

***Executive summary***

**Quality-of-life measures in chronic diseases of childhood**

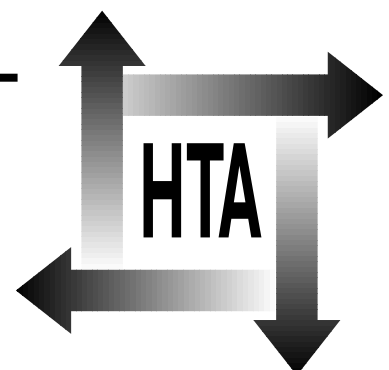
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## Executive summary

### Scope of the report

This report is concerned with the evaluation of measures broadly designed to measure quality of life (QoL) in children and adolescents, either by self-report or proxy raters. Four research questions were identified.

- To what extent are adult measures used in the evaluation of healthcare interventions in children?
- How appropriate are adult measures for use with children?
- To what extent do child self-reports correspond with assessments made by parents and carers?
- How feasible and reliable are proxy measures of QoL in different disease contexts?

### Objectives

- To review the state of the art with regard to measurement of QoL for children.
- To make recommendations regarding the value of currently available measures for different purposes.
- To identify further research needs.

### Method

Electronic databases were searched for the period 1980–July 1999 for articles relating to measures of QoL, health status or well-being in children (under 18 years) with chronic disease. Handsearching of relevant journals and cross-referencing with reference lists in identified articles was also carried out. Key workers in the field were contacted for additional information, and the Internet was searched for relevant websites.

### Results

Forty-three measures were identified (19 generic and 24 disease-specific). Sixteen measures allowed for completion by children and parent/caregiver; seven only allowed for completion by a proxy, and the remainder ( $n = 17$ ) allowed only for child completion.

The measures were described as QoL ( $n = 30$ ), health status, ( $n = 2$ ), perception of illness ( $n = 1$ ), life satisfaction ( $n = 1$ ) and quality of well-being ( $n = 1$ ).

### To what extent are adult measures used in the evaluation of healthcare interventions in children?

Three studies were identified where adult measures were used with very few changes made for children. In 11 studies involving nine separate measures of QoL, adult measures were used as a model for work with children.

### How appropriate are adult measures for use with children?

Adult measures may fail to tap the specific aspects of QoL that are important to the child. Measures based on adult work impose considerable response burden for children, in terms of length, reading skills and response scale. Wording and format of adult measures may need to be modified to account for children's cognitive and language skills. More basic research is needed to determine the level of response burden that children of different ages can manage. Assessments of difficulty (e.g. reading age) need to be routinely included with information about new measures.

### To what extent do child self-reports correspond with assessments made by parents and carers?

Fourteen studies were identified in which concordance between child and parent was investigated, often as part of the development of a new measure. There was some evidence for greater concordance between child and parent for physical functioning compared with social and emotional domains, but greater heterogeneity in the latter measures may contribute to inconsistent results. There was no simple relationship between concordance and moderating variables such as age, gender and illness, but this conclusion was addressed only very rarely.

### How feasible and reliable are proxy measures of QoL in different disease contexts?

Only five papers fulfilled the review criteria. Evaluation is difficult because authors fail to justify their choice of measures, and do not report critical information such as completion rates or missing data.

Use of existing measures can potentially eliminate the time and expense required to develop a comprehensive measure of QoL, but a full battery of standardised tests may be expensive in terms of time for administration and scoring. In addition, battery measures tend to be lengthy and therefore demanding for sick patients. They are not recommended for work with children.

## Recommendations for research

### Minimum criteria for new measures

A set of procedures needs to be established for the development of new measures. These need to draw on the experience gained in development of child and adult measures to date. Basic research to enhance understanding of how children interpret questions in QoL measures is recommended. We need to understand the differences in meaning of items between children and adults, and between children of different ages. Some attempt to develop measures for children of 6 years or more have been reported, and these should be further developed.

Development of new measures should:

- follow established procedures for the development of measures
- take into account theoretical knowledge of children's understanding of illness, emotion, and ability to complete rating scales
- include facility for child and proxy report
- include developmentally sensitive age-appropriate sections
- include generic core and disease-specific modules.

### Clinical appropriateness

There is a need to develop measures that are appropriate for the kind of questions to be

answered in practice. Measures are frequently justified in terms of the value in clinical trials, comparing alternative treatments or assessing interventions. In more everyday contexts, QoL measures may potentially help health professionals and children's families evaluate clinical care. Outcome measures that are sensitive to changes in the child's QoL have considerable value, particularly in children with long-term illness.

To determine how far assessments of QoL can contribute to improved care, we need to move beyond the development of new measures. In order to encourage greater use in clinical practice, it is recommended that:

- developers of new measures need to be clearer about the procedures adopted for identifying the item pool, and more extensive information about their psychometric properties should be provided
- those developing new measures should work more closely with clinicians in order to ensure both the quality of the measures and their appropriateness in different clinical settings
- families should be encouraged to be more involved in the development and application of measures, in order to improve the face validity of measures, and to challenge criticisms that QoL measures impose an unnecessary burden.

## Publication

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# NHS R&D HTA Programme

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Although the National Coordinating Centre for Health Technology Assessment (NCCHTA) commissions research on behalf of the Methodology Programme, it is the Methodology Group that now considers and advises the Methodology Programme Director on the best research projects to pursue.

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