

Displaying PRO Results Graphically: Overview of Recommendations



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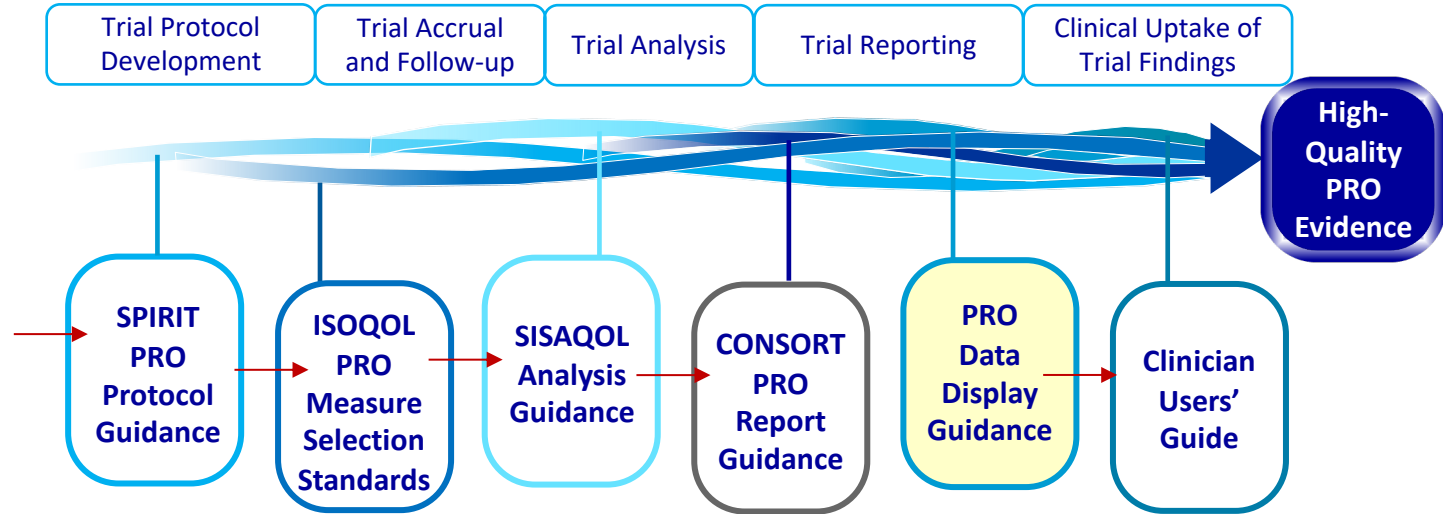
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Overview of Presentations

TheProteusConsortium.org

Introduction to PROs and PROTEUS

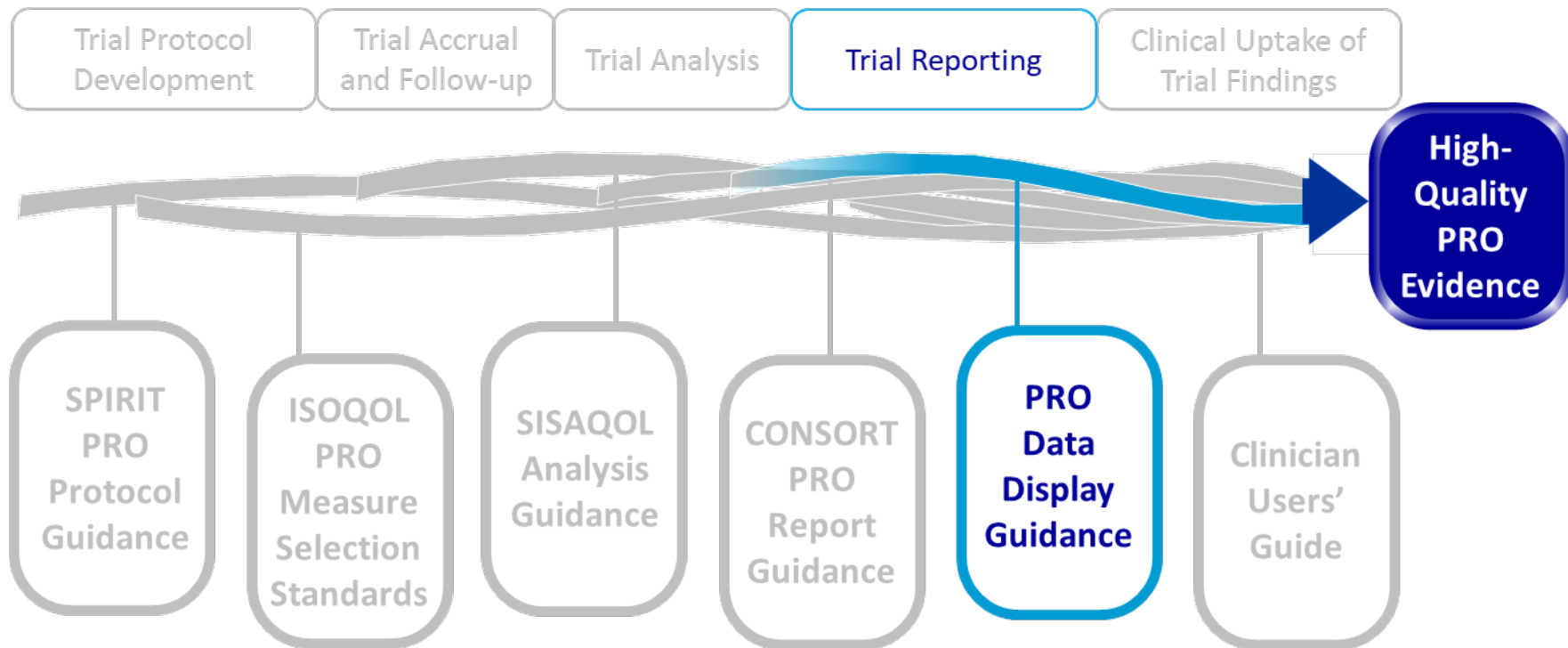
→ Introduction to the PROTEUS Tools



→ Overview of Tool Recommendations

→ How to Apply the Tools

Displaying PRO Results Graphically



Displaying PRO Results Graphically



Why is it needed?

