

Interview Topic Guide

Autistic Experiences of the Perinatal Period



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Information

This pack provides an idea of what will be asked by me (Caitlin) across Interviews 1-3.

If you are reading this pack, you will have received and read the **information pack** or **watched the information video** and provided your **consent to take part**.

Please note that each interview will depend on what your own experiences are, and, to allow for flexibility, questions may be asked that are specific to you and your experiences (based on what you decide to share).

You **do not have to answer every question**; you can **pause** or **stop** the interview anytime.

Regular **breaks** will be encouraged.

Reminder

- 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 3 interviews/chats that are broken into the following:



Interview One

- This is an **initial chat** with me 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, I will **ask you questions** about yourself such as your age, gender, ethnicity, and the year of your most recent birth.
- You can speak to me 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 me.
- You can speak to me 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.



Interview One

- I 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 One - Topic Guide

- The interview will start with **introductions**. I will introduce myself and welcome you.
- I will explain briefly, again the **purpose of the study** and you will have the opportunity to ask questions.



Example:

“Thank you for agreeing to take part in this interview, and for giving up your time.

We are inviting autistic people who have experienced accessing care through pregnancy, childbirth, and/or the postpartum period in England, to an interview with their partner (where possible/desired) to share their experiences (whether positive or negative).

We are interested in finding out more about your experiences of accessing care. We hope to use this information to inform future services on the best ways to care for autistic people through the perinatal period.

Everything you share in this interview will be confidential. We are interested in your view and experiences. However, we are aware that some of the discussions around care experiences may be sensitive area and you may not want to answer all questions – if this is the case just let me know and we'll move onto the next question.

This first chat will last up to an hour.

Let me know if you would like to have a break or stop the interview at any point.

Feel free to ask questions at any stage during the interview.”

I will then give you an explanation of what this current interview is for:

- Better understanding of who you are and what your experiences are (briefly)
- To see if this study is right for you
- To meet each other and become familiar with how the study will run

If you are happy to continue following this chat, I will then move on to asking you some questions. If not, the interview will be ended here, and none of your data will be stored.

Questions about you



I will then ask you the following questions (you do not need to answer them if you do not want to).

- What is your age?
- What is your gender and preferred pronouns?
- When was your last pregnancy/are you currently pregnant (if so, how many weeks)
- When did you last give birth (if you have given birth)
- What is your ethnicity?
- What is the first half of your postcode?
- What is the highest level of education you have received?
- What is your employment status?
- Did you access your perinatal care in England?
- How many children do you have?
- Have you got a formal diagnosis of autism? [if yes – when were you diagnosed?]

Explaining the study and what to expect:

I will then explain the study to you in more detail, specifically **about bringing along something** to help support your discussions. Please **feel free to ask any questions**.

You **are welcome to ask questions at any time**, but if you do not feel comfortable interrupting me, I will stop to ask you if you have questions regularly throughout the interview.



Supporting your story

Throughout interviews two and three, I will give you the space to **use things to help support your discussions** (e.g., photographs, a piece of art, writing, or an object etc.).



I want to give you the space to **bring along something** of your choosing to help you share your experience.



Sometimes, sharing words alone can be difficult. If you feel that it would be helpful to share with me a certain experience **using the support of an object**, then you are welcome to do so.



For example, to help share my feelings, thoughts, or reflections on an experience I have had, sometimes I find it **helpful to write it down as a story** (with a beginning, middle, and end) and share it that way.

Other people have an **object that reminds them of a certain memory** and can help them to share stories attached to that memory. It is also common for people to use photographs to do the same thing.



I will give you **time** between now and interview two to either **choose something** which you would like to bring or **to create something**. Please let me know in the meantime if you need me to send you any resources to help (within reason), for example, paper, pens, pencils, etc. This is something we can arrange.



You may want to **bring different things** to interviews two and three, and that is fine.



You will have time between interviews two and three if you choose to create or choose something new.

During interview one, I will ask you if this sounds like something you would be interested in doing.



Together we can chat about the **different things you might want to bring**. You do not have to decide now. Equally, you do not have to bring anything with you.

You can also bring **multiple things** if you think that would be helpful, and different things to each interview if you would like to.



There will be opportunities for you to ask any questions.

Interview Two - Topic Guide

- 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**, including breaks.
- **There will be additional time at the end for reflection and to debrief, if needed.**

To facilitate discussion, below are some **examples** of what I may ask you as **prompts**. You **do not need to answer every question**. Please feel free to share your story however you find best.



