

Table e-1. Patient-reported outcome measures reviewed for individuals with NF1  $\geq$  8 years of age

| Domain               | PRO measure   |
|----------------------|---|
| Pain Intensity       | <ul style="list-style-type: none"> <li>• Numeric Rating Scale-11</li> <li>• Visual Analog Scale</li> <li>• Faces Pain Scale – Revised</li> <li>• Colored Analog Scale</li> <li>• Oucher</li> <li>• Pieces of Hurt</li> </ul>  |
| Pain Interference    | <ul style="list-style-type: none"> <li>• Pain Interference Index</li> <li>• PROMIS – Pain Interference</li> <li>• Brief Pain Inventory</li> <li>• Neuro-QOL – Pain/Pain Interference</li> <li>• Pain Impact Questionnaire</li> <li>• Multidimensional Pain Inventory</li> <li>• Child Activities and Limitations Questionnaire</li> </ul> |
| Physical Functioning | <ul style="list-style-type: none"> <li>• PROMIS – Physical Functioning</li> <li>• Health Assessment Questionnaire</li> <li>• Functional Disability Index</li> <li>• Pediatric Outcomes Data Collection Instrument</li> <li>• Neuro-QOL Lower Extremity and Upper Extremity</li> <li>• Activities Scale for Kids</li> </ul>                |

Note: When available, all versions (child, parent, adult) of the above PRO measures were reviewed.

