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EuroQoL-5 Dimension Questionnaire-Youth (EQ-5DY)

Availability:	<p>Must register the study in which EQ-5D is to be used by completing the EQ-5D registration form (visit EuroQol-5 Dimension Questionnaire website). The EuroQol Executive Office will then contact by e-mail with information regarding the terms and conditions which apply to 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) 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.</p>
Classification:	<p>Exploratory: Cerebral Palsy (CP)</p> <p>Supplemental: Chiari I Malformation (CM), Spinal Cord Injury (SCI)-Pediatric (ages 8–16)</p>
Short Description of Instrument:	<p>Construct measured: Quality of Life / Self-reported Patient Satisfaction</p> <p>Generic vs. disease specific: Generic</p> <p>Means of administration: Self-Administered</p> <p>Intended respondent: Patient</p> <p># of items: 5</p> <p># of subscales and names of sub-scales: N/A</p> <p># of items per sub-scale: N/A</p> <p>The EQ-5DY consists of two parts: the EQ-5DY section and the EQ VAS section. These sections provide a composite picture of the respondent's health status. The EQ-5DY consists of 5 questions (representing 5 dimensions of mobility, self-care, usual activities, pain/discomfort, and feeling worried, sad or unhappy) each with a single digit response option. The EQ VAS generates a self-rating of health-related quality of life where the endpoints are labeled “The best health you can imagine” and “The worst health you can imagine.”</p>

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Comments/Special instructions:	<p>Scoring: Each of the 5 EQ-5DY 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 ‘9’. Ambiguous values (e.g., the line crosses the VAS twice) should be treated as missing values.</p> <p>Background: 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> <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"> a) Proxy 1: The proxy rates how he /she rates the health of the child 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. <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>
Rationale/ Justification:	<p>Administration: EQ-5DY 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.</p> <p>Feasibility/validity: 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> <p>It has been translated into several languages.</p>

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References:	<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 & 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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