

INFORMATION SHEET FOR PARTICIPANTS

Ethical Clearance Reference Number: HR-19/20-18544

Covid-19 impact on wellbeing in families of children with rare neurodevelopmental and genetic disorders (CoIN) study

We would like to invite you to participate in the CoIN Study, assessing the impact of the novel coronavirus pandemic on mental health and wellbeing in families of children with rare disorders. Before you decide whether you want to take part, it is important for you to understand why the research is being carried out and what your participation will involve. Please take time to read the following information carefully and discuss it with others if you wish. You can contact the study team on coinstudy@kcl.ac.uk if you have any questions.

What is the purpose of the project?

We would like to understand the specific challenges facing families of children with rare disorders during and after the Covid-19 pandemic, and how these relate to mental health and wellbeing in parents and children over time. We hope this will help us to understand the needs of these families at this time and work out the best way to support families now and in the future.

Why have I been invited to take part?

You are invited to take part because you have a child aged 0-16 years old with a rare genetic or neurodevelopmental disorder. You must be at least 16 years old to take part, and able to understand and communicate in English.

What will happen if I take part?

We will ask you to complete an online survey via a weblink shared through a charity, social media or from a research group at a university. You will be asked to answer some questions about you and your child. The questions relate to your family life and relationships, access to healthcare and education, overall health and wellbeing, your child's behaviour and how you are coping during the Covid-19 pandemic. The questions cover quite a lot of areas so that we can get a really good understanding of how things are for you and your family currently.

You don't need any background knowledge and there are no right or wrong answers. The survey should take around 30-40 minutes but you can take a break and come back to it if you wish.

We would also like you to answer some shorter follow-up surveys (around 15-20 minutes each) each month while social isolation is taking place, and a few months after restrictions are lifted as marked by schools fully re-opening. We will ask you for an email address so that we can contact you for these follow-up surveys. We will ask for consent to collect and store your data in accordance with GDPR within the survey.

If you have taken part in previous research led by a member of the CoIN study team (see list below and on our website), you have the option to enter a unique code (if you've been provided with one) or your child's details (name and date of birth) so that we can link the information

you've provided previously. This is entirely optional and you do not have to provide your child's details if you do not want to.

You will also be asked for consent to recontact you for other studies in the future. You do not have to consent to this to take part in the study, and not consenting to this will not have any negative consequences on your participation in the CoIN study. If you do choose to consent to this, we will add you to a contact list that we may use to send information about future studies that are relevant to families with rare disorders. You can contact us to be removed from this list at any time.

What if I don't feel comfortable answering some or all of the questions?

Simply leave it blank and move on to the next one. You may complete the questionnaire in your own time. You may end your participation at any time, for any reason, and we will not ask you why. You can opt out of recontact at any point. 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. If you choose to take part you will be asked to provide your consent.

What are the possible risks of taking part?

There are no significant risks to taking part. The study will involve completing questionnaires that ask questions about mood, stress and distressing events. The start of the survey contains links to services and helplines if you feel distressed while completing the survey and would like to seek support. These links will also be shared at the end of the survey.

What are the possible benefits of taking part?

There are no immediate individual benefits to taking part. We will provide specialised resources and coping tips via our website and during the survey, and these will be updated according to the responses we receive. What you say will help us to understand how pandemics affect the mental health and wellbeing of families of children with rare disorders and to improve support now and in the future.

What will happen to the results of the study?

We will provide information about the results of this study on the study website and rapidly feed back results to rare disorder charities who will share the information. We also expect to publish in scientific journals so that our findings will be peer-reviewed. It is likely our research will be used to inform government policies.

Data handling and confidentiality

All information collected will be stored securely and be kept confidential. We will assign you a unique ID that is linked to your email address, in order to invite you to complete questionnaires over the course of the study. If you have consented to provide your child's details, these will also be linked to your unique ID. Only members of the research team will have access to this information and it will be stored in an encrypted file. All of your answers to the questionnaires will be stored anonymously on our server, separate from personal details. Published data will be anonymised, and no email addresses or personal details 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 community. Your anonymous data may be combined with data collected from other surveys. This may involve your anonymous data being shared with other research groups in King's College London or external organisations. Any organisations with which we share your anonymous data will

enter a data sharing agreement. This data will not be able to be traced back to you. Any data sharing and transfer arrangements are compliant with GDPR and KCL policies.

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?

If you decide to take part, you may withdraw at any point during the questionnaire without giving a reason before submitting your answers by closing the browser. You can opt out of taking part in future surveys at any point by ignoring or unsubscribing from follow-up emails. You will then not be sent any further surveys to complete. If you withdraw from the project, we will keep the information about you that we have already obtained. We aim to publish summary data shortly after surveys are completed. For this reason it will not be possible to withdraw data once you have already submitted it.

Who should I contact for further information?

If you have any questions or require more information about this project, please contact the CoIN study team at the following address: *<enter email address>*

The research is led by Dr Charlotte Tye, Department of Child & Adolescent Psychiatry, King's College London.

Email: charlotte.tye@kcl.ac.uk

Phone: (+44) 020 7848 5272

Address: Institute of Psychiatry, Psychology and Neuroscience – PO80, De Crespigny Park, Denmark Hill, London, United Kingdom, SE5 8AF.

Who should I contact if something goes wrong?

If this project has harmed you in any way or if you wish to make a complaint about the conduct of the project you can contact King's College London using the details below for further advice and information:

The Chair, Psychiatry, Nursing and Midwifery Research Ethics Subcommittee, King's College London, rec@kcl.ac.uk

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

Collaborators: Dr. Kate Baker (Cambridge); Professor Patrick Bolton (KCL); Dr. Hayley Crawford (University of Warwick); Professor Emily Farran (University of Surrey); Dr Megan Freeth (University of Sheffield); Professor Emily Jones (Centre for Brain & Cognitive Development, Birkbeck, University of London); Dr. Sinead Rhodes (The University of Edinburgh); Dr. Jo Moss (University of Surrey); Professor Deborah Riby (University of Durham); Dr. Caroline Richards (University of Birmingham); Dr. Gaia Scerif (University of Oxford); Professor Emily Simonoff (KCL); Dr. Jo Tarver (Aston university); Dr. Jo Van Herwegen (University College London); Dr. Jane Waite (Aston University).