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**Global Patient Reported Outcomes Measurement**  
International Consortium for Health Outcomes Measurement

Sara Maria Sprinkhuizen  
September 10<sup>th</sup> 2015

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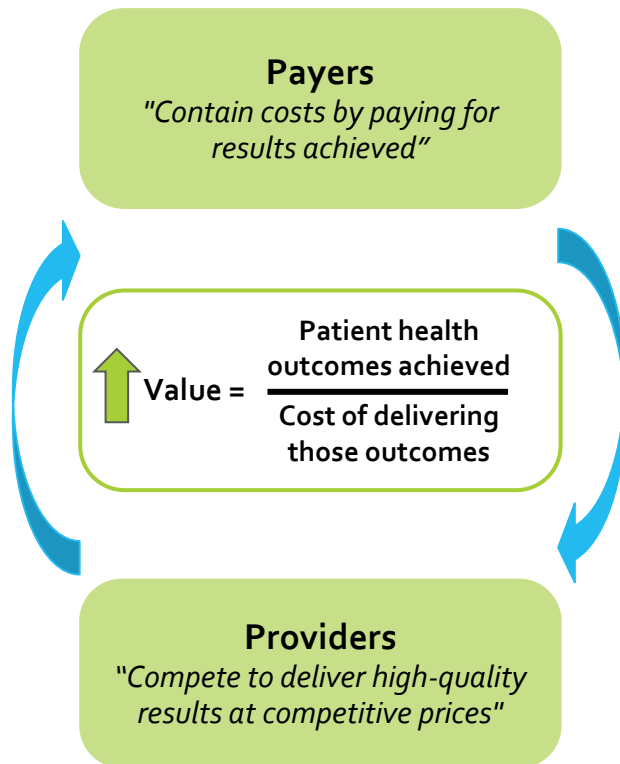
## Why ICHOM?

The role of PROMs in ICHOM Standard Sets

PROMs research and selection

# 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 **differentiate** into areas where they deliver superior outcomes at competitive prices



