

Youth Quality of Life Instrument Facial Differences Module (YQOL-FD) Order Form

Cost: The Youth Quality of Life Instrument Facial Differences Module (U.S. version), Cost variable depending on for-profit or not-for-profit status. Rates subject to change. No returns allowed. **Note: The YQOL-FD must be purchased with the YQOL User's Manual and Interpretation Guide.**

Ordering Information: Fax or mail this order form to:
Seattle Quality of Life Group
University of Washington
Department of Health Services
Box 359455
Seattle, WA 98195-9455
Phone: (800) 291-2193
Fax: (206) 616-3135

Unit Price (*Manual, US English Instrument, Scoring Program*)
Translations (*see Available translations below*)
International Wire transfer (*check if applicable*)

\$500 For profit company purchase of YQOL-FD
 \$200 Not-for profit organization purchase of YQOL-FD
 Free for students* (must submit proof of current registration/identification)
 \$100.00 each x _____ #translations= \$ _____
Sub-total: \$ _____
 \$25 charge for wire transfer

Electronic Files will be sent for all orders

Sub-total _____
Total (Subtotal x Quantity) _____

Available translations

Dutch German Spanish (USA)

Address Information: Please Print. Street Address required for all deliveries.

Name: _____
Institution: _____ Dept/Mail Stop: _____
Street Address: _____
City: _____ State: _____ Zip(Postal) Code: _____
Phone Number: (____) _____ E-mail: _____

USER AGREEMENT

<p style="text-align: center;">Conditions for use of the Youth Quality of Life Instrument Facial Differences Module (YQOL-FD)</p>
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Date: _____, _____, _____
 Day Month Year

CONTACT INFORMATION

Name: _____

Agency/University/Company: _____

Title: _____

Full Address: _____

Country: _____

Phone: _____ Fax: _____

E-mail: _____

SUMMARY OF STUDY

- **Title:**
- **Disease or disorder:**
- **Type of research**
- **Primary outcome measure or end point:**
- **Design:**
- **Number of expected respondents (total):**
- **Number of expected administrations of the questionnaires per respondent:**
- **Length of the follow-up (if any):**
- **Planned study date:**
- **Name of the funder:**
- **Other questionnaires used in the study:**
- **Number of countries/language versions involved:**

SPECIFY:

<input checked="" type="checkbox"/> USA (English)	<input type="checkbox"/> UK (English)	
<input type="checkbox"/> NETHERLANDS (Dutch)	<input type="checkbox"/> USA (Spanish)	

YQOL-FD USER AGREEMENT

IMPORTANT REMARK: THE YQOL-FD MAY BE USED IN THE ABOVE MENTIONED INVESTIGATIONS WHEN THE FOLLOWING AGREEMENT IS COMPLETED AND SIGNED BY “USER”.

« _____ (Person, University, Company) » referred hereinafter as « User » wishes to use the **YQOL-FD** in the above mentioned versions.

The UNIVERSITY OF WASHINGTON distributes the **YQOL-FD** and its translations available in the following languages: U.S. English, U.S. Spanish, and U.K. English.

Therefore, User and UNIVERSITY OF WASHINGTON agree as follows:

1. UNIVERSITY OF WASHINGTON’s obligations

UNIVERSITY OF WASHINGTON shall deliver the original **YQOL-FD** and/or the translations requested by “User” subject to the following conditions:

- The translations requested are available, and
- The present agreement is duly completed and signed by “User”

2. “User”’s obligations

2.1 No modification

“User” shall not modify, abridge, condense, adapt, recast or transform the **YQOL-FD** in any manner or form, including but not limited to any minor or significant change in wordings or organisation in **YQOL-FD**, without the prior written agreement of UNIVERSITY OF WASHINGTON, which agreement shall not be unreasonably withheld or delayed.

2.2 No translation

“User” shall not translate **YQOL-FD**, without the prior written agreement of **Dr. Donald Patrick**.

2.3 No reproduction

“User” shall not reproduce the **YQOL-FD** except for the limited purpose of generating sufficient copies for use in investigations stated hereunder and shall in no event distribute copies of the **YQOL-FD** to third parties by sale, rental, lease, lending, or any other profit-making means.

2.4. Publication

In case of publication of study results, “User” shall cite (1) “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.” And (2) “Patrick DL, Topolski TD, Edwards TC, Aspinall CL, Kapp-Simon KA, Rumsey NJ, Strauss RP, Thomas CR. (2007) Measuring the quality of life of youth with facial differences. *Cleft Palate Craniofac J*. 44(5):538-47.”

2.5 Provision of data

All data, results and reports obtained by, or prepared in connection with the **YQOL-FD** shall remain the User’s property. However, UNIVERSITY OF WASHINGTON may request the User to share data, results and reports obtained through the use of the **YQOL-FD**, which request the User can accept or reject in its sole and unfettered discretion. UNIVERSITY OF WASHINGTON shall ensure the anonymisation of such data at three levels, by the removal of: any patient identification, any university or company identification and any therapy name. UNIVERSITY OF WASHINGTON will classify and reorganize such anonymous data and therefore, shall hold all intellectual property rights regarding these data when and if submitted to the data pool.

UNIVERSITY OF WASHINGTON may provide such reorganized data to third parties, for analysis in education, research, consulting, and specifically for the evaluation of cross-cultural equivalence and development of reference values for this **YQOL-FD** or for any other similar project.

2.6 Payment

2.6.1 Royalty fees (Authors)

The use of the **YQOL-FD** is free of author’s royalty fees.

