

# **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**



© Jarel 2006

# Health authorities, epidemiologists and clinicians seem to be working in floating islands



Give me  
numbers



Here,  
you are



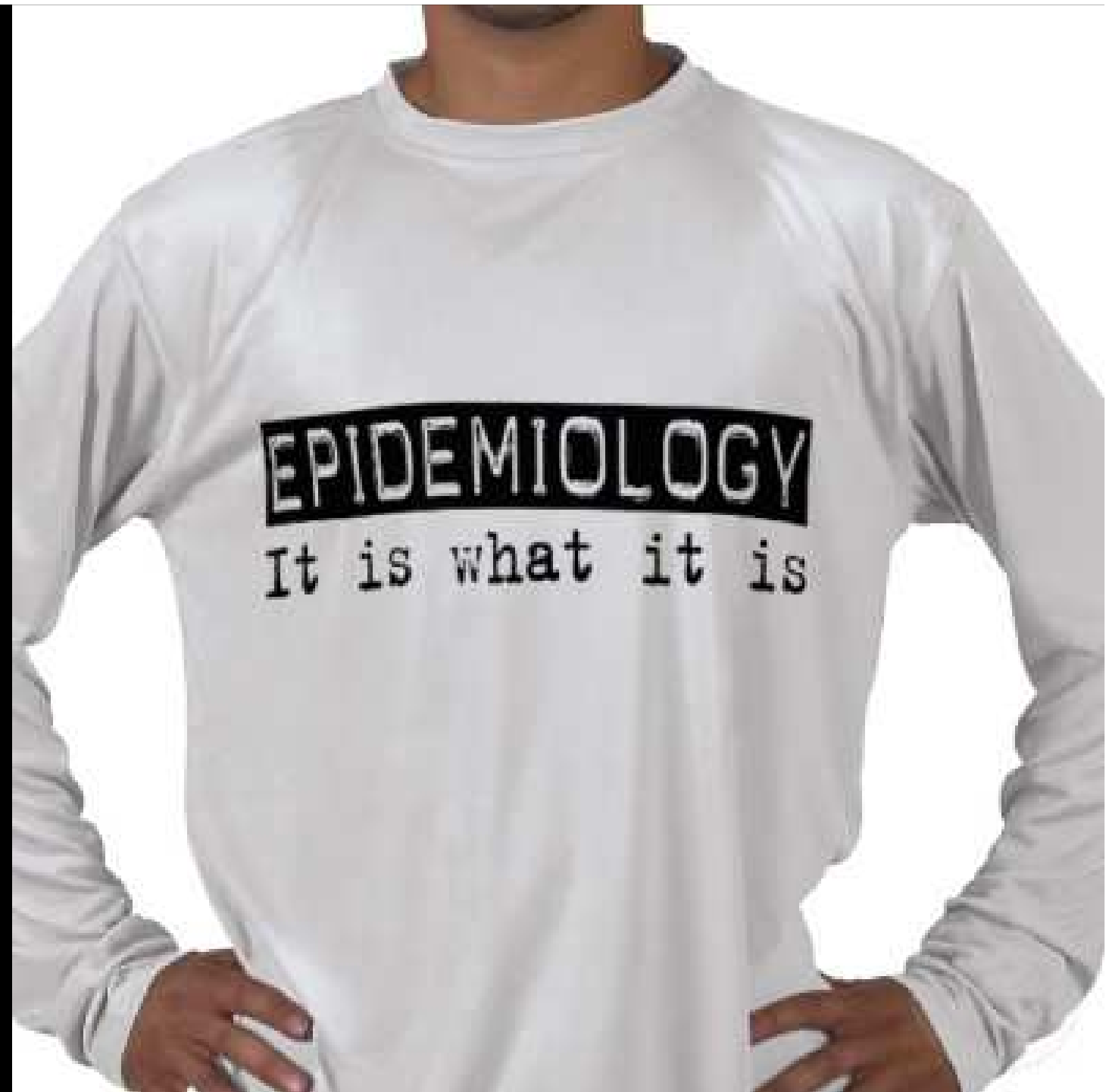
What  
the...



**Clinicians feel their word isn't heard...**  
**Authorities feel their message doesn't get through...**  
**Epidemiologist... publish?**



**What's  
epidemiology?**



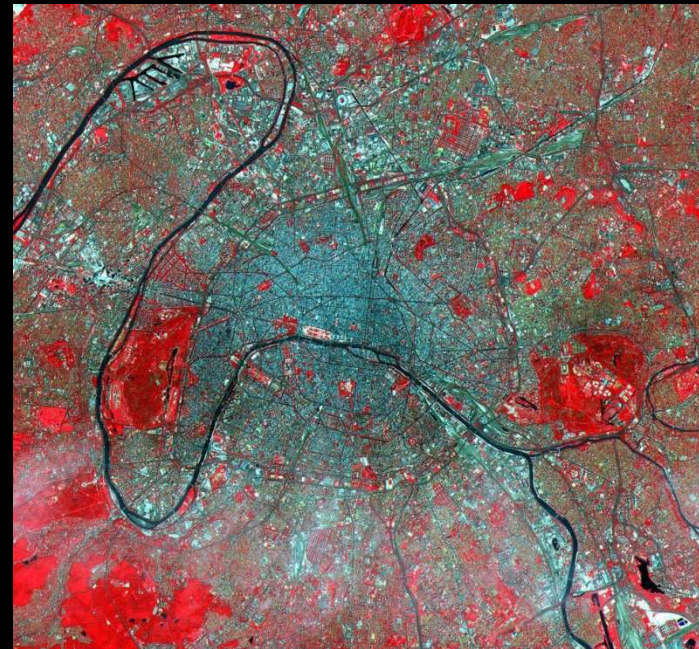
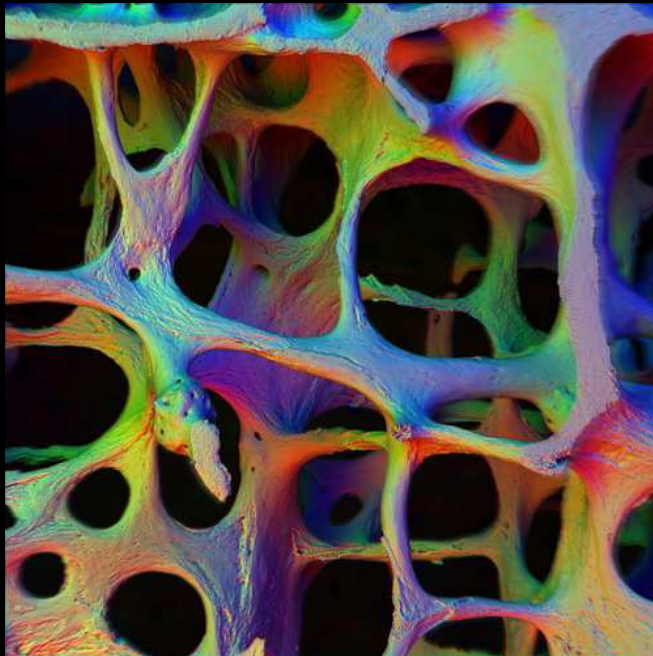


What's epidemiology?



