Linguistic Validation of the Seattle Quality of Life Group Instruments Youth Quality of Life Weight Specific Module (YQOL-W)



Donald L. Patrick, Ph.D., M.S.P.H.

Tari D. Topolski, Ph.D.

Todd C. Edwards, Ph.D.

Anne M. Skalicky, M.P.H.

University of Washington
Department of Health Services
146 North Canal Street, Suite 313
Seattle, Washington 98103-8652
(206) 685-7260
seaqol@u.washington.edu

Note: Do not quote or reproduce without permission of the authors.

Table of Contents

| | | | | Page | | | | |
|-----|--|----------|--|------|--|--|--|--|
| 1.0 | Ger | neral In | formation | 3 | | | | |
| | 1.1 | Quali | ty of Life Instruments and Cultural Adaptation | 3 | | | | |
| | 1.2 | Lingu | iistic Validation | 3 | | | | |
| | 1.3 | Psych | hometric Validation | 4 | | | | |
| 2.0 | The | Lingu | istic Validation Process | 5 | | | | |
| | 2.1 Aim of Linguistic Validation | | | | | | | |
| | 2.2 | The L | inguistic Validation Algorithm | 6 | | | | |
| | 2.3 | Phase | e 1: Forward Translation | 8 | | | | |
| | | 2.3.1 | Definition | 8 | | | | |
| | | 2.3.2 | Means | 8 | | | | |
| | | 2.3.3 | Methodology | 8 | | | | |
| | 2.4 | Phase | e 2: Backward Translation | 8 | | | | |
| | | 2.4.1 | Definition | 8 | | | | |
| | | 2.4.2 | Means | 8 | | | | |
| | | 2.4.3 | Methodology | 9 | | | | |
| | | 2.4.4 | Results of Phase 2 | 9 | | | | |
| | 2.5 | Phase | e 3: Participant Testing | 10 | | | | |
| | | 2.5.1 | Aim | 10 | | | | |
| | | 2.5.2 | Methodology | 10 | | | | |
| | | 2.5.3 | Results of Phase 3 | 10 | | | | |
| 3.0 | Pra | ctical [| Details | 11 | | | | |
| | App | endix | A: YQOL-S AND YQOL-W Translation Agreement | 13 | | | | |
| | App | endix | B: YQOL-S and YQOL-W List of Concepts | 18 | | | | |
| | Appendix C YQOL-S Translation Grid Template | | | | | | | |
| | Appendix D: YQOL-W Translation Grid Template | | | | | | | |
| | Appendix E: Translation Report Template | | | | | | | |
| | Ref | erence | es: | 32 | | | | |

1.0 General information

1.1 QUALITY OF LIFE INSTRUMENTS AND CULTURAL ADAPTATION

As with other instruments, a Patient-Reported Outcome instrument, commonly referred to as quality of life is composed of instructions, items and corresponding response categories or response choices, scoring methods, and methods of interpretation. The linguistic validation of a quality of life instrument is the first step of a process called cultural adaptation which comprises two phases:

- 1. a linguistic validation;
- 2. a psychometric validation

Ideally both phases are involved in cultural adaptation. This brief manual covers only the first phase of the linguistic validation of the Youth Quality of Life Weight-specific instrument. Suggested references are provided in References section to assist investigators interested in carrying out a psychometric validation of the culturally adapted version of the YQOL-S and YQOL-W. We strongly urge users to administer the YQOL-S in conjunction with the YQOL-W, in order to measure generic quality of life, in addition to weight-specific quality of life.

1.2 LINGUISTIC VALIDATION

The linguistic validation of a questionnaire is not a literal translation of the original instrument, but the production of a translation that is conceptually equivalent to the original and culturally acceptable in the country in which the translation will be used.

In order to work towards the establishment of one recognised translation of an instrument in a given language the following points should be followed:

- The translation methodology should be respected and the different phases of the process summarised in a report;
- The translated version of a questionnaire obtained in collaboration with its developer should be recognised as the official version in the country concerned.
- The translated version should be subjected to cognitive interviewing to assure respondent understanding of the items; and

The translated version should be tested for both cross-sectional and longitudinal measurement properties.

As per translation agreement (see Appendix A) with the developers of the Youth Quality of Life-Surveillance and Youth Quality of Life-Weight (YQOL-S AND YQOL-W) questionnaires, the linguistic validation should consist of at least 3 steps:

- Forward translations, (includes the production of a "reconciled" version)
- Backward translation,
- Confirmation by development team.

Cognitive debriefing is also desirable to determine conceptual equivalence, but not required. Processes for cognitive debriefing are included in section 2.5 of this manual.

The questionnaire should always be considered as a whole (e.g. the wording of the response choices may influence the translation of the items, and vice-versa). Instructions are also part of the questionnaire.

The "list of concepts" for the YQOL-S AND YQOL-W instrument (refer to Appendix B) define the underlying concept of each item and should be used as a basis throughout the linguistic validation process.

1.3 PSYCHOMETRIC VALIDATION

This manual is not meant as a resource for psychometric validation of the instrument, but be aware that this type of validation is necessary for complete cultural adaptation. The Scientific Advisory Committee of the Medical Outcomes Trust uses eight criteria in reviewing the psychometric adequacy of research instruments (http://www.outcomes-trust.org/monitor/nov98/8.html):

- 1) Conceptual and Measurement Model,
- 2) Reliability,
- Validity,
- Responsiveness,
- Interpretability,
- Respondent and Administrative Burden, and
- 7) Alternative Forms,
- 8) Cultural and Language Adaptations.

