

## Pediatric Family Satisfaction with Care in the Intensive Care Unit: pFS-ICU 24R©

### How are we doing?





















*We would like to hear your opinions about your child's recent admission to the Pediatric Intensive Care Unit (ICU)*

Your child was a patient in this ICU. The questions that follow ask **YOU** about your child's **most recent ICU admission**. We understand that there were probably many doctors and nurses and other staff involved in caring for your child. We know that there may be exceptions but we are interested in **your overall assessment** of the quality of care we delivered. We understand that this was probably a very difficult time for you and your family members. We would appreciate you taking the time to provide us with your opinion. Please take a moment to tell us what we did well and what we can do to make our ICU better. **Please be assured that all responses are confidential.** The Doctors and Nurses who looked after your child will not be able to identify your responses.

#### PART 1: SATISFACTION WITH CARE





















*Please check one box that best reflects your views. If the question does not apply to your child's stay then check the 'Not Applicable' box (N/A).*

#### HOW DID WE TREAT YOUR CHILD (THE PATIENT)? HOW SATISFIED ARE YOU WITH...
















- |   |   |  |  |  |  |                                 |
|---|---|--|--|--|--|---------------------------------|
| <p>1. <b>Concern and Caring by ICU Staff?</b><br/>The courtesy, respect and compassion <b>your child (the patient)</b> was given.</p> | <br>Very<br>Dissatisfied<br><input type="checkbox"/> 1 | <br>Slightly<br>Dissatisfied<br><input type="checkbox"/> 2 | <br>Mostly<br>Satisfied<br><input type="checkbox"/> 3 | <br>Very<br>Satisfied<br><input type="checkbox"/> 4 | <br>Completely<br>Satisfied<br><input type="checkbox"/> 5 | N/A<br><input type="checkbox"/> |
| <p>2. <b>Symptom Management?</b><br/>How well the ICU staff assessed and treated <b>your child's</b> symptoms.</p>                    |   |  |  |  |  |                                 |
| <p>a. How well the ICU staff assessed and treated your child's <u>pain</u>.</p>   | <br>Very<br>Dissatisfied<br><input type="checkbox"/> 1 | <br>Slightly<br>Dissatisfied<br><input type="checkbox"/> 2 | <br>Mostly<br>Satisfied<br><input type="checkbox"/> 3 | <br>Very<br>Satisfied<br><input type="checkbox"/> 4 | <br>Completely<br>Satisfied<br><input type="checkbox"/> 5 | N/A<br><input type="checkbox"/> |
| <p>b. How well the ICU staff assessed and treated your child's <u>breathlessness</u>.</p>   | <br>Very<br>Dissatisfied<br><input type="checkbox"/> 1 | <br>Slightly<br>Dissatisfied<br><input type="checkbox"/> 2 | <br>Mostly<br>Satisfied<br><input type="checkbox"/> 3 | <br>Very<br>Satisfied<br><input type="checkbox"/> 4 | <br>Completely<br>Satisfied<br><input type="checkbox"/> 5 | N/A<br><input type="checkbox"/> |
| <p>c. How well the ICU staff assessed and treated your child's <u>agitation</u>.</p>  | <br>Very<br>Dissatisfied<br><input type="checkbox"/> 1 | <br>Slightly<br>Dissatisfied<br><input type="checkbox"/> 2 | <br>Mostly<br>Satisfied<br><input type="checkbox"/> 3 | <br>Very<br>Satisfied<br><input type="checkbox"/> 4 | <br>Completely<br>Satisfied<br><input type="checkbox"/> 5 | N/A<br><input type="checkbox"/> |

