



# ICHOM

International Consortium for  
Health Outcomes Measurement  
Newsletter Winter 2014

Dear friends,

For the ICHOM team, 2014 is shaping up to be a productive year. As many of you know, we were thrilled to release our first four Standard Sets – for low back pain, localized prostate cancer, coronary artery disease, and cataracts – at our conference late last year. ICHOM Standard Sets are minimum, yet comprehensive, lists of the outcomes that we recommend caregivers measure for each of the patients they treat. Measuring all of the outcomes in a given Standard Set allows care teams to evaluate the quality of the care they provide and to compare their work to that of their peers. Standard Sets are always defined around a particular medical condition and cover all potential treatment options. I am pleased to announce that we have just launched our Working Group on Parkinson's disease, which is led by Dr. Ryan Uitti, Professor of Neurology at the Mayo Clinic.

In addition, in the coming weeks, we will form Working Groups for advanced prostate cancer, lung cancer, and – in our first work in mental health – depression/anxiety. In 6-8 months, the efforts of these Groups will culminate in Standard Sets of outcomes and associated risk factors that reflect the results of care that matter most to patients suffering from these conditions. For an overview of the Working Group process, please see pages 2-3.

Alongside our ongoing standardization efforts, we are also working to promote – and to support – the implementation of our first four Standard Sets. Since their debut, we have been delighted to find that there is tremendous interest in putting them into practice. Working Group members have indicated in large numbers that they will implement them in their own organizations, and representatives of more than 150 other institutions worldwide have expressed strong interest in doing the same. On page 5, you will find answers to some of the most frequently-asked questions about implementing the Standard Sets. Caregivers who do so will generate the data that will improve performance among physicians and other clinicians around the world; drive quality-focused reimbursement among payers; and, most importantly, improve outcomes for patients. At the same time, accessible, reliable outcomes data will encourage innovation and promote informed decision-making.

The importance of taking on new conditions and helping providers implement the Standard Sets has never been clearer. But we need your continued support. As a non-profit, 501 (c)(3) organization, ICHOM's work depends upon the commitment of our cofounders and our sponsoring partners. I kindly encourage you to review our new sponsorship model on page 6 and to consider partnering with us soon. I hope, also, that you will spread the word about ICHOM. Please share this newsletter with your personal and professional networks, and be sure to reach out to us should you wish to discuss ICHOM at a meeting or conference. We would be happy to provide you with materials to help you do so.

These are exciting times, at ICHOM and across the health care spectrum. We will be in touch again soon. Thank you for your ongoing interest in, and support of, our work.

Warm regards,

Jens Deerberg-Wittram  
ICHOM President



**CAREGIVERS WHO IMPLEMENT THE ICHOM STANDARD SETS WILL GENERATE THE DATA THAT WILL IMPROVE PERFORMANCE AMONG PHYSICIANS AND OTHER CLINICIANS AROUND THE WORLD; DRIVE QUALITY-FOCUSED REIMBURSEMENT AMONG PAYERS; AND, MOST IMPORTANTLY, IMPROVE OUTCOMES FOR PATIENTS.**

# ANATOMY OF A WORKING GROUP

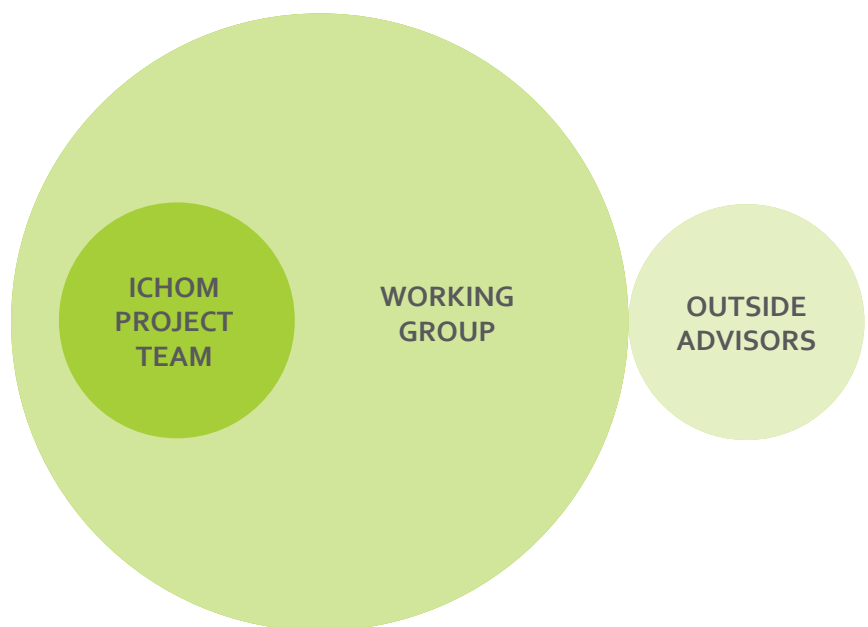
ICHOM Standard Sets are the heart of ICHOM's ambitious agenda: to enable providers everywhere to measure the most important health outcomes, on a condition-specific basis, for every patient they treat. The implementation of the Standard Sets will generate the data that will drive innovation and better care for patients everywhere. But the Standard Sets are only as good as the method used to develop them. Here's a snapshot of our approach.

## Forming a Working Group

The 6-8-month standardization process begins when ICHOM brings together physician leaders, registry experts, and patient representatives from around the world in "Working Groups" to define the results that matter most to patients with a particular condition. Working Group members encompass multiple specialties and work to define a Standard Set of outcomes that is relevant regardless of the treatment used. All Working Group members contribute purely on a voluntary basis and have an equal opportunity to shape the Standard Set.

## ICHOM Project Teams and the structure of a Working Group

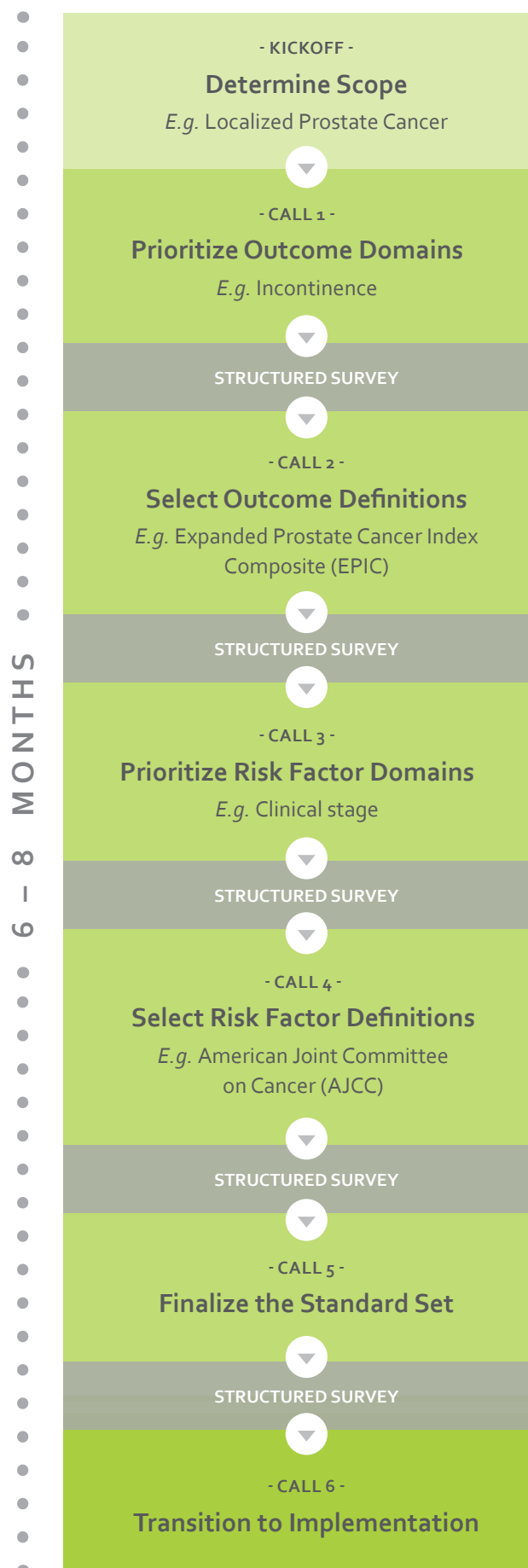
The ideal size of an ICHOM Working Group is 15 members. Each Working Group has a "lead," a senior physician who works closely with the ICHOM project team to develop proposals for the full Working Group to debate. An ICHOM project team is led by a Project Leader, who works in the ICHOM office and liaises between Working Group members, the ICHOM management team, and a Research Fellow, typically a young clinician who provides key research support throughout the standardization process.



## The role of the patient

Every ICHOM Working Group has patient representation. Patients help prioritize outcome domains and, by attending every call, maintain the focus on the patient even during technical discussions. Every Standard Set includes patient-reported outcome measures (PROMs), which capture the impact of treatment on patients' symptoms, functional status, and/or health-related quality of life.

