: [They] talk about anything regarding the illness, or just to get away from the illness in a social environment. (our emphasis)*

- Reclaiming aspects of life

*Karen: They’ve got that [socialising with other people] back, which they didn’t have. Which they lost for a time. (our emphasis)*

- Being able to engage with future events

*Karen: They’re able to look forward to something. (our emphasis)*

Amidst the trauma of receiving a diagnosis of dementia, the Peer Support Networks and Dementia Advisers play a part in providing an infrastructure in which people could find their feet again – find a space in which they could re-narrate their lives, establish social networks that were often different when living with dementia, and find a newly defined purpose to their lives. Having a purpose, and finding a meaning to day-to-day life, is critical to the maintenance of well-being for older people, irrespective of living with dementia (Reed *et al.*, 2008). Ward *et al.* (2011) also point to the benefits of peer support. Let us return to Suzanne again, in conversation with her husband Jim and the interviewer and talking about groups they are now involved with in addition to the Dementia Adviser service, to describe this in her own words:

*Suzanne: And you forbade me to talk to anyone didn't you? About it; because you felt there was a great shame about it didn't you? You were very embarrassed.*

*Suzanne: It was a pivotal part of that (post-diagnostic) journey that she (Dementia Adviser) should be there because without her we would have fallen through that net, we would have fallen through the black hole, I'm convinced. Because we would not have known which direction to go in...*

*Suzanne: We're all thrown in the same boat and, you know, sink or swim... but quite often though, you're in a situation where you can, sort of, help other people and having a social life with the kind of people that we do now, you can help share their worries and woes. (our emphasis)*

One of the Peer Support Network facilitators, let us call her Linda, also recounted this mutual help aspect of peer support:

*Linda: There are some really powerful things going on between people who are sharing the same ideas. Self-help has been something that's been in the culture of response to problems for years and years and years, and in some ways this is an aspect of mutual aid self-help... and I think this is giving permission and structure for carers to actually be able to help each other.*

## **Averting problems**

- **Within the process of re-narrating everyday life Peer Support Network and Dementia Adviser services impacted on the lives of people living with dementia through providing some ways of averting problems.**
- **This was enabled through the flexible approach to support seen within Peer Support Network and Dementia Adviser services, and through attentiveness of staff and supporters within the services.**
- **Peer Support Network and Dementia Adviser services also worked to ensure that future support was in place, thus averting future problems.**

The services in the demonstrator sites also influenced people's experiences through averting problems from occurring, identifying at an early stage that perhaps a situation was deteriorating and taking steps to establish early interventions, or support the family themselves to do so. This is evidenced in the sections on crisis prevention and early intervention within the findings, where core staff and stakeholders as well as commissioners and stakeholders from other local service providers defined crisis prevention as a key role for Peer Support Network and Dementia Adviser and services. People living with dementia themselves also gave examples of support from Peer Support Network and Dementia Adviser services, which averted problems and spoke of the positive impact of this on their experience. The quote above by Suzanne is an example of this: she says that without the intervention of the Dementia Adviser they would have "fallen through the black hole".

It is important to emphasise that these are not crisis intervention services – what they appear to be doing is equipping the families to deal with situations when they arise, or they recognise a deteriorating situation and take steps to avert a problem. They achieve this through raising awareness, enabling peer support and increasing the level of signposting to local support services. In addition to practical support such as information in enabling problems to be averted, there was an emotional aspect to the ways in which Peer Support Network and Dementia Adviser services enabled a different outlook on the future. There was often an interpersonal focus to this emotional support which enabled a greater peace of mind about the future: knowing *who* they would go to in the future when support was

needed and knowing that, because that person had been a source of support in the past they would be in the future. It meant that the staff in the demonstrator services worked attentively with clients and were flexible about the way in which they worked so that they could respond promptly to changing needs. This is evidenced in the sections on timing and flexibility of support in the findings, and in what was said by many of the people with dementia and carers who we interviewed about the positive impact of a person-centred approach to support by Peer Support Network facilitators and Dementia Advisers. This outcome of the work of the demonstrator sites was emphasised by people relating that, were the services to cease and there was a return to previous patterns of support, there would be an increased need for crisis and residential care and increased demand on other statutory services. One stakeholder, a professional who had accessed a Dementia Adviser site, when asked about the consequences should the Dementia Adviser service cease, responded as follows:

*It's like stepping back, probably 10 or 20 years, to be quite honest. Where dementia is medicalised. That would be a real shame, with the amount of progress that there is now about the knowledge of dementia and living...because you say dementia, and you think of poor old souls sat around in chairs, drooling...it's not like that at all. And I think that's the other thing that [Dementia Adviser] does – is make sure that everyone she touches professionally knows that this is about life and that just because someone has got dementia it doesn't mean that they can't still do the shopping. (Stakeholder interview)*

Achieving a service that is able to avert problems and crises is noteworthy. Just as supporting people who are feeling embarrassed (as Jim above was), who are experiencing considerable disruption to their day-to-day lives, and who have cognitive loss, is challenging, so providing a responsive service able to avert problems is even more so. As Karen says in relation to encouraging people to participate in peer support groups: “It's a trust thing... and that takes time”.

This level of connected engagement between the demonstrator site services and people living with dementia can also be illustrated by Suzanne:

*Suzanne: Some people, I found, you talk about something and they don't want to know. With [Dementia Adviser] she was quite prepared to listen to you... she's done a lot for me, and I feel a lot better when I see her or hear from her. I feel fine.*

Karen too talks of how she “would work alongside the families, alongside the carer”. But she goes on then to talk of how “I try to fill in the gaps. I network with other organisations...”. Suzanne too reflects this point in talking about the role of their Dementia Adviser: “She’s helped, sort of, bring all the services together and coordinate things”. So staff in the demonstrator services, through the work of being a Dementia Adviser or in a Peer Support Network, are listening and learning about the people living with dementia that they work with, and are also working in and around other services. Emotional labour, trust, reciprocity and mutuality are features of lay-led interventions that have been argued as enhancing effectiveness in other studies too (Whittemore *et al.*, 2000; Springett *et al.*, 2007).

One further aspect of averting problems is by working to future-proof care situations. There are several components to this, ranging from thinking through ‘just in case’ situations, to supporting people to understand what their future needs might be. This is a complex area because we know that families living with dementia tend to take one day at a time as a deliberate strategy that allows them to cope and moreover allows them to maintain a sense of identity and family position of the person with dementia – allow your mind to go too far forward and what dominates is the dementia and the individual is diminished by that (Clarke and Heyman, 1998). Staff, however, have a better sense of the future trajectory of dementia. So there is a balance to be found between a family’s inclination to time reference from present to past, and staff’s inclination to time reference from present to future. Karen offers us an insight into this temporal dynamic from her point of view:

*Karen: They are dealing [with it] as it's coming. But they don't understand the condition. They don't even understand what's coming, what the future holds for them.*

However, a sense of relief for people with dementia and their supporters came from just knowing that services existed and could be accessed if necessary in the future. Many of the people living with dementia who we interviewed spoke about the role of Peer Support

Network or Dementia Adviser services in helping them to know where to go in the future if they needed more or different support.

### **Enablement and independence**

- **Through re-narration and putting future support in place, people living with dementia were reported as being enabled to live more independently, often for longer periods of time. This in turn enhanced the process of re-narration, creating a positive cycle which can enhance quality of life.**
- **Peer Support Network and Dementia Adviser services had specific roles to play in facilitating social and community engagement, which also contributed to a positive re-narration of everyday life and, through that support, maintaining independence. The role of timely information, in particular at the point of diagnosis, was significant within this.**
- **There are parallels to be drawn between this process, which has potential to enhance self-esteem and confidence, and ideas around health promotion initiatives.**

Both averting problems and re-narrating life lead to, and are in turn supported by, increasing independence, strengthening interdependence, and being enabled to achieve this. In essence, a virtual cycle is established that has the potential to enhance quality of life. Participants spoke of feeling better able to do things themselves (being empowered) through their social networks, the information that they received, the signposting to other services, and the plans they were able to make to manage the challenging aspects of living with dementia. For both Dementia Adviser services and Peer Support Network demonstrator sites, the promotion of independence, control and choice were central to the way in which they worked. Karen, for example, talked about how the Peer Support Network service she worked in was “enabling people to make decisions about their future when they’ve been diagnosed”. In relation to a couple participating in a café and singing group, Karen commented:

*Karen: It’s changed their outlook on life, they’re more positive about life. A reason to go out, if you like, mix with other people, socialise with other people.*

Suzanne too spoke of the way in which the support from a Dementia Adviser had enabled her and her husband Jim (who has dementia) to have an improved quality of life:

*Suzanne, addressing Jim in the interview: I think more people listen to you now since we got a whole new social life and more around people that understand, are prepared to listen. So I think... your situation has improved hasn't it, as our new social life has developed?*

So in what ways did the Dementia Adviser and Peer Support Networks enable people to 'live well with dementia'? The interview findings indicate a number of different ways in which 'living well' was achieved:

1. Through facilitating social and community engagement, which in turn increased confidence and social connectedness – we saw this in the section above on re-narrating life and the way in which Suzanne spoke of their transition from feeling stigmatised through to feeling that they did after all have something to offer others.
2. Through identifying ways of dealing with the more challenging aspects of having dementia, creating a more helpful home environment, for example.
3. Through providing information to allow future planning – and critically doing so in a way that also involved listening to the person with dementia and their supporters.
4. Information and support at the time of diagnosis was of particular importance, helping to manage the emotional and psychological impact of a diagnosis and ways to manage stigma, as well as providing services at a time when few others do and in this way filling the service void between diagnosis and more intensive services.
5. Through signposting to other services.
6. A re-narration of relationships drawing benefit from specific peer relationships with other people with dementia. A significant aspect of this is the commonality of experience of dementia and struggles and challenges faced. There is also a commonality within the re-narration process in the value shift towards 'realising what is important in life' referred to by some of the people with dementia and carers who were interviewed.

There are parallels here to be drawn between these ways of working of Dementia Advisers and Peer Support Networks and definitions of health promotion as "the process of enabling



people to increase control over, and to improve, their health” (World Health Organization, 1986). The importance of working to improve self-esteem and confidence, and the need to do so, cannot be underestimated, with Snyder (2002) and Sorensen *et al.* (2008) among others referring to people living with dementia feeling belittled and socially excluded. The negative attitudes of others towards someone living with dementia and their supporters, whether assumed or real, are referred to by many, including Suzanne and Jim as above (Sterin, 2002; Katsuno, 2005). This can result in a reluctance to disclose the diagnosis to others for fear of being devalued (e.g. Langdon *et al.*, 2007) and a compromised quality of life. This is illustrated by a volunteer working in a Peer Support Network demonstration site: “You know, when a person gets diagnosed, sometimes they want to hide away. And this actually gets them out somewhere where everybody that...you know, we all look upon each other as equal. And that encourages them to take more part in the community.”

The positive benefit for people living with dementia of being in a supportive and inclusive environment is illustrated elsewhere too (Phinney *et al.*, 2007; Genoe *et al.*, 2010). Intervention studies to enhance self-esteem, for example, have demonstrated improved carer mood and health (Gottlieb and Rooney, 2004) and improvements in ability to cope and overall sense of well-being (Gignac and Gottlieb, 1996). Clare *et al.* (2008) go further, suggesting that benefits are not only to individual well-being but also to achieving mutual support and collaborative advocacy through which they can influence societal attitudes, an area of citizenship in dementia also discussed by Bartlett and O’Connor (2007). In creating opportunity for enhanced self-esteem and confidence then, the demonstrator sites offer a way of countering the negative reactions and assumptions that people living with dementia encounter and limiting the consequent social withdrawal and deterioration in quality of life that may well otherwise follow. This process of empowerment and social re-enablement also contributes to the wider social repositioning of people with dementia, for example people with dementia taking up advocacy roles, enabling further development of dementia-friendly communities and potentially influencing future policy and practice.

## **Living well: Autonomy and quality of life**

- **Autonomy, which is widely acknowledged as key to quality of life in dementia care, was promoted through the ways in which information was provided within Peer Support Network and Dementia Adviser services.**
- **This was done through linking context-free dementia-specific information with context-bound person-specific information.**
- **This approach is consistent with ethics of care.**

Respect for autonomy is key to maintaining quality of life in dementia care (e.g. Boyle, 2005) and is associated with increased self-esteem (e.g. Sabat *et al.*, 1999). It is an essential part of the Nuffield Council on Bioethics (2009) framework for ethical decision making for people with dementia. Autonomy concerns a person's capacity for self-determination (or self-governance or self-rule) – the capacity to make decisions for oneself. It is a concept that has many facets, including power, decision making and human rights. Reed and McCormack (2011) describe the autonomous person as “one who examines whether or not an independent decision is appropriate and consistent with the values the person holds or not”. Thus there is a consistency between the values and action of the person, and self-evaluation of this needs to be independent. This independence occurs in two ways: independence from manipulative forces and independence from the impact of others. This suggests that, for people with dementia and those caring for them, it is crucial that there is a shared understanding of the individual's values, support to undertake actions consistent with these values and an absence of the views of others being imposed.

As this research has shown in the interview data, many people with dementia are vulnerable to disempowerment through the actions of others, who may take on the role of decision maker on their behalf (see also Parker and Penhale, 1998). The person with dementia is no longer regarded as an autonomous individual, who is capable of making decisions for themselves. These acts of disempowerment are undertaken by means of interconnected factors and processes ranging from the “collective ideological and cultural through to the interpersonal and psychological” (Innes *et al.*, 2004, p 258). Collopy (1988) wrote that “care can slide toward control, not from malevolence but simply from the dynamic of powerful

and resourceful professionals interacting with vulnerable and weak clients” (p 10). This dynamic of the shifting power in ‘caring’ relationships, and its potential to be a destructive force for people with dementia, was found in a study interviewing 55 people with dementia, family and professional carers by Clarke *et al.* (2010), a dynamic they referred to as the contested territories of everyday life. Reed and McCormack (2011) argue that a dynamic like this occurs when a society’s culture extols youth and vigour, leading to older people being disregarded or devalued, and this also happens when particular value is placed on cognitive ability.

In dementia care, enabling the person with a diagnosis of dementia to maintain independent decision making is hard to uphold, but we are moving on from a position in which people with dementia are assumed to not have views themselves to one in which those views are centre stage, and the role of everyone is to support actions that are consistent with those views. This would suggest that in order to form a view, people with dementia need to have appropriate information, but that others need to listen and hear their views and be prepared to act on them. Maintaining autonomy for people with dementia includes, but involves much more than, the provision of information. It does seem that, in being non-professionally qualified staff and through peer support, the services of Peer Support Network coordinators and Dementia Advisers are able to make connections between the information that they hear about what people want and the information that they know about dementia and other services, and to use this to allow people living with dementia access to support that enables them to increase independent decision making and autonomy.