To promote consistent presentation of PRO data so that clinicians and patients can understand what PRO scores mean

What does it do?

Provides evidence-based recommendations for presenting PRO data clearly to patients and clinicians/researchers

Displaying PRO Results Graphically

Quality of Life Research

<https://doi.org/10.1007/s11136-018-2020-3>



Making a picture worth a thousand numbers: recommendations for graphically displaying patient-reported outcomes data

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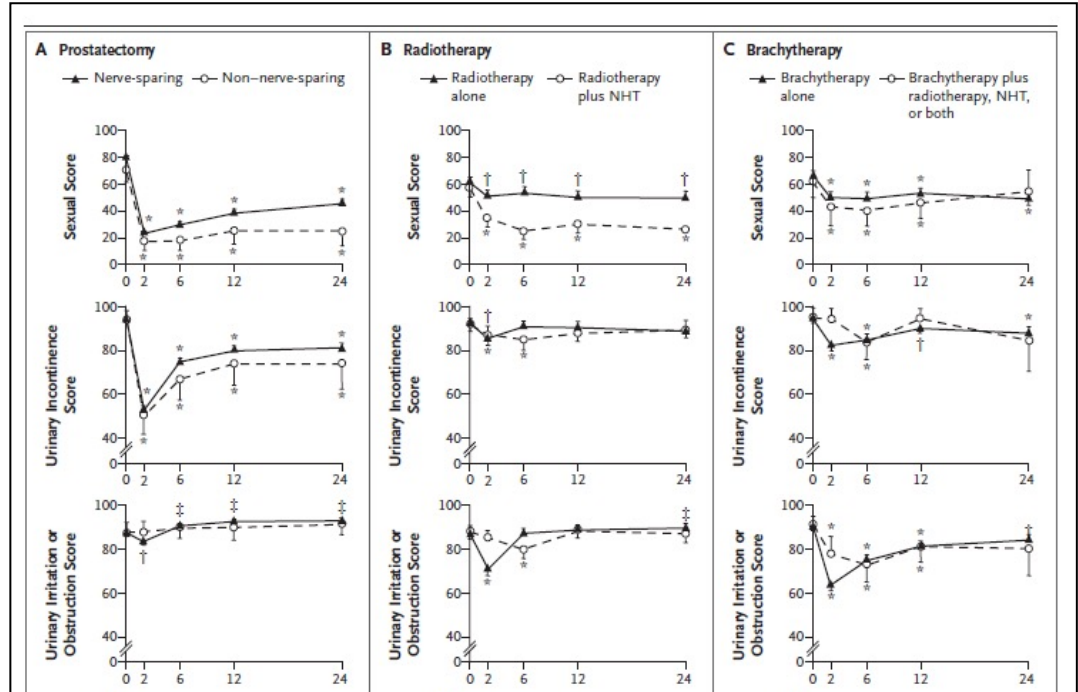
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Why Is This Resource Needed?

- Both patients and clinicians endorse the value of PROs, but also report challenges interpreting the meaning and implications of PRO data



Why Is This Resource Needed?

Barriers to interpreting PRO data include **variation** in:

- PRO instruments
 - Over 800 listed in PROOLID database (<http://proqolid.org/>)
- Scoring
 - Higher scores may be better or worse
- Scaling
 - E.g. 0-100 vs. normed to 50
- Presentation
 - E.g. mean scores vs responders/ graphic vs. tabular



Why Is This Resource Needed?

- Variations in how PRO measures are scored and scaled, and in how the data are reported, make interpretation difficult and limit patients' and clinicians' use of the data in clinical practice
- Clear and standardized graphical presentation of PRO data has the potential to:
 - promote meaningful interpretation of PRO data
 - facilitate their use in practice



Objective of Resource

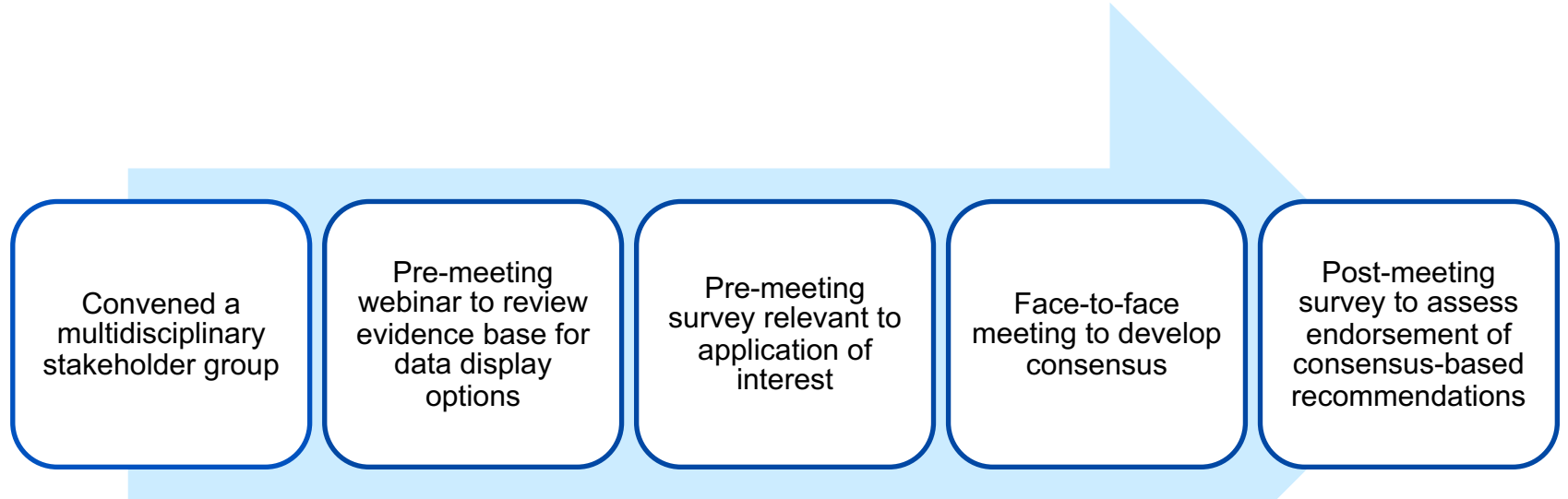
To provide evidence-based recommendations for PRO data display to facilitate ease of interpretation for presenting results to:

- Patients (i.e., educational materials and decision aids)
- Clinicians/researchers (i.e., peer-reviewed publications)

[Also addresses display for individual patient data, though not covered here]



Methods: Modified-Delphi Process



Parameters for recommendations

- Should work on paper (static presentation)
- Presentation in color is possible (but should be interpretable in grayscale)
- Additional functionality in electronic presentation is possible (but not part of standards)

Results for PRO Data Presented to:

- **Patients** (i.e., educational materials and decision aids)
- **Clinicians/researchers** (i.e., peer-reviewed publications)



Overview of Recommendations

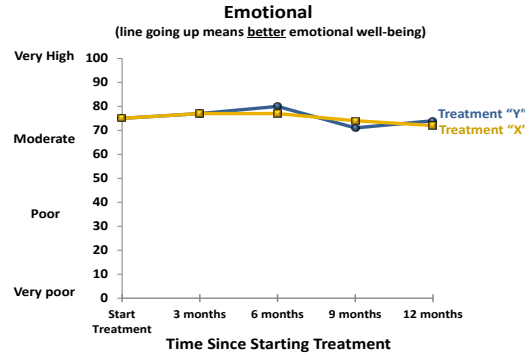
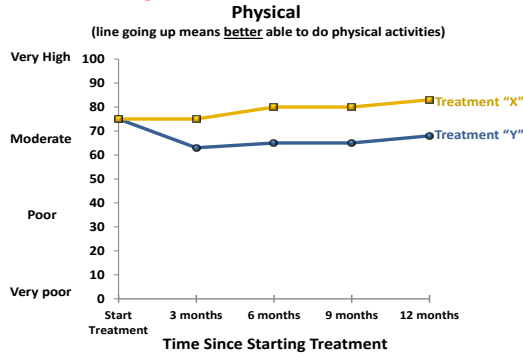
Directionality:

- Use exceptionally clear labeling, titling, and annotations to indicate whether higher scores are better or worse
- Avoid mixing score direction in a single display

Illustrative Example for Presentation to Patients

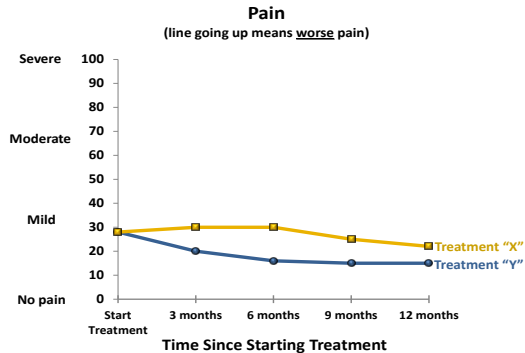
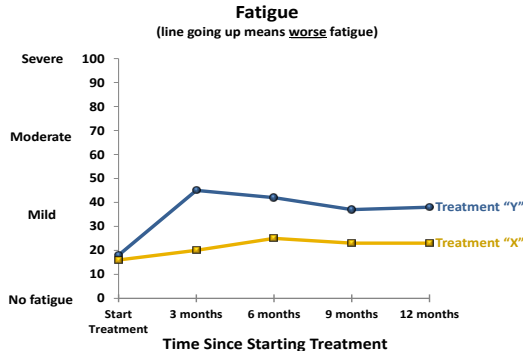
Labels for directionality

Patients' Functioning



Visually separate domains with different directionality

Patients' Symptoms

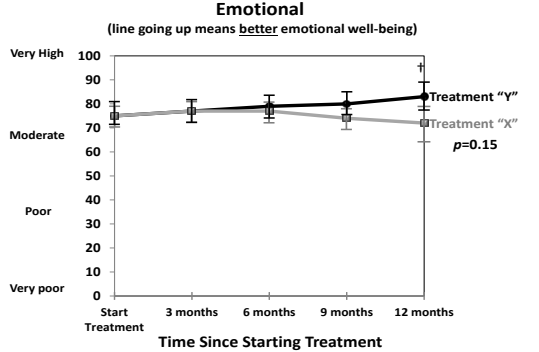
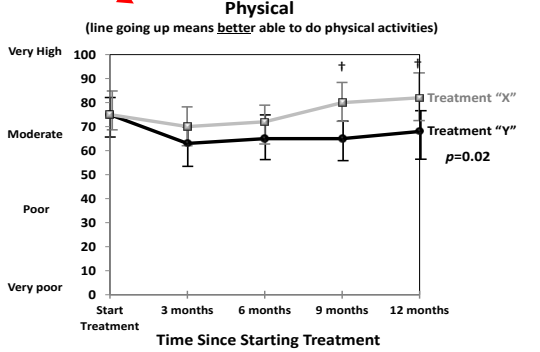


Y-axis labels reinforce directionality

Illustrative Example for Presentation to Clinicians/Researchers

Patients' Functioning

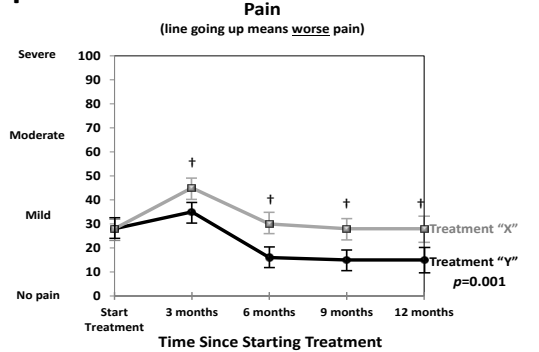
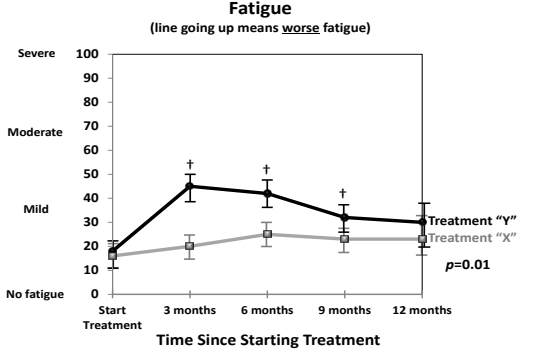
Labels for directionality



Visually separate domains with different directionality

Patients' Symptoms

Y-axis labels reinforce directionality



Legend: For all graphs, p -values are for between-treatment differences over time, and vertical lines indicate 95% confidence limits at each time point.
† indicates differences between treatments that are clinically important.



Overview of Recommendations

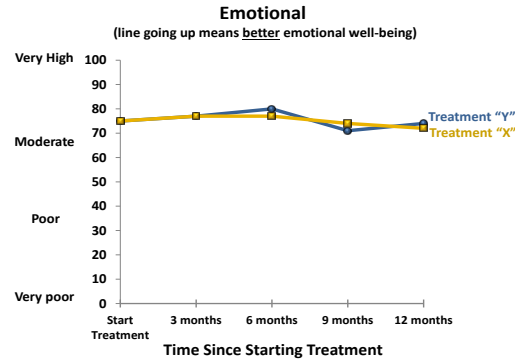
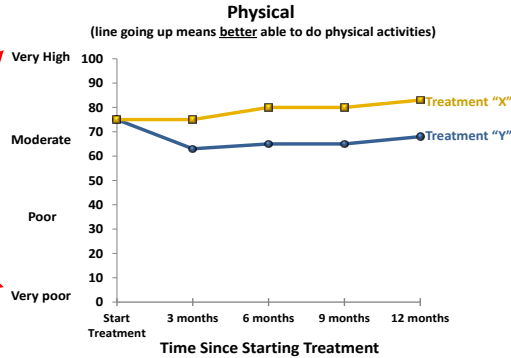
Conveying score meaning:

- If possible, include descriptive labels (e.g., none/mild/moderate/severe) along the y-axis
- Consider including reference values for comparison populations

Illustrative Example for Presentation to Patients

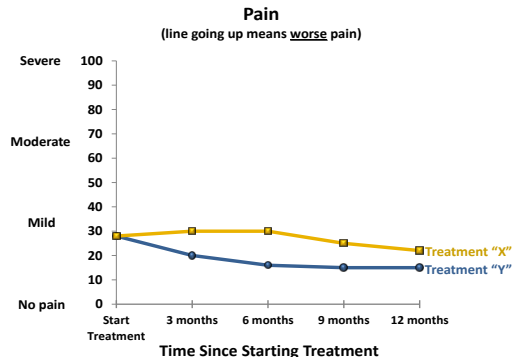
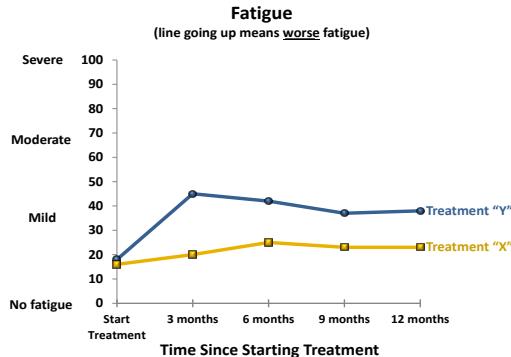
Patients' Functioning

Y-axis descriptive anchor labels



Patients' Symptoms

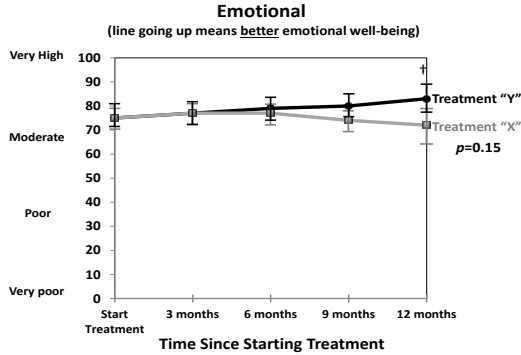
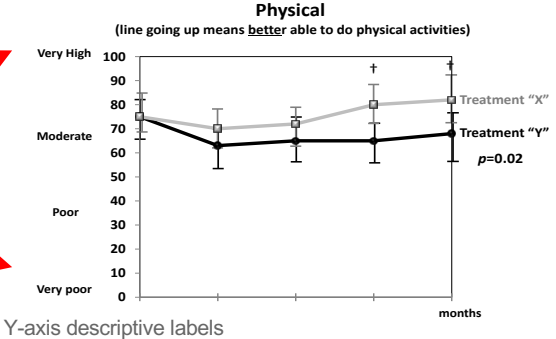
Additional Y-axis labels (when data support their location)



Illustrative Example for Presentation to Clinicians/Researchers

Patients' Functioning

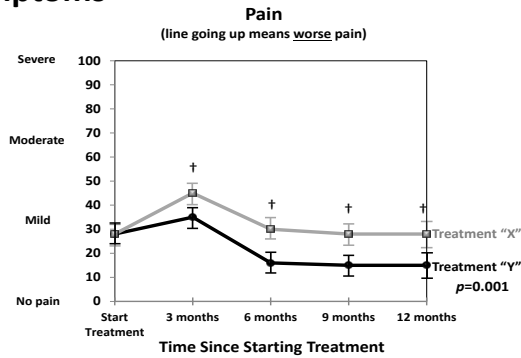
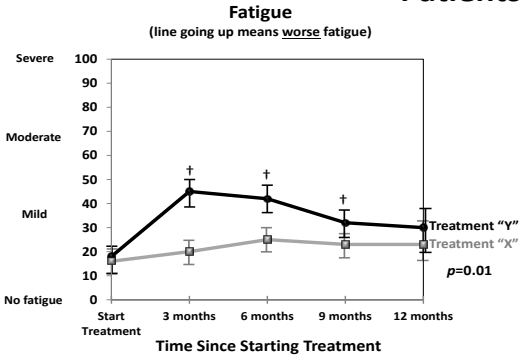
Y-axis descriptive anchor labels



Additional Y-axis labels (when data support their location)



Patients' Symptoms



Legend: For all graphs, *p*-values are for between-treatment differences over time, and vertical lines indicate 95% confidence limits at each time point.
 † indicates differences between treatments that are clinically important.



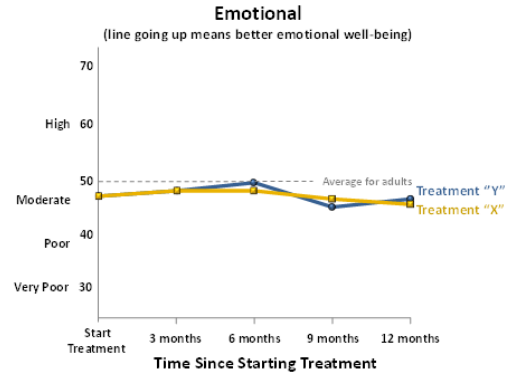
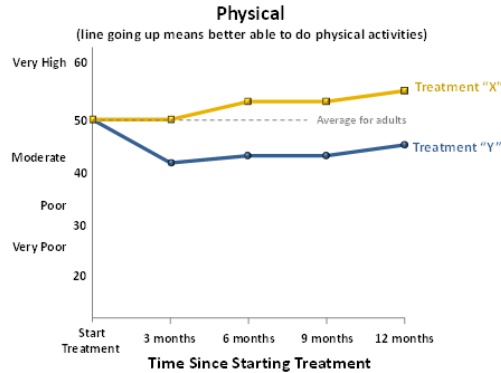
Overview of Recommendations

Normed scoring:

- PRO data presentation should reflect the measure's scoring, whether it is normed or not
- One can decide whether to show the norm visually

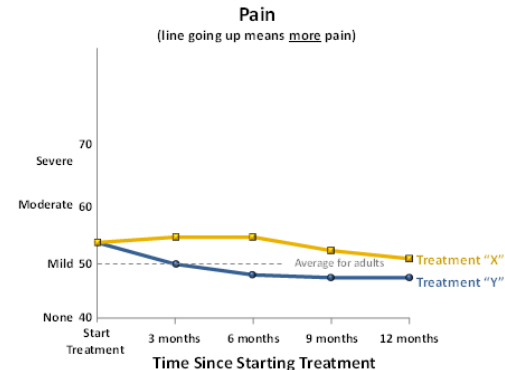
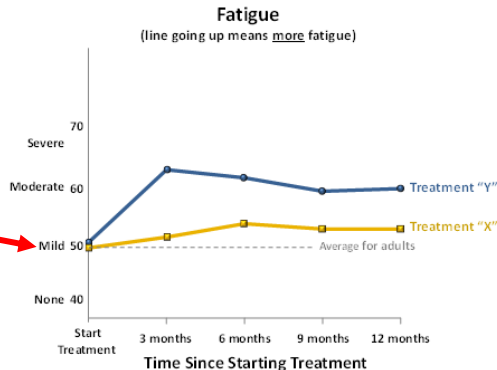
Illustrative Example for Presentation to Patients

Patients' Functioning



Y-axis descriptive labels for normed scoring that also reinforce directionality

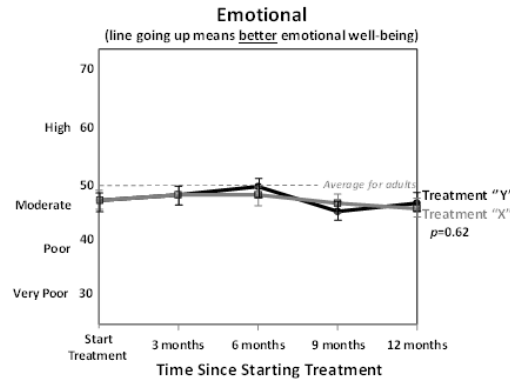
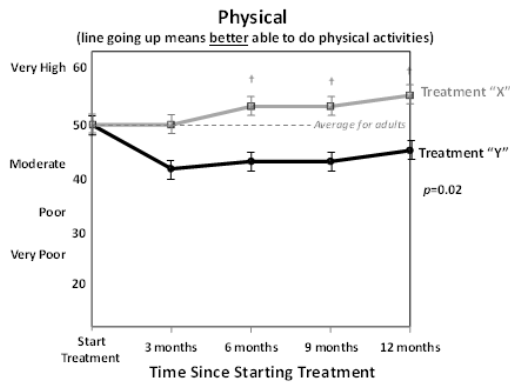
Patients' Symptoms



Display reference population norm visually

Illustrative Example for Presentation to Clinicians/Researchers

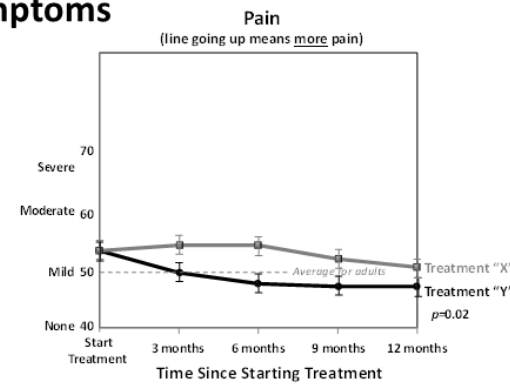
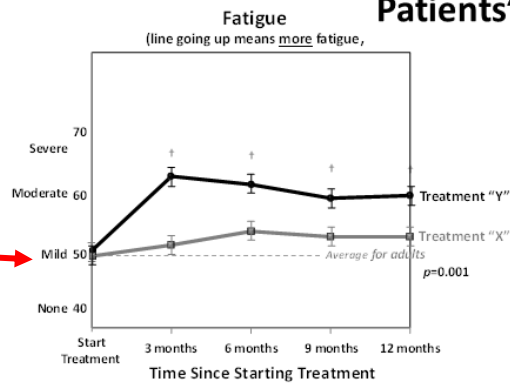
Patients' Functioning



Y-axis descriptive labels for normed scoring that also reinforce directionality

Display reference population norm visually

Patients' Symptoms



Legend: For all graphs, p-values are for between-treatment differences over time.
† indicates differences between treatments that are clinically important.



Overview of Recommendations

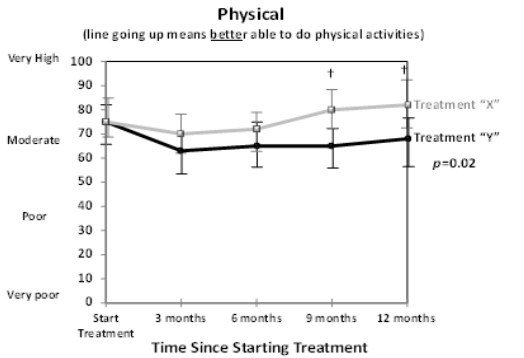
Clinically important differences:

- Include an indication of what differences between scores matter

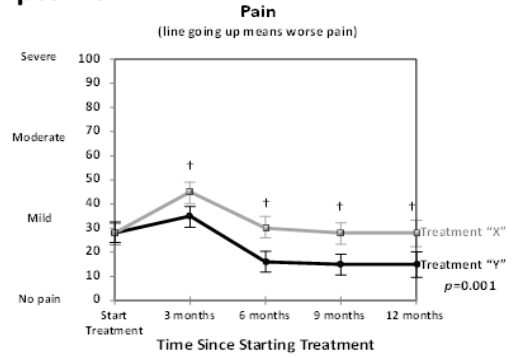
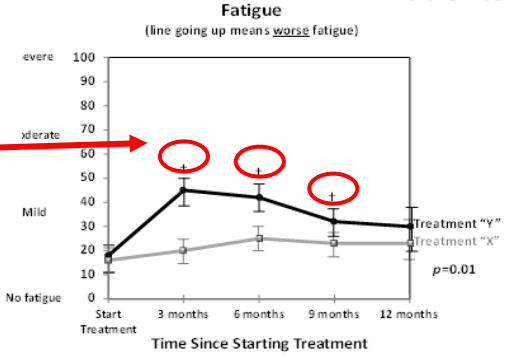


Illustrative Example for Presentation to Clinicians/Researchers

Patients' Functioning



Patients' Symptoms



Symbols illustrating clinically important differences between group scores

Legend explanation

Legend: For all graphs, p -values are for between-treatment differences over time, and vertical lines indicate 95% confidence limits at each time point.
† indicates differences between treatments that are clinically important.

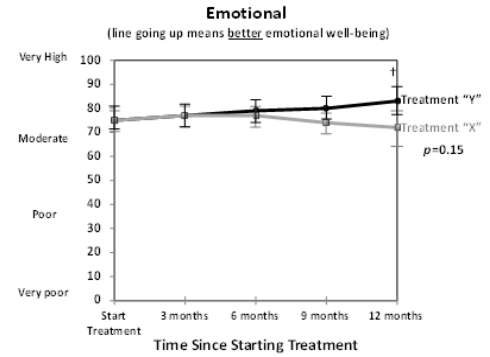
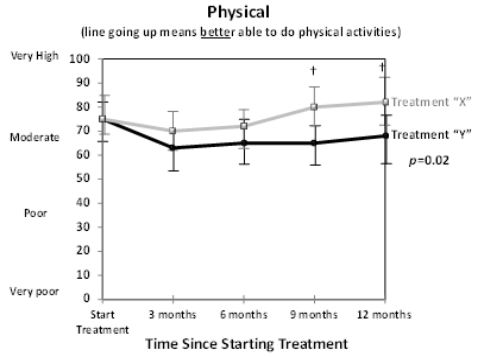
Overview of Recommendations

Conveying statistical significance (for clinicians and researchers only):

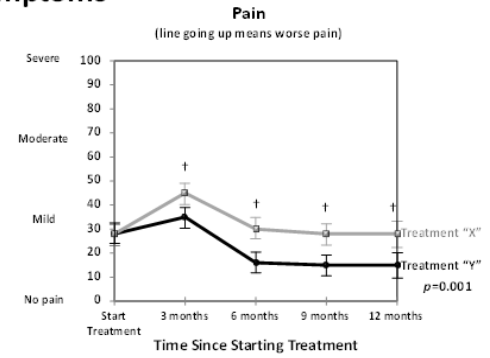
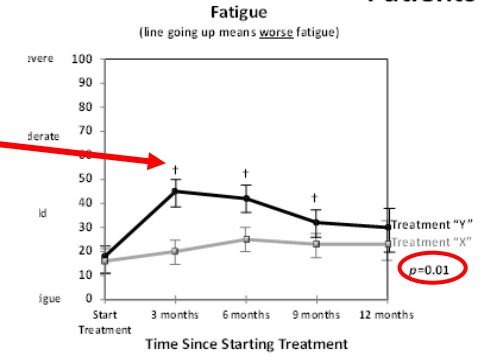
- Confidence intervals should be displayed
- P-values may also be appreciated

Illustrative Example for Presentation to Clinicians/Researchers

Patients' Functioning



Patients' Symptoms



Confidence limits should always be shown

p-values often included but considered optional

Legend explanations

Legend: For all graphs, p-values are for between-treatment differences over time, and vertical lines indicate 95% confidence limits at each time point.
† indicates differences between treatments that are clinically important.

Overview of Recommendations

Proportions changed:

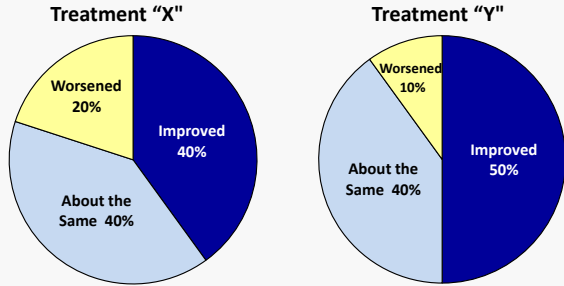
- Pie charts are preferred for patients
- Bar charts, pie charts, or stacked bar charts are reasonable options for clinicians and researchers



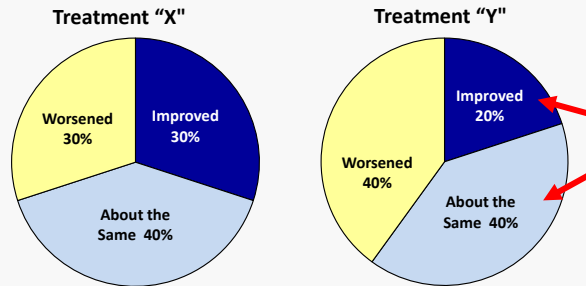
Illustrative Example for Presentation to Patients

Status of 100 patients 9 months after starting treatment

Ability to Do Physical Activities



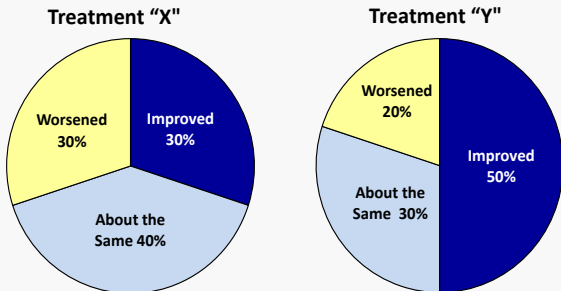
Emotional Well-Being



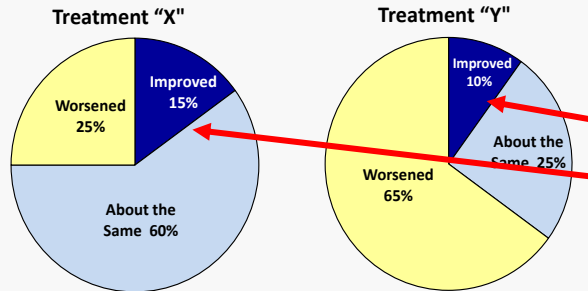
Data labels annotated on each slice

No horizontal line separating domains since directionality not relevant with proportions

Pain



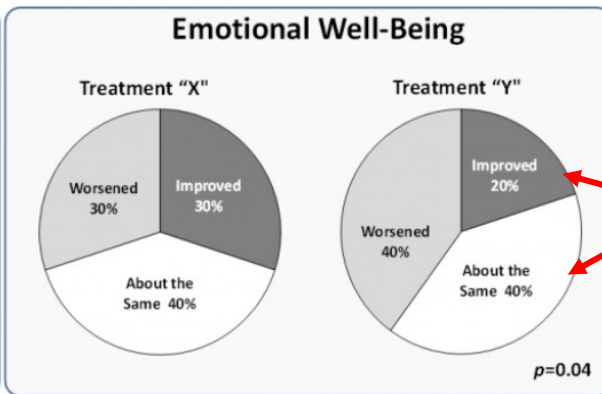
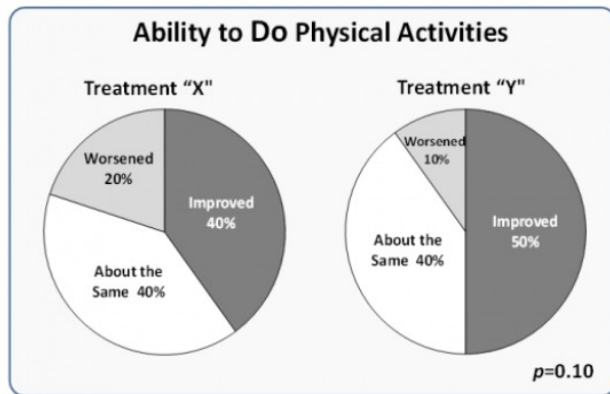
Fatigue



"Improved" slice consistently starts at 12:00 position

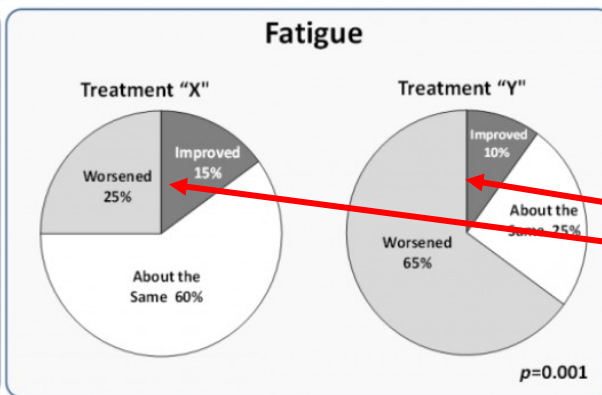
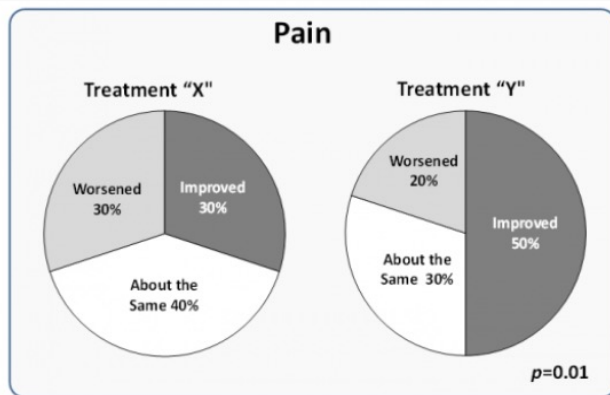
Illustrative Example for Presentation to Clinicians/Researchers

Status of 100 patients 9 months after starting treatment



Data labels annotated on each slice

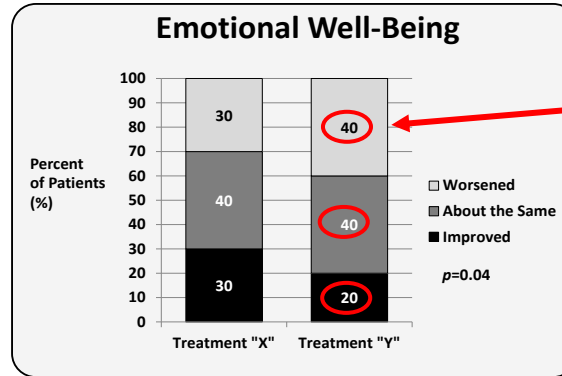
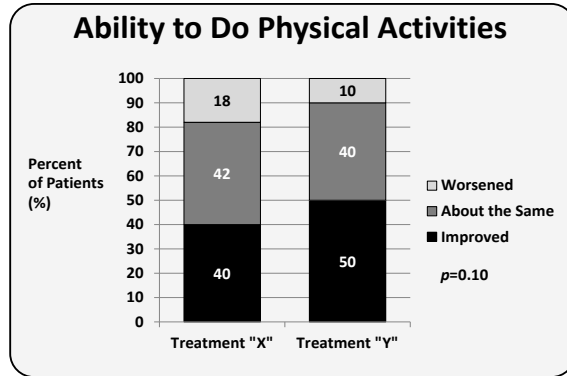
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"Improved" slice consistently starts at 12:00 position

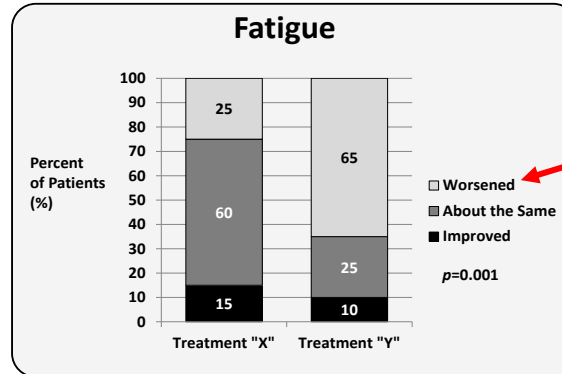
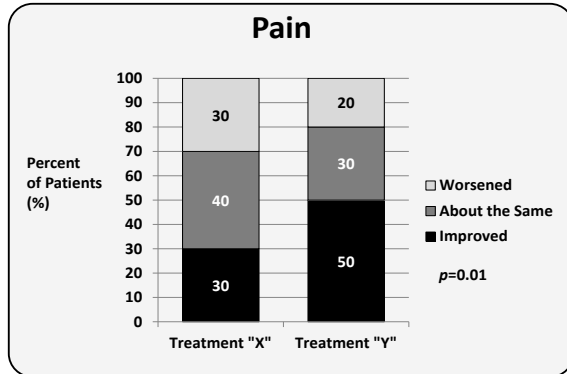
Illustrative Example for Presentation to Clinicians/Researchers

Status of 100 patients 9 months after starting treatment



Data labels annotated on each slice so stacked proportions can be read directly

No horizontal line separating domains since directionality not relevant with proportions



Legend replicated for easy access and order is the same as stacked bar sections

Recap

- PRO data have enormous potential to promote patient-centered care, but for this potential to be realized, clinicians and patients need to be able to understand what PRO scores mean
- To address this, a modified Delphi consensus process was conducted with a broad range of key stakeholders to develop recommendations for PRO data display
- The consensus process produced clear guidance for PRO data display to promote patient-centered care by optimizing accurate and meaningful interpretation of PRO results



Further Reading

Brundage M, Smith K, Little E et al. Communicating patient-reported outcome scores using graphic formats: Results from a mixed methods evaluation. *Quality of Life Research*.24;2457-2472; 2015.

Bantug E, Coles T, Smith K et al. Graphical displays of patient-reported outcomes (PRO) for use in clinical practice: What makes a PRO picture worth a thousand words? *Patient Education and Counselling*. 99;483-490; 2016.

Smith K, Brundage M, Tolbert E et al. Engaging stakeholders to improve presentation of patient-reported outcomes data in clinical practice. *Support Care Cancer*. 4149-4157; 2016.

Brundage M, Blackford A, Tolbert E et al. Presenting comparative study PRO results to clinicians and researchers: Beyond the eye of the beholder. *Quality of Life Research*. 27:75-90; 2018.

Tolbert E, Brundage M, Bantug E, Blackford AL, Smith K, Snyder C; PRO Data Presentation Stakeholder Advisory Board. Picture this: Presenting longitudinal patient-reported outcome research study results to patients. *Medical Decision Making*.38:994-1005;2018.

Tolbert E, Brundage M, Bantug E, Blackford AL, Smith K, Snyder C; PRO Data Presentation Stakeholder Advisory Board. In proportion: Approaches for displaying patient-reported outcome research study results as percentages responding to treatment. *Quality of Life Research*.28:609-20;2019.

Snyder C, Smith K, Holzner B et al. Making a picture worth a thousand numbers: Recommendations for graphically displaying patient-reported outcomes data. *Quality of Life Research*.28:345-35; 2019.