# THE STANDARDIZATION PROCESS



## Putting the “work” in “Working Group”

Working Group members interact primarily via monthly teleconferences. Discussion topics and proposals are developed by the project teams and shared with Working Group members in advance of each discussion. As the figure shows, each teleconference has a discrete purpose and can be regarded as a stepping stone on the way to a finished Standard Set. Decisions are typically made via surveys, which the Project Leader designs based on the proposals of the larger project team and the teleconferences. The surveys are distributed by e-mail to all Working Group members, who vote anonymously.

## Building consensus

Only when a clear majority (greater than two-thirds) of members agree, does the Working Group move forward on each point. Sometimes multiple rounds of debate or deeper review of the available evidence are necessary before consensus is reached. When needed, outside advice is sought from subject matter experts around the world. This requirement for consensus, while sometimes challenging, ensures that the final recommendations have broad, cross-specialty, international support.

## The product

ICHOM Standard Sets – available freely on our website – are ready to be put into practice by care teams around the world. To that end, they define not only what outcomes to measure (e.g., incontinence for localized prostate cancer), but also recommend how best to measure them (using the patient-reported Expanded Prostate Cancer Index Composite (EPIC) 26) and over what time frame (at 6 months and then annually for 10 years). Each Standard Set includes a Data Collection User Manual with this and other information to guide care teams in the implementation process. Finally, each Standard Set is accompanied by corresponding risk factors and initial conditions to enable meaningful risk adjustment.

## Next steps

We invite providers everywhere to begin measuring the Standard Sets as soon as possible. In the coming weeks, we will announce details of our Implementation Network, which will help the organizations implementing the Standard Sets learn from each other and foster best practices. For answers to some of the most frequently-asked questions about implementation, see page 5.

# VISIT THE NEW ICHOM.ORG

Visit [ichom.org](http://ichom.org) today to review all of our Standard Sets and their corresponding Data Collection User Manuals. You will also find all the videos from our most recent conference, information about the ICHOM team, updates on our work, and opportunities to work with us.



The screenshot shows the ICHOM website homepage. At the top is the ICHOM logo and a navigation menu with links: About, ICHOM Approach, Medical Conditions, Measurement in Practice, and Work with us. Below the navigation is a large hero image of a family (a woman, a young girl, and an older man) with a vertical ruler overlaid on the right side. The ruler has labels: 'Low Back Pain' at the top, 'Measuring results that matter' in the middle, and 'Level of back pain' at the bottom. Below the hero image are three columns of text, each with a heading and a 'Read more' link. The first column is titled '01 Who is ICHOM' and describes the organization. The second column is titled '02 Why outcomes' and discusses the importance of patient outcomes. The third column is titled '03 How we work' and describes the organization's approach. Below these columns is a section titled 'ICHOM was founded by' which features the logos of the Institute for Strategy and Competitiveness, BCG (The Boston Consulting Group), and Karolinska Institutet. At the bottom of the page is a green banner with the text 'Get our new brochure to stay informed about ICHOM.' and a 'Download' button with a downward arrow icon.

**ICHOM** About ICHOM Approach Medical Conditions Measurement in Practice Work with us

**Low Back Pain**

**Measuring results that matter**

**Level of back pain**

**01 Who is ICHOM**

The International Consortium for Health Outcomes Measurement (ICHOM) is a non-profit organization founded by three esteemed institutions with the purpose to transform health care systems worldwide by measuring and reporting patient outcomes in a standardized way.

[Read more](#)

**02 Why outcomes**

We believe outcomes are the ultimate measure of success in health care. When seeking treatment, patients want to know what their life will be like after treatment: will I return to work, will I be able to take care of myself, and will my symptoms improve? Helping patients answer these questions is why we formed ICHOM.

[Read more](#)

**03 How we work**

ICHOM organizes global teams of physician leaders, outcomes researchers and patient advocates to define Standard Sets of outcomes per medical condition, and then drives adoption to enable health care providers globally to compare, learn, and improve.

[Read more](#)

**ICHOM was founded by**

**INSTITUTE FOR STRATEGY AND COMPETITIVENESS**

**BCG**  
The Boston Consulting Group

**Karolinska Institutet**

**Get our new brochure to stay informed about ICHOM.**

**Download** 

# FAQ: IMPLEMENTATION

If ICHOM's primary role is to facilitate the development of the Standard Sets, we also believe that we have an important role in the implementation phase. To this end, we will soon launch the ICHOM Implementation Network (IN). This will be an online community, accessible to members only, which will provide support for individuals and organizations as they implement the Standard Sets. In the meantime, to help you and your organizations get started, we have prepared answers to the most frequently-asked questions about implementation. If you have a question that's not addressed here, please contact us at [implement@ichom.org](mailto:implement@ichom.org).

## Do I have to measure every outcome recommended in an ICHOM Standard Set?

Every provider should try to measure every outcome for every patient that he or she treats. ICHOM Standard Sets are designed specifically as "minimum sets," meaning that they include only the most essential outcomes of a given medical condition. Adopters of the Standard Sets may well choose to continue to track various process metrics or even additional outcomes, but we encourage them to collect the Standard Sets – in their entirety – as a starting point. Recognizing the challenge of getting started with outcomes measurement, the adoption of the Standard Set can of course be phased over time, but your ambition should be to measure the entire Set in the target state. We are also currently developing the Implementation Network to help providers achieve this goal.

## Does ICHOM want my data?

We do not ask providers to share their data with us. ICHOM is not a registry. We believe, however, that there is tremendous value generated by providers sharing risk-adjusted data with one another. That's why ICHOM is currently working to set up an infrastructure to advance comparison, not only within organizations, but also across countries. Still, even if you and your colleagues do not choose to share data, we encourage you to use the Standard Sets to measure your own performance.

## Once I start collecting data, what should I do?

We tend to think of the next steps in three levels. The first is to ensure that the data you generate is reported back to the clinicians in your teams. This alone will lead to valuable insight and help drive improvement within your practice or organization. The second level is to

start comparing, when possible, inside your country and region. You will likely find that in some outcome domains you and your teams are performing among the best, while in others there may be room to improve. The third level is to take part in ICHOM's Global Comparison project, which we are currently developing and which we believe is the best way to accelerate learning – and improvement – around the world.

## Next steps: Does ICHOM offer any support to help providers get started?

Each ICHOM Standard Set is accompanied by a Data Collection User Manual, the primary aim of which is to help care teams start measuring the outcomes our Standard Sets recommend. The full Standard Sets and User Manuals are freely available on our website ([ichom.org/medical-conditions/](http://ichom.org/medical-conditions/)) and ready to use – and we encourage providers to start measuring as soon as possible.

At the same time, we recognize that many caregivers face operational or technical obstacles to implementation. That's why we are currently setting up the ICHOM Implementation Network (IN), in which you will be able to access support of several kinds, including helpful guidelines, recommended data-collection tools, as well as a global community of clinicians and others who are implementing the ICHOM Standard Sets. In addition, we will be able to recommend partners that can help you set up your local data collection. We plan to launch the IN in the spring. It will be available to subscribers only, but we are currently developing a membership model aimed at making subscription as accessible as possible. If you wish to be part of the IN, or to learn more about it, please let us know by writing to [implement@ichom.org](mailto:implement@ichom.org). We will reach out to you with details as soon as we can.

# LEVELS OF SPONSORSHIP

*Great impact comes from great support.* To help advance our relationships with our current sponsoring partners – and to gain new ones – we have developed the following membership model. Sponsoring partners of all levels will be showcased on our website and in our publications, and will gain, among other benefits, special access to our annual conference. Sponsoring partners will also gain access to the ICHOM Implementation Network, an exclusive online community connecting caregivers from around the world who are implementing one or more of the ICHOM Standard Sets. One license provides individual access to this community.

## PLATINUM

**\$100,000 +**

- Complimentary seat to selected Harvard Business School Executive Education Seminars on VBHC led by Prof. Michael Porter \*
- One on-site strategy workshop, led by the ICHOM president
- 1-hour lecture on VBHC and Outcomes Measurement
- Access to ICHOM Implementation Network (Unlimited access/sites)
- Six seats at ICHOM's annual conference
- Website presence (with sponsoring status)

## GOLD

**\$50,000 - \$99,999**

- One on-site strategy workshop, led by the ICHOM president
- 1-hour lecture on VBHC and Outcomes Measurement
- Access to ICHOM Implementation Network (3 sites, 10 licenses)
- Four seats at ICHOM's annual conference
- Website presence (with sponsoring status)

## SILVER

**\$25,000 - \$49,999**

- 1-hour lecture on VBHC and Outcomes Measurement
- Access to ICHOM Implementation Network (1 site, 5 licenses)
- Three seats at ICHOM's annual conference
- Website presence (with sponsoring status)

## BRONZE

**\$10,000 - \$24,999**

- Access to ICHOM Implementation Network (1 site, 1 license)
- Two seats at ICHOM's annual conference
- Website presence (with sponsoring status)

**To become a sponsoring partner, contact us at [ichomteam@ichom.org](mailto:ichomteam@ichom.org).**



# OUR SPONSORING PARTNERS

## PLATINUM



## GOLD

Carl Bennet AB

## SILVER



## BRONZE



Cooper-Newell Foundation

## COFOUNDERS





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