CARE Award Metrics: Reflections and Rankings

This white paper presents an overview of CARE Award measurement, and reflects on where successes were seen, where barriers were encountered, and how these lessons can inform future quality improvement (QI) efforts to implement a clinical transformation model for children with medical complexity (CMC). This paper intends to convey the CARE Award experience in the design and implementation of a measurement set for the project aims with this population. While the CARE Award experience offers important lessons for future efforts in this area, the measures reviewed in this paper are not necessarily generalizable to all populations of children and youth with special healthcare needs (CYSHCN).
LEARNING COLLABORATIVE

Care transformation in the CARE Award was implemented in a three-year learning collaborative with teams from each of the 10 participating children’s hospitals and 42 associated primary care practices (PCP). The collaborative used the Institute for Health Care Improvement’s (IHI) Breakthrough Series (BTS) Learning Collaborative model as a template. The improvement approach of a BTS Learning Collaborative is the Model for Improvement, comprised of three fundamental questions that drive all improvement and the PDSA cycle (see Figure 1).

METHODOLOGY

The CARE Award employed three types of measures to assess care transformation success: outcome measures to assess the impact of the intervention on patients, families and providers; process measures to support the integration of new knowledge into daily practice; and balancing measures to assess any potential adverse outcome on the target population. These measures were used in the context of sequential, observable tests of change to accelerate the rates of improvement. Due to timing restrictions, the measures were not tested as part of this project.

Outcome Measures

The CARE Award outcome measures are derived directly from its key driver diagram (a tool that depicts the primary and secondary drivers that lead to achievement of goals). CARE’s key driver diagram was developed using expert faculty and relevant research to articulate the key drivers and pathways that contribute to the achievement of improved health, better care, and lower cost. These drivers were then validated by CARE Award champions from each participating site early in the CARE Award project (See Appendix D).

Using the set of primary and secondary drivers, outcome metrics were established in the following areas:

1. Family experience with care and family health-related quality of life
2. Utilization and cost of health care services
3. Adherence to the principles of a medical home (medical homeness) and provider well-being

Family Experience with Care and Family Health-Related Quality of Life

Nine domains for family experience with care and family health-related quality of life (HRQOL) were chosen using expert opinion and a literature review:

- Access to care
- Care coordination services
- Family care plans
- Patient/family-provider communication

Types of measures and the questions they answer

Outcome measures

How does the system impact the values of patients/families, their health and wellbeing? What are impacts on other stakeholders such as payers, employees, or the community?

Process measures

Are the parts/steps in the system performing as planned? Are we on track in our efforts to improve the system?

Balancing measures

Are changes designed to improve one part of the system causing new problems in other parts of the system? All measures related to the change package were process measures.
An extensive literature review and conversations with experts demonstrated there was no single instrument that assessed all these domains and was also validated in a population of CYSHCN. Therefore, project leaders reviewed patient experience and HRQOL instruments that had been validated and had strong psychometric properties. Four surveys that included the necessary domains and met these criteria were ultimately chosen to create the tool administered to families enrolled in the CARE Award.

Domains and/or questions from these surveys were chosen based on the following criteria:

- Did items map closely to change concepts and key drivers?
- Was the survey length as short as possible to be considerate of family time?
- Were individual questions on family surveys validated for use on their own?
- Was the survey tested or validated for CYSHCN?
- Were the surveys or individual items sensitive to change in a care transformation intervention?

See Table 1 for a description of the domains selected from the surveys.

One limitation of this strategy was that with the exception of the FECC survey, the validity of using individual or a subset of questions from a survey to assess family experience and HRQOL had not been rigorously tested.

### Metrics collected from claims data

#### Hospital Days
Total number of hospital inpatient days during reporting period annualized to one year per 1,000 patients enrolled during reporting period.

#### Emergency Department (ED) Discharges
Total number of ED Visits during reporting period annualized to one year per 1,000 patients enrolled during reporting period/1,000.

#### Total Spend
Sum of total inpatient payments, total pharmacy payments, and total outpatient payments divided by the number of patient years represented during reporting period.

#### Other Areas of Spend and Utilization Reviewed
- All office visits
- Outpatient (OP) facility visits
- OP mental health/substance abuse visits
- OP occupational therapy, physical therapy, and speech therapy visits
- OP radiology services
- OP lab services
- OP major procedure visits
- OP injections and medications services
- Home health days
- Durable medical equipment services
- Prescriptions filled
- Other outpatient services

### Utilization and Cost of Health Care Services
To assess the total cost of care and service utilization, paid claims from state Medicaid programs or Medicaid MCOs from participat-

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**Table 1. CARE Family Survey Tool**

<table>
<thead>
<tr>
<th>Survey</th>
<th>Domains</th>
</tr>
</thead>
<tbody>
<tr>
<td>Consumer Assessment of Healthcare Providers and Systems (CAHPS)</td>
<td>• Patient access</td>
</tr>
<tr>
<td>developed by the Agency for Healthcare Research and Quality</td>
<td>• Patient provider communication</td>
</tr>
<tr>
<td>Family Centered Care Assessment (FCCA) developed by Family Voices</td>
<td>• Decision making interaction</td>
</tr>
<tr>
<td>Family Experience with Care Coordination (FECC) developed by COE4CCN</td>
<td>• Family support</td>
</tr>
<tr>
<td>• Strength-based approach to care</td>
<td>• Care coordination services</td>
</tr>
<tr>
<td>• Care plan</td>
<td>• Family relationships</td>
</tr>
<tr>
<td>Pediatric Quality of Life Family Impact Module (PedsQL-FIM), part of</td>
<td>• Daily activity</td>
</tr>
<tr>
<td>the PedsQL Measurement Model for the Pediatric Quality of Life Inventory</td>
<td>• Worry</td>
</tr>
<tr>
<td>• Communication</td>
<td>• Physical functioning</td>
</tr>
<tr>
<td>• Physical functioning</td>
<td>• Emotional functioning</td>
</tr>
<tr>
<td>• Social functioning</td>
<td>• Cognitive functioning</td>
</tr>
</tbody>
</table>
ing states were acquired and analyzed. Claims reflected baseline data (2-3 year look-back prior to implementation of CARE Award interventions) as well as the three-year Award period.

The target population of CMC was defined with the 3M™ Clinical Risk Group (CRG) Software. This population classification system assigns individuals to a single, severity-adjusted group ranging from one to nine. The CARE Award target population was CRG categories 5b-9*, representing children with significant chronic conditions, children with chronic diseases in multiple organ systems and children with catastrophic medical conditions.

Adherence to Principles of Medical Home and Provider Well-Being
To assess adherence to the medical home principles, the Medical Home Index (MHI) survey was administered. The MHI is a validated self-assessment and classification tool designed to translate the broad indicators defining the medical home (accessible, family-centered, comprehensive, coordinated, etc.) into observable, tangible behaviors and processes of care within any practice setting. It is a way of measuring and quantifying the “medical homeness” of a primary care practice.

The MHI is based on the premise that “medical home” is an evolutionary process rather than a fully realized status for most practices. The MHI measures a practice's progress in this developmental process. Participating sites completed the MHI Short Form at baseline and three subsequent intervals over the course of the CARE Award period.

Provider well-being measurement is essential when changing the care delivery process. It's not only an important consideration for care transformation (provider experience has been added to the “quadruple aim” of health care), but it is also important to ensure that efforts to lower cost and improve family experience with care do not adversely affect provider well-being. Provider well-being also impacts sustainability; if patient experience improves, but provider experience declines drastically, then the initiative likely will not be sustainable. The Physician Worklife Survey (PWL), a validated tool developed by researchers at the Health Services Research Center at the University of North Carolina-Chapel Hill and the University of Wisconsin Medical School, was used to examine the background, training, and work experience of physicians and nurse practitioners at CARE Award sites (see survey domains at right).

Process Measures: Care Delivery Transformation
Process measures were developed to assess the implementation of the CARE Award change package. A change package is an approach to organizing change concepts useful in developing specific ideas for changes that lead to improvement. The CARE Award change package emerged from the key driver diagram, under the guidance of expert faculty and with support of collaborative participants. Evidence based changes were recommended where possible. The change package was the vehicle for care transformation, with successful implementation defined by the adoption of the change package into practice (see Appendices B and C).

Each change concept was assigned core elements to reflect the key measurable components within it. Each site tracked both the overall implementation of the change package and the number of core elements adopted. Table 2 outlines the content of each change concept's process measures and core elements.

*The 3MTM Clinical Risk Groups are a population classification system that assign individuals to a single, severity-adjusted group ranging from 1-9. The CARE Award enrolled children are classified in the CRG 5b-9 groups, which represent children with significant chronic conditions, children with chronic disease in multiple organ systems and children with catastrophic medical conditions.

Survey Domains

Medical Home Index
- Organizational capacity
- Chronic condition management
- Care coordination
- Community outreach
- Data management
- Quality improvement

Physician Worklife Survey
- Background, training, and work experience
- Assessment of ideal job, current practice setting, patient flow and workload
- Context of work
- Satisfaction with work, career and specialty
- Health and well-being
- Possible changes in work life
What was tracked?

- Registry documentation and number of core elements
- Care team documentation in the EMR and number of core elements
- Access plans available for families and number of core elements
- Patient care plans developed and number of core elements, Family needs and assets surveys created to develop care plans

Core elements

<table>
<thead>
<tr>
<th>Change concept</th>
<th>What was tracked?</th>
<th>Core elements</th>
</tr>
</thead>
</table>
| Registry      | Registry documentation and number of core elements                               | • Demographics
• Team contact info and updates
• Location of care
• Status of care coordination
• Status of care plan
• Hospital admissions
• Reviewed every 6 months                                                                                                                                 |
| Dynamic Care Team (DCT) | Care team documentation in the EMR and number of core elements | • Documentation of team members and levels of involvement
• Mechanism to share team contact info
• Protocol to trigger team communication |
| Access Plan   | Access plans available for families and number of core elements                  | • Care team contact information and preferred method of contact
• Communication plans for specific emergent, urgent, routine, and newly risen medical issues
• Reviewed every 6 months |
| Care Plan     | Patient care plans developed and number of core elements, Family needs and assets surveys created to develop care plans | • Narrative clinical summary
• Shared development of short and long term patient goals incorporating needs and assets survey results
• Process for tracking progress towards goals
• Developmental, educational, environmental concerns considered
• Protocol or care using evidence based guidelines across care continuum
• Accessible to all care team members
• Reviewed every 6 months |

Tracking the patients with change concepts in place was fairly straightforward: teams were asked to identify the enrolled patients with change concepts in place and document. Tracking the quality of implementation was harder. Asking teams to indicate which core elements were in place required too much documentation.

To measure how many of the core elements and recommended changes teams implemented, there would have been more than 20 process measures. IHI recommends 10 or fewer measures for monthly data collection – one or two outcome measures, 5-7 process measures, and balancing measures when appropriate. The team settled on asking for the average number of core elements per enrolled patient for each change concept. This assumes the registries could track how many were in place for each patient at each site and an average would require a relatively simple calculation.

A quality score was developed that combined both the overall adoption of the change concept as well as the number of core elements adopted. Line charts like Figure 2 were generated each month to indicate progress towards the combined quality score goals. The quality score could exceed 100 percent if teams exceeded the goal threshold for number of core elements adopted.

Two additional measures were added to the QI process measure collection each month. These included self-reported hospital days and ED visits from their hospital systems. Project organizers knew this data would underrepresent medical utilization due to patients using ad-
ditional health systems, but there was consensus that capturing this data monthly would be beneficial to observing trends and understanding if the outcome measure goals were being met versus waiting on the up to two years data lag for claims data.

Control charts like Figure 3 were generated each month to understand how changes in adoption rates were associated with key project milestones from baseline (May 2015-February 2016); change package adoption (March 2016-September 2016); change package penetration (beginning October 2016, a 75 percent score was reached by the collaborative as a whole for the change package).

**Process Measure Evolution**

Within the 32-month project, important changes and measures were refined and added to the change concepts. Other measures were retired.

The following change package enhancements were created for the last 10 months of the CARE Award. Seven related process measures were tracked:

- Developing care plan goals to address family priorities
- Understanding family decision making and challenges related to utilization of services (especially ED use)
- Providing information to support increased patient/family participation in symptom recognition and management.

These new measures were adopted quickly because teams were involved in their development, ensuring added feasibility of data collection (see Enhanced Measures).

**Balancing Measures**

Because efforts to reduce cost can often cause inadvertent decreases by reducing services or striving solely for efficiency, balancing measures of family and provider satisfaction and family HRQOL are important to consider.
IMPLEMENTATION

The data collection burden for collaborative participants was high. However, through use of an online data tracking website, bimonthly meetings, data analytic support, regular faculty feedback for teams, and biannual in-person meetings, teams remained engaged and achieved high participation rates for each measurement area. Table 3 indicates the types, administrations, and successes of each metric group.

<table>
<thead>
<tr>
<th>Measurement area</th>
<th>Type of assessment</th>
<th>Frequency of data collection</th>
<th>Success rate</th>
</tr>
</thead>
<tbody>
<tr>
<td>Family experience with care and health-related quality of life</td>
<td>Online or telephone survey, 33% random sampling of enrolled patients; changed to 50% midway through award</td>
<td>3; baseline, midpoint, final</td>
<td>90% resurvey rate</td>
</tr>
<tr>
<td>Utilization and cost of healthcare services</td>
<td>Claims data collected from states or Medicaid managed care organizations</td>
<td>Quarterly</td>
<td>10 states/managed care organizations provided data for 100% of hospital sites</td>
</tr>
<tr>
<td>Adherence to the principles of a medical home and provider well-being</td>
<td>Medical Home Index survey completed by clinics based on consensus among staff.</td>
<td>4; baseline, wave 2, wave 3, final</td>
<td>94% resurvey rate</td>
</tr>
<tr>
<td></td>
<td>Physician Worklife Survey completed by providers at participating hospitals and PCPs.</td>
<td>3; baseline, midpoint, final</td>
<td>100% of teams responded</td>
</tr>
<tr>
<td>Care delivery transformation</td>
<td>15 initial measures</td>
<td>Monthly</td>
<td>75% reporting reached by month 7 100% reporting reached by month 13</td>
</tr>
<tr>
<td></td>
<td>7 new measures, added final year of The Award</td>
<td>Monthly</td>
<td>100% reporting reached by month 2</td>
</tr>
<tr>
<td></td>
<td>Hospital days and ED use from hospital information systems</td>
<td>Monthly</td>
<td>90% of teams provided data every month</td>
</tr>
</tbody>
</table>

Table 3: Collaborative Measurement Summary

Photo: Juan Pulido, Children’s Health Children’s Medical Center Dallas, Dallas, Texas
RESULTS

Family Experience with Care and Health-Related Quality of Life

The domains were scored using instructions created by the survey developers so that the lowest possible score was 0 and the highest score was 100. Statistically significant improvements were seen in the unadjusted results of several domains from baseline to final survey administration using a paired t-test. Despite statistical significance, the increases were numerically small. There are many possible reasons for this: some of the baseline scores were already very high, decreasing the opportunity to show improvement. In addition, some areas including how well families function or a parent’s emotional state may be much less sensitive to the change package interventions. When adjustments were made for differences at sites and across population groups, many of the improvements can be attributed to site or group differences. For more information on the adjusted results, see Appendix E. Table 4 includes an overview of the unadjusted results where we saw statistically significant improvements.

Utilization and Cost of Healthcare Services

Hospital days and ED discharges declined through the course of the collaborative. Claims data tracking showed declines in utilization similar to hospital system tracking. Preliminary results from the analyzed claims data are available in the CARE Award Executive Summary.

Adherence to the Principles of the Medical Home and Provider Well-Being

Overall, the collaborative average and all team scores on the MHI rose between baseline and final administration. Domain scores increased across the group, with higher scores occurring at complex care programs than primary care practices in general, but larger jumps occurring for PCPs. The largest improvement occurred in community outreach and chronic condition management. Table 5 includes an overview of the MHI improvements between baseline and final administration for the whole collaborative.

The Physician Worklife Survey showed no major differences in satisfaction or well-being from baseline to final. The results were not paired or attributable to individuals.

<table>
<thead>
<tr>
<th>Survey</th>
<th>Domain</th>
<th>Baseline score</th>
<th>Final score</th>
<th>p-value</th>
</tr>
</thead>
<tbody>
<tr>
<td>CAHPS</td>
<td>Patient Access</td>
<td>76.2</td>
<td>78.8</td>
<td>.029</td>
</tr>
<tr>
<td>FCCA</td>
<td>Decision Making Interaction*</td>
<td>84.8</td>
<td>87.0</td>
<td>.001</td>
</tr>
<tr>
<td></td>
<td>Strength-based Approach to Care</td>
<td>85.4</td>
<td>87.4</td>
<td>.013</td>
</tr>
<tr>
<td></td>
<td>Overall*</td>
<td>84.4</td>
<td>86.4</td>
<td>.003</td>
</tr>
<tr>
<td>PEDSQL-FIM</td>
<td>Daily Activity*</td>
<td>56.1</td>
<td>59.0</td>
<td>.001</td>
</tr>
<tr>
<td></td>
<td>Physical Functioning</td>
<td>69.3</td>
<td>69.7</td>
<td>.004</td>
</tr>
<tr>
<td></td>
<td>Worry</td>
<td>66.7</td>
<td>68.1</td>
<td>.014</td>
</tr>
<tr>
<td></td>
<td>Communication</td>
<td>57.1</td>
<td>59</td>
<td>.005</td>
</tr>
<tr>
<td></td>
<td>Overall*</td>
<td>72.3</td>
<td>73.2</td>
<td>.008</td>
</tr>
</tbody>
</table>

*Indicates that statistical significance was maintained after adjusted analysis.
Care Delivery Transformation

Adherence to the change concept measures increased consistently across all sites, and at the aggregate PCP and Complex Care levels using the quality score previously described. A quality score of 100% meant the goal of 90% of enrolled patients had “high quality” Dynamic Care Teams (DCT), access plans, and care plans in place (therefore, scores could exceed 100% if teams exceeded this goal). This goal was reached at both the PCP and Complex Care sites for DCTs by the proposed deadline of 11/2016. Four of the 10 sites reached all goals at both the PCP and Complex Care level. By March 2017, the overall average for each change concept was “on target” for the goal (scoring at least 80%) and they were declared completed to focus on the change package enhancements and evolved process measures. Table 6 includes an overview of these results.

According to self-reported utilization data, hospital days and ED discharges both declined during implementation of care delivery transformation efforts, with hospital days decreasing more than ED use. Utilization results from October 2015-September 2016 (considered baseline) were compared with results from October 2016- November 2017 (considered final) because an aggregate score of 90% on the change package was reached in October 2016. See Table 7.

<table>
<thead>
<tr>
<th>Table 5. Medical Home Index Results</th>
</tr>
</thead>
<tbody>
<tr>
<td>Domain</td>
</tr>
<tr>
<td>--------</td>
</tr>
<tr>
<td>Overall</td>
</tr>
<tr>
<td>Organizational capacity</td>
</tr>
<tr>
<td>Chronic condition management</td>
</tr>
<tr>
<td>Care coordination</td>
</tr>
<tr>
<td>Community outreach</td>
</tr>
<tr>
<td>Data management</td>
</tr>
<tr>
<td>Quality improvement</td>
</tr>
</tbody>
</table>

Note: percent equals (final baseline)/(baseline) *100.

<table>
<thead>
<tr>
<th>Table 6. Process Measures Results</th>
</tr>
</thead>
<tbody>
<tr>
<td>Change concept</td>
</tr>
<tr>
<td>----------------</td>
</tr>
</tbody>
</table>
| Dynamic Care Team | PCP: 8% Score  
CC: 66% Score | PCP: 123% Score  
CC: 124% Score | PCP: 129% Score  
CC: 128% Score |
| Access Plan | PCP: 0% Score  
CC: 39% Score | PCP: 80% Score  
CC: 77% Score | PCP: 97% Score  
CC: 100% Score |
| Care Plan | PCP: 2% Score  
CC: 34% Score | PCP: 75% Score  
CC: 77% Score | PCP: 86% Score  
CC: 96% Score |

<table>
<thead>
<tr>
<th>Table 7. Self-Reported Utilization Results</th>
</tr>
</thead>
<tbody>
<tr>
<td>System</td>
</tr>
<tr>
<td>--------</td>
</tr>
<tr>
<td>Hospital Information Systems</td>
</tr>
<tr>
<td></td>
</tr>
</tbody>
</table>
MEASUREMENT RANKINGS
Following completion of the collaborative, project participants were asked to rank the various metrics using measure selection criteria validated across various industries and supported by CHA:

**Importance:** If there is improvement in this metric, does it really translate into improved performance/care? Does it move the needle in the bigger picture outcomes? Is it valuable to measure this population of children?

**Usefulness for taking action/making change:** As teams regularly use this measure, how easily does it capture if a change has happened? Would it be indicated quickly and clearly? If a team sees variation in this measure, is that variation definitely linked to the performance, or could it be from other areas?

**Feasibility:** The cost of using the measure and ease of using the measure. How much time, money, energy, etc does it take to collect the data for this? Is this something that can be automatically collected and monitored, or does it mean a physical collection process each time it needs to be measured?

**Continued Use:** Rank the likelihood of continued metrics use after the CARE Award ended.

Nine of the 10 participating sites responded; this included 20 hospital site project directors, project research managers, care coordinators, primary care practice representatives and parent participants.

In addition to this assessment at the end of the Award period, throughout the entire learning collaborative, key staff and users were periodically interviewed to better understand the facilitators and barriers to survey data collection. Adjustments were made when possible and necessary. The following summarizes results from measurement rankings and input.

**Family Experience with Care and Health-Related Quality of Life Ranking**
Table 8 shows results of the measure-ranking survey by metric category, with scores converted to a percentage with 100% being the highest possible user rating, and 0% being the lowest.

Respondents indicated they would likely continue to use some version/components of the patient experience survey, but the individual modules only received continued use scores of 28.6% (FECC) to 50% (CAHPS), despite the relatively high importance ratings for these modules. This could mean several things, including that the modules were not optimal for users in terms of feasibility or users did not believe they had influence/resources to move the needle for these metrics.

Administering surveys is generally viewed as important, but difficult, and therefore feasibility concerns exist. Multiple avenues for survey completion were initially tried in the project: families could respond using an online survey tool or could take the survey over the phone, which was conducted by a subcontracted vendor. This process was only somewhat successful (25% of all surveys completed) with families failing to respond to vendor emails and calls. To increase survey respondents, the CARE Award team purchased tablets for each hospital. Hospital staff then conducted the surveys with parents, either in person or via phone. Families received a $25 gift card for each survey completed. Establishing an efficient process for providing

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**Table 8. Ranking Results: Family Experience and HRQOL**

<table>
<thead>
<tr>
<th>Metric Description</th>
<th>Importance score (n=8)</th>
<th>Usefulness score (n=7)</th>
<th>Feasibility score (n=8)</th>
<th>Continued use score (n=8)</th>
</tr>
</thead>
<tbody>
<tr>
<td>CARE Family Survey Tool</td>
<td>78.6%</td>
<td>66.7%</td>
<td>43.8%</td>
<td>58.3%</td>
</tr>
<tr>
<td>CAHPS: Clinician &amp; Group Survey Domains</td>
<td>71.4%</td>
<td>66.7%</td>
<td></td>
<td>50.0%</td>
</tr>
<tr>
<td>Family Centered Care Assessment by Family Voices (FCCA) Domains</td>
<td>68.8%</td>
<td>66.7%</td>
<td></td>
<td>42.9%</td>
</tr>
<tr>
<td>COE4CCN Family Experiences with Coordination of Care (FECC) Survey Domains</td>
<td>68.8%</td>
<td>64.3%</td>
<td></td>
<td>28.6%</td>
</tr>
<tr>
<td>Pediatrics Quality Of Life Family Impact Module (PEDSQL FIM) Domains</td>
<td>64.3%</td>
<td>42.9%</td>
<td></td>
<td>42.9%</td>
</tr>
</tbody>
</table>
the tablet and gift cards took time, and caused some frustration for participating site project teams. During the project, those responsible for administration indicated that the following strategies improved the survey process:

- Offering a larger incentive
- Someone known to the patient distributing or administering the survey
- Survey administration occurring immediately upon patient consent to join CARE
- Families being surveyed while they were in the clinic
- Survey calls being administered from a hospital phone number rather than a vendor number

Respondents ranked every domain of the survey high on importance. The portions rated most important were the provider access and patient provider communication domains of the CAHPS survey, along with the care plans domain of the FECC survey and the family summary score from the PEDSQL FIM.

CAHPS is generally administered in some form at most hospitals, so most sites find it more feasible than other survey instruments. Patient access to, and communication with, providers are generally more actionable concepts than provider attitudes or patient needs. Respondents and results are crucial to improving outcomes for families. Recent attention has been given to this area, and the FECC survey (and others like it) has been validated to provide results for practices.

The FECC survey was ranked highly. Some issues did arise with correlating the number of final responses to the baseline responses in the care plan questions.

The FCCA survey instrument ranked higher in importance than it did in usefulness for making change. Most CARE Award sites will not continue to use this instrument. Measuring how well family-centered care occurs is important, but addressing deficits takes organizational commitment and may be more difficult to influence in a short period of time.

Of all the survey domains, those in the PEDSQL FIM were ranked the least useful for making change. Despite several studies confirming reliability and validity, many institutions are reluctant to use the survey, possibly because parent functioning and emotional health are not areas where health care providers typically consider themselves having a direct effect. However, the tool is recommended when undergoing a large-scale care redesign (like the CARE Award) because it can be useful for understanding families and the challenges they face in caring for a child with a medically complex condition. Additionally, it may be useful as a balancing measure when undergoing cost-cutting endeavors.

Most respondents indicated they would continue to use some type of patient experience survey, with CAHPS provider access being the most likely from this group of domains.

### Utilization and Cost of Healthcare Services Ranking

Table 9 shows results of the measure-ranking survey by metric category, with scores converted to a percentage; 100% is the highest possible user rating, and 0% is the lowest. In addition to criteria used above, utilization metrics reviewers were also asked about the face

<table>
<thead>
<tr>
<th>Table 9. Ranking Results and Utilization Measures</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Importance score (n=10)</strong></td>
</tr>
<tr>
<td>-----------------------------------------------</td>
</tr>
<tr>
<td>Inpatient days (from hospital data system)</td>
</tr>
<tr>
<td>Emergency department discharges (from hospital data system)</td>
</tr>
<tr>
<td><strong>Claims Data</strong></td>
</tr>
<tr>
<td>Inpatient admits</td>
</tr>
<tr>
<td>Emergency department visits</td>
</tr>
<tr>
<td>All office visits</td>
</tr>
<tr>
<td>Home health days</td>
</tr>
<tr>
<td>Prescriptions filled</td>
</tr>
<tr>
<td></td>
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</tbody>
</table>
validity of the metrics. This means they were asked to consider the extent to which the measure fits appropriately with its intended use and intended level of analysis (individual practitioner, hospital, health plan, health system, etc.) Also important to consider was the extent to which it provides useful information for the intended population of children.

The variability of face validity scores for these metrics is not surprising considering the varying roles of the survey respondents. For example, claims data might appear less valid for providers and program directors (who took this survey more often) than it does for system administrators.

Overall, for inpatient days and ED visits, only 55.6% and 66.7% respondents would continue to use the measure, while 50% indicated they would like to continue to use claims data. Accessing claims data proved to be expensive and time consuming, despite up front payer commitments. Issues related to the acquisition and use of claims data were:

- Claims reporting lagged actual utilization of healthcare services by enrollees by up to two years.
- The varied quality of data received from the states and MCOs made processing a challenge.
- The data sharing agreements with the states required multiple iterations and required involvement of hospital legal teams.
- States agreed to provide data under the guise of the CARE Award, but may be reluctant to provide outside of this project.
- Due to the high cost of obtaining and cleaning claims data, almost all CARE Award programs will not be able to continue to collect it.

Access to utilization and spend data is imperative for understanding the efficiency and effectiveness of both new care delivery and payment models. Access to claims data is also necessary for actuarial risk modeling in the development of risk-based payment models.

Hospital days and ED usage are important metrics for CMC. Hospitalization comprises the largest spend category for these patients. ED usage may be an indicator of the extent to which rising risk or patient fragility is managed, and the extent to which other non-hospital services are available to the patient/family. The literature to date shows promise that better care management can decrease utilization in these two categories. However, when considering CMC utilization, some overall principles are necessary to consider:

- Many admissions for this population are unavoidable or even planned
- Many ED visits are the product of parents making a correct, informed decision based on the advice of their PCP

Most respondents indicated that tracking hospital days and ED usage was important and useful when addressing the needs of this population. Hospital admissions and length of stay may be considered, in addition to hospital days, to understand the results better and effectively assess outliers. CARE Award sites conducted ED visit follow-up phone calls to determine the extent to which the ED visit was avoidable and why. This was a crucial part of analyzing ED utilization and making effective changes, focusing on timely family access to providers with knowledge of their child. Additionally, many sites reported successful behavior change after working with frequent ED users to identify root causes of avoidable ED usage.

Most hospitals plan to continue tracking utilization metrics within their own system to address the quality and cost of their CMC services. However, without tracking services outside the system, such as outpatient visits, home health and pharmacy, up to two-thirds of the spend for these patients may be missed.

### Adherence to the Principle of the Medical Home Ranking Results

Table 10 shows results of the measure-ranking survey by metric category, with scores converted to a percentage with 100% being the highest possible user rating, and 0% being the lowest.

Several studies have shown the benefit of the MHI for evaluating medical homeness and leading QI initiatives in practices. The tool is designed to be completed by consensus among team members representing all practice areas. While its results are useful to track progress over time, it’s not meant to compare practices to each other or average several practice scores.

Most teams indicated the MHI survey process was

<table>
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<tr>
<th>Table 10. Ranking Results: Medical Home Index</th>
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<tbody>
<tr>
<td>Importance score</td>
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<tr>
<td>Medical Home Index Survey (n=5)</td>
</tr>
</tbody>
</table>
useful and they would continue to use it whether or not they seek medical home certification (70% continued use score). Several teams reported using the tool to identify gaps in their care processes and process redesign. The survey was administered four times throughout the CARE Award, and many practice teams had completed it (or a similar version) multiple times before as part of other improvement initiatives. This made the task more straightforward for those teams, and many were glad to understand and complete something without additional effort. Some teams reported issues with the amount of times the survey was administered, but only when it was hard to get the team together for a meeting to reach consensus. This occurred at some smaller sites or clinics with less engaged team members.

Some sites had a domain or overall scores decrease, which is considered normal during a collaborative as teams begin to understand the breadth of their gaps and potential areas for improvement. These decreases, however, could indicate potential reliability issues if different groups or teams took the survey each administration.

While most of the teams completed the MHI to the best of their abilities, and with the most representative group possible, there was some misunderstanding among Practice Transformation Facilitators (PTF) about the instructions they gave to the sites. Therefore, several practices completed the survey by averaging many people’s answers or having the person in charge complete the assessment on their own, instead of a consensus process. After identifying this as an issue during waves 1 and 2, the concept was addressed during team calls and work sessions, but it still appears to have happened on later administrations. This is not ideal because it takes away the crucial consensus-building approach that considers all levels of patient care.

Provider Well-Being Ranking Results
Table 11 shows results of the measure-ranking survey by metric category, with scores converted to a percentage with 100% being the highest possible user rating, and 0% being the lowest.

The PWL survey was administered three times during the CARE Award, and at least nine out of 10 sites were represented in each administration. The survey was administered anonymously due to site-specific institutional review board (IRB) requirements, so no direct comparison of providers was performed. Issues arose because the survey was developed for physicians, not all medical providers, so initially Nurse Practitioners (NP) were not instructed to take the survey. They were later included, but it is unclear what percentage of respondents was NPs. Respondents indicated that it was not a useful or important survey for the CARE Award activities, and taking it was cumbersome. They also indicated they would not continue to use the survey (0.0% continued use score).

Care Delivery Transformation
Table 12 shows results of the measure-ranking survey by metric category, with scores converted to a percentage with 100% being the highest possible user rating, and 0% being the lowest.

Most respondents indicated they would continue tracking these metrics, with 78.6% continuing to use care Plans, 68.8% continuing to use access plans and 56.3% continuing to use DCTs.

Measure reporting began in April 2015 as sites began to enroll patients. There were issues at first with clarification of measure meaning, but by October 2015 most teams were reporting consistently and accurately. When surveyed, most respondents indicated they would continue to measure the amount of change concepts in place for this population.

Respondents indicated that tracking the number of access plans was important to care transformation. A more comprehensive method rather than tracking the number of core elements would have been valuable to determine how useful these are to families. Especially useful for teams was the concept of a contingency
plan, which emerged during change package enhancement and provided families with detailed plans about urgent and emergent scenarios.

Similarly, respondents indicated that care plan volume and quality is important to track. Progress towards goals proved to be the most difficult area for teams to effectively measure, even with sophisticated electronic medical record (EMR) systems.

Patient registries and DCTs are valuable concepts, but effort is needed to make them truly useful. A dynamic registry concept updated regularly and used by the DCT to manage the population would be very valuable. Setting it up to not require extra work and documentation can be challenging with many EMR systems. And, EMRs typically only allow for communication with in-network providers when triggered, limiting DCT communication.

Respondents also indicated that family follow-up calls after ED usage were useful for taking action and making change, but that the feasibility of such activities was low or there were too many other phone calls/surveys occurring from the hospital system for the family to handle. This is consistent with survey administration – the effort is sometimes more than a clinic can sustain. Because of the usefulness of the technique however, it is recommended that a sampling technique be used to ensure that some families are contacted for follow-up after ED use.

Collecting hospital days and ED discharge data at the hospital system was very successful even though hospitalizations and ED visits at outside hospitals were not captured in the claims data. The hospital based data did mirror the trends shown later in the claims data and was useful as a more “real time” measure of utilization which allowed for more timely adjustments to the change concepts. Some sites had issues getting the data reports quickly, but project leaders were able to advocate on behalf of the research managers to receive this data when needed. One site was not able to collect hospital utilization data for the entirety of the CARE Award, but nine were able to do so in a timely manner.

**Change Concept Adherence**

Teams measured both overall adoption of the change concepts, as well as the number of core elements adopted within each change concept. There was confusion as to how change concept adherence was measured. Several teams simply tracked the number of core elements that they knew were present in all their plans. This underestimated a true average by neglecting to count those plans that had additional elements. Others used their registry to check element by element and had a true average of core elements present by plan. Some only counted the plans where they knew every element was in place. This later overestimating their quality but underestimated their quantity. The variance in methods led to confusion between teams and among reviewers about where the quality was lagging. Since only a total number of core elements in place was measured at first, additional discussion during collaborative meetings was needed to determine which core elements were proving most challenging to implement. This led to difficulty in reporting progress and resulted in developing the combined quality score referenced above.

**Documentation of Change Concept Adherence**

When the care delivery transformation metrics were developed, faculty expected that they would be tested on paper before being incorporated into hospital or PCP EMR software. Most teams elected not to use this intermediate step and delayed documentation of adherence until it could be implemented in the EMR. EMR changes took a considerable amount of time, and they typically required several iterations before providers could support them. This changed the introduction of change concepts at several sites. However, the implementation of documentation of change concept adherence in the EMR did help to facilitate change concept sustainability over time.

**OVERALL RECOMMENDATIONS AND CONCLUSION**

Table 13 includes a summary of metric recommendations, taking into account the user experiences as described.

The measures described in this paper proved to be valuable and provided important information for the participants. In almost all the measurement areas, key issues arose concerning feasibility, usability, and measurement burden. Overall, the biggest area of concern for participant sites was that the resources and effort required to maintain this measurement set were not sustainable. Teams indicated they needed a more parsimonious measure set containing feasible, usable and actionable items. The recommended set of measures outlined in this paper is an attempt to propose this more limited set of measures. However, the success of this, or any proposed measurement
set, will depend on additional research to better validate a reduced number of measures as well as the development of new measures that can more efficiently evaluate outcomes in this population.

Although modest improvements were seen in nearly all measured areas, there is still a question of how sensitive these measures are to care transformation. This is particularly true for patient-centered outcomes such as patient experience or family impact. For this three-year initiative, change may be more dependent on the disease trajectory of the child or the impact of social determinants of health. It may be that new measures that assess areas such as family well-being will be needed to better document the impact of care transformation on families.

All CARE Award sites were concerned about the extent of resources needed to collect the CARE Award data and the low likelihood of being able to sustain this level of effort over time. If efforts like this are to continue, more efficient and seamless ways to collect both claims data and patient-centered data will be necessary. Health plan data with EMR data are needed to assess the impact of care model change on the total cost of care.

Documentation of care management work flows in the EMR is needed. While not required, many sites used reports from their EMRs to enhance their CARE Award data collection, with mixed success. The ability to integrate the EMR into the process of care coordination needs to be examined further.

Hospitals must develop new means to engage families in assessing the outcomes of care transformation. Development of patient portals, the use of telehealth encounters, and greater attention to the social determinants of health will likely help the field better understand the relationship between changing the way care is provided, and the health and well-being of the child and family.

<table>
<thead>
<tr>
<th>Table 13. CARE Metric Ranking Findings</th>
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<tr>
<td><strong>Area of Measurement</strong></td>
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<tr>
<td>Family Experience with Care and Health-Related Quality of Life</td>
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<tr>
<td></td>
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<tr>
<td>Utilization and Cost of Healthcare Services</td>
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<tr>
<td>Adherence to the principles of the medical home and provider well-being</td>
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<tr>
<td>Care Delivery Transformation</td>
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</table>
Assessing family experience with health care and health related quality of life (HRQOL) remains a challenge. There is a dearth of surveys addressing these topics that have been validated in children with medical complexity (versus the larger pediatric population). Because of the multifaceted nature of both family experience and HRQOL, multiple surveys may be needed to provide a comprehensive assessment. This however is time consuming and for many families is not feasible. The combination of domains from multiple surveys, as was done in the CARE Award, offers one possible solution. Unfortunately, within the CARE Award survey, there were several subsets of items that had not been previously validated. Hopefully future research will yield surveys that are both valid for this population and are feasible to administer to families.

To improve survey feasibility for families, incentives must be used and the survey must have several options for how and where families can take it.

Health care claims data remain the gold standard for the analysis of the spend in health care, however, the burden for collection of this data is high both in terms of cost and time/effort and will be difficult for individual hospitals to sustain. Until the lag time can be reduced and becomes less costly to access claims data, hospitals will need to rely on their own information systems. Even though the CARE Award has demonstrated the value of internally derived measures of hospital days and ED visits, the inability to capture spend in categories may result in an incomplete picture of healthcare spend.

Care transformation by its very nature mandates the repeated collection of data that documents both the trends in the adoption of change concepts and the evaluation of small tests of change. This requires an assessment of the number of sites that have adopted a change concept over time as well as the fidelity of the change to the core attributes of the change concept. For the CARE Award, a combined metric was created that tracked both the rate of change concept adoption, the fidelity of the adopted change concept and implementation quality. The EMR should be utilized to track the data in a more efficient fashion when possible.

Capturing the participant experience with metrics is a very important way to understand why they are or are not being used optimally, and to garner buy-in from those individuals who collect data. Seeking user input as often as possible is a good way to keep teams engaged, especially if you are able to adjust and enhance the measures for improved project performance.

1. Assessing family experience
2. To improve survey feasibility
3. Health care claims data
4. Care transformation
5. Capturing the participant experience
**CARE Award Defined**
The Coordinating All Resources Effectively (CARE) Award is a landmark national collaborative project aimed at improving quality outcomes and reducing the cost of care for children with complex medical conditions enrolled in Medicaid funded by the Center for Medicare and Medicaid Innovation. Children’s Hospital Association partnered with 10 of the nation’s leading children’s hospitals, eight state Medicaid programs and Medicaid managed care organizations, more than 40 primary care practice sites, and 8,000 children and their families.

The CARE Award was designed to transform care through the provision of appropriate, coordinated care in the right setting, and develop alternative payment models that more effectively align with the new care model.

**Participating Sites**
- Children’s Hospital Colorado (Aurora, CO)
- Children’s Mercy Kansas City (Kansas City, MO)
- Children’s National Medical Center (Washington, DC)
- Cincinnati Children’s Hospital Medical Center (Cincinnati, OH)
- Cook Children’s Hospital Medical Center (Fort Worth, TX)
- Lucile Packard Children’s Hospital Stanford (Palo Alto, CA)
- UCLA Mattel Children’s Hospital (Los Angeles, CA)
- St. Joseph’s Children’s Hospital (Tampa, FL)
- Children’s Hospital of Philadelphia (Philadelphia, PA)
- Wolfson Children’s Hospital (Jacksonville, FL)
CARE Change Concepts Defined

Care transformation in the CARE Award was built on a set of closely related change concepts designed to be developed jointly with families and providers.

1. Each CARE site will have a patient registry
Registries are essential tools for population assessment and management, and quality improvement, both within individual practices and across the continuum of care.

2. Every child/family will have a dynamic care team (DCT)
Care of children with complex needs requires an effective, informed and coordinated team. The family drives the composition of the DCT and is a critical partner to other members of the team. DCT membership is representative of the care continuum that includes health care, and community and educational, providers. DCT members recognize each other by name and role, and have effective systems for timely communication among team members.

3. Every family will have an access plan containing three components:
   a. An after-hours access plan that describes how and when to contact the appropriate clinical provider for health care issues. Every patient and family needs to know who to contact and how to contact them to access the right provider for the right care at all times. A provider must be available 24/7. The access plan should include a listing of all DCT members with contact information and preferred method of contact to expedite access to care.

   b. A contingency plan that contains instructions for parent action when the child experiences a change in condition. It describes how and when to contact the appropriate clinical provider for health care issues. These plans are developed from scenarios suggested by families that are likely to result in their child going to the ED. The contingency plan should contain actions to prevent an acute exacerbation, actions if an exacerbation occurs, and what to do if the child does not improve, e.g. when to call 911 or take the child to the ED. It would also outline the accommodations needed for other children in the house, notification of family members, etc.

   c. An emergency care plan that provides essential information for emergency responders or ED personnel who are not familiar with the child to expedite effective treatment and communication with the child’s medical home/subspecialty providers. This includes a brief medical history and description of child’s baseline condition, current medications, common presenting problems with suggested diagnostic studies and/or treatment, procedures to avoid, important family preferences, a list of the child’s physicians/their contact information and an advanced directive form.

4. Each family will have a care plan based on patient/family goals developed via a shared process between clinicians and child/family
There is a standardized approach (including standardized documents) to care planning used with every child and family. Goals are developed from the assessment of family needs and assets for care planning. Providers and the child/family have the same understanding of roles and acknowledge the same patient goals. Care plan includes action steps to assist child/family attainment of goals. Families and providers across the care continuum have access to the care plan.
Change Package March 2015
and Change Package Enhancements February 2017

<table>
<thead>
<tr>
<th>Change Concept</th>
<th>Each Site will have a Patient Registry</th>
</tr>
</thead>
<tbody>
<tr>
<td>Guiding Principles</td>
<td>Registries are essential tools for population assessment and management and quality improvement, both within individual practices and across the continuum of care. Registry content needs to be reviewed and updated at regular intervals and with major changes with the patient/family; content needs to be current, accessible, and consistent across care settings.</td>
</tr>
<tr>
<td>Core Elements</td>
<td>(1) Patient Demographics: Name, DOB, address, telephone/e-mail contacts, primary family caregivers/legal guardian with preferred contact information. (2) Date of last registry review/update at least every 3 months. (3) DCT roster with contact information; last date of review/update, indication of sharing of access roster with all DCT members. (4) Current Locus of care management, recent changes in LOM (dates), use of LOM checklist to facilitate changes. (5) Status of Care Coordination Needs and Assets survey. (6) Status of care plan development with recommended core elements; date of last review. (7) Hospital admissions for children in registry during the last reporting period; DCT notified of these hospital admissions. (8) Date of last review/update of dynamic care team (DCT) with family.</td>
</tr>
<tr>
<td>Actions</td>
<td>• Enter all patients within one month of enrollment &amp; verify registry information at least every 3 months. • Develop &amp; maintain patient demographic information, DCT roster, and current locus of care management (LOM) status. • Track status of patient/family needs and asset driven care plan development and currency of care plan information review. • Monitor changes in locus of care management (LOM) and use of transfer checklist to facilitate change. • Monitor currency of DCT information and its’ use to communicate information re: any hospital admissions occurring during reporting period to relevant DCT members.</td>
</tr>
<tr>
<td>Measures</td>
<td>1. # new patients entered in registry/total # enrolled patients. 2. Average number of core elements captured (max =8) per patient registry entry. 3. # enrolled patients with registry verified as reviewed in past 3 months/# total enrolled patients.</td>
</tr>
<tr>
<td>Goals/targets</td>
<td>1. By 5/31/15, 100% of patients enrolled in the CARE program will be entered into the registry on a monthly basis. 2. By 8/31/15, 80% of patient registry entries will have 88% (7/8) of registry elements captured. 3. By 8/31/15 90% of enrolled patients will have regularly verified/updated registry entries.</td>
</tr>
<tr>
<td>Change Concept</td>
<td>Every child/family will have a dynamic care team (DCT)</td>
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<td>-----------------------------------------------------</td>
</tr>
<tr>
<td><strong>Guiding Principles</strong></td>
<td>Care of children with complex needs requires an effective, informed, coordinated team. The family is a member of the DCT. Determination of DCT membership is a shared-decision that includes parents, patients and providers. DCT membership is representative of the care continuum that includes healthcare, community and educational providers. DCT members recognize each other by name and role.</td>
</tr>
</tbody>
</table>
| **Core Elements** | • A list of team members are generated by the family and the provider. Both providers and parents cross-validate level of DCT involvement.  
  o (1) Core—actively involved in goal setting and information exchanges  
  o (2) Advisor—periodically informed of patient status  
  • (3) A mechanism is developed that enables team members to access list of DCT members that includes contact information. Examples:  
    o EHR application as available  
    o Email distribution  
    o Electronic Patient Portal  
    o Family DCT Card  
  • (4) Protocol developed as to how and when to trigger team communications—for example:  
    When  
    o Change in health status  
    o Admission to the hospital  
    o Urgent family request  
    o Care coordination challenge  
    How  
    o Email distribution  
    o Epic Inbasket or other similar EHR application  
    o Parent/Provider Electronic Portal  
  • (5) Protocol developed re how to update DCT—for example  
    o Review at clinic  
    o 3 month review  
    o Parent alert to PCP or clinic staff  
    o Ongoing update with parent/provider accessed electronic portal |
| **Actions** | • Develop dynamic care team (DCT) in collaboration with patient/family and validate membership roles  
  • Ensure access to DCT information by all team members  
  • Develop protocols for triggering team communications and updating DCT members |
| **Measures** | 4. # of enrolled patients with designated DCT / total # of enrolled patients  
  5. Average number (max=5) of core elements implemented per patient DCT  
  6. # enrolled patients hospitalized in reporting period whose DCT were notified of admission/Total # of enrolled patients hospitalized within reporting period |
| **Goals/targets** | 4. By 10/31/2015 80% of enrolled patients have a documented DCT  
  5. By 10/31/2015, 80% of documented DCTs for enrolled patients will have 80% (4/5) of core elements implemented  
  6. By 12/31/15 90% of DCTs will be notified when enrolled patients hospitalized |
<table>
<thead>
<tr>
<th>Change Concept</th>
<th>Every family will have an access plan that describes how and when to contact the appropriate clinical provider for health care issues (may be contained within the care plan)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Guiding Principles</td>
<td>Every patient and family need to know who to contact and how to contact them in order to access the right provider for the right care needed at all times. Provider who is knowledgeable of the child/family must be available 24 x 7 for contact</td>
</tr>
</tbody>
</table>
| Core Elements | • (1) Listing of all DCT members (core and advisory) with contact information and preferred method of contact  
• (2) Communication plans negotiated with family for specific emergent, urgent, routine and newly risen medical issues  
• (3) Review of access plan every 6 months or when there is a change in LOM |
| Actions | • Develop Access Plan in collaboration with family  
• Monitor effective use of Access Plan per routine established with family  
• Review Access Plan every 6 months or when there is a change in LOM |
| Measures | 7. # enrolled patients who have an access plan /total # enrolled pts  
8. Average number (max=3) of core elements implemented per patient access plan |
| Goals/targets | 7. By 12/31/15 80% of enrolled patients have documented access plans  
8. By 12/31/15, 80% of access plans for enrolled patients will have 100% (3/3) of core elements implemented |

<table>
<thead>
<tr>
<th>Change Concept</th>
<th>Each family will have a care plan based on shared goals between clinician and family</th>
</tr>
</thead>
</table>
| Guiding Principles | Improve communication across primary and specialty care  
Every patient has access to care coordination services and patient /family know when and how to reach different providers  
There is a standardized approach (including standardized documents) to care planning that is used with every patient and family  
Providers across the care continuum have access to the care plan  
Providers and patient/family have same understanding of roles, acknowledge same patient goals  
Actions where possible should be based on evidence-informed guidelines or expert consensus statements, with input from all members of the DCT |
| Core Elements | All care plans should include shared development of short and long term patient centered goals and:  
• (1) Specify a set of actions, a completion date, and accountable individual with each goal  
• (2) Include a narrative clinical summary  
• (3) Address developmental, educational and environmental concerns as well as health care related issues  
• (4) Be updated at a minimum of every 6 mos or with major changes in health status  
• (5) Have a process for tracking progress toward and/or completion of goals  
• (6) Include a protocol of care including plan for visit/phone contact frequency  
• (7) Document sharing/use of evidence-based guidelines or care protocols to guide |
interventions and standardize care across the continuum

- (8) Be accessible to all members of the DCT
- (9) Incorporate findings from completed care coordination and asset survey

### Actions

- Develop a care plan that contains patient-centered goals, specific goal-focused actions, plan for patient visits/contacts, current narrative summary, findings from needs/asset survey, other related patient healthcare issues and evidence-based intervention guidelines as available
- Develop system to monitor responsibility for elements of the plan, progress toward and/or completion of goals and update of plan at least every 6 months or with major changes in health status
- Ensure care plan content is accessible to all DCT members

### Measures

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<thead>
<tr>
<th>Measure</th>
<th>Description</th>
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<tbody>
<tr>
<td>9.</td>
<td># enrolled patients with completed Care Coordination Needs and Assets survey / total # enrolled patients</td>
</tr>
<tr>
<td>10.</td>
<td># baseline CMC program patients enrolled in CARE with care plans created/updated according to the guidelines / total # baseline CMC program patients enrolled in CARE</td>
</tr>
<tr>
<td>11.</td>
<td>The number of new patients enrolled in CARE who have care plans that were created according to the guidelines / The total number of new patients enrolled in CARE</td>
</tr>
<tr>
<td>12.</td>
<td>Average number of core elements implemented per patient care plan (max = 9)</td>
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### Goals/targets

<table>
<thead>
<tr>
<th>Goal/Target</th>
<th>Description</th>
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<tbody>
<tr>
<td>9.</td>
<td>By 10/31/15, 90% of enrolled patients have a completed Care Coordination Needs and Assets survey completed</td>
</tr>
<tr>
<td>10.</td>
<td>By 9/30/15, 25% of baseline CMC program patients enrolled in the CARE project will have care plans that were completed/updated according to the guidelines</td>
</tr>
<tr>
<td>11.</td>
<td>By 9/30/15, 100% of all new enrolled CARE patients will have completed care plans according to the guidelines</td>
</tr>
<tr>
<td>10/11.</td>
<td>By 12/31/15, 95% of all enrolled CARE patients will have care plans according to guidelines</td>
</tr>
<tr>
<td>12.</td>
<td>By 12/31/15, 80% of patient care plans for enrolled patients will have implemented 89% (8/9) of core elements</td>
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### Change Concept

**Transitions of Care including changes in locus of care management**

In the context of on-going co-management, transitions in the locus of care management (e.g. from the complex care clinic to community-based primary care or from pediatric-based care to adult-based care) or in the setting of care (e.g. from hospital to home) will be safe, seamless, and clearly understood by all members of the DCT (children's hospital-based, community-based, family)

### Guiding Principles

A uniformly high 24/7 standard of care is maintained through all transitions and across all settings and viewed as such by patients and family

Health and wellness goals developed in the care planning process are maintained across all changes in the locus of care management or the setting of care and drive all aspects of care (preventive care; acute care; chronic condition care; emergent care; hospital care) Partnership is maintained among all core members of the dynamic care team, particularly the family
| Core Elements | Transitions of care follow evidence-informed practices with actions derived from a family-centered care planning process  
• (1) Transitions of care utilize a checklist of actions for the originating team and the receiving team; care responsibility remains with the originating team until confirmed acceptance by the receiving team  
• (2) New or changed roles for members of the Dynamic Care Team are discussed with family, agreed upon, and clearly articulated  
• (3) Communication lines (email, telephone) are clear and utilized on a regular/scheduled basis and access plans are updated as needed  
• (4) Care planning process remains on-going with regular updates  
• (5) Locus of management is explicitly designated  
• (6) Protocols for care are provided when needed including emergency management plans  
• (7) Decision support to community-based primary care team is timely, consistent, and accessible and matches the support needs of team  
• (8) Primary care and specialty consultation are available 24/7 to other members of the team and family |
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<tbody>
<tr>
<td>Actions</td>
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</table>
• Create and implement a checklist of actions for use by all teams and patient families during a locus of care management transition.  
• Monitor and communicate new or changed roles/responsibilities for Dynamic Care Team and update access plans as necessary with change in LOM  
• Ensure explicit designation of responsibility for LOM, care planning with regular updates, emergency management plans and primary care and specialty consultation 24/7 |
| Measures | 13. # patients who have had transition in LOM /total # patients enrolled  
14. # patients with documented checklist completion with LOM transition / total # patients with documented transition in LOM  
15. Average number of core elements of checklist implemented during a LOM transition (max = 8) |
| Goals/targets | 13. By 9/30/15, 95% of patients with LOM transition will have documented completion of transition checklist  
14. By 12/31/15, 90% of LOM transition checklists completed will implement 88% (7/8) of core elements |
Key Driver diagram

Primary Drivers

- Enhanced Patient Experience with Care
- Improved Quality of Life for CMC
- Decrease caregiver burden
- Improved Integration with Behavioral Services
- Provide care closer to home and at lower cost
- Payment Model that Sustains High Quality Care and Rewards Savings
- Decreased Utilization of Health Services

Secondary Drivers

- Dynamic Care Team
- Core teams tailored to venue of care
- Shared information and status Across the Team
- Care Coordination Needs and Assets Assessment
- Shared Care Plans and goals
- Patient Registries for Population Management
- Pathways to access care; who, where, when
- Connect families to needed mental and behavioral health service
- Enhanced Care Planning During Transitions
- Protocols to Transfer Locus of Care Management Between Complex Care Program and Community Pediatric Sites
- New Negotiated Risk-Based Payment Models
- Timely Sharing of Utilization/Cost Data

Healthier Children
Better Care
Smarter Spending

CAHPS/ FECC
Peds QL
Peds QL Family Impact Scale
Care Coordination Needs and Assets Assessment
Medical Home Index Short Form
Health Care Utilization and Costs
Patient and Family Experience Survey Unadjusted Results

Patient Experience Survey Results
Baseline to Final

Click to open
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