

Participant Information Leaflet

Project Title

Using Digital Technology in the Early Detection of Neurodegenerative Diseases: the perspective of individuals living with mild cognitive impairment or dementia and their families.

Project background and aim:

The aim of this study is to understand if people living with dementia and their close family would be happy to wear a fitness tracker, a sleep headband and use two smartphone apps for short periods. The devices in this study collect information about people's memory and thinking abilities, physical activity, sleep, heart rate and mood.

This study is part of the Early Detection of Neurodegenerative Diseases (EDoN) Initiative, which is a larger project that aims to develop a way to detect conditions such as dementia years before symptoms occur. Today, dementia and similar conditions are diagnosed when symptoms such as memory loss start. This study aims to understand if these types of technology would be useful for future research. This study will **not** be able to estimate your risk of developing dementia.

As such, we want to speak to people with a diagnosis of mild cognitive impairment (MCI)* or dementia and their family members about using wearable technology, such as smartphones or Fitbits. These discussions will inform future research on early detection of dementia and similar conditions.

Volunteer Criteria

We are interested in speaking to people:

- living with a diagnosis of MCI and their close family
- living with a diagnosis of dementia and their close family
- with the capacity to provide informed consent
- with or without prior experience of wearable technology
- who own a smartphone
- have home WiFi

What does the activity involve?

This is a two-week study. If you agree to take part, a member of the research team will contact you to check your smartphone is suitable. A set of digital devices will then be sent to you, which includes a Fitbit, a Dreem headband and 2 smartphone apps. Instructional booklet guides and video tutorials will be provided to help you set up and use these digital devices. Once you receive the devices a member of the project team will be in touch to answer any questions you may have. You will then be asked to wear/ use the digital device for up to 14 days and to keep a daily diary of your experiences. We will not be reviewing any data from these devices as we are only interested in your experiences of using the devices. During use of the devices you will be able to review all data that is routinely collected by the devices such as step count, heart rate or sleep quality, for your own interest.

At the end of the two weeks, we will invite you take part in a short questionnaire and an informal interview (30-40 minutes) with a member of our project team. The interview will be held via a videocall at a time suitable for you and the questionnaires will be available online through a web link. A member of the project team will ask you questions related to your experiences of using the device, such as whether it was easy or enjoyable to use, comfortable and whether you faced any issues. We will also ask you questions about your age, approximate date of MCI or dementia diagnosis but you do not need to answer these if you would prefer not to. At the end of the activity, we will ask you to return the device using a pre-paid courier service. All your data will be removed from the device following the end of the study.

Setting up	<ul style="list-style-type: none"> You will receive a Fitbit, Dreem headband and 2 smartphone apps Instructional guides will be provided A chat with a member of our team to answer any questions and see how you are getting on
2 weeks	<ul style="list-style-type: none"> Use/ wear the digital devices every day Keep a daily diary of your experiences
Tell us about your experience	<ul style="list-style-type: none"> Informal interview (20-30 minutes) with a member of our project team A short online questionnaire

What do these devices do?



Fitbit is a fitness tracker that you wear as a wristband. It has sensors that detect physical activity, like movement, heart rate and sleep patterns. You will download a smartphone app that will show you information about your physical activity, like how many steps you do in a day. We will not collect this activity information when you wear the fitness tracker.



Dreem is a headband which you wear when you are sleeping at night. It can sense how long you spend in different stages of sleep (eg, dreaming) and how often you wake up during the night. You will download a smartphone app which will show you information about your sleep patterns and sleep stages. You will need to charge the Dreem every day, and press a button on your phone before you go to sleep to “pair” the phone with the headband. We will not collect information about your sleep whenever you use the Dreem.

Mezurio



Mezurio is a smartphone app that you will be asked to use every day for a select number of days, as outlined in the schedule below. It involves different memory tasks and brain puzzles, but will never take more than about ten minutes per day. You will also be asked about how you are feeling each day. We will not collect any information from this app.

Longevity



Longevity is a smartphone app that will run in the background of your phone. This app measures finger motions that you use on the touch screen of your phone, such as typing speed and swiping motion. Once you have turned Longevity on, you will not need to do anything else with it. We will not collect any information from this app and the app will not collect personal information, such as what you are typing or who you are talking to.

What are the benefits of taking part in this activity?

By taking part in this activity you will help the EDoN project team understand how acceptable and usable wearable devices are, which will inform our future research. You will also receive a £20 Marks and Spencer's voucher.

Will my taking part in this activity be kept confidential?

If you decide to take part, your data that you have provided through the questionnaire and interview will be kept confidential. You will not automatically be expected to take part in any future engagement activities. We will require your address so that we can send the digital tools to you. We will only keep this address for as long as it is necessary to send and collect the devices from your home. You will only be identified to the researchers by a unique study number, and all data will be kept securely. You will not be identified in any reports, publications or presentations that include your data.

You will be provided with a participant email address (e.g. participant123@edon.initiative.org) which will contain no personal identifiable information. A password will also be provided to create an account on some of these devices. Information you provide in the Fitbit app and Dreem app will not be accessed by us but will be shared with third parties such as the Fitbit company. This data will not include information in which you could be identified, but it does include information such as your gender, age and step count. If you feel uncomfortable at any point sharing your data with third party companies you can uninstall the app on your phone which will stop data collection.

What will happen to the results of the engagement activity?

We will use the information collected from the questionnaire, interview and diary to ensure enough support is provided to those using the devices, help select digital devices for use in future research and the outcomes will be communicated in publications.

What if something goes wrong, who can I contact?

You will be given full instructions about how to use the digital device via written guides and video links. If you have any problems with using the digital device you can approach a member of the project team:

- Sarah Wilson
Email: sarah.wilson@newcastle.ac.uk
Phone: 07916066660.

To report any formal complaints relating to this study, contact:

- Sarah Slight
Email: sarah.slight@newcastle.ac.uk

Thank you for reading this information sheet and for considering to take part in this research study.

* Mild Cognitive Impairment (MCI) is a diagnosis given by a healthcare professional and means that your mental abilities (cognition) are not as good as they used to be. This usually refers to problems affecting memory, but could involve a change in problem solving, thinking, attention, concentration, language or visual ability.