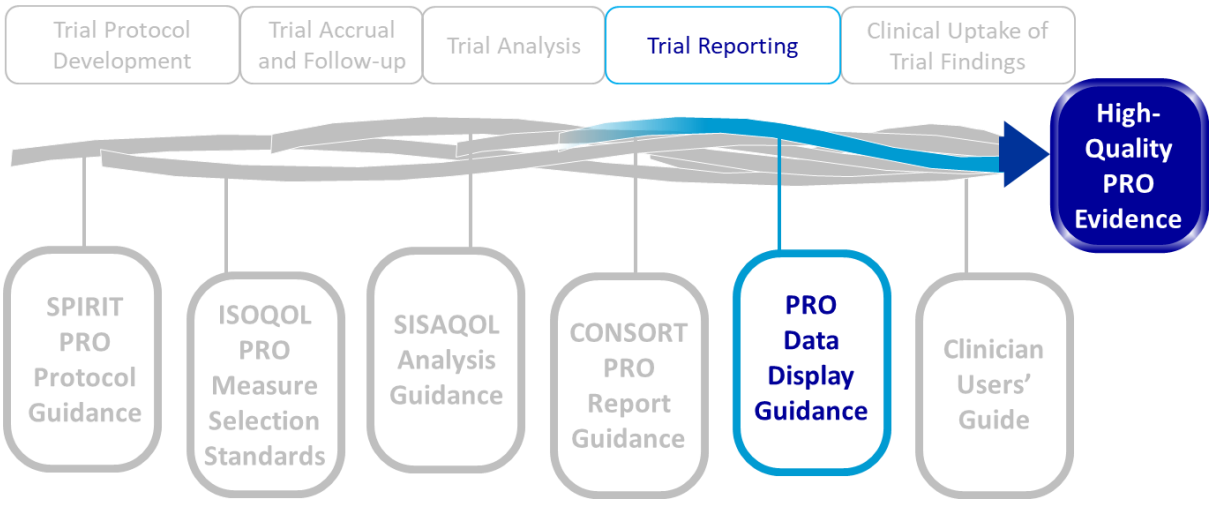
Chapter 6. Graphically Displaying PRO Data



Stakeholder-Driven, Evidence-Based Standards for Presenting PRO data to Patients and Clinicians/Researchers

A specific issue related to the reporting of PRO clinical trial results is the best way to graphically report the findings so that patients and clinicians can easily and accurately interpret the PRO findings. To address this issue, stakeholder-driven, evidence-based recommendations for how to display PRO data to promote understanding and use have been developed.

This chapter summarizes the recommendations for graphically displaying PRO data, for use by clinicians and/or patients.

View PRO Data Display article

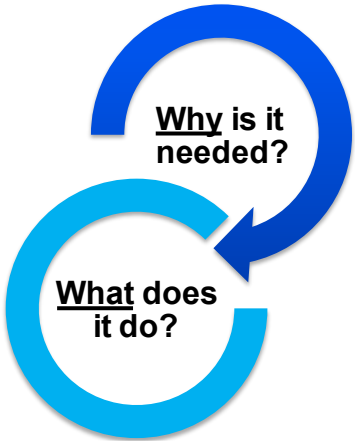
View the Checklists for PRO Data Display:

- Research Results Presented to Patients
- Research Results Presented to Clinicians/Researchers

References

Acknowledgements

Why is This Resource Needed?



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

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

The impetus for developing these recommendations was evidence showing that while both patients and clinicians endorse the value of PROs, they also report challenges interpreting the meaning and implications of PRO data, such as those produced within a clinical trial. These challenges result, in part, from the lack of standardization in how PRO measures are scored and scaled, and in how the data are reported. For example, on some PRO measures, higher scores are always better; on other PRO measures, higher scores reflect “more” of the outcome and are therefore better for function domains but worse for symptoms. Some PRO measures are scaled from 0 to 100, with the best and worst outcomes at the extremes, whereas others are normed to, for example, a general population average of 50. There are also variations in how PRO results are reported—in some cases as mean scores over time, in other cases as the proportion of patients meeting a responder definition (i.e., improved/stable/worsened). These challenges in interpreting PRO results limit patients’ and clinicians’ use of the data in clinical practice.

Objective of Resource

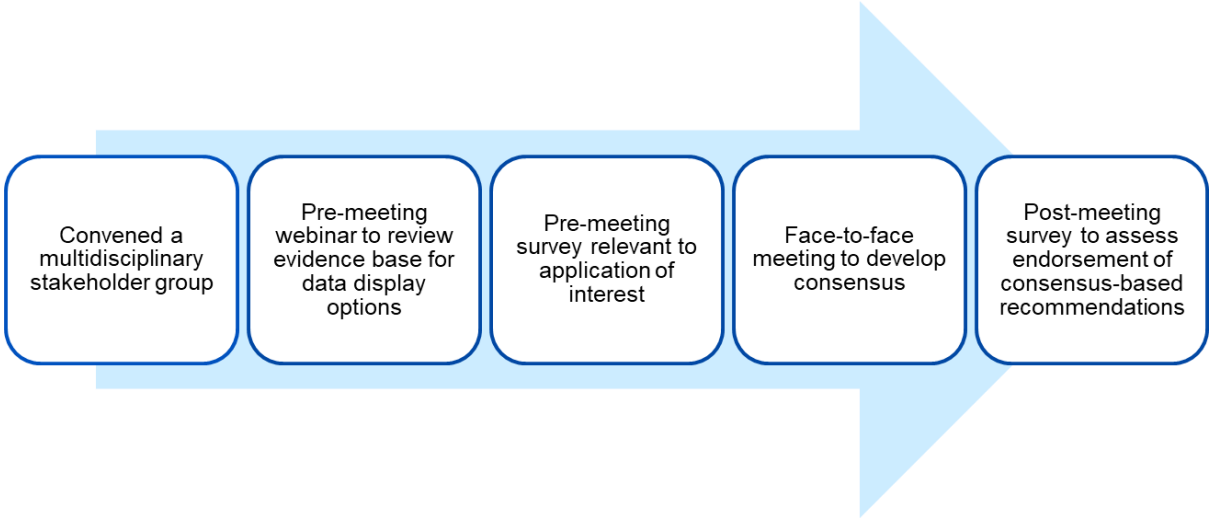
This resource is designed to provide evidence-based recommendations for PRO data display to facilitate ease of interpretation for presenting results to:

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

The resource also provides recommendations for display of individual patient PRO data within clinical practice settings, but these are not covered in this Handbook. If you are interested in learning more about recommendations for displaying individual patient PRO data, please see Snyder et al. (2019).

Methods for Resource Development

This PRO data display resource was developed using a modified Delphi process to establish consensus on evidence-based recommendations for graphically displaying PRO data among a multi-disciplinary group of stakeholders, which included clinicians, patients/caregivers, academics, and journal editors.



Parameters for Recommendations

The following parameters informed the PRO data display considerations:

1. recommendations should work on paper (static presentation)
2. presentation in color is possible (but it should be interpretable in grayscale)
3. additional functionality in electronic presentation is possible (but not part of standards)

Additional guiding principles were also established:

1. displays should be as simple and intuitively interpretable as possible
2. it is reasonable to expect that clinicians will need to explain the data to patients
3. education and training support should be encouraged to be available

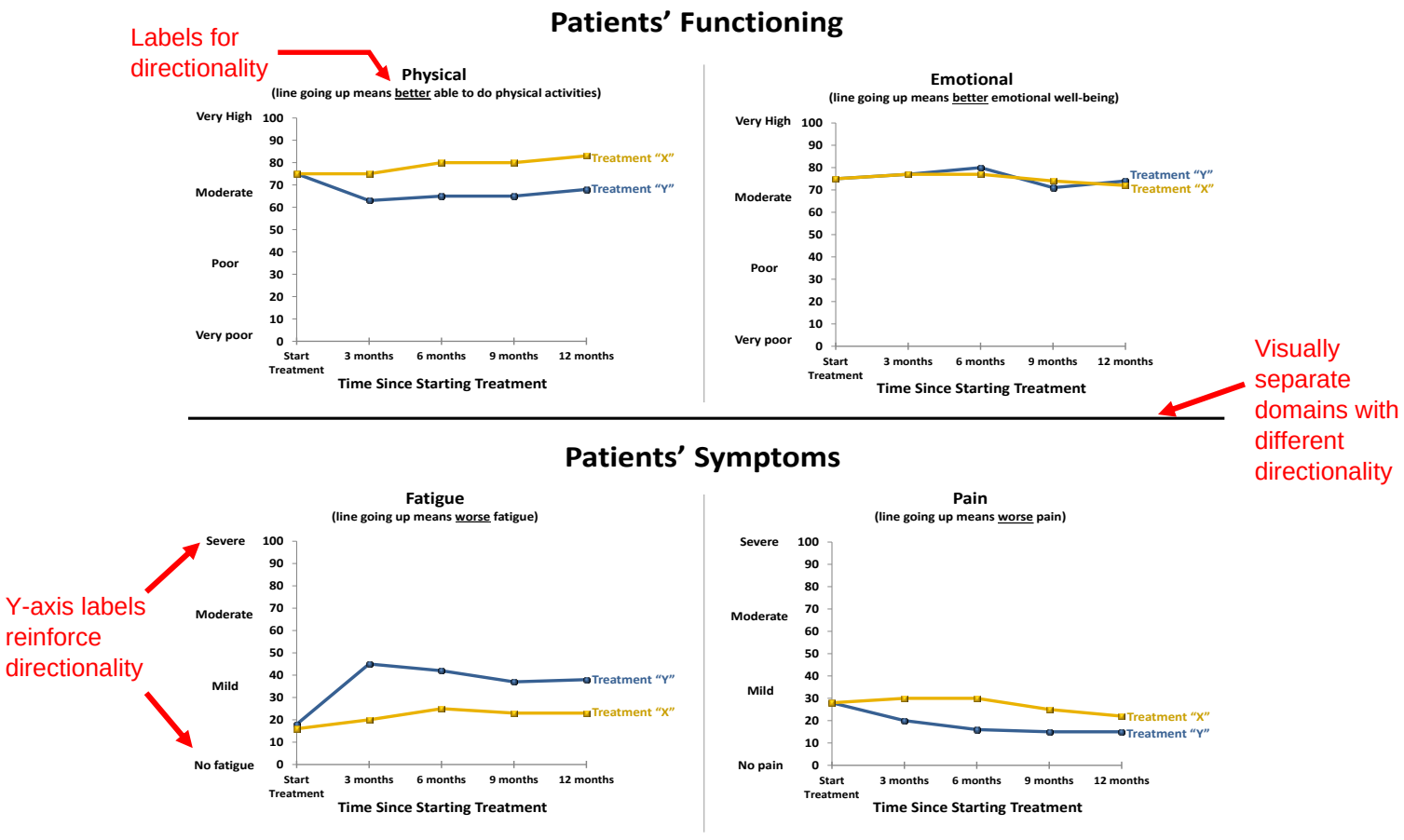
Overview of PRO Data Display Recommendations

In this section, we include several graphs/charts illustrating how to implement the PRO data display recommendations. Graphs/charts in color illustrate recommendations for how to display PRO data to patients, whereas black-and-white figures illustrate recommendations for PRO data display to clinicians or researchers. These graphs shown in black-and-white are common for journal publications, and for printers that clinicians and researchers may have access to.

Directionality

One of the key issues to address in the presentation of PRO data is how to display variations in directionality – that is, how to aid interpretation when higher scores are better for some domains, such as, physical function, but worse for other domains, such as pain.

There are two general recommendations for addressing directionality. First, the graphic should include exceptionally clear labeling, titling, and annotations to help viewers understand whether higher scores are better or worse. Second, domains that differ in scoring directionality should be presented separately.

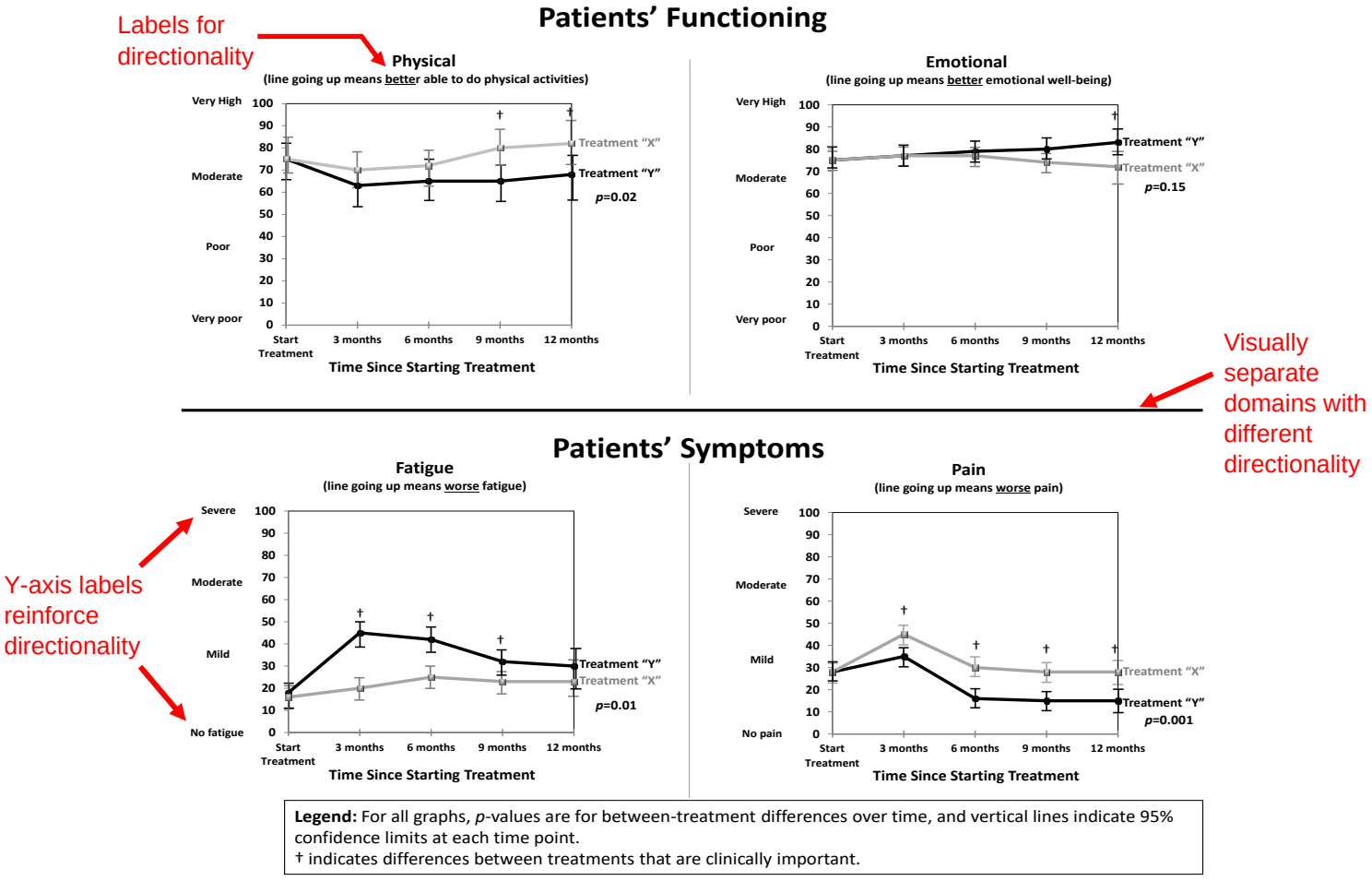


The above illustration shows an example of how to display data to patients. Please note a few key aspects of these graphs.

First, we use a line graph of average scores over time, which was the preferred approach for showing longitudinal data. Different colors are used for the two treatment arms, and the lines are labeled directly, rather than using a legend.

As for directionality, you can see that under each domain title, a header describes whether a line going up indicates improvement or worsening. The functional domains where higher

scores are better are clearly separated from the symptom domains where higher scores are worse. Finally, we have included descriptive labels on the y-axis to help with directionality, as well as to help convey score meaning.



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.

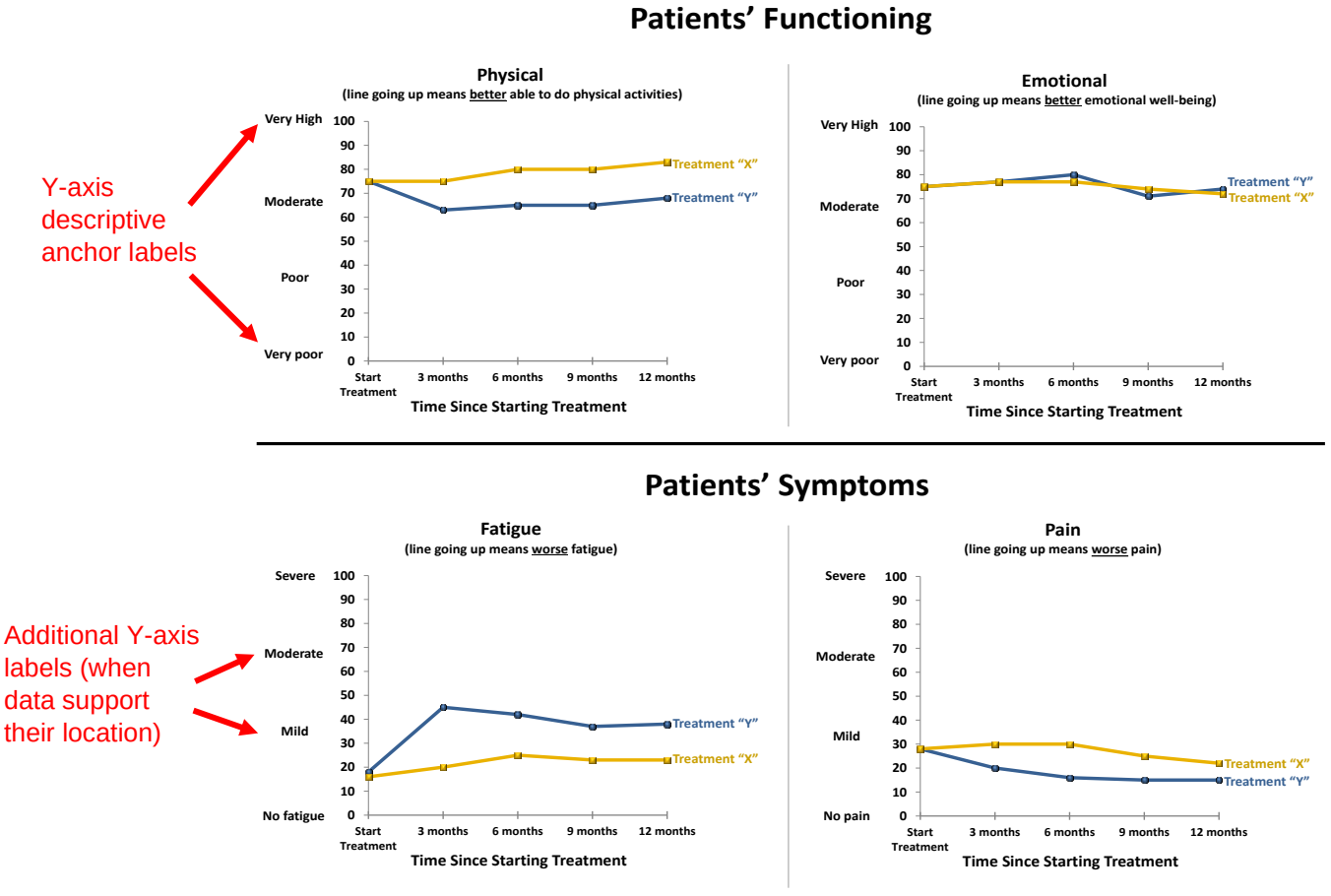
The figure above shows an example of how to display data to clinicians or researchers. Again, we use line graphs of average scores over time, but these versions include additional statistical and other details we will describe later. Similar to the patient graphic, the lines are labeled directly, rather than using a legend.

The same labeling, titling, and annotations are also included here, such as the headers under the domain names, the separation of domains with different scoring directionality, and the y-axis labels.

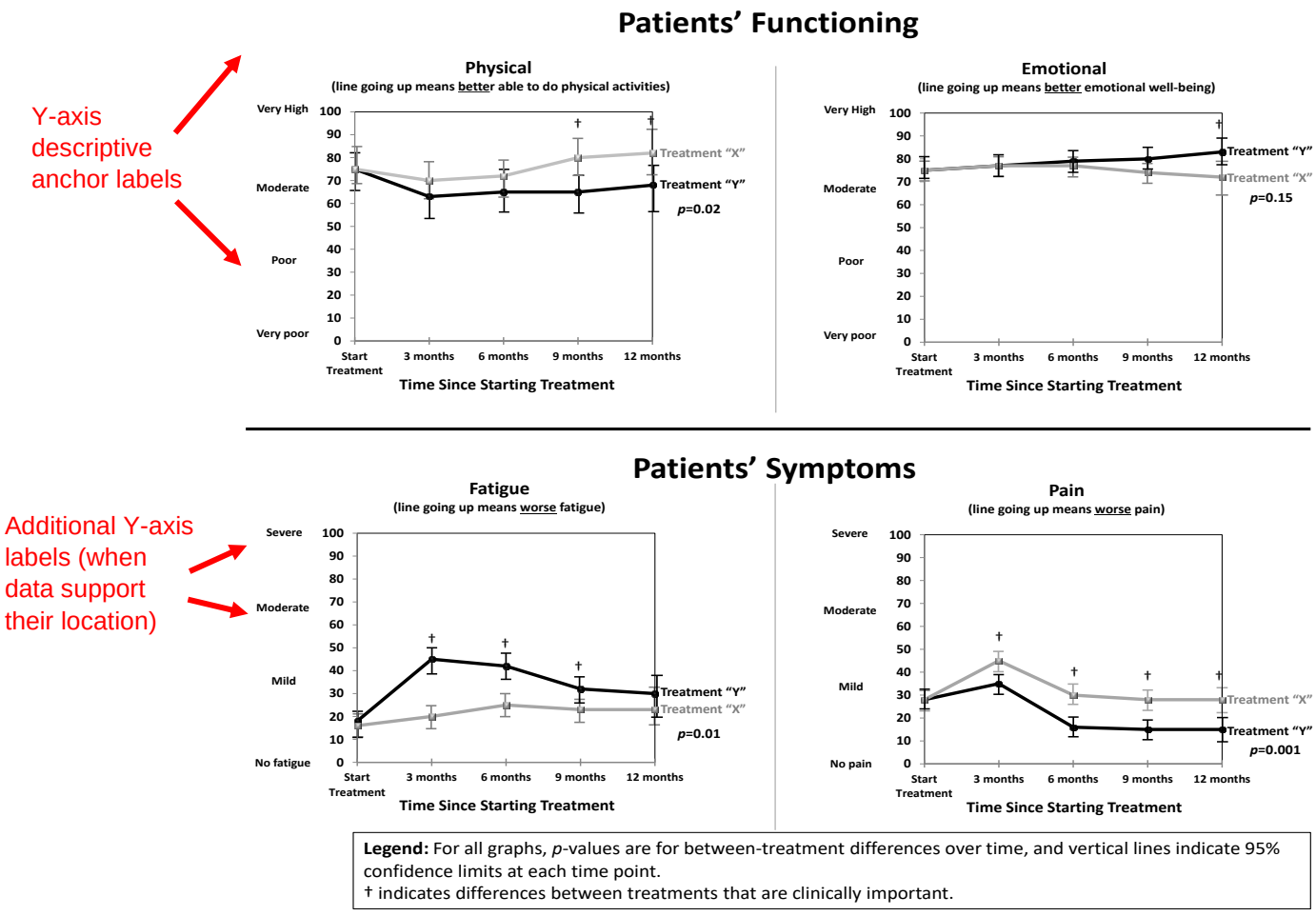
Conveying Score Meaning

The next recommendations relate to conveying score meaning. That is, how to understand whether a score is good or bad, or what level of function or symptoms is represented.

The recommendations suggest including descriptive labels along the y-axis – to the extent that this information is known. In displaying the data, inclusion of reference values for comparison populations may also be considered.



Above is an illustrative example for displaying PRO data to patients, highlighting the descriptive labels along the y-axis. As noted previously, the labels along the y-axis should only be included when there is evidence to support where on the scoring continuum the labels should be placed. The Consensus Panel acknowledged that it would be easier to place the anchor labels, for example, "*none*" and "*severe*", at the extreme ends of the continuum and that it might be more difficult to place the middle labels, for example, "*mild*" and "*moderate*".



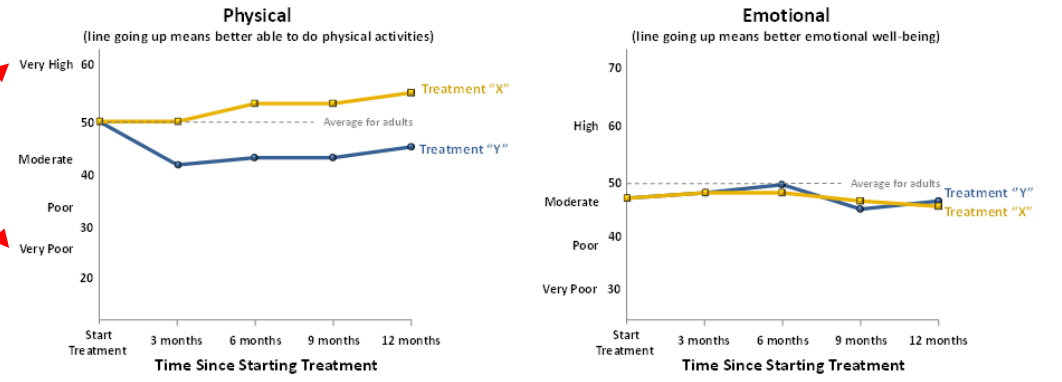
Legend: For all graphs, *p*-values are for between-treatment differences over time, and vertical lines indicate 95% confidence limits at each time point.
† indicates differences between treatments that are clinically important.

This is the clinician/researcher example illustration. The same considerations regarding the y-axis labels apply, with potentially greater knowledge and ability to include the anchor labels compared to the middle labels.

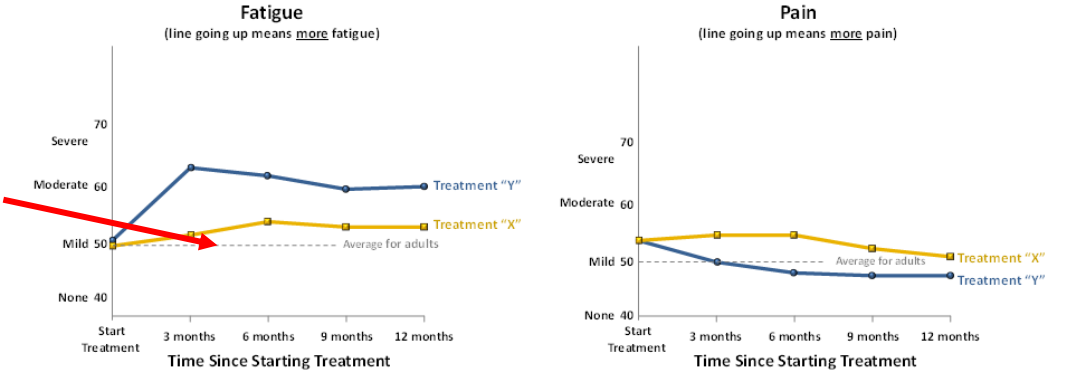
Normed Scoring

The next recommendations address normed scoring. As a reminder, some PRO measures are normed with, for example, a score of 50 representing the general population average. The Consensus Panel recommended displaying the scores based on the questionnaire's scoring metric, whether it is normed or not. Displaying the actual norm is optional.

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



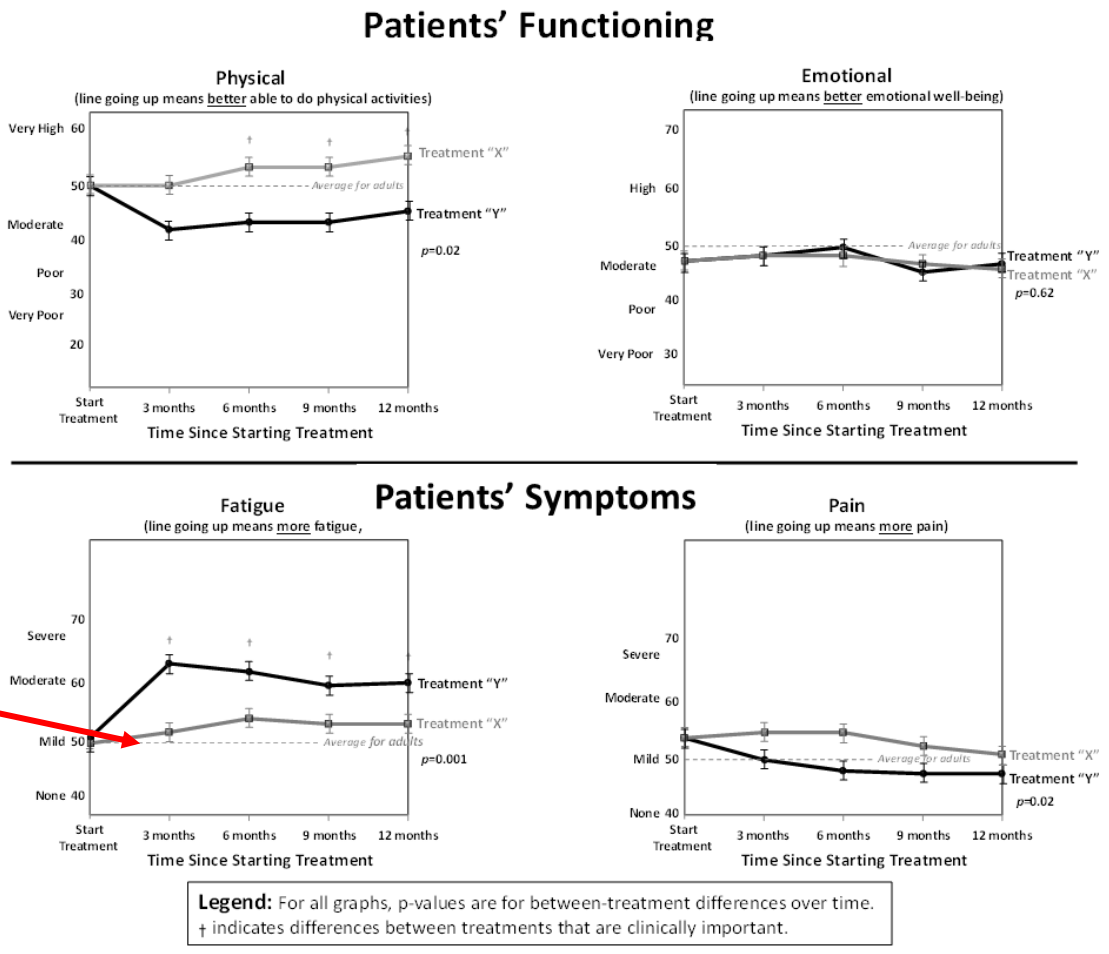
Display reference population norms



The example above shows normed scoring for display to patients. In this case, it does display the general population average of 50 and includes the y-axis descriptive labels. As with the non-normed scoring, the decision of where to position these labels should be evidence-based.

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

Display reference population norms

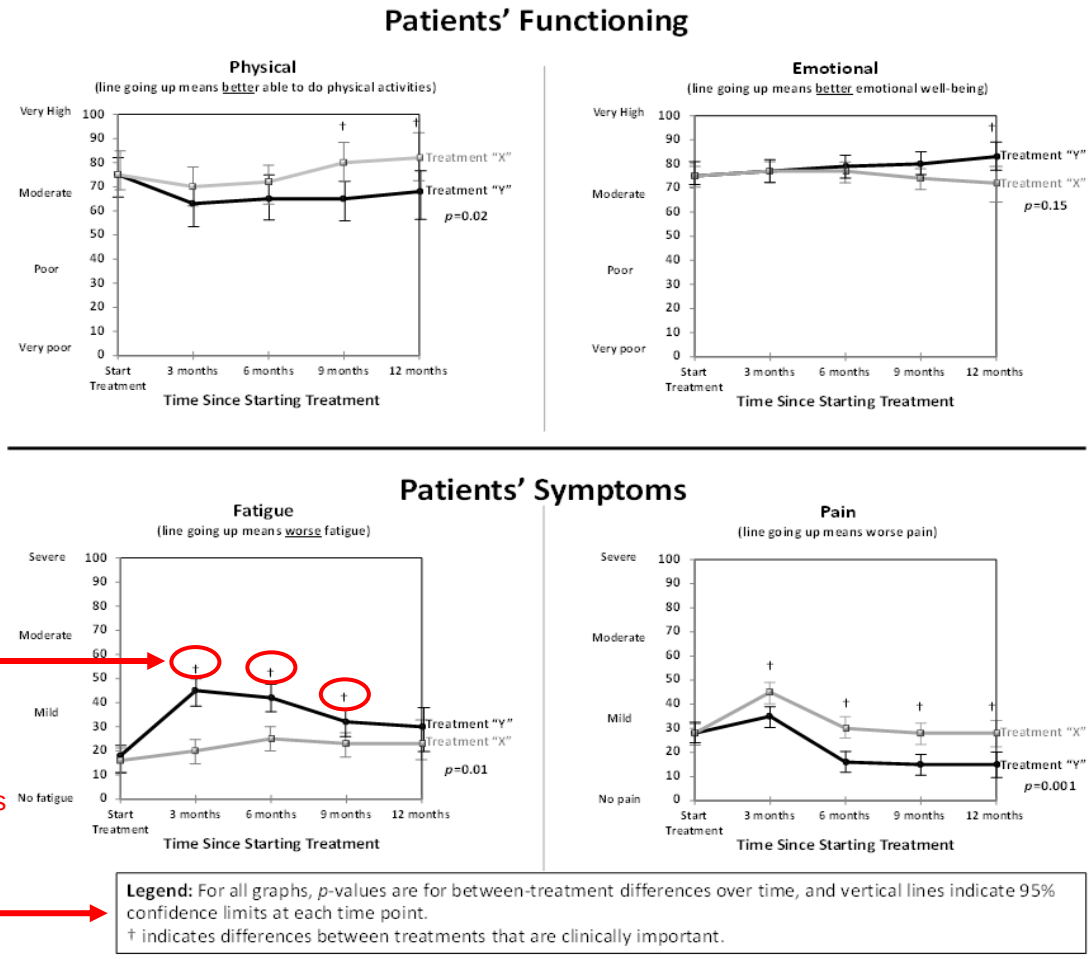


The illustration above provides an example of how to present normed scoring to clinicians/researchers and includes the same annotations as the example for patients.

Clinically Important Differences

The recommendations for PRO data display also address how to indicate whether differences between treatment/intervention arms are clinically important. Although the Consensus Panel agreed it is important for patients to know whether differences are clinically important, there was insufficient evidence to inform how best to convey this information to patients.

For clinicians and researchers, the recommendation is to use a symbol to indicate which differences are clinically important. However, an asterisk should not be used given that it is commonly used to indicate statistical significance in academic journals.



Symbols illustrating clinically important differences between group scores

Legend explanation

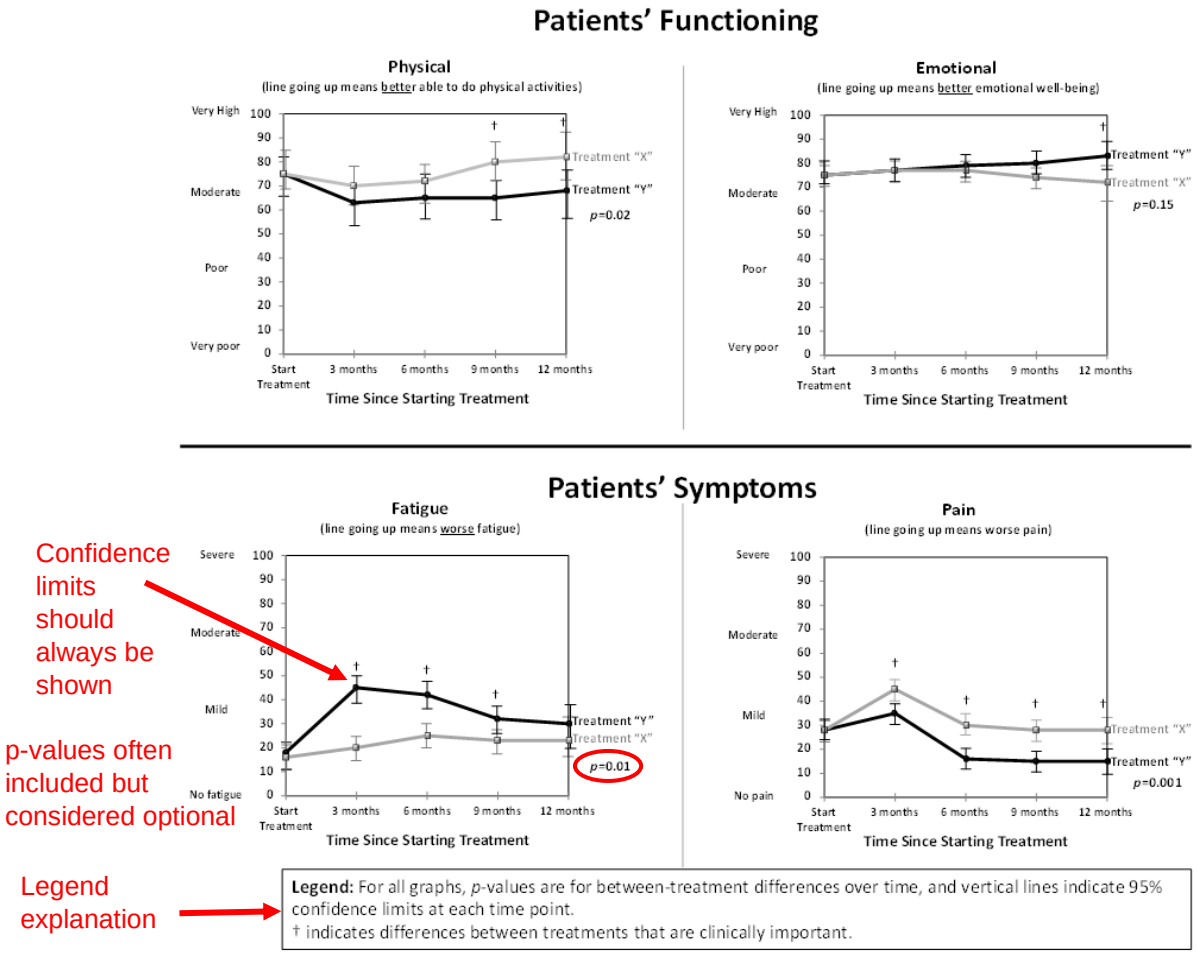
Legend: For all graphs, *p*-values are for between-treatment differences over time, and vertical lines indicate 95% confidence limits at each time point.
† indicates differences between treatments that are clinically important.

In the example above for clinicians/researchers, a cross is used to indicate the time points where the differences are clinically important, and the meaning of this symbol is included in the figure legend.

Conveying Statistical Significance (for clinicians and researchers only)

Finally, while evidence suggests that many patients do not want statistical information included as they find it confusing, many clinicians and researchers were interested in statistical information. For this reason, recommendations regarding how to convey statistical significance only apply for PRO data display to clinicians/researchers.

The consensus-based recommendations are to include confidence intervals in all cases and note that p-values may also be appreciated.



Confidence limits should always be shown

p-values often included but considered optional

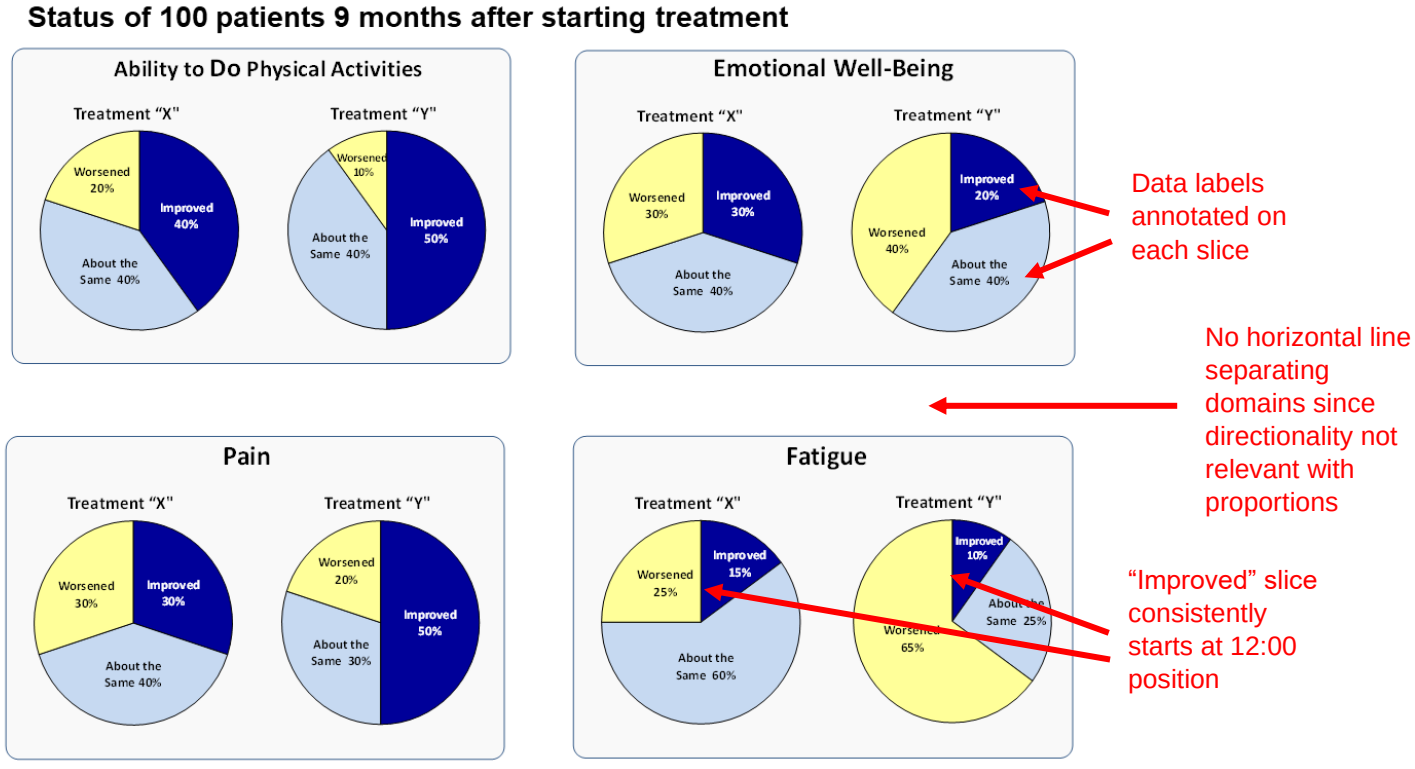
Legend explanation

The example for clinicians and researchers above shows the confidence intervals indicating statistical significance at each time point, and a p-value for the overall difference between groups over time. Both the confidence limits and p-value are explained in the figure legend.

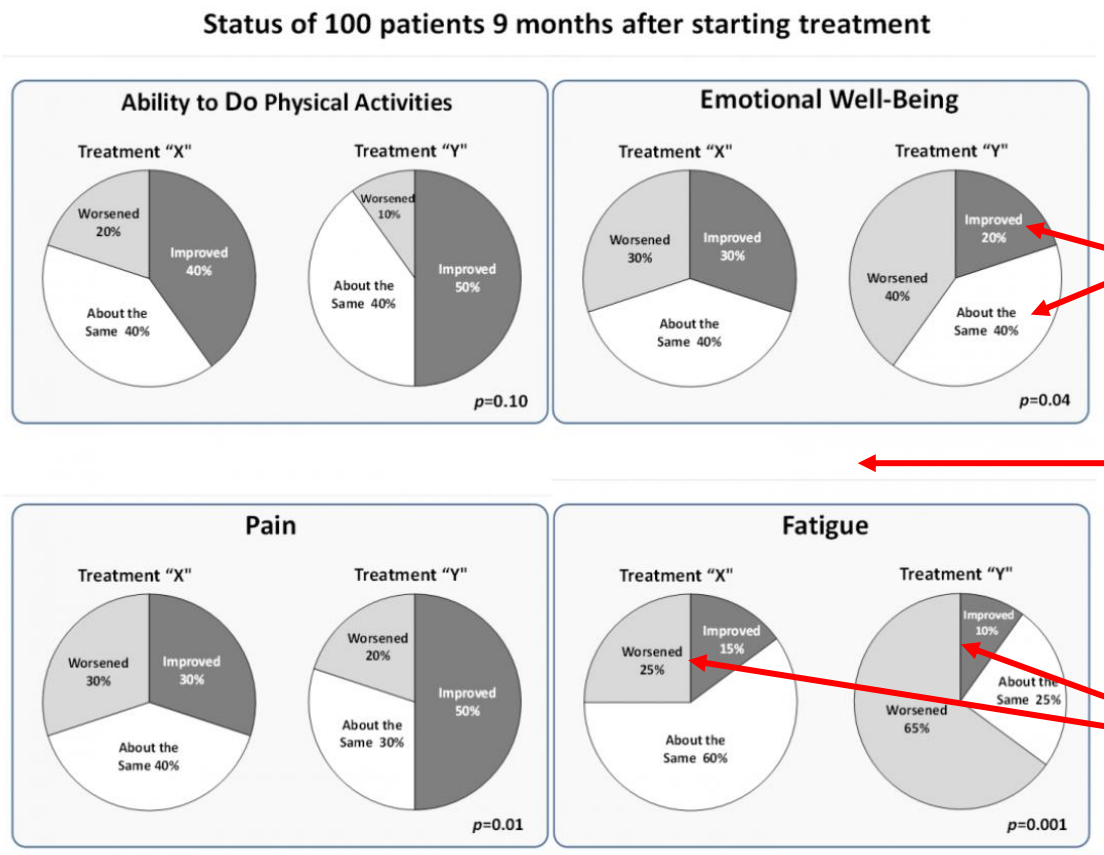
Proportions Changed

Finally, in some instances, clinical trials report the proportion of patients in each arm meeting a responder definition. That is, the proportion of patients who improved, stayed the same, or worsened by some change-score criterion. In cases where a proportion needs to be displayed, the recommendation is to use pie charts for PRO data display to patients. For clinicians and researchers, bar charts, pie charts, or stacked bar charts are reasonable options.

Notably, the evidence supports showing two pie charts with only three slices per pie chart. Showing more than two pie charts or showing more than three slices per pie chart may be more difficult to interpret.

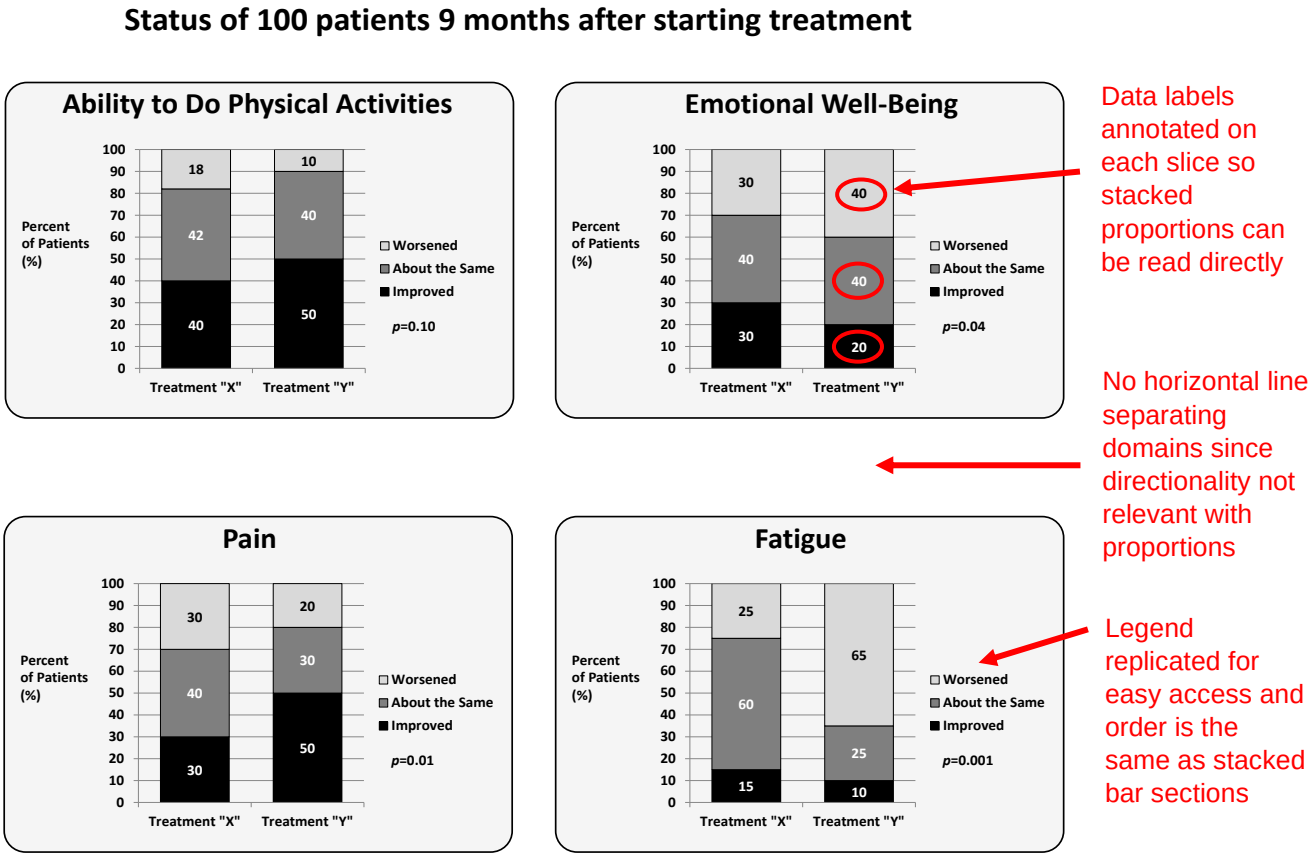


These are example pie charts designed for patients, highlighting specific attributes that aid interpretation of the PRO data display. Each pie slice is labeled directly with the specific percentage and whether improvement, no change, or worsening is represented, negating the need for a legend. Also, the improved pie slice consistently starts at the 12:00 position.



Recommendations for clinicians are similar to those for patients, with the addition of p-values for statistically significant between-arm differences in proportions.

Given that directionality is not an issue with pie charts, there is no separation between the function and symptom domains.



As noted earlier, stacked bar-charts are also appropriate for displaying these responder data to clinicians and researchers. Note that, again, data labels are used to annotate the proportions, and an easily accessible legend is replicated and presented in the same order as the stacked bars.

Checklist for PRO Data Display: Research Results Presented to Patients

Issue	Consensus Statement	Notes/ comments
Directionality of PRO Scores	The Consensus Panel warned against trying to change current instruments–even if only how the data are displayed (e.g., "flipping the axes" where required for symptom scores so that lines going up are always better). PRO data presentation should avoid mixing score direction in a single display.	
Conveying Score Meaning	Descriptive labels (e.g., none/mild/moderate/severe) along the y-axis are helpful and should be used when data supporting their location on the scale are available. In addition to the descriptive y-axis labels, reference values for comparison populations should be considered for inclusion if they are available.	
Normed Scoring	PRO data presentation needs to accommodate instruments the way they were developed, with or without normed scoring. One can decide if/when to show the reference population norm visually (e.g., with a line on the graph), understanding that displaying it might provide additional interpretive value, but potentially at the cost of greater complexity. Comparison to the norm might be less relevant in the context where the primary focus is the choice between treatments. If a norm is displayed: • It is necessary to describe the reference population and label the norm as clearly as possible (recommend "average" rather than "norm") • It also requires deciding what reference population to show (to the extent that options are available). • It will need to be explained to patients that this normed population may not be applicable to a given patient.	
Clinically Important Differences	Patients may find information regarding clinically important differences between treatments to be confusing, but it is important for them to know what differences "matter" if they are going to make an informed decision.	
Proportions Changed	Pie charts are the preferred format for displaying proportion meeting a responder definition (improved, stable, worsened), so long as the proportion is also indicated numerically.	

Checklist for PRO Data Display: Research Results Presented to Clinicians/Researchers

Issue	Consensus Statement	Notes/ comments
Directionality of PRO Scores	PRO data presentation should avoid mixing score direction in a single display. In cases where this is not possible, authors should consider changing the directionality in the display to be consistent. There is a need for exceptionally clear labeling, titling, and other annotations.	
Conveying Score Meaning	Descriptive labels (e.g., none/mild/moderate/severe) along the y-axis are helpful and should be used when data supporting their location on the scale are available. In addition to the descriptive y-axis labels, reference values for comparison populations should be considered for inclusion if they are available.	
Normed Scoring	PRO data presentation needs to accommodate instruments the way they were developed, with or without normed scoring. One can decide if/when to show the reference population norm visually (e.g., with a line on the graph), understanding that displaying it might provide additional interpretive value, but potentially at the cost of greater complexity. Display of the norm might be less relevant in the context where the primary focus is the choice between treatments. If a norm is displayed: • It is necessary to describe the reference population and label the norm as clearly as possible (recommend “average” rather than “norm”) • It also requires deciding what reference population to show (to the extent that options are available).	
Clinically Important Differences	Clinically important differences between treatments should be indicated with a symbol of some sort (described in a legend). The use of an asterisk is not recommended (as it is often used to indicate statistical significance). If there is no defined clinically important difference, that also needs to be in the legend and/or the text of the paper.	
Conveying Statistical Significance	The data suggest that clinicians and others appreciate p-values; however, the Consensus Panel recognizes a move away from reporting them (and toward the use of confidence limits to illustrate statistical significance). Regardless of whether p-values are reported, confidence intervals should always be displayed.	
Proportions Changed	Reasonable options include bar charts, pie charts, or stacked bar charts.	

References

Snyder C, Smith K, Holzner B, Rivera YM, Bantug E, Brundage M; PRO Data Presentation Delphi Panel. Making a picture worth a thousand numbers: Recommendations for graphically displaying patient-reported outcomes data. *Qual Life Res*. 2019;28:345-356.

Further Reading

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 Educ Couns*. 99;483-490; 2016.

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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. *Qual Life Res*.28:609-20;2019.

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