Title: Improving Communication in the PICU for Patients Facing Life-Changing Decisions: the Navigate Study

Short title: The Navigate study

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Document History

Amendment	Date	Changes
Amendment 1	12/2/14	1. Additions were made to the PICU Handbook including the following: - Page 20 “of” added to the text in the margin - Pages 28, 31, and 35 words and their definitions are added for “bradycardia” “hypertension” “hypotension” “tachycardia” and “tachypnea” - Page 45 Information about laundry facilities and getting food is added. 2. Section 4.7 of this protocol was changed to include the CD-RISK-25 scale, a measure of resilience. 3. A typo was corrected on page 6. 4. Modifications were made to Parent Questionnaire 1 including the following: - Page 7 – the bold and underline was removed from the word “fine” - Page 8 – the word “Moderately” was changed to “Moderate” - Pages 9-11 – the CD-RISK-25 items were added 5. Modifications were made to Parent Questionnaire 4 and 5 including the following: -Page 14 of Parent Questionnaire 4 and Page 15 of Parent Questionnaire 5 – the word “Moderately” was changed to “Moderate” - On page 3 added “Did not use” as a response option for intervention questions, added a question about the question prompt list in the back of the PICU handbook, and reworded the question about the use of the diary to include the use of the calendar -Fixed some formatting errors. - On page 12 of Questionnaire 4 changed the wording on the top of the page to read, “The following questions are about decision making in the PICU.” 6. Addition of a cover letter email to the Healthcare team for the Healthcare team member survey 2. 7. On Healthcare team member survey 2 rephrased the question about diary on page 5.
Amendment 2	02/02/2015	1. pg 3: included Cardiac Intensive Care Unit (CICU) as a recruitment location for potential participants of the pilot. 2. pg 4: Inclusion criteria was changed from “will be in the PICU for 3 or more days to “are likely to require PICU care for at least 24 hours from the time a study team member inquires about the patient’s projected length of stay in the PICU (as determined by a member of the patient’s PICU team) or” 3. pg 5: During the daily weekday screening the patients physicians will now be asked “if he/she expects the patient to be discharged from the unit that day or the following day”

		4. pg 6 & pg. 23: Removed the need for a parent to sign a consent form within 24 hours of hearing about the study. Parents are now asked to sign the consent form after they have received a copy and have had enough time to ask questions of the research team, which may be more than 24 hours after hearing about the study. 5. pg 7: Added the option for the Navigator to continue visits with the family transferred to a regular floor bed, when appropriate. 6. pg 8 & pg 14: Included the Navigator Reflection Sheet as a piece of the Navigator Documentation completed at the time of data collection from participants.7. pg. 14: Included the Patient status update in the data collection table 8.Appendix 1: Patient Screening Form: Changed the estimated length of stay from <3 days or ≥3 days to likely to require PICU care for <24 hours or ≥24 hours 9. Added Appendix 5: The Navigator Reflection sheet 10. Added Appendix 6: Patient Status update (place to keep data being collected per section 4.11 of this protocol
Amendment 3	02/26/2015	1. Added Eric Price to the Research Personnel – approved by IRB on 02/26/2015
Amendment 4	02/27/2015	1. Pg 4 Addition of Spanish translated forms 2. Pg 3 &17Changed the target enrollment for the pilot period from 30 patients and up to 60 parents to 60 patients and up to 120 parents. 3. Added the option for Healthcare team members to take part in an interview if unable to take part in the focus group opportunities.
Amendment 5	03/25/2015	1. Appendix 7: Questionnaire 1 added a question regarding household income. 2. Appendix 12 and 13: Questionnaires 4a and 5a have been added to the protocol as surveys for the control arm participants to complete. 3. Appendix 8,9, 10, 11: Questionnaires 2, 3, 4B and 5B: added a line on the first page that indicates how long the survey will take 4. Appendix 15: Added a Thank you letter to parents that will be sent upon discharge from the PICU. 5. Appendix 30: Added the Educational Brochure for the Control Arm
Amendment 6	10/19/2015	1. Addition of language to HTM survey distribution to give healthcare providers post family meeting survey after they participate in a family meeting for a family enrolled in the study. 2. Addition of Appendix 19: HTM Post Family Meeting survey

		3. Removed personnel Eric Price, Kristen James, and Sergio Grajeda from the protocol 4. Updated Farah contact information

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Abbreviations and Definitions of Terms

ANOVA	Analysis of Variance
APNs	Advance Practice Nurses
CAT-T	Communication Assessment Tool-Team
CAT	Communication Assessment Tool
CLT	Central Limit Theorem
Comer Children’s Hospital	Chicago Medicine Comer Children’s Hospital
CPR	Cardiopulmonary Resuscitation
CRRT	Continuous Renal Replacement Therapy
CSACD	Collaboration and Satisfaction about Care Decisions
DM	Decision Making
DRS	Decision Regret Scale
DSMC	Data Safety Monitoring Committee
ECMO	Extracorporeal Membrane Oxygenation
HIPAA	Health Insurance Portability and Accountability Act
HTMs	Healthcare Team Members
ICG	Index of Complicated Grief
ID	Identification
IES-R	Impact of Event Scale – Revised
ITT	Intention-To-Treat
Lurie Children’s Hospital	Ann & Robert H. Lurie Children's Hospital of Chicago
pFS-ICU	Pediatric Family Satisfaction in the Intensive Care Unit
PHI	Person Health Information
PIM2	Pediatric Index of Mortality 2
PICU	Pediatric Intensive Care Unit
PROMIS	Patient Reported Outcomes Measurement Information System

RCT	Randomized Controlled Trial
REDCap	Research Electronic Data Capture
SAP	statistical analysis plan
SWs	Social Workers
UPIRTSOs	Unanticipated Problems Involving Risks to Subjects or Others

Abstract

Parents of children admitted to the PICU often face challenging decisions. Research demonstrates deficiencies in communication in the PICU which could impact decision making. This study team has developed a navigator-based intervention call PICU Supports. PICU Supports aims to provide the following types of support to parents of patients in the PICU: emotional; communication (between HTMs and parents/families as well as among HTMs); decision making; transition out of the PICU (i.e. discharge transitions to a non-PICU hospital bed, a long term care facility, or home); and information. Support is accomplished by navigator engagement with parents and HTMs and the guided use of navigator supported ancillary tools provided to parents and HTMs as needed. During the patient's PICU stay, the navigator activities and use of ancillary tools is directed by the family's needs. Thus PICU Supports uses a predefined framework of activities and tools to provide individualized support directed by the needs of the parent and the patient situation. This research will test PICU Supports in the clinical setting. This will be accomplished by conducting a pilot study of PICU Supports at Ann & Robert H. Lurie Children's Hospital of Chicago (Lurie Children's Hospital), followed by a randomized controlled trial (RCT) comparing the intervention, PICU Supports, to a control, parental receipt of an educational brochure. The RCT will be conducted at Lurie Children's Hospital and at University of Chicago Medicine Comer Children's Hospital (Comer Children's Hospital).

1.0 BACKGROUND INFORMATION AND RATIONALE

Patients admitted to the Pediatric Intensive Care Unit (PICU) may face death or significant morbidity. Three to eight percent of PICU patients die.[1-8] PICU deaths include previously healthy children (e.g., those affected by trauma or infection) and children with complex chronic conditions,[9-13] a group of approximately 500,000 children in the US increasingly seen in PICUs.[14,15] With life-limiting or life-ending illnesses, parents face difficult, value-laden decisions. Past research with parents of children who died in the PICU and PICU healthcare team members (HTMs) shows that parents of dying patients face decisions that affect when, how, and sometimes if their child dies (e.g., withdrawing life-sustaining therapies or avoiding cardiopulmonary resuscitation).[16] Research also shows that parents of dying patients make nonmedical decisions influencing bereavement (e.g., participating in memory-making activities or holding their child during death).[16]

Parents of patients who survive long complicated PICU stays also face difficult life-changing decisions. PICU patients with long stays (>95th percentile for length of stay or >12 days) make up 36% of PICU days of care.[17] Complicated admissions can occur for otherwise healthy patients, but more commonly involve the 53 – 67% of PICU patients with complex chronic conditions.[13,18] For survivors of long, complicated PICU stays, parents may face decisions about: tracheostomy; initiating chronic ventilation; and/or accepting palliative care or limits on life-sustaining therapies, among other potentially life-altering medical decisions. Parents may also face complicated life choices about taking time off from work, spending less time with patients' sibling(s), and talking (or not) to siblings about the patient's illness.

When decisions conflict with parents' and patients' wishes, patients may receive what families perceive as inappropriate care, sometimes too aggressive (such as invasive therapies which the parents feel impose more burdens than benefits), or sometimes not aggressive enough (such as when clinicians recommend withdrawal of life-support for a patient with a very low but present chance of survival despite parents' desires to continue aggressive care). For all parents, decision making that does not fit their goals can result in dissatisfaction, decision regret, and psychological morbidity (e.g., anxiety, depression, post-traumatic stress disorder).[19-21] For parents of children that die, pathological bereavement can result.[19,22-25] Parental psychological morbidity can impact siblings and spousal relationships.[26] HTMs may suffer from moral distress or job dissatisfaction as a result of value clashes with families.[27-29]

Research demonstrates deficiencies in three lines of decision making (DM) communication in the PICU: 1) communication from HTMs to parents; 2) communication from parents to HTMs; and 3) communication among HTMs. A study of PICU family conferences shows deficiencies in communication from HTMs to parents. In that work, 36 parents completed a validated communication assessment tool (CAT) [30] following 18 PICU family conferences.[31] Only 29% of respondents gave an "excellent" rating to the item "talked in terms I could understand," and only 61% to the item "Gave me as much information as I wanted."[31] Analysis of 22 audio-recorded family conferences demonstrated that four key elements of shared decision making[32] were absent more than half the time: assessment of family understanding; assessment of the need for input from others; exploration of the family's role in decision making; and eliciting the family's opinion about decisions.[31] Also, PICU parents and HTMs report shortcomings in communication among HTMs. In a study of bereaved PICU parents, communication and care coordination emerged as a priority for end-of-life care. Parents described inadequate care coordination among the professionals involved in their child's medical care.[33] Parents reported that poor communication eroded their trust in HTMs and created confusion.[33]

Some researchers and clinicians have proposed utilizing navigators to improve communication. Though various definitions exist, one definition of a navigator is "someone who understands the patient's fears and hopes, and who removes barriers to effective care by coordinating services, increasing the patient's chances for survival and quality of life."[34] While developed for cancer patients, [35-37] the navigator concept has been successfully expanded to include different populations. Recently, White et al. demonstrated the feasibility, acceptability and perceived effectiveness of the Four Supports Intervention, which uses a “family support specialist” (akin to a navigator) to improve surrogate decision making for adult ICU patients.[38] Physicians and surrogates reported that the intervention 1) improved the quality and timeliness of communication, 2) facilitated discussion of the patient’s values and preferences, and 3) improved the patient-centeredness of care. Thus there are data supporting the use of a navigator to improve communication and DM in an ICU setting.

This study team has developed a navigator-based intervention call PICU Supports. PICU Supports was developed by adapting the Four Supports Intervention to the needs of the PICU. PICU Support reflects input from this project’s three study advisory groups: 1) parents (parents of children who have been cared for in an intensive care unit setting); 2) healthcare professionals who care for PICU patients (including nurses, social workers, chaplains, and non-PICU subspecialty attendings like oncology physicians); and 3) researchers with expertise in PICU communication and decision making. PICU Supports also reflects input from parents and HTMs who are not part of the study advisory groups, but who participated in interviews and focus groups. PICU Supports aims to provide the following types of support to parents of patients in the PICU: emotional, communication (between HTMs and parents/families as well as among HTMs); decision making; transition out of the PICU (i.e. discharge transitions to a non-PICU hospital bed, a long term care facility, or home); and information. This is accomplished by navigator engagement with parents and HTMs and the guided use of navigator supported ancillary tools provided to parents and HTMs as needed. During the patient’s stay in the PICU, the focus of the navigator activities and use of ancillary tools is directed by the needs of the family. Thus PICU Supports uses a predefined framework of activities and tools to provide individualized support directed by the needs of the parent and the patient situation.

The goal of this research is to test PICU Supports in the clinical setting. This will be accomplished by conducting a pilot study of PICU Supports at Ann & Robert H. Lurie Children's Hospital of Chicago (Lurie Children’s Hospital), followed by a randomized controlled trial (RCT) comparing the intervention, PICU Supports, to a control, parental receipt of an informational brochure. The RCT will be conducted at Lurie Children's Hospital and at University of Chicago Medicine Comer Children’s Hospital (Comer Children’s Hospital).

2.0 STUDY OBJECTIVES

The purpose of this study is to test the use and efficacy of PICU Supports in the clinical setting. The study will accomplish the following aims:

Aim 1. Determine the feasibility, perceived acceptability, and effectiveness of PICU Supports

- Hypothesis 1a. Implementation of PICU Supports is feasible.
- Hypothesis 1b. Parents perceive PICU supports as acceptable and effective.
- Hypothesis 1c. HTMs perceive PICU Supports as acceptable and effective.

Aim 2. Test the impact of PICU Supports during and after PICU discharge on parent outcomes (satisfaction with DM, decision regret, anxiety, depression, post-traumatic stress, and health-related quality of life, and complicated bereavement).

- Hypothesis 2a. PICU Supports improves parental satisfaction with DM.
- Hypothesis 2b. PICU Supports decreases short term parental decision regret.
- Hypothesis 2c. PICU Supports decreases short term parental anxiety, depression, symptoms of post-traumatic stress, health-related quality of life, and complicated bereavement.

Aim 3. Test the impact of PICU Supports on parent and HTM assessments of communication and team collaboration.

- Hypothesis 3a. PICU Supports improves parental assessments of communication between HTMs and parents, and of team collaboration.
- Hypothesis 3b. PICU Supports improves HTM assessments of team collaboration.

3.0 INVESTIGATIONAL PLAN

3.1 General Schema of Study Design

Part 1 of the study will be a pilot conducted at the Lurie Children's Hospital PICU and/or cardiac intensive care unit. During the pilot, enrolled participants will receive the intervention, PICU Supports. Part 2 of the study will be a RCT. During the RCT, enrolled participants will be randomized to receive either the intervention or an informational brochure. The RCT will begin at Lurie Children's Hospital and then expand to Comer Children’s Hospital after the protocol is reviewed and approved by the Comer Children’s Hospital IRB. The intervention can take place in the PICU and/or cardiac intensive care unit. Hereafter, the PICU and cardiac intensive care unit will be referred to as the PICU.

3.2 Study Duration and Number of Participants Projected.

Enrollment for the pilot study will continue for up to four months, or until the parent(s) of 60 patients are enrolled. Enrollment for the RCT will begin approximately two months after completing enrollment for the pilot study or earlier if possible. Enrollment for the RCT will continue until the goal of enrolling parents of 404 patients is met.

Participation of parents enrolled in the study will continue from the point of signing consent until completion of the final study survey, up to 3-5 months after discharge from the PICU. For the pilot we anticipate enrolling at least 60 families, but up to 120 parents depending on how many parents per patient enroll. For the RCT we anticipate enrolling at least 404 families, but it could be as many as 808 parents depending on how many parents per patient enroll.

Patient participation will continue from the point of parental consent and patient assent (if applicable) until discharge from the PICU.

The duration of participation from HTMs will depend in which part of the study a particular HTM participates. The total number of HTMs that will be enrolled is unknown as it will depend on the number of HTMs involved in the care of PICU patients at each site, the number of HTMs participating in focus groups/interviews, and the number of eligible HTMs care for case patients.

3.3 Study Populations

This study will include three groups of participants: case patients; parents of case patients; and HTMs who participate in the care of PICU patients.

3.3.a. Case Patients. Case patients are not the main study participants. Rather, parents and HTMs are the main study participants. However, clinical data will be collected about case patients. The definition of a "case patient", with associated inclusion and exclusion criteria, will determine parental eligibility and, in some cases, HTM eligibility for study participation. Case patients are defined as patients < 18 years of age admitted to the PICU whose parents are English or Spanish-speakers and who:

- are likely to require PICU care for at least 24 hours from the time a study team member inquires about the patient's projected length of stay in the PICU (as determined by a member of the patient's PICU team) or
- have a Pediatric Index of Mortality 2 (PIM2) score ≥ 4% (a PIM2 score predicts risk of mortality based on clinical data collected at the time of admission to the PICU)[39]

Case patients will be included in the study if one of his/her parents agrees to participate in the study and signs a written consent form.

3.3.b. Parents of Case Patients.
Inclusion criteria for parents of case patients:

- Parent of an eligible case patient.
- PICU attending gives permission to approach the parent about the study.
- Parent is an English or Spanish speaker. Following institutional review board (IRB) approval of our study research plan at the lead site (the Lurie Children's Hospital IRB), we will have our materials translated to Spanish or utilize previously translated versions of tools included in our materials. After approval of these materials by the Lurie Children's Hospital IRB (and later the Comer Children's IRB) we will include Spanish speakers.
- Parent provides written consent for participation.

Exclusion criteria for parents of case patients:

- PICU attending does not give permission to approach the parent about the study
- Parent is not an English or Spanish speaker. The study is restricted to English and Spanish speakers because it is not practical or feasible to have our materials translated into all other potentially needed languages and to have interviewers fluent it all other potentially needed languages.
- Parent does not provide written consent to participate.

- The case patient does not provide assent (if able to provide assent).

3.3.c. Healthcare Team Members (HTMs). HTMs who care for PICU patients will be included in the study in four possible ways:

1. The pre-post HTM assessment of team communication – This group will include as many clinicians in the following groups as possible (identified by the site principal investigator): PICU physicians (attendings and fellows); PICU bedside nurses; PICU Advance Practice Nurses (APNs); hospitalists; subspecialty physicians who consult on PICU patients; subspecialty APNs who consult on PICU patients; PICU respiratory therapist; PICU physical/occupational/speech therapists; and social workers (SWs), chaplains, and case managers who follow PICU patients.
2. The verbal feedback/assessment of the intervention – This group will include a convenience sample of HTMs who care for PICU patients. The same people eligible for the pre-post HTM assessment of team communication will be eligible for this component of the study. Participants will be asked to take part in a focus group or an interview to discuss the intervention during or after the pilot study, or during or after the RCT.
3. The written feedback/assessment of communication between healthcare team members and families during a family meeting for a case patient. The participants in this component will be identified by the site principal investigator as a subgroup of providers who participated in a family meeting. This subgroup will include the following HTMs: PICU attending; PICU fellow; social worker (if involved); chaplain (if involved); bedside nurse; PICU resident, APN or hospitalist; and one to two subspecialty attendings.

4. The written feedback/assessment of the intervention. The same people eligible for the pre-post HTM assessment of team communication will be eligible for this component of the study. The actual participants in this component, however, will be a subgroup defined by case patients and identified by the site principal investigator. This subgroup will include the following HTMs caring for the case patient at the time of discharge from the PICU: PICU attending; PICU fellow; social worker (if involved); chaplain (if involved); bedside nurse; PICU resident, APN or hospitalist; and one to two subspecialty attendings.

4.0 STUDY PROCEDURES

4.1. Pre-post HTM assessment of team communication.

Before the pilot starts and after completing the randomized controlled trial, HTMs will be asked to complete a survey, the Healthcare Team Member Communication Survey (see section 4.7.c). This survey will be emailed to potential participants. Participants will complete the survey online using the electronic data capture system REDCap (Research Electronic Data Capture) (see section 5.2.).

4.2. Screening.

Each weekday a study team member will identify case patients via chart review. For screening purposes, the following information on each PICU patient will be collected: sex, date of birth, age, date of admission to the PICU, parents' language, clinical data required to calculate a PIM2 score, and type of patient illness (See Patient Screening Form). If necessary, a study team member will ask one of the patient's physicians (attending, fellow, resident, or APN/hospitalist) if he/she expects the patient to be discharged from the unit that day or the following day. Once deemed eligible for the study, a study team member will ask permission from the patient's PICU attending or fellow to approach the patient's parents for participation in the study. We will record data regarding which parent(s) is/are approached for study participation and, of those approached, who provides consent.

4.3. Consent.

4.3.a. Parents of Case Patients. After determining eligibility, a study team member will approach eligible parents to obtain consent. One or both parents may consent to study participation (See 7.5.b for procedures for obtaining consent).

4.3.b. Case Patients. Most case patients in the study will not be able to provide assent either because of their age, developmental status, and/or medical condition. However, if in the judgment of the study team, a case patient is capable of providing assent, a study team member will obtain oral assent (after obtaining consent from a parent) and document that in the chart.

4.3.c. Healthcare Team Members. The consent process for HTMs depends on the component of the study in which they are participating (See 7.5.c for procedures for obtaining consent).

4.4. Randomization.

All participants in the pilot study will receive the intervention, and thus the pilot study does not require a pre-generated allocation list. During the RCT, participating families (case patients and parents) will be randomized (1:1) to receive either the intervention or an informational brochure (control). Randomization will occur after consent is obtained. The randomization algorithm will employ a random number generator with a pre-specified seed (in order to ensure reproducibility) to generate a list of group (intervention versus control) assignments. A permuted blocking scheme will be used. The pre-generated allocation list will be uploaded into the electronic data capture system, REDCap (see 5.2. for information about REDCap) such that only the study statistician(s) have access to any future assignments. Following consent and enrollment of a given participating family, the study coordinator will use the randomization functionality of the electronic data capture tool that will pull the next sequential assignment from the uploaded pre-generated list, and the tool will display a pop-up window to indicate whether the family will receive the intervention or the control. Additionally, a corresponding "allocation" field will be populated with the assigned group for that family so as to capture allocation in the research database.

4.5. Intervention Details.

The components of the intervention, PICU Support (also referred to in the study materials as the PICU Supports program) can be divided into two categories: navigator activities and ancillary tools. The following subsections describe the intervention that pilot study participants and RCT participants randomized to the intervention arm will receive. All of the intervention activities are meant to provide parental support. As such, if a parent is not interested in a particular part of the intervention, his/her wishes regarding not engaging in certain activities or utilizing a particular tool will be respected. Also, there may be circumstances when an existing team member is accomplishing a task of the navigator or an existing program is accomplishing the same goal of one of the ancillary tools. In such cases, the existing team member and/or existing process will continue and the navigator will provide support on an "as needed" basis.

4.5.a. Navigator activities. The navigator will engage in the following activities (provided they are of interest to the family):

- *Preliminary visits.* The navigator meets with the HTMs to obtain pertinent information about the patient, family, and medical situation. The navigator meets with the family to introduce him/herself, explain his/her role, get acquainted with the family, help orient the family to the PICU, and identify key HTMs with whom the family has a relationship. The navigator provides relevant information to the PICU HTM regarding his/her visit with the family.
- *Weekday visits.* The navigator obtains pertinent information about the patient, family, and medical situation from the HTMs. The navigator meets with the family (in person or via phone). These meetings have four goals: 1) identify and address (if possible) family needs; 2) assess family perception of communication between the family and HTMs; 3) assess family perception of communication among HTMs; and 4) provide general consistent support. These discussions may be an opportunity for the navigator to help parents identify goals (see comments about the diary below) and inform parents about logistics in the PICU (e.g., staffing changes). The navigator will make efforts to support the family's general and communication needs via conversations with the family and HTMs. The navigator provides relevant information to the PICU HTMs regarding his/her visit with the family.
- *Support family meetings.* The navigator will organize weekly meetings between the family and HTMs. This will involve: identifying a time/day; including the appropriate family and HTMs; finding an appropriate space; meeting with the family and HTMs (separately) prior to the meeting to identify goals; participating as needed in the meeting; meeting with the family and HTMs (separately) after the meeting to process and identify unmet needs and help implement next steps (if indicated); and document the meeting in the medical record.
- *Support discharge/end-of-stay activities.* The navigator will provide directed support at the time of discharge to families and HTMs, recognizing that patients who leave the PICU will either be transferred to a non-PICU bed, discharged to home or a long-term care facility, or die in the PICU. This support will be accomplished through: 1) assessing family comfort with the situation; 2) identifying specific family needs pertaining to leaving the PICU; 3) providing appropriate information to the family about issues that may arise after leaving the PICU; 4) facilitating

logistics of transfer/discharge; and 5) checking in with families after discharge from the PICU. Some of these activities may occur during the patient/family stay in the PICU as opposed to just at the immediate time of discharge. As such, the navigator will assess the family discharge needs as part of the weekday visits, when appropriate. The Navigator will continue to meet with a family transferred out of the PICU to a regular hospital bed, if at the time of discharge from the PICU the Navigator feels that continuous support of the family would be of value to the family. In such cases, the Navigator will ask the family if they would like continued support and discuss this with the families medical team. The Navigator may also continue to provide support and weekday family visits if requested by the family

4.5.b. Ancillary Tools. PICU Supports includes tools meant to be used as needed by the family (with support from the navigator) or by the navigator to support HTM communication.

- *PICU Handbook.* This is a book created by the study team to give families basic information about how to support themselves in the PICU and about the kinds of medical issues sometimes encountered in the PICU. It is meant to be used as a resource, such that some people may never refer to it, others may use it often, and still others may use it only as situations arise.
- *Patient/Family Diary.* This is included in the PICU Handbook. Additional pages can be provided to families as needed. The diary provides a structured place for families to keep track of what is happening with their child and to consider the needs and/or goals they have for their child and/or themselves.
- *Frontline provider sheet*. This sheet provides a succinct summary of the family's psychosocial needs. The navigator will provide this sheet to the "frontline provider" (PICU team resident or APN or hospitalist) weekly or more if needed. The navigator will convey this information to the PICU attending as needed.
- *Communication log*. This sheet, to be kept at the patient's bedside, is a list of non-PICU providers who visit the patient and/or family during the day. Each provider will be asked to fill in the log when he/she visits the patient and/or family.
- *End-of-life checklist.* This is a checklist of activities that the navigator should ensure are being tended to by someone on the HTM and/or him/herself.
- *Bereavement packet.* This is a packet of information to be given to families of children who die in the PICU. It provides helpful information relevant to parental and family bereavement.
- *Ancillary information resources.* The navigator will provide families with additional resources as needed/requested to ensure they have adequate information about the issues pertinent to their child. Given the heterogeneity of medical issues cared for in the PICU, these resources will be identified on an as needed basis. Examples of such resources include: websites that provide information about the child's disease and/or educational materials about the child's medical problems. All ancillary information resources will be approved by the site PI prior to being given to a parent.

4.5.c. Navigator documentation of intervention activities. Throughout the PICU admission, the navigator will document his/her activities and provide feedback about his/her experiences via three mechanisms: the Daily Family Data Form, the Navigator Reflection Sheet, and the Family Meeting Form. The Daily

Family Data Form will be completed daily, the Navigator Reflection Sheet will be completed at the time of data collection from the participants, and the Family Meeting Form will be completed after a family meeting. These data will be used to assess navigator fidelity to the intervention. They will also provide information about which components of the intervention parents utilize and the time point(s) during the admission in which they are utilized.

4.6. Control details.

The control group will receive a brochure with general information about the PICU after consent has been obtained. All other care and support for the patients, parents, and family in the control group will be according to the standard of care at each participating site.

4.7. Surveys.

Data collection from parents and HTMs will involve a series of surveys consisting of tools described in Table 1 below.

Table 1. Tools used in Study Surveys.

Name	Domains
Pediatric Family Satisfaction in the Intensive Care Unit, pFS-ICU[40,41]	Provides an assessment of overall satisfaction as well as satisfaction with care and satisfaction with DM.
Collaboration and Satisfaction about Care Decisions (CSACD)[42]	Measures healthcare team collaboration in ICUs.
Support-Short Form 8a[43]*	Measures social support
Decision Regret Scale (DRS)[44]	Measures decision regret; decision harm; and decision appropriateness.
Anxiety-Short Form 8a[45]*	Measures symptoms of anxiety.
Depression-Short Form 8a[45]*	Measures symptoms of depression.
Impact of Event Scale - Revised (IES-R)[46,47]	Measures symptoms of post-traumatic distress. Subscales include: intrusion, avoidance, and hyper-arousal.
Index of Complicated Grief (ICG)** [48]	Designed to assess specific symptoms of grief.
Global Health[49]*	Measures overall health-related quality of life.
Connor-Davidson Resilience Scale 25 (CD-RISC-25)	Measures resilience
Communication Assessment Tool-Team (CAT-T)[30,50,51]	Measures staff-patient communication.
Acceptability and Perceived Effectiveness of Intervention***	Measures acceptability and perceived effectiveness of the PICU Supports Intervention.

* Indicated Patient Reported Outcomes Measurement Information System (PROMIS) measure

** Only for bereaved parents

** Created for this project based on a similar tool used in with the Four Supports pilot study[38]

4.7.a. Surveys collected from parents receiving the intervention. Parents will be asked to complete a series of surveys at various time points during and after their child's admission in the PICU.

1. <u>Parent Survey 1. (Distributed/collected at the time of consent).</u> This survey includes items about parent: demographics; previous experience in an ICU setting; religiosity/spirituality; status of social support (using the Support-Short Form 8a); parental anxiety, depression and global health (using the Anxiety-Short Form 8a, the Depression-Short Form 8a, and the Global Health form respectively); and resilience. Religiosity/spirituality will be assessed by asking two "yes/no" questions: "Is religion an important part of your daily life?" and ''Do you consider yourself a spiritual person?'' These items have been used in previous studies of religiosity and spirituality.[52,53]
2. <u>Parent Survey 2. (Distributed/collected between five and seven days after PICU admission, weekly for one month then monthly during the patient's PICU admission).</u> This survey includes items asking about parental satisfaction with care and decision making in the PICU (using the pFS-ICU) and about parental perception of team collaboration in the PICU (using the CSACD).
3. <u>Parent Survey 3. (Distributed/collected after family meetings).</u> This survey includes items asking about parental perception of communication during the family meeting (using the CAT-T and additional general questions). Family conferences will be identified based on chart review and input from the navigator.
4. <u>Parent Survey 4. (Distributed/collected from parents of surviving patients within 72 hours of PICU discharge, between three and five weeks after PICU discharge, and between three and five months after PICU discharge).</u> This survey includes items asking about: parental satisfaction with care and decision making in the PICU (using the pFS-ICU); parental perception of team collaboration (using the CSACD); parent decision regret (using the DRS); parent anxiety, depression, PTSD, and global health (using the Anxiety-Short Form 8a, Depression-Short Form 8a, Impact of Event Scale – Revised, and Global Health forms, respectively); and parent perception of the intervention acceptability and effectiveness.
5. <u>Parent Survey 5. (Collected from bereaved parents between three and five weeks after PICU discharge, and between four and five months after PICU discharge).</u> This survey includes the same items in Parent Survey 4 as well as additional items from the pFS-ICU about end-of-life care and a measure of complicated grief (using the ICG).

4.7.b. Surveys collected from parents not receiving the intervention. Parents not receiving the intervention will be asked to complete the same series of surveys at the same time points during and after their child's admission in the PICU with the following differences.

1. <u>Parent Survey 1.</u> No difference.
2. <u>Parent Survey 2.</u> No difference.
3. <u>Parent Survey 3.</u> No difference in the survey. Family meetings will be identified based on chart review.
4. <u>Parent Survey 4a.</u> This survey will not include items about the intervention acceptability and effectiveness. It will include one item about the usefulness of the brochure.
5. <u>Parent Survey 5a.</u> This survey will not include items about the intervention acceptability and effectiveness. It will include one item about the usefulness of the brochure.

4.7.c. Surveys collected from Healthcare Team Members.

1. <u>Healthcare Team Member Communication Survey. (Collected before the pilot study and after the randomized control trial).</u> This survey asks participants for basic demographic information and about team communication in the PICU (using the CSACD).
2. <u>Healthcare Team Member Post Family Meeting Survey (Collected after a family meeting for a case patient enrolled in the study).</u> This survey asks participants for feedback about communication between the healthcare team and family during a family meeting. The following HTMs present for a family meeting will be asked to complete this survey: PICU attending; PICU fellow; social worker (if involved); chaplain (if involved); bedside nurse; PICU resident, APN or hospitalist; and subspecialty attendings. The site PI will use his/her discretion to identify the appropriate HTMs for a case patient.
3. <u>Healthcare Team Member Study Survey. (Collected at the time of discharge of case patients).</u> This survey includes items asking about the participants role in the hospital (e.g. physician or social worker); team collaboration (using the CSACD); and perception of the intervention acceptability and effectiveness. The following HTMs caring for a case patient at the time of discharge from the PICU will be asked to complete this survey: PICU attending; PICU fellow; social worker (if involved); chaplain (if involved); bedside nurse; PICU resident, APN or hospitalist; and subspecialty attendings. The site PI will use his/her discretion to identify the appropriate HTMs for a case patient, in the event that a HTM is caring for a case patient on the day of discharge who is relatively new to the case patient (e.g., a new attending takes over the care of the patient on the day of discharge).

<u>4.8. Distribution/Collection of Surveys.</u>

4.8.a. Parent surveys distributed/collected in the hospital. Parent surveys distributed/collected during each participating patient's admission will use a written format. A study team member will give participating parents the survey and request that the completed survey be placed in an envelope and returned to a central location or given to the bedside nurse for a study team member to pick up.

4.8.b. *Parent surveys distributed/collected after PICU discharge.* Parent surveys collected after the patient's PICU discharge can be completed in a written format or electronically. Parents who request the electronic format will provide an email address and will be sent an email with instructions for completing the survey. This will be sent using a functionality of REDCap, the electronic data capture tool for this study (see data collection section 4.11). Two email reminders will be sent (1.5 weeks and 2.5 weeks after the first email) if the survey is not completed. For parents who request a written format, surveys and a self-addressed, stamped envelope will be sent via mail. A study team member will follow-up with parents by phone no more than two times (2.5 and 3.5 weeks after the survey is mailed) to ask for their participation if the survey is not received. Parents will also have the option of completing the survey over the phone with a member of the study team. If a survey is not returned within four weeks of the first mailing and there has been no direct contact made with the participant, a second survey will be mailed to the participant without additional attempts to contact parents by phone.

4.8.c. The Healthcare Team Member Communication Survey. Eligible HTMs will receive information about the study and The Healthcare Team Member Communication Survey via an email communication from REDCap. Two subsequent emails will be sent 1 week and 2 weeks after the initial email to remind potential participants about the study if the surveys are not completed.

4.8.d *The Healthcare Team Member Post Family Meeting Survey.* Eligible HTMs will the Healthcare Team Member Family Meeting Survey in a written format from a study team member or via an email communication from REDCap. If the potential participant completes the survey in written format they will be asked to complete the survey and return it in an envelope provided either directly to a study team member or to a central location. Potential participants who receive the survey via REDCap, will be asked to complete the survey online.

4.8 e. . The Healthcare Team Member Study Survey. Eligible HTMs will receive the Healthcare Team Member Study Survey in a written format from a study team member or via an email communication from REDCap. If the potential participant completes the survey in written format they will be asked to complete the survey and return it in an envelope provided either directly to a study team member or to a central location. Potential participants who receive the survey via REDCap, will be asked to complete the survey online.

4.9. Interviews and Focus Groups.

4.9.a. Parent interviews. Parents will have the option to participate in an audio-recorded, semi-structured interview (lasting about an hour) within five days of PICU discharge (for parents of surviving case patients) or between three and five weeks of discharge (for parents of case patients who die in the PICU). We will wait at least three weeks after a child's death to interview bereaved parents out of respect, as others have done.[54] All efforts will be made to conduct interviews with parents of survivors in the hospital. If necessary, interviews with parents of survivors can be done via phone. Interviews with bereaved parents will be conducted via phone to be sensitive to time and geographic limitations. A letter or email to bereaved parents asking them to complete Parent Survey 5 will also indicate that someone will contact them by phone to ask them if they would like to participate in an interview. It will give parents an option of sending back a form within 2 weeks indicating that they do not want to be called about an interview. If this form is received, parents will not be called to request participation in an interview or to request that they complete Parent Survey 5. Otherwise, a study team member will call parents up to two times (2.5 and 3.5 weeks after the survey is mailed) to ask for their participation in an interview. If both parents would like to participate, each parent will be interviewed separately. Interviewers will use a guide, allowing for modifications as described above. The planned topics for these interviews include perception of care coordination among HTMs; discussion of decisions faced in the PICU; perception of parental involvement in DM; emotional support from HTMs; and acceptability and perceived effectiveness of the navigator (for those randomized to receive the intervention) or the brochure (for those randomized to the control arm). See attached parent interview guide.

4.9.b. HTM Focus Group/Interviews. We will attempt to convene focus groups involving HTMs at least once during or after the pilot study (at Lurie Children's Hospital), and at least once during or after the RCT (at both study sites). All focus groups and interviews will be conducted at the study site hospital and audio-recorded. At each time point (during or after the pilot and during or after the RCT), we will attempt to convene three focus groups: one with PICU attendings, fellows, and APNs or hospitalists; one with subspecialists who cared for patients who received the intervention; and one with non-physician/non-APNs who cared for patients who received the intervention (e.g., case managers, socials workers, chaplains, bedside nurses). During the focus groups, participants will be asked to comment on the intervention acceptability and perceived effectiveness, and impact on HTM workflow (see attached focus group guide). After the focus group the HTMs will be asked to complete a short survey requesting demographic information. For Healthcare team members that wish to provide their feedback but are unable to attend focus groups due to scheduling conflicts, we will offer one on one interviews between the potential participant and a member of the research team. Individuals that participate in interviews will also be asked to complete the same short survey requesting demographic information and the research team member will use the Focus Group guide as the guide for the discussion during the interview (Appendix 20 and 21).

4.10. Plan for PICU readmissions of case patients during the study period.

Families who participate in the pilot will not be eligible for the RCT. During the RCT, if a case patient whose parent(s) previously consented to participate in the study is admitted to the PICU more than once during the study and the family was part of the pilot study or randomized to the intervention group during the RCT, the parent(s) will have the option to continue to receive the intervention on all subsequent admission. However, we will not collect surveys on PICU readmissions. Families who are randomized to the control group will receive usual care on PICU readmissions.

4.11. Data collected.

4.11.a. Patient Screening Information. We will collect the following information about all patients in the PICU on weekdays: sex, date of birth, PICU admission date; anticipated length of stay (per attending), components needed to calculate the PIM2 score, parent’s primary language, and type of patient illness (see Patient Screening Tool).

4.11.b. Case Patients. For case patients whose parents give consent, we will collect the following information via chart review: date of hospital admission; date of PICU and hospital discharge; admission diagnoses/problem list; type of underlying illness; events during their PICU admission (including new tracheostomy tube placement, new gastrostomy tube placement, new chronic ventilations, new DNAR or limitation of therapy orders, new involvement of palliative care, use of cardiopulmonary resuscitation

(CPR), use of Extracorporeal Membrane Oxygenation (ECMO), use of continuous renal replacement therapy (CRRT)); sub-specialists involved in the patient's care; and location of discharge. (See Patient Status Update).

4.11.c. Survey data from parents. We will collect Parent Surveys 1 – 5 and 4a and 5a. (See sections 10.3-10.9 for content of surveys).

4.11.d. Survey data from HTMs. From HTMs we will collect pre- and post-study surveys (the HTM Communication Survey), surveys after a family meeting, and discharge surveys (the HTM Study Survey) as described above; and demographic data following focus groups/interviews (see sections 10.11, 10.12, 10.14 for content of surveys).

4.11.e. Interview data from parents. Audio-recordings of parent discharge one-on-on interviews will be collected.

4.11.f. Focus group/ Interview data from HTMs. Audio-recordings of HTM focus groups/interviews will be collected.

4.11.g. Navigator documentation of intervention activities. The navigator will keep records of his/her activities via two mechanisms; the Daily Family Data Form and the Family Meeting Form (see 10.15 and 10.16).

4.11.h. PICU Supports Ancillary Tools. The PICU Supports ancillary tools will not be collected as part of data from this study and will not become part of the medical record. For example, the parent diary sheets will not be collected, the frontline provider sheets will not be collected or included in the medical record, and the communication log will not be collected or included in the medical record.

Table 2. Study Data Collection

Data Collected	Data Source	Pre/Post study	At PICU Admission	Daily during PICU stay	3-5 days from PICU Admission	During PICU Stay*	After Family Meeting	At PICU Discharge	3-5 weeks After PICU Discharge	3-5 months After PICU Discharge
Patient Screening Tool	Medical Record		X							
Enrollment Tool	Medical Record		X					X		
Parent Survey 1	Parent(s)				X					
Parent Survey 2	Parent(s)					X				
Parent Survey 3	Parent(s)						X			
Parent Survey 4/4a	Parent(s)							X	X	X
Parent Survey 5/5a***	Parent(s)								X	X
Parent Interview	Parent(s)							X	X***	
HTM Communication Survey	HTMs	X								
HTM Post Family Meeting Survey							X			
HTM Study Survey	HTMs							X		
HTM Focus Group/Interview**	HTMs									
Daily Family Data Form	Navigator			X						
The Navigator Reflection Sheet	Navigator		X			X		X		
Patient Status Update	Medical Record					X				
Family Meeting Form	Navigator						X			

*Every week x 4 then monthly

**To be done during the pilot and during the RCT at unspecified times.

***For bereaved parents

5.0. DATA COLLECTION AND MONITORING MANAGEMENT

5.1. Maintaining Study Documents.

Study records, including completed written surveys, report forms, and consent forms, will be maintained in a secured manner as determined by each site's IRB.

5.2. Data entry.

All quantitative data will be managed and stored using the research-focused electronic data capture system REDCap (Research Electronic Data Capture).[55] REDCap is a secure, web-based application for building and managing online surveys and databases. We will use the REDCap server located at Northwestern University as part of the Northwestern University Biomedical Informatics Center (NUBIC) and the Northwestern University Clinical and Translational Sciences Institute (NUCATS). Each site will enter all data into REDCap except for audio recordings of parent interviews and HTM focus groups or interviews. The navigator at each site will enter data directly into REDCap.

All qualitative data with patient identifiers will be maintained at the study site of origin. Recordings will be transcribed by an outside transcription company, Voss Transcription Inc. A study team member will remove all personal identifying information from the recordings and download anonymized transcripts into Dedoose (an online secured, password protected, encrypted qualitative software program).

5.3. Data Safety and Monitoring.

The individuals responsible for data safety and monitoring will be Drs. Michelson (PI) and the statistical team), and an independent Data Safety Monitoring Committee (DSMC). A monthly report about study progress, adverse events, and protocol deviation(s) will be compiled. Protocol adherence will be monitored by tracking completion of the core PICU Supports components (see table 4) for the intervention arm, and distribution of the educational brochure (for the control arm). Return of study surveys will also be tracked (see table 3). The Research Advisors will review the reports regularly for recruitment, data quality, completeness of follow-up, protocol deviations, and availability of resources for study continuation and completion. Periodic reports on these issues will be submitted to the relevant IRBs, the parent advisors, and the HTM advisors, as well as the DSMC).

We will have an independent DSMC chaired by Dr. Jeffrey Burns, chief of Critical Care Medicine and Edward and Barbara Shapiro Chair in Critical Care Medicine at Children's Hospital, Boston. Dr. Burns is an expert in ethics and has extensive experience conducting research on PICU end-of-life care DM.[4,56-59] The DSMC will include a parent and a non-physician HTM to be named prior to starting the RCT. During the RCT, interim reports on enrollment, outcomes, and adverse events will be made available to the chair of the DSMC for review after six and 12 months of data collection and after data collection is complete, or sooner if requested. The frequency of DSMC meetings will be self-determined but not less than annual. The DSMC will monitor the study for overall study progress, data collection, fidelity to the intervention, and unanticipated problems or complaints (see section 7.1.a). The DSMC can stop the study if evidence of substantial harm to the research subjects emerges. A letter summarizing DSMC activity and findings will be filed with the IRB at each participating institution after each DSMC meeting.

6.0 STATISTICAL CONSIDERATIONS

6.1. Sample Size.

6.1.a Pilot study.
Enrollment for the pilot study will continue for between three and four months or until parents of 60 patients are enrolled. No formal sample size calculations were performed for the pilot study as the purpose of the study it to determine whether the intervention, survey, data collection processes, or statistical analysis plan require any modifications prior to implementing the RCT. A sample size of 60 will allow us to estimate population parameters in accordance with the Central Limit Theorem (CLT), thus providing further insight into assumptions and analyses for the RCT.

6.1.b. Randomized Controlled trial.

The primary outcome (for which we determined sample size) for the RCT is percentage of “excellent” scores in the DM domain of the pFS-ICU between three and five weeks from discharge. The unit of randomization is the family, defined as the patient plus one or both parents. Data from the FS-ICU (adult version) shows that percentage of “excellent” scores for the DM component range from 31.7% to 65.4% with an average of 49.8% and a standard deviation of 17.0%.[60] We propose that a 10% difference in scores (e.g., a difference in score from 50% to 60%) would constitute a clinically significant change. Sample was calculated based on the independent two-sample t-test (assuming data from just one parent for each family). Note this is a conservative approach as we anticipate more than one observation available for a proportion of the participating families. Assuming a 5% level of significance for a two-sided test and a standard deviation of 17%, the independent two-sample t-test would have approximately 80% power to detect a 7% (an effect size of 0.41) absolute difference in percentage of “excellent” responses to the DM domain with 82 families in each arm This would give an effect size of 0.41 (difference of 7% / standard deviation of 17%).

We anticipate that approximately 400 and 250 patients/year, at Lurie Children’s Hospital and Comer Children’s Hospital respectively, will meet our inclusion criteria. Planning for 18 and 14 months of enrollment at Lurie Children’s Hospital and Comer Children’s Hospital respectively, there will be a total of 1012 eligible patients. If we anticipate 50% participation rate (a conservative estimate, given 66% participation for our family conference study) we will enroll 506 patients (253/arm). Anticipating 20% loss to follow-up, we will have data from 202 families/arm, more than sufficient to identify a meaningful difference in satisfaction with DM. However, we recognize enrollment can be unpredictable. If we notice less than anticipated enrollment, we will start enrolling patients from the Lurie Children’s Hospital Cardiac Care Unit, a 36-bed ICU for pediatric patients admitted primarily for cardiac-related problems. We plan a subanalysis with the three groups defined by patient outcomes. From our family conference data we anticipate that of patients who meet our inclusion criteria, approximately 25% will die; 25% will face one of our defined life-changing decisions; and 50% will have prolonged PICU stays. We will perform subanalyses on data from 63 parents/arm in groups 1 and 2 and 126 parents/arm in group 3. Effect sizes would be increased to 0.50 – 0.70 in these randomized group comparisons with smaller sample sizes.

