

Involving People with Dementia Project: Exploring How to Best Involve People with Dementia in Service Feedback, Evaluation and Planning

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Executive Summary

Introduction

People with dementia are largely absent from much of the development taking place in relation to service user involvement. This project explores current involvement practices with people who have dementia receiving services within Sheffield Health and Social Care NHS FT (SHSC).

The project was led by SHSC Senior Nurse Jane McKeown and supported by Sheffield Alzheimer's Society Dementia Advisor Ros Witherspoon and SHSC Involvement Worker Faye Mellors. The project was hosted by the Translating Knowledge into Action Theme of NIHR CLAHRC – SY.

Aim

To explore and enhance the processes and range of methods by which people with dementia may be involved with service improvement and planning within SHSC.

Methods

1. A non-systematic review of the literature around involvement and people with dementia in service feedback, evaluation and planning
2. Informal semi structured interviews with staff from services for people with dementia in SHSC.
3. Conversations with people with dementia (and family carers in separate forums / groups) to seek their views on how they can be best involved

Findings

There is a lack of clarity on in what involvement means. People with dementia appeared to understand involvement as:

- Being included and doing something worthwhile; making a contribution, and feeling understood.
- Involvement meant coming together as a group of people with dementia, and this was in fact a priority for them in itself; their concern for each other and for the group often took priority over what activity the group had met for.

People with dementia lack opportunities to get involved and there are barriers to involvement which include: attitudes towards the abilities of people with dementia; a reliance on carer involvement; perceived lack of time; organisational constraints; lack of confidence; the methods used to seek feedback and the environment.

People with dementia offered suggestions on what might enable them to have their voice heard and these include: having access to information about events; transport; methods that take into account the disabilities that dementia brings; and the creation of supportive environments.

People with dementia (and family carers) want to be involved and this can have benefits in terms of self-esteem, confidence, well-being, feeling valued, feeling supported, feeling a part of something bigger.

Additional challenges exist in involving people with more advanced dementia and people from black and minority ethnic (BME) communities.

Staff and managers can lack the understanding and knowledge of the importance and the benefits of involving people with dementia. Additionally staff can lack confidence in involving people with dementia.

Recommendations

The term "Involvement" of people with dementia should be defined from the perspective of people with dementia and articulated to health and social care staff, people with dementia and family carers.

The benefits of involvement should be more widely publicised to all concerned.

Organisational and management structures should promote involvement of people with dementia through a range of methods, recognising the complexity and specific needs of people with memory problems.

The trial and evaluation of a City Wide group for people with dementia to have their voices heard and where organisations can seek the views of people with dementia

Staff working with people with dementia should be supported to engage more freely in a range of involvement methods, supported by information and education

The involvement needs of more isolated people, people from BME groups and people with more advanced dementia need further exploration

Actions for Phase 2 of the Project (April to October 2013)

- The development and evaluation of 3 city wide Dementia Involvement Groups with the engagement of the major Health, Social Care and Academic organisations in Sheffield.

- The trial of a more systematic approach to service feedback, evaluation and planning in one SHSC service and trial of a method of involving people with more advanced dementia
- The development of an educational briefing to be used at Dissemination Events and run a number of Dissemination / Skills Share events in SHSC
- CLAHRC to fund staff member from Alzheimer's Society for further 6 months to support the Dementia Involvement Group

Involving People with Dementia Project: Exploring How to Best Involve People with Dementia in Service Feedback, Evaluation and Planning.

Main Report

1.0 Background

This project evolved from work within Sheffield Health and Social Care (SHSC) NHS FT focussed on the involvement of service users in service feedback, evaluation and planning.

Service user involvement was well established within the Trust and was supported by a Service User Involvement Strategy. Service users with mental health, learning disabilities and substance misuse needs were engaged in a number of groups, forums and initiatives at a range of levels from local care settings to becoming Service User Governors. The NICE Quality Standard on Service User Experience in Adult Mental Health (NICE 2011) had prompted the formation of a Service User Experience Monitoring Unit aimed at assessing the use of the standards in practice.

