



How are standard sets made and implemented?

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Agenda

- **Why create Standard Sets?**
- **End-to-end Standard Set development process**
- **Standard Set Example**
- **Moving onto implementation**

Framing principles for ICHOM Standard Sets

- 1 Outcomes are defined around the **medical condition**, not the specialty or the procedure
- 2 The Standard Set is a “**minimum set**” focused on the outcomes that **matter most to patients**
- 3 Patients are directly involved in defining the Standard Set
- 4 **Patient-reported outcomes** are included in every Standard Set to capture symptom burden, functional status and health-related quality of life
- 5 A “minimum set” of initial conditions/**risk factors** is included to facilitate meaningful comparison
- 6 Time points and sources of data collection are **clearly defined** to ensure comparison of results

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For all conditions and population areas we must first ask the following questions:

Step 1

Is this work needed?

Step 2

Is it feasible to identify measurable outcomes and what work exists already?

ICHOM organises **Working Groups** to define Standard Sets of outcomes we recommend all care providers track



ICHOM facilitates a process with international clinical and registry leaders and patient representatives to develop a global Standard Set of outcomes that really matter to patients, along with corresponding case-mix factors

Clinical and registry leaders

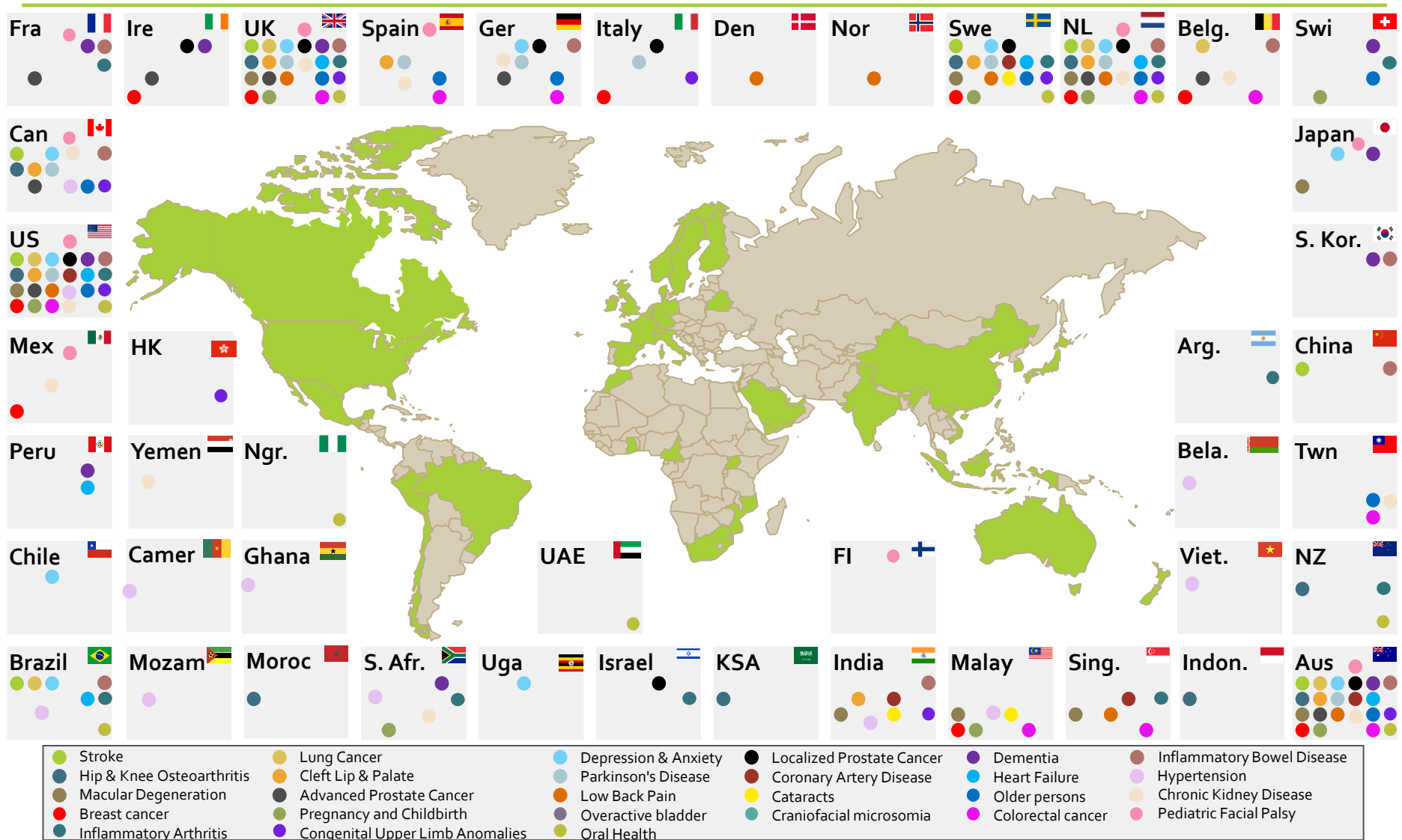


Patient representatives



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ICHOM Working Group members originate from 44 countries



Source: ICHOM; Last Updated: Aug 22, 2017

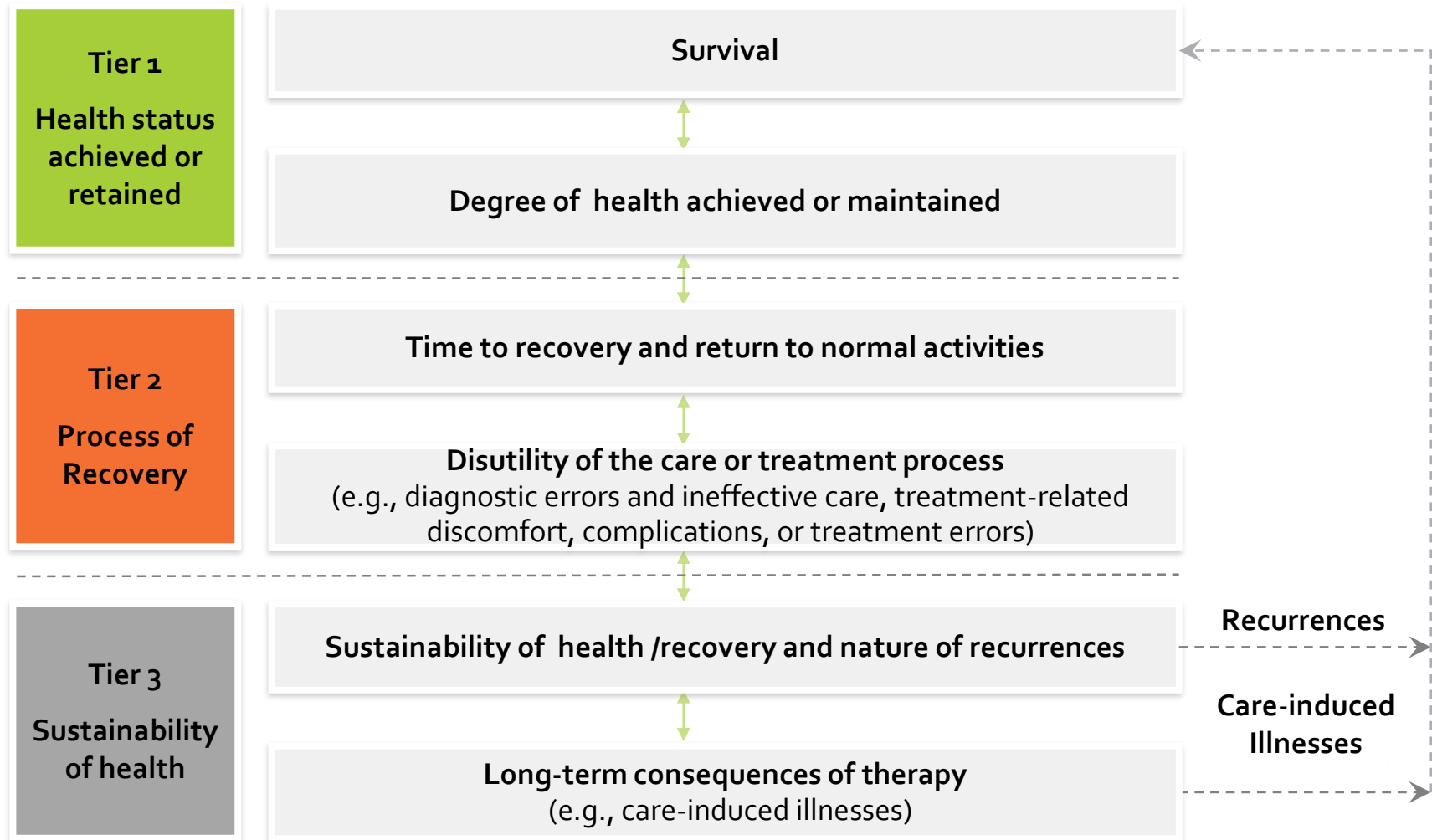
Goal of the Working Group: Recommend a *minimum* Set of outcomes for all providers to track in routine care

Selected outcomes
should...

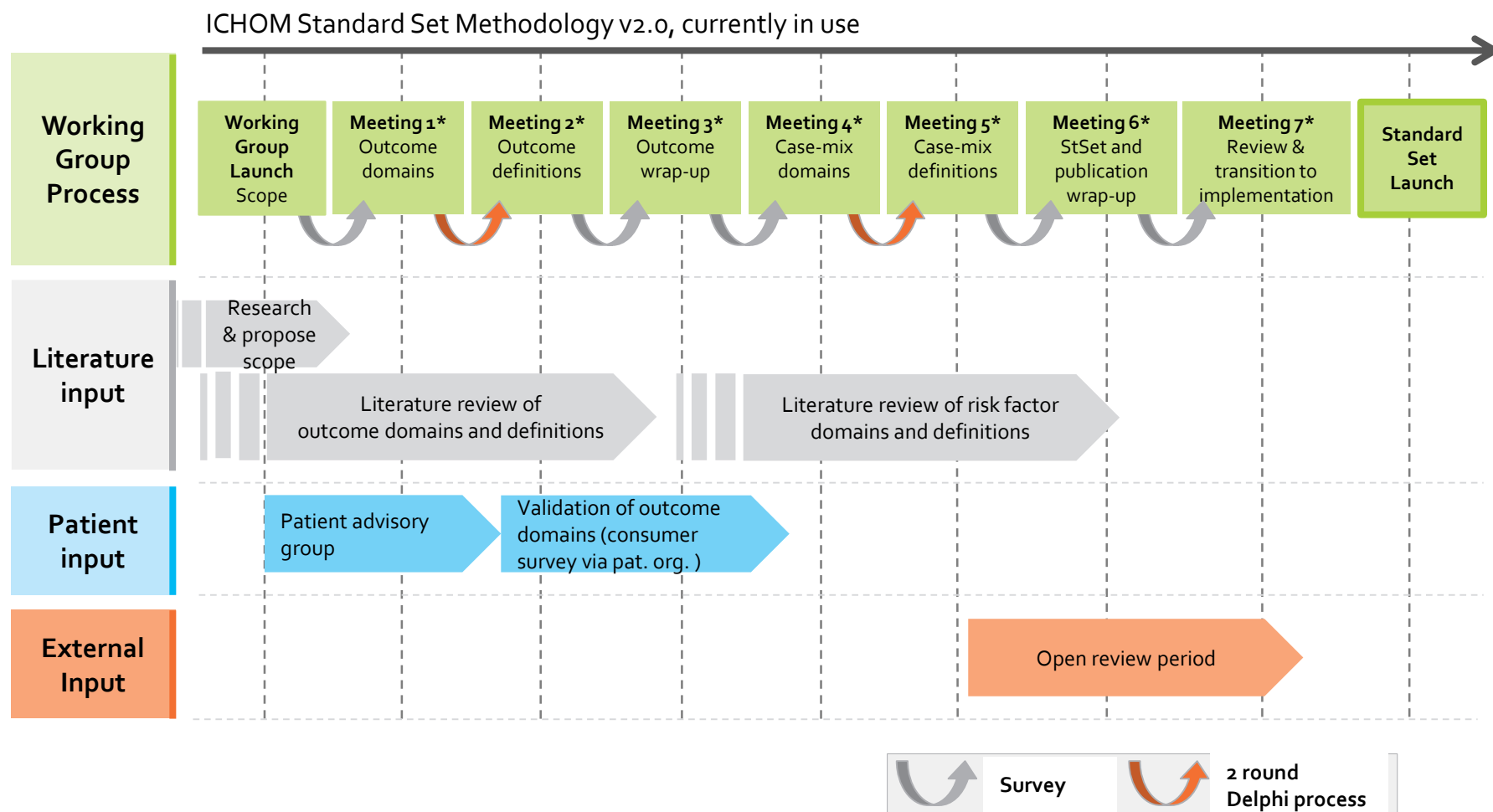
- Represent the **end results** of care, not the process of care.
- Be **important to patients**.
- Be **feasible** to capture.
- Be **modifiable** with quality improvement efforts.
- We are seeking to balance a **comprehensive** view of measurement with a **feasible** recommendation that providers could reliably implement.
- The goal is to **enable outcome measurement** in routine clinical practice to:
 - ✓ Improve decision making between providers and patients.
 - ✓ Facilitate quality improvement.
 - ✓ Allow for benchmarking across organisations.