For parent interviews, we will collect data until reaching "data saturation," the point at which successive information replicates previous data and no new information emerges.[61] This will occur when no new codes emerge during analysis. Saturation will be determined for intervention and control groups separately. We do not anticipate completing more than 40 interviews from the intervention and education control arm each.

6.2. Quantitative Analysis.

This section describes the general statistical approach planned for addressing each of the aforementioned hypotheses. Prior to any database locks, the study statistician(s) will develop a formal statistical analysis plan (SAP). Any modifications to the statistical approaches will be documented via amendments to the SAP as opposed to amendments to the study protocol. The overall approach to statistical analysis will be generalized linear models accounting for clustering by family where both parents respond. This method can be used for both continuous variables using the identity link and categorical variables using the logit link. All results will be considered significant with two-tailed tests and p-value <.05. For statistical analysis we will use SAS software version 9.4 (SAS Institute Inc., Cary, NC).

Initial data analyses will consist of descriptive statistics (counts and percentages for categorical variables; mean, median, standard deviation for continuous variables) for all relevant variables to assess distributional properties, summarize baseline demographic and study data, and compare baseline data across study arms. Distributional assumptions will be assessed prior to conduct of statistical test(s), and where appropriate, nonparametric methods or transformations of variables will be employed. Analysis for parent outcomes (aim 2) will be done on an intention-to-treat (ITT) basis. In cases of extreme amounts of missing data, multiple imputation methods will be used to conduct sensitivity analyses under different assumptions for missing data, as appropriate. All validated surveys will be scored per instrument instructions.

6.2.a. Aim 1 Determine the feasibility, and perceived acceptability and effectiveness of PICU Supports

To address hypothesis 1a. Implementation of PICU Support is feasible:
We will record enrollment rate (number consented/ number approached for consent) and rate of return of study documents (see table 3).

Table 3. Assessing Return of Study Documents

Parent Survey 1 (Initial)	Number returned/number of parents enrolled
Parent Survey 2 (Regularly scheduled feedback)	Number returned/number of possible data collection times
Parent Survey 3 (Post Family Meeting)	Number returned/number of possible data collection times
Parent Survey 4/4a (discharge, 3-5 weeks post discharge, and 3-5 months post discharge)	Number returned/number of patients enrolled (at each time point)
Parent Survey 5/5a (3-5 weeks post discharge, and 3-5 months post discharge)	Number returned/number of patients enrolled (at each time point)
Parent Interview*	Number completed/number of Parents Approached
HTM Study Survey	Number returned/number of HTMs Approached & Number returned/number of patients enrolled

* We do not anticipate interviewing all parents enrolled in the study.

We will record the degree to which the core intervention components are implemented (see table 4 below).

Table 4. Assessing Fidelity to Intervention

Activity	**Measurement**	**Component of PICU Supports**
Initial visit with family	Percent of patients enrolled	Emotional Support
Family provided with PICU Handbook	Percent of patients enrolled	Information Support
Initial visit with PICU HTMs	Percent of patients enrolled	Communication Support
Convene Family Meetings*	Number of meetings/Number of meetings possible**	Communication/Decision Support
Pre-Family Meeting with family	Percent of time per Family Meeting (mean/med/range)	Communication/Decision/Emotional Support
Pre- Family Meeting with HTMs	Percent of time per Family Meeting (mean/med/range)	Communication/Decision Support
Post- Family Meeting with family	Percent of time per Family Meeting (mean/med/range)	Communication/Decision/Emotional Support
Post- Family Meeting with HTM	Percent of time per Family Meeting (mean/med/range)	Communication/Decision Support
Weekday check in with family*	Percent of days possible/patient (mean/med/range)	Communication/Decision/Emotional Support
Weekday check in with HTM***	Percent of days possible/patient (mean/med/range)	Communication/Decision Support
Post-discharge follow-up	Percent of patients enrolled	Transition/Emotional Support

* Will be considered as “occurred” if it is offered but the family or HTM does not need a family meeting or “check in.”

** Minimum number of family meetings is one between three and seven days after admission then one time/week.

*** Includes any member of the PICU healthcare team.

To address hypothesis 1b. Parents perceive PICU supports as acceptable and effective:

We will present descriptive statistics of the results from the questions on Parent Surveys 4 and 5 pertaining to the acceptability and effectiveness of PICU Supports. We will also use data obtained from the parent interviews (Approach to qualitative analysis described in section 6.3).

To address hypothesis 1c. HTMs perceive PICU Supports as acceptable and effective:

We will present descriptive statistics of the results from the questions on the Healthcare Team Member Study Survey pertaining to the acceptability and effectiveness of PICU Supports. We will also use data obtained from the HTM focus group/interview (Approach to qualitative analysis described in section 6.3).

6.2.b. Aim 2. Test the impact of PICU Supports during and after PICU discharge on parent outcomes (satisfaction with DM, decision regret, anxiety, depression, post-traumatic stress, and health-related quality of life).

To address hypothesis 2a. PICU Supports improves parental satisfaction with DM:

The primary outcome for the RCT is percentage of "excellent" scores in the DM domain of the pFS-ICU subscale between three and five weeks from discharge. We will employ a generalized linear (mixed) model with identity link for percent "excellent" scores with fixed study arm and random family effects as independent variables. Introduction of the random family effect will account for the within family correlation among responses for families with more than one response. The model Wald test for the study arm variable will indicate statistical significance (or lack thereof) with respect to outcome when comparing intervention to control. We will also explore inclusion of relevant baseline variables as fixed effects through a modified stepwise model building procedure (as will be explained in the SAP). Secondary analyses will utilize similar techniques to examine differences in long-term follow-up responses (i.e., between three and five months) across study arms.

Secondary outcomes include total pFS-ICU 24 score, CSACD, and CAT. The analyses for primary outcome will be repeated for each of these outcomes. In addition, subgroup analysis will examine three groups defined by patient outcomes: patients that die in the PICU; patients that face one of the defined life-changing decisions; and patients with prolonged PICU stays. We will evaluate demographic and biomedical categorical variables across these groups using chi-squared tests. An Analysis of Variance (ANOVA) will be used to compare continuous data for the three groups when data are normally distributed and the Kruskal-Wallis when data are not normally distributed.

For data collected intermittently during the PICU admission, longitudinal analysis will be done using similar techniques to those mentioned above; however, a fixed time effect will be added to the model, and we will explore the inclusion of a random time effect. Assessment of the group-by-time interaction term will allow identification of differential patterns over time in the two study arms with respect to outcome(s). Again, we will use analyses similar to those above to longitudinally compare scores on the pFS-ICU 24 (total scores and score for the care and DM domains), CSACD, and CAT between the two study arms.

Analyses above will be repeated as appropriate in order to examine the remaining hypotheses for Aim 2. Each relevant outcome will be explored in turn as appropriate for each hypothesis listed below:

- Hypothesis 2b. PICU Supports decreases parental decision regret. Outcome: DRS.
- Hypothesis 2c. PICU Supports decreases short term parental anxiety, depression, symptoms of post-traumatic stress, health-related quality of life, and complicated bereavement. Outcomes: Anxiety-Short Form 8a, Depression-Short Form 8a, IES-R (post-traumatic stress), Global Health scores, and ICG.
- Hypothesis 2d. PICU Supports improves parental assessments of communication between HTMs and parents, and of team collaboration. Outcome: CAT and CSACD.

Any additional exploratory or subgroup analyses for the primary and/or secondary outcomes will be detailed in the formal SAP.

6.2.c. Aim 3. Test the impact of PICU Supports on parent and HTM assessments of communication and team collaboration.

To address hypothesis 3: PICU Supports improves HTM assessments of team collaboration, we will present descriptive statistics (for each relevant study time point: before the pilot study and after the RCT) from the CSACD questions on the Healthcare Team Member Study Survey and also from the Healthcare Team Member Communication Survey.

6.3. Qualitative Analysis.

We will use directed content analysis to evaluate the qualitative data. Directed content analysis is used when existing theory or prior research about a phenomenon is incomplete or would benefit from elaboration.[62] All audio data will be transcribed and personal identifiers removed. Study team members will define key variables and concepts as initial coding categories, then develop operational definitions and coding rules for each category. After initial data review, the categories and definitions will be revised and subcategories identified and defined through an iterative process. Any text not categorized with the initial coding scheme will be given new codes, allowing new ideas and concepts to emerge. The coding schema will be reviewed, refined and clarified as necessary. We will then recode the data with the revised codes. We will continue this iterative process until we do not identify new categories. Categories may be grouped as themes and compared.

7.0. REGULATORY AND ETHICAL CONSIDERATIONS

Study-related documentation will be completed as required by each study site’s IRB. Continuing review documentation will be submitted by the site investigator to the IRB as specified by the site IRB. If protocol changes are needed, we will submit a modification request to both participating study sites’ IRBs. Protocol changes will not be implemented prior to IRB approval unless necessary to eliminate apparent immediate hazards to research subjects. In such a case, the IRBs will be promptly informed of the change following implementation.

If we need to make any adjustments to our intervention or study design based on the pilot we will submit and obtain approvals for the appropriate amendments to the Lurie Children's IRB before starting the randomized controlled trial (RCT).

7.1. Risk assessment.

The study procedures do not pose greater than minimal risk. The main risk to participants is having emotional reactions when discussing experiences that include challenging personal or professional situations. For some, particularly parents, this may impose a psychological burden. However, research on stress from interviews with patients about their illness and with parents about their critically ill child indicates that the risk is minimal and may provide a beneficial outlet for concerns and feelings.[63,64] We will give all participants contact information for a social worker or chaplain to use as a resource if they feel they need additional support.

There is some risk that study personnel may also have adverse emotional reactions to collaborating on research of this nature. Study personnel will also be able to speak with a study team social worker or chaplain if they need additional support.

The final risk to participants is that of a breach of confidentiality. (See section 7.7 for plans to mitigate this risk.)

7.1.a. Identification and Management of Adverse events.

Because this research imposes no more than minimal risk and due to the nature of the research, adverse events are not anticipated. However, study team members, including the navigator, will report any unanticipated problem or complaints to the site PI and/or to Dr. Michelson. Events determined by Dr. Michelson to be unanticipated problems involving risks to subjects or others (UPIRTSOs) will be simultaneously reported by the site principle investigator to the both the Lurie Children's Hospital and Comer Children's Hospital IRBs per policy and also to PCORI. Other adverse events (not UPIRTSOs as determined by Dr. Michelson) will be reported per IRB policy at the time of continuing review. Dr. Michelson will inform the Comer Children's Hospital PI about any UPIRTSOs. Any protocol changes will be handled as described above (Section 7.0)

7.1.b. Identification of parent morbidity.

In the event that we receive a survey from a parent with an anxiety T score of ≥ 67.5 (severe depression-unpublished date) or a depression T score of ≥ 75 (severe depression-unpublished data) or comments on the survey that suggest the parent needs additional support, a study team member will contact the case patient's assigned SW and ask that they contact the parent via phone to follow-up. If it is clear from the information obtained from a particular parent that he/she does not have a working relationship with a SW, a study team member SW or chaplain will contact the parent via phone to follow-up. This is indicated on the consent form.

7.2. Potential benefit of study participation.

This study has the potential to benefit parent participants. Parents in the intervention group may feel better supported in their PICU experience as a result of the PICU Supports intervention, and parents in the control group may benefit from the educational brochure they are provided.

There are no direct benefits to HTM study participants. It is possible that giving parents information about the PICU via the educational brochure (given to parents randomized to the control group) or the PICU Handbook (given to parents randomized to the intervention group) may improve conversations between families and HTMs, thus impacting (perhaps supporting) HTM's interactions with parents. But it is also a possibility that such information could complicate communication and thus negatively impact conversation. Navigator involvement with the parent and HTMs could similarly be supportive (or not) to HTMs.

This research aims to benefit future families of critically ill patients and their HTMs by providing necessary information about the impact of PICU Supports on the experience for parents and HTMs. Benefits could potentially have a long lasting positive impact on patients, families, and HTMs. The minimal risk imposed is greatly outweighed by the significant potential benefit to parents, patients, and HTMs.

7.3. Request for waivers of consent.

A waiver of consent will be requested from the study site IRBs for the screening data collection as it is required for identification of potential participants (preparatory research) and involves no more than minimal risk.

For case patients 12 – 17 years old who are not capable of making decisions we request a waiver of written assent based on the following: "The capability of some or all of the children is so limited that they cannot reasonably be consulted." By definition all case patients will be admitted to the PICU and as such critically ill. The vast majority will not be in any condition to consider a research protocol and give assent. The parent consent form includes information about the data collected for case patients, and thus by signing the parent written consent, parents will be also giving permission for the data collection involved for their child. If in the judgment of the study team a case patient is capable of providing assent, a study team member will obtain oral assent (after obtaining consent from a parent) and document that in the chart.

7.4 Health Insurance Portability and Accountability Act (HIPAA)

A HIPAA waiver will be requested from both study sites for all data with personal health information (PHI) collected without obtaining consent.

7.5. Informed Consent Process.

7.5.a. Case patients. The parent consent form includes information about the data collected for case patients, and thus by signing the parent written consent, parents will be also giving permission for the data collection involved for their child. If in the judgment of the study team a case patient is capable of providing assent, a study team member will obtain oral assent (after obtaining consent from a parent) and document that in the chart.

7.5.b. Parents of case patients. After determining eligibility a study team member will approach parents and explain the details of the study at the patient's bedside or a separate room based on the parent(s) preference. Parents invited to participate in the pilot study will be asked to sign the pilot study consent form and those invited to participate in the RCT will be asked to sign the RCT consent form. These two forms differ because parents in the pilot will receive the intervention while those in the RCT will receive either the intervention or the control. To minimize the possibility of undue influence, a study team member will also verbally explain to all potential participants that the study is voluntary and that their relationship with people at Lurie Children's Hospital or Comer Children's Hospital and anyone on their healthcare team (if applicable) will not change if they choose not to participate. Potential participants will be asked to sign the consent form after they receive a copy of the consent and have had ample time to ask any questions they may have about the study to the research team In all cases the informed consent process will be done in a language understandable to the person giving and obtaining informed consent. A copy of all signed consent forms will be given to participants and maintained in the office of the principle investigator in a locked cabinet/file.

7.5.c. Healthcare team members. The consent process for HTMs depends on the component of the study in which they are participating.

1. The pre-post HTM assessment of team communication. The survey for this component of the study will be preceded by a sheet that contains the appropriate information needed to consider participation. There will be no formal consent form. Rather, completion of the survey will constitute consent.
2. The verbal feedback/assessment of the intervention. All focus group/interview participants will be asked to sign a written consent form prior to participating in the focus group or interview. When contacting participants with information about the date, time, and location of the focus group or interview, a study team member will review the basic study procedures with them. Prior to starting the focus group or interview, a study team member will review the consent form. Potential participants will have an opportunity at that time to ask questions about the study and about the consent form. All participants will be asked to sign the consent form prior to the start of the focus group/interview. All participants will be given a copy of the consent form. A second copy of the consent form will be maintained in the office of the principle investigator.
3. The written feedback/assessment of communication during family meetings. The survey for this component of the study will be preceded by a sheet that contains the appropriate information

needed to consider participation. There will be no formal consent form. Rather, completion of the survey will constitute consent.

4. The written feedback/assessment of the intervention. The survey for this component of the study will be preceded by a sheet that contains the appropriate information needed to consider participation. There will be no formal consent form. Rather, completion of the survey will constitute consent.

7.6. Privacy.

Obtaining consent from parent participants will occur in a room that accommodates the privacy needs of each potential participant.

Obtaining consent from HTMs for participation in focus groups/interviews will occur in a room that accommodates the privacy needs of each potential participant.

7.7. Confidentiality.

All study participants will be given a study identification (ID). Any study materials will utilize the participant's study ID. Each site will maintain a record that links participant's study ID to their name and medical record number (for patients) in case it is necessary to review materials for accuracy. These records will be kept in a secure manner in accordance with IRB protocol. Signed consent forms will be maintained in a locked cabinet/drawer. Only study team members will have access to the consent forms and the codes linking the participants' names and consent forms to the study ID.

All materials made available to the lead site from Comer Children's Hospital will utilize study IDs and/or be de-identified (as in the case of transcribed data from interviews or focus groups).

The audio recordings from interviews and focus groups will be downloaded to a password-protected server at each site using study IDs to label the recordings. The audio recordings will be sent directly from each site to Voss Transcription, Inc. to be transcribed. Study personnel at each site will review the transcripts against the audio recordings for accuracy and remove all personal identifiers. Cleaned transcripts will be loaded into the web-based password protected qualitative software "Dedoose" for analysis. All audio recordings will be destroyed in accordance with IRB regulations.

All written surveys will be maintained at the study site of origin in a locked cabinet. Alternatively, a study site may scan written survey into an electronic file, store the electronic version on a password-protected server, and destroy the written survey. All data from written surveys will be entered into the secured REDCap data management software. The written version of all surveys will be maintained and then destroyed according to IRB protocol.

All study information submitted for publication or available for public viewing will be reviewed by members of the study team to ensure that no identifying data is included. In some cases, study participants may be asked to review information submitted for publication or to be made available for public viewing to ensure that no identifying data is included. Participants will have the option of receiving information about the results of the study. If they chose this option, they will supply information about where we should send these results (this is part of the consent form). Participants will only be sent results with de-identified data in the form of abstracts or manuscripts.

7.8. Cost, Compensation, and Participant Reimbursement.

7.8.a. Study Costs.

All costs related to the study will be paid for from a fund provided to the study Principle Investigator by PCORI.

7.8.b. Participant Reimbursement.

Parent participants will receive $25 for their involvement in the study. This will be provided to them via a gift card mailed to their house after survey 4/4a or survey 5/5a are returned at the time point between three and five weeks after PICU discharge.

HTM will not receive reimbursement for participation. Food and refreshments will be served at focus groups.

8.0. ANTICIPATED STUDY TIMELINE

We anticipate the project will proceed according to the following timeline:

Pilot enrollment: 3 months
Modifications of the intervention (if necessary): 1-2 months
RCT enrollment at Lurie Children's Hospital: 18 months
RCT enrollment at Comer Children’s Hospital: 14 months
Data analysis and manuscript preparation: a minimum of 4 months

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Appendix

Appendix 1. Patient Screening Tool

Appendix 2. Enrollment Tool

Appendix 3. Daily Family Data Form

An abbreviated version of this form is being submitted. Here we present the data collected on day 1. The same data is collected on subsequent days.

Appendix 4. Family Meeting Form

Appendix 5: The Navigator Reflection Sheet

Appendix 6: Patient Status Update

Appendix 7. Parent Survey 1

Appendix 8. Parent Survey 2

Appendix 9. Parent Survey 3

Appendix 10. Parent Survey 4B

Appendix11. Parent Survey 5B

Appendix 12. Parent Survey 4A

Appendix 13. Parent Survey 5B

Appendix 14. Parent Interview Guide

Appendix 15. Thank you Letter to Parents

Appendix 16. Cover letters for parent mailing/email after PICU discharge

The following three letters follow:

- The cover letter for nonbereaved parents to be used for the surveys mailed to parents 3-5 weeks after PICU discharge and 3-5 months after PICU discharge
- The cover letter for bereaved parents to be used for the surveys mailed to parents 3-5 weeks after PICU discharge.
- The cover letter for bereaved parents to be used for the surveys mailed to parents 3-5 monts after PICU discharge.

Appropriate modifications will be made to these letters for those participants enrolled at Comer Children’s Hospital. The final version of the modified letters for Comer Children’s Hospital will be submitted to the IRB prior to starting the RCT at Comer Children’s Hospital.

Appendix 17. Cover letter for HTM email for communication survey

The following will be included in an email to all potential participants eligible to complete the HTM Communication Survey

Appendix 18. HTM Communication Survey

Appendix 19. HTM Post Family Meeting Survey

Appendix 20. Cover letter for HTM email for study survey

Appendix 21. HTM Study Survey

Appendix 22. HTM Focus Group Guide

Appendix 23. Post HTM Focus Group Survey

Appendix 24. PICU Handbook

The PICU Handbook is being submitted as a separate document.

Appendix 25. Patient/Family Diary

Appendix 26. Frontline Provider Sheet

Appendix 27. Communication Log

Appendix 28. Family Conference Chart Note

Appendix 29. End-of-life Checklist

Appendix 30. Bereavement Packet

The following materials will constitute the Bereavement Packet at Lurie Children's Hospital. These materials are currently being given to the parent of any child who dies at Lurie Children's Hospital. A modified version of these materials will be developed for use at Comer Children’s Hospital and will be submitted prior to starting the RCT at Comer Children’s Hospital.

Appendix 31. Educational Brochure

All IRB Approved Documents for 2015-146

Submitted for Continuing Review 07/06/2016

Screening Form

Calculated PIM 2 Score:

Record ID	________________________________
Patient Name:	________________________________
Patient MRN:	________________________________
Date of screening:	________________________________
Date of patient admission to the PICU:	________________________________
Patient date of birth:	________________________________
Patient age on screening date:	________________________________ (Patient is ineligible if older than 18 years)
Patient sex:	○ Female ○ Male
Parents' Language:	○ English ○ Spanish ○ Other (Family ineligible if OTHER is selected)
If "Other" language was selected, please describe	________________________________

PIM 2 SCORE CALCULATION

Elective Admission:	○ Yes ○ No
Recovery post procedure:	○ Yes ○ No
Cardiac Bypass:	○ Yes ○ No
Low risk diagnosis:	○ Yes ○ No

What was the low risk diagnosis?

	Yes	No
Asthma is the main reason for ICU admission	○	○
Bronchiolitis is the main reason for ICU admission	○	○
Croup is the main reason for ICU admission	○	○

Obstructive sleep apnoea is the main reason for ICU admission	○	○
Diabetic keto-acidosis is the main reason for ICU admission	○	○

High risk diagnosis:
○ Yes
○ No

What is the high risk diagnosis?

	Yes	No
Cardiac arrest preceding ICU admission	○	○
Severe combined immune deficiency	○	○
Leukaemia or lymphoma after first induction	○	○
Spontaneous cerebral hemorrhage	○	○
Cardiomyopathy or myocarditis	○	○
Hypoplastic left heart syndrome	○	○
HIV infection	○	○
Liver failure is the main reason for ICU admission	○	○
Neuro-degenerative disorder	○	○

No response of pupils to bright light (>3 mm and both fixed):
○ Yes
○ No
○ Unknown

Mechanical Ventilation (at any time during first hour in ICU):
○ Yes
○ No

Systolic Blood Pressure: ______________________________

Base Excess (mmHg) (arterial or capillary blood): ______________________________

FiO2 *100 / PaO2 (mmHg): ______________________________

Calculated PIM 2 Score: ______________________________
(Only record number, do not include percentage sign)

END PIM 2 CALCULATION

Physician (attending or fellow) assessment of length of stay:
○ < 24 hours
○ ≥ 24 hours
(Patient is ineligible if length of stay is less than 24 hours)

Physician (attending or fellow) gives permission to approach family for study:
○ Yes
○ No
(Patient is ineligible if physician does not give research team permission to approach)

Reason for Admission (check all that apply):

	Yes	No
Acute respiratory illness	○	○
Acute septic illness	○	○
Acute neurological illness (non trauma)	○	○
Trauma patient	○	○
Fluid/electrolyte issues	○	○
Post Operative Care	○	○
Ingestion	○	○
Elective Admission	○	○
Other	○	○

Elective admission reason: ______________________

Describe Other: ______________________

Patient Category:

	Yes	No
Neuromuscular	○	○
Cardiovascular	○	○
Respiratory	○	○
Renal	○	○
Gastrointestinal	○	○
Hematology and immunodeficiency	○	○
Metabolic	○	○
Endocrine	○	○
Rheumatology / Autoimmune disorders	○	○
Other congenital or genetic defect	○	○
Malignancy/Cancer	○	○
Stem Cell Transplant	○	○
Otherwise healthy	○	○
Other	○	○

Describe Other: ______________________

Neuromuscular:

	Yes	No
Brain and spinal cord malformations	○	○
Developmental impairment / Global development delay	○	○
Central nervous system degeneration and disease	○	○
Infantile cerebral palsy	○	○
Epilepsy / Seizure disorder	○	○
Muscular dystrophies and myopathies	○	○
Brain injury	○	○
Other	○	○

Describe Other: ________________________________

Cardiovascular:

	Yes	No
Heart and great vessel malformations	○	○
Cardiomyopathies	○	○
Conduction disorders and dysrhythmias	○	○
Hypertension / Hypotension	○	○
Other	○	○

Describe Other: ________________________________

Respiratory:

	Yes	No
Respiratory malformations	○	○
Chronic respiratory disease	○	○
Cystic fibrosis	○	○
Tracheomalacia / Laryngomalacia	○	○
Pulmonary hypertension	○	○
Bronchopulmonary dysplasia	○	○
Obstructive sleep apnea	○	○
Trach / Vent	○	○
Other	○	○

Describe Other: ________________________________

Renal:

	Yes	No
Congenital anomalies	○	○
Chronic renal failure / Chronic kidney disease	○	○
Other	○	○

Describe Other: ______________________

Gastrointestinal:

	Yes	No
Congenital anomalies	○	○
Chronic liver disease and cirrhosis	○	○
Inflammatory bowel disease	○	○
GERD / Reflux	○	○
Dysphagia	○	○
Esophageal and gastric varices / GI bleed	○	○
G-tube	○	○
Other	○	○

Describe Other: ______________________

Hematology and Immunodeficiency:

	Yes	No
Sickle cell disease	○	○
Hereditary anemias	○	○
Hereditary immunodeficiency	○	○
Human immunodeficiency virus disease	○	○
Other	○	○

Describe Other: ______________________

Metabolic:

	Yes	No
Amino acid metabolism	○	○
Carbohydrate metabolism	○	○
Lipid metabolism	○	○

Storage disorders	○	○
Nutritional disorders	○	○
Other metabolic disorders	○	○

Describe Other: ______________________

Endocrine

	Yes	No
Diabetes	○	○
Thyroid dysfunction	○	○
Other	○	○

Rheumatology / Autoimmune disorders ______________________

Describe Other ______________________

Other congenital or genetic defect:

	Yes	No
Chromosomal anomalies	○	○
Bone and join anomalies	○	○
Diaphragm and abdominal wall	○	○
Other congenital anomalies	○	○

Describe Other: ______________________

PATIENT ELIGIBILITY

Is this patient/family eligible to participate?

○ Yes
○ No
(YES if: Patient is less than 18 years old, Language is English or Spanish, PIM 2 is greater than 4.0 OR Length of stay is greater or equal to 24 hours AND physican gives persmission to approach)

Enrollment Status

Calculated PIM 2 Score:

Record ID ______________________

Enrollment Status	○ Enrolled ○ Screen Failure ○ Not Enrolled (other)

Exclusion Criteria

Screen Failures

	Yes	No
Age	○	○
Language	○	○
Length of Stay	○	○
Clinical team advised not to approach	○	○
Other	○	○

Describe Other: ______________________

Reason Not Enrolled

	Yes	No
Discharged prior to consent	○	○
Parent unavailable	○	○
Parent Refused	○	○
Patient refused assent	○	○
TCU patient	○	○
DCFS	○	○
Previous participation in RCT	○	○
Pilot study participant	○	○
Navigator not available	○	○
Other	○	○

If Other, Please describe: ______________________

Arm Assignment	○ Control (Group A) ○ Intervention (Group B)
If assigned to the Control Arm (Group A): Did the research team give the participant a copy of the brochure?	○ No ○ Yes

If NO was marked above, please provide the reason the brochure was not given to the Control Arm (Group A) participant ______________________

Daily Data Form Navigator

Calculated PIM 2 Score:

Record ID ______________________

********************DAY 1*********************

Today's Date: ______________________

Day of the Week: ______________________

On Day 1: Did the Navigator check in with the family?
- ○ Yes- Met with family in person
- ○ Yes- Met with family over the phone
- ○ Yes- Family declined meeting
- ○ Yes- Family was not available
- ○ No- Navigator not available
- ○ No- Other reason

If No- Other Reason , please describe: ______________________

Check in time: ______________________
(Report using the 24-hour clock (military time) to the nearest quarter hour. EXAMPLE: A check in time of 2:50pm, would be reported as "14:45")

The following were present:

	Yes	No
Mother	○	○
Father	○	○
Patient	○	○
Other	○	○

Describe "Other": ______________________

Check all that apply to today's activities with the family:

	Yes	No (not today)
Diary/ Calendar	○	○
Communication Log	○	○
PICU Handbook	○	○
Question Prompt List	○	○
Bereavement Packet	○	○
End of Life Checklist	○	○
Provided Ancillary Support	○	○

Other	○	○

Describe the "Other" support provided ____________________

Time spent with family: ____________________
(Record in minutes)

Navigator assisted the family with the following:

Day 1

Emotional Support

	Yes	No (not today)
1. Discuss psychological needs of family	○	○
2. Assist family with issues related to psychological needs	○	○
3. Discuss emotional challenges of family	○	○
4. Assist with emotional challenges of family	○	○
5. Other	○	○

Describe what was discussed with the family regarding their psychosocial needs ____________________

Describe how the navigator assisted the family with psychosocial needs ____________________

Describe what was discussed with the family regarding their emotional challenges ____________________

Describe how the navigator assisted the family with emotional challenges ____________________

Describe "Other" ____________________

Navigator assisted the family with the following:

Day 1

Communication Support

	Yes	No (not today)
1. Identify family communication needs (family with Heath care Team Members)	○	○
2. Identify family communication needs (among Health care Team Members)	○	○
3. Assist family communication with Health care Team Members	○	○

4. Assist with communication among Health care Team Members	○	○
5. Help family develop questions for Health care Team Members	○	○
6. Family Conference organization or support	○	○
7. Other	○	○

Describe how the navigator identified family communication needs (family with health care team members) ______________________________

Describe how the navigator identified family communication needs (among health care team members) ______________________________

Describe how the navigator assisted family communication with Health care Team Members ______________________________

Describe how the navigator assisted with communication among Health care Team Members ______________________________

Describe how the navigator helped family develop questions for Health care Team Members ______________________________

Describe how the navigator helped with family conference organization or support ______________________________

Describe "Other" ______________________________

Navigator assisted the family with the following:

Day 1

Decision Support

	Yes	No (not today)
1. Help family process information delivered by healthcare team	○	○
2. Help family develop questions for the healthcare team	○	○
3. Help family get additional information from the healthcare team	○	○
4. Support family during conversation with Health care Team Members	○	○
5. Other	○	○

Describe how the navigator helped family process information delivered by healthcare team ______________________________

Describe how the navigator helped family develop questions for the healthcare team ______________________________

Describe how the navigator helped family get additional information from the health care team ______________________________

Describe how the navigator supported family during conversation with Health care Team Members ______________________________

Describe "Other" ______________________________

Navigator assisted the family with the following:

Day 1

Transition Support

	Yes	No (not today)
1. Assess family comfort with transition/discharge	○	○
2. Provide anticipatory guidance to family when preparing for transition/discharge	○	○
3. Identifying specific family needs pertaining to transition/discharge	○	○
4. Provide appropriate information to family relevant to transition/discharge	○	○
5. Facilitate logistics of transition/discharge	○	○
6. Checking in with family after transition/discharge from the PICU	○	○
7. Other	○	○

Describe how the navigator assessed family comfort with transition / discharge ______________________________

Describe how the navigator provided anticipatory guidance to family when preparing for transition/discharge ______________________________

Describe how the navigator identified specific family needs pertaining to transition / discharge ______________________________

Describe how the navigator provided appropriate information to family relevant to transition/discharge ______________________________

Describe how the navigator facilitated logistics of transition/ discharge ______________________________

Describe when the navigator checked in with family after transition/discharge from the PICU ______________________________

Describe "Other" ______________________________

Navigator assisted the family with the following:

Day 1

Informational Support

	Yes	No (not today)

1. Orient family to the PICU	○	○
2. Identify/provide information resources relevant to the patient's clinical status	○	○

Describe how the navigator oriented the family to the PICU ______________________

Describe how the navigator identified / provided information resources relevant to the patient's clinical status ______________________

Healthcare Team

Day 1 Navigator met with members of the healthcare team
○ Yes
○ No

The following were present:

	Yes - Present	No- Not present
PICU Attending	○	○
PICU Fellow	○	○
PICU APN	○	○
PICU Hospitalist	○	○
PICU Resident	○	○
Non-PICU Physician	○	○
Non Physician Team Member	○	○
Other	○	○

Check all that apply to today's activities with the healthcare team

	Yes	No
Provided Frontline Provider sheet to APN, resident, or Hospitalist	○	○
Verbally confirmed Frontline information with attending	○	○

Time spent with health care team ______________________
(Record in minutes)

Do you (Navigator) perceive communication problems in the following areas? What is your opinion of communication in these areas?

Communication between the healthcare team and family
○ Good
○ Neutral
○ Needs Improvement

Please clarify ______________________

Communication within the PICU team	○ Good ○ Neutral ○ Needs Improvement
Please clarify	__________________________________
Communication between non PICU team member and PICU team members	○ Good ○ Neutral ○ Needs Improvement
Please clarify	__________________________________
Communication between non-physician team members and physician team members	○ Good ○ Neutral ○ Needs Improvement
Please clarify	__________________________________
Other communication issues: (Please clarify)	__________________________________

************************ DAY 2************************

Today's Date:	__________________________________
Day of the Week:	__________________________________
On Day 2: Did the Navigator check in with the family?	○ Yes- Met with family in person ○ Yes- Met with family over the phone ○ Yes- Family declined meeting ○ Yes- Family was not available ○ No- Navigator not available ○ No- Other reason
If No- Other Reason , please describe:	__________________________________
Check in time:	__________________________________ (Report using the 24-hour clock (military time) to the nearest quarter hour. EXAMPLE: A check in time of 2:50pm, would be reported as "14:45")

The following were present:

	Yes	No
Mother	○	○
Father	○	○
Patient	○	○
Other	○	○

Describe "Other": __________________________________

Family Meeting Form (Navigator)

Calculated PIM 2 Score:

Record ID ________________________________

Did a Family Meeting occur this week?
○ Yes
○ No

If No, please give reason: ________________________________

Type of Meeting:
○ Regularly Scheduled by Navigator (weekly)
○ Parent Requested
○ Clinical Reason
○ Other

Describe reason for "Parent Requested" : ________________________________

Describe the "Clinical Reason" : ________________________________

Describe "Other" : ________________________________

Did a pre-family meeting check-in with the family occur?
○ Yes
○ No

The following were present:

	Yes	No
Mother	○	○
Father	○	○
Patient	○	○
Other	○	○

Describe "Other" : ________________________________

Date of pre-meeting check-in with family: ________________________________

Pre-meeting activities with parents:

	Yes	No
Identified questions the parent(s) has (have)	○	○
Talked about parent goals for the meeting and review what to expect	○	○
Determined who the parent(s) want at the meeting	○	○

How much time did the Navigator spend in the pre-meeting with the family? (Total time spend doing tasks / organizing meeting) ________________________________ (Report in minutes)

Did a pre-family meeting check-in with the healthcare team occur?	○ Yes (Present relevant information from parent pre-meeting to the healthcare team prior to the meeting) ○ No
Date of pre-meeting with healthcare team:	__________________________________
How much time did the Navigator spend in the pre-meeting with the healthcare team?	__________________________________ (Report in minutes)
Date of family meeting :	__________________________________
Time of meeting :	__________________________________ (Report using the 24-hour clock (military time) to the nearest quarter hour. EXAMPLE: A meeting occuring at 2:50pm, would be reported as "14:45")

The following were present at the family meeting (check all that apply):

	Yes	No
Mother	○	○
Father	○	○
Patient	○	○
Other	○	○

Describe "Other":	__________________________________
How did the Navigator participate in the meeting?	__________________________________
Did Navigator perform post-meeting follow-up with family?	○ Yes ○ No
If "No", please give reason:	__________________________________
Date of post-meeting follow-up with family:	__________________________________

The following were present (check all that apply):

	Yes	No
Mother	○	○
Father	○	○
Patient	○	○
Other	○	○

Describe "Other":	__________________________________

	Yes	No
Reviewed familiy conference discussion	○	○
Gave parents written notes about the meeting	○	○

Identfieid existing issues/ quesions for parents	○	○
Other	○	○

Describe existing issues: ________________________

Describe "Other": ________________________

How much time (minutes) was spent with family for post-meeting activities? ________________________ (Report in minutes)

Navigator entered template note into patient chart about post-family meeting follow-up:
○ Yes
○ No

If "No", please give reason: ________________________

Did the Navigator give a general update to the healthcare team following post-family meeting with family?
○ Yes
○ No

If "Yes", what was the content of the update? ________________________

If "No", please give reason: ________________________

Navigator Reflection Sheet (Navigator)

Calculated PIM 2 Score:

Record ID ________________________

1. What are the biggest challenges faced by this family? ________________________

2. What communication challenges has this family encountered? ________________________

3. How could the healthcare team better support this family? ________________________

4. How effective do you think you have been in supporting this family? ________________________

5. Did you do a post-discharge follow up with this family?
○ Yes
○ No

Please add comments about the post-discharge follow up with this family ________________________

6. Did this family use the PICU Handbook?
○ Yes
○ No

Please add any comments about the PICU Handbook ________________________

7. Did this family use the Communication Log?
○ Yes
○ No

Please add any comments about the Communication Log ________________________

8. Did this family use the Calendar/Diary?
○ Yes
○ No

Please add any comments about the calendar/diary ________________________

9. Did you use the frontline provider sheet for this family?
○ Yes
○ No

Please add any comments about the frontline provider sheet ________________________

10. Did the family use the Question Prompt list in the PICU Handbook?
○ Yes
○ No

Please add any comments about the question prompt list ________________________

11. Did you schedule a family meeting for this family?
○ Yes
○ No

Please add any comments about family meetings for this family ________________________

12. Did you use the end of life checklist?
○ Yes
○ No

Please add any comments about the end of life check list ________________________

Patient Status Log

Calculated PIM 2 Score:

Record ID	________________________
Readmission of participant?	○ Yes ○ No
Date of patient's admission to the PICU:	________________________
New tracheostomy:	○ Yes ○ No
New Gastrostomy:	○ Yes ○ No
Introduction of chronic ventilation:	○ Yes ○ No
New 'do not resuscitate' order:	○ Yes ○ No
Care Limitations:	○ Yes ○ No
Introduction of Palliative Care team	○ Yes ○ No
Use of cardiopulmonary resuscitation:	○ Yes ○ No
Use of extracorporeal member oxygenation:	○ Yes ○ No
Use of continuous renal replacement therapy:	○ Yes ○ No

Subspecialty services involved in patient's care (check all that apply):

	Yes	No
GI	○	○
Cardiology	○	○
Kidney	○	○
Pulmonary	○	○
Neurology	○	○
General Surgery	○	○
Transplant Surgery	○	○
ENT	○	○
Sleep Medicine	○	○
Endocrinology	○	○

Infectious Disease	○	○
Rheumatology	○	○
Immunology	○	○
Allergy	○	○
Genetics	○	○

Date patient was discharged from the PICU: ______________________

Patient was discharged to:
- ○ Floor
- ○ Home
- ○ Other Facility: Rehab
- ○ Other Facility: Chronic care facility
- ○ Other

Full days in the PICU at the time of discharge: ______________________

Date of discharge from the hospital: ______________________

Patient category defined by patient outcome:
- ○ Patient died
- ○ Patient survived and had a decision made about trach, GT, initiated chronic ventilation, introducing PC, implementing a new order to limit care
- ○ Patient with a prolonged stay of 12 OR MORE days who does not meet above criteria
- ○ Patient with a of stay LESS than 12 days who does not meet above criteria

Was the PI involved in the care of this patient?
- ○ Yes
- ○ No

Was a Social Worker involved in the care of this patient?
- ○ Yes
- ○ No

Was a Chaplain involved in the care of this patient?
- ○ Yes
- ○ No

PICU
SUPPORTS

Thank you for helping us know more about communication in the pediatric intensive care unit (PICU). This survey asks you for information about you. Please complete this survey and return it in the envelope provided.

Parent Survey 1

This survey takes approximately 15-20 minutes to complete

Please mark an “X” in the box next to the answer that best describes you, and/or fill in the blank.

1. **What is your sex?**
   - ☐ Female
   - ☐ Male

2. **What is your relationship to the child who has been admitted to pediatric intensive care unit?**
   - ☐ Mother
   - ☐ Father
   - ☐ Other caregiver____(describe)

3. **What is your Date of Birth?**

Month XX	Day XX	Year XXXX

4. **What racial category best describes you?** **(select all that apply)**
   - ☐ American Indian / Alaska Native
   - ☐ Asian
   - ☐ Black / African American
   - ☐ Native Hawaiian or Other Pacific Islander
   - ☐ White
   - ☐ Other ____(describe)

5. **What ethnic group best describes you?**
   - ☐ Hispanic or Latino
   - ☐ Not Hispanic or Latino

6. **Which category best describes the highest level of education you completed?**
   - ☐ Elementary School
   - ☐ High School
   - ☐ College
   - ☐ Post-Graduate
   - ☐ Other education __________________________________(describe)

Please continue on the next page ➡

7. **What is your total household income?**
   - ☐ $25,000 or less
   - ☐ $25,000 - $49,000
   - ☐ $50,000 - $74,999
   - ☐ $75,000 - $99,000
   - ☐ $100,000 or more

8. **What is your current marital status?**
   - ☐ Single
   - ☐ Married
   - ☐ Living with a partner
   - ☐ Separated
   - ☐ Divorced
   - ☐ Widowed

9. **What is your religious affiliation?** ____________________________________

10. **Is religion an important part of your daily life?**
    - ☐ Yes
    - ☐ No

11. **Do you consider yourself a spiritual person?**
    - ☐ Yes
    - ☐ No

12. **How many siblings does your child have?** _________________

13. **How do you perceive the severity of your child's illness?**
    - ☐ Mild
    - ☐ Moderate
    - ☐ Severe

14. **How many times has your child been hospitalized before?** ____________________

15. **Of those hospitalizations, how many times was your child admitted to the PICU?** ____________________________

Please continue on the next page ➡

16. **Do you or your family have other Intensive Care Unit experiences? (select all that apply)**
    - ☐ Yes – This child has been in the PICU before
    - ☐ Yes – I have another child that has been in the PICU before
    - ☐ Yes – I have had another family member in an adult or pediatric ICU before
    - ☐ Yes – I have been a patient in an ICU before
    - ☐ No – I do not have previous Intensive Care Unit experience

What is today's date

Month XX	Day XX	Year XXXX

Please continue on the next page ➡

Please respond to each statement by marking an “X” in one box per row.

	Never	Rarely	Sometimes	Usually	Always
1. **I have someone to give me good advice about a crisis if I need it.**	☐	☐	☐	☐	☐
2. **I have someone to turn to for suggestions about how to deal with a problem.**	☐	☐	☐	☐	☐
3. **I have someone to give me information if I need it.**	☐	☐	☐	☐	☐
4. **I get useful advice about important things in life.**	☐	☐	☐	☐	☐
5. **I can get helpful advice from others when dealing with a problem.**	☐	☐	☐	☐	☐
6. **My friends have useful information to help me with my problems.**	☐	☐	☐	☐	☐
7. **I have people I can turn to for help with my problems.**	☐	☐	☐	☐	☐
8. **Other people help me get information when I have a problem.**	☐	☐	☐	☐	☐

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Please continue on the next page ➡

For the following questions please think about how you felt **BEFORE your child was admitted to the PICU**.

Please respond to each statement by marking an "X" in one box per row.

	Never	Rarely	Sometimes	Often	Always
1. **I felt worthless.**	☐	☐	☐	☐	☐
2. **I felt helpless.**	☐	☐	☐	☐	☐
3. **I felt depressed.**	☐	☐	☐	☐	☐
4. **I felt hopeless.**	☐	☐	☐	☐	☐
5. **I felt like a failure.**	☐	☐	☐	☐	☐
6. **I felt unhappy.**	☐	☐	☐	☐	☐
7. **I felt that I had nothing to look forward to.**	☐	☐	☐	☐	☐
8. **I felt that nothing could cheer me up.**	☐	☐	☐	☐	☐

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Please continue on the next page ➡

For the following questions please think about how you felt **BEFORE your child was admitted to the PICU**.

Please respond to each statement by marking an “X” in one box per row.

	Never	Rarely	Sometimes	Often	Always
1. **I felt fearful.**	☐	☐	☐	☐	☐
2. **I found it hard to focus on anything other than my anxiety.**	☐	☐	☐	☐	☐
3. **My worries overwhelmed me.**	☐	☐	☐	☐	☐
4. **I felt uneasy.**	☐	☐	☐	☐	☐
5. **I felt nervous.**	☐	☐	☐	☐	☐
6. **I felt like I needed help for my anxiety.**	☐	☐	☐	☐	☐
7. **I felt anxious.**	☐	☐	☐	☐	☐
8. **I felt tense.**	☐	☐	☐	☐	☐

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Please continue on the next page ➡

For the following questions please think about how you felt **<u>BEFORE your child was admitted to the PICU</u>**.

Please respond to each statement by marking an “X” in one box per row.

