Which outcomes are important to measure for a given population?

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5. Which outcomes are important to measure for a given population?

- Which categories of PROs should be measured for a given patient?
- How specifically should the PRO target a particular disease?
- What is the role of the EHR in tailoring outcome assessments?

Advantages/disadvantages may change depending on HOW the outcomes are measured.
Which Categories of PROs Should Be Measured for a Given Patient?

Symptoms
Functioning
Social Health/Social Support
General Health Perceptions
Health-Related Quality of Life

Any combination of these is possible!
Which Categories of PROs Should Be Measured for a Given Patient?

Option 1: Symptoms

Subjective physical or mental experience caused by some underlying disease or health condition, or as an adverse effect (sometimes referred to as a side effect) of a health care intervention.
Which Categories of PROs Should Be Measured for a Given Patient?

Option 1: Symptoms

- Informative for individual patient management
- For clinical research, often more sensitive to changes in underlying health
- Can be indirect measures of quality processes
- Assessment of mental/emotional symptoms may reveal important information
Which Categories of PROs Should Be Measured for a Given Patient?

Option 1: Symptoms

For patients with multiple diseases/health conditions, assessment of all relevant symptoms could be burdensome.

May be difficult for the patient to determine whether a symptom is caused by a condition or disease versus therapy or intervention.
Which Categories of PROs Should Be Measured for a Given Patient?

Option 2: Functioning

How well individuals can carry out activities that may be important for their daily living
Which Categories of PROs Should Be Measured for a Given Patient?

Option 2: Functioning

- Can inform individual patient management
- Typically absent from the patient’s clinical record
- Reflects the net effect of multiple underlying health issues
- Important to multiple stakeholders
- Highly relevant for quality assessment/improvement, population health monitoring, and value-based purchasing
- Potentially observable and may be measured and/or corroborated by other sources
Which Categories of PROs Should Be Measured for a Given Patient?

Option 2: Functioning

- Wide range of possible functions requires prioritization to measure
- Often more challenging to demonstrate the effects of interventions on functioning compared to symptoms
- Interpretation may be difficult if one does not know whether the opportunity for performance was present
Option 3: Social Health/Support

Patients’ perceptions of social functioning including participation in relationships, social interactions, and perceptions of social support or isolation.
Option 3: Social Health/Support

- Provides a more complete picture of day-to-day environment
- Can provide data on a broader definition of health
- May identify need for additional resources
- May reveal other factors that impact adherence
Which Categories of PROs Should Be Measured for a Given Patient?

Option 3: Social Health/Support

- May reveal issues the health care team is ill-equipped to handle
- Interpretation may be difficult if one does not know whether the opportunity for social contact was present
Which Categories of PROs Should Be Measured for a Given Patient?

Option 4: General Health Perceptions

Person’s overall evaluation of his/her health, including perceptions of improvements or decrements in health over time
Which Categories of PROs Should Be Measured for a Given Patient?

Option 4: General Health Perceptions

1. Often drive patients’ health decisions (e.g., to seek care, to discontinue use of a drug, etc)
2. Play a role in tailoring clinical interventions
3. May have prognostic value independent of other clinical data
Which Categories of PROs Should Be Measured for a Given Patient?

Option 4: General Health Perceptions

- Less clinically actionable on their own
- In research, may be poor proxies for the patient’s symptoms and functioning
Which Categories of PROs Should Be Measured for a Given Patient?

Option 5: Health-Related Quality of Life

Broad construct of overall effects of health on quality of life
Which Categories of PROs Should Be Measured for a Given Patient?

**Option 5: Health-Related Quality of Life**

- May provide additional information not reflected in the individual domains measured,
- Can compare across or between populations of patients with similar or different conditions
- A single-item global HRQOL score may quickly screen for improvement/decrement
Which Categories of PROs Should Be Measured for a Given Patient?

Option 5: Health-Related Quality of Life

Clinicians may be uncertain how to provide specific interventions based on a global HRQOL score due to a lack of specificity regarding underlying issues contributing to patients’ perceptions of their HRQOL.
5. Which outcomes are important to measure for a given population?

- Which categories of PROs should be measured for a given patient?
- What is the role of the EHR in tailoring outcome assessments?
- How specifically should the PRO target a particular disease?
How Specifically Should the PRO Target a Particular Disease?

Disease-Specific

Generic
Option 1: Disease-Specific

Those outcomes that are attributed to a particular disease or health condition. Note that in some situations, it might be beneficial to include assessments of both disease-specific and generic PROs.
Option 1: Disease-Specific

- Greater utility for individual patient management versus generic measures
- Patients more likely to feel that the questions are relevant to them
- May have greater ability to demonstrate changes
- Opportunity to combine the use of generic and disease-specific measures
How Specifically Should the PRO Target a Particular Disease?

Option 1: Disease-Specific

- The questionnaire burden increases in proportion to number of diseases/conditions

- Could be redundancy among the multiple disease-specific specific outcome measures (e.g., pain)

- Questionable validity if patient asked to make attribution

- Unclear relevance for patients who are basically healthy
How Specifically Should the PRO Target a Particular Disease?

Option 2: Generic

Those that are relevant across a broad range of patients and healthy people. Examples of generic outcomes include fatigue/energy, pain, and physical functioning.
How Specifically Should the PRO Target a Particular Disease?

**Option 2: Generic**

- Can be used for any person
- Lower chance of redundancy
- Allows comparisons across different types of patients and treatments
- Reflects net effect of multiple diseases/conditions
- Useful for health policy decisions about resource allocation
How Specifically Should the PRO Target a Particular Disease?

**Option 2: Generic**

- Might be less sensitive to changes or differences due to a specific disease
- Less clinically actionable to specialty clinicians
- Patients might not find questions as relevant to immediate health concerns
5. Which outcomes are important to measure for a given population?

Which categories of PROs should be measured for a given patient?

What is the role of the EHR in tailoring outcome assessments?

How specifically should the PRO target a particular disease?
What is the Role of the EHR in Tailoring Outcome Assessments?

**EHR is used** to tailor outcome assessment for an individual patient or a particular disease.

**EHR is not used** to tailor outcome for an individual patient or a particular disease.
What is the Role of the EHR in Tailoring Outcome Assessments?

Option 1: EHR is used to tailor

- Efficiency
- Potentially allows for tailoring of PRO items depending on the answer to screening questions (e.g., via computer adaptive testing)
- Can link to other data within the electronic record to trigger administration
- May link responses to management pathways
Option 1: EHR is used to tailor

Positive responses to screening items may lead to longer questionnaires, including some questions not relevant to the patient.
What is the Role of the EHR in Tailoring Outcome Assessments?

Option 2: EHR is NOT used to tailor

👍 Same measures for all facilitates comparisons across patients/conditions
What is the Role of the EHR in Tailoring Outcome Assessments?

Option 2: EHR is NOT used to tailor

- May not capture all domains related to a specific health condition

- Patients may be dissatisfied or less likely to complete questions if they do not see the relevance to their particular condition
What is the optimal method of data collection and assessment of all relevant patient symptoms for a particular health condition(s) that minimizes patient burden and facilitates integration of data into the EHR?
How does one determine the appropriate balance between administering generic and disease-specific measures depending on the clinical situation?
What is the optimal way of displaying generic or disease-specific patient-reported data alongside clinician-reported observations/assessments within the medical record?
Are there specific features that should be considered in identifying PROs for specific uses and do they differ with the application (e.g., over-arching, specialty-specific, condition-specific, procedure- or treatment-related)?