



COPING

COVID-19 Psychiatry and Neurological Genetics study

INFORMATION SHEET FOR PARTICIPANTS

Ethical Clearance Reference Number: 20/SW/0078

We would like to invite you to participate in the COVID-19 Psychiatry and Neurological Genetics (COPING) study being run by the NIHR BioResource Centre Maudsley (part of the NIHR BioResource) at King's College London, which is the same team that runs the GLAD Study. The COPING study will assess the impact of the novel coronavirus (COVID-19) pandemic on mental and neurological health. Please take the time to read the following information carefully and do not hesitate to get in touch with our team if anything is unclear or if you would like more information.

What is the purpose of the project?

The purpose of the project is to investigate associations between the outbreak of the novel COVID-19 pandemic and mental and neurological health. Previous research has shown that viral pandemics can lead to substantial distress in society and negatively influence mental and neurological health. As COVID-19 is a global pandemic, we are interested in how different factors associated with the virus are affecting the population. Taking part in this research may help us to identify beneficial behaviours and policies that are introduced during global pandemics, in order to better inform potential similar outbreaks in the future. Our aim is to assess the impact of the COVID-19 pandemic on existing and newly occurring mental health or neurological problems, and to make links between demographic factors and personal experiences of the pandemic.

Why have I been invited to take part?

You are being invited to participate in this project because we would like to recruit a wide sample of participants to provide information on their physical, brain and psychological health. As a participant of the GLAD Study and the NIHR BioResource, you are eligible to take part in this project and there are no other exclusion criteria. We are collaborating with other projects (such as the Repeated

Assessment of Mental health in Pandemics (RAMP) study) to recruit as many people as possible to provide the broadest picture of the effects of COVID-19 on the population's health.

What will happen if I take part?

If you choose to take part in the project you will be asked to complete a series of online questionnaires. The first questionnaire will take approximately 30 minutes to complete, with follow up questionnaires sent to you every two weeks during the pandemic. The follow up questionnaires will take approximately 15 minutes to complete and these will occur with a reduced frequency (once a month) once the situation becomes more stable and social distancing restrictions have been fully lifted. We may additionally distribute brief questionnaires (around 5 minutes) after a major change in the pandemic restrictions.

Once you have read this information page, you will confirm that you understand the study procedure and provide consent by clicking through the consent boxes on the consent page. After consenting to take part in COPING, you will be taken to the first online questionnaire which is linked to your unique GLAD ID. To take part in the follow up questionnaires you will be asked to consent for the personal (e.g. name, date of birth) and contact (e.g. your email and phone number) details that you provided GLAD to be used by COPING for the purposes of communication (e.g. newsletters) and receiving these questionnaires. You will have the option to update your contact details if you wish to.

The first questionnaire will ask you a range of questions about your physical, mental and neurological health, questions regarding your views of the COVID-19 outbreak and questions about what behaviours you have engaged in. The follow up questionnaires will be shorter and aim to assess any changes as they develop. If you do not feel comfortable answering a question, simply leave it blank and move on to the next one. Please complete the questionnaire in your own time. If you wish to take a break or finish the questionnaire at a different time, you may leave the page and click the link to come back to where you left off. We will re-contact you about the follow up questionnaires. You may withdraw your participation from the study at any time and without giving a reason.

What are the possible risks of taking part?

Participation is entirely voluntary, and we do not foresee any risks in participating. We will ask you questions regarding your physical and mental health, but if you do not wish to answer a question, you can skip that question or alternatively finish the questionnaire at any time. If at any point in the study you feel distressed, there are links to support networks at the bottom of the questionnaire. We take your wellbeing very seriously, and should you have any questions or concerns, please contact the research team on COPINGstudy@kcl.ac.uk.

What are the possible benefits of taking part?

Although there are no immediate individual benefits to taking part, you will have the unique opportunity to contribute to some innovative and valuable research which may later be used across the world. Individuals may also find it helpful to reflect on the current situation and express their feelings concerning a stressful and unprecedented global event.

