

**APPENDIX A**

**QUESTIONNAIRE**

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**Various aspects of families of preterm infants regarding their attitudes and perceptions of their Neonatal Intensive Care Unit (NICU) experience.**

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- Thank you for agreeing to participate in this study. Please do not write your name on this questionnaire in order for the information received to remain anonymous.

**SECTION A - Background information relating to the family member and to the infant**

**1.1. Information concerning you as the parent**

How old are you?

Younger than 20 years	
20 – 24 years	
25 - 32 years	
33 – 38 years	
39 + years	

What is your gender?

Male	
Female	

What level of education do you have?

Standard 6 to Standard 8	
Standard 9 to Standard 10	
Please specify any post-matric qualifications	

What is your employment status?

Not employed outside home	
Part time employment	
Full time employment	

What is the approximate family income per year? (optional)

Less than R60 000 per year	
R60 000 – R120 000 per year	
R120 000 – R240 000 per year	
More than R240 000 per year	

What is your marital status?

Married	
Single; divorced; separated; widowed (Please specify)	
Living with a partner	

What is your relationship to the child?

Child's own parent	
Relative of the child (aunt, uncle, grandparent)	
Friend of the family	
Other (please specify)	

How many children do you have?

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Is your child, who was in the NICU, one of a multiple birth?

No	
Twin	
Triplet	
Quadruplet	
Other (please specify)	

Who is presently living in your house?

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**1.2. Information concerning your child**

What is your child's date of birth?

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What is your child's gender?

Male	
Female	

What was your child's birth weight?

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How many weeks was your child premature?

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How many weeks did your child spend in the NICU?

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Please tick which professionals were involved in the treatment of your child whilst in the NICU?

Paediatrician	
NICU nursing sister	
Other nursing staff	
Paediatric cardiologist	
Paediatric neurologist	
Paediatric gastroenterologist	
Paediatric surgeon	
Social worker	
Dietician/ nutritionist	
Speech Therapist	
Audiologist	
Eye specialist	
Other (please specify)	

**SECTION B – The Information and support received by the families of NICU graduates**

Were you aware that your child was going to be born prematurely?

Yes	
No	

- **Only answer the following questions in this section if you knew that your baby was going to be premature.**

**1. Before your baby was born**

Please rate your feelings on the importance of receiving information in these areas before your child was born

- 1 = of great importance
- 2 = of some importance
- 3 = neutral
- 4 = of little importance
- 5 = of no importance

	1	2	3	4	5
The way in which the pregnancy will be maintained					
The mother's medical condition					
The complications that the baby could have as a result of being born prematurely					
What to expect during the labour and delivery					

Please state any additional areas in which you received or required information during this time

**INFORMATION RECEIVED**

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**INFORMATION REQUIRED**

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Please mark the ways in which you obtained information before the delivery of your child

Books	
Professionals (e.g. doctors, nurses, therapists ect)	
Internet	
Other parents of premature children	
Other (please specify)	

Please tell me about any difficulties that you had in obtaining the information before your child's delivery

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Who was there to give you support before your child was born?

Spouse/ Partner	
Other family members	
Nursing staff	
Doctor	
Other parents of premature children	
Other (please specify)	

What were your main fears when you found out that your child was going to be born prematurely?

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**2. When your child was hospitalised in the NICU**

Please rate your feelings on the importance of receiving information in these areas while your child was in the NICU

- 1 = of great importance
- 2 = of some importance
- 3 = neutral
- 4 = of little importance
- 5 = of no importance

	1	2	3	4	5
The health of your child					
The care of your child whilst in the NICU					
The purpose of the various machines in the NICU					
The medical language used in the NICU					
Ways to help you to cope with the premature birth of your child					

Please state any additional areas in which you received or required information during this time

INFORMATION RECEIVED

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INFORMATION REQUIRED

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Please mark the ways in which you obtained information while your child was in the NICU

Books	
Professionals (e.g. doctors, nurses, therapists ect)	
Internet	
Other parents of premature children	
Other (please specify)	

Please tell me about any difficulties that you had in obtaining the information while your child was in the NICU

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Who was there to give you support while your child was in the NICU?

Spouse/ Partner	
Other family members	
Nursing staff	
Doctor	
Other parents of premature children	
Other (please specify)	

What were your main fears while your child was in the NICU?

