Question and Answers
ICHOM Board - Webinar 1

1. Are you planning to have the standard set translated in other languages?

Yes but translation involves both the direct translation and the cultural and contextual validation.

2. Is it possible to work with ICHOM to contribute to the development of standard sets in the absence of funding?

Yes it is possible to work with ICHOM in other formats provided the rigorous working group criteria and methodology to develop a new standard set are met. The cost is based on the experience from our previous 33 standard sets. It covers setting up an international group, financing a experienced leader to facilitate the process, finding and engaging patient representatives, organise the workstream between meetings and finalising the set, writing and submitting a peer reviewed paper and harmonising the schedule and semantics with the rest of ICHOM terminology. An ICHOM stamp of approval also has to guarantee that undue dependencies eg. commercial biases have been declared and judged as unimportant for the final result.

3. *How do you choose topics for building standards sets?*

We try to cover as much of the disease burden as we can. Getting the sets together is only half the challenge; getting them verified, ensuring patient involvement and then certifying them against the other standard sets to ensure harmonised terminology is all part of the timely and costly process. We try to align ourselves as much as we can with professional societies, patient interest groups and pro bono foundations in order to fund our standard sets.

4. How have you included the patient, next of kin and caregivers when defining outcomes?

All standard sets are developed together with patients, caregivers and in some cases also family members. They play a very important role in the final choice of metrics. ICHOM has always sought to develop "Outcomes that matter to patients" - and therefore patients are central to the sets. Independent patient derived values are core values of the ICHOM standard sets.The patient and caregiver experience and value is always core to the conversation.

5. Does ICHOM use ICF d and b data?

ICHOM use functional measures as recommended by our expert working groups. The measures are semantically bound to different standards. We stand neutral to different standards but include provenance when including them in the ICHOM standard sets.

6. In finding a sustainable revenue model it will be important to be able to resource set development in disease areas which do not have large pharmaceutical and charitable "interests". An example would be burn care, have you considered this?

We try to align ourselves as much as we can with professional societies, patient interest groups and pro bono foundations in order to fund our standard sets. We agree that would be a major disease group to address. It would seem that it should be in the interest of relevant stakeholder groups, patient advocacy groups as well as NGO's eg. focussed on some developing economies, but be willing to support such a development. We always try to create consortia with members of different background in order to avoid partial interests in the choice of measures. To avoid any perceived risk of commercial bias in metrics choices Pharma and MedTech have typically been excluded from the Standard set development working group.

7. Where can we get more information regarding implementation?

As Professor Porter referenced we have created our Partnership Programme as well as our portal, ICHOM Connect which is our online community to help with Standard Set implementation. Throughout this Conference Series, we will also be providing key and relevant case studies for you to use as a guide.

8. How do you plan to extract the data from HIS and LIS systems for producing the free basic analytics mentioned before?

The free data analytics will pertain to some services and the healthcare provider will have to provide the data in final format following extraction locally. We are currently working on standard instructions for such extractions as a service to the ICHOM community.

9. In order to adopt a patient friendly approach we need to communicate in their language, do you agree?

We completely agree, that is why patients are part of the development of standard sets and it's our priority to shape reporting in a patient accessible way.

10. The other issue is that physicians are losing revenue given changes to their practice, loss of income from elective surgeries — even when there is a compass towards value-based care, it is quite difficult to ignore the realities of salary cuts & other physician disincentives. How are we positioning ICHOM in this conversation?

In most public or private healthcare systems, COVID-19 has added new patients at the expense of elective procedures, but in total adding workload and increased costs for the care system. Fee-for-service based institutions are often dependent on their most profitable lines of business eg. elective orthopedics. The drop in profitable revenues has been catastrophic. Fully integrated systems, or budget healthcare providers have done better built on an alignment with payers on clinical priorities. ICHOM will always stand with the patient and promotes healthcare system changes that will increase patient value. We oppose fee-for-service as the main payment model as it does not promote appropriate care and flexibility in the system - which we believe would have helped many professional provider organizations currently under enormous stress.

11. How can we leverage the ICHOM sets to have more relevance in the consultation room with the patient, thus driving response rates and adoption by professionals?

ICHOM strongly agrees with the importance of rapid reporting from all analysis and results. This increases the relevance in the data and tends to drive transformation and improve the dialogue with the patients. That is a reason why we are making all the standard sets machine-readable, so that they will be easier to integrate into practice software or EMRs. Over time we also want a provider's data to be compatible with local or international benchmarks to help the clinicians to set targets and focus their improvement work.

