Welcome to the webinar:

Improving the quality of rare childhood epilepsy care

May 27, 2020

Pediatric epileptologists

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Parents

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DEE-P CONNECTIONS

Pediatric epilepsy LHS

EPILEPSY LEARNING HEALTHCARE SYSTEM

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Anup Patel MD

- Section Chief of Neurology at Nationwide Children's Hospital
- Associate Professor of Neurology at the Ohio State University College of Medicine
- Leadership team for Pediatric Epilepsy Learning Healthcare System (PELHS)
- President-Elect Child Neurology Foundation (CNF)

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Jeffrey Buchhalter MD, PhD

- Adjunct Professor of Pediatrics, at the University of Calgary, College of Medicine

- Leadership team for Pediatric Epilepsy Learning Healthcare System (PELHS)

- Leadership team for the Epilepsy Learning Healthcare System (ELHS, *all ages*)

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What is QI and Why is it Important?

Jeffrey Buchhalter, MD and Anup Patel, MD
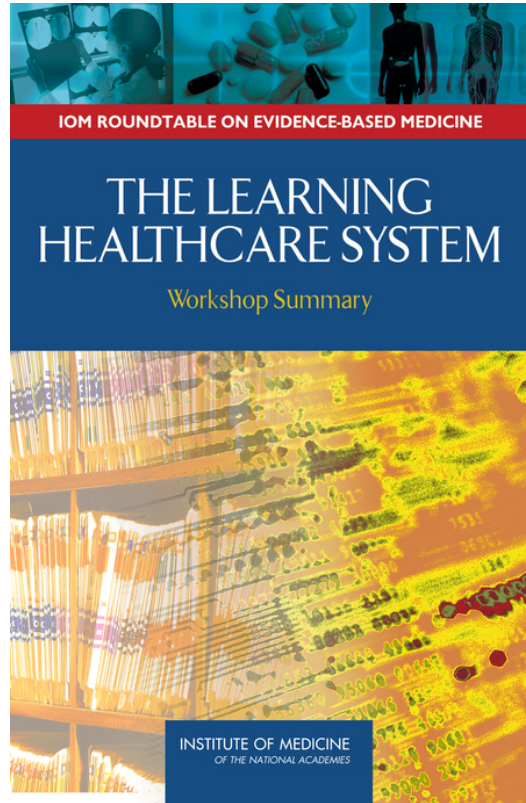
Unmet Needs- Why an Epilepsy LHS is Needed Now

- 30% (overall) of people living with epilepsy are not seizure free, <u>much less for the rares</u>

- Serious injuries, difficult social relationships, school issues and premature death are associated with uncontrolled seizures

- Comorbidities such as sleep, GI, respiratory and behavior are frequently undiagnosed & not treated

- Potentially palliative & curative treatments (medication, surgery, devices, diet) are underutilized due to inadequate access & referral to specialized care

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Approaches to do better

- Continue Randomized Controlled Trials

- Continue basic science discovery- *individual mutations*

- Promote data aggregation from consortia e.g. PERC

- Learn from every patient in a structured way-

Quality Improvement

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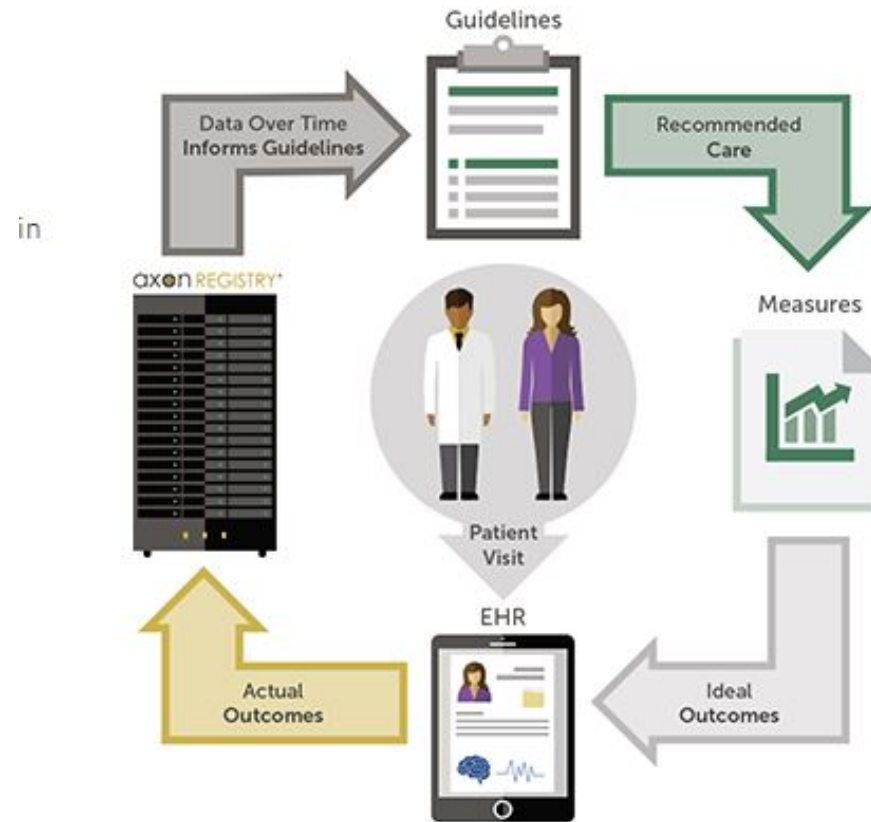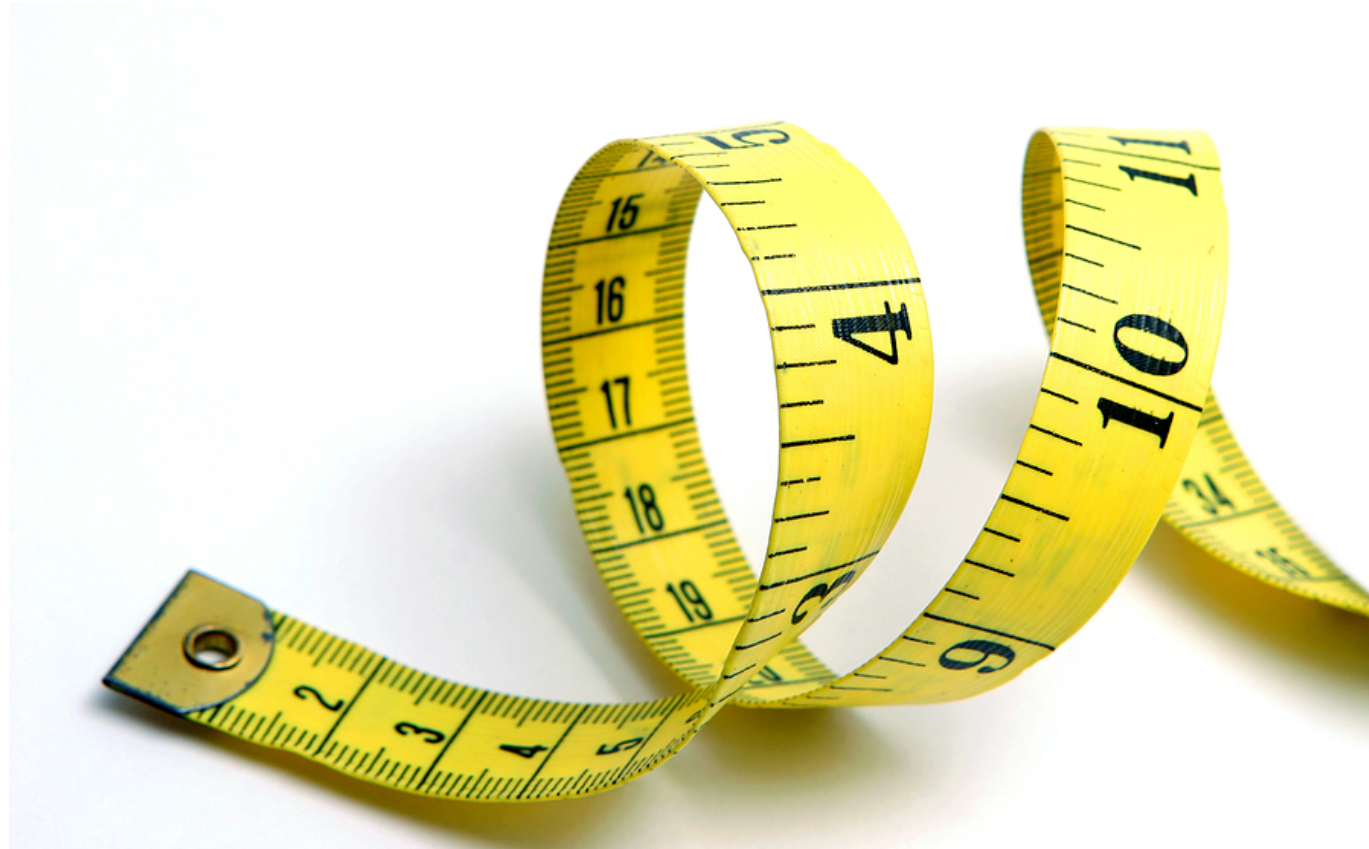
What is a Learning Healthcare System?

2007

- Have **leaders** who are committed to a **culture of continuous learning and improvement**
- Systematically gather and apply **evidence in real-time** to guide care
- Employ **IT** methods to share new evidence with clinicians to improve decision-making
- Promote the **inclusion of patients & *caregivers*** as vital members of the learning team
- **Capture and analyze data and care experiences** to improve care
- Continually assess outcomes refine processes and training to create a **feedback cycle** for learning and improvement

This process is Quality Improvement!

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Quality Cycle

What is a Quality Measure?

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Centers for Medicare and Medicaid

"Quality measures are tools that help us measure or quantify healthcare processes, outcomes, patient perceptions, and organizational structure and/or systems that are associated with the ability to provide high-quality health care and/or that relate to one or more quality goals for health care. These goals include: effective, safe, efficient, patient-centered, equitable, and timely care."

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Types of measures

Quality measures quantify healthcare processes, outcomes, patient perceptions, and organizational structure and/or systems that are associated with the ability to provide high-quality health care.

Structure

What is in place (resources, systems)

Certified stroke center

Process

What is done (treatments and therapies)

tPA w/in 2 hours

Outcome

What will change as a result

90-day Function

Quality Measures Myths

- NOT GUIDELINES!
- Not used for malpractice
- Not to say poor care if provided

What is Quality Improvement

Health Resources And Services Administration

- "Quality improvement (QI) consists of systematic and continuous actions that lead to measurable improvement in health care services and the health status of targeted patient groups. The Institute of Medicine (IOM), which is a recognized leader and advisor on improving the Nation's health care, defines quality in health care as a direct correlation between the level of improved health services and the desired health outcomes of individuals and populations."

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What is a Learning Healthcare System?

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Institutes of Medicine

"As a system in which science, informatics, incentives, and culture are aligned for continuous improvement and innovation, with best practices seamlessly embedded in the delivery process and new knowledge captured as an integral by-product of the delivery experience."

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Ongoing efforts

- Pediatric Epilepsy Learning Healthcare System (PELHS)

- Epilepsy Learning Healthcare System (ELHS, pediatric & adult)

- Quality Committee & Axon Registry (American Academy of Neurology)

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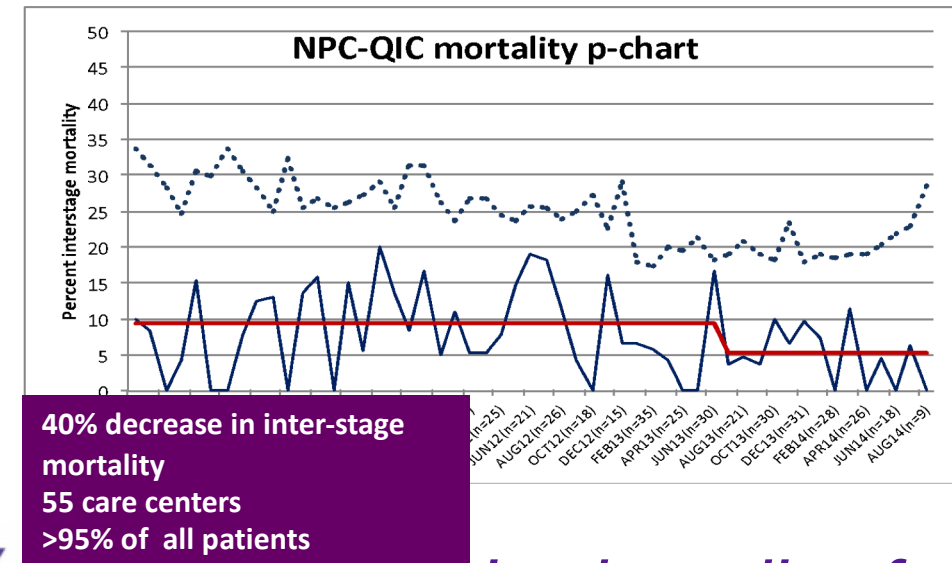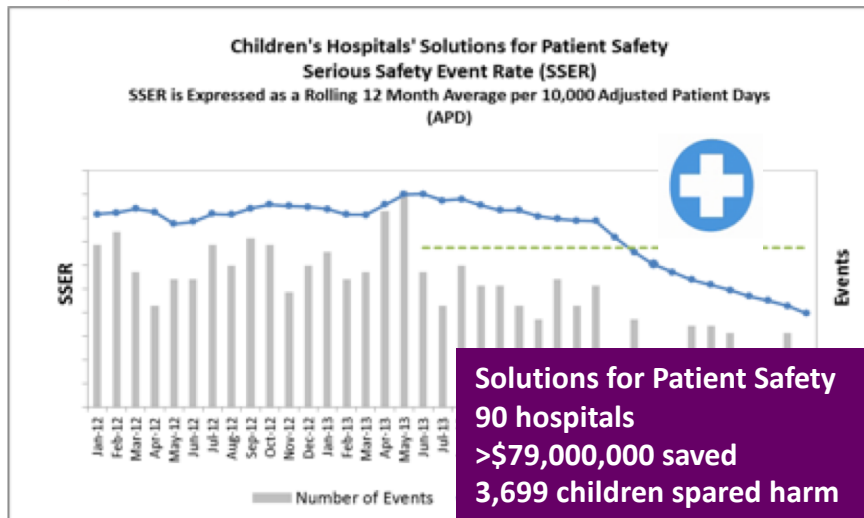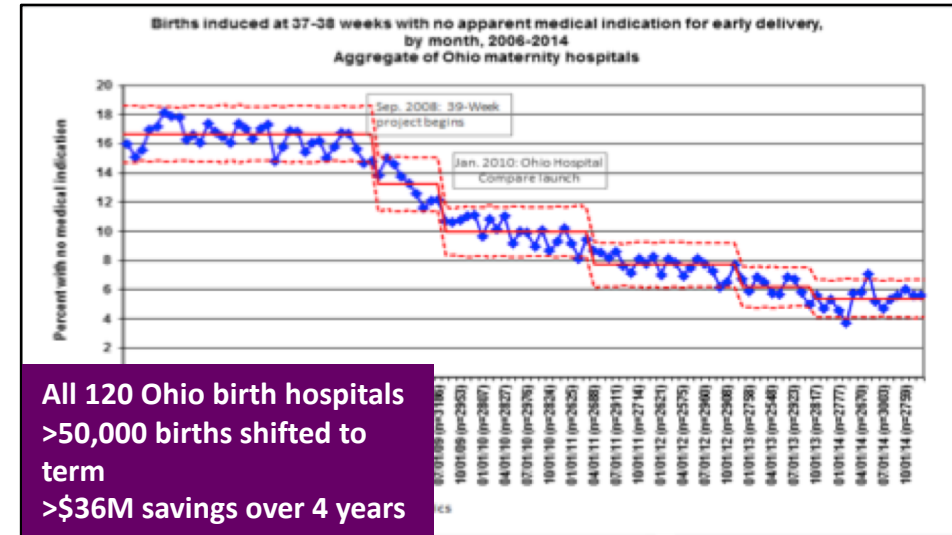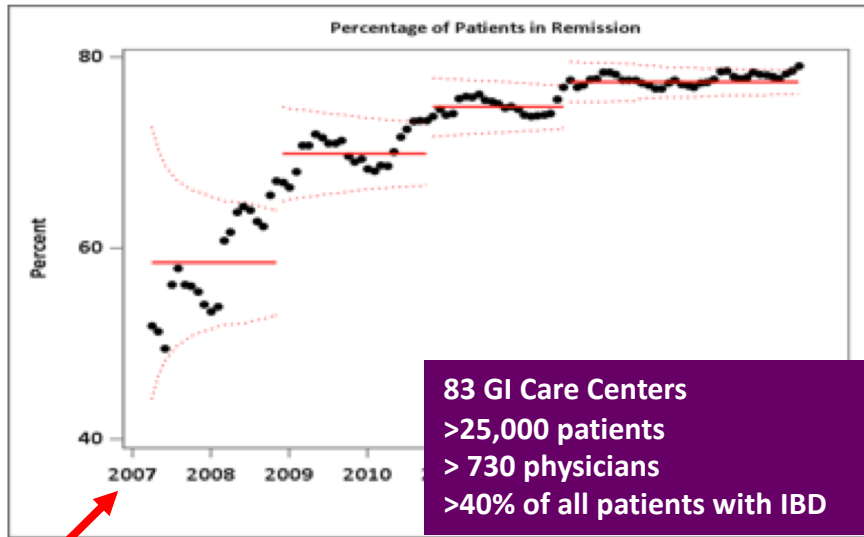# Efforts around data collection and conceptualization