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

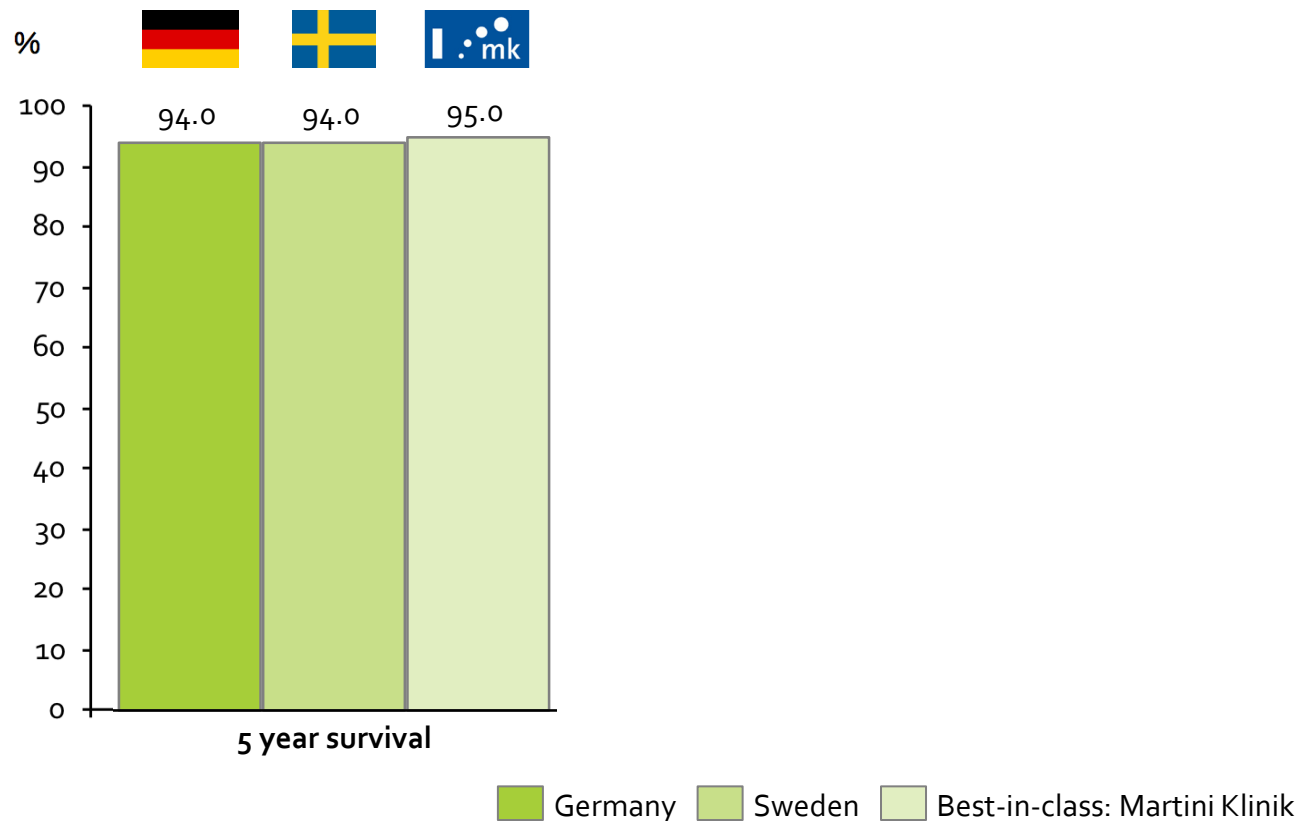


Suppliers will **market their products on value**, showing improved outcomes relative to costs

# This is why measuring and reporting meaningful outcomes matters

## Comparing outcomes of prostate cancer care

Focussing on mortality alone...

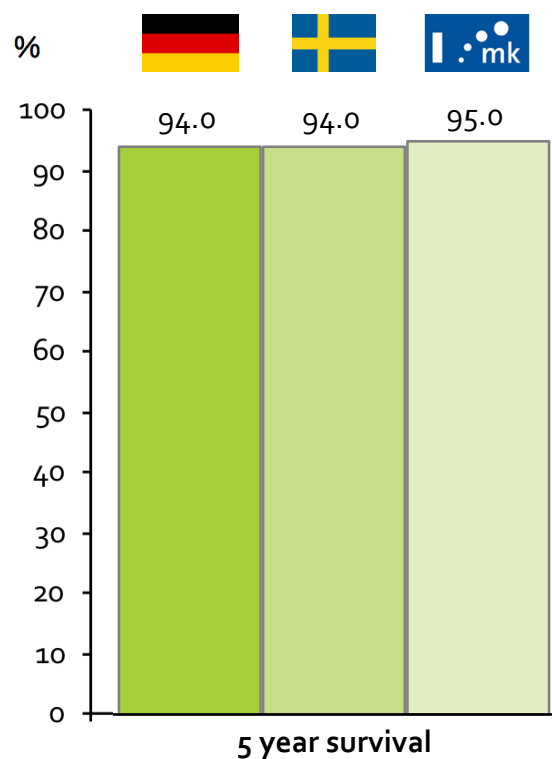


Swedish data rough estimates from graphs; Source: National quality report for the year of diagnosis 2012 from the National Prostate Cancer Register (NPCR) Sweden, Martini Klinik, BARMER GEK Report Krankenhaus 2012, Patient-reported outcomes (EORTC-PSM), 1 year after treatment, 2010

