ICHOM ASD FAQ

Why is there a need for an ICHOM ASD set?

The concept of value-based health care basically says that health care systems will improve by measuring outcomes that really matter to patients. ICHOM believes that information on outcomes is an integral part of the patient-physician interaction and relationship. For any patient, their most important concern is to be healthy and improve their quality of life, in addition to reducing pain, anxiety and psychological stress from medical treatment. Healthcare providers are not measuring outcomes systematically and there is not a standardised method of doing this. In the few places where outcomes are measured, we see huge variation. ICHOM worked with lived experience users, leading providers, and registries to create global standards for measuring and reporting outcomes for autism spectrum disorder.

- ICHOM believes in the uniqueness of the patient-physician relationship that is built on mutual trust, empathy and respect. ICHOM wants to strengthen this relationship by adding systematic reflection and discussion about the results that matter to lived experience users and should inherently matter to physicians alike
- Only by understanding and measuring outcomes can physicians have structured, outcomes-focused conversations with their patients and, in the end, understand how their patients actually fare.
- Global outcome standard sets, specific for a particular medical condition will help patients understand what to expect from their treatment and follow their trajectory compared to their peers
- Discussing differences in outcome results will help patients to participate in improvement processes of their physicians

How was the standard set developed?

- The ASD standard sets are recommendations of measuring global outcomes using patient reported outcomes measures (PROMs) and the focus is creating a core minimum standard set that really matters to patients defined around the ASD that is implementable worldwide.
- Aim is to have balanced outcomes across physical, mental, and well-being and to ensure that patients' representatives and patient advisory groups are directly involved in defining the standard set. PROMs are included in every standard set to capture symptom burden, functional status, quality of life etc.
- The project team consists of an ICHOM Chair, Project Manager, Research Fellow and a Research Associate. There is a working group- composed of 20-25 international volunteer representatives from leading professions such as outcomes experts, clinicians, measurement efforts, patient advocates and scientists who are experts in that field to ensure we have a variety of input.
- This working group guides the publication of the set.

- We had 7 Working Group calls in this standard set development process, each call to discuss outcomes, tools, case mix and timepoints. We do want a minimum number of outcomes so they are implemented easily across the world, usually 10-15 outcomes, but this varies between conditions. In this set we recommend measuring 9 outcomes.
- Every group follows the following process in order to come to a consensus on outcomes, tools and case-mix the project team. The team carried out an extensive and rigorous literature review that captures all the relevant information which is then discussed in one or several Working Group calls.
- In particular, in order to capture the final outcomes, the group has several calls to present and discuss all the outcomes and then it goes through three rounds of Delphi survey which allows each Working Group member to give each outcome a rating of 1 -3 (not important), 4 - 6 (somewhat important), 7 -9 (most important).
- Any outcomes that receive a not important rating are excluded and the rest are carried out to the next round of voting. After outcome discussion we go to PROMS, we do not validate tools, but we come to a consensus on the most appropriate tools to use.
- After the group finalises outcomes, tools, case-mix (risk factors that affect the outcome) and timepoints the standard set goes through an open review period.
- The open review survey is a survey sent out to professionals in the field of that standard set and it gains feedback on the set as a whole. After the open review period the team determines if any final changes or additions are needed based on feedback.
- Once the standard set has been finalised ICHOM produces three documents which are free to access and they are the ICHOM flyer, Reference guide and manuscript.
- ICHOM used the funding to build working groups and the project team, do a literature review, look at cases, publish the set and create the reference guide and flyer, then bring it to conferences and put it out into the world.
- A set typically take between 12-15 months to complete.

How can the standard set be used?

ICHOM's mission is to create international standard sets that can be adopted and implemented worldwide, to reduce the inequalities in healthcare and compare the quality of care. ICHOM have successfully created and developed 39 international standard sets which are currently being implemented in different countries and with different providers. ICHOM's intention is that the set addresses the needs globally.

Were the sponsors involved in steering the set?

The ICHOM ASD sponsors are not involved in steering the project. They are given updates on decisions that have been voted for and finalized by the Working Group. For full transparency, ICHOM have recorded the meetings and created minutes and slides of every stakeholder call.

Did any of Working Group members decide to leave the project?

Once ICHOM decided to split the set into two tracks (based on the complexities of ASD and the clear differences in the Working Group), many Working Group members in newly formed Track B did not agree with this change and decided not to be involved in the project any further. As a result, the ICHOM ASD Project team had to recruit new Working Group members for Track B.

Why does the set have two tracks? What is the rationale?

- Due to a combination of the size of the working group; the complexities of ASD; the disparities of ASD treatment and perhaps most importantly the ICHOM guidelines that initially excluded the consideration of some currently used commercial outcome measures in the USA, it was clear that the process would not result in the endorsement of one set of global measures. The existing US care market would not adopt a standard set that did not at least consider the existing tools required for reimbursement.
- ICHOM has come across this problem with other standard sets where more than one tool was endorsed by the Working Group. Once we allowed for the consideration of existing tools, the decision to create separate tracks was made.
- This was due to the clear differences the Working Group members expressed during calls, surveys and emails. ICHOM does not endorse nor has it endorsed any specific ASD treatment. We did not target the US nor ABA in the development of this set. We did modify our process to allow some currently used commercial outcomes to be considered so that US market needs could be addressed.