

# **Involving people with dementia in the development of a discussion forum – a community-centred approach**

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## **1 Introduction**

### **1.1 Dementia**

Dementia has been defined as a syndrome characterised by the development of multiple cognitive deficits including as least one of the following: aphasia, apraxia, agnosia or a disturbance of executive functioning (Cummings and Khachaturian, 1999). There are an estimated 18 million people worldwide with dementia. Dementia primarily affects older people. The chance of having the condition rises with age to 1 person in 20 over the age of 65, and 1 person in 5 over the age of 80 (ADI 2004). There are many causes of dementia including Alzheimer's disease, vascular dementia and dementia with Lewy bodies (Alzheimer's Society, 2005).

#### *1.1.1 Symptoms of dementia*

The distinction between severe dementia and normal ageing is obvious but establishing the difference between early, mild Alzheimer's disease and age-related cognitive loss can be more difficult (Jones and Ferris 1999).

The cognitive domain which is impaired first and foremost in Alzheimer's disease is memory (Kertesz and Mohs 1999). Working memory is often lost in dementia, but the patchy progression of dementia means that even people in the later stages may retain early learning and access to long laid down memories (McIntosh 1999). Perhaps the most substantial deficits in people with Alzheimer's disease are found on short-term memory tasks that require divided attention (Morris 1994). Alzheimer's disease is also associated with deficits in various aspects of semantic memory functioning, eg categorical organisation (Backman 1998). However, procedural memories are relatively spared (Zanetti 2001).

Subtle language impairment is usually detectable early in the course of Alzheimer's disease (Kertesz and Mohs 1999). People with Alzheimer's disease have been shown to be impaired in their appreciation of the relationship between a word and its attributes (Grossman et al 1996).

Topographical disorientation, ie difficulty in orienting to, navigating through and feeling familiar with one's surroundings has also been identified as a problem for people with Alzheimer's disease (Pai and Jacobs 2004).

The symptoms of dementia are not uniform. People with Alzheimer's disease may experience different symptoms at different times. The types and severity of cognition impairment varies from person to person, especially in the early stages (Kertesz and Mohs 1999).

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

Involving people with dementia in research as participants rather than research subjects is a relatively new concept. Once people have a diagnosis of dementia, assumptions are often made that they do not have views about their care and are unable to express their own history (Allen et al 2003).

However, there is growing recognition that people in the early stages of dementia are able to provide accurate and valid reports of the experience of services provided for them, such as community care (Bamford and Bruce 2000).

When asked, people with dementia have expressed a willingness to participate in research as they perceive it to be doing something worthwhile (Robinson 2002). There may also be a feeling of being taken seriously as a capable person again (Dewing 2002).

Many researchers believe that a collaborative style is appropriate when carrying out research with this population. In such research the person with dementia, carers and researchers explore difficulties and options for their resolution together (Blackman et al 2003).

### *1.2. 2 Focus groups and people with dementia*

Because focus groups have been found to be appropriate for research with people with limited power and influence (Morgan and Kreuger 1993), this method of research has also been used with people with dementia. Group discussions may have a number of potential advantages over individual interview including enhanced quality of interaction, reduced pressure on individuals to respond, mutual support and the opportunity for shared experiences to trigger memory (Bamford and Bruce 2000).

Bamford and Bruce (2002) have described a study with fifteen older people with dementia where formal focus group discussions took place with four to nine people with dementia. They concluded that focus groups are only suitable for researching certain topics and only with certain groups of people with dementia. For example, focus groups will be more useful for people in the earlier stages of dementia and to discuss specific issues rather than broad experiences. It was therefore thought that focus groups may be a suitable research methodology for developing a website for this user group.

Focus groups have proved a useful tool for finding out about the views of people with dementia about their own day centre. For example, Heiser (2002)

describes how a group of people with dementia quickly grasped what the session was about and were forthcoming with their views.

As with all focus groups, interaction may not necessarily be positive. Bamford and Bruce (2002) found that participants with dementia sometimes showed a lack of respect to one another. They feared that negative responses of other participants could undermine a speaker's confidence and feelings of self-worth. Bamford and Bruce have also found that there may be more potential for a dominant participant to exert a significant effect on the findings in group discussions and found problems with parallel conversations independent of group size (Bamford and Bruce 2002).

Using skilled dementia specialists to facilitate the group has been found to be important, especially in giving prompts to move people on to the next question without leading anyone with answers (Heiser 2002).

Time is a big issue in focus group discussions. People with dementia often need time to communicate their thoughts, but it has been found difficult to give them this time in focus group settings (Bamford and Bruce 2002). Researchers advise against trying to tackle lots of topics in one session (Heiser 2002). Each person's abilities such as speech and thought response time need to be considered so that all contributions are valued and acknowledged. Care should be taken to make sure that people feel included even if not playing an active verbal part or if they do not fully understand. For such a person to feel at ease with a sense of belonging is important (Moyes 2002).

### **1.3 A community-centred approach to developing an online community for people with dementia**

One of the most significant developments in the field of dementia care has been the focus on personhood (Kitwood 1997) and people with dementia are increasingly becoming involved in the work of the voluntary organisations such as Alzheimer's Society (Litherland 2004). Developing communities of people with dementia is seen as being very important by the Alzheimer's Society.

#### *1.3.1 Alzheimer's Forum*

Alzheimer's Forum is a website that is run by people with dementia for people with dementia. It was established and is run by a small group of people with dementia at the West Kent branch of the Alzheimer's Society. The aim of Alzheimer's Forum is to 'communicate with people with dementia across the world'. The site features 'contributions from friends' and a 'predicament of the month'. Both features encourage contributions from people with dementia across the country (Alzheimer's Forum 2005).

The people with dementia at Alzheimer's Forum expressed the wish to have a discussion forum on the website. They had contributed to the Alzheimer's Society's main discussion forum (Alzheimer's Talking Point 2005) but had found it too complicated to use. A preliminary needs analysis has been carried out with



|                           |       |          |                       |          |       |       |          |
|---------------------------|-------|----------|-----------------------|----------|-------|-------|----------|
| Frequency of computer use | Daily | 2 x week | Less than once a week | 2 x week | Daily | Daily | 2 x week |
| Use of discussion board   | Once  | Never    | Once                  | Once     | Often | Often | Never    |

## 2.3 Composition of focus groups

The participants were divided into three groups based where possible on their stated ability and ease with using computers. It was decided to group the participants in this way to ensure that all participants would feel confident about expressing their views. It was felt that bringing together people with similar experience, for example of online discussion forums, would be productive (Kitzinger and Barbour 2001). It should also be noted that some of the participants already knew each other and some did not.

- Group 1 consisted of three participants (2 male and one female aged 57, 66 and 82). These participants stated that they were happy using computers. Both the male participants had extensive experience of computer use, used a computer daily and had used online discussion forums extensively.
- Group 2 consisted of two men (aged 60 and 67) who were fairly happy with computers but had little or no experience of using discussion forums.
- Group 3 consisted of one man and one woman (aged 60 and 75) who were not happy using computers.

## 2.4 Focus group discussions

Three different designs were presented for comment.

- Design 1 was a text only design
- Design 2 used a frameset design
- Design 3 used rich media (Flash) design.

Each design was presented to the participants by a member of the design team. The designs were presented with limited functionality as Flash animations projected onto a screen. Flash animations were used rather than paper prototypes for two reasons. Firstly that design 3 (rich media) would be difficult to represent on paper. Secondly each design would have been represented by a different number of sheets. It was felt that if this was done then it might have given to our participants an incorrect impression of the complexity of the different designs.

Each group had a facilitator. The facilitator ensured that each member of the group was able to express his or her views and that they were given sufficient time to understand the concept of each design and to collect and express their thoughts. This is particularly important when asking the views of people with dementia who

may have language and cognitive problems. All views of each of the participants were noted.

The facilitator also acted as note-taker. Each discussion session was completely open with no pre-set questions. Participants were asked to imagine using each system and to comment on what they liked or disliked. They were also encouraged to discuss general issues as defined by Preece and Maloney-Krichmar (2003) such as:

- Dialogue and social support – how easy it would be to perform actions such as reading messages or sending message
- Information display – how the information is designed and structured
- Navigation – how they would find their way around the system

## 3. Results

### 3.1 Design assumptions prior to the focus group

#### 3.1.1 Design group

The three designs were developed before the focus group was established. Following a preliminary needs analysis with the people with dementia responsible for Alzheimer's Forum, a small design group was set up. The group consisted of a technical web designer, a HCI research student and someone involved in providing care and support for people with dementia. Following discussions of the literature review, the perceived needs of people with dementia and the technical constraints, this group decided on the three design options.

#### 3.1.2 Design options

**Design 1:** The text-only design was based on the idea that people with dementia might prefer a design that was very simple. The cognitive load was reduced by only offering a limited choice of options. However, it was thought that people with dementia might have problems with such a design because of the limited availability of cues to establish where in the system the person was and what actions were available.

Therefore the trade-off in this design was between the problems associated with divided attention and the issues associated with 'getting lost'.

**Design 2:** Design two was based on a frameset design. Although usability guidelines (Preece 2001a) warn against using such designs, it was felt that such a design might be appropriate for people with dementia. It was felt that the ability to have all options available on the screen at the same time might avoid a feeling of being lost.

**Design 3:** Design three was an innovative design using Flash. It was felt that a more graphical display might be able to represent better the complexities of the discussion forum.

### 3.2 Results from focus groups discussions

The notes of each discussion were analysed and trends and consensus within the groups identified. As the groups were quite small, there was a lot of consensus in opinions within the groups.

The following tables represent broad categories of comments and indicates which groups voiced this opinion.

