

NEONATAL INSTRUMENT
OF
PARENT SATISFACTION
WITH CARE

McMASTER UNIVERSITY
Faculty of Health Sciences
School of Nursing
1200 Main Street West, Hamilton, Ontario L8N 3Z5

START TIME _____

On behalf of the research team, I would like to thank you for agreeing to participate in this study.

PINK CARD

I How do you think your baby is doing? Please pick an option from the PINK card. Would you say that the baby is...

- 1 DOING BETTER THAN YOU EXPECTED
- 2 DOING AS WELL AS YOU EXPECTED
- 3 DOING WORSE THAN YOU EXPECTED

II This questionnaire has been designed to measure your satisfaction or dissatisfaction with the MEDICAL care your baby has received in the NICU. The MEDICAL caregivers are the neonatologists, fellows, residents and clinical nurse specialists. We have pictures of these individuals to help you remember any interaction you may have had with them.

How much contact would you say you have had with the _____? (*see list below*) Would you say you have had no contact, minimal, some or frequent contact with the _____? (*see list below*)

	No contact	Minimal	Some	Frequent contact
neonatologists	1	2	3	4
fellows	1	2	3	4
residents	1	2	3	4
clinical nurse specialists	1	2	3	4

Please point out those individuals with whom you have had ANY contact.
(*Remove pictures of caregivers not identified*)

III Of these individuals, with whom have you had the MOST contact?
(*Write the name identified by respondent*)

neonatologist _____
fellow _____
resident _____
clinical nurse specialist _____

FOR ALL THE FOLLOWING QUESTIONS PLEASE FOCUS ONLY ON YOUR CONTACT WITH THESE MEDICAL CAREGIVERS. WE DO NOT WANT YOU TO INCLUDE YOUR CONTACT WITH THE STAFF NURSES. Some of the questions may appear similar but we would appreciate your responses to each of them.

IV In general, how satisfied are you with the care your baby has received in the NICU from these MEDICAL caregivers? Please choose an option from the YELLOW card. Would you say you are...

- 1 NOT REALLY SATISFIED
- 2 GENERALLY SATISFIED, BUT SIGNIFICANT AREAS OF DISSATISFACTION
- 3 GENERALLY SATISFIED, BUT MINOR AREAS OF DISSATISFACTION
- 4 QUITE SATISFIED
- 5 MOSTLY SATISFIED
- 6 VERY SATISFIED
- 7 COMPLETELY SATISFIED

BLUE CARD

For the next few questions, please choose an option from this BLUE card.

1. How often did you find the **change of medical caregivers** looking after your baby difficult? Would you say...

- 1 ALL OF THE TIME
- 2 MOST OF THE TIME
- 3 A FAIR BIT OF THE TIME
- 4 SOME OF THE TIME
- 5 A LITTLE OF THE TIME
- 6 VERY LITTLE OF THE TIME
- 7 NONE OF THE TIME

2. How often did these caregivers present your baby's condition in a way which was scary or frightening? Would you say...

- 1 ALL OF THE TIME
- 2 MOST OF THE TIME
- 3 A FAIR BIT OF THE TIME
- 4 SOME OF THE TIME
- 5 A LITTLE OF THE TIME
- 6 VERY LITTLE OF THE TIME
- 7 NONE OF THE TIME

3. How often did the caregivers fail to tell you when they were going off duty? Would you say...

- 1 ALL OF THE TIME
- 2 MOST OF THE TIME
- 3 A FAIR BIT OF THE TIME
- 4 SOME OF THE TIME
- 5 A LITTLE OF THE TIME
- 6 VERY LITTLE OF THE TIME
- 7 NONE OF THE TIME

4. How often did the caregivers fail to tell you who was going to fill in while they were off duty? Would you say...

- 1 ALL OF THE TIME
- 2 MOST OF THE TIME
- 3 A FAIR BIT OF THE TIME
- 4 SOME OF THE TIME
- 5 A LITTLE OF THE TIME
- 6 VERY LITTLE OF THE TIME
- 7 NONE OF THE TIME

5. How often did you feel confused about whom to trust? Would you say...

- 1 ALL OF THE TIME
- 2 MOST OF THE TIME
- 3 A FAIR BIT OF THE TIME
- 4 SOME OF THE TIME
- 5 A LITTLE OF THE TIME
- 6 VERY LITTLE OF THE TIME
- 7 NONE OF THE TIME

