

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

All are on 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 nonmissing for a dependent item to be scored

If items are 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 nonmissing for a multi-item indicator to be scored.

MP=Main Provider

| Indicator ID | Indicator Description | Eligible | Survey Item | Scoring notes |
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| CARE COORDINATION SERVICES | | | | |
| CC2 | Caregivers 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) | Q3 (Someone in MP's office helped manage child's care or treatment from different doctors/providers) | |
| CC3 | Caregivers who report that their child has a designated care coordinator (as identified in CC2) 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), Q3=1 (Someone in MP's office 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) | |

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| CC5 | Caregivers who report having a designated care coordinator (as identified in CC2) 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), Q3=1 (Someone in MP's office helped manage child's care or treatment from different doctors/providers), Q15=1 (Caregiver or child needed or used community services in last 12 mos) | Q16(Person in MP's office who helped manage child's care helped get community services) | |
| CC7 | Caregivers who report having a care coordinator (as identified in CC2) 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), Q3=1 (Someone in MP's office helped manage child's care or treatment from different doctors/providers) | Q7 (In last 3 mos, person contacted you w/o you getting in touch w/them first) | |
| CC8 | Caregivers of children with complex needs who report having a care coordinator and who report that their care coordinator has contacted them in the last 3 months should also report that their care coordinator 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), Q3=1 (Someone in MP's office 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) | | Mean of CC8a and CC8b |

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| CC8a | Caregiver concerns | | Q9 (Care coordinator asked about caregiver concerns) | |
| CC8b | Health changes of the child | | Q10 (Care coordinator asked about health changes of child) | |
| CC8c | Caregivers who report the following: having a designated care coordinator, having a copy of a written shared care plan for their child, and having been contacted by their care coordinator in the last 3 months should also report that their care coordinator asked them about the following: Progress towards goals documented in the patient's shared care plan | Q2=1 (Child visited more than one doctor's office or used more than one kind of health care service in last 12 months), Q3=1 (Someone in MP's office 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), 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, has MP or anyone from MP's office talked w/you about progress child was making toward goals written in shared care plan) | If Q31=3 (Child's shared care plan does not have written goals), score as No |
| CC9 | Caregivers who report their child was referred to see a specialist in the last 12 months and who report having a care coordinator for their child 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), Q3=1 (Someone in MP's office helped manage child's care or treatment from different doctors/providers), Q13=1 (MP told you child needed to see specialist during last 12 mos) | Q14 (Person in MP's office who helped manage child's care contacted you to make sure child got appointment to see specialist) | If Q14=3 (Did not get help managing child's care), score as No |

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| CC10 | Caregivers who report having a care coordinator 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), Q3=1 (Someone in MP's office helped manage child's care or treatment from different doctors/providers) | Q5 (In last 12 mos, person in MP's office who helped manage child's care...) | Give partial credit (No=0, Yes Somewhat=50, Yes Definitely=100), take mean of CC10a-c |
| CC10a | Was knowledgeable about their child's health | | Q5a, Q5b | Mean of rescaled Q5a and Q5b |
| CC10b | Supported the caregiver | | Q5c | |
| CC10c | Advocated for the needs of the child | | Q5d, Q5e | Mean of rescaled Q5d and Q5e |
| MH8 | Caregivers or patients 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 points, Q45=2 (Sometimes): 100/3 points, Q45=3 (Usually): 100*2/3 points, Q45=4 (Always): 100 points |

MESSAGING

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| IE2 | Caregivers/patients 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: | Q17=1 (received written visit summary in last 12 mos) | Q18 (How often did written visit summaries include...) | Give partial credit (Never=0, Sometimes=50, Always=100), take mean of IE2a-f |
| IE2a | Current problem list | | Q18a | |
| IE2b | Current medication list | | Q18b (Rx), Q18c (OTC) | Mean of rescaled Q18b and Q18c |

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| IE2c | Drug allergies | | Q18d (list of "child's allergies", not drug allergies specifically) | |
| IE2d | Specialists involved in the child's | | Q18e | |
| IE2e | Planned follow-up | | Q18f | |
| IE2f | What to do for problems related to the outpatient visit | | Q18g | |
| IE3 | 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) | | Give partial credit (Never=0, Sometimes=50, Always=100), take mean of IE3a and IE3c |
| IE3a | Was easy to understand | | Q19 | |
| IE3c | Was useful | | Q20 | |
| IE4 | Caregivers 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) | |
| IE5 | 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...) | Mean of IE5a-f |
| IE5a | Problem list at time of discharge | | Q23a | |
| IE5b | Medication list at time of discharge | | Q23b (Rx), Q23c (OTC) | Mean of rescaled Q23b and Q23c |

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| IE5c | Drug allergies | | Q23d (list of “child’s allergies”, not drug allergies specifically) |
| IE5d | Specialists involved in the child's care during the hospitalization | | Q23e |
| IE5e | Planned follow-up | | Q23f |
| IE5f | What to do for problems related to the hospitalization | | Q23g |
| IE6 | Caregivers who received a written summary of their child’s hospitalization at discharge (as described in indicator IE5) 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) |
| MH3a | Caregivers 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) If Q26=1 (Yes): 100 points If Q26=2 or 3 (No or Don’t Know): 0 points |
| MH3b | Caregivers 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) | Do not score the N/A's; If no immunizations (meds), do not score MH3b1 (MH3b2); If didn't look at med list, do not score MH3b2 Take mean of MH3b1 and MH3b2 |

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| MH3b1 | 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) | If Q27=3 (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 |
| MH3b2 | 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) | If Q28=3 (no meds in last 12 mos): do not score MH3b2 If Q28=1 (Yes): 100 points for MH3b2 If Q28=2 or 4 (No or Don't Know): 0 points for MH3b2 |
| MH6 | Caregivers who report their child's condition causes difficulty learning, understanding, or paying attention in class should also report that one of their child's health care providers (i.e., primary care physician, specialist physician, care coordinator, NP, nurse, social worker, etc) 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) | If Q37=1 (Yes): 100 points If Q37=2 or 3 (No or Don't Know): 0 points |

PROTOCOLS/PLANS

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| SCP2 | Caregivers 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 points Q29=2 (No): 0 points |
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| SCP4 | Caregivers of children (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 points Q34=2 or 3 (No or Don't Know): 0 points |
| SCP6 | Caregivers 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 points Q32=2 (No): 0 points |