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 interviews. Taking part in an interview will take about 45-60 minutes of your time.

Facts about taking part

3. **What is the purpose of the project and the interviews?**

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 to speak to people with a learning disability who have recently accessed urgent and emergency care. We would like to understand their experiences. The interviews are the second stage of the project. They will be followed by focus groups with people with a learning disability to co-produce the 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 speak to people who have recently used urgent and emergency care services about their experiences.

5. Do I have to take part?

Taking part in an interview 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 one week after your interview has taken place.

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 your interview. Interviews will take place using Microsoft Teams. During your interview you will be asked questions about your experiences of using urgent and emergency care services. This 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.

8. What data will be collected?

Before your interview we will ask you to provide your name, email address or phone number and some other information about you (e.g. your age). During your interview we will record your answers to the open questions asked.

9. What are the possible disadvantages of taking part?

You may be asked to recall some unpleasant experiences. It is your choice what to share with us during your interview.

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 interview transcripts with open access in the Keele Data Repository. This will allow others learn about your experiences. You can opt out of sharing your 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 can stop your interview at any time. You can withdraw (stop taking part) by sending an email at any point up to one week after your interview has taken place. You do not have to give a reason to stop taking part.

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.