

Ripple on the Pond

DEEP: The engagement, involvement and empowerment of people with dementia in collective influencing

Appendix to main report – A stronger collective voice for people with dementia

October 2012

Introduction

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 initially a one year project which finished in 2012.

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. DEEP was funded by the Joseph Rowntree Foundation., which is available at: <http://www.jrf.org.uk/publications/my-home-life>

Acknowledgements

This Appendix was compiled by Toby Williamson, Head of Development & Later Life at the Mental Health Foundation. In addition to those named in the main report we would also like to thank Katrina Jenkins for helping to collate some of the information in this Appendix.

Contents

- 01** **Section 1** – Literature review
- 27** **Section 2** – Survey questionnaires
- 57** **Section 3** – Data tables from questionnaires
- 62** **Section 4** – Selection of group responses from the detailed survey
- 90** **Section 5** - Selection of individual responses from the survey
- 96** **Section 6** – Transcripts of group interviews

Section 1 – Literature review

The literature review is in two Parts. Part 1 is a non-systematic description of some of the key themes relating to service user involvement, participation and empowerment from the perspective of groups of people with different disabilities, illnesses and conditions. Part 2 is rapid, systematic review of literature, focused specifically on service user involvement, participation and empowerment relating to people with dementia.

Part 1 – generic literature review

An important part of DEEP was to consider the experience, learning and expertise that have emerged from “service user” movements involving people with disabilities, illnesses and conditions. Although there are elements which will differ according to the different diagnoses there are also likely to be generic aspects and approaches which are of relevance to the growth of participation and leadership involving people with dementia.

There is an extensive range of books, articles, and guidance on service user participation and empowerment that involves people with other illnesses, disabilities and conditions. There are also a number of well-established organisations that are active in this field, working with, or made up of people with different disabilities, illnesses and conditions. It was not possible within the time and resources available to do a comprehensive review of everything that has been published in this field or to list all those organisations. The methodological approach was therefore much more selective and illustrative than that used for the dementia literature review. Its aim was to identify some key organisations and selected works as examples to illustrate important themes that have emerged about participation and empowerment from these other groups.

Identity and power

Issues of identity and power lie at the heart of participation and empowerment, particularly in relation to people with illnesses and disabilities. How individuals and groups define and identify themselves in relation to participation and empowerment activities they are involved in is clearly a critical issue.

There is an extensive literature covering these issues but recent articles of interest include Armes (2009), Jonson & Larsson (2009), Lakeman (2007), Masterson & Owen (2006), Wallcraft (2004) and Williamson & Crepaz-Keay (2006).

Key issues identified include:

- The terminology that people use to define themselves and groups they are in
- Who is included (and excluded) from groups representing specific illnesses, conditions and disabilities
- Issues of representativeness –how can and do service user groups represent others with the same illness, disability or condition?
- Differentials of power and power dynamics that exist between service user groups and the services or organisations they are seeking to influence
- The tensions created for individuals and groups being identified by, or forming themselves around, a specific disability or diagnostic label, while at the same time challenging the stigma associated with the disability or diagnosis, and even challenging the conceptualisation or validity of the diagnosis or disability
- The risk of groups that are seeking to challenge particular discourses about an illness or disability and formal structures, adopting similar hierarchies and structures to achieve their ends. In doing this they run the risk of becoming over-professionalised, more easily incorporated by the power structures they are seeking to challenge, and excluding services users who are not able or willing to participate in this way

Leadership, activism, empowerment and policy

Official recognition at a national policy level of the importance and value of user involvement goes back a number of years. In 2004 the Department of Health (DH) in England published Patient and Public Involvement in Health: The Evidence for Policy Implementation (Department of Health 2004) which described the benefits of involvement both in relation to an individual's care and treatment as well as in

the planning and delivery of services. In the same year the Social Care Institute for Excellence (SCIE) published a Position Paper summarising six literature reviews looking at the impact and benefits of service user participation for social care services (SCIE 2004).

In 2010 the Office for Disability Issues (ODI) published *Making the most of partnership boards: Advice for disabled people and their organisations*. This encouraged participation through a model of 'co-production' whereby groups of disabled people should work in partnership with public and private sector organisations. Under this approach disability groups were encouraged to "be a partner first, a campaigner second". The Joseph Rowntree Foundation in its 2009 report, *Citizen Involvement* makes the point that pressure from service user groups remains an essential part of public sector reform which, although not always easy to quantify, should not be over regulated by public services.

The importance of sharing power and creating opportunities for dialogues between services and service users is explored more by Hernandez et al (2010) and Bolam et al (2010). Branfield et al (2006, 2009) have a different emphasis that focuses on networking and sharing experience between service user groups as a way of capacity building and increasing service user involvement. McLean and Andersson (2009) suggest some practical tools for doing this.

The impact that more 'bottom up' approaches can have is explored by McMillan et al (2009) in a study about the relatively successful campaign by a group of younger mental health service users in Northern Ireland to change policy, using a human rights approach, around suicide and self-harm. However the study also identified limitations in the way governments engage with service users.

Leadership as a concept can be problematic for service user movements as it implies hierarchy and unequal distributions of power which many service user groups may be explicitly wishing to challenge. O'Hagan (2009) explores this further and suggests that new models of learning may be needed for service user movements which are embedded in the values of empowerment and equality. A collaborative and co-operative model of leadership involving both mental health service users, family carers and service providers in Ireland is discussed by MacGabhán et al (2010).

Wallcraft (2003) is an extremely comprehensive report of mental health service user groups in England. The report was published on behalf of the User Survey Steering Group and details a survey which looked at 318 user groups, representing some 9,000 service users. It describes the development of the movement and the activities that local groups undertake. It also reports on the effectiveness of user involvement, asks how representative the movement is and looks at shared issues and differences. Although many of the groups will probably have changed over the years the issues it covers remain very pertinent.

Wood & Wright (2011) discuss the barriers that older people face in being able to participate in activities that influence their communities. They describe two case studies that illustrate how these barriers can be overcome which demonstrate that older people do want to be involved and are enthusiastic participants when given the opportunity to use their voice.

Planning, design and delivery of services

Clearly evaluations of health and social care services need to take into account the views of people who use them. However there have also been a number of initiatives that have involved service users in undertaking service evaluations, in recognition of the important perspective they can bring in determining what is important to evaluate from a service user perspective, and their ability to engage with service users to elicit their views in ways that professional evaluations may not be able to achieve. A couple of examples include User-Focused Monitoring developed by the Centre for Mental Health (more information available at: <http://www.centreformentalhealth.org.uk/policy/ufm.aspx>), and engaging older people as 'community researchers', working in partnership with academics in reviewing services (Evans et al 2011).

Approaches to developing services that involve partnerships, collaborations or 'co-production' feature significantly in the literature and practical examples of this, together with the challenges they may generate, are also covered in Bolam et al (2010), which uses the concept of "experts by experience" to describe the contribution that mental health service users can make in a service development project on Jersey. Horrocks et al (2010) examine mental health service user involvement in service development in Lancashire and the difficulties of ensuring that

the benefits are experienced by all service users, and it doesn't become tokenistic. Harding et al (2011) describe the involvement of mental health service users in the development of clinical guideline programmes for the National Institute of Clinical Excellence, raising the issue of the relative value of personal versus professional knowledge, and issues of power, decision-making and group dynamics.

Education and training

The involvement of people with illnesses, disabilities and conditions in education and training is well established. This recognises the important learning value for students training to work in health and social care, as well as staff already working in these sectors who are undergoing further training, of hearing directly from service users describing their lives and experiences of receiving care and treatment.

There is an extensive literature in this field including articles on involvement and participation in social work education (Branfield 2009, Matka et al 2010), psychiatry (Babu et al 2008, DiMambro & Moody 2009), and nursing (Jones & Black 2008) as well as inter-professional education (Cooper & Spencer-Dawe 2006, Benbow et al, 2008).

In 2004 (updated in 2011) the Mental Health in Higher Education (MHHE) project published a good practice guide, Learning from experience: involving service users and carers in higher education (MHHE 2011).

There is widespread agreement about the benefits of involving service users in delivering education and training, including for service users themselves in terms of new skills, increased confidence and self esteem. Key issues include:

- the importance of providing training and support to service users
- being clear about the role service users were expected to fulfil in teaching sessions or other aspects of education and training programmes
- properly remunerating service users for their involvement but being mindful of issues this may pose for service users on welfare benefits
- ensuring that students recognise the contributions of service users as an important part of their learning and that they treat service users with respect

Research

Research has been an important area where people with a range of different disabilities, illnesses and conditions have become increasingly active. Having long been the subjects of research (some of dubious ethics, quality or relevance to service users' lived experience) in the late 1990s a number of individuals and organisations undertook research projects or programmes where service users took a lead in determining the research topics and methodologies to be used. Examples of this in the field of mental health include the Mental Health Foundation's user-led research programme Strategies for Living (Mental Health Foundation 2000) and a number of universities, as well as the Institute of Psychiatry have also supported service user research groups. The Foundation went on to support the Service User Research Group in England (SURGE) which was part of the National Institute for Mental Health in England's research network. This produced good practice guidelines for the involvement of service users in mental health research (Guidance for Good Practice Mental Health Research Network, 2005) and a recent article has argued that service user involvement is now in the mainstream of mental health research (Rose et al).

A number of organisations have supported and promoted the active participation of people with disabilities in research with other groups, and more widely. These include the Centre for Disability Studies at Leeds University, the Joseph Rowntree Foundation (JRF), and the service user-led organisation, Shaping Our Lives (SOL). The JRF published Research as empowerment (JRF 2005) which provided a good overview of key issues relating to service user involvement in research. Our lives, our communities (JRF 2007) was an example of people with learning disabilities undertaking and controlling research using their own methods. In 2009 SOL published a report on how service users could be more actively involved in research. Key issues that emerge from the literature include:

- Difficulties of securing funding for service user-led research
- Providing training and support to service users to enable them to undertake

research if they don't have prior knowledge or experience of doing research

- Valuing service user research alongside other research even though it may often be on a smaller scale than large projects run by professional researchers

Organisations

There are also a number of national organisations in the UK which are either led by people with disabilities and long term conditions, or actively promote their involvement and participation.

- Shaping Our Lives is an independent service user-controlled organisation, think tank and network which is open to anyone using "welfare" services (broadly speaking, health and social care services). For more information go to: www.shapingourlives.org.uk
- Disability Rights UK is also a national pan-disability organisation led by disabled people although it has more of a campaigning focus. For more information go to: <http://disabilityalliance.org/>

Other organisations led by people with disabilities/older people that are more specific in who they represent include:

- National Pensioners Convention (NPC) is a campaigning organisation made up of pensioners that represents local pensioner groups and forums. For more information go to: <http://npcuk.org/>
- National Survivor User Network (NSUN) - an independent network of individuals and groups who have direct experience of mental health distress and/or using mental health services in England. A similar group, Voices of experience (VOX) exists in Scotland. For more information go to: <http://www.nsun.org.uk/>
- People First - an organisation run by and for people with learning difficulties to raise awareness of and campaign for the rights of people with learning difficulties and to support self advocacy groups across England and Northern Ireland. Similar organisations exist in Scotland (People First (Scotland)) and Wales (Wales People First). For more information go to www.peopelfirstltd.com
- Voices of Experience (VOX Scotland) – Scotland's national mental health service user-led organisation that works in partnership with mental health and related services to ensure that service users get every opportunity to contribute positively to changes in the services that serve them and wider society. For more info: <http://www.voxscotland.org.uk/>

Most significant long term conditions have specific organisations (usually charities) that seek to represent people with that condition (the Alzheimer's Society being the biggest organisation working in the field of dementia) although not all are led by people with that condition. For obvious reasons they are too numerous to list but National Voices is a coalition with over 150 of these charities working in the field of health and social care, which calls for a stronger patient, service user and public voice in the design and delivery of services. The Office for Disability Issues (ODI) was set up in 2005 to co-ordinate disability policy across government and has produced guidance and other resources to support the involvement of people with disabilities in policy making at: <http://odi.dwp.gov.uk/involving-disabled-people/index.php>. The NHS also promotes involvement through its Local Involvement Networks (LINKs) and national advisory groups such as INVOLVE (<http://www.involve.org.uk/>) which supports greater public involvement in NHS, public health and social care research e.g. Mclean & Andersson 2009). SCIE has an excellent set of resources covering a wide range of participation issues including research and education at <http://www.scie.org.uk/topic/keyissues/participation>.

References

- Armes D. (2009). 'Mission informed discursive tactics of British mental health service-user/survivor movement (BSUSM) resistance to formalization pressures accompanying contractual relationships with purchasing authorities' *Journal of Mental Health* Vol. 18, No. 4, 344-352
- Babu KS, Law-min R, Adlam T, and Banks V (2008). Involving service users in psychiatric education: what do trainees think? *The Psychiatrist*, 32, 28-31
- Benbow S, Taylor L & Morgan K (2008). 'Multiple perspectives: involving users and carers in educating health and social care professionals' *Quality in Ageing*, Vol. 9 Issue 2, 12-17
- Bolam S, Carr, S & Gilbert P (2010). 'The Partnership Project: learning from experts by experience in mental health services; the Jersey Partnership perspective'. *International Journal of Leadership in Public Services*, Vol 6, Issue 2, 54-67.
- Branfield F (2006). *Making User Involvement Work: Supporting service user networking and knowledge*
- Branfield F (2009). *Relationship Matters: Building our knowledge and networks.*
- Cooper H & Spencer-Dawe E (2006). 'Involving service users in interprofessional education narrowing the gap between theory and practice'. *Journal of Interprofessional Care* Jan 2006, Vol. 20, No. 6, 603-617
- DiMambro B & Doody G. (2009). 'Service user organisations: an untapped teaching resource'. *Psychiatric bulletin of the Royal College of Psychiatrists*. Vol 3, No. 33, 72-74.
- Evans S, Corley M, Corrie M, Costley K & Donald C (2011). 'Evaluating services in partnership with older people: exploring the role of 'community researchers'', *Working with Older People*, Vol. 15 Issue 1, 26-33
- Hernandez L, Robson, P & Sampson A (2010). 'Towards integrated participation: Involving seldom heard users of social care services'. *British Journal of Social Work*, 40 (3), 714-736.
- Horrocks J, Lyons C & Hopley P (2010). 'Does strategic involvement of mental health service users and carers in the planning, design and commissioning of mental health services lead to better outcomes?' *International Journal of Consumer Studies*, Vol 34, Issue 5, 562-569.
- Harding E, Pettinari C, Brown D, Hayward M & Taylor, C (2011). 'Service user involvement in clinical guideline development and implementation: Learning from mental health service users in the UK.' *International Review of Psychiatry*, Vol 23, No. 4, 352-357
- Jones K & Black D (2008). 'Involving mental health service users in student education', *Nursing Times*, 104, 29, 32-33
- Jonson H & Larsson A (2009). 'The exclusion of older people in disability activism and policies – a case of inadvertent ageism?' *Journal of Aging Studies*, Vol 23, Issue 1 69-77.
- Joseph Rowntree Foundation (2005). *Research as empowerment*. JRF
- Joseph Rowntree Foundation (2007). *Our lives, our communities*. JRF.
- Lakeman R, McGowan P & Walsh J (2007). 'Service users, authority, power and protest: A call for renewed activism' *Mental Health Practice*, Vol 11, Number 4.
- MacGabhann L, McGowan P, Walsh J & O'Reilly O (2010). 'Leading change in public mental health services through collaboration, participative action, co-operative learning and open dialogue'. *International Journal of Leadership in Public Services*, Vol 1, Issue 6, 39-50.
- Masterson S & Owen S (2006). 'Mental health service user's social and individual empowerment; using theories of power to elucidate far-reaching strategies' *Journal of Mental Health* Vol. 15 Issue 1, 19-34
- McLean S & Andersson E (2009). *Activating Empowerment: Empowering Britain from the bottom up*. INVOLVE

McMillan, F, Browne N, Green S & Donnelly D (2009). 'A card before you leave: Participation and Mental Health in Northern Ireland'. *Health and Human Rights: An International Journal* Vol 11, Issue 1, 61-72.

Matka E, Dawn R, Littlechild R & Powell T (2010). 'Involving service users and carers in admissions for courses in social work and clinical psychology: cross-disciplinary comparison of practices at the University of Birmingham'. *British Journal of Social Work* Vol 40, Issue 7, 2137-2154.

Mental Health Foundation (2000). *Strategies for Living*. Mental Health Foundation

O'Hagan M (2009). 'Leadership for empowerment and equality: a proposed model for mental health user/survivor leadership'. *International Journal of Leadership in Public Services*, Vol 5, Issue 4, 34-43.

Rose D, Fleischman P & Wykes T (2008). 'What are mental health service users' priorities for research in the UK?' *Journal of Mental Health* Jan 2008, Vol. 17, No. 5, 520-530.

Wallcraft, J. (2003). *On our own terms*. Centre for Mental Health

Williamson T & Crepaz-Keay D (2006). 'When opposites attract?' *A life in the day* Volume 10, Issue 3, 3-7

Woods C & Wright M (2011). 'Promoting involvement of older people in shaping policy and practice'. *Working with Older People* Vol. 15, No. 2, 80-86.

Part 2 - DEEP Rapid Literature Review on involving and empowering people with dementia

Aim of rapid literature review

The main aim of this review is to summarise the evidence available about the active engagement and involvement of people with dementia in services, campaigns and research. The review was not intended to be systematic, or necessarily looking to retrieve gold standard evidence, but rather was focused on recovering research and guidance about the involvement of the perspectives of people with dementia in all aspects of their lives.

The focus is not on person centred care on an individual basis, but on examples of activities which have been undertaken to ensure that the voices of people with dementia are heard and incorporated within service design, policy development and campaigning activities (although there are several examples of where people have combined these – see for example Johnson, A, 'Learning lessons: how I live with my Alzheimer's disease' *Journal of Mental Health Training, Education and Practice* Volume 5, Issue 3, 2010 p7-9).

Methodology

Recognising that the research evidence base for this review may be small, the methodology for this review incorporated both a search for peer reviewed research (literature reviews and primary research) and a search for good quality grey literature. Searches were made for evidence on the involvement of people with dementia published in English between the years of 1996 and 2011. Both UK based and international studies were included in the study. A total of 186 peer reviewed articles and 58 grey reports were identified, and following a screening and data extraction processes, 18 articles and 18 grey reports were selected for inclusion in the review.

Results

This review was not designed to be systematic, and consequently does not claim to fully represent the evidence on the involvement and empowerment of people with dementia. Rather, it provides an overview of published dementia research with a focus on involvement in the spheres of service development, research and evaluation, campaigning and training and education.

The review includes 36 papers, of which 18 are peer reviewed articles and 18 are grey reports. Thirty three of the papers were from the UK, two were from the US and one

from Canada. All international papers were included because of the transferability of their learning.

The studies included were primarily qualitative in nature (n=21) although a small number used mixed qualitative and quantitative methodologies (n=4). The remaining 11 articles and reports are international literature reviews, evidence summaries or guidance documents.

Sample sizes tended to be small, ranging from one participant to 308. Given that the methods utilised were primarily qualitative, this is to be expected. However, small sample sizes do inhibit the ability to generalise findings for all people with dementia, and all conclusions reported in this review should therefore be treated with a degree of caution.

The results are presented below according to the type of involvement they explore: activism and campaigning (n=2), policy development (n=2), professional education and staff training (n=3), service development, delivery and evaluation (n=14) and research (n=15). Although there is some degree of overlap between these categories, they broadly point to the different levels of participation as described in Arnstein's Ladder of Citizen Participation, commencing with activities which offer higher levels of participation.

Activism and campaigning

Two studies explore the participation of people with dementia in campaigning and activism to achieve positive change for people with dementia and increase public understanding of the condition.

Clare (2008) explores the experiences of seven members of Dementia Advocacy and Support International (DASNI) through a series of interviews and surveys. DASNI is an internet based self help and mutual support network for people with a dementia diagnosis, which advocates for improved services for people with dementia and aims to empower people with dementia to actively participate in their own care and treatment.

Participants in Clare's study described a number of individual benefits gained from joining DASNI, including peer support, a sense of belonging and increased understanding about their condition(s). Participants also indicated that membership of DASNI had encouraged them to speak out about their condition and challenge the stigma associated with dementia, whether at a local level or through presenting at international conferences. Clare (2008) recognises the potential for the internet to support activism and involvement of people with dementia, both in terms of linking together peers internationally and providing a platform which suits the needs of people with early-stage dementia (for example providing a record of past communications and flexibility in terms of when and how to respond). One of the key challenges for DASNI members highlighted by Clare was achieving consensus on "controversial" issues, such as assisted dying. Nevertheless the "collective strength" gained from membership of DASNI was described as supporting resilience and enabling members to contribute to changing attitudes and practice in a wider context. Clare acknowledges that this small study focused on a number of "exceptional" individuals who held leadership positions within DASNI, but proposes that the example they offer provides an important alternative model for living meaningfully with dementia.

Bartlett (2010) undertook research with 16 people across England and Scotland who had all been involved in dementia activism to a greater or lesser extent. Bartlett describes a variety of methods of activism employed by people with dementia, both at individual and groups levels such as blogging, writing to MPs, lobbying politicians, running a campaign group and presenting at international conferences. The motivations for activism for participants included feelings of exclusion and paternalism which had served to negate their individual identities, and a desire for development and growth in their lives following the initial shock of diagnosis. Participants reported that their activism had increased their wellbeing and self worth as well as being an enjoyable and learning experience.

Policy development

Two studies describe ways in which individuals with dementia have become involved in policy development activities at national levels, and some of the barriers and facilitators to their involvement.

Weaks (2011) describes the work of the Scottish Dementia Working Group (SDWG), which was set up in 2002 to lobby for service improvement for people with dementia. The group comprises over 100 members across Scotland, all of whom have a diagnosis of dementia, and is supported by 3 staff, line managed by Alzheimer Scotland. Following a strategic review in 2010, the group have agreed three priorities for action: early diagnosis, good post diagnosis support and a well trained workforce. Underpinning these priorities is work to increase membership and develop the skills of members, to support greater involvement in campaigning and lobbying activities to achieve these changes.

Amongst the many achievements of the group has been shaping Scotland's national dementia policy agenda through developing strong links with the Scottish Government, sitting on the Scottish Dementia Forum and playing an active role in the consultation for the Scottish Dementia Strategy. Another core area of work for the group has been around training the workforce through giving lectures to a range of health and social care professionals, students and volunteers. Three DVDs have been produced to support these training activities. Members have also been active on work to challenge the stigma associated with dementia, such as challenging negative depictions of dementia in the media and speaking out publicly about their condition.

Weaks describes the original motivations for individual involvement in the group, which include finding out more about their condition, sharing experiences and peer support, but highlights that motivations appear to develop over time, with more experienced members being more drawn by the opportunity to campaign for change and make a difference. However, Weaks also explores some of the costs to being a member of SDWG, which include fatigue and loss of personal time, particularly when travelling to meetings or conferences. One of the challenges the group faces is recruitment, support and retention of members, particularly when individuals become less able to participate. However, the group endeavours to involve people for as long as possible through home visits and peer support.

The benefits experienced by members of SDWG include friendship and camaraderie, increased confidence and self esteem, the development of new skills, being part of an international "dementia family" and pride in seeing changes take place as a result of their direct input.

Levenson (2009) describes the Listening Well project, designed to ensure that the views of people with dementia were authentically included in the development of Northern Ireland's dementia strategy. Using interviews and focus groups with 14 people with dementia, the report presents the recommendations generated by people with dementia on the themes of raising awareness of dementia; improving the experience of diagnosis; improving access to information, support and advocacy after diagnosis, and; further research into the views of seldom heard groups.

Professional education and staff training

Three studies explore the role of people with dementia in professional education and staff training sessions.

Hope (2007) undertook a small exploratory study to discover the extent to which people with dementia were involved in educating professionals who work in dementia care. A survey and focus group were undertaken with members of the Higher Education Network for Dementia (HEDN), a group of academics who seek to promote and influence the provision of dementia education for health and social care professionals. Of those members who took part in the study (number unstated), only one had directly involved people with dementia in carrying out teaching sessions and there were no examples of HEDN members who had involved people with dementia directly in curriculum planning. However, there were some examples of academics incorporating the perspectives of people with dementia in more indirect ways, such as utilising first person written accounts and video recordings. The author argues that these had the advantage of being reusable, and could be less intrusive for the individuals involved, but lacked the power of face to face encounters.

Hope suggests that practical and ethical constraints, combined with the potentially stressful nature of classroom settings all act as barriers to involving people with dementia in education. He highlights the potential role of the internet in providing a source of interactive first hand experiences of people living with dementia which could be of benefit to students in learning contexts.

Dodds (2003) presents two case studies of situations where people with dementia have assisted with educational processes. In one example, an individual with

dementia and their carer gave permission for an audio tape recording of their experiences to be used as training material for student nurses. In this instance, students were invited to offer comments which were fed back to the couple involved and discussed with them, thereby allowing them to obtain feedback on the impact of their story on the students. Dodd indicates that the couple gained positive benefit from this process through feeling that they were contributing and changing perceptions of dementia. As with Hope, Dodds felt that the audio tape method was less intrusive for the individuals involved than speaking in person.

Dodds' second case study involved a person with dementia participating in staff training on an impromptu basis. In this example, the individual shared her experiences of dementia with staff and made suggestions for a proposed reminiscence project within the care home in which she lived. Dodds observed improvements to individual wellbeing during and after the training session as well as positive feedback from staff on the value of involving someone with dementia in this training exercise. In her conclusions Dodds emphasises the importance of reciprocity when seeking to involve people with dementia in education. She argues that it is important that the experience is a positive one for individuals as well as practitioners, that the learning is reciprocal and that their contribution is not an isolated event.

Bartlett (2010) describes two cases where individuals with dementia had been involved in educating health care students. In both of these cases the individuals involved had kept their diagnoses secret until the end of the talk, to subvert student preconceptions about what people with dementia can and cannot do. This had proved a very successful strategy in both instances.

Service development, delivery and evaluation

There is growing recognition that people with dementia have a role to play in evaluating the effectiveness of their support and care. Lorentzon (2007) summarises some of the research and policy evidence which supports the involvement of people with dementia in service planning. She argues that evidence suggests people with dementia want more power over decision making and that dementia research studies have begun to illustrate methods through which the views of people with dementia might be appropriately gathered. However, although Lorentzon recognises that there is greater awareness now of the need to involve people with dementia in service planning, she concludes that this awareness not been translated into action to any great extent within service settings. She argues that it is the role of government and service agencies to facilitate greater involvement and participation by people with dementia.

However, whilst acknowledging Lorentzon's argument that more could be done to turn enthusiasm into action, there were five examples in the grey literature where services had developed approaches to involve people with dementia in service development, particularly within the voluntary sector.

