

Pediatric and Adult Epilepsy

Conditions: All people with Epilepsy, including drug-refractory epilepsy and Developmental and Epileptic Encephalopathy (DEE).
 Populations: Adults and Children from 1 month old



- Details**
- Epilepsy health-related quality of life reported with QOLIE-10 in adults, and QOLCE-16 (parent-report) or CHEQOL-25 (self-report) in children and adolescents.
 - Including Behavioural development, Motor development, and Cognitive development (pediatrics only), & Attention/Inattention and Memory Impairment (all patients).
 - Memory Impairment & Attention/Inattention reported with the PROMIS v2.0 Cognitive Function SF 4a in adults, and CHEQOL-25 in children and adolescents.
 - Behavioural development, Motor development, and Cognitive development measured using the mCHAT (16-48 months) or national assessment methods (>48 months).
 - Including Prolonged/recurrent clustered seizures requiring emergency treatment, Seizure-related injury and Incontinence. Optional patient-report with the LSSS 2.0 in adults.
 - Including seizure type, Seizure frequency, Seizure freedom, Emergence of new seizure type
 - Including impact of epilepsy on education/work and daily life activities
 - Depression and Suicidality reported with the PHQ-9 in adults. Depression measured with the PROMIS Pediatric Item Bank v2.0 – Depressive Symptoms/Parent Proxy Item Bank/ Early Childhood Parent Report SF 4a in children and adolescents. Suicidality in children and adolescents reported with the ASQ. Anxiety reported with the GAD-2 in adults, and PROMIS Anxiety Item Bank SF 8a/Parent proxy SF 8a/Early Childhood Parent Report SF 4a in children and adolescents.
 - Including Sleep Adequacy. Reported by the PROMIS Sleep Disturbance 4a in adults, and the PROMIS Pediatric Sleep Disturbance 4a in children and adolescents.
 - Including pregnancy and delivery complications, and congenital malformations in offspring. Only measured in women of a reproductive age.

For a complete overview of this Set, including definitions for each measure, time points for collection, and associated risk factors, visit <https://connect.ichom.org/patient-centered-outcome-measures/pediatric-and-adult-epilepsy/>

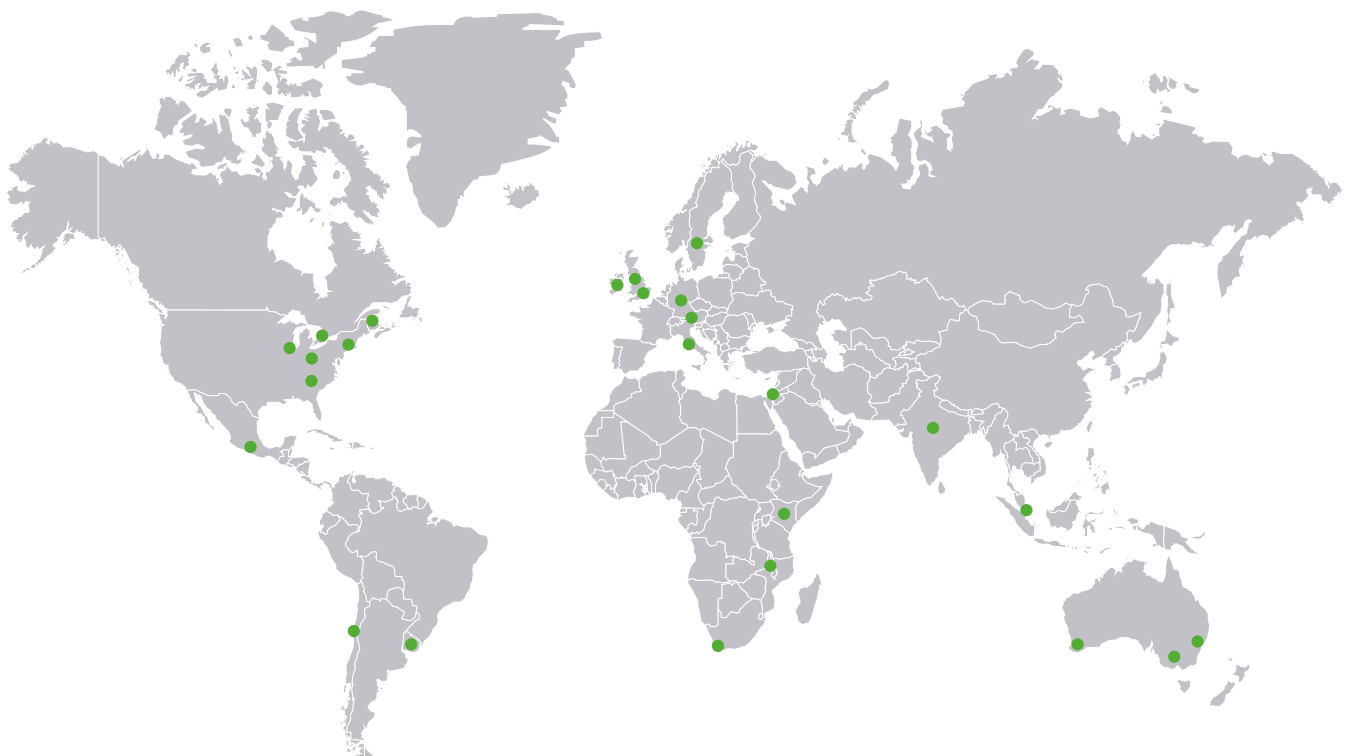
Contributors

For more information about the process of developing a Set of Patient-Centered Outcome Measures, visit ichom.org/how-we-work/

The Sponsors



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