Abstract: Strategic Approaches to Transforming Health Care for Children and Youth with Epilepsy

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Program Funds Requested: Yr1. $ 415,243; Yr2. $415,801; Yr3. $415,377; Yr4. $415,290; Total = $1,661,755

BMC’s Strategic Approaches to Transforming Health Care for Children and Youth with Epilepsy will utilize strategic approaches to expand access to high quality primary and specialty care in underserved populations of children and youth with epilepsy (CYE) seeking specialty care at BMC and University of Massachusetts Memorial Medical Center (UMMMC). Together, these two medical centers serve much of the state’s most underserved CYE, helping to overcome health disparities, geographic barriers, and a dearth of specialized services. Their specialized services attract patients from all 5 New England States.

In 2016 with support from HRSA, BMC’s project team established the Telehealth Epilepsy Care Collaborative (TECC). TECC brought together a network of primary and specialty care providers, CYE, families, epilepsy advocates, and researchers, with a shared mission to improve access to quality health care for CYE throughout Massachusetts. They developed innovative telehealth tools to increase seizure awareness, improve access to high-quality care, and overcome challenges in care coordination. These tools included: 1) a validated Seizure Screenings, creation of the Virtual Patient-Centered Medical Home (VPCMH), and Transitions Together

BMC’s team will implement a comprehensive toolbox of telehealth strategies in line with the project’s objectives to improve care access, shared-decision making, health care transitions, and care coordination for CYE. BMC will partner with UMMC’s Division of Child Neurology and a network of 15 clinical sites (primary and specialty care) in eastern and central Massachusetts. Providers will be trained to better screen for seizures, utilize the VPCMH, and utilize the TRAQ assessment tool to inform transition planning. A QI Network of partnering providers, CYE, families, and the EFNE will work together to plan, implement, test and develop best practices.

The project will increase access to care for CYE using telehealth and overcome barriers to care by using telemedicine to deliver acute epilepsy care, outpatient epilepsy care and mental health for CYE. Seizure screening will be disseminated to new practices and a second medical center. The VPCMH will allow CYE, families, primary care providers, specialists and caregivers to collaborate in one virtual space to enhance shared-decision making and care coordination. Over the next four years, the number of CYE with VPCMHs will be doubled, reaching more non-English speaking CYE, and maximizing the tool’s potential to connect CYE and providers. TRAQ assessments in youth 14-22 years will increase and the Transition Together mentoring program will develop buy-in from youth through group tele-education programs and one-on-one tele-mentorship. The proposed strategies will expand our reach to the approximately 12,996 patients seen by the Network and the 10,000 served by the EFNE. We will expand the scope of our telemedicine program to include acute and outpatient epilepsy care, and teletherapy to provide needed mental health services for CYE. The VPCMH will expand the ability for CYE and their care providers to engage in shared decision making. CYE and their families will be more fully engaged through the Transition Together program. Lastly, we will better demonstrate the ability of the proposed strategies to transform healthcare for CYE by collecting and analyzing data longitudinally, thereby enhancing sustainability.