

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

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Brief Report¹

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¹This report has been written primarily for service commissioners and providers. A lay summary is available as well as the full report with an executive summary.

Introduction

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, 2009) stated that in the next 30 years, the number of people with dementia in England will double to 1.4 million people. Parallel to this is an increase in health, economic and social care issues in society as a whole, at both national and community levels.

Living well with dementia (Department of Health, 2009) was the first national strategy for dementia in England. 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; Care Services Improvement Partnership, 2005; Knapp *et al.*, 2007; National Audit Office, 2007). In recognising the day-to-day experiences of people with dementia and their carers, and the deficits in models of support to date, the National Dementia Strategy (Department of Health, 2009) promoted the use of Peer Support Networks and Dementia Advisers.

Subsequent to the launch of the National Dementia Strategy, implementation plans have promoted its delivery. 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”. 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 *Prime Minister’s Challenge* also highlights the role of high-quality information in support for people with dementia, their carers, and wider networks, a key aspect of Peer Support Network and Dementia Adviser services.

The demonstration sites

In 2010, 40 demonstrator sites were set up and piloted throughout England for an initial 12-month period. The aim of setting up these sites was to promote quality of life and well-being for people with dementia and their carers. Twenty-two of these sites were set up around a Dementia Adviser model (i.e. an adviser or team of advisers who support people with dementia and carers to access information, advice and support). The other 18 were set up around a Peer Support Network model (i.e. support by people with dementia and carers for others in similar positions, usually supported by a Peer Support Network facilitator).

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. 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, and voluntary sector organisations including the Alzheimer's Society, 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. The range of organisational structures meant that for some sites leadership was joint between more than one organisation, but the overall spread of lead organisations was equal between NHS, councils and the voluntary sector. The spread of partnerships within organisational contexts was also equally distributed between the NHS, councils and the voluntary sector.

The Healthbridge evaluation

Aims

1. To describe the range of Peer Support Network 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.

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. The design is represented in Appendix 1. Ethical and governance approval was secured² and processes included ensuring confidentiality and anonymity; ensuring that participants knew who to contact if they needed further information and support; and acknowledging the complexities of consent to research by people with dementia. Processes developed enabled the inclusion of those without capacity to provide informed consent and those for whom English was not a preferred language.

A visual representation of the methods used can be found in Appendix 1.

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, Office for National Statistics, 2010).

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.

² Research Ethic Committee References: SCREC Ref: 10/IEC08/13; ADASS Ref: Rg 10-009.

In-depth case studies: In eight case study sites, geographically spread across England, qualitative interviews with people with dementia and carers (n = 101), including well-being and quality of life measures (ASCOT and DEMQoL, Banerjee *et al.*, 2006), and interviews with staff, volunteers and other stakeholders (n = 82).

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 (CIT); one based within an NHS 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 local council, NHS and Age Concern.

Data analysis

The process of data analysis included: the use of the ASCOT toolkit and SPSS for analysis of ASCOT data entry tool which provided SCRQoL (Social Care Related Quality of Life) scores; IBM SPSS for analysis of activity monitoring data; and EXCEL and NVivo9 (computer assisted qualitative data analysis software) for analysis of the organisational surveys. The process of analysing qualitative data also made use of NVivo9 within a five-stage process: the development of a coding structure using a sample of 25 transcripts; further development of the framework with input from the wider evaluation team; coding of a further sample of 70 transcripts; modelling of the data and verification of models and the emerging findings with the full dataset.

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, 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

Organisational characteristics

This section reports on some of the characteristics of the services and those who accessed them. There was considerable variability of organisational structure in the services but four are described as examples in Appendix 2.

Goals, roles and purposes of Peer Support Network and Dementia Adviser Services

The main goals, roles and purposes of sites specified by site staff were:

- 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, for example BME communities.

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.

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. Within this, there were groups for people with dementia or carers on their own as well as together, with some examples of groups meeting concurrently within the same building. There were also examples of 1:1 peer support, with some examples of formal training for peer supporters.

- Positive aspects of Peer Support Networks included socialising, feeling valued and developing interests, all within the context of interpersonal interaction with people who had common experiences of living with dementia.
- 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.

Accessing Peer Support Network and Dementia Adviser services

People with dementia and carers accessed the services through a range of routes, including: referrals from other professionals; local community links; local voluntary sector organisations; publicity; community events (including presentations from Peer Support Network staff or Dementia Advisers); and word of mouth and evidence from people already accessing services. Staff from the sites which returned data reported that:

- The average number of occasions that the services were accessed during a single week in this developmental period ranged from 14 to 19 per site.
- Of these, 86% were people who had a confirmed diagnosis of dementia, 9% did not have a confirmed diagnosis and 5% were people for whom staff were unsure about their diagnosis.
- 23% were people living alone.
- 51% were male; 49% female.
- 56% of points of contact with services were with Dementia Adviser services. Of these, 37% were people with dementia and 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 and 44% were with carers.
- The majority (79%) of people accessing services were aged between 65 and 85, 12% were identified as having early onset dementia and 9% of people accessing services were aged over 85.
- On 12% of occasions sites were accessed by someone from a BME community (although this varied between sites considerably); with 8.3% of occasions when services were accessed were by people who were identified as English not being their first language.

