EPILEPSY LEARNING HEALTH SYSTEM (ELHS)
2023 IN REVIEW

EPILEPSY LEARNING HEALTHCARE SYSTEM

ELHS Representation

12 U.S. states

14 clinical teams

19 community teams (local Epilepsy Foundations, Rare Epilepsy Network organizations and advocacy non-profits)

19,860 unique patient records in the registry

300+ Action Period (AP) webinars & participants

49,000+ **Case Report Forms completed** for seizure frequency and Patient Reported Outcomes (PRO) - and more in other areas

5,700+ engagements with ELHS-developed tools, website, and social media

24 clinical and community teams represented at Learning Sessions

48 QI Journal Club members

34 site-level data dashboards

QI Championship at Sites
- **64%** of sites contributing data
- **9** sites screening for barriers to medication adherence
- **8** sites using standardized seizure documentation
- **8** sites co-designing a Champion-led Tonic Clonic Seizures Reduction QI project
- **5** sites screening for depression (PHQ-9/NNDDIE)
- **5** sites screening for anxiety (GAD-7)
- **4** sites reporting Quality of Life measures

1 new ELHS-related publication

Nuthalapati P, Thomas L, Donahue MA, Moura LMVR, DeStefano S, Simpson JR, Buchhalter J, Fureman BE, Pellinen J. Improving Seizure Frequency Documentation and Classification. Neurol Clin Pract. 2023 Dec;13(6):e200212. doi: 10.1212/CPJ.0000000000200212. Epub 2023 Oct 19. PMID: 37873534; PMCID: PMC10586801.

8 network-level population health reports

7 Industry partners in the **QI Science Leadership Consortium** (QISLC)

Partners include Cerevel, Engrail, Jazz, Marinus, Neurelis, Sunovion, UCB

124 new followers on Instagram & Twitter

Learn More: epilepsy.com/ELHS

6 posters representing the work of **7 ELHS teams** at the 2023 American Epilepsy Society (AES) conference