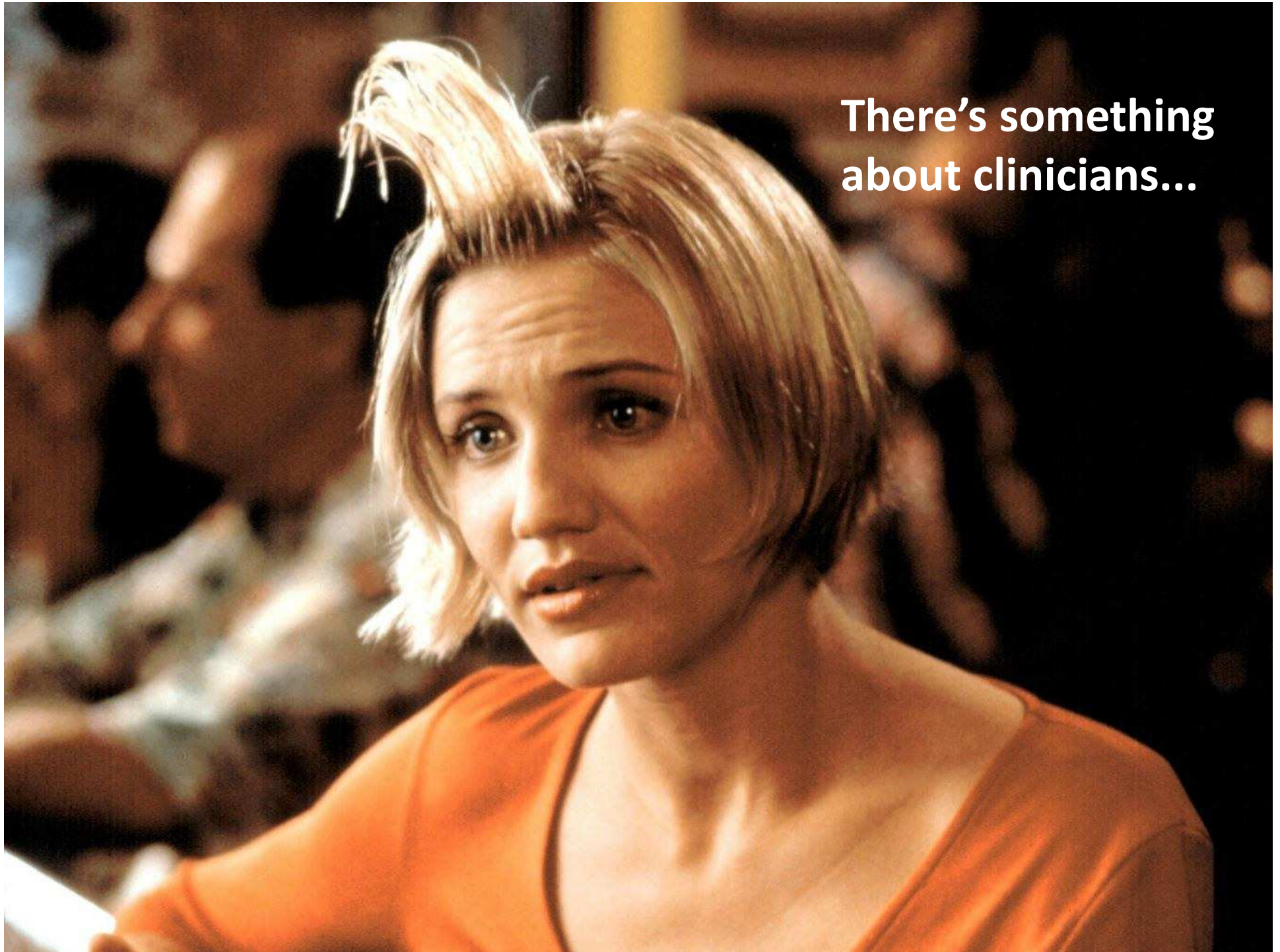


**Keeping distance (looking from above) is as important as having a close look**

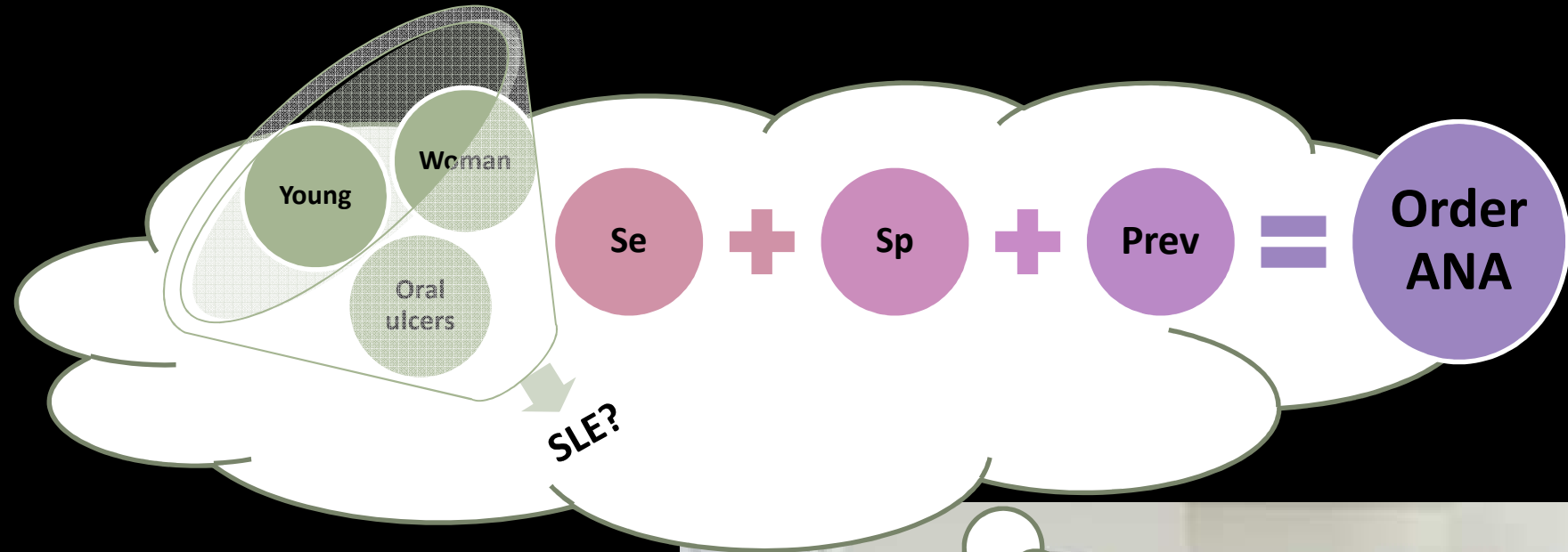




There's something  
about clinicians...



# 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





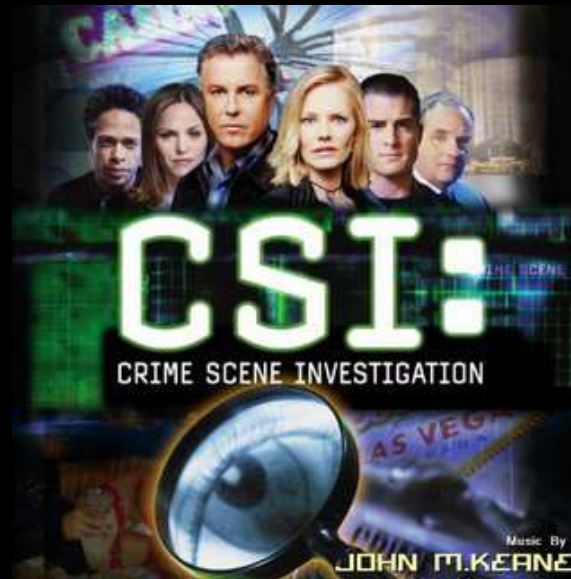
But above all, they do not like epidemiologists because they do not understand their language

- ▶ 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?”*

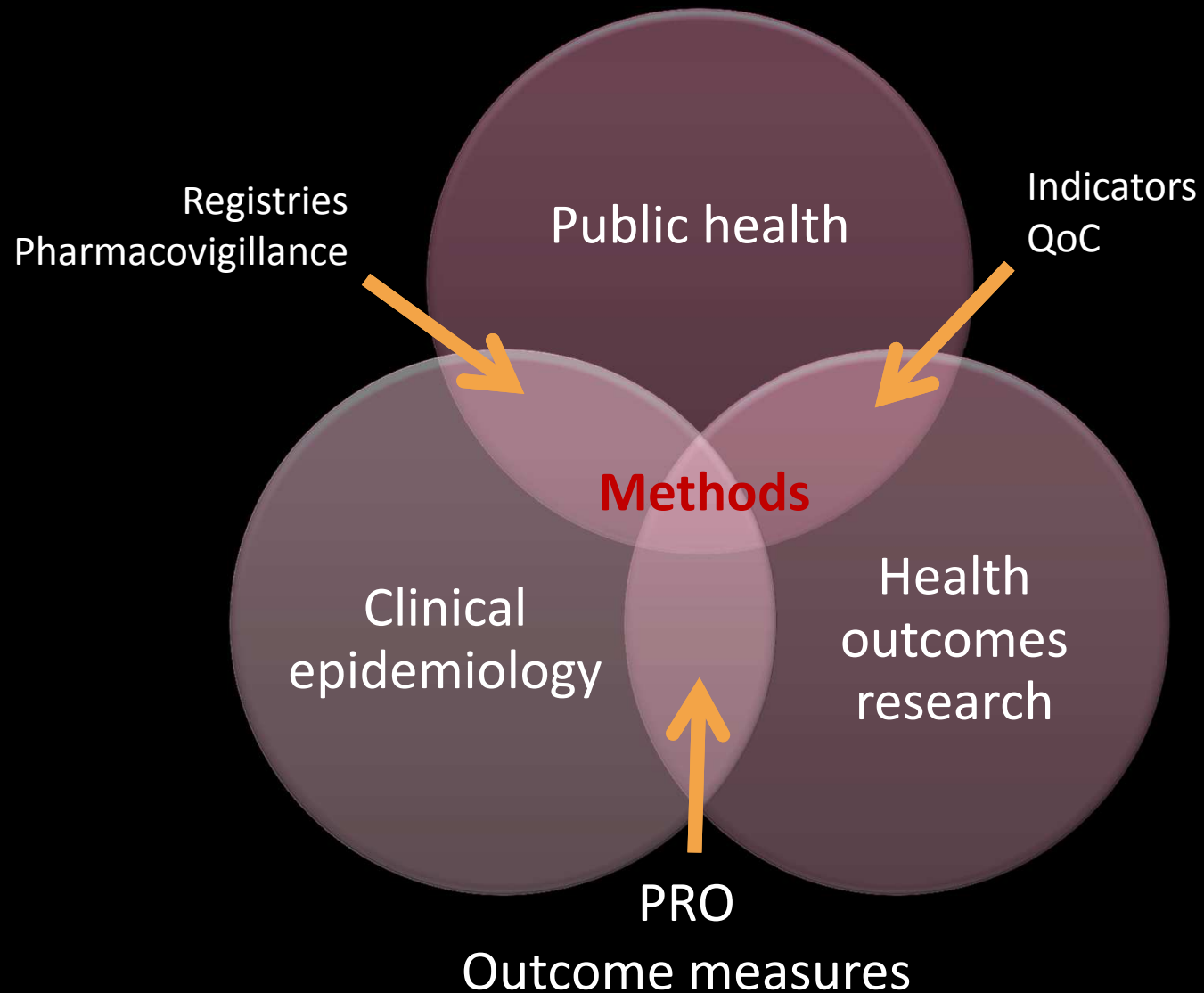
I try to sell epidemiologists to clinicians as any of these...



philosophers  
detectives  
predictors  
cooks  
citizens of the world  
**SERVANTS**



# The major fields of epidemiology



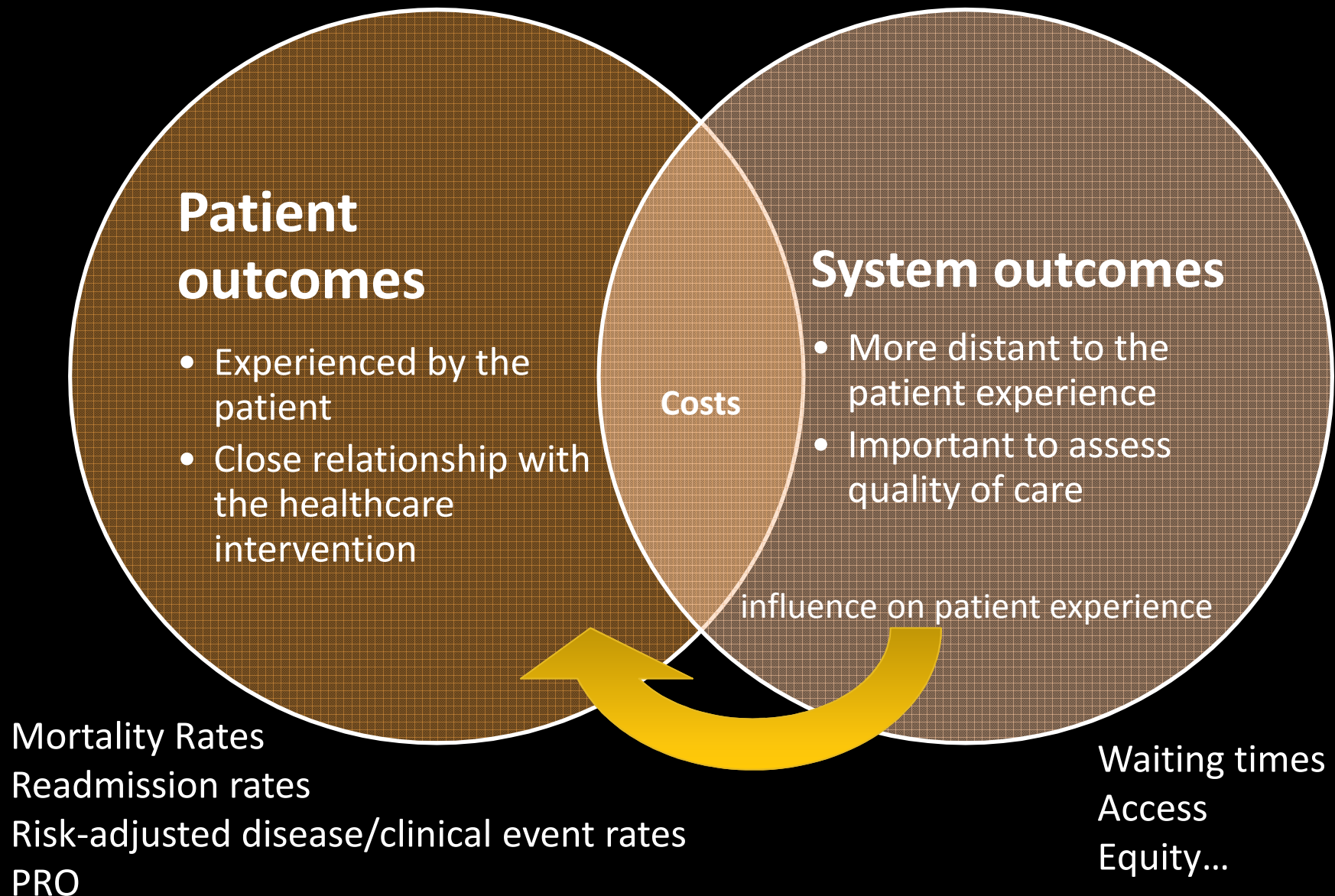


# What is outcome research?

- 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?



# **Epidemiologists need a backward regression to understand variables clinicians use**

**Outcome =  
the end**

- Joint replacement

**Variable = the  
domain**

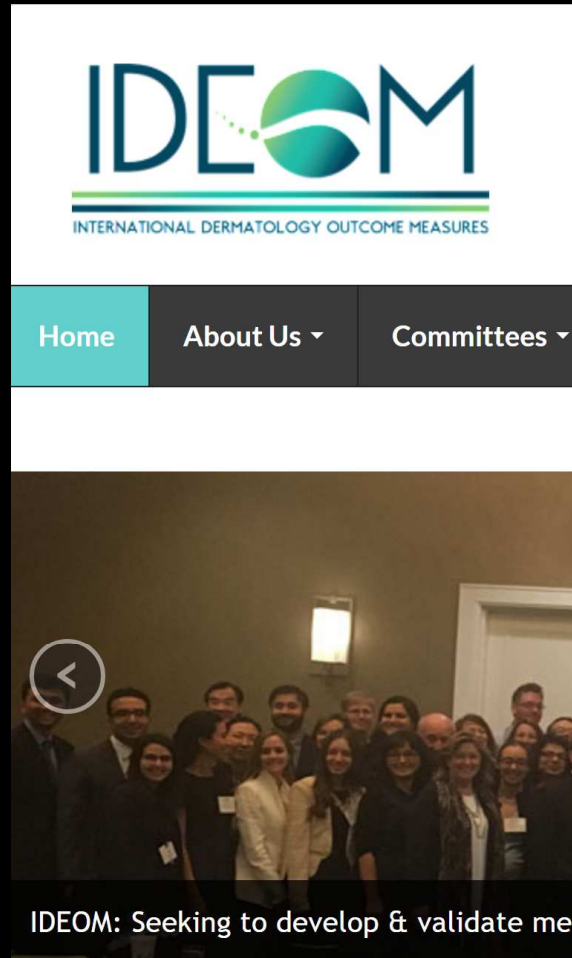
- Erosion / Radiological progression

**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

IDEOM: Seeking to develop & validate measures throughout dermatology. Join Our Efforts!

## Hidradenitis Suppurativa IDEOM's 2nd Working Group

Amit Garg, MD, IDEOM Stakeholder and on the Board of Directors, is spearheading IDEOM's second working group to measure outcomes on Hidradenitis Suppurativa (HS). HS is a chronic inflammatory skin condition that is potentially debilitating and has an impact on several quality of life domains. The inherent unpredictability in HS, both with respect to course of disease and response to treatment, poses significant challenges for patients and physicians alike.

The IDEOM HS Working Group aims to develop a core set of patient-centered outcome measures in Hidradenitis Suppurativa through the alignment of relevant stakeholders with the goals of supporting clinical decision making at the point of care and of identifying which therapies add value in its treatment.

IDEOM is currently seeking grant support and corporate membership support to assist with the HS initiative and will hold its first in person meeting at the IDEOM 2016 meeting in Washington, D.C. this March. Initial stakeholders and leaders of this working group are:

Amit Garg  
Alice Gottlieb  
Robin Christensen  
Linnea Rishøj Thorlacius  
Gabrielle Vinding  
Iben Miller  
Solveig Esmann  
Alexa Kimball  
Gregor Borut Ernst Jemec

For further information, or to get involved, please contact Amanda Pacia by [Email](#) or call (650) 288-5339.

"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

# COUSIN



informed decisions.  
Better health.

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## Core Outcomes Set Initiative (CSG-COUSIN)

- ◆ French Satellite Group
- ◆ [CSG-COUSIN](#)
- ◆ IFDCTN initiative

*"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](http://www.uniklinikum-dresden.de/COUSIN)

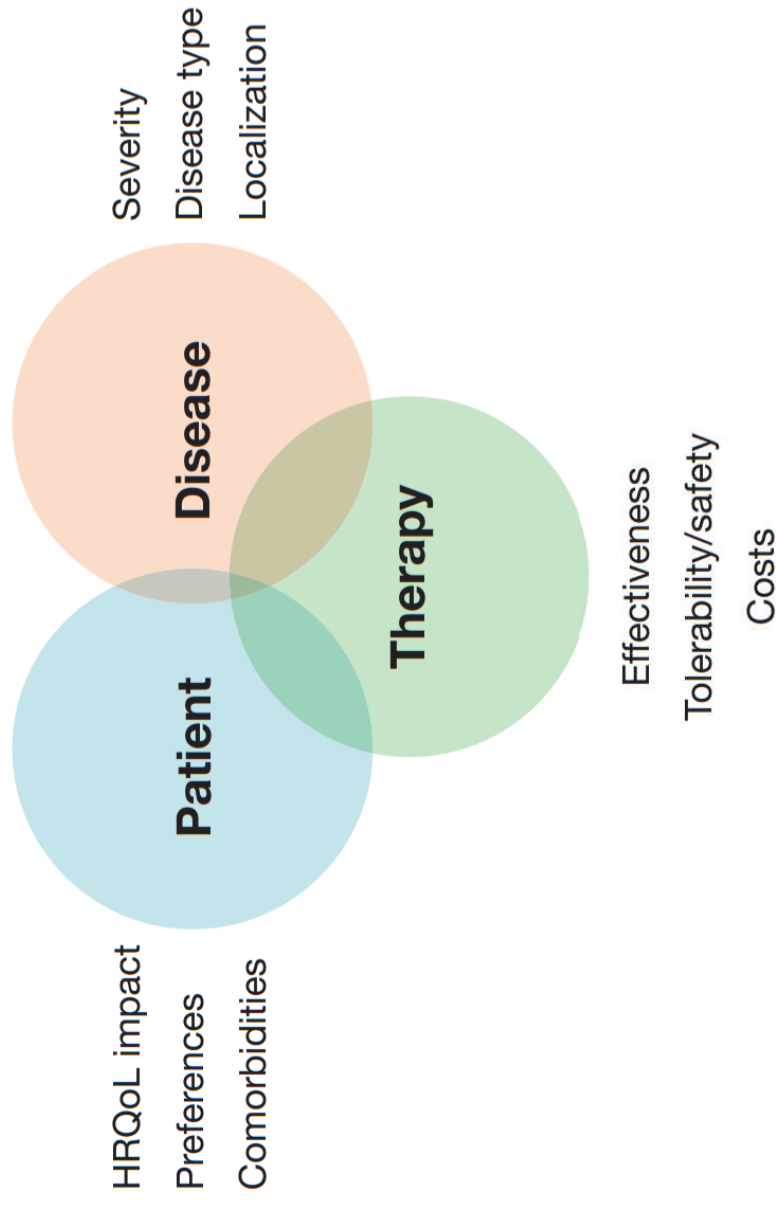
### What is CSG-COUSIN?

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.

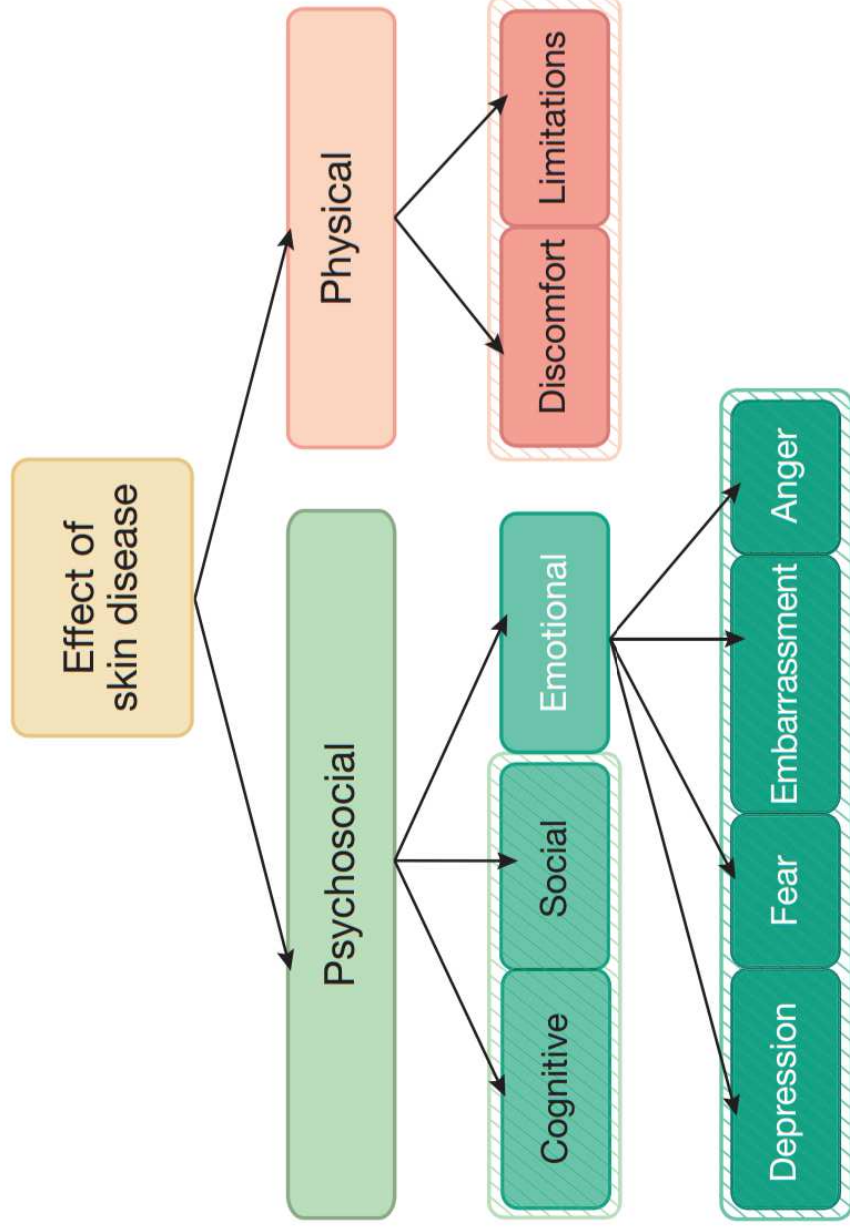
### Contributors

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.



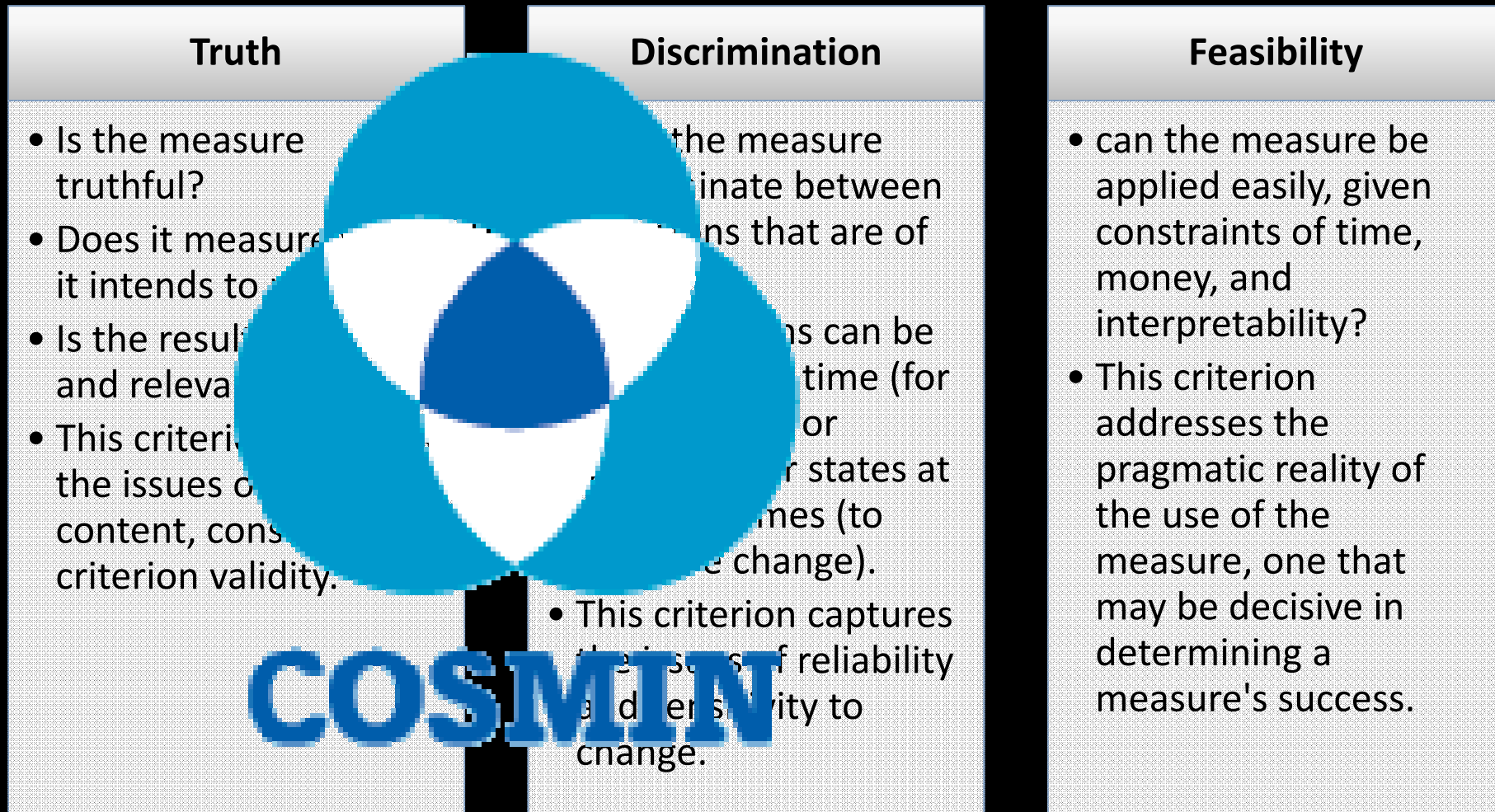


**Figure 1. Clinical outcomes.** Health-related quality-of-life (HRQoL) tools, the relationship among clinical disease severity–assessment measures, and therapeutic intervention data. Illustration by Tamar Nijsten.



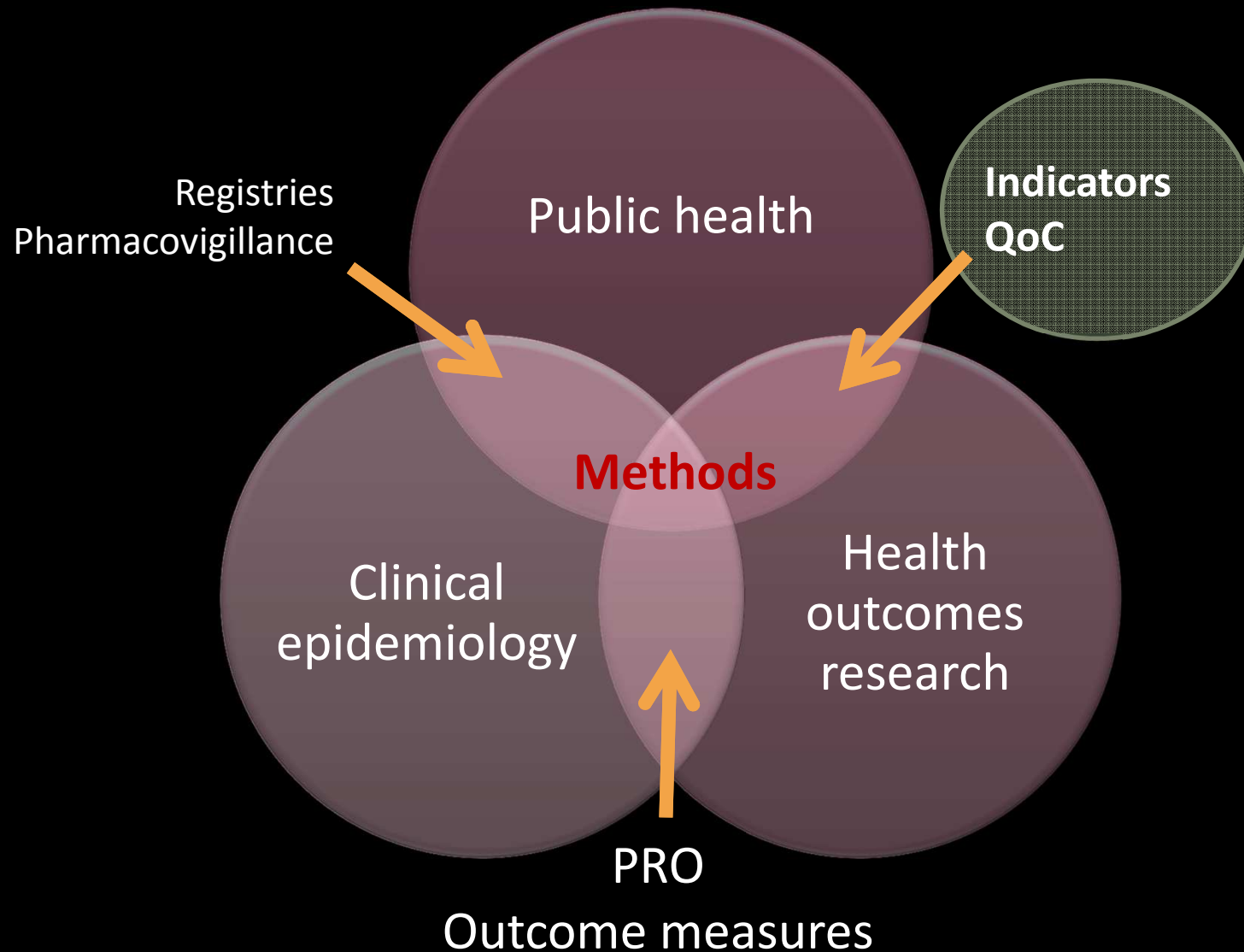
**Figure 2. Conceptual framework representing the effects of skin disease on quality of life.** This hypothesis was based on literature review and directed interviews with patients with skin disease and clinicians who care for them. The boxes with double borders indicate constructs addressed by the eight scales of the Skindex. Adapted from Chren *et al.* (1996).

# The OMERACT\* filter for proper outcome measures



\*Outcome measures in rheumatology

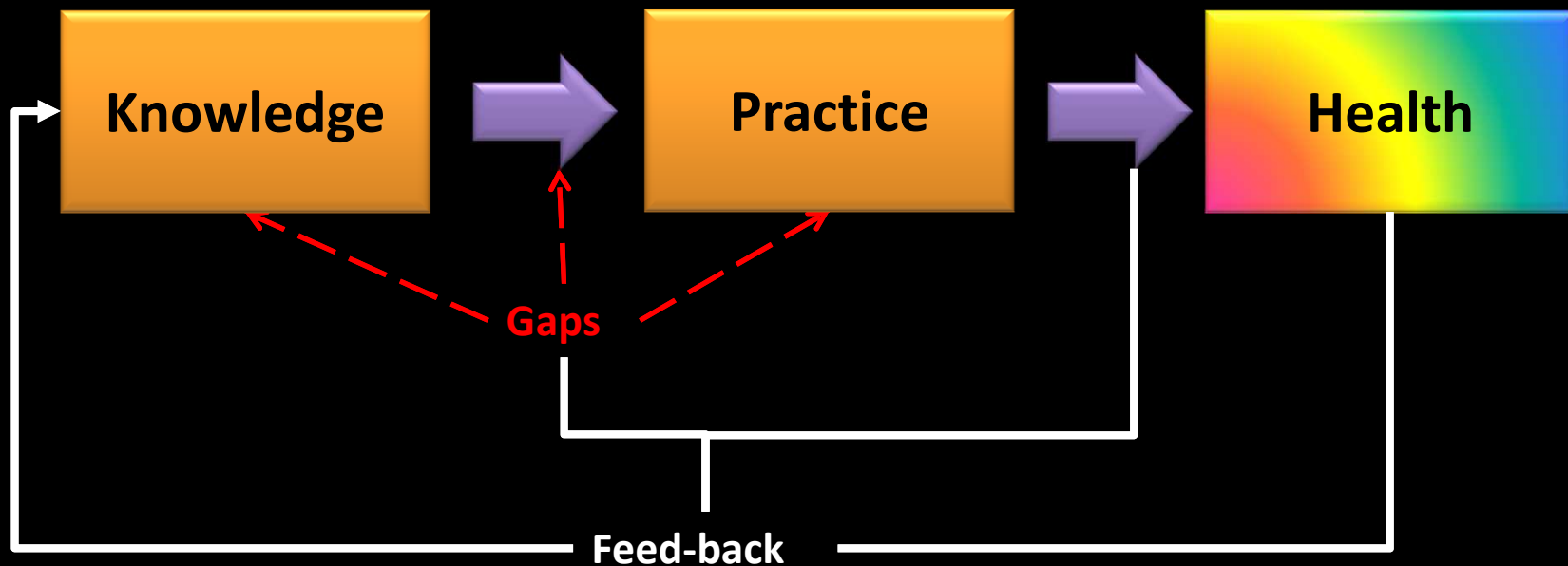
# The major fields of epidemiology





## Institute of Medicine (IOM) definition of quality

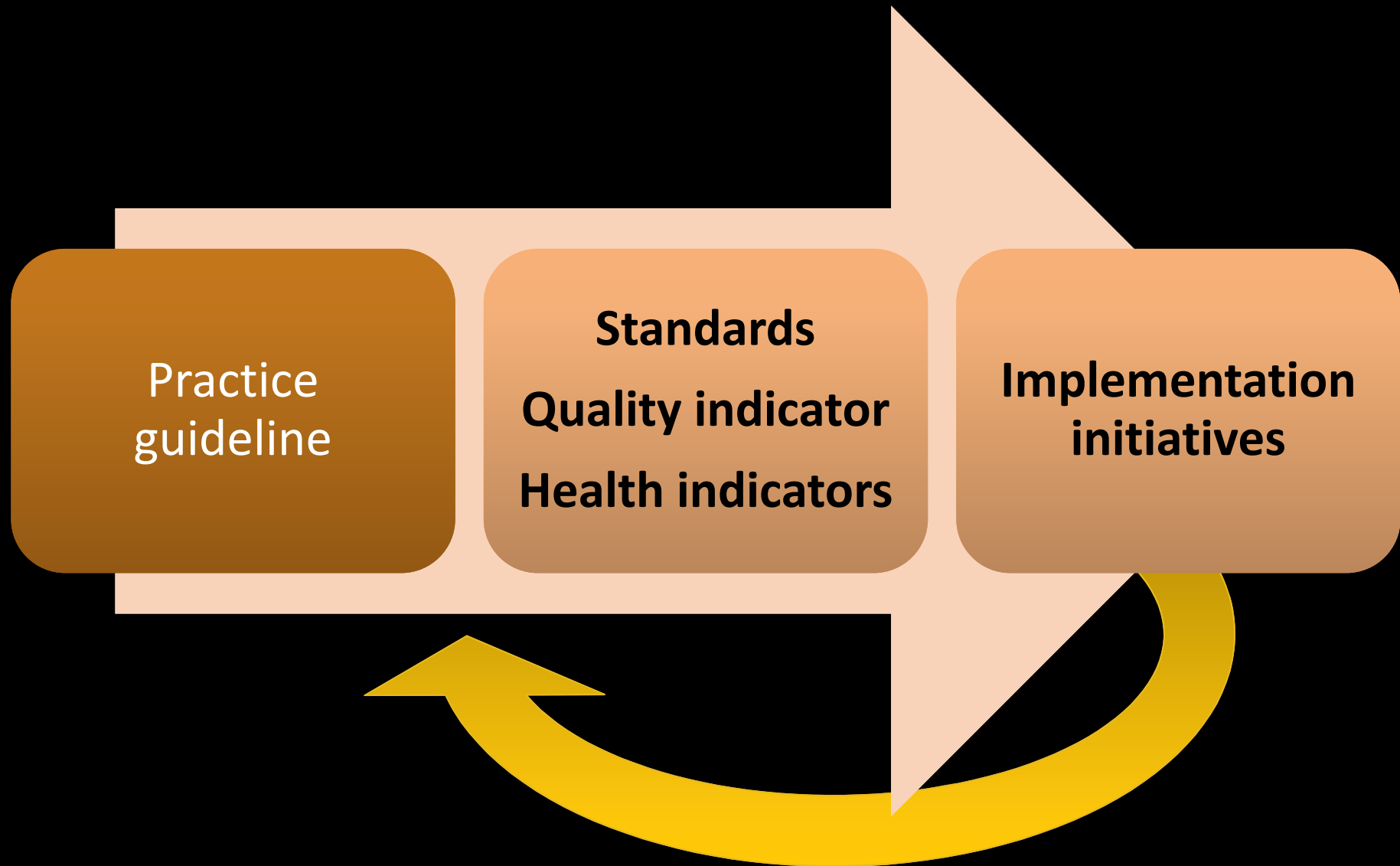
- The degree to which health services for individuals and populations increase the likelihood of desired health outcomes and are consistent with current professional knowledge



# Knowledge to practice

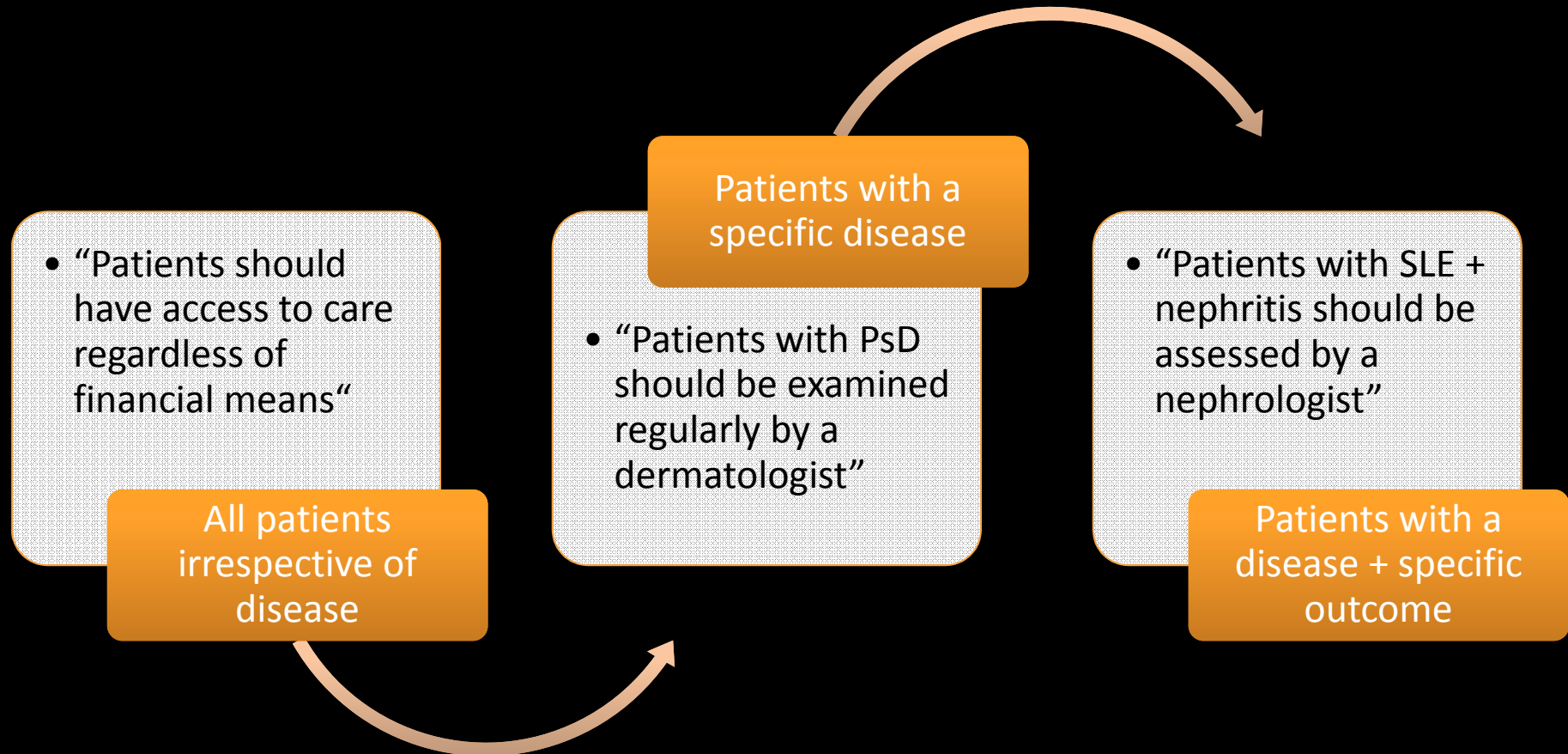


# Ensuring quality: from measure to action



# What's a standard of care

- It's a minimum all patients should be guaranteed



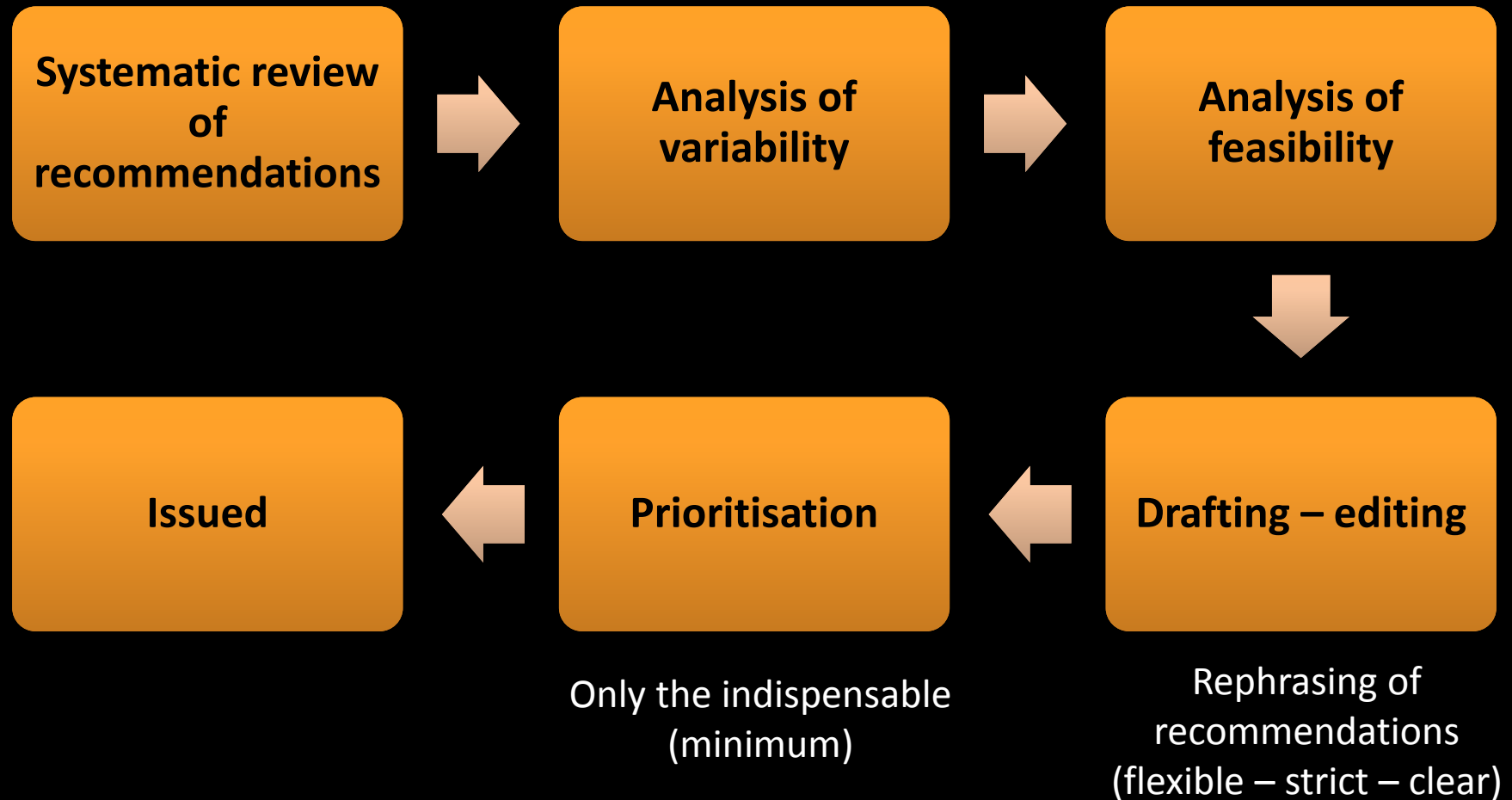


## What are they created for?

- 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

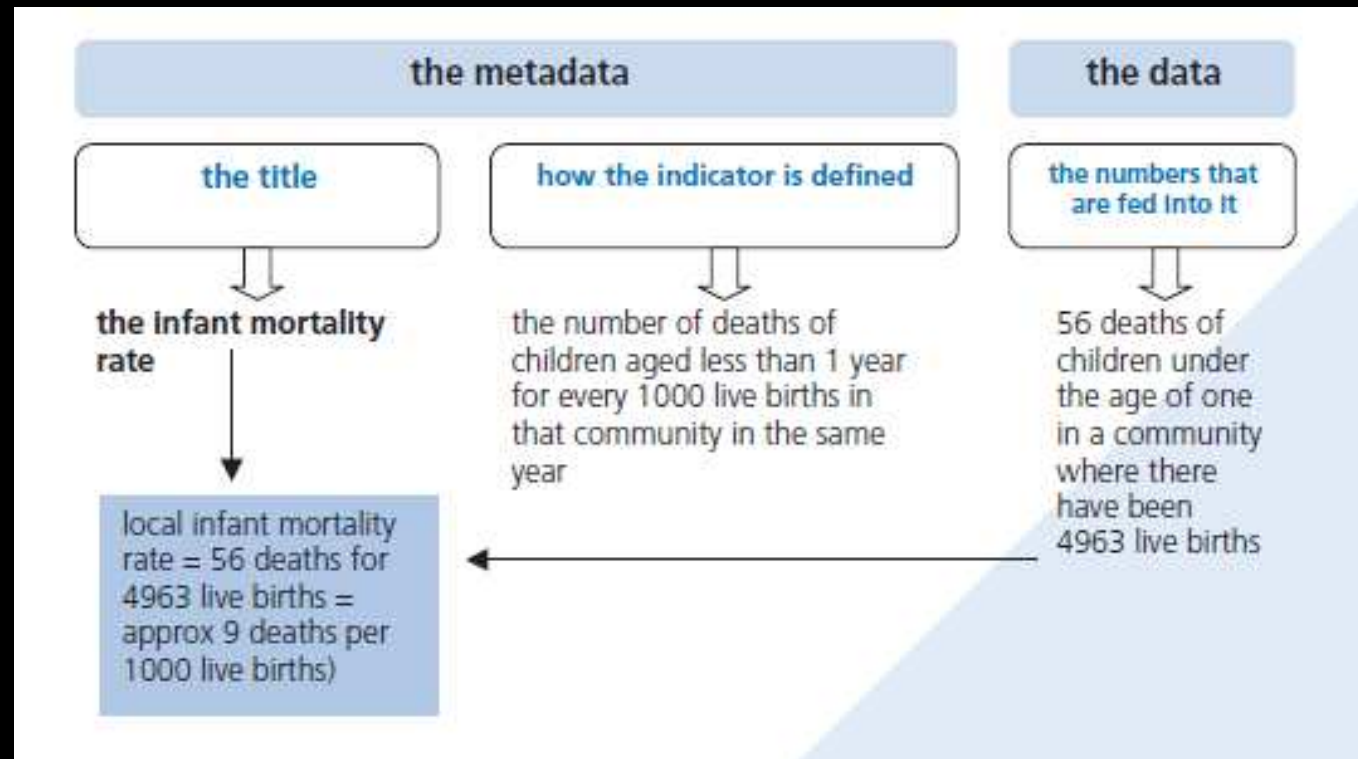


# How are standards of care developed?



# 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



# Types of indicators

## Health indicators

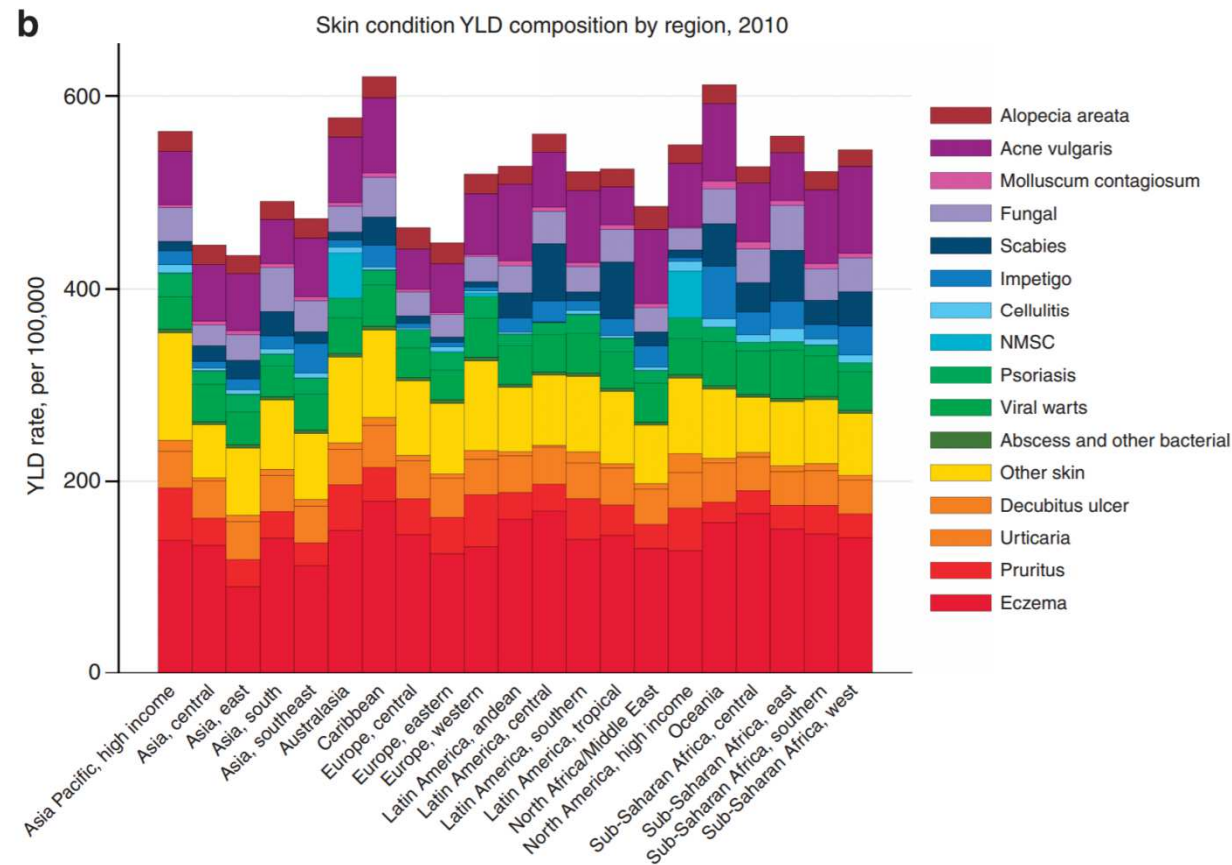
- Socioeconomic
  - Socioeconomic
  - Demographic
- Health status
  - Mortality
  - Morbidity
  - Disability
- Behavioural

## Quality of care

- Structure
  - Access + Resource availability
- Process
  - Productivity
  - Performance
  - Utilization
  - Quality
- Outcome
  - Effectiveness + Cost-effectiveness



# Global burden of disease project



**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?

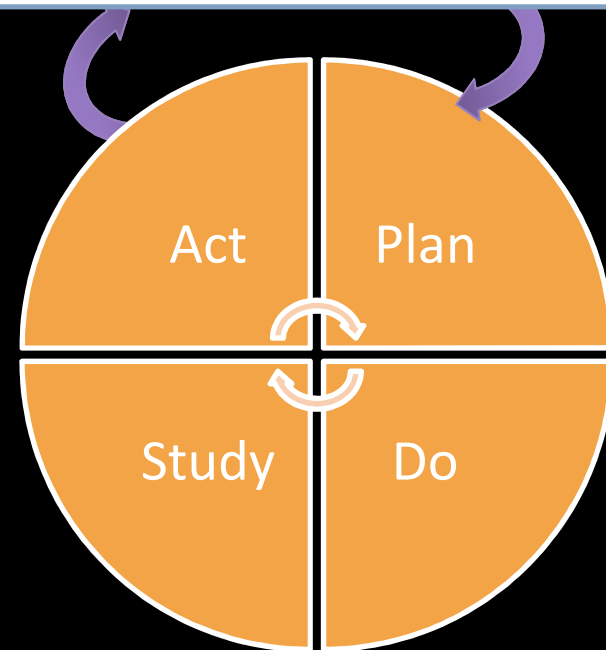
- Understanding / improvement
  - to know how a system works and how it might be improved (research role)
- Measuring performance
  - monitoring if a system is performing to an agreed standard and how (performance/managerial/improvement role)
- For accountability

## 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

Indicator name	Permanent work loss due to MSC	No. knee arthroplasties
<b>Rationale</b>	To evaluate the socio-economic burden of MSC for the society. Needed for planning and health care policy	Volume of surgeries = (prevalence and severity) + availability of appropriate medical resources
<b>Definition</b>	% persons receiving disability pension who receive pension due to MSC (M00-99) in the past year	Knee replacement procedures performed in hospital as day cases or in-patient surgery per 100,000 population
<b>Data source</b>	National statistics/registers	OECD Health Database 2009
<b>Method of measurement</b>	% 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	No. knee replacement procedures performed in hospital as day cases or in-patient surgery per 100,000 population
<b>Unit of measure</b>	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.	Knee replacement procedures performed in hospital as day cases or in-patient surgery per 100,000 population
<b>Periodicity</b>	Annual	Annual

## Two quality indicators for SLE monitoring

	QI1	QI7
QI	IF a patient is diagnosed with SLE THEN the treating physician should assess and record disease activity using a validated index at each visit	If a patient is diagnosed with SLE and treated with CS THEN he/she should undergo an eye assessment for the presence of cataracts and/or glaucoma according with the existing guidelines and this should be documented in the CR
Description	% of total SLE patients registered in a unit (service, department, clinic) in whom a validated activity index is used at each visit	% of patients treated with corticosteroids and undergoing eye assessment for the presence of cataracts/glaucoma
Who measures it?	Treating physician, rheumatology staff, hospital management/External Auditor	
When?	Yearly or at specific cross-sectional audits	
Data source	Clinical Record	Clinical Record, Opticians, Opht.report

M. Mosca, et al. Development of quality indicators to evaluate the monitoring of SLE patients in routine clinical practice, Autoimmunity Reviews, 2011; 10(7):383-8



# 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?



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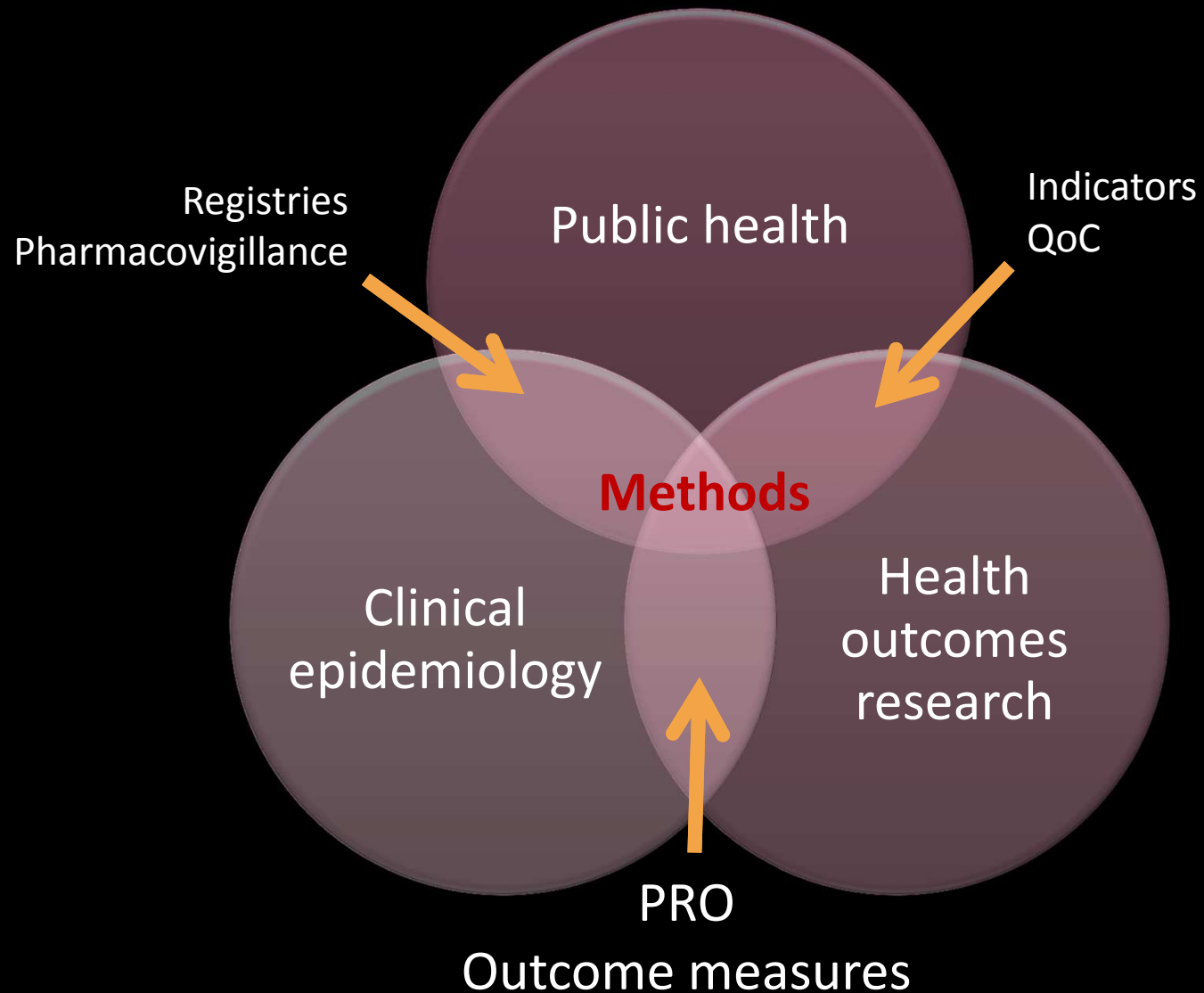
## Important messages about indicators

- 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

Try to reach perfection  
knowing that it's impossible



# The major fields of epidemiology





## 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 ...**