

Carers' experience of Assistive Technology (AT) use in dementia
PARTICIPANT INFORMATION SHEET

Ethics Approval Reference: R57703/RE001

1. What is the purpose of this study?

Dementia describes a set of symptoms that may include memory loss and difficulties with thinking, problem solving or language. Caring for a person with dementia can be demanding for informal carers (family, friends and neighbours) and can affect their mental and physical health and their social lives. Assistive Technology (AT) devices are often electronic. They include talking clocks, electronic medication dispensers, smart gas meters, falls and motion detectors and door exit alarms. While AT is usually aimed at helping the person with dementia, these may also have an impact on carers. Due to the thinking and problem-solving difficulties the person with dementia may have, the carer may need to be an active user of the AT. It is not yet clear what positive or negative effects such technology may have on carers and there is little information on their experience with its use.

Purpose of this research:

This research will explore the experiences of Assistive Technology from the perspective of those looking after and helping persons with dementia at home. It will investigate the types of AT used and preferred, the purposes, benefits and disadvantages of the AT, and how the AT impacts on their burden and wellbeing.

2. Why have I been invited to take part?

You have been invited because you participated in a survey of the 'Carers' experiences of AT use in dementia project' and indicated, that we can invite you for an interview.

To participate in the interview, you need to be:

- Continuing to provide help or support to a person with dementia living at home (e.g. shopping, leisure, personal care, finance).

3. Do I have to take part?

No, your participation is voluntary. You can ask questions about the study before deciding whether to take part. If you agree to take part, you may withdraw from the study at any time, without any penalty and without giving a reason. If you choose to withdraw after the interview, the research team will delete any data including personal information and interview recordings and transcripts, and it will not be used in the analysis.

4. What will happen if I take part in the study?

If you are happy to take part, you will be asked to answer questions in an informal interview, like a conversation. The interview questions will ask you about the impact and effects of using Assistive Technology in helping care for your relative/friend/neighbour. The interview will be audio recorded to allow us to type up your answers. You will never be identified by any of your personal information.

The interview should take approximately 60-90 minutes and will take place at your home, your place of work, by telephone or at the University of [redacted]. The interview location and time will be arranged in discussion with you, to suit your convenience and preference. The interviews will be conducted by [redacted], a doctoral student at the University of [redacted].

5. Are there any potential risks in taking part?

The questions asked during the interview may be personal and occasionally some people feel upset when asked to think about their experiences of looking after a person with dementia. You do not have to answer any question that you would prefer not to answer. If you become upset at any point, the researcher will ask you if you wish to pause or stop the interview. You could then: stop and withdraw your data (the interview recording would be deleted), end the interview and allow the interview recording until that point to be used in the research, or carry on with the interview when you are ready.

The researcher can provide you with an information sheet which contains a list of organisations who you can get in touch with if you feel the need for further support.

6. Are there any benefits in taking part?

You will not receive any direct benefit by taking part in this study. However, the information gained in this research study will provide a better understanding and insight of carers' experiences of using AT and its impact on their well-being. This can be used by health professionals and researchers to support other carers of persons with dementia who use AT.

7. What happens to my data?

The **research data** will be stored and examined using University approved software.

Any information that you have given in the interview that could identify you will be removed from the interview before it is analysed. Confidentiality will be maintained throughout this research study. If you consent to take part, you will be required to sign an informed consent form. To protect your identity, your name will be replaced by a pseudonym in any research reports. Any identifying information like your name, details or other personal information will not be used or disclosed to anyone outside, to any third party or appear on any transcripts, thesis, publications or on any academic paper.

However, there might be certain circumstances in which it may be necessary to breach this confidentiality and disclose information to a third party. This includes situations when someone provides information during the study that raises serious concern about:

- Intention to harm themselves or other people
- Risk to the health, welfare or safety of vulnerable adults such as someone with dementia
- Disclosure of a criminal offence

The researcher will discuss this issue with you before telling anyone else. The researcher will be obliged to share this evidence with his supervisor, who may advise that further action is taken.

Personal / sensitive information such as your name, age, gender, marital status, employment status, telephone number or address details in case of face-face interviews will be stored confidentially using computer software that does not allow anyone else except the researcher and his supervisors access to your data. All paper forms will be stored in a locked cupboard within the Department of [redacted], University of [redacted]. Your personal/sensitive data, including your signed consent forms will be kept separately from audio recordings and transcripts from your interviews. Your answers may be quoted directly in the research publication with information suitably anonymised. All audio recordings will be erased permanently once they have been transcribed. All research data and records will be stored for a minimum retention period of 3 years after publication or public release of the work of the research.

8. Will the research be published?

[Redacted]

Additionally, the research may be published in academic journals and presented in national and international conferences. The University [redacted] is committed to the dissemination of its research for the benefit of society and the economy and, in support of this commitment, has established an online archive of research materials. [redacted].

9. Who is organising and funding the research?

[Redacted]

10. Who has reviewed this study?

This study has been reviewed by, and received ethics clearance through, the University of [redacted] Central University Research Ethics Committee (Reference number: R57703/RE001).

11. Data Protection:

The University of [redacted] is the data controller with respect to your personal data, and as such will determine how your personal data is used in the study. The University will process your personal data for the purpose of the research outlined above. Research is a task that we perform in the public interest. Further information about your rights with respect to your personal data is available from [redacted].

12. Who do I contact if I have a concern about the study or I wish to complain?

If you have a concern about any aspect of this study, you can contact the researchers through an email at [redacted] or [redacted] or [redacted] who will do their best to answer your query. We will acknowledge your concern within 10 working days and give you an indication of how we intend to deal with it. If you remain unhappy or wish to make a formal complaint, please contact the chair of the Research Ethics Committee at the University of [redacted] who will seek to resolve the matter in a reasonably expeditious manner:

[redacted]

13. Further Information and Contact Details

If you would like to discuss the research with someone beforehand (or if you have questions afterwards), please contact:

[Redacted]

Thank you for taking the time to read this information sheet.

