



International Consortium for  
Health Outcomes Measurement

# From Validation to Value

Jennifer Bright, ICHOM President

[j.bright@ichom.org](mailto:j.bright@ichom.org)

ISPOR EU, November 14, 2023



## VISION

Global health, driven  
by outcomes that  
matter to patients.



## MISSION



Standardize and drive  
global adoption of patient-  
centered outcomes  
measurement as the  
benchmark of health and  
value.

Defining global Sets  
Patient- Centered  
Outcome Measures  
matter most to patient

Driving adoption and  
reporting of these  
measures worldwide

Creating better value  
for all stakeholders  
through data for  
action and  
benchmarking

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

- Ensuring that care and healthcare 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



## Framing principles for the development of an ICHOM Set

- 1 Patients are directly involved in developing the Set
- 2 Patient-reported outcomes are included in every Set to capture symptom burden, functional status and health-related quality of life
- 3 The Set is a “minimum set” of measures focused on the outcomes that matter most to patients
- 4 Outcomes are prominent, and defined around the medical condition, not the specialty or the procedure
- 5 Case mix variables/risk factors and data collection time points are included to facilitate meaningful comparison
- 6 Decision-making for designing the set involves an inclusive, multidisciplinary, international and evidence-based modified Delphi consensus process

# ICHOM 10 Years of Impact

**45+** Sets of Patient-Centered Outcome Measures

Measures for **60%** of disease burden



**> 1,000** global consortium of clinical and patient co-creators

**Global Accessible Collaborative Patient-Centered (Now) Interoperable**



**> 450** implementation settings in **42** countries

**> 30,000** VBHC network

# ICHOM 45 Sets available (and counting)

Oncology	Cardiometabolic	Ophthalmological	Life-Course	Mental Health	Neurology	Congenital Anomalies	Gastrointestinal
Breast Cancer	Stroke	Cataracts	Older Person	Depression & Anxiety	Parkinson's disease	Congenital Heart Disease	Inflammatory Bowel Disease
L. Prostate Cancer	Coronary Artery Disease	Macular degeneration	Overall Adult Health	Depression & Anxiety CYP	Dementia	Pediatric Facial Palsy	Renal, Urogenital
A. Prostate Cancer	Atrial Fibrillation	Musculoskeletal	Overall Pediatric Health	Psychotic Disorders	Epilepsy	Congenital Upper Limb Anomalies	Chronic Kidney Disease
Lung Cancer	Heart Failure	Lower Back Pain	Adult Oral Health	Personality Disorders	Spinal Muscular Atrophy	Craniofacial Microsomia	Overactive Bladder
Colorectal Cancer	Heart Valve Disease	Hip & Knee O.A.	Maternal & Child Health	Addiction	Infectious Disease	Cleft Lip & Palate	Kidney Stones
Liver Cancer	Hypertension	Hand & Wrist	Pregnancy & Childbirth	Autism spectrum	COVID-19		
	Diabetes	Inflam. Arthritis	Preterm & Hospitalized Newborn Health	Eating Disorders			
	Venous Thromboembolism	Trauma		Neurodevelopmental Disorders			
	Obesity	Shoulder Surgery					



1,000+ clinical thought leaders  
& patients engaged globally



45k Set downloads



Across 40+ countries

## Leading nations:

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

Published in high  
impact journals,  
e.g.



**European  
Heart Journal**

**JAMA Oncology**

**EUROPEAN  
UROLOGY**

# Heart Valve Disease Set Endorsed by 11 professional societies



## HVD Set Project Leaders



**Emmanuel Lansac**  
Co-Chair



**Hanneke Takkenberg**  
Co-Chair



**Kevin Veen**  
Research Fellow

### Special acknowledgment:

**Vinod Thourani**, *Piedmont Healthcare*

**Rafael Sádaba**, *EACTS*

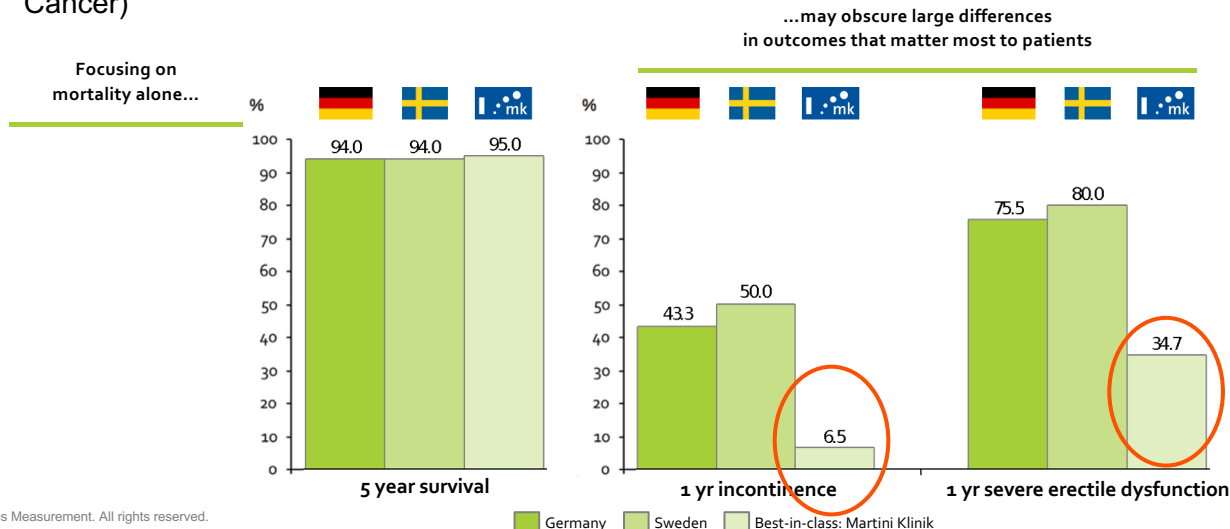
**Sulemaan Akta**, *ESC*

**John Stott**, *Heart Valve Voice*

# ICHOM National Level Impact of ICHOM's Localized Prostate Cancer Set in Germany



- Martini Klinik has consistently been a high performer in patient outcomes
- By 2018, the Klinik had ~2,500 radical prostatectomies performed annually (10% of Germany's total prostatectomy case load)
- The Localized Prostate Cancer Standard Set was endorsed by the **Movember Foundation**
- The Set was adopted by the **German Cancer Society** as part of their requirements for certification process for treatment centers (**130** Clinics in Germany currently using ICHOM Set for Localized Prostate Cancer)





## CAIPaDi - Instituto de Ciencias Médicas y Nutrición Salvador Zubirán

### Centro de Atención Integral al Paciente con Diabetes - Center for Comprehensive Care of Patients with Diabetes

Diabetes-oriented center focused on wellbeing improvement and quality of life of patients living with diabetes through outcomes measurement and a value-based healthcare approach

**Location:** Mexico City, Mexico

**Founded in:** 2013

**Type of organization:**  
Public sector outpatient specialty care services

**Number of patients enrolled in past year:**  
>3000 patients

#### Clinical services:

- Endocrinology
- Diabetes education
- Nutrition
- Physical activity
- Clinical psychology
- Dentistry - focus on periodontics
- Psychiatry
- Ophthalmology / Optometrist
- Foot care
- Enfermery



<https://www.incmnsz.mx/opencms/contenido/departamentos/CAIPaDi/versionenglish.html>  
Diabetes Res Clin Pract. 2019; 15:128–137. doi: 10.1016/j.diabres.2019.04.009