**How are we doing?  
Your Opinions about your Child's ICU stay**

**HOW DID WE TREAT YOU? HOW SATISFIED ARE YOU WITH...**

- |    |  |   |   |  |  |  |                                 |
|----|--|---|---|--|--|--|---------------------------------|
| 3. | <b>Consideration of your needs?</b><br>How well the ICU staff showed an interest in <b>your</b> needs. | <br>Very<br>Dissatisfied<br><input type="checkbox"/> 1 | <br>Slightly<br>Dissatisfied<br><input type="checkbox"/> 2 | <br>Mostly<br>Satisfied<br><input type="checkbox"/> 3 | <br>Very<br>Satisfied<br><input type="checkbox"/> 4 | <br>Completely<br>Satisfied<br><input type="checkbox"/> 5 | N/A<br><input type="checkbox"/> |
| 4. | <b>Emotional support?</b><br>How well the ICU staff provided emotional support to <b>you</b> .         | <br>Very<br>Dissatisfied<br><input type="checkbox"/> 1 | <br>Slightly<br>Dissatisfied<br><input type="checkbox"/> 2 | <br>Mostly<br>Satisfied<br><input type="checkbox"/> 3 | <br>Very<br>Satisfied<br><input type="checkbox"/> 4 | <br>Completely<br>Satisfied<br><input type="checkbox"/> 5 | N/A<br><input type="checkbox"/> |
| 5. | <b>Co-ordination of care?</b><br>The teamwork of all the ICU staff that took care of your child.       | <br>Very<br>Dissatisfied<br><input type="checkbox"/> 1 | <br>Slightly<br>Dissatisfied<br><input type="checkbox"/> 2 | <br>Mostly<br>Satisfied<br><input type="checkbox"/> 3 | <br>Very<br>Satisfied<br><input type="checkbox"/> 4 | <br>Completely<br>Satisfied<br><input type="checkbox"/> 5 | N/A<br><input type="checkbox"/> |
| 6. | <b>Concern and Caring by ICU Staff?</b><br>The courtesy, respect and compassion <b>you</b> were given. | <br>Very<br>Dissatisfied<br><input type="checkbox"/> 1 | <br>Slightly<br>Dissatisfied<br><input type="checkbox"/> 2 | <br>Mostly<br>Satisfied<br><input type="checkbox"/> 3 | <br>Very<br>Satisfied<br><input type="checkbox"/> 4 | <br>Completely<br>Satisfied<br><input type="checkbox"/> 5 | N/A<br><input type="checkbox"/> |

**THE ICU STAFF: HOW SATISFIED ARE YOU WITH...**





















- |    |  |   |   |  |  |  |                                 |
|----|--|---|---|--|--|--|---------------------------------|
| 7. | <b>Skill and Competence of ICU Nurses?</b><br>How well the nurses cared for your child.                                  | <br>Very<br>Dissatisfied<br><input type="checkbox"/> 1 | <br>Slightly<br>Dissatisfied<br><input type="checkbox"/> 2 | <br>Mostly<br>Satisfied<br><input type="checkbox"/> 3 | <br>Very<br>Satisfied<br><input type="checkbox"/> 4 | <br>Completely<br>Satisfied<br><input type="checkbox"/> 5 | N/A<br><input type="checkbox"/> |
| 8. | <b>Frequency of Communication With ICU Nurses?</b><br>How often nurses communicated to you about your child's condition. | <br>Very<br>Dissatisfied<br><input type="checkbox"/> 1 | <br>Slightly<br>Dissatisfied<br><input type="checkbox"/> 2 | <br>Mostly<br>Satisfied<br><input type="checkbox"/> 3 | <br>Very<br>Satisfied<br><input type="checkbox"/> 4 | <br>Completely<br>Satisfied<br><input type="checkbox"/> 5 | N/A<br><input type="checkbox"/> |
| 9. | <b>Skill and Competence of ICU Doctors (All Doctors including Residents)?</b><br>How well doctors cared for your child.  | <br>Very<br>Dissatisfied<br><input type="checkbox"/> 1 | <br>Slightly<br>Dissatisfied<br><input type="checkbox"/> 2 | <br>Mostly<br>Satisfied<br><input type="checkbox"/> 3 | <br>Very<br>Satisfied<br><input type="checkbox"/> 4 | <br>Completely<br>Satisfied<br><input type="checkbox"/> 5 | N/A<br><input type="checkbox"/> |

**THE WAITING ROOM**

- |     |   |   |   |  |  |  |                                 |
|-----|---|---|---|--|--|--|---------------------------------|
| 10. | How satisfied are you with the atmosphere (mood) in the ICU waiting room? | <br>Very<br>Dissatisfied<br><input type="checkbox"/> 1 | <br>Slightly<br>Dissatisfied<br><input type="checkbox"/> 2 | <br>Mostly<br>Satisfied<br><input type="checkbox"/> 3 | <br>Very<br>Satisfied<br><input type="checkbox"/> 4 | <br>Completely<br>Satisfied<br><input type="checkbox"/> 5 | N/A<br><input type="checkbox"/> |
|-----|---|---|---|--|--|--|---------------------------------|

**How are we doing?  
Your Opinions about your Child's ICU stay**

**THE ICU**

11. How satisfied are you with the atmosphere (mood) of the ICU?						N/A
	Very Dissatisfied	Slightly Dissatisfied	Mostly Satisfied	Very Satisfied	Completely Satisfied	
	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4	<input type="checkbox"/> 5	<input type="checkbox"/>
12. How satisfied are you with your participation in daily rounds?						N/A
	Very Dissatisfied	Slightly Dissatisfied	Mostly Satisfied	Very Satisfied	Completely Satisfied	
	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4	<input type="checkbox"/> 5	<input type="checkbox"/>
13. How satisfied are you with <u>your participation in the care</u> of your critically ill child?						N/A
	Very Dissatisfied	Slightly Dissatisfied	Mostly Satisfied	Very Satisfied	Completely Satisfied	
	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4	<input type="checkbox"/> 5	<input type="checkbox"/>
14. Some people want everything done for their health problems while others do not want a lot done. How satisfied are you with the LEVEL <u>or amount</u> of health care your child received in the ICU?						N/A
	Very Dissatisfied	Slightly Dissatisfied	Mostly Satisfied	Very Satisfied	Completely Satisfied	
	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4	<input type="checkbox"/> 5	<input type="checkbox"/>

## How are we doing? Your Opinions about your Child's ICU stay

### PART 2: PEDIATRIC FAMILY SATISFACTION WITH DECISION-MAKING AROUND CARE OF CRITICALLY ILL PATIENTS































**INSTRUCTIONS FOR PARENTS, CAREGIVERS, OR GUARDIANS OF CRITICALLY ILL PATIENTS**

This part of the questionnaire is designed to measure how you feel about YOUR involvement in decisions related to your child's health care. In the ICU, your child may have received care from different people. We would like you to think about all the care your child received when you are answering the questions.

**Please check one box that best reflects your views. If the question does not apply to your child's stay then check the 'Not Applicable' box (N/A)**

#### **INFORMATION NEEDS**

HOW SATISFIED ARE YOU WITH...

- |  |  |  |   |   |   |                                 |
|--|--|--|---|---|---|---------------------------------|
| <p>15. <b>Frequency of Communication With ICU Doctors?</b><br/>How often doctors communicated to you about your child's condition.</p>   | <br>Very Dissatisfied<br><input type="checkbox"/> 1   | <br>Slightly Dissatisfied<br><input type="checkbox"/> 2   | <br>Mostly Satisfied<br><input type="checkbox"/> 3   | <br>Very Satisfied<br><input type="checkbox"/> 4   | <br>Completely Satisfied<br><input type="checkbox"/> 5   | N/A<br><input type="checkbox"/> |
| <p>16. <b>Ease of getting information?</b><br/>Willingness of ICU staff to answer your questions.</p>  | <br>Very Dissatisfied<br><input type="checkbox"/> 1  | <br>Slightly Dissatisfied<br><input type="checkbox"/> 2  | <br>Mostly Satisfied<br><input type="checkbox"/> 3  | <br>Very Satisfied<br><input type="checkbox"/> 4  | <br>Completely Satisfied<br><input type="checkbox"/> 5  | N/A<br><input type="checkbox"/> |
| <p>17. <b>Understanding of Information?</b><br/>How well ICU staff provided you with explanations that you understood.</p>   | <br>Very Dissatisfied<br><input type="checkbox"/> 1 | <br>Slightly Dissatisfied<br><input type="checkbox"/> 2 | <br>Mostly Satisfied<br><input type="checkbox"/> 3 | <br>Very Satisfied<br><input type="checkbox"/> 4 | <br>Completely Satisfied<br><input type="checkbox"/> 5 | N/A<br><input type="checkbox"/> |
| <p>18. <b>Honesty of Information?</b><br/>The honesty of information provided to you about your child's condition.</p>   | <br>Very Dissatisfied<br><input type="checkbox"/> 1 | <br>Slightly Dissatisfied<br><input type="checkbox"/> 2 | <br>Mostly Satisfied<br><input type="checkbox"/> 3 | <br>Very Satisfied<br><input type="checkbox"/> 4 | <br>Completely Satisfied<br><input type="checkbox"/> 5 | N/A<br><input type="checkbox"/> |
| <p>19. <b>Completeness of Information?</b><br/>How well ICU staff informed you what was happening to your child and why things were being done.</p>                                      | <br>Very Dissatisfied<br><input type="checkbox"/> 1 | <br>Slightly Dissatisfied<br><input type="checkbox"/> 2 | <br>Mostly Satisfied<br><input type="checkbox"/> 3 | <br>Very Satisfied<br><input type="checkbox"/> 4 | <br>Completely Satisfied<br><input type="checkbox"/> 5 | N/A<br><input type="checkbox"/> |
| <p>20. <b>Consistency of Information?</b><br/>The consistency of information provided to you about your child's condition (Did you get a similar story from the doctor, nurse, etc.)</p> | <br>Very Dissatisfied<br><input type="checkbox"/> 1 | <br>Slightly Dissatisfied<br><input type="checkbox"/> 2 | <br>Mostly Satisfied<br><input type="checkbox"/> 3 | <br>Very Satisfied<br><input type="checkbox"/> 4 | <br>Completely Satisfied<br><input type="checkbox"/> 5 | N/A<br><input type="checkbox"/> |

