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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

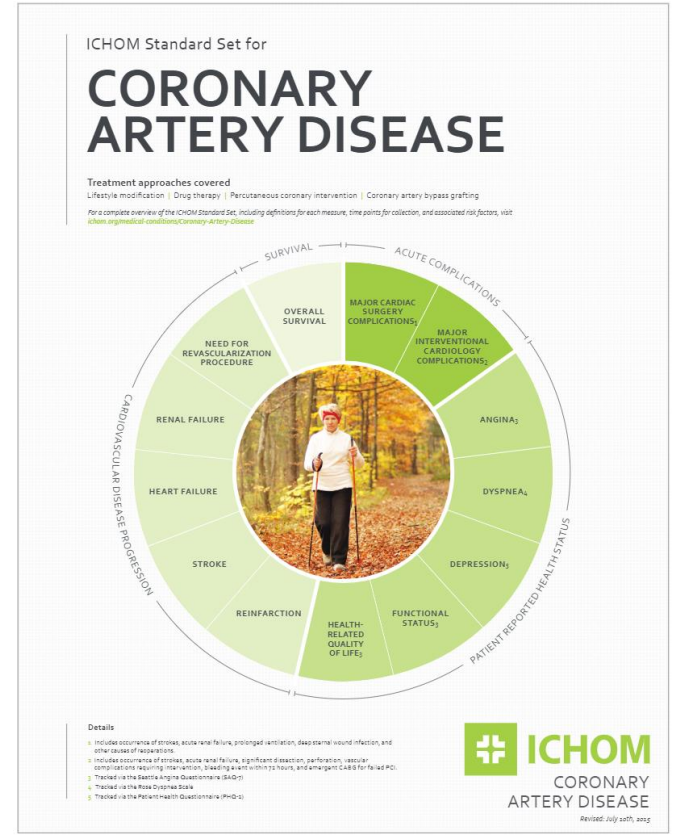
Is it feasible to identify measurable outcomes and what work exists already?

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

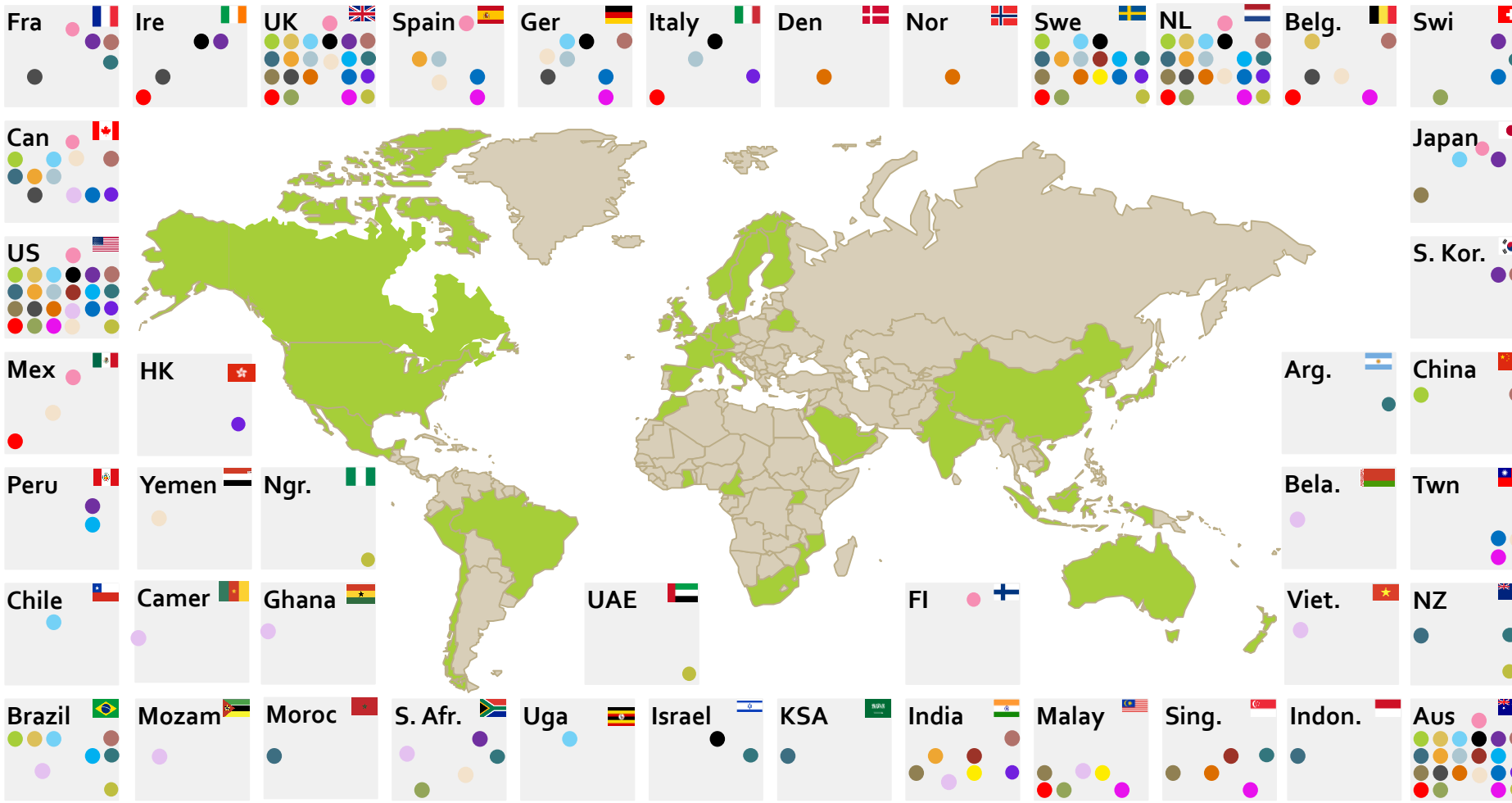
ICHOM facilitates a process with international clinical and registry leaders and patient representatives to develop a global Standard Set of outcomes that really matter to patients, along with corresponding case-mix factors

