

PAIN Questionnaire - Neonatal Intensive Care

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A. The following questions ask about your baby's stay in the neonatal unit

1. Approximately how often do you visit your baby in the neonatal unit? (CHOOSE ONE)

- I stay all the time
- Several times a day
- Once daily
- Every few weeks
- Once a week

2. Please circle how seriously ill you think your baby is at the moment, with 0 = low risk of dying and 5 = high risk of dying. (CHOOSE ONE)

(low risk of dying) well 0 1 2 3 4 5 extremely ill (high risk of dying)

3. How satisfied have you been so far with the care your baby has received in the neonatal unit? (CHOOSE ONE)

- Very Satisfied
- Satisfied
- Somewhat Satisfied
- Somewhat Unsatisfied
- Unsatisfied
- Very Unsatisfied

B. The following questions ask about pain. Please feel free to add additional comments in the space provided.

1. My baby felt pain while in the neonatal unit. (CHOOSE ONE)

- Yes
- No
- Don't Know

2. What do you think causes your baby's pain? (PLEASE LIST)

3. Please circle how much pain you think your baby is feeling **at this moment**, with 0 = no pain and 10 = worst possible pain. (CHOOSE ONE)

0 1 2 3 4 5 6 7 8 9 10

No Pain

Worst Pain

4. Please circle the **worst** pain you think your baby has felt since admission to the neonatal unit. (CHOOSE ONE)

0 1 2 3 4 5 6 7 8 9 10

No Pain

Worst Pain

5. Please circle the **least** pain you think your baby has felt since admission to the neonatal unit. (CHOOSE ONE)

0 1 2 3 4 5 6 7 8 9 10

No Pain

Worst Pain

6. Please circle how much pain you **expected** your baby would have while in the neonatal unit. (CHOOSE ONE)

0 1 2 3 4 5 6 7 8 9 10

No Pain

Worst Pain

7. Please circle how much pain **relief** you expected your baby would have while in the neonatal unit. (CHOOSE ONE)

0 1 2 3 4 5 6 7 8 9 10

No Pain

Worst Pain

8. If you believe that your baby has felt pain while in the neonatal unit, were you worried that your baby might? (CHOOSE ALL THAT APPLY)

- Have immediate medical problems
- Have later medical problems
- Remember having pain
- React to pain differently when he/she is older
- Other (please describe) _____
- I was not worried about any of these things

9. How much verbal information about pain control for your baby have you received? (CHOOSE ONE)

- A lot
- Some
- A little
- None

10. How much written information about pain control for your baby have you received? (CHOOSE ONE)

- A lot
- Some
- A little
- None

11. If you have received either verbal or written information about pain control for your baby, please tell us **when** you received this information. (CHOOSE ALL THAT APPLY)

- On admission
- Daily
- Before procedures
- Occasionally
- Other times (please describe) _____
- I did not receive any information

12. Who have you received information from about pain control for your baby? (CHOOSE ALL THAT APPLY)

- Nurse
- Doctor
- Nurse Practitioner
- Research Nurse
- Other healthcare person (please describe) _____
- Family / Friends
- Internet
- No one

13. How **satisfied** have you been with the amount of information you have received about pain control for your baby? (CHOOSE ONE)

- Very Satisfied
- Satisfied
- Somewhat Satisfied
- Somewhat Unsatisfied
- Unsatisfied

13a. If you have NOT been satisfied with the amount of information you have received about pain control for your baby, please tell us about it:

14. The nurses have shown me how to look for signs of pain in my baby. (CHOOSE ONE)

- Strongly Agree
- Agree
- Somewhat Agree
- Somewhat Disagree
- Disagree
- Strongly Disagree

15. I can tell my baby is in pain by the following signs (please list):

16. The nurses have shown me how to make my baby more comfortable by: (CHOOSE ALL THAT APPLY)

- Positioning
- Pacifier
- Swaddling
- Feeding
- Patting or rocking
- Music / Toys
- Other (please describe) _____
- The nurses did not show me