	Poor	**Fair**	**Good**	**Very Good**	**Excellent**
1. **In general, would you say your health is:**	☐	☐	☐	☐	☐
2. **In general, would you say your quality of life is:**	☐	☐	☐	☐	☐
3. **In general, how would you rate your physical health?**	☐	☐	☐	☐	☐
4. **In general, how would you rate your mental health, including your mood and your ability to think?**	☐	☐	☐	☐	☐
5. **In general, how would you rate you satisfaction with your social activities and relationships?**	☐	☐	☐	☐	☐
6. **In general, how would you rate how well you carry out your usual social activities and roles? (This includes activities at home, at work, and in your community, and responsibilities as a parent, child, spouse, employee, friend, etc.)**	☐	☐	☐	☐	☐

	Not at all	**A little**	**Moderately**	**Mostly**	**Completely**
7. **To what extent are you able to carry out your everyday physical activities such as walking, climbing stairs, carrying groceries, or moving a chair?**	☐	☐	☐	☐	☐

	Never	**Rarely**	**Sometimes**	**Often**	**Always**
8. **How often have you been bothered by emotional problems such as feeling anxious, depressed, or irritable?**	☐	☐	☐	☐	☐

Please continue on the next page ➡

	None	Mild	Moderate	Severe	Very Severe
9. **How would you rate your fatigue on average?**	☐	☐	☐	☐	☐

	0	1	2	3	4	5	6	7	8	9	10
10. **How would you rate your pain on average?**	☐ No Pain	☐	☐	☐	☐	☐	☐	☐	☐	☐	☐ Worst imaginable pain

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For each of the following items, please mark an “x” in the box below what best indicates how much you agree with the following statements as they apply to you **over the month BEFORE your child was admitted to the PICU.** If a particular situation has not occurred recently, answer according to how you think you would have felt.

	Not true at all	**Rarely true**	**Sometimes true**	**Often true**	**True nearly all the time**
1. **I am able to adapt when changes occur.**	☐	☐	☐	☐	☐
2. **I have at least one close and secure relationship that helps me when I am stressed.**	☐	☐	☐	☐	☐
3. **When there are no clear solutions to my problems, sometimes fate or God can help.**	☐	☐	☐	☐	☐
4. **I can deal with whatever comes my way.**	☐	☐	☐	☐	☐
5. **Past successes give me confidence in dealing with new challenges and difficulties.**	☐	☐	☐	☐	☐
6. **I try to see the humorous side of things when I am faced with problems.**	☐	☐	☐	☐	☐
7. **Having to cope with stress can make me stronger.**	☐	☐	☐	☐	☐
8. **I tend to bounce back after illness, injury, or other hardships.**	☐	☐	☐	☐	☐
9. **Good or bad, I believe that most things happen for a reason.**	☐	☐	☐	☐	☐
10. **I give my best effort no matter what the outcome may be.**	☐	☐	☐	☐	☐

	Not true at all	Rarely true	Sometimes true	Often true	True nearly all the time
11. **I believe I can achieve my goals, even if there are obstacles.**	☐	☐	☐	☐	☐
12. **Even when things look hopeless, I don't give up.**	☐	☐	☐	☐	☐
13. **During times of stress/crisis, I know where to turn for help.**	☐	☐	☐	☐	☐
14. **Under pressure, I stay focused and think clearly.**	☐	☐	☐	☐	☐
15. **I prefer to take the lead in solving problems rather than letting others make all the decisions.**	☐	☐	☐	☐	☐
16. **I am not easily discouraged by failure.**	☐	☐	☐	☐	☐
17. **I think of myself as a strong person when dealing with life's challenges and difficulties.**	☐	☐	☐	☐	☐
18. **I can make unpopular or difficult decisions that affect other people, if it is necessary.**	☐	☐	☐	☐	☐
19. **I am able to handle unpleasant or painful feelings like sadness, fear, and anger.**	☐	☐	☐	☐	☐
20. **In dealing with life's problems, sometimes you have to act on a hunch without knowing why.**	☐	☐	☐	☐	☐

	Not true at all	Rarely true	Sometimes true	Often true	True nearly all the time
21. **I have a strong sense of purpose in life.**	☐	☐	☐	☐	☐
22. **I feel in control of my life.**	☐	☐	☐	☐	☐
23. **I like challenges.**	☐	☐	☐	☐	☐
24. **I work to attain my goals no matter what roadblocks I encounter along the way.**	☐	☐	☐	☐	☐
25. **I take pride in my achievements.**	☐	☐	☐	☐	☐

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Thank you very much for helping us know more about how to help the patients and families in the PICU.

Please return this survey in the envelope provided.

PICU SUPPORTS

Agradecemos su ayuda para aprender más acerca de la comunicación en la Unidad de Cuidados Intensivos Pediátricos (PICU). Esta encuesta aborda preguntas acerca de usted. Le pedimos que la conteste y la envíe en el sobre proporcionado.

Encuesta 1 para el padre o la madre de familia

La encuesta toma aproximadamente de 15 a 20 minutos en contestarse

Marque con una X la casilla de la respuesta que mejor le describa o llene el espacio en blanco.

1. **¿Cuál es su sexo?**
   - ☐ Femenino
   - ☐ Masculino

2. **¿Cuál es su relación con el niño que fue admitido en la Unidad de Cuidados Intensivos Pediátricos (PICU)?**
   - ☐ madre
   - ☐ padre
   - ☐ otra ____(descríbala)

3. **¿Cuál es su fecha de nacimiento?**

Mes XX	Día XX	Año XXXX

4. **¿Qué categoría racial lo describe mejor?** (Marque todas las que correspondan)
   - ☐ india nativa americana / nativa de Alaska
   - ☐ asiática
   - ☐ negra / afroamericana
   - ☐ nativo de Hawái o de otra isla del Pacífico.
   - ☐ blanca
   - ☐ otra ____(descríbala)

5. **¿Qué grupo étnico lo describe mejor?**
   - ☐ hispano o latino
   - ☐ no hispano o latino

6. **¿Qué categoría describe mejor el máximo nivel de escolaridad que usted alcanzó?**
   - ☐ primaria
   - ☐ escuela preparatoria o *High School*
   - ☐ título universitario
   - ☐ posgrado
   - ☐ otro tipo de educación _______________________________ (descríbala)

Continúe en la siguiente página ➡

7. ¿Cuál es el ingreso total de su hogar?
   - ☐ $25,000 o menos
   - ☐ $25,000 - $49,000
   - ☐ $50,000 - $74,999
   - ☐ $75,000 - $99,000
   - ☐ $100,000 or más

8. **¿Cuál es su estado civil actual?**
   - ☐ soltero(a)
   - ☐ casado(a)
   - ☐ vivo con mi pareja
   - ☐ separado(a)
   - ☐ divorciado(a)
   - ☐ viudo(a)

9. **¿Cuál es su afiliación religiosa?** ____________________________________

10. **¿La religión es una parte importante de su vida diaria?**
    - ☐ sí
    - ☐ no

11. **¿Se considera una persona espiritual?**
    - ☐ sí
    - ☐ no

12. **¿Cuántos hermanos tiene su hijo?** _________________

13. **¿Cómo percibe la gravedad de la enfermedad de su hijo?**
    - ☐ leve
    - ☐ moderada
    - ☐ grave

14. **¿Cuántas veces ha estado su hijo hospitalizado en el pasado?** _________________

15. **De dichas hospitalizaciones, ¿cuántas veces internaron a su hijo en PICU?** _______

Continúe en la siguiente página ➡

16. **¿Usted o su familia han tenido otras experiencias en la Unidad de Cuidados Intensivos? (Marque todas las que correspondan)**

- ☐ Si – Este hijo ha estado antes en PICU
- ☐ Si – Tengo otros hijo que ha estado internado antes en PICU
- ☐ Si – otro familiar ha estado internado en una unidad de cuidados intensivos para adultos.
- ☐ Si – yo he sido paciente en una unidad de cuidados intensivos
- ☐ No – no tengo experiencias previas en una unidad de cuidados intensivos

17. **Fecha del día de hoy:**

Mes XX	Día XX	Año XXXX

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Responda a cada afirmación marcando sólo una respuesta ("x") por fila.

	Nunca	Rara vez	Algunas veces	A menudo	Siempre
1. **Tengo quien me dé buenos consejos sobre una situación crítica si los necesito**	☐	☐	☐	☐	☐
2. **Tengo a quién recurrir para que me sugiera cómo lidiar con un problema.**	☐	☐	☐	☐	☐
3. **Tengo quien me dé información si la necesito**	☐	☐	☐	☐	☐
4. **Recibo consejos útiles sobre cosas importantes de la vida**	☐	☐	☐	☐	☐
5. **Puedo recibir consejos útiles de otras personas cuando tengo un problema**	☐	☐	☐	☐	☐
6. **Mis amigos/as tienen información útil para ayudarme con mis problemas**	☐	☐	☐	☐	☐
7. **Tengo personas a quienes puedo acudir para que me ayuden con mis problemas**	☐	☐	☐	☐	☐
8. **Otras personas me ayudan a obtener información cuando tengo un problema**	☐	☐	☐	☐	☐

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Continúe en la siguiente página ➡

Para contestar las siguientes preguntas, piense en cómo se sentía **ANTES de que internaran a su hijo en PICU.**

Responda a cada afirmación marcando sólo una respuesta ("x") por fila.

	Nunca	Rara vez	Algunas veces	A menudo	Siempre
1. **Senti que no valia nada**	☐	☐	☐	☐	☐
2. **Me senti indefenso/a (que no podia hacer nada para ayudarme)**	☐	☐	☐	☐	☐
3. **Me sentí deprimido/a**	☐	☐	☐	☐	☐
4. **Me sentí desesperanzado/a**	☐	☐	☐	☐	☐
5. **Me sentí fracasado/a**	☐	☐	☐	☐	☐
6. **Me sentí descontento/a**	☐	☐	☐	☐	☐
7. **Sentí que nada me ilusionaba**	☐	☐	☐	☐	☐
8. **Sentí que nada me podía animar**	☐	☐	☐	☐	☐

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Continúe en la siguiente página ➡

Para contestar las siguientes preguntas, piense en cómo se sentía **ANTES de que internaran a su hijo en PICU.**

Responda a cada afirmación marcando sólo una respuesta ("x") por fila.

	Nunca	Rara vez	Algunas veces	A menudo	Siempre
1. **Sentí miedo**	☐	☐	☐	☐	☐
2. **Tuve dificultad para concentrarme en otra cosa que no fuera mi ansiedad**	☐	☐	☐	☐	☐
3. **Mis inquietudes fueron demasiado para mi**	☐	☐	☐	☐	☐
4. **Me sentí intranquilo/a**	☐	☐	☐	☐	☐
5. **Me sentí nervioso/a**	☐	☐	☐	☐	☐
6. **Sentí que necesitaba ayuda para controlar mi ansiedad.**	☐	☐	☐	☐	☐
7. **Sentí ansiedad**	☐	☐	☐	☐	☐
8. **Me sentí tenso/a**	☐	☐	☐	☐	☐

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Para contestar las siguientes preguntas, piense en cómo se sentía **ANTES de que internaran a su hijo en PICU.**

Responda a cada afirmación marcando sólo una respuesta ("x") por fila.

	Mala	Pasable	Buena	Muy buena	Excelente
1. **En general, diría que su salud es**	☐	☐	☐	☐	☐
2. **En general, diría que su calidad de vida es**	☐	☐	☐	☐	☐
3. **En general, ¿cómo calificaría su salud física?**	☐	☐	☐	☐	☐
4. **En general, ¿cómo calificaría su salud mental, incluidos su estado de ánimo y su capacidad para pensar?**	☐	☐	☐	☐	☐
5. **En general, ¿cómo calificaría su satisfacción con sus actividades sociales y sus relaciones con otras personas?**	☐	☐	☐	☐	☐
6. **En general, califique en qué medida puede realizar sus actividades sociales y funciones habituales. (Esto comprende las actividades en casa, en el trabajo y en el área donde reside, así como sus responsabilidades como padre o madre, hijo/a, cónyuge, empleado/a, amigo/a, etc.)**	☐	☐	☐	☐	☐

	Para nada	Un poco	Moderada-mente	En su mayoría	Completame-nte
7. **¿En qué medida puede realizar sus actividades físicas diarias, como caminar, subir escaleras, cargar las compras o mover una silla?**	☐	☐	☐	☐	☐

Continúe en la siguiente página ➡

	Nunca	Rara vez	Algunas veces	A menudo	Siempre
8. **¿Con qué frecuencia le han afectado problemas emocionales como sentir ansiedad, depresión o irritabilidad ?**	☐	☐	☐	☐	☐

	Ninguno	Leve	Moderado	Intenso	Muy intenso
9. **En promedio, ¿cómo calificaría su cansancio?**	☐	☐	☐	☐	☐

	0	1	2	3	4	5	6	7	8	9	10
10. En promedio, ¿cómo calificaría su dolor ?	☐ **Ningún dolor**	☐	☐	☐	☐	☐	☐	☐	☐	☐	☐ **El peor dolor imaginable**

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Continúe en la siguiente página ➡

En el caso de cada una de las siguientes afirmaciones, marque con una “x” la casilla que mejor indique qué tanto está de acuerdo, según le correspondan a usted. **Piense en el transcurso del mes ANTERIOR a la hospitalización de su hijo en PICU.** Si una situación en particular no ha ocurrido recientemente, responda de acuerdo a lo que usted piensa que hubiera sentido.

	En absoluto	**Rara vez**	**A veces**	**A menudo**	**Casi siempre**
1. **Soy capaz de adaptarme cuando ocurren cambios.**	☐	☐	☐	☐	☐
2. **Tengo al menos una relación intima y segura que me ayuda cuando estoy estresado.**	☐	☐	☐	☐	☐
3. **Cuando no hay soluciones claras a mis problemas, a veces la suerte o Dios pueden ayudarme.**	☐	☐	☐	☐	☐
4. **Puedo enfrentarme a cualquier cosa.**	☐	☐	☐	☐	☐
5. **Los éxitos del pasado me dan confianza para enfrentarme con nuevos desafíos y dificultades.**	☐	☐	☐	☐	☐
6. **Cuando me enfrento con problemas intento ver el lado divertido de las cosas.**	☐	☐	☐	☐	☐
7. **Enfrentarme a las dificultades puede hacerme más fuerte.**	☐	☐	☐	☐	☐
8. **Tengo tendencia a recuperarme pronto tras enfermedades, heridas u otras privaciones.**	☐	☐	☐	☐	☐
9. **Buenas o malas, creo que la mayoría de las cosas ocurren por alguna razón.**	☐	☐	☐	☐	☐
10. **Siempre me esfuerzo sin importar cual pueda ser el resultado.**	☐	☐	☐	☐	☐

Continúe en la siguiente página ➡

	En absoluto	Rara vez	A veces	A menudo	Casi siempre
11. **Creo que puedo lograr mis objetivos, incluso si hay obstáculos.**	☐	☐	☐	☐	☐
12. **No me doy por vencido a pesar de que las cosas parezcan no tener solución.**	☐	☐	☐	☐	☐
13. **Durante los momentos de estrés/crisis, sé dónde puedo buscar ayuda.**	☐	☐	☐	☐	☐
14. **Bajo presión, me centro y pienso claramente.**	☐	☐	☐	☐	☐
15. **Prefiero intentar solucionar las cosas por mi mismo, a dejar que otros tomen todas las decisiones.**	☐	☐	☐	☐	☐
16. **No me desanimo fácilmente ante el fracaso.**	☐	☐	☐	☐	☐
17. **Creo que soy una persona fuerte cuando me enfrento a los desafíos y dificultades de la vida.**	☐	☐	☐	☐	☐
18. **Si es necesario, puedo tomar decisiones no populares o difíciles que afectan a otras persona.**	☐	☐	☐	☐	☐
19. **Soy capaz de manejar sentimientos desagradables y dolorosos como tristeza, temor y enfado.**	☐	☐	☐	☐	☐
20. **Al enfrentarse a los problemas de la vida a veces hay que actuar intuitivamente, aún sin saber por qué.**	☐	☐	☐	☐	☐

Continúe en la siguiente página ➡

	En absoluto	Rara vez	A veces	A menudo	Casi siempre
21. **Tengo muy claro lo que quiero en la vida**.	☐	☐	☐	☐	☐
22. **Siento que controlo mi vida.**	☐	☐	☐	☐	☐
23. **Me gustan los desafíos.**	☐	☐	☐	☐	☐
24. **Trabajo para conseguir mis objetivos sin importarme las dificultades que encuentro en el camino.**	☐	☐	☐	☐	☐
25. **Estoy orgulloso de mis logros.**	☐	☐	☐	☐	☐

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Gracias por permitirnos aprender más acerca de cómo podemos ayudar a los pacientes y sus familias en PICU.

Envíe esta encuesta en el sobre proporcionado.

PICU SUPPORTS

Agradecemos su ayuda para aprender más acerca de la comunicación en la Unidad de Cuidados Intensivos Pediátricos (PICU). Esta encuesta le pide calificar varios aspectos de la atención que su hijo ha recibido, así como su participación en dicha atención. Le pedimos que conteste esta encuesta y la envíe en el sobre proporcionado.

Encuesta 2 para el padre o la madre de familia

La encuesta toma aproximadamente de 15 a 20 minutos en contestarse

Fecha de hoy:

Mes XX	Día XX	Año XXXX

Satisfacción del padre de familia respecto a la atención en la Unidad de Cuidados Intensivos Pediátricos (*Parent Satisfaction with Care in the Intensive Care Unit* ©)

pFS-ICU (24)

¿Cómo estamos trabajando?
Su opinión acerca de la estancia de su hijo en la Unidad de Cuidados Intensivos

Las siguientes preguntas para **USTED** abordan aspectos de la **admisión actual de su hijo en la unidad de cuidados intensivos**. Sabemos que ha habido muchos doctores, enfermeros y otro personal que ha participado en el cuidado de su hijo. Entendemos que puede haber excepciones, pero nos interesa **su opinión en general** acerca de la calidad de la atención que le estamos proporcionando. Estamos conscientes de que probablemente usted y su familia están atravesando por un momento muy difícil. Agradecemos que se tome el tiempo de darnos su opinión. Le pedimos que se tome un momento para decirnos lo que estamos haciendo bien y lo que podemos mejorar en nuestra ICU. Tenga por seguro que todas las respuestas son confidenciales. Los médicos y enfermeros que cuidan de su hijo no podrán identificar sus respuestas.

PARTE I: SATISFACCIÓN CON LA ATENCIÓN

Marque con una “X” sólo UNA de las casillas que mejor describa su opinión. **Si la pregunta no corresponde a la estancia de su hijo, entonces marque “no corresponde” (N/A).**

Cómo tratamos a su niño (el/la paciente):

1. **Preocupación y cuidado por parte del personal de la ICU** (la cortesía, respeto y compasión que se le dio a su niño [el/la paciente])

Excelente	Muy bien	Bien	Aceptable	Mal	N/A
☐	☐	☐	☐	☐	☐

Manejo de síntomas (qué tan bien evaluó y trató el personal de la ICU los síntomas de su niño):

2. **Dolor**

Excelente	Muy bien	Bien	Aceptable	Mal	N/A
☐	☐	☐	☐	☐	☐

3. **Dificultad al respirar**

Excelente	Muy bien	Bien	Aceptable	Mal	N/A
☐	☐	☐	☐	☐	☐

4. **Inquietud**

Excelente	Muy bien	Bien	Aceptable	Mal	N/A
☐	☐	☐	☐	☐	☐

Continúe en la siguiente página ➡

¿Cómo lo estamos haciendo?
Sus opiniones respecto del ingreso de su niño a la Unidad de Cuidados Intensivos (ICU)

¿Cómo lo tratamos a usted?

5. **Tomar en cuenta sus necesidades** (qué tan bien mostró interés el personal de la ICU en las necesidades de usted):

Excelente	Muy bien	Bien	Aceptable	Mal	N/A
☐	☐	☐	☐	☐	☐

6. **Apoyo emocional** (qué tan bien le proporcionó apoyo emocional el personal de la ICU):

Excelente	Muy bien	Bien	Aceptable	Mal	N/A
☐	☐	☐	☐	☐	☐

7. **Coordinación del cuidado** (el trabajo de equipo de todo el personal de la ICU que cuidó a su niño):

Excelente	Muy bien	Bien	Aceptable	Mal	N/A
☐	☐	☐	☐	☐	☐

8. **Preocupación y cuidado por parte del personal de la ICU** (la cortesía, respeto y compasión que le fueron proporcionados a usted):

Excelente	Muy bien	Bien	Aceptable	Mal	N/A
☐	☐	☐	☐	☐	☐

ENFERMERAS

9. **Destreza y capacidad de las enfermeras de la ICU** (qué tan bien cuidan las enfermeras a su niño):

Excelente	Muy bien	Bien	Aceptable	Mal	N/A
☐	☐	☐	☐	☐	☐

10. **Frecuencia de comunicación con las enfermeras de la ICU** (qué tan frecuentemente se comunicaron con usted las enfermeras de la ICU en relación con la condición de su niño):

Excelente	Muy bien	Bien	Aceptable	Mal	N/A
☐	☐	☐	☐	☐	☐

Continúe en la siguiente página ➡

¿Cómo lo estamos haciendo?
Sus opiniones respecto del ingreso de su niño a la Unidad de Cuidados Intensivos (ICU)

MÉDICOS (todos los médicos, incluyendo residentes e internos)

11. **Destreza y capacidad de los médicos de la ICU** (qué tan bien cuidaron los médicos a su niño):

Excelente	Muy bien	Bien	Aceptable	Mal	N/A
☐	☐	☐	☐	☐	☐

LA ICU

12. **¿Cómo fue el ambiente de la ICU?**

Excelente	Muy bien	Bien	Aceptable	Mal	N/A
☐	☐	☐	☐	☐	☐

LA SALA DE ESPERA

13. **¿Cómo fue el ambiente en la sala de espera de la ICU?**

Excelente	Muy bien	Bien	Aceptable	Mal	N/A
☐	☐	☐	☐	☐	☐

14. **A algunas personas les gusta que se haga todo en relación con sus problemas de salud, mientras que a otras no les gusta que se haga mucho. ¿Qué tan satisfecho estuvo usted con el nivel o cantidad de cuidados de la salud que recibió su niño en la ICU?**

☐ muy insatisfecho
☐ un poco insatisfecho
☐ generalmente satisfecho
☐ muy satisfecho
☐ completamente satisfecho

Continúe en la siguiente página ➡

PARTE 2: SATISFACCIÓN DEL PADRE O MADRE DE FAMILIA, PERSONA A CARGO DEL PACIENTE O TUTOR CON LA TOMA DE DECISIONES RESPECTO A LA ATENCIÓN QUE RECIBEN LOS PACIENTES EN ESTADO CRÍTICO

Esta parte del cuestionario está diseñada para medir cómo se siente sobre SU participación en las decisiones relacionadas con la atención médica de su hijo. En la Unidad de Cuidados Intensivos (ICU), su hijo fue atendido por diferentes personas. Queremos que al contestar estas preguntas piense en toda la atención que ha recibido su hijo.

Marque con una “X” sólo UNA de las casillas que mejor describa su opinión.

NECESIDADES DE INFORMACIÓN

1. **Frecuencia de la comunicación con los médicos de la ICU** (qué tan frecuentemente se comunicaron con usted los médicos de la ICU en relación con la condición de su niño):

Excelente	Muy bien	Bien	Aceptable	Mal	N/A
☐	☐	☐	☐	☐	☐

2. **Facilidad para obtener información** (buena disposición del personal de la ICU para responder a sus preguntas):

Excelente	Muy bien	Bien	Aceptable	Mal	N/A
☐	☐	☐	☐	☐	☐

3. **Comprensión de la información** (qué tan bien le proporcionó el personal de la ICU explicaciones que usted comprendió):

Excelente	Muy bien	Bien	Aceptable	Mal	N/A
☐	☐	☐	☐	☐	☐

4. **Honestidad de la información** (la honestidad de la información que le fue proporcionada a usted respecto de la condición de su niño):

Excelente	Muy bien	Bien	Aceptable	Mal	N/A
☐	☐	☐	☐	☐	☐

5. **Totalidad/Integridad de la información** (qué tan bien le informo a usted el personal de la ICU sobre lo que estaba sucediendo con su niño y la razón por la que se estaban haciendo las cosas):

Excelente	Muy bien	Bien	Aceptable	Mal	N/A
☐	☐	☐	☐	☐	☐

6. **Consistencia de la información** (la consistencia de la información que le fue proporcionada a usted respecto a la condición de su niño – obtuvo usted información similar por parte del médico, enfermera, etc.):

Excelente	Muy bien	Bien	Aceptable	Mal	N/A
☐	☐	☐	☐	☐	☐

Continúe en la siguiente página ➡

¿Cómo estamos trabajando?
Su opinión acerca de la estancia de su hijo en la Unidad de Cuidados Intensivos

PROCESO DE TOMA DE DECISIONES

Durante la estancia de su niño en la ICU, se toman muchas decisiones importantes respecto del cuidado de la salud que él o ella recibe. En las siguientes preguntas, elija **una** respuesta del siguiente grupo de ideas que mejor se ajuste a sus puntos de vista:

7. **¿Se sintió usted incluido en el proceso de toma de decisiones?**
   - ☐ Me sentí muy excluido
   - ☐ Me sentí un poco excluido
   - ☐ No me sentí ni incluido ni excluido en el proceso de toma de decisiones
   - ☐ Me sentí un poco incluido
   - ☐ Me sentí muy incluido

8. **¿Se sintió usted apoyado durante el proceso de toma de decisiones?**
   - ☐ Me sentí totalmente agobiado
   - ☐ Me sentí un poco agobiado
   - ☐ No me sentí ni agobiado ni apoyado
   - ☐ Me sentí apoyado
   - ☐ Me sentí muy apoyado

9. **¿Sintió usted que tenía control sobre el cuidado de su niño?**
   - ☐ Realmente sentí que no tenía control y que el sistema de cuidados de la salud asumió el control y ordenó el cuidado que mi niño recibió
   - ☐ Sentí un poco que no tenía control y que el sistema de cuidados de la salud asumió el control y ordenó el cuidado que mi niño recibió
   - ☐ No sentí que no tuviera control ni que tuviera control
   - ☐ Sentí que tenía algo de control sobre el cuidado que mi niño recibió
   - ☐ Sentí que tenía buen control sobre el cuidado que mi niño recibió

10. **Al tomar decisiones, ¿tuvo usted el tiempo suficiente para tratar sus inquietudes y que le respondieran sus preguntas?**
    - ☐ Podría haber utilizado más tiempo
    - ☐ Tuve el tiempo suficiente

Continúe en la siguiente página ➡

Las siguientes preguntas están relacionadas a las decisiones tomadas respecto a su hijo. Encierre en un círculo el número que mejor represente su opinión respecto al proceso del equipo.

11. **Los miembros del equipo planearon en conjunto tomar las decisiones respecto a la atención de su hijo.**

1	2	3	4	5	6	7
Completamente en desacuerdo						Completamente de acuerdo

12. **Los miembros del equipo tuvieron una comunicación abierta entre ellos al tomar las decisiones para su hijo.**

1	2	3	4	5	6	7
Completamente en desacuerdo						Completamente de acuerdo

13. **La responsabilidad de la toma de decisiones para su hijo se compartió entre los miembros del equipo.**

1	2	3	4	5	6	7
Completamente en desacuerdo						Completamente de acuerdo

14. **Los miembros del equipo colaboraron juntos en la toma de decisiones.**

1	2	3	4	5	6	7
Completamente en desacuerdo						Completamente de acuerdo

15. **En el proceso de la toma de decisiones, se tomaron en cuenta las inquietudes de todos los miembros del equipo respecto a las necesidades de hijo.**

1	2	3	4	5	6	7
Completamente en desacuerdo						Completamente de acuerdo

16. **La toma de decisiones para su hijo se coordinó entre los miembros del equipo.**

1	2	3	4	5	6	7
Completamente en desacuerdo						Completamente de acuerdo

17. **¿Qué tanto colaboraron los miembros del equipo en la toma de decisiones para su hijo?**

1	2	3	4	5	6	7
No colaboraron						Colaboraron completamente

18. **¿Qué tan satisfecho está usted con la forma en que se tomaron las decisiones para su hijo? Esto se refiere al proceso de toma de decisiones, no necesariamente a las decisiones mismas.**

1	2	3	4	5	6	7
Nada satisfecho						Muy satisfecho

19. **¿Qué tan satisfecho estuvo usted con las decisiones que se tomaron para su hijo?**

1	2	3	4	5	6	7
Nada satisfecho						Muy satisfecho

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Continúe en la siguiente página ➡

20. **¿Qué otras sugerencias tiene respecto a cómo mejorar la atención proporcionada en la ICU?**

21. **Le pedimos que comparta algún comentario respecto a lo que hicimos bien.**

22. **Añada algún comentario o sugerencias que usted crea podrían ser útiles para el personal de este hospital.**

Gracias por permitirnos aprender más acerca de cómo podemos ayudar a los pacientes y sus familias en PICU.

Envíe esta encuesta en el sobre proporcionado.

PICU
SUPPORTS

Thank you for helping us to know more about communication in the pediatric intensive care unit (PICU). This survey asks you to rate various aspects of the care your child has received and your involvement in that care. Please complete this survey and return it in the envelope provided.

Parent Survey 2

This survey takes approximately15-20 minutes to complete

Today's date is:

Month XX | Day XX | Year XXXX

Parent Satisfaction with Care in the Intensive Care Unit ©
pFS-ICU (24)

How are we doing?
Your opinions about your child's ICU stay

The questions that follow ask **YOU** about your child's **current ICU admission**. We understand that there have been 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 are delivering. We understand that this is probably a very difficult time for you and your family. We would appreciate you taking the time to provide us with your opinions. Please take a moment to tell us what we are doing well and what we can do to make our ICU better. Please be assured that all responses are confidential. The doctors and nurses who are looking after your child will not be able to identify your response.

PART I : SATISFACTION WITH CARE

Please mark an "X" in the ONE box that best describes your feelings. If the question does not apply to your child's stay then please mark "not applicable" (N/A).

How did we treat your child (the patient):

1. **Concern and caring by the ICU staff** (the courtesy, respect, and compassion your child [the patient] was given)

Excellent	Very good	Good	Fair	Poor	N/A
☐	☐	☐	☐	☐	☐

Symptoms management (how well the ICU staff assessed and treated your child's symptoms):

2. **Pain**

Excellent	Very good	Good	Fair	Poor	N/A
☐	☐	☐	☐	☐	☐

3. **Breathlessness**

Excellent	Very good	Good	Fair	Poor	N/A
☐	☐	☐	☐	☐	☐

4. **Agitation**

Excellent	Very good	Good	Fair	Poor	N/A
☐	☐	☐	☐	☐	☐

Please continue on the next page ➡

How are we doing?
Your opinions about your child’s ICU stay

How did we treat you?

5. **Consideration of your needs** (how well the ICU staff showed an interest in your needs):

Excellent	Very good	Good	Fair	Poor	N/A
☐	☐	☐	☐	☐	☐

6. **Emotional support** (how well the ICU staff provided emotional support):

Excellent	Very good	Good	Fair	Poor	N/A
☐	☐	☐	☐	☐	☐

7. **Coordination of care** (the teamwork of all the ICU staff who took care of your child):

Excellent	Very good	Good	Fair	Poor	N/A
☐	☐	☐	☐	☐	☐

8. **Concern and caring by ICU staff** (the courtesy, respect, and compassion you were given):

Excellent	Very good	Good	Fair	Poor	N/A
☐	☐	☐	☐	☐	☐

Nurses

9. **Skill and competence of ICU nurses** (how well the nurses cared for your child):

Excellent	Very good	Good	Fair	Poor	N/A
☐	☐	☐	☐	☐	☐

10. **Frequency of communication with ICU nurses** (how often nurses communicated to you about your child’s condition):

Excellent	Very good	Good	Fair	Poor	N/A
☐	☐	☐	☐	☐	☐

Please continue on the next page ➡

How are we doing?
Your opinions about your child's ICU stay

Physicians (all doctors, including residents and fellows)

11. **Skill and competence of ICU doctors (how well doctors cared for your child):**

Excellent	Very good	Good	Fair	Poor	N/A
☐	☐	☐	☐	☐	☐

The ICU

12. **Atmosphere of ICU was?**

Excellent	Very good	Good	Fair	Poor	N/A
☐	☐	☐	☐	☐	☐

The Waiting Room

13. **The atmosphere in the ICU waiting room was?**

Excellent	Very good	Good	Fair	Poor	N/A
☐	☐	☐	☐	☐	☐

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 or amount of health care your child received in the ICU.**

☐ Very dissatisfied
☐ Slightly dissatisfied
☐ Mostly satisfied
☐ Very satisfied
☐ Completely satisfied

Please continue on the next page

PART 2: PARENT, CAREGIVER, OR GUARDIAN SATISFACTION WITH DECISION-MAKING AROUND CARE 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 Intensive Care Unit (ICU), your child may receive care from different people. We would like you to think about all the care your child has received when you are answering the questions.

Please mark an "X" in the ONE box that best describes your feelings.

INFORMATION NEEDS

1. **Frequency of communication with ICU doctors** (how often doctors communicated to you about your child's condition):

Excellent	Very good	Good	Fair	Poor	N/A
☐	☐	☐	☐	☐	☐

2. **Ease of getting information** (willingness of ICU staff to answer your questions):

Excellent	Very good	Good	Fair	Poor	N/A
☐	☐	☐	☐	☐	☐

3. **Understanding of information** (how well ICU staff provided you with explanations that you understood):

Excellent	Very good	Good	Fair	Poor	N/A
☐	☐	☐	☐	☐	☐

4. **Honesty of information** (the honesty of information provided to you about your child's condition):

Excellent	Very good	Good	Fair	Poor	N/A
☐	☐	☐	☐	☐	☐

5. **Completeness of information** (how well ICU staff informed you what was happening to your child and why things were being done):

Excellent	Very good	Good	Fair	Poor	N/A
☐	☐	☐	☐	☐	☐

6. **Consistency of information** (the consistency of information provided to you about your child's condition – did you get a similar story from the doctor, nurse, etc.):

Excellent	Very good	Good	Fair	Poor	N/A
☐	☐	☐	☐	☐	☐

Please continue on the next page

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 are made regarding the health care she or he receives. From the following questions, pick **one** answer from each of the following set of ideas that best matches your views:

7. **Did you feel included in the decision making process?**
   - ☐ I felt very excluded
   - ☐ I felt somewhat excluded
   - ☐ I felt neither included nor excluded from the decision making process
   - ☐ I felt somewhat included
   - ☐ I felt very included

8. **Did you feel supported during the decision making process?**
   - ☐ I felt totally unsupported
   - ☐ I felt slightly unsupported
   - ☐ I felt neither supported nor unsupported
   - ☐ I felt supported
   - ☐ I felt very supported

9. **Did you feel you had control over the care of your child?**
   - ☐ I felt really out of control and that the health care system took over and dictated the care my child received
   - ☐ I felt somewhat out of control and that the health care system took over and dictated the care my child received
   - ☐ I felt neither in control nor out of control
   - ☐ I felt I had some control over the care my child received
   - ☐ I felt that I had good control over the care my child received

10. **When making decisions, did you have adequate time to have your concerns addressed and questions answered?**
    - ☐ I could have used more time
    - ☐ I had adequate time

Please continue on the next page ➡

The following questions are related to decision making for your child. Please circle the number that best represents your judgment about the team process.

11. **Team members <u>planned together</u> to make decisions about care for your child.**

1	2	3	4	5	6	7
Strongly Disagree						Strongly Agree

12. **<u>Open communication</u> between team members took place as decisions were made for your child.**

1	2	3	4	5	6	7
Strongly Disagree						Strongly Agree

13. **<u>Decision-making responsibilities</u> for your child were <u>shared</u> among team members.**

1	2	3	4	5	6	7
Strongly Disagree						Strongly Agree

14. **Team members <u>cooperated</u> in making decisions.**

1	2	3	4	5	6	7
Strongly Disagree						Strongly Agree

15. **In making decisions, all team members' <u>concerns</u> about your child's need were considered.**

1	2	3	4	5	6	7
Strongly Disagree						Strongly Agree

16. **Decision-making for your child was <u>coordinated</u> among team members.**

1	2	3	4	5	6	7
Strongly Disagree						Strongly Agree

17. **How much <u>collaboration</u> among team members occurred in making decisions for your child?**

1	2	3	4	5	6	7
No Collaboration						Complete Collaboration

18. **How <u>satisfied</u> are you with the way decisions were made for your child? That is with the <u>decision-making process</u>, not necessarily with the decision itself.**

1	2	3	4	5	6	7
Not Satisfied						Very Satisfied

19. **How <u>satisfied</u> were you with <u>decisions</u> made for your child?**

1	2	3	4	5	6	7
Not Satisfied						Very Satisfied

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Please continue on the next page ➡

20. **What other suggestions do you have on how to make care provided in the ICU better?**

21. **Please share any comments on what we did well?**

22. **Please add any comments or suggestions that you feel may be helpful to the staff of this hospital.**

Thank you very much for helping us know more about how to help the patients and families in the PICU.

Please return this survey in the envelope provided.

PICU SUPPORTS

Thank you for helping us to learn more about communication in the pediatric intensive care unit (PICU). This survey asks questions about the meeting you had with members of your healthcare team. Please complete this survey and return it in the envelope provided.

Parent Survey 3

This survey takes approximately 10-15 minutes to complete

Today's date is:

Month XX	Day XX	Year XXXX

Communication is a very important part of quality medical care. We would like to know how you feel about the way your child's healthcare team communicated with you. Your answers are completely confidential, so please be as open and honest as you can. Thank you very much.

Please respond to each statement by marking and "X" in one box per row.

My child's healthcare team…

	Poor	Fair	Good	Very Good	Excellent
1. Greeted me in a way that made me feel comfortable.	☐	☐	☐	☐	☐
2. Treated me with respect.	☐	☐	☐	☐	☐
3. Showed interest in my ideas about my child's health.	☐	☐	☐	☐	☐
4. Understood my main health concerns for my child.	☐	☐	☐	☐	☐
5. Paid attention to me (looked at me, listened carefully).	☐	☐	☐	☐	☐
6. Let me talk without interruptions.	☐	☐	☐	☐	☐
7. Gave me as much information as I wanted.	☐	☐	☐	☐	☐
8. Talked in terms I could understand.	☐	☐	☐	☐	☐
9. Check to be sure I understood everything	☐	☐	☐	☐	☐
10. Encouraged me to ask questions.	☐	☐	☐	☐	☐
11. Involved me in decisions as much as I wanted.	☐	☐	☐	☐	☐
12. Discussed next steps, including any follow up plans.	☐	☐	☐	☐	☐
13. Showed care and concern.	☐	☐	☐	☐	☐
14. Spend the right amount of time with me.	☐	☐	☐	☐	☐

15. Were any decisions about your child’s care discussed during the meeting?

☐ Yes
If “yes,” what decisions were discussed?
____
____
☐ No
☐ Don’t know

16. How well did this meeting help you understand the decisions that may need to be made for your child? *(Please circle one number.)*

1	2	3	4	5
Not at all well				Extremely well

17. Overall, how well did the team communicate with you during the meeting? *(Please circle one number.)*

1	2	3	4	5
Not at all well				Extremely well

18. Overall, how well did this meeting meet your needs? *(Please circle one number.)*

1	2	3	4	5
Not at all well				Extremely well

19. Please describe why the meeting did or did not meet your needs. (Please use the back of the page if you need more space.)

Thank you very much for helping us know more about how to help the patients and families in the PICU.

Please return this survey in the envelope provided.

PICU SUPPORTS

Agradecemos su ayuda para aprender más acerca de la comunicación en la Unidad de Cuidados Intensivos Pediátricos (PICU). Esta encuesta aborda preguntas acerca de la reunión que tuvo con los miembros del equipo médico. Le pedimos que la conteste y la envíe en el sobre proporcionado.

Encuesta 3 para el padre o la madre de familia

La encuesta toma aproximadamente de 10 a 15 minutos en contestarse

Fecha de hoy:

Mes XX | Día XX | Año XXXX

La comunicación es un elemento muy importante para la calidad de la atención médica. Nos gustaría saber cómo se siente respecto a la comunicación que mantuvo con usted el equipo médico. Sus respuestas son completamente confidenciales, así que le pedimos que sea tan honesto como pueda. Muchas gracias.

Responda a cada afirmación marcando sólo una respuesta ("x") por fila.

La atención médica de mi hijo…

	mala	regular	buena	muy buena	excelente
1. Me saludaron de una manera que me hizo sentir bien.	☐	☐	☐	☐	☐
2. Me trataron con respeto.	☐	☐	☐	☐	☐
3. Mostraron interés en mis ideas respecto a la salud de mi hijo.	☐	☐	☐	☐	☐
4. Comprendieron mis inquietudes principales respecto a la salud de mi hijo.	☐	☐	☐	☐	☐
5. Me pusieron atención (me miraron a los ojos y escucharon atentamente).	☐	☐	☐	☐	☐
6. Me dejaron hablar sin interrupciones.	☐	☐	☐	☐	☐
7. Me dieron toda la información que solicité.	☐	☐	☐	☐	☐
8. Hablaron en términos que pude entender.	☐	☐	☐	☐	☐
9. Se cercioraron de que había entendido todo.	☐	☐	☐	☐	☐
10. Me animaron a hacer preguntas.	☐	☐	☐	☐	☐
11. Me incluyeron en la toma de decisiones siempre que lo desee.	☐	☐	☐	☐	☐
12. Hablamos sobre los siguientes pasos, incluyendo los planes de seguimiento.	☐	☐	☐	☐	☐
13. Mostraron cuidado e interés.	☐	☐	☐	☐	☐
14. Pasaron la cantidad adecuada de tiempo conmigo.	☐	☐	☐	☐	☐

15. ¿Se discutió alguna decisión sobre el cuidado de su hijo durante la reunión?

☐ Sí
Si así fue, ¿cuáles decisiones se discutieron?
____
____
☐ No
☐ No sé

16. ¿Qué tan útil fue dicha reunión para ayudarle a comprender las decisiones que pudieran necesitarse tomar para su hijo? *(Encierre una opción).*

1	2	3	4	5
Nada bien				Extremadamente bien

17. En general, ¿qué tan bien se comunicó el equipo con usted durante la reunión? *(Encierre una opción).*

1	2	3	4	5
Nada bien				Extremadamente bien

18. En general, ¿qué tan bien cumplió sus expectativas esta reunión? *(Encierre una opción).*

1	2	3	4	5
Nada bien				Extremadamente bien

19. Describa por qué la reunión cumplió o no con sus necesidades. (Si necesita más espacio, utilice el reverso de la página).

Gracias por permitirnos aprender más acerca de cómo podemos ayudar a los pacientes y sus familias en PICU.

Envíe esta encuesta en el sobre proporcionado.

PICU
SUPPORTS

Thank you for helping us know more about communication in the pediatric intensive care unit (PICU). This survey asks you for information about your experience in the PICU, your reactions to the brochure you received, and about yourself. Please complete this survey and return it in the envelope provided.

Parent Survey 4

This survey takes approximately 30-45 minutes to complete

Today's date is:

Month XX	Day XX	Year XXXX

Please select the answer that **best** reflects your experience.

	Useless	Not Very Useful	Very Useful	Extremely Useful	Did Not Use
1. **How useful to you was the brochure that you received at the beginning of your stay in the PICU?**	☐	☐	☐	☐	☐

2. **Please comment on any parts of the brochure that you found useful.**

3. **Please comment on any parts of the brochure that you did not like.**

4. **How might we improve the brochure?**

Please continue on the next page ➡

5. **Please tell us any other questions/comments you have about the brochure or being in the PICU?**

Please continue on the next page ➡

Parent Satisfaction with Care in the Intensive Care Unit ©
pFS-ICU (24)

How are we doing?
Your opinions about your child's ICU stay

The questions that follow ask **YOU** about your child's **current ICU admission**. We understand that there have been 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 are delivering. We understand that this is probably a very difficult time for you and your family. We would appreciate you taking the time to provide us with your opinions. Please take a moment to tell us what we are doing well and what we can do to make our ICU better. Please be assured that all responses are confidential. The doctors and nurses who are looking after your child will not be able to identify your response.

PART I : SATISFACTION WITH CARE

Please mark an "X" in the ONE box that best describes your feelings. If the question does not apply to your child's stay then please mark "not applicable" (N/A).

How did we treat your child (the patient)?

1. **Concern and caring by the ICU staff** (the courtesy, respect, and compassion your child [the patient] was given)

Excellent	Very good	Good	Fair	Poor	N/A
☐	☐	☐	☐	☐	☐

Symptoms management (how well the ICU staff assessed and treated your child's symptoms):

2. **Pain**

Excellent	Very good	Good	Fair	Poor	N/A
☐	☐	☐	☐	☐	☐

3. **Breathlessness**

Excellent	Very good	Good	Fair	Poor	N/A
☐	☐	☐	☐	☐	☐

4. **Agitation**

Excellent	Very good	Good	Fair	Poor	N/A
☐	☐	☐	☐	☐	☐

Please continue on the next page ➡

How did we treat you?

5. **Consideration of your needs** (how well the ICU staff showed an interest in your needs):

Excellent	Very good	Good	Fair	Poor	N/A
☐	☐	☐	☐	☐	☐

6. **Emotional support** (how well the ICU staff provided emotional support):

Excellent	Very good	Good	Fair	Poor	N/A
☐	☐	☐	☐	☐	☐

7. **Coordination of care** (the teamwork of all the ICU staff who took care of your child):

Excellent	Very good	Good	Fair	Poor	N/A
☐	☐	☐	☐	☐	☐

8. **Concern and caring by ICU staff** (the courtesy, respect, and compassion you were given):

Excellent	Very good	Good	Fair	Poor	N/A
☐	☐	☐	☐	☐	☐

Nurses

9. **Skill and competence of ICU nurses** (how well the nurses cared for your child):

Excellent	Very good	Good	Fair	Poor	N/A
☐	☐	☐	☐	☐	☐

10. **Frequency of communication with ICU nurses** (how often nurses communicated to you about your child's condition):

Excellent	Very good	Good	Fair	Poor	N/A
☐	☐	☐	☐	☐	☐

Physicians (all doctors, including residents and fellows)

11. **Skill and competence of ICU doctors (how well doctors cared for your child):**

Excellent	Very good	Good	Fair	Poor	N/A
☐	☐	☐	☐	☐	☐

Please continue on the next page ➡

The ICU

12. **Atmosphere of ICU was?**

Excellent	Very good	Good	Fair	Poor	N/A
☐	☐	☐	☐	☐	☐

The Waiting Room

13. **The atmosphere in the ICU waiting room was?**

Excellent	Very good	Good	Fair	Poor	N/A
☐	☐	☐	☐	☐	☐

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 or amount of health care your child received in the ICU.**

☐ Very dissatisfied
☐ Slightly dissatisfied
☐ Mostly satisfied
☐ Very satisfied
☐ Completely satisfied

Please continue on the next page ➡

PART 2: PARENT, CAREGIVER, OR GUARDIAN SATISFACTION WITH DECISION-MAKING AROUND CARE 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 Intensive Care Unit (ICU), your child may receive care from different people. We would like you to think about all the care your child has received when you are answering the questions.
Please mark an “X” in the ONE box that best describes your feelings.

