

**PEDIATRIC PALLIATIVE CARE
INSTITUTIONAL SELF-ASSESSMENT TOOL (ISAT)**

for

**Enhancing Family-Centered Care for Children Living
With Life-Threatening Conditions**

HOSPITAL/ADMINISTRATIVE FORM

June 5, 2002

Prepared by:

**Marcia Levetown, MD, FAAP, Deborah L. Dokken, MPA, Alan Fleischman, MD,
Karen S. Heller, PhD, William S. Jose, PhD, Cynda Rushton, DNSc, RN, FAAN,
Robert D. Truog, MD and Mildred Z. Solomon, EdD**

Developed by

**The Center for Applied Ethics and Professional Practice
Education Development Center, Inc.
55 Chapel Street
Newton, MA 02458-1060**

for the project

Enhancing Family-Centered Care for Children Living with Life-Threatening Conditions

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INSTITUTIONAL SELF-ASSESSMENT TOOL (ISAT) – HOSPITAL/ADMINISTRATIVE FORM

Introduction and Instructions

Introduction

The Institutional Self-Assessment Tool (ISAT) was developed as a tool to assist hospitals in conducting a self-assessment related to programs and structures supportive of family-centered palliative care for children with life-threatening diseases.

The tool is divided into two components:

- 1) a **Hospital/Administrative Form** designed to be filled out by someone in an administrative position in the hospital who will be able to answer general questions pertinent to hospital-wide issues, and
- 2) a **Unit Level Form** designed to be filled out by a representative of a local unit (i.e., NICU, PICU, Oncology, HemOnc) who will be able to answer questions pertinent to the unit.

These two instruments are designed to complement each other, and to reduce respondent burden by dividing it between two or more areas of the hospital. The process of collecting and analyzing the results of these questionnaires will be a rewarding experience for those interested in assessing the extent to which there are existing structures, programs, policies and activities specifically targeted to family-centered pediatric palliative care at your institution. In addition, it will provide a fertile basis for discussion and planning of new initiatives or further steps the hospital or particular units may want to undertake in the future.

Instructions for the Site Coordinator

Please identify someone to coordinate the completion of the forms from each of the following areas. This person need not know the answers to all of the questions, but will be responsible for finding out the answers, perhaps by seeking out the knowledge of others in the institution, or by looking through printed materials. The areas we would like you to survey with each of the forms are listed below.

Hospital/Administrative Form. Select one person from the administration of the hospital who will be responsible for collecting the information necessary to complete the questions on this form.

Unit Level Forms. Select one person from each of the following units who will be responsible for collecting the information necessary to complete the questions on this form. Suggested units to survey include NICU, PICU, Pediatric Oncology, Pediatric Cardiology, Pediatric Hematology/Oncology.

Please be sure that each unit completes its own form without collaborating with other units.

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Glossary

Family-centered care:

Family-centered care refers to . . . care that recognizes the central role of the family, however defined by its members, in the health of children. It is based on a partnership of health care professionals, other professionals, the child, and the family. Its goal is to support, respect, encourage, and enhance the strengths and participation of children and families in the child's health care and provide for optimal care of the child." (from: Core Curriculum of Nursing Care of Children and Their Families, 1999)

Interdisciplinary care:

Care provided by health professionals of differing disciplines who regularly meet in person to share perspectives of the patient and together fashion an integrated care plan for each patient. The interdisciplinary care team works collaboratively, is based on norms of respect for contributors from each discipline, and aims to cooperatively promote the patient's interests and quality of care.

Palliative care:

An "active, total approach to care, embracing physical, emotional, social, and spiritual elements. It focuses on enhancement of the quality of life (QOL) for the child and support for the family, and includes the management of distressing symptoms, provision of respite, and care through death and bereavement"¹. "The goal of palliative care is the best quality of life for patients and their families. Many aspects of palliative care are applicable early in the course of disease treatment"².

- 1: Association for Children with Life-threatening or Terminal Conditions and their Families. Royal College of Paediatrics and Child Health. A guide to the development of children's palliative care services. (London: Association for Children with Life-threatening or Terminal Conditions and their Families). 1997. As cited in: Children's International Project on Palliative Care Services (ChIPPS), Compendium of Pediatric Palliative Care. Alexandria, VA: National Hospice and Palliative Care Organization. 2000, page 3.
- 2: World Health Organization. Cancer pain relief and palliative care in children. Geneva, Switzerland, 1998,5. As cited in: Children's International Project on Palliative Care Services (ChIPPS), Compendium of Pediatric Palliative Care. Alexandria, VA: National Hospice and Palliative Care Organization. 2000, page 3.