Although it is rarely possible to evaluate all of these criteria in any single study, the goal is to address as many as possible, especially measurement model, reliability, and validity.

For more information on psychometric validation, please see these papers on the initial validation of the YQOL-S and YQOL-W instrument in reference section.

2.0 The Linguistic Validation Process

2.1 AIM OF LINGUISTIC VALIDATION

The aim of a linguistic validation of a quality of life questionnaire is the production of a version in a language other than the language of the original questionnaire which is **conceptually** equivalent to the original.

Some important definitions and concepts for the linguistic validation process are outlined below:

Definitions;

Quality of Life

 Defined as individuals' perceptions of their position in life in the context of the culture and value systems in which they live, and in relation to their goals, expectations, standards, and concerns.

Conceptual equivalence of constructs and items

• Achieved when the constructs (theoretical notion being measured) exist, are relevant and are acceptable in all cultures. The items should also represent the definition of the constructs. (Example: functional status, pain)

Semantic equivalence

 Obtained when items mean the same thing to people from different groups and in the target and source language. Example: unbearable pain on a 0-10 rating scale.

Operational equivalence

 Ensures that standardized methods of survey administration are appropriate for the target culture. Example: self administration.

5

Source language

Original language in which the questionnaire was developed

Target language

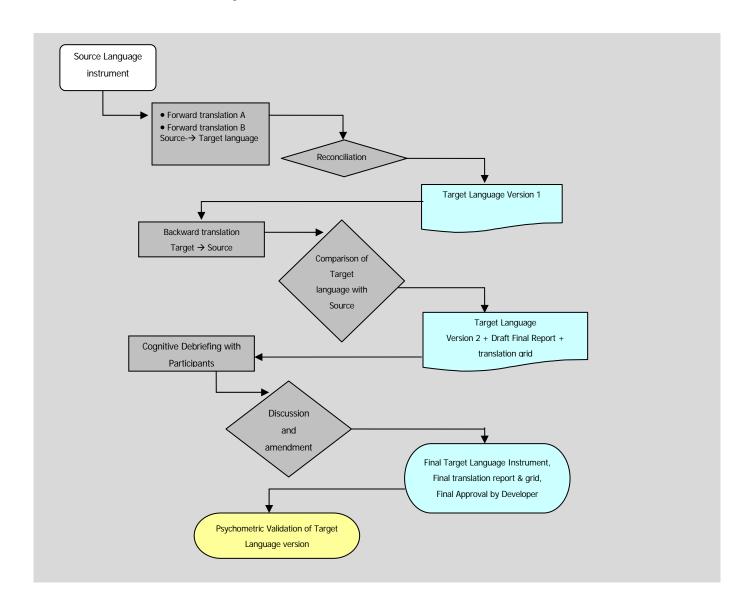
Language into which the questionnaire is translated

2.2 THE LINGUISTIC VALIDATION ALGORITHM

The following individuals will be called upon to assist in the adaptation of the source instrument and validation in the target language:

- Project manager, oversees translation process
- Consultant 1, forward translation 1, forward translation reconciliation process
- Consultant 2, forward translation 2, forward translation reconciliation process
- Consultant 3, backward translation

After the recruitment of bilingual consultants in each country concerned, and having explained the concepts of a linguistic validation in detail, a quality of life instrument is then ideally translated according to the following algorithm:



2.3 Phase 1: Forward translation

2.3.1 **DEFINITION**

The forward translation can be summed up as the first passage from the source language to the target language.

2.3.2 PERSONNEL

It requires:

- The recruitment of two local native target language speakers, bilingual fluency in both written and spoken in source language, and knowledgeable in concepts of quality of life;
- The involvement of the local project manager.

2.3.3 METHODOLOGY

- 1. *Production of 2 forward versions:* each of the translators will produce an independent forward translation of the original source instruments' instructions, items and response choices.
- Production of a pooled version, Version 1: both translators and the local project manager must discuss the translations and agree on a reconciled version. The aim should be the production of a conceptually equivalent translation of the original questionnaire and the language used should be colloquial and easy to understand.

In the case of interpretation problems of the original questionnaire the author can be contacted and according to his explanation of the particular problem the first version in the target language might be modified, leading to the production of a second intermediary forward version.

2.4 Phase 2: Backward translation

2.4.1 **DEFINITION**

It is the translation of the first version of the target translation of the questionnaire back into the source language.

2.4.2 **MEANS**

It requires the recruitment of a local professional translator, **native speaker of the source language**, with knowledge of both the written and spoken forms of the source language, and bilingual in target language.

2.4.3 METHODOLOGY

- 1. Production of the backward translation version of the source language: the translator will translate the reconciled version of the target language questionnaire produced in phase 1 back into the source language. S/he should have no access to the original source version of the questionnaire.
- 2. Comparison of the backward version with the original source version:
 - Done by the local project manager during a meeting with the "back" translator in order to detect any misunderstandings, mistranslations or inaccuracies in the intermediary forward version of the questionnaire.
 - o Will result in changes to the first version, giving rise to the second version.