INFORMATION NEEDS

15. **Frequency of communication with ICU doctors** (how often doctors communicated to you about your child’s condition):

Excellent	Very good	Good	Fair	Poor	N/A
☐	☐	☐	☐	☐	☐

16. **Ease of getting information** (willingness of ICU staff to answer your questions):

Excellent	Very good	Good	Fair	Poor	N/A
☐	☐	☐	☐	☐	☐

17. **Understanding of information** (how well ICU staff provided you with explanations that you understood):

Excellent	Very good	Good	Fair	Poor	N/A
☐	☐	☐	☐	☐	☐

18. **Honesty of information** (the honesty of information provided to you about your child’s condition):

Excellent	Very good	Good	Fair	Poor	N/A
☐	☐	☐	☐	☐	☐

19. **Completeness of information** (how well ICU staff informed you what was happening to your child and why things were being done):

Excellent	Very good	Good	Fair	Poor	N/A
☐	☐	☐	☐	☐	☐

20. **Consistency of information** (the consistency of information provided to you about your child’s condition – did you get a similar story from the doctor, nurse, etc.):

Excellent	Very good	Good	Fair	Poor	N/A
☐	☐	☐	☐	☐	☐

Please continue on the next page

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 are made regarding the health care she or he receives. From the following questions, pick **one** answer from each of the following set of ideas that best matches your views:

21. **Did you feel included in the decision making process?**
    - ☐ I felt very excluded
    - ☐ I felt somewhat excluded
    - ☐ I felt neither included nor excluded from the decision making process
    - ☐ I felt somewhat included
    - ☐ I felt very included

22. **Did you feel supported during the decision making process?**
    - ☐ I felt totally unsupported
    - ☐ I felt slightly unsupported
    - ☐ I felt neither supported nor unsupported
    - ☐ I felt supported
    - ☐ I felt very supported

23. **Did you feel you had control over the care of your child?**
    - ☐ I felt really out of control and that the health care system took over and dictated the care my child received
    - ☐ I felt somewhat out of control and that the health care system took over and dictated the care my child received
    - ☐ I felt neither in control nor out of control
    - ☐ I felt I had some control over the care my child received
    - ☐ 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?**
    - ☐ I could have used more time
    - ☐ I had adequate time

Please continue on the next page ➡

The following questions are related to team collaboration during decision making for your child. Please circle the number that best represents your judgment about the team process.

1. **Team members <u>planned together</u> to make decisions about care for your child.**

1	2	3	4	5	6	7
Strongly Disagree						Strongly Agree

2. **<u>Open communication</u> between team members took place as decisions were made for your child.**

1	2	3	4	5	6	7
Strongly Disagree						Strongly Agree

3. **<u>Decision-making responsibilities</u> for your child were <u>shared</u> among team members.**

1	2	3	4	5	6	7
Strongly Disagree						Strongly Agree

4. **Team members <u>cooperated</u> in making decisions.**

1	2	3	4	5	6	7
Strongly Disagree						Strongly Agree

5. **In making decisions, all team members' <u>concerns</u> about your child's need were considered.**

1	2	3	4	5	6	7
Strongly Disagree						Strongly Agree

6. **Decision-making for your child was <u>coordinated</u> among team members.**

1	2	3	4	5	6	7
Strongly Disagree						Strongly Agree

7. **How much <u>collaboration</u> among team members occurred in making decisions for your child?**

1	2	3	4	5	6	7
No Collaboration						Complete Collaboration

8. **How <u>satisfied</u> are you with the way decisions were made for your child? That is with the <u>decision-making process</u>, not necessarily with the decision itself.**

1	2	3	4	5	6	7
Not Satisfied						Very Satisfied

9. **How <u>satisfied</u> were you with <u>decisions</u> made for your child?**

1	2	3	4	5	6	7
Not Satisfied						Very Satisfied

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Please continue on the next page ➡

The following questions are about decision making in the PICU.

1. **Please write down the MOST important decision made for your child while he/she was in the PICU.**

For the following questions, please think about the decision you have identified above. Then, please mark an "X" in the ONE box per row that best describes your feelings now about this decision.

	Strongly Agree	Agree	Neither Agree Nor Disagree	Disagree	Strongly Disagree
2. **It was the right decision.**	☐	☐	☐	☐	☐
3. **I regret the choice that was made.**	☐	☐	☐	☐	☐
4. **I would go for the same choice if I had to do it over again.**	☐	☐	☐	☐	☐
5. **The choice did my child a lot of harm.**	☐	☐	☐	☐	☐
6. **The decision was a wise one.**	☐	☐	☐	☐	☐

Please continue on the next page ➡

Please respond to each statement by marking an “X” in one box per row.

<u>In the past 7 days</u>…

	Never	Rarely	Sometimes	Often	Always
1. **I felt worthless.**	☐	☐	☐	☐	☐
2. **I felt helpless.**	☐	☐	☐	☐	☐
3. **I felt depressed.**	☐	☐	☐	☐	☐
4. **I felt hopeless.**	☐	☐	☐	☐	☐
5. **I felt like a failure.**	☐	☐	☐	☐	☐
6. **I felt unhappy.**	☐	☐	☐	☐	☐
7. **I felt that I had nothing to look forward to.**	☐	☐	☐	☐	☐
8. **I felt that nothing could cheer me up.**	☐	☐	☐	☐	☐

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Please continue on the next page ➡

Please respond to each statement by marking an "X" in one box per row.

In the past 7 days…

	Never	Rarely	Sometimes	Often	Always
1. **I felt fearful.**	☐	☐	☐	☐	☐
2. **I found it hard to focus on anything other than my anxiety.**	☐	☐	☐	☐	☐
3. **My worries overwhelmed me.**	☐	☐	☐	☐	☐
4. **I felt uneasy.**	☐	☐	☐	☐	☐
5. **I felt nervous.**	☐	☐	☐	☐	☐
6. **I felt like I needed help for my anxiety.**	☐	☐	☐	☐	☐
7. **I felt anxious.**	☐	☐	☐	☐	☐
8. **I felt tense.**	☐	☐	☐	☐	☐

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Please continue on the next page ➡

Please respond to each statement by marking an “X” in one box per row.

	Poor	Fair	Good	Very Good	Excellent
1. **In general, would you say your health is:**	☐	☐	☐	☐	☐
2. **In general, would you say your quality of life is:**	☐	☐	☐	☐	☐
3. **In general, how would you rate your physical health?**	☐	☐	☐	☐	☐
4. **In general, how would you rate your mental health, including your mood and your ability to think?**	☐	☐	☐	☐	☐
5. **In general, how would you rate you satisfaction with your social activities and relationships?**	☐	☐	☐	☐	☐
6. **In general, how would you rate how well you carry out your usual social activities and roles? (This includes activities at home, at work, and in your community, and responsibilities as a parent, child, spouse, employee, friend, etc.)**	☐	☐	☐	☐	☐

	Not at all	A little	Moderately	Mostly	Completely
7. **To what extent are you able to carry out your everyday physical activities such as walking, climbing stairs, carrying groceries, or moving a chair?**	☐	☐	☐	☐	☐

	Never	Rarely	Sometimes	Often	Always
8. **How often have you been bothered by emotional problems such as feeling anxious, depressed, or irritable?**	☐	☐	☐	☐	☐

Please continue on the next page ➡

	None	Mild	Moderate	Severe	Very Severe
9. **How would you rate your fatigue on average?**	☐	☐	☐	☐	☐

	0	1	2	3	4	5	6	7	8	9	10
10. **How would you rate your pain on average?**	☐ No Pain	☐	☐	☐	☐	☐	☐	☐	☐	☐	☐ Worst imaginable pain

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Below is a list of difficulties people sometimes have after stressful life events. Please read each item and then indicate how distressing each difficulty has been for you **during the past 7 days** with respect to your child being in the PICU.

How much were you distressed or bothered by these difficulties?

	Not at all	A little bit	Moderately	Quite a bit	Extremely
1. **Any reminder brought back feelings about it.**	☐	☐	☐	☐	☐
2. **I had trouble staying asleep.**	☐	☐	☐	☐	☐
3. **Other things kept making me think about it.**	☐	☐	☐	☐	☐
4. **I felt irritable and angry.**	☐	☐	☐	☐	☐
5. **I avoided letting myself get upset when I thought about it or was reminded of it.**	☐	☐	☐	☐	☐
6. **I thought about it when I didn't mean to.**	☐	☐	☐	☐	☐
7. **I felt as if it hadn't happened or wasn't real.**	☐	☐	☐	☐	☐
8. **I stayed away from reminders of it.**	☐	☐	☐	☐	☐
9. **Pictures about it popped into my head.**	☐	☐	☐	☐	☐
10. **I was jumpy and easily startled.**	☐	☐	☐	☐	☐
11. **I tried not to think about it.**	☐	☐	☐	☐	☐
12. **I was aware that I still had a lot of feelings about it, but I didn't deal with them.**	☐	☐	☐	☐	☐
13. **My feelings about it were kind of numb.**	☐	☐	☐	☐	☐
14. **I found myself acting or feeling like I was back at that time.**	☐	☐	☐	☐	☐

Please continue on the next page ➡

	Not at all	A little bit	Moderately	Quite a bit	Extremely
15. **I had trouble falling asleep.**	☐	☐	☐	☐	☐
16. **I had waves of strong feelings about it.**	☐	☐	☐	☐	☐
17. **I tried to remove it from my memory.**	☐	☐	☐	☐	☐
18. **I had trouble concentrating.**	☐	☐	☐	☐	☐
19. **Reminders of it caused me to have physical reactions, such as sweating, trouble breathing, nausea, or a pounding heart.**	☐	☐	☐	☐	☐
20. **I had dreams about it.**	☐	☐	☐	☐	☐
21. **I felt watchful and on-guard.**	☐	☐	☐	☐	☐
22. **I tried not to talk about it.**	☐	☐	☐	☐	☐

Thank you very much for helping us know more about how to help the patients and families in the PICU.

Please return this survey in the envelope provided.

Agradecemos su ayuda para aprender más acerca de la comunicación en la Unidad de Cuidados Intensivos Pediátricos (PICU). Esta encuesta aborda preguntas sobre su experiencia en PICU, su opinión respecto al folleto que recibió y preguntas acerca de usted. Le pedimos que la conteste y la envíe en el sobre proporcionado.

Encuesta 4 para el padre o la madre de familia

La encuesta toma aproximadamente de 30 a 45 minutos en contestarse

Fecha de hoy:

Mes XX	Día XX	Año XXXX

Elija la respuesta que **mejor** describa su experiencia.

	Inútil	**No muy útil**	**Muy útil**	**Bastante útil**	**No lo usé**
1. **¿Qué tan útil fue para usted el folleto que recibió al inicio de su estancia en PICU?**	☐	☐	☐	☐	☐

2. **Denos su opinión respecto a las partes del folleto que le parecieron útiles.**

3. **Denos su opinión acerca de las partes del folleto que no le gustaron.**

4. **¿Cómo podemos mejorar el folleto?**

Continúe en la siguiente página ➡

5. **Anote cualquier otra pregunta o comentario que tenga respecto al folleto o a su estancia en PICU:**

Continúe en la siguiente página ➡

Satisfacción del padre de familia respecto a la atención en la Unidad de Cuidados Intensivos Pediátricos (*Parent Satisfaction with Care in the Intensive Care Unit* ©)

pFS-ICU (24)

¿Cómo estamos trabajando?
Su opinión acerca de la estancia de su hijo en la Unidad de Cuidados Intensivos

Las siguientes preguntas para **USTED** abordan aspectos de la **admisión actual de su hijo en la unidad de cuidados intensivos**. Sabemos que ha habido muchos doctores, enfermeros y otro personal que ha participado en el cuidado de su hijo. Entendemos que puede haber excepciones, pero nos interesa **su opinión en general** acerca de la calidad de la atención que le estamos proporcionando. Estamos conscientes de que probablemente usted y su familia están atravesando por un momento muy difícil. Agradecemos que se tome el tiempo de darnos su opinión. Le pedimos que se tome un momento para decirnos lo que estamos haciendo bien y lo que podemos mejorar en nuestra ICU. Tenga por seguro que todas las respuestas son confidenciales. Los médicos y enfermeros que cuidan de su hijo no podrán identificar sus respuestas.

PARTE I: SATISFACCIÓN CON LA ATENCIÓN

Marque con una "X" sólo UNA de las casillas que mejor describa su opinión. Si la pregunta no corresponde a la estancia de su hijo, entonces marque "no corresponde" (N/A).

Cómo tratamos a su niño (el/la paciente):

1. **Preocupación y cuidado por parte del personal de la ICU** (la cortesía, respeto y compasión que se le dio a su niño [el/la paciente])

Excelente	Muy bien	Bien	Aceptable	Mal	N/A
☐	☐	☐	☐	☐	☐

Manejo de síntomas (qué tan bien evaluó y trató el personal de la ICU los síntomas de su niño):

2. **Dolor**

Excelente	Muy bien	Bien	Aceptable	Mal	N/A
☐	☐	☐	☐	☐	☐

3. **Dificultad al respirar**

Excelente	Muy bien	Bien	Aceptable	Mal	N/A
☐	☐	☐	☐	☐	☐

4. **Inquietud**

Excelente	Muy bien	Bien	Aceptable	Mal	N/A
☐	☐	☐	☐	☐	☐

Continúe en la siguiente página ➡

¿Cómo lo tratamos a usted?

5. **Tomar en cuenta sus necesidades** (qué tan bien mostró interés el personal de la ICU en las necesidades de usted):

Excelente	Muy bien	Bien	Aceptable	Mal	N/A
☐	☐	☐	☐	☐	☐

6. **Apoyo emocional** (qué tan bien le proporcionó apoyo emocional el personal de la ICU):

Excelente	Muy bien	Bien	Aceptable	Mal	N/A
☐	☐	☐	☐	☐	☐

7. **Coordinación del cuidado** (el trabajo de equipo de todo el personal de la ICU que cuidó a su niño):

Excelente	Muy bien	Bien	Aceptable	Mal	N/A
☐	☐	☐	☐	☐	☐

8. **Preocupación y cuidado por parte del personal de la ICU** (la cortesía, respeto y compasión que le fueron proporcionados a usted):

Excelente	Muy bien	Bien	Aceptable	Mal	N/A
☐	☐	☐	☐	☐	☐

ENFERMERAS

9. **Destreza y capacidad de las enfermeras de la ICU** (qué tan bien cuidan las enfermeras a su niño):

Excelente	Muy bien	Bien	Aceptable	Mal	N/A
☐	☐	☐	☐	☐	☐

10. **Frecuencia de comunicación con las enfermeras de la ICU** (qué tan frecuentemente se comunicaron con usted las enfermeras de la ICU en relación con la condición de su niño):

Excelente	Muy bien	Bien	Aceptable	Mal	N/A
☐	☐	☐	☐	☐	☐

MÉDICOS (todos los médicos, incluyendo residentes e internos)

11. **Destreza y capacidad de los médicos de la ICU** (qué tan bien cuidaron los médicos a su niño):

Excelente	Muy bien	Bien	Aceptable	Mal	N/A
☐	☐	☐	☐	☐	☐

Continúe en la siguiente página ➡

LA ICU

12. **¿Cómo fue el ambiente de la ICU?**

Excelente	Muy bien	Bien	Aceptable	Mal	N/A
☐	☐	☐	☐	☐	☐

LA SALA DE ESPERA

13. **¿Cómo fue el ambiente en la sala de espera de la ICU?**

Excelente	Muy bien	Bien	Aceptable	Mal	N/A
☐	☐	☐	☐	☐	☐

14. **A algunas personas les gusta que se haga todo en relación con sus problemas de salud, mientras que a otras no les gusta que se haga mucho. ¿Qué tan satisfecho estuvo usted con el nivel o cantidad de cuidados de la salud que recibió su niño en la ICU?**

☐ muy insatisfecho
☐ un poco insatisfecho
☐ generalmente satisfecho
☐ muy satisfecho
☐ completamente satisfecho

Continúe en la siguiente página ➡

PARTE 2: SATISFACCIÓN DEL PADRE O MADRE DE FAMILIA, PERSONA A CARGO DEL PACIENTE O TUTOR CON LA TOMA DE DECISIONES RESPECTO A LA ATENCIÓN QUE RECIBEN LOS PACIENTES EN ESTADO CRÍTICO

Esta parte del cuestionario está diseñada para medir cómo se siente sobre SU participación en las decisiones relacionadas con la atención médica de su hijo. En la Unidad de Cuidados Intensivos (ICU), su hijo fue atendido por diferentes personas. Queremos que al contestar estas preguntas piense en toda la atención que ha recibido su hijo.
Marque con una “X” sólo UNA de las casillas que mejor describa su opinión.

NECESIDADES DE INFORMACIÓN

15. **Frecuencia de la comunicación con los médicos de la ICU** (qué tan frecuentemente se comunicaron con usted los médicos de la ICU en relación con la condición de su niño):

Excelente	Muy bien	Bien	Aceptable	Mal	N/A
☐	☐	☐	☐	☐	☐

16. **Facilidad para obtener información** (buena disposición del personal de la ICU para responder a sus preguntas):

Excelente	Muy bien	Bien	Aceptable	Mal	N/A
☐	☐	☐	☐	☐	☐

17. **Comprensión de la información** (qué tan bien le proporcionó el personal de la ICU explicaciones que usted comprendió):

Excelente	Muy bien	Bien	Aceptable	Mal	N/A
☐	☐	☐	☐	☐	☐

18. **Honestidad de la información** (la honestidad de la información que le fue proporcionada a usted respecto de la condición de su niño):

Excelente	Muy bien	Bien	Aceptable	Mal	N/A
☐	☐	☐	☐	☐	☐

19. **Totalidad/Integridad de la información** (qué tan bien le informo a usted el personal de la ICU sobre lo que estaba sucediendo con su niño y la razón por la que se estaban haciendo las cosas):

Excelente	Muy bien	Bien	Aceptable	Mal	N/A
☐	☐	☐	☐	☐	☐

20. **Consistencia de la información** (la consistencia de la información que le fue proporcionada a usted respecto a la condición de su niño – obtuvo usted información similar por parte del médico, enfermera, etc.):

Excelente	Muy bien	Bien	Aceptable	Mal	N/A
☐	☐	☐	☐	☐	☐

Continúe en la siguiente página ➡

¿Cómo estamos trabajando?
Su opinión acerca de la estancia de su hijo en la Unidad de Cuidados Intensivos

PROCESO DE TOMA DE DECISIONES

Durante la estancia de su niño en la ICU, se toman muchas decisiones importantes respecto del cuidado de la salud que él o ella recibe. En las siguientes preguntas, elija **una** respuesta del siguiente grupo de ideas que mejor se ajuste a sus puntos de vista:

21. **¿Se sintió usted incluido en el proceso de toma de decisiones?**
    - ☐ Me sentí muy excluido
    - ☐ Me sentí un poco excluido
    - ☐ No me sentí ni incluido ni excluido en el proceso de toma de decisiones
    - ☐ Me sentí un poco incluido
    - ☐ Me sentí muy incluido

22. **¿Se sintió usted apoyado durante el proceso de toma de decisiones?**
    - ☐ Me sentí totalmente agobiado
    - ☐ Me sentí un poco agobiado
    - ☐ No me sentí ni agobiado ni apoyado
    - ☐ Me sentí apoyado
    - ☐ Me sentí muy apoyado

23. **¿Sintió usted que tenía control sobre el cuidado de su niño?**
    - ☐ Realmente sentí que no tenía control y que el sistema de cuidados de la salud asumió el control y ordenó el cuidado que mi niño recibió
    - ☐ Sentí un poco que no tenía control y que el sistema de cuidados de la salud asumió el control y ordenó el cuidado que mi niño recibió
    - ☐ No sentí que no tuviera control ni que tuviera control
    - ☐ Sentí que tenía algo de control sobre el cuidado que mi niño recibió
    - ☐ Sentí que tenía buen control sobre el cuidado que mi niño recibió

24. **Al tomar decisiones, ¿tuvo usted el tiempo suficiente para tratar sus inquietudes y que le respondieran sus preguntas?**
    - ☐ Podría haber utilizado más tiempo
    - ☐ Tuve el tiempo suficiente

Continúe en la siguiente página ➡

Las siguientes preguntas están relacionadas a las decisiones tomadas respecto a su hijo. Encierre en un círculo el número que mejor represente su opinión respecto al proceso del equipo.

1. **Los miembros del equipo planearon en conjunto tomar las decisiones respecto a la atención de su hijo.**

1	2	3	4	5	6	7
Completamente en desacuerdo						Completamente de acuerdo

2. **Los miembros del equipo tuvieron una comunicación abierta entre ellos al tomar las decisiones para su hijo.**

1	2	3	4	5	6	7
Completamente en desacuerdo						Completamente de acuerdo

3. **La responsabilidad de la toma de decisiones para su hijo se compartió entre los miembros del equipo.**

1	2	3	4	5	6	7
Completamente en desacuerdo						Completamente de acuerdo

4. **Los miembros del equipo colaboraron juntos en la toma de decisiones.**

1	2	3	4	5	6	7
Completamente en desacuerdo						Completamente de acuerdo

5. **En el proceso de la toma de decisiones, se tomaron en cuenta las inquietudes de todos los miembros del equipo respecto a las necesidades de hijo.**

1	2	3	4	5	6	7
Completamente en desacuerdo						Completamente de acuerdo

6. **La toma de decisiones para su hijo se coordinó entre los miembros del equipo.**

1	2	3	4	5	6	7
Completamente en desacuerdo						Completamente de acuerdo

7. **¿Qué tanto colaboraron los miembros del equipo en la toma de decisiones para su hijo?**

1	2	3	4	5	6	7
No colaboraron						Colaboraron completamente

8. **¿Qué tan satisfecho está usted con la forma en que se tomaron las decisiones para su hijo? Esto se refiere al proceso de toma de decisiones, no necesariamente a las decisiones mismas.**

1	2	3	4	5	6	7
Nada satisfecho						Muy satisfecho

9. **¿Qué tan satisfecho estuvo usted con las decisiones que se tomaron para su hijo?**

1	2	3	4	5	6	7
Nada satisfecho						Muy satisfecho

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Continúe en la siguiente página ➡

Las siguientes preguntas tratan acerca de la toma de decisiones en PICU.

1. **Describa la decisión MÁS IMPORTANTE que tomó para su hijo mientras se encontraba en PICU:**

Para contestar las siguientes preguntas, piense en la decisión que acaba de anotar. Después, marque con una "X", sólo UNA casilla por fila que mejor describa sus sentimientos actuales respecto a esta decisión.

	Completa-mente de acuerdo	**De acuerdo**	**Ni de acuerdo ni en desacuerdo**	**En desacuerdo**	**Completa-mente en desacuerdo**
2. **Fue la decisión correcta**	☐	☐	☐	☐	☐
3. **Me arrepiento de la decisión que se tomó**	☐	☐	☐	☐	☐
4. **Si tuviera que volver a hacerlo, tomaría la misma decisión**	☐	☐	☐	☐	☐
5. **La decisión lastimó mucho a mi hijo(a)**	☐	☐	☐	☐	☐
6. **La decisión fue muy sabia**	☐	☐	☐	☐	☐

Continúe en la siguiente página ➡

Responda a cada afirmación marcando sólo una respuesta ("x") por fila.

<u>En los últimos 7 días...</u>

	Nunca	Rara vez	Algunas veces	A menudo	Siempre
1. **Senti que no valia nada**	☐	☐	☐	☐	☐
2. **Me senti indefenso/a (que no podia hacer nada para ayudarme)**	☐	☐	☐	☐	☐
3. **Me sentí deprimido/a**	☐	☐	☐	☐	☐
4. **Me sentí desesperanzado/a**	☐	☐	☐	☐	☐
5. **Me sentí fracasado/a**	☐	☐	☐	☐	☐
6. **Me sentí descontento/a**	☐	☐	☐	☐	☐
7. **Sentí que nada me ilusionaba**	☐	☐	☐	☐	☐
8. **Sentí que nada me podía animar**	☐	☐	☐	☐	☐

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Responda a cada afirmación marcando sólo una respuesta ("x") por fila.

En los últimos 7 días...

	Nunca	Rara vez	Algunas veces	A menudo	Siempre
1. **Sentí miedo**	☐	☐	☐	☐	☐
2. **Tuve dificultad para concentrarme en otra cosa que no fuera mi ansiedad**	☐	☐	☐	☐	☐
3. **Mis inquietudes fueron demasiado para mi**	☐	☐	☐	☐	☐
4. **Me sentí intranquilo/a**	☐	☐	☐	☐	☐
5. **Me sentí nervioso/a**	☐	☐	☐	☐	☐
6. **Sentí que necesitaba ayuda para controlar mi ansiedad.**	☐	☐	☐	☐	☐
7. **Sentí ansiedad**	☐	☐	☐	☐	☐
8. **Me sentí tenso/a**	☐	☐	☐	☐	☐

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Responda a cada afirmación marcando sólo una respuesta ("x") por fila.

	Mala	Pasable	Buena	Muy buena	Excelente
1. **En general, diría que su salud es**	☐	☐	☐	☐	☐
2. **En general, diría que su calidad de vida es**	☐	☐	☐	☐	☐
3. **En general, ¿cómo calificaría su salud física?**	☐	☐	☐	☐	☐
4. **En general, ¿cómo calificaría su salud mental, incluidos su estado de ánimo y su capacidad para pensar?**	☐	☐	☐	☐	☐
5. **En general, ¿cómo calificaría su satisfacción con sus actividades sociales y sus relaciones con otras personas?**	☐	☐	☐	☐	☐
6. **En general, califique en qué medida puede realizar sus actividades sociales y funciones habituales. (Esto comprende las actividades en casa, en el trabajo y en el área donde reside, así como sus responsabilidades como padre o madre, hijo/a, cónyuge, empleado/a, amigo/a, etc.)**	☐	☐	☐	☐	☐

	Para nada	Un poco	Moderada-mente	En su mayoría	Completame-nte
7. **¿En qué medida puede realizar sus actividades físicas diarias, como caminar, subir escaleras, cargar las compras o mover una silla?**	☐	☐	☐	☐	☐

	Nunca	Rara vez	Algunas veces	A menudo	Siempre
8. **¿Con qué frecuencia le han afectado problemas emocionales como sentir ansiedad, depresión o irritabilidad ?**	☐	☐	☐	☐	☐

Continúe en la siguiente página ➡

	Ninguno	Leve	Moderado	Intenso	Muy intenso
9. **En promedio, ¿cómo calificaría su cansancio?**	☐	☐	☐	☐	☐

	0	1	2	3	4	5	6	7	8	9	10
10. En promedio, ¿cómo calificaría su dolor ?	☐ **Ningún dolor**	☐	☐	☐	☐	☐	☐	☐	☐	☐	☐ **El peor dolor imaginable**

Continúe en la siguiente página ➡

A continuación se encuentra una lista dificultades que en ocasiones presentan algunas personas después de un suceso estresante en su vida. Lea cada declaración y después indique que tan estresante ha sido para usted cada dificultad presentada **durante los últimos 7 días**, con respecto a la hospitalización de su hijo en PICU.

¿Qué tanto le estresaron o molestaron estas dificultades?

	Para nada	Un poco	Moderada-mente	Bastante	Demasiado
1. **Todo lo que le trajo recuerdos y le hizo revivir sus sentimientos.**	☐	☐	☐	☐	☐
2. **Tuve dificultades para mantenerme dormido.**	☐	☐	☐	☐	☐
3. **Otras cosas me lo recordaban constantemente.**	☐	☐	☐	☐	☐
4. **Me sentí irritable y enojado.**	☐	☐	☐	☐	☐
5. **Evitaba molestarme cuando pensaba en ello o algo me lo recordaba.**	☐	☐	☐	☐	☐
6. **Pensaba en ello sin quererlo.**	☐	☐	☐	☐	☐
7. **Sentí como si no hubiera pasado o no hubiera sido real.**	☐	☐	☐	☐	☐
8. **Me alejé de lo que me hacía recordarlo.**	☐	☐	☐	☐	☐
9. **Imágenes sobre ello me venían a la cabeza.**	☐	☐	☐	☐	☐
10. **Estaba nervioso y me sorprendía fácilmente.**	☐	☐	☐	☐	☐
11. **Trataba de no pensar en ello.**	☐	☐	☐	☐	☐
12. **Estaba consciente de que todavía tenía muchos sentimientos, pero no hice nada al respecto.**	☐	☐	☐	☐	☐
13. **Estaba insensible a ello.**	☐	☐	☐	☐	☐
14. **Me encontré actuando y sintiendo que estaba de regreso en ese momento.**	☐	☐	☐	☐	☐

	Para nada	Un poco	Moderada-mente	Bastante	Demasiado
15. **Tuve dificultades para conciliar el sueño**	☐	☐	☐	☐	☐
16. **Tenía oleadas de sentimientos intensos al respecto.**	☐	☐	☐	☐	☐
17. **Trate de eliminarlo de mi memoria.**	☐	☐	☐	☐	☐
18. **Tenía dificultades para concentrarme.**	☐	☐	☐	☐	☐
19. **Los recordatorios me causaron reacciones físicas, como sudoración, dificultad para respirar, náusea o palpitaciones.**	☐	☐	☐	☐	☐
20. **Tenía sueños sobre ello.**	☐	☐	☐	☐	☐
21. **Me sentía vigilante y en guardia.**	☐	☐	☐	☐	☐
22. **Trataba de no hablar de ello.**	☐	☐	☐	☐	☐

Gracias por permitirnos aprender más acerca de cómo podemos ayudar a los pacientes y sus familias en PICU.

Envíe esta encuesta en el sobre proporcionado.

PICU SUPPORTS

Thank you for helping us know more about communication in the pediatric intensive care unit (PICU). This survey asks you for information about your experience in the PICU, about your reactions to the PICU Supports program, and about yourself. Please complete this survey and return it in the envelope provided.

Parent Survey 4

This survey takes approximately 30-45 minutes to complete

Today's date is:

Month XX	Day XX	Year XXXX

The following questions ask you to rate various aspects of the PICU Supports program. Please select the answer that **best** reflects your experience.

	Not at All Helpful	Not Very Helpful	Somewhat Helpful	Extremely Helpful	Unable to Assess
1. **How well did PICU Supports help with communication in the PICU?**	☐	☐	☐	☐	☐

During your child's stay in the PICU, did PICU Supports have a positive impact on:

	Yes	No
2. The quality of communication between you and the healthcare team?	☐	☐
3. The quality of communication within the healthcare team (how healthcare team members communicated with each other)?	☐	☐
4. The timeliness of communication between you and the healthcare team?	☐	☐
5. Your conversations with the healthcare team about your values and preferences for your child's care?	☐	☐
6. Your hospital experience?	☐	☐
7. The family-centeredness of care delivered?	☐	☐

Please continue on the next page ➡

In your view, how useful were the following parts of PICU Supports:

	Useless	**Not Very Useful**	**Very Useful**	**Extremely Useful**	**Did Not Use**
8. The Navigator's weekday visits with you.	☐	☐	☐	☐	☐
9. The communication log kept at your child's bedside.	☐	☐	☐	☐	☐
10. The regular family meetings organized by the navigator.	☐	☐	☐	☐	☐
11. The PICU Handbook that you received.	☐	☐	☐	☐	☐
12. The list of questions in the section of the PICU Handbook called "What are some questions you might want to ask?"	☐	☐	☐	☐	☐
13. The calendar/diary in the back of the PICU Handbook.	☐	☐	☐	☐	☐
14. Any informational/educational materials given to you.	☐	☐	☐	☐	☐

15. **Please comment on any parts of PICU Supports that you found useful.**

Please continue on the next page ➡

16. **Please comment on any parts of PICU Supports that you did not like.**

17. **How might we improve PICU Supports?**

18. **Please tell us any other questions/comments you have about PICU Supports or being in the PICU?**

Please continue on the next page ➡

Parent Satisfaction with Care in the Intensive Care Unit ©
pFS-ICU (24)

How are we doing?
Your opinions about your child's ICU stay

The questions that follow ask **YOU** about your child's **current ICU admission**. We understand that there have been 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 are delivering. We understand that this is probably a very difficult time for you and your family. We would appreciate you taking the time to provide us with your opinions. Please take a moment to tell us what we are doing well and what we can do to make our ICU better. Please be assured that all responses are confidential. The doctors and nurses who are looking after your child will not be able to identify your response.

PART I : SATISFACTION WITH CARE

Please mark an "X" in the ONE box that best describes your feelings. If the question does not apply to your child's stay then please mark "not applicable" (N/A).

How did we treat your child (the patient)?

1. **Concern and caring by the ICU staff** (the courtesy, respect, and compassion your child [the patient] was given)

Excellent	Very good	Good	Fair	Poor	N/A
☐	☐	☐	☐	☐	☐

Symptoms management (how well the ICU staff assessed and treated your child's symptoms):

2. **Pain**

Excellent	Very good	Good	Fair	Poor	N/A
☐	☐	☐	☐	☐	☐

3. **Breathlessness**

Excellent	Very good	Good	Fair	Poor	N/A
☐	☐	☐	☐	☐	☐

4. **Agitation**

Excellent	Very good	Good	Fair	Poor	N/A
☐	☐	☐	☐	☐	☐

Please continue on the next page ➡

How did we treat you?

5. **Consideration of your needs** (how well the ICU staff showed an interest in your needs):

Excellent	Very good	Good	Fair	Poor	N/A
☐	☐	☐	☐	☐	☐

6. **Emotional support** (how well the ICU staff provided emotional support):

Excellent	Very good	Good	Fair	Poor	N/A
☐	☐	☐	☐	☐	☐

7. **Coordination of care** (the teamwork of all the ICU staff who took care of your child):

Excellent	Very good	Good	Fair	Poor	N/A
☐	☐	☐	☐	☐	☐

8. **Concern and caring by ICU staff** (the courtesy, respect, and compassion you were given):

Excellent	Very good	Good	Fair	Poor	N/A
☐	☐	☐	☐	☐	☐

Nurses

9. **Skill and competence of ICU nurses** (how well the nurses cared for your child):

Excellent	Very good	Good	Fair	Poor	N/A
☐	☐	☐	☐	☐	☐

10. **Frequency of communication with ICU nurses** (how often nurses communicated to you about your child's condition):

Excellent	Very good	Good	Fair	Poor	N/A
☐	☐	☐	☐	☐	☐

Physicians (all doctors, including residents and fellows)

11. **Skill and competence of ICU doctors (how well doctors cared for your child):**

Excellent	Very good	Good	Fair	Poor	N/A
☐	☐	☐	☐	☐	☐

Please continue on the next page ➡

The ICU

12. **Atmosphere of ICU was?**

Excellent	Very good	Good	Fair	Poor	N/A
☐	☐	☐	☐	☐	☐

The Waiting Room

13. **The atmosphere in the ICU waiting room was?**

Excellent	Very good	Good	Fair	Poor	N/A
☐	☐	☐	☐	☐	☐

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 or amount of health care your child received in the ICU.**

☐ Very dissatisfied
☐ Slightly dissatisfied
☐ Mostly satisfied
☐ Very satisfied
☐ Completely satisfied

Please continue on the next page ➡

PART 2: PARENT, CAREGIVER, OR GUARDIAN SATISFACTION WITH DECISION-MAKING AROUND CARE 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 Intensive Care Unit (ICU), your child may receive care from different people. We would like you to think about all the care your child has received when you are answering the questions.
Please mark an "X" in the ONE box that best describes your feelings.

INFORMATION NEEDS

15. **Frequency of communication with ICU doctors** (how often doctors communicated to you about your child's condition):

Excellent	Very good	Good	Fair	Poor	N/A
☐	☐	☐	☐	☐	☐

16. **Ease of getting information** (willingness of ICU staff to answer your questions):

Excellent	Very good	Good	Fair	Poor	N/A
☐	☐	☐	☐	☐	☐

17. **Understanding of information** (how well ICU staff provided you with explanations that you understood):

Excellent	Very good	Good	Fair	Poor	N/A
☐	☐	☐	☐	☐	☐

18. **Honesty of information** (the honesty of information provided to you about your child's condition):

Excellent	Very good	Good	Fair	Poor	N/A
☐	☐	☐	☐	☐	☐

19. **Completeness of information** (how well ICU staff informed you what was happening to your child and why things were being done):

Excellent	Very good	Good	Fair	Poor	N/A
☐	☐	☐	☐	☐	☐

20. **Consistency of information** (the consistency of information provided to you about your child's condition – did you get a similar story from the doctor, nurse, etc.):

Excellent	Very good	Good	Fair	Poor	N/A
☐	☐	☐	☐	☐	☐

Please continue on the next page ➡

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 are made regarding the health care she or he receives. From the following questions, pick **one** answer from each of the following set of ideas that best matches your views:

21. **Did you feel included in the decision making process?**
    - ☐ I felt very excluded
    - ☐ I felt somewhat excluded
    - ☐ I felt neither included nor excluded from the decision making process
    - ☐ I felt somewhat included
    - ☐ I felt very included

22. **Did you feel supported during the decision making process?**
    - ☐ I felt totally unsupported
    - ☐ I felt slightly unsupported
    - ☐ I felt neither supported nor unsupported
    - ☐ I felt supported
    - ☐ I felt very supported

23. **Did you feel you had control over the care of your child?**
    - ☐ I felt really out of control and that the health care system took over and dictated the care my child received
    - ☐ I felt somewhat out of control and that the health care system took over and dictated the care my child received
    - ☐ I felt neither in control nor out of control
    - ☐ I felt I had some control over the care my child received
    - ☐ 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?**
    - ☐ I could have used more time
    - ☐ I had adequate time

Please continue on the next page ➡

The following questions are related to team collaboration during decision making for your child. Please circle the number that best represents your judgment about the team process.

1. **Team members planned together to make decisions about care for your child.**

1	2	3	4	5	6	7
Strongly Disagree						Strongly Agree

2. **Open communication between team members took place as decisions were made for your child.**

1	2	3	4	5	6	7
Strongly Disagree						Strongly Agree

3. **Decision-making responsibilities for your child were shared among team members.**

1	2	3	4	5	6	7
Strongly Disagree						Strongly Agree

4. **Team members cooperated in making decisions.**

1	2	3	4	5	6	7
Strongly Disagree						Strongly Agree

5. **In making decisions, all team members' concerns about your child's need were considered.**

1	2	3	4	5	6	7
Strongly Disagree						Strongly Agree

6. **Decision-making for your child was coordinated among team members.**

1	2	3	4	5	6	7
Strongly Disagree						Strongly Agree

7. **How much collaboration among team members occurred in making decisions for your child?**

1	2	3	4	5	6	7
No Collaboration						Complete Collaboration

8. **How satisfied are you with the way decisions were made for your child? That is with the decision-making process, not necessarily with the decision itself.**

1	2	3	4	5	6	7
Not Satisfied						Very Satisfied

9. **How satisfied were you with decisions made for your child?**

1	2	3	4	5	6	7
Not Satisfied						Very Satisfied

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Please continue on the next page

The following questions are about decision making in the PICU.

1. **Please write down the MOST important decision made for your child while he/she was in the PICU.**

For the following questions, please think about the decision you have identified above. Then, please mark an "X" in the ONE box per row that best describes your feelings now about this decision.

	Strongly Agree	Agree	Neither Agree Nor Disagree	Disagree	Strongly Disagree
2. **It was the right decision.**	☐	☐	☐	☐	☐
3. **I regret the choice that was made.**	☐	☐	☐	☐	☐
4. **I would go for the same choice if I had to do it over again.**	☐	☐	☐	☐	☐
5. **The choice did my child a lot of harm.**	☐	☐	☐	☐	☐
6. **The decision was a wise one.**	☐	☐	☐	☐	☐

Please continue on the next page ⇨

Please respond to each statement by marking an “X” in one box per row.

<u>In the past 7 days</u>…

	Never	Rarely	Sometimes	Often	Always
1. **I felt worthless.**	☐	☐	☐	☐	☐
2. **I felt helpless.**	☐	☐	☐	☐	☐
3. **I felt depressed.**	☐	☐	☐	☐	☐
4. **I felt hopeless.**	☐	☐	☐	☐	☐
5. **I felt like a failure.**	☐	☐	☐	☐	☐
6. **I felt unhappy.**	☐	☐	☐	☐	☐
7. **I felt that I had nothing to look forward to.**	☐	☐	☐	☐	☐
8. **I felt that nothing could cheer me up.**	☐	☐	☐	☐	☐

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Please continue on the next page ➡

Please respond to each statement by marking an "X" in one box per row.

In the past 7 days…

	Never	Rarely	Sometimes	Often	Always
1. **I felt fearful.**	☐	☐	☐	☐	☐
2. **I found it hard to focus on anything other than my anxiety.**	☐	☐	☐	☐	☐
3. **My worries overwhelmed me.**	☐	☐	☐	☐	☐
4. **I felt uneasy.**	☐	☐	☐	☐	☐
5. **I felt nervous.**	☐	☐	☐	☐	☐
6. **I felt like I needed help for my anxiety.**	☐	☐	☐	☐	☐
7. **I felt anxious.**	☐	☐	☐	☐	☐
8. **I felt tense.**	☐	☐	☐	☐	☐

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Please respond to each statement by marking an "X" in one box per row.

Please continue on the next page ➡

	Poor	Fair	Good	Very Good	Excellent
1. **In general, would you say your health is:**	☐	☐	☐	☐	☐
2. **In general, would you say your quality of life is:**	☐	☐	☐	☐	☐
3. **In general, how would you rate your physical health?**	☐	☐	☐	☐	☐
4. **In general, how would you rate your mental health, including your mood and your ability to think?**	☐	☐	☐	☐	☐
5. **In general, how would you rate you satisfaction with your social activities and relationships?**	☐	☐	☐	☐	☐
6. **In general, how would you rate how well you carry out your usual social activities and roles? (This includes activities at home, at work, and in your community, and responsibilities as a parent, child, spouse, employee, friend, etc.)**	☐	☐	☐	☐	☐

	Not at all	A little	Moderately	Mostly	Completely
7. **To what extent are you able to carry out your everyday physical activities such as walking, climbing stairs, carrying groceries, or moving a chair?**	☐	☐	☐	☐	☐

	Never	Rarely	Sometimes	Often	Always
8. **How often have you been bothered by emotional problems such as feeling anxious, depressed, or irritable?**	☐	☐	☐	☐	☐

Please continue on the next page ➡

	None	**Mild**	**Moderate**	**Severe**	**Very Severe**
9. **How would you rate your fatigue on average?**	☐	☐	☐	☐	☐

	0	**1**	**2**	**3**	**4**	**5**	**6**	**7**	**8**	**9**	**10**
10. **How would you rate your pain on average?**	☐ No Pain	☐	☐	☐	☐	☐	☐	☐	☐	☐	☐ Worst imaginable pain

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Please continue on the next page ➡

Below is a list of difficulties people sometimes have after stressful life events. Please read each item and then indicate how distressing each difficulty has been for you **during the past 7 days** with respect to your child being in the PICU.

How much were you distressed or bothered by these difficulties?

	Not at all	**A little bit**	**Moderately**	**Quite a bit**	**Extremely**
1. **Any reminder brought back feelings about it.**	☐	☐	☐	☐	☐
2. **I had trouble staying asleep.**	☐	☐	☐	☐	☐
3. **Other things kept making me think about it.**	☐	☐	☐	☐	☐
4. **I felt irritable and angry.**	☐	☐	☐	☐	☐
5. **I avoided letting myself get upset when I thought about it or was reminded of it.**	☐	☐	☐	☐	☐
6. **I thought about it when I didn't mean to.**	☐	☐	☐	☐	☐
7. **I felt as if it hadn't happened or wasn't real.**	☐	☐	☐	☐	☐
8. **I stayed away from reminders of it.**	☐	☐	☐	☐	☐
9. **Pictures about it popped into my head.**	☐	☐	☐	☐	☐
10. **I was jumpy and easily startled.**	☐	☐	☐	☐	☐
11. **I tried not to think about it.**	☐	☐	☐	☐	☐
12. **I was aware that I still had a lot of feelings about it, but I didn't deal with them.**	☐	☐	☐	☐	☐
13. **My feelings about it were kind of numb.**	☐	☐	☐	☐	☐
14. **I found myself acting or feeling like I was back at that time.**	☐	☐	☐	☐	☐

Please continue on the next page ➡

	Not at all	A little bit	Moderately	Quite a bit	Extremely
15. **I had trouble falling asleep.**	☐	☐	☐	☐	☐
16. **I had waves of strong feelings about it.**	☐	☐	☐	☐	☐
17. **I tried to remove it from my memory.**	☐	☐	☐	☐	☐
18. **I had trouble concentrating.**	☐	☐	☐	☐	☐
19. **Reminders of it caused me to have physical reactions, such as sweating, trouble breathing, nausea, or a pounding heart.**	☐	☐	☐	☐	☐
20. **I had dreams about it.**	☐	☐	☐	☐	☐
21. **I felt watchful and on-guard.**	☐	☐	☐	☐	☐
22. **I tried not to talk about it.**	☐	☐	☐	☐	☐

Thank you very much for helping us know more about how to help the patients and families in the PICU.

