

# **Linguistic Validation of the Seattle Quality of Life Group Youth Quality of Life Instrument Facial Differences Module**



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## 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-Facial Differences module. 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-FD.

### 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 Facial Differences Module (YQOL-FD) questionnaire, 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-FD 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,
- 3) Validity,
- 4) Responsiveness,
- 5) Interpretability,
- 6) 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-FD 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.

##### **Source language**

- Original language in which the questionnaire was developed

**Target language**

- Language into which the questionnaire is translated

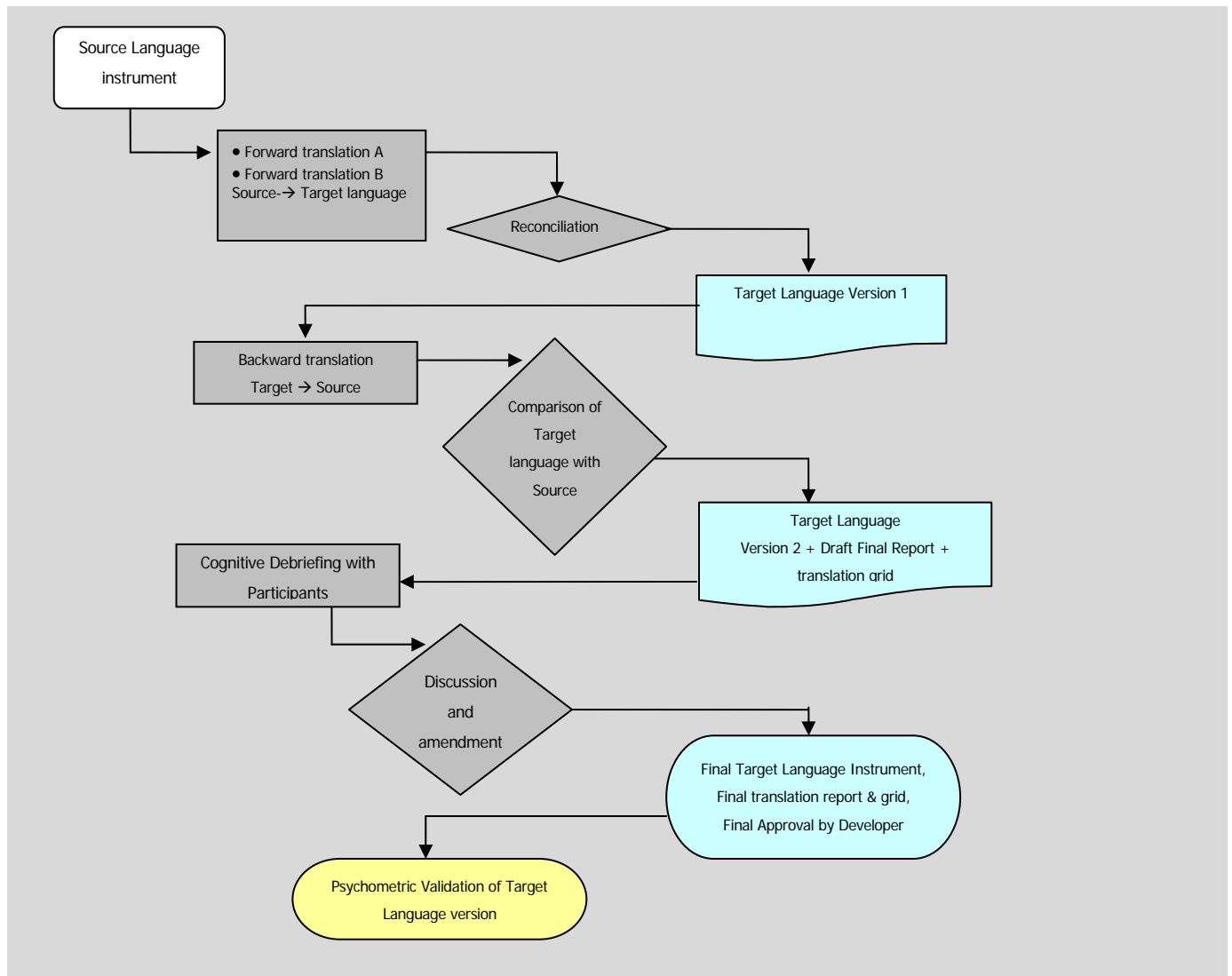
## 2.2 THE LINGUISTIC VALIDATION ALGORITHM

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:

## Linguistic Validation of YQOL-FD instrument



## 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.
2. *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 PERSONNEL

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.
  - Will result in changes to the first version, giving rise to the second version.

*Remark: Phase 3 should not be launched before the YQOL-FD 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-FD team for review.
3. Review of the YQOL-FD 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
<b>Title (1)</b> Youth Quality of Life Instrument— Facial Differences Module								
<b>Item...1-58</b>								

## 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.
2. A report on the interviews should be produced in English: it should outline the number of subjects interviewed, their age, 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-FD 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](mailto: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 98103-9455  
Fax: (206) 616-3135

**IMPORTANT:**

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

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

***NB: This should be done before any YQOL-FD 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-FD.

APPENDIX A:

**USE AND TRANSLATION AGREEMENT**

**Conditions for translation of the Youth Quality of Life Instrument  
Facial Differences Module (YQOL-FD)**

Date: \_\_\_\_\_, \_\_\_\_\_  
Day Month Year

This agreement is made between <\_\_\_\_\_> herein referred to as [User], and the developers, Seattle Quality of Life Group of the University of Washington. The UNIVERSITY OF WASHINGTON distributes the **YQOL-FD** and its translations. Whereas UNIVERSITY OF WASHINGTON has authorized [User] to translate the **YQOL-FD** into <\_\_\_\_\_> [target language], the **YQOL-FD** and all translations hereinafter referred to as **YQOL-FD** subject to the following conditions:

**1. UNIVERSITY OF WASHINGTON's obligations**

UNIVERSITY OF WASHINGTON shall deliver the original **YQOL-FD** 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-FD and in all YQOL-FD versions including but not limited to existing and future translations of YQOL-FD. As owner of the copyright in the YQOL-FD**, 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-FD** 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-FD** (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 Instrument Facial Differences 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-FD** is free from any royalty fee payable to the UNIVERSITY OF WASHINGTON..

### 2.4 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 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:

(1) “Patrick DL, Topolski TD, Edwards TC, Aspinall CL, Kapp-Simon K, Rumsey NJ, Strauss RP, Thomas CR. (2007). Measuring the Quality of Life of Youth with Facial Differences. *Cleft Palate-Craniofacial Journal* 44(5), 538-47.” in reference section of the publication.

### 2.6 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**. 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.

### 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 whether to institute 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.

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.

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
<b>Name:</b>	<b>Name:</b>
<b>Title:</b>	<b>Title:</b>
<b>Signature:</b>	<b>Signature:</b>
<b>Date:</b>	<b>Date:</b>

## APPENDIX B:

### YQOL-FD List of Concepts (perceptual Items)

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

Item	Facet	Domain
Because of how my face looks people have a hard time seeing who I really am		Stigma
Because of how my face looks, I need to prove myself to other people		Stigma
Because of my facial differences, people judge me on how I look		Stigma
Because of how my face looks, people think I am stupid		Stigma
Because of how my face looks, it is difficult to find friends I can trust		Stigma
It is difficult to get a girlfriend or boyfriend because of how my face looks		Stigma
Other people my age are embarrassed to be seen with me because of how my face looks		Stigma
I feel like I do not fit in with other people because of how my face looks		Stigma
People stare at me because of how my face looks		Stigma
I feel uncomfortable meeting people for the first time because of how my face looks		Stigma
I avoid looking in the mirror because of how my face looks		Negative Self-image
I dislike looking at pictures of myself because of how my face looks		Negative Self-image
I feel get away with doing less than I could because of how my face looks		Negative Self-image
Having a facial differences decreases my chances of success in life		Negative Self-image
Because of how my face looks, it is hard for me to walk around in public		Negative Self-image
Because of how my face looks, I feel I have no control over my life		Negative Self-image
Because of how my face looks, I am in touch with other people's feelings		Positive Consequences
Because of how my face looks, I am more accepting of other people		Positive Consequences
I am stronger person because of how my face looks		Positive Consequences
Because of how my face looks, I know more about life than other people my age do		Positive Consequences

My facial difference has helped me to accept other people for who they are	Positive Consequences
Looking more like everyone else is important to me	Negative Consequences
I feel self-conscious because of how my face looks	Negative Consequences
I feel frustrated about how my face looks	Negative Consequences
Because of how my face looks, I have more anger inside me than most people know	Negative Consequences
It makes me angry when grown ups stare at me because of how my face looks	Negative Consequences
I have gotten used to people making fun of how my face looks	Coping
I have learned how to deal with people teasing me because of how my face looks	Coping
I have learned to live with people being curious about how my face looks	Coping
I try not to pay attention to other people when they say things about my face	Coping

**APPENDIX C:****YQOL-FD Translation Grid Template (to be completed by translation project manager)****TEMPLATE FOR REPORTING TO SEAQOL INSTRUMENT DEVELOPMENT TEAM**

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
<b>Title (1)</b> Youth Quality of Life Instrument— Research Version,	<b>(Below is an Example only)</b> Calidad de la vida de jóvenes— Version para investigaciones							
<b>Title (2)</b> Describing Your Life	Describe Tu Vida							
<b>Instructions (1)</b> Following are some statements that you might make about yourself.	A continuación hay algunas declaraciones que posiblemente tú dirías acerca de tu mismo.							
<b>Instructions (2)</b> Please circle the one number on each scale that best describes how closely the statement applies to you.	Por favor marca con un círculo una sola respuesta para cada declaración que describe mejor como se te aplica							

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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
<b>Instructions (3)</b> There are no right or wrong answers; we are only interested in how you feel about your life.	EN GENERAL. No hay respuestas correctas ni equivocadas. Solo nos interesa saber como te sientes con respecto a tu propia vida.							
<b>Response Scale (1)</b> Never, Almost Never, Sometimes, Fairly Often, Very Often	Nunca, A veces, Casi nunca, Con frecuencia, Con mucho frecuencia							
<b>Contextual Items:</b>								
1. How often are you invited to hang out with a group of people? <i>(please circle your answer)</i>								
2. How often do you go out with a girlfriend or boyfriend? <i>(please circle your answer)</i>								
3. How often do people hug you? <i>(please circle your answer)</i>								
4. How often are you left out from doing things that other people your age are doing								

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because of how your face looks? (please circle your answer)								
5. How often do you have to repeat what you say so that others can understand you? (please circle your answer)								
6. How often do you hear other people say something about how your face looks? (please circle your answer)								
7. How often do you get into arguments with your parents or guardians about treatments for your face or head? (please circle your answer)								
8. How often do you notice other people staring at your face? (please circle your answer)								
9. How often do you meet people with a facial difference like yours? (please circle your answer)								
10. How often do you walk around in public? (please circle your answer)								
11. How often do you get into arguments because of how								

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your face looks? (please circle your answer)								
12. How often do you talk with someone about how your face looks? (please circle your answer)								
13. How often are you teased about how your face looks? (please circle your answer)								
14. How often do you explain your facial difference to other people your age? (please circle your answer)								
15. How often do you get invited to parties? (please circle your answer)								
16. How often do you get into physical fights because of how your face looks? (please circle your answer)								
<b>Perceptual Items:</b>								
Response scale1: Not at all, A great deal								
Response scale 2: Not at all, Completely								
17. It is hard to fit in with other people because of how my face looks (please circle the number)								

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18. It makes me angry when grown-ups stare at me because of how my face looks <i>(please circle the number)</i>								
19. It makes me feel better to meet someone who also has a facial difference <i>(please circle the number)</i>								
20. People forget I have a facial difference once they get to know me <i>(please circle the number)</i>								
21. I have trouble getting a girlfriend or boyfriend because of how my face looks <i>(please circle the number)</i>								
22. My facial difference helps me accept other people for who they are <i>(please circle the number)</i>								
23. People find me attractive even though my face looks different <i>(please circle the number)</i>								
24. I can handle people being curious about how my face looks <i>(please circle the number)</i>								



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25. I avoid having my picture taken because of how my face looks <i>(please circle the number)</i>								
26. I am a stronger person because of how my face looks <i>(please circle the number)</i>								
27. I worry that my children will have a facial difference <i>(please circle the number)</i>								
28. I worry that people will say things about my face <i>(please circle the number)</i>								
29. I feel uncomfortable meeting people for the first time because of how my face looks <i>(please circle the number)</i>								
30. Because of how my face looks I am uncomfortable going up to groups of people my age <i>(please circle the number)</i>								
31. I dislike seeing myself in the mirror because of how my face looks <i>(please circle the number)</i>								
32. Because of how my face looks, I am more accepting of other people								

Linguistic Validation of YQOL-FD instrument

<i>(please circle the number)</i>								
33. I feel left out of things because of how my face looks <i>(please circle the number)</i>								
34. Because of my face, I have more anger inside me than most people know <i>(please circle the number)</i>								
35. Because of how my face looks, I know more about life than other people my age do <i>(please circle the number)</i>								
36. Because of how my face looks, people think I am stupid <i>(please circle the number)</i>								
37. I worry that people will make fun of my face <i>(please circle the number)</i>								
38. Because of my facial difference, I worry people will not understand me when I speak <i>(please circle the number)</i>								
39. I worry that people will stare at my face <i>(please circle the number)</i>								
40. I feel frustrated about how my face looks <i>(please circle the number)</i>								

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<i>the number)</i>								
41. Because of how my face looks I worry that other people my age are embarrassed to be seen with me <i>(please circle the number)</i>								
42. Looking more like everyone else is important to me <i>(please circle the number)</i>								
43. I feel uncomfortable being in public because of how my face looks <i>(please circle the number)</i>								
44. People have a hard time seeing who I really am because of how my face looks <i>(please circle the number)</i>								
45. Because of the way my face looks I wish I had never been born <i>(please circle the number)</i>								
46. Because of how my face looks, I feel less in control of my life <i>(please circle the number)</i>								
47. Because of how my face looks it is difficult to find friends I can trust <i>(please circle the number)</i>								
48. I feel shy or								

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self-conscious because of how my face looks <i>(please circle the number)</i>								
49. I feel people expect less of me because of my facial difference <i>(please circle the number)</i>								
50. I can handle being teased about how my face looks <i>(please circle the number)</i>								
51. My facial difference makes me feel less attractive <i>(please circle the number)</i>								
52. It helps me to talk about how my face looks <i>(please circle the number)</i>								
53. Because of my facial difference, I have to work harder to get respect <i>(please circle the number)</i>								
54. I feel that I have less chance of a good life because of the way my face looks <i>(please circle the number)</i>								
55. Because of how my face looks, I am in touch with other people's feelings <i>(please circle the number)</i>								
56. I feel that people judge me by								

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the way my face looks ( <i>please circle the number</i> )								
57. I dislike looking at pictures of myself because of how my face looks ( <i>please circle the number</i> )								
Response scale Not at all different, extremely different								
58. Compared to most faces, my face is ( <i>please circle the number</i> )								

**APPENDIX D:**  
**FINAL REPORTING TEMPLATE**  
**(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:	_____

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