Meeting the Needs of Children with Complex Medical Needs in a Changing Health Care System

Statement of Problem

Children with complex chronic conditions like congenital heart diseases, congenital anomalies, cystic fibrosis, and cancer represent about 7% of all children, but are responsible for 40% of all pediatric costs. These children and their families often navigate multiple health care providers and are consistently at high-risk for emergency department visits and hospitalizations. Many families have very limited options for health care providers and, for some, the nation's children's hospitals are the only place their children can receive specialty care. As health care reform policy debates continue in our country, delivering higher-quality care coordination and improving the quality of life for families of children with complex chronic conditions will be a paramount goal. We must also be attentive to the fact that health insurance reform could introduce potential challenges for families, many of whom are already facing steep out-of-pocket costs for care and limited and timely access to appropriate providers.

Compounding the barriers families experience to receiving adequate, affordable health care is the fact that health care systems are facing growing challenges around capacity management, patient access and patient engagement. For families, this has led to longer wait times for appointments, less individual time with providers, and the difficult task of coordinating multiple appointments and follow-up recommendations among various specialists for children with complex medical conditions.

Description

In response to these challenges, Children's Hospital of Philadelphia's (CHOP) Population Health Innovation team is working to develop and implement programs of tailored population management tools and proactive patient outreach strategies for families of children with complex medical conditions. When goals overlap, the implementation work of the Population Health Innovation team is informed by PolicyLab research and engages PolicyLab content experts. The Population Health Innovation team works with care teams around the health system as they manage patients with complex chronic conditions such as diabetes, asthma, sickle cell disease, and inflammatory bowel disease, as well as various multidisciplinary clinics and a large wellness management program in primary care. The team employs quality improvement methodologies and tools to redesign clinical care team workflows, build and implement electronic health record (EHR)-based proactive care management tools (such as registries, real-time patient management reports and risk scores), and track longitudinal process and outcome measures to ensure that the clinical programs are meeting their care delivery goals.

As the Population Health Innovation team implements new programs throughout the health system and within the community, our teams at PolicyLab have worked with CHOP care teams to develop strong quality improvement designs, as well as robust mixed-methods and quantitative evaluations of the programs' impact. For example, a multidisciplinary working group led by PolicyLab researchers and the Population Health Innovation team worked with asthma care teams to implement and evaluate a multi-faceted population health

approach to keeping youth with asthma out of the hospital. The bundle of integrated services these children received included personalized bedside asthma education, facilitated filling of discharge medications, and connection to community health workers who could facilitate enhanced coordination between inpatient and outpatient care teams. Through the evaluation, we demonstrated a sustained reduction in repeat emergency department visits and hospital readmissions among the highest-risk asthmatic patients.

From the early development of care management programs, to the Population Health Innovation team's high-risk asthma initiatives, to the implementation and adoption of targeted population health management strategies and tools by primary care and specialty care teams, our researchers have demonstrated consistent and reproducible reductions in acute service utilization by patients with complex medical conditions.

Next Steps

Standardizing the work of clinical care teams with quality improvement methods and integrated EHR tools can provide a scalable strategy for health systems to address issues of capacity management, patient access and patient engagement. By providing leadership in the development of new population approaches to care coordination for children, the Population Health Innovation team works to provide a templated design, implementation, and evaluation process for other clinical care teams at CHOP that seek similar ventures to improve population management through improved patient access and engagement. Increasingly, these programs are creating stronger relationships with community service agencies that can assist people outside of the hospital setting, too. These broader initiatives will be the focus of implementation and evaluation studies in the years to come.

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PolicyLab Leads

Chén Kenyon MD, MSHP

Faculty Member

Chén Kenyon is a pediatric hospitalist at Children's Hospital of Philadelphia (CHOP) and an Assistant Professor of Pediatrics at the University of Pennsylvania. He is also a faculty member at PolicyLab and Clinical Futures at CHOP and serves as the faculty lead for PolicyLab's Population Health Sciences

Portfolio. Dr. Kenyon's research focuses on integrating care systems and reducing outcome disparities for children with asthma. His recent work focuses on developing novel interventions to enhance asthma controller medication use in the highest risk children by leveraging mobile health technology and incentives oriented to the child. He also co-leads the Asthma Population Health Workgroup at CHOP, implementing and evaluating network-wide interventions for children and families with different levels of asthma severity and risk.

Dr. Kenyon received his undergraduate degree from the University of Rochester in Mathematics and attended medical school at Boston University School of Medicine. He completed residency training in the Boston Combined Residency Program in Pediatrics, where he served as a chief resident. He then received a Masters in Health Policy Research as a Robert Wood Johnson Clinical Scholar at the University of Pennsylvania, which he finished in 2013.

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Team

Tyra Bryant-Stephens
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Faculty Member

Tyra Bryant-Stephens is a faculty member at PolicyLab at Children's Hospital of Philadelphia (CHOP), senior director of the Center for Health Equity at CHOP and the medical director of the Community Asthma Prevention Program (CAPP). Her research focuses on the use of community-based interventions to improve child asthma outcomes for underserved populations.

Dr. Bryant-Stephens founded CAPP in 1997. As medical director of the program, she leads a staff of 12 that includes registered nurse clinical and educational coordinators as well as lay home visitors. CAPP was designed to improve the health and well-being of children with asthma by providing free asthma classes in the community for parents and their children with asthma. The project also supported a new way of providing education in the homes of children with asthma where parents learned about the types of environmental changes that could be made to improve their child's asthma. In offering home visits and free asthma education, CAPP satisfied a strong need in the West Philadelphia community and received tremendously positive feedback from families and class participants.

In 2000 and 2001, CAPP's success in providing asthma education in the home and community was expanded when Dr. Bryant-Stephens received grants from the U.S. Environmental Protection Agency and the National Institutes of Health (NIH). Through the NIH-funded "Community Partnerships for Asthma Prevention" CAPP was

able to continue to offer free home visits to the West Philadelphia community. Free asthma education classes continued to be offered through a grant from the Pew foundation.

Also in 2001, CAPP received a grant from the Centers for Disease Control and Prevention to expand its work into the North Philadelphia area. In this project, CAPP has worked with a collaborative of partners to implement four main interventions: community asthma education classes, home visits, primary care provider training and education for school's personnel. In 2005 CAPP also began to offer free asthma education classes to children in Philadelphia public and charter schools. In another new project, as part of the Merck Company Foundation's Merck Childhood Asthma Initiative, CAPP is expanding home visiting and community classes to areas of the city that were not previously served—neighborhoods in South, Northwest and Northeast Philadelphia.

Dr. Bryant-Stephens completed her MD at the Bowman Gray School of Medicine at Wakeforest University and her residency in pediatrics at the Medical College of Georgia.

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Related Tools & Publications

- Reducing Repeat Hospital Visits for Children With Asthma
  Policy Briefs
  Mar 2019
- Association of a Targeted Population Health Management Intervention with Hospital Admissions and Bed-days for Medicaid-enrolled Children
  Article
  Dec 2019

Related Projects

Managing the Health of Children with Asthma from the Hospital to the Community
Population Health Sciences