One of the key functions of Peer Support Networks and Dementia Advisers (whether through professionals or lay/peers) is in providing information. This information is used, as shown in this research, to support autonomy and individual decision making, to enable access to services, to build social relationships, to re-narrate a sense of the individual person and their family relationships and to engage with planning a future. Achieving this also reflects the movement towards ever-greater responsibility of individuals for their own health and well-being that has been enshrined in policy development over the last decade. Examples include: the Mental Capacity Act (HM Government, 2005), providing a statutory

framework to enable the maintenance of personal choice and to protect vulnerable people who may not be able to make their own decisions; the Government White Paper *Our Health, Our Care, Our Say* (Department of Health, 2006); and *Putting People First* (Department of Health, 2007). The National Dementia Strategy for England (Department of Health, 2009a) sets out 17 recommendations relating to three specific themes: raising awareness and understanding; early diagnosis and support; and 'living well with dementia', as well as offering the opportunity for a better understanding of dementia. This focus is picked up worldwide, with attention in policy and practice to improving public and professional awareness of dementia and provision of information to people with dementia and their families.

### ***Ethics of care***

This approach of Peer Support Networks and Dementia Advisers is consistent with the 'principles of care', and the accompanying ethic of responsibility, which demands that information is provided in a way that is appropriate to the individual, and to achieve that requires a knowledge of the needs of that individual (Gilligan, 1982). This is distinct from the one-way provision of information (from, say, a practitioner to a person with dementia), which arises from the 'principles of rights' approach:

The morality of rights is predicated on equality and centred on the understanding of fairness, while the ethic of responsibility relies on the concept of equity, the recognition of differences in need. While the ethic of right is a manifestation of equal respect, balancing the claims of other and self, the ethic of responsibility rests on an understanding that gives rise to compassion and care.

Gilligan, 1982, p 164

Tolson and Brown Wilson (2011) provide a very poignant example of information provision that does not adopt a 'principles of care' approach. 'Mr Newman' is a 79-year-old carer for his wife who has dementia. Mr Newman was in hospital following knee replacement surgery. What is of note to the discussion of the principles of care and our evaluation of Peer Support Network and Dementia Adviser services is the manner in which information was delivered to Mr Newman:

All I wanted to know was if she could help me make some arrangements. She gave me a carrier bag full of leaflets, forms and books and told me everything I needed to know was in there and left. I was shaking... If that wasn't bad enough I tipped out the leaflets onto the bed and the one that struck me cold was about funeral plans. All I had wanted was to know if we could get meals delivered until I was back on my feet so that I wouldn't have to keep bothering my daughter.

Tolson and Brown Wilson, 2011, p 159

Mr Newman (in Tolson and Brown Wilson, 2011) goes on to explain how a nurse saw his distress and responded through emotional support:

The staff nurse came over, she didn't say much, she just pulled the curtains round, put the bag of papers in the locker and held me. Bless her, that nurse just understood, she knew when words were not enough. I guess that's about it really for me, good communication is showing you care, really care and respecting people and their dignity.

Tolson and Brown Wilson, 2011, 159

The above example outlines two significant aspects of Mr Newman's care: inappropriate timing and content of information given to him, without support or recognition for his specific circumstances; followed by recognition of his distress (by a different staff member) with emotional support. The differences we have identified within Healthbridge – evidenced in data around timing and flexibility of support, which enables information and advice to be delivered in ways that are appropriate and sensitive to each individual as well as in data relating to the strength of interpersonal support rooted in that same sensitivity – has demonstrated ways in which the two aspects of Mr Newman's experience might have been combined. The result would have been that Mr Newman would have received the information that he and his wife needed at that particular time alongside support to respond to that information, with the emotional and practical support that he needed.

It is timely too, to remind ourselves of the findings from the ASCOT data in this evaluation that showed levels of unmet need for people with dementia and carers in relation to accommodation, occupation and control; and for people with dementia, also, dignity. It

takes us back to the start of this chapter and the discussion about the importance of having a purpose for people in their lives. It reminds us too that we need to be able to support autonomy and decision making in relation to aspects of life that may appear to be outside the responsibility of a specific service – clearly people are sometimes troubled by the state of their accommodation and their quality of life would be improved if this were something that could be addressed. There is certainly a place for social and household care for people with dementia and carers as well as health care. This is also explored in an interview with a senior stakeholder local to one of the Dementia Adviser sites, as in the following quote:

*Senior stakeholder: What we've flagged up with our Dementia Advice service is actually people's needs are informing services a lot more, because people aren't wanting just the traditional service delivery. They are thinking of all sorts of different things to keep themselves well. So it may be looking for a music group, looking for a gardening group. Which is very different from, perhaps, the delivery that adult services have always thought of, delivering care to people...Because if people are coming to us with the diagnosis of dementia, but actually want certain things but the community focus is very different, then we've got to inform that. And I think the Dementia Adviser will do that. I think the service will do that. It has done it already...It's made us think much more of a personalised service for people.*

So far, we have considered autonomy as in the freedom to make decisions (decisional autonomy), but we also need to consider the ability to act on these decisions (executorial autonomy) (Collopy, 1988) and the role of Peer Support Networks and Dementia Advisers in supporting executorial autonomy. It was executorial autonomy in particular that Mr Newman above was seeking but did not receive. Executorial autonomy may include delegated autonomy (Collopy, 1988), in which there is a negotiated (not assumed) process of delegation to act on decisions, and sometimes to make decisions. The latter, delegation of autonomy to make decisions, is enshrined in the Mental Capacity Act (HM Government, 2005) and has led to measures such as advanced directives to ensure that even if someone is unable to make a decision at that point in time, those with delegated autonomy for the individual are as well informed about their preferences as possible. The Mental Capacity Act (HM Government, 2005) also seeks to avert assumed delegation by placing the burden of proof on demonstrating that someone *does not* have capacity rather than that they do, and

that to not have capacity does not apply in all circumstances and at all times. It recognises that an individual may have capacity at varying times and in relation to some decisions and acts. McCormack (2001) describes 'negotiated autonomy', in which autonomy is considered within an interconnected relationship. In this way, there is no one person who is the 'final arbiter' of decisions, but instead there is a framework of negotiation based on an individual's values base.

### ***Context and information***

Peer Support Network coordinators and Dementia Advisers bring to their work with people living with dementia the application of context-free dementia-specific information to a context-bound person-specific situation. At a time when people with dementia (and their family members) are trying to sustain a biographical narrative that has some stability, albeit one that is being re-narrated, it can be jarring to them if they are provided with information in a way that potentially disrupts that biographical narrative through imposition of an illness (dementia) narrative. Heyman (2010) refers to this as "the informational disjunction between prospective and retrospective perspectives" (p 120). This disjunction is, in some regards, critical to the process of re-narration – if there is no disjunction there is no need to change – but if the disjunction is simply too large then it is impossible to bridge, or at least the response to it needs to be supported.

The person-centred approach, highlighted as a national standard in the National Service Framework for Older People (Department of Health, 2001a), has been long advocated in dementia care. It encourages the building of caring relationships, the *sharing* of knowledge and information, together with the promotion of individual emotion, in contrast to concentrating on mere cognition decline. Failing to recognise the differential knowledge bases in managing health and ill health means that we may neglect to acknowledge and support the work engaged in by people with long-term illness to contextualise the received knowledge in creating and recreating their sense of self (Robinson *et al.*, 1997; Clarke *et al.*, 2010). Harré writes: "What people call selves are, by and large, produced discursively, that is in dialogue and other forms of joint action with real and imaged others" (1998, p 68). Thus people with dementia are still engaged in the process of "defending, negotiating and reconstructing an identity for themselves" (Crisp, 1999, p 102) as they make sense of their

diagnosis and their changing relationships with the people around them. This is mirrored by the growth in initiatives associated with personal accounts (e.g. Bryden, 2005; DeBaggio, 2003), life story work and reminiscence (Woods *et al.*, 2009).

Peer Support Networks and Dementia Advisers in dementia care reflect the roles of lay health advisers in public health (i.e. those who work in the health and social care field without a professional registration). Such roles have three broad aims: access to individuals who are marginalised, access from marginalised communities into health and social care systems, and alternative delivery mechanisms to a professional provider. Lay health adviser roles have been promoted increasingly in UK public health policy. Durantini *et al.* (2006) argue that they can be seen as change agents who have an assumed demographic and behavioural similarity to the service user – someone who can ‘talk their language’ in effect. We will explore the assumptions behind these positions, and the implications for Peer Support Networks and Dementia Advisers, in the next section.

### **Distal and proximal knowledge**

- **The position of Peer Support Network and Dementia Adviser services results in them occupying a space that is closer to the direct experiences of people living with dementia.**
- **However, they remain situated between the professional world and the world of people living with dementia, resulting in a balancing of the role between public advocacy and instrumental care for individuals.**

So what is this unique space in the health and social care economy that is occupied by the demonstrator site services and their staff? An answer to this lies in part in the debates about the nature of knowledge and evidence that have pervaded professional practice in the last two decades. Liaschenko and Fisher (1999) and Nolan (2000) argue for three types of knowledge: case knowledge (biomedical and disembodied knowledge of a particular condition), patient knowledge (a ‘case’ in context knowledge) and person knowledge, this latter based on an understanding of an individual biographical life. In any staff in health and social care, all three forms of knowledge are present but to differing levels. The Peer



Support Network facilitators and Dementia Advisers are not professionally qualified and are more akin to lay health workers than they are professionally qualified social workers or nurses. Many working in the services are volunteers. In the in-depth case study interviews, we spoke to Peer Support Network facilitators, Dementia Advisers and volunteers who, whether it be through caring for a loved one with dementia or having someone close to them experience dementia, had direct experience of living with dementia themselves. Some of the people with dementia and carers we interviewed commented on the impact that this experience had on people's ability to understand and empathise with others in similar situations.

They are, therefore, well placed to privilege person knowledge and in many instances the recurrent contact that they have with an individual person living with dementia means that they can develop a detailed, continuous knowledge of the dynamic interplay between care, an individual's response to care and knowledge of changing need. Staff are also well placed to have an awareness of what Nolan (2000) refers to as 'patient' knowledge; that is, Peer Support Networks in particular provide the opportunity for staff to hear about how people with dementia and their supporters interpret their experiences and how they respond to services. The lay health workers that make up Peer Support Network facilitators and Dementia Advisers occupy a space then that is significantly more 'proximal' (Clarke and Wilcockson, 2001) to the perspective of a person living with dementia than many professionally qualified staff have the opportunity to do. In the field of public health too, the white paper *Choosing Health* (Department of Health, 2004) recognised lay knowledge as a form of expertise in its own right and advocated a broad shift from "advice from on high to support from next door" (Department of Health, 2004, p 103).

However, unlike the dominant view of lay health workers as working with the 'hard to reach' who engage in health-harming behaviours such as smoking, Peer Support Network facilitators coordinators and Dementia Advisers are working with a very different group of people – people who find themselves having to manage the unwelcomed entrance of dementia into their lives and to consequently re-narrate and reconstruct their day-to-day relationships and activities. Nonetheless, either directly themselves or through their actions to connect people with information and peer support, the Peer Support Network

coordinators and Dementia Advisers do foster a sharing of experiences in order to achieve what Springett *et al.* (2007) describe as a negotiation of notions of self, identity, health and well-being. They are less likely, compared to many lay health worker services, to be focusing on the socioeconomically disadvantaged and as a result are unlikely to influence health inequalities. For the demonstrator sites, including those that focused on specific groups such as ethnic minority groups, where this evaluation demonstrates a higher level of engagement in services that state a focus on ethnic minority groups, a primary driver was to achieve equality of access to services. There is no evidence to suggest that other marginalised groups (e.g. people with a learning disability or LGBT) had a higher level of engagement. Other lay health services, driven by reducing health inequalities, are more likely to focus on achieving equity of health status by privileging attention on those who are marginalised.

A key question then becomes whether the organisation of the services, within themselves and in relationship to other services, makes best use of this person knowledge. If not, then this knowledge, whilst useful and able to enhance person-centred services within the demonstrator site service, will not be able to be used to best effect in communication between services and in reaching for the prevention of problems and crises. We will return to the organisational location of the services later in this chapter and reflect on this point.

This tension between the accessibility and utility of different forms and sources of knowledge is played out in other public health contexts too. Springett *et al.* (2007), in evaluating a smoking cessation service, found that lay health workers integrated NHS requirements (of evidence-based intervention) with both clients' and their own knowledge about what works. Local culture, tacit knowledge and pre-existing understandings will, argues Nutley *et al.* (2002) always mediate the use of scientific knowledge; so another way in which the staff of the demonstrator services may best work with people with dementia and their supporters is through this filtering of knowledge about dementia in a specific cultural context. We see evidence in the data too of staff in the demonstrator services using their local cultural and contextually bound knowledge to support people, for example Dementia Advisers supporting the immediate networks and communities of a person with dementia to make use of community resources and build on their pre-existing social

networks. Karen also acknowledges the impact of culture on people's understandings of their dementia: "Apart from stigma, some sort of superstition is involved. Some sort of faith aspect as well." The significance of cultural understandings of dementia have been identified elsewhere (e.g. St. John, 2004; Roberts *et al.*, 2003; Moriarty *et al.*, 2011; Botsford *et al.*, 2011) and the challenge is in developing ways of working with people that are supportive of this cultural diversity. One aspect of 'culture', however, is the variation between professional and professionalised understandings of a situation and those understandings and responses held by people living with dementia themselves. These lay understandings of a situation may actually privilege information and dynamics that are beyond the technical knowledge of professionals yet are nonetheless deliberative and purposeful (Clarke, 2008). Such challenges to the power of professional knowledge can of course provoke resistance and scepticism among professional staff (Fox *et al.*, 2005).

There is, however, a further tension for Peer Support Network coordinators and Dementia Advisers in their role sitting between cultures – there is a balance to be achieved between a role of public advocacy and instrumental care for individuals. There is evidence in this evaluation of some demonstrator services working to enlighten public perceptions of dementia and to challenge stigma. Lehmann and Sanders (2007), however, report a move for lay health workers away from advocating for social change. In dementia, more than any other field perhaps, there is a mid-area in which the family assume a very prominent position and who themselves become a focus of attention, as illustrated in the following quote from a stakeholder who was a professional who used one of the demonstrator services:

*It's about education of people around the edges, to make sure that they understand that people can still take active, and valuable control of their lives... the more knowledgeable a community is, or a family is, the better the outcomes for the individual. Because people know how to deal with it. They're not afraid of it.*

This key role of raising awareness and education of members of the public is reflected too in the following quote by a carer:

*We didn't know anything about it. I was saying to [Dementia Adviser], it's not like a fluffy thing, is it? You know, people are more into it now. They don't talk about*

*dementia. It's something that's whispered... I think people need a lot more training on it because it's something that is not to be frightened of.*

At a level sitting between action for social change and instrumental support for individuals too is work to develop services. What Peer Support Network coordinators and Dementia Advisers have been able to do is bring areas of unmet need to the attention of other services, as described in the earlier quote. They do this of course for individuals in working to secure services for people, but they also do this at a more collective level. Similarly, May and Contreras (2006) write about how lay health workers translate information about local health needs into messages of relevance for health professionals, thus raising awareness of gaps in provision and creating additional demand for existing services by removing barriers.