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Organizational/Structural

Question	Response
1. What is your position and role in the hospital?	Please describe:
2. Which of the following describes the institution? (check all that apply)	<p><u>Affiliation</u></p> <p><input type="checkbox"/> Children's Hospital</p> <p><input type="checkbox"/> University-affiliated children's hospital</p> <p><input type="checkbox"/> Community-based children's hospital</p> <p><input type="checkbox"/> University-affiliated teaching hospital with full-time pediatric residents</p> <p><input type="checkbox"/> Community-based teaching hospital</p> <p><input type="checkbox"/> Community hospital</p> <p><input type="checkbox"/> Other (please specify)</p> <p><u>Type</u></p> <p><input type="checkbox"/> Sub-acute</p> <p><input type="checkbox"/> Long-term care</p> <p><u>Legal Status</u></p> <p><input type="checkbox"/> For profit</p> <p><input type="checkbox"/> Not-for-profit</p>
3. Medicaid/Medicare as percentage of total for the last year available, including managed care and per diem.	<p><input type="checkbox"/> Medicaid Discharges as % of Total Discharges</p> <p><input type="checkbox"/> Medicare Discharges as % of Total Discharges</p> <p><input type="checkbox"/> Medicaid Patient Days as % of Total Patient Days</p> <p><input type="checkbox"/> Medicare Patient Days as % of Total Patient Days</p>
4. Number of pediatric beds, i.e., beds set up and staffed that are solely for patients less than age 18 exclusive of NICU, PICU and nursery.	<input type="text"/> Beds
5. Number of NICU beds: For purposes of this survey, NICU is defined as including NICU beds for Level II or Level III care.	<input type="text"/> Beds

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<p>6. Number of PICU beds:</p> <p>For purposes of this survey, PICU is defined as including all intensive care beds for pediatric patients, excluding NICU beds above.</p>	<p>_____ Beds</p>
<p>7. Number of pediatric emergency department “crash” rooms.</p>	<p>_____ Rooms</p>
<p>8. How many children are admitted to the institution each year in the following units or services:</p> <p><u>Exclude</u> admissions for <u>less</u> than 24 hours.</p>	<p>_____ PICU _____ NICU _____ Hematology-Oncology _____ Renal _____ Emergency Department _____ Cardiovascular/Cardiology _____ Pulmonary _____ GI _____ Chronic care _____ Solid organ transplant _____ Other admitting pediatric services (please specify)</p>
<p>9. How many children die each year at the institution on the following services:</p>	<p>_____ PICU _____ NICU _____ Hematology-Oncology _____ Renal _____ Emergency Room _____ Cardiovascular _____ Pulmonary _____ GI _____ Chronic care _____ Other pediatric services (please specify)</p> <p>_____ Home deaths (home health) _____ Home deaths (hospice)</p>
<p>10. Does the institution provide pediatric cardiovascular surgery?</p>	<p>___ Yes ___ No ___ Don't know</p>

