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

<table>
<thead>
<tr>
<th>Indicator ID</th>
<th>Indicator Description</th>
<th>Items used for Eligibility</th>
<th>Items used in Scoring</th>
<th>Scoring Notes</th>
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<tbody>
<tr>
<td>FECC-1</td>
<td>Caregivers of children with medical complexity should report that their child has a designated care coordinator.</td>
<td>Q2=1 (Child visited more than one doctor’s office or used more than one kind of health care service in last 12 months)</td>
<td>Q3a or Q3b (Someone helped manage child’s care or treatment from different doctors/providers.)</td>
<td>Q3a or 3b = 1 (yes) = 100 Q3a and 3b = 2 (no) = 0</td>
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<tr>
<td>FECC-2</td>
<td>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.</td>
<td>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)</td>
<td>Q6 (Knew how to contact person who helped manage child’s care when you needed help or had a question)</td>
<td>Q6 = 1 (yes) = 100 Q6 = 2 (no) = 0</td>
</tr>
<tr>
<td>FECC-3</td>
<td>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.</td>
<td>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</td>
<td>Q16 (Person who helped manage child’s care helped get community services)</td>
<td>Q16 = 1 (yes) = 100 Q16 = 2 (no) = 0</td>
</tr>
</tbody>
</table>
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

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-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

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
FECC-8

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...)

Partial credit for Q5a-e:
Yes Definitely = 100
Yes Somewhat=50
No = 0
If “Not applicable” (Q5d and Q5e only) = don’t score

FECC-8a) Was knowledgeable about their child’s health

FECC-8b) Supported the caregiver

FECC-8c) Advocated for the needs of the child

FECC-8 Measure Score:
Take mean of FECC-8a-c

FECC-15

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)

Partial credit: 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

Partial credit for Q5a-e:
Yes Definitely = 100
Yes Somewhat=50
No = 0
If “Not applicable” (Q5d and Q5e only) = don’t score

FECC-8a: Mean of rescaled Q5a and Q5b

FECC-8b: Mean of rescaled Q5c

FECC-8c: Mean of rescaled Q5d and Q5e (only score if applicable)

FECC-8 Measure Score:
Take mean of FECC-8a-c
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:

- **FECC-9a)** Current problem list
- **FECC-9b)** Current medication list
- **FECC-9c)** Drug allergies
- **FECC-9d)** Specialists involved in the child’s care
- **FECC-9e)** Planned follow-up
- **FECC-9f)** What to do for problems related to the outpatient visit

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...)

Partial credit for Q18a-g:
- Always = 100
- Sometimes =50
- Never = 0

**FECC-9 Measure Score:**
Take mean of FECC-9a-f
**FECC-10**

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)

Partial credit for Q19 and Q20:
- **Always** = 100
- **Sometimes** = 50
- **Never** = 0

**FECC-10 Measure Score:**
Take mean of FECC-10a and FECC-10b

- **FECC-10a**) Was easy to understand
- **FECC-10b**) Was useful

- **Q19**
- **Q20**

**FECC-11**

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

**FECC-12**

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

**FECC-12a**) Problem list at time of discharge

**FECC-12b**) Medication list at time of discharge

- **Q23b (Rx)**, **Q23c (OTC)**

**FECC-12b**: Mean of rescaled Q23b and Q23c

- **Q23d** (list of “child’s allergies”, not drug allergies specifically)
FECC-12d) Specialists involved in the child’s care during the hospitalization

FECC-12e) Planned follow-up

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

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-12 Measure Score:
Take mean of FECC-12a-f
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:

**FECC-20**

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
| FECC-14 | 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 |

| FECC-16 | 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 |

| FECC-17 | Caregivers of children with medical complexity should report that their child’s main provider created an emergency care plan for their child. |
| 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 |

| FECC-18 | 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 |
emergency care plan for their child.