Example questions/topics:

- What were your experiences of being pregnant? (Example: symptoms of sickness, sensitivity to stimulus, fatigue).
- Did you have any physical or emotional/mental health symptoms during pregnancy?
- Can you tell me about the type of care you received during pregnancy?
- Where did you access your care during pregnancy (e.g., midwife appointments, scans etc.)
- Did you access in care in the community (e.g., peer groups)
- How did you find the care you received?
- How helpful were the health professionals?
- In what way did the health professionals tailor the care they provided you to your autism/ autistic needs?
- Was there anything done particularly well during your pregnancy care?
- Were there any times that care could have been improved during your pregnancy?
- What was your experience of giving birth?
- Who attended your birth, e.g., partner, doula, family?
- Did you have a birthing plan? [if yes, was this followed?] [if no, would you have liked one?]
- How was your treatment by health professionals during birth?
- Was there anything you would have liked doing differently during birth?
- What was your overall experience of care during birth?

It may already come up during the discussion of any of the above, however, if you have brought something to support your discussion, you will have the **opportunity to discuss this** and how it **relates to your experiences** of pregnancy and maternity care.



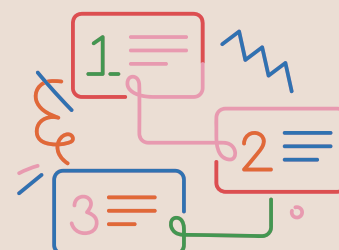
There will also be an opportunity for you to discuss **any other experiences** of your time accessing care through pregnancy and childbirth that you haven't already.



Before ending the interview, you may also discuss when you would like to **schedule Interview Three** based on a date and time that works best for you.



It is recommended that **you have time between each interview** (at least one month) to reflect and process the information from the interviews and if you want to, create or choose something to bring along with you to the next interview.



Interview Three

- This interview will be **recorded** (audio or text)
- It will be aimed at discussing **birth experiences** and the **postnatal period** (up to 6 months after 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**, including breaks.
- There will be **additional time** at the end for **reflection**, and to **debrief**, if needed.



To facilitate discussion, below are some **examples** of what I may ask you as **prompts**. You **do not need to answer every question**. Please feel free to share your story however you find it best.



Example questions/topics:

- What were your experiences of the postpartum period?
- Can you tell me in what ways you adjusted to your new routine with your baby?
- Please describe how you found being a new parent (if first-time parent)?
- Can you tell me about your physical health during the postpartum period?
- Can you tell me about your mental health during the postpartum period?
- How did you feed your baby?
 - If you breastfed, how did you find that?
 - Did you receive any support or education on feeding?
 - If not, was there anything that would have supported you?
- What the level of care in-line with your expectations/needs during the postpartum period?
- Where did you access your care during the postpartum period (e.g., GP appointments, health visitor visits, midwifery support, or community/ family hubs etc.)
- What do you think about the care you received?
- In what ways were the health professionals helpful/unhelpful?
- How did the health professionals tailor the care they provided you to your autism/ autistic needs?

- Can you tell me what was done particularly well during your care postpartum?
- Can you tell me about any times that care could have been improved postpartum?
- How was your treatment by health professionals during the postpartum period?
- Did you attend any baby or parent groups in the postpartum period?
- If yes, what were your thoughts on the group?
- If no, why not?
- Can you tell me what you would have liked done differently during birth?

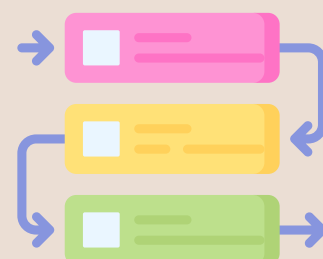
It may already come up during the discussion of any of the above, however, if you have brought something along with you to support your discussion, **you will have the opportunity to discuss this** and how it relates to your **experiences of childbirth** and the **postpartum period**.



There will also be an opportunity for you to discuss **any other experiences** of your time accessing care through the postpartum that you haven't already.



You will also have the chance to speak about **your experiences** across your pregnancy and birth, and **reflect** across the interviews.



Before ending interview three, I **will offer you** a £100 voucher as a **thank you** for taking part in the study. This can be either delivered to you in the post or sent to you digitally via email.



You will also be reminded that, if you would like to, an anonymised transcript can be sent over to **you to proof-check** before analysis.

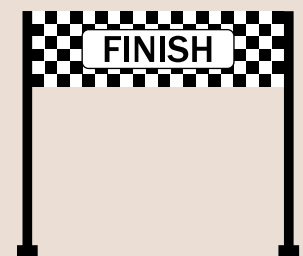


This is to ensure that **your experiences are accurately reflected** in the interpretation of the data.



You will also be asked if you would be willing to be involved in other related **research in the future**.

The interviews will be **completed** once you are happy to end the interview.



Contacts for further information

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

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