6. How often did you receive conflicting information from different MEDICAL caregivers? Would you say...

- 1 ALL OF THE TIME
- 2 MOST OF THE TIME
- 3 A FAIR BIT OF THE TIME
- 4 SOME OF THE TIME
- 5 A LITTLE OF THE TIME
- 6 VERY LITTLE OF THE TIME
- 7 NONE OF THE TIME

7. How often did you feel that your baby was lost in the shuffle of a large unit? Would you say...

- 1 ALL OF THE TIME
- 2 MOST OF THE TIME
- 3 A FAIR BIT OF THE TIME
- 4 SOME OF THE TIME
- 5 A LITTLE OF THE TIME
- 6 VERY LITTLE OF THE TIME
- 7 NONE OF THE TIME

8. How often did you have difficulty finding out who your baby's MEDICAL caregivers were? Would you say...

- 1 ALL OF THE TIME
- 2 MOST OF THE TIME
- 3 A FAIR BIT OF THE TIME
- 4 SOME OF THE TIME
- 5 A LITTLE OF THE TIME
- 6 VERY LITTLE OF THE TIME
- 7 NONE OF THE TIME

9. How often did you find the change of MEDICAL caregivers over the weekends a problem? Would you say...

- 1 ALL OF THE TIME
- 2 MOST OF THE TIME
- 3 A FAIR BIT OF THE TIME
- 4 SOME OF THE TIME
- 5 A LITTLE OF THE TIME
- 6 VERY LITTLE OF THE TIME
- 7 NONE OF THE TIME

10. How often did the caregivers fail to inform you about tests or x-ray results? Would you say...

- 1 ALL OF THE TIME
- 2 MOST OF THE TIME
- 3 A FAIR BIT OF THE TIME
- 4 SOME OF THE TIME
- 5 A LITTLE OF THE TIME
- 6 VERY LITTLE OF THE TIME
- 7 NONE OF THE TIME

11. How often did you have to ask the MEDICAL caregivers to repeat explanations several times? Would you say...

- 1 ALL OF THE TIME
- 2 MOST OF THE TIME
- 3 A FAIR BIT OF THE TIME
- 4 SOME OF THE TIME
- 5 A LITTLE OF THE TIME
- 6 VERY LITTLE OF THE TIME
- 7 NONE OF THE TIME

12. How often were you **uncertain** who to talk to about your baby's condition? Would you say...

- 1 ALL OF THE TIME
- 2 MOST OF THE TIME
- 3 A FAIR BIT OF THE TIME
- 4 SOME OF THE TIME
- 5 A LITTLE OF THE TIME
- 6 VERY LITTLE OF THE TIME
- 7 NONE OF THE TIME

13. How often did the MEDICAL caregivers **fail** to inform you completely about the results of a procedure? Would you say...

- 1 ALL OF THE TIME
- 2 MOST OF THE TIME
- 3 A FAIR BIT OF THE TIME
- 4 SOME OF THE TIME
- 5 A LITTLE OF THE TIME
- 6 VERY LITTLE OF THE TIME
- 7 NONE OF THE TIME

14. How often did the caregivers keep you waiting for results of tests? Would you say...

- 1 ALL OF THE TIME
- 2 MOST OF THE TIME
- 3 A FAIR BIT OF THE TIME
- 4 SOME OF THE TIME
- 5 A LITTLE OF THE TIME
- 6 VERY LITTLE OF THE TIME
- 7 NONE OF THE TIME

15. How often were you informed about something after-the-fact or by accident? Would you say...

- 1 ALL OF THE TIME
- 2 MOST OF THE TIME
- 3 A FAIR BIT OF THE TIME
- 4 SOME OF THE TIME
- 5 A LITTLE OF THE TIME
- 6 VERY LITTLE OF THE TIME
- 7 NONE OF THE TIME

GREY CARD

16. How often did you feel that you knew who was who? Please choose an options from this GREY card.

- 1 NONE OF THE TIME
- 2 A LITTLE OF THE TIME
- 3 SOME OF THE TIME
- 4 A FAIR BIT OF THE TIME
- 5 MOST OF THE TIME
- 6 ALMOST ALL OF THE TIME
- 7 ALL OF THE TIME

17. How often did the MEDICAL caregivers volunteer how they felt about your baby's condition? Would you say...

- 1 NONE OF THE TIME
- 2 A LITTLE OF THE TIME
- 3 SOME OF THE TIME
- 4 A FAIR BIT OF THE TIME
- 5 MOST OF THE TIME
- 6 ALMOST ALL OF THE TIME
- 7 ALL OF THE TIME

YELLOW CARD

18. How satisfied were you with the way the MEDICAL caregivers prepared you for your baby's stay in the NICU? Please an option from this YELLOW card.