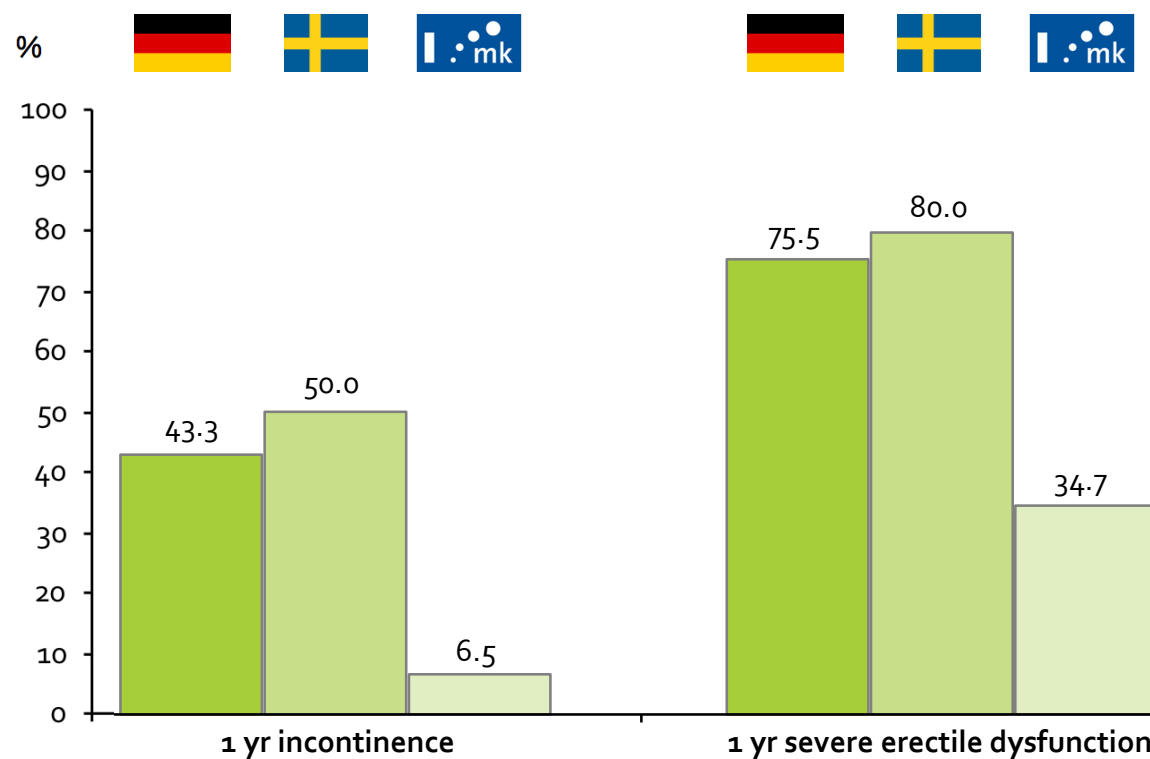
# This is why measuring and reporting meaningful outcomes matters

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

Core missions of ICHOM

*Define internationally recognized Standard Sets of outcomes that matter most to patients along with case-mix factors*

*Provide risk-adjusted international benchmarks on outcomes by medical conditions*

*Become methodological partner with media to publish ratings based on ICHOM outcomes*

Define the Standards

Benchmark on outcomes<sup>1</sup>

Establish outcomes transparency

VBHC

Implement outcomes measurement

*Facilitate adoption of outcomes measurement by*

- *making knowledge available*
- *spurring the development of technologies and alignment of registries*
- *supporting proof-of-concept*

Collaborate to improve value

*Enable international cooperation to improve value by establishing framework for value collaborative*

Develop value-based payment models

*Engage payers and governments to drive wider adoption and transparency through financial incentives or reporting requirements*

Enablers

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

# ICHOM is gaining the support of the health care community

## ICHOM's Strategic and Sponsoring Partners\*

### STRATEGIC PARTNERS



People caring for people



### PLATINUM



### GOLD

Carl Bennet AB



### SILVER



UNIVERSITAIR KANKERCENTRUM LEIDEN DEN HAAG UNIVERSITY CANCER CENTER LEIDEN THE HAGUE



The Children's Hospital of Philadelphia



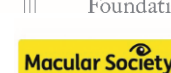
### BRONZE



THE MACULA FOUNDATION EXPANDING THE FIELD OF VISION



Jewish General Hospital Foundation



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Why ICHOM?

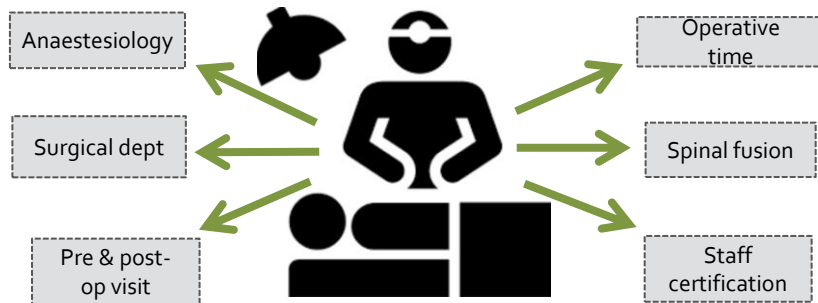
**The role of PROMs in ICHOM Standard Sets**

PROMs research and selection



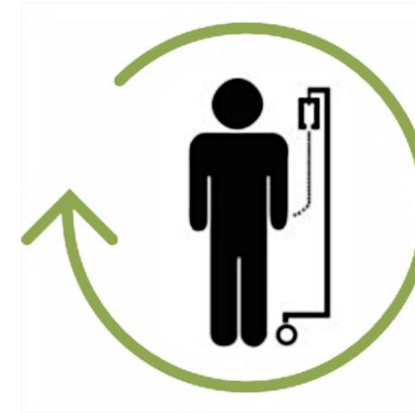
# Putting patients in the center of care shifts its organization and measurements, including collecting PROMs over full care cycle

## Intervention/Clinician/Process-centered



- 1 Care and its measurements organized around discrete medical specialties**
  - Radiology, anesthesiology, surgery
- 2 Care divided in series of discrete services**
  - Individual procedures, interventions, office visits, tests
- 3 Strong focus on structure and process metrics**
  - For example: administration of antibiotics, operative time, staff certifications, care protocols

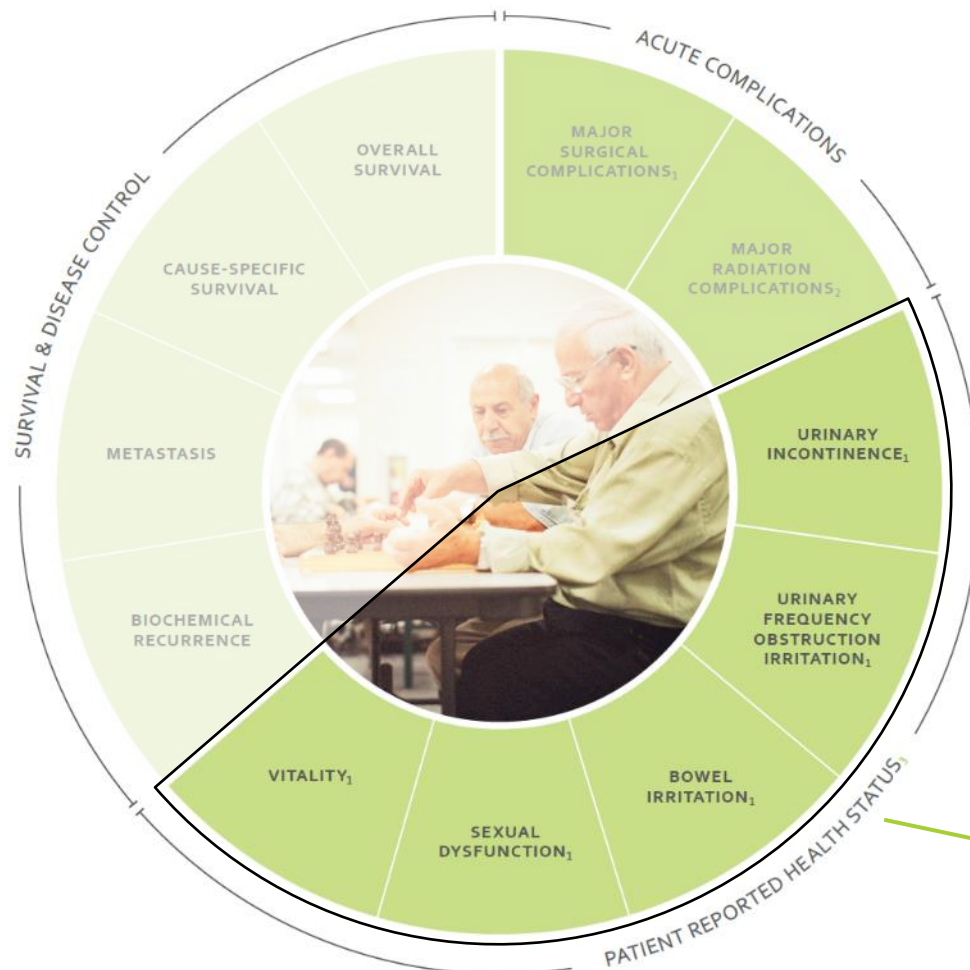
## Patient-centered



- Organization and measurements done at medical condition level**
  - Low back pain StSet: conservative therapy *and* surgery
- Care organized and measured over full cycle of care**
  - Cleft Lip and Palate StSet: measurements over 22 years period
- Patient reported outcomes are highly important**
  - PRO collection is largest component of all ICHOM Standard Sets

# Each ICHOM Standard Set reflects patient-centeredness

E.g. Localized Prostate Cancer



## Treatment approaches covered

- Watchful waiting
- Active surveillance
- Prostatectomy
- External beam radiation therapy
- Brachytherapy
- Androgen Deprivation Treatment
- Other

## Full cycle of care

- From surgical complications to tracking metastasis and overall survival

5 of the 11 outcome domains are **patient-reported**

# We have already developed 12 Standard Sets, with a total of 34 PROMs recommended



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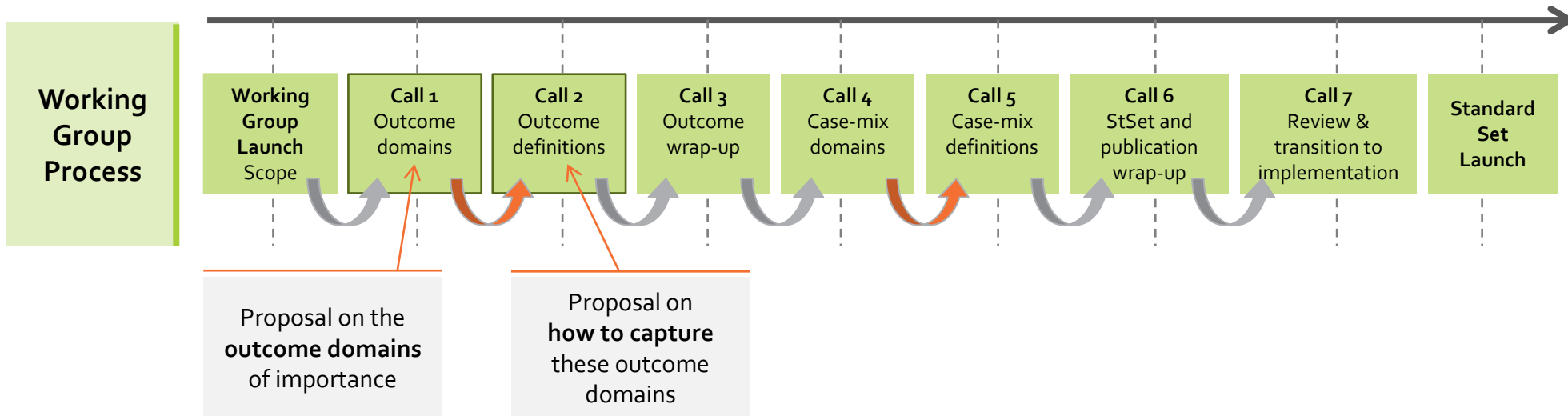
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Why ICHOM?

The role of PROMs in ICHOM Standard Sets

**PROMs research and selection**

# We select outcome domains first, PROMs second, and keep a close look at the developments in the PROMs field



## Working Group teleconferences address outcome domains first, PROMs second

1. Aim is not to 'pollute' our thinking on the domains of importance with certain PROMs
2. Relevant domains will stay, but the way to capture them may change\*

## PROMs development is a very active field

- Lots of new tools are being developed
- Old tools continuously optimized/shortened/improved
- New methodologies are actively being developed
  - *CTT* → *IRT* → *CAT*
- Crosswalks between instruments increasingly available\*\*

\*Every StSet has a SteerCo: reviewing and approving proposed revisions to the Standard Set over time

\*\*Examples: PROsetta Stone <http://www.prosetta.org>; Common Metrics <http://www.common-metrics.org>



# Key elements we research when selecting the best PROM tools for our Standard Sets

PROM selection is based on 5 key elements:

1. Coverage of outcome domains of importance
2. Psychometric Quality - ISOQOL standards
3. Feasibility - Burden of assessment
4. Financial - Licensing aspects
5. Established - Locations in use/# translations

Sample research sheet used to score PROMs

		Brief definition and instruction	Generic PROMs (Any disease)
0	GENERIC INFO	ABBREVIATED NAME This is the name the prom is most known for. For example: EPIC-26	PROM I name
1	CONCEPTUAL & MEASUREMENT	CONCEPTUAL AND MEASUREMENT MODEL Give a generic description and purpose of the PROM.	High
		TARGET POPULATION The intended population(s) for use	High
2	RELIABILITY	TEST-RETEST RELIABILITY (= reproducibility) Stability of scores over time when no change is expected in the concept of	High
		RELIABILITY - INTERNAL CONSISTENCY Extent to which the items comprising a PROM instrument are measuring the	Low
3	VALIDITY	CONTENT VALIDITY The appropriateness of the items and the domains.	High
		CONSTRUCT VALIDITY Evidence that relationships among items, domains, and concepts conform	Med
		RESPONSIVENESS (Ability to detect change) An instrument's ability to detect change over time.	Med
4	INTERPRETABILITY	INTERPRETABILITY The degree to which one can assign easily understood meaning to an	Low
5	TRANSLATION	TRANSLATION List the original languages as well as all available PROM translations (comma	High
6	BURDEN	PATIENT BURDEN Time, energy and literacy demand.	High
		ADMINISTRATIVE BURDEN Literacy demand of the items in the Clinician/administrative/investigator/data analyst burden (time, energy,	High
7	LICENSING	LICENSING Information on licensing and licensing costs	Unknown
8	ESTABLISHED?	LOCATIONS IN USE Number of locations (countries) where PROM is in use	High
		# of CITATIONS Number of citations of original article	Unknown
		YEAR DEVELOPED Year of original publication	High

ICHOM does not create measurement tools, we research the PROMs that are available in the field, per condition

# PROMs quality is researched prior to teleconference

## Comparing the specs of Neuro-QoL, PROMIS-10 and EQ-5D

### Instrument

### Specs

### Outcome domains in Stroke Standard Set

1 NEURO-QoL

2 PROMIS-10  
(Promis Global health)

3 EQ-5D

Year developed	Patient reported	Interviewer reported	External validity for stroke	Technical Quality*	Established	# Translations	# Questions	Estimated minutes to complete
2007	✓	✓	✓✓ ✓	✓✓ ✓	✓	2 *	40-72**	About 4 items per minute
2007	✓	✓	✓✓	✓✓ ✓	✓✓	5-7 ***	10	5-10
1990	✓	✓	✓✓	✓✓ ✓	✓✓ ✓	>160	5	5

mobility	global cognitive function	self care and grooming	feeding	mood	ability to communicate	ability usual activities	social participation	fatigue	pain & other unpl. sens.	patient rep gen health status	patient reported QOL
Green	Green	Green	Red	Green	Green	Green	Green	Green	Green	Green	Green
Green	Green	Red	Red	Green	Red	Green	Green	Green	Green	Green	Green
Green	Red	Green	Red	Green	Red	Green	Red	Red	Green	Green	Green

EQ-5D preference scores can be predicted from PROMIS global items, allowing use in economic evaluations.

**Predicting EuroQol (EQ-5D) scores from the patient-reported outcomes measurement information system (PROMIS) global items and domain item banks in a United States sample**

Dennis A. Revicki · Ariane K. Kawata ·  
Neesha Harnam · Wen-Hung Chen ·  
Ron D. Hays · David Cella

Domain is covered by PROM	Green
Domain is not covered by PROM	Red

**Technical Quality** \* Internal validity, Construct validity, Content validity, Reliability, Responsiveness

\* Translations in English, Spanish. Multiple translations in progress.

\*\* Paper based: 72 Computer Adaptive Testing: 40

\*\*\* Translations in English, Spanish, French, German, Dutch. Translations in progress are: Portugese and simplified Chinese <http://www.nihpromis.org/measures/translations>

# Issues we have encountered in researching and selecting PROMs

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## Issues encountered...

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- 1 PROM does not cover all domains of importance**
  - Stroke PROMIS-10 example
- 2 PROMs not validated in patient population of interest**
  - Pregnancy & Childbirth example
- 3 PROMs not -yet- developed for domain of interest**
  - QoD in Lung Cancer example
- 4 PROMs not well established in the field**
  - Macular Degeneration IVI example
- 5 PROMs very established in the field**
  - HKO Oxford Hip and Knee score example

## ...and how we address them

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Add single item questions that are used by registries

Recommend PROMs that are unvalidated in specific population, but that have been used *in research* in that patient population

Cover domain through other sources (clinical/administrative data), keeping an eye on PROM development

Communicate importance of the instrument, highlight strengths compared to other measures

When crosswalks exists: recommend multiple PROMs. The absence of a crosswalk can be reason not to recommend multiple PROMs.



# Moving the PROMs field to the next level: roles for ICHOM to play, according to experts

## Interviews conducted with PROM developers, researchers and users...

Name	Organization/Position
Ethan Basch	PCORI - Methodology Committee, University of North Carolina at Chapel Hill
Nick Black	Professor of Health Services Research - London School of Hygiene & Tropical Medicine. Chair of National Advisory Group for Clinical Audit & Enquiries
Andrew Bottomley	EORTC QOL group - Head of the QOL Department
John Browne	Department of Epidemiology and Public Health, University College Cork. Oversaw NHS PROMs programme at London School of Hygiene and Tropical Medicine
David Cella	PROMIS - Professor of Psychiatry and Behavioral Sciences; Chair, Department of Medical Social Sciences, Northwestern University. FACIT Measurement System
Mats Lundstrom	EUREQUO, Eynet consultant, developer of Catquest-gSF
Francesca Martinelli	EORTC QOL group - Statistician
Konrad Pesudovs	Foundation Chair of Optometry and Vision Science, School of Medicine, Flinders University
Matthias Rose	PROMIS, Charité Universitätsmedizin Berlin

## ...led to key conclusions on ICHOM's role in the PROMs field

- 1 CONTINUE TO BUILD OUT NUMBER OF CONDITIONS FOR WHICH OUTCOMES ARE MEASURED IN A STANDARD WAY
- 2 BUILD OUT A FRAMEWORK FOR BEST PROM USAGE IN THE CONTEXT OF CARE OPTIMIZATION
- 3 IMPROVE AWARENESS ON THE IMPORTANCE OF PROMS AND CORRECT PROM USAGE
- 4 INCREASE INTERNATIONAL PROM ADAPTIBILITY THROUGH EFFICIENT ASSESSEMENT AND STANDARDIZED REPORTING

