

PRO Data Display Guidance Checklist: Research Results Presented to Patients

Issue	Consensus Statement	Notes/ comments
Directionality of PRO Scores	<p>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).</p> <p>PRO data presentation should avoid mixing score direction in a single display.</p>	
Conveying Score Meaning	<p>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.</p> <p>In addition to the descriptive y-axis labels, reference values for comparison populations should be considered for inclusion if they are available.</p>	
Normed Scoring	<p>PRO data presentation needs to accommodate instruments the way they were developed, with or without normed scoring.</p> <p>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.</p> <p>Comparison to the norm might be less relevant in the context where the primary focus is the choice between treatments.</p> <p>If a norm is displayed:</p> <ul style="list-style-type: none"> • 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	<p>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.</p>	
Proportions Changed	<p>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.</p>	