Epidemiology, outcomes research and quality indicators: using epidemiology to improve quality of clinical care

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We all started in the same school, but life sent us through different pathways
Health authorities, epidemiologists and clinicians seem to be working in floating islands.
Health authorities, epidemiologists and clinicians seem to be working in floating islands.

Give me numbers.

Here, you are.

What the...
Clinicians feel their word isn’t heard...
Authorities feel their message doesn’t get through...
Epidemiologist… publish?
What's epidemiology?

Epidemiology
It is what it is
What’s epidemiology?
Keeping distance (looking from above) is as important as having a close look
There’s something about clinicians...
Clinicians are applying epidemiology all day long!!

They are applying multivariate analyses, probabilities and test utilities!!
...BUT they don’t like epidemiologists!

- Because epidemiologists seem
  - unclear
  - impractical
  - little focused on clinical problems

- Many clinicians believe that epidemiology...
  - is an incomprehensible boredom
  - is useless for daily practice
  - only serves some egomaniacs who work for the WHO, and other agencies alike
But above all, they do not like epidemiologists because they do not understand their language

- Get lost in translation.
- Statisticians / epidemiologists are magicians:
  - Sample size
  - Multivariate analysis
- Treguna mekoides trecorum satis dii makes more sense than “statistical power” or “non-inferiority”

“Could you analyse my database?”
I try to sell epidemiologists to clinicians as any of these...

philosophers
detectives
predictors
cooks
citizens of the world
SERVANTS
The major fields of epidemiology

Registries
Pharmacovigilance

Public health

Indicators
QoC

Clinical epidemiology

Methods

Health outcomes research

PRO

Outcome measures
What is outcome research?

- Health Outcomes Research* refers to the investigation of health care practices.
  - Health services
  - Patients’ experiences, preferences, and values into account

- HOR provides scientific evidence to base decisions made by all who participate in health care.

*Or Outcomes Research
What outcomes are studied in HOR?

Patient outcomes
- Experienced by the patient
- Close relationship with the healthcare intervention

System outcomes
- More distant to the patient experience
- Important to assess quality of care

Costs

Mortality Rates
Readmission rates
Risk-adjusted disease/clinical event rates
PRO

Waiting times
Access
Equity...
Epidemiologists need a backward regression to understand variables clinicians use

Outcome = the end
- Joint replacement

Variable = the domain
- Erosion / Radiological progression

Measurement = the instrument
- SvdH erosion score
Outcomes and measures are a point in common between clinicians and epidemiologists

International Dermatology Outcome Measures is a non-profit organization seeking to develop and validate measures throughout dermatology with an initial focus on psoriatic disease. Launched in 2013, IDEOM seeks to bring together physicians, researchers, government agencies, pharmaceutical companies, payers and patients from around the globe.
"The true finish line is when the patient gets to the right doctor and the right treatment and their disease has minimal to no impact on their quality of life."

Alice Gottlieb, MD, PhD

There are more than 50 proposed outcome measures for patients with psoriasis.
Core Outcomes Set Initiative (CSG-COUSIN)

"Our mission is to develop and implement core outcome sets in dermatology to improve & standardize outcome measurement in clinical trials to make trial evidence more useful."

www.uniklinikum-dresden.de/COUSIN

What is CSG-COUSIN?

CSG-COUSIN is a research group that is open for everyone with an interest in outcomes research and evidence-based dermatology and with enthusiasm to develop and implement Core Outcome Sets (COS) in dermatology.

Contributors

The Cochrane Skin Group - Core Outcome Set Initiative (CSG-COUSIN) is a working group within the international Cochrane Skin Group. CSG-COUSIN was initiated by Prof. Jochen Schmitt and Prof. Hywel Williams in 2014 and supported by the editors of the Cochrane Skin Group.
Figure 1. Clinical outcomes. Health-related quality-of-life (HRQoL) tools, the relationship among clinical disease severity—assessment measures, and therapeutic intervention data. Illustration by Tamar Nijsten.
Figure 2. Conceptual framework representing the effects of skin disease on quality of life. This hypothesis was based on literature review and directed interviews with patients with skin disease and clinicians who care for them. The boxes with double borders indicate constructs addressed by the eight scales of the Skinindex. Adapted from Chren et al. (1996).
The OMERACT* filter for proper outcome measures

**Truth**
- Is the measure truthful?
- Does it measure what it intends to measure?
- Is the result unbiased and relevant?
- This criterion captures the issues of face, content, construct and criterion validity.

**Discrimination**
- Does the measure discriminate between situations that are of interest?
- The situations can be states at one time (for example, disease vs. no disease), or states at two different times (to measure change).
- This criterion captures the issues of reliability and sensitivity to change.

**Feasibility**
- can the measure be applied easily, given constraints of time, money, and interpretability?
- This criterion addresses the pragmatic reality of the use of the measure, one that may be decisive in determining a measure's success.

*Outcome measures in rheumatology*
The major fields of epidemiology

Public health

- Registries
- Pharmacovigilance

Clinical epidemiology

Health outcomes research

Methods

PRO

Outcome measures

Indicators

QoC
Institute of Medicine (IOM) definition of quality

- The degree to which health services for individuals and populations increase the likelihood of desired health outcomes and are consistent with current professional knowledge.
Knowledge to practice
Ensuring quality: from measure to action

Practice guideline

Standards
Quality indicator
Health indicators

Implementation initiatives
What’s a standard of care

- It’s a minimum all patients should be guaranteed

- “Patients should have access to care regardless of financial means”
- “Patients with PsD should be examined regularly by a dermatologist”
- “Patients with SLE + nephritis should be assessed by a nephrologist”

All patients irrespective of disease

Patients with a specific disease

Patients with a disease + specific outcome
What are they created for?

- To provide clear, strict but flexible statements on what should be done
  - All parties (doctor, manager, patient) must understand
  - The indispensable should be clearly stated (nothing beyond this point, in ALL patients...)
  - The rationale, limits, and different ways to reach it should be explained

- To help measuring quality
  - SOC are the base to quality indicators
  - SOC → Checklist
How are standards of care developed?

1. Systematic review of recommendations
2. Analysis of variability
3. Analysis of feasibility
4. Prioritisation
5. Drafting – editing
6. Issued

- Only the indispensable (minimum)
- Rephrasing of recommendations (flexible – strict – clear)
What is an indicator?

- Indicators are succinct measures that aim to describe as much about a system as possible in as few points as possible
- Anatomy

![Diagram showing the anatomy of an indicator with metadata and data components.](image)
<table>
<thead>
<tr>
<th>Types of indicators</th>
<th></th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Health indicators</strong></td>
<td><strong>Quality of care</strong></td>
</tr>
<tr>
<td>• Socioeconomic</td>
<td>• Structure</td>
</tr>
<tr>
<td>• Socioeconomic</td>
<td>• Access + Resource availability</td>
</tr>
<tr>
<td>• Demographic</td>
<td>• Process</td>
</tr>
<tr>
<td>• Health status</td>
<td>• Productivity</td>
</tr>
<tr>
<td>• Mortality</td>
<td>• Performance</td>
</tr>
<tr>
<td>• Morbidity</td>
<td>• Utilization</td>
</tr>
<tr>
<td>• Disability</td>
<td>• Quality</td>
</tr>
<tr>
<td>• Behavioural</td>
<td>• Outcome</td>
</tr>
<tr>
<td></td>
<td>• Effectiveness + Cost-effectiveness</td>
</tr>
</tbody>
</table>
Figure 1. Skin condition years lost due to disability (YLD) composition by region, 2010. (a) Proportion of total YLD, (b) YLD rate per 100,000. NMSC, non-melanoma skin cancer.
What are indicators for?

- **Understanding / improvement**
  - to know how a system works and how it might be improved (research role)

- **Measuring performance**
  - monitoring if a system is performing to an agreed standard and how (performance/managerial/improvement role)

- **For accountability**

Model of improvement

- What are we trying to accomplish?
- How will we know if a change is an improvement?
- What changes can we make that will result in improvement?
## Two health indicators from eumusc.net

<table>
<thead>
<tr>
<th>Indicator name</th>
<th>Permanent work loss due to MSC</th>
<th>No. knee arthroplasties</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Rationale</strong></td>
<td>To evaluate the socio-economic burden of MSC for the society. Needed for planning and health care policy</td>
<td>Volume of surgeries = (prevalence and severity) + availability of appropriate medical resources</td>
</tr>
<tr>
<td><strong>Definition</strong></td>
<td>% persons receiving disability pension who receive pension due to MSC (M00-99) in the past year</td>
<td>Knee replacement procedures performed in hospital as day cases or in-patient surgery per 100,000 population</td>
</tr>
<tr>
<td><strong>Data source</strong></td>
<td>National statistics/registers</td>
<td>OECD Health Database 2009</td>
</tr>
<tr>
<td><strong>Method of measurement</strong></td>
<td>% persons receiving disability pension who receive pension due to MSC (ICD-10 codes M00-99 + S12,S22,S32,S42,S52, S62, S72, S82, S92) in the past year</td>
<td>No. knee replacement procedures performed in hospital as day cases or in-patient surgery per 100,000 population</td>
</tr>
<tr>
<td><strong>Unit of measure</strong></td>
<td>No. persons receiving disability pension who receive pension due to MSC (M00-99) in the past year; Total No. persons receiving disability pension in the past year.</td>
<td>Knee replacement procedures performed in hospital as day cases or in-patient surgery per 100,000 population</td>
</tr>
<tr>
<td><strong>Periodicity</strong></td>
<td>Annual</td>
<td>Annual</td>
</tr>
</tbody>
</table>
## Two quality indicators for SLE monitoring

<table>
<thead>
<tr>
<th>QI1 Description</th>
<th>QI7 Description</th>
</tr>
</thead>
<tbody>
<tr>
<td>% of total SLE patients registered in a unit (service, department, clinic) in whom a validated activity index is used at each visit</td>
<td>% of patients treated with corticosteroids and undergoing eye assessment for the presence of cataracts/glaucoma</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Who measures it?</th>
<th>Yearly or at specific cross-sectional audits</th>
</tr>
</thead>
<tbody>
<tr>
<td>Treating physician, rheumatology staff, hospital management/External Auditor</td>
<td></td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Data source</th>
</tr>
</thead>
<tbody>
<tr>
<td>Clinical Record</td>
</tr>
</tbody>
</table>

How do we generate a QI?

Think-tank / consensus

Decide on domain

Scope

Propose specific figures that can be measured

Assess validity and agreement
How do we assess the validity of an indicator?

Importance and Relevance
• Is it justified?

Validity
• Does it actually measure what it claims is measuring?

Feasibility
• Is it possible to populate the indicator with meaningful data?

Meaningfulness
• What’s the indicator telling us and how precisely?

Implications
• What are we going to do about it?
Are we ready for assessing quality of provider?

Provider Quality Ratings

Our enhanced online provider quality ratings help you make informed decisions about your provider options.

AmeriHealth makes this information available to members through agreements with:

- The Pennsylvania Health Care Quality Alliance (PHCQA) — a coalition of Pennsylvania health care providers and insurers that offers you an easy way to review a variety of health care quality measures on all of the general acute care hospitals in Pennsylvania.

To find a provider, use our convenient online Find a Doctor tool.
Important messages about indicators

- While the indicator needs to be as appropriate as possible, the data need to be as reliable as possible.
- How we select our indicators and the data will often involve making a trade-off between what is convenient (and possible) to collect and the ideal.
- Information systems are key.
The major fields of epidemiology

- Public health
- Clinical epidemiology
- Health outcomes research
- Methods
- Outcome measures
- Registries
- Pharmacovigilance
- PRO
- Indicators
- QoC
Additional uses and techniques of epidemiology key for clinicians

- Classification criteria and definition of disease
  - Prevalence and incidence studies in clinical populations
  - Qualitative research (focus groups and nominal groups)
  - Consensus techniques
  - Validation (Discriminatory capacity and applicability)

- Predictors of outcome
  - Biomarkers
  - Others

- Efficacy and safety

Personalised medicine
Corollary to clinicians: Reasons to put epidemiology in your life

- Helps you accept uncertainty
- You learn to use few data to know what happens
- Teaches you how to put distance between yourself and problems
- Helps you make good questions and decisions
- It helps you to be more efficient:
  - Facing patients
  - Critiquing research
Corollary to epidemiologists:
Know look in your hearts... why don’t you like clinicians?

WHY?
Summary and final remarks

- Epidemiology provides insight on health and disease “from above”, but it has many more uses.
- Outcomes research refers to research which investigates the outcomes of health care practices
  - Patient outcomes → outcome measures
  - System outcomes → indicators
- Both outcome measures and indicators need
  - A generation process
  - A validation process

It is impossible to do them right without understanding
I hope it means the beginning of a long friendship ...