### **Boundary work**

- **The role and remit of Peer Support Network and Dementia Adviser services meant that their work was located within boundaries such as relationships with pre-existing services as well as the tensions between national policy and local need.**
- **Partnerships were key within negotiating these sometimes complex boundaries, although partnership working in itself was at times complex.**
- **The process of locating and establishing organisational space was at times a challenge for Peer Support Network and Dementia Adviser services.**

There were several key ways in which the Peer Support Network and Dementia Adviser services worked with boundaries, and these had a major influence on their own work. Firstly, the Peer Support Network and Dementia Adviser services bordered with pre-existing services, and considerable attention was given to working with other agencies, services and professions. Secondly, the Peer Support Network and Dementia Adviser services and their Steering Groups or Project Boards found themselves needing to reconcile national policy with local need. These two issues shaped the experiences and ambitions of services as they sought to establish themselves, find an organisational space in the local health and social care economy, and become sustainable. Thirdly, the services are considered in that nexus of cost and benefit.

## **Partnerships**

Working in partnership with other services was a crucial aspect of the way in which the Peer Support Network and Dementia Adviser services developed. This is evidenced in the many different occasions on which staff and stakeholders referred to partnership working within the in-depth interviews and within the site surveys. Typically this was formalised through a Steering Group, but much of the experience of partnership working was characterised by the need to identify and occupy a 'space' in service provision that complemented, and did not overlap, with pre-existing services. While this was perhaps the focus in the earlier stages of establishing the services, it was rather rapidly replaced by a focus on seeking continuity of provision despite local and national policy changes and consequent operational changes such as changing roles and personnel. Some felt that the period of being a demonstrator site was always going to be rather short, but this was in any case very much brought to the fore of people's minds with the changing economic context of the UK. The imperative to find alternative funding sources was magnified and exit strategies planned.

The experiences of partnerships were very varied, and were the source of diverse and sometimes very strong views in different demonstrator sites and by different stakeholders. In some areas, the demonstrator site services were welcomed and all parties seemed to recognise that they met a previously unmet need. In other areas, the demonstrator site services were regarded with some concern by other stakeholders as potentially competitive with their own pre-existing services and so resulting in unnecessary duplication of provision – as exemplified by a stakeholder in the following quote:

*It's confused local policy and practice in a very big way. There was clarity previously, now there isn't clarity – there is confusion, there's a reduction in referrals to all the services... I think people now don't know what to do. I think they're more confused now than they were before the service existed. Because they have introduced ambiguity and blurred the role boundaries.*

### ***National policy – local need***

There is a recurring tension evident in the data between local specificity of service provision in response to perceived local need and ideas of universal needs that can be instigated by national policy. This impacted on:

- the process of identifying the demonstrator sites in the first instance (being locally determined responses to a national strategy but approved for funding as a demonstrator site at a national level);
- the initiation of the services (with a variety of degrees of integration and acceptance into pre-existing services);
- the continuation and sustainability of the service (such that despite unchanging local need, national policy implementation imperatives resulted in perceived premature threat to the ongoing viability of the services).

A key issue, then, concerns whether the service developments are driven by current UK policy or by local drivers (including service and professional drivers). This may lead to variability and vulnerability as services are exposed to changing local contexts, set diverse goals and targets, and exposed to changing national policy. Where, arguably, national policy captured emerging but patchy local developments in Peer Support Networks and provision of Dementia Advisers and promoted them into being more mainstreamed in the consciousness of dementia services, this role of national policy also left the demonstrator sites in a vulnerable situation because they could be seen as nationally imposed rather than driven by perceived local need and so potentially somewhat estranged from other local services. The interplay between these local and national dynamics gave rise to concerns about local sustainability.

Intersecting with this local/national dynamic is the tension between an agenda that drives superficial change and one that drives deep change (Clarke *et al.*, 2002). In the former, superficial change arises classically from a cycle of 'new' projects with limited building on previous work or acknowledgement of achievements. Projects have short timescales and minimal project cohesiveness, they are not necessarily needs-driven but are responsive to proposals and so are fixed rather than evolutionary, and exit strategies are planned rather than there being a focus on sustainability and a long-term view. The need to 'prove'

themselves within a short timeframe can result in a drive for publicity about successes and therefore for 'quick wins'. There is evidence of this approach in the data collected in this project but also recognition of, for example, the need for a length of time required for people with dementia to have confidence and trust in staff and services before they fully engage. Others spoke, for example, of learning that the physical location of meetings was important and the need to work with communities to identify suitable locations. Whilst the demonstrator sites provided an excellent opportunity to explore the provision of different services, there was also a counter-pressure in the imperative to prove themselves in order to aim for further funding and sustainability. There is a risk that where the latter dominates, new services are able to do little more than tinker around the edges of pre-existing services.

More fundamental reviews of health and service provision arise from changes that promote deep change. This more permanent learning takes place when there are mechanisms and strategies for knowledge to be exchanged in organisations, when steps are taken to avoid a loss of learning when it is located with individual posts or individual people, when inter-agency partnerships develop to progress learning and there is movement out of the 'comfort zone' (just doing things the way we always have and adhering to the familiar). In this way, activity is seen as evolutionary and knowledge building (from successes and failures) and the mainstreaming and sustainability of activities is integral from the outset.

### ***Organisational space***

So to what extent have the Peer Support Network and Dementia Adviser services in the demonstrator sites achieved deep change and where have they been tripped up by the imperatives around superficial change? The answer to this comes back to whether the Dementia Adviser role and the Peer Support Network services occupy an organisational 'space'. In the previous section we have already argued that the services in the demonstrator sites were able to engage with people with dementia and families in a way that potentially met a 'needs space'. For them to interlink this needs space with an organisational space is akin to being a bridge between social and organisational contexts, something that is a core element of the lay health worker role (Ungar *et al.*, 2004, Racz and Lacko, 2008). We see this in, for example, the way in which the services and their staff work

within a community, using the resources of that community (its volunteers, its public venues, its social networks) to identify and support families living with dementia.

However, where services have struggled sometimes to find an organisational space to work in and with, difficulties with partnerships with other services are manifest. To some extent this is an inherent aspect of any new services and any new role, and indeed staff in the demonstrator sites were aware of this and attended to their relationship with other services (assisted by strategy boards and commissioners). Britten *et al.* (2006) and Ward *et al.* (2009) report that when lay health workers are (mis)perceived as a replacement for professional staff there is the potential for duplication of effort and undermining of each other's roles and position, and this can undermine the work of the service (Ziersch *et al.*, 2000).

Enhancing the acceptability of a new service and reducing role or service conflict can be helped by ensuring that established organisations have some ownership of the new service (e.g. Ward *et al.*, 2009) – the importance of locally determined service need.

A strong relationship with established services and organisations also allows for strong communication and support between all bodies. There is the potential for professional support from established services to staff and volunteers in new roles, although this takes time to establish (Doherty and Coetzee, 2005) and requires an understanding of the role so that it is not seen as a threat (Haour-Knipe *et al.*, 1999). More evident in the Healthbridge evaluation is the communications from the Peer Support Network coordinators and Dementia Advisers to other services as they put in place that part of their work that was raising awareness about dementia and educating and influencing those in generic care roles about being person-centred and orientated to the needs of people with dementia. Whilst there is some suggestion that providing a specialist service means that more generic services actually step back from the issue and allow the specialist services to take on this responsibility (and in so doing possibly become deskilled), this is a very muted message in this data and the much stronger message is that services welcomed and benefited from the presence of such particular focus on dementia. Indeed, specialist services are all the more important when working with those who are 'hard to reach', and we see evidence of this even within this evaluation in relation to services focusing on the needs of BME communities – the other demonstrator sites having a very low level of engagement from



BME communities. Even allowing for reporting omissions however, there is no evidence that the services were accessed by people with a learning disability and dementia, or those who were LGBT.

### ***Costs and benefits***

We are left with a final question about whether the benefits experienced by people living with dementia warrants the expense of Peer Support Networks and Dementia Advisers. This has to be a value judgement. There is ample evidence in this evaluation that people with dementia found that the services added to their quality of life and stakeholders spoke of the services delaying the need for more intense interventions or longer-term care arrangements. As one person with dementia said in an interview: “Everybody agrees it’s done everybody the world of good, you know”; a carer stated that it was “priceless”. There is also evidence of the services working in a way that prevented problems, consequently reducing demand on other services such as secondary care, and reducing the pressure on other services for both people with dementia and carers. As one commissioner said, it was “absolutely something that was worth doing”.

The majority of demonstration sites also felt that what they, other services and people living with dementia got out of the Peer Support Network and Dementia Adviser services grew beyond the service itself, ‘mushrooming’ into a range of spin-off benefits, almost like a form of social micro-credit, in which a small amount of input enables a disproportionately large impact. One aspect of this can be illustrated by one professional who had used a demonstrator site service: “If you support the little things, often the bigger things take longer to really become critical.” ‘Mushrooming’ was compromised by weak partnership working, demonstrating again the importance of the multidisciplinary and multi-sector partnerships discussed above, and there were challenges for many sites in getting up and running. It is essential, therefore, to anticipate the true lead-in time of such innovations and account for these in pre-project planning. The ability to generate evidence of effectiveness, discussed above as a key imperative of any new service with time-limited funding, is severely compromised if a large proportion of time is spent on establishing the service only to find the project ceases a few months later. The financial uncertainty as a result of national policy change and response to the financial recession part way through the first

year of operating exacerbated the awareness of time-limited funding and formed a very significant part of the experience of staff in the demonstrator sites as they worked hard, as did local commissioners, to find ways of sustaining the service. Nor, of course, were the demonstrator site services the only services in the locality experiencing changes, so some of the ancillary services which made a big difference to the accessibility of the Peer Support Network and Dementia Adviser services (such as transport) and other parts of the local health and social care economy also changed.

The funding from the Department of Health was, on the whole, focused into the delivery of the Peer Support Network and Dementia Adviser services, so some of the developmental costs such as Steering Groups and their membership were soaked up in pre-existing budgets, and in some areas non-staff costs such as venues could be accessed for no charge. The expense of the interventions was also limited by the use of volunteers. The value that the staff and the volunteers bring to their work through knowledge of the local communities and services does not translate readily into pounds and pence. Carr *et al.* (2011), in a realist synthesis of research literature, report that there are few studies into lay health workers that provide data on the intervention component costs or that report a standard measure of costs per quality adjusted life-years (QALYs) saved. As a result there is little existing evidence that lay health workers are cost-effective. Like the demonstrator site services of the National Dementia Strategy, lay health worker programmes include elements that are hard to quantify financially. These elements include the time to build trust, the time of volunteers and changing the norms of communities and groups. As a result, analyses are often insensitive to the full range of social benefits. Despite the lack of evidence of cost-effectiveness, Carr *et al.* (2011) did find that there was success in building social capital and showed high levels of acceptability, something that this evaluation would certainly concur with.

However, there is some evidence to support the effectiveness of lay-led self-management programmes, impacting on measures such as self-efficacy, health status and service usage. Such interventions are usually orientated to specific health conditions such as mental health or asthma (Viswanathan *et al.*, 2009; Carr *et al.*, 2011). Similarly, the evaluation of the

Expert Patient Programme in England (Department of Health, 2001b; Kennedy *et al.*, 2005) found that 38% felt that their symptoms were less severe up to 6 months after the course.

Peer Support Networks and Dementia Advisers are relatively low-cost interventions. There is evidence that, with an appropriate and supported organisational 'space', they can make a very genuine difference to the experiences of people living with dementia, they can avert or at least delay the use of high-cost interventions, they can help to shape the attitudes and understandings of other services and of communities about dementia. There are many who were participants in this evaluation who felt this meant that the benefits achieved outweighed the costs of the services.

A large part of judging benefit, however, has to be through reflecting on whether Peer Support Networks and Dementia Advisers help in achieving national and international policy. This is achieved in the following ways:

- Information to support people with dementia, carers and wider networks (National Dementia Strategy, Department of Health, 2009a; Prime Minister's Challenge, Department of Health, 2012).
- Promoting social networks (National Dementia Strategy, Department of Health, 2009a).
- Empowering people living with dementia (Prime Minister's Challenge, Department of Health, 2012), putting them in control and ensuring that services respond to what they want (White Paper: Caring for our future, HM Government, 2012).
- Promoting well-being and crisis prevention (White Paper: Caring for our future, HM Government, 2012).
- Managing dementia as a public health issue (World Health Organization, 2012).

The services established in the demonstrator sites show that they have been driven by a person and relationship centred focus, and with a strong orientation to public health approaches. The services have the potential to facilitate people and relationships with an important focus on building social networks and sharing information, supporting the re-narration of people's lives and enhancing people's control of their lives and their dementia.

Achieving this potential requires them to be in an organisational space that allows them to work in partnership and collaboration with other services, and that values their distinct knowledge of their communities.

### **Critique of methods**

- **The approach taken to the Healthbridge evaluation sought to explore what people made of the Peer Support Network and Dementia Adviser services and to understand variation and social dynamics within the National Dementia Strategy demonstration sites. Rather than seeking to prove whether services were effective, the evaluation sought to articulate ways in which people experience them, and to offer an explanation of why.**
- **There were areas of the evaluation where pragmatics overtook a methodologically ideal approach to data collection. One difficulty encountered was that of finding a counter-narrative from people who were not accessing Peer Support Network and Dementia Adviser services. Inclusion of people who are more marginalised was partially successful.**
- **The strength of the evaluation lies in the multiple data sources which have enabled the development of a jigsaw representing people's experiences within the Peer Support Network and Dementia Adviser sites.**

There are several different perspectives on evaluative research which are underpinned by tensions in science fields about whether social processes such as health care services are static and objective or reflect what people make of them (and so in some ways are constructed socially) (Ovretveit, 1998). Someone holding to the former view is more likely to adopt an experimental approach to evaluation in which factors that lead to variation on the intervention are controlled for. Someone holding the latter view is more likely to adopt a more naturalistic evaluation, valuing an understanding of what leads to variation and appreciating the social dynamics within the innovation. This is the approach adopted in this evaluation of Peer Support Networks and Dementia Advisers within the National Dementia Strategy. Another example of this approach was by Reed *et al.* (2006) in evaluating the National Service Framework for Older People (Department of Health, 2001a) and the role of

specialist nursing. Primarily a 'process' evaluation, this evaluation gives an understanding of how a service works and how it produces what it does. It attempts to describe what people get out of the services and why this is the case, and the conditions under which this can be done most successfully. Typically of this approach to evaluation, the evaluation has a clear theoretical perspective and has used, in the main, methods such as interview, case study and narrative-based surveys (Ovretveit, 1998). Other methods, such as the data on service usage and quality of life measures, have been used in so much as they augment and moderate the messages from the more qualitative approaches. Thus, this evaluation does not prove that Peer Support Networks and Dementia Advisers are effective. What it does do is articulate the ways in which people experience the services, the influence they say it has on them, the ways in which this is achieved and the conditions important to achieving this.

It is important, too, to reflect on who this evaluation is for. Of course the ultimate person this is for, is someone living with dementia! The work has been commissioned by the Department of Health to evaluate aspects of policy and its implementation. There are many others with an interest in the evaluation who are perhaps looking to it to provide information for their purposes – commissioners, perhaps, who need to know whether to commission further services like these, managers and practitioners who need to know how better to provide services – these are not the primary audience of the evaluation but we hope we have provided information that will be helpful as everyone strives to provide dementia care services that best meet the needs of people living with dementia. An evaluation should be read as we would look in a mirror, for it is but reflecting back what has been presented to us and collated and analysed by us – what you see should look familiar yet you may see details from perspectives that are unfamiliar to you and that are informative, and you may see things arranged in patterns that you had not fully appreciated were like this but they help to explain why your individual experiences are as they are.

