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 the UCAN project consultation survey. 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 seeks to 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 professionals across health and social care to take part in our consultation. Taking part in the consultation will take about 10 minutes of your time.

Facts about taking part

3. What is the purpose of the project and the consultation?

The UCAN project has co-produced a tool (a way to make it easier) to help people with a learning disability get access to urgent and emergency care. We need professionals across health and social care to review the usefulness and acceptability of the newly created tool and offer feedback.

4. Why have I been invited?

We are seeking professionals across health and social care to take part in our consultation. We would like at least 50 professionals to take part in the consultation.

5. Do I have to take part?

Taking part in the consultation is entirely your choice. It is up to you to decide whether or not to take part. If you agree to take part in the consultation, you will be asked to digitally consent. You may withdraw (stop taking part) before pressing the submit button by closing your browser window or tab.

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

You will be asked to review the newly created tool that has been co-produced as part of the UCAN project. You will then be asked to rate and comment on the usefulness and acceptability of the tool and offer feedback. This will take about 10 minutes of your time.

7. Expenses and payments

There is no reimbursement (payment) for your time. However, you can opt to take part in the prize draw for a chance to win a £50 voucher.

8. What data will be collected?

We will collect your anonymous answers to open and closed questions about the new co-produced tool.

If you opt to take part in the prize draw, we will ask you to provide your name and email address or phone number so that we can get in touch if you win.

9. What are the possible disadvantages of taking part?

We do not anticipate any disadvantages from taking part in the consultation.

10. What are the possible benefits of taking part?

You may not receive any direct personal benefits from participating, but those using the new tool will benefit from your input to the consultation.

Confidentiality and Withdrawal

11. Will my data be kept confidential?

Limited personal information (contact details) will be collected from consultation participants who opt into the prize draw. You do not have to take part in the prize draw and can just take part in the anonymous consultation if you wish.

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 prize draw entry data (which would identify you) will not be shared with anyone outside the project team unless you agree. The prize winner will be chosen at random (using a random number generator) by an independent professional.

Anonymous data (which does not identify you) will be shared. At the end of the project, we will share the anonymous consultation survey responses with open access in the Keele Data Repository. This will allow others to verify the consultation. You cannot opt out of sharing your anonymous responses. 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 do not have to give a reason to stop taking part in the consultation. You can stop taking part in the consultation before pressing the submit button by closing your browser window or tab. Please note that it will not be possible to withdraw your data after submission.

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.