

Supplemental Information

SURVEY INSTRUMENT: PEDIATRIC CCI: REDUCING EXCESS HOSPITALIZATIONS

Professional Stakeholder Questions

Questions for inpatient professionals:

1. To begin, could you please describe the ways in which your current work contributes to the care of chronically critically ill children, in particular those with repeated and prolonged hospitalizations?
2. And in the past, have you had other roles related to the care of children with chronic critical illness?
3. What has your experience been with the families of chronically critically ill children?
4. What experiences have you had with other professionals involved in the care of chronically critically ill children?
5. How would you characterize the communication between the different professionals involved in the care of individual children with chronic critical illness?
6. Could you tell me what you know about the different locations where infants and children with chronic critical illness might be cared for?
7. Have you had any experience with medical group homes? Do you think these are feasible options for children with chronic critical illness if they are unable to be cared for in a traditional home setting?
8. How is the experience of caring for a child with a chronic critical illness different from that of other hospitalized children?
9. What are your perceptions of why infants and children with chronic critical illness might spend prolonged periods in the hospital, especially in the ICU?
10. What are some of the challenges in your hospital caring for children with chronic critical illness?
11. In your experience, where are the optimal sites of care for these infants and children, and why?
12. In your experience, where are the least optimal sites of care for these infants and children, and why?
13. What do you think are some of the key barriers that keep children like this from spending more time in their preferred location?
14. What keeps children with a chronic critical illness in the hospital?
15. What do you wish inpatient care sites could do differently for children with chronic critical illness?
16. What do you wish families with a child with chronic critical illness could do differently?
17. What kinds of families are particularly vulnerable in cases where a child is experiencing chronic critical illness? Do you have any specific concerns for these families?
18. What do you prioritize in caring for children with chronic critical illness?
19. What do you think palliative care offers children and families affected by chronic critical illness?
20. What is your experience with family or clinician burnout in caring for children with chronic critical illness?
21. Are you aware of any local, state, or national policies that impact the sites of care for infants and children with chronic critical illness?
22. What health care reforms do you think might improve care for children with chronic critical illness?
23. Can you tell me about any experiences you might have had regarding children with chronic critical illness in foster care?
24. What do you wish insurance companies and policymakers could do differently regarding children with chronic critical illness?
25. If you were to plan a research study about children with chronic critical illness, what would you study?
26. Regarding the care for chronically critically ill children and their families, is there anything else we should be asking about or you think we should know?

Additional questions for outpatient professionals:

1. What do you think could keep children with chronic critical illness home and prevent readmissions to the hospital? What challenges are faced in achieving this?
2. What does palliative care offer children with chronic critical illness in the outpatient setting?

3. What are some of the challenges in caring for children with chronic critical illness in the outpatient setting?
4. Have you encountered challenges in navigating inpatient-to-outpatient and outpatient-to-inpatient transitions for children with chronic critical illness?
5. In your experience, how much are outpatient providers included in the inpatient care, coordination of care, or care planning?
6. Additionally, do you find that some outpatient clinicians (eg, primary care physicians) are wary of taking on children with chronic critical illness?

Additional questions for long-term care professionals:

1. What are some of the challenges getting children with chronic critical illness in or out of long-term care?
2. How do long-term care goals differ from hospital goals for children with chronic critical illness?

Additional questions for foster care professionals:

1. What are some of the primary reasons why these children enter foster care?
2. What are the challenges of caring for children with chronic critical illness within the foster care system?
3. What are the barriers to discharging these children from the hospital to foster care? What about the barriers to then keeping them out of the hospital?
4. What can you tell us about how medical care is coordinated for these children? How are medical records maintained and shared?

5. What training is provided to foster parents to care for these children? In your experience, has this training been sufficient?
6. What are the placement options for children with chronic critical illness in foster care? What are the pros and cons of each option?
7. How are medical decisions made for children with chronic critical illness in foster care?
8. Who usually takes part in these conversations involving medical decisions and goals of care? Who do you think should take part in such discussions?
9. What do you and the health care team know about caring for children with chronic critical illness in foster care?
10. What do you see as important interactions between the legal system and medical foster care for children like this?

Additional questions for policy professionals:

1. Who are the best advocates for children with chronic critical illness?
2. Currently, large amounts of money spent in health care are for those with chronic critical illnesses. How can we reduce the amount of spending in this population?
3. What legal barriers are there to care for children with chronic critical illness?

Parent stakeholder questions

1. Could you describe for me what your experience has been with chronically critically ill children, in particular those with repeated and prolonged hospitalizations?

2. And could you describe what your experience has been with other families of chronically critically ill children?
3. What experiences have you had with health care providers involved in the care of chronically critically ill children?
4. Could you tell me what you know about the different locations where infants and children with chronic critical illness might be cared for?^a
5. Why do you think infants and children with chronic critical illness might spend prolonged periods in the hospital, especially in the ICU?^a
6. What are some of the reasons your child fluctuated between hospital care and outpatient care? What might have prevented those hospitalizations?
7. What could hospital staff do differently for children with chronic critical illness?
8. Could you tell me about any experiences you might have had with pediatric palliative care?
9. In your experience, where are the optimal sites of care for these infants and children, and why?^a
10. In your experience, where are the least optimal sites of care for these infants and children, and why?^a
11. What helped your family provide care for your child at home?
12. What financial costs for your family are associated with your child's hospitalization?

13. What costs associated with chronic critical illness do you think don't receive enough attention?
 14. Are you aware of any local, state, or national policies that impact the sites of care for infants and children with chronic critical illness?^a
 15. What health care reforms do you think might improve care for children with chronic critical illness?^a
 16. If you were to plan a research study about children with chronic critical illness, what would you study?^a
 17. Regarding the care for chronically critically ill children and their families, is there anything else we should be asking about or you think we should know?^a
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^aQuestions asked to both professional and parent stakeholders.