People with dementia were, however, largely absent from much of the development taking place. It was with this in mind that a project was proposed through the NIHR CLAHRC-SY to explore current involvement practices with people with dementia.

The project was led through match funding by SHSC Senior Nurse Jane McKeown and was hosted by the Translating Knowledge into Action Theme of CLAHRC - SY. A partnership was formed with the Sheffield Alzheimer's Society and Dementia Advisor Ros Witherspoon funded by CLAHRC to support the project. SHSC Involvement Worker Faye Mellors was recruited to the project through CLAHRC match funding to ensure that the findings from the project were integrated into SHSC involvement work.

2.0 Aims and Objectives

The overarching aim of the project was to explore and enhance the processes and the range of methods by which people who have dementia may be involved with service improvement and planning within SHSC. More specifically the objectives were to:

- Interrogate evidence on the involvement of people who have dementia in health and social care service improvement and planning.

- Undertake this work in collaboration with people who have dementia, their family carers and key stakeholders across SHSC and Sheffield.
- Map out current involvement of people who have dementia across a matrix of involvement types and involvement levels within SHSC services and Governance systems.
- Establish what processes exist within Sheffield beyond SHSC.
- Make recommendations based on the literature search and mapping exercise for relevant processes to be implemented to enhance the involvement of people who have dementia.
- Disseminate learning across the CLAHRC partnership organisations and to facilitate its uptake into undergraduate nursing, medical, allied health professional curricula and continuing professional development.

3.0 Methods

To achieve the stated objectives three strands of work were planned:

- A non-systematic review of the literature around involvement and people with dementia in service feedback, evaluation and planning.
- Conversations with people with dementia (and family carers in separate forums / groups) to seek their views on how they can be best involved.
- Informal semi structured interviews with staff from services for people with dementia in SHSC.

4.0 Ethical Issues

The project was within the remit of the role of the Senior Nurse and was an evaluation rather than research, therefore ethical approval was not required. However ethical principles were applied and the project was explained to staff and people with dementia and people were invited to participate. Staff views and comments are reported generally and not attributed to any particular staff member or care setting to maintain confidentiality. People with dementia attended the Alzheimer's Society Support Groups and an explanation and information sheet was given to them before the conversations took place and also served as a reminder of the conversation afterwards.

5.0 Findings

It is relevant at this point to state how ‘Involvement’ was explained for the purposes of this project. A ‘Matrix’ of service user involvement, presented in 2009 by David Crepaz-Keay at a service user conference was adapted (see Figure 1).

Figure 1: Service User Involvement Matrix Adapted from Crepaz-Keay and Haywood (2009)

Involvement Level →	In Own Care	Team / Ward	Directorate/ Service	Organisation	City Wide
Type of Involvement ↓					
None					
Consultation					
Participation					
User Led					

This considers involvement in health care as taking place across a range of settings from involvement in own care through to involvement at an organisational or national arena. It also considers the ‘level’ of involvement – from none to completely user-led.

What emerged was the complexity in explaining ‘involvement’ to health and social care staff and to people with dementia. We will return to this issue throughout the findings and discussion.

Findings are reported for each of the three work strands and then a discussion brings the findings together. Recommendations are then made for the organisation, for practitioners and for further research.

6.0 Literature Review

6.1 Search strategy

A range of academic, policy and practice guidance was uncovered using search terms: (involvement; engagement; participation): (service user; user; patient; public): (dementia; Alzheimer’s; cognitive impairment; people with dementia); (service planning; services; service evaluation). High quality research into the process of involving people with dementia was scarce, whilst smaller scale local evaluations and policy / practice guidance was more prevalent.

Of particular note was a comprehensive service development guide (Cantley *et al.* 2005) which remains current and helpful. It is interesting that nine years on the guidance has not achieved widespread implementation. As the project progressed we became aware of a Mental Health Foundation Funded Project Dementia Engagement and Empowerment Project (DEEP) (Williamson 2012). Although this work had an emphasis on group involvement and activism, the literature review undertaken for DEEP had relevance for our Sheffield project.

