

ICHOM Patient Charter

The International Consortium for Health Outcomes Measurement (ICHOM, www.ichom.org) is the leading non-profit dedicated to transforming healthcare by focusing on what truly matters to patients. ICHOM accomplishes this by partnering with patients, carers, patient advocates and patient organizations, as well as other stakeholders such as clinicians, scientists, healthcare provider organizations, payers, and policymakers worldwide to improve outcomes that matter most to patients. At our core, we believe that the patient voice is essential to shaping healthcare and health systems, and that this enriches investment in healthcare in a way that takes into account the patient's (and carer's) perspective and insights from their lived experiences. We make committed efforts to amplify patients in the development of our global Sets of patient-centered outcomes, and our work more broadly.

ICHOM seeks to establish a foundation for meaningful collaboration and trust with our patient* community. For this reason, ICHOM has developed a Patient Charter declaring our commitments to the patients, carers and patient advocates we work with. We consider the following principles essential to empowering patients, carers and patient advocates, and ensuring that ICHOM remains transparent and accountable to our community:

1. "I am more than my medical condition."

Although a health condition constitutes an aspect of a patient's life, it does not define them. ICHOM recognizes patients as people and humans, with diverse backgrounds and aspirations in life that go beyond their health conditions that will not be limited by stigma or labels associated with these conditions.

2. "I have the right to be involved in decisions that will impact my health and wellbeing through shared goal-setting with clinicians to improve the articulation and measurement of health outcomes."

ICHOM commits to making sure that the voices of patients are not left out in decisions that have the foremost impact on them, with ICHOM Sets serving as tools to facilitate shared goal setting between clinicians and patients. ICHOM strives to ensure equal representation of patient representatives and lived experience users in our Working Group processes. Recognizing that this is not always possible, ICHOM pledges that patient representatives and lived experience users will comprise a minimum of 20% of all Working Groups for ICHOM initiatives. Beyond representation in Working Groups, ICHOM will amplify patient input in the following ways: holding focus group consultations with patients early in the Working Group

process, soliciting input from patients and patient communities outside of the Working Group (as part of an Open Review validation survey further recognizing patients as crucial research partners), and including patient-reported outcome measures as key components of Sets for patient-prioritized health outcomes.

ICHOM also commits to supporting the development of a shared understanding between patients and clinicians of the outcomes that matter most to patients, to contribute to the alignment of common goals so all stakeholders can work collaboratively towards achieving those outcomes. This will foster mutual accountability and increase trust and partnership.

3. “The expertise of my lived experience is a first-line component of defining health outcomes measurement.”

ICHOM recognizes that patient representatives are experts in their own health experiences, needs, and preferences, and can ensure that ICHOM recommendations align with their goals and values. Patient expertise will be prioritized when developing patient-defined outcomes for Sets of outcome measures, in acknowledgement of the first-hand insights patients can offer. ICHOM recognizes that lived experience perspectives can help shed light on unmet needs of health systems, and incorporating this knowledge can guide the co-design of better informed Sets of Patient-Centered Outcome Measures that can ultimately lead to more impactful healthcare delivery.

4. “I have the right to equal partnership in the design and determination of how outcomes for my health condition should be assessed.”

ICHOM will ensure that the patient representatives collaborating with us are supported and empowered during our initiatives, by providing appropriate information and resources to make co-production of research and other initiatives as accessible as possible. ICHOM will actively facilitate the building of a knowledge base to ensure patient representatives are equal partners and leaders in research initiatives, regardless of their level of research experience.

5. “I have a right to fair compensation for my contribution of lived expertise to research and related initiatives on health outcomes measurement.”

To the extent necessary based on personal circumstances, ICHOM acknowledges the importance of prioritizing equitable participation in outcomes measurement research by minimizing potential financial and resource barriers, and enabling participation from patient



representatives, including those from diverse socioeconomic backgrounds. To this end, ICHOM pledges to compensate (on an opt-in basis) patients participating in Working Groups at a rate commensurate with similar initiatives, for their valued and expert contributions, and investment of their time.

6. "I believe that my participation in research and advocacy efforts contributes to a rich tapestry of patient experiences."

ICHOM acknowledges the importance of research representing a multitude of perspectives and experiences, and commits to ensuring that the international Working Groups for Set development serve as dynamic platforms for these unique voices to be heard. Dissemination of ICHOM Sets will include authentic patient representation, involving them as co-authors in Set-related manuscripts, co-presenters at conferences and champions in advocacy, awareness, and policy change efforts. ICHOM aspires to further reinforce patient voices through the inclusion of patient representation in broader ICHOM governance mechanisms, where they can advocate and influence decision-making to ensure patient rights and best interests are championed.

7. "I own my story, and have the right for what I share of it to be treated with respect."

ICHOM will respect patient privacy, and will honor patient ownership of the stories and data that they share. In addition to complying with regulations, ICHOM will provide safe and respectful spaces for patients to share their stories. ICHOM will also seek the relevant consent for use of these insights as part of Working Group processes or other initiatives.

8. "All patients deserve and are entitled to the above."

ICHOM recognizes that patients are not a homogenous group, but are people and humans, with diverse backgrounds and abilities. ICHOM commits to providing equitable opportunities for participation to patients of different sociocultural and economic backgrounds, geographic regions, and health conditions, and to actively engage patients who have thus far been underrepresented in decision-making. This will cultivate a more diverse, inclusive, and enriched approach to patient-centered outcomes measurement to drive more equitable health system transformation.

*Please note that while ICHOM uses the 'patient' terminology for the sake of clarity and consistency, we fully recognize that there are a range of terms within different communities that are preferred, including clients, consumers, and users.

