Semi-structured Interview Questions

For patients:

1. What do you know about the cleft you were born with?
2. What’s it like having a cleft? What’s it like having lots of surgeries?
3. Can you explain why you’ve had these surgeries? It’s okay if you don’t.
4. Do you ever feel self-conscious, and why? How do you feel about meeting new people?
5. Do kids at school ask you about your cleft/scars or talk about them? If yes, what do they ask? How often do they ask? Do they ever ask things that bother you?
6. How has your cleft affected the way your friends or teachers treat you?
7. Do you think your life be different if you didn’t have a cleft? How so?
8. Do you wish your nose/lip/scar looked better? Can you tell me more about that?
9. Why do you want your nose/lip/scar to look better?
10. Back to the surgeries you’ve had. Did you talk to your parents about surgery? Do they care about what you think?
11. Who helps you make decisions about surgery? Whose opinion matters most and why?
12. How much do you want to help with choices for surgery? Do you want to make final decisions about surgery? If not, why not? If yes, why?
13. How do you feel about decisions that have been made about your care in the past? Were they the right decisions? Do you wish you’d been more or less involved? How did you feel about those decisions at the time?
14. What are your biggest concerns before surgery? What scares you?
15. If you’re involved in making these decisions, what or who helps you decide what to do?
16. Have you ever asked anyone besides a parent or doctor what they thought about this stuff? If not, have you wanted to? Why?
17. What’s your role in decisions about surgery now? How do you feel about those decisions?
18. How have surgeries helped you? Have surgeries accomplished/changed what your parents or doctors said they would accomplish/change? Explain.
19. How do you feel about the surgeries you’ve had so far? Why or why not?
20. Do you feel like you and your family made good choices about surgeries for your cleft? Why or why not?
21. What would you tell a younger kid, who has a cleft, about surgery? About what it’s like to have a cleft?

For caregivers:

**Focus 1**: To understand motivations/drive behind pursuing revision surgeries (focus on cosmetic improvements)

1. What do you know about the cleft your child was born with? What’s your experience been with clefts?
2. How did you feel when you first saw your child’s cleft?
3. How did you address these feelings?
4. During treatment, how does your child understand his/her cleft? How have you explained all the hospital visits and surgeries?
5. How do you think your child views themselves compared with others?
6. What impact has your child’s cleft had on his/her peer relationships? Teacher relationships? School activities?
7. What has your experience been with surgery? How did you feel about it?
8. What’s been challenging about the treatment process surrounding your child’s cleft? Anything that could be changed/improved?
9. How has friend making been for your child?
10. What worries you about your child’s future? What worries you about your child’s future relationships?
11. How often is your child asked about his cleft by his peers? Is it out of malice?
12. If you had a magic wand, are there things you would change about their appearance that might make their lives easier? For example, things that might minimize potential teasing by other children, or help them to fit in better? What would you change?
13. How do you feel about surgeries that could improve your child’s appearance?
14. How did the surgeries live up to your expectations? Do you feel like surgeries accomplished what they were supposed to accomplish?

**Focus 2**: To assess how parents proceeded with the surgical decision-making process for their child and their expectations before surgery.

“Now we will ask you about the decisions you made about treatment for your child’s cleft condition. We are interested in why you chose surgery.”

1. Why did you decide to proceed with surgery in the past?
2. Before you chose surgery for treatment, what were your main concerns about surgery?
3. How did you address those concerns?
4. Who besides yourself was involved in the decision-making process? Do you like having the final say? Why or why not? What role has the surgeon played in making decisions? Has your child played a role?

(spouse/SO, family, friends, doctors; second opinion, research, etc)

1. What were the biggest factors in your decision? (appearance, function, cost, insurance, time)
2. Did insurance or cost play a role? If so, how? If not, why not?
3. Did you and/or your child seek counseling or another form of emotional support?

(support groups) If not, why not? How do you think counseling or support could benefit cleft families? Did you ever need anything like that?

1. How do you feel now about past decisions you’ve made regarding your child’s cleft care? Decisions about surgeries? How did you feel about those decisions at the time they were made? (These questions get at decisional satisfaction, confidence, and regret.) What things were in place that made you feel good/bad about those decisions?
2. Are there decisions you guys are making now about surgery? What surgeries are you thinking about? How do you feel about them? What would make these decisions easier?