Data handling and confidentiality

Your responses will be linked to your GLAD ID and the data you provide will be de-personalised for analysis. We will only ask you to confirm your personal (e.g. name, date of birth) and contact (e.g. email address and phone number) details for the purposes of COPING-related communication (e.g. newsletters) and for us to distribute the follow up questionnaires, if you consent to this. You will be asked to consent for data provided in this study to be securely linked to the data you provided the GLAD Study (including genetic, clinical and questionnaire data) through this unique de-personalised ID. The key that links ID numbers to your personal information is stored securely in the GLAD and NIHR BioResource databases and can only be accessed by members of the GLAD and NIHR BioResource teams. Everyone working at King's College London and the NIHR BioResource has a legal duty to keep personal information confidential.

All your answers to the questionnaires will be de-personalised and stored on our secure server.

How will we use information about you?

We will need to use the information from you for this research project. If you consent to follow-up, this will include your personal (e.g. name) and contact (e.g. email address, phone number) details. People will use this information to do the research, such as to communicate with you about the study and send the follow-up questionnaires. People who do not need to know where you are will not be able to see your personal or contact details. Your data will have a code number (study ID) instead.

We will keep all information about you safe and secure. Once we have finished the study, we will keep the data for as long as the topic is scientifically relevant. This will allow for data analysis and dissemination of our results to the wider scientific community.

Your data will become part of the NIHR BioResource. As a result, we may share de-personalised data with our trusted research partners, which may include commercial companies, via data access requests to ensure that partner aims align with those of the COPING study or NIHR BioResource. Any data that is shared will be provided in a de-personalised form. Any data sharing and transfer arrangements are compliant with GDPR and King's College London (KCL) policies.

We will write our reports in a way that no-one can work out that you took part in the study. Published data will be de-personalised, and no personal identifiable data will be published.

What are my choices about how my information is used?

You can stop being part of the study at any time, without giving a reason, but we will keep the information about you that we already have. We need to manage your records in specific ways in order for the research to be reliable.

Data Protection Statement

Your data will be processed in accordance with the General Data Protection Regulation 2018 (GDPR). If you would like more information about how your data will be processed in accordance with GDPR please visit the link below:

<https://www.kcl.ac.uk/research/support/research-ethics/kings-college-london-statement-on-use-of-personal-data-in-research>

What if I change my mind about taking part?

You are able to withdraw at any point in the project and without giving a reason, by clicking a link to opt-out of future follow up questionnaires. Withdrawing from the project will not affect you in any way and will not impact your participation in the GLAD Study. 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 project, we will keep the information about you that we have already obtained. To safeguard your rights, we will use the minimum personally identifiable information possible.

What will happen to the results of the project?

The results of the project will be summarised in academic research papers, made available online in preprint form in order to allow distribution of results as widely and quickly as possible. Due to the nature of the topic, it is likely that our research will be used to inform government policies, both nationally and internationally. KCL contributes to data sharing of de-personalised data to allow advancement of scientific research, and thus we will respond to individual requests for data sharing from our trusted research partners. We anticipate that published results will be available for general viewing in scientific journals. We will inform participants if and when this occurs.

Who should I contact for further information?

If you have any questions or require more information about this project, please contact study personnel at the following address: COPINGstudy@kcl.ac.uk

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

<https://www.hra.nhs.uk/information-about-patients/>

The research is led by Prof Gerome Breen,
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Denmark Hill, London,
United Kingdom, SE5 8AF

What if I have further questions, or if something goes wrong?

We do not anticipate that anything will go wrong but if you have a concern about any aspect of this project, please call on +44 (0)800 634 4504 and leave a message for the team who will do their best to answer your questions.

If you remain unhappy and wish to complain formally, you can do this by contacting the Director of Research Quality at King's College London:

Gill Dale

Email: gill.dale@kcl.ac.uk

PO Box 05; Institute of Psychiatry, Psychology & Neuroscience

King's College London

16 De Crespigny Park

London SE5 8AF

In the unlikely event that something does go wrong and you are harmed during the research due to someone's negligence, then you may have grounds for a legal action for compensation against King's College London. You may have to pay your legal costs.

Can I access my data?

You have the right to access information held about you. Your right of access can be exercised in accordance with the General Data Protection Regulation (GDPR). You also have other rights including rights of correction, erasure, objection, and data portability. Questions, comments and requests about your personal data can also be sent to the King's College London Data Protection Officer Mr Albert Chan info-compliance@kcl.ac.uk. If you wish to lodge a complaint with the Information Commissioner's Office, please visit www.ico.org.uk.

Thank you for reading this information sheet and for considering taking part in this research.