

PRIORITY Epilepsy

Promoting Improved Outcomes through Resource Integration for
Children and Youth with Epilepsy

Children's Hospital of Philadelphia

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i. Project Abstract

Epilepsy represents the fourth most common neurological condition in the United States. Children and youth with epilepsy (CYE) are a subset of this population, and many reside in both rural and urban areas that are underserved. Children's Hospital of Philadelphia (CHOP)'s catchment area serves the City of Philadelphia and surrounding counties, a significant portion of which is underserved. Populations lacking access to high-quality, coordinated healthcare services are at greater risk for adverse medical outcomes and suffer in the form of lower quality of life. The aim of this proposal is to develop a comprehensive, coordinated system to ensure careful, appropriate treatment for CYE, by creating an integrated quality improvement network to incorporate telehealth and telemedicine; facilitate transition of healthcare services from pediatric providers to adult providers; increase family and patient engagement; and improve primary and specialty care communication, collaboration and co-management. Current quality improvement initiatives focusing on transition and telehealth for CYE have established a learning collaborative between CHOP-Neurology and multiple CHOP primary care sites located in underserved neighborhoods of Philadelphia. PRIORITY Epilepsy will expand this network to include additional primary care sites, as well as Penn Medicine-Neurology. CHOP will also collaborate with the Epilepsy Foundation of Eastern Pennsylvania to further develop outreach and education materials, particularly within the scope of telehealth. CHOP will also collaborate with the American Academy of Pediatrics' Health Initiative SPROUT to improve telehealth resources for CYE. Using this network, PRIORITY Epilepsy will achieve the following objectives by August 2023: 1) Increase by 25 percent, access to care for CYE in the target population through telehealth strategies that provide direct care, including teleconsultation, tele-education, telemedicine, mobile health, etc.; 2) 90 percent of families in the target population report they are partners in shared-decision making in their child's care; 3) Increase by 75 percent the number of completed health care transition readiness assessments of youth (ages 14-22) with epilepsy in the target population; 4) increase by 40 percent, the number of participating primary care providers who report increased communication, collaboration, and co-management with specialty providers. PRIORITY Epilepsy will use standardized and validated quality improvement methodology to improve access to healthcare services to ensure that CYE in underserved areas receive coordinated care using telehealth and telemedicine services, improved targeting of transition resources, stronger family engagement, and strong partnerships with primary care providers. CHOP has existing infrastructure to support these efforts, including: the Office of Digital Health to support telehealth, EPIC based Healthy Planet tools for patient registry development, and a Clinical Data Warehouse that can easily pull patient level data to meet the needs of PRIORITY Epilepsy. The infrastructure that we develop will be adaptable for other chronic medical conditions at CHOP and beyond.