

# Resource Summary Report

Generated by [NIF](#) on Apr 26, 2025

## DISABKIDS

RRID:SCR\_008614

Type: Tool

### Proper Citation

DISABKIDS (RRID:SCR\_008614)

### Resource Information

**URL:** <http://www.disabkids.de>

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**Description:** DISABKIDS is a European project which aims at enhancing the quality of life and the independence of children with chronic health conditions and their families. The project proceeds according to three phases: 1. Development of an instrument (paper/pencil as well as a computer assisted version) to assess quality of life and patient needs in children/adolescents with chronic health conditions. 2. Psychometric testing of the developed instrument in the 7 participating countries in a pilot study with 378 children/ adolescents and a subsequent field study with 1260 children/adolescents and their families (180 families in each country). 3. Implementation and Evaluation of the instrument in routine care The project expects to achieve progress in quality of life assessment in children and adolescents with disabilities a) by focussing on an European co-operation in construction of an assessment instrument for quality of life, in which the persons concerned (children/adolescents and their families) play a major role, b) by addressing needs for care as explicitly voiced by the persons concerned, c) by including psychosocial as well as clinical and socio-economic determinants of quality of life and d) by developing a mode of administration which is practicable for the patient group concerned, so that in using the instrument, current care can be evaluated and future care can be improved by corresponding to the patients' needs. Sponsors: The DISABKIDS project funded by the European Commission within the Fifth Framework Programme (FP5)

**Synonyms:** disabkids

**Resource Type:** software resource

**Funding:**

**Resource Name:** DISABKIDS

**Resource ID:** SCR\_008614

**Alternate IDs:** nif-0000-31962

**Record Creation Time:** 20220129T080248+0000

**Record Last Update:** 20250420T014431+0000

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## Ratings and Alerts

No rating or validation information has been found for DISABKIDS.

No alerts have been found for DISABKIDS.

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## Data and Source Information

**Source:** [SciCrunch Registry](#)

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## Usage and Citation Metrics

We found 24 mentions in open access literature.

**Listed below are recent publications.** The full list is available at [NIF](#).

Hidestrand P, et al. (2025) Impact of Underweight, Overweight, and Obesity on Health-Related Quality of Life in Children with Tetralogy of Fallot Variants. *Pediatric cardiology*, 46(2), 355.

Hormazábal-Aguayo I, et al. (2024) Comprehensive management of children and adolescents with type 1 diabetes mellitus through personalized physical exercise and education using an mHealth system: The Diactive-1 study protocol. *Frontiers in endocrinology*, 15, 1354734.

Truningr MI, et al. (2024) The PompeQoL questionnaire: Development and validation of a new measure for children and adolescents with Pompe disease. *Journal of inherited metabolic disease*, 47(6), 1348.

Agenäs H, et al. (2023) Treatment with pollen allergen immunotherapy improves health-related quality of life in children and adolescents: a three-year follow-up-study. *Allergy, asthma, and clinical immunology : official journal of the Canadian Society of Allergy and Clinical Immunology*, 19(1), 4.

Mathiesen AS, et al. (2023) Self-determination theory interventions versus usual care in people with diabetes: a systematic review with meta-analysis and trial sequential analysis.

Systematic reviews, 12(1), 158.

Kembe J, et al. (2023) Experiences of participation in activities among girls with juvenile idiopathic arthritis: A qualitative study. *Journal of child health care : for professionals working with children in the hospital and community*, 27(4), 599.

Karande S, et al. (2022) Parental-perceived health-related quality of life of school students with borderline intellectual functioning: A cross-sectional questionnaire-based study in Mumbai, Maharashtra, India. *Journal of postgraduate medicine*, 68(4), 213.

Rihm L, et al. (2022) The psychosocial situation of families caring for children with rare diseases during the COVID-19 pandemic: results of a cross-sectional online survey. *Orphanet journal of rare diseases*, 17(1), 449.

Giannakoulakos S, et al. (2022) Physical Activity and Quality of Life among Patients with Cystic Fibrosis. *Children (Basel, Switzerland)*, 9(11).

Brod M, et al. (2021) Psychometric Validation of the Growth Hormone Deficiency-Child Impact Measure (GHD-CIM). *Pharmacoeconomics - open*, 5(3), 505.

Alelayan H, et al. (2021) Assessing health-related quality of life in Chinese children and adolescents with cancer: validation of the DISABKIDS chronic generic module (DCGM-37). *BMC cancer*, 21(1), 204.

Papapostolou G, et al. (2021) Cognitive dysfunction and quality of life during pollen season in children with seasonal allergic rhinitis. *Pediatric allergy and immunology : official publication of the European Society of Pediatric Allergy and Immunology*, 32(1), 67.

Muehlan H, et al. (2021) A Short Form of the Child/Youth Health Care Questionnaire on Satisfaction, Utilization, and Needs in Children and Adolescents with a Chronic Condition (CHC-SUN-SF/YHC-SUN-SF). *International journal of environmental research and public health*, 18(22).

Svensson B, et al. (2020) Health-Related Quality of Life in Children With Earlier Surgical Repair for Right Ventricular Outflow Tract Anomalies and the Agreement Between Children and Their Parents. *Frontiers in cardiovascular medicine*, 7, 66.

Felix J, et al. (2020) Health related quality of life associated with extreme obesity in adolescents - results from the baseline evaluation of the YES-study. *Health and quality of life outcomes*, 18(1), 58.

Sasaki H, et al. (2018) Assessing health-related quality of life in Japanese children with a chronic condition: validation of the DISABKIDS chronic generic module. *Health and quality of life outcomes*, 16(1), 85.

Lundberg V, et al. (2017) Health-related quality of life among Swedish children with Juvenile Idiopathic Arthritis: parent-child discrepancies, gender differences and comparison with a European cohort. *Pediatric rheumatology online journal*, 15(1), 26.

Radsel A, et al. (2017) Health-related quality of life in children and adolescents with cerebral palsy. *Zdravstveno varstvo*, 56(1), 1.

Sasaki H, et al. (2017) Assessing health-related quality of life in young Japanese children with chronic conditions: Preliminary validation of the DISABKIDS smiley measure. *BMC pediatrics*, 17(1), 100.

Öborn H, et al. (2016) Associations between lower urinary tract dysfunction and health-related quality of life in children with chronic kidney disease. *Acta paediatrica (Oslo, Norway : 1992)*, 105(8), 959.