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Part 2 – Participant Information Sheet for survey

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 to complete this survey because you are over 18 years of age and a family member/friend/neighbour of a person with dementia living at home.

To participate in the study, you need to be

- Providing at least 10 hours care (e.g. shopping, leisure, personal care, finance) per week to a person with dementia who lives in their own home (you can be living together with them or in your own home)
- Looking after or supporting a person with dementia who has used at least one electronic AT device (such as those described above) at home within the past year.

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. Your responses to the survey will be anonymous. We would like to interview some of the participants from the survey. If you would like to be considered for an interview, you can express your interest at the end of the survey and provide us with your contact details. You can complete the survey, even if you are not interested in participating in an interview.

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

If you are happy to take part, you can complete the survey online or if you prefer, you can ask for the survey to be mailed to you by post. It should take you approximately 30 minutes to complete the survey. The purpose of this research study is to find out what are the benefits and disadvantages of AT? What are the facilitators or barriers to using AT? What support do carers need to use AT?

5. *Are there any potential risks in taking part?*

The questions asked in the survey 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, you can stop completing the survey and close the browser window or stop the survey and return to it later.

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** submitted through the survey will be stored and examined using University of Oxford approved software.

Confidentiality will be maintained throughout this research study. If you consent to take part, you will be required to sign an informed consent form either online or on paper, if you have requested the survey to be sent to you by post. 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 thesis, publications or on any academic paper.

Personal / sensitive information such as your name, age, gender, marital status, employment status, telephone number or address details in case you agree to 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 Population Health, University of Oxford. Your personal/sensitive data, including your signed consent forms (for the postal survey) will be kept separately from survey data. 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?*

The research will be written up as a doctoral thesis. On successful submission of the thesis, it will be deposited both in print and online in the University archives, to facilitate its use in future research. The thesis will be published open access.

Additionally, the research may be published in academic journals and presented in national and international conferences. The University of Oxford 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. This archive includes digital copies of student theses successfully submitted as part of a University of Oxford postgraduate degree programme.

Holding the archive online gives easy access for researchers to the full text of freely available theses, thereby increasing the likely impact and use of that research.

9. Who is organising and funding the research?

This study is carried out as part of the DPhil (PhD) Programme in Population Health at the Nuffield Department of Population Health, University of Oxford.

10. Who has reviewed this study?

This study has been reviewed by, and received ethics clearance through, the University of Oxford Central University Research Ethics Committee (Reference number: xxx).

11. Data Protection:

The University of Oxford 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 <http://www.admin.ox.ac.uk/councilsec/compliance/gdpr/individualrights/>."

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 researcher through an email at vimal.sriram@dph.ox.ac.uk or by telephone on 01865 743762 or my supervisors Dr Michele Peters (michele.peters@dph.ox.ac.uk) or by telephone on 01865 289428 or Professor Crispin Jenkinson (crispin.jenkinson@dph.ox.ac.uk) or by telephone on 01865 289441, 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 Oxford who will seek to resolve the matter in a reasonably expeditious manner:

Chair, **Medical Sciences Inter-Divisional Research Ethics Committee**; Email: ethics@medsci.ox.ac.uk;
Address: Research Services, University of Oxford, Wellington Square, Oxford OX1 2JD

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:

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