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## **International Consortium for Health Outcomes Measurement**

**2<sup>nd</sup> BRIDGE HEALTH Meeting of the EUBIROD  
Network**

September 22<sup>nd</sup> 2017

# Agenda

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Introduction to VBHc and the ICHOM initiative

Standardisation and Standard Sets

The Diabetes Standard Set

# Variation in health outcomes is a worldwide problem

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**2X** variation in 30-day mortality rate from heart attack in US hospitals



**4X** variation in bypass surgery mortality in the UK hospitals



**5X** Variation of major obstetrical complications among US hospitals



**9X** variation in complication rates from radical prostatectomies in the Dutch hospitals



**18X** variation in reoperation rates after hip surgery in German hospitals



**20X** variation in mortality after colon cancer surgery in Swedish hospitals



**36X** variation in capsule complications after cataract surgery in Swedish hospitals



## How do we define a health outcome?

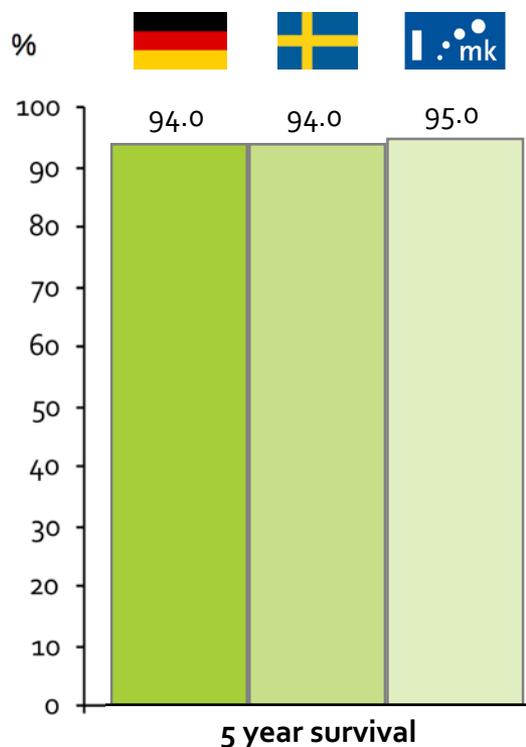
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***“Outcomes are the results people care about most when seeking treatment, including functional improvement and the ability to live normal, productive lives.”*** – ICHOM

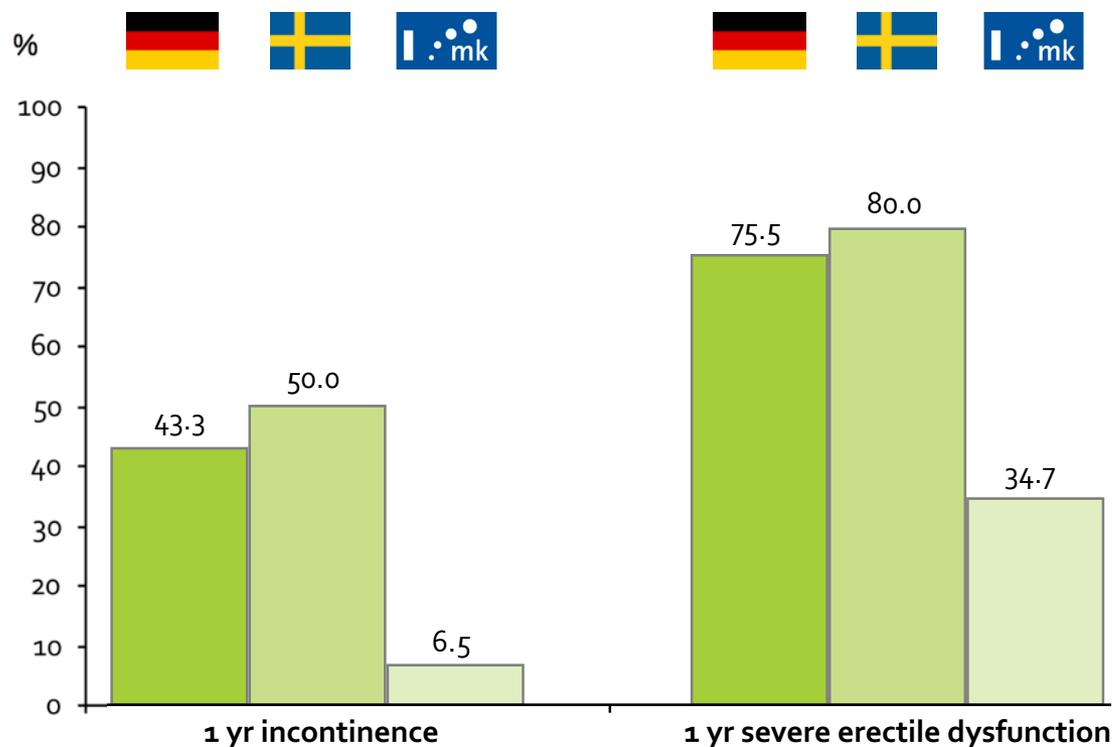
# This is why measuring and reporting meaningful outcomes matters

## Comparing outcomes of prostate cancer care

Focussing on mortality alone...



...may obscure large differences in outcomes that matter most to patients



Germany Sweden Best-in-class: Martini Klinik

Swedish data rough estimates from graphs; Source: National quality report for the year of diagnosis 2012 from the National Prostate Cancer Register (NPCR) Sweden, Martini Klinik, BARMER GEK Report Krankenhaus 2012, Patient-reported outcomes (EORTC-PSM), 1 year after treatment, 2010

# ICHOM was formed to drive the industry towards value-based health care by defining global outcome standards

## Where we come from

Three organisations with the desire to unlock the potential of value-based health care founded ICHOM in 2012:



### ICHOM is a nonprofit

- Independent 501(c)3 organization
- Idealistic and ambitious goals
- Global focus
- Engages diverse stakeholders

## Our mission



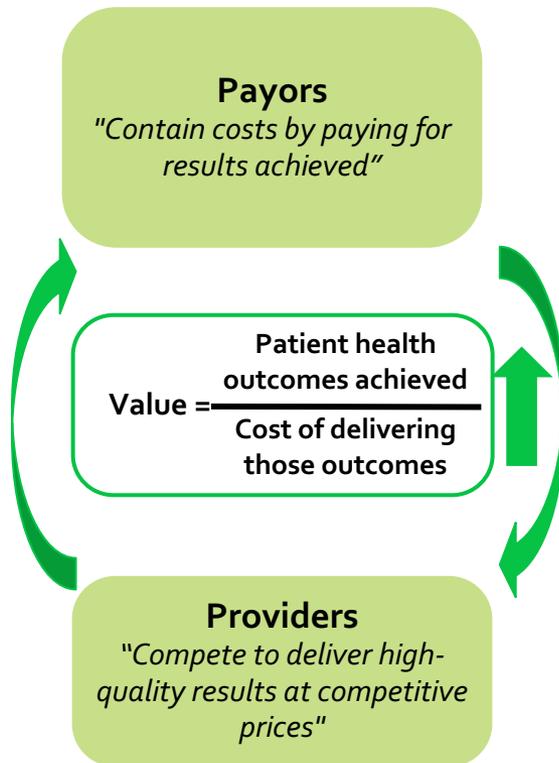
### Our mission

Unlock the potential of value-based health care by **defining global Standard Sets of outcome measures that really matter to patients** for the most relevant medical conditions and by **driving adoption and reporting** of these measures worldwide

$$\text{Value} = \frac{\text{Patient health outcomes achieved}}{\text{Cost of delivering those outcomes}}$$

# ICHOM is founded on the principle of value-based health care

We believe in a model where value is at the center of health care...



... which will impact every stakeholder



Patients will **choose their provider** based on its expected outcomes and their share of the cost



Providers will **compete** to deliver superior outcomes at competitive prices

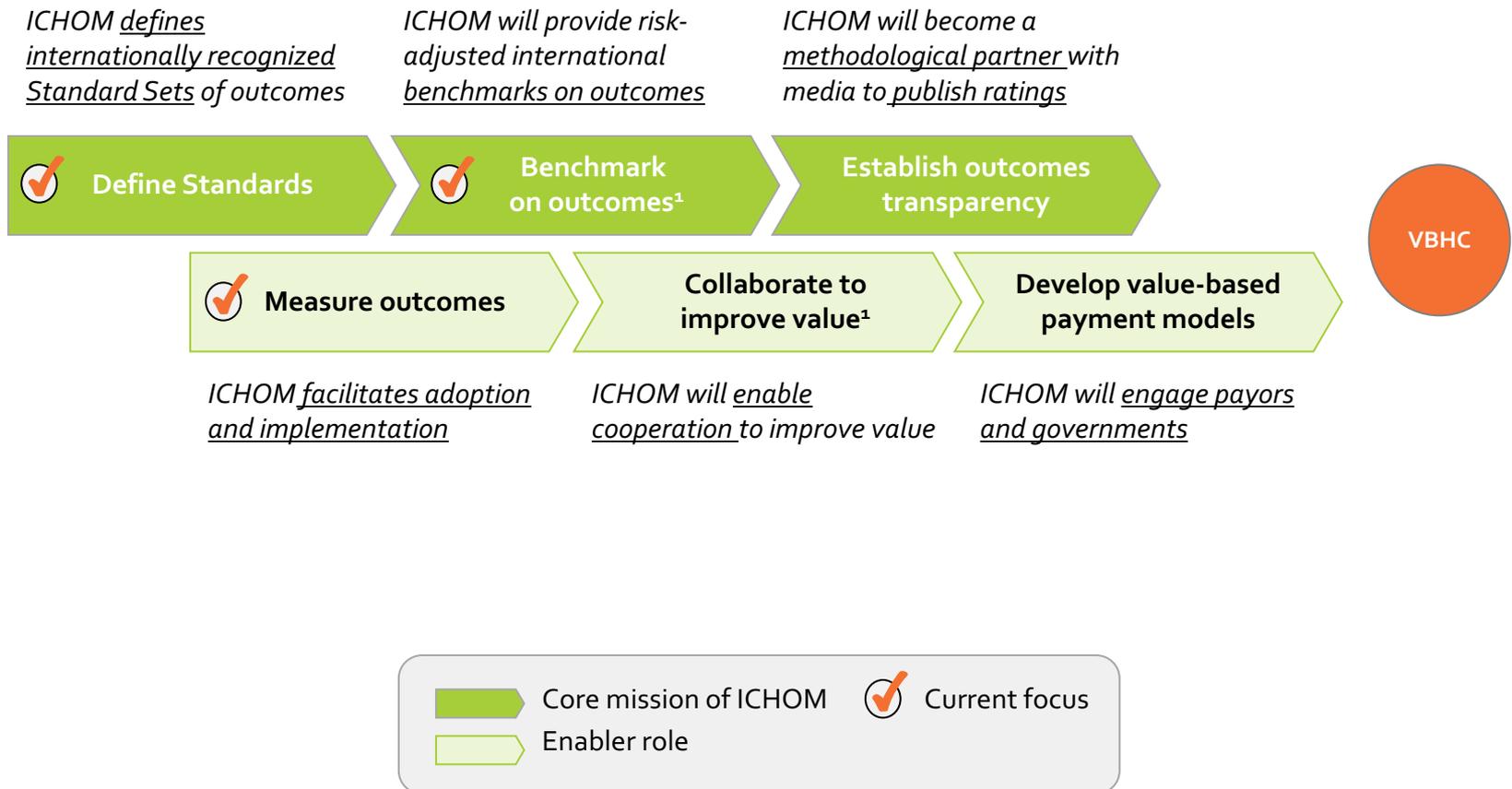


Payors will **negotiate contracts based on results** and encourage innovation to achieve those results



Suppliers will **market their products on value**, showing improved outcomes relative to costs

# ICHOM plays several roles along the journey that will enable value-based health care: our strategic agenda



1. We are exploring the inclusion of resources data in benchmarks but the methodology is to be determined

# We have completed 21 Standard Sets thus far, covering >45% of the disease burden

## Our current 21 Standard Sets



\*Focused on low and middle income countries

## 2016-2017 commitments

1. Chronic kidney disease
2. Inflammatory arthritis
3. Oral health
4. Congenital hand and upper limb malformations
5. Paediatric facial palsy
6. Hypertension\*
7. Type II diabetes
8. Atrial fibrillation
9. Overall adult health
10. Diabetes

## In discussions to launch

1. Mental health package
2. Overall child health
3. Overall cancer
4. Pediatric epilepsy
5. Multiple sclerosis
6. COPD
7. Morbid obesity

Numbers not representing prioritization/likelihood

# Global demand to measure and compare outcomes is impressive

Institutions and registries around the world are already measuring or implementing ICHOM Standard Sets



# OECD & ICHOM collaboration

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OECD and ICHOM sign a Letter of Intent to collaborate on the collection, analysis and publishing of patient reported outcomes for international comparison.

ICHOM looks forward to this collaboration as it will be a significant support for health systems in moving towards value based health care.



L-R: Stefano Scarpetta, Christina Åkerman, Angel Gurria,  
Michael Porter, Gabriela Ramos

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**Standardisation and Standard Sets**

The Diabetes Standard Set

# 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



# Framing principles for ICHOM Working Groups

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- 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 comparability of results

# ICHOM Project Team drives process while engaging Working Group for ratification and broader Reference Group for feedback

## 1 ICHOM Project Team

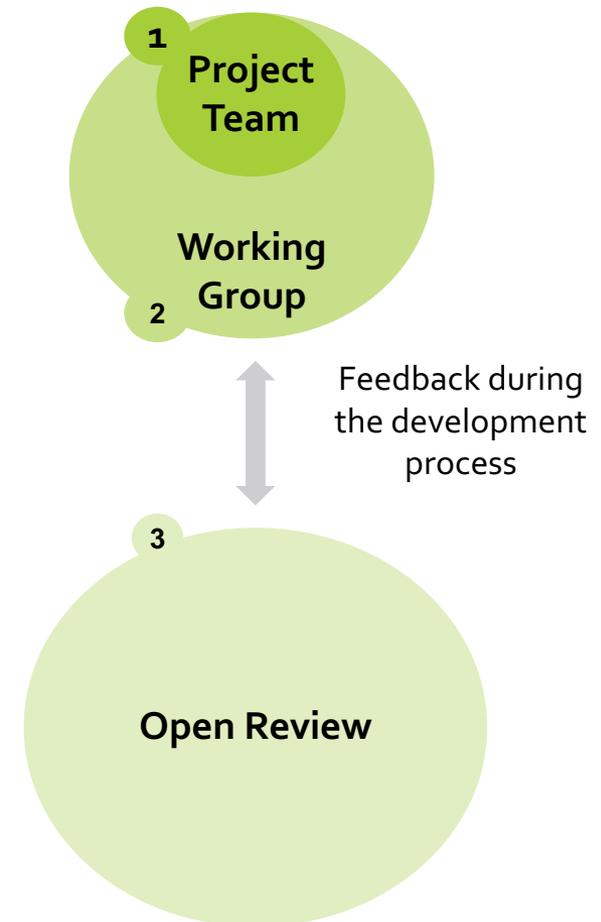
- Composed of: Working Group Chairs, Project Leader, Research Fellows, Standardization Associate
- Drives process of proposals, feedback, and consensus
- Also provides research support and accesses outside expertise

## 2 Working Group

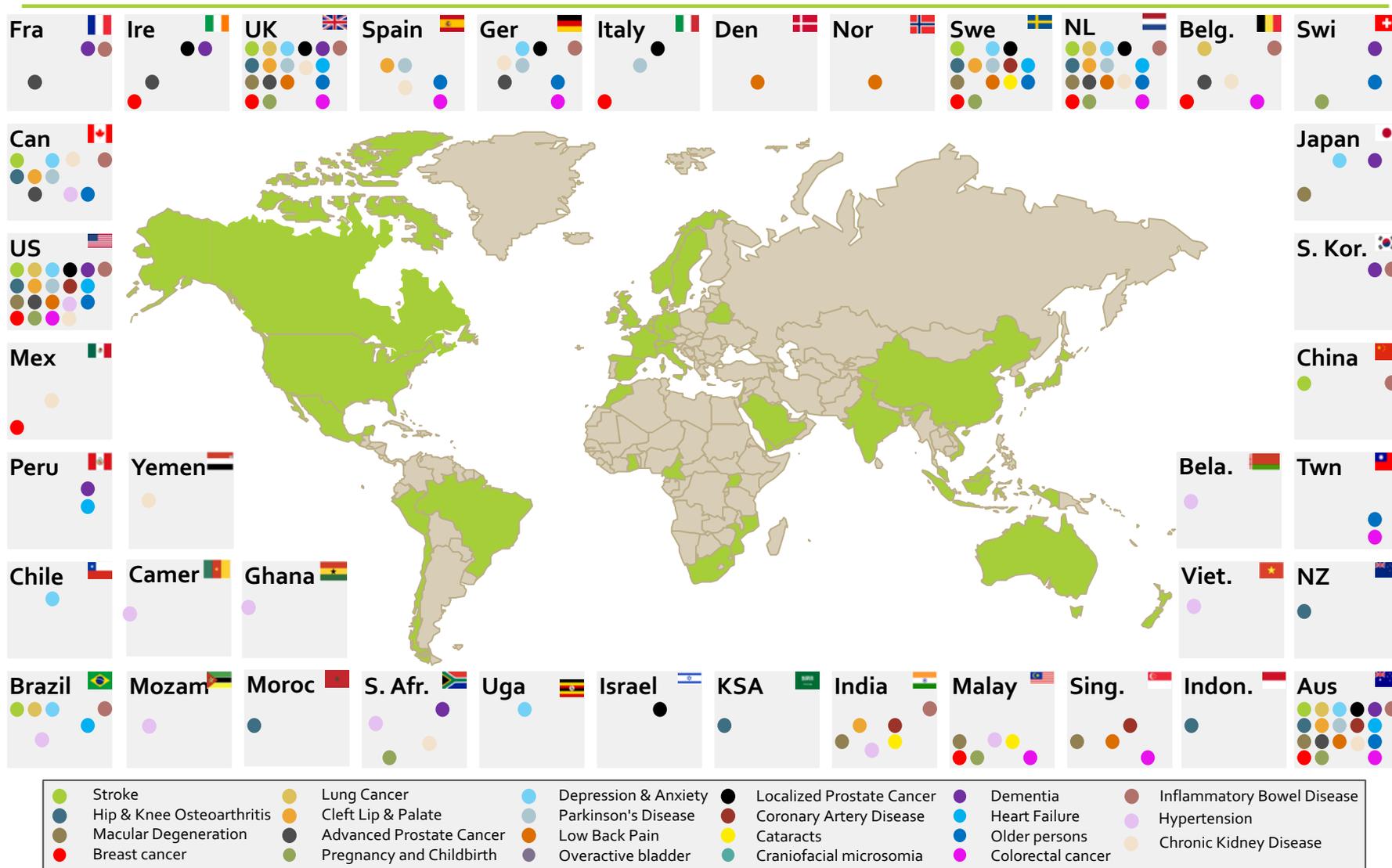
- Composed of international representatives from leading outcomes measurement efforts and patient advocates
- Refines and ratifies proposals made by Project Team
- Guides publication of Standard Set

## 3 Open Review

- Broader set of patients, clinicians, researchers and likely implementers
- Additional stakeholders (e.g., payers, govt, industry)
- Contribute early feedback at key points in Std Set development
- Do not formally join Working Group (i.e., do not vote and do not author publication)



# ICHOM Working Group members originate from 39 countries



Source: ICHOM

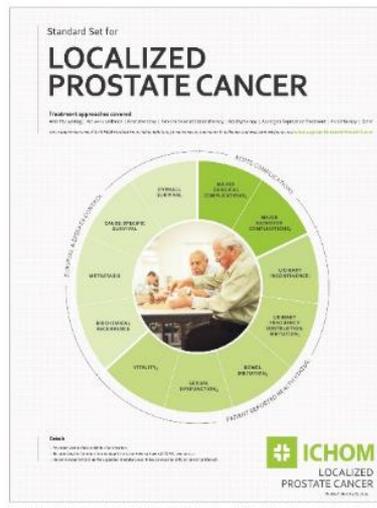
# ICHOM Working Groups also work with patient organisations and charities from around the world

The image features a world map with three regions highlighted in green: North America, Europe, and Australia. Surrounding the map are logos for various international patient organizations and charities. The logos are arranged as follows:

- Top Row:** Foundation for Faces of Children, Crohn's & Colitis AUSTRALIA (making life more liveable), CROHN'S & COLITIS FOUNDATION OF AMERICA, opaaluk.
- Second Row:** LAMP direct, Kidney Health Australia, nras (National Rheumatoid Arthritis Society).
- Third Row:** Alzheimer's Disease International (The global voice on dementia), NIERSTICHTING (Leven gaat voor.), army of women (a program of the Dr. Susan Love Research Foundation).
- Fourth Row:** age UK (Love later life), Continenace Foundation of Australia, Alzheimer's Society (Leading the fight against dementia), AARP (Real Possibilities), associacão amigos do coração, IFSA (BRITISH KIDNEY Patient ASSOCIATION - improving life for kidney patients).
- Fifth Row:** American Heart Association (Learn and Live), Microtia UK, Changing Faces (Changing the way you face disfigurement).
- Sixth Row:** Bowel Cancer Australia, CROHN'S & COLITIS UK, borstkankervereniging nederland.
- Bottom Row:** Breast Cancer Network Australia, Cardiomyopathy UK, FIGHT COLORECTAL CANCER, The Canadian Continenace Foundation, EUROPA DONNA (The European Breast Cancer Coalition), NATIONAL ASSOCIATION FOR CONTINENCE (NAFC), British Heart Foundation, COLON CANCER ALLIANCE.

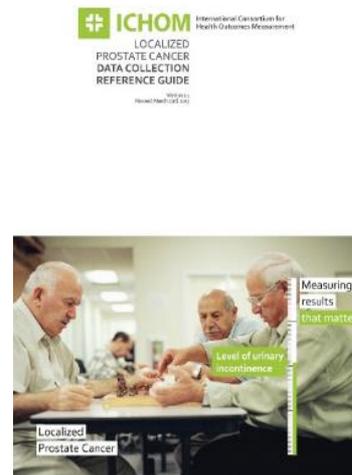
# ICHOM Standard Sets are freely available to promote global adoption

## Flyer



- Two-page overview of ICHOM Standard Set and Working Group

## Reference Guide



- 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](http://www.ichom.org)

## Academic Publication



- Peer-reviewed publication
- Explains process to arrive at Standard Set and motivation for selected measures

# Mayo Clinic Department of Psychiatry & Behavioral Health

## Key Facts

**Condition** | Depression & Anxiety  
**Number of patients** | 2000  
**Profile** | Tertiary care psychiatry  
**Project start date** | 2015  
**PROMs in Use** | ICHOM D&A Standard Set  
**Medical record system** | Cerner

## Aims

- To improve the quality and productivity of clinical conversations through identification of high priority patient concerns
- To implement team-based treatment interventions
- To compare the outcomes the department achieves to other psychiatry departments in order to understand where improvement could be possible

Patient arrives to the clinic and registers at the front desk

Patient completes PROMs on a touch screen computer in the waiting area

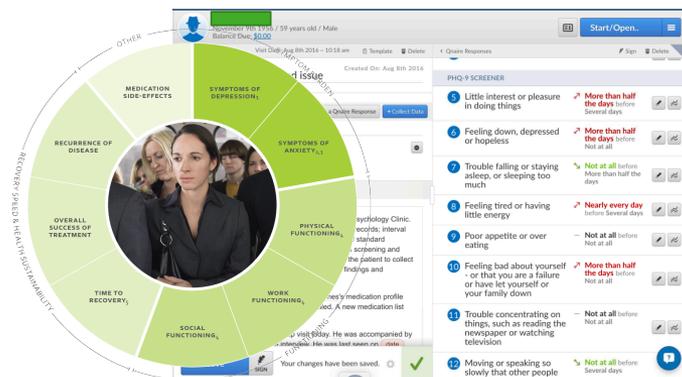
Automated **color-coded** electronic survey reports are populated based on patients' responses to PRO questionnaires

Patient meets with provider, together they review the summary overview

PROM collection program populations PRO scores into narrative for clinical note



*"To make a good decision, you need an expert in the facts (e.g. a health practitioner) and an expert on which features matter most (e.g. the patient) and a way to share their views with each other in ways they prefer."<sup>1</sup>*



## Outcomes

- High satisfaction and ratings by Mayo visitors (4/5 of 1,387 respondents)
- Natural language processing and strategically designed automated report generators are **saving them time - 15 minutes per initial evaluation per patient, on average**

<sup>1</sup>Relationship Power in Health Care: Science of Behavior Change, Decision Making, and Clinician Self-Care, John B. Livingstone, MD, Joanne Gaffney, RN, LICSW CRC Press, Boca Raton, FL (2016)

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**The Diabetes Standard Set**

# The scope of our work on diabetes will cover adults with type 1 and type 2 diabetes

Population	Management approach	Disease stage
<p><b>Adults (aged <math>\geq 18</math> years)*</b></p> <ul style="list-style-type: none"><li>• ICD E10: Type 1 diabetes mellitus</li><li>• ICD E11: Type 2 diabetes mellitus</li></ul>	<ul style="list-style-type: none"><li>• Education and lifestyle</li><li>• Pharmacological</li><li>• Psychosocial care</li><li>• Surgical treatment</li></ul>	<ul style="list-style-type: none"><li>• Early uncomplicated disease</li><li>• Diabetes with co-morbid disease</li><li>• Diabetes with complications</li></ul>

## Exclude:

- Paediatric and neonatal populations (aged  $<18$  years)
- Gestational diabetes<sup>†</sup>
- Secondary diabetes<sup>††</sup>

\*ICHOM will develop a separate Standard Set for the paediatric type 1 and type 2 diabetes population. A separate WG will be convened for this purpose. We aim to begin this work in late 2017/early 2018.

<sup>†</sup>Gestational diabetes has been excluded as the aims of treatment are related to the success of pregnancy and childbirth.

<sup>††</sup>Secondary diabetes has been excluded as there is usually an underlying cause which is the treatment target.

# The Diabetes Working Group: Introducing the Project Team

PROJECT TEAM



Fabrizio Carinci  
Co-chair



Massimo Massi-Benedetti  
Co-chair



Kemi Okunade  
Project Leader



Matt Salt  
Standardisation  
Associate

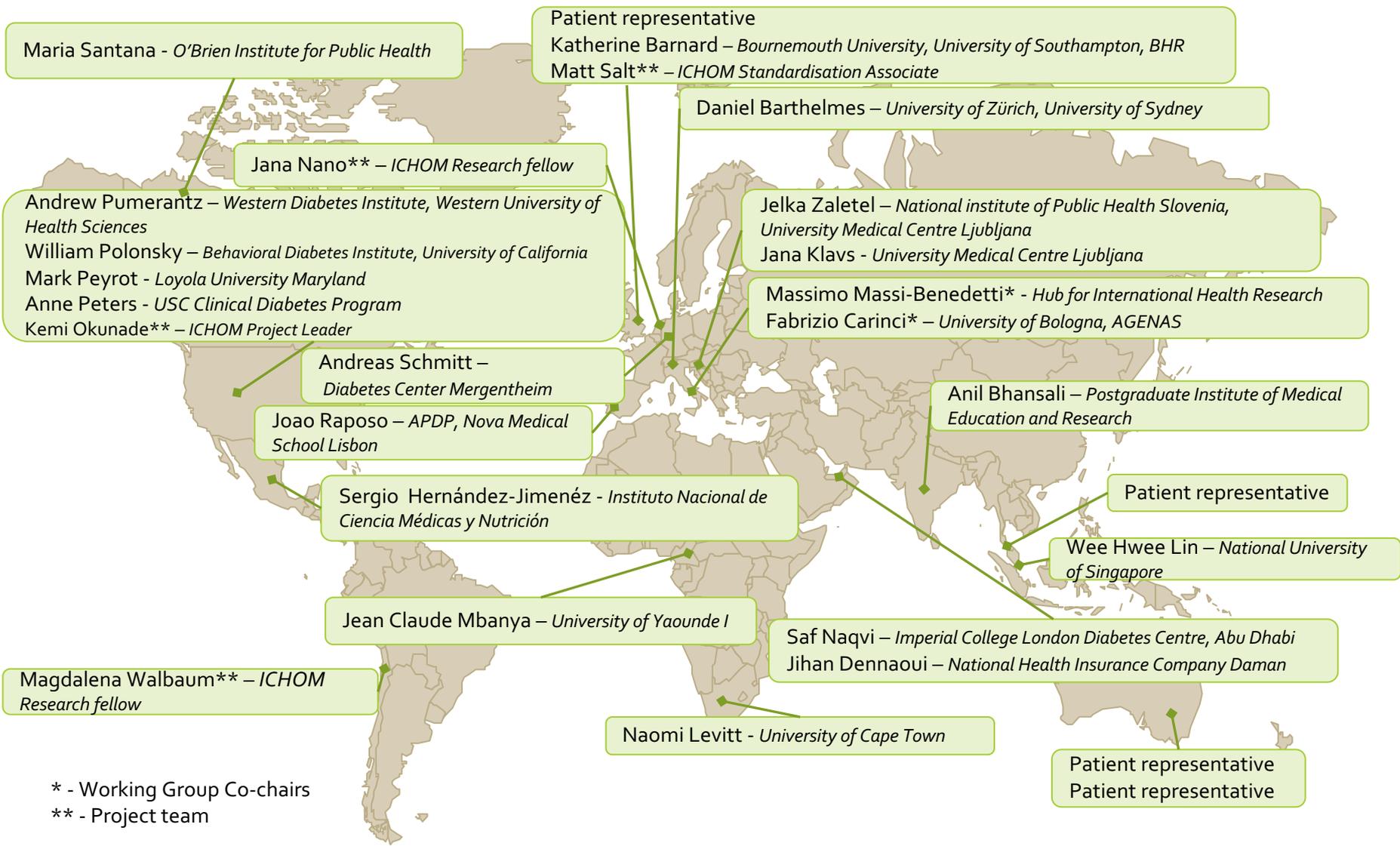


Jana Nano  
Research Fellow



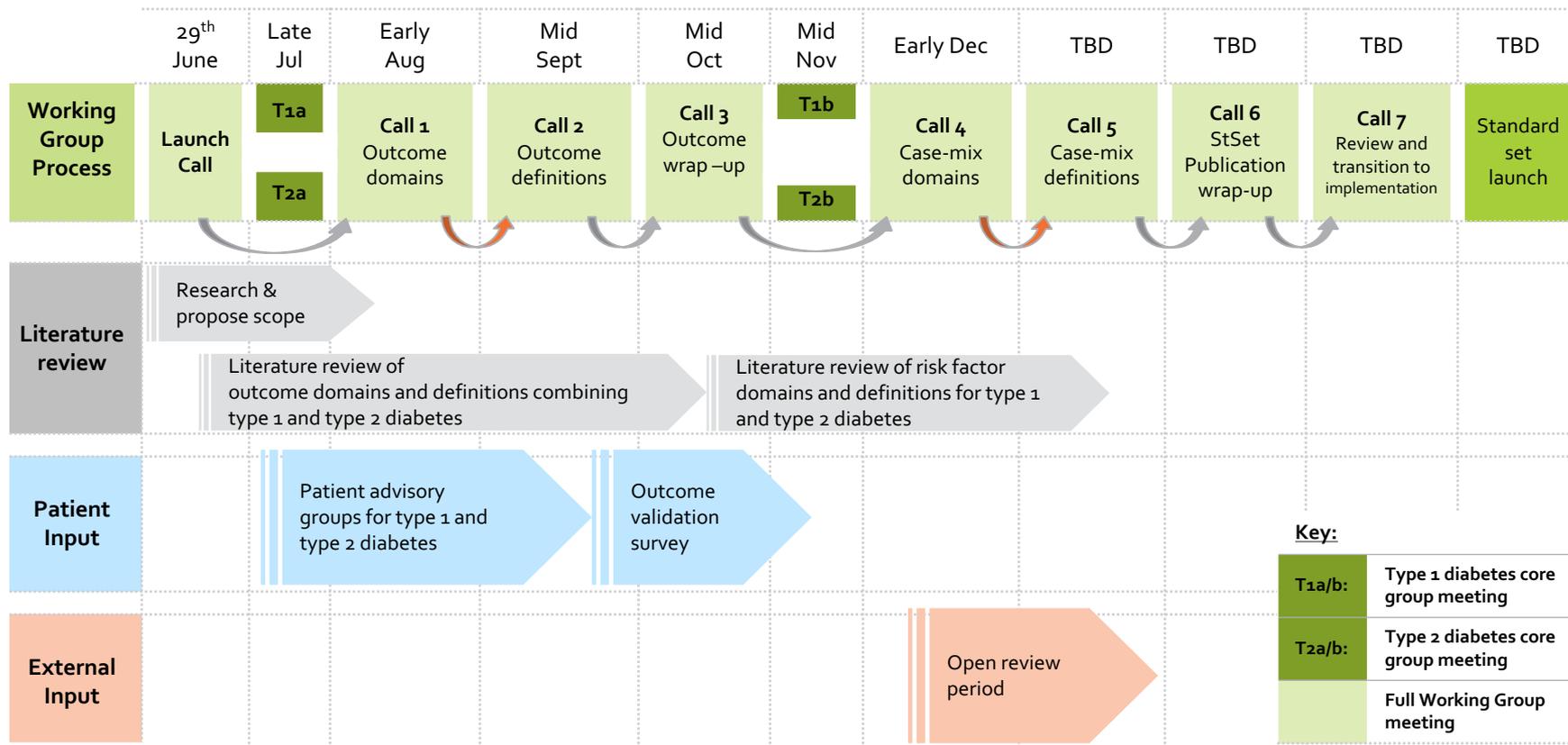
Magdalena  
Walbaum  
Research Fellow

# The ICHOM Diabetes Working Group is made up of professionals and representative of people with diabetes from all over the globe



\* - Working Group Co-chairs  
 \*\* - Project team

# The Diabetes Standard Set includes additional meetings, research and patient input to create a Set that covers type 1 and type 2 diabetes



# In October 2017, delegates from around the world will gather in Washington, DC for the ICHOM Conference

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# ICHOM

Marriott Marquis Washington, DC

October 24 - 26, 2017



