

For immediate release:

International Experts Launch a Foundational Set of Standards to Measure and Enhance Health and Care for Autism Spectrum Disorder Globally

BOSTON, Massachusetts, June 16th 2021: The International Consortium for Health Outcomes Measurement (ICHOM) announced the release of their Autism Spectrum Disorders Set today.

Leading researchers, psychologists, behavioural analysts, and service user representatives from across Europe, the Americas, and Asia have joined forces to establish and launch the first international standard for measuring treatment outcomes for autism spectrum disorders of children and adults over the age of 18 months old. This standard set has two tracks in order to facilitate the implementation of the set, in countries that use specific tools in existing reimbursement models and for those without. Both tracks will be measuring the same outcomes and they will be risk adjusted with the same factors however:

- Track A will recommend tools with cost associated with them to match existing tools in the current reimbursement models
- Track B will recommend tools that are free or have a low cost.

This marks an important, proactive step towards promoting data quality and availability and strengthening autism care and ensuring that the ICHOM ASD set can be implemented globally.

The Chair of the Working Group, Dr Ivy Chong says, “It was a great privilege and incredibly humbling to chair the working groups for the development of the Autism Spectrum Disorders Standard Set. Through ICHOM, experts worked together to align and contribute to a standard set that has the potential to impact the quality of life for autistic individuals and drive value-based healthcare globally. While we recognize this set is a work in progress, my hope is that the adoption and implementation of these standards will align patients, providers, and payers alike, to drive access to an enhanced, uniform standard of care for individuals no matter the setting. I look forward to continuing work for years to come and thank the sponsors, project team, and ICHOM leadership for making this possible.”

The ICHOM ASD Working Group

The Autism Spectrum Disorder Standard Set (ASDSS) was developed by a dedicated ICHOM Working Group, comprised of twenty-two experts and service user representatives. A full list of organizations and representatives involved in this Working Group is available [here](#).

The Autism Spectrum Disorder Standard Set

The ASDSS makes a set of recommendations for how treatment outcomes should be measured in clinical practice. It recommends measuring nine health outcomes covering four domains. For this purpose, it recommends a set of patient- and clinician-reported outcome measures. To help ensure the Standard Set is effective across different intervention contexts, the Working Group also recommends fifteen 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 autism spectrum disorder, 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 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. Over 85% of applied behavioural analysts, psychiatrist, psychologists, occupational therapists, researchers etc. approved of the recommended outcomes and, over 75% of the stakeholders agreed with the recommended measures. Finally, over 85% of the external stakeholders agreed that these outcomes and measures in Track A were feasible to collect in clinical practice.

The Future of ASDSS

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 autism 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.

ICHOM Board Member, James Heywood says "I am honoured to have witnessed the very challenging process to get to a consensus standard for Autism lead by Ivy Chong and the working group. Developing a standard is a largely thankless tasks requiring integrating many disparate and conflicting views into something that becomes a foundation for future knowledge. The process requires all constituents to accept the standard set and enables the beginning of true knowledge"

This collaboration was facilitated by ICHOM and the independent project was made possible by the generous contributions of Hopebridge, United States; InBloom Autism Services, United States; Trumpet Behavioral Health, United States; Learn Behavioral, United States; Center for Autism & Related Disorders (CARD), United States; Autism Learning Partners, United States; Centria Autism, United States. The ICHOM ASD set sponsors are invested to ensure that the best care is provided in the ASD space. The sponsors recognise that the only way to test this is the creation of a standardised method of collecting outcomes in the ASD space that are agreed and meaningful to patients, can be deployed and, that are sensitive to improved intervention. The sponsors are also aware that in the past, ASD is typically not designed to be the space of collaboration, however they have found that this project is a model of collaboration and although this is the beginning of the process they are really looking forward to furthering this outcome set alongside other providers and organisation to standardise outcome measurement.

ICHOM ASD Webinar

ICHOM will be hosting a webinar to present the newly launched ASD Standard set where there will be discussion around project inception, standard set process, the final standard set, implementation of the set in a global scale.

For more information on the ASD Webinar please click [here](#).

For more information on the ASDSS, the standard set flyer can be downloaded [here](#) and the reference guide [here](#).

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.