

DISABKIDS Chronic Generic Module (DCGM-37)

<p>Availability:</p>	<p>Please visit this website for more information about the instrument: DISABKIDS Costs depend on the research. Use of the questionnaire for not-funded and government funded academic research is free but investigators must purchase the DISABKIDS Manual and complete a Collaboration Form. There are costs associated with using the test in commercial studies.</p>
<p>Classification: Short Description of Instrument:</p>	<p>Supplemental: Cerebral Palsy (CP) and Epilepsy</p> <p>Description: This quality of life in chronic disease tool was developed concurrently by researchers from seven European countries (Austria, France, United Kingdom, Netherlands, Sweden, Greece and Germany), all following the same steps. In addition to the generic module, there are seven disease-specific modules, one of which is epilepsy.</p> <p>The DISABKIDS chronic generic module (DCGM-37) consists of 37 Likert-scaled items assigned to six dimensions: Independence, Emotion, Social inclusion, Social exclusion, Limitation, and Treatment. Pilot test results denoted satisfactory internal consistencies of these scales (Petersen, et al., 2004), ranging from $\alpha = .79$ (Social inclusion) to $\alpha = .90$ (Emotion). The sub-scales of these six dimensions of the DCGM-37 can be combined to produce a general score for health-related quality of life (HRQoL), denoted as the DCGM-37 total score. The six sub-scales are additionally associated with three domains, denoted as mental, social, and physical. These HRQoL domains have evolved from the mental, social and physical domains of HRQoL, as conceptualised by the WHO.</p> <p>Scores are averages of the total scores for a dimension. The dimension can be scored if there is no more than one item missing for the dimension. The total health related quality of life is the sum of all dimensions scores rescaled (and transposed) to 0-100, with 100 being the highest quality of life.</p> <p>The instrument has been validated for use in the following languages: English, French, German, Dutch, Greek, and Swedish. All forms of the instrument appear in all these languages.</p> <p>It is usable for children between the ages of 8 to 16 years. There is a proxy version.</p> <p>There is also a short form and a “Smiley Measure”. DISABKIDS Chronic Generic Measure – short form (DCGM-12) is derived from the DCGM-37 and can form 3 domains: mental social and physical. Also a Total score available.</p> <p>DISABKIDS Smiley Measure. Parent report version plus a 6 item version scored on a 5 point scale of smiley faces very happy to very sad. Simple and fast to complete (5 minutes) and is aimed at cognitive levels of children between 4 to 7 developmental years to complete themselves or with help. It can also be used for children above 7 years who have not reached the level of reading ability necessary for the completion of the generic DISABKIDS questionnaire. It takes approximately 5 minutes to complete.</p> <p>Whereas, KIDSCREEN has developed a generic quality of life measure for any child (Ravens-Sieberer et al., 2006). DISABKIDS have developed 2 additional layers of HRQoL (Baars et al., 2005; Carlon et al., 2010; Petersen et al., 2004): i) Chronic generic measures – for use with any child with a chronic condition – facilitates comparison of HRQoL across conditions ii) Condition specific modules for 7 specific conditions, one of which is cerebral palsy. Condition-specific modules exist for asthma, arthritis, cerebral palsy, cystic fibrosis, dermatitis, diabetes, and epilepsy. Developed based on grounded theory</p>

