Going further on cancer outcomes: implementing the ICHOM Standard data sets in Lung and Prostate cancers

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Hon. Professor of Respiratory Medicine, University of Leicester
Clinical Lead for Early Diagnosis, NCRAS, Public Health England
A brief history of Cancer data in England

- 1960’s - 2008 Cancer Registries (a caricature!):
  - Cancer Incidence, 5yr Survival and Mortality
  - At least 2 years after the event
  - Minimal treatment data
  - Very little case-mix adjustment (e.g. poor staging data)

- 2004 - 5 → National Cancer Audits
  - Lung Cancer
  - Colo-rectal cancer
  - Head & Neck Cancers
  - Upper GI cancers

- 2008 → National Cancer Intelligence Network
  - New datasets

- 2013 → Integrated National Cancer Registration Service

- 2016 → Cancer Registration & NCIN merge:
  National Cancer Registration & Analysis Service (NCRAS)
Current data flows into English Cancer Registry

Only one patient outcome: Overall survival!
Trends in surgical resection numbers for lung cancer (UK)

Source: D West, Society of Cardiothoracic Surgeons
Trends in one- & five- year net survival & surgical resections

Sources: S Walters et al. Br J Cancer: 2015;113(5):848-60 (updated) & D West, Society of Cardiothoracic Surgeons
Lung cancer resection rate: trend by age over time

Source: Riaz et al; Thorax, 2012;67(9):811-4
Variation in key patient-reported outcomes after surgery for early prostate cancer

- **5 year survival**: Germany 94.0%, Sweden 94.0%, Martini Klinik 95.0%
- **1 year incontinence**: Germany 43.3%, Sweden 50.0%, Martini Klinik 6.5%
- **1 year severe erectile dysfunction**: Germany 75.5%, Sweden 80.0%, Martini Klinik 34.7%

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 is a nonprofit dedicated to accelerating development, standardization and impact of outcomes measurement worldwide

ICHOM's three founders with the desire to unlock the potential of Value-Based Health Care...

...launched ICHOM in 2012 as a not-for-profit
+ Independent 501(c)3 organization
+ Idealistic and ambitious goals
+ Global focus
+ Engages diverse stakeholders

Their mission:

To define a global standard set of outcome measures that really matter to patients for the most relevant medical conditions...and drive adoption of these measures worldwide to unlock the potential of value-based health care
Support for their work is growing rapidly
ICHOM has completed 21 Standard Sets thus far, covering >45% of the disease burden

Our current 21 Standard Sets

1. Chronic kidney disease
2. Inflammatory arthritis
3. Oral health
4. Congenital hand and upper limb malformations
5. Paediatric facial palsy
6. Hypertension*
7. Type II diabetes
8. Atrial fibrillation

2016-2017 commitments

1. Overall adult health
2. Mental health package
3. Type I diabetes
4. Overall child health
5. Overall cancer
6. Pediatric epilepsy
7. Multiple sclerosis
8. COPD
9. Morbid obesity

*Focused on low and middle income countries

In discussions to launch

1. Overall adult health
2. Mental health package
3. Type I diabetes
4. Overall child health
5. Overall cancer
6. Pediatric epilepsy
7. Multiple sclerosis
8. COPD
9. Morbid obesity

Numbers not representing prioritization/likelihood
ICHOM Cancer standard sets
Who is implementing?

32 Countries
600+ Organizations
13 National Registries
The Lung Cancer Working Group

Matthew Baker*
David Baldwin, Nottingham University Hospitals
Diana Borthwick, Edinburgh Cancer Research Centre
Jesme Fox, Roy Castle Lung Cancer Foundation
Tom Haswell*
Mick Peake, University Hospitals Leicester (Chair)

Franz Schramel, St. Antonius Hospital
Suresh Senan, VU Medical Centre Amsterdam
Michel Wouters, Netherlands Cancer Institute

Jan van Meerbeeck, Antwerp University Hospital

Janet Abrahm, Dana-Farber Cancer Center
David Carbone, Ohio State University Comprehensive Cancer Center
Aileen Chen, Dana-Farber Cancer Center
Marianna Koczywas, City of Hope National Medical Center
Benjamin Kozower, University of Virginia Health System
Kimberley Mak, Dana-Farber Cancer Center
Reza Mehran, MD Anderson Cancer Center

Clarissa Baldatto, Clínicas Oncológicas Integradas

Rob Stirling, Monash University

*Patient representatives
ICHOM Standard Set for Lung Cancer: Outcomes

Treatment approaches covered

- Surgery
- Radiotherapy
- Chemotherapy
- Targeted therapy
- Immunotherapy
- Other

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## ICHOM Standard Set for Lung Cancer:

<table>
<thead>
<tr>
<th>Risk Factor/Initial Condition</th>
<th>Measure Details</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Demographic Factors</strong></td>
<td></td>
</tr>
<tr>
<td>Date of birth</td>
<td>N/A</td>
</tr>
<tr>
<td>Sex</td>
<td>Sex at birth</td>
</tr>
<tr>
<td>Ethnicity</td>
<td>Determined by country</td>
</tr>
<tr>
<td>Educational level</td>
<td>Level of schooling completed</td>
</tr>
<tr>
<td><strong>Baseline Clinical Factors</strong></td>
<td></td>
</tr>
<tr>
<td>Weight loss</td>
<td>Unintentional weight loss</td>
</tr>
<tr>
<td>Comorbidities</td>
<td>Modified Self-administered Comorbidity Questionnaire (SCQ)</td>
</tr>
<tr>
<td>Patient-reported health status</td>
<td>Tracked via EORTC QLQ-C30 and EORTC QLQ-LC13</td>
</tr>
<tr>
<td>Smoking status</td>
<td>Smoking status at diagnosis</td>
</tr>
<tr>
<td>Performance status</td>
<td>ECOG / WHO scale for performance status</td>
</tr>
<tr>
<td>Pulmonary function</td>
<td>Absolute and predicted FEV-1</td>
</tr>
<tr>
<td><strong>Baseline Tumor Factors</strong></td>
<td></td>
</tr>
<tr>
<td>Basis of diagnosis</td>
<td>Diagnosis by clinical, histological or cytological assessment</td>
</tr>
<tr>
<td>Histology</td>
<td>Lung cancer histology</td>
</tr>
<tr>
<td>ALK translocation</td>
<td>Presence of ALK translocation</td>
</tr>
<tr>
<td>EGFR mutation</td>
<td>Presence of activating EGFR mutation</td>
</tr>
<tr>
<td>Clinical stage</td>
<td>Clinical stage per UICC / IASLC / AJCC 7th edition</td>
</tr>
<tr>
<td>Pathological stage</td>
<td>Pathological stage per UICC / IASLC / AJCC 7th edition</td>
</tr>
<tr>
<td><strong>Treatment Factors</strong></td>
<td></td>
</tr>
<tr>
<td>Treatment intent</td>
<td>Curative or palliative treatment intent</td>
</tr>
<tr>
<td>Completed treatment</td>
<td>Completed treatment with or without dose reduction</td>
</tr>
</tbody>
</table>
ICHOM Standard Set for Lung Cancer: Patient-reported outcomes & Quality of Life measures on follow-up

<table>
<thead>
<tr>
<th>Patient population</th>
<th>Measure</th>
<th>Supporting information</th>
<th>Timing</th>
<th>Data source</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Waiting times</strong></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>All patients</td>
<td>Time from diagnosis to treatment</td>
<td>Date of pathology; treatment start date</td>
<td>At start of treatment</td>
<td>Cancer Waiting Times</td>
</tr>
<tr>
<td><strong>Acute complications of treatment</strong></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Patients undergoing surgical resection</td>
<td>Major surgical complications</td>
<td>Presence or absence of a grade 3 Clavien-Dindo complication within 6 months of surgery</td>
<td>Updates at least annually</td>
<td>Clinical / patient</td>
</tr>
<tr>
<td>Patients undergoing radiotherapy</td>
<td>Major radiation complications</td>
<td>Presence or absence of a named grade 3 or 4 Adverse Event whilst on therapy or within 6 months of treatment</td>
<td>Updates at least annually</td>
<td></td>
</tr>
<tr>
<td>Patients-undergoing systemic therapy</td>
<td>Major systemic therapy complications</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td><strong>Quality of life</strong></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>All patients</td>
<td>EORTC QLQC-30 questionnaire</td>
<td>General Health QoL</td>
<td>Baseline, 3, 6 and 12 months post-treatment then annually for life</td>
<td>Patient completed</td>
</tr>
<tr>
<td></td>
<td>EORTC LC13 questionnaire</td>
<td>Lung cancer – specific QoL</td>
<td></td>
<td></td>
</tr>
</tbody>
</table>
Timing of data collection

Example 1: Patient diagnosed with advanced disease*, receives treatment post diagnosis

- Diagnosed with metastatic disease at time of diagnosis
- Diagnosed with LPC, progresses to metastatic disease
- Diagnosed with LPC, progresses to biochemical recurrence and is not eligible for treatment post-worship 6 months

Timing of data collection post-treatment

Example 2: Patient diagnosed with advanced disease*, receives treatment and event happens first year post-treatment

- Initiation of chemotherapy
- Progression of disease

The following questionnaires should be administered at the indicated time points

- Baseline Patient-Reported Form (link)
- Follow-Up Patient-Reported Form (link)
- Baseline Clinical Form (link)
- Follow-Up Clinical Form (link)
- Tracked Ongoing Annually for Life
ICHOM Standard Set for Localized Prostate Cancer: Outcomes

Treatment approaches covered

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

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<tr>
<td><strong>Patient Factors</strong></td>
<td></td>
</tr>
<tr>
<td>Age</td>
<td>Date of birth</td>
</tr>
<tr>
<td>Comorbidities</td>
<td>Modified Self-administered Comorbidity Questionnaire (SCQ)</td>
</tr>
<tr>
<td>Urinary incontinence</td>
<td></td>
</tr>
<tr>
<td>Urinary frequency / urgency / irritation</td>
<td>Tracked via EPIC-26</td>
</tr>
<tr>
<td>Bowel irritation</td>
<td></td>
</tr>
<tr>
<td>Hormonal symptoms</td>
<td></td>
</tr>
<tr>
<td>Sexual dysfunction</td>
<td>Tracked via EPIC-26 + additional questions from the Utilization of Sexual Medications/Devices questionnaire and the EORTC QLQ-PR25</td>
</tr>
<tr>
<td><strong>Baseline Tumor Factors</strong></td>
<td></td>
</tr>
<tr>
<td>Date of diagnosis</td>
<td>Date of initial diagnosis</td>
</tr>
<tr>
<td>PSA level</td>
<td>Most recent PSA value before histologic diagnosis</td>
</tr>
<tr>
<td>AJCC 7th Clinical Stage</td>
<td>cT category, cN category, and cM category</td>
</tr>
<tr>
<td>Number of biopsy cores involved</td>
<td>Number of cores take; number of cores positive</td>
</tr>
<tr>
<td>Greatest percentage involvement</td>
<td>Greatest percentage involvement from biopsy results</td>
</tr>
<tr>
<td>Gleason score</td>
<td>The highest primary and secondary Gleason grade</td>
</tr>
<tr>
<td><strong>Pathological Information</strong></td>
<td></td>
</tr>
<tr>
<td>AJCC 7th Pathologic Stage</td>
<td>pT category, pN category</td>
</tr>
<tr>
<td>Margin status</td>
<td>Negative/Positive (if positive, focal/multifocal)</td>
</tr>
<tr>
<td>Gleason score</td>
<td>The highest primary and secondary Gleason grade</td>
</tr>
</tbody>
</table>
Some challenges of collecting ICHOM datasets

- Additional clinician time (including obtaining consent)
- Development of tools for patient-derived data – range from paper + ‘clerical’ data entry, through clinic-based and/or web-based electronic tools
- Information governance issues around linkage to other routine data
- Level of data completeness – missing data makes interpretation more difficult
Some purposes of collecting ICHOM datasets...

• to collect outcomes other than overall survival that matter to patients, providers and purchasers
• to evaluate in more detail the clinical benefits of treatments and treatment pathways – ‘real world’ outcome data
• to develop an understanding of the ‘value’ of treatment interventions and health care systems – assisting choice both for commissioners and patients
• using an international standard set allows for international comparisons
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- by using an international standard set, to allow for international comparisons

“Take me to a specialist”
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• to evaluate in more detail the clinical benefits of treatments and treatment pathways – ‘real world’ outcome data

• to develop an understanding of the ‘value’ of treatment interventions and health care systems – assisting choice both for commissioners and patients

• by using an international standard set, to allow for international comparisons
Outcomes as the lever to allow the development of a value-based healthcare system

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

**Improve outcomes**
Starting point is to measure and improve the health results that matter most for a patient's condition

**Reduce costs**
Streamline care delivery to only those services that improve outcomes

**Increase value**
Better outcomes at equal or lower cost leads to higher value
Local implementation plan (with support of ICHOM team)

July – September 2017

- work with patients, clinicians and health economists to derive edited datasets
- carry out a ‘Gap analysis’ – identifying those elements that are not already being collected
- carry out pathway mapping to define who collects what, where and when
- develop IT solutions to enable the collection of patient-derived data

September 2017 – March 2018

- to begin testing the feasibility of data collection: for lung cancer at UCH and Barts; for internal UCH prostate cancer patients
- to discuss with other Vanguard teams the potential for extension to other sites