

ICHOM Hand and Wrist Standard Set

ICHOM: work and vision

The International Consortium for Health Outcomes Measurement, ICHOM (www.ichom.org), is a non-for-profit organization with the mission to unlock the potential of value-based health care by: defining global Standard Sets of outcome measures that really matter to patients for important medical conditions and by driving adoption and reporting of these measures worldwide.

We are currently developing a Hand and Wrist Standard Set, with the aim of identifying health care outcomes that are relevant for Adult (≥ 18 years) patients with Hand and Wrist conditions. We seek to balance a comprehensive view of measurements for evaluating hand and wrist conditions with a feasible recommendation that providers can reliably implement. Our aim is that this Standard Set will help to improve health outcomes and standardise the measurement of patient centered outcomes for hand and wrist conditions across the world.

ICHOM Hand and Wrist Standard Set Scope

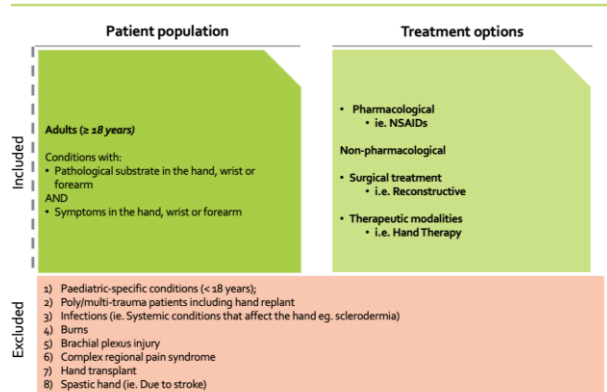


Figure 1 Scope of ICHOM Hand and Wrist Standard Set

Project Process

ICHOM facilitates and organizes teleconference meetings with the Working Group members to work through the development of the Standard Set in a structured way. Additionally, ICHOM facilitates patient engagement activities to gather patient feedback to inform the working group process. The Chair of this Standard Set is Dr. Steven Hovius of Radboud University Medical Center, Netherlands. The ICHOM Hand and Wrist Set Working Group

comprises of 19 international leaders with broad expertise including: researchers in PROMs, registry leaders, quality improvement and data scientists, and clinical leaders.

ICHOM Hand and Wrist Set Working Group members

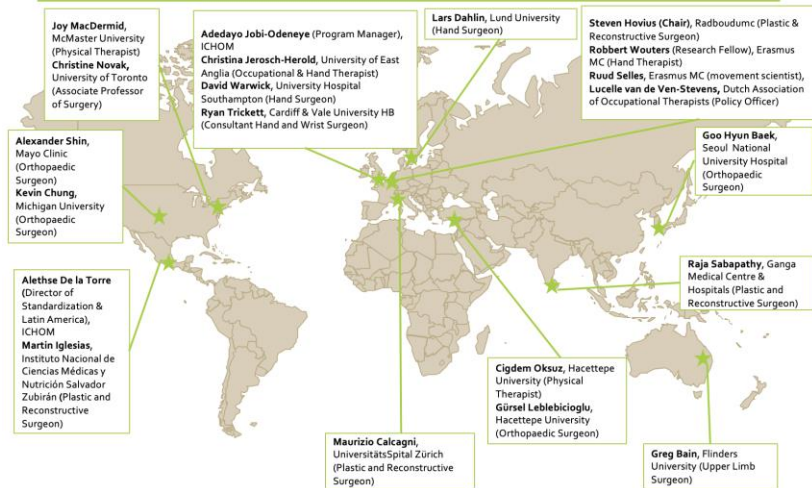


Figure 2 Geographical distribution and composition of the working group

During the Working Group process, a series of systematic reviews of literature are performed and patient surveys are distributed to identify outcomes, outcome measures, and important case-mix variables. Through a modified-Delphi process, outcomes and outcome measures are voted for inclusion in the Set based on working group and patient representative consensus. At the completion of the working group process, the working group will have defined a core list of outcome domains and associated measures that assess success in managing hand and wrist conditions from the patient's perspective. Also, a set of baseline case-mix adjustment variables and standardised

timepoints for outcomes measurement will be defined, to allow for meaningful comparisons and global benchmarking. Lastly, a peer-reviewed journal article detailing the development of the Set will be published and Reference Guide describing instruments that should be used and technical details for implementing the Standard Set will be provided and accessible to interested parties worldwide.

Progress Check

As of May 2019, there have been 12 International Working Group videoconference calls and 6 breakout sessions. The working group has reached consensus on the classification of 5 tracks: a thumb, wrist, finger, nerve, and hand trauma track and their corresponding conditions criteria, outcome measures (tools) and outcome measurement timepoints. The timepoints for outcomes measurements have been categorized as by two tracks 'regular' and 'extended' tracks for cases requiring short or longer follow-up respectively. Following the finalization of the hand trauma track, which is still in progress, the Working Group will be defining a track hierarchy. This hierarchy will guide implementors of the Set on which track(s) to measure cases, and particularly, complex, multi-structure cases, using the Hand and Wrist Standard Set. On June 19th, the working group will be meeting during the 2019 FESSH congress to discuss the track hierarchy. Earlier this month, some of the WG members attended the ICHOM Conference in Rotterdam, Netherlands and the ICHOM team did a site visit of Xpert Clinic.



Figure 3. Working Group members at the 2018 FESSH Congress breakout session

At the conclusion of the formal working group process, the Project Team which hold an open validation period, in which a survey will be distributed to a wider network of patients, clinical and registry leaders, and scientist to provide feedback on the recommendations of the Standard Set. The feedback of the open validation surveys will be used to refine and finalise the Set. The final ICHOM Hand and Wrist Standard Set will be published in the form of a flyer (two-page overview of the ICHOM Standard Set), a reference guide (full detail of the Standard Set for institutions interested in collecting) and an academic publication. All the materials will be published on ICHOM's website and will be open access to promote the dissemination of the work.

Financial

The development of the ICHOM hand and Wrist is at 75% completion. The funding provided by the sponsors, including IFSSH, has been used to pay the salaries of the ICHOM Project Team: Director of Standardisation/Manager oversight, Hand and Wrist Programme Manager (FTE) and Hand and Wrist Research Associate (FTE). Additionally, funds have been used to cover operational and overhead costs of delivering the monthly international conference calls (i.e. office rent, WebEx videoconference subscription and Qualtrics survey platform subscription, research resources, etc.). The funds were also used to cover the cost of travel of the ICHOM project team to the international breakout sessions and for the conference tickets of working group members that attended the ICHOM conference in May 2019. Lastly, the funds will also be used to create the promotional and marketing materials (i.e. ICHOM flyer and reference guide), the journal publication (i.e. fee for open access) and for any future updates and maintenance of the Standard Set.

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