

**ARC East of England
Stevenage Dementia Involvement Group**

GPS location devices



March 2022

Stevenage Dementia Involvement Group

Stevenage Dementia Involvement Group aims to provide opportunities for people with experience of dementia to have their voice heard and to have influence on research and the planning of new services. In each session the group will discuss a particular topic relating to living with dementia or health and social care services in Stevenage.

Stevenage Dementia Involvement Group met face-to-face on 17th March 2022. In attendance were nine people with experience of living with or caring for somebody with dementia.

Attending the group was Chloe Bennett and Becki Hadley (from the University of Hertfordshire) and Su Harvey from The Red Shed Project, Stevenage. Michael Hornberger from the University of East Anglia was the guest researcher, he joined virtually over Microsoft Teams.

The topic of discussion **GPS Location Devices** was introduced by Michael Hornberger. Michael is developing a bid for funding for a project about people with dementia using GPS location devices.

Summary of discussions

Michael introduced the topic of the bid he is developing, and group members were given a handout of the presentation. The project, if funded would look at whether GPS location devices actually reduce the occurrence of people with dementia getting lost. The project would also look at whether GPS location devices reduce carer stress, change the autonomy of people with dementia, reduce admissions to care, cost effective and what the concerns are from people with dementia and their carers about GPS location devices.

Michael invited members of the group to be involved in different aspects of the study, including as co-applicant, reviewing the application before submission and being involved in the project steering committee, if the project is funded. Eight members of the group left their names and contact details to be contacted for further information.



Thoughts about GPS location devices

The group felt positively towards GPS location devices and felt that the project Michael proposed was needed and long overdue. Nobody had experience of using a GPS location device, but one member of the group is currently looking for one to use when they go on holiday. They have found that it is difficult which device to choose as some have very short ranges and some you have to pay for a subscription. The group commented that often you have to have a mobile phone with data on to

use the devices and some people may not always keep their phone with them.

In the presentation, Michael raised that one reason the devices may not be acceptable is because they might affect the autonomy of the person with dementia using it. The group reflected that the autonomy of the carers should be considered too.

Many members of the group had used or knew somebody who had used an emergency pendulum, but these don't currently have tracking abilities. One couple have used a personal alarm watch, which was useful when somebody had fallen over outside, and the ambulance was called due to the watch being pressed.

The group thought that the more GPS location devices are used, the more familiar people will get with them.

Questions from the group

The group were interested to know how much range the GPS location devices had. One member of the group lives in a 5-story block and their neighbour has a device but it only works for a certain distance from the home. Michael informed the group that the devices could be used anywhere across the country and in remote areas. He also mentioned that the devices can pick up movement change at 5 metres and now satellites are being launched to use which will detect movement changes at an even smaller range.



Feedback from the group

The group felt that the information given out was clear and understandable. When asked if there were any negatives to the suggested study, the group said no. When asked if there were any concerns if they were asked to take part in the study the group said no, and all responded positively. It was felt that the technology would make a huge difference to people's lives. Currently carers monitor people with dementia closely and these devices might provide freedom and autonomy to the person with dementia.

The group thought that the devices could be useful in a hospital setting as well as in the community. It was also suggested that it could be useful for the person with dementia and their carer to each have a device so that if somebody stops to help a person with dementia when they get lost they can notify the carer with their location. It was also suggested that a device that the person with dementia and carer can communicate with each other on could be useful.

Conclusion and next steps

This group provided people with experience of living with dementia the opportunity to share their opinions and experiences about GPS location devices. Members of the group have been invited to be involved with the project if they would like to. For the researchers the session provided the opportunity to hear people's experiences with GPS location devices and see if people were interested in more involvement with the project. This summary report has been read and approved by the group members who attended.

The next meeting will take place in April 2022 with the topic to be confirmed.

This group is organised by researchers from the University of Hertfordshire as part of the National Institute of Health Research Applied Research Collaboration (ARC) East of England. For more information, or if you are interested in joining or visiting the group, please contact Nicole Darlington, n.darlington@herts.ac.uk or visit <https://arc-ee.nihr.ac.uk/stevenage-dementia-involvement-group>.