Research study: Models of care for children with medical complexity

Topic guide for interviews with parents

1. Introducing the interview and consenting process
   - Researcher introduces self
   - Explain/reiterate: confidentiality, length of interview, nature of discussion, withdraw at any time, fine to take breaks
   - Any questions
   - Obtain consent
   - Start recording

2. Finding out about the child and family
   - Exemplar opening scripts: “To start off, please could you tell me a little bit about [name of child]”; “... and the rest of your family?...”
   - Probes:
     - child’s favourite activities; nursery/school; personality
     - siblings and ages; family composition
     - name of health condition
     - history of diagnosis

3. Their child’s care
   - Exemplar opening script: “And now, please could you tell me a bit about who looks after the healthcare for your child?...”
   - Probes:
     - Which doctors do you see?
     - Do you see any other specialists?
     - Use of medications
     - Does your child have input from therapists e.g. SALT, physio etc
     - Does your child have input from charities?

4. Follow-up questions on target topic areas:
   - Views on how easy it is to access healthcare for their child
- Views on which services should help them look after their child
- Views on how these services could do that e.g. working together, community services flexible options, remote consultations, opening hours etc

CLOSE
- Express thanks and note moving towards end of interview
- Ask if anything else they would like to add

5. Closure:
- Remind re confidentiality, next steps in research and when findings will be ready
- Check if any questions
- Arrange follow-up contact
- Reiterate appreciation for time and sharing their story.