

Ethnicity and Difference in Health and Care

Carer/guardian Information Leaflet

This information leaflet explains a research project for carers/guardians that support people with a learning disability. There is an easy-read version of this leaflet available. If you would prefer this version, please just ask.



You are being invited to participate in a research study. Before you decide whether to participate, it is important for you to understand why the research is being done and what it will involve.

Please take time to read the following information carefully and feel free to ask us if you would like more information or if there is anything that you do not understand. Please also feel free to discuss this with your friends, relatives and people who support you if you wish.

We would like to stress that you do not have to accept this invitation and you should only agree to take part if you want to. Thank you for reading this.

How can we make care better for people from minority ethnic groups with a learning disability?

When it says 'we' and 'us' this means a group of people that are working together from Learning Disability England, Race Equality Foundation, University of Central Lancashire and Manchester Metropolitan University.

This research project is about people with a learning disability who are from minority ethnic groups. We want to know why this group have poorer health outcomes, and why people with a learning disability from minority ethnic groups are more likely to die younger than people who are white British.

We want to know why it is hard for people from minority ethnic groups with a learning disability to use health care services. One reason is they might speak different languages and find it harder to get information.

Racism is another reason people from minority ethnic groups might not be treated equally. We want to ask carers and people with a learning disability from minority ethnic groups what they think.

Anyone aged 18 years old and older with a learning disability from a minority ethnic group can take part. Young people between the ages of 14 and 17 can take part, but they need the permission of their parent or guardian. Carers and guardians can also take part.

This information sheet is for carers, parents, guardians, and professionals who support people with a learning disability. You have been chosen to take part because you have valuable experience and expertise when it comes to helping people with a learning disability access healthcare. So, we would like to listen and learn from you. We need your help to understand the issues and how to make things better.

Information on how you can take part and what's involved

If you decide to take part, you will be part of a group with 4 or 5 other people. You will talk and listen to other people in the group. In the group there will be people with a learning disability and their carers or the people who support them. We're aiming to run the groups online and where possible some in-person meetings. We will try to be as flexible as possible.

Whichever way you want to take part you will be offered payment for your time. You will receive a voucher for £20 an hour based on the NHS England Expert by Experience rate. We will also give you support to take part and pay any extra costs for travelling or taking part.

In the group we will ask you to tell us about any problems you have had when supporting someone with a learning disability to use health care services. The facilitators will be from the Race Equality Foundation and Learning Disability England.

There will be rules in the group to keep everyone safe and happy. We will agree these together as a group. However, we cannot totally promise that everyone will follow the rules. If we know someone has broken the rules we will let you know, and do our best to support everyone involved. We will remind everyone about the rules at the start of all the meetings.

We will not tell other people that you took part in the research. We will not share your personal information like your name or address with anyone. The only time we will tell someone what you said is if you talk about abuse by someone who is meant to support you and/or people with a learning disability. This is to make sure you and others are safe. Any abuse or bad practice by services will be reported to the people who inspect those services.

Pros and cons for taking part

There might be some benefits of taking part like:

- you will be listened to
- you will help to make services better
- you will be contributing to interesting and important research
- you will meet new people

There might be some of the risks of taking part like:

- you will be asked to tell us what you think
- you will hear other people's experiences and you might choose to share your experiences, which could be difficult
- you may be taking part on a video call
- you could be in a meeting for up to 2 hours (but there will be breaks)
- you will only be able to attend 1-2 meetings, then the project will come to an end.

It is your decision if you want to take part. If you say NO I do not want to take part that is OK. You do not have to take part. No one will mind. You will not be treated any differently.

If you say YES I do want to take part that is OK. But you can always change your mind later. You do not have to take part in all the meetings.

You can leave at any time. We will totally understand and support your decision. Nothing bad will happen and you do not have to give a reason for leaving.

What will happen to the information you give?

Information from the group will be stored on a computer that is protected by a password. The computer password will only be accessible to the researchers. We will audio record the group meetings. This is so we can listen back and hear what everybody said. We will also type notes, this is so we do not forget all the important things discussed in the group.

Your contact information will be collected after you complete the consent form and demographic information form. This information will be safely stored on an internal database within the University of Central Lancashire systems. For this reason, the University of Central Lancashire (UCLan) will be the data processor for this project. A “data processor” is an organisation or individual who holds or processes data. Demographic information including gender, age, religion and ethnicity will also be collected, if you wish to give it. This information relates to the person you care for and will be anonymous. We ask for this information so we can make sure the group is inclusive and diverse.

UCLan will only share your contact information with the facilitators of the workshop meetings, so they can get contact with you. The facilitators will be employees from the Race Equality Foundation and Learning Disability England. Your personal information will be stored for 7 years then the database will be deleted from the UCLan hard drive. Your contact details will be deleted at the end of the study.

We will write a report about what we find out. The report will be shared with you and other people who have taken part. Your name and address will not be put in the report. We will assign all participants a unique number, which means your name will be anonymised and no one will know you took part.

The report will be shared with health and social care professionals. Anyone will be allowed to read the report. This is so as many people as possible can learn from what you have said and make care better based on the recommendations of the research. We may also want to write about what we find out in a research journal. We may also talk about the research findings at conferences and meetings. This is so people who make decisions about health care services can make improvements based on this research project.

Who you can talk to for more information

If you would like to take part or you have any questions please talk to Katie who is a research assistant on this project. Katie's name, telephone number and address are below.



Name: Katie Umpleby

Address: School of Medicine, University of Central Lancashire, Preston PR1 2HE

Telephone : 01772 893919

Email: KUmpleby@uclan.ac.uk

You can also contact Professor Umesh Chauhan who is leading this research project.



Name: Professor Umesh Chauhan

Address: School of Medicine, University of Central Lancashire, Preston PR1 2HE

Telephone: 01772 893771

Email: UChauhan@uclan.ac.uk

The University of Central Lancashire also has information on their website about what is involved when you are a research participant. Please click on this link: www.uclan.ac.uk/legal/privacy-notices/research-participants. We can read through this with you if you are finding this difficult to understand.

Who to contact if you are unhappy or have a problem with the research?

If you are unhappy, or if there is a problem, please feel free to let us know by contacting Principal Investigator, Professor Umesh Chauhan or research assistant Katie Umpleby. Their contact details are on the previous page.

If you remain unhappy or have a complaint which you feel you cannot come to us with, then please contact the Ethics, Integrity and Governance Unit:

OfficerForEthics@uclan.ac.uk

The University strives to maintain the highest standards of rigour in the processing of your data. However, if you have any concerns about the way in which the University processes your personal data, it is important that you are aware of your right to lodge a complaint with the Information Commissioner's Office by calling 0303 123 1113.