



Participant Information Sheet for Parents - Questionnaire

UCL Research Ethics Committee Approval ID Number: _____

YOU WILL BE ABLE TO REQUEST A COPY OF THIS INFORMATION SHEET

Title of Study:

An Investigation of autism stigma in parents of children with ASD

Department:

Clinical, Educational and Health Psychology (Division of Psychology and Language Sciences)

Name and Contact Details of the Researcher(s):

Emma Chettiar – emma.chettiar.18@ucl.ac.uk

Name and Contact Details of the Principal Researcher (Supervisor):

Dr Jessamine Chiappella – j.chiappella@ucl.ac.uk

1. Invitation Paragraph

My name is Emma Chettiar and I am a Trainee Educational Psychologist. As part of my training, I am carrying out a research project which you are being invited to take part in. Before you decide, it is important for you to understand why the research is being done and what participation will involve. Please take time to read the following information carefully and discuss it with others if you wish. Take time to decide whether or not you wish to take part and ask us if there is anything that is not clear or if you would like more information. Thank you for reading this.

2. What is the project's purpose?

This is a two part study and this part of the research is an interview investigating the impact of autism stigma, or stigma by association with an individual with autism, in parents of children with a diagnosis of autism. Autism stigma can be experienced by parents of children with autism and has the potential to make life more difficult for them. We want to increase our knowledge of how mothers and fathers living in the UK are affected. After a child is diagnosed with autism, there are often a range of services and other sources of support that parents are able to access. Research has identified some of these services, however also we want to better understand the impact of autism stigma on parents' engagement with services, as this may help services to support parents better.

3. Why have I been chosen?

You have been selected for this research because you meet the criteria of being a parent of a child with ASD. We want a wide range of parents to participate in this research so if you have a partner or friend who would also be eligible to take part, please do send them the details of this research so that they can take part too.

4. Do I have to take part?



Your participation in the study is entirely voluntary- It is up to you to decide whether or not to take part. If you do decide to take part, you will be able to download this information sheet to keep and you will also be asked to sign a consent form. You can withdraw at any time without giving a reason. If you decide to withdraw after completion of the questionnaire, you will be unable to withdraw your data from the study. This is because the questionnaire is anonymous and it is not possible to identify you.

5. What will happen to me if I take part?

This part of the research project involves completing a questionnaire about life as a parent of a child with autism. This is an online questionnaire and should take a maximum of 20 minutes of your time. You will be asked to give your ethnicity and gender but you will not be asked for any other personal information.

Giving consent to participate in this study will not mean that you are contacted for future research.

6. Will I be recorded and how will the recorded media be used?

You will not be recorded for the purpose of this study. All data from the anonymous questionnaires will be stored on a password protected device and destroyed after 5 years. The reason this will be kept is because the data is contributing to an accreditation and may need to be verified by external professionals.

7. What are the possible disadvantages and risks of taking part?

We recognise that the topic area for this research is sensitive and you will be required to reflect on your role as a parent of a child with autism. Whilst planning this project, however, the researcher has considered any reasonable foreseeable discomforts, disadvantages and risks to participants.

You can choose not to answer a question and you have the right to withdraw at any time. At the end you will receive information about accessing additional support. You will also receive contact details should you have any additional questions about this research.

Should you experience any other unexpected discomforts, disadvantages or risks during the research, this should be brought to the researcher's attention as soon as possible.

8. What are the possible benefits of taking part?

Participants who complete this questionnaire will be given the option to enter into a prize draw to receive a £10 voucher. If you are the winner, you will be contacted at the end of the research to be sent your prize.

Alongside this immediate benefit, it is hoped that this work will provide a better understanding of life as a parent of an autistic child, as well as how the support that mothers of children with autism receive can be improved. We also believe that this research will be enjoyable for participants and will give them an opportunity to present their views and experiences.

9. What if something goes wrong?



In order to ensure your data remains anonymous, a data protection impact assessment (DPIA) will be carried out. This details the measures that will be put in place to minimise the risk of a data breach as well as a protocol for if a data breach was to occur.

If you wish to raise a complaint about your treatment by the researcher, you should contact should the Principal Researcher supervising this project – j.chiappella@ucl.ac.uk

If you feel that your complaint has not been handled satisfactorily by the Supervisor, then you can contact the Chair of the UCL Research Ethics Committee – ethics@ucl.ac.uk

10. Will my taking part in this project be kept confidential?

All the information that we collect about you during the course of the research will be kept strictly confidential. Data will be anonymised and stored securely on a password protected device. Your data will be stored securely for 5 years before being destroyed. You will not be able to be identified in any ensuing reports or publications.

11. Limits to confidentiality

The researcher has a duty of care to report possible harm/danger to the participant or others to relevant authorities. This means that confidentiality may be limited and conditional. If, at any point, I become aware of anything which makes me worried that you or someone else might be in danger of harm, I might have to inform relevant agencies of this.

12. What will happen to the results of the research project?

The results of this project will be presented within the researcher's thesis (estimated date: June/July 2021) and may also be published in a relevant journal so that they can be disseminated more widely.

Once again, you will not be able to be identified in any publication of this project. Your data will be stored securely for 5 years before being destroyed.

13. Local Data Protection Privacy Notice

Notice:

The controller for this project will be University College London (UCL). The UCL Data Protection Officer provides oversight of UCL activities involving the processing of personal data, and can be contacted at data-protection@ucl.ac.uk. The Data Protection Officer is Alex Potts (a.potts@ucl.ac.uk).

This 'local' privacy notice sets out the information that applies to this particular study. Further information on how UCL uses participant information can be found in our 'general' privacy notice:

For participants in research studies, click [here](#)

The information that is required to be provided to participants under data protection legislation (GDPR and DPA 2018) is provided across both the 'local' and 'general' privacy notices.



The categories of personal data used will be as follows:

- Ethnicity
- Gender
- Physical/Mental health (child)

The lawful basis that would be used to process your *personal data* will be ‘performance of a task in the public interest’.

The lawful basis used to process *special category personal data* will be for scientific and historical research or statistical purposes.

Your personal data will be processed for 5 years. If we are able to anonymise or pseudonymise the personal data you provide we will undertake this, and will endeavour to minimise the processing of personal data wherever possible.

If you are concerned about how your personal data is being processed, or if you would like to contact us about your rights, please contact UCL in the first instance at data-protection@ucl.ac.uk.

14. Who is organising and funding the research?

This research is being organised and funded by the Department of Psychology and Language Sciences.

15. Contact for further information

If you require any further information, please do not hesitate to get in contact:

Researcher: Emma Chettiar
emma.chettiar.18@ucl.ac.uk
020 7679 5448 (ex.25448)

Principal Researcher: Dr Jessamine Chiappella
j.chiappella@ucl.ac.uk
020 7679 5448 (ex.25448)

Thank you for reading this information sheet and for considering to take part in this research study. If you now decide to take part, you will be given a copy of the information sheet and signed consent form to keep.