

Health Outcomes / Patient Reported Outcomes

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Conflict of Interest

- None


Bottom line

- I love PROs
- PROs give you a more complete picture of person & disease
- PROs are limited in some circumstances
- Knowing these limitations helps you “choose wisely” and sets research agenda

What is *Value* in health?

- In part: Quality outcomes

What is *Quality*?

- National Academy of Medicine
 - Safe, effective, patient-centered, timely, efficient, equitable
 - Good clinical outcomes
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How measure clinical outcomes

- Disease-specific outcomes
- Patient-reported outcomes

- (I don't think "clinical outcomes" are only disease-specific outcomes)

Disease-specific outcomes

- Examples: Blood test, xray
- Benefit: Objective, “Easy”
 - Interpretation standardized
 - Same for clinical and policy work
- Disadvantages
 - Often not correlated with patient condition
 - Often intermediate (e.g., serum cholesterol or A1c)
 - Therefore often poor window into prognosis

Review

- Up to this point of talk....

VALUE -> OUTCOME -> HEALTH OUTCOMES -> DISEASE-BASED

Assessing Patient-reported Outcomes

- Importance
 - Don't forget symptom
 - Learn new symptom or use
- Types of Assessment
 - Informal
 - Formal

Patient-reported Outcomes

- Informal
 - How are you doing?
 - Are you having any problems?
- Formal – Generic
 - QWB, EuroQol, HUI
- Formal – Disease-specific
 - RAPS, MLHFQ, NYHA

Use of PROs (outside trials)

- Clinical
- Learning healthcare system
- Policy (patient-centredness)

Not “easy”

- “Assess the things we value rather than valuing the things that are the most easily assessed”
- As a rule, if you are interested in policy or scoring a PRO...you can't
 - take a PRO assessment tool off shelf and use indiscriminately
 - sit down and create new PRO by simply writing some questions

Not “easy”

- To learn more....
- Sample references from ISPOR* in *Value in Health*
 - Overall: Rothman et al., 2009;12(8):1075-83
 - Rare diseases: Benjamin et al., 2017;20:238-55

*International Society for Pharmacoeconomics and Outcomes Research

PRO: HUGE Advantages

- Looking at what matters (time horizon caveat)
- Looking at what matters
- Looking at what matters

This lets us work (clinical, policy) with patients that have a disease to improve patient-centered AND disease-centered outcomes (and not looking to improve the disease)

PRO: Significant Disadvantages

- Snapshot of today
 - Therefore often poor window into prognosis
- Development important (Group B strept)
- Fit for purpose?
 - Clinical vs policy

PRO limitation

- A back pain treatment reduces pain but causes occasional slurred speech.
- 2 patients with back pain are treated.
- PRO assessment pre- post-treatment shows both people improved by 45 points (pain improved but speech occasionally slurred).

PRO Limitation

HOWEVER,

- The mail carrier's improved back pain offers her some improvement in quality of life and allows her to return to work. The slurred ***speech is a nuisance*** and she ***continues the treatment***.
- The politician's improved back pain offers her some improvement in quality of life and she is able to return to work. The slurred ***speech is a major problem*** and she ***stops the treatment***.
- Same PRO score; different outcomes

PRO Limitation

- A PRO with generic scoring may be misleading *at the individual level*
- Limits clinical usefulness *if generic scoring*

One Special PRO: Satisfaction

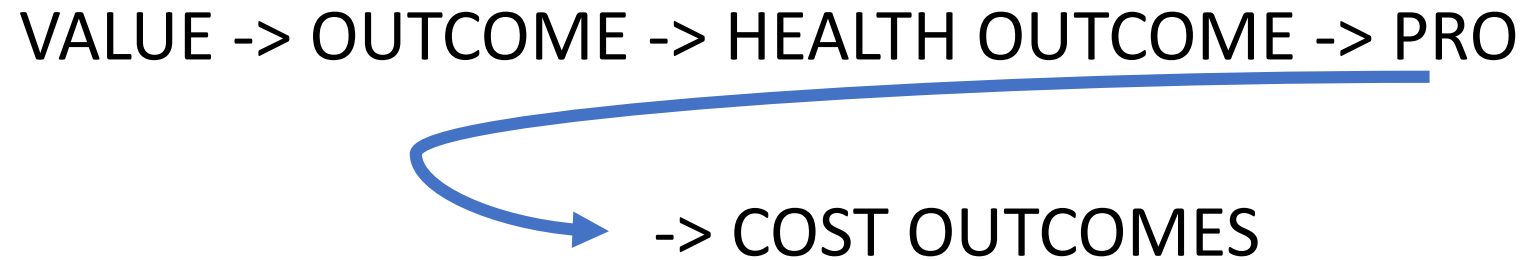
- Satisfaction is a PRO
- It is subjective
- CAVEAT: comparing scores
 - (Why can a 2-star hotel get better reviews than a 4-star hotel?)

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