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<p>Description of Instrument, continued:</p>	<p>thus considered to have some content (face) validity (Petersen et al., 2004; 2005). Good internal reliability alpha .71 – .91 (3). Interrater reliability .14 – .84 across scales (Petersen et al., 2004; 2005). No information on measurement error or responsiveness to change (Petersen et al., 2004; 2005).</p> <p>The DISABKIDS Epilepsy module has been developed as a supplement to the chronic generic module and includes two scales – Impact, which includes anxiety about having seizures and the potential public stigma (5 items) and Social which assesses self-esteem and comparison to others (5 items), in both child and parent versions for the 8-16 year olds and a proxy/parent version for the 4–7 year olds. The scale is measured between 0-100, higher values indicate better adjustment to the epilepsy. Internal consistency values are $\alpha = .90$ for the Impact scale, and .83 for the Social scale.</p> <p>The DISABKIDS Cerebral Palsy module is a 14-item disease specific questionnaire that focuses around the impact of the condition, as well as 2 further items on communications about the conditions. Higher scores indicate better quality of life. The scale is measured between 1-100, higher values indicate better adjustment to the cerebral palsy. Internal consistency values were $\alpha = .80$ for the Impact scale, and $\alpha = .72$ for the Communication scale.</p> <p>Particular Features: The instrument can be done either by paper or using a computer program called RUNQUEST with very minimal computer hardware requirements. The DISABKIDS is copyrighted and is available for a cost.</p> <p>Psychometric Properties: Internal consistency reliabilities (Cronbach's alpha) between 0.70-0.87 and test-retest reliability (ICC: 0.71–0.83). Discriminant validity was shown by girls showing lower quality of life than boys on the physical and emotional domains, adolescents showing lower emotional scores than younger children, family affluence is associated with higher quality of life in all domains and dimensions as is a higher score on the Clinical Global Impression scale. Internal consistency values on the epilepsy scale are $\alpha = 0.90$ for the Impact scale, and 0.83 for the Social scale. Sensitivity to Change: Not tested.</p> <p>Relationships to other variables: DISABKIDS were related to the International Classification of Functioning, Disability and Health (ICF) scales and showed differences and similarities between generic and condition-specific DISABKIDS modules.</p> <p>Strengths and Weaknesses: Strengths: The chronic generic module can be used in conjunction with any of the condition specific modules including the epilepsy module. It has a wide age range. It is available to use internationally because of the concurrent development process in several countries. Weaknesses: Not used or validated in the US. Copyrighted.</p> <p>Source for Materials and Permissions: Prof. Dr. Monika Bullinger Department of Medical Psychology University Hospital of Hamburg-Eppendorf Martinistr. 52, Pav. 69 20246 Hamburg</p>
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<p>Comments / Special Instructions:</p>	<p>Cerebral Palsy module: Developed based on grounded theory thus considered to have some content (face) validity (Petersen et al., 2004; 2005). Good Internal reliability alpha .71-.91 (3). Interrater reliability .14-.84 across scales (Petersen et al., 2004; 2005). No information on measurement error or responsiveness to change.</p>
<p>References:</p>	<p>Key References: Simeoni MC, Schmidt S, Muehlan H, Debensason D, Bullinger M, Group TD. Field testing of a European quality of life instrument for children and adolescents with chronic conditions: the 37-item DISABKIDS Chronic Generic Module. <i>Qual Life Res.</i> 2007; 16(5): 881-893.</p> <p>The DISABKIDS Group. DISABKIDS: The DISABKIDS Group; 2012 [cited 2016 28 June]. Available from: http://www.disabkids.org/questionnaire/disabkids-disease-modules/cerebral-palsy-module/.</p> <p>The DISABKIDS Group. Summary of DISABKIDS Instruments 2012 [cited 2016 06 January]. Available from: http://www.disabkids.org/disabkids-project/instruments/.</p> <p>Additional References:</p> <p>Baars RM, Atherton CI, Koopman HM, Bullinger M, Power M. The European DISABKIDS project: development of seven condition-specific modules to measure health related quality of life in children and adolescents. <i>Health Qual Life Outcomes.</i> 2005;3:70.</p> <p>Carlson S, Shields N, Yong K, Gilmore R, Sakzewski L, Boyd R. A systematic review of the psychometric properties of Quality of Life measures for school aged children with cerebral palsy. <i>BMC Pediatr.</i> 2010;10:81.</p> <p>Fava L, Muehlan H, Bullinger M. Linking the DISABKIDS modules for health-related quality of life assessment with the International Classification of Functioning, Disability and Health (ICF). <i>Disab Rehab.</i> 2009;31(23):1943-1954.</p> <p>Petersen C, Schmidt S, Bullinger M. Brief report: Development and pilot testing of a coping questionnaire for children and adolescents with chronic health conditions. <i>J Pediatr Psychol.</i> 2004;29(8):635-640.</p> <p>Petersen C, Schmidt S, Power M, Bullinger M. Development and pilot-testing of a health-related quality of life chronic generic module for children and adolescents with chronic</p>

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