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Supplemental Digital Content 2

Family-Centered Care Hospital Policies and Practices Scale – Hospitals Caring for Pediatric Patients

This 44-item survey assesses the perceptions of hospital leaders, healthcare professionals, and family support service providers of the family-centeredness of policies and practices. The total and subscale scores can be used to help determine initial priorities and action steps for family-centered care awareness, education, and improvement. It can also be used to track progress over time.

Instructions: Please rate each item according to how it best represents the policies and practices at your children's hospital, pediatric service or in your neonatal or pediatric unit or department.

Family-Centered Care (FCC) Items	Ratings					
	Strongly disagree	Disagree	Neither agree nor disagree	Agree	Strongly agree	Unsure
FCC Culture and Policies (6 items)						
1. Family-centered care is integrated as a core value and priority	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
2. Our mission, vision, values, and/or philosophy of care statements convey a commitment to family-centered care	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
3. Written policies refer to families as essential members of the health care team and not as "visitors"	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
4. We welcome families 24 hours a day, 7 days a week	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
5. Written policies and staff practices make a distinction between families and visitors (i.e., friends, relatives who may wish to visit)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
6. We have protocols for supporting safe sibling presence	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Family Participation in Care and Decision-Making – Part 1 (10 items)						
7. We encourage families to identify how they want to be involved in: Direct care	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
8. We encourage families to identify how they want to be involved in: Care planning and decision-making	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
9. Care planning and decision-making incorporates the cultural and spiritual beliefs and practices of families	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

Family-Centered Care (FCC) Items	Ratings					
10. Physician and nurse practices support family participation in: Direct patient care	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
11. Physician and nurse practices support family participation in: Care planning	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
12. Physician and nurse practices build on the confidence and competence of families to support family participation in: Decision-making	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
13. Physician and nurse practices support family participation in: Daily medical rounds	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
14. Physician and nurse practices support family participation in: Planning transitions and discharge	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
15. Physician and nurse practices support family participation in: Planning end-of-life care	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
16. Physician and nurse practices encourage and support children and adolescents in planning their care, as developmentally appropriate	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

Family Participation in Care and Decision-Making – Part 2 (2 items)	Strongly disagree	Disagree	Neither agree nor disagree	Agree	Strongly agree	Unsure
17. Physician and nurse practices support family participation in: Nurse change of shift	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
18. Physician and nurse practices support families to be present during codes or other emergency situations	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

Information Sharing (5 items)	Strongly disagree	Disagree	Neither agree nor disagree	Agree	Strongly agree	Unsure
19. Families are welcomed as essential members of the health care team in pre-admission materials, family welcome packs and handbooks	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
20. Families are welcomed as essential members of the health care team on our hospital website	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
21. We welcome and support families through signage that is prominent and worded positively	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
22. We provide informational materials that are understandable and appropriate for families we serve (e.g., languages, reading levels, formats)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
23. We provide interpreters when needed	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

Family-Centered Care (FCC) Items	Ratings					
Support for Families (5 items)	Strongly disagree	Disagree	Neither agree nor disagree	Agree	Strongly agree	Unsure
24. We ensure that staff ask families about basic needs that may affect their health (e.g., housing, food insecurity)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
25. We ensure that staff connect families to appropriate community resources, as needed (e.g., social services, parent support associations)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
26. Adequate and comfortable space and furniture (chair and/or bed) provided at the patient's bedside	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
27. We provide peer support programs for families	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
28. We offer financial support to families for parking, meals, overnight accommodation and childcare, as needed	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Staff Education and Performance (6 items)	Strongly disagree	Disagree	Neither agree nor disagree	Agree	Strongly agree	Unsure
29. We describe the necessity of partnering with families as members of the health care team in: Orientation for physicians	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
30. We describe the necessity of partnering with families as members of the health care team in: Orientation for nurses and other clinical staff	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
31. We describe the necessity of partnering with families as members of the health care team in: Inservice and continuing education for physicians	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
32. We describe the necessity of partnering with families as members of the health care team in: Inservice and continuing education for nurses and other clinical staff	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
33. We clearly describe the necessity of partnering with families as members of the health care team in position descriptions	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
34. We clearly describe the necessity of partnering with families as members of the health care team in performance appraisals	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