As discussed in the Methods chapter on pages 46-48, the mixed methods design of this evaluation brings both strengths and weaknesses. Key questions to consider are:

1. Did the theoretical framework thread through the work or was it abandoned after writing the proposal, and was it was the right framework to have used?

2. Were the individual elements of data collection sufficient to create a complete jigsaw such that we can reasonably have a complete picture of the services?
3. What steps were taken to mitigate the weaknesses of individual methods?
4. How far did we go in securing the views of those who are more marginalised?
5. Were there any events outside the control of the evaluation team and the demonstration sites that influenced the data?

We now address each of the above questions in turn:

1. Did the theoretical framework thread through the work or was it abandoned after writing the proposal, and was it was the right framework to have used?

Social learning theory, self-efficacy theory and social network theory formed the cornerstones of the evaluation framework and drove many of the decisions made about data collection, sampling and analysis. One example was in selecting the case study sites using criteria determined by these theories to ensure we had sites that represented a breadth of these perspectives. Was it the right framework to have used? It did mean that from the outset the evaluation was attuned to dementia as a public health issue and this allowed us to explore the roles in the sites in relation to other public health roles such as lay health workers. There could have been other theories that were relevant but the qualitative nature of the work meant that we were able to incorporate these as they arose in the evaluation – one example was the significance of organisational theory which came to the fore as the services became more challenged in sustainability than anyone had originally envisaged.

2. Were the individual elements of data collection sufficient to create a complete jigsaw such that we can reasonably have a complete picture of the services?

The overall design of this mixed methods evaluation is portrayed in Figure 3, illustrating the completeness of data collected, how these informed the outputs and the multiple data sources accessed.

There were undoubtedly areas in which pragmatic issues overtook an 'ideal' set of data. One example is the level of data collected about each person accessing the services – in order for this information to be manageable within each demonstrator site, data was collected at a very aggregated level and this means that we are unable to disaggregate the data in analysis and attribute it to individuals, or link individual characteristics. This is particularly apparent in relation to the use of DEMQoL and ASCOT, where we are unable to link the results to any stage of dementia or any point at which the individual was engaging with the service, and so compromising any sense of before/after intervention analysis. However disappointing, this is marginal to the overall process-orientated evaluation where there is considerable depth of data of the experiences of those using and working with the services. The advantage of the approach taken is in having a high response rate to requests to monitoring data and site surveys so that data that we do have is relatively complete and strong.

### 3. What steps were taken to mitigate the weaknesses of individual methods?

The interrelationship of different strands of data is described in the Methods section (pages 48-53), and indeed in the Findings section. Each aspect embraces a synthesis of different data sources and types, illustrating how these have been used to either add weight to a particular message, or offer a negative example and so moderate the strength of a message. However, in some respects we were disappointed by the difficulties in finding counter-narratives. One example was in seeking people with dementia and carers who did not have access to services like advisers or peer support – the national policy imperative and indeed years of practice which regarded these as good models of practice meant that there were no identifiable areas of England with no service provision with population numbers sufficient to allow the equivalent of a non-intervention group. Another limiting aspect was in the role of the case study site demonstrator service staff in identifying stakeholders and people with dementia and carers for interview – although the final decision on selection was made by the evaluation team, and we did encourage the identification of stakeholders with a range of views, it was possible for the sites to circumscribe who we approached. This approach to recruitment also meant that we were unable to interview people who were unknown to the services and had perhaps chosen to not engage with demonstration site services.

#### 4. How far did we go in securing the views of those who are more marginalised?

Our efforts to access people with dementia and carers who are more marginalised were only partially successful. There are two aspects to this. Firstly, only two people with dementia who did not have capacity to consent (as an indicator of more advanced dementia) were included in the interview data collection. This may represent a relatively low engagement with the services of people with more advanced dementia, but is more likely to represent gatekeepers in the services, screening out people who they felt would be unable to engage with an interview. We did find that some people with dementia were able to engage with the DEMQoL and ASCOT data collection formats more readily than the more open structure of the qualitative interview, and this is to be expected given the more closed answer responses required by DEMQoL and ASCOT. Secondly, we sought to be inclusive of people from a range of cultural and ethnic backgrounds but were only partially successful in this. People from a variety of ethnic and cultural backgrounds (including English-speaking people who were originally from outside the UK as well as people who did not have English as a first language) were involved in the case study site interviews, and indeed we selected the case study sites in part to enable this. However, we had translated all of the ASCOT questionnaires into Urdu, Punjabi and Gujarati and did not receive any completed ones, so people either chose to respond in English or did not engage with this aspect of data collection.

#### 5. Were there any events outside the control of the evaluation team and the demonstration sites that influenced the data?

As outlined by Salisbury *et al.* (2010), the complex nature of carrying out policy evaluations within an increasingly complex health and social care landscape is not unique to the Healthbridge evaluation. The most significant event that was outside anyone's control was the economic downturn globally, the change of Government, and the austerity measures. These occurred midway through the first year of operating for the sites and although no funding was withdrawn from the sites themselves and there was no change in dementia policy, concerns about staffing reductions and inability to sustain the services was not a



surprising preoccupation for the services and coloured engagement with the evaluation team and the content of interviews and site surveys. The individual sites experienced a period of being unsettled and staff had a high level of uncertainty and anxiety about the future for sites and for their own employment. Sites had been supported by a national Implementation Team for the National Dementia Strategy with a network of regional leads. This was removed part way through the period and changed the dynamic between being national policy led and informed and being local needs led.

## **Recommendations**

This evaluation has identified that the demonstrator site services were able to work successfully to meet the needs of people with dementia and carers (and indeed for the wider range of community and other services at times). Peer Support Networks and Dementia Advisers do enable delivery of some aspects of the National Dementia Strategy (Department of Health, 2009a) and they can deliver on more recent policy statements such as the Prime Minister's Challenge (Department of Health, 2012) and the White Paper: Caring for our Future (HM Government, 2012). We better understand, now, how and why this happens. We now also better understand the dynamics and concerns that sometimes limited the ability to fully achieve this. What makes this a unique space for the services to occupy, what enables them to optimise their work, and what learning we need to ensure is built on for future improvement forms the set of recommendations below. These are organised in a way that addresses different audiences: recommendations are made for policy and policy implementation, for health and social care organisations, for practice, and for further research.

### **Recommendations for policy and policy implementation**

Aim: To ensure recognition for, and further development of, the conditions under which services providing peer support and dementia advice and information flourish.

1. Peer support and advice and information are essential components of dementia care to meet the needs of individuals, families and communities. Services that provide these, such as Peer Support Networks and Dementia Advisers, need to continue to be promoted in national policy.

2. A key mechanism for achieving this is through more explicit alignment of dementia care as a major public health concern. There are many features of Peer Support Networks and Dementia Advisers that are akin to the public health model of lay health workers. Dementia care policy therefore needs to be embedded into public health policy and actively promoted, in line with the steer of the World Health Organization (2012).
3. The needs of people to re-narrate their lives and of services to promote inclusion of people with dementia and carers within communities is an issue that transcends 'health' services. Peer Support Networks and Dementia Advisers work in a way that is community-based, and which can have many various lines of alignment to health, social and third sectors. It is important, therefore, that policy continues to promote dementia care in a way that cuts across sector boundaries.
4. Implementation of novel policy initiatives, such as the Peer Support Networks and Dementia Advisers, needs to be underpinned by a strong framework for learning. The Project Lead Network meetings were an example of how this was achieved in part in implementing the demonstrator sites. Mechanisms for supporting learning need to be built into Implementation Plans.
5. Innovation, creativity and the embedding of new services are compromised by short timescales and a 'project'-like approach to their development. Greater attention should be given to securing commitment to sustainability before commencing so that unexpected changes in policy do not result in undue distraction from service delivery.
6. In implementing national policy initiatives, the right balance between the three following dynamics is essential to optimise the outcomes: nationally versus locally driven; specialist versus generic provision; consistency of a singular 'model' versus flexibility to adapt to varying and changing individual and community need. The more that implementation is nationally driven, specialist and a single model the harder it will be to embed in local services. The more implementation is locally driven, generic and flexible, the harder it will be to achieve equity of access to services.

## **Recommendations for organisations**

Aim: To ensure that the support and information needs of people with dementia, their families and communities are met and that the conditions under which services providing peer support and dementia advice and information flourish are promoted.

1. People with dementia, their families and communities have a need for peer support, information and advice. This is a need that can be met by the Peer Support Networks and Dementia Advisers, and this can have a positive impact on quality of life, community awareness and averting problems (and the consequent use of more intensive services). Peer Support Networks and Dementia Advisers also played key roles in tackling stigma faced by people with dementia within the context of social networks. This may or may not be met by other provision. It is necessary to assess local provision in relation to meeting these needs.
2. Peer Support Network and Dementia Adviser services are 'low-cost' interventions. With the right support and organisational space, they are able to play a significant role in meeting the needs of people with dementia which may lead to a reduction in use of more intensive 'high-cost' services. Commissioning of services that enable peer support and information and advice are therefore recommended as part of a suite of provision to ensure that people with dementia are supported to remain independent and with an acceptable quality of life for a longer period than may otherwise be achieved.
3. Innovative services need to have an organisational 'space' within and between health and social care organisations if they are to flourish. This needs to be considered in planning and receiving ongoing support and negotiation from all relevant organisations. The Steering Groups and Project Boards of many of the demonstrator sites were essential but in practice, this collaborative approach was not always sustained throughout organisations. It is important to identify and protect organisation space for innovative services and for this to include clarity of role and purpose.
4. Achieving equality of access to services requires a very proactive approach and a willingness to identify and work with some characteristics that otherwise result in people being marginalised from service provision (such as culture, disability and sexual

- orientation). It is important to review provision in relation to protected characteristics and ensure that services are designed to engage all communities of the population.
5. The Peer Support Networks and Dementia Advisers played a role in supporting the learning about dementia of a wide range of staff and communities, and helped to ensure that services were aware of the needs of people with dementia. Ensuring that all staff are well equipped in skills and knowledge to work with people with dementia is essential to meeting the needs of families, and will mitigate any risk of weakening the generic services by introducing specialist dementia-specific services.
  6. The demonstration sites all had differing organisational arrangements with lead organisations and partnerships with the NHS, councils and third sector organisations. There is no one definitive model on which to base future service development and attention is needed to local solutions to achieve sustainability within the local health and social care economy.

### **Recommendations for practice**

Aim: To ensure that practices with people with dementia and their families and communities are best able to meet their needs by promoting an environment and culture of inclusion.

1. Peer Support Network and Dementia Adviser services have a role to play in understanding the needs of people with dementia and their families and communities, and are able to communicate these to services to ensure that services are best able to be attuned to meeting these needs. They are well placed to support people with dementia and carers to engage in service development activities (as promoted by the Alzheimer's Society, 2012b). It is important therefore that those involved in facilitating peer networks and providing information and support recognise (and have recognised by others) their skills and community-based knowledge, which is a key part of connecting services with meeting needs.
2. The part of staff and volunteers in supporting re-narration by people with dementia and families is a key part of meeting people's needs and helping people to 'live well with dementia'. It is important, therefore, that staff and volunteers are adequately prepared for this through education and training that addresses person-centred care

(for example, being flexible to ensure that there is different information for different people at different times) and relationship centred (for example, attending to the needs of the interpersonal relationships of someone with dementia and their supporters whilst recognising that the needs of each are not the same).

3. Peer Support Networks and Dementia Advisers play a part in combating discriminatory attitudes towards ageing and dementia in their communities, and increasing the knowledge of other practitioners. It is essential that this role is enhanced as part of a range of activities to enhance the capacity of communities to be inclusive of those with dementia.
4. Working alongside other services and organisational bodies is essential for Peer Support Network and Dementia Adviser services in securing an 'organisational space' in which to work and develop. It is necessary, therefore, to work with other staff and managers in all locally relevant services to ensure that there is good communication and clarity in role and purpose.

### **Recommendations for future research**

Aim: To ensure that research continues to inform, and be informed by, dementia policy and practice, specifically in relation to peer support and advice and information activities.

1. In relation to Healthbridge, there will be valuable information arising from the ongoing implementation of Peer Support Networks and Dementia Advisers. Specifically, a follow-up study should explore:
  - a. How the demonstration sites evolve over the next 2–3 years and how this illuminates the processes of embedding or mainstreaming services.
  - b. The views of people with dementia and carers who were part of the Healthbridge evaluation in Peer Support Network and Dementia Adviser services as their journey living with dementia progresses.
  - c. Further development of themes emerging from the Healthbridge evaluation around resources saved with the wider health and social care economy. This would include longitudinal follow-up on issues such as crisis prevention and early intervention leading to people remaining independent for longer.

2. The outcome of the Healthbridge evaluation locates peer support and advice and information for people with dementia and their carers as a public health issue. Considerable research is required to ensure that all of the learning from the public health field is applied to dementia care, and that we continue to learn how best to ensure that needs are met through dementia as a public health concern.
3. The data secured in this project is very rich and warrants re-analysis with an explicit public health frame of analysis. This would be enhanced further by collecting further interview data from those people with dementia and carers in the case study sites to form a longitudinal aspect to understanding health literacy and the contribution of advice, information and peer support to the experiences of re-narration and 'living well with dementia'.

## **Summary**

The services established in the demonstrator sites demonstrate that they have been driven by a person and relationship centred focus, and with a strong orientation to public health approaches. The services have the potential to facilitate people and relationships with an important focus on building social networks and sharing information, supporting the re-narration of people's lives and enhancing people's control of their lives and their dementia. Achieving this potential requires them to be in an organisational space that allows them to work in partnership and collaboration with other services, and which values their distinct knowledge of their communities. In establishing the services, more attention was paid to the 'needs space' than to this 'organisational space' and as a result, for some, inter-organisational conflicts and tensions were present.