Please return this survey in the envelope provided.

PICU SUPPORTS

Agradecemos su ayuda para aprender más acerca de la comunicación en la Unidad de Cuidados Intensivos Pediátricos (PICU). Esta encuesta aborda preguntas acerca de su experiencia en PICU, sus reacciones respecto al programa PICU Supports y acerca de usted. Le pedimos que la conteste y la envíe en el sobre proporcionado.

Encuesta 4 para el padre o la madre de familia

La encuesta toma aproximadamente de 30 a 45 minutos en contestarse

Fecha de hoy:

Mes XX	Día XX	Año XXXX

Las siguientes preguntas le piden calificar varios aspectos del programa PICU Supports. Elija la respuesta que **mejor** describa su experiencia.

	No fue útil en lo absoluto	**No fue muy útil**	**Fue un poco útil**	**Increíble mente útil**	**No lo puedo evaluar**
1. **¿Qué tan útil fue PICU Supports respecto a la comunicación en la unidad?**	☐	☐	☐	☐	☐

Durante la estancia de su hijo en PICU, el programa PICU Supports tuvo in impacto positivo en:

	Sí	**No**
2. La calidad de la comunicación entre usted y el equipo médico	☐	☐
3. La calidad de la comunicación entre el equipo médico (cómo se comunican los miembros entre ellos)	☐	☐
4. La calidad de la comunicación entre usted y el equipo médico	☐	☐
5. Sus conversaciones con el equipo médico acerca de los valores y preferencias respecto a la atención médica de su hijo.	☐	☐
6. Su experiencia en el hospital	☐	☐
7. La posición de la familia respecto a la atención recibida (la atención debe centrarse en la familia)	☐	☐

Continúe en la siguiente página ➡

Desde su punto de vista, ¿qué tan útiles fueron las siguientes partes de PICU Supports?:

	Inútil	**No muy útil**	**Muy útil**	**Extremadamente útil**	**No lo utilicé**
8. Las visitas del Navegador durante la semana	☐	☐	☐	☐	☐
9. El diario de comunicación en la habitación de su hijo.	☐	☐	☐	☐	☐
10. Las reuniones familiares que coordinó regularmente el navegador.	☐	☐	☐	☐	☐
11. El Manual de PICU que usted recibió.	☐	☐	☐	☐	☐
12. La lista de preguntas en la sección del Manual de PICU, llamada “¿Cuáles son algunas preguntas que le gustaría hacer?”	☐	☐	☐	☐	☐
13. El calendario o diario al final del Manual PICU.	☐	☐	☐	☐	☐
14. Todo material informativo o educativo que se le entregó.	☐	☐	☐	☐	☐

15. **Haga un comentario acerca de las partes de PICU Support que le parecieron útiles.**

Continúe en la siguiente página ➡

16. **Haga un comentario acerca de las partes de PICU Support que no le gustaron.**

17. **¿Cómo podríamos mejorar PICU Supports?**

18. **¿Tienen alguna otra pregunta o comentario?**

Continúe en la siguiente página ➡

Satisfacción del padre de familia respecto a la atención en la Unidad de Cuidados Intensivos Pediátricos (*Parent Satisfaction with Care in the Intensive Care Unit* ©)

pFS-ICU (24)

¿Cómo estamos trabajando?
Su opinión acerca de la estancia de su hijo en la Unidad de Cuidados Intensivos

Las siguientes preguntas para **USTED** abordan aspectos de la **admisión actual de su hijo en la unidad de cuidados intensivos**. Sabemos que ha habido muchos doctores, enfermeros y otro personal que ha participado en el cuidado de su hijo. Entendemos que puede haber excepciones, pero nos interesa **su opinión en general** acerca de la calidad de la atención que le estamos proporcionando. Estamos conscientes de que probablemente usted y su familia están atravesando por un momento muy difícil. Agradecemos que se tome el tiempo de darnos su opinión. Le pedimos que se tome un momento para decirnos lo que estamos haciendo bien y lo que podemos mejorar en nuestra ICU. Tenga por seguro que todas las respuestas son confidenciales. Los médicos y enfermeros que cuidan de su hijo no podrán identificar sus respuestas.

PARTE I: SATISFACCIÓN CON LA ATENCIÓN

Marque con una "X" sólo UNA de las casillas que mejor describa su opinión. Si la pregunta no corresponde a la estancia de su hijo, entonces marque "no corresponde" (N/A).

Cómo tratamos a su niño (el/la paciente):

1. **Preocupación y cuidado por parte del personal de la ICU** (la cortesía, respeto y compasión que se le dio a su niño [el/la paciente])

Excelente	Muy bien	Bien	Aceptable	Mal	N/A
☐	☐	☐	☐	☐	☐

Manejo de síntomas (qué tan bien evaluó y trató el personal de la ICU los síntomas de su niño):

2. **Dolor**

Excelente	Muy bien	Bien	Aceptable	Mal	N/A
☐	☐	☐	☐	☐	☐

3. **Dificultad al respirar**

Excelente	Muy bien	Bien	Aceptable	Mal	N/A
☐	☐	☐	☐	☐	☐

4. **Inquietud**

Excelente	Muy bien	Bien	Aceptable	Mal	N/A
☐	☐	☐	☐	☐	☐

Continúe en la siguiente página ➡

¿Cómo lo tratamos a usted?

5. **Tomar en cuenta sus necesidades** (qué tan bien mostró interés el personal de la ICU en las necesidades de usted):

Excelente	Muy bien	Bien	Aceptable	Mal	N/A
☐	☐	☐	☐	☐	☐

6. **Apoyo emocional** (qué tan bien le proporcionó apoyo emocional el personal de la ICU):

Excelente	Muy bien	Bien	Aceptable	Mal	N/A
☐	☐	☐	☐	☐	☐

7. **Coordinación del cuidado** (el trabajo de equipo de todo el personal de la ICU que cuidó a su niño):

Excelente	Muy bien	Bien	Aceptable	Mal	N/A
☐	☐	☐	☐	☐	☐

8. **Preocupación y cuidado por parte del personal de la ICU** (la cortesía, respeto y compasión que le fueron proporcionados a usted):

Excelente	Muy bien	Bien	Aceptable	Mal	N/A
☐	☐	☐	☐	☐	☐

ENFERMERAS

9. **Destreza y capacidad de las enfermeras de la ICU** (qué tan bien cuidan las enfermeras a su niño):

Excelente	Muy bien	Bien	Aceptable	Mal	N/A
☐	☐	☐	☐	☐	☐

10. **Frecuencia de comunicación con las enfermeras de la ICU** (qué tan frecuentemente se comunicaron con usted las enfermeras de la ICU en relación con la condición de su niño):

Excelente	Muy bien	Bien	Aceptable	Mal	N/A
☐	☐	☐	☐	☐	☐

MÉDICOS (todos los médicos, incluyendo residentes e internos)

11. **Destreza y capacidad de los médicos de la ICU** (qué tan bien cuidaron los médicos a su niño):

Excelente	Muy bien	Bien	Aceptable	Mal	N/A
☐	☐	☐	☐	☐	☐

Continúe en la siguiente página ➡

LA ICU

12. **¿Cómo fue el ambiente de la ICU?**

Excelente	Muy bien	Bien	Aceptable	Mal	N/A
☐	☐	☐	☐	☐	☐

LA SALA DE ESPERA

13. **¿Cómo fue el ambiente en la sala de espera de la ICU?**

Excelente	Muy bien	Bien	Aceptable	Mal	N/A
☐	☐	☐	☐	☐	☐

14. **A algunas personas les gusta que se haga todo en relación con sus problemas de salud, mientras que a otras no les gusta que se haga mucho. ¿Qué tan satisfecho estuvo usted con el nivel o cantidad de cuidados de la salud que recibió su niño en la ICU?**

☐ muy insatisfecho
☐ un poco insatisfecho
☐ generalmente satisfecho
☐ muy satisfecho
☐ completamente satisfecho

Continúe en la siguiente página ➡

PARTE 2: SATISFACCIÓN DEL PADRE O MADRE DE FAMILIA, PERSONA A CARGO DEL PACIENTE O TUTOR CON LA TOMA DE DECISIONES RESPECTO A LA ATENCIÓN QUE RECIBEN LOS PACIENTES EN ESTADO CRÍTICO

Esta parte del cuestionario está diseñada para medir cómo se siente sobre SU participación en las decisiones relacionadas con la atención médica de su hijo. En la Unidad de Cuidados Intensivos (ICU), su hijo fue atendido por diferentes personas. Queremos que al contestar estas preguntas piense en toda la atención que ha recibido su hijo.

Marque con una "X" sólo UNA de las casillas que mejor describa su opinión.

NECESIDADES DE INFORMACIÓN

15. **Frecuencia de la comunicación con los médicos de la ICU** (qué tan frecuentemente se comunicaron con usted los médicos de la ICU en relación con la condición de su niño):

Excelente	Muy bien	Bien	Aceptable	Mal	N/A
☐	☐	☐	☐	☐	☐

16. **Facilidad para obtener información** (buena disposición del personal de la ICU para responder a sus preguntas):

Excelente	Muy bien	Bien	Aceptable	Mal	N/A
☐	☐	☐	☐	☐	☐

17. **Comprensión de la información** (qué tan bien le proporcionó el personal de la ICU explicaciones que usted comprendió):

Excelente	Muy bien	Bien	Aceptable	Mal	N/A
☐	☐	☐	☐	☐	☐

18. **Honestidad de la información** (la honestidad de la información que le fue proporcionada a usted respecto de la condición de su niño):

Excelente	Muy bien	Bien	Aceptable	Mal	N/A
☐	☐	☐	☐	☐	☐

19. **Totalidad/Integridad de la información** (qué tan bien le informo a usted el personal de la ICU sobre lo que estaba sucediendo con su niño y la razón por la que se estaban haciendo las cosas):

Excelente	Muy bien	Bien	Aceptable	Mal	N/A
☐	☐	☐	☐	☐	☐

20. **Consistencia de la información** (la consistencia de la información que le fue proporcionada a usted respecto a la condición de su niño – obtuvo usted información similar por parte del médico, enfermera, etc.):

Excelente	Muy bien	Bien	Aceptable	Mal	N/A
☐	☐	☐	☐	☐	☐

Continúe en la siguiente página →

¿Cómo estamos trabajando?
Su opinión acerca de la estancia de su hijo en la Unidad de Cuidados Intensivos

PROCESO DE TOMA DE DECISIONES

Durante la estancia de su niño en la ICU, se toman muchas decisiones importantes respecto del cuidado de la salud que él o ella recibe. En las siguientes preguntas, elija **una** respuesta del siguiente grupo de ideas que mejor se ajuste a sus puntos de vista:

21. **¿Se sintió usted incluido en el proceso de toma de decisiones?**
    - ☐ Me sentí muy excluido
    - ☐ Me sentí un poco excluido
    - ☐ No me sentí ni incluido ni excluido en el proceso de toma de decisiones
    - ☐ Me sentí un poco incluido
    - ☐ Me sentí muy incluido

22. **¿Se sintió usted apoyado durante el proceso de toma de decisiones?**
    - ☐ Me sentí totalmente agobiado
    - ☐ Me sentí un poco agobiado
    - ☐ No me sentí ni agobiado ni apoyado
    - ☐ Me sentí apoyado
    - ☐ Me sentí muy apoyado

23. **¿Sintió usted que tenía control sobre el cuidado de su niño?**
    - ☐ Realmente sentí que no tenía control y que el sistema de cuidados de la salud asumió el control y ordenó el cuidado que mi niño recibió
    - ☐ Sentí un poco que no tenía control y que el sistema de cuidados de la salud asumió el control y ordenó el cuidado que mi niño recibió
    - ☐ No sentí que no tuviera control ni que tuviera control
    - ☐ Sentí que tenía algo de control sobre el cuidado que mi niño recibió
    - ☐ Sentí que tenía buen control sobre el cuidado que mi niño recibió

24. **Al tomar decisiones, ¿tuvo usted el tiempo suficiente para tratar sus inquietudes y que le respondieran sus preguntas?**
    - ☐ Podría haber utilizado más tiempo
    - ☐ Tuve el tiempo suficiente

Continúe en la siguiente página ➡

Las siguientes preguntas están relacionadas a las decisiones tomadas respecto a su hijo. Encierre en un círculo el número que mejor represente su opinión respecto al proceso del equipo.

1. **Los miembros del equipo planearon en conjunto tomar las decisiones respecto a la atención de su hijo.**

1	2	3	4	5	6	7
Completamente en desacuerdo						Completamente de acuerdo

2. **Los miembros del equipo tuvieron una comunicación abierta entre ellos al tomar las decisiones para su hijo.**

1	2	3	4	5	6	7
Completamente en desacuerdo						Completamente de acuerdo

3. **La responsabilidad de la toma de decisiones para su hijo se compartió entre los miembros del equipo.**

1	2	3	4	5	6	7
Completamente en desacuerdo						Completamente de acuerdo

4. **Los miembros del equipo colaboraron juntos en la toma de decisiones.**

1	2	3	4	5	6	7
Completamente en desacuerdo						Completamente de acuerdo

5. **En el proceso de la toma de decisiones, se tomaron en cuenta las inquietudes de todos los miembros del equipo respecto a las necesidades de hijo.**

1	2	3	4	5	6	7
Completamente en desacuerdo						Completamente de acuerdo

6. **La toma de decisiones para su hijo se coordinó entre los miembros del equipo.**

1	2	3	4	5	6	7
Completamente en desacuerdo						Completamente de acuerdo

7. **¿Qué tanto colaboraron los miembros del equipo en la toma de decisiones para su hijo?**

1	2	3	4	5	6	7
No colaboraron						Colaboraron completamente

8. **¿Qué tan satisfecho está usted con la forma en que se tomaron las decisiones para su hijo? Esto se refiere al proceso de toma de decisiones, no necesariamente a las decisiones mismas.**

1	2	3	4	5	6	7
Nada satisfecho						Muy satisfecho

9. **¿Qué tan satisfecho estuvo usted con las decisiones que se tomaron para su hijo?**

1	2	3	4	5	6	7
Nada satisfecho						Muy satisfecho

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Continúe en la siguiente página

Las siguientes preguntas tratan acerca de la toma de decisiones en PICU.

1. **Describa la decisión MÁS IMPORTANTE que tomó para su hijo mientras se encontraba en PICU:**

Para contestar las siguientes preguntas, piense en la decisión que acaba de anotar. Después, marque con una "X", sólo UNA casilla por fila que mejor describa sus sentimientos actuales respecto a esta decisión.

	Completa-mente de acuerdo	**De acuerdo**	**Ni de acuerdo ni en desacuerdo**	**En desacuerdo**	**Completa-mente en desacuerdo**
2. **Fue la decisión correcta**	☐	☐	☐	☐	☐
3. **Me arrepiento de la decisión que se tomó**	☐	☐	☐	☐	☐
4. **Si tuviera que volver a hacerlo, tomaría la misma decisión**	☐	☐	☐	☐	☐
5. **La decisión lastimó mucho a mi hijo(a)**	☐	☐	☐	☐	☐
6. **La decisión fue muy sabia**	☐	☐	☐	☐	☐

Continúe en la siguiente página ➡

Responda a cada afirmación marcando sólo una respuesta ("x") por fila.

En los últimos 7 días...

	Nunca	Rara vez	Algunas veces	A menudo	Siempre
1. **Senti que no valia nada**	☐	☐	☐	☐	☐
2. **Me senti indefenso/a (que no podia hacer nada para ayudarme)**	☐	☐	☐	☐	☐
3. **Me sentí deprimido/a**	☐	☐	☐	☐	☐
4. **Me sentí desesperanzado/a**	☐	☐	☐	☐	☐
5. **Me sentí fracasado/a**	☐	☐	☐	☐	☐
6. **Me sentí descontento/a**	☐	☐	☐	☐	☐
7. **Sentí que nada me ilusionaba**	☐	☐	☐	☐	☐
8. **Sentí que nada me podía animar**	☐	☐	☐	☐	☐

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Continúe en la siguiente página ➡

Responda a cada afirmación marcando sólo una respuesta ("x") por fila.

En los últimos 7 días...

	Nunca	Rara vez	Algunas veces	A menudo	Siempre
1. **Sentí miedo**	☐	☐	☐	☐	☐
2. **Tuve dificultad para concentrarme en otra cosa que no fuera mi ansiedad**	☐	☐	☐	☐	☐
3. **Mis inquietudes fueron demasiado para mi**	☐	☐	☐	☐	☐
4. **Me sentí intranquilo/a**	☐	☐	☐	☐	☐
5. **Me sentí nervioso/a**	☐	☐	☐	☐	☐
6. **Sentí que necesitaba ayuda para controlar mi ansiedad.**	☐	☐	☐	☐	☐
7. **Sentí ansiedad**	☐	☐	☐	☐	☐
8. **Me sentí tenso/a**	☐	☐	☐	☐	☐

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Continúe en la siguiente página ➡

Responda a cada afirmación marcando sólo una respuesta ("x") por fila.

	Mala	Pasable	Buena	Muy buena	Excelente
1. **En general, diría que su salud es**	☐	☐	☐	☐	☐
2. **En general, diría que su calidad de vida es**	☐	☐	☐	☐	☐
3. **En general, ¿cómo calificaría su salud física?**	☐	☐	☐	☐	☐
4. **En general, ¿cómo calificaría su salud mental, incluidos su estado de ánimo y su capacidad para pensar?**	☐	☐	☐	☐	☐
5. **En general, ¿cómo calificaría su satisfacción con sus actividades sociales y sus relaciones con otras personas?**	☐	☐	☐	☐	☐
6. **En general, califique en qué medida puede realizar sus actividades sociales y funciones habituales. (Esto comprende las actividades en casa, en el trabajo y en el área donde reside, así como sus responsabilidades como padre o madre, hijo/a, cónyuge, empleado/a, amigo/a, etc.)**	☐	☐	☐	☐	☐

	Para nada	Un poco	Moderadamente	En su mayoría	Completamente
7. **¿En qué medida puede realizar sus actividades físicas diarias, como caminar, subir escaleras, cargar las compras o mover una silla?**	☐	☐	☐	☐	☐

	Nunca	Rara vez	Algunas veces	A menudo	Siempre
8. **¿Con qué frecuencia le han afectado problemas emocionales como sentir ansiedad, depresión o irritabilidad ?**	☐	☐	☐	☐	☐

Continúe en la siguiente página

	Ninguno	Leve	Moderado	Intenso	Muy intenso
9. **En promedio, ¿cómo calificaría su cansancio?**	☐	☐	☐	☐	☐

	0	1	2	3	4	5	6	7	8	9	10
10. En promedio, ¿cómo calificaría su dolor ?	☐ **Ningún dolor**	☐	☐	☐	☐	☐	☐	☐	☐	☐	☐ **El peor dolor imaginable**

Continúe en la siguiente página ➡

A continuación se encuentra una lista dificultades que en ocasiones presentan algunas personas después de un suceso estresante en su vida. Lea cada declaración y después indique que tan estresante ha sido para usted cada dificultad presentada **durante los últimos 7 días**, con respecto a la hospitalización de su hijo en PICU.

¿Qué tanto le estresaron o molestaron estas dificultades?

	Para nada	**Un poco**	**Moderadamente**	**Bastante**	**Demasiado**
1. **Todo lo que le trajo recuerdos y le hizo revivir sus sentimientos.**	☐	☐	☐	☐	☐
2. **Tuve dificultades para mantenerme dormido.**	☐	☐	☐	☐	☐
3. **Otras cosas me lo recordaban constantemente.**	☐	☐	☐	☐	☐
4. **Me sentí irritable y enojado.**	☐	☐	☐	☐	☐
5. **Evitaba molestarme cuando pensaba en ello o algo me lo recordaba.**	☐	☐	☐	☐	☐
6. **Pensaba en ello sin quererlo.**	☐	☐	☐	☐	☐
7. **Sentí como si no hubiera pasado o no hubiera sido real.**	☐	☐	☐	☐	☐
8. **Me alejé de lo que me hacía recordarlo.**	☐	☐	☐	☐	☐
9. **Imágenes sobre ello me venían a la cabeza.**	☐	☐	☐	☐	☐
10. **Estaba nervioso y me sorprendía fácilmente.**	☐	☐	☐	☐	☐
11. **Trataba de no pensar en ello.**	☐	☐	☐	☐	☐
12. **Estaba consciente de que todavía tenía muchos sentimientos, pero no hice nada al respecto.**	☐	☐	☐	☐	☐
13. **Estaba insensible a ello.**	☐	☐	☐	☐	☐
14. **Me encontré actuando y sintiendo que estaba de regreso en ese momento.**	☐	☐	☐	☐	☐

	Para nada	Un poco	Moderada-mente	Bastante	Demasiado
15. **Tuve dificultades para conciliar el sueño**	☐	☐	☐	☐	☐
16. **Tenía oleadas de sentimientos intensos al respecto.**	☐	☐	☐	☐	☐
17. **Trate de eliminarlo de mi memoria.**	☐	☐	☐	☐	☐
18. **Tenía dificultades para concentrarme.**	☐	☐	☐	☐	☐
19. **Los recordatorios me causaron reacciones físicas, como sudoración, dificultad para respirar, náusea o palpitaciones.**	☐	☐	☐	☐	☐
20. **Tenía sueños sobre ello.**	☐	☐	☐	☐	☐
21. **Me sentía vigilante y en guardia.**	☐	☐	☐	☐	☐
22. **Trataba de no hablar de ello.**	☐	☐	☐	☐	☐

Gracias por permitirnos aprender más acerca de cómo podemos ayudar a los pacientes y sus familias en PICU.

Envíe esta encuesta en el sobre proporcionado.

PICU SUPPORTS

Thank you for helping us know more about communication in the pediatric intensive care unit (PICU). This survey asks you for information about your experience in the PICU, your reactions to the brochure you received, and about yourself. Please complete this survey and return it in the envelope provided.

Parent Survey 5

This survey takes approximately 30-45 minutes to complete

Today's date is:

Month XX	Day XX	Year XXXX

The following questions ask you to rate various aspects of the PICU supports intervention. Please select the answer that **best** reflects your experience.

	Useless	**Not Very Useful**	**Very Useful**	**Extremely Useful**	**Did Not Use**
1. **How useful to you was the brochure that you received at the beginning of your stay in the PICU?**	☐	☐	☐	☐	☐

2. **Please comment on any parts of the brochure that you found useful.**

3. **Please comment on any parts of the brochure that you did not like.**

4. **How might we improve the brochure?**

Please continue on the next page ➡

Version Date:
Participant ID:

17. **Please tell us any other questions/comments you have about the brochure or being in the PICU?**

Please continue on the next page ➡

Parent Satisfaction with Care in the Intensive Care Unit ©
pFS-ICU (24)

How are we doing?
Your opinions about your child's ICU stay

The questions that follow ask **YOU** about your child's **<u>current ICU admission</u>**. We understand that there have been 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 are delivering. We understand that this is probably a very difficult time for you and your family. We would appreciate you taking the time to provide us with your opinions. Please take a moment to tell us what we are doing well and what we can do to make our ICU better. Please be assured that all responses are confidential. The doctors and nurses who are looking after your child will not be able to identify your response.

PART I : SATISFACTION WITH CARE

Please mark an "X" in the ONE box that best describes your feelings. If the question does not apply to your child's stay then please mark "not applicable" (N/A).

How did we treat your child (the patient)?

1. **Concern and caring by the ICU staff** (the courtesy, respect, and compassion your child [the patient] was given)

Excellent	Very good	Good	Fair	Poor	N/A
☐	☐	☐	☐	☐	☐

Symptoms management (how well the ICU staff assessed and treated your child's symptoms):

2. **Pain**

Excellent	Very good	Good	Fair	Poor	N/A
☐	☐	☐	☐	☐	☐

3. **Breathlessness**

Excellent	Very good	Good	Fair	Poor	N/A
☐	☐	☐	☐	☐	☐

4. **Agitation**

Excellent	Very good	Good	Fair	Poor	N/A
☐	☐	☐	☐	☐	☐

Please continue on the next page ➡

How did we treat you?

5. **Consideration of your needs** (how well the ICU staff showed an interest in your needs):

Excellent	Very good	Good	Fair	Poor	N/A
☐	☐	☐	☐	☐	☐

6. **Emotional support** (how well the ICU staff provided emotional support):

Excellent	Very good	Good	Fair	Poor	N/A
☐	☐	☐	☐	☐	☐

7. **Coordination of care** (the teamwork of all the ICU staff who took care of your child):

Excellent	Very good	Good	Fair	Poor	N/A
☐	☐	☐	☐	☐	☐

8. **Concern and caring by ICU staff** (the courtesy, respect, and compassion you were given):

Excellent	Very good	Good	Fair	Poor	N/A
☐	☐	☐	☐	☐	☐

Nurses

9. **Skill and competence of ICU nurses** (how well the nurses cared for your child):

Excellent	Very good	Good	Fair	Poor	N/A
☐	☐	☐	☐	☐	☐

10. **Frequency of communication with ICU nurses** (how often nurses communicated to you about your child’s condition):

Excellent	Very good	Good	Fair	Poor	N/A
☐	☐	☐	☐	☐	☐

Physicians (all doctors, including residents and fellows)

11. **Skill and competence of ICU doctors (how well doctors cared for your child):**

Excellent	Very good	Good	Fair	Poor	N/A
☐	☐	☐	☐	☐	☐

Please continue on the next page ➡

The ICU

12. **Atmosphere of ICU was?**

Excellent	Very good	Good	Fair	Poor	N/A
☐	☐	☐	☐	☐	☐

The Waiting Room

13. **The atmosphere in the ICU waiting room was?**

Excellent	Very good	Good	Fair	Poor	N/A
☐	☐	☐	☐	☐	☐

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 or amount of health care your child received in the ICU.**

☐ Very dissatisfied
☐ Slightly dissatisfied
☐ Mostly satisfied
☐ Very satisfied
☐ Completely satisfied

Please continue on the next page ➡

PART 2: PARENT, CAREGIVER, OR GUARDIAN SATISFACTION WITH DECISION-MAKING AROUND CARE 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 Intensive Care Unit (ICU), your child may receive care from different people. We would like you to think about all the care your child has received when you are answering the questions.
Please mark an "X" in the ONE box that best describes your feelings.

INFORMATION NEEDS

15. **Frequency of communication with ICU doctors** (how often doctors communicated to you about your child's condition):

Excellent	Very good	Good	Fair	Poor	N/A
☐	☐	☐	☐	☐	☐

16. **Ease of getting information** (willingness of ICU staff to answer your questions):

Excellent	Very good	Good	Fair	Poor	N/A
☐	☐	☐	☐	☐	☐

17. **Understanding of information** (how well ICU staff provided you with explanations that you understood):

Excellent	Very good	Good	Fair	Poor	N/A
☐	☐	☐	☐	☐	☐

18. **Honesty of information** (the honesty of information provided to you about your child's condition):

Excellent	Very good	Good	Fair	Poor	N/A
☐	☐	☐	☐	☐	☐

19. **Completeness of information** (how well ICU staff informed you what was happening to your child and why things were being done):

Excellent	Very good	Good	Fair	Poor	N/A
☐	☐	☐	☐	☐	☐

20. **Consistency of information** (the consistency of information provided to you about your child's condition – did you get a similar story from the doctor, nurse, etc.):

Excellent	Very good	Good	Fair	Poor	N/A
☐	☐	☐	☐	☐	☐

Please continue on the next page ➡

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 are made regarding the health care she or he receives. From the following questions, pick **one** answer from each of the following set of ideas that best matches your views:

21. **Did you feel included in the decision making process?**
    - ☐ I felt very excluded
    - ☐ I felt somewhat excluded
    - ☐ I felt neither included nor excluded from the decision making process
    - ☐ I felt somewhat included
    - ☐ I felt very included

22. **Did you feel supported during the decision making process?**
    - ☐ I felt totally unsupported
    - ☐ I felt slightly unsupported
    - ☐ I felt neither supported nor unsupported
    - ☐ I felt supported
    - ☐ I felt very supported

23. **Did you feel you had control over the care of your child?**
    - ☐ I felt really out of control and that the health care system took over and dictated the care my child received
    - ☐ I felt somewhat out of control and that the health care system took over and dictated the care my child received
    - ☐ I felt neither in control nor out of control
    - ☐ I felt I had some control over the care my child received
    - ☐ 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?**
    - ☐ I could have used more time
    - ☐ I had adequate time

Please continue on the next page ➡

25. **Which of the following best describes your views?**
    - ☐ I felt my child’s life was prolonged unnecessarily
    - ☐ I felt my child’s life was slightly prolonged unnecessarily
    - ☐ I felt my child’s life was neither prolonged nor shortened unnecessarily
    - ☐ I felt my child’s life was slightly shortened unnecessarily
    - ☐ 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:**
    - ☐ I felt that he/she was very uncomfortable
    - ☐ I felt that he/she was slightly uncomfortable
    - ☐ I felt that he/she was mostly comfortable
    - ☐ I felt that he/she was very comfortable
    - ☐ 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:**
    - ☐ I felt very abandoned by the health care team
    - ☐ I felt abandoned by the health care team
    - ☐ I felt neither abandoned nor supported by the health care team
    - ☐ I felt supported by the health care team
    - ☐ I felt very supported by the health care team

Please continue on the next page ➡

The following questions are related to team collaboration during decision making for your child. Please circle the number that best represents your judgment about the team process.

1. **Team members <u>planned together</u> to make decisions about care for your child.**

1	2	3	4	5	6	7
Strongly Disagree						Strongly Agree

2. **<u>Open communication</u> between team members took place as decisions were made for your child.**

1	2	3	4	5	6	7
Strongly Disagree						Strongly Agree

3. **<u>Decision-making responsibilities</u> for your child were <u>shared</u> among team members.**

1	2	3	4	5	6	7
Strongly Disagree						Strongly Agree

4. **Team members <u>cooperated</u> in making decisions.**

1	2	3	4	5	6	7
Strongly Disagree						Strongly Agree

5. **In making decisions, all team members' <u>concerns</u> about your child's need were considered.**

1	2	3	4	5	6	7
Strongly Disagree						Strongly Agree

6. **Decision-making for your child was <u>coordinated</u> among team members.**

1	2	3	4	5	6	7
Strongly Disagree						Strongly Agree

7. **How much <u>collaboration</u> among team members occurred in making decisions for your child?**

1	2	3	4	5	6	7
No Collaboration						Complete Collaboration

8. **How <u>satisfied</u> are you with the way decisions were made for your child? That is with the <u>decision-making process</u>, not necessarily with the decision itself.**

1	2	3	4	5	6	7
Not Satisfied						Very Satisfied

9. **How <u>satisfied</u> were you with <u>decisions</u> made for your child?**

1	2	3	4	5	6	7
Not Satisfied						Very Satisfied

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Please continue on the next page ➡

The following questions are about decision making in the PICU.

1. **Please write down the MOST important decision made for your child while he/she was in the PICU.**

For the following questions, please think about the decision you have identified above. Then, please mark an "X" in ONE box per row that best describes your feelings now about this decision.

	Strongly Agree	**Agree**	**Neither Agree Nor Disagree**	**Disagree**	**Strongly Disagree**
2. **It was the right decision.**	☐	☐	☐	☐	☐
3. **I regret the choice that was made.**	☐	☐	☐	☐	☐
4. **I would go for the same choice if I had to do it over again.**	☐	☐	☐	☐	☐
5. **The choice did my child a lot of harm.**	☐	☐	☐	☐	☐
6. **The decision was a wise one.**	☐	☐	☐	☐	☐

Please continue on the next page ➡

Please respond to each statement by marking and “X” in one box per row.

In the past 7 days...

	Never	Rarely	Sometimes	Often	Always
1. **I felt worthless.**	☐	☐	☐	☐	☐
2. **I felt helpless.**	☐	☐	☐	☐	☐
3. **I felt depressed.**	☐	☐	☐	☐	☐
4. **I felt hopeless.**	☐	☐	☐	☐	☐
5. **I felt like a failure.**	☐	☐	☐	☐	☐
6. **I felt unhappy.**	☐	☐	☐	☐	☐
7. **I felt that I had nothing to look forward to.**	☐	☐	☐	☐	☐
8. **I felt that nothing could cheer me up.**	☐	☐	☐	☐	☐

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Please continue on the next page ➡

Please respond to each statement by marking and “X” in one box per row.

In the past 7 days…

	Never	Rarely	Sometimes	Often	Always
1. **I felt fearful.**	☐	☐	☐	☐	☐
2. **I found it hard to focus on anything other than my anxiety.**	☐	☐	☐	☐	☐
3. **My worries overwhelmed me.**	☐	☐	☐	☐	☐
4. **I felt uneasy.**	☐	☐	☐	☐	☐
5. **I felt nervous.**	☐	☐	☐	☐	☐
6. **I felt like I needed help for my anxiety.**	☐	☐	☐	☐	☐
7. **I felt anxious.**	☐	☐	☐	☐	☐
8. **I felt tense.**	☐	☐	☐	☐	☐

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Please continue on the next page ➡

Please respond to each statement by marking an “X” in one box per row.

	Poor	Fair	Good	Very Good	Excellent
1. **In general, would you say your health is:**	☐	☐	☐	☐	☐
2. **In general, would you say your quality of life is:**	☐	☐	☐	☐	☐
3. **In general, how would you rate your physical health?**	☐	☐	☐	☐	☐
4. **In general, how would you rate your mental health, including your mood and your ability to think?**	☐	☐	☐	☐	☐
5. **In general, how would you rate you satisfaction with your social activities and relationships?**	☐	☐	☐	☐	☐
6. **In general, how would you rate how well you carry out your usual social activities and roles? (This includes activities at home, at work, and in your community, and responsibilities as a parent, child, spouse, employee, friend, etc.)**	☐	☐	☐	☐	☐

	Not at all	A little	Moderately	Mostly	Completely
7. **To what extent are you able to carry out your everyday physical activities such as walking, climbing stairs, carrying groceries, or moving a chair?**	☐	☐	☐	☐	☐

	Never	Rarely	Sometimes	Often	Always
8. **How often have you been bothered by emotional problems such as feeling anxious, depressed, or irritable?**	☐	☐	☐	☐	☐

Please continue on the next page ➡

	None	Mild	Moderately	Severe	Very Severe
9. **How would you rate your fatigue on average?**	☐	☐	☐	☐	☐

	0	1	2	3	4	5	6	7	8	9	10
10. **How would you rate your pain on average?**	☐ No Pain	☐	☐	☐	☐	☐	☐	☐	☐	☐	☐ Worst imaginable pain

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Below is a list of difficulties people sometimes have after stressful life events. Please read each item and then indicate how distressing each difficulty has been for you **during the past 7 days** with respect to your child being in the PICU.

How much were you distressed or bothered by these difficulties?

	Not at all	**A little bit**	**Moderately**	**Quite a bit**	**Extremely**
1. **Any reminder brought back feelings about it.**	☐	☐	☐	☐	☐
2. **I had trouble staying asleep.**	☐	☐	☐	☐	☐
3. **Other things kept making me think about it.**	☐	☐	☐	☐	☐
4. **I felt irritable and angry.**	☐	☐	☐	☐	☐
5. **I avoided letting myself get upset when I thought about it or was reminded of it.**	☐	☐	☐	☐	☐
6. **I thought about it when I didn't mean to.**	☐	☐	☐	☐	☐
7. **I felt as if it hadn't happened or wasn't real.**	☐	☐	☐	☐	☐
8. **I stayed away from reminders of it.**	☐	☐	☐	☐	☐
9. **Pictures about it popped into my head.**	☐	☐	☐	☐	☐
10. **I was jumpy and easily startled.**	☐	☐	☐	☐	☐
11. **I tried not to think about it.**	☐	☐	☐	☐	☐
12. **I was aware that I still had a lot of feelings about it, but I didn't deal with them.**	☐	☐	☐	☐	☐
13. **My feelings about it were kind of numb.**	☐	☐	☐	☐	☐
14. **I found myself acting or feeling like I was back at that time.**	☐	☐	☐	☐	☐

Please continue on the next page ➡

	Not at all	A little bit	Moderately	Quite a bit	Extremely
15. **I had trouble falling asleep.**	☐	☐	☐	☐	☐
16. **I had waves of strong feelings about it.**	☐	☐	☐	☐	☐
17. **I tried to remove it from my memory.**	☐	☐	☐	☐	☐
18. **I had trouble concentrating.**	☐	☐	☐	☐	☐
19. **Reminders of it caused me to have physical reactions, such as sweating, trouble breathing, nausea, or a pounding heart.**	☐	☐	☐	☐	☐
20. **I had dreams about it.**	☐	☐	☐	☐	☐
21. **I felt watchful and on-guard.**	☐	☐	☐	☐	☐
22. **I tried not to talk about it.**	☐	☐	☐	☐	☐

Please continue on the next page ➡

Please mark and "x" in one box per row which best describes how <u>you feel right now</u>.

	Never	Rarely	Sometimes	Often	Always
1. **I think about my child so much that it's hard for me to do things I normally do.**	☐	☐	☐	☐	☐
2. **Memories of my child upset me.**	☐	☐	☐	☐	☐
3. **I feel I cannot accept the death of my child.**	☐	☐	☐	☐	☐
4. **I feel myself longing for my child.**	☐	☐	☐	☐	☐
5. **I feel drawn to places and things associated with my child.**	☐	☐	☐	☐	☐
6. **I can't help feeling angry about my child's death.**	☐	☐	☐	☐	☐
7. **I feel disbelief over what happened.**	☐	☐	☐	☐	☐
8. **I feel stunned or dazed over what happened.**	☐	☐	☐	☐	☐
9. **Ever since he/she died it is hard for me to trust people.**	☐	☐	☐	☐	☐
10. **Ever since s/he died I feel like I have lost the ability to care about other people or I feel distant from people I care about.**	☐	☐	☐	☐	☐
11. **I have pain in the same area of my body or have some of the same symptoms as my child had.**	☐	☐	☐	☐	☐
12. **I go out of my way to avoid reminders of my child.**	☐	☐	☐	☐	☐
13. **I feel that life is empty without my child.**	☐	☐	☐	☐	☐
14. **I hear the voice of my child who died speak to me.**	☐	☐	☐	☐	☐
15. **I see my child who died stand before me.**	☐	☐	☐	☐	☐

Please continue on the next page ➡

	Never	Rarely	Sometimes	Often	Always
16. **I feel that it is unfair that I should live when my child died.**	☐	☐	☐	☐	☐
17. **I feel bitter over my child's death.**	☐	☐	☐	☐	☐
18. **I feel envious of others who have not lost their child.**	☐	☐	☐	☐	☐
19. **I feel lonely a great deal of time ever since s/he died.**	☐	☐	☐	☐	☐

Thank you very much for helping us know more about how to help the patients and families in the PICU.

Please return this survey in the envelope provided.

PICU
SUPPORTS

Agradecemos su ayuda para aprender más acerca de la comunicación en la Unidad de Cuidados Intensivos Pediátricos (PICU). Esta encuesta aborda preguntas sobre su experiencia en PICU, su opinión respecto al folleto que recibió y preguntas acerca de usted. Le pedimos que la conteste y la envíe en el sobre proporcionado.

Encuesta 5 para el padre o la madre de familia

La encuesta toma aproximadamente de 30 a 45 minutos en contestarse

Fecha de hoy:

Mes XX	Día XX	Año XXXX

Elija la respuesta que **mejor** describa su experiencia.

	Inútil	**No muy útil**	**Muy útil**	**Bastante útil**	**No lo usé**
1. ¿Qué tan útil fue para usted el folleto que recibió al inicio de su estancia en PICU?	☐	☐	☐	☐	☐

2. Denos su opinión respecto a las partes del folleto que le parecieron útiles.

3. Denos su opinión acerca de las partes del folleto que no le gustaron.

4. ¿Cómo podemos mejorar el folleto?

Continúe en la siguiente página ➡

5. **Anote cualquier otra pregunta o comentario que tenga respecto al folleto o a su estancia en PICU:**

Continúe en la siguiente página ➡

Satisfacción del padre de familia respecto a la atención en la Unidad de Cuidados Intensivos Pediátricos (*Parent Satisfaction with Care in the Intensive Care Unit* ©)

pFS-ICU (24)

¿Cómo estamos trabajando?
Su opinión acerca de la estancia de su hijo en la Unidad de Cuidados Intensivos

Las siguientes preguntas para **USTED** abordan aspectos de la **admisión actual de su hijo en la unidad de cuidados intensivos**. Sabemos que ha habido muchos doctores, enfermeros y otro personal que ha participado en el cuidado de su hijo. Entendemos que puede haber excepciones, pero nos interesa **su opinión en general** acerca de la calidad de la atención que le estamos proporcionando. Estamos conscientes de que probablemente usted y su familia están atravesando por un momento muy difícil. Agradecemos que se tome el tiempo de darnos su opinión. Le pedimos que se tome un momento para decirnos lo que estamos haciendo bien y lo que podemos mejorar en nuestra ICU. Tenga por seguro que todas las respuestas son confidenciales. Los médicos y enfermeros que cuidan de su hijo no podrán identificar sus respuestas.

PARTE I: SATISFACCIÓN CON LA ATENCIÓN

Marque con una "X" sólo UNA de las casillas que mejor describa su opinión. Si la pregunta no corresponde a la estancia de su hijo, entonces marque "no corresponde" (N/A).

Cómo tratamos a su niño (el/la paciente):

1. **Preocupación y cuidado por parte del personal de la ICU** (la cortesía, respeto y compasión que se le dio a su niño [el/la paciente])

Excelente	Muy bien	Bien	Aceptable	Mal	N/A
☐	☐	☐	☐	☐	☐

Manejo de síntomas (qué tan bien evaluó y trató el personal de la ICU los síntomas de su niño):

2. **Dolor**

Excelente	Muy bien	Bien	Aceptable	Mal	N/A
☐	☐	☐	☐	☐	☐

3. **Dificultad al respirar**

Excelente	Muy bien	Bien	Aceptable	Mal	N/A
☐	☐	☐	☐	☐	☐

4. **Inquietud**

Excelente	Muy bien	Bien	Aceptable	Mal	N/A
☐	☐	☐	☐	☐	☐

Continúe en la siguiente página ➡

¿Cómo lo tratamos a usted?

5. **Tomar en cuenta sus necesidades** (qué tan bien mostró interés el personal de la ICU en las necesidades de usted):

Excelente	Muy bien	Bien	Aceptable	Mal	N/A
☐	☐	☐	☐	☐	☐

6. **Apoyo emocional** (qué tan bien le proporcionó apoyo emocional el personal de la ICU):

Excelente	Muy bien	Bien	Aceptable	Mal	N/A
☐	☐	☐	☐	☐	☐

7. **Coordinación del cuidado** (el trabajo de equipo de todo el personal de la ICU que cuidó a su niño):

Excelente	Muy bien	Bien	Aceptable	Mal	N/A
☐	☐	☐	☐	☐	☐

8. **Preocupación y cuidado por parte del personal de la ICU** (la cortesía, respeto y compasión que le fueron proporcionados a usted):

Excelente	Muy bien	Bien	Aceptable	Mal	N/A
☐	☐	☐	☐	☐	☐

ENFERMERAS

9. **Destreza y capacidad de las enfermeras de la ICU** (qué tan bien cuidan las enfermeras a su niño):

Excelente	Muy bien	Bien	Aceptable	Mal	N/A
☐	☐	☐	☐	☐	☐

10. **Frecuencia de comunicación con las enfermeras de la ICU** (qué tan frecuentemente se comunicaron con usted las enfermeras de la ICU en relación con la condición de su niño):

Excelente	Muy bien	Bien	Aceptable	Mal	N/A
☐	☐	☐	☐	☐	☐

MÉDICOS (todos los médicos, incluyendo residentes e internos)

11. **Destreza y capacidad de los médicos de la ICU** (qué tan bien cuidaron los médicos a su niño):

Excelente	Muy bien	Bien	Aceptable	Mal	N/A
☐	☐	☐	☐	☐	☐

Continúe en la siguiente página

LA ICU

12. **¿Cómo fue el ambiente de la ICU?**

Excelente	Muy bien	Bien	Aceptable	Mal	N/A
☐	☐	☐	☐	☐	☐

LA SALA DE ESPERA

13. **¿Cómo fue el ambiente en la sala de espera de la ICU?**

Excelente	Muy bien	Bien	Aceptable	Mal	N/A
☐	☐	☐	☐	☐	☐

14. **A algunas personas les gusta que se haga todo en relación con sus problemas de salud, mientras que a otras no les gusta que se haga mucho. ¿Qué tan satisfecho estuvo usted con el nivel o cantidad de cuidados de la salud que recibió su niño en la ICU?**

☐ muy insatisfecho
☐ un poco insatisfecho
☐ generalmente satisfecho
☐ muy satisfecho
☐ completamente satisfecho

Continúe en la siguiente página ➡

PARTE 2: SATISFACCIÓN DEL PADRE O MADRE DE FAMILIA, PERSONA A CARGO DEL PACIENTE O TUTOR CON LA TOMA DE DECISIONES RESPECTO A LA ATENCIÓN QUE RECIBEN LOS PACIENTES EN ESTADO CRÍTICO

Esta parte del cuestionario está diseñada para medir cómo se siente sobre SU participación en las decisiones relacionadas con la atención médica de su hijo. En la Unidad de Cuidados Intensivos (ICU), su hijo fue atendido por diferentes personas. Queremos que al contestar estas preguntas piense en toda la atención que ha recibido su hijo.
Marque con una “X” sólo UNA de las casillas que mejor describa su opinión.