In 2006 the Alzheimer's Society of Canada (ASOC) published a report on their work to engage people with early stage dementia in their organisation. Researchers interviewed 9 active volunteers about their work for the Society and 24 support group members about their views on becoming a volunteer. They also surveyed staff from across Canada about the role of volunteers in their local branches. The researchers found that the most common role for volunteers within ASOC was in education and awareness raising about dementia, aimed at a range of different audiences including local service clubs, college students and the media. Volunteers had also spoken at national conferences and events, contributed to fundraising activities, were local branch board members and had been involved in policy development.

Current volunteers described a high level of motivation to inform the public about dementia and suggested that their involvement had led to increased self-esteem and had given a "voice" to the experience of living with dementia. Staff surveyed indicated that the volunteers had helped to break down the stigma associated with dementia, had given hope to others and encouraged individuals to seek early diagnosis.

A number of barriers to participation were highlighted by volunteers including conflicting time commitments, transport problems and financial concerns. Volunteers also indicated that there was still a tendency in some parts of ASOC to focus on the limitations of the disease rather than emphasising what people were able to do and contribute to the organisation at that moment in time.

Whilst staff recognised that extra time was required to support volunteers within the organisation, only 14% of staff that responded to the survey indicated that

they provided volunteer training, such as media training, to support volunteers in their roles. A number of useful suggestions were given by volunteers and staff as to how individuals with dementia could be further supported to help them undertake volunteer educator roles. These included: training for staff in supporting volunteers; staff fielding all public speaking and media requests; and support for volunteers to prepare presentations. For those research participants who were not currently volunteers for ASOC, suggestions were made for strategies to encourage their involvement, including providing information on volunteering opportunities and one to one meetings with staff to discuss how they could get involved.

The following recommendations were made to enhance the role of people with dementia within the Alzheimer's Society of Canada; develop a strategic direction, policy statements and goals for consumer inclusion; pursue enhanced funding to free staff to support volunteers and cover volunteer expenses; provide support and training for staff and volunteers; provide information and support for consumers around volunteering; involving people with dementia in advocacy and lobbying.

Beard (2004) describes a qualitative study of 18 people with Alzheimer's disease discussing their involvement in action to inform research, practice and policy within the Alzheimer's Association in America. Beard highlights a number of barriers to involvement including; the limiting impact of dementia itself (both socially and personally); the traditional focus by dementia organisations on the needs of carers rather than individuals with dementia; lack of funding; lack of organisational policies on user involvement; family and carer concerns;

As a facilitator to involvement Beard recognises the commitment which is manifest in many people with dementia to help improve care and support for people with this condition. She also acknowledges the role local dementia support groups have in terms of identifying potential spokespeople and lobbyists who could take this work forward.

Howorth (2011) describes the work of the Open Door network, which was set up to enable people with dementia and their carers to get involved in service design and delivery in Salford. The network is co-ordinated by an individual with dementia, in what is thought to be the first example of someone with dementia actively recruited to a paid position within the NHS. The authors emphasise the significance of the co-ordinator's position as a positive role model for the active and meaningful role individuals with dementia can play. Factors which facilitated the creation of such a position included; offering a short term contract in recognition of the progressive nature of the condition; making the recruitment process as transparent and supportive as possible, such as including individuals with dementia on the interview panel; and a flexible work plan which could be shaped by the co-ordinator.

Chaston (2004) describes the development of PROP (People who Rely on People) in Doncaster, which was set up to enable people with young onset dementia to have a say in the services they were offered. Supported by a committee, members participate in local service planning meetings and national policy consultation events. Amongst its many achievements have been designing care plans, information leaflets and advance directive templates, giving presentations to health professionals on the personal impact of dementia, and being on interview panels for the local young onset dementia service.

Chaston highlights the following factors as contributing to the success of PROP: informal meetings with short agendas; the provision of training to members to support their roles; social activities to forge group identity and independence and self-organisation which enables the group to be responsive to local needs. Amongst the outcomes expressed by members include delaying "institutionalisation", preserving vocational skills, regaining lost confidence and feeling more in control of their future.

McAndrew (2006) describes the involvement of people with dementia in the development of a five year service strategy in Armagh, Northern Ireland. The consultation process used a mixed methodology of one to one interviews and a workshop involving people with dementia, carers and health professionals working together. McAndrew identified that an informal atmosphere and accessible venue supported the involvement of people with dementia.

A discursive article by Ashley and Savitch (2009) explores the potential for paying people with dementia for their education and policy development roles within voluntary organisations. It is argued that payment places the individuals involved on the same footing as paid professionals with whom they are working and fully recognises the value of the work they do and the expertise they bring. However,

inflexible benefit systems can act as a barrier for many people with dementia who may want to seek remuneration for their work. Consequently the authors argue for flexibility in terms of how support and remuneration are imparted and clarity about what can and cannot be provided. The article also emphasises the importance of support and training alongside any payment to enable people with dementia to participate in a range of different ways within organisations.

Guidance to support user participation within services

Four of the papers in this review provide guidance and information to aid services who are exploring the potential for involving people with dementia in service development.

Cantley (2005) in 'Listen to Us', a good practice guide, provides a detailed list of key tasks and approaches for managers and staff to enable the involvement of people with dementia. These include: seeking the views of as wide a range of people with dementia as possible; providing training for staff and service users to support meaningful participation; and providing feedback to individuals who have participated. Cantley is one of the few authors in this review to explore the potential for people with dementia to act as consultants or advisors within services. Cantley also discusses a series of factors which facilitate involvement, such as paying attention to timing, environment, pacing and language; recognition of individuals' contributions; and giving thought to how to support people to move on after they can no longer contribute.

Cantley identifies the following barriers to involving people with dementia: low priority given to meaningful involvement within services; assumptions and prejudices about what people with dementia can contribute; and lack of training available to staff to support the involvement of their clients. Examples of good practice identified by Cantley include the Scottish Dementia Working Group, People Relying On People (PROP) and Dementia Advocacy and Support International (DASNI), all of whom are discussed elsewhere in this review.

The Care Services Improvement Partnership (CSIP, 2007) produced a resource guide for 'Strengthening the involvement of people with dementia', which sits alongside Listen to Us (Cantley, 2005) as a companion document, giving good practice examples to support Cantley's report. CSIP highlight some of the potential positive outcomes for people with dementia resulting from their involvement in service design, delivery and evaluation, including: improved quality of life; better mental health and physical health; increased contribution to society; and reduced public spending on intensive services. CSIP emphasises the importance of not merely consulting people on a one off basis, but involving them in an ongoing process of collaboration and participation. Like Cantley, the authors also highlight the importance of good communication and organisational ethos to achieving meaningful participation.

Litherland (2008), in a book chapter which provides guidance on how to involve people with dementia in service development and evaluation, highlights a number of organisational factors which need to be in place if meaningful involvement is to be achieved. These include flexibility of approach, a responsive and sensitive workforce and an organisational culture which supports and values user involvement. Litherland also emphasises the importance of knowing the purpose of involving people at the outset to make participation a meaningful exercise

Litherland lists the following practices as facilitating the involvement of people with dementia: being respected and listened to; a clear and prompt response to questions and concerns; early diagnosis; acknowledging the diagnosis; and varied opportunities to get involved. In contrast, the following barriers make involvement more difficult: lack of time and money, fear of not being taken seriously, and lack of feedback following participation. Litherland emphasises the heterogeneity of experience of people with dementia, and argues for an inclusive approach which incorporates the views of as many people with dementia as possible, not just those who are more articulate.

She also highlights the importance of timing in enabling people with dementia to have an active voice, and exploiting that "window of opportunity" between diagnosis and the deterioration of health to the extent that individuals can no longer actively participate. Consequently she recommends that organisations wishing to engage people with dementia in their work need to employ a proactive and continuous recruitment process.

Finally, the Involving People Living with Dementia Reference Group (2011) has recently produced a set of resource cards to support the engagement and consultation of people with dementia. The cards cover topics such as general principles, communications, about consultation, developing groups, and involving

people with dementia in recruitment and training, service evaluation and improvement.

User consultation to aid service development and evaluation

Three studies in this review explore the role of user consultation to aid dementia service development and evaluation. This differs from the service development activities described above, in that participants in consultation give their views in a reactive way rather than proactively setting the agenda and priorities for change.

Allan (2001) reports on a project which was designed to enable frontline staff to consult with people with dementia about the services they received. The study, which involved 31 people with dementia and 40 frontline staff, explored different communication and consultation approaches, and the mechanisms required within services to enable good communication to happen. A core component of the project was supporting staff to develop and enhance their communication skills and find their own ways of communicating in a variety of settings and circumstances. Success factors identified included using clear language and avoiding jargon, finding an accessible starting point for discussions, using appropriate pacing and timing and exploiting spontaneous communication opportunities. Three approaches which were explored and found to be beneficial included working with pictures, communication during other activities and focusing on non-verbal communication.

Allan also describes four potential challenges to consulting with people with dementia; factors pertaining to the person with dementia, such as personality dispositions or interests; situational factors such as noise, temperature, space and time of day; staff factors, such as attitudes and confidence levels; and, organisational factors, such as staff levels, organisational ethos and routines.

Staff who participated in the project expressed increased confidence, greater understanding of dementia, and enhanced relationships with service users. Allan concludes that communication with people with dementia to aid service development is possible, but it is a skilled task which requires flexibility of approach and an organisational ethos which views this as a core component of the service.

Bamford (2000) reports on a small consultation exercise to develop a list of appropriate outcomes for community care from the perspective of people with dementia and their carers. From her focus groups and interviews with 15 people with dementia and 7 carers, Bamford found a degree of overlap between the outcomes identified by carers and those by people with dementia (e.g. access to social contact and meaningful activity). However, service users placed greater emphasis on maximising individual autonomy, maintaining a sense of personal identity and feeling safe and secure.

Bamford's findings emphasise the importance of involving service users in selecting service outcomes. However, she acknowledges that the outcomes highlighted by service users in this study have little in common which measures typically used to evaluate community services, which often focus on improving cognitive functioning or reducing problem behaviour. Bamford recommends further research to identify ways to collect information on these outcomes and on the desired service outcomes amongst under-represented populations in this study, e.g. minority ethnic groups, men and younger people with dementia.

Ward (2000) echoes this recommendation to seek the experiences of under-represented groups with a discursive piece which laments the lack of action to ensure that the views and needs of lesbians and gay men with dementia are fully heard with regards to their care needs and preferences. Although this article is now eleven years old, it is doubtful whether there has been any significant move in the intervening years to address this gap. Certainly no other literature on this topic was retrieved during the search process for this review.

Tools to aid user involvement in service delivery

Two papers in this review provide details of particular tools and approaches which may be used to assist user involvement in service delivery.

Ariss (2006) reports on the UK piloting of Partnering with your Doctor (PWYD), an approach developed by the Alzheimer's Association of California to support consumer involvement and effective communication with health professionals for those with early-stage dementia. The PWYD programme consists of three elements: a 90 minute workshop, a booklet and resources to aid consultations. An evaluation of the

Californian PWYD programme found that PWYD increased participants' ability to work effectively and proactively with doctors and other health care professionals and that more than half of participants believed the quality of their care had improved as a result. However, participants in the UK pilot study highlighted a number of barriers to successful implementation of the PWYD approach in the UK; firstly short consultation times with GPs limited the opportunities for meaningful discussion and secondly there was little clarity about how specialist services fitted into the partnership approach advocated by this model. Ariss concludes that whilst PWYD has the potential to enhance user involvement, work needs to take place to adapt and evaluate it within a UK context.

Proctor (2001), in a study of four older women with dementia, employs Brown and Gilligan's Voice Relational Method, which was developed as a method for enabling traditionally subjugated voices to be heard. It focuses on paying attention to "psychological resistance" within interview transcripts, to indicate where people may be burying their feelings and opinions because they diverge from cultural expectations and norms. Proctor recognises that this method may expose power imbalances between health professionals and patients, and suggest areas where participants feel disempowered and not involved appropriately.

Research

Fifteen articles and reports in this review focus on including people with dementia in research activities. This is primarily as research subjects rather than as researchers, and therefore may not be rated as one of the most empowering forms of user involvement. Nevertheless it clearly has a role in enabling unheard voices to be expressed.

Sabat (2003) argues that people with dementia are rarely offered opportunities to contribute within society and construct a more "worthy" social identity. He proposes that research collaboration offers one mechanism to construct a more valued social persona for individuals with dementia; to listen and report on their subjective experiences and to inform practice to enable them to develop more active and meaningful roles in their lives.

The papers included in this section primarily focus on the pros and cons of various research methods and barriers and facilitators to involvement, but some examples of research in action are also included.

Barriers to participation

The voices and experiences of people with dementia, especially those with advanced dementia, often go unheard, sometimes because the level of impairment deems them unable to participate in research. Mozley (1999) explores the extent to which people with differing levels of cognitive impairment are able to answer questions about their quality of life. The author finds that a high percentage (77.5%) of people in her sample with significant cognitive deficits (n=213) were able to respond meaningfully to questions about their quality of life, a higher proportion than had previously been expected. The author concludes that standard screening methods for research participation, e.g. Mini Mental State Examination scores, may therefore not be relevant and other more inclusive ways of screening potential participants should be explored.

Sherratt (2007) argues that one particular barrier to the involvement of people with dementia in research may be "overprotective gatekeeping" on the part of care home managers. Managers, Sherratt suggests, may not give researchers access to their residents because they assume individuals would not be interested in taken part, or because they do not want to unsettle them. To overcome this barrier the author recommends building early relationships with gatekeepers so they understand research process and its potential value.

Facilitators to participation

McKillop (2004), discussing his own experiences of being interviewed about living with dementia, suggests the following factors facilitate more comfortable and easier interview environments; familiar locations; a quiet, informal atmosphere; and an appropriate time of day, for example morning when people may have more energy. McKillop also emphasises the importance of the researcher building a positive relationship with the interviewee and the research being conducted with care and empathy. Finally, McKillop suggests it is useful if researchers provide participants feedback about the progress of the research and accessible summaries of the research findings.

Several research tools have been developed to assist the involvement of people with dementia in interview settings. Murphy (2005, 2007) explores the role of Talking Mats™, a low-technology visual framework, which uses picture symbols to help people with communication difficulties understand and express their views more effectively. Murphy finds that Talking Mats™ can assist the research process, not as a standalone tool, but as one of a range of tools, including speech, gesture and facial expression, which can help communicate messages and meaning. Through using illustrations to discuss key aspects of life and care, participants with language or hearing difficulties are also able to indicate their views. Murphy suggests that, whilst it may not be appropriate for everyone with dementia, Talking Mats™ has a wide range of potential applications within care home settings, including planning daily activities, review meetings, consultation exercises and maintaining and developing relationships.

Establishing capacity and obtaining consent

One common theme in the literature on dementia research is the process for securing meaningful consent for participation, particularly with people who have advanced dementia. Sherratt (2007) describes a recent shift towards increasing the participation of people with advanced dementia in research and evaluation. Central to this change has been the development of more flexible and adaptable methods for both establishing capacity to consent and securing consent itself. Sherratt suggests that a simplified consent process offers one method for opening up research participation to a wider cohort of people with more advanced dementia.

Dewing (2007) describes the ‘process consent’ approach, which views obtaining consent not as a one off exercise at the start of a research study, but as a process that runs through the whole of a research project. It recognises that individual capacity to consent to participation often varies over time and situation and consequently consent needs to be monitored on an ongoing basis. A person deemed unable to give consent to participate on one particular day may be able to give consent on another occasion for example. McKeown (2010), in an appraisal of the process consent model which supports the findings of Dewing, adds that considerable skill and experience are required by researchers using this method to ensure that they are fully understanding of the needs of research participants with dementia.

Key to any consent model is ensuring that the individual concerned is aware of what they are being asked to do. Litherland (2008) suggests using photographs or videos of interviews or focus groups for example, to help explain the research process.

Appropriate research methods

Cheston (2000) reviews five different approaches for gathering the experiences of people with dementia for the purposes of service evaluation: questionnaires and structured interviews; semi-structured interviews; observation; advocacy and focus groups. Cheston finds a role for each of these methods within service evaluation based on individual circumstances and the degree of impairment experienced by participants. Alongside appropriate methodologies is the need to create service cultures in which listening to and incorporating the views of service users is expected and incorporated within standard service provision.

Hubbard (2003) echoes Cheston’s findings and advocates using multiple methodologies, including interviews and observation, within any one study to ensure that the widest range as possible of people with dementia is included. Hubbard also recommends that researchers working with people with dementia should be trained in verbal and non-verbal communication skills, so that each research participant is offered a “bespoke” method for exploring their subjective experience.

Sherratt (2007) argues that qualitative methods offer a more active and engaged role for people with dementia, and are therefore more empowering than quantitative research methodologies.

Examples of research involving people with dementia

Four papers in this review provide examples of research projects which have sought the views of people with dementia.

Williamson (2008) describes a qualitative research project exploring the views of 32 people with dementia and 29 carers. The research focused particularly on people’s experiences of the diagnosis of dementia and how their lives had changed after diagnosis. The research also explored how the diagnostic process could be improved and the stigma attached to dementia challenged. Recommendations for change

including; improving public and GP understanding about dementia; developing better diagnostic assessment services for dementia; providing information which is timely and accessible; and developing stronger peer support networks to help people cope.

In 2010 Williamson followed up his 2008 research with another study exploring the experiences of individuals with dementia, with the aim to inform work to develop a set of quality of life indicators for people with dementia. Using a mixed methodology of interviews, focus groups and postal surveys with 44 participants, the research focused on including the voices of people who are traditionally seldom heard, such as individuals from black and minority ethnic groups and those with severe dementia in care homes.

A set of 10 quality of life indicators were agreed, as follows: relationships and someone to talk to, environment, physical health, sense of humour, independence, ability to communicate, sense of personal identity, ability and opportunity to engage in activities, ability to practice faith or religion, and experience of stigma. The research recommends that policy makers and service providers recognise that good quality of life is achievable for people with dementia, and focus their work to prioritise the enhancement of quality of life for this client group. The report also recommends that methods to monitor quality of life for people with dementia are developed and employed to explore whether individual quality of life is improving or declining and reasons for any change.

Devlin (2007) describes the results of a formative research project to gather the views of people with dementia (alongside carers and members of the general public) to inform the development of a dementia awareness raising campaign. Devlin finds considerable anxiety and fear about dementia amongst the general public, which not only deters help seeking behaviour, but also serves to socially distance people with dementia from the rest of society. User participants in Devlin's study advocate for a campaign which presents realistic and positive images of people with dementia alongside information about support and treatment. Devlin concludes that such a campaign would have the potential to empower people with dementia as well as reduce the fear associated with the condition.

Pratt (2001) explores the effects of diagnosis on 24 individuals with dementia. Through in depth qualitative interviews, the authors found that diagnosis had a profound effect, both psychologically and socially on individual lives. The authors recommend offering support to individuals post diagnosis to help them towards a position where they are better able to cope with their condition.

Discussion

Value of the evidence base

This review sought to gather the available evidence on the involvement of people with dementia in services, campaigning and research. It is clear that little peer reviewed research is available on role of people with dementia in activism, campaigning or service design. Where the research evidence is strongest is in describing appropriate methods for enabling the voices of people with advanced dementia to be heard through research projects. However, even in this area, there is only a small literature base to draw on.

The research included in this review is predominantly qualitative in methodology and small in scale. It is arguable that, given the communication issues people with dementia can experience, qualitative methods are more appropriate than quantitative methods in this case. Indeed several of the authors in this review state as much (Cheston 2000, Hubbard 2003, Sherratt 2007). However, because of the lack of good quality peer reviewed literature available (whether qualitative, quantitative or mixed

methods) any conclusions that can be drawn from the literature must be tentative at best.

It is clear from the evidence available that the grey literature on user involvement with people with dementia is more developed than the academic literature. This may be because this is a field being led primarily by the voluntary sector, who are less likely than academia to publish in peer reviewed journals. Whilst the grey reports in this review provide space for a more detailed exploration of the nuances of user participation, it is clear that support (and funding) should be made available to enable voluntary organisations to publish their findings in peer reviewed journals and therefore contribute their learning to the established evidence base.

Key findings

Recognising the limitations of the evidence available, a number of key findings emerge from the literature included in this review. The evidence indicates that people with dementia are involved in a number of activities to address awareness of their condition and improve the support and care people with dementia receive. This includes participating in research, service evaluation, policy development, professional training, campaigning, awareness raising and activism. However, it would appear that opportunities for meaningful involvement are still patchy, sporadic and often not well supported by health and care professionals.

The literature provides evidence to some of the barriers and facilitators to the involvement of people with dementia as well as some of the individual, organisational and societal benefits to be gained.

Barriers to participation

A number of recurring barriers to the participation of people with dementia were highlighted in the review. These barriers worked at different levels; individual, organisational and societal.

Individual barriers:

- the progressive and limiting nature of the condition
- potential stress and fatigue associated with involvement
- transport problems
- family and carers concerns
- financial concerns

Organisational barriers:

- the stigma and prejudice surrounding dementia, particularly if staff make reductive assumptions about what people with dementia could and could not do
- gaining ethical consent
- lack of funding
- lack of staff training
- lack of organisational policies on user involvement.

Societal barriers:

- stigma and prejudice, deterring people from being involved openly and sharing their story
- benefit system (can deter payment and reimbursement for activities)

Facilitators to participation

- the motivation of those involved to improve the support and care given to people with dementia and reduce the stigma associated with the condition. This motivation drove people to continue with their activities and support the involvement of others
- the peer support and camaraderie provided by fellow participants
- clarity about roles and expectations
- flexible systems within organisations.

Benefits of involvement

At a personal level:

- increased confidence and self-esteem

- improved physical health
- increased understanding about one's condition
- peer support
- friendship
- enhanced skills.

At a wider societal level:

- reducing the stigma associated with dementia
- reduced public spending on intensive services.

Supporting greater involvement by people with dementia

The following recommendations were proposed in the literature:

- Provide training for staff to enable them to support the involvement of people with dementia
- Provide training and support for people with dementia to help them develop their skills and confidence
- Develop organisational cultures that put user involvement at their heart
- Utilise methods that are appropriate for people with a wide range of experiences and degrees of impairment, incorporating where appropriate audio-visual methods and the internet
- Recognise the importance of reciprocity and ensure that individuals involved gain from their experience of participation as well as those who are benefiting from their input

Conclusions and recommendations

Key learning

The evidence included in this review indicates that individuals, organisations and governments have begun to recognise the numerous roles people with dementia are able to play to enhance services and perceptions about dementia in general, including consultation, service development, professional education, activism and campaigning. However, evidence would suggest that involving people with dementia in facilitating change is not standard practice across the board, and that most activity to date takes place at the consultation end of the participation scale, where opportunities for empowerment are more limited.

The literature highlights many barriers to the involvement of people with dementia, such as stigma, practical constraints, organisational culture and the condition itself. However, even given these constraints a number of examples of good practice do exist in this field, including the work of Dementia Advocacy and Support International, the Scottish Dementia Working Group, the Open Doors Network and People Relying on People. These examples all serve to show that meaningful involvement and participation by people with dementia is possible, and provide valuable learning that may be transferrable into other settings.

The evidence in this review recognises that systems and structures need to be in place to support the inclusion of people with dementia, such as training for individuals and staff supporting them, decent reimbursement of time and expenses, clarity about the ways in which people can be involved, using flexible and creative consultation methods to include those with more advanced dementia and providing feedback about the outcomes of any participation process. It is also recognised in the literature that due attention should be given to supporting the gradual disengagement of people who are no longer able to actively participate through sustaining contact and peer support where possible.

Implications for policy and practice

- National policy development should include and reflect the perspectives of people with dementia, incorporating methodologies which support their involvement
- The voices of people with dementia should be embedded within professional education and ongoing staff training and development programmes (primary care, specialist care, social care, voluntary sector)
- Support for the development of a user movement (with recognition that there may be areas of controversy and split opinion within the dementia field, as with all other user movements)
- Promotion of the tools available which support user involvement, e.g. Talking Mats; PWYD
- Encouraging policy makers / organisations etc. towards more meaningful forms of involvement
- Recognising individualism – people will have different views on what good quality care and support constitutes.

Further research required

- More and larger scale studies on the involvement of people with dementia in services, focussing particularly on the outcomes of involvement for the individuals themselves, for the organisations they are involved with and society in general
- Studies exploring the voices and experiences of under-represented groups, such as BME and LGBT individuals with dementia and mechanisms to aid their greater involvement
- Support for groups to write up their work in a way that can be used to inform the evidence base

Methodology

1. Aim of rapid literature review

The main aim of this review is to summarise the evidence available about the active engagement and involvement of people with dementia in services, campaigns and research. The review also aims to summarise some of the evidence available about user movements within other disability and long term condition groups in order to allow for the transference of learning from one disability sphere to another.

2. Scoping the evidence base

2.1 Identifying the evidence: Step 1 (search for reviews and peer reviewed primary research)

The primary focus of the literature review is to obtain high quality academic peer reviewed research on activities which actively involve and engage people with dementia. In order to retrieve this evidence, a select number of databases were chosen that represent literature from a range of fields and disciplines including; Sociology, Community Development, Psychology, Medicine, Gender and race studies

The following databases were searched in October 2011:

- ASSIA: Applied Social Sciences Index and Abstracts
- JSTOR
- Cochrane Database of Systematic Reviews
- MEDLINE
- EMBASE
- CINAHL
- PsycINFO
- Sociological Abstracts

- IBSS
- REGARD
- Social Services Abstracts

Inclusion criteria

Although the primary focus of the review was the UK as a whole, current literature from other countries (e.g. Ireland, New Zealand Australia, United States of America, Canada etc.) was also considered where appropriate.

Exclusion criteria

Only reviews published in English within date constricton (1996-2011) were included in the search.

2.1.1 Search strategy

Database searching at this stage concentrated on retrieving literature reviews and peer reviewed primary research. A number of test searches were performed to establish the most effective strategy, resulting in the following search strategy:

Search: TI (dementia or alzheimers) AND TI (patient or patients or user or users or people or consumer or consumers) AND TI (involve or engage or empower or include or including)

Results: 154

2.1.2 References from the Steering Group

In addition to the database search, references were also obtained from members of the Steering Group.

2.2 Identifying the evidence: Step 2 (Search for other evidence)

In addition to searching for academic literature a search was performed for grey evidence using the Internet and other search strategies listed below:

2.2.1 Free text Google search

The research team performed a free text Internet search for grey literature using the Google search engine. Individual searches using combinations of terms relating to dementia and involvement, engagement and empowerment were used to recover reports and documents. Because of the large number of returns using this approach, only the first 10 pages of each search were scanned for relevant documents / organisations.

