

A STRONGER COLLECTIVE VOICE FOR PEOPLE WITH DEMENTIA

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This report:

- maps groups and projects involving people with dementia across the UK;
- explores what the groups and projects need to support the further development of their work; and
- includes recommendations on how this work can be carried forward.

The Joseph Rowntree Foundation (JRF) commissioned this paper as part of its programme on Dementia & Society, which aims to ensure that the voices and experiences of different people with dementia shape the policy, practice, attitudes and decisions that affect their lives – locally and nationally.

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Executive summary

Introduction and background

The Dementia Engagement & Empowerment Project (DEEP) aimed to explore, support, promote and celebrate groups and projects led by or actively involving people with dementia across the UK that were influencing services and policies affecting the lives of people with dementia. DEEP was a one-year project which finished in 2012.

There are around 800,000 people with dementia in the UK and this figure is set to increase dramatically because of our ageing population; the risk of developing the most common forms of dementia such as Alzheimer's disease increase as one grows older. In recent years dementia has attracted much more public and political attention. All four UK nations either have, or plan to have, national dementia strategies in place to address the challenge that dementia poses.

There is widespread recognition of the benefits of 'service user' or 'citizen' involvement' in public policy, both at an individual and collective level. Although the language of involvement has not been so widely used in the field of dementia the activities of a number of groups and projects involving people with dementia have been similar to those undertaken by groups of people with other disabilities and diagnoses. However, these activities have only begun to develop in the last ten years involving people with dementia; they are much less widespread or established and until DEEP there had been no systematic attempt to map out these groups and activities, and explore what the various groups and projects might want in the future to support the further development of this work.

Overview of DEEP

DEEP aimed to draw a comprehensive picture of leadership, participation and empowerment involving groups and projects of people with dementia. It also aimed to explore what those groups and projects wanted or needed to support the further development of leadership and participation involving people with dementia, including the possibility of a national network. The project had several components:

- A mapping survey involving a literature review, questionnaire and follow up interviews to collect as much information about all the groups and projects

across the UK led by or actively involving people with dementia influencing services and policies.

- A national event to bring groups of people with dementia together to discuss the findings of the survey and the possibility of a national network.
- A published report and film that would capture the activities, learning and information gathered by the survey and the event.
- An extended reference group network of people with dementia to ensure that the key components of DEEP were relevant, meaningful and as far as possible, shaped by people with dementia.

The project was managed through a collaborative partnership led by the Mental Health Foundation, a UK research and development charity, working with Innovations in Dementia, a community interest company, and the Alzheimer's Society.

The mapping survey

There were 85 responses to the questionnaire from groups and projects, and 22 responses from individuals with dementia. Thirteen telephone interviews were undertaken and three face-to-face group interviews.

The national event

The original plan had been to hold one national event, and this took place in February 2012 in London. However, thanks to the offer of support from a group in the North West and an NHS foundation trust, a second event was held in Stockport in March 2012. In total, the two events involved ten groups and 46 people with dementia attending.

Findings

The key findings from the survey and the events were as follows:

- Most groups undertook a mixture of both influencing type work together with peer support and social activities. Some, but not all individuals did both. A number of individuals undertook influencing work independently of groups, or in addition to group activity. Most groups and projects were supported by organisations or services with staff and carers involved. The way that

people with dementia decided what the groups or projects did varied but was usually done through informal structures and processes.

- 'Influencing' type work included national lobbying and meeting with government ministers and officials, local lobbying of services, media work, training and education, participating on advisory groups, awareness raising work, and speaking at events.
- People with dementia were still at an early stage in terms of a "user movement". A lot of people's involvement was still very tentative, as many were still coming to terms with a diagnosis and unsure about whether they wanted to participate in more collective 'influencing' activities that went beyond their own personal situation. Many groups were very new and still in the process of establishing themselves and were at different stages of development compared to more established groups.
- There were high profile groups and individuals active in the field who were showing what can be achieved, but they were exceptional. Most groups were local and relatively informal in terms of their membership, their chosen sphere of influence, and the way they operated, and wanted to remain that way. Some groups faced practical difficulties in terms of funding and most groups found it challenging to include people with more severe dementia or from 'seldom heard' groups (e.g. people with more severe dementia, people with dementia from Black, Asian and minority ethnic communities).
- Although there were a limited number of groups that were at the stage of influencing policy and practice, there were other groups that wanted to know more about how their group could do some of this work. Some groups that were doing influencing work were experiencing some tensions in terms of their growing size and mix of activities they were undertaking.
- Support from organisations/professionals etc. was felt to be important but there was a strong emphasis on people with dementia being the experts and not wanting to be 'taken over' by the agendas of larger organisations.
- Although many participants in the survey and at the events were articulate, active and well informed people with lifelong experiences of influencing through work and families etc. they were not, in the main, activists or campaigners in the stereotypical mould of 'radical' younger people involved in other disability groups / 'causes'.

Supporting the empowerment of people with dementia:

- People needed time to come to terms with their diagnosis before they felt able to be active in terms of influencing policy and practice. Access to appropriate information and support about their own situation, as well as

influencing type work (including hearing from others with dementia), was essential before most people could move into doing the latter. This included building up confidence and being aware of the stigma often associated with a dementia diagnosis.

- Most groups were comfortable operating at a local level, informally, supported by staff, volunteers and carers, and valued a combination of peer support, social activities and some influencing type activities. They recognised the need to include and involve people with more advanced dementia and from 'seldom heard' groups but often found it difficult to know how to do this.

Views about a network:

- The idea of a network was welcomed – the benefits of a collective voice, sharing experiences, and “connectedness” were widely recognised.
- People found it difficult to visualise what a network would do and how it would work in practice. It was agreed that it should have a clear, agreed aims and objectives but there were a number of suggestions about what these might be, and what the membership of a network should be.
- A network would need a practical focus with tangible activities to engage groups.
- Working collectively was thought to be important but also supporting groups working locally – a network should not take over local activity.
- Funding is vital – for meetings, co-ordination, transport, etc.

Reflections, conclusions and recommendations

DEEP provided a snapshot of the relatively early phase of a new 'movement' of people with a specific diagnosis. For a number of reasons including the activism of a few dedicated individuals and groups, the increase in early diagnosis making it more possible for greater numbers of people to get involved in this kind of activity, the higher public and policy profile of dementia, and the support of some key organisations, staff and carers it was clear that the movement was growing significantly although it remained primarily rooted in local groups undertaking local activities.

As with any movement of this nature it faced many challenges but there was widespread recognition and support for the benefits that some form of national network of groups and projects could bring. Because of this, DEEP will continue for another three years, with the support of JRF and other DEEP partners, to help build capacity in existing groups to do more influencing activities, as well as

support the development of new groups and projects led by or involving people with dementia who want to start undertaking these kind of activities for the first time.

In addition to this DEEP made a number of recommendations to governments, organisations providing services and working with people with dementia at both national and local levels, dementia action alliances, specialist media and event organisers, researchers, trainers and educators, organisations wanting to be more 'dementia friendly', and organisations working with 'seldom heard' groups. These urge them to ensure that in a variety of different ways they recognise the importance of the proper involvement of people with dementia in their work, not only as 'service users', but as full citizens of the communities they are part of.

Introduction and background

The Dementia Engagement and Empowerment Project (DEEP) was funded by Joseph Rowntree Foundation as part of its programme of work on [Dementia & Society](#) which asks the question “How can we ensure that the voices and experiences of different people with dementia shape the policy, practice, attitudes and decisions that affect their lives – locally and nationally?”. The focus of this one-year project (2011-2012) was on the growing numbers of groups across the UK led by, or actively involving people with dementia who had come together to participate in activities aiming at influencing services and policies affecting their lives at both a local and national level.

DEEP’S aims were as follows:

- To identify initiatives, groups and activities led by, or actively involving people with dementia that aim to enable people with dementia to have more control over their own lives.
- To develop the capability and potential of people living with dementia in leading and managing initiatives relating to the care and support they receive, policy and service development, their rights as citizens, and the perception and understanding of dementia in the wider society.
- To help plan a process to support the development of a UK network of initiatives, groups and activities led by people with dementia or with their active involvement and participation.

A collaborative approach was taken in delivering the project involving two national charities, the Mental Health Foundation (which co-ordinated the project) and the Alzheimer’s Society, together with a Community Interest Company (CIC), Innovations in Dementia. All three organisations have a demonstrable commitment and track record of work involving the active engagement of people living with dementia.

This report describes the background and context to the project, the mapping survey and the two DEEP events – and ends with reflections and conclusions. The report forms a key output of the project, together with a DVD consisting of views and experiences of people living with dementia about initiatives, activities and groups involving or led by people with dementia, and footage from the national event.

There will also be published separately the following:

- A summary of the key findings.
- The literature review that was undertaken as part of the project.
- An accessible version of the report for people with dementia.
- An online version of the report available from the Mental Health Foundation's website with additional appendices of primary research data collected by the project including:
 - data tables from mapping survey;
 - information about individual groups and projects from the survey;
 - transcripts of focus group interviews from the survey; and
 - views of individuals with dementia about participation, empowerment, and the DEEP project.

Language

Although the stated aims of DEEP use the terms 'leadership' and 'involvement' (or 'participation') it is important to acknowledge that the name of the project includes the terms 'engagement' and 'empowerment'. These were not simply chosen for the purpose of a convenient acronym! The organisations collaborating on the project recognised that a key element of the project was to investigate the nature and degree of "engagement" by people with dementia in groups and collective activities that were influencing services and policies. "Empowerment" denoted the potential effect these groups and activities were having on the people participating in them. All four terms are interlinked but put simply, the project was about investigating, and where possible, supporting and promoting groups that engaged people with dementia in leading or actively participating, thereby potentially empowering them to influence services and policies affecting their lives and the lives of others living with dementia. However, as will be discussed later, some of the language around 'involvement' may not always 'fit' with the experiences or definitions used by people with dementia.

For the purposes of this report the term 'involvement' will be used as shorthand to link the *process* of engagement with the (potential) outcome of *empowerment* for people with dementia (which in some cases, may include leadership).

Prevalence and costs of dementia

There are now 800,000 people with dementia in the UK. Because the size of the population is growing and people are living longer, by 2021 there will be over 1 million people living with dementia in the UK. Dementia describes a range of symptoms which cause a decline in mental ability affecting memory, thinking, problem-solving, concentration and perception. There may also be some physical symptoms. Dementia occurs as a result of the death of brain cells or damage in parts of the brain that deal with our thought processes. It is progressive, which means the symptoms will gradually get worse. The most common form of dementia is Alzheimer's disease which affects 62 per cent of people with dementia, followed by vascular dementia (17 per cent), and a combination of both (10 per cent). At present there is no universally effective treatment or cure for dementia although some medication slows the progress of Alzheimer's diseases.

Two-thirds of people with dementia live in their own homes in the community and one third live in a care home – at least two-thirds of care home residents in the UK have dementia (Alzheimer's Society, 2007a). People with the condition are also core users of NHS care – a quarter of hospital beds are occupied by people with dementia over 65 at any one time. The costs of dementia are significant – it is estimated that it currently costs the NHS, local authorities and families £23 billion a year (Alzheimer's Society, 2007, updated to reflect 2012 figures), and this will grow to £27 billion by 2018 (King's Fund, 2008).

The policy context

The last few years have seen a very significant increase in the policy response to dementia (these are summarised in Appendix A in relation to the emergence of groups and projects involving people with dementia). In 2001 the Department of Health published the National Service Framework (NSF) for Older People which set out service standards for health and social care services for England (Department of Health, 2001). Standard Seven covered the mental health of older people (mental health services for adults below retirement age were covered in a separate NSF, published in 1999) and this included a section on dementia. This was a very limited response to a very significant challenge (and failed to take into account early onset dementia that affects younger people) but it did mark national recognition of the issue. In order to implement the NSF a service development guide was published by the DH in 2005, *Everybody's Business* (Care Services Improvement Partnership, 2005) and this in turn led to

the publication of the resource guide for involvement, *Strengthening the Involvement of People with Dementia* (Care Services Improvement Partnership, 2007).

At the same time, the Mental Capacity Act 2005 was passed by Parliament and came into force in England and Wales in 2007 (Scotland had passed its own capacity legislation in 2000). The Act introduced principles, procedures and safeguards to support people (including people with conditions like dementia) to make decisions for themselves wherever possible, and to protect their rights if decisions had to be made on their behalf. Capacity legislation signified an important shift away from blanket assumptions of incapacity because of diagnosis or disability, towards a greater focus on an individual's right to be independent and self-determining being respected wherever possible. It was widely welcomed by organisations working in the field of dementia (Alzheimer's Society, 2007b).

The following years saw a succession of official reports about dementia including ones from the National Audit Office (2007), the Commission for Social Care Inspection (2008), and the House of Commons Committee on Public Accounts (2008), which identified the need to improve services for people with dementia. Together with growing media interest in dementia and the rising numbers of people with dementia the government in England responded with the publication in 2009 of *Living well with dementia*, the country's first national dementia strategy (Department of Health, 2009). The strategy included 17 objectives aimed at improving the lives of people with dementia and the services they used. People with dementia were involved in the design and consultation stages of the strategy and one of its objectives (Objective 5) was specifically focused on developing peer support and learning for people with dementia and their carers. Scotland, Wales and Northern Ireland also prioritised dementia and developed their own dementia strategies and plans in subsequent years (at the time of writing Wales is still consulting on its dementia strategy, which forms part of its wider mental health strategy) - people with dementia were involved in this work, as well as other important initiatives such as the *Charter of Rights for People with Dementia and their Carers in Scotland* (Cross-Party Group on Alzheimer's, Scottish Parliament, 2009).

The change of government in the UK following the 2010 General Election did not appear to result in a policy change on dementia and the Chancellor specifically identified dementia as a priority for government in his speech on the comprehensive spending review in 2010. However, only certain objectives from

the National Dementia Strategy (NDS) were prioritised by the new government and Objective 5 wasn't one of them. This despite a wider declared commitment to the involvement of service users in healthcare policy, when the Secretary of State for Health gave his support to the disabled people's slogan of '*nothing about us, without us*'. However, the Coalition government did publish an outcomes framework to support implementation of the NDS - all 12 outcomes were written in the first person from the perspective of someone with dementia including statements such as "*I am treated with dignity and respect*", "*I know what I can do to help myself and who else can help me*" and "*I feel part of a community and I'm inspired to give something back*" (Department of Health, 2010).

In order to maintain momentum, a Dementia Action Alliance (DAA) was formed in England in 2010 comprising a wide range of both statutory and non-statutory organisations working to improve the lives of people with dementia. The DAA published a *National Dementia Declaration* based around seven outcomes (also written in the first person from the perspective of someone with dementia) that people with dementia wanted to see in their lives (Dementia Action Alliance, 2010). There are now over 100 members of the DAA but individuals with dementia are able to attend DAA quarterly meetings and actively contribute to discussions about what the DAA is doing.

Yet, as a recent report put it (Alzheimer's Society, 2012):

"Despite the number of people living with dementia, and the associated costs, numerous reports from the National Audit Office (NAO, 2007; 2010), Public Accounts Committee, regulators, NHS Atlas of variation (NHS Right Care, 2011) and Alzheimer's Society show that many people with dementia are being let down. Despite the significant spend on dementia, this is not being developed effectively and too many people are not provided with good quality care and support that meets their needs and aspirations. Furthermore, the quality of care varies considerably across geographical areas."

Perhaps partly in response to the slow progress that was being made 2012 saw an unprecedented intervention by the Prime Minister when he announced his *Challenge on dementia* (Department of Health, 2012) at a conference organised by the Alzheimer's Society (at which several people with dementia spoke). In addition to providing more funding for research and an on-going focus on improving health and social care services, of particular significance was his announcement about creating 'dementia friendly communities' (DFCs) through

working with local communities and a range of organisations, services and businesses who have contact with people with dementia and their families. It is generally agreed that the process of building DFCs must include people with dementia and several DFC projects have demonstrated this inclusive approach (e.g. JRF's 'York Dementia Without Walls', Innovations in Dementia's work for the Local Government Association *Ageing Well* Programme). As the Alzheimer's Society puts it:

"dementia is now a public and political priority in a way that it has never been before." (Alzheimer's Society, 2012)

Empowerment and dementia

It is now widely acknowledged that the direct engagement of people with illnesses and disabilities is of immense benefit in terms of both outcomes for the individual and for service and policy development. The involvement of people with illnesses and disabilities in having an active role in the care, treatment and support they receive has a history that goes back over 40 years. There is extensive literature on both the theory and practice of involvement and some of this is summarised in the literature review published separately, particularly in relation to the focus of DEEP. This also summarises recent literature and guidance specifically focusing on the involvement of people with dementia. However, to provide some background to DEEP and the wider context of the involvement of people with dementia in the UK it is worth making some general observations.