ICHOM Standard Sets focus on the outcomes that matter most to patients

Michael Porter's Outcome Measures Hierarchy



Standard Sets are **defined** through a series of teleconference calls, supported by research and patient input



* Most meetings are telephonic or via video

Patient Advisory Groups are conducted to understand what matters most to people

Aims

- To increase the patient voice within the Standard Set and capture further perspectives based on personal experiences

Methodology

- Well-established methodology (Dukes and Eastern Illinois University) for format, facilitation and consent

Format

- 6-10 focus group representatives attend a recorded videoconference or in-person with facilitated questions and the opportunity to discuss and share perspectives on outcomes that matter to them

**The Stroke Standard Set was developed before patient focus groups and surveys were part of our methodology*

Surveys help determine the outcomes and variables included in a Standard Set

3.(c) Self report of new stroke X days after admission for index event

Definition Stroke within X number of days of index event (which can be stroke or TIA).
Reporting format Patient reported. "Since your stroke (or TIA), has a physician told you that you had a stroke?"
Timing Reported at X number of days after index event

Please note that in this question, we ask you to enter your suggested timeframe (in number of days) after the index event at which this should be captured.

	Yes, agree	No, disagree	If No, please explain
Definition	<input type="radio"/>	<input type="radio"/>	<input type="text"/>
Reporting format	<input type="radio"/>	<input type="radio"/>	<input type="text"/>
Timing	<input type="radio"/>	<input type="radio"/>	<input type="text"/>

3.(d) Please provide any additional comments you have on these measures below:

Please uncheck/check any boxes below according to your thoughts, and provide additional comments/input/alternatives on the measures and their timing in the text boxes to the right:

	Proposed measurement tool	Discharge	90 days	Comment
Ability to communicate - Single item assessment	GWTG	<input checked="" type="checkbox"/>	<input type="checkbox"/>	
Ability to communicate - Battery assessment	NEURO-Qo	<input type="checkbox"/>	<input checked="" type="checkbox"/>	
Mobility - Single item assessment	GWTG	<input checked="" type="checkbox"/>	<input type="checkbox"/>	
Mobility - Battery assessment	NEURO-Qo	<input type="checkbox"/>	<input checked="" type="checkbox"/>	
Ability to return to usual activities - mRS	mRS	<input type="checkbox"/>	<input checked="" type="checkbox"/>	
Ability to return to usual activities - Battery assessment	NEURO-Qo	<input type="checkbox"/>	<input checked="" type="checkbox"/>	
Self care and grooming - mRS	mRS	<input type="checkbox"/>	<input checked="" type="checkbox"/>	
Self care and grooming - Battery assessment	NEURO-Qo	<input type="checkbox"/>	<input checked="" type="checkbox"/>	
Global cognitive function	NEURO-Qo	<input type="checkbox"/>	<input checked="" type="checkbox"/>	
Patient reported general health status	NEURO-Qo	<input type="checkbox"/>	<input checked="" type="checkbox"/>	
Global patient reported HR-QOL	NEURO-Qo	<input type="checkbox"/>	<input checked="" type="checkbox"/>	
Fatigue	NEURO-Qo	<input type="checkbox"/>	<input checked="" type="checkbox"/>	
Mood	NEURO-Qo	<input type="checkbox"/>	<input checked="" type="checkbox"/>	
Feeding	TBD	<input type="checkbox"/>	<input checked="" type="checkbox"/>	
Pain and other unpleasant sensations	TBD	<input type="checkbox"/>	<input checked="" type="checkbox"/>	
Tobacco use	NEURO-Qo	<input type="checkbox"/>	<input checked="" type="checkbox"/>	

III. Measurement of the Risk adjustment variables

During the call, various thoughts were shared on the reporting of the risk adjustment variables. The Working Group was in agreement on the reporting of Age, Gender, Race/Ethnicity, Alcohol Use, Stroke Type, Prior Stroke, Prior TIA, Prior MI, Diabetes mellitus, Atrial Fibrillation, Hypertension.

The reporting of the following items needs to be voted on:

- Smoking
- Stroke severity
- Poststroke functional status
- Coronary artery disease
- Hypertension

Please indicate to us what reporting format you would prefer for these:

1. RISK ADJUSTMENT - Smoking

Proposed reporting:
 "Do you currently smoke, or have you smoked cigarettes or tobacco over the past year?" Y/N

Do you agree with this proposed reporting?

☐ Yes, agree

☐ No, my preferred reporting would be:

2. RISK ADJUSTMENT - Stroke severity

Proposed reporting:
 Stroke severity captured by mRS, and in cases where measuring the mRS is not possible/unavailable, at least the following item should be assessed: Single item level of consciousness (1 fully awake, 1 somnolent, 1 coma)

Do you agree with this proposed reporting?

☐ Yes, agree

☐ No, my preferred reporting would be:

Delphi Method:
70% threshold to include specific variable

We research key elements when selecting the best PROM tools for our Standard Sets

Our PROM selection is based on 5 key elements:

1. **Coverage** of outcome domains of importance
2. **Psychometric Quality** - ISOQOL standards
3. **Feasibility** - Burden of assessment
4. **Financial** - Licensing aspects
5. **Established** - Locations in use/translations

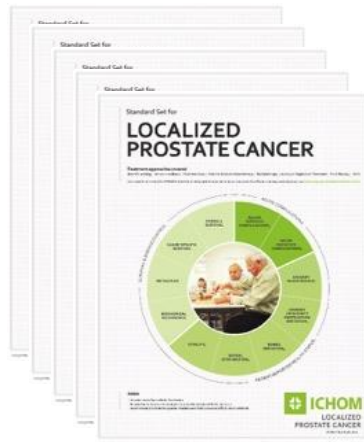
ICHOM does not create measurement tools, we research the PROMs that are available in the field, per condition

Sample research sheet used to score PROMs

		Brief definition and instruction	Generic PROMs (Any disease)
0	GENERIC INFO	ABBREVIATED NAME This is the name the prom is most known for. For example: EPIC-26	PROM I name
1	CONCEPTUAL & MEASUREMENT	CONCEPTUAL AND MEASUREMENT MODEL Give a generic description and purpose of the PROM.	High
		TARGET POPULATION The intended population(s) for use	High
2	RELIABILITY	TEST-RETEST RELIABILITY (= reproducibility) Stability of scores over time when no change is expected in the concept of	High
		RELIABILITY - INTERNAL CONSISTENCY Extent to which the items comprising a PROM instrument are measuring the	Low
3	VALIDITY	CONTENT VALIDITY The appropriateness of the items and the domains.	High
		CONSTRUCT VALIDITY Evidence that relationships among items, domains, and concepts conform	Med
		RESPONSIVENESS (Ability to detect change) An instrument's ability to detect change over time.	Med
4	INTERPRETABILITY	INTERPRETABILITY The degree to which one can assign easily understood meaning to an	Low
5	TRANSLATION	TRANSLATION List the original languages as well as all available PROM translations (comma	High
6	BURDEN	PATIENT BURDEN Time, energy and literacy demand. Literacy demand of the items in the	High
		ADMINISTRATIVE BURDEN Clinician/administrative/investigator/data analyst burden (time, energy,	High
7	LICENSING	LICENSING Information on licensing and licensing costs	Unknown
8	ESTABLISHED?	LOCATIONS IN USE Number of locations (countries) where PROM is in use	High
		# of CITATIONS Number of citations of original article	Unknown
		YEAR DEVELOPED Year of original publication	High

ICHOM Standard Sets are freely available to promote **global adoption**

Flyers



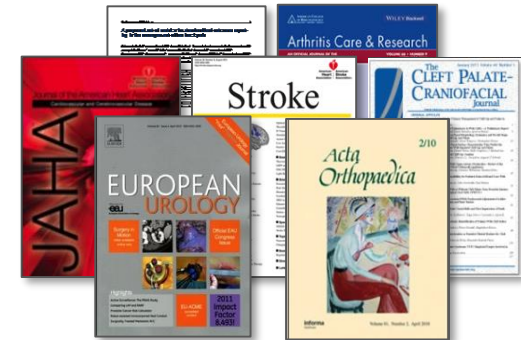
- Two-page overview of ICHOM Standard Set and Working Group
- Flyers are available at www.ichom.org

Reference Guides



- Full detail of Standard Set for institutions interested in collecting
- Includes measure definitions, coding instructions, and sample questionnaires
- Reference Guides available at www.ichom.org

