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

The Epilepsy Learning Healthcare System

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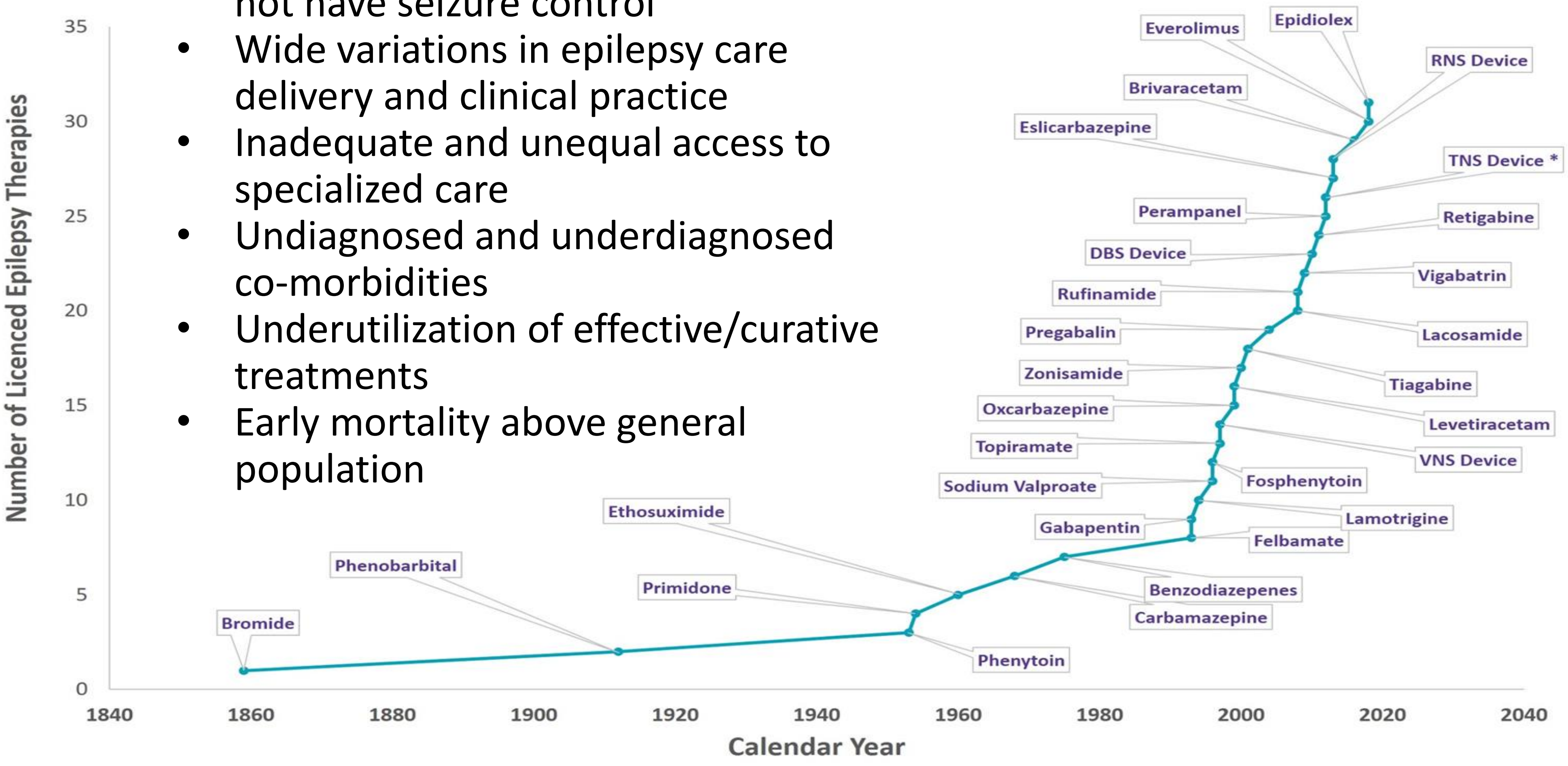
Unmet Need

- 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

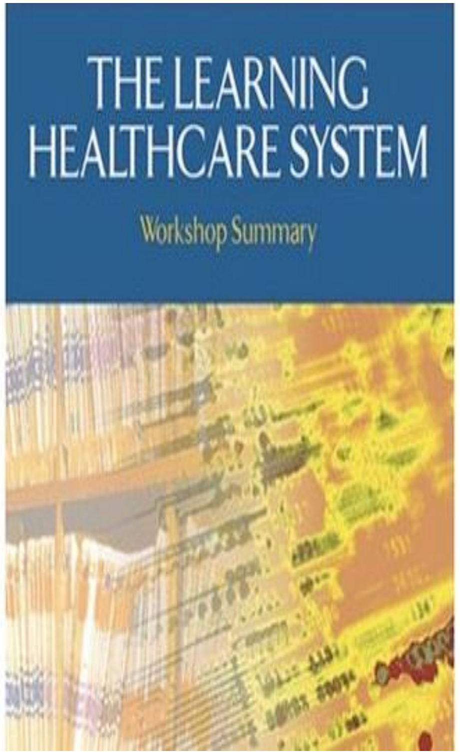
Researchers

EPILEPSY LEARNING HEALTHCARE SYSTEM

*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



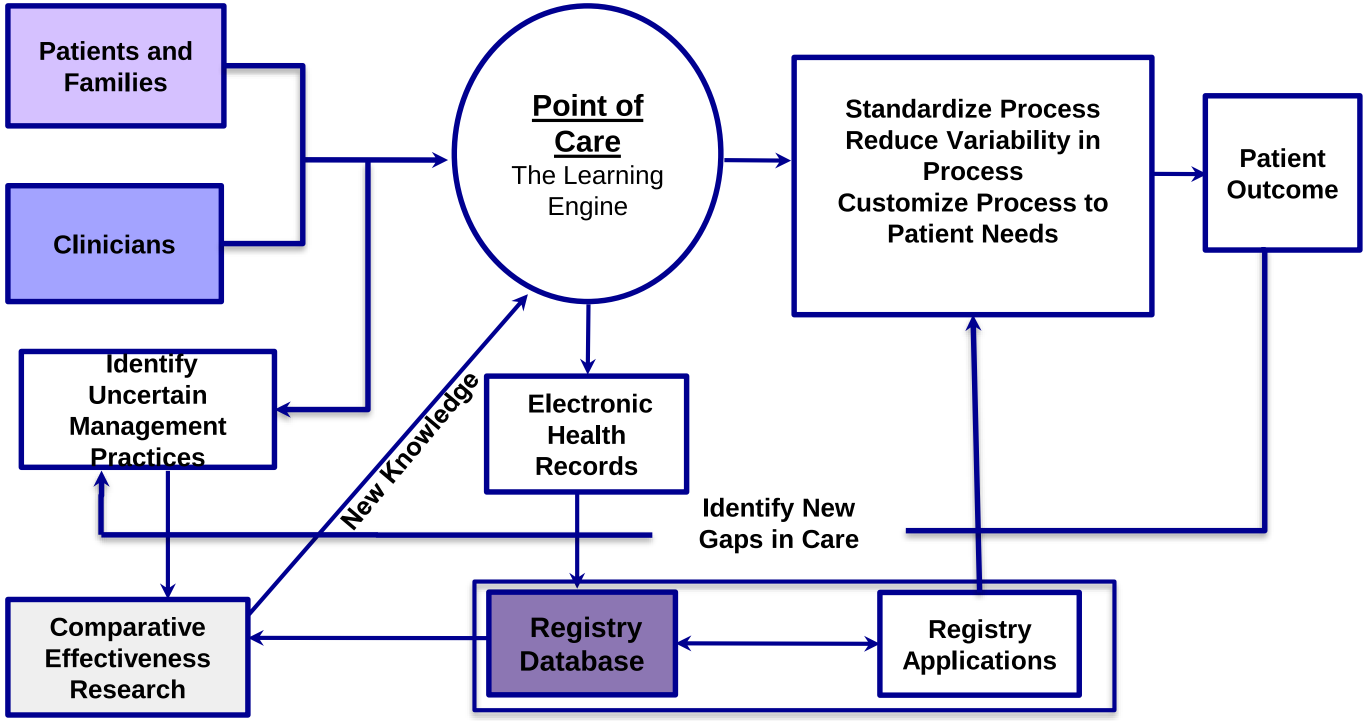
Networks offer

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

Point of Care
The Learning Engine

Standardize Process
Reduce Variability in Process
Customize Process to Patient Needs

