

**ICHOM**

International Consortium for  
Health Outcomes Measurement

# Which outcomes really matter to patients?

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*Chief Scientific Officer, ICHOM*





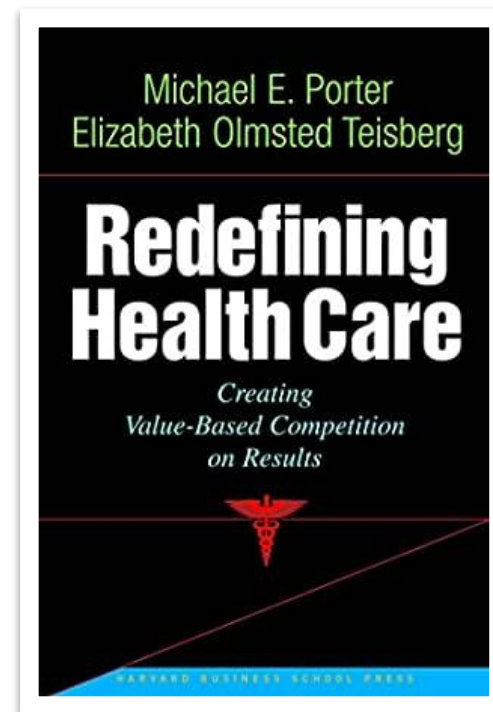


- Member of ICHOM
- Clinician
- Public health specialist
- Global citizen
- Mother of young kids who might one day have breast cancer












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

“Value-based healthcare is a healthcare delivery model in which providers, including hospitals and physicians, are paid based on patient health outcomes.”

“Under value-based care agreements, providers are rewarded for helping patients improve their health, reduce the effects and incidence of chronic disease, and live healthier lives in an evidence-based way.”



# Health systems are taking bold steps to reform around VBC

Global	Regional	Country
<p><b>'Value based health care' web searches have increased 400%, compared to 2012.</b><sup>1</sup></p> 	 <p>Health Ministers from over <b>35 OECD and partner countries are working to make person-centered care the new normal in health systems.</b><sup>3</sup></p>	 <p><b>Dutch parliament urges move to outcome-based payments.</b><sup>5</sup></p>
 <p>The Lancet Global Health Commission on <b>High Quality Health Systems</b> in the <b>SDG Era</b></p> <p>The Lancet defines "high quality care" as safe and respectful with potential to improve outcomes".<sup>2</sup></p>	   <p>The Innovative Medicine Initiative's <b>Big Data for Better Outcomes</b> program will use big data to improve patient outcomes.<sup>4</sup></p>	 <p><b>National program launched in Israel to measure patient reported outcomes</b> for stroke and acute myocardial infarctions.<sup>6</sup></p>
		 <p><b>Wales—The NHS is embracing the principles of prudent healthcare</b> through a patient-centered system.<sup>7</sup></p>
		 <p><b>Portugal—has worked to achieve financial solvency and sustainability,</b> through innovation, outcomes measurement &amp; cost reduction.<sup>5</sup></p>
		 <p><b>New South Wales—Australia— is reforming their health system from volume to value</b><sup>8</sup></p>

Copyright © 2018 by ICHOM. All rights reserved. 5 The Economist 2016; 6 The 5th Annual Transparency in Health Conference, 2017; 7. NHS Wales, 2017; 8. NSW Health Innovation Symposium Elizabeth Koff, Secretary, NSW Health, 2016. Google Trends, 2017; 2. Lancet Global Health Commission on High Quality Health Systems, 2016; 3. ICHOM and OECD Letter of Intent, 2017; 4. IMI 2017; Mark Drakeford, Minister for Health and Social Services 2014; 5. Value Based Health Care Global Assessment

# Which outcomes?: What is often measured vs what matters

## Healthcare indicators

Processes of care, biomarkers, survival

- Survival
- Test result
- Whether test was done (e.g. HbA1c)
- Whether procedure was performed
- Whether medicine was prescribed

## Patient outcomes

“Getting back to a normal joyful life”

- Survival
- Being pain-free
- Caring for myself independently
- Going back to work as soon as possible
- Kicking ball or dancing with my grandchildren

SURVIVAL

+

WELLBEING  
(Physical,  
Mental,  
Social)

# How do we measure?: Many tools, all measuring differently

Questionnaire	Subscales	No. of Items	Response Scale (Likert-Scale)	Scoring System	Recall Period
EORTC QLQ-C30 [19]	Generic	30	4-point	0–100	Past 7 days to 4 weeks
EORTC QLQ-BR23 [20] (updated EORTC QLQ-BR45)	Breast Cancer Subscale	23	4-point	0–100	Past 7 days to 4 weeks
FACT-ES [21]	Endocrine Therapy Subscale	46	5-point	0–184	Past 7 days
FACT-B [22]	Breast Cancer Subscale Trial Outcome Index	37	5-point	0–148 0–96	Past 7 days
EQ-5D-5L EQ-5D-3L [17]	Generic	6	5-point 3-point	Health states and VAS-score 0–100	Today
BREAST-Q (pre- and post-operative) [18]	Mastectomy, Breast Conserving Therapy and Reconstruction module	4–11 (depending on subscale)	3, 4 and 5-point	0–100	Past 7 days

## Challenges facing clinicians, providers, insurers and governments in responding to this demand for change

- **Which outcomes?**
  - Many! - which outcomes matter most?
- **How do we measure? Where can we start?**
  - “Reporting” fatigue
  - Non validated tools
  - Non standardized data collection
  - Interoperability
- **What can we gain value from measuring?**



## A not-for-profit driving transformation to VBHC globally

Established 2012 with a mission to unlock the potential of value-based health care by defining global standards of outcome measures that matter most to patients across a wide range of medical conditions, and driving the adoption and reporting of these measures worldwide.

### ICHOM Founders



**Michael E. Porter,**  
Harvard Business School



**Stefan Larsson,**  
Boston Consulting Group



**Martin Ingvar,**  
Karolinska Institutet

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# ICHOM develops Sets of Patient-Centred Outcome Measures, which are key to:

- Ensuring that care and treatment serves the needs of patients
- Improving quality of care and clinical pathways based on evidence
- Understanding disparities in health status
- Transitioning away from fee-for-service to fee-for-value models

## 1. Outcomes (Diabetes Set)



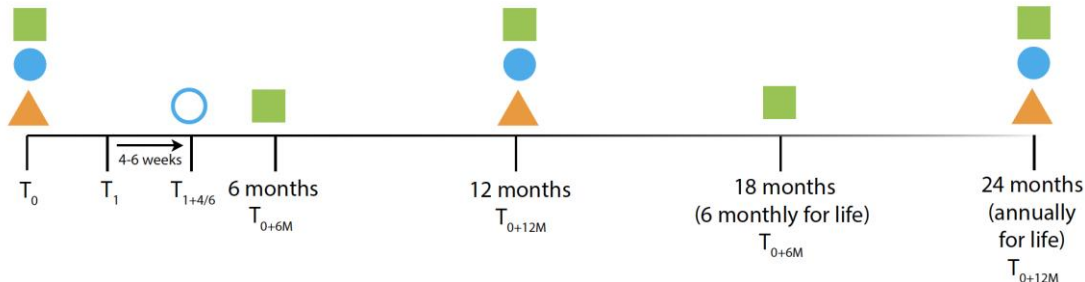
# Standardization helps to draw reliable conclusions from the data

## 2. Validated questionnaires

## 3. Patient population

Conditions	Type 1 Diabetes   Type 2 Diabetes
Populations	Adults Aged 18 years and Above
Treatment Approaches	Non-Pharmacological Therapy   Non-Insulin-based Pharmacological Therapy   Insulin-based Pharmacological Therapy
Excluded Populations	Children and Young persons below 18 years
Excluded Conditions	Diabetes mellitus types other than 1 and 2   Secondary Diabetes   Gestational Diabetes

## 4. Data collection time points



## 5. Case mix factors

### Sociodemographic factors

- Age
- Sex
- Race / ethnicity
- Education level

### Lifestyle behavior

- Smoking status
- Alcohol use
- Physical activity

### Disease factors

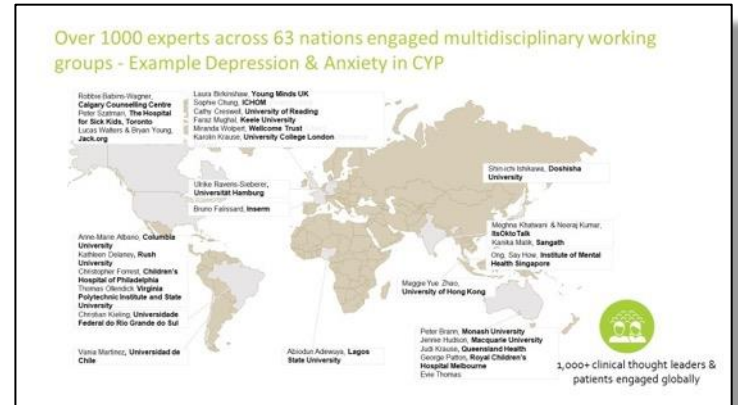
- Diabetes type
- Duration of diagnosis
- Comorbidities

### Treatment factors

- Treatment type

## Patient voice is amplified in various ways

- Inclusion of **patients as active, voting members** in working groups
- Using **Open review surveys** to gather feedback on proposed Sets from multiple patient communities around the world
- Ensuring **Patient-Reported Outcomes** are a key component of the Sets



# Patient Validation Survey

1=Not important      5= Somewhat important      9=Most important

1      2      3      4      5      6      7      8      9

**Quality of Life** - The individual's perception of their position in life in the context of the culture and value systems in which they live and in relation to their goals, expectations, standards and concerns

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**Functional Limitations** (including ability to work) - Restrictions in usual duties and activities, and/or changes in lifestyle, caused by the presence and severity of symptoms following an episode of venous thromboembolism

<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
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**Pain** (including symptom severity) - An unpleasant sensory and emotional experience associated with, or resembling that associated with, actual or potential tissue damage

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We are currently collaborating with patient advocacy organizations in various ways

**ICHOM 2023**  
9 - 11 October | Barcelona  
The Palau de Congressos de Barcelona Conference Centre

Find out more  
[conference.ichom.org](https://conference.ichom.org)

<p><b>Kawaldip Sehmi</b> CEO International Alliance of Patient Organisation (IAPO)</p>	<p><b>Valentina Strammiello</b> Director of Programmes European Patient Forum (EPF)</p>	<p><b>Pedro Carrascal Rueda</b> Managing Director Platform for Patient Organizations (POP)</p>	<p><b>Emily J. Holubowich MPP</b> National Senior Vice President, Federal Advocacy, American Heart Association</p>	<p><b>Paul Villanti</b> Executive Director, Programmes, Movember</p>

**ICHOM-IAPO Patient Charter**

# ICHOM has developed 45 Sets, covering nearly 60% of global burden of disease

## Flyer



- Two-page overview of ICHOM Set and Working Group

## Reference Guide



- Includes measure definitions, coding instructions, and sample questionnaires

## Scientific Publication



- Explains process to arrive at ICHOM Set and motivation for selected measures

Digitized, harmonized term bank

Online VBHC training

Expert pragmatic advice and coaching

ICHOM Learning Collaboratives, powered by Accelerated Insights

Available at [www.ichom.org](http://www.ichom.org)

ICHOM Sets have been developed and published by a global consortium of 1000+ leading clinical scientists and patient representative groups

Results published in leading peer-reviewed journals

Selection of participating institutions shown on the right





# Sets implemented across 444 care settings in over 42 countries

Leading nations:  
 100+ Germany  
 50+ The Netherlands  
 25+ Spain  
 25+ Australia  
 25+ United Kingdom  
 25+ United States

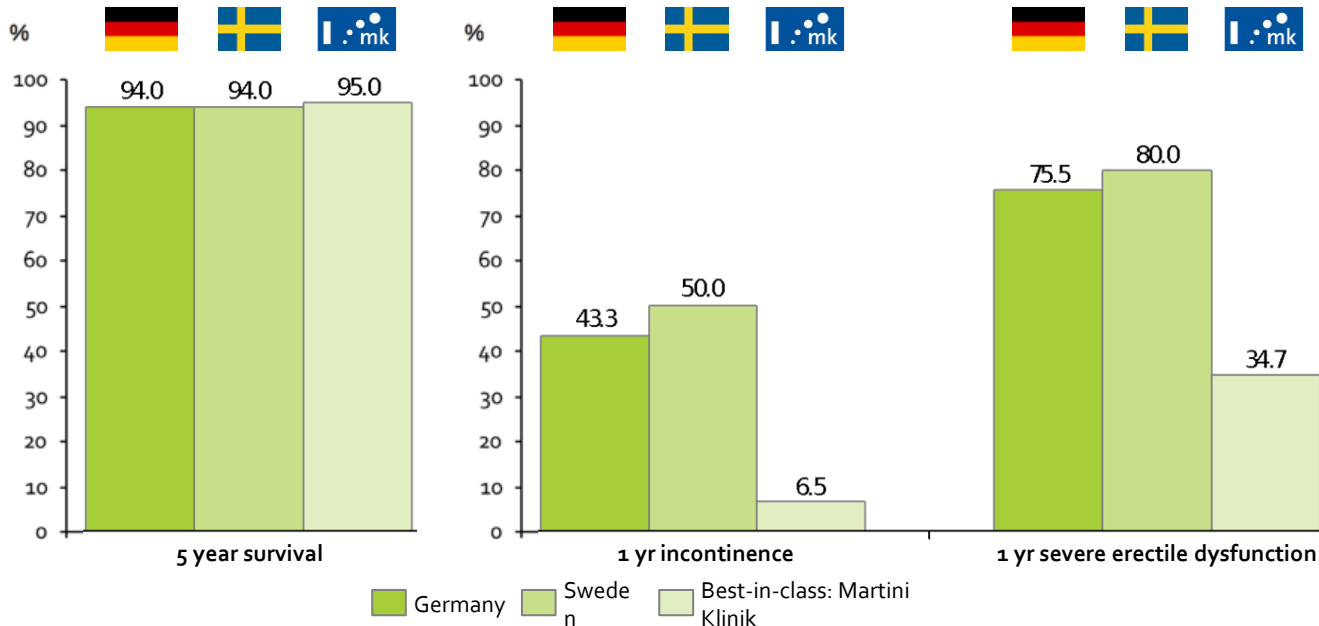


The picture reflects the number of implemented Sets per country

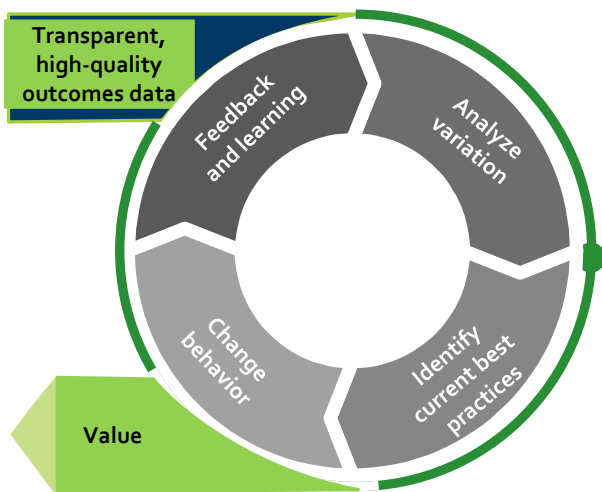
# Implementation success and gains at Martini Klinik

Focusing on mortality alone...

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



# How can measuring outcomes that matter to patients benefit you?



## Key stakeholders



- **Patients** will engage more actively in shared goal setting and self-management



- **Clinicians** will improve rapport with patients and improve quality of care, by learning from each other



- **Hospitals and practices** will optimize clinical pathways, and differentiate where they deliver superior outcomes at competitive prices



- **Payers** will negotiate contracts based on value, not volume, and encourage innovation to achieve those results



- **Life science** will market their products on value, showing improved outcomes relative to costs

## Heightened impetus for Fee-for-Value in the post-Covid era

- Increasing **patient voice** (impending regulation)
- Including ***all* patients** (disabilities, race, unbiased AI)
- Including **primary care** (population health lens)
- “Moral injury” of the healthcare workforce



Balazs Gardi for The New York Times

### **The Moral Crisis of America's Doctors**

The corporatization of health care has changed the practice of medicine, causing many physicians to feel alienated from their work.

By Eyal Press

Published June 15, 2023 Updated June 16, 2023

# Conclusion

- Patient care about quantity and quality of life
- ICHOM's Sets are internationally-endorsed tools for measuring outcomes that matter to patients, in a manner that is standardized, scientifically sound, and incorporates patient voice
- All stakeholders and society stand to gain from putting patients and people first

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The logo for ICHOM is displayed in a large, bold, sans-serif font. The letters are filled with a vibrant green color and contain a collage of various images related to healthcare and industry. The collage includes people in professional settings, such as doctors in white coats, individuals in business attire, and people working at desks or in laboratories. The background of the entire image is a dark blue grid of smaller, semi-transparent versions of the same collage.

We are all ICHOM