

International Experts Launch Project to Define a Set of Standards for Measuring and Tracking Outcomes in Routine Clinical Care for Patients with Epilepsy

Initiative marks an important step toward the first international standard for measuring treatment outcomes for patients with epilepsy

BOSTON, MA (January 19, 2022)—The [International Consortium for Health Outcomes Measurement](#) (ICHOM) announces the kickoff of their Working Group for the Epilepsy Set of Patient-Centered Outcome Measures, marking an important step toward promoting data quality and availability, and strengthening the delivery of high-value health care for epilepsy patients.

This collaboration is facilitated by ICHOM and made possible by the generous contributions of KK Women's and Children's Hospital, Singapore; LivaNova; UCB; and Nile AI.

LivaNova is a global medical technology company that develops a neurostimulator, Vagus Nerve Stimulation Therapy, for the management of drug resistant epilepsy.

Nile is an epilepsy management platform that replaces trying with knowing in epilepsy care through a patient app and Health Care Provider (HCP) portal.

The ICHOM Working Group

The Epilepsy Set of Patient-Centered Outcome Measures will be developed by a dedicated ICHOM Working Group, comprised of 22 international experts including clinicians, researchers, mental health experts, policy makers, patient representatives and advocates from 16 countries.

The Epilepsy Set of Patient-Centered Outcome Measures

The Epilepsy Set will encompass a set of recommendations for how treatment outcomes should be measured in clinical practice. For this purpose, it will recommend a set of patient-, parent-, and clinician-reported outcome measures. To help ensure the Set is relevant across different intervention contexts, the Working Group will also recommend several risk adjustment factors, to be collected along with the outcomes, as well as timepoints for measurement.

Measuring, reporting, and comparing these outcomes will help identify best practices in epilepsy care, ultimately generating value and better outcomes for patients. The outcome measures will be selected according to a number of relevant factors including validity, reliability, brevity, and their availability at low to no cost and in multiple languages. As such, the Set will be assured to have increased adoption across countries and settings.

An open-source Reference Guide will be made available outlining recommendations for administering the set, time points, and a data dictionary for organizations to begin implementation.

Consumer Review Period

The Working Group's recommendations will be validated during an Open Review period, by a large group of external stakeholders from around the world, before the Set is finalized and made

publicly available. In this review, all lived experience patient representatives as well as clinicians, researchers, and policymakers, will be surveyed across a number of different countries, to collect feedback and assess endorsement of the outcomes and measures recommended. The Working Group will discuss the feedback received and address any concerns raised during the survey, before finalizing the Set. The result will establish and launch the first international standard for measuring treatment outcomes for patients with epilepsy.

For more information on the Epilepsy Set of Patient-Centered Outcome Measures, please visit connect.ichom.org/standard-sets/epilepsy.

About The International Consortium for Health Outcomes Measurement (ICHOM)

ICHOM's mission is to unlock the potential of value-based health care by defining global sets of patient-centered 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.

About LivaNova

LivaNova PLC is a global medical technology and innovation company built on nearly five decades of experience and a relentless commitment to provide hope for patients and their families through innovative medical technologies, delivering life-changing improvements for both the Head and Heart. The LivaNova VNS Therapy System is indicated for use as an adjunctive therapy in reducing the frequency of seizures in patients 4 years of age and older with partial onset seizures that are refractory to antiepileptic medications. VNS Therapy is designed to prevent seizures before they occur and stop them if they do. It is a unique treatment approach developed for people with drug-resistant epilepsy—a condition that affects one in three people with epilepsy. Commonly reported side effects are hoarseness, shortness of breath, sore throat and coughing. Side effects typically occur during stimulation and are less noticeable over time. For more information, visit www.VNSTherapy.com/safety.

About Nile

Nile replaces trying with knowing in epilepsy care. Our mission is to enable healthcare providers to find the right treatment faster. Our digital care management platform provides tools for providers and people living with epilepsy and their caregivers to progress to data-driven, personalized care. Nile is a collaboration-driven organization and is welcoming partners in this mission. For more information, visit www.Nile.ai and email info@Nile.ai.

About KK Women's and Children's Hospital

KK Women's and Children's Hospital (KKH) is Singapore's largest tertiary referral centre for Obstetrics, Gynaecology, Paediatrics and Neonatology. Founded in 1858, the academic medical institution specialises in the management of high-risk conditions in women and children. A team of about 500 specialists adopt a compassionate, multidisciplinary and holistic approach to treatment, and harness medical innovations and technology to deliver the best medical care possible.

As an Academic Medical Centre, KKH is a major teaching hospital for all three medical schools in Singapore, Duke-NUS Medical School, Yong Loo Lin School of Medicine and Lee Kong Chian School of Medicine. The 830-bed hospital also runs the largest specialist training programme for Obstetrics and Gynaecology and Paediatrics in the country. Both programmes are accredited by the Accreditation Council for Graduate Medical Education International (ACGME-I), and are highly rated for the high quality of clinical teaching and the commitment to translational research.

For more information, please visit www.kkh.com.sg.