

The Wearable Clinic

Exploring and quantifying preferences of people with long term conditions towards the use of wearable technologies to support collaborative management

Participant Information Sheet: Focus Group

This PIS should be read in conjunction with [The University privacy notice](#).

You are being invited to take part in a research study

Before you decide whether to take part, it is important for you to understand why the research is being conducted and what it will involve. Please take time to read the following information carefully and discuss it with others if you wish. Please ask if there is anything that is not clear or if you would like more information. Take time to decide whether or not you wish to take part. Thank you for taking the time to read this.

What is the Wearable Clinic?

An increasing number of people live with long-term physical and mental health conditions. People can have a role in managing their own health and care, on their own or in partnership with others. The Wearable Clinic is a set of wearable 'smart' devices (e.g. watches, phones and tablet computers) and electronic software tools designed to help people with long term conditions to better manage their health in daily life. We want to understand how to support people to improve their knowledge, skills and confidence in order to manage their own health and care. We also want to know what features of the Wearable Clinic might be more acceptable and valuable for different types of people.

Who will conduct the research?

The study is being led by Professor Niels Peek at the University of Manchester. It will be jointly conducted by a team of researchers from the Centre for Health Informatics at The University of Manchester and the Centre for Health Economics at the University of York.

What is the purpose of this study?

The aim of this study is to understand what people think about using the Wearable Clinic to help them manage more of their own health and care. We want to know what aspects of support and care people would value the most (and the least) and to understand their reasons for this.

Why have I been chosen?

You have been asked to participate in the research because you have indicated that within the last 2 years, you have been affected by one of the conditions that we are interested in for this study - either chronic kidney disease (stage 3a onwards) or serious mental illness (including schizophrenia, bipolar disorder and psychosis).

What would I be asked to do if I took part?

If you decide to take part in the research, you will be asked to complete a short questionnaire about you (e.g. your age, gender etc.), your personal circumstances (e.g. employment status) and your experience with your health condition. You will then be interviewed by researchers alongside others as part of a group (known as a focus group). This will be alongside 8-10 other people with the same health condition to get your views on different ways of supporting you to manage your own health and care. You will be asked about the ways in which you currently manage your condition and the impact on your daily life. You will also be asked your opinions, whether positive or negative, about different ways of managing your own health using digital technologies.

We expect each focus group to last up to 2 hours and to be held at a convenient location in central Manchester during weekdays (between 10-4). We will ask your permission to record the interview using a voice recorder.

What will happen to my personal information?

In order to undertake the research project we will need to collect the following personal information/data about you:

- Brief details about you, your personal circumstances (e.g. employment status) and experience with your health condition.
- An audio recording of you taking part in a group discussion about different ways of managing your own health using digital technologies.
- Your contact details, so that we may arrange your participation and/or send you a summary of findings, should you wish.

Only the research team will have access to this information.

We are collecting and storing this personal information in accordance with the General Data Protection Regulation (GDPR) and Data Protection Act 2018 which legislate to protect your personal information. The legal basis upon which we are using your personal information is “public interest task” and “for research purposes” if sensitive information is collected. For more information about the way we process your personal information and comply with data protection law please see our Privacy Notice for Research Participants (<https://bit.ly/2s4birO>).

The University of Manchester, as Data Controller for this project, takes responsibility for the protection of the personal information that this study is collecting about you. In order to comply with the legal obligations to protect your personal data the University has safeguards in place such as policies and procedures. All researchers are appropriately trained and your data will be looked after in the following way:

- We will only use devices that have been encrypted by University of Manchester and approved for research use to make recordings.
- Voice recordings will be typed up as 'transcripts' by a professional company, approved by the University of Manchester. They will delete the recordings once they have been typed up.
- You and the other participants will be assigned a unique code known only to the research team. The 'key' connecting participants with codes will be password protected and kept separately from other data.
- The researchers will anonymise transcripts as soon as practical by using the unique code and removing any names or other details that could lead others to identify you. These anonymised versions will be used to conduct the analysis and will be kept separately from any data we hold which could identify you, such as voice recordings and consent forms.
- Data from the study - including voice recordings, transcripts and questionnaires – will be kept in secure, electronic, cloud-based storage (University of Manchester research data storage). Consent forms will be kept in locked filing cabinets on our premises. Data will be kept for a period of 5 years after the date of any publication which is based on it. After this period it will be destroyed securely.