6.2 Findings

An examination of this literature leads to some key themes relevant to this project.

6.2.1 Lack of Clarity over the Term Involvement

An initial observation from the literature was the range of terms used to describe 'involvement'. Examples include: Involvement (Alzheimer's Society 2011; Cantley *et al.* 2005); Consultation (Allan 2001); Evaluation (Cheston *et al.* 2000); Listening to the views of people with dementia (Cheston *et al.* 2000; Reid *et al.* 2001); Hearing the voice (Goldsmith 1996); Engagement (Reid *et al.* 2001; McCabe 2010).

The DEEP project state:

*The term 'involvement' will be used as shorthand to link the process of **engagement** with the (potential) outcome of **empowerment** for people with dementia (which in some cases, may include leadership).*
(Williamson 2012:9).

Cantley *et al.* (2005) discuss involvement in terms of five, inter-related, dimensions:

- values and principles;
- purposes and aims;
- models;
- organisational level;
- activities and methods

Some of the different *ways* that people may be involved in service feedback, evaluation and planning is summarised in the Alzheimer's Society Position Statement on involvement as a means of explaining the term (Alzheimer's Society 2011):

- Taking part in planning and decision-making about services.
- Participating in consultations on new health and social care policies.
- Giving feedback on services they use.
- Initiating and/or taking part in research.
- Training staff in how best to provide services.

- Being included on governance boards and working groups of health and social care organisations.

Such a summary can help to give a practical understanding of what involvement might include; however a list may also potentially limit the different opportunities offered to people, particularly if they are not included on the list.

A lack of clarity on what involvement actually means and from who's perspective persists in the literature.

6.2.2 Challenges in Involving People with Dementia

There are reported challenges in involving people with dementia from an organisational and attitude perspective. Additionally the literature points to challenges for the person with dementia, particularly when the disability resulting from the dementia increases and these include:

- Low expectations of what people with dementia could contribute (from paid staff and family carers).
- Involving people with a range of abilities, demographics.
- Maintaining involvement as the person's disability increased.
- Transport and practical support to attend groups.
- Negative organisational cultures.
- Ethical issues such as capacity, consent and confidentiality.
- Low self-esteem and confidence of staff in involving people with dementia
- Negotiating family carer involvement.

(Williamson 2012, Cantley *et al.* 2005, Allan 2001)

6.2.3 Methods of Enabling Involvement

An important insight from the literature is that there is no one best way of involving people with dementia, rather the literature points to a range of different methods that have been used depending on each situation. Indeed Cantley *et al.* (2005) propose that 'trial and error' is a necessary part of any approach to involvement with people with dementia and staff need to have the confidence to face set-backs.

Some of the different methods of involving people include:

- Narratives and stories to reflect on experience of services (Keady *et al.* 2005 Doherty *et al.* 2009, Moyes 2001, Allan 2001).

- Forums and groups (Williamson 2012; Jones and Prendergast 2007).
- Individual approaches (Bamford 2001).
- Organisational strategy (McCabe 2010).
- The use of questionnaires (enhanced if they are completed with a volunteer or helper rather than through self-completion) (Cheston *et al.* 2000).
- Photographs have been described as a useful tool for prompting discussions (Allan, 2001; Bamford and Bruce 2000).
- Supplementing formal discussions with informal conversations (Bamford and Bruce 2000, McKeown *et al.* 2010, Gourlay 2001).
- Use of questions regarding a service (Murphy 2001).
- Creative approaches such as the use of poetry (Killick 2001) photography, walking interviews (Williamson 2012), art work (Allan 2001).
- Talking Mats (Alzheimer's Society 2011).

Proctor (2001) demonstrates the benefits of giving feedback to people with dementia about the results of previous discussions, although they may not always remember previous discussions or involvement they can still comment on the content of what was said.

More importantly seems to be the *way* that any approach is used and commonly reported 'good practice' recommendations include:

- Creating an environment where people feel safe to share their views.
- Arranging transport to and from an event, offering expenses.
- Considering the timing of events to meet people's needs.
- Considering the specific support needs of each individual.
- Thanking people for taking part and valuing their contributions.
- Appropriate venue.
- Refreshments.
- Well briefed and supportive facilitators.

(Cantley *et al.* 2005; Williamson 2012)

6.2.4 Benefits of Involvement for the Person with Dementia

The literature gives some examples of how involvement activities could have benefits for the person with dementia. Building confidence, self-esteem and self-worth was commonly reported as a benefit arising from peer support and involvement (Williamson 2012; Bartlett and O'Connor 2010). Bartlett and O'Connor (2010) also detail the benefits for the person with dementia in terms of enjoyment and learning something new.

Some participants in group involvement described: *"a real sense of 'use it or lose it' "* and Williamson (2012:45) asks the question whether group involvement almost serves as a 'form of therapy' for some people with dementia.

Enhanced knowledge and understanding about dementia as a condition was also a benefit, especially for people recently diagnosed (Williamson 2012); however alongside this came a recognition that people had to be able to accept that they had dementia to become involved.

It appears that only recently has the literature started to explore how involvement might support wellbeing and often as a seemingly unexpected consequence and this highlights an area for further research.

6.2.5 Organisational Considerations

Cantley *et al.* (2005:21) offer a clear vision on how organisational and management structures should support involvement, stating that there needs to be an:

"organisational culture that accepts and expects people with dementia to be involved in a variety of ways."

Amongst other things staff training and support is required alongside a genuine organisational commitment to seeking the views of people with dementia underpinned by person-centred values (Cantley *et al.* 2005, Allan 2001).

7.0 Service Mapping

7.1 Background

Within SHSC Trust people with mental health needs and people with learning disabilities appear to have a range of opportunities to get involved in service feedback, service evaluation and planning if they wish to do so. People with dementia are much less evident in such forums, systems and opportunities. It was decided to ask some questions of a range of Dementia services within SHSC to assess the current practice of involvement for people with dementia.

7.2 Methods

For the purposes of this exercise 'involvement' was described to staff using the previously described 'matrix'. These were developed into a set of questions which

were taken to five different services for people with dementia comprising memory clinics, community services, in-patient wards and social care day centres.

Discussions with these services took place with nurses or social care managers and so a decision was taken to also take the questions to professional group meetings of occupational therapists / physiotherapists, psychologists and medics.

In all the questions were asked of 10 services / groups. Some services did not respond to requests to visit them or it was difficult to organise a mutually convenient time to meet.

Although an interview schedule was organised around a set of questions, in reality the meetings often turned more into a two way conversation and did not follow the predicted structure. Notes were written up following each meeting.

Alongside the meetings, the Service User Experience department maintain data on where service users are involved in some way within SHSC.

7.3 Findings

7.3.1 Involving people with dementia in their own care

Staff reported with confidence that they were involving people with dementia in decisions about their everyday care. Staff in in-patient setting spoke of enabling the person with dementia to make choices over things such as what to wear, what activities to participate in, what to eat. Some staff spoke of where possible '*involving the person in decisions about their future care and living arrangements*'. Staff felt however that sometimes involvement may cause stress for the person with dementia or they may not have the capacity to be involved in some decisions and so staff had to act in the persons 'best interests.

Some staff discussed that people are more likely to be involved in decisions when living in their own homes, as the worker feels like a visitor. There was a suggestion that the person with dementia retains more power over their situation when in their own home than when in hospital. However sometimes the timing of when staff were in contact with a person with dementia, for example if they were particularly unwell, then involvement was felt to be more of a challenge.

This aspect of involvement in a person's care was one that staff seemed more familiar with and were most likely to talk about.

7.3.2 Methods for Involving People in Service Feedback

When staff spoke of service feedback there was a focus on the use of questionnaires that were often sent to the person after a service had ended. There was recognition that these were likely to be completed by the family carer. There was no evidence that people with dementia had advised in any way on the development of such questionnaires.