Remark: Phase 3 should not be launched before the YQOL-W and YQOL-S developers comments are received and integrated in the process.

2.4.4 Results of Phase 2

- 1. Production of a **draft report and translation grid in English** on the issues which were discussed item-by-item and how the final decisions were made (including English equivalents of items and Target language expressions discussed—See template in Appendix C and D).
- 2. Sending of the translation grid and draft report to the YQOL-S and YQOL-W team for review.
- Review of the YQOL-S and YQOL-W development teams' comments by the local project manager and update of the translation, if needed.

| Location of Item (page, item identifier) and original English (source language) | Forward Translation 1 | Forward Translation 2 | Reconciled Forward Translation | Back ward Translation of Forward Translation | Reconciled forward Translation of Item Final Version | Back Translat ion of Final version | Reason for Change & SeaQol Reviewer comments | Sign off by SeaQol group |
|---|--------------------------|--------------------------|--------------------------------------|---|--|--|--|--------------------------------|
| Title (1) Youth Quality of Life Instrument— Weight (YQOL- W), Item1-26 | | | | | | | | |

2.5 Phase 3: Cognitive Debriefing

2.5.1 AIM

To cognitively debrief the translated target language questionnaire on participants in the target language country to determine whether it is acceptable, understood, and whether the language used is simple and appropriate.

2.5.2 METHODOLOGY

The second version of the questionnaire (obtained after phase 2) should be cognitively debriefed on a panel of a minimum of 10 participants (e.g. 5 with a chronic condition and 5 without). The participants should all be native speakers of the target language.

- 1. The comprehension test should be performed through face to face cognitive debriefing interviews during which the interviewer should inquire whether the patient-research participant had any difficulty in understanding the questionnaire and check the patient's interpretation of all items. In case of any problem, the interviewer may propose or test alternatives of translations (if this problem had been anticipated), or ask the person to propose alternatives.
- A report on the interviews should be produced in English: it should outline the number of subjects interviewed, their age, and the time it took to complete the questionnaire, the difficulties encountered, the solutions suggested and retained and how the third version of the questionnaire was produced. (see template for report in Appendix D)

2.5.3 RESULTS OF PHASE 3

Production of the final version of the questionnaire which should be proof-read to be considered as final, and a final report submitted to YQOL-S and YQOL-W developers.

3.0 Practical details

A linguistic validation process is much more time-consuming than a single straightforward translation. Sufficient time should be planned at each step for the production of the translations, meetings with the translators, interviews with participants, discussions and production of reports. From our experience you should allow for each step of a linguistic validation process the following timeframe as a minimum:

Forward translation step: 2 weeks
Backward translation step: 2 weeks
Testing on patients: 2 weeks
Proof-reading and finalisation: 2 weeks

Problems arising from the translation process fall into four categories. Types of Translation Difficulties that can occur are:

- Cultural difficulties: include the proper or improper usage of certain words, phrases based on the culture of a given society, as well as the specifics of the society itself such as the education system, health care system, societal or religious taboos, etc.
- Conceptual / Semantic Difficulties: are those that arise in conveying the meaning of a statement in a foreign language.
- **Idiomatic Difficulties:** correspond to the use of certain phrases, or the means of conveying ideas that are unique to a particular region, country, or society.
- Grammatical difficulties: include difficulties linked for instance to the grammar of a given language.

Producing a high quality translation is labour intensive and time consuming. The people involved in the translation process are critical in determining a questionnaires performance in a new country or culture. The standardized guidelines and centralized review procedures suggested here can improve the quality of the translations and the efficiency with which those translations are produced. To ensure credibility of the investigators of target language translation process we request that you specifically describe the process used through the use of a report (template in Appendix D).

Deadline for the final translation report is within 3 months of signing on translation user agreement. The final report and translation spreadsheet should be submitted to the attention of the SeaQol Instrument Coordinator at seaqol@u.washington.edu or at below address who will forward on to the instrument developer(s) for review.

SeaQol Instrument Coordinator Seattle Quality of Life Group

University of Washington

Box 359455

Seattle, WA 98195

Fax: (206) 616-3135

IMPORTANT:

In accordance with the developers of the YQOL-S and YQOL-W and in order to keep track of your work, you are kindly requested to:

 Complete the user's agreement for the YQOL-S and YQOL-W and return them to the Seattle Quality of Life Group.

<u>NB</u>: This should be done before any YQOL-S and YQOL-W materials will be released to you and before your translation and research work can begin.

- Provide the Seattle Quality of Life Group with a copy of the final version of the questionnaire in your language (both paper and electronic versions) as well as a copy of the final report (paper and electronic) you produced in English for outlining the linguistic validation process.
- Please note that your work will be considered for research and evaluation purposes only. Under no circumstances can you use it for commercial or international studies, or dispatch it to any third party for commercial or other use.
- Donald L. Patrick, Ph.D., Tari D. Topolski, Ph.D., and Todd C. Edwards, Ph.D., at The University of Washington, hold the Copyright of the original and all translations of the YQOL-W.

