

 

**Improving diversity in Southampton Clinical Trials Unit Research**

**Information Sheet**

Thank you for taking an interest in this study.

The information below gives more details about the project. Please get in contact with us at any time if you have any questions.

**Summary points**

* The project aims to improve the ethnic diversity of people taking part in clinical research by working with ethnically diverse communities to design patient-facing materials and an online forum
* Participation in health and care research from different populations is important to help people receive treatment that is effective
* You can take part in one to all of the eight group workshops of up to 18 people
* Each workshop will be up to 2 hours with breaks
* Your involvement in the project will not be shared unless you request otherwise
* Your time will be reimbursed at £25 per hour of workshop
* Travel and parking expenses will also be reimbursed

**What is the purpose of the project?**

The Southampton Clinical Trials Unit is a place where researchers study new medicines and treatments that could help people who need healthcare. Sometimes, not enough different kinds of people join these studies, particularly those from non-White British populations, which can make it hard to understand if and how new treatments work for everyone.

To fix this, we want to work with people from different communities to make materials that everyone can understand. They'll also make a safe place online where people can ask questions about the studies. This way, more people from different backgrounds can join in and help make new health treatments.

**Why have I been asked to be part of the workshops?**

You have been asked to be involved in the workshops because you are from an ethnic group other than White-British, and we would value your views on how we communicate our research studies better to different ethnic groups.

**Who will run the workshops and where will they be held?**

To help support the group and make sure that everyone has a chance to share their thoughts, workshops will be led by people who work at Southampton Clinical Trials Unit. Even though there will be plans for what to talk about, it will feel casual and easy-going. The workshops will happen in places that are easy for everyone to get to, like community centres or buildings at the University of Southampton. We’ll let you know where each workshops will be held before the event.

 **How many workshops will there be, and do I have to take part in all the workshops?**

We are planning to hold up to 8 in-person group workshops over 4 months (April 2024 – July 2024). They will last up to 2 hours, with breaks as and when needed. You don't have to come to all of them if you don't want to. Before each workshop, we'll tell you what we're going to talk about so you can decide if you want to come. If something comes up and you can't make it to a workshop, that's okay too. You don't have to tell us why you can't come.

**What will the workshops involve?**

In the workshops, there will be about 16 people. We'll start by introducing everyone so you can meet them. Then, we'll ask for your thoughts on the words and pictures we use in our research information, like letters and videos. Your ideas will help us make these things better for everyone. We'll also ask for your help to make an online place where people can ask questions about research. This will make it easier for different kinds of people to join in if they want to.

**What are the possible benefits or risks of taking part in these workshops?**

There are no risks; however, if you feel uncomfortable at any time you can leave whenever you want. Your time will be reimbursed at £25 per hour of workshop you attend. In addition, money you need to spend on travel will be reimbursed at the University standard rate of [university milage allowance]. Your total parking amount will also be reimbursed.

**How do I receive payment/ reimbursement?**

We will ask you whether you prefer to receive vouchers or bank payments for your reimbursement after each workshop you attend.

**Will my participation be confidential?**

We'll ask for your name and contact info (like email or phone number) so we can tell you about the workshops. Don't worry, we won't use your name in any notes or reports from the project. Your information will be kept safe with a password on university computers that have a high level of protection. We'll also ask how old you are, what ethnicity you are, your gender and if you’re willing, job role and/or post code to help us understand who's in our group. We won't tell anyone outside our team at the University of Southampton about your involvement. If you want, we might ask if you want to join more projects in the future. If you say yes, we'll keep your information on the University computers for up to 3 years after the project has ended. If you say no, we'll delete it when the project is finished. (At the end of this sheet, there is more detail about how we keep your information safe)

**Will what I say in this project be kept confidential?**

We will not be recording the workshops. People supporting the workshop will write notes of what we discussed, but names will not be used and the notes won’t be shared outside of the project team.

**What will happen to the results of the project?**

You'll see everything we find out from the workshops. We'll use what we learn to make guides and papers that help other groups do better with their research studies.

**Who is running the project?**

The Southampton Clinical Trials Unit, based at the University of Southampton are running this project.

**Who has reviewed the study?**

The study has been reviewed by an ethics committee at the University of Southampton.

**Contact details**

For further information or assistance during the study, please contact: Jacqui, Cherish or Liz on [insert telephone number and email].

**Thank you**

|  |
| --- |
| **Data Protection Privacy Notice****How will we use information about you?**For the purposes of data protection law, the University of Southampton is the ‘Data Controller’ for this study, we will need to use information from you for this research project. Only members of the Project team and responsible members of the University of Southampton may be given access to data about you for monitoring purposes and/or to carry out an audit of the study to ensure that the research is complying with applicable regulations. Individuals from regulatory authorities (people who check that we are carrying out the project correctly) may require access to your data. All of these people have a duty to keep your information, as a stakeholder Group memeber, strictly confidential.This information will include your name, contact details, location and email address, age, gender, ethnicity, current occupation and education level. People will use this information to support the running of the workshop or to be able to describe who was involved in the project 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. 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 project.**Where can you find out more about how your information is used?**You can find out more about how we use your information:* by sending an email to University’s Data Protection Officer (data.protection@soton.ac.uk).
* by asking one of the research team or from our [general privacy policy](https://www.southampton.ac.uk/about/governance/policies/privacy-policy.page).
* by sending an email to rmgroup@soton.ac.ukor by ringing us on [phone number 02381 205454.

The University of Southampton will keep identifiable information about you for 3 years after the study has finished after which time any link between you and your information will be removed. The Data we hold will be pseudonymised, which means that your age, gender ethnic group and occupation will be linked to a number not your name.  |

PRINTED – Your name Signature Date