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**Patient-Centered Health Care:  
From Theory to Reality**

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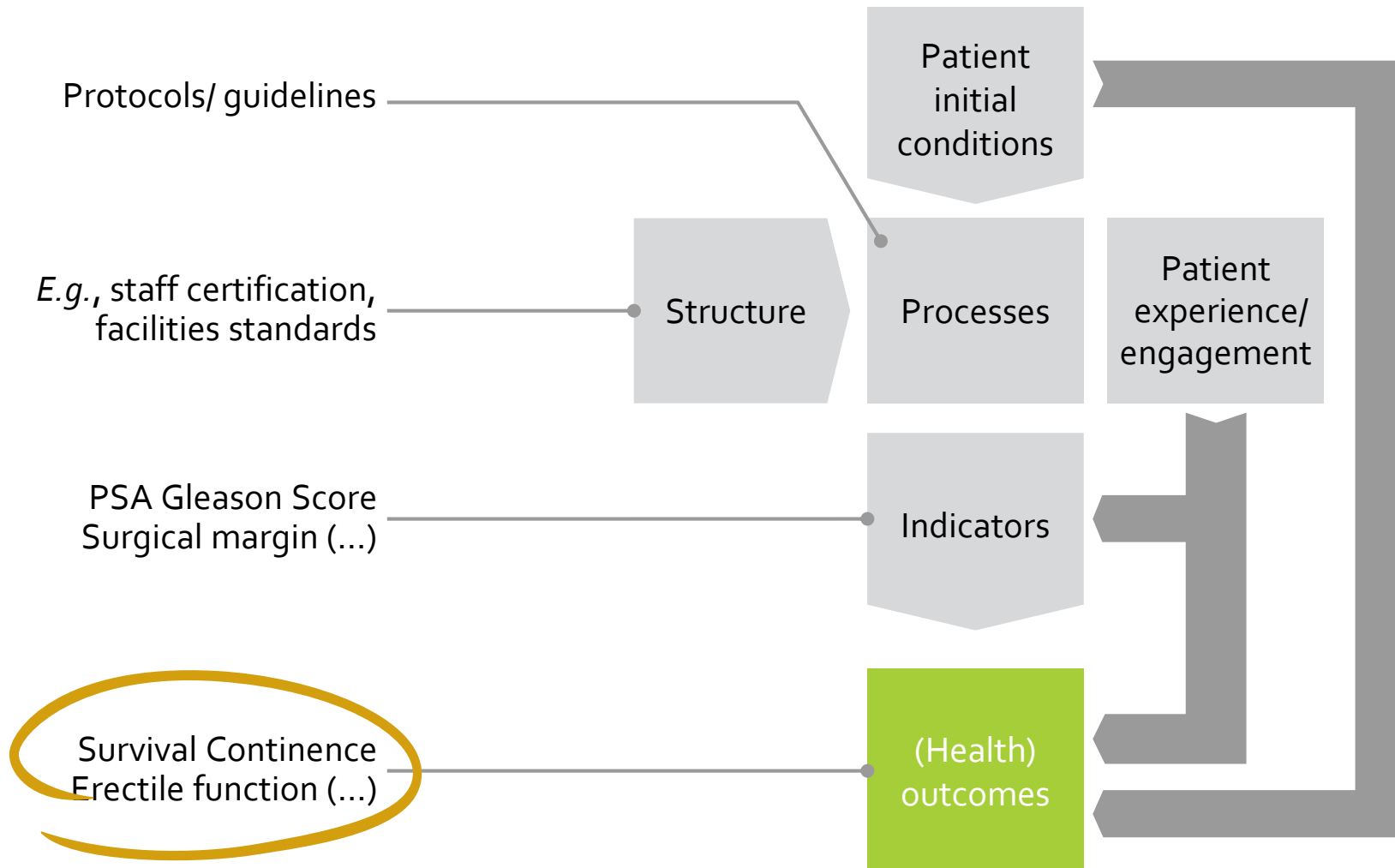
# Putting the focus on the patient