APPENDIX A:

USE AND TRANSLATION AGREEMENT

Conditions for translation of the Youth Quality of Life Surveillance version (YQOL-S) and Youth Quality of Life Instrument Weight version (YQOL-W)

| Date: | | | ., | | | | |
|---------|------------|--------------|---------------------|-------------------------|---------------------|-----------------------|--------------------|
| | Day | Month | Year | | | | |
| This a | agreemer | nt is made | between < | | | | _> herein |
| referre | ed to as [| User], and t | he developers | s, Seattle Quality o | f Life Group of the | University of Washi | ngton. The |
| UNIVE | ERSITY | OF WASHI | NGTON distrib | butes the YQOL- | S and YQOL-W a | and its translations. | Whereas |
| UNIVE | ERSITY | OF WASH | NGTON has | authorized [User |] to translate the | YQOL-S and YQO |)L-W . into |
| < | | | > [target lan | nguage], the YQO | L-S and YQOL-W | and all translations | hereinafter |
| referre | ed to as Y | QOL-S and | d YQOL-W sub | bject to the followi | ng conditions: | | |

1. UNIVERSITY OF WASHINGTON's obligations

UNIVERSITY OF WASHINGTON shall deliver the original **YQOL-S** and **YQOL-W** requested by "User" subject to the following conditions:

The present agreement is duly completed and signed by "User"

2. "User"'s obligations

2.1 No modification

User acknowledges that UNIVERSITY OF WASHINGTON owns all copyright in the YQOL-S and YQOL-W and in all YQOL-S and YQOL-W versions including but not limited to existing and future translations of YQOL-S and YQOL-W. As owner of the copyright in the YQOL-S and YQOL-W, UNIVERSITY OF WASHINGTON has the right to grant this permission.

2.2 Rights of Distribution

[User] acknowledges UNIVERSITY OF WASHINGTON's copyright in the UNIVERSITY OF WASHINGTON and shall not contest such copyright or perform any act or omission adverse to such exclusive right. Further [User] acknowledges that UNIVERSITY OF WASHINGTON holds the unfettered right to use, reproduce and exploit the **YQOL-S** and **YQOL-W** and all of translation(s), throughout the world, for its full term without any cost or conditions.

2.3 Terms of Use

The UNIVERSITY OF WASHINGTON grants [User] the right to use and reproduce the aforesaid translations of the YQOL-S and YQOL-W (in paper or electronic form) in the framework of the study provided that these translations have been produced according to standard recognized methodology of translation as described in "Linguistic Validation of the Youth Quality of Life Instruments Weight Specific Module" manual document. The [User] agrees to provide the Authors with a final translation report and translation grid, and the final version of the translated instrument. The use of the aforesaid translations of the YQOL-S and YQOL-W is free from any royalty fee payable to the UNIVERSITY OF WASHINGTON.

2.4 No reproduction

"User" shall not reproduce the **YQOL-S** and **YQOL-W** 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-S** and **YQOL-W** to third parties that are outside the scope of the defined study, by sale, rental, lease, lending, or any others means.

2.5 Publication

In case of publication of study results, "User" shall cite:

Topolski, T. D., Edwards, T. C., and Patrick .D L. (2002). <u>User's manual and interpretation guide for the Youth Quality of Life (YQOL) Instruments</u>. Seattle, WA: University of Washington, Dept. of Health Services.

2.6 Provision of data

All data, results and reports obtained by, or prepared in connection with the YQOL-S and YQOL-W 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-S and YQOL-W 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-S** and **YQOL-W** or for any other similar project.

3. Copyright Infringement

The YQOL-S and YQOL-W was developed by the Seattle Quality of Life Group at The University of Washington. The UNIVERSITY OF WASHINGTON holds copyright over the YQOL-S and YQOL-W 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-S and YQOL-W**, « User » shall promptly notify UNIVERSITY OF WASHINGTON. UNIVERSITY OF WASHINGTON shall notify such infringement to **Authors**. **Authors** will decide whether to institute proceedings against the infringing party.

4. Confidentiality

All and any information related to the **YQOL-S and YQOL-W** including but not limited to the following: information concerning clinical investigations, creations, systems, materials, software, data and knowhow, 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.

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-S and YQOL-W.

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-S** and **YQOL-W**.

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.

Upon expiration or termination of this Agreement UNIVERSITY OF WASHINGTON may retain in its possession confidential information it acquired from **YQOL-S** and **YQOL-W** 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-S** and **YQOL-W** 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: |

17

APPENDIX B:

YQOL-S and YQOL-W List of Concepts (perceptual Items)

Each item is asking the question in relation to its heading on this list.

