

| THEME | SUBTHEME | ITEM FROM ROUND 1 (PROCESSES OF CARE) | Yes, appropriate | n | Yes, with changes | n | Not appropriate | n | Total | REVISED ITEM FOR ROUND 2 (PROCESSES OF CARE) | Expert comments | |
|--|--|---|---|-----|-------------------|-----|-----------------|----|--|--|--|--|
| Effective Efficient healthcare structures & standards | Accessible Medical Care | 1 I have access to multi-disciplinary expertise in my child's range of condition(s) (e.g., medical nursing, allied health professionals, specialists, social workers, etc). Response options: Never / Seldom / Sometimes / Usually / Always | 88% | 21 | 13% | 3 | 0% | 0 | 24 | I have an easily access to a range of healthcare workers in many disciplines multi-disciplinary expertise to meet my child's needs in my child's range of condition(s) (e.g., doctors, nurses, pharmacists, social workers, therapists medical nursing, allied health professionals, specialists, social workers, etc). | | |
| | | 2 I have access to on-demand assistance and advice from healthcare workers. Response options: Never / Seldom / Sometimes / Usually / Always | 67% | 16 | 33% | 8 | 0% | 0 | 24 | I have an easily receive access to on-demand assistance and advice from healthcare workers when I need it. | | |
| | | 3 Healthcare workers are approachable when I seek their advice. Response options: Never / Seldom / Sometimes / Usually / Always | 83% | 20 | 17% | 4 | 0% | 0 | 24 | I feel comfortable asking my child's healthcare workers are approachable when I seek their advice about my child's care. | | |
| | | 4 Healthcare workers offer convenient ways to obtain and manage my child's medical equipment and supplies. Response options: Never / Seldom / Sometimes / Usually / Always | 79% | 19 | 17% | 4 | 4% | 1 | 24 | Healthcare workers offer convenient ways to help me to obtain and manage my child's medical equipment and supplies. | | |
| | | 5 Healthcare workers facilitate the process of acquiring high-cost medical equipment (e.g. ventilator, suction machine, buggy) that my child needs. Response options: Never / Seldom / Sometimes / Usually / Always / My child does not need high-cost equipment | 75% | 18 | 17% | 4 | 8% | 2 | 24 | Healthcare workers help me in facilitate the process of acquiring high-cost medical equipment (e.g. ventilator, suction machine, buggy) for my child that my child needs. | | |
| | | 6 I receive financial support to support my child's medical expenses that is based on an individualized assessment of my family's needs. Response options: Never / Seldom / Sometimes / Usually / Always | 71% | 17 | 29% | 7 | 0% | 0 | 24 | I receive adequate financial support for to support my child's medical expenses that is based on an individualized assessment of my family's needs. Response options: Yes / No | | |
| | Effective administration and facilities | 1 Healthcare workers offer flexibility in visitation for my child when he/she is critically ill (e.g. allowing multiple caregivers at bedside). Response options: Strongly Disagree / Disagree / Neither Agree nor Disagree / Agree / Strongly Agree / Not applicable to my child | 75% | 18 | 13% | 3 | 13% | 3 | 24 | Healthcare workers offer flexibility in the number of caregivers allowed at bedside visitation for my child when my child needs intensive care he/she is critically ill (e.g. allowing multiple caregivers at bedside). | | |
| | | 2 I have the ability to choose my child's healthcare workers. Response options: Strongly Disagree / Disagree / Neither Agree nor Disagree / Agree / Strongly Agree | 46% | 11 | 21% | 5 | 33% | 8 | 24 | ELIMINATE | | |
| | | 3 My child is fast tracked at Children's Emergency because of his/her chronic and complex needs. Response options: Never / Seldom / Sometimes / Usually / Always / My child has not been to Children's Emergency | 63% | 15 | 25% | 6 | 13% | 3 | 24 | My child is attended to without undue delay fast tracked when we present at the emergency department at Children's Emergency because of his/her chronic and complex needs. | | |
| | | 4 The food provided in hospital is suited to my child's unique needs or preferences. Response options: Never / Seldom / Sometimes / Usually / Always / Not applicable to my child | 71% | 17 | 8% | 2 | 21% | 5 | 24 | The food provided in healthcare facilities hospital can be modified to be suited to my child's unique needs or preferences. | | |
| | | 5 Healthcare workers give me a private and comfortable space to be close to my child when he/she is admitted to hospital or hospice. Response options: Never / Seldom / Sometimes / Usually / Always | 71% | 17 | 17% | 4 | 13% | 3 | 24 | Healthcare workers give me a private and comfortable space to be I am able to stay close to my child when he/she is admitted to hospital or hospice. | | |
| | Professional Qualities of HCWs | Coordination and continuity of care | 1 Healthcare workers work as a team towards the same goals for my child's care. Response options: Never / Seldom / Sometimes / Usually / Always | 92% | 22 | 8% | 2 | 0% | 0 | 24 | NO CHANGE | |
| | | | 2 I have a main healthcare worker or team who has consistent oversight over my child's medical needs. Response options: Yes / No / I don't know | 92% | 22 | 8% | 2 | 0% | 0 | 24 | I have a main healthcare worker who or team who consistently oversees has consistent oversight over my child's medical needs. | |
| | | | 3 I have a healthcare worker or team who coordinates my child's care between different disciplines and services. Response options: Yes / No / I don't know | 92% | 22 | 8% | 2 | 0% | 0 | 24 | I have a healthcare worker who or team who coordinates my child's care between different disciplines, and services, and agencies. | |
| | | | 4 I receive the same information from different healthcare workers. Response options: Never / Seldom / Sometimes / Usually / Always | 67% | 16 | 33% | 8 | 0% | 0 | 24 | I receive consistent the same information from different healthcare workers. | |
| | | | 5 Healthcare workers ensure a smooth transition of care across the different settings my child receives care (e.g., NICU to PICU, Private to Public, going home, hospital admission). Response options: Never / Seldom / Sometimes / Usually / Always | 88% | 21 | 13% | 3 | 0% | 0 | 24 | Healthcare workers ensure a smooth transition of care across the different healthcare settings my child receives care (e.g., NICU to PICU, Private to Public facilities, going home, hospital admission). | |
| | | | 6 Healthcare workers make sure my child's appointments are well coordinated to reduce our hospital visits. Response options: Never / Seldom / Sometimes / Usually / Always | 92% | 22 | 8% | 2 | 0% | 0 | 24 | Healthcare workers make sure coordinate my child's appointments are well coordinated to reduce our hospital visits. | |
| | | Responsive and sensitive communication | 1 Healthcare workers present themselves in an honest and transparent way. Response options: Strongly Disagree / Disagree / Neither Agree nor Disagree / Agree / Strongly Agree | 79% | 19 | 17% | 4 | 4% | 1 | 24 | Healthcare workers present themselves in an honest and transparent way. | |
| 2 I trust my child's healthcare workers. Response options: Strongly Disagree / Disagree / Neither Agree nor Disagree / Agree / Strongly Agree | | | 100% | 24 | 0% | 0 | 0% | 0 | 24 | Healthcare workers make an effort to build a trusting relationship with me. I trust my child's healthcare workers. | | |
| 3 Healthcare workers take responsibility for my child's wellbeing and things that happen to my child under their care. Response options: Never / Seldom / Sometimes / Usually / Always | | | 83% | 20 | 17% | 4 | 0% | 0 | 24 | Healthcare workers take responsibility for my child's wellbeing and things that happen to my child when he/she is under their care. | | |
| 4 Healthcare workers respect my right to information on my child. Response options: Never / Seldom / Sometimes / Usually / Always | | | 88% | 21 | 13% | 3 | 0% | 0 | 24 | Healthcare workers support respect my right to information about on my child by ensuring I am always fully informed . | | |
| 5 Healthcare workers give me information on my child's condition in a timely manner. Response options: Never / Seldom / Sometimes / Usually / Always | | | 92% | 22 | 8% | 2 | 0% | 0 | 24 | NO CHANGE | | |
| 6 Healthcare workers communicate with me in a sensitive way. Response options: Never / Seldom / Sometimes / Usually / Always | | | 92% | 22 | 8% | 2 | 0% | 0 | 24 | Healthcare workers communicate with me in a sensitive way that is sensitive to my needs . | | |
| Competency of healthcare delivery | 1 Healthcare workers have a good sense of urgency so that I am not unnecessarily stressed. Response options: Strongly Disagree / Disagree / Neither Agree nor Disagree / Agree / Strongly Agree | 58% | 14 | 29% | 7 | 13% | 3 | 24 | Healthcare workers have an appropriate good sense of urgency when communicating with me so that additional stress is not created I am not unnecessarily stressed (e.g. not calling multiple times throughout the day for non-urgent issues, informing me about critical news quickly). | | | |
| | 2 Healthcare workers show me genuine care and sincerity. Response options: Never / Seldom / Sometimes / Usually / Always | 92% | 22 | 8% | 2 | 0% | 0 | 24 | NO CHANGE | | | |
| | 3 Healthcare workers are respectful of my spiritual or religious customs and beliefs. Response options: Never / Seldom / Sometimes / Usually / Always / Not applicable to me | 96% | 23 | 4% | 1 | 0% | 0 | 24 | NO CHANGE | | | |
| | 4 Healthcare workers have the necessary knowledge, skills and experience in their fields to meet my child's and family's needs. Response options: Strongly Disagree / Disagree / Neither Agree nor Disagree / Agree / Strongly Agree | 79% | 19 | 21% | 5 | 0% | 0 | 24 | Healthcare workers present their have the necessary knowledge, skills and experience so that I am confident they can meet my child's needs in their fields to meet my child's and family's needs. | | | |
| | 5 Healthcare workers deliver timely medical care for my child. Response options: Never / Seldom / Sometimes / Usually / Always | 83% | 20 | 17% | 4 | 0% | 0 | 24 | Healthcare workers deliver provide timely medical care for my child without undue delay . | | | |
| | 6 Healthcare workers are able to identify and solve my child's medical issues. Response options: Never / Seldom / Sometimes / Usually / Always | 71% | 17 | 29% | 7 | 0% | 0 | 24 | Healthcare workers are able to do all they can to identify and solve treat my child's medical issues. | | | |
| Supporting parent caregivers | Empowering parent-caregivers | 1 Healthcare workers tell me what to look out for so that I know what to do when he/she is unwell without needing to go to the hospital. Response options: Never / Seldom / Sometimes / Usually / Always | 79% | 19 | 21% | 5 | 0% | 0 | 24 | Healthcare workers tell me what to look out for so that I know what to do when my child he/she is unwell, without needing to go to the hospital. | | |
| | | 2 Healthcare workers equip me with skills so that I can confidently care for my child out of the hospital. Response options: Never / Seldom / Sometimes / Usually / Always | 92% | 22 | 8% | 2 | 0% | 0 | 24 | NO CHANGE | | |
| | | 3 Healthcare workers acknowledge and affirm my efforts in caring for my child. Response options: Never / Seldom / Sometimes / Usually / Always | 100% | 24 | 0% | 0 | 0% | 0 | 24 | NO CHANGE | | |
| | | 4 Healthcare workers give me opportunities to bond with my child during hospital or hospice admissions. Response options: Never / Seldom / Sometimes / Usually / Always | 96% | 23 | 4% | 1 | 0% | 0 | 24 | NO CHANGE | | |
| | | 5 Healthcare workers make home visits to give my child medical treatment or care. Response options: Never / Seldom / Sometimes / Usually / Always | 58% | 14 | 25% | 6 | 17% | 4 | 24 | Healthcare workers make home visits to support my caregiving by checking that my child is well taken care of at home give my child medical treatment or care. Response options: Never / Seldom / Sometimes / Usually / Always / Not applicable to my child | | |
| | Providing psychosocial support to parents AND FAMILY | 1 Healthcare workers give me opportunities to advocate or speak up for my child and myself. Response options: Never / Seldom / Sometimes / Usually / Always | 96% | 23 | 0% | 0 | 4% | 1 | 24 | NO CHANGE | | |
| | | 2 Healthcare workers provide me with opportunities to give back to the special needs community e.g. supporting other families, research and funding. Response options: Never / Seldom / Sometimes / Usually / Always / I prefer not to be involved | 79% | 19 | 17% | 4 | 4% | 1 | 24 | Healthcare workers provide me with opportunities to give back to the special needs community when I approach them e.g. letting me supporting other families, participate in research and raising funding. | | |
| | | 3 Healthcare workers support my hopes for my child. Response options: Never / Seldom / Sometimes / Usually / Always | 100% | 24 | 0% | 0 | 0% | 0 | 24 | NO CHANGE | | |
| | | 4 Healthcare workers prepare me for what may lie ahead. Response options: Never / Seldom / Sometimes / Usually / Always | 96% | 23 | 4% | 1 | 0% | 0 | 24 | NO CHANGE | | |
| | | 5 Healthcare workers provide me with a compassionate listening ear. Response options: Never / Seldom / Sometimes / Usually / Always | 100% | 24 | 0% | 0 | 0% | 0 | 24 | NO CHANGE | | |
| Reducing caregiving stress and burdens | 1 Healthcare workers give me emotional and physical space to be alone when I have received difficult news about my child. Response options: Strongly Disagree / Disagree / Neither Agree nor Disagree / Agree / Strongly Agree | 75% | 18 | 17% | 4 | 8% | 2 | 24 | Healthcare workers give me appropriate time and emotional and physical space if I wish to be alone when I have after received difficult news about my child. | | | |
| | 2 Healthcare workers give me access to parent support networks. Response options: Never / Seldom / Sometimes / Usually / Always | 83% | 20 | 17% | 4 | 0% | 0 | 24 | Healthcare workers facilitate my give me access to parent support networks. | | | |
| | 3 Healthcare workers attend to my entire family's needs. Response options: Never / Seldom / Sometimes / Usually / Always / Not applicable to my family | 71% | 17 | 25% | 6 | 4% | 1 | 24 | Healthcare workers assess and where possible help with our attend to my entire family's psychosocial needs resulting from my child's condition . | | | |
| | 4 Healthcare workers give me options for someone skilled to take care of my child so that I can take a break if I need it. Response options: Never / Seldom / Sometimes / Usually / Always | 83% | 20 | 17% | 4 | 0% | 0 | 24 | Healthcare workers help me find give me options for someone skilled to take care of my child so that I can take a break if I need it. | | | |
| | 5 Healthcare workers give me practical suggestions on how we can reduce our family's financial burden. Response options: Never / Seldom / Sometimes / Usually / Always | 83% | 20 | 13% | 3 | 4% | 1 | 24 | Healthcare workers give me practical suggestions on how I can reduce our my child's medical costs family's financial burden. | | | |
| Personalized Collaborative and holistic care | Holistic approach to care for the child | 1 Healthcare workers provide guidance to available resources to reduce my family's financial burden. Response options: Never / Seldom / Sometimes / Usually / Always | 75% | 18 | 21% | 5 | 4% | 1 | 24 | Healthcare workers guide me to provide guidance to available resources to reduce my family's financial burden. | | |
| | | 2 Healthcare workers do their best to avoid my child's hospitalization. Response options: Never / Seldom / Sometimes / Usually / Always | 75% | 18 | 17% | 4 | 8% | 2 | 24 | Healthcare workers do their best to avoid my child's unnecessary and unplanned hospitalization. | | |
| | | 3 Healthcare workers offer specialized transport for my child with mobility needs. Response options: Never / Seldom / Sometimes / Usually / Always / My child does not have mobility needs | 71% | 17 | 21% | 5 | 8% | 2 | 24 | Healthcare workers offer information for us to find specialized transport for my child with who has mobility needs. | | |
| | | 4 Healthcare workers put in effort to foster a personal relationship with my child. Response options: Never / Seldom / Sometimes / Usually / Always | 100% | 24 | 0% | 0 | 0% | 0 | 24 | NO CHANGE | | |
| | | 5 Healthcare workers provide us with allied health support (e.g. therapists) to meet my goals for my child. Response options: Never / Seldom / Sometimes / Usually / Always | 92% | 22 | 8% | 2 | 0% | 0 | 24 | Healthcare workers provide us with appropriate allied health support (e.g. therapists) to meet my goals for my child's development . | | |
| | | 6 Healthcare workers create a child-friendly atmosphere in hospital. Response options: Never / Seldom / Sometimes / Usually / Always | 88% | 21 | 8% | 2 | 4% | 1 | 24 | Healthcare workers do their best to create a child-friendly atmosphere in hospital or hospice. | | |
| | Shared decision-making | 1 Healthcare workers give my child emotional support and encouragement. Response options: Never / Seldom / Sometimes / Usually / Not applicable to my child | 88% | 21 | 13% | 3 | 0% | 0 | 24 | Healthcare workers provide give my child with emotional support and encouragement | | |
| | | 2 I have access to suitable facilities or services for my child's play and engagement. Response options: Strongly Disagree / Disagree / Neither Agree nor Disagree / Agree / Not applicable to my child | 83% | 20 | 17% | 4 | 0% | 0 | 24 | Healthcare workers facilitate my child's I have access to appropriate suitable facilities or services for my child's play and engagement. | | |
| | | 3 Healthcare workers facilitate my child's access to special needs schools. Response options: Strongly Disagree / Disagree / Neither Agree nor Disagree / Agree / Strongly Agree / Not applicable to my child | 88% | 21 | 13% | 3 | 0% | 0 | 24 | Healthcare workers facilitate my child's access to special needs schools when I ask . Response options: Yes / No / Not applicable to my child | | |
| | | 4 Healthcare workers give me complete information on all management options for my child so that I can make informed decisions. Response options: Never / Seldom / Sometimes / Usually / Always | 83% | 20 | 13% | 3 | 4% | 1 | 24 | NO CHANGE | | |
| | | 5 Healthcare workers explain both the benefits and burdens of technology and procedures on my child. Response options: Never / Seldom / Sometimes / Usually / Always | 75% | 18 | 17% | 4 | 8% | 2 | 24 | Healthcare workers clearly explain the pros and cons of different medical both the benefits and burdens of technologies and procedures (Continuous positive airway pressure (CPAP), tracheostomy) on my child so that I am aware of the effects it will have on my child's daily life . | | |
| | | 6 A palliative care team or specialist(s) is an active part of my child's treatment plan. Response options: Yes / No / I don't know | 63% | 15 | 33% | 8 | 4% | 1 | 24 | A palliative care team or specialist(s) participates in is an active-part of my child's treatment plan. | | |

| THEME | SUBTHEME | Round 2 REVISED WORKING ITEM (PROCESSES) | Yes, appropriate | n | Not appropriate | n | Total | | Round 3 REVISED WORKING ITEM (PROCESSES) | Expert comments (if any) | Facilitator Response (if any) | | | |
|---|-------------------------|--|--|---|-------------------------|------------------------|--------------------------|--------------|---|--|--|--|---|---|
| Efficient healthcare structures & standards | Accessible Medical Care | 1 | I can easily access a range of healthcare workers in many disciplines to meet my child's needs (e.g., doctors, nurses, pharmacists, social workers, therapists etc). | 91.67% | 22 | 8.33% | 2 | 24 | Unchanged | Not every discipline / department are accessible complex wording | No changes made in light of majority vote; most panelists found item appropriate. | | | |
| | | 2 | I can easily receive advice from healthcare workers when I need it. | 91.67% | 22 | 8.33% | 2 | 24 | I can easily receive get advice from healthcare workers when I need it. | I can easily access advice from healthcare workers Seems similar to the item below, but the item below feels more patient/family centered Is the question looking at ease of path to receive or readily receive / receive timely advice which maybe time based focused I can easily receive advice for my child from healthcare workers when I need it. get better than receive | For clarity, 'receive' replaced with 'get'. | | | |
| | | 3 | I feel comfortable asking my child's healthcare workers for advice about my child's care. | 91.67% | 22 | 8.33% | 2 | 24 | Healthcare workers make me feel comfortable asking my child's healthcare workers for advice about my child's care. | This one seems to be more about relationships and trust than accessibility Is this asking from the parent's comfort vs My child's healthcare worker makes me feel comfortable to ask advice about my child's care. Why say "my child's healthcare workers" only for this item? (and say not in the previous or next item) | Suggested changes incorporated. | | | |
| | | 4 | Healthcare workers help me to obtain my child's medical equipment and supplies. | 91.67% | 22 | 8.33% | 2 | 24 | Healthcare workers provide the guidance I need help me to obtain my child's medical equipment and supplies. | Does not quite assess accessibility. Prescription of medical equipment is required of healthcare workers. Procurement and purchase may differ in different models of care, eg direct from vendors, which can be equally accessible. The tend to help within their scope of work Not help to obtain but rather advise on how to obtain, incase it breeds | Changes made for clarity. | | | |
| | | 5 | Healthcare workers help me in the process of acquiring high-cost medical equipment (e.g. ventilator, suction machine, buggy) for my child. | 87.50% | 21 | 12.50% | 3 | 24 | ELIMINATE (due to high overlap with the construct of the previous indicator) | Healthcare professionals help me in the process of acquiring appropriate medical equipment for my child (it may not be high cost but it needs to be appropriate) This feels similar to the item above ...through or with the process... Unclear about intent or extent. "help me in the process.." as in provide \$ or facilitate application for financial assistance. drop on the process | Combined with item above and eliminated due to high overlap. | | | |
| | | 6 | I receive adequate financial support for my child's medical expenses. Response options: Yes / No | 91.67% | 22 | 8.33% | 2 | 24 | I have access to receive adequate financial support for my child's medical expenses if needed. Response options: Yes / No / I do not need financial assistance | I have access to financial support for my child's medical expenses if needed. (financial support may come from families, friends, etc). The question may need to be more specific on the source of help. In keeping with the wording of the sub-theme of 'access,' perhaps "I have access to adequate financial support for my child's medical expenses." Qualify where eligible. Unless this question is about perceptions. Most would say not enough in that case. | Most suggested changes incorporated. | | | |
| | | | Round 2 REVISED WORKING ITEM (PROCESSES) | Yes, appropriate | n | Not appropriate | n | Total | | Round 3 REVISED WORKING ITEM (PROCESSES) | | | | |
| | | Effective administration and facilities | 1 | Healthcare workers offer flexibility in the number of caregivers allowed at bedside when my child needs intensive care. | 83.33% | 20 | 16.67% | 4 | 24 | Healthcare workers offer flexibility in the number of caregivers allowed at bedside when my child is in the needs intensive care unit. | Instead of "needs intensive care", how about "is critically ill"? Healthcare institutions offer flexibility in the number of caregivers allowed at the bedside in times of need when my child is in the intensive care unit. (effective) | Pertaining to concerns over institutional policies and the inapplicability to wider setting: item is retained as HCWs are given certain autonomy to allow caregivers when child is in the ICU in Singapore. Furthermore, | | |
| | | | 2 | My child is attended to without undue delay when we present at the emergency department. | 91.67% | 22 | 8.33% | 2 | 24 | Unchanged | Maybe this fits better in the previous one about accessibility? The word "undue" is important As parents may have varied expectations...Will the answers be in a ilkert format? Am not sure if general respondents will understand the use of word undue Is good to have more variety for the children to make them more appetite in eating the meal. Especially western food with a few choices. q ICU is not the best place to be with the care of additional level of care. Data | No changes made in light of majority vote; most panelists found item appropriate. | | |
| | | | 3 | The food provided in healthcare facilities can be modified to suit my child's unique needs. | 87.50% | 21 | 12.50% | 3 | 24 | The food provided in hospital or hospice healthcare facilities can be modified to suit my child's unique needs. | If this item is retained, I might suggest revising the wording, as "stay close" seems vague. | No changes made in light of majority vote; most panelists found item appropriate. | | |
| | | | 4 | I am able to stay close to my child when he/she is admitted to hospital or hospice. | 91.67% | 22 | 8.33% | 2 | 24 | Unchanged | minimize my child's exposure I am not sure if this is only applicable to seriously ill patients. It should apply to ALL patients. Healthcare workers take appropriate action to minimise my child's exposure to other diseases when he/she is admitted in healthcare facilities hospital or hospice instead of healthcare facilities, similar term used in previous item? ok to include, but edit awkward wordin | Most suggested changes incorporated. | | |
| | | | | [New indicators suggested in Round 1 for testing in Round 2] | Yes, appropriate | n | Yes, with changes | n | Not appropriate | n | Total | | | |
| | | | 1 | Healthcare workers offer flexibility in visitation hours when my child needs intensive care. Response options: Never / Seldom / Sometimes / Usually / Always | 66.67% | 16 | 12.50% | 3 | 20.83% | 5 | 24 | ELIMINATE | Change healthcare workers to institutions/facilities Same explanation as above -- this is likely a reflection of institutional policies and not a reflection of the healthcare workers. Healthcare facilities or workers offer.... | Item eliminated as process is not within the control of HCWs. |
| | | | 2 | Healthcare workers offer flexibility in visitation hours when my child is admitted to the general ward. Response options: Never / Seldom / Sometimes / Usually / Always | 54.17% | 13 | 16.67% | 4 | 29.17% | 7 | 24 | ELIMINATE | Not too sure about this - because I don't think most HCW have the authority to offer such flexibility (unlike when in ICU settings) Have to follow to hospital guidelines for visitation hours. Especially in general ward when child is not in critical stage. Same as above Healthcare facilities or workers offer.... is it really the workers who offer flexibility? | Item eliminated as process is not within the control of HCWs. |
| | | | 3 | Healthcare workers offer flexibility in the number of caregivers allowed at bedside when my child admitted to the general ward. Response options: Never / Seldom / Sometimes / Usually / Always | 50.00% | 12 | 20.83% | 5 | 29.17% | 7 | 24 | ELIMINATE | Not too sure about this - because I don't think most HCW have the authority to offer such flexibility (unlike when in ICU settings) when my child is admitted Have to follow to hospital guidelines for visitation hours. Especially in general ward when child is not in critical stage. At times some healthcare worker ignored on some patient's visitors which is more that caregiver at the bed side and pretend as didnt see it as children and caregiver need some rest hope they could expedite visitors except for caregiver after visiting hours. Same as above and add "when needed" | Item eliminated as process is not within the control of HCWs. |
| | | 4 | Healthcare workers refer me to specialists as needed. Response options: Never / Seldom / Sometimes / Usually / Always | 75.00% | 18 | 12.50% | 3 | 12.50% | 3 | 24 | [MOVE TO ACCESSIBLE MEDICAL CARE] Healthcare workers refer me my child to relevant specialists as needed. | I think this is about accessibility Not sure what this question mean. Refer caregivers to specialists for their own health conditions? HCW discusses with me and refers... Need to be specific about which or what types of specialists. Eg. say relevant or appropriate? This item, if retained, goes better with "Accessible Medical Care. | Most suggested changes incorporated. | |
| | | | Round 2 REVISED WORKING ITEM (PROCESSES) | Yes, appropriate | n | Not appropriate | n | Total | | Round 3 REVISED WORKING ITEM (PROCESSES) | | | | |
| | | | 1 | Healthcare workers work as a team towards the same goals for my child's care. (unchanged) | 100.00% | 24 | 0.00% | 0 | 24 | Unchanged | | | | |
| | | | 2 | I have a main healthcare worker who or team who consistently oversees my child's medical needs. | 91.67% | 22 | 8.33% | 2 | 24 | I have a main healthcare worker/ who team who that consistently oversees my child's medical needs. | I have a consistent healthcareworker or team overseeing my child's medical needs main healthcare worker or team (typo) Change to "I have a healthcare worker or team who consistently oversees my child's medical needs." Remove first "who" in the sentence. I have a healthcare worker or a healthcare team who consistently oversees my child's medical needs. | Most suggested changes incorporated. | | |

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|--|---|---|------------------|-------|-------------------|-------|-----------------|----|--|---|--|---|--|
| Coordination and continuity of care | 3 | I have a healthcare worker who or team which coordinates my child's care between different disciplines, services, and agencies. | 87.50% | 21 | 12.50% | 3 | 24 | | | I have a healthcare worker/ who-or team who that coordinates my child's care between different disciplines...services,-and-agencies. | healthcare worker or team who (typo) I have a healthcare worker or a healthcare team which coordinates my child's care between different disciplines, services and agencies. Need to differentiate this from above. Call the one above "healthcare professional". And here "a single healthcare worker who coordinates my child's care between..." The wording is awkward. I assume the first "who" is a typo. avoid double barrel | Most suggested changes incorporated. | |
| | 4 | I receive consistent information from different healthcare workers. | 100.00% | 24 | 0.00% | 0 | 24 | | | Unchanged | | | |
| | 5 | Healthcare workers ensure a smooth transition of care across the different healthcare settings (e.g., NICU to PICU, Private to Public facilities, going home, hospital admission). | 95.83% | 23 | 4.17% | 1 | 24 | | | Healthcare workers ensure a smooth transition of care across the different healthcare settings (e.g., NICU to PICU, Private to Public facilities, going home, hospital or hospice admission). | Add hospice? ...transition of care for my child across... too complex? | Retained as-is; care may extend beyond child's medical care to care structures as well. | |
| | 6 | Healthcare workers coordinate my child's appointments to reduce our hospital visits. | 95.83% | 23 | 4.17% | 1 | 24 | | | Healthcare workers organise coordinate my child's appointments to reduce our hospital visits. | organise" instead of coordinate (to keep distinct from above). "health care workers" sound a little impersonal / abstract. would some type of qualifier like 'my', 'at x clinic', etc make it all read better? | Most suggested changes incorporated. | |
| | [New items suggested in Round 1 for testing in Round 2] | | Yes, appropriate | n | Yes, with changes | n | Not appropriate | n | Total | | | | |
| | 1 | Healthcare workers coordinate my child's care across healthcare and education sectors for my child's medical, developmental and education needs. Response options: Never / Seldom / Sometimes / Usually / Always | 79.17% | 19 | 8.33% | 2 | 12.50% | 3 | 24 | ELIMINATE (due to high overlap with the constructs captured by other indicators) | | | Eliminated due to high overlap with existing items. |
| | 2 | Healthcare workers make sure my child's medical equipment are properly maintained beyond healthcare facilities. Response options: Never / Seldom / Sometimes / Usually / Always | 66.67% | 16 | 12.50% | 3 | 20.83% | 5 | 24 | ELIMINATE | | | Eliminated due to concerns over relevance to HCWs and problems with wider applicability. |
| Responsive and sensitive communication | Round 2 REVISED WORKING ITEM (PROCESSES) | | Yes, appropriate | n | Not appropriate | n | Total | | Round 3 REVISED WORKING ITEM (PROCESSES) | | | | |
| | 1 | Healthcare workers present themselves in an honest way | 91.67% | 22 | 8.33% | 2 | 24 | | | Healthcare workers present themselves in an authentic honest way. | Perhaps use "Authentic" rather than honest Healthcare workers present themselves in an honest and non-judgmental way of | Changes made. | |
| | 2 | Healthcare workers make an effort to build a trusting relationship with me | 100.00% | 24 | 0.00% | 0 | 24 | | | Unchanged | | | |
| | 3 | Healthcare workers take responsibility for my child's wellbeing when he/she is under their care. | 95.83% | 23 | 4.17% | 1 | 24 | | | [MOVE TO COMPETENCY OF HEALTHCARE DELIVERY] | Not really a "communication" response. | Changes made. | |
| | 4 | Healthcare workers support my right to information about my child by ensuring I am always fully informed. | 100.00% | 24 | 0.00% | 0 | 24 | | | Unchanged | May be difficult for layperson to understand the sentence. Suggest rephrase "Healthcare workers ensure that I am informed or have access to information about my child in a timely manner" This is also a complex statement. Perhaps "Healthcare workers ensure that I am fully informed about my child's care." | No changes made in light of majority vote; most panelists found item appropriate. | |
| | 5 | Healthcare workers give me information on my child's condition in a timely manner. | 95.83% | 23 | 4.17% | 1 | 24 | | | Unchanged | | No changes made in light of majority vote; most panelists found item appropriate. | |
| | 6 | Healthcare workers communicate with me in a way that is sensitive to my needs. | 100.00% | 24 | 0.00% | 0 | 24 | | | Unchanged | | | |
| | 7 | (unchanged) Healthcare workers communicate with me in a way that I can understand. | 100.00% | 24 | 0.00% | 0 | 24 | | | Unchanged | | | |
| | 8 | (unchanged) Healthcare workers give me enough time to think about decisions for my child's care. | 100.00% | 24 | 0.00% | 0 | 24 | | | Unchanged | | | |
| | 9 | Healthcare workers have an appropriate sense of urgency when communicating with me so that additional stress is not created (e.g. not calling multiple times throughout the day for non-urgent issues, informing me about critical news quickly). | 83.33% | 20 | 16.67% | 4 | 24 | | | Unchanged | At times some healthcare worker didn't read up the case sheets that is slated in the system especially for the child who is a frequent admission. Some will just woke u up at 3am in the morning to ask a non urgent matter and that makes an anxiety to a parents with a complex care as thinking that the child is in critical for waking up that time. It would be appropriate to read up and not keeping asking the same repeating question "in a way that is sensitive to my needs" should cover this aspect This is a complex statement that I feel is covered by other items. ok item, but too complex wording | No changes made in light of majority vote; most panelists found item appropriate. | |
| | 10 | (unchanged) Healthcare workers show me genuine care and sincerity. | 95.83% | 23 | 4.17% | 1 | 24 | | | [MOVE TO PROVIDING PSYCHOSOCIAL SUPPORT FOR PARENTS AND FAMILY] Healthcare workers show me genuine care and sincerity concern . | Suggest "genuine care and concern", genuine should be sincere. I don't think that sincerity a requirement for "responsive and sensitive" communication. "show me care"? | Most suggested changes incorporated. | |
| | 11 | (unchanged) Healthcare workers are respectful of my spiritual or religious customs and beliefs. | 100.00% | 24 | 0.00% | 0 | 24 | | | Unchanged | | | |
| | [New items suggested in Round 1 for testing in Round 2] | | Yes, appropriate | n | Yes, with changes | n | Not appropriate | n | Total | | | | |
| | 1 | Healthcare workers are sensitive to the cultural issues that may affect my role or ability to care for my child. Response options: Strongly Disagree / Disagree / Neither Agree nor Disagree / Agree / Strongly Agree | 79.17% | 19 | 8.33% | 2 | 12.50% | 3 | 24 | ELIMINATE (due to high overlap with the constructs captured by other indicators) | | | Eliminated due to high overlap with existing items. |
| 2 | Healthcare workers communicate with my child in a way that is sensitive to his/her needs. Response options: Never / Seldom / Sometimes / Usually / Always | 95.83% | 23 | 4.17% | 1 | 0.00% | 0 | 24 | Unchanged | Healthcare workers communicate or care for my child in a way that is sensitive to his/her needs | Care not added to focus on subtheme of communication. | | |
| Competency of Healthcare delivery | Round 2 REVISED WORKING ITEM (PROCESSES) | | Yes, appropriate | n | Not appropriate | n | Total | | Round 3 REVISED WORKING ITEM (PROCESSES) | | | | |
| | 1 | Healthcare workers present their knowledge, skills and experience so that I am confident they can meet my child's needs | 87.50% | 21 | 12.50% | 3 | 24 | | | Healthcare workers assure me of present their capabilities knowledge, skills and experience so that I am confident that they can meet my child's needs. | Vague. "Present their knowledge" but how? I am not able to get at what the item is trying to ask | Changes made for clarity. | |
| | 2 | Healthcare workers avoid unnecessary treatments and investigations on my child. Response options: Strongly Disagree / Disagree / Neither | 87.50% | 21 | 12.50% | 3 | 24 | | | Healthcare workers avoid unnecessary treatments and investigations on my child that are not aligned with my goals for my child's care . | Does not seem to fit with the other items but not sure where it goes. I think this statement is a bit vague. Perhaps "Healthcare workers only provide is this more about accessibility? Perhaps "...in a timely manner" rather than "without undue delay"? Sounds more like efficiency | Most suggested changes incorporated. | |
| | 3 | Healthcare workers provide medical care for my child without undue delay. | 87.50% | 21 | 12.50% | 3 | 24 | | | Healthcare workers provide medical care for my child in a timely manner without undue delay. | is this more about accessibility? Perhaps "...in a timely manner" rather than "without undue delay"? Sounds more like efficiency | Most suggested changes incorporated. | |
| | 4 | Healthcare workers do all they can to identify and treat my child's medical issues. | 91.67% | 22 | 8.33% | 2 | 24 | | | Healthcare workers do all they can to identify and treat manage my child's medical issues. | "do all they can" and "are able to" identify and treat has a subtle, but I feel important difference. I feel the latter might be more appropriate. This is also subject to interpretation. In a palliative care setting, we may not want to identify and "treat" all medical issues but manage symptoms double barrel perhaps add "comfortable and pain-free" | Not changed to "are able to" due to feedback from Round 1 in which majority of experts suggested softer language. | |
| | 5 | (unchanged) Healthcare workers manage my child's physical symptoms to make sure my child is comfortable. | 100.00% | 24 | 0.00% | 0 | 24 | | | Healthcare workers manage my child's physical symptoms to make sure my child is comfortable and pain-free . | Why is there only an item on physical symptoms? What about psychosocial or spiritual? is this 'competency'? | Pain-free" added. Other domains of child's well-being beyond physical are captured in other subthemes. | |
| Professional Qualities of HCWs | Round 2 REVISED WORKING ITEM (PROCESSES) | | Yes, appropriate | n | Not appropriate | n | Total | | Round 3 REVISED WORKING ITEM (PROCESSES) | | | | |
| | 1 | Healthcare workers tell me what to look out for so that I know what to do when my child he/she is unwell. | 87.50% | 21 | 12.50% | 3 | 24 | | | Healthcare workers tell me what to look out for so that I know what-to-do when my child he/she is unwell. | Suggest "Healthcare workers tell me what to look out for so that I know when my child is unwell" If not, it will be an overlap with the next question. Feels similar to the item below | Most suggested changes incorporated. | |
| | 2 | (unchanged) Healthcare workers equip me with skills so that I can confidently care for my child out of the hospital. | 100.00% | 24 | 0.00% | 0 | 24 | | | Unchanged | | | |

| | | | | | | | | | | | | | | |
|---|--|---|--|---------|-------------------|--------|-------------------|-------|---|--|---|---|--|---|
| Supporting parent caregivers | Empowering parent-caregivers | 3 | (unchanged) Healthcare workers acknowledge and affirm my efforts in caring for my child. | 100.00% | 24 | 0.00% | 0 | 24 | | | Unchanged | | | |
| | | 4 | (unchanged) Healthcare workers give me opportunities to bond with my child during hospital or hospice admissions. | 95.83% | 23 | 4.17% | 1 | 24 | | | Healthcare workers give me opportunities to bond with my child during hospital or hospice admissions e.g. through my child's daily care. | "...give me opportunities to bond" feels vague to me. double barrel | Example provided for clarity. | |
| | | 5 | Healthcare workers make home visits to support my caregiving by checking that my child is well taken care of at home. Response options: Never / Seldom / Sometimes / Usually / Always / Not applicable to my child | 91.67% | 22 | 8.33% | 2 | 24 | | | Healthcare workers make home visits to support the care of my child at home by caregiving by checking that my child is well taken care of at home. | Awkward wording at the end. Sound like checking up on the parent which is not empowering. I would leave it as ... support my caregiving. The responses are confusing. What does "always" "usually" , etc mean? Some may also take it to mean home nursing. Yes, but also very complex as worded. How about "Healthcare workers make home visits to support the care of my child at home" Need to specify which HCW and which types of patients you are referring to | Most suggested changes made for clarity. | |
| | | 6 | (unchanged) Healthcare workers give me opportunities to advocate or speak up for my child and myself. | 100.00% | 24 | 0.00% | 0 | 24 | | | Healthcare workers give me opportunities to advocate or speak up for my child and myself. | double barrel | Change has been made to avoid double-barrel indicator. | |
| | | 7 | Healthcare workers provide me with opportunities to give back to the special needs community when I approach them e.g. letting me support other families, participate in research and raising funds. Response options: Never / Seldom / Sometimes / Usually / Always / I prefer not to be involved | 100.00% | 24 | 0.00% | 0 | 24 | | | Unchanged | complex wording | No changes made in light of majority vote; most panelists found item appropriate. | |
| | | [New items suggested in Round 1 for testing in Round 2] | | | Yes, appropriate | n | Yes, with changes | n | Not appropriate | n | Total | | | |
| | | 1 | Healthcare workers provide teleconsultations so that I can confidently make adjustments to my child's medical needs at home e.g. medicine dosage, ventilator settings etc. Response options: Never / Seldom / Sometimes / Usually / Always / Not applicable to my child | 87.50% | 21 | 8.33% | 2 | 4.17% | 1 | 24 | | Healthcare workers provide remote consultations so that I can confidently care for my child at home make adjustments to my child's medical needs at home e.g. medicine dosage, ventilator settings etc. | This overlaps with the responses on accessibility to care. Teleconsult is only a mode of obtaining support. teleconsultations - do you mean just telephone calls, video calls or both | "remote" for clarity; indicator retained as a specific process to enable parent-caregivers' home-caregiving |