2.6.2 Distribution fees (UNIVERSITY OF WASHINGTON)

The use of the **YQOL-FD** in studies is subject to a distribution fee payable to UNIVERSITY OF WASHINGTON, of an amount of 200 dollars for general and administrative expenditures plus 100 dollars per language version requested. This fee includes provision of a user manual and scoring program.

The use of the **YQOL-FD** in non-funded academic research in developing countries or by students is subject to a reduced fee for the instruments and user manual.

2.6.3 Invoicement

For the use of the **YQOL-FD**, at the time of execution of this agreement, “User” shall pay an amount of 200 dollars for general and administrative expenditures plus 100 dollars per language version and “User” shall pay such invoice within thirty (30) days of the date of this agreement.

3. Copyright Infringement

The **YQOL-FD** was developed by the Seattle Quality of Life Group at The University of Washington. The UNIVERSITY OF WASHINGTON holds copyright over the YQOL-FD and all its present and future translations. Each new translation will be made available to third parties once it is available, through UNIVERSITY OF WASHINGTON, under the conditions described in the present document.

If, at any time during the term of this agreement, « User » learns of any infringement by a third party of any Intellectual Property Rights in connection with the **YQOL-FD**, « User » shall promptly notify UNIVERSITY OF WASHINGTON. UNIVERSITY OF WASHINGTON shall notify such infringement to **Authors**. **Authors** will decide to institute or not proceedings against the infringing party.

4. Confidentiality

All and any information related to the **YQOL-FD** including but not limited to the following: information concerning clinical investigations, creations, systems, materials, software, data and know-how, translations, improvements ideas, specifications, documents, records, notebooks, drawings, and any repositories or representation of such information, whether oral or in writing or software stored, are herein referred to as confidential information. Likewise, any information provided by User to **Authors** relating to this Agreement, including information provided in this Agreement, shall be treated as confidential information.

In consideration of the disclosure of any such confidential information to the other, each party agrees to hold such confidential information in confidence and not divulge it, in whole or in part, to any third party except for the purpose specified in this agreement.

5. Use of name

It is agreed that UNIVERSITY OF WASHINGTON shall not disclose, whether by the public press or otherwise, the name of “**User’ or institution**”, to any third party to this agreement except to the copyright holder(s) of the **YQOL-FD**.

6. Liability

6.1 In case of breach of contract

In the event of total or partial breach by UNIVERSITY OF WASHINGTON of any of its obligations hereunder, UNIVERSITY OF WASHINGTON's liability shall be limited to the direct loss or damage (excluding loss of profit and operating losses) suffered by "User" as a result of such breach and shall not include any other damages and particular consequential damages.

6.2 In the scope of the use of the "Questionnaire"

Under no circumstances may **Authors** or UNIVERSITY OF WASHINGTON be held liable for direct or consequential damage resulting from the use of the **YQOL-FD**.

6.3 In the event of non-renewal of this Agreement

In the event of non-renewal of this Agreement by UNIVERSITY OF WASHINGTON for any cause or failure by UNIVERSITY OF WASHINGTON to conclude a new agreement with "User" upon the expiry of this Agreement, UNIVERSITY OF WASHINGTON will have no liability for payment of any damages and/or indemnity to "User".

7. Term and termination

This agreement shall be effective as the date of its signature by "User" and shall continue for a term of 10 (ten) years at least or until the term of the study above mentioned in SUMMARY OF THE STUDY.

Either party may terminate this Agreement immediately upon providing written notice to the other party in the event of: (a) the other party's unexcused failure to fulfil any of its material obligations under this Agreement or (b) upon the insolvency or bankruptcy of, or the filing of a petition in bankruptcy or similar arrangement by the other party. User may terminate this Agreement for any reason upon 90 days written notice.

Upon expiration or termination of this Agreement UNIVERSITY OF WASHINGTON may retain in its possession confidential information it acquired from **YQOL-FD** while under contract. The obligations which by their terms survive termination, include, without limitation, the applicable ownership, confidentiality and indemnification provisions of this Agreement, shall survive termination.

8. Assignment

This Agreement and any of the rights and obligations of “User” are personal to the “User” and cannot be assigned or transferred by “User” to any third party or by operation of law, except with the written consent of UNIVERSITY OF WASHINGTON notified to “User”.

9. Separate Agreement

This Agreement holds for the above mentioned study only. The use of the **YQOL-FD** in any additional study of the “User” will require a separate agreement **without additional fees, unless significant updates have been added to the user manual (new edition, etc.).**

10. Entire Agreement, Modification, Enforceability

The entire agreement hereto is contained herein and this Agreement cancels and supersedes all prior agreements, oral or written, between the parties hereto with the respect to the subject matter hereto.

This Agreement or any of its terms may not be changed or amended except by written document and the failure by either party hereto to enforce any or all of the provision(s) of this Agreement shall not be deemed a waiver or an amendment of the same and shall not prevent future enforcement thereof.

If any one or more of the provisions or clauses of this Agreement are adjudged by a court to be invalid or unenforceable, this shall in no way prejudice or affect the binding nature of this Agreement as a whole, or the validity or enforceability of each/and every other provision of this Agreement.

11. Governing law

This Agreement shall be governed by and construed in accordance with the laws of the State of Washington. Any disputes will be adjudicated first through the UNIVERSITY OF WASHINGTON and subsequently through courts in the State of Washington.

IN WITNESS WHEREOF, the parties hereto have caused this agreement to be executed by their duly authorised representatives as of the date first above written.

User/University/Company:

UNIVERSITY OF WASHINGTON

Name:

Name:

Title:

Title:

Signature:

Signature:

Date:

Date: