International Consortium for Health Outcomes Measurement

Standardisation and the Overall Adult Health Standard Set

3rd March 2017
Agenda

Welcome and introduction       Paul Myres

Introduction to VBHc and the ICHOM initiative       Charlotte Roberts

Welsh context and primary care measures in Wales       Grant Duncan / Paul Myres

ICHOM Standard Sets and Overall Adult Health       Charlotte Roberts

Implementation and benchmarking       Charlotte Roberts

Measuring outcomes at ABUHB       Sally Lewis

Questions and appendix: additional reading       All
Variation in health outcomes is a worldwide problem

2x variation in 30-day mortality rate from heart attack in US hospitals

4x variation in bypass surgery mortality in the UK hospitals

5x Variation of major obstetrical complications among US hospitals

9x variation in complication rates from radical prostatectomies in the Dutch hospitals

18x variation in reoperation rates after hip surgery in German hospitals

20x variation in mortality after colon cancer surgery in Swedish hospitals

36x variation in capsule complications after cataract surgery in Swedish hospitals
How do we define a health outcome?

“Outcomes are the results people care about most when seeking treatment, including functional improvement and the ability to live normal, productive lives.” – ICHOM
We need standardisation so that we can meaningfully and reliably compare the *same* outcomes

Comparing apples with oranges is a lot harder than....

...comparing apples with apples

Measuring different outcomes in different ways makes it impossible to meaningfully compare
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.

---

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 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.

\[
\text{Value} = \frac{\text{Patient health outcomes achieved}}{\text{Cost of delivering those outcomes}}
\]
ICHOM plays several roles along the journey that will enable value-based health care: our strategic agenda

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

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

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

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

Define Standards

Benchmark on outcomes

Establish outcomes transparency

Measure outcomes

Collaborate to improve value

Develop value-based payment models

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

ICHOM will enable cooperation to improve value by establishing value collaboratives

ICHOM will engage payors and governments to realign financial incentives and promote transparency

Core mission of ICHOM

Current focus

Enabler role
ICHOM is gaining the support of the health care community
ICHOM’s Strategic and Sponsoring Partners*

STRATEGIC PARTNERS

PLATINUM

GOLD

SILVER

BRONZE

*As of August 2016

Copyright © 2017 by the International Consortium for Health Outcomes Measurement. All rights reserved.
We have completed 21 Standard Sets, covering 45% of the disease burden as defined by WHO

In 2017, many more will be in development

- Congenital hand and upper limb malformation
- Facial palsy
- Chronic kidney disease
  *Focused on low and middle income countries
- Hypertension*
- Diabetes
- Adult overall health
- Oral health
- Inflammatory arthritis
- Mental health
Global demand to measure and compare outcomes is impressive. Institutions and registries around the world are already measuring or implementing ICHOM Standard Sets.

32 Countries
400 Organizations
13 National Registries
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Primary Care Measures

• Search for PC Measures used in UK or Europe
• 4 stakeholder workshops
• Linked to Standards for Health care in Wales
• >100 reviewed
• 50 feasible
• Top 30 chosen by wider stakeholder group
Primary Care Patient Experience

- 5 Focus groups run by WCVA
- Minimal evidence to support any measures
- Probably best to use questionnaires
- National PROMS & PREMS/ OECD guidance to Ministries of Health
Primary Care Measures
Phase 2

• Is the measure applicable to primary care?
• Would the result be due to activities undertaken by primary care?
• Is it focused on what matters to public and professionals?
• Is it an area with likely high impact on population health?
• Are benefits identifiable?
• Is the measure amenable to change by primary care?
• Can change be monitored meaningfully?
• Is there evidence to support the measure?
Primary Care Measures
Phase 2

- Is the measure precise and understandable?
- Is the measure specific? Statistically fit for purpose, reliable?
- Is the measure practical?
- Does the measure require practitioners to undertake extra work just to collect the data?
- Is the measure timely? Does it reflect the system as it is now or in the future?
<table>
<thead>
<tr>
<th>Title</th>
<th>Circulatory disease mortality rate per 100,000 of the population for those under 75 years of age</th>
</tr>
</thead>
<tbody>
<tr>
<td>Reference number</td>
<td>9</td>
</tr>
<tr>
<td>Measure Definition</td>
<td>The number of premature deaths from: myocardial infarction, ischemic heart disease, stroke.</td>
</tr>
<tr>
<td>A measure of?</td>
<td>Effective Care: Cardiovascular Disease. Reducing health inequalities. Reduced premature mortality from the major causes of death Improved chronic conditions management</td>
</tr>
<tr>
<td>At which level?</td>
<td>Wales / Health board / Cluster level</td>
</tr>
<tr>
<td>Linked to national policy / Frameworks</td>
<td>Cardiovascular Delivery Plan, Stroke Delivery Plan</td>
</tr>
<tr>
<td>Source of the measure</td>
<td>N. NHS Wales outcomes framework PHW Observatory</td>
</tr>
<tr>
<td>Evidence for the measure</td>
<td>Evidence service TBC</td>
</tr>
</tbody>
</table>

**Rationale**

- **Comments**
  The measure reflects the effectiveness of primary care prevention work. Not all attributable to primary care. Much energy is going into prevention in primary care so need to know if this is having an effect.

- **Population Health**
  Premature mortality from cardiovascular disease is experienced disproportionately among deprived populations, although the need for prevention is universal. It’s a leading cause of mortality.

- **Clinical rationale**
  Good preventive care reduces death rate in people under 75.

- **Patient / Public perception**
  The risk factors are widely appreciated, however making changes to reduce them is a challenge.

**Caveats and limitations**
Reducing mortality from heart disease is also the role of public health and secondary care.

**Data source**
ONS

**Delivery time**
- **Report frequency / interval**
  Monthly

**Numerator**
The number of deaths from: myocardial infarction, ischemic heart disease, stroke.

**Denominator**
The population aged under 75

**Cost**
Nil

**Recommendation**
Proceed
4 People with diabetes who have received all key care processes

Measure Definition
- The number of premature deaths from: myocardial infarction, ischemic heart disease, stroke.

Linked to national policy
- Cardiovascular Delivery Plan, Stroke Delivery Plan

Population Health Rationale
- Premature mortality from cardiovascular disease is experienced disproportionately among deprived populations, although the need for prevention is universal. It’s a leading cause of mortality.

Clinical rationale
- Good preventive care reduces death rate in people under 75.

Patient / Public perception
- The risk factors are widely appreciated, however making changes to reduce them is a challenge.

Caveats and limitations
- Reducing mortality from heart disease is also the role of public health and secondary care.

Comments
- The measure reflects the effectiveness of primary care prevention work. Not all attributable to primary care. Much energy is going into prevention in primary care so we need to know if this is having an effect.

Recommendation
- Proceed
11. People reporting they felt involved in any decisions made about their care and support

Measure Definition
• People responding positively to the question “Were you involved as much as you wanted to be in decisions about your care and treatment when you last consulted a primary heath care professional?”

Linked to national policy
• Primary Care Plan

Population Health rationale
• Improved autonomy leads to better population health outcomes

Clinical rationale
• Shared decision making leads to better patient-centred outcomes and less harm.
• Patient experience is important to the concept of clinical excellence (Darzi)

Patient/public perception
• No decision about me without me
• WG prudent public concept (Choosing Wisely Wales)

Caveats/limitations
• Survey methodology / inconsistency
• Requires validation

Comments
• A questionnaire to members of the public is the best way to collect data on patient experience, from the patient perspective. I.e. What is important to patients. This question reflects discussion in five focus groups commissioned by PCQ (Public Health Wales) in November 2015 and January 2016. This question will need refining and validating.

Current Recommendation
• Proceed
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Questions and appendix: additional reading
All
ICHOM organises Working Groups to define Standard Sets of outcomes we recommend all care providers track

ICHOM facilitates a process with international clinical and registry leaders and patient representatives to develop a global Standard Set of outcomes that really matter to patients, along with corresponding case-mix factors.
ICHOM Working Group members originate from 39 countries

Source: ICHOM
ICHOM Working Groups also work with patient organisations and charities from around the world.
A Standard Set is defined through series of teleconference calls, supported by research and patient input.

ICHOM Standard Set Methodology v2.0, currently in use

Working Group Process

- Working Group Launch Scope
- Meeting 1 Outcome domains
- Meeting 2 Outcome definitions
- Meeting 3 Outcome wrap-up
- Meeting 4 Case-mix domains
- Meeting 5 Case-mix definitions
- Meeting 6 StSet and publication wrap-up
- Meeting 7* Review & transition to implementation

Literature input

- Research & propose scope
- Literature review of outcome domains and definitions
- Literature review of risk factor domains and definitions

Patient input

- Patient focus group (FG)
- Validation of outcome domains (distribute survey via patient organisations)

External Input

- Open review period

* Most meetings are telephonic or via video
ICHOM Standard Sets focus on outcomes that matter most to patients

Michael Porter’s Outcome Measures Hierarchy

**Tier 1**
Health status achieved or retained

- **Survival**
- **Degree of health achieved or maintained**

**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 treatment errors)

**Tier 3**
Sustainability of health

- **Sustainability of health/recovery and nature of recurrences**
- **Long-term consequences of therapy**
  (e.g., care-induced illnesses)

Recurrences
Care-induced Illnesses

This short video provides a more personal view of the Working Group experience

http://vimeo.com/11197633
ICHOM Standard Set for Coronary Artery Disease: Outcomes

Treatment approaches covered

- Lifestyle modification
- Drug therapy
- Percutaneous coronary intervention
- Coronary bypass grafting
- Other forms of therapy

© 2017 ICHOM. All rights reserved. When using this set of outcomes, or quoting therefrom, in any way, we solely require that you always make a reference to ICHOM as the source so that this organization can continue its work to define more standard outcome sets.
ICHOM Standard Sets are freely available to promote global adoption

Flyer

- Two-page overview of ICHOM Standard Set and Working Group
- Flyers are available at www.ichom.org

Reference Guide

- Full detail of Standard Set for institutions interested in collecting
- Includes measure definitions, coding instructions, and sample questionnaires
- Reference Guides available at www.ichom.org

Academic Publication

- Peer-reviewed publication
- Explains process to arrive at Standard Set and motivation for selected measures
- Click here for example
The burden of chronic disease is exacerbated by concomitant psychiatric disease and social need

The burden of chronic disease is growing world wide

Chronic conditions represent 47% of global disease burden in 2002 and 60% by 2020

• Heart disease, stroke, depression, cancer are most significant concerns
• In middle and low-income countries 28 million people a year die of chronic, non-communicable disease

Treatment of chronic disease is often complicated by complex medical and social needs

• Having a mental health disorder is a risk factor for developing a chronic condition and vice versa. When mental and medical conditions co-occur, the combination is associated with elevated symptom burden, functional impairment, decreased length and quality of life, and increased costs.

• Anxiety disorders and negative life events are associated with persistence of high healthcare utilization in primary care.

• Multi-morbidity burden is greater, occurs at much earlier age, and the profile of health conditions differs, for adults with intellectual disabilities compared with the general population.

Addressing the unique needs of patients with complex medical and social needs will help to decrease the burden of chronic disease.

We propose a Standard Set for patients with complex medical and social needs that will...

- focus care providers on the unique needs of these patients.

- allow for better evaluation of QI efforts and sharing of improvement strategies due to aligned outcome measurement.

- provide standard outcome measures for calculating and comparing the value of care provided for this population of patients.
The rationale for an Overall Adult Health Standard Set

Traditionally, our work has focused on outcomes of care for specific medical conditions.

However, patients often have multiple conditions and providers (hospitals or departments) generally provide care for variety of conditions.

An Overall Adult Health Standard Set would provide a unified set of outcome measures to:
- Help streamline data collection in and across institutions
- Allow for comparisons across conditions, informing the utilization of resources across organizations
- Provide a single ruler for measuring outcomes prior to the development of disease and during the development and active management of disease to inform health policy and clinical management

The following slides describe our proposed scope and work plan for the Overall Adult Health Standard Set, as well as how we intend this work to provide a unified core for our condition-specific work in the future.
The proposed scope and hierarchal design of the Overall Health Standard Set

**PROPOSED SCOPE**

<table>
<thead>
<tr>
<th>Health state</th>
<th>Healthy</th>
<th>Well controlled disease</th>
<th>Poorly controlled disease and multimorbidity</th>
</tr>
</thead>
<tbody>
<tr>
<td>Service line</td>
<td>Disease prevention and health promotion</td>
<td>Disease control</td>
<td>Care coordination</td>
</tr>
<tr>
<td>Health determinants</td>
<td>Mental and behavioral health</td>
<td>Social need</td>
<td></td>
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</tbody>
</table>

**CORE MODULE: GENERAL ASSESSMENT OF KEY HEALTH DOMAINS**
- Disease risk
- Health behaviours
- Patient activation
- HRQoL
  - Physical health (e.g., functioning, pain, fatigue)
  - Mental health (e.g., depression, anxiety, substance use)
  - Social health (social functioning)
- Health state
- Social need

**ADD-ON MODULES FOR MORE IN-DEPTH ASSESSMENT AS NEEDED**
- Condition-specific add-ons based on ICHOM Standard Sets
- Link to computer adaptive tests (CATs) for more precise assessment of HRQoL domains
- Disease management and care coordination
- Social needs assessment

*A hierarchical design* allows for specific follow-up of identified problem areas.
Our draft work plan builds on our standard process but is expanded to cover the broader work package.

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<th>Month 13</th>
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<td><strong>Consultation meetings</strong></td>
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<td><strong>Call 8 Review and transition to implementation</strong></td>
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<td><strong>Call 1 Core outcome domains</strong></td>
<td><strong>Call 7 St Set and publication wrap-up</strong></td>
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<tr>
<td><strong>Call 2 Medically complex and social needs outcome domains</strong></td>
<td><strong>Call 6 Case-mix definitions</strong></td>
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**Literature input**
- Research & propose scope
- Literature review of outcome domains and definitions
- Literature review of case-mix domains and definitions

**Patient input**
- Patient focus group (FG)
- Focus group A
- Focus group B

**External input**
- Consumer validation survey

**Open review period**

**Additional breakouts as needed**

**Breakout 1a** Medically complex outcomes

**Breakout 1b** Social needs outcomes

**Breakout 2a** Med. complex outcome definitions

**Breakout 2b** Social needs outcome definitions
## The proposed scope for the Standard Set

<table>
<thead>
<tr>
<th>Patient population</th>
<th>Example of interventions</th>
<th>Examples of outcomes</th>
</tr>
</thead>
</table>
| Adults with multi-morbidity or complex social needs interfering with the management of their health | **Medical**  
  - Disease management  
  - Coordination of medical services  
  **Functional**  
  - Care/assistance  
  **Psychological**  
  - Treatment of co-morbid psychiatric conditions  
  **Social**  
  - Community engagement  
  - Group intervention  
  **Other**  
  - Self-management  
 | **Hospitalizations and use of acute care**  
 **Disease progression**  
 **Medication adherence**  
 **Complications and sides effects of treatments**  
 **Physical functioning**  
 **Work status**  
 **Management of ADLs**  
 **Frailty**  
 **Psychiatric functioning**  
 **HRQoL**  
 **Independence**  
 **Basic needs (safe living conditions, appropriate nutrition, assistance as necessary)**  
 **Mortality** |
Is a scope including healthy populations, those with well controlled disease and those with poorly controlled disease and multimorbidity applicable to primary care?

We anticipate these outcomes being applicable to the following services lines; disease prevention and health promotion, disease control and care coordination. Does this align with the needs of primary care outcome measurement?

What do you think the barriers or challenges to implementing patient centered outcomes in primary care may be?
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We are using our experience to document and distribute key success examples

**National effort in the Netherlands**
- To standardize and make transparent outcomes across >20 conditions

**State-wide effort in US State of Michigan**
- To support quality registries with demonstrated significant cost savings

**Institutional effort to integrate outcomes collection**
- For spine surgery patients

**Health board’s approach to value-based health care**
- And the role of outcomes measurement starting with Parkinson’s Disease
We are currently piloting a Global Outcomes Benchmarking program (GLOBE)

Objectives of Global Comparisons project

- Pool health outcomes data from 10-15 leading provider organizations – 2 conditions for pilot
- Risk-adjust raw data and organize comparisons on key indicators
  - Particular focus on patient-reported outcomes
- Provide individual – and confidential – reporting to participating organizations
- Identify the “best-in-class” and publish about their performance

Sample output – Hip and Knee

- Case mix complexity (risk-adjusted)
  - Case-mix average Complexity = 1.0
- Acute complications
  - Mortality
  - Readmissions
- Patient-reported health status
  - Knee pain
  - Knee functioning
  - Work status
  - Time to recovery
  - Health-related QoL
  - Overall satisfaction
- Disease progression
  - Need for surgery
  - Reoperation or revision

Other organizations  Your organizations  World average (for participants)
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Measuring outcomes – what’s the use?

Dr Sally Lewis
Measuring Outcomes

• Why?

• What?

• How?

• So what?

"A physician is obligated to consider more than a diseased organ, more even than the whole man - he must view the man in his world."

Harvey Cushing
What is an outcome?

‘An outcome is a milestone, endpoint or consequence *which matters to a person*’
Why should we measure?

Voltaire (1694-1778)

‘Doctors pour drugs of which they know little, to cure diseases of which they know less, into patients of whom they know nothing’
Why does this matter?

...The top prescription is for your arthritis, but it may cause a heart attack. The second prescription should prevent a heart attack, but it could damage your liver. The third should prevent liver trouble, but it may destroy your spleen. The fourth protects the spleen but has been known to eat away the prostate. The fifth....
Co-production through equal partnership

• Shared goal setting and decision making

• Moving away from a ‘fixing’ role to a ‘facilitating’ role

• Helping patients to navigate the evidence base

• Time consuming – how do we enhance and support primary care to do this?

• Co-designing services
Measurement – WHY and WHAT?

- Improvements in care through innovation and reduction in unwarranted variation
- Benchmark leads to improvement in outcomes
- Provide assurance about patient safety
- Enhances the consultation, supporting shared decision making
- Informs resource allocation & service design across a WHOLE system
- Important in a cost cutting environment
- When triangulated with Patient Level Costing/TDABC

If we do NOT measure COST and OUTCOMES across the WHOLE CYCLE OF CARE we will not be able to assess the VALUE of what we are doing

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HOW will we measure outcomes at ABUHB?

• Preparation phase

• Total engagement with clinical team
• Scoping and scaling
• Process mapping
• Whole system
• IT functionality
IT functionality – what did we learn?

• Integration and single login
• Avoiding duplication
• Point of capture - near or remote
• Real time, integrated data
• Querying and reporting
• Synchronicity with existing organisational processes
Data – of what use?

- Shared decision making
- Are we effective?
- Needs assessment
- Evaluation and evidence for innovation
- Comparing and improving
Organising for value – rebalancing the system

**Existing structure**
- Divisional structure across system
- Budgetary silos
- Planning system but whole system read across
- Relative value of innovations not assessed
- High value interventions often invisible

**Modified for value**
- Maintain Divisions?
- Notional programme spend
- Unified programme plans across Divisions
- New business case process
- Spotlight on upstream intervention
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Appendix: additional viewing and reading on value-based health care and ICHOM

Video Documentary

Harvard Business Review
- Porter, M. Lee, T. The strategy that will fix health care. Accessible here.
- Porter, M. Kaplan, B. How to solve the health care cost crisis. Accessible here.
- Stowell, C. Akerman, C. Better value in health care requires focusing on outcomes. Accessible here.
- Lippa, J. Pinnock, C. Aisenbrey, J. What health care leaders need to do to improve value for patients. Accessible here.

New England Journal of Medicine