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<p>11. Does the institution provide neonatal ECMO?</p>	<p><input type="checkbox"/> Yes <input type="checkbox"/> No <input type="checkbox"/> Don't know</p>																																																			
<p>12. Does the institution provide pediatric ECMO?</p>	<p><input type="checkbox"/> Yes <input type="checkbox"/> No <input type="checkbox"/> Don't know</p>																																																			
<p>13. Does the institution offer pediatric neuro-surgery?</p>	<p><input type="checkbox"/> Yes <input type="checkbox"/> No <input type="checkbox"/> Don't know</p>																																																			
<p>14. Please provide a count for the following professionals devoted <u>solely</u> to care of children at the institution:</p>	<table border="0"> <thead> <tr> <th></th> <th align="center">Number of FTEs</th> <th align="center">Percent of people in each category who are Full Time</th> </tr> </thead> <tbody> <tr> <td>Medical Doctors</td> <td align="center">_____</td> <td align="center">_____</td> </tr> <tr> <td>Registered Nurses.....</td> <td align="center">_____</td> <td align="center">_____</td> </tr> <tr> <td>Advance Practice Nurses</td> <td align="center">_____</td> <td align="center">_____</td> </tr> <tr> <td>Nurse Practitioners.....</td> <td align="center">_____</td> <td align="center">_____</td> </tr> <tr> <td>Licensed Vocational Nurses</td> <td align="center">_____</td> <td align="center">_____</td> </tr> <tr> <td>Child Life Specialists</td> <td align="center">_____</td> <td align="center">_____</td> </tr> <tr> <td>Social Workers</td> <td align="center">_____</td> <td align="center">_____</td> </tr> <tr> <td>Chaplains.....</td> <td align="center">_____</td> <td align="center">_____</td> </tr> <tr> <td>Psychologists</td> <td align="center">_____</td> <td align="center">_____</td> </tr> <tr> <td>Physical Therapists</td> <td align="center">_____</td> <td align="center">_____</td> </tr> <tr> <td>Occupational Therapists.....</td> <td align="center">_____</td> <td align="center">_____</td> </tr> <tr> <td>Art/Music/Creative Therapists.....</td> <td align="center">_____</td> <td align="center">_____</td> </tr> <tr> <td>Hospital-based K-12 Teachers</td> <td align="center">_____</td> <td align="center">_____</td> </tr> <tr> <td>Grief Counselors</td> <td align="center">_____</td> <td align="center">_____</td> </tr> <tr> <td>Bereavement Specialists</td> <td align="center">_____</td> <td align="center">_____</td> </tr> <tr> <td>Others (please specify).....</td> <td align="center">_____</td> <td align="center">_____</td> </tr> </tbody> </table>		Number of FTEs	Percent of people in each category who are Full Time	Medical Doctors	_____	_____	Registered Nurses.....	_____	_____	Advance Practice Nurses	_____	_____	Nurse Practitioners.....	_____	_____	Licensed Vocational Nurses	_____	_____	Child Life Specialists	_____	_____	Social Workers	_____	_____	Chaplains.....	_____	_____	Psychologists	_____	_____	Physical Therapists	_____	_____	Occupational Therapists.....	_____	_____	Art/Music/Creative Therapists.....	_____	_____	Hospital-based K-12 Teachers	_____	_____	Grief Counselors	_____	_____	Bereavement Specialists	_____	_____	Others (please specify).....	_____	_____
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<p>15. Is the institution a pediatric trauma center?</p>	<p> <input type="checkbox"/> Yes <input type="checkbox"/> No <input type="checkbox"/> Don't know If Yes, what level? <input type="checkbox"/> Level 1 <input type="checkbox"/> Level 2 <input type="checkbox"/> Level 3 </p>
<p>16. Do you have dedicated pediatric hospice/palliative care beds?</p>	<p> <input type="checkbox"/> Yes..... If Yes, how many? _____ <input type="checkbox"/> No </p>
<p>17. Do you have pediatric hospice/ palliative care <u>flexible</u> beds?</p>	<p> <input type="checkbox"/> Yes..... If Yes, how many? _____ <input type="checkbox"/> No </p>

Mission Statements & Policies Supporting Palliative Care

Question	Response
<p>18. Do institutional policies / procedures enable the simultaneous provision of palliative care and efforts to prolong life?</p>	<p> <input type="checkbox"/> Yes <input type="checkbox"/> No <input type="checkbox"/> Don't know If Yes, please attach a copy of relevant policies and/or procedures. </p>
<p>19. Do the mission statements, philosophies of care and patient/family bills of rights in this institution endorse family-centered pediatric palliative care?</p>	<p> <input type="checkbox"/> Yes <input type="checkbox"/> No <input type="checkbox"/> Don't know If Yes, please attach copies of all such statements. </p>
<p>20. Is palliative care identified as a priority during employee orientation?</p>	<p> <input type="checkbox"/> Yes <input type="checkbox"/> No <input type="checkbox"/> Don't know </p>
<p>21. Is family-centered care identified as a priority during employee orientation?</p>	<p> <input type="checkbox"/> Yes <input type="checkbox"/> No <input type="checkbox"/> Don't know </p>

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<p>22. Are there institutional statements of principles about the respective roles and responsibilities of the child, parents/family members, and health care providers?</p>	<p><input type="checkbox"/> Yes..... If Yes, who is covered? (check all that apply)</p> <p><input type="checkbox"/> No <input type="checkbox"/> Child</p> <p><input type="checkbox"/> Don't know <input type="checkbox"/> Parent/family members</p> <p><input type="checkbox"/> Health care providers</p> <p><input type="checkbox"/> Other (please specify):</p> <p> </p> <p>If Yes, please attach copies of all such statements.</p>
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Organizational Structures Supporting Palliative Care

