

Participant Information Pack - Autistic Experiences of the Perinatal Period

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Invitation to take part

You have been invited to take part in this study because:

- You are **autistic** (self-identify)/ have an autism diagnosis
- Are aged **18 years old and over**

And you have at least one of the following experiences:

- You have experience of **accessing maternity care in England in the last 2 years.**
- You have **supported a birthing partner through their maternity care in England in the last 2 years.**
- **Maternity care includes:**
 - Attending antenatal or postnatal appointments with a midwife or doctor;
 - pregnancy scans;
 - attending the birth with support from a health professional;
 - visits from a health visitor;
 - or any other supporting during pregnancy or up to one year after birth.



Participant Information

- This pack aims to give you all the information you need before deciding whether you would like to take part in the study.
- The pack provides an overview of the study information, and then provides a more detailed description of what will be involved in the study if you choose to take part.
- Please take the time to carefully read this information before providing your written or verbal consent to take part in the study.
- If you would like to receive this information in video format, please see: (link).
- If you would like more information or to ask questions, please email Caitlin: c.thompson17@newcastle.ac.uk.



Participant Information Overview

<p>Who is carrying out the study?</p>	<p>Caitlin Thompson is the researcher leading the research as part of her PhD qualification at Newcastle University.</p> <p>Caitlin is supported by her supervisors, Dr Ryc Aquino, Professor Judith Rankin, and Dr Fiona Gullon-Scott.</p>
<p>Why is this study being carried out/ why is it important?</p>	<ul style="list-style-type: none">• Autistic people have reported poorer experiences of care during pregnancy, childbirth, and the postpartum period. We want to understand their experiences in better detail.• We want to use this evidence to help make care for autistic people better in the future.
<p>What will happen if I take part?</p>	<ul style="list-style-type: none">• Three interviews which will give you the space to share your story of pregnancy, childbirth, and the postpartum period.• The focus will be on your experiences of care during this time.• You can choose what you share and how you share it.
<p>Do I have to take part?</p>	<ul style="list-style-type: none">• No, it is your choice whether you want to take part or not.
<p>What are the possible benefits of taking part?</p>	<ul style="list-style-type: none">• Helping to better understand and improve autistic people's experiences of accessing care during the perinatal period.• You will be offered a £100 Love2Shop voucher as a thank you.

Participant Information Overview

<p>What are the possible risks of taking part?</p>	<ul style="list-style-type: none">• Taking part in this research is not expected to cause any disadvantages or discomfort to you.• However, if it is distressing for you to talk about any of the topics covered, you can pause or stop the interview at any time.• If you have any concerns about taking part in the interview, we advise you to discuss it with others (for example your family or friends).
<p>What information will be collected?</p>	<ul style="list-style-type: none">• Your name and contact details to arrange the interviews. This will be destroyed at the end of the study.• Audio or text recording of interviews (which will be deleted upon project completion).• Anonymised transcript of interviews• If you choose to use anything to support your discussions during the interviews, these materials will only be saved (e.g., by storing photographs or descriptions of them) if you give consent. This will be confirmed during Interview One.
<p>Who will have access to this information?</p>	<ul style="list-style-type: none">• The researcher (Caitlin) and supervisors (Dr Ryc Aquino, Professor Judith Rankin and Dr Fiona Gullon-Scott).• Your interview transcript may be transcribed by an external transcription company, and if so, they will read over the transcript of your interview before it has been anonymized.• Anonymised information, or materials used to support discussion (if you give your consent), may be used in the write up of a research paper, or shared at a conference, or to health professionals to help improve services in the future.

Participant Information

<p>Who will have access to this information?</p>	<ul style="list-style-type: none">• If you consent to, anonymised data may be used by future researchers for future studies.
<p>How will my data be stored?</p>	<ul style="list-style-type: none">• Anonymised data will be stored for up to ten years in line with university policy, using secure data storage (data.ncl).• Confidential and identifiable information will be destroyed at the end of the study.
<p>What information about me will be kept confidential?</p>	<ul style="list-style-type: none">• All personally identifiable information shared in the interview will be kept confidential.• Direct quotations from the typed-up copy of the interview may be used in publications; however, no identifiable information will be shared.• Unless you provide your consent to share, any materials you may wish to use to support your discussions will be kept confidential.• In exceptional circumstances the researcher may need to break confidentiality if they think you are at serious risk of harm or danger to yourself or others.
<p>Can I withdraw from this study?</p>	<ul style="list-style-type: none">• You are free to withdraw from this study without giving a reason at any point, up until you have provided approval on the anonymous transcript of your interview.• If you decide to withdraw, you can still keep your voucher, and all data collected will be destroyed.• If you wish to withdraw from this study, please contact Caitlin (c.thompson17@newcastle.ac.uk) as soon as possible.

Participant Information

<p>Has this study received ethical approval?</p>	<p>This study was approved by the Faculty of Medical Sciences Research Ethics Committee, part of Newcastle University's Research Ethics Committee. This Committee includes members who are internal to the Faculty. This study was reviewed by members of the Committee, who must provide impartial advice and avoid significant conflicts of interests.</p>
<p>Who should I contact for more information?</p>	<p>Please contact Caitlin if you would like more information or have any questions.</p> <p>Caitlin's email is: c.thompson17@newcasatle.ac.uk.</p>
<p>Who should I contact if I would like to complain?</p>	<p>Dr Ryc Aquino at ryc.aquino@newcastle.ac.uk</p> <p>If you remain unhappy and wish to make a complaint about how your personal data is handled, you can contact the Data Protection Officer who will investigate the matter: Maureen Wilkinson; rec-man@ncl.ac.uk.</p> <p>If you are not satisfied with their response you can complain to the information commissioner's officer (ICO): https://ico.org.uk/</p>

What will happen if I take part?

The information below explains what will be involved in the study.

- The study involves **sharing your story** of pregnancy, childbirth, and the postpartum period (up to one year after birth) **and your experience** of accessing care during this time.
- How you share your **story can be up to you**. The basic requirements are **three interviews/chats** that are broken into the following:

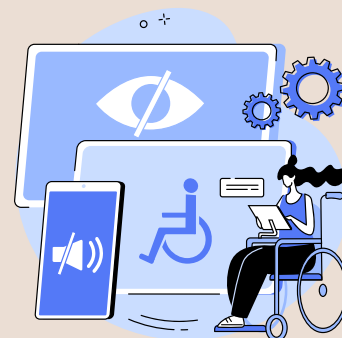
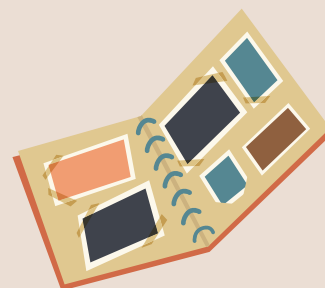
Interview One

- This is an **initial chat** with the researcher (Caitlin) either face to face, email/text correspondence, phone or video call, to talk about the study and **make sure it is right for you**.
- You may **bring along a partner or advocate** or someone to support you to this interview (if in-person for example) and all subsequent interviews if you choose.
- In this chat, Caitlin will **ask you questions** about yourself such as your age, gender, ethnicity, and the year of your most recent birth.



Interview One

- You can speak to Caitlin about the **different methods** you could use to support discussions. You **do not have to use anything** if you do not want to.
- For example, **bringing along photographs** to help jog your memory, or bringing something which **helps you reflect on your experience** such as an object, a piece of art or writing. These are just examples, and you can talk through the different options with Caitlin.
- You can speak to Caitlin about adjusting the interviews to your own **accessibility needs**, such as doing the interviews over email correspondence or video calling without the camera on, for example.
- Caitlin will go over the content of the interviews and go through the **topic guide** with you.
- This will **not** be recorded (audio or text).
- It will last around **45 minutes to 1 hour**.



Interview Two

- This interview **will be recorded** (audio or text).
- We will cover topics such as your **pregnancy journey**, focusing on the **pregnancy** itself and the **care accessed before birth** (or up to now if you are currently pregnant).
- If you have chosen to bring something along with you to support the discussion, we will also discuss whatever **you have brought along** and how it **relates to your experiences** specifically of **pregnancy or accessing maternity care**.
- It will last **between 1 hour and 1 hour 30 minutes (with breaks)**.
- There will be **additional time** at the end for **reflection**, and to **debrief**, if needed.



Interview Three

- This interview **will be recorded** (audio or text)
- It will be aimed at discussing the **birth experience** and the **postnatal period** up until one year post-birth.
- If you have chosen to **bring something along with you** to support your discussion, we will also discuss how **this relates to your experiences**.
- This could be something **different to last time**, and it will relate to your experiences of **childbirth** and/or the **postpartum period**.
- This interview will also aim to summarise and **reflect on your experiences** of pregnancy, the perinatal period, and accessing maternity care as an autistic person.
- It will last **between 1 hour and 1 hour 30 minutes (with breaks)**.
- There will be **additional time** at the end for **reflection**, and to **debrief**, if needed.



Contacts for further information

Please contact Caitlin if you would like more information or have any questions.

Caitlin's **email** is:
c.thompson17@newcasatle.ac.uk.



Telephone number: 07884615687



If you would like to see an information video to supplement this information sheet, please click [here](#) or contact, Caitlin for a link to be sent to you.

