Epilepsy Learning Healthcare System

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Beth Israel Lahey Health
Beth Israel Deaconess Medical Center

TAP TO GO BACK TO KIOSK MENU

Introduction

EPILEPSY IS THE 4TH MOST COMMON NEUROLOGICAL DISEASE AND AFFECTS PEOPLE OF ALL AGE

30% of people living with epilepsy do not have seizure control. Epilepsy often goes undiagnosed or is misdiagnosed. For people with epilepsy, there is often: inadequate access to specialized care, under-utilization of effective or curative treatments and higher rates of death and disability than in the general population.

With the support of the Epilepsy Foundation, the National Association for Epilepsy Centers, the Patient Centered Outcomes Research Institute and the Anderson Center for Health Systems Excellence, the Epilepsy Learning Health System (ELHS) is building a quality improvement and research network dedicated to improving outcomes for children and adults with epilepsy.

Partnering To Improve Outcomes

- ELHS centers learn from every patient at every visit: data is gathered from ELHS clinics across the country into a central registry.
- Data is analyzed centrally to find best practices, which leads to better outcomes for patients and families.
- Clinical and improvement science experts facilitate 2 in-person learning sessions per year. Monthly webinars will enable participants to share improvements and insights with the entire network.
- New ideas are generated and tested in ELHS centers using iterative Plan-Do-Study-Act (PDSA) cycles.
- Patients and families are integrated at every step to drive priorities, design new initiatives, and provide insight.
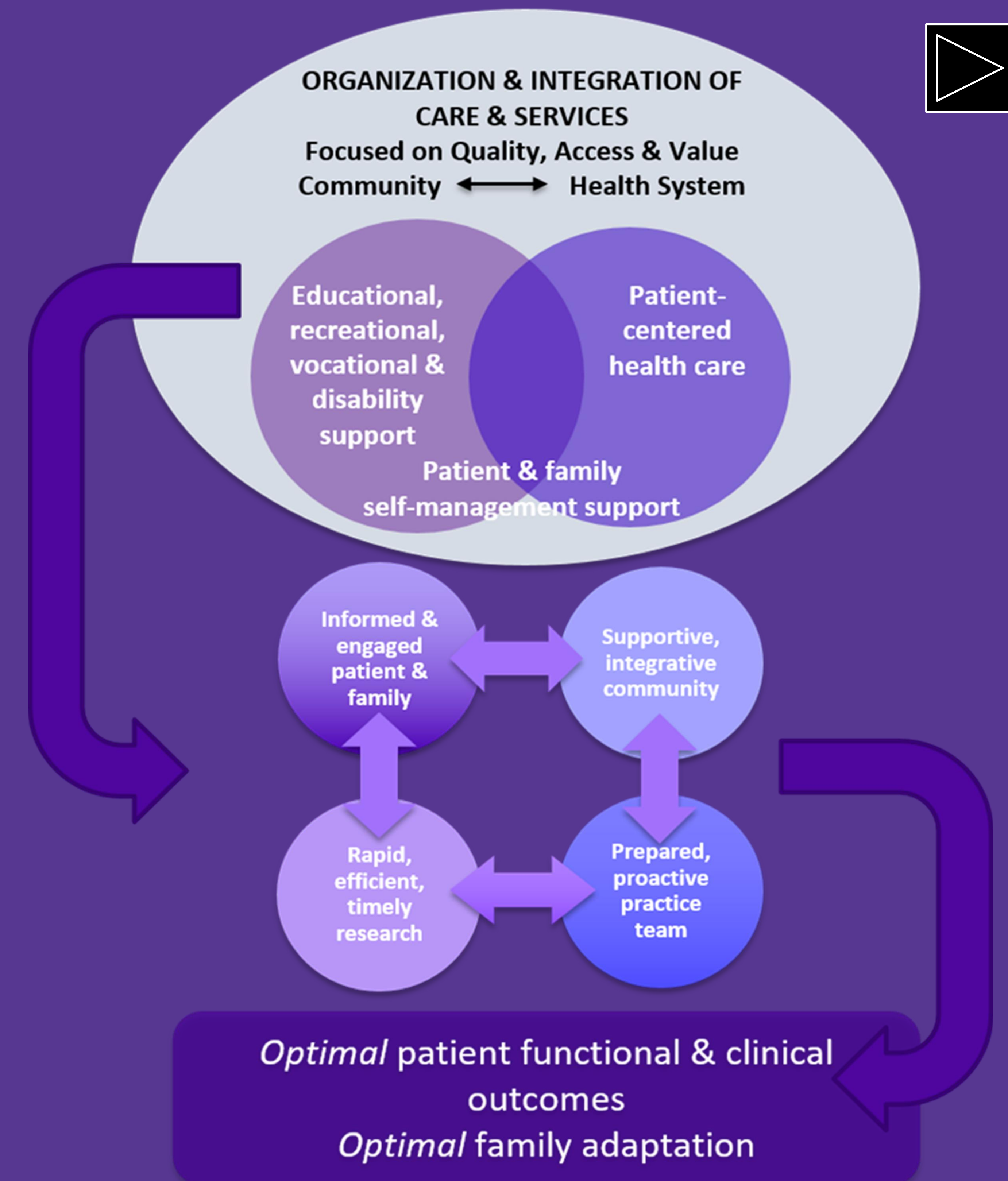
Goal

All people with epilepsy are living their highest quality of life, striving for freedom from seizures and side effects, and we won't stop until we get there.

IMPROVEMENT TEAM

Susan Herman, MD — Site lead
Trudy Pang, MD — Director Women's Clinic
Andrea Donahue — Research Coordinator
Matthew Reed, RN — Epilepsy Nurse
Kyle Rossi, MD — Epilepsy Fellow

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

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Epilepsy Learning Healthcare System

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
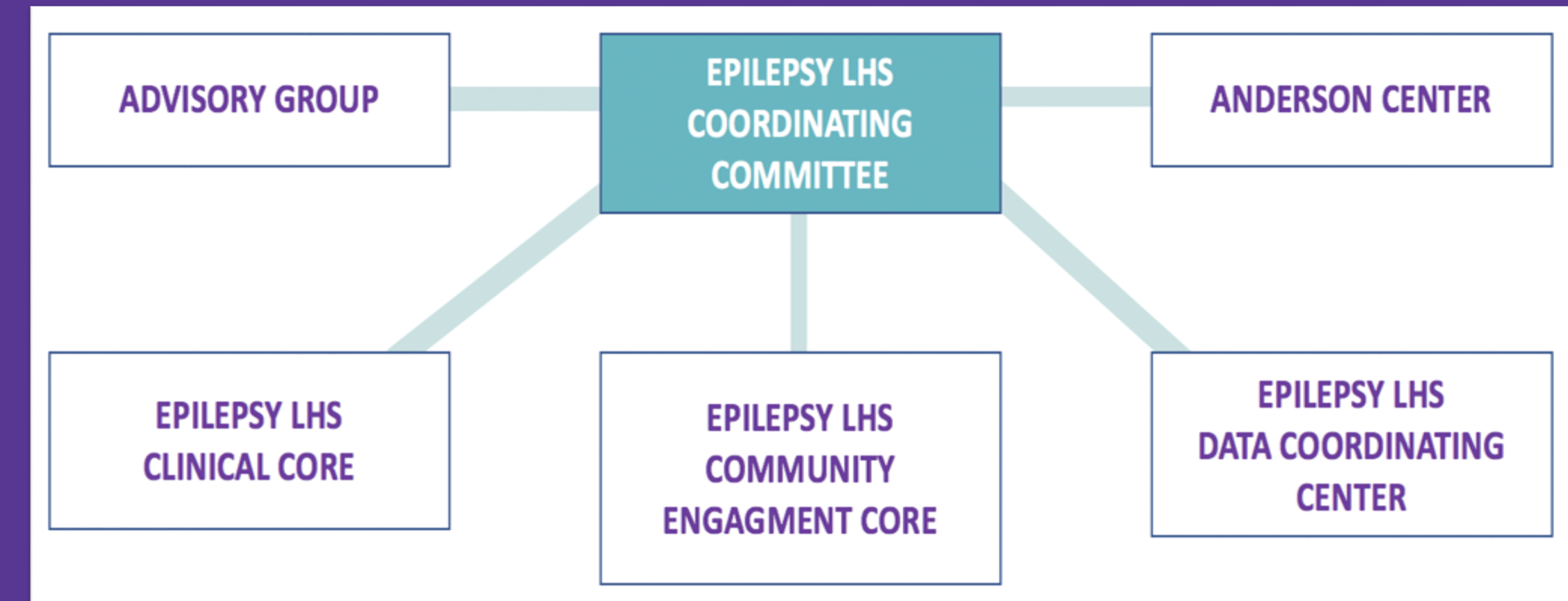- Early mortality above general population

Phase 1 Global Measures

Increase by 50% the percentage of people with epilepsy and their families who…

… have well-documented seizure frequency and severity

… have met their goal for seizure freedom or seizure reduction

… have met their quality of life goals

… are highly activated patients / parents / care partners

… are screened and treated for psychiatric comorbidities

… have documentation of transition planning from pediatric to adult care

… receive timely treatment of status epilepticus

Increase by 50% the percentage of people with drug resistant epilepsy who…

… are referred by the Epilepsy Foundation for comprehensive epilepsy specialty care

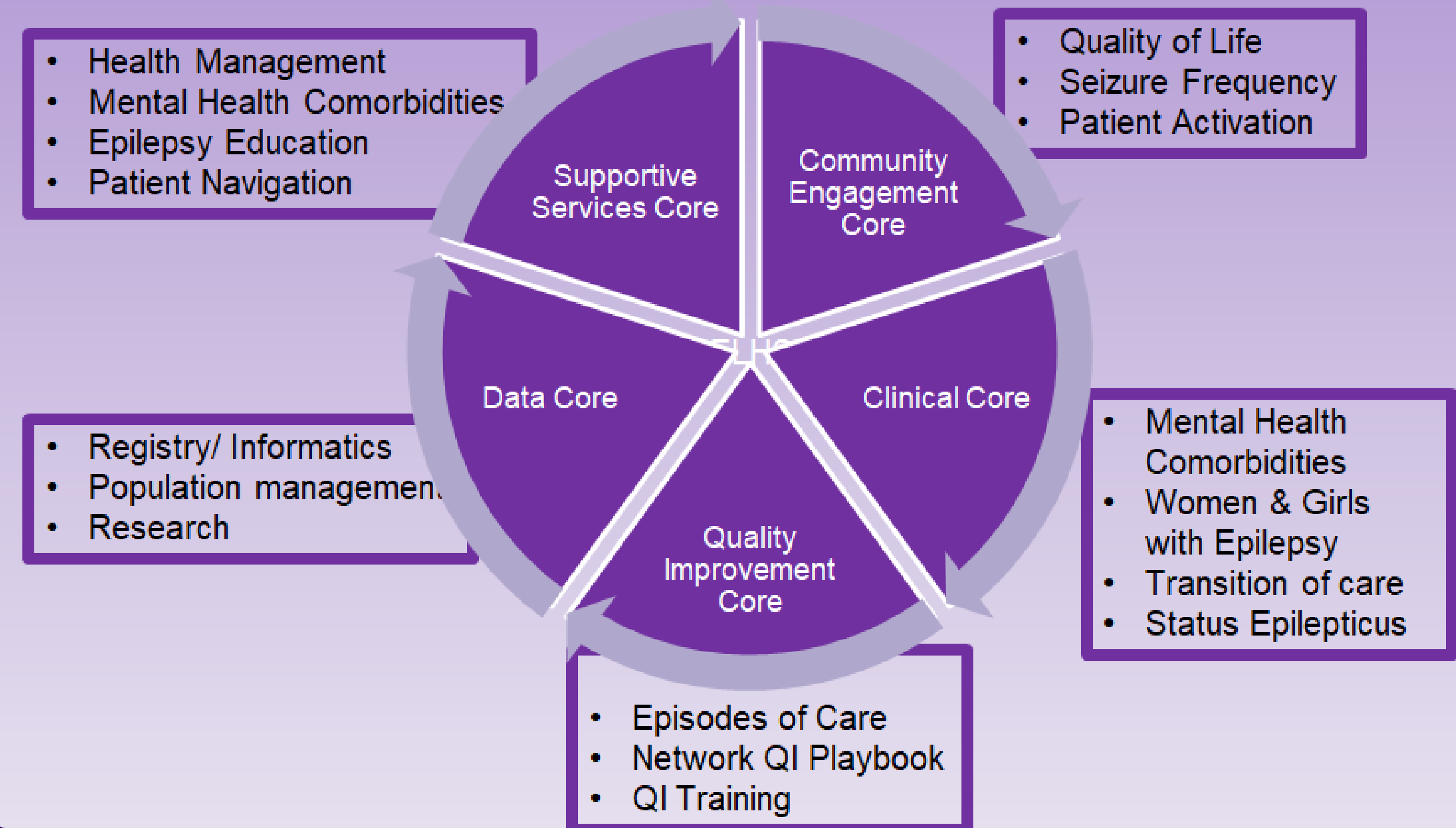… are referred for AND are offered epilepsy surgery (resective, VNS, RNS, DBS)

Increase by 50% the percentage of women with epilepsy who…

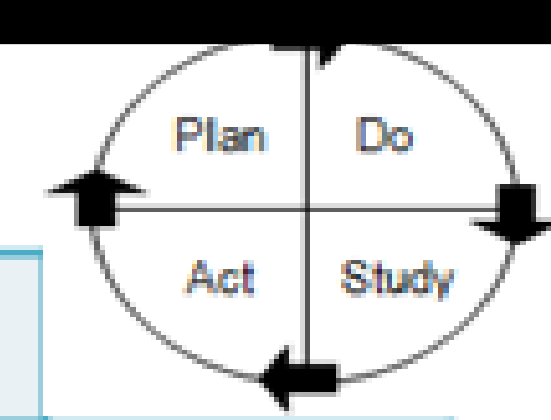… are provided education and evidence-based management of contraception and pregnancy

Network Structure

ADVISORY GROUP

EPILEPSY LHS COORDINATING COMMITTEE

ANDERSON CENTER

EPILEPSY LHS CLINICAL CORE

EPILEPSY LHS COMMUNITY ENGAGMENT CORE

EPILEPSY LHS DATA COORDINATING CENTER

Coordinating Center
Governance, Legal and Regulatory Support

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

- Quality of Life
- Seizure Frequency
- Patient Activation

Supportive Services Core

Community Engagement Core

Data Core

Clinical Core

Quality Improvement Core

- Registry/ Informatics
- Population management
- Research

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

- Episodes of Care
- Network QI Playbook
- QI Training

Epilepsy Learning Healthcare System

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Ramp #: 1	Test #: 1	Test Start Date: 2/13/2019	Test Complete Date: 5/6/2019

Project SMART Aim: Improve patient and provider seizure documentation

What key driver does this test impact? Seizure Documentation

What is the objective of the test? To encourage provider participation and adherence for seizure documentation

PLAN:

A. Briefly describe the test:

Coordinator to obtain results/forms from patients before clinic (PROs and Demographics CRFs). Dr. Herman will test the Provider CRF in clinic with the patient. This will be done to determine feasibility, success and time invested in CRFs.

B. How will you measure the success of this test?

The number of CRFs used (how many patients complete CRFs before clinic). The time it takes to fill out CRFs.

C. What would success look like?

If patients can fill out the questionnaires by themselves (as this will reflect that questions are easy to understand).If the provider will takes < 2min to fill out CRFs, patient takes < 20min and coordinator < 10min (all Demographic CRFs of that day).

D. What do you predict will happen?

70% of patients will accurately fill out the CRFs.
30% will not (for any reason).
We'll get suggestions of how this change can be implemented.

E. Plan for collection of data:

Paper and web-based survey (eventually).

F. Tasks:

List the tasks necessary to complete this test (what)	Person responsible (who)	When	Where
Create data collection form	Andrea Donahue	2/2019	BIDMC
Review clinic schedule	Andrea Donahue	2/2019	BI/Shapiro 8
Test CRFs in clinic	Dr. Herman/Andrea	2/ - 3/28	BI/Shapiro 8
Add questions that will allow for feedback	Dr. Herman/Andrea	3/28	BI/Shapiro 8
Discuss results as a team at a team meeting	Dr. Herman	4/2/19	Epilepsy Meeting
Survey other physicians: how would they feel about implementing these CRFs in their clinic?	Andrea Donahue	4/2/1	Epilepsy Meeting

DO: Test the changes.

