Progress in Establishing a National Quality Measurement and Improvement Strategy for Epilepsy Care & Research: The Epilepsy Learning Healthcare System

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Epilepsy Foundation
• 30% of people living with epilepsy do not have seizure control
• Wide variations in epilepsy care delivery and clinical practice
• Inadequate and unequal access to specialized care
• Undiagnosed and underdiagnosed co-morbidities
• Underutilization of effective/curative treatments
• Early mortality above general population
Recommendation 1.

Validate and Implement Standard Definitions and Criteria for Epilepsy Care and Community Services Use and Costs and Quality of Life Measurement
Recommendation 5.

Develop and Implement a National Quality Measurement and Improvement Strategy for Epilepsy Care
Recommendation 6.
Establish Accreditation of Epilepsy Centers and an Epilepsy Care Network
Recommendation 8.
Improve the Delivery and Coordination of Community Services
Recommendation 12.
Continue and Expand Vision 20-20 Working Groups and Collaborative Partnerships
Who are WE?

PWE & Families
Healthcare Providers
Community Advocates
Researchers
What is a Learning Health System?
Learning Healthcare System

- Patients and providers work together to choose care based on best evidence
- Drive discovery as natural outgrowth of patient care
- Ensure innovation, quality, safety and value
- All in real-time
Networks offer

3-part engaged social network: patients, clinicians and researchers

Integrated data-sharing & technology

Support for QI and research: continuous improvement and learning
Learning System to Improve Outcomes

- Patients and Families
- Clinicians
- Comparative Effectiveness Research
- Electronic Health Records
- Registry Database
- Registry Applications
- Identify Uncertain Management Practices
- Identify New Gaps in Care
- Standardize Process
- Reduce Variability in Process
- Customize Process to Patient Needs
- The Learning Engine

New Knowledge

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Epilepsy Care as a Learning Health System
Epilepsy LHS
Our System
Level Framework
ELHS Vision

“Our vision is for all people with epilepsy to live their highest quality of life, striving for freedom from seizures and side effects, and we won’t stop until we get there.”
Our ELHS Leadership Team

**Confirmed Sites:**
- Partners Healthcare
- Children’s Hospital of Atlanta

**Confirmed Epilepsy Foundation:**
- Epilepsy Foundation New England
- Epilepsy Foundation Ohio

**And Rare Epilepsy Network Partners**

**Exploratory Sites:**
- Beth Israel
- Children’s Hospital of Philadelphia
- Penn State Hershey Children’s
- UT Southwest
- Children’s Hospital of Orange County
- Yale
- University of Illinois at Chicago
- Akron Children’s Hospital
- University of Cincinnati
- Cincinnati Children’s Hospital
- Barrow Neurological Institute
- Hofstra Northwell
- Northwestern
- Rush

**Exploratory Epilepsy Foundation:**
- Epilepsy Foundation Georgia
- Epilepsy Foundation Eastern PA
Learning from EVERY Person with Epilepsy

- Quality Improvement Reports
  - Shared best practices
  - Comparative effectiveness research

Data (clinical + research)
Clinical tools/techniques

- EHLS Core Registry
- Center A
- Center B
- Center C

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ELHS Network Structure

Coordinating Center
Governance, Legal and Regulatory Support

- Self Management
- Mental Health Comorbidities
- Epilepsy Education
- Patient Navigation

- Registry/Informatics
- Population management
- Research

- Quality of Life
- Seizure Frequency
- Patient Activation

- Mental Health Comorbidities
- Women & Girls with Epilepsy
- Transition of care
- Status Epilepticus

- Episodes of Care
- Network QI Playbook
- QI Training

Supportive Services Core
Community Engagement Core
Data Core
Clinical Core
Quality Improvement Core

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The Model for Improvement

What are we trying to accomplish?

How will we know that a change is an improvement?

What changes can we make that will result in improvement?

Act  Plan

Study  Do

Measures tell a team if the changes they make are making a difference.
They tell you where you are and where you are going.
SMART AIMS

By July 1, 2020, ELHS will design and implement a system of co-production that will improve outcomes for people with epilepsy and their families/caregivers in the following specific ways:

- *Improve quality of life from X to Y
- *Improve seizure control from X to Y
- *Improve seizure freedom from X to Y

*= separated by seizure type and epilepsy syndrome
**Seizure Frequency Documentation (KDD)**

**Global Aim**
All people with epilepsy achieve health and are living at their highest quality of life

**SMART Aim**
Increase documentation of seizure frequency for patients with epilepsy from X (baseline for all sites) to Y by December 31, 2019 and sustain for one year.

