

INFORMATION SHEET FOR PARTICIPANTS

Ethical Clearance Reference Number: HR-19/20-18157

YOU WILL BE GIVEN A COPY OF THIS INFORMATION SHEET

Title of project

RAMP Study

Invitation Paragraph

We would like to invite you to participate in this research project which will assess the impact of the novel coronavirus (Covid-19) pandemic on mental health. Before you decide whether you want to take part, it is important for you to understand why the research is being done and what your participation will involve. Please take time to read the following information carefully and discuss it with others if you wish. Ask me if there is anything that is not clear 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 coronavirus pandemic and mental health. Previous research has shown that viral pandemics can cause significant distress in society, and bring about or worsen symptoms of mental health issues. As Covid-19 is a global pandemic and is affecting almost all parts of the world, we are interested in how different factors associated with the virus are affecting the population. Completing this research may help us to identify helpful and unhelpful behaviours and policies that are introduced during global pandemics, which may help to better inform potential similar outbreaks in the future. Our aims are to assess the impact of the Covid-19 pandemic on existing and new mental health problems, and to make links between demographic factors and personal experience of the Covid-19 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 and psychological health, both before and during the Covid-19 pandemic. We have chosen an online social media approach to recruit as many people as possible, to give us the broadest picture of the effects of the disease on the population's health. You are eligible to take part if you are above 16 years old and currently a resident of the United Kingdom (England, Scotland, Wales or Northern Ireland). There are no other inclusion or exclusion criteria.

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 which will last approximately 30 mins. These surveys will be sent to you every two weeks during the pandemic and with reduced frequency (once a month) once the situation becomes more stable, and for up to six months after the lifting of social distancing restrictions.

When you first sign up, you will first be taken to our information page which will explain the process and your rights as participants. Once you have confirmed you have read this page by providing us with informed consent (ticking some boxes on the consent page), you may begin the baseline questionnaire. When you register to complete the questionnaire, you will need to provide your email address, and you will be assigned with a unique ID. You do not need to provide your name or home address, and your responses will be kept completely anonymous. You will need to keep your ID safe for completing any later optional questionnaires. The baseline questionnaire will ask you some demographic information, such as your age, gender identity and level of education. After this we will ask you some questions about your physical health and mental health. We will also ask you questions regarding your views of the novel coronavirus outbreak and what behaviours you may have engaged in. Follow up questionnaires will be a little shorter, with demographic and background items removed.

If you do not feel comfortable answering a question, simply leave it blank and move on to the next one. You may complete the questionnaire in your own time, saving it and returning. You may end your participation at any time, for any reason, and we will not ask you why. We will recontact you about follow-up questionnaires, and may additionally send out brief short questionnaires (5 mins) after a major change or advancement to the pandemic situation. You can opt out of re-contact at any point, for any reason. You can also skip a questionnaire and continue to participate in later surveys. These decisions are entirely yours and we respect your wishes.

Do I have to take part?

Participation is completely voluntary. You should only take part if you want to and choosing not to take part will not disadvantage you in any way. Once you have read the information sheet, please contact us if you have any questions that will help you make a decision about taking part. If you decide to take part we will ask you to sign a consent form and you will be given a copy of this consent form to keep, via a download option on our registration page.

What are the possible risks of taking part?

We do not foresee any risks occurring from your participation. We will ask you some questions regarding your physical and mental health, but if you do not wish to answer any question, you can skip that question or alternatively end the questionnaire at any point. If at any point in the study you feel distressed, there are links to support pages on the questionnaire. We take your safety and wellbeing very seriously, and should you have any questions or concerns, please contact the research team on ramp@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 anonymously express their feelings concerning a stressful and unprecedented global event.

Data handling and confidentiality

Your data will be processed in accordance with the General Data Protection Regulation 2018 (GDPR).

To limit the amount of personal data that are collected, we will only ask for your email address to register to the study, and the local council district of your residence. We will assign you a unique anonymous ID to complete the questionnaire with, that is only linked to your email address in an encrypted file accessible only to members of the study team, in order to invite you to complete questionnaires over the course of the study.

Participants who are members of the GLAD, EDGI or NIHR BioResource cohorts will be asked whether they consent to linking their existing data from these studies with new data collected in the RAMP study. This is entirely optional and declining to do so will have no impact on your ability to continue participating in either of these studies, or related studies in the future.

All of your answers to the questionnaires will be stored anonymously on our server. We will not ask for your name therefore the data cannot be linked back to you. Published data will be anonymised and no email addresses will ever be published. We will retain your data for the duration of the study, and for as long as the topic is scientifically relevant, to allow for data analysis and dissemination of our results to the wider scientific community. Again, this data will not be able to be traced back to you. The data we collect will be accessed by our research team, to organise and analyse the data. We may share anonymised data with our trusted research partners, via official request for authorisation. Any data that is shared will be provided in an anonymous form. Any data sharing and transfer arrangements are compliant with GDPR and KCL policies.

Data Protection Statement

Your data will be processed in accordance with the General Data Protection Regulation 2016 (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 free to withdraw at any point of the project, without having to give a reason. Withdrawing from the project will not affect you in any way. 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 anonymous 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 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: ramp@kcl.ac.uk

The research is led by Dr Katherine Young, Social, Genetic and Developmental Psychiatry Centre, King's College London
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What if I have further questions, or if something goes wrong?

The Chair, Psychiatry, Nursing and Midwifery Research Ethics Subcommittee, Research Ethics Office, Room 4.16/ 4.16A Waterloo Bridge Wing, Franklin Wilkins Building, Waterloo Road, London, SE1 9NH pnm@kcl.ac.uk

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. 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.