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# Outcomes are the “real-world” results that matter to patients

Example: prostate cancer



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

## Where we come from

Three organizations 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



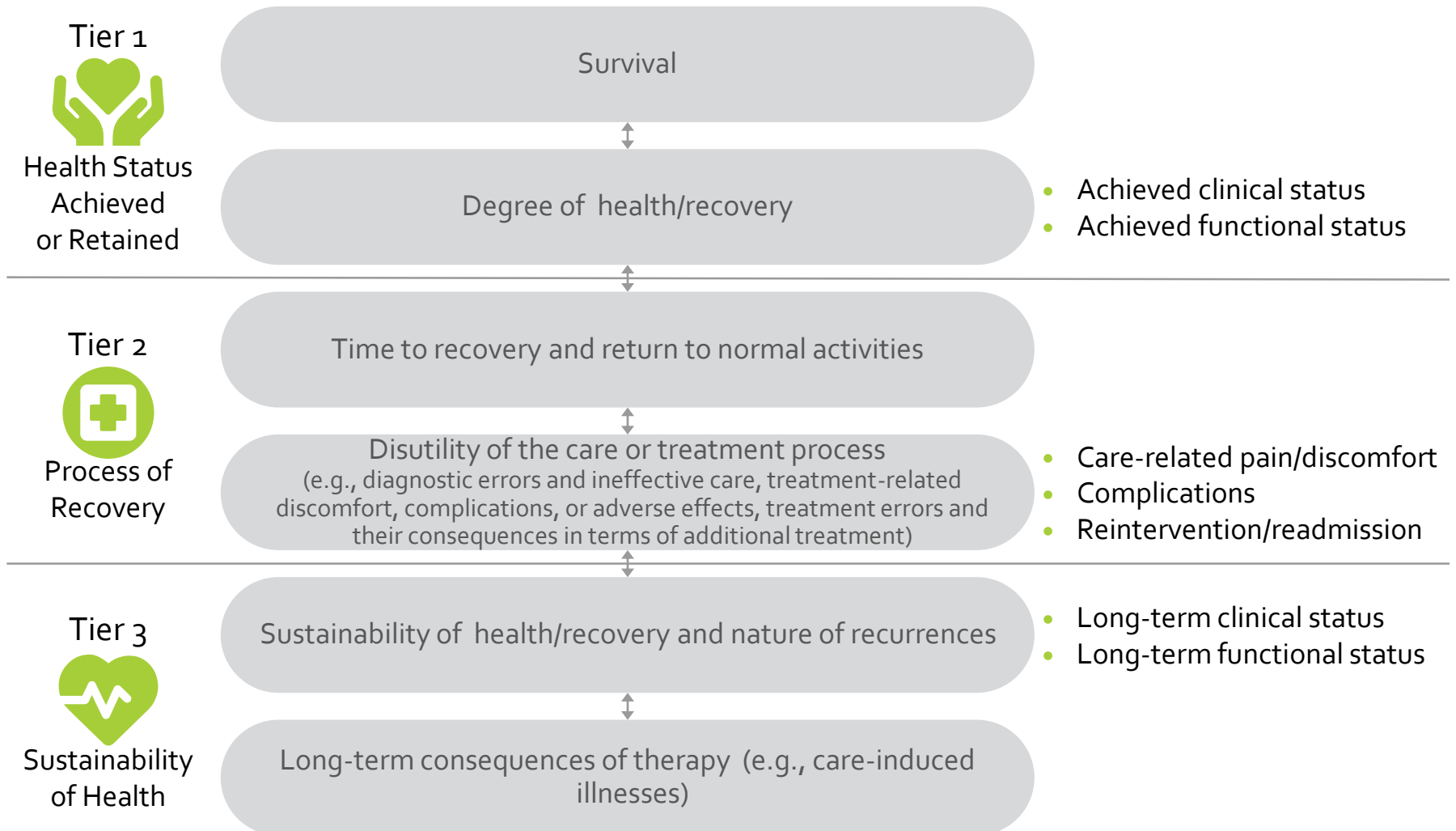
### Our mission

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

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

# The Outcome Measures Hierarchy

Two Dimensions- Clinician Reported and Patient Reported Outcomes



# ICHOM Standard Sets are developed using a robust process led by leading clinical experts

## Principles of Standard Set Development

- 1 Outcomes are **defined around medical conditions**, not specialties or the procedures
- 2 Standard Sets are a “minimum set” **focused on outcomes that matter most** to patients
- 3 **Patients are directly involved** in defining every Standard Set
- 4 **Patient-reported outcomes are part of every Standard Set** and include functional status, symptom burden 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

## Rigorous Development Process

### Diverse teams of leaders collaborate in working groups

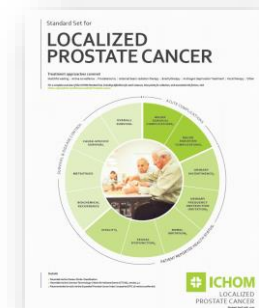
- Internationally-recognized clinical and registry leaders from top institutions
- Patients with 'real-world' experience

### Working groups identify a comprehensive set of potential outcomes that matter to patients

- These are prioritized to develop a "minimum set"



**Outcome Measures in Standard Sets matter most to patients, and are created based on feasibility and reliability**



# International leaders from 9 countries have developed the Breast Cancer Standard Set

Kimberly Allison, **Stanford University**  