***How are we doing?  
Your Opinions about your Child's ICU stay***

**PROCESS OF MAKING DECISIONS**

During your child's stay in the ICU, many important decisions were made regarding the health care she or he received. From the following questions, select only **one** answer from each of the following set of ideas that best matches your views:

**21. How included or excluded did you feel in the decision making process?**

- 1 I felt very excluded
- 2 I felt somewhat excluded
- 3 I felt neither included nor excluded from the decision making process
- 4 I felt somewhat included
- 5 I felt very included

**22. How supported did you feel during the decision making process?**

- 1 I felt totally unsupported
- 2 I felt slightly unsupported
- 3 I felt neither unsupported nor supported
- 4 I felt supported
- 5 I felt very supported

**23. Did you feel you had control over the care of your child?**

- 1 I felt really out of control and that the health care system took over and dictated the care my child received
- 2 I felt somewhat out of control and that the health care system took over and dictated the care my child received
- 3 I felt neither in control or out of control
- 4 I felt I had some control over the care my child received
- 5 I felt that I had good control over the care my child received

**24. When making decisions, did you have adequate time to have your concerns addressed and questions answered?**

- 1 The time I had was definitely inadequate
- 2 The time I had was slightly inadequate
- 3 The time I had was adequate
- 4 The time I had was more than adequate
- 5 I had a substantial amount of time

***How are we doing?  
Your Opinions about your Child's ICU stay***

**If your child died during the ICU stay, please answer the following questions (25-27). If your child did not die, please skip to question 28.**

**25. Which of the following best describes your views:**

- 1 I felt my child's life was prolonged unnecessarily
- 2 I felt my child's life was slightly prolonged unnecessarily
- 3 I felt my child's life was neither prolonged nor shortened unnecessarily
- 4 I felt my child's life was slightly shortened unnecessarily
- 5 I felt my child's life was shortened unnecessarily

**26. During the final hours of your child's life, which of the following best describes your views:**

- 1 I felt that he/she was very uncomfortable
- 2 I felt that he/she was slightly uncomfortable
- 3 I felt that he/she was mostly comfortable
- 4 I felt that he/she was very comfortable
- 5 I felt that he/she was totally comfortable

**27. During the last few hours before your child's death, which of the following best describes your views:**

- 1 I felt very abandoned by the health care team
- 2 I felt abandoned by the health care team
- 3 I felt neither abandoned nor supported by the health care team
- 4 I felt supported by the health care team
- 5 I felt very supported by the health care team

***How are we doing?  
Your Opinions about your Child's ICU stay***

**28. Do you have any suggestions on how to make care provided in the ICU better?**

---

---

---

---

---

---

---

---

---

---

**29. Do you have any comments on things we did well?**

---

---

---

---

---

---

---

---

---

---

**30. Do you have any suggestions on how we could improve the ICU experience for you and your child?**

---

---

---

---

---

---

---

---

---

---

**How are we doing?  
Your Opinions about your Child's ICU stay**

**DEMOGRAPHICS:**

Please complete the following to help us know a little about you and your relationship to the child.

1. **I am:**  Male  Female  Other
  
2. **I am** \_\_\_\_\_ years old
  
3. **I am the child's:**  
 Mother  Father  Grandparent  Foster Parent  
 Stepparent  Other Caregiver: \_\_\_\_\_
  
4. **Before this most recent event, have you been involved as a family member of a patient in an ICU (Intensive Care Unit)?**  
 Yes  No
  
5. **Do you currently live with the child?**  Yes  No  
*If no*, then on average how often do you see the child?  
 More than weekly  Weekly  Monthly  Yearly  Less than once a year
  
6. **Where do you live?**  
 In the city or town where the hospital is located  Out of town
  
7. **Which of the following best describes the highest level of education you have completed?**  
 Did not complete secondary school or high school  
 Completed secondary or high school  
 Had some university education or completed a community college, technical college, or post-secondary program (for example; trade, technical or vocational school)  
 University degree (for example; BA, BSc, BSN)  
 Graduate degree (for example; MD, DDS, DMD, DVM, OD, Master's, or PhD)

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