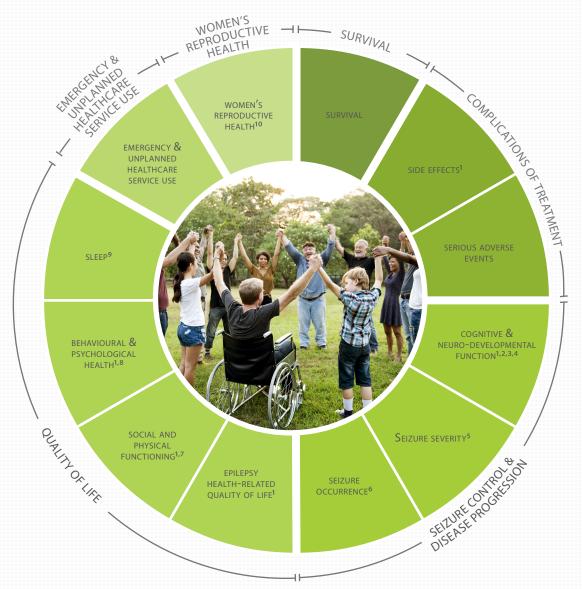
ICHOM Set of Patient-Centered Outcome Measures for

# 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

For a complete overview of this Set, including definitions for each measure, time points for collection, and associated risk factors, visit [LINK]



### Details

1 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.

2 Including Behavioural development, Motor development, and Cognitive development (pediatrics only), & Attention/Inattention and Memory Impairment (all patients).

3 Memory Impairment & Attention/Inattention reported with the PROMIS v2.0 Cognitive Function SF 4a in adults, and CHEQOL-25 in children and adolescents.

4 Behavioural development, Motor development, and Cognitive development measured using the mCHAT (16-48 months) or national assessment methods (>48 months).

5 Including Prolonged/recurrent clustered seizures requiring emergency treatment, Seizure-related injury and Incontinence. Optional patient-report with the LSSS 2.0 in adults. 6 Including seizure type, Seizure frequency, Seizure freedom, Emergence of new seizure type

Including impact of epilepsy on education/work and daily life activities

8 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.

9 Including Sleep Adequacy. Reported by the PROMIS Sleep Disturbance 4a in adults, and the PROMIS Pediatric Pediatric Sleep Disturbance 4a in children and adolescents. 10 Including pregnancy and delivery complications, and congenital malformations in offspring. Only measured in women of a reproductive age

PEDIATRIC AND ADULT EPILEPSY Revised: 03.02.2023

## **ICHOM** Set **CONTRIBUTORS**

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

## The Sponsors





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