

**Table 1: Detailed Measure Specifications and Scoring for FECC Caregiver Survey Indicators**

All are on a 0-100 scale, where higher is better. Survey response items should be coded to reflect that. For dichotomous items, “no” = 0 and “yes” = 100.

More specific instructions are included where applicable in Scoring Notes.

All screener items must be non-missing for a dependent item to be scored.

If items are a part of a yes/no checklist, if at least one item is answered, impute “no” for skipped items in mailed surveys or “don’t know” for telephone surveys (but not for items that telephone respondents refused to answer).

Otherwise, all component items must be non-missing for a multi-item indicator to be scored.

MP=Main Provider

Indicator ID	Indicator Description	Items used for Eligibility	Items used in Scoring	Scoring Notes
<b>CARE COORDINATION SERVICES</b>				
<b>FECC-1</b>	Caregivers of children with medical complexity should report that their child has a designated care coordinator.	Q2=1 (Child visited more than one doctor’s office or used more than one kind of health care service in last 12 months)	Q3a or Q3b (Someone helped manage child’s care or treatment from different doctors/providers.)	Q3a or 3b = 1 (yes) = 100 Q3a and 3b = 2 (no) = 0
<b>FECC-2</b>	Caregivers of children with medical complexity who report that their child has a designated care coordinator (as identified in FECC-1) should report that they know how to access their care coordinator.	Q2=1 (Child visited more than one doctor’s office or used more than one kind of health care service in last 12 months), Q3a = 1 or Q3b = 1 (Someone helped manage child’s care or treatment from different doctors/providers)	Q6 (Knew how to contact person who helped manage child’s care when you needed help or had a question)	Q6 = 1 (yes) = 100 Q6 = 2 (no) = 0
<b>FECC-3</b>	Caregivers of children with medical complexity who report having a designated care coordinator (as identified in FECC-1) and who require community services should also report that their care coordinator helped their child to obtain needed community services in the last year.	Q2=1 (Child visited more than one doctor’s office or used more than one kind of health care service in last 12 months), Q3a = 1 or Q3b = 1 (Someone helped manage child’s care or treatment from different doctors/providers), Q15=1 (Caregiver or child needed or	Q16 (Person who helped manage child’s care helped get community services)	Q16 = 1 (yes) = 100 Q16 = 2 (no) = 0

used community services in last 12 mos)

**FECC-4**

Caregivers of children with medical complexity who report that their child has a designated care coordinator (as identified in FECC-1) should also report that their care coordinator has contacted them (via face-to-face contact, telephone, email, or written correspondence) or attempted to contact them at least once in the last 3 months.

Q2=1 (Child visited more than one doctor's office or used more than one kind of health care service in last 12 months), Q3a = 1 or Q3b = 1 (Someone in helped manage child's care or treatment from different doctors/providers)

Q7 (In last 3 mos, person contacted caregiver w/o caregiver getting in touch w/them first)

Q7 = 1 (yes) = 100  
Q7 = 2 (no) = 0

**FECC-5**

Caregivers of children with medical complexity who report that their child has a designated care coordinator (as identified in FECC-1) should also report that the care coordinator has contacted them in the last 3 months and asked them about the following:

Q2=1 (Child visited more than one doctor's office or used more than one kind of health care service in last 12 months), Q3a = 1 or Q3b = 1 (Someone helped manage child's care or treatment from different doctors/providers), Q7=1 (In last 3 mos, care coordinator contacted you w/o you getting in touch w/them first)

Q9 = Care coordinator asked about caregiver concerns

Q10 = Care coordinator asked about health changes of child

Partial credit:

Rescale Q9 to 0-100:  
Q9 =1 (Never): 0 pts,  
Q9 =2 (Sometimes): 33 pts,  
Q9 =3 (Usually): 66 pts,  
Q9 =4 (Always): 100 pts

Rescale Q10 to 0-100:  
Q10 =1 (Never): 0 pts,  
Q10 =2 (Sometimes): 33 pts,  
Q10 =3 (Usually): 66 pts,  
Q10 =4 (Always): 100 pts

**FECC-5a)** Caregiver concerns

**FECC-5b)** Health changes of the child

FECC-5: Mean of Q9 and Q10

**FECC-6**

Caregivers of children with medical complexity who report having a copy of a written shared care plan for their child, should also report that either their main provider (MP) or someone in the main provider's office asked them about progress towards goals documented in the child's shared care plan

Q29=1 (MP created shared care plan for child), Q30=1 (Caregiver has copy of child's shared care plan)

Q31 (In last 12 mos, MP or another person in MP's office talked with caregiver about progress child was making toward goals written in shared care plan)

Q31 = 1 (yes) = 100  
Q31 = 2 (no) = 0

If Q31=3 (Child's shared care plan does not have written goals), score = 0

**FECC-7**

Caregivers of children with medical complexity who report that their child has a designated care coordinator (as identified in FECC-1) and who report their child was referred to see a specialist in the last 12 months, should also report that the care coordinator contacted them to confirm they were able to get an appointment with the specialist

Q2=1 (Child visited more than one doctor's office or used more than one kind of health care service in last 12 months), Q3a = 1 or Q3b = 1 (Someone helped manage child's care or treatment from different doctors/providers), Q13=1 (main provider told caregiver child needed to see specialist during last 12 mos)

Q14 (Person in who helped manage child's care contacted you to make sure child got appointment to see specialist)

Q14 = 1 (yes) = 100  
Q14 = 2 (no) = 0

If Q14=3 (Did not get help managing child's care), score = 0

<b>FECC-8</b>	Caregivers of children with medical complexity who report that their child has a designated care coordinator (as identified in FECC-1) should also report that their care coordinator:	Q2=1 (Child visited more than one doctor's office or used more than one kind of health care service in last 12 months), Q3a = 1 or Q3b = 1 (Someone helped manage child's care or treatment from different doctors/providers)	Q5 (In last 12 mos, person who helped manage child's care...)	<u>Partial credit for Q5a-e:</u> Yes Definitely = 100 Yes Somewhat=50 No = 0 If "Not applicable" (Q5d and Q5e only) = don't score
	<b>FECC-8a)</b> Was knowledgeable about their child's health		Q5a, Q5b	<b>FECC-8a:</b> Mean of rescaled Q5a and Q5b
	<b>FECC-8b)</b> Supported the caregiver		Q5c	<b>FECC-8b:</b> Mean of rescaled Q5c
	<b>FECC-8c)</b> Advocated for the needs of the child		Q5d, Q5e	<b>FECC-8c:</b> Mean of rescaled Q5d and Q5e (only score if applicable)
				<b>FECC-8 Measure Score:</b> Take mean of <b>FECC-8a-c</b>
<b>FECC-15</b>	Caregivers of children with medical complexity who self-identify as having a preference for conducting medical visits in a language other than English should have access to a professional medical interpreter (live or telephonic) at all visits for which an interpreter is needed.	Q39=1 (Speak language other than English at home), Q41=2 (Prefer to talk w/child's doctors in language other than English), Q44=2, 3, or 4 (Needed professional interpreter during visit to MP some, most, or all visits)	Q45 (How often was professional interpreter available when needed)	<u>Partial credit:</u> rescale Q45 to 0-100: Q45=1 (Never): 0 pts, Q45=2 (Sometimes): 33 pts, Q45=3 (Usually): 66 pts, Q45=4 (Always): 100 pts

## MESSAGING

<b>FECC-9</b>	Caregivers of children with medical complexity who report receiving a written visit summary during the last 12 months from their child's MP's office should report that it contained the following elements:	All caregivers of children with medical complexity  Q17=1 (received written visit summary in last 12 mos)	Q18 (How often did written visit summaries include...)	<u>Partial credit for Q18a-g:</u> Always = 100 Sometimes =50 Never = 0
	<b>FECC-9a)</b> Current problem list		Q18a	
	<b>FECC-9b)</b> Current medication list		Q18b (Rx), Q18c (OTC)	<b>FECC-9b)</b> Mean of rescaled Q18b and Q18c
	<b>FECC-9c)</b> Drug allergies		Q18d (list of "child's allergies", not drug allergies specifically)	
	<b>FECC-9d)</b> Specialists involved in the child's care		Q18e	
	<b>FECC-9e)</b> Planned follow-up		Q18f	
<b>FECC-9f)</b> What to do for problems related to the outpatient visit		Q18g	<b>FECC-9 Measure Score:</b> Take mean of <b>FECC-9a-f</b>	

<b>FECC-10</b>	Caregivers/patients who reported ever receiving a visit summary in the last 12 months from their child's MP's office (as identified in IE2) should report that the summary:	Q17=1 (received written visit summary in last 12 mos)	<u>Partial credit for Q19 and Q20:</u> Always = 100 Sometimes=50 Never = 0	
	<b>FECC-10a)</b> Was easy to understand <b>FECC-10b)</b> Was useful		Q19 Q20	
<b>FECC-11</b>	Caregivers of children with medical complexity should report having been invited to join in hospital rounds during their child's last hospitalization	Q21=1 (child had overnight hospital stay in last 12 mos)	Q25 (Last time child was in hospital, invited to take part in hospital rounds)	Q25 = 1 (yes) = 100 Q25 = 2 (no) = 0
<b>FECC-12</b>	Caregivers/patients should report receiving a written visit summary of their child's last hospitalization at the time of discharge, and they should report the summary contained the following elements:	Q21=1 (child had overnight hospital stay in last 12 mos), Q22=1 (Last time child was in hospital, got written hospital stay summary at discharge)	Q23 (Did written hospital stay summary include...)	Impute "no" for missing values if any responses are provided to Q23a - g  Q23a-g = 1(yes) = 100 Q23a-g = 2 (no) = 0
	<b>FECC-12a)</b> Problem list at time of discharge		Q23a	
	<b>FECC12b)</b> Medication list at time of discharge		Q23b (Rx), Q23c (OTC)	<u>FECC-12b:</u> Mean of rescaled Q23b and Q23c
	<b>FECC-12c)</b> Drug allergies		Q23d (list of "child's allergies", not drug allergies specifically)	

**FECC12d)** Specialists involved in the child's care during the hospitalization

Q23e

**FECC-12e)** Planned follow-up

Q23f

**FECC-12f)** Who to call for problems related to the hospitalization

Q23g

**FECC-12 Measure Score:**

Take mean of **FECC-12a-f**

**FECC-13**

Caregivers of children with medical complexity who receive a written summary of their child's hospitalization at discharge (as described in indicator FECC-12) should report that the information contained in the visit summary was easy to understand

Q21=1 (child had overnight hospital stay in last 12 mos),  
Q22=1 (Last time child was in hospital, got written hospital stay summary at discharge)

Q24 (Hospital stay summary easy to understand)

Q24 = 1 (Yes, definitely) = 100  
Q24 = 2 (Yes, somewhat) = 50  
Q24 = 3 (no) = 0

**FECC-19**

Caregivers of children with medical complexity should report having access to an electronic health record to look up information about their child's visits and health care.

All caregivers of children with medical complexity

Q26 (In last 12 mos, MP's office had web site or app caregiver could use between visits to look up information about child's visits and care)

Q26=1 (Yes) = 100  
Q26=2 or 3 (no or don't know) = 0

**FECC-20**

Caregivers of children with medical complexity who report having access to an electronic health record should also report that it includes the following health information:

Q26=1 (In last 12 mos, MP's office had web site or app caregiver could use between visits to look up information about child's visits and care)

**FECC-20a)** Immunization record

Q26=1 (In last 12 mos, MP's office had web site or app caregiver could use between visits to look up information about child's visits and care)

Q27 (In last 12 mos, MP's web site or app had list of immunizations child has received)

**FECC-20a:**

If Q27=3 or 4 (no immunizations in last 12 mos): do not score  
If Q27=1 (Yes): 100 points  
If Q27=2 or 4 (No or Don't Know): 0 points

**FECC-20b)** List of child's medications

Q26=1 (In last 12 mos, MP's office had web site or app caregiver could use between visits to look up information about child's visits and care)

Q28 (In last 12 mos, MP's web site or app had list of child's meds)

**FECC-20b:**

If Q28=3 (no meds in last 12 mos): do not score  
Q28=1 (Yes): 100 points  
fQ28=2 or 4 (No or Don't Know): 0 points

**FECC-20 Measure Score:**

Take mean of **FECC-20a** and **FECC-20b**

<b>FECC-14</b>	Caregivers of children with medical complexity who report their child's condition causes difficulty learning, understanding, or paying attention in class should also report that someone from the MP's office communicated with school staff at least once a year about the educational impacts of the child's condition.	Q35=1 (Child attended school in last 12 mos), Q36=1 (Because of health condition child has difficulty learning, understanding, or paying attention in class)	Q37 (In last 12 mos, someone from MP's office contacted staff at child's school to make sure they understood how child's condition affected ability to learn, understand, or pay attention)	Q37=1 (Yes) = 100 Q37=2 or 3 (no or don't know) = 0 points
----------------	--	--	---	---

**PROTOCOLS/PLANS**

<b>FECC-16</b>	Caregivers of children with medical complexity should report that their child's primary care provider created a shared care plan for their child.	All caregivers of children with medical complexity	Q29 (MP created shared care plan for child)	Q29=1 (Yes) = 100 Q29=2 (No) = 0
<b>FECC-18</b>	Caregivers of children with medical complexity who are age 15 years or older should report that their child's main provider created a written transition plan for their child.	Q33=1 (Child age 15 or older)	Q34 (MP created transition plan for child)	Q34=1 (Yes) = 100 Q34=2 or 3 (no or don't know) = 0 pts
<b>FECC-17</b>	Caregivers of children with medical complexity should report that their child's main provider created an	All caregivers of children with medical complexity	Q32 (MP created emergency care plan for child)	Q32=1 (Yes) = 100 pts Q32=2 (No) = 0 pts

emergency care plan for their child.