Patient Outcome

Identify Uncertain Management Practices

New Knowledge

Electronic Health Records

Identify New Gaps in Care

Comparative Effectiveness Research

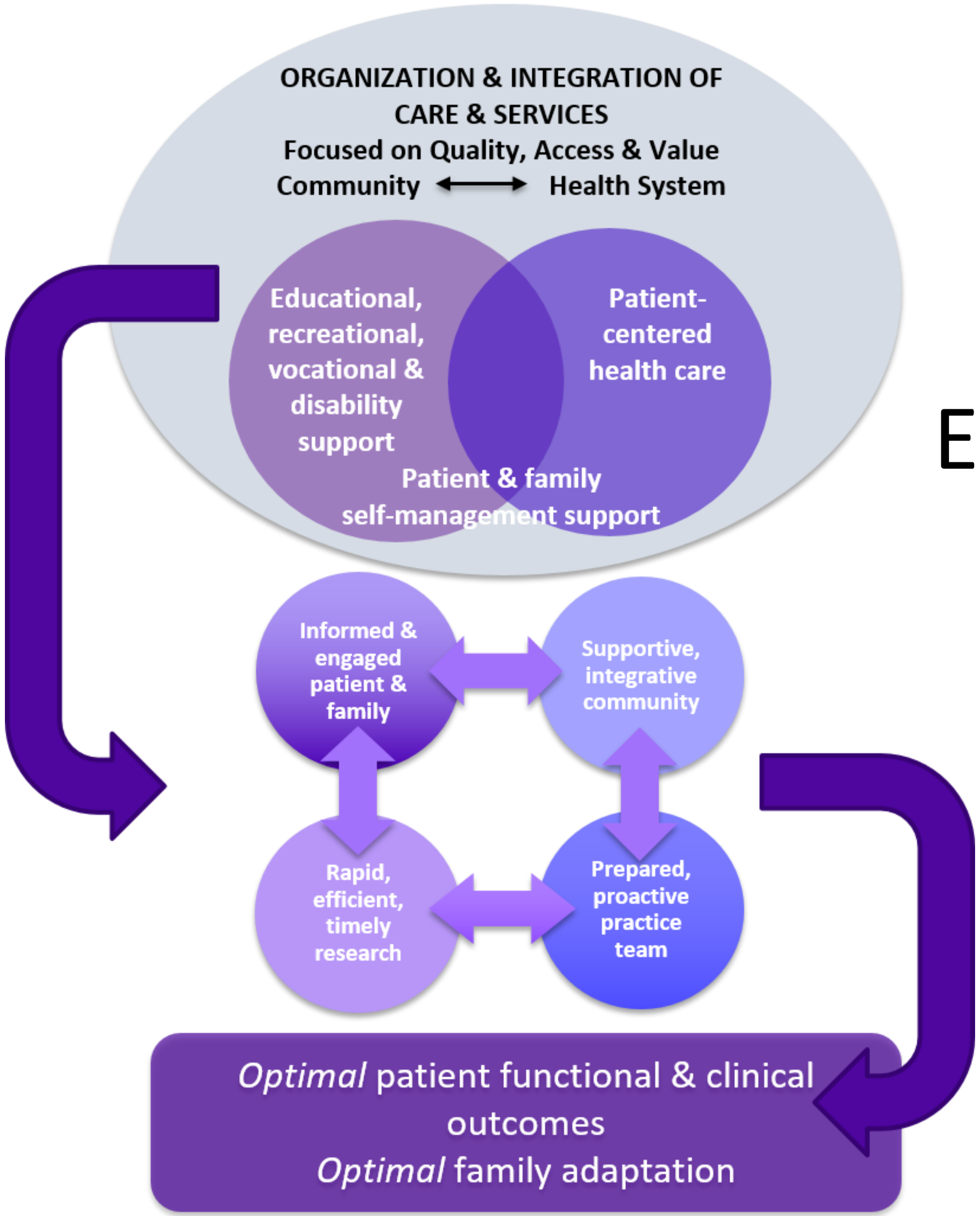
Registry Database

Registry Applications

Epilepsy Care as a *Learning Health System*

Epilepsy LHS

Our System Level Framework



ORGANIZATION & INTEGRATION OF CARE & SERVICES

Focused on Quality, Access & Value

Community ⟷ Health System

Educational, recreational, vocational & disability support

Patient-centered health care

Patient & family self-management support

Informed & engaged patient & family

Supportive, integrative community

Rapid, efficient, timely research

Prepared, proactive practice team

Optimal patient functional & clinical outcomes

Optimal family adaptation

EPILEPSY
LEARNING
HEALTHCARE
SYSTEM

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

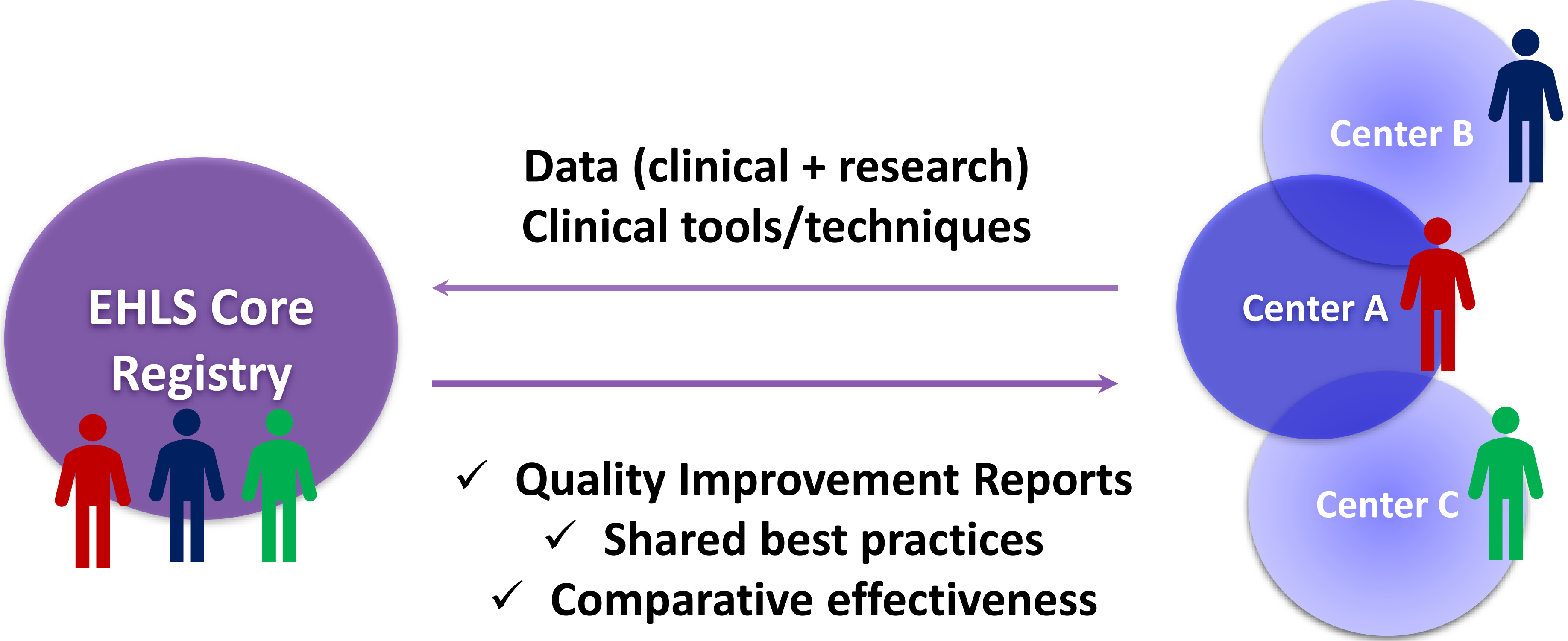
And Rare Epilepsy Network Partners

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

EPILEPSY LEARNING HEALTHCARE SYSTEM



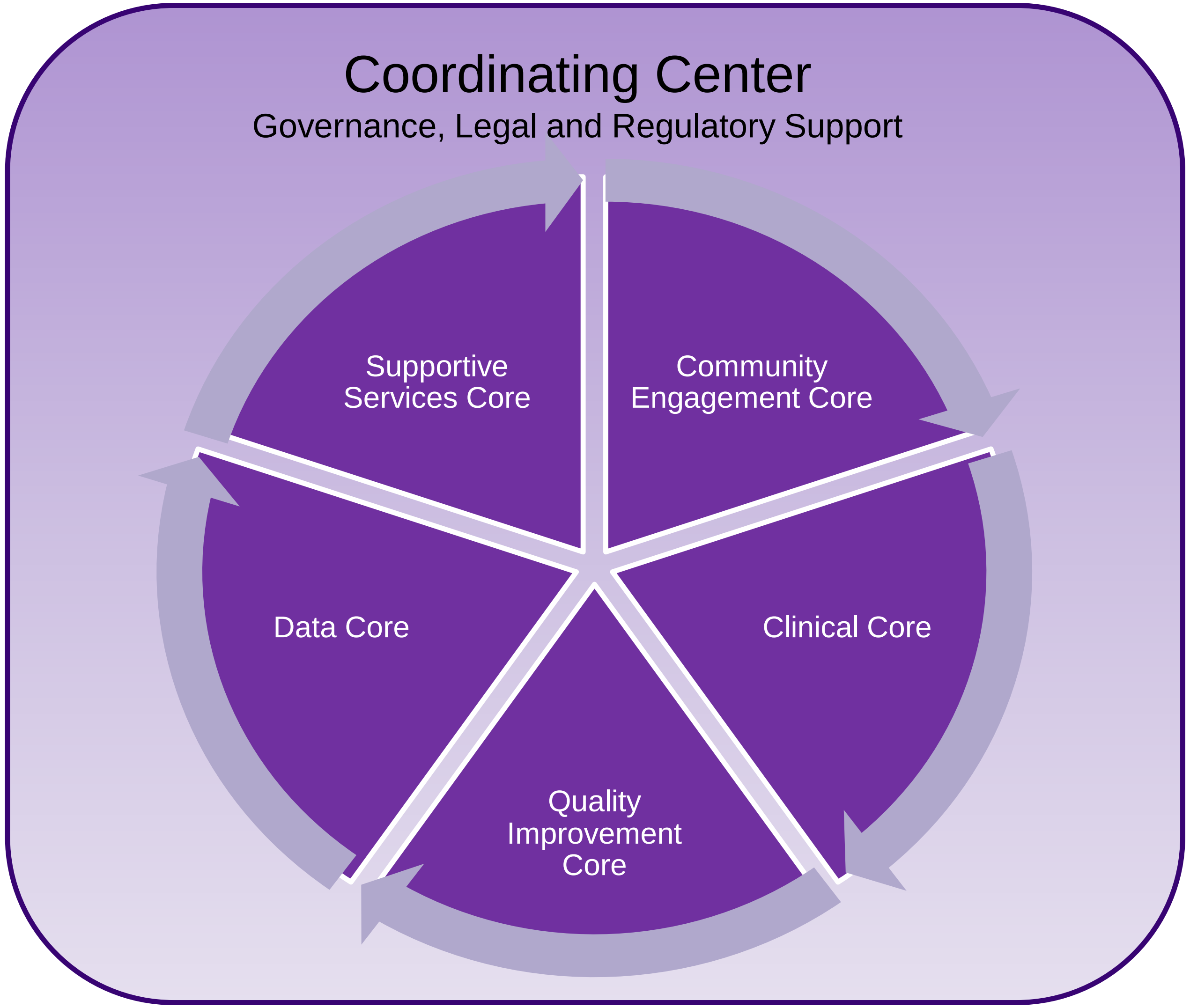
Data (clinical + research)
Clinical tools/techniques

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

ELHS Network Structure

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

- Registry/ Informatics
- Population management
- Research



Coordinating Center

Governance, Legal and Regulatory Support

Supportive Services Core

Community Engagement Core

Clinical Core

Quality Improvement Core

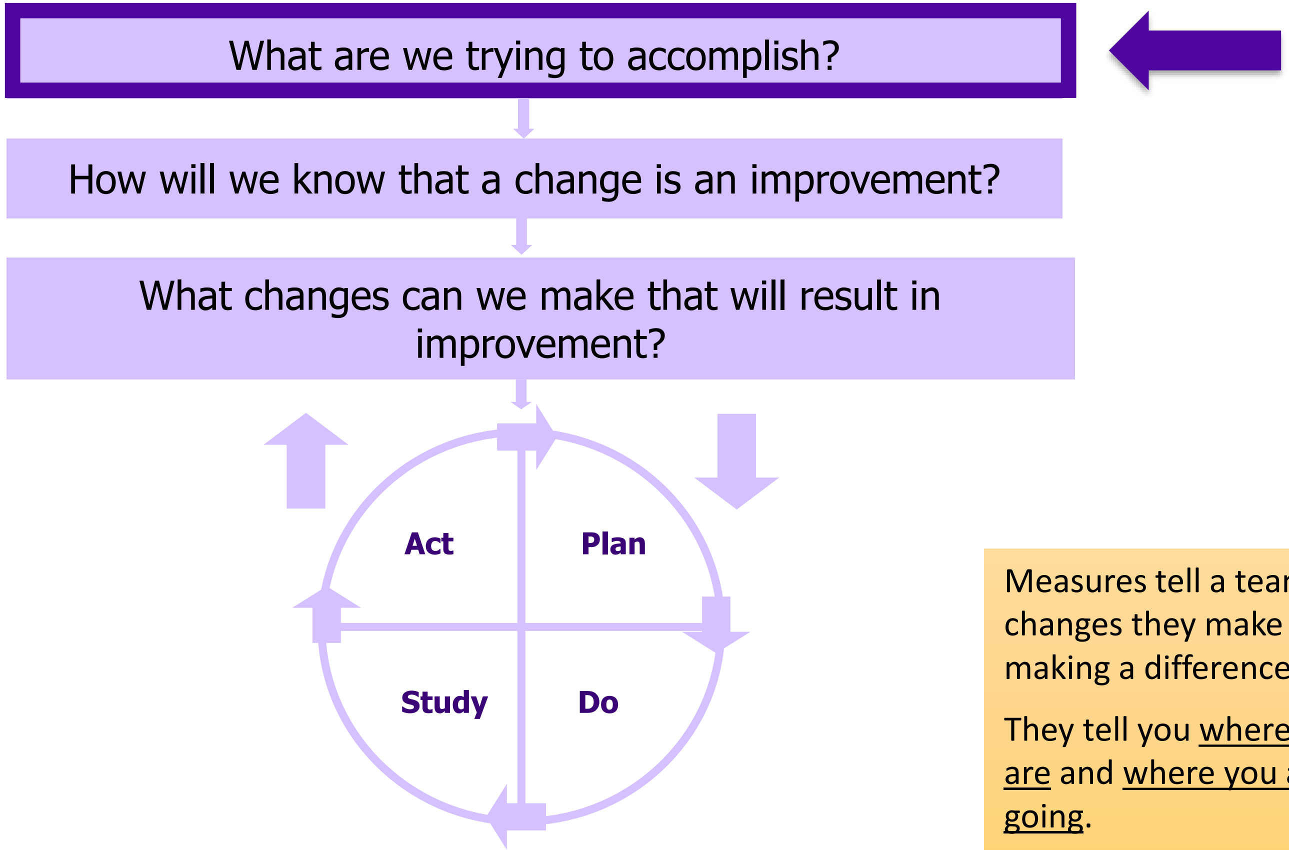
Data Core

- 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