- 1 NOT REALLY SATISFIED
- 2 GENERALLY SATISFIED, BUT SIGNIFICANT AREAS OF DISSATISFACTION
- 3 GENERALLY SATISFIED, BUT MINOR AREAS OF DISSATISFACTION
- 4 QUITE SATISFIED
- 5 MOSTLY SATISFIED
- 6 VERY SATISFIED
- 7 COMPLETELY SATISFIED

19. How satisfied were you with the extent to which the caregivers kept you informed as your baby's condition changed? Would you say...

- 1 NOT REALLY SATISFIED
- 2 GENERALLY SATISFIED, BUT SIGNIFICANT AREAS OF DISSATISFACTION
- 3 GENERALLY SATISFIED, BUT MINOR AREAS OF DISSATISFACTION
- 4 QUITE SATISFIED
- 5 MOSTLY SATISFIED
- 6 VERY SATISFIED
- 7 COMPLETELY SATISFIED

20. How satisfied were you with how often the caregivers offered to meet with you in private? Would you say...

- 1 NOT REALLY SATISFIED
- 2 GENERALLY SATISFIED, BUT SIGNIFICANT AREAS OF DISSATISFACTION
- 3 GENERALLY SATISFIED, BUT MINOR AREAS OF DISSATISFACTION
- 4 QUITE SATISFIED
- 5 MOSTLY SATISFIED
- 6 VERY SATISFIED
- 7 COMPLETELY SATISFIED

21. How satisfied were you with the number of meetings arranged with your baby's doctors to discuss what you might expect for your baby in the future? Would you say...

- 1 NOT REALLY SATISFIED
- 2 GENERALLY SATISFIED, BUT SIGNIFICANT AREAS OF DISSATISFACTION
- 3 GENERALLY SATISFIED, BUT MINOR AREAS OF DISSATISFACTION
- 4 QUITE SATISFIED
- 5 MOSTLY SATISFIED
- 6 VERY SATISFIED
- 7 COMPLETELY SATISFIED

22. How satisfied were you with how the MEDICAL caregivers told you about the long term expectation or outlook for your child? Would you say...

- 1 NOT REALLY SATISFIED
- 2 GENERALLY SATISFIED, BUT SIGNIFICANT AREAS OF DISSATISFACTION
- 3 GENERALLY SATISFIED, BUT MINOR AREAS OF DISSATISFACTION
- 4 QUITE SATISFIED.
- 5 MOSTLY SATISFIED
- 6 VERY SATISFIED
- 7 COMPLETELY SATISFIED

23. How satisfied were you with how much the caregivers were sensitive to the other pressures in your life? Would you say...

- 1 NOT REALLY SATISFIED
- 2 GENERALLY SATISFIED, BUT SIGNIFICANT AREAS OF DISSATISFACTION
- 3 GENERALLY SATISFIED, BUT MINOR AREAS OF DISSATISFACTION
- 4 QUITE SATISFIED
- 5 MOSTLY SATISFIED
- 6 VERY SATISFIED
- 7 COMPLETELY SATISFIED

24. How satisfied were you with the extent to which the caregivers offered personal opinions or experiences about your baby's future condition? Would you say...

- 1 NOT REALLY SATISFIED
- 2 GENERALLY SATISFIED, BUT SIGNIFICANT AREAS OF DISSATISFACTION
- 3 GENERALLY SATISFIED, BUT MINOR AREAS OF DISSATISFACTION
- 4 QUITE SATISFIED
- 5 MOSTLY SATISFIED
- 6 VERY SATISFIED
- 7 COMPLETELY SATISFIED

Have the MEDICAL caregivers told you when your baby will be discharged from the NICU?

- 1 YES (Go to Q28)
- 2 NO

There are 3 questions regarding the discharge procedure. I would like to contact you by telephone after your baby has been discharged to complete these 3 questions. Would that be alright?