#### *Design 1: Text only*

| <b>Category of comment</b>   | <b>Groups voicing this opinion</b> |
|--|------------------------------------|
| Clear, simple design but possibly too unfriendly   | group 2, group 3, group 1          |
| Liked being able to see message while replying   | group 2, group 1                   |
| Text boxes too small – need to see whole message   | group 2, group 3                   |
| Too much scrolling   | group 1, group 2, group 3          |
| Unclear where new message and first message would appear   | group 1, group 2, group 3          |
| Problems with terminology and where fields should be filled in automatically – comments, reply to message, author/username | group 2, group 1                   |
| Difficulty with knowing where you are  | group 2, group 1                   |
| Unclear how to start new thread  | group 2                            |
| Relies on meaningful message subjects  | group 1                            |
| Blank space not explained until reply button clicked   | group 3                            |

There was consensus across the whole focus group about the need to eliminate scrolling. It was perhaps interesting that even the more advanced computer users (group 1) found this necessary. The comment about needing meaningful message subjects only came from group 1. This could reflect their experience in using discussion forums. The confusion around the blank space in the design shown by group 3 may reflect their relative inexperience of using computer systems.

#### *Design 2: Frameset*

| <b>Category of comment</b>  | <b>Groups voicing this opinion</b> |
|---|------------------------------------|
| Too much complex – too much information and choices on one screen | group 2, group 3                   |
| Too much scrolling  | group 1, group 3                   |
| Problems with printing  | group 1                            |

The comments of the experienced users revolved around their knowledge of the problems associated with frameset designs. However, the relatively inexperienced groups found the design confusing.

*Design 3: Rich media (Flash)*

| <b>Category of comment</b>   | <b>Groups voicing this opinion</b> |
|--|------------------------------------|
| Attractive. Simple – graphics rather than text                       | group 2, group 1                   |
| Can see where you are/takes you through the logic of what's going on | group 2, group 1                   |
| Scrolling problem  | group 2, group 3                   |
| Problem with subject and author tags                                 | group 2                            |
| Might need online help   | group 2, group 1, group 3          |
| Problem with scalability   | group 1                            |

Although this design was thought attractive, all participants were worried about their ability (or the ability of others) to use such an innovative design.

## 4. Discussion and conclusions

### 4.1 Advantages of using focus groups

Focus groups are used not to get usability information but rather to explore general attitudes on a given topic (Kunaiavsky 2003). This study has demonstrated that the focus groups are a useful tool for finding out views and opinions of people with dementia about computer interfaces, but that researchers running such groups need to be aware of the issues involved.

In fact, focus group methodology can be particularly suitable for this group of people. Often people with dementia feel isolated. Bringing this group of people with dementia together was a rewarding experience both for the participants and for the facilitators. This physical coming together was perhaps particularly useful if this group of people are to become the core community for the development of an online community.

Although the three groups varied considerably in their experience of using online discussion forums, there was quite high agreement in their opinions about the three design options. Grouping people by perceived skills was found to be useful as the groups were able to contribute to the discussion on a level at which they felt comfortable. The female participant in group 1 expressed a feeling that her views were not so important as the other members of her group. It would probably have been better to have asked her to join Group 2.

### 4.2 Issues when using focus groups with people with dementia

Focus groups are often used in this sort of study with people from the general population. Problems associated with using focus groups for user needs analysis in the general population include ensuring that everyone participates and that there is

interaction within the group. A quiet location without distractions is important and the mix of people within the group need to be considered (Brink et al 2002).

However, this study has shown that traditional human computer interaction focus group methodologies need to be adapted and altered to be an effective methodology for use with people with dementia. The group facilitators in this study came across some of the issues highlighted by researchers in the dementia field (Bamford and Bruce 2002). These include parallel conversations, where participants talk simultaneously or domination of the group by individuals. People with dementia were also found to be easily distracted and spent considerable time telling stories about the past or their condition rather than concentrating on the designs. Some participants could not remember discussions about other designs earlier in the day.

### **4.3 The importance of involving people with dementia**

Very little is known about the computer-interface design needs of people with dementia (Savitch and Zaphiris 2005). Therefore, it is important to find out as much about the user needs as possible.

Preece and Maloney-Krichmar (2003) have identified the link between social interaction on an online discussion forum (sociability) and usability. The community-centred approach involves software design, deciding on initial social policies and development of the community over time (Preece 2001). Involving people with dementia at an early stage in the development of an innovative discussion forum for people like themselves is vitally important. It is only if a group of people with dementia feel ownership and responsibility for the discussion forum that it will succeed.

From this study it is clear that making assumptions about the needs of potential online community groups is not sufficient. Even when these assumptions are being made by people with experience of working with the group in question. The only way to know if the software is suitable is to ask the users.

The clear message for the next phase of the development is that the frameset solution is not a suitable design for a discussion board for people with dementia. This finding is inline with general usability guidelines (Preece 2001a)..

A working prototype will now be developed . It is likely that this prototype will use the graphical interface display but also have text-based alternatives. The prototype will undergo extensive and iterative user testing with people with dementia. The methods used to conduct user testing will be developed taking into account the needs of people with dementia.

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