



ICHOM Set of Patient-Centered Outcome Measures for Bladder Cancer

About ICHOM:

The International Consortium for Health Outcomes Measurement (ICHOM) was founded by Michael E. Porter, PhD - Bishop William Lawrence University Professor at Harvard Business School, Stefan Larsson, MD, PhD, The Boston Consulting Group, and Professor Martin Ingvar, MD, PhD, Karolinska Institutet. The mission of ICHOM is to unlock the potential of value-based health care by defining global Sets of outcome measures that really matter to patients, driving adoption, and reporting of these measures worldwide. We believe that the systematic measurement of Sets of outcomes by institutions around the world will enable, for the first time, global outcome comparisons. We think this will catalyze a new wave of learning for healthcare professionals, as we will be able to see where the most significant outcomes are being achieved and then learn from the processes that they have in place. We also believe that it will really inform patient choice. Since 2012, ICHOM has created Sets of outcomes that matter most to patients for over 40 medical conditions, including mental health, cardiometabolic, oncology, and neurological diseases and conditions. More information can be found at <https://www.ichom.org/patient-centered-outcome-measures/>.

Now, we are planning to develop a globally agreed Set of Patient-Centered Outcome Measures for patients with *Bladder Cancer*.

Who will benefit from the work and why:

Current care metrics for patients tend to capture processes and costs and do not measure whether they achieve the outcomes that matter most to patients. Developing a globally agreed set of outcomes for patients with bladder cancer will enable us to measure and consistently compare outcomes important for this population in countries worldwide. It will allow the identification of those systems with the best outcome results and the subsequent ability to learn from the processes that they have in place. The ability to compare outcomes also supports patient choice.

Project process:

ICHOM facilitates and organizes monthly teleconference meetings with the Working Group members to develop the Set in a structured way. Working Groups are international and multidisciplinary, comprising healthcare professionals and academics with expertise in the condition of interest, outcomes measurement experts, and patient representatives. **Figure 1** and **Figure 2** show the structure of the Working Group and the Working Group process, respectively.

During the meetings, the Project Team facilitates discussion within the Working Group to debate the proposal. Following the call, the Project Manager will administer surveys to assess the degree of consensus within the group and raise any outstanding items for discussion.

This process involves the following steps:

- Defining how we classify the population of patients
- Compiling a list of outcome measures in use by national or regional outcome measurement efforts (including national audits) as well as those in use by leading programs and validated patient-reported outcomes that have been reported in the medical literature
- Defining a prioritised list of outcomes that assess success in managing these conditions from the patient’s perspective
- Agreeing on the best available instrument or definition to measure each domain
- Defining necessary baseline case-mix adjustment variables in order to make comparisons possible
- Developing a reference guide that describes instruments that should be used, and that provides users with the background information to adopt the Set
- Publishing the complete Set of outcomes in a leading journal and presenting at conferences
- Making the Set accessible and freely available to all for global adoption and implementation