2.2.2 Search of key websites

In addition to the free text search, a number of key websites were searched for relevant reports and papers. These comprised:

<http://www.dementiacare.org.uk/>

<http://alzheimers.org.uk/>

<http://www.dementiauk.org/>

<http://dementia.stir.ac.uk/>

<http://www.dementiacentreni.org/>

<http://www.scie.org.uk/publications/dementia/index.asp>

<http://www.dementiacentre.com.au/dementiacentre/>

<http://dementia.ion.ucl.ac.uk/>

<http://www.innovationsindementia.org.uk/>

<http://www.alz.co.uk/>

<http://www.youngdementiauk.org/>

<http://www.dementiaaction.org.uk/>

<http://www.dasninternational.org/>

<http://www.northumbria.ac.uk/sd/academic/sches/research/nedda/>

<http://www.alz.org/>

<http://www.brad.ac.uk/health/Research/dementia/>

Exclusions

The following documents were excluded from the grey literature search: opinion pieces, power-point presentations, and workshop notes. The search also excluded literature relating to person centred care.

3. Results

On the completion of steps one and two, 244 articles and reports were retrieved and exported to Reference Manager. Following screening of the full documents, 36 references were selected for inclusion in the review (18 peer reviewed articles and 18 grey reports).

Summary of included studies and reports

Author / year	Location	Sample	Methodology	Summary	Research focus
Allan, 2001	UK	31 people with dementia, 40 staff	Observation, content analysis	Explores different approaches care home staff can encourage people with dementia to express their views	Service development
Alzheimer Society of Canada, 2006	CAN	33 people with dementia, 81 staff	Interviews, focus groups, surveys	Explores strategies to promote the active participation of people with dementia in policy, research and service delivery	Policy / research / service delivery
Ariss, 2006	UK	15 people with dementia and carers, GPs	Focus groups, interviews	Explores potential implementation of Partnering with your Doctor Programme (PWYD) within UK.	Service provision
Ashley, 2009	UK	1 person with dementia	Case study	Interview with experienced dementia activist	Activism / campaigning
Bamford, 2000	UK	15 people with dementia	Focus groups, interviews	Explores experiences of day care and respite care	Research / service evaluation
Bartlett, 2010	UK	16 people with dementia	Diary-interviews, observation	Explores participants experiences of campaigning and activism	Activism / Campaigning
Beard, 2004	USA	18 people with Alzheimer's Disease,			
12 staff members	Focus groups, interviews	Explores role of people with dementia in informing research and care.	Service provision, research		
Cantley, 2005	UK	N/A	Guidance	Provides guidelines to involving people with dementia in service planning	Service development
Chaston, 2004	UK	N/A	Case study	Describes work of People Relying on People (PROP) group in Doncaster	Service development / Activism / Campaigning

Author / year	Location	Sample	Methodology	Summary	Research focus
Cheston, 2000	UK	People with dementia, (number unclear)	Literature review	Reviews evidence for 5 different research methodologies for gathering the experiences and opinions of people with dementia	Research, service evaluation
Clare, 2008	UK	7 people with dementia	Survey, interviews	Explores benefits and impacts of belonging to Dementia Advocacy and Support International	Activism / campaigning
CSIP Older Peoples Mental Health Programme, 2007	UK	N /A	Guidance	Provides guidelines to involving people with dementia in service planning	Service development
Devlin, 2007	UK	People with dementia, carers (number unclear)	Focus groups, paired interviews	Gathers views of people with dementia and their carers to inform social marketing campaign	Research, Activism / Campaigning
Dewing, 2007	UK	People with dementia, (number unclear)	Two case studies	Describes process consent model to enable people with advanced dementia to participate in research	Research
Dodds, 2003	UK	2 people with dementia, 1 carer	Two case studies	Describes examples of two different methods of people with dementia being including in training and education programmes	Training / Education
Hope, 2007	UK	N/A	Evidence summary	Summarises research and practice in involving people with dementia in professional education	Training / Education
Howorth, 2011	UK	N/A	Case study	Describes work of Open Doors Network in Salford	Service development
Hubbard, 2003	UK	50 people with dementia in care homes	Interviews, observation	Describes challenges and strategies for involving people with advanced dementia in research	Research
Involving People Living with Dementia Reference Group, 2011	UK	N/A	Guidance	Resource cards to aid engagement and consultation with people with dementia	Service development

Author / year	Location	Sample	Methodology	Summary	Research focus
Levenson, 2009	UK	14 people with dementia, 10 carers	Interviews, focus groups	Describes consultation exercise undertaken to inform the development of Northern Ireland's dementia strategy	Policy development
Litherland, 2008	UK	N /A	Evidence summary	Describes research and practice involving people with dementia in service development and summarises appropriate methodologies for involving users.	Service development / evaluation
Lorentzon, 2007	UK	N/A	Evidence summary	Summarises evidence which supports involvement of people with dementia in service planning and research	Service development / research
McAndrew, 2006	UK	21 people with dementia, 26 carers	Interviews, workshop	Describes consultation process to inform dementia service planning in Armagh.	Service development
McKeown, 2010	UK	N /A	Evidence summary	Appraises process consent framework for involving people with dementia in research	Research
McKillop, 2004	UK	1 person with dementia	Interview	Presents the perspective of one person with dementia on appropriateness of interview as a research method	Research
Mozley, 1999	UK	308 people with dementia	Survey, interviews	Explores capacity for people with different levels and types of cognitive impairment to take part in interviews about quality of life	Research
Murphy, 2005	UK	10 people with communication difficulties (7 of whom had dementia)	Interviews	Explores effectiveness of Talking Mats as a means of eliciting the views of people with communication difficulties on their lives and care	Research / service evaluation

Author / year	Location	Sample	Methodology	Summary	Research focus
Murphy 2007	UK	31 people with dementia	Interviews	Evaluates effectiveness of Talking Mats as a means of eliciting the views of people with communication difficulties on their lives and care	Research / service evaluation
Pratt, 2001	UK	24 people with dementia	Interviews	Explores the effects of diagnosis on people with dementia	Research / policy
Proctor, 2001	UK	4 women with dementia	Interviews	Analyses experiences of women using voice relational method which has been developed to give voice to silenced and subjugated voices	Research / service evaluation
Sabat, 2003	USA	N/A	Evidence summary	Explores advantages of engaging with people with Alzheimer's disease as research collaborators	Research
Sherratt, 2007	UK	N /A	Evidence summary	Summarises current guidance and evidence about involvement of people with advanced dementia in research	Research
Ward, 2000	UK	N/A	Editorial	Highlights unheard voice of LGBT individuals with dementia in service design	Service development
Weeks, 2011	UK	N /A	Case study	Describes development and activities of Scottish Dementia Working Group	Campaigning / Activism / Policy / Training
Williamson, 2010	UK	44 people with dementia	Interviews, focus groups, survey	Explores the views of "seldom heard" people with dementia	Research / policy
Williamson, 2008	UK	32 people with dementia, 29 carers	Focus groups, interviews	Presents the experiences of people with dementia in terms of diagnosis and support	Research / policy

References

- Allan K. (2001) *Communication and Consultation: Exploring ways for staff to involve people with dementia in developing services*. Bristol: Joseph Rowntree Foundation.
- Alzheimer's Society of Canada (2006). *Engaging People with Early Stage Alzheimer's Disease in the Work of the Alzheimer's Society: A Research Report*. Toronto: Alzheimer's Society of Canada.
- Ariss SMB, Grant E, Downs M, Fernandez B, Gallagher R, Cherry D et al (2006). 'Piloting a consumer-directed intervention to improve primary care for dementia in the UK'. *Dementia* (14713012); 5(3):456-462.
- Ashley P & Savitch N (2009). 'Valuing the contribution of people with dementia'. *Journal of Dementia Care*; 17(3):16-19.
- Bamford C & Bruce E (2000). Defining the outcomes of community care: the perspectives of older people with dementia and their carers. *Ageing & Society*; 20:543-570.
- Bartlett R (2010). *Campaigning for Social Change: Understanding the motives and experiences of people with dementia*. University of Bradford Research Briefing November 2010.
- Beard RL. (2004). 'Advocating voice: organisational, historical and social milieux of the Alzheimer's disease movement'. *Sociology of Health & Illness*; 26(6):797-819.
- Cantley C, Woodhouse J & Smith M (2005). Listen to Us: Involving people with dementia in planning and developing services. *Dementia North*.
- Chaston D, Pollard N & Jubb D (2004). 'Young onset dementia: a case for real empowerment'. *Journal of Dementia Care*; 12(6):24-25.
- Cheston R, Bender M & Byatt S (2000). 'Involving people who have dementia in the evaluation of services: A review'. *Journal of Mental Health*; 9(5):471-479.
- Clare L, Rowlands J & Quin R (2008). 'Collective Strength: The impact of developing a shared social identity in early-stage dementia'. *Dementia* (14713012); 7(1):9-30.
- Care Services Improvement Partnership (2007). *Strengthening the Involvement of People with Dementia: A Resource for Implementation*. York: Care Services Improvement Partnership.
- Devlin E, MacAskill S & Stead M (2007). 'We're still the same people': developing a mass media campaign to raise awareness and challenge the stigma of dementia'. *International Journal of Nonprofit & Voluntary Sector Marketing*; 12(1):47-58.
- Dewing J (2007). 'Participatory research: a method for process consent with persons who have dementia'. *Dementia* (14713012); 6(1):11-25.
- Dodds P (2003). 'Involving the recipients of dementia care in training for staff'. *Mental Health Practice*; 6(10):34-37.
- Hope K, Pulsford D, Thompson R, Capstick A & Heyward T (2007). 'Hearing the voice of people with dementia in professional education'. *Nurse Education Today*; 27(8): 821-824.
- Howorth M, Riley C, Drummond G & Keady J (2011). 'The Open Doors Network: A pioneering scheme'. *Journal of Dementia Care*; 19(3):20.
- Hubbard G, Downs MG & Tester S (2003). 'Including older people with dementia in research: challenges and strategies'. *Ageing & Mental Health*; 7(5):351-362.
- Involving People Living With Dementia Reference Group (2011). *Involving People Living With Dementia: Making Involvement Count: What Works Resource Pack*. South West Development.
- Levenson R & Williamson T (2009). *Listening Well: People with dementia informing development of health and social care policy*. London: Alzheimer's Society.
- Litherland R (2008). 'Involving people with dementia in service development and

evaluation'. In Downs M, Bowers B. Excellence in dementia care: research into practice. Maidenhead: Open University Press.

Lorentzon M & Bryan K (2007). 'Respect for the person with dementia: fostering greater user involvement in service planning'. *Quality in Ageing*; 8(1):23-29.

McAndrew F & Taylor R (2006). 'How all voices are heard for strategic planning'. *Journal of Dementia Care*; 14(3):22-23.

McKeown J, Clarke A, Ingleton C & Repper J (2010). 'Actively involving people with dementia in qualitative research'. *Journal of Clinical Nursing*; 19(13-14):1935-1943.

McKillop J & Wilkinson H (2004). 'Make it easy on yourself! Advice to researchers from someone with dementia on being interviewed'. *Dementia* (14713012); 3(2):117-125.

Mozley CG, Huxley P, Sutcliffe C, Bagley H, Burns A, Challis D et al (1999). 'Not knowing where I am doesn't mean I don't know what I like': cognitive impairment and quality of life responses in elderly people. *International Journal Of Geriatric Psychiatry*; 14(9):776-783.

Murphy J, Gray CM & Cox S (2007). *Communication and Dementia: How Talking Mats can help people with dementia to express themselves*. York: Joseph Rowntree Foundation.

Murphy J, Tester S, Hubbard G, Downs M, & MacDonald C (2005). 'Enabling frail older people with a communication difficulty to express their views: the use of Talking Mats as an interview tool'. *Health & Social Care In The Community*; 13(2):95-107.

Pratt R & Wilkinson H (2001). *Tell Me the Truth: The effect of being told the diagnosis of dementia from the perspective of the person with dementia*. London: Mental Health Foundation.

Proctor G (2001). 'Listening to older women with dementia: relationships, voices and power'. *Disability & Society*; 16(3):361-376.

Sabat SR (2003). 'Some potential benefits of creating research partnerships with people with Alzheimer's disease'. *Research Policy and Planning*; 21(2):5-12.

Sherratt C, Soteriou T & Evans S (2007). 'Ethical issues in social research involving people with dementia'. *Dementia* (14713012); 6(4):463-4.

Ward R (2000). 'Waiting to be heard – dementia and the gay community'. *Journal of Dementia Care*; 8(3):24-25.

Weaks D, Wilkinson H, Houston A & McKillop J (2011). *Challenging attitudes, challenging ourselves – exploring the benefits and struggles of ten years of the Scottish Dementia Working Group*, Scottish Dementia Working Group.

Williamson T (2008). *Dementia: Out of the shadows*. London: Alzheimer's Society.

Williamson T (2010). *My name is not dementia: People with dementia discuss quality of life indicators*. London: Alzheimer's Society.

**Section 2 -
Questionnaires**

- 1. Detailed questionnaire about groups and projects**
- 2. Short questionnaire about groups and projects**
- 3. Questionnaire for individuals**

Are you working to change the way people with dementia are viewed by society and services?

Dementia Engagement
& Empowerment Project:
[Detailed questionnaire about groups and projects](#)



Are you someone with dementia who is trying to change the way dementia is viewed?

Do you support a person with dementia to speak out or get involved?

If so we would like to hear from you

What is the Dementia Engagement & Empowerment Project (DEEP)?

DEEP aims to collect information about all the inspiring and exciting work across the UK where people with dementia are actively involved in influencing services and policies.

Examples could be:

- doing interviews with the media
- giving talks about dementia
- being a member of an advisory group
- helping to run a support group for people living with dementia

What will DEEP do?

- publicise involvement work by people with dementia
- encourage and support more involvement projects and activities
- share information and examples of good practice around involvement
- help people with dementia and their supporters to get in touch with each other
- show service providers and commissioners the value of involving people with dementia

What will happen to the information collected?

Some information will be available on a map of the UK showing where involvement activities, groups and projects are happening. The map will be available on the DEEP website at www.mentalhealth.org.uk/deep

It will also be contained in a report that will be available later in the year.

There will be a national event that will bring people with dementia and their supporters together.

If there is something you tell us that you want to be kept confidential please tell us or clearly indicate this on the questionnaire. Personal contact details will not be made public.

Is there certain information that is not wanted?

The survey is **not** asking for information about people with dementia being involved in their own care or treatment. Although this is important it is not what DEEP is focusing on.

The survey is **not** evaluating or comparing what different people, groups and projects do — we just want to find out about all the good things that are happening so other people can hear about them.

How can information be included in the survey?

This document contains a questionnaire we would like you to complete. You can do this electronically or print it out and complete by hand. It may be useful to have someone help you do this such as a family member, friend, or someone else who supports you. It may take some time to complete so have some breaks while doing it.

We understand that you might not be able to answer all the questions but please give us as much information as you can. Please try and answer the questions marked '**Key question**'.

Please contact us if you need any help completing the questionnaire. If you want to talk about what you are involved with we can speak to you on the phone and fill the form out for you, or perhaps visit you and make a written record of your activity.

When you have completed it please return it to Toby Williamson at the Mental Health Foundation (contact details overleaf). If you want to complete this questionnaire online you can do so at www.surveymonkey.com/DEEPfull

Please pass the questionnaire on to any other groups or projects involving people with dementia influencing services and policies that you know of, or let us know and we can contact them.

If you want to tell us about things you have done as an individual please contact us and we will send you a questionnaire for individuals to complete.

If you would like to send written information (e.g. leaflets, photos) describing what the activity, groups or project does please do so. Please send these to Toby Williamson at the Mental Health Foundation (contact details overleaf).

Are there other ways of being involved with DEEP?

Yes, the project is actively involving a range of people with dementia who will make up a reference group network that will grow throughout the project. The network will ensure that the project remains relevant to what people with dementia want.

DEEP has funding to run an event near the end of 2011, which will bring groups of people with dementia together.

Please indicate at the end of the questionnaire if you would like to hear more or be involved with these activities.

Who is organising DEEP?

DEEP is a collaborative project between two charities, the Mental Health Foundation and the Alzheimer's Society, and a Community Interest Company, Innovations in Dementia.

It is funded and supported by the Joseph Rowntree Foundation.

How do I get in touch with DEEP?

If you want to know more about the project or need help completing the survey please contact:

Toby Williamson
Mental Health Foundation
Sea Containers House
20 Upper Ground
London SE1 9QB
Tel: 020 7803 1132
Email:
twilliamson@mentalhealth.org.uk

Rachael Litherland/Nada Savitch
Innovations in Dementia
PO Box 616
Exeter EX1 9JB
Tel: 01392 420076
Email:
rachael@myid.org.uk
nada@myid.org.uk

Or go to the DEEP website: www.mentalhealth.org.uk/deep

If you need help or advice about dementia please contact the Alzheimer's Society National Dementia helpline on 0845 300 0336

Questions about the activity, group or project

Please mark answers with an 'X' inside the appropriate boxes unless otherwise stated

1 **Key question** - What is the name of the activity, group or project?

2 How was it set up? When was it set up? Who set it up? If you don't know, can you give us the name of the person and contact details of the person who set it up?

3 Is it part of a larger organisation? If so, what is the name of the organisation?

Yes

No

Don't Know

If yes, what is the name of organisation _____

4 **Key question** - What does the activity, group or project do?

5 Is the activity, group or project primarily:

Local e.g. village, town, county, etc.

Regional e.g. south west, north east, etc.

National i.e. England, Wales, Scotland, Northern Ireland

UK-wide

International

6 Is it aimed at any particular group of people with dementia? If so, please describe who e.g. younger people with dementia, people with a particular type of dementia, people using specific services.

7 Approximately how many people with dementia are involved in the activity, group or project at the moment?

- Less than 5 people
- 5 - 10 people
- 10 - 20 people
- 20 – 40 people
- More than a 100 people

8 How is it funded?

- Not funded
- Voluntary contributions
- Membership fees
- Voluntary sector funded
- PCT/NHS funded
- Local authority funded
- Funding from grant-making trust
- Other (please specify) _____

9 How much annual funding is received?

- Less than £1,000
- £1,000-£5,000
- £5,000-£10,000
- More than £10,000

10 What is the funding for (e.g. staffing, activities etc.)?

11 **Key question** - Who leads or facilitates it (e.g. people with dementia, family carers, staff)?

12 Who administrates it (e.g. people with dementia, family carers, staff)?

13 **Key question** - If it is led by people with dementia please describe how, including what support they receive.

14 **Key question** - What does the activity, group or project do that is led, managed or actively involves people with dementia?

a Therapeutic peer support for members of the group – people helping each other to manage their dementia

Yes

No

Don't Know

b Social, fun activities – meals, walks, outings etc.

Yes

No

Don't Know

c Doing talks about dementia e.g. to train staff

Yes

No

Don't Know

d Interviewing staff working with people with dementia

Yes

No

Don't Know

e Developing information for people about dementia

Yes

No

Don't Know

f Participating in meetings, advisory groups, etc. about services affecting people with dementia

Yes

No

Don't Know

g Helping with the development, research and evaluation of services affecting people with dementia

Yes

No

Don't Know

h Doing interviews about dementia for newspapers, radio, TV, etc.

Yes

No

Don't Know

i Online activity e.g. an internet group for people with dementia, blogging, etc.

Yes

No

Don't Know

j Other (please describe):

15 **Key question** - How is the activity, group or project organised so that it is led, managed or actively involves people with dementia?

People with dementia:

a Help with administrative tasks

Yes

No

Don't Know

Please describe these:

b Lead certain activities

Yes

No

Don't Know

Please describe these:

c Decide what the group/project does

Yes

No

Don't Know

d Work as volunteers

Yes

No

Don't Know

e Work as paid staff

Yes

No

Don't Know

f Are involved in managing the group/project

Yes

No

Don't Know

g Chair meetings of the group/project

Yes

No

Don't Know

h Act as Trustees of the group/project

Yes

No

Don't Know

i Other (please describe):

16 If there are staff, carers, volunteers and other people who do not have dementia involved, what is their role?

a Help with administrative tasks

Paid staff

Carers (relatives, friends)

Volunteers

Others (please specify) _____

b Provide therapeutic/ practical support for members of the group

Paid staff

Carers (relatives, friends)

Volunteers

Others (please specify) _____

c Lead certain activities (please describe) _____

Paid staff

Carers (relatives, friends)

Volunteers

Others (please specify) _____

d Decide what the group/project does

Paid staff

Carers (relatives, friends)

Volunteers

Others (please specify) _____

e Are involved in managing the group/project

Paid staff

Carers (relatives, friends)

Volunteers

Others (please specify) _____

f Chair meetings of the group/project

Paid staff

Carers (relatives, friends)

Volunteers

Others (please specify) _____

g Act as Trustees of the group/ project

Paid staff

Carers (relatives, friends)

Volunteers

Others (please specify) _____

h Other (please describe) _____

Paid staff

Carers (relatives, friends)

Volunteers

Others (please specify) _____

17 **Key question** - What are its key achievements or successes in terms of involving people with dementia?

18 **Key question** - What have been the key challenges in terms of involving people with dementia?

19 Are there other activities that you would like the group to be doing?
(If so, please tell us)

20 What is its future?

21 How does it plan for people with dementia leaving the group?

22 Has it produced any resources (e.g. leaflets, photos, etc.) or information that can be shared? (if so, please tell us about them and/or send examples to us).

23 **Key question** - Please give us the contact details of the activity, group or project.

Name of contact _____

Postal address _____

Email address _____

Website _____

Telephone number _____

24 **Key question** - Do you have anything else you would like to add?

General questions

25 **Key question**- The Dementia Engagement and Empowerment project (DEEP) is currently exploring the potential for developing a national network of groups and initiatives led by people with dementia. Is this something you think would be useful?

Yes

No

Don't Know

26 **Key question** - If you think a network would be useful, what are your views on the role and function of such a network e.g. what could it do, who could be a member, how could it be organised, etc.

27 Please tell us about any reports, guidance or literature about people with dementia trying to influence services and policies that you are aware of.

28 Please tell us about any other activity, group, project or organisation that you are aware of involving people with dementia trying to influence services and policies.

29 **Key question** - As part of this survey we would like to come and talk to some groups/ projects about what has been described in this questionnaire. Would you be willing for us to contact you about this?

Yes

No

Don't Know

30 **Key question** - Would you like more details about how you can further participate in this project and the national event?

Yes

No

Don't Know

31 **Key question** - If you answered 'yes' to question 28 or 29 , please give us your contact details (unless already provided in Question 22).

Name _____

Postal address _____

Email _____

Telephone number _____

32 If you are willing to be contacted by us what is your preferred method:

- Phone call
- A letter by post
- Email

33 Are you happy for us to share the information you have given us about the activity/
project/group on the DEEP website and in the project report?

- Yes No

If you filled out this questionnaire and you do not have a dementia diagnosis please fill in the following questions for carers / staff / supporters

34 Please tell us your role:

- Family member
- Friend
- Social worker
- Nurse
- Care worker
- Support worker
- Other paid worker (please specify) _____
- Volunteer
- Other (please specify) _____

35 Please tell us your connection with the activity, group or project described in Part 1.

36 Are you filling this in with people with dementia?

- Yes No

37 Have you included an expression of support, testimony, or confirmation by people with dementia, as verification of the activity, group or project you have described?

- Yes No

Expression of support:

Thank you for completing this questionnaire.

Please return this by **Monday 31 October 2011** to:

Toby Williamson
Mental Health Foundation
Sea Containers House
20 Upper Ground
London SE1 9QB
Tel: 020 7803 1132
Email: twilliamson@mentalhealth.org.uk
Website: www.mentalhealth.org.uk/deep

Are you working to change the way people with dementia are viewed by society and services?

Dementia Engagement
& Empowerment Project:
Short questionnaire about
groups and projects



Are you someone with dementia who is trying to change the way dementia is viewed?

Do you support a person with dementia to speak out or get involved?

If so we would like to hear from you

What is the Dementia Engagement & Empowerment Project (DEEP)?

DEEP aims to collect information about all the inspiring and exciting work across the UK where people with dementia are actively involved in influencing services and policies.

Examples could be:

- doing interviews with the media
- giving talks about dementia
- being a member of an advisory group
- helping to run a support group for people living with dementia

What will DEEP do?

- publicise involvement work by people with dementia
- encourage and support more involvement projects and activities
- share information and examples of good practice around involvement
- help people with dementia and their supporters to get in touch with each other
- show service providers and commissioners the value of involving people with dementia

What will happen to the information collected?

Some information will be available on a map of the UK showing where involvement activities, groups and projects are happening. The map will be available on the DEEP website at www.mentalhealth.org.uk/deep

It will also be contained in a report that will be available later in the year. This will describe the information collected from the different groups and projects that responded to the survey. It will be made available to anyone interested in people with dementia influencing services and policies. We hope it will encourage more people with dementia to get involved in this type of activity.

Is there certain information that is not wanted?

The survey is **not** asking for information about people with dementia being involved in their own care or treatment. Although this is important it is not what DEEP is focusing on.

The survey is **not** evaluating or comparing what different groups and projects do – we just want to find out about all the good things that are happening so other people can hear about them.

How can information be included in the survey?

This document contains a very short questionnaire to complete. You can print it out and complete by hand. It should only take about 10 minutes.

Alternatively if you want to complete this questionnaire online, you can do so at www.surveymonkey.com/DEEPshort

When you have completed it please return it to Toby Williamson at the Mental Health Foundation (contact details below).

Please pass the questionnaire on to any other groups or projects involving people with dementia influencing services and policies that you know of, or let us know and we can contact them.

If you want to tell us about things you have done as an individual please contact us and we will send you a questionnaire for individuals to complete.

Are there other ways of being involved with DEEP?

Yes, the project is actively involving a range of people with dementia who will make up a reference group network that will grow throughout the project. The reference group will ensure that the project remains relevant to what people with dementia want. Please let us know if you would like to be part of this group.

DEEP has funding to run an event near the end of 2011, which will bring groups of people with dementia together.

Who is organising DEEP?

DEEP is a collaborative project between two charities, the Mental Health Foundation and the Alzheimer's Society, and a Community Interest Company, Innovations in Dementia.

It is funded and supported by the Joseph Rowntree Foundation.

How do I get in touch with DEEP?

If you want to know more about the project or need help completing the survey please contact:

Toby Williamson
Mental Health Foundation
Sea Containers House
20 Upper Ground
London SE1 9QB
Tel: 020 7803 1132
Email:
twilliamson@mentalhealth.org.uk

Rachael Litherland/Nada Savitch
Innovations in Dementia
PO Box 616
Exeter EX1 9JB
Tel: 01392 420076
Email:
rachael@myid.org.uk
nada@myid.org.uk

People with dementia influencing services and policy development – a national survey

Please mark answers with an 'X' inside the appropriate boxes unless otherwise stated

1 What is the name of the activity, group or project?

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

a Therapeutic peer support for members of the group – people helping each other to manage their dementia

Yes

No

Don't Know

b Social, fun activities – meals, walks, outings etc.