Question	Response
<p>23. Is there a hospice that provides pediatric care in your local community?</p>	<p><input type="checkbox"/> Yes</p> <p><input type="checkbox"/> No</p> <p><input type="checkbox"/> Don't know</p> <p>If Yes, does your hospital have a relationship with them to provide services to your patients?</p> <p><input type="checkbox"/> Yes</p> <p><input type="checkbox"/> No</p> <p><input type="checkbox"/> Don't know</p> <p>If Yes, is the relationship:</p> <p><input type="checkbox"/> Formal (there is a written contract)</p> <p><input type="checkbox"/> Informal</p> <p><input type="checkbox"/> Don't know</p>
<p>24. Is there a parent advisory council, or similar formal structure for parent input into the operations of the institution?</p>	<p><input type="checkbox"/> Yes</p> <p><input type="checkbox"/> No</p> <p><input type="checkbox"/> Don't know</p> <p>If Yes, which of the following categories of parents are purposefully recruited to participate? (check all that apply)</p> <p><input type="checkbox"/> None purposefully recruited</p> <p><input type="checkbox"/> Bereaved parents</p> <p><input type="checkbox"/> Parents of NICU survivors</p> <p><input type="checkbox"/> Parents of PICU survivors</p> <p><input type="checkbox"/> Parents of healthy children</p> <p><input type="checkbox"/> Parents of chronically ill children</p> <p><input type="checkbox"/> Parent Advocates</p> <p><input type="checkbox"/> Other parent category (please specify):</p>

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<p>25. Is there a dedicated pediatric <u>palliative care</u> team at the institution?</p>	<p><input type="checkbox"/> Yes <input type="checkbox"/> No <input type="checkbox"/> Don't know</p> <p>If Yes,</p> <p>a) The palliative care team members include: (check all that apply)</p> <p><input type="checkbox"/> Physician <input type="checkbox"/> Registered Nurse <input type="checkbox"/> Social Worker <input type="checkbox"/> Pharmacist <input type="checkbox"/> Child Life Specialist <input type="checkbox"/> Psychologist <input type="checkbox"/> Chaplain <input type="checkbox"/> Art/Music/Creative Therapist <input type="checkbox"/> Physical Therapist <input type="checkbox"/> Occupational Therapist <input type="checkbox"/> Other (please specify)</p> <p>b) Does the team meet as a whole to discuss patients they are managing? <input type="checkbox"/> Yes <input type="checkbox"/> No <input type="checkbox"/> Don't know</p> <p>c) What services does the palliative care team provide? (check all that apply)</p> <p><input type="checkbox"/> Consultation on patient management <input type="checkbox"/> Staff education <input type="checkbox"/> Patient/family education <input type="checkbox"/> Other: (please specify)</p>
<p>26. Is there a pediatric <u>pain management team</u> and/or <u>acute pain service</u> at the institution?</p>	<p><input type="checkbox"/> Yes, Pain Management Team <input type="checkbox"/> Yes, Acute Pain Service <input type="checkbox"/> No, neither <input type="checkbox"/> Don't know</p> <p align="right">- continued -</p>