Funding and resources

- The majority of the core budget was invested in staff, either Peer Support Network facilitators or Dementia Advisers.
- Referred to as a key resource within many sites, 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.
- Staff and stakeholders listed a range of other resources outwith the core budget that had enabled the success of pilot activity. These included practical aspects, such as

venue and office space, and also aspects of resources that came from within pre-existing organisations and structures.

- Service users and carers also reported some costs to them of accessing services.
- Further key components of services included: people, their knowledge, skills and experience and individual contributions from staff and volunteers; strategy and common goals; the strength of these new models of working and practical aspects of services such as venue.
- Peer Support Network and Dementia Adviser services provided early intervention and helped to avert problems and the need for crisis intervention, and as such have 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.
- 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, although uncertainty was also linked with the time-limited period of the demonstration site initiative.
- Staff and stakeholders referred to ways in which the above led to uncertainty and lack of continuity amongst staff, which impacted on organisations and on people who were accessing the services.
- Key factors referred to in relation to successful future funding included gathering evidence of success and the uncertain economic climate that fostered uncertainty and lack of commitment. Eleven of the sites were unable to secure funding beyond a year after the initial demonstration period.

Working with 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 Peer Support Network and Dementia Adviser services and to those interviewed from pre-existing support agencies and organisations.

- Infrastructure was clearly an important element of a successful service. Within this, partnership with other organisations was important.
- There were examples of lack of clarity and confusion in the area of boundaries and roles within and between 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.
- 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.

- 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.

Well-being of people with dementia and carers

The ASCOT (Adult Social Care Outcomes Toolkit) data, which focuses on well-being of people with dementia and carers within eight domains (accommodation, personal cleanliness, nutrition, personal safety, social participation, occupation, dignity and control), provided the following evidence on the well-being of people who were accessing the Peer Support Network and Dementia Adviser sites. The following information was collected from people from all 40 demonstration sites who returned ASCOT questionnaires to the evaluation via post:

- 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.

Timing and flexibility of support 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 want different information at different points along their dementia journey. This was linked to choice and control.
- Flexibility as to where and when support was received was also seen as a strength, and was referred to within crisis prevention and early intervention.

Information and advice

- The need for tailored information and signposting immediately following diagnosis has been highlighted within policy development. Views expressed within this evaluation demonstrated that timing, content, quantity and mode of delivery of information had an impact on people with dementia and carers.
- Within Dementia Adviser services, a range of information was brought together in one place, validated within the role of the Dementia Adviser. Within Peer Support Network services, the emphasis was on a sharing of information rooted in a commonality of experience.
- People with dementia and carers from both Peer Support Network and Dementia Adviser sites spoke about the significance of knowing that these services would be a reliable source of information, as and when they needed it in the future.
- Examples of advice within Dementia Adviser services included legal and financial advice, and advice on managing symptoms.

- Examples of advice within Peer Support Network services included timely access to other support, advice on day-to-day management and strategies for maintaining and improving memory.

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.
- People with dementia and carers spoke about the positive aspects of identifying with other people in a similar position, and the unique quality in peer-to-peer relationships: decreased isolation, increased confidence emerging from discussing struggles and triumphs.
- Some people highlighted difficulties in identifying with other people with dementia and carers, based on assumptions that they are a homogeneous 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.

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.

Awareness raising

- Peer Support Network and Dementia Adviser services played a role in raising awareness and tackling stigma around dementia. For example, visibility of the services within communities was significant within highlighting dementia as a community issue.
- This happened through provision of information, tackling stigma and enabling people with dementia to be more part of their communities, all of which contributed to more positive attitudes, which in turn were linked with crisis prevention and early intervention.

- There was also a role for staff from Peer Support Network and Dementia Adviser sites in educating professionals. Some sites were beginning to develop roles for people with dementia in educating other people, including professionals, about their experiences.

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 under which services providing peer support and dementia advice and information flourish are promoted.

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. 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.
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 – 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. 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 enhance 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 and Dementia Adviser services 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 dementia as a public health concern. 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 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. Locating these initiatives more explicitly within a public health policy framework will be beneficial in meeting the needs of people with dementia and carers.