Defining involvement - purpose

It is widely recognised and accepted, in the UK and elsewhere, that the voice and experience of people in receipt of health and social care services should be listened to. Clearly, it would be impossible to deliver these services if there wasn't some form of interaction and communication between the person using the services and the member of staff providing it. However, for a number of reasons 'service user' involvement has expanded rapidly since the 1960s. The reasons for this are complex and multi-dimensional but include the rise of consumer power, the civil rights movement, public scandals about institutional care, and the recognition that outcomes for both services users and providers could be improved through service users having a greater voice.

Although there is no consistent approach to involvement and engagement from area to area, or across organisations, it is now commonplace in the UK, and has been supported by a number of Government policies, such as the Department of Health's Expert Patient Programme. The Coalition Government has recently indicated its commitment to involvement with its use of the campaigning slogan (taken from the learning disabilities movement), "*nothing about me, without me*".

Defining involvement – nature and degree

The concept of involvement whereby the defining character of the groups affected is a common illness, disability or condition can be viewed in different ways. One useful typology is provided by Crepaz-Keay & Haywood (Mental Health Foundation/OLM-Pavilion, 2009). This divides involvement into three levels:

- Participation in one's own individual care and treatment. Examples of this include:
 - Being able to exercise genuine choice over the care and treatment provided;
 - Being an active participant in health and social care processes for planning one's own care and treatment.

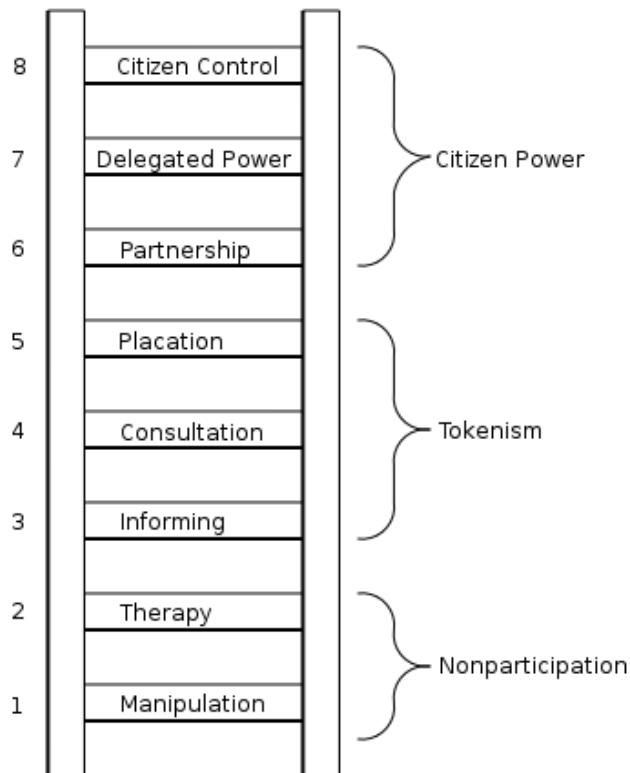
- Participation in the planning, design, and delivery of services that one is using. Examples of this include:
 - Being involved in service planning and evaluation by having a role on committees, steering and advisory groups, and evaluation processes;
 - Having a role in interviewing and training staff.

- Participation in the broader strategic and policy environment. Examples of this include:
 - Having a role on government working parties and meeting with policy makers;
 - Speaking at national conferences.

However, in all three categories the degree of involvement can also vary. This can range from no or only tokenistic involvement, through to care services and other activities entirely led and controlled by people with disabilities and illnesses

(although this does not happen in the broader strategic and policy environment). A useful way of viewing this is Arnstein's 'ladder of participation' (Arnstein, 1969). This is shown in Diagram 1.

Diagram 1



The ladder is a simple representation of degrees of participation in decision-making where there are groups or organisations with power and those without power. The ladder starts with non-participation at the bottom (whereby strategies are used to exclude groups from power) through levels of 'tokenism' where the voices of citizens may be heard but not necessarily acted on, through to active participation involving partnerships and full citizen control at the top. Although based upon a particular view of power dynamics in society and not specifically designed for health and social care services, the ladder does provide a useful way of understanding the degree of influence that people may have (or be permitted) both in their own individual care and in more collective activities that seek to engage services and policies.

However, a critique of the ladder is that it suggests that the lower 'rungs' are not authentic involvement and that there is a hierarchy of participation with full citizen control as being the ultimate and therefore the most desirable level to achieve.

This may not be what people always want or be a level they feel able to operate at, or what is most effective for bringing about the desired change (particularly where large, well established organisations are responsible for the delivery of services or policies).

Another way of looking at involvement which overcomes the hierarchical critique of Arnstein is to view it as a spectrum or 'continuum' without implying any hierarchy or need to move through a process. This allows people to use an approach or 'grow' involvement in a dynamic process that best suits their particular needs, the resources they have, their relationship with services, the time and place they operate in, and how much they want to be defined / involved as 'service users'. This approach has been put forward by Marsh and Macalpine, (Marsh & Macalpine, 1995) and can be framed in terms of both professionals and users, as shown in Diagram 2.

Diagram 2

Approach	Professionals giving users information	Professionals encouraging users to voice their concerns	Professionals re-planning the service to improve users' experiences	Professionals eliciting users' views and feeding the information into re-planning	Users having a real input into the design and planning of the service	Users defining needs
Typical actions	Professionals lead	Consumerism	Using information access, choice, redress	Actively seeking views from individuals and groups, and showing how information was used	Users alongside professionals in decision-making	Users drive whole process

However, Arnstein's use of the term 'citizen' reminds us that people with illnesses and disabilities are not just 'service users', 'patients' or 'clients' of services but are also members of communities and citizens in the societies they live in, with the same rights, entitlements and responsibilities as others (including the right not to be defined in relationship to the service they use just because of having a diagnosis). This raises the wider issue of the types of challenges and supports

that exist for people with illnesses and disabilities to participate and influence generic services, policies and organisations that affect everyone's lives such as neighbourhood development and regeneration, housing, community safety, transport, arts and leisure. A straightforward link can be made with the current focus on 'dementia-friendly' communities but the issues go well beyond this because it takes dementia out of the sphere of medicine and care, into the wider arena of social citizenship, rights, and status (a journey that for example, learning disabilities has been on for many years). Building on the seminal work of Tom Kitwood (Kitwood, 2007) focusing on personhood, this approach has been taken forward by others such as the work of Bartlett and O'Connor (Bartlett & O'Connor, 2010).

Involvement and dementia

Unlike 'functional' mental health problems or other long-term disabilities and conditions, the history of involvement in the field of dementia in the UK is less developed and has a shorter time span. There are a number of possible reasons for this which perhaps reflects certain unique aspects of dementia as a health condition:

- Until very recently dementia had little attention paid to it at policy level, and a lack of investment therefore in developing opportunities for participation and involvement.
- The organic, progressive nature of dementia, combined with late or no diagnosis and the impact that it has on communication, cognitive abilities, and decision-making (mental capacity) meant that it was either seen to be too difficult or too late to get people's views and involvement (or their views were disregarded/unvalued for the same reason).
- There has been little controversy about the nature of dementia as an illness (as compared with schizophrenia, for example), nor has it attracted so much debate (until recently) about stigma and discrimination that other mental illnesses, physical or learning disabilities have, because it has been a fairly invisible illness in society.
- It mainly affects an older population which historically has not been so closely associated with the activism and campaigning of the generation that followed them.
- The lack of a cure or universally effective treatment, and limited services has meant that many people with dementia have had to manage for a number of years with little or no support from health or social care services (apart from the voluntary sector), especially in the earlier to middle stages of

the condition. Isolated from both communities and services people may not relate to the language of 'user involvement', or engage with its activities.

- A relatively strong, well developed carers' movement which, partly because of the nature of dementia, often spoke on behalf of people with dementia, as well as in respect of their own issues.

Nevertheless, over the last ten years the situation has changed significantly. This is probably for several reasons:

- Increased numbers of people being diagnosed early, enabling a number of them to be more active in communities and speak out more (including people who were active in their communities prior to being diagnosed and/or held positions of influence in work).
- The much higher profile that dementia has in society and the priority given to it by Governments across the UK – this has included recognition of the importance of involving people with dementia (see for example, Alzheimer's Disease International, 2003, Care Services Improvement Partnership, 2007, Strengthening the involvement of people with dementia, CSIP, 2007, and working papers on involvement from Alzheimer Europe).
- Voluntary sector organisations enabling people with dementia to have a greater say in their activities (see below).
- (Arguably) a more inclusive and less discriminatory approach to people with long term conditions and disabilities by mainstream society.
- The suggestion that the post-war generation (the so-called 'baby boomers') include many who are more active as citizens and consumers, and more vocal about services they receive, either as someone with early onset dementia or as carers for older relatives with dementia. (Mental Health Foundation, 2012).

This has led to a very significant growth in the involvement and participation of people with dementia in a range of activities, over and above the actual care and treatment they may be receiving for their illness. At a national level there are two notable examples. The Scottish Dementia Working Group (SDWG), an independently constituted group of people living with dementia but supported by Alzheimer's Scotland, has been actively campaigning to improve services for people with dementia and to improve attitudes towards people with dementia over several years. In England, Wales and Northern Ireland the Alzheimer's Society has had its own Living with Dementia Programme that has included the Living With Dementia Group (LWDG), made up of people with dementia, for a number of years.

Members of both groups participated in two conventions held in 2005 and 2006 in Newcastle and Birmingham where people with dementia from across the UK, supported by family members, friends and staff, came together to meet and share experiences. They also played an active role in the development of Scottish and English national dementia strategies and in addition to this the SDWG contributed to a successful campaign for the introduction of a Charter for People with Dementia and Family Carers (Cross-Party Group on Alzheimer's, Scottish Parliament, 2009). Although the LWDG in England has been less active in recent years individual members have continued to play an important role in the development of national policies and strategies. In 2010 the Department of Health in England organised a 'think tank' event, facilitated by the community interest company, Innovations in Dementia, involving people with dementia and a number of organisations with an interest in this work to explore options for supporting the development of stronger, independent representation of people with dementia. This concluded (Innovations in Dementia, 2010) by making the following recommendation to the Department of Health (which to date has not been implemented):

"DH could resource an independent project that facilitates a network of local, regional and national dementia user-led organisations by:

- *Mapping existing dementia user-led organisations. Supporting the networking of those organisations through events and web-based networking;*
- *Providing administrative support that will support the launch of the network of dementia user-led organisations and that will develop sustainable organisational and financial models for the network;*
- *Resourcing the development of a 'dementia academy' that equips people through training and support to take on engagement roles e.g. through a series of best practice seminars."*

The number of groups of people with dementia coming together at a national level has also been reflected by a growing number of initiatives at a local and regional level in the UK. At the same time there has been a growing presence of people with dementia at events and conferences, such as the annual UK Dementia Congress.

Anecdotally, it seems that these different groups have been involved in a variety of activities including:

- raising awareness about dementia by giving interviews, talks and presentations about dementia to the media, health and social care practitioners, students and the general public presentations and raising public awareness;
- lobbying politicians, policy makers and service providers about policies and services for people with dementia;
- participating on advisory groups, committees, and consultative bodies responsible for planning, delivering and evaluating services for people with dementia;
- participating in research and evaluation projects; and
- Developing and sharing experiences and information through face-to-face meetings, online discussions, etc. with other people with dementia.

Despite the growing activity involving initiatives led by or actively engaging people with dementia it has proved difficult to develop and sustain any form of national network of groups involving people with dementia doing these kinds of activities. This perhaps reflects the early phases of a 'movement' of people with a common cause or condition. The LWDG members played a very active role in the development of the National Dementia Strategy, group members and individuals sitting on its working parties. The group became less active as the National Strategy for England has been implemented whilst the Alzheimer's Society has tried to focus on supporting more involvement and participation by people with dementia at local and regional levels. An example of this approach is the development of local Service User Review Panels which facilitate involvement of people with dementia in influencing national pieces of work without the requirement to travel great distances to participate. Although the Scottish Dementia Working Group has continued to thrive, this has been the exception; there has been no equivalent in Wales or Northern Ireland.

At local and regional levels it has been known that there are examples of initiatives and groups where people with dementia have been actively involved in influencing services and policies. But there has also been a lack of comprehensive and reliable information about the different groups that do exist – where they are, who is involved, how they are supported, what they do, how they have developed, what challenges they have faced, their achievements, and their aspirations for the future. In the absence of an independent national network or information it is very difficult to share learning and support the development of further activities and initiatives that enable people living with dementia to take more control over their lives, and the care and support they receive.

Overview of the Dementia Engagement & Empowerment Project (DEEP)

Aims, objectives and outputs

It was against this backdrop that representatives from two charities, the Mental Health Foundation and the Alzheimer's Society in England, and a Community Interest Company, Innovations in Dementia, came together in December 2010 to discuss how they might collaborate on a piece of work to investigate, support, promote and celebrate the various initiatives and groups around the UK that were led by or actively involved people with dementia influencing services and policies.

The Mental Health Foundation had a significant track record of involving people with dementia in research projects it had undertaken as well as a wider commitment to the proper participation of people with other disabilities and illnesses in other work it did. It had recently supported the establishment of the National Survivor User Network (NSUN), an independent network of grassroots organisations led by people with mental health problems [1], and supported a similar network, Voices of Experience (VOX) in Scotland. A key focus of Innovations in Dementia's work was active consultation and involvement with people with dementia and its Directors included individuals who had co-ordinated the LWVG so there was extensive expertise and experience brought to the potential collaboration (see Appendix B for brief summaries of each organisation).

Also involved at this stage was the Joseph Rowntree Foundation (JRF) who were looking to pilot work in the field of dementia with a view to developing a more extensive programme based upon the learning that was gained from this. With its strong emphasis on rights, citizenship, and active involvement in communities by marginalised groups, JRF were keen to explore the potential that the collaboration offered and in February 2011 agreed to fund the Dementia Engagement and Empowerment Project (DEEP).

Aims

The aims of DEEP were as follows:

- To identify initiatives, groups and activities led by, or actively involving people living with dementia that aim to enable people with dementia to have more control over their own lives.
- To develop the capability and potential of people living with dementia in leading and managing initiatives relating to the care and support they receive, policy and service development, their rights as citizens, and the perception and understanding of dementia in the wider society.
- To help plan a process to support the development of a UK network of initiatives, groups and activities led by people with dementia or with their active involvement and participation.

Underpinning these aims were the following objectives:

- To map out what was happening in terms of initiatives, groups and activities led by people with dementia, or with their active engagement and involvement, in the UK and internationally, including comparisons with other disability/long-term conditions groups.
- To 'model' good practice by supporting people with dementia to help plan and participate in the mapping activity and a national event highlighting key messages, and examples of good practice in leadership and involvement of people with dementia.
- To use the mapping exercise, event and on-going involvement of people with dementia to establish a clear plan for taking work forward for an independent UK network of initiatives, groups and activities led by or actively involving people living with dementia.

Based upon these aims and objectives the following outputs were planned.

- A review of the literature.
- A report of the mapping exercise and involvement of people living with dementia in the project itself, that would include a description of the project process, details of all initiatives, groups and activities contacted, key themes around good practice, lessons learned, types of support needed, views on a national network, and recommendations for taking the work forward. This would also include a brief written summary of proceedings/decisions / plans from the national event about the ways in

which people living with dementia and the organisations involved in the project could work together to support the further development of an independent UK network of initiatives, groups and activities led by or actively involving people living with dementia.

- A one-day national event with a programme planned by and featuring people living with dementia as both keynote speakers and active participants in other activities on the day.
- A film consisting of views and experiences of people living with dementia about initiatives, activities and groups involving or led by people with dementia – collected through the mapping exercise, and footage from the national event.
- An accessible summary.

Project activity and management

DEEP consisted of three activities:

- on-going involvement of people living with dementia;
- a mapping survey and literature review (Stage 1); and
- a national event (Stage 2).

The project was underpinned by four key principles that all the organisations and key individuals involved agreed on:

- *Involvement and influence* – enabling people with dementia to influence and be involved in how the project evolved.
- *Iteration* – taking an iterative approach by which the project could develop as it went along, according to what was being said and learnt from people with dementia who it came into contact with.
- *Inclusivity* – ensuring that the project didn't create criteria for involvement that excluded people with dementia, either as individuals or groups, which were interested in being involved.
- *Into the future* – recognising that the involvement of people with dementia in the kinds of activities the project was exploring was still at a developmental stage and that the project should explore ways of promoting and supporting that involvement beyond the project's lifetime.

