

Appendix 1. Caregiver Interview Guide

Introduction: Thank you for meeting with me today, I appreciate your time and insights. Do you have any questions or concerns after reading the study consent document emailed to you?

VERBAL agreement TO RECORD INTERVIEW (INTERVIEWER INITIALS)?

_____ YES

_____ NO

VERBAL agreement TO PARTICIPATE IN INTERVIEW (INTERVIEWER INITIALS)?

_____ YES

_____ NO

TURN ON RECORDING DEVICE NOW

First, I am interested in hearing your thoughts, feelings, and experiences related to tracheostomy decision-making in the NICU. As a reminder, the information you provide will be kept confidential and the results from the interview won't identify you in any way.

To get started, can you tell me about your experience when you were deciding on a tracheostomy for your child?

This is the Child Tracheostomy Decision Guide designed by the Winnipeg Regional Health Authority. We are interested in how we can adapt this tool for parents considering tracheostomy for their child in the NICU.

The Decision Guide

1. What is your overall impression of this guide?
 - The content?
 - The visual appearance?
 - The length of the guide?
2. What do you think is the most important information?

3. Do you think that other parents making this same decision would find this information easy to understand? Why or why not?
4. Do you think the guide encourages one decision over another (that is, tracheostomy vs no tracheostomy)?
5. The tool was designed with a broad patient population in mind. How do you think we could improve the guide for parents of infants in the NICU?
6. Is there anything that should be included that isn't already?

The Decision Process

7. Would this guide have been helpful to you when you were considering a tracheostomy for your child in the NICU? How?
8. When would be the best time to use this guide?
9. Who is the best person to discuss this guide with parents?

The Response

10. How do you think other NICU parents will respond to the guide?
11. Do you have any advice for other parents going through the same decision?
12. Before we end, is there anything else you'd like to discuss?

Thank you so much for your time and participation!

TURN OFF RECORDING DEVICE NOW

Before we finish, I have a few questions that will help us know more about you and others who participated in this research. These will help us in our analysis, but will not identify you in anyway.

1. What is your age? _____ years

2. What is your gender?
☐ Female
☐ Male
☐ Non-binary
☐ Prefer to self-describe as _____
☐ Prefer not to say
3. How many years of formal education have you completed?
☐ 8th grade or less
☐ Some high school
☐ Graduated high school or GED
☐ Vocational School
☐ Associate degree
☐ Bachelor's degree
☐ Graduate or professional degree
4. What is your employment status?
☐ Full time
☐ Part time
☐ Retired
☐ Unemployed
5. What is your relationship to the prior NICU patient?
☐ Parent
☐ Legal guardian
☐ Other _____
6. Please tell me about your health insurance?
☐ Medicaid
☐ Medicare
☐ Employer-based insurance
☐ Tri-Care
☐ Union-based
☐ Self pay (purchase insurance on own)
☐ Other _____
☐ Uninsured (no insurance)
7. How many children do you have? Either living at home or not.

8. How many people currently live in your home?

9. Please tell us your race or ethnicity

☐ White	☐ African American or Black
☐ Asian or Pacific Islander	☐ American Indian or Alaska Native
☐ Hispanic or Latino	☐ Other, specify _____

10. Primary Language spoken at home:

☐ English
☐ Spanish
☐ Other: _____