There were some examples of where different approaches to seeking feedback had been used, such as a visual questionnaire used at the time with the person, or the use of post it notes and feedback immediately after an appointment. These examples provided evidence of good practice but tended to be part of a project or a one off piece of work rather than an on-going means of seeking feedback that as embedded in everyday practice.

7.3.3 An assumption that service user involvement should be taking place

Some staff spoke of knowing that involving service users was an expectation and they *should* be seeking ways. Involvement was seen very much from the perspective of the service or the Trust and little was said about the possible benefits of involvement from the perspective of the person with dementia. There was recognition that 'service user involvement' could be seen as a passing political fad.

What appears to be missing is the link between involving people and respect, autonomy, control and benefits for the person with dementia, as opposed to being something that was expected and must be done.

7.3.4 Involvement in Governance

When talking about the ways that people with dementia might be involved in Governance structures staff discussed the challenges in involving people with dementia in the Trust Governance model. Much of the Governance model within the Trust involves formal meetings and staff generally felt that the meetings were not conducive for people with dementia to attend due to their structure. There was no discussion amongst staff over whether the model was relevant for people with dementia and consequently people with dementia seemed to be excluded from

Governance unless they were 'good enough' to take part. It was more likely that a family carer might be invited to a Governance meeting.

7.3.5 Barriers to Involving People with dementia

Staff were able to identify a number of barriers to involving people with dementia:

- Time was commonly cited as a barrier; not only the time to spend with a person but also the time to analyse the findings from feedback and then make changes based on the feedback.
- The challenge of involving people when their dementia had become more advanced or in a time of crisis was identified. Capacity and consent were also sometimes cited as barriers to involvement.
- Some staff felt that attitudes of other staff might be a barrier to involvement; there were sometimes low expectations of what a person with dementia might be able to achieve.
- Education of staff and knowing how to best involve people was reported as a barrier to involvement. Many staff spoke of wanting systems, models, approaches to involving people with dementia. There was a sense that they wanted to be told the right way to go about it.
- There seemed a lack of confidence in some staff in 'having a go' and issues of time, resources and methods were seen as barriers.
- There was a recognition that not all people want to be involved, whether this related to the type of person they were, their condition or maybe even whether demographics played a part and whether for example there was more involvement by some groups of society than others.

7.5.6 Examples of Embedded Good Practice

There were some examples of good practice and innovative methods taken to involving people with dementia. Two examples are given but other areas of good practice may well exist.

- Darnall Dementia Group has a long history and reputation of working in an inclusive way to involve people with dementia and family carers in service feedback and planning. This has recently been exemplified by a piece of work to develop a Dementia Awareness Toolkit.

- Coping with Forgetting is a group offered by Memory Services which enables people with dementia to meet in a time limited group to discuss and support one another with receiving a diagnosis.

Data Gathered by SHSC on involvement over the past 12 months can be summarised as:

- There is no data suggesting that people with dementia are involved in any aspect of service feedback, evaluation or planning in their own right.
- There are some examples of where services have requested feedback on services, but the nature of the feedback (retrospective questionnaire) means it is most likely that family carers will respond rather than the person with dementia.

This data supports the findings from the Service Mapping Exercise.

8.0 The Views of People with Dementia and Family Carers / Friends

8.1 Background

From the outset of the project it was important to seek the views and involvement of people with dementia, whilst also not seeking to exclude family carers. Links were forged early in the project with the Sheffield Alzheimer's Society to draw on their expertise in working alongside people with dementia and also to seek supported access to people with dementia and family carers who were interested in taking part.

8.2 Methods

The two peer support groups for people with dementia running at the Alzheimer's Society were asked if they would be willing to allow one of their meetings to focus on discussions around involvement. An information sheet was given out and family carers were also invited to take part in discussions in a separate room. Afterwards all came together for lunch.

The Alzheimer's Society also agreed to hand over one of their City Wide Community Dementia Forums to the project and this provided a place for people to experience an aspect of involvement and discuss what it had been like.

