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### EuroQoL-5 Dimension Questionnaire (EQ-5D)

<b>Availability:</b>	Must register the study in which EQ-5D is to be used by completing the EQ-5D registration form (visit <a href="#">EuroQoL-5 Dimension Questionnaire website</a> ). The EuroQoL Executive Office will then contact by e-mail and inform about the terms and conditions which apply to your use of the EQ-5D, including licensing fees (if applicable). Please allow three working days to receive this reply. Licensing fees are determined by the EuroQoL Executive Office on the basis of the user information provided. The amount is dependent upon the type of study, size and/or number of users and requested languages. Without the prior written consent of the EuroQoL Executive Office, you are not permitted to use, reproduce, alter, amend, convert, translate, publish or make available in whatever way (digital, hard-copy etc.) the EQ-5D and related proprietary materials. Any and all copyrights in the EQ-5D, its (digital) representations, and its translations exclusively vest in the EuroQoL Group. EQ-5D™ is a trade mark of the EuroQoL Group.
<b>Classification:</b>	<b>Supplemental - Highly Recommended:</b> Stroke (based on study type, disease stage and disease type) and Parkinson’s Disease (PD) <b>Supplemental:</b> Amyotrophic Lateral Sclerosis (ALS), Headache, Multiple Sclerosis (MS), Neuromuscular Disease (NMD), Spinal Cord Injury (SCI) and Traumatic Brain Injury (TBI) <b>Exploratory:</b> Huntington’s Disease (HD) and Mitochondrial Disease (Mito)

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<b>Short Description of Instrument:</b>	<p><b>Construct measured:</b> Quality of Life / Self-reported Patient Satisfaction</p> <p><b>Generic vs. disease specific:</b> Generic</p> <p><b>Means of administration:</b> Self-Administered</p> <p><b>Intended respondent:</b> Patient</p> <p><b># of items:</b> 5</p> <p><b># of subscales and names of sub-scales:</b> N/A</p> <p><b># of items per sub-scale:</b> N/A</p> <p>EQ-5D, the adult version, can be used for youth over 16</p> <p>For children aged 4–7 a proxy version can be used.</p> <p>Two proxy versions:</p> <ul style="list-style-type: none"><li>a) Proxy 1: The proxy rates how he /she rates the health of the child</li><li>b) Proxy 2: The proxy rates how he/she thinks the child would rate his/her own state if he/she were asked directly and could communicate it.</li></ul> <p>It is recommended to use Proxy 1 (if applicable) and can be applied to children from 4–7 years and to children over 8 years who are not able to complete the EQ-5DY themselves.</p> <p>EQ-5D specific to teenagers and adults, but there is a EQ-5D-Y. (EQ-5D-Youth version) which is an EQ-5D-3L self complete version for children and adolescents aged 7-12.</p> <p>The EQ-5D consists of two parts: the EQ-5D section and the EQ VAS section. These sections provide a composite picture of the respondent's health status. The EQ-5D consists of 5 questions (representing 5 dimensions of mobility, self-care, usual activities, pain/discomfort, and anxiety/depression) each with a single digit response option. The EQ VAS generates a self-rating of health-related quality of life.</p> <p>Studies have found moderate agreement between responses from patients and those from their proxies for some of the domains of the EQ-5D and the agreement between patient and proxy is the best when assessed at six months, rather than two to three weeks, after stroke. Reproducibility is better when patients completed the instrument instead of their proxies. The relationship between the EQ-5D and the Barthel Index and mapping the modified Rankin Scale to the EQ-5D have been explored. With the exception of mental health domain of the SF-36, EQ-5D and SF-36 measure similar domains with similar test-retest reliability.</p>
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<b>Comments/Special instructions:</b>	<p><b>Scoring:</b> Each of the 5 EQ-5D descriptive dimensions has 3 levels: no problems, some problems, severe problems. The respondent indicates his/her health state by ticking in the box against the most appropriate statement in each of the 5 dimensions. This decision results in a 1-digit number expressing the level selected for that dimension. The digits for 5 dimensions can be combined in a 5-digit number describing the respondent's health state. It should be noted that the numerals 1-3 have no arithmetic properties and should not be used as a cardinal score. Missing values should be coded as '999'. Ambiguous values (e.g. the line crosses the VAS twice) should be treated as missing values.