





Barriers and facilitators to EQUitable pArticipation and engagement in research using digiTal mEthods: A qualitative exploration with the public, patients, and staff

Work Package 1: Participant Information Sheet

Introduction

Thank you for taking the time to consider being involved in this study. To help you decide if this is something you might be interested in doing, this sheet will explain why the research is being done and what it means for you. Your participation in the study is voluntary and you can take the time to ask questions before you decide whether to take part. You can discuss the information on the sheet by contacting Cherish Boxall.

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About the study

The option for participants to use digital technology (including smartphone applications, websites and video calls) to take part in research has increased very quickly over the past few years. It's important to understand if the use of digital technology helps or makes it difficult for people to sign up and engage in the research they want to be a part of.

The purpose of this study is to discuss your experiences and preferences of using (or not using) digital technology in the research you're taking part in so that future research may be easier and more convenient to participate in.

The study is being run by the University of Southampton and is funded by the National Institute of Health and Care Research (NIHR), which is the main funder of research in health and social care.

Summary of information

- You will be compensated £10 for your time once the interview is complete
- You've been invited to take part in an interview to discuss your views and experiences of the use of digital technology in research
- Participation is voluntary and you will not be directly affected if you don't wish to take part
- The interview will last for up to an hour over the phone or video call (your preference) and will be recorded so it can be typed into the written word and looked at with other interviews
- Your name, age, or any other information that could identify you will be replaced with a study ID, so your participation is kept confidential.
- All data related to the study is stored on a password-protected document on a secure University of Southampton network with restricted access
- Anonymised findings from the study may be presented at a conference, published in journals or used for other educational purposes.

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Why have I been invited to take part?

You have been invited to take part because you have been involved in a research project that offers the use of digital technology (e.g. provide consent, receive/provide information and/or communicate).

You may have chosen to use digital technology or other methods such as using pen and paper, I'd like to talk to you to understand your thoughts and experiences of using or deciding not to use digital technology in the research you're taking part in.

What will happen if I take part?

If you consent to take part in the study, you will be invited to take part in an interview by phone or video call (your preference). The interview will last up to 1 hour and you will be asked questions such as:

"Where would you like to see digital technology used/ not used to make it easier for you to participate in research?"

You may be invited to interview you again to help provide information on new questions that develop during the study, your participation in a potential follow-up is completely voluntary.

You will be asked to complete a demographic form where one has not already been completed. This will include age, gender, ethnicity, postcode and education so we can see if there are similarities or differences between groups of people.

Will I be compensated for my time?

To thank you and as compensation for your time, you will receive a £10 voucher to your home or email address on completion of the first interview.

What are the pros and cons of taking part?

There are no direct pros or cons to taking part in the interview. The process may help you reflect on your research experience.

What will happen if I can't make or change my mind about the interview?

If you're unable to make a scheduled meeting please contact the lead researcher.

You can change your mind and stop participation before or during the interview without giving a reason and without consequence. If you decide to stop taking part during the interview, all information received to that point will be used in data analysis unless requested otherwise. If you withdraw after the interview, where data analysis has already begun, it may not be possible to withdraw your data because it would have been anonymised (i.e. identifying information removed) and combined with other people's interview data.

What will happen to the information collected?

Video or audio (your preference) recording will be taken using a GDPR-compliant recording feature on a web call platform (i.e. Microsoft Teams). On completion, identifiable information will be deleted and replaced with a unique identifier. The interview recordings will be securely copied to and stored on the University network within 24 hours of completion and deleted from the local computer hard drive and/or web call server. The recording of the interview will be typed up by a University approved company so that similarities and differences can be seen across different interviews. Transcripts will be transferred via secure messaging. All transcripts will be checked for errors, once the transcription has been error checked, the original interview recording will then be deleted.

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A copy of the anonymised (all names of people and locations will be removed) transcripts will be kept for up to 10 years (following the University of Southampton Research Data Policy). To maximise the usefulness of the data collected, it may be shared with other researchers, charities, or NHS trusts, but this will always be in a completely anonymised form.

Will my taking part in this study be kept confidential?

All personal and study information, including your contact details, will be stored securely on the University of Southampton network which is password-protected with restricted access. In the case of an inspection or audit of the study, personal data may be looked at by individuals from regulatory authorities. All material used to share study findings, including quotes, will be anonymous. The recording analysed by the researcher will be listened to/ watched in a private space.

What will happen to the results of the study?

The (anonymised) results may be presented at conferences, published in journals, and used for educational purposes. Please ask us if you would like to receive a copy of the findings.

Who has approved the study?

The study has been reviewed and approved by University Research Ethics Committee and the Health Research Authority (Ref 23/PR/0625).

What if there is a problem?

If you have any concerns you can contact the study team who will be happy to answer any questions. If you are still not happy about anything or want to complain you can contact the Research Governance office at the University of Southampton (email rgoinfo@soton.ac.uk or phone 023 8059 5058).

What do I do know?

If you would like to take part or would like more information, please contact Cherish Boxall on

Email: equate@soton.ac.uk Telephone: 0782 478 6441

If you do not want to take part then you don't need to do anything but it would be very helpful if you could share your reason with the lead researcher.

Thank you

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