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?

Measures tell a team if the changes they make are making a difference.

They tell you <u>where you are</u> and <u>where you are going</u>.

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:

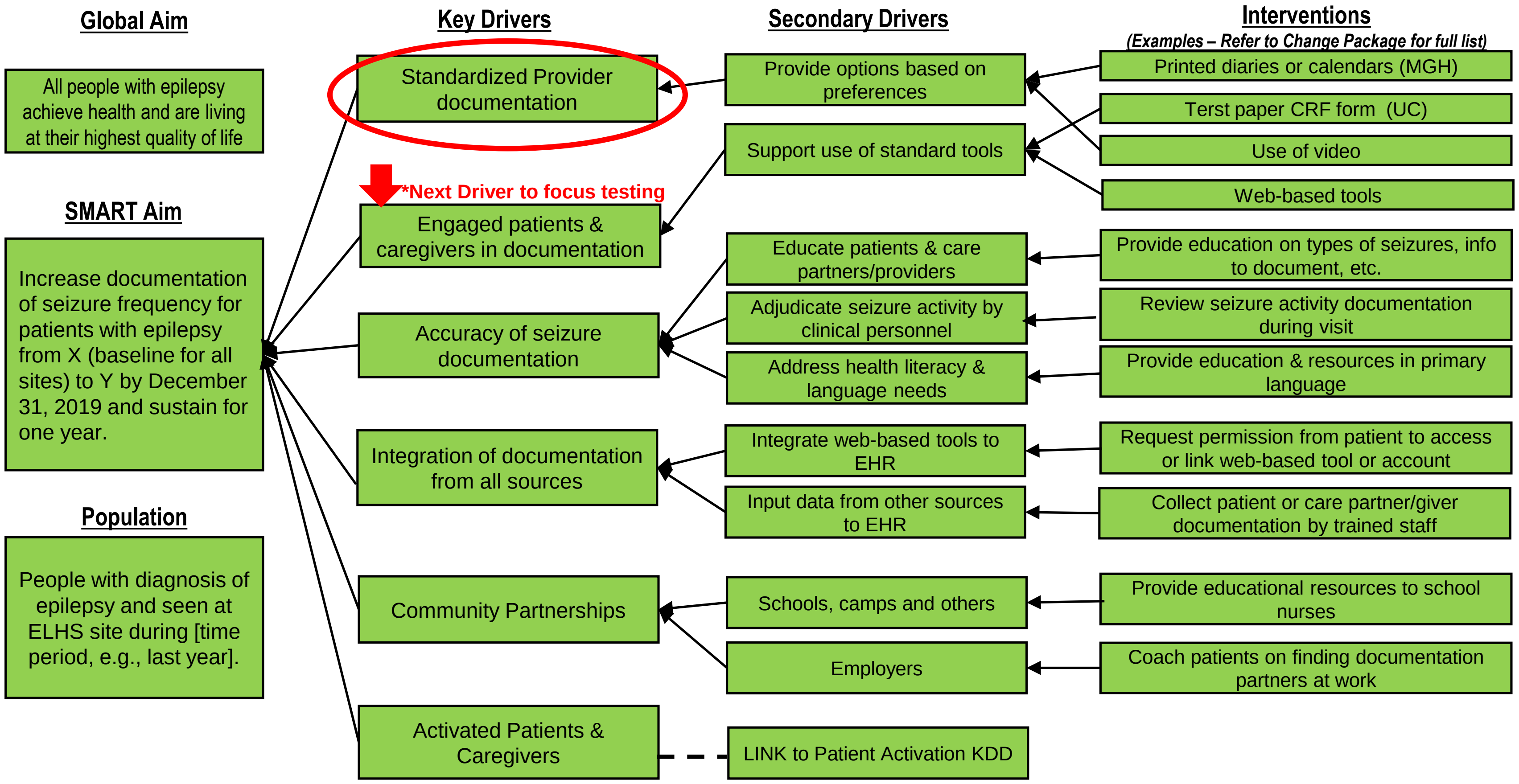
- *Improve quality of life from X to Y
- *Improve seizure control from X to Y
- *Improve seizure freedom from X to Y