You have a number of rights under data protection law regarding your personal information. For example you can request a copy of the information we hold about you, including audio recordings. This is known as a Subject Access Request. If you would like to know more about your different rights, please consult our [privacy notice for research](#) and if you wish to contact us about your data protection rights, please email dataprotection@manchester.ac.uk or write to The Information Governance Office, Christie Building, University of Manchester, Oxford Road, M13 9PL. at the University and we will guide you through the process of exercising your rights.

You also have a right to complain to the [Information Commissioner's Office](#), Tel 0303 123 1113.

If I choose to take part in this study, will my participation be kept confidential?

Your participation in the study will be kept confidential. To check that the study is being carried out correctly, people from The University of Manchester, or other regulatory authorities such as the NHS, may look at the research documents, including your information. This is only for audit purposes. Other than this, only the research team will have access to this information.

The only exception to this is if you say something which leads us to believe that you are at risk of serious harm, to yourself or others. These circumstances are rare, but if it did happen, we would be required to disclose this information, and your participation, to a third party (e.g. emergency services). In this situation, the researcher would try to discuss this with you first. However, please be assured that these are rare circumstances.

Although the researchers will make every effort to maintain confidentiality, the nature of focus groups means that we cannot guarantee confidentiality. We kindly ask all participants to respect the privacy of fellow participants and not repeat what is said in the focus group to others.

Agreeing to voice recordings is an essential condition of taking part in this study. If you are not comfortable with this, you can withdraw from the study at any time. To protect confidentiality, we will arrange for recordings to be typed up and anonymise the transcripts as soon as practical, as described above.

We plan to publish the results of this research in reports, on websites and in scientific journals (online and in print), and give talks at scientific meetings so that others may learn from our findings. We will remove all names, specific locations and other identifying information before writing reports. We may include things that you said during discussions as quotes, but these would not include your name or any other information that could lead others to identify you.

What happens if I do not want to take part or if I change my mind?

It is up to you to decide whether or not to take part. If you do decide to take part you will be given this information sheet to keep and be asked to sign a consent form. If you decide to take part you are still free to withdraw at any time without giving a reason and without detriment to yourself. However, it will not be possible to remove your data from the study once recording of the focus group has started. This does not affect your data protection rights.

Will I be paid for participating in the research?

You will also receive £30 in gift vouchers and reasonable travel expenses up to £10 in cash (receipts required).

What is the duration of the research?

The focus group discussion will last up to a maximum of 2 hours. Up to 30-45 minutes before the focus group starts, the venue will be open for you to register, get refreshments and introduce yourself to the researchers and fellow participants.

Will the outcomes of the research be published?

If you are interested in the findings, then we can send you a copy of the results at the end of the study. If you take part, we will get your permission for this in writing on the study consent form. Alternatively, you can email the researcher at:

lamiece.hassan@manchester.ac.uk

Who has funded this study?

This Study is funded by the Engineering and Physical Sciences Research Council. The University of Manchester has responsibility for managing the research.

Who has reviewed the study?

This study has been reviewed by the University of Manchester Research Ethics Committee 4.

What if I want to make a complaint?

Minor complaints

If you have a minor complaint then you need to contact the researcher in the first instance:

Dr Lamiece Hassan 📞 0161 2751160 ✉️ lamiece.hassan@manchester.ac.uk

Formal complaints

If you wish to make a formal complaint or if you are not satisfied with the response you have gained from the researchers in the first instance then please contact:

The Research Governance and Integrity Manager, Research Office, Christie Building, University of Manchester, Oxford Road, Manchester, M13 9PL, by emailing: research.complaints@manchester.ac.uk or by telephoning 0161 275 2674.

What do I do now?

If you have any queries about the study or if you are interested in taking part then please contact the researcher:

Dr Lamiece Hassan 📞 0161 2751160 ✉️ lamiece.hassan@manchester.ac.uk

This Project Has Been Approved by the University of Manchester's Research Ethics Committee [ref: 3263]