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## **Appendices**

- Appendix A** Examples of service summary, purpose, infrastructure, costs
- Appendix B** Activity and outcome monitoring data collection
- Appendix C** ASCOT questionnaire
- Appendix D** ASCOT questionnaire for non-demonstrator sites
- Appendix E** Organisational surveys (example from March 2012)
- Appendix F** Informational leaflets and invitation letters (case study sites)
- Appendix G** Interview schedule (people with dementia and carers)
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- Appendix I** Consent forms
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## Appendix A: Examples of service summary, purpose, infrastructure, costs

	<b>Dementia Adviser Service A</b>	<b>Dementia Adviser Service B</b>	<b>Peer Support Network Service A</b>	<b>Peer Support Network Service B</b>
<b>Service summary</b>	Provides support and information predominantly for those people who are newly diagnosed with dementia and their carers. A service for those not receiving support from a care manager.	Provides access to three full-time Dementia Advisers based with community mental health teams. Provides information, support, advice and signposting to relevant services if required, to people with dementia after initial diagnosis. Referrals are accepted from a range, including memory clinics, GPs, CMHT, social care, self, voluntary agencies, etc.	Primary focus is to use co-production to support people with dementia to maintain and build positive relationships with each other, families and friends. This approach promotes links between individuals and local communities and provides timely and accessible information.	A county-wide network of memory cafés.
<b>Service purpose</b>	To provide advice, information and signposting throughout the dementia journey. Includes regular home visits (between every 3 and 6 months, at request of the individual). To support people when they have recently been diagnosed, to	To provide people with dementia, after initial diagnosis, with information, advice, support and signposting on to relevant services if required. The service aims to put people with dementia in control of their lives so they are able to 'live well with dementia'.	The Peer Support Network supports people beyond initial diagnosis and early interventions by health and social care services, filling the gap between diagnosis and the need for more intensive care packages and prolonging the person's ability to live	To help communities develop new memory cafés/peer support groups across the county, by going into local communities and gathering together interested partners (GPs, CMHT nurses, local groups (e.g. Older Person's Forums, WI, Rotary Club, Day Services, Carers' Groups),

	<p>signpost to services within the community which may serve to inform and support them in the early stages – the service is designed to contribute to delaying the need for more intense support.</p> <p>Support is withdrawn once the individual accesses a social worker/CPN intervention.</p>		<p>independently for longer, improving quality of life and giving people more choice and control and community access continue working towards meeting the objectives of the National Dementia Strategy. By working in partnership with people with dementia across the health and social care community we are able to facilitate structured peer support for people in the earlier stages of dementia. The support networks enable people with dementia to maintain and build positive relationships with families, friends, communities and within the support groups.</p>	<p>and ‘growing’ peer support groups using a grass roots approach. To help memory cafés/peer support groups become sustainable, by working with groups to increase and improve governance with advice and practical help on constitutions, structure, charitable status, venues, health and safety issues, find/apply for funding, grants, etc., and to develop this advice and guidance into an accessible toolkit. The support and up-skilling of community volunteers is central to sustainability of these groups, and the network is led as much as possible by the needs/wishes of memory cafés, people with dementia and carers.</p>
<b>Lead and partner organisations</b>	<p>The project is managed by a Joint Commissioning Officer at a local council. The Dementia Adviser is based within the Community Mental Health Team for Older</p>	<p>County Council, PCT, NHS Foundation Trust, Alzheimer’s Society. Colleagues from these organisations make up the Project</p>	<p>Adult Social Care are the lead organisation working in close partnership with Partnership Foundation Trust and Alzheimer’s Society. Also working in</p>	<p>Rural Community Council is the lead or host organisation and employs the Memory Group Network Facilitator/Manager. The involvement of other partner</p>

	Adults and is supervised by the Memory Clinic Nurse Prescriber (NHS).	Board and meet regularly. Commissioner from the PCT is the Project Lead, the Alzheimer's Society delivers the service.	partnership with people with dementia to improve services for people with dementia. Other local organisations involved in activity-specific work.	organisations came to an end in July 2011, but they did include Age Concern who provided a part-time support worker to support memory café volunteers to develop meaningful stimulating activities within the cafés and also complete the evaluation and collect data.
<b>Staff employed and volunteers</b>	One Dementia Adviser No volunteers	Three Dementia Advisers Several volunteers	One full-time Peer Support Co-ordinator Volunteers were recruited	One full-time Memory Café Network Manager. Until beginning of August 2011, also employed a part-time support worker. Part-time volunteers
<b>Capital and Infrastructure costs</b>	None: Based within the Community Mental Health Team for Older Adults	£1850.36 spent on IT and office equipment	IT and other equipment was purchased at the start of the project	IT equipment (but most volunteers using home computers) Resources, materials: £2300 Room hire = £8600 per year

## Appendix B: Activity and outcome monitoring data collection

Name / location of demonstrator site:
Name of person completing the form:
Date:



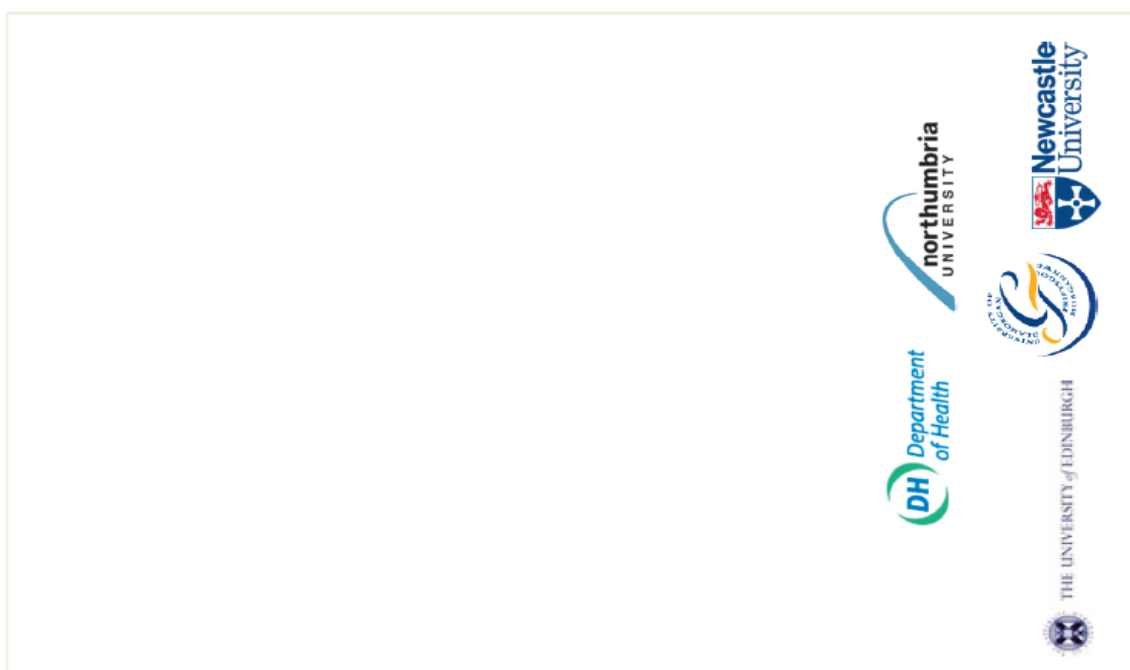
Thank you for taking the time to complete this form. This form will be used to gather information with regard to the day-to-day activity of your demonstrator site. The completed form will be used by the team and the information will not be passed on to anyone outside the team. It is fine to fill in this form with the help of your colleagues on the project. If you have any questions you can also contact either your regional lead and/or Jo Alexjuk from the national evaluation team.

Please complete one form on each day of the first FULL week of March 2012 i.e. week beginning 5<sup>th</sup> March (**five in total per month**) and include as much information as possible and then return all forms either by email or in the post to Jo (contact details below). Please ask us to send you a pre-paid addressed envelope if you want to return your forms by post

*Thank You*

<b>How many have accessed service today?</b>	People with dementia/mild memory problems	Carers	General members of the public	Professional staff
<b>Of which, how many are:</b>	First time contact		Repeat contact	
<b>For the people with dementia, how many:</b>	Have a confirmed diagnosis of dementia		Diagnosis not confirmed	Unknown
	Live alone		Do not live alone	
	Are male		Are female	
	Are under 65 yrs	Are 65-85 yrs	Over 85 yrs	
	How many are from BME communities (Please specify)			
	People from the LGBT community			
	People with a learning disability			
	Use English as a first language		Do not use English as a first language	

## Appendix C: ASCOT questionnaire





## HEALTHBRIDGE

HEALTHBRIDGE is the national evaluation of two parts of the National Dementia Strategy (dementia advisers and peer support networks).

As a person with mild memory problems or dementia, or as a carer, you are in a valuable position to help us understand the experience of living with dementia and the services that you are receiving.

Members of the evaluation team are from Northumbria, Newcastle, Edinburgh and Glamorgan Universities and are experienced research specialists in the field of dementia care.

The evaluation is commissioned by the Department of Health.

## Concerns

If you have any concerns about your own wellbeing or someone else's, please do discuss this with your GP or with a member of staff from peer support network or dementia adviser services.

National advice lines are also available from:

Alzheimer's Society

Tel: 0845 300 0336

Website: [www.alzheimers.org.uk](http://www.alzheimers.org.uk)

or

Dementia UK

Tel: 0845 257 9406

Website: [www.dementiauk.org](http://www.dementiauk.org)

## Acknowledgement

This questionnaire is based on the ASCOT toolkit developed by PSSRU, University of Kent

## How to fill in this questionnaire

This questionnaire asks you about your individual feelings and wellbeing. Please only complete the questionnaire if you feel comfortable in doing so.

Your completed questionnaire will only be used by the evaluation team and the information will be treated with confidence. Only the evaluation team will handle information gathered and it will be stored in a secure place and destroyed after a period of five years.

For each of the nine questions please tick one box in each section relating to the statement which best reflects how you feel.

You may wish to fill in this questionnaire with the help of someone else.

Please tick the appropriate box below to tell us whether you are:

A person with mild memory problems

or

A person with dementia

or

A carer

*Thank You*

1

Which of the following statements best describes how much control you have over your daily life?

By 'control over daily life' we mean having the choice to do things or have things done for you as you like and when you want

Please tick (✓) one box only

- I have as much control over my daily life as I want
- I have adequate control over my daily life
- I have some control over my daily life but not enough
- I have no control over my daily life

## Questions

If you have any questions or would like further information about the study please contact:

If you have any concerns about the study please contact:

2

Thinking about your personal care, by which we mean being clean and presentable in appearance, which of the following statements best describes your situation?

Please tick (✓) one box only

- I feel clean and able to present myself the way I like
- I feel adequately clean and presentable
- I feel less than adequately clean or presentable
- I don't feel at all clean or presentable

## Now you have finished ...

Thank you very much for taking the time to complete this questionnaire.

Please return this questionnaire by either:

a. Giving it back to the dementia adviser or peer support network co-ordinator

or

b. Posting it directly to:

(Pre-paid addressed envelopes are available)

**9** Thinking about the way you are helped and treated, and how that makes you think and feel about yourself, which of these statements best describes your situation?

Please tick (✓) one box only

The way I'm helped and treated makes me think and feel better about myself

The way I'm helped and treated does not affect the way I think or feel about myself

The way I'm helped and treated sometimes undermines the way I think and feel about myself

The way I'm helped and treated completely undermines the way I think and feel about myself

**3** Thinking about the food and drink you get, which of the following statements best describes your situation?

Please tick (✓) one box only

I get all the food and drink I like when I want

I get adequate food and drink at OK times

I don't always get adequate or timely food and drink

I don't always get adequate or timely food and drink and I think there is a risk to my health

### Is there anything else?

Is there anything else you would like us to know about your wellbeing?

**4** Which of the following statements best describes how clean and comfortable your home is?

Please tick (✓) one box only

My home is as clean and comfortable as I want

My home is adequately clean and comfortable

My home is not quite clean or comfortable enough

My home is not at all clean or comfortable

**5** Which of the following statements best describes how safe you feel?

*By feeling safe we mean feeling safe both inside and outside the home. This includes fear of abuse, falling or other physical harm and fear of being attacked or robbed*

Please tick (✓) one box only

- I feel as safe as I want
- Generally I feel adequately safe, but not as safe as I would like
- I feel less than adequately safe
- I don't feel at all safe

**7** Which of the following statements best describes how you spend your time?

*When you are thinking about how you spend your time, please include anything you value or enjoy including leisure activities, formal employment, voluntary or unpaid work and caring for others*

Please tick (✓) one box only

- I'm able to spend my time as I want, doing things I value or enjoy
- I'm able to do enough of the things I value or enjoy with my time
- I do some of the things I value or enjoy with my time but not enough
- I don't do anything I value or enjoy with my time

**6** Thinking about how much contact you've had with people you like, which of the following statements best describes your social situation?

Please tick (✓) one box only

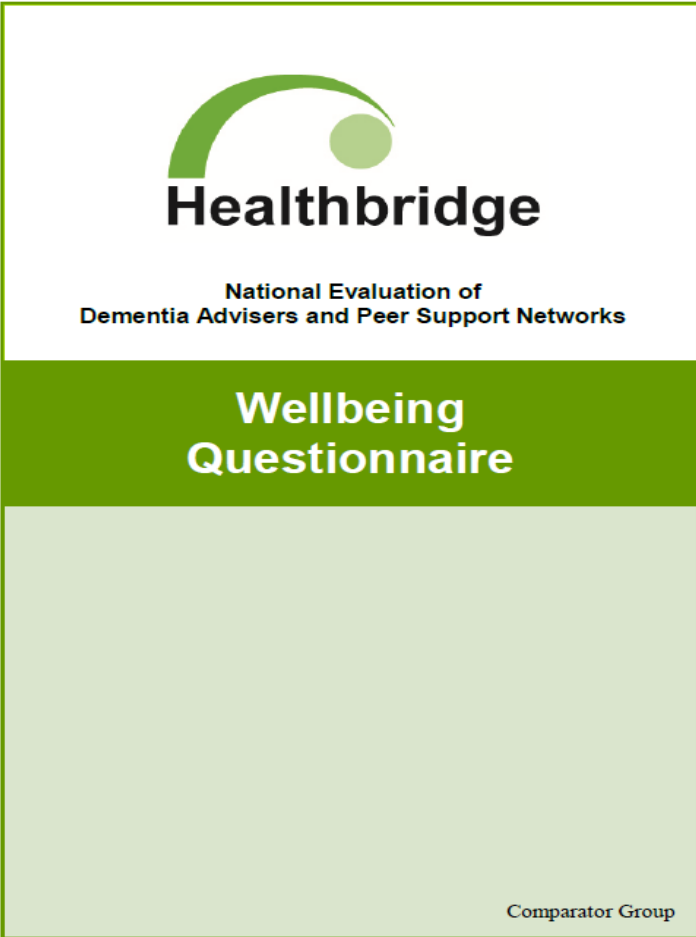
- I have as much social contact as I want with people I like
- I have adequate social contact with people
- I have social contact with people, but not enough
- I have little social contact with people and feel socially isolated

**8** Which of these statements best describes how having help to do things makes you think and feel about yourself

Please tick (✓) one box only

- Having help makes me think and feel better about myself
- Having help does not affect the way I think or feel about myself
- Having help sometimes undermines the way I think and feel about myself
- Having help completely undermines the way I feel about myself

Appendix D: ASCOT questionnaire for non-demonstrator sites



## **HEALTHBRIDGE**

HEALTHBRIDGE is the national evaluation of two parts of the National Dementia Strategy (dementia advisers and peer support networks).

As a person with mild memory problems or dementia, or as a carer, you are in a valuable position to help us understand the experience of living with dementia and the services that you are receiving.

Members of the evaluation team are from Edinburgh, Newcastle, Northumbria and Glamorgan Universities and are experienced research specialists in the field of dementia care.

The evaluation is commissioned by the Department of Health.

## **Acknowledgement**

This questionnaire is based on the ASCOT toolkit developed by PSSRU, University of Kent

## **Concerns**

If you have any concerns about your own wellbeing or someone else's, please do discuss this with your GP or with the Forum Co-ordinator.

National advice lines are also available from:

Alzheimer's Society  
Tel: 0845 300 0336  
Website: [www.alzheimers.org.uk](http://www.alzheimers.org.uk)

or

Dementia UK  
Tel: 0845 257 9406  
Website: [www.dementiauk.org](http://www.dementiauk.org)

## Questions

If you have any questions or would like further information about the study please contact:

If you have any concerns about the study please contact:

## Now you have finished ...

Thank you very much for taking the time to complete this questionnaire.