Academic Publications

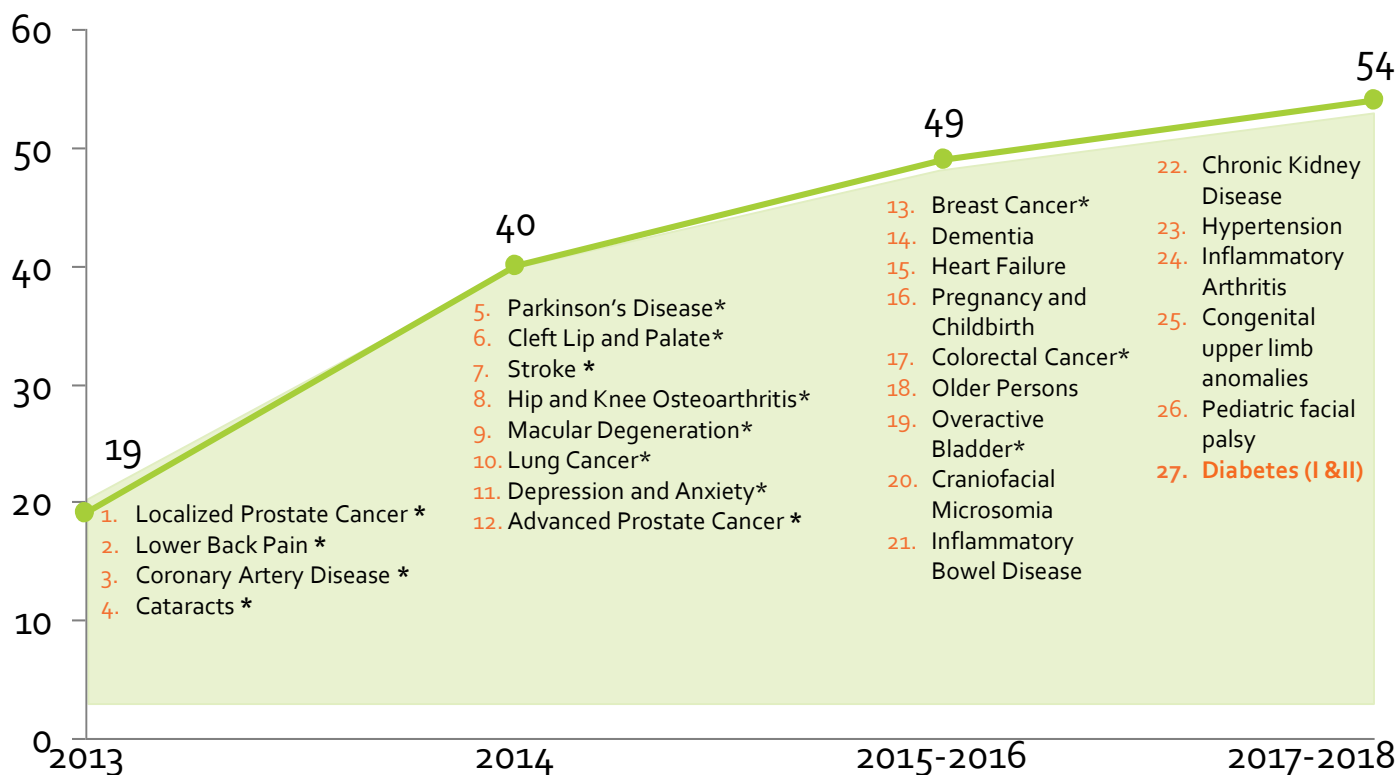


- Several peer-reviewed publications
- Explains process to arrive at Standard Set and motivation for selected measures
- Click [here](#) for example

ICHOM Standard Sets now cover many high impact disease areas

27 ICHOM Standard Sets to-date

Burden of Disease Covered (%)



Committed/ In process

- Oral health
- Atrial fibrillation
- Overall adult health
- Overall pediatric health
- Hand & wrist conditions
- Mental health
- Preterm and hospitalized new born
- Congenital heart diseases