| YQOL-S Item | Facet | | Domain |
|---|----------------------|--------|---------------|
| I feel good about myself | Be oneself | | Self |
| 2. I feel I am getting along with my parents or guardians | Getting along family | g with | Relationships |
| 3. I feel alone in my life | Mental health | | Self |
| 4. I look forward to the future | Bright Future | | Environment |
| 5. I enjoy life | | | General QoL |
| 6. I am satisfied with the way my life is now | | | General QoL |
| 7. I feel life is worthwhile | | | General QoL |
| 8. Compared with others my age, I feel my life is | | | General QoL |
| YQOL-W Item | Facet | | Domain |
| I feel depressed about how much I weigh | Self-esteem | | self |
| 2. I feel ashamed about my weight | Shame | | Self |
| 3. I feel uncomfortable around people who are skinnier than | Self-conscious | ness | Social |
| am4. Because of my weight I feel the need to wear clothes that | Self-conscious | ness | Social |
| hide my body 5. Because of my weight other people think I am | Self-esteem | | Social |
| unattractive 6. Because of my weight I try to hide behind other people | Embarrassmer | nt | Social |
| when I get my picture taken 7. Because of my weight I am embarrassed to exercise around | Self-conscious | ness | Social |
| other people 8. Because of my weight I am embarrassed to eat around | Self-conscious | ness | Social |
| other people 9. Because of my weight I try to avoid people noticing me | Self-conscious | ness | Social |
| 10. I feel I can control how much I weigh | Self-control | | Self |
| 11. Because of my weight I worry about what people say | Self-conscious | ness | Social |
| about me 12. Because of my weight I feel uncomfortable at social | Self-conscious | ness | Social |
| events 13. I feel like a loser when people tease me about my | Self-esteem | | Self |
| weight 14. Because of my weight I feel down on myself | Self-esteem | | Self |
| 15. Because of my weight my body feels uncomfortable when move around | Body discomfo | rt | Environment |

| 16. Because of my weight I try to avoid exercise | Avoidance | Environment |
|--|--------------------|-------------|
| 17. Because of my weight I avoid being seen in a swim suit | Self-consciousness | Self |
| 18. Because of my weight I have problems making friends | Social exclusion | Social |
| 19. My family makes me feel bad about my weight | Acceptance | Social |
| 20. Because of my weight it is hard to find a girlfriend | Social exclusion | Social |
| 21. I think that people stare at me because of my weight | Social exclusion | Social |
| 22. Because of my weight I feel people my age do not include me in things | Social exclusion | Social |
| 23. I worry that my weight will prevent me from getting a good job | Opportunity loss | Environment |
| 24. Because of my weight it is difficult for me to wear the clothes I want to wear | Opportunity loss | Environment |
| 25. Because of my weight it is hard for me to find clothes that fit me | Opportunity loss | Environment |
| 26. Because of my weight exercising is hard for me | Opportunity loss | Environment |

TEMPLATE FOR REPORTING TO SEAQOL INSTRUMENT DEVELOPMENT TEAM- (To be completed by translation project manager) YQOL-S TRANSLATION GRID

| Column A | Column B | Column C | Column D | Column E | Column F | Column G | Column H | Column I |
|---|--------------------------|--------------------------|--------------------------------------|---|--|---|---|--|
| Location of Item (page, item identifier) and original English (source language) | Forward Translation 1 | Forward Translation 2 | Reconciled Forward Translation | Back ward Translation of Forward Translation | Reconciled forward Translation of Item Final Version | Back Translation of Final version | Reason for Change & SeaQol Reviewer comments | Sign off by Instrument Developer |
| Title (1) Describing Your Life | | | | | | | | |
| Title (2) | | | | | | | | |
| Youth Quality of Life Instrument–Surveillance Version | | | | | | | | |
| Instructions (pp. 4) (1) Following are some | | | | | | | | |
| statements that you | | | | | | | | |
| might make about | | | | | | | | |
| yourself. | | | | | | | | |
| Instructions (2) | | | | | | | | |
| Please circle the one | | | | | | | | |
| number on each scale | | | | | | | | |
| that best describes how | | | | | | | | |
| closely the statement | | | | | | | | |
| applies to you IN GENERAL. | | | | | | | | |
| Instructions (3) | | | | | | | | |
| There are no right or | | | | | | | | |
| wrong answers, we are | | | | | | | | |
| only interested in how | | | | | | | | |
| you feel about your life. | | | | | | | | |
| Response Scale (1) | | | | | | | | |
| Not at all, Very Much | | | | | | | | |
| 1. I feel good about | | | | | | | | |
| myself (please circle the | | | | | | | | |
| number) | | | | | | | | |
| 2. I feel I am getting | | | | | | | | |
| along with my parents or guardians (please circle | | | | | | | | |
| the number) | | | | | | | | |
| ule Hullibel) | | | | | | | | |

| 3. I feel alone in my | | | | | |
|------------------------------|----------|------|------|------|--|
| life(please circle the | | | | | |
| number) | | | | | |
| 4. I look forward to the | | | | | |
| | | | | | |
| future (please circle the | | | | | |
| number) | | | | | |
| 5. I enjoy life (please | | | | | |
| circle the number) | | | | | |
| 6. I am satisfied with the | | | | | |
| way my life is now | | | | | |
| (please circle the | | | | | |
| number) | | | | | |
| 7. I feel life is worthwhile | | | | | |
| (please circle the | | | | | |
| number) | | | | | |
| 8. Compared with others | | | | | |
| my age, I feel my life is | | | | | |
| (please circle the | | | | | |
| number) | | | | | |
| Response scale: | | | | | |
| Much worse than others, | | | | | |
| Much better than others | | | | | |
| 9. You have just | | | | | |
| answered some | | | | | |
| questions about how | | | | | |
| your life is now. Which | | | | | |
| areas listed below are | | | | | |
| most important to you? | | | | | |
| Please write in the | | | | | |
| space provided the | | | | | |
| FIVE (5) areas which are | | | | | |
| most important to your | | | | | |
| life in order of | | | | | |
| importance. | | | | | |
| (1) getting support from | | | | | |
| adults in my life | | | | | |
| | | | | | |
| (2) being myself | <u> </u> | | | | |
| (3) believing in myself | | | | | |
| (4) caring for others | | | | | |
| (5) being included in | | | | | |
| things | | | | | |
| (6) having things I enjoy | | | | | |
| doing | | | | | |

