



Trial Number:

## FIRST-ABC Study

### Parent/Guardian Questionnaire

The FIRST-ABC Study aims to find out if High Flow Nasal Cannula is as good as Continuous Positive Airway Pressure when used as the first treatment option for non-invasive breathing support for children in the PICU/HDU

#### Completing this questionnaire

Today's date

/ / 

Did you complete this questionnaire

Alone

☐

With help

☐

#### Directions

- Of great concern to nurses and others who work in a PICU/HDU is the effect of this environment and experience on parents
- This questionnaire contains a number of items that may be stressful to parents while their child is in PICU/HDU
- We are interested in your view of these items
- By stressful, we mean an experience that caused you to feel anxious, upset or tense
- On the questionnaire, you are asked to circle the number that best expresses how stressful each item was for you:

0	Not experienced	3	Moderately stressful
1	Not stressful	4	Very stressful
2	Minimally stressful	5	Extremely stressful



## Child's appearance

Below is a list of items that might describe your child's appearance.

Circle the number that best expresses how stressful each of these items have been for you

Items	Not experienced	Not stressful	Minimally stressful	Moderately stressful	Very stressful	Extremely stressful
1. Puffiness of my child	0	1	2	3	4	5
2. Colour changes in my child (e.g. pale, blue or yellow)	0	1	2	3	4	5
3. Child appearing cold	0	1	2	3	4	5

## Sights and sounds

Below is a list of sights and sounds in an intensive care unit.

Circle the number that best expresses how stressful each of these items have been for you

Items	Not experienced	Not stressful	Minimally stressful	Moderately stressful	Very stressful	Extremely stressful
1. Seeing the heart on the monitors	0	1	2	3	4	5
2. The sound of monitors and equipment	0	1	2	3	4	5
3. The other sick children in the room	0	1	2	3	4	5
4. The sudden sounds of monitor alarms	0	1	2	3	4	5



## Procedures

Below is a list of procedures that may have been done to your child.

Circle the number that best expresses how stressful each of these items have been for you

Items	Not experienced	Not stressful	Minimally stressful	Moderately stressful	Very stressful	Extremely stressful
1. Tubes in my child	0	1	2	3	4	5
2. Suctioning	0	1	2	3	4	5
3. Putting needles in my child for fluids, procedures or tests	0	1	2	3	4	5
4. Making my child cough and deep breath / pounding and clapping on my child's chest	0	1	2	3	4	5
5. Injections / shots	0	1	2	3	4	5
6. Bruises, cuts, incisions on my child	0	1	2	3	4	5

## Communication

Below is a list of items that relate to how professional staff (doctors and nurses) may communicate with you about your child's illness.

Circle the number that best expresses how stressful each of these items have been for you

Items	Not experienced	Not stressful	Minimally stressful	Moderately stressful	Very stressful	Extremely stressful
1. Explaining things too fast	0	1	2	3	4	5
2. Using words I do not understand	0	1	2	3	4	5
3. Telling me different (conflicting) things about my child's condition	0	1	2	3	4	5
4. Not telling me what is definitely wrong with my child	0	1	2	3	4	5
5. Not talking with me enough	0	1	2	3	4	5



## Behaviours and emotional responses

Below is a list of behaviours and emotional responses that your child may have exhibited while in the intensive care unit.

Circle the number that best expresses how stressful each of these items have been for you

Items	Not experienced	Not stressful	Minimally stressful	Moderately stressful	Very stressful	Extremely stressful
1. Confusion	0	1	2	3	4	5
2. Rebellious or uncooperative behaviour	0	1	2	3	4	5
3. Crying or whining	0	1	2	3	4	5
4. Demanding	0	1	2	3	4	5
5. Acting or looking as if in pain	0	1	2	3	4	5
6. Restlessness	0	1	2	3	4	5
7. Inability to talk or cry	0	1	2	3	4	5
8. Fright	0	1	2	3	4	5
9. Anger	0	1	2	3	4	5
10. Sadness or depression	0	1	2	3	4	5

## Behaviours of professional staff

Below is a list of behaviours of the professional staff (doctors and nurses) that you may have observed.

Circle the number that best expresses how stressful each of these items have been for you

Items	Not experienced	Not stressful	Minimally stressful	Moderately stressful	Very stressful	Extremely stressful
1. Joking, laughing or talking loudly	0	1	2	3	4	5
2. Not talking to me enough	0	1	2	3	4	5
3. Too many different people talking to me (e.g. doctors, nurses, staff)	0	1	2	3	4	5
4. Not telling me names or who they are	0	1	2	3	4	5



## Parental roles

*Below is a list of items related to parental roles.*

*Circle the number that best expresses how stressful each of these items have been for you*

Items	Not experienced	Not stressful	Minimally stressful	Moderately stressful	Very stressful	Extremely stressful
1. Not taking care of my child myself	0	1	2	3	4	5
2. Not being able to visit my child when I wanted	0	1	2	3	4	5
3. Not being able to see my child when I wanted	0	1	2	3	4	5
4. Not being able to be with my crying child	0	1	2	3	4	5
5. Not being able to hold my child	0	1	2	3	4	5

## Overall experience

*Using the same rating scale, how stressful, in general, has the total critical care unit experience been for you?*

Not experienced	Not stressful	Minimally stressful	Moderately stressful	Very stressful	Extremely stressful
0	1	2	3	4	5

***We would like to thank you very much for your participation***

***Please hand your completed questionnaire to a member of the hospital research team***