Yes

No

Don't Know

c Doing talks about dementia e.g. to train staff

Yes

No

Don't Know

d Interviewing staff working with people with dementia

Yes

No

Don't Know

e Developing information for people about dementia

Yes

No

Don't Know

f Participating in meetings, advisory groups, etc. about services affecting people with dementia

Yes

No

Don't Know

g Helping with the development, research and evaluation of services affecting people with dementia

Yes

No

Don't Know

h Doing interviews about dementia for newspapers, radio, TV, etc.

Yes

No

Don't Know

i Online activity e.g. an internet group for people with dementia, blogging, etc.

Yes

No

Don't Know

j Other:

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

People with dementia:

a Help with administrative tasks

Yes

No

Don't Know

Please describe these:

b Lead certain activities

Yes

No

Don't Know

Please describe these:

c Decide what the group/project does

Yes

No

Don't Know

d Work as volunteers

Yes

No

Don't Know

e Work as paid staff

Yes

No

Don't Know

f Are involved in managing the group/project

Yes

No

Don't Know

g Chair meetings of the group/project

Yes

No

Don't Know

h Act as Trustees of the group/project

Yes

No

Don't Know

i Other:

4 We would like to collect more detailed information so we can give examples of activities, groups and projects in the final project report. Would you be willing to complete a more detailed survey so we can collect this information?

Yes

No

5 Would you like us to keep in touch so you can hear more about the Dementia Engagement & Empowerment project (DEEP)?

Yes

No

6 Please give us the contact details of the activity, group or project:

a Name of contact:

b Postal address:

c Email address:

d Website:

e Telephone number:

7 Are you happy for us to share the information you have given us about the activity/ project/group on the DEEP website and in the project report?

Yes

No

Please return this survey by **Monday 31 October 2011** to:

Toby Williamson
Mental Health Foundation
Sea Containers House
20 Upper Ground
London SE1 9QB

Are you working to change the way people with dementia are viewed by society and services?

Dementia Engagement
& Empowerment Project:
Questionnaire for individuals



Are you someone with dementia who is trying to change the way dementia is viewed?

Do you support a person with dementia to speak out or get involved?

If so we would like to hear from you

What is the Dementia Engagement & Empowerment Project (DEEP)?

DEEP aims to collect information about all the inspiring and exciting work across the UK where people with dementia are actively involved in influencing services and policies.

Examples could be:

- doing interviews with the media
- giving talks about dementia
- being a member of an advisory group
- helping to run a support group for people living with dementia

What will DEEP do?

- publicise involvement work by people with dementia
- encourage and support more involvement projects and activities
- share information and examples of good practice around involvement
- help people with dementia and their supporters to get in touch with each other
- show service providers and commissioners the value of involving people with dementia

What will happen to the information collected?

Some information will be available on a map of the UK showing where involvement activities, groups and projects are happening. The map will be available on the DEEP website at www.mentalhealth.org.uk/deep

It will also be contained in a report that will be available later in the year.

There will be a national event that will bring people with dementia and their supporters together.

If there is something you tell us that you want to be kept confidential please tell us or clearly indicate this on the questionnaire. Personal contact details will not be made public.

Is there certain information that is not wanted?

The survey is **not** asking for information about people with dementia being involved in their own care or treatment. Although this is important it is not what DEEP is focusing on.

The survey is **not** evaluating or comparing what different people, groups and projects do – we just want to find out about all the good things that are happening so other people can hear about them.

How can information be included in the survey?

This document contains a questionnaire we would like you to complete. You can do this electronically or print it out and complete by hand. It may be useful to have someone help you do this such as a family member, friend, or someone else who supports you. It may take some time to complete so have some breaks while doing it.

We understand that you might not be able to answer all the questions but please give us as much information as you can.

Please contact us if you need any help completing the questionnaire. If you want to talk about what you are involved with we can speak to you on the phone and fill the form out for you, or perhaps visit you and make a written record of your activity.

When you have completed it please return it to Toby Williamson at the Mental Health Foundation (contact details overleaf). If you want to complete this questionnaire online you can do so at www.surveymonkey.com/DEEPindividual

Please pass the questionnaire on to anyone else with dementia who is influencing services and policies that you know of, or let us know and we can contact them. We are also collecting information from groups of people with dementia. If we haven't already contacted a group that you are involved in, please let us know.

If you would like to send us written information (e.g. leaflets, photos) describing what the activities you are involved in please do so. Again please send these to Toby Williamson at the Mental Health Foundation (contact details overleaf).

Are there other ways of being involved with DEEP?

Yes, the project is actively involving a range of people with dementia who will make up a reference group network that will grow throughout the project. The network will ensure that the project remains relevant to what people with dementia want.

DEEP has funding to run an event near the end of 2011, which will bring groups of people with dementia together.

Please indicate at the end of the questionnaire if you would like to hear more or be involved with these activities.

Who is organising DEEP?

DEEP is a collaborative project between two charities, the Mental Health Foundation and the Alzheimer's Society, and a Community Interest Company, Innovations in Dementia.

It is funded and supported by the Joseph Rowntree Foundation.

How do I get in touch with DEEP?

If you want to know more about the project or need help completing the survey please contact:

Toby Williamson
Mental Health Foundation
Sea Containers House
20 Upper Ground
London SE1 9QB
Tel: 020 7803 1132
Email:
twilliamson@mentalhealth.org.uk

Rachael Litherland/Nada Savitch
Innovations in Dementia
PO Box 616
Exeter EX1 9JB
Tel: 01392 420076
Email:
rachael@myid.org.uk
nada@myid.org.uk

Or go to the DEEP website: www.mentalhealth.org.uk/deep

If you need help or advice about dementia please contact the Alzheimer's Society National Dementia helpline on 0845 300 0336

Questionnaire- Activities you are involved with

Please mark answers with an 'X' inside the appropriate boxes unless otherwise stated

1 What kind of things are you involved in as an individual to change the way dementia is viewed? Please give examples.

2 Are you involved in any other activities or groups etc.? Please tell us how you are involved.

3 How long have you done this for ?

- Less than 6 months
 - 6 months-1 year
 - 1-2 years
 - 2-5 years
 - More than 5 years
 - Don't want to say
-

4 Does anyone help you to get involved? Are there are other things that help you to get involved?

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

6 The Dementia Engagement and Empowerment project is currently exploring the potential for developing a national network of groups and initiatives led by people with dementia. Is this something you think would be useful?

Yes

No

Don't Know

7 If you think a network would be useful, what are your views on the role and function of such a network e.g. what could it do, who could be a member, how could it be organised, etc.

8 Please tell us about any reports, guidance or literature about people with dementia trying to influence services and policies that you are aware of.

9 Please tell us about any other activity, group, project or organisation that you are aware of involving people with dementia trying to influence services and policies.

10 Do you have anything else you would like to add?

We would like to know a bit more about you but please don't answer questions 11-15 if you don't want to.

11 What is your age?

18-49

50-64

65-79

80+

Don't want to say

12 What is your gender?

Male

Female

Don't want to say

13 What is your ethnicity?

White

White English

White Irish

White Welsh

White Scottish

Other white background (please specify) _____

Black or Black British

Caribbean

African

Other black background (please specify) _____

Asian or Asian British

Indian

Pakistani

Bangladeshi

Other Asian background (please specify) _____

Shared Heritage

White-Black Caribbean

White-Black African

White-Asian

Other shared heritage (please specify) _____

Chinese or other ethnic group

Chinese

Other (please specify) _____

14 What type of dementia do you have?

Alzheimer's disease

Vascular dementia

Dementia with Lewy Bodies

Fronto-temporal dementia (including Pick's disease)

Other (please specify) _____

Don't want to say

15 How long have you been diagnosed with dementia?

- Less than 6 months
- 6 months-1 year
- 1-2 years
- 2-5 years
- More than 5 years
- Don't want to say

Some general questions

16 As part of this survey we would like to come and talk to some people with dementia about the activities, groups or projects described in this questionnaire. Would you be willing for us to contact you about this?

- Yes No Don't Know

17 Would you like more details about how you can further participate in this project?

- Yes No Don't Know

18 Would you like to be named in the report and in information about DEEP on the Internet?

- Yes No Don't Know

19 If you answered **'yes'** to questions 16, 17 or 18 please give us your contact details:

Name _____

Postal Address _____

Email _____

Telephone Number _____

20 If you are willing to be contacted by us what is your preferred method:

- Phone call
- A letter by post
- Email

If you filled out this questionnaire and you do not have a dementia diagnosis please fill in the following questions.

21 Please tell us your relationship to the person described in the questionnaire:

- Family member
- Friend
- Social worker
- Nurse
- Care worker
- Support worker
- Other paid worker (please specify) _____
- Volunteer
- Other (please specify) _____

22 Did you fill this out with the person?

- Yes No

Thank you for completing this questionnaire.

Please return this by **Monday 31 October 2011** to:

Toby Williamson
Mental Health Foundation
Sea Containers House
20 Upper Ground
London SE1 9QB
Tel: 020 7803 1132
Email: twilliamson@mentalhealth.org.uk
Website: www.mentalhealth.org.uk/deep

Section 3 – Data tables from questionnaires

Geographical location of respondents	Number	%
England	56	69.5
East Anglia	7	8.5
East Midlands	7	8.5
North East	1	1.2
North West	10	12.2
South East	14	17.1
South West	10	12.2
West Midlands	4	4.9
Yorkshire	3	3.7
Northern Ireland	0	0.0
Scotland	5	6.1
Wales	5	6.1
International	1	1.2
Unknown	15	18.3

Q1. What does the activity, group or project so that is led, managed or actively involves people with dementia	Yes		No		Don't Know		No answer	
	n	%	n	%	n	%	n	%
Peer support (people helping each other to manage their dementia)	51	62.2	13	15.9	2	2.4	16	19.5
Social, fun activities – meals, walks, outings, etc.	47	57.3	20	24.4	1	1.2	14	17.1
Doing talks about dementia e.g. to train staff	47	57.3	21	25.6	2	2.4	12	14.6
Interviewing staff working with people with dementia	25	30.5	36	43.9	2	2.4	19	23.2
Developing information for people about dementia	44	53.7	21	25.6	3	3.7	14	17.1
Participating in meetings, advisory groups, etc.	53	64.6	13	15.9	4	4.9	12	14.6
Helping with the development, research and evaluation of services	45	54.9	18	22.0	4	4.9	15	18.3
Doing interviews about dementia for newspapers, radio, TV, etc.	26	31.7	32	31.7	4	4.9	20	24.4
Online activity e.g. an internet group for people with dementia, blogging, etc.	20	24.4	37	45.1	4		21	25.6

Q2. How is the activity, group or project organised so that it is led, managed or actively involves people with dementia?	Yes		No		Don't Know		No answer	
	n	%	n	%	n	%	n	%
Help with administrative tasks	21	25.6	44	53.7	1	1.2	16	19.5
Lead certain activities	44	53.7	27	32.9	3	3.7	8	9.8
Decide what the group/project does	56	68.3	13	15.9	3	3.7	10	12.2
Work as volunteers	29	35.4	35	42.7	1	1.2	17	20.7
Work as paid staff	11	13.4	52	63.4	1	1.2	18	22.0
Are involved in managing the group/project	32	31.7	33	40.2	3	3.7	14	17.1
Chair meetings of the group/project	17	20.7	45	54.9	4	4.9	16	19.5
Act as Trustees of the group/ project	6	7.3	53	64.6	5	6.1	18	22.0

B. Detailed questionnaire – further questions

Q3. When was the project set up?	Number	%
2010s	15	46.9
2000s	10	31.3
1990s	2	6.3
No answer	5	15.5
TOTAL	32	100

Q4. Is the project part of a larger organisation?	Number	%
Yes	22	68.8
No	9	28.1
Don't know	1	3.1
No answer	0	0.0
TOTAL	32	100

Q5. Is the project primarily	Number	%
Local e.g. village, town, county etc.	22	68.8
Regional e.g. South West, North East etc.	1	3.1
National e.g. England, Wales, Scotland	6	18.8
UK-wide	3	9.3
International	0	0.0
No response	0	0.0
TOTAL	32	100

Q6. Is it aimed at any particular group of people with dementia?	Number	%
Yes	15	46.9
No	16	50.0
No response	1	3.1
TOTAL	32	100

Q7. Approximately how many people with dementia are involved in the activity, group or project at the moment	Number	%
Less than 5 people	9	28.1
5 – 10 people	2	6.3
10 – 20 people	9	28.1
20 – 40 people	4	12.5
40 – 100 people	3	9.4
More than 100 people	4	12.5
No response	1	3.1
TOTAL	32	100

Q8. How is it funded?	Number	%
Not funded	3	9.4
Voluntary contributions	4	12.4
Membership fees	2	6.3
Voluntary sector funded	4	12.4
PCT / NHS funded	8	25.0
Local authority funded	8	25.0
Fund from grant making trust	3	9.4
Other	12	37.5
No response	1	3.1
TOTAL	32	100

Q9. How much annual funding is received?	Number	%
Less than £1,000	6	18.7
£1,000 - £5,000	2	6.3
£5,000 - £10,000	2	6.3
More than £10,000	14	43.7
No response	8	25.0
TOTAL	32	100

Q10. If there are staff, carers, volunteers or other people who do not have dementia involved, what is their role?	Paid staff	Carers	Volunteers	Others	No response
Help with administrative tasks	24	7	6	4	3
Provide therapeutic / practical support for members of the group	17	10	10	4	9
Lead certain activities	20	16	9	6	4
Decide what the group / project does	16	18	9	6	7
Are involved in managing the group / project	18	14	8	7	5
Chair meetings of the group / project	12	9	6	6	11
Act as Trustees of the group / project	7	7	4	7	17

C. Individual questionnaire

Q3. How long have you been involved in activities as an individual to change the way dementia is viewed	Number	%
Less than 6 months	1	6.7
6 months – 1 year	0	0.0
1 – 2 years	1	6.7
2 – 5 years	8	53.3
More than 5 years	5	33.3
Don't want to say	0	0.0
No response	0	0.0
TOTAL	15	100

Q4. What is your age	Number	%
18 – 49	0	0.0
50 – 64	5	33.3
65 - 79	8	53.3
80+	1	6.7
Don't want to say	0	0.0
No response	1	6.7
TOTAL	15	100

Q5. What is your gender	Number	%
Male	12	80.0
Female	3	20.0
Don't want to say	0	0.0
No response	0	0.0
TOTAL	15	100

Q6. What is your ethnicity	Number	%
White English	9	60.0
White Irish	0	0.0
White Welsh	0	0.0
White Scottish	4	26.6
Other white background	1	6.7
Black or Black British - Caribbean	0	0.0
Black or Black British - African	0	0.0
Other black background	0	0.0
Asian or Asian British - Indian	0	0.0
Asian or Asian British – Pakistani	0	0.0
Asian or Asian British – Bangladeshi	0	0.0
Other Asian background	0	0.0
Shared heritage – White – Black Caribbean	0	0.0
Shared heritage – White – Black African	0	0.0
Shared heritage – White – Asian	0	0.0
Other shared heritage	0	0.0
Chinese	0	0.0
Other	0	0.0
Don't want to say	0	0.0
No response	1	6.7
TOTAL	15	100

Q7. What type of dementia do you have?	Number	%
Alzheimer's disease	6	40.0
Vascular dementia	5	33.3
Dementia with Lewy Bodies	3	20.0
Fronto-temporal dementia (including Pick's disease)	0	0.0
Other	0	0.0
Don't want to say	0	0.0
No response	1	6.7
TOTAL	15	100

Q8. How long have you been diagnosed with dementia?	Number	%
	Number	%
Less than 6 months	0	0.0
6 months – 1 year	1	6.7
1 – 2 years	1	6.7
2 – 5 years	4	26.6
More than 5 years	9	60.0
Don't want to say	0	0.0
No response	0	0.0
TOTAL	15	100

D. Network development (all questionnaires combined)

Q9. The Dementia engagement and Empowerment Project is currently exploring the potential for developing a national network of groups and initiatives led by people with dementia. Is this something you think would be useful?	Number	%
Yes	39	83.0
No	0	0.0
Don't know	2	4.3
No response	6	12.8
TOTAL	47	100
Don't want to say	0	0.0
No response	0	0.0
TOTAL	15	100

Section 4– Selection of responses from detailed survey

This section contains the detailed response from groups and organisations that responded to the survey. They are divided into three categories:

4.1 Leadership and active involvement groups – groups where the survey response indicated that people with dementia were taking an active role in leading the group as well as participating in its activities

ACE Club - Rhyl, North Wales

Doncaster Dementia Forum – Yorkshire

Hope Group - Brighton

Open Doors Project - Salford, Greater Manchester

Positive Dementia Group – Aberdeen

4.2 Active involvement groups - groups where the survey response indicated that people with dementia were taking an active role in participating in the group's activities but not leading it

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

Bay Tree Voices – Bradford

Circles of Support for People with Dementia – England

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

4.3 Other involvement projects – groups or projects where the survey responses indicated that people with dementia were taking an active role in the groups but this had been on a time limited basis or the focus of the involvement activity was on the service or organisation responsible for the groups

Dementia Advice and Peer Support Service - Age UK Trafford, Greater Manchester

Dementia Advisory Service – Bracknell, Berkshire

The Hair and Care Project – Manchester

The National Council for Palliative Care (NCPC) - Difficult Conversations for Dementia Project, England

Social Care Alba - National Participation Group, Motherwell, Scotland

Telford and Wrekin Dementia Research Group – Shrewsbury

4.1 Leadership and active involvement groups

ACE Club - Rhyl, North Wales

How was it set up? When was it set up? Who set it up? If you don't know, can you give us the name of the person and contact details of the person who set it up?

It was set up in 2002 for younger people living with dementia by an independent mental health nurse Vivienne Davies-Quarrell who approached the local branch of the Alzheimer's Society and health and social care practitioners in the locality to support the initiative in whatever way they could. The branch brokered funds through the local authority carers respite monies and contracted with Vivienne to develop and deliver this not for profit service. However this brokerage agreement ceased in 2010 and since this date Vivienne Davies-Quarrell has become the Patron of a newly constituted group to enable them to seek their own funds.

What does the activity, group or project do?

Raises awareness and educates professionals and communities about the experience of living with young onset dementia; provides peer support and activities for people living with a diagnosis of young onset dementia in the community.

Is it aimed at any particular group of people with dementia? If so, please describe who e.g. younger people with dementia, people with a particular type of dementia, people using specific services:

Younger people and active older people.

Approximately how many people with dementia are involved in the activity, group or project at the moment?

5 - 10 people

Who leads or facilitates it? (e.g. people with dementia, family carers, staff)

ACE members - inclusive of people with dementia, partners and the Patron

Who administrates it? (e.g. people with dementia, family carers, staff)

As above - we all have roles as members.

If the activity, group or project is led by people with dementia, please describe how, including what support they receive:

N/A

What are the activity, project or group's key achievements or successes in terms of involving people with dementia?

Empowerment - Enablement - Recovery Journal publications - book chapters - local, regional and national presentations, seminars. Own constitution.

What have been the key challenges in terms of involving people with dementia?

N/A

Are there other activities that you would like the group to be doing? (if so, please tell us)

We have other activities under development currently.

What is the activity, project or group's future?

In the hands of people living with dementia and reliant on the endeavours and aspirations of people living with dementia.

How does it plan for people with dementia leaving the group?

This is an open group and membership changes over time it is a natural process.

Has it produced any resources (e.g. leaflets photos etc.) or information that can be shared? If so, please tell us about them and / or send examples to us:

We have a website currently being updated to reflect the funding changes and have many other resources currently being rebranded.

Do you have anything else you would like to add?

N/A

If you think a network would be useful, what are your views on the role and function of such a network? e.g. what could it do, who could be a member, how could it be organised etc.?

This is something ACE have been working on and aspiring to and feel strongly that should be independent.

Please tell us your connection with the activity, group or project described:

Pioneer and member of ACE

Contact person: Vivienne Davies-Quarrell

Telephone: 01745 345369

Email: vivienne@ace-alzheimers.com

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

Doncaster Dementia Forum – Yorkshire

How was it set up? When was it set up? Who set it up? If you don't know, can you give us the name of the person and contact details of the person who set it up?

This group was established in July 2010 as part of our Dementia Action Plan implementation in response to the NDS [National Dementia Strategy] 17 objectives. This group was set up through co production and it is now a User and carer run and lead forum. There are several purposes for the forum but the main one is to enable the voice of the person with dementia and their carers to be heard. The chair of the Forum then sits on the Doncaster Older Peoples Mental Health Steering Group (OPMHSG) which is responsible for delivery on the NDS. Eileen Harrington a NHS Doncaster volunteer and ex carer chairs the forum. Contact details are EileenHarrington@talktalk.net

What does the activity, group or project do?

Lobby and influence service development and holds the OPMHSG to account

Is it aimed at any particular group of people with dementia? If so, please describe who e.g. younger people with dementia, people with a particular type of dementia, people using specific services:

Not exclusive by age. The group is for and run by anyone with dementia and or their carers

Approximately how many people with dementia are involved in the activity, group or project at the moment?

20 - 40 people

Who leads or facilitates it? (e.g. people with dementia, family carers, staff)

Ex carer chairs the forum

Who administrates it? (e.g. people with dementia, family carers, staff)

The group, with support from MH [mental health] staff

If the activity, group or project is led by people with dementia, please describe

how, including what support they receive:

Chaired by ex carer attended by people with dementia and carers. Supported by MH staff

What are the activity, project or group's key achievements or successes in terms of involving people with dementia?

Influencing service improvement and development, raising profile of dementia and NDS, raising funds through charity work for Alzheimer's Society

What have been the key challenges in terms of involving people with dementia?

Time and support. Passion drives the commitment. The group has been going strong now for 15 months and has over 20 regular attendees.

Are there other activities that you would like the group to be doing? (if so, please tell us)

The group decides their agenda

What is the activity, project or group's future?

Hopefully get bigger and better and link to new architecture such as Health and Wellbeing Boards and Healthwatch

How does it plan for people with dementia leaving the group?

Support of MH staff as necessary through commissioned services such as Alzheimer's Society.

Has it produced any resources (e.g. leaflets photos etc) or information that can be shared? If so, please tell us about them and / or send examples to us:

Yes. But also co-ordinated and disseminated other material already produced in Doncaster like PROP DVD and NDS 2 year progress report. The group has a Website which is under development: www.helpfordementiaindoncaster.co.uk

Do you have anything else you would like to add?

N/A

If you think a network would be useful, what are your views on the role and function of such a network? e.g. what could it do, who could be a member, how could it be organised etc?

Again sharing and disseminating and supporting and providing a bigger voice for lobbying

Please tell us your connection with the activity, group or project described:

Influenced its development

Contact person: Wayne Goddard

Telephone: 01302 566500

Email: Wayne.goddard@doncasterpct.nhs.uk

Website: n/a

Hope Group - Brighton

How was it set up? When was it set up? Who set it up? If you don't know, can you give us the name of the person and contact details of the person who set it up?

The HOPE group was set up approx 2 years ago by now ex Training and Development Officer.

What does the activity, group or project do?

HOPE is a group of people living with dementia who aim to: 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.

Is it aimed at any particular group of people with dementia? If so, please describe who e.g. younger people with dementia, people with a particular type of dementia, people using specific services:

The members of the group have various types of dementia and some are under 65 and some are over.

Approximately how many people with dementia are involved in the activity, group or project at the moment?

5 - 10 people

Who leads or facilitates it? (e.g. people with dementia, family carers, staff)

Currently facilitated by Kirsty Jones - Learning and Development Officer

Who administrates it? (e.g. people with dementia, family carers, staff)

Kirsty Jones - Learning and Development Officer

If the activity, group or project is led by people with dementia, please describe how, including what support they receive:

Any training sessions or presentations that the group are involved with are also attended by Kirsty Jones - Learning and Development Officer

What are the activity, project or group's key achievements or successes in terms of involving people with dementia?

Work so far..... facilitated workshops for health and social care professionals across Sussex. Involved in Services Users Carers Network with the Universities of Brighton & Sussex. Presented our experiences at a number of conferences and workshops across the country. Involved in an Advisory Panel for a research programme, run by DENDRON. Commissioned by Skills for Care to write and produce a document for personal assistants. Involved in research into the use of Personal Budgets. Shared our experiences through DVD's produced by West Sussex County Council, Frameworks for Change and Pavilion Publishing.

What have been the key challenges in terms of involving people with dementia?

N/A

Are there other activities that you would like the group to be doing? (if so, please tell us):

N/A

What is the activity, project or group's future?

To continue to be involved in providing health and social care staff with their own experience and the importance of involving people with dementia in their own care and support.

How does it plan for people with dementia leaving the group?

This has not yet happened

Has it produced any resources (e.g. leaflets photos etc.) or information that can be shared? If so, please tell us about them and / or send examples to us:

Yes, please see previous question regarding what the group has been involved with.

Do you have anything else you would like to add?

The HOPE group have been fundamental in providing real life experience that health and social care would not otherwise be able to access.

If you think a network would be useful, what are your views on the role and function of such a network? e.g. what could it do, who could be a member, how could it be organised etc.?

Empower people with dementia to be more involved in having a voice. I think there could be a wide membership including people with dementia, their carers, staff etc.

Please tell us your connection with the activity, group or project described:

Learning and Development Officer

Contact person: Kirsty Jones

Telephone: 07702 096264

Email: kirstyjones@westsussex.gov.uk

Website: n/a

Open Doors Project - Salford, Greater Manchester**How was it set up? When was it set up? Who set it up? If you don't know, can you give us the name of the person and contact details of the person who set it up?**

Initial funding was provided by the School of Nursing, Midwifery and Social Work within Manchester University, with a dictate that the service develop a project that would support the principles of user involvement. A steering group was set up involving representatives across all elements of the service (inpatient and Community), volunteers and Manchester University, HR and recruitment service were also involved and after a comprehensive collaborative process our aim was formed to develop a forum of people with personal experience of living with dementia who would act in a consultative role to shape services in the future. The network would also have an educative and supportive function and we aspired that the lead of the forum would be recruited and be an individual with dementia - we believe that we are the first NHS Trust to have employed such an individual. The project sits within Later Life Services (Salford) part of Greater Manchester West NHS Mental Health Foundation Trust led by the Matron/Senior Manager.

What does the activity, group or project do?

Leading on the development of a range of initiatives across Salford such as: A Dementia Cafe Post diagnostic education and support in conjunction with Memory Services. A friendship and support Network for individuals newly diagnosed Part of steering groups in relation to key service redesign Education to professionals in relation to dementia Supporting and disseminating research and developments in dementia in conjunction with the University

Is it aimed at any particular group of people with dementia? If so, please describe who e.g. younger people with dementia, people with a particular type of dementia, people using specific services:

The various elements of this project differ and relate to different people

Approximately how many people with dementia are involved in the activity, group or project at the moment?