**Population**
People with diagnosis of epilepsy and seen at ELHS site during [time period, e.g., last year].

**Key Drivers**
- Standardized Provider documentation
- Engaged patients & caregivers in documentation
- Accuracy of seizure documentation
- Integration of documentation from all sources

**Secondary Drivers**
- Provide options based on preferences
- Support use of standard tools
- Educate patients & care partners/providers
- Adjudicate seizure activity by clinical personnel
- Address health literacy & language needs
- Integrate web-based tools to EHR
- Input data from other sources to EHR

**Interventions**
- Provide education on types of seizures, info to document, etc.
- Review seizure activity documentation during visit
- Provide education & resources in primary language
- Request permission from patient to access or link web-based tool or account
- Collect patient or care partner/giver documentation by trained staff
- Coach patients on finding documentation partners at work

**Project Leader(s):** Susan Herman, Jeffrey Buchhalter, Lidia Moura, Brandy Fureman

**Revision Date:** 2-19-19 Vers. 4

**Web-based tools**

**Printed diaries or calendars (MGH)**

**Test paper CRF form (UC)**

**Use of video**

**Integration of documentation from all sources**

**Provide educational resources to school nurses**

**Coach patients on finding documentation partners at work**

**Activated Patients & Caregivers**

**LINK to Patient Activation KDD**

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Membership & Benefits: Supporting Service Partners

• Local Epilepsy Foundation
  • Community-based support (e.g. 24/7 Helpline)
  • Wellness and self-management tools
  • Seizure First Aid training for patients, families and hospital staff (CNA's on EMU as an example)
  • Free, CDC-sponsored epilepsy training (behavioral and mental health professionals, advanced practice providers, first responders/EMT, community health workers)

• Rare Epilepsy Network
  • Subspecialty consultations
  • Family support
### Value to Stakeholders

#### Patients & Caregivers
- More reliable, effective care for improved outcomes
- Access to supportive services
- Accelerate research for treatments and cures
- Strong voice in care and research priorities
- Opportunities to co-design health system transformation

#### Researchers
- Large-scale, comprehensive clinical, patient-reported, and real-world data
- Infrastructure for prospective data and sample collection
- Size and scale needed for rare epilepsy studies
- Nation-wide network of expertise
- More competitive funding applications
- Streamlined IRB and legal infrastructure

#### Payers
- Improved quality of care and outcomes
- More activated patients
- Engaged, aligned clinicians and researchers
- More predictable risk representative research
- Evidence-generation for value-based assessment

#### Clinicians
- Tools, training and support for better care
- Access to supportive services for patients and families
- National-level career development opportunities
- Opportunities to participate in research
- Opportunities to co-design health system transformation

#### Disease Advocacy Groups
- More value to patients & families
- Faster progress toward treatments and cures
- Increased access to care & services
- Emphasis on patient voice
- Ability to evaluate impact on outcomes

#### Industry
- Real-world data
- Larger studies, more representative populations
- Streamlined study infrastructure
- Access to expertise
- Access to activated patients and clinicians
- Rapid translation of findings to practice

#### Institutions
- Realize core mission faster, cheaper, and better
- Faster learning about best practices by drawing across institutions
- Access to best practice (clinical and research) tools at lower cost
- Builds QI capability on staff
- Increased research opportunities for faculty
- More competitive research applications
- Access to partnerships for expanded supportive services
- Network performance drives local, state, and national advocacy
- Fulfill MOC, CME, US News requirements

#### Federal & Foundation Sponsors
- Speed, efficiency and impact
- More research per dollar
- More representative research
- Ability to evaluate impact on outcomes

#### ELHS Community
- Shared purpose – impacting health
- Highly engaged patients, clinicians, researchers and organizations empowered to transform health system
- Open, continuous innovation: Pooled assets open to all
- Distributed leadership
- Demonstrated results in driving change in care at scale
- Training capability and nation-wide networking
- Size and scale needed for rare epilepsy studies
- Interoperable, federated, curated clinical data from large numbers of patients
- Access to biorepository data
- Streamlined IRB and legal infrastructure
ACKNOWLEDGEMENTS
Thank you!
Sustainability/Growth

- Funding from multiple sources
  - Grants (PCORnet, PCORI)
  - Nonprofits (EF, NAEC)
  - Site commitment/support from division/institutional leadership
    - Site participation fee
    - Time: MD/RN leaders ~2-4 hrs./week; At least one other staff (MA/CRC, 8-20 hrs./week depending on program size)
    - Local IT programming to configure electronic health record (EPIC centers)
    - Travel to learning sessions
  - Industry
  - Philanthropy
Membership & Benefits: Research

- Accelerate generation of new knowledge through research
  - Topics not amenable to RCTs
  - Patients excluded from RCTs (elderly, women, children)
- Overcome barriers for recruitment / collaboration in research studies
- Decrease costs for comparative effectiveness research
- Create databases for “big data” and artificial intelligence research
CEC Members

- Over 30 CEC Members representing a variety of organizations:
  - LGS Foundation
  - Dravet Foundation
  - Ring 14 USA
  - The Brain Recovery Project
  - Local and National EF Staff
  - And many more!

- Participate in developing ELHS projects and workgroups.