# CAIPaDi implementation results

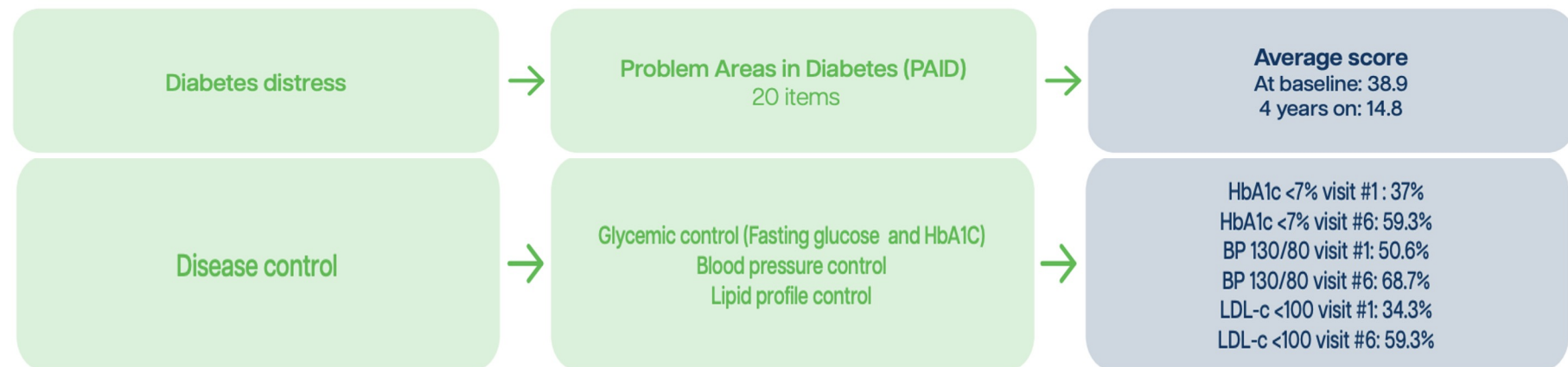
## Resource investment

Healthcare Resource	1st Year	2nd year and plus
CAIPaDi Cost - per patient	1st Year	2nd year and plus
Total Cost (2019 USD) - per patient	\$2,706	\$582

*Each consultation represents approximately \$559 USD per patient.  
The first year of treatment includes 4 visits, after which each visit becomes annual (unless more visits are necessary due to individual circumstances).*

## Summary:

- ~80% Reduction in cost per patient
- >50% reduction in diabetes distress
- 20% more patients in-range glycemic control
- 18% more patients in-range BP
- 25% more patients in-range LDL



# ICHOM Multiple uses for measuring outcomes that matter to patients

**Compare and improve performance that is based on outcomes that matter to patients.** Build a case for value-based contracting, respond to regulatory requirements that are on the horizon

**Effectiveness research utilizing RWD.** Add dimensions of data to enrich evaluation of therapies and medical devices (PROs, SDOH, health related behavior)

**Reduce outcomes disparities / improve equity.** Evaluate outcomes filtered by subgroups of interest

**Goals for collecting patient outcomes**

**Foster self-management,** providing feedback to patients on how they are doing over time and compared with patients like them

**Personalize care.** Avail information for shared decision-making and personalized goal setting

**Improve safety.** Allow clinicians to see how their patients are doing, and alert on those not doing well

**Real time clinical decision support.** Help clinicians determine which pathway will lead to the best outcomes (including quality of life) for the patient in front of them

**Improve outcomes and efficiency, optimize pathways.** Evaluate outcomes and efficiency of care pathways, better match suitable patients with pathways

# ICHOM Collaboration is Essential for Our Work Ahead



**Build Patient-Centered  
Outcome Measure Sets**



**Drive Implementation &  
Shared Learning**



**Influence Policy and  
Payment**

# Thank You

Jennifer Bright

President

[j.bright@ichom.org](mailto:j.bright@ichom.org)

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



<https://vimeo.com/ichom>



[https://twitter.com/ICHOM\\_ORG](https://twitter.com/ICHOM_ORG)



<https://www.facebook.com/ichomteam/>



<https://www.linkedin.com/company/international-consortium-for-health-outcomes-measurement-ichom-/>