Was the cycle carried out as planned? ☑ Yes or ☐ No

Record data and observations.

At least 75% of all patients seen in clinic each day were able to complete CRFs. Most patients took less than 20min, while the rest took longer.
Dr. Herman took less than 3min to complete CRFs in clinic.

What did you observe that was not part of the plan?

Patients needing help from their caregiver or translator to complete CRFs. Some patients coming to clinic late and not having enough time to complete CRF before seeing Dr. Herman.

STUDY:

Did the results match your predictions? ☑ Yes or ☐ No

Compare the result of your test to your previous performance:

Most patients were able to complete questionnaires and a few found it difficult (i.e., not enough time, not in their language, some questions were repetitive or confusing and needed help)

What did you learn?

It would be more time efficient if patients knew that they have to complete CRFs before their clinic visit and possibly ask them to fill them out the day before. Also, it would be helpful to have CRFs available in more languages (in order to capture a wider population).

ACT: Decide to Adapt, Adapt or Abandon (shade one box).

☑ **Adapt.** Improve the change and continue testing the plan. Plan/changes for next test:

We will test StudyTrax and try to collect CRFs electronically. Patients will have the option to fill out CRFs in waiting room by using their phone or the day before at home.
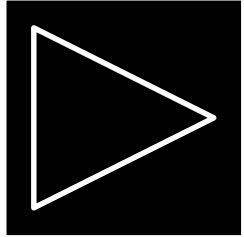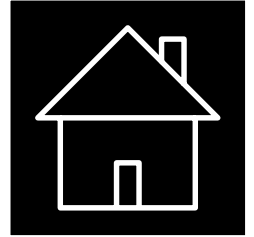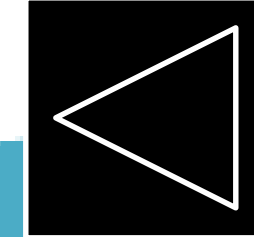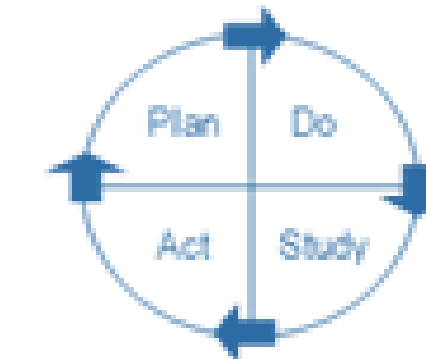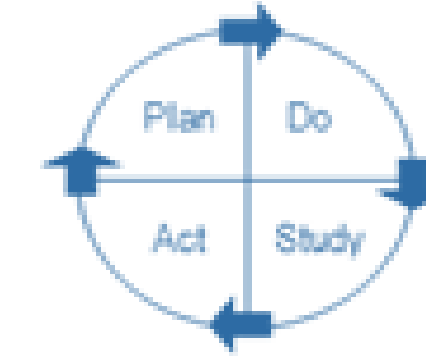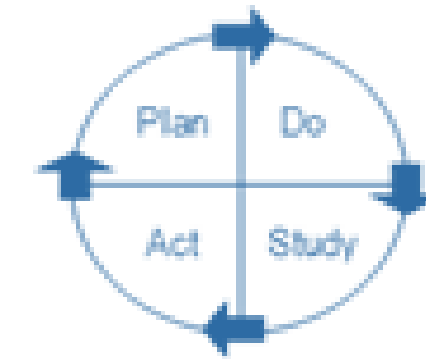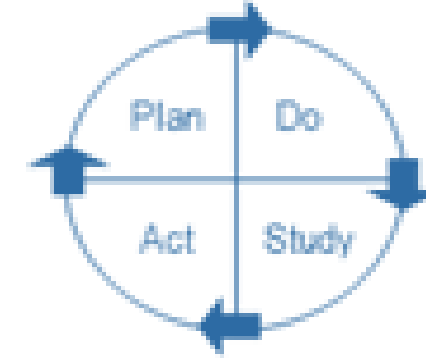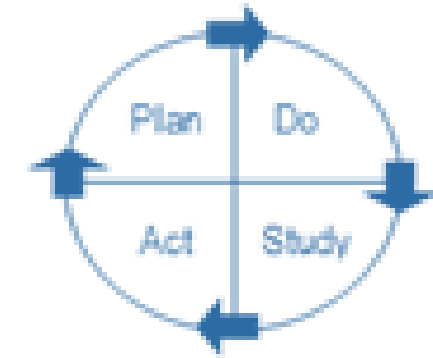
☐ **Adopt.** Select changes to implement on a larger scale and develop an implementation plan and plan for sustainability.

