

**Press Release**  
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## **ICHOM Releases Landmark Manuscript on Heart Valve Disease (HVD) Set of Patient-Centered Outcome Measures with Multiple Global Journal Endorsements**

The International Consortium for Health Outcomes Measurement (ICHOM) is delighted to announce the manuscript publication of the ICHOM Heart Valve Disease (HVD) Set of Patient-Centered Outcome Measures, a landmark initiative designed to transform patient outcome measurement in heart valve disease care globally. The manuscript, published in seven leading cardiology journals simultaneously, defines the critical clinical and quality-of-life outcomes that matter most to patients and healthcare providers.

Heart valve disease is a major global health challenge. In the United States alone, more than 5 million people are diagnosed with heart valve disease each year, leading to over 25,000 deaths annually, according to the Centers for Disease Control and Prevention (CDC). Despite its prevalence, awareness remains low, with 75% of U.S. adults knowing little to nothing about the condition (CDC, [cdc.gov](https://www.cdc.gov)). Studies in Europe have shown that a considerable number of patients with severe valve disease, especially older adults, are not referred for surgery. These findings underscore the need for better implementation of guidelines and the urgent role of standardized outcome measures in improving patient care and informing clinical practices.

The HVD Set marks a pivotal shift in global heart valve disease evaluation, focusing on patient-centered outcomes instead of device performance. Developed by a multi-society task force, including organizations responsible for shaping both North American and European guidelines, the Set reflects a truly international and collaborative effort. Like all of ICHOM's 45 Sets, patient representatives played a key role, working alongside clinicians and researchers to ensure their voices were at the heart of the process. Its synchronous publication across multiple society journals further underscores its global impact and scientific significance.

The HVD Set has received global endorsement from a diverse coalition of leading clinical organizations, including the American College of Cardiology (ACC), the American Heart Association (AHA), the European Society of Cardiology (ESC), and the Society of Thoracic Surgeons (STS), among others. This broad support reinforces the Set's potential to impact standards of care and patient outcomes, and underscores the healthcare community's collective commitment to advancing value-based care in heart valve disease management.

The manuscript has been published in seven of the world's leading cardiology journals, including:

- [\*Circulation: Cardiovascular Quality and Outcomes \(AHA\)\*](#)
- [\*European Heart Journal-Quality of Care and Clinical Outcomes \(ESC\)\*](#)
- [\*European Journal of Cardio-Thoracic Surgery \(EJCTS\) \(EACTS\)\*](#)

- *INNOVATIONS (International Society for Minimally Invasive Cardiothoracic Surgery)*
- [JACC: Advances \(ACC\)](#)
- *Journal of the Heart Valve Society*
- [The Annals of Thoracic Surgery \(Society of Thoracic Surgeons\)](#)

A significant aspect of the HVD Set is its strong focus on the patient perspective. Neil Johnson, Executive Director at the International Alliance of Heart Patient Organisations, Global Heart Hub, comments, “We are thrilled to join the ICHOM Patient Partner Alliance as it underscores our commitment to ensuring that the perspectives of those living with cardiovascular disease are heard and respected. By collaborating with ICHOM, we aim to promote patient-centered care and shared decision-making, ultimately improving health outcomes for all patients. We are delighted to officially endorse this paper, together with our affiliates Heart Valve Voice UK and Heart Valve Voice Canada, whose patient community contributed to the creation of the ICHOM HVD Set.”

“The first ICHOM Set for heart valve disease marks a groundbreaking shift in how we assess treatment success. Instead of focusing solely on the devices used, this new approach prioritizes patient outcomes, providing a more comprehensive picture of care. This initiative is the result of collaboration among multiple societies, with input from patient representatives, to create the first unified evaluation tool for managing heart valve disease. It covers everything from moderate cases to surgical or percutaneous interventions, with a focus on lifelong patient follow-up,” said Hanneke Takkenberg, Emmanuel Lansac, and Kevin Veen, co-chairs of the ICHOM Heart Valve Disease Working Group. “By improving global evaluation methods, we can raise the level of evidence and ultimately enhance heart valve disease patient outcomes. We urge other medical societies to follow this example and form collaborative task forces to develop similar global evaluation tools for their own areas of care.”

The HVD Set provides a structured approach to measuring outcomes across diverse healthcare settings, incorporating both clinical indicators and patient-reported outcomes to fully capture the impact of treatment on patients' lives, including moderate valvular disease, interventional approaches (both surgical and non-surgical) and long-term follow-up. With practical implementation guidance, the Set supports healthcare providers in enhancing care quality, benchmarking performance, and fostering continuous improvement.

Jennifer Bright, President and CEO of ICHOM, highlighted the broader impact of this initiative: “The simultaneous publication in leading cardiology journals underscores the global commitment to defining standardized clinical and quality-of-life outcomes that matter most to patients. This Set represents a landmark consensus and serves as a valuable resource that clinical teams, registries, and regulators can immediately use to begin collecting key data—primary indicators of the quality and effectiveness of HVD interventions. Furthermore, it empowers patient communities by supporting informed decision-making and enabling them to better communicate their treatment priorities to their care teams. We look forward to collaborating with all stakeholders to leverage

these resources and show the powerful impact that a focus on outcomes can have in delivering better care and achieving improved health."

ICHOM is committed to collaborating with stakeholders around the world to implement the HVD Set and improve heart valve disease care through evidence-based outcomes. We extend our gratitude to our Set sponsors, Edwards Lifesciences and Adetec, and our Cardiometabolic Family of Sets Updates sponsor, Novartis, for their support in driving this important initiative forward.

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### **About ICHOM**

The International Consortium for Health Outcomes Measurement (ICHOM) is a non-profit organisation dedicated to transforming healthcare by developing global Sets of Patient-Centered Outcome Measures that define the outcomes that matter most to patients. These Sets provide a universal language for comparing healthcare performance and driving value-based healthcare.

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