# Sweden's extensive experience with outcomes measurement has contributed enormously to ICHOM's work. Thank you all!

## Cataracts

Mats Lundström | EUREQUO

Anders Boman | St Erik Eye Hospital

Ingrid Kossler | European Cancer Patient Coalition

## Cleft Lip and Palate

Anette Lohmander | Karolinska Institutet

## Coronary Artery Disease

Tomas Jernberg | Swedeheart

## Depression and Anxiety

Erik Hedman | Karolinska Institutet

## Hip and Knee Osteoarthritis

Leif Dahlberg | Lund University

Henrik Malchau | University of Gothenburg; Harvard Medical School

Ola Rolfson | University of Gothenburg; Harvard Medical School

## Localized Prostate Cancer

Anna Bill-Axelsson | Uppsala University Hospital; NPCR of Sweden

## Low Back Pain

Peter Fritzell | Ryhov Hospital, SweSpine

Olle Hägg | Spine Center Göteborg, SweSpine

Björn Strömqvist | Lund University, SweSpine

## Macular Degeneration

Inger Westborg | Umeå University; Registercenter Syd/EyeNet Sweden

## Parkinson's Disease

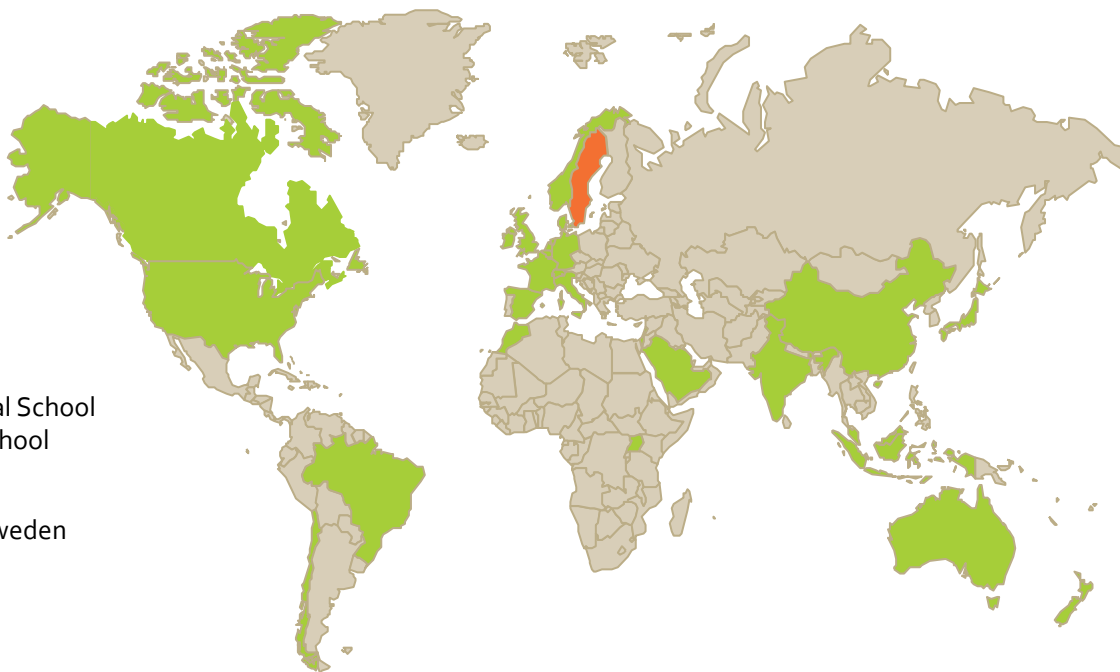
Peter Hagell | Kristianstad University

Per Odin | Skåne University Hospital

Paul de Roos | Uppsala University Hospital

## Stroke

Bo Norrving | Lund University; Swedish Stroke Register (Riksstroke)



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# Overview of the PROMs that are recommended in our first 12 Standard Sets

Standard Set	PROM	Full name PROM	
Advanced prostate cancer	EPIC-26	Expanded Prostate Cancer Index Composite	
	EORTC-QLQ-C30	European Organization for Research and Treatment of Cancer Quality of Life Questionnaire	
Coronary artery disease	SAQ-7	Seattle Angina Questionnaire	
	RDS	Rose Dyspnea Scale	
	PHQ-2	Patient Health Questionnaire	
Cataract	Catquest-9SF	Catquest-9SF	
	ODI	Oswestry Disability Index version 2.1a	
Low back pain	NPRS	Numerical Pain Rating Scale	
	EQ-5D and EQ-VAS	EuroQol-5D descriptive system (EQ-5D-3L) and visual analogue scale (EQ-VAS)	
Lung cancer	EORTC-QLQ-C30	European Organization for Research and Treatment of Cancer Quality of Life Questionnaire	
	EORTC-QLQ-LC13	European Organization for Research and Treatment of Cancer Quality of Life Lung Cancer-Specific Questionnaire	
Localized prostate cancer	EPIC-26	Expanded Prostate Cancer Index Composite	
	USMD	Utilization of Sexual Medications/Devices	
Macular degeneration	IVI	Impact of Vision Impairment Questionnaire	
	PROMIS-10 SF v1.1	Patient Reported Outcomes Measurement Information System Shortform version 1.1 Global Health	
Stroke	NMSQ	International Parkinson's and Movement Disorders Society (IPMDS) Non-motor symptoms questionnaire (NMSQ)	
	MDSUPDRS	Movement Disorder Society (MDSUPDRS) Part I: Non-Motor Aspects of Experiences of Daily Living (nMEDL). Both clinical- and patient reported portions Part II: Motor Aspects of Experiences of Daily Living (M-EDL). Patient-reported	
Parkinsons	PDQ-8	Parkinson's Disease Quality of Life Questionnaire	
	CleftQ	Cleft Q	
Cleft lip and palate	NOSE	Nasal Obstruction NOSE Scale	
	COHIP	COHIP Oral Symptoms Scale	
	ICS	Intelligibility in Context Scale	
	PHQ-9	Patient Health Questionnaire	
Depression and Anxiety	GAD-7	Generalized Anxiety Disorder	
	SPIN	Social Phobia Inventory	
	MI	Mobility Inventory for Agoraphobia	
	IES-R	Impact of Event Scale - Revised for Post-traumatic Stress Disorder	
	PDSS-SR	Panic Disorder Severity Scale	
	OCI-R	Obsessive-Compulsive Inventory	
	WHODAS 2.0	World Health Organization Disability Assessment Schedule 2.0	
	MOS-SSS	Medical Outcomes Study: Social Support Survey	
	CEQ	Credibility and Expectancy Questionnaire	
	Hip and knee osteoarthritis	HOOS-PS	Hip Disability and Osteoarthritis Outcome Score - Physical Function Shortform
		KOOS-PS	Knee Injury and Osteoarthritis Outcome Score - Physical Function Shortform
		EQ-5D and EQ-VAS	EuroQol-5D descriptive system (EQ-5D-3L) and visual analogue scale (EQ-VAS)*
VR-12/SF-12		Veterans RAND 12 (VR-12) Short Form 12 Health Survey (SF-12)*	