



Innovate UK



Rare Partners – Transforming Mental Health Support for Children and Young People with Rare Conditions

Participant Information Sheet: Parent Focus Groups

You are being invited to take part in a research study. Before you decide whether or not to take part, you should understand why the research is being done and what it will involve. Please take time to read the following information. Please contact us if anything is not clear or if you would like more information. Take as much time as you need to decide whether or not you wish to take part.

What is the purpose of the research?

Children with certain genetic conditions and/or neurodevelopmental conditions are at increased risk of experiencing mental health problems; however, parents of children with a genetic and/or a neurodevelopmental condition often report the need for better mental health services and information for their children. Cerebra, a national, charity supporting children with brain conditions, has partnered with Cardiff University to speak with parents of children with genetic and neurodevelopmental conditions to better understand their views and experiences of mental health services. By better understanding service user experiences we hope to identify problems with the availability and functioning of current services and how we can change them to improve outcomes for children and their families. This three year project will end in January 2022.

Who is being asked to take part?

We are hoping to speak to several parents of children who have a genetic and/or neurodevelopmental condition, and we would be very grateful if you would be kind enough to help us with this study. We are asking you if you would like to take part as you have indicated that your child has a genetic condition and/or one or more neurodevelopmental conditions.

You have been invited to take part in a Focus Group because your child has been diagnosed with a genetic condition and/or experiences one or more neurodevelopmental problems. By collecting information from families, we hope to understand more about the difficulties service users experience when accessing services and how services and support could be improved.

Do I have to take part?

It is up to you whether you would like to take part. If you decide to take part, you will be free to withdraw at any time and without giving a reason. If you decide not to take part, or if you decide to withdraw from the study, your decision will not affect the health care of you or your child in any way.

What will happen to me if I take part?

If you agree to take part, you will be given a consent form to read and sign. You will be asked to take part in a Focus Group session with other parents who have one or more children with a genetic and/or neurodevelopmental condition. A researcher will facilitate the session and ask members of the group questions about their children and their views and experiences of mental health or encounters with related child services. The questions will help direct the conversation so that the session should feel like you are having a discussion with the other parents in the group. If your child has not been involved with mental health services, we would still be very grateful for your participation, as we want to gather information about the different experiences parents have had.

The research team will organise the Focus Groups at a convenient location. Any travel expenses you have incurred getting to the Focus Group will be reimbursed. The groups will last approximately 2-3 hours and they will be audio-recorded and transcribed for reliability purposes. We may use a professional service to transcribe the recordings. Identifiable data you disclose in the Focus Group session will become known to the transcribing service, however, this will be under a Confidentiality Agreement so that your information will remain private. In all events your confidentiality will be protected and your identity will not be disclosed to anyone outside of this study.

Once the study team have looked at and interpreted the discussions you have had, we may contact you to ask you for your feedback on our interpretations. Your feedback here is voluntary, and will be very useful in helping us to ensure that we have correctly understood your discussion with the other members of the group.

Once you have taken part in the Focus Group and provided your voluntary feedback on our findings, we will not ask for any further participation from you, but we will keep you updated with our findings if you would like us to.

What about confidentiality?

Any personal information you give about you or your child will be kept strictly confidential. This includes information within any publications, or reports of the data in research journals, online and other media. You will be allocated a unique study identification number that will be associated with the information you provide. Neither yours or your child's name or any other identifying information (for example, date of birth, or address) will be passed on to anybody outside of the study team. We will only break confidentiality in the event that you tell us that you, your child or others are at risk of serious harm.

What will happen to my information in the future?

It is possible that the Focus Groups provide data that may be beneficial for future research studies without any future participation from you. This data may be kept by Cardiff University and Cerebra at the end of the study for use for future research. At the moment, we do not know what this research will involve but it could involve sharing information with different researchers not affiliated with either Cardiff University or Cerebra. We stress however that those organisations will not receive any personal identifying information about you.

What are the possible disadvantages of taking part?

The discussions during the Focus Groups may cover some topics that you could find upsetting. Should you become upset at all, you will be able to take as many breaks from the group as you need for as much time as you need until you feel ready to continue. Should you wish to end your participation in the group, you will be able to do so immediately and without explanation.

What will happen to the results of the research study?

We will share our findings from the Focus Groups with you and the other participants who have taken part in the group sessions. This will include participants and findings from the parent Focus Groups, as well as our findings from Focus Groups we plan to run with voluntary sector representatives and health professionals. Our findings will be anonymous and will not include any identifiable information.

We hope to publish our findings in academic journals. We also hope to share our findings with professionals from the NHS, Welsh Government and charities, as well as the public, both online and via conference presentations throughout the duration of the project. However, again we stress that no identifying information will be published or shared in these instances.

What will happen if I want to withdraw from the study?

If you withdraw from the study before the running of the Focus Group, we will not continue to collect information from you. If you withdraw from the study during or after the group, the information you have provided up till the point of withdrawal will remain in the study. Whether you withdraw before, during or after the group, we will not continue to contact you after you have done so.

Who is funding and responsible for your research?

This study is jointly funded by Cerebra, Welsh Government and Innovate-UK and is supported by the MRC Centre for Neuropsychiatric Genetics and Genomics at Cardiff University. The study was reviewed by the School of Medicine’s Research Ethics Committee at Cardiff University.

Further information

If you would like any further information about the Focus Groups, please do not hesitate to contact the research team. You can contact Lowri O’Donovan, Research Assistant working on the project.

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If you would like to discuss this study with someone independent of the study, please contact Hayley Moss, Research Assistant.

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Thank you for your interest in our study.