Clinical and registry leaders

Patient representatives



ICHOM Working Group members originate from 44 countries



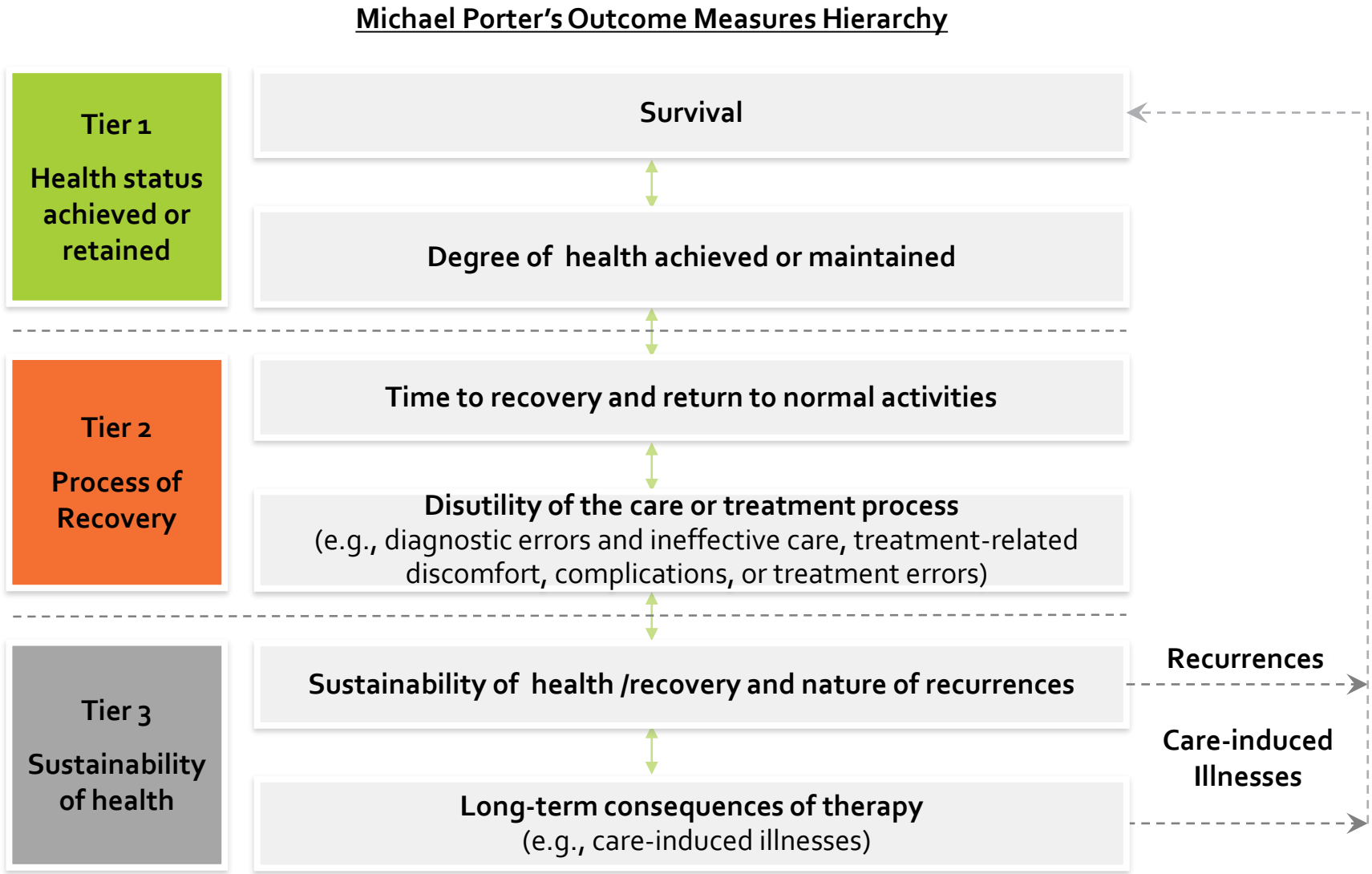
Source: ICHOM; Last Updated: Aug 22, 2017