12. Perhaps a government grant could fund the burn work?
We would love to see that and are in discussions with some - any suggestions?

13. Prevalence of sleep apnea is so high over the world that it could be an interesting topics with a lot of comorbidities...

Agreed, but it is also an example of a diagnosis that requires a standard set development Working group that is neutral to specific professional and commercial interests.

14. Some health system stakeholders still view the term "value" in healthcare as a code word for revenue and profit maximization. How can we move beyond this and create a broader, post-Covid societal movement around measuring and improving outcomes?

We strongly agree and it is unfortunate that the term is used incorrectly in many settings. As you know ICHOM is focussed on outcomes that matter to patients . As stated in the webinar, value is a misused word used in many different settings, it is key that we all are very stringent and precise to correct every instance of misuse. Patient advocacy groups could maybe play a key role for the societal movement you propose - encouraged by ICHOM and the value-based healthcare community.

15. ICHOM is a great organisation, rightly with global aspirations. In the UK routine measurement of PROMs is increasing, mostly based in individual clinical units but there is no real movement towards a more standardised approach across the country. Can ICHOM have a role in globally promoting a country-wide strategy and work with interested parties to catalyse a more standardised approach to outcomes measurement and value-based healthcare?

We see the ICHOM success as dependent on the ability to provide large-scale comparisons between providers and nations. ICHOM has been deeply involved in national level discussions in several countries, Denmark, Netherlands and Australia to name a few. NHS in the UK has in fact commissioned the development of several standard sets, eg. in the psychiatric area. NHS Wales specifically has embraced ICHOM standard set measurement across its provider networks, which will be discussed in our next webinar. Let's open a dialogue about this on ICHOM Connect.

16. Related to COVID-19, is it possible to measure a couple of outcomes to benchmark providers that are organized by IPU instead of those by medical specialty?

We agree with this and there is a discussion about rapidly establishing a standard set for COVID-19. Ideally it should have been part of clinical practice from the start - but could teach us a lot about who is best prepared to meet a similar challenge. The COVID-19 response of most healthcare systems, at least the more successful ones, has been very patient group centered with various experts co-operating both inside outside hospitals. We think it is a fair assumption that more flexible organizations are faster to adapt to a new patient group and meet their needs using outcomes measurement.

17. As you are standardizing the standard sets, are you thinking about how different sets apply to the same individual? Since many people will have multiple conditions or more than one set might apply to them?

Absolutely, the harmonisation work will ensure that the multi diagnosis patients are included in quality development - beyond the current model of risk adjustment for comorbidities. It will highlight what multidiganosis entails for the individual patient.

18. Have you evaluated on the readiness for Value Based Healthcare (Solutions) of different countries? How ready is Germany and which are the key stakeholders to push the discussion / readiness?

It is a complex question. Factors that tend to increase readiness are an existing tradition of open quality measurements, strong academic tradition in care sciences, buy-in in the layer of policy and provider/payers. Surprisingly little is driven by EMR-adoption level. National value-based healthcare maturity studies have been published by many different organizations such as, by Boston Consulting Group, the Economist and the World Economic Forum.

19. The only way fee for services works is if the outcomes are meticulously tracked and each provider is held accountable.

Agree, but you may still get overuse of diagnostics or other elements of the care pathway leading to higher total costs for a defined patient group. Outcomes measurement and ideally external transparency should be part of all payment models.

ICHOM Board:

Board and leadership

Michael E. Porter
Founder of ICHOM,
Professor at HBS

- HBS professor
- Global leader in strategy & competition

Martin Ingvar
Founder of ICHOM,
Professor at Karolinska

- Former Dean of Research at Karolinska Institute

Stefan Larsson
Founder of ICHOM,
BCG Senior MDP

- Leads BCG's research on implementation of VHBC

Jamie Heywood
Co-Founder,
Patients Like Me

- Founded the ALS TDI, founder and CEO of PatientsLikeMe

Daphne Psacharopoulos
CVS Health, Leads
Digital Integration

- Founded and led Healthcare Services at Joslin Diabetes Center

Standard Sets

ICHOM Standard Sets are standardized outcomes, measurement tools, time points and risk adjustment factors for a given condition. Developed by a consortium of experts and patient representatives in the field, our Standard Sets focus on what matters most to the patients. To date, **33 Standard Sets have been published with 6 more in progress.**

Implementation of these Standard Sets allow organizations to begin to measure, analyze and improve outcomes achieved in the delivery of care, set policies around them and empower patient groups.