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**3. Before your child went home from the hospital**

Please rate your feelings on the importance of receiving information in these areas before your child went home

- 1 = of great importance
- 2 = of some importance
- 3 = neutral
- 4 = of little importance
- 5 = of no importance

	1	2	3	4	5
The health of your child					
How to care for your child at home					
Ways in coping with the demands of caring for your child					

Please state any additional areas in which you received or required information during this time

**INFORMATION RECEIVED**

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**INFORMATION REQUIRED**

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Please mark the ways in which you obtained information before your child went home

Books	
Professionals (e.g. doctors, nurses, therapists ect)	
Internet	
Other parents of premature children	
Other (please specify)	

Please tell me about any difficulties that you had in obtaining the information before your child went home

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Who was there to give you support before your child went home?

Spouse/ Partner	
Other family members	
Nursing staff	
Doctor	
Other parents of premature children	
Other (please specify)	

What were your main fears when your child was going home?

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**4. The time after your baby came home**

Please rate your feelings on the importance of receiving information in these areas after your child was discharged from the hospital

- 1 = of great importance
- 2 = of some importance
- 3 = neutral
- 4 = of little importance
- 5 = of no importance

	1	2	3	4	5
How to care for your child					
The health of your child					
Ways in coping with the demands of caring for your child					

Please state any additional areas in which you received or required information during this time

**INFORMATION RECEIVED**

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**INFORMATION REQUIRED**

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Please mark the ways in which you obtained information after your child was discharged

Books	
Professionals (e.g. doctors, nurses, therapists ect)	
Internet	
Other parents of premature children	
Other (please specify)	

Please tell me about any difficulties that you had in obtaining the information after your child was discharged from the hospital

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Who was there to give you support when your child was at home?

Spouse/ Partner	
Other family members	
Nursing staff	
Doctor	
Other parents of premature children	
Other (please specify)	

What were your main fears when your child was at home?

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**Section C - Information regarding adjusting to and coping with the demands of the premature infant**

During your experience, who helped you most to understand your baby?

Spouse/ Partner	
Other family members (please specify)	
Nursing staff	
Doctor	
Other parents of premature children	
Other (please specify)	

Who helped you adjust emotionally to your premature baby?

Spouse/ Partner	
Other family members (please specify)	
Nursing staff	
Doctor	
Other parents of premature children	
Other (please specify)	

Who helped you to get involved in the care of your premature baby?

Spouse/ Partner	
Other family members (please specify)	
Nursing staff	
Doctor	
Other parents of premature children	
Other (please specify)	

The hardest things for you to adjust to as the parent of a premature infant were:

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What factors do you think feel assisted you in coping with the birth of your baby?

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What factors do you feel impacted negatively on the way in which you coped with the birth of your baby?

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**Section D – Additional comments**

What things about your experience would you like to see changed for future parents?

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What advice would you give to future parents of premature infants?

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If you would like to please write down some thoughts about your experience of the NICU and the birth of your premature child

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- Thank you very much for your co-operation.

## **APPENDIX B**

**Cover letter and consent form for participation in the study**

**Cover letter to the hospital manager**

**Cover letters to the paediatricians**

**Cover letter to the matron of the NICU**

Dear Participants,

I am presently studying a Masters degree in Speech Pathology at the University of the Witwatersrand. One of the requirements of the course is the completion of the degree is a research project.

The proposed study aims to explore the experiences of a group of parents of premature infants that have graduated from the Neonatal Intensive Care Unit (NICU) with regards to the opportunities afforded to them in order to communicate with their infants.

I would like to invite you to participate in this study. Should you agree to participate, I will need to provide you with a short questionnaire to complete before meeting you for an interview at a place that is convenient for you. The interview will take approximately an hour and a half, during which I will ask you some questions. There are no right or wrong answers so please feel to give your own opinion. You may retain the right to refuse to answer certain questions and those that you do answer will remain anonymous and all information will be kept confidential. If you agree, I would like to tape record the interview.

By taking part in this study, you will help researchers understand the needs of families of NICU graduates in establishing optimal infant-parent interaction and you will provide useful information on how to better the service provided.

Your participation in this study is voluntary and you may withdraw from this study at any time without it being held against you in any way. If you are interested in the result of the study, I will be only too willing to share the findings with you. Should you require any further information, please do not hesitate to contact me on 073-203-2523 or 447-4888.

Yours sincerely,

Lynzi Crisp  
Researcher

Karen Levin  
Supervisor

## **CONSENT FORM**

I acknowledge that the purpose of the research project has been explained to me. I consent to participate in the study and understand that I may withdraw from the study at any time without it being held against me in any way.

DATE:

NAME:

SIGNATURE:

I hereby consent to have the interview tape-recorded.

