

Antenatal Interview

Interviewee Name: _____ **Date:** _____

Prior to interview: Told Others of Interview Local & Time ____, Extra Batteries ____, Pen & Pad ____, Epilepsy Nurse/ Support Contact Numbers ____

Pre Interview Checklist	X
Understands qualitative study	
Received and read the PIS	
Answer participant's questions	
Consented to take part obtained	
If not participating in trial: Interview consent signed	
Consented to record	

Field Notes (Details of where interviewed, who present, etc.)

Demographic Info

Age: _____

Years had epilepsy: _____

of children: _____

Type of Epilepsy (self-defined):

Stage in pregnancy: _____

Mailing Address: _____

Due Date: _____

Ethnicity (self-identified): _____

Email: _____

Religion: _____

Trial Number: _____

Occupation: _____

Marital Status: _____

RECORDER ON

1. Managing Epilepsy Outside of Pregnancy

What would you like to call your condition? Is this how you usually refer to it?

Take me back to when you first had __[reflect language back]__. Please tell me the story of when this first occurred.

- Prompts: What happened, who was there...
- **What do you call these events (i.e. seizures/episodes/fits)?**
- **Please describe what these [participant's term] are like.**
- How did you receive your diagnosis? When did you receive it?
- How did you feel about the diagnosis?

How does ____ [participant's term] ____ fit into your day to day life? Tell me about what your normal day-to-day life is like.

- Who have you told? Who do you talk to about this?
- Who do you get support from? How do they support you?
- Does [participant's term] interfere with your day to day life? How?

What drugs you have taken in the past? And now?

Epilepsy is often thought of as a stigmatising condition. How do you feel about that? Is that true for you?

2. Preconception Experience

**First-time pregnancy:*

Before becoming pregnant- thinking about your __[epilepsy/participant's term]__ -how did you feel about pregnancy?

- Did you have any concerns/hopes?
- What did you think about your medication and becoming pregnant?

**Those with previous pregnancies:*

Tell me about what your past pregnancy/ies were like.

- Did this influence how you planned for this pregnancy?
- Did you have any concerns/hopes for this second/third/fourth... pregnancy?

Tell me about your labour experience

** All participants*

How did you learn you were pregnant?

- How did you feel?
- How did others (partners, family, etc.) feel?

How did you find information about pregnancy while having [epilepsy/ participant's term] ?

- Prompts: From where? Who?
- What did you think of this information? Was it helpful?

3. Experience of Pregnancy

How do you feel about being pregnant and having epilepsy?

- Has the way you manage your [participant's term] changed? How? Can you give an example?
- How have you changed your life in relation to [participant's term] since becoming pregnant?

As you know you are receiving additional ante-natal care because of your epilepsy, which means that you are in a category of high risk. Has anyone mentioned that to you? How do you feel about being categorised as high risk?

Why did (or didn't*) you decide to take part in this trial?

- *If opted out- can I ask why you chose not to participate?
- How do you feel about the: drug regime, blood tests, hospital visits, and monitoring by the clinic?

4. Weighing Up Risks vs. Benefits

How do you weigh up the risks vs the benefits of having baby while living with [epilepsy /participants' term]?

Cover the following areas through conversation:

- Risks of [epilepsy/participant's term] on *your baby*?
- Risks to *yourself*?

- Benefits of [epilepsy/participant's term] on *your baby*?
- Benefits to *yourself*?

- Risks of epilepsy management/medication on *your baby*?
- Risks to *yourself*?

- Benefits of epilepsy management/medication on *your baby*?
- Benefits to *yourself*?

- Risks of seizures on *your baby*?
- Risks to *yourself*?

If participant sees seizures as positive:

- How do you weigh up the benefits of seizures on *your baby*?
- And the benefits to *yourself*?

Who do you talk to about managing your [epilepsy/participant's terms] during your pregnancy?

What influences how you make decisions regarding managing epilepsy during your pregnancy?

- Who influences these decisions?
- Who supports you? How do they support you?