- 1 YES (Go to Q31)
- 2 NO (Go to Q31)

COMMENTS _____

25. How satisfied were you with the MEDICAL caregivers in preparing you for the discharge of your baby? Would you say...

- 1 NOT REALLY SATISFIED
- 2 GENERALLY SATISFIED, BUT SIGNIFICANT AREAS OF DISSATISFACTION
- 3 GENERALLY SATISFIED, BUT MINOR AREAS OF DISSATISFACTION
- 4 QUITE SATISFIED
- 5 MOSTLY SATISFIED
- 6 VERY SATISFIED
- 7 COMPLETELY SATISFIED

26. How satisfied were you with your involvement in the decision to discharge your baby? Would you say...

- 1 NOT REALLY SATISFIED
- 2 GENERALLY SATISFIED, BUT SIGNIFICANT AREAS OF DISSATISFACTION
- 3 GENERALLY SATISFIED, BUT MINOR AREAS OF DISSATISFACTION
- 4 QUITE SATISFIED
- 5 MOSTLY SATISFIED
- 6 VERY SATISFIED
- 7 COMPLETELY SATISFIED

WHITE CARD

27. How sure were you that your baby's discharge was because the baby was getting better rather than the unit needing the bed? Please choose an option on this WHITE card.

- 1 THE NEED FOR A BED PLAYED A SUBSTANTIAL ROLE IN DECISION
- 2 THE NEED FOR A BED PLAYED SOME ROLE IN DECISION
- 3 NOT COMPLETELY SURE, SUSPECT NEED FOR BED PLAYED ROLE IN DECISION
- 4 MODERATELY SURE BABY WAS READY FOR DISCHARGE
- 5 QUITE SURE BABY WAS READY FOR DISCHARGE
- 6 VERY SURE BABY WAS READY FOR DISCHARGE
- 7 TOTALLY SURE BABY WAS READY FOR DISCHARGE

There are just a few more questions.

28. Were there times when you thought there were incidents in which errors occurred in the medical care of your baby?

- 1 YES
- 2 NO (*Go to Question 33*)

29. How many times did such incidents occur?

_____ Times

30. If your friend was in similar circumstance, would you recommend they come here or go somewhere else for neonatal intensive care?

- 1 COME HERE
- 2 GO SOMEWHERE ELSE

DEMOGRAPHIC INFORMATION

The next few questions are required to describe the parents participating in this study as a group. No individual will be identified in any report of this study.

1. Respondent's gender

- 1 Male
- 2 Female

2. What is your date of birth?

Mother [][] [][] [][]
 Year Month Day

Father [][] [][] [][]
 Year Month Day

3. What is your present marital status?

- 1 Single
- 2 Married
- 3 Commonlaw
- 4 Separated
- 5 Divorced
- 6 Widowed

4. What is the highest level of education that you have completed?

- | | | |
|---------------------|--------|--------|
| 1 Grade 8 or less | Mother | Father |
| 2 Grade 9 - 12 | [] | [] |
| 3 Grade 13 | | |
| 4 Community college | | |
| 5 University | | |

5. What is your occupation?

- | | | |
|--------------------------------------|--------|--------|
| 1 Professional | Mother | Father |
| 2 Management | [] | [] |
| 3 Technicians | | |
| 4 Supervisor | | |
| 5 Clerical/Sales/Service | | |
| 6 Skilled Crafts/Trades | | |
| 7 Farmer | | |
| 8 Labourer | | |
| 9 Self-employed | | |
| 10 Housewife | | |
| 11 Student | | |
| 12 Unemployed (no occupation stated) | | |
| 13 Retired | | |
| 14 Other (Specify _____) | | |

6. Are you presently working:

- | | | |
|-------------------------|--------|--------|
| 1 Full-time | Mother | Father |
| 2 Part-time | [] | [] |
| 3 Unemployed | | |
| 4 Maternity leave | | |
| 5 Retired | | |
| 6 Disabled | | |
| 7 Student | | |
| 8 Other (Specify _____) | | |

GREEN CARD

7. What is the approximate range of your family's gross income from all sources, before taxes, in 1990? Please tell me the number next to the range for your family income on this GREEN card.

- 1 less than \$10,000
- 2 \$10,000 to 19,999
- 3 \$20,000 to 29,999
- 4 \$30,000 to 39,999
- 5 \$40,000 to 49,999
- 6 \$50,000 to 59,999
- 7 more than \$60,000

8. How many children do you have? How old are they?

Number of children _____

_____ weeks

_____ years

_____ years

Thank you again for taking the time to participate in this study, it is very much appreciated and your answers are very helpful.

FINISH TIME _____