| L (/) gotting along with my | |
|--|--|
| (7) getting along with my family | |
| | |
| (8) having freedom | |
| (9) having good friends | |
| (10) having a bright | |
| future (11) having and | |
| (11) having good | |
| physical health (60) to the first term of the fi | |
| (12) looking good | |
| (13) being able to relax | |
| ànd feel good | |
| (14) having enough | |
| money | |
| (15) liking my | |
| neighbourhood | |
| (16) being respected by | |
| my classmates | |
| (17) being safe | |
| (18) going to a good | |
| school and learning | |
| (19) feeling that my life | |
| has meaning and the second sec | |
| Title: The 5 most | |
| important areas to me | |
| (write below) | |
| Response: 1st most | |
| important, 2 nd most | |
| important, 3 rd , 4 th , 5 th | |
| most important | |
| 10. Almost everyone has | |
| areas in their life they | |
| would like to change for | |
| the better. <i>Please write</i> | |
| in the space provided | |
| the FIVE (5) areas in | |
| your life which you would | |
| like to change for the | |
| better in order of | |
| importance. | |
| (1) getting more support | |
| from adults in my life | |
| (2) Feeling that I can be | |
| myself more | |

| | , | | | 1 | |
|--|---|--|--|---|--|
| (3) believing in myself | | | | | |
| more | | | | | |
| (4) caring more for | | | | | |
| others | | | | | |
| (5) being included in | | | | | |
| more things | | | | | |
| (6) having more things I | | | | | |
| enjoy doing | | | | | |
| (7) getting along with my | | | | | |
| family better | | | | | |
| (8) having more freedom | | | | | |
| (9) having better friends | | | | | |
| (10) having a brighter | | | | | |
| future | | | | | |
| (11) having better | | | | | |
| physical health | | | | | |
| (12) improving the way I | | | | | |
| look | | | | | |
| (13) being able to relax | | | | | |
| and feel good more often | | | | | |
| (14) having more money | | | | | |
| (15) having a better | | | | | |
| neighbourhood | | | | | |
| (16) getting more respect | | | | | |
| from my classmates | | | | | |
| (17) Increasing my | | | | | |
| personal safety | | | | | |
| (18) going to a better | | | | | |
| school and learning | | | | | |
| more | | | | | |
| (19) feeling that my life | | | | | |
| has more meaning | | | | | |
| Title: The 5 areas I would | | | | | |
| like to change for the | | | | | |
| better (write below) | | | | | |
| Response: 1st change | | | | | |
| area, 2 nd , 3 rd , 4 th -5 th | | | | | |
| change area | | | | | |
| Demographic Questions | | | | | |
| do not need to undergo | | | | | |
| translation review | | | | | |
| Tanolation Toviov | | | | | |

APPENDIX D:

YQOL-W Translation Grid Template

| Column A | Column B | Column C | Column D | Column E | Column F | Column G | Column H | Column I |
|--|--------------------------|--------------------------|--------------------------------------|---|--|-----------------------------------|--|--|
| Location of Item (page, item identifier) and original English (source language) | Forward Translation 1 | Forward Translation 2 | Reconciled Forward Translation | Back ward Translation of Forward Translation | Reconciled forward Translation of Item Final Version | Back Translation of Final version | Reason for Change & SeaQol Reviewer comments | Sign off by Instrument Developer |
| Title (1) | | | | | | | | |
| Weight and Quality of | | | | | | | | |
| Life Instrument (WQLT)© | | | | | | | | |
| Instructions (1) | | | | | | | | |
| To all participants: Many | | | | | | | | |
| teens are taking part in | | | | | | | | |
| this important survey. | | | | | | | | |
| This survey will help us | | | | | | | | |
| understand your | | | | | | | | |
| thoughts and concerns | | | | | | | | |
| so that better programs | | | | | | | | |
| can be developed to help | | | | | | | | |
| teens better manage | | | | | | | | |
| their weight. | | | | | | | | |
| Instructions (2) | | | | | | | | |
| The questions in this survey ask about a wide | | | | | | | | |
| range of concerns and | | | | | | | | |
| feelings. Some of these | | | | | | | | |
| may or may not be | | | | | | | | |
| important to you. | | | | | | | | |
| Instructions (3) | | | | | | | | |
| This is NOT a test; there | | | | | | | | |
| are no right or wrong | | | | | | | | |
| answers. Please answer | | | | | | | | |
| as honestly as you can. | | | | | | | | |
| Your responses will be | | | | | | | | |
| kept strictly secret. | | | | | | | | |
| Thank you for your help! | | | | | | | | |