5. Tell me about your experience (of care/at the clinic)

- How have your interactions with the doctors/nurses been? Expand/tell me more/give an example
- Your concerns about (what stated in previous questions), have you raised them with nurses/doctors? How did you feel about the information/advice they gave you?
- Do you feel you get all your questions answered?
- Do you have enough time with nurses/doctors?

6. Concerns and Hopes for the Future

- What are your main concerns about the rest of your pregnancy?
- What are your hopes for the rest of the pregnancy?

- Do you have concerns about the labour?
- What are hopes for the labour?

- After the labour, and your baby is born, what are your hopes for your baby?
- Do you have any concerns for your baby?

- Do you have any concerns for yourself after the baby arrives?
- What are your hopes for yourself after the baby arrives?

7. Concluding Questions

Is there anything else we didn't discuss that you would like to talk about?

Do you have questions for me?

RECORDER OFF

Post Interview Checklist	X
<i>Ask participant if could contact us if she has a seizure during pregnancy</i>	
Give or mail voucher	
Type field notes and reflections	
Transcribe demographic details in reporter's notebook	
Save recorded interview in computer and hard drive	
Destroy this form and any written notes	

Postnatal Interview

Interviewee Name: _____ Date: _____

Prior to interview: Told Others of Interview Local & Time ____, Extra Batteries ____, Pen & Pad ____, Epilepsy Nurse/ Support Contact Numbers____,

REVIEW PREVIOUS INTERVIEW(S)____

Make list of previous responses about management of epilepsy and pregnancy, and risks vs. benefits ____

Note participant's term for epilepsy ____

Pre Interview Checklist	X
Answer participant's questions	
Consent for continued participation obtained (verbal)	
Consented to record	

Field Notes (Details of where interviewed, who present, etc.)

RECORDER ON

- 1. Tell me how you have been since we last spoke**
 - How was the rest of the pregnancy
 - Tell me about the labour
 - How have you and the baby been since the labour
- 2. Thinking back, how do you feel about taking your medication while being pregnant?**

[refer to their response in previous interview(s)]
- 3. Is there anything you feel could have been done differently/ better?**
- 4. [If have NOT yet talked about high risk pregnancies before] As you know you received additional ante-natal care because of your epilepsy, which means that**

your pregnancy was categorised as high risk. Had anyone mentioned that to you? How do you feel about your pregnancy being categorised as high risk?

[If have ALREADY talked about high risk pregnancies before] **We talked about your being in a high risk category before. In hindsight, how do you feel about your pregnancy being categorised as high risk?**

5. Are you managing your (epilepsy/participants' own term) any differently now? If so, how? If not [probe more]

- Medication/dosage

6. Thinking back to our conversation about the risks and benefits for your baby – *[remind them of their previous answers]* - how do you feel now about those concerns after your baby has been born?

7. Does your (epilepsy/participant's own term) influence how you care for your child? How? Are you taking extra precautions (in regards to below)?

- Can you an example/tell me about X
- Feeding Child (Breast, bottle, and where)
- Bathing Child
- Rest, Sleep for baby/you, and sleeping arrangements?
- Going outside with your baby?
- **Supports from friends, family?**
- **Supports from health visitors/midwives?**
 - o Visits in home?
 - o Questions answered?
 - o Enough time?
 - o Quality of information?

8. If you did not have (epilepsy/participant's own term) do you think the way you care for your baby day to day would be different?

- **If yes, how?**
- **If no, why not?**

9. Tell me about your experience of being in the Trial

- Can you give an example/ tell me more about X

10. Tell me about your experience of care during the pregnancy

- had questions answered
- enough time with doctors/nurses
- quality of information, responses, diagnosis
- Can you give me an example/tell me more about X

11. Concluding Questions:

Is there anything else we didn't discuss that you would like to talk about?

Do you have questions for me?

RECORDER OFF

Post Interview Checklist	X
Check if received voucher, or verify is coming	
Type field notes and reflections	
Save recorded interview in computer and hard drive	
Destroy this form and any written notes	