



## **Cicada: Coronavirus Chronic Conditions and Disabilities Awareness study**

### **Interview and Workshop Participant Information Sheet**

#### **Why am I being asked to take part in this research?**

We would like to invite you to tell us about what life is or has been like for you during the current coronavirus pandemic. You have been contacted for this project because you have a condition that affects the way you are able to live your life and you have expressed an interest in talking to us.

We would like you to tell us your experiences in the form of an interview and then in 6 and 12 months' time, approximately, to take part in workshops that consider the same topics. Because of the pandemic, we cannot do this face to face with you, so you can choose to do this by phone or by special video chat or through a special link that we can send you, or we could send you an email with questions and then you could reply by email.

Before you decide to take part in this study, it is important for you to understand why the research is being done and what it will involve. Just before the interview and workshops, the researcher will go through this information sheet with you and answer any questions you have. Please feel free to discuss this project with your family, friends, doctor or other trusted people if you wish. You are under no obligation to take part. If there is anything that is not clear, please do ask us what we mean.

#### **What is the purpose of this research?**

We are experiencing an unusual situation with the coronavirus pandemic. People with long-lasting health conditions (that is, conditions that you will have had for more than 3 months) or disabilities often already find it hard to manage daily living. We believe that such challenges could be much worse for many such people during the pandemic, whether or not they are on the 'sheltered persons' list. But others are reporting that nothing has changed much for them. There are also stories of people coping better with their conditions during the pandemic, perhaps because they do not feel under pressure to leave the house, or because other people are taking more time to support them.

This project plans to understand the different situations of people with different conditions and disabilities during the pandemic and shortly afterwards and compare these with people without these experiences. We are also interested in hearing about how ethnicity affects this, and about the experiences of people born outside the UK. This is important to ensure that your voice is heard, as we believe that many people need better help but are not considered for this. It will also give us a better understanding of what life is like for you in general.

Initial findings will be shared widely to try to ensure people with long term conditions and disabilities and those from ethnic minorities or not born in the UK are represented in current planning. At the end of the study, our findings will also mean we can build up a picture of the country's neglected needs for people with long term conditions and disabilities, and ethnic minorities, as well as plan for the consequences of the pandemic on people's health

and feeling of wellbeing. Since we are also collecting data from white British people we will also be able to provide information that can help in planning for this majority group too although that is not our focus.

### **Do I have to take part?**

Participation in the study is completely optional. If you decide not to take part, there will be no effect at all on you and you can simply forget about the study. If you do decide to take part, you will be asked to sign a 'consent form' stating that you are happy to take part; however, you have the right to withdraw from the study at any point without giving a reason if you change your mind. Withdrawing from the study will not affect you in any way.

If you do decide to withdraw from the study, we may ask for your reasons behind this, but you do not have to tell us.

### **What will happen to my data?**

We will involve many people, and analyse all the data together. We will then publish summaries of our analysis and share these summaries in professional meetings so that more people are aware of the different experiences. In these summaries we may include extracts from some interviews and workshops. If we do so, we will make sure the person cannot be recognised from the extract. We will never use your real name. We will store the interviews and workshop recordings on special secure computers at UCL that are designed especially to keep research data safe.

### **Is this study ethical?**

This study has been reviewed by an independent group of people, called the Research Ethics Committee, to protect your safety, rights, well-being and dignity. The study has been approved by the University College London (UCL) Research Ethics Committee (Reference number: 1372, Data protection registration number: Z6364106/2020/06/24).

### **What happens to my information?**

During this study we will collect some personal information from you, such as your name, and contact details – such as your email address - so that we can arrange the interview and workshops. Any personal information that we collect in this study will be kept confidential and safe by the study researchers. If you decide to take part in the study, a code will be used to identify data about you, and we will keep the list that links codes to people's identity locked separately from the data. We will also record the interview and workshops so we can analyse them. All data will be stored in password-protected folders on secure computers on a secure drive, which will only be accessible to the research team.

Your personal identifiable information will be kept until your participation in the study has ended which is expected to be within 2 years. After this period your personal details will be destroyed.

We will keep the interview and workshop data for 15 years which is usual practice, in a secure place at UCL.

We will never use the recordings in any presentation or publication. The recordings will be destroyed as soon as they are no longer required, which may mean after they have been

transcribed (with all information removed that could identify you) or at the end of the study whichever is sooner.

All information that you provide (either written or electronic) will be held as confidential by University College London (UCL). It might be important to look at the data in years to come, so we will keep anonymised data (including transcriptions of the data) for 20 years and then it will be destroyed. We will ask you if it can be shared with other researchers but we will not share it with anyone apart from them. All research data will be used strictly within the terms of the Data Protection Act 2018 and in compliance with GDPR.

If you decide to withdraw from the study, we will destroy the interview recordings and transcriptions. We will edit the workshops though this may be too hard to do. Researchers may also ask about your reasons for withdrawing from the study. Learning about the reasons why participants may drop out of the study will help us understand how to improve what we do. Again, if you do not want to let us know why you have decided to withdraw, this is absolutely fine.

### **What are the possible disadvantages of taking part?**

We believe that this study is safe and do not expect you to suffer any harm or injury because of taking part.

If you become distressed whilst taking part, we will stop the session and ask if you want to continue. If you want to continue, we will give you time to recover before continuing. If you wish to stop, you are free to do so, and we will provide the contact details of professional people you may wish to talk to.

### **What are the possible benefits of taking part?**

Overall, we do not know whether you will experience any direct benefits from taking part in this research, but we hope that you will enjoy and value your role in helping us to develop reports to make people including the government more aware of your experiences.

### **Who is organising this research?**

The research is sponsored by University College London (UCL). Carol Rivas is the Chief Investigator and has overall responsibility for the study.

### **What will happen to the results of the project?**

The results of this research will be reported by University College London (UCL). We also want to publish results in scientific journals and present the findings at research conferences and to government and other professionals. Please be assured that your name will not be used in any report or publication, and only anonymised quotations may be used. If you would like a summary of the findings you can tick a box on the consent form provided and we will send it to you when it is finished.

### **Local Data Protection Privacy Notice**

**Notice:**

The controller for this project will be University College London (UCL). The UCL Data Protection Officer provides oversight of UCL activities involving the processing of personal data, and can be contacted at [data-protection@ucl.ac.uk](mailto:data-protection@ucl.ac.uk)

This 'local' privacy notice sets out the information that applies to this particular study. Further information on how UCL uses participant information can be found in our 'general' privacy notice:

For participants in health and care research studies, click [here](#)

The information that is required to be provided to participants under data protection legislation (GDPR and DPA 2018) is provided across both the 'local' and 'general' privacy notices.

The lawful basis that will be used to process your personal data are: 'Public task' for personal data and 'Research purposes' for special category data.

Your personal data will be processed so long as it is required for the research project. If we are able to anonymise or pseudonymise the personal data you provide we will undertake this, and will endeavour to minimise the processing of personal data wherever possible.

If you are concerned about how your personal data is being processed, or if you would like to contact us about your rights, please contact UCL in the first instance at [data-protection@ucl.ac.uk](mailto:data-protection@ucl.ac.uk).

**What if there is a problem or you would like more information about the study?**

If you have any concerns or questions about this study, you should speak to Carol Rivas who can be reached at [ioe.cicada.study@ucl.ac.uk](mailto:ioe.cicada.study@ucl.ac.uk). If you are unhappy and after speaking to Carol wish to complain formally, you can do this by contacting the UCL research incidents team at [research-incidents@ucl.ac.uk](mailto:research-incidents@ucl.ac.uk).

**Thank you for taking the time to read this information sheet**