For more information on our standard sets, please contact l.fialho@ICHOM.org
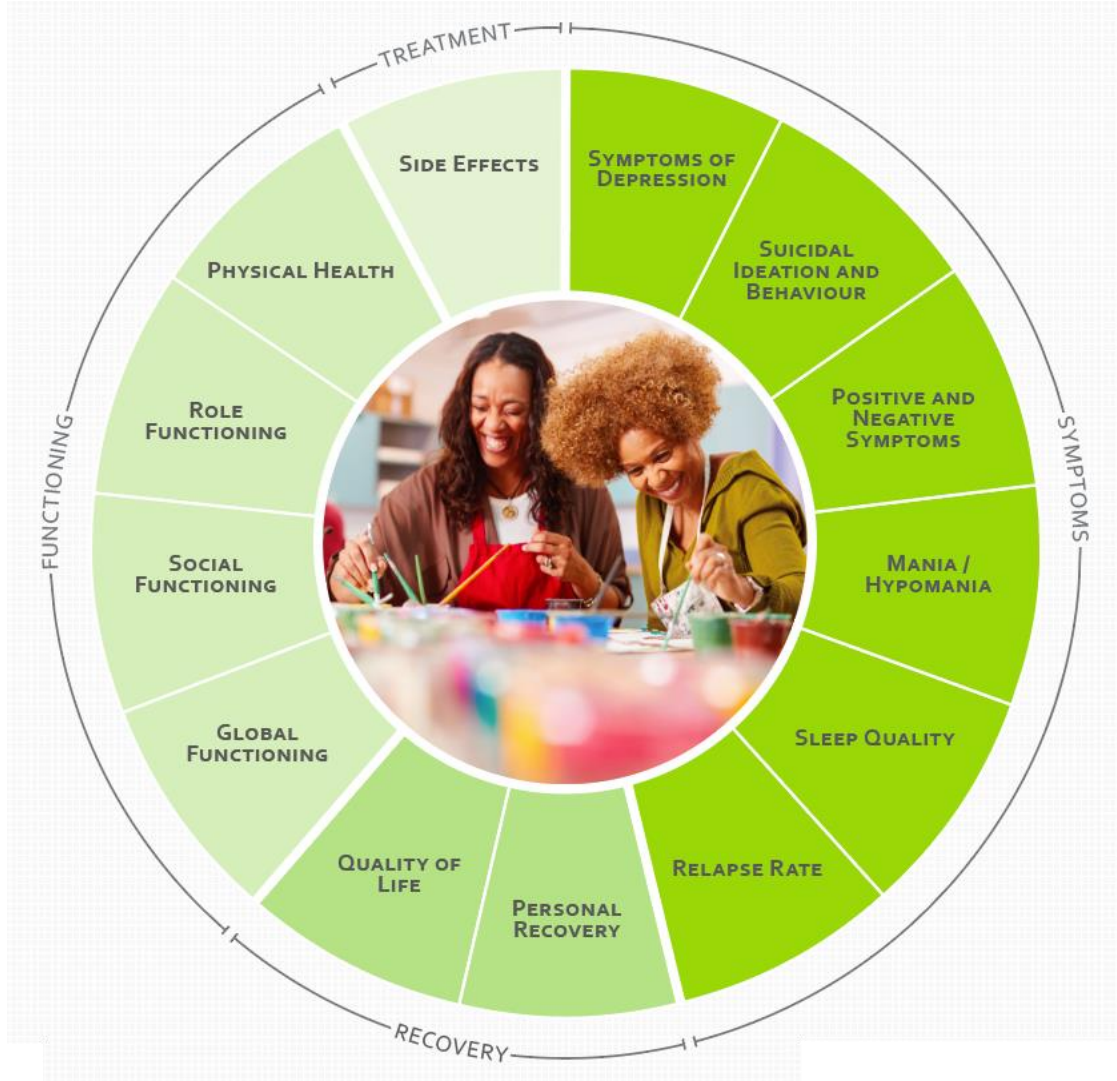
Harmonization

Based on the feedback we have received from sites and true to the goal of making patient-centered standard outcome measures available on a global scale, we currently are crafting plans of how to facilitate the implementation of the ICHOM standard sets.

One approach to accomplishing this and to drive adoption of the standard sets across the world, is to translate them to a machine-readable format and map to external standards and terminologies. We have completed a pilot program for this project in which four sets went through the process of being harmonized. We are now continuing the project with the rest of our standard sets, prioritizing for update by the end of 2020.

