

For immediate release:

International Experts Launch a Standard Set of Outcomes to Measure and Improve Personality Disorders Care Globally

BOSTON, Massachusetts, June 2, 2020: The International Consortium for Health Outcomes Measurement (ICHOM) announced the release of their Personality Disorders Standard Set today.

Leading mental health researchers, practitioners, and service user representatives from across Europe, North America, Asia, and Australia have joined forces to establish and launch the first international standard for measuring treatment outcomes for adults and adolescents aged 12 and above with personality disorders. 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 NSW Agency for Clinical Innovation, Australia; Providence Health Care, USA; and Region Västra Götaland, Sweden.

The ICHOM Working Group

The Personality Disorders Standard Set (PDSS) was developed by a dedicated ICHOM Working Group, comprised of 17 international experts and service user representatives, from ten different countries. A full list of organizations and representatives involved in this Working Group is available on ICHOM's website.

The Personality Disorders Standard Set

The PDSS makes a set of recommendations for how treatment outcomes should be measured in clinical practice. It recommends measuring 14 health outcomes across the four broad domains of Mental Health, Behaviour, Functioning, and Recovery, as a minimum, for adults and young people seeking mental health support for personality disorders. For this purpose, it recommends a set of eight patient- and clinician-reported outcome measures. To help ensure the Standard Set is relevant across different intervention contexts, the Working Group also recommends 15 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 personality disorder mental health care; ultimately generating value and better outcomes for service users. The selected outcome measures being available in several languages, the Standard 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 organisations to begin implementation.

Lived experience working group member, Lucie Langford, shares, "Being able to contribute to something positive and meaningful for people with Personality Disorders has been a privilege. I am happy to have used my lived experience with a Personality Disorder as a strength to help others. This work is vital because patient partners were able to collaborate with the other members of the working group to capture and integrate what is important to help in our recovery. I was struck by how often our working group conversations centered around functional recovery and quality of life. In my experience, even though the inclusion of patient partners in healthcare and

research has advanced, many research professionals are still hesitant to engage with persons living with such a complex psychiatric condition. I believe that our work will inspire further collaboration between these groups and I am hopeful that the outcome will produce a valuable working model that enables patients to reach the recovery goals that are important to us.”

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, 96% of lived experience experts from Australia, 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. Over 80% of mental health practitioners, researchers, and policymakers surveyed across 17 countries, approved of the outcomes and measures recommended. There was over 75% agreement with risk adjustment variables recommended by the Working Group.

The Future of PDSS

From its inception, ICHOM has made Standard Sets open source. Now that this recommendation is finalised, 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. Michael Crawford of Imperial College London, says, “In recent years concerted efforts have been made to improve the quality of health care that people with personality disorder receive. But attempts to find out what works best for whom have been hampered because people working in different countries have used different methods for assessing patient outcomes. The publication of the Personality Disorder Standard Set by ICHOM provides an exciting opportunity to improve collaboration between different services within and between countries. By adopting these standards, clinicians and patients will find it easier to identify and share good practice and help shape better services for people with these complex emotional health needs.”

The standard 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 Personality Disorders Standard 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.