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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 – Community Feedback

We would like to invite you to participate in community feedback on the CoIN study. The aim of community feedback is to learn how we can develop the survey participants complete as part of the CoIN study. Developing the survey will enable us to ask questions that prioritise the challenges faced by these families and their needs. Therefore, we can better understand the impact of the novel coronavirus pandemic on the mental health and wellbeing of 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 community feedback?

We would like to understand whether the online survey families complete as part of the CoIN study is agreeable and whether the information gathered captures the specific impact of Covid-19 on the daily life and wellbeing of families of children with a rare disorder. The feedback questionnaire will include questions relating to the content of the survey, the information collected, and the experience of completing the survey. We hope by gaining feedback from families we will be able to develop the survey to ensure we are asking questions that capture the challenges they are facing. This will help us to better 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 already completed the initial CoIN study survey and consented to being recontacted for future studies. Your child is aged 0-16 years old and has a rare genetic and 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?

You will be given a copy of the questions included in the online survey to read. You will then be asked to complete some questions about the survey. The questions relate to the content of the survey, the information collected, and the experience of completing the survey. In total, it should take you approximately 30 minutes to read through the survey and complete the feedback questionnaire.

You do not need any background knowledge to complete the community feedback questionnaire but must have taken part in the CoIN study. There are no right or wrong answers.

We will also ask you for consent to be contacted for reimbursement of your time. 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 or any other future studies. 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 feedback 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. 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 in taking part. The study will involve completing a questionnaire that asks questions about the content of the survey, the information collected, and the experience of completing the survey. 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.

Will I be reimbursed for my time?

If you provide your email and consent to be contacted for reimbursement, you will be sent a gift voucher worth £25 upon completion of the community feedback. You are not obliged to accept reimbursement for your time. If you would prefer not to be reimbursed, you do not have to provide consent to be recontacted for reimbursement. Not consenting to this will not impact your participation in community feedback and will not have any negative consequences on your participation in the CoIN study or other research studies.

What will happen with the results of community feedback?

We will use the information you provide to update and develop our survey and monthly follow-up, such that they are more user friendly and capture questions addressing the challenges faced by families of children with rare disorders.

Data handling and confidentiality

All of the information collected will be stored securely and be kept confidential. 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 questionnaire will be stored anonymously on our server, separate from personal details.

We will retain your data for the duration of the study.

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. If you withdraw from the project, we will keep the information about you that we have already obtained. We aim to update our existing initial survey and follow-ups shortly after community feedback 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: coinstudy@kcl.ac.uk

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

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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.