We are working in collaboration with the Boston Consulting Group to harmonize all standard sets to create data that is interoperable to help promote transparency on patient health outcomes. The overall purpose of this project is to improve implementation practices by allowing all set outcomes/variables to be easily machine read by EHR systems used in healthcare settings.

For more information on our Harmonization Project, please contact c.nielsen@ICHOM.org

Implementation Programme

The ICHOM partnership programme has been created to meet the needs of healthcare providers for high quality implementation and support ICHOM in creating a Partner Network. Membership of this network is by invite-only and offers a multitude of benefits including:

•1-day training to Implementation Partner staff on an annual basis. - a maximum of 10 staff trained per organization

•The partner will receive the annual certification title: "ICHOM Certified" and will be approved to brand themselves as an "ICHOM Partner" and declare themselves as "ICHOM Certified" on their organization's website and marketing platforms

•The Implementation Partner will receive an annual organizational membership for all trained staff to the ICHOM Connect

•ICHOM will refer organizations seeking support with implementation and related usage of ICHOM Standard Sets and data to its list of certified Implementation Partners

For more information on our Partner Programme, please contact l.naylor@ICHOM.org

ICHOM Connect

ICHOM Connect is our new online portal which is helping the value-based healthcare community implement standard sets. Currently we have over 500 members globally.

ICHOM Connect was created to support organizations who required help to implement standard sets. The need to benchmark and share knowledge with each other is greater than ever before. Our powerful tool will help you:

- Engage with like-minded individuals and facilitate discussion with your peers

- Debate with organizations who share similar challenges as you

- Discuss value-based healthcare with other key players

- Hear outcomes and analysis from organisations who have completed implementation

- Gain access to exclusive documents including whitepapers, articles and conference materials

For more information on joining ICHOM Connect, please contact t.gintner@ICHOM.org

Benchmarking

The next phase for ICHOM is to scale adoption of our Standard Sets and launch analytics and benchmarking to accelerate our impact:

• Develop standard sets to measure outcomes that matter to patients in collaboration with global scientific leaders and patients

•Popularize sets across global ecosystem through conferences, webinars, ICHOM Connect. Implement sets at providers to understand path to scaling adoption

•Scale adoption of sets by developing products that facilitate implementation

•Benchmark outcomes measure to further unlock value-based healthcare

For more details on our Benchmarking Project, please contact s.wissig@ICHOM.org

Conference Series

The ICHOM Conference Series 2020 is a number of regular online events, concluding with our annual conference on 16-18 November 2020.

Despite the travel restrictions imposed by Covid-19, we want you to have the opportunity to access our cutting-edge content from our expert speakers. Our events will enable you to keep in touch with the community while understanding new developments in value-based healthcare.

The Conference Series launched with our first webinar on 27 May 2020.

For more information on speaking or joining our Series as a delegate, please contact a.clements@ICHOM.org

ICHOM CONFERENCE SERIES 2020

Wed 27th May	24th June	29th July
May Webinar	**June Webinar**	**July Virtual Conference**
ICHOM BOARD: ICHOM Strategy & VBHC in a Global Pandemic	A Value Based Approach to Healthcare Leadership: Preserving the value thought in a pandemic Why Outcomes Measurement is critical Innovations in PROMs Collection	The Healthcare System of the Future Exploring the importance of VBHC The role of VBHC in Virtual Medicine
15:00 BST / 10:00 EST / 16:00 CET (45-60 minutes)	(45-60 minutes)	(3 hours)

23rd Sept	16th – 18th Nov
Sept Webinar	**November Conference**
Shared Decision Making in Practice Co-producing Healthcare with Patients	Patient-Centered Healthcare and the Value Based Approach Making Change Happen
(45-60 minutes)	(2 days)

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ICHOM Conference Series 2020
2nd Webinar · 24th June
15:00 BST/ 10:00 EST/ 16:00 CEST

A Value Based Approach to Healthcare Leadership

- Preserving the value thought in a pandemic
- Why outcomes measurement is vital
- Innovations in PROMs collection
- What about PREMs?

Managing healthcare services in the current environment requires a very fluid approach.

Treatment for non-COVID related healthcare has been de-prioritised during this period and leaders have had to take a crisis management position.

In the wake of COVID-19, there will be profound and long-lasting impacts on healthcare delivery. Providers will have high volumes of backlog to pick up and may need to reset the system and do things differently.

What does a value based approach to leadership and healthcare delivery mean and how have healthcare leaders been preserving the value thought through this time?

Why is outcomes measurement so critical and how have healthcare leaders prioritised PROMs capture through the pandemic? What innovations in PROMs capture have been employed? What about PREMs?

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