NECESIDADES DE INFORMACIÓN

15. **Frecuencia de la comunicación con los médicos de la ICU** (qué tan frecuentemente se comunicaron con usted los médicos de la ICU en relación con la condición de su niño):

Excelente	Muy bien	Bien	Aceptable	Mal	N/A
☐	☐	☐	☐	☐	☐

16. **Facilidad para obtener información** (buena disposición del personal de la ICU para responder a sus preguntas):

Excelente	Muy bien	Bien	Aceptable	Mal	N/A
☐	☐	☐	☐	☐	☐

17. **Comprensión de la información** (qué tan bien le proporcionó el personal de la ICU explicaciones que usted comprendió):

Excelente	Muy bien	Bien	Aceptable	Mal	N/A
☐	☐	☐	☐	☐	☐

18. **Honestidad de la información** (la honestidad de la información que le fue proporcionada a usted respecto de la condición de su niño):

Excelente	Muy bien	Bien	Aceptable	Mal	N/A
☐	☐	☐	☐	☐	☐

19. **Totalidad/Integridad de la información** (qué tan bien le informo a usted el personal de la ICU sobre lo que estaba sucediendo con su niño y la razón por la que se estaban haciendo las cosas):

Excelente	Muy bien	Bien	Aceptable	Mal	N/A
☐	☐	☐	☐	☐	☐

20. **Consistencia de la información** (la consistencia de la información que le fue proporcionada a usted respecto a la condición de su niño – obtuvo usted información similar por parte del médico, enfermera, etc.):

Excelente	Muy bien	Bien	Aceptable	Mal	N/A
☐	☐	☐	☐	☐	☐

Continúe en la siguiente página ➡

¿Cómo estamos trabajando?
Su opinión acerca de la estancia de su hijo en la Unidad de Cuidados Intensivos

PROCESO DE TOMA DE DECISIONES

Durante la estancia de su niño en la ICU, se toman muchas decisiones importantes respecto del cuidado de la salud que él o ella recibe. En las siguientes preguntas, elija **una** respuesta del siguiente grupo de ideas que mejor se ajuste a sus puntos de vista:

21. **¿Se sintió usted incluido en el proceso de toma de decisiones?**
    - ☐ Me sentí muy excluido
    - ☐ Me sentí un poco excluido
    - ☐ No me sentí ni incluido ni excluido en el proceso de toma de decisiones
    - ☐ Me sentí un poco incluido
    - ☐ Me sentí muy incluido

22. **¿Se sintió usted apoyado durante el proceso de toma de decisiones?**
    - ☐ Me sentí totalmente agobiado
    - ☐ Me sentí un poco agobiado
    - ☐ No me sentí ni agobiado ni apoyado
    - ☐ Me sentí apoyado
    - ☐ Me sentí muy apoyado

23. **¿Sintió usted que tenía control sobre el cuidado de su niño?**
    - ☐ Realmente sentí que no tenía control y que el sistema de cuidados de la salud asumió el control y ordenó el cuidado que mi niño recibió
    - ☐ Sentí un poco que no tenía control y que el sistema de cuidados de la salud asumió el control y ordenó el cuidado que mi niño recibió
    - ☐ No sentí que no tuviera control ni que tuviera control
    - ☐ Sentí que tenía algo de control sobre el cuidado que mi niño recibió
    - ☐ Sentí que tenía buen control sobre el cuidado que mi niño recibió

24. **Al tomar decisiones, ¿tuvo usted el tiempo suficiente para tratar sus inquietudes y que le respondieran sus preguntas?**

    - ☐ Podría haber utilizado más tiempo
    - ☐ Tuve el tiempo suficiente

Continúe en la siguiente página ➡

25. **Cuál de las siguientes opciones describe mejor su opinión:**
    - ☐ Siento que la vida de mi hijo se prolongó de manera innecesaria.
    - ☐ Siento que la vida de mi hijo se prolongó un poco más de lo necesario.
    - ☐ Siento que la vida de mi hijo no se prolongó ni acortó de manera innecesaria.
    - ☐ Siento que la vida de mi hijo se acortó un poco de manera innecesaria.
    - ☐ Siento que la vida de mi hijo se acortó de manera innecesaria.

26. **Durante las últimas horas en la vida de su hijo, ¿cuál de las siguientes describe mejor su opinión?:**
    - ☐ Siento que él o ella estuvo muy incómodo
    - ☐
    - ☐ Siento que él o ella estuvo un poco incómodo
    - ☐ Siento que él o ella estuvo en su mayoría cómodo
    - ☐ Siento que él o ella estuvo muy cómodo
    - ☐ Siento que él o ella estuvo completamente cómodo

27. **Durante las últimas horas en la vida de su hijo, ¿cuál de las siguientes describe mejor su opinión?:**
    - ☐ Me sentí muy abandonado por el equipo de profesionales de la salud
    - ☐ Me sentí abandonado por el equipo de profesionales de la salud
    - ☐ No me sentí abandonado ni apoyado por el equipo de profesionales de la salud
    - ☐ Me sentí apoyado por el equipo de profesionales de la salud
    - ☐ Me sentí muy apoyado por el equipo de profesionales de la salud

Continúe en la siguiente página ➡

Las siguientes preguntas están relacionadas a la colaboración del equipo en las decisiones tomadas respecto a su hijo.

Encierre en un círculo el número que mejor represente su opinión respecto al proceso del equipo.

1. **Los miembros del equipo planearon en conjunto tomar las decisiones respecto a la atención de su hijo.**

1	2	3	4	5	6	7
Completamente en desacuerdo						Completamente de acuerdo

2. **Los miembros del equipo tuvieron una comunicación abierta entre ellos al tomar las decisiones para su hijo.**

1	2	3	4	5	6	7
Completamente en desacuerdo						Completamente de acuerdo

3. **La responsabilidad de la toma de decisiones para su hijo se compartió entre los miembros del equipo.**

1	2	3	4	5	6	7
Completamente en desacuerdo						Completamente de acuerdo

4. **Los miembros del equipo colaboraron juntos en la toma de decisiones.**

1	2	3	4	5	6	7
Completamente en desacuerdo						Completamente de acuerdo

5. **En el proceso de la toma de decisiones, se tomaron en cuenta las inquietudes de todos los miembros del equipo respecto a las necesidades de hijo.**

1	2	3	4	5	6	7
Completamente en desacuerdo						Completamente de acuerdo

6. **La toma de decisiones para su hijo se coordinó entre los miembros del equipo.**

1	2	3	4	5	6	7
Completamente en desacuerdo						Completamente de acuerdo

7. **¿Qué tanto colaboraron los miembros del equipo en la toma de decisiones para su hijo?**

1	2	3	4	5	6	7
No colaboraron						Colaboraron completamente

8. **¿Qué tan satisfecho está usted con la forma en que se tomaron las decisiones para su hijo? Esto se refiere al proceso de toma de decisiones, no necesariamente a las decisiones mismas.**

1	2	3	4	5	6	7
Nada satisfecho						Muy satisfecho

9. **¿Qué tan satisfecho estuvo usted con las decisiones que se tomaron para su hijo?**

1	2	3	4	5	6	7
Nada satisfecho						Muy satisfecho

Continúe en la siguiente página ➡

Las siguientes preguntas tratan acerca de la toma de decisiones en PICU.

1. **Describa la decisión MÁS IMPORTANTE que tomó para su hijo mientras se encontraba en PICU:**

Para contestar las siguientes preguntas, piense en la decisión que acaba de anotar. Después, marque con una "X", sólo UNA casilla por fila que mejor describa sus sentimientos actuales respecto a esta decisión.

	Completa-mente de acuerdo	**De acuerdo**	**Ni de acuerdo ni en desacuerdo**	**En desacuerdo**	**Completa-mente en desacuerdo**
3. **Fue la decisión correcta**	☐	☐	☐	☐	☐
4. **Me arrepiento de la decisión que se tomó**	☐	☐	☐	☐	☐
5. **Si tuviera que volver a hacerlo, tomaría la misma decisión**	☐	☐	☐	☐	☐
6. **La decisión lastimó mucho a mi hijo(a)**	☐	☐	☐	☐	☐
7**. La decisión fue muy sabia**	☐	☐	☐	☐	☐

Continúe en la siguiente página ➡

Responda a cada afirmación marcando sólo una respuesta ("x") por fila.

En los últimos 7 días...

	Nunca	Rara vez	Algunas veces	A menudo	Siempre
1. **Senti que no valia nada**	☐	☐	☐	☐	☐
2. **Me senti indefenso/a (que no podia hacer nada para ayudarme)**	☐	☐	☐	☐	☐
3. **Me sentí deprimido/a**	☐	☐	☐	☐	☐
4. **Me sentí desesperanzado/a**	☐	☐	☐	☐	☐
5. **Me sentí fracasado/a**	☐	☐	☐	☐	☐
6. **Me sentí descontento/a**	☐	☐	☐	☐	☐
7. **Sentí que nada me ilusionaba**	☐	☐	☐	☐	☐
8. **Sentí que nada me podía animar**	☐	☐	☐	☐	☐

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Continúe en la siguiente página ➡

Responda a cada afirmación marcando sólo una respuesta ("x") por fila.

En los últimos 7 días...

	Nunca	Rara vez	Algunas veces	A menudo	Siempre
1. **Sentí miedo**	☐	☐	☐	☐	☐
2. **Tuve dificultad para concentrarme en otra cosa que no fuera mi ansiedad**	☐	☐	☐	☐	☐
3. **Mis inquietudes fueron demasiado para mi**	☐	☐	☐	☐	☐
4. **Me sentí intranquilo/a**	☐	☐	☐	☐	☐
5. **Me sentí nervioso/a**	☐	☐	☐	☐	☐
6. **Sentí que necesitaba ayuda para controlar mi ansiedad.**	☐	☐	☐	☐	☐
7. **Sentí ansiedad**	☐	☐	☐	☐	☐
8. **Me sentí tenso/a**	☐	☐	☐	☐	☐

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Continúe en la siguiente página ➡

Responda a cada afirmación marcando sólo una respuesta ("x") por fila.

	Mala	Pasable	Buena	Muy buena	Excelente
1. **En general, diría que su salud es**	☐	☐	☐	☐	☐
2. **En general, diría que su calidad de vida es**	☐	☐	☐	☐	☐
3. **En general, ¿cómo calificaría su salud física?**	☐	☐	☐	☐	☐
4. **En general, ¿cómo calificaría su salud mental, incluidos su estado de ánimo y su capacidad para pensar?**	☐	☐	☐	☐	☐
5. **En general, ¿cómo calificaría su satisfacción con sus actividades sociales y sus relaciones con otras personas?**	☐	☐	☐	☐	☐
6. **En general, califique en qué medida puede realizar sus actividades sociales y funciones habituales. (Esto comprende las actividades en casa, en el trabajo y en el área donde reside, así como sus responsabilidades como padre o madre, hijo/a, cónyuge, empleado/a, amigo/a, etc.)**	☐	☐	☐	☐	☐

	Para nada	Un poco	Moderada-mente	En su mayoría	Completame-nte
7. **¿En qué medida puede realizar sus actividades físicas diarias, como caminar, subir escaleras, cargar las compras o mover una silla?**	☐	☐	☐	☐	☐

	Nunca	Rara vez	Algunas veces	A menudo	Siempre
8. **¿Con qué frecuencia le han afectado problemas emocionales como sentir ansiedad, depresión o irritabilidad ?**	☐	☐	☐	☐	☐

Continúe en la siguiente página ➡

	Ninguno	Leve	Moderado	Intenso	Muy intenso
9. **En promedio, ¿cómo calificaría su cansancio?**	☐	☐	☐	☐	☐

	0	1	2	3	4	5	6	7	8	9	10
10. En promedio, ¿cómo calificaría su dolor ?	☐ **Ningún dolor**	☐	☐	☐	☐	☐	☐	☐	☐	☐	☐ **El peor dolor imaginable**

Continúe en la siguiente página ➡

A continuación se encuentra una lista dificultades que en ocasiones presentan algunas personas después de un suceso estresante en su vida. Lea cada declaración y después indique que tan estresante ha sido para usted cada dificultad presentada **durante los últimos 7 días**, con respecto a la hospitalización de su hijo en PICU.

¿Qué tanto le estresaron o molestaron estas dificultades?

	Para nada	**Un poco**	**Moderada-mente**	**Bastante**	**Demasiado**
1. **Todo lo que le trajo recuerdos y le hizo revivir sus sentimientos.**	☐	☐	☐	☐	☐
2. **Tuve dificultades para mantenerme dormido.**	☐	☐	☐	☐	☐
3. **Otras cosas me lo recordaban constantemente.**	☐	☐	☐	☐	☐
4. **Me sentí irritable y enojado.**	☐	☐	☐	☐	☐
5. **Evitaba molestarme cuando pensaba en ello o algo me lo recordaba.**	☐	☐	☐	☐	☐
6. **Pensaba en ello sin quererlo.**	☐	☐	☐	☐	☐
7. **Sentí como si no hubiera pasado o no hubiera sido real.**	☐	☐	☐	☐	☐
8. **Me alejé de lo que me hacía recordarlo.**	☐	☐	☐	☐	☐
9. **Imágenes sobre ello me venían a la cabeza.**	☐	☐	☐	☐	☐
10. **Estaba nervioso y me sorprendía fácilmente.**	☐	☐	☐	☐	☐
11. **Trataba de no pensar en ello.**	☐	☐	☐	☐	☐
12. **Estaba consciente de que todavía tenía muchos sentimientos, pero no hice nada al respecto.**	☐	☐	☐	☐	☐
13. **Estaba insensible a ello.**	☐	☐	☐	☐	☐
14. **Me encontré actuando y sintiendo que estaba de regreso en ese momento.**	☐	☐	☐	☐	☐

	Para nada	Un poco	Moderada-mente	Bastante	Demasiado
15. **Tuve dificultades para conciliar el sueño**	☐	☐	☐	☐	☐
16. **Tenía oleadas de sentimientos intensos al respecto.**	☐	☐	☐	☐	☐
17. **Trate de eliminarlo de mi memoria.**	☐	☐	☐	☐	☐
18. **Tenía dificultades para concentrarme.**	☐	☐	☐	☐	☐
19. **Los recordatorios me causaron reacciones físicas, como sudoración, dificultad para respirar, náusea o palpitaciones.**	☐	☐	☐	☐	☐
20. **Tenía sueños sobre ello.**	☐	☐	☐	☐	☐
21. **Me sentía vigilante y en guardia.**	☐	☐	☐	☐	☐
22. **Trataba de no hablar de ello.**	☐	☐	☐	☐	☐

Marque con una "x" sólo una casilla por fila que mejor describa cómo se siente usted ahora mismo.

	Nunca	En raras ocasiones	Algunas veces	A menudo	Siempre
1. **Pienso tanto en mi hijo que se me dificulta hacer las cosas que hago normalmente.**	☐	☐	☐	☐	☐
2. **Los recuerdos de mi hijo me hacen sentir mal.**	☐	☐	☐	☐	☐
3. **Siento que no puedo aceptar la muerte de mi hijo.**	☐	☐	☐	☐	☐
4. **Anhelo volver a ver o estar con mi hijo.**	☐	☐	☐	☐	☐
5. **Me siento atraída a lugares y cosas asociadas con mi hijo.**	☐	☐	☐	☐	☐
6. **No puedo evitar sentir enojo por la muerte de mi hijo.**	☐	☐	☐	☐	☐
7. **No puedo creer lo que sucedió.**	☐	☐	☐	☐	☐
8. **Me siento pasmado y aturdido con lo que sucedió.**	☐	☐	☐	☐	☐
9. **Desde que murió mi hijo, se me dificulta confiar en la gente.**	☐	☐	☐	☐	☐
10. **Desde que murió mi hijo, siento que perdí la capacidad de interesarme por los demás o me siento distante de mis seres queridos.**	☐	☐	☐	☐	☐
11. **Siento dolor en el mismo lugar del cuerpo o tengo algunos de los mismos síntomas que tenía mi hijo.**	☐	☐	☐	☐	☐
12. **Hago todo lo posible por evitar las cosas que me recuerdan a mi hijo.**	☐	☐	☐	☐	☐
13. **Siento que la vida no tiene sentido sin mi hijo.**	☐	☐	☐	☐	☐
14. **Escucho que mi hijo que se murió me habla.**	☐	☐	☐	☐	☐
15. **Veo frente a mí a mi hijo que se murió.**	☐	☐	☐	☐	☐

	Nunca	En raras ocasiones	Algunas veces	A menudo	Siempre
16. **Siento que es injusto que yo viva cuando mi hijo se murió.**	☐	☐	☐	☐	☐
17. **Me siento amargado por la muerte de mi hijo.**	☐	☐	☐	☐	☐
18. **Siento envidia de otras personas que no han perdido un hijo.**	☐	☐	☐	☐	☐
19. **Desde que se murió mi hijo, me siento solo la mayor parte del tiempo.**	☐	☐	☐	☐	☐

Gracias por permitirnos aprender más acerca de cómo podemos ayudar a los pacientes y sus familias en PICU.

Envíe esta encuesta en el sobre proporcionado.

PICU
SUPPORTS

Thank you for helping us know more about communication in the pediatric intensive care unit (PICU). This survey asks you for information about your experience in the PICU, about your reactions to the PICU Supports program, and about yourself. Please complete this survey and return it in the envelope provided.

Parent Survey 5

This survey takes approximately 30-45 minutes to complete

Today's date is:

Month XX	Day XX	Year XXXX

:

The following questions ask you to rate various aspects of the PICU supports intervention. Please select the answer that **best** reflects your experience.

	Not at All Helpful	**Not Very Helpful**	**Somewhat Helpful**	**Extremely Helpful**	**Unable to Assess**
1. **How well did PICU Supports help with communication in the PICU?**	☐	☐	☐	☐	☐

During your child's stay in the PICU, did PICU Supports have a positive impact on:

	Yes	**No**
2. The quality of communication between you and the healthcare team?	☐	☐
3. The quality of communication within the healthcare team (how healthcare team members communicated with each other)?	☐	☐
4. The timeliness of communication between you and the healthcare team?	☐	☐
5. Your conversations with the healthcare team about your values and preferences for your child's care?	☐	☐
6. Your hospital experience?	☐	☐
7. The family-centeredness of care delivered?	☐	☐

Please continue on the next page ➡

In your view, how useful were the following parts of PICU Supports:

	Useless	Not Very Useful	Very Useful	Extremely Useful	Did Not Use
8. The Navigator's weekday visits with you.	☐	☐	☐	☐	☐
9. The communication log kept at your child's bedside.	☐	☐	☐	☐	☐
10. The regular family meetings organized by the navigator.	☐	☐	☐	☐	☐
11. The PICU Handbook that you received.	☐	☐	☐	☐	☐
12. The list of questions in the section of the PICU Handbook called "What are some questions you might want to ask?"	☐	☐	☐	☐	☐
13. The calendar/diary in the back of the PICU Handbook	☐	☐	☐	☐	☐
14. Any informational/educational materials given to you.	☐	☐	☐	☐	☐

14. **Please comment on any parts of PICU Supports that you found useful.**

Please continue on the next page ➡

15. **Please comment on any parts of PICU Supports that you did not like.**

16. **How might we improve PICU Supports?**

17. **Please tell us any other questions/comments you have about PICU Supports or being in the PICU?**

Please continue on the next page ➡

Parent Satisfaction with Care in the Intensive Care Unit ©
pFS-ICU (24)

How are we doing?
Your opinions about your child's ICU stay

The questions that follow ask **YOU** about your child's **current ICU admission**. We understand that there have been 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 are delivering. We understand that this is probably a very difficult time for you and your family. We would appreciate you taking the time to provide us with your opinions. Please take a moment to tell us what we are doing well and what we can do to make our ICU better. Please be assured that all responses are confidential. The doctors and nurses who are looking after your child will not be able to identify your response.

PART I : SATISFACTION WITH CARE

Please mark an "X" in the ONE box that best describes your feelings. If the question does not apply to your child's stay then please mark "not applicable" (N/A).

How did we treat your child (the patient)?

1. **Concern and caring by the ICU staff** (the courtesy, respect, and compassion your child [the patient] was given)

Excellent	Very good	Good	Fair	Poor	N/A
☐	☐	☐	☐	☐	☐

Symptoms management (how well the ICU staff assessed and treated your child's symptoms):

2. **Pain**

Excellent	Very good	Good	Fair	Poor	N/A
☐	☐	☐	☐	☐	☐

3. **Breathlessness**

Excellent	Very good	Good	Fair	Poor	N/A
☐	☐	☐	☐	☐	☐

4. **Agitation**

Excellent	Very good	Good	Fair	Poor	N/A
☐	☐	☐	☐	☐	☐

Please continue on the next page ➡

How did we treat you?

5. **Consideration of your needs** (how well the ICU staff showed an interest in your needs):

Excellent	Very good	Good	Fair	Poor	N/A
☐	☐	☐	☐	☐	☐

6. **Emotional support** (how well the ICU staff provided emotional support):

Excellent	Very good	Good	Fair	Poor	N/A
☐	☐	☐	☐	☐	☐

7. **Coordination of care** (the teamwork of all the ICU staff who took care of your child):

Excellent	Very good	Good	Fair	Poor	N/A
☐	☐	☐	☐	☐	☐

8. **Concern and caring by ICU staff** (the courtesy, respect, and compassion you were given):

Excellent	Very good	Good	Fair	Poor	N/A
☐	☐	☐	☐	☐	☐

Nurses

9. **Skill and competence of ICU nurses** (how well the nurses cared for your child):

Excellent	Very good	Good	Fair	Poor	N/A
☐	☐	☐	☐	☐	☐

10. **Frequency of communication with ICU nurses** (how often nurses communicated to you about your child's condition):

Excellent	Very good	Good	Fair	Poor	N/A
☐	☐	☐	☐	☐	☐

Physicians (all doctors, including residents and fellows)

11. **Skill and competence of ICU doctors (how well doctors cared for your child):**

Excellent	Very good	Good	Fair	Poor	N/A
☐	☐	☐	☐	☐	☐

Please continue on the next page ➡

The ICU

12. **Atmosphere of ICU was?**

Excellent	Very good	Good	Fair	Poor	N/A
☐	☐	☐	☐	☐	☐

The Waiting Room

13. **The atmosphere in the ICU waiting room was?**

Excellent	Very good	Good	Fair	Poor	N/A
☐	☐	☐	☐	☐	☐

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 or amount of health care your child received in the ICU.**

☐ Very dissatisfied
☐ Slightly dissatisfied
☐ Mostly satisfied
☐ Very satisfied
☐ Completely satisfied

Please continue on the next page ➡

PART 2: PARENT, CAREGIVER, OR GUARDIAN SATISFACTION WITH DECISION-MAKING AROUND CARE 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 Intensive Care Unit (ICU), your child may receive care from different people. We would like you to think about all the care your child has received when you are answering the questions.
Please mark an "X" in the ONE box that best describes your feelings.

INFORMATION NEEDS

15. **Frequency of communication with ICU doctors** (how often doctors communicated to you about your child's condition):

Excellent	Very good	Good	Fair	Poor	N/A
☐	☐	☐	☐	☐	☐

16. **Ease of getting information** (willingness of ICU staff to answer your questions):

Excellent	Very good	Good	Fair	Poor	N/A
☐	☐	☐	☐	☐	☐

17. **Understanding of information** (how well ICU staff provided you with explanations that you understood):

Excellent	Very good	Good	Fair	Poor	N/A
☐	☐	☐	☐	☐	☐

18. **Honesty of information** (the honesty of information provided to you about your child's condition):

Excellent	Very good	Good	Fair	Poor	N/A
☐	☐	☐	☐	☐	☐

19. **Completeness of information** (how well ICU staff informed you what was happening to your child and why things were being done):

Excellent	Very good	Good	Fair	Poor	N/A
☐	☐	☐	☐	☐	☐

20. **Consistency of information** (the consistency of information provided to you about your child's condition – did you get a similar story from the doctor, nurse, etc.):

Excellent	Very good	Good	Fair	Poor	N/A
☐	☐	☐	☐	☐	☐

Please continue on the next page ➡

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 are made regarding the health care she or he receives. From the following questions, pick **one** answer from each of the following set of ideas that best matches your views:

21. **Did you feel included in the decision making process?**
    - ☐ I felt very excluded
    - ☐ I felt somewhat excluded
    - ☐ I felt neither included nor excluded from the decision making process
    - ☐ I felt somewhat included
    - ☐ I felt very included

22. **Did you feel supported during the decision making process?**
    - ☐ I felt totally unsupported
    - ☐ I felt slightly unsupported
    - ☐ I felt neither supported nor unsupported
    - ☐ I felt supported
    - ☐ I felt very supported

23. **Did you feel you had control over the care of your child?**
    - ☐ I felt really out of control and that the health care system took over and dictated the care my child received
    - ☐ I felt somewhat out of control and that the health care system took over and dictated the care my child received
    - ☐ I felt neither in control nor out of control
    - ☐ I felt I had some control over the care my child received
    - ☐ 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?**
    - ☐ I could have used more time
    - ☐ I had adequate time

Please continue on the next page ➡

25. **Which of the following best describes your views?**
    - ☐ I felt my child's life was prolonged unnecessarily
    - ☐ I felt my child's life was slightly prolonged unnecessarily
    - ☐ I felt my child's life was neither prolonged nor shortened unnecessarily
    - ☐ I felt my child's life was slightly shortened unnecessarily
    - ☐ 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:**
    - ☐ I felt that he/she was very uncomfortable
    - ☐ I felt that he/she was slightly uncomfortable
    - ☐ I felt that he/she was mostly comfortable
    - ☐ I felt that he/she was very comfortable
    - ☐ 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:**
    - ☐ I felt very abandoned by the health care team
    - ☐ I felt abandoned by the health care team
    - ☐ I felt neither abandoned nor supported by the health care team
    - ☐ I felt supported by the health care team
    - ☐ I felt very supported by the health care team

Please continue on the next page ➡

The following questions are related to team collaboration during decision making for your child. Please circle the number that best represents your judgment about the team process.

1. **Team members planned together to make decisions about care for your child.**

1	2	3	4	5	6	7
Strongly Disagree						Strongly Agree

2. **Open communication between team members took place as decisions were made for your child.**

1	2	3	4	5	6	7
Strongly Disagree						Strongly Agree

3. **Decision-making responsibilities for your child were shared among team members.**

1	2	3	4	5	6	7
Strongly Disagree						Strongly Agree

4. **Team members cooperated in making decisions.**

1	2	3	4	5	6	7
Strongly Disagree						Strongly Agree

5. **In making decisions, all team members' concerns about your child's need were considered.**

1	2	3	4	5	6	7
Strongly Disagree						Strongly Agree

6. **Decision-making for your child was coordinated among team members.**

1	2	3	4	5	6	7
Strongly Disagree						Strongly Agree

7. **How much collaboration among team members occurred in making decisions for your child?**

1	2	3	4	5	6	7
No Collaboration						Complete Collaboration

8. **How satisfied are you with the way decisions were made for your child? That is with the decision-making process, not necessarily with the decision itself.**

1	2	3	4	5	6	7
Not Satisfied						Very Satisfied

9. **How satisfied were you with decisions made for your child?**

1	2	3	4	5	6	7
Not Satisfied						Very Satisfied

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Please continue on the next page ➡

The following questions are about decision making in the PICU.

1. **Please write down the MOST important decision made for your child while he/she was in the PICU.**

For the following questions, please think about the decision you have identified above. Then, please mark an "X" in ONE box per row that best describes your feelings now about this decision.

	Strongly Agree	**Agree**	**Neither Agree Nor Disagree**	**Disagree**	**Strongly Disagree**
2. **It was the right decision.**	☐	☐	☐	☐	☐
3. **I regret the choice that was made.**	☐	☐	☐	☐	☐
4. **I would go for the same choice if I had to do it over again.**	☐	☐	☐	☐	☐
5. **The choice did my child a lot of harm.**	☐	☐	☐	☐	☐
6. **The decision was a wise one.**	☐	☐	☐	☐	☐

Please continue on the next page ➡

Please respond to each statement by marking and “X” in one box per row.

In the past 7 days...

	Never	Rarely	Sometimes	Often	Always
1. **I felt worthless.**	☐	☐	☐	☐	☐
2. **I felt helpless.**	☐	☐	☐	☐	☐
3. **I felt depressed.**	☐	☐	☐	☐	☐
4. **I felt hopeless.**	☐	☐	☐	☐	☐
5. **I felt like a failure.**	☐	☐	☐	☐	☐
6. **I felt unhappy.**	☐	☐	☐	☐	☐
7. **I felt that I had nothing to look forward to.**	☐	☐	☐	☐	☐
8. **I felt that nothing could cheer me up.**	☐	☐	☐	☐	☐

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Please respond to each statement by marking and “X” in one box per row.

In the past 7 days…

	Never	Rarely	Sometimes	Often	Always
1. **I felt fearful.**	☐	☐	☐	☐	☐
2. **I found it hard to focus on anything other than my anxiety.**	☐	☐	☐	☐	☐
3. **My worries overwhelmed me.**	☐	☐	☐	☐	☐
4. **I felt uneasy.**	☐	☐	☐	☐	☐
5. **I felt nervous.**	☐	☐	☐	☐	☐
6. **I felt like I needed help for my anxiety.**	☐	☐	☐	☐	☐
7. **I felt anxious.**	☐	☐	☐	☐	☐
8. **I felt tense.**	☐	☐	☐	☐	☐

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Please continue on the next page ➡

Please respond to each statement by marking an “X” in one box per row.

	Poor	Fair	Good	Very Good	Excellent
1. **In general, would you say your health is:**	☐	☐	☐	☐	☐
2. **In general, would you say your quality of life is:**	☐	☐	☐	☐	☐
3. **In general, how would you rate your physical health?**	☐	☐	☐	☐	☐
4. **In general, how would you rate your mental health, including your mood and your ability to think?**	☐	☐	☐	☐	☐
5. **In general, how would you rate you satisfaction with your social activities and relationships?**	☐	☐	☐	☐	☐
6. **In general, how would you rate how well you carry out your usual social activities and roles? (This includes activities at home, at work, and in your community, and responsibilities as a parent, child, spouse, employee, friend, etc.)**	☐	☐	☐	☐	☐

	Not at all	A little	Moderately	Mostly	Completely
7. **To what extent are you able to carry out your everyday physical activities such as walking, climbing stairs, carrying groceries, or moving a chair?**	☐	☐	☐	☐	☐

	Never	Rarely	Sometimes	Often	Always
8. **How often have you been bothered by emotional problems such as feeling anxious, depressed, or irritable?**	☐	☐	☐	☐	☐

Please continue on the next page ➡

	None	Mild	Moderately	Severe	Very Severe
9. **How would you rate your fatigue on average?**	☐	☐	☐	☐	☐

	0	1	2	3	4	5	6	7	8	9	10
10. **How would you rate your pain on average?**	☐ No Pain	☐	☐	☐	☐	☐	☐	☐	☐	☐	☐ Worst imaginable pain

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Below is a list of difficulties people sometimes have after stressful life events. Please read each item and then indicate how distressing each difficulty has been for you **during the past 7 days** with respect to your child being in the PICU.

How much were you distressed or bothered by these difficulties?

	Not at all	**A little bit**	**Moderately**	**Quite a bit**	**Extremely**
1. **Any reminder brought back feelings about it.**	☐	☐	☐	☐	☐
2. **I had trouble staying asleep.**	☐	☐	☐	☐	☐
3. **Other things kept making me think about it.**	☐	☐	☐	☐	☐
4. **I felt irritable and angry.**	☐	☐	☐	☐	☐
5. **I avoided letting myself get upset when I thought about it or was reminded of it.**	☐	☐	☐	☐	☐
6. **I thought about it when I didn't mean to.**	☐	☐	☐	☐	☐
7. **I felt as if it hadn't happened or wasn't real.**	☐	☐	☐	☐	☐
8. **I stayed away from reminders of it.**	☐	☐	☐	☐	☐
9. **Pictures about it popped into my head.**	☐	☐	☐	☐	☐
10. **I was jumpy and easily startled.**	☐	☐	☐	☐	☐
11. **I tried not to think about it.**	☐	☐	☐	☐	☐
12. **I was aware that I still had a lot of feelings about it, but I didn't deal with them.**	☐	☐	☐	☐	☐
13. **My feelings about it were kind of numb.**	☐	☐	☐	☐	☐
14. **I found myself acting or feeling like I was back at that time.**	☐	☐	☐	☐	☐

Please continue on the next page ➡

	Not at all	A little bit	Moderately	Quite a bit	Extremely
15. **I had trouble falling asleep.**	☐	☐	☐	☐	☐
16. **I had waves of strong feelings about it.**	☐	☐	☐	☐	☐
17. **I tried to remove it from my memory.**	☐	☐	☐	☐	☐
18. **I had trouble concentrating.**	☐	☐	☐	☐	☐
19. **Reminders of it caused me to have physical reactions, such as sweating, trouble breathing, nausea, or a pounding heart.**	☐	☐	☐	☐	☐
20. **I had dreams about it.**	☐	☐	☐	☐	☐
21. **I felt watchful and on-guard.**	☐	☐	☐	☐	☐
22. **I tried not to talk about it.**	☐	☐	☐	☐	☐

Please continue on the next page ➡

Please mark and "x" in one box per row which best describes how you feel right now.

	Never	Rarely	Sometimes	Often	Always
1. **I think about my child so much that it's hard for me to do things I normally do.**	☐	☐	☐	☐	☐
2. **Memories of my child upset me.**	☐	☐	☐	☐	☐
3. **I feel I cannot accept the death of my child.**	☐	☐	☐	☐	☐
4. **I feel myself longing for my child.**	☐	☐	☐	☐	☐
5. **I feel drawn to places and things associated with my child.**	☐	☐	☐	☐	☐
6. **I can't help feeling angry about my child's death.**	☐	☐	☐	☐	☐
7. **I feel disbelief over what happened.**	☐	☐	☐	☐	☐
8. **I feel stunned or dazed over what happened.**	☐	☐	☐	☐	☐
9. **Ever since he/she died it is hard for me to trust people.**	☐	☐	☐	☐	☐
10. **Ever since s/he died I feel like I have lost the ability to care about other people or I feel distant from people I care about.**	☐	☐	☐	☐	☐
11. **I have pain in the same area of my body or have some of the same symptoms as my child had.**	☐	☐	☐	☐	☐
12. **I go out of my way to avoid reminders of my child.**	☐	☐	☐	☐	☐
13. **I feel that life is empty without my child.**	☐	☐	☐	☐	☐
14. **I hear the voice of my child who died speak to me.**	☐	☐	☐	☐	☐
15. **I see my child who died stand before me.**	☐	☐	☐	☐	☐

Please continue on the next page ➡

	Never	Rarely	Sometimes	Often	Always
16. **I feel that it is unfair that I should live when my child died.**	☐	☐	☐	☐	☐
17. **I feel bitter over my child's death.**	☐	☐	☐	☐	☐
18. **I feel envious of others who have not lost their child.**	☐	☐	☐	☐	☐
19. **I feel lonely a great deal of time ever since s/he died.**	☐	☐	☐	☐	☐

Thank you very much for helping us know more about how to help the patients and families in the PICU.

Please return this survey in the envelope provided.

Agradecemos su ayuda para aprender más acerca de la comunicación en la Unidad de Cuidados Intensivos Pediátricos (PICU). Esta encuesta aborda preguntas acerca de su experiencia en PICU, sus reacciones respecto al programa PICU Supports y acerca de usted. Le pedimos que la conteste y la envíe en el sobre proporcionado.

Encuesta 5 para el padre o la madre de familia

La encuesta toma aproximadamente de 30 a 45 minutos en contestarse

Fecha de hoy:

Mes XX	Día XX	Año XXXX

:

Las siguientes preguntas le piden calificar varios aspectos del programa PICU Supports. Elija la respuesta que **mejor** describa su experiencia.

	No fue útil en lo absoluto	**No fue muy útil**	**Fue un poco útil**	**Increíble mente útil**	**No lo puedo evaluar**
1. **¿Qué tan útil fue PICU Supports respecto a la comunicación en la unidad?**	☐	☐	☐	☐	☐

Durante la estancia de su hijo en PICU, el programa PICU Supports tuvo in impacto positivo en:

	Sí	**No**
2. La calidad de la comunicación entre usted y el equipo médico	☐	☐
3. La calidad de la comunicación entre el equipo médico (cómo se comunican los miembros entre ellos)	☐	☐
4. La calidad de la comunicación entre usted y el equipo médico	☐	☐
5. Sus conversaciones con el equipo médico acerca de los valores y preferencias respecto a la atención médica de su hijo.	☐	☐
6. Su experiencia en el hospital	☐	☐
7. La posición de la familia respecto a la atención recibida (la atención debe centrarse en la familia)	☐	☐

Continúe en la siguiente página ➡

Desde su punto de vista, ¿qué tan útiles fueron las siguientes partes de PICU Supports?:

	Inútil	**No muy útil**	**Muy útil**	**Extremadamente útil**	**No lo utilicé**
8. Las visitas del Navegador durante la semana	☐	☐	☐	☐	☐
9. El diario de comunicación en la habitación de su hijo.	☐	☐	☐	☐	☐
10. Las reuniones familiares que coordinó regularmente el navegador.	☐	☐	☐	☐	☐
11. El Manual de PICU que usted recibió.	☐	☐	☐	☐	☐
12. La lista de preguntas en la sección del Manual de PICU, llamada “¿Cuáles son algunas preguntas que le gustaría hacer?”	☐	☐	☐	☐	☐
13. El calendario o diario al final del Manual PICU.	☐	☐	☐	☐	☐
14. Todo material informativo o educativo que se le entregó.	☐	☐	☐	☐	☐

15. **Haga un comentario acerca de las partes de PICU Support que le parecieron útiles.**

Continúe en la siguiente página ➡

16. **Haga un comentario acerca de las partes de PICU Support que no le gustaron.**

17. **¿Cómo podríamos mejorar PICU Supports?**

18. **Tienen alguna otra pregunta o comentario?**

Continúe en la siguiente página ➡

Satisfacción del padre de familia respecto a la atención en la Unidad de Cuidados Intensivos Pediátricos (*Parent Satisfaction with Care in the Intensive Care Unit* ©)

pFS-ICU (24)

¿Cómo estamos trabajando?
Su opinión acerca de la estancia de su hijo en la Unidad de Cuidados Intensivos

Las siguientes preguntas para **USTED** abordan aspectos de la **admisión actual de su hijo en la unidad de cuidados intensivos**. Sabemos que ha habido muchos doctores, enfermeros y otro personal que ha participado en el cuidado de su hijo. Entendemos que puede haber excepciones, pero nos interesa **su opinión en general** acerca de la calidad de la atención que le estamos proporcionando. Estamos conscientes de que probablemente usted y su familia están atravesando por un momento muy difícil. Agradecemos que se tome el tiempo de darnos su opinión. Le pedimos que se tome un momento para decirnos lo que estamos haciendo bien y lo que podemos mejorar en nuestra ICU. Tenga por seguro que todas las respuestas son confidenciales. Los médicos y enfermeros que cuidan de su hijo no podrán identificar sus respuestas.

PARTE I: SATISFACCIÓN CON LA ATENCIÓN

Marque con una “X” sólo UNA de las casillas que mejor describa su opinión. Si la pregunta no corresponde a la estancia de su hijo, entonces marque “no corresponde” (N/A).

Cómo tratamos a su niño (el/la paciente):

1. **Preocupación y cuidado por parte del personal de la ICU** (la cortesía, respeto y compasión que se le dio a su niño [el/la paciente])

Excelente	Muy bien	Bien	Aceptable	Mal	N/A
☐	☐	☐	☐	☐	☐

Manejo de síntomas (qué tan bien evaluó y trató el personal de la ICU los síntomas de su niño):

2. **Dolor**

Excelente	Muy bien	Bien	Aceptable	Mal	N/A
☐	☐	☐	☐	☐	☐

3. **Dificultad al respirar**

Excelente	Muy bien	Bien	Aceptable	Mal	N/A
☐	☐	☐	☐	☐	☐

4. **Inquietud**

Excelente	Muy bien	Bien	Aceptable	Mal	N/A
☐	☐	☐	☐	☐	☐

Continúe en la siguiente página ➡

¿Cómo lo tratamos a usted?

5. **Tomar en cuenta sus necesidades** (qué tan bien mostró interés el personal de la ICU en las necesidades de usted):

Excelente	Muy bien	Bien	Aceptable	Mal	N/A
☐	☐	☐	☐	☐	☐

6. **Apoyo emocional** (qué tan bien le proporcionó apoyo emocional el personal de la ICU):

Excelente	Muy bien	Bien	Aceptable	Mal	N/A
☐	☐	☐	☐	☐	☐

7. **Coordinación del cuidado** (el trabajo de equipo de todo el personal de la ICU que cuidó a su niño):

Excelente	Muy bien	Bien	Aceptable	Mal	N/A
☐	☐	☐	☐	☐	☐

8. **Preocupación y cuidado por parte del personal de la ICU** (la cortesía, respeto y compasión que le fueron proporcionados a usted):

Excelente	Muy bien	Bien	Aceptable	Mal	N/A
☐	☐	☐	☐	☐	☐

ENFERMERAS

9. **Destreza y capacidad de las enfermeras de la ICU** (qué tan bien cuidan las enfermeras a su niño):

Excelente	Muy bien	Bien	Aceptable	Mal	N/A
☐	☐	☐	☐	☐	☐

10. **Frecuencia de comunicación con las enfermeras de la ICU** (qué tan frecuentemente se comunicaron con usted las enfermeras de la ICU en relación con la condición de su niño):

Excelente	Muy bien	Bien	Aceptable	Mal	N/A
☐	☐	☐	☐	☐	☐

MÉDICOS (todos los médicos, incluyendo residentes e internos)

11. **Destreza y capacidad de los médicos de la ICU** (qué tan bien cuidaron los médicos a su niño):

Excelente	Muy bien	Bien	Aceptable	Mal	N/A
☐	☐	☐	☐	☐	☐

Continúe en la siguiente página ➡

LA ICU

12. **¿Cómo fue el ambiente de la ICU?**

Excelente	Muy bien	Bien	Aceptable	Mal	N/A
☐	☐	☐	☐	☐	☐

LA SALA DE ESPERA

13. **¿Cómo fue el ambiente en la sala de espera de la ICU?**

Excelente	Muy bien	Bien	Aceptable	Mal	N/A
☐	☐	☐	☐	☐	☐

14. **A algunas personas les gusta que se haga todo en relación con sus problemas de salud, mientras que a otras no les gusta que se haga mucho. ¿Qué tan satisfecho estuvo usted con el nivel o cantidad de cuidados de la salud que recibió su niño en la ICU?**

☐ muy insatisfecho
☐ un poco insatisfecho
☐ generalmente satisfecho
☐ muy satisfecho
☐ completamente satisfecho

Continúe en la siguiente página ➡

PARTE 2: SATISFACCIÓN DEL PADRE O MADRE DE FAMILIA, PERSONA A CARGO DEL PACIENTE O TUTOR CON LA TOMA DE DECISIONES RESPECTO A LA ATENCIÓN QUE RECIBEN LOS PACIENTES EN ESTADO CRÍTICO

Esta parte del cuestionario está diseñada para medir cómo se siente sobre SU participación en las decisiones relacionadas con la atención médica de su hijo. En la Unidad de Cuidados Intensivos (ICU), su hijo fue atendido por diferentes personas. Queremos que al contestar estas preguntas piense en toda la atención que ha recibido su hijo.

Marque con una "X" sólo UNA de las casillas que mejor describa su opinión.

NECESIDADES DE INFORMACIÓN

15. **Frecuencia de la comunicación con los médicos de la ICU** (qué tan frecuentemente se comunicaron con usted los médicos de la ICU en relación con la condición de su niño):

Excelente	Muy bien	Bien	Aceptable	Mal	N/A
☐	☐	☐	☐	☐	☐

16. **Facilidad para obtener información** (buena disposición del personal de la ICU para responder a sus preguntas):

Excelente	Muy bien	Bien	Aceptable	Mal	N/A
☐	☐	☐	☐	☐	☐

17. **Comprensión de la información** (qué tan bien le proporcionó el personal de la ICU explicaciones que usted comprendió):

Excelente	Muy bien	Bien	Aceptable	Mal	N/A
☐	☐	☐	☐	☐	☐

18. **Honestidad de la información** (la honestidad de la información que le fue proporcionada a usted respecto de la condición de su niño):

Excelente	Muy bien	Bien	Aceptable	Mal	N/A
☐	☐	☐	☐	☐	☐

19. **Totalidad/Integridad de la información** (qué tan bien le informo a usted el personal de la ICU sobre lo que estaba sucediendo con su niño y la razón por la que se estaban haciendo las cosas):

Excelente	Muy bien	Bien	Aceptable	Mal	N/A
☐	☐	☐	☐	☐	☐

20. **Consistencia de la información** (la consistencia de la información que le fue proporcionada a usted respecto a la condición de su niño – obtuvo usted información similar por parte del médico, enfermera, etc.):

Excelente	Muy bien	Bien	Aceptable	Mal	N/A
☐	☐	☐	☐	☐	☐

Continúe en la siguiente página ➡

¿Cómo estamos trabajando?
Su opinión acerca de la estancia de su hijo en la Unidad de Cuidados Intensivos

PROCESO DE TOMA DE DECISIONES

Durante la estancia de su niño en la ICU, se toman muchas decisiones importantes respecto del cuidado de la salud que él o ella recibe. En las siguientes preguntas, elija **una** respuesta del siguiente grupo de ideas que mejor se ajuste a sus puntos de vista:

21. **¿Se sintió usted incluido en el proceso de toma de decisiones?**
    - ☐ Me sentí muy excluido
    - ☐ Me sentí un poco excluido
    - ☐ No me sentí ni incluido ni excluido en el proceso de toma de decisiones
    - ☐ Me sentí un poco incluido
    - ☐ Me sentí muy incluido

22. **¿Se sintió usted apoyado durante el proceso de toma de decisiones?**
    - ☐ Me sentí totalmente agobiado
    - ☐ Me sentí un poco agobiado
    - ☐ No me sentí ni agobiado ni apoyado
    - ☐ Me sentí apoyado
    - ☐ Me sentí muy apoyado

23. **¿Sintió usted que tenía control sobre el cuidado de su niño?**
    - ☐ Realmente sentí que no tenía control y que el sistema de cuidados de la salud asumió el control y ordenó el cuidado que mi niño recibió
    - ☐ Sentí un poco que no tenía control y que el sistema de cuidados de la salud asumió el control y ordenó el cuidado que mi niño recibió
    - ☐ No sentí que no tuviera control ni que tuviera control
    - ☐ Sentí que tenía algo de control sobre el cuidado que mi niño recibió
    - ☐ Sentí que tenía buen control sobre el cuidado que mi niño recibió

24. **Al tomar decisiones, ¿tuvo usted el tiempo suficiente para tratar sus inquietudes y que le respondieran sus preguntas?**

    - ☐ Podría haber utilizado más tiempo
    - ☐ Tuve el tiempo suficiente

Continúe en la siguiente página ➡

25. **Cuál de las siguientes opciones describe mejor su opinión:**
    - ☐Siento que la vida de mi hijo se prolongó de manera innecesaria.
    - ☐ Siento que la vida de mi hijo se prolongó un poco más de lo necesario.
    - ☐Siento que la vida de mi hijo no se prolongó ni acortó de manera innecesaria.
    - ☐Siento que la vida de mi hijo se acortó un poco de manera innecesaria.
    - ☐Siento que la vida de mi hijo se acortó de manera innecesaria.

