PARTICIPANT INFORMATION

Version 2.0 dated 30/09/2024

This project is called UCAN - helping people with a learning disability access urgent and emergency care.

Email Dale Nixon if you have any questions: d.nixon@keele.ac.uk. Dale is the Learning Disability Nurse leading the UCAN project.

1. Invitation

We would like to invite you to take part in an interview for the UCAN project. Taking part is voluntary (your choice). Before you decide, we would like to tell you more about the project and what you will be asked to do. The following information will help you decide if you would like to take part. It should answer any questions you have, but if not, you can email or call project lead Dale Nixon on 01782 733265. Please feel free to talk to others about taking part in the UCAN project.

2. Project Summary

The UCAN project will support people with a learning disability to access urgent and emergency care. This is important because in times of ill health it can be difficult to do this. People with a learning disability are more likely to experience poor health. We are looking for people who have a learning disability to take part in our focus groups. Taking part will involve attending two focus groups. Each focus group will take about 45-60 minutes of your time.

Facts about taking part

3. What is the purpose of the project and the focus groups?

The UCAN project will co-produce (create together) a tool (a way to make it easier) to help people with a learning disability get access to urgent and emergency care. We need work together with people with lived experience of a learning disability to co-produce a new tool.

4. Why have I been invited?

We are seeking people with a learning disability who are aged 18 or over. We want to work with people who can talk about their experiences.

5. Do I have to take part?

Taking part in the focus groups is entirely your choice. It is up to you to decide whether or not to take part. If you agree to take part, you will be asked to digitally consent. You may withdraw (stop taking part) by sending an email at any point up to the first focus group. After this it will not be possible to withdraw your data.

6. What will happen to me if I take part?

You will be asked to provide some information such as your email address or phone number so that we can get in touch. We will agree on a date and time for the focus groups. The focus groups will take place using Microsoft Teams. During the focus groups you will be asked to talk about how to make it easier to get access to urgent and emergency care. Each focus group will take about 45-60 minutes of your time.

7. Expenses and payments

There is reimbursement for your time. You will receive a £20 voucher for taking part in each focus group.

8. What data will be collected?

Before you take part in a focus group, we will ask you to provide your name, email address or phone number and some other information about you (e.g. your age). During the focus groups we will record the discussion and save anything we create together.

9. What are the possible disadvantages of taking part?

Sometimes it can be difficult to work in a group setting.

10. What are the possible benefits of taking part?

You may not receive any direct personal benefits from participating, but our new tool (a way to make it easier) will help people to get access to urgent and emergency care.

Confidentiality and Withdrawal

11. Will my data be kept confidential?

Some personal information (such as your contact details) will be collected from you.

Data, including personal information, will be held in line with the Keele University [retention schedules](#) and [policy](#). All data will be stored securely in the Keele University cloud storage (Microsoft Forms, Teams or OneDrive). When it is no longer required, the data will be securely destroyed.

The raw data (which would identify you) will not be shared with anyone outside the project team unless you agree. The only exception to this would be in the event of a safeguarding concern.

Anonymous data (which does not identify you) will be shared. At the end of the project, we will share the anonymous focus group transcripts with open access in the [Keele Data Repository](#). This will allow others learn about how we created the new tool. You cannot opt out of sharing the group transcript. Anonymous data will be presented at academic conferences, used in project reports and published in academic journals. It could also be made available to the funder of the project.

12. What will happen if I don't want to carry on?

You may withdraw (stop taking part) by sending an email at any point up to the first focus group. After this it will not be possible to withdraw your data.

You can withdraw (stop taking part) in the focus group session at any point. You do not have to give a reason to stop taking part. We will not be able to remove your data from the group transcript.

Further Information and Contacts

13. What if there is a problem?

If you have a query, concern or complaint about any aspect of this project, in the first instance you should contact Dale Nixon (d.nixon@keele.ac.uk). If your concern is not resolved by the project team, you should contact the Faculty of Medicine and Health

Sciences Research Ethics Committee (health.ethics@keele.ac.uk) quoting project reference 0921.

14. Who is funding the project?

This project is being funded by the [RCN Foundation](). The RCN Foundation is an independent charity who support nurses to improve the health and wellbeing of the public.

15. Who has reviewed the project?

Projects involving people are reviewed by an ethics committee. They make sure that the project team will take care of everyone who takes part in the project. The UCAN project has been reviewed by the Keele University Faculty of Medicine and Health Sciences Faculty Research Ethics Committee (Project Reference: 0921).

Thank you

Thank you for taking time to read this information and for considering taking part in the UCAN project. If you do agree to take part your consent will be confirmed digitally on the next page. To save a copy of this information you can right click to print or save.