Family-Centered Care (FCC) Items	Ratings					
Cultural Sensitivity Education (3 items)	Strongly disagree	Disagree	Neither agree nor disagree	Agree	Strongly agree	Unsure
35. We provide orientation and education programs to prepare physicians for culturally sensitive practice	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
36. We provide orientation and education programs to prepare nurses and other clinical staff for culturally sensitive practice	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
37. We provide orientation and education programs to prepare hospital leaders for culturally sensitive practice	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Family Participation in Healthcare Improvement (7 items)	Strongly disagree	Disagree	Neither agree nor disagree	Agree	Strongly agree	Unsure
38. We collect information about the family experience of care through surveys or post-discharge phone calls	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
39. We collaborate with families to improve the experience of care, quality, equity, and/or safety through a family advisory council or family participation on hospital committees	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
40. Family advisors reflect the race, ethnicity, linguistic, gender, sexual orientation, and socio-economic diversity of communities served by the hospital	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
41. We communicate the efforts and impact of family advisors to hospital leaders	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
42. Our hospital leaders, through their words and actions, hold all staff accountable for family-centered care	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
43. Our hospital leaders provide rewards and recognition for family-centered practice by hospital staff	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
44. Our hospital leaders invest time and financial and personnel resources in family-centered care initiatives	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Total score (sum scores 1=strongly disagree to 5=strongly agree; point range: 41-205); 8 sub-scales						

Partnership with Family Support Organization Items	Ratings					
45. Does your hospital have a partnership with any community-based organization that provides family housing and support services (e.g., Ronald McDonald House Charities, etc.)	<input type="radio"/> Yes	<input type="radio"/> No	<input type="radio"/> Unsure			
<p>If no, skip to next section.</p> <p>If yes, please complete the following items:</p>						
46. Having a partnership with an organization that provides family housing and support services helps our children's hospital or my neonatal or pediatric unit/department in the following ways...	Strongly disagree	Disagree	Neither agree nor disagree	Agree	Strongly agree	Unsure
46.1. Enhances our ability to provide family-centered care	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
46.2. Reduces costs to families	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
46.3. Increases parent/caregiver understanding of child's care plan	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
46.4. Reduces the length of time a child stays in the hospital	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
46.5. Improves parent/caregiver satisfaction with hospital care	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
46.6. Reduces the burden on our hospital in assisting families with lodging	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
46.7. Reduces the burden on our hospital in assisting families with food	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
46.8. Reduces the burden on our social work department in connecting families to community resources	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
46.9. Enhances the quality of care our hospital provides	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
46.10. Reduces costs to our hospital	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
46.11. Increases the number of patients the hospital serves	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
46.12. Enhances our hospital's reputation	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

Hospital and Leader Demographics Items	Ratings
47. How many <u>neonatal/pediatric</u> inpatient beds does your hospital have? (check one)	<input type="radio"/> Less than 100 beds <input type="radio"/> 100 beds or more
48. How is medical care paid for at your hospital? (check one)	<input type="radio"/> Most care is paid for by public funds <input type="radio"/> Most care is paid for by health insurance or by the family <input type="radio"/> A mix of public funds, health insurance and family
49. Is your hospital affiliated with a medical school and/or university?	<input type="radio"/> Yes <input type="radio"/> No
50. Is your hospital a referral center for pediatric specialty care for your region or country?	<input type="radio"/> Yes <input type="radio"/> No
51. Does your hospital have an active family advisory council that meets at least 6 times a year?	<input type="radio"/> Yes <input type="radio"/> No
52. In what role do you spend most of your time? (check the <u>one</u> that best fits)	<input type="radio"/> Hospital leader (non-clinical) <input type="radio"/> Hospital medical leader <input type="radio"/> Hospital nursing leader <input type="radio"/> Hospital family services leader <input type="radio"/> Unit/department leader (non-clinical) <input type="radio"/> Unit/department medical leader <input type="radio"/> Unit/department nursing leader <input type="radio"/> Physician, patient care <input type="radio"/> Nurse, patient care <input type="radio"/> Therapist, social worker <input type="radio"/> Other clinical role <input type="radio"/> Other non-clinical role
53. How long have you been working in your profession?	<input type="radio"/> Less than 5 years <input type="radio"/> 5-9 years <input type="radio"/> 10-14 years <input type="radio"/> 15-20 years <input type="radio"/> More than 20 years

Please add below any comments about family-centered care at your hospital or neonatal or pediatric unit/department:
