

FAMILY CENTERED CARE ASSESSMENT TOOL – PEDIATRIC RESUSCITATION v 1.2

1. Sharing information with patient and family	Place a check mark each time behavior occurs	Total count	Global rating
1.1 Provider introduces self / team to child / parent*, with orienting statement about team / room / situation			
1.2 Team leader explains primary assessment/plan of action.			
1.3 Provider explains status / procedure to parent using medical terminology			
1.4 Provider explains status / procedure to parent using lay language			
1.5 Provider checks parents’ understanding of information that is shared			
1.6 Provider / team explains potentially distressing intervention before (ideally), during, or after it occurs			
1.7 Team spontaneously provides patient / parent with updates on patient status			
1.8 Team provides updates on patient status, prompted by patient / parent request			
1.9 Provider responds curtly (e.g., dismissive → overtly rude) to family member question			
1.10 Provider responds to parent question and elaborates to provide explanation			
1.11 Provider defers response to parent question while actively engaged in care			
1.12 Team designates a specific staff member as family liaison (before patient arrival, or upon entry of family member) FOR RCT CODING: Observe consistent person acting as family liaison			
1.13 Multiple team members at a time ask questions or provide info to parent			
1.14 At end of procedure, or other transition point, provider summarizes prior events and next steps			
GLOBAL RATING OF TEAM PERFORMANCE (1-10 where 1 = poor, 10 = excellent) SHARING INFORMATION WITH PATIENT AND FAMILY →			

* For all items, “parent” refers to child’s parent, primary caretaker, or other adult family present w/ child

2. Promoting family involvement in care / decisions	Place a check mark each time behavior occurs	Total count	Global rating
2.1 Provider asks family member for child's name			
2.2 Provider asks child for his / her name			
2.3 Provider asks parent about child's medical history or history of present illness.			
2.4 Provider asks child about his/her own medical history or history of present illness.			
2.5 Provider asks parent if s/he wants to be with child during acute care / procedure.			
2.6 Provider allows parent who has chosen to be present to change mind / leave room, as intervention progresses.			
2.7 Provider asks adolescent if there is anyone who they want to have with them during acute care / procedure.			
2.8 Provider praises family member's actions			
2.9 Provider promotes specific future care behaviors			
2.10 Provider shares aloud information gathered from parent			
2.11 Team obtains or acknowledges family's wishes regarding treatment/diagnostic procedure			
2.12 Provider asks parent to hold / or otherwise soothe child – to facilitate intervention/ procedure			
2.13 Provider explains specific procedure to child and checks child's understanding			
GLOBAL RATING OF TEAM PERFORMANCE (1-10 where 1 = poor, 10 = excellent) PROMOTING FAMILY INVOLVEMENT IN CARE / DECISIONS →			

3. Addressing family needs / family distress	Place a check mark each time behavior occurs	Total count	Global rating
3.1 Provider offers comfort items to family member			
3.2 Provider engages family member in non-procedure-related talk.			
3.3 Provider explicitly checks parent emotional status / coping			
3.4 Provider / team observes behavioral indicators of parent emotional distress and acts to address this			
3.5 Provider asks parent to move – for stated practical purpose			
3.6 Provider asks parent to move – w statement re parent distress			
3.7 Provider makes specific suggestion to parent about where to stand / sit in order to see or touch child.			
3.8 Providers engage in non-procedure / non-medical talk with each other.			
3.9 Provider verbally expresses lack of clarity about treatment plan/procedural details			
3.10 Provider touches family member on hand/arm/shoulder – or provider’s physical position otherwise makes it clear they are listening to family member			
3.11 Provider makes reassuring statement to family member			
3.12 Provider makes positive statement to parent conveying realistic hope			
3.13 Provider makes positive statement to parent conveying vague or unrealistic expectations re: future course			
3.14 Team requests additional resources for family, e.g. Calls for consult from social work/child life/chaplain.			
3.15 Provider uses humor – with family member			
GLOBAL RATING OF TEAM PERFORMANCE (1-10 where 1 = poor, 10 = excellent) ADDRESSING FAMILY NEEDS / DISTRESS →			

4. Addressing child distress (pain & emotional distress)	Place a check mark each time behavior occurs	Total count	Global rating
4.1 Provider offers child (medically appropriate) choices about positioning, timing, pain management strategies			
4.2 Provider offers specific physical comfort measures			
4.3 Providers asks child to rate his / her pain.			
4.4 Provider observes behavioral indicators of child pain, and probes to assess further.			
4.5 Based on child pain rating, provider alters pain management strategy.			
4.6 Provider asks child about feelings / emotions			
4.7 Provider observes behavioral indicators of child emotional distress, and probes to assess further.			
4.8 Provider engages child in non-procedure-related talk.			
4.9 Providers engage in medical discussion with each other, in front of child	N/A IN RESUSCITATION SCENARIOS	N/A	
4.10 Provider verbally expresses lack of clarity about treatment plan / procedural details.			
4.11 Specific provider moves to be near child's head / in line of sight, to offer information or distraction.			
4.12 Provider makes reassuring statement to child about specific procedure			
4.13 Provider makes broad reassuring statement to child			
4.14 Provider makes broad statement praising child			
4.15 Provider provides specific, accurate praise for a child action			
4.16 Provider apologizes to child for past or future action			
4.17 Provider uses humor – with child			
GLOBAL RATING OF TEAM PERFORMANCE (1-10 where 1 = poor, 10 = excellent) ADDRESSING CHILD PAIN AND EMOTIONAL DISTRESS →			
CHECK HERE IF NO OPPORTUNITY -> (CHILD WAS NOT AWAKE / CONSCIOUS DURING ANY PART OF THE ENCOUNTER)			

5. Promoting effective emotional support for child	Place a check mark each time behavior occurs	Total count	Global rating
5.1 Provider makes specific suggestion to parent about where to stand / sit in order that child can see parent.			
5.2 Provider commands or suggests that child do something – to facilitate care			
5.3 Provider commands or suggests that child do something – to facilitate child coping			
5.4 Provider actively engages child in a distracting activity or conversation just before / during a potentially painful or distressing procedure			
5.5 Provider makes specific suggestion for <u>parent</u> action to support child during acute care / procedure			
5.6 Provider makes specific suggestion for <u>parent</u> to use distraction during acute care / procedure			
5.7 Provider asks child or parent about child’s preferred coping strategy			
GLOBAL RATING OF TEAM PERFORMANCE (1-10 where 1 = poor, 10 = excellent) PROMOTING EFFECTIVE EMOTIONAL SUPPORT FOR CHILD →			
CHECK HERE IF NO OPPORTUNITY -> (CHILD WAS NOT AWAKE / CONSCIOUS DURING ANY PART OF THE ENCOUNTER)			

6. Cultural competence	Place a check mark each time behavior occurs	Total count	Global rating
6.1 Provider asks about child’s and family’s religious/spiritual background			
6.2 Provider asks about medically-relevant cultural values.			
6.3 Provider / team ask about child’s preferred language.			
6.4 Provider / team ask about parents’ preferred language.			
6.5 Provider / team call for interpreter services if applicable.			
GLOBAL RATING OF TEAM PERFORMANCE (1-10 where 1 = poor, 10 = excellent) CULTURAL COMPETENCE →			

SCORING GUIDE

The Family-Centered Care Assessment Tool – Pediatric Resuscitation can be utilized as a QI / self-assessment tool for health care teams in any emergency department who are involved in pediatric resuscitation.

How were items selected?

Items are derived from research evidence and best practice guidelines for specific practices associated with child and family outcomes such as reducing patient / parent distress during medical care, reducing risk for ongoing patient / parent posttraumatic stress reactions, and improving patient / parent satisfaction with care.

Important note: **Shaded** items are behaviors for which there is evidence of a negative association with desired outcomes.

Scoring

- During video review (of simulated patient care), an observer checks each time a specific behavior occurs, and, if desired, tallies a final count for each behavior.
- The observer then provides a global rating of the effectiveness of the team in achieving the domain-specific aim, taking into account observed behaviors, statements, and other non-verbal and contextual information.

ITEM DEFINITIONS / EXAMPLES TO AID IN SCORING

1. Sharing information with patient and family	
CODE	DEFINITION / EXAMPLE
1.1 Provider introduces self / team to child / parent, with initial orienting statement about team / room / situation	“Hi Mom, I’m Dr. X, we’re all going to work together to take care of your baby”
1.2 Team leader explains primary assessment/plan of action.	Resuscitation leader explains assessment / plan directly to patient, parent, or other family member
1.3 Provider explains status / procedure to parent using medical terminology	“We’re concerned that your daughter had pneumonia which is now disseminated”
1.4 Provider explains status / procedure to parent using lay language	“We’re going to have to put a breathing tube in her throat to help her breathe”
1.5 Provider checks parents’ understanding of information that is shared	“Mom, do you understand what’s going on? Do you have any questions?”
1.6 Provider / team explains potentially distressing intervention before (ideally), during, or after it occurs	Provider gives violent back blows to infant, then explains why
1.7 Team spontaneously provides patient / parent with updates on patient status	Provider gives update without prompt from parent / family member
1.8 Team provides updates on patient status, prompted by patient / parent request	After parent question, provider gives update
1.9 Provider responds curtly (e.g., dismissive → overtly rude) to family member question	Mom asks what is happening. Provider states “We’re intubating her.” [with no other explanation from team]
1.10 Provider responds to parent question and elaborates to provide explanation	
1.11 Provider defers response to parent question while actively engaged in care	“I’ll explain all of this to you in a little bit, but right now I need to focus on taking care of your daughter.”
1.12 Team designates a specific staff member as family liaison (before patient arrival, or upon entry of family member)	

1. Sharing information with patient and family	
CODE	DEFINITION / EXAMPLE
1.13 Multiple team members at a time ask questions or provide info to parent	Multiple team members speak to parent at same time or in close succession
1.14 At end of procedure, or other transition point, provider summarizes prior events and next steps	e.g. explain transfer, admission, imaging, etc

2. Promoting family involvement in care / decisions	
CODE	DEFINITION / EXAMPLE
2.1 Provider asks family member for child's name	
2.2 Provider asks child for his / her name	
2.3 Provider asks parent about child's medical history or history of present illness.	
2.4 Provider asks child about his/her own medical history or history of present illness.	
2.5 Provider asks parent if s/he wants to be with child during acute care / procedure.	
2.6 Provider allows parent who has chosen to be present to change mind / leave room, as intervention progresses.	Provider explicitly offers this option upon observing parent distress, or is supportive / respectful of parent choice in response to parent decision / query.
2.7 Provider asks adolescent if there is anyone who they want to have with them during acute care / procedure.	
2.8 Provider praises family member's actions	"You did the right thing by bringing him/her here as soon as you did"
2.9 Provider promotes specific future care behaviors	To parent of infant: "It's always good to keep an eye on how they're feeding"
2.10 Provider shares (aloud with team) information gathered from parent	"Dad's saying the child has had a fever for a few days and has had decreased urine output"
2.11 Team obtains or acknowledges family's wishes regarding treatment/diagnostic procedure	Provider asks family's preferences before making decision about initiating a therapy / ordering diagnostic test, e.g. CT scan
2.12 Provider asks parent to hold / or otherwise soothe child – to facilitate intervention/ procedure	Provider asks parent explicitly to calm a flailing child to facilitate IV placement
2.13 Provider explains specific procedure to child and checks child's understanding	"Here's what we're doing next. ...so can you explain that back to me in your own words?"

3. Addressing family needs / family distress	
CODE	DEFINITION / EXAMPLE
3.1 Provider offers comfort items to family member	"Can we get you anything? A chair? Cup of water?"
3.2 Provider engages family member in non-procedure-related talk.	Talks with family member about topics not related to procedure or the child's illness / injury
3.3 Provider explicitly checks parent emotional status / coping	Asks "How are you doing, Dad?"
3.4 Provider / team observes behavioral indicators of parent emotional distress and acts to address this	"Looks like this is pretty hard to see, would you like to sit over here for a few minutes?"
3.5 Provider asks parent to move – for stated practical purpose	Explicitly states reason for move that is related to patient care / patient safety

3. Addressing family needs / family distress	
CODE	DEFINITION / EXAMPLE
	"Here, why don't you stand over here so we have room to get this IV in?"
3.6 Provider asks parent to move – w statement re parent distress	Explicitly states reason for move that is related to parent distress / safety / well-being. "Can you sit over here? Sometimes it's scary to see us put the tube in his throat."
3.7 Provider makes specific suggestion to parent about where to stand / sit in order to see or touch child.	
3.8 Providers engage in non-procedure / non-medical talk with each other.	
3.9 Provider verbally expresses lack of clarity about treatment plan/procedural details	"Does anyone know which ET tube size we need?"
3.10 Provider touches family member on hand/arm/shoulder – or provider's physical position otherwise makes it clear they are listening to family member	Provider pats family member on hand / arm / shoulder
3.11 Provider makes reassuring statement to family member	General / broad reassurance, e.g. "We're going to do our best to take care of her"
3.12 Provider makes positive statement to parent conveying realistic hope	"We're doing our very best to take care of her. Based on our experience with things like this, I think she'll probably feel a lot better by tomorrow."
3.13 Provider makes positive statement to parent conveying vague or unrealistic expectations re: future course	"Don't worry, Mom, it will all be OK"
3.14 Team requests additional resources for family	May include calling for consult from social work / child life / chaplain.
3.15 Provider uses humor – with family member	

4. Addressing child distress (encompassing pain & emotional distress)	
CODE	DEFINITION / EXAMPLE
4.1 Provider offers child (medically appropriate) choices about positioning, timing, pain management strategies	
4.2 Provider offers specific physical comfort measures	e.g., swabbing dry lips, stroking child's forehead, patting child on hand/arm/shoulder
4.3 Providers asks child to rate his / her pain.	
4.4 Provider observes behavioral indicators of child pain, and probes to assess further.	
4.5 Based on child pain rating, provider alters pain management strategy.	
4.6 Provider asks child about feelings / emotions	General inquiry about child's emotional state, e.g., "How are you doing?"

4. Addressing child distress (encompassing pain & emotional distress)	Place a check mark each time behavior occurs
CODE	DEFINITION / EXAMPLE
4.7 Provider observes behavioral indicators of child emotional distress, and probes to assess further.	More specific inquiry, usually tied to a provider observation:, e.g. "You look like you might be feeling worried?"
4.8 Provider engages child in non-procedure-related talk	Talks with child about topics not related to procedure or the child's illness / injury
4.9 Providers engage in medical discussion with each other, in front of child.	Team members talking aloud about current status: "She's still only satting 91%."
4.10 Provider verbally expresses lack of clarity about treatment plan / procedural details:	"Does anyone know which ET tube size we need?"
4.11 Specific provider moves to be near child's head / in line of sight, to offer information or distraction.	
4.12 Provider makes reassuring statement to child about specific procedure	"This should help you breathe better"
4.13 Provider makes broad reassuring statement to child	General / broad reassurance, e.g "You're OK"
4.14 Provider makes broad statement praising child	"You're doing great", "You're being so brave"
4.15 Provider provides specific, accurate praise for a child action	"You held still for that, even though it was hard. Good job!"
4.16 Provider apologizes to child for past or future action	"I'm sorry sweetie, I know that hurt you." Or "I'm sorry, I have to press there again."
4.17 Provider uses humor – with child	

5. Promoting effective emotional support for child	
CODE	DEFINITION / EXAMPLE
5.1 Provider makes specific suggestion to parent about where to stand / sit in order that child can see parent.	
5.2 Provider commands or suggests that child do something – to facilitate care	Commands that aim to facilitate care / conduct of procedures: "Can you hold really still for me, while we put this on you?")
5.3 Provider commands or suggests that child do something – to facilitate child coping	Commands that aim to help child manage / cope with potentially painful or distressing procedure. (e.g., aim to help child manage "Squeeze my hand really hard while they check your leg.")
5.4 Provider actively engages child in a distracting activity or conversation just before / during a potentially painful or distressing procedure	"What's your favorite movie?" or "Let's look over here [away from active procedure site] and count the number of X's you see."
5.5 Provider makes specific suggestion for <u>parent action</u> to support child during acute care / procedure	"Dad, why don't you come over here and hold his hand while we do this?"
5.6 Provider makes specific suggestion for <u>parent</u> to use distraction during acute care / procedure	"Dad, why don't you come over here and talk with him about last night's game while we do this?")
5.7 Provider asks child or parent about child's preferred coping strategy	"Do you want me to tell you everything that's happening, or would you rather look over here so you don't have to see it?")

6. Cultural competence (taking child/family culture into account)	
CODE	DEFINITION / EXAMPLE
6.1 Provider asks about child’s and family’s religious / spiritual background	e.g. Chaplain asks “does s/he have any religious or spiritual affiliation of any sort?”
6.2 Provider asks about medically-relevant cultural values.	
6.3 Provider / team ask about child’s preferred language.	
6.4 Provider / team ask about parents’ preferred language.	
6.5 Provider / team call for interpreter services if applicable.	

Global Rating Guide

1 = poor

- Team exhibits no or few desired FCC/TIC behaviors
- Team may exhibit potentially detrimental behaviors
- Team misses opportunities to enact FCC/TIC behaviors

5 = satisfactory

- Evidence that the team actively addresses the goal of the domain(s)
- Within each domain, team exhibits all or nearly all behaviors defined as crucial
- No or few potentially detrimental behaviors
- Team may miss some opportunities to enact FCC/TIC behaviors

10 = excellent

- Evidence that the team actively addresses the goal of each domain
- Actions are well-executed (in the judgement of expert raters)
- Actions are effective, as evidenced by patient or family member verbal / behavioral response where appropriate
- Within each domain, team exhibits all behaviors defined as crucial
- No potentially detrimental behaviors
- No missed opportunities to enact FCC/TIC behaviors

	ALWAYS POSSIBLE (missed opportunity if not observed)	CRUCIAL
Domain 1	1.1 introduction to family member	1.2 explain primary assessment
	1.2 explain primary assessment	1.6 if applicable, if distressing intervention occurs a team member explains to the family what happened and why
	1.7 OR 1.8 keep family informed of status	1.14 update next steps
	1.14	
Domain 2	2.1 OR 2.2 acquire child's name	2.3 medical history
	2.3 medical history	2.5 for new invasive procedure,
	2.5	2.6 if applicable
		2.7 if applicable, child chooses who's with them
		2.11 if applicable
Domain 3	3.3 OR 3.4,	3.3 OR 3.4
	3.10	3.5 OR 3.6 if applicable
	3.12	3.10
Domain 4 *	TBD	TBD
Domain 5 *	5.1	5.1
	5.5	5.7 if applicable
Domain 6	6.3-6.4 observe or explicitly check language preference	6.2 if possible without inhibiting care
		6.3-6.4 ask or observe language use Language preference cannot be assumed. Crucial to explicitly check language preference unless early observation shows that parent [or child] responds verbally in clear and explicit English. (i.e. more than nodding assent or 1-2 word responses)
		6.5 if applicable

* Applicable only if child awake / aware.