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

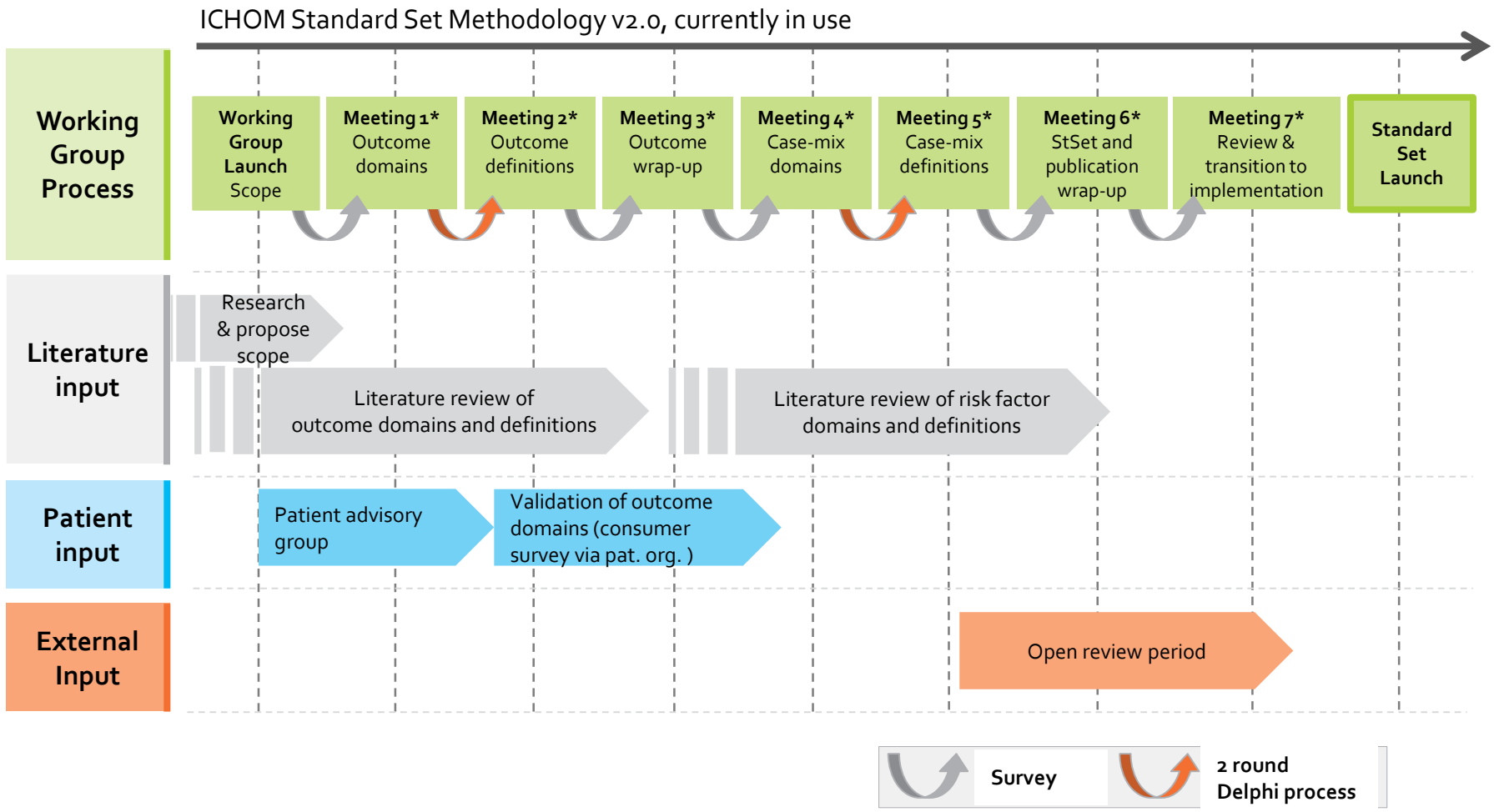
Selected outcomes should…

- 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