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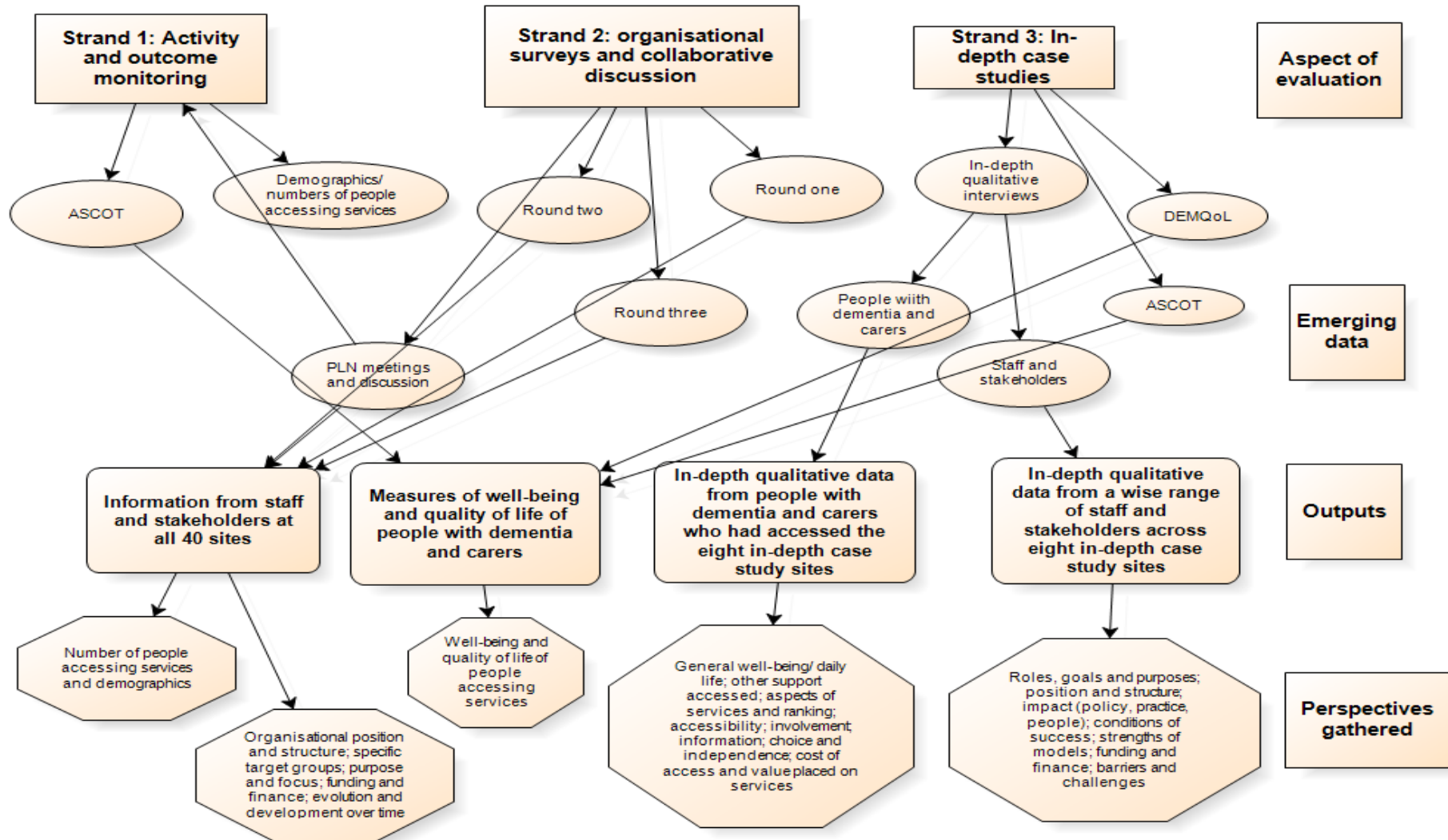
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Appendix 1. Design of the mixed methods evaluation



Appendix 2. Examples of service summary, purpose, infrastructure, costs

	Dementia Adviser Service A	Dementia Adviser Service B	Peer Support Network Service A	Peer Support Network Service B
Service summary	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.
Service Purpose	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 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. Support is withdrawn once the individual accesses a social worker/CPN intervention	To provide people with dementia after initial diagnosis, 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 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	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), 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

			networks enable people with dementia to maintain and build positive relationships with families, friends, communities and within the support groups.	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.
Lead and partner organisations	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 Adults and is supervised by the Memory Clinic Nurse Prescriber (NHS).	County council, Primary Care Trust, NHS Foundation Trust, Alzheimer's Society. Colleagues from these organisations make up the Project Board and meet regularly. Commissioner from the PCT is the Project Lead, the Alzheimer's Society delivers the service.	Adult Social Care are the lead organisation working in close partnership with Partnership Foundation Trust and Alzheimer's Society. Also working in partnership with people with dementia to improve services for people with dementia. Other local organisations involved in activity-specific work.	Rural Community Council is the lead or host organisation and employs the Memory Group Network Facilitator/Manager. The involvement of other partner organisations came to an end in July 2011, but they did include Age UK (formerly Age UK) 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.
Staff employed and volunteers	One Dementia Adviser No volunteers	Three Dementia Advisers Several volunteers	One full-time Peer Support Coordinator. 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
Capital and infrastructure costs	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