

For immediate release:

International Experts Launch a Foundational Set of Standards to Measure and Improve Neurodevelopmental Disorders Care Globally

BOSTON, Massachusetts, July 21st, 2022: The International Consortium for Health Outcomes Measurement (ICHOM) announced the release of their Neurodevelopmental Disorders Set of Patient-Centered Outcome Measures today.

Leading researchers, health and social care professionals, and service user representatives from across Europe, Africa, the Americas, Asia, and Australia have joined forces to establish and launch the first international standard for measuring treatment outcomes for children and adolescents with neurodevelopmental disorders aged between 3 and 20 years. This marks an important step towards promoting data quality and availability, and strengthening mental health care for this group.

This collaboration was facilitated by ICHOM and made possible by the generous contributions of NHS England and NHS Improvement.

The ICHOM Working Group

The Neurodevelopmental Disorders (NDD) Set was developed by a dedicated ICHOM Working Group, comprised of 29 international experts and service user representatives, from thirteen different countries. A full list of organizations and representatives involved in this Working Group is available on ICHOM's website.

The Neurodevelopmental Disorders Set

The NDD Set makes a set of recommendations for how treatment outcomes should be measured in clinical practice. It recommends measuring thirteen outcomes across the two broad domains of Key Common Co-Existing Problems and Impact, Functioning, and Quality of Life, in addition to a total of thirteen disorder-specific core symptoms for the conditions of ADHD, communication disorders, motor disorders, and specific learning disorders as a minimum for children and adolescents seeking support for neurodevelopmental disorders. For this purpose, it recommends a set of thirteen patient- and clinician-reported outcome measures, seven of which are disorder-specific. To help ensure the NDD Set is relevant across different intervention contexts, the Working Group also recommends twenty 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 neurodevelopmental disorder mental health care; ultimately generating value and better outcomes for service users. The selected outcome measures being available in several languages, the NDD Set is assured to 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.

Lived experience Working Group member, Alison Clink shares, "I would like thank ICHOM for inviting me to be part of the NDD Set. It has shown that this work is essential to ensure the best pathway for patients for a diagnosis of a neurodevelopmental disorder. It has been a great insight to see all the professionals being part of a team to ensure a positive outcome for

neurodevelopmental disorders."

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, over 90% of lived experience experts from Portugal and the United Kingdom reported that they would be happy for these outcome measures to be part of routine care and support. Of the health and social care practitioners and researchers and educators surveyed across sixteen countries, between 60% and 84% approved of the recommended shared and disorder-specific outcomes and measures. Over 85% agreement was reached for the risk adjustment variables recommended by the Working Group, and over 78% agreed with the proposed timepoints for measurement.

The Future of the NDD 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 mental health 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.

The chair of the Working Group, Prof. David Coghill (University of Melbourne), says, "I am proud to have been able to contribute to this important piece of work. Measurement based care is just starting to take off within our field and the ICHOM Neurodevelopmental Disorders Set provides clinicians from around the world the tools they require to properly engage in applying measurement-based care within their day-to-day clinical practice. This has the potential not only to improve clinical outcomes but also to improve communication between clinicians and their patients."

The Set reference guides, flyers, data dictionaries and press releases have moved to ICHOM Connect and are still available free of charge. Please log in or register to gain access to unlimited ICHOM resources at a single click of a button. Visit connect.ichom.org today to access the materials for the Neurodevelopmental Disorders 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 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.