These guided the work and reinforced the collaborative approach. More details on the principles can be found in Appendix C.

Project Steering Group

A Project Steering Group was established which included representatives from the:

- Mental Health Foundation;
- Alzheimer's Society;
- Innovations in Dementia;
- National Dementia Strategy Implementation Team, Department of Health (although the closure of most of this team in March 2011 meant that this representation could not be sustained); and
- Joseph Rowntree Foundation.

Dr. Ruth Bartlett from the Bradford Dementia Group at Bradford University was invited onto the Steering Group because of her research expertise in this field. During the course of the project she moved to a post at Southampton University but remained involved.

The role of the Group was to oversee, help co-ordinate and steer the project, receive regular updates on progress, help address any problems or obstacles that might arise, and provide a clear line of accountability for the project to the funder.

For a project about leadership and active involvement by people with dementia it may appear odd that no-one with dementia was represented on the Steering Group. However, with the exception of the SDWG, there was no national body representing people with dementia from which people could be invited to join the group. It was also thought that through the activities of DEEP, as well as Innovations in Dementia liaising regularly with an extended 'virtual' reference groups network of people with dementia (see below) involved in local and regional activities, there would be a number of opportunities for people with dementia to influence and steer the project without having to attend the steering group. This also avoided any issues about which people with dementia would be selected. It was also felt important not to present DEEP as 'the network' of groups involving people with dementia – its purpose was more exploratory than this to enable people with dementia to define what, if at all, that network might look like. Had the Steering Group appeared as if it was steering the network this could inhibit or skew other views and ideas that people with dementia may have.

However, this did make it difficult at times to explain DEEP to the individuals and groups it came into contact with. The involvement of organisations that were not led by people with dementia meant that reassurance had to be given that DEEP was genuinely being driven by the agenda as it emerged from individuals and groups it had contact with, as opposed to corporate agendas of one or more of the collaborating organisations. Some confusion also arose initially about DEEP being an initiative or network that was led by and involving people with dementia in its own right. It was encouraging that DEEP did develop an identity of its own, separate from the collaborating organisations, but this had to be qualified and explained in terms of the relatively short life span of the project and that it represented a vehicle to support the development of a network, rather than the network itself. In this respect it represented a possible 'change agent' project, the potential of which would only be realised if this was what people with dementia wanted.

On-going involvement of people living with dementia

In keeping with the underlying principles of DEEP it was essential that the project should involve and include people with dementia in how it developed.

The original DEEP proposal that was submitted to the JRF for funding was developed in consultation and with the support of individuals and groups of people living with dementia, including the Scottish Dementia Working Group. This was important in advising and validating the approach and overall structure of what the project aimed to do.

As the Steering Group did not have anyone with dementia on it, it was vital to ensure the on-going involvement of people living with dementia throughout the project through other means. To do this, an extended Reference Group Network, made up of people living with dementia, was established and supported by Innovations in Dementia. This included a number of individuals and groups already known to Innovations in Dementia (iD) and through other DEEP contacts but it also had the capacity to expand as the project progressed. 'Network' denoted that the group was 'virtual' and consideration was given to providing it with an online presence (e.g. Facebook page). Members of the network were consulted about this at an early stage but it was felt that regular communication and updates via iD would be sufficient to keep them involved and consulted. iD updated members of the reference group after every Steering Group meeting and by midway through the project there were five groups contributing to the network as well as several individuals.

The role of the network in Stage 1 of the project was to inform the mapping exercise; help shape the questions and approach taken (including definitions of 'involvement', 'leadership', etc.); provide information about their own initiatives, activities and groups as well as others known to the network; help promote and disseminate information about the project and put the project in contact with others. This proved to be crucial in developing the questionnaire that formed part of the survey – three groups and eight individuals agreed to complete the draft questionnaire and provide feedback. This consultation resulted in significant changes being made to the questionnaire including:

- Giving groups the option of completing a short questionnaire about their activities or, if they had time, a much more detailed questionnaire about the group.
- Amending the questions to take into account the diversity of activities the groups were involved with.
- Developing a questionnaire for individuals with dementia who were not involved with a group or wanted to describe their own activities even if they were part of a group.

The network also took a lead in shaping the national events in Stage 2. Groups who had experience of attending events in the past were consulted about aspects of designing and running events. These ranged from the length and make up of presentations to having clear instructions and people to help and the importance of food.

Working with a network of groups and individuals allowed the project to access a range of expertise and experiences for information, views, advice and guidance. A key reason for working with a reference group network rather than separate groups was to avoid limiting involvement to those people who are able to travel to and take part in central meetings. Therefore, we took the approach of 'going to them' rather than expecting 'them to come to the project'.

We involved some national groups (such as SDWG), held some local and regional meetings with groups, initiatives or activities involving or led by people with dementia (for example, EDUCATE in Stockport and the Forget Me Not group in Swindon), and also attempted to include organisations working with seldom heard groups, e.g. people with more severe dementia in care homes or from Black, Asian and minority ethnic communities.

In addition to meetings with groups and individuals, the project produced a regular printed 'reference group network update' about how the project was developing. A simple and short format was used covering 'what's been happening', 'what's next' and ways in which the project needed feedback on particular issues.

'Membership' of the network evolved as groups and individuals with dementia engaged in the project. Respondents to the questionnaires who had asked to be kept in touch with the project were added to the mailing list to receive the printed update. Over 30 new groups or individuals were added to the list. In addition several groups (the Hope group in Brighton, and Open Doors in Salford) were visited and views collected (including where relevant, comments were made in face-to-face interviews that formed part of the DEEP survey).

The reference group network was by definition an informal and loose association of individuals and groups, which acted as a sounding board for the project. By taking this approach we enabled many people with dementia to be involved in the project as possible with the time and resources we had. This approach was particularly effective for gaining feedback about the questionnaire design and how the event(s) should be run. In addition, this approach allowed the project to collect rich data about the experiences of people with dementia in different groups. Many of the people we engaged with would not have been willing and/or able to attend a formal reference group meeting for a variety of different reasons.

However, this approach has its drawbacks. It is difficult to ensure that people felt that they had a key role to play in the project generally outside specific activities (such as questionnaire design). However, this was also due to the nature of the project which was a difficult concept to explain. If the project was longer and had more resources it would have been good to have linked the groups together more with each other directly – the links were via organisations managing the project. We aimed to grow the network as the project developed. It proved difficult with the time available to do more than keep people informed about the project. It was difficult to ascertain how effective the update was in engaging people with dementia in the project; although it informed them of progress, there was little response to requests for feedback. The more proactive approach of visiting different groups and individuals was naturally more effective.

It is also worth noting that iD discussed with members of the reference group their role in relation to the project Steering Group. Members of the reference group indicated they were comfortable with a loose, inclusive approach rather

than a more formalised one. None of the groups wanted to participate formally in the Steering Group, preferring to retain their energy and focus on local activities and/or their own priorities. Asking members of the reference group to assist with tangible tasks (e.g. piloting the questionnaire, helping plan the national events) was felt to be the most useful way of engaging with them.

The mapping survey – methodology and findings

The aim of Stage 1 was to identify and map out initiatives, activities and groups led by people with dementia, or with their active engagement and involvement. This involved the following components:

- literature review;
- mapping questionnaire; and
- follow-up interviews.

Literature review

A desktop literature search was carried out of studies, reports, and guidance (Including international examples) relating to the involvement of people with dementia in activities or groups influencing services and policies.

Information was also gathered about user-led initiatives and user involvement in other disability/long term conditions groups through a brief literature search in order to highlight useful learning and relevant guidance that could help shape and support DEEP and groups it had contact with. A number of service user-led organisations that do not have a specific dementia focus were contacted through the mapping survey for this purpose to provide opportunities to link with non-condition specific organisations.

As might be expected, there was a very extensive literature on this wider field of service user involvement and leadership and because of time and resource limitations this part of the mapping had to be restricted to identifying a small number of examples to illustrate key learning. It was not possible to analyse the information in great detail but it was useful in flagging up key issues relevant to DEEP. The review is being published separately (see www.mentalhealth.org.uk/publications/).

Mapping questionnaire

A fundamental part of DEEP was to collect as much information as possible about as many groups led by or actively involving people with dementia who were trying to influence services and policies. Because no such survey had been done before in the field of dementia there was no template for a successful methodology or survey design. Furthermore, DEEP was in a situation of 'not

knowing what it didn't know about' i.e. there could be a number of groups and projects involving people with dementia at local levels which none of the organisations collaborating on DEEP knew about but which should be included in the survey if possible. It was agreed at the beginning that a mapping questionnaire be designed and disseminated to collect information on the basis of the following criteria:

- It needed to be designed and written in a way that was accessible to people with dementia who had the capacity and ability to complete it. It therefore needed to collect information through different mediums e.g. online, hard copy, being read out and someone else filling it in, completed by doing a telephone interview, even just as a prompt to encourage groups to send in leaflets about what they did.
- It should also be designed so that supporters of groups (e.g. staff) could complete it on behalf of a group, but that a testimony or witness statement should be included from people with dementia endorsing this.
- It needed to make clear what kind of groups and activities it was asking about and that it was not asking for information about people with dementia being involved in their own care or treatment – important though that was, it was not the focus of DEEP.
- It should be used to cascade on to other groups as widely as possible.
- It needed to invite and encourage groups to get more involved with DEEP.
- It did not require ethical approval because it was information gathering on groups, projects and activities, and not on individuals' care and treatment.
- It should offer a way of publicising what groups did, providing they gave permission for this, but also emphasise confidentiality for respondents who wanted this.
- It should have some key questions to answer, even if groups / individuals weren't able to answer the whole questionnaire (e.g. about the leadership/involvement of the group by people with dementia, etc.).
- It should also collect information about relevant literature and guidance.
- It should ask for people's views about a possible national network of groups and projects involving people with dementia.
- As questionnaires were returned an online map of the UK should be set up on the Mental Health Foundation DEEP webpage that would be populated with groups and projects that responded.
- It should include information to assist people who needed help or became distressed (this involved directing them to the Alzheimer's Society helpline).

A draft questionnaire for groups was developed but before it was piloted it was agreed also to develop a questionnaire for *individuals* with dementia who were involved in influencing and campaigning work. This was in recognition that the Living with Dementia Group was not operating as a collective body but a number of individuals associated with it, but not necessarily involved with other groups, were still active in doing this kind of work. It was felt that some individuals who were actively involved with groups might also want to complete a questionnaire about what they were doing personally.

Development and piloting phase

The questionnaires were piloted with five groups and eight individuals. Some were sent the questionnaires, but staff from iD spoke with two groups and five individuals (both face to face and over the phone) to talk people through the questionnaires. This proved crucial in helping to shape the final design for the survey. The questionnaire provoked much good debate and conversation among the groups themselves – this was positive but also generated a number of issues, as outlined below. The key themes that emerged from this piloting phase were summarised in a report from iD as follows:

- The questionnaire was too long.
- The tone of the questionnaire was too challenging, suggesting through the examples that this is what was considered to be ‘good involvement’. There was the risk of alienating both groups, and staff supporting them, by appearing to be evaluating their service.
- There is a balance in many groups between ‘therapy / support’, social activities and enjoyment, and influencing policy activities. It was felt important that the questionnaire could accommodate this mix.
- For some individuals there was a feeling that their local groups could be doing (or used to do) more – it was felt important to collect information about expectations and wishes.

As a result of these comments the following changes were made to the questionnaires:

- It was decided to have a choice of two questionnaires for groups and organisations to complete. One was designed as a very short questionnaire with mainly multiple choice answers to enable it to be easy to understand and complete. The questions focused on gathering basic contact information about the group or project, what it did, and how people with

dementia were actively involved in it. The second questionnaire was more detailed with a number of open text questions in order to gather more information about the group or project. Anyone completing the short questionnaire was encouraged to go on and complete the longer questionnaire but it was emphasised that there was no obligation to do so.

-
- The preamble to all the questionnaires was altered to include the following:
 - Shortening and simplifying the introductory section as well some of the questions asking for more complex information.
 - A very 'upbeat' opening to encourage people to participate and use it as an opportunity to promote and celebrate their group or project.
 - Emphasising that it was recognised that leadership and active involvement could take many shapes and forms and the intention of the survey was not to evaluate or compare activities but simply to gather information on the potential diversity that existed.
 - Information about DEEP and encouraging groups and projects to become more involved if they wanted to (e.g. through the Reference Group) but also to promote and disseminate the survey to others ('cascading').

All three questionnaires are reproduced in an appendix in the report available on the Mental Health Foundation website (www.mentalhealth.org.uk/publications/).

Launch of survey

The three questionnaires were launched on 11 August 2011 and it was agreed to keep the survey open until October 2011 in order to allow for people with dementia to have time to participate in it, as well as for it to be cascaded as widely as possible. The launch included a press release and information sent out to a wide variety of organisations in both the statutory and non-statutory sectors, with national and local, with a dementia focus or with a wider service user / citizen involvement and empowerment focus (see Table 1 below). A large number of organisations had extensive networks through their memberships, having local and regional offices, or by being umbrella bodies so they were actively encouraged to 'cascade' the questionnaire via these networks. The questionnaires were available to complete either in hard copy or electronically (through Survey Monkey).

At the beginning of October a follow up reminder was sent out to encourage more respondents (although the response rate had already been good). Particular attention was paid to encouraging responses from organisations representing 'seldom heard' groups (e.g. Black, Asian and minority ethnic groups) to try and ensure that the voice of people with dementia from these groups was not missed.

Table 1

Questionnaire sent to contacts by type of organisation	Number
Not for profit dementia organisations e.g. Alzheimer's Society, Dementia UK	33
Generic not for profit organisations e.g. Age UK, National Service User Network	39
Statutory sector contacts	33
Academic organisations	18
'For profit' organisations e.g. care providers	6
Registered Social Landlords e.g. Housing 21, Anchor	5
Individual contacts	20
Others	8
Total	162

Follow up group interviews

Respondents were asked to indicate if they would be willing to participate in a follow up interview either as part of a group or as an individual. This enabled more in depth information gathering with individuals and groups in a range of settings to collect a lot more detail about initiatives led by/involving people living

with dementia. Face-to-face group interviews took place with the following groups:

- EDUCATE, Stockport;
- Hope Group, Brighton;
- Open Doors, Salford;
- Scottish Dementia Working Group; and
- Torbay Dementia Leadership Group.

Telephone interviews were carried out with 15 other groups and projects identified as clearly indicating active involvement of people with dementia, through the more detailed survey. These were undertaken by staff from Innovations in Dementia and the Mental Health Foundation through face-to-face meetings/discussions and follow-up telephone interviews. These used questions based upon an agreed interview schedule – these are contained in the transcript of one interview which is reproduced in an appendix in the report available on the Mental Health Foundation website (www.mentalhealth.org.uk/publications/). Not all the interviews were recorded so the analysis also drew on the interviewer's notes.

At all stages of the survey the emphasis was firmly placed on the views and experiences of people living with dementia who had been involved in the initiatives, activities and groups that the mapping exercise and reference group network identified and included as being the primary source of information. However, it was also recognised that staff, family carers and volunteers who are part of organisations supporting these initiatives may well also be important sources of information and that it would not be excluded for that reason alone, providing it was a genuine representation of the initiatives that people with dementia who were involved could recognise and endorse (a section on the questionnaires was included specifically for people with dementia to endorse what had been written).

Analysis and findings from the survey are contained in the next section.

Use of film and still photography to collect information

To enable people living with dementia to contribute to both the mapping exercise and the reference group network some interviews and meetings were also recorded on film and in still life photography. Not only did this help with the collection of information but it also ensured that participants' views could feature

in the films made at the national events even if they were unable to attend in person. It had been planned to show some of these clips at the national events but this did not prove possible. However still photography involving both a digital camera and a Polaroid Instamatic was used very successfully (and allowed the pictures to be shown on the same day at the event).

DEEP also commissioned a film company, Salmagundi Films, to film the national events (see below) and produce a five-minute 'taster' film for use in conference presentations etc. together with a longer film (15-20 minutes) for training use by groups of people with dementia etc. The intention is that the films will also be available on the websites of the collaborating organisations, and DVDs containing the films, together with other footage will be distributed to all the groups that featured in them.

The full and explicit consent of participants to be filmed at the events was obtained.

Analysis of results

This section presents a summary of the *key findings* from the three survey questionnaires, (hereafter referred to as the 'surveys'). These findings are supported by data tables available in an appendix to the report available on the Mental Health Foundation website (www.mentalhealth.org.uk/publications/). Also included in an appendix to that report is virtually the full transcript of the group interview carried out with members of the Scottish Dementia Working Group. It is reproduced in full (with the group's permission) because it illustrates very well both the personal journeys of people with dementia but also the development, achievements and challenges of the largest and most long-standing national group led by people with dementia.