The Alzheimer's Society had been asked to support Sheffield City Council in a Listening Exercise about services and a question was asked during that process about what being involved had been like for the person.

Notes were maintained from these discussions and forums and form the basis of the findings.

8.3 Findings – People with dementia

8.3.1 What do people with dementia think involvement is?

People with dementia seemed to understand 'involvement' in broader, more general terms than the health and social care staff. There seemed to be two strong themes in the way they responded to the term.

Firstly it was about being included. There was a strong sense in which people understood that they did not normally have a voice and that being included was strongly appreciated. Most people who attended groups/activities expressed their appreciation of being included as a way in which they could 'help'. Involvement was about doing something worthwhile, making a contribution, and feeling understood.

Secondly, was that people with dementia saw themselves as a group that had loyalty and attachment to one another. Involvement meant coming together as a group of people with dementia, and this was in fact a priority for them in itself; their concern for each other and for the group often took priority over what activity the group had met for.

The challenge therefore in exploring involvement with people with dementia has been to listen to what is being offered, rather than trying match what is said to questions being asked. Our experience has been that the people who took part had a great deal to say and when talking in a relaxed, familiar group they often had moving insights and clear reflections but that this quite often came out of more unstructured discussions rather than as responses to specific questions.

8.3.2 Benefits of Involvement for the People with Dementia

The benefits of involvement were articulated as:

"Getting involved in activities I may enjoy."

"It can help improve our well-being."

"It can be a two way process and we can help each other."

"Being involved is a way to help, to respond to the help we are getting from others."

"It may benefit the experience of people who follow us."

8.3.3 Feedback from people with dementia on different methods for involvement

Throughout the project, various methods of involvement have been trialled and/or discussed to seek the views of people with dementia about different approaches.

Very early on, telephone interviews and retrospective form filling were rejected immediately as unsuitable for obvious reasons relating to short term memory loss.

The following methods generated some very useful feedback.

8.3.3.1 Face to face interviews

People with dementia spoke of not feel very confident in one-to-one situations, some spoke of preferring to have partner or carer present, although this was not the case for everyone. Additionally it was important to remember that many people with dementia live alone and would be reluctant to let a stranger into their home.

People can feel embarrassed and stressed in one-to-one interviews, and it would help if the person interviewing was known to them and that the interview was relaxed and informal.

One-to-one interviews in the clients own home, was the method used by the Alzheimer's Society in a recent survey undertaken for the Sheffield City Council. The feedback from people with dementia (taken at the time of the interview) on this method was:

Positives

- The person asking the questions was known to them and helped them relax (the interviewer was a member of Alzheimer's Society team that the person had known for some time).
- The questions had been interesting.
- That they felt very positive about being asked their views.
- That they felt positive about helping Alzheimer's Society and other people with dementia.

- They all expressed enjoyment of the interview, (even 4 participants who became upset when talking about the future).

Challenges

- The first question (What things have been most important to you since you were diagnosed?) was very open and this threw quite a few participants. Perhaps because it came at the beginning of the interviews, before people had been able to relax, the question appeared to have been quite stressful.
- Some questions were too complex, and needed to be simplified (where the person was asked to comment on two things in the same question).
- Prompts were sometimes distracting (a sheet of alternatives was offered for one question).
- Being asked questions about things they had not experienced (going to a day centre). Many people found speculating about what they might do or feel in situations not easy.
- Some participants and some interviewers felt that there had not been enough time. (The information sheet had indicated that the interview would be an hour, but several interviews ran over this).

8.3.3.2 Questionnaires.

Most people said that they needed help to fill in questionnaires, which was likely to be a carer. Questionnaires were the same as form filling which they talked about avoiding since having memory problems.

People talked about feeling panic when looking at forms/questionnaires.

However, it was said that questionnaires could be made more friendly for people with dementia to complete. Clear YES/NO options were best, with some space for additional comments. Attention should be paid to layout, colour, font size, with the aim of making the questionnaire clear and concise.

8.3.3.3 Small groups

The main activity/method favoured by most people with dementia was small groups. Comments regarding small groups included:-

"Can work better because people trigger each other."

