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| **Participant Information**  **Exploring the experience of being a mother with Autism** |
| 1. **Background**   York St John University would like to invite you to take part in the following research project.  Before agreeing to take part, please read this information sheet carefully and let us know if anything is unclear or you would like further information. |
| 1. **What is the purpose of the study?**     The purpose of the study is to explore the experience of being a mother with an autism spectrum condition (sometimes known as autism spectrum disorder, autism, or Asperger’s syndrome). The study aims to investigate the strengths and difficulties that are experienced by mothers who have an ASC. |
| 1. **Why have I been invited to take part?**     You have been invited to take part because we would like mothers with ASC to share their experience of being a mother with this condition. We would also like mothers with ASC to help to shape the research in this area by informing us about what topics they feel are important for researchers to explore. |
| 1. **What will I have to do?**   We will interview you for 60-90 minutes on your own (or with someone of your choosing if that is more comfortable for you) about your experience of being a mother with ASC. We can send you the questions in advance so that you can think about your answers. Interviews can be conducted in person, over telephone or Skype. If you are not comfortable with these methods, you can provide answers over encrypted email instead. |
| 1. **Do I have to take part?**     No, participation is optional. If you do decide to take part, you will be given a copy of this information sheet for your records and will be asked to complete a participant consent form. You can decline to answer some questions during the interview if you prefer.  If you change your mind at any point during the study or up to a month after you participate, you will be able to withdraw your participation without having to provide a reason. If we have already analysed and included the data you provide in our study, we will not be able to extract it after this time. However, we can endeavour not to use your quotations in publications or presentations if you stipulate this. |
| 1. **Will you share my data with 3rd parties?**     Data will be accessible to the project team at York St John University only. We will transcribe the interviews you provide so that we can analyse them to identify themes and subthemes. We will anonymise the interview transcripts by removing references to specific people, places and dates. We will use the transcripts to write publications for academic journals and to present at national and/or international conferences.  As researchers we also have to be aware of the wellbeing of our research participants. Therefore, we will ask for your GP details and obtain your consent to contact them if we are very concerned about your wellbeing or about your family’s wellbeing. If we do have any serious concerns that we need to pass on, we would normally be able to discuss this with you first. Serious concerns would relate to significant mental health problems that are not being treated, or child/adult safeguarding issues.  A number of additional options for sharing data are available to you. You can choose:     * If you consent to anonymised transcripts of your interviews being used by the research team at York St John University for other research projects and teaching purposes. * If you consent to us making anonymised transcripts of your interview available to other researchers through an online data-sharing platform. This would enable other research teams to analyse the information that you provided. More information about sharing research data is available here: <https://www.ukdataservice.ac.uk/manage-data/legal-ethical/consent-data-sharing/inform-participants> |
| 1. **Will you transfer my data internationally?**     No. |
| 1. **Will I be identified in any research outputs?**   As researchers we aim to publish and present this research, however your data will be combined with the data from other participants, and nobody will be individually identifiable from the publications. We can consult with you if you would like to review any publications before they are sent to academic journals to ensure that you are satisfied that the papers do not identify you or your family. |
| 1. **Questions or concerns**     If you have any questions about this participant information sheet or concerns about how your data is being processed, please contact Dr Fionnuala Larkin in the first instance. If you are still dissatisfied, please contact the University’s Data Protection Secretary at [us@yorksj.ac.uk](mailto:us@yorksj.ac.uk).  Contact Details: Dr Fionnuala Larkin, School of Psychological and Social Sciences,  York St John University, Lord Mayors Walk, York,YO31,7EX.  E-mail: f.larkin@yorksj.ac.uk |

**Exploring the experience of being a mother with Autism**

**CONSENT FORM**

Please tick the relevant boxes to indicate your agreement:

I have read and understood the study information sheet, or it has been read to me.

I know who the researchers are and how to contact them I have any questions.

I consent voluntarily to be a participant in this study and understand that I can refuse to answer questions and I can withdraw from the study at any time up to a month after the interview, without having to give a reason.

I consent to give my GP’s details, and for serious concerns about my wellbeing or my family’s wellbeing, to be passed on by the research team if necessary.

[Optional] I consent to the named researchers using the data I provide in further research projects.

[Optional] I consent to pseudo-anonymised transcripts of my interview and basic information about me (age, family structure) being made available to other research teams through an online data-sharing facility.

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| **Signatures**  Name of participant [IN CAPITALS]:  \_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_  Signature:  Date:  **GP Surgery:**  **GP Phone Number:** | Name of researcher [IN CAPITALS]:  \_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_  Signature:  Date: |