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	<p>If Yes,</p> <p>a) The pain management team or acute pain service members include: (check all that apply)</p> <ul style="list-style-type: none"><input type="checkbox"/> Physician<input type="checkbox"/> Registered Nurse<input type="checkbox"/> Social Worker<input type="checkbox"/> Pharmacist<input type="checkbox"/> Child Life Specialist<input type="checkbox"/> Psychologist<input type="checkbox"/> Physical Therapist<input type="checkbox"/> Occupational Therapist<input type="checkbox"/> Chaplain<input type="checkbox"/> Art/Music/Creative Therapist<input type="checkbox"/> Other (please specify) <p>b) Does the team meet as a whole to discuss patients they are managing?</p> <ul style="list-style-type: none"><input type="checkbox"/> Yes<input type="checkbox"/> No<input type="checkbox"/> Don't know <p>c) What services does the pain management team provide? (check all that apply)</p> <ul style="list-style-type: none"><input type="checkbox"/> Consultation on patient management<input type="checkbox"/> Staff education<input type="checkbox"/> Patient/family education<input type="checkbox"/> Other: (please specify)
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<p>27. Is there an Office of Ethics, Ethics Consultant, and/or Ethics Committee within the institution?</p>	<p> <input type="checkbox"/> Yes <input type="checkbox"/> No <input type="checkbox"/> Don't know </p> <p>If Yes, members of the Ethics Committee include the following: (check all that apply)</p> <p><u>Hospital Personnel</u></p> <p> <input type="checkbox"/> Physician <input type="checkbox"/> Biomedical Ethicist <input type="checkbox"/> Chaplain <input type="checkbox"/> Social Worker <input type="checkbox"/> Psychologist <input type="checkbox"/> Registered Nurse <input type="checkbox"/> Administrator <input type="checkbox"/> Hospital Lawyer <input type="checkbox"/> Risk Management Specialist <input type="checkbox"/> Member of the Board of Trustees <input type="checkbox"/> Other members of the hospital community (please specify) </p> <p><u>Community Members</u></p> <p> <input type="checkbox"/> Parents of former patients <input type="checkbox"/> Clergy members <input type="checkbox"/> Lawyers <input type="checkbox"/> Local educators <input type="checkbox"/> Other (please specify) </p> <p>If No, what mechanism(s) exist at this institution for resolution of conflicts about issues of clinical care? (Please describe.)</p>
<p>28. Ethics committee or ethics consultation can be initiated by: (check all that apply)</p>	<p> <input type="checkbox"/> Attending Physician <input type="checkbox"/> Any member of the health care team <input type="checkbox"/> Any family member <input type="checkbox"/> Don't know <input type="checkbox"/> Other (please specify): </p>

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<p>29. Who must consent to an ethics consultation? (check all that apply)</p>	<p><input type="checkbox"/> Attending Physician <input type="checkbox"/> Parent or family <input type="checkbox"/> Other Health Care Provider <input type="checkbox"/> No one <input type="checkbox"/> Don't know <input type="checkbox"/> Other (please specify)</p>
<p>30. Is there a designated health care professional responsible for coordinating overall care of each child living with a life-threatening condition, across care settings?</p>	<p><input type="checkbox"/> Yes <input type="checkbox"/> No <input type="checkbox"/> Don't know</p> <p>If Yes, which health care professional is most likely to assume this role?</p> <p><input type="checkbox"/> Attending Physician <input type="checkbox"/> Registered Nurse <input type="checkbox"/> Advance Practice Nurse <input type="checkbox"/> Nurse Case Manager <input type="checkbox"/> Social Worker <input type="checkbox"/> Fellow <input type="checkbox"/> Resident <input type="checkbox"/> Don't know <input type="checkbox"/> Other (please specify)</p>
<p>31. For children who are readmitted frequently, is there a professional member of the child's care team who is designated to communicate with community physicians and programs involved with the child outside the institution?</p>	<p><input type="checkbox"/> Yes <input type="checkbox"/> No <input type="checkbox"/> Don't know</p> <p>If Yes, which health care professional is most likely to assume this role?</p> <p><input type="checkbox"/> Attending Physician <input type="checkbox"/> Registered Nurse <input type="checkbox"/> Advance Practice Nurse <input type="checkbox"/> Nurse Case Manager <input type="checkbox"/> Social Worker <input type="checkbox"/> Don't know <input type="checkbox"/> Other (please specify)</p>

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<p>32. Is there a policy that chronically ill children are assigned the same caregiver or care team at each hospital admission?</p>	<p> <input type="checkbox"/> Yes <input type="checkbox"/> No <input type="checkbox"/> Don't know </p> <p> If Yes, which personnel are the same at each hospital admission? (check all that apply) </p> <p> <input type="checkbox"/> Attending Physician <input type="checkbox"/> Primary Care Physician <input type="checkbox"/> Registered Nurse <input type="checkbox"/> Advance Practice Nurse <input type="checkbox"/> Nurse Practitioner <input type="checkbox"/> Social Worker <input type="checkbox"/> Psychologist <input type="checkbox"/> Don't know <input type="checkbox"/> Other (please specify) </p>
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Facilities/Space Supporting Palliative Care

