

Appendix II: Participant Information Sheet

Title of study: Developing an online resource for parents of children with autism spectrum disorder (ASD): A focus group study

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We would like to tell you about the above study and invite you to take part in it to help design an online resource for parents of children with autism spectrum disorder.

About autism spectrum disorder

Autism Spectrum Disorder (ASD) including autism and Asperger's syndrome, is a neurodevelopmental disorder characterised by impaired social interaction, verbal and non-verbal communication, restricted and repetitive behaviour. ASD affects 1.13% of the population worldwide. It is estimated that approximately about three quarters of a million people in the UK are caring for a child with ASD. However, provision of support and resources for children with ASD and their parents from health and social care services in the UK is scarce. Parents quite often rely on support and information from voluntary sectors and/or informal support network.

What is the study about?

We aim to develop an online multi-component resource for parents of children with ASD. The online resource aims to promote parent's mental wellbeing and perceived efficacy in caring for their children, through providing information on ASD and related caring issues, and peer-to-peer support between parents. This study aims to explore parents' views and ideas in designing such a resource in the best possible way – i.e. its content and ways to access and use it are meaningful for parents.

Who are we inviting to participate?

We are inviting parents who have a child with ASD (with or without any other concurrent physical health or mental health conditions) for the study. In addition to biological parents, adoptive or step parents are also welcome. Parents need to be aged 18 or above, and able to participate in discussion in English.

What will happen if you agree to take part in the study?

You will be invited to attend an one-off meeting with a few other parents. During the group meeting, we will facilitate all the participants to discuss their ideas and views on what should be included in an online resource and how best to design it, in order to provide information and support for parents, like yourself. This discussion is expected to take approximately 90 minutes. The discussion will be audio recorded, with everyone's permission. After the group discussion, the recording will be transcribed into a written record in an anonymised manner, i.e. no personal identifiable data included in the written record that could link you or any participants to the discussion. We will analyse the study findings from the written record and destroy the audio-recording once the written record is checked to be accurate and complete. The findings will then be used to help develop further studies to build the online resource. Focus group participants will be given a summary of the main findings.

Where and when will the study take place?

We expect to hold three to four group meetings, each with about 4 to 8 participants, with a maximum of two group facilitators. We will organise the group meetings in University of Reading Whiteknights campus and at a time most convenient for the majority of participants, including early evenings, between April and August 2018.

Will you be compensated for your time?

Yes. To thank you for taking the time to participate, we will offer you a £10 goodwill payment at the conclusion of the focus group. We will also reimburse you for the travel expenses incurred for attending the meeting (maximum £20 per person due to budget limit).

Are there any risks involved in participating?

The risk involved in participating in this study is minimal. The discussion will be facilitated around the focus group study aim which is about the content and design of an online resource for parents. However, you may find sharing or hearing experiences relating to caring for a child with ASD emotionally arousing. You do not need to feel compelled or under pressure to discuss any topics throughout the discussion. The researcher (who will facilitate the group discussion) will remind participants there are no right or wrong answers and to treat each other respectfully. The lead-researcher, a qualified mental health nurse, will offer support for any participant who wants to discuss their experiences of participating in the focus group and signpost them to a relevant agency, if anyone requests such support.

Are there any benefits involved in participating?

We hope that you will enjoy the opportunity to meet with other people with similar experience and to discuss your views on how best to design an online resource. Your ideas and perspectives will help make the resource meaningful and helpful for people like yourself.

How will we maintain your privacy and confidentiality?

Everything you discuss will remain confidential within the limits of the law. During the group meeting, we will ask all participants to use only their own and one another's first name in their discussion. Discussion involving others, e.g. their family members or healthcare professionals, will be kept to a minimum and if really necessary only involve non-identifiable

data (e.g. a clinic in Reading). We will ask all participants to respect one another's privacy and confidentiality that what discussed during the focus group stay within the group.

Your personal details that are collected for administrative purposes (e.g. consent form, reimbursement record) will be stored in a locked cupboard within the researcher's office and only the researcher will have access to such data. Other data collected (e.g. discussion content) will be assigned with an anonymous code (e.g. FG1P4). The information linking that code to your name will be stored securely and separately from the data you provide us. All information collected for the project will be destroyed after a period of 5 years from the completion of the project has elapsed.

Please note that:

Taking part in this study is completely voluntary, you may withdraw your cooperation at any time without having to give any reason.

Please feel free to ask any questions that you may have about this study at any point.

This application has been reviewed by the University Research Ethics Committee and has been given a favourable ethical opinion for conduct.

Thank you for your help.

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