## INTERNATIONAL CONSORTIUM FOR HEALTH OUTCOMES MEASUREMENT NEWSLETTER SUMMER 2013

Dear friends of ICHOM,

### OUTCOMES ARE RESULTS THAT MATTER TO PATIENTS.

This definition has become our mantra, a short formulation no less expressive for its simplicity. While many still confuse outcomes with process measures, structural criteria, and clinical indicators, at ICHOM we recognize that measuring these alone cannot systematically improve health care delivery.

That is why our approach is different. By defining outcomes from the patient's point of view, we showcase an essential perspective that is too often ignored.

From the beginning, we at ICHOM have agreed that involving patients and patient advocacy groups in our daily work is critical to our success. This is reflected not least in our working groups, which bring ICHOM project teams and leading medical experts our working groups, which bring ICHOM project teams and leading medical experts together with patient representatives to define condition-specific minimum outcome sets. Already, we have seen great success in this effort. With our working groups, patients and physicians are meeting at eye level to discuss the outcomes that need to be measured, documented, and reported. This collaborative approach is a key element of ICHOM's work and, we believe, a crucial aspect of the value-based delivery model we champion.

We are proud and grateful that our approach has inspired the support of some of the world's leading patient organizations. Most recently, our Prostate Working Group, which we launched at the meeting of the American Urological Association in early which we launched at the meeting of the American Urological Association in early which we launched at the meeting of the American Urological Association in early which we launched at the meeting of the American Urological Association in early which we launched at the meeting of the American Urological Association in early which we launched at the meeting of the American Urological Association in early which we launched at the meeting of the American Urological Association in early which we launched at the meeting of the American Urological Association in early which we launched at the meeting of the American Urological Association in early which we launched at the meeting of the American Urological Association in early which we launched at the meeting of the American Urological Association in early which we launched at the meeting of the American Urological Association in early which we launched at the meeting of the American Urological Association in early which we launched at the meeting of the American Urological Association in early which we launched at the meeting of the American Urological Association in early which we launched at the meeting of the American Urological Association in early which we launched at the meeting of the American Urological Association in early which we have also a support of the American Urological Association in early which we have a support of the American Urological Association in early which we have a support of the American Urological Association in early which we have a support of the American Urological Association in early which we have a support of the American Urological Association in early which we have a support of the American Urological Association in early which we have a support of the American Urological Association in

Sincerely,

Dum.

Jens Deerberg-Wittram

ICHOM President

# BACK ON TRACK

In early May, the ICHOM team visited Scottsdale, Arizona to launch our latest medical condition working group – this time in low back pain. Spine surgeons, physiatrists, and outcomes researchers from 13 countries joined the meeting to discuss ICHOM as a model for international collaboration (see photo below). There was great debate among the attendees about which low back pain conditions to prioritize and which specialties to involve in the process, but all agreed on the need for international comparisons based on an ICHOM measurement standard.

Progress continues, as well, with our other two medical condition working groups that were launched late last year: cataracts and coronary artery disease. Both have doubled the number of countries involved and now cover the four corners of the world, ranging from Malaysia and Australia to Catalonia and the United Kingdom. These working groups are deep in the process of debating which outcomes should be included in the ICHOM standard and how to measure them.

We have made strides elsewhere, too. We are happy to announce the addition of several new colleagues over the last months. Three new project leaders have joined our team and will help us deepen and expand our standardization efforts. Hailing from three countries, they bring added insight into how to extend our work into their respective health systems. We are also pleased to have on board Research Fellows in each of our condition working groups. These bright young physicians are dedicating a portion of their time to bolster the clinical expertise of our project teams, which is an invaluable help. Please see below for pictures of our new team members.

Our ICHOM team and our working groups look forward to announcing ICHOM Standards Sets for our four priority conditions at our annual conference this fall. We are confident this will be the beginning of a revolutionary change in health care, in which any provider can start measuring outcomes and compare his performance to that of leading providers around the world.





Included representatives from Sweden, Norway, Denmark, Germany, Belgium, Netherlands, Switzerland, Scotland, England, US, Singapore, Hong Kong, and Australia

# BEST PRACTICES IN OUTCOMES COLLECTION AND REPORTING

In the last months we have done a great number of interviews with provider organizations, quality registries, IT-tech suppliers, and representatives of other organizations working in the field of outcome measurement. These conversations have left no doubt that outcome measurement is happening today, and that there are terrific examples from which to learn. All of these organizations are innovators, those that just started as well as those that have been collecting outcome data for twenty years, and while they remain the exception rather than the rule, their pioneering efforts point the way forward for other organizations.

At ICHOM, one of our most important aims is to gather their hard-earned lessons in outcome measurement and spread it to others. In that spirit, we have drawn the following ten lessons, and have highlighted below a few examples that showcase how this is approached today:

Four lessons for highly effective outcome data collection

- 1 USE MULTIPLE SOURCES FOR DATA COLLECTION
- 2 MAKE DATA COLLECTION PART OF CARE PROCESS AND WORKFLOW
- 3 USE 'CUSTOMER-CENTRIC' FORMS/TOOLS
- 4 BUILD MULTI-STEP DATA VERIFICATION PROCESS

Six lessons for highly effective outcome reporting and use of data in practice improvement

- MAKE DATA READILY ACCESSIBLE (REAL-TIME)
- CREATE SIMPLE AND VISUAL REPORTING FORM & SUMMARY SCORES
- MAKE COMPARISONS AND BENCHMARK DATA
- USE DATA FOR DECISION SUPPORT IN CARE DELIVERY
- PUBLICLY REPORT TRANSPARENT,
  RISK-ADJUSTED DATA ON OUTCOMES
- 10 FACILITATE AND 'HARDWIRE'
  A LEARNING CULTURE

# BEST PRACTICES IN OUTCOMES AND REPORTING

- Use multiple sources for data collection
- + Provider questionnaire
- + Patient questionnaire (PROMs)
- + Exisiting clinical data sources
- + Existing administrative data ICHOM defines minimum set of outcomes to be measured per medical condition



Make data readily accessible (real-time)

Partners HealthCare PROM reports give real-time feedback to users



Create simple and visual reporting form & summary scores

STS Registry uses star rating system and composite score in public reporting



Make Data collection part of care process and workflow

Duke Oncology and Partners PROMs Programs integrate data collection to minimize additional steps beyond existing 'workflow'



Make comparisons and benchmark data

Australia and Sweden's joint registries compared results and implemented change



Use 'customer-centric' forms/tools

Sweden Rheumatology Quality Registry heavily involves the end-user in the design of tools



Use data for decision support in care delivery

Aravind Physicians use web-tool dashboard to review their outcome data and address issues



Build multi-step data verification process

STS uses automated check and assigned data managers for data entry and auditing



Publicly report transparent, risk-adjusted data on outcomes

SART Registry reports to patients access to IVF outcomes by clinic on their website



Facilitate and 'hardwire' a learning culture

Aravind clinics in India convene clinical teams and supporting staff weekly to discuss quality and address concerns



We are continually looking for more examples that showcase best practices from those championing outcome measurement. If you know anyone or any organization doing outstanding work in outcome collection and/or reporting, we hope you will reach out to Pieter de Bey from the ICHOM team (p.de.bey@ichom.org) so we can help share these examples with the world.

Please also contact Pieter for additional information on the data-collection methods
—and their applications around the world—highlighted here.

# **NEW FACES**

WE ARE HAPPY TO ANNOUNCE THE ADDITION OF SEVERAL NEW COLLEAGUES OVER THE LAST MONTHS THAT WILL HELP US WITH OUR EXPANDING STANDARDIZATION EFFORTS.

### **PROJECT LEADERS**



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