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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 – Parent/carer Interviews

We would like to invite you to participate in an interview about your family's experiences across the Covid-19 pandemic as a member of the CoIN Study community. The aim of completing interviews is to gain information about families' experiences that elaborates on and complements information gathered from the CoIN study surveys. In addition, to asking families detailed questions, interviews serve as the opportunity for families to explore specific experiences, positive or negative, that might only be relevant to their family. This will allow us to 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 an interview?

We would like to understand more detail about the specific experience of individual families of children with rare disorders across the coronavirus pandemic. We hope by gaining elaborate detail of individual experiences will have a richer understanding of individual challenges, complementing data collected in the CoIN study surveys. Additionally, the opportunity to discuss issues relevant to specific families will enable us to develop the survey to ensure we are asking questions capturing the priorities of families. 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 have been invited to take part because you have already completed the initial CoIN study survey and consented to be contacted about future studies. Your child is aged 0-16 years old and has a rare neurodevelopmental and genetic 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 contacted by a member of the CoIN study research team via email to arrange an interview time that is suitable for you. After which they will invite you to a Zoom (a video conferencing platform) meeting to conduct your interview.

The interview we will conduct is known as a 'semi-structured interview'. This means that the interviewer will have a list of set questions they would like to ask, but they will also have the flexibility to explore issues that are important to you and may only affect your family. This means the interview will be guided by the set questions, but if there's anything important you feel is not covered you will get the opportunity to talk about it at the end of the interview. The interview questions will focus on your experiences across the pandemic period, including the effect on you and your child's, health, mood, relationships and routines. The questions will also ask about your support networks, coping methods and access to Covid-related resources. These questions cover similar themes as those

in the CoIN study surveys, but an interview allow us the opportunity to explore specific questions and responses in more detail.

You do not need any background knowledge to take part in an interview 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 an interview, and not consenting to this will not have any negative consequences on your participation in the CoIN study or any 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 tell the interviewer that you do not feel comfortable answering that question and they will move on to the next one. 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 will 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 single 30-40-minute interview, including questions about you family's specific experience of the coronavirus pandemic. Our study website (www.coinstudy.co.uk) contains links to services and helplines if you feel distressed while completing or after finishing the interview and would like to seek support. You will be reminded of where you can access links to services and helplines at the end of the interview .

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 social media, 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 when you register to take part in an interview and consent to be contacted for reimbursement, you will be sent a gift voucher worth £25 upon completion of the interview. 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 the interview 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 the interview?

The information you provide will help us understand the specific challenges faced by families of children with rare disorders to develop support to help them now and in the future. We will also use the information you provide to update and develop our survey and monthly follow-ups, such that they include questions addressing the priorities of 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 interview questions 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>.

The only exception to maintaining confidentiality would be if we suspected that an individual was at serious risk of harm. These issues may arise during interview-based research. If such a situation were to arise, we would deal with it on a case-by-case basis in consultation with our team's clinical experts, according to King's College London policy. This may also involve notification to the relevant authorities.

What if I change my mind about taking part?

If you decide to take part, you may withdraw at any point during the interview without giving a reason by asking the interviewer to terminate your interview. 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 interviews 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.