- Quality Improvement

- Comparative effectiveness

- Surveillance and Epidemiology

QI Examples

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QI Changing Outcomes in Serious Pediatric Disorders

Percentage of Patients in Remission

83 GI Care Centers
>25,000 patients
> 730 physicians
>40% of all patients with IBD

Births induced at 37–38 weeks with no apparent medical indication for early delivery, by month, 2006-2014
Aggregate of Ohio maternity hospitals

All 120 Ohio birth hospitals
>50,000 births shifted to term
>$36M savings over 4 years

Children's Hospitals' Solutions for Patient Safety
Serious Safety Event Rate (SSER)
SSER is Expressed as a Rolling 12 Month Average per 10,000 Adjusted Patient Days
(APD)

Solutions for Patient Safety
90 hospitals
>$79,000,000 saved
3,699 children spared harm

NPC-QIC mortality p-chart

40% decrease in inter-stage mortality
55 care centers
>95% of all patients

DEE-P CONNECTIONS

Pediatric epilepsy LHS

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Seizure Rescue Medication Project

- Reached out to caregivers and patients about thoughts on rescue medications

- Surveyed caregivers on rescue medication preferences, barriers, fears, etc.

- Caregivers made a huge impact as their voices were heard

- Decreased under-dosed medications from 3.5% to 0.6%

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Emergency Department Reduction Project

- Multidisciplinary team convened with advocacy, caregivers, social work, etc.

- Goal to decrease ED visits for children with epilepsy

- Identified caregiver reasons for ED use for epilepsy care

- Decreased ED visits from 13 to 11.6 per 1000 patients per month

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Call to Action!

Questions for your Careproviders?

- Are you (your group) participating in an epilepsy learning healthcare system?
  - If no- "Why not?"
  - If no- "Would you like me to get you some additional information?" (refer to us)
  - If yes- "Great, thanks, how can I help?"

- Would you like me to write a letter to your chairperson, CEO to get support for you to join?

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