

Understanding Families' Experiences Following a Non-Syndromic Craniosynostosis Diagnosis:
A Qualitative Study - Parent Interview Guide ID # _____

Interview Guide #1

Thank you for agreeing to this first interview to discuss your child's craniosynostosis diagnosis.

Pre Diagnosis – When you first learned that your child might have something wrong with the development of their skull. Thinking back to *before your visit with the surgeon* here today;

1. Can you tell me when and how you noticed there was an issue for your child and who was the first person to notice it?
2. After realizing something was wrong, did you have any main concerns or worries?
3. Can you tell me who referred you and your child to the health centre? Do you recall how long you waited before you received this appointment?
4. Can you tell me about what you were feeling before the consultation with your child's surgeon?
 - a. Did you do any research on your own?
 - b. Did you know what craniosynostosis was before the consultation?
 - c. What did you want to address at the consultation today?
5. Were you aware of the potential need for surgery?
 - a. If so, what were your thoughts on corrective surgery going into the consultation?
 - b. If not, what did you think the option(s) may be for your child?

Post Consultation- Once the diagnosis was made;

6. Please tell me about the consultation with your surgeon.
 - a. What were your thoughts and feelings during the consult?
 - b. Did you have questions for the surgeon? Was the surgeon able to provide you with the information that you needed?
 - c. What type of information did you receive during the consult? What format did you receive the information (written, verbal)?
 - d. Do you have access to other resources should you have additional questions before the surgery?
7. Please tell me about how you made the decision to have corrective surgery for your child.
 - a. Did the consultation have any influence on your decision?
 - b. Were there any factors that influenced your decision?
 - c. Do you believe this will impact the quality of life of your child?
8. In closing, is there anything else you would like to include?

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Interview Guide #2

Thank you for meeting with me for a second interview. It's been about three months since your child's surgery; today we will discuss your experience with your child's surgery and recovery.

Following Surgery

1. Please tell me about the days leading up to the surgery.
 - a. How were you feeling?
 - b. Did you have a thorough understanding of what the surgery entailed?
 - c. Were you comfortable with your decision to go ahead with surgery?
2. Please tell me what your experience with your child's surgery was like.
 - a. How did you feel in the days and weeks following the surgery?
 - b. How did others respond to you during your child's recovery?
 - c. Were there any particularly challenges in the recovery?
 - d. How did you deal with the challenges that arose?
3. Please tell me how you feel now about your decision to have reconstructive surgery for your child?
 - a. Is there anything you would change about the experience?
 - b. If you were making the decision now, would you do it again?
4. Has this experience impacted your life for you and your child?
5. What do you think health professionals should know about parents' experiences with craniosynostosis?
6. In closing, is there anything else you would like to include?