**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 who would like to invite you to take part in a study of the lives of people with learning disabilities through the coronavirus pandemic. UK Research and Innovation have funded this research.

We will be speaking to 1000 adults with learning disabilities. However, we know that some adults with learning disabilities will not be able to talk to researchers. We want to speak to family members or care workers/paid support staff of these adults who know the person with a learning disability really well.

This information will help you decide if you want to take part or not. 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 because you are a family member or a care worker/paid support staff of someone aged 16 or older who has a learning disability.

If the person that you care for would prefer to speak to a researcher and answer the survey questions themselves, please do not complete the survey yourself. If this is the case, please contact us and speak to the researcher about this.

**What will I have to do?**

You will be asked to fill in an online survey. You will be asked to fill in the survey 3 times during the next year to see if anything changes for the person that you care for. 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. There will be questions about health, well-being, finances, and support.

The survey will also ask some questions about you and what it has been like to care for someone during a pandemic.

**Do I have to take part?**

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

If you decide that you do not want us to have your answers anymore, that is ok, we will delete them. We will be writing regular reports on the answers people give us, so if we have already written a report including your answers we cannot change that.

**Are there any risks if I participate?**

There are not any risks to taking part. But, 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: Brenda Garrard from PAMIS [b.garrard@dundee.ac.uk](mailto:b.garrard@dundee.ac.uk) who will be able to tell you where to get the help you need.

**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 tell people who can make things better for people with learning disabilities.

**What will happen to the results of the research study?**

We will tell people what we find out in different ways such as reports, talks and the internet. The survey is confidential, your name will not be used.

The data from the survey will be stored safely for ten years. We will ask you if we can keep your name and email address or phone number for two years so we can contact you about future research. There is more information about how we keep everyone’s answers safe at the end of this sheet.

**Who has reviewed this research project?**

The ethics committee at Manchester Metropolitan University has reviewed and approved this project. UK Research and Innovation reviewed and funded this research.

**Who can I contact about this study?**

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| A person smiling for the camera  Description automatically generated  A person smiling for the camera  Description automatically generated | If you live in Scotland and have any questions you could ask the researchers, Roseann Maguire [roseann.maguire@glasgow.ac.uk](mailto:roseann.maguire@glasgow.ac.uk)  or Amanda Gillooly [amanda.gillooly@glasgow.ac.uk](mailto:amanda.gillooly@glasgow.ac.uk)  or call or text them on 0141 211 3902 |
| Chris Hatton - Stay Up Late**C:\Users\01900112\AppData\Local\Microsoft\Windows\INetCache\Content.MSO\FA92DE2C.tmp** | 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](mailto:C.Hatton@mmu.ac.uk)) or Professor Richard Hastings ([R.Hastings@Warwick.ac.uk](mailto:R.Hastings@Warwick.ac.uk)). |
| https://webcdn.mmu.ac.uk/profiles/img/profile-images/KhatidjaChantler-crop-145x145-5e8b287b6894f.jpg | If you want to complain about the research you can contact Professor Khatidja Chantler, Head of Ethics Committee, Faculty of Health, Psychology and Social Care, Manchester Metropolitan University, Brooks Building, 53 Bonsall Street, Manchester, M15 6GX. [K.Chantler@mmu.ac.uk](mailto:K.Chantler@mmu.ac.uk), 0161 247 1316 |
| **C:\Users\01900112\OneDrive - MMU\Covid-19 & Learning Disability\Ethics Docs\Photosymbols\Data Protection Act.png** | If you are not happy about how we managed your personal data, you can contact our Data Protection Officer [legal@mmu.ac.uk](mailto:legal@mmu.ac.uk) or call them on 0161 247 3331 or write to them with this address: Data Protection Officer, Legal Services, All Saints Building, Manchester Metropolitan University, Manchester, M15 6BH |
| **C:\Users\01900112\OneDrive - MMU\NIHR\Ethics Docs\Photosymbols\Indiana question.png** | For general advice and support about coronavirus you could ask:  Enable Scotland phone 0300 0200 101 [enabledirect@enable.org.uk](mailto:enabledirect@enable.org.uk) |





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| **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](https://www2.mmu.ac.uk/data-protection/).  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](mailto: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/> |