



For immediate release:

**International Experts Launch a Foundational Set of Standards
to Measure and Improve Adult and Pediatric Epilepsy Care Globally**

BOSTON, Massachusetts, March 14th, 2023: The International Consortium for Health Outcomes Measurement (ICHOM) announced the release of their Adult and Pediatric Epilepsy of Patient-Centered Outcome Measures today.

Leading epilepsy researchers, practitioners, and patient representatives from across Europe, the Americas, Asia, and Australia have joined forces to establish and launch the first international standard for measuring treatment outcomes for children, adolescents and adults with epilepsy aged 1 month and above. This marks an important step towards promoting data quality and availability, and strengthening epilepsy care for this group.

This collaboration was facilitated by ICHOM and made possible by the generous contributions of KK Women's and Children's Hospital, LivaNova PLC, Nile and UCB.

The ICHOM Working Group

The Adult and Pediatric Epilepsy Set was developed by a dedicated ICHOM Working Group, composed of 26 international experts and service user representatives, from 17 different countries. A full list of organizations and representatives involved in this Working Group is available on ICHOM's website.

The Adult and Pediatric Epilepsy Set

The Epilepsy Set makes a set of recommendations for how treatment outcomes should be measured in clinical practice. It recommends measuring 13 health outcomes across 5 broad domains of Quality of Life, Seizure Control and Disease Progression, Complications of Treatment, Emergency & Unplanned Healthcare Services Use, and Women's Reproductive Health, as a minimum, for children, adolescents, and adults seeking healthcare support for epilepsy. For this purpose, patient- and clinician-reported outcome measures that are feasible to implement are recommended to assess the set outcomes. To help ensure the Epilepsy Set is relevant across different intervention contexts, the Working Group also recommends 19 risk adjustment factors, to be collected along with the outcomes, as well as timepoints for measurement.

Measuring, reporting, and comparing these outcomes can help identify best practices in epilepsy health care; ultimately generating value and better outcomes for service users. The selected outcome measures are available in several languages, which help to assure that the Epilepsy Set will have increased adoption across countries. An open-source Reference Guide is available that outlines recommendations for administering the Set, time points, and a data dictionary for organizations to begin implementation.





Consumer Review Period

The Working Group's recommendations were validated during an Open Review period, in a large group of external stakeholders from around the world. In this review, 91% of lived experience experts from multiple countries agreed that the Set captures all important outcomes that matter most for people with epilepsy, and 98% agreed that it would be helpful to have this type of information collected to help support care for people with Epilepsy. Of the epilepsy practitioners, researchers, and policymakers surveyed across nine countries, more than 80% approved of the recommended outcome measures. Over 85% agreement was reached for the risk adjustment variables recommended by the Working Group.

The Future of the Epilepsy Set

From its inception, ICHOM has made Sets of Patient-Centered Outcome Measures open source. Now that this recommendation is finalized, the real work can begin, ushering in a new season for value-based epilepsy care. It will be invaluable to learn from implementation pilots that may emerge across the globe and inform future iterations of this global set of standards.

Dr. Anne T Berg, Chair of the Working Group, says, "*The ICHOM Epilepsy working group has achieved a milestone by identifying a set of patient-important and patient-reported health outcomes that are critical to the vast majority of people living with epilepsy. The range of outcomes reflect the broad impact of epilepsy and can be used to monitor quality improvement initiatives in epilepsy care settings . The Working Group achieved this with hard work and the support of ICHOM.*"

The Set reference guides, flyers, data dictionaries and press releases are freely available on ICHOM Connect. Please log in or register to gain access to unlimited ICHOM resources at a single click of a button. Visit [ICHOM Connect](#) today to access the materials for the Adult and Pediatric Epilepsy Set.

More Information on The International Consortium for Health Outcomes Measurement: *ICHOM's mission is to unlock the potential of value-based health care by defining global standard sets of outcome measures that matter most to patients and driving adoption and reporting of these measures worldwide to create better value for all stakeholders. ICHOM was founded in 2012 by Professor Michael E. Porter of Harvard Business School, the Boston Consulting Group, and Karolinska Institute.*

Visit www.ichom.org or contact info@ichom.org for more details.