DATE:

NAME:

SIGNATURE:

Dear (name of Manager of Hospital)

I am presently studying a Masters degree in Speech Pathology at the University of the Witwatersrand. One of the requirements of the course is the completion of a research project.

The proposed study aims to explore the experiences of a group of parents of premature infants that have graduated from the Neonatal Intensive Care Unit (NICU) with regards to the opportunities afforded to them in order to communicate with their infants. It is proposed that parents will be asked to complete a questionnaire, which will be followed by a private interview conducted at a time and place convenient to the parents.

Premature infants are considered to be at a greater risk for a delay in development and thus the role of the Speech-Language Pathologist is continually developing both within the Neonatal Intensive Care Unit environment and after the infant has been discharged. A family-centred philosophy has been adopted when intervening with infants that are at risk for future difficulties. The information that will be obtained from this study hopes to contribute to a better understanding of the individual needs of families of Neonatal Intensive Care Unit graduates and thus allow for the provision of better service delivery.

I am requesting permission to perform this study at (name of hospital). In order for me to conduct the research I would need to familiarise myself with the Neonatal Intensive Care Unit environment through non-participatory observation. The proposed duration of observation needed within the Neonatal Intensive Care Unit is five 3-hour periods during various times of the day and night that is convenient to the staff of the Neonatal Intensive Care Unit.

The families contacted will participate voluntarily and will be informed that they would be entitled to withdraw from the study with no repercussions. All means will be taken for the name of the hospital, professionals associated with the hospital and the participants to remain anonymous.

The proposed study will be submitted to the University of the Witwatersrand Ethics Committee for Research on Human Subjects for permission to conduct this research project. Thus the study will not be conducted or data collected before ethical clearance has been obtained.

The results of the study will be made available to the professionals involved in the Neonatal Intensive Care Units and any other individuals that request the information.

If you agree to the above proposal, please could you provide me with written permission.

Please do not hesitate to contact me, on either 073-203-2523 or 447-8444, in the event that you require any additional information regarding the study.

Yours faithfully,

Lynzi Crisp

Dear (name of paediatrician),

I am presently studying a Masters degree in Speech Pathology at the University of the Witwatersrand. One of the requirements of the course is the completion of a research project.

The proposed study aims to explore the experiences of a group of parents of premature infants that have graduated from the Neonatal Intensive Care Unit (NICU) with regard to the opportunities that were afforded to them in order to communicate with their infants. It is proposed that parents will be asked to complete a questionnaire, which will be followed by a private interview conducted at a time and place convenient to the parents.

Premature infants are considered to be at a greater risk for a delay in development and thus the role of the Speech-Language Pathologist is continually developing both within the Neonatal Intensive Care Unit environment and after the infant has been discharged. A family-centred philosophy has been adopted when intervening with infants that are at risk for future difficulties. The information that will be obtained from this study hopes to contribute to a better understanding of the individual needs of families of Neonatal Intensive Care Unit graduates and thus allow for the provision of better service delivery.

I am requesting permission to perform this study at (name of hospital). In order for me to conduct the research I would require access to the hospital files in order to be able to contact families suitable for the study. In addition, it would be necessary for me to access the files of the subjects that have received treatment from you after their discharge from the NICU in order to obtain additional information.

The families contacted will participate voluntarily and will be informed that they would be entitled to withdraw from the study with no repercussions. All means will be taken for the name of the hospital, professionals associated with the hospital and the participants to remain anonymous.

The proposed study will be submitted to the University of the Witwatersrand Ethics Committee for Research on Human Subjects for permission to conduct this research project. Thus the study will not be conducted or data collected before ethical clearance has been obtained.

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If you agree to the above proposal, please would you provide me with written permission.

Please do not hesitate to contact me, on either 073-203-2523 or 447-4888, in the event that you require any additional information regarding the study.

Yours faithfully,

Lynzi Crisp

Dear (name of Matron of NICU)

I am presently studying a Masters degree in Speech Pathology at the University of the Witwatersrand. One of the requirements of the course is the completion of a research project.

The proposed study aims to explore the experiences of a group of parents of premature infants that have graduated from the Neonatal Intensive Care Unit (NICU) with regards to the opportunities afforded to them in order to communicate with their infants. It is proposed that parents will be asked to complete a questionnaire, which will be followed by a private interview conducted at a time and place convenient to the parents.

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If you agree to the above proposal, please could you provide me with written permission.

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Yours faithfully,

Lynzi Crisp