| Supporting parent caregivers | Providing psychosocial support to parents and family | Round 2 REVISED WORKING ITEM (PROCESSES) | | | Yes, appropriate | n | Not appropriate | n | Total | Round 3 REVISED WORKING ITEM (PROCESSES) | | | | |
| | | 1 | (unchanged) Healthcare workers support my hopes for my child. | 100.00% | 24 | 0.00% | 0 | 24 | | | Unchanged | what does it mean to support hope | No changes made in light of majority vote; most panelists found item appropriate. | |
| | | 2 | (unchanged) Healthcare workers prepare me for what may lie ahead. | 100.00% | 24 | 0.00% | 0 | 24 | | | Unchanged | | | |
| | | 3 | (unchanged) Healthcare workers provide me with a compassionate listening ear. | 100.00% | 24 | 0.00% | 0 | 24 | | | Unchanged | a little too informal | No changes made in light of majority vote; most panelists found item appropriate. | |
| | | 4 | Healthcare workers give me appropriate time and space if I wish to be alone after receiving difficult news about my child. | 100.00% | 24 | 0.00% | 0 | 24 | | | Unchanged | | | |
| | | 5 | Healthcare workers facilitate my access to parent support networks. | 100.00% | 24 | 0.00% | 0 | 24 | | | Healthcare workers facilitate my access to available parent support networks. | "to available parent support networks" these networks may not always be available Social supports network? Not all are parents to the child. What about practical /resources supports ? eg home respite services, daycare services | Most suggested changes made for clarity. "Parents" retained as this is currently designed as a parent-reported measure. | |
| | | 6 | Healthcare workers assess and where possible help with our family's psychosocial needs resulting from my child's condition. | 100.00% | 24 | 0.00% | 0 | 24 | | | Unchanged | | | |
| [New items suggested in Round 1 for testing in Round 2] | | | Yes, appropriate | n | Yes, with changes | n | Not appropriate | n | Total | | | | | |
| 1 | Healthcare workers refer me to professional psychosocial support if I should need it for myself. | 91.67% | 22 | 4.17% | 1 | 4.17% | 1 | 24 | | Unchanged | perhaps add: "and other family members The response above should cover. Layperson would consider all healthcare workers "professionals" | No changes made in light of majority vote; most panelists found item appropriate. | | |
| Supporting parent caregivers | Reducing caregiving stress and burdens | Round 2 REVISED WORKING ITEM (PROCESSES) | | | Yes, appropriate | n | Not appropriate | n | Total | Round 3 REVISED WORKING ITEM (PROCESSES) | | | | |
| | | 1 | Healthcare workers help me find options for someone skilled to take care of my child so that I can take a break if I need it. | 91.67% | 22 | 8.33% | 2 | 24 | | | Unchanged | | | |
| | | 2 | Healthcare workers give me practical suggestions on how I can reduce my child's medical costs. | 95.83% | 23 | 4.17% | 1 | 24 | | | Unchanged | | | |
| | | 3 | Healthcare workers guide me to available resources to reduce my family's financial burden | 100.00% | 24 | 0.00% | 0 | 24 | | | Unchanged | overlaps with the one just before | No changes made in light of majority vote; most panelists found item appropriate. | |
| | | 4 | Healthcare workers do their best to avoid my child's unnecessary and unplanned hospitalization. | 95.83% | 23 | 4.17% | 1 | 24 | | | Healthcare workers do their best to help us avoid my child's unnecessary and unplanned hospitalization. | Suggest "Healthcare workers do their best to prevent unnecessary and unplanned hospitalization for my child" Minor wording suggestion: "Healthcare workers do their best to help us avoid unnecessary hospitalizations for my child." loaded question? ...workers help us in finding specialized... | Most suggested changes made for clarity. | |
| | | 5 | Healthcare workers offer information for us to find specialized transport for my child who has mobility needs. | 95.83% | 23 | 4.17% | 1 | 24 | | | Healthcare workers offer information on for us to find specialized transport for my child who has mobility needs. | Reword | Most suggested changes made for clarity. | |
| | | [New items suggested in Round 1 for testing in Round 2] | | | Yes, appropriate | n | Yes, with changes | n | Not appropriate | n | Total | | | |
| 1 | I am given sufficient time to find and train a long-term caregiver or domestic helper before my child leaves healthcare facilities. | 95.83% | 23 | 0.00% | 0 | 4.17% | 1 | 24 | | Unchanged | I think this is complicated, as it could be dependent upon the facility, the insurance/payor, or the availability of long-term caregivers in the home setting. | No changes made in light of majority vote; most panelists found item appropriate. | | |
| Supporting parent caregivers | Holistic approach to care for the child | Round 2 REVISED WORKING ITEM (PROCESSES) | | | Yes, appropriate | n | Not appropriate | n | Total | Round 3 REVISED WORKING ITEM (PROCESSES) | | | | |
| | | 1 | (unchanged) Healthcare workers put in effort to foster a personal relationship with my child. | 100.00% | 24 | 0.00% | 0 | 24 | | | Unchanged | | | |
| | | 2 | Healthcare workers provide us with appropriate allied health support (e.g. therapists) to meet my goals for my child's development. | 91.67% | 22 | 8.33% | 2 | 24 | | | Healthcare workers provide us with I receive appropriate allied health support (e.g., therapists) to meet my goals for my child's development. | therapists are healthcare workers. And therapy may be provided in the community. To meet my goals is quite different from discussed/ set / or shared goals some goals may or may not be "realistic". Question may not capture this. | Shared goal-setting is captured in other indicators; current indicator specifically focuses on provision of allied health support that parents feel is sufficient for their set-goals. | |
| | | 3 | Healthcare workers do their best to create a child-friendly atmosphere in hospital or hospice. | 91.67% | 22 | 8.33% | 2 | 24 | | | Healthcare workers do their best to create a child-friendly atmosphere in the hospital or hospice. | This is assuming it is an adult hospital or hospice? the hospital or hospice | Both children's and adult hospitals and hospices can be sterile and/or non-stimulating for the child. | |
| | | 4 | Healthcare workers provide my child with emotional support. | 100.00% | 24 | 0.00% | 0 | 24 | | | Unchanged | | | |
| | | 5 | Healthcare workers facilitate my child's access to appropriate facilities or services for play and engagement. | 95.83% | 23 | 4.17% | 1 | 24 | | | Unchanged | In the hospital? If in the community, the coordination of care section has taken care of that. | No changes made in light of majority vote; most panelists found item appropriate. | |
| | | 6 | Healthcare workers facilitate my child's access to special needs schools when I ask. Response options: Yes / No / Not applicable to my child | 91.67% | 22 | 8.33% | 2 | 24 | | | Healthcare workers facilitate my child's access to special needs schools when I ask. Response options: Yes / No / My child does not need special needs school | Suggest change "when I ask" to "when needed". The child may not need special needs schools and healthcare workers would not facilitate that. The question below might be better | Modified response options to allow parents to state whether child needs special needs school. | |
| [New items suggested in Round 1 for testing in Round 2] | | | Yes, appropriate | n | Yes, with changes | n | Not appropriate | n | Total | | | | | |