As the short survey is an abbreviated version of the main survey, short and main survey results are presented together. The results of the individual survey are then described separately. The findings are supplemented by information gathered in the pilot stage and follow up interviews.

Responses to the different stages included:

- Seven individuals and three groups were involved in the piloting phase and their responses are included in this report but not in the statistical findings from the surveys.

- Fifty short survey responses and 32 main survey responses are included in the detailed analysis (82 responses in total), together with fifteen individual responses.
- Thirteen follow-up telephone interviews and three face-to-face group interviews.

Methodological note

Responses to the survey came from a wide variety of sources. Despite the focus of the questionnaire being on groups actively involving or led by people with dementia that were seeking to influence services and policies, a detailed analysis of the main survey results (not the short survey because the responses had insufficient detail) indicated that this focus had been liberally interpreted. Several service providers and groups focused primarily on carers had also responded. In some responses the active involvement of carers appeared to be presented as an appropriate proxy for the involvement of people with dementia which was not the focus of the survey and cannot really be defined as the involvement of people with dementia. Some service providers were trying to involve people with dementia in having more say over the service that they were using. Again, this was not the focus of the survey but it was felt important to acknowledge these activities as positive efforts to support people with dementia to at least have a say over the service they were using. Furthermore, several groups that actively involved people with dementia were time limited projects, and others were only at the stage of *aspiring* to do this in the future. Table 2 below summarises the breakdown of respondents from this analysis, including additional information obtained through the pilot and follow up interviews.

Table 2

Please note: groups and projects were placed in one category only although all ten of the groups / projects where there was leadership by people with dementia also had active involvement of people with dementia.

Leadership and / or active involvement of people with dementia in the group / project?	Number of groups / projects
Yes, leadership	10
Yes, active involvement in 'influencing' type activities	7
Yes, leadership / active involvement but focused only on the service that people were using or time limited to a specific project	7
No	6
Not clear	10
Others (making plans for future leadership)	3

However, the inclusion of these groups means that some of the findings should be treated with caution and these are noted as appropriate, below.

Details of all the groups and projects that DEEP identified as being in the top two categories of Table 3 are included in Appendix D.

Short and main survey results

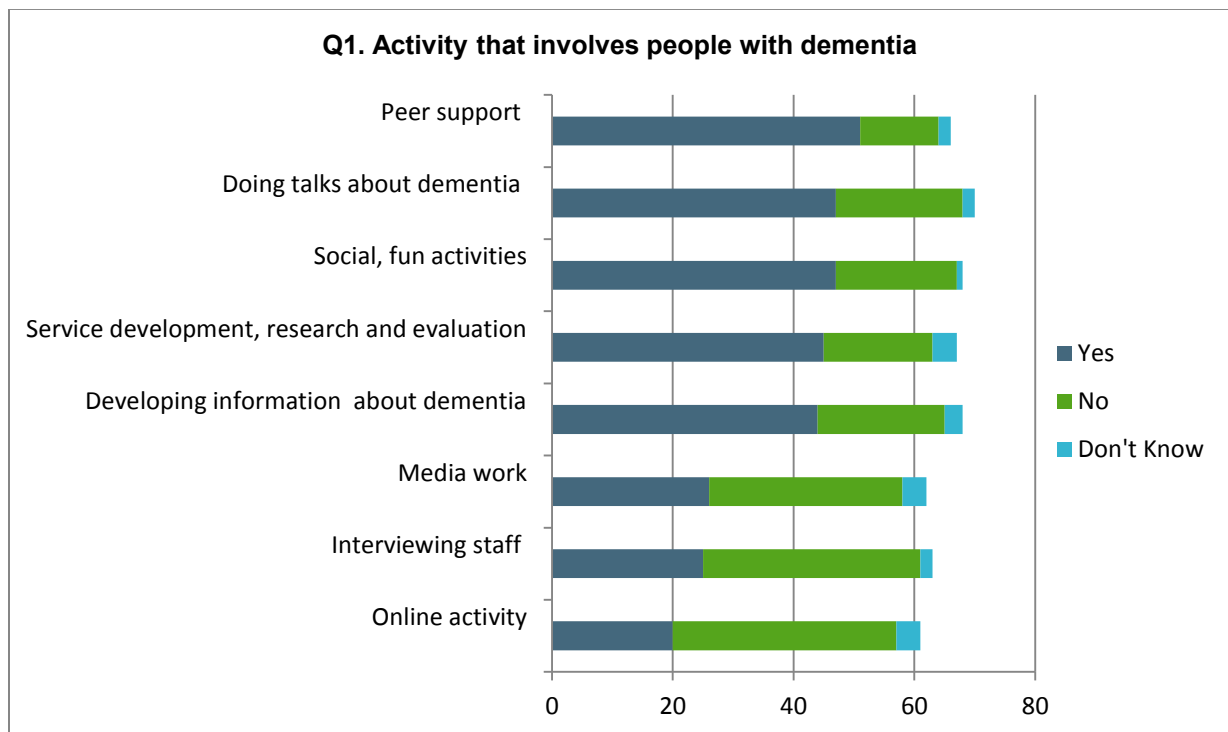
Where were the groups based?

56 of the responses were from projects in England (69.5 per cent of total responses), 5 (6.1 per cent) from Scotland, 5 (6.1 per cent) from Wales, and one (1.2 per cent) international response was also received. No responses were

received from Northern Ireland and 15 respondents did not state their geographical location.

Q1. What does the activity, group or project do that is led, managed or actively involves people with dementia?

Responders to the short survey and the main survey were both asked to list participatory activities involving people with dementia within their projects. They were given the same series of options to choose from, and the results for the two surveys together were combined and are presented below:



The most common type of participatory activity that people with dementia were reported to be involved in was meetings or advisory groups (n=53, 64.6 per cent of 82 total responders), followed by peer support (n=51, 62.2 per cent), social activities (n=47, 57.3 per cent) and doing talks about dementia (n=47, 57.3 per cent). Least common activities were online activity (n=20, 24.4 per cent) and interviewing staff (n=25, 30.5 per cent).

The involvement of people with dementia in interviewing staff is very much to be welcomed but without having further details of what this involvement actually meant it should be treated with caution.

It should also be noted that running roughly in parallel with DEEP were the 20 demonstrator sites for the peer support networks in England, set up under the National Dementia Strategy. Not all of these sites responded to the survey and they are being independently evaluated by researchers at Northumbria and Edinburgh Universities. The evaluation is not due to be completed until September 2012.

Advisory Group Involvement: Circles of Support for People with Dementia, Dorset

'The Advisory group has been established and the first meeting held, with a strong focus on ensuring that the voices and needs of people with dementia [are] being heard and guiding the project's direction... people with dementia on the Advisory Group have all been involved in planning and starting to implement the work.'

Peer Support: Dementia Advice and Peer Support Service, Trafford

'A number of peer support groups operate in venues across Trafford. We invite people with dementia and their family carers to come along, and the 'activities' of the group are guided by ideas, suggestions and feedback from participants. Generally, people with dementia are encouraged to support each other, engage in stimulating activities, and have an opportunity to have their voice heard.'

Seven organisations listed additional ways in which people with dementia were involved in activities. These comprised:

- development of DVDs/learning resources for staff training purposes;
- parliamentary work;
- commenting on policies and strategies, e.g. Review panels;
- speaking at conferences;
- delivering staff training; and
- giving views about services.

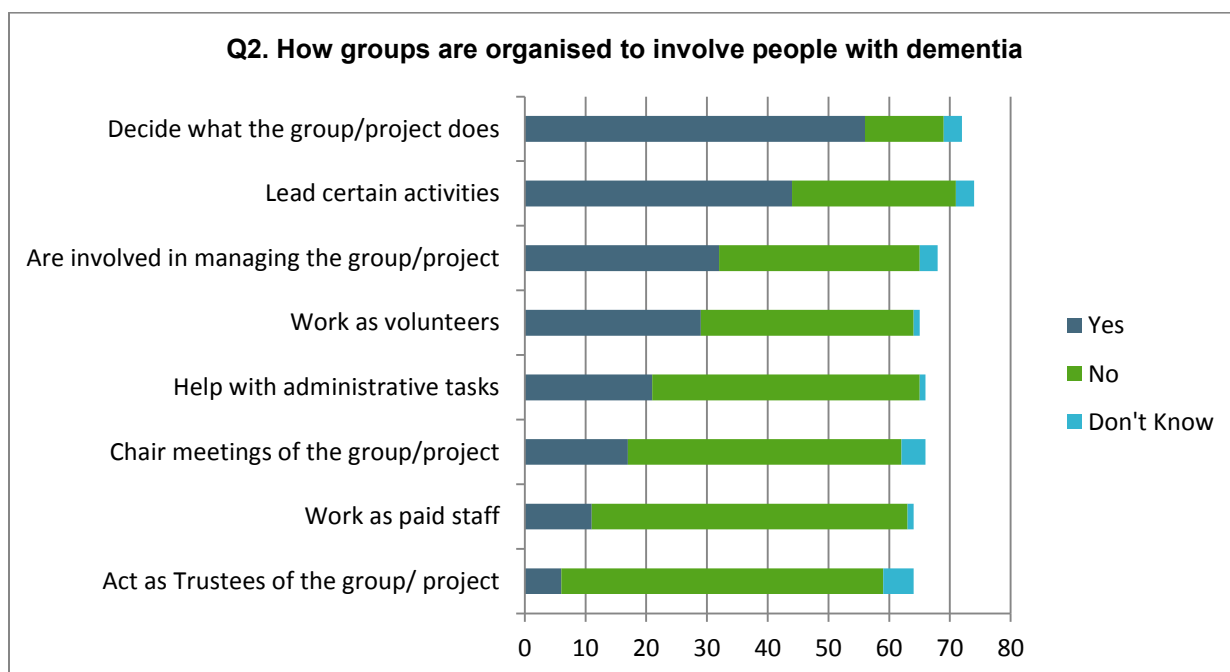
Discussion point – not setting the bar too high

In piloting the questionnaire one or two groups felt that the questions implied that people living with dementia should be actively involved in all activities but that this was not always possible or what was wanted in some groups. The questionnaires were amended for this reason but it raised the important point that

individuals and groups need to be accepting and inclusive of different types and levels of involvement – this helps groups not to feel there is a ‘hierarchy of empowerment’ or that what they are doing isn’t “good enough” but allows them to self-define involvement and participation (within some broad parameters) which is an important part of the empowerment process. It also provides groups with an opportunity to learn and develop from other groups doing different activities.

Q2. How is the activity, group or project organised so that it is led, managed or actively involves people with dementia?

Respondents to the short and main surveys were also asked to describe ways in which individuals with dementia were involved in the organisation of projects and groups (see Chart Q2 below):



The most common way in which people with dementia were reported as being involved in projects was deciding what the group or project did (n=56, 68.3 per cent of 82 total respondents), followed by leading certain activities (n=44, 53.7 per cent). The least common ways in which individuals with dementia were reported to be involved were acting as trustees (n=6, 7.3 per cent) and working as paid staff (n =11, 13.4 per cent).

The importance of good support and facilitation by staff was consistently emphasised in the group interviews. Key decisions were made by people living with dementia collectively – these formed the framework of the group’s activities which staff supported.

Discussion – people with dementia working as paid staff

The employment of people with dementia and their involvement as trustees of organisations is to be welcomed providing they are given the appropriate information and support to undertake these roles. However, in the main survey only one organisation was identified as employing a person with dementia as a paid member of staff so the figure of 11 projects where people with dementia worked as paid staff is a little surprising, particularly since only one organisation described this in more detail in the free text box in the questionnaire. It may be that the question was more widely interpreted as meaning any paid work (e.g. a sessional fee for someone with dementia to sit on an interview panel, attend an advisory group, or do a teaching session for staff). In one or two cases a very thorough analysis indicated that some respondents may have misinterpreted the question and thought it was simply asking if the project had paid staff or trustees in general. It would be of great interest to explore these issues further but without having more details these findings should be treated with caution.

Work as paid staff: Open Doors Support Network, Manchester

‘Successfully employing an individual with dementia [has been] a positive statement of our commitment and a symbol of hope for others newly diagnosed.’

Main survey results

About the projects

Respondents to the main survey (n=32) were asked a series of questions about the nature and structure of the projects they were describing (the full data tables are available in an appendix in the report available on the Mental Health Foundation website: www.mentalhealth.org.uk/publications/). A large proportion of the projects described had only very recently been set up; 15 (46.9 per cent) projects having been launched since 2010. The majority (n=22, 68.8 per cent) of projects described were part of a larger organisation such as the Alzheimer’s Society, Alzheimer Scotland, Age UK, NHS or local authority. They were also primarily supporting local communities, e.g. village, towns or cities (n=22, 68.8 per cent), rather than operating regionally, nationally or UK-wide.

Roughly half of the projects described (n=15, 46.9 per cent) were aimed at particular groups of people with dementia, such as those in the early stages,

younger people with dementia, individuals utilising specific NHS services, or specific minority ethnic groups such as South Asian people. The other half of the projects (n=16, 50.0 per cent) were aimed at people of any age with any type of dementia. However, the detailed analysis of groups identified none with a specific focus on people from 'seldom heard' groups.

The projects described tended to be small in scale, with 62.5 per cent (n=20) involving fewer than 20 people in total. However, it is worth highlighting that four large projects involving more than 100 people with dementia were also included in the sample.

Projects received funding from a wide variety of sources, with statutory (NHS and Local Authority) sources of funding dominating (n=16, 50.0 per cent), followed by voluntary sector funding (n=4, 12.4 per cent). Just under half (n=14, 43.8 per cent) received annual funding of more than £10,000 and one-third (n=10, 31.4 per cent) received less than this. The remaining eight projects did not answer this question. Funding was used for a mix of staff costs, travel, premises, activities and materials and refreshments.

To aid the participation of people with dementia, a range of different techniques and forms of support were employed within projects. These included:

- Using creative consultation methods such as photo-elicitation (using photography as research evidence) and walking interviews.
- Practical support such as covering expenses and arranging travel for participants.
- Staff and carers accompanying participants to meetings or providing guidance and facilitation where required e.g. taking notes, support in meetings, feeding back information and helping prioritise work.
- Thanking individuals for their participation and regularly recognising the value of their contributions.
- Getting the timing right of meetings, e.g. lunchtime so family carers can go off and have lunch together.
- Using a tape recorder, phone or camcorder to record meetings etc.

From the group interviews the additional points came out:

- Limiting the size of the group – this enabled quieter people to participate, helped group members remember who people were, etc.

- The group having a mission statement and ground rules – and sticking to them.

The National Council for Palliative Care – Difficult Conversations for Dementia project

‘Although the project wasn’t led by people with dementia, those involved were very well supported emotionally and practically. For example, when people attended the All Party Parliamentary Group I booked and arranged all travel (NCPC paid), arranged a meeting place, ensured people were ok going into the House of Commons, made sure they were ok getting home, emailed the next day to make sure they were ok and had enjoyed the day. With people bank members, I make sure that we offer good support if people speak at conferences. I always try to work in a way that people are most comfortable and make a particular point of thanking people properly, and making it clear how much their contribution is appreciated. We also share information about impact of involvement.’

Key achievements

When asked to describe projects’ key achievements or successes in terms of involving people with dementia, respondents highlighted the importance of enabling the voices of people with dementia to be heard, whether in terms of influencing service design and delivery or in terms of raising awareness of dementia within communities and challenging the stigma which is often associated with this condition.

People with dementia had influenced dementia services in a number of ways including:

- Raising awareness of dementia and challenging stigma by speaking at conferences, writing publications and journal articles, and doing interviews with the media.
- Involvement in practitioner training, either directly or through involvement in the creation of training materials, DVDs, etc.
- Sitting on advisory groups to steer the direction of individual projects.
- Involvement in the governance and peer review of services, e.g. developing and monitoring service standards, reviewing how services involve people with dementia.

- Contributing to the creation of national Dementia Strategies and local dementia plans.
- Employing someone with dementia in a paid role – and enabling them to decide how to carry out their role (which may result in it focusing on supporting others with dementia, rather than a wider influencing role).
- Bringing people with dementia together, helping them deal with a diagnosis and meet others.
- Influencing the design and layout of facilities.
- Lobbying politicians.
- Fundraising.
- Acting as ‘ambassadors’ for services, organisations or people with dementia in general. This was important both in terms of motivating, encouraging and demonstrating what people with dementia could achieve, but also raising awareness and understanding of the issues by speaking from personal experience. It should also be noted that several individuals who participated in the survey are official ‘Ambassadors’ for the Alzheimer’s Society.

“It’s actually great to feel part of something with someone else who has the same problems as you and nobody understands this illness more than someone else with the illness, that’s the truth.”

Scottish Dementia Working Group member

From the group interviews the additional achievements were identified:

- Sitting on interview panels;
- Reviewing documents and services;
- Involvement in writing research papers;
- Getting a town (Torbay) to declare itself ‘dementia-friendly’ (with considerable media publicity attached).

More nebulous but important aspects of the groups’ activities included the sense of active participation and involvement, collective feelings of having achieved things, and mixing with other people with dementia. People were pleased to be in demand from professionals and other organisations and that the value of their expertise and experience was recognised.

Discussion point – participation as a form of therapy?

Respondents also identified some of the benefits which had been accrued for the individuals involved such as improved mental health and wellbeing, increased standards of care and support, and enhanced knowledge and understanding about dementia. Some pointed to the positive therapeutic effect of being involved in these activities, not only in terms of (re)building confidence, self-esteem and self-worth, but also a subjective sense of slowing down the actual progress of the dementia itself – a real sense of ‘use it or lose it’. Unlike the mental health service user movement which frequently challenges psychiatric diagnoses or the learning disabilities self-advocacy movement which emphasises rights and participation, irrespective of the diagnosis, the evidence from DEEP indicates that not only was there an acceptance of a dementia diagnosis (though getting this was often a long and painful journey) but being involved in these kinds of groups also was a form of self-management of the illness.

“We bring news in [to the group] and take ideas out [into the world].”

Forget Me Not Group, Swindon

“People with dementia who usually lack a voice in practitioner education (i.e. those in long term care, with language problems or severe cognitive impairment) are directly involved in the students’ learning, through naturalistic encounters.”

Bay Tree Voices, Bradford

“Involving People Living with Dementia Reference group has recently developed ‘what works’ resource cards when involving, engaging and consulting with people. These cards are for staff (in any setting) to use as reference tool and have been written and designed by people living with dementia, individuals, carers, volunteers and staff. The focus of these cards is to strengthen opportunities, for staff to facilitate and support people to express their preferences, get involved in activities whilst recognising their current abilities.”

Involving People With Dementia Project, Bristol

“So with the power of the group, we’ve got legislation changed, the workstreams and the charter of rights for people with diagnosis. That wasn’t happening before. We’ve come a long, long way. There’s lots of people in other countries seeing that we’ve managed to get the law changed, we’ve managed to get this done.”

Scottish Dementia Working Group

“Individuals in the group have made a huge difference in challenging people’s perceptions of dementia and how it may affect someone. They have done a lot to educate people, raise awareness and have also been a huge support to each other and others with dementia.”

Positive Dementia Group, Aberdeen

Key challenges

Alongside the successes associated with user involvement, respondents also pointed to a number of challenges inherent to any project aiming to encourage greater participation by people with dementia.

A central challenge was ensuring that it was not just those with the loudest voices who were heard and that a wide variety of people with different degrees of impairment, and from different equalities groups, were also included. Widespread and diverse participation was viewed as crucial to preventing involvement activities being seen as halfhearted or tokenistic in design. Flexible approaches to involvement were seen as one mechanism for enabling widespread participation to take place.

“Ensuring that we hear the clear voice of the people with dementia. For some people this has not been a challenge at all, for other, naturally quieter, people we need to ensure that we hear and take note of their thoughts and views in a way which suits them – for example on a one-to-one basis rather than in a larger group. We need to constantly check the language we are using and avoid jargon.”

Bay Tree Voices, Bradford

Low expectations about what user involvement and participation could mean for people with dementia were also cited as a key challenge. This not only affected staff but individuals themselves and their carers too. There was a perceived need

therefore to raise expectations in all three groups, and show what was possible in this area.

“Convincing other people that it was possible to have an employee with dementia and keep this meaningful and non-tokenistic. Instilling hope.”

Open Doors Support Network, Manchester

Another difficulty mentioned by respondents was the progressive nature of dementia itself which could make consistency of involvement over a period of time a challenge. To address this it was thought that encouraging early involvement by people with mild to moderate dementia was key, but respondents recognised that they had not always been able to do so effectively. Ensuring people had enough support to enable them to stay involved was also thought to be crucial.

One person who was interviewed during the pilot stage about the groups they were involved in found it harder to answer questions because of his dementia. He was aware of this limitation which he found frustrating but he also described some frustrations about not understanding how decisions were made about what the group did – or it not being properly explained. He saw little point in a network because involvement with the group (when it worked well for him) was the most important thing – perhaps an important insight into the role of groups as the experience of dementia progressing affects individuals.

The importance of ensuring events involving people who did not have dementia (such as educational and training events) were set up and managed in ways that ensured people with dementia were listened to and respected was also emphasised. This involved practical considerations such as the size of the group, and supporting people with dementia to prepare in advance.

“Learning from our experience earlier in the year, four people with dementia attended, each with a supporter (who had agreed, with the former, to remain quiet unless asked to contribute). The people with dementia had decided on the three themes to talk about, had in most cases prepared what they wanted to say, and invited questions. It was by no means a ‘perfect’ discussion. Any group discussion for people with short-term memory impairment creates challenges and these were recognised openly. However, good humour and careful and sensitive repetition helped to ensure this was again a positively reviewed session by all – contributors and students.”

Foundations in Relationship-Centered Care, University of Sheffield

Finally, practical issues such as transport and rural isolation were highlighted as barriers to **involvement by individual respondents**.

From the group interviews the additional challenges were identified:

- Groups don’t work for people ‘in denial’ about their dementia – people must have accepted their diagnosis.
- There were different views about whether groups should incorporate some form of therapy or focus on simply sharing and discussing information about dementia – but most agreed that more generic peer support was important.
- Whether people should be paid for their involvement (see discussion point above). This provoked different responses (and a lively debate at a session for DEEP at the 2010 UK Dementia Congress). Some groups and individuals were happy to contribute on an entirely voluntary basis; others felt that payments should be discretionary, or mandatory. Although the majority of people involved in the groups were of retirement age this did not come up as a factor in its own right. The debate seemed to be more of a reflection of increasing recognition of the value and contribution that the groups were making and how this should best be remunerated.
- Some frustration was expressed by individuals who had been involved with the Alzheimer’s Society Living With Dementia Group that it wasn’t functioning in the way it had been previously. But it was also recognised that its size (some meetings involved up to 40 people), dynamic and different personalities made it difficult for it to function effectively and people understood the reasons for devolving it. However there was still a desire for some sort of national body for individuals with dementia, similar to the LWDG.

- Travelling to unfamiliar environments (e.g. national events) was identified as an obstacle. It was pointed out that people could easily get tired travelling long distances and being in unfamiliar surroundings (the significance of this was reinforced when one group didn't attend either of the DEEP events for these reasons).

“Those with dementia who don't have access to transport or who live alone are also more difficult to engage due to practical concerns, and enabling access from a wider range of social / economic backgrounds to reflect the true nature of dementia's diversity therefore poses more challenges.”

Dementia Advice and Peer Support Service, Trafford

The future

When asked about other activities the projects would like to develop in the future the following areas and priorities were identified:

- educating GPs and other professionals;
- developing videos to aid training;
- people with dementia leading group activities;
- intergenerational opportunities;
- sharing personal experiences of living with dementia through newsletters and online through personal blogs etc.; and
- wider participation and involvement from seldom heard groups of people with dementia, e.g. minority ethnic communities, those who also have learning disabilities, people in the later stages of dementia living in care homes and hospitals.

From the group interviews the additional points came out:

- Developing ways of evaluating the impact of the groups (e.g. by collecting feedback).
- Some groups talked in terms of the group and its activities being part of an evolutionary process as members came and went but the core values would stay the same and there would be a sense of self perpetuation in the identity of the group.

“The group would like to do more to educate GPs as some of them have had very poor experiences while others have had excellent support. The groups were involved in working with the Foxtrot theatre company to put on a piece of interactive theatre aimed at educating GPs around diagnosis. The performance has been held twice now and has been very well received by social work staff, CPNs, care workers etc. and one or two GPs but it has been very hard to get more GPs to attend despite showing it in their protected learning time.”

Positive Dementia Group, Aberdeen

Funding was clearly central to the future of the many of the projects described, with seven respondents highlighting the importance of obtaining further funding for the survival of the work. Several groups and individuals spoke of the effect that the difficult economic climate was having on groups, as well as questioning the commitment of bigger organisations to properly supporting the participation and empowerment of people with dementia. Some groups had experienced funding cuts and faced uncertain futures.

When asked about how projects plan for people with dementia leaving, a variety of different responses were described. Some respondents indicated that this process occurred naturally and there was no formal strategy or process; individuals would for example recognise themselves that they were no longer able to cope with their involvement and decide to leave after discussion with the group. In other cases a move into a care or nursing home could act as a cut off point for the involvement. Continuing to support the person after they left the group was felt to be important, as well as having ways of remembering people who had died.

One project had set up time limited periods for involvement, so that after two years direct participation was phased out. Another project regularly reviewed participation to ensure that involvement was manageable for those concerned. In most cases, effort was made to ensure that participation continued for as long as it could, and that links with organisations were maintained after direct participation had ceased.

“As dementia affects everyone differently, people leave the group in different ways. With some it is their relatives who make the decision but for most, it is the realisation that they are no longer able to effectively engage with the activities of the group and they make their own decision to leave. This can be a difficult time for all the groups. However, we would never ask anyone to leave, however advanced their dementia and would always do our best to support them to remain involved in whatever capacity.”

Scottish Dementia Working Group

Individual survey

About respondents

Fifteen responses to the individual survey are described here. All of those who responded were white (n=14, 93.3 per cent), the vast majority were male (n=12, 80.0 per cent) and most (n=8, 53.3 per cent) fell into the 65-79 years age bracket. There were no responses received from anyone under the age of 50. The most common type of dementia experienced by respondents was Alzheimer’s disease (n=6, 40.0 per cent) followed by vascular dementia (n=5, 33.3 per cent). Most respondents (n=9, 60.0 per cent) had been diagnosed with dementia for more than 5 years.

Activities

Respondents were asked about their activity to change the way dementia is viewed. The majority (n=13, 86.7 per cent) had been involved in this type of activity for over two years, with five of these having been involved for over five years. Nine of the fifteen respondents (60.0 per cent) were involved in more than one type of participation activity.

The most common form of participation was (figures include information collected from the pilot questionnaires done with 8 individuals) giving talks or presentations, whether to students, professionals, voluntary organisations or groups (12 responses), followed by media work, e.g. radio, TV interviews or newspaper interviews (7 responses).

Other types of participation activity were as follows:

- writing articles or book chapters for publication (5 responses);
- board/Committee / Steering Group membership (5 responses);
- policy development and advisory roles, e.g. NICE/SCIE dementia guideline development, national dementia strategies (5 responses);
- fundraising (3 responses);
- research participation (2 responses);
- blogging (2 responses);
- making training materials, e.g. DVDs, CDs etc. (2 response);
- ambassador work for the Alzheimer's Society;
- campaigning, e.g. for Dementia Awareness Day (1 response);
- lobbying government (1 response);
- acting as a Patron for a voluntary organisation (1 response); and
- acting as a trustee for an organisation (1 response).

"I have written chapters in 3 books, I contribute a blog to an on-line training newsletter. I give lectures to various organisations and groups – mostly about the experience of having a diagnosis of early dementia."

Individual with Vascular Dementia

"I hold my bucket out at fundraising events... Sit on a committee on fundraising for local hospital (with my wife)... Answer questions and give feedback for various projects... Part of a drug trial – we are Patient and Public Involvement reps."

Individual with Alzheimer's Disease

Groups and organisations that individuals participated in and for were a mix of local and national organisations from across the voluntary and statutory sectors. These included:

- Alzheimer's Society;
- Alzheimer Scotland;
- Dementia Leadership Group;
- Department of Health;
- EDUCATE;
- Innovations in Dementia;
- Mental Health Foundation;

- Positive Dementia Group;
- Scottish Dementia Working Group; and
- Making Involvement Count.

Barriers and facilitators to participation

In terms of factors which aided their activity, individuals highlighted the important role that family members, carers and friends played in supporting their participation, such as accompanying them to meetings or to talks and presentations. Individual staff members within local NHS services and voluntary organisations were also highlighted for their supportive role, particularly for providing information and keeping individuals up to date. Finally support from fellow peers with dementia was also highlighted as a factor which aided participation through providing help, encouragement and understanding. However alongside these facilitating factors, a number of barriers to participation – including inaccessible venues and transport difficulties – were also described by respondents.

“My wife assists me at these events, and I get support from staff as and when needed.”

Individual with Dementia with Lewy Bodies

“When I was diagnosed I got a lot of help and encouragement in meeting and working with others who had similar problems to myself.”

Individual with Dementia with Lewy Bodies

“Many relevant meetings are held within a cluster of locations that are difficult for people to reach, particularly with wheelchairs, so I feel that there is a great big inarticulate chunk of sufferers whose voice is never heard.”

Individual with Alzheimer’s disease

How can people with dementia be supported more, to lead activities, groups and projects that aim to influence services and policies?

When individuals were asked how people with dementia could be supported to lead activities and influence services, the most common response was to encourage greater understanding on the part of service providers, policy makers and the general public of the abilities and potential of people with dementia. It was felt that too much attention was still placed on the limiting nature of dementia and a more respectful attitude which listened to the views and experiences of people with dementia was required. Taking this one step further, one respondent argued that it was the responsibility of services to pro-actively ask people with dementia to become involved with how services were run.

Another suggestion for how people with dementia could be supported to become involved was to provide more practical support to aid involvement, such as using accessible venues and maintaining regular communication. Finally it was suggested that greater sharing between those involved in participation activities across the country would support the involvement of people with dementia and give encouragement about what is possible in areas when participation is less well developed.

“There should be more recognition of the abilities of many with an early diagnosis which makes it rewarding to help and encourage others and to try to improve care of all sorts for those in a later stage of their illness. I hope more and more projects will enable those with dementia to lead fuller lives. Sometimes it feels like we are a very few crying in the wilderness.”

Individual with Vascular Dementia

Subsequent to the survey being carried out an email exchange took place between DEEP and an individual who was part of an informal network of people living with dementia, exploring the possibility of this network being supported by DEEP. Comments from the person's email are reproduced (with the person's permission) in an appendix to the report available on the Mental Health Foundation website (www.mentalhealth.org.uk/publications/). It demonstrates the growth in both confidence and assertiveness among people with dementia in wanting to have their voice heard and be in control of involvement and empowerment initiatives.

Value and role of a national network of groups led by people with dementia

Participants in the main and individual surveys (n=47) were asked their views on the potential for developing a national network of groups and initiatives led by people with dementia.

Thirty nine respondents (83.0 per cent) indicated that they thought such a network would be useful, two did not know and six did not answer this question. A wide variety of thoughts and suggestions about the purpose and function of such a network were provided by respondents, and these are summarised below:

Purpose of a network

In terms of the purpose of the network, a number of different roles were mooted:

- Raising public awareness of dementia and challenging the stigma associated with this condition.
- Campaigning and lobbying for change at a national policy level.
- Providing peer support to inspire individuals with dementia to get involved and achieve change within their own services and communities.
- Sharing good practice in dementia support and identifying gaps in service provision throughout the country.
- Collaborative working between groups on key issues and challenges.
- Sharing useful tools and resources to aid user involvement within services, e.g. training packages, DVDs etc.

“[People with dementia] are voices in a wilderness and I think, just because we know and we manage to come through the doors and meet up with others, we should empower them by sharing our experiences with them and helping them to do it themselves. We can do that through a network.”

Scottish Dementia Working Group

“It’s the ripple on the pond effect.”

Forget Me Not Group, Swindon

Activities of a network

A number of practical suggestions were made about what a network might actually do, in order to achieve its purposes. These included:

- helping groups find out more about each other through things like a national newsletter.
- supporting regional meetings and road shows to bring groups of people with dementia together.
- employing people with dementia to do some of the work e.g. talks, training for other groups; and
- organising training and support to help groups led by people with dementia set up and develop.

“What we did last year...was because there was lots of us and we had lots of different ideas, we couldn't do everything so we had a priority day type thing and we made priorities and it was done democratically, it was round the table and we got three main aims. Training is one, post-diagnostic support and early diagnosis where the GPs come into it a lot.”