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



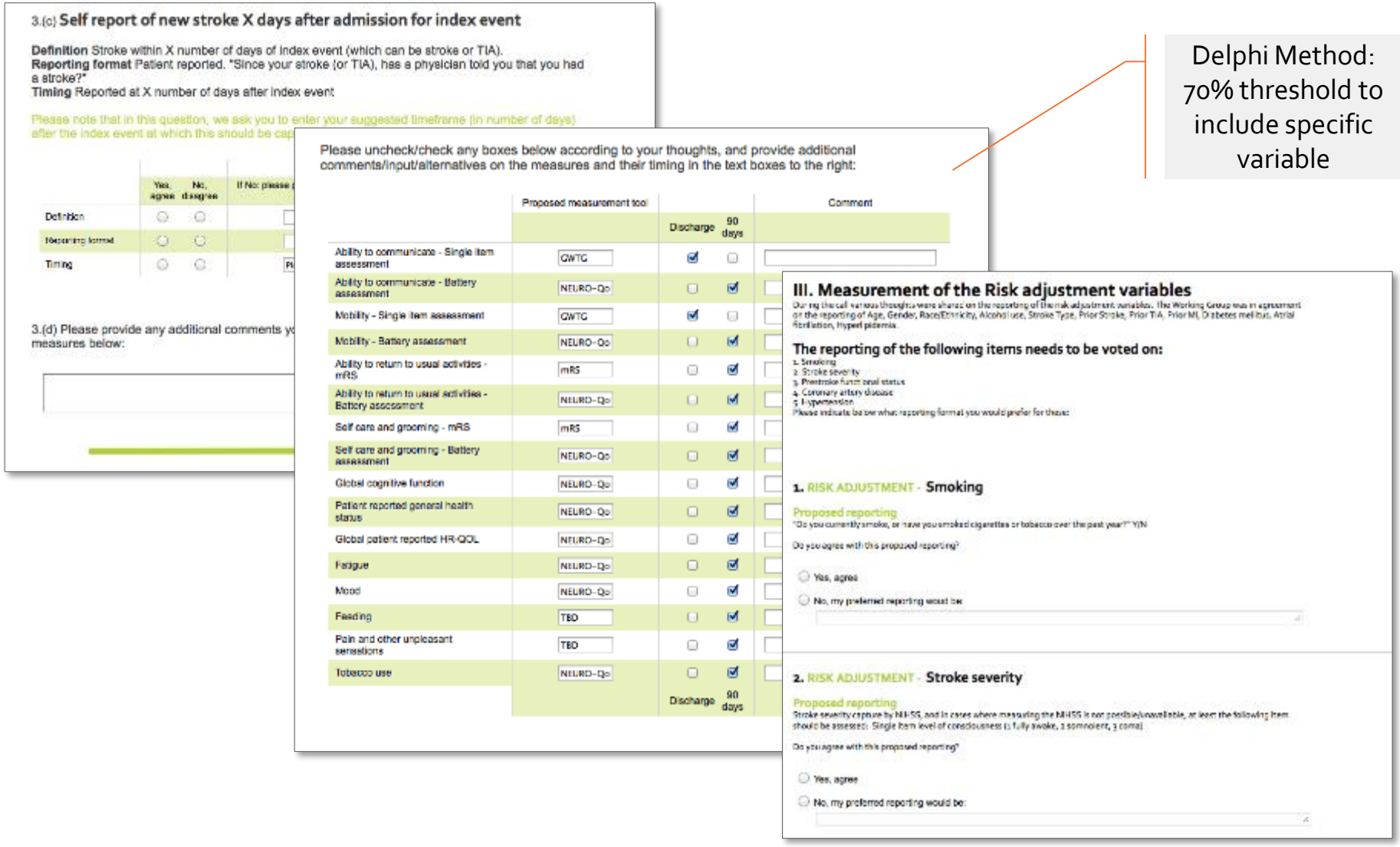
* Most meetings are telephonic or via video

