

PARTICIPANT INFORMATION

Version 2.0 dated 30/09/2024

Our project is called UCAN. We want to help people with a learning disability to access urgent and emergency care such as 999 or the doctor during the night-time.



Dale is a Learning Disability Nurse. He is the UCAN project leader. He will be able to answer any questions you have. You can get in touch with Dale by using his email address d.nixon@keele.ac.uk or by telephone on 01782 733265.



Would you like to take part in the UCAN project?

We think it is important to talk to people with a learning disability about their lives.



We want to get this right. It is important that we listen carefully to what you say.



Taking part is your choice. We want to tell you more about the UCAN project. We want you to understand what you will be asked to do.



If you have a question or are unsure about taking part, you can contact Dale.



You can get in touch with Dale by using his email address d.nixon@keele.ac.uk or by telephone on 01782 733265



Talking to other people can help you decide about taking part in the UCAN project.



All about the project

The UCAN project will help people with a learning disability. It will help people to access urgent and emergency care services such as 999 or the doctor during the night-time.



People with a learning disability are more likely to suffer poor health. When you are unwell it can be difficult to get help.



We are looking for people to take part. If you have a learning disability you can take part.



Taking part will take some of your time. We will ask you to join us for two group chats (focus groups). Each time we meet together it will take no longer than 60 minutes.



All about taking part

Why are we doing the project?

The UCAN project is working with people with a learning disability. Together we will create (co-produce) a tool. A tool is a way to make things easier.



We want the tool to help make it easier to get access to urgent and emergency care such as 999 or the doctor during the night-time.



Why are group chats (focus groups) needed?

A group chat (focus group) is a way of working together.



It lets us listen and talk about our experiences.



A group chat (focus group) helps us work out together what can help people with learning disabilities.



We want to make a new tool that can make things easier. We want to help make it easier to get access to urgent and emergency care such as 999 or the doctor during the night-time.



Why have I been asked to take part?

We are looking for people to take part our group chats (focus groups). If you have a learning disability you can take part. We are looking for people who can talk about their experiences. We want to work together in the group chats (focus groups) to make a way to make things easier (a new tool).



Do I have to take part?

No. Taking part is your choice. It is up to you to decide.



If you want to take part, you will be asked to say that you agree (consent). You can give your consent digitally using your computer, tablet or phone.



You can stop taking part (withdraw) before the first group chat (focus group). To stop taking part you will need to send an email to us.



What will happen to me if I take part?

We will need some information such as your email address or phone number. This is so that we can get in touch.



We will check with you when it will be best to talk. We will agree the best day and time with you and the other people taking part.



We will use Microsoft Teams to speak together.



In the group chat (focus group) we will ask some questions. We will ask everyone to take turns to speak.



We want to understand what will make it easier to access urgent and emergency care services such as 999 or the doctor during the night-time.



Taking part will take some of your time. We will ask you to join us for two group chats (focus groups). Each time we meet together it will take no longer than 60 minutes.



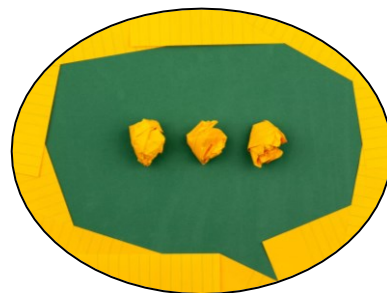
Expenses and payments

We will give you a £20 voucher each time you take part.



What data will be collected?

We want to collect important information (data). We will ask everyone who is taking part some questions.



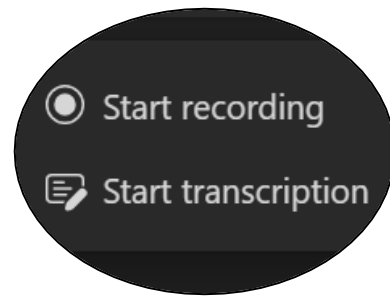
We will need your name and email address or phone number (contact details) so we can get in touch. We will ask you for some other information about you such as your age.



During the focus groups we will ask open questions. An open question lets you think of an answer.

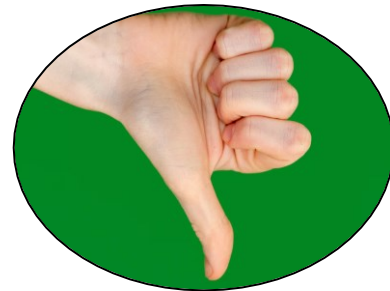


We will record the group chats (focus groups). We will save anything we create together.



Are there any negatives to taking part?

Sometimes it can be difficult to work together. Talking in a group can be tricky.



What good things might happen if I take part?

With your help, we can make a new tool (a way to make things easier). It will help people use urgent and emergency care services such as 999 or the doctor during the night-time.



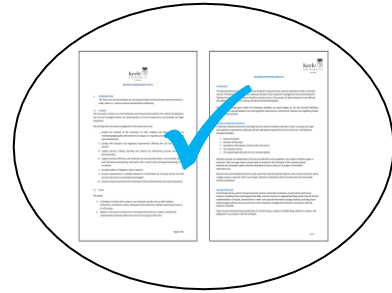
Confidentiality and Withdrawal

Will my information (data) be kept safe (confidential)?

If you take part, we will ask you for some personal information. For example, we will ask your name and email address or phone number (contact details).