Scottish Dementia Working Group

Structure of a network

It was suggested that if a network were to be set up, that it would be useful for it to be based within a host organisation who could provide financial and staff support. However, it was clear that the network should be seen to be as independent as possible, both from government and possibly also from large dementia charities as well, who could be viewed as too close to government from time to time. There was also a strong feeling that the network should not be too centralised in London, but should offer regional and local meetings to encourage widespread participation. Face to face meetings could be complemented by online resources and social networking opportunities and postal newsletters/magazines for those who do not have access to a computer.

The Scottish Dementia Working Group was highlighted several times as a model that could be adopted or adapted for other parts of the UK.

Support for a more traditional structure tended to be expressed by those who had been more involved with national groups (e.g. Living With Dementia Group, Scottish Dementia Working Group).

From the group interviews the following points were made about a possible network:

- The geographical challenges e.g. people not wanting to travel, keeping a network local, familiar, responsive, and involving a lot of face to face contact.
- Importance of a network in supporting the autonomy and feel of local groups was stressed.
- It should not be hierarchical – for some groups even being ‘represented’ by group members at other meetings and feeding back is difficult. It was suggested that communication and decision-making through the network could be supported by contributing summaries of group discussions on issues the network was discussing and / or groups attending network events collectively.

“The Scottish Dementia Working Group keeps going, I believe, because there is no main voice it is a collective voice and that we hand over the baton, if you like, we almost mentor people up to take an active part and then the ones who get to a certain age and stage take a step back. I think that’s what keeps it going and that’s what keeps the energy going. It’s always freshly flowing.”

Scottish Dementia Working Group

- It was acknowledged that for a network to work nationally it would require some central organisation and staff, but it should be accountable to and monitored by people living with dementia who should also make the key decisions.

“The paid co-ordinators, they help to keep us on that line because we’re wildcards! We can go off on a tangent. They help us to maintain that.”

Scottish Dementia Working Group

- The idea of an annual national event as part of the network’s activities was popular – there were lots of suggestions (partly stemming from discussion

about the two DEEP events) about the practical organisation of events for people living with dementia.

Membership of the network

Respondents felt that membership should include anyone with a diagnosis of dementia, not just those at the earlier stages or who were more articulate. Steps should therefore be taken to seek out and include those in the more advanced stages of the condition, people with dementia living in care homes, people with dementia from Black, Asian and minority ethnic groups, and people with learning disabilities and dementia. To enable their engagement individuals may need support from members of staff or family/carers.

“Those with dementia who don't have access to transport or who live alone are also more difficult to engage due to practical concerns, and enabling access from a wider range of social / economic backgrounds to reflect the true nature of dementia's diversity therefore poses more challenges.”

Dementia Advice and Peer Support Service, Trafford

There were mixed views about whether membership should only be for groups led by or actively involving people with dementia, or for individuals as well, and whether it should also include carers and professionals. On the one hand it was argued that a good mix of perspectives would be of benefit to all, whereas on the other hand some individuals felt that including only those with dementia would ensure their voices were placed centre stage. As a potential solution to this division, one respondent suggested having different levels of membership, where people with dementia were core members, and others were given “supporter” status or similar. From the group interviews the importance of support from family carers and professionals was also stressed.

Discussion point – carers, practitioners and services: allies or adversaries?

Although the difference in experience between someone with dementia and a family carer was recognised and people with dementia wanted to have their voice heard in its own right, there was very little sense of ‘us and them’, or an adversarial relationship with professionals / services. Unlike the mental health service user movement where stigma, together with psychiatry or mental health services more widely are often seen as fundamentally problematic (sometimes in terms of being “oppressive”), or the learning disabilities movement where the

attitudes of society are often seen as the problem, the evidence from DEEP tended to indicate that getting better treatments for dementia and improving services and care more generally remained a key focus. It might be argued that the more radical activism associated with the learning disability or mental health service user movements is because they have tended to involve a younger generation of people and that older generations often have less energy or are more conservative in their campaigning methods and goals. There may be some truth in this but it could also be argued that DEEP has provided clear evidence that collective action by people with dementia is still in its early stages and unless some of its goals are achieved quickly then more vociferous and radical activities may emerge. Frustrations were certainly expressed by both groups and individuals about slow, inadequate or tokenistic responses to what some of the groups were doing, or the care and treatment of people with dementia more widely. Some of the discussion in the transcript from the SDWG in the appendix to the report available on the Mental Health Foundation website articulates this very well (www.mentalhealth.org.uk/publications/).

Summary

The findings from these three surveys – although not providing a conclusive or comprehensive picture – do illustrate the range of ways in which people with dementia are increasingly being involved in services, policy making and campaigning; whether through sitting on planning groups and committees, advising policy makers and service planners, or raising awareness about what it is like to live with dementia with professionals, students and the general public as a whole.

A number of challenges exist to ensuring the meaningful participation of people with dementia, including:

- Involving those from seldom heard groups such as BME communities and those at the more advanced stage of the condition.
- Negative attitudes about the capabilities of people with dementia.
- Practical challenges such as transport and financial constraints.
- Adequate and sustainable funding.

To ensure participation is as widespread and meaningful as possible the following factors were thought to be helpful:

- Organisational cultures which focus on the abilities and potential of people with dementia rather than the potentially limiting nature of the condition.
- Flexible approaches and diverse opportunities for involvement – one size will not fit all.
- Practical support from organisations, particularly with regards to transport arrangements, information provision and support for preparing and delivering presentations.
- Providing opportunities for peer support where individuals with dementia can encourage and help others to become actively involved in influencing change – learning from each other.

There was widespread support for the concept of a UK-wide national dementia participation network, to support the greater involvement of people with dementia in making changes to services, governmental policy and public attitudes towards dementia. The exact structure and set up of this network will require detailed thought and planning, but it is clear from the findings from these surveys that the views and experiences of people with dementia will need to be at the very centre of the network and it will be for people with dementia to set and agree the network's priorities and activities.

The DEEP national events

A key intention of the project was to hold a one-day national event for individuals and groups of people with dementia that had been identified through the project and the survey. The purpose of the event was as follows:

- To launch the findings of the mapping exercise.
- To showcase successful examples of initiatives, groups and activities led by or actively involving people living with dementia.
- To offer an opportunity for people with dementia to come together, discuss and plan ways to take the work forward and to consider whether the development of a UK network of initiatives, groups and activities led by or actively involving people living with dementia would be useful.

It was agreed that the programme for the event should be planned by, and feature people living with dementia as both speakers and active participants in other activities on the day. This planning would take place through the project reference group network, supported by iD. Organisational and practical support (e.g. finding a venue, inviting and contacting participants, organisation on the day, etc.) would be provided by the Alzheimer's Society, together with members of the Project Steering Group, but this was done in close co-ordination with the reference group network via iD, and would be built around accommodating their proposed programme for the event and particular access needs of the people with dementia who were attending.

Participants

It was originally anticipated that the event would be for an audience of up to 100 participants. People living with dementia involved in groups identified through the survey would be actively encouraged and supported to attend the event which would be free to them and also a friend, family carer or other supporter (e.g. member of staff) if needed. There would also be a small number of participants who did not have dementia from the key organisations supporting DEEP, and possibly some key figures working in the field of dementia who would be interested and sensitive to what the events were trying to achieve (although it was subsequently decided not to extend the invite in order to avoid the potential of people with dementia feeling they were in a goldfish bowl). The decision to invite other participants without dementia to the event was left with members of the reference group network.

It was therefore anticipated that around 40-50 people with dementia would attend and the rest of the numbers be made up by their supporters or carers, and staff involved in facilitating the events.

Development of the events

Considerable attention was paid in the planning of the event to ensure that the venue, other practical arrangements, and the programme were as accessible and 'dementia friendly' as possible. A venue was identified in central London and iD supported a small group of people with dementia to visit it – this resulted in broad approval being given for the venue.

iD shared their expertise from organising similar events in the past and members of the reference group also made a number of practical suggestions about how the day should be run. The fact that the event was also going to be filmed also raised a number of issues, including:

- Ensuring the day wasn't too long and the start and finish times allowed for people travelling to the events.
- Having a round table, café style set up to allow lots of opportunities for informal discussion.
- Minimising the number of presentations but providing participants with the headline findings from the survey to stimulate discussion.
- Supporting people with dementia to do as much of the speaking as possible – and making that clear to other participants.
- Providing participants with opportunities to meet other individuals and groups.
- Capturing as much as possible of what was discussed both through taking notes and filming the events.

To help members of the reference group think about the event a very simple draft programme was produced by the steering group. This suggested that the discussion in the morning should focus on the experiences, achievements, etc. of the individuals and groups that were represented at the event, and the afternoon would focus on people's views of a possible national network. This seemed reasonable because of the very favourable response in the survey given to the idea of a national network. The response from the reference group was favourable to this suggested programme.

In November 2011 an offer of hosting an additional DEEP event was received from the Pennine NHS Foundation Trust and staff based in Stockport supporting the EDUCATE group. Although this had some disadvantages (e.g. fewer numbers at each event, the logistics of organising two events, etc.) it was decided to accept the offer. There were a number of distinct advantages of having two events including:

- choice of dates and venues;
- not London-centric;
- several groups/individuals active in the north/Scotland;
- learning from the first event could be used for the second event;
- less pressure to get it absolutely right at the first event;
- less travelling time / overnight stays;
- build up more momentum for a possible network; and
- more opportunity for staff learning / support for events.

It was therefore decided to hold two events.

London event

The London event took place on 22 February 2012. Thirteen people with dementia attended from the following groups:

- Circles of Support for People with Dementia;
- EDUCATE;
- Forget Me Not; and
- Living with Dementia Group.

The event went extremely well from the feedback received on the day and after the event and it was agreed that the structure of the event was very successful.

Stockport event

The Stockport event took place on the 13 March 2012 based upon the same programme as the London event. 33 people with dementia attended from the following groups:

- EDUCATE;
- Living with Dementia Group;

- ACE Club;
- Forget Me Not;
- Scottish Dementia Working Group;
- Age UK Trafford;
- In Two Minds;
- Open Doors Project; and
- Early Onset Dementia Group.

The event also went well but its size, some practical difficulties around its organisation, the involvement of groups that were more focused on peer support and social activities and less on 'influencing' activities, and the presence of individuals with dementia who had only recently been diagnosed meant that some people found it harder to understand and engage with, compared to the London event. The themes that emerged from the events are described in the next section.

Key themes from the morning discussions – groups and activities

The groups in general

- Most groups combined both peer support and social activities ('inward focused activities') with 'influencing' type work such as doing talks and participating in service development ('outward focused activities').
- Most groups were quite 'young' and were still developing, often incrementally and eclectically, according to what the members wanted to do and requests that came to it for work (e.g. doing talks).
- Some groups were beginning to face challenges around their growing size and the different activities they were involved with. Some group members didn't feel that peer support / social activities always fitted comfortably with the influencing type work. In this respect they were in danger of becoming victims of their own success but also being multi-purpose in trying to meet a very wide range of needs and expectations. More established groups had found ways of addressing these issues by being more structured in their activities and use of time.
- People who had joined groups primarily to deal with being diagnosed with dementia were looking for the inward focused activities and often were not wanting or ready to be involved in the outward focused activities. Most groups were primarily providing (peer) support and social activities and only

a small part of their activity was influencing (SDWG being an exception). It was apparent at the Stockport event that a number of the participants with dementia (and their groups) fell into this category. The London event involved more individuals who had been involved with influencing type activities. However it is important that individuals and groups who are doing the outward focused activities recognise that they are the exception and therefore need to be sensitive and inclusive when engaging with other groups. This approach has the double benefit of keeping groups grounded in the reality of where others are at, while at the same time enabling learning to be shared and groups to see possible activities and directions that they could develop themselves.

- The structure of groups was often fairly informal as was decision-making in the groups. Again, this reflects that most were fairly 'young' groups which had not necessarily been established to do outward focused work, and therefore didn't have structures or processes which were geared around this.

Benefits, achievements, activities and approaches

- Inevitably peer support was mentioned a lot as both an activity and an achievement. Groups supported people who had just received a diagnosis, were coming to terms with it, and trying to cope with dementia. This was also important for family carers. It was agreed there were lots of benefits of doing this collectively.
- Where groups were involved in influencing services and policies it was agreed also that there were lots of benefits of doing this collectively. These activities included (reflecting the findings from the survey):
 - awareness raising;
 - training and speaking to professionals;
 - lobbying local services; and
 - participating in local service advisory groups.
- Building up the confidence and self-esteem of group members was seen to be a benefit of both peer support and influencing-type activities.
- The groups generally took a holistic, 'whole person' approach to dementia rather than focusing solely on the medical aspects of the illness and its symptoms but there was wide spread acceptance of dementia as an objective illness which remained the focus of many of the group's activities, as well as the raison d'être for the group itself.

- Support from organisations/professionals, etc., was felt to be important but there was a strong emphasis on people with dementia being the experts (by experience), and ensuring that activities were determined primarily by people with dementia, using fairly informal methods and with a strong local focus.
- There were mixed views about the benefits of employing people with dementia which reflected the findings from the survey.
- Focusing on tangible, practical activities was felt to be important e.g.:
 - making check outs in shops dementia friendly;
 - renewal of driving licences; and
 - dementia-friendly public transport.

Challenges for the groups

- A number of practical challenges were identified including:
 - uncertainties about funding; and
 - transportation (to attend groups), especially in rural areas.
- There was some concern expressed about people ‘coming out’ as having dementia, the stigma that was attached to this, and not wanting only to be known by one’s dementia diagnosis.
- The importance of including socially isolated people with dementia and people in later stages of dementia was widely recognised but groups struggled with knowing how to put this into practice.

Key themes from the afternoon discussions – a national network of groups?

How might a network be organised?

- Having support from an organisation and dedicated (paid) staff to co-ordinate was generally seen as important but there was a strong feeling that these must be accountable to the network and to all groups involved. It was considered important that staff should offer continuity, experience, inspiration, and commitment – they should also have good communication skills and the right personality. There were some concerns about a big, national organisation doing this because it might ‘take over’, and have a

different agenda to what the groups wanted. It was seen as particularly important that a national network should not take over local activity (there was the suggestion of a 'virtual network').

- Local activities / groups should remain the focus. A network should not detract but support this. Some groups/individuals (especially at the Stockport event) struggled to conceptualise a national network – their concerns were local and revolved around their own diagnosis, support issues, etc.
- A network should not be overly bureaucratic and should avoid jargon but would need some central organisation and a way of ensuring the views of all member groups are all represented and that it was accountable to those groups.
- Regular face-to-face meetings were felt to be very important (suggestions included an annual conference, regional 'road shows'). This would also require funding to enable people to attend and participate but there was also the suggestion that meetings could be tacked on to existing conferences.
- Funding would also be necessary to:
 - pay for core costs (i.e. staff, administration, etc.);
 - enable supporters/carers to support people to participate in a network;
 - enable people to attend and meet up at events; and
 - pay people for their contributions (e.g. doing talks, training, etc.).
- There were mixed views about online networking because this could exclude people or would require groups to have IT resources/support, but there was general agreement that a network should have an online presence.
- There were mixed views about employing an individual with dementia as part of a staff team supporting a network.

What might a network do?

- It was agreed that it was important to have a clear purpose for a network.
- Communicating between groups, sharing good practice and information (some wanted it to provide basic information about dementia), and having a network newsletter/bulletin was felt to be useful.
- A network could play a very valuable role in connecting local groups/people with dementia.

- It could also operate at a national level by influencing national policies (e.g. national dementia strategies) as well as linking with other organisations (e.g. the Dementia Action Alliance).
- A network could help build capacity at a local level to support the development of new groups and groups wanting to expand their activities (e.g. regional meetings/road shows, providing resources, toolkits on how to develop groups, how to campaign locally, etc.).
- Develop/support campaigns on tangible, practical issues (see suggestions above about group activities).
- Other suggested activities/benefits included awareness raising, confidence-building, having an enjoyable, social aspect to it.

Who should be part of a network?

- There was a widespread feeling it should be as inclusive as possible but different views were expressed about status of membership for:
 - people with dementia – core members;
 - groups led by people with dementia – core members;
 - groups involving people with dementia or supporting the involvement of people with dementia in service provision / development – some difference of views; and
 - there were mixed views about the involvement of family carers, professionals and other paid staff, and other supporters. It was widely recognised that they had a vital role in enabling people with dementia to participate and for groups to function well but it was also felt important that they should be accountable to individuals and groups in the network, not in charge of it.
- A network needs to find ways to involve ‘harder to reach’ groups (and support local groups to do this) and help groups with members whose dementia is deteriorating.

