Coordinating All Resources Effectively for Children With Medical Complexity (CARE Award)

Building Data to Manage a Pediatric Population

November 2016

Learn about the data processes in this pilot effort to manage a specific population of children, funded by the Center for Medicare and Medicaid Innovation (CMMI). The knowledge gained can support future efforts for improving the financing, organization and delivery of care for children with medical complexity. Within the CARE Award, teams constructed the development of data resources specifically to monitor care management factors leading to appropriate utilization to both decrease the burden on families and impact the spend trajectory for state Medicaid programs. Ultimately, these data sources will also inform options for new population-based payment models.

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Introduction

The overall aim of the Coordinating All Resources Effectively (CARE) for Children with Medical Complexity project, funded by the Center for Medicare and Medicaid Innovation (CMMI), is to inform sustainable change in health care delivery with new care management techniques supported by new payment models. The 10 CARE Award children’s hospitals and Children’s Hospital Association (CHA) are focused on improving care and reducing unnecessary spend for children with medical complexity (CMC). This paper captures lessons learned in developing the data and informatics framework needed to understand population-based care for these children. The data framework allowed the monitoring of project results which may influence the way health care for this population is financed, organized and delivered.

Within the data framework, four domains or types of data were identified for collection and evaluation. This paper describes in detail the development of the framework, the four domains of data, and the lessons learned for long-term sustainability of future similar efforts. Measurement, reporting and resource requirements for the overall effort are also addressed.

First Data Domain | Enrollment Data
Identifying the population is critical to understanding the outcomes from care management and potential to impact spend on a population basis.

Second Data Domain | Survey Data
Survey data were collected to provide insights on patient/family experiences, physician work-life balance and medical homes. These indicators signal the extent of care transformation and the impact on both families and providers.

Third Data Domain | Care Transformation Data
Industry experts in the care of CMC and CARE participants moved through a collaborative process to develop an initial change package to support care delivery transformation efforts. The change package includes five concepts: patient registry, dynamic care teams, access plans, care planning and transitions of care. For each change concept, guiding principles, common core elements of change and quality measures were developed. These five change concepts are foundational to impact long-term project goals.

Fourth Domain | Claims Data
Claims data were collected to identify cost and utilization patterns as well as variance across patient groupings. CARE teams worked with the states/managed care organizations (MCOs) to access patient identifiable data detail across the continuum of care.

The combination of the data framework and these four data sources is expected to reveal how health care can be shaped to achieve better care, smarter spending and healthier children – the overall aim of the CARE Award.
1. CARE Informatics Framework

1.1 A Children’s Hospital Perspective on Data Detail

“I am interested in participating in the CARE Award for three reasons: (1) We have a ‘no sparrow shall fall’ philosophy. As we transform care we want to be able to expand our radar to avoid missing care management opportunities for any child in our service area. To do this, we need to develop a structured registry approach which is one aspect of the award. (2) This is our dress rehearsal for the STAR Kids Program starting in 2016 where our Supplemental Security Income (SSI) population is moved to managed care. We can use this as a learning opportunity to make a more positive experience for this population. (3) We want to demonstrate Triple Aim results for this population given its unique attributes including evolving or escalating medical, family and social needs.

In our organization we are interested in understanding the role of culture and biology in a child’s development. For this population, it is sometimes difficult to improve their physical status. But we can understand the impact of epigenetics and work toward a holistic approach which benefits the family and thus maximizes the child’s development. Family experience is the key to maximizing health outcomes and development.

Structures and measures with specific populations, due to heterogeneity of certain attributes, have to be broken down to pinpoint what is important in order to provide optimal health care. Success in health care transformation through comprehensive study requires analysis at the individual patient level (e.g., physical, psychosocial family and health care structure elements) and as well as aggregate. Each stakeholder involved in the change process has a separate interest: providers want to know the optimal care delivery structures; payers want to know which measures are important; states/managed care organizations want to know the informatics elements to capture and how to set-up data sources; the Centers for Medicare & Medicaid Services (CMS) team wants to understand efficiencies and appropriate utilization. Monitoring the individual pieces that collectively impact the care model uncovers what influences the changing dynamics. This level of monitoring pinpoints how to create a sustainable health care delivery system that helps a child to reach his or her full developmental potential.”

-Larry Tubb, Senior Vice President, System Planning, The Center for Children’s Health, Cook Children’s Health Care System
1.2 The Population Focus for CARE

An estimated 13 to 18 percent of all children in the U.S. have special health care needs (children with special health care needs (CSHCN)) as identified using a definition developed by the Maternal and Child Health Bureau (MCHB). Within the CSHCN group exists a smaller group, children with medical complexity. Approximately two-thirds of all children with medical complexity are covered by Medicaid. Although these children represent only six percent of the total pediatric Medicaid population, they incur 40 percent of Medicaid spending on children. Inpatient care represents up to 80 percent of their costs.

1.3 Informatics Goals for CARE Success

An increasing number of children’s hospitals have developed hospital-based CMC programs to address the challenge of meeting intense medical and care coordination needs for this population. Nine of the 10 CARE Award hospitals have such a program (one has a virtual CMC program) and are looking to expand care management to the primary care setting and align the payment model to support the necessary infrastructure. While the results of care improvement programs have been promising, little is known about the incremental benefits that could be achieved from comprehensive reform of both care delivery and reimbursement.

Through participation in a collaborative learning and improvement community within the CARE Award, practice transformation facilitators (PTFs) are helping to translate change concepts with the Quality Improvement (QI) teams at the primary care practice level. Primary care practices are being supported through initial quality improvement initiatives via shared resources for practice improvement and care coordination. Collaborating children’s hospitals are providing tools and guidance to support the care of these children within the community including the evidence-based practices and other system innovations. The CARE project is helping to build this infrastructure for expansion.

The overall aim of the project is to inform sustainable change in health care delivery through new payment models supporting improved care and reduced costs for CMCs. This translates to three goals: better care, smarter spending and healthier children. By improving the overall quality of care for the identified CMC population, the CARE team hopes to reduce unnecessary spend, minimize the number of emergency department (ED) visits, enhance the patient/family experience and decrease family burden. Figure 1 displays these three goals and the primary drivers needed to achieve them.
1.3.1 CARE Informatics Framework Structure

To create the infrastructure needed for care delivery and payment model reform, the following informatics framework was built (Figure 2). The framework supports the capture of project results and helps teams understand what elements are important to obtain based on a definitional framework of CMC developed by researchers Eyal Cohen⁴ and Jay Berry⁵. Cohen describes health and quality of life as centered on care management being shared between a medical home, transitional care facilities, rehabilitation units and community habitats (e.g., home, school). The CARE Award data domains represent a subset of the elements captured in definitional framework quadrants.
1.3.2 Clinical Risk Groups for Population Definition

Many researchers historically identified less than one percent of the pediatric population as having the most complex medical conditions. CHA selected the following categorization for CMC which includes a bit broader representation of the population with varying health characteristics and complexity of needs. The 3M Clinical Risk Group (CRG) grouper⁶, depicted in Figure 3, is a categorical clinical system that classifies individuals into mutually exclusive categories and assigns each person to a severity level if s/he has a chronic health condition. CMC in the project are identified as CRGs 5b-9. Other groupers commonly used in research studies include: Complex Chronic Conditions⁶ (CCCs) and Pediatric Medical Complexity Algorithm⁷ (PMCA).

**Figure 3**

<table>
<thead>
<tr>
<th>MEDICAL COMPLEXITY</th>
</tr>
</thead>
<tbody>
<tr>
<td>NON-CHRONIC (CRGs 1,2)</td>
</tr>
<tr>
<td><strong>Brief Description</strong></td>
</tr>
<tr>
<td>Acute conditions that will not last one year</td>
</tr>
<tr>
<td>Chronic conditions that will last one year and are likely to be episodic in manifestation</td>
</tr>
<tr>
<td>Potentially curable with adequate treatment</td>
</tr>
<tr>
<td>Not likely to last into adulthood</td>
</tr>
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</table>

From an analytics perspective, the five categories are easy to use and relevant when evaluating cost and utilization in claims data for care management purposes. CRGs give analytic insight on spend management and utilization.
1.3.3 Study Design Embedded in Framework Development

Health services researchers will also use the CARE Award data to conduct a research study that has been approved by the Institutional Review Board (IRB). The target population will consist of enrolled children in the age group 0-21 meeting the criteria for CRGs 5b-9. Using repeated measures, the study objective is to document the effect of the implemented CARE model.

Primary outcome measures consist of (1) patient experience as measured on the CAPHS Patient-Centered Medical Home (PCMH) survey (child version and children with chronic conditions supplement), PedsQL Family Impact Module, (2) quality of life as measured by the PedsQL and (3) payments which will include total medical expenditures, inpatient hospitalization, ED visit, and primary and specialty care office visit expenditures.

Secondary outcome measures consist of (1) provider experience as measured by the Physician Work-life Survey, (2) health services utilization as measured by ED visits, inpatient hospitalizations, hospital days, unplanned hospital readmission rates, inpatient length of stay, number of primary care and specialty care office visits, and (3) receipt of appropriate preventive services.

1.3.4 Informatics Framework Timeline

Monitoring the changes in both care delivery and reimbursement across 10 hospitals in seven states and Washington, D.C., over three years for the highest spend pediatric population required significant dedication to removing obstacles and keeping momentum in data acquisition and analytics. Although there have been some delays due to acquisition of claims data and ramp-up of change concepts, the project is on track to fulfill data needs to measure end term goals. Figure 4 displays the current timeline, actual completions and projected targets.
2. Data Acquisition Across the Four Domains

The role of data is to measure, monitor, inform and direct. It is used to build models, forecast and provide support for predicted/tested outcomes. The CARE Award data sources are used collectively to target the challenge of caring for CMC, allowing for analytics to be run at the patient level. Obtaining this level of specificity is new to the industry in terms of identifying the opportunities for care management for this population. For the CARE Award, the process for data acquisition across the four domains is as follows:

- State claims data are submitted securely to a contracted claims data support consulting firm. These data are then sent securely to CHA.
- Hospital enrollment data are submitted securely to the same consulting firm to match to the claims data, and enrollment data are also transmitted securely back to CHA.
- Patient/family experience survey data are collected securely by both a third-party vendor and the hospitals and are transmitted securely back to CHA.
- Data related to the care delivery change concepts are managed through CHA’s quality improvement project using an external vendor for data collection, management and reporting. Data are extracted and moved into CHA’s reporting tool to monitor and communicate progress and trends. The data contain no personal health information.

All inbound and outbound data files and reports are transferred using a secure FTP server at CHA and controlled by specific user access. An archive policy is in place to delete files from the server at a predetermined timeframe. A process is in place for the deletion, and documentation of the deletion, of all identifiable data after August 31, 2020 or earlier if required under individual data sharing agreements. Figure 5 illustrates the networking of the data sources, measures and goals for the CARE Award.

**Figure 5**
2.1 Domain 1: Enrollment Data

Patient level data detail is essential to understand the varying nature of the disease states and multiple conditions potentially presenting in any one child. The CMC population represents less than six percent of the pediatric population but is quite heterogeneous in both medical and psychosocial needs. For the CARE Award, patient level data were acquired to provide the best opportunity for understanding the correlation of the change concepts to specific subsets of the population. Additional effort was required to adhere to necessary privacy regulations in obtaining and working with this level of data detail. In addition, states/MCOs required extensive documentation on the criticality of patient level claims data within the data sharing agreements.

- **Key Takeaways**: Accessing patient level detailed data for the project to link across utilization, patient experience and care management change concepts is necessary to understand the impact of care management due to significant variations in each child’s condition.

2.1.1 Collection & Structure

A patient listing form was structured to accurately match patients with claims data and identify providers responsible for patient care management. The fields represent the minimum set of patient information to confirm matching capability. At each site, research managers enrolled CMCs by recording information on the patient listing form and securely transferring that form to the claims data vendor. The vendor, which directly receives data coming from states, then matches patient names with claims data for reporting. Table 1 lists requested information on the patient listing form which dictated how the enrollment data would be structured.

<table>
<thead>
<tr>
<th>Field Name</th>
</tr>
</thead>
<tbody>
<tr>
<td>Enrollee Number</td>
</tr>
<tr>
<td>Patient Last Name</td>
</tr>
<tr>
<td>Patient First Name</td>
</tr>
<tr>
<td>Patient Middle Initial</td>
</tr>
<tr>
<td>DOB (mm/dd/yyyy)</td>
</tr>
<tr>
<td>Gender (M. F)</td>
</tr>
<tr>
<td>Policy Number</td>
</tr>
<tr>
<td>Patient Consent Obtained</td>
</tr>
<tr>
<td>Enrolled Date (mm/dd/yyyy)</td>
</tr>
<tr>
<td>Dis-enrollment Date (mm/dd/yyyy)</td>
</tr>
<tr>
<td>Reason for Dis-enrollment</td>
</tr>
<tr>
<td>Care Management Duration</td>
</tr>
<tr>
<td>CMC Classification (Reason for Enrollment)</td>
</tr>
<tr>
<td>Patient Primary Contact Last Name</td>
</tr>
<tr>
<td>Patient Primary Contact First Name</td>
</tr>
<tr>
<td>Patient Primary Contact Email</td>
</tr>
<tr>
<td>Patient Primary Contact Phone Number (Numeric Format)</td>
</tr>
<tr>
<td>Primary Contact Relationship to Patient</td>
</tr>
<tr>
<td>Preferred Primary Language (Primary Contact)</td>
</tr>
</tbody>
</table>
Within enrollment, it was necessary to construct certain parameters so that the data would correlate with other data sources used in the overall analysis of care management. Demographic information was requested as it accurately ties to claims data coming in from the states. The primary care physician (PCP) was needed to understand where the majority of care management was taking place and to monitor only the changes in the focus of care management. Family contact information was used for the distribution of the patient experience survey and language in communication. Duration of care management provided clarity around the impact of the CARE Award versus previous care management techniques. Lastly, enrollment status, which became a very critical question for the survey data source, signaled when a patient dis-enrolled from the project.

2.1.2 Sustainability Check

Enrollment
This process captured the necessary information to align with the analytics of the claims data and patient/family experience.

2.2 Domain 2: Survey Data

Success of the CARE model will be partially assessed using a collection of measures obtained through three independent surveys: Patient/Family Experience Survey, Physician Work-life Balance Survey and Medical Home Index Survey. These surveys provide information regarding project implementation as well as provider, staff and patient attitudes, behaviors and experiences. Overall, these data are the basis for the project outcome measures for purposes of quality improvement and project evaluation.

- Key Takeaways: Capturing the patient/family experience is one of the most important outcomes for the project in terms of prioritizing family-centered care and recognizing the chronic and complex nature of the child where improvement of the condition may not occur.
2.2.1 Collection & Structure: Patient/Family Survey, Physician Survey and Medical Home Index Survey

**Patient/Family Survey**

The impact on the patient/family experience is one of the primary outcome measures. As change concepts are being implemented at the clinics, the patient/family experience is being monitored to determine the improvement of health and well-being of children and families/caregivers. The Patient Experiences with Care Survey is a compilation of four different surveys: Pediatric Quality of Life Family Impact Module (PedsQL FIM), Family Experience with Coordination of Care (FECC), Family Voices Tool (FV Tool) and Consumer Assessment of Healthcare Providers and Systems (CAHPS). Subject matter experts knowledgeable in the clinical provision of care, system structures and family experiences selected the specific domains and questions for the survey.

**ISSUE OF CARE COORDINATOR SERVICES – FECC**

**Sample Question 1:** In the last 12 months, did you know how to contact the person who helped you with managing your child’s care when you needed help or had a question?

- a. Yes
- b. No

**ISSUE OF PATIENT ACCESS – CAHPS**

**Sample Question 2:** In the last 12 months, how often were you able to get the care your child needed from this provider’s office during evenings, weekends or holidays?

- a. Never
- b. Sometimes
- c. Usually
- d. Always

**ISSUE OF CARE COORDINATOR SERVICES – FECC**

**Sample Question 3:** In the last 12 months, did the person in the main provider’s office who helped you with managing your child’s care seem informed and up-to-date about the care your child got from other providers? Would you say:

- a. Yes, definitely
- b. Yes, somewhat
- c. No

The Patient/Family Experience Survey tracks the patient experience at baseline, one-year and two-years from the time the patient/family consents to participate. The key outcome metric pulled from this survey is family burden - the goal is to improve family functioning in relation to overall care by 10 percent. Table 2 lists the methodology used for survey scoring.
### Table 2

<table>
<thead>
<tr>
<th>Survey</th>
<th>Methodology</th>
</tr>
</thead>
<tbody>
<tr>
<td>FECC</td>
<td>Weighted average of seven items concerning Care Coordination Services</td>
</tr>
<tr>
<td>CAHPS</td>
<td>Average of six items concerning Access to Care, Care, and Information (n=3) and How Well Providers Communicate with Patients (n=3)</td>
</tr>
<tr>
<td>Family Voices</td>
<td>Average of seven items concerning Strength-based Approach to Care (n=2), Family Support (n=1) and Shared Decision Making (n=4)</td>
</tr>
<tr>
<td>PedsQL Family Impact Module</td>
<td>Average of all 36 items</td>
</tr>
</tbody>
</table>

The process flow, illustrated in Figure 6, assures secure transfer and exchange of patient data.

**Figure 6**

[Diagram of process flow]
Physician Work-life Balance Survey

CMCs and their families develop close relationships with the primary care and complex care physicians. These physicians are at the center of care management and are entrusted with delivering care plans. The Physician Work-life Balance Survey monitors the burden on physicians and non-physician providers (e.g., nurse practitioners (NPs) and physician assistants (PAs)) as CMC enrollment ramps up and care coordination responsibilities increase.

Sample Question 1: Which of the following best describes your CARE Award role in the care of children with medical complexity?
   a. Primary care physician working at a hospital-based complex care clinic
   b. Specialist or subspecialist working at a hospital-based complex care clinic
   c. Primary care physician working at a primary care office
   d. Other (please specify)

Sample Question 2: During a typical week, about how many hours do you spend?
   a. In the office seeing patients?
   b. In the hospital seeing patients?
   c. On other patient-related activities (e.g., phone call, paperwork, consultation)?
   d. On other work-related activities (e.g., administration, teaching)?

The overall goal is for physicians to maintain a healthy work mindset while simultaneously incorporating changes in care management and increasing the intake of CMCs. To obtain this measurement, a calculated average of all four items in the global job satisfaction domain is used. The research manager coordinates the survey distribution (illustrated in Figure 7). Physicians are encouraged to take the survey twice per year.

Figure 7
Medical Home Index Survey
Many CMCs have multiple providers with limited cross-communication on the management of their care. The receipt of fragmented care may lead to both sub-optimal health and utilization of health services for the patient. Through the project, programs or sites are creating a community of information sharing and education. The Medical Home Index Survey assesses the ability of PCP offices and complex care programs to manage the care of CMCs.

Sample Question 1: Cooperative Management between Primary Care Provider and Specialist - Which level best describes your practice?
   a. Level 1 – Specialty referrals occur in response to specific diagnostic and therapeutic needs; families are the main initiators of communication between specialists and their PCP.
   b. Level 2 – In addition to Level 1, specialty referrals use phone, written and/or electronic communications; the PCP waits for or relies upon the specialists to communicate back their recommendations.
   c. Level 3 – The PCP and family set goals for referrals and communicate these to specialists; together they clarify co-management roles among family, PCP and specialists, and determine how specialty feedback to the family and PCP is expressed, used and shared.
   d. Level 4 – In addition to Level 3, the family has the option of using the practice in a strong coordinating role; parents as partners with the practice manage their child’s care using specialists for consultations and information (unless they decide it is prudent for the specialist to manage the majority of their child’s care).

Sample Question 2: Care Coordination/Role Definition - Which level best describes your practice?
   a. Level 1 – The family coordinates care without specific support; they integrate office recommendations into their child’s care.
   b. Level 2 – The PCP or a staff member engages in care support activities as needed; involvement with the family is variable.
   c. Level 3 – Care coordination activities are based upon ongoing assessments of child and family needs; the practice partners with the family (and older children) to accomplish care coordination goals.
   d. Level 4 – Practice staff offer a set of care coordination activities, their level of involvement fluctuates according to family needs/wishes. A designated care coordinator ensures the availability of these activities including written care plans with ongoing monitoring.

Each set of questions is translated to a score of zero to 100, with all 14 themes measured then averaged to calculate the total score. With implementation of each individual change concept, changes made through collaboration will hopefully drive improved Medical Home Index scores. Figure 8 shows the flow of the survey process.
2.2.2 Sustainability Check

**Patient/Family Survey:**

A. CARE Award teams began with an anonymous survey administration process using a third-party vendor, but moved to a more labor intensive survey process facilitated by CARE teams in an effort to boost survey participation. Teams worked tenaciously to make personal connections with families to explain the context for the survey and value to patient care for children with complex conditions and assuring them their responses would still be anonymous. This resulted in a sufficient increase to survey participation and the additional benefit of improved patient and family relationships.

B. The CARE survey design and content are not validated/agreed upon across the industry in totality. Providers must consider evolving available patient/family experience surveys to obtain (1) specific nationally recognized quality measures reportable to payers and (2) measures which support care management goals and enable continuous quality improvement.

**Physician Work-life Balance Survey:**

While the CARE Award team selected one survey instrument, this survey did not adequately address provider satisfaction (physicians and nurse practitioners) in terms of the movement toward optimal care coordination and population health. It should be expanded to reflect the entire care team experience.

**Medical Home Index Survey:**

Medical home surveys provide industry vetted standards and serve to address the multidisciplinary practice applications for wellness, prevention and coordinated care.
2.3 Domain 3: Care Transformation Data

The CARE Award concentrates significantly on care management techniques such as improved communication and coordination between specialists and PCPs, family access to providers, coordination on patient transfer and a patient/family care plan built on patient/family focused goals. The overall aim of the CARE Award is to inform sustainable change in health care delivery through new payment models supporting improved care and reduced costs for children with complex conditions. PCP offices work with on-site CMC programs for co-managing care and seamless transitions in the locus of care management for individual children as appropriate based on health status, shared goals and availability of resources.

- **Key Takeaways:** Successfully transforming care requires sustained effort and monitoring, robust implementation of QI methodology, and real-time data comparisons of progress. It is necessary to measure and account for both the implementation of the change concepts and the integrity of the underlying functions or interventions within each change concept.

2.3.1 Collection & Structure

The collaborative data provides quality improvement measures with a focus on data points within the five change concepts of the CARE Award. The data points will be used to conduct analysis across the full continuum of care and between all the players of the care team across the system. Table 3 represents a subset of the measurements associated with the five change concepts.

**Table 3**

<table>
<thead>
<tr>
<th>Five Collaborative Change Concepts Measures</th>
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<tbody>
<tr>
<td>Patients enrolled as program participant in practice registry</td>
</tr>
<tr>
<td>Percentage of patients with dynamic care team (DCT)</td>
</tr>
<tr>
<td>Percentage of patients with access plan</td>
</tr>
<tr>
<td>Patients with completed and updated care plans</td>
</tr>
<tr>
<td>Total patients with change in locus of care management</td>
</tr>
</tbody>
</table>

- Registries as a first step, then moving towards the use of electronic data systems are essential for population assessment and management and quality improvement, both within individual practices and across the continuum of care.
- Care of children with complex needs requires an effective, informed and coordinated team – including the patient/family. DCT membership is representative of the care continuum that includes health care, community and educational providers.
- The access plan identifies the contact to the appropriate clinical provider for health care issues at all times.
• Communication with the patient/family across primary and specialty care is emphasized through the care plan. Actions should be based on an assessment of care coordination needs and assets of the patient/family and where possible should be based on evidence-informed guidelines or expert consensus statements.
• Number of children with transitions in the locus of care management (e.g., from complex care to primary care) or the care setting (e.g., from hospital to home) point to maintenance of partnerships among core members and processes as changes in care are being made.

2.3.2 Sustainability Check

Collaborative:
Use of the existing Institute for Healthcare Improvement (IHI) collaborative web-based platform created efficiencies in monitoring progress across the 10 hospital sites and 50 primary care sites. The platform allowed for the accurate capture of needed data points to monitor (1) successful implementation of the CARE change concepts, (2) progress toward project goals to reduce ED and hospital utilization as a component of overall reductions in cost of care for CMC. Detailed self-assessments provided monthly by each CARE QI team via the platform also allowed faculty evaluators to access more detailed information on the change processes underway at each site and tests of quality being conducted to support change. Faculty, in return, provided QI teams with evaluation of these activities, offered suggestions and posed questions to support continued QI work, helped teams network on areas of common challenge, and identified issues for team education.

2.4 Domain 4: Claims Data

To produce data-driven decisions, the CARE Award analysts are acquiring, standardizing and conducting claims data analyses to understand the health care experiences of the targeted CMC population. The use of claims data is expected to detail the variability in resource utilization across patient segments, measure the impact of optimal care management, and identify optimal care delivery model options. Ultimately, the claims data will also assist in determining the construct of a value based payment model.

In a previous study of CMC data trends, CHA learned:

• The complex care business is complex and heterogeneous – “the eclectic nature of the complex population is striking.”
• Payment models will require analysis of variation within levels of complexity.
• The Medicaid business is substantially different from the commercial business, potentially emphasizing the impact of socioeconomic factors in patient management.

**Key Takeaways:** Overcoming challenges with collection, quality and comparability, teams believe claims data remain a vital component for population management results. The accurate analysis of data across the full continuum of care is necessary to understand the opportunity for improved care management, with lower spend in the care
of children within the program. This information is not readily available outside of the claims data. A foundation of trust enables the operational flexibility needed between the hospitals and the state Medicaid agencies. Leadership and open communication establishes shared views of urgency and supports this foundation. Overall, this work highlights the need for resources and well-developed data intake processes for state all payer claims databases or regional health improvement collaboratives to create standards across payers.

Claims Data Acquisition Strategies:

1. **Identify the data provider (who takes the responsibility):** state, all payer claims database, Medicaid managed care organization.
2. **Gain trust with key stakeholders.** Initial executive-level conversations should comprehensively cover use of the data to gain trust. Know what data you need and why you need it. Negotiate breadth of data available.
3. **Request and provide data sharing agreements and business associate agreements.** Identify the review process for both sides for completion.
4. **Plan to handle messy data.** Partner with an experienced claims data analytics team to identify, impute, standardize and risk adjust necessary data elements.
5. **Identify key questions data can answer.** Recognize a potential six-month acquisition timeframe plus ongoing data lag.

In approaching the payer for the data transfer process, Truven provided a layout template and worked with the payer to conduct a gap analysis for required fields. This afforded the quickest route for the receipt of data and the simplest route for payers to provide data. Table 4 lists the data requested from payers and its intended purpose.

**Table 4**

<table>
<thead>
<tr>
<th>Type of Data</th>
<th>Justification</th>
</tr>
</thead>
<tbody>
<tr>
<td>Membership Detail by Month (Policy ID, Date of Birth, Gender, Name)</td>
<td>Support care management operations</td>
</tr>
<tr>
<td>Dates in Day, Month, Year (Specify which date fields are needed and why.)</td>
<td>Accurately report utilization of services</td>
</tr>
<tr>
<td>Physician and Hospital Identifying Information</td>
<td>Attribute spending and utilization tied to physicians and hospital networks delivering services to the CMC population</td>
</tr>
<tr>
<td>Claims Line Detail</td>
<td>Support accurate reporting of health care utilization at a service level and roll up into service categories and to support accurate patient risk stratification</td>
</tr>
<tr>
<td>Allowed Amount</td>
<td>Support accurate reporting of total health care spending over time and quantify savings achieved due to the CARE interventions</td>
</tr>
</tbody>
</table>
2.4.1 Collection & Structure
Sites provided lists of facility and physician identifiers within their networks (shown in Figure 9 (Network Facility Data Collection Template) and Figure 10 (Professional Data Collection Template)). The payer sent three file layouts: medical, drug and eligibility. Together these data sources provided the information necessary to produce the CARE claims data reports.

Figure 9

Network Facility Data Collection Template

<table>
<thead>
<tr>
<th>Facility Name</th>
<th>CCN (Medicare Provider ID)</th>
<th>State Provider ID (If Applicable)</th>
<th>Facility Type (Hospital, SNF, Home Health, etc.)</th>
<th>Relationship (Owned or Affiliated)</th>
<th>Market or City (Optional - if Multiple)</th>
</tr>
</thead>
</table>

CMS Certification Number (CCN), Federally Qualified Health Center (FQHC), Skilled Nursing Facility (SNF)

Figure 10

Network Professional Data Collection

<table>
<thead>
<tr>
<th>Provider Last Name</th>
<th>Provider First Name</th>
<th>Provider Middle Initial</th>
<th>Credential (MD, DO, etc.)</th>
<th>Specialty</th>
<th>Physician Group (If Multiple)</th>
<th>NPI</th>
<th>State Provider ID (If Applicable)</th>
<th>Relationship (Employed or Affiliated)</th>
<th>Market or City (Optional - if Multiple)</th>
</tr>
</thead>
</table>

Use of claims data was structured around industry measures, a subset provided in Table 5.

Table 5

<table>
<thead>
<tr>
<th>Claims Data Measures</th>
</tr>
</thead>
<tbody>
<tr>
<td>Annualized unplanned hospital readmissions per 1,000 hospitalizations</td>
</tr>
<tr>
<td>Annualized number of ED visits per 1,000 patients</td>
</tr>
<tr>
<td>Per member per year (PMPY) total medical expenditures</td>
</tr>
<tr>
<td>Per member per year (PMPY) inpatient medical expenditures</td>
</tr>
<tr>
<td>Annualized ratio of inpatient to outpatient costs</td>
</tr>
</tbody>
</table>
Annualized number of inpatient days per 1000 patients

- Unplanned hospital readmissions were included due to the importance in measurement and payment for adults.
- ED expenses are monitored and may signal access, protocol or condition management issues (e.g., a child was not well monitored, a family was not properly instructed on how to identify emerging issues, or contact information for emergencies or questions was not provided).
- Medical expenses are monitored to determine if improved patient management decreases expenditures.
- Inpatient expenses represent the largest proportion of total cost of care for CMC. In most instances, keeping a child out of the hospital is the most preferred scenario regardless of expense.
- The direction of the ratio of inpatient to outpatient points to the amount of care being provided in the inpatient realm.
- The number of inpatient days is viewed as the most important measure due to the cost basis and burden of care. Utilization patterns are not measured by number of admissions or length of stay. Hospitalization occurs for a myriad of reasons and the objective is not to discourage necessary care.

2.4.2 Sustainability Check

State/ MCO data collection:

A high level of resource commitment to payer relationships in working through the process for data collection and updating is required. A high level of expertise is necessary to standardize and run quality checks among the data; therefore, outsourcing the claims reporting to Truven enabled quicker turnaround. Claims data are a must-have resource. No other known data source was currently available to understand utilization and spend across the continuum and in- and out-of-network spend. These elements are necessary to move to effective population-based care.

3. Measuring the Impact–Analytics & Reporting

The overall analytic objective is to conduct a longitudinal study using repeated measures to document the effect of the implementation of a new care model on patient experience, caregiver burden, provider experience, quality of life, utilization of health services and total cost of care in children with complex medical conditions. Table 6 lists the outcome measures used.
Table 6

<table>
<thead>
<tr>
<th>Outcome Measures</th>
<th>Data Source</th>
</tr>
</thead>
<tbody>
<tr>
<td>Patient experience as measured on the CAPHS PCMH survey (child version and children with chronic conditions supplement), PedsQL FIM</td>
<td>Survey</td>
</tr>
<tr>
<td>Quality of life as measured by the PedsQL FIM (measures family burden)</td>
<td>Survey</td>
</tr>
<tr>
<td>Payments which will include total medical, inpatient hospitalization, emergency department visit and primary and specialty care office visit expenditures</td>
<td>Claims</td>
</tr>
<tr>
<td>Provider experience as measured by the Physician Work-life Survey</td>
<td>Survey</td>
</tr>
<tr>
<td>Health services utilization as measured by ED visits, inpatient hospitalizations, hospital days, unplanned hospital readmission rates, inpatient length of stay, number of primary care and specialty care office visits</td>
<td>Claims</td>
</tr>
</tbody>
</table>

The nature of health care transformation in the project precludes the implementation of all transformation measures at a single point in time. Fifteen measures, at some point in time, will be implemented at each practice site.

3.1 Analysis Plan

The general analytic approach will be to assess changes in outcomes over time using interrupted or repeated time series methodologies. The specific statistical model for each outcome will depend on the underlying distribution of the outcome. All models will include a site-specific and practice-specific effect to account for any clustering of outcomes within site or practice. Furthermore, all models will be multi-variable models to adjust for potential changes in cohort characteristics over time that may be confounded with the effect of the CARE model implementation (i.e., rolling/incremental enrollment). Proposed covariates to be included in initial multi-variable models include the following: patient demographics (age at enrollment, race, gender, and median household income approximated by zip code), severity of medical complexity (CRG level, number and combination of complex chronic conditions), and length of enrollment in current care coordination program, if applicable.

Categorical variables will be described using frequencies and percentages whereas continuous variables will be described using mean, median, standard error (SE) and interquartile range (IQR) values, as appropriate. Descriptive comparisons of demographic information between pre- and post-CARE model implementation will be made using chi-square tests for categorical...
variables, the Wilcoxon sign-rank test for comparison of medians in non-normally distributed data, or a paired t-test for comparison of means in normally distributed data.

### 3.2 Reporting

Aggregated reports, as shown in Figure 11, comparing the changes in spending and utilization by general service categories (e.g., inpatient, outpatient, ER, primary care office visits, specialty care office visits, etc.) for the CMC population will be produced for a historical baseline and then quarterly. This information will be used to identify and track opportunities to improve quality and lower cost for the CMC population. Benchmarks have been produced for pooled data and a purchased national data set, MarketScan data. Table 7 and Table 8 (from the CHA CARE Report: Medicaid Pediatric Annual Utilization and Mean Spending High Level Comparison) represent claims data reference points from the first five hospitals to produce initial data on spending and utilization. There has been consistency across the hospitals when comparing patients enrolled.

**Key Takeaways** For utilization and spending, which vary from state to state depending on payment arrangements, the initial enrolled population has a five-fold higher proportion of children in the highest complexity category, CRG 9, than a national reference dataset.

Table 9 is a sample claims distribution of in-network and out-of-network spend for the enrolled population. Sites provided facility IDs and National Provider Identifier (NPIs) to identify network providers in the claims data. Data acquired from additional states/MCOs will be incorporated in the pooled data benchmark report to accurately reflect current utilization and measurement of project success.

**Figure 11**

<table>
<thead>
<tr>
<th>Report Title</th>
<th>Worksheet Name</th>
</tr>
</thead>
<tbody>
<tr>
<td>High Level Summary - Risk Group and Spending Distribution: Medicaid Pediatrics</td>
<td>High Level Summary</td>
</tr>
<tr>
<td>Medicaid Population Distribution</td>
<td>Pop Dist</td>
</tr>
<tr>
<td>Medicaid Pediatric Annual Utilization Summary</td>
<td>Summary Utilization</td>
</tr>
<tr>
<td>Medicaid Pediatric Annual Use Rate Summary</td>
<td>Use Rates</td>
</tr>
<tr>
<td>Medicaid Pediatric Payments per Beneficiary per Year by Service Category</td>
<td>Mean Spending</td>
</tr>
<tr>
<td>Primary Physician Summary for CMC Population</td>
<td>Primary Physician Summary</td>
</tr>
<tr>
<td>Primary Physician Utilization for CMC Population</td>
<td>Primary Physician Utilization</td>
</tr>
<tr>
<td>Primary Physician Use Rates for CMC Population</td>
<td>Primary Physician Use Rates</td>
</tr>
<tr>
<td>Primary Physician Mean Spending for CMC Population</td>
<td>Primary Physician Mean Snd</td>
</tr>
<tr>
<td>Facility Network Payment Distribution for CMC Population</td>
<td>Facility Network Payment Profile</td>
</tr>
<tr>
<td>Facility Detail Utilization for CMC Population</td>
<td>Facility Detail Utilization</td>
</tr>
<tr>
<td>Professional Network Payment Distribution for CMC Population</td>
<td>Prof Network Payment Profile</td>
</tr>
<tr>
<td>Outpatient Breakouts</td>
<td></td>
</tr>
</tbody>
</table>
### Table 7

<table>
<thead>
<tr>
<th>Claims Data 2012 – 2014</th>
<th>Person Years (N)*</th>
<th>Pooled Enrolled Population</th>
<th>Truven Health 12 State Medicaid Reference</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Person Years (N)</strong></td>
<td>1,494</td>
<td>100%</td>
<td>100%</td>
</tr>
<tr>
<td><strong>Health Status Group Distribution</strong></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>5b Significant Lifelong Chronic Disease</td>
<td>188</td>
<td>13%</td>
<td>$10,544</td>
</tr>
<tr>
<td>6 Significant Chronic Diseases in Multiple Organ Systems</td>
<td>848</td>
<td>57%</td>
<td>$27,138</td>
</tr>
<tr>
<td>7 Dominant Chronic Diseases in 3 or more Organ Systems</td>
<td>76</td>
<td>5%</td>
<td>$91,942</td>
</tr>
<tr>
<td>8 Dominant/Metastatic Malignancy</td>
<td>37</td>
<td>3%</td>
<td>$34,350</td>
</tr>
<tr>
<td>9 Catastrophic</td>
<td>345</td>
<td>23%</td>
<td>$75,609</td>
</tr>
</tbody>
</table>

*Person Years is based on annualized count of beneficiaries based on member months and counts each beneficiary for each year enrolled in Medicaid over a specified time period.

Pooled eligible and enrolled data are from five hospitals.
Table 8

<table>
<thead>
<tr>
<th>Claims Data 2012 – 2014</th>
<th>Pooled Enrolled Population</th>
<th>Truven Health 12 State Medicaid Reference</th>
</tr>
</thead>
<tbody>
<tr>
<td>Approx. 500 Enrolled Patients</td>
<td>Use / 1000</td>
<td>Spend / Bene</td>
</tr>
<tr>
<td>Service Category Use Rate and Mean Spend</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Inpatient Admits</td>
<td>657</td>
<td>$10,878</td>
</tr>
<tr>
<td>Inpatient Days</td>
<td>5,023</td>
<td>2,251</td>
</tr>
<tr>
<td>Inpatient LOS</td>
<td>8.0</td>
<td>10.6</td>
</tr>
<tr>
<td>Emergency Department Visits</td>
<td>1,749</td>
<td>$719</td>
</tr>
<tr>
<td>All Office Visits</td>
<td>9,378</td>
<td>$661</td>
</tr>
<tr>
<td>OP Facility Visits</td>
<td>236</td>
<td>$21</td>
</tr>
<tr>
<td>OP MHSA Visits</td>
<td>17,415</td>
<td>$1,811</td>
</tr>
<tr>
<td>OP OT, PT, ST Visits</td>
<td>17,265</td>
<td>$1,345</td>
</tr>
<tr>
<td>OP Radiology Services</td>
<td>2,976</td>
<td>$313</td>
</tr>
<tr>
<td>OP Lab Services</td>
<td>8,910</td>
<td>$241</td>
</tr>
<tr>
<td>OP Major Procedure Visits</td>
<td>690</td>
<td>$1,476</td>
</tr>
<tr>
<td>OP Injections and Medications Services</td>
<td>1,408</td>
<td>$142</td>
</tr>
<tr>
<td>Home Health Days</td>
<td>20,470</td>
<td>$4,814</td>
</tr>
<tr>
<td>Durable Medical Equipment Services</td>
<td>4,032</td>
<td>$2,219</td>
</tr>
<tr>
<td>Prescriptions Filled</td>
<td>37,717</td>
<td>$4,782</td>
</tr>
</tbody>
</table>

Pooled eligible and enrolled data are from five hospitals.

<table>
<thead>
<tr>
<th>Service Category</th>
<th>Owned Facility Payments</th>
<th>Out-of-Network Facility Payments</th>
</tr>
</thead>
<tbody>
<tr>
<td>Total Facility Payments</td>
<td>50.0%</td>
<td>50.0%</td>
</tr>
<tr>
<td>Inpatient</td>
<td>985.0%</td>
<td>5.0%</td>
</tr>
<tr>
<td>Total Outpatient (OP)</td>
<td>33.0%</td>
<td>67.0%</td>
</tr>
<tr>
<td>Emergency Department</td>
<td>90.0%</td>
<td>10.0%</td>
</tr>
<tr>
<td>OP Mental Health Service Act (MHSA)</td>
<td>10.0%</td>
<td>90.0%</td>
</tr>
<tr>
<td>OP Occupational, Physical and Speech Therapy</td>
<td>30.0%</td>
<td>70.0%</td>
</tr>
<tr>
<td>OP Radiology</td>
<td>99.0%</td>
<td>1.0%</td>
</tr>
<tr>
<td>OP Lab</td>
<td>99.0%</td>
<td>1.0%</td>
</tr>
<tr>
<td>OP Major Procedures</td>
<td>99.0%</td>
<td>1.0%</td>
</tr>
<tr>
<td>OP Injections and Medications</td>
<td>100.0%</td>
<td>0.0%</td>
</tr>
<tr>
<td>OP Other</td>
<td>90.0%</td>
<td>10.0%</td>
</tr>
<tr>
<td>Skilled Nursing Facility</td>
<td>0.0%</td>
<td>0.0%</td>
</tr>
<tr>
<td>Home Health</td>
<td>0.0%</td>
<td>100.0%</td>
</tr>
</tbody>
</table>
4. Skills & Staffing Expertise

4.1 Forecasting

In the year prior to the CARE Award, CHA engaged financial and actuarial consultants to evaluate utilization and spend data for the previous five years. These analyses laid the foundation for setting the CARE Award utilization and spending goals submitted in the project proposal. An external reviewer, as required by the award, validated these estimations. Dobson DaVanzo & Associates (DD), a health economics and policy consulting firm assisted with this analysis.

4.2 Managing Claims Data

Clinical, financial and analytical expertise was necessary for the evaluation and management of claims data to support appropriate use of resulting data reports.

*Type/Experiences*

- **Data collection**: Site payment champions
- **Data acquisition, standardization and reporting**: Truven Health Analytics
- **Data analytics**: CHA analytics team
- **Analysis of complex care delivery**: CARE physicians

*Estimated Expense*

- Approximately $3,000,000

*Timeframe*

- Three years

4.3 Supporting Survey Processes

Both the Qualtrics vendor and individual site research managers support distribution of the three surveys. An on-site iPad survey process was adopted to facilitate more timely survey responses.

*Type/Experiences*

- **E-mail and phone surveys**: Qualtrics
- **On-site iPad surveys**: Research managers
- **Project management**: CHA staff
**Estimated Expense**

- Approximately $150,000

**Timeframe**

- Three years

### 4.4 Reporting

The CARE Award supported resources for internal analytics, reporting and web-based data collection. CHA contracted with the Institute for Healthcare Improvement for their collaborative web product. CHA employed statistical and analytic staff and incorporated the use of Business Objects for reporting.

**Type/Experiences**

- **Database Administrator**: 0.16 FTE
- **Technical Support**: 0.08 FTE
- **Analyst, Reporting**: 0.08 FTE
- **Analyst, Project Evaluation**: 0.08 FTE
- **Analyst, Collaborative**: 0.08 FTE
- **Administrative Leader**: 0.5 FTE
- **Central data system**: web-based application for sharing data and viewing reports (IHI extranet)
- **Reporting tool**: licensed SAP Business Objects

**Timeframe**

- Three years
5. Conclusion

The future financing, organization and delivery of care for children with complex medical conditions depends upon adequate data resources to establish appropriate targets and measures in the movement toward value based care and population management. The data framework was designed with input from leading pediatric complex care researchers, industry leaders in data management and actuarial modeling, and families of children with complex conditions. The framework tests whether payer data sources can demonstrate the impact on utilization, spend and family well-being when changes in care delivery are made. The analytical tools and processes built upon the framework draw from published efforts over the previous five years analyzing utilization trends for complex children. The data framework serves as a starting point for state Medicaid programs, Medicaid managed care entities and children’s health systems working together to understand the optimal care management and financing of this high need pediatric population. Future papers will discuss lessons learned and key findings from the CARE Award efforts to transform care delivery and payment models as the project concludes.
Acknowledgments

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Truven Health Analytics
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Steven Martin
Kevin Miller
Ryan Olenski


7 Associated materials, including SAS code and instructions, are available here: http://www.seattlechildrens.org/research/child-health-behavior-and-development/mangione-smith-lab/measurement-tools/

8 Institute for Healthcare Improvement (IHI) Extranet. IHI is an independent not-for-profit organization for health care professionals and systems. http://www.ihi.org/Pages/default.aspx.


10 Truven Health MarketScan® Multi-State Medicaid Database of Medicaid patients under 18