Question	Response
<p>33. Does the institution have a planning committee or group involved with facilities expansion or renovation?</p>	<p> <input type="checkbox"/> Yes <input type="checkbox"/> No <input type="checkbox"/> Don't know </p> <p> If Yes, does it include children or parents/family members of children with life-threatening conditions who have been cared for in this institution? </p> <p> <input type="checkbox"/> Yes <input type="checkbox"/> No <input type="checkbox"/> Don't know </p>

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Needs of the Family in Palliative Care

Question	Response
<p>34. Do institutional mission statement(s) or policies reflect the following?</p>	<p><u>Yes</u> <u>No</u></p> <p><input type="checkbox"/> <input type="checkbox"/> Parents' access to their child will be unlimited.</p> <p><input type="checkbox"/> <input type="checkbox"/> Other family members' access to the child will be unlimited.</p> <p><input type="checkbox"/> <input type="checkbox"/> Parents will be invited to be present during procedures involving their child.</p> <p><input type="checkbox"/> <input type="checkbox"/> Other family members will be invited to be present during procedures involving the child.</p> <p><input type="checkbox"/> <input type="checkbox"/> Parents will be notified immediately if there is a significant change in their child's health.</p> <p><input type="checkbox"/> <input type="checkbox"/> Other family members will be notified immediately if there is a significant change in the child's health.</p> <p><input type="checkbox"/> <input type="checkbox"/> Parents will be given the option to be present during resuscitation procedures.</p> <p><input type="checkbox"/> <input type="checkbox"/> Other family members will be given the option to be present during resuscitation procedures.</p>

Assessment and Identification

Question	Response
<p>35. Is there a standardized mechanism within the institution to enable the assessment and implementation of preferences of families of children with life-threatening conditions regarding:</p>	<p><u>Yes</u> <u>No</u></p> <p><input type="checkbox"/> <input type="checkbox"/> Whom they wish to have access to their child (family members, friends, others), even when the parents are not present</p> <p><input type="checkbox"/> <input type="checkbox"/> When they wish to be with their child</p> <p><input type="checkbox"/> <input type="checkbox"/> How they wish to be involved in their child's care</p> <p><input type="checkbox"/> <input type="checkbox"/> In what ways it is most effective and convenient for them to share information and raise questions/concerns with health care professionals</p> <p><input type="checkbox"/> <input type="checkbox"/> Practical and/or psychosocial issues for which family members need support</p>

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Communication and Decision-Making

Question	Response
<p>36. Is there a policy that states families should receive updates about their child's condition and treatment?</p>	<p> <input type="checkbox"/> Yes <input type="checkbox"/> No <input type="checkbox"/> Don't Know </p> <p>If Yes, does the policy specify that the frequency of updates is at least: (check all that apply)</p> <p> <input type="checkbox"/> Daily <input type="checkbox"/> Weekly <input type="checkbox"/> With significant changes in status <input type="checkbox"/> Don't know <input type="checkbox"/> Other (please specify) </p> <p>If Yes, is the communication accomplished by: (check all that apply)</p> <p> <input type="checkbox"/> Bedside rounds <input type="checkbox"/> Face-to-face meetings <input type="checkbox"/> Bedside journal <input type="checkbox"/> Telephone call <input type="checkbox"/> Secure email <input type="checkbox"/> Other (please specify) </p>

Support and Resources

Question	Response
<p>37. Are any of the following offered <i>within the institution</i> to support the practical and emotional needs of families of children with life-threatening conditions?</p>	<p><u>Practical Needs</u></p> <p> <input type="checkbox"/> Vouchers for food, parking, and transportation <input type="checkbox"/> Listings of hotels, restaurants near the institution <input type="checkbox"/> Housing for families of children with prolonged hospital stays <input type="checkbox"/> Access to long-distance and local telephone service, without charge <input type="checkbox"/> Assistance with insurance, Medicaid, and other financial issues <input type="checkbox"/> Other (please specify) <input type="checkbox"/> Don't know </p> <p align="right">- continued -</p>