| 1 | [If child attends special needs school] Healthcare workers engage my child's school on my child's medical needs in school. Response options: Never / Seldom / Always | 83.33% | 20 | 16.67% | 4 | 0.00% | 0 | 24 | | [If child attends special needs school] Healthcare workers engage my child's school to support his/her on my child's medical needs while in school. Response options: Never / Seldom / Always | Not all children with serious illness attend special needs schools. Perhaps [if child attends school] Healthcare workers work with my child's school to support | Most suggested changes made for clarity. | | |
| 2 | Healthcare workers assess my child's developmental milestones and progression. Response options: Never / Seldom / Sometimes / Usually / Always | 91.67% | 22 | 8.33% | 2 | 0.00% | 0 | 24 | | Healthcare workers assess my child's developmental milestones and progression where appropriate. | Minor wording suggestion: "...milestones and progress, if appropriate." | Most suggested changes made for clarity. | | |
| 3 | I receive adequate financial support for my child's non-medical expenses e.g., special needs education, therapy, etc. Response options: Yes / No | 66.67% | 16 | 12.50% | 3 | 20.83% | 5 | 24 | | [MOVE TO REDUCING BURDEN] I receive adequate financial assistance support for my child's non-medical expenses if needed e.g., special needs education, therapy, etc. | Additional indicator of "not fully supported" I think this fits better under the sub theme on reducing burden May not receive if there is no need. Suggest "have access if needed" | Most suggested changes made. | | |
| Collaborative and holistic care | | Round 2 REVISED WORKING ITEMS (PROCESSES) | | | Yes, appropriate | n | Not appropriate | n | Total | Round 3 REVISED WORKING ITEM (PROCESSES) | | | | |
| | | 1 | (unchanged) Healthcare workers give me complete information on all management options for my child so that I can make informed decisions. | 100.00% | 24 | 0.00% | 0 | 24 | | | Healthcare workers give me complete information on all possible management options for my child so that I can make informed decisions. | | No expert comments; however, upon considering comments in the below indicator, facilitators clarified the items more explicitly. | |
| | | 2 | Healthcare workers clearly explain the pros and cons of different medical technologies and procedures on my child (e.g. Continuous positive airway pressure (CPAP), tracheostomy) so that I am aware of the effects it will have on my child's daily life. | 87.50% | 21 | 12.50% | 3 | 24 | | | Healthcare workers clearly explain the pros and cons of all management options for my child different medical technologies and procedures on my child so that I can make informed decisions. am aware of the effects they it will have on my child's daily life e.g. Continuous positive airway pressure (CPAP), tracheostomy, tube feeding. | Overlap with above question To include feeding care etc as not all kids are on trach or NIVs ...effects they will... ok, but too complex wording | This indicator focuses on communicating all possible effects of various management options to parents to enable informed decision-making. | |
| 3 | A palliative care team or specialist(s) participates in my child's treatment plan. | 83.33% | 20 | 16.67% | 4 | 24 | | | [MOVE TO HOLISTIC APPROACH TO CARE FOR CHILD] I am able to discuss my child's treatment plan with a palliative care team or specialist(s) if I want to. | Not sure how this relates to decision-making. Maybe it fits under accessibility Why is the purpose of this response? Not all children require palliative care Need to explain "palliative care"? | Indicator has been reworded and shifted to another subtheme. We are retaining the indicator given that all children falling into the spectrum of serious illness categories "would benefit from some elements of the palliative care approach and from knowing about the support that is available from children's palliative care services" (https://www.togetherforshortlives.org.uk/changing-lives/supporting-care-professionals/introduction-childrens-palliative-care/categories-of-life-limiting-conditions/) | | | |

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|------------------------|---|---|---------|----|--------|---|----|--|--|--|---|---|
| Shared decision-making | 4 | [If parent responds yes to prior item] Healthcare workers introduced the palliative care team or specialist(s) at an appropriate time. Response options: Yes / No | 87.50% | 21 | 12.50% | 3 | 24 | | | [MOVE TO HOLISTIC APPROACH TO CARE FOR CHILD] [If parent responds yes to prior item] Healthcare workers introduced the palliative care team or specialist(s) at an appropriate time. Response options: Too late / Late / Neither late nor early / Early / Too early | Accessibility Suggest response be likert format: e.g. Too late/ Late/ Neither late or early/ Early / Too early Not appropriate but "early". why change to past tense here? | Response options changed. Indicator has shifted to another subtheme. Past tense as this is one of the few indicators that would have already happened at a single time point in the past (if parent had responded yes to the earlier indicator) |
| | 5 | Healthcare workers discussed how the scope of care can be tailored to provide comfort for my child when I was given a poor prognosis of my child's condition. | 87.50% | 21 | 12.50% | 3 | 24 | | | When I was given the a-poor-prognosis of my child's condition, healthcare workers discussed with me how the scope of care can be tailored to provide comfort for my child. | Some overlap with first question This is a very complex sentence and for some parents, the poor prognosis might have been given months or years ago. Suggest to remove the " poor"instead" was given the news on the prognosis of my child's condition." It may not matter how poor the prognosis be if question is used for all cases with varying prognosis looking at shared decision making. When I was given a poor....condition, healthcare workers discussed how care can be tailored to provide comfort for my child with me complex logic | Most suggested changes made for clarity. |
| | 6 | Healthcare workers listen to my inputs regarding my child's care. | 100.00% | 24 | 0.00% | 0 | 24 | | | Unchanged | Overlap with previous response on listening | No changes made in light of majority vote; most panelists found item appropriate. |
| | 7 | I am as involved as much as I wish to be in decision-making about my child's treatment. | 91.67% | 22 | 8.33% | 2 | 24 | | | I am as involved as much as I wish to be in decision-making about my child's care treatment. Response options: Strongly agree / Agree / Neither agree nor disagree / Disagree / Strongly disagree | Suggest : I am involved in the decision-making about the care plan for my child I am involved.. | As much as I wish to be' deemed an important component to retain as parents have varying levels of preference for involvement. |
| | 8 | Healthcare workers provide care to my child while considering my family's preferences for treatments. | 91.67% | 22 | 8.33% | 2 | 24 | | | Healthcare workers considering my family's preferences for treatments when providing care to my child. | Healthcare workers consider my family's preferences for treatment, when providing care to my child. Overlap with above This is vague. While considering or "according to ..." | Most suggested changes made for clarity. |