

For immediate release:

International Experts Launch a Foundational Set of Standards to Measure and Improve Care for Congenital Heart Disease Globally

BOSTON, Massachusetts, April, 9, 2020: The International Consortium for Health Outcomes Measurement (ICHOM) announced the release of their Congenital Heart Disease Standard Set today.

Health professionals, patient advisors, and recognized leaders from across Europe, the Americas, Asia, and Africa have joined forces to establish and launch a global set of outcomes that reflect what matters most to pediatric and adult individuals with minor, moderate, major or complex and critical congenital heart conditions.

This collaboration is facilitated by ICHOM and made possible by the generous contributions of the Children's National Hospital, Boston Children's Hospital, Erasmus University Medical Center, Cincinnati Children's Hospital Medical Center, Sant Joan de Déu Barcelona Children's Hospital, The Hospital for Sick Kids, Kardias A.C. Foundation, Children's HeartLink and the American College of Cardiology.

The Congenital Heart Disease Standard Set (CHDSS) was developed by the ICHOM Congenital Heart Disease Working Group, comprised of 30 international experts and patient representatives, from 24 organizations across 15 countries. A full list of organizations and representatives involved in the ICHOM Congenital Heart Disease Working Group is available [here](#).

The Congenital Heart Disease Standard Set

The CHDSS is a minimum core set of standards, comprised of Patient, Parent, and Clinician - Reported Outcome Measures already being collected by most practices in routine clinical care. The CHDSS measures 14 outcomes under the ICHOM framework for comprehensive outcomes measurement. These overarching domains are Overall Health, Social Health, Mental Health, and Physical Health.

To help ensure the Standard Set is relevant across contexts, the Working Group also recommended a minimum set of 20 Case-Mix, risk adjustment factors, to be collected along with the outcomes measured.

For pediatric patients, outcomes are assessed using two patient-reported and two clinician-reported outcome measures. In adult patient populations, outcomes will be assessed with five patient-reported measures and one clinician-reported measure. Measuring, reporting, and comparing these outcomes can help develop best practices in care for adult and pediatric congenital heart disease; ultimately generating value and better outcomes for patients worldwide. With PROM's available in several languages, the Standard Set is slated to have increased adoption across countries.

An open-source [Reference Guide](#) has also been created, outlining recommendations for administering the set, time points, and a data dictionary for organizations to begin implementation.

Consumer Review Period:

The 14 Outcomes recommended by the Working Group were also validated during an Open Review period. Patients and parents of children with congenital heart disease from Pakistan, Switzerland, the United States, and the United Kingdom were surveyed and asked how important they felt the outcomes chosen to be measured by the Working Group were. 88% of parents felt that all important pediatric outcomes are covered by the set and 95% of the patient respondents felt the same about the adult outcomes.

Over 80% of professionals and administrators surveyed across 14 countries, approved of the measures and outcomes recommended by the Working Group for pediatric and adult patients. 88% agreed with the scope and timeline proposed by the set for measuring outcomes and over 90% approved of the case-mix variables chosen by the Working Group.

The Future of CHDSS:

From its inception, ICHOM has made Standard Sets open source. Now that this recommendation is finalized, the real work can begin, ushering in a new season for Value Based 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, Gerard Martin, M.D., FAAP, FACC, FAHA, Children's National Hospital says, "having a global set of outcomes that matters most to adult patients and parents of children with congenital heart disease will provide a road map for healthcare professionals and organizations engaged in setting care strategies for this population around the world. I would like to acknowledge the efforts of the Working Group and ICHOM staff for their incredible effort on this project."

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

The CHDSS will also be featured at the ICHOM 2020 Conference being held in Barcelona from November 16-18. More details can be found at conference.ichom.org

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.