

Carer information leaflet – GPS Trackers in Dementia study

Background:

Dementia is a common problem in the UK and worldwide, it affects lots of people and can affect them in different ways. Often people have problems with their memories and in doing all the things that they normally like to do independently.

One way in which it can affect some people is that it can make them more likely to get lost when they are out and about. If someone with dementia gets lost outside when they are by themselves, there is a risk they could come to some serious harm. Potentially the police may need to be called in trying to find them, and they may need to go to hospital afterwards.

There are lots of things that can be done to help people with dementia not come to any harm if they get lost or wander when they are by themselves. One thing which might be helpful is something called a GPS tracker (GPS stands for global positioning system). This is a small piece of technology that can be worn as a keyring or necklace, which can let people know where the wearer is at all times.

If someone wears one of these GPS devices, if they were to get lost, someone could help find them and bring them to safety quickly by tracking where they are. The device can be easily tracked by a family member or friend using a mobile phone or computer.

We hope that using these trackers can prevent people with dementia from coming to any harm as well as giving peace of mind to those that help to look after them.

What is the study?

The aim of our research is to test whether these devices are easy to use, and whether they are helpful to the wearers and their carers.

We are aiming to recruit pairs of people (a 'wearer' and a 'carer' in each pair) to be a part of a research study to investigate this. Each pair would be given a GPS tracker that would come with software to help locate it. The trackers have batteries which need to be charged from time to time. They also use data, similar to mobile phone data. This is supplied and paid for by the research study. It should last six months. The devices would be yours to keep, even if you pull out of the study for any reason. At the end of the study period, if you wish to carry on using the device, you would have to make any payments for more data.

Why am I being asked to take part?

The Barnsley or Wakefield Memory team has identified that your relative or friend has either a diagnosis of a dementia or mild cognitive impairment, which makes them suitable for this study.

Do I have to take part?

No. If you do not wish to take part it will not affect your relative or friend's care from the Memory team in anyway whatsoever. If you do wish to take part you will be free to withdraw at any point.

What would taking part involve for me?

If you would like to take part you will receive an initial telephone or video call to go through the study information and take your consent. If it is felt that, owing to your relative or friend's memory problems, they are not able to consent to take part in this research, then we will seek consent from a family member on their behalf. It could be the case that initially they are felt to have the ability to consent, then they lose this during the study due to a deterioration in their dementia. If this occurs we will ask the participants next of kin or close family member to decide whether they should continue with the study, and if so, provide consent on their behalf.

The study will involve filling out some initial questionnaires about how you and your relative or friend find life. You will then be given the GPS tracker and shown how to set it up and use it.

We will contact you periodically throughout the study period, which is 6 months long, to see how you are getting on with the tracker. At the end of the study (6 months) we will ask you to repeat some of the questionnaires. We will also invite all carers in the study to attend a focus group (either in person or online) to discuss their experiences of using the tracker, with the opportunity to be interviewed for the benefit of the research study. Participation in the focus group and/or interviews will be completely voluntary.

At the end of the study, the tracker will be your relative or friend's to keep.

What are the possible benefits of taking part?

The main benefit of taking part is that it could help other people in the future who have a diagnosis of dementia. These GPS trackers could help keep your relative or friend safer if they were ever to get lost.

What are the possible risks of taking part?

The tracking devices may not work, or there may be problems remembering to wear them or with the software.

Will my taking part in the research be kept confidential?

To maintain confidentiality participants in the research will be allocated a study number and research data will be kept separate from identifiable information, this will only be accessed by members of the research team.

Any personal information will be anonymised at the point of analysis and you will not be identifiable in the research write up

How will we use information about you?

We will need to use information from you for this research project. This information will include your

- Name and contact details
- NHS Number

People will use this information to do the research or to check your records to make sure that the research is being done properly. People who do not need to know who you are will not be able to see your name or contact details. Your data will have a code number instead.

We will keep all information about you safe and secure.

Once we have finished the study, we will keep some of the data so we can check the results. We will write our reports in a way that no-one can work out that you took part in the study.

What are your choices about how your information is used?

- You can stop being part of the study at any time, without giving a reason up to the point of analysis of data where it would not be possible to withdraw your contribution, but we will keep information about you that we already have.
- We need to manage your records in specific ways for the research to be reliable. This means that we won't be able to let you see or change the data we hold about you.
- If you agree to take part in this study, you will have the option to take part in future research using your data saved from this study.

Where can you find out more about how your information is used?

You can find out more about how we use your information : www.hra.nhs.uk/patientdataandresearch and

- at www.hra.nhs.uk/information-about-patients/
- by asking one of the research team
- by sending an email to gps@swyt.nhs.uk / Emmanuel.nwofe@swyt.nhs.uk , or
- by ringing us on 01924 316289 / 07765 283534

What if there is a problem?

We do not expect that taking part in this research project will cause any problems, and we hope that you, and the person who cares for you, will gain some satisfaction from taking part. However, should you have any concerns, complaint, or suffer from any unforeseen harm as a result of involvement in this research, in the first instance, please speak to the Contact Person named at the bottom of this information sheet. If your concerns cannot be resolved satisfactorily by talking to them, you can complain formally through the National Health Service complaint mechanisms. Details of how to do this can be obtained from the Contact Person below.

What will happen to the findings of this study?

The findings will be used to make recommendations to the NHS and Local Authorities about whether GPS trackers could be useful for people with

dementia. They will be published in social care and medical journals but

nothing that could identify you, or the person you care for, will be included in any report or publication. We will send you a summary of the results as soon as they are published.

Who is organising and funding the study?

The study is being organised by the NHS trust which is responsible for your treatment (South West Yorkshire NHS Foundation trust). The funding for the GPS tracker devices has been provided by South Yorkshire Police. Some additional funding for the study has come through the University of Huddersfield

Who has reviewed the research study?

This study has been reviewed by an NHS Research Ethics Committee which has given approval for the study to be run in the NHS. It has also been peer reviewed the University of Huddersfield.

What happens next?

If you are interested in this study, we will contact you to answer any questions and arrange for someone to come and have a more in-depth conversation with you over the phone or video messaging software. If you then confirm that you are still interested you will be asked to sign a consent form to confirm this. If you want to think about it for longer, or discuss it with friends or relatives, then you can delay your decision.

Thank you for considering taking part in this research study and taking time to read this information sheet.

Contact person:

If you would like any further information about this study, then please contact:

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