Information Sheet on the Youth Quality of Life (YQOL) Instruments

Frequently Asked Questions

Q: What is the YQOL-R?

A: The YQOL-R is a generic quality of life (QoL) measurement designed for all youth ages 11-18, including those with and without disabilities. It is an easy-to-understand self-administered questionnaire. A readability analysis has confirmed that the YQOL is readable at the 4th grade level. The YQOL instrument has been developed in modular form. Table 1 shows the modular applications and the number of items associated with each module.

Table 1. YQOL Modular Development with Applications

	YQOL-S: surveillance	YQOL-R: research & program evaluation	Scores
Group-Level			
Perceptual	8 items	41 items	4 domain scores & 1 overall score
Contextual	5 items	15 items	individual items

The questions compromising the YQOL-S were selected from the questions on the YQOL-R to reflect issues of most likely importance to policy makers, rather than to be representative of the YQOL-R as a whole. Thus it *cannot* be viewed as a short form of the longer module with the same psychometric properties.

Both modules have two types of items, contextual (i.e., can be reported by others), and perceptual (i.e., known only to the youth themselves).

In addition to a total score, four domains have been identified from the YQOL-R: Sense of Self, Social Relationships, Culture and Community, and General Quality of Life. The YQOL-S is designed for monitoring leading indicators of QoL in adolescent populations, and is not scored by domain, as each question is regarded as a social indicator in itself. The YQOL scores are transformed to a **0-100** scale for easy interpretability, higher scores indicating better QoL.

There are also craniofacial condition-specific modules of the YQOL available (see below).

Q: How were the YQOL instruments developed?

A: Early decisions made regarding the development of the YQOL instruments were based on extensive reviews of the adolescent health-related quality of life literature (conducted by the authors), which revealed a shortage of instruments that met criteria considered essential for the understanding and assessment of adolescent QoL (Edwards, Huebner, Connell, and Patrick, 2002), generally, and in craniofacial populations specifically (see below). QoL is defined as a subjective judgment of the quality of one's own life, and is not equivalent with health or functional status. The YQOL instruments were defined according to a *needs-based* model that identifies QoL as the degree to which most or all human needs are met.

The YQOL instruments were designed to include the most important concerns of youth, and was developed through tree types of data: (a) in-depth interviews with youth ages 11-18 with and without disabilities, from many different settings, asking what was important to their life; (b) focus groups with youth ages 11-18 with and without disabilities, with primary caregivers of youth with and without disabilities, and with youth health and welfare professionals; and (c) consultation with existing assessment instruments, such as the National Longitudinal Adolescent Health Survey (ADD Health). To the maximum possible extent, the content of the measure was defined by adolescents themselves and the items written in their own language.

Q: What are the applications of the YQOL?

A: The preliminary validation of the YQOL-R indicates that it is an appropriate tool for evaluating the effectiveness of programs which are designed to improve the lives of young people. A major application of the YQOL-R is to assess the effectiveness of interventions for adolescents with physical and other disabilities, including attention-deficit hyperactivity disorder (ADHD). The instrument takes 15 minutes to complete. Psychometric validation of the YQOL-R for cross-sectional studies has shown it to have good reliability and validity, and has been shown to discriminate between general population, attention-deficit hyperactivity disorder, craniofacial, and mobility disability groups (Edwards, Huebner, Connell, & Patrick, 2002; Edwards, Patrick, Topolski, Aspinall, Mouradian, & Speltz, in press; Patrick, Edwards, & Topolski, 2002; Topolski, Edwards, & Patrick, in press; Topolski, Edwards, Patrick, Varley, Way & Buesching, 2004).

The YQOL-S has been used to examine the relationship between QoL and health risk behavior (Topolski, Patrick, Connell, Edwards, & Huebner, 2001), and mobility disability (Edwards, Patrick, & Topolski, 2003), and is an appropriate tool for assessing and monitoring QoL indicators in diverse adolescent populations. It requires only 1 minute to complete and can be easily added to ongoing school-based or other surveys, such as the Youth Risk Behavior Survey (YRBS).

Q: Which translations are available?

A: The original instrument was developed in the US. At this point Croatian, Dutch, English (UK), English (US), Polish, Portuguese (Brazil) and Spanish (US), and Spanish (Puerto Rico) translations are available. The YQOL-S is also available in Dutch, English (UK), English (US), French, German, Greek, Polish, Spanish (Castilian), and Spanish (US).

Q: May we have permission to use the YQOL?

A: The YQOL-R and YQOL-S are copyrighted in the United States by the University of Washington. Please do not use either instrument without permission. Any use of the measures requires that the wording of items, instructions, and scoring be kept standardized. A user's agreement is available from the authors.

Condition-Specific Instruments

Q: What are the Youth Quality of Life Instrument - Facial Differences Module (YQOL-FD) and Craniofacial Surgery Attitudes Measure (CSAM)?

A: The YQOL-FD and CSAM are craniofacial-specific quality of life (QoL) instruments designed for youth with congenital *and* acquired facial differences ages 11-18. The YQOL-FD assesses five domains: negative consequences of having a facial difference, negative self image, experienced stigma, positive consequences of having a facial difference, and coping. The CSAM assesses two domains: attitudes regarding past surgical experience, and attitudes toward future surgeries, including satisfaction with past surgery, and perceived need for more surgery.

Both modules are easy-to-understand and self-administered. The grade reading levels of the modules are as follows (+/- 0.5): YQOL-FD Contextual = 4.6, YQOL-FD Perceptual = 3.4, and CSAM Perceptual = 4.1. Like the YQOL generic instruments, the YQOL-FD and CSAM have been developed in modular form. Table 1 shows the modular applications and the number of items associated with each module. There are no individual-level components specific to these modules.

Table 1. YQOL-FD and CSAM Modular Development

	YQOL-FD	CSAM
Perceptual	30 items	32 items
Contextual	18 items	0 items
Scores	5 domain scores	2 domain scores

Like the YQOL generic instruments, the YQOL-FD modules has two types of items, contextual (i.e., can be reported by others), and perceptual (i.e., known only to the youth themselves). The CSAM has only perceptual items. Again, like the YQOL generic, scores are transformed to a **0-100** scale for easy interpretability, higher scores indicating better QoL.

Q: What are the applications of the YQOL-FD and CSAM instruments?

A: Preliminary validation of the YQOL-FD and CSAM indicates that they are appropriate tools for evaluating the effectiveness of interventions (medical, as well as psychosocial) which are designed to improve the lives of young people with

craniofacial conditions. Psychometric validation of the YQOL-FD and CSAM for cross-sectional studies has shown them to have good reliability and validity.

Q: Which YQOL FD and CSAM translations are available?

A: The original instruments were developed in the US. At this point American English, UK English, and Mexican Spanish translations are available.

Q: May we have permission to use the YQOL instruments?

A: The YQOL-R, -S, -FD, and CSAM are copyrighted in the United States by the University of Washington. Please do not use either instrument without permission. Any use of the measures requires that the wording of items, instructions, and scoring be kept standardized. A user's agreement is available from the authors.

Q: Where can I obtain the YQOL instruments?

A: The American English YQOL-S and the YQOL Disability Screener are available online free of charge at www.seaqolgroup.org. All other materials are available from the authors at:

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More information on the YQOL instruments and the Seattle Quality of Life Group is also available online at www.seaqolgroup.org

References

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