Defining a Standard Set of Patient-Centered Outcome Measures after Stroke

Joel Salinas
Massachusetts General Hospital & Harvard Medical School
Sara Sprinkhuizen
International Consortium for Health Outcomes Measurement

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Disclosure

Presenters
▪ Joel Salinas - Massachusetts General Hospital & Harvard Medical School
▪ Sara Sprinkhuizen - International Consortium for Health Outcomes Measurement (ICHOM)

ICHOM has received financial support for this work from the American Heart Association / American Stroke Association
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Agenda

Introduction to ICHOM

The ICHOM Stroke Standard Set
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

Payers
"Contain costs by paying for results achieved"

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

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

Providers
"Compete to deliver high-quality results at competitive prices"

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

Focussing on mortality alone...

...may obscure large differences in regaining function post stroke

A new standard is needed to measure what patients really care about

Moving from here
- e.g., Time to treatment
- e.g., Staff certification, facilities standards, stroke unit
- e.g., MRI, Lab results

To here
- Survival
- Feeding
- Fatigue
- Social participation
- Ability to work (…)

(Health) outcomes
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ICHOM was formed to drive the industry towards value-based health care by defining global outcome standards

<table>
<thead>
<tr>
<th>Where we come from</th>
<th>Our mission</th>
</tr>
</thead>
<tbody>
<tr>
<td>Three organizations with the desire to unlock the potential of value-based health care founded ICHOM in 2012:</td>
<td>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</td>
</tr>
</tbody>
</table>

ICHOM is a nonprofit
- Independent 501(c)3 organization
- Idealistic and ambitious goals
- Global focus
- Engages diverse stakeholders

Value = Patient health outcomes achieved / Cost of delivering those outcomes
ICHOM plays several roles along the journey that will enable value-based health care: our strategic agenda

**Define Standards**
ICHOM defines internationally recognized Standard Sets of outcomes and related case-mix factors

**Benchmark on outcomes**
ICHOM will provide risk-adjusted international benchmarks on outcomes by medical condition

**Establish outcomes transparency**
ICHOM will become a methodological partner with media to publish ratings based on ICHOM outcomes

**Measure outcomes**
ICHOM facilitates adoption and implementation by sharing knowledge and supporting proof-of-concept

**Collaborate to improve value**
ICHOM will enable cooperation to improve value by establishing value collaboratives

**Develop value-based payment models**
ICHOM will engage payers and governments to realign financial incentives and promote transparency

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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**

**ACI**
NSW Agency for Clinical Innovation

**santeon**
Catharina Ziekenhuis
Martini Ziekenhuis
Medisch Spectrum Twente
OLVG
SL Antonius Ziekenhuis

**GOLD**

**IUGA**
International Urogynecological Association

**DICA**
Dutch Institute for Clinical Auditing

**American Heart Association**
**American Stroke Association**

**BRONZE**

**PLATINUM**

**Alliance of Dedicated Cancer Centers**

**NHS England**

**Hobbes Foundation**

**The Children's Hospital of Philadelphia**

**Hoag Orthopedic Institute**

**Harvard Pilgrim Health Care**

**Carl Bennet AB**

**SILVER**

**British Heart Foundation**

**Boston Children's Hospital**

**NHS**

**SickKids**

**Clinical Commissioning Group**

**Générale de santé**

**UNIVERSITAIR KANKERZIEKENHUIS LEEUWARDEN**

**UNIVERSITY CANCER CENTER OOSTERHOUT**

**UNIVERSITAIR KANKERZIEKENHUIS LEUVEN**

**MD Anderson Physicians Network**

**The Macula Foundation**

**MAYO CLINIC**

**Istituto Clinico Humanitas**

*As of September 10, 2015*
Agenda

Introduction to ICHOM

The ICHOM Stroke Standard Set
ICHOM organizes Working Groups to define Standard Sets of outcomes we recommend all care providers track

ICHOM facilitates a process with international physician and registry leaders and patient representatives to develop a global Standard Set of outcomes that really matter to patients

A few facts
- 300 physicians, patient representatives and outcomes experts involved so far
- All participants volunteer their time, 2-3 hours per month
- 8-10 months to develop a Standard Set
We have already developed 12 Standard Sets, covering 35% of the disease burden

2015 targets
- Dementia
- Frail elderly
- Heart Failure
- Pregnancy and childbirth
- Breast cancer
- Colon cancer
- Overactive bladder
- Craniofacial microsomia
- Inflammatory bowel disease
How do we tackle proper measurement? By bringing together stroke measurement experts from across the world

Stephanie Gething, Aneurin Bevan University Health Board, Wales
Charlie Davie, UCLPartners Academic Health Science Network, Royal Free London NHS Foundation Trust, London

Julie Bernhardt, The Florey Institute of Neuroscience and Mental Health, Melbourne

Gerard Ribbers, Erasmus Medical Center; Rijndam rehabilitation center, Rotterdam

Bo Norrvring, Lund University; Swedish Stroke Register (Riksstroke), Lund

Liping Liu, Capital Medical University, Beijing Tiantan Hospital, Beijing

Eric Smith, University of Calgary; AHA GWTG, Calgary
Frank Silver, University of Toronto; Ontario Stroke Registry, Toronto
Patrice Lindsay, Heart and Stroke Foundation of Canada; WSO, ON

Sheila Martins, Hospital Moinhos de Vento; National Stroke Registry; Brazilian Stroke Society, Porto Alegre

Lee Schwamm, MGH/Harvard Medical School; AHA GWTG, Paul Coverdell National Acute Stroke Registry, Stroke Joint Commission, Boston, MA
Joel Salinas, MGH/Harvard Medical School, Boston, MA
Mary George, Centers for Disease Control and Prevention; Paul Coverdell National Acute Stroke Registry, Atlanta, GA
Adam Kelly, University of Rochester Medical Center, NY
Linda Williams, VA HSR&D Stroke QUERI, Indiana University School of Medicine, Indianapolis, IN
Teri Ackerson*, American Heart Association
Louise Morgan, American Heart Association, NJ

*Patient/carer representative
Standard Set is defined through 7 Working Group teleconference calls, each focused on a specific part of the work.
Surveys are used for decision-making regarding variables included in the Standard Set.

Delphi Method: 2/3 majority includes specific variable.
Watch this short video to get a more personal view of the Working Group experience

http://vimeo.com/111976337
Our end-product: a Standard Set, with domains that should be systematically measured, and clear definitions

**Scope**

- Adults only (>18 year)
- Patients who have been hospitalized for an index **ischemic stroke** (IS) or **intracerebral hemorrhage** (ICH)
- Patients with subarachnoid hemorrhage (SAH) are **excluded**
- Inclusion of **transient ischemic attack** (TIA) or patients with IS or ICH who are evaluated but not hospitalized is not required

The Reference Guide contains all the details of the Stroke Standard Set, and can be downloaded from [www.ichom.org](http://www.ichom.org)
The following timeline is proposed to capture the outcome domains for patients with stroke

- Entrance into outcome tracking system for Stroke
  - Baseline characteristics / Risk adjustment variables
  - Clinician reported
  - PROMs (patient reported outcome measures) - **discharge assessment**
  - PROMs (patient reported outcome measures) - **90 days full battery assessment**
  - Survival

* Discharge or 7 days, whichever comes first
** 90 days post admission + 30 days window (90 to 120 days post index event)
## Overview of outcomes and measures in Standard Set

### Category

<table>
<thead>
<tr>
<th>Acute complications</th>
<th>Survival and disease control</th>
<th>Patient reported health status</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td></td>
<td>Cognitive and Psychiatric functioning</td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
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</tbody>
</table>

### Outcomes

<table>
<thead>
<tr>
<th>Outcomes</th>
<th>Discharge</th>
<th>90 days</th>
</tr>
</thead>
<tbody>
<tr>
<td>Symptomatic intracranial hemorrhage</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Overall survival</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Disease recurrence</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Smoking cessation</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Global cognitive function</td>
<td>PROMIS-10</td>
<td></td>
</tr>
<tr>
<td>Mood</td>
<td>PROMIS-10</td>
<td></td>
</tr>
<tr>
<td>Pain and other unpleasant sensations</td>
<td>PROMIS-10</td>
<td></td>
</tr>
<tr>
<td>Fatigue</td>
<td>PROMIS-10</td>
<td></td>
</tr>
<tr>
<td>Ability to return to usual activities</td>
<td>PROMIS-10 &amp; Single question</td>
<td></td>
</tr>
<tr>
<td>Self care and grooming</td>
<td>PROMIS-10 &amp; mRS**</td>
<td></td>
</tr>
<tr>
<td>Feeding</td>
<td>Dressing &amp; Toiletting</td>
<td></td>
</tr>
<tr>
<td>Ability to communicate</td>
<td>Single question</td>
<td></td>
</tr>
<tr>
<td>Social participation</td>
<td>Single question</td>
<td></td>
</tr>
<tr>
<td>Patient reported general health status</td>
<td>PROMIS-10</td>
<td></td>
</tr>
<tr>
<td>Global patient reported health-rel. QOL</td>
<td>PROMIS-10</td>
<td></td>
</tr>
</tbody>
</table>

* Captured with single item questions on mobility, dressing & toileting  
**Simplified mRS questionnaire (smRSq) is included as comparison tool in roll-out phase of Standard Set  
* Also captured as measure for pre-stroke functional status
Next to outcomes, we need to capture patients’ baseline characteristics to reach goal of enabling global comparisons

Information on baseline characteristics is needed to make meaningful comparisons (adjust for case-mix)

- **Baseline characteristics**
  - Capture the initial state of the patient before treatment to allow adjustment for differences in patient populations across providers
  - For example:
    - Demographics
    - Baseline health status
    - Prior treatments
  - We do not consider the following as baseline characteristics:
    - Differences in care delivery models
The full list of risk adjustment variables included in the Stroke Standard Set

<table>
<thead>
<tr>
<th>Risk adjustment variable</th>
<th>Measures</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Demographic factors</strong></td>
<td></td>
</tr>
<tr>
<td>Age</td>
<td>Date of birth</td>
</tr>
<tr>
<td>Sex</td>
<td>Sex at birth</td>
</tr>
<tr>
<td>Ethnicity</td>
<td>Country specific reporting</td>
</tr>
<tr>
<td>Living location</td>
<td>Pre and 90 days post stroke</td>
</tr>
<tr>
<td>Living alone</td>
<td>Pre and 90 days post stroke</td>
</tr>
<tr>
<td>Prestroke functional status</td>
<td>Mobility, Toileting and Dressing</td>
</tr>
<tr>
<td><strong>Stroke type and severity</strong></td>
<td></td>
</tr>
<tr>
<td>Stroke type</td>
<td>IS; ICH; TIA</td>
</tr>
<tr>
<td>Stroke severity</td>
<td>NIHSS &amp; Level of Consciousness</td>
</tr>
<tr>
<td>Duration of symptoms</td>
<td>&lt; 1h; 1h - 1 day; &gt; 1 day; Unable to determine</td>
</tr>
<tr>
<td>Prior Stroke</td>
<td>Y/N</td>
</tr>
<tr>
<td>Prior TIA</td>
<td>Y/N</td>
</tr>
<tr>
<td>Prior MI</td>
<td>Y/N</td>
</tr>
<tr>
<td>Coronary artery disease</td>
<td>Y/N</td>
</tr>
<tr>
<td>Atrial fibrillation</td>
<td>Y/N</td>
</tr>
<tr>
<td>Diabetes mellitus</td>
<td>Y/N</td>
</tr>
<tr>
<td>Hypertension</td>
<td>Y/N</td>
</tr>
<tr>
<td>Hyperlipidemia</td>
<td>Y/N</td>
</tr>
<tr>
<td>Smoking status</td>
<td>Y/N</td>
</tr>
<tr>
<td>Alcohol use (&gt; 1 drink/day)</td>
<td>Y/N</td>
</tr>
<tr>
<td><strong>Vascular and systemic</strong></td>
<td></td>
</tr>
<tr>
<td>Length of hospital stay</td>
<td>Date of admission &amp; discharge</td>
</tr>
<tr>
<td>Diagnostic evidence base</td>
<td>Clinical alone; Clinical + MRI; Clinical + CT</td>
</tr>
<tr>
<td>Rehabilitation</td>
<td>Dedicated rehabilitation during acute or post acute care</td>
</tr>
<tr>
<td>Discharge destination</td>
<td>Discharge following acute care hospitalization</td>
</tr>
<tr>
<td>IV Thrombolytic therapy</td>
<td>Patient received IV Thrombolytic therapy</td>
</tr>
<tr>
<td>Thrombectomy</td>
<td>Patient underwent Thrombectomy</td>
</tr>
<tr>
<td>Hemicraniectomy</td>
<td>Patient underwent Hemicraniectomy</td>
</tr>
<tr>
<td>Comfort care (optional item)</td>
<td>Did care goals shift from treatment &amp; recovery to emphasis on comfort?</td>
</tr>
</tbody>
</table>
Where do we go from here?

- Dedicated to implementation of all Standard Sets
- Supports institutions and registries that are learning about this, ensuring Standard Sets are part of their work
- ICHOM helps by facilitating processes and sharing knowledge, acknowledging that there is no “one-fits-all” standard implementation strategy
- A steering committee will revise and update the Stroke Standard Set annually based on feedback from implementers
- AHA/ASA committed to the Standard Set project and implementation process
- AHA/ASA will drive awareness of the Standard Set through global connections
- Standard Set seen as excellent starting point and resource for incorporating into in-patient stroke registry as well as in physicians practice setting/outpatient arena
- Push is to have registries adopt and adapt wherever they can
  - Ensuring these measures are incorporated in AHA/ASA programs
  - Advocating for inclusion of the Standard Set in the global arena through quality initiatives and projects
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Global demand to measure and compare outcomes is impressive
Institutions around the globe are implementing and measuring ICHOM Standard Sets

Every week new organizations reach out to ICHOM expressing interest in starting to measure health outcomes
In case you want to know more, please visit our website or contact us

The Stroke Standard Set manuscript got accepted in Stroke last week!

Website  http://www.ichom.org

Email  ichomteam@ichom.org
Global Health

Please respond to each item by marking one box per row.

Excellent