17. How do you think these ways of comforting your baby have helped your baby's pain? (CHOOSE ONE)

- Went away
- Decreased a lot
- Decreased a little
- Made no difference
- Made it a little worse
- Made it a lot worse
- Don't know

18. I feel confident that the staff can tell when my baby is in pain. (CHOOSE ONE)

- Strongly Agree
- Agree
- Somewhat Agree
- Somewhat Disagree
- Disagree
- Strongly Disagree

18a. If you have not felt confident that the staff can tell when your baby is in pain, please tell us more about your feelings:

19. Have you ever disagreed with either the nurses or doctors about whether your baby was feeling pain?

- Yes
- No

19a. If yes, please tell us about it:

20. I am satisfied that the nurses make my baby more comfortable. (CHOOSE ONE)

- Strongly Agree
- Agree
- Somewhat Agree
- Somewhat Disagree
- Disagree
- Strongly Disagree

20a. If you have not been satisfied that the nurses make your baby comfortable, please tell us more:

21. My baby has received medicine for pain. (CHOOSE ONE)

- Yes
- No
- Don't Know

22. Sometimes my baby didn't have pain, but received other medications to make him/her calm. (CHOOSE ONE)

- Yes
- No
- Don't Know

23. If your baby has received medicine for pain, in what way do you think the medicine has helped your baby's pain? (CHOOSE ONE)

- Went away
- Decreased a lot
- Decreased a little
- Made no difference
- Made it a little worse
- Made it a lot worse
- Don't know

24. If your baby has received medicine for pain, how satisfied have you been that the medicine helped your baby feel less pain? (CHOOSE ONE)

- Very Satisfied
- Satisfied
- Somewhat Satisfied
- Somewhat Unsatisfied
- Unsatisfied
- Very Unsatisfied

24a. If you were not satisfied that the medicine made your baby feel less pain, please tell us more:

25. If you felt like the medication did not help your baby's pain, did you tell anyone?

- Yes (please describe who) _____
- No

26. If you did tell someone, how long did it take before a member of staff did something to help relieve your baby's pain? (CHOOSE ONE)

- Less that 10 minutes
- 11-20 minutes
- 21-30 minutes
- 31-60 minutes
- More than 1 hour
- I asked but my baby didn't receive it
- I never asked for help

27. When my baby received pain medication I was worried that he/she would: (CHOOSE ALL THAT APPLY)

- Become addicted
- Stop breathing
- Be very sleepy
- Was terminally ill
- Not get enough
- I was not worried
- Other (please describe) _____

28. The staff have been supportive with my concerns about my baby's pain. (CHOOSE ONE)

- Strongly Agree
- Agree
- Somewhat Agree
- Somewhat Disagree
- Disagree
- Strongly Disagree

28a. If the staff have not been supportive, please tell us more:

29. Have you been present with your baby while they were undergoing a painful procedure?
(CHOOSE ONE)

- Never
- Sometimes
- Often
- Always

30. Have you been asked if you wanted to be present during painful procedures? (CHOOSE ONE)

- Never
- Sometimes
- Often
- Always
- Don't know
-

31. When a painful procedure was being done on my baby I would most often prefer to:
(CHOOSE ONE)

- Stay at my baby's bedside
- Stay and assist by providing comfort
- Leave the room
- Other (please describe) _____

32. How much involvement would you like to have had in your baby's pain management?
Please describe:

33. Please tell us what role you play in the management of your baby's pain:

34. Please tell us what role you think you **should** play in the management of your baby's pain:

35. Is there anything else you would like to know about infant pain?

- Yes
- No

35a. If there is anything else you would like to know about pain, please tell us more:

36. Is there anything else you would like us to know at this time?

- Yes
- No

36a. If there is anything else you would like us to know, please tell us more:

37. Do you have any suggestions as to how we could improve your baby's pain management?

- Yes
- No

37a. If you do have any suggestions, please describe them: