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. Following are some highlights from the full publication:

**The Four Data Domains**

**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.

- **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.

**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.

- **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.

**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 the following concepts: patient registry, dynamic care teams, access plans, and care planning. 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.

- **Key Takeaways**: Successfully transforming care requires sustained effort and monitoring, robust implementation of quality improvement (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.

**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.

- **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.

**CARE Informatics Framework**

To create the infrastructure needed for care delivery and payment model reform, the following informatics framework was built (Figure 1). 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 Cohen and Jay Berry. 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.

CHA selected the 3M Clinical Risk Group (CRG) categorization for CMC to represent the population with varying health characteristics and complexity of needs. It 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 Conditions (CCCs) and Pediatric Medical Complexity Algorithm (PMCA).

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.
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. It 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.

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2 Berry, J. et. al. “The Landscape of Medical Care for Children with Medical Complexity”. Children’s Hospital Association, www.childrenshospitals.net/cmclitreview


4 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/