26. **Durante las últimas horas en la vida de su hijo, ¿cuál de las siguientes describe mejor su opinión?:**
    - ☐Siento que él o ella estuvo muy incómodo
    - ☐
    - ☐Siento que él o ella estuvo un poco incómodo
    - ☐Siento que él o ella estuvo en su mayoría cómodo
    - ☐Siento que él o ella estuvo muy cómodo
    - ☐Siento que él o ella estuvo completamente cómodo

27. **Durante las últimas horas en la vida de su hijo, ¿cuál de las siguientes describe mejor su opinión?:**
    - ☐Me sentí muy abandonado por el equipo de profesionales de la salud
    - ☐Me sentí abandonado por el equipo de profesionales de la salud
    - ☐No me sentí abandonado ni apoyado por el equipo de profesionales de la salud
    - ☐Me sentí apoyado por el equipo de profesionales de la salud
    - ☐Me sentí muy apoyado por el equipo de profesionales de la salud

Continúe en la siguiente página ➡

Las siguientes preguntas están relacionadas a la colaboración del equipo en las decisiones tomadas respecto a su hijo.

Encierre en un círculo el número que mejor represente su opinión respecto al proceso del equipo.

1. **Los miembros del equipo planearon en conjunto tomar las decisiones respecto a la atención de su hijo.**

1 2 3 4 5 6 7
Completamente en desacuerdo … Completamente de acuerdo

2. **Los miembros del equipo tuvieron una comunicación abierta entre ellos al tomar las decisiones para su hijo.**

1 2 3 4 5 6 7
Completamente en desacuerdo … Completamente de acuerdo

3. **La responsabilidad de la toma de decisiones para su hijo se compartió entre los miembros del equipo.**

1 2 3 4 5 6 7
Completamente en desacuerdo … Completamente de acuerdo

4. **Los miembros del equipo colaboraron juntos en la toma de decisiones.**

1 2 3 4 5 6 7
Completamente en desacuerdo … Completamente de acuerdo

5. **En el proceso de la toma de decisiones, se tomaron en cuenta las inquietudes de todos los miembros del equipo respecto a las necesidades de hijo.**

1 2 3 4 5 6 7
Completamente en desacuerdo … Completamente de acuerdo

6. **La toma de decisiones para su hijo se coordinó entre los miembros del equipo.**

1 2 3 4 5 6 7
Completamente en desacuerdo … Completamente de acuerdo

7. **¿Qué tanto colaboraron los miembros del equipo en la toma de decisiones para su hijo?**

1 2 3 4 5 6 7
No colaboraron … Colaboraron completamente

8. **¿Qué tan satisfecho está usted con la forma en que se tomaron las decisiones para su hijo? Esto se refiere al proceso de toma de decisiones, no necesariamente a las decisiones mismas.**

1 2 3 4 5 6 7
Nada satisfecho … Muy satisfecho

9. **¿Qué tan satisfecho estuvo usted con las decisiones que se tomaron para su hijo?**

1 2 3 4 5 6 7
Nada satisfecho … Muy satisfecho

Continúe en la siguiente página

Las siguientes preguntas tratan acerca de la toma de decisiones en PICU.

1. **Describa la decisión MÁS IMPORTANTE que tomó para su hijo mientras se encontraba en PICU:**

Para contestar las siguientes preguntas, piense en la decisión que acaba de anotar. Después, marque con una "X", sólo UNA casilla por fila que mejor describa sus sentimientos actuales respecto a esta decisión.

	Completa-mente de acuerdo	**De acuerdo**	**Ni de acuerdo ni en desacuerdo**	**En desacuerdo**	**Completa-mente en desacuerdo**
3. **Fue la decisión correcta**	☐	☐	☐	☐	☐
4. **Me arrepiento de la decisión que se tomó**	☐	☐	☐	☐	☐
5. **Si tuviera que volver a hacerlo, tomaría la misma decisión**	☐	☐	☐	☐	☐
6. **La decisión lastimó mucho a mi hijo(a)**	☐	☐	☐	☐	☐
7**. La decisión fue muy sabia**	☐	☐	☐	☐	☐

Continúe en la siguiente página ➡

Responda a cada afirmación marcando sólo una respuesta ("x") por fila.

En los últimos 7 días...

	Nunca	Rara vez	Algunas veces	A menudo	Siempre
1. **Sentí miedo**	☐	☐	☐	☐	☐
2. **Tuve dificultad para concentrarme en otra cosa que no fuera mi ansiedad**	☐	☐	☐	☐	☐
3. **Mis inquietudes fueron demasiado para mi**	☐	☐	☐	☐	☐
4. **Me sentí intranquilo/a**	☐	☐	☐	☐	☐
5. **Me sentí nervioso/a**	☐	☐	☐	☐	☐
6. **Sentí que necesitaba ayuda para controlar mi ansiedad.**	☐	☐	☐	☐	☐
7. **Sentí ansiedad**	☐	☐	☐	☐	☐
8. **Me sentí tenso/a**	☐	☐	☐	☐	☐

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Continúe en la siguiente página ➡

Responda a cada afirmación marcando sólo una respuesta ("x") por fila.

En los últimos 7 días...

	Nunca	Rara vez	Algunas veces	A menudo	Siempre
1. **Senti que no valia nada**	☐	☐	☐	☐	☐
2. **Me senti indefenso/a (que no podia hacer nada para ayudarme)**	☐	☐	☐	☐	☐
3. **Me sentí deprimido/a**	☐	☐	☐	☐	☐
4. **Me sentí desesperanzado/a**	☐	☐	☐	☐	☐
5. **Me sentí fracasado/a**	☐	☐	☐	☐	☐
6. **Me sentí descontento/a**	☐	☐	☐	☐	☐
7. **Sentí que nada me ilusionaba**	☐	☐	☐	☐	☐
8. **Sentí que nada me podía animar**	☐	☐	☐	☐	☐

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Continúe en la siguiente página ➡

Responda a cada afirmación marcando sólo una respuesta ("x") por fila.

	Mala	Pasable	Buena	Muy buena	Excelente
1. **En general, diría que su salud es**	☐	☐	☐	☐	☐
2. **En general, diría que su calidad de vida es**	☐	☐	☐	☐	☐
3. **En general, ¿cómo calificaría su salud física?**	☐	☐	☐	☐	☐
4. **En general, ¿cómo calificaría su salud mental, incluidos su estado de ánimo y su capacidad para pensar?**	☐	☐	☐	☐	☐
5. **En general, ¿cómo calificaría su satisfacción con sus actividades sociales y sus relaciones con otras personas?**	☐	☐	☐	☐	☐
6. **En general, califique en qué medida puede realizar sus actividades sociales y funciones habituales. (Esto comprende las actividades en casa, en el trabajo y en el área donde reside, así como sus responsabilidades como padre o madre, hijo/a, cónyuge, empleado/a, amigo/a, etc.)**	☐	☐	☐	☐	☐

	Para nada	Un poco	Moderadamente	En su mayoría	Completamente
7. **¿En qué medida puede realizar sus actividades físicas diarias, como caminar, subir escaleras, cargar las compras o mover una silla?**	☐	☐	☐	☐	☐

	Nunca	Rara vez	Algunas veces	A menudo	Siempre
8. **¿Con qué frecuencia le han afectado problemas emocionales como sentir ansiedad, depresión o irritabilidad ?**	☐	☐	☐	☐	☐

Continúe en la siguiente página ➡

	Ninguno	Leve	Moderado	Intenso	Muy intenso
9. **En promedio, ¿cómo calificaría su cansancio?**	☐	☐	☐	☐	☐

	0	1	2	3	4	5	6	7	8	9	10
10. En promedio, ¿cómo calificaría su dolor ?	☐ **Ningún dolor**	☐	☐	☐	☐	☐	☐	☐	☐	☐	☐ **El peor dolor imaginable**

Continúe en la siguiente página ➡

A continuación se encuentra una lista dificultades que en ocasiones presentan algunas personas después de un suceso estresante en su vida. Lea cada declaración y después indique que tan estresante ha sido para usted cada dificultad presentada **durante los últimos 7 días**, con respecto a la hospitalización de su hijo en PICU.

¿Qué tanto le estresaron o molestaron estas dificultades?

	Para nada	Un poco	Moderada-mente	Bastante	Demasiado
1. **Todo lo que le trajo recuerdos y le hizo revivir sus sentimientos.**	☐	☐	☐	☐	☐
2. **Tuve dificultades para mantenerme dormido.**	☐	☐	☐	☐	☐
3. **Otras cosas me lo recordaban constantemente.**	☐	☐	☐	☐	☐
4. **Me sentí irritable y enojado.**	☐	☐	☐	☐	☐
5. **Evitaba molestarme cuando pensaba en ello o algo me lo recordaba.**	☐	☐	☐	☐	☐
6. **Pensaba en ello sin quererlo.**	☐	☐	☐	☐	☐
7. **Sentí como si no hubiera pasado o no hubiera sido real.**	☐	☐	☐	☐	☐
8. **Me alejé de lo que me hacía recordarlo.**	☐	☐	☐	☐	☐
9. **Imágenes sobre ello me venían a la cabeza.**	☐	☐	☐	☐	☐
10. **Estaba nervioso y me sorprendía fácilmente.**	☐	☐	☐	☐	☐
11. **Trataba de no pensar en ello.**	☐	☐	☐	☐	☐
12. **Estaba consciente de que todavía tenía muchos sentimientos, pero no hice nada al respecto.**	☐	☐	☐	☐	☐
13. **Estaba insensible a ello.**	☐	☐	☐	☐	☐
14. **Me encontré actuando y sintiendo que estaba de regreso en ese momento.**	☐	☐	☐	☐	☐

	Para nada	Un poco	Moderada-mente	Bastante	Demasiado
15. **Tuve dificultades para conciliar el sueño**	☐	☐	☐	☐	☐
16. **Tenía oleadas de sentimientos intensos al respecto.**	☐	☐	☐	☐	☐
17. **Trate de eliminarlo de mi memoria.**	☐	☐	☐	☐	☐
18. **Tenía dificultades para concentrarme.**	☐	☐	☐	☐	☐
19. **Los recordatorios me causaron reacciones físicas, como sudoración, dificultad para respirar, náusea o palpitaciones.**	☐	☐	☐	☐	☐
20. **Tenía sueños sobre ello.**	☐	☐	☐	☐	☐
21. **Me sentía vigilante y en guardia.**	☐	☐	☐	☐	☐
22. **Trataba de no hablar de ello.**	☐	☐	☐	☐	☐

Marque con una "x" sólo <u>una</u> casilla por fila que mejor describa <u>cómo se siente usted ahora mismo</u>.

	Nunca	En raras ocasiones	Algunas veces	A menudo	Siempre
1. **Pienso tanto en mi hijo que se me dificulta hacer las cosas que hago normalmente.**	☐	☐	☐	☐	☐
2. **Los recuerdos de mi hijo me hacen sentir mal.**	☐	☐	☐	☐	☐
3. **Siento que no puedo aceptar la muerte de mi hijo.**	☐	☐	☐	☐	☐
4. **Anhelo volver a ver o estar con mi hijo.**	☐	☐	☐	☐	☐
5. **Me siento atraída a lugares y cosas asociadas con mi hijo.**	☐	☐	☐	☐	☐
6. **No puedo evitar sentir enojo por la muerte de mi hijo.**	☐	☐	☐	☐	☐
7. **No puedo creer lo que sucedió.**	☐	☐	☐	☐	☐
8. **Me siento pasmado y aturdido con lo que sucedió.**	☐	☐	☐	☐	☐
9. **Desde que murió mi hijo, se me dificulta confiar en la gente.**	☐	☐	☐	☐	☐
10. **Desde que murió mi hijo, siento que perdí la capacidad de interesarme por los demás o me siento distante de mis seres queridos.**	☐	☐	☐	☐	☐
11. **Siento dolor en el mismo lugar del cuerpo o tengo algunos de los mismos síntomas que tenía mi hijo.**	☐	☐	☐	☐	☐
12. **Hago todo lo posible por evitar las cosas que me recuerdan a mi hijo.**	☐	☐	☐	☐	☐
13. **Siento que la vida no tiene sentido sin mi hijo.**	☐	☐	☐	☐	☐
14. **Escucho que mi hijo que se murió me habla.**	☐	☐	☐	☐	☐
15. **Veo frente a mí a mi hijo que se murió.**	☐	☐	☐	☐	☐

	Nunca	En raras ocasiones	Algunas veces	A menudo	Siempre
16. **Siento que es injusto que yo viva cuando mi hijo se murió.**	☐	☐	☐	☐	☐
17. **Me siento amargado por la muerte de mi hijo.**	☐	☐	☐	☐	☐
18. **Siento envidia de otras personas que no han perdido un hijo.**	☐	☐	☐	☐	☐
19. **Desde que se murió mi hijo, me siento solo la mayor parte del tiempo.**	☐	☐	☐	☐	☐

Gracias por permitirnos aprender más acerca de cómo podemos ayudar a los pacientes y sus familias en PICU.

Envíe esta encuesta en el sobre proporcionado.

Parent Interview Guide:

(To be completed at discharge for non-bereaved & 3-5weeks post discharge for bereaved)

1. Goal of interview: Obtain overview of the PICU experience and develop rapport.
    a. I would like to talk with you about your child's recent PICU stay. Please describe what happened during [insert child's name] recent stay in the PICU?

2. Goal of interview: Obtain information about the positive and negative aspects of communication with HTMs during their PICU experience.
    a. Based on your experience, how would you describe communication between you and the healthcare team?
    b. Please describe (or give examples about) some of the good aspects of communication between you and the healthcare team. (i.e. what seemed to go well in terms of your communicating with the healthcare team?)
    c. Please describe (or give examples about) aspects of communication between you and the healthcare team that you wished had gone better. (i.e. what did not seem to go well in terms of your communication with the healthcare team?)

3. Goal of interview: Obtain information about perceptions of care coordination among HTMs during their child's PICU admission.
    a. Along with the PICU team, which, if any, other specialty teams were involved in your child's care?
    b. How was communication between the PICU team and the other specialty teams involved in your child's care? Please describe or give examples.
    c. How was communication among the people on the PICU team? Please describe or give examples.
    d. During your child's stay in the PICU, what interactions did you have with social workers, chaplains, case managers, and/or child-life specialists?
    e. How was communication between the PICU team and social workers, chaplains, case managers, and/or child-life specialists that you interacted with? Please describe or give examples.

4. Goal of interview: Obtain information about decisions that parents faced during their child's PICU admission.
    a. What kind of decisions did you and the healthcare team make for your child during your child's PICU admission?
    b. How did you learn that those decisions needed to be made? (i.e. how was information about such decision presented to you?)

5. Goal of interview: Obtain information about parents' involvement in decision making during their child's PICU admission.
    a. How involved did you feel about the decisions made for your child during your child's PICU admission?
    b. Would you have liked to be more involved in decisions made about your child during your child's PICU admission?
    c. How could the healthcare team have involved you more?

6. Goal of interview: Obtain information about perceptions of the emotional support they received during their child's PICU admission
    a. Describe the emotional support you received from the healthcare team during your child's PICU admission.
    b. How did the healthcare team support you emotionally during your child's PICU admission? Please describe or give examples.
    c. How could the healthcare team have provided more emotional support during your child's PICU admission? Please describe or give examples.

7. Goal of interview: Obtain information about the acceptability of having a navigator or receiving an education brochure.
    a. What was it like to have a navigator during your child's PICU admission?
        Or What was it like to receive an education brochure when your child was admitted to the PICU?
    b. What things about the navigator did you like?
        Or What things about the brochure did you like?
    c. What things about the navigator did you not like?
        Or What things about the brochure did you not like?
    d. What was it like to receive the PICU handbook when your child was admitted to the PICU? Did you use the Question Prompt list in the handbook? Or the Calendar/Diary in the back of the handbook? What was it like to have the Communication Log? What did you like about these tools? What did you not like?

8. Goal of interview: Obtain information about the effectiveness of the navigator or education brochure.
    a. How did the navigator impact your experience in the PICU? Or How did the brochure impact your experience in the PICU?
    b. How did the navigator impact communication between you and the healthcare team during your child's PICU admission? Or How did the brochure impact communication between you and the healthcare team during your child's PICU admission?
    c. How did the navigator impact communication among the healthcare team members caring for your child?

9. Goal of interview: Obtain information about other topics important to parents
    a. What else you would like to share about your child's PICU stay that impacted your experience?

[Date]

[Participant]
[Address]
[Address]

Dear [Participant],

Thank you for participating in the study called, *Improving Communication in the Pediatric Intensive Care Unit for Patients Facing Life-Changing Decisions: The Navigate Study*.

As a doctor who works in the pediatric intensive care unit (PICU), I see children and their families struggling with critical illness all the time. I am committed to finding better ways to support families of children in the PICU. Through your involvement in this project, we hope to know more about what can be done to help others like you and your family.

As part of this study, we will be contacting you in the future to complete 2 additional surveys. I appreciate your continued support of this project.

No one understands better than you the difficulties faced by a family when a child is critically ill. Thank you for sharing your experiences with us. Please do contact me if you have any questions or other comments about this project.

Thank you for your time and participation

Sincerely,

Kelly Michelson
Attending Physician/Pediatric Intensive Care Unit
Ann & Robert H. Lurie Children's Hospital of Chicago
Email: kmichelson@luriechildrens.org
Phone: 312-227-1606

[Date]

[Participant]
[Address]
[Address]

Estimado(a) [Participant]

Agradecemos su participación en el estudio titulado: "Mejoramiento del proceso de comunicación en la Unidad de Cuidados Intensivos Pediátricos para los pacientes que se enfrentan a decisiones que suponen un cambio de vida (*Navigate Study*)" .

Como médica integrante del equipo que conforma la Unidad de Cuidados Intensivos Pediátricos (PICU, *Pediatric Intensive Care Unit*), con frecuencia soy testigo de todas las dificultades que afrontan los niños que padecen enfermedades críticas y sus familias, y estoy comprometida a encontrar una mejor forma de apoyar a las familias de los niños hospitalizados en PICU. A través de su participación en este proyecto, esperamos aprender más acerca de lo que se puede hacer para ayudar a otras personas que se encuentran en situaciones similares a la suya.

Como parte de este estudio, nos comunicaremos con ustedes en el futuro para que contesten otras dos encuestas. Agradecemos su apoyo continuo para este proyecto.

Nadie entiende mejor que usted las dificultades que enfrenta una familia cuando un hijo está en estado crítico. Agradecemos que nos comparta sus experiencias. Le pido que se comunique conmigo si tiene preguntas o comentarios acerca de este proyecto.

Gracias por su tiempo y participación.

Atentamente,

Kelly Michelson
Médica adjunta de la Unidad de Cuidados Intensivos Pediátricos
Ann & Robert H. Lurie Children's Hospital of Chicago
Correo electrónico: kmichelson@luriechildrens.org
Teléfono: 312-227-1606

[Date]

[Potential Participant]
[Address]
[Address]

Dear [Potential Participant],

Thank you for your participation in our research project, *Improving Communication in the Pediatric Intensive Care Unit for Patients Facing Life-Changing Decisions: The Navigate Study.*

The staff at Ann & Robert H. Lurie Children's Hospital of Chicago is committed to helping patients and their families throughout all aspects of illness. Children like [child's name] remind us how fragile health can be. As a doctor who works in the pediatric intensive care unit (PICU), I see children struggling with critical illness all the time. Continuing our goal of learning how to provide the best support possible to children and their families in the PICU, we would like to follow up with you about your experience in the PICU, your views on the research that you participated in, and how your are doing after your child's stay in the PICU.

Enclosed is a survey for you to complete and return to us in the self-addressed stamped envelope provided.

If we do not receive this packet back within 2 weeks, our study team will call you to remind you to complete the survey. If you do not wish for someone to call you about this, please let us know by sending back the attached form in the envelop provided.

If you have any questions please feel free to contact the Study Coordinator, Laura Campbell (312-227-1618, lacampbell@luriechildrens.org), or myself, Dr. Kelly Michelson (312-227-1606, email kmichelson@luriechildrens.org).

No one understands better than you the difficulties faced by a family when a child is critically ill. We hope to learn from your experiences by hearing your story and the stories of other families whose children have been admitted to the pediatric intensive care unit.

Thank you for your time and participation

Sincerely,

Kelly Michelson
Attending Physician/Pediatric Intensive Care Unit
Ann & Robert H. Lurie Children's Hospital of Chicago

DECLINE Participation

☐ Please **DO NOT** call my home about the study called, **“***Improving Communication in the Pediatric Intensive Care Unit for Patients Facing Life-Changing Decisions: The Navigate Study.***”**

[Date]

[Potential Participant]
[Address]
[Address]

Estimado(a) [Potential Participant]:

Agradecemos su participación en nuestro proyecto de investigación, *"Estudio de navegación (Navigate Study): Mejoramiento del proceso de comunicación en la Unidad de Cuidado Intensivo Pediátrico para los pacientes que se enfrentan a decisiones que suponen un cambio de vida"*:

El personal del Ann & Robert H. Lurie Children's Hospital of Chicago se compromete a ayudar a los pacientes y sus familias a lo largo de todos los aspectos de la enfermedad. Los niños como [child's name] nos recuerdan lo frágil que puede ser la salud. Como médica integrante del equipo que conforma la Unidad de Cuidados Intensivos Pediátricos (PICU, *pediatric intensive care unit*), con frecuencia soy testigo de todas las dificultades que afrontan los niños que padecen enfermedades críticas. Para continuar trabajando por nuestro objetivo, de aprender a proporcionar el mejor apoyo posible a los niños y sus familias en PICU, nos gustaría tener seguimiento con usted acerca de su experiencia en PICU, su opinión sobre la investigación en la que participó y cómo se encuentra después de la estancia de su hijo en PICU.

Adjunta se encuentra una encuesta para que usted la conteste y nos la envíe en el sobre estampado que también le proporcionamos.

Si no recibimos el paquete en el transcurso de 2 semanas, nuestro equipo del estudio le contactará por teléfono para recordarle contestar la encuesta. Si no desea recibir una llamada acerca de este asunto, le pedimos que nos lo haga saber enviando el formulario adjunto en el sobre que le proporcionamos.

Si tiene preguntas, no dude en contactar a la coordinadora del estudio, Laura Campbell (312-227-1618, lacampbell@luriechildrens.org), o a mí, la Dra. Kelly Michelson (312-227-1606, kmichelson@luriechildrens.org).

Nadie comprende mejor que usted las dificultades enfrentadas por una familia cuando un hijo se encuentra en estado crítico. Esperamos aprender de sus experiencias y las de otras familias cuyos hijos han sido internados en la unidad de cuidados intensivos pediátricos.

Le agradecemos su tiempo y su participación.

Atentamente,

Kelly Michelson
Médica adjunta de la Unidad de Cuidados Intensivos Pediátricos
Ann & Robert H. Lurie Children's Hospital of Chicago

RECHAZAR la participación

☐ Por favor NO LLAMEN a mi hogar acerca del *“Estudio de navegación (Navigate Study): Mejoramiento del proceso de comunicación en la Unidad de Cuidado Intensivo Pediátrico para los pacientes que se enfrentan a decisiones que suponen un cambio de vida”*.

[Date]

[Potential Participant]
[Address]
[Address]

Dear [Potential Participant],

Thank you for your participation in our research project, *Improving Communication in the Pediatric Intensive Care Unit for Patients Facing Life-Changing Decisions: The Navigate Study.*

The staff at Ann & Robert H. Lurie Children's Hospital of Chicago is committed to helping patients and their families throughout all aspects of illness. Children like [child's name] remind us that, despite our efforts, there are some patients we simply cannot save. As a doctor who works in the pediatric intensive care unit (PICU), I am witness to this sad fact too often. Continuing our goal of learning how to provide the best support possible to children and their families in the PICU, we would like to follow up with you about your experience in the PICU, your views on the research that you participated in, and how your are doing after your child's stay in the PICU.

Enclosed is a survey for you to complete and return to us in the self-addressed stamped envelope provided. In addition to the survey, you may also take part in a telephone interview.

If we do not receive the survey packet back within 2 weeks, our study team will call you to ask if you are interested in participating in an interview and remind you to complete the survey. If you do not wish for someone to call you about this, please let us know by sending back the attached form in the envelop provided.

If you have any questions please feel free to contact the Study Coordinator, Laura Campbell (312-227-1618, lacampbell@luriechildrens.org), or myself, Dr. Kelly Michelson (312-227-1606, email kmichelson@luriechildrens.org).

No one understands better than you the difficulties faced by a family when a child is dying. We hope to learn from your experiences by hearing your story and the stories of other families whose children have died in the intensive care unit.

Thank you for your time and participation.

Sincerely,

Kelly Michelson
Attending Physician/Pediatric Intensive Care Unit
Ann & Robert H. Lurie Children's Hospital of Chicago

DECLINE Participation

☐ Please **DO NOT** call my home about the study called, **“***Improving Communication in the Pediatric Intensive Care Unit for Patients Facing Life-Changing Decisions: The Navigate Study.***”**

[Date]

[Potential Participant]
[Address]
[Address]

Estimado(a) [Potential Participant]:

Agradecemos su participación en nuestro proyecto de investigación, *"Estudio de navegación (Navigate Study): Mejoramiento del proceso de comunicación en la Unidad de Cuidado Intensivo Pediátrico para los pacientes que se enfrentan a decisiones que suponen un cambio de vida"*:

El personal del Ann & Robert H. Lurie Children's Hospital of Chicago se compromete a ayudar a los pacientes y sus familias a lo largo de todos los aspectos de la enfermedad. Los niños como [*child's name*] nos recuerdan que, a pesar de nuestro esfuerzo, a veces existen pacientes que simplemente no podemos salvar. Como médica integrante del equipo que conforma la Unidad de Cuidados Intensivos Pediátricos (PICU, *pediatric intensive care unit*), desafortunadamente he sido testigo de este hecho demasiadas veces. Para continuar trabajando por nuestro objetivo, de aprender a proporcionar el mejor apoyo posible a los niños y sus familias en PICU, nos gustaría tener seguimiento con usted acerca de su experiencia en PICU, su opinión sobre la investigación en la que participó y cómo se encuentra después de la estancia de su hijo en PICU.

Adjunta se encuentra una encuesta para que usted la conteste y nos la envíe en el sobre estampado que también le proporcionamos. Además, también puede participar en una entrevista telefónica.

Si no recibimos el sobre con la encuesta en el transcurso de 2 semanas, nuestro equipo del estudio le contactará por teléfono para preguntarle si le interesa participar en una entrevista y recordarle contestar la encuesta. Si no desea recibir una llamada acerca de este asunto, le pedimos que nos lo haga saber enviando el formulario adjunto en el sobre que le proporcionamos.

Si tiene preguntas, no dude en contactar a la coordinadora del estudio, Laura Campbell (312-227-1618, lacampbell@luriechildrens.org), o a mí, la Dra. Kelly Michelson (312-227-1606, kmichelson@luriechildrens.org).

Nadie comprende mejor que usted las dificultades enfrentadas por una familia en el proceso de perder un hijo. Esperamos aprender de sus experiencias y las de otras familias cuyos hijos fallecieron en la unidad de cuidados intensivos.

Le agradecemos su tiempo y su participación.

Atentamente,

Kelly Michelson
Médica adjunta de la Unidad de Cuidados Intensivos Pediátricos
Ann & Robert H. Lurie Children's Hospital of Chicago

RECHAZAR la participación

☐ Por favor NO LLAMEN a mi hogar acerca del *“Estudio de navegación (Navigate Study): Mejoramiento del proceso de comunicación en la Unidad de Cuidado Intensivo Pediátrico para los pacientes que se enfrentan a decisiones que suponen un cambio de vida”*.

[Date]

[Potential Participant]
[Address]
[Address]

Dear [Potential Participant],

Thank you for your participation in our research project, *Improving Communication in the Pediatric Intensive Care Unit for Patients Facing Life-Changing Decisions: The Navigate Study.*

The staff at Ann & Robert H. Lurie Children's Hospital of Chicago is committed to helping patients and their families throughout all aspects of illness. Children like [child's name] remind us that, despite our efforts, there are some patients we simply cannot save. As a doctor who works in the pediatric intensive care unit (PICU), I am witness to this sad fact too often. Continuing our goal of learning how to provide the best support possible to children and their families in the PICU, we would like to follow up with you about your experience in the PICU, your views on the research that you participated in, and how your are doing after your child's stay in the PICU.

Enclosed is a survey for you to complete and return to us in the self-addressed stamped envelope provided

If we do not receive this packet back within 2 weeks, our study team will call you to remind you to complete the survey. If you do not wish for someone to call you about this, please let us know by sending back the attached form in the envelop provided.

If you have any questions please feel free to contact the Study Coordinator, Laura Campbell (312-227-1618, lacampbell@luriechildrens.org), or myself, Dr. Kelly Michelson (312-227-1606, email kmichelson@luriechildrens.org).

No one understands better than you the difficulties faced by a family when a child is dying. We hope to learn from your experiences by hearing your story and the stories of other families whose children have died in the intensive care unit.

Thank you for your time and participation.

Sincerely,

Kelly Michelson
Attending Physician/Pediatric Intensive Care Unit
Ann & Robert H. Lurie Children's Hospital of Chicago

DECLINE Participation

☐ Please **DO NOT** call my home about the study called, **“***Improving Communication in the Pediatric Intensive Care Unit for Patients Facing Life-Changing Decisions: The Navigate Study.***”**

[Date]

[Potential Participant]
[Address]
[Address]

Estimado(a) [Potential Participant]:

Agradecemos su participación en nuestro proyecto de investigación, *"Estudio de navegación (Navigate Study): Mejoramiento del proceso de comunicación en la Unidad de Cuidado Intensivo Pediátrico para los pacientes que se enfrentan a decisiones que suponen un cambio de vida"*:

El personal del Ann & Robert H. Lurie Children's Hospital of Chicago se compromete a ayudar a los pacientes y sus familias a lo largo de todos los aspectos de la enfermedad. Los niños como [*child's name*] nos recuerdan que, a pesar de nuestro esfuerzo, a veces existen pacientes que simplemente no podemos salvar. Como médica integrante del equipo que conforma la Unidad de Cuidados Intensivos Pediátricos (PICU, *pediatric intensive care unit*), desafortunadamente he sido testigo de este hecho demasiadas veces. Para continuar trabajando por nuestro objetivo, de aprender a proporcionar el mejor apoyo posible a los niños y sus familias en PICU, nos gustaría tener seguimiento con usted acerca de su experiencia en PICU, su opinión sobre la investigación en la que participó y cómo se encuentra después de la estancia de su hijo en PICU.

Adjunta se encuentra una encuesta para que usted la conteste y nos la envíe en el sobre estampado que también le proporcionamos.

Si no recibimos el paquete en el transcurso de 2 semanas, nuestro equipo del estudio le contactará por teléfono para recordarle contestar la encuesta. Si no desea recibir una llamada acerca de este asunto, le pedimos que nos lo haga saber enviando el formulario adjunto en el sobre que le proporcionamos.

Si tiene preguntas, no dude en contactar a la coordinadora del estudio, Laura Campbell (312-227-1618, lacampbell@luriechildrens.org), o a mí, la Dra. Kelly Michelson (312-227-1606, kmichelson@luriechildrens.org).

Nadie comprende mejor que usted las dificultades enfrentadas por una familia en el proceso de perder un hijo. Esperamos aprender de sus experiencias y las de otras familias cuyos hijos fallecieron en la unidad de cuidados intensivos.

Le agradecemos su tiempo y su participación.

Atentamente,

Kelly Michelson
Médica adjunta de la Unidad de Cuidados Intensivos Pediátricos
Ann & Robert H. Lurie Children's Hospital of Chicago

RECHAZAR la participación

☐ Por favor NO LLAMEN a mi hogar acerca del *“Estudio de navegación (Navigate Study): Mejoramiento del proceso de comunicación en la Unidad de Cuidado Intensivo Pediátrico para los pacientes que se enfrentan a decisiones que suponen un cambio de vida”*.

Dear Colleague,

I am writing to you to ask for your participation in a short survey as a part of a research study funded by the Patient-Centered Outcomes Research Institutes.

The purpose of this study is to understand and support better communication in the pediatric intensive care unit (PICU) between parents of critically ill children and the healthcare team and among the healthcare team. For this study we will be testing an intervention called PICU Supports. PICU Supports uses a navigator (a person) as well as other tools to support communication and decision making in the PICU. Prior to starting the PICU Supports program I am interested in getting information about how healthcare team members who care for PICU patients view communication in the PICU.

I am reaching out to you because you are a healthcare provider who cares for PICU patients and families of PICU patients. I am interested to know *how you perceive communication in the PICU, specifically around the decision making process for patients in the PICU.* I am requesting that you complete this survey now, before the program is introduced, and then again after the program has concluded (in about 2 years).

This survey will take about 10 minutes to complete and is an important piece in learning about communication in the PICU. Please click on the link below to participate.

For more information about this study please feel free to contact me, or visit Clinical Trials.gov

Thank you in advance for your participation,
Kelly Michelson

Healthcare Team Survey 1

PICU
SUPPORTS

Thank you for helping us to know more about communication in the pediatric intensive care unit. This survey asks you for some basic information about yourself and your opinion about communication among healthcare team members involved in the care of PICU patients.

Today's date is:

Month XX	Day XX	Year XXXX

Research Study Title: Improving Communication in the PICU for Patients Facing Life-Changing Decisions: the Navigate Study

From: Ann & Robert H. Lurie Children’s Hospital of Chicago

Principle Investigator: Kelly Michelson, MD, MPH, email: kmichelson@luriechildrens.org, telephone: 312-227-1606

Sponsor: Patient-Centered Outcomes Research Institute (PCORI)

The purpose of this study is to understand and support better communication in the pediatric intensive care unit (PICU) between parents of critically ill children and the healthcare team and among the healthcare team. The study will determine the benefits or lack of benefits of a program called “PICU Supports,” an intervention dedicated to supporting communication. We are doing this study because we think that the PICU Supports program may improve patient and family experiences, particularly when parents of PICU patients are involved in making difficult decisions for their child. You are being asked to complete this survey because you are a healthcare provider who cares for PICU patients and families of PICU patients. We are interested in your views about collaboration among healthcare team members in the PICU.

This survey asks questions about you and your views on team collaboration in the PICU. It should take no more than 10 minutes to complete.

By completing this survey you are agreeing to participate in the research study. Participation is completely voluntary: you do not have to participate. You may also skip any question you do not wish to answer. Your choice about participation will not change any present or future relationships with Lurie Children's Hospital.

There are no anticipated benefits to participants. There will be no costs to you for participating in this research study. This study has minimal risk to you. The only risk is that someone outside of the study team may become aware of your participation. The study team will do everything possible to keep your information confidential. Your e-mail address will not be linked to your responses. Only a study ID number generated by REDCap (this online data entry system) will be linked to your responses. Your contact information will be stored in a password protect file and will not be disclosed to anyone outside of the research team.

If you have any questions, please contact Dr. Kelly Michelson (Principle Investigator) at ext. 71606 or Ms. Laura Campbell (Research Coordinator) at ext. 71618, or visit Clinical Trials.gov

Please read the header of each page prior to answering the questions.

Thank you for helping us to know more about communication in the pediatric intensive care unit!!

Please continue on the next page ➡

Please mark an "X" in the box next to the answer that best describes you, and/or fill in the blank.

1. **What is your sex?** ☐ Female ☐ Male

2. **What year were you born in?** ____________
Year XXXX

3. **What is your position at the hospital?**
   - ☐ Advanced Practice Nurse
     Please indicate your specialty ________________________
   - ☐ Attending Physician
     Please indicate your specialty ________________________
   - ☐ Chaplain
   - ☐ Child-life Specialist
   - ☐ Fellow Physician
     Please indicate your specialty ________________________
   - ☐ PICU Hospitalist
   - ☐ Resident Physician
     Please indicate your specialty ________________________
   - ☐ Staff Nurse
   - ☐ Social Worker
   - ☐ Other ____(describe)

4. **How many years have you been in your current position**? ____________

5. **What racial category best describes you? (select all that apply)**
   - ☐ American Indian / Alaska Native
   - ☐ Asian
   - ☐ Black / African American
   - ☐ Native Hawaiian or Other Pacific Islander
   - ☐ White
   - ☐ Other ____(describe)

6. **What ethnic group best describes you?**
   - ☐ Hispanic or Latino
   - ☐ Not Hispanic or Latino

Please continue on the next page ➡

Please *circle the number* that best represents **your** judgment about collaboration **among PICU team members** in making decisions for PICU patients

By “**PICU team members**” we mean PICU attendings, fellows, advance practice nurses, social workers, chaplains, child-life specialists, respiratory therapists, or any other PICU-focused healthcare team member.

By “**decisions**”, please consider the range of care decisions encountered in the PICU.

1. **PICU team members plan together to make decisions about care for PICU patient.**

1 2 3 4 5 6 7
Strongly Disagree Strongly Agree

2. **Open communication between PICU team members takes place as decisions are made for PICU patients.**

1 2 3 4 5 6 7
Strongly Disagree Strongly Agree

3. **Decision-making responsibilities for PICU patients are shared among PICU team members.**

1 2 3 4 5 6 7
Strongly Disagree Strongly Agree

4. **PICU team members cooperate in making decisions for PICU patients.**

1 2 3 4 5 6 7
Strongly Disagree Strongly Agree

5. **In making decisions, all PICU team members’ concerns about patients’ needs are considered.**

1 2 3 4 5 6 7
Strongly Disagree Strongly Agree

6. **Decision-making for PICU patients is coordinated among PICU team members.**

1 2 3 4 5 6 7
Strongly Disagree Strongly Agree

7. **How much collaboration among PICU team members occurs in making decisions for PICU patients?**

1 2 3 4 5 6 7
No Collaboration Complete Collaboration

8. **How satisfied are you with the way decisions are made for PICU patients, that is with the decision-making process, not necessarily with the decisions themselves?**

1 2 3 4 5 6 7
Not Satisfied Very Satisfied

9. **How satisfied were you with decisions made for PICU patients?**

1 2 3 4 5 6 7
Not Satisfied Very Satisfied

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Please continue on the next page ➡

Please circle the number that best represents **your** judgment about collaboration **between PICU team members and non-PICU team members** in making decisions for PICU patients

Definitions of PICU team members and decision making remain the same as the above.
By **"Non- PICU team members"** we mean any subspecialty, general pediatrics, or non-PICU based healthcare team member who cares for patients in the PICU (including attendings, fellows, advance practice nurses, social workers, chaplains, child-life specialists)

1. **PICU and non-PICU team members plan together to make decisions about care for PICU patient.**

   1 2 3 4 5 6 7
   Strongly Disagree Strongly Agree

2. **Open communication between PICU and non-PICU team members takes place as decisions are made for PICU patients.**

   1 2 3 4 5 6 7
   Strongly Disagree Strongly Agree

3. **Decision-making responsibilities for PICU patients are shared among PICU and non-PICU team members.**

   1 2 3 4 5 6 7
   Strongly Disagree Strongly Agree

4. **PICU and non- PICU team members cooperate in making decisions for PICU patients.**

   1 2 3 4 5 6 7
   Strongly Disagree Strongly Agree

5. **In making decisions, all PICU and non-PICU team members' concerns about patients' needs are considered.**

   1 2 3 4 5 6 7
   Strongly Disagree Strongly Agree

6. **Decision-making for PICU patients is coordinated among PICU and non-PICU team members.**

   1 2 3 4 5 6 7
   Strongly Disagree Strongly Agree

7. **How much collaboration among PICU and non-PICU team members occurs in making decisions for PICU patients?**

   1 2 3 4 5 6 7
   No Collaboration Complete Collaboration

8. **How satisfied are you with the way decisions are made for PICU patients, that is with the decision-making process, not necessarily with the decisions themselves?**

   1 2 3 4 5 6 7
   Not Satisfied Very Satisfied

Please continue on the next page ➡

9. **How <u>satisfied</u> were you with <u>decisions</u> made for PICU patients?**

1	2	3	4	5	6	7
Not Satisfied						Very Satisfied

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Thank you very much for helping us know more about how to help the patients and families we care for.

Please return this survey in the envelope provided.

Dear Colleague,

I am writing to you to ask for your participation in a short survey as a part of a research study called, “The Navigate Study” funded by the Patient-Centered Outcomes Research Institute.

You recently participated in the care of XX (initials) who was in bed 16- ____ and admitted to the PICU with XX (indication for admission to the PICU). This patient/family was enrolled in The Navigate Study and received the intervention called PICU Supports.   I am interested to know your opinion of the PICU Supports intervention used during the care of XX (initials) and the impact of the PICU Supports intervention on communication in the PICU. If you need additional information to identify this patient, please contact Laura Campbell (lacampbell@luriechildrens.org).

This survey will take about 10 minutes to complete.

For more information about this study please feel free to contact me, or visit ClinicalTrials.gov

To participate in this study please click on the link below

Thank you in advance for your participation.

Sincerely,
Kelly Michelson, MD

Thank you for helping us to learn more about communication in the pediatric intensive care unit (PICU). This survey asks you for some basic information about your opinion about communication among healthcare team members involved in the care of PICU patients and the effectiveness of the PICU Supports program.

Healthcare Team Survey 2

Today's date is:

Month XX | Day XX | Year XXXX

Research Study Title: Improving Communication in the PICU for Patients Facing Life-Changing Decisions: the Navigate Study

From: Ann & Robert H. Lurie Children's Hospital of Chicago

Principle Investigator: Kelly Michelson, MD, MPH, email: kmichelson@luriechildrens.org, telephone: 312-227-1606

Sponsor: Patient-Centered Outcomes Research Institute (PCORI)

Study Purpose: The purpose of this study is to understand and support better communication in the pediatric intensive care unit (PICU) between parents of critically ill children and the healthcare team and among the healthcare team. We are interested in your views about the benefits or lack of benefits to our program called "PICU Supports." We are doing this study because we think that providing families with an intervention dedicated to supporting communication may improve patient and family experiences, particularly when parents are involved in making difficult decisions for their child. You are being asked to be in a research study because you are a healthcare provider who cares for PICU patients and families of PICU patients and because you have cared for a family receiving the PICU Supports program. We are interested in your views about the benefits or lack of benefits to the "PICU Supports" program.

Components in this Research Study Survey: This survey asks question about you, your views on team collaboration in the PICU and on acceptability and effectiveness of the PICU Supports program

Confidentiality: Your responses will remain confidential. Any reports about the information obtained in this study will be presented without any person identifying information.

Voluntary Participation/Withdrawal: Taking part in this study is completely voluntary. You are free to not answer any questions or to not participate. Your choice about participation will not change any present or future relationships with Lurie Children's.

Compensation and Costs: There will be no costs to you for participating in this research study. You will receive no compensation for participating in this study.

Risks: Participation risks are minimal. Some people may have emotional reactions when completing the survey.

Research Study Procedures: When you are finished completing the questions in this survey, please place it in the envelope provided and return it as instructed.

For more information about this study please contact Dr. Kelly Michelson (Principle Investigator) at ext. 71606 or Ms. Laura Campbell (Research Coordinator) at ext. 71618, or visit Clinical Trials.gov

<u>Participation: By completing the survey you are agreeing to participate in this study.</u>

These questions are related to decision making for the patient enrolled in The Navigate Study.

Continue on to Next Page ➡

Please circle the number that best represents your judgment about the team process and the decision(s).

1. **Team members plan together to make decisions about care for this patient.**
1 2 3 4 5 6 7
Strongly Disagree Strongly Agree

2. **Open communication among team members takes place as decisions were made for this patient.**
1 2 3 4 5 6 7
Strongly Disagree Strongly Agree

3. **Decision-making responsibilities for this patients were shared among team members.**
1 2 3 4 5 6 7
Strongly Disagree Strongly Agree

4. **Team members cooperated in making decisions.**
1 2 3 4 5 6 7
Strongly Disagree Strongly Agree

5. **In making decisions, all PICU team members' concerns about this patients' needs were considered.**
1 2 3 4 5 6 7
Strongly Disagree Strongly agree

6. **Decision-making for this patient was coordinated among team members.**
1 2 3 4 5 6 7
Strongly Disagree Strongly Agree

7. **How much collaboration among team members occurred in making decisions for this patient?**
1 2 3 4 5 6 7
No Collaboration Complete Collaboration

8. **How satisfied are you with the way decisions were made for this patients, that is with the decision-making process, not necessarily with the decisions themselves?**
1 2 3 4 5 6 7
Not Satisfied Very Satisfied

9. **How satisfied were you with the decisions made for this patient?**
1 2 3 4 5 6 7
Not Satisfied Very Satisfied

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Continue on to Next Page ➡

Please respond to each question or statement by marking an "X" in the appropriate box.

