



The Coronavirus and People with Learning Disabilities Study

Wave 4 Information Sheet

Invitation

We are a group of university researchers (from Manchester Metropolitan University, The University of Warwick, The University of South Wales, The University of Glasgow, Ulster University and The University of Kent) who would like to invite you to take part in Wave 4 of the Coronavirus and People with Learning Disabilities Study. The study is about the lives of people with learning disabilities across the UK now and through the coronavirus pandemic. The National Institute for Health and Care Research (NIHR) have funded this research.

The study so far has included interviews with around 500 adults with learning disabilities and around 300 family members or paid carers completed online surveys. We know that some adults with learning disabilities are not able to talk to researchers so family members or paid carers are invited to take part on behalf of the person with a learning disability that they care for or support.

This information will help you decide if you want to take part in the study. Take time to decide if you want to take part. Ask us any questions you have.

Why have I been invited?

You have been asked to take part because you are a family member or a paid support staff of someone aged 16 or older who has a learning disability. You have also been asked to take part because we want to increase participation in the research from people from minority ethnic groups.

What will I have to do?

You will be asked to fill in an online survey. The survey should take less than 30 minutes to complete.

What will I be asked about?

The survey will ask questions about different aspects of the life of the person you care for (e.g., questions about health, testing for Covid-19, well-being, living circumstances, cost of living, and support). The survey will also ask some questions about you and your well-being.

Do I have to take part?

It is up to you to decide. You can download and keep a copy of this information sheet. When you start the survey, you will be taken to a page where you will be asked if you consent to taking part. If you change your mind about taking part, you can stop and exit the survey.

Are there any risks if I participate?

There are not any risks to taking part. If you feel any distress when you answer the questions, close the survey and leave the study. If you feel distressed after you answered the survey or if you need any help, please contact:

Mencap Learning Disability Helpline: phone: 0808 808 1111, Email: helpline@mencap.org.uk.

Are there any advantages if I participate?

We hope you will think it is interesting and enjoy completing the survey. The researchers will find things out and share the study findings with people and organisations who can make things better for people with learning disabilities.

Informed consent

Before you start the online survey, there will be a reminder that starting the survey is giving consent to take part in the study.

What information about me will you collect and why?

We will collect some personal information about you (this might include your name, email) to allow us to contact you about the study's findings and possible future research. We will also collect your responses to online survey questions about the person with learning disabilities that you care for / support.

How will my information be stored and how will you look after it?

Data will be kept within the Qualtrics software. Qualtrics data will be downloaded weekly into Excel and SPSS software and stored on Manchester Metropolitan University's secure password protected Research Data Storage (RDS) platform.

How will you use my information?

Data from the survey will be analysed using SPSS and Nvivo software to report on the lives of people with learning disabilities. Participants will be anonymous in all reports and other project outputs.

Will my data be sent anywhere else, or shared with other people or organisations?

Anonymised Qualtrics data will be transferred from Manchester Metropolitan University to Warwick University for data analysis. Data sharing will be under the terms of a Research Collaboration Agreement which defines use and agrees confidentiality and information security provisions. The University never sells personal data to third parties. An anonymised dataset will be deposited in a safeguarded open access repository at the end of the project for use in future research and learning. Personal data will not be shared. Data will not leave the UK.

When will you destroy my information?

The data and your personal data will be stored safely for ten years. Your rights to access, change or move your information are limited, as we need to manage your information in specific ways in order for the research to be reliable and accurate. If you withdraw from the study, we will keep the information about you that we have already obtained.

Data Protection Law

The way we look after your information is ruled by UK law. Under UK law, we need to have a very good reason for using your information (this is called a 'lawful basis'). Sometimes, we might also want to use sensitive information about you, like information about your health, religion and ethnic background. This is called 'special category information'. We collect all this information from you to help with our research, which aims to benefit everyone (this means that it is in the 'public interest').

You have the right to make choices about your information under UK law. If you have any questions or would like to ask us to do something with your information, you can ask the researcher (contact details are below).

You can stop being a part of the study at any time, without giving a reason. You can ask us to delete your data at any time, but it might not always be possible. If you ask us to delete information within one week of completing the survey, we will make sure this is done. If you ask us to delete data after this point, we might not be able to.

What will happen to the results of the research study?

We will share the results of the study with participants, organisations that support people with learning disabilities, policy makers, and other researchers. We will tell people what we find out in different ways such as reports, social media, presentations, academic journal articles.

Who has reviewed this research project?

The Faculty of Health and Education ethics committee at Manchester Metropolitan University has reviewed and approved this project. The National Institute for Health and Care Research (NIHR) reviewed and funded this research.

Who can I contact about this study?

If you have any questions about the research, please contact: Dr Sue Caton, S.Caton@mmu.ac.uk 07425374068. If you have any comments or concerns about the research you can talk to either of the Principal Investigators: Professor Chris Hatton (C.Hatton@mmu.ac.uk) or Professor Richard Hastings (R.Hastings@Warwick.ac.uk).

If you want to complain about the research, you can contact the Faculty Head of Ethics at Manchester Metropolitan University, Dr Claire Fox, by emailing her FOHE-ethics@mmu.ac.uk

If you are not happy about how we managed your personal data, you can contact Manchester Metropolitan Data Protection Officer dataprotection@mmu.ac.uk Tel: 0161 247 3331 Legal Services, All Saints Building, Manchester Metropolitan University, Manchester, M15 6BH

You have the right to complain directly to the UK Information Commissioner's Office if you would like to complain about how we process your personal data: <https://ico.org.uk/global/contact-us/>