Figure 1

Working Group Structure

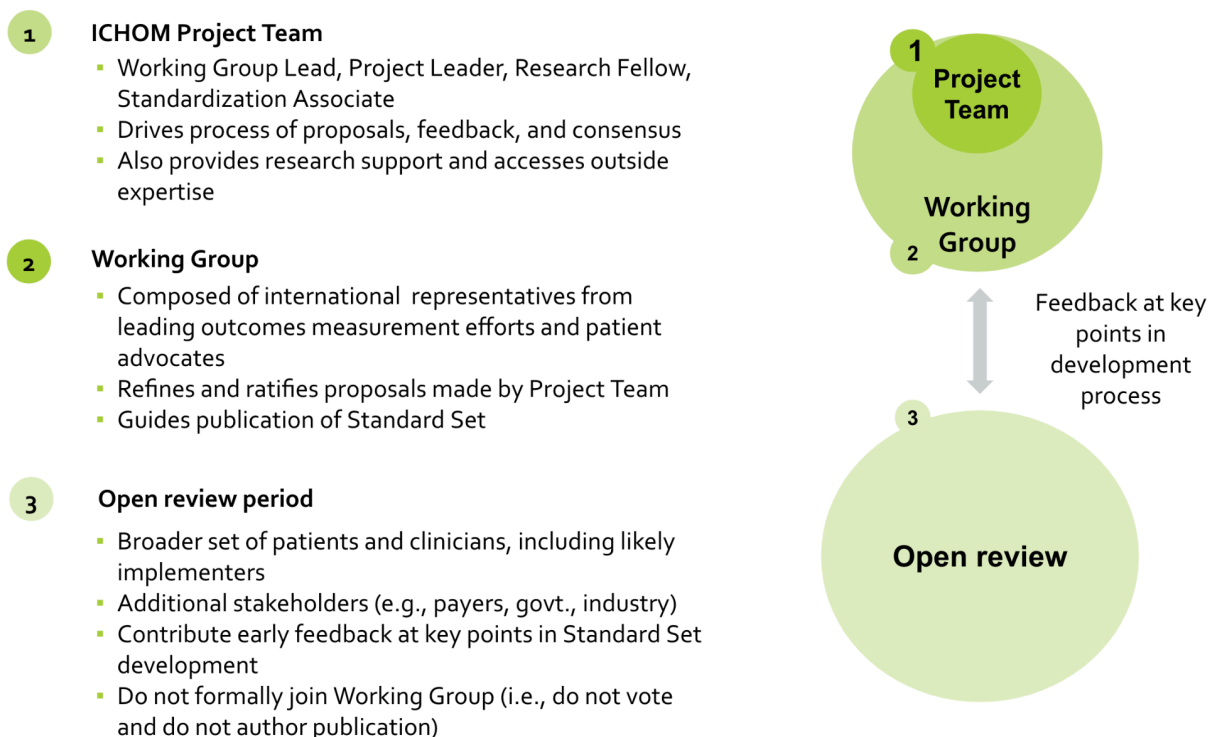


Figure 2

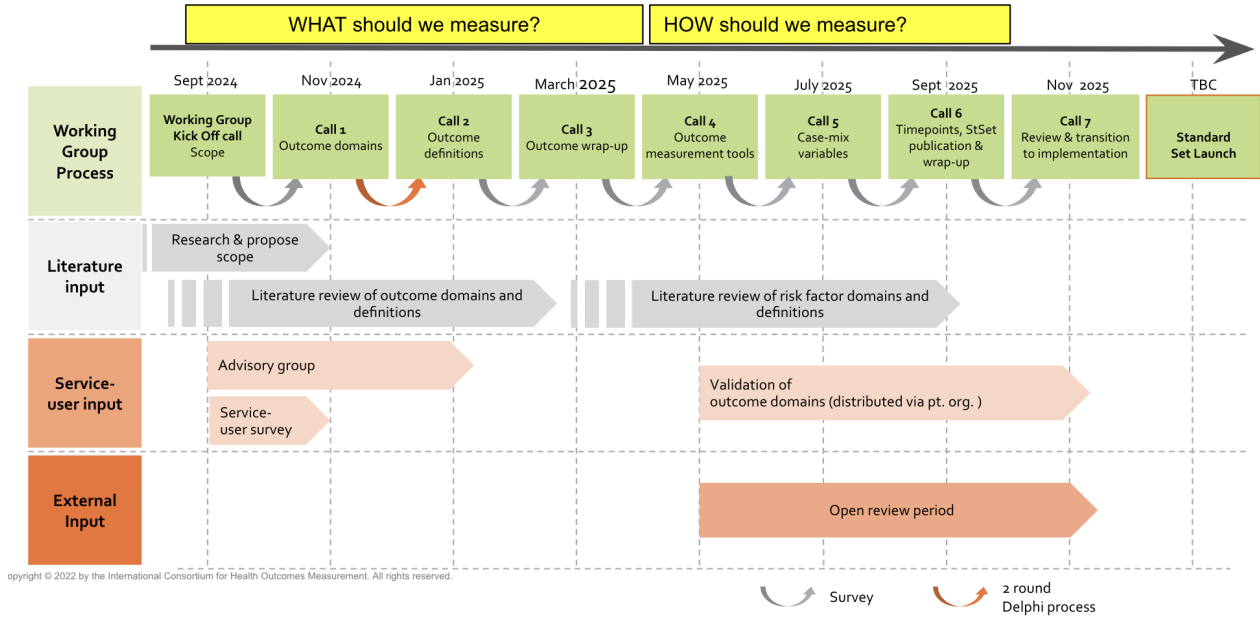


Figure 3 Example of ICHOM materials showing reference guide and outcome circle. Other materials can be downloaded from <https://www.ichom.org/patient-centered-outcome-measure/>.

Localized Prostate Cancer Data Collection Reference Guide
 Version 2.0.5
 Revised April 17, 2017

ICHOM Standard Set for LOCALIZED PROSTATE CANCER

Treatment approaches covered: Watchful waiting | Active surveillance | Prostatectomy | External beam radiation therapy | Brachytherapy | Androgen Deprivation Treatment | Focal therapy | Other

For a complete overview of the ICHOM Standard Set, including definitions for each measure, time points for collection, and associated risk factors, visit [ichom.org/medical-conditions/Localized-Prostate-Cancer](https://www.ichom.org/medical-conditions/Localized-Prostate-Cancer)

Outcome Circle:

- OVERALL SURVIVAL
- CAUSE-SPECIFIC SURVIVAL
- METASTASIS
- BIOCHEMICAL RECURRENCE
- VITALITY
- SEXUAL DYSFUNCTION
- ACUTE COMPLICATIONS
- MAJOR SURGICAL COMPLICATIONS
- MAJOR RADIATION COMPLICATIONS
- URINARY INCONTINENCE
- URINARY FREQUENCY OBSTRUCTION IRRITATION
- BOWEL IRRITATION
- PATIENT REPORTED HEALTH STATUS

Measuring results that matter
 Level of urinary incontinence

Localized Prostate Cancer

Details:
 1. Recorded via the Common Data Element Classification
 2. Recorded via the Common Terminology Criteria for Adverse Events (CTCAE), version 4.0
 3. Recommended to track via the Expanded Prostate Cancer Index Composite (EPIC v6 version preferred)

ICHOM LOCALIZED PROSTATE CANCER
 Revised: April 20th, 2015



Your involvement in this Set development as a **Working Group** member:

Expectations

- 2-4 hours per month for 12-15 months
- Teleconference every 4-6 weeks with reviews and surveys between the calls
- Valuable inputs as an expert in the field
- Opportunity to engage with international colleagues to define the next quality standard
- Co-author the Set development publication in a peer-reviewed journal

Criteria for selection of Working Group members

Inclusion Criteria	Requirements
1. Expertise	<ul style="list-style-type: none">● An adult (or caregiver of someone) who has or has experienced bladder cancer.● Interested in co-producing research (ICHOM will ensure participants fully understand the process before and throughout participation).
2. Suitability	<ul style="list-style-type: none">● Be able to participate during discussions / teleconferences / surveys● Be able to provide inputs as a field expert● Be able to communicate in English● Accept and sign participation form, to be provided following an introductory call

For further details, please contact

Project Manager: Christina Nielsen (c.nielsen@ichom.org)