

Welcome

47TH
Annual Meeting

PHOENIX

May 17-20, 2026



SYSTEM REDESIGN:

How cutting edge information capabilities, population health management and co-production can enable a new era for clinical trials

Brandy E Fureman, PhD FAES
May 19, 2026

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ANNUAL MEETING

DISCLOSURES

- 100% Salary support from the **Epilepsy Foundation**, a non-profit organization, which reports revenue from individual donors, state and Federal grants, and corporate sponsorships including all of the 2025 Research Roundtable member companies and others.
- Received public health or research grants from **CDC, PCORI, PCORnet, NIH, the Hearst Foundation, PhRMA Foundation, UCB, and Jazz Pharmaceuticals.**
- Hold equity options in **Enliten AI**
- Independent Consultant, **Neuroscience Navigators, LLC**

My Perspectives...



NIH/NINDS Program Officer

- DSMBs
- Clinical Research Consortium
- Epilepsy CDEs
- Observational Studies
 - NEAD, MONEAD, FEBSTAT, EPGP
- Clinical Trials
 - RAMPART, ESETT
 - ERSET, ROSE Trials
 - CAE Trial

Epilepsy Foundation Principal Inv.

- Research Roundtable in Epilepsy
- Rare Epilepsy Network Registry
- Human Epilepsy Project 2
- CDC Cooperative Agreement for Epilepsy Public Health
- Epilepsy Learning Healthcare System (ELHS)
- Health Equity in Neuroscience Research - Epilepsy

THE CURRENT CHALLENGE

- Growing protocol complexity and operational burden (and expense)
- Recruitment, retention, and representation barriers
- Fragmented digital data and underused information systems

→ Result: Slow, expensive evidence generation that often falls short of public health needs *and* fails to translate positive results to standard of care in a timeframe that matters

THE OPPORTUNITY:

**Leveraging better real-world care AND
research capabilities of
“Learning Health Networks”**

Health Care System

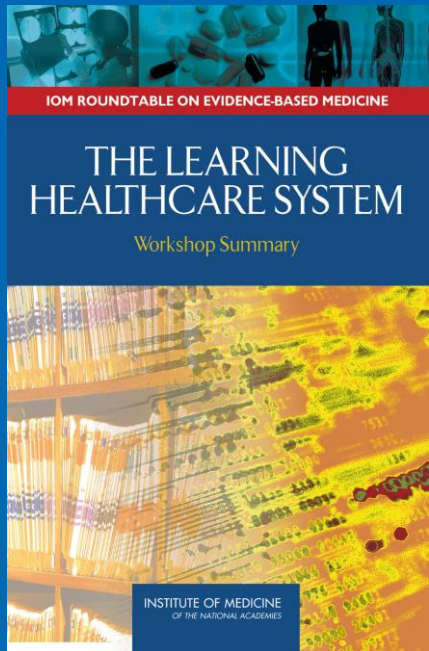
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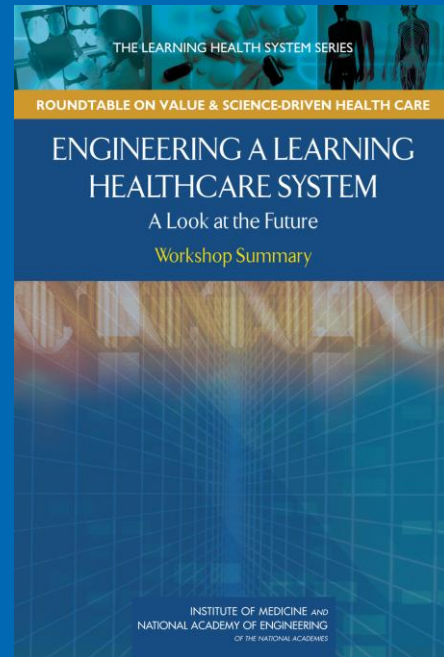
**“Every system is perfectly designed
...to get the results it gets”**

-Paul Bataldan

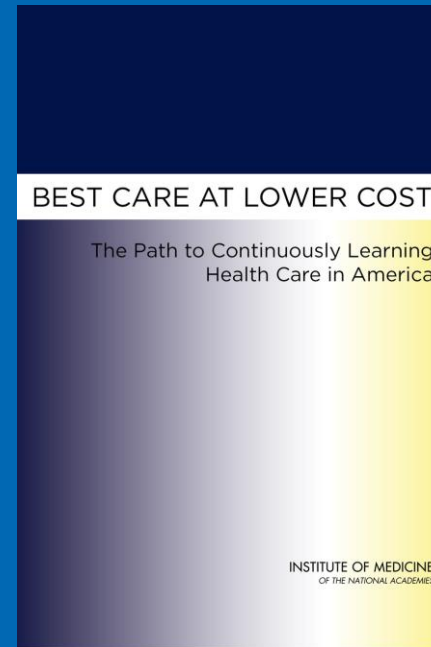
Concept → Design → Transformation



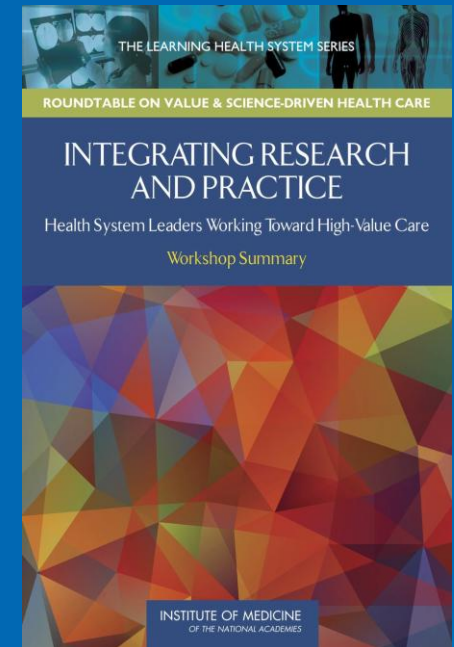
2007
The Learning
Healthcare System



2008
Engineering a
Learning Healthcare
System



2013
Best Care at Lower
Cost



2015
Integrating Research
and Practice

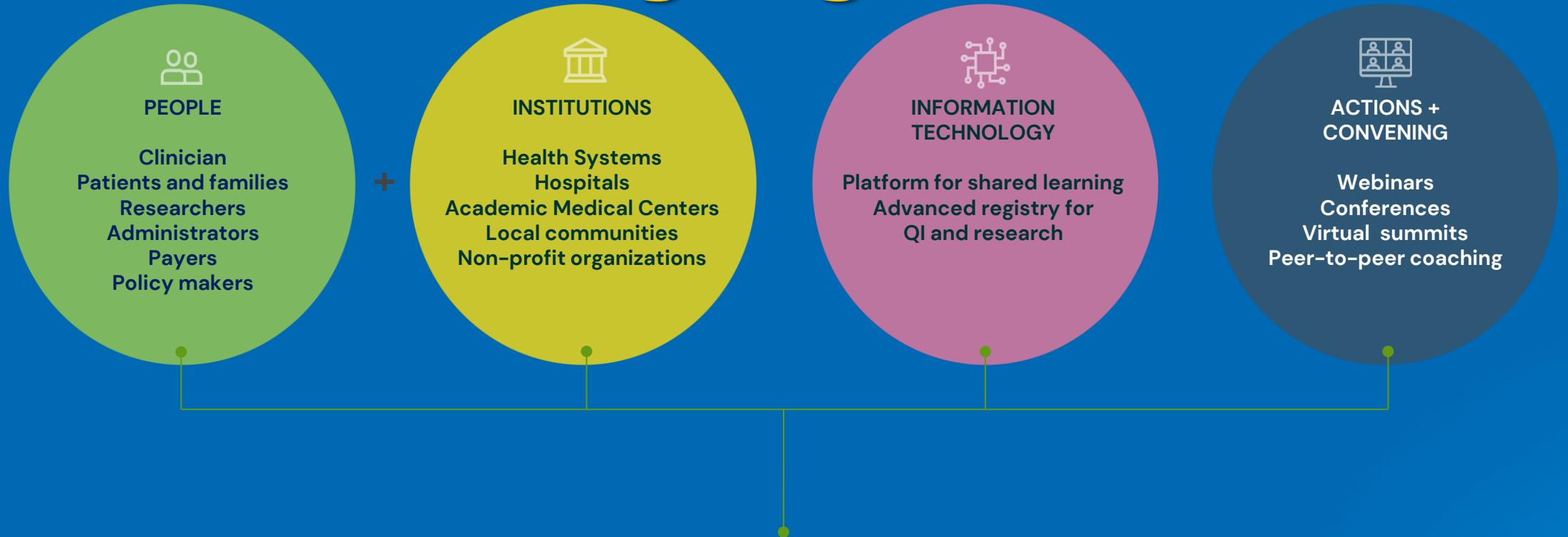


Meet Orleans

<https://www.youtube.com/watch?v=IntogAhn1V0>



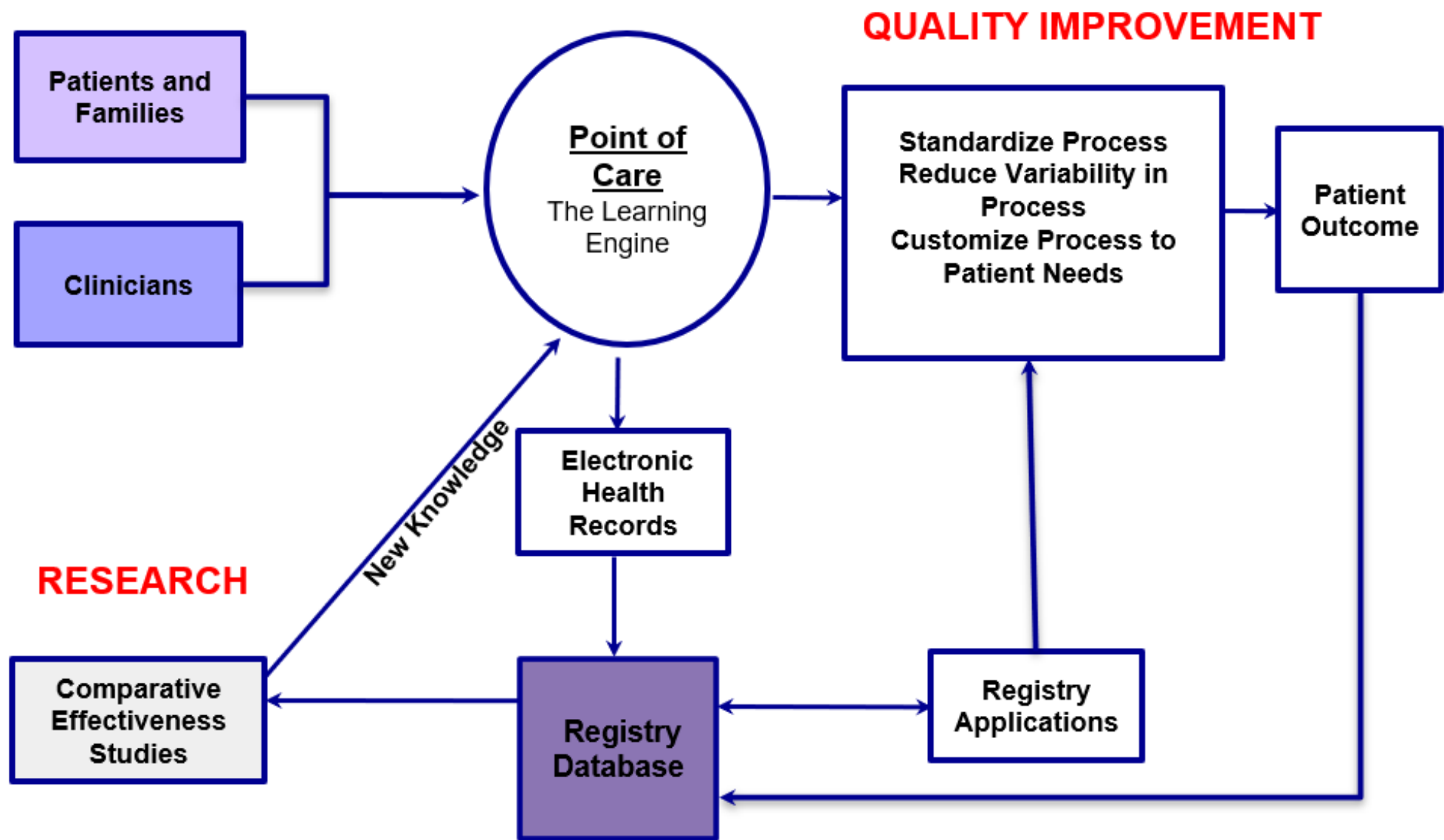
Learning Health Networks Bring Together:



RESULTS:

Improved outcomes and well-being by orders of magnitude.


Safer, more reliable care processes.



Slide credit: Adapted from CCHMC Anderson Center for Health Systems Excellence

Our Learning Health Network Partners

7 Networks • 7 Conditions • One Platform




Pancreatic Cancer

Canopy Cancer Collective



Juvenile Idiopathic Arthritis

PR-COIN




Pediatric IBD (Crohn's & Colitis)

ImproveCareNow




Rett Syndrome

International Rett Syndrome Foundation



Bipolar Disorder

Bipolar Action Network



Pediatric Kidney Disease

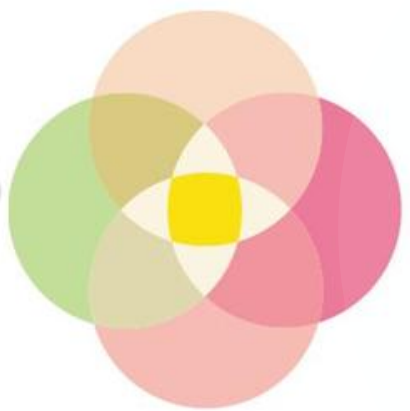
Improving Renal Outcomes Collaborative



Autism Spectrum Disorder

Autism Care Network

Results



**HEALTHIER
TOGETHER**



Healthier Together Results

Increased remission from 60% to 82% among children and youth with Crohn's Disease and Ulcerative colitis across **110 centers** and **30,000 patients**.

– *ImproveCareNow Network*

Across 140+ children's hospitals in the "Solutions for Patient Safety Network" (examples):

- Decreased serious safety events by 32%
- Adverse drug events by 74%
- Unplanned extubations by 42%

In 2020, these results and more **saved 18,631 children** from serious harm and **saved \$380 million**.

40% reduction in mortality from hypoplastic left heart syndrome (HLHS) and **reduced growth failure from 30% to <10% for 95% of all children** with this condition in the U.S.

– *National Pediatric Cardiology QI Collaborative*

Decreased stroke rates by 50% in children with heart failure who require a cardiac assist device **across 50 hospitals**.

– *ACTION Network*

Used real-world data **to achieve FDA approval** for life-saving cardiac devices in children previously available only to adults.

– *ACTION Network*

Healthier Together Results

Decreased elective preterm birth 75% across birth hospitals in Ohio (**sustained reduction of >65,000** elective preterm births over 10 years)

– *Ohio Perinatal Quality Collaborative*

Reduced births before 32 weeks' gestation by **6.6%** across Ohio, including reductions in repeat early preterm births in women insured by Medicaid (**17% decrease**) and African American women (**20% decrease**)

– *Ohio Perinatal Quality Collaborative*

Reduced late-onset infections in infants born at 22 to 29 weeks gestation by **20%** among 24 NICUs in Ohio

–*Ohio Perinatal Quality Collaborative*

Reduced hospital length of stay for infants with Neonatal Opioid Withdrawal Syndrome by **2 days** across all of Ohio

– *Ohio Perinatal Quality Collaborative*

Healthier Together Results

43% improvement (from 46% to 66%) in the percentage of 11,000 Cincinnati Public School children proficient in 3rd grade reading reflecting hundreds of additional urban children reaching the target

– *All Children Thrive Network*

18% reduction in bed days (about 190 fewer days in the hospital/year) for children in the 3 poorest neighborhoods of Cincinnati with 8,800 children

– *All Children Thrive Network*

Reduced acute rejections in children with kidney transplants 44% across 12 pediatric nephrology centers.

– *Improving Renal Outcomes Collaborative*

More than **\$75 million in grant funding** from NIH, AHRQ, CMS, PCORI and other sponsors.

More than **140 publications across leading journals** including *JAMA, British Medical Journal, Pediatrics, Neurology, American Journal of Transplantation, Mayo Clinic Proceedings, JAMA Pediatrics* and many more.

BEFORE LEARNING HEALTH NETWORKS

It takes 17 years from evidence to application in practice

Widespread disparities in practice

Inefficiencies slow study completion which prevent approval for treatments, therapies, tests, and devices.

Physicians lack the data to tell their patients what to expect based on the last 1,000 patients like them.

Patients and families not involved in deciding research priorities

The old model cannot keep up with the explosion of new evidence and technology

AFTER LEARNING HEALTH NETWORKS

Less than 3 years to design and diffuse new evidence (e.g. new models of care for opioid exposed babies, treatment of infants with hypoplastic left heart syndrome, etc.)

Reliable implementation of evidence and best practices across hundreds of hospitals that ordinarily compete

Large patient registries with real-time data shared transparently across hundreds of healthcare organizations.

Patient designed educational tools and videos. Patient-driven research priorities

The new model is adaptive, dynamic and fast. Everyone can contribute.



Why Do We Need an Epilepsy Learning Health System?

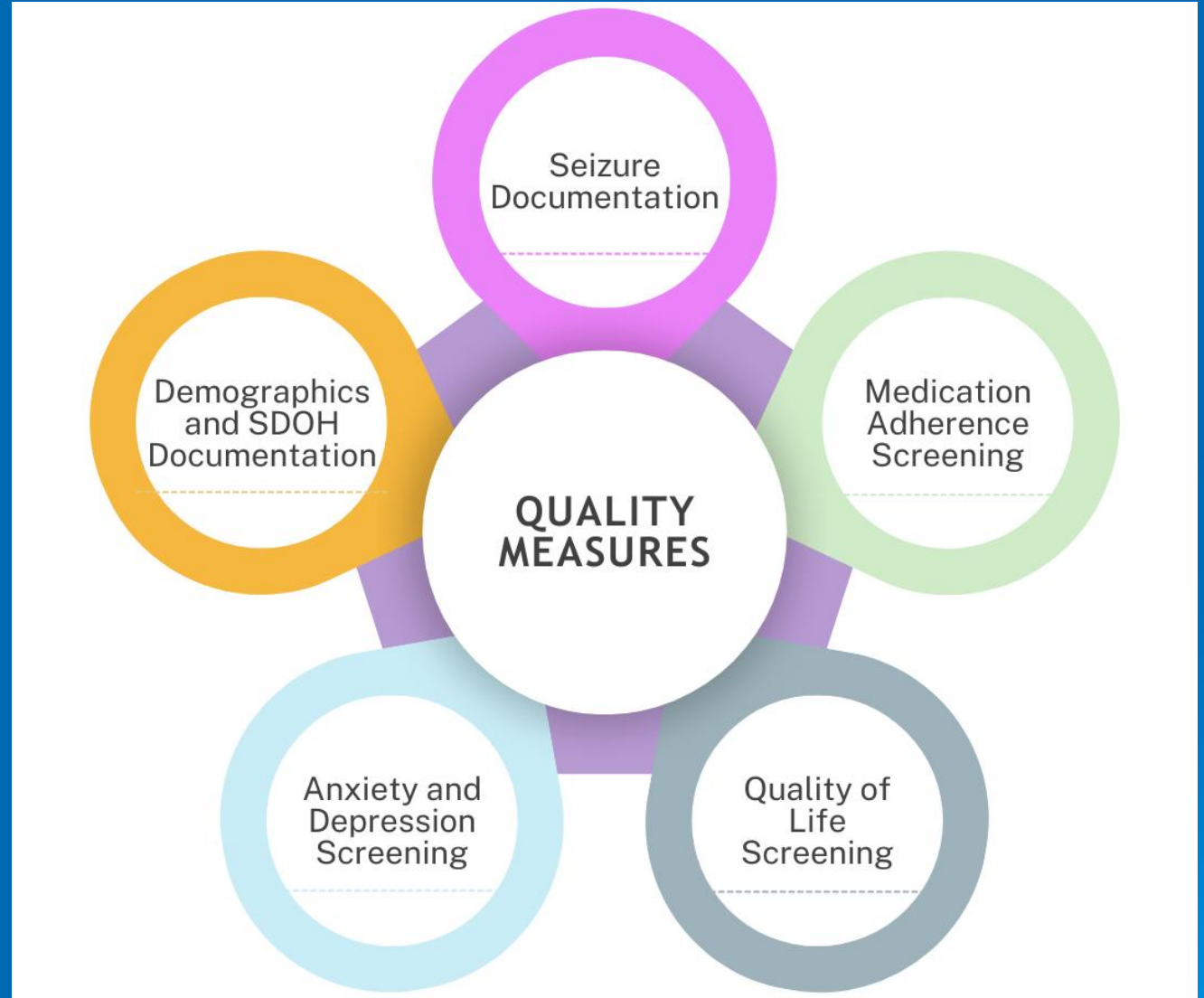
- To improve seizure control and quality of life for all people living with the epilepsies

...AND WE WON'T STOP UNTIL WE GET THERE

ELHS Quality Measures (Real World Data)

$$\text{Percent Completed} = \frac{\text{Number of Completed Forms}}{\text{Total Number of Visits}}$$

$$\text{Percent Screened} = \frac{\text{Number Screened}}{\text{Total Number of Visits}}$$



Different Perspectives. Shared Understanding.

Many ways to describe the same thing. One goal: better care for patients.

partial-onset
seizure

focal impaired
awareness
seizure

focal impaired
consciousness
seizure

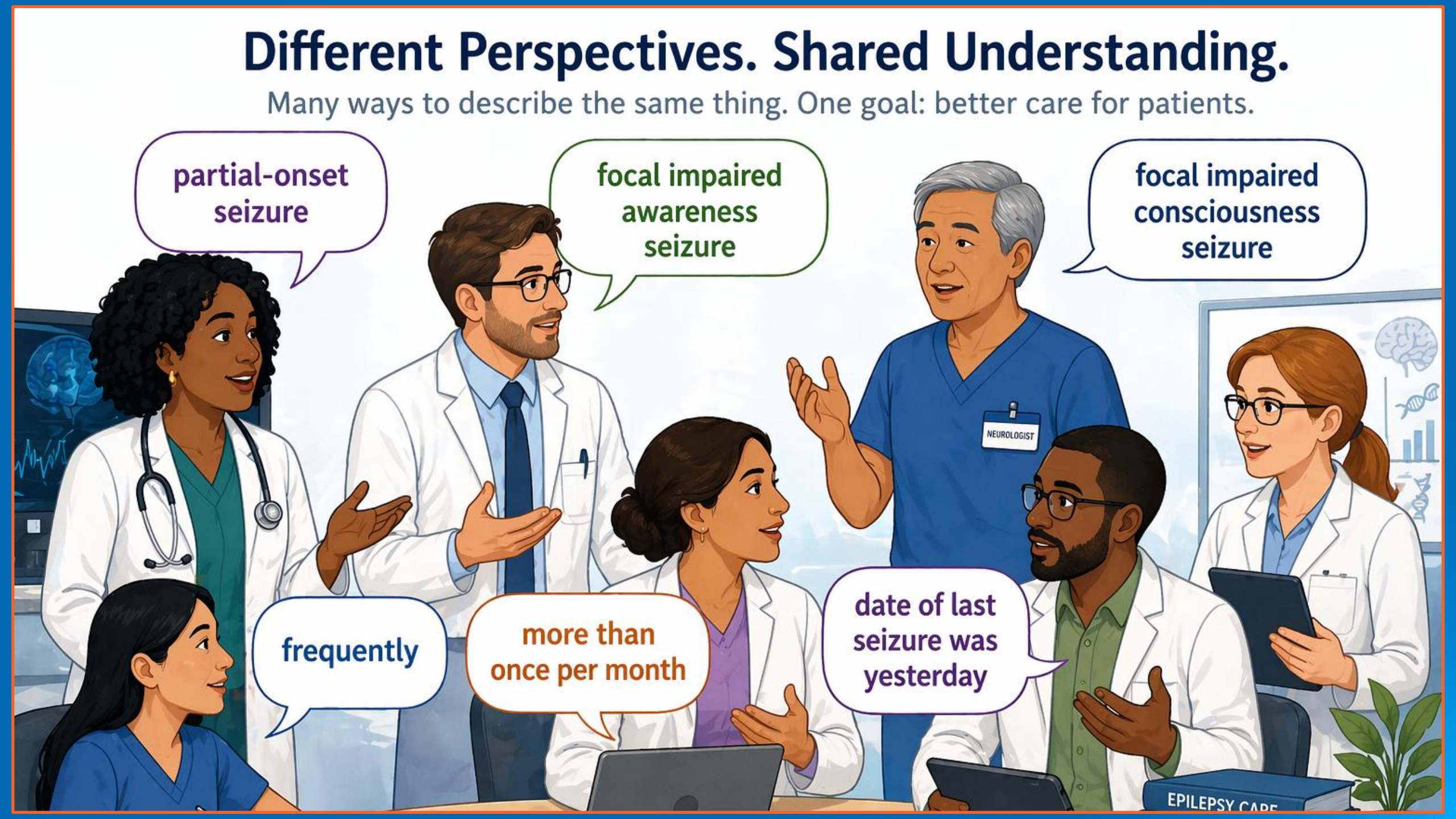
frequently

more than
once per month

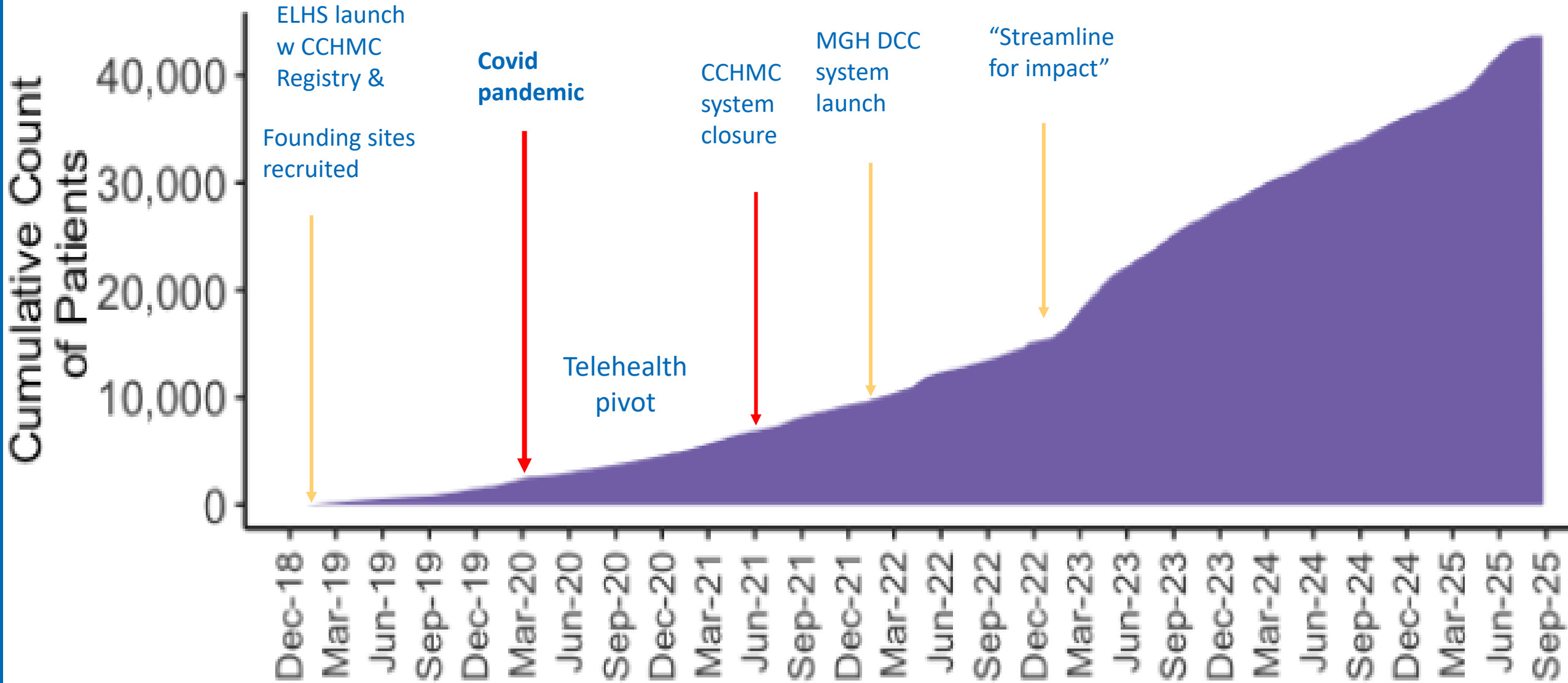
date of last
seizure was
yesterday

NEUROLOGIST

EPILEPSY CARE



Total Patients in Registry with Visits: 43,670 as of September 19, 2025



THE EVOLUTION OF THE ROLE OF PATIENTS IN CLINICAL TRIALS





FROM “SUBJECTS” → TO “PARTICIPANTS” → TO “CO-PRODUCERS”

PAST

SUBJECTS

Patients were studied.







-  Limited information
-  Little or no input in decisions
-  Seen as data sources
-  Focus on study needs

PRESENT

PARTICIPANTS

Patients are involved.







-  Better information and communication
-  Input in some study decisions
-  Contributors to research
-  Focus on shared goals

FUTURE

CO-PRODUCERS

Patients are partners.



-  Equal partnership and trust
-  Shared decision-making throughout
-  Co-creating value and solutions
-  Focus on real-world impact



Stronger together. When patients are co-producers, clinical trials are more relevant, inclusive, and impactful—leading to **better outcomes for all.**

REN

Rare Epilepsy Network

Find rare epilepsy organizations that each provide disorder specific information, education, support, research, and community.



Meet REN's Member Organizations: <https://bit.ly/RENpartners>

Follow us on Twitter: twitter.com/RareEpilepsy

Follow us on Linked In: <https://bit.ly/RENli>

Contact Us at: info@rareepilepsynetwork.org

Don't see your disorder? Contact us today.



Community-Based Participatory Research



ELHS: Proof of Concept



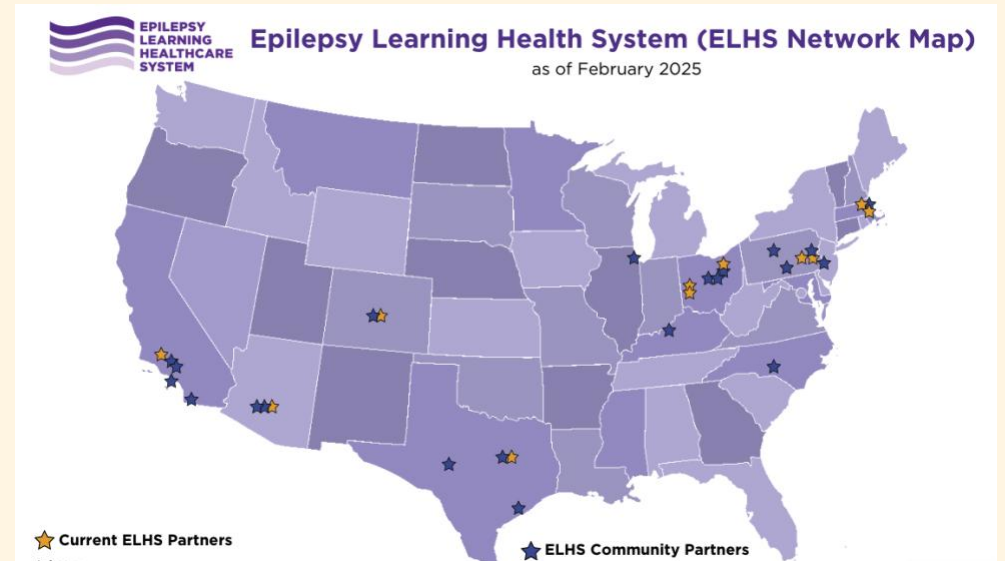
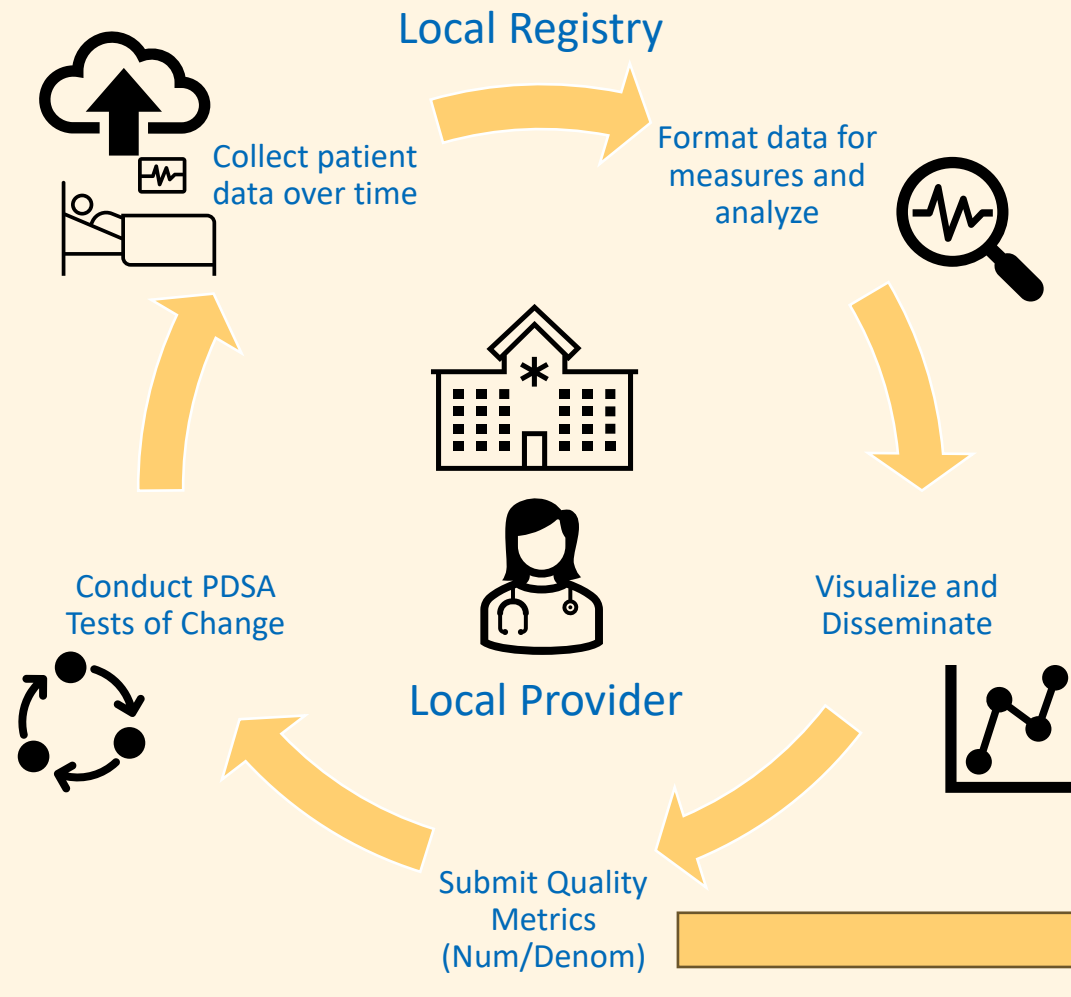
123,000+ visits recorded in ELHS from 43,000+ patients.



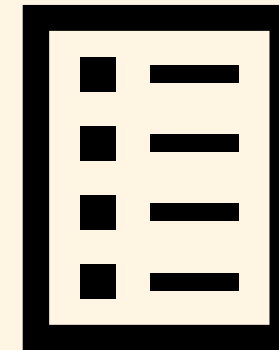
42,000+ medication adherence screenings completed.



29,000+ quality of life screenings completed.



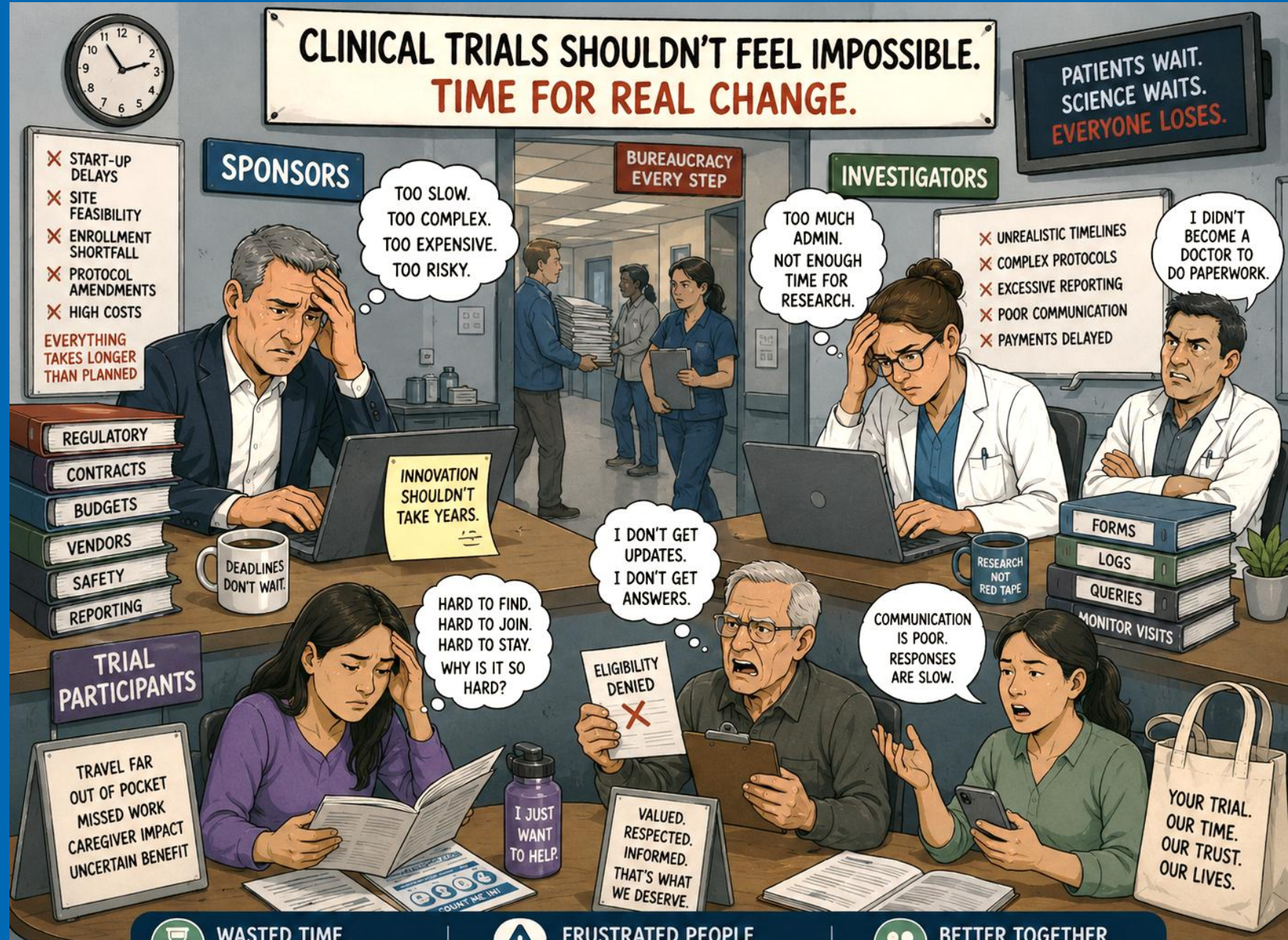
Aggregated Quality Metric Performance



Network Registry of Quality Measure Performance

Federated ELHS Model - 2026

Clinical Trials System



WASTED TIME.
WASTED RESOURCES.



FRUSTRATED PEOPLE.
MISSED OPPORTUNITIES.



BETTER TOGETHER.
BETTER FOR PATIENTS.

SIMPLIFY. COMMUNICATE. RESPECT. DELIVER.

RE-DESIGN the SYSTEM:

Leverage the current opportunities for:

- Cutting-Edge Information Capabilities**
- Population Health Management**
- & Patient/Family Co-production**

to enable a New Era for Clinical Trials

Interoperability & Real World Data

- Standardized operational definitions for diagnosis and outcome assessment
- Better visibility into population heterogeneity and site distribution
- Continuous natural history data
- Long-term follow-up with regular processes of care



Faster, more accurate cohort ascertainment, trial design assumptions, and long-term follow-up

Population Health Management

- Better visibility into clinical needs and equity gaps
- Trials regularly included as option in shared decision-making
- Trial opportunities offered through trusted healthcare provider



Rapid ability to assess population by diagnosis, treatment, outcome, comorbidities, concomitant medicines, etc.

Co-Production with Patient Advocacy Groups

- Identify meaningful outcomes
- Reduce participant burden
- Shape inclusive eligibility criteria
- Co-design recruitment and equity strategies
- Provide participant support and disseminate results




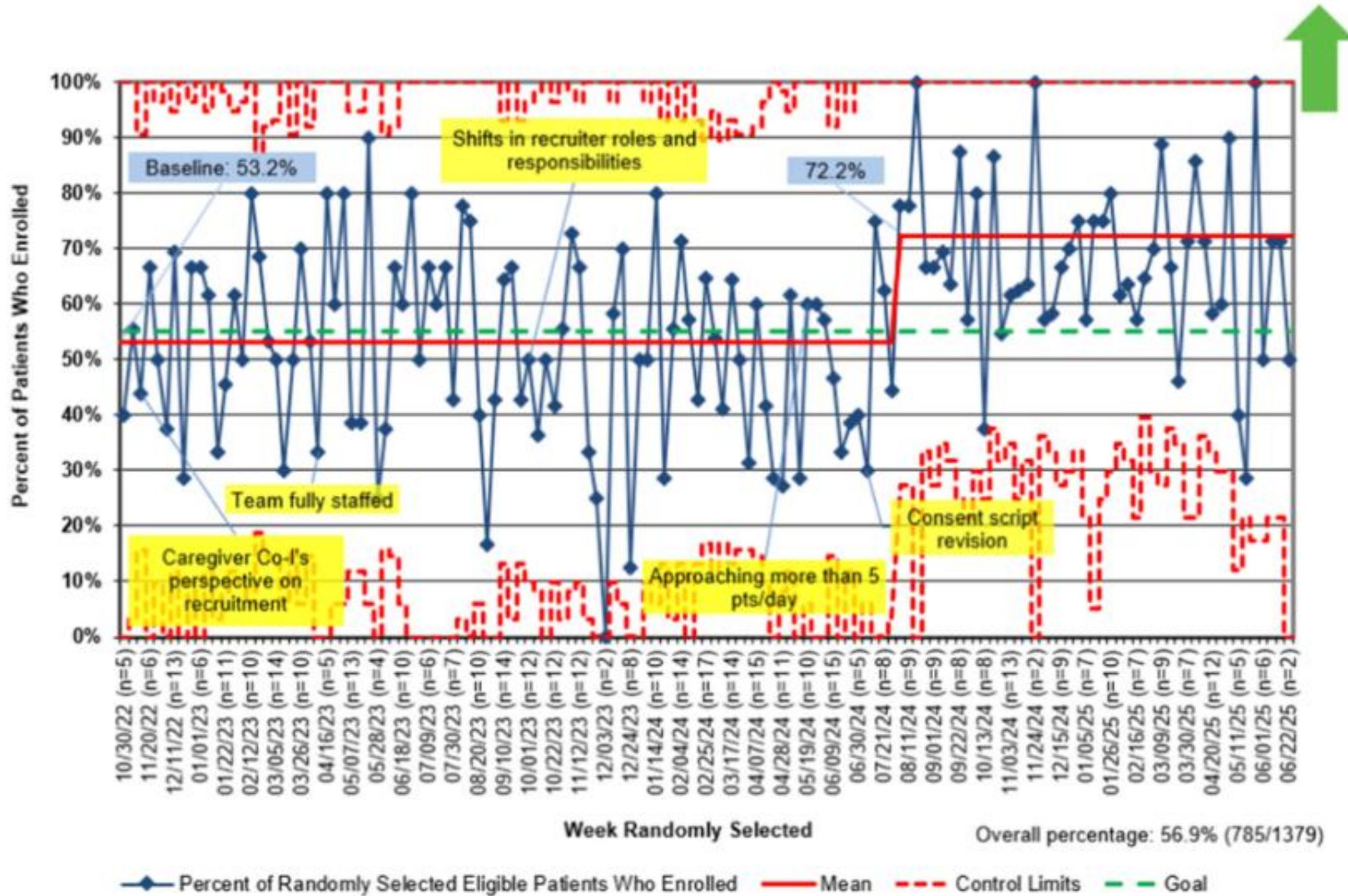
Advocacy partnerships are among the most powerful levers for improving relevance, equity, and trust.

Quality Improvement Methods for Efficient Clinical Trials

ORIGINAL RESEARCH

Applying the model for improvement to enhance recruitment and retention in a discharge intervention randomized controlled trial

Calise Curry BA¹ | Skyler Patterson BA¹ | Allison M. Wiedeman BS, CCRP¹ |
Jasmine Parker BS, CCRP¹ | Elisabeth Peskin MS¹ | Kerry Tepe MHI¹ |
Dianna Bosse BA¹ | Ramya Sri Lakshmi Adapa MPH¹  |
Patrick W. Brady MD, MSc^{1,2,3} | Katherine Auger MD, MSc^{1,2,3} |
Hadley Sauers-Ford MPH, CCRP¹ | the Garnering Effective Telehealth 2 Help Optimize
Multidisciplinary Team Engagement (GET2HOME) Study Team



Conclusions: We increased enrollment and intervention fidelity rates while maintaining high retention rates in a randomized trial by improving enrollment processes and survey completion methods. QI methods can facilitate optimized trial enrollment and intervention fidelity.

Trial System Redesign through LHN

- **Invest in Site Infrastructure**

- Invest in Learning Health Networks to support standing site infrastructure for QI, population health management AND research- reduces burden on participants, sites, AND sponsors

- **Access RWD**

- Use real-world data and community insights to identify unmet needs, access broader numbers of participants and reduce barriers to participation.

- **Share Agency**

- Co-produce protocols and feedback loops with patient advocacy groups and participants to ensure trials align with lived experience and are feasible.

- **Accelerate Impact**

- Use AI and automation to streamline operations and produce rapid, credible public health evidence that is quickly translated into practice.

CALL TO ACTION

Before leaving this meeting:

- Identify one Learning Health Network that involves your population of interest, and reach out to learn:
 - One LHN information capability your team can leverage
 - One opportunity to engage with LHN care providers, researchers, and PFPs
 - The level of LHN experience/interest in conducting clinical trials as a network
- Identify one patient advocacy group to involve earlier and more deeply in your next trial, and reach out to connect



THANK YOU

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