

The story of your journey – transitions in

1. Can you provide a bit of background to that specific health experience (admission to the NICU), perhaps starting with what happened when you first felt that something wasn't right?
- What was your first reaction?
2. When you were first in contact with the NICU, What happened and what stands out in your mind about that?
 3. During diagnosis... when you first discussed with staff what might be wrong and what the next steps might be, what happened and what stands out in your mind about that?
- How did you feel this was handled?
4. How long was it between your baby being born and transfer to the NICU? What was it like during that time?
 5. What were your first impressions of the NICU (the clinic reception desk, waiting area, the general place, other people there, staff)?
 6. What are your memories of that first visit to the NICU?
- PROMPTS: (Did you feel that things were communicated clearly and sensitively? Did staff provide you with enough information to make you feel informed and supported through any decisions you made?)
7. How did you find the treatment that you and your baby received?
 8. And during your baby's treatment, how much support did you feel you received? (Was it enough?)
 9. Can you tell me about the relationships you had with the staff that provided your baby's care - How did the staff speak to and relate to you?
- Perhaps you can give me an example of a good relationship with a member of staff? Was there a particular staff member you felt related to you well? (What was that like?)

- Was there any staff member which you felt was not so good or could have been better in putting you at ease? (Can you tell me more?)

- 10. To what extent did the staff understand a little about you and your life more broadly as a person, (who you are, what and who is important to you) – not just in relation to your baby’s condition?

- 11. Can you tell me about an example of when you felt the care you and your baby received was really great? (Why? What made it so great?)

- 12. Conversely, can you perhaps tell me about a time when you came away feeling the care you received was not so great?

- 13. Who was involved in your baby’s care? To what extent did you feel you had a say in this / understand who everyone was?

- 14. How did the unit / healthcare routines enable you and your loved ones to be involved in your baby’s care?

- 15. If you could change any one thing about the experience you had, what would that be?

- 16. What would you say are the crucial points in the journey – moments of truth?

- 17. Based on your first-hand experience, if you were looking to redesign and improve the services for NICU families where would you begin

Finally, is there anything else you’d like to say to further the discussion that you don’t think we’ve covered?

The story of your journey – transitions out

1. How long was your baby in the NICU?
2. What were your first impressions of the NICU (the clinic reception desk, waiting area, the general place, other people there, staff)?
3. Can you provide a bit of background about preparing to leave the NICU. When did that process begin?
4. When you first discussed with staff what the next steps might be (in relation to being discharged from the NICU), what happened and what stands out in your mind about that?
5. Did you feel that things were communicated clearly and sensitively when you were preparing for discharge? Did you feel that staff provided you with enough information to make you feel informed and supported through any decisions you made?
6. And during your baby's treatment, how much support did you feel you received? (Was it enough?)
7. Can you tell me about the relationships you had with the staff that provided your baby's care - How did the staff speak to and relate to you?
 - Perhaps you can give me an example of a good relationship with a member of staff? Was there a particular staff member you felt related to you well? (What was that like?)
 - Was there any staff member which you felt was not so good or could have been better in putting you at ease? (Can you tell me more?)
8. To what extent did the staff understand a little about you and your life more broadly as a person, (who you are, what and who is important to you) – not just in relation to your baby's discharge?
9. Can you tell me about an example of when you felt the care you and your baby received was really great? (Why? What made it so great?)
10. Conversely, can you perhaps tell me about a time when you came away feeling the care you received was not so great?
11. Who was involved in your baby's care? To what extent did you feel you had a say in this / understand who everyone was?

12. How did the unit / healthcare routines enable you and your loved ones to be involved in your baby's care while you were preparing for discharge?
 13. If you could change any one thing about the experience you had, what would that be?
 14. Did you feel ready to go home when you did?
 15. Tell me about the follow-up after you went home. What happened and what stands out in your mind about that?
 16. What would you say are the crucial points in the journey – moments of truth?
 17. Based on your first-hand experience, if you were looking to redesign and improve the services for NICU families where would you begin
- Finally, is there anything else you'd like to say to further the discussion that you don't think we've covered?