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Giving People with Dementia a Voice in Research

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Abstract. This paper presents an exploration into the involvement of people with dementia (PWD) in research. Dementia-friendly consent documentation was developed to address the known issue of obtaining consent when involving PWD in research. Questionnaires were explored as a research method to elicit data from PWD. The documentation and method were evaluated using Reflective Practice. The dementia-friendly documentation was found to be accessible, and an adapted questionnaire method elicited the perspective of PWD, though suggestions are given to improve the approach.

Keywords. Research Methods, Inclusive Design, Design for Dementia, Human Factors

1. Introduction

With 850,000 people living with dementia in the UK, and this number forecast to increase to over 1 million by 2025, and over 2 million by 2051, the need for society to support these people is of paramount importance (Alzheimer's Society, 2014). As with any user group, their needs and desires need to be identified and understood if products and services are to provide support. However, user needs for people with dementia (PWD) have largely been defined by the bio-medicalisation of the condition, with little attention being paid to subjective experiences (Beattie et al., 2004). The opportunities available to PWD have been limited by researchers' perception of assumed inability and incompetence, rendering such contributions as invalid or at best unreliable (Gillies, 2000; Bamford and Bruce, 2000; Lloyd, Gatherer and Kalsy, 2006). Ethical reasons have been cited for PWD not being active participants in the past (Hellstrom, 2007), with obtaining consent and the potential to cause anxiety by using inappropriate methods being two of the areas that researchers have expressed concern over.

This study acknowledged that PWD are capable and insightful about their needs (Beattie et al., 2004; Gill et al., 2011; Moyle, 2010) and aimed to explore how PWD can be supported as participants in Human Factors research. Issues concerning informed consent, and using questionnaires as a method to elicit data from PWD were addressed. Documentation was designed to be dementia-friendly and then evaluated with the involvement of PWD using a Reflective Practice model.

2. Methods

2.1 Materials

Guidance on how to design information to be dementia-friendly was extracted from literature. Guidelines such the Dementia Engagement and Empowerment Project (DEEP; 2013) were used to develop the participant information sheet, informed consent form, and questionnaire. Clear and meaningful language was used, in a 'chunked' format, with appropriate icons and

imagery. The participant information and informed consent sheets were combined, (including all the key information required to be approved by Loughborough University (LU) Ethical Committee) to support and facilitate the transfer of information to participants. The volume of information presented to PWD was reduced in comparison to standard documentation at LU to prevent participants feeling overwhelmed or anxious, and to allow for impaired short-term memory.

All the research documentation (sample section in Figure 1) was reviewed by both PWD and the organiser of the dementia support group in which the research was conducted. This enabled adjustments to be made prior to the study commencing.

The purpose of this study is to explore how people living with memory loss or dementia use products which give access to information. If you have any questions about this study, please contact the researcher.

The purpose and details of this study have been explained to me.

YES NO

YES NO

Figure 1 - A section of the dementia-friendly consent form

2.2 Participants

Fifteen participants were recruited on a voluntary basis from a community support group (Hardy Group) held in Derby, UK. PWD and their carers were invited to participate in a questionnaire study during the monthly support group meeting.

2.3 Procedure

Several support group meetings were attended prior to data collection to introduce the researchers to, and build rapport with the group members. Rapport with participants is known to be particularly important when involving PWD (Lloyd et al., 2006).

Individuals wanting to participate in the study were provided with the dementia-friendly information and consent form. Participants were supported to complete the questionnaire, exploring the use of technologies by PWD and their carers (Allen, Hignett & Cook, 2016; Allen et al., 2016), using an interview style.

Following each questionnaire, a method reflection form was completed, to capture information about any successes or challenges identified within both the design of the study documentation and procedure, or the dynamics observed between participant dyads (PWD and their carer).

The data captured using this process was then analysed using Driscoll's 'What? So What? Now What?' Reflective Practice model (1994), to evaluate the documentation and methodological approach used.

3. Results

The output from the reflective practice for the completed method reflection sheets are presented as three topics:

3.1 Document Design

The participant information and consent form redesign proved to be accessible to PWD, with the use of chunking and icons in particular appearing to aid participants. PWD were able to comprehend and complete the documentation with minimal support from their carer. The success of the documents supports their use within future studies, as they enable good practice of involving PWD in research as consenting participants.

3.2 Data Collection Procedure

As expected with PWD, maintaining their focus for prolonged periods of time was challenging. During data collection, the questionnaire was supplemented with an additional sheet of topic-specific visuals to provide a continuous visual reminder of the conversation topic. When comparing participants' concentration between those provided with the sheet and those without, this seemed to increase concentration levels of PWD. The importance of conducting research in a quiet environment was also highlighted with participants struggling to retain focus as a result of the loud environment. This will have to be considered in future research involving PWD, as sensory overstimulation could reduce the quantity and quality of the data collected.

3.3 PWD and Carer Dynamics

The personal dynamics between dyads of PWD and their carer can have an impact on the data collected as it was observed that this can alter the perspective being obtained on any given topic. This was noted in particular when a carer of a dyad spoke on behalf of the PWD that they cared for, and reduced the input of the PWD during the interview.

Whilst it is ethically advisable to have a carer present, to provide support to the PWD if required, it is clear that an alternative to seeking both perspectives simultaneously needs to be sought. It is important to obtain both perspectives fully, as PWD are often found to have differing opinions to their carer (Gill et al., 2011; Steeman et al., 2007). Thus, developing a method to facilitate this is important if the opinions and needs of PWD are to be fully identified. Adjustments to the approach will be made within future studies, and reflected upon, in order to develop an ethical approach that ensures complete data is obtained from all stakeholders. It is suggested that briefing the carer more explicitly on their role and the contribution desired from them prior to data collection with the PWD may be one way to address this issue.

4. Discussion and Conclusion

The participant information and consent form design enabled PWD to access the study as a participant, rather than relying on a carer-by-proxy involvement, as has been previously found in literature. Whilst this research has not addressed the inclusion of PWD living with the latter stages of dementia in research, it does provide evidence that PWD living in the community can be supported to contribute to research. Future studies will use this documentation for research into HCI accessibility for PWD and how this may impact their independence.

It is clear that even common research methods, such as questionnaires, require adapting if they are to be used with PWD. Considerations must be given to the language, visual aids to fully engage participants, the environment in which data is collected, and the management of the dynamics between the PWD and their carer. Whilst PWD may be keen to contribute to research, if methods are not appropriately designed, this may result in barriers to their inclusion in research.

From a humanistic perspective, PWD should have a voice in matters of concern to them (Slaughter et al., 2007), and thus, every effort should be made to promote their inclusion in research.

Consent documentation design that enables PWD to contribute to research has been developed. This addresses a key issue expressed by researchers, cited in literature, regarding obtaining consent from a vulnerable group in an ethical manner without causing undue anxiety or stress (Hellstrom et al., 2007).

The results of the use of questionnaires with PWD will inform the methods used in future studies as guidelines are developed for best practice of involving PWD as participants.

This study has shown that PWD can participate in Human Factors research when the methods and procedure are user-sensitive; when their needs are considered and they are supported to do so. As Beattie et al. (2004) stated, the question should not be '*should we include people with dementia?*', but '*What are the ways to promote inclusive and participatory research for people with dementia?*' This study has addressed a small part of that question, and future research will continue to explore ways to give PWD a voice in research.

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