

For immediate release:

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

BOSTON, Massachusetts, July 5th, 2022: The International Consortium for Health Outcomes Measurement (ICHOM) announced the release of their Eating Disorders Set of Patient-Centered Outcome Measures today.

Leading researchers, health and social care professionals, and service user 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 eating disorders aged 6 and above. 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 and the National Eating Disorders Association.

The ICHOM Working Group

The Eating Disorders (EAD) Set was developed by a dedicated ICHOM Working Group, comprised of 27 international experts and service user representatives, from fourteen different countries. A full list of organizations and representatives involved in this Working Group is available on ICHOM's website.

The Eating Disorders Set

The EAD Set makes a set of recommendations for how treatment outcomes should be measured in clinical practice. It recommends measuring twelve health outcomes across the four broad domains of Eating Disorder Cognitions and Behaviors, Other Psychological Symptoms, Quality of Life and Social and Emotional Functioning, and Physical Health and Clinical Outcomes as a minimum, for children, adolescents, and adults seeking support for eating disorders. For this purpose, it recommends a set of eleven patient- and clinician-reported outcome measures, five of which are included for child and adolescent patients, and the remaining six for adult patients. To help ensure the EAD Set is relevant across different intervention contexts, the Working Group also recommends twenty-three 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 eating disorder mental health care; ultimately generating value and better outcomes for service users. The selected outcome measures being available in several languages, the EAD 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, James Downs shares, "It has often been difficult for me to know what to expect when seeking help for my eating disorder, or to understand the progress of my treatment and recovery. Whilst I have experienced some good care and can identify what's helped me, we need to guarantee more consistent standards of monitoring and

treatment for people with eating disorders. This has to take place throughout the course of their treatment and recovery - whichever settings they may be in and whichever professionals they are being supported by. By having an agreed standard of care which takes into account the perspectives of professionals, patients and carers, we can bring better care within reach for people like me. Producing these sets of outcome measures is an important step in that direction."

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, 97% of lived experience experts from Mexico, Portugal, Singapore, the United Kingdom, and the United States 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, researchers, policymakers, and advocacy representatives surveyed across nine countries, 87% approved of the recommended outcome measures. Over 90% agreement was reached for the risk adjustment variables recommended by the Working Group.

The Future of the EAD 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 co-chair of the Working Group, Dr. Christine Peat of the University of North Carolina at Chapel Hill School of Medicine, says, "The Eating Disorders Set represents a crucial step in unifying the field with respect to outcomes measurement. The Set will allow patients and their loved ones, clinicians, and researchers to have a shared understanding of important treatment outcomes, and thereby improve the quality of care provided."

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 Eating 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.