Please return this questionnaire by either:

a. Giving it back to the Forum co-ordinator

or

b. Posting it directly to:

## How to fill in this questionnaire

This questionnaire asks you about your individual feelings and wellbeing. Please only complete the questionnaire if you feel comfortable in doing so. You are being asked to complete this questionnaire on one occasion only.

Your completed questionnaire will only be used by the evaluation team and the information will be treated with confidence. Only the evaluation team will handle information gathered and it will be stored in a secure place and destroyed after a period of five years.

For each of the nine questions please tick one box in each section relating to the statement which best reflects how YOU feel.

You may wish to fill in this questionnaire with the help of someone else.

Please tick the appropriate box below to tell us whether you are:

A person with mild memory problems

or

A person with dementia

or

A carer



1

Which of the following statements best describes how much control you have over your daily life?

*By 'control over daily life' we mean having the choice to do things or have things done for you as you like and when you want*

Please tick (✓) one box only

I have as much control over my daily life as I want

I have adequate control over my daily life

I have some control over my daily life but not enough

I have no control over my daily life

2

Thinking about your personal care, by which we mean being clean and presentable in appearance, which of the following statements best describes your situation?

Please tick (✓) one box only

I feel clean and able to present myself the way I like

I feel adequately clean and presentable

I feel less than adequately clean or presentable

I don't feel at all clean or presentable

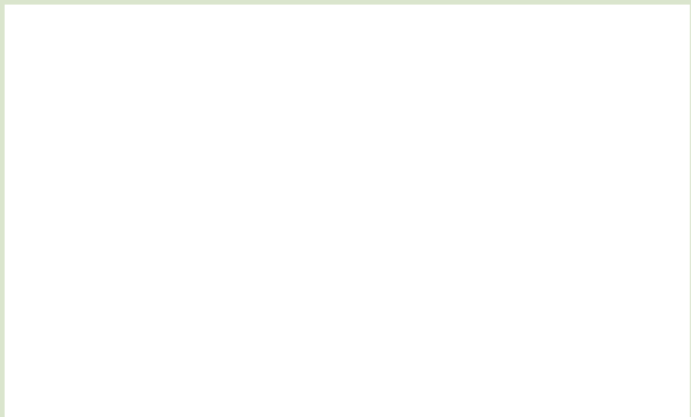
11

Where have you been able to get advice, if at all?



12

Is there anything else you would like us to know about your wellbeing?



**9** Thinking about the way you are helped and treated, and how that makes you think and feel about yourself, which of these statements best describes your situation?

Please tick (✓) one box only

The way I'm helped and treated makes me think and feel better about myself

The way I'm helped and treated does not affect the way I think or feel about myself

The way I'm helped and treated sometimes undermines the way I think and feel about myself

The way I'm helped and treated completely undermines the way I think and feel about myself

**10** What opportunities do you have to meet other people in a similar situation? Would you like to have more opportunities?

**3** Thinking about the food and drink you get, which of the following statements best describes your situation?

Please tick (✓) one box only

I get all the food and drink I like when I want

I get adequate food and drink at OK times

I don't always get adequate or timely food and drink

I don't always get adequate or timely food and drink and I think there is a risk to my health

**4** Which of the following statements best describes how clean and comfortable your home is?

Please tick (✓) one box only

My home is as clean and comfortable as I want

My home is adequately clean and comfortable

My home is not quite clean or comfortable enough

My home is not at all clean or comfortable

**5** Which of the following statements best describes how safe you feel?

*By feeling safe we mean feeling safe both inside and outside the home. This includes fear of abuse, falling or other physical harm and fear of being attacked or robbed*

Please tick (✓) one box only

- I feel as safe as I want
- Generally I feel adequately safe, but not as safe as I would like
- I feel less than adequately safe
- I don't feel at all safe

**6** Thinking about how much contact you've had with people you like, which of the following statements best describes your social situation?

Please tick (✓) one box only

- I have as much social contact as I want with people I like
- I have adequate social contact with people
- I have social contact with people, but not enough
- I have little social contact with people and feel socially isolated

**7** Which of the following statements best describes how you spend your time?

*When you are thinking about how you spend your time, please include anything you value or enjoy including leisure activities, formal employment, voluntary or unpaid work and caring for others*

Please tick (✓) one box only

- I'm able to spend my time as I want, doing things I value or enjoy
- I'm able to do enough of the things I value or enjoy with my time
- I do some of the things I value or enjoy with my time but not enough
- I don't do anything I value or enjoy with my time

**8** Which of these statements best describes how having help to do things makes you think and feel about yourself?

Please tick (✓) one box only

- Having help makes me think and feel better about myself
- Having help does not affect the way I think or feel about myself
- Having help sometimes undermines the way I think and feel about myself
- Having help completely undermines the way I feel about myself

## Appendix E: Organisational surveys: example from March 2012

<b>HEALTHBRIDGE</b>	
<b>Case Study Site Survey</b>	
<p>Thank you for taking the time to complete this form. This form will be used to gather information about the changes that have taken place in all of the demonstration sites since their inception.</p> <p>The completed forms will be used by the team and the information will not be passed on to anyone outside the team. It is fine to fill in this form with the help of your colleagues on the project. If you have any questions you can also contact Jo Alexjuk from the national evaluation team.</p> <p>Please fill out the form with as much information as possible and then return it either by email or in the post to Jo – the contact information is at the end of this form. Please ask us to send you a post paid envelope if you want to return your form by post.</p> <p>Please send your completed form to us by <b><u>the end of March 2012</u></b></p> <p style="text-align: right;"><b>Thank You</b></p>	
<b>1. Title of your service</b> (Please use separate forms for each service if you provide more than one)	
<b>2. About your service</b>	
Is your service either a: <b>Dementia Adviser site</b> <input type="checkbox"/> <b>Peer Support Network site</b> <input type="checkbox"/>	
(Please include a brief summary of your service as currently provided)	

**3. Please describe the overall purpose of your service now and how this has changed since it started (if at all)**

Here, we inserted what each individual site had told us about their purpose in the previous organisational survey, and asked them to comment on whether this had changes, and if so, how.

However big or small the changes to your service, please try to describe them here or in Question 4.

-

**4. Please indicate how much your service, as it is now, develops:**

(Please note that you may tick/highlight more than one box)

	A lot	A little	Not at all
<b>a. social networks</b> e.g. promoting relationships and connections between people that live within the same locality and who share similar experiences of living with dementia	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
<b>b. social learning</b>			

e.g. providing opportunities for people to learn how to handle situations differently			
<b>c. personal value and effectiveness</b> e.g. encouraging people to take control	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
<b>5. This is achieved by:</b> (Please note that you may tick/highlight more than one box)			
	<b>A lot</b>	<b>A little</b>	<b>Not at all</b>
<b>a. helping people access services</b> e.g. providing a 'bridge' between individuals and organisations	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
<b>b. helping provide information for other people</b> e.g. individual one-to-one tailored message giving	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
<b>c. helping people get emotional support from others</b> e.g. caring, trust, love	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
<b>d. helping people share information with each other</b> e.g. advice, suggestions	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
<b>e. helping people access practical support</b> e.g. tangible aid and services	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
<b>Any other ways in which you achieve your aims and purpose?</b>			

--

**6. Please describe the lead and partner organisations in your partnership and how these have changed since you started**

(Please give a brief description of their roles)

--

**7. The service is designed to benefit:**

(Please tick a box for each client group)

	Special focus	General focus	Not really our focus
People with dementia	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Carers	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Professional carer	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
BME communities (please specify)	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Younger people with dementia	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
People with a learning disability	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
People from the LGBT community	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

People newly diagnosed with dementia	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
People from socio-economically deprived areas	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
General public awareness	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
<b>Other</b> (please describe briefly)			
<b>8. About your service :</b>			
Please if possible give a general indication about your service as it is <b>currently</b> arranged and indicate how this has changed since the service began, (if at all)			
Number of staff employed (fte)			
Volunteer time (total hours per week)			
Any capital costs associated with buildings/equipment/IT etc (please describe briefly)			



Any other infrastructure costs (please describe briefly)	
Variable costs such as transport/food/stationery/materials etc per month	
Typical costs incurred by people with dementia and carers to access the service per contact	
Frequency of contact with the person with dementia or carer e.g. one-off, weekly for 6 weeks, monthly ongoing	

### 9. Commissioning activity

Who is now funding the service, at what level, and for how long is this funding in place?

Could you describe briefly, what arrangements / negotiations have taken place to secure current funding (if any)

Please describe what you think the future may be in relation to funding for the service and timescales

---

## 10. Your details

Your full contact details are:

Name

Address

Telephone number

Email address

---

**Thank you very much for your time**

Please return this information by email or post by **the end of March 2012** to:

## Appendix F: Information leaflets and invitation letters (case study sites)

### What will happen to the information that is gathered?

- Please be assured that your name will not appear in any documentation.
- All information will be treated with confidence and stored in a secure place.
- The information that is gathered will be analysed (including if you withdraw from the study).
- Only the evaluation team will handle information gathered and it will be destroyed after a period of five years.
- We will send a report to the Department of Health and will let people know the findings of this work to try to improve services in the future.

### Please be assured that

- You are not obligated to take part in this evaluation.
- Taking part or not taking part in the evaluation will not effect any services which you may be receiving now or in the future.

- You can withdraw from the evaluation project at any time and you will not be contacted again.
- All dementia advisers and peer support network groups involved will receive a summary of the final evaluation report.

If at any time you would like to discuss your situation then local support is available by contacting:

If you have any questions or would like further information about the study please contact:

If you have any concerns about the study please contact:



National evaluation of  
dementia advisers and  
peer support networks

Information for  
Participants

## Questions you may have about the evaluation study

### What is the evaluation study about?

The new National Dementia Strategy has been developed by the Department of Health to try to improve services for people who live with dementia.

The strategy encourages the use of peer support networks and dementia advisers.

Currently little is known about these activities, therefore the team intend to evaluate the pilot peer support networks and dementia advisers that have been set up in England.

### Who is undertaking the study and why?

Led by Northumbria University other members of our team have been brought together from Newcastle University, Edinburgh University and Glamorgan University

Members include experienced research specialists in the field of either dementia, health and/or social care.

### What is the aim of the study?

1. To describe the range of pilot services and to support their development
2. To assess these new service models in relation to:
  - ♦ influence on the wellbeing of people with dementia and carers
  - ♦ contribution to achieving the objectives of the National Dementia Strategy
  - ♦ how the pilot services work with other health and social care services
3. To identify ways in which the new service models help people with dementia and carers

### Why have you been asked?

As a person with mild memory problems, or a person with dementia, or as a carer you are in a valuable position to help us understand the experience of living with dementia and the services that you are receiving.

### What are you being asked to do?

You will be asked take part in a face-to-face, semi-structured interview which will be audio recorded.

The format of the interview will be either on a one-to-one basis or participating in a group interview and will last for no longer than one hour.

Participating in the interviews will give you the opportunity to explore and discuss your experiences of the peer support network or dementia adviser activity.

During the interview you may also be asked to complete questions about your quality of life.

**Please be assured that**

- You are not obligated to take part in this evaluation
- Taking part or not taking part in the evaluation will **not** effect your work with services in any way
- You can withdraw from the evaluation at any time

**What will happen to the information that is gathered?**

- Please be assured that your name will not appear in any documentation
- All information will be treated with confidence and stored in a secure place
- The information that is gathered will be analysed (including if you withdraw from the study)

- Only the evaluation team will handle information gathered and it will be destroyed after a period of five years
- We will send a report to the Department of Health and will let people know the findings of this work to try to improve services in the future

If you have any questions or would like further information about the study please contact:

If you have any concerns about the study please contact:



National evaluation of dementia advisers and peer support networks

Information for Staff and Volunteers

HEALTHBRIDGE Information for Staff and Volunteers

## Questions you may have about the evaluation study

### What is the evaluation study about?

The new National Dementia Strategy has been developed by the Department of Health to try to improve services for people who live with dementia. The strategy encourages the use of peer support networks and dementia advisers

Currently little is known about these activities, therefore the team intend to evaluate the pilot peer support networks and dementia advisers that have been set up in England

### Who is undertaking the study and why?

Led by Northumbria University other members of our team have

been brought together from Newcastle University, Edinburgh University and Glamorgan University

Members include experienced research specialists in the field of either dementia, health and/or social care

### What is the aim of the study?

1. To describe the range of pilot services and to support their development
2. Assess these new service models in relation to:
  - ♦ influence on the wellbeing of people with dementia and carers
  - ♦ contribution to achieving the objectives of the National Dementia Strategy

3. To identify ways in which the new service models help people with dementia and carers

### Why have you been asked?

You are in a valuable position to help us understand the activity of the demonstrator sites and the impact it has had on local policy, practices and experiences of people with dementia and carers

### You are being asked to:

To take part in a semi-structured interview which we would prefer to audio record. The interview will be done either face-to-face or by telephone lasting for the duration of one hour

Participating in the interviews will give you the opportunity to explore and discuss your experiences of the National Dementia Strategy

## APPENDIX F: Informational leaflets and invitation letters (case study sites)

### What will happen to the information that is gathered?

- Please be assured that your name or the name of the person with mild memory problems or dementia will not appear in any documentation.
- All information will be treated with confidence and stored in a secure place.
- The information that is gathered will be analysed (including if they withdraw from the study).
- Only the evaluation team will handle information gathered and it will be destroyed after a period of five years.
- We will send a report to the Department of Health and will let people know the findings of this work to try to improve services in the future.

### Please be assured that

- Taking part or not taking part in the evaluation will not effect any current or future services which the person with mild memory problems or dementia may receive.

- The person with mild memory problems or dementia is not obligated to take part in this study.
- The person with mild memory problems dementia or dementia can withdraw from the evaluation project at any time and they will not be contacted again.

If at any time you would like to discuss your situation then local support is available by contacting:

If you have any questions or would like further information about the study please contact:

If you have any concerns about the study please contact:



National evaluation of  
dementia advisers and  
peer support networks

Information for  
Consultees

## Questions you may have about the evaluation study

### What is the evaluation study about?

The new National Dementia Strategy has been developed by the Department of Health to try to improve services for people who live with dementia. The strategy encourages the use of peer support networks and dementia advisers.

Currently little is known about these activities, therefore the team intend to evaluate the pilot peer support networks and dementia advisers that have been set up in England.

### Who is undertaking the study and why?

Led by Northumbria University other members of our team have been brought together from Newcastle University, Edinburgh University and Glamorgan University.

Members Include experienced research specialists in the field of either dementia, health and/or social care.

### What is the aim of the study?

1. To describe the range of pilot services and to support their Development
2. To assess these new service models in relation to:
  - ♦ influence on the wellbeing of people with dementia and carers
  - ♦ contribution to achieving the objectives of the National Dementia Strategy
  - ♦ how the pilot services work with other health and social care services
3. To identify ways in which the new service models help people with dementia and carers

### Why have you been asked?

As a consultee acting on behalf of a person with mild memory problems or

dementia you are in a valuable position to ensure that the best wishes of that person and their own preferences are respected.

### What are you being asked to do?

The person with mild memory problems or dementia is being asked to take part in a face-to-face, semi-structured interview which will be audio recorded.

The format of the interview will be either on a one-to-one basis or participating within a group interview and will last for a duration of one hour.