20 - 40 people

Who leads or facilitates it? (e.g. people with dementia, family carers, staff)

The Project sits within Reach Beyond which is an innovative service that aims to engage staff, service users, carers and citizens of Salford to work together to develop meaningful patient and public involvement in service delivery and design. Reach Beyond uses a host of people as volunteers. The manager of Reach Beyond provides

line management for Mike Howorth.

Who administrates it? (e.g. people with dementia, family carers, staff)

There is a part time administrator attached to Reach Beyond who supports the Open Doors Project

If the activity, group or project is led by people with dementia, please describe how, including what support they receive:

This has been covered earlier, but the whole service sits firmly within Salford Later Life services and is over seen by the Matron/Senior Manager for Dementia Services.

What are the activity, project or group's key achievements or successes in terms of involving people with dementia?

Successfully employing an individual with dementia - a positive statement on our commitment and a symbol of hope for others newly diagnosed. Participating meaningfully in the provision of the post diagnostic education programmes. The development of the support network, dementia cafe and engagement with services. The main success is seeing individuals gain from the wisdom of talking to someone who clearly understands how it feels to have dementia.

What have been the key challenges in terms of involving people with dementia?

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

Are there other activities that you would like the group to be doing? (if so, please tell us):

The project has far outgrown our expectations and at the moment working to capacity, my vision is to have the funding infrastructure to have a team of 'mikes' with first hand experiences of dementia and enable these to really shape services and work alongside our staff.

What is the activity, project or group's future?

See point 19 - the funding continues to be renewed annually - we need to ensure that this is embedded permanently.

How does it plan for people with dementia leaving the group?

This would depend on who the people were and the reasons for their leaving. We acknowledge the progressive nature of the illness and as such Mike is on short term contract which is reviewed regularly, if he was to leave we are confident that we could recruit again and have learned valuable lessons from our initial recruitment.

Has it produced any resources (e.g. leaflets photos etc.) or information that can be shared? If so, please tell us about them and / or send examples to us:

Production of DVD

Do you have anything else you would like to add?

We are delighted that the OPEN DOORS NETWORK has been shortlisted in the Innovation in Mental Health Category of the 2011 Health Service Journal Awards.

If you think a network would be useful, what are your views on the role and function of such a network? e.g. what could it do, who could be a member, how could it be organised etc.?

It could reach out to those who are more difficult to engage in a more organised way. It could empower those with personal experience to become the experts. Pooling resources to have larger scale impact

Please tell us your connection with the activity, group or project described:

Matron/senior manager

Contact person: Gillian Drummond

Telephone: 07771972628

Email: gillian.drummond@gmw.nhs.uk

Website: n/a

Positive Dementia Group – Aberdeen

How was it set up? When was it set up? Who set it up? If you don't know, can you give us the name of the person and contact details of the person who set it up?

It was set up more than 5yrs ago when my ex-colleague took on the post of Involvement Officer for Alzheimer Scotland in Aberdeen. She set the group up in partnership with Gordon Edgar, the Development Officer (Service User/Carer consultation) in Aberdeen City Council. Myself (Sarah Geoghegan) and Gordon are now the main contact for the group.

What does the activity, group or project do?

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.

Is it aimed at any particular group of people with dementia? If so, please describe who e.g. younger people with dementia, people with a particular type of dementia, people using specific services:

It's aimed at people in the early stages of dementia who want to use their experience to encourage a more positive attitude towards dementia and have their views heard.

Approximately how many people with dementia are involved in the activity, group or project at the moment?

10 - 20 people

Who leads or facilitates it? (e.g. people with dementia, family carers, staff)

Staff chair and minute the meetings but the people with dementia input and guide what the meetings cover.

Who administrates it? (e.g. people with dementia, family carers, staff)

Staff

If the activity, group or project is led by people with dementia, please describe how, including what support they receive:

People with dementia can input what they would like to include in meetings but it is facilitated by 2/3 members of staff.

What are the activity, project or group's key achievements or successes in terms of involving people with dementia?

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.

What have been the key challenges in terms of involving people with dementia?

Recognising everyone's strengths and weaknesses and ensuring that everyone feels

involved but are comfortable with what they take on.

Are there other activities that you would like the group to be doing? (if so, please tell us)

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 group 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 1 or 2 GPs but it has been very hard to get more GPs to attend despite showing it in their protected learning time.

What is the activity, project or group's future?

The group will continue to run for as long as it can and aims to increase general awareness of dementia and reduce stigma.

How does it plan for people with dementia leaving the group?

Until now, when someone has deteriorated to the point that they are no longer suitable for the group, it has been a mutual decision after talking it through with them as they are normally the first to feel that they are not coping so well.

Has it produced any resources (e.g. leaflets photos etc.) or information that can be shared? If so, please tell us about them and / or send examples to us:

They worked with members of the Scottish Dementia Working Group to produce a DVD called 'Through Our Eyes, a life with dementia'. This is available from the SDWG (www.sdwg.org.uk) and clips can be viewed on the website. It's an excellent training and awareness raising tool.

Do you have anything else you would like to add?

N/A

If you think a network would be useful, what are your views on the role and function of such a network? e.g. what could it do, who could be a member, how could it be organised etc.?

It would be useful to know what other groups are doing and it could be that we work together on projects together as would have a larger voice. An online network/forum could be a way of keeping in touch and then group leaders can feed information to the groups and from the group.

Please tell us your connection with the activity, group or project described:

Dementia Advisor

Contact person: Sarah Geoghegan

Telephone: 01224 644627

Email: sgeoghegan@alzscot.org

Website: www.alzscot.org

Contact person: Gordon Edgar

Telephone: 01224 522782

Email: gedgar@aberdeencity.gov.uk

Website: n/a

4.2 Active involvement groups

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

How was it set up? When was it set up? Who set it up? If you don't know, can you give us the name of the person and contact details of the person who set it up?

Service User Review Panels were set up in December 2010 by the Alzheimer's Society Quality and Evaluation team.

What does the activity, group or project do?

Facilitate the involvement of people with dementia into a selection of materials, tools, and policies being developed by the Alzheimer's Society such as questionnaires, consent forms, and our strategic direction.

Is it aimed at any particular group of people with dementia? If so, please describe who e.g. younger people with dementia, people with a particular type of dementia, people using specific services:

N/A

Approximately how many people with dementia are involved in the activity, group or project at the moment?

10 - 20 people

Who leads or facilitates it? (e.g. people with dementia, family carers, staff)

Staff

Who administrates it? (e.g. people with dementia, family carers, staff)

Staff

If the activity, group or project is led by people with dementia, please describe how, including what support they receive:

The facilitation of the groups encourages people with dementia to make decision about what is discussed and who attends the group.

What are the activity, project or group's key achievements or successes in terms of involving people with dementia?

The review panels have been a pilot project that, as well as improving some of our policies and tools, is being written up to inform best practice and to be a part of developing more widespread involvement of people with dementia in the work of the Alzheimer's Society.

What have been the key challenges in terms of involving people with dementia?

N/A

Are there other activities that you would like the group to be doing? (if so, please tell us)

N/A

What is the activity, project or group's future?

The review panels have recently come to an end of their 6 months pilot. The final report is being written and will include recommendations for future development.

How does it plan for people with dementia leaving the group?

It discusses with those who have been involved the services they would use and where possible ensures that they can access other appropriate services.

Has it produced any resources (e.g. leaflets photos etc.) or information that can be shared? If so, please tell us about them and / or send examples to us:

N/A

Do you have anything else you would like to add?

This project has drawn on numerous reports, guidance and literature. Please contact me for further details.

If you think a network would be useful, what are your views on the role and function of such a network? e.g. what could it do, who could be a member, how could it be organised etc.?

N/A

Please tell us your connection with the activity, group or project described:

Project lead and facilitator.

Contact Person: Jane Tooke

Telephone: 0207 423 5135

Email: jane.tooke@alzheimers.org.uk

Website: n/a

Bay Tree Voices – Bradford

How was it set up? When was it set up? Who set it up? If you don't know, can you give us the name of the person and contact details of the person who set it up?

The project started in April 2011 as collaboration between Bay Tree Resource Centre, Leeds and the Division of Dementia Studies at the University of Bradford.

What does the activity, group or project do?

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

Is it aimed at any particular group of people with dementia? If so, please describe who e.g. younger people with dementia, people with a particular type of dementia, people using specific services:

Older people with dementia using day and residential care services - particular focus on people who tend to be left out of mainstream service-user activities.

Approximately how many people with dementia are involved in the activity, group or project at the moment?

10 - 20 people

Who leads or facilitates it? (E.g. people with dementia, family carers, staff)

It is the result of a collaborative process, shaped by the normal life of the resource centre and the things the clients express an interest in at each visit.

Who administrates it? (E.g. people with dementia, family carers, staff)

Project lead at University of Bradford.

If the activity, group or project is led by people with dementia, please describe how, including what support they receive:

Active client involvement in the film-making process is facilitated using methods such as photo-elicitation and walking interviews.

What are the activities, project or group's key achievements or successes in terms of involving people with dementia?

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.

What have been the key challenges in terms of involving people with dementia?

Ensuring meaningful involvement and consent. Whilst people with dementia are happy to take part, this does not necessarily mean that they consent to having their image shown to other people. WE have had to develop a very detailed protocol for dealing with ethical issues.

Are there other activities that you would like the group to be doing? (If so, please tell us)

Further funding has recently been awarded for a project using participatory video to increase social participation. It is intended that this will extend the work to contexts outside the University and its students.

What is the activity, project or group's future?

The project is allied with a number of current policy drivers such as the personalisation agenda, digital inclusion, dementia workforce development etc., so it has good potential for continuing and spreading to other organisations and care environments. The availability of closed membership video sharing sites such as Vimeo makes the wider dissemination of film an attractive approach to public engagement for people with dementia.

How does it plan for people with dementia leaving the group?

Not applicable at present

Has it produced any resources (e.g. leaflets photos etc.) or information that can be shared? If so, please tell us about them and / or send examples to us:

DVD currently in production.

Do you have anything else you would like to add?

We also involve people with dementia in our course management team, and in teaching and assessing students, but this is less a project than a part of our on-going practice.

If you think a network would be useful, what are your views on the role and function of such a network? E.g. what could it do, who could be a member, how could it be organised etc.?

Raising public awareness; campaigning on human rights issues; challenging negative and stereotypical views of people with dementia; producing publicity materials; political lobbying. It is vital that this isn't just for articulate, younger, former professional, majority culture people with dementia.

Please tell us your connection with the activity, group or project described

Facilitator and administrator.

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

How was it set up? When was it set up? Who set it up? If you don't know, can you give us the name of the person and contact details of the person who set it up?

Funded by the Department of Health's Innovation, Excellence and Service Development Fund, led by the National Development Team for Inclusion (NDTi) and Innovations in Dementia (ID), set up in Spring 2011 by both organisations working in partnership.

What does the activity, group or project do?

Development of circles of support for people living with dementia

Is it aimed at any particular group of people with dementia? If so, please describe who e.g. younger people with dementia, people with a particular type of dementia, people using specific services:

People with dementia living in the community

Approximately how many people with dementia are involved in the activity, group or project at the moment?

Less than 5

Who leads or facilitates it? (e.g. people with dementia, family carers, staff)

An advisory group has been set up to guide the project, which has 4 people with dementia and 32 family carers among its members. NDTi and ID are leading on the project delivery, working with organisations in 4 pilot sites.

Who administrates it? (e.g. people with dementia, family carers, staff)

NDTi and ID

If the activity, group or project is led by people with dementia, please describe how, including what support they receive:

Membership of the advisory group, support to come to meetings and take part in the project generally, e.g. face to face meetings with the project team to contribute to development of materials. Practical support such as covering expenses, booking and arranging travel with other team members where required, all expenses of taking part covered.

What are the activity, project or group's key achievements or successes in terms of involving people with dementia?

The Advisory group has been established and first meeting held, with a strong focus on ensuring that the voices and needs of people with dementia being heard and guiding the project's direction. Partner organisations have been recruited to work on the project in each pilot site and the people with dementia on the Advisory Group have all been involved in planning and starting to implement the work in the sites. Publicity, support and training materials have been developed, with strong input from people with dementia. People with dementia are also acting as ambassadors for the project in different areas and have given talks to groups of people who may be interested in becoming involved and developing their own Circle of Support.

What have been the key challenges in terms of involving people with dementia?

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.

Are there other activities that you would like the group to be doing? (if so, please tell us):

As the project develops, other activities are likely to emerge.

What is the activity, project or group's future?

The project funding is for 3 years, from April 2011, during which time we hope to demonstrate that this is an effective way of working with people with dementia and helping to support them to live positively and inclusively within their communities. Following the project, we envisage that the approach will be embedded as a way of working within organisations which support people living with dementia in our communities.

How does it plan for people with dementia leaving the group?

The Circles of Support will be set up and implemented in a way which encourages them to continue beyond the project timescale. The people with dementia who are involved in the project will still have connections to the organisations in each site area, therefore we expect that the involvement of people with dementia will continue and be sustained within the sites with this way of working.

Has it produced any resources (e.g. leaflets photos etc.) or information that can be shared? If so, please tell us about them and / or send examples to us:

Yes. Publicity materials to recruit organisations and individuals to be involved in the project, which can be viewed on the following web page www.ndti.org.uk/major-projects/circles-of-support-for-people-with-dementia/ More information / resources are currently in development

Do you have anything else you would like to add?

The 4 sites (and organisations which we are working with in each) are: Dorset (Alzheimer's Society Dorset); Portsmouth (Age UK Portsmouth); West London (Alzheimer's Society, Hounslow) and Devon (Upstream).

If you think a network would be useful, what are your views on the role and function of such a network? e.g. what could it do, who could be a member, how could it be organised etc.?

Roles: - Influence public perceptions of dementia - challenge the myths and fears, e.g. by demonstrating the achievements and capabilities of people living with dementia - Inspire people with dementia to get involved in different activities and help them to live positively within their communities - Help people to network with each other and work together to achieve positive, lasting change - Provide information on initiatives and activities on different areas and how people can get involved - Help to spread good practice Membership could include people with dementia, carers and anyone who is working on projects or initiatives which involve people with dementia Some central organisation (e.g. through a host organisation), perhaps with regional networks?

Please tell us your connection with the activity, group or project described:

Project Manager

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

How was it set up? When was it set up? Who set it up? If you don't know, can you give us the name of the person and contact details of the person who set it up?

Two year funded project commissioned by South West Dementia Partnership sitting in Alzheimer's Society South West.

What does the activity, group or project do?

Objectives: To work in partnership across health, primary, social care and third sector (voluntary) organisations, to strengthen and enable engagement and involvement

with those living with dementia: individuals, their families and carers. (for example development of 'what works' resource cards) Learn and encourage people to learn from other people's experiences, and work towards developing a local reporting tool; to define measure and monitor the improvements that have been made as a consequence of engaging and involving those people living with dementia. This will inform the implementation of the National Dementia Strategy; service delivery for the future and local, regional and national practice. Build a South West Dementia Network of Involvement Opportunities with the communities across the South West that offers a coordinated approach through which people living with dementia and their carers can communicate their views in shaping what help and support is needed now and in the future.

Is it aimed at any particular group of people with dementia? If so, please describe who e.g. younger people with dementia, people with a particular type of dementia, people using specific services:

Considered all groups of people living with dementia. Developing and sharing tools and techniques for staff and organisations to build capacity and confidence when engaging with people living with dementia individuals; their families and friends.

Approximately how many people with dementia are involved in the activity, group or project at the moment?

10 - 20 people

Who leads or facilitates it? (e.g. people with dementia, family carers, staff)

Project is led by PM [Project Manager] and people living with dementia as advisors to project.

Who administrates it? (e.g. people with dementia, family carers, staff)

PM and project sponsor (South West Area Manager Alzheimer's Society)

If the activity, group or project is led by people with dementia, please describe how, including what support they receive:

N/A

What are the activity, project or group's key achievements or successes in terms of involving people with dementia?

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.

What have been the key challenges in terms of involving people with dementia?

People staff and organisations believing they involve people with dementia - when asked how people demonstrate the same method - questionnaires and through the voice of the carer.

Are there other activities that you would like the group to be doing? (if so, please tell us)

Working with seldom heard groups. PM receives calls from Learning Disability Organisations to develop workshops and training opportunities - unable to facilitate this at this time. Working closely with Health and Social Care Faculties to create opportunities for people with dementia to teach and share lived experiences.

What is the activity, project or group's future?

Disseminate the resource cards to different health and social care settings across the south west, west region and internally through Alzheimer's Society

How does it plan for people with dementia leaving the group?

PM contacts the advisors regularly on a monthly basis in the best way and preference of the individual. The advisor is kept up to date with the project its next steps and what is required during this stage.

Has it produced any resources (e.g. leaflets photos etc.) or information that can be shared? If so, please tell us about them and / or send examples to us:

The Resource cards - launch 7th October 2011

Do you have anything else you would like to add?

N/A

If you think a network would be useful, what are your views on the role and function of such a network? e.g. what could it do, who could be a member, how could it be organised etc.?

Sharing practice and what works develop and strengthen confidence in staff to do things differently use the Scottish Dementia Working Group model

Please tell us your connection with the activity, group or project described:

Project Manager

Contact person: Anne Rollings

Telephone: 0117 9672992

Email: anne.rollings@alzheimers.org.uk

Website: n/a

4.3 Other involvement projects (time limited involvement projects and/or where the involvement has focused on a particular service)

Dementia Advice and Peer Support Service - Age UK Trafford, Greater Manchester

How was it set up? When was it set up? Who set it up? If you don't know, can you give us the name of the person and contact details of the person who set it up?

The project started in 2009 with funding from the local authority and the department of health to run a peer support network alongside a dementia advice service. Initiated as a project between different agencies, Age UK Trafford now operates service with close connections with the local carers centre.

What does the activity, group or project do?

Two dementia advisors help people to understand dementia, suggest constructive ways of managing different situations by looking at individual circumstances, and support the carer and the person with dementia as individuals to enable the person with dementia to have a voice. The dementia advisers also support access to relevant benefits, care services, anything else that is relevant, as well as providing talks to other agencies about dementia. The project as a whole aims to enable people with dementia to have a voice, retain their value and place in society, and improve the prospects for quality of life for those who develop dementia. The dementia advisers provide as much or as little contact and support as each situation merits, and the service is not time-limited - we will support people through accessing higher level services as the condition progresses. 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. A range of professionals are invited to join us to talk, and often learn at the same time, according to what people are interested in, we also have outings

and memory events where people with dementia are invited to offer their opinions / experiences / suggestions on health, social care and general services in facilitated workshops. Age UK Trafford has continued close involvement with the development and implementation of Trafford's dementia strategy, leading consultation with people with dementia, and facilitating representation of people with dementia on a local mental health commissioning panel. In addition, Age UK Trafford runs commissioned day support for people with dementia across the borough.

Is it aimed at any particular group of people with dementia? If so, please describe who e.g. younger people with dementia, people with a particular type of dementia, people using specific services:

The project is aimed at people with mild to moderate cognitive impairment, pre or post diagnosis, but we will support and advise anyone with dementia at whatever stage and their carers. All types of dementia are included and the distribution of conditions largely reflects the general trends, i.e. high incidence of Alzheimer's and Vascular Dementia, or a mix, and smaller numbers of FTLD and Lewy Bodies, including some 'younger' members in their late 50s / early 60s.

Approximately how many people with dementia are involved in the activity, group or project at the moment?

More than 100 people

Who leads or facilitates it? (e.g. people with dementia, family carers, staff)

Two dementia advisors facilitate the groups and organise the sessions, and people with dementia are encouraged to then take the lead as much as possible, supporting each other with the activity, initiating conversation. Family carers are able to come and simultaneously facilitate their own activity.

Who administrates it? (e.g. people with dementia, family carers, staff)

Staff administer the groups, including writing a bi-monthly newsletter

If the activity, group or project is led by people with dementia, please describe how, including what support they receive

N/A

What are the activity, project or group's key achievements or successes in terms of involving people with dementia?

Individuals have reported a lift in mood and reduced feelings of isolation through being involved, and there have been personal changes in feeling valued and quality of life. Increased confidence to participate is an important outcome as some who have been reluctant to come now ask "when is it time to come to the group?" One common theme is the loss of true social value when general groups of older people do not fully understand or appreciate the way dementia affects people. People with dementia who come to peer support say they often feel more accepted and included than they do in general social groups, and appreciate this - they have asked for a short break / holiday that would enable them to relax in the company of others so have this arranged for later this year. We have also raised the profile of dementia in the local community, increasing visibility and removing the stigma that people face. Prior to peer support, non-commissioned support in Trafford was predominantly geared towards helping carers, so the service represents a change in the experience of having dementia in Trafford. Although the project is aimed at those in the early dementia, or pre-diagnosis stage, we have been able to support those at a late stage (and their carers) to quickly access services they were unaware of such as Age UK Trafford specialist dementia day support and respite for carers. In terms of wider access, the opportunity for a group who may otherwise find it difficult to actively influence local decisions about services, has meant people with dementia could personally offer their experiences and thoughts to commissioners through structured consultation events. We like to have a moan and find out information we wouldn't otherwise know.

What have been the key challenges in terms of involving people with dementia?

The challenge has been to encourage those who have a mild-moderate impairment to become actively involved now, because a general response to diagnosis is to carry on "as normal" for as long as possible. This matches the challenges of encouraging

early diagnosis, and we have worked with the GPs to challenge current attitudes of waiting until the person “needs” support. Because there are so many factors which influence the workability of someone’s input into the groups, including severity of the condition, co-existing health problems, personality and desire to make a difference, involvement may only be “in the moment”. One of our group social leaders was encouraging and befriending others one week, but before the next meeting had a large stroke, and the group dynamics therefore shifted as the success of that group had been determined by the gelling of personalities. That element is not always ‘plan-able’ so it has been about adjusting expectations of ‘involvement’ and ‘success’ according to the individual circumstances. It is often the carers who initiate contacts with the group and while we do provide support for carers, we strive to separate the needs of the carers from the person with dementia, and to get past the carer to genuinely hear the voice of the person with dementia. 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.

Are there other activities that you would like the group to be doing? (if so, please tell us)

We have a newsletter to keep people up to date with the service, and ideally this would include more input from people with dementia, to include their experiences, opinions, ideas written in their own words. We would also like to open up access via the internet such as an online forum or blog, accessing a wider percentage of the population, including minority ethnic communities and those who use alternative methods of communication, and enable people with dementia to identify hobbies or talents / skills that they could use to lead the group in activities if they wish to. We have run a beginners computer course for carers and will be running more into the aeon of setting up E support groups to help reduce social isolation.

What is the activity, project or group’s future?

We are constantly trying to develop the project to keep it relevant and up to date - now we are improving our existing links with the local memory service and social work teams so that we will be better placed to make contact with people at the point of diagnosis. As continued funding will always be an uncertainty, the search for what works and what doesn’t, what there is a need for and different ways to achieve this, has to be somewhat anticipatory and persistent. It may be that use of online technology will be a way to continue to build the project’s profile and networking with other projects and related organisations. Hopefully we will be able to continue to enable people to have their voice heard, particularly in developing services and the dementia strategy and to raise the profile and quality of life with dementia in Trafford.

How does it plan for people with dementia leaving the group?

The peer support groups are intended to be a short term (over a period of 6-9 months) to enable people to develop their own networks of support. The variation in need / impairment and timing of diagnosis means that group members do not always start and finish together, but often a number of people are ready to join us at a similar time so there is to some extent a ‘natural’ group development process. The groups run alongside our dementia advice service so the dementia advisors are well placed to support individuals as their needs change and they move on. We keep in touch as long as support is wanted. Because presently people with dementia do not have responsibility for management or particular tasks, making provision for these after they have left is not an issue.

Has it produced any resources (e.g. leaflets photos etc.) or information that can be shared? If so, please tell us about them and / or send examples to us:

We have a general service leaflet with details of the groups, and have photos of events and trips as well as an information pack we provide to people initially. The newsletter is sent out bi-monthly, monochrome copy included. We also have been developing a number of simple factsheets which will be added to over time which and have developed a couple of presentations aimed at different audiences.

Do you have anything else you would like to add?

N/A

If you think a network would be useful, what are your views on the role and function of such a network? e.g. what could it do, who could be a member, how could it be organised etc?

If nothing else, an information sharing role would enable projects to identify where there is a need for something, what is not being done in a particular area, what is being done that works well, what can be done jointly to benefit two areas, etc. If it opens up communication and coherence of campaign, people's experiences of dementia will have a chance of being more consistent across the country - and people have a chance of knowing what other areas have that they can ask for in their own area (thinking of PCT / local authority) to improve services. Of course it could also co-ordinate campaigns to influence national policy and would provide strength in numbers. Those who attend our groups would also like to meet others and share experiences.

Please tell us your connection with the activity, group or project described:

Dementia Adviser

Contact person: Lise Davies & Joanne Rankin (Dementia Advisors) Karen Patel (Care Services Manager) Ann Marie Jones (Chief Executive)

Telephone: 0161 746 3944

Email: dementia.adviser@ageuktrafford.org.uk

Website: www.ageuktrafford.org.uk / www.ageuktrafford.blogspot.com / @dementiaadviser

Dementia Advisory Service – Bracknell, Berkshire

How was it set up? When was it set up? Who set it up? If you don't know, can you give us the name of the person and contact details of the person who set it up?

It was initially set up through the National Dementia Strategy - Demonstrator Site Programme. Bracknell Forest Council was one of twenty two pilot demonstrator sites which were established to test the different ways of providing support for people with dementia and their carers and also to explore the most effective ways to increase access to information and support. The Dementia Advisory Service commenced in November 2009.

What does the activity, group or project do?

The service provides an identifiable point of contact for people with dementia and their carers. It also signposts people to appropriate universal, mainstream and/or specialist services as well as enabling people to navigate and access support.

Is it aimed at any particular group of people with dementia? If so, please describe who e.g. younger people with dementia, people with a particular type of dementia, people using specific services:

People who are newly diagnosed with dementia are supported until a time when they may require more intense support from either a Care Manager or CPN (Community Psychiatric Nurse).

Approximately how many people with dementia are involved in the activity, group or project at the moment?

40 - 100 people

Who leads or facilitates it? (e.g. people with dementia, family carers, staff)

The Dementia Adviser Project Board leads the service. Members are from: Bracknell Forest Council; Berkshire East PCT; a local voluntary organisation; representations from local dementia groups; Berkshire Healthcare Trust and Carers.

Who administrates it? (e.g. people with dementia, family carers, staff)

The Dementia Adviser

If the activity, group or project is led by people with dementia, please describe how, including what support they receive:

N/A

What are the activity, project or group's key achievements or successes in terms of involving people with dementia?