1. **What is your position at the hospital?**
   - ☐ Advanced Practice Nurse
     Please indicate your specialty ____________________________
   - ☐ Attending Physician
     Please indicate your specialty ____________________________
   - ☐ Chaplain
   - ☐ Child-life Specialist
   - ☐ Fellow Physician
     Please indicate your specialty ____________________________
   - ☐ PICU Hospitalist
   - ☐ Resident Physician
     Please indicate your specialty ____________________________
   - ☐ Staff Nurse
   - ☐ Social Worker
   - ☐ Other ____(describe)

	Not at All Helpful	Not Very Helpful	Somewhat Helpful	Extremely Helpful	Unable to Assess
2. **How helpful was PICU Supports in supporting communication in the PICU?**	☐	☐	☐	☐	☐

	Not at All Integrated	Not Very Integrated	Somewhat Integrated	Extremely Integrated
3. **How much did the navigator integrate with the clinical team?**	☐	☐	☐	☐

	Less time	The same amount of time	More Time
4. **Compared to other families, did you spend the same, more, or less time with the family?**	☐	☐	☐

	Yes	No
5. **Would you recommend PICU Supports to a friend if one of their family members were admitted to the PICU?**	☐	☐

Continue on to Next Page ➡

Compared to families that are not part of this study, did PICU Supports have a positive impact on:

	Yes	No
6. The quality of communication between the patient’s family and the healthcare team?	☐	☐
7. The quality of communication within the healthcare team?	☐	☐
8. The timeliness of communication between the patient’s family and the healthcare team?	☐	☐
9. The family’s ability to articulate their values/preferences to the healthcare team regarding the care of their child?	☐	☐
10. The hospital experience for the family?	☐	☐
11. The family-centeredness of care delivered?	☐	☐

In your view how useful were the following components of PICU Supports:

	Not at All Helpful	Not Very Helpful	Somewhat Helpful	Extremely Helpful	Unable to Assess
12. **The Navigator’s weekday visits with the family.**	☐	☐	☐	☐	☐
13. **The Navigator’s reports to the healthcare team about the family.**	☐	☐	☐	☐	☐
14. **The communication log kept at the patient’s bedside.**	☐	☐	☐	☐	☐
15. **The regular family meetings organized by the navigator.**	☐	☐	☐	☐	☐
16. **The PICU Handbook that the family received.**	☐	☐	☐	☐	☐
17. **The “Frontline provider sheet” given to the healthcare team by the navigator.**	☐	☐	☐	☐	☐
18. **The calendar/diary in the back of the PICU Handbook.**	☐	☐	☐	☐	☐

Continue on to Next Page ➡

Please comment on any components of the PICU Supports program that you found useful.

Please comment on any components of the PICU Supports program that interfered with your work or with the care of the patient and/or family.

Any other suggestions/comments?

Thank you very much for helping us know more about how to help the patients, families and healthcare providers in the PICU.

Please return this survey in the envelope provided.

HTM Focus Group Guide

1. Obtain general feedback on PICU Supports
    a. Having had patients and families who received the PICU Supports program, what is your general impression about PICU Supports?
    b. What parts of PICU Supports seemed to work well?
    c. What parts of PICU Supports did not work well and why?

2. Obtain feedback on specific components of PICU Supports
    a. What impact did the navigator have on communication between parents/families and HTMs?
    b. What impact did the navigator have on communication among HTMs (within the PICU and between the PICU and non-PICU HTMs)
    c. What kind of support do you feel the navigator was able to give parents/families and patients (if relevant).
    d. What was the impact for you of the following parts of PICU Supports:
        i. The regular family meetings
        ii. The frontline provider sheet
        iii. The communication log
        iv. The PICU Handbook
        v. The parent diaries
        vi. Any informational/educational materials given to the parents

3. Obtain feedback on the impact of PICU Supports on HTM workflow.
    a. How did PICU Supports impact your workflow?
    b. How did PICU Supports impact the workflow of others on the team?

4. Obtain feedback on how to improve PICU Supports.
    a. How could the navigator better support parents/families, patients, and HTMs?
    b. What else could we do to improve PICU Supports?

PICU
SUPPORTS

Healthcare Team
Post-Focus Group Questionnaire

Thank you for helping us to learn more about communication in the pediatric intensive care unit. Before you leave, please complete this questionnaire which asks you for some basic information about yourself and your reactions to participating in this discussion.

Today's date is:

Month XX	Day XX	Year XXXX

Please mark an X in the box next to the answer that best describes you, and/or fill in the blank.

1. What is your gender? ☐ Female ☐ Male

2. What year were you born in? ____________
Year XXXX

3. What is your position at the hospital?

☐ Advanced Practice Nurse
Please indicate your specialty ________________________
☐ Attending Physician
Please indicate your specialty ________________________
☐ Chaplain
☐ Child-life Specialist
☐ Fellow Physician
Please indicate your specialty ________________________
☐ PICU Hospitalist
☐ Resident Physician
Please indicate your specialty ________________________
☐ Staff Nurse
☐ Social Worker
☐ Other ____(describe)

4. How many years have you been in your current position? ____________

5. What racial category best describes you? (select all that apply)

☐ American Indian / Alaska Native
☐ Asian
☐ Black / African American
☐ Native Hawaiian or Other Pacific Islander
☐ White
☐ Other ____(describe)

Please continue on the next page ➡

6. What ethnic group best describes you?

   ☐ Hispanic or Latino
   ☐ Not Hispanic or Latino

7. Overall, how easy or hard was it for you to participate in this research?

   ☐ Very Easy
   ☐ Easy
   ☐ Neither Easy nor Hard
   ☐ Hard
   ☐ Very Hard

Please explain below.

8. Please include any other information or comments below.

Please continue on the next page ➡

WEEKLY PARENT DIARY/ LOG

Date	Events	Goals/Concerns	Questions/Requests/Notes

PICU SUPPORTS

CHILD NAME (First and Last) ____DATE________________

Family Issues (Include Cultural or Religious Issues)

Examples:
Two other kids at home
Mom works
Dad is usually here overnight

Family Identified Needs/Goals

Example: It is important to the family that x y and z happen

Key Team Members	Family Communication Preferences	Family Availability (Days and Times)
Examples: The family really likes to work with Dr. X Dad likes the Social Workers	In the room (in front of child) Outside of room (nothing discussed in front of the child) Family does not want to include Aunt Susie in any of the communication	Example: The family plans to be here Mondays and Fridays after 5pm and Wednesdays and Thursdays in

This information is not part of the patient's medical record. This check in log is being used for research purposes only (specifically study IRB #, Michelson). If you have any questions about this sheet or the research study, please contact Kelly Michelson 312-227-1606 or kmichelson@luriechildrens.org****

Prepared by:

CHILD NAME (First and Last) ____________________________________DATE_______________

Family Issues (Include Cultural or Religious Issues)

Family Identified Needs/Goals

Key Team Members	Family Communication Preferences	Family Availability (Days and Times)

This information is not part of the patient's medical record. This check in log is being used for research purposes only (specifically study IRB #, Michelson). If you have any questions about this sheet or the research study, please contact Kelly Michelson 312-227-1606 or kmichelson@luriechildrens.org****

Prepared by:

Date______________________

****FOR NON-PICU CARE PROVIDERS ONLY****

Please fill out the information below when you visit this patient or his/her family (PLEASE PRINT)

NAME (PLEASE PRINT)	**SERVICE** (PLEASE PRINT)	**ROLE** (ex: attending, fellow, physical therapist etc.)	**TIME IN**	**Please Check one** Talked with Family/Pt	
				YES	**NO**

****** The Information on this sheet is not part of your child's treatment. This information is not part of the patient's medical record. This check in log is being used for research purposes only (specifically study IRB #, Michelson). If you have any questions about this sheet or the research study, please contact Kelly Michelson 312-227-1606 or kmichelson@luriechildrens.org******

COMMUNICATION LOG V 09/12/14

PICU SUPPORTS

Family Meeting Note

Date:

Time:

Participants in the meeting:

Use of an interpreter: (yes/no)

Discussion:

Plans:

Navigator

Pager number

End Of Life Checklist

Calculated PIM 2 Score:

Record ID ________________________________

Before Death of Patient: Family Activities

Navigator to assess and assist with the following if desired by family:

(Check YES for any task completed by the Navigator)

	No	Yes
1. Memory making activities	○	○
2. Religious / Spiritual needs	○	○
3. Information needs on dying process	○	○
4. Support from family/friends	○	○
5. Sibling/other children needs	○	○
6. Patient needs	○	○

Before Death of Patient: Healthcare Team Activities

Navigator to assess and assist with the following:

(Check YES for any task completed by the Navigator)

	No	Yes
7. Organ donation: (Contact Gift of Hope)	○	○
8. Autopsy: (Did someone ask the family?)	○	○
9. Medical Examiner Case: (Is this an ME case?)	○	○
10. Contacting relevant PICU and non-PICU Healthcare team members (including primary care physician) about impending situation	○	○
11. Update care team on families emotional/informational needs	○	○

After Death of Patient: Family Activities

Navigator to assess and assist with the following:

(Check YES for any task completed by the Navigator)

	No	Yes
12. Support family during completion (if needed)	○	○
13. Provide bereavement packet to family	○	○
14. Accompany family out of hospital (navigator or other appropriate person if desired by family)	○	○
15. Follow-up phone call	○	○

After Death of Patient: Healthcare Team Activities

Navigator to assess and assist with the following:

(Check YES for any task completed by the Navigator)

	No	Yes
16. Note in chart	○	○
17. Assist with notifying Healthcare Team members of death (if needed)	○	○
18. Help debrief Healthcare Team members (if appropriate)	○	○

HEARTLIGHT

Coping with
grief when
your child dies

Support for families coping
With illness and loss

Institutional Review Board (IRB) #2015-146, ***The Navigate Study.*** *Dr. Kelly Michelson. The content of this brochure has been approved by the IRB.*

Table of Contents

Message to parents

On behalf of The Navigate Study, we want to extend to you and your family our condolences on the death of your child. Whether expected or unexpected and regardless of age or cause, your child's death may be impossible to comprehend and will surely change your family's life forever. The death of a child is undoubtedly one of the most difficult experiences anyone could face in their lifetime.

Heartlight, the bereavement program at Lurie Children's, offers support groups, resources, educational materials, and can assist with the impact of grief on you and your other children at school or work. This is offered at no cost to you.

Please do not hesitate to call if you ever need support or someone to talk with. We hope we can be a resource and support to you and your family.

Heartlight can be reached at 312.227.3930.

Parents' grief

Initial reaction

Every individual is unique in their reactions following the death of a child. Many parents describe feelings of shock, overwhelming numbness or "being in a fog." You may feel unable to respond to people and events around you. Some conversations may seem distant and difficult to recall, yet other details may seem crystal clear. You may be unable to ask questions or hear details concerning your child's death. Decisions concerning the funeral and burial arrangements may be difficult for you. Or you may find comfort in the structure and the responsibility of the funeral preparations. You may become focused on taking care of others and the tasks necessary, and, it may be only after many days or weeks that you being to "feel" the loss.

Delayed responses to grief

Some parents may not experience the full scope of their loss until sometime after the death — perhaps weeks or months later. The deep emotional and physical pain of grief can emerge with intense feelings of anger, sorrow, fear and emptiness. You may question circumstances related to your child's death. Feelings of guilt concerning what you should or should not have done may surface. You may remember or even re-experience past feelings of loss from your own childhood or adulthood. And many parents are surprised by what does trigger certain emotions or memories of their child.

Coping with responses from other people

The death of a child is particularly tragic, and, consequently, some people may feel uncertain as to what to say or do, or how to effectively support you. Friends and family may be at a loss for words, or fearful that they may say the wrong thing. Some people may unintentionally say things that are upsetting or insensitive. How you respond will probably depend on the particular situation and your level of emotional energy at that time. Sometimes you may choose to ignore things that seem hurtful, while other times you may choose to say, "That is not helpful to me." Do not hesitate to let people know what they CAN DO to help you. Others may offer their opinion on how you should handle things, but don't be afraid to say NO. Your responsibility is to you and your family.

Physical reactions to grief

Physical ailments may appear or become aggravated by the grief you are experiencing. Physical reactions may include difficulty eating or over-eating, upset stomach, physical exhaustion, headaches, heart palpitations, nervousness or shortness of breath. Many parents struggle with their short-term memory and an inability to concentrate. This is normal, but if these reactions persist or interfere with your responsibilities, seek help from your doctor or a counselor.

You may find that you are unable to sleep or that you sleep all the time. When you do sleep, you may dream of your child. Some may find great comfort in these dreams, while others may find them unsettling. And it is not uncommon for one family member to have a dream, leaving others feeling jealous or angry when they have not. Be patient with yourself. Over time, you may find that your dreams, and those of others, may become a source of healing and comfort. In addition, you may feel other signs of your child's presence throughout your day and all around you.

Coping with anger

Anger is a common and normal reaction following the death of a child. You may feel angry toward the physicians and nurses, or your spouse and other family members. You may wonder if somehow they caused your child's death. You may question your faith and feel anger toward God or the higher power you believe in. Seeing other families with children may also be painful, causing you to feel jealous of their opportunity to be together. You may feel angry at their apparent lack of appreciation for each treasured moment with their children, and contrast that with your inability to spend any more time with your child.

Anger also may be directed toward yourself in the form of self-blame or feelings of failure and shame. These feelings may challenge your perception of yourself as a competent, loving and protective parent. Some parents even question their ability to care for surviving or subsequent children. You may feel less than a whole person. While these are natural feelings during this time, it is important to remember your strengths as a parent, that you did all that you could to care for your child and you tried to meet their needs in the best possible way. Remembering all the positive times spent with your child will ultimately be a source of great comfort.

Coping with loneliness

Children consume a large amount of a parent's time and energy each and every day. After the death of a child, you may feel an overwhelming sense of loneliness. Even though you may be surrounded by family and friends who love and care for you, your grief isolates you. This may be accompanied by a yearning for your child and a physical sensation of aching inside your body. Your arms and legs may feel heavy and clumsy.

You may feel as though you are functioning on a different emotional level than those around you. It may be difficult to put the experience of your grief into words. Many parents describe times when they feel as though they have lost all control of their emotions. Sometimes they fear they are losing their minds. Some parents may attempt to fill the emptiness by wishing to have another child. This is a decision that is usually best postponed during the immediate period after a child's death to allow time for parents to mourn their loss. After a time, you may be more emotionally prepared to welcome a new baby into your life.

Coping with memories of your child

Many parents report a sense of yearning or searching for their child. You may feel an overwhelming desire to hold your child in your arms again, to be reunited. You may long for the smell or the touch of their skin. The frustration in not being able to fulfill this desire may be experienced as restlessness, irritability and depression. You may struggle to keep a clear picture in your mind of your child's appearance and special mannerisms. Many parents fear forgetting their child.

Share your memories with others and encourage them to share any thoughts, memories or reflections they may have with you. Each story is an amazing gift. You may even want to write them down so that you won't need to worry about forgetting them. If you have surviving children, allow them to share their thoughts, feelings and memories. Many siblings find great comfort in talking about their brother or sister who died. It can be helpful to provide a special memory box where these memories can be stored and brought out whenever you or your children feel the need to reminisce. You may also find it comforting to keep special remembrances of your child or to be able to talk with others who hold memories of your child. Remembrances may include a picture, a name bracelet, a blanket, a lock of hair, an article of clothing, a special toy or cards from family and friends.

Relationships with family and friends

Immediately after the death of your child, relatives and friends may gather around you to offer their comfort and support. You may find there are special people you wish to have near you and with whom you can share some of your feelings. On the other hand, you may want some time alone. It is important to let people know what your specific needs may be. Relatives and friends may be able to offer special help by attending to the details of arrangements that must be made immediately after your child's death. Or just by helping with any household daily needs or the care of surviving children.

It may help to know that these experiences are common for families grieving the death of a child. It is important to acknowledge that everyone responds differently to grief and this grief may influence how family members relate to each other. Keeping the lines of communication open is important during this healing process.

The death of a child touches immediate and extended family members and friends. The way each person expresses his or her grief may vary markedly. Spouses may experience the death differently and each works through grief in his or her own way. You may feel "out-of-synch" with each other. Other children in the family may not fully understand events and changes in family behaviors associated with a death. It may be difficult for you to respond to the grief of others when you are struggling with your own grief. Family members sometimes find it hard to support and comfort each other.

You may find as time goes on that relatives and friends are less available for support. At a time when you still need someone who will listen and care about you, relatives and friends may be returning to their daily routines. The care and support you felt at the time of your child's death may seem to be gone. You may sense that people are uncomfortable hearing about your continuing grief. People may suggest that it is time to put your grief aside and return to routine activities. You may feel as though you must hide your grief inside. At times, people may say things, though with good intentions, that may be hurtful to you.

It is very important during this period that you find someone who will listen, someone who is willing to bear your grief with you, someone who can continue to share your child with you. This may be a family member, close friend or maybe a professional. Some parents find it helpful to talk with other parents who have experienced the death of a child. There are groups available to meet this need.

Helping children cope with death

Parents are often concerned about how to explain death to other children — siblings, cousins, neighbors, schoolmates and friends. It is important to give children truthful answers in a loving and supportive manner. Children do not understand death in the same way adults do. Their understanding of death depends on their age and their level of cognitive development.

Infants

Even though infants do not have an understanding of death, they are directly affected by separation from their nurturer and their caregiver's emotions. Infants respond to the emotion around them. Distress is visible in an infant when suffering a loss, but usually they can be easily soothed. Infants have few language skills, so you have to rely on their behaviors. Symptoms may include change in sleeping patterns, crankiness, crying and clinging.

Preschool and toddlers

Young children often confuse fantasy and reality. They typically understand death as a separation, something like sleep. They need to hear that death is not like going to sleep. When someone dies, their body no longer works, they are not alive anymore, so they cannot wake up again. Young children also have "magical thinking" powers and fantasize about the return or healing of the person who died. Because they believe wishes come true, they may believe that they can wish the person back or that they caused the person to die. They need reassurance that they did not cause the person to die, that it is not their fault and that a person who has died cannot return.

A death in the family can cause lots of changes in the family dynamic. Common reactions of young children following a death include clinging to their primary caregiver, crankiness, fear someone else or they themselves will die, difficulty sleeping, regressive behavior (such as bedwetting) or changes in their eating patterns. For young children, the changes in routines can be difficult. It is helpful to maintain as much consistency in routines as is possible for your preschooler. They benefit from close contact with a person significant to them. They need to be able to talk about the person who died. They may be sad for a short time and then go about their play as if nothing had happened. Their ability to tolerate the pain associated with grief is limited, and frequently use play as a way of coping. Preschoolers learn from example and model how other people react to death. A simple explanation about why people cry may be helpful. For example, you may say that people cry when they are sad or because they miss the person who died. Crying helps the hurt feel better. When someone dies, it often takes a long time for the hurt to feel better.

School-aged children

School-aged children, six to 12, have a more realistic understanding of death. They realize that people can die from accidents or illnesses. They are often curious about what happens to someone's body when they die. They may wonder what happens at autopsies, wakes, funerals and burials. Children may still feel guilty about being "bad" or somehow causing the death. These children may associate mutilation and punishment with death. They may think about death as a person — a ghost or "bogeyman."

Around the age of seven or eight years old, children begin to realize that death is irreversible. The death of a loved one may cause them to be anxious. Many children worry that someone else in their family may die. It may help to reassure them that most people live a long, long time and you can talk about the things you do to take care of yourself. But, it is also common for children to worry who will take care of them if something would ever happen to you. It may be helpful to discuss a care plan with them.
It may help children to know that when someone dies, they will not actually see him or her again, but he or she can be alive in their memories. You may want to help them think of ways they can remember the child who died.

By the time children are 10 or 12 years of age, they are able to understand that death is inevitable, universal and irreversible. How they view death is greatly influenced by the reactions of others, especially their parents, as well as their religious beliefs.
School-aged children need honest, realistic answers to their questions. Adults may find their questions upsetting, especially if they are struggling with their own grief. Avoiding questions or not responding to questions honestly will cause children to be more anxious. Even if you are not able to tolerate the pain of hearing their questions, it is important to find someone who they can talk to.

Adolescents

Adolescents are already struggling with issues of separation and individuation. They are often compelled to act like adults, while their coping mechanisms and ability to understand death may be more similar to a child’s. Adolescents typically demonstrate mood swings. When someone dies, they may idolize the person one minute and condemn him or her the next minute. Their grief may be expressed with sobbing or embarrassed laughter. The peer group is especially important during the teen years. Teenagers are apt to worry about what others think of them. They may not want anyone to see them cry, so they may appear stoic and “cool.” Physical symptoms such as headaches, stomach problems or changes in menstrual patterns may develop. Teenagers often struggle with philosophical or spiritual issues. Some examples might be: “If we’re all going to die anyway, why bother living?” “Why love somebody and become close when they’re just going to leave you?” “If God loves us, why does God let people die?” “It isn’t fair that a child dies.” “Why my brother or sister or our family?” “Why not me?” “Why...?” An adolescent’s understanding of death is more complex and their questions can also be more complex. They find the unanswerable questions terribly frustrating — as indeed adults do, too. In general, adolescents are also very vulnerable to engage in risky behavior, but even more so during this time. Teenagers need open, honest and loving support from adults and the opportunity to explore their questions without judgment.

Participation of children in funeral or burial services

Parents often wonder whether children should attend funeral or burial services. Sharing times of special significance like this can help children understand the experience and deal with their own feelings of sadness and loss. It is important to give children the choice and allow them to make an informed decision about whether or not they want to attend or participate in the rituals of your family's religious and cultural traditions.

Often the fear of the unknown is more upsetting than the reality of the situation. For this reason, children need to know what to expect. They need to know how the room will look, what will happen during the service and how the dead person will look if the casket is open. It is often helpful to bring children to the wake or funeral before many visitors arrive. This provides a quiet, private time to say good-bye. Allow children to stay as long as they wish and respect their need to leave when they desire. This helps to give them the control they need in this situation. It may be helpful to have someone else available to care for the children during the service so you are able to do what you need for yourself. Children are children first and often need to express their grief in small doses.

Living with grief

The range and intensity of sorrow and grief is different for every person. Everyone grieves in his or her own way, and in his or her own time. Your grief experience may be influenced by past experiences, cultural and family traditions, relationship with the child, circumstances surrounding the death and current life stressors. There is no right way to grieve other than the way that feels right to you.

There may be moments when a passing memory, a special date, holiday, a particular smell, a song or a food will trigger some intense feelings of grief. As time passes, the intensity will decrease and you may feel better prepared to cope with these experiences.

Final thoughts

Regardless of our age, we all grieve when someone we love dies. Most, if not all parents say that the death of their child is one of the most devastating experiences of their lives. Grieving is painful, but necessary. Grief is a very personal journey, but most parents find that their pain lessens in time. Sadness changes from a bitter emotion to a feeling that allows for memories of happier times to exist beside the pain. We hope you are able to remember your child with deep love and be able to appreciate the gift of his or her life.

Notes

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Glossary of Terms – cont.

NOT all of these words/situations will apply to your child.

Central line (IJ, femoral line, subclavian): Special intravenous catheter placed in a large vein (usually near the neck or groin) to give fluids, medications, or nutrition and to draw blood samples for laboratory testing.

Continuous renal replacement therapy (CRRT): A temporary form of dialysis that runs continuously. CRRT can remove toxins and extra fluid from the body.

Defibrillator: A machine that delivers electric shock to attempt to reset an abnormal heart rhythm.

DNAR/DNR (Do not attempt resuscitate/Do not resuscitate): An order telling doctors and nurses *not* to perform CPR if the patient stops breathing or if their heart stops. A DNAR order is ONLY placed after a conversation with and agreement from the parents. A DNAR/DNR order does NOT mean taking away other treatments.

EKG (electrocardiogram): A tracing of the electrical signals of the heart.

Endotracheal tube (ETTube): A tube that is placed in the airway (trachea) through the mouth or nose and attached to a breathing machine to help the patient breathe.

Extubation: The process of removing an endotracheal tube (ETTube) from a patient.

Gastrostomy tube (G-tube): A feeding tube that is surgically placed directly from the surface of the belly into the stomach.

Intubation: The process of placing an endotracheal tube (ETTube) when a patient is unable to breathe on his/her own and needs a breathing machine.

Mechanical ventilator (breathing machine): A machine used to help a patient breathe.

Nasal cannula: Plastic tube that fits around the head with two short prongs into the nostrils. It provides the patient with oxygen (from a tank or wall source).

Nasogastric tube (NGT, NG), orogastric tube (OGT, OG): A tube placed through the nose or mouth into the stomach. It is used to give medicines and feedings or to drain stomach contents.

Palliative Care: Care that focuses on reducing pain and discomfort and increasing quality of life.

Pulse oximeter: A device that measures the amount of oxygen carried by the blood.

Sedation: Medicine to make patients sleepy, relaxed, and less aware of uncomfortable or distressing conditions.

Vasoactive medications (inotropes, pressors, drips): medications given continuously to raise or lower the blood pressure and support the heart.

Pediatric Intensive Care Unit ("PICU")
&
Cardiac Intensive Care Unit ("CICU")
Parent Guide

This brochure has some basic information that we hope will be helpful while your child is in the PICU or CICU.

We recognize that this can be a very stressful time for you, your child, and your family. Please ask any questions you might have, and ask as many times as you need. We are here to help!

General Information

Parking: Parking at the Huron-Superior garage costs $10 for less than 7 hours and $15 for 7 to 24 hours, with a validated ticket (costs are higher if the ticket is not validated by the hospital). Tickets can be validated at the second floor concierge desk in Lurie Children's before you leave for the garage. The Erie-Ontario garage, a few blocks away, is another option. For extended stays, please ask your nurse or social worker about additional options.

Visiting Hours: For parents or guardians, visitation is available 24 hours. For all other visitors, visitation is from 10:00 AM to 8:30 PM - Limit 3 people at one time.

Isolation and Visitor Restrictions: Our patients are vulnerable, even a common cold could make them very ill. To help protect them, during the winter no visitors under the age of 14 are allowed, and only two people at a time may be in your child's room. No one who feels sick should visit. If your child has symptoms of a virus, you will be asked to wear a gown, gloves and a mask when you are in the room. Please remember to wash your hands when entering and leaving your child's room.

Sleep: Parents may stay with their child 24/7. If you live far away and your child will be hospitalized for a while, please ask your nurse or social worker for information about rooms that may be available to you. **It is important for parents to take time to sleep, eat and get fresh air. You can ask your nurse to let you know when it would be a good time to do these things.**

Flowers are not allowed in the PICU or CICU.

The PICU/CICU Team

The PICU/CICU team does "rounds" on patients every morning between 8 am and noon. "Rounds" are a time to review how your child is doing and discuss treatment plans for the day. You are a very important part of your child's care team and will be invited to participate in rounds.

- **Advanced Practice Nurses** (APNs) are nurses with additional education and training who work collaboratively within the healthcare team to manage critically ill infants and children.
- **Case Managers** serve as the link between the hospital and your insurance plan, and help coordinate your child's discharge or transfer.
- **Chaplains** provide support for you and your child. They are trained to work with people of all faiths and can help to connect you with resources from your religious tradition
- **Child-life specialists** help your child cope with being in the PICU/CICU. They are experts in child development and can also help with siblings or other young family members.
- **Dietitians** help manage your child's nutrition, including IV feedings.
- **Medical students, residents, and fellows** are doctors in various stages of training.
- **Nurses** in the PICU/CICU have been specially trained to care for critically ill children.
- **Pharmacists** monitor all medicines and dosages during the course of your child's illness.
- **Respiratory (breathing) therapists** (RTs) use oxygen and other therapies to help children who have trouble breathing.
- **Physical, occupational, and speech therapists** focus on increasing your child's strength, flexibility, and function, and reducing risk during activities such as swallowing or transferring out of bed.
- **Physicians (doctors):** Several teams of doctors may be caring for your child, including PICU/CICU specialists (intensivists), surgeons, and other specialists. An attending physician heads each team.
- **Social workers** support and guide you to resources as needed during your child's stay in the PICU/CICU.

Clinical Research

Part of our mission is to use research to find better ways to take care of children and their families. If your child qualifies, you may be asked for permission to include your child in one of our current studies. Participation is voluntary (optional), and if you decide not to participate it will not affect your child's care.

What Can I Do To Help?

Work with you nurse to understand how to interact with your child if you are unsure during the course of their treatment. Your nurse can also guide you in maintaining safety when helping your child with bathing, feeding, diapering, and other care. We encourage you to bring in favorite toys or blankets to make your child feel more comfortable. You can also bring pictures of your child to help the PICU/CICU staff see your child the way you do.

Please ask questions as many times as needed for you to feel comfortable. Your child's care team understands that being in the PICU/CICU can be stressful and that you may not remember everything the first time you hear it. Consider writing down the names of your child's PICU/CICU team members and their roles. If you think of questions when the doctors or APNS are not around, ask your child's nurse, or write them down to ask later.

Procedures

Certain procedures may need to be performed in order to help your child get better (for example, intubation, central line placement – see glossary). Unless it is an emergency, we will take the time to explain all procedures to you and ask your permission to proceed. If a procedure needs to be performed emergently, there will be people available to explain what is happening and answer your questions.

Glossary of Terms

Below are some words that you MIGHT hear in the PICU or CICU. NOT all of these words/situations will apply to your child.

Blood gas: Blood test that measures the amounts of oxygen and carbon dioxide in a patient's blood.

CPR (cardiopulmonary resuscitation): A procedure to try to restart the heart if a patient has a **cardiac arrest**—that is, if the patient's heart and breathing stop. This procedure combines pressing on the chest, giving rescue breathing and administering medications and sometimes electric shocks.

Cardiac monitor: Screen that shows your child's vital signs (heart rate, blood pressure, oxygen levels, breathing rate). Your child will be connected to this monitor by several wires and cables.

Catheter (tube, line, drain): Plastic tube placed in a blood vessel (vein or artery) or another part of the body (such as a bladder catheter to drain urine).

Términos de Glosario -

NO todas estas palabras/situaciones se aplicarán al caso de su hijo/a.

Línea central (intrayugular, línea femoral, subclavia): Un catéter intravenoso especial que se le coloca en una vena grande (usualmente cerca del cuello o la ingle) para administrar líquidos, medicamentos o nutrición y para extraer muestras de sangre para pruebas de laboratorio.

Terapia de reemplazo renal continua (CRRT, por sus siglas en inglés): Una forma de diálisis temporal que corre continuamente. La CRRT puede remover toxinas y líquidos en exceso del cuerpo.

Desfibrilador: Una máquina que emite un choque eléctrico para intentar restaurar un ritmo cardíaco anormal.

ONR/ONIR (Orden de no reanimar/Orden de no intentar reanimación, o DNAR/DNR por sus siglas en inglés): Una orden que instruye a los médicos y enfermeros a *no* realizar RPC si el/la paciente deja de respirar o si su corazón se detiene. Una ONIR SOLAMENTE se implementa después de una conversación con los padres y su acuerdo. Una ONIR/ONR NO significa que se le vaya a quitar otros tratamientos.

ECG (electrocardiograma, o EKG, por sus siglas en inglés): Un trazado de las señales eléctricas del corazón.

Tubo endotraqueal: Un tubo que se coloca en la vía respiratoria (tráquea) por la boca o la nariz y conectada a un respirador mecánico para ayudarle al paciente respirar.

Extubación: El proceso de remover el tubo endotraqueal del paciente.

Sonda gástrica (G-tube): Una sonda de alimentación que se coloca directamente de la superficie de la panza al interior del estómago mediante intervención quirúrgica.

Intubación: El proceso de colocar un tubo endotraqueal cuando el/la paciente no puede respirar por sí solo/a y necesita un respirador mecánico.

Ventilador (respirador) mecánico: Una máquina que se usa para ayudarle al paciente respirar.

Cánula nasal: Tubo plástico que cabe alrededor de la cabeza con dos puntas cortas en las fosas nasales. Le suple oxígeno al paciente (de un tanque o una fuente de la pared).

Sonda nasogástrica (NGT, NG), sonda orogástrica (OGT, OG): Tubo que se introduce desde la nariz o la boca y que llega hasta el estómago. Se utiliza para administrar medicamentos y alimentaciones o para drenar los contenidos del estómago.

Atención paliativa: Atención que se enfoca en reducir el dolor o malestar y aumentar la calidad de vida.

Pulsioxímetro: Un dispositivo que mide la cantidad de oxígeno que lleva la sangre.

Sedación: Medicamentos para poner a los pacientes somnolientos, relajados y menos conscientes de condiciones incómodas o angustiantes.

Medicamentos vasoactivos (inotropos, presores, sueros): medicamentos que se administran de manera continua para subir o bajar la presión sanguínea y brindar apoyo al corazón.

Unidad de Cuidado Intensivo Pediátrico ("PICU")

&

Unidad de Cuidado Cardiaco Intensivo ("CICU")

Guía para los padres

Este folleto contiene información básica que esperamos le sea de utilidad mientras su hijo o hija esté en la PICU/CICU.

Reconocemos que esto puede ser un momento de mucho estrés para usted, su hijo o hija y su familia. Por favor háganos cualquier proyecto que pueda tener y hágala las veces que necesite. ¡Estamos aquí para ayudar!

Información General

Estacionamiento: El estacionamiento en el garaje de la Huron y la Superior cuesta $10 por menos de 7 horas y $15 por entre 7 y 24 horas, <u>con un boleto validado</u> (los costes son mayores si el boleto no se valida por el hospital). Los boletos se pueden validar por los conserjes en la recepción del segundo piso en Lurie Children's antes de dirigirse hacia el garaje. Otra opción es el garaje de la Erie y la Ontario, unas cuadras del hospital. Para estadías extendidas, pida a su enfermero(a) o trabajador(a) social acerca de opciones adicionales.

Horas de visita: Para los padres o tutores, visitación está disponible las 24 horas. Para todos los de más visitantes, las horas de visita son desde las 10:00 AM hasta las 8:00 PM - Con un límite de 3 personas a la vez.

Aislamiento y restricciones de visitantes: Nuestros pacientes son vulnerables, hasta un resfriado común podría causar que se enfermen gravemente. Para ayudar a protegerlos, durante el invierno, no se permiten ningunos visitantes menores de la edad de 14 años, y solamente dos personas pueden estar en la habitación de su hijo o hija a la vez. <u>Nadie que se siente enfermo debe visitar.</u> Si su hijo o hija presenta síntomas de un virus, se le pedirá que usted se ponga una bata, guantes y una máscara cuando esté en su habitación. Favor de recordarse de siempre lavarse las manos al entrar y al salir de la habitación de su hijo o hija.

Dormir: Los padres pueden quedarse con su hijo o hija las 24 horas del día, los 7 días de la semana. Si viven lejos y su hijo estará hospitalizado/a por un tiempo, pídale información de su enfermero(a) o trabajador(a) social acerca de habitaciones que pueden estar disponibles para usted. **Es importante que los padres tomen su tiempo para dormir, comer y salir al aire libre. Puede pedir que su enfermero(a) le deje saber cuándo sería buen momento para hacer estas cosas.**

No se permiten flores en la PICU o CICU.

El Equipo de la PICU/CICU

El equipo de la PICU/ CICU hace "rondas" sobre los pacientes cada mañana entre las 8 a.m. y el mediodía. Las "rondas" son un tiempo para revisar cómo le va a su hijo/a y discutir planes de tratamiento para el día. Usted es una parte muy importante del equipo de atención médica de su hijo o hija y se le invitará a participar en las rondas.

- **Los enfermeros de práctica avanzada** (APN) son enfermeros con educación y capacitación adicional que trabajan de manera colaborativa como parte del equipo de atención médica para manejar a los lactantes y niños críticamente enfermos.
- **Los manejadores de casos** sirven como un enlace entre el hospital y su plan de seguro médico, y ayudan a coordinar el alta o traslado de su hijo o hija.
- **Los capellanes** brindan apoyo para usted y su hijo o hija. Se han adiestrado para trabajar con personas de todas las creencias religiosas y pueden ayudarle a conectarse con recursos de su tradición religiosa.
- **Los especialistas de vida infantil** ayudan a su hijo o hija a lidiar con estar en la PICU/CICU. Son expertos en el desarrollo infantil y también pueden ayudar con los hermanos u otros familiares jóvenes.
- **Los dietistas** ayudan a manejar la nutrición de su hijo o hija, inclusive las alimentaciones por vía intravenosa.
- **Los estudiantes médicos, los residentes y los médicos becarios** son médicos que se encuentran en diferentes etapas de adiestramiento.
- **Los enfermeros** en la PICU/CICU se han adiestrado especialmente para cuidar a los niños críticamente enfermos.
- **Los farmacéuticos** monitorean todos los medicamentos y las dosis durante el transcurso de la enfermedad de su hijo o hija.
- **Los terapeutas respiratorios** (RT) usan la terapia de oxígeno y otras terapias para ayudar a los niños que presentan dificultad respiratoria.
- **Los terapeutas físicos, ocupacionales y del habla** se enfocan en aumentar la fuerza, la flexibilidad y función de su hijo o hija y en reducir el riesgo durante actividades tales como la deglución o el levantarse de la cama.
- **Médicos (doctores):** Varios equipos de médicos pueden estar cuidando a su hijo o hija, inclusive el de los especialistas (intensivistas) de la PICU/CICU, cirujanos y otros especialistas. Un(a) médico(a) adjunto(a) encabeza cada equipo.
- **Los trabajadores sociales** le apoyan y guían a los recursos según se necesiten durante la estadía de su hijo o hija en la PICU/CICU.

Investigación clínica

Parte de nuestra misión es de utilizar la investigación para encontrar mejores maneras de cuidar a los niños y sus familias. Si su hijo/a reúne los requisitos, es posible que solicitemos su autorización para incluirlo/la en uno de nuestros estudios actuales. La participación es voluntaria (opcional), y si decide no participar, ello no afectará la atención médica de su hijo/a.

¿Qué puedo hacer para ayudar?

Consulte con su enfermero(a) para entender cómo interactuar con su hijo o hija a lo largo de su tratamiento. Su enfermero(a) también puede orientarle respecto al mantenimiento de seguridad al ayudar a su hijo a bañarse, alimentarse, cambiarle el pañal y otros cuidados. Le animamos a traer los juguetes favoritos o frisas para hacerle sentir más cómodo(a) a su hijo o hija. También puedes traer fotos de su hijo o hija para ayudar a los empleados del PICU/CICU a ver a su hijo o hija de la misma manera que usted.

Por favor haga preguntas cuántas veces necesite para que se siente más cómodo(a). El equipo de atención médica de su hijo o hija entiende que estar en la PICU/CICU puede ser estresante y que puede que no recuerde todo la primera vez que lo escuche. Considere apuntar los nombres de los miembros del equipo de la PICU/CICU de su hijo o hija y sus roles. Si se le ocurren preguntas cuando los médicos o los APN (enfermeros(as) especializados) no estén, pregunte al/ a la enfermero(a) de su hijo o hija, o apúntelas y pregunte después.

Procedimientos

Puede que ciertos procedimientos tengan que realizarse para ayudar a su hijo o hija a mejorarse (por ejemplo, la intubación, la colocación de un catéter central - véase el glosario. A menos que sea una emergencia, tomaremos el tiempo de explicarle todos los procedimientos y pedir su permiso de proceder. Si un procedimiento tiene que realizarse urgentemente, habrá personas disponibles para explicar lo que esté pasando y contestar sus preguntas.

Glosario de términos

A continuación hay algunas palabras que QUIZÁS escuchará en la PICU/CICU. NO todas estas palabras/situaciones se aplicarán al caso de su hijo/a.

Gasometría arterial: Una prueba de la sangre que mide la cantidad de oxígeno y dióxido de carbono en la sangre del/ de la paciente.

RCP (resucitación cardiopulmonar): Un procedimiento para intentar reanimar el corazón si el/la paciente sufre un paro cardíaco--o sea, si el corazón y la respiración del/de la paciente se detienen. Este procedimiento combina la presión sobre el pecho, la respiración de rescate y la administración medicamentos y a veces choques eléctricos.

Monitor cardíaco: Una pantalla que demuestra los signos vitales de su hijo o hija (ritmo cardíaco, presión sanguínea, niveles de oxígeno y frecuencia respiratoria). A su hijo o hija se le conectará a este monitor por medio de varios alambres y cables.

Catéter (sonda, tubo, línea, drenaje): Un tubo plástico que se coloca en un vaso sanguíneo (vena o arteria) u otra parte del cuerpo (tal como un catéter de la vejiga para el drenaje de orina).

Dear Colleague,

I am writing to you to ask for your participation in a short survey as a part of a research study called, "The Navigate Study" funded by the Patient-Centered Outcomes Research Institute.

You recently participated in the care of XX (initials) who was in bed 16- ____ and admitted to the PICU with XX (indication for admission to the PICU). This patient/family was enrolled in The Navigate Study and received the intervention called PICU Supports. I am interested to know your opinion of the PICU Supports intervention used during the care of XX (initials) and the impact of the PICU Supports intervention on communication in the PICU. If you need additional information to identify this patient, please contact Laura Campbell (lacampbell@luriechildrens.org).

This survey will take about 10 minutes to complete.

For more information about this study please feel free to contact me, or visit ClinicalTrials.gov

To participate in this study please click on the link below

Thank you in advance for your participation.

Sincerely,
Kelly Michelson, MD

PICU
SUPPORTS

Thank you for helping us learn more about communication in the pediatric intensive care unit (PICU) and cardiac intensive care unit (CICU). This survey asks questions about the family meeting you participated in for a family enrolled in the Navigate Study. Please complete this survey and return it in the envelope provided.

Healthcare Team Post Family Meeting Survey

This survey takes approximately 10-15 minutes to complete

Today's date is:

Month XX	Day XX	Year XXXX

Research Study Title: Improving Communication in the PICU for Patients Facing Life-Changing Decisions: the Navigate Study

From: Ann & Robert H. Lurie Children's Hospital of Chicago

Principle Investigator: Kelly Michelson, MD, MPH, email: kmichelson@luriechildrens.org, telephone: 312-227-1606

Sponsor: Patient-Centered Outcomes Research Institute (PCORI)

The purpose of this study is to understand and support better communication in the pediatric intensive care unit (PICU) and cardiac intensive care unit (CICU) between parents of critically ill children and the healthcare team and among the healthcare team. The study will determine the benefits or lack of benefits of a program called "PICU Supports," an intervention dedicated to supporting communication. We are doing this study because we think that the PICU Supports program may improve patient and family experiences, particularly when parents of PICU/CICU patients are involved in making difficult decisions for their child. You are being asked to complete this survey because you are a healthcare provider who participated in an organized family meeting for a patient enrolled in the Navigate Study. We are interested in your views about communication between healthcare team members and the family during the family meeting.

This survey asks questions about views on communication during a patient's family meeting. It should take no more than 10 minutes to complete.

By completing this survey you are agreeing to participate in the research study. Participation is completely voluntary: you do not have to participate. You may also skip any question you do not wish to answer. Your choice about participation will not change any present or future relationships with Lurie Children's Hospital.

There are no anticipated benefits to participants. There will be no costs to you for participating in this research study. This study has minimal risk to you. The only risk is that someone outside of the study team may become aware of your participation. The study team will do everything possible to keep your information confidential. Your name or e-mail address will not be linked to your responses. Only a study ID number generated by REDCap (the online data entry system) will be linked to your responses. Your contact information will be stored in a password protected file and will not be disclosed to anyone outside of the research team.

If you have any questions, please contact Dr. Kelly Michelson (Principle Investigator) at ext. 71606 or Ms. Laura Campbell (Research Coordinator) at ext. 71618, or visit Clinical Trials.gov

Please read the instructions prior to answering the questions.

Thank you for helping us know more about communication in the PICU/CICU!!

Communication is a very important part of quality medical care. We would like to know how you feel about the way the healthcare team communicated with the patient's family during the family meeting. Your answers are completely confidential, so please be as open and honest as you can. Thank you very much.

Please respond to each statement by marking and "X" in one box per row.

<u>The healthcare team…</u>

	Poor	**Fair**	**Good**	**Very Good**	**Excellent**
1. Greeted the family in a way that made them feel comfortable.	☐	☐	☐	☐	☐
2. Treated the family with respect.	☐	☐	☐	☐	☐
3. Showed interest in the family's ideas about their child's health.	☐	☐	☐	☐	☐
4. Understood the family's main health concerns for their child.	☐	☐	☐	☐	☐
5. Paid attention to the family (looked at them, listened carefully).	☐	☐	☐	☐	☐
6. Let the family talk without interruptions.	☐	☐	☐	☐	☐
7. Gave the family as much information as they wanted.	☐	☐	☐	☐	☐
8. Talked in terms the family could understand.	☐	☐	☐	☐	☐
9. Checked to be sure the family understood everything	☐	☐	☐	☐	☐
10. Encouraged the family to ask questions.	☐	☐	☐	☐	☐
11. Involved the family in decisions as much as they wanted.	☐	☐	☐	☐	☐
12. Discussed next steps, including any follow up plans.	☐	☐	☐	☐	☐
13. Showed care and concern.	☐	☐	☐	☐	☐
14. Spent the right amount of time with the family.	☐	☐	☐	☐	☐

Please continue on the next page ➡

Please mark an “X” in the box next to the answer that best describes you, and/or fill in the blank.

1. **What is your sex?** ☐ Female ☐ Male

2. **What year were you born in?** ____________
Year XXXX

3. **What is your position at the hospital?**
   - ☐ Advanced Practice Nurse
     Please indicate your specialty ________________________
   - ☐ Attending Physician
     Please indicate your specialty ________________________
   - ☐ Chaplain
   - ☐ Child-life Specialist
   - ☐ Fellow Physician
     Please indicate your specialty ________________________
   - ☐ PICU Hospitalist
   - ☐ Resident Physician
     Please indicate your specialty ________________________
   - ☐ Staff Nurse
   - ☐ Social Worker
   - ☐ Other ____(describe)

4. **How many years have you been in your current position**? ____________

5. **What racial category best describes you? (select all that apply)**

   - ☐ American Indian / Alaska Native
   - ☐ Asian
   - ☐ Black / African American
   - ☐ Native Hawaiian or Other Pacific Islander
   - ☐ White
   - ☐ Other ____(describe)

6. **What ethnic group best describes you?**
   - ☐ Hispanic or Latino
   - ☐ Not Hispanic or Latino