You are being asked, based on your knowledge of the individual whether you feel participating in this study is something they would wish to do.

Participating in the interviews will give the person with mild memory problems or dementia the opportunity to explore and discuss their experience of the peer support network or dementia adviser activity.

During the interview they may also be asked to complete questions about their quality of life and wellbeing.



Invitation letter: People with dementia or mild memory problems

University logo and address

Dear [ ]

We are trying to find out how helpful some parts of the new National Dementia Strategy are. This strategy has been developed by the Department of Health to try to improve services for people who live with dementia.

We would be very grateful if you could think about being involved in this work. Your experience of living with memory loss or dementia and of receiving services is very valuable. The enclosed leaflet provides you with some information about the evaluation. Please discuss this with your family carer or a member of staff or volunteer before you decide whether to be involved.

If you are interested in being involved and would like to know more about this, please complete the slip below and return it to us. A member of staff or volunteer could send this to us if you prefer. We will then contact you to discuss your possible involvement. If you agree, we will ask you to sign a consent form before you become involved – it is important that you have a full understanding of what being involved entails.

Please do not hesitate to contact us if you would like to discuss this more.

Thank you very much for taking the time to think about being involved.

Yours sincerely

Professor Charlotte Clarke

---

Yes, I would like to consider being involved in the National Dementia Strategy evaluation

My name is: .....

I prefer to be contacted by:

- Letter – my address is:
  
- Phone – my number is:
  
- e-mail – my address is:
  
- please talk to a family member or carer first – their name and address or telephone number is:

Invitation letter: Consultees and carers

University logo and address

Dear [ ]

We are trying to find out how helpful some parts of the new National Dementia Strategy are. This strategy has been developed by the Department of Health to try to improve services for people who live with dementia.

We would be very grateful if you could think about being involved in this work. As a carer or as a person acting as a consultee for a person with mild memory problems or dementia you are in a valuable position to help us understand the experience of living with dementia and the services that you are receiving. The enclosed leaflet provides you with some information about the evaluation. If you are interested in being involved and would like to know more about this, please complete the slip below and return it to us. A member of staff or volunteer could send this to us if you prefer. We will then contact you to discuss your possible involvement. We will ask you to sign a consent form before you become involved – it is important that you have a full understanding of what being involved entails.

Please do not hesitate to contact us if you would like to discuss this more.

Thank you very much for taking the time to think about being involved.

Yours sincerely

Professor Charlotte Clarke

---

Yes, I would like to consider being involved in the National Dementia Strategy evaluation

My name is: .....

I prefer to be contacted by:

- Letter – my address is:
  
- Phone – my number is:
  
- e-mail – my address is:

Hello

We are trying to find out how helpful some parts of the new National Dementia Strategy are. We would be very grateful if you could think about being involved in this work. The enclosed leaflet provides you with some information about the evaluation.

If you are interested in being involved and would like to know more about this, please complete the slip below and return it to us in the S.A.E. provided. We will then contact you to discuss your possible involvement.

Please do not hesitate to contact us if you would like to discuss this more.

Thank you very much for taking the time to think about being involved.

Yours sincerely

Professor Charlotte Clarke  
Principal Investigator

✂-----

**Please return this to:** Jo Alexjuk, Northumbria University, Research & Enterprise Rm.H009, Coach Lane Campus East, Benton Newcastle NE7 7XA, in the S.A.E. provided.

Yes, I would like to consider being involved in the National Dementia Strategy evaluation

My name is: .....

I prefer to be contacted by:

- Letter – my address is: .....  
.....
- Phone – my number is: .....
- E-mail – my address is: .....

## Appendix G: Interview schedule (people with dementia and carers)

HEALTHBRIDGE – interview schedules

### Interview schedule - Interviews with people with dementia and carers

Participants are to be invited to discuss in interviews:

- |  |  |
|--|--|
| 1 <sup>st</sup><br>Interview                   | 1. General questions around wellbeing and their daily lives and the dementia, and ask about peer support etc prior to dementia –e.g. what activities etc they engaged in and if these changed post diagnosis. This is stage dependant.   |
| 1 <sup>st</sup><br>Interview                   | 2. Did they use any other service –be clear that we are going to focus on the demonstrator service – ask about how they found out about it, in what ways they have used it etc and their experiences of using peer support networks or dementia advisors.  |
| 1 <sup>st</sup><br>Interview                   | 3. Their perspective of the intended and actual outcomes of contact. Including any unintended. Any suggestions for improvements? Any examples of things that have happened that they really liked?   |
| 2 <sup>nd</sup><br>Interview                   | 4. Perceived ways in which the new service models contribute to their wellbeing and resilience in relation to: <ol style="list-style-type: none"> <li>a. accessibility of services,</li> <li>b. involvement and information,</li> <li>c. support for making choices and independence.</li> </ol> |
| 2 <sup>nd</sup><br>Interview                   | 5. What does it cost them to use/be involved in the intervention e.g. work time lost; travel expenses; time spent doing other things.  |
| 2 <sup>nd</sup> /3 <sup>rd</sup><br>Interviews | 6. What other services do they use and have they reduced the use of these services as a result of the project  |
|  | 7. What they would do if the service did not exist or what did they do before the service existed.   |
|  | 8a. If they had to pay for this service, how much would they be prepared to pay  |
|  | (emphasising that there is no intention of making them pay but this is just a method for us to gain an understanding in monetary terms of how they value the project).   |
|  | 8b. Which aspects of the service is most important to you? What is the next most important ...   |

## Appendix H: Interview schedule (stakeholders)

HEALTHBRIDGE – interview schedules

### Interview schedule – Stakeholder Interviews

Participants are to be invited to discuss in interviews:

1. Definitions of the role of the pilot activity.
2. Ideas about its goals and purpose.
3. Views and experiences of the way the demonstrator site activity works within the wider health and social care system. – prompts – explain their role and involvement including length of time in general dementia and with the demonstrator site.
4. Perceived impact on local policy and practices – what were the local policies and practise and then impact – get to give actual examples.
5. Perceived impact on people with dementia and carers – are there differences between the different groups – probe for actual examples of impact.
6. The conditions that are regarded as essential to the successful development of the activity.
7. Perceived strengths of the theory and models of intervention. – probe for both theory and model, including social networking
- 8a. (i) What were the costs of the intervention i.e. the setting up and running costs ?  
(ii) Were all the setting up and running costs covered by the budget provided?  
(iii) What aspects of the intervention have been covered by 1. Staff and 2. Volunteer time and resources?
- 8b. (i) What are the main components of the intervention?  
(ii) Please rank the components in order of importance (not necessarily whether achieved they have been achieved or not)  
  
Please state the most important as 1. and then order subsequent components in descending order
9. Identification of any problematic/challenges areas and if/how they were overcome
10. Any other comments.

## Appendix I: Consent forms



### HEALTHBRIDGE - National evaluation of dementia advisers and peer support networks

#### Consent to participate

As a person with mild memory problems or a person with dementia:

I understand and agree to take part in an interview for the national evaluation of dementia advisers and peer support network activity	Yes <input type="checkbox"/> No <input type="checkbox"/>
I understand and agree to the interview being audio recorded	Yes <input type="checkbox"/> No <input type="checkbox"/>
I have read and fully understand the information leaflet for participants and have had the opportunity to ask any questions I may have relating to the evaluation	Yes <input type="checkbox"/> No <input type="checkbox"/>
I agree to take part in the evaluation and understand that this will not affect my access to any services that I currently use	Yes <input type="checkbox"/> No <input type="checkbox"/>
I understand that I can withdraw from the evaluation study at anytime and will not be contacted again with regard to the evaluation if I choose not to be involved	Yes <input type="checkbox"/> No <input type="checkbox"/>
I understand that I will not be personally named in any report and that anything I say will be treated with confidence (unless I say something that indicates that either myself or someone else is at risk of harm and this would be discussed with me prior to telling anyone else)	Yes <input type="checkbox"/> No <input type="checkbox"/>
I understand that any information collected will be kept in a secure way	Yes <input type="checkbox"/> No <input type="checkbox"/>
I understand that anonymised data will be used even if, for whatever reason, I choose to withdraw from the study afterwards	Yes <input type="checkbox"/> No <input type="checkbox"/>
I understand that information collected will be managed by the evaluation team only and will be destroyed after a period of five years	Yes <input type="checkbox"/> No <input type="checkbox"/>

<p>I agree that if I lose the capacity to decide to take part during the evaluation:</p> <p>i) I grant permission for the study team to contact a “named consultee” (next of kin and not a paid carer) to revisit the consent process</p> <p>And</p> <p>ii) I am happy for any anonymised data collected prior to loss of capacity to be used in data analysis</p>	<p>Yes <input type="checkbox"/></p> <p>No <input type="checkbox"/></p> <p>Yes <input type="checkbox"/></p> <p>No <input type="checkbox"/></p>
<p>I understand that information collected will be managed by the evaluation team only and will be destroyed after a period of five years</p>	<p>Yes <input type="checkbox"/></p> <p>No <input type="checkbox"/></p>
<p>I understand that I will be given access to the final summary of the evaluation report</p>	<p>Yes <input type="checkbox"/></p> <p>No <input type="checkbox"/></p>

Information about the research has been discussed and fully understood

Signature of participant ..... Date .....

Signature of researcher ..... Date .....  
 Contact details to be added



HEALTHBRIDGE - National evaluation of dementia advisers and peer support networks

Consent to participate

As a carer:

I understand and agree to take part in an interview for the national evaluation of dementia advisers and peer support network activity	Yes <input type="checkbox"/> No <input type="checkbox"/>
I understand and agree to the interview being audio recorded	Yes <input type="checkbox"/> No <input type="checkbox"/>
I have read and fully understand the information leaflet for participants and have had the opportunity to ask any questions I may have relating to the evaluation	Yes <input type="checkbox"/> No <input type="checkbox"/>
I agree to take part in the evaluation and understand that this will not affect my access to any services that I currently use	Yes <input type="checkbox"/> No <input type="checkbox"/>
I understand that I can withdraw from the evaluation study at anytime and will not be contacted again with regard to the evaluation if I choose not to be involved	Yes <input type="checkbox"/> No <input type="checkbox"/>
I understand that I will not be personally named in any report and that anything I say will be treated with confidence (unless I say something that indicates that either myself or someone else is at risk of harm and this would be discussed with me prior to telling anyone else)	Yes <input type="checkbox"/> No <input type="checkbox"/>
I understand that any information collected will be kept in a secure way	Yes <input type="checkbox"/> No <input type="checkbox"/>
I understand that anonymised data will be used even if, for whatever reason, I choose to withdraw from the study	Yes <input type="checkbox"/> No <input type="checkbox"/>
I understand that information collected will be managed by the evaluation team only and will be destroyed after a period of five years	Yes <input type="checkbox"/> No <input type="checkbox"/>
I understand that I will be given access to the final summary of the evaluation report	Yes <input type="checkbox"/> No <input type="checkbox"/>

Information about the research has been discussed and fully understood

Signature of participant ..... Date .....

Signature of researcher ..... Date .....

Contact details to be added

NDS Consent form (Carers)





HEALTHBRIDGE - National evaluation of dementia advisers and peer support networks

Consent to participate

As a consultee acting on behalf of a person with mild memory problems or a person with dementia:

I understand and agree that the person with mild memory problems or dementia would choose to take part in an interview for the national evaluation of dementia advisers and peer support network activity	Yes <input type="checkbox"/> No <input type="checkbox"/>
I understand and agree that the person with mild memory problems or dementia will accept the interview being audio recorded	Yes <input type="checkbox"/> No <input type="checkbox"/>
I have read and fully understand the information leaflet for consultees and have had the opportunity to ask any questions I may have relating to the evaluation	Yes <input type="checkbox"/> No <input type="checkbox"/>
I agree that the person with mild memory problems or dementia is to take part in the evaluation and understand that this will not affect access to any services that they currently use	Yes <input type="checkbox"/> No <input type="checkbox"/>
I understand both the person with mild memory problems or dementia and myself can withdraw from the evaluation study at anytime and that we will not be contacted again with regard to the evaluation if we choose not to be involved	Yes <input type="checkbox"/> No <input type="checkbox"/>
I understand that I or the person with mild memory problems or dementia will not be personally named in any report and that anything I/they say will be treated with confidence (unless I/they say something that indicates that either they or someone else is at risk of harm and this would be discussed with me prior to telling anyone else)	Yes <input type="checkbox"/> No <input type="checkbox"/>
I understand that any information collected will be kept in a secure way	Yes <input type="checkbox"/> No <input type="checkbox"/>
I understand that any anonymised data will still be used even if, for whatever reason, they choose to withdraw from the study	Yes <input type="checkbox"/> No <input type="checkbox"/>
I understand that information collected will be managed by the evaluation team only and will be destroyed after a period of five years	Yes <input type="checkbox"/> No <input type="checkbox"/>
I understand that I will be given access to the final summary of the evaluation report	Yes <input type="checkbox"/> No <input type="checkbox"/>

Information about the research has been discussed and fully understood

Signature of participant ..... Date .....  
 Signature of researcher ..... Date .....  
 Contact details to be added



## HEALTHBRIDGE - National evaluation of dementia advisers and peer support networks

### Consent to participate

**As a member of staff / volunteer:**

I agree to take part in an interview for the National Evaluation of dementia advisers and peer support network activity	Yes <input type="checkbox"/> No <input type="checkbox"/>
I understand and agree to the interview being audio recorded	Yes <input type="checkbox"/> No <input type="checkbox"/>
I have read and fully understand the information leaflet for staff and volunteers and have had the opportunity to ask any questions I may have relating to the evaluation	Yes <input type="checkbox"/> No <input type="checkbox"/>
I understand that taking part in the evaluation will not affect my work or volunteering activity at all	Yes <input type="checkbox"/> No <input type="checkbox"/>
I understand that I can withdraw from the evaluation study at anytime and will not be contacted again with regard to the evaluation if I choose not to be involved	Yes <input type="checkbox"/> No <input type="checkbox"/>
I understand that I will not be personally named in any report	Yes <input type="checkbox"/> No <input type="checkbox"/>
I understand that any information collected will be kept in a secure way	Yes <input type="checkbox"/> No <input type="checkbox"/>
I understand that information collected will be managed by the evaluation team only and will be destroyed after a period of five years	Yes <input type="checkbox"/> No <input type="checkbox"/>
I understand that I will be given access to the final summary of the evaluation report	Yes <input type="checkbox"/> No <input type="checkbox"/>

Information about the research has been discussed and fully understood

Signature of participant ..... Date .....

Signature of researcher ..... Date .....

Contact details to be added

Study ID

## ***DEMQOL (version 4)***

**Instructions:** Read each of the following questions (in bold) verbatim and show the respondent the response card.

**I would like to ask you about your life. There are no right or wrong answers. Just give the answer that best describes how you have felt in the last week. Don't worry if some questions appear not to apply to you. We have to ask the same questions of everybody.**

**Before we start we'll do a practise question; that's one that doesn't count. (*Show the response card and ask respondent to say or point to the answer*) In the last week, how much have you enjoyed watching television?**

**a lot      quite a bit      a little      not at all**

*Follow up with a prompt question: **Why is that? or Tell me a bit more about that.***

For all of the questions I'm going to ask you, I want you to think about the last week.