"Strength in numbers – permission to say negative things."

"Give support to each other."

"Able to be 'real' ...because people..... are experiencing the same issues."

"More confident because with like-minded people."

"Less likely to need support from (carer/relative)."

"Social aspect of the group is a big positive."

Telling important stories and reaffirming identity is a strong feature of people with dementia coming together and it was important that whenever people with dementia met, even for 'involvement' activities, that there was time for these types of conversations. These 'identity affirming' conversational threads were sometimes used when it was hard to stay on track with the topic, and this way of dealing with 'getting lost' in a discussion was well recognized by several people. As one person said:

"The reason I find this difficult is because of my condition."

8.3.3.4 Formal meetings

People spoke of feeling exposed in public meetings, that they might not be ready to have their diagnosis known so openly. Getting to venues which were unfamiliar might be an issue and noisy, busy, large venues could be intimidating and may affect mood, thinking and ability to participate.

However, it was also said that listening to a good speaker or film could be enjoyable.

In summary, people with dementia said the most important points for getting involved were:

"Familiar faces are helpful."

"Important that the person helping or asking the questions is aware we have dementia and has some knowledge about how it affects us so they can 'allow for it' ."

"Friendly and relaxed atmosphere."

"Being able to give immediate feedback (no point in asking for feedback much after the event or we will have forgotten!)"

8.4 Findings – Family Carers and Professionals

Feedback from the carer's and professionals identified three major themes: carer's own issues; barriers; and opportunities.

8.4.1 Carer issues

Carers spoke a lot about their situations. There was a strong theme of not feeling that they were listened to either, let alone the person they looked after. Additionally, a lack of resources and support for themselves and the person with dementia came up throughout the discussions.

One of the positives that carers mentioned, also mentioned by people with dementia, was the opportunity that involvement events/activities gave them to be together within a supportive community. This was compared to the majority of 'support' activities that were offered to either the person with dementia or the carer separately.

Carers recognised that they might influence feedback from the person they supported and it was generally accepted that people with dementia and carers did need to have opportunities to have their say, both separately and together.

8.4.2 Barriers

Barriers were perceived as a twofold consequence of factors related to: public awareness and organisations and to do with people with dementia.

8.4.2.1 Factors related to public awareness and organisations

Carers described negative attitudes and suggested that people with dementia were not seen as being able to voice a valuable opinion; that they were seen 'as their illness' rather than 'who they were'. Carer's reported that once diagnosed, the person with dementia was almost disregarded.

Negative attitudes were likely to affect motivation to seek feedback from people with dementia.

Organisational practices were relevant and carers said that most organisations seek feedback retrospectively and impersonally, in the form of postal questionnaires. Also many involvement activities involve formal meetings and organisational language. These factors would all deter involvement from people with dementia.

8.4.2.2 Factors related to people with dementia

Involvement takes courage. Carers said that they felt anxious and under confident in voicing their opinions and thought it would be even more difficult for people with dementia.

Environment is important and people with dementia need to feel relaxed and 'not put on the spot'. Stress and anxiety could negatively affect thinking and word finding.

Information about events where people with dementia could 'have a say' was sparse. This was relevant also to carers and professionals, who talked about missing events they would have wanted to go to because they were not well advertised. They felt that this would be an even greater problem for people with dementia who may need explanations, encouragement, reminders and support to attend events. They felt that organisations relied on the 'usual suspects' rather than make the effort in reaching out to people who may need more support and encouragement to get involved. Several people said that they missed the local Alzheimer's Society newsletter which is no longer published, but which used to print a diary of events every 3 months.

8.4.3 Opportunities

Carers and professionals talked about ways to create opportunities for people with dementia to be more involved. Several of these points were made by people with dementia as well.

It was considered important that involving people with dementia would require careful listening, relaxed pace, conversational style interviewing, and attention being given to non-verbal communication as well as what people said.

Also very important, was timing and immediacy. Feedback needed to be sought at the time of an event activity.