</p> <p><b>Background:</b> EQ-5D is a standardized measure of health status developed by the EuroQol Group in order to provide a simple, generic measure of health for clinical and economic appraisal. Applicable to a wide range of health conditions and treatments, it provides a simple descriptive profile and a single index value for health status that can be used in the clinical and economic evaluation of health care as well as in population health surveys. The EQ-5DY is the child-friendly version of the EQ-5D, with language modifications, such as changing the word "depression" to "sad" (Burström et al., 2011). The main differences between the EQ-5D and the EQ-5D-Y are revisions to domain definitions, introduction of age-appropriate wording and adaptations to layout. The purpose of the adaptation was to clarify the meaning of dimensions for younger respondents and to establish that items referred exclusively to health-related impairment and not to age-related difficulties. For example, "self-care" was modified to "looking after myself" and the usual activities domain listed going to school, hobbies, sports, playing, and doing things with family or friends as the examples of activities (Burström et al., 2014; Wille et al., 2010).</p>
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<b>Rationale/ Justification:</b>	<p><b>Strengths/ Weaknesses:</b> The EQ-5D self-report questionnaire (EQ-5D) essentially consists of two pages comprising the EQ-5D descriptive system (page 2) and the EQ VAS (page 3). There is also an optional page of demographic questions. There is also an extended version of EQ-5D that incorporates the valuation task but this is only used for valuation studies and is not relevant for clinical users.</p> <p><b>Mitochondrial Disease specific advantages:</b></p> <p>This is a simple and well validated scale with no recall bias as it asks for status "right now". It also has visual analog scale which can be used for longitudinal assessments of mitochondrial patients. It is a good "quick" questionnaire, translated in many languages and although non-specific to mitochondrial disease, it is deemed helpful in capturing data in the pediatric group as a supplement to a more elaborate questionnaire.</p> <p><b>Mitochondrial Disease specific limitations:</b></p> <p>Generic, non disease specific. Might not capture all the nuances of the intricate mitochondrial patients limitations. No instrument for children under the age of 7.</p> <p><b>Psychometric Properties:</b> Test-retest reliability: ICC =.81 (Canadian study population); Construct validity: Spearman correlation with other utility measures: SF-6D, r=.70; HUI-III, r=0.80; Correlates with EDSS: Spearman r= -.66 in a Canadian study population, Pearson r= -.54 in a German study population; 9HPT: r= - 0.56; timed 25-foot walk: r= -.63; ambulation index: r= -.68; Ceiling effects may be evident in patients with less marked disability.</p> <p><b>Administration:</b> EQ-5D is designed for self-completion by respondents and is ideally suited for use in postal surveys, in clinics, and in face-to-face interviews. It is cognitively undemanding, taking only a few minutes to complete. Instructions to respondents are included in the questionnaire. It is currently available in 102 languages.</p> <p><b>Feasibility/validity:</b> Feasibility and discriminative validity of the EQ-5D-Y was supported in a Swedish patient sample with children and adolescents with functional disability, but additional studies with more participants are necessary (Burström et al., 2014).</p>
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<b>References:</b>	<p>Additional References:</p> <p>Burström K, Bartonek A, Brostrom EW, Sun S, Egmar AC. EQ-5D-Y as a health-related quality of life measure in children and adolescents with functional disability in Sweden: testing feasibility and validity. <i>Acta Paediatr.</i> 2014;103(4):426–435.</p> <p>Burström K, Egmar AC, Lugner A, Eriksson M, Svartengren M. A Swedish child-friendly pilot version of the EQ-5D instrument--the development process. <i>Eur J Public Health.</i> 2011;21(2):171–177.</p> <p>Noyes J &amp; Edwards RT. EQ-5D for the assessment of health-related quality of life and resource allocation in children: a systematic methodological review. <i>Value Health.</i> 2011;14(8):1117–1129.</p> <p>Wille N, Badia X, Bonsel G, Burström K, Cavrini G, Devlin N, Egmar AC, Greiner W, Gusi N, Herdman M, Jelsma J, Kind P, Scalone L, Ravens-Sieberer U. Development of the EQ-5D-Y: a child-friendly version of the EQ-5D. <i>Qual Life Res.</i> 2010;19(6):875–886.</p>
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