

**NINDS CDE Notice of Copyright  
International Pediatric Mitochondrial Disease Score (IPMDS)**

<b>Availability:</b>	Freely available as soon as the instrument has been validated
<b>Classification:</b>	Exploratory for pediatric Mitochondrial Disease
<b>Short Description of Instrument:</b>	<p>The instrument was designed to measure general disease severity in the whole spectrum of children (? – 18 years) with mitochondrial disease. The IPMDS consists of 3 domains:</p> <ol style="list-style-type: none"> <li>1. Complaints and symptoms (23 questions)</li> <li>2. Physical examination (21 items)</li> <li>3. Functional abilities (13 items ≥ 6 years of age; 10 &lt; 6 years of age)</li> </ol>
<b>Comments/Special instructions:</b>	<p><b>Scoring:</b> The score is calculated by dividing the patient’s score by the maximal score for that patient (some items may be left out for several reasons).</p> <p>In order to familiarize examiners with the utilization of the IPMDS and its scoring principles, a training session, in which the items are practiced in a in a roleplay at least twice, is recommended. There is also an instructional video.</p> <p>In order to familiarize examiners with the utilization of the IPMDS and its scoring principles, a training session, in which the items are practiced in a in a roleplay at least twice, is recommended. There is also an instructional video.</p> <p><b>Administration:</b> about 30 minutes, by a trained physician (history taking, physical examination and functional abilities)</p>
<b>Rationale/Justification:</b>	<p><b>Strengths/Weaknesses:</b></p> <p>Limitations for use in mitochondrial disease patients: Time consuming, although the exercises are fun to perform it may be a burden to the patient, dependent on patient cooperation (functional abilities)</p> <p>Advantages for use in mitochondrial disease patients: Generally applicable, measures patient important symptoms and functions, may be sensitive to change.</p> <p>Validations studies testing feasibility, inter- and intrarater reliability, test-retest reliability and validity are currently running.</p> <p>This instrument has not yet been used, but it has been tested in children aged 0-18 years.</p>
<b>References:</b>	No reference yet