# Youth Quality of Life Short Form (YQOL-SF) Instrument

## **Seattle Quality of Life Group**

## Frequently Asked Questions

#### Q: What is the YQOL-SF?

**A:** The YQOL is a generic measure of youth quality of life (YQOL) for all youth ages 12-18 years, including those with and without chronic conditions and disabilities. The short form of this instrument consisting of 16 items is known as YQOL-SF. It has been developed with Rasch methodology. It is an easy-to-understand self-administered questionnaire. A readability analysis has confirmed that the YQOL-SF is readable at the 4th grade level.

The YQOL-SF 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-SF scores are transformed to a **0-100** scale for easy interpretability, higher scores indicating better QoL.

### Q: How was the YQOL-SF instrument developed?

**A:** Early decisions made regarding the development of the YQOL-SF instrument was 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-SF instrument is defined according to a *needs-based* model that identifies QoL as the degree to which most or all human needs are met.

The YQOL-SF instrument was designed to include the most important concerns of youth, and was developed through three types of data: (a) in-depth interviews with youth ages 12-18 with and without disabilities, from many different settings, asking what was important to their life; (b) focus groups with youth ages 12-18 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.

The original response scale used for YQOL ranged from 0 (not at all) to 10 (a great deal or completely). The scores are summed and then transformed to a 0-100 scale, with a higher score representing a higher quality-of-life. The Multi-Trait/Multi-Item Analysis program was used to investigate the scaling assumptions and ensure appropriateness of the scale range for each item. However, Rasch methodology showed a different type of response scale to be preferred.

Currently, the response scale for the short form ranges from 1 = not at all/very little to 3 = very much or completely. Rasch analysis was used to determine the use of an appropriate response scale as well as the selection of the 16 items for the short form.

## Q: What are the applications of the YQOL-SF?

**A:** The preliminary validation of the YQOL-SF 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-SF is to assess the effectiveness of interventions for adolescents with physical and other disabilities, including attention-deficit hyperactivity disorder (ADHD). The instrument takes less than 15 minutes to complete.

#### Q: Which translations are available?

**A:** The original instrument was developed in the US. But many different languages are available, please visit <a href="https://www.seagolgroup.org">www.seagolgroup.org</a>.

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

**A:** The YQOL-SF is 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 YQQL-SF instrument?

**A**: The American English YQOL-SF is available online free of charge at <a href="https://www.seagolgroup.org">www.seagolgroup.org</a>. All other materials are available from the authors at:

Seattle Quality of Life Group University of Washington, Department of Health Services Box 359455 Seattle, WA 98195-9455

Phone: (206) 685-6530

Email: <a href="mailto:seagol@u.washington.edu">seagol@u.washington.edu</a>

More information on the YQOL instruments and the Seattle Quality of Life Group is also available online at <a href="https://www.seaqolgroup.org">www.seaqolgroup.org</a>

#### References

Ayala NC, Edwards TC, Patrick DL (in press). Youth Quality-of-Life Instrument. In Alex C. Michalos (Ed.), <u>Encyclopedia of Quality of Life Research</u>. Springer.

- Edwards, T.C., Huebner, C.E., Connell, F.A., and Patrick, D.L. (2002). Adolescent quality of life, part I: Conceptual and measurement framework. <u>Journal of Adolescence</u>, 25(3), 275-286.
- Edwards, T.C., Patrick, D.L., and Topolski, T.D. (2003). Quality of life of adolescents with disabilities. <u>Journal of Pediatric Psychology</u>, 28, 233-241.
- Edwards, T.C., Patrick, D.L., Topolski, T.D., Aspinall, C., Mouradian, W.E., & Speltz, M.L. (2005). Approaches to craniofacial-specific quality of life assessment in adolescents. Cleft Palate-Craniofacial Journal, 42(1), 19-24.
- Patrick D.L., Edwards, T.C., and Topolski, T.D. (2002). Adolescent quality of life, part II: Initial validation of a new instrument. <u>Journal of Adolescence</u>, 25(3), 287-300.
- Topolski, T.D., Edwards, T.C., Patrick, D.L. (2005). Quality of life: How do adolescents with facial differences compare with other adolescents? <u>Cleft Palate Craniofacial Journal</u>, 42(1), 25-32.
- Topolski, T.D., Edwards, T.C., Patrick, D.L., Varley, P., Way, M.E. and Buesching, D.P. (2004). Quality of life of adolescent males with attention-deficit hyperactivity disorder. <u>Journal of Attention Disorders</u>, 7(3), 163-173.
- Topolski, T.D., Patrick, D.L., Edwards, T. C., Huebner, C. E., Connell, F. A., and Mount, K. K. (2001). Quality of life and health-risk behavior among adolescents. <u>Journal of Adolescent Health</u>, 29, 426-435.