| Column A | Column B | Column C | Column D | Column E | Column F | Column G | Column H | Column I |
|---|--------------------------|--------------------------|--------------------------------------|---|--|---|---|--|
| Location of Item (page, item identifier) and original English (source language) | Forward Translation 1 | Forward Translation 2 | Reconciled Forward Translation | Back ward Translation of Forward Translation | Reconciled forward Translation of Item Final Version | Back Translation of Final version | Reason for Change & SeaQol Reviewer comments | Sign off by Instrument Developer |
| Title 2: How Does Your | | | | | | | | |
| Weight Affect Your Life? | | | | | | | | |
| Instructions: Following | | | | | | | | |
| are sentences that | | | | | | | | |
| describe how you may | | | | | | | | |
| feel about yourself and | | | | | | | | |
| your weight. After you read each sentence | | | | | | | | |
| choose the one number | | | | | | | | |
| that best describes how | | | | | | | | |
| you feel about your life | | | | | | | | |
| RIGHT NOW. | | | | | | | | |
| After you read each | | | | | | | | |
| sentence, please circle | | | | | | | | |
| one number on the scale | | | | | | | | |
| from 0 (Not at all) to 10 | | | | | | | | |
| (Very Much) that best | | | | | | | | |
| describes how YOU | | | | | | | | |
| FEEL ABOUT YOUR | | | | | | | | |
| LIFE RIGHT NOW. | | | | | | | | |
| Response Scale (1): | | | | | | | | |
| Not at all, Very much | | | | | | | | |
| 1. I feel depressed | | | | | | | | |
| about how much I weigh | | | | | | | | |
| (please circle one | | | | | | | | |
| number) | | | | | | | | |
| 2. I feel ashamed about | | | | | | | | |
| my weight (please circle one number) | | | | | | | | |
| 3. I feel uncomfortable | | | | | | | | |
| around people who are | | | | | | | | |
| skinnier than I am | | | | | | | | |
| (please circle one | | | | | | | | |
| number) | | | | | | | | |
| Hulling!) | | | | | | | <u>l</u> | |

| Column A | Column B | Column C | Column D | Column E | Column F | Column G | Column H | Column I |
|--|--------------------------|--------------------------|--------------------------------------|---|--|-----------------------------------|--|--|
| Location of Item (page, item identifier) and original English (source language) | Forward Translation 1 | Forward Translation 2 | Reconciled Forward Translation | Back ward Translation of Forward Translation | Reconciled forward Translation of Item Final Version | Back Translation of Final version | Reason for Change & SeaQol Reviewer comments | Sign off by Instrument Developer |
| 4. Because of my weight | | | | | | | | |
| I feel the need to wear | | | | | | | | |
| clothes that hide my | | | | | | | | |
| body (please circle | | | | | | | | |
| one number) | | | | | | | | |
| 5. Because of my weight | | | | | | | | |
| other people think I am | | | | | | | | |
| unattractive (please | | | | | | | | |
| circle one number) 6. Because of my weight | | | | | | | | |
| I try to hide behind other | | | | | | | | |
| people when I get my | | | | | | | | |
| picture taken (please | | | | | | | | |
| circle one number) | | | | | | | | |
| 7. Because of my weight | | | | | | | | |
| I am embarrassed to | | | | | | | | |
| exercise around other | | | | | | | | |
| people (please circle | | | | | | | | |
| one number) | | | | | | | | |
| 8. Because of my weight | | | | | | | | |
| I am embarrassed to eat | | | | | | | | |
| around other people | | | | | | | | |
| (please circle one | | | | | | | | |
| number) | | | | | | | | |
| 9. Because of my weight | | | | | | | | |
| I try to avoid people | | | | | | | | |
| noticing me (please circle one number) | | | | | | | | |
| 10. I feel I can control | | | | | | | | |
| how much I weigh | | | | | | | | |
| (please circle one | | | | | | | | |
| number) | | | | | | | | |
| 11. Because of my | | | | | | | | |
| weight I worry about | | | | | | | | |
| what people say about | | | | | | | | |
| me (please circle one | | | | | | | | |
| number) | | | | | | | | |

| Column A | Column B | Column C | Column D | Column E | Column F | Column G | Column H | Column I |
|--|--------------------------|--------------------------|--------------------------------------|---|--|-----------------------------------|--|--|
| Location of Item (page, item identifier) and original English (source language) | Forward Translation 1 | Forward Translation 2 | Reconciled Forward Translation | Back ward Translation of Forward Translation | Reconciled forward Translation of Item Final Version | Back Translation of Final version | Reason for Change & SeaQol Reviewer comments | Sign off by Instrument Developer |
| 12. Because of my | | | | | | | | |
| weight I feel | | | | | | | | |
| uncomfortable at social | | | | | | | | |
| events (please circle | | | | | | | | |
| one number) | | | | | | | | |
| 13. I feel like a loser | | | | | | | | |
| when people tease me | | | | | | | | |
| about my weight | | | | | | | | |
| (please circle one | | | | | | | | |
| number) | | | | | | | | |
| 14. Because of my | | | | | | | | |
| weight I feel down on | | | | | | | | |
| myself (please circle | | | | | | | | |
| one number) | | | | | | | | |
| 15. Because of my | | | | | | | | |
| weight my body feels | | | | | | | | |
| uncomfortable when I | | | | | | | | |
| move around (please | | | | | | | | |
| circle one number) | | | | | | | | |
| 16. Because of my | | | | | | | | |
| weight I try to avoid | | | | | | | | |
| exercise (please circle | | | | | | | | |
| one number) | | | | | | | | |
| 17. Because of my | | | | | | | | |
| weight I avoid being | | | | | | | | |
| seen in a swim suit | | | | | | | | |
| (please circle one | | | | | | | | |
| number) | | | | | | | | |
| 18. Because of my | | | | | | | | |
| weight I have problems | | | | | | | | |
| making friends | | | | | | | | |
| (please circle one | | | | | | | | |
| number) | | | | | | | | |
| 19. My family makes me | | | | | | | | |
| feel bad about my | | | | | | | | |
| weight (please circle | | | | | | | | |
| one number) | | | | | | | | |

| Column A | Column B | Column C | Column D | Column E | Column F | Column G | Column H | Column I |
|---|--------------------------|--------------------------|--------------------------------------|---|--|-----------------------------------|--|--|
| Location of Item (page, item identifier) and original English (source language) | Forward Translation 1 | Forward Translation 2 | Reconciled Forward Translation | Back ward Translation of Forward Translation | Reconciled forward Translation of Item Final Version | Back Translation of Final version | Reason for Change & SeaQol Reviewer comments | Sign off by Instrument Developer |
| 20. Because of my weight it is hard to find a girlfriend or boyfriend (please circle one number) | | | | | | | | |
| 21. I think that people stare at me because of my weight (please circle one number) | | | | | | | | |
| 22. Because of my weight I feel people my age do not include me in things (please circle one number) | | | | | | | | |
| 23. I worry that my weight will prevent me from getting a good job (please circle one number) | | | | | | | | |
| 24. Because of my weight it is difficult for me to wear the clothes I want to wear (please circle one number) | | | | | | | | |
| 25. Because of my weight it is hard for me to find clothes that fit me (please circle one number) | | | | | | | | |
| 26. Because of my weight exercising is hard for me (please circle one number) | _ | | _ | | _ | | | _ |

APPENDIX E:

FINAL REPORTING TEMPLATE FOR TRANSLATION TEAM

(Project Manager to fill out)

Overview of Translation Process

| 1. Project Manager Name: |
|-------------------------------------|
| 2. Title/Position/Affiliation: |
| 3. Overview of translation process: |
| |
| |
| |
| |
| |
| |
| PHASE 1: Forward Translation |
| Forward translator #1: |
| Title/Position/Affiliation: |
| Knowledge of Source language: |
| Knowledge of Target language: |
| Date Completed: |
| |
| Forward translator #2: |
| Title/Position/Affiliation: |
| Knowledge of Source language: |
| Knowledge of Target language: |
| Date Completed: |
| Translation issues in Phase 1: |
| |
| |
| |
| |
| |

PHASE 2: Back Translation

| Backward translator #1: |
|---|
| Title/Position/Affiliation: |
| Knowledge of Source language: |
| Knowledge of Target language: |
| Date Completed: |
| Translation issues in Phase 2: |
| |
| |
| |
| PHASE 3: Cognitive Debriefing |
| Cognitive debriefing interview conducted: |
| Title/Position/Affiliation: |
| Date Completed: |
| Mean Age:Mean Time to complete: |
| Translation issues in Phase 3: |
| |
| |
| |
| Solutions: |
| |
| |
| Date Final draft of instrument completed: |
| Date final draft sent to SeaQol team: |

Translation References:

Bonomi AE, Patrick DL, Bushnell DM, Martin ML Validation of the United States' version of the World Health Organization Quality of Life (WHOQOL) instrument. J of Clinical Epidemiology 53:1-12, 2000.

Brislin RW. The wording and translation of research instruments. In: Lonner WJ, Berry JW, eds. Field methods in cross-cultural research. Beverly Hills: Sage, 1986:137-164

Edwards, T.C., Huebner, C.E., Connell, F.A., & Patrick, D.L. (2002). Adolescent Quality of Life, Part I: Conceptual and measurement model. <u>Journal of Adolescence</u>. 25(3), 275-286.

MAPI Research Institute. Patient-Reported Outcomes (PRO) Measures: Linguistic Validation Procedures, May 2002.

Mauro Niero, Martin ML, Thomas Finger, Ramona Lucas, Isabelle Mear, Diane Wild, Laura Glauda, Donald L. Patrick. Multi-Cultural Development of Two New Obesity-specific Health-Related Quality of Life and Symptom Measures: The OWLQOL (Obesity and Weight Loss Quality of Life) Instrument and the WRSM (Weight-Related Symptom Measure). *Clinical Therapeutics* 24 (4): 690-700, 2002.

Patrick, D.L., Edwards, T.C., & Topolski, T.D. (2002) Adolescent Quality of Life, Part II: Initial Validation of a New Instrument. Journal of Adolescence. 25(3), 287-300.

Patrick DL, Martin ML, Bushnell DM, Marquis P, Andrejasich CM, Buesching DP. Cultural adaptation of a quality-of-life measure for urinary incontinence. European Urology 36:427-435, 1999.

Patrick DL, Wild DJ, Johnson ES, Wagner TH, Martin ML. Cross-cultural validation of quality of life measures. In: Quality of Life Assessment: International Perspectives (Eds. J. Orley and W Kuyken) Berlin/Heidelberg: Springer-Verlag, 1994:19-32.0

Stewart AL, Napoles-Springer A. Health-Related Quality of Life Assessments in Diverse Population Groups in the United States. Medical Care 2000; 38 (9) suppl II:102-124.