Other events

In order to encourage participation and make contact with as many groups as possible as well as raising awareness of DEEP in general, presentations about the project were given at several events during 2011 and early 2012, all involving

a wide range of people working or involved in the field of dementia. The most notable of these were:

- *UK Dementia Congress, November 2011, Liverpool.* DEEP had a parallel session at the Congress, a UK-wide event, and invited a number of groups and projects to talk about their activities, as well as describing DEEP in general. The groups that presented were:
 - ACE Club;
 - The Hope Group;
 - EDUCATE;
 - SDWG; and
 - Open Doors.

There was also a lively discussion after the presentations which touched upon issues of payment to people with dementia for involvement activities, and the possibility of a totally independent network of individuals with dementia.

- *Alzheimer's disease International Conference, March 2012, London.* A presentation was given about DEEP as part of a session on advocacy and dementia.
- *Scottish Dementia Congress, March 2012, Edinburgh.* DEEP ran a joint session shared with the SDWG involving a presentation about DEEP, and the current and two ex-chairs of the SDWG talking about the work of the group.

Reflections, conclusions and recommendations

Overview of context

It is only in the last 15 years that a public discourse about dementia has emerged in the UK. However, until very recently people with dementia were 'talked about' in this discourse, but rarely 'talked with'. And when they were talked about it wasn't often they were talked about as people, but usually just as a container for the more important issue, dementia itself. The dementia 'discourse' ticked all the boxes of a medical model dominating conceptualisation of a much more complex issue. And whether it was professionals, charities, media or politicians the 'd' of dementia seemed to be reflected in the vocabulary used to describe the condition – 'a devastating disease', 'deficit', 'a living death' (though virtually never 'disability'). In the absence of cures or universally effective treatments people were frequently ignored or at the receiving end of stigma, or therapeutic nihilism. If attention was paid to them, the focus was almost entirely on controlling symptoms and finding causes or a cure. It was almost entirely bio-medicalised as an illness. The person, their life – past, present and future – sense of self, agency, and subjective experience, was treated as almost irrelevant so corrosive was the effect of a dementia diagnosis on personhood.

Much of this discourse is still evident in 2012. And few would argue that people with dementia should not have the right to expect professionals and scientists to make as much effort as possible to find and apply effective treatments as has been done with other long term conditions that are equally as severe in their disabling symptoms. But in the same way that it is correct not to contest this, so too should the discourse about participation, empowerment, citizenship and social justice that is present with other long-term conditions be applied to, with, and by people with dementia.

The last 10 years have seen remarkable developments in the awareness, understanding, and public profile of dementia and this has made significant inroads into the negative discourse of therapeutic hopelessness, stigmatisation, and almost total 'disabilisation' of people with dementia. A quick look at Table 3 in Appendix A indicates the sheer quantity of dementia-related policy announcements, etc. that have occurred and many of these have not only challenged that discourse but have tried to do this with the active involvement of people with dementia. This has not always been easy or worked smoothly but it is nevertheless a very significant change. People with dementia have become

visible, as 'real' people able to express their views, experiences, hopes, fears, frustrations and many other things, not just about their dementia but about their lives in general. Agency, self, subjective experience, empowerment, personhood, participation, citizenship, leadership, have all been shown to be viable, credible, achievable concepts that can be made real and meaningful by individuals and groups of people with dementia, just as they have been for people with other illnesses, conditions and disabilities. DEEP has shown this to be happening at a national level, but just as importantly at a local level.

On the basis of what people with dementia have said as part of DEEP it also seems reasonable to assert that the recent 'challenges' on dementia announced by Prime Minister David Cameron cannot be addressed and overcome without the active involvement of people with dementia in both the methods used and evaluation of success. Ensuing health and social care services are meeting the needs of people with dementia, that communities are becoming truly 'dementia-friendly', and that research is addressing topics important to people with dementia must involve people with dementia (as well as families and professionals) in the process as well as in term of measuring outcomes and success. Groups of people with dementia at both local and national levels are well placed to become involved in this work if they so wish and are invited to do so. If they are not invited, but want to be involved, then they should be supported to make their voice heard and responded to positively.

However, it should also be recognised that a 'dementia service user involvement movement' or 'dementia rights movement' still barely exists as compared to many other disability groups, and for lots of people with dementia involved in groups and projects those phrases are not ones that they would recognise or accept. Most groups and projects are small, local, relatively recently established, and involve partnerships and support from mainstream health, social care or third sector organisations. They tend to combine activities focused solely on their members, such as social events and peer support, with more outward facing 'influencing' activities that may not involve all members or be such a regular part of their day to day functioning.

Collective 'activism' involving people is still small scale and in its early days (perhaps with the exception of the SDWG) and this may be frustrating for those eager to develop a national movement (or network) and achieve objectives which will make a real difference to the lives of people with dementia through influencing at a national level, research, services, policies, communities and society. The fact that dementia is a progressive and terminal condition should not be underestimated when recognising the frustration that many people with

dementia feel, who have these aspirations. Enabling people with dementia to come together, share experiences and learning, and plan these kinds of activities was an important theme that emerged from DEEP. Arnstein's concept of 'citizen control' is clearly the type of goal that some individuals and groups with dementia are aiming for.

Yet it is also important to give just as much recognition and support to local groups doing local activities to influence at local levels. The very fact that these groups are grassroots, provide peer support and social activities for members, as well as opportunities to influence, makes them accessible and inclusive of people with dementia who may get involved for a wide variety of reasons. These groups, and individuals involved with them, may participate at all sorts of different levels of Arnstein's ladder because this is what they choose to do and feel comfortable with – over time they may aspire to 'citizen control' but this should not be something imposed upon them or required of them to 'prove' they are led by or actively involving people with dementia. This is where Marsh & Macalpine's work is much more useful in understanding where the different groups that engaged with DEEP were 'at'. Enabling these kinds of groups to come together and share their experiences and learning was also an important theme that emerged from DEEP.

There was virtually a unanimous consensus that there would be real benefits in a national network that can connect groups involved in the activities identified through DEEP. By making this an inclusive network which includes groups and projects led by or actively involving people with dementia choosing to operate anywhere, or in a multiplicity of places on Marsh & Macalpine's 'continuum', groups can learn and develop from each other, stay connected with grassroots local activity as well as potentially become more involved in national influencing work. At one of the events the phrase '*think locally, act nationally*' was suggested as a way of conceptualising a possible network (although a group like the SDWG are clearly thinking and acting nationally), but the findings from DEEP indicate a slightly more nuanced version of this is more appropriate along the lines of '*think locally, act locally, network nationally*'.

Despite the more positive dementia discourse and political attention that is being paid to it the current ideological and economic climate does not generate optimism that there will be a significant increase in resources from the public sector for dementia. Furthermore, initiatives to support the involvement and empowerment of people with dementia are seen by many to be luxury 'add-ons' which can be ill-afforded compared to the resource demands of direct health and

social care provision, and research. But DEEP has shown that collective involvement and empowerment has real value not only for people with dementia but the services they use, the communities they live in, and the policies that affect their lives. For this value to be sustained and built upon commitment and resources are needed to support and develop existing groups as well as building capacity by supporting new groups to be set up and develop.

DEEP has been a snapshot in time of a new, emerging movement in the field of disability. The next section summarises the main themes, next steps, and recommendations but it is hope that this report and the associated films will be an important record not only of the project but of that movement more broadly. The moment in time is well encapsulated by Professor Murna Downs from the Bradford Dementia Group, a university initiative that is committed to the active involvement of people with dementia, in her title for a recent conference presentation, 'From invisible patient to citizen and activist – dementia comes of age' (*British Society of Gerontologists Annual Conference, July 2012*). But time moves on and it seems therefore fitting to conclude with a quote from one of the groups, that captures the sense of change and impact that has occurred and will take place in the future – “*it’s the ripple on the pond effect*”.

Summary of key findings

The DEEP project aimed:

- To identify initiatives, groups and activities led by, or actively involving people living with dementia that aim to enable people with dementia to have more control over their own lives and the decisions that affect them.
- To develop the capability and potential of people living with dementia in leading and managing initiatives relating to the support they receive, policy and service development, their rights as citizens, and the perception and understanding of dementia in the wider society.
- To initiate a process supporting the development of a UK network of initiatives, groups and activities led by people with dementia or with their active involvement and participation.

The key findings from the survey and the events were as follows:

- Most groups undertook a mixture of both influencing type work together with peer support and social activities. Some but not all individuals did both. A number of individuals undertook influencing work independently of groups,

or in addition to group activity. Most groups and projects were supported by organisations or services with staff and carers involved. The way that people with dementia decided what the groups or projects did varied but was usually done through informal structures and processes.

- Influencing type work included national lobbying and meeting with government ministers and officials, local lobbying of services, media work, training and education, participating on advisory groups, awareness raising work, and speaking at events.
- People with dementia were still at an early stage in terms of a 'user movement'. A lot of people's involvement was still very tentative, as many were still coming to terms with a diagnosis and unsure about whether they wanted to participate in more collective 'influencing' activities that went beyond their own personal situation. Many groups were very new and still in the process of establishing themselves and were at different stages of development compared to more established groups.
- There were high-profile groups and individuals active in the field who were showing what can be achieved, but they were exceptional. Most groups were local and relatively informal in terms of their membership, their chosen sphere of influence, and the way they operated, and wanted to remain that way. Some groups faced practical difficulties in terms of funding and most groups found it challenging to include people with more severe dementia or from 'seldom heard' groups (e.g. people with more severe dementia, people with dementia from Black, Asian and minority ethnic communities).
- Although there were a limited number of groups that were at the stage of influencing policy and practice, there were other groups that wanted to know more about how their group could do some of this work. Some groups that were doing influencing work were experiencing some tensions in terms of their growing size and mix of activities they were undertaking.
- Support from organisations/professionals, etc., was felt to be important but there was a strong emphasis on people with dementia being the experts and not wanting to be 'taken over' by the agendas of larger organisations.
- Although many participants in the survey and at the events were articulate, active and well informed people with lifelong experiences of influencing through work and families etc. they were not, in the main, activists or campaigners in the stereotypical mould of 'radical' younger people involved in other disability groups/'causes'.

Supporting the empowerment of people with dementia:

- People needed time to come to terms with their diagnosis before they felt able to be active in terms of influencing policy and practice. Access to appropriate information and support about their own situation, as well as influencing type work (including hearing from others with dementia), was essential before most people could move into doing the latter. This included building up confidence and being aware of the stigma often associated with a dementia diagnosis.
- Most groups were comfortable operating at a local level, informally, supported by staff, volunteers and carers, and valued a combination of peer support, social activities and some influencing type activities. They recognised the need to include and involve people with more advanced dementia and from 'seldom heard' groups but often found it difficult to know how to do this.

Views about a network:

- The idea of a network was welcomed – the benefits of a collective voice, sharing experiences, and 'connectedness' was widely recognised.
- People found it difficult to visualise what a network would do and how it would work in practice. It was agreed that it should have a clear, agreed aims and objectives but there were a number of suggestions about what these might be, and what the membership of a network should be.
- A network would need a practical focus with tangible activities to engage groups.
- Working collectively was thought to be important but also supporting groups working locally – a network should not take over local activity.
- Funding is vital – for meetings, co-ordination, transport, etc.

Next steps

The vision underpinning JRF's proposed new programme on dementia 'Dementia Without Walls' (2012-2015) is that the UK is a good place for those of us who have dementia to live, and live well. The difference the JRF wants to help make is: People living with dementia are *more understood, more heard, more included, more connected and more supported* – with and by each other, their local communities and society as a whole.

JRF will be supporting a continuation project which will build on DEEP, involving the organisations that collaborated on DEEP (Innovations in Dementia, The Mental Health Foundation, the Alzheimer's Society, and the groups led by or actively involving people with dementia).

The goal is to support the development of a collective voice of people with dementia through investing in emerging and established groups. 'DEEP2' will support the more established and ambitious groups in sharing their knowledge and expertise, building capacity around the UK (e.g. ways of harnessing social media and other new technologies for empowerment and influence). It will also seek to demonstrate the value of supporting networks led by people with dementia to actual and potential funders by collecting evidence of the impact of this on policy and practice. The project will build capacity in groups that are at an earlier stage and in parts of the country where there are no groups genuinely led by people with dementia that have been identified, and consider how to sustain itself beyond current JRF funding.

DEEP2 will use the expertise of the existing involvement groups to build capacity elsewhere and to support the development of a network of groups of people with dementia. People with dementia will be supported to be co-producers at every stage of the project, and to be fully engaged in the project from the outset.

Groups, and individuals within groups, will be recruited to formally participate in DEEP2. Roles and approaches to enable people to participate in a range of ways, depending on their individual circumstances, will be defined. People with more advanced dementia will be enabled to participate by routinely using a range of engagement methods. Groups will be helped to share knowledge and ideas with each other to enable capacity building, with the aim of setting up a functioning network that is sustainable and able to grow, and that reflects the wishes of people with dementia.

The project will be working proactively with individuals within groups, and groups as a whole, to become more confident, learn new skills and have opportunities for engagement, at a local and national level (where this is desired). It will link with any other emerging networks of people with dementia, including individuals not connected to groups, who feel the DEEP project is of relevance to them. The project may also produce resources to assist other organisations to further their engagement with people with dementia.

The project will keep abreast of, and link groups of people with dementia to, relevant initiatives, including work on dementia friendly communities, the implementation of the national dementia strategies, and dementia action alliances.

The main outcomes will be:

1. A stronger collective voice of people with dementia, with more confidence and capacity to influence attitudes, policies and provision.
2. Empowered individuals within groups who feel more confident and aware of engagement and influencing opportunities, and what they can achieve.
3. Empowered groups who are having influence at a local, regional or national level.

Recommendations

On the basis of DEEP's findings a number of recommendations can be made for groups, projects, services, and organisations in contact with people with dementia. Involvement and empowerment of people with dementia should not be regarded as something that is done solely as a discrete piece of work or a particular project (although this may be necessary as well) but as integral to the work of any organisation that is seeking to improve the lives of people with dementia. Not all of these organisations will necessarily have the skills, knowledge or experience to know how to involve people with dementia but the groups and projects identified through DEEP, and the organisations that have been involved with DEEP, can provide advice and guidance to help them to do this. The success of future involvement and empowerment work depends as much on the support of other organisations as it does on the commitment and hard work of the groups themselves.

Here are our specific recommendations as to how this support and commitment can be demonstrated:

For groups led by/actively involving people with dementia or groups planning to do this in the future, that want to participate in a network:

- Discuss and identify how they would like to develop their influencing activities and what support they would want from a network to do this. Also discuss and identify their achievements, experiences, and expertise in this type of work which they could share with others through a network.

- Discuss and agree how they would want a network to engage with them and be accountable to them for its work.
- Be supported to engage people with dementia from 'seldom heard' groups, e.g. Black, Asian and minority ethnic groups, people with learning disabilities, people with more severe dementia, etc.
- Be supported to engage effectively with organisations and services, work collaboratively, share learning, and develop tools to measure impact.
- Where desired, to be supported to build alliances with involvement and empowerment initiatives involving people with other disabilities and illnesses, as well as carers' groups.

For governments/DH:

- Ensure that all dementia policy initiatives have clear plans for the proper involvement of people with dementia in their design, implementation and evaluation.
- Ensure that this involvement includes active engagement with local groups and projects for people with dementia, as well as high profile, prominent campaigners.
- Offer support and resources (including 'in kind', e.g. venues, access to training, etc.) for the proper involvement of people with dementia in on-going implementation of national dementia strategies, and the PM's challenge, in the design, development and evaluation of initiatives addressing the challenge.
- Promote positive stories of involvement and empowerment to the national media.

For national and local organisations providing services and/or working with people with dementia:

- Clinical commissioning groups, health boards, local authorities, service provider organisations (third sector and 'for profit') – develop and implement involvement plans for people with dementia, with the required support and resources.
- Allocate resources to capacity build local groups and projects and support the development of a national network to link groups together.
- Avoid cuts in funding for groups and projects wherever possible but work in partnership with other organisations to share resources (including 'in kind, e.g. venues) to enable groups under threat of closure to continue.

- Implement practical guidance to be developed by DEEP partners on involving people living with dementia in meetings, events, etc.
- Invite groups to contribute to staff training, design and evaluation of services, etc.
- Signpost individuals with dementia following diagnosis to local involvement groups where the person is expressing an interest in this kind of activity.

For dementia action alliances:

- Develop and implement involvement plans for people with dementia, with the required support, resources and reporting on implementation of those plans.
- Ensure that a commitment to involvement and empowerment is expressed in strategies and public declarations.
- Support groups with resources and ‘in kind’ support e.g. paying expenses, facilitating participation, etc.
- Promote positive stories of involvement and empowerment to the national media.