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



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 analyist burden (time, energy,	High
7	LICENSING	LICENCING	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

1: Reeve et al. ISOQOL recommends minimum standards for patient-reported outcome measures used in patient-centered outcomes and comparative effectiveness research. Qual Life Res (2013) 22:1889–1905

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

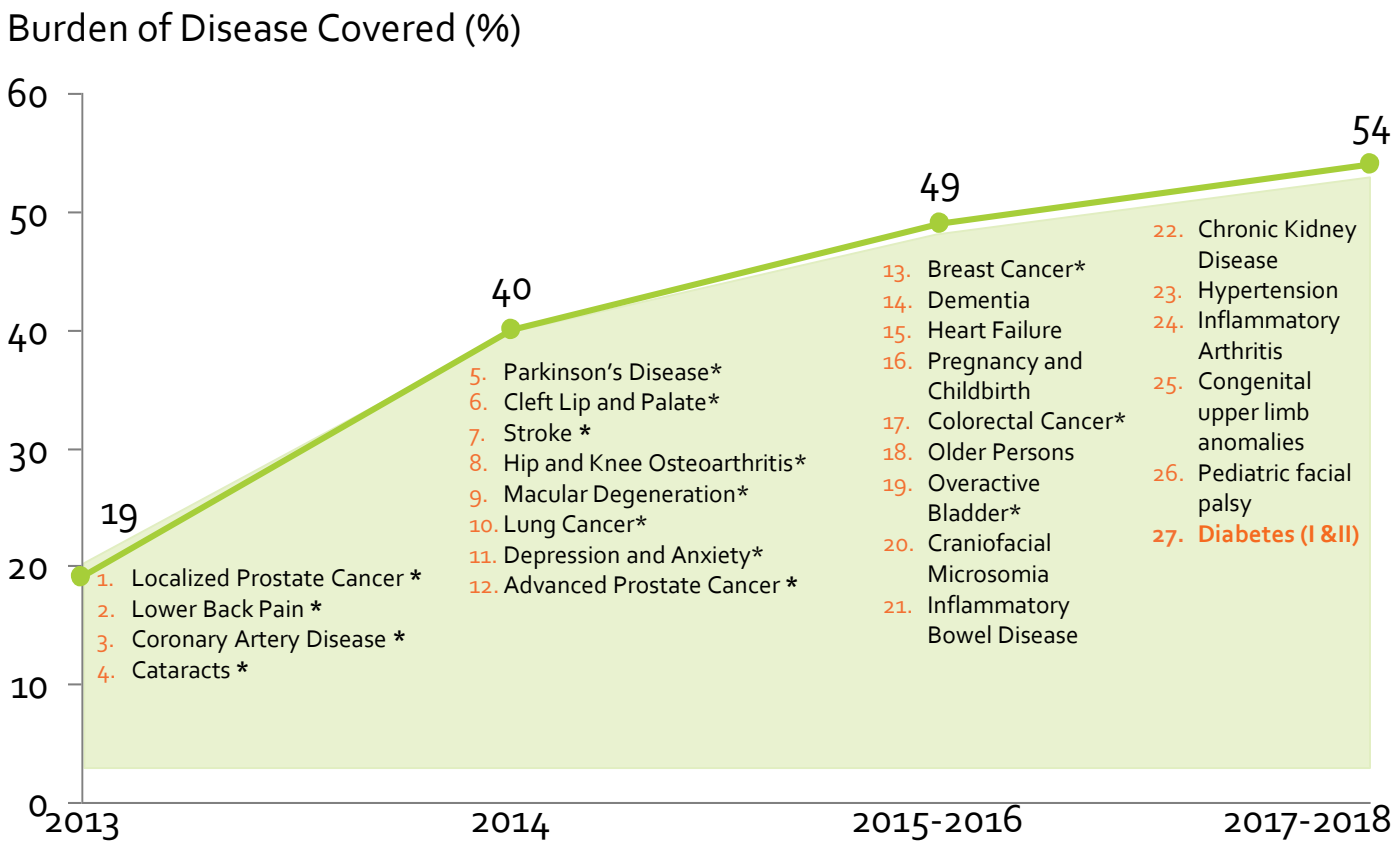
- Full detail of Standard Set for institutions interested in collecting
- Includes measure definitions, coding instructions, and sample questionnaires
- Reference Guides available at www.ichom.org