Patricia Ganz, **University of California Los Angeles**  
Reshma Jagsi, **University of Michigan**  
Henry Kuerer, **MD Anderson Cancer Center**  
Sarah McLaughlin, **Mayo Clinic Jacksonville**  
Ann Partridge, **Dana-Farber Cancer Institute**  
Dereesa Reid\*, **Hoag Orthopedic Institute**  
Thomas Smith, **John Hopkins Institute**

John Browne, **University College Cork**

Yvonne Wengström, **Karolinska Institutet**

Linetta Koppert, **Erasmus MC Cancer Institute**  
Marc Mureau, **Erasmus MC Cancer Institute**  
Mark Stoutjesdijk, **Ikazia Hospital Rotterdam**  
Marie-Jeanne Vrancken Peeters, **Antoni van Leeuwenhoek**  
Anne Knip\*, **Breast Cancer Association NL**

Karen Benn\*, **Europa Donna**

Francois Duhoux, **Cliniques Universitaires Saint-Luc**

Felicia Knaul\*, **Cancer de Mama**

Cheng Har Yip, **Subang Jaya Medical Centre**

Rodney Cooter, **Monash University**  
Geoff Delaney, **South Western Sydney Local Health District**  
Wee Loon Ong, **Peter MacCallum Cancer Centre**  
Christobel Saunders, **University of Western Australia**  
Lisa Sheeran, **Peter MacCallum Cancer Centre**  
Patricia Hancock\*, **Breast Cancer Network Australia**

\*Patient representatives

# The Breast Cancer Standard Set Flyer represents a high-level overview of the outcomes, scope and treatments



## Scope

All patients (men and women) with newly pathologically diagnosed invasive breast cancer (stage I-IV) and DCIS

### Exclude:

- Rare tumor (e.g. Phyllodes tumor)
- Lobular carcinoma in situ (LCIS)
- Patients with recurrent disease at baseline

## Treatment Approaches covered

- Surgery
- Radiotherapy
- Chemotherapy
- Targeted therapy
- Hormonal therapy

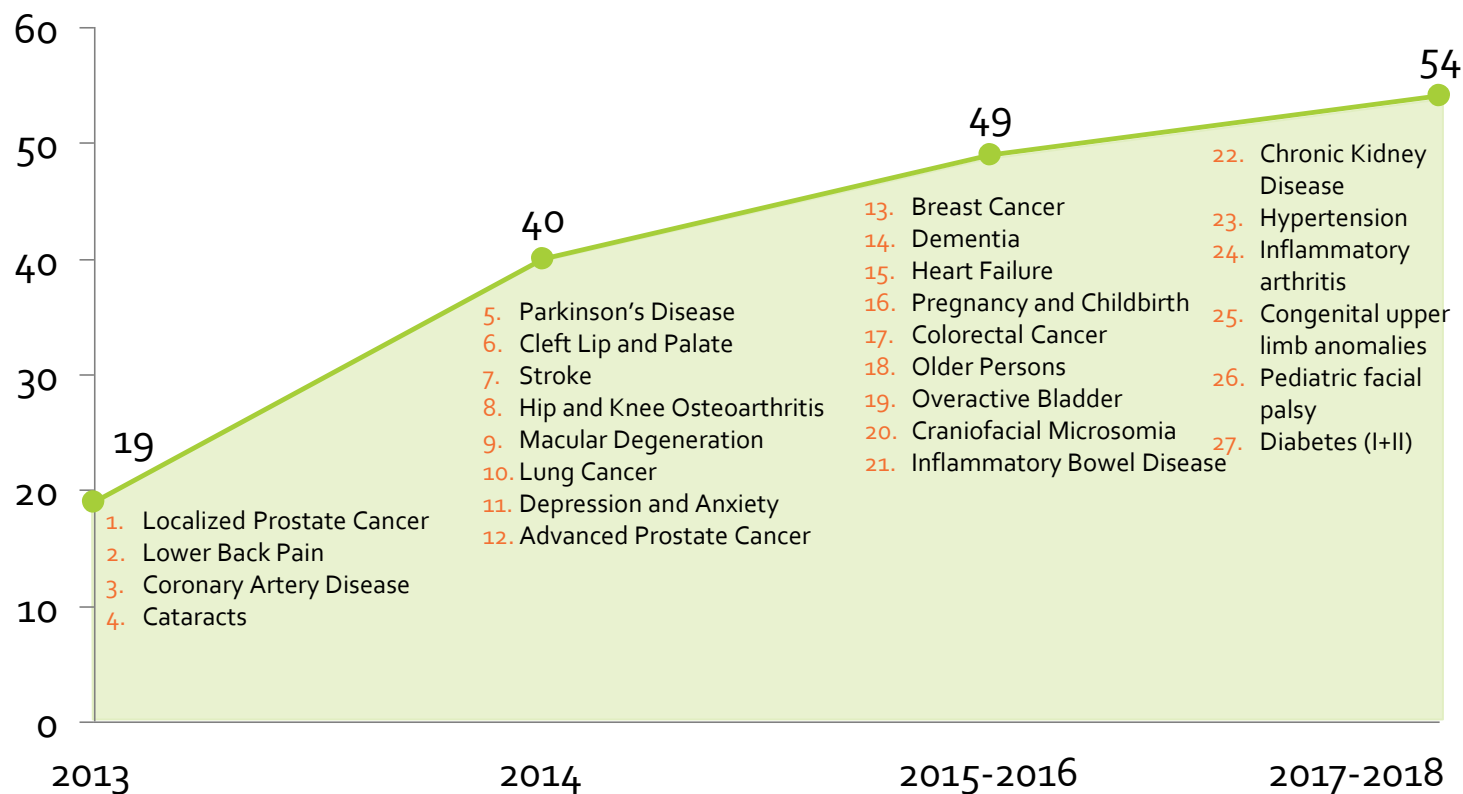
### Exclude:

- Investigational agents or techniques

# ICHOM Standard Sets now cover >50% of global disease burden

## 27 ICHOM Standard Sets to-date

Burden of Disease Covered (%)



### Committed/ In process

- Oral health
- Atrial fibrillation
- Overall adult health
- Overall pediatric health
- Hand & wrist conditions
- Anxiety, Depression and OCD in children and young people
- Personality disorders
- Psychotic disorders
- Substance misuse

# Global outcomes benchmarking pilots are breaking new ground

Benchmarking pilot is collecting and comparing outcomes across the globe

Currently collecting Cataract and Hip/Knee/Osteoarthritis Standard Set data from leading providers across the globe