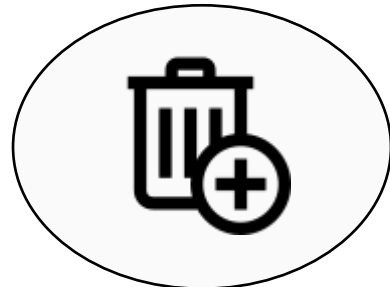
All important personal information (data) will be kept safe. Keele University has rules that we must follow. These are called the data [retention schedule](#) and [policy](#).



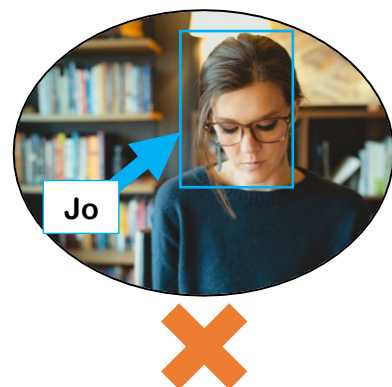
All important personal information (data) will be safe (stored securely). Data will be stored in the Keele University digital space for keeping data. This also known as a cloud space. Keele University uses Microsoft Forms, Teams and OneDrive cloud spaces.



When it is no longer needed the information (data) will be securely destroyed. This means that no one will be able to use it anymore.



The information (data) which would let other people know who you are (identify you) will not be shared. We will not share it with anyone outside the project team unless you agree. We may need to break this rule if you tell us that you or someone else are not safe (at risk).



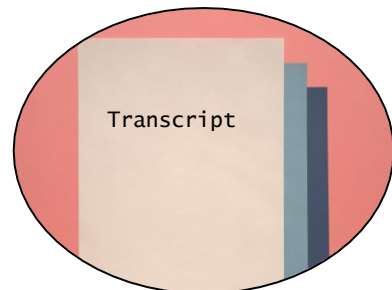
Anonymous information (data) will be shared.
Anonymous data does not let other people know who
you are (identify you).



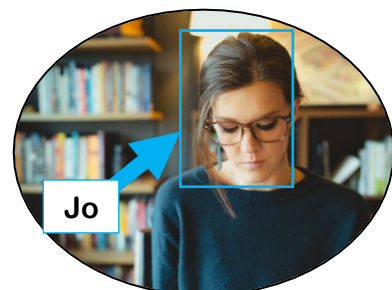
The recording we make of the group chat will be sent
to a person called a transcriber.



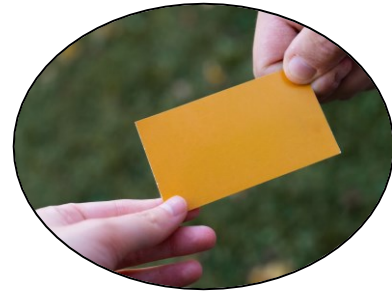
They will listen carefully and write out what was said.
This is called a transcript.



We will make sure that no one reading the transcript
can identify you. The transcript will be anonymous. It
will not include your name or anyone else's name.



At the end of our project, we want to share the group transcripts. They will be put in a place where other people can read them. This is called the [Keele Data Repository](#). Sharing will help other people learn about how we worked together.



Anonymous information (data) will be included in project reports. It will be included in an academic journal article. It could be presented at a conference.



It could also be shared with the RCN Foundation. The RCN Foundation is the funder of the UCAN project.



What if I want to stop taking part?

You can ask to stop taking part in the group chat (focus group) at any time. We will not be able to take out your data (information).



You can stop taking part (withdraw) before the first group chat (focus group). To stop taking part you will need to send an email to us.



You do not have to say why you want to stop taking part.



Further Information and Contacts

What if I have a problem?

If you have a question or are unhappy about taking part, you can contact Dale. You can get in touch with Dale by using his email address d.nixon@keele.ac.uk or by telephone on 01782 733265.



If you are still unhappy you can contact the Faculty of Medicine and Health Sciences Research Ethics Committee. You can get in touch with them by using their email address health.ethics@keele.ac.uk. Mention 'Project 0921' in the email.



Who is funding the project?

The [RCN Foundation](#) is the funder of the UCAN project. This means they have given some money to make the project happen. The RCN Foundation is a charity. They support nurses to improve health and wellbeing.



Who has checked (reviewed) the project?

This project has been checked (reviewed) by the Faculty of Medicine and Health Sciences Faculty Research Ethics Committee at Keele University. They check to make sure that the project team will take care of everyone who takes part in the project.

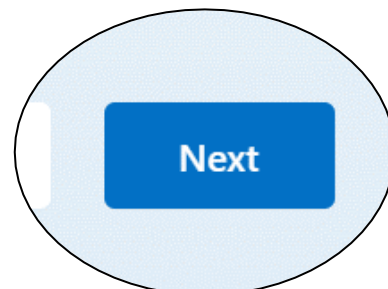


Thank you

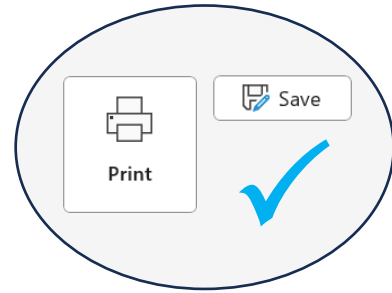
Thank you for reading this information. Thank you for thinking about taking part in the UCAN project.



If you want to take part, you will need to say that you agree (consent). You will be asked to give your consent digitally on the next page.



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