**Appendix 1: Interview topic guide**

These are example prompts which will be used throughout the interview. This is not a definitive/exhaustive list of questions to be asked.

**Intro**

* Thank you for agreeing to take part in this interview today. I’ll be recording the interview and I just want to check you are happy to continue given everything you’ve read in the study information leaflet and the consent form
* In this interview I am going to ask you about your child and the experiences you had in neonatal care and the PICU. I will start by asking you to give me an overview of your child’s journey through these services and then will focus on the PICU element of that journey
* I know that these topics could be quite upsetting. If you need to pause or stop at any time then please let me know.
* I have a telephone number for you and if our internet connectivity becomes a problem, I will call you to continue the interview if you are happy for me to do so.

**Tell me about your child**

* Tell me about your child and your journey through pregnancy, birth and admissions to neonatal and paediatric intensive care

**Preparation for readmission**

* Let’s focus on the PICU admission now, can you tell me a little about your child at the time they were admitted to PICU (e.g. age)
* When did you first realise that your child was unwell? (if acute admission)
* What did you do when your child became unwell?
* What support and help did you seek for you and your child? (e.g. ambulance, A&E, calling GP)
* What happened to lead to your child being ultimately admitted to the PICU?

**Experiences in the PICU**

* Can you describe the time you and your child spent on the PICU?
* What involvement did you have in your child’s care?
* What support (emotional and practical) did you have available to you (and your husband/partner/family) whilst your child was in PICU?
* How was the admission similar or different from your experiences in the neonatal unit?
* What helped you cope with the experience?
* What, if anything, could have been done differently to improve your experience?

**Transitions out of PICU**

* After your time in the PICU, tell me about any additional hospital experience (e.g. time on a ward, ambulance transfer to home)?

**Returning home after PICU**

* Can you tell me about the final day in hospital and how you prepared to go home from hospital?
* How did you feel as you left the hospital?
* What happened when you got home?
* What support did you have at home?
* Tell me about the first day and night at home after PICU?
* Were your experiences similar or different to when you came home from neonatal care?

**Messages for clinicians and other parents**

* What message would you like to give other parents who have experienced their baby requiring neonatal and paediatric intensive care?
* What messages would you like to give to neonatal or paediatric healthcare professionals?
* What, if anything, do you think was done well during the care you and your baby received?
* What, if anything, do you think could have been done differently to improve the care you and your baby received?

**Final thoughts**

* I’d just like to take a moment to check I’ve asked you everything I wanted to ask.
* Was there anything else you wanted to tell me?
* Thank you for your time today.

**Additional sections as needed**

**If the parent has experienced the death of their child or children (select appropriate questions)**

* If you feel able, can you tell me about the time leading up to your child’s death?
* What involvement did you have in decision making around that time?
* Were you involved in discussions about moving your child (e.g. to hospice, to home as appropriate)?

**If the parent experienced healthcare during the COVID-19 pandemic**

* Can you tell me about any restrictions (e.g. visiting) and how that affected you?
* What aspects of care and planning do you feel were impacted by the pandemic?