**26 March 2020**

**Participant Information Sheet**

**Title of Project:** *COVID-19 pandemic and disabled people>*

**Introduction**

*We would like to invite you to take part in a research study. Joining the study is entirely up to you. Before you decide, you need to understand why the research is being done and what it would involve. One of our team will go through this information sheet with you, and answer any questions you may have. Ask questions if anything you read is not clear or you would like more information. Please feel free to talk to others about the study if you wish. Take time to decide whether or not to take part*.

**What is the purpose of the study?**

*The London School of Hygiene & Tropical Medicine (LSHTM) and the University of Glasgow are conducting research about how the COVID-19 pandemic is affecting disabled people, in terms of health, wellbeing and social inclusion.*

**Why have I been asked to take part?**

*You have been invited because you or your child have experience of disability, and you have been identified by a voluntary organisation or disabled people’s organisation as being a possible participant.*

**Do I have to take part?**

*No. It is up to you (and potentially your child with disability) to decide to take part or not. If you don’t want to take part, that’s ok. Your decision to participate or not participate will have no effect on any health and social services you receive. We will not share your decision with anyone outside the research team, including to the voluntary organisation or disabled people’s organisation that identified you as a possible participant..*

*We will discuss the study together and give you, or read out to you, a copy of this information sheet. If you agree to take part, we will then ask you to agree the terms of a consent form, taking oral consent which will be recorded.*

*If you give us permission, we will follow the same process with your child, if they are able to consent (14-18). If they are only able to assent (aged 10-14), we will record their assent. If they are younger than 10, or have an intellectual disability which means they are unable to understand about the study, they will be unable to participate in the study.*

**What will happen to me if I take part?**

*You will be contacted by one of our researchers to arrange a telephone interview, beginning with the oral consent process. If you are Deaf you can organise an email or Whatsapp interview. This will be scheduled at a time of your own convenience. If you have a child with disability who has capacity and agrees to participate, we will do a telephone interview with them following the interview with you, including the consent or assent process as relevant.*

**What will I have to do?**

*We will conduct a telephone interview. The interview will last between 30 minutes and 60 minutes.*

*We will record the interview so that I can accurately remember what you have told me. You can tell us anything you want concerning your experiences during the Covid-19 pandemic. You can end this interview at any time or refuse to answer any questions. The same process and rights apply to your child with disability, if they are willing to participate.*

**What are the possible risks and disadvantages?**

*You may feel distressed at discussing your own experiences, or those of disabled people in general.*

**What are the possible benefits?**

*Participation in this study is completely voluntary. We cannot offer any compensation or other benefits to you for participating in this study. The information we get from the study will help our knowledge and understanding of how a pandemic such as Covid-19 affects disabled people. It may help agencies cater better or message better concerning the needs of disabled people.*

**What if something goes wrong?**

*If you have a concern about any aspect of this study, you should ask to speak to the researchers who will do their best to answer your questions (contact details below). If you remain unhappy and wish to complain formally, you can do this by contacting Patricia Henley at* [*rgio@lshtm.ac.uk*](mailto:rgio@lshtm.ac.uk) *or +44 (0) 20 7927 2626.*

*The London School of Hygiene & Tropical Medicine and the University of Glasgow hold insurance policies which apply to this study. If you experience harm or injury as a result of taking part in this study, you may be eligible to claim compensation.*

**Can I change my mind about taking part?**

*Yes. You or your child can withdraw from the study at any time. You just need to tell the researcher that you don’t want to be in the study anymore. This will make no difference to any health or social services you receive, or any support from the organisation through whom you became involved.. If you withdraw from the study we will destroy all tape recorded interviews, and not use any data collected.*

**What will happen to information collected about me?**

*All information collected from you will be kept private and will be anonymised immediately after transcription.. Only the study staff will be allowed to look at information about you. We will keep all information about you safe and secure.*

*Your personal details, meaning your name and other identifiable information, will be kept in a different safe place to the other study information and will be destroyed within 10 years of the end of the study.*

*At the end of the project, the study data will be archived at the UK data archive, and all information that could potentially identify you will be removed.*

**What are your choices about how your information is used?**

*You can stop being part of the study at any time, without giving a reason,*

**Where can you find out more about how your information is used?**

*You can find out more about how we use your information at:*

* [*https://www.lshtm.ac.uk/files/research-participant-privacy-notice.pdf*](https://www.lshtm.ac.uk/files/research-participant-privacy-notice.pdf)
* *by asking one of the research team*
* *by sending an email to* [*DPO@lshtm.ac.uk*](mailto:DPO@lshtm.ac.uk)
* *<for UK studies> at* [*https://www.hra.nhs.uk/information-about-patients/*](https://www.hra.nhs.uk/information-about-patients/)

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

*The study results will be published in a journal so that policy-makers and practitioners can learn from them. We will also share the learning with policy-makers and practitioners directly. Your personal information will not be included in the study report and there is no way that you can be identified from it.*

**Who is organising and funding this study?**

*London School of Hygiene & Tropical Medicine and the University of Glasgow are the sponsor for the research and they have full responsibility for the project including the collection, storage and analysis of your data, and will act as the Data Controller for the study. This means that we are responsible for looking after your information and using it properly.*

**Who has reviewed this study?**

*All research involving human participants is looked at by an independent group of people, called a Research Ethics Committee, to protect your interests. This study has been reviewed and approved by The London School of Hygiene & Tropical Medicine Research Ethics Committee (<ref:>).*

**Further information and contact details**

Thank you for taking time to read this information sheet. If you think you will take part in the study please read and sign the consent form.

If you would like any further information, if you are in England, please contact Professor Tom Shakespeare who can answer any questions you may have about the study. If you are in Scotland, please contact Professor Nicholas Watson who can answer any questions you may have about the study.

Contact details:

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07816 442 779

[Nicholas.watson@glasgow.ac.uk](mailto:Nicholas.watson@glasgow.ac.uk)

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