The Dementia Advisory service is developed in conjunction with those people who use the service. Any person diagnosed with dementia and their carers who access the service are provided with support which is tailor-made to the individual. Individuals decide on the level of support they require; the amount and type of support and how this support is delivered. To achieve this the Dementia Adviser consults both the person with a diagnosis of dementia and their carers regularly. This consultation takes place informally during home visits and more formally with an annual evaluation on service delivery. Therefore people with a diagnosis of dementia are given the opportunity to influence the development of the service and their personal support. An outcome of this approach has been the development of a new 'User-Led' group. This group was set up as a direct result of feedback from people using the service. People wanted an opportunity to meet up with others in a similar situation for social get-togethers. The Dementia Adviser facilitated the development of a committee which includes both carers and people with a diagnosis of dementia. This group now meets regularly and is completely user-led. The Dementia Adviser also produces a Newsletter which is distributed to all the people on her caseload. Within the Newsletter there is an opportunity for people to correspond and have their views published.

What have been the key challenges in terms of involving people with dementia?

The initial evaluation requested that they were completed by the person with a diagnosis of dementia. However feedback from the evaluation indicates that many carers have a great deal of influence over an individuals' independence choice, control and well-being, therefore future evaluations of the Dementia Advisory Service should consider the information and support received by the carer, as this could indirectly impact on individuals' independence, choice, control and well-being.

Are there other activities that you would like the group to be doing? (if so, please tell us)

N/A

What is the activity, project or group's future?

Funding will need to be secured annually at present.

How does it plan for people with dementia leaving the group?

People with a diagnosis of dementia are supported throughout their journey or until they require more intense support from a Care Manager or CPN. If this is the case, the Dementia Adviser writes a discharge letter to the individual detailing that the support is being handed over.

Has it produced any resources (e.g. leaflets photos etc) or information that can be shared? If so, please tell us about them and / or send examples to us:

The Dementia Adviser Leaflet and Newsletter

Do you have anything else you would like to add?

N/A

If you think a network would be useful, what are your views on the role and function of such a network? e.g. what could it do, who could be a member, how could it be organised etc?

N/A

Please tell us your connection with the activity, group or project described:

N/A

Contact person: Karen White

Telephone: 01344 823220

Email: karen.white@berkshire.nhs.uk

Website: N/A

The Hair and Care Project – Manchester

How was it set up? When was it set up? Who set it up? If you don't know, can you give us the name of the person and contact details of the person who set it up?

It is a research project led by Dr Richard Ward and funded by ESRC.

What does the activity, group or project do?

Research

Is it aimed at any particular group of people with dementia? If so, please describe who e.g. younger people with dementia, people with a particular type of dementia, people using specific services:

Yes we are interested in people with advancing dementia but are involving people in the early stages of dementia as advisors and informers.

Approximately how many people with dementia are involved in the activity, group or project at the moment?

10 - 20 people

Who leads or facilitates it? (e.g. people with dementia, family carers, staff)

Researcher without dementia

Who administrates it? (e.g. people with dementia, family carers, staff)

Researcher without dementia

If the activity, group or project is led by people with dementia, please describe how, including what support they receive:

N/A

What are the activity, project or group's key achievements or successes in terms of involving people with dementia?

I don't think what we are doing is groundbreaking in any way but we are trying to involve people with dementia to be key informants to our work - and it is a way of giving work to an existing group of people with dementia who are developing their skills as trainers/consultants etc as a peer support group.

What have been the key challenges in terms of involving people with dementia?

Ensuring that they are being involved in way that is useful and not tokenistic.

Are there other activities that you would like the group to be doing? (if so, please tell us)

Yes, we would like more involvement in our research team in all of our project work with people with dementia involved in an active way and also in terms of guiding our research agenda too.

What is the activity, project or group's future?

Not really applicable for to our project

How does it plan for people with dementia leaving the group?

N/A

Has it produced any resources (e.g. leaflets photos etc) or information that can be shared? If so, please tell us about them and / or send examples to us:

N/A

Do you have anything else you would like to add?

I am not sure that our research project is a particularly useful indication of user involvement - it is the beginning of something - trying to involve an existing group and going to their meetings to discuss and consult with them rather than having one or two people sitting on our advisory group in a tokenistic way. We have tried to utilise this existing group of people with dementia in a positive and helpful way.

If you think a network would be useful, what are your views on the role and function of such a network? e.g. what could it do, who could be a member, how could it be organised etc?

I think it would need a clear set of functions, as networks can sometimes be nebulous. You can have different levels of membership - from user groups to friends of ..etc.

Please tell us your connection with the activity, group or project described:

Researcher

Contact person: Sarah Campbell

Telephone: 0161 275 7609

Email: sarah.campbell@manchester.ac.uk

Website: N/A

The National Council for Palliative Care NCPC) - Difficult Conversations for Dementia Project, England

How was it set up? When was it set up? Who set it up? If you don't know, can you give us the name of the person and contact details of the person who set it up?

NCPC's people bank is a group of people who have personal experience of a life-limiting condition (either as a patient, carer or former carer). This group was set up by NCPC. The Difficult Conversations project was also set up by NCPC but jointly funded by the National End of Life Care Programme. It started in April 2010 and finished in July 2011

What does the activity, group or project do?

General activities undertaken by people bank (which includes people affected by dementia) are giving policy input, media work, helping produce good practice guidance, speaking at training/conferences, being part of our specialist groups about different aspects of palliative care and online involvement (e.g. blogs, Facebook, twitter) The Difficult Conversations project drew on the experiences of 50 people affected by dementia, exploring how, when and with whom they would like to have conversations about their end of life care wishes, and what they'd like to talk about it. This involved telephone calls, emails and group discussions. Findings were collated to produce 'Difficult Conversations' guidance which has now been published and widely distributed among health and social care professionals. Those involved were invited to the launch at the joint All Party Parliamentary Groups (APPG) for Palliative care and dementia. We suggested that they might like to invite their MPs. Several MPs attended and met with those who attended. The impact of the project is that many people across the UK are using this guidance to help people with dementia think and plan ahead for the end of life, thus improving quality of life. Other spin-offs are that (a) one MP has become involved in a local campaign to raise awareness of dementia (b) people who were involved have become further involved by inviting their MPs to

future APPGs (d) Following the APPG where Difficult Conversations was launched, The national clinical director for dementia made a personal promise to specifically focus on improving palliative and end of life care for people with dementia. (e) The Alzheimer's society nominated the book as their book of the month (f) Learning will be shared at our national dementia conference on 12th December and those who were involved will take part in the training (f) People who were involved in Difficult Conversations have become more involved in NCPC's work, working more closely with their MPs and getting involved in policy/good practice work we're doing.

Is it aimed at any particular group of people with dementia? If so, please describe who e.g. younger people with dementia, people with a particular type of dementia, people using specific services:

No - it's aimed at anyone affected by dementia.

Approximately how many people with dementia are involved in the activity, group or project at the moment?

40 - 100 people

Who leads or facilitates it? (e.g. people with dementia, family carers, staff)

The project was led and facilitated by NCPC's Involvement manager, but the experiences of people affected by dementia were the core material for producing the guidance. People bank is also led/facilitated by NCPC's involvement manager

Who administrates it? (e.g. people with dementia, family carers, staff)

NCPC's involvement manager (both the difficult conversations project and people bank).

If the activity, group or project is led by people with dementia, please describe how, including what support they receive:

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 make share information about impact of involvement.

What are the activity, project or group's key achievements or successes in terms of involving people with dementia?

This has been answered in the question about what the project involved.

What have been the key challenges in terms of involving people with dementia?

We are very keen to involve people with dementia themselves. One of the challenges is the vulnerability of people with dementia i.e. when travelling, communication etc. Also, we've found some people with dementia to be a bit unpredictable mood-wise. We are very supportive and understanding, knowing that this is likely to be related to dementia, but at the same time others can sometimes feel a little uncomfortable. We find it difficult to involve people from minority ethnic groups due to the stigma attached to dementia. People are less comfortable speaking out.

Are there other activities that you would like the group to be doing? (if so, please tell us)

Yes - more people with dementia directly involved and leading activities on dementia.

What is the activity, project or group's future?

The Difficult Conversations project is now complete, but we are trying to secure sponsorship so that it's rolled out to every memory clinic in the country (and obviously continuing to promote it nationally) The People Bank will continue as it is.

How does it plan for people with dementia leaving the group?

There was no 'group' as such for the Difficult Conversations project, but all who were involved have been invited to join our People Bank so that they can continue to have a say.

Has it produced any resources (e.g. leaflets photos etc) or information that can be shared? If so, please tell us about them and / or send examples to us:

<https://www.committedgiving.uk.net/ncpc/publications/Product.aspx?id=358>

<http://www.youtube.com/watch?v=-S--Y2mpESw>

Do you have anything else you would like to add?

Feel free to ring for more information. Not sure I've been completely clear!

If you think a network would be useful, what are your views on the role and function of such a network? e.g. what could it do, who could be a member, how could it be organised etc?

What could it do: provide guidance and support on involving people with dementia
Who would be a member: Anyone who wanted to improve the way they involve people with dementia - could be NHS, voluntary, local, national - anything
A group of people affected by dementia could lead this project. Perhaps it could be led by Innovations in Dementia's think tank. They would employ a reference group of 'professionals' whom they could bounce ideas off about how their ideas would work in practice, within the workplace.

Please tell us your connection with the activity, group or project described:

I lead on 'user involvement' at NCPC and Dying Matters.

Contact person: Jo Black

Telephone: 020 697 1520

Email: J.Black@ncpc.org.uk

Website: www.ncpc.org.uk www.dyingmatters.org

Social Care Alba - National Participation Group, Motherwell, Scotland

How was it set up? When was it set up? Who set it up? If you don't know, can you give us the name of the person and contact details of the person who set it up?

Founded by Stephen Wilson, Director of Social Care Alba to improve the quality of care and support people receive. The group's aims are "To educate and empower people to reach their full potential"

What does the activity, group or project do?

Brings together service users, families, carers, social work, advocacy, health, education, disability groups and more with the aim of improving the quality of people's lives. The group will consider individual cases to through to National campaigns.

Is it aimed at any particular group of people with dementia? If so, please describe who e.g. younger people with dementia, people with a particular type of dementia, people using specific services:

The group is aimed at adults and is open to all.

Approximately how many people with dementia are involved in the activity, group or project at the moment?

Less than 5 people

Who leads or facilitates it? (e.g. people with dementia, family carers, staff)

It is facilitated by Stephen Wilson as interim chair whilst a permanent chair is sought. We are looking for a person with dementia/family or carer to lead the group.

Who administrates it? (e.g. people with dementia, family carers, staff)

Currently this is supported by Social Care Alba staff. We are currently looking to become a charitable group. When this is achieved we will move this role to another member of the group.

If the activity, group or project is led by people with dementia, please describe how, including what support they receive:

N/A

What are the activity, project or group's key achievements or successes in terms of involving people with dementia?

Creating a network from which new ideas and best practise can be shared

What have been the key challenges in terms of involving people with dementia?

No real challenges other than encouraging people to get involved

Are there other activities that you would like the group to be doing? (if so, please tell us)

Linking with national projects, research or other groups

What is the activity, project or group's future?

Creating a network across Scotland and holding an annual conference.

How does it plan for people with dementia leaving the group?

Each member has a 2 year involvement. If people with dementia leave we support them through keeping in touch, relaying messages between the person and the group and ensuring relationships are maintained where they wish it.

Has it produced any resources (e.g. leaflets photos etc) or information that can be shared? If so, please tell us about them and / or send examples to us:

Not yet as it is a relatively new group but this is planned. We are currently seeking funding to support us.

Do you have anything else you would like to add?

We welcome new members no matter where you live. We would love to be involved with other groups nationally as well as with any research or best practise initiatives.

If you think a network would be useful, what are your views on the role and function of such a network? e.g. what could it do, who could be a member, how could it be organised etc?

Bringing together existing groups to look individually and collaboratively at new ideas. Raising the voice of people with dementia through co-working/production

Please tell us your connection with the activity, group or project described:

I established and fund the group

Contact person: Stephen Wilson

Telephone: 0845 0945 279

Email: office@social-care.org

Telford and Wrekin Dementia Research Group – Shrewsbury

How was it set up? When was it set up? Who set it up? If you don't know, can you give us the name of the person and contact details of the person who set it up?

It was set up through Telford and Wrekin Council's Dementia Providers Forum; which is a forum of local service providers that meets up every 3 months to discuss best practice, experiment with new initiatives and evaluate how best to implement policy. The need was identified to improve meaningful communication with people with dementia in care settings. The reason for this is so that care staff have tools to help them engage with people with dementia and consult them on their views of the services they are receiving. We believe that by doing so, service providers will be able to deliver truly person centred care for people with dementia. The communication tools that will be trialled are walking interviews, photo elicitation techniques, talking mats and theatre groups. These will then be evaluated and service providers in the area will be able to read the evaluations, make a judgement of whether the tools would benefit their consultation/communication efforts with service users and access the resources (apart from theatre groups) via the local care representative organisation, 'Shropshire Partners in Care'. Members of this organisation will be able to rent the tools, such as the Talking Mats, after the research has been completed. It was set up summer 2011 as a sub group to the Dementia Providers Forum; and the research has been taken on by several service providers September 2011.

What does the activity, group or project do?

It was set up through Telford and Wrekin Council's Dementia Providers Forum; which is a forum of local service providers that meets up every 3 months to discuss best practice, experiment with new initiatives and evaluate how best to implement policy. The need was identified to improve meaningful communication with people with dementia in care settings. The reason for this is so that care staff have tools to help them engage with people with dementia and consult them on their views of the services they are receiving. We believe that by doing so, service providers will be able to deliver truly person centred care for people with dementia. The communication tools that will be trialled are walking interviews, photo elicitation techniques, talking mats and theatre groups. These will then be evaluated and service providers in the area will be able to read the evaluations, make a judgement of whether the tools would benefit their consultation/communication efforts with service users and access the resources (apart from theatre groups) via the local care representative organisation, 'Shropshire Partners in Care'. Members of this organisation will be able to rent the tools, such as the Talking Mats, after the research has been completed. It was set up summer 2011 as a sub group to the Dementia Providers Forum; and the research has been taken on by several service providers September 2011.

Is it aimed at any particular group of people with dementia? If so, please describe who e.g. younger people with dementia, people with a particular type of dementia, people using specific services:

The research is carried out by local service providers in Telford and Wrekin, and will focus on improving communication efforts in different care settings, including Day Care, Domiciliary, Extra Care and Care Homes. The research is carried out by private, non profit providers and charities (Age UK Shropshire, Telford and Wrekin).

Approximately how many people with dementia are involved in the activity, group or project at the moment?

20 - 40 people

Who leads or facilitates it? (e.g. people with dementia, family carers, staff)

Service providers carry out the research; care staff facilitate these efforts. People with dementia participate as they use the communication tools and their feedback will make up the evaluations of the effectiveness of each communication tool.

Who administrates it? (e.g. people with dementia, family carers, staff)

A member of one of the participating service providers administrates the research.

If the activity, group or project is led by people with dementia, please describe how, including what support they receive:

N/A

What are the activity, project or group's key achievements or successes in terms of involving people with dementia?

We have just started the period of research. The successes and achievements that we hope to gain from this research is greater rapport between staff and service users as both participate in the research, improved communication with people with dementia for the purposes of getting their views on the service they receive and how it can be improved, and so a greater development towards personalised services in the area. The aim of having the communication tools as a shared resource for local providers will enable providers beyond those who participated in the research to benefit from access to tools that can help service users with dementia express themselves. These achievements will be county wide and will cover different care settings.

What have been the key challenges in terms of involving people with dementia?

A key challenge so far has been, ironically, the purpose of why the research group was formed: to overcome communication barriers so as to find out what service users think of the services they receive. Also staff commitment takes some encouragement but yields the rewards once staff see the effects of their efforts.

Are there other activities that you would like the group to be doing? (if so, please tell us)

Not at the moment.

What is the activity, project or group's future?

The future is to evaluate the research and provide a shared resource of communication tools for all service providers in the Borough. Shared learning, in addition to access to the communication tools, will lead to developments in local services that can help people with dementia to get their voices heard and receive person centred services. We would also like to feed the research back to all service users and ask if they would like to trial anything else in terms of communication tools.

How does it plan for people with dementia leaving the group?

Due to the fact that the project is led by service providers, service users with dementia have constant access to the Research Group, can share their thoughts and participate in the use of the communication tools.

Has it produced any resources (e.g. leaflets photos etc) or information that can be shared? If so, please tell us about them and / or send examples to us:

Has explained in 20, we intend to disseminate the evaluations of the communication tools for all local service providers to access. Evaluation will be loaded onto the Shropshire Partners in Care website which members can access, and send out by request. We would be happy to share the research evaluations with DEEP.

Do you have anything else you would like to add?

We would like to share the research with national providers and perhaps add different communication tools that we can research if other service providers outside of the Borough have found value in communication tools that we have not heard about.

If you think a network would be useful, what are your views on the role and function of such a network? e.g. what could it do, who could be a member, how could it be organised etc?

Perhaps it could be SCIE/ research lead, with few London-centric events and meetings if possible. If it could disseminate best practice via a website or e-newsletter that would be great.

Please tell us your connection with the activity, group or project described:

Manage the project.

Contact person: Grace Dyke

Telephone: 01743 283200

Email: gdyke@coveragecareservices.co.uk

Website: www.coveragecareservices.co.uk

Section 5– Selection of individual responses from the survey

This section contains responses from individuals with dementia who participated in the survey together with an email correspondence DEEP had with a person living with dementia.

Please note – all the respondents gave their consent to their responses/emails being published.

What kind of things are you involved in as an individual to change the way dementia is viewed? Please give examples.

- A** Member in Scottish Dementia Working Group [SDWG] based in Glasgow. The SDWG is a campaigning group which works toward improving the lives of people diagnosed as having dementia. All members have this diagnosis. Currently we are involved in implementing the Scottish Government Strategy for dementia. Member give talks on aspects of dementia, attends conferences, e.g. I attended [an Alzheimer Europe conference...], have given talks to professional, etc.
- B** Give presentations to students and health professionals. Also carer groups. Lobby members of government. Write articles.
- C** Writing an article on how I cope with dementia and the tools I find useful.
- D** Working with the Department of Health and universities to enhance the experience of those with dementia, and also to raise awareness.
- E** 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.
- F** Formally a Council Member and Trustee of the UK Alzheimer's Society, Ambassador and Founder member of the Lewy Body Society, Associate of Innovations in Dementia, Alzheimer's Research Trust supporter and presenter, Presenter throughout the UK and Internationally for the last 12 years (97 presentations in 2010), University of Worcester – Association for Dementia Studies Steering Board, Holder of an Honorary MA from University of Worcester for work in the dementia field, Member of Alzheimer Europe working group on Advanced Directives, Collaborator - The UK Mental Capacity Act 2005, Member NICE/SCIE Dementia Guideline Development Group - CG 42, Advisor to the National Audit Office (NAO) on dementia (twice), Member of the External Reference Group - National Dementia Strategy, Stakeholder member – National Dementia Strategy with particular reference to Living with Dementia, Memory Clinics, Peer to Peer Support, End of Life and Assistive Technology, Member and co-founder of Memory Services Accreditation Network (MSNAP), committee member and accreditation panel member, Royal College of Psychiatry – Mental Health User and Carer Group, Mental Health Foundation – Dementia Choices Personal Budgets Steering Committee (now completed), Royal College of Physicians – Pharmacological Working Group (now completed), Boards for DeNDRoN (Dementia and Neurodegenerative Disease) both in Primary Care and in Dementia, DeNDRoN North West Local Research Network Management Committee, EVIDEM (Evidence in Dementia), Patron - South West Yorkshire Partnership NHS Foundation Trust (Mental Health) Collaborative and their "Portrait of a Life" project, Member - Electronic Social Care Records Implementation Board (ESCR), Department of Health. (now completed), Contributing author "The Oxford Textbook of Old Age Psychiatry – 2009", Author of several papers on dementia, mental health and social care, Broadcaster (Radio and Television), Manchester and Cheshire End of Life NHS Working Group, also National Council for Palliative Care.
- G** Our Positive Dementia Group (PDG). Giving talks to students. Guest social workers at PDG meetings. Radio interviews. Taking part in a number of research projects.
- H** ... speaker at Dementia Forums, to help with training. I speak at various locations. I was involved with making a documentary on a DVD and CD. I have spoken out on interviews at local radio stations.
- I** Helping others - try to keep them happy. Lost three friends at the moment with dementia - very sad. Pray every night - helps me to survive thank God.
- J** I give talks called "Living with Alzheimers"
- M** Monthly Dementia group meeting. Participating in education of NHS staff about dementia. Talking to interested groups at their premises.

N I am the chairperson of the Dementia Leadership Group, I advise the South West Dementia partnership, volunteer for Alzheimer Society, media, TV, radio, newspapers. Blog all over the world. Creator of Dementia Awareness Day. Involved in opening 1st ever memory cafe in the USA.

O I hold my bucket out at fundraising events for Alzheimer's Society. Sit on a committee on fundraising for local hospital (with my wife). Answer questions and give feedback for various projects for Innovations in Dementia. Part of a drug trial - we are Patient and Public Involvement reps.

Are you involved in any other activities or groups etc? Please tell us how you are involved.

B Vice chair of SDWG, which is a group run by and for people with dementia.

C Contributing to newsletters worldwide and keeping contact with all friends I met through Alz/Scot [Alzheimers Scotland].

D Helping to train nurses to understand the needs of those with dementia.

E Chairman for 12 years and still a member of the Dementia Group of Christian Council on Ageing. Former national trustee of Alzheimer's Society (also for about 12 years) until 2005 when my vascular disease of the brain was diagnosed. Still a member of Research Network. Participated in reference group for the Dementia Strategy and now co-chair of Implementation Reference Group. On steering group of several research projects and also participated in research projects with other people with dementia e.g. Ruth Bartlett's Activism studies. Focus Group for Mental Health Foundation. Was involved with local Alzheimer's Society Branch when it existed. Was involved with 'Living with Dementia Group...Hope to help in establishing a new style group with more autonomy (like Scottish Group).

F Retired Company Director Public plc (Computing), Assistive Technology – own consultancy company carrying out research, Governor - 5 Boroughs Partnership NHS Foundation Trust (Mental Health), Formally a Non-Executive Director of Warrington PCT, Member - Warrington Mental Health Partnership Board, Warrington User and Carer Forum, Altrincham Genealogical Society, Old Salians (ex. Grammar School Association), Subbrit – Cold war Association, Royal Air force Association, Member of the Institute of Electrical and Electronic Engineers (Professional Body), Member of the Chartered Institute of Environmental Engineers (Professional Body), Fellow of the Chartered Institute of Management (Professional Body), Member of the Chartered Institute of Marketing (Professional Body).

J Church community - raising awareness.

M Working with the Alzheimer's Society to try to raise the profile of dementia. Participate at events and give talks about living with dementia for the Society.

N Speak at conferences, training of staff regarding dementia.

Does anyone help you to get involved? Are there other things that help you to get involved?

A The SDWG does contact persons diagnosed with dementia and try to recruit members. When I was diagnosed I got a lot of help and encouragement in meeting and working with others who had similar problems to myself.

B Support workers. Help with transport.

C My service providers who are my close friends and all at Alz/Scot who showed me a way forward.

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

E My husband is very supportive and is himself a befriender for Alzheimer's Society... My faith is also strong motivator and much of my writing is related to the spiritual needs of those with dementia.

F Working in care homes whenever I have a moment, I visit many care homes but usually don't talk about this as I regard this work as very personal to me.

J A friend comes with me to do talks.

K A complete and deafening, 'NO'. Many meetings, committees and activities are invariably held in places near to the HQ of the organisers. Often this is not the best place to suit the need of the sufferers. 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. A glance at the addresses of the participants would show that large areas of the organisers franchise have little representation, while tiny concentrated areas are overwhelmed with local people. The result is that the problems of the isolated sufferers (which markedly differ from those in intensely selected areas) are rarely, if ever taken into account.

N My wife and full time carer.

O Yes - my wife and staff at local Alzheimer's Society. Receive various newsletter and magazine which keep in touch - only source of information I get. Transport is a recurring problem.

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

A In Scotland a national strategy on dementia has been agreed and is being implemented. The SDWG is involved in the implementation at a high level in government. We have been invited to be involved as the "voice of people with dementia" who have first-hand experience of the problems encountered.

B Good quality support and encouragement and flexibility in working time.

C Simple. Stimulation not medication.

D By treating them with respect and looking at the person and not the illness.

E 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.

F People with dementia do need support but more than that they need their independence whenever possible. I am a long-time advocate of people with dementia being funded and given the opportunity to support themselves. To be over-supportive can be totally counterproductive in that it endorses the fact that they are losing their abilities, in a way it becomes patronising. To offer financial support so that people with dementia can get on with supporting themselves with a rider that, if you need us, we are always there for you; that is the very best way of helping. To us it is obvious but to others it seems incomprehensible. One's independence is an extremely valuable thing. We are no lesser mortals because we have a diagnosis.

H More understanding from doctors and general public. More awareness of support. They have a valuable input and knowledge base to help, support others, both with or without dementia. I feel that seeing dementia from the inside gives me a better idea of what is needed to help me, these services could then be more understanding of my needs.

J Provision of support to enable activities. Friendship.

M Local dementia groups, ideally managed by permanent NHS staff, with support from volunteers. Encourage regular visiting between the various groups to try and disseminate best practice, and also to help morale in isolated areas.

N Being asked to be involved in policy making, interviews and opinions.

O Funding

Do you have anything else you would like to add?

- B** People with dementia need to meet up with one another.
- C** I use my nursing skills to adapt to my condition and help others.
- H** There should be more information given when first diagnosed and getting to help quicker. Better training with perhaps General Practitioners. Quicker diagnosis. More services more readily available.
- K** Because only a small section of sufferers are able to get to particular meetings, it is important to let the mass of their absent fellows know what has transpired - by widely issuing reports and by drawing people in by alternative means - after all, dementia is not just the prerogative of those that can get to meetings - far from it. Yet, seemingly, that appears to be the main means of roping-in people to activities.
- O** We need people who get things done - people who make things happen, go-getters. The key thing is reliability.

If you think a network would be useful, what are your views on the role and function of such a network, e.g. what could it do, who could be a member, how could it be organised, etc?

