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Health Services Research Unit, Nuffield Department of Population Health

Richard Doll Building, Old Road Campus, Oxford OX3 7LF

Experience of using Assistive Technology to support persons with dementia

Research project advisory group members wanted:

We are seeking family members and friends of persons with dementia to join the project advisory group for a doctoral student research project at the Nuffield Department of Population Health, University of Oxford.

Background:

When developing research, it is important to understand patients and carers needs to ensure that it is in the best interests of the population group under study. It is our belief that the quality, relevance and impact of our research will be improved by including the end recipients of this project in shaping and contributing to the research process.

For this reason, we would like to invite up to three people who support a person with dementia (sometimes referred to as a carer) to act as advisors on this research project. For the purposes of our study, a carer is defined as a family member, friend or neighbour who helps with tasks like regular shopping, housework, washing and dressing, going out, managing finances, keeping appointments or gives emotional support for a person with dementia. The research focuses on assistive technology in dementia and having used electronic Assistive Technology will be helpful.

Research Project:

The research project is part of doctoral research with the aim to identify how carers experience the use electronic Assistive Technology when providing support for a person with dementia.

Assistive Technology are products such as talking clocks, electronic medication dispensers, robotic vacuum cleaners, smart gas meters, communication books, GPS navigation systems, falls and motion detectors, smart phone apps and door exit alarms.

The project is being carried out by doctoral student Mr. Vimal Sriram and is supervised by Professor Crispin Jenkinson and Associate Professor Michele Peters. This research study has been granted ethical approval from the University of Oxford Research Ethics Committee under reference R57703/RE001.

What would this involve?

You would be working in partnership as part of a project advisory group with the doctoral student, the supervisors and other informal carers to advise and support the research project. The advisory group will meet twice a year. Activities will include

- Supporting the development of research materials and tools
- Supporting interpretation of study findings
- Assisting with the dissemination of research findings
- Supporting compiling materials for journals, social media and blogs.

Nature of commitment:

You do not need any previous experience, just a willingness to attend occasional meetings and to give your perspective as someone with experience of helping or assisting a person with dementia.

The position is voluntary, but support will be provided, and all travel and out-of-pocket expenses will be reimbursed.

We are expecting the project advisory group to meet twice a year at the Nuffield Department of Population Health, Health Services Research Unit, Richard Doll Building, Old Road Campus, Oxford OX3 7LF. You may also be invited to review project related questions for surveys and interview questions with other informal carers and support dissemination activities (publication in a scientific journal, writing up the research for a website etc.) planned as part of the research. This should not take more than 1-2 hours at any given time.

Support provided:

You will have the opportunity to discuss the role with the doctoral research student before you join the advisory group. If you decide to join the advisory group, we will continue to support you by:

- Sending you papers in good time before a meeting.
- Being available to discuss any queries on the phone that may arise from your participation
- Regular feedback on the progress of the project.

You can access further information on patient and public involvement in research from the following websites

- 1. http://bit.ly/Invresources
- 2. http://bit.ly/PIResearch

What we need from you:

The following are some of the qualities we hope you can add:

- An ability to be creative and supportive and advice on what matters to persons with dementia and their carers.
- The ability to manage and plan your own time and a commitment to attend meetings as agreed.

- Commitment to prepare for meetings by reading information sent to you in advance.
- To maintain confidentiality of all aspects of meetings attended and information that you may receive as part of your involvement in the advisory group.

What will you gain?

- More information about assistive technology and its impact on others in a similar situation to you.
- Learning about why research matters and an opportunity to influence research
- An insight into how health care research is carried out.
- New skills for your C.V.
- The satisfaction of contributing and helping to improve research and future services for carers and persons with dementia.

Travel:

You may be required to travel to the Nuffield Department of Population Health, University of Oxford, for the advisory group meeting. Reasonable travel expenses will be paid. Reviewing documents can be carried out from your home within an agreed period of time.

Payment:

We will discuss payment details with each individual member of the advisory group. The costs covered will include standard class rail fare, reimbursed bus fares or mileage for travel to and from the Nuffield Department of Population Health. We will also offer remuneration at the standard costs (approximately £20 per hour) as advised by INVOLVE (http://www.invo.org.uk/resource-centre/). You are completely free to accept or decline the offer.

Timeline:

This project advisory group will run from February 2019 until January 2021. You will be able to withdraw from the group at any time.

Leaving a project:

Since you are a volunteer you may leave the project at any time. As we value your input however, we would ask you to give us as much notice as possible if you intend to leave.

Accountability:

The research project supervisors will hold accountability for the project supervisory group.

Further Information:

For further information about the project you can visit the research project website on: http://bit.ly/atindementia.

If you are interested in finding out more, please contact Vimal Sriram on 01865 743762 or via email on vimal.sriram@dph.ox.ac.uk