Rev 2: 04-07-16

*= separated by seizure type and epilepsy syndrome

Seizure Frequency Documentation (KDD)

Project Leader(s): Susan Herman, Jeffrey Buchhalter, Lidia Moura, Brandy Fureman **Revision Date: 2-19-19 Vers. 4**



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 — *Next Driver to focus testing
- Accuracy of seizure documentation
- Integration of documentation from all sources
- Community Partnerships
- Activated Patients & Caregivers

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
- Schools, camps and others
- Employers
- LINK to Patient Activation KDD

Interventions

(Examples – Refer to Change Package for full list)

- Printed diaries or calendars (MGH)
- Terst paper CRF form (UC)
- Use of video
- Web-based tools
- 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
- Provide educational resources to school nurses
- Coach patients on finding documentation partners at work

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

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

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

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

Federal & Foundation Sponsors

- Speed, efficiency and impact
- More research per dollar
- More representative research
- Ability to evaluate impact on outcomes

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

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

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

pcori

Cincinnati Children's

National Association NAEC of Epilepsy Centers

TESS RESEARCH FOUNDATION
Treatments for Epilepsy & Symptoms of SLC13A5

REN
Rare Epilepsy Network

International Foundation For CDKL5 Research
HOPE · LOVE · CURE

AICARDI SYNDROME FOUNDATION

KCNQ2 Cure

Hypothalamic Hope Hamartomas
Giving Hope. Getting Answers.

The Cute Syndrome Foundation
www.TheCuteSyndrome.com

DRAVET SYNDROME FOUNDATION
Raising hope & changing lives through research

Rettsyndrome.org
ACCELERATING RESEARCH. EMPOWERING FAMILIES.

Tuberous Sclerosis Alliance

EPILEPSY FOUNDATION

The Carson Harris Foundation

DOOSE SYNDROME EPILEPSY ALLIANCE
Joining Forces to Create Change

ring14 USA

THE · JACK · PRIBAZ · FOUNDATION
KCNQ2
TOGETHER IN SEARCH FOR A CURE

LGS FOUNDATION
LENNOX-GASTAUT SYNDROME

RC20 ALLIANCE
EDUCATION. SUPPORT. FUNDING.

DUP15q ALLIANCE

PHRF

infantilespasms community
caregivers supporting caregivers

PCDH19 alliance

Bridge the Gap SYNGAP Education & Research Foundation

Aaron's Ohtahara Foundation

RASopathiesNet
Connect ~ Collaborate ~ Cure

NORSE INSTITUTE

pcornet The National Patient-Centered Clinical Research Network

pmsf

WISHES FOR ELLIOTT ADVANCING SCN8A RESEARCH

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.