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	<p><u>Social/Emotional Needs</u></p> <p><input type="checkbox"/> Play areas for healthy siblings</p> <p> <input type="checkbox"/> Supervised</p> <p> <input type="checkbox"/> Unsupervised</p> <p><input type="checkbox"/> Child Life services for healthy siblings</p> <p><input type="checkbox"/> Psychological consulting for siblings</p> <p><input type="checkbox"/> Support groups for parents and siblings</p> <p><input type="checkbox"/> Other (please specify)</p> <p><input type="checkbox"/> Don't know</p>
<p>38. Is there a Family Resource area within the institution available to the families of children with life-threatening conditions?</p>	<p><input type="checkbox"/> Yes</p> <p><input type="checkbox"/> No</p> <p><input type="checkbox"/> Don't Know</p> <p>If Yes,</p> <p>a) which the following types of information are located in this area? (check all that apply)</p> <p><input type="checkbox"/> Information in lay terms about common life-threatening conditions of childhood</p> <p><input type="checkbox"/> Information about parents supporting each other</p> <p><input type="checkbox"/> Information about supporting siblings</p> <p><input type="checkbox"/> Information about medical and psychosocial support resources in surrounding communities</p> <p><input type="checkbox"/> Listing of peer parent supporters</p> <p><input type="checkbox"/> Listings of parent and sibling support organizations</p> <p><input type="checkbox"/> Listing of respite programs and providers in surrounding communities</p> <p><input type="checkbox"/> Listing of pediatric-oriented home health programs</p> <p><input type="checkbox"/> Listing of pediatric-oriented hospice programs</p> <p><input type="checkbox"/> Information about grief and loss</p> <p><input type="checkbox"/> Other (please specify)</p> <p>b) are the resources and information updated regularly?</p> <p><input type="checkbox"/> Yes</p> <p><input type="checkbox"/> No</p> <p><input type="checkbox"/> Don't Know</p> <p>c) are organizations/programs verified by hospital personnel who are familiar with standards for such services?</p> <p><input type="checkbox"/> Yes</p> <p><input type="checkbox"/> No</p> <p><input type="checkbox"/> Don't Know</p> <p align="right">- continued -</p>

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	d) is there internet access for parents and siblings? <input type="checkbox"/> Yes <input type="checkbox"/> No <input type="checkbox"/> Don't Know
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Bereavement

Question	Response
39. Is there a formalized bereavement program that includes both pre- and post-death support and interventions?	<input type="checkbox"/> Yes, pre-death components <input type="checkbox"/> Yes, post-death components <input type="checkbox"/> No <input type="checkbox"/> Don't know
40. Is a memorial service provided by the institution for bereaved families?	<input type="checkbox"/> Yes <input type="checkbox"/> No <input type="checkbox"/> Sometimes <input type="checkbox"/> Don't know If Yes , is this service: <input type="checkbox"/> Annual <input type="checkbox"/> Semi-annual <input type="checkbox"/> Quarterly <input type="checkbox"/> Monthly <input type="checkbox"/> Don't know interval <input type="checkbox"/> Other (please specify)
41. Does the institution provide small group services of remembrance with direct caregivers and family members?	<input type="checkbox"/> Yes <input type="checkbox"/> No <input type="checkbox"/> Only on some units <input type="checkbox"/> Don't know
42. For which of the following does the institution provide bereavement support groups: (check all that apply)	<input type="checkbox"/> Parents <input type="checkbox"/> Siblings <input type="checkbox"/> Pre-school <input type="checkbox"/> School age <input type="checkbox"/> Teens <input type="checkbox"/> Grandparents <input type="checkbox"/> Other Relatives <input type="checkbox"/> Friends/classmates <input type="checkbox"/> Other (please specify)

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<p>43. Does the institution provide school-based bereavement intervention for classmates?</p>	<p><input type="checkbox"/> Yes <input type="checkbox"/> No <input type="checkbox"/> Don't know</p>
<p>44. Which of the following referral services for bereavement care does the institution provide? (check all that apply)</p>	<p><input type="checkbox"/> Community-based support groups <input type="checkbox"/> Community-based counselors <input type="checkbox"/> Regional support group referrals <input type="checkbox"/> Parent peer support group <input type="checkbox"/> Online support group listings</p>
<p>45. Does the institution send bereavement cards to families as part of a standardized practice?</p>	<p><input type="checkbox"/> Yes <input type="checkbox"/> No <input type="checkbox"/> Don't know</p> <p>If Yes,</p> <p>a) is this activity: <input type="checkbox"/> Hospital-based <input type="checkbox"/> Unit-based <input type="checkbox"/> Diagnosis-group based <input type="checkbox"/> Don't know</p> <p>b) which units/services participate? (check all that apply) <input type="checkbox"/> PICU <input type="checkbox"/> NICU <input type="checkbox"/> Hematology-Oncology <input type="checkbox"/> Renal <input type="checkbox"/> Emergency Room <input type="checkbox"/> Cardiovascular <input type="checkbox"/> Pulmonary <input type="checkbox"/> GI <input type="checkbox"/> Chronic care <input type="checkbox"/> Other (please specify)</p> <p>c) when are bereavement cards sent? <input type="checkbox"/> At/soon after death <input type="checkbox"/> One month after death <input type="checkbox"/> At birthday <input type="checkbox"/> At winter holidays <input type="checkbox"/> At anniversary of death <input type="checkbox"/> 1st anniversary <input type="checkbox"/> 2nd anniversary <input type="checkbox"/> 3rd anniversary or later <input type="checkbox"/> Other (please specify)</p> <p>If Yes, are the bereavement cards: <input type="checkbox"/> Signed by individual provider(s) <input type="checkbox"/> "Generic" signature <input type="checkbox"/> Other (Please describe)</p>

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<p>46. Is there a paid person in charge of coordinating bereavement activities?</p>	<p><input type="checkbox"/> Yes <input type="checkbox"/> No <input type="checkbox"/> Don't know</p> <p>If Yes, does this person coordinate activities by:</p> <p><input type="checkbox"/> Hospital <input type="checkbox"/> Diagnostic group <input type="checkbox"/> Unit (please specify which units) <input type="checkbox"/> Don't know</p> <p>If Yes, who is in charge of coordinating bereavement activities?</p> <p><input type="checkbox"/> Physician <input type="checkbox"/> Registered Nurse <input type="checkbox"/> Social worker <input type="checkbox"/> Chaplain <input type="checkbox"/> Grief Counselor <input type="checkbox"/> Other (please specify)</p>
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Care of the Professional Caregivers

Question	Response
<p>47. Which of the following is the institution doing on a routine basis to ensure the well-being of personnel who care for children living with life-threatening conditions and their families? (check all that apply)</p>	<p><input type="checkbox"/> Providing paid time and relief of clinical duties to attend patients' funerals/visitations/memorials</p> <p><input type="checkbox"/> Providing an atmosphere of respect for all disciplines (Please describe how is this accomplished.)</p> <p><input type="checkbox"/> Providing mentors</p> <p><input type="checkbox"/> Sending condolence cards to personnel who were extensively involved with a patient who has died</p> <p><input type="checkbox"/> Providing flexibility in scheduling to accommodate personnel grieving after the loss of a patient</p> <p><input type="checkbox"/> Providing effective education on palliative care topics</p> <p><input type="checkbox"/> Individual counseling</p> <p><input type="checkbox"/> Employee assistance office</p> <p><input type="checkbox"/> Group counseling/support meetings</p> <p><input type="checkbox"/> Encouraging open communication/exchange of views among all disciplines involved in the child's care</p> <p><input type="checkbox"/> Providing self-care opportunities on the unit such as</p> <p style="padding-left: 40px;"><input type="checkbox"/> Massage</p> <p style="padding-left: 40px;"><input type="checkbox"/> Music</p> <p style="padding-left: 40px;"><input type="checkbox"/> Quiet Space</p> <p style="padding-left: 40px;"><input type="checkbox"/> Staff Lounge</p> <p style="padding-left: 40px;"><input type="checkbox"/> Other (please specify)</p> <p><input type="checkbox"/> Opportunities to discuss troubling cases, for example:</p> <p style="padding-left: 40px;"><input type="checkbox"/> Debriefing while child is living</p> <p style="padding-left: 40px;"><input type="checkbox"/> Debriefing after death</p> <p style="padding-left: 40px;"><input type="checkbox"/> Ethics rounds</p> <p style="padding-left: 40px;"><input type="checkbox"/> Policies on professional relationships and boundaries</p> <p style="padding-left: 40px;"><input type="checkbox"/> Palliative Care rounds</p> <p style="padding-left: 40px;"><input type="checkbox"/> Patient Care consensus conference</p> <p style="padding-left: 40px;"><input type="checkbox"/> Other (please specify)</p> <p><input type="checkbox"/> Don't know</p> <p><input type="checkbox"/> Other (please specify)</p>

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Thank you for your effort in answering these questions.

Finally, do you have any further comments about the care you provide and its impact on children, families or care providers?