☐ **Abandon.** Discard this change idea and try a different one.

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EPILEPSY LEARNING HEALTHCARE SYSTEM

*To be completed prior to beginning PDSA testing

	Cycle 1		Cycle 2		Cycle 3		Cycle 4		Cycle 5	
Test Description:	Feasibility of CRFs		PRO CRFs with PHQ9 and GAD7 as options for Mental Health		Feasibility of CRFs		Feasibility of CRFs		Feasibility of CRFs with other providers	
Test Population (description & n =):	Adult patients with Epilepsy n = 12		Adult patients with Epilepsy n = 12		Adult patients with Epilepsy n = 10		Adult patients with Epilepsy n = 17		Adult patients with Epilepsy n = 30	
Location of test:	BIDMC/Shapiro 8		BIDMC/Shapiro 8		BIDMC/Shapiro 8		BIDMC/Shapiro 8		BIDMC/Shapiro 8	
Date (From – To):	2/4/19	2/11/19	2/14/19	2/21/19	2/25/19	2/28/19	3/7/19	3/14/19	4/22	4/25
Duration (# hours/days):	Day 1 = 4 hours	Day 2 = 4 hours	Day 1 = 4 hours	Day 2 = 2 hours	Day 1 = 3 hours	Day 2 = 3 hours	Day 1 = 4 hours	Day 2 = 5 hours	Day 1 = 4 hours	Day 2 = 5 hours
Test Conditions (vary degree, size &/or intensity):	Testing adult patients with epilepsy diagnosis (n = 12; total for 2 days)		Testing adult patients with epilepsy diagnosis (n = 12; total for 2 days)		Testing adult patients with epilepsy diagnosis (n = 10; total for 2 days)		Testing adult patients with epilepsy diagnosis (n = 17; total for 2 days)		Testing adult patients with epilepsy (n = 24; total for 2 days & 2 providers)	
Test Results:	Confusing for patients; they had multiple options for Mental Health & QOL		Patients were not confused. Most patients completed PRO CRF in time before clinic		Some patients able to finish but at least half had to finish after clinic visit		Some patients taking too long before clinic and not able to finish after clinic		Prediction: providers will adapt CRF into their routine but might start with 2 questions at a time	
Action (Adapt, Adopt or Abandon):	Adapt: only questionnaires kept for mental health = PHQ9 & GAD7 (that are routinely used at BIDMC)		Adopt		Adopt		Adapt: we'll try using StudyTrax so patients can complete CRFs before clinic		(Test pending)	

EPILEPSY LEARNING HEALTHCARE SYSTEM

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- Roll out standardized case report forms in epilepsy clinics
- Epilepsy providers at BIDMC will incorporate data collection into their daily practice
- We will utilize StudyTrax to facilitate electronic data capture from patients before and during clinic visits
- We will work with IT to optimize data collection and integration into Web OMR
- The changes and adaptations will be made through PDSA cycles
- We will share innovations with the rest of the ELHS nationally

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

Data Sources

Provider Reported Data

- Enrollment/Consent ①
- Provider Reported CRFs ②

Patient Reported Data

③ Demographic
- Participant info ④
- Patient Reported CRFs ⑤

Additional Data – Second generation ELHS

- EHR data (e.g., encounter, diagnosis, procedures, labs, vital signs)
- Claims data (e.g., drug dispensing, hospitalizations, ED visits, etc.)
- Other (death/Cause of death)

EPILEPSY FOUNDATION

ELHS Data Center (Epilepsy Foundation)

(**where necessary and possible**: data integration, quality check, validation, curation, annotation, automation)

Integration Layer

ELHS Registry (Anderson Center)

Database

Application / Visualization Layer

Dashboards

Description of data collection at different levels.