



Coronavirus and People with Learning Disabilities - a study of the lives of people with learning disabilities through the coronavirus pandemic

Information Sheet

What is this information about?



We are university researchers. Researchers ask people questions to find out new information.



The coronavirus pandemic has meant a lot of changes for everybody.



We want to ask people with learning disabilities about how coronavirus has affected their lives.



UK Research and Innovation have paid for us to do this research.



This information will help you decide if you want to take part in the research or not.



Take time to decide if you want to take part. Ask the researcher any questions you have.

Why Me?



You have been asked because you are aged 16 or older and have a learning disability.

What will I have to do?



We will want to ask you some questions. We will want to ask you some questions again later in the year. This would be three times in total.

The researchers can speak to you in different ways. It could be:



Telephone



Messenger



Zoom



WhatsApp



FaceTime



Skype

Ask us if there is another way you prefer.



Before we start the conversation, the researchers will ask you again if you want to take part.



The researchers will ask you questions and they will fill in a questionnaire with the answers you give.



They will speak to you for about an hour each time we meet. The researcher will ask if you want to have a break.

What will I be asked about?



The researchers will ask you about your health.



The researchers will ask you how you have been feeling.



The researchers will ask you about your job, volunteering and benefits.



The researchers will ask you about services and support you receive.

What will happen to the results of the research study?



What we talk about is confidential. That means we will keep it private.

We will not use your name.



We will tell people what we find out in different ways.

We will tell people what we have found. What you have told us may go in reports, what you have told us may go on the internet and we may present our findings to people who work with people with a learning disability.

Do I have to take part?



It is up to you to decide.



You can say **yes** or **no**.

If you do not want to take part, it will not make any difference to your rights, benefits or support.



If you change your mind about taking part that is ok, you can just stop.

If you don't want us to have your answers anymore, that is ok, we will remove them.

We will be writing regular reports on the answers people give us so if we have already written a report we cannot change that.

Are there any risks if I take part?



When universities do research projects we have to think about whether there are any risks to taking part.

There are no risks to taking part but talking about coronavirus might make you feel sad or upset.

If you do not like answering the questions we can stop.

If you feel unhappy after we have finished or you need any help, please contact: Learning Disability England
Telephone: 0300 111 0444 or email:

info@LDEngland.org.uk who will be able to tell you where to get the help you need.



If the researcher is worried about your safety or the safety of other people then they will need to tell someone. They will talk to you about this.

Are there any good things if I participate?



We hope you will think it is interesting and enjoy talking to us.

The researcher will find things out and tell people who can make things better for people with learning disabilities.

Keeping your information safe



We will keep all the information you tell us in a safely on the computers at the Universities.

There is more information about how we keep everyone's answers safe at the end of this sheet. You might want to ask someone to look at this with you to help you decide if you want to take part.

Who has given permission for this project to take place?



The ethics committee at Manchester Metropolitan University has reviewed and approved this project.

UK Research and Innovation also know about this research.

Who can I ask about this?



If you live in England and want to take part in the research or have any questions you could ask the researcher, Sue Caton, s.caton@mmu.ac.uk or call or text on 07425 374068.



If you have any comments or concerns about the research you can talk to Professor Chris Hatton (C.Hatton@mmu.ac.uk) or Professor Richard Hastings (R.Hastings@Warwick.ac.uk).

They are both in charge of this research.



If you want to complain about the research you could tell Professor Khatidja Chantler, by emailing her K.Chantler@mmu.ac.uk, or leaving a message for her on this number: 0161 247 1316



If you are not happy about how we managed your personal data, you can tell the Data Protection Officer legal@mmu.ac.uk or call them on 0161 247 3331.



For general advice and support about coronavirus you could ask: Mencap Learning Disability Helpline: phone: **0808 808 1111**, email: helpline@mencap.org.uk.



Data Protection Information

When you agree to participate in this research, we will collect from you personally-identifiable information.

The Manchester Metropolitan University ('the University') is the Data Controller in respect of this research and any personal data that you provide as a research participant.

The University is registered with the Information Commissioner's Office (ICO), and manages personal data in accordance with the General Data Protection Regulation (GDPR) and the University's Data Protection Policy.

We collect personal data as part of this research (such as name, telephone numbers or age). As a public authority acting in the public interest we rely upon the 'public task' lawful basis. When we collect special category data (such as medical information or ethnicity) we rely upon the research and archiving purposes in the public interest lawful basis.

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.

We will not share your personal data collected in this form with any third parties.

If your data is shared this will be under the terms of a Research Collaboration Agreement which defines use, and agrees confidentiality and information security provisions. It is the University's policy to only publish anonymised data unless you have given your explicit written consent to be identified in the research. **The University never sells personal data to third parties.**

Your data will only be retained for as long as is necessary to achieve the research purpose. Personal data will be held by the researchers from each UK nation and will not be shared wider than is necessary to carry out the research. Each participant will be allocated a participation number for identification purposes. Data will be kept by each researcher in a restricted access folder on a University owned encrypted laptop or within the Qualtrics software. Qualtrics data will be downloaded weekly and stored on Manchester Metropolitan University's Research Data Storage (RDS) platform. Where consent is audio recorded, these files will be transferred to RDS. Anonymised Qualtrics data will be transferred to Warwick University for data analysis. An anonymized dataset will be deposited in a safeguarded open access repository at the end of the project for use in future research and learning.

For further information about use of your personal data and your data protection rights please see the [University's Data Protection Pages](#).

If you have any concerns regarding the personal data collected from you, our Data Protection Officer can be contacted using the legal@mmu.ac.uk e-mail address, by calling 0161 247 3331 or in writing to: Data Protection Officer, Legal Services, All Saints Building, Manchester Metropolitan University, Manchester, M15 6BH. You also have a right to lodge a complaint in respect of the processing of your personal data with the Information Commissioner's Office as the supervisory authority. Please see:

<https://ico.org.uk/global/contact-us/>