It was suggested that feedback could be obtained in a variety of contexts where people with dementia are present, that it doesn't just have to be meetings and groups for that purpose.

9.0 Discussion

There were a number of common themes from across the three streams of findings and equally some unique perspectives.

Common themes included the lack of clarity on in what involvement means. In health and social care speak, the word 'involvement' is used as an umbrella term for 'consultation', 'participation' and 'engagement' activities aimed at enabling and supporting service users to influence the health and social care agenda. For staff working in clinical areas involvement is more relevant to joint decision making and choices in everyday care. Perhaps most importantly were the ways that people with dementia appeared to understand involvement – in terms of:

- It was about being included and doing something worthwhile; making a contribution, and feeling understood.
- Involvement meant coming together as a group of people with dementia, and this was in fact a priority for them in itself; their concern for each other and for the group often took priority over what activity the group had met for.

The lack of opportunities for people with dementia is reflected in the literature, through service mapping and through conversations with people with dementia and family carers. A whole range of barriers to involvement were identified which included attitudes towards the abilities of people with dementia, time, organisational constraints, lack of confidence, motivation, information, methods used to seek feedback, the environment.

However there were also a number of suggestions and identified ways of involving people with dementia that emerged from the literature and from people with dementia themselves and family carers. These include having access to information about events, transport, methods that take into account the disabilities that dementia brings, the creation of supportive environments.

A theme only emerging recently in the literature, but identified strongly by people with dementia in this project was the desire to be involved and indeed the positive benefits that being involved can have on self-esteem, confidence, well-being, feeling valued, feeling supported, feeling a part of something bigger.

An aspect that this report has raised and been unable to offer solutions to is how to involve people with more advanced dementia or people who are more isolated. The group of people with dementia who have informed this project have largely been able to get out of their homes and join in group activities. Similarly there is little about the involvement needs of people from BME communities, either in the literature or from within this project.

One final theme emerging seems to relate to staff understanding and knowledge of the importance and the benefits of involving people with dementia, beyond a purely

policy / Governance driven activity. This is closely linked with the need for staff to embrace a range of creative approaches and move beyond the use of a retrospective survey approach. Alongside this is the need for an organisational commitment to seek a more meaningful approach to involving people with dementia and learning from what people with dementia have to say.

10.0 Conclusion

This report has drawn together understandings of how people with dementia might be better involved in service feedback, evaluation and planning. A number of common themes have been identified from the literature, service mapping and discussions with people with dementia and family carers. However some less reported themes have been identified.

The next stage of the project is to trial some of the different methods of involvement and to implement the recommendations into practice through an action plan.

11.0 Recommendations

- The term “Involvement” of people with dementia needs to be defined from the perspective of people with dementia. This needs to then be clearly articulated to health and social care staff, people with dementia and family carers and friends.
- The benefits of involvement need to be more widely publicised to people with dementia, their family carers and care staff.
- Organisational and management structures need to promote involvement of people with dementia through a range of ways, recognising the complexity and specific needs of people with memory problems and moving away from a reliance on retrospective questionnaires and surveys
- Trial and evaluation of forums / groups specifically where people with dementia are given the opportunity to have their voices heard and where organisations can come and seek the views of people with dementia
- Staff working with people with dementia need to be supported to engage more freely in a range of involvement methods, supported by information and education

- The involvement needs of more isolated people, people from BME groups and people with more advanced dementia need further exploration.

12.0 Actions for Phase 2 of the Project (April to October 2013)

- The development and evaluation of 3 city wide Dementia Involvement Groups with the engagement of the major Health, Social Care and Academic organisations in Sheffield.
- The trial of a more systematic approach to service feedback, evaluation and planning in one SHSC service
- The trial of a method of involving people with more advanced dementia The development of an educational briefing to be used at Dissemination Events
- To run a number of Dissemination / Skills Share events in SHSC (?Sheffield)
- CLAHRC to support a staff member from the Alzheimer's Society to help develop and evaluate the Dementia Involvement Groups 1.5 days a month between April and October 2013.

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