For specialist health and social care media, and media sections in relevant organisations:

- Incorporate regular features and comments written by people with dementia and reflecting the work of groups and projects involving people with dementia.
- Promote positive stories of involvement and empowerment to the wider media.

For event organisers:

- Incorporate sessions at dementia-related events for groups of people with dementia to talk about their involvement and empowerment activities and work.
- Provide support and resources to enable people with dementia to attend these events.

For trainers and educators:

- Build in regular sessions led by people with dementia in the training and education of students and staff on professional training or dementia-related courses.

For researchers and research networks:

- Involve groups of people with dementia in helping to identify research topics, advising on research findings, discussion and dissemination of findings (recognising this can also help demonstrate research "impact").
- Undertake research on topics identified as important by people with dementia.

For organisations planning to make themselves and their communities more 'dementia friendly':

- Involve groups of people with dementia in developing and evaluating their plans, and providing resources and support to enable their participation to do this.

For health and social care organisations (including third sector organisations) working with 'seldom heard' groups:

Support people with dementia who wish to be involved in influencing activities to participate in existing groups or projects, or to use learning from these groups to develop new groups reflecting the particular needs and issues of those involved.

Notes

1. 'Survivor' can denote being a survivor of a mental health problem and/or a survivor of mental health services where individuals have had particularly negative experiences of care and treatment.

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About the author

Toby Williamson has been Head of Development & Later Life at the Mental Health Foundation since 2002. For the last five years he has been responsible for the Foundation's mental health in later life and dementia programme, as well as leading on its mental capacity work. He has also led on policy work at the Foundation and for 18 months was seconded to work at the Ministry of Justice to work on their Mental Capacity Act Implementation Programme. Before joining the Foundation he worked and managed adult mental health services where he was involved in setting up and managing a variety of services for people with severe and enduring mental health problems living in the community. Throughout his career Toby has had a strong commitment to the active involvement of people with mental health problems and conditions such as dementia, in services or work he has been responsible for. He has personal and family experience of both mental health difficulties and dementia.

Appendices

Appendix A:

Table 3: Summary of policy initiatives and the development of groups and projects involving people with dementia

Year	Group / event involving people with dementia	Geographical coverage	Size	National policy development
1996	Forget Me Not	Local – Swindon	10-20	
2000	Living With Dementia Group	England	40+	
2001	-	-	-	<i>National Service Framework for Older People (DH)</i>
2002	ACE Club	Local – Rhyl, North Wales	5-10	
2003	Scottish Dementia Working Group	Scotland	100+	
2005	-			<i>Everybody's Business – Service Development Guide (CSIP / DH)</i> Mental Capacity Act (MCA) passed by Parliament
2006	1 st UK Convention of People with Dementia – Newcastle upon Tyne	UK	50+	<i>Dementia Guidelines (National Institute for Health & Clinical Excellence)</i>
	Positive Dementia Group	Local – Aberdeen	10-20	
2007	2 nd UK Convention of People with Dementia – Birmingham	UK	50+	<i>Strengthening the Involvement of People with Dementia (CSIP / DH)</i>

				<p><i>Dementia UK 2007</i> (Alzheimer's Society)</p> <p><i>Improving Services and Support for People with Dementia</i> (National Audit Office - NAO)</p> <p>MCA comes into force</p>
2008	The HOPE Group	Local – Brighton	5-10	<p><i>Improving Services and Support for People with Dementia</i> (Public Accounts Committee)</p> <p><i>See me, not just the dementia</i> (CSCI)</p>
2009	Early Dementia Users Co-operative Aiming To Educate (EDUCATE)	Local – Stockport	20-40	<p><i>Living Well with Dementia – National Dementia Strategy</i> (DH)</p> <p><i>Charter of Rights for People with Dementia and their Carers in Scotland</i> (Scottish Parliament Cross Party Group on Alzheimer's Disease)</p>
	Torbay Dementia Leadership Group	Local – Torbay	5-10	
	Doncaster Dementia Forum	Local – Doncaster	20-40	<p>General Election</p> <p><i>Improving dementia services in England – an interim report</i> (NAO)</p>

2010	Open Doors Support Network	Local – Salford	20-40	<i>Quality Outcomes for People with Dementia</i> (DH)
	Think tank event on user-led dementia organisations at DH	England	3	<i>National Dementia Strategy</i> (Scottish Government) Dementia Action Alliance formed (England)
2011	DEEP commences	UK	n/a	<i>National Dementia Vision</i> (Welsh Government) <i>Improving Dementia Services in Northern Ireland</i>
2012	-			<i>Prime Minister's challenge on dementia</i> (DH)

Appendix B: Summaries of the organisations that collaborated on DEEP

Mental Health Foundation

The Mental Health Foundation is the leading UK charity working in mental health and learning disabilities and has significant experience in research, service improvement and workforce development, including service user involvement and empowerment, and policy and public affairs.

The Mental Health Foundation is unique in the way it works: it brings together teams that undertake research, audit, develop services, design training, influence policy and raise public awareness within one organisation. It tackles challenging issues and tries different approaches, using its knowledge to raise awareness, help tackle stigma attached to mental illness, dementia and learning disabilities, and promote coping strategies, recovery and prevention. It does this by working with statutory and voluntary organisations and enabling them to provide better support for people with mental health problems, including dementia, and promote mental well-being. The Foundation also works to influence policy, including Government at the highest levels. It has long standing commitment and track record in undertaking projects focused on the empowerment and involvement of people with mental health problems and conditions such as dementia.

For more information: www.mentalhealth.org.uk.

Innovations in Dementia

Innovations in Dementia community interest company (CIC) is a national organisation that tests opportunities that enable people with dementia to live life to the fullest, promoting a more positive view of dementia. The organisation works with people with dementia, partner organisations and professionals to help people with dementia keep control of their lives by testing new and positive projects and adopting a rights-based approach to challenge discrimination and stigma. It achieves this through the delivery of innovative projects, a training and consultancy service and by influencing dementia practice. Work is generated by, and in response to, the wishes of people with dementia. People with dementia are involved in all aspects of the work of Innovations in Dementia and it works hard to engage with people no matter how advanced their dementia.

For more information: www.innovationsindementia.org.uk.

Alzheimer's Society

The Alzheimer's Society is the leading support and research charity for people with dementia, their families and carers. Its mission is to champion the rights of everyone with dementia and those who care for them.

Alzheimer's Society is a membership organisation, which works to improve the quality of life of people affected by dementia in England, Wales and Northern Ireland. Many of its 25,000 members have personal experience of dementia, as carers, health professionals or people with dementia themselves, and their experiences help to inform our work.

The Society's work takes a wide range of forms. Through its network of local services, the Society touches the lives of over 30,000 people every week, providing practical services and support for people with dementia and their carers. The Society carries out campaigning and lobbying to influence government policies and raise awareness of the challenges faced by people with dementia and the people who care for them. Through its research programme it works to improve the knowledge we have about dementia and its treatment.

The Society's values include a commitment to work proactively to ensure that it reaches out to involve people from every group and community as well as commitments to quality, integrity, innovation, mutual respect and to achieving the best quality of life for people with dementia. Its operating principles include putting people with dementia at the centre of everything it does and working collaboratively where there are clear benefits for people with dementia. It has done this through the Living With Dementia Programme which has a particular focus on growing local capacity around involvement and participation – an example of this approach is the development of local Service User Review Panels which facilitate involvement of people with dementia in influencing national pieces of work without the requirement to travel great distances to participate.

For more information: www.alzheimers.org.uk

Appendix C: Key principles underpinning the project – the four ‘I’s

Involvement and influence – the project will aim to ‘model’ good practice in its involvement of people living with dementia. This will be done primarily through a reference group led by people living with dementia, supported by Innovations in Dementia. There will be active involvement and influence by the very group the project is focusing on – the group will be asked for their views about the questions to be asked in the scoping research and they will take a lead in shaping the programme and other substantive parts of the event. The project will also aim to establish a national network of individuals and groups of people living with dementia who want to shape and lead work in this field in the future.

Iterative – the project needs to be sufficiently flexible to allow the different components and phases of the project to inform each other thereby enhancing and expanding the project. There will be an ongoing process of engagement and involvement of individuals and groups of people with dementia in the project that will enable them as far as possible to actively contribute to shaping the project, and the work that follows. As far as time and resources permit, the scoping research will be informed by the views of people living with dementia who are part of the reference group (as well as the project steering group) but will also be the source for identifying new initiatives, groups and activities involving individuals who may want to be part of the reference group. As far as possible it is also the intention that individuals, groups etc. can join in and participate in the project at the event stage and in making plans for how the work will be taken forward.

Inclusive – the project will not approach the scoping research with fixed, pre-determined ideas about what constitutes initiatives “led”, “controlled” or “properly involving” people living with dementia. At this stage it will be important to allow self definitions of these concepts according to the views of people responding to the survey. The project will also actively seek to engage people living with dementia from ‘seldom heard’ groups e.g. people with more severe dementia / living in care homes, people from Black Asian and minority ethnic groups with dementia etc. The scoping research will contain explicit questions asking about any initiatives actively involving (or led by) people with dementia from these groups.

Into the future – the project will have a strong emphasis on how people living with dementia can be supported to shape and lead work in this field in the future e.g. identifying possible resources to support building a network of initiatives, groups

and organisations led or substantively controlled by people with dementia, capacity building groups, organisations, and individuals with dementia to lead this work, etc. As indicated in the aims, objectives and outputs a key part of the project will be to plan and initiate a process for taking work forward to develop a UK network of initiatives, groups and activities led by or actively involving people living with dementia.

Appendix D: Information about Groups

LEADERSHIP AND ACTIVE INVOLVEMENT GROUPS

ACE Club – Rhyl, North Wales

The ACE Club raises awareness and educates professionals and communities about the experience of living with young onset dementia; it also provides peer support and activities for people living with a diagnosis of young onset dementia in the local community.

Contact person: Vivienne Davies-Quarrell

Telephone: 01745 345369

Email: vivienne@ace-alzheimers.com

Website: <http://ace.glendevon-care.com/>

Doncaster Dementia Forum – Yorkshire

The Forum lobbies and influences local service development and holds the local Older People's Mental Strategy Group to account.

Contact person: Wayne Goddard

Telephone: 01302 566500

Email: Wayne.goddard@doncasterpct.nhs.uk

Website: n/a

EDUCATE (Early Dementia Users Co-operative Aiming To Educate) – Stockport

EDUCATE looks to give people living in the Stockport area with dementia a voice through involvement in training, or speaking to others about their experiences of having dementia.

Contact person: Mark Perry

Telephone: 0161 419 6016

Email: markperry@nhs.net

Website: n/a

Forget Me Not – Swindon

Forget Me Not are a group of people with dementia under the age of 65 who come together for peer support and social activities as well as raising awareness about dementia with professionals and in their communities.

Contact person: Lynda Hughes

Telephone: 01793 436775

Email: Lynda.hughes@awp.nhs.uk

Website: n/a

Hope Group – Brighton

HOPE is a group of people living with dementia who aim to: increase the knowledge of all staff and students in health and social care by sharing our experiences of living with dementia; to improve the situation of people with dementia and their carers by raising awareness through training; to work in partnership with professionals to promote better working relationships for the benefit of professionals and people living with dementia.

Contact person: Kirsty Jones

Telephone: 07702 096264

Email: kirsty.jones@westsussex.gov.uk

Website: n/a

Living with Dementia Group – England

The Living With Dementia Group (LWDG) has been part of the Alzheimer's National Living With Dementia Programme which has involved people with dementia sharing their experiences and knowledge, and raising awareness of dementia at local and national levels through a wide range of activities including giving presentations, media work, influencing policymakers and acting as a consultative body for the Society. The Society is currently reviewing its approach to involvement as the first stage of a new 5 year development programme.

Contact person: Gaynor Smith

Telephone: 0207 423 5158

Email: gaynor.smith@alzheimers.org.uk

Website: www.alzheimers.org.uk/involvement

Open Doors Project – Salford, Greater Manchester

The Open Doors Project employs a person with dementia and leads on the development of a range of initiatives across Salford, including a dementia cafe providing post-diagnostic education and support (in conjunction with memory services), a friendship and support network for individuals newly diagnosed, participates in steering groups in relation to key service redesign, provides education to professionals in relation to dementia, and supports and disseminates research and development in dementia in conjunction with Manchester University.

Contact person: Gillian Drummond

Telephone: 07771972628

Email: gillian.drummond@gmw.nhs.uk

Website: n/a

Positive Dementia Group – Aberdeen

The group has been involved in awareness raising through giving talks to students, chaplains, social workers etc. They have also been involved in media work (e.g. radio interviews, TV, newspaper articles & 'Through Our Eyes' DVD). Some members have spoken at conferences about their experience. They have also been involved in consultation by the local authority/NHS to use their experiences and comments in influencing policies/strategies including more recently the Scottish Dementia Strategy. Some are involved in research too.

Contact person: Sarah Geoghegan

Telephone: 01224 644627

Email: sgeoghegan@alzscot.org

Website: www.alzscot.org

Scottish Dementia Working Group (SDWG) – Scotland

The SDWG is a national campaigning and awareness raising group made up of over 100 people with dementia.

Contact person: Martin Sewell

Telephone: 0141 418 3939

Email: sdwg@alzscot.org

Website: www.sdwg.org.uk

Torbay Dementia Leadership Group – Devon

This is an Empowerment Group of people with an early diagnosis of dementia which provides peer support, discusses matters and services concerning people with dementia, and is active in influencing local services and organisations.

Contact person: Norms McNamara

Telephone: 01803 669216

Email: norrms@gmail.com

Website: n/a

ACTIVE INVOLVEMENT GROUPS

Alzheimer's Society Research Network – England

Alzheimer's Society Research Network is a team of over 200 carers and people with dementia who are involved in setting the Society's research priorities, prioritising and commenting on grant applications, sitting on grant selection panels, monitoring on-going projects funded by Alzheimer's Society and telling others about the results of the research.

Contact Person: Matt Murray

Telephone: 0207 423 3603

Email: matt.murray@alzheimers.org.uk

Website: www.alzheimers.org.uk/researchnetwork

Alzheimer's Society Service User Research Panels (SURPS) – England

SURPS are small groups of people with dementia who use existing Alzheimer's Society services and who meet regularly to review organisational tools such as evaluation questionnaires, materials such as information leaflets, and processes such as service development. They also respond to requests from external organisations to discuss issues or developments relevant to dementia. SURPS are facilitated by a member of Alzheimer's Society staff but in a way that prioritises the needs, choices and views of panel members. In this way SURPS act as a way for people with dementia to make their voices heard.

Contact Person: Jane Tooke

Telephone: 0207 423 5135

Email: jane.tooke@alzheimers.org.uk

Website: n/a

Bay Tree Voices – Bradford

People with dementia involved in making film clips which are used in educating care practitioners.

Contact person: Andrea Capstick

Telephone: 01274 235192

Email: a.j.capstick@bradford.ac.uk

Website: n/a

Circles of Support for People with Dementia – England

A project to develop circles of support for people with dementia – people with dementia are actively involved in advising on the project.

Contact Person: Alison Macadam

Telephone: 01202 471423

Email: alison.macadam@ndti.org.uk

Website: www.ndti.org.uk

Involvement Project – Involving people living with Dementia – South West England

The project worked in partnership across health, primary, social care and voluntary organisations, to strengthen and enable engagement and involvement with those living with dementia in the south west. This has included developing 'what works for involvement' resource cards); measuring and monitoring the improvements that have been made as a consequence of engaging and involving those people living with dementia to inform the implementation of the National Dementia Strategy; and building a network of involvement opportunities for people with dementia across the south west that offers a coordinated approach through which they can communicate their views in shaping what help and support is needed now and in the future.

Contact person: Anne Rollings

Telephone: 0117 9672992

Email: anne.rollings@alzheimers.org.uk

Website: n/a

Memory Services National Accreditation Programme (MSNAP) – England

MSNAP works with services to assure and improve the quality of memory services for people with memory problems / dementia and their carers. Involving service users and carers in MSNAP is a priority, and people with first hand experience of using memory services are encouraged to get involved in all stages of the accreditation process.

Contact person: Emily Doncaster

Telephone: 020 7977 6644

Email: edoncaster@cru.rcpsych.ac.uk

Website: www.rcpsych.ac.uk/memory-network

West Berkshire Empowerment Group – Berkshire

The Empowerment Group, all of whom have memory problems, meet monthly over lunchtime followed by a meeting to discuss steering the work of the local Alzheimer's Society, GPs, Memory Clinics, NHS services etc.

Contact Person: Claire Garley

Telephone: 01635 500869

Email: claire.garley@alzheimers.org.uk

Website: n/a

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