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

Early Lessons Learned from the Project

September 2016

This publication was made possible by Grant Number 1C1CMS331335 from the Department of Health and Human Services, Centers for Medicare & Medicaid Services. The contents of this publication are solely the responsibility of the authors and do not necessarily represent the official views of the U.S. Department of Health and Human Services or any of its agencies. Pub # 2904, approved 12/14/2016.
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Introduction

Ten children’s hospitals and the Children’s Hospital Association (CHA) are transforming the health care delivery system to improve care for 8,000 children with complex medical conditions. This ambitious endeavor, benefitting children, families, providers and payers, is supported by a national Health Care Innovation Award (HCIA) from the Center for Medicare and Medicaid Innovation (CMMI). The Coordinating All Resources Effectively for Children with Medical Complexity Award (CARE Award) began September 1, 2014. The 10 partner hospitals set out to improve care and reduce costs for this pediatric population by engaging all stakeholders in the redesign of care delivery and payment models. This paper reviews the project purpose, design and achievements from the activation phase (the first 18 months of the project).
Delivery System Transformation

A National Imperative
While all children’s hospitals work to improve children’s health, the pace and approach by which hospitals implement strategies for creating a healthier pediatric population vary widely. Industry-wide, it is clear that shifting from volume-based to value-based care offers significant benefits for society while reducing unnecessary demands on the health system (Can Hospitals Heal America’s Communities?). In fact, 38 percent of children’s hospitals responding to a Children’s Hospital Association (CHA) survey on population health indicated they are putting payment models in place to support greater accountability for children’s health (CHA Population Health Survey). However, it is a very complex undertaking to simultaneously transform care delivery and the financial structure that supports it.

Improving Care for the Most Vulnerable Pediatric Patient Population
Of the nation’s 76 million children, three million have complex medical conditions. These children are vulnerable and have highly variable care needs. They frequently visit the emergency department (ED), which often results in hospitalizations. Their parents typically provide the bulk of care and provider communication, serving as the information hub for pediatric subspecialists and anyone else who provides care or services (figures 1-2). By improving care coordination with providers and families, children’s hospitals are positioned to reduce avoidable utilization, improve patient and family experience, and bend the cost curve in serving these children. However, new payment models are needed to support sustainable change.

Medicaid: The Payer of Interest
Of the three million children with complex medical conditions (CMC), two million are covered by Medicaid. Their numbers are small (six percent of total Medicaid enrollees) but their costs are high (40 percent of the medical spend in Medicaid) (figures 1-2). Medicaid serves as a critical payer for children with complex medical conditions because their medical needs often exceed the coverage available through private payers (Optimizing Health Care for Children with Medical Complexity).

Need for Sustainable Change
Fee-for-service reimbursement is aligned with current utilization and spending patterns. Demand for high quality, efficient care makes risk-based reimbursement and population health strategies appealing. However, executives involved in global risk today suggest financial sustainability will require scale, capacity, data, partners and knowledge of patients served (Children’s Hospitals Today). The amount of risk, if any, children’s hospitals should absorb is difficult to determine for the heterogeneous populations served. Nonetheless, alternative payment models are needed to support what clinical, operational and financial transformation can achieve -- healthier children, better care, smarter spending and the creation of value.
Figures 1 and 2
Family Impact, CMC Enrollment and Expenditures

Family Impact

14% of families spend 11 hours or more weekly on care coordination.

54% of families had a family member stop working to care for their child.

Children Utilizing Health Care

- 40% of all children depend on Medicaid.
- 6% of children on Medicaid are medically complex.

Distribution of Medicaid Funding for Children

- 60% of funds go to preventative and typical care for 94% of children on Medicaid.
- 40% of funds go to treat the 6% of children on Medicaid who are medically complex.

About the CARE Award

The 10 CARE hospitals (figure 3) and CHA initiated this project to help children’s hospitals and the broader health care industry understand the intricacies of payment and care delivery system reform for children with complex conditions. For many children’s hospitals, this serves as a first step in their approach to population health starting with an extremely important patient cohort.

**Figure 3**
About the CARE Hospitals

The partnering children’s hospitals manage children with complex medical conditions in a variety of ways – from supporting hospital-based clinics that have existed 10 or more years to having no clinic. They vary in their geographic reach, physician network structures and enrollment targets. Three hospitals are implementing new clinical programs (one is virtual) to coordinate the care for this specific pediatric population. More details on their complex care programs will be provided in future material.

<table>
<thead>
<tr>
<th>Hospitals</th>
<th>Licensed Beds</th>
<th>Medicaid % Patient Days</th>
<th>Admissions</th>
<th>ED Visits</th>
<th>Enrollment Target</th>
<th>CMC Clinic Tenure</th>
<th>Medical Home Certified</th>
<th>EMR</th>
</tr>
</thead>
<tbody>
<tr>
<td>Children's Hospital Colorado (Aurora, CO)</td>
<td>593</td>
<td>52.8%</td>
<td>17,593</td>
<td>85,141</td>
<td>1,578</td>
<td>Long-standing</td>
<td>State of Colorado</td>
<td>Epic</td>
</tr>
<tr>
<td>Children's Mercy Kansas City (Kansas City, MO)</td>
<td>354</td>
<td>53.8%</td>
<td>14,399</td>
<td>110,927</td>
<td>1,016</td>
<td>New</td>
<td>NCQA Level 3</td>
<td>Cerner</td>
</tr>
<tr>
<td>Children's National Medical Center (Washington, DC)</td>
<td>313</td>
<td>57.1%</td>
<td>15,609</td>
<td>123,032</td>
<td>773</td>
<td>Long-standing</td>
<td>NCQA Level 3</td>
<td>Cerner; eClinica I-Works</td>
</tr>
<tr>
<td>Cincinnati Children's Hospital Medical Center (Cincinnati, OH)</td>
<td>629</td>
<td>53.8%</td>
<td>19,427</td>
<td>166,038</td>
<td>1,080</td>
<td>Long-standing</td>
<td>--</td>
<td>Epic</td>
</tr>
<tr>
<td>Cook Children's Health Care System (Fort Worth, TX)</td>
<td>430</td>
<td>56.9%</td>
<td>10,337</td>
<td>100,619</td>
<td>471</td>
<td>New</td>
<td>--</td>
<td>Athena</td>
</tr>
<tr>
<td>Lucile Packard Children's Hospital Stanford (Palo Alto, CA)</td>
<td>302³ 4</td>
<td>43% ³ ⁴</td>
<td>13,644⁴ ³ ⁴</td>
<td>17,410⁴ ³ ⁴</td>
<td>860</td>
<td>Long-standing</td>
<td>--</td>
<td>Epic</td>
</tr>
<tr>
<td>Mattel Children's Hospital (Los Angeles, CA)</td>
<td>145²</td>
<td>55%²</td>
<td>4,200²</td>
<td>18,000²</td>
<td>485</td>
<td>Long-standing</td>
<td>In process</td>
<td>Epic</td>
</tr>
<tr>
<td>St. Joseph's Children's Hospital (Tampa, FL)</td>
<td>186²</td>
<td>62%²</td>
<td>7,615²</td>
<td>52,764²</td>
<td>900</td>
<td>Long-standing</td>
<td>Cerner; eClinica I-Works</td>
<td></td>
</tr>
<tr>
<td>The Children's Hospital of Philadelphia (Philadelphia, PA)</td>
<td>535</td>
<td>42.2%</td>
<td>22,478</td>
<td>80,949</td>
<td>411</td>
<td>New</td>
<td>Yes</td>
<td>Epic</td>
</tr>
<tr>
<td>Wolfson Children's Hospital (Jacksonville, FL)</td>
<td>233</td>
<td>57%</td>
<td>9,438</td>
<td>59,845</td>
<td>490</td>
<td>Long-standing</td>
<td>--</td>
<td>Epic</td>
</tr>
</tbody>
</table>

Sources: ¹ Children's Hospital Annual Benchmark Report, FY2015; ² CARE Award project plan; ³ Self-reported; ⁴ Includes OB beds, admission and % Medicaid/Stanford Healthcare ED;
CARE, one of 10 projects focused on this specific patient population, was funded as a second round award from CMMI in 2014. Awardees were selected for compelling new models for high-need populations. CHA’s subsidiary organization, National Association of Children’s Hospitals and Research Institutions (NACHRI), is the prime award recipient on record with the participating hospitals as sub-awardees.

The project formally kicked-off with the hospital partners in September 2014. The final budget was approved in December 2014. The first nine months of the award were completely focused on start-up. Formal implementation of the interventions began May 1, 2015, when the first patient was enrolled at St. Joseph’s Children’s Hospital. Of note, the first hospital payment model was inked one year later on May 1, 2016, also by St. Joseph’s Children’s Hospital. The project period ends August 31, 2017.

**Aims**

The project aim is to inform sustainable change in health care delivery through new payment models supporting improved care and reduced costs for children with complex medical conditions. What is learned through this endeavor may contribute to larger-scale innovations and transformation among the CARE hospitals and, ultimately, many others across the U.S.

Through the implementation of five key change concepts for care delivery, the award participants hope to see:

- An increase in family function (based on responses to the patient experience survey)
- A decrease in emergency department visits among the enrolled patient population as a result of the implementation of change concepts (based on claims data)
- A decrease in patient days among the enrolled patient population as a result of the implementation of change concepts (based on claims data)

Here are some key metrics that are being monitored as part of the award implementation (reflecting numbers through May 2016):

- 80% of patient enrollment (based on the project target) has been achieved to date. Enrollment is on track.
- About 7% of patients/families have completed the family experience surveys necessary to measure the project results (target = 25%). This is a current focus area to improve.
- 18 family members at the 10 participating sites are engaged in the CARE Award as advisors at the participating sites.
- 39 primary care practice teams at the 10 participating sites are engaged in care transformation activities.

**Project Approach**

**Definition of Children with Medically Complex Conditions**

One child with complex medical conditions truly has unique characteristics and needs that are different from another child defined with complex medical conditions. General characteristics of these children may include: chronic and severe health conditions, significant health service needs, functional limitations, technological supports and high resource utilization, but there is no standard definition. However, to support patient enrollment and project design, teams agreed to utilize the **3M Clinical Risk Group (CRG)** categories 5b-9 to apply to claims data ([figure 4](defining_children_with_medical_complexities)). The CRG grouper is a powerful tool for identifying and tracking patients over time ([Defining Children With Medical Complexities](defining_children_with_medical_complexities)).
Figure 4
CRG Definition

<table>
<thead>
<tr>
<th>Brief Description</th>
<th>NON-CHRONIC (CRGs 1,2)</th>
<th>EPISODIC CHRONIC (CRGs 3,4)</th>
<th>LIFELONG CHRONIC (CRG 5*)</th>
<th>COMPLEX CHRONIC (6,7,9)</th>
<th>MALIGNANCI ES (CRG 8)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Acute conditions that will not last one year</td>
<td>Chronic conditions that will last one year and are likely to be episodic in manifestation</td>
<td>More severe primary condition in one body system that is more likely to cause significant, long-lasting health impairment</td>
<td>Significant chronic condition in two or more body systems or</td>
<td>Malignancies requiring active treatment</td>
<td></td>
</tr>
<tr>
<td>Fracture, Pneumonia, Appendicitis, Trauma</td>
<td>Potentially curable with adequate treatment</td>
<td>Not likely to last into adulthood</td>
<td>Progressive or life limiting chronic conditions or</td>
<td>Conditions requiring a dependency on technology</td>
<td></td>
</tr>
<tr>
<td>Asthma, Depression, Conduct disorders</td>
<td>Sickle cell disease, Congenital heart disease</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

*3M Clinical Risk Groups (CRG) were used to define this patient population. Category 5 is broken into two subcategories by the Children’s Hospital Association – 5a and 5b. A patient in category 5b has a “single dominant chronic disease likely to cause significant, long-lasting health impairment” such as sickle cell disease or congenital heart disease. Source: CHA analysis; JAMA Pediatr. 2013 Feb;167(2):170-7. doi: 10.1001/jamapediatrics.2013.432.

Project Design

Two main work efforts exist within the CARE Award (figure 5):

- The Care Transformation work focuses on redesigning care delivery to enable the most appropriate coordinated care in the right setting.
- The Payment Model work moves hospitals toward negotiation of new payment options to support the new clinical model.

The evolution of these two endeavors, as well as their alignment, provides an exceptional learning opportunity that combines the clinical and financial aspects of the delivery system necessary to sustain impactful system improvements.
Care Transformation

The care transformation work was based on the Institute for Healthcare Improvement’s quality improvement (QI) collaborative model. A total of 48 QI teams are engaged in the collaborative including nine hospital-based QI teams (one hospital implemented a virtual team) and 39 collaborating primary care practice (PCP)-based QI teams. All QI teams were strongly encouraged to include family members or have strong connections to parent/family advisory groups that are experienced in managing complex medical conditions. Teams began implementing the following change concepts to facilitate improvement:

1. Data registry of enrolled patients
   - Providers across the continuum of care use registries to assess and manage their population as well as improve quality of care.
   - Registry content must be reviewed and updated at regular intervals and when major changes with the patient/family occur. Content should be current, accessible and consistent across care settings.

2. Dynamic care team (DCT)
   - An effective, informed and coordinated team is needed to care for children with complex needs.
   - The patient’s family members are integral to the DCT.
   - Parents, patients and providers determine together who should belong on the DCT.
   - DCT membership can include health care, community and educational providers.
   - DCT members recognize each other by name and role.

3. Individualized access plans
   - Every patient/family needs to know how to contact the appropriate person to meet their needs at all times.
   - A provider who is knowledgeable about the patient/family must be available 24/7.

4. Shared care plans with patient/family-focused goals to improve communication across all care venues
   - Every patient has access to care coordination services and the patient/family know when and how to reach different providers.
   - Standardized approaches and documentation are used in care planning with every patient/family.
   - Providers across the care continuum can access the care plan.
   - Providers and the patient/family have the same understanding of roles and patient goals.
   - Actions, when possible, should be based on evidence-informed guidelines or expert consensus statements, with input from all members of the DCT.

5. Effective transitions of locus of care management
   - Patients and families view a uniformly high, 24/7, standard of care maintained through all transitions and across all settings.
   - Health and wellness goals developed in the care planning process are maintained across all changes in the locus of care management and care settings. They drive all aspects of care (e.g., preventive care, acute care, chronic condition care, emergent care, hospital care).
   - The partnership is maintained among all core members of the DCT, particularly the family.

Regarding the QI change concepts, three key staff members from each children’s hospital were selected to work together in transforming care for each child in the collaborating PCP sites: practice transformation facilitator, care coordinator, and medical social worker. Their roles are as follows:

- Practice transformation facilitators work with primary care practices to guide QI team development and functions, making sustainable changes in care management processes through relationship building, coaching, QI and education.
• Care coordinators work with PCP site providers to manage patient care plans in partnership with families and the health care team while offering education, role modeling, mentoring, etc.
• Medical social workers collaborate with PCP site providers to manage mental health care plans in partnership with families and the health care team while providing education, role modeling, mentoring, etc.

**Payment Model**

Claims data and actuarial services support each hospital in designing an appropriate payment model for local negotiating. Hospitals in eight states and Washington, D.C., are collaborating with four Medicaid state agencies and five Medicaid managed care organizations to obtain claims data on a quarterly basis. Payment models are expected to vary across sites – ranging from shared savings models to care coordination fees and infrastructure payments.

Milliman Consulting provides technical actuarial support to each hospital for the design work. Models will include expected reimbursement and expenses, trending for future savings targets, sensitivity of financial result-to-cost estimates, and sensitivity toward random fluctuations in utilization and large claim amounts. Once complete, sites will individually:

1. Finalize the model
2. Begin negotiation with the state Medicaid program or managed care organization
3. Continue plan development and negotiations
4. Begin to implement or shadow the new payment model
5. Monitor payment and costs on a quarterly basis

The first few payment models emerged in the last half of the second project year (spring-summer 2016).

**Institutional Review Board (IRB)**

The CARE Award offers a unique opportunity to contribute to an emerging body of knowledge on innovative care delivery models for children with complex medical conditions and their families. It will highlight the effect on patient/family satisfaction with the care experience, cost and service utilization as well as the family impact. The extensive data collection effort across 10 sites and 39 QI teams is unprecedented. Clinicians, health system administrators, payment specialists and advocates will be informed by project best practices and outcomes to sustain and spread promising solutions for the future.
The use of an Institutional Review Board (IRB) was pursued to facilitate further data analysis and publication of project data, and assure human subject protection for all CARE-enrolled patients and families. The project was designed to leverage the advantages of a central IRB using a reliance model. The Children’s National Medical Center provided the central IRB. However, four participating institutions relied on their own IRBs rather than the central IRB for the CARE Award.

Recently the National Institutes of Health (NIH) recognized the importance of adopting a central IRB in “the Final NIH Policy on the Use of a Single Institutional Review Board for Multi-Site Research.” (Final NIH Policy, June 21, 2016). The NIH policy, effective May 25, 2017, supports the effectiveness and efficiency of multi-site research administration and oversight by requiring the use of a single IRB for non-exempt human subjects’ research protocols funded by the NIH.

**Project Team Roles**

Multidisciplinary hospital- and primary care-based teams collaborate on the two main CARE Award work groups along with other project champions such as their project director, executive sponsor and/or CEO. Key team roles per hospital site include:

<table>
<thead>
<tr>
<th>Key Roles for Project Execution</th>
<th>Project Resources</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Executive sponsors</strong> ensure organizational support is in place and barriers are mitigated when escalated by project directors.</td>
<td>Reports provided to project directors.</td>
</tr>
<tr>
<td><strong>Project directors</strong> oversee the project work, address resource allocation, and keep their CEOs or identified executive sponsors informed of progress and barriers.</td>
<td>Monthly webinars and aggregate progress reports provide interim updates and connection points on progress. Project newsletters and custom progress reports are disseminated quarterly to facilitate project communication within individual organizations.</td>
</tr>
<tr>
<td><strong>Payment model champions</strong> design and negotiate new payment models for the enrolled population. Additionally, payment model champions are responsible for claims data acquisition that supports payment model development.</td>
<td>Monthly newsletter updates and biweekly calls for all 10 sites. Custom reports and calls support individual organizational analyses and development of payment model options.</td>
</tr>
<tr>
<td><strong>Care champions</strong> lead quality improvement and care transformation by engaging others from their organization, primary care practices and family members, and implementing the change package.</td>
<td>Monthly training by webinar and in-person learning sessions. Sessions include data review, peer sharing, lessons learned and next steps on change concepts. QI huddles occur biweekly. Participants address common issues, share lessons learned and successes.</td>
</tr>
<tr>
<td><strong>Research managers</strong> are responsible for CARE data assets, understanding progress metrics and problem solving data processing issues.</td>
<td>Weekly reports on enrollment and survey progress with the opportunity to report efforts on each and hear from others on successful implementation tactics.</td>
</tr>
</tbody>
</table>
Additional project team roles include grant managers assigned to handle the administrative processing of award contract terms, finances, and federal rule and IRB compliance.

Project oversight is provided by a CARE governance committee representing senior executives from several partner hospitals, CHA’s senior leaders, the CARE project director and medical director.

CHA’s project team reports to an HCIA project officer on a weekly basis to discuss progress and challenges. Formal reporting to CMMI occurs quarterly.

A research committee made up of several senior clinical researchers was formed to advise the development of the research protocol and its approval by central and site-specific IRBs. After approval of the research protocol, the research committee was repurposed into the Publications Steering Committee. Although research is not funded as a part of this award, this committee was formed to review and approve all proposals for data analyses as well as all abstracts, manuscripts for journal submission and presentations (CMMI approval still required). The goal of the committee is to ensure quality control of the data analyses and guarantee the scientific merit of all publications and presentations.

**Budget**

CMMI awarded $23 million for the three-year CARE Award. Budgets were designed to stimulate start-up and then be reduced in subsequent years as payment reform would make the clinical care design sustainable. The majority of expenses went to contractors – data management and processing, consulting, industry experts and hospital partners.

Of the $10.5 million CARE Award budget in year one, 83 percent was allocated to contractual needs: data management, industry experts, and partnering hospital payments. The budget was decreased to $7.2 million (72 percent toward contractuals) in year two. Due to implementation delays, about $5.6 million from year one was carried forward to year two and 98 percent of the carryover related to the contractual aspects of the budget.

About 30 percent of contractuals was needed for claims and survey data acquisition and processing, and actuarial services in year one, which reduced to 20 percent in the year two budget (Truven Health Analytics provided claims data processing and reporting. Qualtrics provided survey administration and analysis, and Milliman provided actuarial services). Actuarial services related to approximately 100 hours of consulting time per hospital to assist in their payment model designs. Another four percent in year one and six percent in year two related to outsourcing the IRB and grant administration to Children’s National Medical Center.

For care transformation, industry knowledge on the patient population, delivery of care and transformational quality improvement methods was provided via contract with experts. The CARE Award medical director and faculty served in these roles. These experts accounted for five percent of the year one budget and six percent in year two (Acknowledgments).

**Hospital Budgets**

The hospital budget in year one was $5.4 million (or 62 percent of the CARE Award budget), reducing to $3.5 million in year three (or 68 percent of the CARE Award budget). Payment models were anticipated to begin in year two of the award. Each hospital received a standardized budget in year one of $538,608 that was constructed within the CARE proposal prior to project approval. The CARE project hospital budgets were not designed to cover all costs as each hospital is organized and resourced differently. Each hospital budget included allocations for project administration and key clinical staff for project implementation.
Clinical engagement of primary care physicians was a critical aspect of the budget for project activation. The hospital budget included payments of nearly $200,000 in year one, reducing to $92,000 in year two, to engage physicians in the care transformation work. The budget allocation was based on a per-member-per-month (PMPM) calculation to reflect an equal distribution of patients enrolled; however, the payment was intended to support non-clinical time devoted to care transformation quality improvement work.

Portions of key care transformation staff covered by each hospital budget (year one and year two):
- Practice transformation facilitator (PTF) – 0.8 to 0.4 full time equivalent (FTE)
- Care coordinator – 0.5 to 0.25 FTE
- Medical social worker – 0.4 to 0.2 FTE

Project staff covered in each hospital budget (year one and year two):
- Research manager – 1.0 FTE
- Project director – 0.2 FTE

In addition to salaries, budgetary items included learning session travel, PTF training and local travel, technology support and other administrative expenses.

The budget structure became an increasing barrier as each organization varied in their grant structures, policies and organizational needs. Late into year one, hospitals were allowed to budget again within federal guidelines. This supported coverage of unbudgeted costs, such as claims data acquisition, additional resources for enrolling and consenting patients, unbudgeted staff time for project administration, family stipends and application of indirect costs.

Project delays provided CHA as the awardee an opportunity to evaluate how budget adjustments could further advance the project goals. An additional $620,000 was allocated from CHA’s budget to assist the 10 CARE hospitals with barriers to implementation. Due to the timing of the allocation, much of this was bundled with other hospital unobligated expenditures and requested for carryover in year two to continue the activation phase of the project. With solid implementation progress in year one, the requests for year two were approved.

**Implementation**

The CARE team as a whole experienced several delays with patient enrollment. The central IRB granted approval on February 5, 2015. Several hospitals also had to seek approval through their local IRBs, with three being finalized by May 29, 2015, and a fourth being approved in July 2015. In most cases, business associate agreements and contractual agreements were established prior to IRB approval, but some organizations required the IRB approval prior to the contractual agreement.

Three hospitals had significant challenges recruiting care coordinators and social workers to support the QI work at collaborating PCP sites. Two hospitals implemented broader regional primary care practice recruitment strategies and agreements were not finalized until early in the second year. Hospitals completed all necessary agreements with collaborating PCP practices by December 2015, and enrollment followed, reaching 25 percent of the target by the end of the first year of the award (chart 1).
Project Metrics

Data were needed to monitor and assess four primary components of the CARE Award:

- Patient enrollment
- Family and physician experience
- Health care quality and care coordination
- Health care spend

Business associate agreements were needed to protect patient privacy across all involved entities: the children’s hospital, Medicaid agency or managed care organization, CHA and its contractors. Figure 6 demonstrates the flow of data from the intake process to reports.

Claims data for each participating hospital served as an essential resource for calculating baseline and ongoing resource use and medical spending, identifying and validating the patient population for enrollment, and developing actuarial modeling for payment model options. Due to the unique aspects of each market, claims data acquisition occurred independently and over a long time period. When received, data analysts processed and standardized the data according to industry standards and project needs.
Hospitals receive data via monthly QI reports and the following metrics:

- **Site utilization (monthly)**
  - Hospital days/1,000 enrolled patients (monthly data rolled into quarterly)
  - ED discharges/1,000 enrolled patients (monthly data rolled into quarterly)
- **Claims data (quarterly)**
  - Annualized hospital days/1,000 patients
  - Annualized number of ED visits/1,000 patients
  - Total medical expenditures (PMPY)
  - Inpatient medical expenditures (PMPY)
  - ED visit expenditures (PMPY)
  - Annualized ratio of inpatient to outpatient costs
- **Surveys (baseline, six months, one year, two years)**
  - Patient Experience (Hybrid design: the Consumer Assessment of Healthcare Providers and Systems (CAHPS™) Clinician and Group Survey, the Family Experiences with Coordination of Care (FECC) Survey, the Family Voices survey, and the Pediatrics Quality of Life Inventory™ (PedsQL) Family Impact module)
  - Medical Home Index (Pediatrics short version)
  - Physician Work-Life Balance
Initial Learning

Top 10 Challenges for CARE Project Activation

The CARE Award teams had some unexpected setbacks during the activation phase. The following are key learnings experienced in the project (in no particular order):

<table>
<thead>
<tr>
<th>Challenges</th>
<th>Learning</th>
</tr>
</thead>
<tbody>
<tr>
<td>1 Budget</td>
<td>• Adjust financing to align project priorities.</td>
</tr>
<tr>
<td>2 Approvals and processing for contracts and IRB</td>
<td>• Pre-approvals could expedite a laborious six- to nine-month process.</td>
</tr>
<tr>
<td></td>
<td>• Adequate resources are needed to move agreements forward.</td>
</tr>
<tr>
<td></td>
<td>• Additional process may be needed to coordinate efficiently.</td>
</tr>
<tr>
<td>3 Recruiting, hiring or reassigning dedicated staff</td>
<td>• Creative use of staff can fill gaps due to market demand for key staff, such as medical social workers.</td>
</tr>
<tr>
<td>4 Claims data requests</td>
<td>• Use finesse and an understanding of local issues.</td>
</tr>
<tr>
<td></td>
<td>• Letters of support developed in advance of the project were influential.</td>
</tr>
<tr>
<td>5 Time to enroll and consent children</td>
<td>• On average, this takes about 15 minutes; however, processes need refinement before this can be achieved.</td>
</tr>
<tr>
<td>6 Primary care physician relationships</td>
<td>• New physician practice agreements were often required.</td>
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<tr>
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<td>• The agreement process is time consuming.</td>
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<tr>
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<td>• New communication and collaboration processes were needed.</td>
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<tr>
<td>7 New family relationships</td>
<td>• Family input is essential for delivery system transformation, and sensitivity is needed to identify and support barriers to engagement.</td>
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<tr>
<td>8 Culture</td>
<td>• Bilingual staff and translated materials are needed for non-English speaking families.</td>
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<td>• Care transformation requires staff to focus on the patient at the center of the care system rather than the provider.</td>
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<tr>
<td>9 Communications</td>
<td>• Reports communicating project goals and progress were needed for all 10 teams to maintain focus, anticipate upcoming project implementation needs, and share regularly with stakeholders and executives.</td>
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<td>• New communication processes were needed within teams and with new team members, such as physicians and families.</td>
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<tr>
<td>10 Translation of high-level goals into tactics</td>
<td>• Fundamental changes in care practices were identified to achieve care transformation goals.</td>
</tr>
</tbody>
</table>

Despite these initial challenges, course corrections ensued and participants continue to strongly progress toward the project goals. They have also learned that even mature complex care programs can find care transformation improvement opportunities by learning from others implementing novel programs.
Additional Learning and Observations

Executive Sponsorship

CEO and senior leadership determine organizational priorities and their initial involvement in the project proposal helped establish buy-in needed for implementation and addressing barriers. Executives at CARE hospitals provided strong support and have a vision for how this work can intertwine with other population health organizational strategies. Observations from successful implementation include:

- CEO-driven mandate to transform
  - Reflect it in hospital or health system overall strategy/goals.
  - Define transformation.
- Shared understanding of the goals
  - Promote wide-spread knowledge of priorities and tactics.
  - Provide education on structured care coordination.
- Proactive planning
  - Data sources and acquisition strategy
  - Hiring or redeploying staff
- Contingency plans
  - Identify and manage dependencies and limitations (e.g., agreements, staff, partners, data systems, processes).

Primary Care Practices

Established physician networks do allow for more rapid practice adoption. If those networks are not already in place, relationships can grow given ample time and attention. Collaboration was fostered by CARE participants when these guidelines were followed:

- Clearly define roles.
  - Defining roles for care management team members is critical and sometimes harder than expected.
- Acknowledge resource availability.
  - This represents a huge barrier at the practice level.
  - Enhance relationships with telehealth/EMR connectivity, parent mentors and shared care coordination.
  - Be aware of existing productivity incentives within practices.
- Collaborate on quality improvement.
  - Create an open learning environment.
  - The practice level differs from the corporate level.
  - Allow experts to guide and focus teams.
  - Alignment and education are needed on both sides.
  - Identify and focus on what is most impactful to outcomes.
  - Know and manage stakeholder agendas.
- Support practice changes.
  - Take inventory of the existing care coordination infrastructure.
  - Consistent focus on impactful interventions is needed to decrease inpatient and ED utilization.
Care Coordination
Care coordination is a fundamental principal of care transformation as it balances the care process with the needs of the patient/family, and scales to different patient populations. Lessons learned from CARE participants include:

- Select the right level of care coordination.
  - This should be based on an assessment of individual care coordination needs and the assets of the child/family.
- Emphasize collaboration.
  - Collaboration should be promoted across stakeholder lines.
  - Many types of connections are needed between hospitals, clinicians and families.
- Listen to families.
  - Family needs must be represented in all aspects of care transformation.
- Identify staffing needs early to allow adequate hiring time.

Payers
For the complex care patient population, traditional payment models may not be sustainable. Payers suggest that changes should fit within existing model constructs for ease in administration and to account for small numbers in the complex population. Children’s hospital executives hope to match the model to the needs of the patient for optimal care management and efficiencies. Five hospitals are collaborating with state Medicaid agencies for claims data and new payment models. The remaining five are working with Medicaid managed care organizations. Payment models under consideration through the award include a care management fee plus shared savings and potentially an upfront infrastructure support payment. Considerations in working with payers include:

- Build and maintain relationships with payers.
  - Let data serve as the foundation.
  - Leverage preexisting payment reforms.
- Anticipate delays with payment redesign discussions.
  - Not all payers will be open to change, particularly for small populations.
  - Options must align with what works locally as well as with the needs of this patient population.
  - Use waiting periods as opportunities to validate proposed models.

Data Management
The intricacies of data needed to support system transformation could benefit from more foresight. Special processes are needed to accommodate a six-month lag from a patient event to obtaining claims data, such as retroactively calculating baselines and using administrative data as a proxy for patient identification. Lessons learned from CARE participants related to building out data for improvement include:

- Build trust to acquire data.
  - Adapt agreements to reflect concerns at the state or national levels and protect mutual interests.
- Dedicate information technology (IT) resources.
  - Leverage EMR systems for patient identification, monitoring change concepts and creating reporting.
• Assess current data system capabilities.
  – Patient information needs to be accessible to all members of the care team, including families.
• Obtain technical expertise.
  – Claims data are heterogeneous in terms of variables and quality across states.
  – Truven conducted standardization and quality checks within a four-to-six week timeframe.
  – There are always discrepancies to resolve when matching up patients, particularly as Medicaid patients may drop in and out of the program.
• Risk-stratify your population.
  – Risk stratification supports effective deployment of care teams.
Going Forward

The remainder of year two will focus on moving from activation to full implementation, while year three will prioritize measuring and monitoring performance toward outcome goals: family functioning, utilization and medical spending. As more learning from implementation surfaces, information will be shared with all children’s hospitals nationally. Care transformation teams are exchanging successful change concept implementation strategies now as they establish plans to sustain the transformed delivery system. A critical factor to sustain the improvements is the implementation of new payment models in the final half of the award.

Initial Spread Plan

Stakeholders guiding plans for spread include CARE governance, CHA Quality Board Committee, CHA QI Subcommittee, CHA senior leadership (CEO, chief operating officer (COO), chief financial officer (CFO) and chief information officer (CIO). Initial plans reported to CMMI were:

1. Engage stakeholders on strategy to:
   - Sustain industry successes.
   - Spread to (or among) more children’s hospitals.
   - Spread to (or among) more pediatric populations/settings.
2. Establish infrastructure among collaborative participants.
   - Negotiated payment models should cover costs going forward.
   - Implement the evidence-based change package and proven quality improvement methods for care delivery.
3. Leverage convening opportunities for administrative, clinical and financial leaders.
   - CHA conferences
   - Affinity group meetings
   - Ad hoc based on topic

Initial plans will be adjusted as the work progresses to achieve the overall project aims.

<table>
<thead>
<tr>
<th>Timeframe*</th>
<th>Communication Goals</th>
<th>Communication Vehicles</th>
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<tbody>
<tr>
<td>Year 1</td>
<td>Awareness, initial engagement and knowledge exchange</td>
<td>1. CHA vehicles: Conferences, Connections Newsletter, Town Hall webinars</td>
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<td>(9/2014-8/2015)</td>
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| Year 2     | Awareness and broaden engagement and knowledge exchange on early findings | 2. Targeted CHA affinity groups:  
   ○ CFO  
   ○ Revenue Cycle  
   ○ Quality and Safety Leaders |
| (9/2015-8/2016) |                                                 |                        |
| Year 3     | Engagement and knowledge exchange on early findings | 3. Peer-reviewed journal publications |
| (9/2016-8/2017) |                                              |                        |
| Post Award | Engagement and knowledge exchange on final results | 4. Industry/other presentations (e.g., Pediatric Academic Societies) |

* Note: communication spread requires a six- to eight-week lead time for approval by HCIA.
Conclusion
The CARE Award project is an important transformational step, along with others, as children’s hospitals and payers move toward greater accountability in population health and the development of supporting payment reform models. Activation of the CARE Award consumed the first year of the project period. With all of this hard work coming together toward the beginning of year two, the most essential tasks with activating the project have begun: recruiting and consenting patients.

While the project is positioned to successfully achieve its aims, there are several more hurdles to accomplish moving into the remainder of the second year. The effort to acquire and process claims data and to then develop and negotiate payment models remains for seven hospitals to complete. Full implementation of the change concepts for all enrolled children is expected to occur in the third year with results calculated at the project’s conclusion from September to November 2017, the post-award period for analysis.

The ability of CHA to scale the work to a broader network of children’s hospitals will be determined as results become more apparent and if children’s hospitals express a desire to further collaborate. We are excited to help 8,000 children in the 10 communities involved with this project and will share the CARE project results more broadly to ultimately improve care for the three million children in need.
## Acknowledgments

(September 2014 – February 2016)

<table>
<thead>
<tr>
<th>Hospitals</th>
<th>Project Directors</th>
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<td>Other Teams</td>
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References


Appendix 1
CMMI-Funded Projects on Children with Medical Complexity

The Health Care Innovation Awards funded through the Center for Medicare and Medicaid Innovation include 18 models under development. Round one of the awards launched in 2012 and round two started in 2014. In total, 146 recipients received three-year project awards, ranging from $1 million to $30 million in funding. Ten projects relate to children with complex medical conditions with $128 million in combined funding (see below).

Round One Awards
- The Research Institute of Nationwide Children’s Hospital, OH
- University of Cleveland Hospitals/UH Rainbow Babies and Children’s Hospital, OH
- North Carolina Community Networks including Carolinas Medical Center, Duke University, Vidant Medical Center, University of North Carolina, and Wake Forest Baptist Medical Center, NC
- Denver Health and Hospital Authority including Mental Health Center of Denver, CO

Round Two Awards
- Boston Medical Center, MA
- Clifford W. Beers Guidance Clinic, Inc., CT
- National Association of Children’s Hospitals and Related Institutions on behalf of the Children’s Hospital Association including 10 partner hospitals, CA, CO, DC, FL, MO, OH, PA, TX
- Seattle Children’s Hospital, WA
- The Board of Trustees of the University of Illinois, IL
- Wisconsin Department of Health Services including Children’s Hospital of Wisconsin, WI

Sources: https://innovation.cms.gov/and www.hhs.gov