HOW WILL PRO DATA BE DISPLAYED IN THE EHR?

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PCORI User’s Guide to Integrating PRO in EHRs  
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Background

• No established best approach but rather a range of options

• Available resources and technical constraints shape options

• Approach should maximize accurate interpretation & ease of use
Key Considerations for Displaying PRO Data

1. Target audience and context of use
2. Presentation format
3. Distribution of PRO scores
4. Individual-level vs. population-level scores
5. Complexity of the display
Example PRO Display

1. TARGET AUDIENCE & CONTEXT OF USE
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• Options
  • Clinicians
  • Patients
  • Non-clinical audiences (administrators, researchers,...)

• Consider purpose, context of use, and experience of target audience (i.e., who views the data)
Displays for Clinicians

Advantages

• Alert clinicians to problems, foster communication, facilitate interventions
• Help clinicians engage patients in shared decision-making
• Support panel management in clinical practice

Disadvantages

• Require time and familiarity with PROs to interpret
• Could negatively impact workflows
• Important information could be overlooked if displays and workflows are not well-designed
Displays for Patients

**Advantages**
- Engage patients in self-monitoring and empowers shared decisions
- Provide comparisons to similar patients to encourage decision-making and behavior change

**Disadvantages**
- Require sufficient literacy and numeracy to interpret
- Comparisons to other patients could be misleading or cause distress
- Patients may lack familiarity with PROs or their clinical relevance
Displays for Other Audiences

**Advantages**

- Secondary use of PRO data for QI or CER offers efficiencies
- Potential novel insights about patient experience, population or intervention differences, or facilitate prediction about outcomes
- Can be used to monitor or prompt changes in program performance or research interventions

**Disadvantages**

- Data privacy and security measures must ensure confidentiality and prevent misuse, esp. for vulnerable groups
- Non-clinical use of PROs collected in clinical care may require approvals
- PRO data collected for clinical care and used in secondary analyses may be misinterpreted without context, data quality, or case-mix adjustments
2. PRESENTATION FORMAT
PRESENTATION FORMAT

• Options
  • Numeric formats: tables, text
  • Visual formats: charts, graphs, pictographs
• Optimal format guided by user needs, capabilities, workflows, and context of use (e.g., numeracy)
• Options may be constrained by EHR capabilities or resources to build and configure
Numeric Formats

Advantages

• Provide specificity of PRO data
• Simple to configure as is a standard feature supported in most EHRs
• Clinicians are generally familiar with numeric displays for other clinical data

Disadvantages

• Take time and effort to interpret changes and trends
• Require a lot of screen space to illustrate changes and trends
• Spotting abnormal scores or significant changes over time can be challenging unless data are flagged or highlighted
Visual Formats

Advantages

• Graphs and charts can be easy and quick to understand & allow for pattern recognition
• Pictographs can improve comprehension for those with limited literacy/numeracy
• Certain formats are well-suited for specific purposes
  • Pie charts show proportions
  • Line graphs show trends
  • Pictograph arrays show probabilities

Disadvantages

• May require significant resources to configure, custom build, and integrate into EHR
• Interpretation, preference, and comprehension can differ by user type
• Can obscure underlying raw PRO data, which may be important for clinical decision-making
3. DISTRIBUTION OF PRO SCORES
DISTRIBUTION OF PRO SCORES

• Options
  • Longitudinal trends
  • Cross-sectional comparisons
  • Change scores (e.g., improvement from baseline)

• Consider spread of scores over time or individuals
• Match how display distributes scores for intended use
Longitudinal Trends

Advantages

• Enable examining change in scores over time “at-a-glance”
• Facilitate estimating future score projections

Disadvantages

• Require scores from multiple time points
• Missing data may not be appropriately represented leading to misinterpretation
• May need contextual data (clinical events) to understand changes over time
• Standards are needed for reference ranges and optimal number of time points to trend
Cross-Sectional Comparisons

Advantages

• Provide insight into magnitude of symptoms, treatments, or other factors at single point in time
• Require scores for only one point in time to describe prevalence or risk in a population

Disadvantages

• Capture only overall magnitude without insight into the underlying or process
• Single time point does not capture relevant longitudinal trends
Change Scores

**Advantages**
- Enables assessment of improvement or decline from a reference point (e.g., baseline)
- Potential insight into clinically meaningful differences
- Requires PRO data at only two time points

**Disadvantages**
- Captures overall magnitude of change without insight into process or underlying trend behind the change
- May have discordance between meaningful change from patient vs. clinician perspectives
- Evidence and standards are needed to identify clinically meaningful differences
4. INDIVIDUAL VS. POPULATION-LEVEL SCORES
INDIVIDUAL VS. POPULATION-LEVEL SCORES

• Options
  • Individual scores from single patient
  • Population scores from multiple patients (e.g., panel)
  • Consider quality metrics (MCID, CI, Ref. Range) and clinical context (primary care vs. subspecialty)
Individual-Level Scores

Advantages

• Useful for patient self-monitoring and self-management
• Useful for screening, monitoring patient progress, informing treatment and shared decision-making

Disadvantages

• May require contextual information (e.g., population thresholds) to aid interpretation
• Data privacy and security measures must be used to ensure confidentiality of PRO data when shared
Population-Level Scores

Advantages

- Provide context about similar patients for shared decision-making
- Aid panel or population health management by clinicians or administrators
- Useful for assessment to shift clinical practice towards higher quality care
- Potential for large scale discovery into patient experience, treatment outcomes, natural course of disease

Disadvantages

- May need contextual information to optimize utility
- Require thoughtful selection of parameters around which to aggregate PRO scores
- Data privacy/security measures must ensure confidentiality for populations where identification has consequences
- Outliers can skew data and risk adjustment may be required
5. COMPLEXITY OF THE DISPLAY
COMPLEXITY OF THE DISPLAY

• Options
  • Simple: Static, “just the scores”
  • Complex: Interactive (e.g., filter data, toggle format) with contextual detail (e.g., clinical events, color-coding, CI, etc.)

• Consider degree to which contextual detail and functionality are incorporated into display

• Options may be constrained by EHR capabilities or resources to build and configure
Simple Static Displays

Advantages

• Quick to view and interpret
• Minimize detail, which reduces cognitive burden
• Tend to require little prior knowledge to use or interpret
• Many patients and clinicians prefer simple displays
• Generally easier and less costly to configure and build than complex displays

Disadvantages

• Can lack details and contextual information that aids interpretation and comprehension of PRO data
• Can potentially lead to inaccurate interpretation
• May not meet users’ needs when further details and interactivity are desired
Complex Interactive Displays

Advantages:

- Interactive features enable users to dynamically explore data (e.g., filter, pan, zoom)
- Enables inclusion of explanatory information or clinical data alongside PROs to aid & contextualize interpretation
- Can present multiple PRO domains in single “dashboard” or screen

Disadvantages:

- Excessive detail and functionality adds time, cognitive load, and potentially distract from accurate interpretation
- May require training for use, interpretation, and navigation
- May require significant technical resources to customize within EHRs
- May need multiple interfaces to support various audiences
KEY INFORMATION GAPS & RESEARCH QUESTIONS

• How can we design user-friendly displays with actionable insights that maximize accurate, timely interpretation?
• Which formats are best for displaying different types of PROs to different audiences?
• What contextual data best facilitates interpretation of PROs?
• What standards can facilitate PRO display in the EHR?
• Where are the optimal locations for PRO displays in the EHR and clinical workflows?
• In what circumstances should restrictions be placed on non-clinical use of PROs?
EXAMPLES OF PRO DATA DISPLAYS
Report for Patient: Individual’s PROMIS Pain Interference Score

Line Graphs Showing Distribution of Population-level Scores Over Time

Images courtesy of Ben Strong MD, and John Ginnetti MD, University of Rochester Medical Center
Composite Line Graphs of Individual Patient Scores with Color Coded Severity

Stacked Bar Chart Improvement in % of Population by Level of Disease Activity

56 years old, 19 months since surgery
Current PSA: <0.05
Pathology
Gleason 3 + 4          Organ confined        PSA Before Surgery: 1.69
Alert
- Erectile dysfunction. 1* Alert.
- Urinary dysfunction > 1 yr after surgery. 1* Alert
Surveys
Most Recent Survey: Wednesday, March 02, 2011. 5 weeks ago

Erectile function
- Baseline Score (Physician): 4
- Baseline Score (Patient): 29 / 30 (Good)
- Current Erection sufficient MOST TIMES
- Current Score: 20 / 30 (Intermediate)

Urinary function
- Baseline Score (Physician): 2
- Baseline Score (Patient): 21 / 21 (Good)
- Current: 1 pad per day
- Current Score: 18 / 21 (Good)

Bowel function
- No bowel symptoms

Quality of life
- Current Score: 6 / 10

Clinician Color-Coded Tabular Report of Scores Over Time

Report for Clinicians and Patients Using Line Graphs and Tables and Color-coding

Patient Display (top) and Clinician Display (bottom)

Line Graph (left) and Pictograph (right) of Individual Patient Scores Over Time

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