First I'm going to ask about your feelings. In the last week, have you felt.....

- |   |                                |                                      |                                   |                                     |
|---|--------------------------------|--------------------------------------|-----------------------------------|-------------------------------------|
| 1. cheerful? **   | <input type="checkbox"/> a lot | <input type="checkbox"/> quite a bit | <input type="checkbox"/> a little | <input type="checkbox"/> not at all |
| 2. worried or anxious?  | <input type="checkbox"/> a lot | <input type="checkbox"/> quite a bit | <input type="checkbox"/> a little | <input type="checkbox"/> not at all |
| 3. that you are enjoying life? **                             | <input type="checkbox"/> a lot | <input type="checkbox"/> quite a bit | <input type="checkbox"/> a little | <input type="checkbox"/> not at all |
| 4. frustrated?  | <input type="checkbox"/> a lot | <input type="checkbox"/> quite a bit | <input type="checkbox"/> a little | <input type="checkbox"/> not at all |
| 5. confident? **  | <input type="checkbox"/> a lot | <input type="checkbox"/> quite a bit | <input type="checkbox"/> a little | <input type="checkbox"/> not at all |
| 6. full of energy? **   | <input type="checkbox"/> a lot | <input type="checkbox"/> quite a bit | <input type="checkbox"/> a little | <input type="checkbox"/> not at all |
| 7. sad?   | <input type="checkbox"/> a lot | <input type="checkbox"/> quite a bit | <input type="checkbox"/> a little | <input type="checkbox"/> not at all |
| 8. lonely?  | <input type="checkbox"/> a lot | <input type="checkbox"/> quite a bit | <input type="checkbox"/> a little | <input type="checkbox"/> not at all |
| 9. distressed?  | <input type="checkbox"/> a lot | <input type="checkbox"/> quite a bit | <input type="checkbox"/> a little | <input type="checkbox"/> not at all |
| 10. lively? **  | <input type="checkbox"/> a lot | <input type="checkbox"/> quite a bit | <input type="checkbox"/> a little | <input type="checkbox"/> not at all |
| 11. irritable?  | <input type="checkbox"/> a lot | <input type="checkbox"/> quite a bit | <input type="checkbox"/> a little | <input type="checkbox"/> not at all |
| 12. fed-up?   | <input type="checkbox"/> a lot | <input type="checkbox"/> quite a bit | <input type="checkbox"/> a little | <input type="checkbox"/> not at all |
| 13. that there are things that you wanted to do but couldn't? | <input type="checkbox"/> a lot | <input type="checkbox"/> quite a bit | <input type="checkbox"/> a little | <input type="checkbox"/> not at all |

Next, I'm going to ask you about your memory. In the last week, how worried have you been about.....

- |   |                                |                                      |                                   |                                     |
|---|--------------------------------|--------------------------------------|-----------------------------------|-------------------------------------|
| 14. forgetting things that happened recently? | <input type="checkbox"/> a lot | <input type="checkbox"/> quite a bit | <input type="checkbox"/> a little | <input type="checkbox"/> not at all |
| 15. forgetting who people are?                | <input type="checkbox"/> a lot | <input type="checkbox"/> quite a bit | <input type="checkbox"/> a little | <input type="checkbox"/> not at all |
| 16. forgetting what day it is?                | <input type="checkbox"/> a lot | <input type="checkbox"/> quite a bit | <input type="checkbox"/> a little | <input type="checkbox"/> not at all |

17. **your thoughts being muddled?**     a lot                       quite a bit                       a little                       not at all
18. **difficulty making decisions?**     a lot                       quite a bit                       a little                       not at all
19. **poor concentration?**             a lot                       quite a bit                       a little                       not at all

Now, I'm going to ask you about your everyday life. In the last week, how worried have you been about.....

20. **not having enough company?**     a lot                       quite a bit                       a little                       not at all
21. **how you get on with people close to you?**                       a lot                       quite a bit                       a little                       not at all
22. **getting the affection that you want?**                       a lot                       quite a bit                       a little                       not at all
23. **people not listening to you?**     a lot                       quite a bit                       a little                       not at all
24. **making yourself understood?**     a lot                       quite a bit                       a little                       not at all
25. **getting help when you need it?**     a lot                       quite a bit                       a little                       not at all
26. **getting to the toilet in time?**     a lot                       quite a bit                       a little                       not at all
27. **how you feel in yourself?**         a lot                       quite a bit                       a little                       not at all
28. **your health overall?**                 a lot                       quite a bit                       a little                       not at all

We've already talked about lots of things: your feelings, memory and everyday life. Thinking about all of these things in the last week, how would you rate.....

29. **your quality of life overall? \*\***     very good                       good                       fair                       poor

\*\* items that need to be reversed before scoring

## **DEMQOL - Carer (version 4)**

Instructions: *Read each of the following questions (in bold) verbatim and show the respondent the response card.*

**I would like to ask you about \_\_\_\_\_ (your relative's) life, as you are the person who knows him/her best. There are no right or wrong answers. Just give the answer that best describes how \_\_\_\_\_ (your relative) has felt in the last week. If possible try and give the answer that you think \_\_\_\_\_ (your relative) would give. Don't worry if some questions appear not to apply to \_\_\_\_\_ (your relative). We have to ask the same questions of everybody.**

**Before we start we'll do a practise question; that's one that doesn't count. (Show the response card and ask respondent to say or point to the answer). In the last week how much has \_\_\_\_\_ (your relative) enjoyed watching television?**

**a lot      quite a bit      a little      not at all**

*Follow up with a prompt question: **Why is that? or Tell me a bit more about that.***

For all of the questions I'm going to ask you, I want you to think about the last week.

First I'm going to ask you about \_\_\_\_\_ (your relative's) feelings. In the last week, would you say that \_\_\_\_\_ (your relative) has felt.....

- |  |                                |                                      |                                   |                                     |
|--|--------------------------------|--------------------------------------|-----------------------------------|-------------------------------------|
| 1. cheerful? **                                      | <input type="checkbox"/> a lot | <input type="checkbox"/> quite a bit | <input type="checkbox"/> a little | <input type="checkbox"/> not at all |
| 2. worried or anxious?                               | <input type="checkbox"/> a lot | <input type="checkbox"/> quite a bit | <input type="checkbox"/> a little | <input type="checkbox"/> not at all |
| 3. frustrated?                                       | <input type="checkbox"/> a lot | <input type="checkbox"/> quite a bit | <input type="checkbox"/> a little | <input type="checkbox"/> not at all |
| 4. full of energy? **                                | <input type="checkbox"/> a lot | <input type="checkbox"/> quite a bit | <input type="checkbox"/> a little | <input type="checkbox"/> not at all |
| 5. sad?  | <input type="checkbox"/> a lot | <input type="checkbox"/> quite a bit | <input type="checkbox"/> a little | <input type="checkbox"/> not at all |
| 6. content? **                                       | <input type="checkbox"/> a lot | <input type="checkbox"/> quite a bit | <input type="checkbox"/> a little | <input type="checkbox"/> not at all |
| 7. distressed?                                       | <input type="checkbox"/> a lot | <input type="checkbox"/> quite a bit | <input type="checkbox"/> a little | <input type="checkbox"/> not at all |
| 8. lively? **  | <input type="checkbox"/> a lot | <input type="checkbox"/> quite a bit | <input type="checkbox"/> a little | <input type="checkbox"/> not at all |
| 9. irritable?  | <input type="checkbox"/> a lot | <input type="checkbox"/> quite a bit | <input type="checkbox"/> a little | <input type="checkbox"/> not at all |
| 10. fed-up   | <input type="checkbox"/> a lot | <input type="checkbox"/> quite a bit | <input type="checkbox"/> a little | <input type="checkbox"/> not at all |
| 11. that he/she has things<br>to look forward to? ** | <input type="checkbox"/> a lot | <input type="checkbox"/> quite a bit | <input type="checkbox"/> a little | <input type="checkbox"/> not at all |

Next, I'm going to ask you about \_\_\_\_\_ (your relative's) memory. In the last week, how worried would you say \_\_\_\_\_ (your relative) has been about.....

- |   |                                |                                      |                                   |                                     |
|---|--------------------------------|--------------------------------------|-----------------------------------|-------------------------------------|
| 12. his/her memory in general?                          | <input type="checkbox"/> a lot | <input type="checkbox"/> quite a bit | <input type="checkbox"/> a little | <input type="checkbox"/> not at all |
| 13. forgetting things that<br>happened a long time ago? | <input type="checkbox"/> a lot | <input type="checkbox"/> quite a bit | <input type="checkbox"/> a little | <input type="checkbox"/> not at all |
| 14. forgetting things that<br>happened recently?        | <input type="checkbox"/> a lot | <input type="checkbox"/> quite a bit | <input type="checkbox"/> a little | <input type="checkbox"/> not at all |
| 15. forgetting people's names?                          | <input type="checkbox"/> a lot | <input type="checkbox"/> quite a bit | <input type="checkbox"/> a little | <input type="checkbox"/> not at all |
| 16. forgetting where he/she is?                         | <input type="checkbox"/> a lot | <input type="checkbox"/> quite a bit | <input type="checkbox"/> a little | <input type="checkbox"/> not at all |
| 17. forgetting what day it is?                          | <input type="checkbox"/> a lot | <input type="checkbox"/> quite a bit | <input type="checkbox"/> a little | <input type="checkbox"/> not at all |

- his/her thoughts being muddled?  a lot  quite a bit  a little  not at all
18. difficulty making decisions?  a lot  quite a bit  a little  not at all
19. making him/herself understood?  a lot  quite a bit  a little  not at all

Now, I'm going to ask about \_\_\_\_\_ (*your relative's*) everyday life. In the last week, how worried would you say \_\_\_\_\_ (*your relative*) has been about.....

20. keeping him/herself clean (eg washing and bathing)?  a lot  quite a bit  a little  not at all
21. keeping him/herself looking nice?  a lot  quite a bit  a little  not at all
22. getting what he/she wants from the shops?  a lot  quite a bit  a little  not at all
23. using money to pay for things?  a lot  quite a bit  a little  not at all
24. looking after his/her finances?  a lot  quite a bit  a little  not at all
25. things taking longer than they used to?  a lot  quite a bit  a little  not at all
26. getting in touch with people?  a lot  quite a bit  a little  not at all
27. not having enough company?  a lot  quite a bit  a little  not at all
28. not being able to help other people?  a lot  quite a bit  a little  not at all
29. not playing a useful part in things?  a lot  quite a bit  a little  not at all
30. his/her physical health?  a lot  quite a bit  a little  not at all









We've already talked about lots of things: \_\_\_\_\_ (*your relative's*) feelings, memory and everyday life. Thinking about all of these things in the last week, how would you say \_\_\_\_\_ (*your relative*) would rate.....




31. his/her quality of life overall? \*\*  very good  good  fair  poor

\*\* items that need to be reversed before scoring



## Appendix K: Initial coding framework

 Access to new services	
	How easy or hard
	How new services are accessed
	Location
	Others not receiving services
	Publicity
	Referrals
	Transport

	Advice
	Advocacy
	ASCOT (well-being questionnaire)

	Cleanliness of home
	Column L
	Control
	Food and drink
	How having help makes people think and feel
	How ways in which helped makes people think and feel
	Other comments
	Personal care
	Safety
	Social contact
	Spend time
	What else want to know


	Awareness
---	-----------



	Awareness of dementia
--	-----------------------

	Dementia as a priority issue
	GP and other health professionals

	New services and awareness
--	----------------------------

	Wider community impact
--	------------------------

	Support for wider networks
--	----------------------------



	Barriers and challenges
	Being a carer
	Being a demonstration site

	Partnership working
	Specific roles








	Time in dementia care
--	-----------------------

--

	Steering Groups and Project Boards
	Timescale
	Transition of new services beyond demonstration period

	Choice
	Components of intervention

	Ranking of components
--	-----------------------

	Conditions essential to success of new services
	Confidence
	Control
	Coping
	Crisis prevention
	Cure and medication
	Dementia Adviser role

	Examples of support
--	---------------------




	DEMqoL
---	--------

	Everyday life
	Feelings
	Memory
	Overall quality of life






	Diagnosis
---	-----------

	Experiences of diagnosis
	Impact of diagnosis

	Role of new services at point of diagnosis
	Support at time of diagnosis

	Early intervention
	Early onset dementia
	Empowerment

	Empowerment through strategies to cope
--	--

	Enabling
	End of life
	Expectations of new services
	Fighting for support
	Funding and finance

	Core costs
	Staffing costs



Venue	

	Other resources
--	-----------------



Service users' resources	
--------------------------	--

Transport	
Volunteers	






	Resources saved by new services
	Uncertainty

	Future support
	General well-being and daily life

	Change in activities since diagnosis
--	--------------------------------------



	Goals, roles and purposes of new services
	How services could be improved

	Future ideas
--	--------------



	Humour
	Identifying with others in similar position
	If service didn't exist
	
	

	Impact of new services
	Impact of new services on people with dementia vs impact on carers

	Shared understanding
--	----------------------

	Independence
	Information

	Aspect of new service
	Empowerment through information

	Isolation
	IT and social media




	Confusion or disagreement
	Faith
	Language of project
	My biggest problem
	Not taking support

	Journeys
--	----------

	Biographical disruption
	Critical junctures

	Future
	Past
	Present

	Perceptions of life
	Perceptions of self
	Reflections
	Role of new services in journey.




	'Living well with dementia'
	Memorable quotes
	Models of intervention. DA and PSN

	Comparison of PSN and DA models
	Strengths of models
	Weaknesses of models

	Mushrooming
---	-------------

	Advice and information
	Funding






	Knowledge of services
	Peer support

	Negative aspects
	Networking
	Other services or support accessed

	Alongside new services
	As a result of support from new services
	Prior to accessing new services

	Peer Support Networks
---	-----------------------

	Facilitator's role
	Peer support outside of formal PSN activities
	Positive aspects
	Specific activities



	Peer support
	People benefitted. Examples from staff and stakeholders
	Person-centred approach
	Personal qualities of staff and volunteers
	Phil's nodes
	Policy

	Local
--	-------

	Impact.
	Local dementia strategy
	Local evaluations

	National
--	----------

	National Dementia Strategy
--	----------------------------

	Public health
	Relationship of new services to pre-existing services



	Filling a gap in service provision
	How new services fit in with pre-existing services
	New services as a link between pre-existing services
	Overlaps with pre-existing services

	Blurring of boundaries or remit
--	---------------------------------





	Signposting
--	-------------

	Respite
	Risk
	Routine



	Disability issues
	Finding a cure
	Support from family

	Self-esteem
	Service user involvement

	Barriers and challenges
	Carers
	Importance
	People with dementia
	What worked well

	Specific or 'harder to reach' communities
	Stress and anxiety
	Taking part in Healthbridge
	Theoretical framework

	Self-efficacy theory
	Social learning theory
	Social network theory

	Timing and flexibility of support from new services
	Volunteers

	Carers as volunteers
	People with dementia as volunteers
	Role of volunteers
	Training for volunteers
	Volunteers as a resource

## Appendix L: NVivo word tree

An example of a word tree generated when I wanted to look for data about people learning more about available benefits. Simply created a text search using the criteria "benefit\*" so using a wild card.

8/10/2012