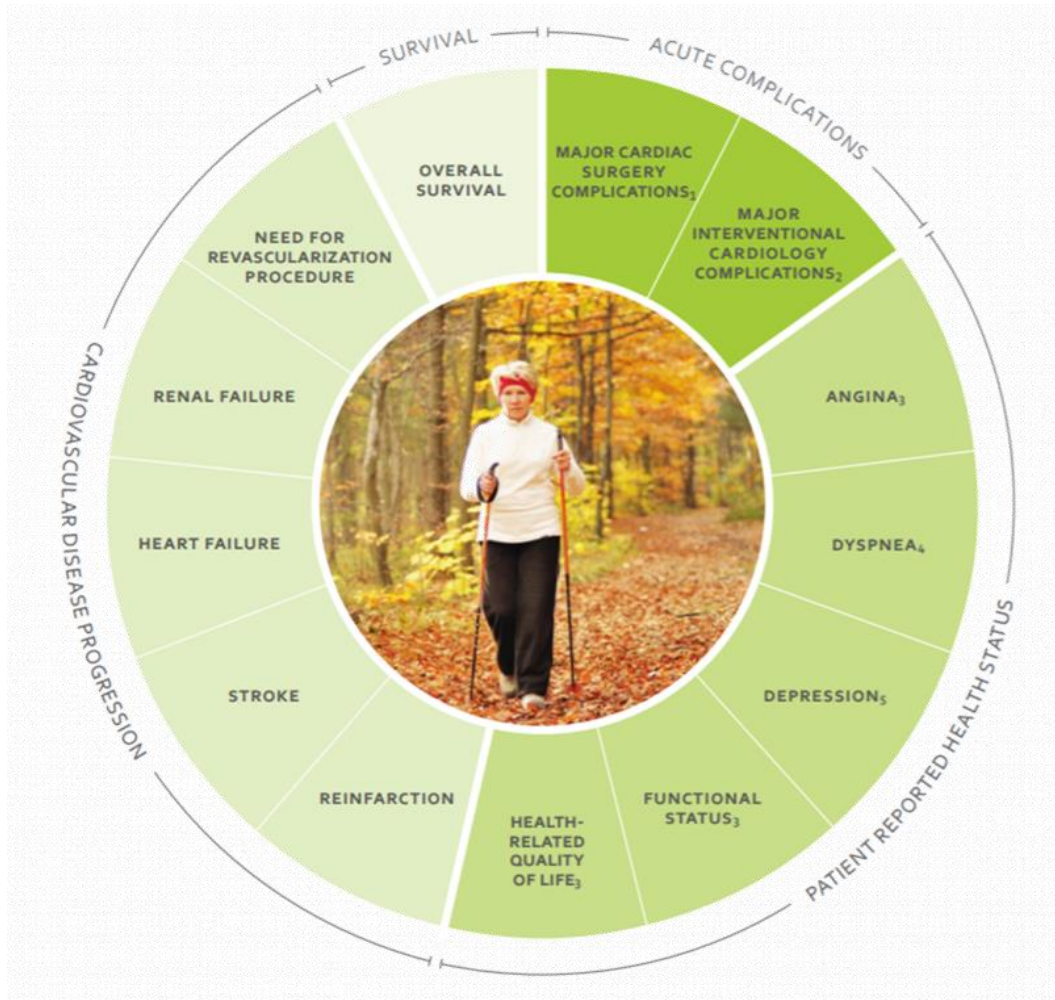
• 15 Standard Sets published to date in peer-reviewed journals

Percentage of global disease burden coverage is based on *Global Burden of Disease Study 2016. Global Burden of Disease Study 2016 (GBD 2016) Results. Seattle, United States: Institute for Health Metrics and Evaluation (IHME), 2016.*

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ICHOM Standard Set for Coronary Artery Disease: Outcomes



Conditions Covered

- Asymptomatic Coronary Artery Disease
- Stable Angina
- Acute Coronary Syndrome (Includes AMI)

Treatment Modalities Covered:

- Lifestyle Modification
- Drug Therapy
- Percutaneous Coronary Intervention (PCI)
- Coronary Artery Bypass Grafting (CABG)

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Coronary Artery Disease: Data Dictionary

Variable ID: HF

Variable: Past medical history: Heart failure

Definition: Indicate if the patient has a documented history of heart failure

Supporting Definition: Heart failure is defined as physician documentation or report of any of the following clinical symptoms of heart failure described as unusual dyspnea on light exertion, recurrent dyspnea occurring in the supine position, fluid retention; or the description of rales, jugular venous distension, pulmonary edema on physical exam, or pulmonary edema on chest x-ray presumed to be cardiac dysfunction. A low ejection fraction alone, without clinical evidence of heart failure does not qualify as heart failure

Inclusion Criteria: All patients

Timing: At time of diagnosis

Data Source: Clinical*

Type: Single answer

Response Options: 0 = No

1 = Yes

ICHOM is gaining the support of the health care community



*As of June 29th 2017

THANK YOU

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