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



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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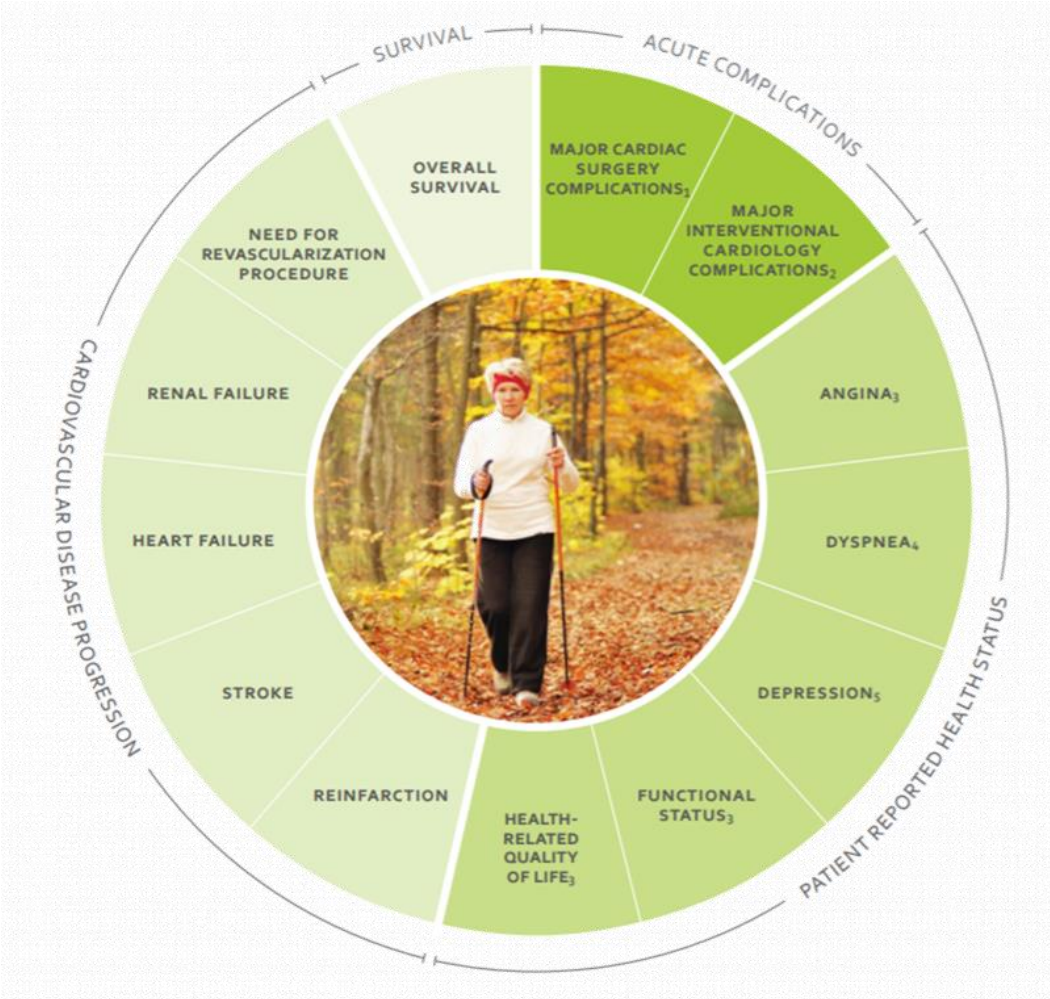
ICHOM Standard Set for Coronary Artery Disease: Outcomes



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)

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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