Putting the focus on the patient
Outcomes are the “real-world” results that matter to patients

Example: prostate cancer

- **Structure**: Protocols/guidelines
  - E.g., staff certification, facilities standards
  - PSA Gleason Score
  - Surgical margin (...)

- **Processes**: Patient initial conditions

- **Patient experience/engagement**: Patient experience/engagement

- **Indicators**: (Health) outcomes
  - Survival Continence
  - Erectile function (...)

Example: prostate cancer outcomes
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

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

Tier 1
Health Status
Achieved or Retained
Survival
Degree of health/recovery
• Achieved clinical status
• Achieved functional status

Tier 2
Process of Recovery
Time to recovery and return to normal activities
Disutility of the care or treatment process
(e.g., diagnostic errors and ineffective care, treatment-related discomfort, complications, or adverse effects, treatment errors and their consequences in terms of additional treatment)
• Care-related pain/discomfort
• Complications
• Reintervention/readmission

Tier 3
Sustainability of Health
Sustainability of health/recovery and nature of recurrences
Long-term consequences of therapy (e.g., care-induced illnesses)
• Long-term clinical status
• Long-term functional status

Source: NEJM Dec 2010
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"
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 Stoutjedijk, Ikazia Hospital Rotterdam
Marie-Jeanne Vrancken Peeters, Antoni van Leeuwenhoek
Anne Knip*, Breast Cancer Association NL

Karen Benn*, Europa Donna

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 (%)

- Localized Prostate Cancer
- Lower Back Pain
- Coronary Artery Disease
- Cataracts
- Parkinson’s Disease
- Cleft Lip and Palate
- Stroke
- Hip and Knee Osteoarthritis
- Macular Degeneration
- Lung Cancer
- Depression and Anxiety
- Advanced Prostate Cancer
- Breast Cancer
- Dementia
- Heart Failure
- Pregnancy and Childbirth
- Colorectal Cancer
- Older Persons
- Overactive Bladder
- Craniofacial Microsomia
- Inflammatory Bowel Disease
- Chronic Kidney Disease
- Hypertension
- Inflammatory arthritis
- Congenital upper limb anomalies
- Pediatric facial palsy
- Diabetes (I+II)

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

Benchmarks 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

<table>
<thead>
<tr>
<th></th>
<th>Countries</th>
<th>Sites</th>
<th>Patients (Since '16)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Cataracts</td>
<td>8</td>
<td>53</td>
<td>60k</td>
</tr>
<tr>
<td>Hip/Knee/Osteoarthritis</td>
<td>5</td>
<td>25</td>
<td>6k</td>
</tr>
</tbody>
</table>

- 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

Transparent, high-quality outcomes data

Value

Feedback and learning

Analyze variation

Identify current best practices

Change behavior
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