- A** In Scotland we have concentrated in publicity and openness and influencing government policy.
- B** Campaign, anyone with dementia and someone with lots of financial support and dedicated people who believe that people with dementia can contribute back to society.
- C** It would enhance communication and learning by sharing experiences as carers and clients.
- D** I feel that these groups can play a vital role in getting people who have had the diagnosis of dementia out in the community, raising awareness, and help promote the illness in any way possible. I do feel that anyone who has dementia should get involved if they are able to attend...
- F** Very much along the line of the Dementia Action Alliance, providing the 'glue' between different group of people with dementia who are trying to support themselves ensuring we all have an opportunity to act in concert.
- H** Self help groups, planning what's needed, it would greatly support both sufferers and carers. Small pocket groups around the country, perhaps meeting 6 monthly or yearly for bigger conferences. The best mix of a group would be sufferers, carers, professionals, local authority and society input by all.
- J** Network should be local and regional. Increase awareness. People with dementia can be a member.
- K** The current means of contacting sufferers by way of meetings and activities, leaves the mass of people untouched...My feeling is that such people are a very highly selected minority. A lot depends on whether the organisers want to have an easy life singing along with a small select group of reasonably able and well located sufferers or whether they change their spots and make a determined effort to seek out the bulk of the people whose voice and view is hardly ever heard.
- M** Very useful, the further the network spreads the less people will feel isolated.
- N** The most important role and function of DEEP in my opinion is to give back to people with dementia what has been lost, which is a voice, and the confidence to speak out.
- O** Yes, if you could find the right people to run it. Family carers are important - they look after us - they are the first point of call. Funding 20 new people would be difficult. Hierarchies are difficult - don't want to be at the bottom of a heap - communication will be a problem. Similar to the Living with Dementia magazine. Need to promote 'what's in it for me'.

Please tell us about any reports, guidance or literature about people with dementia trying to influence services and policies that you are aware of.

A We have contributed to many Alzheimer's Scotland publications, SDWG has produced papers. We have also produced training DVDs.

D Groups of people with dementia work on many projects around the UK, helping write reports, some of which are done by the Mental Health Foundation, Department of Health and the [Alzheimers] Society.

Please tell us about any other activity, group, project or organisation that you are aware of involving people with dementia trying to influence services and policies.

D Many charities involve people with dementia to help promote the illness and attempt to influence the services. In my case I am also working with the Department of Health on the Workforce advisory group, helping promote better services all round.

F There is an excellent Scottish dementia working group north of the border.

G Scottish Dementia Working Group- very good, effective and hopefully, more "politically" powerful.

Email correspondence from a person living with dementia

Please note – the correspondent gave his consent to these emails being published.

3 May 2012

Dear Toby,

...We want to create in England and Wales an autonomous and independent group that can help us voice our concerns, help to build social support and solidarity, help us to innovate around service offerings and which will help us to challenge stereotype and stigma. We aspire to great things and we have been realistic about the steps necessary to achieve them.

We are writing to ask for a financial contribution that will help us to achieve this. The money we are requesting will help to fund a one week residential event in the autumn to act as a springboard toward creating a sustainable network and a user led support organisation to sustain it. The idea of running a residential workshop arose from the experience of a small core group at a residential event last year. The output from that event inspired us and empowered us to plan for a user led network. We first talked about repeating the experience of a residential event while preparing and delivering our road-show. Attendance at conferences, seminars and workshops has introduced us to other groups and projects involving people with the lived experience of dementia. Most groups are small local gatherings which often have been struggling and most projects have had their funding withdrawn in the current straightened financial climate for voluntary sector organisations.

Our isolation results in feelings of powerlessness, helplessness and hopelessness in individuals and in groups. Our geographic distribution across the country is unequal which makes keeping in touch difficult. We need to be able to relax with each other, to build the safety required to enable us to dream big dreams and to create the strategies that will make them come true. We need to enjoy each other to achieve the degree of intimacy which cannot be achieved in occasional one day business meetings. People with dementia need the reassurance of extended contact that will help us to recover our confidence in our ability to collaborate and to contribute; from each according to the ability and from each according to our strengths. Planning is already underway.

Dementia affects all sectors of society. People with dementia are diverse. Dementia respects no class, or colour, or ethnic origin or any other factor. We want our residential event to reflect the diversity of needs and purposes evidenced in the types of groups we invite and the focus or emphasis that each group has. We want our workshop to be designed from the outset to be inclusive and we want to reach people who might normally exclude themselves. Our workshop will welcome and encourage

representation to reflect the composition of the whole constituency. We will actively reach out and invite disadvantaged groups and individuals...

...With very best wishes...

4 May 2012

Dear Toby

Thanks for the prompt reply. The people I have been contacting about a national group have been beavering away at this for years and years (at least 10 years) without getting very far. In fact most of them have been trying to get a working group established for England and Wales for much longer than I have myself and I've been giving it my best shot for just four years. Some of the folk I'm working with will also be some of the folk who filled in the DEEP questionnaire BUT I only found out about the DEEP project when we met in Liverpool because I'm not on any of the membership databases anywhere and, consequently, I wasn't invited to contribute a questionnaire or invited to either of the DEEP consultations in the South or in the North. The learning from this is that there are quite a large number of people who are part of small local support groups and networks. We are obviously not on your radar and your project wasn't something we had got wind of either. The learning from this is that a genuinely representative group will comprise not just the people you have approached but must also include the people you didn't manage to reach.

I'm absolutely convinced that there is a good chance that we have been working with many of the same people in parallel but separately. I got started in this direction because people we work with in our All Ages Dementia Advocacy Project and because the folk we met at the Young Dementia UK support groups said that they felt isolated and out of touch. We started looking for like-minded individuals in earnest when the research project that has been led by Ruth Bartlett (2008) put us in touch with very large numbers of other people with dementia who had the same ambition; to build a national support group. When Ruth funded a small residential event for us (2011) we got to meet the Scottish Dementia Working Group they began to mentor us through the steps and processes to raise awareness and to build support. That first residential event put us onto the winning formula for getting to achieve agreement; individuals with dementia need the space, the time and the safety to get there and we have the evidence to prove it.

Even though we are all volunteers and we are all new to the business of raising funds we have already had some modest success. We are not going away and we are not giving up. Here we are four years later (2012) and it is all starting to happen at last. The chance to have contact with the Prime Minister was a real bonus. I have written to him and Number 10 have sent a response. I also got a chance to talk with Paul Burstow [Minister of State for Health with responsibility for dementia at the Department of Health] at the Dementia Congress in Liverpool...

All of us have had the experience of being picked up and then dropped by sponsor stakeholders. All of us are deeply allergic to tokenism. None of us want to be exploited for PR value and then abandoned. We are mostly sufficiently canny to know that paternalism is not for us. We don't want to be part of a network run for us. We want to be part of a network run by us. We'll build a user led group, some autonomy, some dignity and some independence; even if that means that we have to fight for every penny. We've been running for four years funding everything from our own pockets. None of us have very deep pockets either. We've got a passion and we've got determination and we've got some urgency because our capacity cannot be taken for granted. We also have skilled mentors and we've got some very generous and committed allies. It really would be great to have some resources too.

...Best wishes...

Section 6 – Transcripts of group interviews

6.1 Transcript of DEEP group interview with the Early Dementia Users' Cooperative Aiming To Educate (EDUCATE)

6.2 Transcript of DEEP focus Group with Scottish Dementia Working Group (SDWG)

6.3 Transcript of DEEP group interview focus with Torbay Dementia Leadership Group

Please note – all the groups have given their consent to these transcripts being published. All personal references by name have been removed together with any passages where the groups discussed a named organisation or private individual.

6.1 Transcript of DEEP group interview with the Early Dementia Users' Cooperative Aiming To Educate (EDUCATE)

Eleven people from the EDUCATE Group took part including a family carer plus the interviewer from Innovations in Dementia.

A: What does EDUCATE do?

B: Well on our trips out, we go and speak to various people who range from professionals to ordinary members of the public and we try to share with them what it's like to live with dementia. And please, I say to people, never be scared of the word dementia. It's just a word, it just means it's a physical problem in your brain. Never, never, never walk by on the other side. Please, just love us for who we are. That's all I ever ask.

C: The whole idea of our group was to extend public and in particular, professional recognition of what it is like to be an Alzheimer's sufferer. Alzheimer's being only one form of dementia. And god only knows, doctors in particular if they've not specialised as the consultants do, you know very little about it. Um, one of our main aims what to sort of extend, not re-educate but extend people's knowledge of what the indispositions are of having dementia. And having things go wrong beyond one's control, without having lost forever any of our faculties. They're all stored away for us neatly as our makers intended. But accessing them is very, very difficult and sometimes impossible. And it makes us look like people that should be thrown on the scrap heap or put in an asylum where they won't hurt the rest of society.

B: EDUCATE is important because it means that a number of different people can come together once a month to meet, to compare notes, to seek advice if they need to, and get support from one another.

The impact that EDUCATE has

A: I think, when we went to the Town hall one, which was at Duckingfield, I think it was mainly financial people there so there weren't, they were the ones that handle the money basically. And we stood there, me and [name], it was me and [name], and we told our tales and I think people kind of, I think they realised how important things are for us to keep going as we do.

D: Uh, very worried, I was, before I came here. Um, having been diagnosed with early dementia, I'm very worried and um, the first, had to cry when I first came (to partner): Oh you weren't with me when that happened. And then I um, I kept coming to EDUCATE and it's the best thing that ever happened to me because I learn from everybody else that's here, they tell me oh what they've been through and everybody says what they've been through and um, it's a project where people go to all diff, all other...what do they call when they like um...(partner: "educate other people") yep, educate other people, different projects, got different people. They're, well they're not chosen, there's a leaflet with all the different venues on, and certain people go to them. Might be two, might be three or four. We went to the college to stand up and talk about, the students talk about uh, our, my experience of what I've had.

E: It's a tremendous project and everybody has a voice, everybody has an opinion and they have really valid opinions, they back each other up. And they're a really strong group, and they say "no we don't think we ought to be this", "no we don't think that's right" or "yes we think we should do that" and you know, that its, in their own homes, on their own they wouldn't be able to do that. Because each one of them has their own partner or spouse or family who actually tend to be restrictive because they're a bit worried about them, and they can really have the freedom to talk that I think maybe they don't always have in other parts of their lives. And that comes across really clearly.

F: I felt I've been thrown a lifeline, because between being diagnosed and being introduced to In Two Minds, I felt in limbo, I didn't know what to expect and what was going to, how I was going to deal with it. Consequently I became quite depressed. But once I saw all the other people, I think there was about six of us there, and many of them younger than me like [name], it was such an inspiration to me that I've never looked back. I just haven't. And if I'm feeling a bit down, sometimes I'll phone [name] just to hear the voice of another person who knows what I feel like.

G: I think EDUCATE is very good because there are a lot of people with hang ups, sufferers from the conditions that bring them to the group, and there are other people with hang ups who know nothing about the condition and have some very strange ideas such as, someone I heard of who said she said as she got into a taxi that she'd got Alzheimer's and the taxi driver was quite surprised to the extent that he said "you're not violent, are you?" Um, there is a lot of misunderstanding; there are lots of difficulties for people because they're not able to represent themselves well. And that doesn't just apply to people with dementia, who are not able to represent themselves well. And I think it's an important role for this group and in fact I think this group was set up for more or less therapeutic reasons. My interest is in policy development but only because I've done it my whole life or a large part. And whilst I can still function reasonably well, it's what I want to do.

A: Most people are really interested in it, and some people get quite upset with it. You do see people crying in the audience which is a bit of a shame because we don't cry. But I can understand that its, it's probably a powerful message that we're sending across. People don't understand what it's like unless you live with it, you know. That's all you can, really.

H: Um, it feels like a life saver, it is absolutely a life saver. Without it, I wouldn't be anywhere. And I mean, anywhere. It's actually a while since we'd been isn't it, and we missed it as well you know when we're not here.

F: The social aspect of it as well, yeah

H: As well, yeah. Of course, yeah. And it's just, seeing everybody and when everybody's here, you know when it's full like this, I know it's quite noisy some of the time, isn't it. But even so...

F: It's still relaxing, being in each other's company.

H: Yeah, absolutely.

I: And I think, it's having a role in actually making important changes. I mean perhaps just one example I can give is where I attended a meeting with two or three buddies who were speaking and there was a, a GP in the audience who had a particular role I think in GP training. And he was, well I would use the word very moved in fact, by what this educator was saying about getting a diagnosis. And he afterward asked if she would actually be willing at some point to come and speak to a larger group of GPs as part of their training because he recognised how much GPs themselves needed to be sort of educated around dementia and needed to understand people's perspective on diagnosis. And that's just one example, I'm sure I could give many more.

J: I'm here to support my husband. We have been married for some 50 years now, and we've been together. So, not one person has Alzheimer's or dementia. the family has Alzheimer's or dementia. and although I am, well I know sometimes I think I'm losing it as well, but my role is to make sure [name] can do the things that he wants to do. And we go to places together and we um, we fulfil the obligation that we take on when we say we'll go and talk to people.

H: It's always like a big fun fair I think because everybody's amazed you know, at the um, actually you know that somebody's actually got together and you know produced this sort of thing, to actually come and do it. And it works, you know, it does absolutely work, doesn't it.

F: It does, and usually most audiences are very appreciative of what we are able to tell them. Even though it's only a little bit of insight into the mind of a dementia sufferer. Everybody thinks it's all doom and gloom and I think they find it quite refreshing that we can laugh at ourselves and each other and nobody takes any offence. It gets you through the day laughing at it.

H: Absolutely. You know for me it's a job, and I'm not wasting, you know I'm not sat in a chair and all that. I'm out doing a job. That's how I feel about it.

F: It's a nice way to feel about it.

H: That's how I feel about it, it's my job.

F: I just find it very rewarding, to think that maybe, in fact I know, I do reach some people. Whether I have spoken to people who think they may be in the early stages of dementia and haven't had the courage to go and find out. And certainly listening to

other people has helped me so I'm quite happy doing what I'm doing now. yeah.

I: Well, the role of a buddy is to support the educators in their role. And that um one of the practical things can be about picking the educator up from their home and taking them to the venue where they're going to be talking. And just generally being there as a buddy and a support, making sure we got to the right room, showing them where the loo is or making sure they don't get lost on the way back, got a cup of coffee. You know, all those kind of things. And then perhaps if appropriate, when the educator is speaking to whatever the audience is, perhaps occasionally if they need it, um you know to put in an odd word or a bit of a prompt. But to be honest, that is actually really rare because the educators are just so good. And um, and, you know they can, well now I'm lost for words in the way that they're usually not when they're speaking.

B: So I've only been to a couple of meetings, the monthly meetings, and I've been a buddy once. And I must say, I'm just really impressed with what people do. And every time I'm stunned by what everybody comes out with and how they talk about themselves and the various problems. And when I was a buddy that gave me real a chance in the car, you know to meet up with the lady that I took to the meeting and she was telling me about herself. And she told me almost her life story which was actually what she then told to the group when we went. And the whole thing was just really, really, I...it was inspiring really because they, I begun to understand, I mean having been a social worker for many years and having done the job from that side that to come and sit sort of in the middle in a way, in a volunteering capacity was just very different. And um, and I think it's a tremendous project.

F: Yeah, it's just no such thing is there.

H: No, absolutely not. we can just carry on, um, I can't say normally but um you know I don't I think the way, when I first came to EDUCATE, I really didn't know what I was coming in to. But now, you know, I couldn't be without it. You know, and it, knowing that other people find you know when we went to the Town Hall the other week, um, people were asking us about Alzheimer's and you know, a guy came along and said you know my wife's got it, got some. You know I'm really worried about her and all. And we chatted, didn't we.

F: Yes

H: Chatted with him about it, and he went off quite happy didn't he.

F: Yes when he saw that on the surface it's not like a broken leg, it doesn't show. So nobody's going to patronise about it, most of the time. And when people see that you can carry on like that, it gives them a boost as well. Which I'm quite happy about because like I said, the lift it gave me was unbelievable to find that I was still able to do and cope with things myself and that was one of the things....

K: I think that's actually the best way to get the most appropriate management for dementia. Because what is important perhaps to a medical person may not be you know something that you know, isn't really causing me problems so what's all the fuss about?

The future of the group

B: Well I think it depends very much on the funding but hopefully it will continue coz I think people coming to EDUCATE need this to continue and I hope it does.

About a network

K: I think the potential that a small group of people might highjack the whole thing, I think it's unlikely. Um especially with reminders that I think that you could get a clique who think they know it all.

On leading a group

B: Perhaps I'd better rephrase that. If I were asked to do anything, I do it to the best of my ability. If I were told, guide you what to do, yes the answer might be yes. Yeah, so I change that and say yes I would, if I was giving guidance what to do, yeah.

Q: what do you think about this idea of networking people together?

K: I think it's excellent. I think that especially for relatively isolated areas I think it's very important that they know there are other people in the same boat. And I think there

should be more networking and intermingling so they can have a good laugh with a different group of people and realise yeah they're normal, for dementia anyway.

H: Well personally I think to myself, I need to go somewhere and get in a corner and try and unravel all the things, you know, to help me and to help other people but I can't. I just can't do it, you know, myself. But this is a way for me doing the job, um that you're doing for us. you know you're doing the talking for us and most of the thinking, probably more than most of the thinking as well. And we need people like you to help us and we can get to where we want to get to and help other people. I think that's what this is really about, to let everybody know that it's not the end of the world. You don't sit down in a chair and that's it you're finished, you're not. You know, there's much, much else to do, and else to, you know, to see.

F: I think the groups getting together, if nothing else, we could all learn a little bit from each other. And um, it's only by joining a group and then a group being interviewed by people like yourself that word does get around and carry on. And you can enjoy it, I can even laugh with [name], she laughs, everybody laughs.

A: I think it's probably interesting, I think I've not quite got to grips with it at the moment. Um but the more I hear about it, the more I probably, I never can do it quietly, read something quietly about it, I can take it in better. Big groups aren't good for me.

D: Yeah, I wouldn't like to be in charge because I'd be worrying about it before I went. I wouldn't like to be given a position to do. Like I'm in this role, when there this vice... is that what you mean? There was this vice...(to partner) what do you call it? (partner: vacancy for vice captain coming up) And I was asked to and I just can't do it because I wouldn't be able to cope with it because I've got this memory problem and I would worry all night the day before. So it wouldn't, doing what I'm doing now to help me with my dementia, I'd just go overboard because that would take over.

K: Getting the balance between people with dementia and the administration so that neither takes over completely. It needs to work synergistically.

B: What it was hoped that I would do, what was being aimed at and what my role was and how to approach that role.

Do you think that responsibility would worry you?

K: I think that's difficult, especially with, you know, if you do have dementia. Um, I have problems with numeracy for example so I have trouble working out, you know, what, really what the time is and certainly major problems with trying to deal with cash and that sort of thing. So you know there are things that need to be worked around.

G: I think however realistic it may be, I think it's really quite important to be aware that there are questions of stamina and understanding and confidence and memory all of which make it very difficult to be coherent, consistent, keep good records, perform at the right time, being at the right place at the right time and all of these things. They don't have to be denied, they have to be faced and adjusted to. But they're not very suitable to development of a consistent organisation. Nevertheless, this organisation has, as you can tell, four people with these particular difficulties. And what is the best way of keeping faith is to take a serious notice of the, a sympathetic notice of the context in which people with these conditions make proposals and have ideas.

J: It's remarkable that we found a role that people who can go out and talk have actually made themselves feel much better because they have a role perhaps of something to do with the professional life that they've led before. Perhaps that they can get great satisfaction from that, but you couldn't expect people to organise themselves and to work out how to get from A to B necessarily or what needs to be done. That's the role for professional people, that's the role of the paid people in any kind of society.

G: The thing is that you have to have ideals, big ideals, in order to aspire so if I turned it round the other way if I've done a lot of social research. If you find people who have what they think is a good idea, then you give them the credit for having that good idea but it does need knocking into shape really. It doesn't mean giving up what you aspire to, those aspirations are very important. But you give the people who had the good idea credit and you try to understand them in the same way as you'd like them to try to understand you, and your limitations.

C: There's always something to be learned from other groups of people but I believe that because of the nature of the life and experiences I've had. And all the benefits I've received throughout my life, I've always tried to give something back. And to find myself in my advanced years, and it's only what 3 or 5 years ago, maybe 5 and I'm nearly 80 now, that I was eventually diagnosed as having Alzheimer's and many other people suffer this forty year earlier than I have. And they may well look round at one another but that is true. And that's what doctors have to come to terms with to. It's going to be, and should be now, a regular part of their surgeries and they should know what to do, when to do it and to be ensured that there are facilities there to get it done. Even if it's only prescribing a medication which is appropriate to the particular need. I've got that and I would like everyone else to have that. And early diagnosis is the most important of all.

A: Thoroughly enjoy it. We meet people that we see, people that we know, like you. And we do meet other people that we've seen before you know and it's nice to be all, to be together. Like... and what have you, she's got great..., ain't she. I couldn't have that..., I just haven't got the ability to talk like that. But that's life, isn't it. We all have different things that we can do.

6.2 Transcript of DEEP focus Group with Scottish Dementia Working Group (SDWG)

Eight members of the SDWG participated plus the researcher from the Mental Health Foundation.

How did you find out about the group?

CPN.

And they suggested that it might be something that you would be interested in?

It was Alzheimer Scotland,...they brought me here to my first meeting.

It was [name], when I was first diagnosed.

What were your thoughts about it?

We were in a muddle. It was called the Candlelight group. We just went along, me,... and a few others. It was something different from sitting in the house, put it that way. Then we got really involved. It's like everything else, it's something new, you don't know what you're going into and you just think, "I'll just go along to keep everybody happy" and you go along and it's good.

[Name] was one of the original people who went along with [name].

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

You mean you understand it?? 'Cos I haven't got a clue!!

Alzheimer Scotland has come a long way. Ours was a fun group. Ours wasn't as serious as this group. Although it was serious, there was parts of it that weren't. We never went into the nitty gritty of things. Later on we did, when it was taken seriously.

I think, almost from what I gather, the group came together and then the Scottish Dementia Working Group evolved out of what people wanted and they wanted to campaign. They wanted to have that because you can get a lot of self-help groups but campaigning groups were a no-no and they wanted to make a difference and make a change and [name] who then chaired it, it was his integrity and his keeping the people and being strong on that. We are independent, it is our voice. That came across very, very strong and it was his integrity to say that we can all have a point of view but when we go out to speak as part of the group, we speak on behalf of the group, so when you're doing something you feel yourself kind of putting a hat on and saying, I'm speaking on behalf of the Scottish Dementia Working Group and, in my view, that changes how you're seen and you're going to come in now and tell what you've seen

happening, you're seeing [name] and [name] put that Scottish Dementia Working Group hat on and [name] talking in Hamilton.

My experience is very different. The dementia bit with me took so long for me to find out what was going on. Obviously I was ill and at the time I had problems and my wife couldn't handle that situation. I wasn't a good boy either, I was all over the place, I didn't know what was happening, how it happened and then I would have a nurse who came to visit me in the house and helped me slightly. And then other people came and said, we'd like you to come down to this meeting where I met this lady. Remember we did these drawings way back in the days? And meeting similar people to me. They were all different, there were Castlemilk people, all sorts of people, we did everything and said we would meet again next week. I went through all that and then I came into this era and the first time I came here, I said, 'I won't be back'. Truthfully, I just couldn't handle it. They were talking above my head and I've said this a few times but the good thing is, I spoke to [name] this morning, my son has come back from Australia and walked in on me and we were sitting chatting and I was making the tea and I was feeling really good, not only with him and he said, 'I'm not too sure if I'm talking to my right dad here', I said, 'what do you mean?' He said, 'that's not the dad when I went away, you were causing all sorts of havoc. 'Now I've walked in here and you're rabbiting away, speaking to me like it should be. Back then, at that time I was taking it out on people, you don't know by the way, you really don't know. There's an Australian thing called walkabout, if you go with all your pals, and I don't drink, I don't smoke or anything. There's only so much you can take. What [name] is saying, is it's better than medicine when you come in here. We come in here, we're not really sure of our emotions or what we're saying or doing or understanding and I always say, the Scottish Dementia Working Group loved me better. The people actually accepted us for who we were. They didn't try to change us, they didn't try to make us get better quicker, they allowed us to get comfortable in our own time and then once you got your voice you were encouraged to go out there and say it when you were comfortable with it. That's not a method, that's not a methodology, that's not written down, it's not something that we do, and it's something that's instinctively known by the people who have got the diagnosis. It becomes second nature. And I think because we accept each other, we learn to accept ourselves. The therapeutic effect is unbelievable because my 'party piece' is speaking about immediate post-diagnosis and I don't know if you remember, there used to be a song in the last ten years called 'Last Night a DJ saved my life'. Well that happened to me with a CPN, or a team of CPNs and it was just like night and day, and then, of course, I get 'kidnapped' by my friend here, hog-tied and brought along here and never looked back.

So what would you say that collectively you want to achieve?

We want recognition for people with dementia and for doctors to understand. Nobody can understand the illness unless they've got it. For doctors to listen to us and not talk over us and talk to someone who's with you. Talk to us and try and understand, this is an illness that centres in the mind.

Try putting doctors and understanding in the same sentence there!

It doesn't happen. As soon as you get to hospital they just talk over you.

So, they just see the dementia?

They don't see the person, they just see the word.

And they make a whole load of assumptions.

A lot of it is based on arrogance, they treat you as a number, they don't treat you right. There's no individuality.

That's why Henry Simmonds talks about personalisation. Henry Simmonds is the Chief Executive of Alzheimer Scotland and he talked about personalisation and various things like that. We're all different. We can all have even the one same type of dementia but we're all different, different personalities and we're all at different stages. With the campaigning I want people to see, when they hear the word dementia, you say what type, so that you're aware that there's different types. When you hear the word dementia, I don't want them to visualise a picture of the wanderer with their jammy's on that doesn't know their name. It's more than memory. It affects our senses, it has physical symptoms that can appear or not appear, depending on where in the brain you're being affected. And that is being lost. It's so vital. It just blows my brain away that they haven't caught on. The number of people who will say to you, 'well everybody does that'. The fridge door syndrome, standing looking in the fridge,

wondering what you had gone into the fridge for. Or why did I go up the stairs? Yes, people do that but it's more than that. When other people say that to me, it's a cliché, saying 'I do that.' That's normality, people do that but it's different, it changes our brain and attitude and all that. So when the Scottish Dementia Working Group, and what I would like to be made known, is that it's going to be 10 years old next year and we're having all these various functions, but there's many people in nursing homes, many people that for the past ten years, brought us to where we are. You're only seeing us, [name], you were one of the ones who was there at the beginning, you know all the faces that are not here. So what's important to put down is that 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. So when we talk about early diagnosis it's not my early diagnosis, I've been diagnosed five years. I can't remember what it was like when I was diagnosed. It's [name] and [name] and the new ones who come, it's all the new blood. What I feel we talk about is when it comes to the next stage, it will be our voice because that's what we will be living and feeling and breathing at that time. And I think that's where it makes it vibrant and very, very good. And I don't know any other group that does that.

Is there an ideal number of people that you need to keep it going?

The bigger the better. How many members do we have?

Over 115 over Scotland. And it changes because if you think about it, people go into nursing homes, they get too sick, they can't come to the meetings and then you get your new ones in so there seems to be a mass of to-ing and fro-ing, it's never the same ones.

We went through to Edinburgh a couple of weeks ago to speak to Nicola Sturgeon [Scottish Deputy First Minister and Cabinet Secretary of Health and Wellbeing] and she is committed, so much so that she's setting up quarterly meetings with the group which I think is an incredible investment. Because you don't get Ministerial time handed to you like that unless somebody is really driving it. And it's Nicola Sturgeon and her staff who, I can't say enough.

I think too, Nicola Sturgeon did say that she had great respect for the Scottish Dementia Working Group because of their work ethics and that when we meet her, we being the Scottish Dementia Working Group, we let her know beforehand what we're going to do so that she can answer our questions. There's mutual respect and support and she knows that we're not there to tell her stories or waste her time so that is why again the Working Group has got that respect and if she has got ten meetings and she's running behind, one of the meetings she won't cancel is the Working Group one because what [name] has made plain to her is if the Minister is working behind, he's taught us to say we recognise that you're running behind, we'll cut our questions down and we'll be respectful of whatever else you're doing. That's how the Working Group has gained that type of respect and [name] and [name], 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. If you're writing up your research, there are many groups. My daughter works for the NHS. She came along to one of these meetings to see what went on. She's a District Nurse, she sits in on loads of meetings. She was blown away with the agenda, with the way we keep to the protocol. She said, 'Mum, the Working Group, I was looking round the table, I didn't know who had dementia because you were all playing your part, you knew what you were doing and all the rest of it. And she thought, this is not dementia that I nurse and she learnt another side of dementia and she learnt that we were focused, we were well prepared, which is why we've got co-ordinators, we prepare, if you put preparation in and help people with a diagnosis of dementia, we can function but we need time to respond and prepare and that's why it works. An understanding of it. We also, at the end of every Committee and Group meeting, the Chair and the Vice Chair debrief with the Co-ordinators and the person who scribes and we sit and we say, did that go well. For instance, maybe [name] hearing aids, what can we do to help the people who are sensory impaired? We'll get the hearing people out, the loop system. We look after ourselves and enable ourselves to function at this high level. That's what we do, we're respectful. If someone says, I don't feel like I'm getting my say, we'll look and we'll say, what can we do, why was that? I even brought these with us (holds up card with 'I want to speak' on it) so that we can do 'I want to speak'.

They're really useful things to have, if you need them they're there.

Maybe you can give me an example of one of the things that you're working on

just now, one of the issues that you're trying to grapple with.

Will we say GPs? That's an ongoing one. Its déjà vue some of it... When I say we I mean the old-timers. You seem to be five or six steps ahead. We were polite and suggested things but we kind of stood back. This group in this day and age are just jumping straight in, no nonsense. I think it's the radical wing of dementia!

What I'm saying is, we're only standing on your shoulders, you know.

Yes, but it's like, did they say that. If the wean (child) said that they would get a slap for being cheeky. Don't get me wrong its great and I'll be the echo in the corner, yes that's right because we didn't do any of that then, to an extent.

But you were a smaller group. You started out and there were only about five or six of you. We're talking about 115. There's a lot of people going out there.

Yes, we had lots of meetings in Edinburgh and we went abroad just the same but you seem to have a better voice.

But you started that, you set the foundations, you got people starting to listen. Like on the shoulders of giants.

I just see a big, big difference how great you have come on now. But it's because of all that early work. You've started to get people to listen and now they really want to listen. But you've helped shape that change.

But what we did last year, we being the Scottish Dementia Working Group, 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. So that's what we're doing, its early diagnosis, post-diagnostic support and training.

Training for who?

Professionals – CPNs, medical world, care inspectorates, consultants.

It's puzzling me, when we first came into the building, who's idea was first to come into the building in the first place?

I think it was [name]. [name] who came around with [name]. Sorry, no [name]. Somebody brought us in and then we developed. They've written the story up and we're going to tell it. Because the Group is 10 years old it was suggested that we try to do the history of it so Heather Wilkinson was some researcher like yourself. She does work for the Joseph Rowntree Trust as well. And then [name] was the first paid co-ordinator and [name] was there for quite a number of years.

Was there not somebody before [name]?

No, maybe not a paid co-ordinator.

There was, I'm sure.

There was someone before [name] but she wasn't a paid co-ordinator.

There were other people involved, including [name].

We were upstairs and there was a big dome, it was all glass.

That's right, upstairs. Like a garden. Who was in there?

You would need to ask [name], because [name] is the only one who was about then. But it's all written down because we need it written down. But what makes the group as well is that it's quite expensive. I never thought of money or funding or anything but Alzheimer Scotland, and this is where the difference would be, Alzheimer Scotland supported us financially along with the Big Lottery and grants from various places, like Comic Relief. But Alzheimer Scotland, they actually took a back-seat, they never really interfered in anything. Jim Jackson came once a year to meet us but it tended to be the group. You never really got to know them at all. Recently, since Henry Simmonds came on board, it's been slightly different. He's got a different priority as well and he wants us more involved. He meets us normally three times a year. He doesn't tell us

what to say or do but he meets us three times a year, he lets us know what Alzheimer Scotland is working on and asks what we're working on as well. So although we're independent we are a partnership and what we're finding is that this year is the first time Alzheimer Scotland is fully funding us, although the Government gives us £12,000. As [name] says, in England Alzheimer's Society, the people who have got all of the various groups, they're frustrated because they haven't got the same. It's almost like kids. Our 'parents', if you like, are funding us but they're leaving us alone to be independent...

Has there ever been thought of floating off and becoming an independent?

No. For us it's a marriage made in heaven. I think that's what [name] calls it. Yes, we disagree and have thoughts but that's a healthy, good quality relationship. There's Alzheimer Scotland and then there's the militant branch! And I think they almost know that there's no way they can control us. So they're better humouring us! See the next time my family say I'm a rebel without a cause you'll say, aye, I've got a cause!

Could you tell me about one of the things you're really proud of, one of your successes? Something you've thought, 'yes, we've managed to achieve that'.

DVDs. There's a lot of very good DVDs out which are used as training aids. They've also been used for people who have a diagnosis to show to them it's not the end of the road, there is a new path you can actually follow.

I'm very proud of the fact that I still live on my own and all my bills are paid. Things like that. It inspires me.

For a lot of people, it's giving them back their life, the quality of their life.

Yes, and I think what I'm proud of as well is the respect that the Scottish Dementia Working Group have internationally as well as nationally and it was earned and it is the Scottish Dementia Working Group that have earned that and what happens is if people are talking and they're talking about dementia it would be very rare if the Scottish Dementia Working Group's name is not brought up at a point in time and that's internationally and nationally and that's something I think that we should hold our head up for and be very very proud of because it's been a lot of members and a lot of work and you don't get that respect, you earn that respect. [Name] was in Warsaw and you know for a fact that you heard and felt that respect. Almost when you hear it, you remember the Scottish Dementia Working Group that they almost think 'wow, you're so fortunate', and it makes you feel very, very special. Even at the Liverpool conference, the most recent one, people were stepping back, impressed...

Is it a cultural thing here, because we're a small nation, that makes it easier or do you think it could be replicated in other places?

There is an attitude, a Scots thing, I've had a number of people say to me, how do you manage it, being such a small country and such a small organisation, and move so far forward. There is an element somewhere in the Scottish psyche, partly national pride, and also, they're quite happy to turn around and 'bite your bum'. They'll take so much and then say, no it's not moving forward. We want to make a difference. And the Scottish Dementia Working Group is used as a floor plan for outputs in other countries, as a road to travel to get it done. Then they all make it different for their country. They use the basis and then change it to make it German or whatever. You empower people, you give them respect and power.

I think what happens as well, years ago, say likes of us, they wouldn't hear that, you were put in either a home or your family looked after you. There's nothing like this and when this came on the scene all my friends are saying, 'you're going where?', is it a home?' No, it's just a big building where we go and talk. And who are these people because they're the type that their mothers, they all gathered round as a big family, whereas nowadays there's not really a lot of big families. No, I go on a Saturday and I pick up my mother and Jean goes on a Thursday and there's always somebody there, outwith medical help type of thing, they didn't have that and they were all working. That was the same with my Dad. I took this and was still looking after my Dad. I came here as well. I was really lucky, but my generation and above that, my mother and my father's generation, if they got dementia they were stuck in a home or else the family had to look after them and it's really a big thing on the family. A lot of people don't think that. If you said to anybody here, who came with a carer? Nobody. So that's a big leap forward, that we can actually manage to cope ourselves. I think once people start to tell you, you've got this condition, you should be doing this and doing that you get a mindset and you become a mental or emotional cripple and you need all

the support to keep you going. Now it's different. Years ago you could do that, these places had never been heard of and I think it's a great leap for us all. And I think to meet others who have got the same condition, when you hear by osmosis. It's not that they tell you, it's almost by osmosis and you think, well if [name] can learn to paint, or do photography, because they tell you that you can't learn anything new when you get a diagnosis, you come to the group and you hear them say, I've just learnt this and I've just done that. The fact that you might need to learn it five times over. I started painting again, I wasn't well, I was in hospital and I knew I was getting better when I could paint again. So it's empowering people.

We come in here and we build, not the same life, a different life with dementia. One of the strange things now is that you've got to remind people that you meet that you have a diagnosis because they think that you're totally normal.

Like me, the diagnosis goes out of the window. They say, 'you've not got Alzheimer's'. It was you that said I had it. I say that I have a dementia problem. But they were putting it down to 'oh, she's having a nervous breakdown because of my father'.

They take the fear out of it. You look around you, what the hell is it, it's scary.

And if you forget something, nobody is going to shout at you.

So that message gets out beyond this group so that everybody knows.

They make you feel childish again, you feel that you're going into yourself at times. I've been noticing that of late. Life has always had problems. I don't think I ever grew up emotionally, that's why I couldn't deal with life. I was an alcoholic for twenty years. Alcohol was a solution for me, it gave me courage and confidence. Take that away and you're left with a frightened wee boy and that's what I've now got to deal with and I believe that this group has helped me to deal with that. I can stand up for myself and be counted. I could never ever do that before.

Like you, we talked about standing on the shoulders of giants, like [name] we have given two people with Korsakoff's the ability to stand up.

One time this year we were at Glasgow University, they'd invited us along to speak, it was to nurses. It would have blown you away because these nurses couldn't believe it because it made the books alive because most people think Korsakoff's - they end up in a home immediately, and we had someone on that stage with Korsakoff's, Alzheimer's, Vascular Dementia, Lewy Body, nearly every type of dementia and these nurses could ask, what does it feel like, we know this, I thought your short term memory was that bad that you weren't able to do things, and they heard them say, I'm living alone, I'm able to do that. They couldn't believe it and it put a different ethos right from the beginning of their training, right through. And that's what the working group does.

Do you feel that you are role models then?

I think we are ambassadors.

And what we do is we empower one another. We're not always upbeat. When you come in you might be hitting a low point, it might have been when you have been flooded, or whatever, and then you'll have [name] turn round and say, that's alright, I set the kitchen on fire twice, and this is what I did. And you think, well then, I can do this.

So called normal people can do exactly the same thing, set a kitchen on fire, have a flood, or whatever. If they can cope, we can cope.

We went to St Andrews, we had a power cut, I'm in the house by myself, it was dark, don't panic, I thought to myself. My husband was out buying fish and chips. So I'm by myself in the dark so I thought, I'll open these blinds and then I get the light from the street so I could see a wee bit.

It's part of human nature. If you didn't open the blinds and the room goes dark, it's exactly the same room as with the lights on but suddenly it's got beasties and people crawling all over the place!

Yes, I was terrified!

That's what happens when you first get a diagnosis of dementia. You get this unknown thing and you start to become fearful because there's no logic to it. You do

things and you think, why did I do that? It's not until you can actually step back from this precipice because you're going to throw yourself away and say, what am I doing this for. You've really got to empower yourself and if you're not surrounded by the right people, god help you. I can think of a number of people in this room who had the wrong people round them and it gave them for a long time, misery and lack of security.

And then [name] said a great thing to me one time, she had a great gardener in the Black Isle. She said, on that same vein, [name], see when you're weeding your garden, sometimes you have to weed certain people out of your life because they're choking you and you can't grow because they're trying to enforce you to be the person you were before your diagnosis and that's not going to be possible so you have to grow into who you are and you just have to love these people and let them get on with your life. Weed them out.

That's really good, because I'm sitting here thinking my friends will say, [name] you can do this, you can go round the doors as part of the housing committee, and I'm thinking, no, I can't do that and they look at me as if I've got two heads because I totally forget. Before I was always the first one with my hand up, I was in there, I was campaigning, I was away doing this and that and then all of a sudden I couldn't do it and I was saying, what are you talking about, I never did that. I would just sit there and shake my head. I just can't believe half the things I have done. I just totally forget.

I think the big problem for a lot of people is fear itself. Rather than trying to solve it. If you try and solve it, you solve all sorts of things along the road.

Or accept it. Accept where you are.

You're not going to get rid of dementia. You're not going to get rid of your diagnosis so you learn to adapt and go along new paths. That's it.

You cope with it. Put up with the medication.

We keep bringing in dementia. People say to me, you've got dementia. I say, that's correct. But you're going to the Fives (football). I say, that's correct. I'm going to do this and I'm going to do the next thing and I'll keep doing things until somebody says something to me. But I went over it and somebody said, [name] out driving his car, who says you can't drive your car. Two doctors said, you've got dementia, you've got an illness and you shouldn't be driving. I said, I've been driving since I was fifteen, all my life I've never been booked, I've never been done for anything, I now don't have a car, I've had to get it taken away. I'm fighting that bit.

I've got a friend who's blind who's more sympathetic towards me with dementia than I am towards him in blindness. He says I'm only blind, you don't even know the world that I see, it's a great place! He meets lovely people all the time. You don't know what you're missing! I'd rather be blind. If someone said, I'm going to give you your eyesight back, he'd be brokenhearted.

That strikes a chord because to an extent, I've got this theory, we don't ever talk about people who talk about dementia. I'm talking about partners and carers, they're the sufferers. Those are the people who suffer.

My father, aged 94 when he died, he was still telling me what to do, he said, remember [name], you've got to come down here. Ninety-odds and he's telling me, now don't forget. He'll phone me up and say remember to bring me down such and such. And I say, right Dad, I can remember that, then I think no I won't remember that, I'm kidding him on, on the phone and that's one thing I've learnt. Never lie. It's no good lying because people catch you out.

We were in a shop and there was this guy sitting in a wheelchair with his wife (not in the same wheelchair!). He said, you know this dementia, is the best disease I've ever had. I said, I bet your wife doesn't say that. No, she takes the brunt of it. I just have a ball. And that's the way my life is going.

That applies to every illness, if you've got a really bad illness, it's always the person looking after you. I was in hospital and I think it was my family who suffered more. Never mind the dementia, running back and forward, not being able to bend down, I still can't to an extent. They have to do everything for me.

But if you listen to [name], who's not here today sadly, [name] said at the beginning of the group (he was the first Chair), he said that carers have their group and carers were being listened to but the people with dementia didn't have anywhere to go and they

didn't have people to listen to. At the beginning when this group started, and I think it still happens now and again, the doctor will say, 'and how is she?' and talk to the carer and they'll say, 'how's things going?'. That's what the group started to campaign against because it's like anything else, you will see the eyes of dementia through the carers eyes and it's totally different going through the eyes of the person with the diagnosis and that's why at the Scottish Dementia Working Group we recognise our carers, we accept that they're wonderful but they have their own campaigning group and their own rights. We campaign for our rights which is the rights of people with dementia.

See my notes here, everything I get when I come here, I've not done it this time but before when I went to the doctors, I would say, [name], give these minutes to the doctor. I was nothing like pamphlets or anything like that. It was what I actually said, that went to my doctor because he would say, 'what do you think is the matter with you [name]? Is everything just getting on top of you?' And I'm looking and saying, I really don't know. He had me convinced that I was depressed and I was acting as if I was depressed. I would say, 'doctor, I'm not feeling very good today', because it was that type of doctor that you could go in and talk to but this wasn't getting through to him, that I was forgetting. I mean, a 90 year old telling you what to do. They can remember and you can't.

I think that's why the group does early diagnosis as a priority because that's what we hear all the time. People are taking years to get diagnosed, maybe getting conned into the fact and made to believe that you are depressed or you've got all of these other things wrong with you before they actually come and it's almost a relief we hear in the group to know what's wrong and then we can get on with the rest of our lives.

He thought I was depressed because of my parents and that was it but when started coming here, what you've got written down, the minutes of the meeting, I would give it to the doctor. The receptionist would ask, [name] have you got the minutes'. 'Yes, I've not forgotten them'. And I would give them to the doctor. But it has taken him all that time to realise what was the matter with me.

And then when we were talking about early diagnosis if everybody who has the beginnings of dementia was diagnosed the NHS would collapse. They don't have the facilities. They're almost saying, we can only cope with so many a year so we need to watch what we're doing here. But the early diagnosis, and it's been proven with the group work and Stirling University, if you diagnose someone early enough it will save the government money in the long run because you can get the appropriate medication, you can get, like [name] is saying, learning to live on your own, you're not bringing carers in until it is necessary and when you do bring your carers in, you can let them know beforehand so all of that saves money. And that's why campaigning, because people will say, 'you'll not get much campaigning done, there's not much money there', but we say, if you look at our priorities you'll actually save money. Not to do it is going to cost you more so if you listen to what we're saying it will save money because [name], again another campaigning thing was on anaesthesia, he had spoken about it a lot of times, then unfortunately had to get an anaesthetic and had had not the best of results, but the outcome we have found is that my husband had to get an anaesthetic and he was getting refused it because of his dementia but cutting a long story short he was operated on at the Jubilee Hospital, out quicker than anybody else, off all medication, is able to walk and he's actually saved the government a fortune and it's stopped carers who were going to get put in, so if they had cost-effected it out, if they hadn't given him the operation, how much would it have cost the government and that's what the Working Group do. They'll look at a scenario that wasn't good and we tell the story and then we tell the story of the good news and how it would save you money. Back it up.

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. It's a good matrix to base our organisation on. And then the other thing that we got changed was that they were putting an advert on the television about a man with his pyjamas on at a certain stage in dementia and the group changed it. And that's what it is, the power, the collective voice, people sitting down and talking. But they put their hand up and said, right ok, we made a mistake, sorry.

There was a clinic years ago that you went to and they gave you placebos and also the proper tablet, it was a trial. It was the Memory Clinic. They were actually taking people off medication and giving them placebos. That person being taken off medication didn't know he was being taken off medication, that's doing nobody any good. You

were told that it might be blanks or it might be tablets. But it wasn't for the benefit of the people, it was for the benefit of the drugs companies.

I almost got involved with them, I went for two consultations.

My doctor suggested I go, but I'm happy with what I've got.

Is there anything else that you want to tell me about before we finish up?

What is the outcome the Joseph Rowntree Trust is looking for?

We are going to write a report and make a series of recommendations based on what people have told us. One of the questions we have been asking in the survey is, is there a need for some kind of UK-wide network to pull people together?

It wouldn't work. Part of the problem is the population of England and the population of Scotland, going by mathematics they are nowhere similar. Also attitude, people in London think that people in Newcastle are strange, to put it mildly!

I think there is, in a way, a need for a collective, united voice of dementia.

It would dilute the Scottish issues.

I don't mean the Scottish issue, I think a united voice so that you could have a data like, say we were coming across something, we were going to Liverpool, or there was something going on, rather than just wee pockets of people crying out in the wilderness, that you could almost say that you were going there. It's to know who's out there. Should the Scottish Dementia Working Group ignore the people across the borders?

It's not ignoring them. Do you believe the organisations in London would be quite happy to share their finances with organisations north of the border.

No, we're not talking about that, we're talking about sharing information.

The people in South Yorkshire can get no information from London and London doesn't even recognise them, and they're part of the same group. If you make it one big thing you're not going to get the information.

You're missing the point, it's not one big Scottish Dementia Working Group, it's a network, where if I was going to London I could get in touch with this network and say, I'm going to go for three months to Liverpool, can you connect me up with people with a diagnosis. It's a network, it's not a taking over of your finances, it's not a taking over of what your priorities are, you're not going to stop people like [name] from being there.

[Name] became active after he went to the Lake District because up until that point nobody had bothered with him and he wasn't empowered at all. He went to the Lake District and he was set on fire. At the beginning of the year Larry was dying on his feet.

[Name] is helping as an individual to help these people. They 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.

6.3 Transcript of DEEP group interview focus with Torbay Dementia Leadership Group

Six people from the Torbay Dementia Leadership Group took part plus the interviewer from Innovations in Dementia.

About the group

A: What we do within the TLG [Torbay Dementia Leadership Group] is we take on certain pieces of work, certain pieces of information and we try to make them dementia friendly. Unfortunately these days, people are snowed under with hundreds

and hundreds of pages of documents, where we insist on we only deal with bullet points. And if someone sends us a document that is 20, 30 pages long then we will send it back and say send it again as in bullet points then we will make the references and make the opinions what we've got about the points. And then send it back. We've done this for the NHS, we done this for the Alzheimer's Society and um, other people as well. So it's just to make this more useful and more friendly for people with dementia.

B: Yep, that's what it's going to have to be like you know. Maybe with your help (to A) because you know how to do these sort of things.

Could you describe something you're proud of, that you've achieved as a group?

B: We are a group as a whole, we are. Everybody is in here is, are friends, and if anyone comes in sometimes one or two people might come. We might say yes can I help, oh but I didn't know that but my friend she's got...she's not very happy about this...and we don't know what to do... if you, I mean, if you know what I mean.

C: I would agree that the dementia group has been very, very helpful to me, um I enjoy the company of all of us that are present. We discuss matters that do affect our lives and we hope, living with hope that in the future we will have some greater help perhaps through medicine.

B: Oh yep, because at the moment, every one of us in on tablets.

C: Yep, yep.

B: And that's like you me and me, it's the first thing for us. You know, so that's, if anything goes wrong, it goes into that side of it. And if its oh a-ok, it goes to the other side, and we can see what's happening.

D: Yeah, we can learn from each other.

B: Mm, you're better at saying things like that than I am.

D: And helping each other if uh, you know if we had an experience similar to what they're suffering. So it's all helpful.

What difference do you think you're making of being part of this group?

D: Well it's someone to talk to about the disease we've all got and you know, it's helpful just to do that.

[general agreement]

C: it's useful, we talk to people in our life about it and they accept the um, the answer that you give them. you know, what is Alzheimer's. It's hard to describe but we do our best to do that.

So you're raising awareness?

[General agreement]

A: I think if anybody asked us what was the greatest piece of work we've ever done, it's actually being established. It's actually being a group, and staying as a group for so long. [general agreement] Because we're telling people out there that even though we've got dementia, we're still a working group. We still all volunteer, we've still got a working group, we've still got a life and we can still do what we do and I think we do it very well. And I think also one of the greatest things we've ever done is to give other people hope in that direction, to know that once you've got a diagnosis, it's not the end. Because there are people like us about and they can not only come and talk to us but they can say well we can do it. And I'm sure other people in the country want to do something similar to this.

D: And remember there are a lot of people with this disease that are sat on the couch at home, lonely.

B: But no one is like saying, yes can I help you, oh what's that for, what's that for. Oh I didn't know that was there, can you help me please. You know what I mean, I'm not very good at saying it but.

What do you each get from being involved in the group?

E: I just started and I think it's very good, it makes it different.

A: I think it gives people ownership and responsibilities. I think because when they come to group they take ownership of what they're doing and they're responsible because of the work that they're doing. And they're very proud of what we do, aren't we? [general agreement] We're very, very proud of what we do. And we're also unique in the country because I think I'm right in saying that we're the only group in the country whereas each and every one of us has a diagnosis. Whereas other groups are mixed with people who have dementia and carers, other leaderships groups is not purely for people with a diagnosis. And it works.

What do you both get from being involved in this group?

D: Well as I've said, it's the company of people with the disease and the friendship and we learn from their experiences.

B: If people come in and we look at them, can we help you. And it's oh I didn't know that was that, can you tell me how to do this please. You know and having to say oh this is it, would you like some help?

A: That's right, people watching this video will probably think, which we've all come across, oh they don't look like they've got dementia. um I've yet to see anybody who... what does anybody look like who's got dementia? you know? What we're doing is showing people that even though we've got a diagnosis we can still do it, you know.

D: We also meet the wives and friends and helpers you know so we're meeting people where if we weren't in this group we could be sat at home watching television all the time.

[general agreement]

A: Yeah, death by day time TV.

And this idea of forming some kind of network, we don't know what it would look like, with other groups around the country, how would that make you feel?

A: I feel it would benefit once the contacts are made and once we start getting emails from each other all over the country and swapping ideas, that will make a huge difference and that's what I would like to see sooner rather than later.

D: Yes because there might be very good ideas around the country that we have never heard of.

B: Exactly!

D: You know we could take them.

Do you have any idea of how this network might work? You mentioned kind of being in touch via the internet?

A: Yeah, I mean there's a lot of ways you could do it. You could do it by internet, you could do it by Skype if you're very clever. Or you could even do, I believe you can even four or five people on at the same time. I have absolutely no idea how to do it myself but there are out, there's loads of different avenues what you could go down. Maybe even just having simple emails which we can share amongst the group and we can discuss what they're discussing and give feedback between each other and then take it on to a level maybe later on. But small steps at first. But you know the first thing, the most important thing is making contact with other people first. Because as D says, they might have a lot more ideas than we've had and then we could pass these ideas on to the people of Torbay, which would benefit them in turn.

F: I think it's an ideal way to learn to understand what you haven't got a clue over coz I still don't understand a lot of it. And it hasn't been that long has it, not really. But I find that when I do come here, it's very rare that I go home not feeling better than when I came out.

B: Exactly!

F: You know, it does pick you up and you can find how other people deal with this

which you're so used to doing things in a certain way.

B: It's like you go into the chemist, have you got so and so. Oh I didn't know that was that, I thought it was something different. And they put it to one side, they don't know what they're looking at.

C: Uh, I'm very thankful for the fact that I've got in the locality seven grandchildren which treat grandpa just as any other grandpa would be. And I find that really super, you know, if there's something to show me, something to listen to, then they do it. Because two of them are very involved in music and you know I find it so rewarding and hopefully that there will be a cure found before they're of age to encounter it [Alzheimer's].

Mental Health Foundation

**Colechurch House
1 London Bridge Walk
London SE1 2SX
United Kingdom**

**Telephone
020 7803 1121**

**Email
info@mentalhealth.org.uk
Website
www.mentalhealth.org.uk**

**Registered Charity No.
England 801130
Scotland SC039714
Company Registration No. 2350846**

© Mental Health Foundation 2012

**changing
minds**