## Progress and Impact

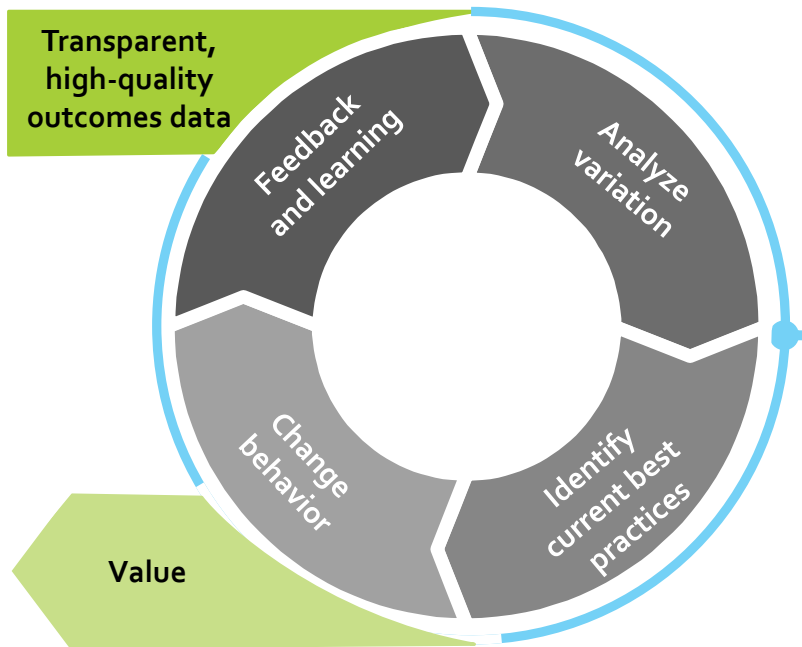
	Countries	Sites	Patients (Since '16)
Cataracts	8	53	60k
Hip/Knee/Osteoarthritis	5	25	6k

- ✓ Risk-adjustment of raw data and benchmark on key indicators—focusing on patient-reported outcomes
- ✓ Individual reporting to participating organizations
- ✓ “Best-in-class” organizations identified with intent to publish about their performance

Sample output (Hip/Knee/Osteoarthritis)



# Outcome measurement empowers stakeholders to generate value



## Key stakeholders



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



- **Clinicians** will improve quality of care by **comparing performance** and learning from each other



- **Hospitals** will **differentiate** into areas where they deliver superior outcomes at competitive prices



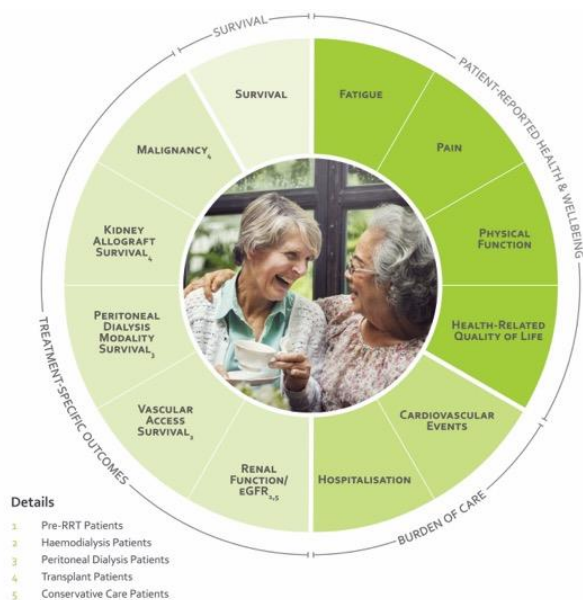
- **Payers** will **negotiate contracts** based on results, not volume, and encourage innovation to achieve those results



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

# There is an overlap between outcomes that matter to patients in core sets design for use in clinical practise (ICHOM) and in clinical trials (SONG)

## ICHOM Standard Set for Chronic Kidney Disease



## SONG Standardise Outcomes in Nephrology



Fatigue, cardiovascular disease, mortality, vascular access, PD-failure, graft survival